Urology Services Inquiry

Urology Services Inquiry | 1 Bradford Court | Belfast BT8 6RB
T: 02890 251005 | E: info@usi.org.uk | W: www.urologyservicesinquiry.org.uk

Note: An addendum to this statement was received by the Inquiry on 5 May 2023 and can be found at WIT-94679 to WIT-94680. Annotated by the Urology Services Inquiry.

Leanne McCourt
C/O Southern Health and Social Care Trust
Craigavon Area Hospital,
68 Lurgan Road, Portadown,
BT63 5QQ

20 September 2022

Dear Madam,

Re: The Statutory Independent Public Inquiry into Urology Services in the Southern Health and Social Care Trust

Provision of a Section 21 Notice requiring the provision of evidence in the form of a written statement

I am writing to you in my capacity as Solicitor to the Independent Public Inquiry into Urology Services in the Southern Health and Social Care Trust (the Urology Services Inquiry) which has been set up under the Inquiries Act 2005 ('the Act').

I enclose a copy of the Urology Services Inquiry's Terms of Reference for your information.

You will be aware that the Inquiry has commenced its investigations into the matters set out in its Terms of Reference. The Inquiry is continuing with the process of gathering all of the relevant documentation from relevant departments, organisations and individuals. In addition, the Inquiry has also now begun the process of requiring individuals who have been, or may have been, involved in the range of matters which come within the Inquiry's Terms of Reference to provide written evidence to the Inquiry panel.

The Urology Services Inquiry is now issuing to you a Statutory Notice (known as a Section 21 Notice) pursuant to its powers to compel the provision of evidence in the form of a written statement in relation to the matters falling within its Terms of Reference.

The Inquiry is aware that you have held posts relevant to the Inquiry's Terms of Reference. The Inquiry understands that you will have access to all of the relevant information required to provide the witness statement required now or at any stage throughout the duration of this Inquiry.

Should you consider that not to be the case, please advise us of that as soon as possible.

The Schedule to the enclosed Section 21 Notice provides full details as to the matters which should be covered in the written evidence which is required from you. As the text of the Section 21 Notice explains, you are required by law to comply with it.

Please bear in mind the fact that the witness statement required by the enclosed Notice is likely (in common with many other statements we will request) to be published by the Inquiry in due course. It should therefore ideally be written in a manner which is as accessible as possible in terms of public understanding.

You will note that certain questions raise issues regarding documentation. As you may be aware the Trust has already responded to our earlier Section 21 Notice requesting documentation from the Trust as an organisation. However if you in your personal capacity hold any additional documentation which you consider is of relevance to our work and is not within the custody or power of the Trust and/or has not been provided to us to date, then we would ask that this is also provided with this response.

You will also note several references to documents referenced, but not attached to this Notice (e.g. at Para's 24, 31, 32, 36 and 40).These documents are Inquiry 'BATES Referenced' documents. BATES referencing is the Inquiry's pagination system whereby the source of the document is recorded and a number attributed to the document depending on the order in which it was received e.g. TRU 84719, which is a Trust source document and is the 84,719th page of documents received from the Trust. Please speak to the Trust legal advisor concerning these documents.

If it would assist you, I am happy to meet with you and/or the Trust's legal representative(s) to discuss what documents you have and whether they are covered by the Section 21 Notice.

You will also find attached to the Section 21 Notice a Guidance Note explaining the nature of a Section 21 Notice and the procedures that the Inquiry has adopted in relation to such a notice. In particular, you are asked to provide your evidence in the form of the template witness statement which is also enclosed with this correspondence. In addition, as referred to above, you will also find enclosed a copy of the Inquiry's Terms of Reference to assist you in understanding the scope of the Inquiry's work and therefore the ambit of the Section 21 Notice.

Given the tight time-frame within which the Inquiry must operate, the Chair of the Inquiry would be grateful if you would comply with the requirements of the Section 21 Notice as soon as possible and, in any event, by the date set out for compliance in the Notice itself.

If there is any difficulty in complying with this time limit you must make application to the Chair for an extension of time before the expiry of the time limit, and that application must provide full reasons in explanation of any difficulty.

Finally, I would be grateful if you could acknowledge receipt of this correspondence and the enclosed Notice by email to [redacted].

Please do not hesitate to contact me to discuss any matter arising.

Yours faithfully

[redacted]

Anne Donnelly
Solicitor to the Urology Services Inquiry

Tel: [redacted]
Mobile: [redacted]

THE INDEPENDENT PUBLIC INQUIRY INTO
UROLOGY SERVICES IN THE
SOUTHERN HEALTH AND SOCIAL CARE TRUST

Chair's Notice

[No 73 of 2022]

Pursuant to Section 21(2) of the Inquiries Act 2005

WARNING

If, without reasonable excuse, you fail to comply with the requirements of this Notice you will be committing an offence under section 35 of the Inquiries Act 2005 and may be liable on conviction to a term of imprisonment and/or a fine.

Further, if you fail to comply with the requirements of this Notice, the Chair may certify the matter to the High Court of Justice in Northern Ireland under section 36 of the Inquiries Act 2005, where you may be held in contempt of court and may be imprisoned, fined or have your assets seized.

TO:

Leanne McCourt
C/O Southern Health and Social Care Trust
Headquarters
68 Lurgan Road
Portadown
BT63 5QQ

IMPORTANT INFORMATION FOR THE RECIPIENT

1. This Notice is issued by the Chair of the Independent Public Inquiry into Urology Services in the Southern Health and Social Care Trust on foot of the powers given to her by the Inquiries Act 2005.

2. The Notice requires you to do the acts set out in the body of the Notice.

3. You should read this Notice carefully and consult a solicitor as soon as possible about it.

4. You are entitled to ask the Chair to revoke or vary the Notice in accordance with the terms of section 21(4) of the Inquiries Act 2005.

5. If you disobey the requirements of the Notice it may have very serious consequences for you, including you being fined or imprisoned. For that reason you should treat this Notice with the utmost seriousness.

WITNESS STATEMENT TO BE PRODUCED

TAKE NOTICE that the Chair of the Independent Public Inquiry into Urology Services in the Southern Health and Social Care Trust requires you, pursuant to her powers under section 21(2)(a) of the Inquiries Act 2005 ('the Act'), to produce to the Inquiry a Witness Statement as set out in the Schedule to this Notice by **noon on 1st November 2022.**

APPLICATION TO VARY OR REVOKE THE NOTICE

AND FURTHER TAKE NOTICE that you are entitled to make a claim to the Chair of the Inquiry, under section 21(4) of the Act, on the grounds that you are unable to comply with the Notice, or that it is not reasonable in all the circumstances to require you to comply with the Notice.

If you wish to make such a claim you should do so in writing to the Chair of the Inquiry at: **Urology Services Inquiry, 1 Bradford Court, Belfast, BT8 6RB** setting out in detail the basis of, and reasons for, your claim by **noon on 25th October 2022**.

Upon receipt of such a claim the Chair will then determine whether the Notice should be revoked or varied, including having regard to her obligations under section 21(5) of the Act, and you will be notified of her determination.

Dated this day 20th September 2022

Signed: [redacted]

Christine Smith QC
Chair of Urology Services Inquiry

SCHEDULE
[No 73 of 2022]

SECTION 1 – GENERAL NARRATIVE

General

1. Having regard to the Terms of Reference of the Inquiry, please provide a narrative account of your involvement in or knowledge of all matters falling within the scope of those Terms. This should include an explanation of your role, responsibilities and duties, and should provide a detailed description of any issues raised with or by you, meetings you attended, and actions or decisions taken by you and others to address any concerns. It would greatly assist the inquiry if you would provide this narrative in numbered paragraphs and in chronological order. The Inquiry is aware that you have previously been provided with a questionnaire. If you replied and wish to rely on that questionnaire in reply to any question, please attach that questionnaire as an Appendix to your reply to this Notice and identify the section on which you rely. However, you are encouraged to provide answers that are as full as possible, including further details or information not contained in your questionnaire.

2. Please also provide any and all documents within your custody or under your control relating to the terms of reference of the *Urology Services Inquiry* ("USI"). Provide or refer to any documentation you consider relevant to any of your answers, whether in answer to Question 1 or to the questions set out below. Place any documents referred to in the body of your response as separate appendices set out in chronological order and properly indexed. If you are in any doubt about document provision, please do not hesitate to contact the Trust's Solicitor, or in the alternative, the Inquiry Solicitor.

3. Unless you have specifically addressed the issues in your reply to Question 1 above, please answer the remaining questions in this Notice. If you rely on your answer to Question 1 in answering any of these questions, please specify precisely which paragraphs of your narrative you rely on. Alternatively, you may incorporate the answers to the remaining questions into your narrative and simply refer us to the relevant paragraphs. The key is to address all questions posed and, as far as possible, to address your answers in a chronological format. If there are questions that you do not know the answer to, or where someone else is better placed to answer, please explain and provide the name and role of that other person.

Your role

4. Please explain the way in which communications take place between (i) the patient and the CNS (i.e. the Clinical Nurse Specialist) and (ii) the CNS and consultants within Urology Services. If the answer to this question depends upon the context in which the CNS is dealing with patients, please explain. In your view, are these communication pathways effective? If no, why not and how could they be improved?

5. Who was your line manager both operationally and clinically? How effective was your relationship with these individuals? If separate individuals, do you consider that this separation of oversight caused any difficulties to your practice or for patient care and risk management?

6. To whom did you report if you had any problems fulfilling your role or had concerns about patient care and safety?

7. Did you ever report any problems? If so, please provide full details, including any outcomes. Were you satisfied with how any concerns you raised were handled? Please explain.

8. Did you and do you have adequate administrative support to carry out your role properly? If no, please explain. If yes, please describe your use of admin staff.

9. Did you and do you feel supported in your role? Have you had opportunities for professional development?

10. Do you consider that the introduction of nurse led activities has contributed to improved patient care overall? If yes, please explain.

11. The Inquiry has received information which references the following terms: Keyworker, Specialist Nurse, Cancer Nurse Specialist, Urologist Nurse Specialist.

    Do these names refer to the same individuals/roles, as they appear to be used interchangeably, are they functions within one role, or are they all different individuals/roles? Please explain your answer so that the Inquiry has a complete picture of these individuals/roles and their relevance within the patient care pathway.

Electronic systems for communication

12. The Inquiry is keen to understand how you and other staff communicate using electronic systems and how updates and next steps are communicated between staff. Please give a brief outline of your use of electronic systems in your role (naming any systems), such as the Patient Administration System, and how and for what purpose you use them. Please include the systems you use to update on patient engagement, requests or follow ups. If this differs from the systems used by clinicians, please explain. Do these systems have prompts built in to alert staff that tasks or follow ups are outstanding?

13. If the above roles are carried out via any other method, please explain in full.

14. How do you think methods of communication and action planning could be improved to ensure follow ups and other matters central to clinical care are not missed or delayed?

Staff Performance Reviews

15. Did you complete Staff Performance Reviews and, if so, with whom? Did you ever identify problems or concerns via this route? What is your view of the effectiveness of such Reviews in terms of both your nursing practice and as a way of improving service provision?

Concerns

16. During your tenure within urology services generally, including your past and current role(s), did you have concerns regarding the practice of any practitioner? If so, did you speak to anyone and what was the outcome? Please explain your answer in full, including names and dates, referencing any relevant documentation.

17. Is it your experience that, following a concern being raised, you were informed of the outcome or any resultant change in practice/procedure? If yes, how was this done?

Weekly meetings with Head of Service

18. The Inquiry has received information which indicates that the Head of Service held weekly meetings with Lead Nurses/Clinical Nurse Specialists. Is this your experience? If so,

(i) Was there an agenda to these meetings? If so, who decided on the agenda?
(ii) How were topics identified for discussion?
(iii) How were outcomes from these meetings recorded and implemented and how were relevant staff informed of these outcomes? Please provide or signpost the inquiry to any relevant documents.

19. Did the CNS and clinicians regularly meet to discuss patient care? If yes, please provide all details. If no, do you think such meetings would enhance patient care and safety?

20. Please detail all other meetings you attended which touched on matters of governance in urology, stating their frequency, who else attended, and how outcomes from such meetings would be implemented and monitored.

21. What is your overall view of the efficiency and effectiveness of governance processes and procedures within urology as relevant to your role?

Regional Review of Urology Services, Team South Implementation Plan (2010)

22. The Inquiry has received information that Martina Corrigan had a responsibility to implement and monitor the Regional Review of Urology Services, Team South, published on 14 June 2010. Were you one of the CNS's who engaged with Martina Corrigan on this matter?

(i) If so, what was your involvement?
(ii) Were your views taken on board? If yes, how? If no, why not?
(iii) Is there anything which could have been done differently at that stage or since that may have limited the extent of the problems subsequently experienced in urology and which lead to this Inquiry?

23. Do you consider that the role and functions of CNS were resourced properly from the outset? If not, what impact do you consider this had on service provision and patient care and safety generally?

Concerns and Risks identified

24. The NHS National Peer Review Programme produced the *National Peer Review Report: Northern Ireland 2015: An overview of the findings from the 2015 National Peer Review of Cancer Services in Northern Ireland* (TRU 84695). The table below shows the incidence of the common issues raised as immediate risks and serious concerns across the trusts. Those relevant to the Southern Trust (and Inquiry) are (TRU 84719):
    (i) Absence or inadequate CNS provision.
    (ii) Delays in seeing routine referrals.
    (iii) Shortage of consultants in the specialty, or over reliance on locum consultants.
    (iv) Absence of core membership of, or lack of attendance at, MDT leading to a significantly low percentage of MDT meetings being quorate.
    (v) Lack of specialist radiologist or histopathologist input to the service or MDT.

From your perspective during your tenure as a CNS, did you have knowledge of or experience the risks and concerns set out at (i) – (v) above? If so, please provide full details. Did you report or speak about these issues with anyone else? If yes, who did you speak/report to and what happened?

25. If you did experience the issues at (i) – (v), what is your view of how those risks and serious concerns came about?

26. In your view, what is or was the impact on patient safety and care planning of the issues at (i) – (v), and what was done or could have been done to address these problems? Please provide examples as relevant.

27. In your experience, do the concerns and risks at (i) – (v) continue to exist?

28. Did you ever speak to anyone or complain about any other matter impacting upon your role or on patient care? If yes, please provide full details and what, if anything happened as a result.

29. How are concerns raised regarding patient care and safety, or problems with your role in general impacting on patient care, reflected in nursing documents? Are governance concerns recorded or reported by CNSs reflected in Trust governance documents?

30. What could improve the ways in which concerns are dealt with to enhance patient experience and increase your effectiveness in carrying out your role?

Patient Experience Surveys

31. PHA (supported by Macmillan Cancer Support) commissioned a regional cancer patient experience survey (CPES) in 2015 (AOB 01714), the first time the survey was undertaken in Northern Ireland. Access to a clinical nurse specialist came out as a key issue. Was this survey, *or any external patient survey*, and its findings, ever brought to your attention, and if so how and by whom? What, if anything, was done to address concerns about access to CNSs following this or any survey raising similar concerns? Please explain your answer in full.

32. The Southern Trust carried out its own *Urology Cancer Patient Experience Survey* in August 2015 (AOB 01721) and found that 75% of patients had the opportunity to meet a Clinical Nurse Specialist and 50% were provided with contact details of a clinical nurse specialist. Was this survey, *or any internal patient survey*, and its findings, ever brought to your attention, and if so how and by whom? What, if anything, was done to address concerns about access to CNSs following the survey or any other feedback received on this issue? Please explain your answer in full.

33. How, in general, is feedback to inform practice relayed to the CNS staff?

34. In your view, is there a potential for breakdown in communication for patients regarding their care if the CNS is not part of their care team? Do you consider that the absence of a CNS in a patient's care pathway presents a risk to patient care and safety? If yes, please provide examples.

35. What is your view of the effectiveness of patient satisfaction surveys as a means of informing development, planning and delivery of services? Are these survey outcomes shared with staff? Do management act on suggestions?

Secured slots for patient discussions following MDT meetings

36. The 2015 *National Peer Review Report: Northern Ireland 2015* also identified good practice within urology Southern Trust (TRU 84717), including having *Secured slots in clinic following MDT meeting for patient discussion (Southern)*. Please explain, as relevant, your experience of how these slots for patient meetings operated, who attended, the effectiveness of these slots, and whether they were a regular post MDT feature and remain so? If these slots no longer operate, why not and what, if anything, replaced this system?

37. What type of information was sought from or provided to the patient during these slots?

38. Were these meetings recorded? If so, where?

39. What is your view of the effectiveness of these meeting slots? Do you consider they enhanced patient care, experience and safety? Please explain your answer.

Attendance at MDTs

40. The Inquiry is interested in MDT (Multi-disciplinary Team) attendance. By way of example, the *Urology MDT Annual Report for January - December 2016* recorded CNS attendance at 98%. By contrast, radiologist attendance was 58% and oncologist attendance was 28% (AOB 01710). In 2019, CNS attendance was 98% while the Clinical Oncologist representation was 5% (TRU 104183). What in your experience, if anything, is the impact on MDT meetings when other specialists are absent from these meetings and also as regards patient care planning and governance generally? Please provide examples as relevant.

41. Do you consider that the role of the CNS was valued within the MDT? Please explain your answer.

42. Did you feel able to contribute to MDT discussions generally? If not, please explain in full.

43. At MDT meetings and generally, were your views sought by clinicians on proposed patient care pathways?

44. Did you feel able to contribute to MDT discussions if you did not agree with the proposed plan for a patient?

45. Was it your experience that differing views on proposed patient care pathways were discussed among the clinicians at MDTs? How, in your experience or knowledge, were differing views on what treatment a patient should receive resolved at MDTs?

46. How were patient outcomes and decisions made at MDTs recorded and acted upon?

47. What, if any, role did the CNS have in ensuring that MDT decisions regarding patient care and treatment were followed through? If not the CNS, who was responsible for this and how was it done?

48. What is your view of how CNS and other professionals communicated within MDT? If there were problems with communication, is it your view that this impacted or had the potential to impact on patient care and care planning?

49. Did you experience any other difficulties with MDT generally or clinician care and practice which may have impacted on your role, patient care and clinical risk?

Uro-oncology consultations

50. The Inquiry has received information which indicates that communication was difficult with some consultants "that CNSs were not invited to be present at uro-oncology consultations by all consultants. Please provide any information you have on this issue, whether through first-hand experience or through having heard the concerns of others, including any information relating to the consultants who adopted this approach and your understanding of their reasons for doing so.

    If you were directly involved, please provide details on anyone you spoke to on this issue, when you spoke to them, and what, if anything was done to address the issue. Does this issue persist? If not, how was it resolved?

Nurse-led services

51. The Inquiry has received information that nurse-led services were met with resistance from some of the medical staff who felt that those roles were not a nurse role. What, if anything, do you know about this resistance from medical staff? You should include all relevant details in your answer.

52. Do you share the view that nurse-led procedures and prescribing has released pressure on the medical teams? Do you consider that urology nurse-led procedures have any other advantage for patients in terms of waiting lists, follow-up or general outcomes?

53. Do you feel the CNS carrying out nurse-led roles and procedures has increased urology capacity overall and, if so, is the role of the CNS adequately supported by management to fulfill their role?

Involvement of the CNS

54. The Inquiry has received information that Mr O'Brien did not routinely permit the Clinical Nurse Specialists to provide support as key worker to his oncology patients. Please provide any information you have on this issue, whether through first-hand experience or having heard the concerns of others. If you were directly involved, please provide details on anyone you spoke to on this issue, when you spoke to them, and what, if anything was done to address the issue.

55. In the report concerning the nine serious adverse incidents which were reviewed in 2020-21 and which concerned cancer patients in the care of Urology Services, it was found that the nine patients had not been referred to a Cancer Nurse Specialist, contact numbers had not been given, and a Cancer Nurse Specialist had not been given the opportunity to provide support and discharge duties to the patients. Please provide any information you have on this issue, whether through first-hand experience or having heard the concerns of others.

If you were directly involved, please provide details on anyone you spoke to on this issue, when you spoke to them, and what, if anything was done to address the issue. Does this issue persist?

Learning

56. Are you now aware of governance concerns arising out of the provision of urology services, which you were not aware of during your tenure? Identify any governance concerns which fall into this category and state whether you could and should have been made aware and why.

57. Having had the opportunity to reflect, do you have an explanation as to what went wrong within Urology services and why?

58. What do you consider the learning to have been from a governance perspective regarding the issues of concern within Urology services and regarding the concerns involving Mr. O'Brien in particular?

59. Do you think there was a failure to engage fully with the problems within Urology Services? If so, please identify who you consider may have failed to engage, what they failed to do, and what they may have done differently. If your answer is no, please explain in your view how the problems which arose were properly addressed and by whom.

60. Do you consider that, overall, mistakes were made by you or others in handling the concerns identified? If yes, please explain what could have been done differently within the existing governance arrangements during your tenure?

    Do you consider that those arrangements were properly utilised to maximum effect? If yes, please explain how and by whom. If not, what could have been done differently/better within the arrangements which existed during your tenure?

61. Do you think, overall, the governance arrangements were fit for purpose? Did you have concerns about the governance arrangements and did you raise those concerns with anyone? If yes, what were those concerns and with whom did you raise them and what, if anything, was done?

62. If not specifically asked in this Notice, please provide any other information or views on the issues raised in this Notice. Alternatively, please take this opportunity to state anything you consider relevant to the Inquiry's Terms of Reference and which you consider may assist the Inquiry.

NOTE:

By virtue of section 43(1) of the Inquiries Act 2005, "document" in this context has a very wide interpretation and includes information recorded in any form. This will include, for instance, correspondence, handwritten or typed notes, diary entries and minutes and memoranda. It will also include electronic documents such as emails, text communications and recordings. In turn, this will also include relevant email and text communications sent to or from personal email accounts or telephone numbers, as well as those sent from official or business accounts or numbers. By virtue of section 21(6) of the Inquiries Act 2005, a thing is under a person's control if it is in his possession or if he has a right to possession of it.

UROLOGY SERVICES INQUIRY

USI Ref: Notice 73 of 2021
Date of Notice: 20th September 2022

Witness Statement of: Leanne McCourt

I, Leanne McCourt, will say as follows:-

SECTION 1 – GENERAL NARRATIVE

General

1. **Having regard to the Terms of Reference of the Inquiry, please provide a narrative account of your involvement in or knowledge of all matters falling within the scope of those Terms. This should include an explanation of your role, responsibilities and duties, and should provide a detailed description of any issues raised with or by you, meetings you attended, and actions or decisions taken by you and others to address any concerns. It would greatly assist the inquiry if you would provide this narrative in numbered paragraphs and in chronological order. The Inquiry is aware that you have previously been provided with a questionnaire. If you replied and wish to rely on that questionnaire in reply to any question, please attach that questionnaire as an Appendix to your reply to this Notice and identify the section on which you rely. However, you are encouraged to provide answers that are as full as possible, including further details or information not contained in your questionnaire.**

1.1 Throughout this narrative, I will refer to my questionnaire and have included this document in my folder of attachments.

1.2 I began my career in Urology when I qualified as a staff nurse in September 2006. I took up a post as a Band 5 staff nurse in 2 South Urology (Craigavon Hospital) until April 2010.

1.3 This post included such duties as:

a) Admission of elective and emergency urology patients;
b) Discharge planning;
c) Pre and post op care nursing care;
d) Caring for patients with a range of Urological Conditions;
e) Ensure patient and family aware of plan of care;
f) Assisting with Urodynamic Studies;
g) Assisting with preoperative assessment clinic;

1.4 I was extremely fulfilled within this role and had excellent opportunities to learn and enhance my practice. The staff on the urology ward were extremely knowledgeable and very amenable to teaching junior members of staff. in my experience it was a very well run and organised ward.

1.5 At the end of 2009, the urology ward was reconfigured and moved to 4 North, where an emergency surgical admissions component was incorporated within the one ward. At the time I recall this reconfiguration as something that was announced once the “deal had been done”. I was still considered a junior staff member at this time and so, perhaps for this reason, staff at my level were not consulted. I duly moved to 4 North with a number of the original urology team. I am someone whose outlook is generally positive, and I endeavoured to make the best of this new situation. Unfortunately, I did not settle into this new arrangement, as I felt I was no longer getting enough urology experience and there was insufficient time for teaching and learning. We were advised that we could apply for a transfer within six months if we were dissatisfied within this role.

1.6 I duly applied for a transfer to the Mandeville Unit and moved there in April 2010. I gained a wealth of experience and training here, working first as a chemotherapy nurse until December 2012, then as a cancer research nurse until March 2017. I also worked within a secondment role with acute oncology as a nurse specialist from November 2016 until February 2017.

1.7 At the end of 2016, I applied for a band 6 Urology CNS post (two posts were advertised) within the Thorndale Unit. *Please see 1. Band 6 CNS JD and 2. Band 6 Clinical Sister JD.* At the time of interview, I was informed by the interviewing panel, that the role had been changed and it was now a Clinical Sister’s post that we were being interviewed for. I completed the interview and to my surprise, was subsequently offered the post. I had prepared for an entirely different interview. At this point I had not fully decided if I wanted to accept the Clinical Sister’s post, I was still unsure as to why the post had been changed. All my correspondence from the Business Services Organisation (BSO) prior to and subsequently still refers to a band 6 CNS post. I contacted the Head of Service, Martina Corrigan, whom I had never met before and arranged to see her. At this meeting, she informed me that there had been an element left out of the job description/criteria and this meant the role had to be changed at the last minute. She also informed me that, in the future there would be Urology CNS posts coming up and that I would be in a good position to apply for these if I was working within the Thorndale Unit.

1.8 After careful consideration, I accepted the Clinical Sister post and commenced this role in April 2017. I then learned that my newly appointed Charge Nurse colleague, Jason Young, had had a very similar experience. I have attached the job descriptions for the Band 6 CNS role and Band 6 Clinical Sister role above. The role I applied for is very different from the role I actually ended up working in. The post was mainly concerned with management/organisation type roles, whereas the CNS role had more of a focus on Keyworker and nurse-led clinics. The keyworker role did account for a small proportion of my duties at this time. This post included such duties as:

a) Assisting the ward manager with daily managerial duties in a busy diagnostic and treatment Urology Outpatient Unit;
b) Implementation and ongoing duties relating to E-Roster, Annual leave etc.;
c) Undertaking staff appraisals and clinical supervision sessions;
d) Risk assessment completion re. COSHH, DSE etc. for Thorndale;
e) Ensuring staff training up to date and arranging training for the unit;
f) Undertaking regular Audits;
g) Fortnightly attendance at Sister's Meetings;
h) Assisting with Urodynamics clinics;
i) Teaching of clean intermittent self-catheterisation;
j) Performing male and female catheterisation;
k) Responding to Datix incidents;
l) Link nurse for safeguarding issues;
m) Assisting with running of prostate diagnostic service;
n) Keyworker for patients diagnosed with urological cancers;
o) Attendance at MDM

1.9 I also work "as and when" within GP out-of-hours service as a nurse triager (Band 6) from September 2017 until present.

1.10 I then applied for and obtained the Band 7 Macmillan Urology CNS role, taking up post in March 2019 until present. Unfortunately, I was still responsible for managerial duties within the Thorndale Unit (referred to in questions 9 and 24), meaning that my nurse-led activity was considerably curtailed until this aspect of my role was taken over by the manager of the Outpatients' Department in March/April 2021.

<u>Urology CNS (Macmillan Post) Band 7</u>

1.11 This post includes duties such as:

a) On appointment to post as Band 7 CNS, I still had duties and management responsibilities as outlined above. Band 5 staff and HCA's only became the responsibility of a separate OPD Manager from March 2021;
b) Learning transrectal and then transperineal prostate biopsy procedure to become independent with own nurse led clinics;
c) Attendance at MDM;
d) Keyworker at results clinics;
e) Rescue work in relation to keyworker patients;
f) Writing policies for Nurse Led clinics and SOP's for TP biopsy service;
g) Setting up and implementing new Nurse led Holistic needs assessment clinics and Prostate Cancer review clinics (Active Surveillance and Watchful Waiting);
h) maintaining E-roster for CNS team;
i) Member of NICAN CRG and CNS Forum;

1.12 In order to progress within my nursing career and to continue to develop skills, I also undertake ongoing courses and learning, some of which are listed below.

a) 2006 BSc Adult Nursing Sciences (QUB. First Class);
b) 2010 Certificate in Urodynamics Studies (Bristol University);
c) 2011 Administration of Systemic Anticancer Therapies (Stand alone module QUB);
d) 2015 Certificate in Advanced Communication
e) 2016 Health Assessment Module (UU);
f) 2018 Post Grad. Certificate in Non-medical Prescribing

1.13 Throughout the course of this witness statement, I will detail concerns I had regarding the practice of two consultants, namely Mr [redacted] and Mr O'Brien (question 7). I will also touch upon concerns raised by the CNS team during a period of redeployment during the Covid pandemic. I will detail the nature of these concerns, to whom I reported them and the feedback received.

1.14 I will also specify my experience of support around nurse-led services and how they can help to support patient care and aid with reduction in waiting lists by freeing up consultant time (questions 8-10, 51-53).

1.15 Additionally, I will summarise the governance meetings I attended and my understanding of the governance structures within the Southern Health and Social Care Trust within questions; 15,18, 19 ,20,21 and 29.

1.16 Regarding governance concerns and learning from these, I can truthfully say, that prior to this process I was only aware of what I have included in my answer to question seven. I feel it is regrettable that it has taken a root cause analysis into a review of a serious adverse incident and then a public inquiry for me to become aware of issues that were longstanding and previously known about Mr O'Brien's practice. I have expressed my views on this within questions 56-61. *Please see:*

3. Root Cause Analysis report 2021

1.17 I also feel compelled to express how privileged I feel to work within the current team of urology nurses, consultants and Head of Service. As a team, we strive to make a difference to our patients in challenging times, with some excellent examples of innovation and teamwork. These current proceedings have been very difficult for the team and I hope it will strengthen our resolve to learn from this, move forward and ensure this can never happen again. We must also remember the patients and families involved and this should be our motivation to provide safe, effective and evidence-based care.

1.18 I would also like to note, that I have listed occasions within this document (questions 48+50) where I found Mr O'Brien to be condescending in tone, but this was not always the case. If I needed advice from him, he was professional and forthcoming. When I was a junior staff nurse, he would have taken time to explain things and help me to learn. He was very dedicated to care of his patients and I would describe him as "kind and caring" to his patients in clinic. I recall one such time where I was present when a life-changing diagnosis was given to a young man. Mr O'Brien offered to drive him to the oncology appointment he had arranged for him later that day as he was concerned the young man was distressed and shaken.

1.19 This process is difficult and discordant for me as there was the consultant I knew to be kind and caring, albeit arrogant and condescending at times and then there was the consultant mentioned within the Root Cause Analysis report and the findings that have now led to a Public Inquiry.

2. Please also provide any and all documents within your custody or under your control relating to the terms of reference of the *Urology Services Inquiry* ("USI"). Provide or refer to any documentation you consider

relevant to any of your answers, whether in answer to Question 1 or to the questions set out below. Place any documents referred to in the body of your response as separate appendices set out in chronological order and properly indexed. If you are in any doubt about document provision, please do not hesitate to contact the Trust's Solicitor, or in the alternative, the Inquiry Solicitor.

2.1 Any documents referenced in this statement can be located in folder S21 73 of 2022 – Attachments.

3. Unless you have specifically addressed the issues in your reply to Question 1 above, please answer the remaining questions in this Notice. If you rely on your answer to Question 1 in answering any of these questions, please specify precisely which paragraphs of your narrative you rely on. Alternatively, you may incorporate the answers to the remaining questions into your narrative and simply refer us to the relevant paragraphs. The key is to address all questions posed and, as far as possible, to address your answers in a chronological format. If there are questions that you do not know the answer to, or where someone else is better placed to answer, please explain and provide the name and role of that other person.

Your role

4. Please explain the way in which communications take place between (i) the patient and the CNS (i.e. the Clinical Nurse Specialist) and (ii) the CNS and consultants within Urology Services. If the answer to this question depends upon the context in which the CNS is dealing with patients, please explain. In your view, are these communication pathways effective? If no, why not and how could they be improved?

i) the patient and the CNS

4.1 The CNS is normally present with the patient and the Consultant at the time a diagnosis is given. At this face-to-face appointment, the CNS also gives the patient a contact card, site-specific written information for their diagnosis and a written record of the consultation which includes information on the next steps and a core cancer information pack. The CNS also records this on progress notes (ECR), the Cancer Patient Pathway system (CaPPS) and by way of an electronic patient proforma. The CNS may be present at subsequent face-to-face appointments as the patient receives, e.g., staging scan results, further MDM discussion outcomes. *Please see:*

4. Record of consultation

4.2 Subsequent to this, all newly diagnosed patients are offered a Holistic Needs Assessment (HNA) telephone appointment. If this offer is accepted, patients will receive a concerns checklist from our Macmillan Support Worker, to be completed prior to the telephone appointment with the CNS. If they need assistance to do this, the support worker facilitates this. The HNA appointments are normally carried out over the telephone, but can be face to face for various reasons, e.g., patient preference or to ameliorate communication difficulties. *Please see:*

5. Concerns checklist

4.3 The majority of contact after this between the patient and CNS is via the telephone and can include conversations around treatment decisions and various patient queries. Patient queries are recorded as a progress note on ECR, in this way if the patient has further queries and a particular CNS is not available, the rest of the CNS team are able to assist as they can review the conversation to date.

4.4 I also carry out nurse led prostate cancer review clinics for patients on active surveillance or watchful waiting- the majority of these clinics are conducted via telephone, the patient is then sent a copy of the clinic letter.

4.5 Due to my involvement in the nurse led transperineal prostate biopsy clinic, I may also have face-to-face contact with patients prior to their diagnosis. A written information leaflet is posted to the patient prior to the appointment, I then counsel and consent the patient prior to carrying out the biopsy. Patients are also given a written discharge advice sheet with safety advice and worsening symptom instructions. Patients are also verbally informed of timeframes and logistics of when/how to expect their results. *Please see:*

6. TP biopsy information leaflet

7. Prostate Biopsy Discharge Advice Sheet TP BIOPSIES V1 March 21

4.6 In my view, communication between CNS and patient is effective and as illustrated above this is achieved via an array of modalities.

(ii) CNS and consultants

4.7 Communication between these two groups also takes place in a number of ways.

4.8 It may be face to face prior and during and after consultations with the patient. This is normally documented by way of a clinic letter dictated by the consultant. The CNS also records this on progress notes (ECR), the Cancer Patient Pathway system (CaPPS) and by way of an electronic patient proforma.

4.9 As the CNS office is based in Thorndale Outpatients' Dept., communication with the consultant happens regularly on an ad hoc, informal basis.

4.10 We also communicate weekly at the multidisciplinary meeting (MDM), this is done via a hybrid model of face-to-face attendees as well as those linking in remotely.

4.11 I also email consultants regularly with regard to patient queries/treatment decisions and normally receive a prompt and comprehensive response.

4.12 Consultants also email the CNS team regularly, e.g., to set up "Hot Patient" appointment in Thorndale- this is normally reserved for urgent cases when once triaged require urgent review, e.g., patients with testicular masses or those that have newly diagnosed metastatic prostate cancer.

4.13 On occasion consultants and CNS will communicate via telephone in Thorndale, e.g., the consultant on call may inform the CNS team of a newly diagnosed inpatient requiring CNS input. A mutually convenient time is arranged for the CNS and consultant to meet the patient/family on the ward to discuss and convey the diagnosis.

4.14 The CNS and consultant teams also engage regularly at scheduled meetings, e.g., weekly departmental meetings and Audit/Patient Safety Meeting. Attendance at these meetings is also a combination of face-to-face and remote link-in.

4.15 In the main, I consider the communication pathways between CNS and Consultant to be effective. I feel my views and opinions are listened to and respected. On occasion, there are logistical/connection and difficulties with remote access which make the process of communication more difficult. However, this has to be balanced in the context of the pandemic where if not for remote access, many meetings would not have been able to happen at all.

5. Who was your line manager both operationally and clinically? How effective was your relationship with these individuals? If separate individuals, do you consider that this separation of oversight caused any difficulties to your practice or for patient care and risk management?

5.1 My operational line manager (Head of Service) was Martina Corrigan and more recently Wendy Clayton. I have had several clinical line managers/Lead Nurses during my role in Thorndale. They are as follows: Dorothy Sharpe, Linda Hamilton, Sarah Ward and Paula McKay.

5.2 Whilst working as a Band 6 Clinical Sister I would have also reported to Jenny McMahon and Kate O'Neill (CNSs). I worked closely in the Thorndale Unit with the CNSs and had a very practical, trusting and effective relationship with them.

5.4 I do not feel that the dual aspect of this role caused difficulties to my practice or compromised patient care per se. Each party had their knowledge, skills and viewpoints in a particular area and I think this was beneficial to the CNS team. When Dorothy Sharpe and Martina Corrigan were in post, I feel there was much less of a physical/visible presence within Thorndale. I am also unsure if the lines of communication between these two parties was regular, as I did not receive frequent feedback to this effect. Having said that, they did always respond to any email correspondence I sent, but would not routinely have met with me face-to face whilst I was a clinical sister. I believe that there were meetings between the HoS, Lead Nurse and CNS that I as a clinical sister was not party to as it was not required within my role.

5.5 More recently there is much more of a regular physical presence of both the Lead Nurse (originally Sarah Ward, now Paula McKay) and also HoS, Wendy Clayton. I also now feel that the operational and clinical managers work closely together and keep each other abreast of any matters discussed/raised by the CNS team. They are both very aware and supportive of activities, accomplishments or challenges within the CNS team.

6. To whom did you report if you had any problems fulfilling your role or had concerns about patient care and safety?

6.1 If I had clinical concerns, these were raised with the Lead nurse. For operational concerns, I would have raised these with the Head of Service.

6.2 On occasion, I also raised concerns with Mr Haynes (Urology Consultant and Divisional Medical Director) and Mr Glackin (Urology Consultant) as I valued their clinical advice as urology Consultants.

7. Did you ever report any problems? If so, please provide full details, including any outcomes. Were you satisfied with how any concerns you raised were handled? Please explain.

7.1 The following concerns are also mentioned in my completed Urology Services Enquiry Employee Questionnaire. *Please see:*

8. Leanne McCourt Inquiry Questionnaire

I raised a concern in [redacted] regarding Locum Urology Consultant [redacted] in relation to patient confidentiality. Mr [redacted] was enquiring if a patient was listed for prostate biopsy the following week and when I asked for the details, he opened his IPhone and had a photograph of the outpatient clinic list with outcomes recorded on it.

7.2 I then asked him if it was his personal phone or a Trust phone. He told me it was his phone and locked with a fingerprint. I told him he should not have photos of patient details on his phone, as it is not secure or encrypted. He then proceeded to tell me that the Consultants are part of an encrypted group that enables them to securely hold photos- they subscribe to this. He also said this is the only way they could have records should there be litigation in 20 years' time.

7.3 Shortly after, Mr Glackin (Urology Consultant) then entered the Unit and I explained to him what had happened. He confirmed the Urology Consultants were not in any such group and to tell [redacted] to remove the images from his phone.

7.4 I discussed this with Jenny McMahon and we both agreed that this needed to be escalated to the Lead Nurse. (Martina Corrigan was off at that point and unavailable).

7.5 I then emailed Lead Nurse Dorothy Sharpe on 6/7/2018 and then spoke with her in person, informing her of what I had discovered. She told me she would inform Ronan Carroll (Surgical AD) and get back to me. This was confirmed in an email. *Please see:*

9. Mr [redacted]*'s email*

7.6 The incident was also raised by Dorothy/Ronan to Mr Haynes (Divisional Medical Director) and he spoke with me and asked for an outline of what had occurred. He told me he planned to speak with [redacted] that afternoon.

7.7 Jenny McMahon (CNS) phoned me to home later that day to tell me Mr Haynes had spoken with Richard (cannot recall surname) and that it was an Information Governance issue. This could mean me having to be interviewed. I do not recall hearing or being contacted further in relation to this issue. Mr [redacted] is no longer employed by the Trust.

7.8 I do not feel satisfied with the handling of my concern as I was never informed of the outcome or if any measures were put in place.

7.9 I also had concerns regarding two of Mr O'Brien's patients from late 2019 to mid-2020. Patient details have been redacted to preserve confidentiality. *Please see:*

10. Mr O'Brien emails

7.10 I had concerns regarding the timeframe of Mr O'Brien's clinical letters being available on ECR as it made the keyworker role more difficult. I also had concerns about delayed referral for additional treatment. If I had not been physically in the room with the patient for the appointment I would not have been party to what had been discussed if the patient had then contacted me with a query.

7.11 The queries noted below are in relation to scan appointments or oncology referrals/appointments of two patients.

Patient 1 [redacted]:

7.12 03/03/20 – email from patient regarding further clinical appointment with Mr O'Brien. As the letter from previous appointment on 20th Feb was not on Electronic Care Record (ECR), I was unable to advise the patient and signposted him to Mr O'Brien's Secretary Noleen Elliott.

7.13 I also noted that I did not see a referral to Oncology on ECR for consideration of radical treatment – I emailed Noleen regarding this. To the best of my recollection, I did not receive a response. MDM outcome from 6/2/20 was referral for radical treatment.

7.14 11/03/20- emailed Oncology Secretary – no referral received.

7.15 11/03/20- discussed issue with Mr Haynes (Consultant Urologist/Divisional Medical Director) and emailed him the details.

7.16 17/03/20 - Letter of referral dictated by Mr O'Brien to oncology, typed 17/3/20. This concerned me as the outcome from MDM (6/2/22) was referral to clinical oncology, with the referral not being completed until 3 weeks after the patient had been reviewed. In my experience, the consultant normally completes the required referrals directly after (or as soon as possible) reviewing the patient. I am unsure if this referral was prompted due to involvement by Mr Haynes.

7.17 10/04/20- Oncology appointment for patient.

7.18 4/12/2021- Letter to patient re Lookback Exercise stating, “No issues of clinical concern have been identified and your current plan is completely satisfactory.”

Patient 2 [redacted]

7.19 16/12/19- phone call to Thorndale Unit from patient enquiring re CT scan. To the best of my knowledge, I had not been previously been introduced to this patient as a keyworker. The Clinic letter from 13/12/19 had not been typed. I checked SECTRA (radiology system) and did not see a CT scan ordered. Emailed Mr O’Brien and he replied stating he had now requested the CT. Outcome from MDM 28/11/19 was: “for review by Mr O'Brien to request CT C/A/P and consider early referral to Oncology.”

7.20 11/03/20- emailed Oncology Secretary – no referral received.

7.21 11/03/20- discussed issue with Mr Haynes (Consultant Urologist/Divisional Medical Director) and emailed him the details.

7.22 16/04/20- phone call from patient asking for his recent PSA blood test result and enquiring about radiotherapy appointment.

7.23 I did not see a referral letter for radiotherapy on ECR and so emailed Mr O’Brien (cc secretary Noleen Elliott) enquiring. To the best of my knowledge, I did not receive a response.

7.24 11/07/2020- referral letter on ECR to oncology

7.25 14/07/2020- Phone call from patient telling me his PSA has increased to 20. Also informed me he was telephoned by Mr O’Brien on Saturday and told to change his hormone treatment to injections and that he had been referred to Oncology.

7.26 07/08/2020- Oncology appointment for patient

7.27 4/12/2021- Letter to patient re Lookback Exercise stating, “No issues of clinical concern have been identified and your current plan is completely satisfactory.”

7.28 From the patient perspective, I am satisfied that they received their definitive treatment. However, I do feel that the two patients involved could have endured more anxiety than they ought to have due to the prolonged referral time. From my perspective, I feel I could have been better informed regarding what had or had not been done about my concerns.

7.29 The above concerns are also listed in my questionnaire submission to the Urology Services Inquiry. *Please see:*

8. Leanne McCourt Inquiry Questionnaire

7.30 At a Departmental Meeting in January 2021, the CNS team, raised concerns to our Head of Service and the Urology Consultants regarding the proposed redeployment of the entire urology CNS team during the pandemic. We highlighted how this would affect patient support, as there would be no one available to address concerns or queries or to perform the keyworker role for newly diagnosed patients. We had proposed a "rota" system whereby a member of the CNS team was allocated a day to remain in Thorndale to be available. I feel our concerns were not addressed adequately; we were informed that the Consultants could manage without us. We were duly redeployed from 18/01/2021 until the beginning of March 2021. I feel this sequence of events did firstly impact on patient care during this time and secondly, damage relationships within the team as we felt our roles were not valued.

7.31 I am unsure if this redeployment plan was applied to all specialties in the same way or to the same degree during this period of redeployment.

8. Did you and do you have adequate administrative support to carry out your role properly? If no, please explain. If yes, please describe your use of admin staff.

8.1 Prior to my managerial duties in Thorndale being transferred to the manager of Outpatients, administrative support was not an issue as my nurse-led activity was limited.

8.2 However now that my nurse-led prostate cancer follow up clinic is operational, there is inadequate cover in terms of administrative support. This has been highlighted at several meetings about nurse-led services. *Please see:*

11. Nurse led review meeting on 130821

12. Nurse led review meeting on 230921

13. Nurse led review meeting on 021221

14. Nurse led review meeting on 270122

15. Nurse led review meeting on 240222

16. Nurse led review meeting on 210422

17. Nurse led review meeting on 260522

18. Nurse led review meeting on 300622

19. Nurse led review meeting on 300822

20. FW notes from Urology Nurse led review meeting on 300822

8.3 There is currently one part-time (18.75 hours) administrative assistant in place for five Urology Nurse Specialists and this has proven to be insufficient for the volume of duties that need to be actioned, e.g., booking of clinics, posting of blood forms and typing of clinic letters.

8.4 There is also a Ward Manager's Assistant in post within Thorndale (full-time), however when this person is on leave or sick, the CNS admin assistant is expected to cover some of her duties also. This further impacts on her availability to carry out essential clerical responsibilities for the CNS team.

8.5 This often leads to a delay in GPs/patients receiving their clinic letters regarding outcomes and scans/blood results. It is very frustrating as I am committed to operating a safe, efficient and effective nurse led clinic.

8.6 In order to reduce the typing backlog, the Ward Manager's Assistant has been typing CNS letters as overtime; however, this is not a regular arrangement and does properly address the issue.

8.7 As CNSs we also have no one to manage a DARO list (discharged awaiting results/outcome). It is my understanding that consultants can avail of this system as an extra layer of safety for patients awaiting results. The list is held and managed by their secretaries and is reviewed on a monthly basis to highlight any outstanding results. It was discussed at Nurse Led meetings and it was decided that CNSs did not require this facility as patients are added to waiting lists. Retrieval of scan results is also more difficult in the CNS role, as even though the CNS may order the scan, the arrangement of the radiology system is such that the result will automatically be added to the consultant's ECR sign-off list, but not to the CNSs. We have to spend considerable time manually "looking" for results whilst also not having a DARO list to refer to. This has been remedied for blood results in relation to my nurse-led clinics as I now have my own blood code (set up with the laboratory system and ECR). The blood results automatically populate onto my ECR sign off list. I feel that as nurse-led services are evolving to incorporate more extensive roles, the infrastructure and support around them has not kept pace. *Please see:*

11. Nurse led review meeting on 130821

12. Nurse led review meeting on 230921

13. Nurse led review meeting on 021221

14. Nurse led review meeting on 270122

15. Nurse led review meeting on 240222

16. Nurse led review meeting on 210422

17. Nurse led review meeting on 260522

18. Nurse led review meeting on 300622

19. Nurse led review meeting on 300822

20. FW notes from Urology Nurse led review meeting on 300822

8.8 The aforementioned issues do not affect my prostate biopsy clinics and HNA clinics, as the administrative arrangement is different. The biopsy clinics are booked and typed in a rota system by Mr Glackin's and Mr Hayne's secretaries. With the HNA clinics, there is a Macmillan support worker in place to arrange the appointments and to upload the completed care plans to ECR.

9. Did you and do you feel supported in your role? Have you had opportunities for professional development?

9.1 When I attained my CNS role in March 2019, I still had responsibility for all of my previous managerial duties related to my Clinical Sister's post. This meant that I did not initially have capacity to develop nurse-led services. This was highlighted at our monthly Lead Nurse meetings. It did take time to advance this, with managerial duties being passed to the Out-Patient manager in March/April 2021. *Please see:*

11. Nurse led review meeting on 130821

12. Nurse led review meeting on 230921

13. Nurse led review meeting on 021221

14. Nurse led review meeting on 270122

15. Nurse led review meeting on 240222

16. Nurse led review meeting on 210422

17. Nurse led review meeting on 260522

18. Nurse led review meeting on 300622

19. Nurse led review meeting on 300822

20. FW notes from Urology Nurse led review meeting on 300822

9.2 Since being released to progress nurse led services I do feel supported within my role. I have since been mentored by Mr Glackin and Mr Haynes to competently and safely undertake transperineal prostate (TP) biopsy. This has resulted in a nurse-led TP biopsy service for Southern Trust patients.

10. Do you consider that the introduction of nurse led activities has contributed to improved patient care overall? If yes, please explain.

10.1 I do consider the introduction of nurse-led activities to have contributed to and improved patient care.

10.2 One example is the prostate biopsy service. Until recently waiting times for consultant performed, TP biopsies were 10-12 weeks, resulting in patients also having to be sent to the independent sector to help facilitate more timely access. Since the initiation of the nurse-led TP service, waiting times have now been reduced to 2-3 weeks. This improvement in waiting times has hastened the patient journey in terms of time to diagnosis and definitive treatment.

10.3 HNA clinics have also improved patient care, with all newly diagnosed patients now being offered an opportunity to address queries and concerns at a nurse led HNA appointment.

10.4 The keyworker role has also been enhanced as the CNS is now allocated to consultant results clinics. This has been facilitated by expansion of the CNS team and also the pre-existing team being released from managerial duties.

11. The Inquiry has received information which references the following terms: Keyworker, Specialist Nurse, Cancer Nurse Specialist, Urologist Nurse Specialist.

Do these names refer to the same individuals/roles, as they appear to be used interchangeably, are they functions within one role, or are they all different individuals/roles? Please explain your answer so that the Inquiry has a complete picture of these individuals/roles and their relevance within the patient care pathway.

11.1 I am of the opinion that the names listed above are broadly used interchangeably especially by patients and families.

11.2 In terms of particulars, the term “specialist” is usually reserved for nurses that have undergone further training and education to enhance their skills and knowledge.

11.3 The NICaN Urology Cancer Clinical Guidelines 2016 (page 116) even uses various names to refer to the role: Urology CNS, Uro-oncology nurse specialist, keyworker and CNS. This is also a feature in the Macmillan census of the cancer nursing and support workforce in Northern Ireland in 2021 (page16). The cancer patient experience surveys refer to a CNS. The contact card given to the patient at time of diagnosis has the term Keyworker on the card, with each CNS physically writing their name on the appropriate space on the card. *Please see:*

21. NICaN Urology Cancer Clinical Guidelines 2016
22. 2021-census-of-the-cancer-workforce-in-ni (macmillan.org.uk)

11.4 I have also encountered further variations of names for the keyworker, e.g., Macmillan Nurse, named nurse.

11.5 Within Thorndale, the CNS is normally the keyworker for the patient, however, on the rare occasion when a CNS is not available, this role is delegated to a clinical Sister or experienced staff nurse. This largely occurred when there were fewer CNSs in post.

11.6 They refer to functions within one role and a patient may have more than one keyworker/specialist nurse on their cancer pathway; this is especially relevant if they have been referred to the Belfast Trust for, e.g., radiotherapy or chemotherapy.

Electronic systems for communication

12. The Inquiry is keen to understand how you and other staff communicate using electronic systems and how updates and next steps are communicated between staff. Please give a brief outline of your use of electronic systems in your role (naming any systems), such as the Patient Administration System, and how and for what purpose you use them. Please include the systems you use to update on patient engagement, requests or follow ups. If this differs from the systems used by clinicians, please explain. Do these systems have prompts built in to alert staff that tasks or follow ups are outstanding?

12.1 Within my role, I use a variety of electronic systems as listed below;

a) email between myself and consultant, other CNSs, admin, cancer tracker. The outcomes from MDM are also emailed to the team via the MDM co-ordinator.

b) ECR. Clinic letters, recent inpatient stays, scan and blood results and MDM discussions are uploaded to ECR and are an invaluable source in terms of identifying what the "next steps" are. ECR is also used by consultants, CNS's to place orders, e.g., CT scans, MRI scans, and ultrasound scans. I also use the "Uniview" function on ECR to view MRI images to help plan my TP biopsies. Consultants use this function too; it can be especially useful during consultation to help demonstrate results to patients.

c) G2 digital dictation. This is the system used to dictate clinic/procedure outcomes. Once transcribed, the letters are uploaded to ECR.

d) Patient Administration System. I do not have in-depth knowledge or access to all the functions of PAS. I am able to use it to, e.g., look up contact details for patients and to check for upcoming appointments. I often need clarification of the codes used within the system and usually seek the advice of CNS admin or consultant secretaries for further clarification.

e) Progress notes (on ECR). The CNS team use this function after various episodes of patient contact, e.g. at diagnosis, after dealing with a patient query- ensuring other team members have access to what was discussed and outcomes. I also use this function to upload TP biopsy proformas to ECR after the patient has undergone the procedure, specifics are recorded e.g. number of biopsies taken and from which areas of the prostate. Due to the aforementioned typing delays (question 4), the CNS team also transcribe the appointment particulars onto a progress note. This can be invaluable as it can take several weeks for a letter to be typed and you may receive a query in the interim.

f) SECTRA I use this system to view appointment dates and times for upcoming scans. This is especially useful if a patient phones regarding a scan appointment.

g) CaPPS. The CNS team use this system to record their first contact with a newly diagnosed patient.

h) CNS proforma. The CNS team complete this electronic form following first contact with a newly diagnosed patient. The Macmillan support worker then uploads the details to a spreadsheet that in turn is used to capture data for the regional cancer CNS key performance indicators. It is also used to generate the Heath Needs Assessment (HNA) appointment.

i) MDM proforma. The consultants and CNS team use this electronic form in order to provide the essential information needed to generate an MDM discussion for a patient.

12.2 Regarding inbuilt prompts to alert staff that tasks or follow-ups are outstanding, the only system listed above that has this is the ECR results element. As previously discussed, even if a scan is requested by a CNS, the result automatically populates on the consultant's worklist for sign off, not the CNS's worklist.

12.3 As described previously, the CNS team do not have access to a DARO list for their nurse led services. Due to this I also keep a spreadsheet of outstanding scans/results that need followed up or actioned once they become available. Otherwise, I have no other way of keeping track of outstanding tasks.

13. If the above roles are carried out via any other method, please explain in full.

13.1 Apart from my individual spreadsheet mentioned above, I am unaware of the above roles being carried out by any other method.

14. How do you think methods of communication and action planning could be improved to ensure follow ups and other matters central to clinical care are not missed or delayed?

14.1 I think communication and action planning could be improved by:

a) -enabling CNS to have access to a managed DARO list
b) -all scan and blood results should automatically populate onto the ECR worklist of the person who ordered them
c) -increased admin support for CNS services
d) -increased tracking post MDM decision, not just up to the point of MDM

Staff Performance Reviews

15. Did you complete Staff Performance Reviews and, if so, with whom? Did you ever identify problems or concerns via this route? What is your view of the effectiveness of such Reviews in terms of both your nursing practice and as a way of improving service provision?

15.1 I completed annual Staff Performance Reviews, known as a Knowledge and Skills Framework Development (KSF) review. This was carried out with the lead nurse and included an appraisal against the KSF job outline. Areas of achievement are identified and a Personal Development Plan (PDP) produced. This includes, e.g., development activities and undertaking agreed learning. *Please see:*

23. Specialist Nurse Band 7 post outline

15.2 I used these opportunities to agree areas for my professional development, e.g., progressing my learning in order to become competent in the prostate biopsy process and the progression of nurse-led services. I did also raise that my management duties where an obstacle to achieving this.

15.3 Eventually this did lead to management duties being removed from my CNS role, it did take considerable time for this to happen and this was not the only forum that I raised the issue in. The KSF and PDP is useful for highlighting courses or further induction that you are interested in undertaking and so from this perspective, I feel they are effective in progressing nursing practice and improving service provision.

Concerns

16. During your tenure within urology services generally, including your past and current role(s), did you have concerns regarding the practice of any practitioner? If so, did you speak to anyone and what was the outcome? Please explain your answer in full, including names and dates, referencing any relevant documentation.

16.1 This area is addressed in my answer to question, where I have listed specific concerns in relation to Mr [redacted] and Mr O'Brien. I did not have any other concerns regarding the practice of any other practitioners or further concerns about the two aforementioned clinicians.

17. Is it your experience that, following a concern being raised, you were informed of the outcome or any resultant change in practice/procedure? If yes, how was this done?

17.1 In my experience, I was not informed of the outcome or any changes in practice/procedure following a concern being raised.

Weekly meetings with Head of Service

18. The Inquiry has received information which indicates that the Head of Service held weekly meetings with Lead Nurses/Clinical Nurse Specialists. Is this your experience? If so,

(i) Was there an agenda to these meetings? If so, who decided on the agenda?

(ii) How were topics identified for discussion?

(iii) How were outcomes from these meetings recorded and implemented and how were relevant staff informed of these outcomes? Please provide or signpost the inquiry to any relevant documents.

18.1 The introduction of a weekly meeting with Head of Service (HoS) was initiated by our current HoS, Wendy Clayton at the beginning of 2021. It is referred to as the Departmental Meeting. The attendees normally consist of HoS, Urology Consultants, Specialty Urology Doctors, Registrars, Outpatient Manager and the CNS team. It occurs each Thursday at 12:45.

18.2 i) There was an agenda for these meetings, normally attached to the email invitation. There were recurring topics that were discussed most weeks, e.g., Covid and elective activity and we were updated in these areas by the HoS. Any other member of the team could table a topic for discussion; this was done via an email to the HoS.

18.3 ii) As in answer i), the meetings were a combination of recurrent topics, mixed with current/new/one-off subjects that were pertinent to the urology team. During the 'any other business' section of the meeting, Wendy would also address each group and ask if we had anything else we wanted to discuss or bring to the attention of the meeting.

18.4 iii) The minutes of these meeting were saved in the "L" shared drive and can be accessed by all members of the team. Attendance at these meeting is normally very good as the day and time has been set where most have the capacity to link in. It is the responsibility of staff not present, to review the minutes for any discussions relevant to them.

18.5 I have not attached the meetings in my documents as they are too numerous. However, they are found on the "L" drive.

19. Did the CNS and clinicians regularly meet to discuss patient care? If yes, please provide all details. If no, do you think such meetings would enhance patient care and safety?

19.1 The CNS and clinicians meet each Thursday at the multidisciplinary meeting to discuss patient care. If I have any queries outside this time I can approach any of my clinical colleagues via face-to-face or by email. This has not been a frequent or regular occurrence as consultants normally respond promptly with sound advice.

19.2 CNS team would also attend the speciality specific Urology Morbidity and Mortality Meetings. These meetings occur on a monthly basis with approximately 8/12 of the meetings being speciality specific.

20. Please detail all other meetings you attended which touched on matters of governance in urology, stating their frequency, who else attended, and how outcomes from such meetings would be implemented and monitored.

20.1 Thorndale Ward Meetings- six monthly. Attended by CNS, Staff Nurses and Health Care Assistants. Minutes were taken, with views and opinions valued. These were circulated for approval. Covered areas such as training, new policies/procedures, housekeeping issues, governance etc. For example, if new training needed to be implemented this was arranged and a log kept of the training, this was facilitated by the Clinical Sisters and then more recently the CNS team as at this time, we were also managing the Unit. These Unit meetings no longer occur, as Clinical Sisters, Staff Nurses and Healthcare Assistants are now under the management of the OPD. *Please see:*

24. Ward Meeting March 2020

20.2 Sisters Meetings- usually every 2 weeks. Attended by Surgery and Elective care Sisters from Southern Health and Social Care Trust (SHSCT) and Lead Nurses - remote link-in facilitated. Mainly inpatient issues discussed and only a small proportion was applicable to Outpatients Dept. Minutes were circulated and monitoring and implementation of any matters would have been carried out by the Ward Sisters and the Lead Nurses. I attended these meeting whilst in my role as a Clinical Sister.

20.3 Monthly 1:1 meeting with Lead Nurse - normally attended by Lead Nurse, CNS team and HoS (if available). Minutes were taken and areas covered included staffing, governance, training, equipment, clinical issues etc. Outcomes were implemented and monitored by both the CNS team and the lead nurse. These meetings are no longer happening as they have been replaced by a weekly Departmental Meeting. *Please see:*

25. Lead Nurse Meeting Nov 20

20.4 Urology Morbidity and Mortality Meetings. Occured on a monthly basis with 8/12 meetings being Urology specific- the CNS Team attends the Urology specific meetings. Others present include Urology Consultants, Speciality Doctors, Registrars and occasionally the Urology Ward Manager. Minutes were taken. These meeting were a good opportunity for learning and debating clinical issues. Specific tasks were allocated to specific members, e.g.,if more information was required to complete a morbidity/mortality case, then the Consultant in charge of their care was tasked to obtain this. The team at the next meeting would then discuss it. Audit presentations were also included in this meeting and again specific members were assigned to complete and present to the meeting.

20.5 Task and Finish Group Meetings. Established August 2021, to action the outcomes of the Urology SAI Recommendations 2021. Initially these meetings happened monthly, they are now less frequent. I was nominated to be a representative from the Urology CNS team. Below is an example of an attendance record from a meeting that occurred on 08/11/2021:

20.6 Dr Shahid Tariq (Co-Chair),Ronan Carroll Assistant Director (Co-Chair),Barry Conway, Assistant Director, Martina Corrigan, Assistant Director, Mary Haughey, Cancer Service Improvement Lead, Amie Nelson Head of Service, Wendy Clayton, Head of Service Chris Wamsley, Head of Service Clair, Quin, Head of Service, Sarah Ward, Head of Service, Tracey McGuigan, Lead Nurse, Paula McKay, Lead Nurse, Leanne McCourt, Clinical Nurse Specialist Urology, Matthew Kelly, Clinical Nurse Specialist, Janet Johnston, Social Worker Fiona Sloan, Family Liaison Officer, Catherine English, Head & Neck Cancer Nurse Specialist, Jane Scott, Acting Operational Support Lead ATICS/SEC

20.7 A Red, Amber, Green table (RAG) was used to detail and show progress for tasks needing to be actioned and the person/group of people allocated to do this. This would be included within the minutes of the meetings and circulated via email.

20.8 Urology Cancer MDT Business Meeting Biannual meeting held after MDT meeting. Attended by Urology Consultants, Radiology Consultant, Pathology Consultant, Urology Cancer CNS's, Macmillan Service Improvement Lead, HoS and MDT coordinator. A copy of the Operational Policy is circulated prior to the meeting, with attendees invited to comment. Topics such as ongoing/upcoming audits, update on various services within urology, e.g., provision of nurse-led services and red flag waiting times were also tabled for discussion. Minutes were circulated and ongoing themes discussed at subsequent meetings.

21. What is your overall view of the efficiency and effectiveness of governance processes and procedures within urology as relevant to your role?

21.1 Within my Urology role, there are a number of processes and procedures relevant to my role. These consist of both SHSCT policies and external guidance from professional bodies.

21.2 SHSCT policies are located on SharePoint and include:

a) Nursing and Midwifery Accountability and Assurance Framework. This was developed to ensure there are clear and effective lines of accountability and assurance for the professional governance of the

Nursing and Midwifery workforce in the Southern Health and Social Care Trust;

b) Whistleblowing policy for raising concerns at work;

c) Conflict, Bullying and Harassment Policy- replaces Working Well Together policy and Harassment at Work policy;

d) Nursing Supervision policy.

e) We are also provided with mandatory and role specific training, with a record of this being kept on the Trust's e-learning platform. This is discussed and assessed yearly at Appraisal/KSF/PDP meeting with the Lead Nurse.

21.3 Within Urology Nursing, the CNS team have also written various Standard Operational Policies (SOP), to ensure that detailed instruction is available ensuring that any team member can carry out a task correctly each time it is performed. *Please see:*

26. Standard Operating Procedure for Ultrasound Transperineal Probe Decontamination

21.4 Prior to setting up new Nurse Led review clinics, we (whole CNS Team) met with Lisa Houlahan (Head of Nursing, Patient Safety, Quality and Experience, Southern Health & Social Care Trust) and Sarah Ward (Lead Nurse) in May 2021. Issues discussed include the need for a Nurse Led Clinic policy to be written and endorsed at both Departmental and Trust level. To the best of my recollection, minutes of this meeting were not circulated with the attendees. The respective CNSs wrote these policies and accompanying screening policies. I have included a draft copy of the Nurse Led Prostate Cancer Review Policy and the screening policy that I was involved in writing. The policies have been endorsed at a local level by the Urology Consultants at a Departmental meeting, but not yet at Trust level as there have been issues around which forum the policies should be presented and signed off at (*please see 11. Nurse led review meeting on 130821, 12. Nurse led review meeting on 230921, 13. Nurse led review meeting on 021221, 14. Nurse led review meeting on 270122, 15. Nurse led review meeting on 240222, 16. Nurse led review meeting on 210422, 17. Nurse led review meeting on 260522, 18. Nurse led review meeting on 300622, 19. Nurse led review meeting on 300822, 20. FW notes from Urology Nurse led review meeting on 300822).* The Urology Consultants and HoS agreed that the Nurse Led clinics could proceed as they had been signed off locally; we are still waiting for an outcome with regard to the sign off of the policies at Trust level. This is despite there being a Trust process for sign-off of nurse led policies. *Please see:*

27. Draft Corporate Policy Template Nurse led Prostate Cancer follow up

28. Draft Policy Screening Template Prostate Cancer Nurse Led Clinics

21.5 The Datix system is also available to all staff and can be utilised to highlight concerns/near misses to improve governance, safety and quality.

21.6 As a CNS working within Urology in SHSCT, I feel there are adequate efficient and effective governance processes in place from a nursing perspective.

21.7 I am also regulated by the Nursing and Midwifery Council (NMC) and must maintain my status on the NMC register yearly in order to practise. I also have to revalidate my registration every three years via a robustly governed process. I adhere to the principles and standards for practice and behaviour as laid down in the NMC Code.

21.8 Externally I am also led by Regional, National and International guidelines and professional bodies. These include:

a) British Association of Urological Nurses- various guidelines;
b) British Association of Urological Surgeons- various guidelines;
c) European Association of Urology- various guidelines;
d) Federation of Surgical Specialty Associations (FSSA) – guidelines to assist with prioritising care during Covid 19;
e) National Institute for Health and Care Excellence (NICE);
f) Northern Ireland Cancer Network (NICaN);
g) Northern Ireland Practice and Education Council for Nursing and Midwifery (NIPEC);
h) Royal Marsden Manual of Clinical Nursing Procedures;
i) Royal Pharmaceutical Society- A competency framework for all prescribers.

21.9 These regional and national guidelines enhance the governance arrangements already in place within the Trust and NMC. They support my practice and validate my clinical decision-making.

Regional Review of Urology Services, Team South Implementation Plan (2010)

22. The Inquiry has received information that Martina Corrigan had a responsibility to implement and monitor the Regional Review of Urology Services, Team South, published on 14 June 2010. Were you one of the CNS's who engaged with Martina Corrigan on this matter?

(i) If so, what was your involvement?

(ii) Were your views taken on board? If yes, how? If no, why not?

(iii) Is there anything which could have been done differently at that stage or since that may have limited the extent of the problems subsequently experienced in urology and which lead to this Inquiry?

22.1 I was not involved in engagement with Martina Corrigan during this process and so I am unable to make comment on the questions above.

23. Do you consider that the role and functions of CNS were resourced properly from the outset? If not, what impact do you consider this had on service provision and patient care and safety generally?

23.1 I was not involved in this process. However, I do not feel the role and functions of CNS were adequately resourced. The two CNSs in post were also responsible for managerial duties, thereby reducing their availability for duties associated with a conventional CNS role. This impacted upon their ability to develop nurse-led services which may well have helped to reduce waiting times for patients.

Concerns and Risks identified

24. The NHS National Peer Review Programme produced the *National Peer Review Report: Northern Ireland 2015: An overview of the findings from the 2015 National Peer Review of Cancer Services in Northern Ireland* (TRU 84695). The table below shows the incidence of the common issues raised as immediate risks and serious concerns across the trusts. Those relevant to the Southern Trust (and Inquiry) are (TRU 84719):

(i) Absence or inadequate CNS provision;

(ii) Delays in seeing routine referrals;

(iii) Shortage of consultants in the specialty, or over reliance on locum consultants;

(iv) Absence of core membership of, or lack of attendance at, MDT leading to a significantly low percentage of MDT meetings being quorate;

(v) Lack of specialist radiologist or histopathologist input to the service or MDT.

From your perspective during your tenure as a CNS, did you have knowledge of or experience the risks and concerns set out at (i) – (v) above? If so, please provide full details. Did you report or speak about these issues with anyone else? If yes, who did you speak/report to and what happened?

24.1 When this report was released in 2015, I was not working within Urology or as a CNS. However, since coming into post, the points listed above are still relevant to varying degrees.

24.2 i) Although I was employed as a clinical sister in Urology from April 2017 and then as a CNS from March 2019, I did experience issues around absence or inadequate CNS provision from 2017. As mentioned in question 1, my initial application for Urology CNS was changed at time of interview to a clinical sister's post. I did still undertake a portion of Key Worker activity and attending the MDM, but could not support the single cancer CNS as much as was previously expected as I had other responsibilities within my role. It is my understanding that Kate O'Neill and Jenny McMahon did raise this as a concern with the HoS (Martina Corrigan). When I was successful in my application and appointed to the role of Urology CNS in March 2019, this predicament did not really change until management duties were removed from the CNS team in March 2021. The first official document I have where this is raised is at the monthly Lead Nurse meeting in August 2019 (*please see 29. Lead Nurse 1 to 1 Thorndale Meeting Aug 2019*). Eventually a Band 6 for OPD was appointed but as mentioned previously, there was no real change in my role until I was absolved of managerial duties in 2021. CNS provision has improved since the appointment of two further CNSs (one for benign service and one for cancer service) in September 2020.

24.3 ii) When initially in post, given the ongoing consultant recruitment issues, I was aware there was focus on managing the red flag/urgent patients. I was not fully aware of the implications for the routine cases and so I did not raise this issue. I now have a greater understanding of this issue, but unfortunately, it is not within my power to be able to fix it.

24.4 iii) When I came into post in 2017, there was a shortage of substantive urology consultants in post. This shortfall has been bridged to some degree by the use of locum consultants. Unfortunately, this remains an issue, with two substantive posts remaining unfilled. I did not raise this as a concern as it was already a known concern.

24.5 iv) When I began attending MDM in 2017, there were challenges around quoracy at MDM, especially regarding regular oncology attendance. On occasion, this led to delays in decision-making and to mitigate this, the patient would have been discussed at the regional meeting. I did not raise this as an issue as it is my understanding that this is noted and raised as a challenge in the annual MDT report.

24.6 v) Similar to point iv), there were challenges around radiology and pathology cover at MDM. This was especially evident when the usual pathologist/radiologist was on annual leave. Again, it did on occasion lead to delays with the patient having to be discussed at regional if the MDM team were aware that the pathologist/radiologist was going to be absent the following week. I did not raise this as an issue as it is my understanding that this is noted and raised as a challenge in the annual MDT report.

25. If you did experience the issues at (i) – (v), what is your view of how those risks and serious concerns came about?

25.1 i) My view of why there was an absence of or inadequate CNS provision is there was a chronic, longstanding underfunding of this area of the workforce. This is corroborated in the Macmillan “Specialist adult cancer nurses in Northern Ireland. A census of the specialist adult cancer nursing workforce in the UK” report of 2014 which states that the CNS workforce in Northern Ireland has not kept pace with the increasing number of people diagnosed with cancer each year. Concerns are also raised regarding an aging CNS workforce in Northern Ireland. *Please see:*

30. CNS-census-report-northern-ireland

31. A census of the specialist adult cancer nursing workforce in Northern Ireland 2021

32. Macmillan Partnership Application 2014

25.2 The lack of CNS in the SHSCT results in patient inequality and patients being disadvantaged when compared regionally. *Please see:*

30. CNS-census-report-northern-ireland

31. A census of the specialist adult cancer nursing workforce in Northern Ireland 2021

32. Macmillan Partnership Application 2014

25.3 At a national level it is acknowledged that NI has a shortage of CNS posts compared to the rest of the UK and this gap is widening.

Table 1: UK Benchmarking – WTE Cancer CNS : Cancer Incidence

	ancer Incidence (2013)	VTE Adult Cancer CNS	Average CNS caseload / WTE
Wales	19,026	184.3	103
Scotland	31,013	265.0	117
England	280,000	3088.0	91
Ireland	11,000*	76.2**	144

urce Macmillan census of the specialist adult cancer nursing workforce NI 2014, whereby incidence data sourced from personal correspondence with the biostatisticians/researchers at the Northern Ireland Cancer Registry in August 2014

15/16 position and includes 11 WTE charitably funded posts with no exit strategy.

25.4 This issue is slowly being addressed but as it did not happen overnight and will take considerable time to redress it.

26. In your view, what is or was the impact on patient safety and care planning of the issues at (i) – (v), and what was done or could have been done to address these problems? Please provide examples as relevant.

26.1 i) Absence or inadequate CNS provision meant that fewer patients had a named keyworker or for those that did, access to the keyworker would have been on a more limited basis. This could result in less support and advice for patients and their families, leading to a more disjointed journey for them. This Reduced CNS provision also meant that there were less CNS-led clinics, meaning a reduction in the "freeing up" of Consultant time for the more complex cases.

26.2 This redress is in progress as per the exert below from the Macmillan Partnership Application. *Please see:*

30. CNS-census-report-northern-ireland

31. A census of the specialist adult cancer nursing workforce in Northern Ireland 2021

32. Macmillan Partnership Application 2014

"The five year incremental, prioritised Cancer CNS workforce plan has been approved through HSCB / PHA senior management team and has Department of Health support. The cancer CNS workforce expansion is a commissioning priority commencing 2016/17 for 5 years and was outlined in the commissioning plan. A Urology CNS is included within the plan for 2018 /2019. This was included in the plan as a Band 6 post but the Service Manager has requested the post be appointed at Band 7. This has been discussed and agreed with the Nurse Consultant PHA / NICAN. There is an overwhelming deficit in the number of CNSs within SHSCT. By increasing the number of nurse specialists and through inclusion of support worker roles within the CNS workforce plan this will support skill mix by assisting in the delivery and co-ordination of care, education and support, under the supervision of Clinical Nurse Specialists for patients with cancer.

26.3 There are currently two Urology CNSs within the Trust providing care for patients with all urological disorders. Investment in a 1.0 WTE Urology CNS will further enhance the uro-oncology service and the development and co-ordination of the service. This CNS will work primarily with patients with prostate and renal cancer. The 0.25WTE band 3 support worker will provide administrative support for the team and act as a point of contact for patients to ensure the most effective use of resources."

26.4 In addition to the investment of the 1.0 WTE (my post), there have also been two further Urology CNSs appointed in 2020.

26.5 ii) As priority has been given to reviewing red flag and urgent cases, the routine cases have not been reviewed. This will have caused frustration and distress to the patients concerned and due to the time periods involved may lead to routine issues becoming more urgent. I am unsure how this issue can be adequately addressed given the volume of appointments required versus the number of urology consultants in post.

26.6 In my experience, the red flag cases are “safer” to triage and manage as there are clear guidelines as to what is required. The “routine” cases can be more ambiguous and would require experienced management to avoid inappropriate use of resources and a potential detrimental effect on waiting lists. Going forward, triage of red flag referrals could be an area that the CNS team could assist with, providing suitable training, protocols and resources were in place.

26.7 iii) The shortage of consultants and over reliance on locum cover long-term is not good for the service. It results in the consultants in post having a greater workload than if there were more members in the team, e.g., having to be on call more often means less time for planned OPD clinics and planned theatre time. I imagine it can also affect work life balance for those involved. Having different locums in post for short periods can also impact on continuity of care for patients and makes working relationships in the team more difficult as it does take time for people to settle in and become established within the Unit. The consultants in post are managing a very difficult situation to the best of their ability and I feel they are supported by HoS (Wendy Clayton). There have been several attempts to recruit substantive Consultants into post but to date this has not been successful. This was also a topic of discussion at the recent Urology Team “away day” – what changes can be made to the application process to make it more attractive to potential candidates.

26.8 iv) Absence of core membership, in particular oncology representation, made the decision-making process at MDM more difficult and lengthy. The expertise of the oncologist was not available to help make decisions about the appropriateness of additional oncology treatments. This meant that more cases had to be referred and discussed at the regional meeting. As mentioned previously, this was highlighted in the MDM Operational Report. In more recent times, this has been addressed and the situation has improved dramatically. There is now regular representation at the SHSCT MDM by clinical and medical oncology.

26.9 v) In my view, the lack of radiology representation impacted more on patient care than the lack of histopathology, as it was a more frequent occurrence. As in point iv) above this on occasion did lead to delays in decision-making, with cases having to be discussed regionally. More recently, we now have two radiologists who have been appointed to cover MDM meaning that absence of radiology cover rarely happens now.

27. In your experience, do the concerns and risks at (i) – (v) continue to exist?

27.1 i) In my experience the level of CNS cover has improved to a point where I am not concerned as previously. However, we have had a recent retirement in our team and the successor has not yet been appointed. The post has been advertised.

27.2 ii) In my experience, this concern does continue to exist.

27.3 iii) In my experience, this concern does continue to exist. The most recent advertising drive has been unsuccessful.

27.4 iv) In my experience, this situation has improved in terms of oncology representation to the point that it is no longer a risk.

27.5 v) In my experience, this situation has improved and is no longer a concern.

28. Did you ever speak to anyone or complain about any other matter impacting upon your role or on patient care? If yes, please provide full details and what, if anything happened as a result.

28.1 Please see reply to question 7.

29. How are concerns raised regarding patient care and safety, or problems with your role in general impacting on patient care, reflected in nursing documents? Are governance concerns recorded or reported by CNSs reflected in Trust governance documents?

29.1 Within the Nursing and Midwifery Accountability and Assurance Framework, there are sections that deal with professional requirements, governance structures- including roles and responsibilities. It also encompasses learning development and support as well as instruction raising and handling concerns and compliance issues. However, this is an “overarching” document and does not reflect concerns or problems within individual or departmental nursing roles. These documents may exist but I am not aware of any governance documents that record or report this other than the Datix system which is used by an individual to raise issues or concerns.

29.2 Externally, the NMC publish outcomes of their professional hearings and I feel there is lot that can be learned from this. It is very clear and transparent whilst protecting patient identity. *Please see:*

33. Nursing and Midwifery accountability and assurance framework

30. What could improve the ways in which concerns are dealt with to enhance patient experience and increase your effectiveness in carrying out your role?

30.1 If CNSs were made aware of the outcome of concerns raised by others (once appropriately dealt with) or even made aware of the outcome of concerns raised by themselves, I feel this could improve my ability to carry out my role and hence have a positive impact on patient care. I would have more awareness of events that led to a negative impact on patient care (for whatever reason) and so could learn from these errors, oversights or misjudgements. Secondly, I would then not go on to make similar misjudgements and would be more cognisant of the work of others.

Patient Experience Surveys

31. PHA (supported by Macmillan Cancer Support) commissioned a regional cancer patient experience survey (CPES) in 2015 (AOB 01714), the first time the survey was undertaken in Northern Ireland. Access to a clinical nurse specialist came out as a key issue. Was this survey, *or any external patient survey*, and its findings, ever brought to your attention, and if so how and by whom? What, if anything, was done to address concerns about access to CNSs following this or any survey raising similar concerns? Please explain your answer in full.

31.1 I was not working as a CNS or within the Urology Department when the findings of this report were published and so cannot make comment on this in relation to Urology or the CNS role at that time. However I do now understand that the CPES 2015 report was used to illustrate the need and request the funding for more CNS provision in Northern Ireland, this is documented in Macmillan Partnership Application. *Please see:*

30. CNS-census-report-northern-ireland

31. A census of the specialist adult cancer nursing workforce in Northern Ireland 2021

32. Macmillan Partnership Application 2014

32. The Southern Trust carried out its own *Urology Cancer Patient Experience Survey* in August 2015 (AOB 01721) and found that 75% of patients had the opportunity to meet a Clinical Nurse Specialist and 50% were provided with contact details of a clinical nurse specialist. Was this survey, *or any internal patient survey*, and its findings, ever brought to your attention, and if so how and by whom? What, if anything, was done to address concerns about access to CNSs following the survey or any other feedback received on this issue? Please explain your answer in full.

32.1 I was not working as a CNS or within the Urology Department when the findings of this report were issued and so cannot comment on this in relation to Urology or the CNS role at that time.

32.2 However, I was involved in the Urology Service Patient Experience Survey March 2020. 118 patients with a renal, prostate or bladder cancer diagnosis within the previous 12 months were invited to participate with 68 patients (58%) completing and returning the survey. *Please see:*

34. Urology Service: Patient Experience Survey March 2020

32.3 The key findings in relation to the CNS role are as follows:

a. The majority of respondents (88%) said they were given the name of their CNS. This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 73%, the NI score was 66% and the regional prostate CPES response rate was 83%.

b. 75% of respondents were able to contact their CNS or key worker if they had questions or needed additional information

c. 85% were able to get information or answers from their CNS they could understand all or most of the time. This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 95%, the NI score was 93% and the regional prostate CPES response rate was 93%.

d. At the end of the survey, patients were asked for feedback on future service developments in the Urology Cancer Service in relation to the provision of a Clinical Nurse Specialist clinic to get results of investigations and to attend a nurse-led clinic for follow-up appointments. 79% of respondents were happy to attend a Nurse Specialist clinic for results of investigations, 7% would not be happy, 4% were unsure, 13% did not answer.
e. Patients were also asked if they would be happy to attend a Nurse Specialist Clinic for follow-up appointments after treatment had finished? 79% of respondents were happy to attend a Nurse Specialist clinic for results of investigations, 6% would not be happy, 3% were unsure, 12% did not answer,

32.4 The findings above show that progress was ongoing in terms of number of patients given details of a named CNS (I am mindful that our smaller survey cannot be directly compared with the much larger CPES survey) but that work was still needed around access to information and answers from their CNS. At this point in time there were two Urology Cancer CNS's in post (still with managerial responsibilities) and funding was being sought to appoint two further CNS's (one for benign services and one for cancer services).

33. How, in general, is feedback to inform practice relayed to the CNS staff?

33.1 There are several ways in which feedback informs practice and is relayed to CNS staff.

33.2 This can come directly from the patient and their family in verbal form. There are also other methods for patients to comment on their care, e.g., the Care Opinion online platform; this feedback is then relayed to the Health Care Professionals concerned.

33.3 Feedback can also take the form of patient surveys as previously mentioned in answer to questions 31 and 32.

33.4 Patricia Thompson (CNS) and I are currently working on a project with Macmillan whereby patients are invited to have one-to-one conversations with a Macmillan Peer Facilitator. Peer facilitators are people affected by cancer who have been recruited by Macmillan in a voluntary capacity and have undertaken bespoke facilitation and safeguarding training to enable them to engage with their peers around specific issues and provide feedback of their findings to Macmillan and their partners. Peer-led engagement is based on the principles of shared understanding, empathy and respect for each individual's cancer experience, resulting in meaningful conversations about 'what matters'. It is hoped this will provide authentic feedback and reflection, and help inform future service improvements and developments. We hope to have the finalised report in the near future; this will be presented at the departmental meeting and an action plan developed in conjunction with Mary Haughey (Macmillan Service Improvement Lead) as to how best improve on any areas raised.

33.5 At our weekly departmental meeting, there is also a section for complaints and compliments and any relevant matters are brought to staff's attention.

33.6 The Datix system can also be a way of providing feedback, but exposure is limited as it usually only the persons concerned that are involved in addressing the Datix.

33.7 There are also regular patient safety communications via Trust email. These are normally concerned with medication incidents.

34. In your view, is there a potential for breakdown in communication for patients regarding their care if the CNS is not part of their care team? Do you consider that the absence of a CNS in a patient's care pathway presents a risk to patient care and safety? If yes, please provide examples.

34.1 In my view, there is a potential for breakdown in communication for patients if the CNS is not part of their care team but it should not be a risk to their care or safety.

34.2 According to the Macmillan CNS impact brief and the NICaN Clinical Guidelines 2016 and the MDM operation policy (*please see 35. Macmillan CNS impact brief, 21. NICaN Clinical Guidelines 2016 and 36. V2 Urology Cancer MDT Operational Policy 2020)* the role of the CNS as a keyworker is a supportive one. A patient's cancer journey can be complex and involve care from different teams at different points (e.g., Urologist and Clinical/Medical Oncologist). The CNS provides a constant link throughout this course and can achieve this by being a point of contact for queries or giving appropriate and relevant information. They can also liaise with other professionals involved in the patient's care. The CNS as a keyworker can also signpost/ refer patients to other services that can offer tailored support for their needs, e.g., counselling or benefits advice.

35. What is your view of the effectiveness of patient satisfaction surveys as a means of informing development, planning and delivery of services? Are these survey outcomes shared with staff? Do management act on suggestions?

35.1 In my view, patient satisfaction surveys can highlight needs or deficits within a service. The results of these surveys can then be used to request or lobby for additional resources. The actual results of surveys relevant to me have been shared, e.g., local urology surveys and CPES 2018 survey. I believe management do act on suggestions, as the CPES surveys have been instrumental in increasing the CNS workforce in Northern Ireland.

Secured slots for patient discussions following MDT meetings

36. The 2015 *National Peer Review Report: Northern Ireland 2015* also identified good practice within urology Southern Trust (TRU 84717), including having *Secured slots in clinic following MDT meeting for patient discussion (Southern)*. Please explain, as relevant, your experience of how these slots for patient meetings operated, who attended, the effectiveness of these slots, and whether they were a regular post MDT feature and remain so? If these slots no longer operate, why not and what, if anything, replaced this system?

36.1 These slots remain in operation, with each Urologist provided with six protected review slots per week (taken from the MDT Operational Policy). It is the intention of the MDT that all patients receive this review by the end of the first week following their MDM discussion. If this is not possible, on occasion the Chair of MDM may allocate the review of any patient to another consultant. This occasionally happens during periods of annual leave where the outcome of the meeting is particularly time dependent, e.g., oncology referral post testicular cancer diagnosis.

36.2 Following MDM discussion, the chair for that meeting signs off the outcomes. There is also an email sent to the core members and Urology Consultant's secretaries by the MDM co-ordinator, detailing which patients need a post MDM clinic review. The MDM co-ordinator tracks these appointments to ensure the appropriate patients receive a review appointment.

36.3 The secretaries then appoint these patients to the protected review slots in the responsible consultant's next review clinic.

36.4 Those present at the clinic review are consultant, CNS, occasionally a medical student and the patient/family.

36.5 These protected review slots mean that the patient and their family are informed of the outcome of their MDM discussion in a timely way, leading to prompt commencement of treatment /ordering of scans or referral on to other departments. It also helps the CNS to plan activity by being present at these consultations.

37. What type of information was sought from or provided to the patient during these slots?

37.1 During these slots, the patient is provided with:

a) Site specific written information (pertaining to their particular diagnosis);
b) If appropriate, written information on treatment options, e.g. ,for prostate cancer – radiotherapy, hormone treatment, radical prostatectomy;
c) If appropriate, BAUS information sheets in relation to surgery;
d) Permanent record of consultation *(please see 4. Record of consultation)* - detailing their diagnosis and what to expect next. If they consent to an HNA appointment this will also be indicated with an approximate appointment date;
e) Cancer information core pack – leaflets about local services, benefits advice, etc.;
f) Keyworker contact card – with CNS name and telephone number.

37.2 The CNS gives all of the above documentation to the patient.

37.3 During the consultation, the Consultant will seek from the patient such information as their family/home situation, fitness and their knowledge of the findings to date. This helps to ascertain patient wishes and appropriateness for treatment options. Once the outcome of the MDM meeting has been discussed with the patient, the consultant will also ask questions to ensure that the patient has understood, and will also invite the patient/family to ask their own questions. If there is a choice of treatment decisions to be made and the patient needs time to consider this, another appointment will be arranged to discuss further if the patient wishes.

38. Were these meetings recorded? If so, where?

38.1 These meetings with the patient are recorded by the consultant in the medical notes, with a letter then being dictated and uploaded to ECR as well as a paper copy being posted to the intended recipient e.g. GP or Oncologist.

38.2 The CNS also records these episodes on ECR progress notes, CaPPS and via the CNS proforma.

39. What is your view of the effectiveness of these meeting slots? Do you consider they enhanced patient care, experience and safety? Please explain your answer.

39.1 My view of these protected review slots is that they do enhance patient care and their experience as the consultant has a number of these protected slots within their review clinics, enabling the secretary to appoint post MDM patients for prompt review. This results in less time for the patient to wait to hear the results, hopefully, reducing their anxiety. These protected review slots also mean that the patient and their family are informed of the outcome of their MDM discussion in a timely way, leading to prompt commencement of treatment /ordering of scans or referral on to other departments. It also helps the CNS to plan activity and be present for these consultations.

39.2 Ensuring that outcomes are managed in an organised and timely manner, in my opinion, also enhances safety.

Attendance at MDTs

40. The Inquiry is interested in MDT (Multi-disciplinary Team) attendance. By way of example, the *Urology MDT Annual Report for January - December 2016* recorded CNS attendance at 98%. By contrast, radiologist attendance was 58% and oncologist attendance was 28% (AOB 01710). In 2019, CNS attendance was 98% while the Clinical Oncologist representation was 5% (TRU 104183). What in your experience, if anything, is the impact on MDT meetings when other specialists are absent from

these meetings and also as regards patient care planning and governance generally? Please provide examples as relevant.

40.1 In my experience, when other specialists are absent from the meeting, this can lead to a delay in patient discussion and therefore delayed decision-making as the patient discussion would have to be deferred. The consequence of this could mean delayed referral for treatment.

40.2 Periodically, this happened on consecutive weeks for example if an MDM member was on annual leave. On these occasions, the chair of the local meeting would request an "ad hoc" discussion about the patient at the end of the link into the specialist meeting as a way of mitigating this.

40.3 With the Urology Cancer MDT Operational policy there is also provision made if a decision needs to be made prior to the next MDM. On these occasions, the Clinician concerned may contact their colleague to arrange/discuss management. These decisions are to be recorded in the patient's medical notes, with the outcome then being discussed and endorsed at the next MDT meeting.

41. Do you consider that the role of the CNS was valued within the MDT? Please explain your answer.

41.1 I consider the role of the CNS to be valued within MDT. We are regularly asked for our view or opinion on patient care. The CNS will frequently have had additional contact with the patient/family prior to the meeting by way of telephone conversations regarding updates or addressing queries, and so can have further insight into current circumstances or patient expectation/ opinion.

41.2 As I also carry out the prostate biopsies, I am often asked for my opinion on the technicalities of the procedure or how well it was tolerated etc. This can assist when the decision-making process if the procedure needs to be repeated, e.g., a general anaesthetic procedure may be more appropriate than under local anaesthetic.

41.3 I do feel that my views are listened to and taken account of with respect by all of the attendees.

42. Did you feel able to contribute to MDT discussions generally? If not, please explain in full.

42.1 I do feel able to contribute to MDT discussions generally and as mentioned previously, the CNS contribution is regularly actively sought by other members. I also refer patients from my nurse-led clinics for discussion at MDM and so will complete the MDM proforma to ensure the relevant information is available for the chair of the meeting to present these patients.

43. At MDT meetings and generally, were your views sought by clinicians on proposed patient care pathways?

43.1 CNS views are sought by clinicians on care pathways, both at MDM and in general. As mentioned previously, the CNS will often have a more in depth knowledge of the patient's personal circumstances or their expectations/ views going forward. For example, the CNS may have an awareness that the patient would not be fit to or want to (for various) reasons, travel to Belfast for four weeks of radiotherapy. In these circumstances, I ensure that this information is communicated and recorded at MDM. This enables the decision-making process to be reflective of the patient's wishes and the Consultant can then explore the options further at the review meeting. In addition, if the patient has expressed a wish for direct referral on for further adjuvant treatment, the CNS can relay this at MDT and the referral can be expedited. This can happen if a patient is aware of their diagnosis to date and is just waiting on a staging scan to be discussed at MDM prior to onward referral. The patient is sent a letter detailing the outcome; the referral can be made directly at the MDM meeting, negating the necessity for the patient to wait on another review appointment.

44. Did you feel able to contribute to MDT discussions if you did not agree with the proposed plan for a patient?

44.1 I do feel able to contribute to MDT discussions if I do not agree with the proposed plan. This is normally for the aforementioned reasons, the CNS, on occasion will have additional insight into personal circumstances.

45. Was it your experience that differing views on proposed patient care pathways were discussed among the clinicians at MDTs? How, in your

experience or knowledge, were differing views on what treatment a patient should receive resolved at MDTs?

45.1 It is my experience that on occasion, different views on proposed patient care were discussed among clinicians at MDT. This could be due to findings of a new study or new guidelines needing to be taken into consideration. In my experience, this always took the form of healthy debate and was conducted professionally, with a satisfactory outcome being reached. On the rare occasion where a final decision could not be made, the case would be listed for discussion at the specialist meeting.

46. How were patient outcomes and decisions made at MDTs recorded and acted upon?

46.1 As per the MDT Operational Policy.

46.2 The MDM co-ordinator, recorded patient outcomes and decisions made at MDT. This is normally updated on CaPPS at the time the patient is discussed. The co-ordinator then sends these entries to the Chair of the meeting for sign off. A MDM letter is then generated for the GP and posted to the GP. This generated letter is also uploaded onto ECR. The MDM co-ordinator would, then circulate an email with the validated outcomes, to the MDM members, with a separate email detailing patients that require a protected review in clinic. The co-ordinator will also ensure that direct referrals are implemented. The co-ordinator tracks these outcomes to ensure regional access targets are met.

46.3 The secretary then arranges the protected review appointments for the patient with the consultant. During this appointment the outcome of the MDT meeting is discussed and a plan of treatment actioned.

47. What, if any, role did the CNS have in ensuring that MDT decisions regarding patient care and treatment were followed through? If not the CNS, who was responsible for this and how was it done?

47.1 The CNS did not have a role in ensuring that MDT decisions are followed through. As previously mentioned in the NICaN Guidelines and the Macmillan

CNS impact brief, the role of the CNS as a keyworker is a supportive one (*please see 35. Macmillan CNS impact brief, 21. NICaN Clinical Guidelines 2016 and 36. V2 Urology Cancer MDT Operational Policy 2020).* This support role can involve the CNS for example, addressing patient queries regarding expected upcoming appointments or scans. I often, after being contacted by the patient, check up on dates. Using ECR, SECTRA or PAS I am oftentimes aware of the scan or appointment date before the patient receives the confirmation letter.

47.2 It is the role of the co-ordinator and secretary – to ensure the patient receives the review appointment, the co-ordinator to ensure direct referrals are processed. The Consultant is responsible for imparting the MDM decision to the patient and ensuring that the appropriate plan is actioned.

47.3 If, for example, I have listed a nurse-led patient for discussion and the outcome is that he remains suitable for nurse led care under the prostate cancer active surveillance pathway, I will arrange a review at a nurse led clinic and action this plan. The outcome from the MDM meeting will clearly state that the CNS will action the MDM plan.

48. What is your view of how CNS and other professionals communicated within MDT? If there were problems with communication, is it your view that this impacted or had the potential to impact on patient care and care planning?

48.1 It is my view that the CNS and other professional members of the MDM predominantly did communicate professionally and with respect.

48.2 I do recall an occasion where this did not happen and I felt it was very unprofessional at the time. I do not remember the exact date, but I do recall it was after the start of the Covid pandemic as several members were remotely linked into MDM. Mr O’Donoghue (Consultant Urologist) was chairing the MDM that week and had commenced the meeting two or three minutes prior to the scheduled start time of 2.15 pm. Mr O’Brien (Consultant Urologist) then joined the meeting at approximately 2.15 to discover the first patient (I believe it may have been one of this patients) already being discussed. I do not recall the exact words spoken by Mr O’Brien when he realised this, but I do recall I was made to feel very uncomfortable by the way he spoke to Mr O’Donoghue. It reminded me of the way a parent may chastise a “naughty” child and lasted several minutes. The meeting then continued as normal and patient care and planning was not impacted.

48.3 I felt this incident was worthy of mention as in my opinion, it was a very disrespectful way for Mr O'Brien to address Mr O'Donoghue, especially in front of colleagues. I do recall asking Mr O'Donoghue after the meeting if he was "O.K." and he told me he was. I am not sure if this was ever formally escalated.

49. Did you experience any other difficulties with MDT generally or clinician care and practice which may have impacted on your role, patient care and clinical risk?

49.1 The only other difficulty that I am aware of is difficulty linking into the specialist meeting (Belfast). At approx. 3.15pm, the physical members of the SHSCT team pause the local meeting and link in to the specialist meeting in Belfast. If the local chair is not physically present, they also link into Belfast remotely to present the SHSCT patients. There appears to be a technical issue with the remote chair linking in and the consultants physically present at our local meeting often have to present the patient to Belfast. This occurs each time the Chair is linking in remotely and is not physically attending the MDM in Craigavon Hospital. It can happen several times per month, depending on who is chairing the meeting. The chair of the meeting is allocated time within their schedule to prepare the patient histories for the meeting and so if another consultant has to be present these, they may not be fully aware of the particulars of the case other than what is written on the MDM summary.

Uro-oncology consultations

50. The Inquiry has received information which indicates that communication was difficult with some consultants "that CNSs were not invited to be present at uro-oncology consultations by all consultants. Please provide any information you have on this issue, whether through first-hand experience or through having heard the concerns of others, including any information relating to the consultants who adopted this approach and your understanding of their reasons for doing so.

50.1 It was not my general experience that CNSs were not invited to be present at uro-oncology consultations by all consultants. It is not that CNSs were actively discouraged from being present at uro-oncology consultations, but prior to 2019; the presence of a keyworker in the actual appointment or an introduction after the appointment was by "invitation only". This has since changed due to expansion of the CNS team and as we now have capacity to actively screen results clinics for those patients requiring a keyworker. In my experience, certain consultants would have sought more keyworker input than others would. I do not know why some individual consultants adopted this approach more than others. I do recall Mr O'Brien stating in general conversation to me, "Keyworker, what is this Keyworker role?". I do not recall the specific date or who else was in the vicinity at the time of this conversation. When he arrived to do his clinic, I had said to him that I was available as keyworker for his clinic. In my opinion, his response was verbalised in the context of a condescending tone, I was "taken aback" and do not accurately recall my response. Consultants were aware of the importance of the keyworker role as per Kate O'Neill's email from June 2017 (*please see. 1. Sister Charge Nurse Band 6 Job Description, 37. Keyworkers email to Sarah Ward and Wendy Clayton, 38. Presentation overview of keyworker activity and 39. Email from Kate O'Neill re keyworker). I*t is also listed within the Nican Clinical Guidelines document 2016. *Please see:*

35. Macmillan CNS impact brief, 21. NICaN Clinical Guidelines 2016 and 36. V2 Urology Cancer MDT Operational Policy 2020

50.2 I would like to put this response in context.

50.3 Whist I was employed as a Clinical Sister in Thorndale from April 2017- March 2019, the focus of my position was not that of a keyworker, although it did comprise a limited part of my role. *Please see:*

1. Sister Charge Nurse Band 6 Job Description, 37. Keyworkers email to Sarah Ward and Wendy Clayton, 38. Presentation overview of keyworker activity and 39. Email from Kate O'Neill re keyworker

50.4 I have also included an email with figures that I had kept of my keyworker activity as well as a presentation I delivered at a Urology Morbidity and Mortality meeting (I am unsure of the date). *Please see 35. Macmillan CNS impact brief, 21. NICaN Clinical Guidelines 2016 and 36. V2 Urology Cancer MDT Operational Policy 2020*. It should also be noted that the working pattern of the CNS, influenced which Consultant Clinics she covered.

50.5 Keyworker figures for one CNS are as follows:

a.

July 2017- 26th Feb 2019 (worked as clinical sister and so keyworker was not a central part of my role)	Number of patients
AJG (Glackin)	4

AOB (O'Brien)	1
JOD (O'Donoghue)	16
MDH (Haynes)	35
MY (Young)	6
[redacted]	13
TOTAL	**75**

b.

27th Feb 2019- March 20	Number of patients
AJG (Glackin)	23
AOB (O'Brien)	14
DH (Hennessey)	3
JOD (O'Donoghue)	32
MDH (Haynes)	121
MTY (Tyson)	5
MY (Young)	14
[redacted]	4
TOTAL	**216**

c.

April 20-March 21	Number of patients
AJG (Glackin)	44
AOB (O'Brien)	1
Elamin	1
JOD (O'Donoghue)	46
NK (Khan)	1
MDH (Haynes)	55
MY (Young)	11
SOM (Omer)	5
TOTAL	**164**

d.

April 21- 14th Oct 21	Number of patients

AJG (Glackin)	15
JOD (O'Donoghue)	27
NK (Khan)	19
MDH (Haynes)	33
MY (Young)	10
SOM (Omer)	15
UPRITCHARD	1
TOTAL	**120**

50.6 As mentioned, previously I was also undertaking Clinical Sister Duties, but the consultant/s in clinic would have been made aware of who was available to carry out the keyworker role. We endeavoured to see that there was always someone available for this role to the best of our ability. However, it was not always possible due to CNS staffing and other responsibilities as previously mentioned. If this was not the case, the consultants had access to information packs, leaflets and CNS contact cards within each clinical room cupboard in Thorndale and could provide these to the patients.

50.7 Prior to 2019, the CNS would not always have been present in the room when the patient was given their diagnosis. However, the consultant would have informed the "keyworker" and given us the medical notes, the patient would have been asked to wait and the "keyworker" would then have taken them to a clinical room, discussed the diagnosis, and given the appropriate information. My understanding at the time is that the process did commonly occur in this order as there may have been more than one results clinic running, there was only one cancer CNS in post until March 2019, with the clinical sister also involved in running a busy diagnostics unit.

50.8 I was appointed to the CNS role in 2019, but as previously mentioned; managerial duties still formed a significant proportion of my role. When the Covid pandemic impacted in April 2020, we lost the ability to review patients in Thorndale, with appointments that needed to be face-to-face – predominantly newly diagnosed patients, moving to the Ambulatory Care Unit at the front of Craigavon Hospital. This Unit was only available on certain days and at certain times due to other specialities using it too. This meant that the CNS was very closely involved in co-ordinating the appointments at this time. As there were less managerial duties owing to our Band 5 nurses and Health Care Assistants, having been redeployed, the CNS was always available to be present during these consultations. When we eventually were able to move these appointments back to Thorndale and then with the "dropping" of managerial duties, this practice continued. With three CNSs in post, a CNS is now delegated for each results clinic (excepting in exceptional circumstances e.g. sick leave) and the CNS actively screens the clinic beforehand and is aware of patients needing keyworker input. Currently, given that the CNS team now has expanded, is no longer responsible for managerial duties and each member now has a job plan, the role of proactive keyworker is made much more evident. I would say the issue no longer exists.

If you were directly involved, please provide details on anyone you spoke to on this issue, when you spoke to them, and what, if anything was done to address the issue. Does this issue persist? If not, how was it resolved?

Nurse-led services

51. The Inquiry has received information that nurse-led services were met with resistance from some of the medical staff who felt that those roles were not a nurse role. What, if anything, do you know about this resistance from medical staff? You should include all relevant details in your answer.

51.1 I have not experienced resistance from medical staff in the setting up and progression of my nurse-led services. As previously indicated, my nurse-led services did not actually commence until October 21, with preparation for these beginning March/April 2021. All of the current consultants refer into and use my nurse-led services regularly. I also had great support in learning the prostate biopsy technique from Mr Glackin and Mr Haynes.

52. Do you share the view that nurse-led procedures and prescribing has released pressure on the medical teams? Do you consider that urology nurse-led procedures have any other advantage for patients in terms of waiting lists, follow-up or general outcomes?

52.1 I do share the view that nurse-led procedures and prescribing have released pressure on medical teams. This benefit is evident in several spheres of the patient journey and experience. Key impact of CNS led activity: Macmillan CNS impact brief). *Please see:*

35. Macmillan CNS impact brief, 21. NICaN Clinical Guidelines 2016 and 36. V2 Urology Cancer MDT Operational Policy 2020

a) Free up the consultant resource to concentrate on patients that are more complex. Leading to a reduction in waiting lists;
b) Intervening to management side effects, reducing and preventing unplanned admissions;
c) Empowering patients to make informed decisions about their condition or treatment;
d) Addressing the holistic needs of patients;
e) Delivering safe effective, evidence based care;
f) Value for money by freeing up consultant time and reducing admissions and GP appointments;
g) Identifying and implementing service improvement and efficiencies;
h) Perceived as more accessible than consultants – able to address queries in a more timely way;
i) Provide continuity of care for patients.

53. Do you feel the CNS carrying out nurse-led roles and procedures has increased urology capacity overall and, if so, is the role of the CNS adequately supported by management to fulfill their role?

53.1 As previously mentioned, I do feel that CNS activity has increased urology capacity. I do feel supported by management except in the issues previously mentioned in question 8 around administration support.

Involvement of the CNS

54. The Inquiry has received information that Mr O'Brien did not routinely permit the Clinical Nurse Specialists to provide support as key worker to his oncology patients*.* Please provide any information you have on this issue, whether through first-hand experience or having heard the concerns of others. If you were directly involved, please provide details on anyone you spoke to on this issue, when you spoke to them, and what, if anything was done to address the issue.

54.1 As evidenced by my previous figures (question 50), the number of cancer patients for whom I was keyworker was fewer than for other consultants. I would also like to note that these are the figures of one CNS and not the CNS team. It should also be considered, that the number of patients attending Mr O'Brien's review clinic had been amended prior to me taking up post. His clinic appointment slots were longer and so he reviewed less patients per clinic. I am of the understanding that this arrangement came about between Mr O'Brien and the HOS (Martina Corrigan) as there had been previous issues around clinics overrunning and affecting staff and patients- I have no written evidence of this or email trails as it happened prior to my role. I believe other staff members made me aware of this verbally.

54.2 I was a keyworker for a number of his patients, I have no insight as to how Mr O'Brien selected which patients needed or received CNS input. I did not raise this as a concern.

55. In the report concerning the nine serious adverse incidents which were reviewed in 2020-21 and which concerned cancer patients in the care of Urology Services, it was found that the nine patients had not been referred to a Cancer Nurse Specialist, contact numbers had not been given, and a Cancer Nurse Specialist had not been given the opportunity to provide support and discharge duties to the patients. Please provide any information you have on this issue, whether through first-hand experience or having heard the concerns of others.

55.1 The SAI investigation findings have been shared with the Urology team. As mentioned previously, I have no understanding as to how Mr O'Brien decided which patients he referred for keyworker input. I was not aware of the scale of the issue prior to the SAE report and subsequent findings.

55.2 The Urology CNS team responded via email to the draft findings of this report to Patricia Kingsnorth on 29/03/2021 (*please see 40. Email to Patricia Kingsnorth fw important urology draft SAI reports).* We were able to access this draft report via viewing the Egress files- we were not permitted to download a copy of this and I am therefore unable to supply it. Our comments were then forwarded to the chair of the review, Dr Dermot Hughes.

55.3 Within this email we highlighted the supportive role of the keyworker and our aversion to the keyworker being referred to as a "failsafe" regarding the implementation of key actions from MDM. This is not a described function of the keyworker and is not mentioned within any of our guidance- NICaN 2016 or the MDM operational policy.

55.4 If a patient contacted us regarding a scan/appointment/referral this would have been escalated to the appropriate consultant. CNSs do not receive notification when a scan is ordered or reported, it remains the responsibility of the individual ordering the scan to action any findings. We also stated that with the increase in numbers to the CNS team, comes an additional nurse-led caseload of patients and a move towards independent practice and if we would be provided with a "failsafe mechanism"?

55.6 When the official SAI report was released, some of the terminology highlighted above had been amended but it still referred to the CNS ensuring that "key actions had taken place".

If you were directly involved, please provide details on anyone you spoke to on this issue, when you spoke to them, and what, if anything was done to address the issue. Does this issue persist?

55.7 I believe this issue no longer exists as CNS staffing level and role is now such that we can individually appoint a CNS to be available for review clinics (on the rota). This nominated nurse then actively screens the clinic list and is present at the time of consultation.

Learning

56. Are you now aware of governance concerns arising out of the provision of urology services, which you were not aware of during your tenure? Identify any governance concerns which fall into this category and state whether you could and should have been made aware and why.

56.1 I am now aware of governance concerns that I was not aware of during my tenure.

56.2 I learned from the Root Cause Analysis Report (*please see 41. Attachment from email to Patricia Kingsnorth – queries in relation to SAI reports and 42. Email to Patricia Kingsnorth fw important urology draft SAI reports)* regarding anti-androgen prescribing and that, it had been previously challenged and was long known, leading to the drawing up of regional guidelines on hormonal therapy.

56.3 It was also revealed in this report, that MDM tracking service was limited and the consultant/secretary led process was variable and resulted in deficits. This latter component had been known form a previous review.

56.4 The SAE report also made note that the "use of Clinical Nurse Specialists" was longstanding and known internally; this was never brought to my attention until I became aware of the current investigations.

56.5 I was also not aware that the MDM was under-resourced regarding tracking, in that there was no whole of pathway tracking (SAE report).

56.6 The disconnect and inaction of cancer services was also unknown to me as was the fact that Oncology and Radiology attendance were escalated but not other issues. I am still not aware of the specifics of these "other issues" as mentioned in the Root Cause Analysis Report of 2021*. Please see:*

41. Attachment from email to Patricia Kingsnorth – queries in relation to SAI reports

42. Email to Patricia Kingsnorth fw important urology draft SAI reports

56.7 The SAI report also refers to a previous SAI from 2016 related to non-conformance with red flag referral pathways. This was signed off in May 2020, I was not aware of this.

56.8 I also learned of governance issues within the urology services, relating to Mr O'Brien's practice from a newspaper article in the Irish News (dated 07/06/2021). It gave details of unactioned triage being found in a filing cabinet, a haphazard triage system dating back 25 years, Mr O'Brien being asked to triage and still not doing it despite multiple attempts to address this issue, only clearing his triage list so he could attend a conference in Spain. It mentions multiple attempts by many service directors (past and present) to resolve issues with Mr O'Brien. The article also mentioned "pockets of non-compliance" from other consultants regarding triage, but that compliance had improved. I am of the belief that the information printed in the article does refer in part to the issues highlighted by the SAE report of 2021, but at the time, I was unaware of the level of detail mentioned in this article.

56.9 In or around August 2020, Kate O'Neill and I were asked by Martina Corrigan and Mr Haynes to undertake a piece of work that involved screening through a spreadsheet list of pathology results (168 patients Dec 2018- June 2020) of Mr O'Brien's patients to ensure that patients had been informed of results and that appropriate follow-up was in place. We were also asked to do the same for a radiology list of 1536 patients.

56.10 We received little guidance on the actual process we were to use (p*lease see 42. pathology email to Martina Corrigan and Mark Haynes)* but did proceed to complete the pathology spreadsheet. We did find issues related to timelines- not dictating until several weeks after the appointment, not ordering radiology until dictation done, not following MDM outcome, unsure if all patients were aware of their result. It was at this time I released the potential extent of the issue. I am not sure how the original lists were generated, but it indicated to me that there might have been ongoing issues. We did submit our findings to Martina and Mark but that we were not comfortable proceeding with the radiology queries, to the best of my knowledge, we did not receive a response.

56.11 During the autumn of 2020, I was also involved in supporting "look back" clinics. These were patients of Mr O'Brien and Mr Haynes reviewed them. It was at this point, I realised the issues around bicalutamide prescribing and potentially how far back this issue went.

56.12 I feel I should have been made aware of the aforementioned governance concerns within urology. My NMC Code, states that I should prioritise people, practise effectively, preserve safety and promote professionalism and trust. I feel that my ability to do this could be undermined if I am not aware of important, impactful issues within my service. I understand why I may not have made been aware during the investigative stage, but I was also not made aware of conclusions once investigations had been completed.

57. Having had the opportunity to reflect, do you have an explanation as to what went wrong within Urology services and why?

57.1 On reflection, I feel there are a number of circumstances that led to the current situation.

a) lack of transparency and learning from previous issues
b) insufficient CNS in appropriate roles
c) insufficient substantive urology consultants in post
d) no "whole of pathway tracking" at MDM
e) limited utilisation of audit in respect to actioning of MDM outcomes
f) limited relationship between urology and cancer services
g) absence of quoracy in MDT

58. What do you consider the learning to have been from a governance perspective regarding the issues of concern within Urology services and regarding the concerns involving Mr. O'Brien in particular?

58.1 I consider the learning to be that openness and transparency needs to be affected to ensure learning from previous concerns is put into action and not let slip only to be perpetually repeated. There should not only be a duty of candour to patients, but to the professionals in the team as well as in this way we can have influence over outcomes. There are issues that are out with our control, e.g., budget constraints, but if the team is not aware of the issues with someone's practice or issues within structure or processes we are powerless to stop patients coming to harm or to improve future quality and standards.

59. Do you think there was a failure to engage fully with the problems within Urology Services? If so, please identify who you consider may have failed to engage, what they failed to do, and what they may have done differently. If your answer is no, please explain in your view how the problems which arose were properly addressed and by whom.

59.1 I do feel there was a failure to engage fully with problems within Urology Services. I am not au fait with the processes/protocols in place for addressing medics who are underperforming or deviating from safe practice or how this process is escalated and by whom. I believe that had these persons managed Mr O'Brien robustly and assuredly, when issues first became apparent, then the outcome may well have been different.

60. Do you consider that, overall, mistakes were made by you or others in handling the concerns identified? If yes, please explain what could have been done differently within the existing governance arrangements during your tenure?

60.1 As previously mentioned, those in managerial positions did not properly address the identified concerns from the outset over Mr O'Brien. Standards and working practices were permitted to "slip back". Robust, strong leadership was needed to deal with issues/personalities and this may not have been in place to the required degree.

60.2 With hindsight, I would have also raised the concerns I listed in question 7 in relation to Mr O'Brien, with the HoS and lead nurse. I am now aware that different parties were aware of certain issues but that only a limited number of people may have had an awareness of the whole picture.

Do you consider that those arrangements were properly utilised to maximum effect? If yes, please explain how and by whom. If not, what could have been done differently/better within the arrangements which existed during your tenure?

60.3 I do not consider governance arrangements to be fully utilised as learning and findings were not shared with the wider team, and so practice did not change. Outcomes should have been disclosed more widely and as this could have helped to better improve patient care and to prevent further harm.

61. Do you think, overall, the governance arrangements were fit for purpose? Did you have concerns about the governance arrangements and did you raise those concerns with anyone? If yes, what were those concerns and with whom did you raise them and what, if anything, was done?

61.1 With the benefit of hindsight, I do not think governance arrangements were fit for purpose, although prior to these current findings I would have said there were adequate governance arrangements in place.

61.2 There was insufficient sharing of learning, inadequate management of findings and implementation of scrutiny to ensure practice had changed and remained as such.

62. If not specifically asked in this Notice, please provide any other information or views on the issues raised in this Notice. Alternatively, please take this opportunity to state anything you consider relevant to the Inquiry's Terms of Reference and which you consider may assist the Inquiry.

62.1 I have included all information/views known to me about issues raised in this notice.

NOTE:

By virtue of section 43(1) of the Inquiries Act 2005, "document" in this context has a very wide interpretation and includes information recorded in any form. This will include, for instance, correspondence, handwritten or typed notes, diary entries and minutes and memoranda. It will also include electronic documents such as emails, text communications and recordings. In turn, this will also include relevant email and text communications sent to or from personal email accounts or telephone numbers, as well as those sent from official or business accounts or numbers. By virtue of section 21(6) of the Inquiries Act 2005, a thing is under a person's control if it is in his possession or if he has a right to possession of it.

<u>Statement of Truth</u>

I believe that the facts stated in this witness statement are true.

Personal Information redacted by the USI

Signed: ____________ [redacted] ____________________

Date: ___________10/11/2022____________

S21 73 of 2022

Witness statement of: Leanne McCourt

Table of Attachments

Attachment	Document Name
1	Sister Charge Nurse Band 6 JOB DESCRIPTION
2	Job Description - Specialist Nurse BAND 6
3	Root Cause Analysis report 2021
4	Record of consultation
5	Concerns checklist
6	TP biopsy information leaflet
7	Prostate Biopsy Discharge Advice Sheet TP BIOPSIES V1 March 21
8	Leanne McCourt Inquiry Questionnaire
9	Mr [redacted]'s email
10	Mr O'Brien emails
11	Nurse led review meeting on 130821
12	Nurse led review meeting on 230921
13	Nurse led review meeting on 021221
14	Nurse led review meeting on 270122
15	Nurse led review meeting on 240222
16	Nurse led review meeting on 210422
17	Nurse led review meeting on 260522
18	Nurse led review meeting on 306022
19	Nurse led review meeting on 300822
20	FW notes from Urology Nurse led review meeting on 300822
21	NICaN Urology Cancer Clinical Guidelines 2016, page 116
22	2021-census-of-the-cancer-workforce-in-ni (macmillan.org.uk)
23	Specialist Nurse Band 7 post outline

24	Ward Meeting March 2020
25	Lead Nurse Meeting Nov 20
26	Standard Operating Procedure for Ultrasound Transperineal Probe Decontamination
27	Draft Corporate Policy Template Nurse led Prostate Cancer follow up
28	Draft Policy Screening Template Prostate Cancer Nurse Led Clinics
29	Lead Nurse 1 to 1 Thorndale Meeting Aug 2019
30	cns-census-report-northern-ireland
31	A census of the specialist adult cancer nursing workforce in Northern Ireland 2021
32	Macmillan Partnership Application 2014
33	Nursing and Midwifery accountability and assurance framework
34	Urology patient experience survey 2020 results
35	Macmillan CNS impact brief,
36	V2 Urology Cancer MDT Operational Policy 2020
37	Keyworkers email to Sarah Ward and Wendy Clayton
38	Presentation overview of keyworker activity
39	Email from Kate O’Neill re keyworker
40	Email to Patricia Kingsnorth fw important urology draft SAI reports
41	Attachment from email to Patricia Kingsnorth – queries in relation to SAI reports
42	pathology email to Martina Corrigan and Mark Haynes

SOUTHERN HEALTH AND SOCIAL CARE TRUST

JOB DESCRIPTION

JOB TITLE: Sister/Charge Nurse Band 6

LOCATION: Thorndale Unit, Surgical and Elective Care Division
Craigavon Area Hospital

REPORTS TO: Specialist Nurse

RESPONSIBLE TO: Lead Nurse (SEC)

JOB SUMMARY: The postholder will:

- Support the Specialist Nurse in his/her general management function and in the co-ordination of high quality services to patients and relatives.
- Under the direction of the Specialist Nurse, lead in the development of all aspects of nursing within the Unit, through the professional development of nursing staff, the implementation of evidence based practice and clinical audit.
- Function as the principal support to the Specialist Nurse, who has continuing responsibility deputising when required.

In particular, the postholder will have delegated responsibility for –

- the development and supervision of clinical practice;
- the assessment, development, implementation and evaluation of programmes and standards of care;
- teaching and supervision of nursing staff and health care support workers;
- the co-ordination of high quality patient focused care;
- ensuring that staff comply with professional and clinical policies, guidelines and protocols.

1.0 Professional Role

1.1 Promote a patient centred approach to care within the Unit.

1.2 Ensure practice reflects the standards set in the NMC Code of Professional Conduct.

1.3 Lead and enable nursing staff to implement proven research/evidence-based practice for the enhancement of patient care.

1.4 Prepare reports for and receive reports from the nursing team, ensuring effective nurse to nurse communication.

1.5 Ensure effective communication with patients/relatives to enable them to understand the nature of the care, treatment and progress.

1.6 Participate in the development of clinical pathways.

1.7 Act as an effective role model and mentor for all Registered Nurses and Nursing Auxiliaries and provide advice and support as required.

1.8 Assist the Specialist Nurse in the identification of areas of professional development within the Scope of Professional Practice and in the development of competency based practice.

1.9 Assist the Specialist Nurse in the co-ordination of the multidisciplinary team to achieve the highest possible standard of patient care.

1.10 Ensure health promotion and rehabilitation are an integral part of patient care.

1.11 Ensure adherence to Professional and Clinical Policies, Guidelines and Protocols within the Trust.

1.12 Assist the Specialist Nurse with formal appraisals and development of junior staff and nursing auxiliaries.

1.13 Develop, in association with the Specialist Nurse, the implementation and auditing of quality assurance programmes to optimise patient care within the Unit.

1.14 Participate in the implementation of the Trust's Strategy for Nursing and Midwifery within the Unit.

2.0 Managerial Role

2.1 Deputise for the Specialist Nurse as required and work shifts of duty in accordance with the Specialist Nurse arrangements.

2.2 Assist in the duty rotas/annual leave arrangements to ensure that the Unit’s appropriate skill mix is maintained in the absence of the Specialist Nurse.

2.3 Ensure a safe environment for patient care, identify clinical risk and in the presence of risk, inform the appropriate department to take corrective action.

2.4 Assist the Specialist Nurse with Risk Assessments.

2.5 Manage accidents/incidents or hazards according to the Trust's Policies and Procedures.

2.6 Prepare and implement orientation and induction programmes for new members of staff in association with the Specialist Nurse.

2.7 Assist the Specialist Nurse to maintain systems and processes to ensure a co-ordinated service is delivered to patients and relatives.

2.8 Participate in the assessment of staff performance and progress.

2.9 Observe for any signs of ill health or stress factors in staff and report same to the Specialist Nurse.

2.10 Assist the Specialist Nurse to collate information in response to complaints.

2.11 With the Specialist Nurse, ensure that there is an effective communication structure between all members of the multidisciplinary team.

2.12 Participate in Research and Audit as required.

2.13 Participate in Recruitment and Selection for the appropriate grade of staff.

2.14 Ensure that all staff are familiar with and adhere to all Policies and Procedures within the Trust.

2.15 Assist the Specialist Nurse in the monitoring of ward expenditure.

3.0 Educational Role

3.1 Identify own educational needs through performance appraisal with the Specialist Nurse.

3.2 Assist the Specialist Nurse in actively encouraging professional development of staff, and facilitate staff to meet PREP requirements.

3.3 Assist the Specialist Nurse in identifying staff training needs to meet existing and developing services.

GENERAL REQUIREMENTS

The post holder must:

- Carry out his/her duties with full regard to the Trust's Equal Opportunities Policy.
- Co-operate fully with the implementation of the Trust's Health and Safety arrangements and take appropriate remedial action on reports of any accidents/incidents, defects with work equipment or inadequate safety arrangements to his/her manager.
- Accept individual responsibility for ensuring a suitable, clean, uncluttered and safe environment for members of the public, staff, patients/clients and their relatives.
- Accept legal responsibility for all records held, created or used as part of his/her duties (including manual or electronic records).
- Comply with the Trust's Smoke Free Policy.
- Treat those whom he/she comes into contact with in the course of work, in a courteous manner.
- Accept that this job description will be subject to review in the light of changing circumstances and should be regarded as providing guidance within which the individual works rather than something which is rigid and inflexible.

July 2016

Personnel Specification

JOB TITLE **Sister/Charge Nurse Band 6**

DIRECTORATE **Surgical and Elective Care**

Ref No: **July 2016**

Notes to applicants:

1. You must clearly demonstrate on your application form how you meet the required criteria – failure to do so may result in you not being shortlisted.

2. Proof of qualifications and/or professional registration will be required if an offer of employment is made – if you are unable to provide this, the offer may be withdrawn.

3. This criterion will be waived in the case of a suitable applicant whose disability prohibits driving but who is able to organise suitable alternative arrangements in order to meet the full requirements of the post.

Knowledge, skills and experience required:

Applicants must provide evidence by the closing date for application that they are a permanent employee of the Southern Health and Social Care Trust and have:

ESSENTIAL CRITERIA

1. Registered nurse Part 1 of the NMC register

2. Hold a Diploma or relevant Professional qualification or agree to do same

AND

- Experience of taking charge of a ward or unit within the Acute setting.

- Demonstrate expertise in the management of patients with urological conditions

- Evidence of how patient care has been enhanced through continuing professional development or practice development

- a full current driving licence with access to a car or access to a form of transport to meet the mobility needs of the post.

SHORTLISTING

A shortlist of candidates for interview will be prepared on the basis of the information contained in the application form. It is therefore essential that all applicants demonstrate through their application how and to what extent their experience and qualities are relevant to this post and the extent to which they satisfy each criterion specified

Southern Health and Social Care Trust

Southern Health and Social Care Trust

JOB DESCRIPTION

Title:	Specialist Nurse - Urology
Band :	Band 6
Reports to:	Clinical Nurse Specialist
Accountable to:	Assistant Director of ATICs, Surgery and Elective Care

Job summary

The post holder will be expected to deliver on the five functions listed below:

- Be a designated Key Worker
- Deputise as a core member of the Cancer Urological multidisciplinary team
- Deliver Nurse-Led activity including nurse led clinics and telephone work
- Education, training and Audit
- Identify and contribute to the service development and policy development

Key Worker Function:

The post holder will:

- Act as a point of contact for patients, ensuring that patients have access to information and support services and provides ongoing holistic assessments.
- The postholder should provide physical, emotional, psychological and spiritual support to patients and carers and coordination of care services.

Multi-disciplinary Team

The post holder will:

- Will be a deputy core member of the multi-disciplinary team, both locally and regionally.

Nurse-led activity

Nurse-led activity can be direct or indirect therefore the postholder will provide nurse-led clinics in an outpatient and inpatient setting and this will be on a face to face or via telephone consultations.

This nurse-led activity will be on the Craigavon Area Hospital Site

There are four levels that this nurse-led activity will provide:

Level 1 - simplest level of intervention
Level 2 - single patient contact to resolve a specific problem
Level 3 - short-term involvement for multiple problems
Level 4- interventions when patients require ongoing specialist advice and support for complex problems

Education & Development

The post holder will:

Education, training and audit are inherent aspects of the Specialist Nurse role and should permeate all aspects of this role:

- Develop and deliver specific and relevant specialist teaching programmes for all disciplines and grades of staff, client group and carers within the Trust and, in relation to the Urology specialism.

- Review and evaluate all teaching programmes and lead on the development of new programmes when a need is identified.
- Maintain the education of colleagues in clinical areas who contribute to the patient pathway.
- Identify own development needs in line with service requirements within personal development plan.
- Develop and distribute educational leaflets in relevant formats, for staff and patients relating to service and patient pathway.
- Ensure personal and peer support and clinical supervision needs are met.
- Act as mentor/preceptor and resource person for all nursing and support staff, as appropriate to the role.
- Provide clinical supervision in order to support development of individuals and practice.
- Ensure mentorship training is updated annually.
- Ensure clinical environment is conducive to supporting the education and learning of all staff and students.
- Provide educational and training opportunities to pre registration nursing students to ensure placements satisfy the relevant elements of their learning agreement.
- Provide an environment that encourages client centred involvement where clients are facilitated to ask for help, advice and education.
- Contribute to clinical governance outcomes.

Contribute to the service development and policy development

The post holder will:

- Contribute to and develop specialist policies and procedures, and to ensure the effective delivery of care.
- To implement policies, and inform members of the multidisciplinary team of any changes
- To support and work with other appropriate professionals to ensure a holistic and comprehensive approach to nursing care. To support and advise patients through the various stages of treatment.
- To use audit and research evidence to improve and develop the service.
- Be responsible for producing appropriate training programmes to develop staff.

GENERAL REQUIREMENTS

The post holder will be required to:

1. Ensure the Trust's policy on equality of opportunity is promoted through his/her own actions and those of any staff for whom he/she has responsibility.

2. Co-operate fully with the implementation of the Trust's Health and Safety arrangements, reporting any accidents/incidents/equipment defects to his/her manager, and maintaining a clean, uncluttered and safe environment for patients/clients, members of the public and staff.

3. Adhere at all times to all Trust policies/codes of conduct, including for example:
    - Smoke Free policy
    - IT Security Policy and Code of Conduct
    - standards of attendance, appearance and behaviour

4. All employees of the Trust are legally responsible for all records held, created or used as part of their business within the Trust including patients/clients, corporate and administrative records whether paper-based or electronic and also including emails. All such records are public records and are accessible to the general public, with limited exception, under the Freedom of Information Act 2000 the Environmental Information Regulations 2004 and the Data Protection Acts 1998. Employees are required to be conversant with the Trusts policy and procedures on records management and to seek advice if in doubt.

5. Take responsibility for his/her own ongoing learning and development, including full participation in KSF Development Reviews/appraisals, in order to maximise his/her potential and continue to meet the demands of the post.

6. Represent the Trust's commitment to providing the highest possible standard of service to patients/clients and members of the public, by treating all those with whom he/she comes into contact in the course of work, in a pleasant, courteous and respectful manner.

7. Understand that this post may evolve over time, and that this Job Description will therefore be subject to review in the light of changing circumstances. Other duties of a similar nature and appropriate to the grade may be assigned from time to time.

This Job Description will be subject to review in the light of changing circumstances and is not intended to be rigid and inflexible but should be regarded as providing guidelines within which the individual works. Other duties of a similar nature and appropriate to the Band may be assigned from time to time.

It is a standard condition that all Trust staff may be required to serve at any location within the Trust's area, as needs of the service demand

Southern Health
and Social Care Trust

PERSONNEL SPECIFICATION

Job Title:	Specialist Nurse - Urology
Band:	Band 6
Directorate:	Acute
Salary:	£26,041 - £34,876
Hours:	Full-time

The following are essential criteria which will initially be measured at Shortlisting Stage although may also be further explored during the interview stage;

1. Currently a Registered Nurse (Adult) on the Live NMC Register
2. Have 3 years' experience of working in an acute setting at Band 5 in the last 5 years which includes a broad range of clinical experience within a surgical setting.
3. Have a minimum of 6 months experience of working in an acute urology ward/department at Band 5 or above in the last 5 years which includes a broad range of clinical urology experience.
4. Demonstrate ability to work effectively as part of a multi-disciplinary team
5. Experience in taking responsibility for the management of a clinical area
6. Hold a current driving licence valid for use in the UK and have, on appointment access to a car.

(note: this criterion will be waived in the case of applicants who are prevented from driving due to a disability, providing the applicant can organise suitable alternative arrangement in order to the requirements of the post in full.)

The following are essential criteria which will be measured during the interview stage.

1. Evidence of post registration education and willing to undergo training relevant to the post.
2. Sound knowledge and skills of the NMC code and standards
3. Ability and knowledge on how to undertake audit and feedback appropriately
4. Flexibility to work hours required to do the job
5. Ability to work as part of a team
6. Ability to work unsupervised
7. Computer skills or willingness to undergo training
8. Excellent interpersonal skills
9. Excellent communication skills to meet the needs of the post in full

WE ARE AN EQUAL OPPORTUNITIES EMPLOYER

Successful applicants may be required to attend for a Health Assessment

All staff are required to comply with the Trusts Smoke Free Policy

July 2016

Southern Health
and Social Care Trust

Root Cause Analysis report on the review of a Serious Adverse Incident including Service User/Family/Carer Engagement Checklist

Organisation's Unique Case Identifier:
Personal information redacted by USI
[redacted]

Date of Incident/Event: Multiple dates

HSCB Unique Case Identifier:

Service User Details: (*complete where relevant*)
D.O.B: Gender: Male Age:

Responsible Lead Officer: Dr Dermot Hughes

Designation: Former Medical Director Western Health and Social Care Trust. Former Medical Director of the Northern Ireland Cancer Network (NICAN)

Report Author: The Review Team

Date report signed off: 26 February 2021

Date submitted to HSCB: 1 March 2021

1.0 EXECUTIVE SUMMARY

The purpose of the review is to consider the quality of treatment and the care provided by Doctor 1 to the patients identified and to understand if actual or potential harm occurred. The review findings will be used to promote learning, to understand system wide strengths and weaknesses and to improve the quality and safety of care and treatment provided. Nine patients have been identified as potentially suffering harm. This review will examine the timelines of each individual case and analyse if any deficits in treatment or care has occurred. As part of the review the cancer pathways will be used to determine where learning can be extracted.

The SHSCT recognise the life changing and devastating consequences to the 9 families. It wishes to offer an unequivocal apology to all the patients and their families involved in this review. This was not the cancer care they expected and should not have been the cancer care they received.

2.0 THE REVIEW TEAM

Dr Dermot Hughes – External Independent Chair former Chair of the NICAN. Former Medical Director Western Health and Social Care Trust.
Mr Hugh Gilbert - Expert External Clinical Advisor from the British Association of Urological Surgeons BAUS
Mrs Fiona Reddick – Head of Cancer Services (SHSCT)
Ms Patricia Thompson – Clinical Nurse Specialist (Formally from SET / recently SHSCT)
Mrs Patricia Kingsnorth – Acting Acute Clinical Governance Coordinator (SHSCT)

3.0 SAI REVIEW TERMS OF REFERENCE

The aims and objectives of this review are to:

- To carry out a systematic multidisciplinary review of the process used in the diagnosis, multidisciplinary team decision making and subsequent follow up and treatment provided for each patient identified, using a Root Cause Analysis (RCA) Methodology.
- To review individually the quality of treatment and care provided to each patient identified and consider any factors that may have adversely influenced or contributed to subsequent clinical outcomes.
- To engage with patients / families to ensure where possible questions presented to the review team or concerns are addressed within the review.
- To develop recommendations to establish what lessons are to be learned and how our systems can be strengthened regarding the delivery of safe, high

3.0 SAI REVIEW TERMS OF REFERENCE

quality care.

- Examine any areas of good practice and opportunities for sharing learning from the incidents.
- To share the report with the Director of Acute Services/ Medical Director of SHSCT/ HSCB/ Patients and families involved/ Staff involved.

4.0 REVIEW METHODOLOGY

The review will follow a review methodology as per the Regional Serious Adverse Incident Framework (2016) and will be cognisant of the rights of all involved to privacy and confidentiality and will follow fair procedures. The review will commence in October 2020 and will be expected to last for a period of 4 months approximately, provided unforeseen circumstances do not arise. Following completion of the review, an anonymised draft report will be prepared by the review team outlining the chronology, findings and recommendations. All who participated in the review will have an opportunity to provide input to the extracts from the report relevant to them to ensure that they are factually accurate and fair from their perspective.

Prior to finalising the report, the Lead Reviewer will ensure that the Review Team apply Trust quality assurance processes to ensure compliance of the review process with regional guidance prior to delivery of the final report to the Review Commissioner. The Review Commissioner will seek assurance that the quality assurance process has been completed.

5.0 DESCRIPTION OF INCIDENT/CASE

The review team conducted individual reviews on 9 patients on their treatment and care. A summary of each case is discussed within this report.

Causal deficits in their care and contributory factors were identified.

[redacted]

[redacted] was diagnosed with prostate cancer and was started on an anti-androgen therapy as opposed to Androgen Deprivation Therapy (ADT). This did not adhere to the Northern Ireland Cancer Network (NICAN) Urology Cancer Guidelines (2016). These Guidelines had been signed off by the Southern Health and Social Care Trust (SHSCT) Urology Multi-Disciplinary Meeting (MDM), as their protocols for Cancer Peer Review (2017). This guidance was issued when Dr 1 was the regional chair of the Urology Tumour Speciality Group and should have had full knowledge of its contents. Following discussion with the families, the review team noted that there was no discussion with [redacted] that the treatment given was at variance with regionally recommended practice. There was no evidence of informed consent to this alternative care pathway.

The review team have identified that during the MDM that a quorum had not been met. This was due to the absence of an oncologist from these meetings. Even so, the recommendations made by the MDM were not actioned by Dr 1. Members of the MDT may not have been aware of this, but similar practice in prescribing an anti-androgen had been challenged. Any challenges made regarding the appropriateness of treatment options were not minuted nor was the issue escalated.

The Review Team suggested that the initial assessment of [redacted] was satisfactory although rather prolonged, the subsequent management with unlicensed anti-androgenic treatment (Bicalutamide) at best delayed definitive treatment. Bicalutamide (50mg) is currently only indicated before (as an anti-flare agent) or in combination with a LHRH analogue (Complete Androgen Blockade) Bicalutamide monotherapy (150mg) is not recommended for use as a continuing treatment for intermediate risk localised prostate cancer (reference is EAU guidelines), and further it decreases overall survival. Treatment for prostate cancer is based on achieving biochemical castration (Testosterone <1.7 nmol/l), which is best accomplished by the use of a LHRH analogue, by an LHRH antagonist or by bilateral subcapsular orchidectomy.

[redacted] did not have Urology Cancer Nurse Specialist allocated to his care. The review team questioned this and it was established that whilst there were no resources for a Urology Cancer Nurse Specialist to attend any outreach clinics, their contact numbers should have been provided to the patient.

The Review Team conclude that [redacted] received unconventional and inadequate treatment. The expected multi-professional involvement in his care was omitted. [redacted]'s disease progressed whilst being inadequately treated. The opportunity to offer him radical treatment with curative intent was lost.

5.0 DESCRIPTION OF INCIDENT/CASE

[redacted]

[redacted] was diagnosed clinically and biochemically with prostate cancer, and was commenced on bicalutamide 50mgs. Bicalutamide (50mg) is currently only indicated as a preliminary anti-flare agent (or in combination with a LHRH analogue) and is only prescribed before definitive hormonal (LHRH analogue) treatment. The review team note that this treatment was not in adherence with the Northern Ireland Cancer Network (NICAN) Urology Cancer Guidelines (2016), which was signed off by the Southern Health and Social Care Trust (SHSCT) Urology Multi-disciplinary Meeting, as their protocols for Cancer Peer Review (2017). This guidance was issued when Doctor 1 was the chair of this group and had full knowledge of its contents. The review team note that, following discussion with [redacted] he was unaware that his care given was at variance with regionally recommended best practice. There was no evidence of informed consent to this alternative care pathway.

A biopsy result taken at the time of transurethral resection of prostate (TURP) showed benign disease (low volume sample 2g from central area of prostate). There were no further investigations to explore the clinical suspicion of prostate cancer.

The possibility of localised prostate cancer was considered from the time of presentation because the PSA was elevated; however, there was no record in the medical notes of any digital rectal examination (DRE) findings. During the operation further signs might have been elicited and appropriate biopsies could have been performed. TURP is not an adequate way to biopsy the prostate gland for suspected prostate cancer. The Review Team conclude that sufficient evidence of localised prostate cancer was apparent from the time of presentation. A correct course of action would have been to arrange appropriate staging scans and biopsies. [redacted] should have undergone investigation with a MRI scan of the prostate and pelvis and a bone scan should have been considered. A transrectal biopsy performed either at the time of the TURP or separately, would have secured the diagnosis.

Arrangement could then have been made to start conventional Androgen Deprivation Therapy (a LHRH analogue) with referral on to an oncologist for consideration of external beam radiotherapy (EBRT) potentially with radical intent. However, the patient was apparently lost to follow up after his appointment in July 2019.

[redacted]

[redacted] was referred to urology service following a visit to ED in December 2018. He was reviewed promptly by Dr 1 in January 2019. Investigations were arranged and a diagnosis of a large right-sided renal carcinoma was made. He was counselled regarding the risks and benefits of surgical intervention and chose to proceed with the high-risk surgery.

On 6 March 2019 [redacted] was admitted for an elective radical nephrectomy. The procedure was undertaken as planned and he was transferred to the intensive care unit (ICU) to support his blood pressure. He was later transferred to the ward. He developed a bacteraemia (infection) which was successfully managed with the advice of the microbiology team. Follow up CT scans were performed in June with a planned follow up in July 2019. This did not happen. [redacted] was admitted to Ward 3 North following an ED admission. He was reviewed again via telephone in November

5.0 DESCRIPTION OF INCIDENT/CASE
2019 by Dr 1 who arranged for a repeat CT scan to be performed on 17 December 2019 with a plan for review in January 2020. This did not happen. The CT scan report was available on 11 January 2020 which showed a possible sclerotic metastasis in a vertebral body which had not been present on the previous CT scans. This report was not actioned until July 2020 when a new consultant reviewed the care. [redacted] was subsequently diagnosed with prostate cancer. The Review Team find that the treatment and care in relation to management of the renal tumour was of a high standard. High-risk surgery was performed successfully following informed consent as to the risks and benefits of the surgery. A urology review was planned for July 2019 following the CT scan report in June but this didn't happen. [redacted] appeared to be lost to review. The scan performed in December 2019 with a plan to review in January was not actioned and the plan for review did not happen. This resulted in a delay of 6 months in diagnosis of a prostate cancer from the scan result. This would be approximately a delay of 18 months from his first presentation in ED in November 2018. [redacted] [redacted] attended ED on 24 December 2018 with retention of urine. A urinary catheter was inserted, and a urology consultant review was planned to coincide with a trial removal of catheter with a specialist nurse. [redacted] was placed on the waiting list for a TURP. A normal PSA result (2.79 ng/l) was noted. On 19 June 2019 [redacted] underwent a TURP. The procedure notes describe the prostate tissue as having "endoscopic appearances of prostatic carcinoma". Histology confirmed adenocarcinoma (Gleason score 5+5) in 90% of the resected tissue. His case was discussed at MDM on 25 July 2019 who noted there was no evidence of metastases on a CT abdomen and pelvis. It recommended a CT scan of chest and a bone scan to check for spread outside the prostate. Further, a LHRH agonist as ADT should be commenced. In August 2019 a bone scan and CT scan were requested together with an ultrasound scan of the urinary tract to assess bladder emptying. Doctor 1 prescribed Bicalutamide (50mgs once daily), in order to 'assess its tolerability in a generally frail man' and in the 'light of the low presenting PSA'. The Review Team could not locate any record in the medical notes of a digital rectal examination being performed at any point during this patient's medical treatment. This may well have provided evidence to support the malignant nature of the prostate gland prompting a swifter biopsy. The patient was discussed at MDM on 25 July 2019 when the recommendation for ADT (a LHRH analogue) was made. He should have been started on this hormonal therapy to achieve "castration testosterone levels" as soon as the diagnosis of poorly differentiated prostate cancer was made. Instead he was started on an inadequate dose of a drug (bicalutamide) which was not licensed for the treatment of prostate cancer and was contrary to the recommendations at MDM. This therapy was not in adherence with the Northern Ireland Cancer Network (NICAN) Urology Cancer Clinical Guidelines (2016) which were signed off by the Southern Health and Social Care Trust (SHSCT) Urology Multi-disciplinary Team, as their standard of care for Cancer Peer Review (2017). This guidance was issued when Dr 1 was the regional

5.0 DESCRIPTION OF INCIDENT/CASE

chair of the Urology Tumour Speciality Group and should have had full knowledge of its contents. There was no evidence in the medical notes or from speaking with [redacted]'s family of informed consent to this alternative care pathway.

[redacted] should have been referred to an oncologist to at least allow consideration of other treatment options. His care was not coordinated with the palliative care team. The diagnosis of possible metastasis which would not have changed best practice was nevertheless pursued in a dilatory fashion. The Review Team suggested that when the patient developed anaemia consideration should have been given to the possibility of this being due to malignant involvement of the bone marrow, rather than an effect of severe chronic disease.

The Review Team noted that [redacted]'s case was not brought back to MDM for rediscussion and multi-disciplinary input despite disease progression.

[redacted]

[redacted] was diagnosed with testicular cancer. His case was discussed at MDM.He attended for CT chest, abdomen and pelvis on 9 July 2019 which indicated no evidence of metastases (cancer spread). The following day the patient had a left inguinal orchidectomy (removal of left testicle and full spermatic cord) carried out. Pathology of the resection specimen found that the tumour was a classical seminoma measuring 2.6cm across. Although the tumour was confined to the testes, it did involve the rete testis (exit tubules from the testis) and , in addition, intratubular germ cell neoplasia was seen. These findings indicate an increased risk of spread. [redacted]'s case was discussed at the Urology MDM on 25 July 2019. The plan was for Doctor 1 to review the patient in outpatients and refer him to oncology.

The patient was reviewed on 23 August 2019 and it was noted that [redacted] had an uncomplicated recovery and his operative wound had healed satisfactorily. It was agreed that he would be reviewed in SWAH again in February 2020 by Doctor 1 to determine if the patient wished to have a testicular prosthesis implanted. The referral to oncology was made on 25 September 2019.

Although, this presentation was unusual, the progress of the patient's investigation and treatment up to the orchidectomy was of a high standard. However, the 2 month delay in his referral to a Medical Oncologist complicated treatment choices. Whether this will compromise the long-term outcome is uncertain as this treatment is recommended to be given within 6 weeks as per the designated protocol.(1,2,3)

The Review Team acknowledge that there is limited oncology presence within the Urology MDT and the date when the patient's case was discussed there was no oncologist present.

The vast majority of the Urology MDMs within the Southern Trust are non-quorate due to the absence of an oncologist and does not meet the existing guidelines. (0% quorate for 2019).

Whilst it was the primary responsibility for the consultant in charge to make the referral to oncology a failsafe mechanism to ensure agreed actions took place, such

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as an MDM administration tracker, was not in place.

Alternatively, the allocation of a Urology Cancer Specialist Nurse as a Key Worker would have supported the patient on his journey as well as having ensured key actions had taken place. [redacted] was not referred to a Urology Cancer Nurse Specialist nor was any contact details provided to him. The MDM guidelines indicate "all newly diagnosed patients have a Key Worker appointed, a Holistic Needs Assessment conducted, adequate communication and information, advice and support given, and all recorded in a Permanent Record of Patient Management which will be shared and filed in a timely manner"(4). This did not happen. A Key Worker/ Urology Cancer Nurse Specialist would have prompted the oncology referral sooner.

[redacted]

[redacted] presented with possible prostate cancer and was commenced on bicalutamide 50mgs indefinitely or until biopsy results were available. The diagnosis of prostate cancer was confirmed by biopsy in July 2019. The patient was discussed at the MDM on 8 August 2020. The diagnosis of intermediate-risk organ confined prostate cancer was agreed. The plan was that Doctor 1 should review the patient and discuss management by surveillance or by active treatment with curative intent.

When [redacted] was reviewed by a locum consultant in October 2020 the patient did not recall any conversation about the options of external beam radiotherapy (EBRT) as a radical treatment and Active Surveillance. A Urology Cancer Nurse Specialist was appointed as the Key Worker at this review, not having one at time of diagnosis.

Bicalutamide (50mg) is currently only indicated as a preliminary anti-flare agent and is only prescribed before definitive hormonal (LHRH analogue) treatment. Bicalutamide monotherapy (150mg) is not recommended for use as a continuing treatment for intermediate risk localised prostate cancer.

The presence of a Urology Cancer Nurse Specialist would support the patient on his journey as well as working collaboratively with the multidisaplinary team to ensure key actions had taken place. [redacted] was not referred to a Cancer Nurse Specialist. This is in contrast to declaration for Cancer Peer Review 2017 "all newly diagnosed patients have a Key Worker appointed, a Holistic Needs Assessment conducted, adequate communication and information, advice and support given, and all recorded in a Permanent Record of Patient Management which will be shared and filed in a timely manner" (4). This did not happen.

[redacted]

[redacted] was diagnosed in June 2016 with a renal mass measuring 2.5 cms in diameter on the anteromedial cortex of the lower pole of the left kidney. The case was presented to MDM in July 2016, and the recommendation was for active surveillance with interval CT scans. These were carried out at the scheduled times.

On 23 August 2018 his case was discussed at MDM. The July 2018 scan was reviewed and now showed the lesion to measure 3.0cm. The MDM recommended to review and discuss with the patient the options of continuing active surveillance or

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open partial nephrectomy. The case was to be discussed at the Regional Small Masses MDM.

On 28 March 2019 at MDM the renal mass was noted to be enlarging. A further recommendation for Dr 1 to discuss the options of laparoscopic radical nephrectomy versus continued surveillance with its attendant risks was made.

On 29 March 2019 the patient was reviewed by a Locum Consultant Urologist. It was noted that the patient had a 3.1cms left sided kidney mass since July 2018 and this mass was increasing slowly in size. It was noted that the CT would be repeated in November 2019.

On 13 November 2019 a CT scan was performed which showed a further increase in size of lesion to 3.5 cms. No action was taken.

The overall progress of this patient's management was, on balance, acceptable even though the result of the November 2019 CT scan was not acted on.

The Regional Small Renal Mass MDM was developed to oversee the management of this group of patients. An appropriate referral to this group was omitted, despite the MDM's recommendation on at least two occasions.

The patient was reviewed in 29 March 2019 by locum consultant who appears not to have had an update from the MDM held on 28 March 2019.

The patient underwent laparoscopic radical nephrectomy on 25 November 2020 and was discharged on 27 November 2020 with a planned follow up. On 15 January 2021 Dr. 5 reviewed [redacted]. He was noted to be doing well. Histopathology confirmed the left kidney mass was pT1a grade 3 papillary carcinoma (mixed oncocytic and type 2) kidney cancer. A plan for CT chest abdomen and pelvis in 12 month was agreed.

[redacted]

[redacted] was diagnosed with penile cancer. The pathology confirmed squamous cell carcinoma of the prepuce. There was both lymphovascular invasion and perineural infiltration, both of which are associated with an increased risk of metastatic disease, at presentation and subsequently.

The MDM was a virtual meeting conducted by a single urologist. Its plan was that Doctor 2 would review the patient and arrange for a CT scan of the Service User's chest, abdomen and pelvis to complete staging. The CT scan (26 July 2019) showed a single enlarged, left inguinal lymph node measuring 1.3cms in its short axis. Otherwise, there was no evidence of metastatic disease.

At the MDM of 12 September 2019 it was agreed that the [redacted] should undergo a left inguinal lymphadenectomy. There does not appear to have been any discussion regarding the referral of [redacted] to a supra-regional penile cancer MDT.

The Review Team found that the MDM recommendations did not follow NICE

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guidance for the management of penile cancer (6,7,8) and that there was an opportunity at each meeting to intervene and question [redacted]'s management.

The treatment provided to this patient was contrary to the NICAN Urology Cancer Clinical Guidelines (2016) for Penile Cancer where it states that local care is restricted to diagnosis. This Guidance was adopted by the SHSCT Urology MDT and evidenced by them as their protocols for cancer peer review 2017. Dr 1 was chair of the NICAN Urology Tumour Speciality Group when the guidance was issued.

The initial clinical assessment of [redacted] would have benefited from staging imaging either before or immediately after the original circumcision. All cases of penile cancer should be discussed by the supra-network MDT as soon as the diagnosis is confirmed by biopsy.

The clinical stage G2 pT1 should have led to a consideration of surgical staging with either a bilateral inguinal lymph node dissection (ILND) or sentinel node biopsy (SNB). This omission reduced the likelihood of [redacted]'s 5 year survival from 90% to less than 40%. The left ILND yielded only 5 nodes, which might be considered at the lower limit of that expected in experienced hands.

The consent form signed by the surgeon and patient is inadequate as it does not state the rationale for the procedure nor the potential complications. The timings between the steps in treatment and management were unduly long and failed to the show the urgency needed to manage penile cancer.

[redacted]

[redacted] was seen on 27 October 2014 with lower urinary tract symptoms that continued despite medical treatment. Doctor 1 discussed options with [redacted] and he decided to proceed to surgery (TURP).

A letter dated 11 November 2016 [redacted]'s General Practitioner asked for [redacted] TURP to be expedited.

The Patient underwent TURP on 29 January 20 and histology confirmed prostatic adenocarcinoma.

Collation of Multidisciplinary meetings should have a fail-safe whereby lists of all urological cancers by site and SNOMED code are generated weekly. This system was not in place.

Although Doctor 1 planned to review the patient in April 2020, he was not seen until August 2020 at an appointment arranged by another doctor who has continued care. The patient had done well following his TURP. The histology was explained as an incidental finding that required continuing surveillance with an up to date serum PSA level and a prostate MRI scan.

[redacted] was informed on 9 September 2020 that the serum PSA level was within the normal range and that the MRI scan did not show any features of prostate cancer. The prostate cancer was considered unlikely to represent a threat during the patient's life expectancy and would not be anticipated to require any treatment other

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than surveillance with PSA monitoring.

6.0 FINDINGS

Diagnosis and Staging

- 5 of the 9 patients in this review experienced significant delay in diagnosis of their cancer. This was related to patients with prostate cancer and reflected variable adherence to regionally agreed prostate cancer diagnostic pathways, NIACN Urology Cancer Clinical Guidelines (2016).
- [redacted] had a delay of over 15 months from presentation.
- The review team could not find evidence of a Digital Rectal Examination in the notes of [redacted] - potentially missing an opportunity to detect his high grade cancer earlier in his pathway.
- [redacted] had a slow initial diagnostic pathway which was outside expected cancer care time-frames.
- [redacted] had a delayed diagnosis of a metastatic prostate cancer following successful treatment of Renal Cancer. This was due to non-action on a follow-up CT scan report.
- [redacted] had a delayed diagnosis of Prostate cancer due to non-action on a histopathology report at TURP.
- [redacted] with penile cancer had a 5 week wait between referral and first appointment. Subsequent time to diagnosis and MDM were appropriate. He had a 17 week wait for a CT scan for staging.
- [redacted] was on a renal mass surveillance programme - a recommendation at MDM to discuss his case with the regional small renal lesion team was not actioned and it is not known if they would have suggested earlier intervention.

Targets

- Three of the nine patients were said to have met one of their 31 / 62 day targets.
- [redacted] was said to have met his diagnostic target for 31 days despite his tissue cancer diagnosis being missed and the patient suffering an 8 month delay.
- [redacted] was said to have met his 62 day (1st treatment) target but had been referred down a pathway that did not meet the NICAN Urology Cancer Guidelines 2016. A regional Penile Cancer Pathway was agreed in January 2020.
- [redacted] was said to have met his diagnostic target of 31 days despite having a delay from initial presentation of 15 months.

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Multidisciplinary Meeting

- The MDM made appropriate recommendations for 8 of the 9 patients but there was no mechanism to check actions were implemented - this included, further investigations, staging, treatment and appropriate onward referral.
- Dr 1 was present for the discussions and party to the recommendations, 8 of which were compliant with National and Regional Guidelines.
- In the case of the 5 patients with Prostate cancer, 5 patients were referred to the Multidisciplinary Meeting and had appropriate MDM recommendations.
- [redacted] and [redacted] to start Androgen Deprivation Therapy with LHRHa while [redacted] was advised to have active surveillance or curative intent radiotherapy. None of these recommendations were implemented.
- NICAN Regional Hormone Therapy Guidelines for Prostate cancer 2016 were not followed.
- [redacted] had a delayed diagnosis of prostate cancer and was belatedly seen at the Urology MDM 15 months after his first presentation. The recommendations from this MDM were correct but not implemented. Regional NICAN Hormone Therapy Guidelines for Prostate Cancer 2016 were not followed
- [redacted] had an unexpected diagnosis of cancer at TURP. His diagnosis on pathology report was not actioned and he was discussed at MDM 8 months after his surgery and pathological diagnosis of cancer. His subsequent MDM recommendations were correct.
- Two patients had renal cancer. [redacted] was initially appropriately discussed at MDM with action on recommendations. However a routine CT scan in December 2019 was not actioned, leading to a delayed re-presentation to MDM with a second primary diagnosis of metastatic prostate cancer.
- [redacted] was on a surveillance pathway for a small renal lesion he was appropriately discussed at MDM. The meetings were not always quorate but a radiologist was present on 4 out of 5 occasions. An MDM recommendation to seek input from the regional small lesion group was not actioned.
- [redacted] had a testicular tumour and was appropriately discussed at MDM with the recommendation onward referral to the regional testicular oncology team. This recommendation was time critical but did not happen.
- [redacted] was appropriately discussed at the local MDM at diagnostic stage. Unfortunately his treatments and further discussions were restricted to local level and did not meet the NICAN Urology Cancer Guidelines 2016. [redacted] should have been referred to the Regional / Supra-Regional Penile Cancer Network according to NICAN Urology cancer guidelines 2016 and, although a Regional Penile Cancer Pathway was only agreed in January 2020, referral to a specialist with appropriate experience should have been pursued.
- Collation of MDM lists did not include a fail-safe list from histopathology. This would ensure all tissue diagnoses of cancer were cross checked against clinician declared cases. This would capture unexpected cases of cancer as in [redacted] or as in [redacted] where a delayed diagnosis presented to the GI surgeons

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for initial biopsy.

- The patient’s care was through a Multidisciplinary Team process but unfortunately they did not benefit from it. The Multidisciplinary Meeting failed in its primary purpose to ensure patients received best care as defined by Regional and National Guidelines.
- The Urology MDM was under resourced and frequently non quorate due to lack of professionals. The MDM had quorate rates of 11% in 2017, 22% in 2018 0% in 2019 and 5% in 2020. This was usually due to lack of clinical oncology and medical oncology. Radiology had only one Urology Cancer Specialist Radiologist impacting on attendance but critically meaning there was no independent Quality Assurance of images by a second radiologist prior to MDM.
- The Urology MDM was under resourced for appropriate patient pathway tracking. The Review Team found that patient tracking related only to diagnosis and first treatment (that is 31 and 62 day targets). It did not function as a whole system and whole pathway tacking process. This resulted in preventable delays and deficits in care.
- Safe cancer patient care and pathway tracking is usually delivered by a three pronged approach of MDT tracking, Consultants and their Secretaries and Urology Specialist Nurses, in a Key Worker role. The Review found that these 9 patients were not referred to Specialist Nurses and contact telephone numbers were not given. Therefore the CNS were not given the opportunity to provide support and discharge duties to the 9 patients who suffered as as consequence. The MDM tracking system was limited. The consultant / secretary led process was variable and resulted in deficits. The weakness of the latter component was known from previous review.
- As patients were not re-discussed at MDM and Urology Cancer Nurse Specialist were not involved in care, non implementation of these MDM recommendations was unknown to others in the MDM. One patient D presented as an emergency and his care was changed to the MDM recommendation by another consultant.

Multidisciplinary working and referral

- The review team noted repeated failure to appropriately refer patients
- [redacted] Patient 1 should have been referred to oncology initially and then to palliative care as his disease progressed.
- [redacted] Patient 9 should have had an earlier diagnosis and referral to oncology.
- [redacted] Patient 4 should have been referred to oncology and palliative care.
- [redacted] Patient 2 should have been referred to oncology for time critical care.
- [redacted] Patient 6 should have been referred to oncology.
- [redacted] Patient 7 should have been referred to the Small Renal Mass Team.
- [redacted] Patient 3 should have been referred to the Regional / Supra-Regional Penile Cancer Network according to NICAN Urology cancer guidelines 2016 but a

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Regnional Penile Cancer Pathway was only agreed in January 2020. [redacted] [redacted] should have been referred to the Regional / Supra-Regional Penile Cancer Network according to NICAN Urology cancer guidelines 2016 and, although a Regional Penile Cancer Pathway was only agreed in January 2020, referral to a specialist with appropriate experience should have been pursued.

- Patients were not aware that the care given varied from Regional Standards and MDM recommendations. They could not have given informed consent to this.
- All patients were not referred to Urology Cancer Nurse Specialists despite this resource being increased by the Southern Health and Social Care Trust. Peer Review 2017 was informed that this resource was available to all. Their contact numbers were not made available.
- As patients were not re-discussed at MDM and Urology Cancer Nurse Specialist were not involved in care, non referral was an unknown to others within the MDM.

Patient Support and Experience

All patients or families reported a positive experience with their treating consultant initially.

All patients and families were unaware of the additional support available to other patients.

Where patients had disease progression, they expressed concern at the disjointed nature of service provision and the inability to access supportive care. As they were unaware of the normal support mechanisms they believed this to be the normal standard of care or a standard that had been compromised by Covid 19 Pandemic.

All patients and their families were shocked by the fact that their care was not supported and that the care did not follow MDM recommendations. This was especially true when appropriate care should have entailed onward referral to oncology or palliative care.

Affects of Covid

- Some patient's planned review appointments did not go ahead but were rescheduled virtually. Some of the patients did not have their planned review in March / April 2020.

- The review team after speaking with the families and hearing their stories learned that for many of these patients they could not access services in their locality due to the covid restrictions. At the time two families described having difficulty accessing district nursing services for intravenous antibiotics in the community as services were stood down. One family expressed dismay at having difficulties visiting their loved one prior to his passing in hospital due to the covid restrictions and the emotional impact this has had on their grieving process. Others described how when catheters blocked they could not access

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support from their GP and where hence referred to the Emergency Department which the review team agree was not the best place for them. The review team are of the opinion that access to a specialist nurse could have offered support for these families and provide direction to the appropriate services.

Governance / Leadership

- The review team considered the treatment and care of 9 patients who were treated under the care of Dr 1 Consultant Urologist. Individual reviews were conducted on each patient. The review team identified a number of recurrent themes following each review.
- The treatment provided to 8 out of 9 patients was contrary to the NICAN Urology Cancer Clinical Guidelines (2016). This Guidance was adopted by the Southern Health and Social Care Trust Urology Multidisciplinary Team and evidenced by them as their protocols for Cancer Peer review (2017). The Guidance was issued following Dr.1 & Chairmanship of the Northern Ireland Cancer Network Urology Cancer Clinical Reference Group.
- The Urology MDM made recommendations that were deemed appropriate in 8 of 9 cases and were made with contribution and knowledge of Dr.1. Many of the recommendations were not actioned or alternative therapies given. There was no system to track if recommendations were appropriately completed.
- The MDT guidelines indicate “all newly diagnosed patients have a Key Worker appointed, a Holistic Needs Assessment conducted, adequate communication and information, advice and support given, and all recorded in a Permanent Record of Patient Management which will be shared and filed in a timely manner”. None of the 9 patients had access to a Key Worker or Cancer Nurse Specialist. The use of a CNS is common for all other urologists in the SHSCT urology multidisciplinary team allowing any questions or concerns that patients’ have to be addressed. This did not happen.
- The review team considered if this was endemic within the Multidisciplinary Team and concluded that it was not. Patients booked under other consultant urologists had access to a specialist nurse to assist them with their cancer journey.
- Statements to Urology Cancer Peer Review (2017) indicated that all patients had access to a Key worker / Urology Cancer Nurse Specialist. This was not the case and was known to be so.
- The Urology Cancer Nurse Specialist play an integral role of the MDT and should be facilitated on all the MDM to advocate on patient’s best interest throughout the patient’s journey. This should include independently referring and discussing patients at MDT.
- The Review Team regard absence of Specialist Nurse from care to be a clinical risk which was not fully understood by Senior Service Managers and the Professional Leads. The Review team have heard differing reports around escalation of this issue but are clear that patients suffered significant deficit because of non inclusion of nurses in their care. While this is the primary responsibility of the referring consultant, there is a responsibility on the SHSCT

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to know about the issue and address it.

- Assurance audits of patient pathways within the Urology Cancer Services were limited between 2017 and 2020. They could not have provided assurance about the care delivered.
- Because of resource, the MDM was very focused on first presentation at MDM and did not have a role in tracking subsequent actions if it lay outside 31 and 62 day targets. Tracking of patients was flawed by limitations within the MDM systems and the lack of Specialist Urology Nurses from their Key Worked role. Two of the three normal safety nets for patient pathway completion were,in essence absent. A collaborative approach did not appear to be actively encouraged within the MDT.
- Annual business meetings had an expressed role in identifying service deficits and drawing up an annual work plan to address them. Cancer Patient Pathway compliance audits were limited and did not identify the issues within this report.
- Governance of professionals within the MDT ran through their own directorates but there was no functioning process within Cancer Services to at least be aware of concerns - even if the responsibility for action lay elsewhere within the Southern Health and Social Care Trust. There was disconnect between the Urology MDT and Cancer Services Management. The MDT highlighted inaction by Cancer Services on Oncology and radiology attendance at MDM, but did not escalate other issues.
- The Review team found that issues around prescribing and the use of Clinical Nurse Specialists were of long standing. They were known internally and in the case of prescribing externally (Regional Oncology Services). The Northern Ireland Cancer Network drew up specific Guidance on Hormonal Therapy in Prostate Cancer in 2016 following concerns about this issue. The Guidance was not subject to audit within the Southern Health and Social Care Trust.
- The Review team were concerned that the leadership roles focused on service delivery while having a limited process to benchmark quality, identify deficiencies and escalate concerns as appropriate. Senior managers and clinical leaders in medicine and nursing were unaware of the issues detailed in this report.
- There had been a previous SAI signed off in May 2020 regarding adherence to Cancer Red Flag referral Pathways. The SAI process started in July 2016. The review team is concerned that, as part of early learning, assurances regarding other aspects of the cancer pathway were not sought. Clinical Leadership within Cancer Services were unaware of issues leading to the SAI in 2016.
- Patients in this review were not referred back appropriately to MDM as their diseased progressed. This meant there was no access to oncology and palliative care for many patients, when needed. Care needs within the community were unmet and patients left isolated.

7.0 CONCLUSIONS

The Review Team would like to thank the patients and their families for their contribution to the report and their willingness to share their experiences. The process was difficult and at times traumatic for them.The review team acknowledge that this report may cause distress to the patient and their families, however the team has endeavoured to produce a complete and transparent account of each patient's journey.

The Review of nine patients has detailed significant healthcare deficits while under the care of one individual in a system. The learning and recommendations are focused on improving systems of multidisciplinary care and it's governance. It is designed to deliver what was asked of the Review Team by patients and families -" *to ensure that this does not happen again or that another patient suffers".*

The Patients in this review received uni-professional care despite a multidisciplinary resource being available to all others. Best Practice Guidance was not followed and recommendations from MDM were frequently not implemented or alternative treatments chosen. There was knowledge of that prescribing practice varied from regional and national guidelines in the Southern Health and Social care Trust, as well as more widely across the Cancer Network. This was challenged locally and regionally, but not effectively, to provide safe care for all patients. Inappropriate non referral of patients to oncology and palliative care was unknown.

The primary duty of all doctors, nurses and healthcare professionals is for the care and safety of patients. Whatever their role, they must raise and act on concerns about patient safety. This did not happen over a period of years resulting in MDM recommendations not being actioned, off guidance therapy being given and patients not being appropriately referred to specialists for care. Patients were unaware that their care varied form recommendations and guidance. They could not and did not give informed consent to this.

The systems of governance within the Urology SHSCT Cancer Services were ineffective and did not provide assurance regarding the care and experience of the nine patients in the review. Assurance audits were limited, did not represent whole patient journey and did not focus on areas of known concern. Assurances given to Peer review were not based on systematic audit of care given by all.

While it is of little solace to the patients and families in this review, The Review team sought and received assurances that care provided to others adhered to recommendations on MDM and Regional / National Guidance.

Four of the nine patients suffered serious and significant deficits in their care. All patients had sub-optimal care that varied from regional and national guidelines.

As part of the Serious Adverse Incident process, the Review Team had requested input fromDr 1. This related to the timelines of care, for the nine patients involved in the SAI reviews and specifically formed part of the root cause analysis. This fell under professional requirements to contribute to and comply with systems to protect patients and to respond to risks to safety. To date a response has not been received.

8.0 LESSONS LEARNED

The review identified Cancer Care given by Dr 1 that did not follow agreed MDM recommendations nor follow regional or national best practice guidance. It was care given without other input from Cancer Specialist Nurses, Oncology and palliative care. It was inappropriate, did not meet patient need and was the antithesis of quality multidisciplinary cancer care.

Ensure all patients receive appropriately supported high quality cancer care irrespective of the professional delivering care.

Ensure all cancer care is multidisciplinary and centred on patients physical and emotional need.

Have processes in place to provide assurances to patients and public that care meets these requirements.

That the role of the Multidisciplinary Meeting Chair is defined by a Job Description with specific reference to Governance, Safe Care and Quality Care. It should be resourced to provide this needed oversight.

9.0 RECOMMENDATIONS AND ACTION PLANNING

The recommendations represent an enhanced level of assurance. They are in response to findings from nine patients where Dr 1 did not adhere to agreed recommendations, varied from best practice guidance and did not involve other specialist appropriately in care. They are to address what was asked of the Review by families - "that this does not happen again".

Recommendation 1.

The Southern Health and Social Care Trust must provide high quality urological cancer care for all patients.

This will be achieved by - Urology Cancer Care delivered through a co-operative multi-disciplinary team, which collectively and inter-dependently ensures the support of all patients and their families through, diagnosis, treatment planning and completion and survivorship.

Timescale – Immediate and ongoing

Assurance - Comprehensive Pathway audit of all patients care and experience. This should be externally benchmarked within a year by Cancer Peer Review / External Service Review by Royal College.

Recommendation 2.

All patients receiving care from the SHSCT Urology Cancer Services should be appropriately supported and informed about their cancer care. This should meet the standards set out in Regional and National Guidance and meet the expectation of Cancer Peer Review.

9.0 RECOMMENDATIONS AND ACTION PLANNING

This will be achieved by - Ensuring all patients receive multidisciplinary, easily accessible information about the diagnosis and treatment pathway. This should be verbally and supported by documentation. Patients should understand all treatment options recommended by the MDM and be in a position to give fully informed consent.

Timescale - Immediate and ongoing

Assurance - Comprehensive Cancer Pathway audit and Patient experience.

Recommendation 3.

TheSHSCT must promote and encourage a culture that allows all staff to raise concerns openly and safely.

This will be achieved by - Ensuring a culture primarily focused on patient safety and respect for the opinions of all members in a collatorative and equal culture. The SHSCT must take action if it thinks that patient safety, dignity or comfort is or may be compromised. Issues raised must be included in the Clinical Cancer Services oversight monthly agenda. There must be action on issues escalated.

Timescale – Immediate and ongoing

Assurance - Numbers of issues raised through Cancer Services, Datix Incidents identified, numbers of issues resolved, numbers of issues outstanding.

Recommendation 4.

The Trust must ensure that patients are discussed appropriately at MDM and by the appropriate professionals.

This will be achieved by - All MDMs being quorate with professionals having appropriate time in job plans.This is not solely related to first diagnosis and treatment targets. Re-discussion of patients, as disease progresses is essential to facilitate best multidisciplinary decisions and onward referral (e.g. Oncology, Palliative care, Community Services).

Timescale - 3 months and ongoing

Assurance - Quorate meetings, sufficient radiology input to facilitate pre MDM QA of images - Cancer Patient pathway Audit - Audit of Recurrent MDM discussion - Onward referral audit of patients to Oncology / Palliative Care etc.

Recommendation 5.

The Southern Health and Social Care Trust must ensure that MDM meetings are resourced to provide appropriate tracking of patients and to confirm agreed recommendations / actions are completed.

This will be achieved by - Appropriate resourcing of the MDM tracking team to encompass a new role comprising whole pathway tracking, pathway audit and pathway assurance. This should be supported by a safety mechanisms from laboratory services and Clinical Nurse Specialists as Key Workers. A report should be generated weekly and made available to the MDT. The role should reflect the enhanced need for ongoing audit / assurance. It is essential that current limited clinical resource is focused on patient care.

Timescale - 3 months

Assurance - Comprehensive Cancer care Pathway audit - Exception Reporting and escalation

Recommendation 6.

The Southern Health and Social Care Trust must ensure that there is an appropriate Governance Structure supporting cancer care based on patient need, patient experience and patient outcomes.

This will be achieved by - Developing a proactive governance structure based on comprehensive ongoing Quality Assurance Audits of care pathways and patient experience for all. It should be proactive and supported by adequate resources.This should have an exception reporting process with discussion and potential escalation of deficits. It must be multidisciplinary to reflect the nature of cancer and work with other directorates.

Timescale - 3 months

Assurance - Cancer Pathway Audit outcomes with exception discussion and escalation. Data should be declared externally to Cancer Peer Review

Recommendation 7.

The role of the Chair of the MDT should be described in a Job Description, funded appropriately and have an enhanced role in Multidisciplinary Care Governance.

Timescale - 3 months

Recommendation 8.

All patients should receive cancer care based on accepted best care Guidelines (NICAN Regional Guidance, NICE Guidance, Improving Outcome Guidance).

This will be achieved by - Ensuring the multi-disciplinary team meeting is the primary forum in which the relative merits of all appropriate treatment options for the management of their disease can be discussed. As such, a clinician should either defer to the opinion of his / her peers or justify any variation through the patient's documented informed consent.

Timescale – Immediate and ongoing

Assurance - Variance from accepted Care Guidelines and MDM recommendations

should form part of Cancer Pathway audit. Exception reporting and escalation would only apply to cases without appropriate peer discussion.

9.0 RECOMMENDATIONS AND ACTION PLANNING

Recommendation 9.

The roles of the Clinical Lead Cancer Services and Associate Medical Director Cancer Services should be reviewed. The SHSCT must consider how these roles can redress Governance and Quality Assurance deficits identified within the report.

Timescale - 3 months

Recommendation 10.

The families working as "Experts by Experience" have agreed to support implementation of the recommendations by receiving updates on assurances at 3, 6 and 12 monthly intervals.

Recommendation 11

The Southern Health and Social Care Trust should consider if assurance mechanisms detailed above, should be applied to patients or a subset of patients retrospectively.

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4. Peer review Self-Assessment report for NICaN 2017
5. Northern Ireland Cancer Network (NICAN) Urology Cancer Guidelines (2016)
6. EAU guidelines for penile cancer: section 6.2.1 (2019)
7. NICE improving outcomes in urological cancer (2002)
8. NICAN Urology Cancer Clinical Guidelines (March 2016), Penile Cancer treatment Section 9.3 (3).

9.0 RECOMMENDATIONS AND ACTION PLANNING

10.0 DISTRIBUTION LIST

Mr Shane Devlin – Chief Executive SHSCT

Mrs Melanie McClements – Director of Acute Services SHSCT

Dr Maria O'Kane – Medical Director SHSCT

Mrs Heather Trouton Executive Director of Nursing, Midwifery and AMPs

PHA

HSCB

Checklist for Engagement / Communication with Service User[1]/ Family/ Carer following a Serious Adverse Incident

(This checklist should be completed in full and submitted to the HSCB along with the completed SAI Review Report <u>for all levels of SAI reviews)</u>

Reporting Organisation SAI Ref Number:	Personal information redacted by USI [redacted]	**HSCB ref Number:**	Personal information redacted by USI [redacted]

SECTION 1

INFORMING THE SERVICE USER[1] / FAMILY / CARER

1) Please indicate if the SAI relates to a single service user, a number of service users or if the SAI relates **only** to a HSC Child Death notification *(SAI criterion 4.2.2)* **Please select as appropriate (✓)**	**Single Service User**		**Multiple Service Users***	x	**HSC Child Death Notification only**	
	Comment: ***If multiple service users involved please indicate the number involved**					

2) Was the Service User[1] / Family / Carer informed the incident was being investigated as a SAI? **Please select as appropriate (✓)**	**YES**		**NO**	
	If **YES**, insert **date informed**:			
	If **NO**, please select <u>**only one**</u> rationale from below, for **NOT INFORMING** the Service User / Family / Carer that the incident was being investigated as a SAI			
	a) No contact or Next of Kin details or Unable to contact			
	b) Not applicable as this SAI is not 'patient/service user' related			
	c) Concerns regarding impact the information may have on health/safety/security and/or wellbeing of the service user			
	d) Case involved suspected or actual abuse by family			
	e) Case identified as a result of review exercise			
	f) Case is environmental or infrastructure related with no harm to patient/service user			
	g) Other rationale			
	If you selected c), d), e), f) or g) above please provide further details:			
For completion by HSCB/PHA Personnel Only (**Please select as appropriate (✓)**)				
Content with rationale?	**YES**		**NO**	

SHARING THE REVIEW REPORT WITH THE SERVICE USER[1] / FAMILY / CARER

(complete this section where the Service User / Family / Carer has been informed the incident was being investigated as a SAI)

3) Has the Final Review report been shared with the Service User[1] / Family / Carer? **Please select as appropriate (✓)**	**YES**	x	**NO**	
	If **YES**, insert date informed: **all informed 26 October 2020**			
	If **NO**, please select <u>**only one**</u> rationale from below, for **NOT SHARING** the SAI Review Report with Service User / Family / Carer			
	a) Draft review report has been shared and further engagement planned to share final report			
	b) Plan to share final review report at a later date and further engagement planned			
	c) Report not shared but contents discussed ***(if you select this option please also complete 'I' below)***			

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[1] *Service User or their nominated representative*

This checklist should be completed in line with the HSCB Procedure for the reporting and follow up of SAIs October 2013 and the HSC Guidance for staff on engagement/communication with Service Users[1] / Families/Carers following a SAI

SHARING THE REVIEW REPORT WITH THE SERVICE USER[1] / FAMILY / CARER

(complete this section where the Service User / Family / Carer has been informed the incident was being investigated as a SAI)

Continued overleaf	**d)** No contact or Next of Kin or Unable to contact	
	e) No response to correspondence	
	f) Withdrew fully from the SAI process	
	g) Participated in SAI process but declined review report	
	(if you select any of the options below please also complete 'l' below)	
	h) concerns regarding impact the information may have on health/safety/security and/or wellbeing of the service user[1] family/ carer	
	i) case involved suspected or actual abuse by family	
	j) identified as a result of review exercise	
	k) other rationale	
	l) If you have selected **c), h), i), j), or k)** above please provide further details:	

For completion by HSCB/PHA Personnel Only (**Please select as appropriate** (✓))

Content with rationale?	**YES**		**NO**	

SECTION 2

INFORMING THE CORONER'S OFFICE
(under section 7 of the Coroners Act (Northern Ireland) 1959)

(complete this section for all death related SAIs)

1) Was there a Statutory Duty to notify the Coroner at the time of death? **Please select as appropriate** (✓)	**YES**		**NO**	
	If **YES**, insert **date informed**:			
	If **NO**, please provide details:			
2) Following or during the review of the SAI was there a Statutory Duty to notify the Coroner? **Please select as appropriate** (✓)	**YES**		**NO**	
	If **YES**, insert **date informed**:			
	If **NO**, please provide details:			
3) If you have selected 'YES' to any of the above **'1' or '2'** has the review report been shared with the Coroner? **Please select as appropriate** (✓)	**YES**		**NO**	
	If **YES**, insert **date report shared**:			
	If **NO**, please provide details:			

DATE CHECKLIST COMPLETED	**1.3.2021**

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[1] *Service User or their nominated representative*

This checklist should be completed in line with the HSCB Procedure for the reporting and follow up of SAIs October 2013 and the HSC Guidance for staff on engagement/communication with Service Users[1] / Families/Carers following a SAI

Southern Health and Social Care Trust
Department of Urology

Permanent Record Of Consultation

Addressogram label or patient details

Patient Name

DOB

H&C Number

Consultant Name:	
Diagnosis:	
Management Plan:	
Key worker contact details given? **Key worker name:** ____________________	Yes ☐ No ☐
Cancer Specific Information given: **Comments:**	Yes ☐ No ☐
Core/general Information Pack given: **Comments:**	Yes ☐ No ☐
Plan for Holistic needs assessment: **Comments:**	Yes ☐ No ☐
Signed by:	**Date:**

Contact Number for Keyworker: [redacted]

Concerns Checklist – identifying your concerns

Patient's name or label

☐

Key worker: ____________________

Date: ____________________

Contact number: ____________________

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need.

If any of the problems listed have caused you concern recently and you wish to discuss them with a key worker, please score the concern from 1 to 10, with 10 being the highest. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

Physical concerns

☐ Breathing difficulties
☐ Passing urine
☐ Constipation
☐ Diarrhoea
☐ Eating, appetite or taste
☐ Indigestion
☐ Swallowing
☐ Cough
☐ Sore or dry mouth or ulcers
☐ Nausea or vomiting
☐ Tired, exhausted or fatigued
☐ Swelling
☐ High temperature or fever
☐ Moving around (walking)
☐ Tingling in hands or feet
☐ Pain or discomfort
☐ Hot flushes or sweating
☐ Dry, itchy or sore skin
☐ Changes in weight
☐ Wound care
☐ Memory or concentration
☐ Sight or hearing
☐ Speech or voice problems
☐ My appearance
☐ Sleep problems
☐ Sex, intimacy or fertility
☐ Other medical conditions

Practical concerns

☐ Taking care of others
☐ Work or education
☐ Money or finance
☐ Travel
☐ Housing
☐ Transport or parking
☐ Talking or being understood
☐ Laundry or housework
☐ Grocery shopping
☐ Washing and dressing
☐ Preparing meals or drinks
☐ Pets
☐ Difficulty making plans
☐ Smoking cessation
☐ Problems with alcohol or drugs
☐ My medication

Emotional concerns

☐ Uncertainty
☐ Loss of interest in activities
☐ Unable to express feelings
☐ Thinking about the future
☐ Regret about the past
☐ Anger or frustration
☐ Loneliness or isolation
☐ Sadness or depression
☐ Hopelessness
☐ Guilt
☐ Worry, fear or anxiety
☐ Independence

Family or relationship concerns

☐ Partner
☐ Children
☐ Other relatives or friends
☐ Person who looks after me
☐ Person who I look after

Spiritual concerns

☐ Faith or spirituality
☐ Meaning or purpose of life
☐ Feeling at odds with my culture, beliefs or values

Information or support

☐ Exercise and activity
☐ Diet and nutrition
☐ Complementary therapies
☐ Planning for my future priorities
☐ Making a will or legal advice
☐ Health and wellbeing
☐ Patient or carer's support group
☐ Managing my symptoms

☐ **I have questions about my diagnosis, treatments or effects**

Key worker to complete ☐ Copy given to patient ☐ Copy to be sent to GP

WE ARE MACMILLAN. CANCER SUPPORT

Southern Health and Social Care Trust
Quality Care - for you, with you

TRANSPERINEAL ULTRASOUND-GUIDED BIOPSIES OF THE PROSTATE GLAND

This leaflet contains evidence-based information about your proposed urological procedure. It has been adapted from the British Association of Urological Surgeons patient information leaflet which represents best practice in UK urology. You should use it in addition to any advice already given to you.

Key Points

- Transperineal ultrasound-guided biopsy of the prostate is undertaken to check for prostate cancer
- There is, at present, no more reliable way than biopsies for checking for prostate cancer
- The commonest side-effects are bleeding and reduced urinary flow, but infection is rare
- Many of the prostate cancers diagnosed are not life-threatening; they may require no active treatment, only careful monitoring

What does this procedure involve?

Putting an ultrasound probe into your rectum (back passage) to scan your prostate. Guided by ultrasound, biopsies are taken from the prostate through the perineum (the skin between the scrotum and rectum). We usually take between 12 and 40 samples, depending on the size of your prostate and the indication for the procedure.

What are the alternatives?

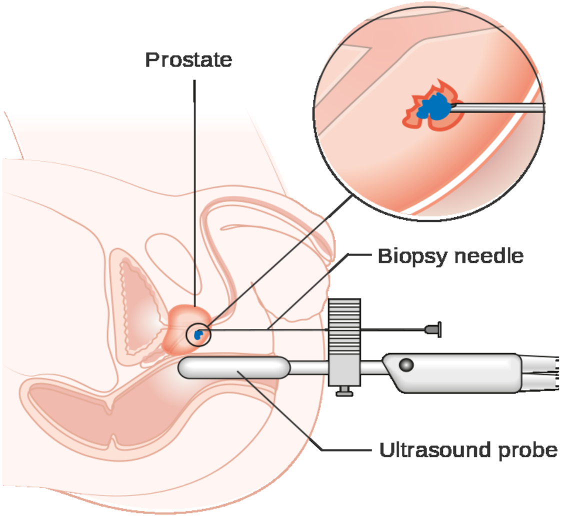
- **Observation with repeat blood tests** – repeating your blood tests and only investigating further if the PSA levels rise
- **MRI scanning**– using advanced multiparametric MRI scanning, it may be possible to detect tumour(s) in your prostate at an early stage

What happens on the day of the procedure?

The urologist (or a member of their team) will briefly review your history and medications, and will discuss the procedure again with you to obtain your consent.

Details of the procedure

- we normally carry out the procedure under a local anaesthetic and you will be awake throughout the procedure. A small number of patients will require a general anaesthetic, this will have been discussed with you in advance by your Consultant.
- we position you in special supports which allow the clinician to access the skin behind your scrotum
- we normally examine your prostate first, by rectal examination using a gloved finger, before inserting the ultrasound probe
- in a select group of patients who are deemed to be of increased risk of infection, we will give either an antibiotic tablet or an injection (depending on local antibiotic policy), after we have checked carefully for any allergies
- the probe is as wide as a man's thumb and approximately 10 cm (four inches) long
- to take biopsies from the prostate, we use a special guide so that all areas of the prostate can be included
- the biopsy needles are guided into position using the ultrasound scanner (pictured)



- we may get additional biopsy guidance by superimposing multiparametric MRI images on the ultrasound scans
- we take between 12 and 40 biopsy samples, depending on the size of your prostate and the indication for the procedure

- the procedure takes 15 to 25 minutes to complete
- we would expect that you would be discharged within 1 hour of the procedure provided you are feeling well and have passed urine

Are there any after-effects?

The possible after-effects and your risk of developing them are shown below. Some are self-limiting or reversible, but others are not. The impact of these after-effects can vary a lot from patient to patient; you should ask your surgeon's advice about the risks and their impact on you as an individual:

After-effect	Risk
Blood in your urine for up to 10 days	🟩 Almost all patients
Blood in your semen which can last up to six weeks (this poses no risk to you or your sexual partner)	🟩 Almost all patients
Bruising in your perineal area	🟨 Between 1 in 2 & 1 in 10 patients
Discomfort in your prostate caused by bruising from the biopsies	🟨 Between 1 in 2 & 1 in 10 patients
Temporary problems with erections caused by bruising from the biopsies	🟧 1 in 20 patients (5%)
Inability to pass urine (acute retention of urine)	🟧 1 in 20 patients (5%)
Bleeding in your urine preventing you from passing urine (clot retention)	🟧 1 in 50 patients (2%)

Failure to detect a significant cancer in your prostate	Between 1 in 10 & 1 in 50 patients
Need for a repeat procedure if biopsies are inconclusive or your PSA level rises further	Between 1 in 10 & 1 in 50 patients
Bleeding in your urine requiring emergency admission for treatment	1 in 100 patients (1%)
Infection in your urine requiring antibiotics	1 in 100 patients (1%)
Septicaemia (blood infection) requiring emergency admission for treatment	1 in 1000 patients (0.1%)

What can I expect when I get home?

- you will have some blood in your urine which may last several days, often with the occasional blood clot
- we advise you to drink plenty of fluid to help stop this bleeding
- you often see blood in your semen for up to six weeks
- you will be given advice about your recovery at home
- your GP will be forwarded a letter in relation to the procedure
- if the bleeding in your urine does not stop, you should contact your GP or specialist nurse for further advice
- if you are unable to pass urine at all, you should contact your GP immediately or go to your local Emergency Department
- if you have a fever or are feeling generally unwell, you should contact your GP immediately or go to your local Emergenct Department
- we will review the results of your biopsies in a multidisciplinary team (MDT) meeting within two weeks
- we will let you and your GP know the results as soon as possible, and arrange an outpatient appointment for you to discuss what action is needed

General information about surgical procedures

Before your procedure

Please tell a member of the medical team if you have:

- an implanted foreign body (stent, joint replacement, pacemaker, heart valve, blood vessel graft);
- a regular prescription for a blood thinning agent (such as warfarin, aspirin, clopidogrel, apixaban, rivaroxaban or dabigatran);
- a present or previous MRSA infection; or
- a high risk of variant-CJD (e.g. if you have had a corneal transplant, a neurosurgical dural transplant or human growth hormone treatment);
- discontinue any herbal or vitamin supplements (over the counter preparations that are not prescribed by your Doctor) two weeks prior to the procedure.

Before you go home

We will tell you how the procedure went and you should:

- make sure you understand what has been done;
- ask the clinician if everything went as planned;
- let the staff know if you have any discomfort;
- ask what you can (and cannot) do at home;
- make sure you know what happens next; and
- ask when you can return to normal activities.

We will give you advice about what to look out for when you get home. Your surgeon or nurse will also give you details of who to contact, and how to contact them, in the event of problems.

Driving after your procedure

We would recommend someone else drives you to and from your appointment where possible.

What sources have we used to prepare this leaflet?

This leaflet uses information from consensus panels and other evidence-based sources including:

- the Department of Health (England);
- the Cochrane Collaboration; and
- the National Institute for Health and Care Excellence (NICE).

It also follows style guidelines from:

- the Royal National Institute for Blind People (RNIB);
- the Information Standard;
- the Patient Information Forum; and
- the Plain English Campaign.

This booklet has been adapted with modifications for use within the Southern Health and Social Care Trust with kind permission from the British Association of Urological Surgeons.

Southern Health and Social Care Trust

Prostate Biopsy Discharge Advice Sheet

The possible after-effects and your risk of getting them are shown below. Some are self-limiting or reversible, but others are not. We have not listed very rare after-effects (occurring in less than 1 in 250 patients) individually. The impact of these after-effects can vary a lot from patient to patient; you should ask your surgeon's advice about the risks and their impact on you as an individual:

After-effect	Risk
Please note: the after-effects listed below are seen only if you had prostate biopsies taken	
Blood in your urine for up to 10 days	Almost all patients
Blood in your semen which can last for up to 6 weeks (this poses no problem for you or your sexual partner)	Almost all patients
Bruising in your perineal area	Between 1 in 2 & 1in 10 patients
Blood in your stools (from your bowel)	Almost all patients
Inability to pass urine (acute retention of urine)	1 in 20 patients (5*%)
Discomfort in your prostate from bruising due to the biopsies	Between 1 in 2 & 1 in 10 patients
Infection in your urine requiring antibiotics	1 in 100 patients (1%)
Temporary problems with erections caused by bruising from the biopsies	1 in 20 patients (5%)
Bleeding in your urine, preventing you from passing urine (clot retention)	1 in 50 patients (2%)
Septicaemia (blood infection) requiring emergency admission for treatment	1 in 1000 patients (0.1%)
Failure to detect a significant cancer in your prostate	Between 1 in 10 & 1 in 50 patients

Version 1 March 2021
K. O'Neill and L. McCourt

Bleeding in your urine requiring emergency admission for treatment	1 in 100 patients (1%)
Need for a repeat procedure if biopsies are inconclusive or your PSA level rises further	Between 1 in 50 & 1 in 50 patients

Risk Associated with TP Biopsies (BAUS 2017)

Infection To reduce the risk of urine infection following the procedure, you are advised to drink plenty of fluid (2-3 litres per day) to help flush out the bladder.

Anticoagulant Therapy (medicine to thin your blood) If you are on anticoagulant therapy and stopped taking your tablets for the biopsy, please recommence taking your normal medication as advised by staff, generally the day following your biopsy provided you don't have significant bleeding. If you are concerned contact your own doctor.

Review. Your biopsy results will be discussed in a multidisciplinary team (MDT) meeting. Following this, we will let you (and your GP) know the results as soon as possible. This may be in the form of a letter, face to face consultation or a telephone review.

If you experience any of the following, please contact your GP or local Emergency Department for advice:

- You are unable to pass urine
- You develop a high temperature (more than 38.3)
- You are passing blood clots in your urine or from your back passage
- Pain that is not relieved with simple pain relief

If you have any queries please contact the Thorndale Unit [redacted]
Mon – Fri 8.30 am – 4:30pm.

USI QUESTIONNAIRE FOR TRUST AND OTHER RELEVANT STAFF MEMBERS

SECTION A

Personal Details / Employment History

1. State your full name.

   Leanne Emma McCourt

2. State your home address, email address and mobile phone number.

[redacted]

[redacted]

   Prefer not to give personal mobile number and do not have a work mobile. Work landline number is [redacted]

3. Outline your professional qualifications.

   2006 BSc Adult Nursing Sciences (QUB. First Class)

   2010 Certificate in Urodynamics Studies (Bristol University)

   2011 Administration of Systemic Anticancer Therapies (Standalone module QUB)

   2016 Health Assessment Module (UU)

   2018 Post Grad Certificate in Non-medical Prescribing

4. State the dates of your employment with the SHSCT.

   Commenced employment with SHSCT in Sept 2006- ongoing – see quest 5.

5. State the job title(s) of the post(s) you have held at the SHSCT and if applicable, state the grade(s) at which you were employed. If you held more than one position, please provide this information in chronological order with the earliest posts first, and state the years in which you held each post.

   Staff Nurse Band 5 Sept 2006-Dec 2012

   Clinical Research Band 5 Nurse Dec 2012- March 2017

   Acute Oncology Nurse (secondment) Band 7 Nov 2016-Feb 2017

   Clinical Sister Band 6 April 2017- March 2019

   Nurse Triage GPOOH Band 6 Sept 2017- ongoing

   Urology CNS Band 7 March 2019- ongoing

6. State each of the locations in which you were employed, by reference to the hospital, the department and the ward, where applicable. If it is appropriate to do so, please indicate the medical/urological specialism which was being delivered at each location where you were employed.

   - **Sept 2006- April 2010 SHSCT- Urology Surgical ward**
   - **April 2010- Dec 2012 SHSCT- Mandeville Chemotherapy Unit Chemotherapy Nurse Band 5**

-Dec 2012- March 2017 -SHSCT- Mandeville Unit Clinical Research Band 5

-Nov 2016-Feb 2017-SHSCT -Mandeville Unit Acute Oncology Nurse (secondment) Band 7

-April 2017- March 2019- SHSCT- Thorndale Unit – Urology Outpatients Clinical Sister Band 6

-Sept 2017- ongoing- SHSCT – GP Out of Hours Nurse Triage Band 6

-March 2019- ongoing- SHSCT- Thorndale Unit Urology CNS (Macmillan) Band 7

SECTION B

Role Within Urology Services

7. Provide a full description of the duties you were required to carry out in each of the post(s) you held in the Urology Department.

Staff Nurse Urology Ward Band 5

- **Admission of elective and emergency urology patients**
- **Discharge planning**
- **Pre and post op care nursing care**
- **Caring for patients with a range of Urological Conditions**
- **Ensure patient and family aware of plan of care**
- **Assisting with Urodynamic Studies**
- **Assisting with preoperative assessment clinic**

Clinical Sister Thorndale Band 6

Of note, this is not the post I applied for- it was originally advertised as a Band 6 Urology Nurse Specialist Post. Candidates were informed of the change of role at time of interview.

-Assisting the ward manager with daily managerial duties in a busy diagnostic and treatment Urology Outpatient Unit

-Implementation and ongoing duties relating to E-Roster, Annual leave etc.

-Undertaking staff appraisals and clinical supervision sessions

-Risk assessment completion re COSHH, DSE etc. for Thorndale

-Ensuring staff training up to date and arranging training for the unit

-Undertaking regular Audits

-Fortnightly attendance at Sister's Meetings

-Assisting with Urodynamics clinics

-Teaching of clean intermittent self-catheterisation

-Performing male and female catheterisation

-Responding to Datix incidents

-Link nurse for safeguarding issues

-Assisting with running of prostate diagnostic service

-Keyworker for patients diagnosed with urological cancers

- Attendance at MDM

Urology CNS (Macmillan Post) Band 7

-on appointment to post as Band 7 CNS, I still had duties and management responsibilities as outlined above. Band 5 staff and HCA's only became the responsibility of a separate OPD Manager from March 2021

- **Learning TRUS and then TP prostate biopsy procedure to become independent with own nurse led clinics**
- **Attendance at MDM**
- **Keyworker at results clinics**
- **Rescue work in relation to keyworker patients**
- **Writing policies for Nurse Led clinics and SOP's for TP biopsy service**
- **Setting up and implementing new Nurse led Holistic needs assessment clinics and Prostate Cancer review clinics (Active Surveillance and Watchful Waiting)**
- **E-roster for CNS team**
- **Member of NICAN CRG and CNS Forum**

8. If you worked as part of a team in any of the posts which you held in the Urology Department, identify by name and job title each of the persons who worked in that team.

Staff Nurse Urology Ward Band 5

- **Too numerous and long ago to accurately recall all staff**
- **Ward Manager was Shirley Tedford**
- **Sister was Margaret Wilson**

Clinical Sister Thorndale Band 6 + Urology CNS (Macmillan Post) Band 7

Kate O'Neill- Urology CNS Band 7 (now 8a)

Jenny McMahon- Urology CNS Band 7 (now 8a)

Jason Young - Charge Nurse Band 6 and now Urology CNS Band 7

Dolores Campbell- Staff Nurse Band 5

Janice Holloway -Staff Nurse Band 5

Mairead Leonard -Staff Nurse Band 5

Nuala Mulholland- Staff Nurse Band 5

Martina O'Neill – HCA Band 3

Julie Ann Lavery- HCA Band 3

Urology Consultants- permanent and Locum

Urology Trainees

Thorndale Admin : Gemma Robinson

9. If you were responsible for managing staff in any post which you held in the Urology Department, identify who you managed, state their job title and outline how you performed your role as their line manager.

During my role as Clinical Sister and Urology CNS (up to March 21), I managed:

Dolores Campbell- Staff Nurse Band 5

Janice Holloway -Staff Nurse Band 5

Mairead Leonard -Staff Nurse Band 5

Nuala Mulholland- Staff Nurse Band 5

Martina O'Neill – HCA Band 3

Julie Ann Lavery- HCA Band 3

With Support of Jason Young (Charge Nurse):

E-roster, clinical supervision and appraisal.

Staff allocation

Arranging staff training

I was available to staff on a daily basis as we all worked in the same unit. I was easily accessible and any minor issues that occurred were dealt with at the time

in a fair manner e.g. allocating annual leave, sickness cover. I never had cause to escalate any significant issues during this time as none arose.

I arranged clinical supervision, KSF and mandatory training for staff.

Clinical allocations were designated on a daily basis.

10. Provide the following information:

(a) Identify the line manager(s) to whom you reported in each post held by you in the Urology Department;

(b)Explain how they managed you in each post; and

(c) How and what were you expected to report to them?

Staff Nurse – Urology Ward

Reported to Ward Manager (Shirley Tedford) or Ward Sister (Margaret Wilson)

Day to day management in relation to off duty and ward allocations. Both parties had a physical presence on the Ward and so were easily accessible should issues arise.

I do not recall a direct discussion/instruction about what to report, but I was aware of my Code of Conduct and the SHSCT Policies in place. I do recall Ward Meetings being held for Nursing and HCA staff.

Clinical Sister Thorndale Band 6 + Urology CNS (Macmillan Post) Band

Reported to immediate managers in Unit- CNS Kate O'Neill and CNS Jenny McMahon for everyday queries and day to day running of unit e.g. sickness cover, annual leave etc. Also held Ward Meetings in Thorndale for nursing and HCA staff.

Clinical issues/ queries were reported to the Lead Nurse –Dorothy Sharpe, Linda Hamilton, and Sarah Ward. I could contact them for advice via telephone, email or face to face.
Sarah Ward also implemented Thorndale Unit Meeting approx. every month.

Head of Service- Martina Corrigan for operational queries/issues where more senior contribution was required. Contactable when needed via telephone, email or face to face.

I would also have linked in and liaised with Consultant Colleagues re clinical queries but they were not my line managers.

There was never any formal discussion over what I was expected to report. However, I knew that if I needed advice on any issue or query, I was able to do this in a timely and effective way. My choice of who to raise an issue to would have depended on the issue in question and who was best placed to assist with this. I was also aware of my Code of Conduct and the SHSCT Policies in place.

11. The Inquiry is particularly interested in any meetings (formal or informal) you attended at which issues relating to governance were discussed. This could include discussions around, but not limited to, matters such as record-keeping, patient treatment, patient contact and any matters touching upon risk and/or patient health and safety. In each of the posts which you held in the Urology Department, were you required to attend any form of regular meeting with management or colleagues at which such issues were discussed? If so, please address the following:
    a. Give the name or title of each kind of meeting which you were required to attend with management or colleagues, by reference to each post which you held?
    b. How often did each such meeting take place?
    c. Who attended each such meeting?
    d. Were the meetings minuted or recorded to the best of your knowledge?
    e. Did you feel able to fully contribute your view(s) to each such meeting? If you were unable to do so, please explain why you feel you were unable to do so?
    f. Describe the general purpose of each kind of regular meeting you were required to attend, and outline the issues it considered?

g. In general, how successful was each kind of meeting in achieving its purpose? Please explain your answer with reasons.

Thorndale Ward Meetings- six monthly. Encouraged as many staff as possible to attend. Minutes were taken, with views and opinions valued. Covered areas such as training, new policies/procedures, housekeeping issues, governance etc. I feel these meetings were successful and also meant that team members had some ownership with shaping new services, career progression etc. within the Unit. I no longer organise these meetings as staff are now under the management of the Outpatients Department.

Sisters Meetings- usually every 2 weeks. Attended by Surgery and Elective care Sisters from SHSCT- remote link in facilitated. Mainly inpatient issues discussed and only a small proportion was applicable to Out Patients Dept.

I felt my contribution was limited, as the topics discussed did not relate to Out Patients Dept. and were more relevant to the wards e.g. falls, pressure sores and medication incidents or new paperwork used on Wards. It was however a good opportunity to network and put a "name to the face". I no longer attend Sister's meetings as my role has changed.

Monthly 1:1 meeting with Lead Nurse - normally attended by Lead Nurse, Kate O'Neill, Jenny McMahon and Jason Young and myself. Minutes were taken and views and opinions valued. Covered areas such as staffing, governance, training, equipment, clinical issues etc. I felt these meetings were successful as were able to openly discuss issues such staffing, RQIA prep, training and set up of new Nurse led services. These meetings are no longer happening as they have been replace by a weekly Departmental Meeting (initiated when Wendy Clayton undertook role of Acting Head of Service).

Urology Morbidity and Mortality Meetings. Occurs on a monthly basis with 8/12 meetings being Urology specific- CNS Team attend the Urology specific meetings.

Normally attended by CNS, Consultants, Speciality Doctors and Registrars. HOS and Urology Ward Manager would have attended, schedule permitting. Minutes were taken. These meeting were a good opportunity for learning and debating clinical issues. The team is encouraged for their views and opinions during the discussion. Pre Covid they were face to face which I feel worked better than Zoom, as you were able to gauge response and engage in conversation more efficiently.

Weekly Cancer Multidisciplinary meeting- occurs each Thursday afternoon at 2.15. A patient preview list is circulated day before. Attended by Urology Consultants and there is rota as to who chairs each week. Also in attendance are: Urology CNS's, Clinical and Medical Oncology Consultants (recent addition to the local meeting), Radiology Consultant (schedule permitting), Consultant Pathologist, Palliative Care Nurse Specialist and the MDM Co-ordinator. Video conferencing with the Specialist Urological Cancer MDT at Belfast City Hosptital takes place at 3.30 pm every Thursday. Testis Cancer cases are discussed by videoconference at 2pm every other Thursday.

A treatment plan and diagnosis is recorded for each patient on ECR and a copy sent to the GP. I feel views and opinions, overall, are valued and members treated with respect. One issue that arises from time to time is the availability of the radiology consultant to attend due to other clinical commitments. On these occasions, cases that required radiology expertise have to be deferred until the following week. This will hopefully improve going forward as a second radiologist is now in post.

SECTION C

Raising Concerns or Complaints

- **Policies and Procedures / Workplace Culture within SHSCT Urology Department.**

12. Outline your understanding of the procedures which were in place within the SHSCT to enable a member of staff to raise concerns or to make complaints about any aspect of the arrangements for the delivery of patient treatment or patient care and safety within the Urology Department.

I am aware of the "Whistleblowing" Policy, Working Well Together Policy and the use of Datix. I am also aware how to access them. However, I also felt able to raise a concern to Kate or Jenny on a one to one basis regarding day-to-day issues and know that I would be listened too and a solution found. If more senior advice was required, I also had no issue with raising this with Lead Nurse, HOS or Consultant using the most appropriate mode- one to one, email or telephone call. If I had clinical issues, the Lead Nurse would normally have been my first point of contact, whereas Operational issues were the domain of the HOS.

13. If different, outline your understanding of the procedures which were in place within the SHSCT to enable a member of staff to raise concerns or to make complaints about the performance of work colleagues within the Urology

Department, whether those colleagues were nursing, medical, administrative or managerial.

N/A

14. Do you consider that the available procedures were accessible for employees to raise concerns or make complaints about such matters as the delivery of patient treatment, the care and safety of patients and the performance of work colleagues within the Urology Department, or, in your experience, was it procedurally difficult to raise concerns? Please provide reasons to explain your answer.

I never found it procedurally difficult to raise concerns, as there was always a "go to" person if issues arose.

15. Do you consider that the prevailing culture in the Urology Department during your time there encouraged employees to raise concerns or make complaints about such matters as the delivery of patient treatment, the care and safety of patients, the performance of work colleagues, or in your experience were employees discouraged from raising concerns? Please provide reasons to explain your answer.

I was never discouraged from raising concerns and did feel I would be treated with respect and my opinion valued should I ever need to do this.

- **Mr. Aidan O'Brien**

16. Did you ever have occasion to work with Mr. Aidan O'Brien (Consultant Urologist), whether directly or indirectly? If so, please address the following:
    a. Outline how regularly you worked with Mr. O'Brien (e.g. daily, weekly, monthly), and over what period of time did you work with him?
    b. At what location(s) did you work with Mr. O'Brien?
    c. Providing as much detail as you can, explain the capacity in which you worked with Mr. O'Brien, outlining your respective roles and duties? It will be helpful if as part of your answer you could clarify whether the work with Mr. O'Brien was in association with surgery/theatre, clinics, multidisciplinary meetings, administrative issues or something else?

I worked with Mr O'Brien whilst I was a staff nurse in the Urology ward- usually daily depending on call, leave etc.
In Thorndale Unit, I would have worked with him approximately twice a week- when he had clinics in the Unit and I would have attended the MDM meeting.
From 2019, he was no longer seeing "new" patients in clinic but did continue with his review and urodynamic clinics. This was in preparation for his retirement.

On the ward, my interaction would have in relation to feeding back on patient progress, occasionally assisting with the ward round if Sister was unavailable, seeking guidance re patient care etc.

Within Thorndale, I would have assisted with Urodynamics studies on patients of Mr O'Brien. I also performed flow studies and post-void residuals for patients in clinic, as well as assisting with flexible cystoscopies and arranging dates for prostate biopsy, catheter change/insertion etc. I was also available as a key worker when needed.

17. As a consequence of working with Mr. O'Brien, or otherwise, did you have any concern about how Mr. O'Brien performed any aspect of his duties? If so, please answer the following:
    - (i) Fully explain the nature of your concern, and what it related to?
    - (ii) Was this a one-off or time limited concern or was it an ongoing concern, and if the latter, over what period of time was it an ongoing concern?
    - (iii) How would you have been expected to raise these concerns, by what means or method?
    - (iv) Did you raise this concern with Mr O'Brien or anyone else, and if so, provide their name and job title?
    - (v) When did you raise your concern?
    - (vi) Explain how you raised your concern and was it raised formally or informally?

(vii) What was done about your concern?

(viii) Was the outcome made known to you? If so, what was the outcome?

(ix) Do you consider that your concern was satisfactorily addressed?

(x) If you did have a concern about how Mr O'Brien performed any aspect of his duties but **did not** raise it with him or anyone else, please explain why you did not do so.

I had concerns re 2 patients from late 2019- mid 2020. See attached emails- patient's details have been redacted to preserve patient confidentiality.

I had concerns regarding the timeframe of Mr O'Brien's clinical letters being available on ECR as it made the keyworker role more difficult. I also had concerns about delayed referral for additional treatment. If I had not physically been in the room with the patient for the appointment it made the keyworker role more challenging, as I was not party as to what had been discussed if the patient contacted me with a query.

The queries noted below are in relation to scan appointments or oncology referrals/appointments of two patients.

Patient 1 [redacted]:

03/03/20 – email from patient regarding further clinical appointment with Mr O'Brien. As the letter from previous appointment on 20th Feb was not on ECR, I was unable to advise the patient and signposted him to Mr O'Brien's Secretary Noleen Elliott.

I also noted that I did not see a referral to Oncology on ECR for consideration of radical treatment – I emailed Noleen regarding this. To the best of my recollection, I did not receive a response. MDM outcome from 6/2/20 was referral for radical treatment.

11/03/20- emailed Oncology Secretary – no referral received.

11/03/20- discussed issue with Mr Haynes (Consultant Urologist/Divisional Medical Director) and emailed him the details.

17/03/20 -Letter of referral dictated by Mr O'Brien to oncology, typed 17/3/20.

10/04/20- Oncology appointment for patient.

4/12/2021- Letter to patient re Lookback Exercise stating, "No issues of clinical concern have been identified and your current plan is completely satisfactory."

Patient 2 [redacted]:

16/12/19- phone call to Thorndale Unit from patient enquiring re CT scan. To the best of my knowledge, I had not been previously introduced to this patient as a keyworker. Clinic letter from 13/12/19 not typed, checked SECTRA and did not see CT scan ordered. Emailed Mr O'Brien and he replied stating he had now requested the CT. Outcome from MDM 28/11/19 was: "for review by Mr O'Brien to request CT C/A/P and consider early referral to Oncology."

11/03/20- emailed Oncology Secretary – no referral received.

11/03/20- discussed issue with Mr Haynes (Consultant Urologist/Divisional Medical Director) and emailed him the details.

16/04/20- phone call from patient asking for his recent PSA blood test result and enquiring about radiotherapy appointment.

I did not see a referral letter for radiotherapy on ECR and so emailed Mr O'Brien (cc secretary Noleen Elliott) enquiring. To the best of my knowledge, I did not receive a response.

11/07/2020- referral letter on ECR to oncology

14/07/2020- Phonecall from patient telling me his PSA has increased to 20. Also informed me he was telephoned by Mr O'Brien on Saturday and told to change to his hormone treatment to injections and that he had been referred to Oncology.

07/08/2020- Oncology appointment for patient

4/12/2021- Letter to patient re Lookback Exercise stating, "No issues of clinical concern have been identified and your current plan is completely satisfactory."

- **Concerns Generally**

Save to the extent that you have addressed the issue in your responses to the questions set out above, please address the following:-

18. In each post which you held, who did you consider to be your direct line manager with whom you could raise concerns regarding patient treatment, the care and safety of patients, or the performance of work colleagues within the Urology Department? Please provide a name and job title in each case.

Whilst working as a staff Nurse on the ward, my direct line manager was Sister Shirley Tedford

Whilst working as a Clinical Sister and the as a CNS in Thorndale, my direct line manager was the Lead Nurse re clinical issues. There have been several people in this role during my employment; their details are, Dorothy Sharpe, Linda Hamilton, and Sarah Ward.
For operational issues, my Line manager was the Head of Service, Martina Corrigan.

19. Did you ever raise a concern or a complaint, whether formally or informally, in connection with the arrangements for the delivery of patient treatment, the care and safety of patients, or the performance of work colleagues within the Urology Department. If so, please address the following:

a. Fully explain the nature of your concern or complaint, and who and what it related to?

b. Who did you raise the concern or complaint with (name and job title)?

c. When did you raise it? Please provide a specific date, or an approximate date?

d. Did you raise the matter formally or informally?

e. What was done about your concern?

f. Was the outcome made known to you? If so, what was the outcome?

g. Do you consider that your concern or complaint was satisfactorily addressed?

I raised a concern in July 2018 regarding Locum Urology Consultant [redacted] in relation to patient confidentiality.

Mr [redacted] was enquiring if a patient was listed for TRUS biopsy the following week and when I asked for the details, he opened his IPhone and had a photograph of the outpatient clinic list with outcomes recorded on it.

I then asked him if it was his personal phone or a Trust phone. He told me it was his phone and locked with a fingerprint. I told him he should not have photos of patient details on his phone, as it is not secure or encrypted. He then proceeded to tell me that the Consultants are part of an encrypted group that enables them to securely hold photos- they subscribe to this. He also said this is the only way they could have records should there be litigation in 20 year's time.

Shortly after, Mr Glackin (Urology Consultant) then entered the Unit and I explained to him what had happened. He confirmed the Urology Consultants were not in any such group and to tell [redacted] to remove the images from his phone.

I discussed this with Jenny McMahon and we both agreed that this needed escalated to the Lead Nurse. (Martina Corrigan was off at present and unavailable).

I then emailed Lead Nurse Dorothy Sharpe on 6/7/2018 and then spoke with her in person, informing her of what I had discovered. She told me she would inform Ronan Carroll (Surgical AD) and get back to me. This was confirmed in an email. (see attached)

This was also escalated by Dorothy/Ronan to Mr Haynes (Divisional Medical Director) and he spoke with me and asked for an outline of what had occurred. He told me he planned to speak with [redacted] that afternoon.

Jenny McMahon phoned me to home later that day to tell me Mr Haynes had spoken with Richard (cannot recall surname) and that it was an Information Governance issue. This could mean that I may have to be interviewed.

I do not recall hearing or being contacted further in relation to this issue. Mr [redacted] is no longer employed by the Trust.

20. Did you ever have a concern or cause for complaint in connection with the arrangements for the delivery of patient treatment, the care and safety of patients, or the performance of work colleagues within the Urology Department, which you **did not** raise for any reason. If so, please address the following:
    a. Fully explain the nature of your concern or complaint, and who and what it related to?
    b. When did that concern or cause for complaint arise?
    c. Fully explain why you did not raise the concern or complaint?
    d. Are you aware of what happened in respect of the matter about which you were concerned? For example, was the matter otherwise addressed or resolved, or did the matter continue to be a problem?

N/A

21. Are you aware of any colleague raising a concern or making a complaint in connection with the arrangements for the delivery of patient treatment, the care and safety of patients, or the performance of work colleagues within the Urology Department? If so, please address the following:

    a) Identify by name and job title, the colleague who raised the concern or complaint?

b) How were you made aware that the colleague had a concern or complaint?

c) Describe the nature of the concern or complaint and who and what it related to?

d) When was the concern or complaint raised, and was this done formally or informally?

e) Who was the concern or complaint raised with (name and job title)?

f) To the best of your knowledge, explain what was done about the concern or complaint which was raised, and what the outcome was?

N/A

- **Management and Governance**

22. During your time working in the Urology Department were you ever at any time left concerned or dissatisfied with the standard of management or governance attaching to the arrangements for the delivery of patient treatment, the care and safety of patients or the performance of work colleagues? If so, and save to the extent that this has already been addressed in your answers above, please answer the following:

    a. Fully explain the nature of your concern or dissatisfaction, and what it related to?

b. Did you raise this concern or dissatisfaction with anyone else, and if so, provide their name and job title?

c. When did you raise your concern?

d. Explain how you raised your concern, whether formally or informally?

e. What was done about your concern?

f. Was the outcome made known to you? If so, what was the outcome?

g. Do you consider that your concern was satisfactorily addressed?

h. If you did have a concern about the standard of management or governance attaching to the arrangements for the delivery of patient treatment, the care and safety of patients or the performance of work colleagues but did not raise it, please explain why you did not do so?

N/A

- **Other**

23. Provide any documents in your possession which may be relevant to any of the matters contained in your responses.

Emails attached

24. Given the Inquiry's Terms of Reference, is there anything else you would wish to add in order to assist the Inquiry with its work?

N/A

SECTION D

Signature Clause

Signature: [redacted]

Print Name: Leanne McCourt

Dated: 16/05/2022

From: [redacted]

Sent: 06 July 2018 10:17

To: [redacted]

Subject: issue

Hi Leanne , following on from our discussion this am , I have given all the information to Mr Carroll who is taking it forward
Thanks
Dorothy

Dorothy Sharpe
Lead Nurse SEC
Ext [redacted] –CAH
MOB - [redacted]

This item has been archived by HP Consolidated Archive. View Restore

From: [redacted]
Sent: 03 March 2020 09:40
To: McCourt, Leanne
Subject: RE: personal

Thank you,

[redacted]

From: McCourt, Leanne
Sent: 03 March 2020 08:14
To: [redacted]
Subject: RE: personal

Hi [redacted]

Your clinic apt from Feb 20 has not yet been typed so I am unable to see exactly what Mr O'Brien had planned. You could ring his secretary Noleen on ex[redacted] and she may be able to advise you on an appointment date- by that stage it will be 3 months since your last PSA so you could get this updated.

Thanks,

Leanne

From: [redacted]
Sent: 02 March 2020 16:14
To: McCourt, Leanne
Subject: RE: personal

Good afternoon Leanne

I wonder if you could answer a query for me. At my last appointment with Mr O'Brien, he advised that he would like to see me again sometime in April. Will the date for this appointment come to me by your department or do I have to follow it with Appointments? Also, do I need to get up-to-date bloods carried out on my PSA reading with my GP practice for the appointment with Mr O'Brien? I am sorry for emailing you, but it was only after I had left my appointment that these questions came to mind.

Regards

[redacted]

From: [redacted]
Sent: 27 January 2020 12:11
To: McCourt, Leanne
Subject: personal
Importance: High

[redacted]

Good morning Leanne

Sorry for emailing you. I am aware that my case was being discussed with Mr O'Brian and staff in the City Hospital last Thursday. I have texted him asking for some feedback but have not heard from him. Would you have any feedback on this discussion?

[redacted]

[redacted]

[redacted]

From: McCourt, Leanne <Personal Information redacted by the USI>
Sent: 03 March 2020 08:25
To: Elliott, Noleen
Subject: FW: personal

Hi Noleen,

Please see below.
I see that Feb's Clinic apt letter is not yet on ECR- just checking that this Gent has been referred for radical treatment in BCH.
Could you let me know.

Thanks,

Leanne

From: Personal Information redacted by the USI
Sent: 02 March 2020 16:14
To: McCourt, Leanne
Subject: RE: personal

Good afternoon Leanne

I wonder if you could answer a query for me. At my last appointment with Mr O'Brien, he advised that he would like to see me again sometime in April. Will the date for this appointment come to me by your department or do I have to follow it with Appointments? Also, do I need to get up-to-date bloods carried out on my PSA reading with my GP practice for the appointment with Mr O'Brien? I am sorry for emailing you, but it was only after I had left my appointment that these questions came to mind.

Regards

Personal Information redacted by the USI

Southern Health and Social Care Trust
Quality Care - for you, with you

10,000 #hello my name is...

From: Personal Information redacted by the USI
Sent: 27 January 2020 12:11
To: McCourt, Leanne

Importance: High

Good morning Leanne

Sorry for emailing you. I am aware that my case was being discussed with Mr O'Brian and staff in the City Hospital last Thursday. I have texted him asking for some feedback but have not heard from him. Would you have any feedback on this discussion?

Personal Information redacted by the USI

[redacted]

[redacted]

[redacted]

[redacted]

From: McCourt, Leanne <[redacted]>
Sent: 12 March 2020 09:33
To: Haynes, Mark
Subject: RE: BCH REFERRAL

[redacted]s not expecting a BCH apt – he is quite vulnerable in that he has anxiety issues and can get quite fixated and muddled.
I have been corresponding with [redacted] via email (social worker in the Trust). I phoned him this morning as things can get lost in translation via email.
He knows [redacted] on a personal level and tells me [redacted] has been waiting on a referral. As the last clinic letter is not typed, [redacted] has told me that AOB wanted to delay referral until PSA lower. [redacted] was anxious re this and so tells me AOB agreed to refer at last apt.

L

From: Haynes, Mark
Sent: 12 March 2020 09:21
To: McCourt, Leanne
Subject: RE: BCH REFERRAL

So they are not chasing oncology appointments or expecting them?

From: McCourt, Leanne
Sent: 12 March 2020 08:16
To: Haynes, Mark
Subject: RE: BCH REFERRAL

To the best of my knowledge the only appointment they are expecting is another appointment with Mr O'Brien.

L

From: Haynes, Mark
Sent: 11 March 2020 15:14
To: McCourt, Leanne
Subject: RE: BCH REFERRAL

Are they both expecting oncology appointments?

Mark

From: McCourt, Leanne
Sent: 11 March 2020 13:20
To: Haynes, Mark
Subject: BCH REFERRAL

Hi Mark,

In reference to the 2 patients we discussed this morning.
Dr Mitchell's secretary has emailed me back and they have not received a referral.

[redacted]

Thanks,

Leanne

Leanne McCourt

Macmillan Urology Nurse Specialist
Thorndale Unit
Craigavon Hospital
Ex [redacted]

[redacted]

[redacted]

[redacted]

[redacted]

From: McCourt, Leanne <[redacted]>
Sent: 17 December 2019 09:33
To: O'Brien, Aidan
Subject: RE: CT SCAN [redacted]

Thanks Aidan.

Leanne

From: O'Brien, Aidan
Sent: 16 December 2019 14:19
To: McCourt, Leanne
Subject: RE: CT SCAN [redacted]

Leanne,

I have requested the CT scan.

Thank you,

Aidan.

From: McCourt, Leanne
Sent: 16 December 2019 12:46
To: O'Brien, Aidan
Subject: CT SCAN [redacted]

Hi Aidan,

[redacted] has been in contact with me regarding his upcoming CT scan- I have checked SECTRA and do not see one listed yet, could you order ?

Many thanks,

Leanne
Leanne McCourt

Macmillan Urology Nurse Specialist
Thorndale Unit
Caraigavon Hospital
Ex [redacted]

From: McCourt, Leanne <[redacted]>
Sent: 16 April 2020 11:58
To: O'Brien, Aidan
Cc: Elliott, Noleen
Subject: [redacted]

Hi Aidan,

I had a phone call from [redacted] enquiring about his most recent PSA – it has dropped further to 17.71.

He was enquiring about radiotherapy and I have explained that with the current situation with COVID that there is a delay.
I just wanted to check that he has been referred as I don't see anything on ECR.

Thanks,

Leanne

Leanne McCourt

Macmillan Urology Nurse Specialist
Thorndale Unit
Craigavon Hospital
Ex [redacted]

From: McCourt, Leanne
Sent: 06 July 2018 10:50
To: Sharpe, Dorothy
Subject: RE: issue

Thanks Dorothy.

L

From: Sharpe, Dorothy
Sent: 06 July 2018 10:17
To: McCourt, Leanne
Subject: issue

Hi Leanne , following on from our discussion this am , I have given all the information to Mr Carroll who is taking it forward
Thanks
Dorothy

Dorothy Sharpe
Lead Nurse SEC
Ext [redacted] CAH
MOB - [redacted]

From: Haughey, Mary
Sent: 02 September 2021 12:12
To: Quin, Clair; Muldrew, Angela; McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate
Subject: Notes from Nurse-led review meeting on 13/08

Dear all

Going forward, we agreed to meet on the last Thursday of each month at 9.15am, therefore the next meeting is scheduled for **Thursday 30th September at 9.15am.**

Just to advise that I am unable to attend this meeting as I am on a course. Could we change this meeting to Thursday 23rd September at same time for this month only?

Please see summary notes below from our meeting on 13th August 2021:

Area	Discussion / action
1. Staffing update	Both the admin worker and support workers are in post. The support worker will be based half time with Stacy / Niamh. There is discussion ongoing between Angela and Jane regard future line- management of the support worker – it is felt that this is best placed under Angela as there may be times that cross-cover is required across the support workers.
2. Policies / Protocols	The policies and protocols for the nurse-led review clinics are with Ronan Carroll for approval and sign off. Leanne & Mark have updated the regional pathways in line with current NICE guidance – these will be reviewed at the next Urology CRG meeting for approval / sign off. Patient information leaflets about the clinics have been developed and shared with the Trust cancer service user group for review/comment.
3. Recording / coding for clinics	It was agreed that the HNA would be completed at the first review appointment with the patient – this would be recorded as an HNA. Following this appointment, future review appointments will be coded under nurse-led review. CNS's to agree start dates for their clinics.
4. eHNA	The CNS's and support worker have attended the eHNA training and accounts have been set-up. It is hoped to get these set up shortly.
5. Virtual health &wellbeing events	Mary advised that many of the tumour sites are moving to virtual health & wellbeing events and Sharon Clarke is helping

	to facilitate / co-ordinate these. It was agreed to set up a meeting with Sharon to discuss further.
6. Future meetings	It was agreed to meet initially on a monthly basis – the last Thursday of each month at 9.15am. Wendy / Mary will co-ordinate the meetings.

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 26 October 2021 14:53
To: Quin, Clair; Muldrew, Angela; McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate
Subject: Notes from Nurse-led review meeting on 23/09

Dear all

Please see summary notes below from the last Nurse-led review meeting on 23rd September. The next meeting is scheduled for **Thursday 28th October 2021 at 9.15am.**

Area	**Update 13/08**	**Update 23/09**
1. Staffing update	Both the admin worker and support workers are in post. The support worker will be based half time with Stacy / Niamh. There is discussion ongoing between Angela and Jane regard future line-management of the support worker – it is felt that this is best placed under Angela as there may be times that cross-cover is required across the support workers.	It has been agreed that Becky will be line- managed by Angela. The administrator, Catherine Kelly, is not in the CNS admin support role as she is helping out in Thorndale reception due to staff shortages.
2. Policies / Protocols	The policies and protocols for the nurse-led review clinics are with Ronan Carroll for approval and sign off. Leanne & Mark have updated the regional pathways in line with current NICE guidance – these will be reviewed at the next Urology CRG meeting for approval / sign off.	Ronan has signed off the Screening policy. He is linking with Melanie and Heather Trouton in relation to who signs off the nurse-led clinic policies / protocols. It was noted that for other tumour sites, the local policies were not signed off once they were adopting / adhering to regionally agreed guidance and the consultants were in agreement. **Action**: *Clair Q / Mary will check with Louise Gribben in relation to the process used to set up her nurse-led clinics and will also contact Lisa Ranaghan to seek clarity in relation to sign off.* Revised guidance was presented at the last NICAN Urology CRG meeting

	Patient information leaflets about the clinics have been developed and shared with the Trust cancer service user group for review/comment.	– there were a few small tweaks. It will also be reviewed at the regional Urology CNS Forum meeting next week.
3. Recording / coding for clinics	It was agreed that the HNA would be completed at the first review appointment with the patient – this would be recorded as an HNA. Following this appointment, future review appointments will be coded under nurse-led review. CNS's to agree start dates for their clinics.	Angela advised that the coding has been set-up for the HNA / Review clinics. She has put in requests for the CNS's to access the shared drive for the CNS database, and contacted Edith Doyle in relation to having a drop down for the CNS proforma in a PDF format. Clinics cannot start until the policies/protocols are signed off. There was also discussion on clarifying the role of the admin worker to support the review clinics following the first appointment. **Action**: *Angela to link with Jane Scott to clarify role/duties of the administrator* Leanne / Kate advised that Mr Glackin and Mr Haynes are happy to proceed with nurse-led clinics once the process for follow-up of results has been agreed. There was discussion on the CNS's utilising the DARO code on PAS for patients discharged awaiting result outcomes. Angela advised that once she had spoken with Jane to clarify admin role, an SOP would be developed to indicate all steps involved and by whom. This could be shared with the consultants to provide reassurance.
4. eHNA	The CNS's and support worker have attended the eHNA training and accounts have been set-up. It is hoped to get these set up shortly.	Becky, in her role as Support Worker, will be able to support the CNS's with setting up the eHNA assessments and completing referrals to voluntary / community support services. The Head & Neck team have started their eHNAs

		and Becky advised the system is straight forward to use. There was some discussion on the importance of offering a HNA to all newly diagnosed patients. This is part of the CNS KPIs and will be captured in the CNS proforma / database as this information will be required in the future by the HSCB/PHA.
5. Virtual health &wellbeing events	Mary advised that many of the tumour sites are moving to virtual health & wellbeing events and Sharon Clarke is helping to facilitate / co-ordinate these. It was agreed to set up a meeting with Sharon to discuss further.	The CNS's met with Sharon Clarke to plan a virtual health & wellbeing event for next month.
6. Future meetings	It was agreed to meet initially on a monthly basis – the last Thursday of each month at 9.15am. Wendy / Mary will co-ordinate the meetings.	Date of next meeting: **Thursday 28TH October @ 9.15am**

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 06 December 2021 09:04
To: Quin, Clair; Muldrew, Angela; McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate; Murray, Rebecca M; McKay, Paula
Subject: Notes from Nurse-led review meeting on 02/12/21

Dear all

Please see summary notes below from the last Nurse-led review meeting held on 2nd December 2021. The next meeting is scheduled for **Thursday 27th January 2022 at 9.00am.**

Area	Update 28/10	Update 02/12
1. Staffing update	**Action:** *Matthew is meeting with Catherine & Amanda on 28/10 to review roles and to arrange typing training for Catherine.* Angela advised that she is moving to a new role: MDT Administrator & Project officer. Vicky's post is to be replaced and the new postholder will manage Becky and the other support workers going forward. In the interim, Sinead Lee will provide line management support.	Catherine has completed training and waiting on audio equipment to arrive.
2. Policies / Protocols	The clinic policies and protocols will need to be presented at the Acute Senior Nurse meeting for sign off. This is chaired by Chris Wamsley who is on A/L this week but Sarah will follow up with him next week. In the meantime, as the clinicians have signed off, it was agreed to go ahead and plan the nurse-led clinics. The revised guidance was presented at the last CNS Forum meeting and all agreed with the proposed changes. Leanne has forwarded notes of the meeting to NICAN. It will be put on the agenda for final sign off at the next Urology CRG meeting.	No further update in relation to this. **Action**: *Mary to follow-up with Sarah / Chris* Guidance to be signed off at the next Urology CRG meeting.
3. Recording / coding for clinics	Coding has been set up for the eHNA and nurse-led clinics.	Completed.

	Action: *Mathew to forward codes to CNS's.* Becky has started to input data into the CNS database. It was agreed that Becky would do the admin support for the first Nurse-led clinic as it will also incorporate the eHNA. Following this, Catherine will provide the CNS admin support. It was agreed that Catherine's role will be monitored as the clinics develop as it was highlighted that she is also providing admin support to the other Urology nurses. **Action**: *Angela will link with Jane Scott next week to develop the SOP for the admin process which will be shared with the group and the clinicians.*	Becky is developing an electronic proforma for the CNS's which will have drop-down boxes, this should help to standardise the process for all sites. **Action**: *Angela / Becky to explore how to submit the proforma using Java script* Leanne drafted an SOP and sent to all for review. It was noted that all patients come to the clinic with their PSA result, Catherine will check that this is done and it will be built into the pathway. DARO is not required as patients are put on a review waiting list. Urgent codes are not required. Patient's letter advises that they can book bloods through the phlebotomy drive-through in Armagh if they are not able to access through GP practice. It was noted that another drive-through is planned for Lurgan. **Action:** *Angela / Matthew to tweak the SOP and re-circulate to all.*
4. eHNA	It was agreed to go ahead and to start planning the eHNA clinics as it will take 2-3 weeks to get bloods arranged. Leanne will contact Tony and Mark to advise. There will be 3 clinics per week, with approximately 7 patients per clinic. **Action:** *Leanne / Kate & Patricia to send Angela the clinic templates for their clinics and the days / times so that the patients can be added to the waiting lists.*	Leanne has held x2 clinics to date and both have gone well. Kate is starting a clinic next week. Becky has supported with the set-up of the electronic assessments. Going forward it was noted that as numbers increase, patients will be offered 3 follow-up options: face-to-face, telephone or letter. The last 2 options will be recorded as virtual activity on PAS. A text reminder is not required.
5. Virtual health &wellbeing events	An initial meeting with Sharon Clarke took place and speakers / topics identified. 120 patients have been identified to invite to the virtual event. **Action:** *Mary will ask Sharon to contact the nurses in relation to*	A virtual HWB event is planned for 19/01/22. Patients have been identified to invite. Staff are working on content for their presentations. Sharon / Caroline are supporting the team with this.

	technical support to record the video presentations and to agree a date for the event.	
6. Patient Experience		**Action:** *Mary to meet with team to review last patient experience survey & action plan, and to develop a new patient experience survey.* Leanne is exploring Care Opinion as an option.
7. Future meetings	Date of next meeting: **Thursday 25th November at 9.15am**	Date of next meeting: **Thursday 27th January 2022 at 9am**

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 28 January 2022 14:46
To: Quin, Clair; Muldrew, Angela; McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate; Murray, Rebecca M; McKay, Paula; Lee, Sinead
Subject: Notes from Nurse-led review meeting on 27/01/22

Dear all

Please see summary notes below from the last Urology Nurse-led review meeting on Thursday 27th January 2022 at 9.00am. The next meeting is scheduled for **Thursday 24th February at 9am –** a zoom link will be sent out closer to the time.

Area	**Update 02/12**	**Update 27/01/2022**
Attendees		Mary Haughey; Angela Muldrew; Clair Quin; Sarah Ward; Paula McKay; Jane Scott; Emma Mullen; Leanne McCourt; Patricia Thompson
Apologies		Wendy Clayton; Matthew McAlinden; Kate O'Neill; Catherine Kelly; Becky Murray
1. Staffing update	Catherine has completed training and waiting on audio equipment to arrive.	Not sure if equipment has arrived – Jane / Matthew can you advise please? **Action:** Mary to include Sinead Lee in future meetings as she currently line manages the support workers.
2. Policies / Protocols	No further update in relation to this. **Action**: *Mary to follow-up with Sarah / Chris* Guidance to be signed off at the next Urology CRG meeting.	Mary had been advised that the nurse-led policies were on the agenda for sign off at the Acute Senior Nurse meeting in December but has been unable to get confirmation. **Action:** *Sarah will contact Ronan Carroll to seek confirmation and a copy of the minutes. Also to clarify what the next steps are re. uploading docs to share-point.* Leanne advised that she is starting to work next on the policy for TP biopsies.
3. Recording /	Becky is developing an electronic	Angela advised that the electronic

coding for clinics	proforma for the CNS's which will have drop-down boxes, this should help to standardise the process for all sites. **Action**: *Angela / Becky to explore how to submit the proforma using Java script* Leanne drafted an SOP and sent to all for review. It was noted that all patients come to the clinic with their PSA result, Catherine will check that this is done and it will be built into the pathway. DARO is not required as patients are put on a review waiting list. Urgent codes are not required. Patient's letter advises that they can book bloods through the phlebotomy drive-through in Armagh if they are not able to access through GP practice. It was noted that another drive-through is planned for Lurgan. **Action:** *Angela / Matthew to tweak the SOP and re-circulate to all.*	CNS proforma is developed. There is a new IT person in post with responsibility for share-point so they will link with him in relation to the function required to submit the form directly to the support workers once it is completed. The form will be available on the cancer services share-point tile. **Action**: *Angela will advise all when the form is available for use.* **Action:** *Angela & Matthew to finalise the Admin SOP.*
4. eHNA	Leanne has held x2 clinics to date and both have gone well. Kate is starting a clinic next week. Becky has supported with the set-up of the electronic assessments. Going forward it was noted that as numbers increase, patients will be offered 3 follow-up options: face-to-face, telephone or letter. The last 2 options will be recorded as virtual activity on PAS. A text reminder is not required.	Leanne advised that eHNA clinics are ongoing and they work better when the patient has completed the concerns checklist before the consultation. Becky has been able to support with this [redacted] There has been a mix of telephone and face-to-face appointments and both seem to work well. The care plans are scanned and uploaded to NIECR. Angela advised that Leanne can send the patient list for the next clinics to the generic support worker email address and these will be picked up by either Stacy or Emma in Becky's absence. The Nurse-led review clinics are going well though are still ad-hoc. Leanne has been liaising with the consultants to encourage them to refer patients on active surveillance and watch & wait

		pathways to nurse-led review. Outcomes are dictated and recorded in the progress notes section on NIECR.
5. Virtual health &wellbeing events	A virtual HWB event is planned for 19/01/22. Patients have been identified to invite. Staff are working on content for their presentations. Sharon / Caroline are supporting the team with this.	Due to service & staffing pressures, the virtual HWB event planned for 19th January was cancelled. It is proposed to put this back to March. Mary suggested that some work could still be done in preparation for the event in relation to some of the presentations and will ask Sharon to contact the team to progress.
6. Patient Experience	**Action:** *Mary to meet with team to review last patient experience survey & action plan, and to develop a new patient experience survey.* Leanne is exploring Care Opinion as an option.	Meeting was held recently with Care Opinion and a plan to utilise this as a mechanism for patient feedback was agreed. Mairead and Christine will attend the Urology departmental meeting on 3 Feb at 1.15pm. Following this, general awareness and responder training will be arranged for the team. Also exploring digital storytelling and peer review volunteers as options to get patient feedback. Leanne advised that she has a patient who is interested in joining the Cancer Service user Group after he completes his treatment and will keep Mary updated. Sarah advised that the previous patient experience surveys were shared with the Urology service user group for review and comment. This will be fed back to the team for future consideration. **Action:** *Mary to meet with the team to review the last CPES results and action plan and plan for next patient experience survey*.
7. Future meetings	Date of next meeting: **Thursday 27th January 2022 at 9am**	**Date of next meeting: Thursday 24th Feb at 9am via zoom**

Kind regards
Mary

Mary Haughey

Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 24 February 2022 15:09
To: Quin, Clair; Muldrew, Angela; McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate; Murray, Rebecca M; McKay, Paula; Lee, Sinead
Subject: Notes from Nurse-led review meeting on 24/02/22

Dear all

Please see summary notes below from the Urology Nurse-led review meeting on Thursday 24th February 2022 at 9.30am. The next meeting is scheduled for **Thursday 31st March at 9.30am –** a zoom link will be sent closer to the time.

Area	**27/01/2022**	**Update 24/02/2022**
Attendees	Mary Haughey; Angela Muldrew; Clair Quin; Sarah Ward; Paula McKay; Jane Scott; Emma Mullen; Leanne McCourt; Patricia Thompson	Mary Haughey; Leanne McCourt; Catherine Kelly; Angela Muldrew; Paula McKay; Becky Murray; Sinead Lee
Apologies	Wendy Clayton; Matthew McAlinden; Kate O'Neill; Catherine Kelly; Becky Murray	Wendy Clayton; Matthew McAlinden; Kate O'Neill; Jane Scott; Patricia Thompson; Clair Quin; Sarah Ward
1. Staffing update	Not sure if equipment has arrived – Jane / Matthew can you advise please? **Action:** Mary to include Sinead Lee in future meetings as she currently line manages the support workers.	Catherine is still waiting on the audio equipment. The nurse-led review clinics are starting on 28/02. **Action:** Mary to email Matthew for an update.
2. Policies / Protocols	Mary had been advised that the nurse-led policies were on the agenda for sign off at the Acute Senior Nurse meeting in December but has been unable to get confirmation. **Action:** *Sarah will contact Ronan Carroll to seek confirmation and a copy of the minutes. Also to clarify what the next steps are re. uploading docs to share-point.* Leanne advised that she is starting to work next on the policy for TP biopsies.	Still unclear if the nurse-led policies have been signed off. **Action**: Paula advised that she will follow up with Ronan next week.

3. Recording / coding for clinics	Angela advised that the electronic CNS proforma is developed. There is a new IT person in post with responsibility for share-point so they will link with him in relation to the function required to submit the form directly to the support workers once it is completed. The form will be available on the cancer services share-point tile. **Action**: *Angela will advise all when the form is available for use.* **Action:** *Angela & Matthew to finalise the Admin SOP.*	The CNS proforma is now available electronically on the cancer services sharepoint tile from this week. Once it is completed it will automatically be sent to the generic support worker email address. There is now no need to send daily sheets / additional proformas to the Support workers.
4. eHNA	Leanne advised that eHNA clinics are ongoing and they work better when the patient has completed the concerns checklist before the consultation. Becky has been able to support with this though [redacted]. There has been a mix of telephone and face-to-face appointments and both seem to work well. The care plans are scanned and uploaded to NIECR. Angela advised that Leanne can send the patient list for the next clinics to the generic support worker email address and these will be picked up by either Stacy or Emma in Becky's absence. The Nurse-led review clinics are going well though are still ad-hoc. Leanne has been liaising with the consultants to encourage them to refer patients on active surveillance and watch & wait pathways to nurse-led review. Outcomes are dictated and recorded in the progress notes section on NIECR.	Angela circulated an updated Admin SOP for review. Leanne advised that the combined HNA/review clinic is not working. A lot of the patients do not want an eHNA so it's not making best use of the time allocated. It was agreed that going forward there would be a separate eHNA clinic on a Wed morning. Becky will manage this admin process and Catherine will manage the admin process for all of the review clinics. The SOP will be amended to reflect this new development. There are approximately 12 patients left who will attend the combined clinic and following this, Leanne will advise Becky of the patients who require an eHNA appointment. This process will also enable high risk patients to avail of an eHNA. Patricia has started her eHNA clinics and a short meeting was held to confirm the cohort of patients suitable for the eHNA clinic. **Action:** Mary to liaise with colleagues in BT to find out if patients who attend Belfast for

		treatment (radiotherapy / surgery) are offered an HNA.
5. Virtual health &wellbeing events	Due to service & staffing pressures, the virtual HWB event planned for 19th January was cancelled. It is proposed to put this back to March. Mary suggested that some work could still be done in preparation for the event in relation to some of the presentations and will ask Sharon to contact the team to progress.	Date for the next virtual HWB event to be agreed. In the meantime, Mary will ask Sharon & Caroline to link with team to support with pre-recording the presentations. **Action:** Mary to link with Sharon & Caroline to arrange a meeting with the Urology nurses.
6. Patient Experience	Meeting was held recently with Care Opinion and a plan to utilise this as a mechanism for patient feedback was agreed. Mairead and Christine will attend the Urology departmental meeting on 3 Feb at 1.15pm. Following this, general awareness and responder training will be arranged for the team. Also exploring digital storytelling and peer review volunteers as options to get patient feedback. Leanne advised that she has a patient who is interested in joining the Cancer Service user Group after he completes his treatment and will keep Mary updated. Sarah advised that the previous patient experience surveys were shared with the Urology service user group for review and comment. This will be fed back to the team for future consideration. **Action:** *Mary to meet with the team to review the last CPES results and action plan and plan for next patient experience survey.*	Care opinion team attended the departmental meeting. Posters have been circulated following the meeting along with dates for the responder training. Leanne and Mary met with Maura McClean from Macmillan in relation to the peer facilitator project. A further meeting to take this forward has been arranged for 03/03.
7. Future meetings	**Date of next meeting: Thursday 24th Feb at 9am via zoom**	**Date of next meeting: Thursday 31st March at 9.30am via zoom**

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead

Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 25 April 2022 07:56
To: McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate; Murray, Rebecca M; Lee, Sinead; Kelly, Catherine F
Cc: Quin, Clair
Subject: Notes from Nurse-led review meeting on 21/04/22

Dear all

Please see summary notes below from the Urology Nurse-led review meeting on Thursday 21st April 2022 at 9.15am. The next meeting is scheduled for **Thursday 26st May at 9.15am and** a zoom link has been sent.

Area	**24/02/2022**	**Update 21/04/2022**
Attendees	Mary Haughey; Leanne McCourt; Catherine Kelly; Angela Muldrew; Paula McKay; Becky Murray; Sinead Lee	Mary Haughey; Leanne McCourt; Patricia Thompson; Angela Muldrew; Becky Murray; Sinead Lee
Apologies	Wendy Clayton; Matthew McAlinden; Kate O'Neill; Jane Scott; Patricia Thompson; Clair Quin; Sarah Ward	Wendy Clayton; Matthew McAlinden; Kate O'Neill; Jane Scott; Clair Quin; Sarah Ward; Paula McKay
1. Staffing update	Catherine is still waiting on the audio equipment. The nurse-led review clinics are starting on 28/02. **Action:** Mary to email Matthew for an update.	There is a back log of typing as Catherine has been covering the Thorndale Unit due to a vacant post. Wendy Clayton is aware and has arranged additional admin support to address the typing backlog. Matthew is working to fill the vacant post.
2. Policies / Protocols	Still unclear if the nurse-led policies have been signed off. **Action**: Paula advised that she will follow up with Ronan next week.	**Action:** Mary to follow-up with Paula
3. Recording / coding for clinics	The CNS proforma is now available electronically on the cancer services sharepoint tile from this week. Once it is completed it will automatically be sent to the generic support worker email address. There is now no need to send daily sheets / additional proformas to the Support workers.	The nurses are using the CNS proforma. Small issue raised in relation to the mandatory box required for the date of the HNA appointment, as this is not always known. The Support Worker uses the month as a guide for the appointment. After some discussion it was agreed that in the HNA part of the

		CNS proforma, there will be an option to either add in the date of the HNA (if done retrospectively or if appt is already planned) **OR** to use the free text box named '*Additional info'* to add in a comment for example "Review in 8 weeks". **Action:** Sinead will take forward and advise all when the change has been made
4. eHNA	Angela circulated an updated Admin SOP for review. Leanne advised that the combined HNA/review clinic is not working. A lot of the patients do not want an eHNA so it's not making best use of the time allocated. It was agreed that going forward there would be a separate eHNA clinic on a Wed morning. Becky will manage this admin process and Catherine will manage the admin process for all of the review clinics. The SOP will be amended to reflect this new development. There are approximately 12 patients left who will attend the combined clinic and following this, Leanne will advise Becky of the patients who require an eHNA appointment. This process will also enable high risk patients to avail of an eHNA. Patricia has started her eHNA clinics and a short meeting was held to confirm the cohort of patients suitable for the eHNA clinic. **Action:** Mary to liaise with colleagues in BT to find out if patients who attend Belfast for treatment (radiotherapy / surgery) are offered an HNA.	Leanne advised that the separate eHNA clinics are working better. There are only 3 patients left from the combined clinic. There can be up to 4 patients per clinic and this can be very intensive depending on the complexity and number of issues raised. Leanne and Patricia both advised that the majority of the patients do not complete the concerns checklist beforehand so they complete this as part of the assessment appointment. It was agreed that Becky would contact all the patients by telephone one week after the appointment letter is sent out to check if they have received it and are able to complete. If not, Becky will complete this with the patient over the telephone. Mary also advised that Becky is able to do some of the non-clinical referrals for patients. A session is being arranged for the Support Workers next week with Sharon and Caroline from the MISS to get an update on all of the services / support available.
5. Virtual health &wellbeing events	Date for the next virtual HWB event to be agreed.	Sharon & Caroline have made contact with Mr O'Donoghue in

	In the meantime, Mary will ask Sharon & Caroline to link with team to support with pre-recording the presentations. **Action:** Mary to link with Sharon & Caroline to arrange a meeting with the Urology nurses.	relation to his presentation recording. The nurses have not been able to meet as yet due to service pressures.
6. Patient Experience	Care opinion team attended the departmental meeting. Posters have been circulated following the meeting along with dates for the responder training. Leanne and Mary met with Maura McClean from Macmillan in relation to the peer facilitator project. A further meeting to take this forward has been arranged for 03/03.	Work is ongoing with Macmillan peer facilitator programme to enable facilitated conversations with a range of patients to get a better understanding of their experience at different stages of the pathway. A patient flyer has been developed and questions are being agreed.
7. Future meetings	**Date of next meeting: Thursday 31st March at 9.30am via zoom**	**Date of next meeting: Thursday 26th May at 9.15am.**

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 18 June 2022 13:57
To: McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate; Murray, Rebecca M; Lee, Sinead; Kelly, Catherine F; Quin, Clair; McKay, Paula
Subject: Notes from Nurse-led review meeting on 26/05/22

Dear all

Please see summary notes below from the Urology Nurse-led review meeting on Thursday 26th May 2022 at 9.15am. The next meeting is scheduled for **Thursday 30th June at 9.15am and** a zoom link will be sent.

Area	**21/04/2022**	**26/05/22**
Attendees	Mary Haughey; Leanne McCourt; Patricia Thompson; Angela Muldrew; Becky Murray; Sinead Lee	Mary Haughey; Leanne McCourt; Becky Murray; Sinead Lee; Paula McKay; Kate O'Neill
Apologies	Wendy Clayton; Matthew McAlinden; Kate O'Neill; Jane Scott; Clair Quin; Sarah Ward; Paula McKay	Wendy Clayton; Clair Quin; Patricia Thompson; Sarah Ward; Matthew McAlinden
1. Staffing update	There is a back log of typing as Catherine has been covering the Thorndale Unit due to a vacant post. Wendy Clayton is aware and has arranged additional admin support to address the typing backlog. Matthew is working to fill the vacant post.	There is still a back-log in typing from end of February and could impact on review of those patients on a 3 monthly or 6 monthly basis. A new admin staff member has been appointed but has to complete audio typist training. The issue has been escalated to Wendy and Paula agreed to follow up. **Action:** Paula to follow up with Wendy / Jane / Matthew
2. Policies / Protocols	**Action:** Mary to follow-up with Paula to check if policies are signed off	**Action:** Paula will link with the HOS and AD to confirm if the policies were signed off at the Acute Nursing Governance meeting or if they still need to be presented.
3. Recording / coding for clinics	The nurses are using the CNS proforma. Small issue raised in relation to the mandatory box required for the date of the HNA appointment, as this is not always known. The Support Worker uses	Sinead updated the CNS Proforma with option to add in date or to use the free text box. Nurses advised that this is working well.

	the month as a guide for the appointment. After some discussion it was agreed that in the HNA part of the CNS proforma, there will be an option to either add in the date of the HNA (if done retrospectively or if appt is already planned) **OR** to use the free text box named '*Additional info'* to add in a comment for example "Review in 8 weeks". **Action:** Sinead will take forward and advise all when the change has been made	
4. eHNA	Leanne advised that the separate eHNA clinics are working better. There are only 3 patients left from the combined clinic. There can be up to 4 patients per clinic and this can be very intensive depending on the complexity and number of issues raised. Leanne and Patricia both advised that the majority of the patients do not complete the concerns checklist beforehand so they complete this as part of the assessment appointment. It was agreed that Becky would contact all the patients by telephone one week after the appointment letter is sent out to check if they have received it and are able to complete. If not, Becky will complete this with the patient over the telephone. Mary also advised that Becky is able to do some of the non-clinical referrals for patients. A session is being arranged for the Support Workers next week with Sharon and Caroline from the MISS to get an update on all of the services / support available.	eHNA clinics are ongoing and working well. Mary has arranged for a session with MISS for Leanne and Patricia to find out more about the support services available for people affected by cancer. Caroline Davies is also developing a directory of services which will be shared with all staff. In relation to HNA's for patients who attend Belfast for treatment, Mary advised that this is currently not happening as the support worker post is vacant and it is hoped to re-start it once the post is filled.
5. Virtual health	Sharon & Caroline have made	No further update in relation to

&wellbeing events	contact with Mr O'Donoghue in relation to his presentation recording. The nurses have not been able to meet as yet due to service pressures.	this at the moment and it will be kept on the agenda.
6. Patient Experience	Work is ongoing with Macmillan peer facilitator programme to enable facilitated conversations with a range of patients to get a better understanding of their experience at different stages of the pathway. A patient flyer has been developed and questions are being agreed.	Mary had a meeting with Maura and the peer facilitators to provide context / background for the work and to go through the draft questions. Leanne & Patricia have identified the patients. It was agreed that a cover letter and flyer would be posted to all the patients initially and then Becky would follow-up with a telephone call to seek consent. Once the patients consented their details would be sent to Maura McClean in Macmillan so that appointments could be arranged.
7. Future meetings	**Date of next meeting: Thursday 26th May at 9.15am.**	**Date of next meeting: Thursday 30th June at 9.15am**

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 14 July 2022 15:17
To: McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate; Murray, Becky; Lee, Sinead; Kelly, Catherine F; Quin, Clair; McKay, Paula
Subject: Notes from Urology Nurse-led review meeting on 30/06/22

Dear all

Please see summary notes below from the Urology Nurse-led review meeting on Thursday 30th June 2022 at 9.15am.

A date for the next meeting has not been agreed as yet until the Urology CNS's advise which day / time suits best.

Area	**26/05/22**	**Update 30/06/22**
Attendees	Mary Haughey; Leanne McCourt; Becky Murray; Sinead Lee; Paula McKay; Kate O'Neill	Mary Haughey; Becky Murray; Sinead Lee; Kate O'Neill; Wendy Clayton
Apologies	Wendy Clayton; Clair Quin; Patricia Thompson; Sarah Ward; Matthew McAlinden	Leanne McCourt; Paula McKay; Patricia Thompson; Clair Quin; Matthew McAlinden; Sarah Ward
1. Staffing update	There is still a back-log in typing from end of February and could impact on review of those patients on a 3 monthly or 6 monthly basis. A new admin staff member has been appointed but has to complete audio typist training. The issue has been escalated to Wendy and Paula agreed to follow up. **Action:** Paula to follow up with Wendy / Jane / Matthew	New member of staff has commenced and the typing back log has since been addressed.
2. Policies / Protocols	**Action:** Paula will link with the HOS and AD to confirm if the policies were signed off at the Acute Nursing Governance meeting or if they still need to be presented.	Ronan Carroll advised that the next Acute Nursing Governance meeting will be held on Monday 4th July, chaired by Mary Burke. He advised that the policies are sent to Mary Burke for sign off at the meeting and copied to Paula McKay who attends this meeting and who will be able to explain what they are. Once they are signed off, they can be uploaded to share-point.

		Action: Wendy agreed to forward the policies to Paula and Mary Burke and request that these are tabled for sign off.
3. Recording / coding for clinics	Sinead updated the CNS Proforma with option to add in date or to use the free text box. Nurses advised that this is working well.	No further update in relation to this.
4. eHNA	eHNA clinics are ongoing and working well. Mary has arranged for a session with MISS for Leanne and Patricia to find out more about the support services available for people affected by cancer. Caroline Davies is also developing a directory of services which will be shared with all staff. In relation to HNA's for patients who attend Belfast for treatment, Mary advised that this is currently not happening as the support worker post is vacant and it is hoped to re-start it once the post is filled.	eHNA clinics are ongoing for Leanne and Patricia. Becky advised that all is going well and there are no issues from her end. Kate advised that she hopes to commence her eHNA clinics soon. Kate to forward clinic details to Sinead so that a clinic template can be completed and set-up.
5. Virtual health &wellbeing events	No further update in relation to this at the moment and it will be kept on the agenda.	Mr O'Donoghue agreed to do the consultant presentation fo the virtual HWB event though he is currently on A/L. Preparation for this is to be progressed when the nursing team are back from A/L.
6. Patient Experience	Mary had a meeting with Maura and the peer facilitators to provide context / background for the work and to go through the draft questions. Leanne & Patricia have identified the patients. It was agreed that a cover letter and flyer would be posted to all the patients initially and then Becky would follow-up with a telephone call to seek consent. Once the patients consented their details would be sent to Maura McClean in Macmillan so that appointments could be arranged.	Becky has been contacting the patients and updating the spreadsheet with those patients who have agreed to be contacted. The details have been forwarded to Maura McClean in Macmillan. The peer facilitators are currently arranging dates with the patients who gave consent. It is hoped that this will be completed by end of July. Sarah Ward has been working with Service Users to develop a patient survey to compliment the Macmillan piece of work. This is

		currently being finalised. Patients identified for this will be different to those identified for the peer facilitator conversations.
7. Future meetings	**Date of next meeting: Thursday 30th June at 9.15am**	The CNS will have TRUS biopsy clinics on a Thursday morning going forward. **Action:** Kate agreed to speak to Leanne and Patricia to agree an alternative day / time for the next meeting, which will probably be in September. Mary will email all to advise.

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 31 August 2022 10:31
To: McAlinden, Matthew; Clayton, Wendy; Scott, Jane M; Ward, Sarah; Thompson, PatriciaA; McCourt, Leanne; ONeill, Kate; Murray, Becky; Lee, Sinead; Kelly, Catherine F; Quin, Clair; McKay, Paula
Subject: RE: Notes from Urology Nurse-led review meeting on 30/0822

Dear all

Please see summary notes below from the Urology Nurse-led review meeting on Tuesday 30th August 2022 at 2pm:

Area	**30/06/22**	**30/08/22**
Attendees	Mary Haughey; Becky Murray; Sinead Lee; Kate O'Neill; Wendy Clayton	Mary Haughey; Kate O'Neill; Leanne McCourt; Matthew McAlinden; Jane Scott; Paula McKay
Apologies	Leanne McCourt; Paula McKay; Patricia Thompson; Clair Quin; Matthew McAlinden; Sarah Ward	Patricia Thompson; Clair Quin; Sarah Ward; Becky Murray; Sinead Lee; Wendy Clayton
1. Staffing update	New member of staff has commenced and the typing back log has since been addressed.	Leanne advised that the typing was up to date over the summer though it was starting to build up again. Matthew will link with staff to encourage them to use a quiet room for audio-typing and to check if over-time is required to catch up.
2. Policies / Protocols	Ronan Carroll advised that the next Acute Nursing Governance meeting will be held on Monday 4th July, chaired by Mary Burke. He advised that the policies are sent to Mary Burke for sign off at the meeting and copied to Paula McKay who attends this meeting and who will be able to explain what they are. Once they are signed off, they can be uploaded to share-point. **Action**: Wendy agreed to forward the policies to Paula and Mary Burke and request that these are tabled for sign off.	Wendy had advised that the July meeting was cancelled and it was not listed on the August agenda. As previously discussed the policies can be used as they are signed off by the consultants. Ronan will bring to the meeting when he returns from A/L. Leanne advised that the prostate follow-up policy needs updated to include repatriation of patients who had a radical prostatectomy in Belfast. **Action**: Leanne to update prostate follow-up policy and to get sign off from all of the consultants.

3. Recording / coding for clinics	No further update in relation to this.	
4. eHNA	eHNA clinics are ongoing for Leanne and Patricia. Becky advised that all is going well and there are no issues from her end. Kate advised that she hopes to commence her eHNA clinics soon. Kate to forward clinic details to Sinead so that a clinic template can be completed and set-up.	Leanne advised that Becky has a spreadsheet which she updates in relation to patients who were contacted in relation to their eHNA appointment. Becky was [redacted] week and it has not been updated for this week. **Action:** Mary to get an update from Sinead and to advise Leanne.
5. Virtual health &wellbeing events	Mr O'Donoghue agreed to do the consultant presentation fo the virtual HWB event though he is currently on A/L. Preparation for this is to be progressed when the nursing team are back from A/L.	Paula to check if Clare Crothers would be willing to do the presentation for the virtual HWB event. **Action:** Mary to arrange a meeting next week with Sharon Clarke to take forward event before end of the year.
6. Patient Experience	Becky has been contacting the patients and updating the spreadsheet with those patients who have agreed to be contacted. The details have been forwarded to Maura McClean in Macmillan. The peer facilitators are currently arranging dates with the patients who gave consent. It is hoped that this will be completed by end of July. Sarah Ward has been working with Service Users to develop a patient survey to compliment the Macmillan piece of work. This is currently being finalised. Patients identified for this will be different to those identified for the peer facilitator conversations.	Mary has contacted Maura McClean for an update and will advise the team when she hears back from her. **Action:** Mary to seek update from Sarah in relation to the patient survey
7. Future meetings	The CNS will have TRUS biopsy clinics on a Thursday morning going forward. **Action:** Kate agreed to speak to Leanne and Patricia to agree an alternative day / time for the next	Kate and Leanne advised that the TRUS biopsy clinics are going very well. They have been able to identify and offer appointments to patients who were previously sent to the IS.

	meeting, which will probably be in September. Mary will email all to advise.	Leanne is running 7 clinics per week. **Action:** Leanne to forward Matthew the clinic codes which have HNA in the title. Matthew to arrange to get these changed.

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

From: Haughey, Mary
Sent: 31 August 2022 12:07
To: McCourt, Leanne
Subject: FW: Notes from Urology Nurse-led review meeting on 30/0822

Leanne – FYI below

From: Lee, Sinead <[redacted]>
Sent: 31 August 2022 10:57
To: Haughey, Mary <[redacted]>
Subject: RE: Notes from Urology Nurse-led review meeting on 30/0822

Hey Mary,

I tried to call Becky there but she was busy. Looks like she won't be in this week. I need to have a look at the eHNA's to see who we can appoint.
I will have to train Janine tomorrow.

After I speak to Becky today I will send out an email to all CNS's

Best
S

From: Haughey, Mary <[redacted]>
Sent: 31 August 2022 10:47
To: Lee, Sinead <[redacted]>
Subject: RE: Notes from Urology Nurse-led review meeting on 30/0822

No worries Sinead.

Is there any update on Becky? Leanne was going to cancel her eHNA clinic this afternoon but wasn't sure about next week..I said I would link with you for an update.

Many thanks
Mary

From: Lee, Sinead <[redacted]>
Sent: 31 August 2022 10:41
To: Haughey, Mary <[redacted]>; McAlinden, Matthew <[redacted]>; Clayton, Wendy <[redacted]>; Scott, Jane M <[redacted]>; Ward, Sarah <[redacted]>; Thompson, PatriciaA <[redacted]>; McCourt, Leanne <[redacted]>; ONeill, Kate <[redacted]>; Murray, Becky <[redacted]>; Kelly, Catherine F

<[redacted]>; Quin, Clair <[redacted]>; McKay, Paula <[redacted]>
Subject: RE: Notes from Urology Nurse-led review meeting on 30/0822

Morning,

Apologises I was off on annual leave yesterday

Best
S

From: Haughey, Mary <[redacted]>
Sent: 31 August 2022 10:31
To: McAlinden, Matthew <[redacted]>; Clayton, Wendy <[redacted]>; Scott, Jane M <[redacted]>; Ward, Sarah <[redacted]>; Thompson, PatriciaA <[redacted]>; McCourt, Leanne <[redacted]>; ONeill, Kate <[redacted]>; Murray, Becky <[redacted]>; Lee, Sinead <[redacted]>; Kelly, Catherine F <[redacted]>; Quin, Clair <[redacted]>; McKay, Paula <[redacted]>
Subject: RE: Notes from Urology Nurse-led review meeting on 30/0822

Dear all

Please see summary notes below from the Urology Nurse-led review meeting on Tuesday 30th August 2022 at 2pm:

Area	**30/06/22**	**30/08/22**
Attendees	Mary Haughey; Becky Murray; Sinead Lee; Kate O'Neill; Wendy Clayton	Mary Haughey; Kate O'Neill; Leanne McCourt; Matthew McAlinden; Jane Scott; Paula McKay
Apologies	Leanne McCourt; Paula McKay; Patricia Thompson; Clair Quin; Matthew McAlinden; Sarah Ward	Patricia Thompson; Clair Quin; Sarah Ward; Becky Murray; Sinead Lee; Wendy Clayton
1. Staffing update	New member of staff has commenced and the typing back log has since been addressed.	Leanne advised that the typing was up to date over the summer though it was starting to build up again. Matthew will link with staff to encourage them to use a quiet room for audio-typing and to check if over-time is required to catch up.
2. Policies / Protocols	Ronan Carroll advised that the next Acute Nursing Governance meeting will be held on Monday	Wendy had advised that the July meeting was cancelled and it was not listed on the August agenda.

	4th July, chaired by Mary Burke. He advised that the policies are sent to Mary Burke for sign off at the meeting and copied to Paula McKay who attends this meeting and who will be able to explain what they are. Once they are signed off, they can be uploaded to share-point. **Action**: Wendy agreed to forward the policies to Paula and Mary Burke and request that these are tabled for sign off.	As previously discussed the policies can be used as they are signed off by the consultants. Ronan will bring to the meeting when he returns from A/L. Leanne advised that the prostate follow-up policy needs updated to include repatriation of patients who had a radical prostatectomy in Belfast. **Action**: Leanne to update prostate follow-up policy and to get sign off from all of the consultants.
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4. eHNA	eHNA clinics are ongoing for Leanne and Patricia. Becky advised that all is going well and there are no issues from her end. Kate advised that she hopes to commence her eHNA clinics soon. Kate to forward clinic details to Sinead so that a clinic template can be completed and set-up.	Leanne advised that Becky has a spreadsheet which she updates in relation to patients who were contacted in relation to their eHNA appointment. Becky was off [redacted] and it has not been updated for this week. **Action:** Mary to get an update from Sinead and to advise Leanne.
5. Virtual health &wellbeing events	Mr O'Donoghue agreed to do the consultant presentation fo the virtual HWB event though he is currently on A/L. Preparation for this is to be progressed when the nursing team are back from A/L.	Paula to check if Clare Crothers would be willing to do the presentation for the virtual HWB event. **Action:** Mary to arrange a meeting next week with Sharon Clarke to take forward event before end of the year.
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	Sarah Ward has been working with Service Users to develop a patient survey to compliment the Macmillan piece of work. This is currently being finalised. Patients identified for this will be different to those identified for the peer facilitator conversations.	survey
7. Future meetings	The CNS will have TRUS biopsy clinics on a Thursday morning going forward. **Action:** Kate agreed to speak to Leanne and Patricia to agree an alternative day / time for the next meeting, which will probably be in September. Mary will email all to advise.	Kate and Leanne advised that the TRUS biopsy clinics are going very well. They have been able to identify and offer appointments to patients who were previously sent to the IS. Leanne is running 7 clinics per week. **Action:** Leanne to forward Matthew the clinic codes which have HNA in the title. Matthew to arrange to get these changed.

Kind regards
Mary

Mary Haughey
Macmillan Cancer Service Improvement Lead
Craigavon Area Hospital
Mobile: [redacted]

NICaN Urology Cancer Clinical Guidelines

March 2016

V1.3

Document Title	Guidelines for the Referral, Diagnosis, Treatment and Management of Urological Cancer
Document Date	March 2015 – version 1.1 January 2016 – version 1.2 March 2016 – version 1.3
Document Purpose	This guidance has been produced to support the diagnosis, treatment and management of urological cancer. Treatment decisions for individual patients require the weighing of a multiplicity of factors, which cannot all be accounted for in a CMG. The CMG provides a description of the range of treatment options available for a clinical scenario. To maximise the benefit of multi-professional working management strategies for the individual are best discussed with a multidisciplinary meeting (MDM).
Authors	Surgical: New NI guidelines have been developed by Ali Thwaini, Consultant Urologist, BHSCT, for Bladder, Prostate, Penile, Renal Cell, Testicular & Upper Urinary Tract Urothelial Cell Carcinomas Imaging: Yorkshire Cancer Network Imaging Guidelines (These guidelines have been adopted by the Network group as they reflect NI Practice) Pathology: Royal College of Pathologists Standards and Minimum Datasets for reporting Cancers (These guidelines have been adopted by the Network group as they reflect NI Practice) Systemic Anti-cancer Therapy Protocols: Reference to separate guidance developed on behalf of the NI Cancer Network and the HSCB Radiotherapy Protocols: These guidelines have been adopted by the Network group as they reflect NI Practice) Urological Nursing Sections: Kate O'Neill (SHSCT), Kerry Chambers (WHSCT), Patricia Thompson (SEHSCT), Hazel Kerr (SEHSCT) Follow up section: Transforming Cancer Follow Up Project team

Version 1	Original Draft
Version 1.1	Reformatted with inclusion of new Surgical guidelines, Imaging, Pathology, Clinical Nurse Specialist, Follow Up and Specialist Radiographer Sections
Version 1.2	Discussed at the Regional Urology Network Group Meeting on 29th January 2016
Version 1.3	Amendments following circulation January2016 Population base adjusted to reflect updated NISRA figures and NW urology population base NG12 Urology referral guidelines replace red flag guidelines Reference to guidance regarding 150 robotic prostatectomies requirement removed

Regional Agreements	Electronically agreed and issued 18th March 2016 (of note any change in commissioning arrangements will require inclusion)
Agreed:	
Review:	April 2017

Contents Page No

1.0 INTRODUCTION

Urological cancers include a range of tumours with different presentations including:

- Prostate cancer
- Bladder cancer
- Kidney cancer
- Testicular cancer
- Penile cancer

Prostate cancer is a form of cancer that develops in the prostate. Advanced prostate cancer can spread to other parts of the body. It accounts for 24% of all new cancers in UK males, and in 20-30% of cases, prostate cancer spreads to other locations in the body. In Northern Ireland, the average number of cases per year between 2009-2013 was 1,039 per year (figures provided by NI Cancer Registry).

Bladder cancer is any of several types of malignant growths of the urinary bladder and isthe 4th most common male tumour. The most common type of bladder cancer begins in cells lining the inside of the bladder and is called transitional cell carcinoma. Incidence of bladder cancer is higher in males than in females, with over 6,400 cases in 2009 in males compared to under 2,400 in females. In Northern Ireland, the average number of cases per year between 2009-2013 was 211 per year, with a breakdown of 150 males and 61 females (figures provided by NI Cancer Registry).

Kidney cancer is a form of cancer that develops in the kidneys. Kidney cancer is often asymptomatic until an advanced stage. In approximately one third of cases, the tumour is detected incidentally during imaging carried out for other reasons. The two most common types of kidney cancer, reflecting their location within the kidney, are renal cell carcinoma (RCC) and urothelial cell carcinoma (UCC) of the renal pelvis.

In Northern Ireland, the average number of cases per year between 2009-2013 was 288 per year, with a breakdown of 173 males and 115 females (figures provided by NI Cancer Registry).

Testicular cancer or cancer of the testicles is one of the less common cancers. It usually affects younger men between the ages of 15 and 49. Testicular cancer is relatively uncommon, accounting for just 1% of all cancers that occur in men. The most common type of testicular cancer is known as ‘germ cell testicular cancer’, which accounts for around 95% of all cases. In Northern Ireland, the average number of cases per year between 2009-2013 was 65 per year (figures provided by NI Cancer Registry).

Penile cancer is a rare type of cancer that occurs on the skin of the penis or within the penis. In the UK, around 550 men are diagnosed with cancer of the penis each year. It most commonly affects men over 60 years of age. Over the last 30 years, the number of penile cancer cases has increased by more than 20%, possibly due to changes in sexual practices.

2.0 NETWORK CONFIGURATION OF THE UROLOGY CANCER SERVICES

Northern Ireland Cancer Network has three cancer MDTs which diagnose and treat patients with urological cancers. These are held at the following locations:

- Craigavon Area Hospital – Southern HSC Trust
- Belfast City Hospital – combined team for Belfast HSC Trust and South Eastern HSC Trust
- Altnagelvin Hospital – combined team for Western HSC Trust & Northern HSC Trust

The catchment populations of these MDTs are shown below:

Urology MDT	**Catchment**[1]
SHSCT	366,000
Combined for: BHSCT and SEHSCT	366,000 341,085
Combined for: WHSCT and NHSCT	297,000 467,000 *Of note the population base for urology is 480,000 representing the upper two thirds of both the NHSCT & WHSCT*
Total	**1,830,000**

Each MDT meets on a weekly basis. All MDTs have named surgeons who deal with urological cancers.

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[1] *Source: NISRA, 2013 MYEs*

3.0 REFERRAL GUIDELINES FOR UROLOGY CANCER

Patients can be referred to their local hospital as 'red flags' (i.e. suspect cancer) by their GPs under the following NICE guidance:

This section is a direct lift from the NICE NG12 Suspect Cancer: Recognition and Referral (June 2015).

Prostate cancer

Refer men using a suspected cancer pathway referral (for an appointment within 2 weeks) for prostate cancer if their prostate feels malignant on digital rectal examination. **[new 2015]**

Consider a prostate-specific antigen (PSA) test and digital rectal examination to assess for prostate cancer in men with:

- any lower urinary tract symptoms, such as nocturia, urinary frequency, hesitancy, urgency or retention **or**
- erectile dysfunction **or**
- visible haematuria. **[new 2015]**

Refer men using a suspected cancer pathway referral (for an appointment within 2 weeks) for prostate cancer if their PSA levels are above the age-specific reference range. **[new 2015]**

Bladder cancer

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for bladder cancer if they are:

- aged 45 and over and have:
    - unexplained visible haematuria without urinary tract infection **or**
    - visible haematuria that persists or recurs after successful treatment of urinary tract infection, **or**
- aged 60 and over and have unexplained non-visible haematuria **and** either dysuria or a raised white cell count on a blood test. **[new 2015]**

Consider non-urgent referral for bladder cancer in people aged 60 and over with recurrent or persistent unexplained urinary tract infection. **[new 2015]**

Renal cancer

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for renal cancer if they are aged 45 and over and have:

- unexplained visible haematuria without urinary tract infection **or**
- visible haematuria that persists or recurs after successful treatment of urinary tract infection. **[new 2015]**

Testicular cancer

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for testicular cancer in men if they have a non-painful enlargement or change in shape or texture of the testis. **[new 2015]**

Consider a direct access ultrasound scan for testicular cancer in men with unexplained or persistent testicular symptoms. **[new 2015]**

Penile cancer

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for penile cancer in men if they have either:

- a penile mass **or** ulcerated lesion, where a sexually transmitted infection has been excluded as a cause, **or**
- a persistent penile lesion after treatment for a sexually transmitted infection has been completed. **[new 2015]**

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for penile cancer in men with unexplained or persistent symptoms affecting the foreskin or glans. **[new 2015]**

3.1 Haematuria Referral Guideline – please see Appendix 1

4.0 UROLOGY CARE PATHWAYS

Cancer Care Pathways outline the steps and stages in the patient journey from referral to diagnostics, staging, treatment, follow up, rehabilitation and if applicable onto palliative care.

Timed effective care pathways are central to delivering quality and timely care to patients throughout their cancer journey and to the delivery of an equitable service.

Please see **appendix 2** for the care pathways for:

- Prostate
- Renal Tumour
- Testicular Cancer Pathway
- Transitional Cell Carcinoma
- Castration Resistant Prostate Cancer
- Penile Cancer Pathway

5.0 REGIONAL GUIDELINES FOR THE IMAGING OF UROLOGICAL CANCERS

Document Title	**Guidelines for the Imaging of Urological Cancers**
Document Date	**March 2015 – Version 2**
Document Purpose	**This guidance has been produced to support the diagnosis, treatment and management of urological cancer** **Treatment decisions for individual patients require the weighing of a multiplicity of factors, which cannot all be accounted for in a CMG. The CMG provides a description of the range of treatment options available for a clinical scenario. To maximise the benefit of multi-professional working management strategies for the individual are best discussed with a multidisciplinary meeting (MDM).**
Authors	**Dr Arthur Grey – Consultant Radiologist** **Dr Stephen Vallelly – Consultant Radiologist** **Dr Eoin Napier – Consultant Radiologist**
Version Changes	**Version 1 – issued to Regional Group 7/4/11** **Version 1.1 – the updated Yorkshire Cancer Network Imaging Guidelines for the Investigation and Treatment of Urological Cancers were reviewed by the authors in September 2014 and they agreed to adopt the updated guidelines as they reflected NI Practice. The guidelines were circulated to the Urology Network Group for sign off on 17 April 2015. Copies of the Yorkshire Cancer Network Imaging Guidelines are available at http://www.ycn.nhs.uk/**

6.0 REGIONAL PATHOLOGY GUIDELINES FOR UROLOGICAL CANCERS

Document Title	**Regional Pathology Guidelines for Urological Cancers**
Document Date	**Version 2 29th January 2016**
Document Purpose	**The guidance has been produced to support the pathological diagnosis and staging of Urological Malignancies**
Author	**Dr G McClean**
Evidence	**Royal College of Pathologists Standards and Minimum Datasets for reporting Cancers;** **Dataset Adult Renal Parenchymal Cancer Histopathology Reports Nov 2006** https://www.rcpath.org/resourceLibrary/dataset-adult-renal-parenchymal-cancer-histopathology-reports.html **Dataset for penile and distal urethral cancer histopathology reports July 2015** https://www.rcpath.org/resourceLibrary/dataset-for-penile-and-distal-urethral-cancer-histopathology-reports.html **Dataset for histopathology reports for prostatic carcinoma (2nd edition) October 2009** https://www.rcpath.org/resourceLibrary/dataset-for-histopathology-reports-for-prostatic-carcinoma.html **Dataset for the histological reporting of testicular neoplasms May 2014** https://www.rcpath.org/resourceLibrary/dataset-for-the-histological-reporting-of-testicular-

	neoplasms.html **Dataset for tumours of the urinary collecting system** **(renal pelvis, ureter, urinary bladder and urethra) (2nd edition) April 2013** https://www.rcpath.org/resourceLibrary/dataset-for-tumours-of-the-urinary-collecting-system--renal-pelvis--ureter--urinary-bladder-and-urethra.html

Version changes

Version 1 – 23rd March 2015

Version 2 – 29th January 2016. Replacement of dataset for penile histopathology with dataset released July 2015. Update of website addresses for all datasets.

Statement:

Via Consultation with Pathologists at all Trusts it has been confirmed that all Pathologists in Northern Ireland are reporting to the standards laid down by the Royal College of Pathologists in the following College Publications and that there is no additionality of practice.

Dr Gareth McClean

7.0 REGIONAL SYSTEMIC ANTI-CANCER THERAPY PROTOCOLS FOR UROLOGICAL CANCERS

Document Title	**Systemic Anti-cancer Therapy Protocols**
Document Date	**2015**
Document Purpose	Please refer to separate NICaN guidance documents for the Systemic Anti-cancer Therapy Protocols for Bladder, Penile, Testicular Germ Cell tumours, Prostate and Renal Cell. These documents are available on the NICaN website **www.cancerni.net.**

8.0 REGIONAL RADIOTHERAPY PROTOCOLS FOR UROLOGICAL CANCER

Document Title	**Radiotherapy Protocols**
Document Date	**2015**
Document Purpose	Radiotherapy is delivered in the Northern Ireland Cancer Centre at the Belfast City Hospital with a second department due to open in Altnagelvin in 2016. The Cancer Centre is equipped with 10 Linear Accelerators and a full range of conventional and CT simulation equipment. The Radiotherapy Department employs approximately 90 radiographers. The department is accredited by ISO9000 and Charter mark standards. There is a modern treatment planning system with 10 planning terminals. A comprehensive radiology service is available within the Cancer Centre and in the main City Hospital. IMRT is routinely delivered for radically treating prostate cancer, radiotherapy may also be used palliatively for all urological cancers. Further details of treatment regimens and fractionations are contained within treatment protocols are located in the radiotherapy department. For further information please contact Joanne McCarthy Clinic Coordinator joanne.mccarthy@[redacted] cristiona.mccavana[redacted]

9.0 REGIONAL GUIDELILNES FOR THE SURGICAL TREATMENT AND MANAGEMENT OF UROLOGY CANCER

Document Title	**Guidelines for the Surgical Treatment and Management of Urological Cancer**
Document Date	March 2011 – Final Version January 2016 – Version updated and finalised
Document Purpose	This guidance has been produced to support the diagnosis, treatment and management of urological cancer Treatment decisions for individual patients require the weighing of a multiplicity of factors, which cannot all be accounted for in a CMG. The CMG provides a description of the range of treatment options available for a clinical scenario. To maximise the benefit of multi-professional working management strategies for the individual are best discussed with a multidisciplinary meeting (MDM)
Authors	Ali Thwaini, BHSCT
Version Changes	It was agreed at the Urology Network Meeting on 11th June 2014 to review the Surgical components of the EAU guidelines for urological cancers. Mr Ali Thwaini has developed new Urological surgical guidelines to reflect practice within NI. It was agreed at the Urology Network Meeting on 17th April 2015 that the EAU guidelines for Kidney would continue to be adopted by the Network group until the guideline has been reviewed by the relevant core members to highlight exceptions in practice in NI.

9.1 Bladder Cancer Surgical Guidelines (2014)

Bladder Cancer

Epidemiology:
Bladder cancer is the ninth most commonly diagnosed cancer worldwide, with more than 380,000 new cases each year and more than 150,000 deaths per year, and an estimated male-female ratio of 3.8:1. At any one time, 2.7 million people have a history of urinary bladder cancer. Recently, overall and stage-specific age-adjusted incidence rates of bladder cancer have been analysed in the U.S. (5 year survival and mortality rates between 1973 and 2009). Although the analysis of the Surveillance, Epidemiology and End Results (SEER) database implies some limitations it is worrying to note that in the last 30 years the mortality rate associated with bladder cancer has not changed substantially, highlighting gaps in diagnosis, monitoring and management of these patients (3). At the initial diagnosis of bladder cancer, 70% of cases are diagnosed as non-muscle-invasive bladder cancer (NMIBC) and approximately 30% as muscle-invasive bladder cancer (MIBC). Among patients treated with radical cystectomy because of MIBC, 57% had muscle invasion at presentation, while 43% were initially 8 MUSCLE-INVASIVE AND METASTATIC BLADDER CANCER - LIMITED UPDATE APRIL 2014 diagnosed with NMIBC that progressed despite organ-preserving treatment (4). Approximately one-third of patients diagnosed with MIBC have undetected metastases at the time of treatment for the primary tumour (5), while 25% of patients who undergo radical cystectomy present with lymph node involvement at the time of surgery.

Risk factors:
Tobacco smoking:

- is the most well-established risk factor for bladder cancer, causing 50-65% of male cases and 20-30% of female cases
- the incidence of bladder cancer is directly related to the duration of smoking and the number of cigarettes smoked per day
- the risk of bladder cancer is also higher in those who start smoking at a young age or who are exposed to environmental tobacco smoke during childhood
- the reduction of bladder cancer was about 40% within 1-4 years of quitting smoking and 60% after 25 years of cessation.

Occupational exposure:

- is the second most important risk factor for bladder cancer. Work-related cases have accounted for 20-25% of all bladder cancer cases in several series.
- substances involved in chemical exposure include benzene derivatives and aryl amines (2-naphthylamine, 4-ABP, 4,4'-methylenedianiline, and o-toluidine), and it is likely to occur in occupations in which dyes, rubbers, textiles, paints, leathers, and chemicals are used .

- risk of bladder cancer due to occupational exposure to carcinogenic aromatic amines is significantly greater after 10 years or more of exposure; the mean latency period usually exceeds 30 years.
- carcinogens can be inactivated by a metabolic acetylation pathway. The presence of an NAT2 slowacetylation genotype has been associated with a higher risk of bladder cancer (16), suggesting that patients who are slow acetylators may be more susceptible to bladder cancer than rapid acetylators. Other risk factors include phenacetin, which the International Agency for Research on Cancer (IARC) included in 1987 among proven human carcinogens. Some studies have suggested that the risk of bladder cancer due to phenacetin is dose-dependent; however, the data concerning its metabolite acetaminophen are controversial.

Radiotherapy: Increased rates of secondary bladder malignancies have been reported after external-beam radiotherapy (EBRT) for gynaecological malignancies, with relative risks of 2-4.

Dietary factors have been considered to be related to bladder cancer; however, the links remain controversial. Currently, there is limited evidence of a causal relationship between bladder cancer and dietary factors.

Bladder schistosomiasis (bilharzia) is the second most common parasitic infection after malaria, with about 600 million people exposed to infection in Africa, Asia, South America, and the Caribbean.

Chronic urinary tract infection: bladder cancer, particularly invasive squamous cell carcinoma, has been linked to the presence of chronic urinary tract infection (UTI) distinct from schistosomiasis. A direct association between bladder cancer and UTIs has been observed in several case-control studies, which have reported a two-fold increased risk of bladder cancer in patients with recurrent UTIs in some series.

Chemotherapy: The use of cyclophosphamide, an alkylating agent used to treat lymphoproliferative diseases and other nonneoplastic diseases, has been correlated with subsequent development of MIBC, with a latency period of 6-13 years. Acrolein is a metabolite of cyclophosphamide and is responsible for the increase in the incidence of bladder cancer. This effect occurs independently of the association of haemorrhagic cystitis with the same treatment and was counteracted with concomitant application of mercapto-ethanesulfonate (MESNA).

Synchronous and metachronous upper urinary tract tumours: In some cases, there is an association between upper tract urothelial carcinoma (UTUC) and bladder cancer.

- The incidence of UTUC after a diagnosis of NMIBC has been reported to be between 1.7% and 26%. Although synchronous UTUC and NMIBC are uncommon, 46% of UTUCs are invasive. In a retrospective review of 1,529 patients with primary non-muscle-invasive bladder carcinoma who underwent initial examination of the upper urinary tract with excretory urography, those with a tumour in the bladder trigone were almost six times more likely to develop a synchronous tumour in the upper urinary tract. Examination of the upper urinary tract alone in patients with a tumour in the trigone or with multiple bladder tumours was capable of diagnosing 41% or 69% of UTUCs, respectively.
- In multiple and high-risk tumours, there is an increased risk of tumour recurrence in the upper urinary tract.
- Carcinoma in situ (CIS) in the bladder is an important risk factor for subsequent upper urinary tract recurrence . It has been shown in various studies that tumour involvement of the distal ureter at RC is an independent risk factor for metachronous upper urinary tract (mUUT) recurrence, with an approximate 2.6-fold increase in the relative risk.
- The overall incidence of bladder cancer developing after treatment for UTUC has been reported in the literature as 15-50%.

Gender:

- women were more likely to be diagnosed with primary muscle-invasive disease than men (85% vs. 51%).
- women are more likely to be older than men when diagnosed, with a direct effect on their survival. In addition, delayed diagnosis is more likely in women after haematuria is observed, as the differential diagnosis in women includes diseases that are more prevalent than bladder cancer.
- Differences in the gender prevalence of bladder cancer may be due to other factors besides tobacco and chemical exposure. In a large prospective cohort study, postmenopausal status was associated with an increase in bladder cancer risk, even after adjustment for smoking status.

Ethnic and socioeconomic status: There are limited data on this topic, but a study based on 13,234 cases diagnosed in the SEER database in the period 1979-2003 showed that the survival time from diagnosis was significantly lower among cancer cases in patients with low socioeconomic status (SES) compared with those with higher SES. Hazard ratios for all causes and cancer-specific mortality among blacks in comparison with whites for eight of the most common types of cancer combined lost statistical significance after adjustment for SES factors and treatments. However, blacks still had unfavourable prognoses in comparison with whites even after adjustment for SES and treatment for tumours such as breast, colorectal, and urinary bladder cancer (44).

Genetic factors: There is growing evidence that genetic susceptibility factors and family associations may influence the incidence of bladder cancer. The relationship between family history of cancer and risk of bladder cancer was examined in the Spanish Bladder Cancer Study. It was found that family history of cancer in first-degree relatives was associated with an increased risk of bladder cancer; the association being stronger among younger patients. Shared environmental exposure was recognised as a potentially confounding factor.

TNM classification of urinary bladder cancer (2009)

T - Primary Tumour	
Tx	Primary tumour cannot be assessed
T0	No evidence of primary tumour
Ta	Non-invasive papillary carcinoma
Tis	Carcinoma in situ: “flat tumour”
T1	Tumour invades subepithelial connective tissue
T2	Tumour invades muscle
T2a	Tumour invades superficial muscle (inner half)
T2b	Tumour invades deep muscle (outer half)
T3	Tumour invades perivesical tissue:
T3a	Microscopically
T3b	Macroscopically (extravesical mass)
T4	Tumour invades any of the following: prostate stroma, seminal vesicles, uterus, vagina, pelvic wall, abdominal wall
T4a	Tumour invades prostate stroma, seminal vesicles, uterus, or vagina
T4b	Tumour invades pelvic wall or abdominal wall
N - Regional Lymph Nodes	
Nx	Regional lymph nodes cannot be assessed
N0	No regional lymph-node metastasis
N1	Metastasis in a single lymph node in the true pelvis (hypogastric, obturator, external iliac, or presacral)
N2	Metastasis in multiple lymph nodes in the true pelvis (hypogastric, obturator, external iliac, or presacral)
N3	Metastasis in common iliac lymph node(s)
M - Distant Metastasis	
M0	No distant metastasis
M1	Distant metastasis

World Health Organization grading for bladder cancer

1973 WHO grading
Urothelial papilloma
Grade 1: well differentiated
Grade 2: moderately differentiated
Grade 3: poorly differentiated

2004 WHO grading
Flat lesions Hyperplasia (flat lesion without atypia or papillary aspects)
Reactive atypia (flat lesion with atypia)
Atypia of unknown significance
Urothelial dysplasia
Urothelial CIS is always high-grade
Papillary lesions
Urothelial papilloma (completely benign lesion)
Papillary urothelial neoplasm of low malignant potential (PUNLMP)
Low-grade papillary urothelial carcinoma
High-grade papillary urothelial carcinoma

Non-muscle-invasive (Ta, T1 and CIS) Bladder Cancer

Diagnosis and Initial Treatment Steps

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

Papillary (Ta, T1) Tumours

The diagnosis of papillary BC ultimately depends on cystoscopic examination of the bladder and histological evaluation of the resected tissue.

The standard initial therapy for Ta and T1 papillary bladder tumours is complete macroscopic transurethral resection (TURB), including a part of the underlying muscle. TURB should be performed systematically in individual steps, which Non-muscle invasive (Ta, T1, CIS) Bladder Cancer 11 are described in the full version of the guidelines. Small tumours (< 1 cm) can be resected en bloc, including a part of the underlying muscle. Larger tumours should be resected separately in fractions, which include the exophytic part of the tumour, the underlying bladder wall with the detrusor muscle and the edges of the resection area. The specimens from different fractions must be referred to the pathologist in separate containers.

A second TURB 2-6 weeks after initial resection is recommended in the following situations:

- After incomplete initial TURB, if there was no muscle in the specimen after initial resection (with exception of Ta low grade (G1) tumours);
- In all T1 tumours and in all high grade (G3) tumours (except primary CIS).

CIS

CIS is diagnosed by a combination of cystoscopy, urine cytology, and histological evaluation of multiple bladder biopsies.

Biopsies are taken from suspect areas. In patients with positive urine cytology and no papillary tumour, multiple biopsies from normal looking mucosa including prostatic urethra (random

biopsies) are recommended. If equipment is available, photodynamic diagnosis (PDD) is a useful tool to target the biopsy in these patients. Urine cytology is useful in the diagnosis and follow-up of CIS. CIS cannot be eradicated by TURB and further treatment is mandatory.

Guidelines for primary assessment of NMIBC	GR
Patient history should be taken and recorded regarding all important information with a possible association with bladder cancer, including risk factors and suspicious symptoms.	A
Renal and bladder US may be used during the initial work-up in patients with haematuria.	C
At the time of the initial diagnosis of bladder cancer, CT urography (or IVU) should be performed only in selected cases (e.g., tumours located in the trigone).	B
Cystoscopy is recommended in all patients with symptoms suggestive of bladder cancer. It cannot be replaced by cytology or by any other non-invasive test.	A

Guidelines for primary assessment of NMIBC	GR
Cystoscopy should describe all macroscopic features of the tumour (site, size, number and appearance) and mucosal abnormalities. A bladder diagram is recommended.	C
Voided urine cytology is advocated to predict high grade tumour before TURB.	C
Cytology should be performed on fresh urine with adequate fixation. Morning urine is not suitable because of the frequent presence of cytolysis.	C

TURB	GR
TURB should be performed systematically in individual steps: • bimanual palpation under anaesthesia; • insertion of the resectoscope, under visual control with inspection of the whole urethra; • inspection of the whole urothelial lining of the bladder; • biopsy from prostatic urethra (if indicated); • cold-cup bladder biopsies (if indicated); • resection of the tumour; • bimanual palpation after resection; • protocol formulation; • formulation of order form for pathological evaluation.	C
Perform resection in one piece for small papillary tumours (< 1 cm), including part from the underlying bladder wall.	B
Perform resection in fractions (including muscle tissue) for tumours > 1 cm in diameter.	B
Biopsies should be taken from abnormal-looking urothelium. Biopsies from normal-looking mucosa (trigone, bladder dome, and right, left, anterior and posterior bladder walls) are recommended only when cytology is positive or when exophytic tumour has a non-papillary appearance.	C
Biopsy of the prostatic urethra is recommended for cases of bladder neck tumour, when bladder CIS is present or suspected, when there is positive cytology without evidence of tumour in the bladder, or when abnormalities of the prostatic urethra are visible. If biopsy is not performed during the initial procedure, it should be completed at the time of the second resection.	C
Biopsy of the prostatic urethra should be taken from abnormal areas and from the precollicular area (between 5 and 7 o'clock position) using a resection loop. In primary non-muscle-invasive tumours when stromal invasion is not suspected, the cold-cup biopsy with forceps can be used.	C
If equipment is available, fluorescence-guided (PDD) biopsy should be performed instead of random biopsies when bladder CIS or high-grade tumour is suspected (e.g., positive cytology, recurrent tumour with previous history of a high-grade lesion)	B
The specimens from different biopsies and resection fractions must be referred	C

TURB	GR
to the pathologist in separate containers and labelled separately.	
TURB protocol must describe all steps of the procedure, as well as the extent and completeness of resection.	C
A second TURB is recommended in the following situations: • after incomplete initial TURB; • if there is no muscle in the specimen after initial resection, with exception of Ta G1 tumours and primary CIS; • in all T1 tumours; • in all G3 tumours, except primary CIS.	A
When done, a second TURB should be performed within 2-6 weeks after initial resection.	C

Classification and pathological report	**GR**
Depth of tumour invasion is classified according to the TNM system.	A
For histological classification, 1973 and 2004 WHO grading systems are used. Until the WHO 2004 is validated by more prospective trials and incorporated into prognostic models, both classifications should be used.	A
Whenever the terminology NMIBC is used in individual cases, the tumour stage and grade should be mentioned.	A
The pathological report should specify tumour location, tumour grade, depth of tumour invasion, presence of CIS, and whether the detrusor muscle is present in the specimen.	A
The pathological report should specify the presence of LVI or unusual histology	C

CIS = carcinoma in situ;
CT = computed tomography;
IVU = intravenous urography;
LVI = lymphovascular invasion;
PDD = photodynamic diagnosis;
US = ultrasound;
TURB = transurethral resection of the bladder

Prognostic Factors and Adjuvant Treatment

It is recommended to stratify patients according to prognostic factors into three risk groups that will facilitate treatment recommendations. Their definition, which takes into account the EORTC risk tables probabilities of recurrence and especially progression, can be found in Table 3. For individual prediction of the risk of tumour recurrence and progression at different intervals after TURB, application of EORTC risk tables and calculator (http://www.eortc.be/tools/bladdercalculator/) is strongly recommended.

Table 3: Treatment recommendations in Ta, T1 tumours and CIS according to risk stratification

Risk Category	**Definition**	**Treatment recommendation**
Low-risk Tumours	Primary, solitary, Ta, LG/ G1, < 3 cm, no CIS	One immediate instillation of Chemotherapy
Intermediate risk tumours	All cases between categories of low and high risk	One immediate instillation of Chemotherapy followed by further instillations, either chemotherapy for a maximum of 1 year or 1-year full dose BCG
High-risk Tumours	Any of the following: • T1 tumours; • HG/G3 tumours; • CIS; • Multiple and recurrent and large (> 3 cm) Ta G1G2 tumours (all these conditions must be presented)	Intravesical full dose BCG instillations for 1-3 years or cystectomy (in highest-risk tumours)
Subgroup of highest-risk tumours	T1G3 associated with concurrent bladder CIS, multiple and/or large T1G3 and/or recurrent T1G3, T1G3 with CIS in prostatic urethra, micropapillary variant of urothelial carcinoma, LVI	Radical cystectomy should be considered
	BCG failures	Radical cystectomy is recommended

CIS = carcinoma in situ; HG = high-grade; LG = low-grade;
LVI = lymphovascular invasion

Since there is considerable risk for recurrence and/or progression of tumours after TURB, adjuvant intravesical therapy is recommended for all stages (Ta, T1, and CIS). Immediate postoperative instillation of chemotherapy within 6 hours after TURB is recommended in tumours presumed to be at low or intermediate risk, except in cases of bladder perforation or severe bleeding. The choice of drug (mitomycin C, epirubicin, or doxorubicine) is optional. Intravesical chemotherapy reduces the risk of recurrence but not progression and is associated with minor side-effects. Intravesical immunotherapy with Bacillus Calmette-Guérin (BCG) (induction and maintenance) is superior to intravesical chemotherapy in reducing recurrences and in preventing or delaying progression to muscle-invasive bladder cancer. However, intravesical BCG is more toxic. The individual choice

of further intravesical adjuvant therapy depends on the patient’s risk (Table 3). In patients at highest risk of progression (Table 3), radical cystectomy should be considered in patients with BCG failure since they are unlikely to respond to further BCG therapy; radical cystectomy is therefore the preferred option.

Recommendations for adjuvant therapy in Ta, T1 tumours and for therapy of CIS	GR
Smokers with confirmed NMIBC should be counselled to stop smoking.	B
The type of intravesical therapy should be based on risk groups.	A
One immediate chemotherapy instillation is recommended in tumours presumed to be at low or intermediate risk.	A
In patients with low-risk tumours, one immediate instillation of chemotherapy is recommended as the complete adjuvant treatment.	A
In patients with intermediate-risk Ta tumours, one immediate instillation of chemotherapy should be followed by 1-year full-dose BCG treatment, or by further instillation of chemotherapy for a maximum of 1 year.	A
In patients with high-risk tumours, full-dose intravesical BCG for 1-3 years is indicated.	A
In patients with CIS in the epithelial lining of the prostatic urethra, TUR of the prostate followed by intravesical instillation of BCG can be offered.	C
In patients at highest risk of tumour progression (Table 3), immediate radical cystectomy should be considered.	C
In patients with BCG failure, radical cystectomy is indicated.	B
In patients with BCG failure ineligible for radical cystectomy, gemcitabine or MMC in combination with hyperthermia are options.	C

Intravesical chemotherapy	GR
One immediate instillation should be administered within 24 hours after TURB.	C

One immediate instillation of chemotherapy should be omitted in any case of overt or suspected intra- or extra-peritoneal perforation (after extensive TURB, or bleeding requiring bladder irrigation).	C
The optimal schedule of further intravesical chemotherapy instillation and its duration is not defined and should not exceed 1 year.	C
If intravesical chemotherapy is given, it is advised to use the drug at its optimal pH and to maintain the concentration of the drug during instillation by reducing fluid intake.	B
The length of individual instillation should be 1-2 hours.	C

BCG intravesical immunotherapy	GR
Absolute contraindications of BCG intravesical instillation are: • during the first 2 weeks after TURB; • in patients with macroscopic haematuria; • after traumatic catheterization; • in patients with symptomatic urinary tract infection.	C
The management of side effects after BCG intravesical instillation should reflect their type and grade	C

BCG = bacillus Calmette-Guérin;
CIS = carcinoma in situ;
MMC = mitomycin C;
TUR = transurethral resection;
TURB =transurethral resection of the bladder

Follow-up for Non-Muscle Invasive Bladder Tumours

As a result of the risk of recurrence and progression, patients with Ta, T1 bladder tumours and with CIS need to be followed up. However, the frequency and duration of cystoscopy and imaging should reflect the individual patient's degree of risk.

When planning the follow-up schedule and methods, the following aspects should be considered:

- The prompt detection of muscle-invasive and HG/G3 nonmuscle-invasive recurrence is crucial because a delay in diagnosis and therapy can be life-threatening.

- Tumour recurrence in the low-risk group is nearly always low stage and LG/G1.

Small, non-invasive (Ta), LG/G1 papillary recurrence does not present an immediate danger to the patient, and early detection is not essential for successful therapy (LE: 2b).

Fulguration of small papillary recurrences on an outpatient basis could be a safe option that reduces the therapeutic burden.

- The first cystoscopy after TURB at 3 months is a very important prognostic indicator for recurrence and progression. The first cystoscopy should thus always be performed.

3 months after TURB in all patients with Ta, T1 tumours and CIS.

- In tumours at low risk, the risk of recurrence after 5 recurrence-free years is low.
- Discontinuation of cystoscopy or its replacement with less invasive methods can be considered.
- In tumours originally intermediate- or high-risk, recurrences after 10 years tumour-free are not unusual. Therefore, lifelong follow-up is recommended.
- The risk of upper urinary tract recurrence increases in patients with multiple and high-risk tumours.
- Positive urine test results have a positive impact on the quality of performed follow-up cystoscopy). It supports the adjunctive role of urine tests during follow-up.

The following recommendations are only based on retrospective experience.

Recommendations for follow-up	GR
The follow-up of Ta, T1 tumours and CIS is based on regular cystoscopy.	A
Patients with low-risk tumours should undergo cystoscopy at 3 months. If negative, subsequent cystoscopy is advised 9 months later, and then yearly for 5 years.	C
Patients with high-risk tumours should undergo cystoscopy and urinary cytology at 3 months. If negative, subsequent cystoscopy and cytology should be repeated every 3 months for a period of 2 years, and every 6 months thereafter until 5 years, and then yearly	C
Patients with intermediate-risk Ta tumours should have an in-between follow-up scheme using cystoscopy and cytology, which is adapted according to personal and subjective factors.	C
Regular (yearly) upper tract imaging (CT-IVU or IVU) is recommended for high-risk tumours.	C
Endoscopy under anaesthesia and bladder biopsies should be performed when office cystoscopy shows suspicious findings or if urinary cytology is	B

Recommendations for follow-up	GR
positive	
During follow-up in patients with positive cytology and no visible tumour in the bladder, R-biopsies or biopsies with PDD (if equipment is available) and investigation of extravesical locations (CT urography, prostatic urethra biopsy) are recommended.	B

CIS = carcinoma in situ;
CT-IVU = computed tomography intravenous urography;
IVU = intravenous urography;
PDD = photodynamic diagnosis;
R-biopsies = random biopsies.

Bladder Cancer – Muscle invasive and metastatic

DIAGNOSIS AND STAGING

Primary diagnosis

Symptoms: Painless haematuria is the most common presenting complaint. Others include urgency, dysuria, increased frequency, and in more advanced tumours, pelvic pain and symptoms related to urinary tract obstruction.

Physical examination: including rectal and vaginal bimanual palpation. A palpable pelvic mass can be found in patients with locally advanced tumours. In addition, bimanual examination under anaesthesia should be carried out before and after TURB, to assess whether there is a palpable mass or if the tumour is fixed to the pelvic wall. However, considering the discrepancy between bimanual examination and pT stage after cystectomy (11% clinical overstaging and 31% clinical understaging), some caution is suggested with the interpretation of bimanual examination.

Endoscopic bladder imaging: Ultimately, the diagnosis of bladder cancer is made by cystoscopy and histological evaluation of resected tissue. In general, cystoscopy is initially performed in the office using flexible instruments. If a bladder tumour has been visualised unequivocally in earlier imaging studies, such as computed tomography (CT), magnetic resonance imaging (MRI), or ultrasound (US), diagnostic cystoscopy may be omitted and the patient can proceed directly to TURB for histological diagnosis. A careful description of the cystoscopic findings is necessary. This should include documentation of the site, size, number, and appearance (papillary or solid) of the tumours, as well as a description of mucosal abnormalities. Use of a bladder diagram is recommended. The use of photodynamic diagnosis could be considered, especially if a T1 high-grade tumour is present, to find associated CIS. The additional presence of CIS may lead to a modified treatment plan. Photodynamic diagnosis is highly sensitive for the detection of CIS; with experience, the rate of false-positive results may be similar to that with regular white-light cystoscopy.

Urinary cytology and urinary markers: Examination of voided urine or bladder washings for exfoliated cancer cells has high sensitivity in high-grade tumours (LE: 3) and is a useful indicator in cases of high-grade malignancy or CIS. Positive urinary cytology may originate from a urothelial tumour located anywhere in the urinary tract. Evaluation of cytology specimens can be hampered by low cellular yield, UTIs, stones or intravesical instillations, but for experienced readers, specificity exceeds 90% (LE: 2b). However, negative cytology does not exclude tumour. Cytology should be performed on fresh urine with adequate fixation. Early morning urine is not suitable as cytolysis may often be present. There is no known urinary marker specific for the diagnosis of invasive bladder cancer.

Random bladder and prostatic urethral biopsy: Bladder tumours are often multifocal and can be accompanied by CIS or dysplasia. These lesions may present themselves as velvet-like, reddish areas, indistinguishable from inflammation, or may not be visible at all. The biopsies from normal-looking mucosa in patients with invasive bladder tumours, so-called random biopsies (R-biopsies) show a low yield. Fluorescence cystoscopy is performed using filtered blue light after intravesical instillation of a photosensitiser, such as 5-aminolevulinic acid (5-ALA), and more recently, hexaminolaevulinate (HAL), following approval by the European Medicines Agency. It has been confirmed that fluorescence-guided biopsy and resection are more sensitive than conventional procedures in detecting malignant tumours, particularly CIS (9-12) (LE: 2a). However, false-positive results may be induced by inflammation, or recent TURB or intravesical instillation therapy. A recent multicentre, prospective, international trial showed that, in experienced hands, the rate of false-positive results is no higher than that seen for regular, white-light cystoscopy (7). Material obtained by random or directed biopsies must be sent for pathological assessment in separate containers. The involvement of the prostatic urethra and ducts in men with bladder tumours has been reported. The exact risk is not known, but it seems to be higher if the tumour is located on the trigone or bladder neck, in the presence of bladder CIS, and in multiple tumours (LE: 3). Involvement of the prostatic urethra can be determined either at the time of primary TURB or by frozen section during the cystoprostatectomy procedure. A frozen section has a higher negative predictive value and is more accurate.

Second resection: In the case of high-grade non-muscle-infiltrative tumour, residual disease is observed in 33-53% of patients (18-24). In order to reduce the risk of understaging, a second TURB resection is often required to determine the future treatment strategy. In consultation with the patient, orthotopic neobladder should be considered in case reconstructive surgery does not expose the patient to excessive risk (as determined by comorbidity and age). Age greater than 80 years is often considered to be the threshold after which neobladder reconstruction is not recommended, however, there is no exact age for strict contraindication. In most large series coming from experienced centres, the rate of orthotopic bladder substitution after cystectomy for bladder tumour is up to 80% for men and 50% for women. Nevertheless, no randomized controlled studies comparing conduit diversion with neobladder or continent cutaneous diversion have been performed. Diagnosis of urethral tumour before cystectomy or positive urethral frozen section leads to uretrectomy and therefore excludes neobladder reconstruction. If indicated, in males urethral frozen section has to be performed on the cysto-prostatectomy specimen just under the verumontanum and on the inferior limits of the bladder neck for females. When there are positive lymph nodes, orthotopic neobladder can nevertheless be considered in case of N1 involvement (metastasis in a single node in the true pelvis) but not for N2 or N3 tumours. Oncological results after orthotopic neobladder substitution or conduit diversion are similar in terms of local or distant metastasis recurrence, but secondary urethral tumours seem less common in patients with neobladder compared with those with conduits or continent cutaneous diversions.

Imaging for staging MIBC: The treatment and prognosis for MIBC is determined by tumour stage and grade. In clinical practice, CT and MRI are the imaging techniques used. The purpose of using imaging for staging MIBC is to determine prognosis and provide information to assist treatment selection. Tumour staging must be accurate to ensure the correct choice of treatment is made. Imaging parameters required for staging MIBC are:

- extent of local tumour invasion;
- tumour spread to lymph nodes;
- tumour spread to the upper urinary tract and other distant organs (e.g., liver, lungs, bones, peritoneum, pleura, and adrenal glands).

CT imaging for local staging of MIBC: The advantages of CT include high spatial resolution, shorter acquisition time, wider coverage in a single breath hold, and lower susceptibility to variable patient factors. Computed tomography is unable to differentiate between stages Ta and T3a tumours, but it is useful for detecting invasion into the perivesical fat (T3b) and adjacent organs. The accuracy of CT in determining extravesical tumour extension varies from 55% to 92% and increases with more advanced disease.

MRI for local staging of invasive bladder cancer: Magnetic resonance imaging has superior soft tissue contrast resolution compared with CT, but poorer spatial resolution. In studies performed before the availability of multidetector CT, MRI was reported as more accurate in local assessment. The accuracy of MRI for primary tumour staging varies from 73% to 96% (mean 85%). These values were 10-33% (mean 19%) higher than those obtained with CT. Dynamic contrast-enhanced (DCE) MRI may help to differentiate bladder tumour from surrounding tissues or post-biopsy reaction, because enhancement of the tumour occurs earlier than that of the normal bladder wall, due to neovascularisation. In 2006, a link was established between the use of gadolinium-based contrast agents and nephrogenic systemic fibrosis (NSF), which may result in fatal or severely debilitating systemic fibrosis. Patients with impaired renal function are at risk of developing NSF and the non-ionic linear gadolinium-based contrast agents should be avoided (gadodiamide, gadopentetate dimeglumine and gadoversetamide). A stable macrocyclic contrast agent should be used (gadobutrol, gadoterate meglumine or gadoteridol). Alternatively, contrast-enhanced CT could be performed using iodinated contrast media (LE: 4).

TREATMENT

Recommendations for treatment failure of non-muscle-invasive bladder cancer

Recommendations	**GR**
In all T1 tumours at high risk of progression (i.e., high grade, multifocality, CIS, and tumour size, as outlined in the EAU guidelines for non-muscle-invasive bladder cancer [7]), immediate radical treatment is an option	**C**
In all T1 patients failing intravesical therapy, radical treatment should be offered.	**B**

CIS = carcinoma in situ

NEOADJUVANT CHEMOTHERAPY

Advantages and disadvantages:

- Chemotherapy is delivered at the earliest time-point, when the burden of micrometastatic disease is expected to be low.

- Potential reflection of in vivo chemosensitivity.

- Tolerability of chemotherapy and patient compliance are expected to be better before rather than after cystectomy.
- Patients might respond to neoadjuvant therapy and reveal a favourable pathological status, determined mainly by achieving pT0, a negative lymph node status, and negative surgical margins.

- Delayed cystectomy might compromise the outcome in patients not sensitive to chemotherapy (8,9), although published studies on the negative effect of delayed cystectomy only entail series of chemonaive patients. There are no trials or large patient series indicating that delayed surgery, due to neoadjuvant chemotherapy, has a negative impact on survival.

Conclusions	**LE**
Neoadjuvant cisplatin-containing combination chemotherapy improves overall survival (5-8% at 5 years).	1a
Neoadjuvant treatment of responders and especially patients who show complete response (pT0 N0) has a major impact on OS.	2
Currently, no tools are available to select patients who have a higher probability to benefit from neoadjuvant chemotherapy. In the future, genetic markers, in a personalised medicine setting, might facilitate the selection of patients for neoadjuvant chemotherapy and to differentiate responders from non-responders.	

Recommendations	**GR**
Neoadjuvant chemotherapy is recommended for T2-T4a, cN0M0 bladder cancer and should always be cisplatin-based combination therapy.	A
Neoadjuvant chemotherapy is not recommended in patients who are ineligible for cisplatin-based combination chemotherapy.	A

RADICAL SURGERY AND URINARY DIVERSION

Radical cystectomy is the standard treatment for localised MIBC in most western countries. Recent interest in patients' quality of life (QoL) has increased the trend toward bladder preservation treatment modalities, such as radio- and/or chemotherapy. Performance status (PS) and age influence the choice of primary therapy, as well as the type of urinary diversion, with cystectomy being reserved for younger patients without concomitant disease and with a better PS. The value of assessing overall health before recommending and proceeding with surgery was emphasised in a multivariate analysis. The analysis found an association between comorbidity and adverse pathological and survival outcome following radical cystectomy. PS and comorbidity have a different impact on treatment outcome and must be evaluated independently. Controversy remains about age, radical cystectomy and the type of urinary diversion. Cystectomy is associated with the greatest risk reduction in disease-related and non-disease-related death in patients aged > 80 years. The largest, retrospective, single-institution study on cystectomy to date found that patients aged > 80 years had increased postoperative morbidity but not increased mortality. Although some patients successfully underwent a neobladder procedure, most patients were treated with an ileal conduit diversion. It is particularly important to evaluate the function and QoL of elderly patients using a standardised geriatric assessment, as well as carrying out a standard medical evaluation.

Each network should agree clear guidelines on treatment and follow up of bladder cancer which ensure that cystectomy is considered for patients with muscle-invasive or high-risk recurrent disease. Cystectomy is a complex operation which should be undertaken only by specialist surgeons working in cancer centres. Ideally, all radical cystectomies undertaken in each network should be carried out by a single team. Teams providing this form of surgery should carry out a cumulative total of at least 50 radical operations (cystectomies or radical prostatectomies) for bladder or prostate cancer per year.

Timing and delay of cystectomy:

Patients treated > 90 days after the primary diagnosis showed a significant increase in extravesical disease (81 vs 52%). Delay in cystectomy affects treatment outcome and the type of urinary diversion. In organ-confined urothelial cancer of the bladder, the average time from primary diagnosis to cystectomy was 12.2 months in patients who received a neobladder and 19.1 months in those who received an ileal conduit. This was even more noticeable with organ-confined invasive cancer; the average time to surgery was 3.1 months with a neobladder and 15.1 months with an ileal conduit (8). Similar results have been observed in a series of 247 patients: recurrence-free survival and OS were significantly better in patients treated before 90 days compared to others treated after 90 days.

LN removal at the time of cystectomy:

The extent of LND has not been established to date. Standard lymphadenectomy in bladder cancer patients involves removal of nodal tissue cranially up to the common iliac bifurcation, with the ureter being the medial border, and including the internal iliac, presacral, obturator fossa and external iliac nodes (10). Extended lymphadenectomy includes all lymph nodes in the region of the aortic bifurcation, and presacral and common iliac vessels medial to the crossing ureters. The lateral borders are the genitofemoral nerves, caudally the circumflex iliac vein, the lacunar ligament and the lymph node of Cloquet, as well as the area described for standard lymphadenectomy. A super-extended lymphadenectomy extends cranially to the level of the inferior mesenteric artery.

Morbidity and mortality from cystectomy:

The perioperative mortality was reported as 1.2-3% at 30 days and 2.3-5.7% at 90 days. In a large single-centre series, early complications (within 3 months of surgery) were seen in 58% of patients. Late morbidity is usually due to the type of urinary diversion. Early morbidity associated with radical cystectomy for NMIBC (at high risk for disease progression) is similar and no less than that associated with muscle-invasive tumours. In general, lower morbidity and (perioperative) mortality have been observed by surgeons and in hospitals with a higher caseload and therefore more experience.

Survival:

According to a multi-institutional database of 888 consecutive patients undergoing radical cystectomy for bladder cancer, the 5-year recurrence-free survival was 58% and the cancer-specific survival was 66%. Recent external validation of postoperative nomograms for bladder-cancer-specific mortality showed similar results, with 5-year OS of 45% and cancer-specific survival of 62%. Recurrence-free survival and OS in a large single-centre study of 1,054 patients was 68% and 66% at 5 years and 60% and 43%, at 10 years, respectively. The 5-year recurrence-free survival in node-positive patients who underwent cystectomy was considerably less at 34-43%. However, in patients with a low level of lymph node metastasis, the survival is better. In a surgery only study, the 5-year recurrence-free survival was 76% in patients with pT1 tumours, 74% for pT2, 52% for pT3, and 36% for pT4. Another study reported 10-year disease-specific survival and OS rates of 72.9% versus 49.1% for organ-confined disease (defined as pT < 3a), and 33.3% versus 22.8% for non-organconfined disease. A trend analysis according to the 5-year survival and mortality rates of bladder cancer in the United States, between 1973 and 2009 with a total of 148,315 bladder cancer patients, revealed an increased stage-specific 5-year survival rate for all stages, except for metastatic disease. However, no changes in mortality were recorded among localized and regional stage. In patients with visceral metastases an increase in mortality rates was observed, but differences were minor, and hardly of any clinical importance.

Recommendations:

Recommendations	**GR**
Radical cystectomy is recommended in T2-T4a, N0 M0, and high-risk non-MIBC (as outlined above).	A
Do not delay cystectomy for > 3 months because it increases the risk of progression and cancerspecific mortality.	B
Preoperative radiotherapy is not recommended in subsequent cystectomy with urinary diversion.	A
Lymph node dissection should be an integral part of cystectomy. Extended	B

Recommendations	**GR**
LND is recommended.	
The urethra can be preserved if margins are negative. If no bladder substitution is attached, the urethra must be checked regularly.	B
Laparoscopic cystectomy and robot-assisted laparoscopic cystectomy are both management options. However, current data have not sufficiently proven the advantages or disadvantages for oncological and functional outcomes.	C
Before cystectomy, the patient should be fully informed about the benefits and potential risks of all possible alternatives, and the final decision should be based on a balanced discussion between patient and surgeon.	B
Pre-operative bowel preparation is not mandatory. “Fast track” measurements may reduce the time of bowel recovery.	C
An orthotopic bladder substitute should be offered to male and female patients lacking any contraindications and who have no tumour in the urethra or at the level of urethral dissection.	B

NON-RESECTABLE TUMOURS

Recommendations	LE	GR
In patients with inoperable locally advanced tumours (T4b), primary radical cystectomy is a palliative option and cannot be offered as curative treatment.		B
In patients with symptoms palliative cystectomy may be offered. Prior to any further interventions, surgery-related morbidity and quality of life should be fully discussed with the patient.	3	B

BLADDER-SPARING TREATMENTS FOR LOCALIZED DISEASE

Transurethral resection of bladder tumour (TURBT)

Recommendation	**LE**	**GR**
Transurethral resection of bladder tumour (TURB) alone is not a curative treatment option in most patients.	2a	B

External beam radiotherapy (EBRT)

Based on available trials, a Cochrane analysis has demonstrated that radical cystectomy has an overall survival benefit compared to radiotherapy. However, external radiotherapy is an alternative treatment in patients unfit for radical surgery. The target dose for curative radiotherapy for bladder cancer is 60-66 Gy, with a subsequent boost using external radiotherapy or interstitial brachytherapy. The daily dose is usually 1.8-2 Gy and the course of radiotherapy should not extend beyond 6-7 weeks to minimize the repopulation of cancer cells. The use of modern standard radiotherapy techniques results in major, related, late morbidity of the urinary bladder or bowel in less than 5% of tumour-free patients. Overall, 5-year survival rates in patients with MIBC range between 30% and 60%, depending on whether they show a complete response (CR) following radiotherapy. Cancer-specific survival rates are between 20% and 50%.

Conclusions:

Conclusions	**LE**
External beam radiotherapy alone should only be considered as a therapeutic option when the patient is unfit for cystectomy or a multimodality bladder-preserving approach.	3
Radiotherapy can also be used to stop bleeding from the tumour when local control cannot be achieved by transurethral manipulation because of extensive local tumour growth.	3

Recommendation:

Recommendation	**GR**
Surgical intervention or multimodality treatment are the preferred curative therapeutic approaches because they are more effective than radiotherapy alone.	B

Chemotherapy

Chemotherapy alone rarely produces durable CRs. In general, a clinical CR rate of up to 56%, as reported in some series, must be weighed against a staging error of > 60%. Response to chemotherapy is a prognostic factor for treatment outcome and eventual survival, though it may be confounded by patient selection. For very selected patients, a bladder-conserving strategy with TURB and systemic cisplatin-based chemotherapy, preferably with MVAC, may allow long-term survival with intact bladder. However, this approach cannot be recommended for routine use.

Conclusion:

Conclusion	**LE**
With cisplatin-based chemotherapy as primary therapy for locally advanced	2b

tumours in highly selected patients, complete and partial local responses have been reported.	
Recommendation	**GR**
Chemotherapy alone is not recommended as primary therapy for localized bladder cancer.	A

Multimodality bladder-preserving treatment

Recent organ-preservation strategies combine TURB, chemotherapy and radiation (1,2). The rationale for performing TURB and radiation is to achieve local tumour control. Application of systemic chemotherapy, most commonly as methotrexate, cisplatin and vinblastine (MCV), aims at the eradication of micrometastasis. Many protocols use cisplatin and/or 5-FU and, recently, gemcitabine with radiation, because of their established role as radiosensitizers. Cisplatin-based chemotherapy in combination with radiotherapy, following TURB, results in a CR of 60-80%.

Conclusions:

Conclusions	**LE**
In a highly selected patient population, long-term survival rates of multimodality treatment are comparable to those of early cystectomy.	3
Delay in surgical therapy can compromise survival rates.	2b

Recommendations	**GR**
Transurethral resection of bladder tumour alone cannot be offered as a standard curative treatment option in most patients.	B
Radiotherapy alone is less effective than surgery and is only recommended as a therapeutic option when the patient is unfit for cystectomy or a multimodality bladder-preserving approach.	B
Chemotherapy alone is not recommended as primary therapy for MIBC.	A
Surgical intervention or multimodality treatments are the preferred curative therapeutic approaches as they are more effective than radiotherapy alone.	B
Multimodality treatment could be offered as an alternative in selected, well-informed, well-selected and compliant patients, especially for whom cystectomy is not an option.	B

ADJUVANT CHEMOTHERAPY

Adjuvant chemotherapy after radical cystectomy for patients with pT3/4 and/or lymph node positive (N+) disease without clinically detectable metastases (M0) is under debate and still infrequently used.

The general benefits of adjuvant chemotherapy include:

- Chemotherapy is administered after accurate pathological staging, therefore treatment in patients at low risk for micrometastases is avoided.
- No delay in definitive surgical treatment.

The drawbacks of adjuvant chemotherapy are:

- Assessment of in vivo chemosensitivity of the tumour is not possible and overtreatment is an unavoidable problem.
- Delay or intolerability of chemotherapy, due to postoperative morbidity.

Conclusions:

Conclusion	**LE**
Neither randomised trials nor two meta-analyses have provided sufficient data to support the routine use of adjuvant chemotherapy.	1a
Recommendations	GR
Adjuvant chemotherapy should only be given within clinical trials, whenever possible.	A
Adjuvant cisplatin based combination chemotherapy may be offered to patients with pN+ disease if no neoadjuvant chemotherapy has been given.	C

METASTATIC DISEASE

Conclusions	LE
In a first-line setting, PS and the presence or absence of visceral metastases are independent prognostic factors for survival.	1b
In a second-line setting, negative prognostic factors are: liver metastasis, PS > 1 and low haemoglobin (< 10 g/dL) 1b Cisplatin-containing combination chemotherapy can achieve median survival of up to 14 months, with long-term disease-free survival reported in ~15% of patients with nodal disease and good PS.	1b
Single-agent chemotherapy provides low response rates of usually short duration.	2a
Carboplatin combination chemotherapy is less effective than cisplatin-based	2a

Conclusions	LE
chemotherapy in terms of complete response and survival.	
Non-platinum combination chemotherapy produces substantial responses in first- and second-line settings, but has not been tested against standard chemotherapy in patients who are fit or unfit for cisplatin combination chemotherapy.	2a
There is no defined standard chemotherapy for unfit patients with advanced or metastatic urothelial cancer.	2b
Vinflunine reaches the highest level of evidence ever reported for second-line use.	1b
Post-chemotherapy surgery after partial or complete response may contribute to long-term diseasefree survival.	3
Zoledronic acid and denosumab have been approved for all cancer types including urothelial cancer, because they reduce and delay skeletal related events in metastatic bone disease.	1b

Recommendations	GR
First-line treatment for fit patients: Use cisplatin-containing combination chemotherapy with GC, PCG, MVAC, preferably with G-CSF, or HD-MVAC with G-CSF.	A
Carboplatin and non-platinum combination chemotherapy is not recommended.	B
First-line treatment in patients ineligible (unfit) for cisplatin: Use carboplatin combination chemotherapy or single agents.	C
For cisplatin-ineligible (unfit) patients, with PS2 or impaired renal function, as well as those with 0 or 1 poor Bajorin prognostic factors and impaired renal function, treatment with carboplatin-containing combination chemotherapy, preferably with gemcitabine/carboplatin is indicated.	A
Second-line treatment: In patients progressing after platinum-based combination chemotherapy for metastatic disease, vinflunine should be offered. Alternatively, treatment within a clinical trial setting may be offered.	A
Zoledronic acid or denosumab is recommended for treatment of bone metastases.	B

9.2 Prostate cancer

Epidemiology

Prostate cancer is the most common cancer in elderly males in Europe. It is a major health concern, especially in developed countries with their greater proportion of elderly men in the general population. The incidence is highest in Northern and Western Europe (> 200 per 100,000), while rates in Eastern and Southern Europe have showed a continuous increase. There is still a survival difference between men diagnosed in Eastern Europe and those in the rest of Europe. Overall, during the last decade, the 5-year relative survival percentages for prostate cancer steadily increased from 73.4% in 1999-2001 to 83.4% in 2005-2007.

There are three well-established risk factors for PCa:

- increasing age;
- ethnic origin;
- heredity

Genetics:

- If one first-line relative has PCa, the risk is at least doubled. If two or more first-line relatives are affected, the risk increases by 5-11-fold.
- A small subpopulation of individuals with PCa (about 9%) have true hereditary PCa. This is defined as three or more affected relatives, or at least two relatives who have developed early onset disease, i.e. before age 55.
- Patients with hereditary PCa usually have an onset six to seven years earlier than spontaneous cases, but do not differ in other ways.

Geography:

- The frequency of autopsy-detected cancers is roughly the same in different parts of the world.
- This finding is in sharp contrast to the incidence of clinical PCa, which differs widely between different geographical areas, being high in the USA and northern Europe and low in South-East Asia.
- However, if Japanese men move from Japan to Hawaii, their risk of PCa increases. If they move to California their risk increases even more, approaching that of American men.

Metabolic syndrome and prostate cancer:

- Metabolic syndrome is weakly and non-significantly associated with the risk of PCa, but associations vary with geography.
- Among single components of the syndrome (body mass index, dysglycaemia or dyslipidaemia, high triglycerides, low HDL cholesterol) only hypertension and waist circumference >102 cm were associated with a significantly greater risk of PCa, increasing it by 15% ($p = 0.035$) and 56% ($p = 0.007$), respectively.

Chemoprevention in prostate cancer:

- Currently, there are no data to suggest that medical intervention would effectively reduce progression of PCa.
- Several 5-alpha-reductase inhibitors (5-ARIs) have been studied to assess their effect on reducing risk of developing PCa. Although it seems that 5-ARIs have a potential benefit in preventing or delaying the development of PCa (~25%, only of Gleason 6 cancer), this must be weighed against treatment-related sideeffects as well as the potential increased risk of high-grade PCa. None of the available 5-ARIs have been approved for this indication.

SCREENING FOR PROSTATE CANCER:

Prostate cancer screening is one of the most controversial topics in urological literature. The main summary of findings from literature published on PCa screening is the Cochrane review published in 2013. Its findings are as follows:

- Screening was associated with an increased diagnosis of PCa (RR: 1.3; 95% CI: 1.02-1.65).

- Screening was associated with more localized disease (RR: 1.79; 95% CI: 1.19-2.70) and less advanced PCa (T3-4, N1, M1) (RR: 0.80; 95% CI: 0.73-0.87).

- From the results of five RCTs, representing more than 341,000 randomized men, no PCa-specific survival benefit was observed (RR: 1.00; 95% CI: 0.86-1.17). This was the main objective of all the large trials.

- From the results of four available RCTs, no overall survival benefit was observed (RR: 1.00; 95% CI: 0.96-1.03).

ERSPC: at 11 years of median follow-up, there was a 21% reduction in PCa-specific mortality and a 29% reduction after adjustment for non-compliance. However, there is still no overall survival benefit.

Thus, an individualized risk-adapted strategy for early detection might be offered to a well-informed man with a least 10-15 years of individual life expectancy. Men who have less than a 15-year life expectancy are unlikely to benefit based on the PIVOT and the ERSPC trials. Screening is associated with minor and major harms such as overdiagnosis and overtreatment.

Recommendations:

Recommendations	**LE**	**GR**
An individualized risk-adapted strategy for early detection might be offered to a well-informed man with a good performance status and at least 10-15 years of life expectancy.	3	B
Early PSA testing in men at elevated risk of having PCa: • men over 50 years of age • men over 45 years of age and a family history of PCa • African-Americans • men with a PSA level of > 1 ng/mL at 40 years of age • men with a PSA level of > 2 ng/mL at 60 years of age	2b	A
A risk-adapted strategy might be considered (based on initial PSA level), which may be every 2 years for those initially at risk, or postponed up to 8 years in those not at risk. 3 C The age at which early diagnosis of PCa should be stopped is influenced by life expectancy and performance status; men who have < 15-year life expectancy are unlikely to benefit based on the PIVOT and the ERSPC trials.	3	A

DIAGNOSIS:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

Digital rectal examination:

- Most prostate cancers are located in the peripheral zone of the prostate and may be detected by DRE when the volume is about 0.2 mL or larger.
- In about 18% of all patients, PCa is detected by a suspect DRE alone, irrespective of the PSA level.
- A suspect DRE in patients with a PSA level up to 2 ng/mL has a positive predictive value of 5-30%.
- An abnormal DRE is associated with an increased risk of a higher Gleason score and should therefore be considered an indication for prostate biopsy.

Prostate-specific antigen (PSA):

PSA is a kallikrein-like serine protease produced almost exclusively by the epithelial cells of the prostate, which is organ- but not cancer specific. Thus, serum levels may be elevated in the presence of benign prostatic hypertrophy (BPH), prostatitis and other non-malignant conditions. The level of PSA as an independent variable is a better predictor of cancer than suspicious findings on DRE or transrectal ultrasound (TRUS).

PSA and the risk of prostate cancer:

PSA level (ng/mL)	**Risk of PCa (%)**	**Risk of Gleason > 7 PCa (%)**
0.0-0.5	6.6	0.8
0.6-1.0	10.1	1.0
1.1-2.0	17.0	2.0
2.1-3.0	23.9	4.6
3.1-4.0	26.9	6.7

Practical modifications of serum PSA value that may improve the specificity of PSA in the early detection of PCa have been described. They include:

- PSA density;
- PSA velocity; defined as the absolute annual increase in serum PSA (ng/mL/year).
- PSA doubling time: the exponential increase in serum PSA over time, reflecting a relative change.
- age-specific reference ranges;
- The free/total PSA ratio: between 4 ng/mL and 10 ng/mL and a negative DRE, PCa was found on biopsy in 56% of men with f/t PSA < 0.10, but in only 8% of men with f/t PSA > 0.25.

PCA3: is an increasingly studied new biomarker that is detectable in urine sediments obtained after three strokes of prostatic massage during DRE. The costly Progensa urine test for PCA3 is now commercially available. The amount of the prostate-specific non-coding mRNA marker PCA3 normalized against PSA mRNA (urine sediment) gives a PCA3 score. This is superior to total PSA and percent-free PSA in the detection of PCa in men with elevated PSA levels as it shows slight but significant increases in the area under the receiveroperator characteristics curve (AUC) for positive biopsies. The main current indication for the PCA3 urine test may be to determine whether a man needs a repeat biopsy after an initially negative biopsy outcome, but its cost-effectiveness remains to be shown.

Prostate biopsy:

- Indications: PSA level and/or a suspicious DRE.
- The first elevated PSA level should not prompt an immediate biopsy.
- The PSA level should be verified after a few weeks by the same assay under standardized conditions (i.e. no ejaculation, no manipulations such as catheterisation, cystoscopy or transurethral resection, and no urinary tract infections) in the same diagnostic laboratory, using the same methods.
- It is now considered the standard of care to perform prostate biopsies guided by ultrasound.

Types of prostatic biopsy:

- Transrectal approach is used for most prostate biopsies, with ultrasound-guided periprostatic block as state-of-the-art. The British Prostate Testing for Cancer and Treatment (PROTECT) Study recommended 10 core biopsies, with > 12 cores being not significantly more conclusive.
- Transperineal approach is another alternative used by some urologists, with less incidence of biopsy related sepsis, but requires sedation or general anaesthetic (GA). There are two types:
    - Template biopsy requiring 24-30 cores using the brachytherapy grid and is performed under GA, with higher tumour detection rate (38%), but with a higher incidence of acute urinary retention (AUR) (up to 10%).
    - Targeted biopsy, which requires less cores and is more tolerated and less incidence of AUR.

- Diagnostic transurethral resection of the prostate: is a poor tool for cancer detection.

- Transition zone sampling during baseline biopsies gives a very low detection rate and should therefore be confined to repeat biopsies.

- Indications for a repeat biopsy are:
    - rising and/or persistently elevated PSA;
    - suspicious DRE, 5-30% risk of cancer;
    - atypical small acinar proliferation (ASAP), 40% risk of cancer;
    - extensive (multiple biopsy sites) prostatic intra-epithelial neoplasia (PIN), 20-30% risk of cancer.
    - **Consider multiparametric MRI (using T2- and diffusion-weighted imaging) for men with a negative transrectal ultrasound 10–12 core biopsy to determine whether another biopsy is needed.**
    - **Do not offer another biopsy if the multiparametric MRI (using T2- and diffusion-weighted imaging) is negative, unless any of the risk factors above is present.**

- An isolated high-grade PIN as finding is no longer considered an indication for repeat biopsy.

- Antibiotics prior to biopsy: Oral or intravenous antibiotics are state-of-the-art treatment. Optimal dosing and treatment time vary. Quinolones are the drugs of choice, with ciprofloxacin being superior to ofloxacin, but increased resistance to quinolones associated with a rise in severe infectious complications after biopsy has been reported in the past few years.

- Percentage of complications per biopsy session, irrespective of the number of cores:

Complications	**Percentage of biopsies affected**
Haematospermia	37.4
Haematuria > 1 day	14.5
Rectal bleeding< 2 days	2.2
Prostatitis	1.0
Fever > 38.5°C (101.3°F)	0.8
Epididymitis	0.7
Rectal bleeding > 2 days ± requiring surgical intervention	0.7
Urinary retention	0.2
Other complications requiring hospitalisation	0.3

The role of imaging

- **TRUS:** Grey-scale TRUS is not adequately reliable at detecting areas of PCa. It is therefore used as a guide to direct systematic biopsies of the prostate gland.

- **Multiparametric MRI:**
  - has excellent sensitivity for detecting aggressive Gleason > 7 cancers
  - mMRI is particularly good at accurately detecting anterior tumours that are usually missed by systematic biopsy and therefore trigger a (targeted) repeat biopsy.
  - cost-effectiveness of mMRI as a triage test before the first biopsy has not been assessed.
  - Inter-reader variability is also a current concern, especially outside reference centres.

Recommendations for the diagnosis of prostate cancer:

Recommendations	LE	GR
Prostate cancer should be graded according to the ISUP 2005 modified Gleason grading system. 2a A The decision to biopsy should be based on PSA testing and DRE.	2b	A
For initial diagnosis, a core biopsy of 10-12 systematic transrectal or transperineal peripheral zone biopsies should be performed under ultrasound imaging guidance.	2a	B
Transrectal prostate needle biopsies should be taken under antibiotic protection.	1b	A
Local anaesthetic by periprostatic infiltration is recommended for prostate needle biopsies.	1a	A
Prostate core biopsies from different prostatic sites should be submitted separately for processing and pathology reporting.	3	A
Processing and reporting of prostatectomy specimens by pathology should follow the guidelines provided by the 2010 ISUP consensus meeting.	3	A

STAGING FOR PROSTATE CANCER

T - Primary tumour	
TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
T1	Clinically inapparent tumour not palpable or visible by imaging
T1a	Tumour incidental histological finding in 5% or less of tissue resected
T1b	Tumour incidental histological finding in more than 5% of tissue resected

T1c Tumour identified by needle biopsy (e.g. because of elevated PSA level) T2 Tumour confined within the prostate T2a Tumour involves one half of one lobe or less T2b Tumour involves more than half of one lobe, but not both lobes T2c Tumour involves both lobes T3 Tumour extends through the prostatic capsule T3a Extracapsular extension (unilateral or bilateral) including microscopic bladder neck involvement T3b Tumour invades seminal vesicle(s) T4 Tumour is fixed or invades adjacent structures other than seminal vesicles: external sphincter, rectum, levator muscles, and/or pelvic wall
N - Regional lymph nodes
NX Regional lymph nodes cannot be assessed N0 No regional lymph node metastasis N1 Regional lymph node metastasis
M - Distant metastasis
MX Distant metastasis cannot be assessed M0 No distant metastasis M1 Distant metastasis M1a Non-regional lymph node(s) M1b Bone(s) M1c Other site(s)

- Provisional treatment intent should be determined (radical or non-radical) before decisions on imaging are made.

- Imaging should not be routinely offered to men who are not candidates for curative intent.

- Isotope bone scans should be offered when hormonal therapy is being deferred through watchful waiting to asymptomatic men who are at high risk of developing bone complications.

- Multiparametric MRI (or CT if MRI is contraindicated) should be offered for men with histologically proven prostate cancer if knowledge of the T or N stage could affect management.

- Urological cancer MDTs should assign a risk category (below) to all newly diagnosed men with localised prostate cancer.

Risk stratification for men with localised prostate cancer

Level of risk	PSA		Gleason score		Clinical stage
Low risk	<10 ng/ml	and	≤6	and	T1–T2a
Intermediate risk	10–20 ng/ml	or	7	or	T2b
High risk[1]	>20 ng/ml	or	8–10	or	≥T2c
[1] High-risk localised prostate cancer is also included in the definition of locally advanced prostate cancer.					

- CT of the pelvis should not be offered to men with low- or intermediate-risk localised prostate cancer (see table 1).
- Isotope bone scans should not be routinely offered to men with low-risk localised prostate cancer.
- Positron emission tomography imaging should not be offered for prostate cancer in routine clinical practice.

TREATMENT:

LOCALIZED PROSTATE CANCER (stage T1-T2c, Nx-N0, M0):

DEFERRED TREATMENT (ACTIVE SURVEILLANCE/ WATCHFUL WAITING):

Definitions:

Active surveillance is active monitoring, aiming at the proper timing of curative treatment; an active decision not to treat the patient immediately.

- The patient remains under close surveillance, and treatment is prompted by predefined thresholds indicative of the presence of a potentially life-threatening disease, while taking the patient's life-expectancy into consideration.

- The treatment options are intended to be *curative*.
- Aim is to reduce overtreatment in patients with clinically confined very low-risk PCa, without giving up the option of curative treatment.

Patients selected for active surveillance:

The various series have applied several eligibility criteria for enrolment in active surveillance programmes (D'Amico, Epstein, PRIAS, etc.):

- clinically confined PCa (T1-T2);
- Gleason score < 7 for most studies;
- PSA < 10-15 ng/mL;
- prostate cancer volume criteria on biopsies, e.g. number of positive biopsies, maximum cancer involvement of biopsy.

Protocol for active surveillance

There are several studies with variable protocols for the active surveillance patients. However, NICE recommends the following:

Timing	**Tests** [1]
At enrolment in active surveillance	Multiparametric MRI if not previously performed
Year 1 of active surveillance	Every 3–4 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3] Every 6–12 months: DRE[4] At 12 months: prostate rebiopsy
Years 2–4 of active surveillance	Every 3–6 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3]

	Every 6–12 months: DRE[4]
Year 5 and every year thereafter until active surveillance ends	Every 6 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3] Every 12 months: DRE[4]

[1] If there is concern about clinical or PSA changes at any time during active surveillance, reassess with multiparametric MRI and/or rebiopsy.

[2] May be carried out in primary care if there are agreed shared-care protocols and recall systems.

[3] May include PSA doubling time and velocity.

[4] Should be performed by a healthcare professional with expertise and confidence in performing DRE.

Triggers for active treatment:

- A PSA doubling time (PSADT) with a cut-off value ranging between < 2 and < 4 years.
- Gleason score progression to > 7 during systematic follow-up biopsies, at intervals ranging from one to four years.
- Patients' requests for treatment are based mainly on anxiety.
- Radiological progression, supported with an updated biopsy.

Recommendations:

Recommendations - active surveillance	LE	GR
Active surveillance is an option in patients with the lowest risk of cancer progression: over 10 years of life-expectancy, cT1-2, PSA < 10 ng/mL, biopsy Gleason score < 6 (at least 10 scores), < 2 positive biopsies, minimal biopsy core involvement (< 50% cancer per biopsy).	2a	A
Follow-up should be based on DRE, PSA and repeated biopsies. The optimal timing for follow-up is still unclear.	2a	A
Patients with biopsy progressions should be recommended to undergo active treatment.	2a	A

Watchful waiting is the delayed application of palliative treatment options. The rationale behind watchful waiting is the observation that PCa often progresses slowly, and is predominantly diagnosed in older men in whom there is a high incidence of co-morbidity and related high competitive mortality. Watchful waiting can be considered as an option for treating patients with localized PCa and a limited life-expectancy, or for older patients with less aggressive cancers.

Recommendations:

Recommendations - watchful waiting	LE	GR
Watchful waiting may be offered to all patients not willing to accept the side-effects of active treatment, particularly patients with a short life-expectancy.	1b	A
When on watchful waiting, the decision to start any non-curative treatment should be based on symptoms and disease progression.	1a	B

RADICAL PROSTATECTOMY

- Radical prostatectomy can be offered to men with intermediate-risk localised prostate cancer.
- Radical prostatectomy can be offered to men with high-risk localised prostate cancer when there is a realistic prospect of long-term disease control.
- Patients for radical prostatectomy should be referred to urological cancer team that has a specialist interest in urological cancer and all team members must attend a majority of meetings. The team should carry out a cumulative total of at least 50 radical operations for prostate or bladder cancer per year.
- Commissioners of urology services should consider providing robotic surgery to treat localised prostate cancer.
- Commissioners should ensure that robotic systems for the surgical treatment of localised prostate cancer are cost effective by basing them in centres that are expected to perform at least 150 robot-assisted laparoscopic radical prostatectomies per year.

Low risk prostate cancer (cT1-T2a, Gleason score < 6 and PSA < 10 ng/mL):

- Patients should be informed about the results of two randomized trials comparing retropubic RP versus watchful waiting (WW) in localized PCa.
- In the SPCG-4 study, the survival benefit associated with RP was similar before and after 9 years of follow-up and was also observed in men with low-risk PCa, and was confined to men < 65 years of age.

- In the PIVOT trial, a preplanned subgroup analysis of men with low-risk tumours showed that RP did not significantly reduce all-cause mortality.
- The decision to offer RP in cases of incidental cancer should be based upon the estimated probability of clinical progression compared to the relative risk of therapy and potential benefit to survival.
- In stage T2a patients with a 10-year life expectancy, RP is one of the recommended standard treatments, as 35-55% of these patients will show disease progression after 5 years if not treated.
- Extended pelvic lymph node dissection (eLND) is not necessary in low-risk PCa because the risk for positive lymph nodes does not exceed 5%.

Intermediate-risk, localized prostate cancer (cT2b-T2c or Gleason score = 7 and/or PSA 10-20 ng/mL):

- Radical prostatectomy is one of the recommended standard treatments for patients with intermediate risk PCa and a life expectancy of > 10 years.
- The prognosis is excellent when the tumour is confined to the prostate, based on pathological examination
- Although active monitoring could be proposed for some selected patients with intermediate-risk localized tumours, however, when the tumour is palpable or visible on imaging and clinically confined to the prostate, disease progression can be expected in most long term survivors.
- An eLND should be performed in intermediate-risk PCa if the estimated risk for positive lymph nodes exceeds 5%.
- Limited LND should no longer be performed because this misses at least half of the nodes involved

High-risk localized and locally advanced prostate cancer (Gleason score 8-10 and/or PSA > 20 ng/mL):

- RP is a reasonable treatment option in selected patients.
- RP is offered after all treatments have been discussed at the multidisciplinary team, with the pros and cons of each therapy has been considered by the patients with regard to their own individual circumstances.
- If RP is performed, pelvic eLND must be performed, because the estimated risk for positive lymph nodes is 15-40%.
- The patient must be informed about the likelihood of a multimodal approach.
- Neoadjuvant androgen depriviation therapy before RP does not provide a significant DSF or OS advantage over prostatectomy alone.

Complications and functional outcome in RP and RALP:

Complication, mean %	**Retropubic RP**	**RALP**
Continence*	80-97	89-100
Potency *	51-81	26-63
Peri-operative death	0.1	0.04
Readmission	3.0	3.5
Reoperation	2.3	0.9
Vessel injury	0.04	0.08
Nerve injury	0.4	0.4
Ureteral injury	1.5	0.1
Bladder injury	0.05	0.07
Rectal injury	0.5	0.3
Bowel injury	0	0.09
Ileus	0.8	0.8
Deep vein thrombosis	1.0	0.3
Pulmonary embolism	0.5	0.3
Pneumonia	0.5	0.05
Myocardial infarction	0.2	0.2
Haematoma	1.6	0.7
Lymphocele	3.2	0.8
Anastomotic leakage	10.0	3.5
Fistula	0.07	0.03
Bladder neck/anastomotic stricture	2.2	0.9
Sepsis	0.2	0.1
Wound infection	2.8	0.7

RALP = robot-assisted laparoscopic prostatectomy
RP = radical prostatectomy
***** The major limitations of the included studies were the frequent retrospective study design and the use of different assessment tools preventing a proper comparison between techniques and series.

RADIOTHERAPY

Radical Radiotherapy:

- There have been no randomized studies comparing radical prostatectomy (RP) with either external-beam radiotherapy (EBRT) or brachytherapy for localized prostate cancer (PCa).

- The National Institutes of Health (NIH) consensus statement in 1988 stated that external irradiation offers the same long-term survival results as surgery.
- EBRT provides a QoL at least as good as that following surgery. A recent systematic review has provided a more sophisticated overview of outcomes from trials that meet the criteria for stratifying patients by risk group, standard outcome measures, numbers of patients, and minimum median follow-up period.
- Radiotherapy continues to be an important and valid alternative to surgery alone for curative therapy.
- Intensity-modulated radiotherapy (IMRT), with or without image-guided radiotherapy (IGRT), is the gold standard for EBRT.
- All centres that do not yet offer IMRT should plan to introduce it as a routine method for the definitive treatment of PCa.
- Radiotherapy can be offered to men with intermediate-risk localised prostate cancer.
- Radiotherapy can be offered to men with high-risk localised prostate cancer when there is a realistic prospect of long-term disease control.
- Radiotherapy should be offered for localised prostate cancer a minimum dose of 74 Gy to the prostate at no more than 2 Gy per fraction.
- Men with intermediate- and high-risk localised prostate cancer should be offered a combination of radical radiotherapy and androgen deprivation therapy, rather than radical radiotherapy or androgen deprivation therapy alone.
- Men with intermediate- and high-risk localised prostate cancer should be offered 6 months of androgen deprivation therapy before, during or after radical external beam radiotherapy.
- Androgen deprivation therapy can be continued for up to 3 years for men with high-risk localised prostate cancer and the benefits and risks of this option should be discussed with them.
- Incidence of late toxicity and outcome by Radiation Therapy Oncology Group (RTOG) grade (from EORTC trial 22863):

Toxicity	Grade 2 %	Grade 3 %	Grade 4 %	Any significant toxicity (> grade 2)%
Cystitis	4.7	0.5	0	5.3
Haematuria	4.7	0	0	4.7
Urinary stricture	4.7	1.3	1	7.1
Urinary incontinence	4.7	0.5	0	5.3
Overall GU toxicity	12.4	2.3	1†	15.9

Toxicity	Grade 2 %	Grade 3 %	Grade 4 %	Any significant toxicity (> grade 2)%
Proctitis	8.2	0	0	8.2
Chronic diarrhoea	3.7	0	0	3.7
Small bowel obstruction	0.2	0.2	0	0.5
Overall GI toxicity	9.5	0.2	0	9.8
Leg oedema	1.5	0	0	1.5
Overall toxicity*	19.0	2.7	1	22.8
Potency after 1 year	--	--	--	55
Secondary malignancy	--	--	--	0.16

- Men with signs or symptoms of radiation-induced enteropathy should be offered care from a team of professionals with expertise in radiation-induced enteropathy.

- The nature and treatment of radiation-induced enteropathy should be included in the training programmes for oncologists and gastroenterologists.

- Full investigations should be carried out, including flexible sigmoidoscopy, in men who have symptoms of radiation-induced enteropathy to exclude inflammatory bowel disease or malignancy of the large bowel and to ascertain the nature of the radiation injury.

- Caution should be used when performing anterior wall rectal biopsy after brachytherapy because of the risk of fistulation.

Immediate (adjuvant) post-operative external irradiation after RP:

There’s currently conflicting evidence with biochemical free and overall survival advantages of adjuvant versus salvage radiotherapy in the following post RP patients:

- Patients classified as pT3 pN0.
- Positive margins (highest impact)
- Capsule rupture, and/or invasion of the seminal vesicles

- with a PSA level of < 0.1 ng/mL.

RADICALS trial outcome is awaited. However, currently two options can be offered in the framework of informed consent. These are:

- Immediate adjuvant radiotherapy to the surgical bed (79,81-83,86) after recovery of urinary function; or
- Clinical and biological monitoring followed by salvage radiotherapy (SRT) before the PSA exceeds 0.5 ng/mL.
- Immediate post-operative radiotherapy after radical prostatectomy, even to men with margin-positive disease, other than in the context of a clinical trial.

Post radiotherapy biochemical failure:

- After primary RT, with or without short-term hormonal manipulation, the RTOG-ASTRO Phoenix Consensus Conference definition of PSA failure (with an accuracy of > 80%) is any PSA increase > 2 ng/mL higher than the PSA nadir value, regardless of the serum concentration of the nadir.
- In patients with BCF who are candidates for local salvage therapy, prostate multiparametric MRI can guide biopsy.
- Selected patients with localized PCa at primary treatment and histologically proven recurrence without evidence of metastatic disease should be treated with salvage RP (SRP).
- Due to the increased rate of treatment-related complications and side effects, SRP and salvage brachytherapy should only be performed in experienced centres.
- Permanent seed implantation, high-intensity focused ultrasound (HIFU) and cryosurgical ablation are treatment options in carefully selected patients without evidence of metastasis and with histologically proven local recurrence.

Experimental therapeutic options to treat clinically localized PCa:

- High frequency focused ultrasound (HIFU) has been shown to have a therapeutic effect in low-stage PCa, but prospective randomized comparison studies are not available to support its routine use.
- Cryotherapy for PCa compares unfavourably with external-beam radiation for the preservation of sexual function. Similarly this modality should be used in the context of clinical trials.
- Focal therapy of any sort is investigational, and the follow-up and retreatment criteria are unclear.

- In patients who are unfit for surgery or radiotherapy, cryotherapy can be an alternative treatment for PCa but cannot be recommended as a therapeutic alternative outside clinical trials.
- If HIFU is offered, the lack of long-term comparative outcome data (> 10 y) should be discussed with the patient.

LOCALLY ADVANCED PROSTATE CANCER (stage T3-T4, Nx-N0, M0):

DEFERRED TREATMENT

- Only indicated in selected patients with non-poorly differentiated T3 tumours and a life expectancy of less than 10 years.
- Significant risk factors associated with a worse outcome hence indications of active treatment are:
    - patients with a baseline PSA > 50 ng/mL.
    - in patients with a baseline PSA < 50 ng/mL, a PSADT of < 12 months carries the risk of PCa related death (approximately 7.5-fold).

RADICAL RADIOTHERAPY

- In patients with locally advanced PCa T3-4 N0 M0, concomitant and adjuvant hormonal therapy for a total duration of 3 years, with external-beam irradiation for patients with WHO 0-2 performance status, is recommended, as it improves the overall survival.
- In a subset of patients with T2c-T3 N0-X and a Gleason score of 2-6, short-term androgen deprivation therapy ADT before and during radiotherapy can be recommended, as it may favourably influence the overall survival.

ADT monotherapy:

- ADT monotherapy can be offered to patients with locally advanced disease who are unwilling or unable to receive any form of associated local treatment.
- Immediate castration should be considered in the most aggressive situations (PSA > 50 ng/mL, PSADT < 12 months).
- Otherwise a wait-and-see policy with deferred treatment at clinical progression is a reasonable option.

RADICAL PROSTATECTOMY

- RP is optional in highly selected patients with cT3b-4 N0 or any cT N1 PCa in the context of a multimodality approach.
- When nodal involvement is detected after surgery:
    - Adjuvant ADT is recommended when > 2 nodes are involved;
    - Expectant management is optional when the patient has undergone eLND and < 2 nodes show microscopic involvement.

Focal therapeutic options:

High-intensity focused ultrasound and cryotherapy should not be offered to men with locally advanced prostate cancer other than in the context of controlled clinical trials comparing their use with established interventions.

METASTATIC PCa (stage M1):

ANDROGEN DEPREVATION THERAPY (ADT):

- In patients with symptomatic metastatic prostate cancer, ADT is recommended to palliate symptoms and to reduce the risk for potentially catastrophic sequelae of advanced disease (spinal cord compression, pathological fractures, ureteral obstruction, extraskeletal metastasis).

- In patients who are asymptomatic from their metastatic disease:
    - Immediate ADT can be used to defer progression to a symptomatic stage and prevent serious disease progression-related complications.
    - An active clinical surveillance protocol is an acceptable option in clearly informed patients if survival is the main objective.

- Anti-androgens are initially used to reduce the risk of the ‘flare-up’ phenomenon in patients with advanced metastatic disease who are to receive an LHRH agonist.

- It may be sufficient to give an anti-androgen for some weeks of concomitant use, starting treatment on the same day as an LHRH analogue is started, or for up to 7 days before the first LHRH analogue injection.

- Anti-androgens as monotherapy can be considered as an option in highly selected and motivated patients with a low PSA.

- Intermittent ADT:
    - When this method is used, it should reproduce what has been used in clinical trials; treatment is usually stopped when the PSA level is < 4 ng/mL (M1) and < 0.5-4 ng/mL (relapsing). Treatment is usually re-started when the PSA is > 4-10 (relapsing) and > 10-20 ng/mL (M1).
    - This can be used in patients with asymptomatic metastatic disease and are very motivated, with a major PSA response after the induction period.
    - Other cohort includes patients relapsing after radiotherapy; patients with a clear response after the induction period.

Contraindications of ADT

Therapy	**Contraindications**	**LE**	**GR**
Bilateral orchiectomy	Psychological reluctance to undergo surgical castration.	3	A
Oestrogens	Known cardiovascular disease.	2b	B
LHRH agonists monotherapy	Patients with metastatic disease at high risk for clinical ‘flare-up’ phenomenon.	2b	A
ADT, anti-androgen	Localized PCa as primary monotherapy (except in some high-risk localized situations in patients unwilling or unable to receive any form of local treatment).	1b	A

DEFERRED TREATMENT:

- Only indicated in asymptomatic patients with a strong wish to avoid treatment-related side-effects
- If a deferred treatment policy is chosen for a patient with advanced PCa, close follow-up must be possible.

RADICAL RADIOTHERAPY

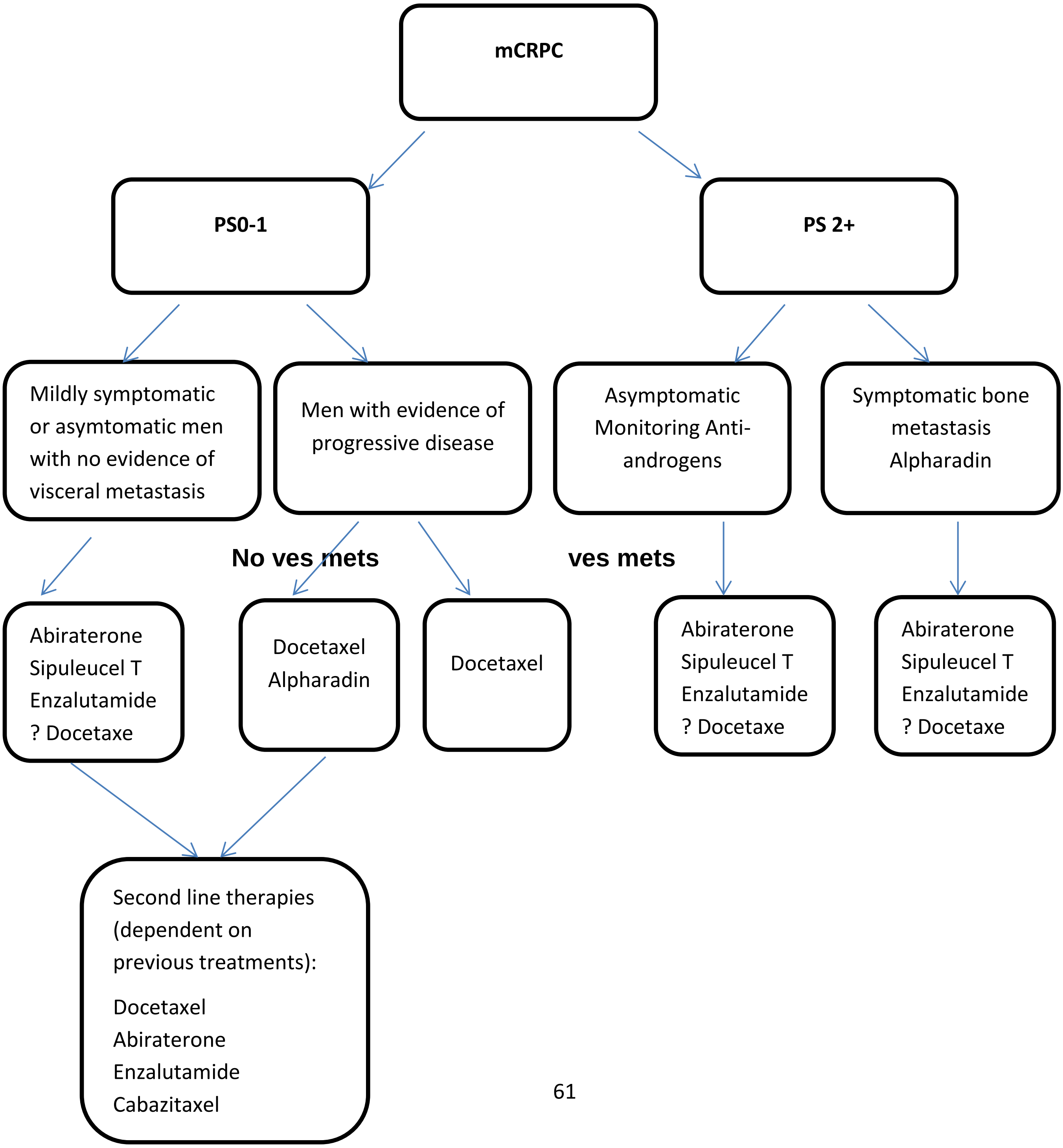
- In patients with very high-risk PCa c-pN1 M0, with no severe comorbidity, pelvic external irradiation and immediate long-term adjuvant hormonal treatment is recommended, as it may improve the overall survival, disease-specific failure rate, metastatic failure rate, and biochemical control.

CASTRATION-RESISTANT PCa (CRPC)

Defined as:

- Castrate serum testosterone < 50 ng/dL or 1.7 nmol/L plus either:
    - Biochemical progression: Three consecutive rises of PSA, 1 week apart, resulting in two 50% increases over the nadir, with PSA > 2 ng/mL. or
    - Radiological progression: The appearance of two or more bone lesions on bone scan or enlargement of a soft tissue lesion using RECIST (Response Evaluation Criteria in solid tumours).

Flowchart of the potential therapeutic options after PSA progression following initial hormonal therapy:



- Patients with mCRPC should be counselled, managed and treated by a multidisciplinary team.

FOLLOW UP

Guidelines for follow-up of prostate cancer patients with curative intent/watchful waiting:

- Men should be clearly advised with prostate cancer about potential longer-term adverse effects of treatment and when and how to report them.
- Men with prostate cancer who have chosen a watchful waiting regimen with no curative intent should normally be followed up in primary care in accordance with protocols agreed by the local urological cancer MDT and the relevant primary care organisation(s). Their PSA should be measured at least once a year.
- PSA levels for all men with prostate cancer who are having radical treatment should be checked at the earliest 6 weeks following treatment, at least every 6 months for the first 2 years and then at least once a year thereafter.
- DRE is not routinely offered to men with localised prostate cancer while the PSA remains at baseline levels [NICE].
- After radical prostatectomy, a serum PSA level of more than 0.2 ng/mL can be associated with residual or recurrent disease.
- After radiation therapy, a rising PSA level over 2 ng/mL above the nadir PSA, rather than a specific threshold value, is the most reliable sign of recurrent disease.
- Both a palpable nodule and a rising serum PSA level can be signs of local disease recurrence.
- Detection of local recurrence by imaging studies is only recommended if it will affect the treatment plan. In most cases, a biopsy is not necessary before second-line therapy.
- Routine bone scans and other imaging studies are not recommended in asymptomatic patients with no signs of biochemical relapse. If a patient has bone pain or other symptoms of disease progression, re-staging should be considered irrespective of the serum PSA level.
- In asymptomatic patients, a disease-specific history and a serum PSA measurement supplemented by DRE are the recommended tests for routine

follow-up. These should be performed at 3, 6 and 12 months after treatment, then every 6 months until 3 years, and then annually [EAU].

- After at least 2 years, follow-up can be performed outside hospital (for example, in primary care) by telephone or secure electronic communications to men with a stable PSA who have had no significant treatment complications, unless they are taking part in a clinical trial that requires formal clinic-based follow-up. Direct access to the urological cancer MDT should be offered and explained.

Guidelines for follow-up of prostate cancer patients on ADT:

- Patients should be evaluated at 3 and 6 months after the initiation of treatment.
- As a minimum, tests should include serum PSA measurement, DRE, serum testosterone, and careful evaluation of symptoms in order to assess the treatment response and side effects.
- In patients undergoing intermittent androgen deprivation, PSA and testosterone should be monitored at set intervals during the treatment pause (one or three months).
- Follow-up should be tailored for the individual patient, according to symptoms, prognostic factors and the treatment given.
- In patients with stage M0 disease with a good treatment response, follow-up is scheduled every 6 months, and as a minimum should include a disease-specific history, DRE and serum PSA determination.
- In patients with stage M1 disease with a good treatment response, follow-up is scheduled for every 3 to 6 months. As a minimum, this should include a disease-specific history, DRE and serum PSA determination, and is frequently supplemented with haemoglobin, serum creatinine and alkaline phosphatase measurements. The testosterone level should be checked, especially during the first year.
- Patients (especially with M1b status) should be advised about the clinical signs that could suggest spinal cord compression.
- When disease progression occurs, or if the patient does not respond to the treatment given, follow-up needs to be individualized.
- In patients with suspected progression, the testosterone level must be checked. By definition, CRPC is based on the assumption that the patient has a testosterone level of at least < 50 ng/mL.
- Routine imaging of stable patients is not recommended.

9.3 PENILE CANCER

Penile carcinoma is mostly a squamous cell carcinoma (SCC) but other types of carcinoma exist as well. It usually originates from the epithelium of the inner prepuce or the glans. Also, penile SCC occurs in several histological subtypes. Penile SCC shares similar pathology with SCC of the oropharynx, the female genitalia (cervix, vagina and vulva) and the anus and it is therefore assumed that it also shares to some extent the natural history.

EPIDEMIOLOGY

- In Western countries, primary penile cancer is uncommon, with an incidence of less than 1.00 per 100,000 males in Europe and the United States.

- Incidence is also affected by race and ethnicity in North America, with the highest incidence of penile cancer found in white Hispanics (1.01 per 100,000), followed by a lower incidence in Alaskan, Native American Indians (0.77 per 100,000), blacks (0.62 per 100,000) and white non-Hispanics (0.51 per 100,000), respectively.

- In contrast, in some other parts of the world such as South America, South East Asia and parts of Africa the incidence of penile cancer is much higher and can represent 1-2% of malignant diseases in men.

- Penile cancer is common in regions with a high prevalence of human papilloma virus (HPV). The annual age-adjusted incidence is 0.7-3.0 per 100,000 men in India, 8.3 per 100,000 men in Brazil and even higher in Uganda, where it is the most commonly diagnosed cancer in men.

- There are no data linking penile cancer to HIV or AIDS.

- In European countries, the overall incidence has been stable from the 1980s until today. Recently, an increased incidence has been reported from Denmark and the UK.

- A longitudinal study from the UK has confirmed a 21% increase in incidence over the period 1979-2009.

- The incidence of penile cancer increases with age, with an age peak during the sixth decade of life. However, the disease does occur in younger men.

RISK FACTORS AND PREVENTION

Risk factors	Relevance
• Phimosis	OR 11-16 versus no phimosis
• chronic penile inflammation (balanoposthitis related to phimosis) • balanitis xerotica obliterans (lichen sclerosus)	Risk
• sporalene and UV-A phototherapy for various dermatologic conditions such as psoriasis	Incidence rate ratio 9.51 with > 250 treatments
• smoking	5-fold increased risk (95% CI: 2.0-10.1) versus nonsmokers
• HPV infection condylomata acuminata	22.4% in verrucous SCC and 36-66.3% in basaloid-warty
• Rural areas, low socio-economic status, unmarried	Risk
• multiple sexual partners early age of first intercourse	3-5-fold increased risk of penile cancer

- Neonatal circumcision reduces the incidence of penile cancer in countries and cultures where this is routinely practiced.
- The lowest incidence of penile cancer is reported from Israel amongst Jews (0.3/100,000/ year).
- Medical circumcision in adult life does not influence the incidence of penile cancer.
- The controversial discussion about any preventive value of neonatal circumcision must take into consideration that circumcision removes about 50% of the tissue that can develop penile cancer.
- The protective effect of neonatal circumcision against invasive penile cancer (OR 0.41) - which does apparently not apply to CIS (OR 1.0) - is much weaker when the analysis is restricted to men without a history of phimosis (OR 0.79, 95% CI 0.29-2).

TNM clinical and pathological classification of penile cancer (2009)

T - Primary Tumour	
Tx	Primary tumour cannot be assessed
T0	No evidence of primary tumour
Ta	Non-invasive carcinoma
Tis	Carcinoma in situ
T1	Tumour invades subepithelial connective tissue
T1a	Tumour invades subepithelial connective tissue without lymphovascular invasion and is not poorly differentiated or undifferentiated (T1G1-2)
T1b	Tumour invades subepithelial connective tissue with lymphovascular invasion or is poorly differentiated or undifferentiated (T1G3-4)
T2	Tumour invades corpus spongiosum and/or corpora cavernosa
T3	Tumour invades urethra
T4	Tumour invades adjacent structures
N - Regional Lymph Nodes	
Nx	Regional lymph nodes cannot be assessed
N0	No palpable or clinically visible inguinal lymph-node
N1	Palpable mobile unilateral inguinal lymph node
N2	Palpable mobile multiple unilateral or bilateral inguinal lymph nodes
N3	Fixed inguinal nodal mass or pelvic lymphadenopathy, unilateral or bilateral
M - Distant Metastasis	
M0	No distant metastasis
M1	Distant metastasis
Pathological classification	
The pT categories correspond to the clinical T categories. The pN categories are based upon biopsy or surgical excision.	
pN - Regional Lymph Nodes	
pNX	Regional lymph nodes cannot be assessed
pN0	No regional lymph node metastasis
pN1	Intranodal metastasis in a single inguinal lymph node
pN2	Metastasis in multiple or bilateral inguinal lymph nodes
pN3	Metastasis in pelvic lymph node(s), unilateral or bilateral or extranodal extension of any regional lymph node metastasis
pM - Distant Metastasis	
pM0	No distant metastasis
pM1	Distant metastasis
G - Histopathological Grading	
GX	Grade of differentiation cannot be assessed
G1	Well differentiated
G2	Moderately differentiated
G3-4	Poorly differentiated/undifferentiated

Premalignant penile lesions (precursor lesions)

Lesions sporadically associated with SCC of the penis

- Cutaneous horn of the penis
- Bowenoid papulosis of the penis
- Lichen sclerosus (balanitis xerotica obliterans)

Premalignant lesions (up to one-third transform to invasive SCC)

- Intraepithelial neoplasia grade III
- Giant condylomata (Buschke-Löwenstein)
- Erythroplasia of Queyrat or Bowen’s disease
- Paget’s disease (intradermal ADK)

Histological subtypes of penile carcinomas, their frequency and outcome

Subtype	Frequency (% of cases)	Prognosis
common SCC	48-65	depends on location, stage and grade
basaloid carcinoma	4-10	poor prognosis, frequently early inguinal nodal metastasis
warty carcinoma	7-10	good prognosis, metastasis rare
verrucous carcinoma	3-8	good prognosis, no metastasis
papillary carcinoma	5-15	good prognosis, metastasis rare
sarcomatoid carcinoma	1-3	very poor prognosis, early vascular metastasis
mixed carcinoma	9-10	heterogeneous group
pseudohyperplastic carcinoma	< 1	foreskin, related to lichen sclerosus, good prognosis, metastasis not reported
carcinoma cuniculatum	< 1	variant of verrucous carcinoma, good prognosis, metastasis not reported
pseudoglandular carcinoma	< 1	high grade carcinoma, early metastasis, poor prognosis
warty-basaloid carcinoma	9-14	poor prognosis, high metastatic potential (12) (higher than in warty, lower than in basaloid SCC)
adenosquamous carcinoma	< 1	central and peri-meatal glans, high grade carcinoma, high metastatic potential but low mortality
mucoepidermoid carcinoma	< 1	highly aggressive, poor prognosis
clear cell variant of penile carcinoma	1-2	exceedingly rare, associated with HPV, aggressive, early metastasis, poor prognosis, outcome lesion dependent, frequent lymphatic metastasis

DIAGNOSIS AND STAGING

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer:
  GPs should refer men with suspicious penile lesions such as growths, swelling at or near the glans, painless ulcers which do not appear to be due to infection, or other unexplained abnormalities such as plaques on the skin or foreskin of the penis, to a local urological cancer team.

Recommendations for the diagnosis and staging of penile cancer

Recommendations	**GR**
Primary tumour: • Physical examination, recording morphology, extent and invasion of penile structures. • MRI with artificial erection in selected cases with intended organ preserving surgery.	**C**
Inguinal lymph nodes: • Physical examination of groins, recording number, laterality and characteristics of inguinal nodes. • If nodes are not palpable, invasive lymph node staging in high-risk patients. • If nodes are palpable, a pelvic CT may be indicated, PET/CT is an option.	**C**
Distant metastases: • In N+ patients, abdomino-pelvic CT scan and chest X-ray are required for systemic staging. • PET/CT scan is an option. • In patients with systemic disease or with relevant symptoms, a bone scan may be indicated.	**C**

TREATMENT

Patients with penile cancer should be managed by specialist penile cancer teams working at the supra-network level. Such teams should serve up to four networks, with a combined population base of at least four million for penile cancer and expect to manage a minimum of 25 new patients each year. The team should include members of the specialist urological cancer team who work in the cancer centre within which it is based, and it should also have access to expertise in plastic surgery.

All penile cancer cases should be discussed with the supranetwork team prior to proposed treatment if not referred directly to that team.

Local care is classed as:
(i) The diagnostic process only.
Local care should be carried out by local teams for their catchment.

It should also be carried out by specialist teams and supranetwork teams for the local catchment of their host locality.

Specialist care is classed as:
(i) Resection (except in cases needing penile reconstruction or lymph node resection).

All resections should be carried out in the host hospital of the team.

(ii) Radiotherapy and chemotherapy. The site(s) where this is carried out should be agreed in the
network guidelines.

Specialist care may be delivered by:

- A specialist urological team without a supranetwork interest in penile cancer provided this is agreed in the network guidelines and with the relevant supranetwork team. It should not be delivered by local urological teams.

- A supranetwork team for referring specialist teams provided this is agreed in the network guidelines.

- The supranetwork team for the local catchment of their host locality.

Supranetwork care is classed as:
Resection in cases needing penile reconstruction or lymph node resection.

All resections should be carried out in one of the hospitals named as part of the facilities of the host locality. All such operations should be carried out in the same hospital.

Supranetwork care should be delivered by the *supranetwork team only.* This is not subject to alteration by the network guidelines.

- The aims of the treatment of the primary penile cancer lesion are complete tumour removal with as much organ preservation as possible while radicality of the treatment should not be compromised.
- A local recurrence in itself has little influence on long-term survival so that organ preservation strategies are justified.
- There are no randomised controlled trials for any of the surgical management options of localised penile cancer, neither are there any observational studies comparing different surgical approaches or studies comparing surgical and non-surgical treatment modalities.
- The available studies all have one or more form of bias such as bias of selection, performance, detection, attrition, selective reporting or publication. Thus, the overall quality of the existing evidence must be regarded as low.
- Penile preservation appears to be superior in functional and cosmetic outcomes and should be offered as the primary treatment modality to men with localised penile cancer.
- Histological diagnosis with local staging must be obtained in all cases, especially if non-surgical treatment modalities are considered
- The treatment of the primary tumour and that of the regional nodes can be done as staged procedures.
- In both cases, it is essential to remove all malignant tissue with negative surgical margins.
- Patients must be counselled about all relevant treatment modalities.
- There are a variety of local treatment modalities for small and localized penile cancer including
    - excisional surgery,
    - external beam radiotherapy,
    - brachytherapy and laser ablation which are used to treat localized invasive disease.

Treatment of superficial non-invasive disease (CIS)

- For penile CIS, topical chemotherapy with imiquimod or 5-FU is an effective first-line treatment.
- Toxicity and adverse events of these topical treatments are relatively low but the efficacy is limited.
- Complete responses have been reported in up to 57% of cases of CIS.
- For the reason of a high rate of persistence and/or recurrence, close and long-term surveillance of such patients is required.
- If topical treatment fails it should not be repeated. Laser treatment can be used for CIS.
- Photodynamic control may be used in conjunction with CO2 laser treatment.
- Alternatively, total or partial glans resurfacing can be offered as a primary treatment modality for CIS and as a secondary treatment in case of treatment failure with topical chemotherapy or laser therapy.
- Glans resurfacing is a surgical technique which consists of complete abrasion of the glandular epithelium with covering by a split skin graft.
- With glans resurfacing for presumed non-invasive disease, up to 20% of patients are found to have superficial invasive disease.

Treatment of invasive disease confined to the glans (category Ta/T1a)

- Penis-preserving strategy is recommended.
- Prior to conservative treatment modalities, it is mandatory to obtain histopathological diagnosis by biopsy.
- All patients must be circumcised before considering conservative non-surgical treatment modalities.
- For tumours confined to the prepuce, radical circumcision alone may be curative, if negative surgical margins are confirmed by definitive histology.
- For all surgical treatment options, the intra-operative assessment of surgical margins by frozen section is recommended as tumour-positive margins lead to local recurrence.
- Total removal of the glans (glansectomy) and prepuce does have the lowest recurrence rate among the treatment modalities for small penile lesions (2%).
- Negative surgical margins are imperative when using penile-conserving treatments and a margin of 5 mm is considered oncologically safe.
- Treatment choice should depend on tumour size, histology including stage and grade, localization especially relative to the meatus, as well as patient preference as there are no documented differences in the long term local recurrence rates between surgery, laser and radiation therapy.

Summary of reported complications and oncological outcomes of local treatments

treatment	**complications**	**local recurrence**	**nodal recurrence**	**cancer-specific deaths**
Nd:YAG laser	none reported	10-48%	21%	2-9%
CO2-laser	bleeding, meatal stenosis(both < 1%)	14-23%	2-4%	none reported
Lasers (unspecified)	bleeding (8%), local infection 2%	11-26%	2%	2-3%
Moh's micrographic surgery	local infection 3%, meatal stenosis 6%	32%	8%	3-4%
Glans resurfacing	none reported	4-6%	not reported	not reported
Glansectomy	none reported	8%	9%	none reported
Partial penectomy	not reported	4-13%	14-19%	11-27%
Brachytherapy	meastal stenosis> 40%	10-30%	not reported	not reported
Radiotherapy	urethral stenosis 20-35%, glans necrosis10-20%	not reported	not reported	not reported

Recommendations for stage-dependent local treatment of penile carcinoma

Recommendations			
Primary tumour	Organ-preserving treatment is to be considered whenever possible	LE	GR
Tis	• Topical treatment with 5-fluorouracil or imiquimod for superficial lesions with or without photodynamic control. • Laser ablation with CO2 or Nd:YAG laser. • Glans resurfacing.	3	C
Ta, T1a (G1, G2)	• Wide local excision with circumcision CO2 or Nd:YAG laser surgery with circumcision.	3	C

Recommendations			
	• Laser ablation with CO2 or Nd:YAG laser. • Glans resurfacing. Glansectomy with reconstructive surgery, with or without skin grafting. • Radiotherapy by external beam or as brachytherapy for lesions < 4 cm.		
T1b (G3) and T2 confined to the glans	• Wide local excision plus reconstructive surgery, with or without skin grafting. • Laser ablation with circumcision. • Glansectomy with circumcision, with reconstruction. • Radiotherapy by external beam or brachytherapy for lesions < 4 cm in diameter.	3	C
T2 with invasion of the corpora cavernosa	• Partial amputation and reconstruction. • Radiotherapy by external beam or brachytherapy for lesions < 4 cm in diameter.	3	C
T3 with invasion of the urethra	• Partial penectomy or total penectomy with perineal urethrostomy.	3	C
T4 with invasion of other adjacent structures	• Neoadjuvant chemotherapy followed by surgery in responders. Alternative: palliative external beam radiation. • Local recurrence after conservative treatment Salvage surgery with penis-sparing treatment in small recurrences or partial amputation. • Large or high stage recurrence: partial or total amputation	3	C

Management of regional lymph nodes

- The development of lymphatic metastases in penile cancer follows some anatomic rules.
- The inguinal and the pelvic lymph nodes are the regional drainage system of the penis.
- The superficial and deep inguinal lymph nodes are thereby the first regional nodal group reached by lymphatic metastatic spread.
- Spread to the inguinal lymph nodes can be uni- or bilateral from any primary penile cancer.
- The second regional lymph node groups are the ipsilateral pelvic lymph nodes.

- Pelvic nodal disease does not seem to occur without ipsilateral inguinal lymph node metastasis and cross-over metastatic spread from one inguinal side to the other pelvic side has never been reported in penile cancer.
- Further metastatic lymph node spread from the pelvic nodes to paraaortic and paracaval nodes is outside the regional lymph node drainage system of the penis and is therefore classified as systemic metastatic disease.
- The management of regional lymph nodes is decisive for long-term patient survival.
- Cure can be achieved in metastatic disease confined to the regional lymph nodes.
- Lymphadenectomy is the treatment of choice for patients with inguinal lymph node metastases but multimodal treatment combining surgery and polychemotherapy is often indicated.
- Management of the regional lymph nodes should be stage-dependent. In clinically node-negative patients (cN0), there is a definite risk of micro-metastatic lymph node involvement in about 25% of cases which is related to local tumour stage and grade.
- In clinically positive lymph nodes (cN1/cN2), metastatic disease is highly likely and no time should be wasted on antibiotic treatment before surgical treatment.
- With enlarged fixed inguinal lymph nodes (cN3), multimodal treatment by chemotherapy and surgery is indicated. Capsular penetration and extranodal extension in lymph node metastasis even if present in only one node carries a high risk of progression and is classified as pN3 which also requires multimodal treatment.

Recommendations for treatment strategies for nodal metastases

Regional lymph nodes	**Management of regional lymph nodes is fundamental in the treatment of penile cancer**	**LE**	**GR**
No palpable inguinal nodes (cN0)	• Tis, Ta G1, T1G1: surveillance. • > T1G2: invasive lymph node staging by bilateral modified inguinal lymphadenectomy or DSNB.	2a	B
Palpable inguinal nodes (cN1/cN2)	Radical inguinal lymphadenectomy.		
Fixed inguinal lymph nodes (cN3)	• Neoadjuvant chemotherapy followed by radical inguinal lymphadenectomy in responders. • Pelvic lymphadenectomy Ipsilateral pelvic lymphadenectomy is indicated if two or more inguinal nodes are involved on one side (pN2) and in extracapsular nodal metastasis (pN3).	2a	B

Regional lymph nodes	**Management of regional lymph nodes is fundamental in the treatment of penile cancer**	**LE**	**GR**
Adjuvant chemotherapy	• Indicated in pN2/pN3 patients after radical lymphadenectomy • Radiotherapy Radiotherapy is not indicated for the treatment of nodal disease in penile cancer.	2b	B

Chemotherapy

- Multimodal treatment can improve patient outcome in many tumour entities.
- The value of adjuvant chemotherapy after radical inguinal lymphadenectomy in node-positive penile cancer has a long-term disease-free survival (DFS) as opposed those without chemotherapy of (84% vs 39% respectively).
- There is limited evidence to support the use of neoadjuvant chemotherapy for patients with fixed, unresectable nodal disease, particularly with a triple combination including cisplatin and a taxane, whenever feasible.

Recommendations for chemotherapy in penile cancer patients

	LE	**GR**
Adjuvant chemotherapy (3-4 cycles of TPF) is an option for patients with pN2-3 tumours.	2b	C
Neoadjuvant chemotherapy (4 cycles of a cisplatin and taxane-based regimen) followed by radical surgery is recommended in patients with non-resectable or recurrent lymph node metastases.	2a	B
Chemotherapy for systemic disease is an option in patients with limited metastatic load.	3	C

FOLLOW UP

Recommendations for follow-up in penile cancer

	Interval of follow-up Years 1-2	**Interval follow-up Years 3-5**	**Examinations examination and investigations**	**Minimum duration of follow-up**	**GR**
Primary tumour: penile preserving treatment	3 months	6 months	Regular physician or self examination Repeat biopsy after topical or laser treatment for CIS.	5 years	C
Amputation	3 months	1 year	Regular physician or self examination	5 years	C
Recommendations for follow-up of the inguinal lymph nodes: Surveillance	3 months	6 months	Regular physician or selfexamination	5 years	C
pN0 at initial treatment	3 months	1 year	• Regular physician or self examination. • Ultrasound with FNAB optional.	5 years	C
pN+ at initial treatment	3 months	6 months	• Regular physician or selfexamination • Ultrasound with FNAC optional, • CT/MRI optional.	5 years	C

9.4 Renal Cell Carcinoma

Epidemiology:

- Renal cell carcinoma (RCC) represents 2-3% of all cancers.
- In 2012, there were approximately 84,400 new cases of RCC and 34,700 kidney cancer-related deaths in the European Union.
- In Europe, overall mortality rates for RCC increased up to the early 1990s, and stabilised or declined thereafter. Mortality has decreased since the 1980s in Scandinavian countries and since the early 1990s in France, Germany, Austria, the Netherlands, and Italy. However, in some European countries (Croatia, Estonia, Greece, Ireland, Slovakia), mortality rates still show an upward trend.
- Different RCC types have specific histopathological and genetic characteristics.
- There is a 1.5:1 male predominance, with peak incidence between 60 and 70 years.
- Having a first-degree relative with kidney cancer also increases the risk of RCC.
- Literature results are inconclusive regarding the association of specific dietary habits and occupational exposure to RCC.
- Moderate alcohol consumption appears to have a protective effect for unknown reasons.
- Effective prophylaxis includes avoidance of cigarette smoking and obesity.

Aetiology:

- Smoking:
    - The RR of RCC for ever-smokers is 1.38 times higher than that for non-smokers
    - A strong dose-response relationship between number of cigarettes smoked and increased risk of RCC has been established; Smokers with a history of ≥20 pack-years have an increased risk of RCC 1.35 times that of never-smokers

- Obesity:
    - Increasing body weight and body mass index (BMI) incrementally increases the risk of developing RCC
    - Being overweight (BMI 25–29.9 kg/m2) increases the risk of RCC by 1.35 times versus BMI

- Hypertension and antihypertensive therapy:
    - The presence of hypertension is estimated to increase the RR of RCC by 1.4–1.9 times compared with normotensive individuals
    - Systolic blood pressure ≥160 mmHg increases the RR of RCC by 2.5 times versus <120 mmHg.

  - Diastolic blood pressure ≥100 mmHg increases the RR of RCC by 2.3 times versus <80 mmHg.
  - Treatment with diuretics also increases the risk of RCC (OR 1.43), but this is only significant in women

- End-stage renal disease:
  - Patients undergoing dialysis for end-stage renal disease are estimated to have a 3.6 times higher RR of developing renal cancer than healthy individuals.

- Renal cancer syndromes:

Disease	**Renal and other tumours**	**Gene mutation**
Von Hippel–Lindau disease	Clear cell RCC: Clear cell renal cysts Retinal and central nervous system haemangioblastomas, phaeochromocytoma, pancreatic cyst and endocrine tumour, endolymphatic sac tumour, epididymal and broad ligament cystadenomas	VHL
Birt-Hogg-Dubé syndrome	Hybrid oncocytic RCC, chromophobe RCC, oncocytoma, clear cell RCC multiple and bilateral Cutaneous lesions (fibrofolliculoma +++, trichodiscoma, acrochordon), lung cysts, spontaneous pneumothorax, colonic polyps or cancer	Folliculin (FLCN)
Hereditary papillary RCC	Type 1 papillary RCC: multiple and bilateral	MET
Hereditary leiomyomatosis and RCC	Type 2 papillary RCC: solitary and aggressive Uterine leiomyoma and leiomyosarcoma, cutaneous leiomyoma and leiomyosarcoma	Fumarate hydratase
Tuberous sclerosis complex	Angiomyolipoma, clear cell RCC, cyst, oncocytoma: bilateral and multiple Facial angiofibroma, subungual fibroma, hypopigmentation and café au lait spots, cardiac rhabdomyoma, seizure, mental retardation, CNS tubers, lymphangioleiomyomatosis	TSC-1 TSC-2
Familial clear cell RCC	Clear cell RCC	Unknown

Diagnosis:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.
- Many renal masses remain asymptomatic until the late stages of the disease.
- More than 50% of renal cell carcinomas (RCCs) are detected incidentally when noninvasive imaging is used to investigate a variety of nonspecific symptoms and other abdominal diseases.
- The classic triad of flank pain, gross haematuria and palpable abdominal mass is now rare (<10%).
- Other clinical symptoms include new onset varicocele or bilateral lower extremity oedema; these symptoms should initiate radiological examinations.
- Renal Cell Carcinoma Paraneoplastic syndromes are found in approximately 30% of patients with symptomatic RCCs.
- A few symptomatic patients present with symptoms caused by metastatic disease, such as bone pain or persistent cough.

Investigations:

- Radiological and other investigations of RCC Radiological investigations of RCC include CT imaging, before and after intravenous contrast to verify the diagnosis and provide information on:
    - function and morphology of the contralateral kidney
    - assess tumour extension
    - extrarenal spread
    - venous involvement
    - enlargement of lymph nodes and adrenals.
- Abdominal US and magnetic resonance (MR) imaging are supplements to CT.
- Contrast enhanced US can be helpful in specific cases (e.g., chronic renal failure with a relative contraindication for iodinated or gadolinium contrast media, complex cystic masses, and differential diagnosis of peripheral vascular disorders such as infarction and cortical necrosis).

- Magnetic resonance imaging can be used in patients with possible venous involvement, or allergy to intravenous contrast.
- Chest CT is the most accurate chest staging; a routine chest X-ray should be done as a minimum only.
- Indications of renal biopsy:
  - for histological diagnosis of radiologically indeterminate renal masses
  - to select patients with small renal masses for surveillance approaches
  - to obtain histology before ablative treatments
  - to select the most suitable form of targeted pharmacologic therapy in the setting of metastatic disease.
- Total renal function should always be evaluated.
- In patients with any sign of impaired renal function, a renal scan and total renal function evaluation should be undertaken to optimise the treatment decision.

Staging system:

The current UICC 2009 TNM (Tumour Node Metastasis) classification is recommended for the staging of RCC.

T - Primary tumour		
TX		Primary tumour cannot be assessed
T0		No evidence of primary tumour
T1		Tumour ≤ 7 cm in greatest dimension, limited to the kidney
	T1a	Tumour ≤ 4 cm in greatest dimension, limited to the kidney
	T1b	Tumour > 4 cm but ≤ 7 cm in greatest dimension
T2		Tumour > 7 cm in greatest dimension, limited to the kidney
	T2a	Tumour > 7 cm in greatest dimension but ≤ 10 cm
	T2b	Tumour > 10 cm limited to the kidney
T3		Tumour extends into major veins or perinephric tissues, but not into the ipsilateral adrenal gland and not beyond Gerota's fascia
	T3a	Tumour grossly extends into the renal vein or its segmental (muscle-containing) branches, or tumour invades perirenal and/or renal sinus (peripelvic) fat but not beyond Gerota's fascia
	T3b	Tumour grossly extends into the vena cava below diaphragm
	T3c	Tumour grossly extends into vena cava or its wall above the diaphragm or invades the wall of the vena cava
	T4	Tumour invades beyond Gerota's fascia (including contiguous extension into the ipsilateral adrenal gland)
N - Regional lymph nodes		
NX		Regional lymph nodes cannot be assessed
N0		No regional lymph node metastasis

N1	Metastasis in a single regional lymph node
N2	Metastasis in more than one regional lymph node
M - Distant metastasis	
M0	No distant metastasis
M1	Distant metastasis

Histopathological classification:

Fuhrman nuclear grade is the most commonly used grading system. The most aggressive pattern observed defines the Fuhrman grade. The most common histological subtypes of rCC are below:

Histological subtype	**Frequency (%)**
clear cell RCC	80-90%),
papillary RCC	10-15%),
chromophobe RCC	4-5%
collecting duct carcinoma	1%

- Generally, the RCC types have different clinical courses and responses to therapy.

Recommendations for diagnosis and staging of RCC:

Recommendations for the diagnosis and staging of RCC	GR
The Fuhrman grading system and classification of RCC subtype should be used	B
In a patient with one or more suspicious laboratory or physical findings, the possible presence of RCC should be suspected	B
Contrast-enhanced abdominal CT and MRI are recommended for the work-up of patients with RCC. These are the most appropriate imaging modalities for renal tumour staging prior to surgery	A
A chest CT is most sensitive for assessment of the lung, but at least a plain chest radiograph should be taken for clinical staging	A
In patients at risk for bone metastases (raised alkaline phosphatase level or bone pain), further evaluation with a bone scan is needed	A
Evaluation of renal function is recommended before treatment decision in any patient in whom renal impairment is suspected	B
Percutaneous biopsy is recommended in active surveillance strategies in order to stratify the follow-up according to tumour histology	B

Recommendations for the diagnosis and staging of RCC	GR
Percutaneous biopsy is always required before ablative therapy and systemic therapy without previous pathology	A
When biopsy is indicated, good-quality needle cores should be obtained with a coaxial technique in order to increase the safety of the procedure and maximize its diagnostic yield	B

Recommendations for “other renal tumours”:

Recommendations for “Other renal tumours”	LE	GR
Except for angiomyolipomas, most of these less common renal tumours cannot be differentiated from RCC on the basis of radiology and should therefore be treated in the same way as RCC.	3	C
Bosniak cysts ≥ type III should be treated surgically. When possible, a nephron-sparing procedure should be performed in Bosniak type III.	3	C
In oncocytomas verified on biopsy, follow-up is an option.	3	C
In angiomyolipomas, treatment (surgery, thermal ablation, and selective arterial embolisation) can be considered in only very well selected cases. A nephron-sparing procedure is preferred	3	C
In advanced uncommon types of renal tumours, a standardised oncological treatment approach does not exist.	4	C

Bosniak classification of renal cysts:

Bosniak category	**Features**	**Work-up**
I	Simple benign cyst with a hairline-thin wall without septa, calcification, or solid components. Same density as water and does not enhance with contrast medium.	Benign
II	Benign cyst that may contain a few hairline-thin septa. Fine calcification may be present in the wall or septa. Uniformly high-attenuation lesions < 3 cm in size, with sharp margins without enhancement.	Benign
IIF	These may contain more hairline-thin septa. Minimal enhancement of a hairline-thin septum or wall. Minimal thickening of the septa or wall. The	Follow-up. Some are malignant.

Bosniak category	Features	Work-up
	cyst may contain calcification, which may be nodular and thick, with no contrast enhancement. No enhancing soft-tissue elements. This category also includes totally intrarenal, non-enhancing, high attenuation renal lesions > 3 cm. Generally well-marginated.	
III	These are indeterminate cystic masses with thickened irregular walls or septa with enhancement.	Surgery or active surveillance Over 50% are malignant
IV	Clearly malignant containing enhancing soft-tissue components.	Surgery. Most are malignant

Guidelines for primary treatment for RCC:

- Based on the available oncological and QoL outcomes, the current evidence suggests that localised renal cancers are best managed by nephron-sparing surgery (partial nephrectomy) rather than by radical nephrectomy, irrespective of the surgical approach.
- Radical nephrectomy with complete removal of the tumour-bearing kidney with perirenal fat and Gerota’s fascia is currently recommended only for patients with localised RCC, who are not suitable for nephron-sparing surgery due to locally advanced tumour growth, when partial resection is technically not feasible due to an unfavourable localisation of the tumour or local growth.
- Complete resection of the primary RCC either by open or laparoscopic surgery offers a reasonable chance for cure.
- If pre-operative imaging is normal, routine adrenalectomy is not indicated.
- Lymphadenectomy should be restricted to staging because extended lymphadenectomy does not improve survival.
- In patients who have RCCs with tumour thrombus and no metastatic spread, prognosis is improved after nephrectomy and complete thrombectomy.
- Embolisation of the primary tumour is indicated in patients with gross haematuria or local symptoms (e.g. pain), in patients unfit for surgical intervention, and before surgical resection of large skeletal metastases. No benefit is associated with tumour embolisation before routine radical nephrectomy.

Nephron sparing surgery (NSS):

- Absolute indications for partial nephrectomy are
    - anatomical or functional solitary kidney or
    - bilateral RCC.
- Relative indications are
    - a functioning opposite kidney affected by a condition that might impair renal function and
    - hereditary forms of RCC with a high risk of developing a tumour in the contralateral kidney.
- Elective indications also localised unilateral RCC with a healthy contralateral kidney, which is the recommended approach, when technically feasible, since recurrence-free and long-term survival rates are similar to those for radical nephrectomy.
- Even in selected patients with a tumour diameter of up to 7 cm, nephron-sparing surgery has achieved results equivalent to those of a radical approach.
- If the tumour is completely resected, the thickness of the surgical margin (> 1 mm) does not correlate with the likelihood of local recurrence.
- If RCCs of larger size are treated with nephron-sparing surgery, follow-up should be intensified, as there is an increased risk of intrarenal recurrences.
- These procedures should only be delivered under the care of members of the specialist urology team and this is not subject to change by the network's own guidelines (National Cancer Action Team- Manual of Cancer Services 2011).

Laparoscopic radical and partial nephrectomy:

- Laparoscopic radical and partial nephrectomy Laparoscopic radical nephrectomy has a lower morbidity compared with open surgery.
- It has become an established surgical procedure for RCC.
- Whether done retro- or transperitoneally, the laparoscopic approach must duplicate established, open surgical, oncological principles.
- Long-term outcome data indicate equivalent cancer-free survival rates versus open radical nephrectomy.
- Thus, laparoscopic radical nephrectomy is now considered the standard of care for patients with T1 and T2 RCCs, who are not treatable by nephron-sparing surgery.
- Laparoscopic radical nephrectomy should not be performed in patients with T1 tumours for whom partial resection is indicated. Laparoscopic and robot assisted nephron-sparing surgery has become available treatment options in experienced hands.
- Laparoscopic partial resection has a risk for longer intraoperative ischaemia time than open partial nephrectomy and therefore carries a higher risk for reduced long-term renal function.
- The oncological outcome seems comparable in available series.

- Robotic-assisted partial nephrectomy requires further evaluation and more mature data before any conclusive technical recommendations can be made.
- Conclusion: Radical nephrectomy, preferably laparoscopic, is recommended for patients with localised RCC, who are not suitable for nephron-sparing surgery. Nephron-sparing surgery is the standard of care despite the surgical approach.

Minimally invasive alternative treatment:

- Minimally invasive techniques, such as ablation with percutaneous radio-frequency, crytherapy, microwave, and high-intensity focused US (HIFU), are suggested alternatives to surgery.
- Microwave therapy should only be used within the context of research.
- Potential advantages of these techniques include reduced morbidity, outpatient therapy, and the ability to treat high-risk patients not fit for conventional surgery.
- These experimental treatments might be recommended for selected patients with small, incidentally found, renal cortical lesions, elderly patients, patients with a genetic predisposition to multiple tumours, patients with a solitary kidney, or patients with bilateral tumours.
- The oncological efficacy remains to be determined for both cryotherapy and RFA, which are the most often used minimally invasive techniques.
- Current data suggest that cryoablation, when performed laparoscopically, results in fewer re-treatments and improved local tumour control compared with RFA.
- Current evidence on the safety and efficacy of percutaneous radiofrequency ablation (RFA) for renal cancer in the short and medium term appears adequate to support the use of this procedure provided that normal arrangements are in place for clinical governance, consent and audit, and provided that patients are followed up in the long term.
- For both treatments, tumour recurrence rates are higher compared with nephron-sparing surgery.
- Further research is needed to determine the oncological success rate and complications associated with these procedures.
- NICE encourages collection and publication of data on the long-term outcomes of these procedures.

Adjuvant therapy:

- Adjuvant tumour vaccination may improve the duration of the progression-free survival (PFS), which is especially important in patients at high risk of metastases, e.g. T3 RCC. Cytokine therapy does not improve survival after nephrectomy.
- Although there is no current data supporting adjuvant therapy with targeting agents, three worldwide phase III randomised trials are ongoing.

- Outside controlled clinical trials, there is no indication for adjuvant therapy following surgery.

Surgical treatment for metastatic RCC (mRCC):

- Nephrectomy of the primary tumour is curative only if surgery can excise all tumour deposits.
- For most patients with mRCC, nephrectomy is palliative.
- In a meta-analysis of two randomised studies, comparing nephrectomy + immunotherapy versus immunotherapy alone, increased long term survival was found in patients who underwent prior nephrectomy.
- For targeting agents, there is no current knowledge whether cytoreductive surgery is advocated before or after successful medical therapy. The CARMENA and SURTIME trials comparing cytoreductive nephrectomy with neoadjuvent/adjuvant (respectively) targeted therapy versus control arms of nephrectomy alone are awaited.
- However, in the absence of available evidence data, cytoreductive nephrectomy is recommended when possible.
- Complete removal of metastases contributes to improved clinical prognosis.
- Metastasectomy should be carried out in patients with resectable disease and a good PS.
- It should also be considered in patients with residual and respectable metastatic lesions, who have previously responded to systemic therapy.

Radiotherapy for metastasis:
For selected patients with non-resectable brain or osseous lesions, radiotherapy can induce significant symptom relief.

Systemic chemotherapy for mRCC:
Chemotherapy as monotherapy should not be considered effective in patients with mRCC.

Immunotherapy for mRCC:

- Interferon-alpha monotherapy is no longer recommended as first-line therapy for mRCC.
- Interferon alpha monotherapy still has a role only in selected cases (good performance status, clear cell type, lung metastases only).
- Interleukin-2 has more side effects than INF-α.
- High-dose IL-2 is associated with durable complete responses in a limited number of patients.

- Interleukin-2 can be considered as monotherapy in selected patients with a good prognosis profile.
- A combination of bevacizumab and IFN-α is more effective than IFNα in treatment-naïve, low-risk and intermediate-risk tumours.
- Vaccination therapy with tumour antigen 5T4 showed no survival benefit over the first-line standard of care.

Recommendations:

Recommendations for immunotherapy	**GR**
Monotherapy with IFN-α or high-dose bolus IL-2 can only be recommended as a first-line treatment for mRCC in selected patients with clear cell histology and good prognostic factors.	A
Bevacizumab + IFN-α is recommended as first-line therapy in low-risk and intermediate-risk patients.	B
Cytokine combinations, with or without additional chemotherapy, do not improve the overall survival in comparison with monotherapy.	A

Drugs targeting VEGF or mammalian target of rapamycin (mTOR):

- Recent advances in molecular biology have led to the development of several novel agents for the treatment of mRCC.
- In sporadic clear cell RCC, HIF accumulation due to von Hippel-Lindau (VHL) inactivation results in overexpression of VEGF and PDGF, both of which promote neoangiogenesis and contributes to the development and progression of RCC.
- At present, several targeting drugs have been approved both in the USA and in Europe for the treatment of mRCC:
- Their general inability to produce durable CRs necessitates chronic treatment in most patients
- The benefits must therefore be weighed against the overall burden of treatment, including acute and chronic toxicity, time and cost.

Recommendations:

Recommendations	**GR**
Sunitinib is recommended as first-line therapy in favorable-risk and intermediate-risk patients.	A
Bevacizumab + IFN-α is recommended as first-line therapy in favourable-risk and intermediate-risk patients.	A
Sorafenib is recommended as a second-line treatment for mRCC after	A

Recommendations	**GR**
cytokine failure.	
Pazopanib is recommended as first-line or after cytokine failure in favourable-risk and intermediaterisk patients.	A
Temsirolimus is recommended as first-line treatment in poor-risk patients.	A
Everolimus is recommended as second-line treatment after failure of tyrosine kinase inhibitors.	A
Axitinib is recommended as second-line treatment after failure of cytokines or tyrosine kinase inhibitors.	A

EAU recommendations for first and second line systemic therapy in mRCC:

Treatment	**Risk or prior treatment**	**Recommended agent**
First-line	Low- or intermediate-risk mRCC	Sunitinib Bevacizumab + IFN-a Pazopanib
	High-risk mRCC	Temsirolimus
Second-line	Prior cytokine therapy	Sorafenib Pazopanib
	Prior VEGFR therapy Prior mTOR inhibitor therapy	Everolimus Clinical trials

Surveillance following surgery for RCC:

- The aim of surveillance is to detect either local recurrence or metastatic disease while the patient is still surgically curable.
- There is no evidence for whether early versus later diagnosis of recurrence improves survival.
- Depending on the availability of new effective treatments, more strict follow-up schedules may be required, particularly as there is a higher local recurrence rate after cryotherapy and RFA.
- At present there is no evidence-based standard for the follow-up of patients with RCC as well as the optimal duration of follow-up.
- It is therefore a need for a surveillance algorithm that monitors patients after treatment for RCC that recognises not only the patient’s risk profile but also treatment efficacy.

Algorithm for surveillance following treatment for RCC taking into account patient risk profile and treatment efficacy

Risk profile	Treatment	Surveillance						
		6 months	1 year	2 years	3 years	4 years	5 years	After 5 years
Low	RN/PN only	US	CT	US	CT	US	CT	Discharge
Inter-mediate	RN/PN/cryo/ RFA	CT	US	CT	US	CT	CT	CT alternate 2 years
High	RN/PN/cryo/ RFA	CT	CT	CT	CT	CT	CT	CT alternate years

Recommendations:

Recommendations	LE	GR
Surveillance after treatment for RCC should be based on a patient's risk factors and the type of treatment delivered.		C
For low-risk disease, CT/MRI can be used infrequently.	4	C
In the intermediate-risk group, intensified follow-up should be performed, including CT/MRI scans at regular intervals in accordance with a risk-stratified nomogram.	4	C
In high-risk patients, the follow-up examinations should include routine CT/MRI scans.	4	C
There is an increased risk of intrarenal recurrences in larger-size (> 7 cm) tumours treated with nephron-sparing surgery, or when there is a positive margin. Follow-up should be intensified in these patients		C

9.5 Testicular Cancer

Background:

- Testicular cancer represents between 1% and 1.5% of male neoplasms and 5% of urological tumours in general, with 3-10 new cases occurring per 100,000 males/per year.
- Data from the Surveillance Epidemiology and End Results (SEER) Program during the years 1973 to 1998 show a continuing increased risk among Caucasian men in the USA only for seminoma.
- Only 1-2% of cases are bilateral at diagnosis.
- There is a clear predominance (90-95%) of germ cell tumours
- Peak incidence is in the third decade of life for non-seminoma, and in the fourth decade for pure seminoma.
- Familial clustering has been observed, particularly among siblings
- Epidemiological risk factors for the development of testicular tumours are:
    - ➢ history of cryptorchidism or undescended testis (testicular dysgenesis syndrome)
    - ➢ Klinefelter's syndrome
    - ➢ familial history of testicular tumours among first-grade relatives (father/brothers)
    - ➢ the presence of a contralateral tumour or TIN
    - ➢ infertility.

PATHOLOGICAL CLASSIFICATION

The recommended pathological classification (modified from the 2004 version of the World Health Organization [WHO] guidance) is shown below:

- **Germ cell tumours**
    - ➢ Intratubular germ cell neoplasia, unclassified type (IGCNU)
    - ➢ Seminoma (including cases with syncytiotrophoblastic cells)
    - ➢ Spermatocytic seminoma (mention if there is sarcomatous component)
    - ➢ Embryonal carcinoma
    - ➢ Yolk sac tumour
    - ➢ Choriocarcinoma
    - ➢ Teratoma (mature, immature, with malignant component)
    - ➢ Tumours with more than one histological type (specify percentage of individual components)
- S**ex cord/gonadal stromal tumours**
    - ➢ Leydig cell tumour
    - ➢ Malignant Leydig cell tumour

  - Sertoli cell tumour - lipid-rich variant - sclerosing - large cell calcifying
  - Malignant Sertoli cell tumour
  - Granulosa cell tumour - adult type - juvenile type
  - Thecoma/fibroma group of tumours
  - Other sex cord/gonadal stromal tumours
    - incompletely differentiated
    - mixed
  - Tumours containing germ cell and sex cord/gonadal stromal (gonadoblastoma)
- **Miscellaneous non-specific stromal tumours**
  - Ovarian epithelial tumours
  - Tumours of the collecting ducts and rete testis
  - Tumours (benign and malignant) of non-specific stroma.

DIAGNOSIS:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

- **Clinical examination.**
- **Testicular imaging:**
  - US serves to confirm the presence of a testicular mass and to explore the contralateral testis.
  - Its sensitivity in detecting a testicular tumour is almost 100%, and it has an important role in determining whether a mass is intra- or extratesticular
  - Ultrasound of the testis has to be performed in young men without a palpable testicular mass who have retroperitoneal or visceral masses or elevated serum human chorionic gonadotrophin (hCG) or AFP or in men consulting for fertility problems
  - Ultrasound may be recommended in the follow-up of patients at risk, when other risk factors than microlithiasis are present (e.g. size < 12 ml or

  - atrophy, inhomogeneous parenchyma). Solely, the presence of microlithiasis is not an indication for a regular scrotal US
  - MRI of the scrotum offers a sensitivity of 100% and a specificity of 95-100%, but its high cost does not justify its use for diagnosis.
- **Serum tumour markers at diagnosis**
  - AFP (produced by yolk sac cells)
  - hCG (expression of trophoblasts)
  - LDH (lactate dehydrogenase).
- **Inguinal exploration and orchidectomy**
- **Organ-sparing surgery:** indicated in:
  - In synchronous bilateral testicular tumours
  - metachronous contralateral tumours
  - in a tumour in a solitary testis with normal pre-operative testosterone levels
  - organ preserving surgery can be performed when the tumour volume is less than 30% of the testicular volume and surgical rules are respected
  - the rate of associated TIN is high (at least up to 82%)
  - all patients must be treated with adjuvant radiotherapy (16-20 Gy) at some point.

STAGING

Serum tumour markers:

- The mean serum half-life of AFP and hCG is 5-7 days and 2-3 days, respectively.
- Tumour markers have to be re-evaluated after orchidectomy to determine half-life kinetics.
- Marker decline in patients with clinical stage I disease should be assessed until normalisation has occurred.
- Markers before start of chemotherapy are important to classify the patient according to the International Germ Cell Cancer Collaborative Group (IGCCCG) risk classification.
- The persistence of elevated serum tumour markers after orchidectomy might indicate the presence of metastatic disease (macro- or microscopically), while the normalisation of marker levels after orchidectomy does not rule out the presence of tumour metastases.
- During chemotherapy, the markers should decline; persistence has an adverse prognostic value

Radiological staging:

- Abdominopelvic CT offers a sensitivity of 70-80% in determining the state of the retroperitoneal nodes.
- Magnetic resonance imaging (MRI) produces similar results to CT in the detection of retroperitoneal nodal enlargement.
- MRI can be helpful when abdominopelvic CT or US are inconclusive, when CT is contraindicated because of allergy to contrast media, or when the physician or the patient are concerned about radiation dose.
- There is no evidence to support the use of the fluorodeoxyglucose (FDG)-PET in the staging of testis cancer.
- It is recommended in the follow-up of patients with seminoma with any residual mass at least 6 weeks after chemotherapy in order to decide on watchful waiting or active treatment.
- The use of FDGPET is not recommended in the re-staging of patients with non-seminomatous tumours after chemotherapy.

Recommended tests for staging at diagnosis

Test	**Recommendation**	**GR**
Serum tumour markers	AFP hCG LDH	A
Abdominopelvic CT	All patients	A
Chest CT	All patients	A
Testis US (bilateral)	All patients	A
Bone scan	In case of symptoms	
Brain scan (CT/MRI)	In case of symptoms and patients with metastatic disease with multiple lung metastases and high beta-hCG values	

Further investigations

Fertility investigations: Total testosterone LH FSH Semen analysis	B
Sperm banking should be offered	A

TNM classification for testicular cancer (UICC, 2009):

pT Primary tumour

pTX	Primary tumour cannot be assessed
pT0	No evidence of primary tumour (e.g. histological scar in testis)
pTis	Intratubular germ cell neoplasia (testicular intraepithelial neoplasia)
pT1	Tumour limited to testis and epididymis without vascular/lymphatic invasion: tumour may invade tunica albuginea but not tunica vaginalis
pT2	Tumour limited to testis and epididymis with vascular/lymphatic invasion, or tumour extending through tunica albuginea with involvement of tunica vaginalis
pT3	Tumour invades spermatic cord with or without vascular/lymphatic invasion
pT4	Tumour invades scrotum with or without vascular/lymphatic invasion

N Regional lymph nodes clinical

NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis with a lymph node mass 2 cm or less in greatest dimension or multiple lymph nodes, none more than 2 cm in greatest dimension
N2	Metastasis with a lymph node mass more than 2 cm but not more than 5 cm in greatest dimension, or multiple lymph nodes, any one mass more than 2 cm but not more than 5 cm in greatest dimension
N3	Metastasis with a lymph node mass more than 5 cm in greatest dimension

pN Pathological

pNX	Regional lymph nodes cannot be assessed
pN0	No regional lymph node metastasis
pN1	Metastasis with a lymph node mass 2 cm or less in greatest dimension and 5 or fewer positive nodes, none more than 2 cm in greatest dimension
pN2	Metastasis with a lymph node mass more than 2 cm but not more than 5 cm in greatest dimension; or more than 5 nodes positive, none more than 5 cm; or evidence or extranodal extension of tumour
pN3	Metastasis with a lymph node mass more than 5 cm in greatest dimension

M Distant metastasis

MX	Distant metastasis cannot be assessed
M0	No distant metastasis
M1	Distant metastasis
M1a	Non-regional lymph node(s) or lung
M1b	Other sites

S Serum tumour markers

Sx	Serum marker studies not available or not performed				
S0	Serum marker study levels within normal limits				
	LDH (U/l)		hCG (mIU/mL)		AFP (ng/mL)
S1	< 1.5 x N	and	< 5,000	and	< 1,000
S2	1.5-10 x N	or	5,000-50,000	or	1,000-10,000
S3	> 10 x N	or	> 50,000	or	> 10,000

Prognostic-based staging system for metastatic germ cell cancer (International Germ Cell Cancer Collaborative Group (IGCCCG):

Good-prognosis group Non-seminoma (56% of cases) 5-year PFS 89% 5-year survival 92%	All of the following criteria: • Testis/retroperitoneal primary • No non-pulmonary visceral metastases • AFP < 1,000 ng/mL • hCG < 5,000 IU/L (1,000 ng/mL) • LDH < 1.5 x ULN
Seminoma (90% of cases) 5-year PFS 82% 5-year survival 86%	All of the following criteria: • Any primary site • No non-pulmonary visceral metastases • Normal AFP • Any hCG • Any LDH
Intermediate prognosis group Non-seminoma (28% of cases) 5-year PFS 67% 5-year survival 72%	• Testis/retroperitoneal primary • AFP 1,000 - 10,000 ng/mL or • No non-pulmonary visceral metastases • hCG 5,000 - 50,000 IU/L or • LDH 1.5 - 10 x ULN
Seminoma (10% of cases) 5 years PFS 75% 5-year survival 80%	All of the following criteria: • Any primary site • Non-pulmonary visceral metastases • Normal AFP • Any hCG • Any LDH
Poor prognosis group Non-seminoma (16% of cases) 5-year PFS 41% 5-year survival 48%	Any of the following criteria: • Mediastinal primary • Non-pulmonary visceral metastases • AFP > 10,000 ng/mL or • hCG > 50,000 IU/L (10,000 ng/mL) or • LDH > 10 x ULN
Seminoma	No patients classified as poor prognosis

Prognostic factors for occult metastatic disease in testicular cancer

	For seminoma	For non-seminoma
Pathological (for stage I)		
Histopathological type invasion of the primary tumour	• Tumour size (> 4 cm)	• vascular/lymphatic
	• Invasion of the rete testis	• Proliferation rate > 70% • Percentage of embryonal carcinoma > 50%
Clinical (for metastatic disease)		
• Primary location • Elevation of tumour marker levels • Presence of non-pulmonary visceral metastasis		

TREATMENT: STAGE I GERM CELL TUMOURS

Supranetwork Testicular Team

- The minimum catchment population for the specialist treatment of testicular cancer is two million.
- Supranetwork teams for testicular cancer deliver supranetwork care for their referring catchment.
- The minimum catchment population of two million means that currently no cancer network in England should host more than one such team on the basis of their own network population and some networks will not be able to host a team, needing to refer such patients to a team in a neighbouring network.
- In order that supranetwork teams for testicular cancer experience the full range of practice for the disease, they are required to deliver all of the care including local care to at least part of their network, usually the local catchment of their host locality. For testicular teams to add their full potential value to patient care, some surgical procedures and their immediate post-op care are required to be restricted to certain named hospitals.

Stage I seminoma

- After modern staging procedures, about 15-20% of stage I seminoma patients have subclinical metastatic disease, usually in the retroperitoneum, and will relapse after orchidectomy alone.

Surveillance

- The actuarial relapse rate is in the order of 15-20% at 5 years, and most of the relapses are first detected in infra-diaphragmatic lymph nodes.
- In patients with low risk the recurrence under surveillance is as low as 6%.
- Chemotherapy, according to the IGCCCG classification, is a possible treatment for seminoma relapse under surveillance.
- The overall cancer-specific survival rate reported under surveillance performed by experienced centres is 97-100% for seminoma stage I.
- The main drawback of surveillance is the need for more intensive follow-up, especially with repeated imaging examinations of the retroperitoneal lymph nodes, for at least 5 years after orchidectomy.
- There is a small but clinically significant risk of relapse more than 5 years after orchidectomy for stage I seminoma, which supports the need for long term surveillance.

Adjuvant chemotherapy

- Compared with adjuvant radiotherapy, studies did not show a significant difference with regard to recurrence rate, time to recurrence and survival after a median follow-up of 4 years.
- Adjuvant carboplatin therapy using a dosage of one course AUC 7 is an alternative to radiotherapy or surveillance in stage I seminoma.

Adjuvant radiotherapy

- Seminoma cells are extremely radiosensitive.
- Adjuvant radiotherapy to a para-aortic (PA) field or to a hockeystick field (para-aortic and ipsilateral iliac nodes), with moderate doses (total 20-24 Gy), will reduce the relapse rate to 1-3%.
- After modern radiotherapy, nearly all relapses will first occur outside the irradiated field (supradiaphragmatic lymph nodes or in the lungs).
- Adjuvant irradiation of supradiaphragmatic lymph nodes is not indicated in seminoma stage I. With regard to the irradiation dose, the MRC recently finished a large randomised trial of 20 Gy versus 30 Gy PA radiation in stage I seminoma that showed equivalence for both doses in terms of recurrence rates.
- The rate of severe radiation-induced long-term toxicity is < 2%. Moderate chronic gastrointestinal (GI) side-effects are seen in ~5% of patients, and moderate acute GI toxicity in ~60%.

Retroperitoneal lymph node dissection (RPLND)

- Post RPLND incidence of retroperitoneal relapses is high (9.5%).
- This policy should not be recommended in stage I seminoma.

Risk-adapted treatment

- Using tumour size > 4 cm and rete testis invasion, patients with seminoma stage I may be subdivided into a low-and high-risk group of occult metastatic disease.
- Patients with and without both risk factors have a risk of occult disease of 32% and 12%, respectively.
- These risk factors were introduced by an analysis of retrospective trials (29). A prospective trial based on these risk factors (no risk factors: surveillance; both risk factors: two courses of carboplatin AUC 7) showed the feasibility of a risk-adapted approach.
- Early data with limited follow-up indicate that patients without either risk factor have a 6.0% risk of relapse at 5 years.
- Patients in the high risk group treated with carboplatin experienced a 1.4% relapse rate at mean follow-up of 34 months.
- However, given the fact that cure is achieved in ~100% in patients with stage I seminoma whatever therapy used (adjuvant radiotherapy, adjuvant chemotherapy, or surveillance) and that the relapse rate in large surveillance series not using risk factors is ~15-20%, indicates a risk of over-treatment. Therefore, the therapeutic decision should be shared with an informed patient.

Guidelines for the treatment of seminoma stage I

Guidelines	GR
Surveillance is the recommended management option (if facilities available and patient compliant).	A
Carboplatin-based chemotherapy (one course at AUC 7) is recommended.	B
Adjuvant treatment is not recommended for patients at very low risk.	A
Radiotherapy is not recommended as adjuvant treatment.	A

NSGCT stage I

- Up to 30% of NSGCT patients with clinical stage I (CS1) disease have subclinical metastases and will relapse if surveillance alone is applied after orchidectomy

Surveillance

- The largest reports of the surveillance strategy indicate a cumulative relapse rate of ~30%, with 80% of relapses occurring during the first 12 months of follow-up, 12% during the second year and 6% during the third year, decreasing to 1% during the fourth and fifth years, and occasionally even later.

- About 35% of relapsing patients have normal levels of serum tumour markers at relapse.
- About 60% of relapses are in the retroperitoneum. Despite very close follow-up, 11% of relapsing patients presented with large-volume recurrent disease.
- Based on the overall cancer-specific survival data, surveillance within an experienced surveillance programme may be offered to patients with non-risk stratified clinical stage I non-seminoma as long as they are compliant and informed about the expected recurrence rate as well as the salvage treatment.

Primary chemotherapy

- Two courses of chemotherapy with cisplatin, etoposide and bleomycin (PEB) as primary treatment for high-risk patients (having ~50% risk of relapse) are recommended , with a relapse rate of only 2.7% was reported, with very little long-term toxicity.
- Adjuvant chemotherapy do not seem to adversely affect fertility or sexual activity.
- Long term (> 20 years) side effects of adjuvant chemotherapy in this setting are currently unknown.
- It is important to be aware of slow-growing retroperitoneal teratomas after primary chemotherapy.

Risk-adapted treatment

- It is based on the risk factor vascular invasion.
- Risk-adapted treatment is an equally effective alternative treatment of choice in CS1 NSGCT.
- If applied, patients with vascular invasion are recommended to undergo adjuvant chemotherapy with two cycles of PEB, and patients without vascular invasion are recommended to undergo surveillance.
- The Swedish-Norwegian Testicular Cancer Project (SWENOTECA) recently showed that in a large population-based study with a risk-adapted approach within a management programme and a median follow-up of 4.7 years, the relapse rate was 3.2% for patients with vascular invasion treated with only one adjuvant PEB.
- Taken together, ~300 patients with high-risk CS I have been adjuvantly treated with 1 x PEB with a follow-up of > 5 yrs. As long as 1 x PEB has not been proven superior or at least equivalent to 2 courses PEB, this adjuvant treatment cannot be recommended outside of a clinical trial or a prospective registry.

Retroperitoneal lymph node dissection

- If performed, ~30% of patients are found to have retroperitoneal lymph node metastases, which corresponds to pathological stage II (PS2).
- 10% of the PS1 patients relapse at distant sites.
- The main predictor of relapse in CS1 NSGCT is histopathological evidence of vascular invasion by tumour cells in, or near, the primary tumour in the testis.
- For CS1, patients without vascular invasion have only a 15-20% risk of relapse on surveillance, compared with a 50% relapse rate in patients with vascular invasion.
- The risk of relapse for PS1 patients is < 10% for those without vascular invasion and ~30% for those with vascular invasion.
- If two (or more) courses of cisplatin-based chemotherapy are given adjuvant to RPLND in PS2 cases, the relapse rate is reduced to < 2%, including teratoma relapse).
- The risk of retroperitoneal relapse after a properly performed nerve-sparing RPLND is very low (< 2%), as is the risk of ejaculatory disturbance or other significant side-effects.
- If there is a rare indication to perform a staging RPLND, a laparoscopic or robot-assisted RPLND is feasible in expert hands. This minimal-invasive approach cannot be recommended as a standard approach outside of a specialised laparoscopic centre.
- In a randomised comparison of RPLND with one course of PEB chemotherapy, adjuvant chemotherapy significantly increased the 2-year recurrence-free survival to 99.41% (confidence interval [CI] 95.87%, 99.92%) as opposed to surgery, which had a 2-year recurrence-free survival of 92.37% (CI 87.21%, 95.50%).
- Therefore, one course of adjuvant PEB is superior to RPLND with regard to recurrence rates in patients unstratified for risk factors . In the SWENOTECA data mentioned in section 7.3.3 it was also found that one adjuvant PEB reduced the number of recurrences to 3.2% in the high-risk and to 1.4% in the low-risk patients.

CS1S with (persistently) elevated serum tumour markers

- If the marker level increases after orchidectomy, the patient has residual disease. If RPLND is erformed, up to 87% of these patients have pathologically documented nodes in the retroperitoneum (165). An
- US examination of the contralateral testicle must be performed, if this was not done initially.
- The treatment of true CS1S patients is still controversial. They may be treated with three courses of primary PEB chemotherapy and with follow-up as for CS1B patients after primary chemotherapy, or by RPLND. The presence of vascular invasion may strengthen the indication for primary chemotherapy as most CS1S with vascular invasion will need chemotherapy sooner or later anyway.

Guidelines for the treatment of NSGCT stage I

NSGCT stage 1	**GR**
CS1 risk-adapted treatments based on vascular invasion or surveillance without using risk factors are recommended treatment options.	A
Risk-adapted treatments for CS1 based on vascular invasion	
CS1A (pT1, no vascular invasion): low risk	
If the patient is willing and able to comply with a surveillance policy, long-term (at least 5 years) close follow-up should be recommended.	A
In low-risk patients not willing (or suitable) to undergo surveillance, adjuvant chemotherapy or nerve-sparing RPLND are treatment options. If RPLND reveals PN+ (nodal involvement) disease, chemotherapy with two courses of PEB should be considered.	A
CS1B (pT2-pT4): high risk	
Primary chemotherapy with two courses of PEB should be recommended (one course of PEB within a clinical trial or registry).	A
Surveillance or nerve-sparing RPLND in high-risk patients remains an option for those not willing to undergo adjuvant chemotherapy. If pathological stage II is revealed at RPLND, further chemotherapy should be considered.	A

TREATMENT: METASTATIC GERM CELL TUMOURS

The treatment of metastatic germ cell tumours depends on:
- the histology of the primary tumour;
- prognostic groups as defined by the IGCCCG.

Low-volume metastatic disease (stage IIA/B)

Seminoma:

- The standard treatment for stage IIA/B seminoma has been radiotherapy.
- The radiation dose delivered in stage IIA and IIB is approximately 30 Gy and 36 Gy, respectively.
- The standard radiation field compared with stage I will be extended from the PA region to the ipsilateral iliac field (the hockey-stick field).
- Overall survival is almost 100%. Conversely, dose reduction to 27 Gy has been associated with 11% of relapses.

Non-seminoma

- Initial chemotherapy is recommended in all advanced cases of NSGCT (except for stage II NSGCT disease without elevated tumour markers, which alternatively can be managed by primary RPLND or surveillance to clarify stage).
- If surveillance is chosen, one follow-up after 6 weeks is indicated to document whether the lesion is growing, remaining stable or shrinking.
    - ➢ A shrinking lesion is likely to be of non-malignant origin and should be observed further.
    - ➢ A stable or growing lesion indicates either teratoma or an undifferentiated malignant tumour.
    - ➢ If the lesion is growing without a corresponding increase in the tumour markers AFP or beta-hCG, RPLND should be performed by an experienced surgeon because of suspected teratoma.
    - ➢ Patients with a growing lesion and a concomitant increase in the tumour markers AFP or beta-hCG should not undergo surgery; they require chemotherapy with PEB according to the treatment algorithm for patients with metastatic disease and IGCCCG recommendations.
- An alternative to the surveillance strategy in marker-negative II A/B non-seminoma with suspicion of an undifferentiated malignant tumour is a (CT-guided) biopsy, if technically possible.
- There is insufficient published data on PET scans in this situation.
- Patients not willing to undergo primary chemotherapy have the option of primary nerve-sparing RPLND with adjuvant chemotherapy (two cycles of PEB) in case of metastatic disease.
- Primary chemotherapy and primary RPLND are comparable options in terms of outcome but side-effects and toxicity are different, allowing for involvement of the patient in selecting the treatment of choice. The cure rate with either approach will be close to 98%.

Advanced metastatic disease

- The primary treatment of choice for advanced disease is three or four cycles of PEB combination chemotherapy, depending on the IGCCCG risk classification. This regimen has proven superiority to cisplatin, vinblastine and bleomycin (PVB) in patients with advanced disease.
- Good prognosis group (IGCCCG Classification):
    - ➢ standard treatment consists of three cycles of PEB
    - ➢ in very selected cases where bleomycin is contraindicated, four cycles of EP.
- Intermediate prognosis group (5-year survival rate of ~80%):
    - ➢ four cycles of PEB as standard treatment.
- Poor prognosis group (5-year progression-free survival is 45-50%):
    - ➢ standard treatment consists of four cycles of PEB, or etoposide and ifosfamide (PEI) with similar effect but more toxicity.

- ➢ poor-prognosis patients should be transferred to a reference centre because a better outcome was reported for intermediate and poor prognosis patients who had been treated within a clinical trial in a high volume centre.
- ➢ There are no general recommendations for treatment modifications for patients with a poor general condition (Karnofsky < 50%) or extended liver infiltration (> 50%).
- ➢ Patients with extended pulmonary infiltration are at risk for acute respiratory distress syndrome: adapting the doses of the PEB regimen in the first cycle of chemotherapy (only 3 days of EP without bleomycin) was suggested to reduce the risk of early death in this setting.

Residual tumour resection

- A residual mass of seminoma should not be primarily resected, irrespective of the size, but controlled by imaging investigations and tumour markers.
- FDG-PET has a high negative predictive value in patients with residual masses after treatment of seminoma but false positive results can be a problem and scans should not be performed < 2 months after chemotherapy.
- In patients with residuals of > 3 cm, FDG-PET should be performed in order to gain more information on the viability of these residuals.
- In patients with residuals of < 3 cm, the use of FDG-PET is optional.
- On progression, salvage therapy is indicated (chemotherapy, salvage surgery, radiotherapy) .
- In patients with concurrent hCG elevation, progressing seminoma after first-line chemotherapy should be treated by salvage chemotherapy (or radiotherapy if only small volume recurrence is present).
- Progressing patients without hCG progression should undergo histological verification (e. g. by biopsy or open surgery) before salvage chemotherapy is given. In the case of non-seminoma and complete remission after chemotherapy (no tumour visible), residual tumour resection is not indicated.
- The long-term relapse rate in this patient group is 6-9%, however, one third of the late relapsing patients will not survive.
- In the case of any visible residual mass and marker normalisation, surgical resection is indicated. In patients with lesions < 1 cm, there still is an increased risk of residual cancer or teratoma although the role of surgery in this setting is debated.
- In persistent larger volume retroperitoneal disease, all areas of primary metastatic sites must be completely resected within 4-6 weeks of completion of chemotherapy.
- If technically feasible, a nerve-sparing procedure should be performed.

- Overall, following PEB induction chemotherapy, only 10% of residual masses contain viable cancer, 50% contain mature teratoma, and 40% contain necrotic-fibrotic tissue.
- As yet, no imaging investigations, including PET or a prognosis model, are able to predict histological differentiation of the non-seminomatous residual tumour. Thus, residual tumour resection is mandatory in all patients with residual disease > 1 cm.
- The extent of surgery should be based on the risk of relapse of an individual patient and quality of life issues. If possible, all the masses should be resected, because a complete resection, in the setting of viable malignant cells, is more critical than recourse to post-operative chemotherapy.
- There is growing evidence that “template” resections in selected patients yield equivalent long-term results compared to bilateral systematic resections in all patients.
- Mere resection of the residual tumour (so called “lumpectomy”) should not be performed.
- The histology may diverge in different organ sites. Resection of contralateral pulmonary lesions is not mandatory in case pathologic examination of the lesions from the first lung shows complete necrosis.

Consolidation chemotherapy after secondary surgery

- After resection of necrosis or mature/immature teratoma, no further treatment is required.
- In the case of incomplete resection of other germ cell tumour pathologies, two adjuvant cycles of conventionally dosed cisplatin-based chemotherapy may be given in certain subgroups (e.g. ‘poor prognosis’ patients).
- After complete resection of ‘vital’ tumour < 10% of the total volume, especially in patients with an initially good prognosis group according to IGCCCG, the relapse rate is very low and adjuvant chemotherapy is not beneficial for preventing further relapse.
- The prognosis will definitely deteriorate if vital malignant neoplasm is found in resection specimens after second- and third-line chemotherapy. In this latter situation, post-operative chemotherapy is not indicated and is unable to improve the prognosis.

Systemic salvage treatment for relapse or refractory disease

- Cisplatin-based combination salvage chemotherapy will result in long-term remissions for about 50% of the patients who relapse after first-line chemotherapy (255). The.

- Regimens of choice are four cycles of PEI/VIP (etoposide, ifosfamide, cisplatin), four cycles of TIP (paclitaxel, ifosfamide, cisplatin) or four cycles of VeIP (vinblastine, ifosfamide, cisplatin)
- Due to the lack of evidence, it is therefore of the utmost importance that these rare patients are treated within clinical trials and at experienced centres.

Treatment of brain metastases

- Brain metastases occur in the frame of a systemic relapse and rarely as an isolated relapse.
- The longterm survival of patients presenting with brain metastases at initial diagnosis is poor (30-40%)
- 5-year survival-rate for brain metastasis as a recurrent disease is even poorer (2-5%)
- Chemotherapy is the initial treatment in this case, and some data support the use of consolidation radiotherapy, even in the case of a total response after chemotherapy.
- Surgery can be considered in the case of a persistent solitary metastasis, depending on the systemic state, the histology of the primary tumour and the location of the metastasis.

FOLLOW-UP AFTER CURATIVE THERAPY

Recommended follow-up schedule in a surveillance policy: stage I non-seminoma

Procedure	**Year**	**Year**	**Year**	**Year**
	1	**2**	**3-5**	**6-10**
Physical examination	4 times	4 times	Once/year	Once/year
Tumour markers	4 times	4 times	Once/year	Once/year
Plain radiography chest	Twice	Twice		
Abdominopelvic CT	Twice (at 3 and 12 months)			

Recommended follow-up schedule after retroperitoneal lymphadenectomy or adjuvant chemotherapy: stage I non-seminoma

Procedure	**Year**	**Year**	**Year**	**Year**

	1	**2**	**3-5**	**6-10**
Physical examination	4 times	4 times	Once/year	Once/year
Tumour markers	4 times	4 times	Once/year	Once/year
Plain radiography chest	Twice	Twice		
Abdominopelvic CT	Once	Once		

Recommended follow-up schedule for post-orchidectomy surveillance, radiotherapy or chemotherapy: stage I seminoma

Procedure	**Year**	**Year**	**Year**	**Year**
	1	**2**	**3-5**	**6-10**
Physical examination	4 times	4 times	Once/year	Once/year
Tumour markers	4 times	4 times	Once/year	Once/year
Plain radiography chest	Twice	Twice		
Abdominopelvic CT	Once	Once		

Recommended minimum follow-up schedule in advanced NSGCT and seminoma

Procedure	**Year**	**Year**	**Year**	**Year**
	1	**2**	**3-5**	**Thereafter**
Physical examination	4 times	4 times	Twice/year	Once/year
Tumour markers	4 times	4 times	Twice/year	Once/year
Plain radiography chest	Twice	Twice	Twice/year	Once/year
Abdominopelvic CT	Twice	Twice	As indicated	As indicated
Chest CT	As indicated	As indicated	As indicated	As indicated
Brain CT	As indicated	As indicated	As indicated	As indicated

9.6 Upper Urinary Tract Urothelial Cell Carcinomas

Epidemiology:

- Upper urinary tract urothelial cell carcinomas (UUT-UCCs) are uncommon and account for only 5-10% of urothelial carcinomas
- The estimated annual incidence of UUT-UCCs in Western countries is about one or two new cases per 100,000 inhabitants.
- Pyelocaliceal tumours are about twice as common as ureteral tumours.
- In 8-13% of cases, concurrent bladder cancer is present.
- Recurrence of disease in the bladder occurs in 30-51% of UUT-UCC patients
- Recurrences in the contralateral upper tract are observed in 2-6%.
- 60% of UUT-UCCs are invasive at diagnosis.
- Upper urinary tract urothelial cell carcinomas have a peak incidence in people in their 70s and 80s, and UUT-UCC is three times more prevalent in men than in women.
- There are familial/hereditary cases of UUT-UCCs linked to hereditary nonpolyposis colorectal carcinoma (HNPCC)

Risk factors:

- Tobacco and occupational exposure remain the principal exogenous risk factors for developing these tumours. Exposure to tobacco increases the relative risk of developing a UUT-UCC from 2.5 to 7
- UUT-UCC “amino tumours” are related to occupational exposure to certain aromatic amines. These aromatic hydrocarbons are used in many industries (e.g., dyes, textiles, rubber, chemicals, petrochemicals, and coal). They are responsible for the carcinogenicity of certain chemicals, including benzidine and β-naphthalene. The estimated risk (odds ratio) of developing UCC after exposure to aromatic amines is 8.3.
- Upper urinary tract tumours resulting from phenacetin consumption almost disappeared after the product was banned in the 1970s.
- Although the incidence of Balkan endemic nephropathy is also on the decline, roles have been proposed for aristolochic acid and the consumption of Chinese herbs in the physiopathology and induction, respectively, of this nephropathy.
- One polymorphism specific to UUT-UCC has been reported so far. A variant allele, SULT1A1*2, which reduces sulfotransferase activity, enhances the risk of developing UUT-UCC.
- Epidermoid carcinoma of the UUT is associated with chronic inflammatory and infectious disease arising from stones in the UUT.

TNM classification of UUT-UCC (2009)

T - Primary Tumour	
Tx	Primary tumour cannot be assessed

T0 No evidence of primary tumour Ta Non-invasive papillary carcinoma Tis Carcinoma in situ T1 Tumour invades subepithelial connective tissue T2 Tumour invades muscle T3 (Renal pelvis) Tumour invades beyond muscularis into peripelvic fat or renal parenchyma (Ureter) Tumour invades beyond muscularis into periureteric fat T4 Tumour invades adjacent organs or through the kidney into perinephric fat
N - Regional Lymph Nodes
Nx Regional lymph nodes cannot be assessed N0 No regional lymph-node metastasis N1 Metastasis in a single lymph node 2 cm or less in the greatest dimension N2 Metastasis in a single lymph node more than 2 cm but not more than 5 cm in the greatest dimension or multiple lymph nodes, none more than 5 cm in greatest dimension N3 Metastasis in a lymph node more than 5 cm in greatest dimension
M - Distant Metastasis M0 No distant metastasis M1 Distant metastasis

World Health Organization grading for bladder cancer

1973 WHO grading
Urothelial papilloma
Grade 1: well differentiated
Grade 2: moderately differentiated
Grade 3: poorly differentiated

Diagnosis:

The following guidelines for urgent referral (within two weeks) have been published by the Department of Health:

- Macroscopic haematuria in adults.
- Microscopic haematuria in adults over 50 years.
- Swellings in the body of the testis.
- Palpable renal masses.
- Solid renal masses found on imaging.
- Elevated age-specific prostate specific antigen (PSA) in men with a 10 year life expectancy.
- A high PSA (>20ng/ml) in men with a clinically malignant prostate or bone pain.
- Any suspected penile cancer.

Imaging:

CT Urogram (CTU)

- CTU is the gold standard for exploration of the upper urinary tract and has replaced intravenous excretory urography.
- It must be conducted under optimal conditions, particularly with acquisition of an excretory phase.
- The detection rate of UUT-UCC is satisfactory for this type of imaging: 96% sensitivity and 99% specificity for polypoid lesions between 5 and 10 mm.
- Sensitivity drops to 89% for polypoid lesions < 5 mm and 40% for polypoid lesions < 3 mm.

Magnetic resonance imaging (MRI):

- MRI urography is indicated in patients who cannot be subjected to a CTU.
- The detection rate of MRI is 75% after contrast injection for tumours < 2 cm.
- MRI urography with contrast injection, however, remains contraindicated in selected patients with severe renal impairment (< 30 ml/min creatinine clearance) due to the risk of nephrogenic systemic fibrosis.
- Magnetic resonance urography without contrast is less helpful compared with CTU in diagnosing UUT-UCCs.

Cystoscopy and urinary cytology

- Positive urine cytology is highly suggestive of UUT-UCC when bladder cystoscopy is normal and if CIS of the bladder or prostatic urethra has been excluded.
- Cytology is less sensitive for UUT-UCC than for bladder tumours, even for high-grade lesions, and it should ideally be performed in situ (i.e. in the renal cavities).
- A positive cytology may be valuable in staging because it has been associated with muscle-invasive and nonorgan-confined disease.

Diagnostic ureteroscopy

- Ureteroscopy is a better approach to diagnose UUT-UCCs.
- Flexible ureteroscopy is especially useful when there is diagnostic uncertainty, when conservative treatment is being considered, or in patients with a solitary kidney.
- The possible advantages of ureteroscopy should be discussed in the preoperative assessment of any UUT-UCC patient. Combining ureteroscopic biopsy grade, ipsilateral hydronephrosis, and urinary cytology may help decision making on radical nephroureterectomy (RNU) versus endoscopic treatment.

Guidelines for the diagnosis of UUT-UCC

Recommendations	GR
Urinary cytology	A
Cystoscopy to rule out a concomitant bladder tumour	A
CTU	A

Prognostic factors:

- Upper urinary tract urothelial cell carcinomas that invade the muscle wall usually have a very poor prognosis.
- The 5-yr specific survival is < 50% for pT2/pT3 and < 10% for pT4.
- Tumour stage and grade: the primary recognised prognostic factors.
- Age: poor prognosis with advanced age at diagnosis.
- Gender: no relation.
- Tumour location: no relation.
- Lymphovascular invasion: is present in approximately 20% of UUT-UCCs and an independent predictor of survival.
- Extensive tumour necrosis: is an independent predictor of clinical outcomes in patients who undergo RNU.
- The tumour architecture (e.g., papillary vs. sessile) of UUT-UCCs appears to be associated with prognosis after RNU. A sessile growth pattern is associated with worse outcomes (LE: 3) (8,63,69).
- The presence of concomitant CIS in patients with organ-confined UUT-UCC is associated with a higher risk of recurrent disease and cancer-specific .

Treatment

Localised disease:

- Radical nephroureterectomy (RNU)with excision of the bladder cuff is the gold standard treatment for UUT-UCCs, regardless of the location of the tumour in the upper urinary tract
- The RNU procedure must comply with oncologic principles, which consist of preventing tumour seeding by avoiding entry into the urinary tract during tumour resection.
- Resection of the distal ureter and its orifice is performed because it is a part of the urinary tract with considerable risk of recurrence.
- After removal of the proximal part, it is almost impossible to image or approach it by endoscopy during follow-up.
- Plucking/endoscopic resection of the distal ureter (apart from ureteral stripping) are non-inferior to excision of the bladder cuff.

- A delay > 45 d between diagnosis and resection of the tumour constitutes a risk for disease progression.
- Lymph node dissection associated with RNU is of therapeutic interest and allows for optimal staging of the disease.
- Lymphadenectomy in pN+ allows for reduction of the tumour mass to guide patients towards adjuvant treatments.
- Anatomic sites of lymphadenectomy have not yet been clearly defined.
- The number of lymph nodes to be removed depends on the tumour location.
- Lymphadenectomy appears to be unnecessary in cases of TaT1 UUT-UCCs.
- The safety of laparoscopic RNU has not yet achieved final proof. In early experience, there were reports of retroperitoneal metastatic dissemination and dissemination along the trocar pathway when large tumours were manipulated in a pneumoperitoneal environment.
- Recent data, however, show a tendency towards equivalent oncologic results between laparoscopic RNU and open surgery.
- In addition, the laparoscopic approach appears to be superior to open surgery only with regard to functional outcomes.
- When considering laparoscopic RNU the following precautions must be considered:
    - Entering the urinary tract should be avoided.
    - Direct contact of the instruments with the tumour should be avoided.
    - Laparoscopic RNU must take place in a closed system.
    - Morcellation of the tumour should be avoided, and an endobag is necessary to extract the tumour.
    - The kidney and ureter must be removed en bloc with the bladder cuff.
    - Invasive, large (T3/T4 and/or N+/M+), or multifocal tumours are contraindications for laparoscopic RNU, until proven otherwise.

Guidelines for radical management of UUT-UCC: radical nephroureterectomy

Indications for RNU for UUT-UCC	GR
Suspicion of infiltrating UUT-UCC on imaging	B
High-grade tumour (urinary cytology)	B
Multifocality (with two functional kidneys)	B
Techniques for RNU in UUT-UCC Open and laparoscopic access are equivalent in terms of efficacy	B
Bladder cuff removal is imperative	A
Several techniques for bladder cuff excision are acceptable except stripping	C
Lymphadenectomy is recommended in case of invasive UUT-UCC	C

Conservative surgery

- Conservative surgery for low-risk UUT-UCCs allows for preservation of the upper urinary renal unit while sparing the patient the morbidity associated with open radical surgery
- Conservative management of UUT-UCCs can be considered in imperative cases (renal insufficiency, solitary functional kidney) or in elective cases (i.e. when the contralateral kidney is functional) for low-grade, low-stage tumours.
- The choice of technique depends on technical constraints, the anatomic location of the tumour, and the experience of the surgeon.
    - ➢ Ureteroscopy: Endoscopic ablation can be considered in highly selected cases (96,97,98) and in these situations:
        - ▪ A flexible rather than a rigid ureteroscope, laser generator, and pliers (pluck) for biopsies are available.
        - ▪ The patient is informed of the need for closer, more stringent surveillance.
        - ▪ A complete resection is advocated.
    - ➢ Segmental resection:
        - ▪ It provides adequate pathologic specimens for definitive staging and grade analysis while also preserving the ipsilateral kidney.
        - ▪ Segmental resection is possible for the treatment of low- and high-risk tumours of the distal ureter .
        - ▪ It is necessary, however, to ensure that the area of tissue around the tumour is not invaded.
        - ▪ Segmental resection of the iliac and lumbar ureter is associated with a failure rate greater than that for the distal pelvic ureter.
        - ▪ Open resection of tumours of the renal pelvis or calices has almost disappeared.
        - ▪ Resection of pyelocaliceal tumours is technically difficult, and the recurrence rate is higher than for tumours of the ureter.
    - ➢ Percutaneous access:
        - ▪ It is considered for low-grade or non-invasive UUT-UCCs in the renal cavities.
        - ▪ This treatment option may be offered to patients with low-grade tumours in the lower caliceal system that are inaccessible or difficult to manage by ureteroscopy.
        - ▪ A theoretical risk of seeding exists in the puncture tract and in perforations that may occur during the procedure.
        - ▪ This approach, however, is being progressively abandoned due to enhanced materials and advances in distal-tip deflection of recent ureteroscopes.
    - ➢ Adjuvant topical agents:
        - ▪ BCG or mitomycin C in the urinary tract by percutaneous nephrostomy via a three-valve system open at 20 cm (after

complete eradication of the tumour), or even through a ureteric stent is technically feasible after conservative treatment of UUT-UCCs or for the treatment of CIS.
- The medium-term results are similar to those observed for the treatment of bladder tumours but have not been confirmed in long-term studies.

Guidelines for conservative management of UUT-UCC

Indications for conservative management of UUT-UCC	**GR**
Unifocal tumour	B
Small tumour	B
Low-grade tumour (cytology or biopsies)	B
No evidence of an infiltrative lesion on MDCTU	B
Understanding of close follow-up	B
Techniques used in conservative management of UUT-UCC	
Laser should be used in case of endoscopic treatment	C
Flexible ureteroscopy is preferable over rigid ureteroscopy	C
Open partial resection is an option for pelvic ureteral tumours	C
A percutaneous approach remains an option in small low-grade caliceal tumours unsuitable for ureteroscopic treatment	C

Advanced disease:

- There are no benefits of RNU in metastatic (M+) disease, although it can be considered a palliative option.
- Because UUT-UCCs are urothelial tumours, platinum-based chemotherapy is expected to produce similar results to those seen in bladder cancer.
- Limited evidence to support the used of neoadjuvant chemotherapy in RNU.
- Adjuvant chemotherapy (depending on patient fitness and renal function) achieves a recurrence-free rate of up to 50% but has minimal impact on survival.
- Adjuvant radiotherapy may improve local control of the disease.
- When given in combination with cisplatinum, it may result in a longer disease-free survival and longer overall survival.
- Radiation therapy appears to be scarcely relevant nowadays both as a unique therapy and associated with chemotherapy as a tumour adjuvant.

Follow-up

- Strict follow-up of UUT-UCC patients after surgical treatment is mandatory to detect metachronous bladder tumours.
- Bladder recurrence after treatment of a primary UUT-UCC varies considerably from 15% to 50%. Thus the bladder should be observed in all cases.
- A prior history of bladder cancer and upper tract tumour multifocality are the risk factors most often reported for bladder tumours following UUT-UCCs.
- The surveillance regimen is based on cystoscopy and urinary cytology for at least 5 yr.
- When conservative treatment is performed, the ipsilateral upper urinary tract requires careful follow-up due to the high risk of recurrence.

Guidelines for follow-up of UUT-UCC patients after initial treatment

After RNU, over at least 5 yr	**GR**
Noninvasive tumour Cystoscopy/urinary cytology at 3 mo and then yearly	C
MDCTU every year	C
Invasive tumour Cystoscopy/urinary cytology at 3 mo and then yearly	C
MDCTU every 6 mo over 2 yr and then yearly	C
After conservative management, over at least 5 yr	
Urinary cytology and MDCTU at 3 mo, 6 mo, and then yearly	C
Cystoscopy, ureteroscopy and cytology in situ at 3 mo, 6 mo, and then every 6 mo over 2 yr, and then yearly	C

10.0 UROLOGICAL NURSING

It is well-documented that the CNS plays an essential role within the cancer multidisciplinary team (MDT) in providing high-quality care from diagnosis throughout the patient journey (National Peer Review Programme, 2014). The National Institute for Clinical Excellence (NICE) (2002) called for major changes in improving outcomes for patients with Urological Cancers. In particular they recommended that the CNS should have specific knowledge and expertise and should be trained in advanced communication skills. More recently, NICE (2014) emphasised that the CNS can ensure that patients have information that is tailored to their individual needs, therefore enhancing shared decision making. The CNS is also in an excellent position to provide individualised care following treatment which promotes cancer survivorship (National Cancer Survivorship Initiative, 2011). A recent Macmillan census on specialist nurses workforce in Northern Ireland (2014) has highlighted that cancer care teams of the future will need to have more flexibility working with people who are living with cancer. This census emphasised that the role of the CNS must be optimised to support those living in the community with a diagnosis of cancer.

The combination of improved life expectancy, advancements in diagnostics and treatment, and increased use of PSA testing in primary Care have all contributed to a significant rise in Urological cancer diagnosis. In Northern Ireland the number of new cases of Urological cancers diagnosed annually has increased and the associated workload creating significant challenges for Urological cancer teams and further demands on Uro-Oncology Clinical Nurse Specialists (CNS).

10.1 Responsibilities of the Uro-oncology Specialist Nurses

All patients should be assigned a key worker (usually a CNS) at the time of diagnosis, and appropriate arrangements should be in place to facilitate easy access to the key worker during working hours and an appropriate source of advice in his/her absence, as per National Cancer Peer Review standards. All patients should be offered a holistic needs assessment (HNA) at diagnosis and subsequently if their disease status changes. Patients should be offered advice and support to address any immediate concerns – physical, mental, spiritual or financial – on completion of the HNA with onward referrals made as necessary.

The responsibilities of the uro-oncology CNS include, ensuring patients undergoing investigations for suspected cancers have adequate information and support. On diagnosis, the CNS has a supportive role and will help ensure that the patient and significant others are equipped to make informed decisions regarding their ongoing treatment and care. The CNS may have a role in the review of patients following treatment for urological cancer. The CNS also has a key role in equipping the patient to live with and beyond the urological cancer, as advocated by the National Cancer Survivorship Initiative (2011). National Cancer Survivorship Initiative (2011) has also recommended the use of Holistic Needs Assessment (HNA) by the CNS to assess patient’s needs for physical, psychological, social, spiritual and financial support at key points of their journey. A structured pack has been provided for use by professionals to assist with this process (NCAT, 2010). This HNA approach and subsequent care planning is a process which would ensure that people’s needs are met in a timely and appropriate way and that resources are targeted to those who need them most. As a result of the HNA patients should be appropriately referred or signposted to any required support services.

Where cystectomy is considered, the involvement of the Stoma Therapist and/or Urology Clinical Nurse Specialist soon after diagnosis is essential. Patients should be offered the opportunity to meet a patient who has had a cystectomy and urinary diversion to help the decision making process. Patients who may have problems with urinary incontinence should be given information about local continence services.

11.0 SUPPORTIVE AND PALLIATIVE CARE

Supportive care is available to people with cancer and their carers throughout the patient pathway, from pre-diagnosis onwards and is a term used to describe all services that may be required to support people with cancer and their carers(NICE,2004). It is identified by NICE (2004) that patients and carers may have a series of problems preceding diagnosis (when cancer is suspected) which may include physical and anxiety related symptoms which require appropriate management, and information should be available for patients at this stage if they require it. As recognised by NICE (2004) supportive care is the responsibility of all health and social care professionals involved in delivering care and effective communication within teams will enable a seamless transition from one service to another if and when required.

Patients with advanced urological cancer may benefit from supportive and palliative care. Palliative care is defined by the World Health Organization (WHO, 2014) as an approach that improves the quality of life of patients and their families, facing the problems associated with life threatening illness. Uncontrolled symptoms can adversely affect quality of life and a patient’s ability to cope with their illness, therefore, early identification, thorough assessment and treatment of pain and other problems, physical, psychological and spiritual, is essential (WHO 2014). The overall goal of palliative care is to help manage the symptoms and difficulties that may arise with disease progression, through appropriate support and intervention.

Palliative Care is an integral part of the multidisciplinary team and patients may require palliative care at different stages of the patient pathway (NICE, 2004). Generalist palliative care is the level of care required by most people and is provided by non-palliative/ end of life care specialist’s i.e. primary and secondary health care teams (Living Matters, Dying Matters, 2010). Specialist palliative care may be required for those patients with more demanding care needs, i.e. unresolved symptoms and complex psychosocial, end of life and bereavement issues (Living Matters, Dying Matters, 2010).Referral to Specialist Palliative Care may be made at any time in the course of the disease when the patient wishes and would benefit from it.

References:

Living Matters, Dying Matters (2010) A Palliative and End of Life Care Strategy for Adults in Northern Ireland www.dhsspsni.gov.uk

Macmillan (2014) Specialist adult cancer Nurses in Northern Ireland: A census of the specialist adult cancer nursing workforce in the UK, 2014. Macmillan Cancer Support.

National Cancer Action Team (2010) Holistive Needs Assessment for people with cancer: a practical guide for health care professionals. www.ncsi.org.uk

National Cancer Survivorship Initiative (2011) Consequences of Cancer Treatment. National Cancer Survivorship Initiative: London.

National Institute for Clinical Excellence (2002) Guidance on Cancer Services Improving Outcomes in Urological Cancers. NICE.

National Institute for Clinical Excellence (2004) Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. London: NICE.

National Institute for Clinical Excellence (2014) Prostate Cancer: diagnosis and treatment. NICE: London.

National Peer Review Programme (2014) Manual for Cancer Services- Urology Measures.

World Health Organisation (2014) http://www.who.int./cancer/palliative/definition/en/

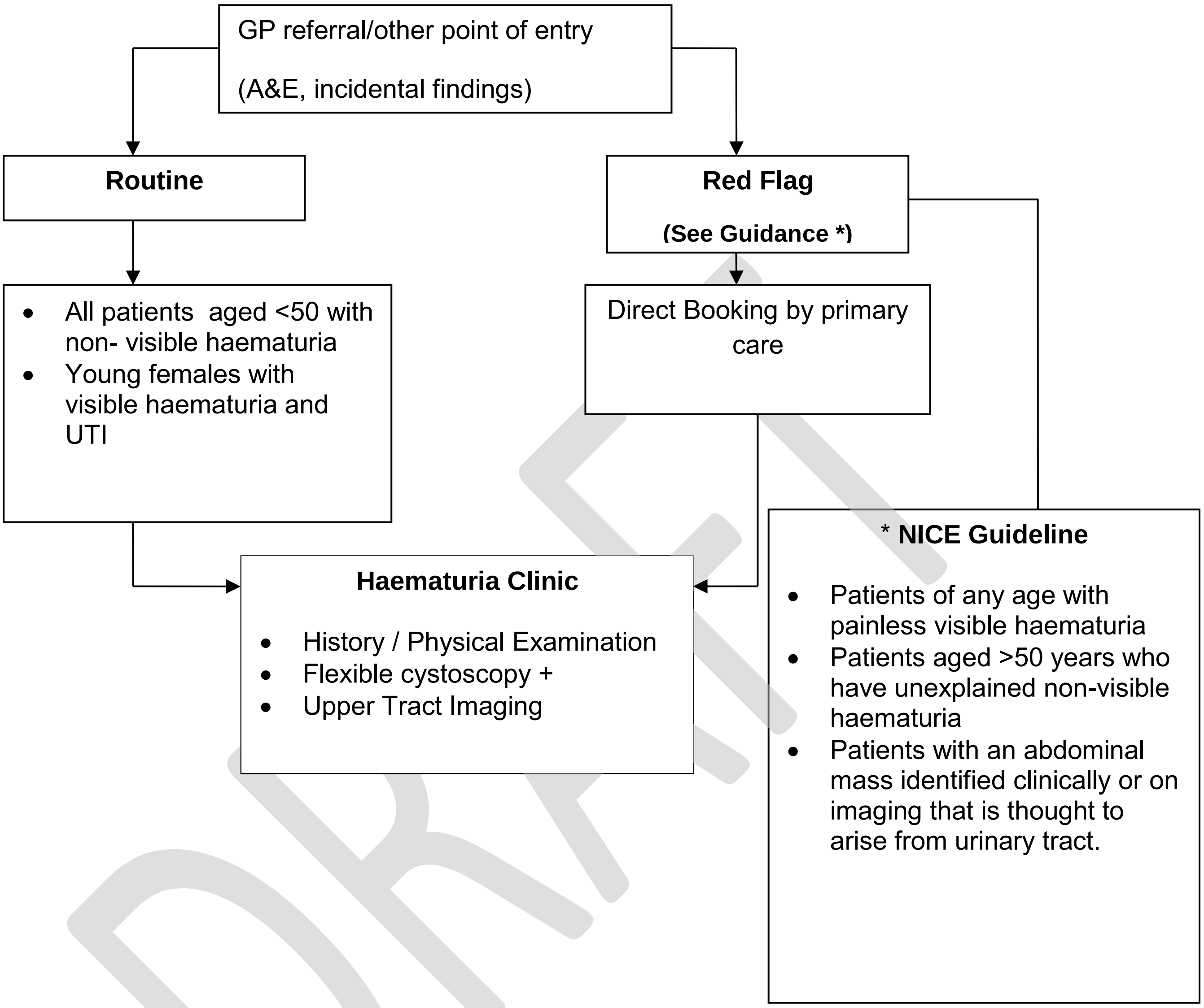
APPENDICES

1. **Haematuria Referral Guideline**

2. **Urology Care Pathways:**
   Prostate Pathway,
   Renal Tumour
   Testicular Cancer Pathway
   Transitional Cell Carcinoma
   Castration Resistant Prostate Cancer
   Penile Cancer Pathway

3. **Guidelines for nurse led follow up prostate cancer pathways**

Haematuria Referral Guideline



GP referral/other point of entry

(A&E, incidental findings)

Routine

- All patients aged <50 with non- visible haematuria
- Young females with visible haematuria and UTI

Red Flag

(See Guidance *)

Direct Booking by primary care

Haematuria Clinic

- History / Physical Examination
- Flexible cystoscopy +
- Upper Tract Imaging

*** NICE Guideline**

- Patients of any age with painless visible haematuria
- Patients aged >50 years who have unexplained non-visible haematuria
- Patients with an abdominal mass identified clinically or on imaging that is thought to arise from urinary tract.

NOTE: Please Consider Nephrology referral as well as referral to haematuria clinic if the patient has any of the following:

- Diabetes
- Proteinuria
- Hypertension

Appendix 2; Urology Care Pathways

Cancer Care Pathways outline the steps and stages in the patient journey from referral through to diagnostics, staging, treatment, follow up, rehabilitation and if applicable onto palliative care.

Timed effective care pathways are central to delivering quality and timely care to patients throughout their cancer journey and to the delivery of an equitable service. These pathways have been developed following with reference to available best practice guidance. They represent an 'ideal' pathway that can be adapted for local use. The timelines on the pathway are intended to facilitate the proactive management of patients within the access standards and it is to be noted that for some urological tumours, the patient will move much quicker through the pathway (e.g. testicular cancer).

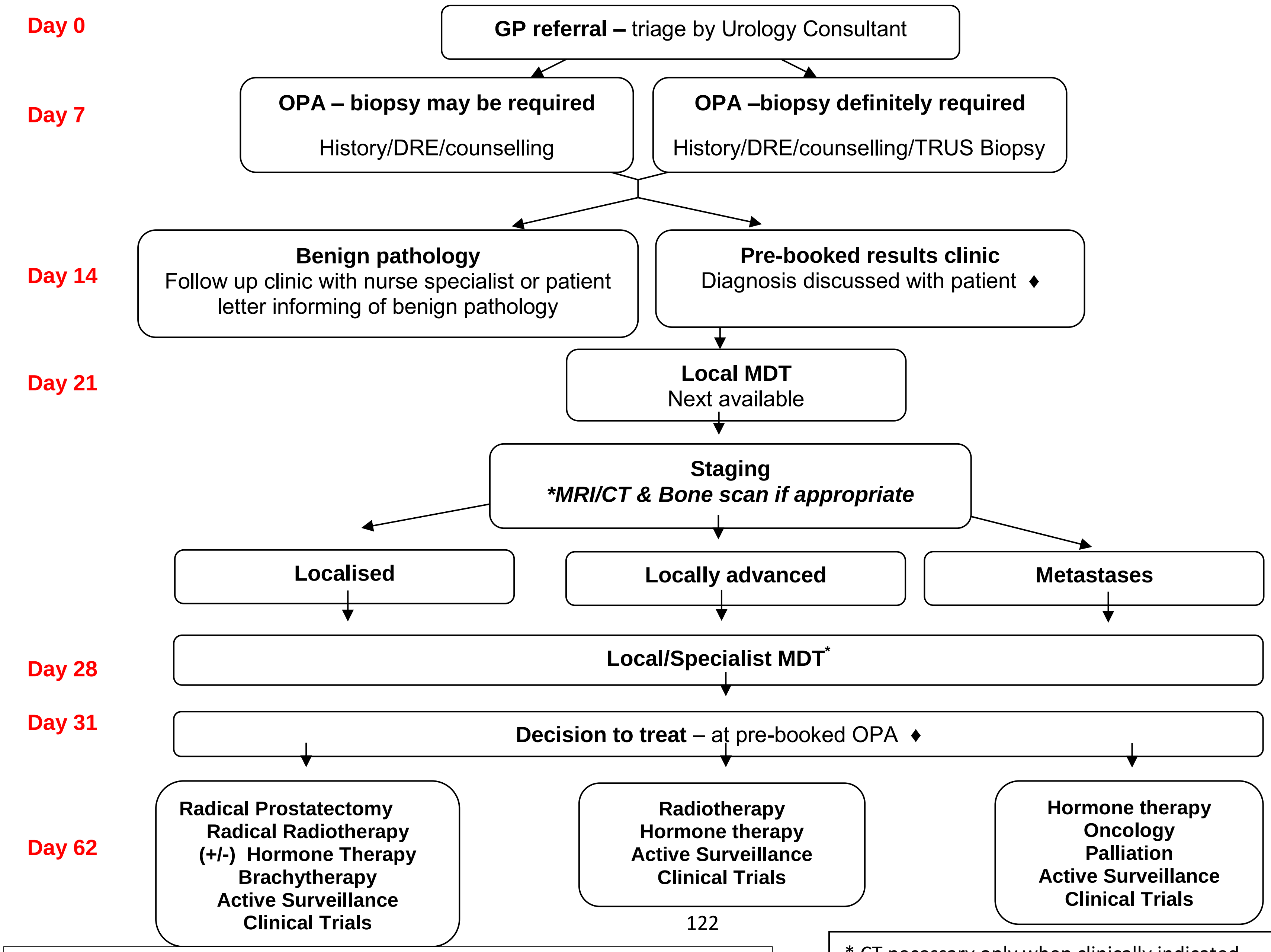
The pathways are in draft form and amendments have been made following discussion at the workshop of the NICaN Regional Urology group held on Thursday 2nd October, 2008

Document History

V1 Draft discussed at workshop 2/10/08
V2 Draft discussed 29/1/09 and amendments noted
Version 3 circulated for final comments 26/02/09
Pathways agreed at regional meeting 23/4/09

Appendix 2 of NICaN Urology Cancer Clinical Guidelines

Prostate Pathway



Day 0

GP referral – triage by Urology Consultant

Day 7

OPA – biopsy may be required
History/DRE/counselling

OPA –biopsy definitely required
History/DRE/counselling/TRUS Biopsy

Day 14

Benign pathology
Follow up clinic with nurse specialist or patient letter informing of benign pathology

Pre-booked results clinic
Diagnosis discussed with patient ♦

Day 21

Local MDT
Next available

Staging
MRI/CT & Bone scan if appropriate

Localised

Locally advanced

Metastases

Day 28

Local/Specialist MDT*

Day 31

Decision to treat – at pre-booked OPA ♦

Day 62

Radical Prostatectomy
Radical Radiotherapy
(+/-) Hormone Therapy
Brachytherapy
Active Surveillance
Clinical Trials

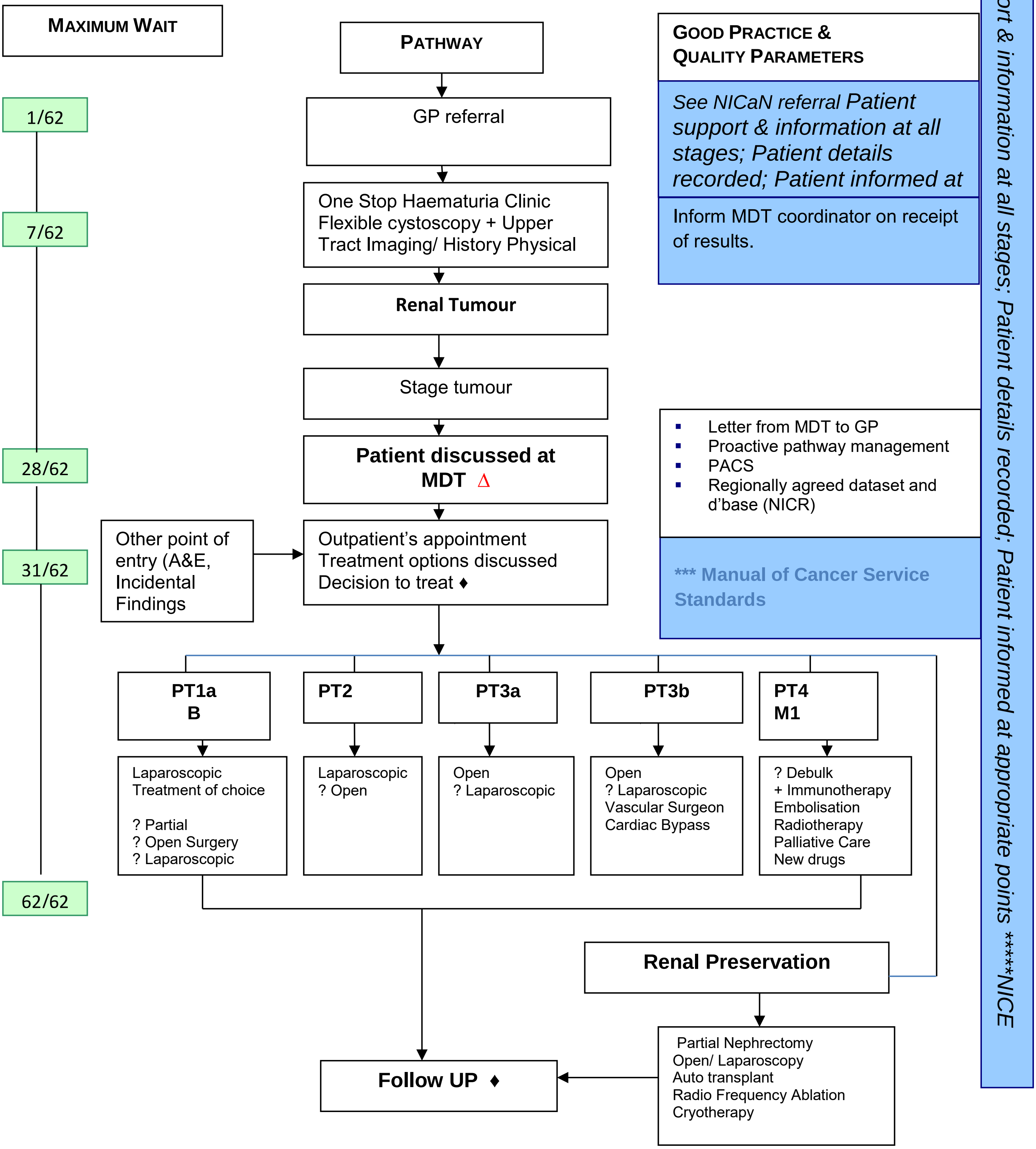
Radiotherapy
Hormone therapy
Active Surveillance
Clinical Trials

Hormone therapy
Oncology
Palliation
Active Surveillance
Clinical Trials

* CT necessary only when clinically indicated

Appendix 2 of NICaN Urology Cancer Clinical Guidelines

Renal Tumour



MAXIMUM WAIT

1/62

7/62

28/62

31/62

62/62

PATHWAY

GP referral

One Stop Haematuria Clinic
Flexible cystoscopy + Upper Tract Imaging/ History Physical

Renal Tumour

Stage tumour

Patient discussed at MDT Δ

Other point of entry (A&E, Incidental Findings

Outpatient's appointment
Treatment options discussed
Decision to treat ♦

PT1a B
Laparoscopic
Treatment of choice

? Partial
? Open Surgery
? Laparoscopic

PT2
Laparoscopic
? Open

PT3a
Open
? Laparoscopic

PT3b
Open
? Laparoscopic
Vascular Surgeon
Cardiac Bypass

PT4 M1
? Debulk
+ Immunotherapy
Embolisation
Radiotherapy
Palliative Care
New drugs

Renal Preservation

Partial Nephrectomy
Open/ Laparoscopy
Auto transplant
Radio Frequency Ablation
Cryotherapy

Follow UP ♦

GOOD PRACTICE & QUALITY PARAMETERS

See NICaN referral Patient support & information at all stages; Patient details recorded; Patient informed at

Inform MDT coordinator on receipt of results.

- Letter from MDT to GP
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

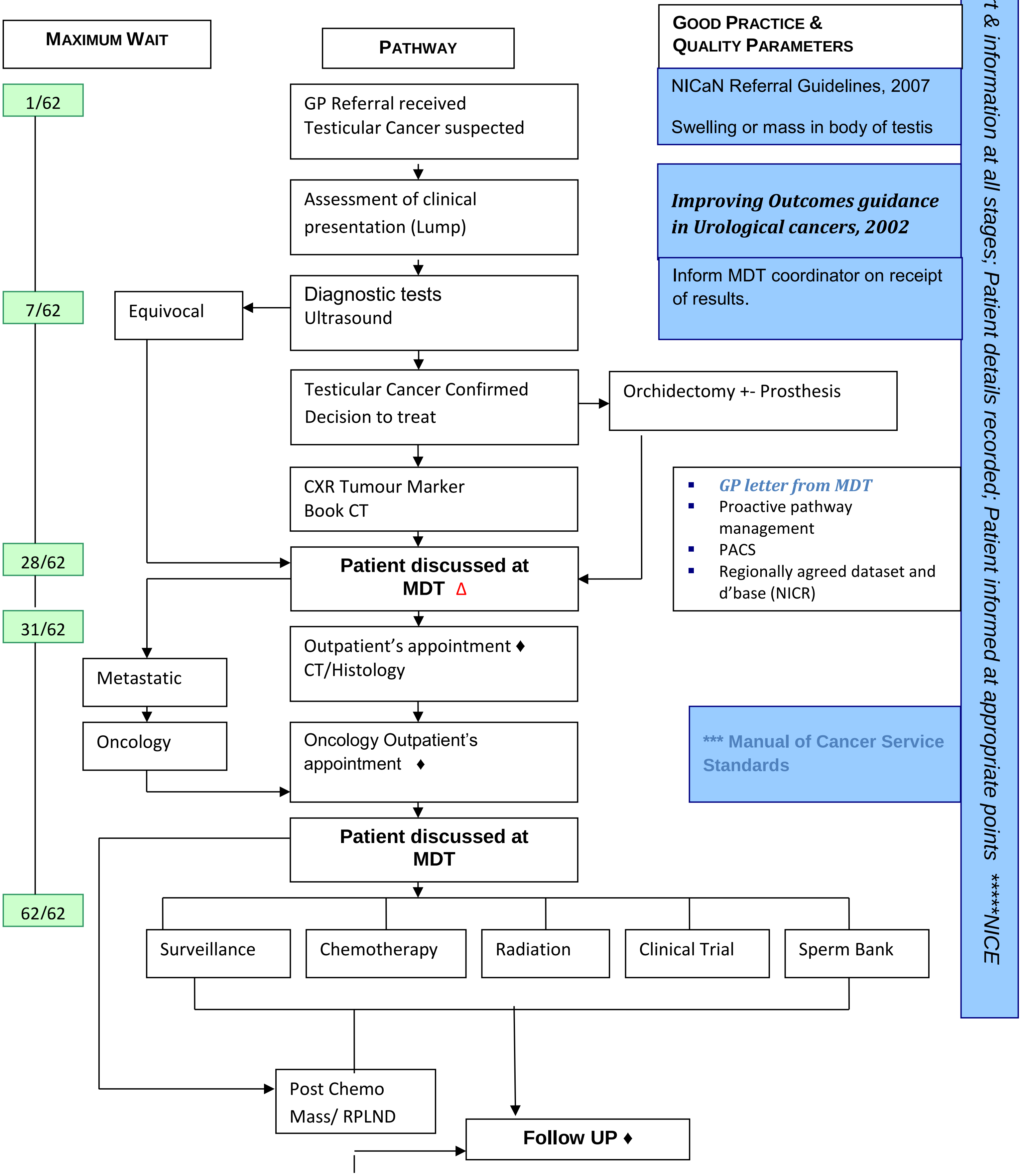
***** Manual of Cancer Service Standards**

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE*

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

Appendix 2 of NICaN Urology Cancer Clinical Guidelines

Testicular Cancer Pathway



MAXIMUM WAIT

1/62

7/62

28/62

31/62

62/62

PATHWAY

GP Referral received
Testicular Cancer suspected

Assessment of clinical presentation (Lump)

Diagnostic tests
Ultrasound

Equivocal

Testicular Cancer Confirmed
Decision to treat

Orchidectomy +- Prosthesis

CXR Tumour Marker
Book CT

Patient discussed at MDT Δ

Metastatic

Oncology

Outpatient's appointment ♦
CT/Histology

Oncology Outpatient's appointment ♦

Patient discussed at MDT

Surveillance

Chemotherapy

Radiation

Clinical Trial

Sperm Bank

Post Chemo
Mass/ RPLND

Follow UP ♦

GOOD PRACTICE & QUALITY PARAMETERS

NICaN Referral Guidelines, 2007

Swelling or mass in body of testis

Improving Outcomes guidance in Urological cancers, 2002

Inform MDT coordinator on receipt of results.

- *GP letter from MDT*
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

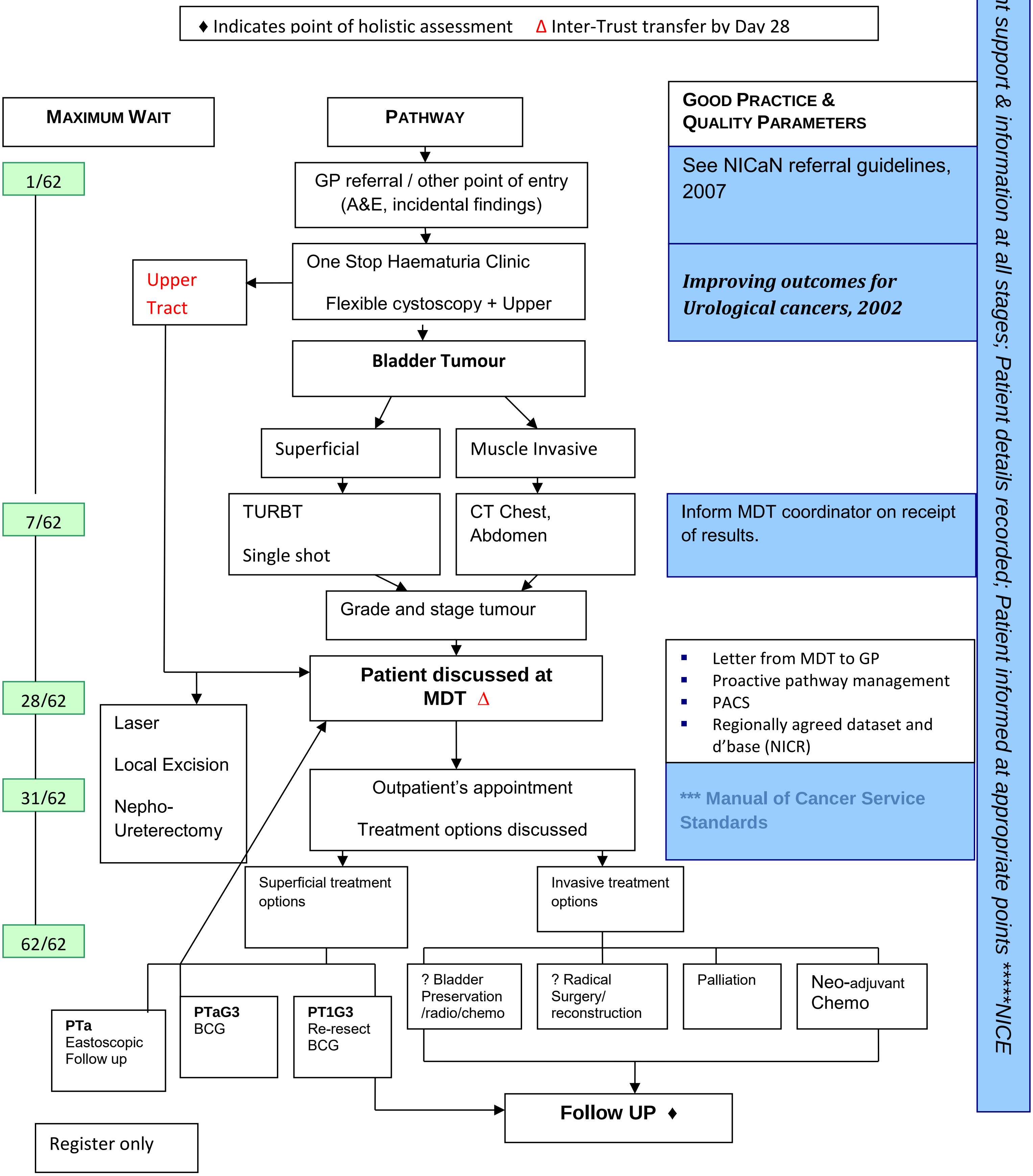
***** Manual of Cancer Service Standards**

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE*

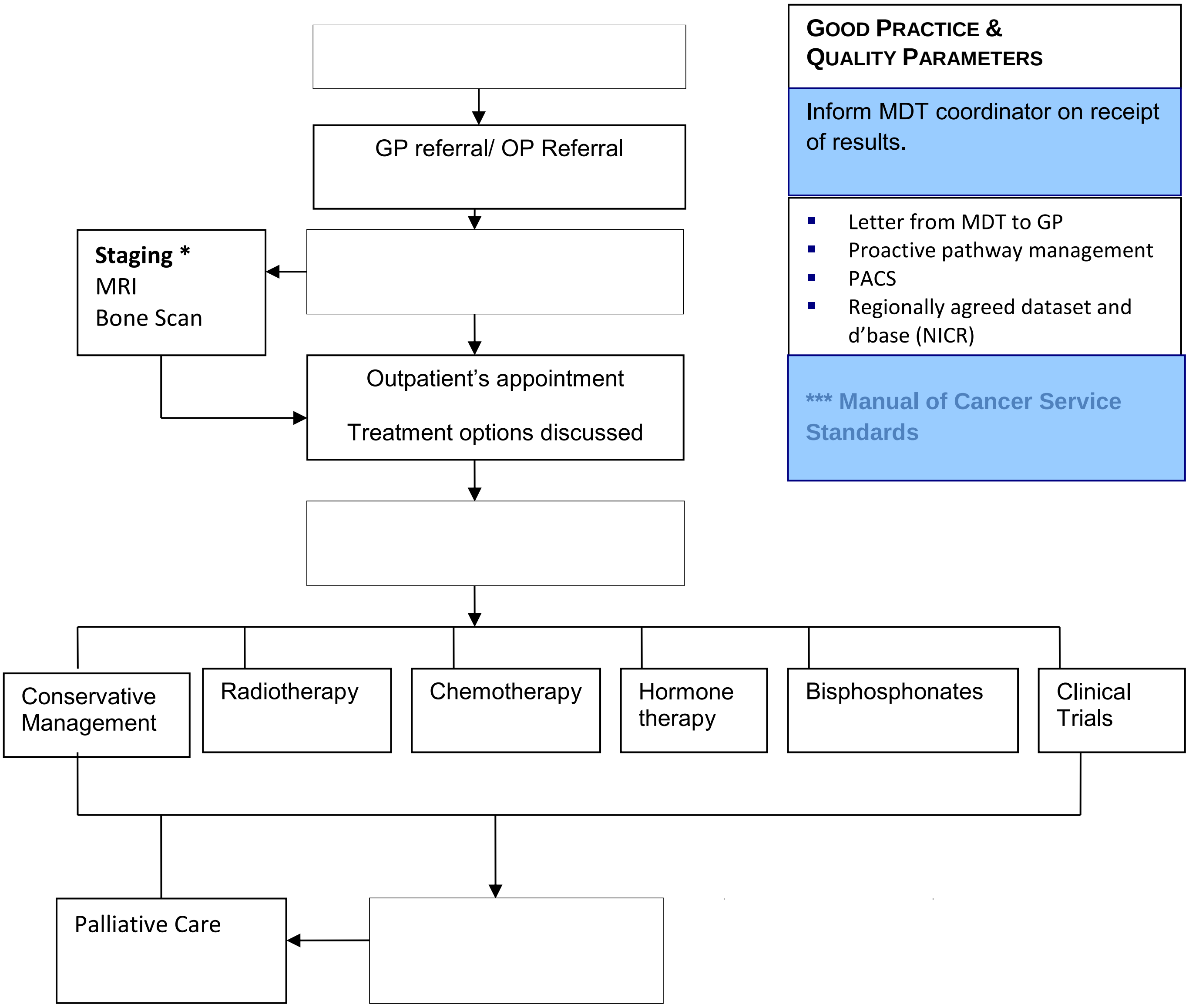
V1.3

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

Appendix 2 of NICaN Urology Cancer Clinical Guidelines



Castration Resistant Prostate Cancer



GOOD PRACTICE & QUALITY PARAMETERS

Inform MDT coordinator on receipt of results.

- Letter from MDT to GP
- Proactive pathway management
- PACS
- Regionally agreed dataset and d'base (NICR)

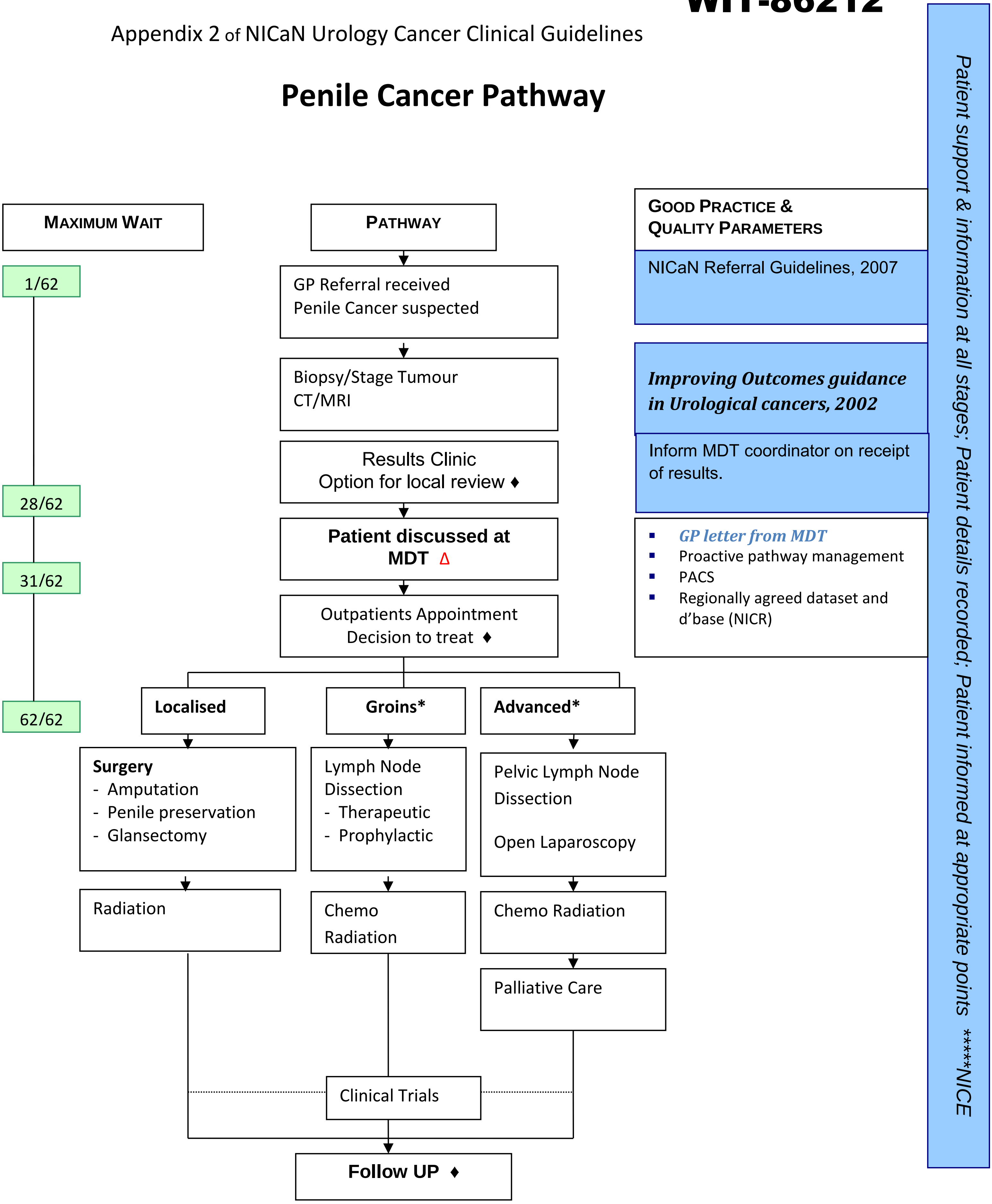
*** Manual of Cancer Service Standards

*Patient support & information at all stages; Patient details recorded; Patient informed at appropriate points ****NICE*

* MRI/Bone Scan as clinically indicated

Appendix 2 of NICaN Urology Cancer Clinical Guidelines

Penile Cancer Pathway



V1.3 ♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28

References

- NICE (2002) Improving Outcomes in Urological Cancer
  http://www.nice.org.uk/guidance/index.jsp?action=byID&o=10889

- NICE (2008) Prostate Cancer: Diagnosis and Treatment
  http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11924

- British Association Of Urological Surgeons Guidelines
  http://www.baus.org.uk/

- European Association Of Urology
  http://www.europeanurology.com/

Policy Code / Reference No:

Trust Logo

Add Trust Name

Title:	**Guidelines for Nurse Led Assessment and Follow up of patients with stable Prostate Cancer**		
Author(s)	*Adapted from SET*		
Ownership:			
Approval by:	**NICaN Urology NSSG Group**	**Approval date:**	**29th November 2013**
Operational Date:		**Next Review:**	
Version No.	**3** **Supercedes**	**N/A**	
Links to other policies	**Policy for consent to examination, Treatment and Care, European Association of Urologists (Feb, 2012) Guidelines on Prostate Cancer**		

1.0 INTRODUCTION / PURPOSE OF GUIDELINE

This document outlines the guiding principles for nurse led prostate cancer follow-up and should be closely followed. However these guidelines are only a foundation and it is recommended that nurses maintain their continuing education in this specialist area of care.

The aim of this guideline is to set a minimum standard for nurse led assessment and follow up of patients with prostate cancer which will:

- Enable the follow up of patients with prostate cancer who are on the watchful wait or hormone treatment pathway
- Promote the education of patients about their disease management and potential for self directed aftercare
- Monitor patient progress and enable detection of progression and refer to the appropriate Consultant Urologist
- Enable holistic assessment
- Identify late effects of treatment quickly, provide support and signpost to the appropriate service if necessary
- Inform patients about and refer them to specialists services that can help with their medical, practical, emotional and rehabilitation needs
- Support patients living with and beyond cancer
- Offer patients a choice of follow-up

1.1 Objectives

The objectives of this guideline are to improve and maintain standards of clinical practice and quality of care patients receive by:

- Providing evidence based guidance for establishing and maintaining a nurse led clinic for the assessment of patients with prostate cancer, promoting excellence in the care that is delivered
- Reducing variation in clinical practice and encouraging uniformity of practice
- Providing a framework from which individual practitioners can apply their own level of clinical expertise and competency
- To ensure that all patients entering the prostate cancer follow up service are on the appropriate risk stratified pathway (Appendix 5 & 6)
- Helping nurses and health care providers to make informed decisions, aiding the education process and reducing the risk of clinical negligence
- Identifying competencies for nursing care
- Aiding development of locally agreed guidelines
- Promoting audit

1.2 Background

The NHS is undergoing radical changes particularly in its approach to cancer. Traditional nursing roles are being challenged in a bid to meet the demands of the changing NHS climate. Prostate cancer follow up forms a substantial part of the urology outpatient workload. Nurse led clinics are becoming increasingly common, offering patients an alternative method of follow up either via more convenient clinics or the telephone. By developing these new roles and services, nurse are playing a key role in increasing patient choice, reducing waiting times, increasing accessibility to services and improving the quality of care

New standards have been developed within the Cancer Services Framework that are intended to ensure that patients experience the best possible quality of life after treatment by:

- providing new models of follow-up which focus on health and wellbeing
- improving access to psychological support

2.0 DEFINITIONS/SCOPE OF THE GUIDELINE

These guidelines should be used by suitably trained health care professionals who are providing nurse led follow up to patients with prostate cancer. Patients will enter nurse led follow up services on a clearly defined follow up pathway following discussion at MDM.

Recommended exclusion criteria

- Patients who do not wish to be followed up by a nurse
- Patients who require adjuvant treatment in the form of radiotherapy or chemotherapy
- Patients with dementia/short term memory loss (unless meeting patients with carer present)
- Patients who develop resistance to Hormone Therapy during follow up and require referral to oncologist
- Patients deemed unsuitable for review at a nurse led clinic by the consultant in charge

3.0 ROLES/RESPONSIBILITIES

Implementation of these guidelines is the responsibility of those involved in nurse led follow-up of prostate cancer patients.

Accountability is a key concern for all registered nurses today. Professional accountability is defined as being responsible for your actions and for the outcomes of these actions as part of the framework of clinical Governance, which aims to provide good quality, cost-effective evidence based care (Tilley & Watson 2004)

Nurses need to be aware of their limitations as well as their clinical competence. If there are any areas in which they do not feel clinically competent to undertake an activity they should decline the activity until the appropriate learning and practice activities have been achieved to demonstrate competency (NMC 2008)

Nurses are responsible for ensuring their own educational preparation and experience to safely perform the role. They should maintain documented evidence of completion of continuing education and of demonstrating clinical competence

Competencies required for assessing patients with prostate cancer can be found in (Appendix 2)

4.0 KEY GUIDELINE PRINCIPLES

4.1 Key Policy Statement

The purpose of the nurse led clinic is to enhance the quality of care and to promote the health and well being of patients who have been treated for prostate cancer. The clinic will also facilitate the provision of emotional support for patients and their families/carers requiring the opportunity to discuss treatment or care options
Nurse led clinics have been shown to improve the quality of care in the following ways:

- Provide continuity of care for patients and their family
- Provide information, education and support
- Be accessible to patients and their family
- Release consultant time to see more complex patients
- Apply the principles of transforming cancer follow up

A risk stratified model of aftercare in line with the National Cancer Survivorship Initiative will be utilised and patients will be stratified into different arms of the follow up pathway according to their staging and personal characteristics by the Consultant.

Risk stratified means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, (what type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short term and long term) and the person (whether they have other illnesses or conditions, and how much support that they feel they need).

This will include the ongoing follow up of patients who are clinically stable and are stratified into the relevant pathway

Watchful waiting	(Pathway 1)
Active surveillance	(Pathway 2)
Raised PSA – negative biopsy	(Pathway 3)
Post radical surgery	(Pathway 4)
Post brachytherapy	(Pathway 5)
Post radical radiotherapy	(Pathway 6)

4.2 Policy Principles

Patients with prostate cancer who are on the pathways outlined above will be risk stratified into a pathway as discussed below

- Self-Care with Support and Open Access

    - No routine outpatient attendances
    - Stable disease pattern
    - After treatment with curative intent
    - Holistic assessment completed and care plan agreed
    - Information and/or some form of educational intervention
    - Surveillance tests with results by post or phone co-ordinated by a provider
    - Ability to re access system with/without reference to GP

- Shared Care – where patients continue to have face to face or telephone contact with professionals as part of continuing follow up.

    - Planned follow up either as an outpatient or planned phone follow up
    - Clinical examination required
    - High clinical or individual risks identified (disease, treatment, person)
    - Multi professional input required
    - Patients with co-morbidities
    - Those who decline or are considered to be unable to self manage

4.3 Long-term follow-up

Definitive guidance on the long term follow-up for patients with prostate cancer is included within the pathways which are concordant with NICE and European Association of Urologists Clinical Management Guidelines on Prostate Cancer.

4.4 Telephone Review Protocol

A telephone review service enables the Clinical Nurse Specialist to follow up patients through an alternative route and thereby reduce unnecessary hospital appointments for patients who have stable disease and are not fit to travel.

This service will be offered to those patients referred to the nurse led clinic and a telephone assessment protocol will be utilised. See appendix 7

4.5 Holistic Needs Assessment (HNA)

The HNA is used to identify and address patient's needs and concerns. The HNA may build on action plans developed from previous assessments. The HNA should be conducted during the follow-up appointment. The patient or carer is encouraged to complete the form and the assessor uses this as a guide to explore their needs and collaboratively develop an appropriate action or care plan

An agreed Holistic Needs Assessment (HNA) tool will be utilised within the aftercare pathways

4.6 Support Information and Education

The consultant or clinical nurse specialist should offer patients support information tailored to the individual. This should cover as a minimum:

- Disease Progression
- Fatigue
- Pain
- Urinary Symptoms
- Finances/benefits
- Nutrition/exercise
- Signposting
- Health and well being

4.7 Rapid Access Protocol

Prostate cancer follow-up is the responsibility of the MDT. All patients should be able to access the Consultant responsible for their care through the Urology CNS. Any patient that contacts the Urology CNS with worrying symptoms will be seen by a Consultant promptly. If necessary, their case should be discussed by the MDT.

4.8 Triage Protocol

Each patient will be able to contact the Urology CNS outside of scheduled follow up appointments The Urology CNS will triage the patient on their concerns/issues to the most appropriate member of the Urology team or refer on to other agencies accordingly. Outcomes may include:

- Face to face consultant appointment promptly
- Face to face Nurse led clinic (where appropriate)
- Advised to contact GP
- Advised to attend the emergency department
- Signpost to other support agencies e.g. Citizens Advice Bureau (CAB), AHP, Counselling

Only clinical issues will result in a clinical appointment.

5.0 IMPLEMENTATION OF POLICY

5.1 Dissemination

Urology Clinical Nurse Specialists

Urology Consultants

Oncologists

6.0 MONITORING

Monitoring of these guidelines is the responsibility of the Urology Nurse under the direction of the line manager.

7.0 EVIDENCE BASE / REFERENCES

Evidence:

BAUN (2008) Guidelines for nurse-led assessment and follow up of men with stable prostate cancer British Association for Urological Nurses
Cox A, Jenkins V, Catt S, Langridge C, Fallowfield LJ Information needs and experiences: an audit of UK cancer patients. European Journal of Oncology Nursing 2006; 10(4):263-72, doi:10.1016/j.ejon.2005.10.007
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http://www.uroweb.org

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nicr/FileStore/PDF/Survival/Filetoupload,81422,en.pdf

Nursing and Midwifery Council (NMC): The Code: Standards of conduct, performance and ethics for nurses and midwives (2008)

Service Framework for Cancer Prevention, Treatment and Care (2011)

Tilley, S. Watson, R. (2004) Accountability in Nursing and Midwifery. 2nd Edition. London: Blackwell Publishing.

8.0 CONSULTATION PROCESS

Cancer Services User Forum

NICaN Regional Urology Group

9.0 APPENDICES / ATTACHMENTS

See attached

10.0 EQUALITY STATEMENT

In line with duties under the equality legislation (Section 75 of the Northern Ireland Act 1998), Targeting Social Need Initiative, Disability discrimination and the Human Rights Act 1998, an initial screening exercise to ascertain if this policy should be subject to a full impact assessment has been carried out.
The outcome of the Equality screening for this policy is:

Major impact ☐

Minor impact ☐

No impact ☐

SIGNATORIES

(Policy – Guidance should be signed off by the author of the policy and the identified responsible director).

________________________________ **Date:**
Name
Title:

________________________________ **Date:**
Name
Title:

________________________________ **Date:**
Name
Title:

________________________________ **Date:**
Name
Title:

Appendix 1

Prostate Cancer Review Assessment Form

Name……………………………………………….

Unit No……………………………………………..

DOB…………………………

Consultant…………………………   GP………………………………

Date:……………. Time………………

Type of review: Telephone   ☐   Clinic Contact ☐

Treatment Pathway: Hormone Treatment   ☐Watchful Waiting ☐

Histology Gleason's Score ……………….. TNM …………………

PSA

PSA Trigger..

Date of PSA……….…..... Current PSA...........................   Previous PSA......................

PSA obtained from ECR……………………………………

Record what was discussed with patient

Changes in Urinary Symptoms

Storage	Yes / No
Voiding	Yes / No
Pain	Yes / No
Haematuria	Yes / No

If yes to any of the above, please comment and record advice given

General Symptoms

Hot Flushes	Yes/No
Tiredness	Yes/No
Weight gain	Yes/No
Breast Pain	Yes/No
Bone pain	Yes/No
Sexual Problems	Yes/No
Change in bowel pattern	Yes/No

Additional comments

Problems and concerns

Has patient had a Holistic Needs Assessment Yes/No

If yes, Date of HNA ………………………………………………..

Discuss resolution of any problems identified in previous HNA ☐

Are there any new concerns Yes/No

- Financial
- Psychological
- Information and Support

Please record any issues

Follow up

Nurse Led follow up 3 months yes/no 6months Yes/No

Referral to:

Urologist Yes/No
Oncologist Yes/No

Letter to GP ☐
Letter to Consultant ☐

Signature of CNS…………………………

Appendix 2
Competencies for Nurse-led Follow-up

Competencies required assessing patients with stable prostate cancer include:

- Advanced nurse practitioner/clinical nurse specialist having been employed for a minimum of twelve months working with a urologist/oncologist in the follow up setting

- Demonstrate a full understanding of the network site specific group pathways for prostate cancer. As agreed by the local tumour network

- To be enrolled in or be undertaking, a programme of study in their specialist area of nursing practice which has been accredited for at least 20 CAT points at level 3 (DH2004) e.g. Health Assessment module

- Have advanced communication skills – to have enrolled in, or be undertaking a recognised course/module in communication skills (DH 2004)

- In order to run a clinic the individual must be a core member or extended member of the urology multidisciplinary team

- To be able to demonstrate knowledge of the disease trajectory in Prostate Cancer

- To be able to demonstrate knowledge of risk stratified pathways

- To have competent consultation and symptom analysis skills. To have worked under supervision for a minimum of six months and have been deemed competent by the consultant urologist/oncologist

- To be able to demonstrate knowledge of the tests and investigation required during follow up of prostate cancer patients

- To be competent at performing DRE (if appropriate)

- To be competent in the assessment of lower urinary tract symptoms (LUTS) and facilitate onward referral to LUTS clinic is required

- To be competent in bladder palpation

- To be competent in the assessment of bladder empting

- To demonstrate ability to advise on erectile dysfunction and know where and how to refer to appropriate service

- To be able to demonstrate knowledge of survivorship issues

- To be able to demonstrate knowledge of rehabilitation services

- Demonstrate knowledge of drugs and treatments used in prostate cancer including side effect

Appendix 3

Guideline for Nurse Led Assessment Protocol

Actions

Discuss

- Nurse led clinic
- History/treatment to date
- Timeline for routine follow up such as PSA, DRE and Admission Profile

Physical Examination

Carry out physical assessment including:

- Digital Rectal Examination (DRE)
- International Prostate Symptom Score (IPSS) if required

Symptoms

Is the patient experiencing any symptoms .

- Hot Flushes
- Ask about pain – any new pain lasting more than a week (use locally agreed pain scale)
- Weight loss/gain
- Fatigue
- Sexual dysfunction
- Neurological symptoms – Numbness, tingling or odd sensations in limbs
- Lower Urinary tract symptoms
- Haematuria
- Gynaecomastia
- Change in bowel habit
- Deterioration in renal function

Is the patient experiencing any symptoms suggestive of local or metastatic disease

- Abdominal /Pelvic /Skeletal pain
- Weight loss
- Anorexia
- Nausea or vomiting

Ask about any other symptoms/concerns

- PSA at each visit if rising discuss with consultant
- Admission Profile at each visit
- FBP at first visit
- Ultrasound renal tracts following discussion with Consultant

Perform holistic assessment suggested tools:

- Macmillan Concerns Checklist & Care-plan

Nurse to check information has been provided and tailored to the individual patient. This will include information about:

- Timeline for tests and investigations
- Survivorship programme
- Rapid Access to service
- Contact numbers
- What symptoms need to be reported
- Consequences and side effects of the treatment
- Holistic Assessment
- Rehabilitation services

Discuss and offer referral to:

- Community Health and Well-being Clinics
- Signposting to other services

Care plan
Letter to patient
Letter to GP & referring consultant with copy of assessment form,

To include:

- Date and time of nurse consultation
- Patients identifiable details
- Diagnosis
- Treatment,
- Assessment summary,
- Most recent PSA reading
- Date of next nurse appointment
- Potential or actual problems identified during the consultation.

Adapted from BAUN (British Association for Urological Nurses) - Guidelines for nurse-led assessment and follow up of men with stable prostate cancer (2008)

Appendix 4

Problem Management Plan

This plan will help to identify the appropriate actions when there is a change in the patients condition/needs during nurse led assessment and follow-up of patients with prostate cancer.

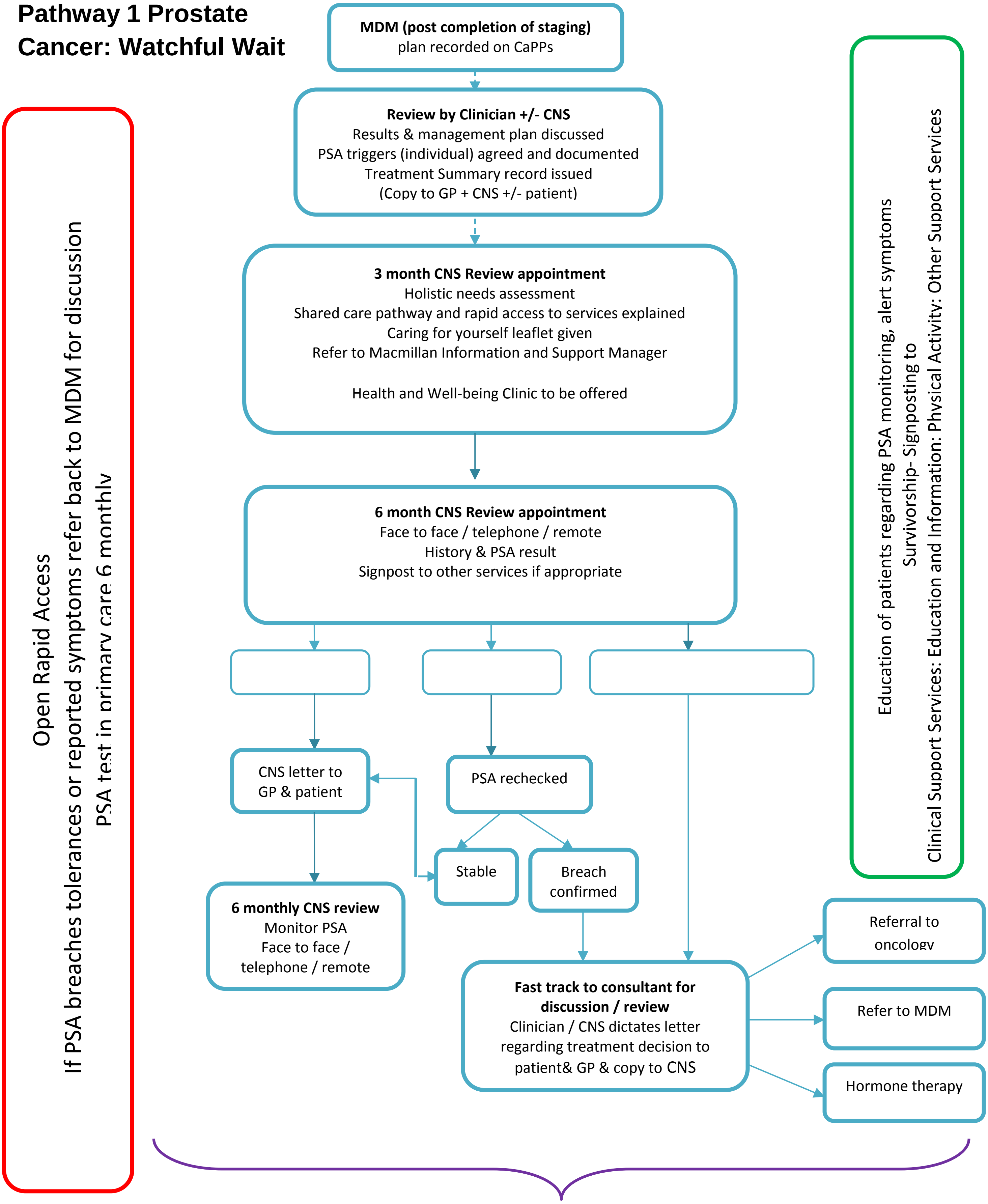
Problem	Management plan
Sudden Rise in PSA	Repeat PSA as determined by consultant
Lower urinary tract symptoms that are more bothersome to the patient	Refer to LUTS clinic Urinalysis to exclude UTI Refer or discuss with appropriate consultant
Haematuria	Exclude UTI Assess lower urinary tract symptoms Refer for investigations
Hot flushes	Give support and advice and discuss with consultant
Pain - new onset bone pain	Request investigations – bone profile, pain and neurological assessment(use locally agreed pain scale) Consider MSCC Appropriate referral to urologist/ oncologist for further management
Change in bowel habit	Assess asking about change in consistency regularity. Give advice or refer to specialist as appropriate
Weight loss	If unexplained weight loss refer to consultant. Refer to dietician if appropriate
Gynaecomastia	Discuss with consultant and if required refer to oncologist
Deterioration in renal function	Discuss and if appropriate refer back to urologist Assess for poor bladder emptying by post void residual scan Order USS of renal tracts if appropriate

Problem	Management plan
Weight gain, fatigue general malaise and anaemia	Give advice Consider referral for physical activity programme Check haemoglobin and if below normal levels discuss with consultant
Sexual Dysfunction	Assess for erectile dysfunction Give advice and consider referral to ED clinic if appropriate
Psychological needs	At time of the assessment any psychological concerns identified through use of NICaN Concerns Checklist will be discussed with the patient. Refer as appropriate to: Health and well being clinics Support groups Counselling Service Clinical psychologist
Financial concerns	Refer to CAB
Information needs	Discuss information needs Give written information if appropriate Consider onward referral if required Refer to Macmillan Information and Support Centre

Adapted from BAUN (British Association for Urological Nurses) - Guidelines for nurse-led assessment and follow up of men with stable prostate cancer (2008)

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 1 Prostate Cancer: Watchful Wait



MDM (post completion of staging)
plan recorded on CaPPs

Review by Clinician +/- CNS
Results & management plan discussed
PSA triggers (individual) agreed and documented
Treatment Summary record issued
(Copy to GP + CNS +/- patient)

3 month CNS Review appointment
Holistic needs assessment
Shared care pathway and rapid access to services explained
Caring for yourself leaflet given
Refer to Macmillan Information and Support Manager

Health and Well-being Clinic to be offered

6 month CNS Review appointment
Face to face / telephone / remote
History & PSA result
Signpost to other services if appropriate

CNS letter to GP & patient

6 monthly CNS review
Monitor PSA
Face to face / telephone / remote

PSA rechecked

Stable

Breach confirmed

Fast track to consultant for discussion / review
Clinician / CNS dictates letter regarding treatment decision to patient& GP & copy to CNS

Referral to oncology

Refer to MDM

Hormone therapy

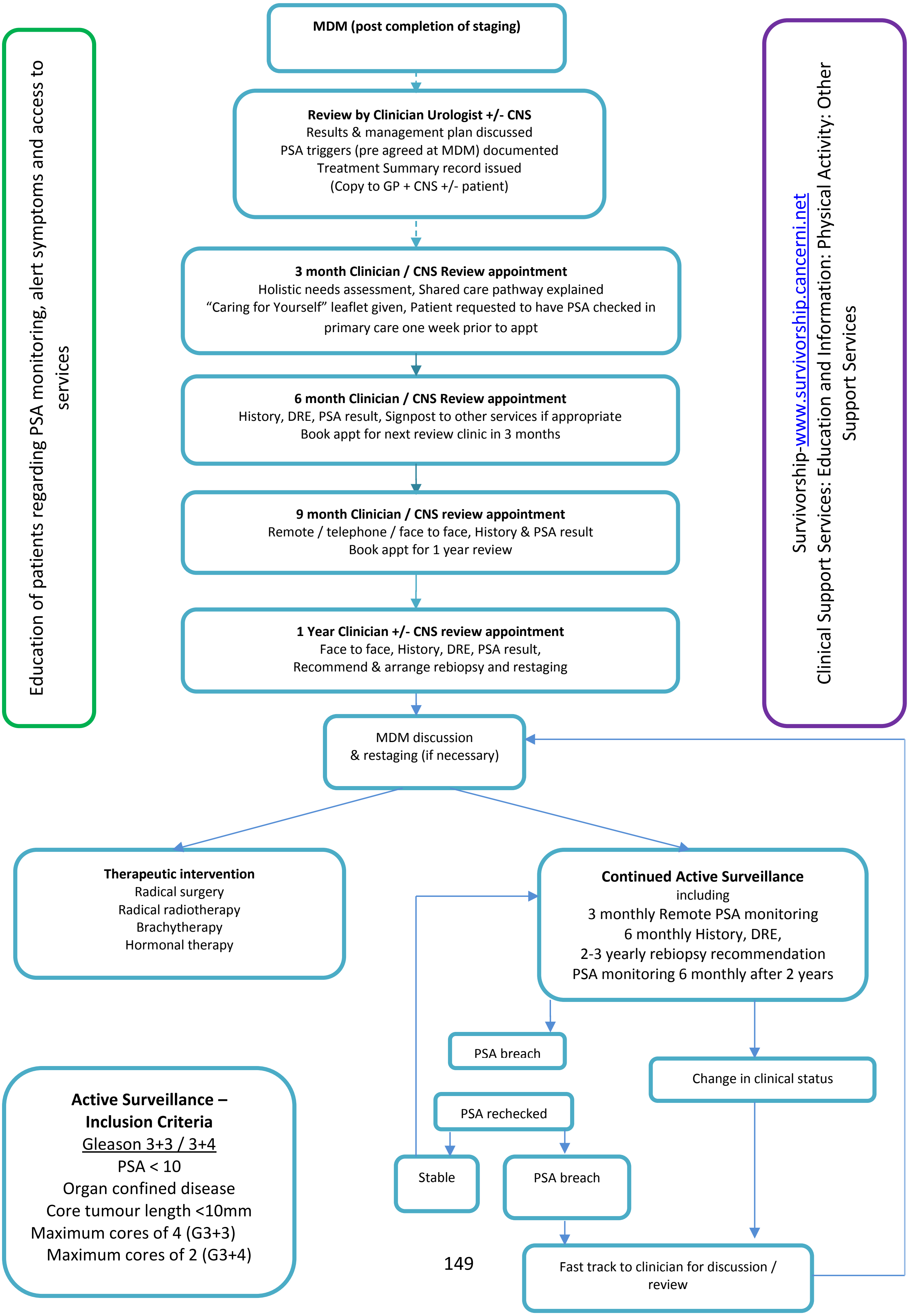
Open Rapid Access
If PSA breaches tolerances or reported symptoms refer back to MDM for discussion
PSA test in primary care 6 monthly

Education of patients regarding PSA monitoring, alert symptoms
Survivorship- Signposting to
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Watchful waiting – Adapted from NICE Guidance 2008
'Watchful Waiting is the form of continued review of Prostate Cancer patients for whom future therapeutic intervention with curative intent has been considered to be inappropriate'.

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 2 Prostate Cancer: Active Surveillance



Education of patients regarding PSA monitoring, alert symptoms and access to services

MDM (post completion of staging)

Review by Clinician Urologist +/- CNS
Results & management plan discussed
PSA triggers (pre agreed at MDM) documented
Treatment Summary record issued
(Copy to GP + CNS +/- patient)

3 month Clinician / CNS Review appointment
Holistic needs assessment, Shared care pathway explained
"Caring for Yourself" leaflet given, Patient requested to have PSA checked in primary care one week prior to appt

6 month Clinician / CNS Review appointment
History, DRE, PSA result, Signpost to other services if appropriate
Book appt for next review clinic in 3 months

9 month Clinician / CNS review appointment
Remote / telephone / face to face, History & PSA result
Book appt for 1 year review

1 Year Clinician +/- CNS review appointment
Face to face, History, DRE, PSA result,
Recommend & arrange rebiopsy and restaging

Survivorship-www.survivorship.cancerni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

MDM discussion
& restaging (if necessary)

Therapeutic intervention
Radical surgery
Radical radiotherapy
Brachytherapy
Hormonal therapy

Continued Active Surveillance
including
3 monthly Remote PSA monitoring
6 monthly History, DRE,
2-3 yearly rebiopsy recommendation
PSA monitoring 6 monthly after 2 years

PSA breach

Change in clinical status

PSA rechecked

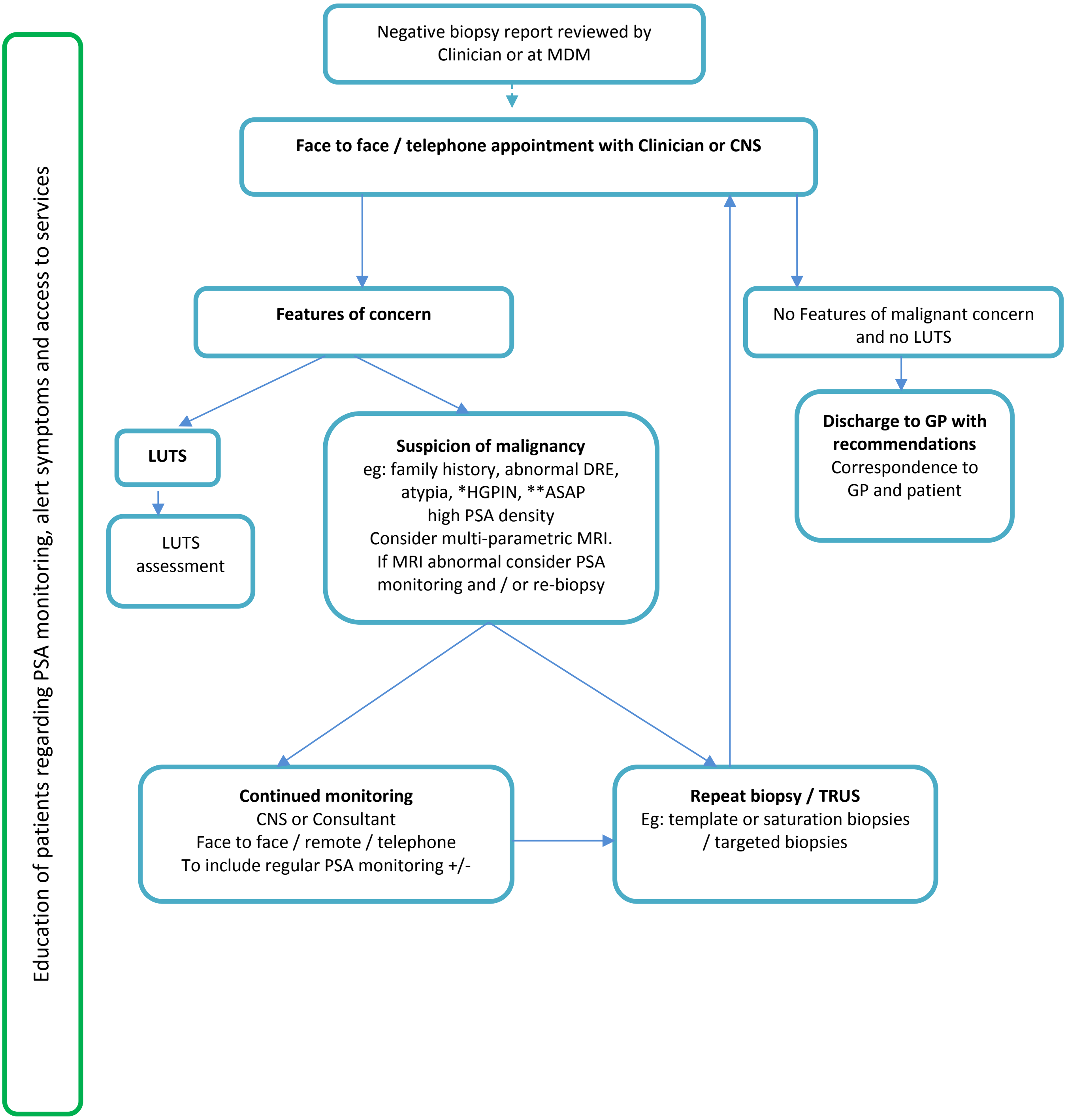
Stable

PSA breach

Fast track to clinician for discussion / review

Active Surveillance – Inclusion Criteria
<u>Gleason 3+3 / 3+4</u>
PSA < 10
Organ confined disease
Core tumour length <10mm
Maximum cores of 4 (G3+3)
Maximum cores of 2 (G3+4)

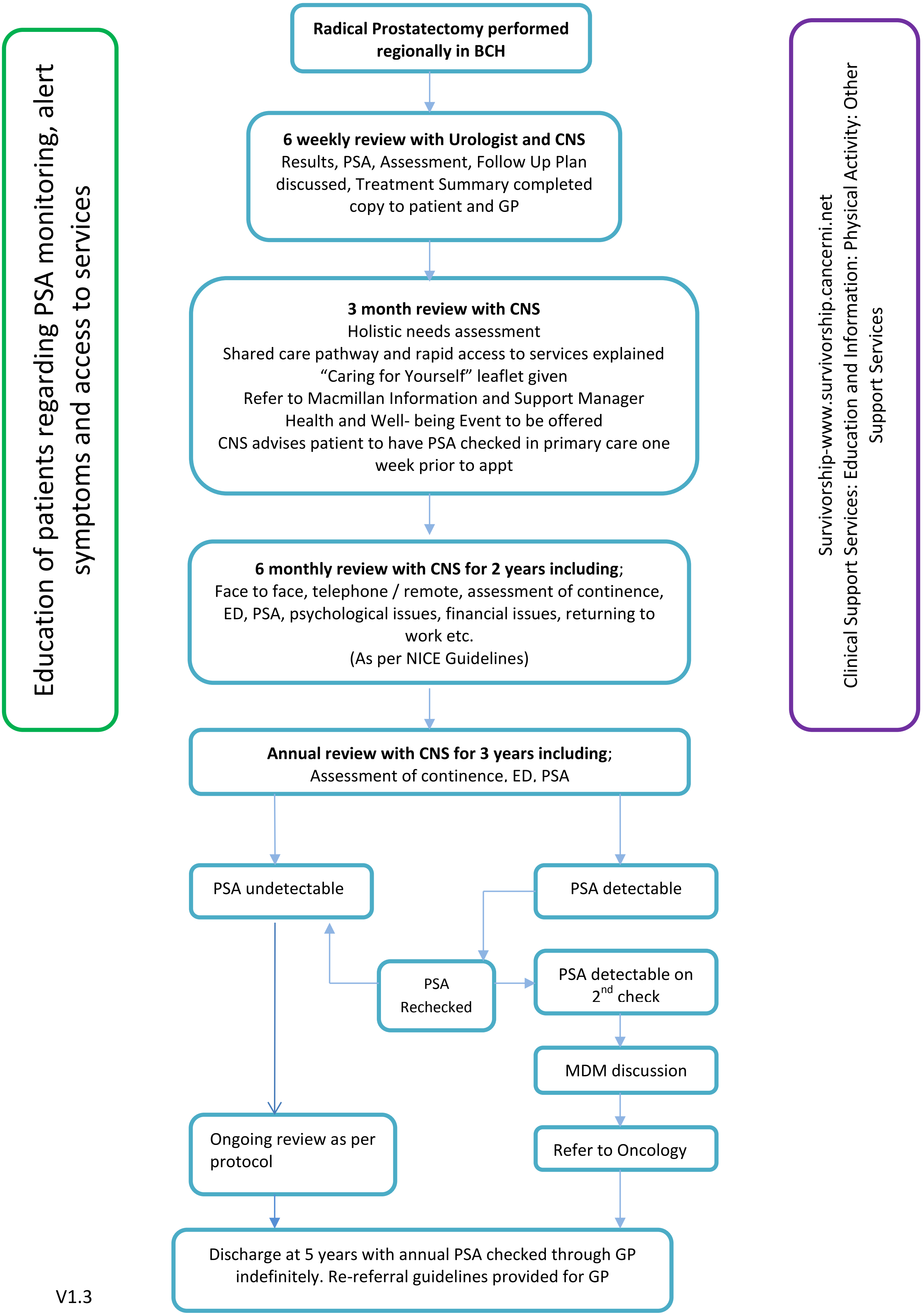
Pathway 3 Raised PSA & Negative Biopsy



*HGPIN – High grade prostatic intra-epithelial neoplasia
**ASAP – Atypical small acinar proliferation

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 4 Prostate Cancer: Radical Surgery – Negative margins



Education of patients regarding PSA monitoring, alert symptoms and access to services

Radical Prostatectomy performed regionally in BCH

6 weekly review with Urologist and CNS
Results, PSA, Assessment, Follow Up Plan discussed, Treatment Summary completed copy to patient and GP

3 month review with CNS
Holistic needs assessment
Shared care pathway and rapid access to services explained
"Caring for Yourself" leaflet given
Refer to Macmillan Information and Support Manager
Health and Well- being Event to be offered
CNS advises patient to have PSA checked in primary care one week prior to appt

6 monthly review with CNS for 2 years including;
Face to face, telephone / remote, assessment of continence, ED, PSA, psychological issues, financial issues, returning to work etc.
(As per NICE Guidelines)

Annual review with CNS for 3 years including;
Assessment of continence, ED, PSA

PSA undetectable

PSA detectable

PSA Rechecked

PSA detectable on 2nd check

MDM discussion

Refer to Oncology

Ongoing review as per protocol

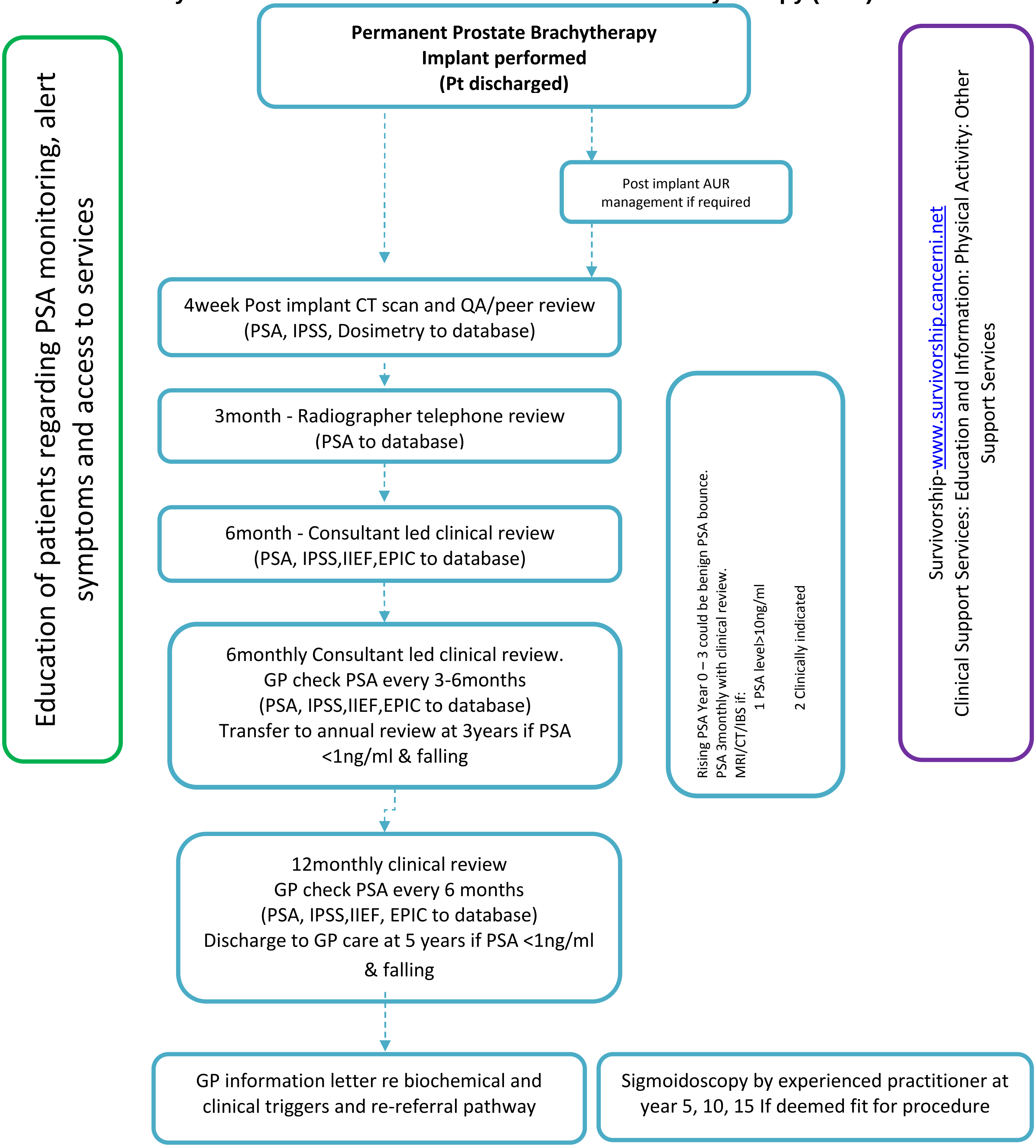
Discharge at 5 years with annual PSA checked through GP indefinitely. Re-referral guidelines provided for GP

Survivorship-www.survivorship.cancerni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

V1.3

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 5 Prostate Cancer: Permanent Prostate Brachytherapy (LDR)



Education of patients regarding PSA monitoring, alert symptoms and access to services

Permanent Prostate Brachytherapy
Implant performed
(Pt discharged)

Post implant AUR management if required

4week Post implant CT scan and QA/peer review
(PSA, IPSS, Dosimetry to database)

3month - Radiographer telephone review
(PSA to database)

6month - Consultant led clinical review
(PSA, IPSS,IIEF,EPIC to database)

6monthly Consultant led clinical review.
GP check PSA every 3-6months
(PSA, IPSS,IIEF,EPIC to database)
Transfer to annual review at 3years if PSA <1ng/ml & falling

12monthly clinical review
GP check PSA every 6 months
(PSA, IPSS,IIEF, EPIC to database)
Discharge to GP care at 5 years if PSA <1ng/ml & falling

Rising PSA Year 0 – 3 could be benign PSA bounce.
PSA 3monthly with clinical review.
MRI/CT/IBS if:
1 PSA level>10ng/ml
2 Clinically indicated

Survivorship-www.survivorship.cancerni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

GP information letter re biochemical and clinical triggers and re-referral pathway

Sigmoidoscopy by experienced practitioner at year 5, 10, 15 If deemed fit for procedure

Selection criteria for Permanent Prostate Brachytherapy

Clinical inclusion criteria:
Organ confined prostate cancer T1 or T2
Estimated life expectancy >10yrs
Gleason 6 and PSA <15ng/ml
Gleason 7 and PSA <15ng/ml

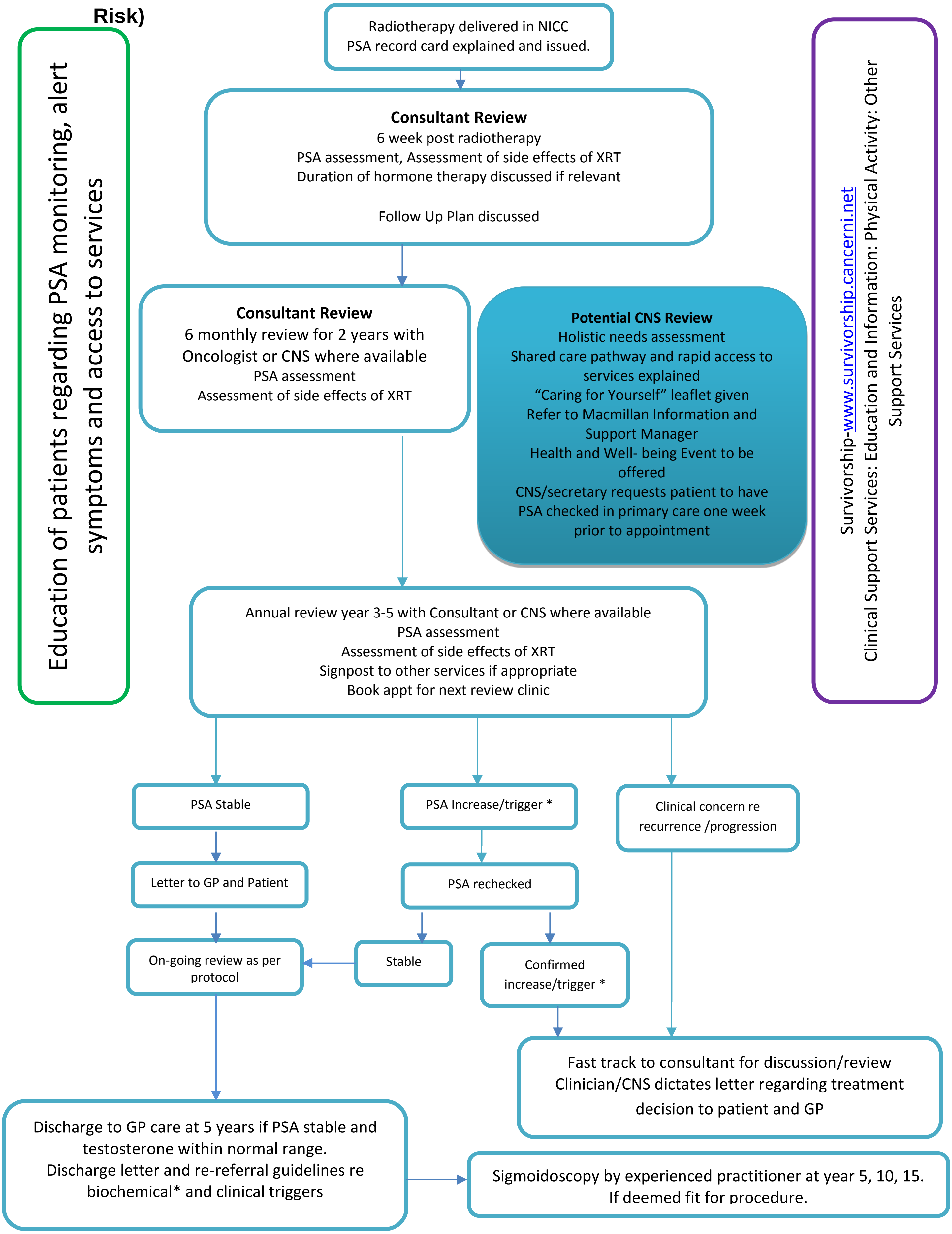
Clinical exclusion criteria for brachytherapy:
Prostate volume >50ml (> 65ml prior to hormonal cytoreduction)
IPSS >9. (Would consider for implant is <15 & Qmax >12ml/sec)
Life expectancy <5years
Large or poorly healed TURP defect
Unacceptable operative risk
Relative contraindications for brachytherapy:
Large median lobe

Selection criteria for combined Permanent Prostate Brachytherapy + EBRT

Selected men with:
High volume Gleason 7 or
Low volume Gleason >7 or
Early T3a disease
May be suitable for dose escalation with combination therapy and should be referred for discussion to central

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 6: Prostate Cancer: Radiotherapy+/-Hormones (Low Intermediate Risk)



Education of patients regarding PSA monitoring, alert symptoms and access to services

Radiotherapy delivered in NICC
PSA record card explained and issued.

Consultant Review
6 week post radiotherapy
PSA assessment, Assessment of side effects of XRT
Duration of hormone therapy discussed if relevant

Follow Up Plan discussed

Consultant Review
6 monthly review for 2 years with Oncologist or CNS where available
PSA assessment
Assessment of side effects of XRT

Potential CNS Review
Holistic needs assessment
Shared care pathway and rapid access to services explained
"Caring for Yourself" leaflet given
Refer to Macmillan Information and Support Manager
Health and Well- being Event to be offered
CNS/secretary requests patient to have PSA checked in primary care one week prior to appointment

Survivorship-www.survivorship.cancerni.net

Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Annual review year 3-5 with Consultant or CNS where available
PSA assessment
Assessment of side effects of XRT
Signpost to other services if appropriate
Book appt for next review clinic

PSA Stable

Letter to GP and Patient

On-going review as per protocol

PSA Increase/trigger *

PSA rechecked

Stable

Confirmed increase/trigger *

Clinical concern re recurrence /progression

Fast track to consultant for discussion/review
Clinician/CNS dictates letter regarding treatment decision to patient and GP

Discharge to GP care at 5 years if PSA stable and testosterone within normal range.
Discharge letter and re-referral guidelines re biochemical* and clinical triggers

Sigmoidoscopy by experienced practitioner at year 5, 10, 15.
If deemed fit for procedure.

*Phoenix definition of Biochemical failure:
Absolute increase of 2.0ng/ml above the post treatment PSA nadir

Low risk PSA<10 & G6 and T2
Intermediate risk PSA 10-20 or G7 and T2

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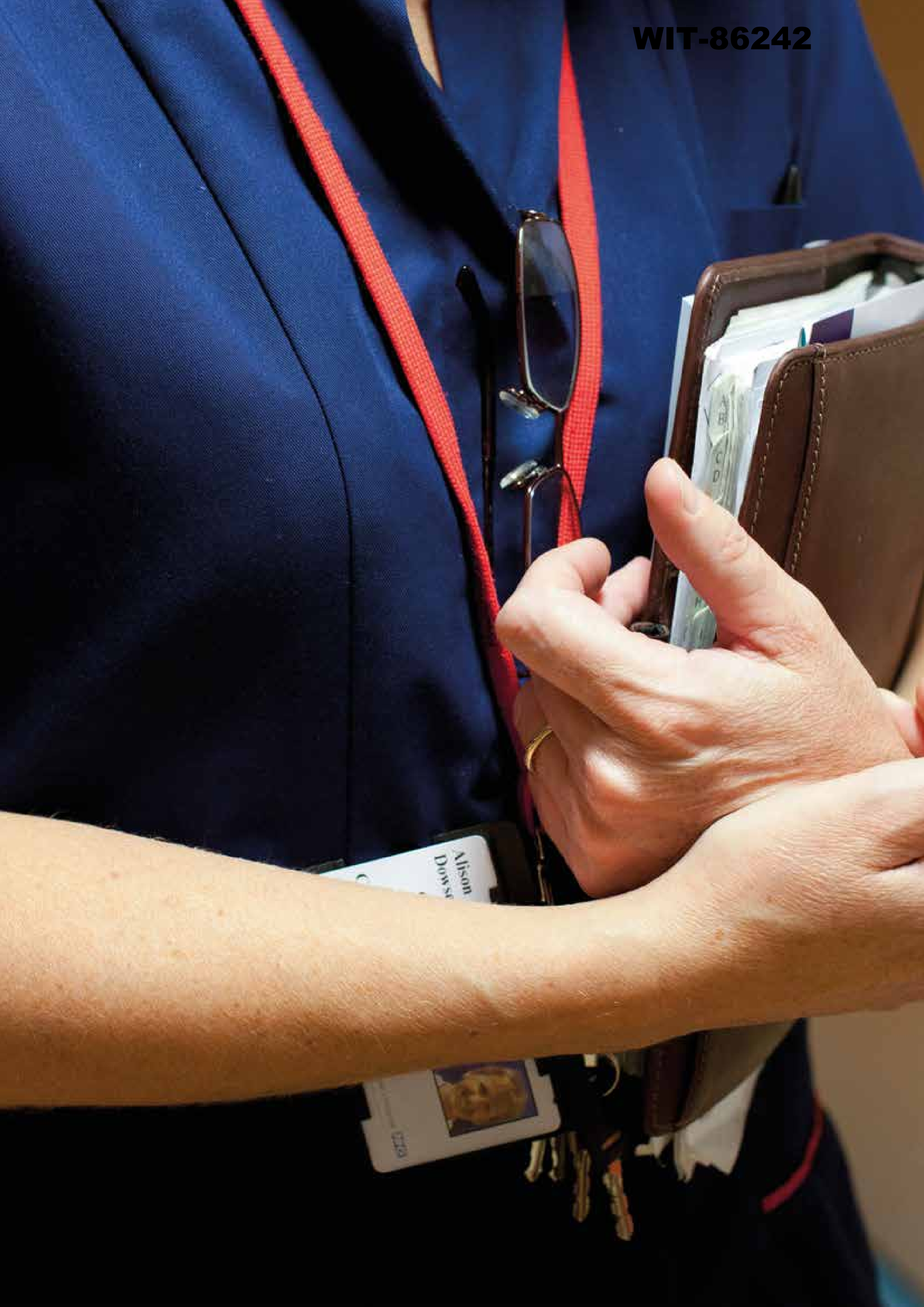
WE ARE MACMILLAN. CANCER SUPPORT

Specialist adult cancer nurses in Northern Ireland

A census of the specialist adult cancer nursing workforce in the UK, 2014


THINGS TO DO

Contents


Alison
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Foreword

Macmillan first established Clinical Nurse Specialists (CNS) in the 1970s. Since then the numbers have grown so that now there are 1,305 whole time equivalent specialist adult cancer nurses with Macmillan in their job title across the UK.

We have therefore long been a strong advocate for the role that specialist cancer nurses play in supporting people affected by cancer, and in ensuring they receive timely and person-centred care. Recent cancer patient experience surveys in England and Wales have provided evidence that patients who had a named Clinical Nurse Specialist (CNS) in charge of their care reported more favourably on aspects of their experience[1,20].

It is therefore fitting that this year we have commissioned the first UK-wide census of the specialist cancer nurse workforce, to provide a robust picture of the numbers and location of these nurses across all four of the UK nations. This report presents the findings of the census in Northern Ireland.

In completing this census, we have relied on our partners in Health and Social Care to provide information and have been heartened to receive tremendous support for our approach. In a time of considerable change and financial constraint across the UK, the census returned an overall response rate of 97%. In Northern Ireland the response was better still: 100%.

We have learnt a lot about the workforce and how it is changing to respond to environmental, demographic and policy challenges. These challenges are different in the four nations of the UK, and so the data presented in this report should be interpreted in light of the local context.

The specialist adult cancer nurse workforce in Northern Ireland has grown by just 2% since the last census of this kind was carried out in 2011. This compares to a 10% increase in England and shows the size of the workforce in Northern Ireland is not keeping pace with the increasing number of people diagnosed with cancer each year.

There are two themes that emerge strongly across the UK, as things we need to respond to soon:

- Our specialist cancer nurse workforce is ageing. In some areas of practice in some parts of the UK, our data suggests that as many as half of the nurses currently providing cancer care are over 50. It is likely that the majority of these will retire in the next five to 10 years.
- In Northern Ireland, the age profile of our lung and colorectal CNS workforce, in particular, gives rise for concern.
- There are considerable variations in the provision of specialist cancer nurse expertise for those diagnosed with different cancer types and across different geographic locations.

We at Macmillan would welcome the opportunity to work with providers, commissioners and workforce planners to support planning to address these challenges, with the aim of ensuring that everyone affected by cancer has good outcomes and experience of care through access to a specialist cancer nurse.

Heather Monteverde

Heather Monteverde
General Manager for Northern Ireland
Macmillan Cancer Support

Ciarán Devane

Ciarán Devane
Chief Executive
Macmillan Cancer Support

1. Introduction

1.1 Background

The specialist adult cancer nursing census was originally designed to map the specialist adult cancer nursing population by cancer type and locality in order to inform commissioning intentions and workforce planning.

The first two censuses in 2007[2] and 2008[3] were developed and led by the cancer network nurse director and colleagues, before they handed over management to the National Cancer Action Team (NCAT) and Mouchel Management Consulting Limited, who led on the 2010[4] and 2011[5] censuses respectively. Further iterations expanded data collection to include role title, banding and geography. In 2014, Macmillan Cancer Support commissioned the census working with Mouchel (the partner of the Centre of Workforce Intelligence).

The 2014 census of specialist adult cancer nurse workforce has leant on the significant experience and expertise provided by the continued involvement of three senior cancer nurses and healthcare scientists/professional colleagues: Professor Alison Leary and Paul Trevatt, who had developed the original census, and Steve Candler.

It is the first UK-wide census, however, to take account of the significant differences in policy and delivery of cancer care in the Celtic nations, the data has been presented in separate reports and should be interpreted in light of the relevant national context.

The census took place at a time of significant financial constraint across the UK and a budget crisis in Northern Ireland against a background of rising demand and demographic pressures.

It may be useful to read this document in conjunction with other resources such as: ·

- *Excellence in cancer care: The contribution of the Clinical Nurse Specialist.* NCAT, 2010[6].
- *Clinical nurse specialists in cancer: Provision, proportion and performance.* NCAT 2010[4] and 2011[5].
- *Advanced level nursing: A position statement.* Department of Health, 2010[7].
- *Manual of cancer services.* Department of Health, 2004[8].
- *National Cancer Action Team. Cancer peer review report – Northern Ireland cancer network*[9]
- *Coordinated cancer care: better for patients, more efficient.* NHS Confederation briefing, 2010[10].

While this document does offer information regarding the ratio of specialist cancer nurses to incidence of cancer and two-year prevalence across Northern Ireland, this does not represent guidance on appropriate caseload. It merely demonstrates variance of provision of these posts by tumour type.

This report aims to strengthen the argument for maintaining and expanding the provision of specialist nurse expertise in Northern Ireland in order to ensure that the growing number of people being diagnosed and living with cancer receive a good patient experience.

1.2 Methods

This census was primarily based on the approach adopted for previous censuses, in particular the work undertaken by NCAT in the most recent census in England[5].

A census of the specialist cancer nursing workforce was undertaken in Northern Ireland in 2008[3]. This included nurses specialising in paediatrics and young adults, who are excluded from this census. Numbers of cancer CNSs were also reported in a discussion paper by the Northern Ireland Cancer Network Public Health Agency[11], but there has been no systematic means of monitoring the specialist cancer nursing workforce.

In 2011, the Northern Ireland cancer network undertook an internal census using similar methodology as that used by NCAT in England. Whilst this work was not published, the data was validated by nurse directors and is used as a comparison for the data in the 2014 census.

Data was collected over an eight-week period between April and June 2014. However, the workforce numbers collected were a 'snapshot' of the population on the day of the census, 24 April 2014. The data was primarily collected using a bespoke spreadsheet with drop-down menus.

Areas of enquiry were informed by the previous four censuses undertaken in England.

Areas of practice are broadly based on the NICE Improving Outcomes Guidance definitions[12]. Consistent with 2011, the areas of practice include 'acute oncology services' (AOS), as it was recommended in the 2009 NCAG report *Chemotherapy services in England: Ensuring quality and safety* that all hospitals with emergency departments should establish this service[13].

All posts are recorded as whole time equivalents (WTE) in adult cancer care where 1 WTE is equivalent to a 37.5 hour week.

Additional information was collected on the age and gender of post holders and on vacant posts. Data was also collected on if nurses cover 'cancer of unknown primary'.

Spreadsheets were returned from lead cancer nurses / cancer managers in hospital trusts. Some further checking and completion was undertaken to ensure complete records were provided where possible. NHS Trust Lead Cancer Nurses and Directors of Nursing were involved, as well as the Nurse Consultant for the Northern Ireland Cancer Network as appropriate. Data was returned electronically from trusts to Mouchel for analysis. One month was given for data to be returned, with a further extension to enable appropriate dissemination and support for returns. Collection was completed by 13 June 2014.

Census process:

- Project team and Mouchel agreed census tool design and data fields
- Spreadsheet and instructions for completion were sent out to lead cancer nurses or equivalent in each trust or hospital across the UK
- Data entry completed at trust level
- Completed spreadsheets returned to Mouchel
- Records checked with respondents for completeness and accuracy as appropriate
- Analysis by Mouchel and project team
- Data tables produced for review and key findings identified
- Report

1.3 Selection criteria

The census was aimed at hospital-based specialist adult cancer nurses working in adult cancer care only.

Inclusion criteria were kept consistent with previous censuses where possible.

Inclusion criteria: all nurse posts that:

- treat, support and manage the health concerns of adult cancer patients and work to promote the health and wellbeing of the patients they care for (including post holders who perform a role in education, research and audit in adult cancer care)
- deliver predominantly secondary care
- are registered (Agenda for Change bands 5 to 9 only)
- are funded by any source (e.g. NHS, charity, pharmaceutical)
- are vacant posts as well as those filled on 24 April 2014.

Exclusion criteria: posts that:

- specialise only in chemotherapy, radiotherapy, palliative care, pain management or non-patient facing roles
- work 'as and when required', e.g. bank and agency staff
- are community nurse specialists
- work in paediatrics or with teenagers and young adults
- are research nurses.

All posts reported that met the inclusion criteria are referred to as specialist cancer nurses. In this report we also refer to Clinical Nurse Specialists (CNS), who have a specific job title and are a subset of specialist cancer nurses. For Northern Ireland, these terms are almost coterminous as 96.9% of the total specialist cancer nurse workforce is made up of CNSs.

2. Context and background

The Northern Ireland Cancer Services Framework (2009) states that all patients should be assessed by a CNS at the time of diagnosis, at the end of each stage of treatment and, where necessary, throughout their cancer journey.[14] The results of this latest specialist adult cancer nurses census in Northern Ireland will help commissioners and service providers to monitor the success of this service framework standard by looking at geographical variations and tumour group differences.

At the last Northern Ireland Assembly Election in 2011, there was cross-party support for an increase in CNS numbers to ensure that everyone newly diagnosed with cancer had access to one. However, despite broad political backing for the service framework standard, the intervening years have seen only a small rise in specialist adult cancer nurses numbers. The 2011 Northern Ireland cancer network census identified 56 nurses[15], this census identified only one additional nurse. This growth is not sufficient to keep pace with the growing cancer population.

Every year in Northern Ireland, 9,000 people are diagnosed with cancer (this excludes 3,738 cases of common but not generally serious non-melanoma skin cancer)[26]. In total, 55,000 people are currently living with cancer – and that number is expected to rise to more than 110,000 by 2030, if current trends continue.[16]

Now, more than ever, the specialist workforce has a vital role to play in delivering high-quality, compassionate and person-centred care. In line with the Department of Health's 'Transforming Your Care' policy (2011)[17], this includes providing care closer to home and supporting a drive for efficiency, while improving health outcomes and maximising resources.

The CNS role is at the heart of Macmillan's strategic partnership with the Health and Social Care Board on Transforming Cancer Follow Up (TCFU), which is designed to change the way cancer services are delivered. The TCFU initiative extends beyond the hospital setting into the local community. It focuses on informed individual care planning that enables patients to self-manage their condition, while ensuring appropriate surveillance is provided in a timely manner. As the first point of contact, the CNS works closely with patients and clinical colleagues to respond to patients' emerging needs, reducing emergency admissions and unplanned care and arranging rapid access to support if required.

The sustainability and growth of TCFU depends on the provision of adequate CNS numbers. The programme has not yet achieved its full potential in some tumour groups due to the lack of specialist cancer nurses.[18]

The National Cancer Peer Review Report for Northern Ireland (2010) consistently highlighted the lack of adequate CNS staffing as a limitation on the quality of services provided across the different health trusts. The 2010 report called for a review of specialist workforce numbers.[19] A second round of the review of cancer multidisciplinary teams (MDTs) in Northern Ireland will take place later this year, and will provide an opportunity to compare the two sets of data in order to draw further insights.

The Public Health Agency has also commissioned Northern Ireland's first cancer patient experience survey (CPES) in partnership with Macmillan, which will start in November 2014. The results are expected to be published in mid 2015 and will provide further information about the impact of the specialist workforce and the percentage of patients who have access to a CNS.

Recent analysis of patient experience surveys in England and Wales have clearly demonstrated the correlation between patients reporting they had a named CNS in charge of their care and more favourable patient experience. The results in Wales showed that, where a CNS took on the role of key worker, patient experience was further improved.[20]

Patients frequently identify CNSs as one of the most important health care professionals they come into contact with.[20] This survey of the specialist workforce will allow commissioners, service providers and clinical teams to benchmark the provision and deployment of CNS staff. Understanding patterns of access is fundamental when it comes to matching the specialist workforce to patients' needs. Every cancer patient should have access to a CNS, regardless of their type of cancer or where they live.

2.1 Headline findings

Total specialist adult cancer nursing workforce
The census of the specialist adult cancer nursing workforce in Northern Ireland achieved a response rate of 100%. Returns were received from all five Health and Social Care Trusts in the Northern Ireland Cancer Network.

The total reported specialist adult cancer nursing workforce for the Northern Ireland Cancer Network in 2014 was 57.4 WTE, compared with 56.1 in 2011 (after community oncology posts are excluded). This represents a 2% increase in WTE over three years.

Breast cancer is the most common majority area of practice (33.8% of specialist adult cancer nurses WTE). This is the same as in 2011. This was followed by lung (13.1%) and colorectal cancer specialists (11.3%). There are important variations in the numbers of CNSs per tumour site, in particular the census found only one brain / central nervous system (CNS), one Acute Oncology Service and one sarcoma nurse in Northern Ireland.

Numbers of posts have marginally increased in five areas of practice (breast, colorectal, gynaecology, urology and upper GI), reduced in two others (haematology and malignant dermatology) and stayed the same in five (acute oncology services, brain and central nervous system, head and neck, lung and sarcoma) since 2011.

Of the total specialist cancer nursing workforce WTE in Northern Ireland, 15% (8.6 WTE) were reported as providing cover for cancers of unknown primary. The main areas of practice reporting providing this cover were breast (4 out of 19 WTE) and colorectal (2 out of 7 WTE) specialist adult cancer nurses.

Clinical Nurse Specialists

The largest section of the specialist adult cancer nursing workforce by job title was adult Clinical Nurse Specialist – equivalent to 55.6 WTE (97.0% of the total workforce). There were 1.8 WTE nurse practitioners.

Overall, 79.4% of CNSs were banded at Agenda for Change (AfC) band 7; the remaining were band 6. There are no band 8 AfC (nurse consultant posts or other senior practitioners) reported in the specialist adult cancer nursing workforce in Northern Ireland.

Macmillan specialist cancer nurses

In total, 31% of the specialist adult cancer nursing population in Northern Ireland are titled Macmillan Cancer Support posts, compared to 31% in 2011.

Vacancies

This census was the first specialist adult cancer nurse census to collect data on vacancies. The reported vacancy rate is relatively low compared to the job vacancies per 100 employee jobs in human health and social work activities (not specific to any area of practice) in the UK measured by the Office for National Statistics vacancy survey[20].

Workforce characteristics

All reported post holders were female.

Data on the age profile of filled posts highlights that 30% of the total specialist cancer nursing workforce in Northern Ireland were reported as being over 50 years of age, with one post holder under 30 years of age.

Out of the 6.5 WTE in nurses in lung cancer care 3 were over 50. 3.4 WTE of the 6.5 WTE nurses in colorectal cancer care are aged 50 or over.

There are no reported specialist cancer nurses over the age of 59 in Northern Ireland.

Ratio of nurses

When provision of specialist adult cancer nursing posts is mapped to incidence of cancer in Northern Ireland, the ratio varies from 70 in sarcoma to 355 in urology.

When provision of specialist adult cancer nursing posts is mapped to the number of people living up to two years post a cancer diagnosis (two-year prevalence in 2010), the ratios vary from 103 in sarcoma to 577 in urology.

3. 2014 census results

This section presents detailed data collected in the census supporting headline findings. New data is presented for the first time on the age and gender of post holders, posts that are vacant and data on WTEs that reported supporting cancer of unknown primary.

Table 1: Total specialist adult cancer nursing workforce by area of practice and Health and Social Care Trust, WTE, Northern Ireland, 2014.

The area of practice with the largest proportion of the workforce is reported as breast cancer, accounting for about 34% of the total reported specialist cancer nursing workforce. This is followed by lung (about 13%) and colorectal (about 11%).

Health and Social Care Trust	Acute oncology service	Brain/central nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only*	Urology – All uro-oncology*	Total
Belfast Health and Social Care Trust	0	1.0	7.0	1.0	2.0	2.0	1.0	2.0	0	1.0	2.0	0.6	1.0	20.6
Northern Health and Social Care Trust	0	0	3.4	0.5	0	1.0	0	1.5	0	0	0	0	0	6.4
South Eastern Health and Social Care Trust	0	0	2.8	2.0	1.0	1.0	1.0	1.0	1.8	0	0	0	1.0	11.6
Southern Health and Social Care Trust	1.0	0	2.6	2.0	0.5	1.0	0	1.0	0	0	0.5	0	0	8.6
Western Health and Social Care Trust	0	0	3.6	1.0	0.6	0	1.0	2.0	0	0	0	0	2.0	10.2
Total	1.0	1.0	19.4	6.5	4.1	5.0	3.0	7.5	1.8	1.0	2.5	0.6	4.0	57.4

*The urology specialist adult cancer nurse workforce has been divided into two groups to uncover the size of the specialist prostate cancer workforce. A majority area of practice of 'Urology – prostate only' was defined as a nurse post where 95% or more of the time the nurse spends in adult cancer care is in prostate cancer or suspected prostate cancer. 'Urology -All uro-oncology' is the rest of the urology specialist adult cancer nurse workforce who spend less than 95% of their time in adult cancer care in prostate cancer or suspected prostate cancer. This definition is designed to identify only the most specialised nurses as a generalist urology nurse may expect to see frequent cases of prostate cancer given the high incidence of prostate cancer. It can be difficult for lead cancer nurses to accurately and consistently classify nurses so the data should be used to build a general picture of the urology workforce rather than draw detailed quantitative conclusions.

Fig. 1: Total specialist adult cancer nursing workforce by area of practice, WTE, Northern Ireland, 2014.

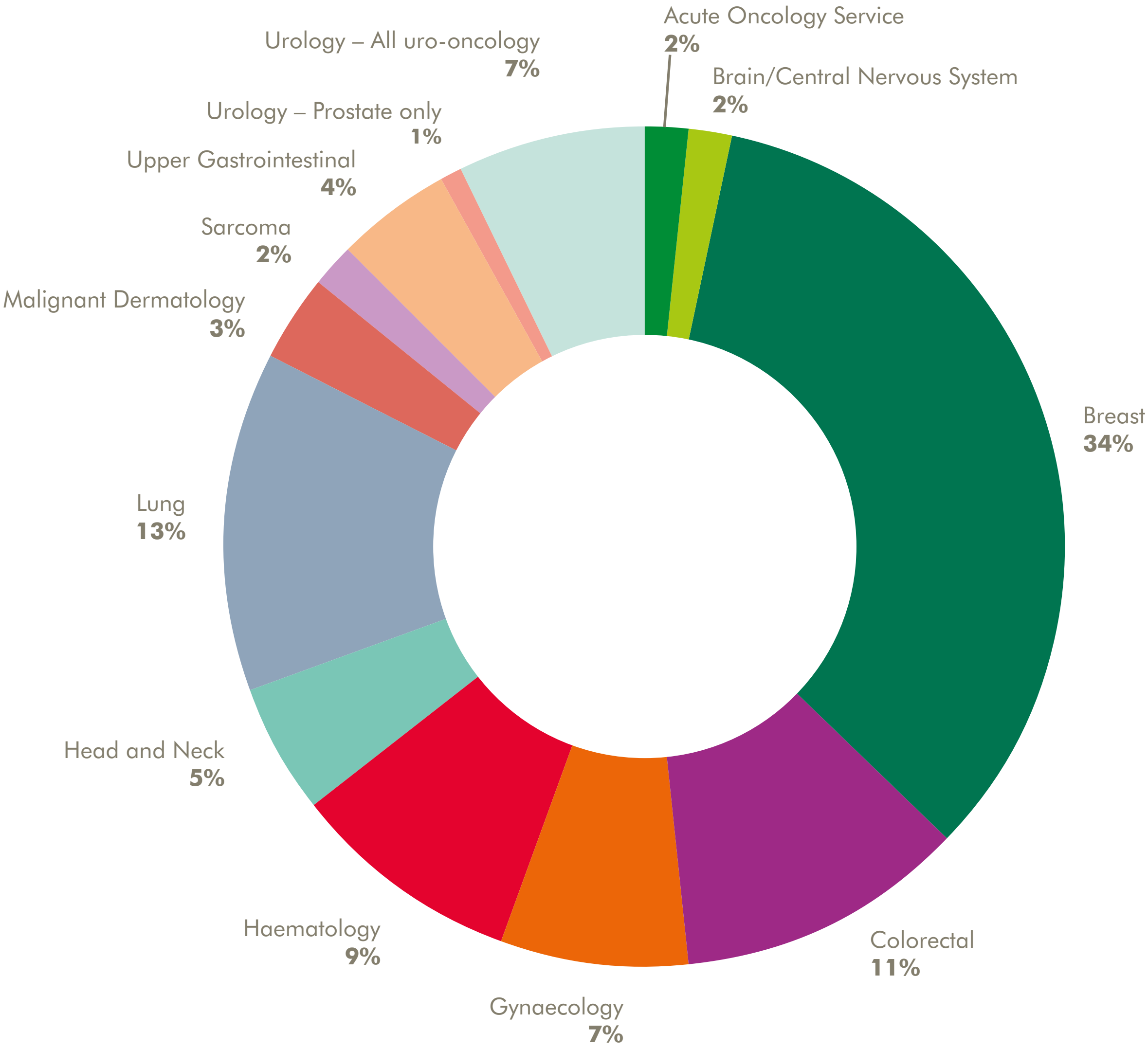


Table 2: Clinical Nurse Specialist (CNS) workforce by area of practice and Health and Social Care Trust, WTE, Northern Ireland, 2014

The area of practice with the largest proportion of the CNS workforce is reported as breast cancer, accounting for about 33% of CNSs, followed by lung (about 13%) and colorectal (about 12%).

Health and Social Care Trust	Acute oncology service	Brain/central nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only	Urology – All uro-oncology	Total
Belfast Health and Social Care Trust	0	1.0	5.8	1.0	2.0	2.0	1.0	2.0	0	1.0	2.0	0	1.0	18.8
Northern Health and Social Care Trust	0	0	3.4	0.5	0	1.0	0	1.5	0	0	0	0	0	6.4
South Eastern Health and Social Care Trust	0	0	2.8	2.0	1.0	1.0	1.0	1.0	1.8	0	0	0	1.0	11.6
Southern Health and Social Care Trust	1.0	0	2.6	2.0	0.5	1.0	0	1.0	0	0	0.5	0	0	8.6
Western Health and Social Care Trust	0	0	3.6	1.0	0.6	0	1.0	2.0	0	0	0	0	2.0	10.2
Total	1.0	1.0	18.2	6.5	4.1	5.0	3.0	7.5	1.8	1.0	2.5	0	4.0	55.6

Fig. 2: Total CNSs by area of practice, percentage, Northern Ireland, WTE, 2014

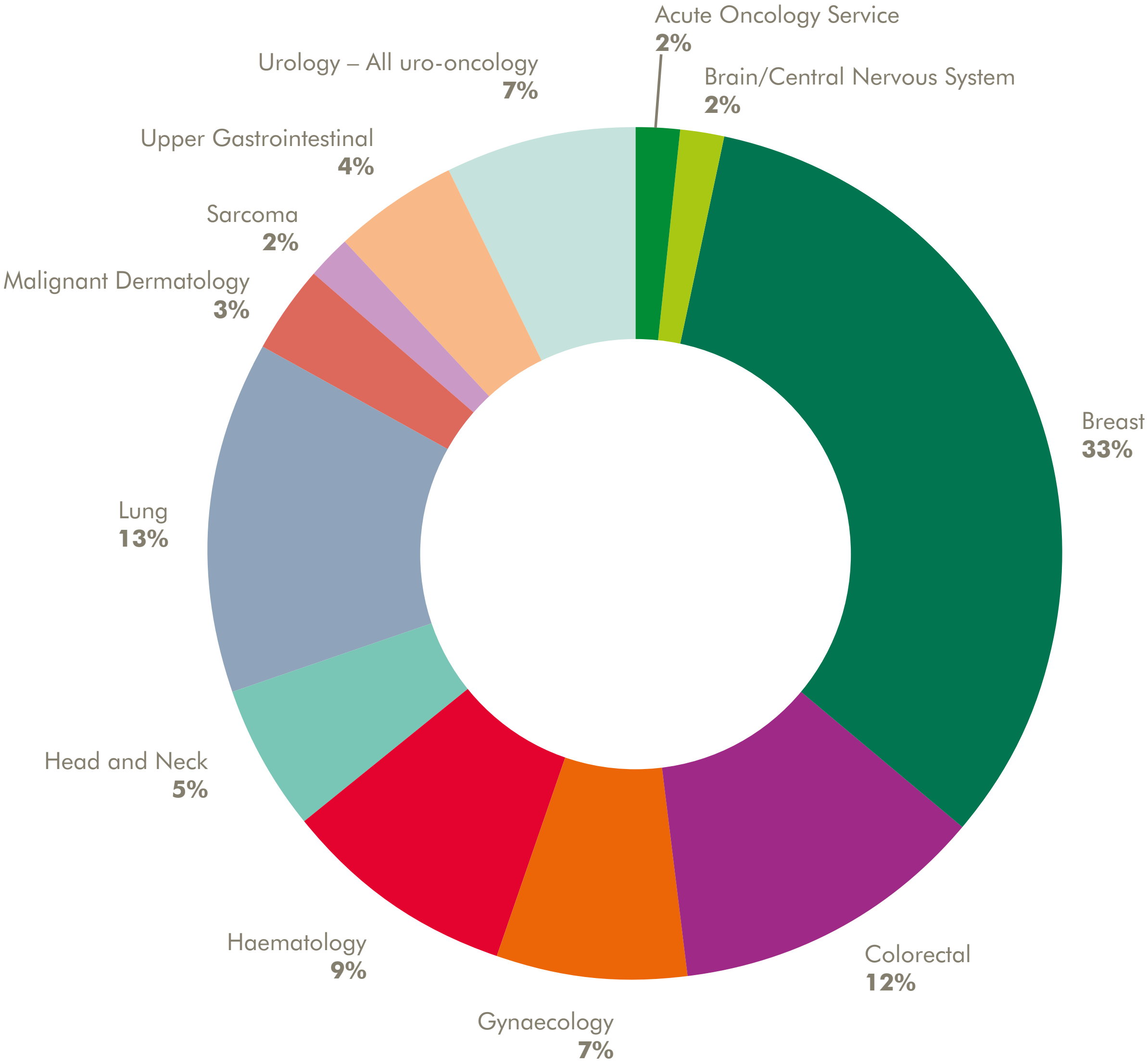


Table 3: Total specialist adult cancer nursing workforce by job title and area of practice, WTE, Northern Ireland, 2014

There was no reported advanced nurse practitioners, nurse consultants or nurse specialists across all areas of practice.

Area of practice	Advanced nurse practitioner	Clinical nurse specialist	Nurse consultant	Nurse practitioner	Nurse specialist	Other	Total
Acute oncology service	0	1.0	0	0	0	0	1.0
Brain/central nervous system	0	1.0	0	0	0	0	1.0
Breast	0	18.2	0	1.2	0	0	19.4
Colorectal	0	6.5	0	0	0	0	6.5
Gynaecology	0	4.1	0	0	0	0	4.1
Haematology	0	5.0	0	0	0	0	5.0
Head and neck	0	3.0	0	0	0	0	3.0
Lung	0	7.5	0	0	0	0	7.5
Malignant dermatology	0	1.8	0	0	0	0	1.8
Sarcoma	0	1.0	0	0	0	0	1.0
Upper gastrointestinal	0	2.5	0	0	0	0	2.5
Urology – prostate only	0	0	0	0.6	0	0	0.6
Urology – All uro-oncology	0	4.0	0	0	0	0	4.0
Total	0	55.6	0	1.8	0	0	57.4

Fig. 3: Total specialist adult cancer nursing workforce by job title, WTE, Northern Ireland, 2014

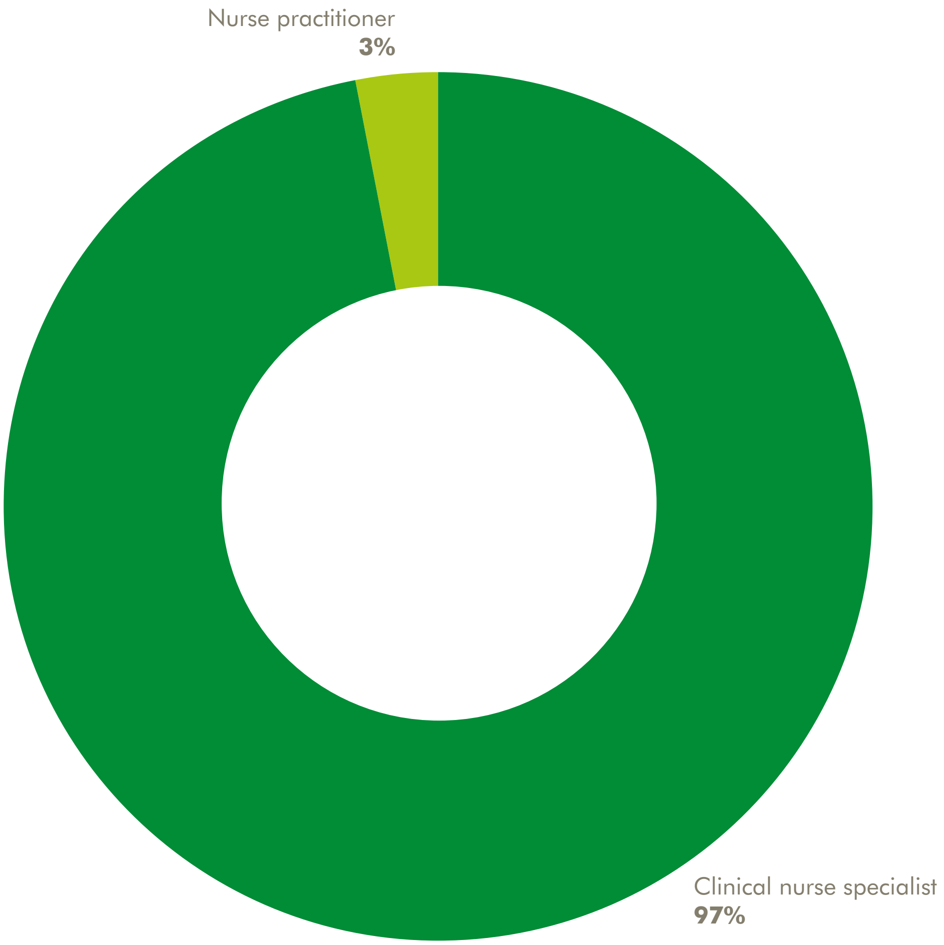


Table 4: CNS workforce by Agenda for Change (AfC) banding and area of practice, WTE, Northern Ireland, 2014

Band 7 posts make up the largest proportion of the reported WTE, accounting for about 79%. The band 6 posts are mainly in breast cancer care. 49% of the breast cancer workforce (WTE) is in band 6. The rest of the band 6 workforce is in colorectal cancer care.

Area of practice	Band 6	Band 7	Band 8a and above	Not known	Total
Acute oncology service	0	1.0	0	0	1.0
Brain/central nervous system	0	1.0	0	0	1.0
Breast	9.4	8.8	0	0	18.2
Colorectal	2.0	4.5	0	0	6.5
Gynaecology	0	4.1	0	0	4.1
Haematology	0	5.0	0	0	5.0
Head and neck	0	3.0	0	0	3.0
Lung	0	7.5	0	0	7.5
Malignant dermatology	0	1.8	0	0	1.8
Sarcoma	0	1.0	0	0	1.0
Upper gastrointestinal	0	2.5	0	0	2.5
Urology – Prostate only	0	0	0	0	0
Urology – All uro-oncology	0	4.0	0	0	4.0
Total	11.4	44.2	0	0	55.6

No band 5 posts were reported

Fig. 4: Total specialist adult cancer nursing workforce by Agenda for Change banding, percentage, Northern Ireland, 2014

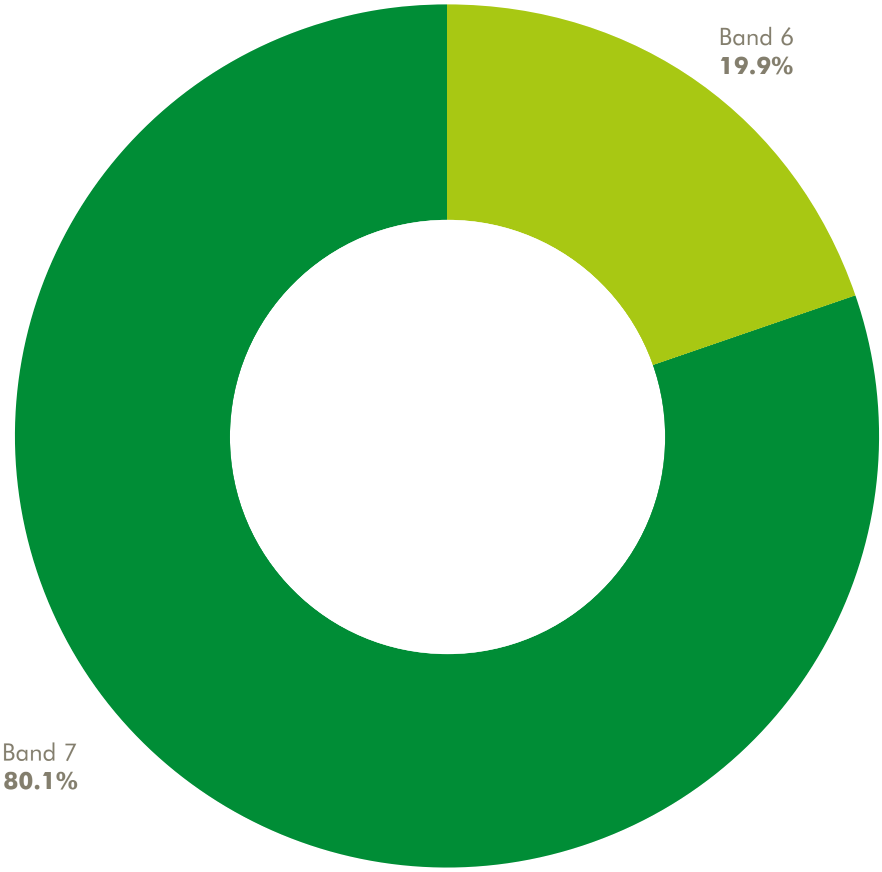


Table 5: Macmillan specialist cancer nurse workforce, WTE, Northern Ireland, 2014

Macmillan Cancer Support continues to provide support for 31% of the reported WTE.

Macmillan Cancer Support posts	WTE
Macmillan CNS	16.8
Other Macmillan cancer specialists	1.0
Total	17.8

Fig. 5: Specialist adult cancer nursing workforce Macmillan Cancer Support posts, CNS and other, percentage, WTE, Northern Ireland, 2014

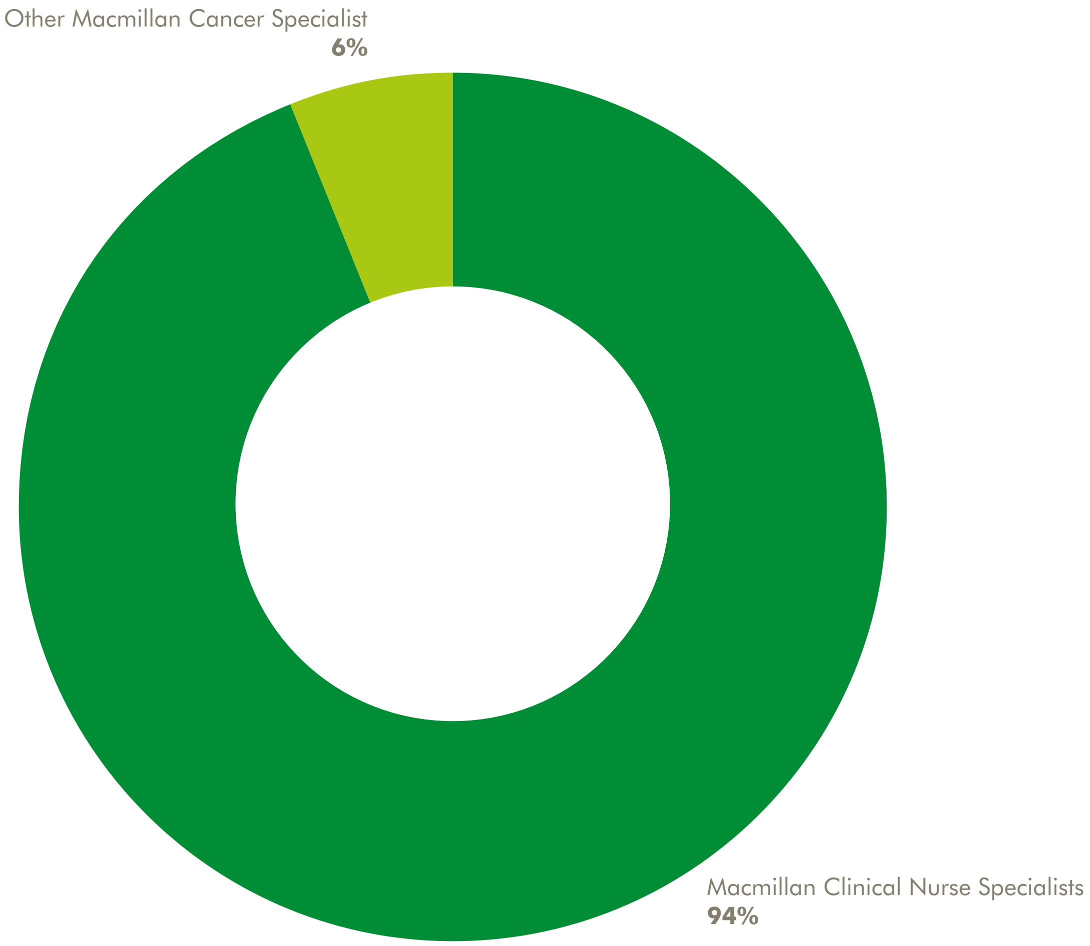


Fig. 5a: Macmillan Cancer Support specialist adult cancer nursing workforce as a proportion of total specialist adult cancer nursing workforce by area of practice, WTE, Northern Ireland, 2014

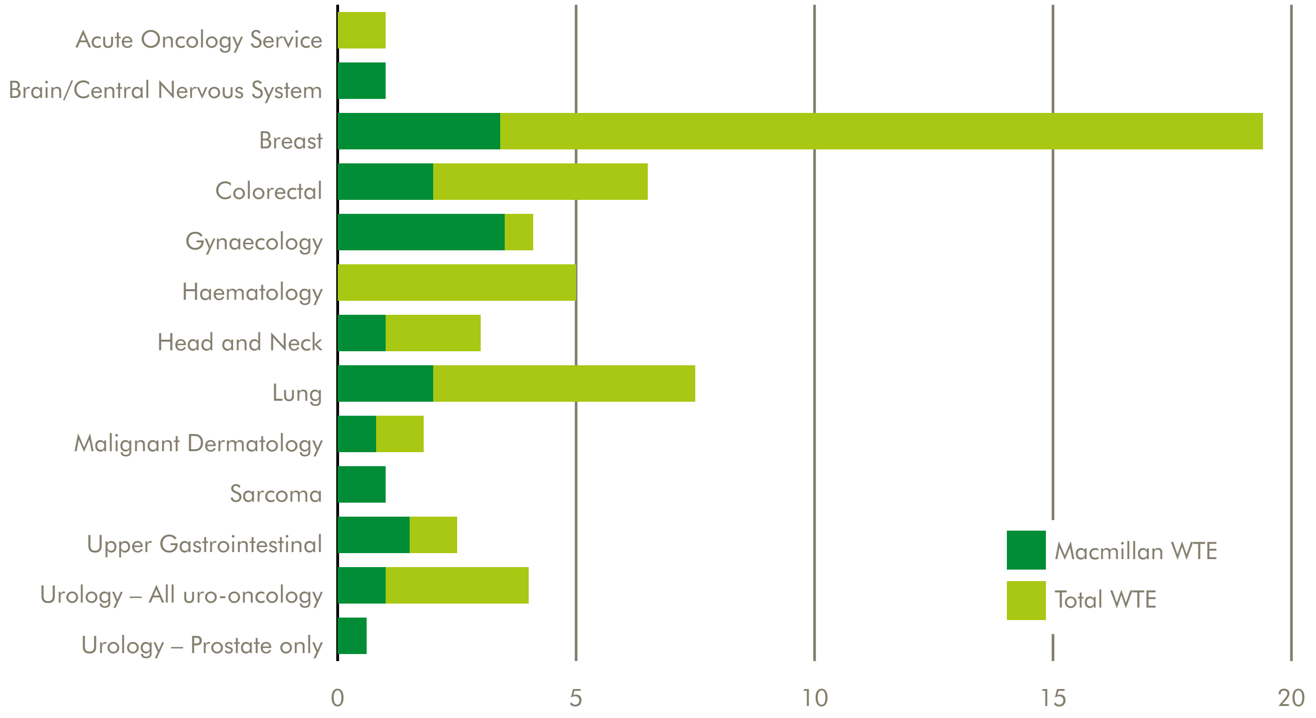


Table 6: Total specialist adult cancer nursing workforce reporting cover for cancer of unknown primary, WTE, Northern Ireland, 2014

This is the first time that this data has been collected and reported. About 15% of the total WTE (filled and vacant posts) was reported as covering cancer of unknown primary.

Does the post/post holder cover cancer of unknown primary?	WTE
Yes	8.6
No	48.8
Not known	0
Total	57.4

Table 7: Total specialist adult cancer nursing workforce reporting cover for cancer of unknown primary by area of practice, WTE, Northern Ireland, 2014

The highest proportion of the posts reported as covering cancer of unknown primary were in breast cancer (about 42% of the total reported WTE covering cancer of unknown primary).

Majority Area of practice	WTE that cover CUP	% of all nurses covering CUP (WTE)
Acute oncology service	1.0	11.6%
Brain/central nervous system	0	0.0%
Breast	3.6	41.9%
Colorectal	2.0	23.3%
Gynaecology	0.5	5.8%
Haematology	0	0.0%
Head and neck	0	0.0%
Lung	1.0	11.6%
Malignant dermatology	0	0.0%
Sarcoma	0	0.0%
Upper gastrointestinal	0.5	5.8%
Urology – prostate only	0	0.0%
Urology – All uro-oncology	0	0.0%
Total	8.6	100.0%

Table 8: Total specialist adult cancer nursing workforce by gender, WTE, Northern Ireland, 2014

This is the first time that this data has been collected and reported. All of the WTEs are reported as female.

Gender	WTE	% of total (WTE)
Female	56.4	100.0%
Male	0.0	0.0%
Declined	0.0	0.0%
Not known	0.0	0.0%
Total	56.4	100.0%

Table 9: Total specialist adult cancer nursing workforce by Agenda for Change banding and gender, WTE, Northern Ireland, 2014

The majority of reported WTE are females populating band 7 posts (about 81%). There are no WTE reported at bands 8a and above.

Gender	5	6	7	8a	8b	8c	8d	9	Not known	Total
Female	0	11.4	45.0	0	0	0	0	0	0	56.4
Male	0	0	0	0	0	0	0	0	0	0
Declined	0	0	0	0	0	0	0	0	0	0
Not known	0	0	0	0	0	0	0	0	0	0
Total	0	11.4	45.0	0	0	0	0	0	0	56.4

Table 10: Total specialist adult cancer nursing workforce by area of practice and gender, WTE, Northern Ireland, 2014

The highest proportion of WTE by area of practice for females is reported as breast cancer (about 34% of filled posts). There were no reported WTE for males. The lowest WTE was reported in acute oncology service, brain/central nervous system and sarcoma (1 filled post in each).

Area of practice	Female	Male	Declined	Not known	Total
Acute oncology service	1.0	0	0	0	1.0
Brain/central nervous system	1.0	0	0	0	1.0
Breast	19.4	0	0	0	19.4
Colorectal	6.5	0	0	0	6.5
Gynaecology	4.1	0	0	0	4.1
Haematology	5.0	0	0	0	5.0
Head and neck	3.0	0	0	0	3.0
Lung	6.5	0	0	0	6.5
Malignant dermatology	1.8	0	0	0	1.8
Sarcoma	1.0	0	0	0	1.0
Upper gastrointestinal	2.5	0	0	0	2.5
Urology – Prostate only	0.6	0	0	0	0.6
Urology – All uro-oncology	4.0	0	0	0	4.0
Total	56.4	0	0	0	56.4

Table 11: Total specialist adult cancer nursing vacancies by Agenda for Change band, WTE, Northern Ireland, 2014

In the United Kingdom in April and June 2014, there were 2.4 vacancies per 100 employee jobs overall and 2.4 vacancies per 100 employee jobs in human health and social work activities[21]. In this census, in Northern Ireland, we found one vacant post per 67 filled jobs – equivalent to 1.5 vacancies per 100 filled jobs. Although the rates are not directly comparable, this suggests that there may be fewer vacancies amongst specialist cancer nurses in Northern Ireland than there are across the UK as a whole.

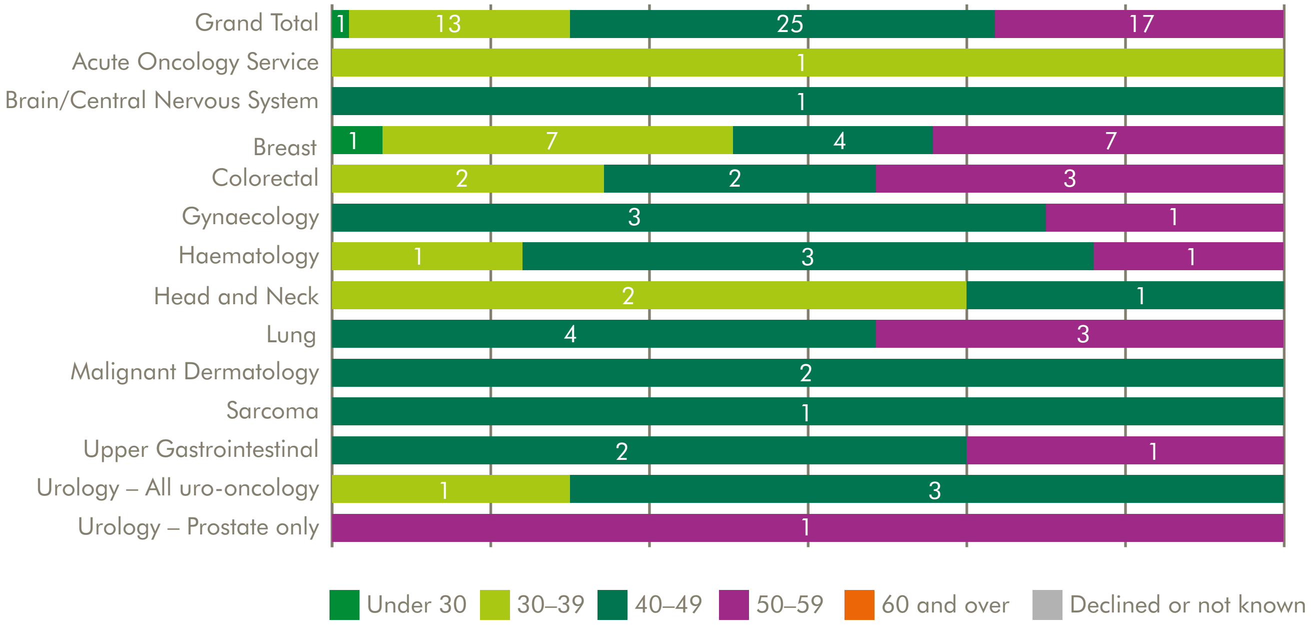
Band	5	6	7	8a	8b	8c	8d	9	Total
Number of vacancies (WTE)	0	0	1.0	0	0	0	0	0	1.0

Table 12: Specialist adult cancer nursing workforce by area of practice and age banding, WTE, Northern Ireland, 2014

The highest WTE is reported as age 40–49 (about 44% of the total reported WTE). None of the total reported WTE were age 60 and over. (Data may indicate that the specialist cancer nursing workforce stops working before they reach the age of 60 as there are many nurses in the age 50 to 59 age group).

Age range	Acute oncology service	Brain/ nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only	Urology – All uro-oncology	Percentage of total
Under 30	0.0% (0.0)	0.0% (0.0)	100.0% (1.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	1.8% (1.0)
30–39	7.4% (1.0)	0.0% (0.0)	50.9% (6.8)	11.9% (1.6)	0.0% (0.0)	7.4% (1.0)	14.9% (2.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	7.4% (1.0)	23.8% (13.4)
40–49	0.0% (0.0)	4.0% (1.0)	16.6% (4.2)	6.0% (1.5)	12.4% (3.1)	12.0% (3.0)	4.0% (1.0)	14.0% (3.5)	7.2% (1.8)	4.0% (1.0)	8.0% (2.0)	0.0% (0.0)	12.0% (3.0)	44.4% (25.1)
50–59	0.0% (0.0)	0.0% (0.0)	43.8% (7.4)	20.1% (3.4)	5.9% (1.0)	5.9% (1.0)	0.0% (0.0)	17.8% (3.0)	0.0% (0.0)	0.0% (0.0)	3.0% (0.5)	3.6% (0.6)	0.0% (0.0)	30.0% (16.9)
60 and over	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)
Declined	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)
Not known	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)
% of total	1.8% (1.0)	1.8% (1.0)	34.4% (19.4)	11.5% (6.5)	7.3% (4.1)	8.9% (5.0)	5.3% (3.0)	11.5% (6.5)	3.2% (1.8)	1.8% (1.0)	4.4% (2.5)	1.1% (0.6)	7.1% (4.0)	100.0% (56.4)

Fig. 6: Filled specialist cancer nursing workforce, by majority area of practice and age banding, WTE, Northern Ireland, 2014



4. Ratio of specialist adult cancer nursing workforce to incidence and two year-prevalence

It is important to put the variation in the distribution of specialist cancer nurses in the context of the varying levels of need. It is impossible to do this while fully taking into account the many aspects of need and service design. However, as a very crude measure, we have mapped WTE onto new cancer cases (incidence in 2012) and onto the number of people living up to two years post a cancer diagnosis (two-year prevalence in 2010).

However, there are many caveats to this approach. These ratios do not, therefore, reflect the caseload of the specialist nurse, nor do they demonstrate the variations in the level of support needed depending on the type and stage of cancer.

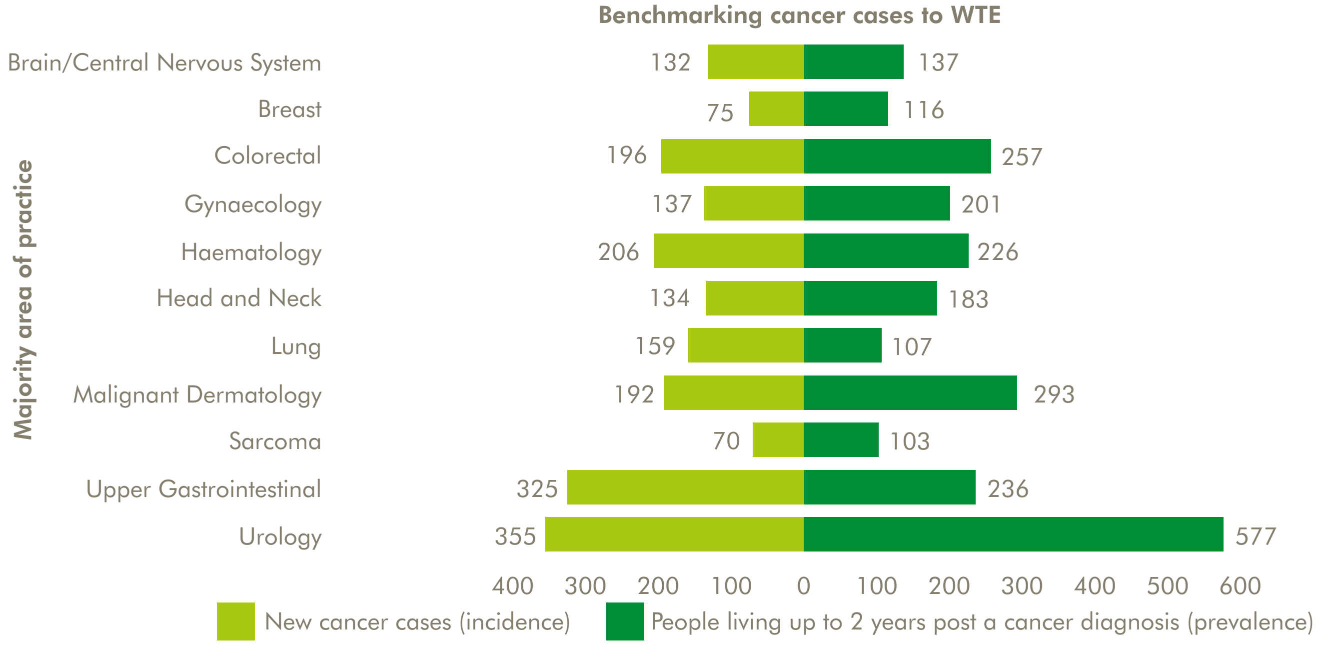
Table 13: Range of ratios of incidence and two-year prevalence per WTE by area of practice, Northern Ireland, 2014

	New cancer case (incidence) per WTE	People living up to two years post cancer diagnosis (prevalence) per WTE
Brain/central nervous system	132	137
Breast	75	116
Colorectal	196	257
Gynaecology	137	201
Haematology	206	226
Head and neck	134	183
Lung	159	107
Malignant dermatology	192	293
Sarcoma	70	103
Upper gastrointestinal	325	236
Urology	355	577

Source: Two-year prevalence data sourced from National Cancer Intelligence Network. 2014. Macmillan-NCIN work plan – 20-year cancer prevalence for the period 1991–2010 by cancer type for each UK nation, the UK combined and England Strategic Clinical Networks. Data sourced and presented in collaboration with the Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, the Information Services Division Scotland and the Northern Ireland Cancer Registry. For cancer definitions, see appendix.

Source: Incidence data sourced from personal correspondence with the biostatisticians/researchers at the Northern Ireland Cancer Registry (August 2014).

Fig. 7: Specialist cancer nursing workforce ratios against incidence and prevalence for Northern Ireland overall, WTE, 2014



The figure above shows the variation in the ratios across tumour types. For both measures, urology has the highest ratio of cases per WTE. This is based on the assumption that urology nurses are responsible for a diverse cancer population that includes large numbers of prostate cancer cases as well as bladder, kidney, testicular cancer and carcinoma in situ cases.

The differences in the pattern seen in the ratio of new cases and people living up to two years post a cancer diagnosis mainly reflects the differences in short term survival. This also highlights the complexity of the issue and the sophistication needed in workforce planning.

5. Observations and areas for further exploration

There appears to have been a very small increase in the numbers of specialist adult cancer nurses (WTE) since 2011.

As both incidence and prevalence of cancer increase in Northern Ireland[16,] inequities exist between different tumour types in terms of the provision of specialist adult cancer nursing posts.

The previously identified gaps in CNS provision have increased and this must be addressed to fulfil the commitment that everyone newly diagnosed with cancer has access to a CNS.

This census has found only one acute oncology services post – the same as in 2011. Funding has now been agreed with Macmillan for seven posts across Northern Ireland, to deliver a Northern Ireland-wide service.

The variation in area of practice of posts holders covering cancer of unknown primary suggests that there are no clearly agreed care pathways. Further work is required to establish how best to meet the needs of people with cancer of unknown primary and how to support the workforce to deliver this care. This will be addressed through the development of the acute oncology service within Northern Ireland.

Macmillan continues to develop new posts to support clinical nurse specialist and advanced nurse practitioner posts to improve their expertise, as support worker roles have been demonstrated to release as much as 30% of CNS capacity.[25]

Clearly, the combination of an increase in incidence and prevalence and a lack of growth in specialist cancer nurse capacity requires concerted and coordinated plans to address.

Summary

There appears to have been a marginal increase in CNS posts since 2011.

However, the specialist adult cancer nursing workforce in general is not expanding sufficiently to keep pace with the growing numbers of people being diagnosed and living with cancer.

This census provides intelligence in assessing how far commitments set out in the Northern Ireland Cancer Services Framework (2009) have been achieved.

However, despite broad political backing for the service framework standard, the intervening years have seen only a small rise in CNS numbers. The 2011 Northern Ireland cancer network census identified 56 nurses[15], this census identified only one additional nurse. This growth is not sufficient to keep pace with the growing cancer population.

Furthermore, delivery of the joint initiative between Macmillan and the Health and Social Care Board TCFU, which relies on the provision of adequate CNS numbers, has not yet achieved its full potential in some tumour groups due to the lack of specialist cancer nurses.[18]

Future planning and recommendations

Those responsible for commissioning services will undoubtedly be expecting value for money as well as high-quality services for patients. Workforce planning will be crucial in achieving improvements in outcomes, and the specialist cancer nursing census is a valuable tool to inform commissioning networks and other funding bodies in the drive for world-class cancer services.

There are still marked inequities in the provision of specialist nursing expertise for those diagnosed with different cancer types, as well as some degree of variance across geographical locations. Evidence from all the recent National cancer patients experience surveys in England and Wales pointed towards the provision of specialist nursing expertise as an important indicator of the quality of cancer services and the experience of care reported by patients.

Commissioners and providers may therefore be interested in examining the ratio of specialist nurses to new cases of cancer within their localities more closely, along with data from hospital trust patient experience surveys and other sources such as the National Cancer Peer Review programme.

In the context of the severe financial constraints in Northern Ireland, Macmillan service development teams would wish to support this analysis and to work in partnership to establish a joint plan to reform and modernise the specialist cancer nursing workforce.

Proposals for future work

In thinking about the future specialist cancer nursing workforce, Macmillan has published a discussion document to encourage consideration and debate about how best to respond to the challenges facing the UK's health and social care systems. As people live longer, the incidence of cancer and other long-term conditions continues to rise, leading to an increase in the number of people with multiple health issues. Multiple morbidities are becoming the norm, with many people with cancer also living with two or more other conditions.[24]

In this context, Macmillan is looking at what the cancer care teams of the future must look like. They will need to be more flexible, working with people living with cancer to identify their concerns and support them in managing their own care. The specialist cancer nursing workforce will be a key part of a whole system of care that will need to be required to support the growing numbers of people living in the community after a cancer diagnosis.

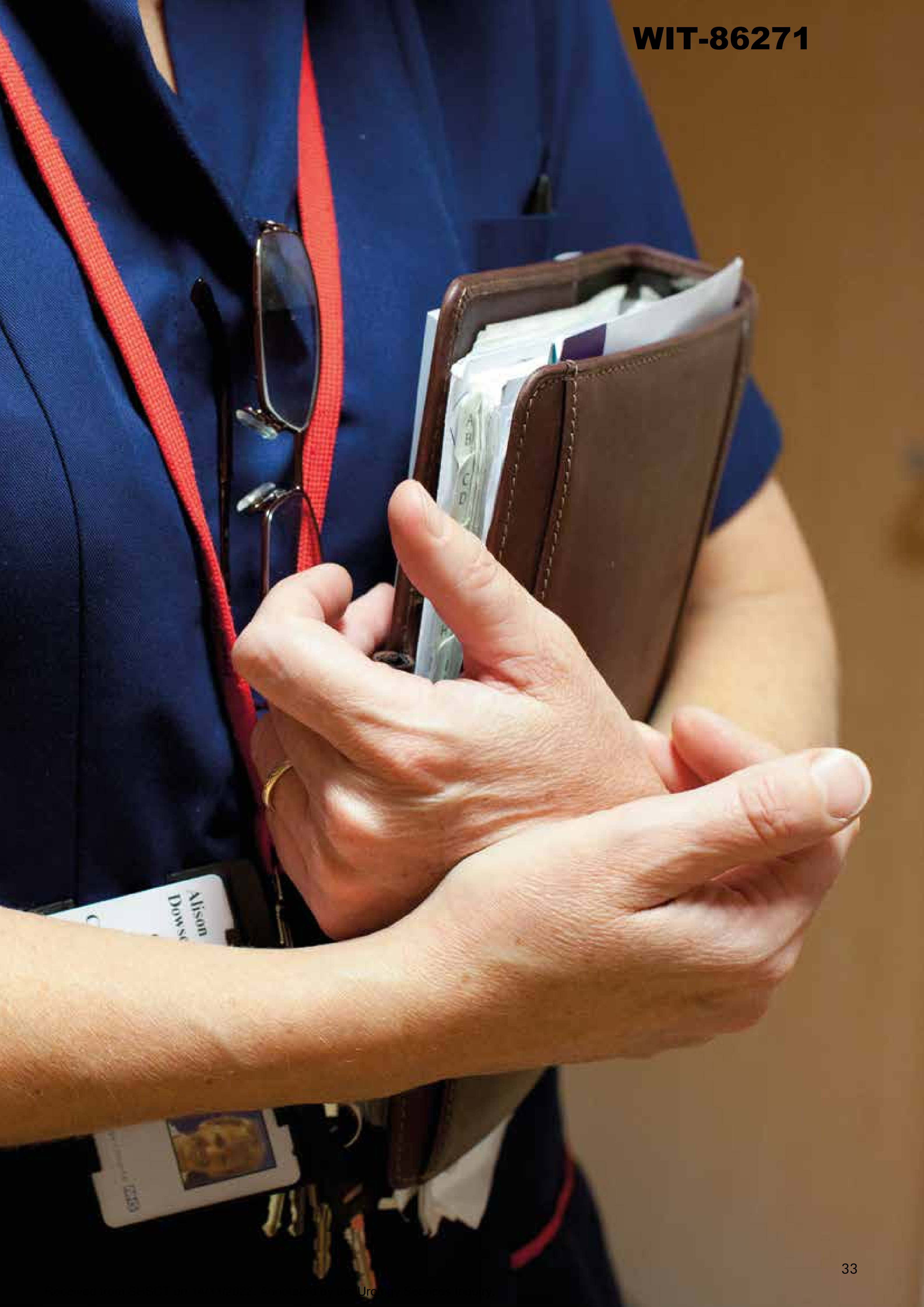
Macmillan's plans include:

- identifying how best to optimise the specialist cancer nurse workforce, building on the success of introducing skill mix in our One-to-One Support pilots, where support workers have been demonstrated to release CNS time for more complex care;
- re-establishing a role development programme that will support nurses wishing to establish themselves as specialists in cancer care;
- developing new roles that will support people with complex care coordination at key points in their care pathway;
- mapping interventions that specialist nurses offer across different cancer patient pathways to determine best practice; and
- continuing the specialist cancer nursing census every two years.

The Public Health Agency has also commissioned Northern Ireland's first cancer patient experience survey, in partnership with Macmillan. The results are expected to be published in mid 2015 and will provide further information about the impact of the specialist workforce and the percentage of patients with access to a CNS. Recent analysis of patient experience surveys in England and Wales have clearly demonstrated the correlation between access to a CNS and more favourable patient experience. The results also showed that in Wales, where a CNS took on the role of key worker, patient experience was further improved.[20]

Macmillan will continue work with partners to explore the use of markers other than incidence and two-year prevalence to help estimate the true caseload of specialist nurses, such as volume of patients seen by a multidisciplinary team.

Additionally, Macmillan will continue to work with its partners at the Health and Social Care Board, Public Health Agency, National Cancer Peer Review team, the Northern Ireland Cancer Network, Department of Health, Social Service and Public Safety, charitable organisations and the Centre for Workforce Intelligence, with the aim of providing robust data on this important element of the specialist cancer workforce and addressing inequities wherever they are identified.


Alison

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Appendix

Cancer definitions used calculating the ratio of specialist adult cancer nursing workforce by incidence and two-year prevalence

Majority area of practice	**Cancer types used in the ratios**
Brain/nervous system	Incidence is based on brain and nervous system (C47, C70–C72, C75.1–C75.3), two-year prevalence is based on brain, nervous system and eye, including benign neoplasm (C47, C69, C70–C72, D33)
Breast	Breast with in situ (C50,D05)
Colorectal	Colorectal with anus (C18–21)
Gynaecology	Gynaecology (C51–C58)
Haematology	Haematology (C81–C85, C88, C90–C96)
Head and neck	Head and neck with thyroid (C00–C14, C30–C32, C73)
Lung	Respiratory (C33–C34, C37–C39, C45)
Malignant dermatology	Skin – malignant melanoma (C43)
Sarcoma	Sarcoma (C40–C41, C46, C48–C49)
Upper gastrointestinal	Upper GI (C15–C16, C22–C25)
Urology	Urology including prostate and testicular (C60–C68) and bladder in situ (D09 in the incidence data and D090 in the two-year prevalence)

The census and report is endorsed by the following bodies:

British Association of Head and Neck Oncology Nurses

National Lung Cancer Forum for Nurses

Breast Cancer Care

National Colorectal Cancer Nurses network

British Association of Urological Nurses

United Kingdom Oncology Nursing Society

Centre for Workforce Intelligence

Mouchel

National Forum of Gynaecological Oncology Nurses

mouchel
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November 23, 2010

Postoutline: ST304 Specialist Nurse Band 7

Created On: 15/06/2010

Created By: Dearbhla Curran

Originating Organisation: Southern Health & Social Care Trust

Post Outline is Approved

Purpose: :

Pay Band: Band 7

Reporting To: Line Manager

KSF Dimensions, Levels And Indicators

Dimension Type	Dimension Number	Dimension Name	Second Gateway (Full Outline)		Foundation Gateway (Subset Outline)	
			Level	Indicator	Level	Indicator
Core	C1	COMMUNICATION	4	A,B,C,D,E,F	4	A,B,C,D,E,F
Core	C2	PERSONAL AND PEOPLE DEVELOPMENT	3	A,B,C,D,E,F,G	3	A,B,C,D
Core	C3	HEALTH, SAFETY AND SECURITY	2	A,B,C,D,E,F	2	B,C,D,E,F
Core	C4	SERVICE IMPROVEMENT	2	A,B,C,D,E,F	2	A,B,C,D,E,F
Core	C5	QUALITY	3	A,B,C,D,E,F,G	3	A,B,C,D,E,F,G
Core	C6	EQUALITY AND DIVERSITY	2	A,B,C,D	2	A,B,C,D
Specific	HWB1	PROMOTION OF HEALTH AND WELLBEING AND PREVENTION OF ADVERSE EFFECTS ON HEALTH AND WELLBEING	2	A,B,C,D,E,F,G	2	A,B,C,D,E,F,G
Specific	HWB6	ASSESSMENT AND TREATMENT PLANNING	3	A,B,C,D,E,F,G,H,I,J	3	A,B,C,D,E,F,G,H,I,J
Specific	HWB7	INTERVENTIONS AND TREATMENTS	3	A,B,C,D,E,F,G,H,I	3	A,B,C,D,E,F,G,H,I

Second Gateway (Full Outline)	**Foundation Gateway (Subset Outline)**
COMMUNICATION - Level: 4	COMMUNICATION - Level: 4
Level Indicators: a) identifies: - the range of people involved in the communication - potential communication differences - relevant contextual factors - broader situational factors, issues and risks b) communicates with people in a form and manner which: - is consistent with their level of understanding, culture, background and preferred ways of communicating - is appropriate to the purpose of the communication and its longer term importance - is appropriate to the complexity of the context - encourages effective communication between all involved - enables a constructive outcome to be achieved c) anticipates barriers to communication and takes action to improve communication d) is proactive in seeking out different styles and methods of communicating to assist longer term needs and aims e) takes a proactive role in producing accurate and complete records of the communication consistent with legislation, policies and procedures f) communicates in a manner that is consistent with legislation, policies and procedures.	**Level Indicators:** a) identifies: - the range of people involved in the communication - potential communication differences - relevant contextual factors - broader situational factors, issues and risks b) communicates with people in a form and manner which: - is consistent with their level of understanding, culture, background and preferred ways of communicating - is appropriate to the purpose of the communication and its longer term importance - is appropriate to the complexity of the context - encourages effective communication between all involved - enables a constructive outcome to be achieved c) anticipates barriers to communication and takes action to improve communication d) is proactive in seeking out different styles and methods of communicating to assist longer term needs and aims e) takes a proactive role in producing accurate and complete records of the communication consistent with legislation, policies and procedures f) communicates in a manner that is consistent with legislation, policies and procedures.

Examples Of Application: Identifies the range of people that effective communication takes place with including patients, relatives the general public all secondary care multidisciplinary team and general practitioners, practice nurses and chronic disease management team. Demonstrates a full understanding of the differences in communication between relatives and the multidisciplinary team, ensuring speech, language and content appropriate for the purpose. Adopts different communication processes to aid patients and their families understand their respiratory condition. Including breaking bad news or imparting sensitive news whilst gaining their consent to initiate care or treatments. Communication differences may relate to different levels of understanding and knowledge regarding their respiratory condition, uses social theories to aid acting as an effective advocate for the patient and their relatives to establish meaningful communication through trust. Use effective history taking to elicit accurate responses, enabling correct deferential diagnosis and effective management plans. Demonstrates effective interpersonal communication skills including

verbal, non-verbal, face to face, e-mailing, letter writing and written reports. Communicates with all multidisciplinary team members in primary and secondary care about complex issues relating to respiratory patients, whilst using a variety of strategies and resources to promote quality patient care. Liaising with external agencies. Communicates with Senior Nurses regarding service delivery. Delivers information regarding audit and research to professionals including research committees , multiprofessional colleagues both internal and external to the Trust. Demonstrates the ability to anticipate barriers such as language, cultural and situational barriers in communication or when effective communication between agencies break down and impact on patient services. Able to seek logical solutions to breakdown in communication and promotes effective communication. Such as communicating with a range of professionals from the multidisciplinary team in negotiating discharge planning of a complex respiratory patient. Discusses how to effectively communicate in difficult circumstances e.g. breaking bad news, addressing complaints about service , speaking in coroners court etc. Demonstrates the ability to seek out different styles and methods to enhance communication and assist long term needs and aims. Such as team meetings where planning long term respiratory goals and focus, teaching sessions. Communicates with senior nurse to present orally and written reports on respiratory service needs and the strategy used to meet desired outcomes. Ensures that all records of communication are timely, clear and accurate in accordance with Trust Guidelines and NMC document standards. Actively promotes writing notes in a timely fashion ensuring best levels of accuracy. Audits notes to of respiratory patients to ensure clarity of management plans. Demonstrates detailed understanding and application of Trusts policies , protocols and guidelines in ensuring accurate and complete documentation , such as sickness and absence records, annual leave records , freedom of information. Maintains confidentiality at all times.

Examples of Application: Demonstrates the ability to anticipate barriers such as language, cultural and situational barriers in communication or when effective communication between agencies break down and impact on patient services. Able to seek logical solutions to breakdown in communication and promotes effective communication. Such as communicating with a range of professionals from the multidisciplinary team in negotiating discharge planning of a complex respiratory patient. Discusses how to effectively communicate in difficult circumstances e.g. breaking bad news, addressing complaints about service , speaking in coroners court etc. Ensures that all records of communication are timely, clear and accurate in accordance with Trust Guidelines and NMC document standards. Actively promotes writing notes in a timely fashion ensuring best levels of accuracy. Audits notes to of respiratory patients to ensure clarity of management plans. Demonstrates detailed understanding and application of Trusts policies , protocols and guidelines in ensuring accurate and complete documentation , such as sickness and absence records, annual leave records , freedom of information. Maintains confidentiality at all times.

Second Gateway (Full Outline)

PERSONAL AND PEOPLE DEVELOPMENT - Level: 3

Level Indicators:

a) reflects on and evaluates how well s/he is applying knowledge and skills to meet current and emerging work demands and the requirements of the KSF outline for his/her post
b) identifies own development needs and sets own personal development objectives in discussion with his/her reviewer
c) takes responsibility for own personal development and maintains own personal development portfolio
d) makes effective use of learning opportunities within and outside the workplace evaluating their effectiveness and feeding back relevant information
e) enables others to develop and apply their knowledge and skills in practice

f) contributes to the development of others in a manner that is consistent with legislation, policies and procedures
g) contributes to developing the workplace as a learning environment.

Foundation Gateway (Subset Outline)

PERSONAL AND PEOPLE DEVELOPMENT - Level: 3

Level Indicators:

a) reflects on and evaluates how well s/he is applying knowledge and skills to meet current and emerging work demands and the requirements of the KSF outline for his/her post
b) identifies own development needs and sets own personal development objectives in discussion with his/her reviewer
c) takes responsibility for own personal development and maintains own personal development portfolio
d) makes effective use of learning opportunities within and outside the workplace evaluating their effectiveness and feeding back relevant information

Examples Of Application: Prepares and participates in own and respiratory team annual KSF PDR in line with the Trust policy, reflecting on all achievements in the last 12 months against set objectives and performance. Reflects on practice regularly using a recognised model of reflection to aid in evaluating knowledge ,skills and practices to recognise areas for improvement and ensure KSF consistent with job outline. Keeps an updated portfolio as recommended by the NMC to reflect on practice and experiences. Identifies and agrees own development need with line manager through annual KSF PDR. Attends specific study days on respiratory care and applying new knowledge and skills to current practice. Attends Trust 's statutory training: fire training, manual handling and lifting and basic life support. Develops own competencies skills in respiratory care, such as arterial blood sampling and non-invasive ventilation and demonstrate competency at all times. Identified skills to develop general respiratory service. Reflects and adopts appropriate practices that respiratory team identify that are needed for the post. Identifies current and future development needs in line with KSF taking an active part in PDR. Keeps updated on Trust policies, protocols and guidelines and utilises in practice. Keeps updated in specific respiratory field reading professional magazines, accessing the internet to identify changing practices . Be fully compliant and updated in professional issues as recommended in NMC Code of Conduct. Meets regularly with peers in respiratory care across region to establish levels of practice and skills , setting targets to meet areas of further development. Initiates regular meetings with line manager and clinical lead to identify any changes requires in current practice, attending work shops and attending conferences to meet specified outcomes. Responsible for the development and support of staff in respiratory team and in clinical areas in relation to respiratory skills, knowledge and practice. Encourages individuals to undertake a honest self assessment of competency and provides the necessary feedback. Challenges team members on poor practice and initiates plans to support in further learning in line with Trust guidelines and protocols. Promotes and enables other staff and multidisciplinary team to apply their skills and knowledge and provides an environment that encourages further learning. Provides clinical supervision for staff within the Trust. Leads the KSF PDRs for individuals within the respiratory team, providing the necessary support for further development and areas for further improvement in line with Trust KSF policy. Actively promotes workplace learning and encourages staff to learn for one another. Provides time for the team to meet and reflect on individual and team performance in delivery of respiratory services. Initiates training sessions and encourages others to make the most of opportunities to develop and apply skills and knowledge. Meets regularly with other respiratory nurses from the region and actively encourages all respiratory team members to participate. Identifies and discusses with senior staff within the Trust, constraints that relate to poor performance of staff and poor respiratory service. Acts as a resource to the Trust to assess, plan and deliver training on numerous respiratory issues (non-invasive ventilation, chest drain management, oxygen management) to multidisciplinary team. Develops other staff in a manner consistent with Trust policies and procedures in relation to respiratory care and ensures that they are aware of these policies, such as adherence to coin policy in relation to Tuberculosis management. Develops and be responsible for initiating and maintaining a respiratory developmental framework for nurses within the Trust. Acts as a role model and nurtures and encourages staff development.

Examples of Application: Prepares and participates in own and respiratory team annual KSF PDR in line with the Trust policy, reflecting on all achievements in the last 12months against set objectives and performance. Reflects on practice regularly using a recognised model of reflection to aid in evaluating knowledge ,skills and practices to recognise areas for improvement and ensure KSF consistent with job outline. Keeps an updated portfolio as recommended by the NMC to reflect on practice and experiences. Identifies and agrees own development need with line manager through annual KSF PDR. Attends specific study days on respiratory care and applying new knowledge and skills to current practice. Attends Trust 's statutory training: fire training, manual handling and lifting and basic life support. Develops own competencies skills in respiratory care, such as arterial blood sampling and non-invasive ventilation and demonstrate competency at all times. Identified skills to develop general respiratory service. Reflects and adopts appropriate practices that respiratory team identify that are needed for the post. Identifies current and future development needs in line with KSF taking an active part in PDR. Keeps updated on Trust policies, protocols and guidelines and utilises in practice. Keeps updated in specific respiratory field reading professional magazines, accessing the internet to identify changing practices . Be fully compliant and updated in professional issues as recommended in NMC Code of Conduct. Meets regularly with peers in respiratory care across region to establish levels of practice and skills , setting targets to meet areas of further development. Initiates regular meetings with line manager and clinical lead to identify any changes requires in current practice, attending work shops and attending conferences to meet specified outcomes. Responsible for the development and support of staff in respiratory team and in clinical areas in relation to respiratory skills, knowledge and practice. Encourages individuals to undertake a honest self assessment of competency and provides the necessary feedback. Challenges team members on poor practice and initiates plans to support in further learning in line with Trust guidelines and protocols.

Second Gateway (Full Outline)

HEALTH, SAFETY AND SECURITY - Level: 2

Level Indicators:

a) identifies and assesses the potential risks involved in work activities and processes for self and others
b) identifies how best to manage the risks

c) undertakes work activities consistent with:
- legislation, policies and procedures
- the assessment and management of risk

d) takes the appropriate action to manage an emergency summoning assistance immediately when this is necessary
e) reports actual or potential problems that may put health, safety and security at risk and suggests how they might be addressed
f) supports others in maintaining health, safety and security.

Examples Of Application: Identifies and manages risk involved in work place environment and risk relating to activities and processes to self and other in the Trust. Demonstrated ability to manage or help other manage risks in accordance to the Trust policy, procedure and guidelines. e.g. ensuring a risk assessment of the environment , process and knowledge staff who are caring for patients who have underwater seal drainage bottles in place. Demonstrates a working knowledge of National Policies and Trust's Policies, Procedures and Guidelines in relation the Health and Safety at Work, Caldicott Principles, Manual Handling and Lifting policy, helping staff to minimise risk of exposure and potential exposure to vulnerable patients. Demonstrates an understanding of the risks associated with the clinical environment and have the ability to effectively manage those risks by allocating extra resources, education or awareness training to ensure safety of staff , patients and the general public. e.g. ensuring outpatient areas for respiratory patients are well ventilated and staff have access to oxygen and emergency equipment and are adequately trained and prepared to use equipment inline with Trust Resuscitation Policy. Fully compliant in completing Accident/Incident Forms. Demonstrate the ability to complete risk assessment documentation in line with Trust policy and allocate resources to manage risk. e.g. ensuring pregnant staff have a maternity risk assessment completed to ensure they and other staff are aware of potential risks and limitation imposed. Leads in continuous assessment of potential risks and demonstrates the ability through role modelling to manage those risks effectively . e.g. learning from complaints, reacting competently in a timely manner to hazard notices and learning from untoward incidents and near misses.

Foundation Gateway (Subset Outline)

HEALTH, SAFETY AND SECURITY - Level: 2

Level Indicators:

b) identifies how best to manage the risks

c) undertakes work activities consistent with:
- legislation, policies and procedures
- the assessment and management of risk

d) takes the appropriate action to manage an emergency summoning assistance immediately when this is necessary

e) reports actual or potential problems that may put health, safety and security at risk and suggests how they might be addressed

f) supports others in maintaining health, safety and security.

Examples of Application: Demonstrates a working knowledge of National Policies and Trust's Policies, Procedures and Guidelines in relation the Health and Safety at Work, Caldicott Principles, Manual Handling and Lifting policy, helping staff to minimise risk of exposure and potential exposure to vulnerable patients. Demonstrates an understanding of the risks associated with the clinical environment and have the ability to effectively manage those risks by allocating extra resources, education or awareness training to ensure safety of staff , patients and the general public. e.g. ensuring outpatient areas for respiratory patients are well ventilated and staff have access to oxygen and emergency equipment and are adequately trained and prepared to use equipment inline with Trust Resuscitation Policy. Fully compliant in completing Accident/Incident Forms. Demonstrate the ability to complete risk assessment documentation in line with Trust policy and allocate resources to manage risk. e.g. ensuring pregnant staff have a maternity risk assessment completed to ensure they and other staff are aware of potential risks and limitation imposed. Leads in continuous assessment of potential risks and demonstrates the ability through role modelling to manage those risks effectively . e.g. learning from complaints, reacting competently in a timely manner to hazard notices and learning from untoward incidents and near misses.

Second Gateway (Full Outline)

SERVICE IMPROVEMENT - Level: 2

Level Indicators:

a) discusses and agrees with the work team
- the implications of direction, policies and strategies on their current practice
- the changes that they can make as a team
- the changes s/he can make as an individual
- how to take the changes forward

b) constructively makes agreed changes to own work in the agreed timescale seeking support as and when necessary

c) supports others in understanding the need for and making agreed changes

d) evaluates own and other’s work when required to do so completing relevant documentation

e) makes constructive suggestions as to how services can be improved for users and the public

f) constructively identifies issues with direction, policies and strategies in the interests of users and the public.

Foundation Gateway (Subset Outline)

SERVICE IMPROVEMENT - Level: 2

Level Indicators:

a) discusses and agrees with the work team
- the implications of direction, policies and strategies on their current practice
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d) evaluates own and other’s work when required to do so completing relevant documentation

e) makes constructive suggestions as to how services can be improved for users and the public

f) constructively identifies issues with direction, policies and strategies in the interests of users and the public.

Examples Of Application: Demonstrates the ability to identify and evaluate service improvement . Meets regularly with senior nurse and clinical respiratory lead to evaluate by auditing current respiratory service and plan potential service development that service demands and as resources allow. Takes a clinical lead for nursing in the strategic planning of services, writing business plans, operational policies, standards, protocols and guidelines. Discusses and agrees with senior nurse and clinical respiratory lead how respiratory services could be improved. Through the use of audit and following suggestions by patients from patients questionnaire or complaints. Meets respiratory nurses from across region to discuss and plan service indicators, benchmarking form each area. Demonstrates understanding and need for service improvement in line with NICE and British Thoracic Society guidelines in relation to respiratory services available. Prioritises competing interests by evaluating development need against resource availability and takes action on how best to resolve situation. Demonstrates a working knowledge of National service recommendations and takes steps to initiate into service, such as ensuring better access to respiratory service in line with Designed for Life (2005). Improves the respiratory service within specified time constraints. Shows initiative and leads the service in developing or changing depending on new policies or guidelines either local or national that have been agreed on . Positively supports others within Trust and with new changes and helping overcome problems or breakdowns in communication. Being available and flexible when time frames change to ensure safe effective service provision. Acts in a professional way as NMC Code of Conduct advises. Consistent in ensuring policies and strategies for respiratory services are firmly embedded in the culture and values of the staff working in Trust and seeks ways to improve and develop new policies and strategies that are sympathetic with tradition and background e.g. introducing, developing and implementing policies, protocols and new procedures to deal with patients requiring non-invasive ventilation. Ensures medical and nursing staff were informed and trained to a standard that they felt comfortable to change the way they had always dealt with non-invasive ventilation. Ensures that these strategies protocols and plans are embedded in practice through regular updates and support. Demonstrates the ability to enable other staff to understand and support changes respiratory service, through information, education and support. Leads in directing, developing and planning to improve respiratory service in line with clinical medical lead, senior nurse and other multidisciplinary team members following recommendations from audits, suggestions from patient questionnaires, complaints and directives from national agencies. Alters own and others practice in line with with agreed improvements such as the changes in practice , protocols, procedure and strategy for Tuberculosis surveillance/diagnosis. Shares achievements with other in respiratory and multidisciplinary team and challenges traditional practices that are not research based in a non-threatening, supportive manner. Demonstrates evaluation of respiratory service improvement takes place in partnership with others, taking an active role in agreeing and formulating plans for further improvement e.g. being a major contributor along with the general manager to assess the service improvements needed in supplying an oxygen service to users and developing a plan of action to further enhance services. Appraises draft policies and strategies in respiratory care services, and analysing their effect on local users e.g. the delivery of respiratory services to chronic respiratory patients and their cares and making recommendations for improvement where problems/complaints or potential risks have occurred.

Examples of Application: Demonstrates the ability to identify and evaluate service improvement. Meets regularly with senior nurse and clinical respiratory lead to evaluate by auditing current respiratory service and plan potential service development that service demands and as resources allow. Takes a clinical lead for nursing in the strategic planning of services, writing business plans, operational policies, standards, protocols and guidelines. Discusses and agrees with senior nurse and clinical respiratory lead how respiratory services could be improved. Through the use of audit and following suggestions by patients from patients questionnaire or complaints. Meets respiratory nurses from across region to discuss and plan service indicators, benchmarking form each area. Demonstrates understanding and need for service improvement in line with NICE and British Thoracic Society guidelines in relation to respiratory services available. Prioritises competing interests by evaluating development need against resource availability and takes action on how best to resolve situation. Demonstrates a working knowledge of National service recommendations and takes steps to initiate into service, such as ensuring better access to respiratory service in line with Designed for Life (2005). Improves the respiratory service within specified time constraints. Shows initiative and leads the service in developing or changing depending on new policies or guidelines either local or national that have been agreed on. Positively supports others within Trust and with new changes and helping overcome problems or breakdowns in communication. Being available and flexible when time frames change to ensure safe effective service provision. Acts in a professional way as NMC Code of Conduct advises. Consistent in ensuring policies and strategies for respiratory services are firmly embedded in the culture and values of the staff working in Trust and seeks ways to improve and develop new policies and strategies that are sympathetic with tradition and background e.g. introducing, developing and implementing policies, protocols and new procedures to deal with patients requiring non-invasive ventilation. Ensures medical and nursing staff were informed and trained to a standard that they felt comfortable to change the way they had always dealt with non-invasive ventilation. Ensures that these strategies protocols and plans are embedded in practice through regular updates and support.

Second Gateway (Full Outline)

QUALITY - Level: 3

Level Indicators:

a) acts consistently with legislation, policies, procedures and other quality approaches and promotes the value of quality approaches to others
b) understands own role in the organisation and its scope and identifies how this may develop over time
c) works as an effective and responsible team member and enables others to do so
d) prioritises own workload and organises and carries out own work in a manner that maintains and promotes quality
e) evaluates the quality of own and others' work and raises quality issues and related risks with the relevant people
f) supports the introduction and maintenance of quality systems and processes in own work area
g) takes the appropriate action when there are persistent quality problems.

Foundation Gateway (Subset Outline)

QUALITY - Level: 3

Level Indicators:

a) acts consistently with legislation, policies, procedures and other quality approaches and promotes the value of quality approaches to others
b) understands own role in the organisation and its scope and identifies how this may develop over time
c) works as an effective and responsible team member and enables others to do so
d) prioritises own workload and organises and carries out own work in a manner that maintains and promotes quality
e) evaluates the quality of own and others' work and raises quality issues and related risks with the relevant people
f) supports the introduction and maintenance of quality systems and processes in own work area
g) takes the appropriate action when there are persistent quality problems.

Examples Of Application: Ensures that self and other respiratory nurses within the service provide a quality service to patients and demonstrates knowledge and understanding of relevant policies that affect quality of service i.e. learning from near misses/complaints. Personally demonstrates a professional work approach and ensures other in scope of responsibility do so also, in accordance with the NMC Code of Conduct. Meets regularly with senior nurse, general manager and clinical medical lead to discuss quality of respiratory service. Through audit practices ensures that service is patient centred and adherence to recognised national guidelines from NICE and the British Thoracic society to underpin consistent quality care. With senior clinical lead sets targets for care and analysis outcomes through audit, patient questionnaires and producing an annual report of respiratory service. Fully aware of own role within the Trust and is able to discuss, demonstrate and provide evidence of the contribution made to improving respiratory care for individual patients and for the respiratory service in general. Recognises own educational needs, through reflecting on practice and feedback from line manager and other within the respiratory team, and takes steps to develop knowledge, skills and competencies relevant to roles and responsibilities. Able to provide evidence of achievements for the last 12 months for self and all other members of the respiratory team for specific training and Trust statutory training. Recognises, respects and promotes the varying role in the respiratory team and ensure that all the team members do the same. Actively makes contributions through ensuring effective communication with, primary care teams such as chronic management disease team and practice nurses relating to respiratory patients and enables timely continuity of quality care. Organises work daily by prioritising requests from ward areas and ensures that patients are seen in order of need. Ensures that ward/area staff are verbally informed of management plan (appropriate for that respiratory condition as set by NICE and British Thoracic Society Guidelines) and provided with documented advice to ensure appropriate quality respiratory care give. Also ensures that allocates resources are used to best advantage . Acts as a resource to members in the team providing support to those who require it. Evaluates quality of own and other multidisciplinary team work through audit practices. Is competent in assessing, planning, implementing and evaluating respiratory patient care and promotes the delivery of a high standard of care at all times. Supports and encourages respiratory team and staff within the Trust to reach required standards in care, ensuring they understand their accountability in delivering quality respiratory care .

Discusses risks in break down of delivery of care with respiratory team and /or with appropriate area managers and discussed developments to rectify deficits in quality. Leads on the setting and maintaining of agreed standards in respiratory care within the respiratory team and with a range of multidisciplinary staff within the Trust and in partnership with the primary care chronic management team. Initiates the development of care pathways, protocols, procedures and new ways of working and be able to provide evidence of this e.g. developed care pathways, protocols or procedures. Audits practices such as adherence to the Trust oxygen guidelines and non-invasive ventilation protocol. Takes appropriate action when persistent quality problems occur by informing ward/area manager of problem in respiratory care and leads on the development of action plans and the implementation of changes in practice.

Examples of Application: Ensures that self and other respiratory nurses within the service provide a quality service to patients and demonstrates knowledge and understanding of relevant policies that affect quality of service i.e. learning from near misses/complaints. Personally demonstrates a professional work approach and ensures other in scope of responsibility do so also, in accordance with the NMC Code of Conduct. Meets regularly with senior nurse, general manager and clinical medical lead to discuss quality of respiratory service. Through audit practices ensures that service is patient centred and adherence to recognised national guidelines from NICE and the British Thoracic society to underpin consistent quality care. With senior clinical lead sets targets for care and analysis outcomes through audit, patient questionnaires and producing an annual report of respiratory service. Fully aware of own role within the Trust and is able to discuss, demonstrate and provide evidence of the contribution made to improving respiratory care for individual patients and for the respiratory service in general. Recognises own educational needs, through reflecting on practice and feedback from line manager and other within the respiratory team, and takes steps to develop knowledge, skills and competencies relevant to roles and responsibilities. Able to provide evidence of achievements for the last 12 months for self and all other members of the respiratory team for specific training and Trust statutory training. Recognises, respects and promotes the varying role in the respiratory team and ensure that all the team members do the same. Actively makes contributions through ensuring effective communication with, primary care teams such as chronic management disease team and practice nurses relating to respiratory patients and enables timely continuity of quality care. Organises work daily by prioritising requests from ward areas and ensures that patients are seen in order of need. Ensures that ward/area staff are verbally informed of management plan (appropriate for that respiratory condition as set by NICE and British Thoracic Society Guidelines) and provided with documented advice to ensure appropriate quality respiratory care give. Also ensures that allocates resources are used to best advantage . Acts as a resource to members in the team providing support to those who require it.

Second Gateway (Full Outline)

EQUALITY AND DIVERSITY - Level: 2

Level Indicators:

a) recognises the importance of people's rights and acts in accordance with legislation, policies and procedures
b) acts in ways that:
- acknowledge and recognise people's expressed beliefs, preferences and choices
- respect diversity
- value people as individuals

c) takes account of own behaviour and its effect on others

d) identifies and takes action when own or others' behaviour undermines equality and diversity.

Examples Of Application: Postholder will recognise and act in ways which uphold relevant Legislation, Trust Policy and Procedure in relation to Equality & Diversity, Equal Opportunities, eg the 5 standards of improving the patient & client experience (respect, attitude, behaviour, communication, privacy & dignity), age, religion, gender, etc. Ensuring that they treat everyone they come into contact with appropriately, recognising that everyone has the right to their own personal views and perspectives and ensuring that they are not discriminated against in any way due to their culture, faith, beliefs, etc. Postholder must be able to identify when equality and diversity is not being promoted and do something about this, eg challenging inappropriate behaviour and/or as supervisor/line manager bring issues to the immediate attention of the staff member involved and agree appropriate course of action to ensure that discrimination does not occur again.

Foundation Gateway (Subset Outline)

EQUALITY AND DIVERSITY - Level: 2

Level Indicators:

a) recognises the importance of people's rights and acts in accordance with legislation, policies and procedures
b) acts in ways that:
- acknowledge and recognise people's expressed beliefs, preferences and choices
- respect diversity
- value people as individuals

c) takes account of own behaviour and its effect on others

d) identifies and takes action when own or others' behaviour undermines equality and diversity.

Examples of Application: Postholder will recognise and act in ways which uphold relevant Legislation, Trust Policy and Procedure in relation to Equality & Diversity, Equal Opportunities, eg the 5 standards of improving the patient & client experience (respect, attitude, behaviour, communication, privacy & dignity), age, religion, gender, etc. Ensuring that they treat everyone they come into contact with appropriately, recognising that everyone has the right to their own personal views and perspectives and ensuring that they are not discriminated against in any way due to their culture, faith, beliefs, etc. Postholder must be able to identify when equality and diversity is not being promoted and do something about this, eg challenging inappropriate behaviour and/or as supervisor/line manager bring issues to the immediate attention of the staff member involved and agree appropriate course of action to ensure that discrimination does not occur again.

Second Gateway (Full Outline)

PROMOTION OF HEALTH AND WELLBEING AND PREVENTION OF ADVERSE EFFECTS ON HEALTH AND WELLBEING - Level: 2

Level Indicators:

a) works effectively with people to identify their concerns about health and wellbeing and the target groups for any approaches
b) identifies how the health and wellbeing of the target group can be improved through promotion and/or prevention approaches consistent with legislation, policies and procedures
c) involves people in the target group in the planning and development of the approaches
d) designs approaches that are based on evidence and the interests of the target group
e) enables people to participate effectively in the promotion of their health and wellbeing and the prevention of adverse effects
f) acts as a resource for improving health to the people in the target group keeping a record of what has been done
g) reviews with people from the target group the effectiveness of the approaches in improving their health and wellbeing.

Foundation Gateway (Subset Outline)

PROMOTION OF HEALTH AND WELLBEING AND PREVENTION OF ADVERSE EFFECTS ON HEALTH AND WELLBEING - Level: 2

Level Indicators:

a) works effectively with people to identify their concerns about health and wellbeing and the target groups for any approaches
b) identifies how the health and wellbeing of the target group can be improved through promotion and/or prevention approaches consistent with legislation, policies and procedures
c) involves people in the target group in the planning and development of the approaches
d) designs approaches that are based on evidence and the interests of the target group
e) enables people to participate effectively in the promotion of their health and wellbeing and the prevention of adverse effects
f) acts as a resource for improving health to the people in the target group keeping a record of what has been done
g) reviews with people from the target group the effectiveness of the approaches in improving their health and wellbeing.

Examples Of Application: Works effectively with internal end external agencies on a range of diseases to identify concerns about health and wellbeing of respiratory patients. Such as working in partnership with the smoking cessation service to plan and implement strategies on how best to inform, advise and support people who are smoking, or wish to stop smoking. Initiates and leads strategies to promote health enhancing activities e .g. smoking cessation, vaccinations. Identifies how health and well being can be improved through heath promotion and has a working knowledge of national strategies such as Designed for Life and national guidelines for health promotion in Asthma and Chronic Obstructive Pulmonary Disease. Applies these to practice e.g. actively taking part of the pulmonary rehabilitation team that helps in re-educating patients through information, education and exercise programmes that enable patients and their families take better control of their specific respiratory diseases. Involves individuals in the target group to identify health related risks, and develops in partnership an individual plan of care to aid reduce risk and

improve general health. Such as improving exercise tolerance of patients with Chronic Obstructive Pulmonary Disease through three times weekly programmes. Designs approaches that are evidence based from NICE and British Thoracic Society guidelines on promoting health and wellbeing for respiratory patients, and ensures that they have access to this advice. Such as individual assessment and advice on a regular basis, providing written information in inpatient areas and in outpatient respiratory clinics, and providing information and advice on accessible notice boards. Enables respiratory patients to participate in their own health and wellbeing and preventing adverse effects through active participation in pulmonary rehabilitation programmes and individual health promotion plans. Acts as a resource in Trust and participates in health promotion days offering respiratory measurement testing and advice to trust staff, patients , relatives and the general public, such as lung cancer awareness and national COPD day. Meets regularly with voluntary groups such as the British Lung Foundation to develop health promotion strategies through patient self help groups. Documents all activities in line with Trust policies and NMC Code of Conduct approaches in health promotion, such as a comprehensive audit of objective and subjective measurements and the start and completion of every pulmonary rehabilitation programme.

Examples of Application: Works effectively with internal end external agencies on a range of diseases to identify concerns about health and wellbeing of respiratory patients. Such as working in partnership with the smoking cessation service to plan and implement strategies on how best to inform, advise and support people who are smoking, or wish to stop smoking. Initiates and leads strategies to promote health enhancing activities e .g. smoking cessation, vaccinations. Identifies how health and well being can be improved through heath promotion and has a working knowledge of national strategies such as Designed for Life and national guidelines for health promotion in Asthma and Chronic Obstructive Pulmonary Disease. Applies these to practice e.g. actively taking part of the pulmonary rehabilitation team that helps in re-educating patients through information, education and exercise programmes that enable patients and their families take better control of their specific respiratory diseases. Involves individuals in the target group to identify health related risks, and develops in partnership an individual plan of care to aid reduce risk and

improve general health. Such as improving exercise tolerance of patients with Chronic Obstructive Pulmonary Disease through three times weekly programmes. Designs approaches that are evidence based from NICE and British Thoracic Society guidelines on promoting health and wellbeing for respiratory patients, and ensures that they have access to this advice. Such as individual assessment and advice on a regular basis, providing written information in inpatient areas and in outpatient respiratory clinics, and providing information and advice on accessible notice boards. Enables respiratory patients to participate in their own health and wellbeing and preventing adverse effects through active participation in pulmonary rehabilitation programmes and individual health promotion plans. Acts as a resource in Trust and participates in health promotion days offering respiratory measurement testing and advice to trust staff, patients , relatives and the general public, such as lung cancer awareness and national COPD day. Meets regularly with voluntary groups such as the British Lung Foundation to develop health promotion strategies through patient self help groups. Documents all activities in line with Trust policies and NMC Code of Conduct approaches in health promotion, such as a comprehensive audit of objective and subjective measurements and the start and completion of every pulmonary rehabilitation programme.

Second Gateway (Full Outline)

ASSESSMENT AND TREATMENT PLANNING - Level: 3

Level Indicators:

a) evaluates relevant information to plan the range and sequence of assessment required and determines:
- the specific activities to be undertaken
- the risks to be managed
- the urgency with which assessments are needed

b) selects appropriate assessment approaches, methods, techniques and equipment, in line with
- individual needs and characteristics
- evidence of effectiveness
- the resources available

c) respects people's dignity, wishes and beliefs; involves them in shared decision making; and obtains their consent

d) prepares for, carries out and monitors assessments in line with evidence based practice, and legislation, policies and procedures and/or established protocols / established theories and models

e) monitors individuals during assessments and takes the appropriate action in relation to any significant changes or possible risks

f) evaluates assessment findings/results and takes appropriate action when there are issues

g) considers and interprets all of the information available using systematic processes of reasoning to reach a justifiable assessment and explains the outcomes to those concerned

h) determines and records diagnosis and treatment plans according to agreed protocols / pathways / models and that are:
- consistent with the outcomes of the assessment
- consistent with the individual's wishes and views
- include communications with other professions and agencies
- involve other practitioners and agencies when this is necessary to meet people's health and wellbeing needs and risks
- are consistent with the resources available
- note people's wishes and needs that it was not possible to meet

i) monitors and reviews the implementation of treatment plans and makes changes within agreed protocols / pathways / models for clinical effectiveness and to meet people's needs and views

j) identifies individuals whose needs fall outside protocols / pathways / models and makes referrals to the appropriate practitioners with the necessary degree of urgency.

Foundation Gateway (Subset Outline)

ASSESSMENT AND TREATMENT PLANNING - Level: 3

Level Indicators:

a) evaluates relevant information to plan the range and sequence of assessment required and determines:
- the specific activities to be undertaken
- the risks to be managed
- the urgency with which assessments are needed

b) selects appropriate assessment approaches, methods, techniques and equipment, in line with
- individual needs and characteristics
- evidence of effectiveness
- the resources available

c) respects people's dignity, wishes and beliefs; involves them in shared decision making; and obtains their consent

d) prepares for, carries out and monitors assessments in line with evidence based practice, and legislation, policies and procedures and/or established protocols / established theories and models

e) monitors individuals during assessments and takes the appropriate action in relation to any significant changes or possible risks

f) evaluates assessment findings/results and takes appropriate action when there are issues

g) considers and interprets all of the information available using systematic processes of reasoning to reach a justifiable assessment and explains the outcomes to those concerned

h) determines and records diagnosis and treatment plans according to agreed protocols / pathways / models and that are:
- consistent with the outcomes of the assessment
- consistent with the individual's wishes and views
- include communications with other professions and agencies
- involve other practitioners and agencies when this is necessary to meet people's health and wellbeing needs and risks
- are consistent with the resources available
- note people's wishes and needs that it was not possible to meet

i) monitors and reviews the implementation of treatment plans and makes changes within agreed protocols / pathways / models for clinical effectiveness and to meet people's needs and views

j) identifies individuals whose needs fall outside protocols / pathways / models and makes referrals to the appropriate practitioners with the necessary degree of urgency.

Examples Of Application: Evaluates relevant information to plan the range and sequence of assessment for respiratory patients. Prioritises patient assessments urgency from referral letter. Identifies the specific respiratory information needed to fully assess individual patients that aids in differential diagnosis, treatment planning and continuous evaluation, whilst identifying and minimising risk to patients. Such as ensuring the patient meets the criteria for safely having spirometry performed. Selects appropriate assessment approaches , methods, techniques and equipment relevant to individual patient need. Through full explanation of possible treatment plans are given allowing patients to be aware of and discuss limitations of management and or medication. Uses nationally recognised Guidelines from NICE and the British Thoracic society in relation to the assessment strategy, performance and individual patient treatment and management plans and evaluations. Treats all patients with dignity and respect and ensures documented privacy is maintained. Ensures all assessment and respiratory measurements are only undertaken following patient consent. All treatment plans are based on national NICE and British Thoracic Society guidelines and are then individually tailored to meet the patients wishes and beliefs. Acknowledges and complies with Trust, NICE and British Thoracic Society Guidelines in relation to polices and procedures to prepare, perform and monitor respiratory assessments. Such as gaining consent from the patient to perform arterial blood gas sampling and ensuring that safety and correct procedure is carried out to ensure accurate meaningful measurement with minimal risk to the patient. Continually monitors patients during assessment and takes timely and appropriate action to any significant changes or detrimental outcomes occur. Such as stopping spirometry if the patient is complaining of dizziness or chest pain and initiating a plan of action to help recover the patient following the event, accurately documenting in the case notes. Evaluates and takes appropriate action on assessment findings in line with Trust protocols and NICE and British Thoracic Society Guidelines. Such as bring the results of a sputum specimen to the attention of one of the respiratory medical team and initiating , co-ordinating and organising appropriate medication in a timely fashion. Demonstrates own accountability and responsibility by applying a working knowledge and skill in interpreting respiratory assessment findings in a systematic way and explains findings to patient and medical staff to initiate appropriate management. Such as physically assessing, comprehensive history taking and performing objective respiratory measurement testing and advising the medical staff orally and through documentation the appropriate management plan to initiate. Demonstrates own accountability and responsibility for determining working diagnosis and recording it and the appropriate action plans that are consistent with the assessment outcomes in accordance with Trust protocol, The NMC Code of Conduct using the recognised Guidelines for NICE and The British Thoracic Society when dealing with patients with asthma, COPD, or Tuberculosis. The assessment has taken place with the consent of the patient using Trust Consent Policy and plans in collaboration with the individual patient the best course of action. Communicates with colleagues in primary and secondary care to continue to meet patients needs and regularly discusses on-going care of patients with relevant practice nurses and chronic disease management team. Risks are identified with the patient during assessment and management planning where both positive and negative outcomes are discussed. All management plans set, are achievable and are consistent with the resources available to the patient either in secondary or primary care. Demonstrates accountability and responsibility in regularly monitoring the management plans with the individual to ensure desired outcomes achieved, and changing treatment plans where problems or difficulties arise in accordance with the NICE and British Thoracic Society Guidelines for treatment of asthma, COPD and Tuberculosis. Such as the three day review of asthmatic patients following discharge from hospital, management plans are discussed with the individual and changes are made consistent with agreed national guidelines when outcomes are not as favourable as expected. All changes are accurately documented in accordance with professional guidelines. Identifies patients who do not fit into recognised protocol for asthma or chronic obstructive pulmonary disease and recognises limitations in own knowledge and skills, passing on cases to more skilled practitioner in a timely manner. Meets daily with respiratory nurse specialist to discuss difficult to manage cases and regularly meets with senior respiratory physician to discuss more complex respiratory

Examples of Application: Evaluates relevant information to plan the range and sequence of assessment for respiratory patients. Prioritises patient assessments urgency from referral letter. Identifies the specific respiratory information needed to fully assess individual patients that aids in differential diagnosis, treatment planning and continuous evaluation, whilst identifying and minimising risk to patients. Such as ensuring the patient meets the criteria for safely having spirometry performed. Selects appropriate assessment approaches , methods, techniques and equipment relevant to individual patient need. Through full explanation of possible treatment plans are given allowing patients to be aware of and discuss limitations of management and or medication. Uses nationally recognised Guidelines from NICE and the British Thoracic society in relation to the assessment strategy, performance and individual patient treatment and management plans and evaluations. Treats all patients with dignity and respect and ensures documented privacy is maintained. Ensures all assessment and respiratory measurements are only undertaken following patient consent. All treatment plans are based on national NICE and British Thoracic Society guidelines and are then individually tailored to meet the patients wishes and beliefs. Acknowledges and complies with Trust, NICE and British Thoracic Society Guidelines in relation to polices and procedures to prepare, perform and monitor respiratory assessments. Such as gaining consent from the patient to perform arterial blood gas sampling and ensuring that safety and correct procedure is carried out to ensure accurate meaningful measurement with minimal risk to the patient. Continually monitors patients during assessment and takes timely and appropriate action to any significant changes or detrimental outcomes occur. Such as stopping spirometry if the patient is complaining of dizziness or chest pain and initiating a plan of action to help recover the patient following the event, accurately documenting in the case notes. Evaluates and takes appropriate action on assessment findings in line with Trust protocols and NICE and British Thoracic Society Guidelines. Such as bring the results of a sputum specimen to the attention of one of the respiratory medical team and initiating , co-ordinating and organising appropriate medication in a timely fashion. Demonstrates own accountability and responsibility by applying a working knowledge and skill in interpreting respiratory assessment findings in a systematic way and explains findings to patient and medical staff to initiate appropriate management. Such as physically assessing, comprehensive history taking and performing objective respiratory measurement testing and advising the medical staff orally and through documentation the appropriate management plan to initiate. Demonstrates own accountability and responsibility for determining working diagnosis and recording it and the appropriate action plans that are consistent with the assessment outcomes in accordance with Trust protocol, The NMC Code of Conduct using the recognised Guidelines for NICE and The British Thoracic Society when dealing with patients with asthma, COPD, or Tuberculosis. The assessment has taken place with the consent of the patient using Trust Consent Policy and plans in collaboration with the individual patient the best course of action. Communicates with colleagues in primary and secondary care to continue to meet patients needs and regularly discusses on-going care of patients with relevant practice nurses and chronic disease management team. Risks are identified with the patient during assessment and management planning where both positive and negative outcomes are discussed. All management plans set, are achievable and are consistent with the resources available to the patient either in secondary or primary care. Demonstrates accountability and responsibility in regularly monitoring the management plans with the individual to ensure desired outcomes achieved, and changing treatment plans where problems or difficulties arise in accordance with the NICE and British Thoracic Society Guidelines for treatment of asthma, COPD and Tuberculosis. Such as the three day review of asthmatic patients following discharge from hospital, management plans are discussed with the individual and changes are made consistent with agreed national guidelines when outcomes are not as favourable as expected. All changes are accurately documented in accordance with professional guidelines. Identifies patients who do not fit into recognised protocol for asthma

cases.	or chronic obstructive pulmonary disease and recognises limitations in own knowledge and skills, passing on cases to more skilled practitioner in a timely manner. Meets daily with respiratory nurse specialist to discuss difficult to manage cases and regularly meets with senior respiratory physician to discuss more complex respiratory cases.

Second Gateway (Full Outline)	**Foundation Gateway (Subset Outline)**
INTERVENTIONS AND TREATMENTS - Level: 3	INTERVENTIONS AND TREATMENTS - Level: 3
Level Indicators: a) respects individuals' dignity, wishes and beliefs; involves them in shared decision making; and obtains their consent b) identifies with the individuals concerned: - goals for the specific activities to be undertaken within the context of the overall treatment plan and the individual's physiological and/or psychological functioning - the nature of the different aspects of the intervention / treatment - the involvement of other people and/or agencies - relevant evidence-based practice and/or clinical guidelines - any specific precautions or contraindications to the proposed interventions / treatments and takes the appropriate action c) prepares appropriately for the intervention / treatment to be undertaken d) undertakes the intervention / treatment in a manner that is consistent with: - evidence-based practice and/or clinical guidelines / established theories and models - multidisciplinary team working - his/her own knowledge, skills and experience - legislation, policies and procedures and/or established protocols e) monitors individuals' reactions to interventions/treatment and takes the appropriate action to address any issues or risks f) reviews the effectiveness of the interventions/treatments as they proceed and makes any necessary modifications g) provides feedback to the person responsible for the overall treatment plan on its effectiveness and the health and wellbeing and needs of people h) makes accurate records of the interventions/treatment undertaken and outcomes i) responds to, records and reports any adverse events or incidents relating to the intervention/treatment with an appropriate degree of urgency.	**Level Indicators:** a) respects individuals' dignity, wishes and beliefs; involves them in shared decision making; and obtains their consent b) identifies with the individuals concerned: - goals for the specific activities to be undertaken within the context of the overall treatment plan and the individual's physiological and/or psychological functioning - the nature of the different aspects of the intervention / treatment - the involvement of other people and/or agencies - relevant evidence-based practice and/or clinical guidelines - any specific precautions or contraindications to the proposed interventions / treatments and takes the appropriate action c) prepares appropriately for the intervention / treatment to be undertaken d) undertakes the intervention / treatment in a manner that is consistent with: - evidence-based practice and/or clinical guidelines / established theories and models - multidisciplinary team working - his/her own knowledge, skills and experience - legislation, policies and procedures and/or established protocols e) monitors individuals' reactions to interventions/treatment and takes the appropriate action to address any issues or risks f) reviews the effectiveness of the interventions/treatments as they proceed and makes any necessary modifications g) provides feedback to the person responsible for the overall treatment plan on its effectiveness and the health and wellbeing and needs of people h) makes accurate records of the interventions/treatment undertaken and outcomes i) responds to, records and reports any adverse events or incidents relating to the intervention/treatment with an appropriate degree of urgency.

Examples Of Application: The postholder will respect patient/client dignity, wishes and beliefs, ensuring that consent is obtained prior to all activities being undertaken. Identifies with patient/client the intended outcome of the activity to be undertaken and who else may be involved in this activity, eg multidisciplinary teams, social services, etc. Prepare for and undertake the activity following clinical guidelines, own knowledge and experience and appropriate legislation, eg maintaining accurate and contemporaneous documentation and records in line with Trust policies and NMC Rules, etc. Carry out risk assessment at initial booking appointment and throughout patient/client contact with service. Review care plans, evaluating their effectiveness and making necessary changes when necessary ensuring effective communication with patient/client and wider team. Maintains all records in a contemporaneous manner in line with Trust, NMC policies and procedures and guidelines, e.g. Data protection Act, FOI, etc.	Examples of Application: The postholder will respect patient/client dignity, wishes and beliefs, ensuring that consent is obtained prior to all activities being undertaken. Identifies with patient/client the intended outcome of the activity to be undertaken and who else may be involved in this activity, eg multidisciplinary teams, social services, etc. Prepare for and undertake the activity following clinical guidelines, own knowledge and experience and appropriate legislation, eg maintaining accurate and contemporaneous documentation and records in line with Trust policies and NMC Rules, etc. Carry out risk assessment at initial booking appointment and throughout patient/client contact with service. Review care plans, evaluating their effectiveness and making necessary changes when necessary ensuring effective communication with patient/client and wider team. Maintains all records in a contemporaneous manner in line with Trust, NMC policies and procedures and guidelines, e.g. Data protection Act, FOI, etc.

Document has ended

Southern Health and Social Care Trust

Quality Care - for you, with you

Ward: Thorndale Ward Meeting
03/03/2020 Present:
Kate O'Neill, Jennifer McMahon, Leanne McCourt, Kate McCreesh, Dolores Campbell Mairead Leonard, Janice Holloway, Martina O'Neill, Julie Ann Lavery, Graham Woolsey, Gemma Robinson

Apologies:

Ref	Topic	Discussion
1.	**RQIA**	Ongoing preparation.
2.	**Clinical Governance**	Coronavirus ID pathway- pinned to NoticeBoard. TVN information and link nurse- Dolores Campbell. Penile erosion- any incidents need reported to TDU managers for escalation to Wendy McQuillan and Martina Thompson.
3	**New Policies/ Documents**	NICAN working on regional policies for intraoperative MMC instillation , red flag haematuria referrals.
	Datix	Fall when voiding following cystoscopy and urethral dilatation . Appropriate disposal of confidential information.
	Audits	Recent quarterly audit- satisfactory. Flexible cystoscopy- Wesam looking at use of normal saline and non-return valve.
	Complaints / compliments	Recent donation to Acute Fund. Continue to record thank you cards on intranet.

Ref	Topic	Discussion
	Equipment	New equipment for TP biopsy arrived, training to follow.
	IPC	Ongoing issues with hand hygiene audit in relation to compliance. Offenders to be challenged and issue escalated if non-compliance continues.
4	**Staffing (Levels)**	Staff thoughts on covering days when activity reduced AM or PM – need for "on at shift". New HCA assistant. Expression of interest Band 5..
5	**Staff Development**	Band 7 interviews imminent. Band 6 OPD – start of April ? when starting in TDU. TP training to commence for Consultants and CNS's.
	Training	Keep e-learning up to date.
	KSF/ Supervision	Ongoing.
	Revalidation	Individual responsibility to ensure process is up to date
	Sickness	Refer to policy
6	**New Initiatives**	Botox training has commenced and further clinics will follow over the next few months. Adjustment to New Patient Appointment letters re addition of "attending with a full bladder and length of appointment. Patient feedback questionnaire in conjunction with Mary Haughey- due to be posted to patients next week.
7	**Environmental**	
8	**Estates**	Call bell system now fully operational.

Ref	Topic	Discussion
9	**AOB**	MMC- new delivery system and delivery of IVC in DHH – Janice. STC-KON has requested noise impact assessment. Maintenance requests- whoever reports issue need to follow-up with maintenance to ensure it has been resolved. Reminder for everyone to be mindful and respect others at all times (colleagues and patients).

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Ward: Thorndale
Present: Kate O'Neill, Jenny McMahon, Jason Young, Wendy Clayton and Sarah Ward
Date: 11.11.2020
1:1 Sisters Meeting

Ref	Topic	Discussion	Owner/Date
1.	**RQIA**	To be ready ☺	CNS/ LN
2.	**Unscheduled care and patient flow**	Increasing number of patients requiring TRBT. 70 were sent out to SET- 10 done last week and Martina to chase up on a potential gap (but verbally assured these were done and results to follow) 4 on Monday list coming and 8 on Mr Haines list next week. Still a volume of patients requiring the procedure under GA. As we are down to one emergency list per week the challenge is who gets priority	CNS/ WENDY

Ref	Topic	Discussion	Owner/Date
3	**<u>Governance</u>**		
	New Policies/ Documents	Nil new from previous	CNS/ LN
	Datix INPUT DATIX NUMBERS OF THOSE TO BE COMPLETED	Nil new datix in system. Clinics ongoing with Mr Haines to follow up on AOB	
4	**Audits** WARD SISTERS TO PROVIDE COPIES OF NQI RESULTS AND THE COMPLETED ACTION PLAN FOR ADDRESSING ISSUES	Nil issues	
	Complaints	Nil new	
	Equipment	Laptops x2 provided to CNS. Facilitating WFH. Still awaiting webcams	

Ref	Topic	Discussion	Owner/Date
	IPC **INPUT MOST RECENT HAND HYGIENE AND COMMODE AUDITS**	Nil new issues. Updated on the challenges within the hospital and level of Covid	
5	**Staffing (Levels)** **INPUT STAFF COMING AND LEAVING INCLUDING START AND FINISH DATES**	Will need to discuss with Jo and Josie the plans for staffing for covering the new locum coming in for 4 weeks. They will predominately cover the backlog in outpatient clinics and some red flags and prostates.	CNS
6	**Staff Development** **Training** **WARD SISTERS TO HAVE TRAINING PERCENTAGES AVAILABLE AND INPUTTED PRIOR TO MEETING**	Patricia probation due and Jasons is scheduled. Sarah as previous will send out to Patricia	LN

Ref	Topic	Discussion	Owner/Date
	Clinical Educational Practitioner Actions	Nil issues	LN/ CNS
	KSF/ Supervision **WARD SISTERS TO HAVE RECORDS OF COMPLETION INPUTTED PRIOR TO THE MEETING AND INCLUDE THOSE SCHEDULED TO BE COMPLETED**	All up to date for this year. Supervision completed last week for all and minutes/ action circulated	
	Clinical Educational Practitioner Actions		
	Revalidation **As Above for action by ward sisters**	Nil due soon	
7	**Clinical** **P/Ulcers** **WARD SISTERS TO PROVIDE**	Nil issues	

Ref	Topic	Discussion	Owner/Date
	EVIDENCE OF COMPLETED RCA (G2 on ward) AND G3 & ABOVE WITH LEAD NURSE **Falls** **Diabetic**	Nil issues Nil issues	
8	**New Initiatives**	Consideration if theatre lists not increasing the potential scoping of DPU possibly on a wed or thurs depending on consultant's schedules. To be reviewed if possibility	WENDY/ CNS
9	**Environmental**	Thorndale is occupied by some admin staff and need to ensure appropriate access to unit	LN
10	**Estates**	Issues of moving equipment to STH site. Will keep us updated if any challenges. Transport being arranged	CNS
11	**Sucession Planning/ Staff Development**		
	AOB	To consider validating the TRBT and TURP long waiters. Potentially by Saba, and a telephone review. To be discussed further	Wendy

Ref	Topic	Discussion	Owner/Date
		To review the clinics for Saba and confirm what she can do. Currently doing reviews and not quite ready for red flag reviews or bad news. Quite tight turnaround for the booking of patients, and quite intensive to pull out what she can do. Consider the reviews for consultant specific waiting since 2015. Can an admin role support the filtering of the appropriate patients for her?	

signed

Standard Operating Procedure for Ultrasound Transperineal Probe Decontamination

Title	STANDARD OPERATING PROCEDURE FOR TRIPLANE TRANSDUCER PROBE (E14C4t) CLEANING USING NANOSONICS TROPHON SYSTEM AND TRISTEL TRIO- 3 PART DECONTAMINATION SYSTEM (INTERIM MEASURE)	
Version Number	V1.0	**Supersedes:**
Author	Leanne McCourt	
Page Count	12	
Date of Implementation	July 2021	
Date of Review	August 2022	**To be Reviewed by:** Urology CNS's
Approved by	Personal Information redacted by the USI [redacted] Wendy Clayton Acting Head of Service for Urology, ENT and Outpatients	

Table of amendments

Version	Date	Author	Notes on amendments

This is an interim SOP to incorporate a hybrid solution (Trophon and TristelTrio) for the decontamination of triplane transducer probe (E14C4t).

Probe **MUST** be decontaminated prior to the first use of the day, between patients and following the last patient of the day.

Treatment couch should be cleaned with an Appropriate Sanitising wipe * prior to the first use of the day, between patients and following the last patient of the day.

General good hand hygiene practice and the "bare below the elbow" policy should be strictly adhered to.

A daily cleaning regime of the ultrasound scanning systems and in particular frequent and thorough cleaning of the probe cradle holders should be followed as per manufacturer's instructions.

Preliminary Checks (Trophon System)

1. Wake system from sleep by pressing the blue illuminated button. This is best done at least 15minutes before start of list /clinic.
2. Initiate daily cycle.
3. Check that sufficient Trophon consumables are available (i.e. Nanonebulant cartridges, Chemical Indicators, Printer Roll).
4. Scanners with 2 cradle holders:- identify one holder for clean probes and one for contaminated probes

5. Scanners with 1 cradle holder:- the contaminated probe should be decontaminated immediately after use and **MUST NOT** be returned to the cradle holder after use

6. **If a contaminated probe is accidently placed in the cradle holder then the cradle holder must be cleaned immediately with an Appropriate Sanitising wipe 1/2, followed by 70% alcohol wipe.**

Preliminary Checks (Tristel Trio system)

7. Check that sufficient Tristel Trio system consumables are available for number of patients on list (i.e. 3 wipes and sufficient spray per examination).

8. Arrange room to ensure decontamination process can be followed easily. Clinical waste bin and trolley should be in close proximity when undertaking the decontamination process.

9. Any problems experienced whilst using this system should be reported **immediately** to the nurse in charge of the clinic.

Probe Preparation and Initiating the Disinfection Cycle of Trophon System

10. Following completion of the ultrasound scan remove probe sheath and detach the dummy channel bracket.

11. Thoroughly clean along the full length of the cable from the scanner towards probe tip using an Appropriate Sanitising wipe *. Repeat with the dummy channel bracket. Ensure that a clean to dirty technique is followed until any soiled organic matter has been visibly removed. (In the cases of heavy soiling more than one wipe may have to be used) Take care not to rub or bend the instrument and pay particular attention to edges, ridges and indentations.

The probe should not be wet going into the Trophon chamber, therefore gently dry the probe surface using a lint free wipe, tissue, or white couch roll
N.B.*Do not use blue couch roll as this could damage the lens of the probe*

12. Scan medical instrument tag (attached to probe). When the Trophon unit is ready for use the control panel message will state: **LOAD PROBE AND INDICATOR**

13. Open the Trophon chamber door and place probe only (**the dummy channel bracket <u>MUST NOT</u> be placed within the Trophon**) in chamber ensuring secure positioning of probe cable in the silicone probe cable holder and that probe tip is above the embossed line
N.B. ***The chamber will be hot***

14. Place the single use chemical indicator (CI) red side up in the CI holder located in the chamber door

15. Close chamber door securely

16. The control panel message will state: **IS THE PROBE CLEAN AND DRY?** If the probe has been cleaned with an Appropriate Sanitising wipe$^{1/2}$ and thoroughly dried then confirm by selecting “YES”

17. Scan operator card. Door will lock. To start the disinfection cycle press the green start/disinfect button

18. The 7 minute disinfection cycle will now commence- **clean** the ultrasound system probe holder

19. Steps 12 to 17 should be completed within 50 seconds otherwise the system will request user to remove probe, close door and restart process.

Cycle Completion, Traceability Management and Probe Removal

20. Upon completion of the disinfection cycle the system will sound a single Audible beep. **N.B. THE CHAMBER WILL BE HOT**
The control panel message will state: "Remove probe and chemical indicator"
Wearing gloves and holding the probe securely, carefully release the Cable from the chamber and gently dry the probe surface using lint free wipe, tissue, or white couch roll.
PLEASE BE AWARE THAT THE CABLE MAY BE DAMAGED IF NOT REMOVED FROM CABLE CLIP CAREFULLY
N.B.*Do not use blue couch roll as this could damage the lens of the probe*

21. Control panel message will state "Confirm chemical indicator Pass/Fail". Select appropriate option and scan operator card. Select "OK". The printer will automatically print 2 labels at the end of the decontamination cycle. Operator to sign label. Place 1 in patient notes and the other in the log book.

22. Open the chamber door and verify that the chemical indicator colour change indicates a **PASS** when compared with the colour assessment chart located on the chemical indicator box. Wearing gloves remove and dispose of the used chemical indicator in the normal waste container.

    If the chemical indicator colour change indicates a **FAIL** when compared with the colour assessment chart located on the chemical indicator box repeat the process from step 12.

    If failure persists remove the Trophon from use and report as per point 39

23. Carefully place the probe in a **clean** tray and cover with green Cleanascope sleeve and close the Trophon chamber door.

24. At the end of each list/clinic the labels printed after the last probe has been decontaminated in the Trophon system should be placed in the Trophon logbook as a record of probe decontamination.

Power, Sleep Mode, Wake Up and Warm Up

25. The Trophon system should not be powered down, it is designed to be powered 24/7. The fluid based chemicals need to be regularly refreshed and circulated throughout the system to ensure optimal functionality and efficacy.

26. Any unavoidable power loss, e.g. to relocate the system, should be kept to as short a timescale as possible.

27. The Trophon system is designed to enter a low power consumption/sleep mode after complete inactivity of 2 hours. To reactivate Trophon press the blue illuminated button, after which the system will enter a WARM UP phase taking approximately 6-10 minutes prior to being ready for use. During this time the chamber door will remain locked.

Storage and Management of Trophon Consumables

28. The Trophon Nanonebulant cartridges should be stored in a locked or restricted access area as per COSHH regulations.

29. The chemical Indicators (CIs) should be kept out of sources of direct light and heat. It is recommended that the CI strips are left inside the silver box and removed as required. ***Do not store chemical indicator box on top of Trophon***

30. The expiry date of the consumables should be checked prior to use. ***Any expired products should not be used***

Replacing the Nanonebulant Chemical Cartridge

31. When the Nanonebulant chemical cartridge needs to be replaced the control panel message will state “remove and empty waste drawer”. Action this, panel will now read **CARTRIDGE EMPTY, REPLACE CARTRIDGE NOW?**

32. From the options available select **OK** by pushing the corresponding black button below. Control panel will state “Scan disinfectant”. Scan the new cartridge against the Autotrace symbol on the Trophon and press “next”. Scan operator card to confirm.

33. The system will perform a brief safety check prior to the cartridge drawer being electronically unlocked and opened.

34. Once open, wearing gloves, remove the empty cartridge from the system, remove the cap of the new cartridge and insert the replacement cartridge in to the drawer and close.

35. The Nanonebulant cartridge is sealed and as a safety feature is only punctured once inside the Trophon unit.

36. Empty/used cartridges can be disposed of in general or recyclable waste.

37. The Nanonebulant cartridge lasts for 30 days after cartridge has been inserted (approximately 40 cycles). After this time the system will require a purging process, which can take up to 45 minutes. **Staff should monitor when the cartridge will expire to ensure the purging process is not required during a list/clinic. NB if the system is run each morning the cartridge will be replace before the 30 days.**

38. Staff can check the status of the cartridge and commence the cartridge replacement process at first day each month a suitable time using the MENU button on the front of the system and plan accordingly.

Fault Management and Reporting

39. The Trophon units are covered by a full support contract. In the event of a system fault or issue, contact Estates Decontamination Technical Services:
Tel: [redacted] (Select option 5)
E-mail: [redacted]

When reporting faults the following information should be provided.
Site Name:
Trophon Asset / Serial Number:
Contact Name:
Contact Telephone Number:
Department:
Fault Code:
Description of fault:

If unable to contact Estates then ring Nanosonics on: [redacted] and inform Estates on the above email address

40. In the event of a Trophon system breakdown please report immediately to Principal Lead Sonographer/Lead Midwife and revert to using Tristel 3 wipe system for decontaminating the probes until the Trophon system has been repaired.

Dummy Channel Bracket Preparation and use of Tristel Trio System

Once the probe has been placed in the Trophon machine, proceed as follows with the dummy channel bracket using Tristel Trio system.

Wipe is only for use on non-lumened heat sensitive re-usable medical devices.

The Tristel Trio Wipes System is a three-part decontamination procedure intended for use on heat sensitive semi-critical, non-lumened medical devices.

The following steps should be adhered to in order to minimise iatrogenic spread.

The Tristel Trio Wipes System effectively addresses three primary steps as part of the five required in the decontamination process, pre-cleaning, disinfection, rinsing, drying and storage.

The complete process must be followed each time for correct decontamination process to be complete. All 3 wipes and spray must be used.

Do not use Tristel Sachets or spray if they show any signs of damage.

PRE-CLEAN WIPE

1. **Step 1**
   Put on gloves (One pair of gloves may be used when using all **three** wipes in succession.)

   Step 2
   To dispense a wipe, take a sachet, tear and remove the wipe.

   Step 3

Unfold the wipe and lay out on the palm of your gloved hand.

Step 4

Thoroughly clean the dummy channel bracket (In cases of heavy soiling more than one wipe may have to be used).

Step 5
Discard the wipe to clinical waste.

TRISTEL SPORICIDAL WIPE

2. **Step 1**
   To dispense a wipe, take one sachet, tear and remove one wipe.

   Step 2
   Unfold the wipe and lay out on the palm of your gloved hand.

   Step 3
   Take the lid off the foam bottle. Note that the foam bottle label is identified as ACTIVATOR FOAM. If the foam bottle is being used for the first time, depress the pump two to four times to prime the foamer. The first output from the foam bottle can be left on the wipe, to be followed by four complete pumps. The foam bottle is then primed for subsequent wipes.

   For all subsequent wipes, pump four measures of the Tristel Activator Foam onto the wipe.

   When using a 50ml Activator Foam bottle pump four measures of foam onto the wipe.

Remember, activate the wipe as soon as you have removed it from the sachet and use it immediately. An activated wipe will have a faint odour of Chlorine dioxide, ClO_2.

Step 4
Scrunch the wipe for 15 seconds. Ensure that it is evenly covered with foam. Presence of 'chlorine like' odour confirms the wipe is ready to use.

Step 5
Wipe the surface of the dummy channel bracket until it has been covered with Tristel.

Step 6
Once the entire surface has been wiped and covered with Tristel, wait 30 seconds.

Step 7
Discard the wipe to clinical waste.

Following decontamination with a Tristel Sporicidal Wipe, the bracket should be thoroughly rinsed before re-use on the next patient, or storage. Tristel Rinse Wipe should be used.

TRISTEL RINSE WIPE

10. **Step 1**
To dispense a wipe, take a sachet, tear and remove the wipe.

Step 2
Unfold the wipe and lay out on the palm of your gloved hand.

Step 3
Thoroughly wipe the surface that has been decontaminated.

Step 4
Discard the wipe and gloves to clinical waste.

11. Place dummy channel bracket in clean tray next to corresponding decontaminated probe. The tray should be covered with a green Cleanascope sleeve.

On completion of the procedure, apron and gloves should be removed and hands thoroughly washed with soap and water.

Cycle Completion and Traceability Management

There are two labels on the reverse of the SPORICIDAL WIPE sachet; these labels should not be removed from the packet until the patient is in the examination room. Fill out details of the patient & decontamination cycle on these labels recording the probe used and unique patient identifier (Hospital number).

One label should then be placed in the patient's transperineal admission documentation. The second label should be placed in TRISTEL log book. This is required for traceability purposes.

At the end of each list/clinic after the probe has been decontaminated, the label from the SPORICIDAL WIPE sachet should be used to complete the record of decontamination in the TRISTEL book. This is required for traceability purposes.

*Appropriate Wipe

* Clinell Sanitising Wipes or Sanicloth wipes are recommended for use on the E14C4t probe

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The Management of Nurse Led Clinics for Active Monitoring of Patients with Prostate Cancer (Active Surveillance and Watchful Waiting)

Lead Policy Author & Job Title:	Leanne McCourt & Kate O'Neill Clinical Nurse Specialists in Urology
Directorate responsible for document:	Acute
Issue Date:	01 July 2021
Review Date:	01 July 2023

Policy Checklist

Policy name:	The Management of Nurse Led Clinics for Active Monitoring of Patients with Prostate Cancer (Active Surveillance and Watchful Waiting)
Lead Policy Author & Job Title:	Leanne McCourt & Kate O'Neill Clinical Nurse Specialists in Urology
Director responsible for Policy:	Melanie McClements
Directorate responsible for Policy:	Acute
Equality Screened by:	Click here to enter text.
Trade Union consultation?	Yes ☐ No ☒
Policy Implementation Plan included?	Yes ☐ No ☒
Date approved by Policy Scrutiny Committee:	Click here to enter a date.
Date approved by SMT:	Click here to enter a date.
Policy circulated to:	Eg Directors, Assistant Directors, Heads of Service for onward distribution to line managers, Global email, Staff Newsletter
Policy uploaded to:	Eg SharePoint, Trust website

Version Control

Version:	**Version 1.0**		
Supersedes:	**N/A**		
Version History			
Version	**Notes on revisions/modifications and who document was circulated or presented to**	**Date**	**Lead Policy Author**
Eg Version 1_0	Click here to enter text	Click here to enter a date.	Click here to enter text
Eg Version 2_0	Click here to enter text	Click here to enter a date.	Click here to enter text

Contents

1.0 Introduction

1.1 Prostate cancer follow up forms a substantial portion of the urology outpatient workload. On average there were 213 cases of prostate cancer diagnosed in the SHSCT each year between 2014 and 2018 (NI Cancer Registry 2018). In order to meet the demands on the service Urology Clinical Nurse Specialists will provide nurse led face to face and virtual clinics for those patients with prostate cancer that are suitable for Active Surveillance or Watchful Waiting.

1.2 The NHS is undergoing radical changes particularly in its approach to cancer. Nurse led clinics are becoming increasingly common, offering patients an alternative method of follow up. By developing these new roles and services, nurses are playing a key role in reducing waiting times, expanding accessibility to services and improving the quality of care.

1.3 This document outlines the policy principles for nurse led prostate cancer follow up and in accordance with the Trusts Key Principles for Policy development.

1.4 However this policy is only a foundation and it is recommended that nurses maintain their continuing education in this specialist area of care.

2.0 Purpose and Aims

2.1 The aim of this policy is to set a minimum standard for nurse led follow up of patients with prostate carcinoma which will:

- ✓ Enable the follow up of patients with prostate cancer (active surveillance / watchful waiting)
- ✓ Promote the education of patients about their disease management and potential for self-management
- ✓ Enable holistic assessment
- ✓ Inform patients about specialist services that can help with their medical, practical, emotional and rehabilitation needs and refer to the appropriate service
- ✓ Identify the need for additional supportive interventions and to refer onto other members of the multidisciplinary team as necessary
- ✓ Identify signs of disease progression; provide support and refer promptly to MDT
- ✓ Support patients living with and beyond cancer

3.0 Objectives of this Policy

3.1 The objectives of this policy are to improve and maintain standards of clinical practice and quality of care to patients. These are

- ✓ Provide evidence for establishing and maintaining a nurse led clinic for prostate cancer follow up (active surveillance / watchful waiting), promoting excellence in the care that is delivered
- ✓ Reduce variation in clinical practice and encouraging uniformity of practice
- ✓ Provide a framework from which individual practitioners can apply their own level of clinical expertise and competency
- ✓ Ensure that all patients entering the prostate cancer follow up service are on the appropriate risk stratified pathway
- ✓ Support nurses and health care providers to make informed decisions, aiding the education process and reducing the risk of clinical negligence
- ✓ Identify competencies for nursing care
- ✓ Aid development of a locally agreed policy
- ✓ Establish a yearly audit cycle

4.0 Policy Statement

4.1 The purpose of the nurse led clinic is to enhance the quality of care and to promote the health and wellbeing of patients who are living with prostate cancer. The clinic will also facilitate the provision of emotional support for patients and their families/carers requiring the opportunity to discuss treatment or care options.

4.2 A risk stratified model of aftercare in line with the NICAN Guidelines for Nurse Led Assessment and Follow up of patients with stable Prostate Cancer (2016) (Appendix 1) will be utilised and patients will be stratified in their follow up pathway via the MDM.

4.3 Risk stratified means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, (what type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short term and long term) and the person (whether they have other illnesses or conditions, and how much support that they feel they need). This will include the on-going follow up of patients who are clinically stable and are stratified into the relevant pathway

5.0 Scope of Policy

5.1 This policy applies to the Urology CNS team who are providing nurse led follow up to patients with prostate cancer. Patients will enter nurse led follow up services on a clearly defined follow up pathway following discussion at MDM.

6.0 Responsibilities

6.1 The SHSCT Trust Chief Executive as 'Accountable Officer' has overall responsibility for ensuing that the aims of this policy are met and has a responsibility to invest in training and education for all health care professionals.

6.2 Within the Acute directorate, the Director, Assistant Director, Head of Service and Lead Nurse have responsibility for the effective application of this policy.
6.3 The Lead Nurse has a responsibility to ensure that appropriate systems are in place to monitor and review staff performance, registration and training requirements.
6.4 It is the responsibility of the Urology Consultants to determine suitability and referral to this service as per the MDM outcome.
6.5 It is the responsibility of the Urology CNS team to be familiar with and adhere to this policy and follow the agreed processes.

7.0 Legislative Compliance, Relevant Policies, Procedures and Guidance

7.1 This policy has been developed in accordance with the following list of legislation, guidance and standards:

National Institute for Health and Clinical Excellence (NICE) Prostate Cancer diagnosis and treatment (2019)
https://www.nice.org.uk/guidance/ng131

NICAN Guidelines for Nurse Led Assessment and Follow up of patients with Stable Prostate Cancer (March 2016 & currently under review)

Urology Multidisciplinary Operational Policy (2020)

8.0 Equality & Human Rights Considerations

8.1 This policy has been screened for equality implications as required by Section 75 and Schedule 9 of the Northern Ireland Act 1998. Using the Equality Commission's screening criteria; no significant equality implications have been identified. Similarly, this procedure has been considered under the terms of the Human Rights Act 1998 and was deemed compatible with the European Convention Rights contained in the Act.

9.0 Sources of Advice & Further Information

9.1 This policy should be read in conjunction with related policies and procedures.

Appendix 1

NICAN Guidelines for Nurse Led Assessment and Follow up of patients with stable Prostate Cancer (2016)
Urology-CMG-Mar-2016.pdf

National Institute for Health and Clinical Excellence (NICE) Prostate Cancer diagnosis and treatment (2019)
https://www.nice.org.uk/guidance/ng131

Urology Multidisciplinary Operational Policy (2020)

NI Cancer Registry Prostate Cancer Statistics 1993-2018
https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/Prostate/

Appendix 2

Competencies for Nurse-led Follow-up

Competencies required assessing patients with stable prostate cancer include:

- Advanced nurse practitioner/clinical nurse specialist having been employed for a minimum of twelve months working with a urologist/oncologist in the follow up setting
- Demonstrate a full understanding of the network site specific group pathways for prostate cancer. As agreed by the local tumour network
- To be enrolled in or be undertaking, a programme of study in their specialist area of nursing practice which has been accredited for at least 20 CAT points at level 3 (DH2004) e.g. Health Assessment module
- Have advanced communication skills – to have enrolled in, or be undertaking a recognised course/module in communication skills (DH 2004)
- In order to run a clinic the individual must be a core member or extended member of the urology multidisciplinary team
- To be able to demonstrate knowledge of the disease trajectory in Prostate Cancer
- To be able to demonstrate knowledge of risk stratified pathways
- To have competent consultation and symptom analysis skills. To have worked under supervision for a minimum of six months and have been deemed competent by the consultant urologist/oncologist
- To be able to demonstrate knowledge of the tests and investigation required during follow up of prostate cancer patients
- To be competent at performing DRE (if appropriate)
- To be competent in the assessment of lower urinary tract symptoms (LUTS) and facilitate onward referral to LUTS clinic is required
- To be competent in bladder palpation
- To be competent in the assessment of bladder empting

- To demonstrate ability to advise on erectile dysfunction and know where and how to refer to appropriate service

- To be able to demonstrate knowledge of survivorship issues

- To be able to demonstrate knowledge of rehabilitation services

- Demonstrate knowledge of drugs and treatments used in prostate cancer including side effect

Appendix 3

Guideline for Nurse Led Assessment Protocol

Patient Assessment

Local guidelines for nurse led follow up of patients with stable prostate cancer have been developed based on NICAN (March 2016) and NICE (May 2019) guidelines.

- On referral to the nurse led review clinic, the patient will be informed and provided written information on the purpose of the clinic, how it will function and the contact details
- On referral the patients GP will also be informed of the patients management plan
- At their appointment the Urology CNS will assess the patients general health and wellbeing, and complete the assessment .
- At each appointment the CNS will confirm that the patient wishes to remain on the current pathway and that this remains appropriate for them.
- If bloods were not done in advance of patient attendance, they should be taken at the end of the assessment and reviewed by the Urology CNS when reports available. Patients will be contacted if any abnormalities are present or actions need to be taken based on blood results
- If any concerns or abnormalities in blood results are identified they will be discussed with the patient and rapid access initiated to either Consultant Urologist or MDM whichever is appropriate
- Documentation of required intervention will be made on ECR
- An advice letter will be dictated to the GP
- Further review appointment will be determine

Actions
Discuss • Nurse led clinic • History/treatment to date

- Timeline for routine follow up such as PSA, DRE and Admission Profile

Physical Examination

Carry out physical assessment including:

- Digital Rectal Examination (DRE)
- International Prostate Symptom Score (IPSS) if required

Symptoms

Is the patient experiencing any symptoms .

- Hot Flushes
- Ask about pain – any new pain lasting more than a week (use locally agreed pain scale)
- Weight loss/gain
- Fatigue
- Sexual dysfunction
- Neurological symptoms – Numbness, tingling or odd sensations in limbs
- Lower Urinary tract symptoms
- Haematuria
- Gynaecomastia
- Change in bowel habit
- Deterioration in renal function

Is the patient experiencing any symptoms suggestive of local or metastatic disease

- Abdominal /Pelvic /Skeletal pain
- Weight loss
- Anorexia
- Nausea or vomiting

Ask about any other symptoms/concerns

Tests and investigations

- PSA at each visit if rising discuss with consultant
- Admission Profile at each visit
- FBP at first visit
- Ultrasound renal tracts following discussion with Consultant

Holistic Assessment

Perform holistic assessment suggested tools:

- Macmillan Concerns Checklist & Care-plan

Information

Nurse to check information has been provided and tailored to the individual patient.
This will include information about:

- Timeline for tests and investigations
- Survivorship programme
- Rapid Access to service
- Contact numbers
- What symptoms need to be reported
- Consequences and side effects of the treatment
- Holistic Assessment
- Rehabilitation services

Rehabilitation

Discuss and offer referral to:

- Community Health and Well-being Clinics
- Signposting to other services

Documentation

Care plan
Letter to GP & referring consultant (copy to patient) with copy of assessment form,

To include:

- Date and time of nurse consultation
- Patients identifiable details
- Diagnosis
- Treatment,
- Assessment summary,
- Most recent PSA reading
- Date of next nurse appointment
- Potential or actual problems identified during the consultation.

Appendix 4

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NURSE LED CLINIC PROFORMA ACTIVE SURVEILLANCE
HNA REVIEW

Patient Details: CNS: Confirm if patient wishes to remain on Active Surveillance pathway Yes/no	Date: Consultant:

STAGING PSA trigger:
Date of diagnosis: PSA at diagnosis: DRE at diagnosis: MRI result at diagnosis: Gleason score at diagnosis:

CURRENT RESULTS
Current PSA : DRE findings: ECOG: Current Meds:

LUTS	Sexual Function
IPSS Score: LUTS: Storage symptoms: Voiding symptoms: Dysuria : Haematuria:	IIEF Score:

HNA:

Concerns: 1. 2. 3.	Information given/signposting:

Next Review:

Letter dictated to

Patient ☐

Consultant ☐

GP ☐

Southern Health
and Social Care Trust
Quality Care - for you, with you

NURSE LED CLINIC PROFORMA ACTIVE SURVEILLANCE
4 MONTH TELEPHONE/FACE TO FACE REVIEW

Patient Details: CNS: Confirm if patient wishes to remain on Active Surveillance pathway Yes/no	Date: Consultant:

STAGING PSA trigger:
Date of diagnosis: PSA at diagnosis: DRE at diagnosis: MRI result at diagnosis: Gleason score at diagnosis:

CURRENT RESULTS
Current PSA : ECOG: Current Meds:

LUTS	Sexual Function
IPSS Score: LUTS: Storage symptoms: Voiding symptoms: Dysuria : Haematuria:	IIEF Score:

Next Review:

Letter dictated to

Patient ☐

Consultant ☐

GP ☐

Appendix 5

Clinic Schedule

HNA clinic will be confirmed in advance and the patient informed via the support worker.

The nurse led clinic will be confirmed in advance and the patient informed by the Referral and Booking Centre.

A blood form will accompany the appointment letter in order for PSA to be obtained one week in advance with either the Practice Nurse or Drive Through Phlebotomy Service.

The initial appointment will incorporate a HNA therefore it is limited to 4 patients per session; subsequent review clinic will be limited to 7 patients.

When the CNS is on leave, the clinic will be cancelled.

Referral Protocol

Patients will be referred by the Consultant Urologist or the Urology MDM in a manner that specifies the patients management plan as per NICAN (March 2016) and NICE May 2019) guidelines. This will be actioned by way of an electronic referral form.

A decision about active surveillance/watchful waiting must have been made in partnership with the patient .

A ceiling for PSA level will be set (based on 2 x successive rises in PSA / consideration of doubling time and symptom progression).

Appendix 6

Recommended exclusion criteria

Patients who do not wish to be followed up by a nurse

Patients who require adjuvant treatment in the form of radiotherapy or chemotherapy

Patients with dementia/short term memory loss (unless meeting patients with carer present)
Patients who develop resistance to Hormone Therapy during follow up and require referral to oncologist

Patients deemed unsuitable for review at a nurse led clinic by the consultant in charge

Appendix 7

Rapid Access Protocol

All patients should be able to access the Consultant responsible for their care through the Urology CNS. Any patient that contacts the Urology CNS with worrying symptoms will be seen by a Consultant promptly. If necessary, their case should be discussed by the MDT.

Each patient will be able to contact the Urology CNS outside of scheduled follow up appointments The Urology CNS will triage the patient on their concerns/issues to the most appropriate member of the Urology team or refer on to other agencies accordingly. Outcomes may include:

- Face to face consultant appointment promptly
- Face to face Nurse led clinic (where appropriate)
- Advised to contact GP
- Advised to attend the emergency department
- Only clinical issues will result in a clinical appointment.

Appendix 8
Referral Form

Patient Details:

Date: Click here to enter a date.

Pathway: Choose an item.

Consultant: Choose an item.

Date of MDM: Click here to enter a date.

Diagnosis:

WHO Performance Status: Choose an item.

PSA at diagnosis:

DRE at diagnosis:

MRI result at diagnosis (if appropriate):

Gleason score at diagnosis (if appropriate):

PSA trigger:

Please email completed form to: **Macmillan Support Worker (once in post)**

Appendix 9

Patient Information Leaflet

What is a nurse-led follow-up clinic?

Within the Southern Trust we provide a variety of nurse-led face to face and telephone clinics for patients with various urological cancers.

The clinic is conducted by a team of Urology Clinical Nurse Specialists with specific training related to urological cancers and their management.

While some of the clinics will be held face to face at a hospital setting within the Southern Trust, you may be offered the opportunity to have a virtual/telephone review instead.

First appointment at nurse-led face to face follow-up clinic.

You will receive a letter with a date for a face to face review appointment.
Your **first** appointment will take about half an hour. The letter will inform you **if** you require any blood tests to be carried out in advance of the appointment. (These bloods should be organised through arrangement with the treatment room at your local GP practice or drive through phlebotomy service).

At your first appointment you will also be offered the opportunity to engage in an Holistic Needs Assessment. This will help the nurse to identify and address your needs and concerns and to develop a Personalised Care and Support Plan.

You will be sent a short questionnaire to complete prior to your appointment, this will enable the nurse to identify any needs or concerns you may have. If you prefer to do this online there will be instructions on how to do this.

At your appointment, the nurse will have a conversation with you to discuss your answers. A plan can then be made to help you address your concerns.

We will also discuss:

- Your general health and well being
- Your specific blood/scan results

If there is any cause for concern the nurse will arrange for you to be reviewed by the appropriate medical professional.
If there is no cause for concern, arrangements will be made for your next telephone/face to face review.
You and your GP will receive a letter which will summarise the points covered during your review appointment.

How does a telephone clinic work?

You will receive a letter with a date for a telephone review appointment. The letter will inform you **if** you require any blood tests to be carried out in advance of the appointment. (These bloods should be organised through arrangement with the treatment room at your local GP practice or drive through phlebotomy service).

The telephone review should take around 10-15minutes.

On the date and time of your appointment the nurse will telephone you and discuss:

- Your general health and well being
- Your specific blood/scan results
- Identify any wider problems or concerns you may have in relation to your general health and wellbeing.

If there is any cause for concern the nurse will arrange for you to be reviewed by the appropriate medical professional.

If there is no cause for concern, arrangements will be made for your next telephone/face to face review.

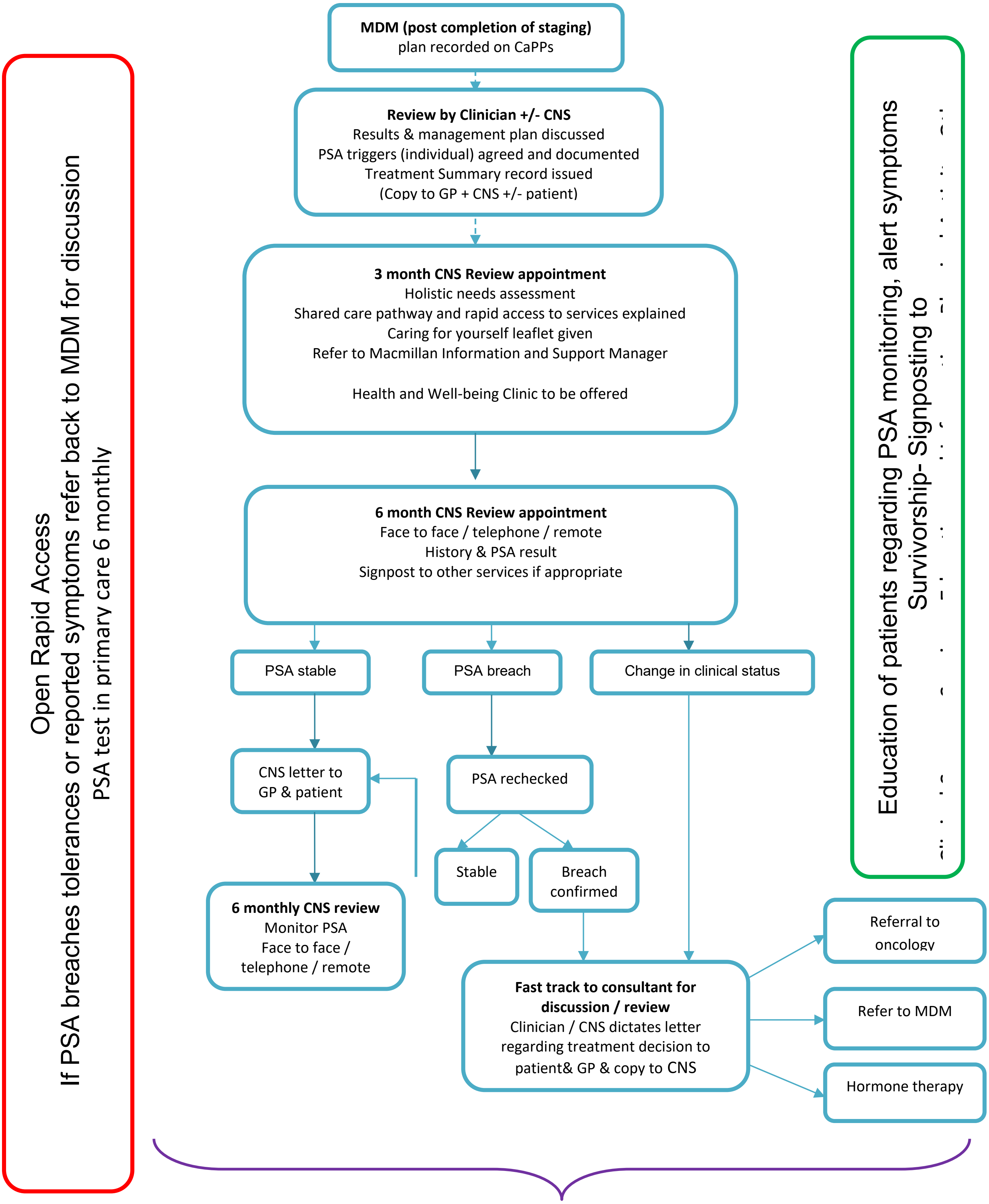
You and your GP will receive a letter which will summarise the points covered during your review call.

What are the benefits of having a telephone appointment ?

- Fewer visits to hospital
- No transport costs
- No problems with hospital parking
- No need for you or your family to take time off work.
- Continuity of care speaking to same nurse at each appointment.

From time to time you may be asked via a questionnaire to help us evaluate the nurse led service; this will help us improve the service we provide for others in the future.

Appendix 10

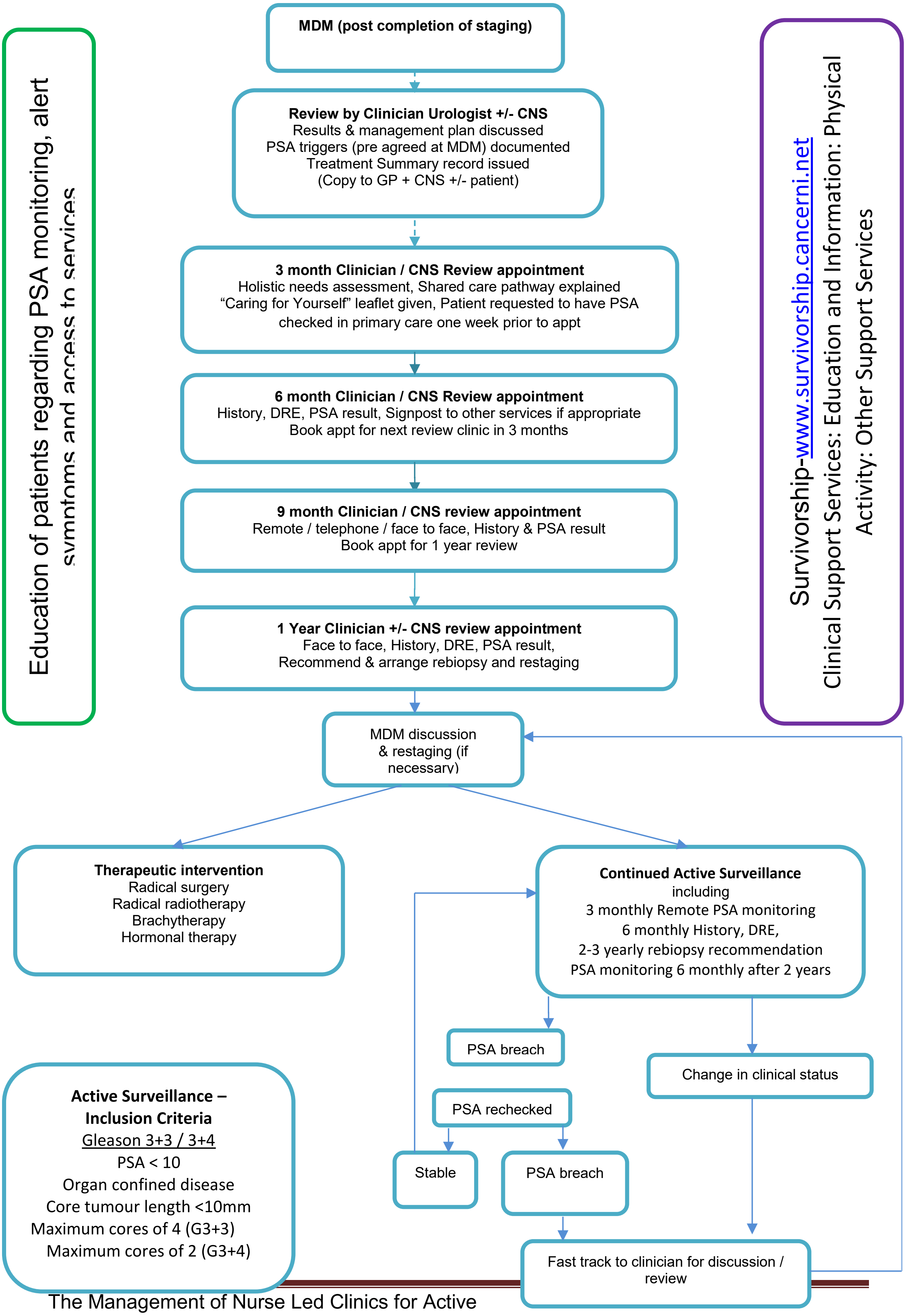


Watchful waiting – Adapted from NICE Guidance 2008

'Watchful Waiting is the form of continued review of Prostate Cancer patients for whom future therapeutic intervention with curative intent has been considered to be

Pathway 2 Prostate Cancer: Active Surveillance

Education of patients regarding PSA monitoring, alert symptoms and access to services



MDM (post completion of staging)

Review by Clinician Urologist +/- CNS
Results & management plan discussed
PSA triggers (pre agreed at MDM) documented
Treatment Summary record issued
(Copy to GP + CNS +/- patient)

3 month Clinician / CNS Review appointment
Holistic needs assessment, Shared care pathway explained
"Caring for Yourself" leaflet given, Patient requested to have PSA checked in primary care one week prior to appt

6 month Clinician / CNS Review appointment
History, DRE, PSA result, Signpost to other services if appropriate
Book appt for next review clinic in 3 months

9 month Clinician / CNS review appointment
Remote / telephone / face to face, History & PSA result
Book appt for 1 year review

1 Year Clinician +/- CNS review appointment
Face to face, History, DRE, PSA result,
Recommend & arrange rebiopsy and restaging

MDM discussion & restaging (if necessary)

Therapeutic intervention
Radical surgery
Radical radiotherapy
Brachytherapy
Hormonal therapy

Continued Active Surveillance
including
3 monthly Remote PSA monitoring
6 monthly History, DRE,
2-3 yearly rebiopsy recommendation
PSA monitoring 6 monthly after 2 years

PSA breach

Change in clinical status

PSA rechecked

Stable

PSA breach

Fast track to clinician for discussion / review

Active Surveillance – Inclusion Criteria
Gleason 3+3 / 3+4
PSA < 10
Organ confined disease
Core tumour length <10mm
Maximum cores of 4 (G3+3)
Maximum cores of 2 (G3+4)

Survivorship-www.survivorship.cancerni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

Southern Health and Social Care Trust
Quality Care - for you, with you

Equality, Good Relations and Human Rights Screening Template

Completed Screening Templates are public documents and will be posted on the Trust's website

See 'Equality, Good Relations and Human Rights Screening Guidance Notes' (on SharePoint) for further background information on the relevant legislation and for help in answering the questions on this template.

(1) Information about the Policy/Proposal

(1.1) Name of the policy/proposal

The Management of Nurse Led Clinics for Active Monitoring of Patients with Prostate Cancer (Active Surveillance and Watchful Waiting)

(1.2) Is this a new, existing or revised policy/proposal?

New

(1.3) What is it trying to achieve (intended aims/outcomes)?

The purpose of this policy is to determine a minimum standard for Clinical Nurse Specialist (CNS) assessment and follow up of patients with prostate cancer which will:

- Enable the follow up of patients with prostate cancer who are on the watchful wait or hormone treatment pathway
- Promote the education of patients about their disease management and potential for self-directed aftercare
- Monitor patient progress and enable detection of progression and refer to the appropriate Consultant Urologist
- Enable holistic assessment
- Identify late effects of treatment quickly, provide support and signpost to the appropriate service if necessary
- Inform patients about and refer them to specialists services that can help with their medical, practical, emotional and rehabilitation needs
- Support patients living with and beyond cancer
- Offer patients a choice of follow-up

(1.4) Are there any Section 75 categories which might be expected to benefit from the intended policy/proposal?

Male patients who been diagnosed with Prostate Cancer and require follow up on Active Surveillance or Watchful Waiting pathways. Males over the age of 50 are most likely to benefit from the mentioned policy proposal as prostate cancer mainly affects men over 50, and your risk increases with age.

All S75 categories including staff, actual and potential service users – patients, clients and visitors.

(1.5) Who owns and who implements the policy/proposal - where does it originate, for example DoH, HSCB, the Trust?

Southern Health and Social Care Trust Policy – implemented by Managers and staff

(1.6) Are there any factors that could contribute to/detract from the intended aim/outcome of the policy/proposal/decision? (Financial, legislative or other constraints?)

The Coronavirus Pandemic could potentially lead to delays in the implementation of the proposed policy.

(1.7) Who are the internal and external stakeholders (actual or potential) that the policy/proposal/decision could impact upon? (E.g. staff, service users, other public sector organisations, trade unions, professional bodies, independent sector, voluntary and community groups etc.)

Internal Stakeholders

Internal Stakeholders include Staff, Consultant Urologist and the Clinical Nurse Specialist in Urology, who are responsible for the selection of the patients suitable for nurse led Prostate Cancer follow up

External Stakeholders

External Stakeholders would include Service users.

(1.8) Other policies with a bearing on this policy/proposal (for example regional policies) - what are they and who owns them?

Guidance has been provided by:

- NICE (2019) Prostate cancer: diagnosis and management
- NICaN Guidelines for Nurse Led Assessment and Follow up of patients with stable Prostate Cancer (2015)
- Guidance for nursing and midwifery staff on chaperoning
- Information governance policy 2018
- Coronavirus Act 2020
- PPE Guidelines
- Health and Safety Legislation (Duty of Care)
- Human Rights Act -1998
- Disability Discrimination Act – 1995
- Department of Health, Social Services and Public Safety: Safeguarding Vulnerable Adults, Regional Adult Protection Policy and Procedural Guidance
- UN Principles for Older People
- Section 75 of the Northern Ireland Act
- Trust's approved Equality Scheme

(2) Available evidence

Evidence to help inform the screening process may take many forms. What evidence/information (both qualitative and quantitative) have you gathered to inform this policy? *NB: Specify the details for each of the Section 75 categories for any staff affected, the Trust Workforce, any patients/clients affected and the Trust general population in the following tables **if appropriate**.*

2.1 Staff Affected by this Policy/Proposal & Composition of Southern Trust Workforce

Section 75 Group	***Southern Trust Workforce Profile as at 1 January 2021***	***Percentage***
Gender	Female	**85.1%**
	Male	**14.9%**
Religion	Protestant	**35.6%**
	Roman Catholic	**56.7%**
	Neither	**7.7%**
Political Opinion	Broadly Unionist	**9.7%**
	Broadly Nationalist	**10.1%**
	Other	**7.8%**
	Do Not Wish To Answer/Not Known	**72.4%**
Age	16-24	**6.5%**
	25-34	**25.0%**
	35-44	**25.3%**
	45-54	**21.8%**
	55-64	**18.4%**
	65+	**3.0%**
Marital Status	Single	**31.6%**
	Married	**59.1%**
	Not Known	**9.3%**
Dependent Status	Caring for a Child/Children / Dependant Older Person / Person With a Disability	**19.0%**
	None	**31.1%**
	Not Known	**49.9%**
Disability	Yes	**2.5%**
	No	**78.7%**
	Not Known	**18.8%**
Ethnicity	Bangladeshi	**0.02%**
	Black African	**0.21%**
	Black Caribbean	**0.02%**
	Black Other	**0.02%**
	Chinese	**0.1%**
	Filipino	**0.4%**
	Indian	**0.72%**
	Irish Traveller	**0.02%**
	Mixed Ethnic	**0.12%**
	Pakistani	**0.15%**
	White	**80.1%**
	Not Known	**18.1%**
Sexual Orientation *towards:*	Opposite Sex	**57.3%**
	Same Sex	**1.0%**
	Same and Opposite Sex	**0.1%**
	Do Not Wish To Answer/Not Known	**41.6%**

2.2 Patients / Clients Affected

Section 75 Group	***Make up of Patients/Clients Affected***	***Percentage***
Gender	Female Male	**This clinic is predominantly for the review of men with prostate cancer. The following people may also be affected by prostate cancer. They will also be reviewed at this clinic without prejudice.** **trans women** **non-binary people who were assigned male at birth** **some intersex people.**
Religion	Protestant Roman Catholic Other	**As per table 2.3**
Political Opinion	Broadly Unionist Broadly Nationalist Other Do Not Wish To Answer/Not Known	**As per table 2.3**
Age	0-15 16-24 25-44 45-64 65-84 85+	**As the risk of prostate cancer increases with age, the patient make up will comprise mainly (but not exclusively)of those aged 50 years and above**
Marital Status	Single	**As per table 2.3**

	Married/Civil Partnership Other/Not Known	
Caring Responsibility	Caring for a Child/Children/Dependant Older Person/Person(s) With a Disability None Not Known	**As per table 2.3**
Disability	Yes No Not Known	All service users will be considered disabled under the Disability Discrimination Act 1995 (DDA) as they have a diagnosis of cancer
Ethnicity	Bangladeshi Black African Black Caribbean Black Other Chinese Filipino Indian Irish Traveller Mixed Ethnic Pakistani White Not Known	**As per table 2.3**
Sexual Orientation *towards:*	Opposite Sex Same Sex Same and Opposite Sex Do Not Wish To Answer/Not Known	**As per table 2.3**

2.3 Southern Trust's Area Population Profile – Census 2011

Section 75 Group	***Trust's Area Population Profile (Population of 358,034)***	***Percentage***
Gender	Female Male	**50.36** **49.64**
Religion	Protestant Roman Catholic Other	**39.15** **56.69** **4.16**
Political Opinion	Not collected	
Age	0-15 16-24 25-44 45-64 65-84 85+	**22.73** **12.25** **28.45** **23.40** **11.69** **1.48**
Marital Status (aged 16+ years)	Single Married/Civil Partnership	**34.99** **50.24**

	Other	**14.77**
Dependent Status	Caring for a Child/Children/Dependant Older Person/Person(s) With a Disability	**11.34% of usually resident population provide unpaid care**
Disability	Yes No	**19.64** **80.36**
Ethnicity	Asian Other Bangladeshi Black African Black Caribbean Black Other Chinese Indian Irish Traveller Mixed Ethnic Group Other Pakistani White	**0.20** **0.01** **0.11** **0.01** **0.10** **0.22** **0.17** **0.15** **0.29** **0.16** **0.07** **98.51**
Sexual Orientation	Estimated 6-10% of persons identify as lesbian, gay, bisexual – *Source: 2012 report by Disability Action & Rainbow Project*	

(3) Needs, experiences and priorities

(3.1) Taking into account the information above what are the different needs, experiences and priorities of each of the Section 75 categories and for both service users and staff.

Section 75 Category	***Details of Needs, Experiences and Priorities***	
	Staff	***Service Users***
Gender	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	In the main, Male service users will use this service
Age	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	The majority of service users will be over the age of 50
Religion	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	These guidelines have been written to meet the needs of all service users regardless of religion
Political Opinion	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	These guidelines have been written to meet the needs of all service users regardless of political opinion
Marital Status	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	These guidelines have been written to meet the needs of all service users regardless of marital status
Dependent Status	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	These guidelines have been written to meet the needs of all service users regardless of dependency status
Disability	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a	All service users will be considered disabled under the Disability Discrimination Act 1995 (DDA) as they have a diagnosis of cancer

Section 75 Category	Details of Needs, Experiences and Priorities	
	Staff	**Service Users**
	negative effect on the staff delivering the service.	
Ethnicity	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	Males from the BAME background have a higher risk of developing prostate cancer. These guidelines have been written to meet the needs of all service users regardless of ethnicity
Sexual Orientation	This is a clinical policy and will in the main affect service users. It is not envisaged by implementing such guidelines that there will be a negative effect on the staff delivering the service.	These guidelines have been written to meet the needs of all service users regardless of sexual orientation

(3.2) Provide details of how you have involved stakeholders, views of colleagues, service users and staff etc when screening this policy/proposal.

This policy was reviewed via the Urology Departmental meeting, which includes representation from Urology Clinical Nurse Specialists, Urology Consultants, Head of Service and Lead Nurse.

Service users can decline referral to the nurse led service without prejudice to their care.

(4) Screening Questions

You now have to assess whether the impact of the policy/proposal is major, minor or none. You will need to make an informed judgement based on the information you have gathered.

(4.1) What is the likely impact of equality of opportunity for those affected by this policy/proposal, for each of the Section 75 equality categories?

Section 75 category	***Details of policy/proposal impact***		***Level of impact? Minor/major/none***
	Staff	***Service Users***	
Gender	N/A – Will not affect staff groups	As this is a Prostate Cancer follow up clinic, no women will be reviewed. Men with prostate cancer on Active Surveillance or Watchful Waiting pathways will be reviewed in a more timely fashion. Thereby enabling the Urology service as a whole, to be more efficient by releasing more time for consultants to review more complex cases across all genders.	Minor Positive
Age	N/A – Will not affect staff groups	As the risk of prostate cancer increases with age, the patient make up will comprise mainly (but not exclusively) of those aged 50 years and above. Men with prostate cancer on Active Surveillance or Watchful Waiting pathways in these age groups will be reviewed in a more timely fashion. Thereby enabling the Urology service as a whole, to be more efficient by releasing more time for consultants to review more complex cases across all age groups.	Minor Positive

Religion	N/A – Will not affect staff groups	Impacts all within this group equally Includes provision regardless of religious belief.	None
Political Opinion	N/A – Will not affect staff groups	Impacts all within this group equally Includes provision regardless of political opinion.	None
Marital Status	N/A – Will not affect staff groups	Impacts all within this group equally Includes provision regardless of marital status.	none
Dependent Status	N/A – Will not affect staff groups	Impacts all within this group equally Includes provision regardless of dependent status.	none
Disability	N/A – Will not affect staff groups	All service users will be considered disabled under the Disability Discrimination Act 1995 (DDA) as they have a diagnosis of cancer.	none
Ethnicity	N/A – Will not affect staff groups	As BAME males are more at risk of developing prostate cancer. Men with prostate cancer on Active Surveillance or Watchful Waiting pathways from the BAME community will be reviewed in a more timely fashion. Thereby enabling the Urology service as a whole, to be more efficient by releasing more time for consultants to review more complex cases across all ethnicities.	Minor Positive
Sexual Orientation	N/A – Will not affect staff groups	Impacts all within this group equally Includes provision regardless of sexual orientation.	None

(4.2) Are there opportunities to better promote equality of opportunity for people within Section 75 equality categories?	
Section 75 category	***Please provide details***
Gender	As this is a Prostate Cancer follow up clinic, no women will be reviewed
Age	As the risk of prostate cancer increases with age, the patient make up will comprise mainly (but not exclusively)of those aged 50 years and above
Religion	n/a
Political Opinion	n/a
Marital Status	n/a
Dependent Status	n/a
Disability	n/a
Ethnicity	As black males are more at risk of developing prostate cancer, men with prostate cancer on Active Surveillance or Watchful Waiting pathways from the black community will be reviewed in a more timely fashion. (1 in 4 black men will get prostate cancer in their lifetime. Black men are more likely to get prostate cancer than other men, who have a 1 in 8 chance of getting prostate cancer.) Thereby enabling the Urology service as a whole, to be more efficient by releasing more time for consultants to review more complex cases across all ethnicities.
Sexual Orientation	n/a

(4.3) To what extent is the policy/proposal likely to impact on good relations between people of different religious belief, political opinion or racial group? minor/major/none		
Good relations category	***Details of policy/proposal impact***	***Level of impact Minor/major/none***
Religious belief	n/a	none

Political opinion	n/a	none
Racial group	n/a	none

(4.4) Are there opportunities to better promote good relations between people of different religious belief, political opinion or racial group?	
Good relations category	***Please provide details***
Religious belief	n/a
Political opinion	n/a
Racial group	n/a

(5) Consideration of Disability Duties

(5.1) How does the policy/proposal encourage disabled people to participate in public life and promote positive attitudes towards disabled people?

All service users will be considered disabled under the Disability Discrimination Act 1995 (DDA) as they have a diagnosis of cancer
As part of audit and quality improvement, regular feedback will be sought from service users to ensure needs continue to be met.

The Trust is committed to ensuring it meets its obligations within the Disability Discrimination Act 1995 and the United Nations Convention on the Rights of People with Disabilities.

The Trust has a number of policies/plans in place including a Disability Action Plan as well as staff training, aimed at encouraging disabled people participation in public life and promoting positive attitudes towards disabled people including staff with disabilities.

The Trust is committed to Equal Opportunities.

(6) Consideration of Human Rights

The Trust has a duty to act compatibly and must take Human Rights considerations into account in its day-to-day functions/activities.

(6.1) How does the policy/proposal impact on Human Rights?
Complete for each of the articles

Article	Positive impact	Negative impact = human right interfered with or restricted	Neutral impact
Article 2 – Right to life			x
Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment			x
Article 4 – Right to freedom from slavery, servitude & forced or compulsory labour			x
Article 5 – Right to liberty & security of person			x
Article 6 – Right to a fair & public trial within a reasonable time			x
Article 7 – Right to freedom from retrospective criminal law & no punishment without law			x
Article 8 – Right to respect for private & family life, home and correspondence.			x
Article 9 – Right to freedom of thought, conscience & religion			x
Article 10 – Right to freedom of expression			x
Article 11 – Right to freedom of assembly & association			x
Article 12 – Right to marry & found a family			x
Article 14 – Prohibition of discrimination in the enjoyment of the convention rights			x
1st protocol Article 1 – Right to a peaceful enjoyment of possessions & protection of property			x
1st protocol Article 2 – Right of access to education			x

Please note: If you have identified potential negative impact in relation to any of the Articles in the table above, speak to your line manager and/or

Equality Unit on tel: [redacted]. It may also be necessary to seek legal advice.

(6.2) Please outline any actions you will take to promote awareness of human rights and evidence that human rights have been taken into consideration in decision making processes.

Ongoing Human Rights Awareness Training and staff completion of 'Making a Difference' – Equality, Good Relations and Human Right e-learning training. Considering human rights aspects as an integral part of the Trust's decision making processes and in this instance policy development, implementation and review

As part of audit and quality improvement, regular feedback will be sought from service users to ensure needs continue to be met.

(7) Screening Decision

(7.1) Given the answers in Section 4 of this template, how would you categorise the impacts of this decision or policy/proposal? *(Please tick one option below and list your reasons for the decision in 7.2 below)*

Major impact		**EQIA Required?** ***(Delete as appropriate)***	
			No

Minor impact	X Positive	Mitigation Required	Alternative Policy Required
			No

No impact		**Screened Out**

(7.2) Please give reasons for your decision and detail any mitigation or alternative policies considered.

This policy will have a minor positive impact on men with prostate cancer on Active Surveillance or Watchful Waiting pathways . There will also be a minor positive impact for all service users or Urology Services as Consultant time will be released to review more complex cases.

(7.3) Do you consider the policy/proposal needs to be subjected to ongoing screening? NB: for strategies/policies that are to be put in place through a series of stages – screen at various stages during implementation.

Yes	
No	X

(8) Monitoring

(8.1) Please detail how you will monitor the effect of the policy/proposal for equality of opportunity and good relations, disability duties and human rights?

As part of audit and quality improvement, regular feedback will be sought from service users to ensure needs continue to be met.

Approved Lead Officer: **Is this our Assistant Director, HOS or Lead Nurse ?**

Position: ____________________

Email: ____________________

Telephone No: ____________________

Date: ____________________

Policy/proposal screened by: ____

Please forward completed screening template to [redacted] for inclusion in the Trust's Policy Screening Reports which are uploaded to the Trust's website.

Southern Health
and Social Care Trust

Quality Care - for you, with you

Thorndale Unit:
1:1 UNS's / Lead Nurse
Present: Kate O'Neill, Jenny McMahon, Leanne McCourt, Sarah Ward

Date:7th August

Ref	Topic	Discussion	Owner/Date
1.	**Staffing (Levels)**	Updated that Band 6 Outpatients posts have closed, 51 applicants prior to shortlisting. Anticipate interviews in next few weeks. Will update as we know more. To chase if Ereq was ever put out for band 2/3 HCA: Sarah to check with Martina	Lead Nurse Sarah Ward
2.	**Staff Development** **Training** **KSF/ Supervision** **Revalidation**	All Training up to date Leanne McCourt KSF due. Date allocated in calendar Mon 19th August @ 11am Kate O'Neills with Sarah Ward. To drop down to unit	All staff and Sarah Ward
3.	**Governance**	Botox clinics (Jenny). New unit based info folder completed. For use when x2 CNS posts are filled for training.	UNS's

Ref	Topic	Discussion	Owner/Date
	New Policies/ Documents **Datix** **Audits** **Complaints** **Equipment**	Antibiotic pathway to be confirmed. Discussion ongoing. No active datix X1 Nil return recorded for HH. This was investigated and the return was in fact received. This has been amended on the report. Nil active complaints Wish list has been established. X2 Scanners requested but cost £8000 each. Advised to order addiotnal small hand held scanner at this time. Scanners are used extensively in unit.	
4.	**RQIA**	Unit feels prepared. Copy of new RQIA framework to be left in for unit reference only.	UNS and al staff
5.	**Clinical Issues**	New Nurse Lead clinics commencing in September. Raised PSA clinics will be running with Kate and Leanne however we need to secure the band 6s in post and have the band 2/3 to assist.	UNS and Lead Nurse/ HOS
6.	**New Initiatives**		
7.	**Environmental**	Nil current issues. No issues getting minor estates work completed. Advised to escalate if any problems.	UNS

Ref	Topic	Discussion	Owner/Date
8.	**Estates**	As above	
9.	**Sucession Planning**	HCA staff member has shown particular enthusiasim in work. Displaying an interest in the service. Have had discussion regarding OU application in future and will encourage her to aim for this. Advises that criteria this year was focused on K101 course and how HCA can avail of this via Unison.	UNS/ All staff
10.	**AOB**	Josie Mathews will be taking over as Lead Nurse. Made aware by HOS and advised today that this does not have a defined date and will happen when staffing secured etc. No change to escalation at present. Admissions to ED. Remains an issue when patients take unwell and have to be escorted to ED and be triaged. Crash team also don't seem to be aware where Thorndale and Stone Treatment Centre are located, this has been flagged to Bernie O'Connor to ensure staff being trained for Crash team are aware of these areas. Learning Disability Day in Sept- advised that Band 5 is the link nurse and Sarah is happy that they attend this day and feedback. Important to have someone allocated the role.	UNS/ Lead Nurse

Signed:
Date:

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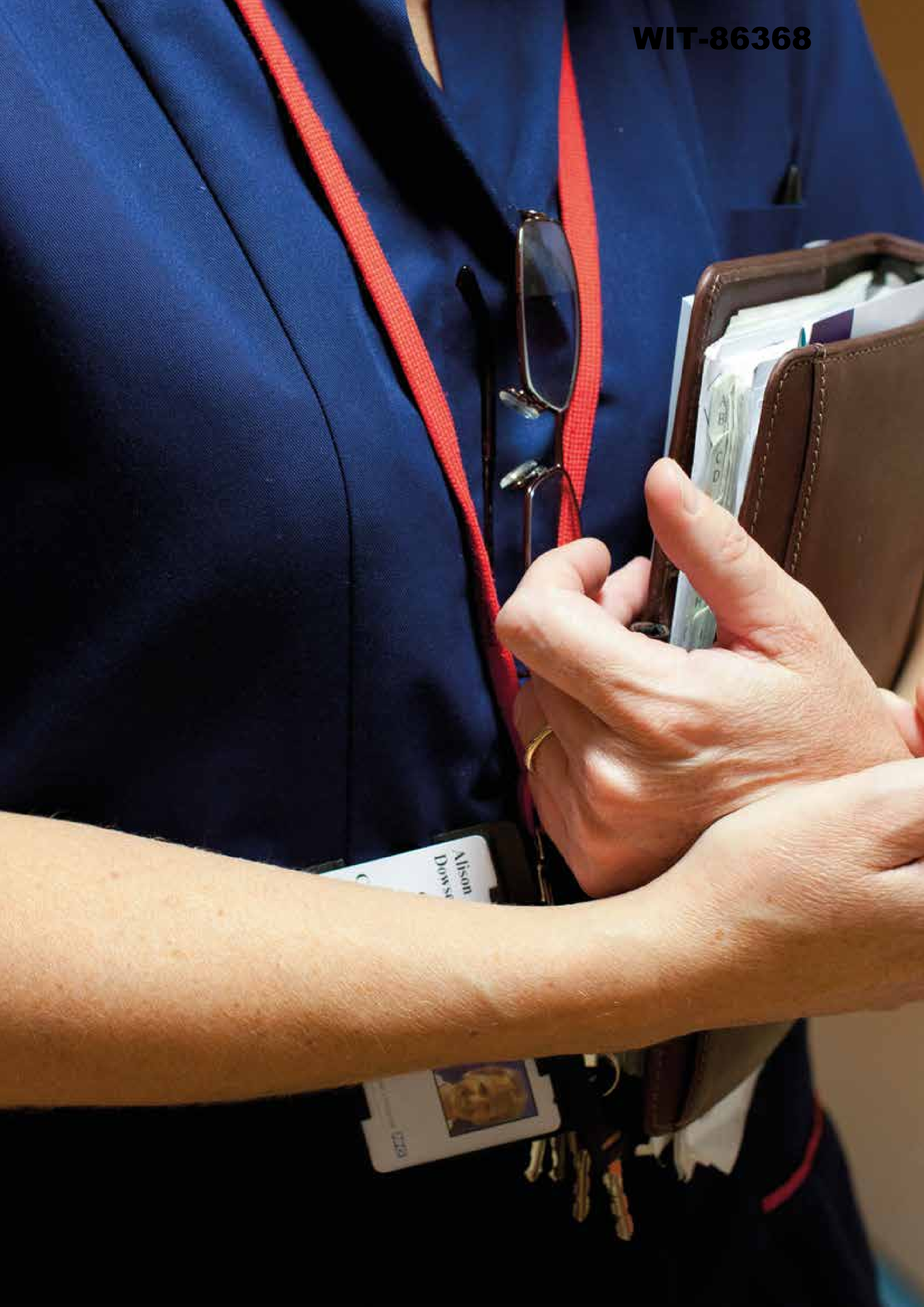
WE ARE MACMILLAN. CANCER SUPPORT

Specialist adult cancer nurses in Northern Ireland

A census of the specialist adult cancer nursing workforce in the UK, 2014


THINGS TO DO

Contents


Alison
Dows

Foreword

Macmillan first established Clinical Nurse Specialists (CNS) in the 1970s. Since then the numbers have grown so that now there are 1,305 whole time equivalent specialist adult cancer nurses with Macmillan in their job title across the UK.

We have therefore long been a strong advocate for the role that specialist cancer nurses play in supporting people affected by cancer, and in ensuring they receive timely and person-centred care. Recent cancer patient experience surveys in England and Wales have provided evidence that patients who had a named Clinical Nurse Specialist (CNS) in charge of their care reported more favourably on aspects of their experience[1,20].

It is therefore fitting that this year we have commissioned the first UK-wide census of the specialist cancer nurse workforce, to provide a robust picture of the numbers and location of these nurses across all four of the UK nations. This report presents the findings of the census in Northern Ireland.

In completing this census, we have relied on our partners in Health and Social Care to provide information and have been heartened to receive tremendous support for our approach. In a time of considerable change and financial constraint across the UK, the census returned an overall response rate of 97%. In Northern Ireland the response was better still: 100%.

We have learnt a lot about the workforce and how it is changing to respond to environmental, demographic and policy challenges. These challenges are different in the four nations of the UK, and so the data presented in this report should be interpreted in light of the local context.

The specialist adult cancer nurse workforce in Northern Ireland has grown by just 2% since the last census of this kind was carried out in 2011. This compares to a 10% increase in England and shows the size of the workforce in Northern Ireland is not keeping pace with the increasing number of people diagnosed with cancer each year.

There are two themes that emerge strongly across the UK, as things we need to respond to soon:

- Our specialist cancer nurse workforce is ageing. In some areas of practice in some parts of the UK, our data suggests that as many as half of the nurses currently providing cancer care are over 50. It is likely that the majority of these will retire in the next five to 10 years.
- In Northern Ireland, the age profile of our lung and colorectal CNS workforce, in particular, gives rise for concern.
- There are considerable variations in the provision of specialist cancer nurse expertise for those diagnosed with different cancer types and across different geographic locations.

We at Macmillan would welcome the opportunity to work with providers, commissioners and workforce planners to support planning to address these challenges, with the aim of ensuring that everyone affected by cancer has good outcomes and experience of care through access to a specialist cancer nurse.

Heather Monteverde

Heather Monteverde
General Manager for Northern Ireland
Macmillan Cancer Support

Ciarán Devane

Ciarán Devane
Chief Executive
Macmillan Cancer Support

1. Introduction

1.1 Background

The specialist adult cancer nursing census was originally designed to map the specialist adult cancer nursing population by cancer type and locality in order to inform commissioning intentions and workforce planning.

The first two censuses in 2007[2] and 2008[3] were developed and led by the cancer network nurse director and colleagues, before they handed over management to the National Cancer Action Team (NCAT) and Mouchel Management Consulting Limited, who led on the 2010[4] and 2011[5] censuses respectively. Further iterations expanded data collection to include role title, banding and geography. In 2014, Macmillan Cancer Support commissioned the census working with Mouchel (the partner of the Centre of Workforce Intelligence).

The 2014 census of specialist adult cancer nurse workforce has leant on the significant experience and expertise provided by the continued involvement of three senior cancer nurses and healthcare scientists/professional colleagues: Professor Alison Leary and Paul Trevatt, who had developed the original census, and Steve Candler.

It is the first UK-wide census, however, to take account of the significant differences in policy and delivery of cancer care in the Celtic nations, the data has been presented in separate reports and should be interpreted in light of the relevant national context.

The census took place at a time of significant financial constraint across the UK and a budget crisis in Northern Ireland against a background of rising demand and demographic pressures.

It may be useful to read this document in conjunction with other resources such as: ·

- *Excellence in cancer care: The contribution of the Clinical Nurse Specialist.* NCAT, 2010[6].
- *Clinical nurse specialists in cancer: Provision, proportion and performance.* NCAT 2010[4] and 2011[5].
- *Advanced level nursing: A position statement.* Department of Health, 2010[7].
- *Manual of cancer services.* Department of Health, 2004[8].
- *National Cancer Action Team. Cancer peer review report – Northern Ireland cancer network*[9]
- *Coordinated cancer care: better for patients, more efficient.* NHS Confederation briefing, 2010[10].

While this document does offer information regarding the ratio of specialist cancer nurses to incidence of cancer and two-year prevalence across Northern Ireland, this does not represent guidance on appropriate caseload. It merely demonstrates variance of provision of these posts by tumour type.

This report aims to strengthen the argument for maintaining and expanding the provision of specialist nurse expertise in Northern Ireland in order to ensure that the growing number of people being diagnosed and living with cancer receive a good patient experience.

1.2 Methods

This census was primarily based on the approach adopted for previous censuses, in particular the work undertaken by NCAT in the most recent census in England[5].

A census of the specialist cancer nursing workforce was undertaken in Northern Ireland in 2008[3]. This included nurses specialising in paediatrics and young adults, who are excluded from this census. Numbers of cancer CNSs were also reported in a discussion paper by the Northern Ireland Cancer Network Public Health Agency[11], but there has been no systematic means of monitoring the specialist cancer nursing workforce.

In 2011, the Northern Ireland cancer network undertook an internal census using similar methodology as that used by NCAT in England. Whilst this work was not published, the data was validated by nurse directors and is used as a comparison for the data in the 2014 census.

Data was collected over an eight-week period between April and June 2014. However, the workforce numbers collected were a 'snapshot' of the population on the day of the census, 24 April 2014. The data was primarily collected using a bespoke spreadsheet with drop-down menus.

Areas of enquiry were informed by the previous four censuses undertaken in England.

Areas of practice are broadly based on the NICE Improving Outcomes Guidance definitions[12]. Consistent with 2011, the areas of practice include 'acute oncology services' (AOS), as it was recommended in the 2009 NCAG report *Chemotherapy services in England: Ensuring quality and safety* that all hospitals with emergency departments should establish this service[13].

All posts are recorded as whole time equivalents (WTE) in adult cancer care where 1 WTE is equivalent to a 37.5 hour week.

Additional information was collected on the age and gender of post holders and on vacant posts. Data was also collected on if nurses cover 'cancer of unknown primary'.

Spreadsheets were returned from lead cancer nurses / cancer managers in hospital trusts. Some further checking and completion was undertaken to ensure complete records were provided where possible. NHS Trust Lead Cancer Nurses and Directors of Nursing were involved, as well as the Nurse Consultant for the Northern Ireland Cancer Network as appropriate. Data was returned electronically from trusts to Mouchel for analysis. One month was given for data to be returned, with a further extension to enable appropriate dissemination and support for returns. Collection was completed by 13 June 2014.

Census process:

- Project team and Mouchel agreed census tool design and data fields
- Spreadsheet and instructions for completion were sent out to lead cancer nurses or equivalent in each trust or hospital across the UK
- Data entry completed at trust level
- Completed spreadsheets returned to Mouchel
- Records checked with respondents for completeness and accuracy as appropriate
- Analysis by Mouchel and project team
- Data tables produced for review and key findings identified
- Report

1.3 Selection criteria

The census was aimed at hospital-based specialist adult cancer nurses working in adult cancer care only.

Inclusion criteria were kept consistent with previous censuses where possible.

Inclusion criteria: all nurse posts that:

- treat, support and manage the health concerns of adult cancer patients and work to promote the health and wellbeing of the patients they care for (including post holders who perform a role in education, research and audit in adult cancer care)
- deliver predominantly secondary care
- are registered (Agenda for Change bands 5 to 9 only)
- are funded by any source (e.g. NHS, charity, pharmaceutical)
- are vacant posts as well as those filled on 24 April 2014.

Exclusion criteria: posts that:

- specialise only in chemotherapy, radiotherapy, palliative care, pain management or non-patient facing roles
- work 'as and when required', e.g. bank and agency staff
- are community nurse specialists
- work in paediatrics or with teenagers and young adults
- are research nurses.

All posts reported that met the inclusion criteria are referred to as specialist cancer nurses. In this report we also refer to Clinical Nurse Specialists (CNS), who have a specific job title and are a subset of specialist cancer nurses. For Northern Ireland, these terms are almost coterminous as 96.9% of the total specialist cancer nurse workforce is made up of CNSs.

2. Context and background

The Northern Ireland Cancer Services Framework (2009) states that all patients should be assessed by a CNS at the time of diagnosis, at the end of each stage of treatment and, where necessary, throughout their cancer journey.[14] The results of this latest specialist adult cancer nurses census in Northern Ireland will help commissioners and service providers to monitor the success of this service framework standard by looking at geographical variations and tumour group differences.

At the last Northern Ireland Assembly Election in 2011, there was cross-party support for an increase in CNS numbers to ensure that everyone newly diagnosed with cancer had access to one. However, despite broad political backing for the service framework standard, the intervening years have seen only a small rise in specialist adult cancer nurses numbers. The 2011 Northern Ireland cancer network census identified 56 nurses[15], this census identified only one additional nurse. This growth is not sufficient to keep pace with the growing cancer population.

Every year in Northern Ireland, 9,000 people are diagnosed with cancer (this excludes 3,738 cases of common but not generally serious non-melanoma skin cancer)[26]. In total, 55,000 people are currently living with cancer – and that number is expected to rise to more than 110,000 by 2030, if current trends continue.[16]

Now, more than ever, the specialist workforce has a vital role to play in delivering high-quality, compassionate and person-centred care. In line with the Department of Health's 'Transforming Your Care' policy (2011)[17], this includes providing care closer to home and supporting a drive for efficiency, while improving health outcomes and maximising resources.

The CNS role is at the heart of Macmillan's strategic partnership with the Health and Social Care Board on Transforming Cancer Follow Up (TCFU), which is designed to change the way cancer services are delivered. The TCFU initiative extends beyond the hospital setting into the local community. It focuses on informed individual care planning that enables patients to self-manage their condition, while ensuring appropriate surveillance is provided in a timely manner. As the first point of contact, the CNS works closely with patients and clinical colleagues to respond to patients' emerging needs, reducing emergency admissions and unplanned care and arranging rapid access to support if required.

The sustainability and growth of TCFU depends on the provision of adequate CNS numbers. The programme has not yet achieved its full potential in some tumour groups due to the lack of specialist cancer nurses.[18]

The National Cancer Peer Review Report for Northern Ireland (2010) consistently highlighted the lack of adequate CNS staffing as a limitation on the quality of services provided across the different health trusts. The 2010 report called for a review of specialist workforce numbers.[19] A second round of the review of cancer multidisciplinary teams (MDTs) in Northern Ireland will take place later this year, and will provide an opportunity to compare the two sets of data in order to draw further insights.

The Public Health Agency has also commissioned Northern Ireland's first cancer patient experience survey (CPES) in partnership with Macmillan, which will start in November 2014. The results are expected to be published in mid 2015 and will provide further information about the impact of the specialist workforce and the percentage of patients who have access to a CNS.

Recent analysis of patient experience surveys in England and Wales have clearly demonstrated the correlation between patients reporting they had a named CNS in charge of their care and more favourable patient experience. The results in Wales showed that, where a CNS took on the role of key worker, patient experience was further improved.[20]

Patients frequently identify CNSs as one of the most important health care professionals they come into contact with.[20] This survey of the specialist workforce will allow commissioners, service providers and clinical teams to benchmark the provision and deployment of CNS staff. Understanding patterns of access is fundamental when it comes to matching the specialist workforce to patients' needs. Every cancer patient should have access to a CNS, regardless of their type of cancer or where they live.

2.1 Headline findings

Total specialist adult cancer nursing workforce

The census of the specialist adult cancer nursing workforce in Northern Ireland achieved a response rate of 100%. Returns were received from all five Health and Social Care Trusts in the Northern Ireland Cancer Network.

The total reported specialist adult cancer nursing workforce for the Northern Ireland Cancer Network in 2014 was 57.4 WTE, compared with 56.1 in 2011 (after community oncology posts are excluded). This represents a 2% increase in WTE over three years.

Breast cancer is the most common majority area of practice (33.8% of specialist adult cancer nurses WTE). This is the same as in 2011. This was followed by lung (13.1%) and colorectal cancer specialists (11.3%). There are important variations in the numbers of CNSs per tumour site, in particular the census found only one brain / central nervous system (CNS), one Acute Oncology Service and one sarcoma nurse in Northern Ireland.

Numbers of posts have marginally increased in five areas of practice (breast, colorectal, gynaecology, urology and upper GI), reduced in two others (haematology and malignant dermatology) and stayed the same in five (acute oncology services, brain and central nervous system, head and neck, lung and sarcoma) since 2011.

Of the total specialist cancer nursing workforce WTE in Northern Ireland, 15% (8.6 WTE) were reported as providing cover for cancers of unknown primary. The main areas of practice reporting providing this cover were breast (4 out of 19 WTE) and colorectal (2 out of 7 WTE) specialist adult cancer nurses.

Clinical Nurse Specialists
The largest section of the specialist adult cancer nursing workforce by job title was adult Clinical Nurse Specialist – equivalent to 55.6 WTE (97.0% of the total workforce). There were 1.8 WTE nurse practitioners.

Overall, 79.4% of CNSs were banded at Agenda for Change (AfC) band 7; the remaining were band 6. There are no band 8 AfC (nurse consultant posts or other senior practitioners) reported in the specialist adult cancer nursing workforce in Northern Ireland.

Macmillan specialist cancer nurses
In total, 31% of the specialist adult cancer nursing population in Northern Ireland are titled Macmillan Cancer Support posts, compared to 31% in 2011.

Vacancies
This census was the first specialist adult cancer nurse census to collect data on vacancies. The reported vacancy rate is relatively low compared to the job vacancies per 100 employee jobs in human health and social work activities (not specific to any area of practice) in the UK measured by the Office for National Statistics vacancy survey[20].

Workforce characteristics
All reported post holders were female.

Data on the age profile of filled posts highlights that 30% of the total specialist cancer nursing workforce in Northern Ireland were reported as being over 50 years of age, with one post holder under 30 years of age.

Out of the 6.5 WTE in nurses in lung cancer care 3 were over 50. 3.4 WTE of the 6.5 WTE nurses in colorectal cancer care are aged 50 or over.

There are no reported specialist cancer nurses over the age of 59 in Northern Ireland.

Ratio of nurses
When provision of specialist adult cancer nursing posts is mapped to incidence of cancer in Northern Ireland, the ratio varies from 70 in sarcoma to 355 in urology.

When provision of specialist adult cancer nursing posts is mapped to the number of people living up to two years post a cancer diagnosis (two-year prevalence in 2010), the ratios vary from 103 in sarcoma to 577 in urology.

3. 2014 census results

This section presents detailed data collected in the census supporting headline findings. New data is presented for the first time on the age and gender of post holders, posts that are vacant and data on WTEs that reported supporting cancer of unknown primary.

Table 1: Total specialist adult cancer nursing workforce by area of practice and Health and Social Care Trust, WTE, Northern Ireland, 2014.

The area of practice with the largest proportion of the workforce is reported as breast cancer, accounting for about 34% of the total reported specialist cancer nursing workforce. This is followed by lung (about 13%) and colorectal (about 11%).

Health and Social Care Trust	Acute oncology service	Brain/central nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only*	Urology – All uro-oncology*	Total
Belfast Health and Social Care Trust	0	1.0	7.0	1.0	2.0	2.0	1.0	2.0	0	1.0	2.0	0.6	1.0	20.6
Northern Health and Social Care Trust	0	0	3.4	0.5	0	1.0	0	1.5	0	0	0	0	0	6.4
South Eastern Health and Social Care Trust	0	0	2.8	2.0	1.0	1.0	1.0	1.0	1.8	0	0	0	1.0	11.6
Southern Health and Social Care Trust	1.0	0	2.6	2.0	0.5	1.0	0	1.0	0	0	0.5	0	0	8.6
Western Health and Social Care Trust	0	0	3.6	1.0	0.6	0	1.0	2.0	0	0	0	0	2.0	10.2
Total	1.0	1.0	19.4	6.5	4.1	5.0	3.0	7.5	1.8	1.0	2.5	0.6	4.0	57.4

*The urology specialist adult cancer nurse workforce has been divided into two groups to uncover the size of the specialist prostate cancer workforce. A majority area of practice of 'Urology – prostate only' was defined as a nurse post where 95% or more of the time the nurse spends in adult cancer care is in prostate cancer or suspected prostate cancer. 'Urology -All uro-oncology' is the rest of the urology specialist adult cancer nurse workforce who spend less than 95% of their time in adult cancer care in prostate cancer or suspected prostate cancer. This definition is designed to identify only the most specialised nurses as a generalist urology nurse may expect to see frequent cases of prostate cancer given the high incidence of prostate cancer. It can be difficult for lead cancer nurses to accurately and consistently classify nurses so the data should be used to build a general picture of the urology workforce rather than draw detailed quantitative conclusions.

Fig. 1: Total specialist adult cancer nursing workforce by area of practice, WTE, Northern Ireland, 2014.

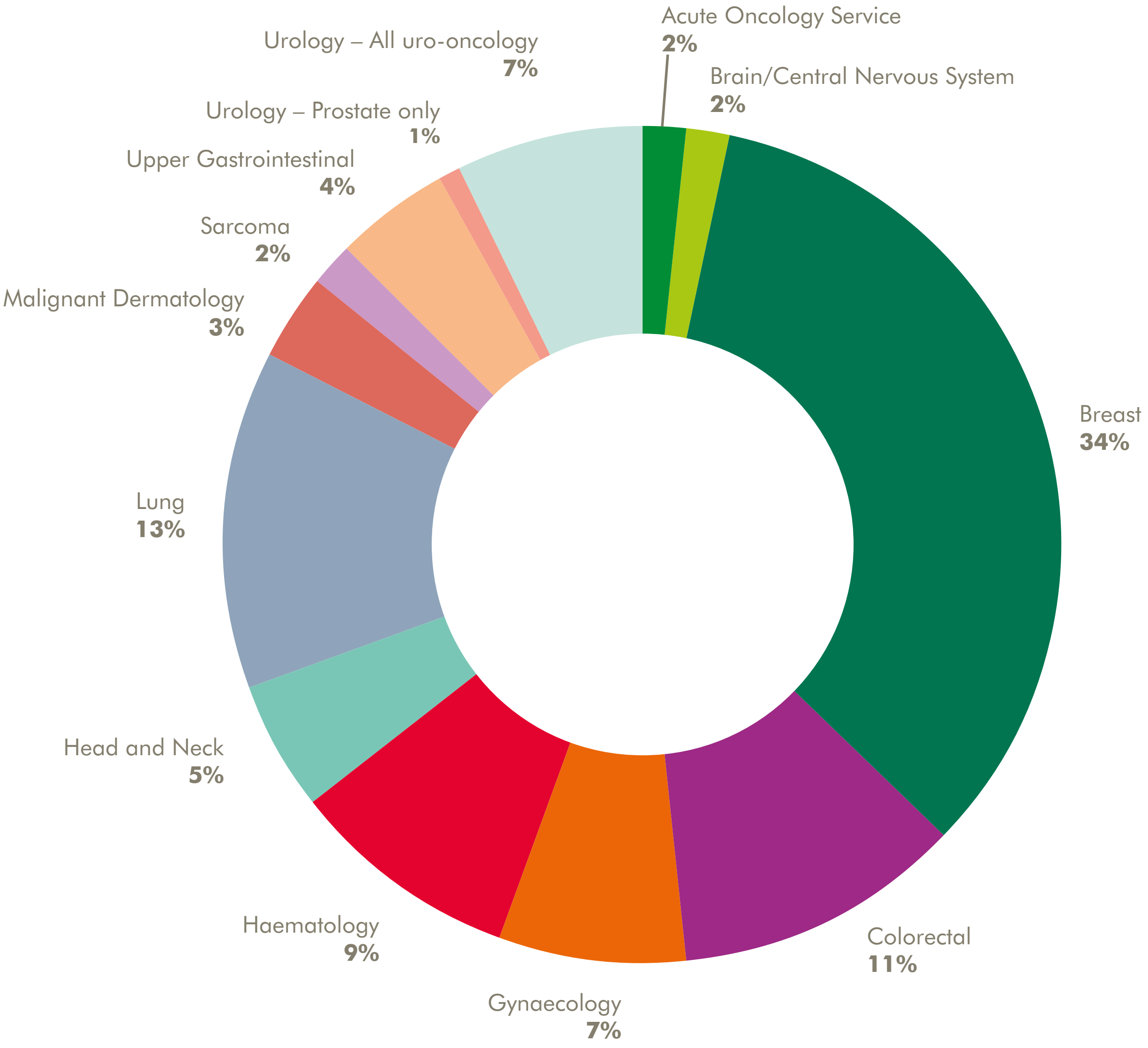


Table 2: Clinical Nurse Specialist (CNS) workforce by area of practice and Health and Social Care Trust, WTE, Northern Ireland, 2014

The area of practice with the largest proportion of the CNS workforce is reported as breast cancer, accounting for about 33% of CNSs, followed by lung (about 13%) and colorectal (about 12%).

Health and Social Care Trust	**Acute oncology service**	**Brain/central nervous system**	**Breast**	**Colorectal**	**Gynaecology**	**Haematology**	**Head and neck**	**Lung**	**Malignant dermatology**	**Sarcoma**	**Upper gastrointestinal**	**Urology – Prostate only**	**Urology – All uro-oncology**	**Total**
Belfast Health and Social Care Trust	0	1.0	5.8	1.0	2.0	2.0	1.0	2.0	0	1.0	2.0	0	1.0	18.8
Northern Health and Social Care Trust	0	0	3.4	0.5	0	1.0	0	1.5	0	0	0	0	0	6.4
South Eastern Health and Social Care Trust	0	0	2.8	2.0	1.0	1.0	1.0	1.0	1.8	0	0	0	1.0	11.6
Southern Health and Social Care Trust	1.0	0	2.6	2.0	0.5	1.0	0	1.0	0	0	0.5	0	0	8.6
Western Health and Social Care Trust	0	0	3.6	1.0	0.6	0	1.0	2.0	0	0	0	0	2.0	10.2
Total	1.0	1.0	18.2	6.5	4.1	5.0	3.0	7.5	1.8	1.0	2.5	0	4.0	55.6

Fig. 2: Total CNSs by area of practice, percentage, Northern Ireland, WTE, 2014

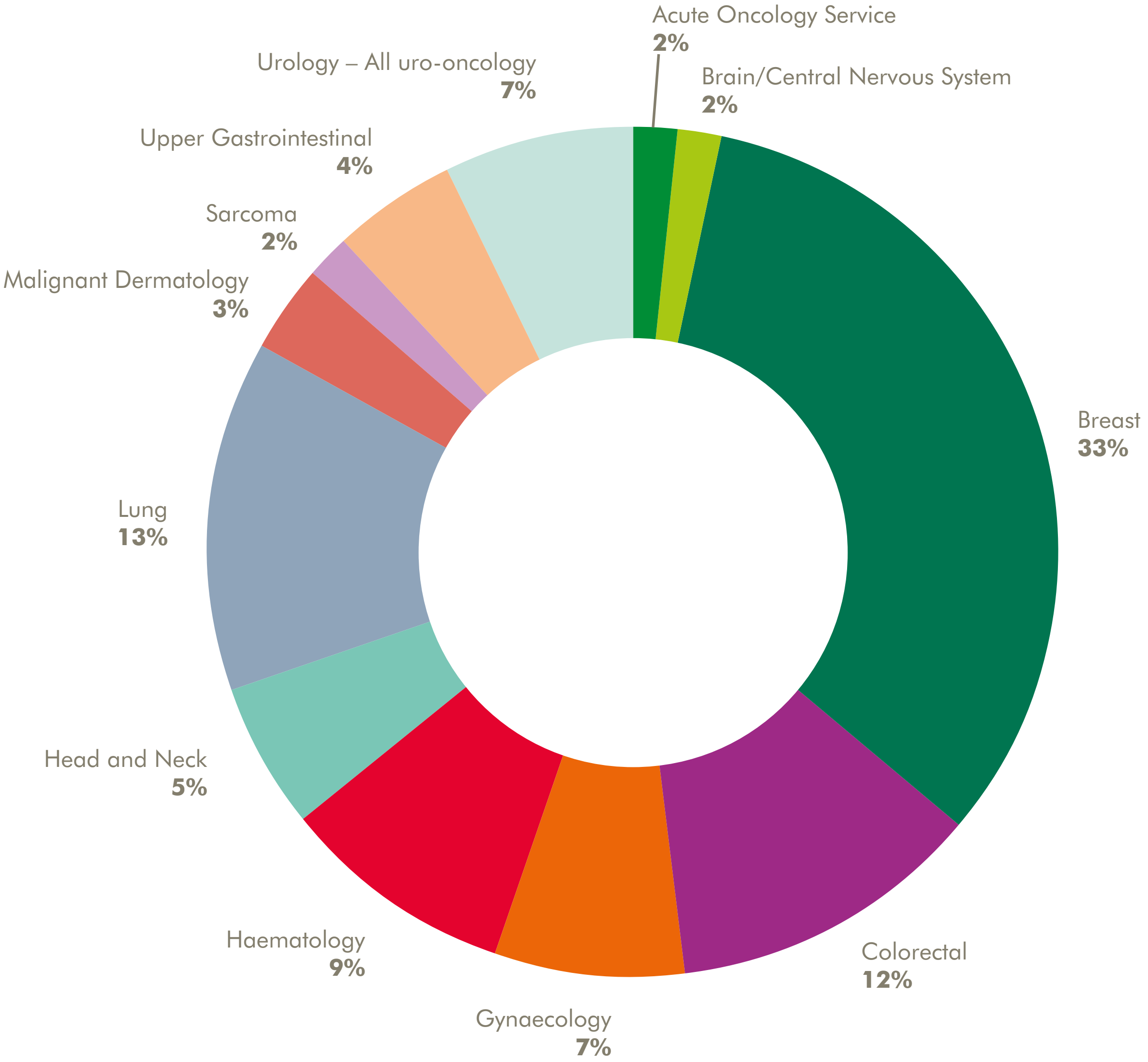


Table 3: Total specialist adult cancer nursing workforce by job title and area of practice, WTE, Northern Ireland, 2014

There was no reported advanced nurse practitioners, nurse consultants or nurse specialists across all areas of practice.

Area of practice	Advanced nurse practitioner	Clinical nurse specialist	Nurse consultant	Nurse practitioner	Nurse specialist	Other	Total
Acute oncology service	0	1.0	0	0	0	0	1.0
Brain/central nervous system	0	1.0	0	0	0	0	1.0
Breast	0	18.2	0	1.2	0	0	19.4
Colorectal	0	6.5	0	0	0	0	6.5
Gynaecology	0	4.1	0	0	0	0	4.1
Haematology	0	5.0	0	0	0	0	5.0
Head and neck	0	3.0	0	0	0	0	3.0
Lung	0	7.5	0	0	0	0	7.5
Malignant dermatology	0	1.8	0	0	0	0	1.8
Sarcoma	0	1.0	0	0	0	0	1.0
Upper gastrointestinal	0	2.5	0	0	0	0	2.5
Urology – prostate only	0	0	0	0.6	0	0	0.6
Urology – All uro-oncology	0	4.0	0	0	0	0	4.0
Total	0	55.6	0	1.8	0	0	57.4

Fig. 3: Total specialist adult cancer nursing workforce by job title, WTE, Northern Ireland, 2014

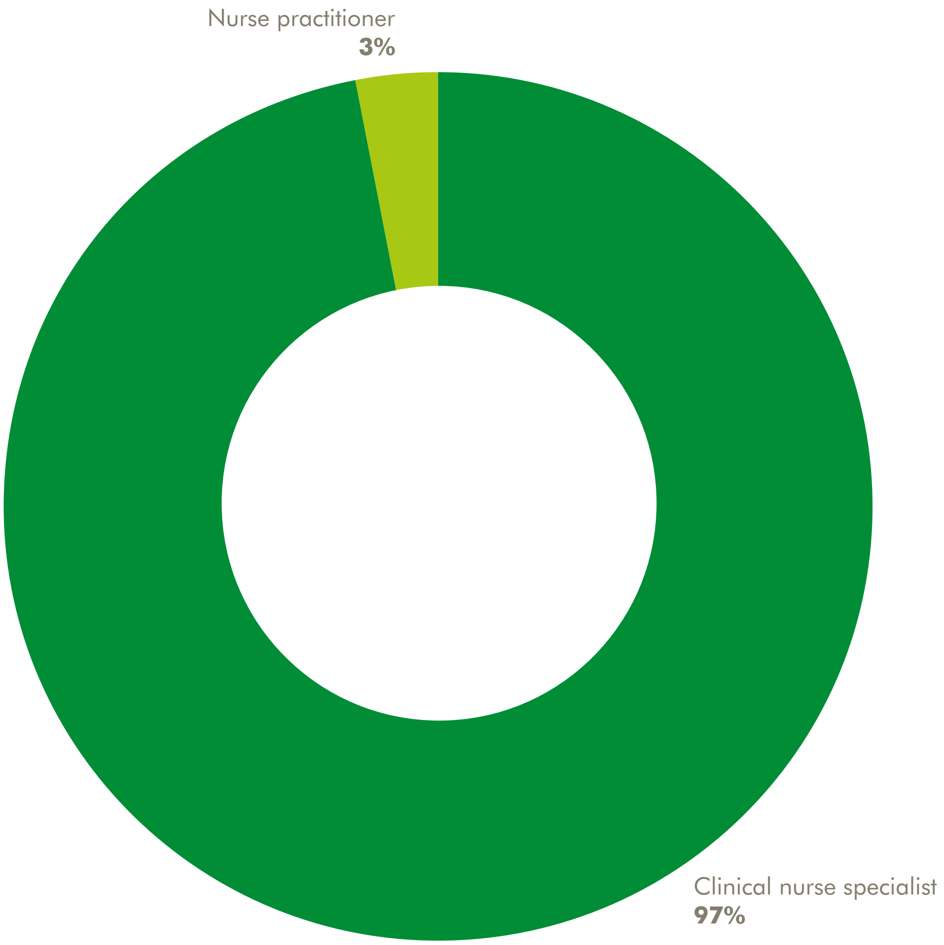


Table 4: CNS workforce by Agenda for Change (AfC) banding and area of practice, WTE, Northern Ireland, 2014

Band 7 posts make up the largest proportion of the reported WTE, accounting for about 79%. The band 6 posts are mainly in breast cancer care. 49% of the breast cancer workforce (WTE) is in band 6. The rest of the band 6 workforce is in colorectal cancer care.

Area of practice	Band 6	Band 7	Band 8a and above	Not known	Total
Acute oncology service	0	1.0	0	0	1.0
Brain/central nervous system	0	1.0	0	0	1.0
Breast	9.4	8.8	0	0	18.2
Colorectal	2.0	4.5	0	0	6.5
Gynaecology	0	4.1	0	0	4.1
Haematology	0	5.0	0	0	5.0
Head and neck	0	3.0	0	0	3.0
Lung	0	7.5	0	0	7.5
Malignant dermatology	0	1.8	0	0	1.8
Sarcoma	0	1.0	0	0	1.0
Upper gastrointestinal	0	2.5	0	0	2.5
Urology – Prostate only	0	0	0	0	0
Urology – All uro-oncology	0	4.0	0	0	4.0
Total	11.4	44.2	0	0	55.6

No band 5 posts were reported

Fig. 4: Total specialist adult cancer nursing workforce by Agenda for Change banding, percentage, Northern Ireland, 2014

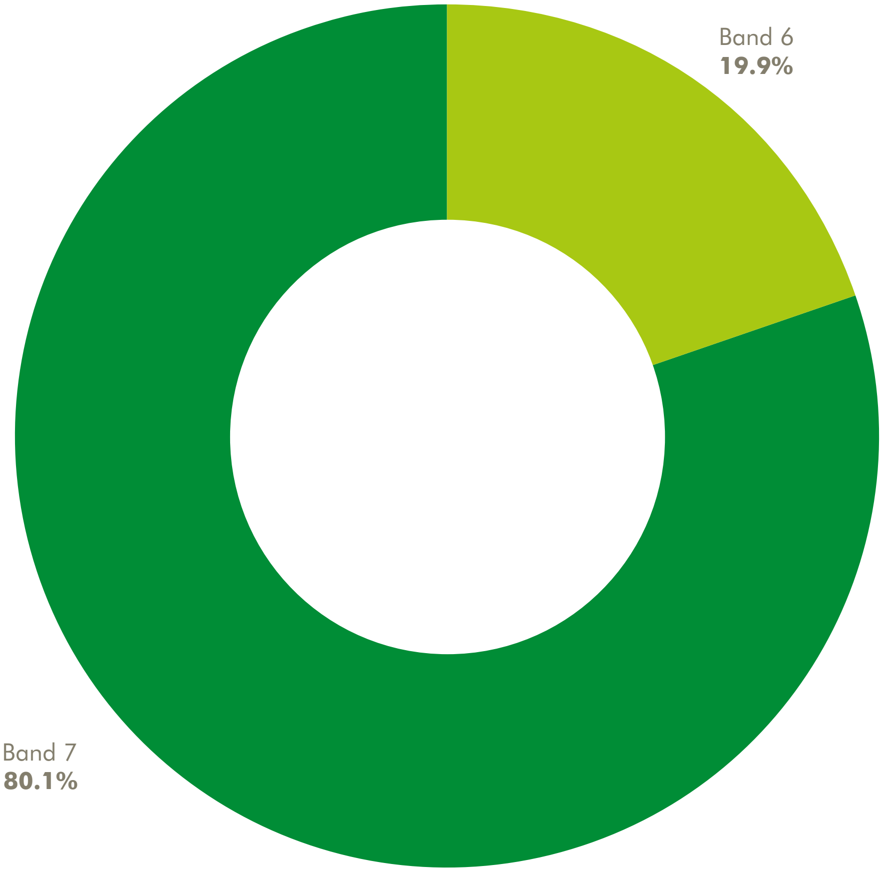


Table 5: Macmillan specialist cancer nurse workforce, WTE, Northern Ireland, 2014

Macmillan Cancer Support continues to provide support for 31% of the reported WTE.

Macmillan Cancer Support posts	**WTE**
Macmillan CNS	16.8
Other Macmillan cancer specialists	1.0
Total	17.8

Fig. 5: Specialist adult cancer nursing workforce Macmillan Cancer Support posts, CNS and other, percentage, WTE, Northern Ireland, 2014

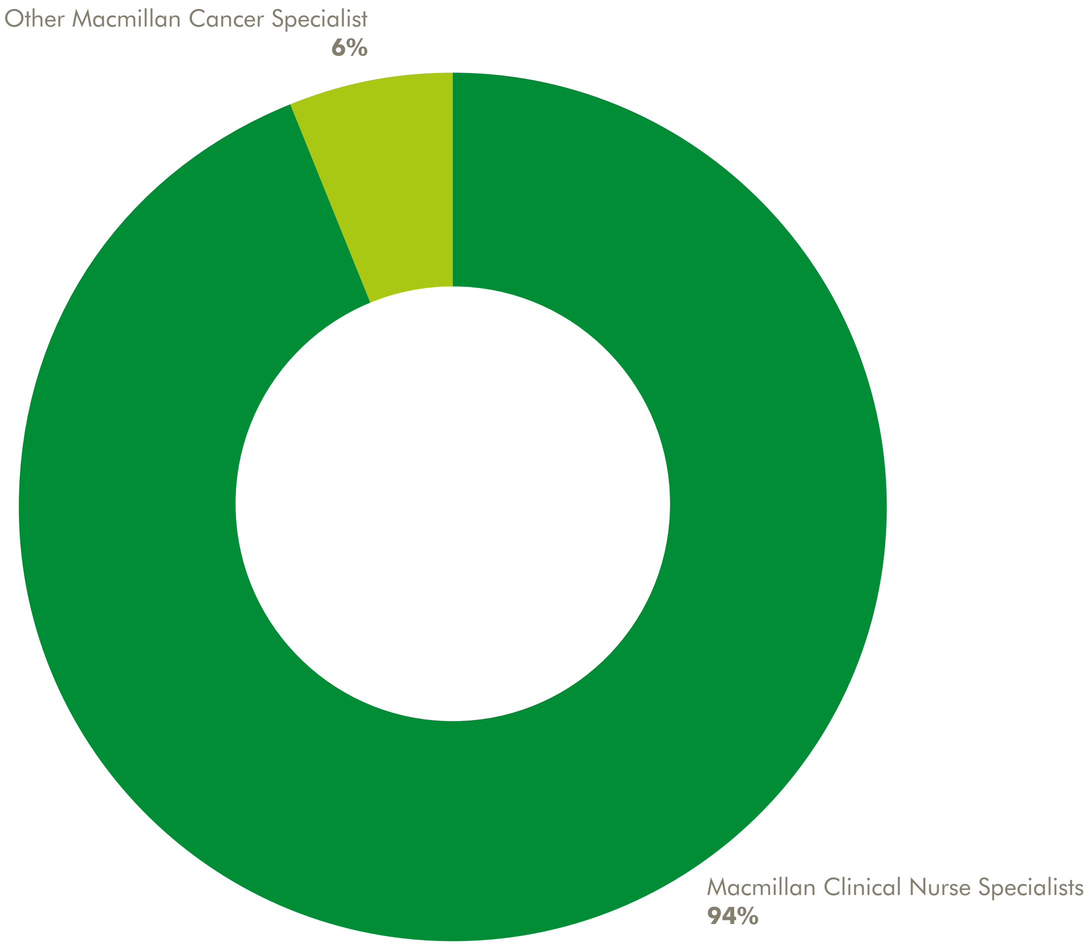


Fig. 5a: Macmillan Cancer Support specialist adult cancer nursing workforce as a proportion of total specialist adult cancer nursing workforce by area of practice, WTE, Northern Ireland, 2014

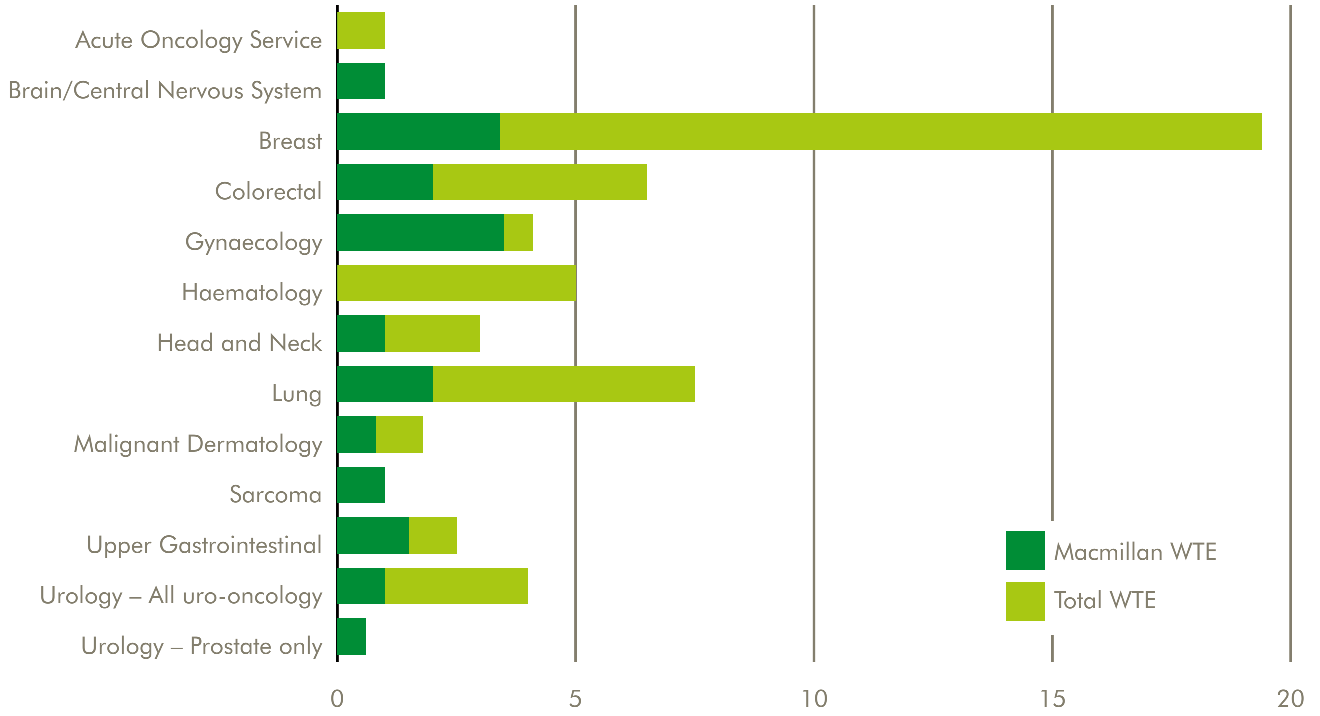


Table 6: Total specialist adult cancer nursing workforce reporting cover for cancer of unknown primary, WTE, Northern Ireland, 2014

This is the first time that this data has been collected and reported. About 15% of the total WTE (filled and vacant posts) was reported as covering cancer of unknown primary.

Does the post/post holder cover cancer of unknown primary?	WTE
Yes	8.6
No	48.8
Not known	0
Total	57.4

Table 7: Total specialist adult cancer nursing workforce reporting cover for cancer of unknown primary by area of practice, WTE, Northern Ireland, 2014

The highest proportion of the posts reported as covering cancer of unknown primary were in breast cancer (about 42% of the total reported WTE covering cancer of unknown primary).

Majority Area of practice	WTE that cover CUP	% of all nurses covering CUP (WTE)
Acute oncology service	1.0	11.6%
Brain/central nervous system	0	0.0%
Breast	3.6	41.9%
Colorectal	2.0	23.3%
Gynaecology	0.5	5.8%
Haematology	0	0.0%
Head and neck	0	0.0%
Lung	1.0	11.6%
Malignant dermatology	0	0.0%
Sarcoma	0	0.0%
Upper gastrointestinal	0.5	5.8%
Urology – prostate only	0	0.0%
Urology – All uro-oncology	0	0.0%
Total	8.6	100.0%

Table 8: Total specialist adult cancer nursing workforce by gender, WTE, Northern Ireland, 2014

This is the first time that this data has been collected and reported. All of the WTEs are reported as female.

Gender	WTE	% of total (WTE)
Female	56.4	100.0%
Male	0.0	0.0%
Declined	0.0	0.0%
Not known	0.0	0.0%
Total	56.4	100.0%

Table 9: Total specialist adult cancer nursing workforce by Agenda for Change banding and gender, WTE, Northern Ireland, 2014

The majority of reported WTE are females populating band 7 posts (about 81%). There are no WTE reported at bands 8a and above.

Gender	5	6	7	8a	8b	8c	8d	9	Not known	Total
Female	0	11.4	45.0	0	0	0	0	0	0	56.4
Male	0	0	0	0	0	0	0	0	0	0
Declined	0	0	0	0	0	0	0	0	0	0
Not known	0	0	0	0	0	0	0	0	0	0
Total	0	11.4	45.0	0	0	0	0	0	0	56.4

Table 10: Total specialist adult cancer nursing workforce by area of practice and gender, WTE, Northern Ireland, 2014

The highest proportion of WTE by area of practice for females is reported as breast cancer (about 34% of filled posts). There were no reported WTE for males. The lowest WTE was reported in acute oncology service, brain/central nervous system and sarcoma (1 filled post in each).

Area of practice	Female	Male	Declined	Not known	Total
Acute oncology service	1.0	0	0	0	1.0
Brain/central nervous system	1.0	0	0	0	1.0
Breast	19.4	0	0	0	19.4
Colorectal	6.5	0	0	0	6.5
Gynaecology	4.1	0	0	0	4.1
Haematology	5.0	0	0	0	5.0
Head and neck	3.0	0	0	0	3.0
Lung	6.5	0	0	0	6.5
Malignant dermatology	1.8	0	0	0	1.8
Sarcoma	1.0	0	0	0	1.0
Upper gastrointestinal	2.5	0	0	0	2.5
Urology – Prostate only	0.6	0	0	0	0.6
Urology – All uro-oncology	4.0	0	0	0	4.0
Total	56.4	0	0	0	56.4

Table 11: Total specialist adult cancer nursing vacancies by Agenda for Change band, WTE, Northern Ireland, 2014

In the United Kingdom in April and June 2014, there were 2.4 vacancies per 100 employee jobs overall and 2.4 vacancies per 100 employee jobs in human health and social work activities[21]. In this census, in Northern Ireland, we found one vacant post per 67 filled jobs – equivalent to 1.5 vacancies per 100 filled jobs. Although the rates are not directly comparable, this suggests that there may be fewer vacancies amongst specialist cancer nurses in Northern Ireland than there are across the UK as a whole.

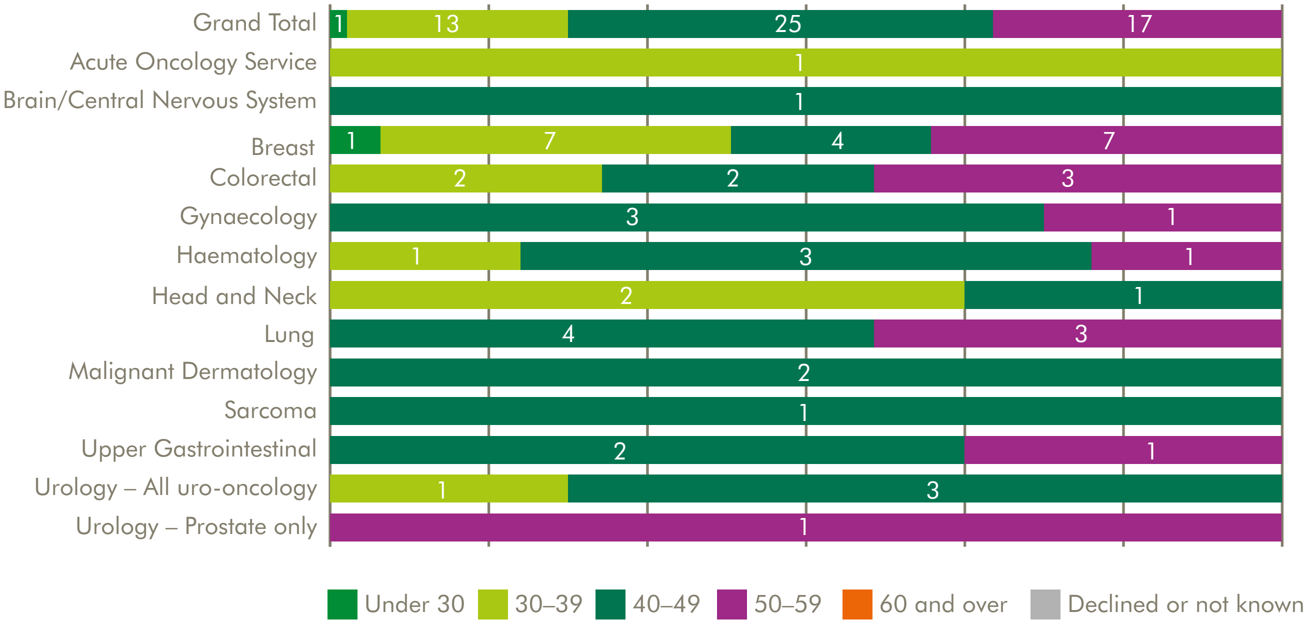
Band	5	6	7	8a	8b	8c	8d	9	Total
Number of vacancies (WTE)	0	0	1.0	0	0	0	0	0	1.0

Table 12: Specialist adult cancer nursing workforce by area of practice and age banding, WTE, Northern Ireland, 2014

The highest WTE is reported as age 40–49 (about 44% of the total reported WTE). None of the total reported WTE were age 60 and over. (Data may indicate that the specialist cancer nursing workforce stops working before they reach the age of 60 as there are many nurses in the age 50 to 59 age group).

Age range	Acute oncology service	Brain/ nervous system	Breast	Colorectal	Gynaecology	Haematology	Head and neck	Lung	Malignant dermatology	Sarcoma	Upper gastrointestinal	Urology – Prostate only	Urology – All uro-oncology	Percentage of total
Under 30	0.0% (0.0)	0.0% (0.0)	100.0% (1.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	1.8% (1.0)
30–39	7.4% (1.0)	0.0% (0.0)	50.9% (6.8)	11.9% (1.6)	0.0% (0.0)	7.4% (1.0)	14.9% (2.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	7.4% (1.0)	23.8% (13.4)
40–49	0.0% (0.0)	4.0% (1.0)	16.6% (4.2)	6.0% (1.5)	12.4% (3.1)	12.0% (3.0)	4.0% (1.0)	14.0% (3.5)	7.2% (1.8)	4.0% (1.0)	8.0% (2.0)	0.0% (0.0)	12.0% (3.0)	44.4% (25.1)
50–59	0.0% (0.0)	0.0% (0.0)	43.8% (7.4)	20.1% (3.4)	5.9% (1.0)	5.9% (1.0)	0.0% (0.0)	17.8% (3.0)	0.0% (0.0)	0.0% (0.0)	3.0% (0.5)	3.6% (0.6)	0.0% (0.0)	30.0% (16.9)
60 and over	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)
Declined	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)
Not known	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)	0.0% (0.0)
% of total	1.8% (1.0)	1.8% (1.0)	34.4% (19.4)	11.5% (6.5)	7.3% (4.1)	8.9% (5.0)	5.3% (3.0)	11.5% (6.5)	3.2% (1.8)	1.8% (1.0)	4.4% (2.5)	1.1% (0.6)	7.1% (4.0)	100.0% (56.4)

Fig. 6: Filled specialist cancer nursing workforce, by majority area of practice and age banding, WTE, Northern Ireland, 2014



4. Ratio of specialist adult cancer nursing workforce to incidence and two year-prevalence

It is important to put the variation in the distribution of specialist cancer nurses in the context of the varying levels of need. It is impossible to do this while fully taking into account the many aspects of need and service design. However, as a very crude measure, we have mapped WTE onto new cancer cases (incidence in 2012) and onto the number of people living up to two years post a cancer diagnosis (two-year prevalence in 2010).

However, there are many caveats to this approach. These ratios do not, therefore, reflect the caseload of the specialist nurse, nor do they demonstrate the variations in the level of support needed depending on the type and stage of cancer.

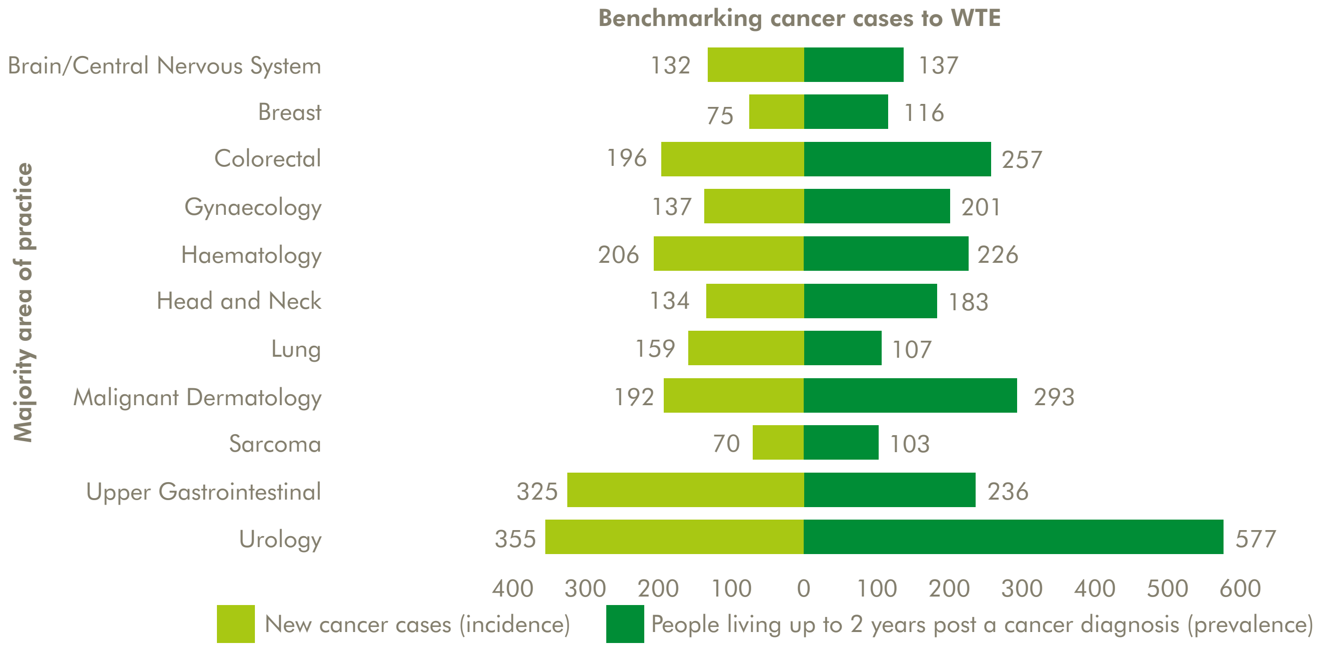
Table 13: Range of ratios of incidence and two-year prevalence per WTE by area of practice, Northern Ireland, 2014

	New cancer case (incidence) per WTE	People living up to two years post cancer diagnosis (prevalence) per WTE
Brain/central nervous system	132	137
Breast	75	116
Colorectal	196	257
Gynaecology	137	201
Haematology	206	226
Head and neck	134	183
Lung	159	107
Malignant dermatology	192	293
Sarcoma	70	103
Upper gastrointestinal	325	236
Urology	355	577

Source: Two-year prevalence data sourced from National Cancer Intelligence Network. 2014. Macmillan-NCIN work plan – 20-year cancer prevalence for the period 1991–2010 by cancer type for each UK nation, the UK combined and England Strategic Clinical Networks. Data sourced and presented in collaboration with the Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, the Information Services Division Scotland and the Northern Ireland Cancer Registry. For cancer definitions, see appendix.

Source: Incidence data sourced from personal correspondence with the biostatisticians/researchers at the Northern Ireland Cancer Registry (August 2014).

Fig. 7: Specialist cancer nursing workforce ratios against incidence and prevalence for Northern Ireland overall, WTE, 2014



The figure above shows the variation in the ratios across tumour types. For both measures, urology has the highest ratio of cases per WTE. This is based on the assumption that urology nurses are responsible for a diverse cancer population that includes large numbers of prostate cancer cases as well as bladder, kidney, testicular cancer and carcinoma in situ cases.

The differences in the pattern seen in the ratio of new cases and people living up to two years post a cancer diagnosis mainly reflects the differences in short term survival. This also highlights the complexity of the issue and the sophistication needed in workforce planning.

5. Observations and areas for further exploration

There appears to have been a very small increase in the numbers of specialist adult cancer nurses (WTE) since 2011.

As both incidence and prevalence of cancer increase in Northern Ireland[16,] inequities exist between different tumour types in terms of the provision of specialist adult cancer nursing posts.

The previously identified gaps in CNS provision have increased and this must be addressed to fulfil the commitment that everyone newly diagnosed with cancer has access to a CNS.

This census has found only one acute oncology services post – the same as in 2011. Funding has now been agreed with Macmillan for seven posts across Northern Ireland, to deliver a Northern Ireland-wide service.

The variation in area of practice of posts holders covering cancer of unknown primary suggests that there are no clearly agreed care pathways. Further work is required to establish how best to meet the needs of people with cancer of unknown primary and how to support the workforce to deliver this care. This will be addressed through the development of the acute oncology service within Northern Ireland.

Macmillan continues to develop new posts to support clinical nurse specialist and advanced nurse practitioner posts to improve their expertise, as support worker roles have been demonstrated to release as much as 30% of CNS capacity.[25]

Clearly, the combination of an increase in incidence and prevalence and a lack of growth in specialist cancer nurse capacity requires concerted and coordinated plans to address.

Summary

There appears to have been a marginal increase in CNS posts since 2011.

However, the specialist adult cancer nursing workforce in general is not expanding sufficiently to keep pace with the growing numbers of people being diagnosed and living with cancer.

This census provides intelligence in assessing how far commitments set out in the Northern Ireland Cancer Services Framework (2009) have been achieved.

However, despite broad political backing for the service framework standard, the intervening years have seen only a small rise in CNS numbers. The 2011 Northern Ireland cancer network census identified 56 nurses[15], this census identified only one additional nurse. This growth is not sufficient to keep pace with the growing cancer population.

Furthermore, delivery of the joint initiative between Macmillan and the Health and Social Care Board TCFU, which relies on the provision of adequate CNS numbers, has not yet achieved its full potential in some tumour groups due to the lack of specialist cancer nurses.[18]

Future planning and recommendations

Those responsible for commissioning services will undoubtedly be expecting value for money as well as high-quality services for patients. Workforce planning will be crucial in achieving improvements in outcomes, and the specialist cancer nursing census is a valuable tool to inform commissioning networks and other funding bodies in the drive for world-class cancer services.

There are still marked inequities in the provision of specialist nursing expertise for those diagnosed with different cancer types, as well as some degree of variance across geographical locations. Evidence from all the recent National cancer patients experience surveys in England and Wales pointed towards the provision of specialist nursing expertise as an important indicator of the quality of cancer services and the experience of care reported by patients.

Commissioners and providers may therefore be interested in examining the ratio of specialist nurses to new cases of cancer within their localities more closely, along with data from hospital trust patient experience surveys and other sources such as the National Cancer Peer Review programme.

In the context of the severe financial constraints in Northern Ireland, Macmillan service development teams would wish to support this analysis and to work in partnership to establish a joint plan to reform and modernise the specialist cancer nursing workforce.

Proposals for future work

In thinking about the future specialist cancer nursing workforce, Macmillan has published a discussion document to encourage consideration and debate about how best to respond to the challenges facing the UK's health and social care systems. As people live longer, the incidence of cancer and other long-term conditions continues to rise, leading to an increase in the number of people with multiple health issues. Multiple morbidities are becoming the norm, with many people with cancer also living with two or more other conditions.[24]

In this context, Macmillan is looking at what the cancer care teams of the future must look like. They will need to be more flexible, working with people living with cancer to identify their concerns and support them in managing their own care. The specialist cancer nursing workforce will be a key part of a whole system of care that will need to be required to support the growing numbers of people living in the community after a cancer diagnosis.

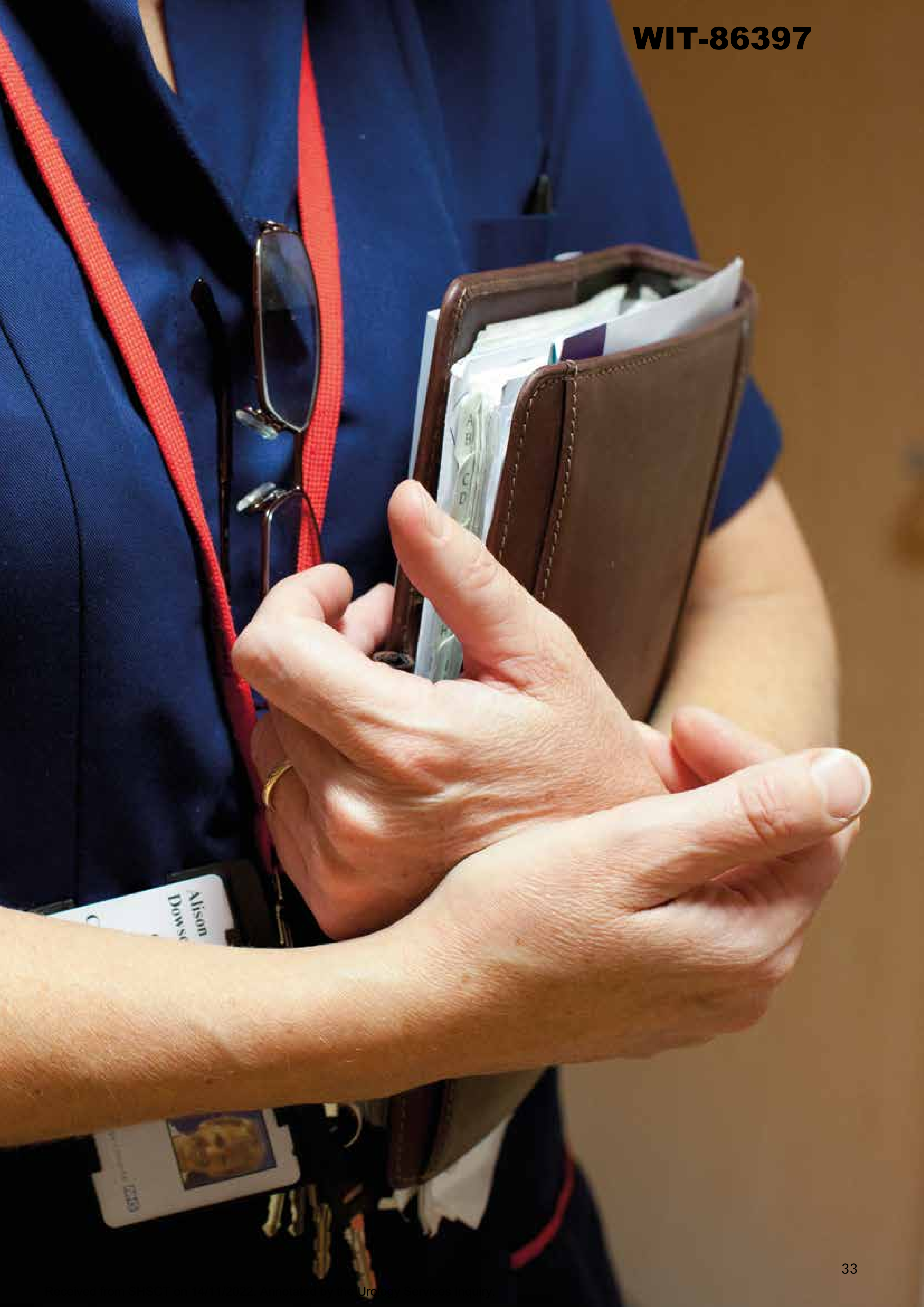
Macmillan's plans include:

- identifying how best to optimise the specialist cancer nurse workforce, building on the success of introducing skill mix in our One-to-One Support pilots, where support workers have been demonstrated to release CNS time for more complex care;
- re-establishing a role development programme that will support nurses wishing to establish themselves as specialists in cancer care;
- developing new roles that will support people with complex care coordination at key points in their care pathway;
- mapping interventions that specialist nurses offer across different cancer patient pathways to determine best practice; and
- continuing the specialist cancer nursing census every two years.

The Public Health Agency has also commissioned Northern Ireland's first cancer patient experience survey, in partnership with Macmillan. The results are expected to be published in mid 2015 and will provide further information about the impact of the specialist workforce and the percentage of patients with access to a CNS. Recent analysis of patient experience surveys in England and Wales have clearly demonstrated the correlation between access to a CNS and more favourable patient experience. The results also showed that in Wales, where a CNS took on the role of key worker, patient experience was further improved.[20]

Macmillan will continue work with partners to explore the use of markers other than incidence and two-year prevalence to help estimate the true caseload of specialist nurses, such as volume of patients seen by a multidisciplinary team.

Additionally, Macmillan will continue to work with its partners at the Health and Social Care Board, Public Health Agency, National Cancer Peer Review team, the Northern Ireland Cancer Network, Department of Health, Social Service and Public Safety, charitable organisations and the Centre for Workforce Intelligence, with the aim of providing robust data on this important element of the specialist cancer workforce and addressing inequities wherever they are identified.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Appendix

Cancer definitions used calculating the ratio of specialist adult cancer nursing workforce by incidence and two-year prevalence

Majority area of practice	Cancer types used in the ratios
Brain/nervous system	Incidence is based on brain and nervous system (C47, C70–C72, C75.1–C75.3), two-year prevalence is based on brain, nervous system and eye, including benign neoplasm (C47, C69, C70–C72, D33)
Breast	Breast with in situ (C50,D05)
Colorectal	Colorectal with anus (C18–21)
Gynaecology	Gynaecology (C51–C58)
Haematology	Haematology (C81–C85, C88, C90–C96)
Head and neck	Head and neck with thyroid (C00–C14, C30–C32, C73)
Lung	Respiratory (C33–C34, C37–C39, C45)
Malignant dermatology	Skin – malignant melanoma (C43)
Sarcoma	Sarcoma (C40–C41, C46, C48–C49)
Upper gastrointestinal	Upper GI (C15–C16, C22–C25)
Urology	Urology including prostate and testicular (C60–C68) and bladder in situ (D09 in the incidence data and D090 in the two-year prevalence)

The census and report is endorsed by the following bodies:

British Association of Head and Neck Oncology Nurses

National Lung Cancer Forum for Nurses

Breast Cancer Care

National Colorectal Cancer Nurses network

British Association of Urological Nurses

United Kingdom Oncology Nursing Society

Centre for Workforce Intelligence

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Macmillan Cancer Support, registered charity in England and Wales (261017),
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CANCER WORKFORCE IN NORTHERN IRELAND

A census of the cancer nursing and support workforce in Northern Ireland in 2021

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Contents

Foreword

In 2016, Macmillan Cancer Support and the Northern Ireland Health and Social Care Board worked together to invest in a workforce plan for cancer Clinical Nurse Specialists (CNS), and Support Workers committing to creating around 43.3 (recurrently funded) new specialist cancer nursing and 19.6 support worker roles over the following five years (up to 2021)[1]. This was a significant step in building a workforce that delivers high quality personalised care for people living with cancer. The posts were established, and their purpose shaped by an agreed work plan enabling recognition of the key functions of their role.

Despite this improvement, patients report a gap between their needs and the number of specialist cancer nurses available. Cancer Patient Experience Survey (CPES) data showed that the number of respondents stating they had been given the name of a CNS who would support them through their treatment increased from 72% in 2015 to 82% in 2018[2]. Further progress will be needed to deliver the cancer strategy recommendation to “ensure that all patients, including children and young people, diagnosed with cancer have access to a Clinical Nurse Specialist throughout the entire care pathway.”[3]

This census has been undertaken within the context of increasing demands on the cancer workforce, a growing population of people living with cancer, a more complex cancer care environment and significant disruption to services during the COVID-19 pandemic. There are an estimated 82,000 people living with cancer in Northern Ireland, this will rise to 114,000 by 2030[4]. This means that within 10 years, the number of people living with cancer will be over 40% higher, the cancer workforce will need to meet this patient demand despite already being stretched now[5].

The COVID-19 pandemic had a disruptive impact on cancer services, a backlog in cancer care has developed with professionals reporting seeing more people with apparent later stage presentation of cancers. This is within the context of services already under pressure, for instance Cancer Waiting Times targets were consistently missed before the impact of COVID-19[6]. The cancer nursing workforce have a key role to play in supporting services to rebuild better. This will include enabling new models of care, maximising skill mix and multidisciplinary working, and continued introduction of advanced nursing roles across care settings to address a more complex cancer care environment of the future. As we emerge from the pandemic and deal with its legacy, it will be important to take account of the longer-term workforce implications, including the ongoing physical and psychological strain on the wellbeing of our nursing workforce.

The 10-year Northern Ireland Cancer Strategy contains the ambitious vision of delivering “equitable and timely access to the most effective, evidence-based referral, diagnosis, treatment, support and person-centred cancer care”[7]. Clinical Nurse Specialists will be pivotal to delivering this vision, playing a key role across the pathway in delivering

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[1] Cancer Clinical Nurse Specialist (CNS) Workforce Plan (HSCB/ PHA) Public Health Agency; personal communication. January 2022.

[2] Northern Ireland Cancer Patient Experience Survey, 2018. All trusts report. Quality Health, published January 2019.

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[6] Northern Ireland waiting time statistics: cancer waiting times April to June 2021. Department of Health NI, published 30 September 2021.

[7] A Cancer Strategy for Northern Ireland 2021–2031. Department of Health NI. Accessed January 2022.

person-centred care. Patient experience is an important consideration for those involved in workforce planning and access to a named Clinical Nurse Specialist can support a more positive experience. The Northern Ireland Cancer Patient Experience Survey (2018)[8] has shown that the majority of people reported their overall experience of care positively (an average of 8.97/10), with increased positive experiences notable when there has been access to a Clinical Nurse Specialist, people who reported being given the name of their Clinical Nurse Specialist have statistically higher scores on 47 of the other 48 questions in the survey.

A census was undertaken in 2014 in NI across cancer services with key recommendations used for workforce planning purposes. The passage of time and advancements within the cancer workforce have influenced adaption from the criteria used in the 2014 to accommodate the 2021 intelligence required. Macmillan has undertaken this Census (2021) in partnership with Department of Health, and Lead Nurse Managers across Health and Social Care (HSC) Trusts to collate and describe the size and composition of the workforce supporting people living with cancer in Northern Ireland.

It can take years to see investment in training staff deliver improvements in the front end of healthcare and much work is going to be required to build the workforce capable of delivering the cancer strategy and meeting rising demand. This Census will provide key evidence to inform strategic workforce planning addressing future sustainability and supporting a framework for career progression that includes the next stage of Cancer Clinical Nurse Specialist expansion, developing the wider workforce skills mix and ensuring a balanced workforce age profile.

It will inform a commissioning perspective for a future cancer workforce in the face of a changing HSC infrastructure for NI and the workforce impacts of Brexit and the COVID-19 pandemic. The report offers valuable information which will be used by leaders, workforce planners and commissioners to enable transformation and modernisation of services. The point in time data provided will inform Department of Health high level workforce strategy and planning aligned to the Cancer Strategy 2021[9], and Cancer Recovery plan 2021[10]. The census will also facilitate a view of the population health approach within nursing and support workforce to improve outcomes for all people living with cancer and ensure people with cancer have access to the right support at the right time.

The census will increase our understanding of the qualifications held by our workforce and their educational status. It will provide workforce planners with information to inform education commissioning and succession planning to ensure that cancer nurses and support workforce have the right knowledge and skills to deliver services for current and future cancer populations.

We would like to acknowledge our thanks to the Department of Health for the funding to enable the census to happen, the Public Health Agency and NICaN Lead Nurse Reference Group who were pivotal in ensuring the robustness of the data gathered. And finally, to Rocket Science, who led the way to provide clarity, information and data expertise to support the development of the census report.

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[10] Cancer Recovery Plan 2021/22–23/24. Department of Health NI, published 24 June 2021.

Executive summary

Macmillan Cancer Support, in partnership with the Department of Health (DoH), Northern Ireland (NI), commissioned a census of the cancer nurses and support staff delivering cancer care by type and locality on the 17th September 2021.

Overall, at the time of the census, there were 754 posts (672.4 WTE) who treat, support and manage the health concerns and wellbeing of cancer patients for more than 50% of their time.

This workforce is made up of (for definitions of each of these groups see Appendix B):

Adult cancer specialist nurses

165 posts 144.8 WTE

Adult cancer care nurses

67 posts 61.3 WTE

Adult chemotherapy nurses

266 posts 238.3 WTE

Children, teenager and young adult (CTYA) nurses

48 posts 38.5 WTE

Nursing support workforce

93 posts 83.2 WTE

includes cancer support workers:

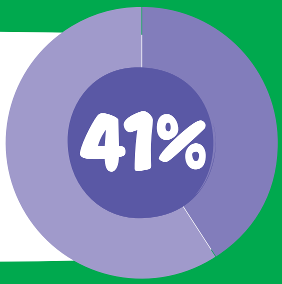
26 posts 22.7 WTE

Growth since 2014

The number of adult cancer specialist nurses with the job title Clinical Nurse Specialist has grown.

55.6 WTE in 2014 TO 93.0 WTE in 2021

41% of adult cancer specialist nurses have part-time roles



Main areas of practice of adult cancer specialist nurses (% of all WTE)

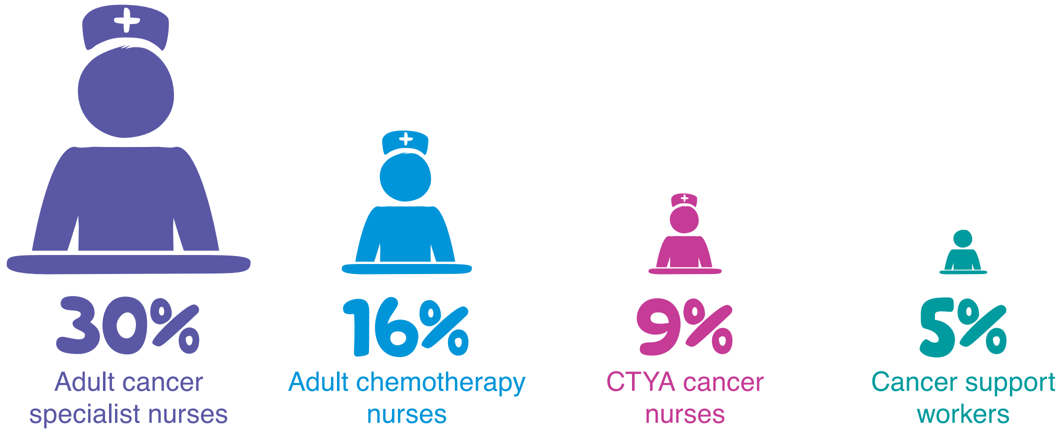
19% Breast

14% Haematology

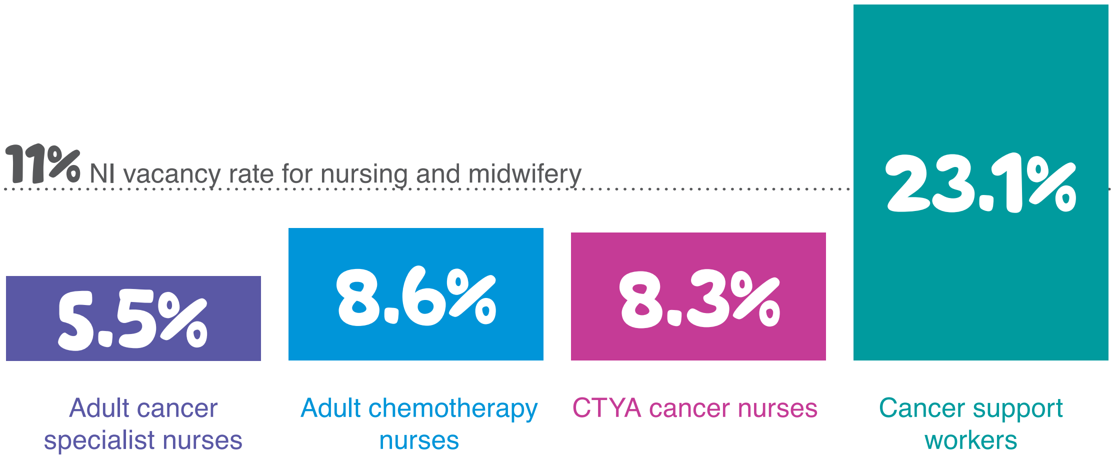
12% Urology

10% Lung

Percentage of the workforce aged 50 or over (% filled posts)
23% of the overall cancer workforce is aged 50 or over.



Vacancy rates
At the time of the census, vacancy rates for nurses were lower than the Northern Ireland vacancy rate for nursing and midwifery (11%)[11].



Training and development to support holistic personalised care

Qualification	Adult cancer specialist nurses	Adult chemotherapy nurses	CTYA cancer nurses	Cancer support workers
Advanced communication skills training	74%	7%	14%	N/A
Trained in eHNA within the last 18 months	37%	0%	2%	24%

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[11] Northern Ireland Health and Social Care Workforce Vacancies Tables, June 2021. Department of Health, NI, published 25 August 2021. Accessed November 2021.

Background and methodology

Background

Macmillan Cancer Support, in partnership with the Department of Health (DoH) Northern Ireland (NI), commissioned a census of the nurses and support staff delivering cancer care in 2021. This research maps the workforce by cancer type and locality.

The census aims to provide a wide understanding of the cancer workforce. The current study includes nurses delivering adult cancer care (specialist and other), adult chemotherapy nurses, children, teenager and young adult cancer nurses, and support staff.

Although the methodology was based on previous censuses for other UK nations, comparison across the UK nations is difficult as national requirements resulted in variation in inclusion criteria.

The 2021 NI census will assist in understanding:

- variation of cancer nursing workforce across the country;
- where and what succession planning is needed;
- the skill mix of the workforce;
- potential for further development of specialist and advanced nursing roles;
- the commissioning of nurse education to support the cancer nursing workforce.

Methodology

The approach for the 2021 Northern Ireland (NI) census followed a similar methodology to that of the England and Wales 2017 census and the Scotland 2019 census[12,13,14,15]. The main point of difference in the 2021 Northern Ireland census is that it includes children, teenager and young adult cancer nurse posts, and does not include specialist palliative care nurses.

Full inclusion and exclusion criteria for this census can be found in Appendix B.

Rocket Science designed a bespoke Excel tool to be completed by each of the five Health and Social Care Trusts (HSCTs) in NI, to gather a snapshot of the workforce on the 17th September 2021. The census tool, with accompanying guidance and a Frequently Asked Questions (FAQs) document, were circulated on 14th September 2021. An identified data lead from each HSCT was given until 15th October 2021 to gather and return their data. Weekly meetings with data leads were held to discuss and resolve any issues about data collection to ensure comparative data capture. As not all trusts were represented at every meeting the FAQs were updated to reflect decisions agreed in these meetings and re-circulated to all data leads.

The census attained a 100% response rate, data was collected from all five HSCTs in NI.

To ensure robustness in the results, a data audit process was built in, including sense checking analysis with the NICaN Nurse Leaders Reference Group and triangulation with ongoing work by the Public Health Agency of NI to support Clinical Nurse Specialist workforce planning. Whilst numbers do not totally align, small variances can be explained by the timing of the work and inclusion criteria in relation to which posts should be counted.

Full details of the process are provided in Appendices B–D. In addition, for comparison purposes, Appendix A sets out differences in methodology between this and the 2014 NI census.

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[12] Specialist adult cancer nurses in Northern Ireland. A census of the specialist adult cancer nursing workforce in the UK, 2014. Macmillan Cancer Support.

[13] Cancer workforce in England. A census of cancer, palliative and chemotherapy speciality nurses and support workers in England in 2017. Macmillan Cancer Support.

[14] Cancer workforce in Wales. A census of cancer, palliative and chemotherapy speciality nurses and support workers in Wales in 2017. Macmillan Cancer Support.

[15] Cancer workforce in Scotland. A census of cancer, palliative, chemotherapy speciality nurses, support workers and Improving the Cancer Journey link workers in Scotland in 2019. Macmillan Cancer Support.

Health and Social Care Trusts (HSCTs)

A range of sections in the analysis include data disaggregated by geography. Geography is indicated using the HSCTs in NI, whose areas are provided on the map below.

HSC Trust areas

1 Belfast
Incidence 1,934
Population 359,230

2 Northern
Incidence 2,572
Population 480,194

3 South Eastern
Incidence 1,972
Population 364,191

4 Southern
Incidence 1,831
Population 388,688

5 Western
Incidence 1,551
Population 303,207

Health and Social Care Trusts by single year of age and gender (mid 1991 to mid 2020). GOV.UK. Accessed December 2021.

Cancer incidence, survival, mortality and prevalence by cancer type. 2019 data. Northern Ireland Cancer Registry. Accessed October 2021.

1. ADULT CANCER CARE WORKFORCE

This section describes nurses delivering adult cancer care in Northern Ireland (NI). These nurses were on Agenda for Change bands 5 to 9[16] at the time of the census and spend over 50% of their time directly supporting people living with cancer.

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[16] NHS terms and conditions of service (Agenda for Change) NHS Employers. Accessed January 2022

Overall, the adult cancer care workforce captured through the census, comprises 347 posts (312.4 WTE). A summary analysis is provided in section 1.1.

These nurses have been grouped as follows:

- 165 posts in **adult cancer specialist nurse roles** (144.8 WTE) this includes:
  - 139 posts for clinical nurse specialists, which includes acute oncology (121.2 WTE)
  - 26 posts for advanced practitioners (23.6 WTE)
- 67 posts in other **adult cancer care nurse roles** (61.3 WTE)
- 115 **staff nurse posts** working in haematology and oncology wards (106.3 WTE)

It should be noted that within the adult cancer specialist nurse roles, there are 5 part-time post-holders (3.1 WTE) who are also counted as part-time post-holders in the children, teenager and young adult cancer nurses in section 3, as they split their time between work with adults and work with teenagers and young adults.

This work aimed to capture a comprehensive picture of the cancer nursing workforce. During data collection trusts agreed that it was appropriate to include staff nurses spending more than 50% of their time working directly with cancer patients. As a result, staff nurses working in haematology and oncology wards in cancer centres in Belfast and Western trusts spending more than 50% of their time working directly with cancer patients were captured. However, during the audit of this report it was clear that the data captured does not provide a full picture for this staff group.

Data on staff nurses gathered through the census are described separately in Box 1 in section 1.1.2 below. For more information on additional estimates for this nursing group provided after the census was concluded by the NICaN Nurse Leaders Reference Group, please go to Appendix E.

Section 1.2 provides a more detailed analysis of adult cancer specialist nurses. We have identified these 'cancer specialist nurses' as those posts which satisfy the following categories:

- the job title specifies 'specialist' or 'practitioner';
- Agenda for Change band 6 and above;
- over 50% of the post-holder's time is spent supporting adults living with cancer;
- post-holders have a documented training record declaring them specialist in cancer care or have been appointed with their agreed willingness to undertake a cancer qualification.

This definition was shared and agreed by NICaN Nurse Leaders Reference Group and has been adhered to for reporting purposes.

Analysis of two subgroups of the cancer specialist nurses is provided:

- **'clinical nurse specialists'** these roles function as key workers for cancer patients but have a variety of job titles (Clinical Nurse Specialist, Cancer Nurse Specialist and Nurse Specialist) This group includes those working in acute oncology services;
- **'advanced practitioners'** these roles have specialist clinical practice but do not have a key worker function.

Full details on inclusion and exclusion criteria of posts captured can be found in Appendix B and nursing role definitions are in Appendix C.

1.1 Adult cancer workforce – summary

Table 1 summarises the adult cancer care workforce and defines adult cancer specialist nurses as distinct from other cancer care nurse roles.

Table 1: Nurses delivering adult cancer care, job titles, number of posts, NI 2021

Job title	Number of posts	Percentage posts	WTE
Adult cancer specialist nurses	**165**	**48%**	**144.8**
Clinical Nurse Specialist	106	31%	93.0
Nurse Specialist	21	6%	17.6
Cancer Nurse Specialist	12	3%	10.6
Oncology Nurse Practitioner	14	4%	11.9
Haematology Nurse Practitioner	4	1%	4.0
Advanced Nurse Practitioner Trainee	3	1%	2.8
Nurse Practitioner	2	1%	1.9
Advanced Nurse Practitioner	1	0%	1.0
Haematology Transplant Coordinator	2	1%	2.0
Other adult cancer care nurses	**67**	**19%**	**61.3**
Clinical Research Nurse	23	7%	20.9
Deputy Sister	19	5%	17.8
Sister	8	2%	7.3
Nurse	8	2%	6.9
Triage Helpline Nurse	2	1%	2.0
Clinical Research Manager	1	0%	1.0
Lead CRN/Manager	1	0%	1.0
Clinical Staff Nurse	1	0%	1.0
Senior Nurse	1	0%	1.0
Lead Nurse	1	0%	1.0
Nurse Manager	1	0%	0.8
Pre-Assessment Nurse	1	0%	0.6
Sub-total (not including staff nurses)	**232**	**67%**	**206.1**
Staff Nurse	115	33%	106.3
Overall total (including staff nurses)	**347**	**100%**	**312.4**

Table 2: Nurses delivering adult cancer care, job title, HSCT, WTE, NI 2021

Job title	Belfast	Western	South Eastern	Southern	Northern	Total WTE
Adult cancer specialist nurses	**57.5**	**20.7**	**27.3**	**20.2**	**19.2**	**144.8**
Clinical Nurse Specialist	25.0	15.7	20.9	17.6	13.9	93.0
Nurse Specialist	14.0	1.0		0.6	1.9	17.6
Cancer Nurse Specialist	3.8	4.0	0.8	1.0	1.0	10.6
Oncology Nurse Practitioner	7.7	0.0	2.0	0.0	2.3	11.9
Haematology Nurse Practitioner	3.0	0.0	1.0	0.0	0.0	4.0
Advanced Nurse Practitioner	0.0	0.0	0.0	1.0	0.0	1.0
Nurse Practitioner	1.0	0.0	0.9	0.0	0.0	1.9
Advanced Nurse Practitioner Trainee	1.0	0.0	1.8	0.0	0.0	2.8
Haematology Transplant Coordinator	2.0	0.0	0.0	0.0	0.0	2.0
Other adult cancer care nurses	**36.6**	**22.3**	**1.0**	**1.4**	**0.0**	**61.3**
Clinical Research Nurse	16.7	1.8	1.0	1.4	0.0	20.9
Deputy Sister	10.1	7.7	0.0	0.0	0.0	17.8
Sister	5.3	2.0	0.0	0.0	0.0	7.3
Nurse	0.5	6.4	0.0	0.0	0.0	6.9
Triage Helpline Nurse	0.0	2.0	0.0	0.0	0.0	2.0
Clinical Research Manager	0.0	1.0	0.0	0.0	0.0	1.0
Lead CRN / Manager	1.0	0.0	0.0	0.0	0.0	1.0
Clinical Staff Nurse	1.0	0.0	0.0	0.0	0.0	1.0
Senior Nurse	1.0	0.0	0.0	0.0	0.0	1.0
Lead Nurse	1.0	0.0	0.0	0.0	0.0	1.0
Nurse Manager	0.0	0.8	0.0	0.0	0.0	0.8
Pre-Assessment Nurse	0.0	0.6	0.0	0.0	0.0	0.6
Total (not including staff nurses)	**94.1**	**43.0**	**28.3**	**21.6**	**19.2**	**206.1**
Staff Nurse	73.0	33.3				106.3
Overall total	**167.0**	**76.3**	**28.3**	**21.6**	**19.2**	**312.4**

1.1.1 Adult cancer specialist nurses

Adult cancer specialist nurses are identified as a subset of the overall adult cancer care workforce. This workforce includes clinical specialist nurses and practitioners (see Appendix B for inclusion/exclusion criteria and Appendix C for definitions).

There are 165 posts in this group (144.8 WTE). The following roles are included:

Clinical nurse specialist roles

- Clinical Nurse Specialist (including acute oncology)
- Cancer Nurse Specialist
- Nurse Specialist

Advanced practitioner roles

- Oncology Nurse Practitioner
- Haematology Nurse Practitioner
- Advanced Nurse Practitioner
- Advanced Nurse Practitioner Trainee
- Haematology Transplant Coordinator
- Nurse Practitioner.

These posts are analysed in detail in section 1.2.

1.1.2 Other adult cancer care nurses

Nursing roles which sit outside of the adult cancer specialist nurse definition (Appendix B) include the following roles in the tables below. These posts play a significant part within the cancer patient pathways of care. There are 67 posts within this group (61.3 WTE) including 60 filled posts and 7 vacant posts, a 10% vacancy rate. Most of these posts are in Belfast and Western HSCTs, which are cancer centres.

Table 3: Other adult cancer care nurses, job titles, HSCT, WTE, NI 2021

Job title	Belfast	Western	South Eastern	Southern	Northern	Total WTE
Clinical Research Nurse	16.7	1.8	1.4	1.0	0.0	20.9
Deputy Sister	10.1	7.7	0.0	0.0	0.0	17.8
Sister	5.3	2.0	0.0	0.0	0.0	7.3
Nurse	0.5	6.4	0.0	0.0	0.0	6.9
Triage Helpline Nurse	0.0	2.0	0.0	0.0	0.0	2.0
Senior Nurse	1.0	0.0	0.0	0.0	0.0	1.0
Lead CRN/Manager	1.0	0.0	0.0	0.0	0.0	1.0
Clinical Research Manager	0.0	1.0	0.0	0.0	0.0	1.0
Clinical Staff Nurse	1.0	0.0	0.0	0.0	0.0	1.0
Lead Nurse	1.0	0.0	0.0	0.0	0.0	1.0
Nurse Manager	0.0	0.8	0.0	0.0	0.0	0.8
Pre-Assessment Nurse	0.0	0.6	0.0	0.0	0.0	0.6
Total	**36.6**	**22.3**	**1.4**	**1.0**	**0.0**	**61.3**

Qualifications held by adult cancer care nurses (not including adult cancer specialist nurses or staff nurses) at the time of the census are shown in Table 4.

Table 4: Other adult cancer care nurses, number and percentage of qualifications and training, filled posts, NI 2021

	Number of filled posts with qualification	Percentage filled posts with qualification
Qualifications		
BSc in Nursing or other health-related subject	46	77%
Diploma in Nursing	24	40%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	12	20%
Health Assessment and Clinical Reasoning	8	13%
Advanced Methods in Research and Development in Health and Social Care	6	10%
Postgraduate Diploma in Specialist Practice – Palliative Care	3	5%
Non-Medical Prescribing Qualification V300	2	3%
Masters in Professional Nursing	1	2%
PhD	1	2%
MSc Advanced Nursing Practice or relevant programme	0	0%
Training in Radiotherapy Nursing	28	47%
Training		
PICC training (Central Venous Access Devices competency assessment)	49	82%
Chemotherapy Competency*	47	78%
Advanced Communications Skills training	22	37%
Sage and Thyme Communication Skills training	17	28%
Trained in eHNA** within the last 18 months	4	7%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

** Electronic Holistic Needs Assessment.

Table 5: Other adult cancer care nurses, number and percentage of qualifications and training, filled posts, Agenda for Change (AfC) band, NI 2021

	Number of filled posts with qualifications						Percentage filled posts with qualifications
AfC band	**5**	**6**	**7**	**8A**	**8B**	**All**	**All**
Number of filled posts – totals	4	39	14	1	2	60	100%
Qualifications							
BSc in Nursing or other health-related subject	3	33	8	1	1	46	77%
Diploma in Nursing	0	14	8	1	1	24	40%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	0	6	4	1	1	12	20%
Health Assessment and Clinical Reasoning	0	4	4	0	0	8	13%
Advanced Methods in Research and Development in Health and Social Care	0	2	2	1	1	6	10%
Postgraduate Diploma in Specialist Practice – Palliative Care	0	3	0	0	0	3	5%
Non-Medical Prescribing Qualification V300	0	1	1	0	0	2	3%
Masters in Professional Nursing	0	0	1	0	0	1	2%
PhD	0	1	0	0	0	1	2%
MSc Advanced Nursing Practice or relevant programme	0	0	0	0	0	0	0%
Training in Radiotherapy Nursing	2	17	8	1	0	28	47%
Training							
PICC training (Central Venous Access Devices competency assessment)	4	33	11	0	1	49	82%
Chemotherapy Competency*	4	34	8	0	1	47	78%
Advanced Communications Skills training	1	15	6	1	0	23	38%
Sage and Thyme Communication Skills training	0	10	7	0	0	17	28%
Trained in eHNA** within the last 18 months	1	2	1	0	0	4	7%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

** Electronic Holistic Needs Assessment.

Box 1 – Staff nurses delivering cancer care, Agenda for Change (AfC) band and HSCT, NI 2021

Staff nurses

This work aimed to capture a comprehensive picture of the cancer nursing workforce. During data collection trusts agreed that it was appropriate to include inpatient staff nurses spending more than 50% of their time working directly with cancer patients.

The posts captured are described below:

- These post-holders spending more than 50% of their time working with cancer patients, are based in haematology and oncology wards but do not have specialist status.
- 87% of these staff nurse posts are at AfC band 5.
- These captured posts are located in cancer centres in Belfast and Western Trusts.

The table below shows 115 (106.3 WTE) staff nurse posts captured across these two cancer centres. This includes 79 posts in Belfast Trust (73.0 WTE) and 36 posts in the Western Trust (33.3 WTE).

	Belfast			Western			Total		
AfC band	**Number of posts**	**WTE**	**WTE %**	**Number of posts**	**WTE**	**WTE %**	**Number of posts**	**WTE**	**WTE %**
5	64	59.1	81%	36	33.3	100%	100	92.4	87%
6	14	12.9	18%			0%	14	12.9	12%
7	1	1.0	1%			0%	1	1.0	1%
Total	**79**	**73.0**	**100%**	**36**	**33.3**	**100%**	**115**	**106.3**	**100%**

NB. After data was finalised, the NICaN Nurse Leaders Reference Group recognised that the number of staff nurses captured was incomplete during report review. Although the census data could not be altered at this stage, additional estimates for this nursing group were provided for all trusts by the NICaN Nurse Leaders Reference Group as personal communications and are provided in Appendix E. The figures will enable more appropriate comparison of this staff group across trusts in NI.

1.2 Adult cancer specialist nurses

We have identified 'cancer specialist nurses' as those posts which satisfy the following categories:

- The job title specifies 'specialist' or 'practitioner';
- The AfC Band 6 and above;
- Over 50% of the post holder's time is spent supporting adults living with cancer;
- Post-holders have a documented training record declaring them specialist in cancer care or have been appointed with their agreed willingness to undertake a cancer qualification.

Analysis of two subgroups of the cancer specialist nurses is provided:

- **'clinical nurse specialists'** these roles function as key workers for cancer patients but have a variety of job titles (Clinical Nurse Specialist, Cancer Nurse Specialist and Nurse Specialist). These also include those working in acute oncology services;
- **'advanced practitioners'** these roles have specialist clinical practice but do not have a key worker function.

Nursing role definitions can be found in Appendix C.

Overall, there are 165 adult cancer specialist nurse posts across NI (144.8 WTE).

1.2.1 Job title

The most common role for adult cancer specialist nurses is Clinical Nurse Specialist at 64% (93.0 WTE), followed by Nurse Specialist at 13% (17.6 WTE). All other roles made up less than 10% of cancer specialist nurses.

Nursing role definitions can be found in Appendix C.

Table 6: Adult cancer specialist nurse workforce, job titles, number of posts, NI 2021

Job title	Number of posts	Percentage	WTE
Clinical Nurse Specialist	106	64%	93.0
Nurse Specialist	21	13%	17.6
Cancer Nurse Specialist	12	7%	10.6
Total Clinical Nurse Specialists*	**139**	**84%**	**121.2**
Oncology Nurse Practitioner	14	8%	11.9
Haematology Nurse Practitioner	4	2%	4.0
Advanced Nurse Practitioner Trainee	3	2%	2.8
Nurse Practitioner	2	1%	1.9
Haematology Transplant Coordinator	2	1%	2.0
Advanced Nurse Practitioner	1	1%	1.0
Total Advanced Practitioners	**26**	**16%**	**23.6**
Total	**165**	**100%**	**144.8**

*Clinical Nurse Specialists include those working in acute oncology.

Table 7: Adult cancer specialist nurse workforce, WTE, HSCT, specialists and practitioners, NI 2021

HSCT	Clinical Nurse Specialist WTE	Percentage total	Advanced Practitioners WTE	Percentage total	Total adult cancer specialist nurses	Percentage total
Belfast	42.8	75%	14.7	25%	57.5	100%
South Eastern	21.7	79%	5.7	21%	27.3	100%
Western	20.7	100%	0	0%	20.7	100%
Southern	19.2	95%	1.0	5%	20.2	100%
Northern	16.9	88%	2.3	12%	19.2	100%
Total	**121.2**	**84%**	**23.6**	**16%**	**144.8**	**100%**

1.2.2 Age

The census showed that 40–49 was the most common age group among cancer specialist nurses, with 36% (56 filled posts) in this group. Cancer centres (Belfast and Western HSCT) have the highest proportion of nurses 30–39.

Table 8: Adult cancer specialist nurse workforce by age group, number of filled posts, NI 2021

Age group	Number of posts	Percentage
Under 30	3	2%
30–39	49	31%
40–49	56	36%
50–59	46	29%
60 and over	2	1%
Total	**156**	**100%**
Vacant	9	

Table 9: Adult cancer specialist nurse workforce by age, HSCT, number of filled posts NI 2021

	Under 30		30–39		40–49		50–59		60 and over		Total	
HSCT	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Belfast		0%	23	38%	19	32%	18	30%	0	0%	60	100%
South Eastern	1	3%	8	26%	12	39%	10	32%	0	0%	31	100%
Northern	1	4%	7	29%	10	42%	4	17%	2	8%	24	100%
Southern		0%	3	14%	10	48%	8	38%	0	0%	21	100%
Western	1	5%	8	40%	5	25%	6	30%	0	0%	20	100%
Total	**3**	**2%**	**49**	**31%**	**56**	**36%**	**46**	**29%**	**2**	**1%**	**156**	**100%**

1.2.3 Gender

96% (149 filled posts) of cancer specialist nurses were female.

Table 10: Adult cancer specialist nurse workforce by gender, number of filled posts, NI 2021

Gender	Number of posts	Percentage
Female	149	96%
Male	3	2%
Other	0	0
Not disclosed	4	3%
Total	**156**	**100%**
Vacant	9	

1.2.4 Nationality

97% (151 filled posts) of cancer specialist nurses were from the UK.

Table 11: Adult cancer specialist nurse workforce by nationality, number of filled posts, NI 2021

Nationality	Number of posts	Percentage
UK	151	97%
EU*	5	3%
Rest of world	0	0%
Total	**156**	**100%**
Vacant	9	

*EU is likely to include some staff who identify as Irish.

1.2.5 Part-time roles

59% (97 filled posts) of cancer specialist nurses were full-time. The proportion of full-time roles varied across HSCTs with a maximum of 73% (16 filled posts) in Southern HSCT and minimum of 38% (9 filled posts) in Northern HSCT.

It should be noted that 5 of the part-time post holders in the table below are also counted as part-time posts in children, teenager and young adult cancer workforce section, as these post-holders also work with children, teenagers and young adults.

Table 12: Adult cancer specialist nurse workforce, full-time/part-time by HSCT, number of posts, NI 2021

	Full-time		Part-time		Total	
HSCT	**N**	**%**	**N**	**%**	**N**	**%**
Belfast	41	64%	23	36%	64	100%
South Eastern	18	58%	13	42%	31	100%
Northern	9	38%	15	63%	24	100%
Western	13	54%	11	46%	24	100%
Southern	16	73%	6	27%	22	100%
Total	**97**	**59%**	**68**	**41%**	**165**	**100%**

1.2.6 Setting

Just under half (44%) of the adult cancer specialist nurses WTEs work in cancer centres. The majority of adult cancer specialists (65%) work from hospital outpatients as the main location of care. No posts were located in a community setting.

Table 13: Adult cancer specialist nurse workforce, settings and main locations of care, WTE, NI 2021

	Main location of care – WTE					
Setting	**Day care or day unit**	**Hospital outpatient**	**Inpatient**	**Telephone**	**Community settings***	**Total**
Cancer centre	11.8	48.6	3.9	0.4	0	64.7
Cancer unit	13.6	11.9	7.4	2.5	0	35.4
Non cancer-specific setting	1.9	33.7	8.2	1.0	0	44.7
Total	**27.2**	**94.2**	**19.5**	**3.9**	**0**	**144.8**

*Community settings include patient or care home, health clinic or centre.

A secondary location of care (where the post-holder delivers care for at least 25% of patient facing time) was reported for 108.1 WTEs. These additional care locations are provided in Table 14.

Table 14: Adult cancer specialist nurse workforce, other locations of care, WTE, NI 2021

Other location of care	WTE	Percentage
Inpatient	42.7	30%
Telephone	39.1	27%
Hospital outpatient	17.4	12%
Day care or day unit	8.9	6%
Care is concentrated in a single location	36.7	25%
Total	**144.8**	**100%**

1.2.7 Affiliation

46% (62.4 WTE) of filled cancer specialist nurse posts had Macmillan in the job title and 46% (62.8 WTE) had no affiliations in the job title. Just 8% (10.5 WTE) had another charity in the job title. Over half of cancer specialist nurse vacancies (54%, 3.9 WTE) have Macmillan in the job title.

Table 15: Adult cancer specialist nurse workforce, post affiliations, WTE, NI 2021

	Filled		Vacant		Total	
Affiliations	**WTE**	**%**	**WTE**	**%**	**WTE**	**%**
It has Macmillan in the job title	62.4	46%	3.9	54%	66.3	46%
It has no affiliations in the job title	62.8	46%	3.3	46%	66.0	46%
It has another charity in the job title	10.5	8%	0	0%	10.5	7%
Data not available	2.0	1%	0	0%	2.0	1%
Total	**137.7**	**100%**	**7.1**	**100%**	**144.8**	**100%**

Data was not available for 3 posts (2.0 WTE).

1.2.8 Vacancy rates

There is a 5.5% vacancy rate across HSCTs for cancer specialist nurses with this ranging from 0% in South Eastern HSCT and Northern HSCT, to 16.7% in Western HSCT.

Table 16: Adult cancer specialist nurse workforce by HSCT, vacancy rates, number of posts, NI 2021

HSCT	Filled	Vacant	Vacancy rate
Belfast	60	4	6.3%
South Eastern	31	0	0.0%
Northern	24	0	0.0%
Western	20	4	16.7%
Southern	21	1	4.5%
Total	**156**	**9**	**5.5%**

1.2.9 Agenda for Change (AfC) banding

Adult cancer specialist nurses are by definition AfC band 6 and above. In NI 73% (106.3 WTE) of cancer specialist nurses were at AfC band 7; 25% (36.5 WTE) were at band 6 and 1% (2.0 WTE) were at band 8A.

Table 17: Adult cancer specialist nurse workforce, AfC banding, WTE, NI 2021

AfC band	WTE	Percentage
6	36.5	25%
7	106.3	73%
8A	2.0	1%
Total	**144.8**	**100%**

The number of the adult cancer specialist nurse WTEs working in each area of practice varies. The areas of practice with the highest workforce are breast (27.5 WTE), haematology (20.9 WTE) and urology (16.7 WTE). The highest vacancy rate is within brain/central nervous system, at 50% (2 vacant posts). There are 9 filled posts that are 'not cancer type specific'; and 2 oncology posts.

Table 18: Adult cancer specialist nurse workforce, by area of practice, vacancy rates, number of posts, total WTE, NI 2021

Area of practice	Filled posts	Vacant posts	Vacancy rate	Total WTE
Breast	30	1	3.2%	27.5
Haematology	23	1	4.2%	20.9
Urology	17	1	5.6%	16.7
Lung	17	0	0.0%	15.1
Malignant dermatology	12	1	7.7%	11.2
Upper gastrointestinal	11	0	0.0%	9.6
Colorectal	10	1	9.1%	9.4
Gynaecology	8	1	11.1%	8.6
Head and neck	9	0	0.0%	8.1
Brain/central nervous system	2	2	50.0%	2.6
Sarcoma	3	0	0.0%	2.0
Hepato-pancreato-biliary	3	0	0.0%	2.5
Oncology	2	0	0.0%	1.8
Not cancer type specific	9	1	10.0%	8.9
Total	**156**	**9**	**5.5%**	**144.8**

Within the clinical specialist nurse subgroup, the most common areas of practice are breast (21.3 WTE) and lung (14.1 WTE)

Table 19: Adult cancer specialist nurse workforce, clinical nurse specialists, by area of practice, vacancy rates, number of posts, total WTE, NI 2021

Clinical specialist nurses* by area of practice	Filled posts	Vacant posts	Vacancy rate	Total WTE
Breast	23	1	4.2%	21.3
Lung	16	0	0.0%	14.1
Haematology	15	1	6.3%	12.9
Urology	14	1	6.7%	14.5
Malignant dermatology	10	1	9.1%	9.5
Colorectal	10	1	9.1%	9.4
Head and neck	9	0	0.0%	8.1
Upper gastrointestinal	8	0	0.0%	6.8
Gynaecology	7	1	12.5%	7.6
Brain/central nervous system	2	2	50.0%	2.6
Sarcoma	3	0	0.0%	2.0
Hepato-pancreato-biliary	3	0	0.0%	2.5
Oncology	2	0	0.0%	1.8
Not cancer type specific	8	1	11.1%	8.1
Total	**130**	**9**	**6.5%**	**121.2**

*This subgroup includes the following job titles: Clinical Nurse Specialist, Cancer Nurse Specialist and Nurse Specialist, and includes those working in acute oncology services.

For the nurse practitioner subgroup, the most common areas of practice are haematology (8.0 WTE) and breast (6.3 WTE).

Table 20: Adult cancer specialist nurse workforce, practitioners, by area of practice, vacancy rates, number of posts, WTE, NI 2021

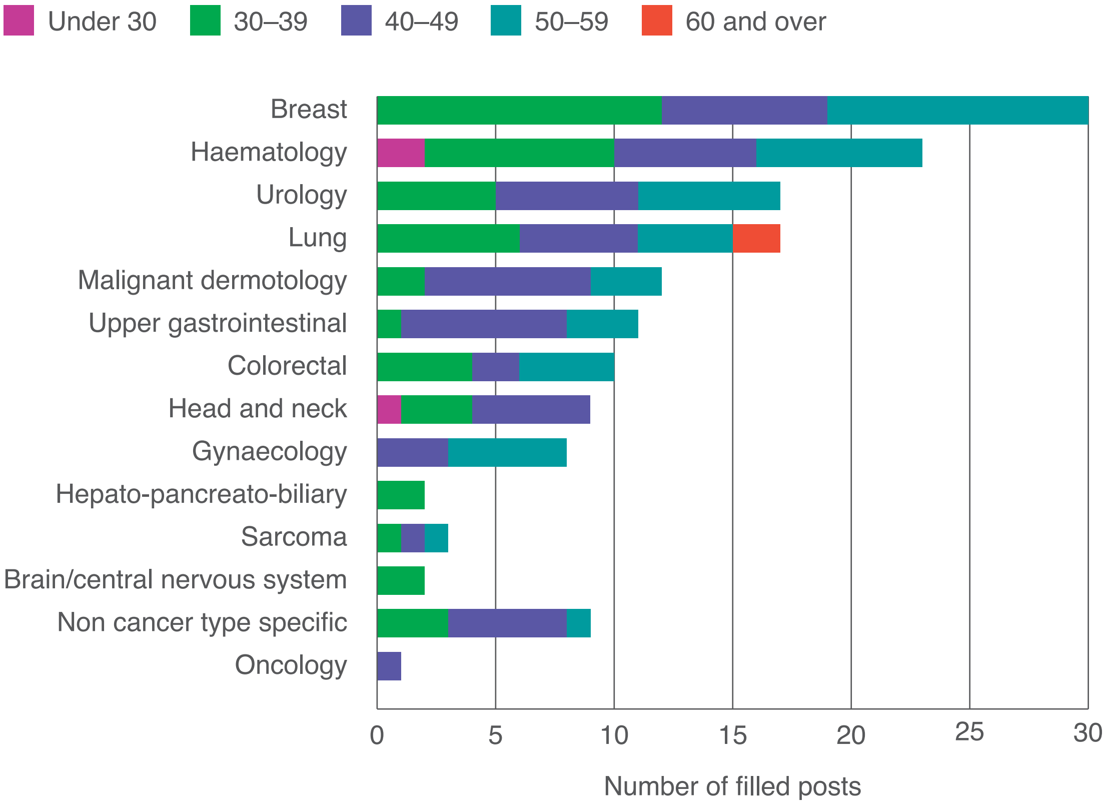
Practitioners* by area of practice	Filled posts	Vacant posts	Vacancy rate	WTE
Haematology	8	0	0%	8.0
Breast	7	0	0%	6.2
Urology	3	0	0%	2.1
Upper gastrointestinal	3	0	0%	2.8
Malignant dermatology	2	0	0%	1.7
Gynaecology	1	0	0%	1.0
Lung	1	0	0%	1.0
Not cancer type specific	1	0	0%	0.8
Total	**26**	**0**	**0%**	**23.6**

*This subgroup includes the following job titles: Oncology Nurse Practitioner, Haematology Nurse Practitioner, Advanced Nurse Practitioner Trainee, Nurse Practitioner, Haematology Transplant Coordinator, Advanced Nurse Practitioner.

Table 21: Adult cancer specialist nurse workforce, (including clinical nurse specialists and practitioners), areas of practice by HSCT, WTE posts, NI 2021

HSCT	Belfast		Northern		South Eastern		Southern		Western		Total	
Area of practice	**WTE**	**%**	**WTE**	**%**	**WTE**	**%**	**WTE**	**%**	**WTE**	**%**	**WTE**	**%**
Breast	9.9	17%	4.8	25%	5.6	20%	3.6	18%	3.6	17%	27.5	19%
Haematology	10.9	19%	2.0	10%	2.8	10%	2.2	11%	3.0	15%	20.9	14%
Urology	5.4	9%	0.7	4%	2.9	10%	3.0	15%	4.7	23%	16.7	12%
Lung	5.0	9%	3.6	19%	3.0	11%	2.0	10%	1.5	7%	15.1	10%
Malignant dermatology	2.6	5%	1.5	8%	3.7	13%	1.6	8%	1.8	9%	11.2	8%
Upper gastrointestinal	5.6	10%	1.0	5%	1.0	4%	1.0	5%	1.0	5%	9.6	7%
Colorectal	2.5	4%	2.5	13%	2.4	9%	1.0	5%	1.0	5%	9.4	6%
Gynaecology	4.0	7%	1.0	5%	1.0	4%	1.0	5%	1.6	8%	8.6	6%
Head and neck	3.7	7%	0	0%	1.4	5%	2.0	10%	1.0	5%	8.1	6%
Brain/central nervous system	2.6	4%	0	0%	0	0%	0	0%	0	0%	2.6	2%
Hepato-pancreato-biliary	2.5	4%	0	0%	0	0%	0	0%	0	0%	2.5	2%
Sarcoma	1.0	2%	0	0%	1.0	4%	0	0%	0	0%	2.0	1%
Oncology	1.8	3%	0	0%	0	0%	0	0%	0	0%	1.8	1%
Not cancer type specific	0	0%	2.0	10%	2.6	10%	2.8	14%	1.5	7%	8.9	6%
Total	**57.5**	**100%**	**19.2**	**100%**	**27.3**	**100%**	**20.2**	**100%**	**20.7**	**100%**	**144.8**	**100%**

Figure 1: Adult cancer specialist nurse workforce, areas of practice, age, number of filled posts, NI 2021

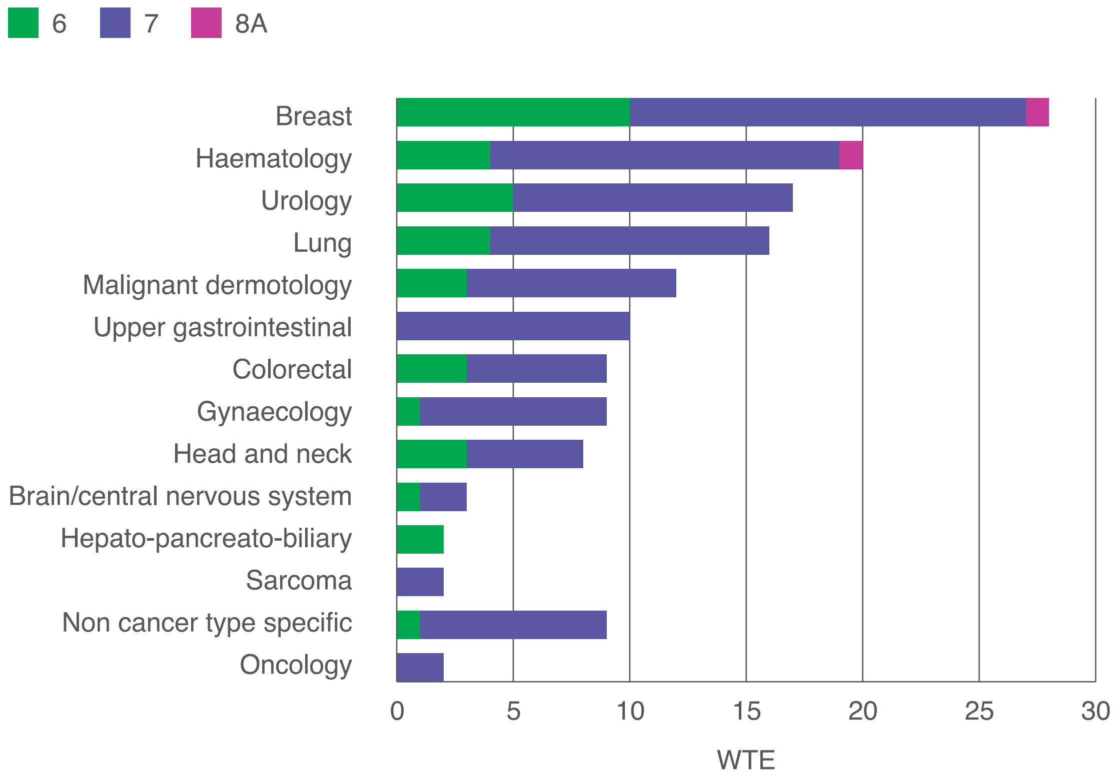


17 posts (12%) also reported a secondary area of practice where the post holder delivers care for at least 25% of their patient facing time. These secondary areas of practice, and the associated numbers of posts, are provided below.

Table 22: Adult cancer specialist nurse workforce, secondary areas of practice, number of posts, NI 2021

Secondary area of practice	Number of posts	Percentage
Urology	3	2%
Colorectal	3	2%
Not cancer type specific	3	2%
Lung	3	2%
Gynaecology	2	1%
Head and neck	1	1%
Brain/central nervous system	1	1%
Malignant dermatology	1	1%
Not applicable (one area of practice only)	148	90%
Total	**165**	**100%**

Figure 2: Adult cancer specialist nurse workforce, AfC banding by area of practice, WTE, NI 2021



1.2.11 Cancer clinical specialist nurse caseloads

This section focuses on '**clinical nurse specialists**' these roles function as key workers for cancer patients but have a variety of job titles (Clinical Nurse Specialist, Cancer Nurse Specialist and Nurse Specialist). This group includes nurses working in acute oncology services and are included in 'not cancer type specific' area of practice.

While there are many roles who support patients with cancer, cancer Clinical Nurse Specialists (CNSs) play an important role in the management of individual patients as their key worker[17]. Through the NI cancer strategy the intention is that every cancer patient should have access to a cancer clinical nurse specialist. This section summarises the theoretical caseloads that the adult clinical nurse specialists currently experience in their area of practice.

Incidence and prevalence 2019 data has been sourced from the NI cancer registry. This is the most recent published data. Please see Appendix A for details in methodology.

The ratio of cancer incidence to adult clinical nurse specialist WTE varied by area of practice, from 139.0 new cases per WTE for urology to 53.5 for Sarcoma.

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[17] A Cancer Strategy for Northern Ireland 2021-2031, Department of Health NI. Accessed January 2022.

Table 23: Adult cancer specialist nurse workforce, ratio of cancer incidence to cancer clinical nurse specialist WTE by area of practice, NI 2021

Area of practice	Clinical nurse specialists* WTE	Percentage of all adult cancer specialist nurses WTE**	Incidence[18]	Ratio incidence to WTE posts
Breast	21.3	77%	1,685	79.1
Urology	14.5	87%	2,020	139.0
Lung	14.1	93%	1,353	95.9
Haematology	12.9	62%	739	57.4
Malignant dermatology†	9.5	85%	410	43.1
Colorectal	9.4	100%	1,222	130.0
Head and neck	8.1	100%	551	67.6
Gynaecology	7.6	88%	593	78.0
Upper gastrointestinal***	9.3	77%	916	98.9
Brain/central nervous system	2.6	100%	163	63.7
Sarcoma	2.0	100%	107	53.5
Not cancer type specific	8.1	91%	N/A	N/A
Oncology	1.8	100%	N/A	N/A
Total	**121.2**	**84%**	**9,759**	**80.5**

* Clinical nurse specialists = Clinical nurse specialists, cancer nurse specialists, nurse specialists.

** Adult cancer specialist nurses = cancer clinical nurse specialists + nurse practitioners.

*** In this analysis: upper gastrointestinal = upper gastrointestinal + hepato-pancreato-biliary.

† Please note that dermatology cancer clinical nurse specialists will support both malignant and some non-melanoma skin cancer patients. It is estimated by NI Public Health Agency that 20% of non-melanoma skin cancer patients require the support of clinical nurse specialists. These additional non-melanoma patients are not included in this calculation.

Across HSCTs, the ratio of cancer incidence to cancer clinical specialist nurse WTE was highest in Northern trust (152.5 new cases per WTE) and lowest in Belfast trust (47.4).

NB. Incidence data is based on the locality of patient regardless of where they are treated. The Belfast trust low incidence to WTE ratio does not reflect the demand they meet. As a tertiary cancer centre, they will deliver additional care for patients with complex need from the catchments of other trusts.

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[18] Cancer incidence, survival, mortality and prevalence by cancer type. 2019 data by site. Northern Ireland Cancer Registry. Accessed October 2021.

Table 24: Adult cancer specialist nurse workforce, ratio of cancer incidence to clinical nurse specialist WTE by HSCT, NI 2021

HSCT	Clinical nurse specialist* WTE	Percentage of all adult cancer specialist nurses** WTE	Incidence	Ratio incidence to WTE posts
Belfast	40.8	74%	1,934	47.4
Northern	16.9	88%	2,572	152.5
South Eastern	22.3	80%	1,972	88.6
Southern	20.6	95%	1,831	88.9
Western	20.7	100%	1,551	75.1
Total	**121.2**	**84%**	**9,860**	**81.4**

* Clinical nurse specialist = Clinical Nurse Specialists, Cancer Nurse Specialists, Nurse Specialists.

** Adult cancer specialist nurses = cancer clinical nurse specialists + nurse practitioners.

The ratio of 5-year cancer prevalence to WTE posts was highest for Urology (512.4), Colorectal (393.9) and Breast (346.8).

Table 25: Adult cancer specialist nurse workforce, ratio of 5-year prevalence to clinical nurse specialist WTE by area of practice, NI 2021

Area of practice	Clinical nurse specialists* WTE	Percentage of all adult cancer specialist nurses** WTE	5-year prevalence[19]	Ratio prevalence to WTE posts
Breast	21.3	77%	7,386	346.8
Urology	14.5	87%	7,447	512.4
Lung	14.1	93%	1,855	131.5
Haematology	12.9	62%	2,940	228.3
Malignant dermatology†	9.5	85%	1,748	183.6
Colorectal	9.4	100%	1,264	393.9
Head and neck	8.1	100%	1,706	209.4
Gynaecology	7.6	88%	3,703	264.2
Upper gastrointestinal***	9.3	77%	2,008	136.5
Brain/central nervous system	2.6	100%	270	105.5
Sarcoma	2.0	100%	313	156.5
Not cancer type specific	8.1	91%	N/A	N/A
Oncology	1.8	100%	N/A	N/A
Total	**121.2**	**84%**	**30,640**	**252.8**

* Clinical nurse specialist = Clinical Nurse Specialists, Cancer Nurse Specialists, Nurse Specialists.

** Adult cancer specialist nurses = cancer clinical nurse specialists + nurse practitioners.

*** In this analysis: upper gastrointestinal = upper gastrointestinal + hepato-pancreato-biliary.

† Please note that dermatology cancer clinical nurse specialists will support both malignant and some non-melanoma skin cancer patients. It is estimated by NI Public Health Agency that 20% of non-melanoma skin cancer patients require the support of clinical nurse specialists. These additional non-melanoma patients are not included in this calculation.

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[19] Cancer incidence, survival, mortality and prevalence by cancer type. 5-year prevalence refers to patients diagnosed in 2015–2019 who were alive at the end of 2019. Northern Ireland Cancer Registry. Accessed October 2021. (Patients are included only once using their most recent diagnosis of this cancer type.)

1.2.12 Qualifications

The three most common qualifications for adult cancer specialist nurses (including clinical nurse specialists and practitioners) in post are BSc Nursing (91%, 142 filled posts), Advanced Communications Skills training (74%, 116 filled posts) and Postgraduate Diploma in Specialist Practice – Cancer Care Oncology (51%, 80 filled posts). Thirteen other qualification types are held by adult cancer specialist nurses in post.

Table 26: Adult cancer specialist workforce, number and percentage of qualifications and training, filled posts, NI 2021

	Number of filled posts with qualification	Percentage filled posts with qualification
Number of filled posts – totals	**156**	**100%**
Qualifications		
BSc nursing/other health-related subject	142	91%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	80	51%
Health Assessment and Clinical Reasoning	79	51%
Diploma in Nursing	65	42%
Non-Medical Prescribing Qualification V300	64	41%
Training in Radiotherapy Nursing	23	15%
Masters in Professional Nursing	14	9%
Postgraduate Diploma in Specialist Practice – Palliative Care	10	6%
Advanced Methods in Research and Development in Health and Social Care	8	5%
MSc Advanced Nursing Practice (or other relevant programme)	6	4%
PhD	2	1%
Training		
Advanced Communications Skills training	116	74%
PICC training (Central Venous Access Devices competency assessment)	77	49%
Chemotherapy Competency*	63	40%
Trained in eHNA** within the last 18 months	58	37%
Sage and Thyme Communication Skills training	47	30%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

** Electronic Holistic Needs Assessment.

Overall, a greater proportion of AfC band 7 compared to band 6 posts held qualifications in each of the areas listed; with the greatest difference seen for Health Assessment and Clinical Reasoning, Postgraduate Diploma in Specialist Practice – Cancer Care Oncology, and Advanced Communications Skills training. The exception is being trained in eHNA within the last 18 months, where just over half of band 6 (53%) were trained compared with a third of band 7 (33%) posts.

Table 27: Adult cancer specialist workforce, number and percentage of qualifications and training, filled posts, Agenda for Change (AfC) banding, NI 2021

	Number of filled posts with qualifications				Percentage filled posts with qualifications
AfC band	**6**	**7**	**8A**	**All**	**All**
Number of filled posts – totals	**38**	**116**	**2**	**156**	**100%**
Qualifications					
BSc in Nursing or other health-related subject	33	107	2	142	91%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	14	65	1	80	51%
Health Assessment and Clinical Reasoning	2	75	2	79	51%
Diploma in Nursing	10	54	1	65	42%
Non-Medical Prescribing Qualification V300	0	63	1	64	41%
Training in Radiotherapy Nursing	4	18	1	23	15%
Masters in Professional Nursing	2	11	1	14	9%
Postgraduate Diploma in Specialist Practice – Palliative Care	2	8	0	10	6%
Advanced Methods in Research and Development in Health and Social Care	0	7	1	8	5%
MSc Advanced Nursing Practice or relevant programme	0	5	1	6	4%
PhD	0	2	0	2	1%
Training					
Advanced Communications Skills training	26	88	2	116	74%
PICC training (Central Venous Access Devices competency assessment)	19	57	1	77	49%
Chemotherapy Competency*	14	48	1	63	40%
Trained in eHNA** within the last 18 months	20	38	0	58	37%
Sage and Thyme Communication Skills training	9	38	0	47	30%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

** Electronic Holistic Needs Assessment.

Table 28a: Adult cancer specialist workforce, number and percentage of qualifications and training, filled posts, areas of practice, NI 2021

Area of practice	Qualifications									
	Number of filled posts (total)	BSc in Nursing or other health-related subject	Health Assessment and Clinical Reasoning	Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	Non-Medical Prescribing Qualification V300	Diploma in Nursing	Masters in Professional Nursing	Postgraduate Diploma in Specialist Practice – Palliative Care	Advanced Methods in Research and Development in Health and Social Care	MSc Advanced Nursing Practice or relevant programme
Brain/central nervous system	2	2	1	1	0	0	1	0	0	0
Breast	30	27	7	12	5	12	0	0	0	1
Colorectal	10	10	3	7	1	4	1	1	1	0
Gynaecology	8	7	4	5	4	5	1	0	0	0
Haematology	23	23	17	14	17	11	5	1	1	2
Head and neck	9	9	2	6	2	3	0	0	1	0
Hepato-pancreato-biliary	3	0	0	0	0	2	0	0	0	0
Lung	17	16	11	6	8	5	1	6	0	1
Malignant dermatology	12	12	9	6	5	2	1	0	1	1
Not cancer type specific	9	8	5	7	4	3	2	0	1	0
Oncology	2	2	1	1	1	1	1	0	1	0
Sarcoma	3	1	1	1	0	3	0	0	0	0
Upper gastrointestinal	11	9	9	7	8	8	0	1	0	0
Urology	17	16	9	7	9	6	1	1	2	1
Total	**156**	**142**	**79**	**80**	**64**	**65**	**14**	**10**	**8**	**6**
Percentage	100%	91%	51%	51%	41%	42%	9%	6%	5%	4%

Table 28b: Adult cancer specialist workforce, number and percentage of qualifications and training, filled posts, areas of practice, NI 2021

Area of practice	Number of filled posts (total)	Qualification		Training				
		Training in Radiotherapy Nursing	PhD	PICC training*	Advanced Communications Skills training	Chemotherapy Competency**	Trained in eHNA*** within the last 18 months	Sage and Thyme Communication Skills training
Brain/central nervous system	2	0	0	2	1	0	0	2
Breast	30	1	0	10	24	11	10	5
Colorectal	10	1	0	5	8	3	4	5
Gynaecology	8	1	0	3	8	2	4	2
Haematology	23	3	0	17	16	20	6	6
Head and neck	9	2	1	4	7	1	6	3
Hepato-pancreato-biliary	3	1	0	1	1	1	3	1
Lung	17	1	0	8	13	3	4	4
Malignant dermatology	12	1	0	3	9	1	3	6
Not cancer type specific	9	3	0	9	5	9	1	2
Oncology	2	1	0	2	1	2	0	1
Sarcoma	3	0	0	0	2	1	3	0
Upper gastrointestinal	11	4	0	7	8	6	5	5
Urology	17	4	1	6	13	3	9	5
Total	**156**	**23**	**2**	**77**	**116**	**63**	**58**	**47**
%	100%	15%	1%	49%	74%	40%	37%	30%

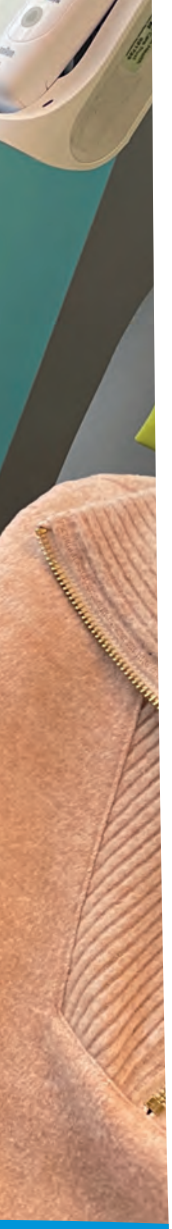
* Central Venous Access Devices competency assessment.

** Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

*** Electronic Holistic Needs Assessment.

2. ADULT CHEMOTHERAPY NURSES

This section describes the adult chemotherapy nurse workforce in Northern Ireland (NI). These nurses were on Agenda for Change (AfC) bands 5 to 7 and spend over 50% of their time directly supporting adults living with cancer. The census includes nurses who deliver cytotoxic drugs and provide adult cancer patients with advice, education and support to ensure that the risks and toxicities were minimised. Full details on inclusion and exclusion criteria can be found in Appendix B.



Based on the data returned by the five trusts, there were 266 (238.3 WTE) adult chemotherapy nurse posts in NI at the time of the census. This number includes both filled and vacant posts, as well as posts where data is not known. 65% (172 posts) of posts were full-time and 35% (94 posts) were part-time.

2.1 Job title

Adult chemotherapy nurses have a range of job titles, with the largest proportion working as Staff Nurses (62%, 150.4 WTE).

Table 29: Chemotherapy nurse workforce, job titles, number of posts, NI 2021

Job title	Number of posts	Percentage	WTE
Staff Nurse	164	62%	150.4
Clinical Staff Nurse	46	17%	36.4
Chemotherapy Nurse	19	7%	17.0
Deputy Sister	16	6%	15.6
Sister	8	3%	7.8
Unknown	7	3%	5.3
Chemotherapy Sister	4	2%	4.0
Deputy Charge Nurse	1	0%	1
Practice Education Development Nurse	1	0%	0.8
Total	**266**	**100%**	**238.3**

2.2 Age

The census showed that 30–39 was the most common age group among adult chemotherapy nurses at 36% (87 filled posts), closely followed by under 30 at 30% (72 posts filled).

Table 30: Chemotherapy nurse workforce by age group, number of filled posts, NI 2021

Age group	Number of posts	Percentage
Under 30	72	30%
30–39	87	36%
40–49	46	19%
50–59	34	14%
60 and over	4	2%
Total	**243**	**100%**
Vacant	23	

Four out of five HSCTs (South Eastern, Northern, Western, Southern) had 30–39 as the most common age group for adult chemotherapy nurses. For the remaining HSCT, the largest proportion of adult chemotherapy nurses were under 30.

Table 31: Chemotherapy nurse workforce by age, trust, number of filled posts, NI 2021

Age group	Under 30		30–39		40–49		50–59		60 and over		Total	
HSCT	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Belfast	53	35%	45	29%	33	22%	20	13%	2	1%	153	100%
South Eastern	7	26%	10	37%	6	22%	4	15%	0	0%	27	100%
Northern	7	28%	15	60%	0	0%	2	8%	1	4%	25	100%
Southern	1	5%	10	53%	4	21%	4	21%	0	0%	19	100%
Western	4	21%	7	37%	3	16%	4	21%	1	5%	19	100%
Total	**72**	**30%**	**87**	**36%**	**46**	**19%**	**34**	**14%**	**4**	**2%**	**243**	**100%**

2.3 Gender

98% (239 filled posts) of adult chemotherapy nurses were female.

Table 32: Chemotherapy nurse workforce by gender, number of filled posts, NI 2021

Gender	Number of posts	Percentage
Female	239	98%
Male	4	2%
Other	0	0%
Not disclosed	0	0%
Total	**243**	**100%**
Vacant	23	

2.4 Nationality

Where nationality was reported, 88% (215 filled posts) of adult chemotherapy nurses were from the UK.

Table 33: Chemotherapy nurse workforce by nationality, number of filled posts, NI 2021

Nationality	Number of posts	Percentage
UK	215	88%
EU*	9	4%
Rest of world	19	8%
Total	**243**	**100%**
Vacant	23	

*EU is likely to include some staff who identify as Irish.

2.5 Part-time roles

The majority of adult chemotherapy nurses were in full-time posts at 65% (172 filled posts). This ranged from 74% (14 filled posts) in Western Trust to 57% (13 filled posts) in Southern Trust. Just over a third of adult chemotherapy nurses were in part-time posts (94 filled posts).

Table 34: Chemotherapy nurse workforce, full-time/part-time (including vacancies) by HSCT, number of posts, NI 2021

	Full-time		Part-time		Total	
HSCT	**N**	**%**	**N**	**%**	**N**	**%**
Belfast	111	65%	60	35%	171	100%
South Eastern	18	67%	9	33%	27	100%
Northern	16	62%	10	38%	26	100%
Southern	13	57%	10	43%	23	100%
Western	14	74%	5	26%	19	100%
Total	**172**	**65%**	**94**	**35%**	**266**	**100%**

2.6 Vacancy rates

The majority of adult chemotherapy nurse posts were filled (243) and 23 reported as vacant. The overall vacancy rate for adult chemotherapy nurses was 8.6%. This vacancy rate was higher for Oncology only, at 14%, compared to Haematology only or Both Haematology and Oncology at 5.7%, and 5.9% respectively.

Table 35: Chemotherapy nurse workforce by area of practice, vacancy rates, number of posts, NI 2021

Area of practice	Filled	Vacant	Vacancy rate
Oncology only	80	13	14.0%
Both Haematology and Oncology	83	5	5.7%
Haematology only	80	5	5.9%
Grand total	**156**	**9**	**5.5%**

Table 36: Chemotherapy nurse workforce by HSCT, vacancy rates, number of posts, NI 2021

HSCT	Filled	Vacant	Vacancy rate
Belfast	153	18	10.5%
South Eastern	27	0	0.0%
Northern	25	1	3.8%
Southern	19	4	17.4%
Western	19	0	0.0%
Total	**243**	**23**	**8.6%**

2.7 Areas of practice

Adult chemotherapy nurses were roughly evenly split between the three areas of practice: Oncology only at 35%, (82.8 WTE), Both Haematology and Oncology at 33% (79.4 WTE), and Haematology only at 32% (76.0 WTE).

Table 37: Chemotherapy nurse workforce, area of practice, WTE, NI 2021

Area of practice	WTE	Percentage
Oncology only	82.8	35%
Both Haematology and Oncology	79.4	33%
Haematology only	76.0	32%
Total	**238.3**	**100%**

2.8 Agenda for Change (AfC) banding

Over two-thirds (164.2 WTE) of adult chemotherapy nurses were at AfC band 5. The AfC banding profile varies between HSCTs; Southern Trust has the highest proportion of posts at band 5 at 84% (17.0 WTE), Belfast Trust has the highest proportion of posts at band 6 at 32% (49.2 WTE), and Northern Trust has the highest proportion of posts at band 7 at 8% (1.8 WTE).

Table 38: Chemotherapy nurse workforce, AfC Banding, WTE, NI 2021

AfC band	WTE	Percentage
5	164.2	69%
6	64.3	27%
7	9.8	4%
Total	**238.3**	**100%**

Table 39: Chemotherapy nurse workforce by HSCT, AfC banding, WTE, NI 2021

	AfC band 5		AfC band 6		AfC band 7		Total	
HSCT	**WTE**	**Percentage**	**WTE**	**Percentage**	**WTE**	**Percentage**	**WTE**	**Percentage**
Belfast	99.0	65%	49.2	32%	5.0	3%	153.2	100%
South Eastern	18.2	75%	5.2	21%	1.0	4%	24.4	100%
Northern	15.5	68%	5.6	24%	1.8	8%	22.9	100%
Southern	17.0	84%	2.3	11%	1.0	5%	20.3	100%
Western	14.4	83%	2.0	11%	1.0	6%	17.4	100%
Total	**164.2**	**69%**	**64.3**	**27%**	**9.8**	**4%**	**238.3**	**100%**

2.9 Affiliation

Practically all (99%) the filled adult chemotherapy nurses have no affiliation to a charity in their job title. Only 0.8 WTE have Macmillan in the job title and 1.0 WTE of vacant adult chemotherapy nurse posts have another charity.

Table 40: Chemotherapy nurse workforce, post affiliations, NI 2021

	Filled		Vacant		Total	
Affiliation	**WTE**	**Percentage**	**WTE**	**Percentage**	**WTE**	**Percentage**
It has no affiliations in the job title	215.0	100%	21.5	96%	236.5	99%
It has another charity in the job title	0	0%	1.0	4%	1.0	0%
It has Macmillan in the job title	0.8	0%	0	0%	0.8	0%
Total	**215.8**	**100%**	**22.5**	**100%**	**238.3**	**100%**

2.10 Setting

The majority (72%) of adult chemotherapy WTEs are located in cancer centres. Adult chemotherapy nurses in cancer units (26% of all WTE) deliver care in a day care or day unit location.

Table 41: Chemotherapy nurse workforce, settings and main locations of care, WTE, NI 2021

	Main location of care – WTE		
Setting	**Day care or day unit**	**Inpatient**	**Total**
Cancer centre	93.5	77.9	171.5
Cancer unit	61.2	0	61.2
Non-cancer specific setting	0	5.7	5.7
Total	**154.8**	**83.6**	**238.3**

2.11 Qualifications

The three most common qualifications for adult chemotherapy nurses in post are PICC training (96%, 234 filled posts). Chemotherapy Competency (88%, 213 filled posts) and BSc in Nursing or other health-related subject (85%, 205 filled posts). Nine other qualification types are held by adult chemotherapy nurses in post. Tables 42–44 provide details.

Table 42: Chemotherapy nurse workforce, number and percentage of qualifications and training, filled posts, NI 2021

	Number of filled posts with qualification	Percentage filled posts with qualification
Number of filled posts – totals	243	100%
Qualifications		
BSc in Nursing or other health-related subject	206	85%
Diploma in Nursing	55	23%
Training in Radiotherapy Nursing	15	6%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	14	6%
Health Assessment and Clinical Reasoning	3	1%
MSc Advanced Nursing Practice or relevant programme	2	1%
Postgraduate Diploma in Specialist Practice – Palliative Care	1	0%
Non-Medical Prescribing Qualification V300	1	0%
Masters in Professional Nursing	0	0%
PhD	0	0%
Advanced Methods in Research and Development in Health and Social Care	0	0%
Training		
PICC training (Central Venous Access Devices competency assessment)	234	96%
Chemotherapy Competency*	213	88%
Advanced Communications Skills training	18	7%
Sage and Thyme Communication Skills training	15	6%
Trained in eHNA** within the last 18 months	0	0%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

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Table 43: Chemotherapy nurse workforce, number and percentage of qualifications and training, filled posts, AfC

	Number of filled posts with qualifications, AfC band				Percentage filled posts with qualifications
AfC band	**5**	**6**	**7**	**All**	**All**
Number of filled posts – totals	159	74	10	243	100%
Qualifications					
BSc in Nursing or other health-related subject	142	55	9	206	85%
Diploma in Nursing	27	26	2	55	23%
Training in Radiotherapy Nursing	10	3	2	15	6%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	3	7	4	14	6%
Health Assessment and Clinical Reasoning	1	1	1	3	1%
MSc Advanced Nursing Practice or relevant programme	1	1	0	2	1%
Postgraduate Diploma in Specialist Practice – Palliative Care	0	1	0	1	0%
Non-Medical Prescribing Qualification V300	0	0	1	1	0%
Masters in Professional Nursing	0	0	0	0	0%
PhD	0	0	0	0	0%
Advanced Methods in Research and Development in Health and Social Care	0	0	0	0	0%
Training					
PICC training (Central Venous Access Devices competency assessment)	150	74	10	234	96%
Chemotherapy Competency**	131	73	9	213	88%
Advanced Communications Skills training	7	8	3	18	7%
Sage and Thyme Communication Skills training	8	5	2	15	6%
Trained in eHNA** within the last 18 months	0	0	0	0	0%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

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Table 44: Chemotherapy nurse workforce, number and percentage of qualifications and training, filled posts, area of practice, NI 2021

Area of practice	Number of filled posts with qualifications, area of practice				Total percentage
	Both Haematology and Oncology	Haematology only	Oncology only	Total	
Number of filled posts (total)	83	80	80	243	100%
Qualifications					
BSc in Nursing or other health-related subject	71	66	69	206	85%
Diploma in Nursing	23	16	16	55	23%
Training in Radiotherapy Nursing	8	1	6	15	6%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	7	3	4	14	6%
Health Assessment and Clinical Reasoning	2	0	1	3	1%
MSc Advanced Nursing Practice or relevant programme	0	0	2	2	1%
Postgraduate Diploma in Specialist Practice – Palliative Care	0	1	0	1	0%
Non-Medical Prescribing Qualification V300	1	0	0	1	0%
Masters in Professional Nursing	0	0	0	0	0%
PhD	0	0	0	0	0%
Advanced Methods in Research and Development in Health and Social Care	0	0	0	0	0%
Training					
PICC training (Central Venous Access Devices competency assessment)	81	75	78	234	96%
Chemotherapy Competency*	72	68	73	213	88%
Advanced Communications Skills training	14	4	0	18	7%
Sage and Thyme Communication Skills training	7	6	2	15	6%
Trained in eHNA** within the last 18 months	0	0	0	0	0%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

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3. CHILDREN, TEENAGER AND YOUNG ADULT CANCER NURSES

This section describes the children, teenager and young adult cancer nurse workforce in Northern Ireland (NI). These nurses were on Agenda for Change (AfC) bands 5 to 7, with over half (54%, 21 WTE) on AfC band 5.

Based on the data returned by the five trusts, there were 48 (38.5 WTE) children, teenager and young adult cancer posts in NI at the time of the census. This number includes both filled and vacant posts. 54% (26 posts) of posts were full-time and 46% (22 posts) were part-time.

3.1 Job title

There are six job titles for children, teenager and young adult cancer nurses, with the largest population working as Paediatric Haematology and Oncology Nurses.

Table 45: Children, teenager and young adult cancer nurse workforce, job titles, number of posts, NI 2021

Job title	Number of posts	Percentage	WTE
Paediatric Haematology and Oncology Nurse	23	48%	21.0
Deputy Sister	9	19%	7.4
Teenage and Young Adult Clinical Nurse Specialist	8	17%	3.5
Paediatric Haematology and Oncology Nurse Specialist	5	10%	4.1
Clinical Research Nurse	2	4%	1.5
Sister	1	2%	1.0
Total	**48**	**100%**	**38.5**

3.2 Age

The census showed that 30–39 was the most common age group among children, teenager, and young adult cancer nurses, with 39% (17 filled posts) in this group. This was followed by under 30, with 34% (15 filled posts) in this category.

Table 46: Children, teenager and young adult cancer nurse workforce by age group, number of filled posts, NI 2021

Age group	Number of posts	Percentage
Under 30	15	34%
30–39	17	39%
40–49	8	18%
50–59	3	7%
60 and over	1	2%
Total	**44**	**100%**
Vacant	4	

Table 47: Children, teenager and young adult cancer nurse workforce by age, trust, number of filled posts, NI 2021

Age group	Under 30		30–39		40–49		50–59		60 and over		Total	
HSCT	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Belfast	15	38%	15	38%	6	15%	2	5%	1	3%	39	100%
Southern	0	0%	2	100%	0	0%	0	0%	0	0%	2	100%
Western	0	0%	0	0%	0	0%	1	100%	0	0%	1	100%
Northern	0	0%	0	0%	1	100%	0	0%	0	0%	1	100%
South Eastern	0	0%	0	0%	1	100%	0	0%	0	0%	1	100%
Total	**15**	**34%**	**17**	**39%**	**8**	**18%**	**3**	**7%**	**1**	**2%**	**44**	**100%**

3.3 Gender

95% (42 filled posts) of children, teenager and young adult cancer nurses were female.

Table 48: Children, teenager and young adult cancer nurse workforce by gender, number of filled posts, NI 2021

Gender	Number of posts	Percentage
Female	42	95%
Male	2	5%
Other	0	0%
Not disclosed	0	0%
Total	**44**	**100%**
Vacant	4	

3.4 Nationality

89% (39 filled posts) of children, teenager and young adult cancer nurses were from the UK.

Table 49: Children, teenager and young adult cancer nurse workforce by nationality, number of filled posts, NI 2021

Nationality	Number of posts	Percentage
UK	39	89%
EU*	4	9%
Rest of world	1	2%
Total	**44**	**100%**
Vacant	4	

*EU is likely to include some staff who identify as Irish.

3.5 Part-time roles

Overall, just under half (46%, 22 filled posts) of children, teenager and young adult cancer nurses were part-time. In all HSCTs except Belfast Trust, 100% of the workforce were part-time. In Belfast, 60% (26 filled posts) were full-time. It should be noted that 5 of the part-time post holders in the table below are also counted as part-time posts in the adult cancer care workforce section, as these post-holders also work with adults.

Table 50: Children, teenager and young adult cancer nurse workforce, full-time/part-time by HSCT, number of posts, NI 2021

	Full-time (37.5 hours per week)		Part-time (<37.5 hours per week)		Total	
HSCT	**N**	**%**	**N**	**%**	**N**	**%**
Belfast	26	60%	17	40%	43	100%
Southern	0	0%	2	100%	2	100%
Western	0	0%	1	100%	1	100%
Northern	0	0%	1	100%	1	100%
South Eastern	0	0%	1	100%	1	100%
Total	**26**	**54%**	**22**	**46%**	**48**	**100%**

3.6 Vacancy rates

The majority of children, teenager and young adult cancer nurses were filled with only 4 posts reported as vacant, compared to 44 that were filled. The overall vacancy rate for children, teenager and young adult cancer nurses was 8.3%. Belfast was the only HSCT in which there was a vacancy rate higher than 0%.

Table 51: Children, teenager and young adult cancer nurse workforce by area of practice, vacancy rates, number of posts, NI 2021

Area of practice	Filled	Vacant	Vacancy rate
Not cancer type specific	40	4	9.1%
Bone marrow transplant	1	0	0.0%
Solid tumour	1	0	0.0%
Leukaemia	1	0	0.0%
Neuro-oncology	1	0	0.0%
Total	**44**	**4**	**8.3%**

Table 52: Children, teenager and young adult cancer nurse workforce by HSCT, vacancy rates, number of posts, NI 2021

HSCT	Filled	Vacant	Vacancy rate
Belfast	39	4	9.3%
Southern	2	0	0.0%
Western	1	0	0.0%
Northern	1	0	0.0%
South Eastern	1	0	0.0%
Total	**44**	**4**	**8.3%**

3.7 Areas of practice

90% (34.6 WTE) of children, teenager and young adult cancer nurses do not have a specific area of practice. The remaining children, teenager and young adult cancer nurses work fairly evenly across five areas of practice.

Table 53: Children, teenager and young adult cancer nurse workforce, area of practice, WTE, NI 2021

Area of practice	WTE	Percentage
Not cancer type specific	34.6	90%
Bone marrow transplant	1.0	3%
Solid tumour	1.0	3%
Leukaemia	1.0	3%
Neuro-oncology	0.9	2%
Total	**38.5**	**100%**

3.8 Agenda for Change (AfC) banding

Just over half (55%, 21 WTE) of children, teenager and young adult cancer posts were at AfC band 5. 24% of children, teenager and young adult cancer nurses were at band 6 (9.1 WTE) and 22 % were at band 7 (8.4 WTE).

Table 54: Children, teenager and young adult cancer nurse workforce, AfC banding, WTE, NI 2021

AfC band	WTE	Percentage
5	21.0	55%
6	9.1	24%
7	8.4	22%
Total	**38.5**	**100%**

Table 55: Children, teenager and young adult cancer nurse workforce, AfC banding by trust, WTE, NI 2021

	AfC band 5		AfC band 6		AfC band 7		Total	
HSCT	**WTE**	**Percentage**	**WTE**	**Percentage**	**WTE**	**Percentage**	**WTE**	**Percentage**
Belfast	21.0	57%	8.9	24%	7.0	19%	36.9	100%
Southern	0	0%	0.2	50%	0.2	50%	0.4	100%
Western	0	0%	0	0%	0.4	100%	0.4	100%
South Eastern	0	0%	0	0%	0.4	100%	0.4	100%
Northern	0	0%	0	0%	0.4	100%	0.4	100%
Total	**21.0**	**55%**	**9.1**	**24%**	**8.4**	**22%**	**38.5**	100%

3.9 Affiliation

90% (31.3 WTE) of filled posts for children, teenager and young adult cancer nurses have no affiliation for Macmillan or another charity in their job title, and 100% (3.5 WTE) of vacancies for children, teenager and young adult cancer nurses have no affiliations in their job title.

Table 56: Children, teenager and young adult cancer nurse workforce, post affiliations, NI 2021

	Filled		Vacant		Total	
Affiliation	**WTE**	**Percentage**	**WTE**	**Percentage**	**WTE**	**Percentage**
It has no affiliations in the job title	31.3	90%	3.5	100%	34.8	90%
It has another charity in the job title	3.7	10%	0	0%	3.7	10%
It has Macmillan in the job title	0	0%	0	0%	0	0%
Total	**35.0**	**100%**	**3.5**	**100%**	**38.5**	**100%**

3.10 Setting

58% of the children teenager and young adult cancer nurse workforce (22.2 WTE) works in an inpatient location. 97% (37.3 WTE) work in a cancer centre.

Table 57: Children, teenager and young adult cancer nurse workforce, settings and main locations of care, WTE, NI 2021

	Main location of care – WTE			
Setting	**Day care or day unit**	**Hospital outpatient**	**Inpatient**	**Total**
Cancer centre	11.8	3.4	22.2	37.3
Cancer unit	1.2	0	0	1.2
Total	**12.9**	**3.4**	**22.2**	**38.5**

3.11 Qualifications

The three most common qualifications for children, teenager and young adult cancer nurses in post are BSc in Nursing or other health-related subject (98%, 43 filled posts), PICC training (95%, 42 filled posts), and Chemotherapy Competency (77%, 34 filled posts). Ten other qualification types are held by children, teenager and young adult cancer nurses in post.

Table 58: Children, teenager and young adult cancer nurse workforce, number and percentage of qualifications and training, filled posts, NI 2021

	Number of filled posts with qualification	Percentage filled posts with qualification
Qualifications		
BSc in Nursing or other health-related subject	43	98%
MSc modules in teenager and young adult cancer care	7	16%
Diploma in Nursing	5	11%
Health Assessment and Clinical Reasoning	5	11%
Haematology modules from Queen’s University Belfast	5	11%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	4	9%
Non-Medical Prescribing Qualification V300	4	9%
Masters in Professional Nursing	1	2%
Postgraduate Diploma in Specialist Practice – Palliative Care	0	0%
MSc Advanced Nursing Practice or relevant programme	0	0%
PhD	0	0%
Advanced Methods in Research and Development in Health and Social Care	0	0%
Training in Radiotherapy Nursing	0	0%
Training		
PICC training (Central Venous Access Devices competency assessment)	42	95%
Chemotherapy Competency*	34	77%
Advanced Communications Skills training	6	14%
Sage and Thyme Communication Skills training	3	7%
Trained in eHNA** within the last 18 months	1	2%
Cancer survivorship module	0	0%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

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Table 59: Children, teenager and young adult cancer nurse workforce, number and percentage of qualifications and training, filled posts, AfC band, NI 2021

Qualification	Number of filled posts with qualifications, AfC band				Percentage filled posts with qualifications
AfC band	**5**	**6**	**7**	**All**	**All**
Number of filled posts – totals	22	9	13	44	100%
Qualifications					
BSc in Nursing or other health-related subject	22	8	13	43	98%
MSc modules in teenager and young adult cancer care	1	2	4	7	16%
Diploma in Nursing	0	2	3	5	11%
Health Assessment and Clinical Reasoning	0	0	5	5	11%
Haematology modules from Queen's University Belfast	0	2	3	5	11%
Postgraduate Diploma in Specialist Practice – Cancer Care Oncology	0	1	3	4	9%
Non-Medical Prescribing Qualification V300	0	0	4	4	9%
Masters in Professional Nursing	0	0	1	1	2%
Postgraduate Diploma in Specialist Practice – Palliative Care	0	0	0	0	0%
MSc Advanced Nursing Practice or relevant programme	0	0	0	0	0%
PhD	0	0	0	0	0%
Advanced Methods in Research and Development in Health and Social Care	0	0	0	0	0%
Training in Radiotherapy Nursing	0	0	0	0	0%
Training					
PICC training (Central Venous Access Devices competency assessment)	22	9	11	42	95%
Chemotherapy Competency*	13	9	12	34	77%
Advanced Communications Skills training	0	0	6	6	14%
Sage and Thyme Communication Skills training	0	1	2	3	7%
Trained in eHNA** within the last 18 months	0	0	1	1	2%
Cancer survivorship module	0	0	0	0	0%

* Please note that Chemotherapy Competency training includes both academic modules and training delivered internally by trusts.

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4. NURSING SUPPORT WORKFORCE

This section describes the cancer support workforce in Northern Ireland (NI). These individuals were on Agenda for Change (AfC) bands 3 and 4 and spend over 50% of their time directly supporting adults living with cancer. Administrative roles and band 2 roles have not been included in these numbers.

The posts captured at the time of the census include:

- **26** (22.7 WTE) **cancer support worker** roles, which were introduced in 2016 during the first Clinical Nurse Specialist (CNS) expansion to work alongside the CNS;
- **67** (60.5 WTE) **other support roles**, mostly **health care assistants** (**60** posts) within cancer services.

Full details on inclusion and exclusion criteria are in Appendix B, cancer support worker role definition can be found in Appendix C.

Based on the data returned by the five trusts, there were overall 93 cancer support workforce posts in Northern Ireland at the time of the census (83.2 WTE). This number includes both filled and vacant posts. 64% (60 posts) were full-time and 36% (34 posts) were part-time.

Additionally, Belfast Trust has band 4 link workers 4 WTE (5 posts) working to a social prescribing model of support and upskilled in undertaking holistic needs assessment. These link workers have been included in the census as supporting people living with cancer will be a part of their role, but they are not aligned to the CNS workforce and are counted within the other support roles.

All trusts also have band 3 Information and Support workers, but these have not been included in the census.

4.1 Job title

Support workers have a wide range of job titles, with the largest proportion working as Healthcare Assistants (52%, 43.9 WTE). Overall, there are 26 support worker posts (22.7 WTE) that work with adult clinical nurse specialists to deliver personalised care for people living with cancer.

Table 60: Cancer support workforce, job titles, number of posts, NI 2021

Job title	Number of posts	Percentage	WTE
Support Worker	11	12%	9.4
Clinical Nurse Specialist Support Worker	6	6%	5.5
Cancer Support Worker	9	10%	7.7
Subtotal – cancer support worker	**26**	**28%**	**22.7**
Healthcare Assistant	49	52%	43.9
Senior Healthcare Assistant	11	12%	10.6
Link Worker	5	5%	4.0
Healthcare Support Worker	2	2%	2.0
Subtotal – other support roles	**67**	**72%**	**60.5**
Total	**93**	**100%**	**83.2**

4.2 Age

The census showed that 30–39 was the most common age group among the cancer support workforce, with 37% (32 filled posts) in this group.

Table 61: Cancer support workforce by age group, number of filled posts, NI 2021

Age group	Number of posts	Percentage
Under 30	14	16%
30–39	31	37%
40–49	18	21%
50–59	18	21%
60 and over	5	6%
Total	**86**	**100%**
Vacant	7	

Table 62: Cancer support workforce by age, trust, number of filled posts, NI 2021

All roles	Under 30		30–39		40–49		50–59		60 and over		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Belfast	11	19%	20	34%	10	17%	14	24%	3	5%	58	100%
Western	2	13%	5	31%	5	31%	3	19%	1	6%	16	100%
Southern	1	25%	1	25%	1	25%	0	0%	1	25%	4	100%
Northern	0	0%	3	60%	2	40%	0	0%	0	0%	5	100%
South Eastern	0	0%	2	67%	0	0%	1	33%	0	0%	3	100%
Total	**14**	**16%**	**31**	**36%**	**18**	**21%**	**18**	**21%**	**5**	**6%**	**86**	**100%**

Cancer support workers only	Under 30		30–39		40–49		50–59		60 and over		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Western	1	14%	4	57%	2	29%	0	0%	0	0%	7	100%
Belfast	0	0%	4	80%	0	0%	1	20%	0	0%	5	100%
Northern	0	0%	3	60%	2	40%	0	0%	0	0%	5	100%
Southern	1	50%	1	50%	0	0%	0	0%	0	0%	2	100%
South Eastern	0	0%	1	100%	0	0%	0	0%	0	0%	1	100%
Total	**2**	**10%**	**13**	**65%**	**4**	**20%**	**1**	**5%**	**0**	**0%**	**20**	**100%**

4.3 Gender

90% (78 filled posts) of the cancer support workforce were female.

Table 63: Cancer support workforce by gender, number of filled posts, NI 2021

Gender	Number of posts	Percentage
Female	77	90%
Male	9	10%
Other	0	0%
Not disclosed	0	0%
Total	**86**	**100%**
Vacant	7	

4.4 Nationality

91% (79 filled posts) of the cancer support workforce were from the UK.

Table 64: Cancer support workforce by nationality, number of filled posts, NI 2021

Nationality	Number of posts	Percentage
UK	79	91%
Rest of world	4	5%
Not known	2	3%
EU*	1	1%
Total	**86**	**100%**
Vacant	7	

*EU is likely to include some staff who identify as Irish.

4.5 Part-time roles

Part-time posts were common among the cancer support workforce. However, most posts were full-time across all HSCTs.

Table 65: Cancer support workforce, full-time/part-time by HSCT, number of posts, NI 2021

	Full-time (37.5 hours per week)		Part-time (<37.5 hours per week)		Total	
HSCT	**N**	**%**	**N**	**%**	**N**	**%**
Belfast	37	60%	25	40%	62	100%
Western	13	76%	4	24%	17	100%
Southern	4	80%	1	20%	5	100%
Northern	4	67%	2	33%	6	100%
South Eastern	2	67%	1	33%	3	100%
Total	**60**	**65%**	**33**	**35%**	**93**	**100%**

4.6 Vacancy rates

Most cancer support workforce posts were filled, with only 7 posts (5.7 WTE) reported as vacant. The overall vacancy rate was 7.4.

Table 66: Cancer support workforce by area of practice, vacancy rates, number of posts, total WTE, NI 2021

All roles	Filled posts	Vacant posts	Vacancy rate	Total WTE
Oncology	32	1	3.0%	29.1
Not cancer type specific	26	5	16.1%	28.3
Haematology	18	0	0.0%	16.8
Breast	3	0	0.0%	2.5
Colorectal	1	1	50.0%	1.5
Lung	2	0	0.0%	1.5
Malignant dermatology	1	0	0.0%	1.0
Hepato-pancreato-biliary	1	0	0.0%	0.5
Gynaecology	1	0	0.0%	1.0
Upper gastrointestinal	1	0	0.0%	1.0
Total	**86**	**7**	**7.5%**	**83.2**

Cancer support workers only	Filled posts	Vacant posts	Vacancy rate	Total WTE
Not cancer type specific	8	5	38.5%	11.6
Breast	3	0	0.0%	2.5
Haematology	2	0	0.0%	2.0
Colorectal	1	1	50.0%	1.5
Lung	2	0	0.0%	1.5
Hepato-pancreato-biliary	1	0	0.0%	0.5
Upper gastrointestinal	1	0	0.0%	1.0
Malignant dermatology	1	0	0.0%	1.0
Gynaecology	1	0	0.0%	1.0
Grand total	**20**	**6**	**23.1%**	**22.7**

Vacancies were recorded in all areas except for the South Eastern trust.

Table 67: Cancer support workforce by HSCT, vacancy rates, number of posts, total WTE, NI 2021

All roles	Filled posts	Vacant posts	Vacancy rate	Total WTE
Belfast	58	4	6.5%	54.9
Western	16	1	5.9%	15.6
Southern	4	1	20.0%	5.4
Northern	5	1	16.7%	5.3
South Eastern	3	0	0.0%	2.5
Total	**86**	**7**	**7.4%**	**83.7**

Cancer support workers only	Filled posts	Vacant posts	Vacancy rate	Total WTE
Belfast	5	3	37.5%	7.0
Western	7	1	12.5%	6.8
Southern	2	1	33.3%	3.0
Northern	5	1	16.7%	5.3
South Eastern	1	0	0.0%	0.5
Total	**20**	**6**	**23.1%**	**22.7**

4.7 Areas of practice

51% (11.6 WTE) of cancer support workers were non-cancer type specific and 48% (29.1 WTE) of other support roles worked in oncology. 48% (11 WTE) of cancer support workers have an area of practice, with the main area being breast (11%, 2.5 WTE).

Table 68: Cancer support workforce, area of practice, WTE, NI 2021

Area of practice	Cancer support worker		Other support roles		Total	
	WTE	Percentage	WTE	Percentage	WTE	Percentage
Breast	2.5	11%	0	0%	2.5	3%
Colorectal	1.5	7%	0	0%	1.5	2%
Gynaecology	1.0	4%	0	0%	1.0	1%
Haematology	2.0	9%	14.8	24%	16.8	20%
Hepato-pancreato-biliary	0.5	2%	0	0%	0.5	1%
Lung	1.5	7%	0	0%	1.5	2%
Malignant dermatology	1.0	4%	0	0%	1.0	1%
Upper gastrointestinal	1.0	4%	0	0%	1.0	1%
Not cancer type specific	11.6	51%	16.6	28%	28.3	34%
Oncology	0	0%	29.1	48%	29.1	35%
Total	**22.7**	**100%**	**60.5**	**100%**	**83.2**	**100%**

4.8 Agenda for Change (AfC) banding

94% (78.9 WTE) of support workers were at AfC band 3.

Table 69: Children, teenager and young adult cancer nurse workforce, AfC banding, WTE, NI 2021

AfC band	WTE	Percentage
3	78.4	94%
4	4.8	6%
Total	**83.2**	**100%**

94% of all posts were at band 3. The AfC banding profile varies between HSCTs, with Belfast and Northern Trusts having posts at both bands 3 and 4, and other trusts having all posts at band 3.

Table 70: Cancer support workforce by HSCT, AfC banding, WTE, NI 2021

	AfC band 3		AfC band 4		Total	
HSCT	**WTE**	**%**	**WTE**	**%**	**WTE**	**%**
Belfast	50.9	93%	4.0	7%	54.9	100%
Western	15.6	100%	0	0%	15.6	100%
Southern	4.9	100%	0	0%	4.9	100%
Northern	4.5	85%	0.8	15%	5.3	100%
South Eastern	2.5	100%	0	0%	2.5	100%
Total	**78.4**	**94%**	**4.8**	**6%**	**83.2**	**100%**

4.9 Affiliation

30% (25.2 WTE) of the cancer support workforce have 'Macmillan' in their job title. Most have no affiliations in the job title.

Table 71: Cancer support workforce, post affiliations, NI 2021

	Filled		Vacant		Total	
Affiliation	**WTE**	**%**	**WTE**	**%**	**WTE**	**%**
It has no affiliations in the job title	54.5	70%	1.0	17%	55.5	66%
It has Macmillan in the job title	20.9	27%	3.7	65%	24.6	30%
It has another charity in the job title	2.0	3%	1.0	17%	3.0	4%
Total	**77.5**	**100%**	**5.7**	**100%**	**83.2**	**100%**

4.10 Setting

Just under three-quarters (61.7 WTE) of support workers are based in cancer centres; and just under a third (26 WTE) provide care as day care or in a day unit.

Table 72: Cancer support workforce, settings and main locations of care, WTE, NI 2021

	Main location of care – WTE					
Setting	**Inpatient**	**Day care or day unit**	**Hospital outpatient**	**Not known**	**Patient home**	**Total**
Cancer centre	26.5	20.3	8.5	6.5	0	61.7
Non cancer specific setting	0.5	1.8	5.3	3.0	4.0	15.1
Cancer unit	0	3.9	3.0	0	0	6.9
Total	**27.0**	**26.0**	**16.8**	**9.5**	**4.0**	**83.2**

4.11 Qualifications

Only 23% of all support workers have Sage and Thyme Communications Skills training and another 24% have been trained in eHNA within the last 18 months.

Table 73: Cancer support workforce, qualifications, filled posts, NI 2021

	Qualifications				Training			
	NVQ Level 2 (Administration or Health and Social Care)		NVQ Level 3 (Administration or Health and Social Care)		Sage and Thyme Communications Skills training		Trained in eHNA* within the last 18 months	
	N	%	N	%	N	%	N	%
Yes	46	53%	54	62%	20	23%	20	24%
No	22	26%	14	17%	60	70%	64	74%
Not known	18	21%	18	21%	6	7%	2	2%
Total	**86**	**100%**	**86**	**100%**	**86**	**100%**	**86**	**100%**
Vacant posts	7							

*Electronic Holistic Needs Assessment.

Conclusions

This census provides the latest snapshot of the cancer nursing workforce in Northern Ireland (NI) and allows mapping across locality and cancer type. A key aim in conducting this census was to feed into cancer workforce planning currently ongoing as part of the NI cancer workforce strategy development.

Overall, at the time of the census (17th September 2021), we captured 754 posts (672.4 WTE) who treat, support and manage the health concerns and wellbeing of cancer patients for more than 50% of their time.

This cancer workforce is made up of the following (for definitions of each of these groups see Appendix B):

- 165 posts in **adult cancer specialist** roles (144.8 WTE) (inclusive of cancer clinical nurse specialists and advanced practice roles)
- 67 posts in other **adult cancer care** roles (61.3 WTE)
- 115 posts in **staff nurse** roles working in adult wards delivering cancer care (106.3 WTE)
- 266 posts in **adult chemotherapy nurse** roles administering SACT (238.3 WTE)
- 48 posts in **children, teenager and young adult cancer nurse** roles (38.5 WTE),
- 93 posts in the **nursing support workforce** (83.2 WTE) with 22.7 WTE **cancer support workers** working directly with Cancer Nurse Specialists (CNS) to support people with a cancer from diagnosis and enable personalised care during treatment and into aftercare.

All cancer nurses and nursing support workforce are focused within an acute inpatient or outpatient setting. Only five link workers (band 4 community posts) deliver care within patients' homes, but they do not have a focused cancer remit.

Overall, just under 1 in 5 (19%) of the wider cancer workforce is affiliated to a charity. This increases to over 1 in 2 (56%) of clinical nurse specialists and all of the cancer support workers. 46% of the adult cancer specialist nurses are affiliated to Macmillan and 92% of the cancer support workers. 10% of all children, teenager and young adult cancer nursing posts are affiliated to a charity, all are non-Macmillan.

Part-time roles were more common for children, teenager and young adult cancer nurses (46%) compared with the adult cancer specialist workforce (41% of filled posts) and adult chemotherapy nurses (35%).

The overall vacancy rate for the cancer workforce identified through this census (8%) is lower than that for all registered Nursing and Midwifery staff in June 2021 published by the Department of Health[20] (11% for all registered Nursing and Midwifery staff). However, there is variation:

- adult cancer specialist nurses have the lowest vacancy rate at 5.5% compared with 8.6% for adult chemotherapy nurses;
- brain/central nervous system (50%) and gynaecology (12.5%) are the areas of practice with the highest vacancy rates for adult cancer clinical nurse specialists;
- Western HSC Trust has the highest vacancy rates in adult cancer specialist nurses with 16.7% of posts unfilled;
- Southern HSC Trust has the highest vacancy rates in adult chemotherapy nurses (17.4% of posts unfilled) and support workers (17%).

Whilst direct comparisons cannot be made with the data from the 2014 census as the inclusion criteria differ (please see Appendix A), it is worth noting the following points:

- the total reported specialist adult cancer nursing workforce for the Northern Ireland Cancer Census in 2014 was 57.4 WTE. This increased to 144.8 WTE in 2021;
- in 2014, 55.6 WTE had a job title of Adult Clinical Nurse Specialist (97.0% of all specialists) and in 2021, 93 WTE shared the same job title (64% of all specialists).

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[20] Northern Ireland Health and Social Care Workforce Vacancies Tables, June 2021. Department of Health NI, published 25 August 2021.

There are indications that the adult cancer specialist nursing workforce has grown since the last census. However, it is important to set this growth within the context of increased demand.

In 2019 there were 984 more new cancer cases than in 2014, (an increase of 10%). Additionally, between 2014 and 2019 an additional 6,155 people were added to the 10-year prevalence population (an increase of 15%).[21]

So, it is important to understand the ratio of new cases to each Clinical Nurse Specialist (CNS) WTE. Across all main area of practice the ratio of new cases to WTE has decreased, except for Breast where in 2014, the ratio of new cases per adult cancer clinical specialist nurse WTE (those performing a key worker role) was 75, compared with 79.1 new cases per CNS WTE in 2021. The two areas of practice showing the greatest change are:

- upper gastrointestinal cancer, a change from 365 new cases per WTE in 2014 compared with 98.9 new cases per WTE in 2021;
- urology, a change from 374 new cases per WTE in 2014 compared with 139 new cases per WTE in 2021.

Despite the improved ratios, developing the workforce and succession planning to identify the Clinical Nurse Specialists of the future needs consideration.

The census showed that 40–49 was the most common age group among adult cancer specialist nurses, (36%), whilst 30–39 was the most common age group among adult chemotherapy nurses (36%), and children, teenager and young adult cancer nurses (39%). Adult cancer specialist nurses aged 50 or over accounts for 30% of this group, while only 16% of adult chemotherapy nurses are aged 50 or over and just 9% of those supporting children, teenagers and young people.

There may be opportunities to develop nurses in adult chemotherapy and children, teenager and young adult cancer nurses into future adult cancer specialist nurses, especially the 142 band 5 nurses aged under 40.

Additionally, the 2021 census has demonstrated that there are some gaps in the qualifications held by staff in post.

Advanced communication skills can enhance the delivery of personalised care and the Department of Health in NI have committed to ensure that all health care professionals who are expected to carry out sensitive communication complete an advanced communication skills training programme[22]. However, only three-quarters (74%) of the adult cancer specialist nurses have undertaken Advanced Communications Skills training, compared with just 7% of adult chemotherapy nurses, and 14% of children, teenage and young adult cancer nurses.

It is also worth noting that just over half (51%) of adult cancer specialist nurses have achieved a Postgraduate Diploma in Specialist Practice – Cancer Care Oncology, and just over a third (37%) have been trained in eHNA within the last 18 months.

Overall, 93 (83.2 WTE) nursing support workforce posts were captured in Northern Ireland, mostly band 3 and, of these, 22.7 WTEs are cancer support workers aligned to adult cancer clinical specialist nurses. Over half of the support workforce (53%) is aged under 40 and three quarters of cancer support workers (75%) are under 40. There might be opportunity to support the career progression for these roles and grow them into band 4 roles.

Only 58% of the cancer support workers were trained in eHNA within the last 18 months and 23% had undertaken Sage and Thyme Communication Skills training.

The findings of this census point to areas for further development and contribute to the evidence base being used to understand the demand-based workforce needs of the future.

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[21] All Cancers exclude (NMSC)1993–2019. Cancer incidence, survival, mortality and prevalence. Northern Ireland Cancer Registry. Accessed October 2021.

[22] A Cancer Strategy for Northern Ireland 2021–2031. (Draft) Department of Health NI. Accessed November 2021.

Recommendations

The findings of this census demonstrate the importance of a strategic approach to ensuring cancer workforce sustainability, this is the focus of recommendations set out below. Such an approach will require a number of components, including supporting adoption of best practice, addressing training challenges, funding barriers, high vacancy rates in some areas and ensuring workforce planning can offer opportunities for career progression. Workforce planning should include a focus on skill mix and flexible working to empower the nursing and support worker professions to continue to enhance the personalised care experienced by people living with cancer. There is a need to continue to grow and develop the cancer workforce, identify talent and interest in cancer specialisation early in the nursing career, provide opportunity to release staff for training and development and support the retention of cancer nursing staff.

1. **The Department of Health should enhance career pathways to support nurses to develop skills and qualifications necessary to become specialist cancer nurses.**

   Cancer workforce planning should include a strong emphasis on the need for succession planning and developing the skills and competencies required to build and sustain the cancer clinical nurse specialist workforce. This should encompass consideration of what skills will be required to deliver the high-quality cancer care through implementing the cancer strategy. The census results show that some trusts have particularly high vacancy rates when compared within NI and with other UK jurisdictions, resolving this on a sustained basis will require a strategic approach to developing pathways to become specialist cancer nurses. There is a need to map out where cancer nurses interface with patients during their cancer pathway, what skills are required at each point and how nurses can be supported in developing these.

2. **The recommendations from this census should support Health and Social Care workforce planning to help inform training, recruitment and retention.**

   The census results demonstrate differences between trusts on the uptake of part-time working and availability of promoted posts, as well as a wide variety of training courses being undertaken by staff. A strategic approach to workforce planning will need to address workforce sustainability by ensuring there are opportunities for progression. A co-ordinated approach from commissioners, academics, services and professional bodies will support consistent and robust recruitment and training pathways.

   A workforce retention plan will require exploring opportunities for flexible working, continuing professional development and career progression. New and more flexible ways of working will be essential in ensuring the Health and Social Care Northern Ireland (HSC NI) is a modern employer and is able to keep pace with employment practices in the wider public and private sector. Finally, the nursing workforce is in general ageing[23]. More needs to be done to keep this workforce, with all the skills it has acquired, in place for longer. Flexible working initiatives may be particularly effective if they are especially attentive to those at the end of their careers.

3. **A skills mapping approach should be applied to all roles. This should include setting up regional task group on career progression and training opportunities.**

   Census results demonstrate considerable variation in the training undertaken within some parts of the cancer workforce. A skills mapping approach should focus first on skills rather than roles, and consider how to build necessary skills, knowledge

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[23] Nursing workforce not growing fast enough to meet demand warns RCN, May 2021, Royal College of Nursing. Accessed November 2021.

and experience to deliver high-quality and personalised care for people with cancer. This should also provide a basis for a flexible workforce, moving across traditional boundaries. Addressing this should form part of the focus of skills mapping alongside development and alignment of competency frameworks.

We captured 93 nursing support posts in NI to support people with cancer alongside clinical professionals. These roles are utilised in a variety of ways to meet patient needs and a strategic approach to building the capacity of this workforce through training could help ensure that clinical staff time is used as effectively as possible, freeing up time and skills of clinical staff to focus on patients with more complex needs. Analysis is required to highlight the reasons for differences between trusts in the deployment of these roles in relation to the variation and reason for this. The outcome of this work should determine potential for a more consistent approach across the five trust areas.

4. **The Department of Health should support all cancer nurses to undertake communications training.**

   The census demonstrates that NI cancer services are a significant distance away from meeting the cancer strategy recommendation to ensure all health care professionals who are expected to carry out sensitive communication complete an advanced communication skills training programme. A regional training programme should be explored to support the cancer workforce to complete these programmes. Special attention should be given to professions where uptake has been lower such as chemotherapy nurses and those supporting children, teenagers and young adults.

5. **The Department of Health should ensure every person diagnosed with cancer is offered a holistic needs assessment (HNA).**

   This should ensure every person diagnosed with cancer is offered an opportunity to be assessed, has a quality person centred conversation around their individual needs and receives a care plan which wraps around support based on their individual needs. The cancer workforce is vital to implementing HNA and the DoH should work with Macmillan Cancer Support and others to embed HNA, including electronic holistic needs assessment (eHNA), training across the cancer workforce. Embedding HNA and care planning as an essential part of the pathway is key to delivering personalised care for everyone with cancer in NI.

6. **Department of Health to continue with Cancer Nurse Specialist expansion and progress the next stage within the workforce planning process.**

   These census results demonstrate the success of the CNS expansion programme in recent years, most cancer types have experienced a large improvement in the ratio between people living with cancer and number of CNSs. However, the census also shows this improvement hasn’t been uniform and there is significant work to be done to ensure that everyone living with cancer can access a named CNS regardless of where they live, across all cancer types and at all of stages their journey. To resolve this the DoH should progress the next stage of CNS expansion and should ensure there is sufficient funding to train the staff for these roles. This should include budget to both facilitate backfill within the service to accommodate uptake of specialist and advanced levels of training required to sustain a knowledgeable, skilled and competent workforce (including postgraduate qualification). This is important in enabling continued career progression thereby, maintaining a strong pipeline of candidates with the skills and competencies required to take up higher banded roles.

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Appendices

Appendix A: Comparison to Northern Ireland census 2014

Inclusion criteria for this census were broader than criteria for the 2014 census. A comparison of the main differences between 2014 and 2021 inclusion and exclusion criteria is provided in the table below.

Inclusion criteria

2014	2021
Adult cancer nurses working in adult cancer care only	Registered nurses who are working in provision of cancer care with children, teenagers and young adults, and support workers/healthcare assistants were also included in the 2021 census
Are registered (Agenda for Change bands 5 to 9 only)	Unregistered posts (support workers and healthcare assistants who frequently see people with cancer) were included in this census
Deliver predominantly secondary care	Provide secondary and tertiary care in both hospitals and the community
Are funded by any source (e.g. NHS, charity, pharmaceutical)	HSCT employees only – including those who see private patients treated in the HSCTs

Exclusion criteria

2014	2019
Specialise only in chemotherapy, radiotherapy, palliative care, pain management or non-patient facing roles	Adult chemotherapy nurses were included in the 2021 census. All other 2014 exclusion criteria apply.
Work 'as and when required', e.g. bank and agency staff	Bank and agency staff were also excluded from the 2021 census
Work in paediatrics or with teenagers and young adults	Registered nurses who are working in provision of cancer care with children, teenagers and young adults were included in the 2021 census
Research nurses	Research nurses who spend more than 50% of their time in direct person to person activity in cancer care were included in the 2021 census

Incidence and prevalence data for the 2014 and all other census conducted by Macmillan have been calculated through bespoke analysis of ICD10 codes as shown below:

Area of practice	Cancer types used in 2014 NI census (ICD10 code)
Brain/central nervous system	Incidence is based on brain and nervous system (C47, C70–C72, C75.1–C75.3), two-year prevalence is based on brain, nervous system and eye, including benign neoplasm (C47, C69, C70–C72, D33)
Breast	Breast with in situ (C50, D05)
Colorectal	Colorectal with anus (C18–21)
Gynaecology	Gynaecology (C51–C58
Haematology	Haematology (C81–C85, C88, C90–C96)
Head and neck	Head and neck with thyroid (C00–C14, C30–C32, C73)
Lung	Respiratory (C33–C34, C37–C39, C45)
Malignant dermatology	Skin – malignant melanoma (C43)
Upper gastrointestinal and hepato-pancreato-biliary	Upper GI (C15–C16, C22–C25)
Urology	Urology including prostate and testicular (C60–C68) and bladder in situ (D09 in the incidence data
Sarcoma	Sarcoma (C40–C41, C46, C48–C49)

This bespoke analysis was not possible for 2021. Published data for 2019 was used to reproduce the area of practice groups as far as possible. The rows highlighted show that identical codes have been used. The following ICD10 codes were included in the 2021 census:

Area of practice	Cancer types used in 2021 NI census from public data referring to 2019 data (ICD10 codes)
Brain/central nervous system	C70–C72, C75.1–C75.3, C47
Breast	Breast (malignant and in situ) (C50, D05)
Colorectal	C18–C20
Gynaecology	C53–C57.4
Haematology	C81–C86, C90–C95
Head and neck	C00–C14, C30–C32, C73
Lung	C33–C34
Malignant dermatology	C43
Upper gastrointestinal and hepato-pancreato-biliary	C15–C16
Urology	C61, C62, C64, C67
Sarcoma	Coding not specified in released dataset

Where comparisons to 2014 have been made, 2014 data was recalculated to mirror the groups used for 2019 data.

Appendix B: Methodology

The methodology that Rocket Science adopted to carry out the research was outlined in the following steps:

1. Rocket Science designed a bespoke Microsoft Excel tool to be completed by each of the Health and Social Care Trusts (HSCTs) in Northern Ireland (NI) in order to gather a snapshot of the workforce on 17th September 2021.
2. A feedback session was held with Cancer Lead Nurses and Managers from across the five HSCTs and other key stakeholders, including staff at Macmillan, to review the tool and to share feedback.
3. The census tool was circulated to HSCTs on 14th September 2021 with an instruction manual and FAQs on how to use the tool, inclusion/exclusion criteria, and instructions on secure data transfer. A Data Protection Impact Assessment (DPIA) was in place between Macmillan (data controllers), Rocket Science (data processors) and HSCTs.
4. HSCTs were asked to return their data by 15th October 2021. Continuous support was provided by Rocket Science to assist the completion and return of the data. This included four 'data clinics', online drop-in sessions which were jointly run by Rocket Science and Macmillan to support the identified lead from each trust to draw on comparable data to complete the template.
5. The study received a 100% response rate, meaning that data for the cancer nurse workforce was collected from all five HSCTs in NI.
6. Rocket Science audited the data to ensure accuracy and consistency, which included follow-up contact with each HSCT. Data amendments were recorded accordingly. Macmillan also audited to confirm data amendment for further quality control.
7. Analyses were double-checked with the NICaN Nurse Leaders Reference Group and triangulated with ongoing work by the Public Health Agency of NI to support CNS workforce planning.

Analysis and reporting took place in October and November 2021.

Inclusion and exclusion criteria

Inclusion criteria for all parts of the census

This work aimed to capture a comprehensive picture of the cancer nursing workforce. For all posts:

- posts who treat, support and manage the health concerns and health and wellbeing of cancer patients (includes organisation of recovery package);
- posts who spend more than 50% of their time in direct person to person activity in cancer care, including over the telephone;
- HSCT employees only – including those who see private patients treated in the HSCTs;
- provide secondary and tertiary care in both hospitals and the community;
- clinical research or clinical trial nurses within cancer care;
- any post vacant or filled on the 17th of September 2021.

In reporting the following groups were identified:

- **Nurses delivering adult cancer care**. Registered nurse working in provision of cancer care and bands 5–9. These included:
- **Adult cancer specialist nurses**. The following definition was agreed with the NICaN Nurse Leaders Reference Group. Please note that this group includes 'clinical specialist nurses' who function as key workers for cancer patients and 'practitioners' that have specialist clinical practice roles.

Posts which satisfy the following categories:

- – the job title specifies nurse 'specialist' or 'practitioner' (please see Appendix C for role definitions);
- – Agenda for Change band 6 and above;
- – the post holder's time is spent supporting adults living with cancer;
- – post-holders have a documented training record declaring them specialist in cancer care or have been appointed with their agreed willingness to undertake a cancer qualification.

- **Other adult cancer care nurses**. Other nurses meeting the general census inclusion criteria that do not meet the cancer specialist criteria.
- **Staff nurses**. Nurses working in wards that meet the census criteria and who are band 5.
- **Adult chemotherapy nurses**. Registered in cancer care (posts that require a registered health professional who has been assessed as being competent and has a documented training record which declares them capable of the unsupervised administration of systemic anti-cancer therapy) and AfC bands 5–9. Includes those who deliver cytotoxic drugs and provide adult cancer patients with advice, education, and support to ensure that the risks and toxicities were minimised. Includes those who were in ambulatory/outpatient chemotherapy units (solid tumour, haematology) or inpatient wards.
- **Children, teenage and young adult cancer nurses**. Registered nurses who are working in provision of cancer care with children, teenagers and young adults, and bands 5–9.
- **Support workforce who frequently see people with cancer**. Unregistered posts, more than 50% of time spent in person to person activity in cancer care, under supervision by a registered cancer professional, band 3–4. Excludes those not employed by the HSCT and those working in Macmillan Cancer Information and Support Centres. Please note that this group includes 'cancer support workers' that work with clinical specialist nurses to provide personalised support to people living with cancer and 'other support workers' which are part of the support network for cancer patients but work in a different way. (Please see Appendix C for role definitions).

Exclusion criteria for all parts of the census

- Student nurses
- Agency nurses
- Band 1 and 2 staff
- Bank and agency staff
- Palliative care nurses
- Surgical nurses.

Analysis notes

The reader should bear in mind the following when studying the census results:

- **Raw Whole Time Equivalent**: as per reporting on England and Wales census (2017) and the Scotland census (2019) we have calculated the Whole Time Equivalent (WTE) and this is indicated where you see WTE in the results. For instance, 2 people x 0.5 (18.75 hrs) = 1 WTE ie. 37.5 hrs. WTEs are reported to 1 decimal place. Please note that as a result of rounding up/down the decimals involved in WTE calculations, some totals will not always match the number of WTEs listed.
- **Demographic details**: including age, gender and nationality were only applicable for filled posts.
- **Data gaps**: the majority of census responses were full and comprehensive. However, there were some data gaps for individual posts. The following table provides a breakdown of the gaps in data:

Variable	Number of posts missing data
Affiliation (to Macmillan/another charity)	8 – adult cancer care
Primary area of practice	3 – adult cancer care
Secondary area of practice	3 – adult cancer care
Proportion of time spent supporting people with a cancer diagnosis	4 – adult cancer care 1 – children TYA 3 – support workers
Type of place where the post holder delivers care	3 – adult cancer care 11 – support workers
Other key location of care	3 – adult cancer care 14 – support workers
Gender	5 – adult cancer care
Qualifications	1 – adult cancer care 5 – support workers
Does the post holder delivery chemotherapy	1 – children TYA
Acute oncology service (Y/N)	1 – children TYA
Secondary metastatic disease (Y/N)	1 – children TYA 2 – support workers

Appendix C: Nursing roles definitions

The following cancer specialist nursing role definitions are in use in Northern Ireland:

Advanced Nurse Practitioner[24] – A nurse who works autonomously using a person-centred approach within the expanded scope of practice. They undertake comprehensive health assessment and differential diagnosis. They can prescribe care and treatment or appropriately refer and/or discharge patients. They provide complex care using expert decision – making skills and act as an educator, leader, innovator and contributor to research.

Oncology Nurse Practitioner[24] – A nurse practitioner (NP) in either Oncology or Haematology is an advanced practice registered nurse. A NP will have undertaken additional post registration training to assess patient needs, order and interpret diagnostic and laboratory tests, diagnose disease, formulate and prescribe treatment plans. NP training covers basic disease prevention, coordination of care, and health promotion. NPs work as part of a clinical team, the Consultant retains overall responsibility for the patient.

The scope of practice for a NP is defined by legal jurisdiction. In some places, NPs are required to work under the supervision of a physician, and in other places they can practice independently.

Clinical Nurse Specialist[25,26] – Clinical Nurse Specialists (CNSs) are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases such as cancer. The high-level activities of CNSs consist of:

- Providing a keyworker role, acting as a key point of contact for patients, ensuring that patients have access to information and support services and providing holistic assessments
- Using and applying technical knowledge of cancer and treatment to oversee and coordinate services, personalise ‘the cancer pathway’ for individual patients and to meet the complex information and support needs of patients and their families.
  - Acting as the key accessible professional for the multidisciplinary team.
  - Providing direct and indirect nurse- led activity including nurse led clinics and telephone follow up.
- Education, training and audit are inherent aspects of the cancer CNS role and permeate all aspects of their work
- Contributing to service improvements and policy development

Cancer Support Worker[25] – A key role which assists in the delivery and co-ordination of care, education and support under the supervision of the Clinical Nurse Specialist, for patients with Cancer. They are able to obtain and collate data for reports, governance and patient care.

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[24] Develop a Career Framework for Specialist Nurses. Northern Ireland Practice & Education Council for Nursing and Midwifery. Accessed November 2021.

[25] Cancer Clinical Nurse Specialist Workforce Plan. 2016 Department of Health NI. Accessed November 2021.

[26] Impact briefs Clinical nurse specialist. Macmillan Cancer Support. Accessed November 2021.

Appendix D: Information collected

The census asked each HSCT to collect data on the following variables:

Variable	Task
Record Number	Please take the next allocated record number on the sheet.
Job Title	Please select from the drop-down menu (values available will differ depending on role type). Please select 'Other' if appropriate.
Other Job Title	Enter job title (only use if 'Other' selected for Job Title).
Macmillan Cancer Support or other charity in job title	Please select from 'It has Macmillan in the job title', 'It has another charity in the job title', or 'It has no affiliations in the job title'.
Banding	Please select from the drop-down menu (values available will differ depending on role type).
Area of Practice	Please select the area of practice in which the post holder most frequently delivers care from the drop-down menu (e.g. lung, sarcoma, neurology).
Secondary Area of Practice	If more than 25% of patient facing time is spent on a secondary area of practice, please select this area.
Is this post based on an Acute Oncology Service?	Please select 'Yes' or 'No' from the drop-down menu.
Does the post cover secondary/ metastatic disease	Please select 'Yes' or 'No' from the drop-down menu as appropriate.
Proportion of time spent supporting people with a cancer diagnosis	Please enter a whole number between 0–100. For example, if the post works 2 days a week and 1 day is supporting people with cancer, then please record 50.
Type of Setting	Please select from the drop-down menu. Please use the following definitions to select the correct value. Available options are 'Cancer unit', 'Cancer centre', 'Non cancer specific setting'. A Cancer Unit treat people with more common oncology and haemato-oncology diagnosis, but do not have a radiotherapy service. A Cancer Centre is a designated facility providing treatment for people with oncology and haemato-oncology diagnosis including common and rarer cancers. Both Belfast and North West Cancer Centres provide radiotherapy services.

Variable	Task
Type of place where the postholder delivers care	Please select the main location where the post holder delivers care from the drop-down menu options. If applicable, please also select the other key location of care for the post (more than 25% of patient facing time is spent). If this is not applicable, please select the option 'Care is concentrated in a single location'.
Contracted Whole Time Equivalent (WTE) of the post	Please record the WTE (the value should include all contracted hours of the post not just time patient facing activity or cancer care). This should be an appropriate decimal value between 0 and 1 (e.g. 0.5). Only complete this section if you have not completed the Contracted Hours per Week column.
Contracted hours per week	Please include all contracted hours of the post not just time patient facing activity or cancer care. For example, 18.75 hours. Only complete this section if you have not completed the Contracted WTE of the post column.
Is post Filled or Vacant	Please select from the drop-down menu options Filled or Vacant. If a post used to exist but has been reconfigured it should not be counted as a vacancy.
Length of Vacancy	Please select from the drop-down menu options the length of time the post has been vacant if applicable.
Education and Training	Please select yes or no for each of the education and training options offered along the top of the page. Do not complete for vacant posts.

The following information was collected for filled roles only:

Variable	Task
Gender	Please select from the drop-down menu Options Male, Female, Other, Prefer not to say, Not known, Not applicable.
Age range	Options Under 30, 30–39, 40–49, 50–59, 60 and over, Not applicable.
Nationality	Please select from the drop-down menu. Options UK, EU excluding the UK, Rest of world, Declined, Not known. For EU please include those from the EU's (European Union) member states or European Economic Area. These are: Austria, Belgium, Bulgaria, Croatia, Republic of Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, Iceland, Liechtenstein, Norway and Switzerland.
Education and Training	Please select yes or no for each of the education and training options offered along the top of the page. Do not complete for vacant posts.

Appendix E: Limitations

Potential limitations in the census methodology include:

- Gaps in the data. Some HSCTs submitted partial or incomplete data, as detailed in Appendix B.
- Inconsistencies in the data. Despite support and auditing, it was likely that there were still inconsistencies in the data, where different HSCTs have interpreted the criteria in different ways.
- Misreported data. The data were all self-reported, usually by a single individual who collected data on a wide range of posts and post-holders. It was not possible to verify individual returns, and therefore misreported data may be included.
- The census was a snapshot of one single day (17th September 2021).

Additional information on staff nurses:

This work aimed to capture a comprehensive picture of the cancer nursing workforce.

During data collection trusts agreed that it was appropriate to include staff nurses spending more than 50% of their time working directly with cancer patients. The data captured in this census represented staff nurses in haematology and oncology wards in cancer centres only.

After data was finalised, the NICaN Nurse Leaders Reference Group recognised that the number of staff nurses captured was incomplete. Although the census data could not be altered at this stage, additional estimates for this nursing group were provided for all five trusts by the NICaN Nurse Leaders Reference Group as personal communications.

These estimates are based on nurses required for the number of funded inpatient beds. The cancer nurse to bed ratios in cancer centres vary, with a range between 1.6–2 WTE nurses per bed depending on use of side rooms. The resulting estimates are:

Belfast	165.9 WTE
NWCC	46.91 WTE
SET	14.0 WTE
NHSCT	10.8 WTE
SHSCT	14.4 WTE

At Macmillan, we give people with cancer everything we've got. If you're diagnosed, your worries are our worries. We will move mountains to help you live life as fully as you can.

For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk.

Macmillan.org.uk

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Macmillan Partnership Application

Sections to be completed where applicable – If a section does not apply please clearly state N/A. Please see separate guidance notes for more details about the type of information required before completing. If the application requires a project management approach, please use project management documentation (e.g. Gant chart – please see guidance notes)

NAME OF SERVICE / PROJECT LOCATION AND CONTACT DETAILS FOR WHICH FUNDING IS REQUESTED.	
Name of service / Project: Macmillan CNS Workforce Plan – 1.0WTE Band 7 Macmillan Urology Cancer Clinical Nurse Specialist and 0.25 WTE Band 3 Macmillan Support Worker	**Name of Partner Organisation:** Southern Health and Social Care Trust
Name of Clinical Alliance / Strategic Clinical Network / Integrated Cancer Systems (if applicable): **NI Cancer Network**	**Geographical catchment area:** The Southern Health and Social Care Trust (SHSCT) was formed in April 2007. It is responsible for providing services across the council areas of Armagh, Banbridge, Craigavon, Dungannon and Newry and Mourne. The Southern Trust is an integrated organistion and thus provides a mix of both acute hospital and community health and social care services to a resident population of approximately 360,000 people. Cancer services at the Southern Trust is incorporated into all acute services as per specific tumour site.
Contact details of person submitting the application / leading the service development / project	Name: Martina Corrigan Title: Head of ENT, Urology, Ophthalmology & Outpatients Address: Craigavon Area hospital, 68 Lurgan Road, Portadown. Co. Armagh. BT 63 5QQ Telephone no: [redacted] Email: [redacted]

Contact details of the senior manager /commissioner sponsoring the service development / project	Name: Mrs Esther Gishkori Title: Director of Acute Services Address: Craigavon Area Hospital, 68 Lurgan Road, Portadown. Co Armagh. BT63 5QQ Telephone no: Personal Information redacted by the USI Email: Personal Information redacted by the USI
Name and contact details of the member of the Macmillan Service Development Team	Name: Ruth Thompson Partnership Manager Telephone no: Personal Information redacted by the USI Email: Personal Information redacted by the USI
PS@MAC number(s) [compulsory Macmillan use]**:**	
Is a Cancer Environment build envisaged? ***If yes, the Administrator <u>must</u> inform CE of the PS@MAC number.**	No*

PART ONE SUSTAINABILITY

1.1 Please indicate whether the post or service is:

Permanent	Yes ☒ No ☐
Project / fixed term	Yes ☐ No ☐
Pilot	Yes ☐ No ☐

- **What is the organisation's level of commitment to this post or service?**

The five year incremental, prioritised Cancer CNS workforce plan has been approved through HSCB / PHA senior management team and has Department of Health support. The cancer CNS workforce expansion is a commissioning prioirity commencing 2016/17 for 5 years and was outlined in the commissioning plan. A Urology CNS is included within the plan for 2018 /2019. This was included in the plan as a Band 6 post but the Service Manager has requested the post be appointed at Band 7. This has been discussed and agreed with the Nurse Consultant PHA / NICAN

	Comments
Is pick up funding confirmed in writing?	Yes – the CNS expansion plan is an incremental expansion over 5 years and the HSCB will pick up funding recurrently. The Trust will also provide the difference in salary from B6 to B7 to support the HSCB contribution towards the post.
Is pick up funding confirmed pending a successful evaluation – if so what will the evaluation be based on?	Yes – confirmed through the CNS expansion plan

Is the business case for sustainability to be submitted through the local funding process	No
No pick up funding anticipated	
For project / pilot posts – is there a letter of support from the employing organisation / commissioner and evidence to show how the recommendations will be taken forward?	Yes ☐ No☐ If no give reason:
For project / pilot posts – Explain why this is a project or pilot and not a sustainable service	N/A

PART TWO BACKGROUND

2.1 Identify the key issues / problems that currently have an impact on people affected by cancer that you are trying to address through the proposed project / service

The role of the Clinical Nurse Specialists (CNS) in contributing to high quality cancer care is now well acknowledged and understood. CNSs are at the front line of cancer care, they are the main point of contact for patients, significantly improved patient experience and deliver services for individual patients according to need and patient choice. They play a vital role in the coordination of patient care and successful implementation of iniatives to improve cancer services. To date CNS commissioning within Northern Ireland has been ad hoc and opportunistic with provision significantly lower than the rest of the UK.

The number of people diagnosed with cancer each year is rising, with one in three of the population developing some form of cancer by the time they reach 75 years of age. In Northern Ireland, 11,000 people are diagnosed with cancer. Driven by the ageing population, this number is expected t orise by 25% for men and by 24% for women by 2020. By 2035, the number of cases per year is projected to be 7,181 male and 6,967 for female cases, a 65% rise among men and 63% rise in women. The prevalent population in 2014 was reported as 63,500 people living with cancer, which is estimated to rise to 110,000 by 2030. In addition, cancer is responsible for approximately one quarter of all deaths occurring in Northern Ireland causing more deaths than any of ischemic heart disease, stroke or other diseases of the circulatory or respiratory systems.

In 2015, the NI Cancer Patient Experience Survey (CPES) reported 72% of patients having access to a CNS, much lower than England 89% (2014), and Wales 88% (2013). Key driver analysis demonstrates the support of a CNS is the most important contributing factor to people reporting a positive experience of care. In April 2014, the Macmillan Adult cancer CNS census of the Specialist Adult Cancer Workforce reported 57.4WTE in N.I. with the majority area of practice being Breast (33.8%), with minimal provision in Urology. This is significantly lower than other UK countries when incidence rates are compared to whole time equivalent posts.

This is further compounded by results from the 3 year NI Cancer Peer Reveiw Programme of Multi Disciplinary Teams (Local and Specialist). Lack of access and single handed CNS provision were found as immediate risks or serious concerns in 17 out of the 30 MDTs Peer reviewed to date.
Currently in the Southern Trust, there is 1.0 WTE Nurse Specialist for the Urology service. Some progress has been made to implement the key worker role for cancer patients, but this has been limited due to lack of resources. Therefore not all patients are supported at key stages of their pathway including at the time of receiving their diagnosis and not all benefit from the skills, knowledge and expertise of a CNS.

The Transforming Cancer Follow Up (TCFU) Programme Evaluation (2015) has provided a strong evidence base for the effectiveness of risk stratified models of follow up within Breast and Prostate cancer. Risk stratification has the potential to improve patients experience, health and wellbeing and improve resource utilisation. Pivotal to the success of risk stratified models of follow up is the involvement and availability of CNSs. Urology nurse led follow-up pathways have been agreed regionally but have not been implemented in SHSCT due to lack of dedicated staff. For further development to occur, additional staff are required.

There is an overwhelming deficit in the number of CNSs within SHSCT. By increasing the number of nurse specialists and through inclusion of support worker roles within the CNS workforce plan this will support skill mix by assisting in the delivery and co-ordination of care, education and support, under the supervision of Clinical Nurse Specialists for patients with cancer.

Within SHSCT, there were 746 new patients with urological cancers diagnosed in 2016.

There are currently two Urology CNSs within the Trust providing care for patients with all urological disordrers. Investment in a 1.0 WTE Urology CNS will further enhance the uro-oncology service and the development and co-ordination of the service. This CNS will work primarily with patients with prostate and renal cancer. The 0.25WTE band 3 support worker will provide administrative support for the team and act as a point of contact for patients to ensure the most effective use of resources.

2.2 How will the proposed project/service/scheme address the issues /problems identified in 2.1

The proposed workforce plan would aim to recruit 1 WTE Band 7 Clinical Nurse Specialist, and 0.25 WTE Band 3 support worker.

The staff will work closely with the appropriate Multi-disciplinary teams to provide:

(i) Key worker function

(ii) Act as core member of the tumour specific multidisciplinary team

(iii) Nurse-led activity to include nurse led clinics and telephone work

(iv) Education / Training / Audit

(v) Identify and contribute to service development and policy development

Through expansion of the cancer Urology CNS and support worker team the care of patients could be improved as follows:

- The staff would work closely with the MDTs ensuring all patients would be supported as they progress in a timely manner along the appropriate diagnostic pathway
- The CNS will contribute to the MDT discussion by acting as the key worker for patients as recommended by the Manual of Cancer Services (2004)
- Patients would have a HNA and care plan with sign posting to appropriate services as recommended in the Living With and Beyond Cancer report (2013), Recovery Package & NI Cancer Services Framework
- Patients and their caregivers would have appropriate, timely information and support at each stage of their pathway to enable them to deal with physical, social, emotional or sexual issues that may arise (Improving Outcomes, 2004)
- The proposed post holders would work across internal interfaces between medicine, surgery and oncology to ensure effective transfer of information. They will also liaise with staff in the Cancer Centre.
- The post holders will work across external service boundaries between primary and secondary care to aid implementation of the TYC principles, improve continuity of care and ensure patients experience a seamless transition from acute to primary care.
- Patients could be managed through the new service models of risk-stratified follow-up in line with the regional move towards Transforming Cancer Follow-up and where appropriate and in conjunction with the medical team, nurse-led and self-directed aftercare could be introduced in close collaboration with the local Macmillan Service Improvement Manager
- Introduction of nurse-led and self-directed follow up could help to minimise any backlog of review appointments, allowing consultants more time to spend with new and complex cases
- The nurse-led activity may be direct or indirect; inpatient, outpatient or via telephone; and provided within an acute, community or primary care setting dependent on the requirements of the patient group involved.
- The CNS will provide a telephone advice number to patients to ensure patients can access follow-up advice thus reducing unnecessary anxiety, avoidable re-admissions and GP visits. The Support Worker will be involved in triaging calls.
- Patient education is a fundamental part of the post holders' roles and will be provided in a variety of ways including the provision of health and wellbeing events to support the SHSCT cancer survivorship

program and the national Recovery Package, enabling patients to be empowered and better manage their lifestyles and any on-going support needs.

- The post-holders will keep abreast of the development of local services that may be utilised to support the patient groups and signpost the patients and their carers to those services relevant to their needs
- The post-holders in conjunction with core services will refer appropriate patients to local cancer rehabilitation and self-management programmes e.g. physical activity programmes delivered by qualified staff in leisure centres or the HOPE programme
- Education, training and audit will be inherent aspects of the CNS role and they will contribute to advancing the body of knowledge in their respective areas and ensure their skills and competencies meet those outlined in appropriate frameworks (e.g. NIPEC (2006) and Macmillan (2014)
- The Urology CNS will have dedicated sessions in their workplan to support the development of policies, guidelines and protocols to ensure the services provide a patient-centred, evidence based service to all patients
- The support worker will enable more effective use of nursing time
- Close links will be established with the local Macmillan Health & Wellbeing Manager and Macmillan Benefits Advisers to ensure patients receive the most up to date support and information relevant to their needs
- The teams will work closely with the local Trust Volunteer Manager to ensure volunteers can be utilised where possible in the support and development of services for patients
- The teams will liaise with the regional Macmillan Work Support and Rehabilitation Service to incorporate appropriate service developments locally
- Post holders will liaise with local and national teams and networks to ensure the services remain abreast with current changes in practice.

When planning this application three options were considered:

Option Number/ Description	Shortlisted (S) or Rejected (R)	Reason for Rejection
1. Status Quo - Continue with existing arrangements	R	Without investment in cancer nurse specialists, the immediate risks and serious concerns flagged through the National Peer review process would not be addressed in regard to CNSs across the tumour MDT sites. Patient experience will continue to be impacted upon negatively without the expansion of CNSs across all Trusts, with NI having the lowest reported access to CNSs across the UK. Any further progress with nurse led follow-up and supported self-care models through the transforming cancer follow-up across tumour sites would not be realised.
2. Introduce clinical nurse specialists as per agreed workforce plan in partnership with Macmillan and Friends of the Cancer centre.	S	This is the preferred option and would introduce the regionally agreed risk based, prioritised, incremental workforce plan for the expansion of the clinical nurse specialists to support the patients across NI. The CNSs will work closely with their respective multi-disciplinary teams and in line with the regionally agreed commissioning specification and address National Peer Review measures. The partnership arrangement with Macmillan and Friends of the Cancer centre allows for the incremental planned and managed introduction of cancer nurse specialists within NI across all Trust thus ensuring equity for patients.
3. Introduce clinical nurse	R	To introduce the clinical nurse specialists as per

specialists as per agreed workforce plan without a partnership arrangement with Macmillan and Friends of the Cancer centre.		agreed workforce plan without a partnership arrangement with Macmillan and Friends of the Cancer centre would have the potential to increase the CNS provision however given the current financial constraints within HSC, the number of CNSs who could be recruited would be significantly reduced due to affordability, thus introducing risk with some services and specialities with a continued lack of investment in CNSs.

Option 2 allows expansion of the CNS role and ensures that all patients receive a patient-centred service that meets the information and support needs of them and their families.

2.3 How does this service / project address inequality? *(please refer to guidance notes)*

The NI Cancer Registry (2013) have identified that there were 69,377 people living with cancer in NI at the end of 2010. There were an average of 2497 cancers (including non-melanoma skin cancer; NMSC) diagnosed each year in the Southern Health and Social Care Trust between 2010 and 2014. This represents 20.4% of all cancer diagnoses in Northern Ireland during this time period.

The lack of CNSs in the SHSCT results in patient inequality and patients being disadvantaged when compared regionally. The Northern Ireland Cancer Patient Experience Survey 2015 results show that in the SHSCT only 68% of patients were given the name of the CNS in charge of their care; this was the lowest percentage in NI. At a national level it is acknowledged that NI has a shortage of CNS posts compared to the rest of the UK and this gap is widening.

Table 1: UK Benchmarking – WTE Cancer CNS : Cancer Incidence

	Cancer Incidence (2013)	WTE Adult Cancer CNS	Average CNS caseload / WTE
Wales	19,026	184.3	103
Scotland	31,013	265.0	117
England	280,000	3088.0	91
N Ireland	11,000*	76.2**	144

**Source Macmillan census of the specialist adult cancer nursing workforce NI 2014, whereby incidence data sourced from personal correspondence with the biostatisticians/researchers at the Northern Ireland Cancer Registry in August 2014*
***2015/16 position and includes 11 WTE charitably funded posts with no exit strategy.*

Prior to the initiation of the Regional CNS Workforce Plan, Northern Ireland was bottom of the UK for the total number of CNSs per region. This lack of CNSs equates to an unequal service for patients as research has shown that CNSs can significantly improve patient care and quality of life. A 2009 Macmillan report stated that "CNSs can help improve quality of life for people with cancer through assisting with decision making, symptom management and emotional support".

The plan also includes the introduction of support workers, which has been shown in the UK and NI to maximise the capacity of CNSs. Oliver and Leary's (2012) research found 20-30% of CNS interventions were non clinical administrative duties which could be performed by a clerical worker allowing more effective use of nursing time. The inclusion of support worker roles within the CNS workforce plan will support skill mix by assisting in the delivery and co-ordination of care, education and support, under the supervision of Clinical Nurse Specialists, for patients with cancer.

Other areas of inequality will also be addressed through this project. Primarily the Trust catchment area includes pockets of social deprivation and the opportunity for patients to have holistic needs assessment and attend HWBCs with advice on smoking cessation, lifestyle changes will be beneficial.

Secondly as there is a significant elderly population in the Trust locality it is planned to offer services including nurse led telephone clinics. Thirdly, there will be access to materials for those who are visually or audibly

impaired upon request.
Finally as the key elements of the workplan for the new staff would be in line with the TYC and TCFU programmes of change. Both programmes have undergone an Equality Impact Assessment and meet the required criteria.

Between 2010 and 2014 there were 1621 people diagnosed in Northern Ireland with urological cancer.
Within the Southern trust area, at the end of 2014, there were 2305 people living up to 22 years post al cancer diagnosis.Within the SHSCT on average there are 204 people diagnosed with a new urology cancer each year per 100,000 people, this is similar to the NI average. In 2016 there were 746 new diagnoses in SHSCT. The population in the Trust area is approx 369,500.
The introduction of this additional Urology CNS will help to further develop the existing Urology cancer nursing service in SHSCT and ensure full implementation of the recovery package including nurse-led follow-up for all patients living with urological cancers. Given the increase in patients living with urology cancers this is particularly pertinent.

2.4 How have users / people affected by cancer been involved in the proposed service development /project. Outline the plans for longer term user involvement in the service / project development (please refer to guidance notes)

Service user questionnaires for Peer Review in 2014/15 have identifed the need for improved information. In addition a postal survey of cancer patients in NI highlighted that just under 40% of patients have unmet needs (Santin, 2011).

The survey identified that patients did not recall being given written information about other sources of support i.e. financial support, local support groups or services offering psychological, social, spiritual/cultural support. Other patients stated that they were not provided with enough information at their diagnosis, forcing them to contact GPs instead.

These findings have been reiterated by the lower scoring Cancer Patient Experience Survey answers; the list below NI scores are given first and England 2014 CPES scores second denoted within { }.

- Q14 - given written information about the type of cancer they had: substantially lower score in NI 64% {72%}
- Q18 - given written information about the side effects of treatment 78% {82%}
- Q21 - given the name of a CNS in charge of their care 72% {89%}
- Q29 - taking part in cancer research discussed with the patient 18% {31%}
- Q33 - given written information about the operation they were having beforehand 66% {76%}

Northern Ireland cancer services seem to be less successful at giving written information on cancer, at various points along the pathway, than is the case elsewhere. The proportion of patients having access to a CNS is lower than elsewhere - and this is known to be a key driver of high scores given by patients about their care in both England and Wales. This insight into patients unmet needs has been taken on board and has resulted in the development of this proposal as it is believed additional CNS will help to provide patients and their family members with the information and support they require at a timely point in their pathway. The support worker will assist the clinical staff to co-ordinate the patient pathways, establish a robust data collection and collation system and support health and wellbeing events.

Once the posts are established service user feedback will be utilised to develop the posts and ensure they remain patient-focused. This feedback will be taken from a number of sources including patient surveys and future health and wellbeing events. Within Southern Trust significant improvements have been made within the Urology team in that the Clinical Nurse Specialist sees patients from the point of a cancer diagnosis and offers support and advice in conjunction with contact numbers. The regional patient experience survey has demonstrated positive feedback on the benefits of a having a clinical Nurse Specialist at the point of diagnosis for ongoing support and advice.

IF THIS IS A SERVICE - COMPLETE PART 3

2.5

There is a cancer user forum which meets quarterly, however communication is passed in the intervening months, for e.g. the Urology MDT patient information leaflet when developed was reviewed by the cancer service user forum and changes made based on their feedback.

IF THIS IS A SERVICE - COMPLETE PART 3

IF THIS IS A PROJECT – COMPLETE PARTS 3 AND 4

IF THIS IS A CANCER ENVIRONMENTS/BUILDING SCHEME COMPLETE PARTS 3 AND 4 AND ALSO COMPLETE PART 5

PART THREE SERVICE SPECIFICATION please refer to guidance before completion

(NOTE: Macmillan may, if the bid is developed further, ask its partner organisations to create an Operational Policy which expands on the information provided in the sections below a template will be provided).

3.1 Service aim

The aims and anticipated outcomes should clearly reflect the evidence of need for this project /service as identified in Part One? Please see the guidance notes and refer to Macmillan's nine outcomes

a) *Describe the overall aim of the proposed service, outlining who the project / service is for / aimed at*

b) *Identify the anticipated outcomes of the project / service (the outcomes you would expect to see during the lifetime of the project / service). Outline the impact we expect the service/project to have – i.e. what we want to achieve through it and how we will achieve it (things that can be quantified and collected through monitoring data*

c) *Outline the anticipated numbers of clients /people affected by cancer that the service/project will allow access to.*

d) *Outline how this service /project will be integrated with the wider health and social care services that are providing a service for people affected by cancer*

e) *Outline how volunteers will be supporting the service /project, and outline ongoing plans for volunteer support and engagement including how it will achieve Macmillan's Volunteer Quality Standards*

f) *What are the Learning & Development requirements to deliver the service / project? Either for the individuals within the service, associated team members or the organisation*

(a) Service Aim: To develop, introduce and evaluate the introduction of an additional Urology Clinical Nurse Specialist and Support Worker to address the physical, psyschological, social, information and support needs of Urology cancer patients throughout their pathway in the SHSCT and maintain person centred care in line with DHSSPSNI Nursing and Midwifery Strategy (2015). This will contribute to more efficient and effective service delivery, an improved patient experience throughout the pathway and support the commissioning of future service provision. The proposed plan will also ensure that NI HSC services have a healthy, productive workforce, who are appropriately skilled trained, and provide the highest quality healthcare services at the right time in the right place.

(b) Outcomes

The Regional CNS Workforce Plan suggested KPIs by which Cancer CNSs could measure outcomes. These have now been refined and the regionally agreed CNS Outcomes and KPIs are included below. The CNS will report on these KPIs annually.

1. Service Improvement

Improved clinical practices and pathways are person centred and aligned to current strategy

- The CNS will provide evidence of how they have played a key role in ongoing service improvements e.g
    - Risk stratified pathways
    - New regional / local guidelines
    - Implementing elements of the Recovery Package
- The CNS ensures patient feedback influences ongoing service improvements

2. Service Delivery

Clinical support is well coordinated across the treatment pathway

- Number of patients referred to the MDT Meeting (new / re-referrals)

- Number of patients referred to the CNS to act as keyworker

- % of patients taking part in an experience survey who report they were given / offered contact details of key worker

- Number of nurse-led clinic appointments (face to face / telephone / HNA)
- % of MDT meetings CNS is in attendance

- Number of patients, for whom the CNS is key worker, who are contacted within 48 hrs of a working week following referral/diagnosis

3. Holistic Approach

The holistic needs of patients and carers are identified and addressed

- Number of patients known to the CNS who are offered a HNA

- % of patients completing HNA for whom a care plan is developed

4. Patient Information and Support

Patients and carers get answers when they need them and are well informed and supported

- % of patients who participate in an experience survey who report that they received the right information at the right time and at the right level from their CNS and felt supported by the CNS

5. Supporting Professional Activities

The CNS will fulfil all non-clinical aspects of their role

- Education & Training:
    - Evidence of continuing personal & professional development
    - Provision of formal / informal teaching sessions for other staff
- Research & Audit:

  - Involvement in service audits
  - Participate in / lead on research projects
- Leadership & Management:
  - Interpretation and implementation of national guidelines
  - Policy and protocol development
  - Representation at regional / national forums
  - Promotion of service

Support Worker outcomes:
- To support the CNSs to provide a patient-centred service
- To assist with the co-ordination of multidisciplinary clinics
- To ensure patient phone calls are registered, managed and addressed by appropriate staff in an timely manner
- To guide patients through the use of self-assessment tools and support the administration of holistic needs assessment
- To provide sign-posting to patients and family members to appropriate services
- To assist at health and wellbeing events and any rehabiliation sessions
- To establish and maintain a robust and accurate database for the services
- To support and contribute to audit, governance, research and service development within the cancer teams.

These service outcomes are in line with six of the nine Macmillan outcomes for people living with cancer, i.e.
- I understand, so I can make good decisions.
- I get the treatment & care which is best for my cancer and my life
- Those around me are well supported.
- I am treated with dinity and respect
- I know what I can do to help myself and who else can help me
- I can enjoy life

(c) Anticipated numbers that the service will support
There were an average of 2497 cancers (including non-melanoma Urology cancer; NMSC) diagnosed each year in the Southern Health and Social Care Trust between 2010 and 2014. This represents 20.4% of all cancer diagnoses in Northern Ireland during this time period.
Between 2010-2014 in SHSCT, there were 2305 people living up to 22 years post diagnosis with either an urological cancer (ref: www.lcini.macmillan.org.uk). In 2016, there were 746 new patients diagnosed with urological cancer.
Many more people with an urology cancer are living longer, surviving initial treatment and going in and out of remission. The proposed new posts will enable a much greater proportion of these patients to receive the support of a CNS during the diagnosistic phase and the immediate pre and post-operative period. The teams will also provide a service to those already living with cancer, to those who present with a recurrent cancer and to those who require long term monitoring of their condtion.

Through supporting both new and current patients it is anticipated that a high proportion of family members will be supported by the teams. There is also the opportunity to increase volunteering opportunities through the Health and wellbeing events and potential rehabilitation programmes.

(d) Integration with the wider HSC services that are providing a service for people affected by cancer
These posts will be closely linked to the priorities outlined by the Northern Ireland Cancer Network (NICaN), The Cancer Service Framework for Northern Ireland and the Transforming Cancer Follow Up Project. The proposed staff will work collaboratively with the wider health and social care team in the Trust to ensure that service boundaries do not impact on the patient pathway. Furthermore, they will collaborate with teams across

other local trusts and through out the UK to ensure an evidence based, equitable service is provided acting as a link in the seamless preparation of the patients for treatment.

The post holders will work across primary and secondary care to provide a support service for advice to primary care and links with all those along the patient's cancer journey, this ranges from the general outpatients department, consultant staff, other clinical nurse specialists as appropriate, social work information and support services and to voluntary agencies supporting integrated working with primary care as key patient groups traditionally followed up in secondary care will move via risk stratification to either self-directed follow up or coordinated care.

The Trust's developing model for Health and Well Being events (HWB) will also link closely with the new postholders and through redesign of the services patients will be referred to HWB events. These events rely strongly on partnerships with a wide number of voluntary groups and volunteers including Macmillan support services, Citizens' Advice Bureau, Cancer Focus NI.

The Trust will build effective collaborative working models with partners at both strategic and operational levels thus providing significant opportunities to enhance its ability to address the needs of those with cancer across all care settings.
The post-holders will play key roles in the MDTs and will be incorporated into the current services delivered by the trust.

The new staff will work closely with other Macmillan funded staff within the trust. Particularly they will liase with:

- Macmillan Health & Wellbeing Manager to ensure patients receive information and signposting appropriate to their needs
- Macmillan Service Improvement Manager to aid implementation of the TCFU principals in cancer services
- Macmillan Benefits Advisers to ensure patients receive the financial advice and support they require
- Trust Volunteer Manager to utilise volunteers where approriate in cancer services e.g. at Health and wellbeing events
- Macmillan Move More Coordinators to ensure patients are encouraged to reamin physically active during and after cancer treatment.

(e) Volunteer Support and Engagement
Through working closely with the SHSCT Volunteer Manager, the postholders will identify suitable volunteers who are willing to help at events. If should also be possible for the staff to identify patients or family members who are at a suitable phase in their pathway who may wish to act as volunteers to provide the patient perspective at Health and wellbeing events.

(f) Learning and development needs
All nursing practice is underpinned by the Nursing and Midwifery Council Code of Professional Practice (2015)5 which provides clear guidance on development, responsibilities and accountability. In addition, if not already attained the nurse will be required to complete an Oncology specialist practice module and if required the Health Assessment and Independent Nurse Prescribing course at QUB to ensure they are able to undertake nurse-led clinics.
The post-holders will also be encouraged to undertake continous professional development that is appropriate to their developing roles. The CNS will self-assess their skills and competencies against a suitable competency framework to identify their specific development needs and take measures to address these. These may include a variety of inhouse training courses, in conjunction with Macmillan specific training that will enable them to develop personally and professionally.
Learning and development needs will be identified through supervision, annual staff development and performance review in line with Trust procedure.

3.2 Service Evaluation / Demonstrating Impact

a) *What measures / methods will be used to evaluate the project / service.*
b) *Identify what the longer term impact will be resulting from the outcomes.*
c) *Is there any baseline data needed now in order to assess impact after the project? – Identify how the basic monitoring data (outputs) will be collected and who will be responsible, and how you intend to capture outcomes and who will be responsible.*
d) *Identify who the evaluation will be shared with and methods of sharing*

The assurance of safety, quality and experience through appropriate performance measures has been integral to the development of the workforce plan. The monitoring and evaluation of the plan will be led by the PHA/HSCB with key workforce metrics agreed with nursing workforce leads in PHA and HSCTs. Success will be monitored though the KPIs and any unintended consequences of the changes identified so that corrective action can be taken. This has been agreed through the regional ADs performance and service improvement monthly meetings. Specific monitoring processes will be developed and agreed at the outset of the posts.

The CNS will be expected to report on the regiaonlly agreed Cancer CNS KPIs, outlined in the previous section, on an annual basis.

Evaluations will endeavour to identify the successful areas of work undertaken and will also aim to highlight areas that have not been successful to ensure future service development learn from any issues identified. These evaluations will aim to collect quantitative and qualitative data from a variety of sources including those receiving the service e.g. patients and family members, those working within the multidisciplinary teams and those working outside the acute setting e.g. GPs.

On-going quantitative monitoring of the services will be achieved through data collection as per Trust audit process and requirements for service improvement, peer review standards for cancer patients, contribution to the Macmillan minimum data set. This data will be collected by the post holders on an on-going basis and will utilise data available through internal hospital systems including the Cancer Patient Pathway System (CaPPS), the local laboratory system, Theatre Management System and Patient Administration System.

The service will engage with patients, carers and others who use it. One of the most reliable standards against which to measure the quality of the service is the patient's experience. Feedback from those who use the service will provide a credible outcome measure to demonstrate the value of the service and to evaluate if the service is meeting its aims and objectives.

A range of methodologies and data systems will be employed to critically assess the impact of the service in relation to meeting the needs of those for whom it has been established. These include:

- Patient experience surveys (conducted at least every 2 years)
- Evaluation of any events or programmes organised by the team
- 6-monthly follow up with a sample of individuals who have accessed the service to determine if needs have been met

The post holders will liaise with the current MDTs and formative evaluation will be used on an on-going basis to ensure that the new roles are developing appropriately and meeting the needs of the team. The post holders will be expected to update to the site specific MDM Business Meetings and Lead Cancer Team to ensure the service is evolving as per the service development plan and in accordance with local and regional strategies.

3.3 Governance
It is important that services operate within a governance framework to ensure that they are safe, efficient and effective. Good governance will also help provide evidence to support the future sustainability of the service.

Please provide information on the governance arrangements for the service. This should include information about:

- *Standards the service will be working to (e.g. locally developed, professional or national)*
- *Staff performance review process*
- *Achieving Macmillan Volunteer Quality Standards*
- *Learning and development for the individuals within the service*
- *Customer satisfaction*
- *Outline details of the project team, decision making and change management forums*
- *Project reporting mechanisms.*
- *Outlining of any risks and how to mitigate against them*

The Trust has a governance structure in place, which incorporates the key elements of clinical and social care governance (safe and effective care), risk management/organisational controls, and financial governance. This integrated governance framework ensures an integrated approach to all aspects of health and social care delivery
All staff will adhere to all aspects of governance as outlined by the Trust including policies and procedures. All Trust policies are available on the Intranet and new policies introduced are highlighted and discussed at Team Meetings. Any specific policies will be developed for the service and risks identified and added to the departments risk register.

The postholder will complete a comprehensive induction corporately, in conjunction with Macmillan and departmentally. Any initial learning needs will be identified and an action plan developed.

An outline for the Knowledge and Skills Framework will be developed for the postholder and will provide the framework for an annual appraisal. This will include development of a Personal Development Learning Plan. The Postholder will be expected to contribute to the annual Departmental and Directorate User Consultation Plan, Audit Plan and Safety Quality and Patient Experience Plan.

There is a range of professional standards that the post holders will be working to, these include:

- Nursing and Midwifery Council (NMC, 2015) The Code: Standards of conduct, performance and ethics for nurses and midwives
- NMC (2007) Standards for Medicines management
- NMC (2005) Standards of proficiency for nurses and midwife prescribers
- Royal College of Nursing (RCN, 2008) Advanced Nurse Practitioners: An RCN guide to the advanced nurse practitioner role, competencies and programme accreditation

Dietetic professional standards include

- Health Professional Council (HPC) Standards of proficiency
- HPC Standards of conduct, performance and ethics
- HPC Standards for continuing professional development

Staff performance review process
All staff will participate in the Trust standard performance review process: Knowledge and Skills Framework. The nursing post holders will be line managed and supervised by the relevant assistant service manager. The support workers will be managed by the appropriate administrative team. All post holders will be accountable to the Assistant Director for the service area within which they sit. Staff performance will be monitored through

regular supervision, and good practice in project management including a project initiation document, Gantt charts in relation to key milestones and a risk register to manage the project.

Annual reports will be submitted to Macmillan Cancer Support, highlighting the progress relative to the objectives and expected outcomes of the postholders. The postholders will particpate in regular Service Reviews with the Macmillan Partnership Quality Lead.

Learning and Development
As outlined in section 3.1 (f) Learning and development needs will be identified for the staff and supported where approriate.

Customer satisfaction
As outlined in 3.2 patient satisfaction will assessed through a variety of means.

Project team, decision making & change management forums
The proposed new post holders will work within the already established MDTs. They will work collaboratively with the teams in planning and delivering services that is focused on the needs of patients. Any changes to the current services will be managed through the MDT and implementation will be a trust wide collaborative approach.

Reporting Mechanisms
At a working level the staff will report to their line manager at regular supervisory meetings. At a strategic level progress will be reported to the MDT Business meetings and to the monthly Lead Cancer Team meeting within the Trust.

3.4 Macmillan profile and the Macmillan experience

There is an expectation that all services/ developments/builds funded by Macmillan Cancer Support will be sustained following the initial funding period (with the exception of discrete projects) and will carry the name Macmillan and the appropriate agreed levels of branding for as long as the post / service exists. It is vital that those using the service will recognise that they have had a high quality Macmillan experience. Please explain in this section:

- *How the service will be Macmillan-branded?*
- *Will the Partner Organisation agree to the service and facilities carrying the Macmillan name e.g. 'Macmillan Information and Support Centre' and the charity's brand being displayed on and inside the Centre?*
- *How will the post holder / service help raise the profile of Macmillan Cancer Support?*
- *Any possible co-branding issues?*
- *How will patients recognise that Macmillan is a partner in this service through the experience they receive?*
- *How will volunteers receive an optimum experience in line with Macmillan standards?*
- *Please add any other information you feel is relevant*

The proposed service will promote the Macmillan profile and ensure all who avail of the service recognise that they have received a high quality Macmillan experience through the following key areas:

- The postholders' title will carry the name 'Macmillan' for the life time of the post.
- All promotional materials e.g. banners, posters etc will be co-branded bearing Macmillan logo and that of Southern Health & Social Care Trust as the partner organisation.
- The Macmilllan logo will be used on all stationary, publications relating to this service and on information resources produced by the team for use at health and wellbeing events
- The profile of Macmillan Cancer Support will be raised by presenting Macmillan as a funder of a range of services not just palliative care nursing for which they are renowned.
- The service will endorse Macmillan's strategy for support and information and their commitment to

patient and public involvement.

- Macmillan's Communications Dept will be utilised to assist in generating publicity
- The team will work with the Macmillan Partnership Manager, Macmillan Partnership Quality Lead and the Macmillan L&D Manager to gain support in service development, review, quality and educational needs
- Collaboration with the Southern Health & Social Care Trust Communications Team will be utilised to promote the service within the Trust.

- Staff will also endeavour to identify appropriate 'Case Studies' for Macmillan to promote the work related to this service

The postholder will promote Macmillan Cancer Support as an organisation and highlight the work that the organisation does at all opportunities through:

- Joint publicity and promotion of the service by Macmillan and the Trust
- All marketing will use the agreed Macmillan /Trust format
- All users will be given details of the Macmillan Cancer Service Improvement manager
- Work closely with Macmillan Cancer Support marketing and communications departments and agree all publicity materials.

Key: Red = High, Amber = Medium, Green = Low

Table 1: Risk Matrix

		Consequence				
		Insignificant (1)	Minor (2)	Moderate (3)	Major (4)	Catastrophic (5)
Likelihood	Almost certain (5)	**5 L**	**10 M**	**15 M**	**20 H**	**25 H**
	Likely (4)	**4 L**	**8 L**	**12 M**	**16 H**	**20 H**
	Possible (3)	**3 L**	**6 L**	**9 M**	**12 M**	**15 M**
	Unlikely (2)	**2 L**	**4 L**	**6 L**	**8 L**	**10 M**
	Rare (1)	**1 L**	**2 L**	**3 L**	**4 L**	**5 L**

Risk Identified	Score prior to mitigation	Mitigation	Score following mitigation
Unable to appoint suitable qualified nursing staff	9M	Partnership working with Southern Trust to enable appropriate nurse training and development	6L
Not all patients will make use of the additional staff	12M	The criteria for patients which are suitable to receive this service is suitably wide to ensure adequate uptake.	6L
Support workers may not have the combination of skills required for these posts i.e. clerical and clinical knowledge and experience	12M	Staff will receive additional training in the area where deficits are identified	6L

PART FOUR - PROJECT SPECIFICATION – please refer to guidance before completion

4.1 Outline initial project plan including key milestones and timelines

Urology CNS Team Development Plan - Gantt chart 2018 – 2019

Phase 1 - Actions	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
Clerical and Managerial Teams to meet to discuss new CNS team: a)Agree and draft job descriptions b)Agree and draft job plans Submit MPA to Macmillan	🟧											
Begin recruitment process through HR		🟧	🟧									
Appoint Urology B6 CNS and B3 Support Worker				🟧								
Correlate baseline data					🟧	🟧						
Discuss evaluation methodology						🟧						
Draft Nurse Led Protocols for Clinical Oncology/Surgery						🟥	🟥					
Training for CNS and Support Worker Posts						🟥	🟥	🟥				
Establish Nurse led Clinics									🟥	🟥		
Agree and establish rapid access patients										🟥	🟥	
Engage with unit teams										🟥	🟥	
Implement recovery package												🟥

4.2 Sustainability

How will the project outputs / outcomes be embedded locally>
Outline what the exit strategy will be.
What is required in order for the benefits to be sustained?

Given the CNS expansion has been led by the PHA and HSCB this provides a sustainable mechanism to build and expand the cancer CNS workforce in NI. With the introduction of KPIs against the agreed generic cancer CNS commissioning specification, sustainability will be achieveable and good monitoring against the KPIs will provide evidence of this.

This plan was approved by senior management team at HSCB/PHA in December 2015, with the first cohort of staff to be recruited in 2016/17. Charitable funding is being made available to support this plan with senior management team agreement to the tapered funding model to facilitate the 5 year incremental growth in the CNS workforce totalling 7 million over the next 11 years. The workforce plan takes account of the role of clinical nurse specialists (CNS) in contributing to high quality cancer care at the front line and the clear analysis that when patients have access to CNSs, this significantly improves patient experience. To date cancer CNS commissioning within Northern Ireland has been ad hoc and opportunistic, with provision significantly lower than the rest of the UK.

During the lifetime of the expanision plan, the associated outputs will be effectively monitored and evaluated to provide an in-depth insight into the impact achieved. This will be achieved via the use of and application of effective monitoring and evaluation systems and processes through the introduction of KPIs against the agreed generic cancer cCNS commissioning specification. Sustainability will be achieveable by ensuring embedding of protocols and pathwats into routine service and good monitoring against the KPIs will provide evidence of this.

Macmillan Application for Funding: Cost Profile: Complete the number of columns as appropriate according to the proposed funding model.

Basic salary plus on costs for **each grade** of staff (e.g. employers pension and NI contributions)

	Year One (16/17)	Year Two (17/18)	Year Three (18/19)	Year Four (19/20)	Year Five (20/21)	Year Six (21/22)
Macmillan contributions	**90%**	**80%**	**70%**	**60%**	**50%**	**20%**
Band 7 CNS	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
Band 3 Support Worker (0.25WTE)	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]

Travel costs

	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
Band 7 CNS	£1000	£1000	£1000	£1000	£1000	£1000
Band 3 Support Worker (0.25WTE)	-	-	-	-	-	-

Capital Costs (please specify)

Set up costs – Year One Only (please specify)

£1000

Volunteer costs (if appropriate)

	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
	NA	NA	NA	NA	NA	NA

Learning & Development (if appropriate)

	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
	NA	NA	NA	NA	NA	NA

User Engagement or Other – please give breakdown

Totals

	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
Totals	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]

Total contribution requested from Macmillan and the specified period of funding
Salaries:
Band 7: £[redacted]
Band 3 (0.25 WTE): £[redacted]
Travel: £[redacted]
Set up costs: £1000

Macmillan Contribution over 6 years - £230,793

The Partner Organisation has seen the principles set out in Appendix A (the Grant Agreement) setting out the Conditions of Grant for Capital Projects. These (and any other project specific conditions set out in the Schedules to Appendix A) will be discussed and mutually agreed prior to the application for Outline Scheme Approval (Stage 1) from Macmillan's Board of Trustees.

Signed Date

Position in Organisation

Southern Health
and Social Care Trust

Quality Care - for you, with you

Nursing and Midwifery
Accountability and Assurance Framework

Heather Trouton
Executive Director of Nursing, Midwifery & AHPs
February 2022
Version 5

APPENDIX 1 – FRAMEWORK LOGIC MODELS

1. PURPOSE

The Accountability and Assurance Framework for Nursing and Midwifery (hereafter referred to as the 'Framework') has been developed to ensure there are clear and effective lines of accountability and assurance for the professional governance of the Nursing and Midwifery workforce in the Southern Health and Social Care Trust (hereafter referred to as the 'Trust').

The Framework sets out the arrangements, which assure the standards of practice, conduct and professionalism of the workforce. It enables the Trust, through the Executive Director of Nursing, Midwifery and AHPs (EDoN) to assure itself that effective governance systems are in place to enable the achievement of the professional standards and regulation requirements that nurses and midwives must uphold in order to be registered to practice (NMC, 2015; NMC 2016) and that services provided by the Nursing and Midwifery workforce are safe and of a high quality.

The Framework creates an environment, which enables nurses and midwives to:

- Practice in accordance with The Code (NMC, 2015), the organisational vision and corporate objectives to ensure the best possible care and treatment experience for service users and families.
- Maintain the standards of conduct of practice and to provide high-quality services and promote public trust and confidence in Nursing and Midwifery services.
- Be responsible for their continuous learning and development.
- Highlight and address areas of concern and risk if required.

The Framework details the professional nursing structure and supporting mechanisms essential to the governance of the Nursing and Midwifery workforce. It may evolve in light of experience, learning and service reconfiguration or development.

2. STRATEGIC CONTEXT

HSC Trusts have corporate accountability for maintaining and improving the quality of services in the form of Clinical and Social Care Governance. The responsibility of oversight and assurance for the quality of Nursing and Midwifery is devolved to the Executive Directors of Nursing and Midwifery. Individually, nurses and midwives are professionally accountable to the Nursing and Midwifery Council (NMC) but they also have a contractual accountability to their employer and are accountable, in law, for their actions.

This Framework sets out how the EDoN provides assurance to the Chief Executive, Trust Board and the Chief Nursing Officer (CNO) on the quality and professionalism of Nursing and Midwifery. When implemented, the Framework provides evidence that structures and processes are in place to provide the right level of support, scrutiny and assurance across all Nursing and Midwifery services.

This Framework reflects the five standards outlined in the Assurance Framework for Professional Nursing and Midwifery Practice in Northern Ireland (2019, draft version 5)

Standard 1: There must be explicit and effective lines of nursing and midwifery accountability from every registrant in every care and service setting to the EDoN and through to CNO.

Standard 2: There must be collective professional leadership across every care and service setting that maximises the unique contribution of Nursing and Midwifery to safe and effective care.

Standard 3: Person-centred practice must be prioritised and embedded across every care and service setting.

Standard 4: Practice environments must be conducive to promoting positive health and well-being in every care and service setting.

Standard 5: The Nursing and midwifery workforce must be supported and equipped for practice across every care and service setting.

3. PROFESSIONAL REQUIREMENTS

As an aid to using the Professional Assurance Framework some of the underlying terminology is clarified below.

3.1 Accountability and Responsibility

The terms ‘responsibility’ and ‘accountability’ should not be used interchangeably.

Responsibility can be defined as a set of tasks or functions that an employer, professional body, court of law or some other recognised body can legitimately demand.

Accountability can be defined as demonstrating an ethos of being answerable for all actions and omissions, whether to service users, peers, employers, standard-setting / regulatory bodies or oneself.

3.2 Scope of Practice

Nurses and midwives must work within the parameters of their designated role and capability. This was formerly known as the Scope of Professional Practice but guidance on this has subsequently been incorporated into the NMC Code.

3.3 Delegation Framework for Nursing & Midwifery Practice (NIPEC 2017)

The purpose of delegation is to ensure the most appropriate use of skills within a health and social care team to achieve **person-centred outcomes**.

Delegation is defined as the process by which a nurse or midwife (delegator) allocates clinical or non-clinical tasks and duties to a competent person (delegatee).
The delegator remains accountable for the overall management of practice (NIPEC, 2019).

4. FRAMEWORK INTERVENTIONS

The Trust has a range of mechanisms in place to support assurance and accountability of the Nursing and Midwifery workforce.

Governance Structures, Roles and Responsibilities

Audit, Assurance and Compliance Arrangements

Learning, Development and Support

Workforce

Registration / Revalidation

Raising and Handling Concerns

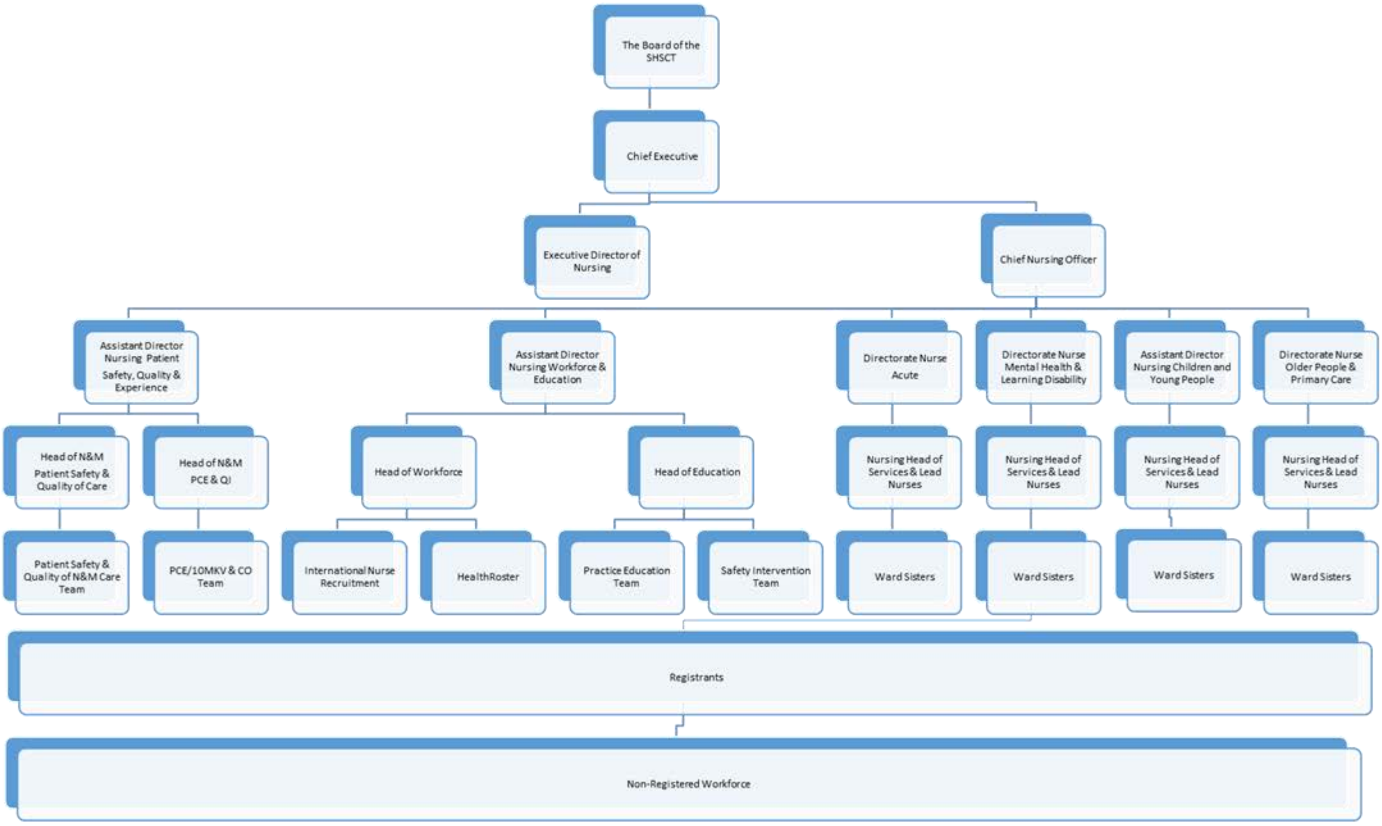
Nursing Quality in the Independent Sector

Figure 1: Accountability and Assurance Interventions

Each of the interventions is explored in detail in the following chapters.

5. GOVERNANCE STRUCTURES, ROLES AND RESPONSIBILITIES

The professional Nursing and Midwifery accountability and leadership structures within the SHSCT are as outlined below.



The above configuration has potential for further change depending on the agreed Nursing structure in operational directorates

5.1 Professional Accountability Roles and Responsibilities

Trust Board

The Board of the Southern Health and Social Care Trust has a responsibility to ensure that safe, high-quality care is provided and is underpinned by the public service values of accountability, probity and openness (Southern Health and Social Care Trust, 2017).

Chief Executive

The Chief Executive is the accountable officer of the Trust and holds ultimate accountability for the delivery of clinical, care and professional governance and adherence to the guidance issued by the Department of Health (DoH) in respect of governance.

Executive Director of Nursing, Midwifery & AHPs

The EDoN is responsible to Trust Board for providing robust triangulated evidence regarding the quality of professional nursing and midwifery practice, associated workforce issues and patient experience. This is done so that the Trust Board may make informed and sound decisions in fulfilling their joint responsibility regarding quality assurance and patient safety. That evidence should also include issues regarding escalation so that the Trust Board are informed of the risks and challenges the organisation faces. In addition, the EDoN is directly accountable to the CNO in respect of professional nursing and midwifery practice within the Trust.

In order to do this effectively, the EDoN is responsible for ensuring that there are robust and effective assurance structures and processes in place from every care and service setting through to the EDON. These structures and processes should drive improvement in the quality of nursing care and address any identified suboptimal standards of care.

The EDoN is responsible for ensuring that nursing care provided to patients is of a high standard meeting recognised professional standards and statutory requirements.

The EDoN provides professional leadership by ensuring professional issues are considered as part of strategic professional and operational service delivery.

Corporate Nursing Team

Assistant Director of Nursing and Midwifery (Patient Safety, Quality & Experience)

The Assistant Director of Nursing and Midwifery (Patient Safety, Quality & Experience) reports to the EDoN and is responsible for providing assurances that the Trust has robust arrangements in place to achieve high standards of professional governance to support the delivery of quality Nursing and Midwifery care. He / she works closely with the nursing operational Assistant Directors / Directorate Nurses to provide assurances.

The Assistant Director has oversight of established triggers and processes for the escalation of concerns about practitioner conduct, capability and / or fitness to practice and advise on legislation, rules, standards and guidance pertaining to nursing and midwifery.

In addition, the Assistant Director develops and reviewing policies, procedures and protocols to ensure that these promote best Nursing and Midwifery practice and the delivery of high quality care.

The Assistant Director is responsible for ensuring that the EDoN is able to fulfil her / his role at Trust Board. This includes ensuring that robust assurance processes are implemented and their effectiveness monitored. He / she is responsible for ensuring that the EDoN is briefed about each clinical area and that issues of concern are escalated accordingly.

The Assistant Director will formulate a quarterly assurance paper that summarises the overall position in relation to Nursing and Midwifery assurance, including any action planned to address risks and areas of concern. This will be submitted to the Performance Committee via SMT.

He / she will ensure that the risk register accurately reflects the risk associated with the challenges nursing and midwifery are currently facing.

The Assistant Director is responsible for ensuring that nursing care provided to patients is of a high quality, meeting national standards and statutory requirements. Where significant quality and safety issues are identified, he / she in conjunction with the operational Nursing Assistant Director / Directorate Nurse will initiate a thorough assessment of the clinical / service area and formulation of an improvement plan and ensure that the EDoN is briefed regarding the situation.

The Assistant Director is responsible for leading on the improvement of patient experience in line with regional priorities and in response to patient / client experience feedback.

Head of Nursing & Midwifery (Patient Safety and Quality of Care)

This Head of Nursing (Patient Safety and Quality of Care) is responsible for providing professional leadership and has managerial responsibility for the safety and quality of nursing care across the Trust.

The Head of Nursing works collaboratively across operational directorates to ensure high standards of patient experience and compassionate care, whilst promoting compliance with relevant standards and indicators of the safety and quality of nursing and midwifery.

He/she supports the Assistant Director of Nursing, Patient Safety, Quality and Experience in strategic development of nursing and midwifery standards, policies and procedures, quality initiatives and the development and implementation of key performance indicators.

He/she is responsible for all aspects of the operational management of the Nurse Governance Team and Information Analysist, in addition to any temporary staff aligned to the team to support regional or local initiatives. He/she will provide clear leadership to all staff within their sphere of responsibility and will be responsible for effective financial management and the efficient use of all resources.

Head of Nursing & Midwifery (Patient & Client Experience & Quality Improvement)

Head of Nursing & Midwifery (Patient & Client Experience & Quality Improvement) is responsible for providing strong professional leadership and taking a lead role in ensuring high standards of quality and patient/client experience. Specifically, the Head of Nursing will support the Assistant Director with improving Nursing & Midwifery assurance using quality improvement methodology across the Trust, working collaboratively with internal and external stakeholders. They will help to build capacity and capability in improvement science across the nursing and midwifery workforce.

The Head of Nursing has managerial responsibility for the Patient and Client Experience (PCE) Team, including the PCE / 10,000 More Voices Facilitator, Care Opinion Facilitator, Virtual Visiting Service and provides oversight and support to the Patient Experience Feedback Pilot Manager and staff.

Assistant Director of Nursing and Midwifery, Workforce Development and Training

The Assistant Director of Nursing and Midwifery, Workforce Development and Training is responsible for all aspects of the Trust's arrangements for post registration Nursing and Midwifery training and education and for the Nursing and Midwifery pre-registration clinical placement oversight function. This requires the development and maintenance of partnership working with Department of Health (DoH), Public Health Agency (PHA), Health and Social Care Board (HSCB), universities, colleges and other training providers. They have a commissioning, performance management and quality assurance role for training, which will be provided both internally and externally to the Trust.

The Assistant Director of Nursing and Midwifery Workforce Development and Training contributes to the Trust's corporate workforce planning and development. This involves engaging with colleagues from human resources and other disciplines in designing and putting in place various training programmes and arrangements including Qualifications and Credit Framework (QCF).

Head of Nursing and Midwifery Education and Workforce Development

The Head of Nursing and Midwifery Education and Workforce Development is responsible for the development of a learning and assessment education governance framework to ensure the NMC requirements are met; providing strong professional leadership, and facilitating learning and development through effective education strategies. This includes leading on Trust-wide training needs analyses; coordinating post registration education requirements, pre-registration education requirements and the education and development of Nursing and Midwifery support staff with all internal and external stakeholders.

They are also responsible for leading and coordinating workforce development initiatives related to the Nursing and Midwifery workforce.

Head of Nursing and Midwifery Workforce Planning and Utilisation

The Head of Workforce Planning and Utilisation is responsible for the planning and utilisation of the Nursing and Midwifery Workforce across the Trust. He / she leads workforce planning and utilisation of the nursing and midwifery workforce using appropriate and relevant strategies for workforce measurement and appropriate use of skill mix, as well as contribute to the Trust's corporate workforce planning and development agenda. They provide support and leadership to Directorates in changing working practices in nursing roles to ensure the nursing and midwifery workforce is dynamic, responsive and adaptive to the needs of patients / clients and the public and will help to build capacity and capability to support workforce innovation and new role development. Working with a wide range of stakeholders key actions as outlined in the Trust's Nursing and Midwifery Workforce Action Plan (SHSCT 2019) will be completed through the implementation of effective workforce strategies.

Safe Staffing Nursing and Midwifery lead

The Safe Staffing Nursing and Midwifery Lead is responsible for the implementation of the

Public Health Agency Delivering Care policy framework for nursing and midwifery workforce within the Southern Trust. He/she works in close collaborative partnership with regional and directorate colleagues to develop models for safe staffing across all programmes of care. They have a strong remit for implementation of workforce planning, recruitment and retention initiatives and raising the profile of the nursing and midwifery profession.

Operational Nursing Teams

Nursing Operational Assistant Directors / Directorate Nurses

The Directorate Nurses / Nursing Assistant Director in CYP are directly accountable and responsible for the professional nursing and midwifery practice within their Division / Directorate. They jointly report to the operational directors (operational issues) and EDoN (professional issues) and work in conjunction with the Assistant Directors of Nursing (Patient Safety, Quality and Experience and Workforce Development and Training) to provide assurances regarding nursing and midwifery practice and workforce and training within their areas of responsibility.

Nursing Heads of Service

Heads of Service who are registered nurses / midwives are accountable and responsible for the professional nursing and midwifery practice within their service areas. They will operationally report to the Operational Assistant Directors within their Division / Directorate and work in conjunction with the Directorate Nurse/Nursing Assistant Director in CYP and the Assistant Directors of Nursing (Patient Safety, Quality and Experience and Workforce Development and Training) and Heads of Nursing to provide assurances regarding nursing and midwifery practice and workforce and training within their areas of responsibility.

Lead Nurses / Nurse Managers / Ward Sisters / Charge Nurses / Team Leads

This group of senior nurses will provide clinical, professional and managerial leadership to ensure the objectives and quality standards of the Framework are met. They will inspire, motivate and empower nurses, midwives and wider health care teams to continually improve the patient experience and provide effective nursing care to enhance patient safety.

They are responsible for the quality of nursing / midwifery care in their area and will deliver on this by ensuring that their staff are inducted and trained to effectively and safely carry out their duties, facilitate supervision and the implementation of staff support policies. They will escalate concerns regarding practitioners' conduct, capability or fitness to practice as required, following discussion, they will progress actions agreed, monitor and feedback.

Nursing and Midwifery Staff

All Nursing and Midwifery registrants are responsible for meeting the regulatory standards of conduct and practice as set out for their profession by the Nursing and Midwifery Council (NMC) professional regulatory body. They are individually responsible to ensure they maintain their professional registration. They must comply with Trust policies and procedures and their on-going professional development designed to support them in the delivery of safe and effective care.

Nursing Assistants

Nursing Assistants are required to meet the Standards for Nursing Assistants (DoH, 2018) and, to comply with Trust policies and procedures designed to support them in delivering safe and effective care.

Maternity Support Workers

Maternity Support Workers are required to complete the Regional Maternity Support programme; to comply with Trust policies and procedures designed to support them in delivering safe and effective care.

5.1 Supporting Arrangements

N&M Patient Safety and Quality of Care Team

The N&M Patient Safety and Quality of Care Team support and facilitate teams to achieve improvements in Nursing and Midwifery care through a variety of approaches including quality improvement and practice development.

Practice Education Team

This team consists of Practice Education Facilitators, led by a Practice Education Coordinator. Under the direction of the Assistant Director of Nursing and Midwifery Workforce Development and Training, the team's remit is to develop and sustain an effective learning culture, infrastructure and environment for Nursing and Midwifery students on a Trust-wide basis within a NMC approved governance framework. They also evaluate the effectiveness of pre and post-registration learning and education activities to provide enhanced value added benefits reflected in improved quality of care of patients and clients. Another of the team's remit is to lead on the implementation, monitoring and evaluation of the Trust's new registrant Induction, Rotation and Preceptorship programmes.

Revalidation Team

The Nursing and Midwifery Revalidation Team support operational directorates and the corporate nursing team to provide the EDoN with oversight and assurance with regards to Nursing and Midwifery revalidation. The remit of this team will be extended to provide assurances around other aspects of the framework, including supervision.

5.2 Professional Governance Forums

There are a number of professional fora across directorates which support the EDoN in providing assurances regarding the quality of professional nursing and midwifery practice. These fora promote an ethos of awareness, continuous learning, accountability and improvement. They are essential in supporting corporate governance arrangements, specifically in relation to promoting continuous professional education and development and ensuring professional standards and regulatory requirements are in place and adhered to. They ensure professional processes are monitored and reviewed and that all risks related to the nursing and midwifery workforce are considered and where necessary mitigated against through timely and effective action planning and dissemination of learning.

6. AUDIT, ASSURANCE AND COMPLIANCE ARRANGEMENTS

The Trust monitors Nursing and Midwifery professional governance through a suite of performance and quality indicators designed to ensure that the care, treatment and support are of a consistently high quality throughout the system. These are communicated down through professional nursing and midwifery structures and action plans developed as required to provide assurance.

6.1 Accountability Reporting

The EDoN compiles an Executive Director of Nursing and Midwifery report twice yearly to Trust Board to provide assurances regarding professional nursing and midwifery practice. In addition, the EDoN will table a performance report to the Performance Committee on a quarterly basis.

6.2 Monitoring Arrangements

Nursing and Midwifery practice is reviewed and monitored through a range of processes and fora as outlined in the table below.

Key Performance / Quality Indicator and Reports	Description	Frequency of Review	Reviewed / Monitored through
Executive Director of Nursing, Midwifery and AHPs Reporting	A summary of activity and developments within the Nursing and Midwifery profession.	Twice Yearly reports to Trust Board Quarterly reports to the Performance Committee	• Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Senior Management Team • Performance Committee • Trust Board
Induction status reporting	Compliance with Trust Nursing and Midwifery Induction Requirements - New registrants - Registrants - Role specific	Biannual	• EDON Assurance meetings with Directorates • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Performance Committee
Preceptorship requirements reporting	Compliance Nursing and Midwifery preceptorship requirements	Quarterly	• EDON Assurance meetings with Directorates • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Senior Management Team • Performance Committee
Audit of Compliance with Mandatory Training	Scorecards of mandatory training performance	Quarterly	• EDON Assurance meetings with Directorates • Local and Directorate management meeting • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF)
Nursing and Midwifery Supervision Audit	Audit of supervision practice against Supervision Standards.	Quarterly	• EDON Assurance meetings with Directorates • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Performance Committee
Audit of Compliance with Annual KSF and Personal Development Plans	Sample audit of Personal Development Plan completion	An annual audit of PDP completion	• EDON Assurance meetings with Directorates • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery

Key Performance / Quality Indicator and Reports	Description	Frequency of Review	Reviewed / Monitored through
			Governance Forum (SNMGF)
Compliance with Standards for Learning and Assessment in Practice (NMC, 2008)	Mentor register reports Placement evaluation reports Educational Audits	Biannual Biannual Biannual	• EDON Assurance meetings with Directorates • Practice Education Team • Directorate Nursing and Midwifery Governance Fora. • Senior Nursing and Midwifery Governance Forum (SNMGF) • Performance committee
Post registration Education service level agreement usage , including DNA rate	Post registration Education service level agreement usage , including DNA rate	Bi annual	• EDON Assurance meetings with Directorates • Operational director • SNMGF • Performance committee
Audit of Compliance with Normative Staffing	Monitoring report Phases 1-11	Biannual	• EDON Assurance meetings with Directorates • Directorate Nursing and Midwifery Governance Fora. • Office of Chief Executive and Executive Director of Nursing
Revalidation and Registrations Status Reporting	Compliance with NMC registration requirements	Quarterly	• EDON Assurance meetings with Directorates • Directorate management and governance Fora • Directorate Nursing and Midwifery Governance Fora • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Performance committee
Fitness to Practice	Summary of Nursing and Midwifery staff referred to NMC	Bi annual	• EDON Assurance meetings with Directorates • Performance committee • SNMGF • Operational Directorates
Compliance with regional and locally agreed clinical NQI's and KPIs including PACE and Patient Safety Thermometer data.	Compliance with regional clinical NQI Bundles and other relevant safety / practice indicators	Monthly	• Ward Sisters / Charge Nurses • Lead Nurses
		Quarterly	• EDON Assurance meetings with Directorates • Directorate Nursing and Midwifery Governance Fora • Operational Director • Senior Nursing and Midwifery Governance Forum (SNMGF) • Trust Performance Committee
Patient Experience Feedback	Utilise the feedback of service users and / or carers to improve services. Includes 10,000 voices feedback.	Monthly	• Directorate Governance Fora • Operational Director
		Quarterly	• EDON Assurance meetings with Directorates • Trust Senior Management Team • Patient and Client Experience Steering Group • Trust Patient and Client Experience Committee

Key Performance / Quality Indicator and Reports	Description	Frequency of Review	Reviewed / Monitored through
Nursing Quality in the Independent Sector	Monitored via the Trust Independent Sector Governance Forum	Bi annual	• Operational Director • Trust performance committee • Monthly meetings with AD PSQE

The EDoN and Corporate Nursing Team meet with the Operational Directors and Assistant Directors on a quarterly basis to review performance data and agree priority actions.

In addition the Head of Nursing (Patient Safety and Quality of Care) attends the weekly Corporate Governance meeting taking forward any issues relevant to nurses and midwives.

6.3 Information Systems

To support the Nursing and Midwifery Accountability and Assurance Framework there are a number of information systems alongside the need to manually collate information:

- HRPTS Workforce Information System
- DATIX Complaints and Incident Management System
- Allocate HealthRoster System, including SafeCare
- Easy Information Management System (EIMS) – Mentor Register
- E-CATS – Health Visiting and District Nursing
- Filemaker
- HCAT System
- Revalidation register

7. LEARNING, DEVELOPMENT AND SUPPORT

There are systems in place to monitor workforce volumes, highlight issues and to ensure that the Nursing and Midwifery workforce have the appropriate knowledge, skills and support needed to provide high-quality care.

Corporate Induction

The Trust Induction Policy (SHSCT, 2016) requires all newly appointed staff to attend a Corporate Induction (in addition to a Departmental Induction / orientation). The programme comprises of information of common interest across all staff groups and contributes to building a commonality of understanding amongst the workforce. New employees are required to attend Corporate Induction ideally within three months of commencement but no longer than six months following appointment.

Corporate Professional Welcome

The Corporate Nursing Team deliver a Corporate Professional Welcome programme to all newly appointed nursing and midwifery registrants taking up post in the Southern Trust. The programme is facilitated on a monthly basis and focuses on HSC values and Professional roles and responsibilities, and provides the new appointees with an opportunity meet members of the Corporate Nursing team.

Nursing Assistant Induction and Developmental pathway

An induction and development pathway is available for Nursing Assistants who have taken up post in the Trust. The programme, facilitated by the Trust's Vocational Workforce Assessment Centre team, is underpinned by the DoH (2018) Standards for Nursing Assistants, and supports both the role and career progression of Nursing Assistants, equipping them with the necessary knowledge, skills and attitudes to fulfil their role.

Specialty / Departmental Induction

The Trust Induction Policy (2016) requires all new employees to undertake specialty / departmental induction commencing on the first day in the workplace and ending when the individual becomes fully integrated into the department to ensure they have the information they may need to undertake the requirements of the post and to undertake the requirements of the job / professional role.

Preceptorship Programme

The Practice Education Team delivers a Preceptorship Programme to new registrants. The duration of the programme is six months and runs concurrently with induction and the probationary period. A Preceptorship procedure (SHSCT, 2020) details the requirements for the Preceptorship Programme. The Trust reports annually to the Chief Nursing Officer (CNO) and quarterly to Trust Board regarding compliance with the Preceptorship Framework (DHSSPS, 2013).

Nursing and Midwifery Supervision & Annual Appraisal

The learning and development requirements of the Nursing and Midwifery workforce are identified through the Trust supervision and appraisal systems. The Trust considers the implementation of supervision and KSF processes as a critical priority in valuing staff and supporting their development to help achieve the key objective of safe, high-quality health and social care. The outcome of supervision activities informs the individual's KSF and Personal Development Plans, including identification of training requirements.

Corporate Mandatory Training

The Trust Corporate Mandatory Training Policy (Southern Health and Social Care Trust, 2021) details the training requirement that is essential for the roles and responsibilities of posts, as well as meeting the Trust corporate targets. The policy denotes the mandatory training requirements for nursing, midwifery and nursing assistant staff groups.

Role Specific Training

All clinical areas ensure Nursing and Midwifery staff undertake role specific training to deliver safe and effective care. This is managed locally by the Ward Sister / Charge Nurse / Team Lead and all registrants.

Continuous Professional Development (CPD) Maintenance

All nursing and midwifery registrants have access to educational programmes provided through the Clinical Education Centre Level Agreement and the Education

Commissioning Plan which provides them with opportunities to maintain Post Registration Training and Learning and gain recognition for learning.

Clinical Education Centre (CEC) – Service Level Agreement (SLA)

All nursing and midwifery registrants have access to the CEC which provides them with a range of programmes to maintain continuous professional development. Monitoring and uptake is ongoing throughout the financial year through monthly reports from the CEC. The procedure for the Management of the Nursing and Midwifery SLA with the CEC provides guidance on all courses available and with the CEC (SHSCT, 2021)

Education Commissioning Cycle – Training Needs Analysis

As part of the Regional Education Commissioning Group chaired by the DoH funds are allocated for education to each HSC Trust. The completion of an annual Training Needs Analysis facilitates Nursing and Midwifery staff to undertake further education including stand-alone modules, short courses and specialist practice to facilitate the development of skills, knowledge and expertise for practitioners. The procedure for the Management of Nursing and Midwifery Post-Registration Education Commissioning provides guidance on all aspects of the Nurse Education Commissioning process (SHSCT, 2021)

8. WORKFORCE

The Trust recognises that ensuring appropriate nurse staffing is a key element in influencing the quality of care. Given this, a comprehensive Nursing and Midwifery Workforce Action Plan 2019 – 21 was implemented, this plan is currently under review for the period 2022 - 24.

8.1 Recruitment

Active recruitment of Nursing and Midwifery staff occurs on an ongoing basis via an open advertisement with the Business Services Organisation (BSO). Targeted recruitment via International Nurse Recruitment, UK wide recruitment fairs and local recruitment is managed by the HR Trust's recruitment team and the Corporate Nursing Team in a planned process. Monthly vacancy reports are reviewed by Directorates and escalation processes are in place to address staff shortages.

8.2 Delivering Care Project (Normative Staffing).

The Delivering Care Project continues to be implemented (DHSSPS, 2014). It aims to support the provision of high quality care which is safe and effective in hospital and community settings, through the development of a framework to determine staffing ranges for the Nursing and Midwifery workforce in a range of major specialties. Bi annual monitoring reports are completed and the Trust works closely with the PHA in all stages of implementation and review. This includes the monitoring of the ongoing Delivering Care Investment 2021- 2026.

9. REGISTRATION / REVALIDATION

The Trust has developed an infrastructure to support the registration of the Nursing and Midwifery workforce which enhances the professional regulation of the workforce and reinforces the individual's responsibility to provide quality Nursing and Midwifery services.

Monitoring at Operational Level

While the responsibility to maintain registration lies with the registrant, line managers are responsible for ensuring that registered nurses and midwives have a valid registration and are on the NMC Register (SHSCT, 2017c).

HRPTS Oversight & NMC Registration Employer Centralised Oversight

The Trust has a dedicated Revalidation Team which record and monitor Nursing and Midwifery workforce registration and renewal status. The regional HRPTS system is used for central recording and monitoring of workforce registration and renewal status. Monthly reports are issued to managers on registration and renewal status.

Pre-Employment Checks

The Trust Recruitment and Selection Procedure (SHSCT, 2010) stipulates a pre-recruitment phase which involves the development and approval of personnel specifications and a range of checks to be undertaken pre- employment.

NMC Registration and Renewal Processes

The Trust Policy on the Validation and Monitoring of Registration with a Professional Regulatory Body (SHSCT, 2017d) defines the approach for registration and the maintenance of Nursing and Midwifery professional registration.

10. RAISING AND HANDLING CONCERNS

The Trust has a range of mechanisms for raising and handling concerns which are designed to ensure the Nursing and Midwifery workforce achieve and maintain appropriate standards of conduct, performance and behaviour.

Identification of Poor or Variable Performance

Concerns about poor or variable performance are identified through supervision, probationary reviews, incidents, complaints, patient feedback, whistleblowing and managerial engagement with front-line teams. Depending on the severity and potential impact of the issues identified a line manager may seek to resolve locally through identification of further training and development needs, increased supervision or enact the Trust's management of probationary, capability or disciplinary procedures.

Probationary

All Nursing and Midwifery appointments are subject to a probationary period which is normally 6 months duration, during which time progress is monitored. In the event of unsatisfactory progress, despite appropriate support and / or counselling, employment will be terminated with appropriate notice either during or at the end of the probationary period in accordance with the Trust's procedure for probationary periods (SHSCT, no year).

Management of Capability, Conduct or Health Concerns

The Trust Capability Procedure (SHSCT, 2015a) has been designed for use in situations where there is evidence of '*a genuine lack of capability rather than a deliberate failure on the part of the employee to perform to the standards of which he / she is capable*'.

The Trust Disciplinary Procedure (SHSCT, 2015b) is designed to help and encourage all employees to achieve and maintain appropriate standards of conduct, performance and behavior.

Line managers work very closely with the Trust Occupational Health Department and Attendance Management Team to appropriately manage health concerns related to the Nursing and Midwifery workforce.

Management of Fitness to Practice Referrals to NMC and NMC Investigation Process

Trust Procedures for initiating and managing a referral to a Professional Regulatory Body and the Independent Safeguarding Authority and Requesting the DHSSPS to issue an ALERT (SHSCT, 2015c) outline the processes to be followed should this be required. All referrals to NMC for fitness to practice and requested for a CNO alert to be issued should be discussed with and quality assured by the Assistant Director of Nursing (Patient Safety, Quality and Experience) and approved by the EDoN.

The corporate nursing team are in the process of setting up a pilot of 'Nurses in Difficulty Clinics' to support both nurses and midwives involved in internal HR and other investigations and NMC investigations and hearings and their line managers.

11. NURSING QUALITY IN THE INDEPENDENT SECTOR

There are robust processes in place for assuring the quality and safety of services commissioned from third or independent sector providers.

Contracts

Where externally provided services are commissioned by the Trust, the same high levels of compliance with Trust safety and quality standards are required to be implemented by the Provider through adherence to robust, descriptive contracts. The contracts stipulate clear arrangements for monitoring that these standards are met. Advice and guidance can be sought from the Operational Assistant Directors or Assistant Directors of Nursing as required.

If concerns are identified regarding the conduct, capability or fitness to practice of a registrant not employed by the Trust the Trust Procedures for initiating and managing a referral to a Professional Regulatory Body and the Independent Safeguarding Authority and Requesting the DHSSPS to issue an ALERT (SHSCT, 2015c) should be followed.

Contract Management and Monitoring

There are identified contract managers who undertake both formal and informal contract management and monitoring. At a minimum, an Independent / 3rd Party Contractor is subject to an annual formal Contract Management meeting.

The majority of Independent / 3rd Party Contractors engaged with by the Trust are registered with RQIA and subject to their ongoing monitoring and inspection.

12. REFERENCES

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Southern Health and Social Care Trust (2015b) *Disciplinary Procedure*

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Southern Health and Social Care Trust (2020) Policy for the management of the Nursing and Midwifery Council Standards for Education and Training Parts 1, 2 and 3, and Standards of proficiency for registered nurses (NMC 2018) and Midwives (NMC 2019)

Southern Health and Social Care Trust (2021) *Procedure for the Management of the Nursing and Midwifery Service Level Agreement with the Clinical Education Centre*

Southern Health and Social Care Trust (2021) *Procedure for the Management of Nursing and Midwifery Post-Registration Education Commissioning*

Southern Health and Social Care Trust (2020) *Preceptorship Procedure for Nurses, Midwives and Specialist Community Public Health Nurses*

Southern Health and Social Care Trust (2017) *Board Assurance Framework*

Southern Health and Social Care Trust (2017a) *Procedure on the Identification, Management and Monitoring of Practice Placements for Students who are undertaking NMC approved programmes.*

Southern Health and Social Care Trust (2017b) *Procedure for Maintaining the Trust Register.*

Southern Health and Social Care Trust (2017c) *Policy on the Validation and Monitoring of Registration with a Regulatory Body*

Southern Health and Social Care Trust (2017d) *Professional Registration Policy*

Southern Health and Social Care Trust (2019) *Nursing and Midwifery Workforce Action Plan 2019-21*

Appendix 1

Southern Health and Social Care Trust

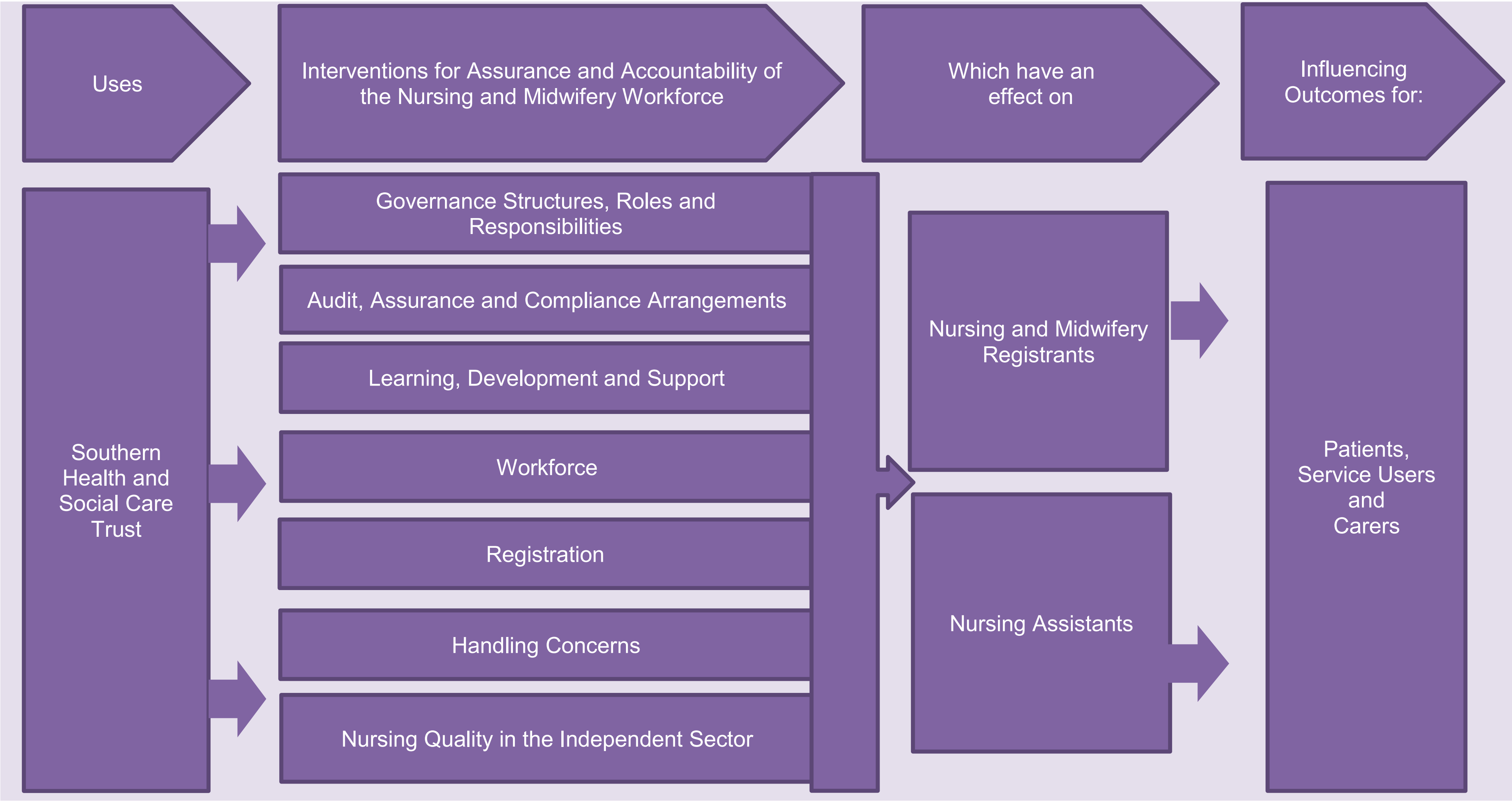
Quality Care - for you, with you

Nursing and Midwifery Accountability and Assurance

Logic Models

Southern Health
and Social Care Trust
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery



Uses

Interventions for Assurance and Accountability of the Nursing and Midwifery Workforce

Which have an effect on

Influencing Outcomes for:

Southern Health and Social Care Trust

Governance Structures, Roles and Responsibilities

Audit, Assurance and Compliance Arrangements

Learning, Development and Support

Workforce

Registration

Handling Concerns

Nursing Quality in the Independent Sector

Nursing and Midwifery Registrants

Nursing Assistants

Patients, Service Users and Carers

Southern Health and Social Care Trust
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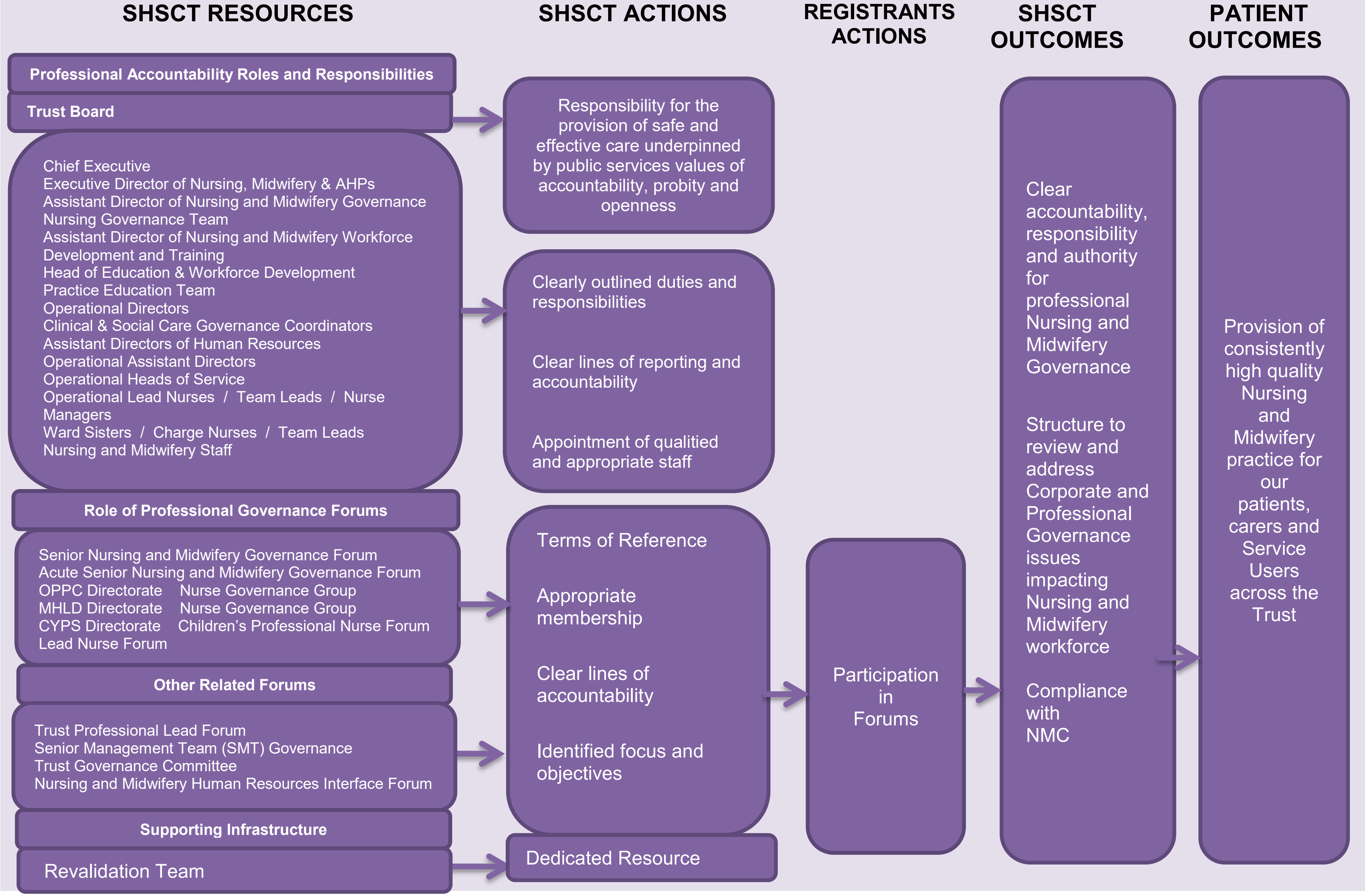
Accountability and Assurance Framework
Nursing and Midwifery

Governance Structures, Roles and Responsibilities



SHSCT RESOURCES

Professional Accountability Roles and Responsibilities

Trust Board

Chief Executive
Executive Director of Nursing, Midwifery & AHPs
Assistant Director of Nursing and Midwifery Governance
Nursing Governance Team
Assistant Director of Nursing and Midwifery Workforce Development and Training
Head of Education & Workforce Development
Practice Education Team
Operational Directors
Clinical & Social Care Governance Coordinators
Assistant Directors of Human Resources
Operational Assistant Directors
Operational Heads of Service
Operational Lead Nurses / Team Leads / Nurse Managers
Ward Sisters / Charge Nurses / Team Leads
Nursing and Midwifery Staff

Role of Professional Governance Forums

Senior Nursing and Midwifery Governance Forum
Acute Senior Nursing and Midwifery Governance Forum
OPPC Directorate Nurse Governance Group
MHLD Directorate Nurse Governance Group
CYPS Directorate Children's Professional Nurse Forum
Lead Nurse Forum

Other Related Forums

Trust Professional Lead Forum
Senior Management Team (SMT) Governance
Trust Governance Committee
Nursing and Midwifery Human Resources Interface Forum

Supporting Infrastructure

Revalidation Team

SHSCT ACTIONS

Responsibility for the provision of safe and effective care underpinned by public services values of accountability, probity and openness

Clearly outlined duties and responsibilities

Clear lines of reporting and accountability

Appointment of qualitied and appropriate staff

Terms of Reference

Appropriate membership

Clear lines of accountability

Identified focus and objectives

Dedicated Resource

REGISTRANTS ACTIONS

Participation in Forums

SHSCT OUTCOMES

Clear accountability, responsibility and authority for professional Nursing and Midwifery Governance

Structure to review and address Corporate and Professional Governance issues impacting Nursing and Midwifery workforce

Compliance with NMC

PATIENT OUTCOMES

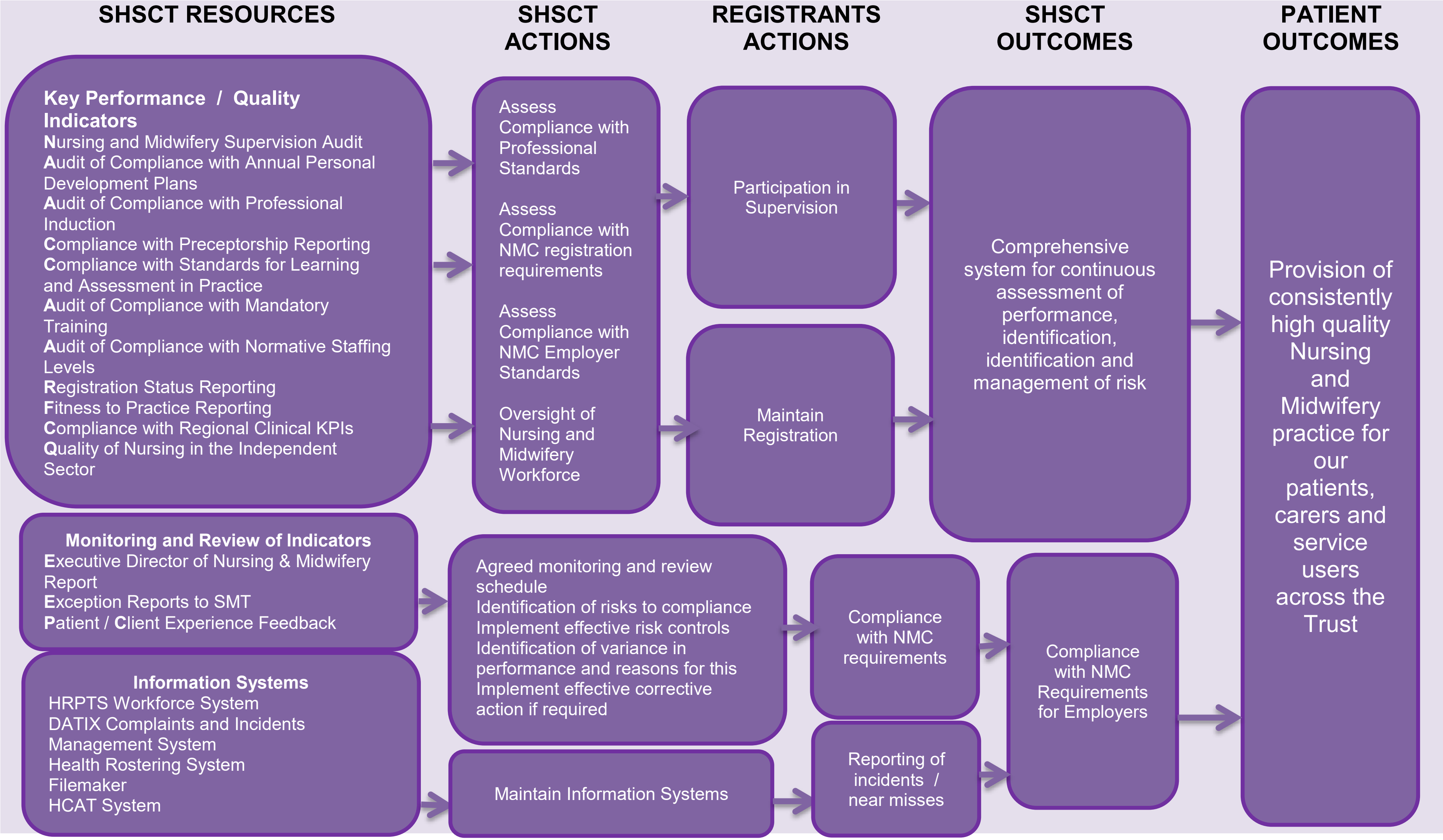
Provision of consistently high quality Nursing and Midwifery practice for our patients, carers and Service Users across the Trust

Southern Health and Social Care Trust

Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Audit, Assurance and Compliance Arrangements



SHSCT RESOURCES

Key Performance / Quality Indicators
Nursing and Midwifery Supervision Audit
Audit of Compliance with Annual Personal Development Plans
Audit of Compliance with Professional Induction
Compliance with Preceptorship Reporting
Compliance with Standards for Learning and Assessment in Practice
Audit of Compliance with Mandatory Training
Audit of Compliance with Normative Staffing Levels
Registration Status Reporting
Fitness to Practice Reporting
Compliance with Regional Clinical KPIs
Quality of Nursing in the Independent Sector

Monitoring and Review of Indicators
Executive Director of Nursing & Midwifery Report
Exception Reports to SMT
Patient / Client Experience Feedback

Information Systems
HRPTS Workforce System
DATIX Complaints and Incidents Management System
Health Rostering System
Filemaker
HCAT System

SHSCT ACTIONS

Assess Compliance with Professional Standards

Assess Compliance with NMC registration requirements

Assess Compliance with NMC Employer Standards

Oversight of Nursing and Midwifery Workforce

Agreed monitoring and review schedule
Identification of risks to compliance
Implement effective risk controls
Identification of variance in performance and reasons for this
Implement effective corrective action if required

Maintain Information Systems

REGISTRANTS ACTIONS

Participation in Supervision

Maintain Registration

Compliance with NMC requirements

Reporting of incidents / near misses

SHSCT OUTCOMES

Comprehensive system for continuous assessment of performance, identification, identification and management of risk

Compliance with NMC Requirements for Employers

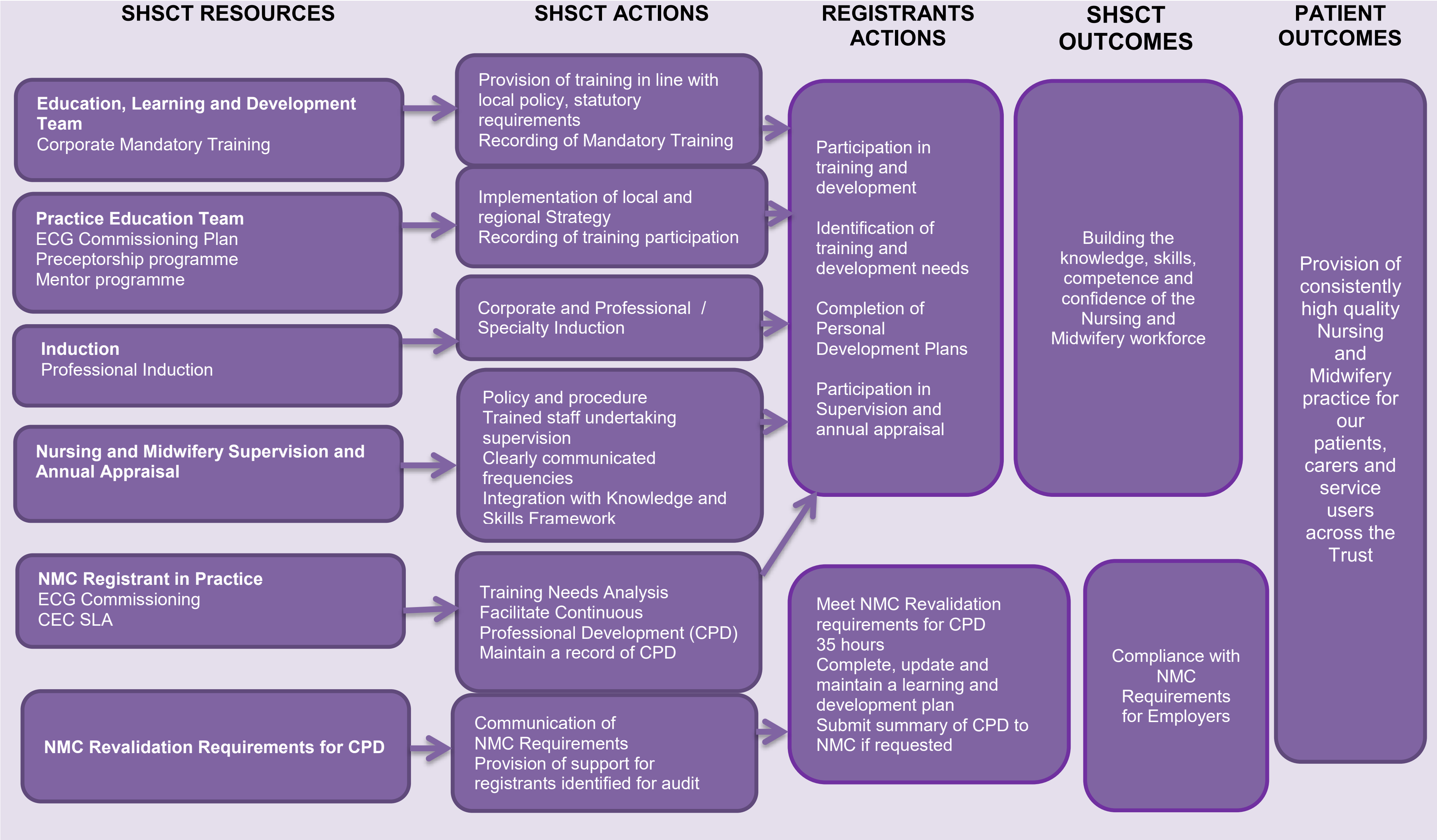
PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery practice for our patients, carers and service users across the Trust

Southern Health and Social Care Trust
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Learning, Development and Support



SHSCT RESOURCES

Education, Learning and Development Team
Corporate Mandatory Training

Practice Education Team
ECG Commissioning Plan
Preceptorship programme
Mentor programme

Induction
Professional Induction

Nursing and Midwifery Supervision and Annual Appraisal

NMC Registrant in Practice
ECG Commissioning
CEC SLA

NMC Revalidation Requirements for CPD

SHSCT ACTIONS

Provision of training in line with local policy, statutory requirements
Recording of Mandatory Training

Implementation of local and regional Strategy
Recording of training participation

Corporate and Professional / Specialty Induction

Policy and procedure
Trained staff undertaking supervision
Clearly communicated frequencies
Integration with Knowledge and Skills Framework

Training Needs Analysis
Facilitate Continuous Professional Development (CPD)
Maintain a record of CPD

Communication of NMC Requirements
Provision of support for registrants identified for audit

REGISTRANTS ACTIONS

Participation in training and development

Identification of training and development needs

Completion of Personal Development Plans

Participation in Supervision and annual appraisal

Meet NMC Revalidation requirements for CPD 35 hours
Complete, update and maintain a learning and development plan
Submit summary of CPD to NMC if requested

SHSCT OUTCOMES

Building the knowledge, skills, competence and confidence of the Nursing and Midwifery workforce

Compliance with NMC Requirements for Employers

PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery practice for our patients, carers and service users across the Trust

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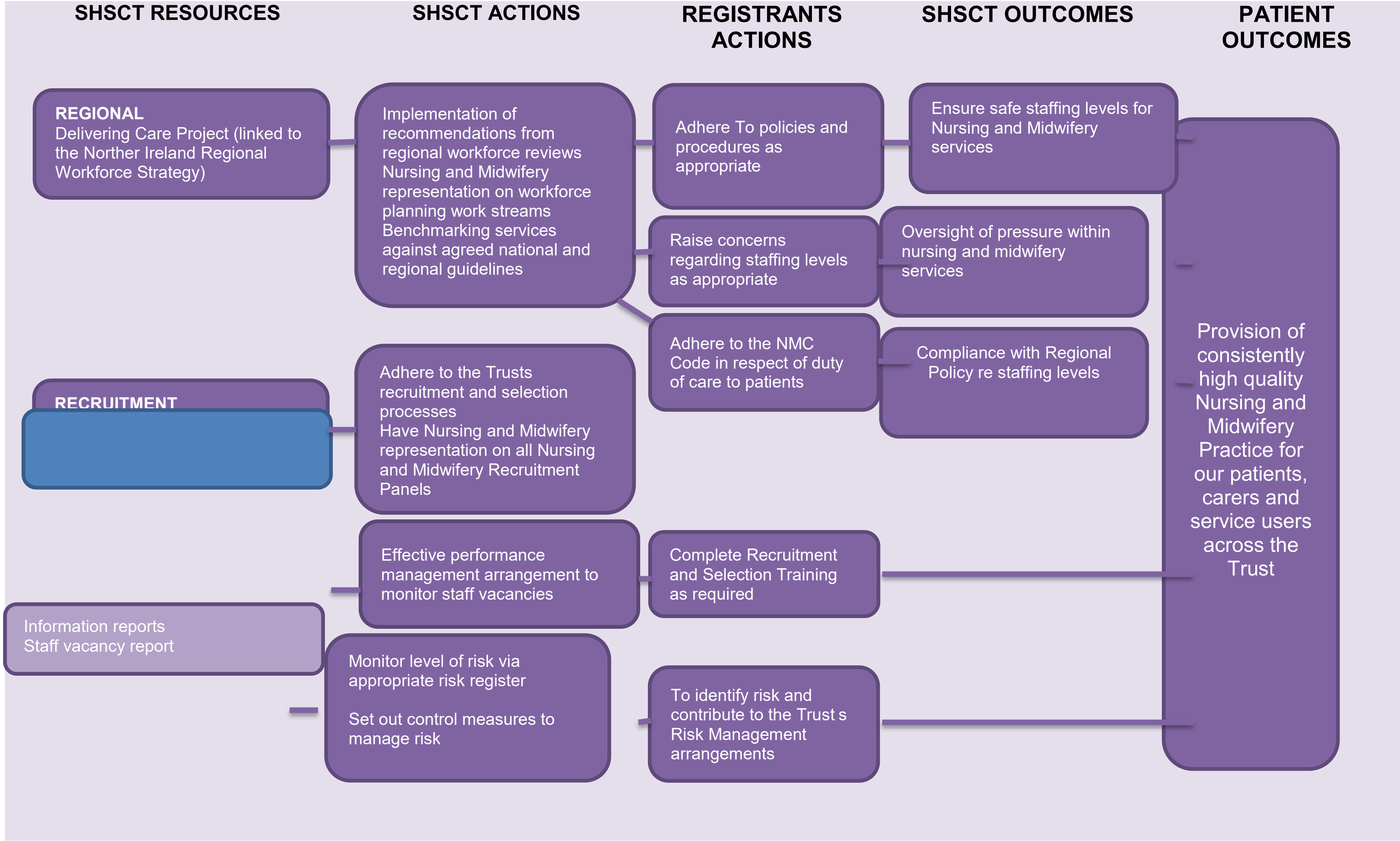
Workforce



SHSCT RESOURCES

REGIONAL
Delivering Care Project (linked to the Norther Ireland Regional Workforce Strategy)

RECRUITMENT
[redacted]

Information reports
Staff vacancy report

SHSCT ACTIONS

Implementation of recommendations from regional workforce reviews
Nursing and Midwifery representation on workforce planning work streams
Benchmarking services against agreed national and regional guidelines

Adhere to the Trusts recruitment and selection processes
Have Nursing and Midwifery representation on all Nursing and Midwifery Recruitment Panels

Effective performance management arrangement to monitor staff vacancies

Monitor level of risk via appropriate risk register

Set out control measures to manage risk

REGISTRANTS ACTIONS

Adhere To policies and procedures as appropriate

Raise concerns regarding staffing levels as appropriate

Adhere to the NMC Code in respect of duty of care to patients

Complete Recruitment and Selection Training as required

To identify risk and contribute to the Trust s Risk Management arrangements

SHSCT OUTCOMES

Ensure safe staffing levels for Nursing and Midwifery services

Oversight of pressure within nursing and midwifery services

Compliance with Regional Policy re staffing levels

PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

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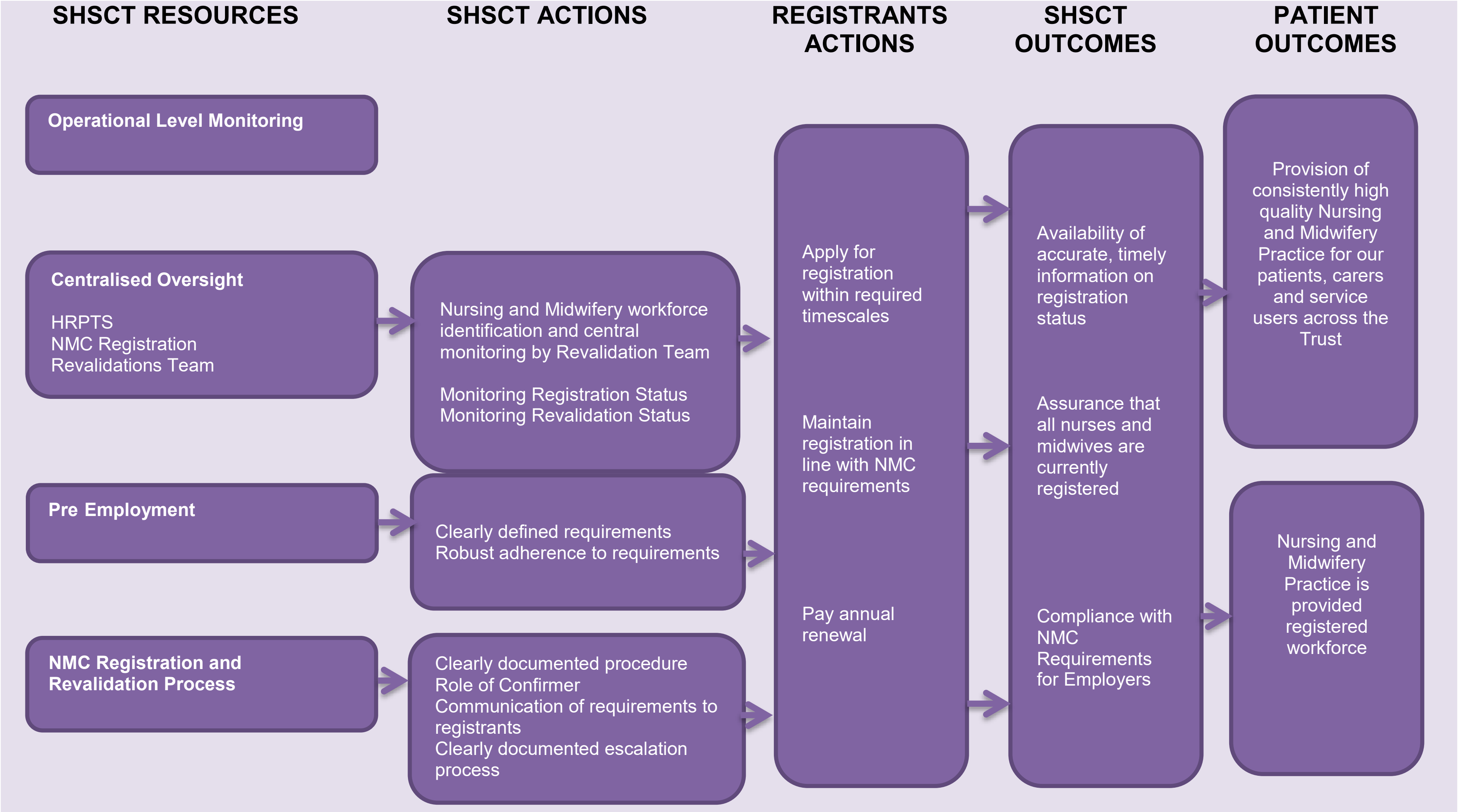
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Registration



SHSCT RESOURCES

Operational Level Monitoring

Centralised Oversight

HRPTS
NMC Registration
Revalidations Team

Pre Employment

NMC Registration and Revalidation Process

SHSCT ACTIONS

Nursing and Midwifery workforce identification and central monitoring by Revalidation Team

Monitoring Registration Status
Monitoring Revalidation Status

Clearly defined requirements
Robust adherence to requirements

Clearly documented procedure
Role of Confirmer
Communication of requirements to registrants
Clearly documented escalation process

REGISTRANTS ACTIONS

Apply for registration within required timescales

Maintain registration in line with NMC requirements

Pay annual renewal

SHSCT OUTCOMES

Availability of accurate, timely information on registration status

Assurance that all nurses and midwives are currently registered

Compliance with NMC Requirements for Employers

PATIENT OUTCOMES

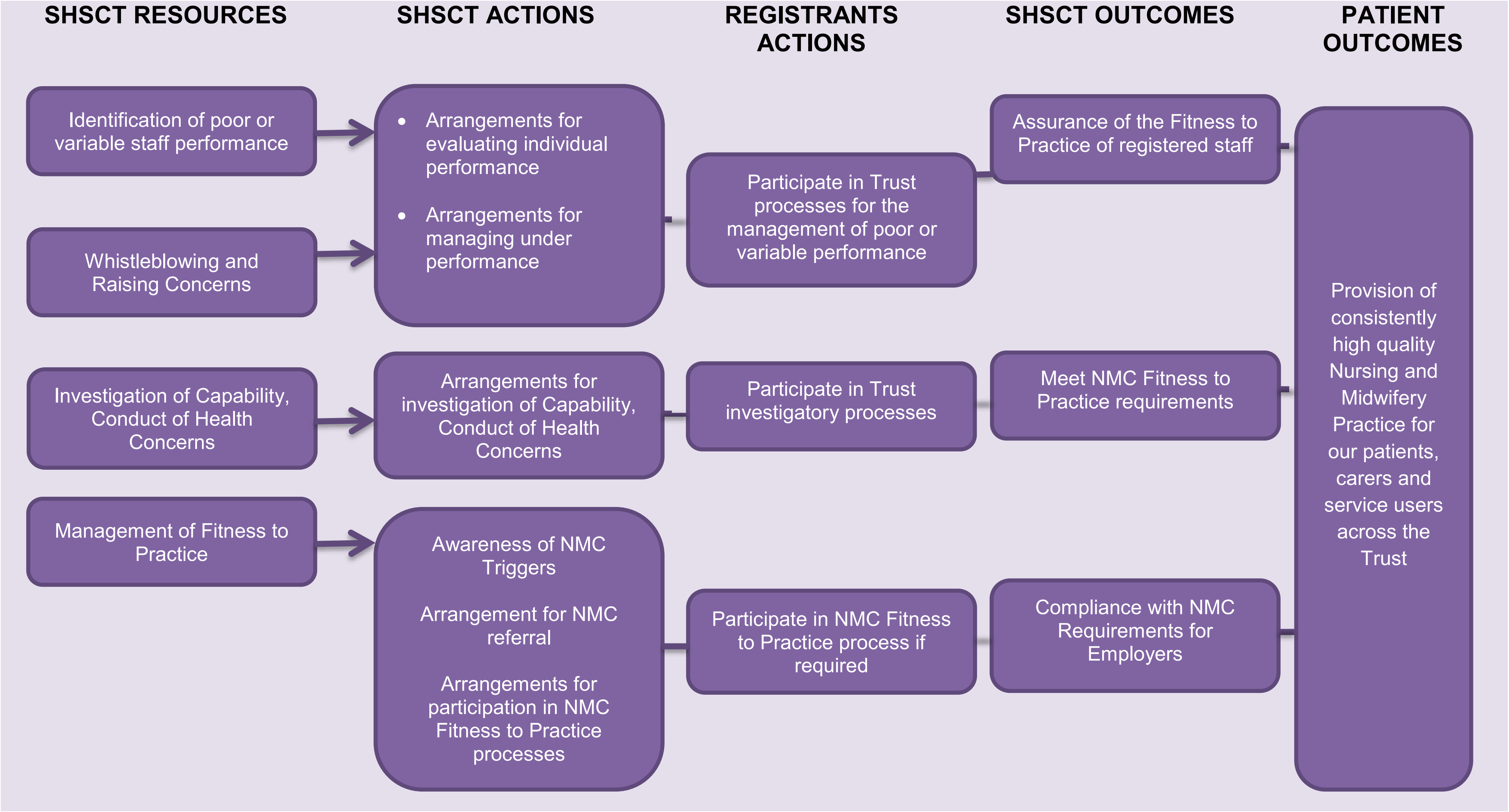
Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

Nursing and Midwifery Practice is provided registered workforce

Southern Health and Social Care Trust
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Handling Concerns



SHSCT RESOURCES

Identification of poor or variable staff performance

Whistleblowing and Raising Concerns

Investigation of Capability, Conduct of Health Concerns

Management of Fitness to Practice

SHSCT ACTIONS

- Arrangements for evaluating individual performance
- Arrangements for managing under performance

Arrangements for investigation of Capability, Conduct of Health Concerns

Awareness of NMC Triggers

Arrangement for NMC referral

Arrangements for participation in NMC Fitness to Practice processes

REGISTRANTS ACTIONS

Participate in Trust processes for the management of poor or variable performance

Participate in Trust investigatory processes

Participate in NMC Fitness to Practice process if required

SHSCT OUTCOMES

Assurance of the Fitness to Practice of registered staff

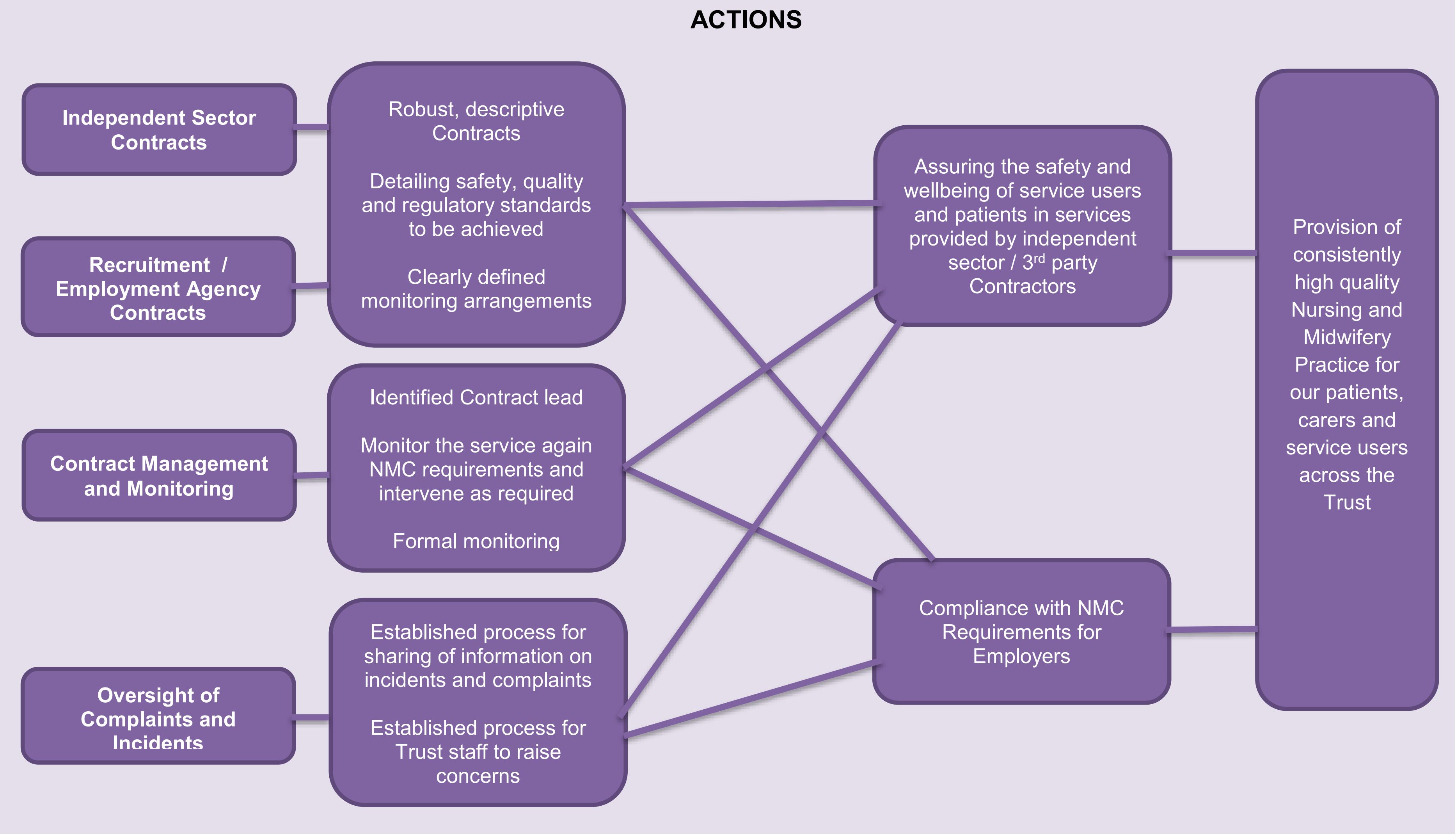
Meet NMC Fitness to Practice requirements

Compliance with NMC Requirements for Employers

PATIENT OUTCOMES

Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

Accountability and Assurance Framework
Nursing and Midwifery
Quality of Nursing in the Independent Sector



SHSCT RESOURCES

SHSCT ACTIONS

REGISTRANTS ACTIONS

SHSCT OUTCOMES

PATIENT OUTCOMES

Independent Sector Contracts

Recruitment / Employment Agency Contracts

Contract Management and Monitoring

Oversight of Complaints and Incidents

Robust, descriptive Contracts

Detailing safety, quality and regulatory standards to be achieved

Clearly defined monitoring arrangements

Identified Contract lead

Monitor the service again NMC requirements and intervene as required

Formal monitoring

Established process for sharing of information on incidents and complaints

Established process for Trust staff to raise concerns

Assuring the safety and wellbeing of service users and patients in services provided by independent sector / 3rd party Contractors

Compliance with NMC Requirements for Employers

Provision of consistently high quality Nursing and Midwifery Practice for our patients, carers and service users across the Trust

Urology Service: Patient Experience Survey

March 2020

The Urology cancer team, as part of their service improvement plan to seek feedback from patients on the urology service, issued a patient feedback survey to 118 patients who were diagnosed with a prostate, bladder or renal cancer over the previous 12 months. There was a response rate of 58% (i.e. 68 patients completed and returned the survey).

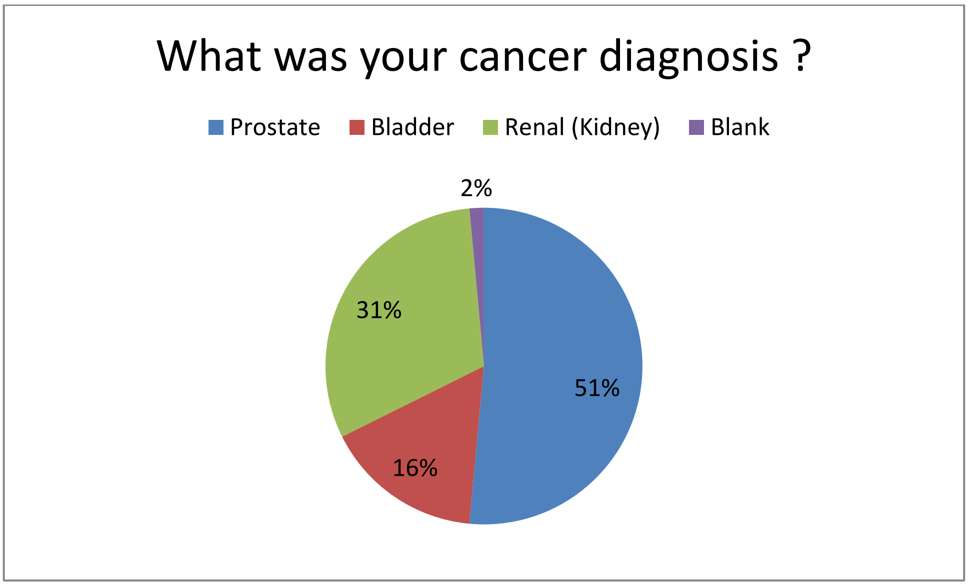
The survey asked questions in relation to their hospital visit and the results from the survey along with the feedback from the NI Cancer Patient Experience Survey (2018) will help the team to look at the service currently provided and to plan for the future to make sure they are meeting the on-going needs of patients and families.

68/118 Responses (58%)

Summary of results:

- The majority of respondents had a prostate cancer (51%), followed by a renal cancer (31%) and then a bladder cancer (16%)
- 87% of respondents rated the hospital signage directing them to the unit as excellent or very good, 83% rated the reception / waiting area as excellent or very good and 57% rated the disabled parking (if applicable) as excellent or very good
- 100% of respondents indicated that staff introduced themselves when they first met.
- 97% rated the level of politeness and courtesy shown to them as excellent or very good
- 95% rated the level of privacy and dignity when being examined or when discussing treatment as excellent or very good
- 74% of respondents advised they were asked which name they would prefer to be called by.
- 92% of respondents were told sensitively that they had cancer
- 94% of respondents were given easy to understand written information about their cancer.
- 85% of respondents were able to find / offered a staff member to discuss any worries or fears.
- The majority of respondents (88%) said they were given the name of their CNS.
- 82% were definitely told about future side effects before treatment.

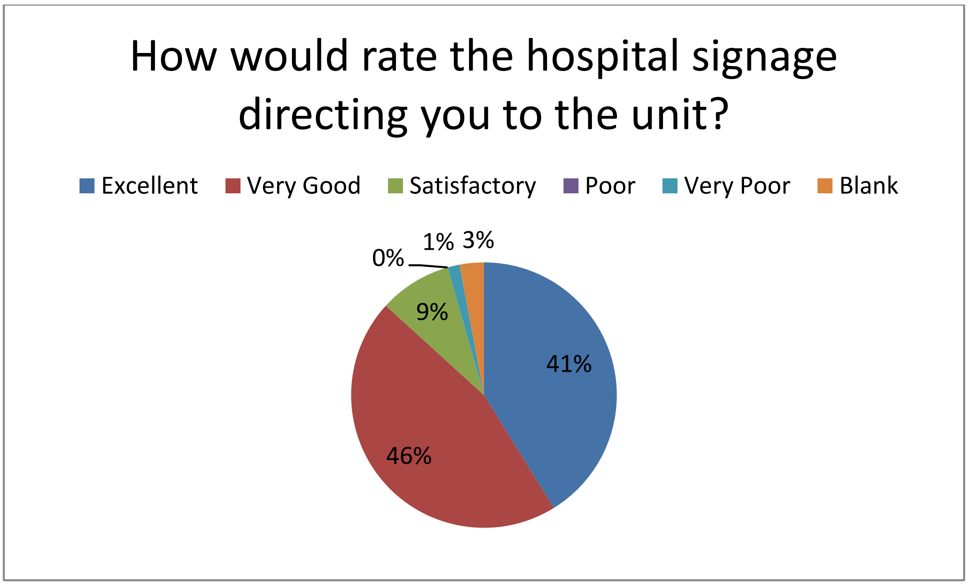
ABOUT YOU (The Patient)



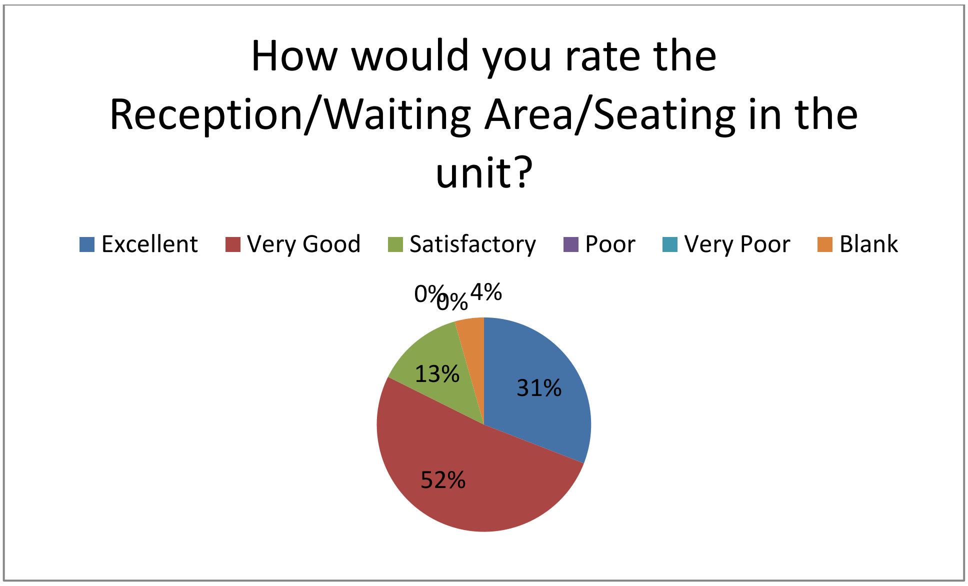
- 35 of respondents had a prostate cancer
- 11 had a bladder cancer
- 21 had a renal cancer

1 person didn't answer the question

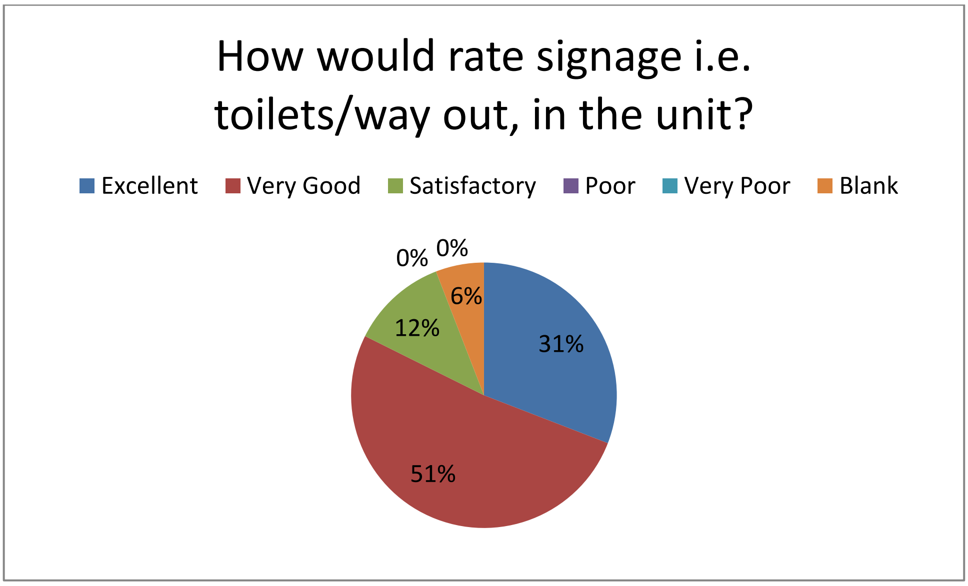
First Impressions



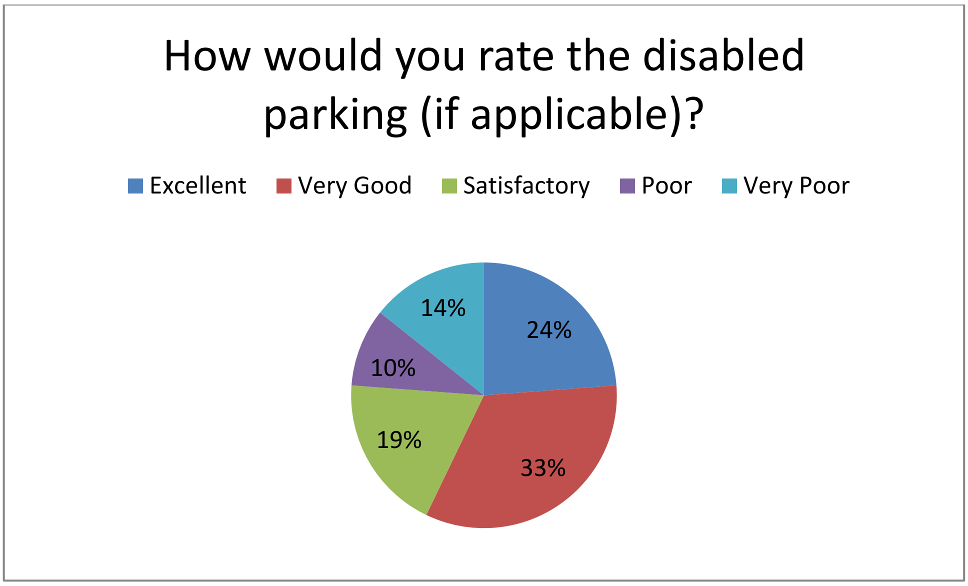
The majority of respondents (59/68) rated the hospital signage directing them to the unit as Excellent or Very Good, with only 1 respondent rating this as Very Poor.



The majority of respondents (56/68) rated the reception/waiting area/seating in the unit as Excellent or Very Good.



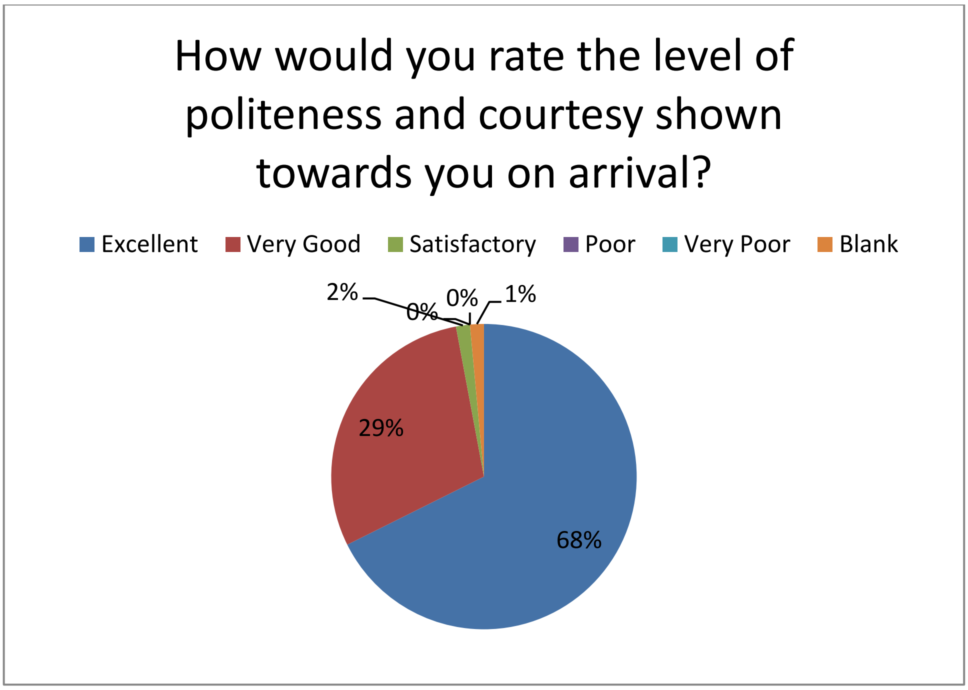
The majority of respondents (56/68) rated the signage in the unit as Excellent or Very Good.



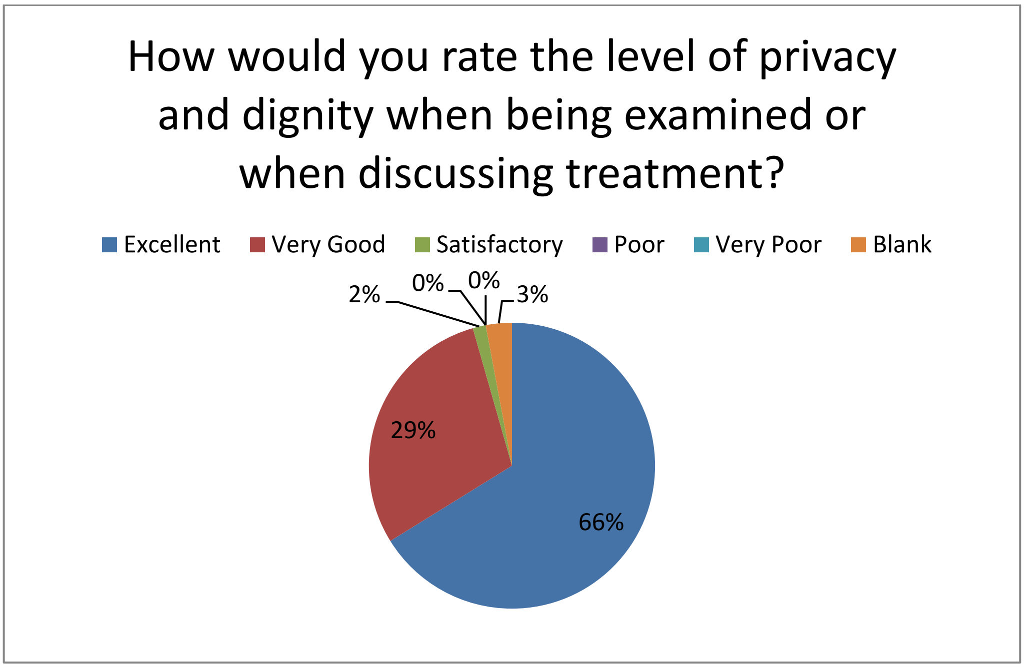
21 of the respondents answered the above question with 57% rating this as excellent or very good.

Our Staff

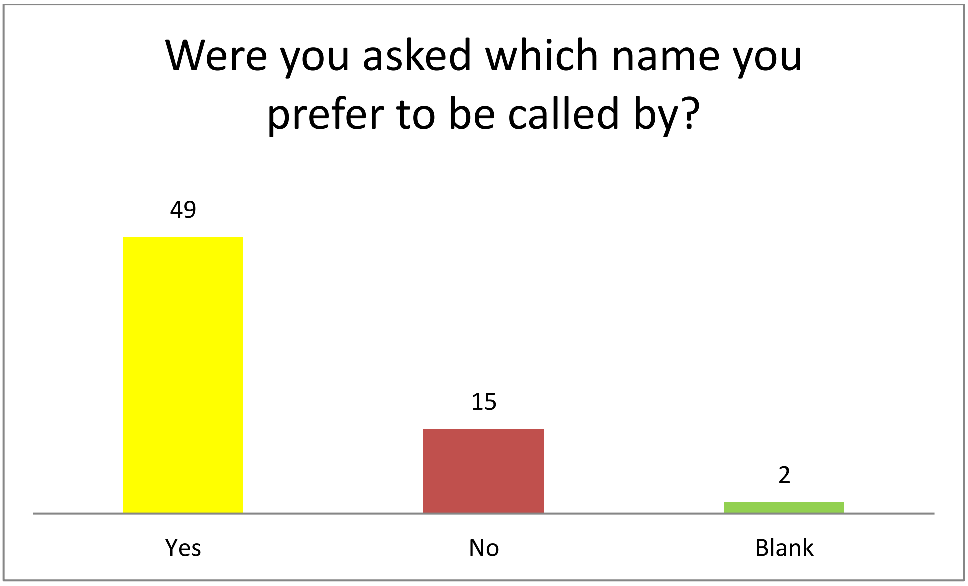
All of the respondents that answered this question indicated that staff introduced themselves when they first met.



The majority of respondents (97%) rated the level of politeness and courtesy shown to them on arrival as excellent or very good.



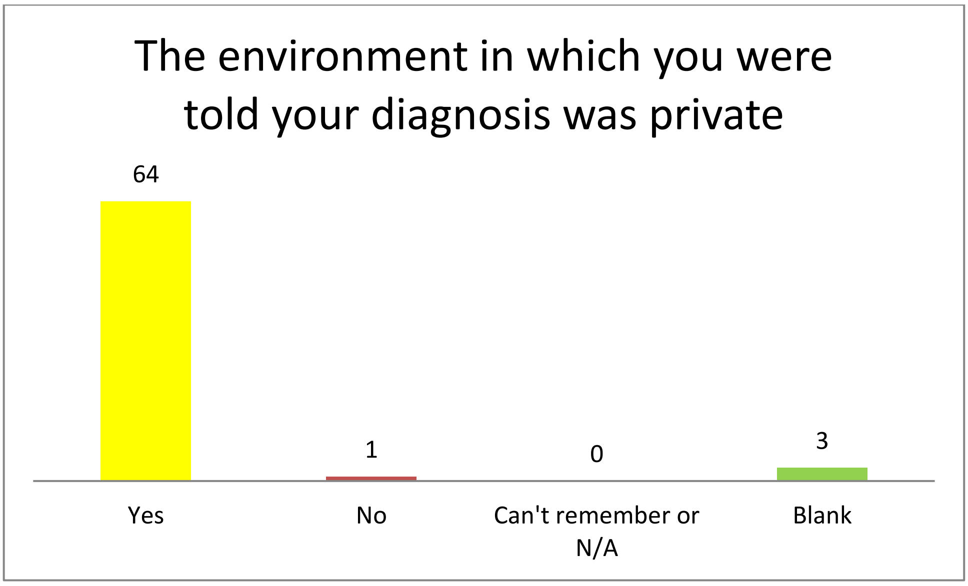
The majority of respondents (65/68) rated the level of privacy and dignity when being examined or when discussing treatment as Excellent or Very Good.



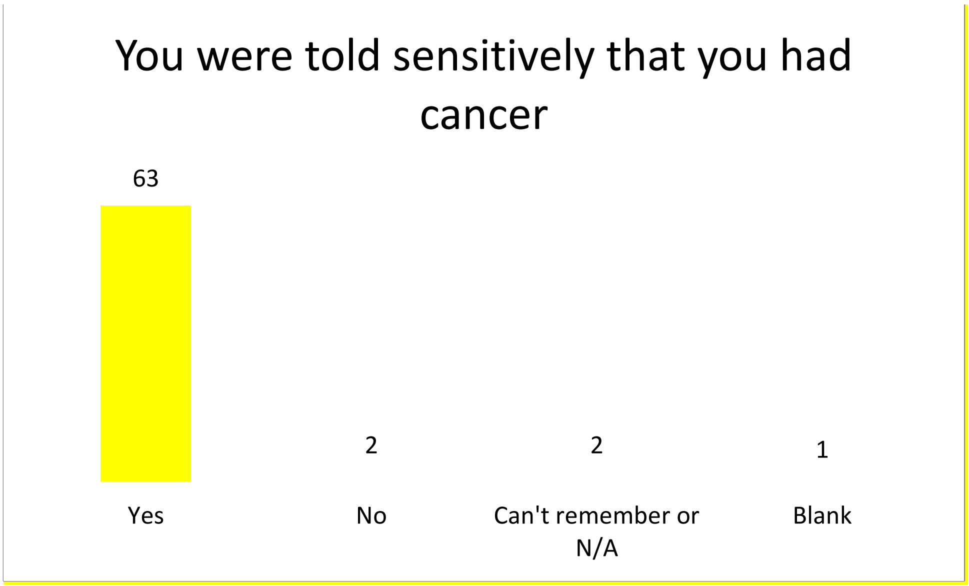
74% of respondents advised they were asked which name they would prefer to be called by.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES Urology responses was 76% and the NI score was 73%.

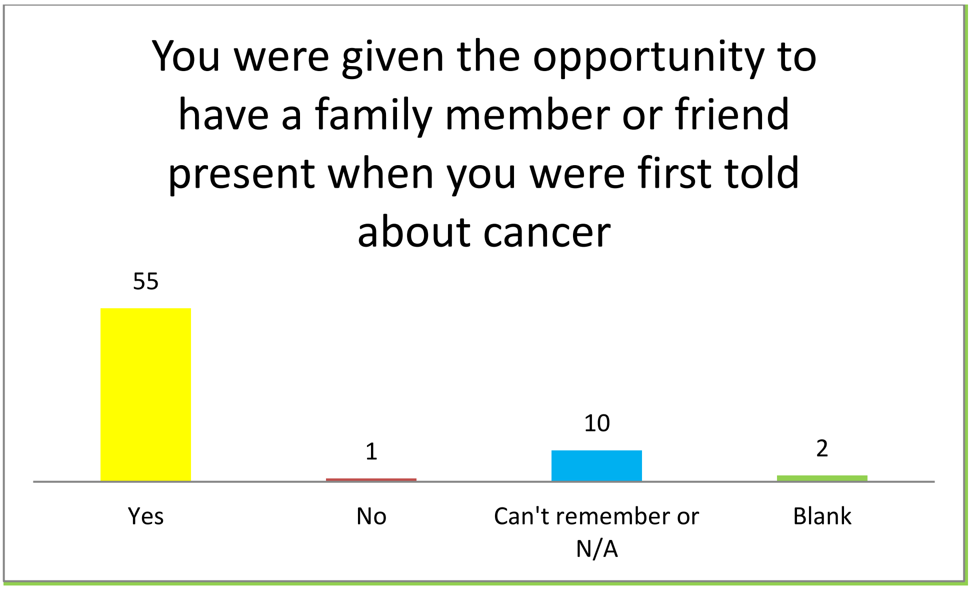
With regard being told your diagnosis, how would you describe the following:



94% of respondents agreed the environment where they were told their diagnosis was private

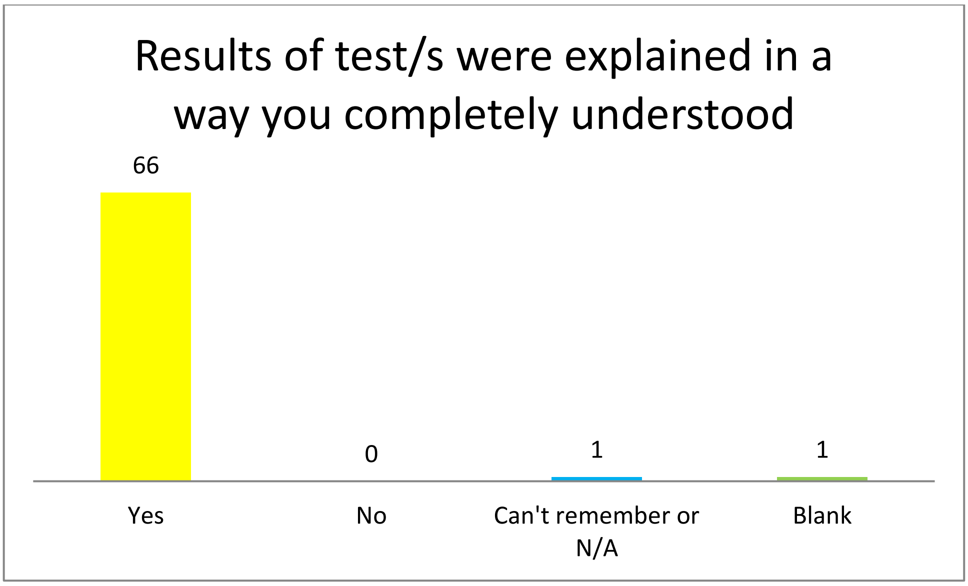


92% of respondents were told sensitively that they had cancer

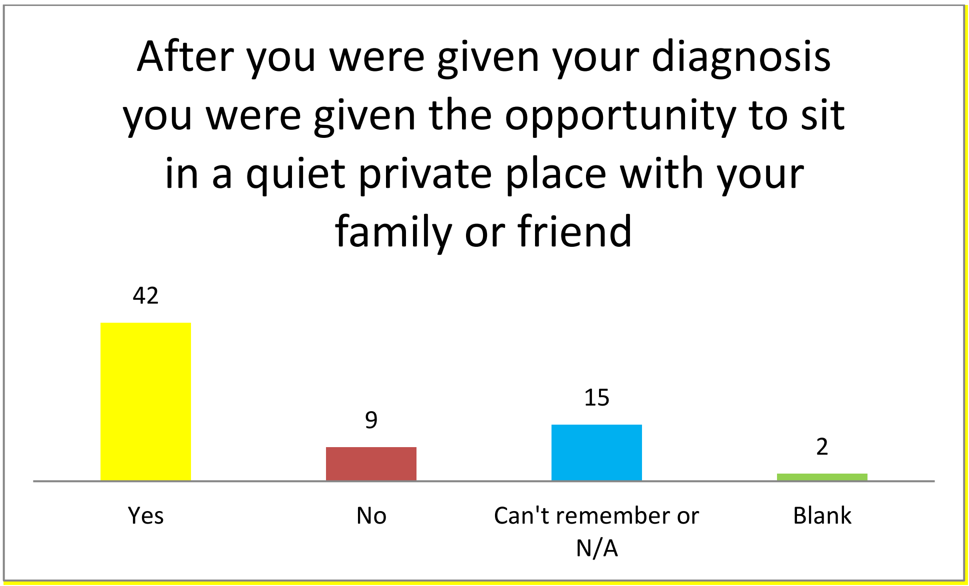


81% of respondents were given the opportunity to have a family member or friend present when they were first told about cancer.

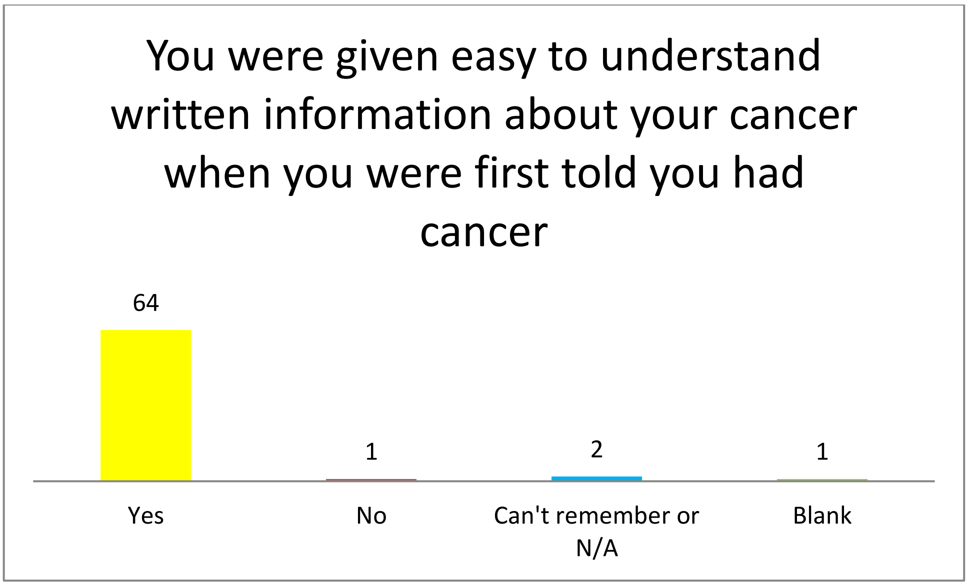
This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT urology responses was 75% the same as the NI score. The score for the regional Prostate responses was 79%.



97% of respondents indicated that results of tests were explained in a way they completely understood

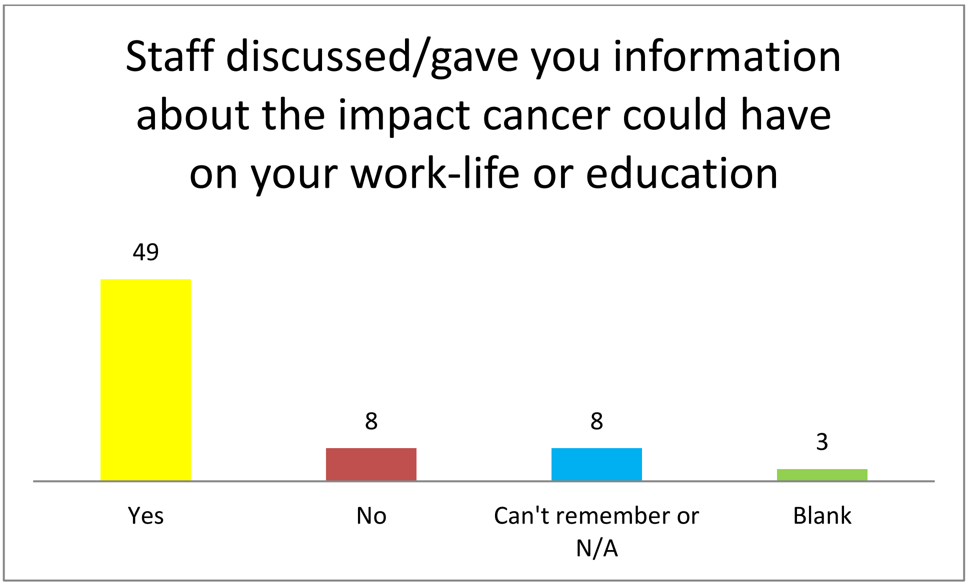


62% of respondents were given the opportunity to sit in a quiet private place with a family member or friend



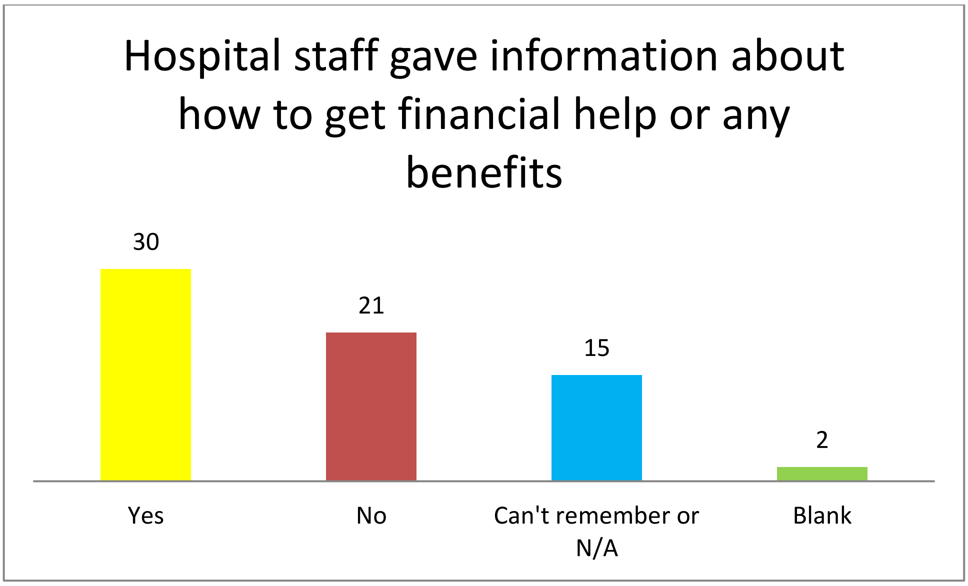
94% of respondents were given easy to understand written information about their cancer.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 66%, the NI score was 61% and the regional prostate CPES response rate was 74%.



72% of respondents indicated that staff discussed or gave them information about the impact cancer could have on their work-life or education.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 77%, the NI score was 72% and the regional prostate CPES response rate was 89%.

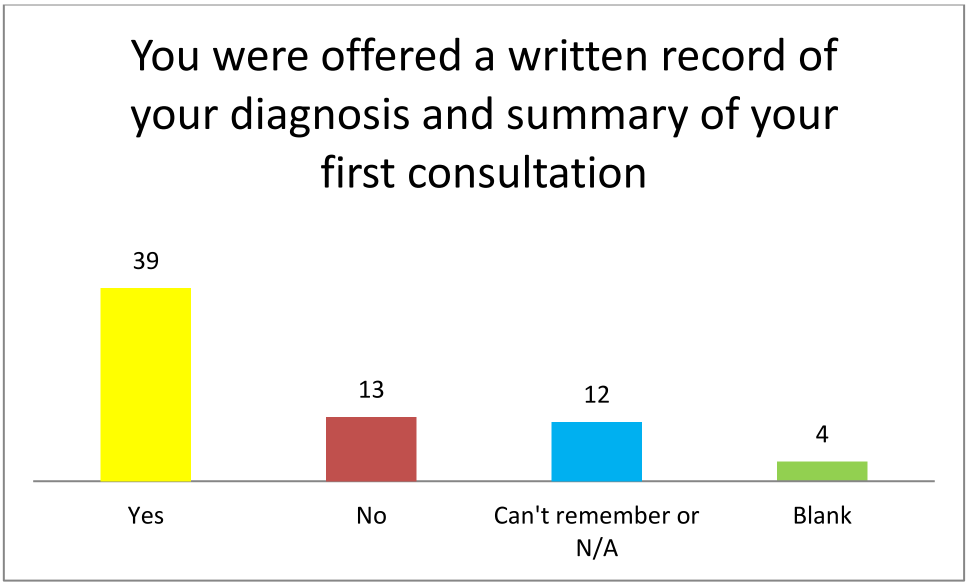


44% of respondents indicated that hospital staff gave information about how to get financial help or any benefits.

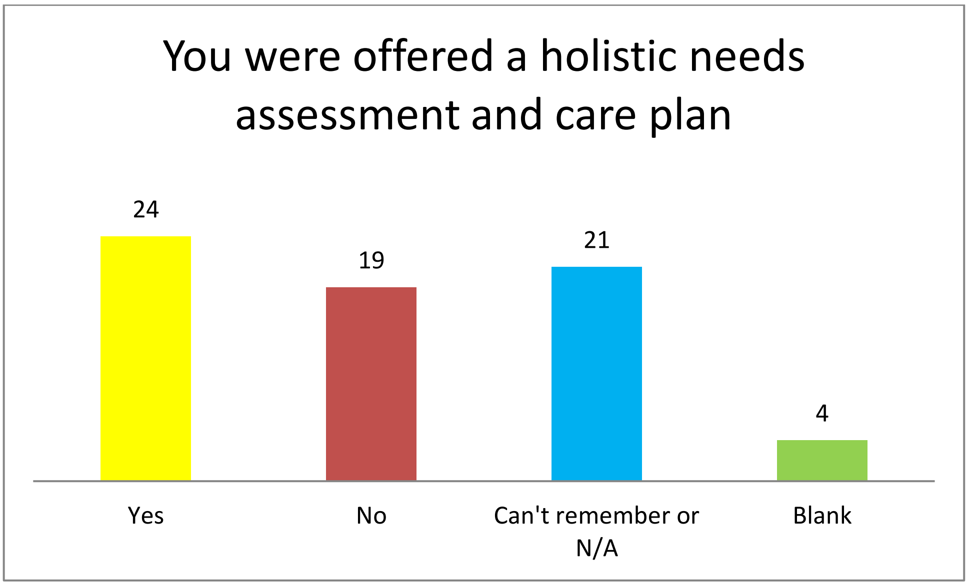
This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 35%, the NI score was 44% and the regional prostate CPES response rate was 66%.

85% of respondents were able to find / offered a staff member to discuss any worries or fears.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 50%, the NI score was 49% and the regional prostate CPES response rate was 75%.



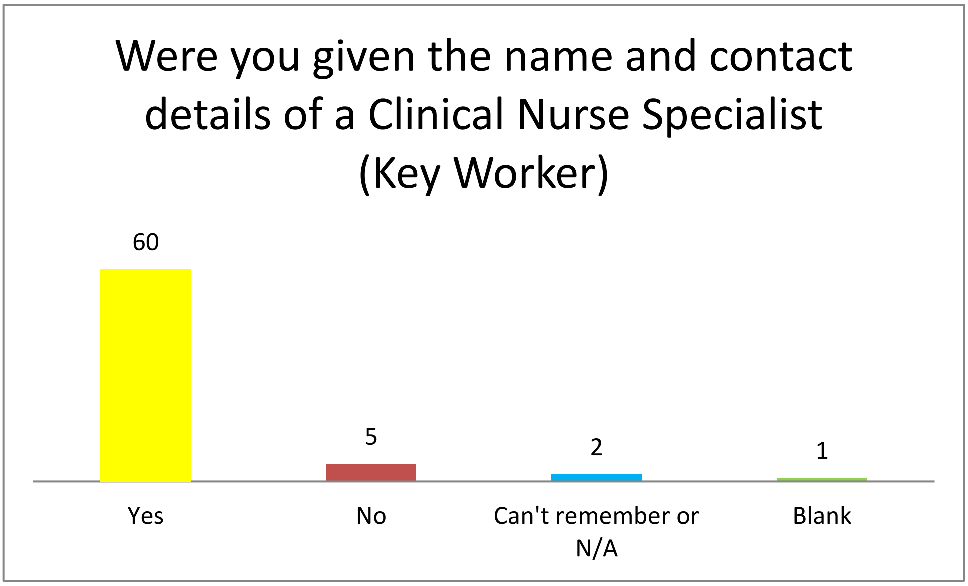
57% of respondents were offered a written record of their diagnosis and summary of their first consultation.



35% were offered a holistic needs assessment and care plan
31% can't remember
28% indicated that they were not offered a holistic needs assessment and care plan

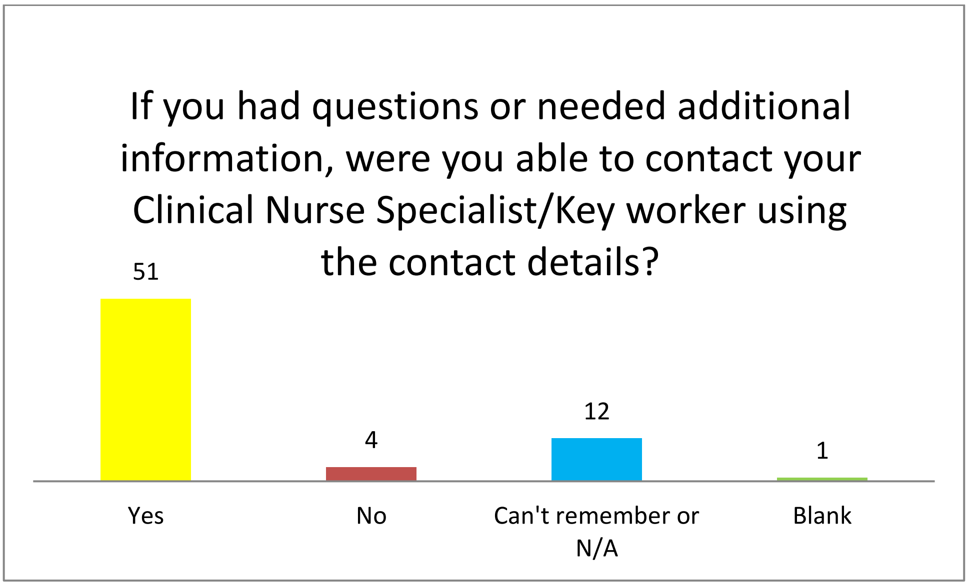
This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 29%, the NI score was 19% and the regional prostate CPES response rate was 22%.

About your Clinical Nurse Specialist (Key Worker)

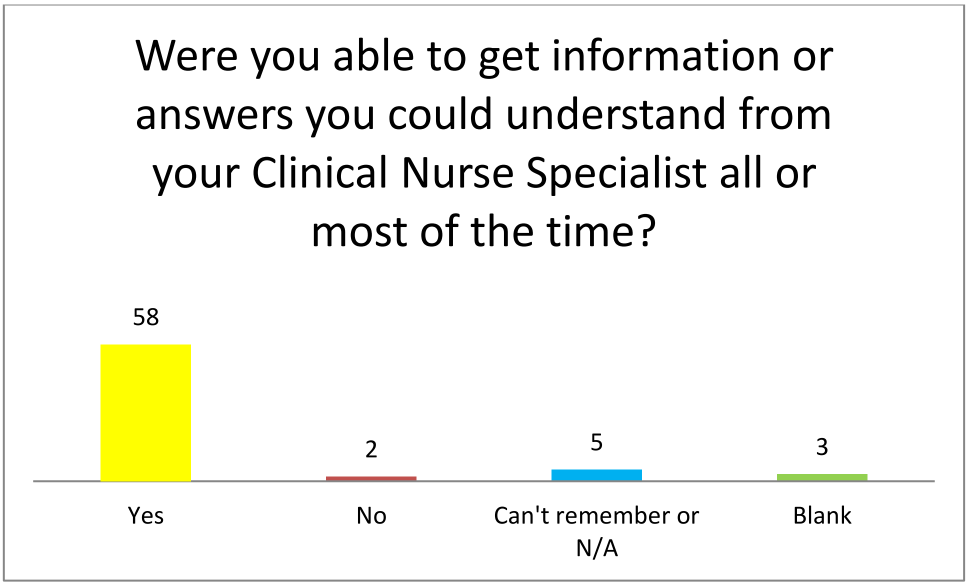


The majority of respondents (88%) said they were given the name of their CNS.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 73%, the NI score was 66% and the regional prostate CPES response rate was 83%.

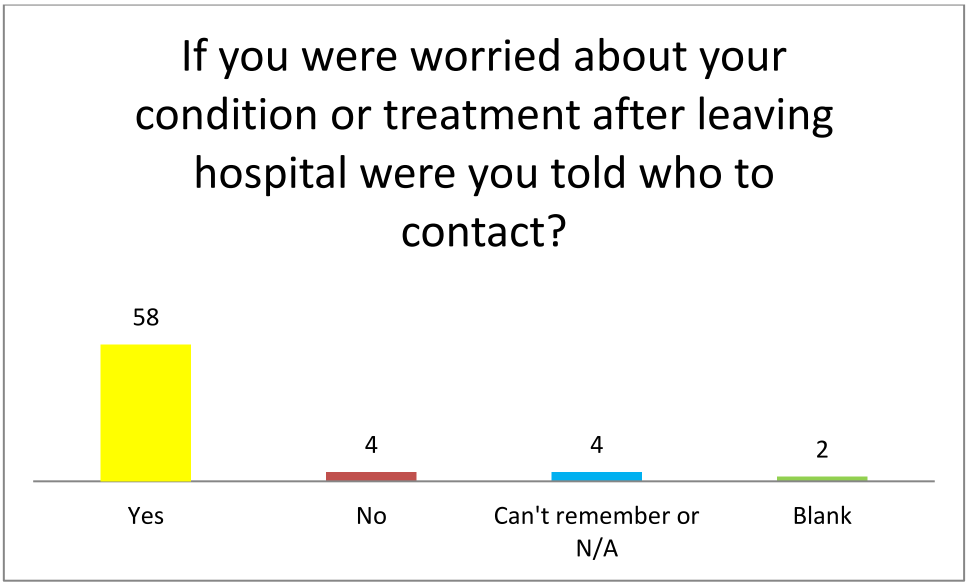


75% of respondents were able to contact their CNS or key worker if they had questions or needed additional information



85% were able to information or answers from their CNS they could understand all or most of the time.

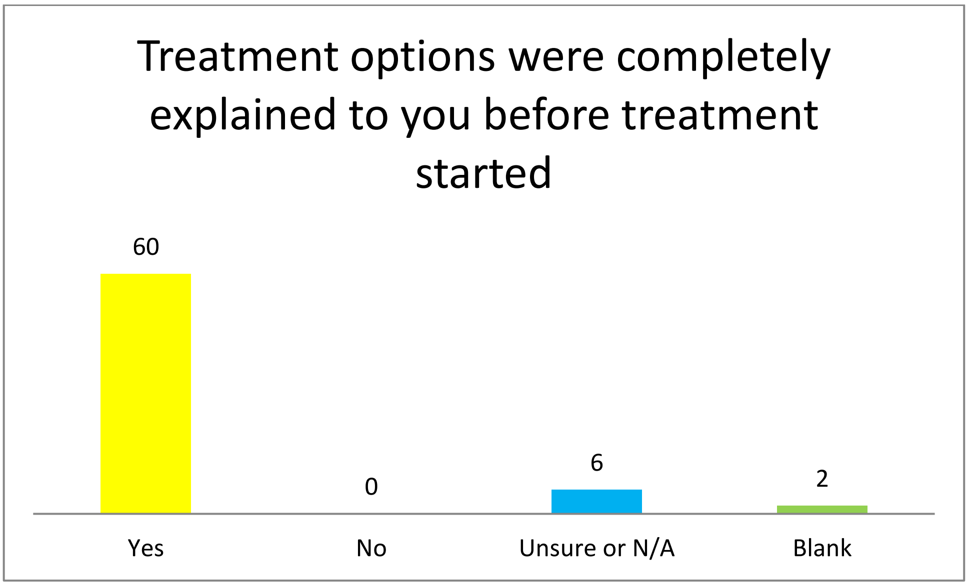
This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 95%, the NI score was 93% and the regional prostate CPES response rate was 93%.



85% of respondents were told who to contact if they were worried after leaving hospital.

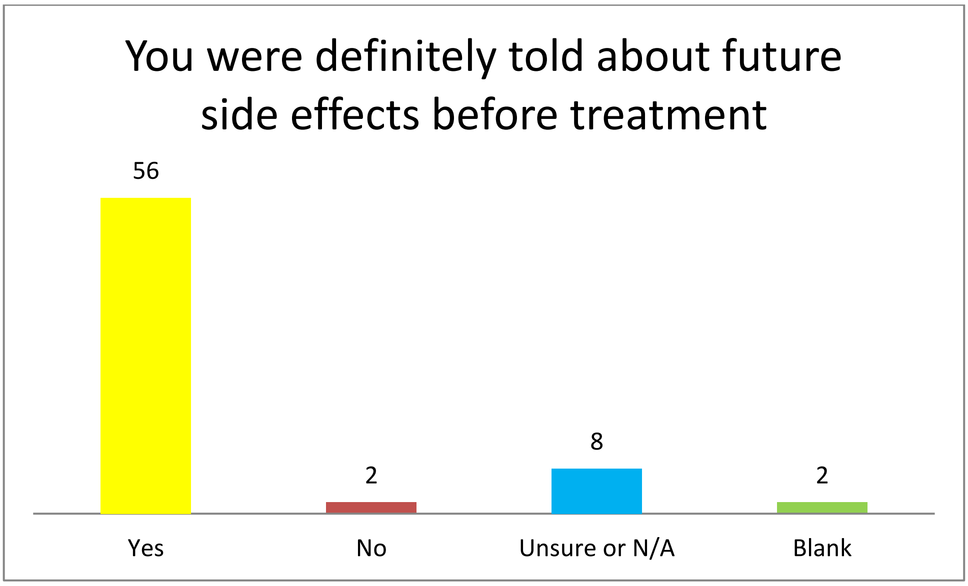
This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 83%, the NI score was 85% and the regional prostate CPES response rate was 94%.

With regard deciding the best treatment available for you, how would describe the following:



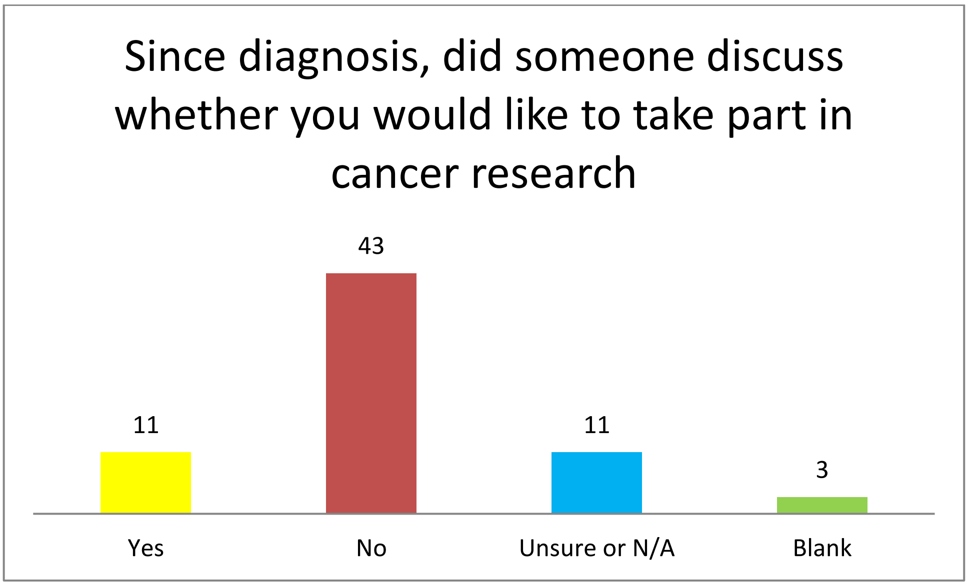
88% of respondents indicated that treatment options were completely explained to them before treatment started.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 82%, the NI score was 86% and the regional prostate CPES response rate was 90%.



82% were definitely told about future side effects before treatment.

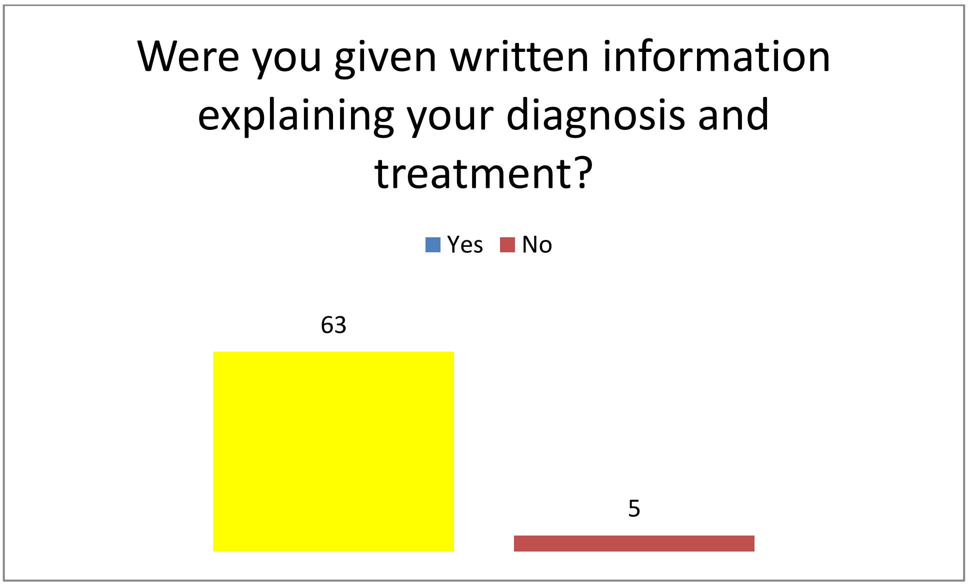
This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 65%, the NI score was 51% and the regional prostate CPES response rate was 68%.



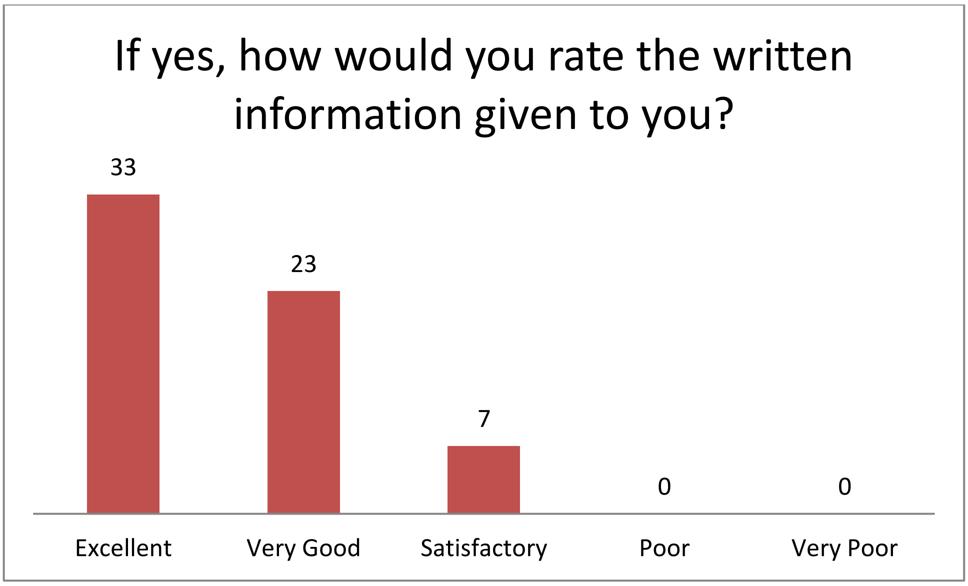
16% of respondents said they asked if they would like to take part in Cancer Research.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 4%, the NI score was 5% and the regional prostate CPES response rate was 31%.

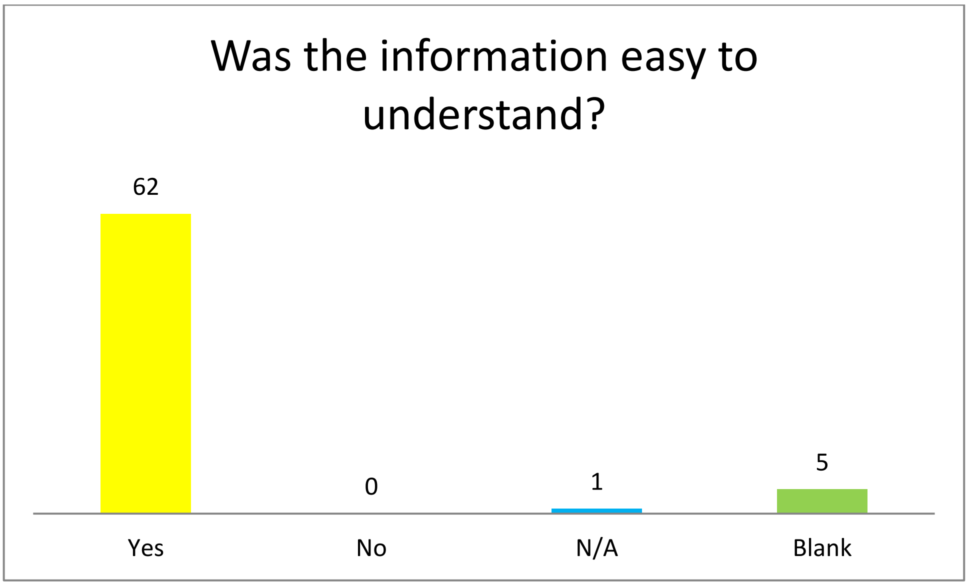
Information



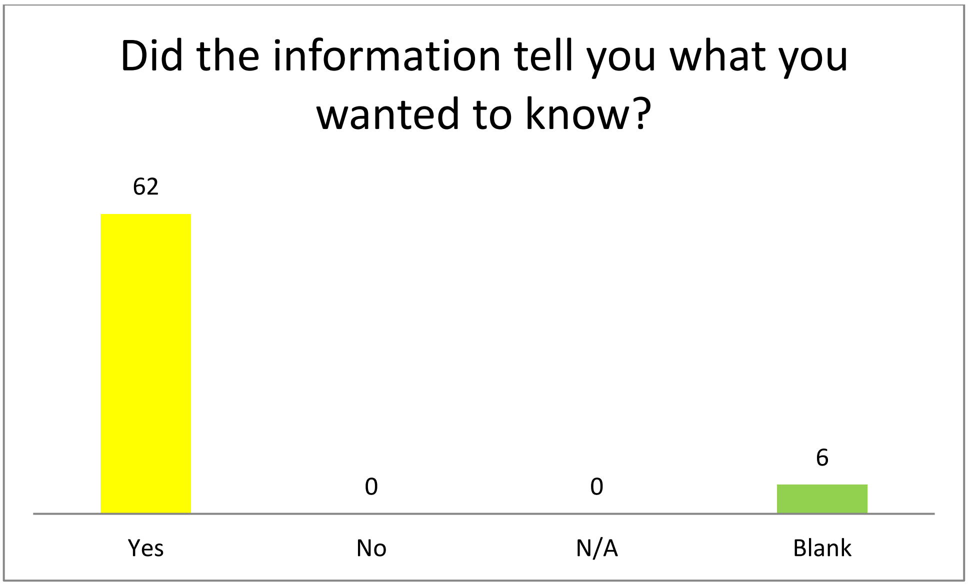
92% of respondents were given written information explaining their diagnosis and treatment.



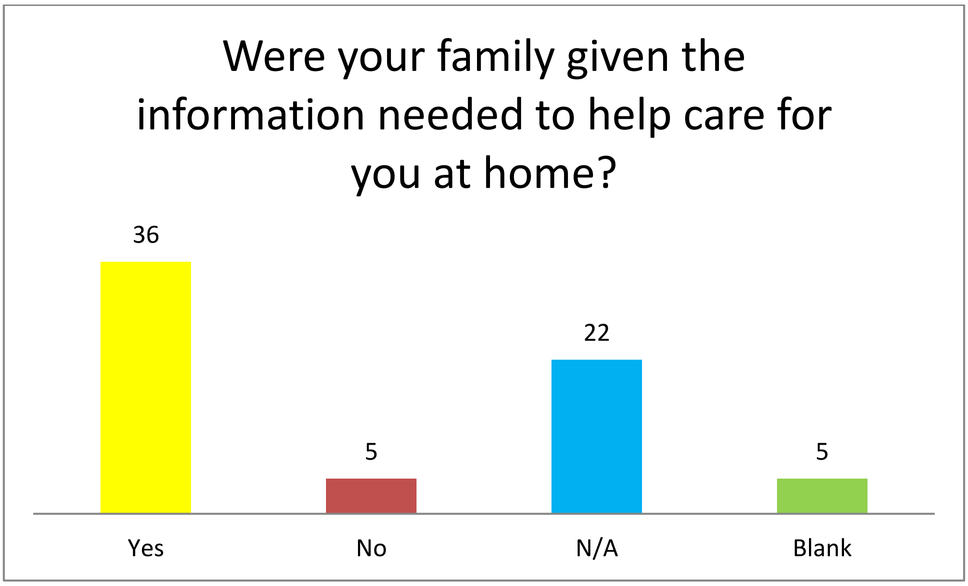
The majority of respondents (89%) rated the written information given to them as Excellent or Very Good.



91% found the information easy to understand.

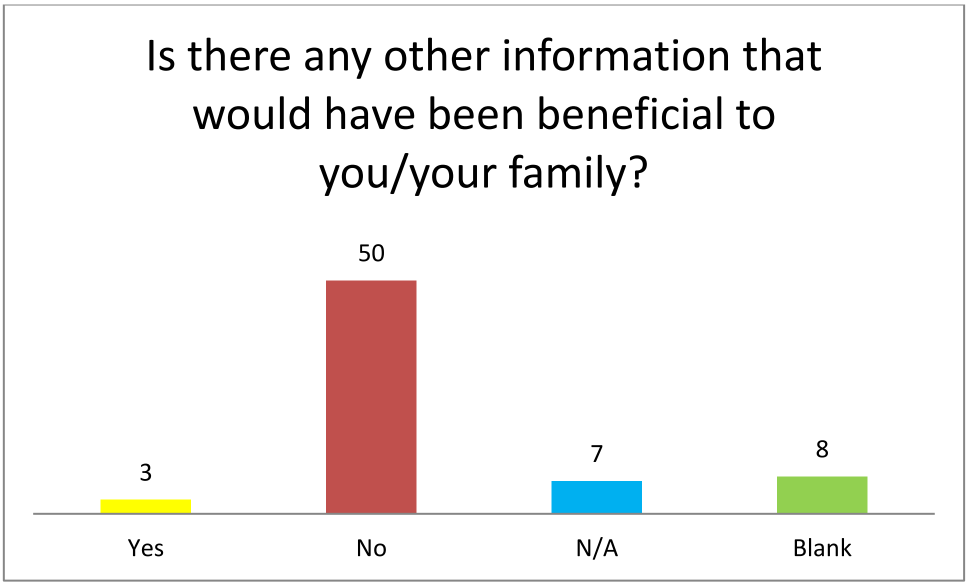


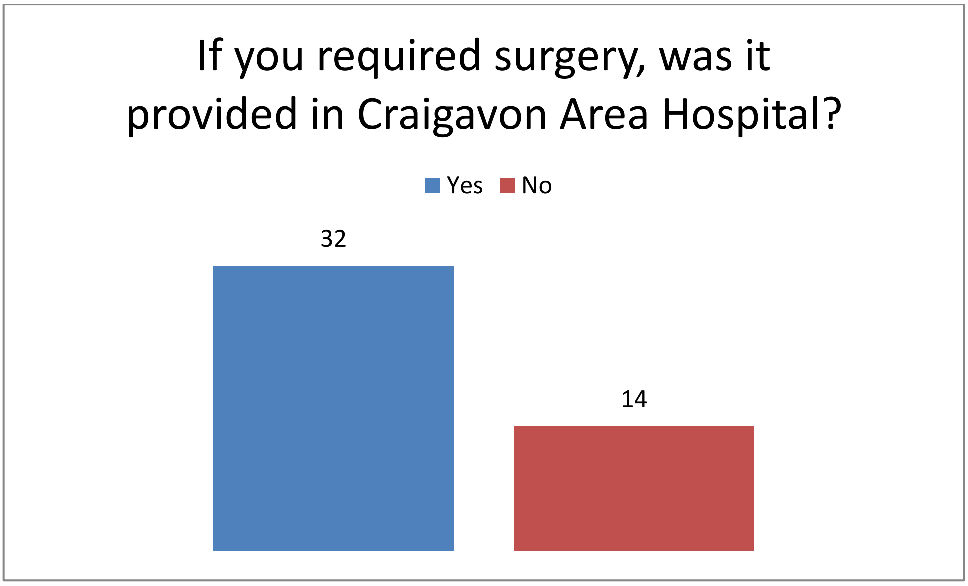
100% of respondents who answered this question (n=62) said the information told them what they wanted to know.



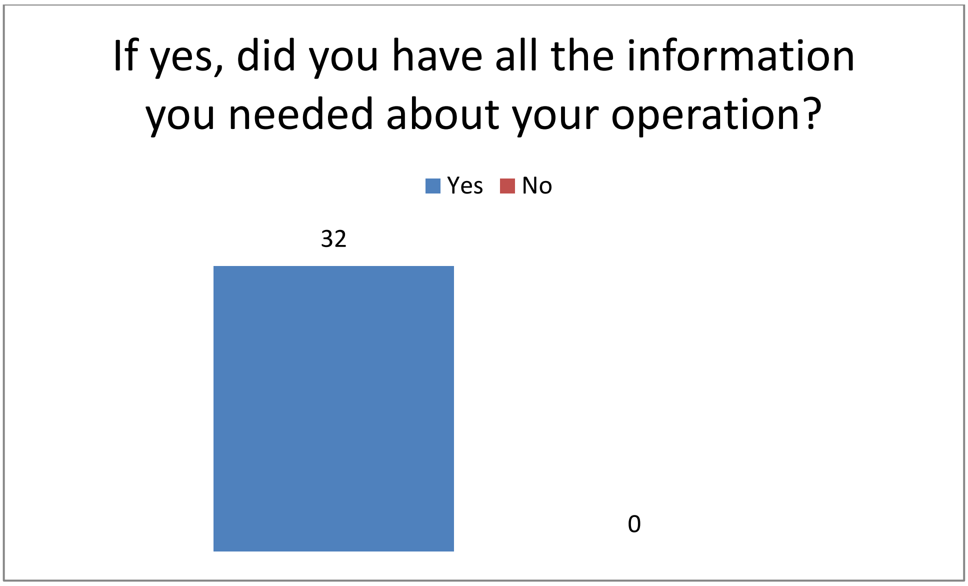
57% of respondents indicated that their families were given information to help care for them at home.

This is a question that was asked in the 2018 regional Cancer Patient Experience Survey. The score for the SHSCT CPES urology responses was 69%, the NI score was 62% and the regional prostate CPES response rate was 68%.





70% of respondents who required surgery, had this completed in CAH (32/46)

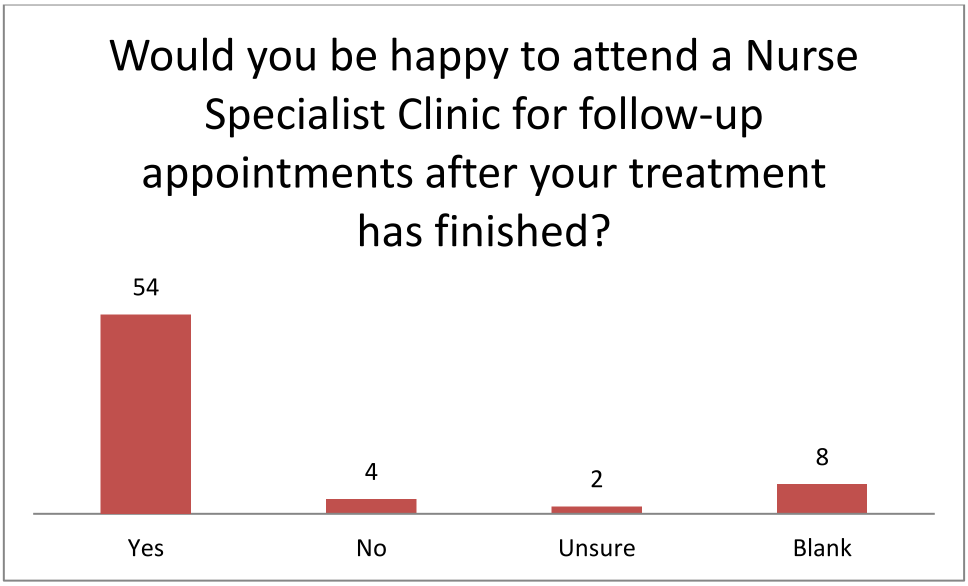


100% of respondents had all the information they needed about their operation.

Future Service Developments

At the end of the survey, patients were asked for feedback on future service developments in the Urology Cancer Service in relation to the provision of a Clinical Nurse Specialist clinic to get results of investigations and to attend a nurse-led clinic for follow-up appointments:

79% of respondents were happy to attend a Nurse Specialist clinic for results of investigations, 7% would not be happy, 4% were unsure, 13% did not answer.



79% of respondents were happy to attend a Nurse Specialist clinic for results of investigations, 6% would not be happy, 3% were unsure, 12% did not answer

<u>Patients were invited to add any other comments/suggestions for improvement:</u>

- Very satisfied with all the care and treatment I received during my kidney operation - May 2019 - Cannot give enough praise to the Consultants, nurses etc. during my 3 day stay in the Urology department.
- Can some of it be done from STH?
- When I went to the Mater Private Hospital I seen every person involved in my operation on the day. Instead of individual appointments. Doctor first. After care nurse second. Anaesthetist third. ECG and blood results all back in the one day. Maybe the way forward.
- Very impressed with care given by medical and nursing staff both at Outpatient and inpatient services.
- I travel too far to Craigavon Hospital without seeing my Consultant
- No complaints
- Went to City Hospital under Mr xxxx, a gentleman, explained everything to our family all doing well since treatment.
- Build a bigger carpark!
- Since my diagnosis is incomplete and treatment not yet started I cannot decide the best option.
- We were very happy that Mr xxxx spoke with us. We would prefer to speak with Mr xxxxx. We have an appointment with him for 31st March. The provision of chilled, filter water.
- No complaints whatsoever everything was just fine thank you.
- I had a very positive and supportive experience as a patient under Mr xxxxx in CAH. Both Mr xxxxx and Nurse xxxxx took me and my husband through a difficult diagnosis with great care and professionalism. Thank you so much.
- 8 weeks from removal of kidney tumour. Awaiting regular long term follow up with scans when are these expected……?

IMPACT BRIEFS

WE ARE MACMILLAN. CANCER SUPPORT

CANCER CLINICAL NURSE SPECIALISTS

What are they?

Clinical Nurse Specialists (CNSs) are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases such as cancer.

Macmillan funds Cancer Clinical Nurse Specialists to support health care professionals in delivering effective, efficient services and to improve the quality of care for cancer patients.

> ***"The Macmillan nurses really helped me. They provided me with emotional support. There was a couple of times I felt a bit depressed, I spoke to a couple of nurses and they gave me a lot of advice and basically they listened."***

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan's direct and indirect services, available at www.macmillan.org.uk/impactbriefs

Need

The number or people living with cancer will double to **four million** by 2030.[6]

The cancer journey is complex, involving care interventions by a range of different professionals. CNSs work with other professionals to provide and improve cancer care for patients.

Reach

Macmillan helps to fund or support **4,323** nurse posts in cancer care (many of which are CNS).[1]

Impact

Macmillan Nurses (many of which are CNS) helped and supported a total of over **554,896** patients in 2014 [24]

The average Macmillan nurse helped **158** cancer patients in 2014 [24]

http://www.macmillan.org.uk/impactbriefs

WE ARE MACMILLAN. CANCER SUPPORT

IMPACT BRIEFS

Understanding the impact of Macmillan's services

CANCER CLINICAL NURSE SPECIALISTS

INTRODUCTION

Macmillan helps to fund or support over 4,300 Clinical Nurse Specialist (CNS) posts in cancer care to support healthcare professionals in developing and delivering effective and efficient services and to improve quality of care for cancer patients.

CNSs are key workers, they treat and manage the health concerns of patients and work to promote health and wellbeing in the patients they care for. They use their skills and expertise in cancer care to provide physical and emotional support, coordinate care services and to inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes.

CNSs also reduce treatment costs, increase efficiency, drive innovation and provide valuable information for service redesign as well as enable multidisciplinary care and communication between different teams.

KEY FINDINGS

- **CNSs role in patients' cancer journey**
  The cancer journey is complex and disjointed and involves the care interventions from various multi-site professionals such as oncologists, surgeons and counsellors. The CNS role provides and reinforces relevant information and appropriate liaison with other professionals and agencies to improve the cancer care process for patients.

  CNSs improve quality and experience of care for patients, reinforce patient safety, demonstrate leadership and increase productivity and efficiency.

- **Variation in access to CNSs**
  Access to CNSs varies both geographically and by tumour site, leading to inequalities in patient experience. On average there is only one lung cancer nurse in England for every 161 people diagnosed with lung cancer, compared to 117 people per breast cancer nurse.

- **Value for money**
  CNSs represent good value for money. They reduce the number of emergency admissions, the length of hospital stay, the number of follow-up appointments, the number of medical consultations and provide support to enable people to be cared for and to die in their place of choice.

DETAILED FINDINGS

1. What is the issue?

i) Why are Clinical Nurse Specialists required by people living with cancer?

Each year just over 335,000 people are diagnosed with cancer in the UK.[2, 3, 4, 5] There are currently 2.5 million people living with cancer and it is estimated that this will double to four million people by 2030.[6] This rise is due to improvements in treatments, incidence increases and an ageing and growing population.[7]

The cancer journey is complex and disjointed and involves the care interventions from various multi-site professionals such as oncologists, surgeons and counsellors. Patients should have access to high quality, effective healthcare and CNSs have an important role to play in meeting their needs and expectations.

Research shows that current models of care are not identifying or meeting the needs of all patients living with cancer and that the current cancer workforce needs to adapt to improve care and support for cancer patients. The role of the key worker (one which a typical CNS would commonly hold) needs to become embedded in practice and the current and future workforce need to be developed with specific skills and specialist knowledge in cancer, for example understanding and supporting the management of consequences of cancer treatment.[8]

Further evidence highlights that the current system also faces challenges in expanding sufficiently to support the increasing number of cancer survivors. Improved survivorship services will have significant cost implications for the NHS and the wider economy and will require investment. Assessment and care planning, for example, requires CNSs time which may cost an estimated £15–20 million per year in England in staff time costs.[9]

> *'Emotional support should be accessible to all patients, as psychological wellbeing is important when so much has to be faced.*
>
> *Often the psychological aspect of breast cancer is not considered a high priority by health professionals. Although this is understandable when their focus is on clinical issues, it should be an integral part of the overall care. The role of CNSs is crucial in this respect'*
>
> ***Mother and breast cancer survivor*** [12]

The role of Clinical Nurse Specialists
The CNS role provides and reinforces relevant information and appropriate liaison with other professionals and agencies to improve the cancer care process for patients.[10]

The main functions of the specialist nurse role can be described as:

- technical
- information provision
- emotional support
- and coordination[11].

The high-level activities of CNSs can be separated into five main functions. In the context of cancer care these consist of:

- Using and applying technical knowledge of cancer and treatment to oversee and coordinate services, personalise ‘the cancer pathway’ for individual patients and to meet the complex information and support needs of patients and their families.
- Acting as the key accessible professional for the multidisciplinary team.
- Undertaking proactive case management and using clinical acumen to reduce the risk to patients from disease or treatments.
- Using empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines as appropriate.
- Using technical knowledge and insight from patient experience to lead service redesign, to implement improvements and make services responsive to patient need.[13]

Evidence shows that CNSs can save resources leading to greater efficiency and better outcomes. CNSs identify the specific physical and emotional needs of people and co-ordinate different parts of system to work together to address those needs and help provide care closer to home. CNSs work across different teams and their experience is often invaluable to senior management as they can advise on the specificities of service provision to inform service redesign.[14]

In 2013 74% of patients with a CNS said they were given easy to understand written information about the type of cancer they had, compared to 49% without. 74% of those with access to a CNS agreed that they had been involved in their treatment as much as they wanted to be, compared to only 57% of those that did not have a CNS; and 54% would have liked more financial information and advice but did not receive it.[15,16]

ii) Why are there inconsistencies in access to Clinical Nurse Specialists?

Access to cancer CNSs varies both geographically and by tumour site, leading to inequalities in patient experience.[17, 18, 19] On average, there is only one lung cancer nurse in England for every 161 people diagnosed with lung cancer, compared to 117 people per breast cancer nurse. A 2013 survey by the UK Lung Cancer Coalition found that almost a quarter (22%) of lung cancer patients surveyed had not received continuous support from a CNS or key worker.[20]

Working environment

A 2008 Royal College of Nursing (RCN) survey revealed the scale of the potential loss of CNS expertise. More than a third of CNSs said their organisations had a vacancy freeze in place, almost half reporting being at risk of being downgraded and 68% had to see more patients. The survey also revealed that 1 in 4 specialist nurses were at risk from redundancy and 45% were asked to work outside their specialty to cover staff shortages.[21] In the current challenging financial climate there is a real danger of care providers reducing staffing to achieve short-term savings, without consideration of the risk to patient care and to longer-term cost implications.[22]

> *‘I understand that the nurses are under pressure but we would have liked more honesty and counselling support.’*[20]
>
> **Lung cancer carer,**
> **South West**

> *‘I was dependent on the nurses who already have a heavy workload...’*[20]
>
> **Female lung cancer patient,**
> **North West**

Insufficient increase in posts

Although there has been a small increase in CNS posts since 2007 in brain/central nervous system, lung, upper gastrointestinal and haematological cancers, the increase is insufficient to keep pace with the current growth in cancer prevalence.[35]

Challenges preventing quality care provision

A 2007 survey of breast care nurses found that almost 50% of nurses felt unable to provide the quality of care to all breast cancer patients that they would like to. This was due to a variety of reasons including increased workload because of new, additional duties, staff shortages, and redeployment to other areas, e.g. general wards.[23] This example shows that there is a high demand for specialist nurses.

There is also inconsistency in job titles of roles that can be categorised as a CNS. Recent research found that almost 50 different job titles are in use for nurse specialists working in the field of urological cancers. Inconsistency in job titles has also been related to ambiguity in terms of the requirements and duties of the CNS role.[22] A recent HSJ supplement favoured the title of 'specialist nurse in advanced practice'[14] for these types of roles.

In addition, the specific services offered by CNSs may vary across the cancer care pathway as there is no minimum standard for the skills and knowledge required to function in a nurse specialist role.

2. What is Macmillan doing to address the issue?

In 2014, Macmillan had provided funding for or 'adopted' over 3,500 nurse posts. The nurses in these posts in 2014 helped over 554,000 cancer patients.[24] In addition to these patients, our Macmillan Nurses helped many more carers, family members and friends. The average Macmillan Nurse helped 158 cancer patients across the whole year in 2014.[24]

Macmillan supports the position of CNSs in cancer care by 'pump-prime' funding. Macmillan typically funds the posts for 3 years or less before the partner organisation continues supporting the role. These CNSs are often referred to as 'Macmillan nurses' and retain this title when charitable funding ends.

Macmillan nurses are registered nurses, who have been educated to first degree level and have completed post graduate learning or who are working towards post graduate qualifications. They are clinical experts within a specialist field such as young people, palliative care or specific cancer types.[16]

The Macmillan CNS provides leadership, innovation and expertise, directly, when patients have highly complex care needs that require specialist assessment and care planning, or indirectly, by supporting and guiding others to provide care and support.[25]

Macmillan supports the introduction of CNS posts for people with cancer to develop a structured, supportive service for people and their families.

The objectives of the Macmillan CNS are to:[10]

- support healthcare professionals
- develop needs-based education and training for staff
- standardise and develop patient information
- empower patients to be proactive in their own care
- deliver relevant health promotion messages to patients and the public.

One to one CNS care is central to the patient-focused 'no decision about me without me' principle set by the Department of Health.[43] Macmillan is working in partnership with the Department of Health and equivalent in Scotland, Wales and Northern Ireland, to develop and improve the current cancer CNS workforce, to make the role more fit for purpose in today's health environment and increase cancer CNS skills. Part of this work has been to produce a report to support clinical teams, commissioners and providers to understand and evaluate the contribution of CNSs in cancer as they plan their local workforce and service improvement strategies. The report can be found on the external Macmillan website. Macmillan has also contributed to an economic analysis of providing the required number of CNSs to meet the needs of all cancer patients. The results show significant potential savings for the NHS if workforce gaps are filled.[26]

3. What is the impact of CNSs?

CNSs across the country are already transforming patients' experiences of cancer care. Below is an overview of the impact a CNS has[13]:

Impact of key CNS led activity

Improving quality and experience of care.

- Managing complex, individual and changing information and support needs of patients and carers.
- Supporting patients in choices around treatment and care.
- Enhancing recovery and delivering care flexibility and closer to home.
- Facilitating set up of support groups

Reinforcing Safety

- Delivering safe, nurse led services.
- Identifying and taking action to reduce risks.
- Facilitating rapid re entry into acute services, if appropriate.

Increasing productivity and efficiency

- Intervening to manage treatment side effects and/or symptom control, preventing unplanned admissions
- Providing nurse led services that free up consultant resource.
- Empowering patients to self manage their condition.

Demonstrating leadership

- Educating the wider healthcare team and acting as a mentor.
- Identifying and implementing service improvement and efficiencies.
- Determining measurable outcomes, auditing practice, and sharing good practice and innovation.

i) Improving quality and experience of care

The English government's cancer reform strategy highlights that patients regularly emphasise the role of the CNS in improving their cancer experience.[27]

Access to a CNS has been shown to play a vital role in delivering high quality, patient-centred care and treatment to people with cancer. Patients allocated a CNS have been shown to be more positive about the experience of their care. This could be because patients supported by a CNS receive holistic care that includes emotional and practical support as well as addressing physical needs. Often patients can build closer bonds with their CNS and ask different kind of questions which they may not want to ask their doctor.[14] Access to a CNS has also been identified as increasing the chances of a patient receiving chemotherapy and helping to reduce emergency admissions and inpatient stays. Close connection with patients allows CNSs to ensure that new symptoms and potential diseases can be diagnosed earlier.[14]

The results of the 2014 National Cancer Patient Experience Survey support this. 89% of patients reported that they had been given the name of the CNS in charge of their care. Of these over 91% reported that the CNS had definitely listened carefully. Patients with a CNS responded far more positively than those without a CNS on a range of items related to information, choice and care.[15]

Recent research into complex treatment decisions for patients with advanced lung cancer showed that CNSs play a valuable role in supporting decision making and are seen as trusted sources of information.[28]

The National Lung Cancer Audit 2010 shows that in 2009 65% of patients seen by a lung CNS received cancer treatment compared to 30% of those who did not see a lung CNS. The audit collected data on more than 37,000 patients in the UK, representing approximately 95% of the expected number of new lung cancer cases.[29]

A UK survey of the experiences of men with prostate cancer found that specialist nurses were ranked the highest amongst healthcare professionals and help-lines, for the provision of emotional support around the time of diagnosis and treatment decision-making.[30] Macmillan nurses provide outcomes for patients that correspond to their emotional needs.[31]

Research has shown that significantly more patients who received nurse-led follow up from lung cancer CNSs died at home, which was their preferred location, rather than in a hospital or hospice: 40% compared to 23% receiving conventional medical follow up.[32] Additionally, in 2009 65% of people with lung cancer seen by a lung CNS received cancer treatment compared to 30% of those who did not see a lung CNS.[33]

A 2009 study of rheumatology clinical nurse specialists showed that almost a quarter of physical clinical interventions involved enhancing self-management principles and managing unresolved symptoms using specialist knowledge and assessment.[34]

CNSs provide holistic care by utilising and signposting to different service providers.

> *'The Macmillan nurses not only provided me with psychological, spiritual and emotional help, but also practically and financially. When the going got tough, they were there for us in every aspect.'*[35]
>
> **Cancer Patient**

> *'Most specialist nurses in advanced practice, even if they're based in the acute sector, practise in the community. For instance, 30 per cent of a specialist nurse in advanced practice's work is generally done over the phone. So that's supporting patients in the community and supporting community practitioners of all types to manage increasingly complex care needs.'*
>
> ***Alison Leary, professor of healthcare modelling at London South Bank University***

Much of specialist nursing is primarily caring for patients who have long term conditions and who really need to be able to support their self care in the long term – which reduces the burden on all health services. Patients may be identified as not coping well can be referred to a self management programme and to other resources.

Although most CNSs in cancer are based in the acute sector, they may work with services in the in the community. This allows them to build partnerships between different healthcare professionals based in various settings. They can also recommend patient referrals to the most appropriate services according to their specific needs because CNSs have a good understanding about what support is available and appropriate CNSs are known for their ability to facilitate multidisciplinary care between different healthcare organisations.[14]

ii) Reinforcing safety

> *'My Macmillan nurse has been there from day one. She's been a fantastic support. Any questions I have, to do with medication, symptoms or anything else, she's there.'* [35]
>
> **Cancer Patient**

CNSs help improve patient experience and safety[36] because they have in-depth knowledge of the physical, psychological and social effects of a specific condition and play a key role in the management of patient care. They have considerable experience, are highly qualified and carry out a range of functions that make them a key member of a multi-disciplinary team (MDT).[37] A lot of CNSs have many years of experience in advance practice and they are equally familiar with technical aspects and case management.[14]

Patient safety and level of inadequate staffing are often interlinked. Between April 2008 and March 2009 more than 33,000 patient safety incidents were recorded as relating to the lack of suitably trained or skilled staff. [38]

Cancer CNSs coordinate ward admissions for patients who are unwell, expedite outpatient clinic appointments, reorganise reviews to minimise cancelled procedures or operations and give advice on managing medication throughout the cancer journey. This enables patients to move through the system as smoothly as possible and diverts pressure away from other professionals such as doctors and the ward nursing team.[39]

A study in 2009 to monitor the complex workload of CNSs in rheumatology care revealed the importance of CNSs in providing safe advice on medication, showing that more than a quarter of physical clinical interventions involved management of medication including dealing with toxicity and rescue work associated with the unexpected adverse effects of treatments.[27]

iii) Demonstrating leadership

A 2010 Department of Health report illustrates the ability for CNS roles to influence, lead and advance practice and demonstrates the extent to which advanced nursing practice can support positive patient outcomes.[40]

CNSs have a much greater role in the delivery of healthcare than they had five years ago. Between 2005 and 2010 the number of referrals to a specialist nurse clinic rose from 115,000 to 650,000; an average increase of approximately 107,000 a year. It is therefore evident that GPs and consultants are more likely now than ever to refer patients to specialist nurses.[41,42]

Cancer CNSs have clearly demonstrated their commitment to work collaboratively with their colleagues to ensure that patients have access to best practice, equity of care and continuity of care throughout the cancer journey.[21]

> *"The Macmillan nurses really helped me. They provided me with emotional support. There was a couple of times I felt a bit depressed, I spoke to a couple of nurse and they gave me a lot of advice and basically they listened."*
>
> **Cancer Patient** [35]

CNSs provide support to their colleagues and can be seen as experts by other members of the MDT, providing specialist advice and guidance to colleagues on a range of issues including symptom control and patient communication.[22] CNS expertise is essential to the functioning of MDTs and they are often nominated as the 'key worker' within the team.[43] They also have experience dealing with complex patients and clinical cases which equips them with good problem solving skills.[14]

iv) Increasing productivity and efficiency

Need for increased cancer support posts

In 2010 The Department of Health commissioned Frontier Economics to conduct an economic analysis of the impact of providing enough posts for one to one support for all cancer patients in England. Frontier Economics estimated that around 1,200 new posts, a combination of specialists and support staff, are required to provide one to one care for all patients in England with cancer. The cost of this expansion in the workforce would be about £60m per year. Based on evidence that 12% of the associated workload is administrative rather than clinical, and assuming that this portion of the work could be handled by lower grade staff, the report indicates that the annual bill of £60m would be more than offset by savings of £89m per year.[44]

Lowering admission rates

CNSs ensure that patients are in hospitals only when they absolutely have to be there by providing appropriate advice and noticing any early symptoms of developing conditions. They can also help patients to self-help and manage their conditions reducing the need for additional stays in hospital.

By delegating administrative tasks and adopting a proactive management approach to patient care with the CNS as the key worker, a lung cancer nursing service in London has reported that the rate of lung cancer admissions for non-acute problems fell from 4 per month to 0.3 per month. Clinical nurse specialists who practise proactive case management and re-focus services in line with best practice therefore represent a good return on investment.[45]

Value for money

Many organisations have already noticed economic benefits of having CNSs. For the thousands of people across the UK living with long term conditions, including cancer, several studies have shown that as a substitute for other health care professionals, including doctors, specialist nurses are both clinically and cost effective.[21] A study by the RCN found that outpatient work done by Rheumatology Nurse Specialists is worth on average each year £72,128 per nurse and saves £175,168 per nurse by freeing up consultant appointments. Telephone consultations also save £72,588 per nurse by reducing the number of GP appointments.[27]

CNSs represent good value for money, through reducing costs in primary care and saving consultants' time.[27] For example, recent research into delivery methods of follow up after colorectal cancer treatment found that telephone follow-up proved a viable alternative to hospital follow-up.[46] A number of functions performed by CNSs used to be performed by consultants but are now currently undertaken by CNSs.

CNSs experience of working in and with multi disciplinary teams means they can work to support different service providers in a range of settings: GPs, community nurses, district nurse teams.[14]

A survey conducted by the National Lung Cancer Nurses Forum and the UK Lung Cancer Coalition shows lung cancer nurses in England carry out more than a total of 71,000 hours of unpaid overtime every year – saving employing trusts nearly £1.5m per annum.[47]

An economic modelling analysis by Macmillan in 2009, focusing on the role of the CNS, suggested that service improvements along the cancer pathway could release about 10% of cancer expenditure in the Manchester area.[48] This related only to breast and lung patients admitted through the two week wait system in one health economy, however if extrapolated to a national level then the economic benefits could be significant.[49]

Cost of a Macmillan nurse[50]*

These amounts can fund a Macmillan nurse to help people living with cancer and their families receive essential medical, practical and emotional support.

Cost	CNS
1 Day	£204
1 Week	£1,020
1 Month	£4,418
1 Year	£53,021

*For more detailed costs of these and other Macmillan services see be.macmillan.org.uk to download The Cost of Macmillan's Services fact sheet.

More effective and efficient treatments

Management of serious side effects by CNSs can help to avoid chemotherapy dose reductions, delays and omissions and thereby improve the likely efficiency of treatment.[35]

A report by the RCN found that studies show benefits of specialist nursing roles include reducing referral times, length of hospital stays and the risks of post-surgery complications.[10]

Since 2005-06, there has been a 465% increase in outpatient attendances at specialist nurse clinics – a rise of more 100,000 outpatients a year.[51] Cancer CNSs hold follow-up clinics for cancer patients reducing the number of follow-up clinics and therefore increasing medical staff capacity to see new patients[52]. Evidence has shown that lung cancer patients receiving CNS led follow up had significantly fewer medical consultations with a hospital doctor in the three months following cancer treatment than conventional medical follow-up services.[53] This has also been demonstrated for breast cancer patients in several trials.[54] When specialist care via access to a Cancer CNS was compared to routine medical follow-up, results showed that point of need access can be provided by suitably trained specialist nurses and provides a fast, responsive management system at a time when patients really need it.[55]

Case study – secondary breast cancer CNS benefits [57]

CNSs working in metastatic breast cancer prevent emergency admissions to hospital. They provide an alternative to unscheduled care by helping keep patients in the community. They do this by working with community teams and GPs to provide clinical solutions to complex problems. A total of 60% of the CNS's work is dealing with community-based issues. CNS prevent unscheduled care episodes approximately 26 times per year.

CNSs working with metastatic breast cancer patients reduce new to follow-up ratios in cancer units, releasing clinic and outpatient time for new patients. A CNS specialising in metastatic breast cancer will see an average of 13 follow-up patients per week in an outpatient setting. Matched against DH tariffs this represents £53,040 in income and the potential release of 13 slots to new patients (raising £159,120 per 48 week year). This means CNSs working with metastatic breast cancer patients can speed up pathways, help trusts meet targets, allow new patients to be seen and therefore generate more income.[22]

CONCLUSION

The number of people living with cancer is expected to increase from 2 million to 4 million by 2030. Therefore, the number of people requiring specialist care and support will increase throughout the cancer pathway.

Cancer CNSs possess a wide variety of skills and expertise and use this knowledge to ensure that cancer patients experience the best possible care and support.

Cancer CNSs can help to improve quality of life for people with cancer through assisting with decision making, symptom management and emotional support. Cancer CNSs also help empower patients to self-manage their conditions leading to reduced costs for healthcare providers through hospital appointments, emergency admissions and consultant time. They take a holistic approach to treatment and they can also link up different health and social care services together.

Macmillan continues to fund and support cancer CNSs and urgently needs more charitable donations to keep these services supporting cancer patients and their families. Go to www.macmillan.org.uk/donate or call 0300 1000 200 to make a donation.

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Southern Health and Social Care Trust
Quality Care - for you, with you

- Operational Policy -
Urology Cancer Services

Policy Author: Mr Anthony Glackin

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Date 5th November 2020

Signed: [redacted]

The Urology MDT members agreed this Operational Policy at the AGM held on:

Date Agreed: 5th November 2020

Version: 2.0

Operational policy review date: November 2021

The following Operational Policy for the Southern Health and Social Care Trust's Urology Multidisciplinary team provides an overview of the service, how it is accessed by patients and coordinated across the Trust services.

The Operational Policy for the Urology MDT and will be reviewed on an annual basis at the Annual General Meeting. It has been developed to ensure all relevant members of staff are aware of the purpose and organisation of the MDT meeting.

Two other documents have been developed, which should be read in conjunction with this operational policy. They are the annual work plan, which outlines the direction of the service in the incoming year and the annual report, which details the work completed in the past year, achievements and areas of work outstanding which need to be rolled into the incoming year.

Introduction

Background

The Southern Health and Social Care Trust (SHSCT) was formed on 1 April 2007. The Southern Trust (ST) is an integrated Trust, providing acute and community hospital services together with a range of community health and social services to a population of approximately 324,000 people.

Southern Trust Urological Cancer Services

The Southern Trust has provided an Urology service for patients living in the southern part of Northern Ireland since 1992. Outpatient services are located at a dedicated unit, the Thorndale Unit, based in Craigavon Area Hospital. The Unit is staffed by Consultant Urologists, Clinical Nurse Specialists, Staff Nurses and Health Care workers, in addition to visiting Radiographers and Radiologists.

Following a review of urological service provision in Northern Ireland in 2008/09, the trust took on responsibility for the provision of services to the population of County Fermanagh, with effect from 1st January 2013. County Fermanagh has a population of approximately 62,000.

Within the SHSCT, urological cancer services include surgery to treat kidney, urothelial, penile and testicular cancers. The service does not provide radical pelvic surgery for prostate and bladder cancer.

In addition to all of the urological services provided at Craigavon Area Hospital, other services provided include endoscopic and day case surgery at South Tyrone Hospital in Dungannon, outpatient clinics at Banbridge Polyclinic, Armagh Community Hospital and South West Acute Hospital in Enniskillen, County Fermanagh.

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SECTION 1: STRUCTURE AND FUNCTION OF THE MDT

1.0 Purpose of the MDT

MDTs bring together staff with the necessary knowledge, skills and experience to ensure high quality diagnosis, treatment and care for patients with cancer. MDT working has been advocated in each of the NICE Improving Outcomes Guidance and is strongly supported by clinicians.

The primary aim of the SHSCT Urology Cancer MDT is to ensure equal access to diagnosis and treatment for all patients in the agreed catchment area with Urology cancer. In order to achieve this aim we provide a high standard of care for all patients including: efficient and accurate diagnosis, treatment and ensuring continuity of care.

The MDT ensures a formal mechanism for multidisciplinary input into treatment planning and ongoing management and care of patients with Urology cancer with the aim of improving outcomes and to:

- Provide an opportunity for multidisciplinary discussion of all new cases of Urology cancer presenting to the team
- To assess newly diagnosed cancers and determine, in the light of all available information and evidence, the most appropriate treatment and care plan for each individual patient
- Ensure care is delivered according to recognised guidelines
- Ensure that the MDT work effectively together as a team regarding all aspects of diagnosis, treatment and care
- Facilitate communication with other professional groups within the hospital and between the MDT and other agencies e.g. primary care, palliative care
- Facilitate collection and analysis of high quality data to inform clinical decision making and to support clinical governance/audit
- Promote multidisciplinary decision making regarding the team’s operational policies
- Support implementation of service improvement initiatives
- Ensure incorporation of new research and best practice into patient care
- Ensure mechanisms are in place to support entry of eligible patients into clinical trials, subject to patients fully informed consent
- Provide education to senior and junior medical, nursing and allied health staff.

1.1 Membership Arrangements

Core and extended membership of the Urology cancer MDT is detailed below:

Core Membership **(14-2G-101)**

Position	Name	Cover
Consultant Urological Surgeon*/**	Anthony Glackin	Mark Haynes John O'Donoghue
Consultant Urological Surgeon	John O'Donoghue	Anthony Glackin Mark Haynes
Consultant Urological Surgeon	Mark Haynes	Aidan O'Brien John O'Donoghue
Consultant Urological Surgeon	Aidan O'Brien *(retired in June 2020)*	Mark Haynes Anthony Glackin
MDT Co-ordinator	Shauna McVeigh	Member of Cancer Tracker Team
Consultant Clinical Oncologist	vacant	vacant
Consultant Medical Oncologist**	Dr Adam Uprichard *(medical oncology rep from May 2020)*	vacant
Consultant Radiologist	Dr Marc Williams	vacant
Consultant Histopathologist (EQA certified)	Dr Gareth McClean	Dr R.Shah
Clinical Nurse Specialist	Kate O'Neill ***	Leanne McCourt
Palliative Care Nurse	Stephanie Reid	Member of Palliative Care Nursing Team

** Lead Clinician*
*** Lead for clinical trial recruitment*
****Lead for patient involvement, information & service improvement*

1.2 Extended Membership (14-2G-105)

Position	Name	Cover
Consultant Urological Surgeon	Michael Young Matthew Tyson	Anthony Glackin Mark Haynes John O'Donoghue
Consultant Psychologist	Dr Mary Daly	Nurse Counsellor (Cancer Focus)
Consultant in Palliative Care Medicine	Dr Osmond Morris Dr Sarah Cousins	Clinical Nurse Specialist
Stoma / Coloproctology Nurse Specialist	Claire Young	Clinical Nurse Specialist

1.3 Leadership Arrangements and Responsibilities (14-2G-101)

The Lead Clinician for the Urology Cancer MDT is Mr Anthony Glackin. The Trust and the Clinical Director for Cancer Services, Mr David McCaul, has agreed the position and the responsibilities (See Appendix 1).

Key Responsibilities of the Lead Clinician:

- Chair the weekly MDT meeting or delegate to a named deputy
- Ensure that patient management is planned and with input and consensus from the full panel of core members (or their nominated cover)
- Provide leadership for staff within the MDT and facilitate regular business meetings
- Lead the clinical activity of the MDT, working to agreed guidelines, ensuring a high quality integrated service which meets, local, regional and national standards.
- Provision of clear communication to all staff within the MDT and facilitation of effective team working
- Actively participate in the NICaN Urology network meeting and contribute to its work
- Ensure that regional clinical management guidelines are produced and revised regularly
- To be responsible for MDT performance monitoring against activity for National, Network and Trust targets
- To ensure that there are mechanisms in place to assess all patients with cancer for eligibility into clinical trials or research projects
- To ensure the collection of the appropriate cancer minimum dataset, working with the teams and MDT Coordinator
- To establish an audit programme and review of outcomes (this will include audits carried out across the Network)
- To ensure that local policies and guidelines are written, agreed and followed by the MDT and that these complement the Network guidelines
- Working in partnership with key stakeholders to lead on and promote a programme of service improvement and development for the MDT
- Ensuring the integration of patients/users and carers in assessment of service and service improvement

The Clinical Lead may wish to delegate some of these duties but will remain responsible for their completion.

1.4 MDT Quorum and Attendance (14-2G-102) (14-2G-104)

It is intended that all core members of the MDT attend at least two thirds of all meetings. However, in the event that a core member cannot attend they will agree an individual who will be expected to cover the MDT meeting in their absence. In addition the core members needed for a quorum or their cover should aim to attend all meetings so the MDT will be quorate for at least 95% of meetings.

The quorum for the urology cancer MDT is made up of the following core members or their cover: urology surgeon, clinical oncologist (with responsibility for chemotherapy), imaging specialist, histopathologist, clinical nurse specialist and MDT Co-ordinator.

It is the responsibility of the individual to sign in on arrival. A record of attendance of meetings will be kept by the MDT coordinator. Attendance records of the MDT will be calculated on a quarterly basis and fed back to the individual core member.

1.5 Chairing of meetings

The chairing of MDMs is shared by Mr Glackin, Mr O'Donoghue and Mr Haynes on a rotational basis. The person appointed to chair each MDM is decided at least one month previously. Adequate preparation time is included in Job Plans in a pro rata, annualised, quantitative manner.

1.6 MDT Review (14-2G-103)

The MDM takes place every Thursday, unless otherwise notified, and begins promptly at 14:15 in the tutorial room, Medical Education Centre in Craigavon Area Hospital. The meeting takes place in a room with video conferencing facilities, enabling communication by video to Daisy Hill Hospital, Newry, and with the Specialist MDM in Belfast.

Video conferencing with the Specialist Urological Cancer MDT is scheduled to take place at 3.30 pm every Thursday. Testis Cancer cases are discussed by video-conference at 2pm every other Thursday.
It is the policy of the Southern MDT that all MDMs should finish by 5pm at the latest. It has been the experience of the MDT that the number of cases to be discussed has had to be limited to 40 in order to enable the MDM to finish by 5pm.

All new cases of urological cancer and those following urological biopsy will be reviewed. Patients with disease progression or treatment related complications will also be discussed and a treatment plan agreed. Patient's holistic needs will be taken into account as part of the multidisciplinary discussion. The Clinician who has dealt with the patient will represent the patient and family concerns and ensure the discussion is patient-centred.

All meetings are supported and organised by the MDT Coordinator. The MDT Coordinator is responsible for collating the information on all patients being discussed and ensuring that all the necessary information is available to enable clinical decisions to be made.

Responsibilities of the MDT Coordinator:

- Ensuring all cancer patients are discussed at the MDT meeting
- Inserting notes onto the pro forma and ensuring it has been signed-off as being a correct record of the meeting's discussion (this forms the main body of the MDT letter to GP)
- Insertion of clinical summaries and updates onto CaPPs
- Filing the pro forma into the relevant notes and forwarding a copy to the oncology department of those patients who need to be referred to the oncologists

- Posting a summary sheet or the pro forma to the referring General Practitioner within 24 hours of the MDT discussion taking place
- Recording the MDT attendance for every meeting
- Adding any patient on the MDT list not discussed (notes, films or results missing, lack of time), to the following week's list
- Prospectively track all patients with cancer or suspected cancer in achieving the regional cancer access targets
- Ensuring that all patients with cancer or suspected cancer have pre booked appointments and treatment in line with cancer access targets and to raise delays with the MDT
- Ensuring that direct referrals or inter trust transfers are implemented
- Liaising with the Specialist MDT Co-ordinator prior to any MDM when it is intended to discuss patients with that MDM
- Maintaining timely and accurate data collection, within the databases

1.7 Referrals to the MDT meeting

All referrals to the MDT meeting should be through any core member of the team to the MDT Coordinator who will then add the patient to the MDT list for discussion.

Clinicians will place cases for presentation onto the meeting agenda by informing the MDT Coordinator of the relevant case details by the day before the MDM at 12.00 hrs. In all instances it is the responsibility of the presenting clinician to ensure all appropriate clinical results are available for the meeting.

1.8 MDM Documentation

It is the responsibility of the MDM Co-ordinator to make a documentary record of the MDM, including a record of attendance, and it is the responsibility of the Chair to approve that record.

It is the responsibility of both the MDM Chair and the MDT Co-ordinator to ensure the accuracy of the completed textual record of Clinical Summaries, Updates and MDM Plans of all patients discussed at the MDM, and so that the documentation, in correspondence format, may be sent without delay to Family Doctors and to other clinicians to whom it had been agreed patients would be referred (see Appendix 2).

1.9 Protocol for taking action between meetings (14-2I-203)

When clinical circumstance dictates it may be necessary to give patients results and decide treatment plans prior to the next MDT meeting. The clinician responsible for the patient’s care may contact the relevant member by telephone to arrange the management. These decisions will be recorded in the patient notes. Additionally this decision will be subsequently discussed and endorsed at the next MDT meeting. The MDT Coordinator will ensure that results from any investigations (including those initiated as part of the agreed emergency plan) are available.

1.10 Protocoled care

Non muscle invasive bladder cancer

Utilising the categories described in NICE Guideline NG2:

The Consultant Chairing the MDM will be responsible for assigning and recording the risk category for bladder cancer cases based on the information provided to the MDM.

New and recurrent low risk urothelial cancer cases are to be listed for noting at MDM. The responsible Consultant Urologist will arrange appropriate endoscopic surveillance and further management.

New intermediate risk urothelial cancer cases are to be listed for noting at MDM. The responsible Consultant Urologist will arrange a 6 week course of intravesical therapy, with either mitomycin C or epirubicin, to be followed by endoscopic surveillance and further management.

If intermediate-risk non-muscle-invasive bladder cancer recurs after a course of intravesical therapy, refer the person's care to a specialist urology multidisciplinary team.

All cases of high risk urothelial cancer are to be listed for discussion at MDM. Offer the choice of intravesical BCG (Bacille Calmette-Guérin) or radical cystectomy to people with high-risk non-muscle-invasive bladder cancer, and base the choice on a full discussion with the person, the clinical nurse specialist and a urologist who performs both intravesical BCG and radical cystectomy.

If induction BCG fails (because it is not tolerated, or bladder cancer persists or recurs after treatment with BCG), or if the patient wishes to consider primary radical cystectomy, the person's care can be referred to the specialist Urology Multidisciplinary Team at the Belfast Trust.

Muscle invasive bladder cancer
All cases must be listed for MDM and notified to the specialist urology multidisciplinary team at the Belfast Trust as soon as possible in order to expedite timely treatment (do not wait for staging investigation results before advising the specialist urology multidisciplinary team of the case). All cases will require discussion at the specialist urology multidisciplinary team meeting at the Belfast Trust.

Penile Cancer
Direct referral to the regional penile cancer service is the preferred option. In cases of clinical uncertainty initial assessment may be required by the designated local penile cancer lead (Mr Glackin, SHSCT) followed by referral to the regional penile cancer service in accordance with the NW Penile Cancer operational policy 2019-2020.

Testis Cancer
All cases of confirmed testis cancer are to be listed for discussion at MDM following completion of staging, histology and tumour markers, and for referral to the Testis Cancer specialist multidisciplinary team at the Belfast Trust.

Kidney cancer
All cases must be discussed at MDM.

Prostate Cancer
Clinicians should utilise the grid below to guide the choice of staging investigations. Following completion of staging all cases of confirmed prostate cancer must be listed for discussion of management options at MDM.

		PSA			
Gleason Grade	Grade group	<10	≥10, <20	≥20, <40	≥40
3+3=6	1	MRI	MRI	MRI, BS	BS, CT, MRI if no mets on BS / CT
3+4=7	2	MRI	MRI	MRI, BS	BS, CT, MRI if no mets on BS / CT
4+3=7	3	MRI	MRI, BS	MRI, BS	BS, CT, MRI if no mets on BS / CT
3+5=8 4+4=8 5+3=8	4	MRI, BS	MRI, BS	MRI, BS	BS, CT, MRI if no mets on BS / CT
4+5=9 5+4=9 5+5=10	5	MRI, BS	MRI, BS	MRI, BS, CT	BS, CT, MRI if no mets on BS / CT

SECTION 2: CO-ORDINATION OF CARE/PATIENT PATHWAYS

2.1 Clinical Guidelines and Pathways (14-2G-106) (14-2G-110)

The MDT has participated through the Northern Ireland Cancer Network in the development of Clinical Guidelines and Pathways for Urology cancer. This includes referral to the regional Teenager & Young Adult service as appropriate for patients aged between 14-25 years.

2.2 Regular Prostate Clinic & Regular Haematuria Clinic (14-2G-107) (14-2G-108)

New urgent suspected cancer referrals are triaged electronically by Consultant Urologists who may choose to request imaging or laboratory tests prior to the patient’s attendance at a New Patient Clinic in order to expedite timely management. There are four New Patient Clinics held each week in the Thorndale Unit. New urgent suspected cancer referrals are given priority of appointment. Each Consultant Urologist provides one New Patient Clinic each week for a total of 9 patients. In addition middle grade urologists see 6 new patients at each clinic under the supervision of a Consultant. Weekly haematuria clinics are provided on the Craigavon and Daisy Hill sites.

The New Patient Clinics are staffed by Clinical Nurse Specialists and Practitioners, Health Care Assistants and Radiographers, in order to facilitate patients having further assessment during their visit to the New Patient Clinic. Further investigations include ultrasound scanning of the urinary tract, uroflowmetry, flexible cystoscopy and transrectal ultrasound guided prostate biopsy. It is also usual to have scrotal ultrasound scanning performed if there is a suspicion of testicular tumour.

2.3 Agreed Policy for Patient Access to MDT to Discuss Treatment Options (14-2G-109)

In keeping with regional guidelines patients with prostate, kidney, testis and high risk non-muscle invasive or muscle invasive urothelial cancers requiring radical treatment or management of advanced/metastatic disease are referred to the Specialist Urology MDT in Belfast Trust whereby patients will be offered a meeting to discuss treatment options prior to deciding which modality of treatment to use.

Patients with suspected penile cancer are referred to the newly established regional service in the Western Trust at the time of initial referral and assessment.

Patient Review following MDM discussion

If it has been agreed at MDM that the patient is to be reviewed to be advised of the further assessment or management as recommended by the MDT and stipulated in the MDM Plan, a Review Appointment will be made at the Review Clinic of the responsible Consultant Urologist. Each is provided with six oncology review slots per week. It is the policy of the MDT that all patients are reviewed by the end of the first week following their MDM discussion. If that is not possible, the Chair of MDM may exercise the right to allocate the review of any patient to that of another consultant, if it is considered pertinent to do so.

When it has been concluded by the MDT that a patient's further management may have options, as may be the case in organ confined, prostatic carcinoma, then the patient will be advised of all of those options at review, and will be provided with written information regarding each option. Importantly, it is the policy of MDT that such patients are offered the opportunity of referral to consultant specialists relating to each management modality, such as oncologists, for their further advice, so that the patient may arrive at an optimally informed choice.

2.4 Treatment Planning (14-2G-111)

All applicable patient information should be available for the case discussion to proceed.

Case discussion incorporates the patient's age, clinical condition and any psychosocial aspects impacting on clinical management. All patients are discussed at diagnosis or prior to this where confirmation of malignancy is complex.

The MDT should agree and record the multidisciplinary treatment planning decision (i.e. to which modality of treatment - surgery, oncology, best supportive care).
The CaPPS system is used for collecting data on patients and documenting MDT decisions.
The MDT outcome report (Appendix 2) acts as the patient's individual treatment plan and includes:

- The patient's identity
- The diagnosis at the time of making the referral decision: benign, malignant (with histological confirmation), malignant (without histological confirmation)
- The multidisciplinary treatment planning decision (i.e. to which modality(s) of treatment – surgery, radiotherapy, chemotherapy, hormone therapy or supportive care or combinations of the same, that are to be referred for consideration)
- Confirmation that the holistic needs of the patient have been taken into account

Investigation plans and treatment recommendations are formulated during the meeting and recorded in narrative format by the MDT Co-ordinator.
The chairperson should articulate a summary of the recommendations arising from the discussion before proceeding to the next case.

2.5 Attendance at the Network meetings (14-2G-110)

A representative from the team will attend the Network Meetings as follows:

- The MDT will provide representation from either the Lead Clinician or a deputy to all the meetings with minimum attendance of two thirds of meetings.

- The MDT will engage with the Network to develop and implement network-wide clinical, referral, imaging and pathology guidelines.

Mr Mark Haynes is the Clinical Lead of the network's Urology Clinical Reference Group.

2.6 Supportive Care and Rehabilitation Services

A comprehensive range of supportive care and rehabilitation services are available for Urology cancer patients. Referral to these services can be made by members of MDT, directly or by way of MDM, by Key Workers, while some can be accessed by patients directly.

2.6.1 Physiotherapy Services

A wide range of physiotherapy is available at Craigavon Area Hospital and to varying degrees at all the other hospitals within the catchment area of the Urology Service.

2.6.2 Stoma Care Services

A readily accessible, stoma care service is available at Craigavon Area Hospital.

2.6.3 Clinical Psychology & Counselling Services

A Clinical psychology service is provided by the Psychology Department based in Moylinn House, Craigavon and referrals can be made by members of the MDT. Counselling services for people affected by cancer are provided on the Craigavon Area Hospital site in partnership with Cancer Focus NI. Staff complete an electronic referral to the service on behalf of the patient. Referrals are triaged and prioritised as appropriate by the Nurse Counsellors.

2.6.4 Community Continence Services

There is a Community Continence Service serving the Southern Trust catchment area. Referrals are accepted by email. The service is highly regarded by MDT.

2.6.5 Pre-chemotherapy Education Sessions & Helpline

All patients requiring chemotherapy are invited to attend a pre-chemotherapy education session in the Mandeville Unit at Craigavon Area Hospital. A 24 hour Helpline service is available for advice and support for patients who are receiving chemotherapy.

2.6.7 Macmillan Benefits Service

Macmillan Cancer Support in partnership with Community Advice provides Benefits Service advisers based in Craigavon Area Hospital. A telephone helpline is also available and advisers can arrange office appointments or ward visits so that everyone affected by cancer can access financial help. Referrals are accepted by staff on behalf of the person affected by cancer or by self-referral.

2.6.8 Macmillan Information and Support Service

The Macmillan Information and Support Service is available to anyone affected by cancer and living within the Southern Trust area. There are Information and Support centres based in Craigavon Area Hospital and Daisy Hill Hospital. The service also provides information and support over the phone or by email for those not able to access the service in person.
The Trust in partnership with Macmillan Cancer Support provide a self-management programme called **H.O.P.E** (Helping to Overcome Problems Effectively) aimed at helping patients with cancer manage the day-to-day impact of living with the disease.

2.6.9 Other Support Services

The Southern Trust has developed strong partnerships with local charities and support centres which offer a range of services such as complementary therapies, counselling, family support, welfare rights advice and short courses etc.
Information about these groups and services are available by contacting the Macmillan Information and Support Service.

SECTION 3: PATIENT EXPERIENCE

3.1 Key Worker (14-2G-113)

The identification of the Key Worker(s) will be the responsibility of the designated MDT Core Nurse member.

It is the joint responsibility of the MDT Clinical Lead and of the MDT Core Nurse Member to ensure that each Urology cancer patient has an identified Key Worker and that this is documented in the agreed Record of Patient Management. In the majority of cases, the Key Worker will be a Urology Clinical Nurse Specialist (Band 7) or Practitioner (Band 6). It is the intent that all Key Workers will have attended the Advanced Communications Skills Course.

Patients and families should be informed of the role of the Key Worker. Contact details are given with written information, and in the Record of Patient Management.

As patients progress along the care pathway, the Key Worker may change. Where possible, these changes should be kept to a minimum. It is the responsibility of the Key Worker to identify the most appropriate healthcare professional to be the patient's next Key Worker. Any changes should be negotiated with the patient and carer prior to implementation, and a clear handover provided to the next Key Worker.

Urology Clinical Nurse Specialists and Practitioners should be present or available at all patient consultations where the patient is informed of a diagnosis of cancer, and should be available for the patient to have a further period of discussion and support following consultation with the clinician, if required or requested. They may also be present, and should be available, when patients attend for further consultations along their pathway.

Key responsibilities of the Key Worker:

- Act as the main contact person for the patient and carer at a specific point in the pathway
- Should be present when the cancer diagnosis is discussed and any other key points in the patients journey
- Offer support, advice and provide information for the patient and their carers, referring to Macmillan Information and Support Service as appropriate to enable access to services
- Ensure continuity of care along the patients pathway and that all relevant plans are communicated to all members of the MDT involved in the patients care
- Ensure that the patient and carer have their contact details, that these contact details are documented and available to all professionals involved in that patients care
- Support the patient in identifying their needs, review these as required and co-ordinate care accordingly
- Liaise and facilitate communication between the patient, carer and appropriate health professionals and vice versa

- Offer verbal and written information with regard to diagnosis, investigations, treatment options and support groups
- Assist to empower patients as appropriate

3.2 Patient Information (14-2G-114)

The key worker will offer the patient and their carers a core information pack and a variety of information at various stages of their pathway, pertaining to their condition as well as any diagnostic procedures or treatments.

This information includes information specific to the MDT's cancer site and its treatment options (including names and functions / roles of the team treating them), information specific to that MDT about local provision of services, information about patient involvement groups / self-help groups, information about services offering psychological, social/cultural, financial information and effects of living with cancer and dealing with its emotional effects.

For patients with sensory, cognitive or language difficulties bespoke information can be arranged via the Macmillan Health & Wellbeing Manager.
Additionally a regional interpreting service is offered with trained health related interpreters. The Trust also has a contract with the 24 hour telephone interpreting service to ensure that patients have support in the planned or emergency situation.

Patients are offered information by appropriate staff in a phased manner relevant to the stage of their journey. For teenager and young adults, additional support is provided through the Regional Teenager and Young Adult (TYA) service, and appropriate information leaflets are available (see TYA regional pathway Appendix 5).

3.3 Permanent Record of Consultation (14-2G-115)

At a results clinic an identified member of the multidisciplinary team will effectively convey the patient diagnosis and recommendations of the meeting to the patient, to assist them in participating in decision making about ongoing treatment and care. This is undertaken in line with the Trust Breaking Bad News policy. The patient is given the opportunity to have a family member or friend with them.

Patients will also be offered the opportunity of a permanent record or summary of the consultation when their diagnoses and management is discussed.
Following the initial pilot of a patient record to capture all key information, the MDT has agreed to work towards full implementation.

3.4 Patient Feedback (14-2G-116)

Feedback from service users is obtained on a regular basis both formally and informally. Feedback on patient's experience will be sought using a range of mechanisms including patient surveys, focus groups, complaints, compliments, and participation in the patient and public involvement processes within the Trust.

The Trust has participated in two regional Cancer Patient Experience Surveys exploring the patient experience throughout their cancer journey, and completed a local patient feedback survey. Findings have been presented and discussed at an operational meeting and an action plan agreed.

Complaints and compliments will be monitored by the Head of Service and lessons learned will be discussed in the Operational Meetings.
There is the opportunity via the Cancer Services User Forum to present new service developments or information leaflets to capture patients' views.

SECTION 4: CLINICAL OUTCOMES/INDICATORS

4.1 Clinical Indicators Review/Audit (14-2G-217)

The MDT will annually review its data and discuss progress of audits or discuss the completed results, as relevant, of audits. These should be presented at one of the regular network group meetings.
Data on compliance with the Cancer Access Standards in relation to the 31 and 62 day targets will also be reviewed.

4.2 Clinical Trials (14-2G-218)

Clinical trials in Urological Cancers are conducted in Northern Ireland, either as participants in UK and International studies, or designed by the Cancer Centre in Belfast. Recruitment of Urological Cancer patients to clinical trials now accounts for over 20% of all cancer patients recruited to cancer clinical trials in Northern Ireland.

The MDT will promote recruitment to clinical trials both locally and regionally with support from the Clinical Trials Research Nurse. The MDT should produce a report at least annually on clinical trials, for discussion with the network group.

4.3 Attendance at Advanced Communication Skills Training (14-2G-219)

All core members of the team who have direct clinical contact with patients will complete advanced communications skills training.

4.4 Communication with Primary Care (14-2G-220)

The importance of timely communication with primary care is essential.
Where a patient is given a diagnosis of Urology cancer it will be the responsibility of the relevant MDT member to ensure that the patients GP is informed in writing by the end of the next working day of the diagnosis being given (Appendix 3).
An audit of timeliness of GP notification will take place annually.

APPENDIX 1: Clinical Lead appointment letter

Southern Health
and Social Care Trust

……………………………..

Consultant Urology Surgeon,

Craigavon Area Hospital

October 2019

Dear Mr Glackin

Re: Clinical Lead for the Urology Cancer Team

Further to our recent discussion, I understand that the Urology cancer team members have nominated you as the clinical lead for the service.

I would like to confirm your position as Clinical Lead for the Urology Cancer Service from 1st October 2019. This term of office will be for an initial 3 years, after which time it will be reviewed.

The role and responsibilities for the lead are detailed in the operational policy for the service.

I would like to welcome you to the wider Cancer team and thank you for your agreement to act as the Clinical Lead.

Yours sincerely

Personal Information redacted by the USI

[redacted]

Mr David McCaul

Clinical Director

Cancer & Clinical Services

APPENDIX 2: MDT Outcomes Proforma

MDM Report from Urology MDM @ The Southern Trust

RE: xxxxxxxxxxxxxxx
Address:xxxxxxxxxxxxxx
DOB, Hospital Number: xxxxxxx , HCN: xxxxxxx
Contact Tel: xxxxxxxxxxx

MDM Report from the Urology MDM @ The Southern Trust on 13/10/2016
Diagnosis Renal clear cell carcinoma
Histology Clear cell adenocarcinoma, NOS,
Laterality: left

MDM Update
CONSULTANT MR GLACKIN: This [redacted] old man was found to have a solid, left renal lesion on ultrasound scanning in April 2016. His previous medical history included recurrent [redacted].

Renal CT scanning on 11 May 2016 confirmed the presence of an enhancing mass lesion in the upper pole of the left kidney, highly suspicious for renal cell carcinoma.

Discussed @ Urology MDM 26.05.16. This gentleman has been found to have a lesion of the upper pole of his left kidney, characteristic of a renal cell carcinoma, and considered suitable for partial nephrectomy. For review by Mr Glackin to arrange a CT chest, a DMSA renogram and to arrange surgery.

There was no evidence of thoracic metastatic disease on CT scanning of his chest in July 2016. Renography in August 2016 indicated that his left renal differential function was 45%. Mr X was admitted on the 30th September 2016 for a Left Open Partial Nephrectomy.

Histology showed a clear cell adenocarcinoma. Fuhrman nuclear grade III. Tumour necrosis - no. Local invasion - pT1a. Lymphovascular invasion - no. Lymph nodes - none submitted. Margins – on macroscopic examination, tumour was present at the base margin. This was confirmed microscopically. pT1a.

MDM Action
Discussed at Urology MDM 13.10.16. This gentleman has had a renal cell carcinoma of his left kidney resected by partial nephrectomy. The patient has been advised of the pathological findings.

For review by Mr Glackin in 6 weeks to request a renal CT scan in January 2017. To be rediscussed at MDM with CT report.

Radiology
CT Findings
Latest Findings from CT performed on 25/07/2016

CT chest without contrast.
Findings
No lung mass seen. There is no hilar or mediastinal lymphadenopathy.
No bony lesion visualised.

Conclusion
No thoracic metastasis seen.

Comorbidity Summary

Personal Information redacted by the USI

APPENDIX 3: MDT Letter to GP

Urology MDM @ the Southern Trust

<GP Name>
<GP Address>
<GP Address>
<GP Address>
<GP postcode>

RE: <Patient Name>
<Patient Address>
<DOB>, <Hospital Number>, <HCN>

Dear <GP Name>

This patient was discussed at the Urology MDM @ The Southern Trust
On 13/10/2016.

Diagnosis: Renal clear cell carcinoma

MDM Update:
CONSULTANT MR GLACKIN: This [redacted] old man was found to have a solid, left renal lesion on ultrasound scanning in April 2016. His previous medical history included recurrent [redacted]. Renal CT scanning on 11 May 2016 confirmed the presence of an enhancing mass lesion in the upper pole of the left kidney, highly suspicious for renal cell carcinoma.

Discussed @ Urology MDM 26.05.16. This gentleman has been found to have a lesion of the upper pole of his left kidney, characteristic of a renal cell carcinoma, and considered suitable for partial nephrectomy. For review by Mr Glackin to arrange a CT chest, a DMSA renogram and to arrange surgery.

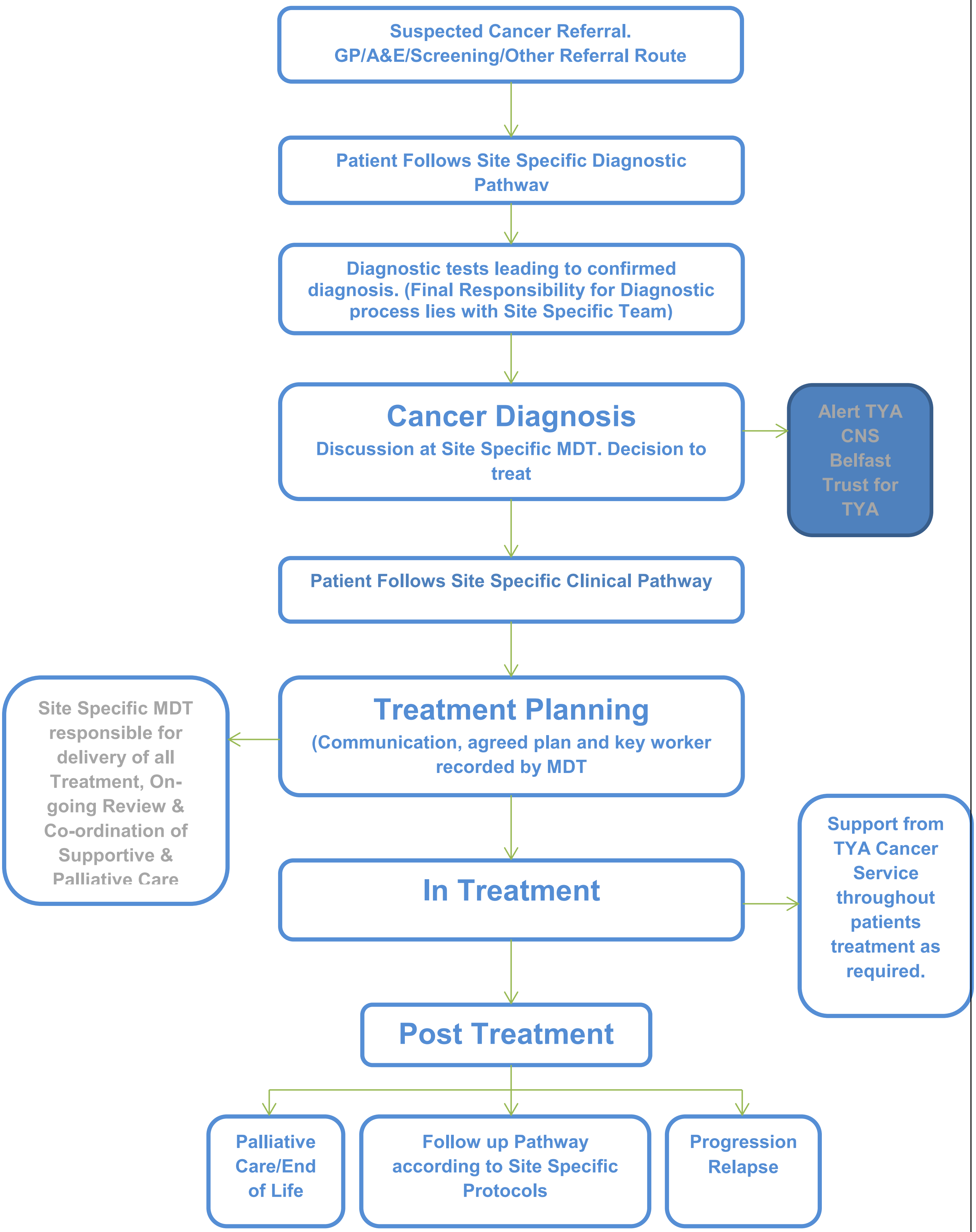
There was no evidence of thoracic metastatic disease on CT scanning of his chest in July 2016.

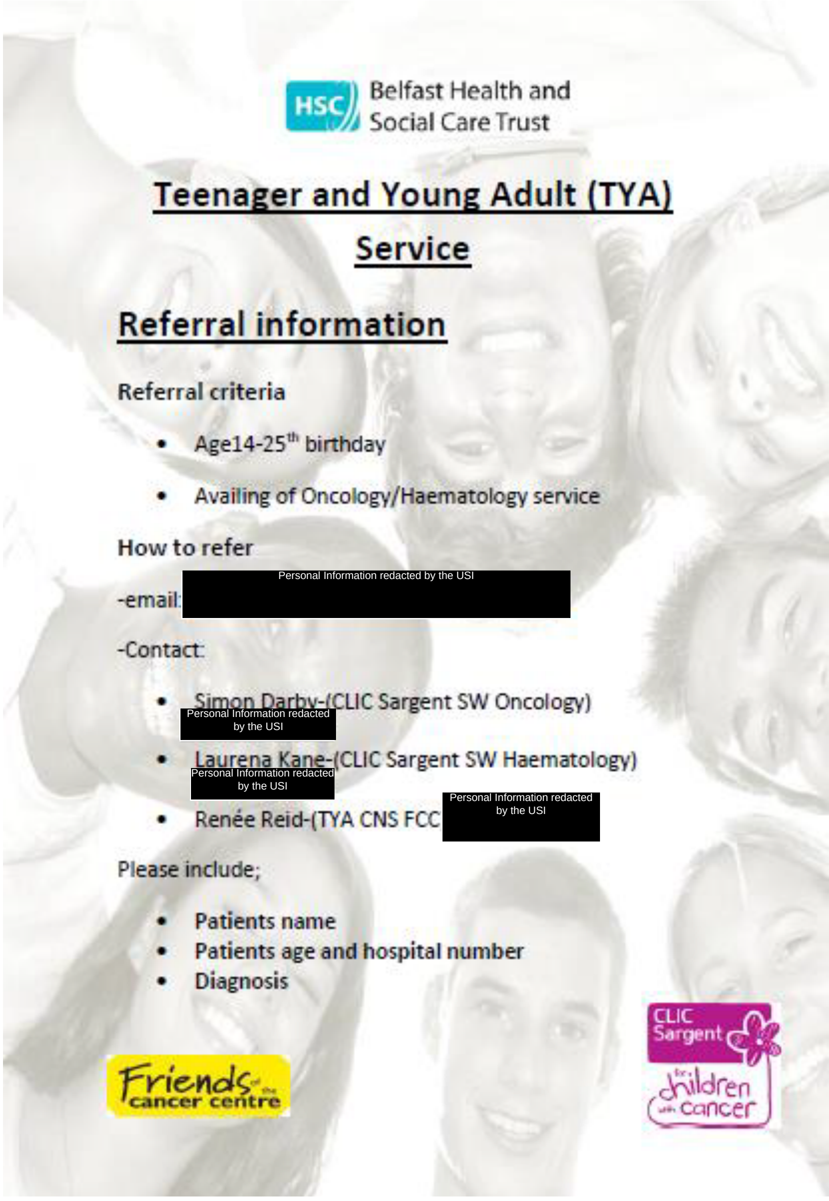
Renography in August 2016 indicated that his left renal differential function was 45%. Mr X was admitted on the 30th September 2016 for a Left Open Partial Nephrectomy.

Histology showed a clear cell adenocarcinoma. Fuhrman nuclear grade III. Tumour necrosis - no. Local invasion - pT1a. Lymphovascular invasion - no. Lymph nodes - none submitted. Margins - on macroscopic examination, tumour was present at the base margin. This was confirmed microscopically. pT1a.

MDM Plan:
Discussed at Urology MDM 13.10.16. This gentleman has had a renal cell carcinoma of his left kidney resected by partial nephrectomy. The patient has been advised of the pathological findings. For review by Mr Glackin in 6 weeks to request a renal CT scan in January 2017. To be rediscussed at MDM with CT report.

Appendix 4: Regional referral pathway for Teenagers & Young Adults





Belfast Health and Social Care Trust

Teenager and Young Adult (TYA) Service

Referral information

Referral criteria

- Age14-25th birthday
- Availing of Oncology/Haematology service

How to refer

-email: [redacted]

-Contact:

- Simon Darby-(CLIC Sargent SW Oncology) [redacted]
- Laurena Kane-(CLIC Sargent SW Haematology) [redacted]
- Renée Reid-(TYA CNS FCC [redacted]

Please include;

- Patients name
- Patients age and hospital number
- Diagnosis

From: McCourt, Leanne
Sent: 14 October 2021 13:51
To: Clayton, Wendy; Ward, Sarah
Subject: FIGURES 2107-PRESENT
Attachments: OVERVIEW OF KEYWORKER ACTIVITY.pptx

Hi Wendy and Sarah,

I have kept a record of keyworker numbers form 2017. (I previously worked in research – so it data was key).

I've also attached small piece of work my keyworker activity – it was presented at audit.

July 2017- 26th Feb 2019 (worked as clinical sister and so keyworker was not a central part of my role)	Number of patients
AJG	4
AOB	1
JOD	16
MDH	35
MY	6
[redacted]	13
TOTAL	**75**

27th Feb 2019- March 20	Number of patients
AJG	23
AOB	14
DH	3
JOD	32
MDH	121
MTY	5
MY	14
[redacted]	4
TOTAL	**216**

April 20-March 21	Number of patients
AJG	44

AOB	1
Elamin	1
JOD	46
NK	1
MDH	55
MY	11
SOM	5
TOTAL	**164**

April 21- 14th Oct 21	Number of patients
AJG	15
JOD	27
NK	19
MDH	33
MY	10
SOM	15
UPRITCHARD	1
TOTAL	**120**

Thanks,

Leanne

Leanne McCourt

Macmillan Urology Nurse Specialist
Thorndale Unit
Craigavon Hospital
Ex [redacted]

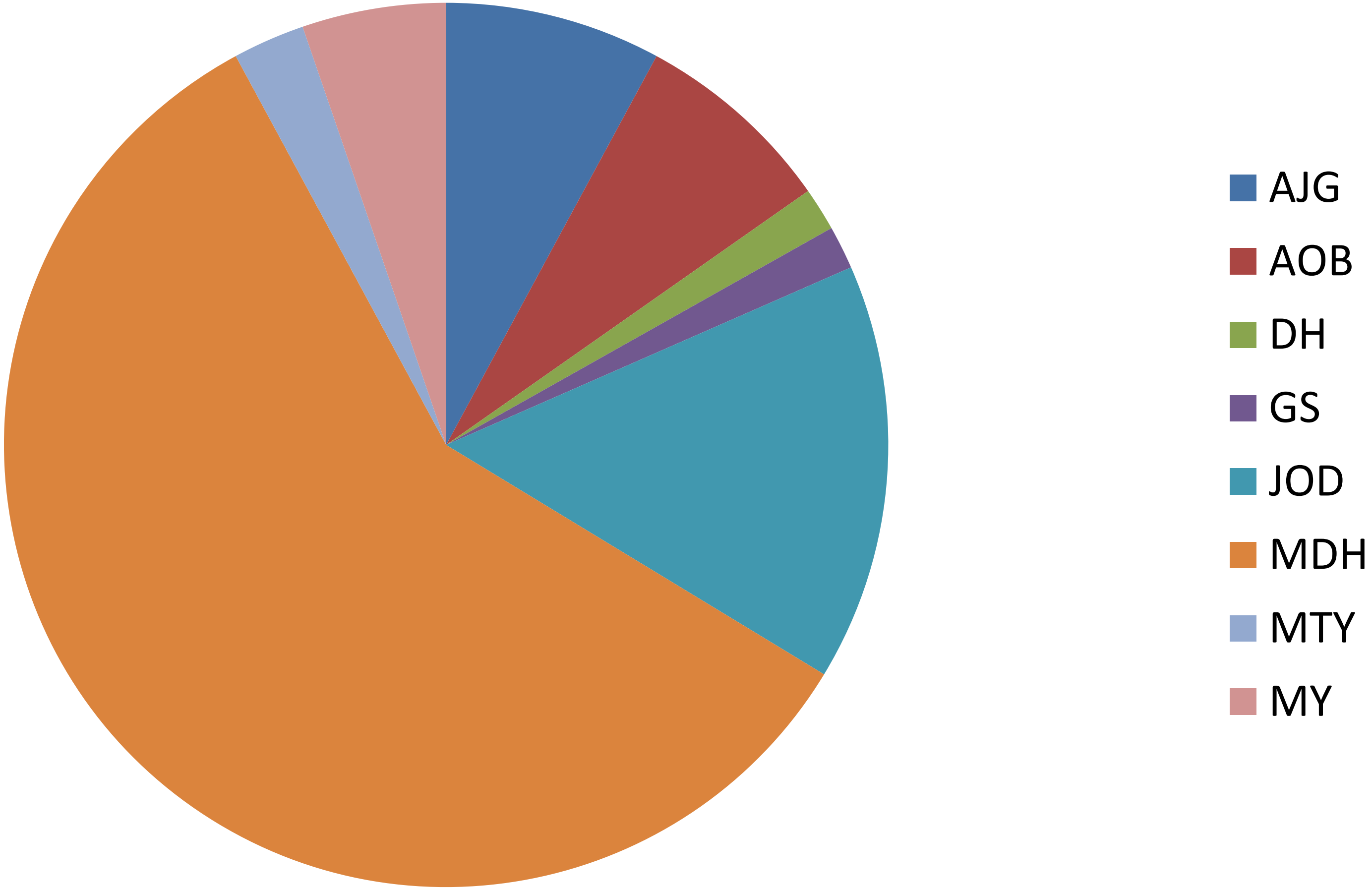
OVERVIEW OF KEYWORKER ACTIVITY

Feb 2019-Jan 2020

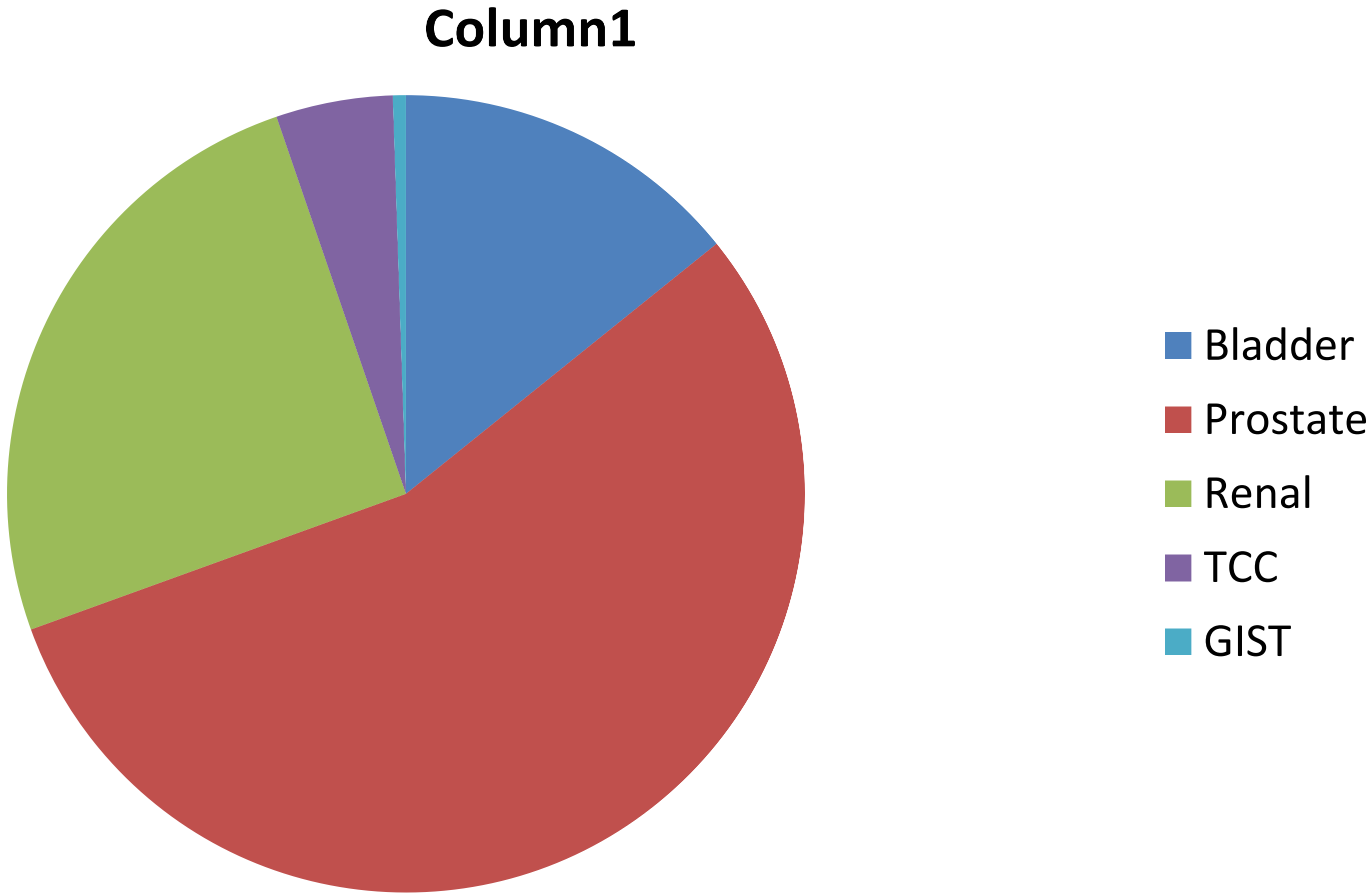
Based on figures from 1 CNS

Leanne McCourt

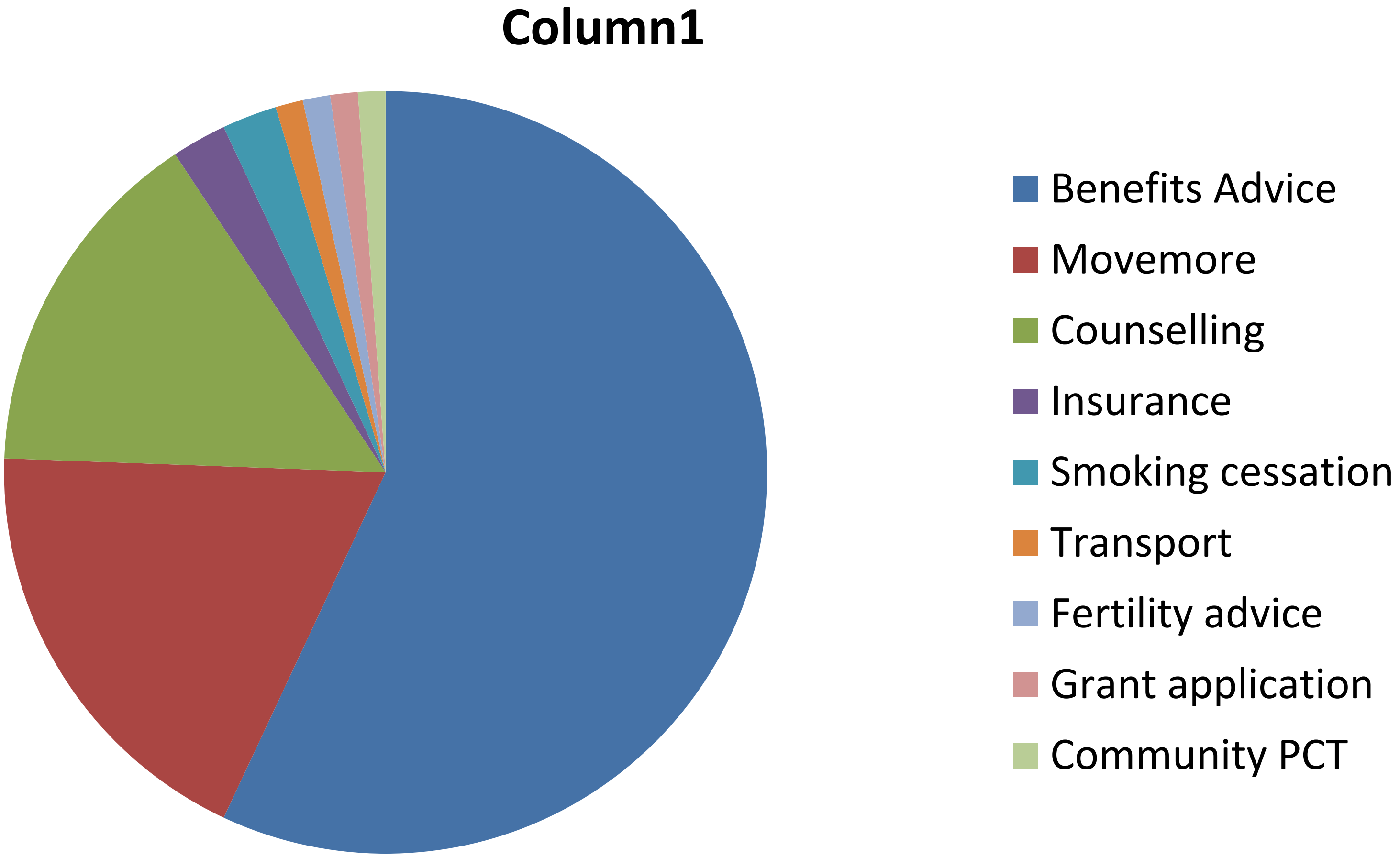
Breakdown from Feb 19-Jan 20
n= 190



Breakdown of disease areas



Signposting/referral



NUMBER OF ENCOUNTERS

- Additional contacts after initial consultation
- 108 individual encounters (recorded)

Majority were telephone conversations

Drop in

Inpatient

Spreadsheet amended going forward to more easily record and collate data

Encounter reasons

- Support and reassurance
- Increase of symptom severity- side effects and disease progression
- Appointment queries (clinic or scan)
- Arranging admission- blood transfusion and pleurex drain insertion
- Benefits
- DS 1500

Limitations

- Based on records of 1 CNS only
- Dependent on working pattern of CNS as to which Consultant Clinics were covered
- Going forward with new structure in TDU- CNS to be assigned to each Consultant MDM results clinic. Named Nurse to rotate on a regular basis.

From: ONeill, Kate
Sent: 16 June 2017 11:51
To: O'Brien, Aidan; Young, Michael; Glackin, Anthony; Haynes, Mark; ODonoghue, JohnP; Jacob, Thomas
Cc: McMahon, Jenny; McCourt, Leanne; Young, Jason
Subject: RE: Issue raised at the Thorndale Unit Meeting today

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For all Consultant colleagues:

Following discussion at the above meeting today, can we ask that all patients who require the input of a Key Worker would be offered the option to meet with the appropriate member of staff on the day. Patients have informed us of the benefit of meeting with the staff member and it makes it much easier for them to make contact via telephone should/when any queries arise.

For all patients who require intravesical treatments it is so useful as Janice/Kate Mc Creesh can often provide the necessary information, answer queries and indeed offer the commencement date of treatment in agreement with the patient. It also allows them to identify issues in relation to eg. Transport concerns etc

Thanks for your ongoing support in improving the patient experience.

Regards,
Kate

From: McMahon, Jenny
Sent: 29 March 2021 20:04
To: Kingsnorth, Patricia
Cc: ONeill, Kate; McCourt, Leanne; Thompson, PatriciaA; Young, Jason
Subject: FW: IMPORTANT - UROLOGY DRAFT SAI REPORTS
Attachments: Queries in relation to SAI reports.docx

Dear Patricia
Please find enclosed comments from the Urology CNS team regarding the draft reports.
Kind regards
Jenny McMahon

From: Wallace, Stephen
Sent: 16 March 2021 18:12
To: Carroll, Ronan; Young, Michael; Glackin, Anthony; Haynes, Mark; Omer, Shawgi; ODonoghue, JohnP; Khan, Nasir; ONeill, Kate; McMahon, Jenny; McCourt, Leanne; Thompson, PatriciaA; Young, Jason; Corrigan, Martina; Conway, Barry; McCaul, David
Cc: McClements, Melanie; Kingsnorth, Patricia; OKane, Maria
Subject: IMPORTANT - UROLOGY DRAFT SAI REPORTS

Dear Colleagues,

As discussed with Martina Corrigan on 4th March you are aware that the Urology SAIs being conducted by Dr Dermot Hughes and his team relating to 9 patients were in their final stages. I would now like to confirm that these processes have concluded.

As agreed the draft copies of the SAI reports are now available for you to review via the Trust Egress system, you will receive a separate email with details of how to access these. Mr O'Brien has asked that a copy of correspondence he has issued to the Trust regarding this matter should be included with the draft reports. This can also be found in the draft report folder.

If you have any comments on the factual accuracy of any of the reports Dr Hughes would be grateful if you would provide these via Patricia Kingsnorth, Acute Governance coordinator (Personal Information redacted by the USI by the 30th March 2021.

Please note that the Egress files cannot be downloaded or saved and only viewed on the system. **I am ask that you do not share the draft reports further via any medium or platform due to the draft sensitive nature of the content.**

Regards
Dr Maria O'Kane
Medical Director

Queries/ Comments in relation to SAI reports

1. Terms of Reference (TOR)

The SAI TOR makes reference to interviews with staff – just to clarify that the CNS team have not been interviewed at any stage throughout the process. We were however introduced to the review team via zoom meeting on 22.2.21.

Please note for proof reading, some TOR are repeated twice within individual case presentations and some also still include patient initials rather than XX.

2. Roles & Responsibilities of CNS/Keyworker

Regarding responsibilities of the Uro-oncology Specialist Nurses, NICaN Urology Cancer Clinical Guidelines March 2016 advise:

All patients should be assigned a key worker (usually a CNS) at the time of diagnosis, and appropriate arrangements should be in place to facilitate easy access to the key worker during working hours and an appropriate source of advice in his/her absence, as per National Cancer Peer Review standards.

All patients should be offered a holistic needs assessment (HNA) at diagnosis and subsequently if their disease status changes.

Patients should be offered advice and support to address any immediate concerns – physical, mental, spiritual or financial – on completion of the HNA with onward referrals made as necessary.

The responsibilities of the uro-oncology CNS include, ensuring patients undergoing investigations for suspected cancers have adequate information and support.

On diagnosis, the CNS has a supportive role and will help ensure that the patient and significant others are equipped to make informed decisions regarding their ongoing treatment and care.

The CNS may have a role in the review of patients following treatment for urological cancer. The CNS also has a key role in equipping the patient to live with and beyond the urological cancer, as advocated by the National Cancer Survivorship Initiative (2011). National Cancer Survivorship Initiative (2011) has also recommended the use of Holistic Needs Assessment (HNA) by the CNS to assess patient's needs for physical, psychological, social, spiritual and financial support at key points of their journey.

A structured pack has been provided for use by professionals to assist with this process (NCAT, 2010). This HNA approach and subsequent care planning is a process which would ensure that people's needs are met in a timely and appropriate

way and that resources are targeted to those who need them most. As a result of the HNA patients should be appropriately referred or signposted to any required support services.
Where cystectomy is considered, the involvement of the Stoma Therapist and/or Urology Clinical Nurse Specialist soon after diagnosis is essential. Patients should be offered the opportunity to meet a patient who has had a cystectomy and urinary diversion to help the decision making process. Patients who may have problems with urinary incontinence should be given information about local continence services.

The SHSCT MDM operational policy (latest draft 2020) advises the role of the keyworker is to…

Act as the main contact person for the patient and carer at a specific point in the pathway

Should be present when the cancer diagnosis is discussed and any other key points in the patients journey

Offer support, advice and provide information for the patient and their carers, referring to Macmillan Information and Support Service as appropriate to enable access to services

Ensure continuity of care along the patients pathway and that all relevant plans are communicated to all members of the MDT involved in the patients care

Ensure that the patient and carer have their contact details, that these contact details are documented and available to all professionals involved in that patients care

Support the patient in identifying their needs, review these as required and co-ordinate care accordingly

Liaise and facilitate communication between the patient, carer and appropriate health professionals and vice versa

Offer verbal and written information with regard to diagnosis, investigations, treatment options and support groups

Assist to empower patients as appropriate

CNS COMMENTS

The CNS team believe the use of the word “failsafe” in reference to the CNS/keyworker role is inaccurate and there are numerous references to this term throughout the report (examples below). As identified above in both the NICAN guidelines and the SHSCT MDM operational policy, the ‘failsafe’ function is not described as a responsibility of the CNS/keyworker. Neither is the assertion that the keyworker has a role to ensure all key actions take place as is described in the overarching report ([redacted] &[redacted]). The overarching report also refers to a 3 pronged approach to safe cancer patient care and pathway tracking involving MDM tracking, consultants and their secretaries and the urology nurse specialists. In point 10 of the governance findings, the review team again infer that the absence of a key worker equates to the absence of a safety net for patient pathway completion.

Example: Case [redacted]

MDM not funded to provide appropriate tracking and focuses on 31 + 62 day targets. This combined with the absence of CNS represents a major risk. There was no effective “failsafe” mechanism.

Example: Case [redacted]

A Specialist Nurse would also have been a “failsafe” for identifying the delayed scan report and bringing it back to the MDM sooner.

Example: Case [redacted]

However the normal “failsafe” mechanism would include an administration tracker or keyworker to ensure agreed actions such as onward referral take place.

As a CNS team, we would view the role of keyworker to reflect the supportive role outlined in the above documents. If a patient contacted their keyworker/CNS to enquire as to date of scan / review appointment / onward referral that would be escalated to the consultant. We do not receive notification when scans are ordered / reported. It is the responsibility of the individual who requests a scan to action the findings. In addition and with recent expansion of the CNS team there is an increasing need for the CNS team to hold their own caseload of cancer patients. If the keyworker has a responsibility as a ‘failsafe’ for the Consultant, as the CNS team move more toward independent practice would they also be provided with a “failsafe mechanism?

The CNS team in the SHSCT has increased in recent years as below:

- CNS X 2 in situ from July 2005

- 3rd CNS appointed March 2019 (Interviews for CNS X 2 planned January 2017 were changed on the day to Clinical Sister/Charge Nurse & this created a 2 year delay)
- 4th & 5th CNS appointed late summer 2020

Where a CNS was not available for a results clinic this task was delegated to either Clinical Sister/Charge Nurse/Experienced Staff Nurse. This service did not cover outreach clinics. As above there would not have been an expectation that the CNS/keyworker/delegated staff nurse would have a responsibility to follow up scan results / review appointments or ensure onward referral. The role has traditionally been viewed as a supportive role with the onus on the patient to make contact and re-engage as they needed.

3. Other considerations from report

- Case [redacted] The review team have been informed that Dr 1 excluded all CNSs from the care of his patients at clinics.

The CNS team do not believe this to be an accurate representation as we would have been introduced to patients when there was a need for interventions such as catheter changes, nephrostomy tube management, dressings, onward referral to for example to community continence or district nursing services or other AHP service..

- Overarching report findings 10 : Governance / Leadership Point 4/5/6.
  The review team have stated that the use of a CNS is common for all other urologists within the SHSCT MDM team.

The CNS team with recent expansion is more readily available to provide this resource in person if required however this has not always been the case due to other services running parallel / competing demands on the CNS time. However if the CNS was not available on the day, the keyworker contact number / Thorndale unit number would have been available to all urologists to provide. Point 8 in this report acknowledges that it is the primary responsibility of the consultant to enlist the support of the CNS.

- Point 8. The review team regard the absence of a specialist nurse from care to be a clinical risk which was not fully understood by Senior Service Managers/Professional Leads. The review team have heard differing reports around the escalation of this issue.

The CNS team are not clear on what is meant by the 'differing' reports regarding escalations or the potential implications this may have had on their role.

- Recommendation 4.

Should this also include sufficient oncology input at MDM meetings?

- Recommendation 5.

Comment regarding clinical nurse specialist as fail safe mechanism has been addressed above.

From: McCourt, Leanne
Sent: 22 September 2020 15:08
To: Corrigan, Marna ; Haynes, Mark
Subject: CONFIDENTIAL

Afternoon Marna and Mark,

Please find attached the completed pathology spreadsheet.

Kate and I feel that this information should be read in the following context.

We were not afforded the opportunity to discuss this request face to face to clarify the following:

- terms of reference or outcome measures
- your expectations in relation to this piece of work
- our capability/limitations within our role as specialist nurses
- the potential that this may be perceived as not open/transparent/independent given that this work is in relation to a former colleague
- we both feel uncomfortable in the uncertainty of whom this information may be shared with

The process we followed was

- Viewed pathology report on NIECR
- Viewed MDM recommendation where appropriate
- Checked recommendation had been actioned and provided comments where appropriate
- Emailed secretaries for the few urgent flexible cystoscopies that were required

We would request that you acknowledge that we do not possess the insight/experience/holistic view that for example a consultant urologist would bring to a work stream such as this. Going forward, we both feel that to attempt to address radiology queries would be overwhelming in terms of volume and associated risk of oversight of a significant clinical issue. Collectively we feel that it would be more appropriate for someone with a medical background to undertake this piece of work.

We hope you understand and respect our reservations.

Regards,
Leanne & Kate