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

Kate O'Neill
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 Personal Information redacted by the USI

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

Yours faithfully

Personal Information redacted by USI

Anne Donnelly
Solicitor to the Urology Services Inquiry

Tel: Personal Information redacted by the USI
Mobile: Personal Information redacted by the USI

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

Chair's Notice

[No 71 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:

Kate O'Neill
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.**

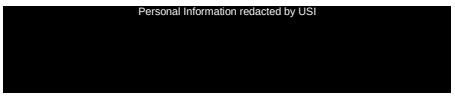
APPLICATION TO VARY OR REVOKE THE NOTICE

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: 

Christine Smith QC
Chair of Urology Services Inquiry

Urology Services Inquiry

SCHEDULE
[No 71 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.

Urology Services Inquiry

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?

Urology Services Inquiry

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?

Urology Services Inquiry

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?

Urology Services Inquiry

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

UROLOGY SERVICES INQUIRY

USI Ref: Section 21 Notice No. 71 of 2022
Date of Notice: 20th September 2022

Note: An addendum to this statement was received by the Inquiry on 10 May 2023 and can be found at WIT-94681 to WIT-94909. Annotated by the Urology Services Inquiry.

Witness Statement of: Kathleen (Kate) O'Neill

I, Kate O'Neill, 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.**

Urology Services Inquiry

1.1 As part of the previous USI questionnaire, I attached job descriptions outlining my roles and responsibilities throughout my career within the urology services. I note my questionnaire did not have page numbers etc. and have therefore now inserted page numbers. These job descriptions cover the period from a Staff Nurse role in 1992 when Urology services commenced, through Ward Manager role from March 2000 – July 2005, G and H grade and Band 7 Urology CNS from July 2005 to June 2019 and finally Band 8a Urology CNS from June 2019 to present.

1.2 It should be noted that from my appointment to Clinical Nurse Specialist (CNS) in 2005, until the Ward Manager from the Outpatient Department acquired the responsibility for Thorndale Unit and its nursing staff from Band 3-Band 6 in 2021, the job descriptions did not accurately reflect the roles I undertook on a daily basis. When first appointed in 2005, and up until 2007, we had no unit to function within, therefore I engaged with a variety of departments including the Estates Department to design the floor space within the modular build that would become Thorndale Unit, and assist with the ordering of all equipment that was required. This activity is detailed in my reply to Question 7.

1.3 During this time, I assisted my colleague Jenny McMahon CNS with the provision of benign nurse-led activity, in a variety of areas throughout the hospital that could provide us with any suitable accommodation. From 2007 onwards, in the absence of a Ward Manager, given my background in Ward Management, I undertook many of the roles that is required of a Ward Manager, and was part of the core compliment of nursing staff for all clinical activity. The concern that my colleague Jenny McMahon and I had in relation to the lack of a Ward Manager and how it may impact upon our development as CNSs were escalated to Noleen O'Donnell, Lead Nurse and Martina Corrigan Head of Service (HoS) and are explained in reply to Question 7.

1.4 In my entire career, I have had no managerial responsibility in relation to Mr O'Brien.

Raising Concerns

1.5 Within this witness statement, I have provided information that demonstrates that I have been proactive in escalating concerns, which were either operational in nature or relating to fellow practitioners. Operational challenges in relation to staffing which effected my ability to fully perform my role, in particular the need for a Ward Manager and the necessity for additional CNSs, have been detailed in my replies to Questions 7, 8, 54 and 55. Where there were concerns regarding the practice of any practitioner, I engaged immediately with the HoS, Lead Nurse and Medical colleagues as illustrated in reply to Question 16.

Governance

1.6 In recognising that governance is everyone's responsibility, I have provided detail of any meetings that I attended at which governance issues were discussed. The details of these meetings are provided in my replies to Questions 20 and 21 and are very much nursing focused. I have never held a position that included the managerial governance responsibility for medical staff.

Addressing Concerns and Risks

1.7 The Regional Review of Adult Urology Services (2009), Team South Implementation Plan (2010), National Peer Review visit in 2015, and both external and internal patient satisfaction surveys undertaken in 2015 raised various concerns and risks within Urology services. These included CNS and Consultant shortages over a variety of specialties which impacted on delays in seeing routine reviews, quoracy at MDT and over reliance on locum Consultants. I engaged with the HoS and colleagues in a variety of ways to address the challenges identified at that time. Details are provided in my replies to Questions 22-35.

Multidisciplinary Team (MDT) Structure and Meetings

1.8. The Urology MDT was established in 2010 by Mr M Akhtar, Consultant Urologist. The membership of MDT included Consultant Urologists, and representatives from Histopathology, Radiology, Oncology, alongside CNSs from Urology and Palliative Care. They were known as core members. From the outset of MDT difficulties in maintaining quoracy were apparent. The very purpose of MDT is to bring together the expertise and skills of all participants to assess, plan and manage care to meet the needs of the patient. I have provided detail of my role within MDT, the challenge of being the sole Urology CNS with an Oncology focus for many years, how MDT functioned and the challenges in maintaining/addressing quoracy issues in my replies to Questions 36-49.

Nurse-Led Services and Keyworker Activity

1.9 The majority of my current job plan is involved in providing independent nurse-led services and the provision of Keyworker support to patients with a diagnosis of a urological cancer. I have outlined the establishment of nurse-led services and their benefits in my replies to Questions 10, 52 and 53, the challenges presented through under resourcing in my reply to Questions 7 and 8, and resistance to nurse-led services in my reply to Question 51. The role of the CNS in relation to the responsibilities in MDT and the provision of keyworker support are provided in my reply to Question 34.

Learning

1.10 The Lookback exercise (January 2019 – June 2020) and the findings of the SAIs were made known to me in March 2021. I have detailed in my reply to Question 56, my engagement with the HoS and colleagues within the Urology service to address, and where possible, at a nursing level, assist with addressing the governance concerns which arose. I do not have an explanation as to what went wrong within urology services but upon reflection, I provided detail of what I viewed as potential contributing factors along with

several questions that I have in relation to how services were managed. I have detailed these issues in my reply to Questions 57-61.

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 All documents referenced in this statement are attached to this statement and can be found in S21 71 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?

4.1 Communication between the patient and the Clinical Nurse Specialist (CNS) occurs through a variety of means.

4.2 During face to face encounters within the clinical setting, (most often in the presence of a relative) upon receipt of results or at a time of review. This setting allows for the introduction of CNS practitioners to establish a nurse/patient relationship, facilitates the provision of supportive written documentation such as British Association of Urological Surgeons (BAUS) 'Patient information leaflet on Radical Nephrectomy Laparoscopic, which is site specific to the patient's condition and for the provision of contact details for engagement with the CNS in their role as Keyworker. For those newly diagnosed with prostate cancer, I would provide the booklet produced by Prostate Cancer UK (PCUK): Prostate Cancer A Guide for men who have just been diagnosed (2019). Inside this booklet, I record the results known to date specific to the patient, such as Prostate Specific Antigen (PSA) level at time of prostate cancer diagnosis, Gleason grading, number of samples positive on biopsy and staging investigations required. In addition the name of the Consultant Urologist and CNS/Keyworker are recorded along with the CNS contact number. As per MDT outcome, a selection of booklets relevant to the patient's stage of disease are provided. These booklets include Radical Prostatectomy, External Beam Radiotherapy, Brachytherapy, Hormone Therapy and Active Surveillance, all produced by PCUK. These booklets assist the patient in making an informed decision regarding their treatment choice, with the support of the Consultant and CNS. *Please see:*

1. Radical Laparoscopic keyhole Nephrectomy

4.3 **During diagnostic procedures.** Here the CNS has the opportunity to explain procedures, obtain consent, answer questions and provide clarity where necessary on the next steps of the patient journey.

4.4 **Telephone conversations.** When patient initiated, this is most often to seek assistance from their CNS in their role as Keyworker. Examples would include clarification of their treatment choice, discussing results or concerns they may have regarding their condition, or for supportive comfort as they move toward end of life care. When CNS initiated, it is more likely to confirm for example the detail of an urgent appointment.

4.5 **Virtual Clinic.** The concept of a virtual clinics is explained to the patient at the time of a face to face appointment and patient consent is obtained for ongoing review to occur in this manner This form of interaction increased significantly during and post Covid 19. At present, I use virtual clinics (at which the patient does not attend) to communicate blood results and ongoing review plans via a dictated letter to the patient. A copy of the letter which outlines the outcome of the virtual review is forwarded to the General Practitioner (GP), the patient, and uploaded onto the Northern Ireland Electronic Care Record (NIECR). I apply the Guidelines for Nurse Led Assessment and Follow Up of patients with Stable Prostate Cancer, Northern Ireland Cancer Network (NICAN) 2016, attached as evidence. With the engagement/agreement of the SHSCT Consultant Team, I undertake follow up for two groups of patients outlined in the above NICAN document. They include those in the pathways numbered one and two, for Watchful Waiting and Active Surveillance. At any time in their journey, should the patient request or the CNS determine the need for Consultant input the patient is fast-tracked back and offered an urgent Consultant appointment.
Please see:

3. 20160401 question 4 Urology

4.6 While I believe these communication pathways are effective, there is room for improvement in the management of the typing of dictated letters from CNS clinics. From 2013 to 2021, in the absence of administrative support for the CNS team, there was a dependence on the Consultant secretaries to fulfil this role in addition to their own schedule. In 2021, a part-time administrative support appointment was made. This role however is shared across the benign and oncology CNS team. This results in competing demands. For the administrative support, it is time consuming to contact patients, to ensure clinics are fully booked, to liaise with ambulance and interpreting services and to complete typing in a timely manner. In the absence of a secretary assigned to the CNS team there is often a delay of up to eight weeks in typing completion. Additional hours of administrative support or a designated secretary for the CNS team would improve this situation.

4.7 Communication between the CNS and the Consultants within Urology Services also occurs through a variety of means.

4.8 **Face to face** the majority of communication is within the clinical setting on a face to face basis. This provides an opportunity to discuss each patient's encounter and to progress their pathway.

4.9 **Weekly MDT** Attendance at MDT creates an environment for combined discussion with input from all practitioners.

4.10 **Email** this format is used to relay messages for example of the need for an urgent appointment to be accommodated, queries from patients or proposed meetings.

4.11 **Zoom** This format of communication has increased significantly during and post Covid 19 and is used for structured meetings such as the weekly Departmental meeting or the monthly Patient Safety Meeting.

4.12 **Telephone** there has always been an agreed understanding that telephone communication with each Consultant is readily available when there is an urgent need to discuss any concern regarding a patient, for example if a relative phoned to state their father's nephrostomy tube had fallen out. This

would result in the organisation of an urgent outpatient appointment with the Consultant in Thorndale Unit. Whilst accessible at all times, telephone communication would be used to a lesser extent.

4.13 I do believe these pathways are effective. My work focus is primarily Oncology related, and as I am a core member of the MDT and support uro-oncology review clinics in the Thorndale Unit (and more recently) in the Armagh Community Hospital where Consultants undertake outpatient clinics. I would traditionally have had quite a high level of access to the Consultants. Post Covid 19, Consultant activity now stretches over more sites within the Trust and indeed across Trust boundaries therefore reducing face to face access somewhat.

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 I have had a variety of managers both operationally and clinically throughout my career. As previously provided to the USI through the questionnaire, (pages 7-8 in questionnaire), the individuals are listed below:

Post	Manager
D/E Grade Staff Nurse in 2 South Urology (1992-March 2000)	Clinical Manager The late Sr Eileen O'Hagan (RIP) Operational Manager Ms Noleen O'Donnell
G Grade Ward Manager 2 South	Clinical and Operational Manager

Urology (March 2000-July 2005)	Ms Noleen O'Donnell Head of General Surgery, Urology & ENT
Band 7 Urology CNS (July 2005-June 2019) Band 8A Urology CNS (June 2019-present)	Clinical and Operational Manager up to 2009 Ms Noleen O'Donnell (2005-2009) Operational Manager Martina Corrigan (2009-2019) Head of Service Wendy Clayton (2019-present) Interim Head of Service Clinical Manager **Various Lead Nurses**: Dorothy Sharpe Gillian Henry Connie Connolly Linda Hamilton Josie Matthews Sarah Ward Paula McKay

5.2 Throughout my time within the urology service, I have experienced effective working relationships with line managers.

5.3 In Lead Nurses, I have witnessed a variety of approaches in terms of visibility, frequency of meetings/encounters and different forms of communication, such as verbally, via email or through the provision of minutes. I have found all to be approachable and supportive. It should be noted that Lead Nurses may have had little or no experience in Urological nursing. This meant that at the time of appointment of each Lead Nurse, it was necessary that my colleague Jenny McMahon and I took time to explain for example, our role, the nature of

the clinical activity we undertook, the current pressures/issues within the service, the priorities going forward in relation to service development and the educational needs of the team.

5.4 Prior to 2009, my line manager had both clinical and operational responsibility. From 2009 to present, the line manager for operational and clinical activity became separate entities, with formal separation between the Head of Service and the Lead Nurse. I did not consider that this separation of oversight caused any difficulties to my practice or for patient care and risk management. I considered the various skill sets that each individual brought to these encounters to be beneficial and indeed enhanced discussions. All three participants, the Head of Service, Lead Nurse and CNSs would have worked together to address issues of patient care and risk management.

5.5 One of the challenges within this setting was that on occasions, scheduled, planned meetings were cancelled at short notice. Martina Corrigan was the Head of Service (HoS) for four specialties, Urology, Ear Nose and Throat, Ophthalmology and Outpatients. Lead Nurses also had oversight of various areas outside of urology. This presented competing challenges on occasions. A recurring theme for cancellation of meetings were the annual winter bed pressures within the Trust. The input of the HoS and Lead Nurse was required to assist in the management of the staff compliment throughout the Trust. However, in their absence, for whatever reason, there was always accessibility to their colleagues such as another Lead Nurse or HoS for advice/guidance or resolution of any urgent issues, such as the need for sign off on an item of urgent equipment. On other occasions, queries with the HoS or Lead Nurse were resolved through email communication.

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

6.1 I reported any problems fulfilling my role or concerns about patient care and safety directly to my line manager at that specific time. From 2009, when line management functions separated to operational and clinical activity, both

managers would have been informed from this point forward. Where appropriate, such as issues relating to trainee doctors or locum Consultants, in addition to the HoS, problems were reported to the Consultant team. An example would be where a trainee or locum Consultant did not arrive for the clinic. This may have been an error in scheduling such as being booked for an outpatient clinic and a theatre session at the same time.

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 Yes, I have reported problems at various stages throughout my career, the details of which were submitted as part of my questionnaire response, in pages 17-22. I have added additional information to that previously submitted for clarification.

7.2 It is important to note that the problems I reported occurred at a time when there was a regional vacancy scrutiny process in place. I have been advised, by Emma Stinson, Business Support Manager/Document Librarian, that this process in the main covered 2010-2015, a time when many changes and developments were planned within urology services. This scrutiny process meant that any job vacancy had to be presented by the HoS to directorate level and then to the Senior Management Team (SMT) who then either approved or declined the advertisement progressing. Martina Corrigan was able to clarify via a Zoom call on 06/10/2022 that there was difficulty in determining the source of funding, in particular for CNS posts. She also advised that this problem spanned over a number of years.

7.3 The problems reported included:

The need for a Ward Manager:

After my appointment to the Urology CNS role in 2005, the first few years were spent working in collaboration with the Urology Project Group to establish the needs of the service, and with the Estates Department to design

a purposeful unit where urology outpatient activity would take place. This activity was supported through Integrated Clinical Assessment and Treatment (ICATS) monies. Alongside this, I would have assisted with any clinical activity undertaken within the unit. When the modular Thorndale Unit opened in 2007, there was no unit manager to undertake the day-to-day running of the unit or the management of nursing staff within the unit. These roles were shared between my colleague Jenny McMahon and myself. This was discussed verbally with Noleen O'Donnell from 2007 onwards and with Martina Corrigan from 2009 onwards. I am unable to provide any email evidence in relation to these discussions. Martina Corrigan was able to clarify that recruitment was difficult within the inpatient setting at this time and therefore priority sat with that area. Our unit was considered as small with limited staff and was not seen as the most urgent area to have a Band 7 manager appointed.

7.4 The management of the unit required significant time resource attending to the following:

(a) Scheduling resources/staffing and activity for all urology clinics inclusive of the Stone Treatment Clinic

(b) Managing annual leave/sick leave
(c) Appraisals and revalidation
(d) Knowledge and Skills Framework (KSF) performance review
(e) Managing equipment/risk assessment
(f) Facilitating appropriate education and training
(g) Conducting audits
(h) Providing a safe work environment

7.5 I am unaware of any other CNS team within the SHSCT having a managerial role such as this. It may therefore have been unique to the urology service and Jenny McMahon and I in particular. On meeting other Urology CNS's at regional meetings, we understood that none of them had this type of role to undertake. It was evident that this would have an impact on our development and capability to provide the level of independent nurse led activity anticipated

within the urology services plan, as we were included in the staff compliment for all core clinical activity within the unit.

7.6 From 2007 onwards, this problem was recognised as an ongoing issue during meetings with Noleen O'Donnell with a desire to recruit appropriate team members to support our roles. The discussions around a resolution to this issue were recurring and thorough in nature. It was eased somewhat with the temporary upgrade of two Band 5 Staff Nurses to Band 6 Clinical Sisters from January 2014 to December 2016. These temporary positions were replaced by the full-time permanent appointment of two Band 6 Clinical Sisters/Charge Nurse in 2017. The necessity for a Ward Manager was not fully resolved until 2021 when the Outpatient Department Ward Manager acquired managerial responsibility for Thorndale Unit, and the managerial responsibility for Band 3 to Band 7 nursing staff within the unit. I am satisfied that the issue was resolved; however it was a prolonged process.

7.7 **The need for additional Clinical Nurse Specialists:**

The time resource required for undertaking Ward Management roles had a direct impact on the ability to expand nurse led services. On the background of the recommendations of the Review of Urology Services published in 2009, the Trust undertook an implementation plan for what was to be known as Team South. When published in 2010, this plan indicated that two additional Urology CNS's would be advertised by September 2010 with a view to be in post by February 2011. As this did not occur, Jenny McMahon and I raised this issue on an ongoing basis during meetings with both the HoS and Lead Nurses with a desire to recruit additional CNS's.

7.8 We were regularly advised that this issue was being progressed. The lack of appointments to the CNS team created an inability to progress the development of additional nurse-led services such as prostate cancer follow-up. These concerns and associated limitations were known to and recognised by our Consultant colleagues. The discussions around a resolution to this issue were recurring and comprehensive in nature.

7.9 From January 2014 to December 2016 two Band 5 Staff Nurses were temporarily upgraded to Band 6 to assist with the managerial elements within the unit and this eased pressures somewhat.

7.10 There was an intention to appoint two Urology CNS in 2017. On the day of interview however the candidates were informed on presentation for interview that the job title had changed to Clinical Sister/Charge Nurse. Jenny McMahon and I questioned Martina Corrigan as to why this was the case and Martina stated that it was due to some technicality within the advert. This resulted in two appointments to Clinical Sister/Charge Nurse roles. Once again, we looked at potential job plans and service development needs within the unit and discussed these with the HoS and Lead Nurse. By 2019 two Urology CNS's were appointed (one with Oncology focus, one with benign focus) and a further appointment was made in late 2020.

7.11 These appointments allowed the HoS, Lead Nurse and CNS team to establish meaningful job plans that facilitated the establishment of further nurse-led services as are evidenced in detail later in this response.

7.12 The Closure of the Urology Ward in 2009:

I have provided details in relation to my concerns regarding the closure of the Urology Ward in 2009 in my reply to Question 22.

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 When first appointed to the CNS role I had access to a dedicated secretary, which was adequate at that time. However, after her appointment to the position of Consultant secretary to Mr Haynes in 2014, there was no dedicated replacement. This resulted on a dependence on individual Consultant secretaries to complete administrative activities for me, including booking and sending for patients for the Nurse-led Transrectal and later the

Transperineal Prostate Biopsy Clinic, typing of dictated letters from various clinics, and email communication regarding patient queries. It was therefore a disjointed and time-consuming approach to resolve administrative issues. More recently, the secretarial staff have been relocated to a modular build outside of the main hospital building. This removes the opportunity for regular face to face access to discuss or resolve issues, instead requiring this to be resolved via telephone or email.

8.2 Within the last year, an administrative support worker has been appointed to support the entire CNS team and is located within the Thorndale Unit. As this is not a full time appointment, there are competing challenges placed upon this support worker from the CNS team. For me, this member of staff would filter incoming keyworker enquires and would email the queries as appropriate for my attention.

8.3 While this has resulted in an improvement in administrative support to the CNS team, I believe it is inadequate. Despite the daily workload there appears to be no cover during sickness or annual leave episodes, which for me increases interruptions during clinical activity to resolve queries.

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

9.1 At all stages of my career, I have felt supported in my role. I have found nursing, medical and managerial colleagues both approachable and supportive in progressing my professional development. This would have included support to attend study days/courses/conferences and where appropriate this would have included time out from the clinical setting and on occasion financial assistance through educational grants. Medical colleagues readily support direct supervision for areas of advanced practice such as training for undertaking prostate biopsies.

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

10.1 Yes, I do consider that the introduction of nurse led activities has contributed to improved patient care overall. To date patients and their families have provided anecdotal satisfaction to new services. In knowing their CNS, patients have reported increased accessibility for them and their family. This direct access provides additional opportunities for provision of information, education and support on an ongoing basis contributing to improved continuity of care for patients and their family. The benefits of CNSs have been evidenced over the years by various bodies such as Macmillan in their publication, Clinical Nurse Specialists An Evidence Review 2012. *Please see:*

4. clinicalnursespecialistsanevidencereview2012

10.2 I have been or am currently involved in the following nurse led activities:

(a) The introduction of One Stop Clinics to the urology service was enhanced by the CNS ability to perform diagnostic procedures such as Flexible Cystoscopy and Transrectal Prostate Biopsy, releasing the Consultants to see more new patients at the clinic as they did not have to perform the diagnostics. This overall approach accelerated the diagnostic pathway through combining a variety of diagnostics in one appointment and in doing so reduced patient anxiety levels. Patient feedback on one-stop clinics was very positive. This approach to patient care was recognised as good practice when discussed informally at Northern Ireland Cancer Network (NICAN) meetings, during approximately 2015-2017. It resulted in visits from representatives from Urology Clinical and Management Teams for other Trusts, the Health and Social Care Board and Local Commissioning Teams, with a view to determine if this type of clinic could be replicated across Northern Ireland. The establishment of these clinics also directly led to the urology team receiving recognition through the award of Frontline Team of the Year and Overall winner at the Trust Excellence Awards in 2016.

(b) The introduction of firstly a Nurse led Transrectal Prostate Biopsy clinic followed more recently by the introduction of a Transperineal Prostate biopsy service has increased the opportunity for the establishment of a patient/nurse relationship throughout the patient's diagnostic journey. Anecdotal feedback has been positive in that patients have stated that it is satisfying to meet familiar staff during diagnostics and upon receipt of results and during appropriate ongoing follow up. The SHSCT has been the only Trust within the region to provide a nurse-led service prostate biopsy service. At present we are collectively working to resolve the backlog for prostate biopsy (a result of limited access to diagnostics during Covid 19) and our desire is to return to a pre-pandemic position where there was no waiting list for this procedure (except for delays resultant/imposed by other medical issues).

(c) Nurse led virtual clinics for the management of those with stable prostate cancer have resulted in the avoidance of unnecessary trips to the hospital as results are communicated via letter. Patients avail of the contact number within the letter for the clarification of any issues or concerns.

10.3 A holistic approach to care is provided at all nurse led services encompassing the physical, emotional, psychological and social aspects of patient need. Patients are given a direct contact number, with a named practitioner (their Keyworker) whom they can liaise with throughout their diagnostic and treatment journey and where appropriate through protocol led follow up, such as the NICAN guidelines for Nurse Led Prostate Cancer Follow-up (2016). Patients have indicated that the provision of a contact number through the function of Keyworker has reduced their need to make repeated attempts through various resources (e.g. GP, Consultant secretary) to obtain the information/support/direction they require in relation to their urological care. This was of particular importance during Covid 19 when access to services was difficult and levels of anxiety and concern were heightened.

10.4 Responses to patient enquires are prompt and where necessary appropriate signposting or onward referral to other services such as the palliative team are completed. In preparation for surgical procedures, patients are actively encouraged to give up smoking, with referrals to the Smoking Cessation team. Support for pre/post -operative well-being involves referrals to the "The Macmillan Move More Programme" which is an innovative project to help anyone who has been diagnosed with cancer in the local area to get active and remain active. Where appropriate signposting is considered throughout all patient encounters. An example is patients whose illness affects them financially are referred to the Macmillan Benefits Service.

10.5 The most recent introduction of Holistic Needs Assessment (HNA) has enhanced the approach to patient care further by offering an online or face to face appointment when the patient and CNS discuss the patients physical, psychological, spiritual and social needs. The focus is on the patient as a whole, the discussion is led by them and for them, and an action plan is completed to address their top concerns.

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 There has been variation and associated confusion in relation to nursing titles for many years, especially for those undertaking advanced practice. At various conferences, that I have attended both regionally and nationally I have seen the variety of titles listed above used by practitioners who perform

similar roles. In the context of this setting, my understanding is that the titles provided to the USI are variations of the one role. However, I would determine that a Keyworker is part of the Urology CNS role for those engaging in Oncology activity.

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 I use the following electronic systems to communicate with other staff and to fulfil my role:

(a) Patient Administration System – to view patient details/contact numbers/pending appointments, to check on a waiting list for an appointment or procedure and any previous Did Not Attend (DNA) or Cannot Attend (CAN) episodes.

(b) Northern Ireland Electronic Care Record (NIECR) to view patient details/contact numbers/GP details, to view letters from Urological and Oncological interactions with patient/radiological and laboratory results, to request radiological scans, to view current medication list/allergy status, to insert progress notes, to view MDT outcome, to facilitate preparation for pending clinics and to view upcoming MDT lists.

(c) Cancer Patient Pathway System (CAPPS) to upload information on a patient's first encounter with the CNS at the time of receipt of cancer diagnostics.

(d) G2 mobile dictation for the dictation of letters from diagnostic clinics or follow up results.

(e) Microsoft Outlook 2016 for emails regarding appointments, patient queries, admin support, colleague queries, notification of meetings and the sharing of minutes of meetings.

(f) Zoom for participation in meetings including MDT, Departmental and Patient Safety and to undertake online mandatory and role specific training and supervision sessions.

(g) Shared drive to store CNS prostate biopsy spreadsheet, to save minutes of meetings and to view the urology rota.

(h) Sectra ris to view pending radiology appointments.

(i) Health roster/HRPTS/Employee online for personal data and rota.

(j) E-learning – for completion of mandatory training.

(k) Datix system is used to record incident/accidents/near misses.

12.2 At present, the above systems do not have prompts built in to alert me that tasks or follow ups are outstanding. My understanding is that Consultants have alerts built it to advise them of various results that are awaiting sign off. Updates and next steps are communicated through the MDT, departmental meetings, face to face during clinical encounters or via email.

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

13.1 I am not aware of any other methods used to communicate the above roles.

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 would suggest the following:

(a) Improvement in administrative support for CNS team would minimise delays in typing.

(b) An increase in access to prompts to alert nursing staff of outstanding issues would allow results to be actioned promptly.

(c) I am aware of the ongoing work in relation to the potential role out of Encompass which is a Health and Social Care Northern Ireland (HSCNI) wide initiative that will introduce a digital integrated care record to Northern Ireland. This should result in improved access to information to all practitioners and improve efficiency in relation to the speed at which communication between different providers across the region occurs. I also understand that patients may have some limited access to their records allowing them to be more involved in their care planning.

(d) Expansion of the MDT tracking input in the patient pathway to include the monitoring of the outcomes from MDT to determine that for example necessary investigations are requested/completed and onward referrals made to tertiary service providers have been actioned. Availability of the Discharge Awaiting Results Outcome (DARO) system for the CNS team – (currently only available to Consultants). This system has the ability to alert practitioners that results are available for sign off, minimising any unnecessary delays.

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 Staff Performance Reviews are completed on an annual basis with the Lead Nurse. This is not a forum used for discussion of problems or concerns. The focus is on your own achievements throughout the previous year and completion of a professional development plan for the following year. A record of completed mandatory and specialty specific training is agreed in this setting. As indicated previously, the Lead Nurse may have had limited or no experience in urological nursing and therefore other opportunities to share learning were agreed. An example of this approach was in 2007, in agreement with Noleen O'Donnell, Lead Nurse, Jenny McMahon and I established a Urology Peer Learning Group with CNS's from the community continence team to discuss/share learning. These meetings took place in the Medical Education Centre at Craigavon Area Hospital.

15.2 In preparation for staff performance review I would have provided my plans for the following year and the Lead Nurse would have assisted with their facilitation. The effectiveness of such reviews depended on the knowledge and experience of the Lead Nurse. Where the Lead Nurse was familiar with urological nursing, there was full engagement in relation to nursing practice and improving service provision. Where the Lead Nurse was not familiar with urological nursing, in addition to staff performance reviews, I would have used opportunities to discuss nursing practice and ways of improving service provision with other CNS's at regional and national meetings. The Lead Nurse however still played a pivotal role in facilitating expansion of nursing practice and improvements of service provision, in collaboration with the HoS.

15.3 I have provided examples of the plans discussed with the Lead Nurses during staff performance reviews.

15.4:

Lead Nurse	Date	Plans for the following 12months
Paula McKay	25/07/2022	Involvement in the newly established SHSCT CNS forum Achieve sign off for Transperineal prostate biopsy Develop further nurse led services
Sarah Ward	03/04/2019	Progressing CNS job plans with HoS & Lead Nurse Establish nurse led prostate cancer review clinic with colleague Update Job Description

Please see:

5. PDP Paula McKay 2022

6. PDP Sarah Ward 2019

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 I have provided this information previously via my questionnaire (pages 20-21) in relation to raising concerns with amendments for clarity:

16.2 **While working as a Urology CNS in Thorndale Unit (2010)**

During the period May – October 2010, my colleague Jenny McMahon CNS and I became increasingly concerned regarding the physical/mental well-being of [redacted] who worked several clinical sessions per week in [redacted]. Such were our levels of concern we spoke to the following personnel:

(a) Lead Nurse and Head of Service: Noleen O'Donnell and Martina Corrigan (May 2010).
(b) Urology Consultants: Mr O'Brien, Mr Young & Mr Akhtar (May 2010).
(c) Lead Nurses for SEC: Heather Trouton & Caitriona McGoldrick (June 2010).
(d) Lead Nurse for Cancer Services: Alison Porter (October 2010)

16.3 The matter was discussed informally on repeated occasions from May – October 2010, and whilst I/we did not put this in writing formally, a copy of communication in rough format is attached as evidence below which outlines the specifics of our concerns and to whom they were reported. *Please see:*

16.4 I did feel that our level of concern was recognised and acknowledged with assurance from both the HoS and the collective Consultant team that appropriate support for the member of staff concerned would be sought and provided. Whilst I cannot provide evidence, it is my understanding that face-to-face meetings occurred between the member of staff and the consultant team on an ongoing basis and that the matter was discussed within the medical management structure with Mr Eamon Mackle. I believe the staff member left the Trust in [redacted].

16.5 **While working as a Urology CNS in Thorndale Unit (unable to specify date but thought to be during 2012)**:

Around this period of time, the rotational registrar training programme included a trainee call Dr [redacted] [redacted]. Within a short period of time following his arrival, our nursing team in the Thorndale Unit expressed concerns regarding his capability and confidence in relation to performing flexible cystoscopy. As a CNS and co-manager of the unit at the time, I immediately spoke with the Head of Service Martina Corrigan and Mr Michael Young Lead Clinician for Urology. Such was our nursing team's level of concern that I stated that the flexible cystoscopy list planned for that afternoon would not take place unless someone senior would be in the room to supervise Dr [redacted] performance. Mr Young Consultant Urologist attended for the duration of the clinic and deemed Dr [redacted] performance and technique as satisfactory that afternoon.

16.6 At some stage later (date unknown) while I was on holiday in the [redacted], I was contacted via telephone by Staff Nurse Dolores Campbell, to inform me that I had to immediately forward an email of any concerns I had regarding Dr [redacted] to management. Staff Nurse Dolores Campbell may have been directed by someone in the HR department who managed medical staff (I cannot be sure). I asked Staff Nurse Dolores Campbell to inform the

member of staff from the HR department that I expressed my preference to do this on my return to work the following week as I was on leave, needed time to recall events, had no personal computer access and would therefore have to use a computer in the communal area of the hotel. I felt very uncomfortable regarding this. I was further contacted by my colleague a short time later on the same day to state that my response must be provided by 5pm that day. With reluctance and with little preparation, I provided an email as requested. I do not have access to a copy of the content of this email as it was not sent from a personal account. On my return to work, I was requested to attend the management floor of the hospital where I was asked a variety of questions by Mr Robin Brown Consultant Surgeon, regarding our concerns in relation to Dr Personal Information redacted by the USI. Mr Brown, who recorded notes, conducted this meeting. I was not contacted thereafter and I cannot recall receiving any feedback or further contact in relation to the matter. I do not have any knowledge of how much longer this trainee remained in the Trust.

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 relation to the examples provided in answer to question 16, I cannot demonstrate that I was informed of the outcome or any resultant change in practice/procedure.

17.2 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 It is my experience that meetings were held with Martina Corrigan HoS and Lead Nurse however, the frequency of these meetings varied over the years depending on the availability of the HoS/Lead Nurse and the demands within the service. My recollection is that they occurred more likely on a monthly basis. There were periods of time when the HoS was not available due other competing work commitments and I have provided examples of this in reply to question 5 above. During these times, the Lead Nurse would have continued to meet with Jenny Mc Mahon and myself on a more ad hoc basis, though would have provided a visible presence by calling into the unit on a regular basis to discuss any issues.

18.2 Whilst there may not have been a set agenda, topics which were discussed frequently included, staffing, service development, educational needs and equipment requirements. The topics for discussion were suggested by either Martina Corrigan or the CNS team though most topics were recurring in nature given the ongoing development plans within the unit.

18.3 Formal minutes would have been recorded intermittently, though Jenny McMahon or I would often have written notes/bullet points in a meeting book, which was kept in the Thorndale Unit. Nursing staff for whom we had management responsibility for were informed of progress/outcomes through either face to face communication (as team numbers were small), via email or at ward meetings. Progress with educational requirements, service development or equipment needs were shared with Martina Corrigan and the two CNSs on each occasion we met.

18.4 In parallel, weekly sisters/ward managers meetings took place which the Lead Nurse generally chaired. Here information such as important circulars, current issues and challenges within the Trust were discussed/disseminated. As either Jenny McMahon or I attended these meetings, this was a regular opportunity to speak with the Lead Nurse.

18.5 I have indicated earlier that throughout my time as a CNS the various Lead Nurses applied differing management approaches. For example, when Sarah Ward became Lead Nurse, the weekly meeting became structured with a set time and an agenda. Minutes were recorded and shared.

18.6 More recently, under the guidance of Wendy Clayton as HoS, a Weekly Departmental Meeting has replaced HoS/Lead Nurse/CNS meetings. The entire Urology team is involved including Consultants, medical trainees, Lead Nurse, CNS team, Outpatient Manager, and administrative support to record minutes. The meeting occurs every Thursday from 12:45 to 13:30. There is an agenda circulated in advance and minutes are saved in a shared drive. There is allocated time within job plans to facilitate attendance at this meeting. This has resulted in a much more structured approach with improved attendance. This meeting allows operational issues to be discussed in the presence of medical and nursing staff.

18.7 As indicated above the format of the agenda improved dependent upon the HoS/Lead Nurse. In my early years as a CNS, there was less formality while in recent times the agenda is more structured. Examples of agenda from various years have been provided previously as attachments to the questionnaire (in relation to formal or informal meetings pages 9-12). *Please see:*

8. Thorndale department meeting question

9. Minutes of meetings with HoS MC, Kate and Jenny Thorndale 03 04 2015

18.8 There were set topics for discussion for example Covid update, actions from previous meeting, staffing, elective/outpatient update, CNS update and any other business. Additional topics for discussion were suggested via email from any of the participants.

18.9 The Departmental meeting has administrative support to record minutes, which are now stored in a shared drive. During the period of time while the CNS also performed the role of Ward Manager relevant staff within our team were informed of outcomes through ward meetings, face to face or by email communication.

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 Yes, as an Oncology CNS I did and continue to meet regularly with clinicians to discuss patient care. The majority of discussion regarding patient care takes place on a weekly basis, within the setting of the MDT, and on a monthly basis within the setting of the Patient Safety Meeting (PSM). Outside of these settings, individual cases would be discussed on a daily basis during clinical encounters. All Consultants are accessible/contactable via telephone regarding any urgent issues the CNS may encounter.

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 Copied in part from previous questionnaire section on meetings at which issues relating to governance were discussed (pages 10-12). I have made some adjustments for clarity.

20.2:

Post	**Name/Title of Meetings/ Frequency**	**Attended by**	**Minutes**	**How outcomes would be implemented and monitored**
D/E Grade S/N in 2	Approx. quarterly ward	All grades of day/night	Recorded in a book and	Implemented and monitored by Ward

South Urology	meetings usually held in the evenings	nursing staff and Consultants on occasions	shared with staff. All staff had access to this book to view updates	Manager where possible
G Grade Ward Manager 2 South Urology	Approx. quarterly ward meetings usually held in the evenings	All grades of day/night nursing staff and Consultants on occasions	Recorded in a book and shared with staff All staff had access to this book to view updates	Implemented and monitored by Ward Manager where possible
	Sisters meeting every 1-2 weeks	Ward managers from all surgical wards	Minutes circulated via email	Implemented and monitored by Ward Manager/Lead Nurse

Band 7/8A Urology Nurse Specialist	Sisters meetings every 1-2 weeks	Ward managers from all surgical wards	Minutes circulated via email	Implemented and monitored by Ward Manager/Lead Nurse/HoS
	Thorndale Ward Meetings (1-3 times annually pre-covid)	Nursing and admin Staff from the unit	Minutes recorded and shared with unit staff via email	Implemented and monitored by CNS(in absence of Ward Manager)/Lead Nurse
	Head of Service/Lead Nurse meeting (Regular & Ad hoc basis)	HoS, Lead Nurse & CNS team	Formal minutes were recorded intermittently though the	Implemented and monitored by HoS/Lead Nurse/CNS

			CNS would have kept brief notes in a meeting book which was kept within Thorndale Unit. Progress was shared verbally on an ongoing basis.	
	Departmental meetings (weekly)	HoS, Medical staff (all levels) and CNS team	Minutes stored in a shared drive with access to all the urology team.	Implemented and monitored by HoS
	Urology Multidisciplinary	All core members of MDT, support	Minutes circulated via email.	Implemented and monitored by Chair of MDT

	Meeting (weekly)	staff and trainees. (Also linked into regional meeting)		
	Patient Safety Meeting (approx. 7-8 per year) The other months are specialty specific and regional (CNS does not attend)	HoS, Medical staff (all levels) and CNS team	Minutes circulated via email	Implemented and monitored by Chair of PSM

20.3 In the company of Jenny McMahon CNS, I met with Dawn Connolly, Patient Safety Governance Lead for Acute Services on 29/06/2010. This was to complete a Nursing Governance Baseline to ensure that all registered nurses within Thorndale Unit had up to date registration, alongside regular supervision and appraisal sessions. I have attached evidence relating to this meeting. My recollection is that this was a one off meeting. *Please see:*

10. Dawn Connolly Governance meeting

11. Dawn Connolly Governance meeting 2

20.4 As a team of CNSs we met with Lisa Houlihan, Head of Nursing Patient Safety and Governance in May 2021. (I cannot locate minutes for this meeting). At this meeting we discussed the need for completion of policies for each of the nurse-led services and for the identification of a study supervisor (a Consultant Urologist) for each CNS. Brian McGuire from the governance team was identified as a link to assist/guide us with these policies. We met with Brian via Zoom and in person on occasions over the summer of 2021. Policies for each nurse led clinic (occurring at that time) were completed during Autumn 2021 and were agreed for implementation by the Consultant team and HoS. They currently sit with senior management for official sign off. As each new service develops, further policies will be produced. All policies require updating on a regular basis and therefore this will remain a work in progress.

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 The Urology specialty sits within the Surgery and Elective Care division under the Acute Services Directorate.

21.2 In relation to my day to day practice, the Trust recommends referral to the Royal Marsden Manual of Clinical Nursing Procedures for standard nursing procedures. The Royal Marsden Manual is accessible on Sharepoint via the Trust Intranet. I consider the access to the Royal Marsden as efficient and effective in relation to standard procedures.

21.3 Sharepoint provides a variety of functions. It stores policies and procedures such as the Whistleblowing Policy and Your Right to Raise a Concern. In addition, Sharepoint lists mandatory e-learning which requires completion, some annually, others every two or three years. This e-learning is checked for adherence with the Lead Nurse on an annual basis.

21.4 Recent initiatives within the Trust include the launch of the Nursing and Midwifery Accountability and Assurance Framework (Feb 2022) and the provision of Supporting Nurses in Difficulty Clinics (April 2022). These clinics are designed to support nurses experiencing issues within the workplace for whatever reason and streamlining the process to assist managers in dealing with fitness to practice issues. It is my view that these initiatives will provide more robust structures to support nurses and managers in relation to governance issues. *Please see:*

12. Supporting Nurses in Difficulty

13. Nursing and Midwifery Accountability and Assurance Framework

21.5 In relation to nurse led services, prior to the establishment of a service it is necessary to first demonstrate the necessary specific knowledge around the service and the competencies to perform the procedure. For example, prior to undertaking nurse led prostate biopsy I undertook a period of training under the direct supervision of Mr Glackin and Mr Haynes Consultant Urologists to demonstrate both my technical capability for performing the procedure and the necessary knowledge related to the procedure. When competencies were achieved, sign off was completed by the Consultants, and the HoS provided written documentation for me to undertake this extended practice. As policies for specific specialties are not readily available, the CNS team in consultation with and the agreement of the Consultants and HoS have written policies specific to a variety of urology nurse-led services. These policies reflect the guidance of various sources such as NICAN, National Institution of Clinical Excellence (NICE), British Association of Urological Surgeons (BAUS), British Association of Urological Nurses (BAUN), and the European Association of Urologists (EAU). The above organisations and publications are excellent resources which promote and guide uniformity in practice in relation to establishing new services, steering protocol guided care, promoting the value of audit, benchmarking and evidence informed practice. It is my view that governance processes in relation to nurse led services are efficient and effective.

21.6 Within Thorndale Unit, there have been minimal accidents, incidents, near misses and complaints. Where these occur, the Datix system is used for recording and the governance team are contactable and supportive with guidance where needed to complete a Datix. Any incident within the unit is shared with staff and used as an opportunity to learn.

21.7 For professional governance I apply the standards set out by The Nursing and Midwifery Council (NMC). This is an independent professional regulator for nurses and midwives in the UK. They exist to protect the public and maintain the register of qualified nurses and midwives and set the standards of education, training, conduct and performance to which as a practitioner I must adhere. The NMC produce and update a variety of publications on a regular basis. These include for example:

(a) The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates (March 2015)

(b) Future Nurse: Standards of proficiency for registered nurses (May 2018)

21.8 Revalidation is the process that all nurses and midwives in the UK need to follow to maintain their registration with the NMC. In order to demonstrate that I have kept my skills and knowledge up to date, and in order to remain on the NMC register, I am duty bound to fulfil a regular revalidation process every three years. My last revalidation discussion was with my current Lead Nurse Paula McKay in July 2022, in preparation for revalidation in October 2022.

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 Yes, I was involved at a Trust level with Martina Corrigan alongside my colleague Jenny McMahon. We met on a regular basis engaging with Martina Corrigan to progress the recommendations of the Regional Review in relation to Team South and in particular in relation to the outpatient setting where nursing input was central. This work was undertaken with the engagement of the Consultant team and included the following:

(a) Single visit clinics: The establishment of single visit clinics meant that the patient had as many investigations performed in the one visit. This included prostate and haematuria assessment clinics. We assisted with the design of leaflets for both these clinics advising the patient how to prepare for the clinic attendance and what to expect on the day. We also negotiated the nursing staff compliment required to facilitate the clinic safely, inclusive of discussion on training requirements.

(b) Clinic templates: We considered the number of patients that would attend each clinic based upon the number of referral letters into the service and concluded that prostate and haematuria referrals had the highest priority, followed by general Red Flag referrals and then review slots. The clinic template was amended and adapted several times in those early months of their implementation as we fine-tuned the functioning of the clinic.

(c) Design of Pathways: We designed pathways into the service based on NICAN referral pathways. In addition to engagement with Consultants I believe GP representatives were involved in this process. As the prostate diagnostic process is lengthy, we established what was then termed Day 1

that involved clinical examination and ultrasound scanning, Day 2 prostate biopsy, Day 3 histology results

(d) Appointment of CNSs: The regional review identified the need for an additional two CNS. We engaged with Martina Corrigan to determine proposed further development of nurse led services and clarification of job descriptions. It was anticipated that these advertisements would be released quickly with a view to appointments occurring by early 2011.

22.2 In relation to my involvement, it is my view that my views were taken on board at all times. I felt that the CNS team were integral in the design and success of the clinics established at that time.

22.3 In relation to what if anything could have been done differently at that time which may have limited the extent of the problems later experienced, I believe the delay in the proposed appointment of two additional CNSs had a direct impact on the limited availability to provide support to the patient during their cancer journey and in particular in relation to the keyworker role.

22.4 It is important to note that prior to Martina Corrigan's appointment to the SHSCT in 2009 there was a Surgical Reconfiguration Group established that year with the view to closing surgical beds on the Craigavon site. It is my view that the plans of the above group and the recommendations from the Regional Review of Adult Urology Services were different or competing.

22.5 The Regional Review of Adult Urology Services in NI took place with the findings published in 2009. Two of the many recommendations were:

(a) To ensure high quality nursing services and effective and efficient use of highly specialised equipment and instruments it is essential that nurses working in Urology wards, theatres and other departments are fully trained and competent in the field of Urology.

(b) In relation to Arrangements for Elective and Non Elective Services there was to be a main acute elective and non-elective inpatient unit in Craigavon.

22.6 Despite the above recommendations, a decision was made by the Surgical Reconfiguration Group on behalf of and in consultation with Senior Management Team to close the 19 bedded Urology Ward and disseminate the urology inpatients throughout the general surgical wards. All nursing staff (from within the urology ward who were at various stages of newly qualified, undergoing additional training and highly skilled staff) were to be redeployed throughout these wards.

22.7 This decision resulted in a very unsettling time for staff who had invested effort in developing their urological competencies. It contributed to poor staff morale, resulted in some staff deciding to leave their posts and presented issues with recruitment and retention of a highly skilled team.

22.8 I voiced my concern regarding the potential effect this plan may have on the safe delivery of patient care (particularly in the early stages of this process) and the impact this may have on the long term plans to future-proof the skilled nursing team. This concern was stated at both the weekly sisters meetings and at any ad hoc meetings planned around this decision. Noleen O'Donnell and Simon Gibson Assistant Director of Acute Services attended these ad hoc meetings at that time. I cannot determine if minutes were recorded and I felt that my concerns were not acknowledged. It appeared to me that the decision had been made in advance, and nothing I had to say would have influenced any change to the proposal to close the urology unit based within 2 South. I recall expressing my disappointment in relation to this matter to Simon Gibson at the last meeting. I included information relating to the ward closure in the questionnaire under Management and Governance (pages 33-34):

22.9 A meeting also took place in the Thorndale Unit where the Consultant team, CNS team and Mr Jerome Marley were present. A letter was composed to outline our concerns in relation to, among other issues, the proposed closure of the urology ward. This letter was forwarded to management, and I have attached a copy as evidence. I cannot recall any feedback in relation to this letter and the Ward Reconfiguration proceeded. *Please see*

14. Response to Trust's proposals for Ward Reconfiguration

22.10 I am unsure if anything could have been done differently. It is necessary to recall the challenges in those years. The vacancy scrutiny in place from 2010 to 2015 and the turnover of Consultants were likely to have impacted upon the ability to progress development at the expected pace. Likewise, the delay of appointments in CNSs as proposed created significant gaps in service provision. Displacement of highly skilled urological nursing staff resulted in ongoing challenges to promote post-graduate urological education from that time forward. This occurred despite Jenny McMahon and I organising educational sessions in the Medical Education Centre, creating opportunities for ward based staff to spend time in the Thorndale Unit setting and promoting additional third level education.

22.11 When Martina Corrigan was appointed, these concerns were discussed with the Consultant and CNS team. At some later stage (possibly in 2010), urology beds were relocated to a 19 bedded area within 3 South, however the specialty had incurred a loss of highly skilled nursing staff during this period.

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 do not consider that the role and functions of the CNS were resourced properly from the outset. The absence of a unit manager, lack of dedicated clerical support and being counted within core nursing staff for all clinical activity severely restricted my ability to progress, advance and develop my role in providing independent nurse led services and to provide adequate keyworker input. The prolonged process to appoint additional CNS members contributed further to delays in service development.

23.2 As service development progress was delayed, the impact upon patient care would have been most evident in the inability to provide keyworker input for every patient with a cancer diagnosis.

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 Yes, I did have knowledge of the above. In relation to:

*(a)*The absence or inadequate CNS provision. At the time of this review in 2015, I remained the only CNS with an oncology focus. This issue was repeatedly brought to the attention of the HoS and Lead Nurse by my colleague Jenny McMahon and I. Our concerns were acknowledged and we were assured that

the recruitment process was being addressed. One-stop clinics occurred during Monday – Thursday within the timetable. As I was counted in the core nursing team and also as I was now performing prostate biopsies, I would have worked these days and only occasionally on a Friday. These competing demands therefore limited Keyworker access at times. In preparation for the visit from the Peer Review Team in 2015, on the 15th May, I emailed the Consultant team (six at that time), Martina Corrigan and Jenny McMahon to clarify the proposed information to be provided by the nursing team at the point of diagnosis. *Please see:*

15. Email involvement pathway recording form

16. Email involvement

(b) Delays in seeing routine referrals: The regional review of urology services identified this as an issue in 2009. As part of the Team South implementation plan my colleague Jenny McMahon and I were asked by the HoS to assist with this issue, the details of which are contained in Appendix 2 of Team South plan. I can recall engagement with the Referral and Booking Centre. I collected one file containing routine referrals at a time and worked my way through them, dividing them into the four categories suggested. Category 1 – urgent appointment required (automatically arrange an urgent review appointment), Category 2 – Decision required on review management (engage with Consultant to determine a plan), Category 3 – Query discharge based on clinical results available (clarify discharge plan with Consultant) and Category 4 – Patient Administration System error or duplication (clarify with Consultant to discharge from PAS). I cannot recall how long I was involved in this process or how many files there were. I do not have records to evidence this work. During this period of time I would have spoken with Martina Corrigan in relation to the progress I had made, and to the Consultant team on occasions for advice/guidance in relation to providing clarity where I had any doubt as to whether a routine referral should be upgraded to urgent or red flag.

(c) Shortage of consultants in the specialty, or an over reliance on locum consultants: I was aware of this ongoing manpower shortage. While not directly involved in the management of this issue it did have an impact on my role. The recurring appointment of locum staff required time to introduce new staff to the unit, explain the processes in place and discuss any day-to-day issues. As this issue was known to the HoS and the Senior Management Team, I did not feel there was a necessity for me to speak to anyone regarding this problem.

(d) Absence of core membership of, or lack of attendance at MDT leading to a significantly low percentage of MDT meetings being quorate: I would have known about these issues as I was a core member of MDT. These issues were discussed with regularity at MDT. Attendance was recorded in the minutes and it is my understanding that the issue was raised through the MDT Chair to the HoS and Senior Management Team. I would not have been directly involved in the management of this issue, nor can I provide any record to demonstrate these discussions took place.

(e) Lack of specialist radiologist or histopathologist input to the service or MDT: Again, I would have known about these issues as I was a core member of MDT. These issues were discussed with regularity at MDT. Attendance was recorded in the minutes and it is my understanding that the issue was raised through the MDT Chair to the HoS and Senior Management Team. I would not have been directly involved in the management of this issue, nor can I provide any record to demonstrate these discussions took place.

24.2 At that time, CNS's did not attend meetings where management and medical colleagues discussed operational issues. Since Wendy Clayton as interim HoS established Departmental Meetings (from 2019 to present) the entire urology team would be present when operational issues are discussed. Outside of the

MDT meeting, I have no insight as to how these issues were addressed within the management structure.

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 The ongoing recruitment issues for medical and nursing practitioners within the Trust contributed to the risks and serious concerns listed. Some issues may have been outside the remit of the Trust, such as Oncology input at MDT as my understanding is that this service was managed regionally.

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 Given there was only one CNS with an Oncology focus, and the fact that this CNS still had managerial responsibility for the unit, it limited the ability to provide a CNS for each patient with a cancer diagnosis. While there were fluctuations as to how many Consultants were in place, during 2015 there were six, all holding one results clinic per week. At all times, Macmillan packs and information booklets containing contact cards were available within each consultation room. Where a CNS was not available this information could be provided by the Consultant. A focus to appoint additional CNSs at an earlier stage would have contributed to additional CNS input. This issue limited accessibility for patient access to a CNS for ongoing support throughout their cancer journey.

26.2 Demand and capacity issues would have had a direct impact on seeing routine referrals. This resulted in patients waiting many years to be assessed for conditions, that while considered routine, may have had a significant impact on their quality of life on a daily basis. Delays also resulted in ongoing anxiety for the patient while awaiting appointment. This meant that patient

may have requested repeated interaction with primary care services such as the Continence Team, GP or potentially attendance to the Emergency Department. Priority was given to Red Flag and urgent referrals. Addressing recruitment and retention would have assisted with this issue.

26.3 A shortage of Consultants and an over reliance on locum Consultants may have contributed to a prolonged diagnostic pathway. Having a Consultant appointment can often result in discharge from services with reassurance following assessment, or discharge to primary care with advice for ongoing care. This relieves anxiety for the patient. This deficit in Consultants meant that even when assessed and added to an inpatient waiting list, patients experienced waiting times in terms of years for what would be considered as routine surgery in urology such as Transurethral Resection of Prostate (TURP) for urinary symptoms.

26.4 Absence of core members/ specialist radiologist or a histopathologist created a delay in patient discussion at MDT. On occasions, this would have occurred repeatedly over a period of consecutive weeks (especially over holiday periods). This resulted in a delay in the completion of patient discussions which may have caused delay in onward referral to tertiary service providers, or a delay in adding to the inpatient waiting list for surgery.

26.5 Where discussion had concluded and results were available to the Consultant Urologist, during holiday periods there was an agreement in place that Consultants would provide opportunities to review colleagues' patients in an attempt to avoid unnecessary delays especially for the most complex/urgent cases. In is my understanding that this agreement was later formalised within the Operational Policy for the Urology MDT around 2015/2016. Quoracy was an issue that was discussed at MDT. Attendance was recorded in minutes and absences brought to the attention of senior management periodically by the MDT Chair, and through the AGM.

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

27.1(i) Two more CNS's with Oncology focus have now been appointed improving CNS provision within clinics but my understanding is that there is a regional recognition that SHSCT requires one further CNS for Oncology

27.2(ii) I am not in a position to comment on the current delays in relation to routine referrals but am aware of involvement of the Independent Sector to assist with capacity issues.

27.3(iii)Despite exhaustive attempts recruitment to consultant vacancies remain an issue.

27.4 (i)-(v) At the latest AGM for the MDT held on 22nd September 2022 significant improvements in support from both Oncology and Radiology in particular were discussed and noted. Backfill for the Histopathologist is under negotiation.

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 Covid 19 presented many challenges to the safe provision of health care. These included:

(a) Suspension of outpatient and day procedure unit diagnostics such as prostate biopsy and flexible cystoscopy.
(b) Extreme limitations/challenges associated with appointing the most urgent of Red Flag referrals (safe space for consultations were at a premium).
(c) Access to theatre sessions (staff redeployment to assist in ICU).
(d) Waiting times for surgery worsened.

28.2 Collectively as a CNS team we discussed these concerns with the HoS and Consultants at the Departmental Meeting (unsure of the date) during 2020/2021. Agreement was reached with the Independent and Private Sectors to assist in diagnostics and surgical procedures. While services have

resumed within the Outpatient and Day Procedure settings, external resources continue to be utilised to ease pressures.

28.3 Another concerning factor arose, when in January 2021, the entire Urology CNS team was informed by Sarah Ward Lead Nurse, that they would be redeployed to assist with providing nursing care for inpatients throughout the Trust. Collectively we expressed our concern to Wendy Clayton HoS and Consultant colleagues at a Departmental meeting on 14/01/2021 regarding the impact this would have in relation to for example:

(a) No provision of a CNS to any patient with a new urological diagnosis.
(b) The risk of a lack of provision of site specific information or contact number for support.
(c) No provision of a prompt telephone response to patient queries when they contacted the unit.

28.4 Despite the concerns raised, we were advised by the Lead Nurse and HoS that the redeployment would proceed with no scaled down CNS support in place. I am unsure if this approach was applied across all CNS teams and specialties within the Trust.

28.5 The recurring appointment of Locum Consultants also places demands/pressures upon the CNS. Discussions with the HoS and Consultant colleagues were regular and informal in relation to feedback and the resolution of any issues. Examples of issues discussed were time keeping, efficiency within the clinic setting in terms of the number of diagnostics undertaken or communication/language difficulties. These issues were acknowledged by Martina Corrigan and the Consultant Team and local resolution was sought. More recently, under Wendy Clayton's management I have noticed an improved Induction Programme for Locum Consultants. It would appear that more preparation is in place for new appointees with improved access to electronic systems and explanation of roles and responsibilities of those within the urology team.

28.6 Within my answer to question 22, I have provided a synopsis of my concerns regarding the impact of the closure of the Urology in-patient unit and the resulting immediate and future impact this would have on staff.

28.7 The modular build of Thorndale Unit which opened in 2007 was allocated for temporary use by the Urology team until such times as appropriate space became available within the main hospital footprint. Over time, issues became apparent which indicated that the location of the unit was quite isolated at the rear of the hospital. These issues were raised with the HoS and Lead Nurses. Patients and relatives reported that access was difficult, particularly for our elderly population, those using public transport and those requiring disability access. I recall completing an IR1 (used prior to Datix) in relation to a patient falling while making his way to the unit. For staff a major concern was no direct access to the hospital in cases of emergency. It is important to note that Thorndale Unit is not a traditional Outpatient setting, invasive procedures are performed with associated risk. This resulted on occasions in the need for a 999 call to transfer patients who became unwell to the Emergency Department. Over the next few years, through negotiation with Martina Corrigan, Simon Gibson, the Estates Department and the Patient Support Team, firstly a link corridor was built in late 2009 to connect the unit to the hospital. This did not provide a solution however as it's use was complicated by having to move through a waiting area, which at times was occupied by children. Space was then located with the Outpatient setting and the planning began again to design a purposeful unit for Urological diagnostics. This unit was opened in 2013 and remains in use at present.

28.8 In my capacity as Ward Manager in Thorndale Unit, it was important to maintain efficiency during clinic sessions. Recurring themes included the over running of clinics. This resulted in staff not able to have their breaks at the allocated time or having to remain in the unit after their shift had ended. While this was not specific to Mr O'Brien, it would occur with frequency at his clinics. The overruns were most apparent during one-stop clinics and Oncology review clinics. I did discuss this recurring theme with Mr O'Brien and Martina

Corrigan individually as early as 2010 in order to seek a resolution. Clinic templates were adjusted on several occasions over the next five years to reduce numbers in attendance firstly down from 12 to 10 and then to 8 patients. Staff lunch breaks were staggered with some affect. However, persistent late evening finishes required one member of staff to remain in the unit on a rotational basis, with the time owing returned later.

28.9 Another part of the role as Ward Manager was equipment management. This was time-consuming at times. An equipment register required maintaining, asset numbers assigned to all equipment and maintenance records kept. The two CNSs would raise equipment issues with Martina Corrigan as equipment neared its end of capacity in relation to safe use. I would have used this approach to negotiate equipment for new services, such as most recently new Ultrasound equipment for the performance of Transperineal prostate biopsy.

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 I do not have direct access to Trust governance documents. I sought some clarification regarding Trust governance documents, in relation to this question from Wendy Clayton HoS. Nursing concerns regarding patient care and safety are recorded on a divisional risk register (which includes all of surgery and elective care). The HoS adds any urology risks onto this register. There is also an Acute Directorate risk register that sits with the Director and Assistant Directors (AD's). All performance issues which include urology are included. The HoS meets with the AD and other Heads of service to update quarterly.

29.2 I have provided detail in my answer to question 20 of governance meetings with Dawn Connolly in relation to a governance baseline for the Thorndale Unit and with Lisa Houlihan in relation to policies for nurse-led services and the need for a study supervisor.

29.3 In relation to day-to-day activity, I would have used various systems such as Datix for reporting accidents/incidents and the IT Portal for issues with connection to various electronic platforms.

29.4 I would record and report concerns regarding patient care and safety in a variety of ways. To demonstrate this I will apply an example where a gentleman attended with a view to having prostate biopsy performed. While admitting the gentleman it was noted that while the patient felt well, his pulse level was very low i.e. <40. I indicated to the Radiologist who was performing biopsies that day that I felt his procedure should not take place. This was recorded in the nursing admission documentation, and the patient's Consultant was informed. The patient was accompanied by a member of nursing staff to the Emergency Department for assessment. He was admitted as an inpatient, later transferred to the Royal Victoria Hospital and had a Pacemaker inserted that evening. Following a period of recuperation, he returned to the Thorndale Unit to undergo his biopsy and expressed his gratitude to all the staff involved. Another example would be when a patient arrives for prostate biopsy as requested by the Consultant, but on arrival is unsure as to whether he wishes to proceed or not. I would take time to discuss the risk/benefit of proceeding or not. When an agreement is reached, I would communicate this information to the Consultant and dictate a letter to the GP outlining the decisions on the day. Where necessary, this patient would be discussed at MDT.

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 Throughout my career I have applied a proactive approach in dealing with any concerns patients may raise with a view to resolving them at the time. All levels of staff engage with the CNS to seek resolution to issues. Likewise, the CNS team would raise issues that required assistance to resolve with the management structure through the HoS or Lead Nurse. Complaints within Thorndale Unit have never been an issue.

30.2 I believe that a prompt/honest response to patient queries/concerns/complaints is invaluable. Engagement with the patient and relative provides clarity in relation to what is achievable within the service, and often avoids formal complaints. It is important to be clear with patients regarding how long they should expect to wait for results. For example for TP biopsy, I inform the patient of the necessity for histopathology reports and MDT discussion to take place before a plan of care can be offered/discussed. The patient is informed this process may take several weeks.

30.3 For patients with stable prostate cancer, the offer of virtual clinics has been beneficial for patients who expressed concern regarding the distance they had to travel for consultation or discussion of results. I believe this service could be extended further in the future.

30.4 For staff and service users feedback from management in relation to any concerns raised is beneficial as a means to improve the service in the future.

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 Yes, a copy of the pre-published report of the above survey was emailed to be by Fiona Reddick, (Head of Cancer Services) on 24th July 2015. I forwarded this email to the staff within Thorndale Unit on 27/07/2015 advising them to read the items relevant to the Trust. Fiona Reddick then emailed the published survey on 12/10/2015.

31.2 In this email we were advised of the appointment of Mary Haughey, Macmillan Cancer Service Improvement Lead for the Trust, who would lead on processing the recommendations. I met with Mary Haughey in late 2015 and beyond to develop an action plan to address the concerns identified in relation to CNS access, allocation of a keyworker, holistic needs assessment and a permanent record of management. This action plan is provided in my answer to question 33. The concerns raised within the survey were discussed on an ongoing basis over several years with Mary Haughey, the HoS and Lead Nurse. They had been a common feature for some time and again I was reassured by the HoS that the recruitment of further CNS members was progressing.

31.3 In relation to CNSs two additional staff were appointed in January 2017, however as stated earlier they were appointed as Clinical Sister and Charge Nurse not CNSs therefore the resource issue continued.

31.4 An attempt was made to allocate all patients with a keyworker but the CNS resource issue meant that a solution was challenging and remained so. While consideration was given to plan for Holistic Needs Assessment the staffing deficit meant that this was not resolved until more recently. A pilot was completed over a three month period in relation to the completion of a Permanent Record of Management. With staff challenges, while this initiative was accepted as necessary it has only truly been completed over the last few years.

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 Yes, the survey was brought to my attention through an email from Fiona Reddick on 06/10/2015. The concerns raised within the survey were similar to those discussed in question 31 including access to the CNS and the provision of

contact details. They were discussed on an ongoing basis during 2015/2016 with Mary Haughey, the HoS and Lead Nurse. I met with Mary Haughey periodically to address and seek solutions to the concerns identified. An action plan is attached in my answer to question 33. The issues had been a common feature for some time and again I was reassured by the HoS that the recruitment of further CNS members was progressing.

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

33.1 There are various methods applied to inform practice relayed to the CNS.

33.2 In the past, and now collectively as an Oncology CNS team, information relating to surveys would be emailed to me by Mary Haughey and a meeting organised to discuss feedback with a view to organising service improvements. This information would be shared with the HoS and Lead Nurse, with a view to determining means to improve service provision.

33.3 I have enclosed a service improvement action plan shared with me by Mary Haughey based on patient feedback from external and internal patient satisfaction surveys undertaken during 2015/2016. This action plan was included in the Urology MDT Annual Report in 2017. *Please see:*

17. Action Plan form

33.4 The Departmental meeting and Patient Safety Meeting are used as avenues to share best practice, circulars, proposals for changes in practice for example those resulting from audit presentations.

33.5 The Lead Nurse would bring to the attention of the CNS issues relevant to practice, this could be communicated verbally or via email. The CNS would in turn cascade this information to nursing staff within the team via email or at ward meetings.

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 It would be my view that there is a potential for breakdown in communication for patients regarding their care if the CNS is not part of their care team. “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 HSJ Workforce. Time For some Advanced Thinking? The Benefits of Specialist Nurses. An HSJ Supplement. 2015. (accessed October 2022).

34.2 In my view, the involvement of the CNS enhances the patient experience through the face to face introduction/meeting, the provision of appropriate supportive documentation related to their condition, alongside the explanation of the Keyworker role and the provision of a contact number. The CNS can act as a conduit into the service at a time of worry, concern or distress therefore providing a holistic approach to patient care.

34.3 The MDT Operational Policy (2022) outlines the CNS responsibilities as:

(a) Contributing to the multidisciplinary discussion and patient assessment/care planning decision of the team at their regular meetings.

(b) Providing advice, support and symptom control to patients throughout their cancer journey.

(c) Providing expert nursing advice and support to other health professionals in the nurse’s specialist area of practice.

(d) Involvement in clinical audit.

(e) Leading on patient communication issues and co-ordination of the patient pathway for patients referred to the team – acting as the keyworker or responsible for nominating the key worker for the patient’s dealings with the team.

(f) Leading on the patient and user involvement in the service

(g) Leading on the management of patients suitable for self-directed aftercare (SDA).

(h) Contributing to the management of the service.

(i) Utilising research in the nurse's specialist area of practice.

(j) Holding the relevant qualifications and undertaking additional training as required to provide expert advice and support.

34.4 The absence of the CNS from the patient's care pathway removes opportunities for the CNS to execute the responsibilities outlined above. During the last year a CNS Proforma (attached as evidence) has been implemented for completion by the CNS when they first meet a patient with a new diagnosis of cancer. This proforma will provide useful information for audit in the future. The detail contained with the proforma are explained in my reply to Question 38. *Please see:*

18. CNS proforma

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 My view is that patient satisfaction surveys provide the patient with an opportunity to record their personal experience with a view to guiding/improving services in the future for those with similar conditions. It is important to recognise that the Urological population includes a significant cohort of the elderly population. While not relevant to all, issues such as cognitive ability to complete questionnaires could present significant challenges for some. Questionnaires by their nature can be lengthy and cumbersome to complete. Survey outcomes are shared with staff in a variety of ways, for example discussed at ward meetings and via email as demonstrated in my answer to question 31. Suggestions from surveys are discussed with management as a means to structure progress on challenges/deficits within the service. Examples of how management acted upon suggestions has been provided previously in answer to questions 31 and 32 through my engagement with Mary Haughey.

35.2 Secured slots for patient discussions following MDT meetings

36. The 2015 *National Peer Review Report: Northern Ireland 2015* also lidentified 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 Following MDT, the MDT co-ordinator for the day records the outcomes for each patient discussed. At the earliest opportunity, the Chair of MDT for the day checks the outcomes for accuracy. The outcomes are signed by the Chair of MDT as accurate. The MDT co-ordinator then emails the core members of MDT and the Consultant secretaries the outcomes. The Consultant secretary is responsible for appointing patients following their discussion at MDT to a review clinic within a protected slot.

36.2 At that time (2015) the clinic would have been attended by the Consultant, patient +/- family member, occasionally a medical trainee and when available the CNS.

36.3 These protected slots were effective in offering the patient a timely follow-up following MDT discussion. The protected slots were a regular post MDT feature then, and remain so. In more recent times following the recruitment of two further CNSs with an Oncology focus, every effort is made within the schedule to facilitate a CNS presence at each results clinic where protected slots are a feature.

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

37.1 I can only clarify the nature of information sought and provided from clinics at which I was involved. Following introductions, the Consultant provided a

recap of the patient diagnostic journey to date, and the outcome of the MDT discussion was then communicated to the patient. The next stage of investigations/planned surgery/onward referral or proposed discharge were outlined. Opportunities for questions and clarity were provided to the patient and relative. When present, the CNS provided a pack containing site-specific information along with a contact card with the CNS name and telephone number written on it. A Macmillan pack containing information on supportive services was also provided and an A4 page recording this provision of information was completed and filed inside the patient's medical notes. During the last few years, a Permanent Record of Management is also completed (a copy of which is given to the patient) and attached as evidence. Information recorded here includes, the Consultant Name, the diagnosis, the management plan, keyworker name and contact details. In more recent times an offer has been made for a Holistic Needs Assessment appointment at a separate time. *Please see:*

19. Permanent record of management

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

38.1 Consultants documented details of the encounter in a variety of ways. Some wrote a synopsis of the encounter in bullet points in the patient medical records and dictated a letter to the GP, while others dictated a letter only. Some Consultants copied the letter to the patient. In 2015, the CNS would have completed a record of the information provided to the patient and as stated in my answer to question 37, this was filed in the medical notes. More recently, over the last 2-3years, the CNS would complete a summary of the encounter on progress notes on NIECR.This would not have been completed previously in this manner. Where appropriate the CNS also updates the CAPPS system. A Cancer CNS Proforma is now also completed. This proforma records for example the patient details, diagnosis, treatment choice, date referred to the CNS, date seen by the CNS, if the patient wishes to have

a holistic needs assessment and a record of services to which the CNS has signposted the patient.

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 I believe that these protected slots are most effective when the Consultant, patient (and a relative where possible) and the CNS are present. The encounter provides an opportunity for the establishment of a relationship between the patient/family and the practitioners if this has not occurred already. It can be a distressing time for patients/family to receive news of cancer diagnosis and to understand the necessity for further investigations to determine an appropriate treatment plan if a treatment plan has not been determined at MDT. An example is where additional staging investigations may be required before a definitive treatment choice can be reached. A further MDT discussion would take place where this occurs.

39.2 I believe that engagement at these protected slots, with the Consultant, CNS, patient and family enhances patient care, experience and safety through the provision of written information which supports the verbal communication, the opportunity to ask questions to clarify queries, and through the patient/family being actively encouraged to engage with the CNS in their role as Keyworker via telephone should they have any questions/worries or concerns as they move through their journey.

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 As indicated in my answer to question 26 absence of core members such as the specialist Radiologist/ Oncologist or Histopathologist created a delay in patient discussion at MDT. On occasions, this would have occurred repeatedly over a period of consecutive weeks (especially over holiday periods). These absences resulted in delay in patient discussion, care planning and timely onward referral. On occasions to minimise delay for the most urgent of cases, the MDT Chair would have requested input from the Regional Urology Specialty MDT in a bid to progress patient pathways.

40.2 In cases where discussions were completed locally but the Consultant Urologist due to see the patient was on holiday, there was an agreement in place that Consultants would provide opportunities to review colleagues' patients within protected review slots in an attempt to avoid unnecessary delays especially for the most complex/urgent cases. Around 2015/2016 this agreement was written into the Operational Policy for the Urology MDT.

40.3 The absence of core members from Oncology and Radiology services in particular, within the MDT had a direct impact on progressing the patient pathway. It is my experience that every effort was made within the MDT to seek solutions to these issues, such as linking into the Regional Urology Specialty MDT when necessary. An example is where a patient pathway was time critical and the Radiologist was absent, the SHSCT MDT Chair, whichever Consultant Urologist that may be, on occasion with suggestion from any of the core members of MDT, requested the specialist input of the Radiologist present at the Regional meeting to assist with clarification on a scan to allow the patient pathway to progress.

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

41.1 Yes, I believe the role of the CNS was valued within the MDT. From the outset, I have felt included in the team. My presence at MDT allowed me, on patients' behalf to bring information to the team that they may not necessarily have known without my input. An example would be an occasion when the patient disclosed they were the sole carer for a spouse and felt that this may have a significant impact on their choice of treatment plan.

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

42.1 I would not be a confident speaker in any public forum; it takes a significant amount of effort on my own behalf. Within the MDT setting, as my knowledge base grew and as the core members were familiar, over time my contribution would have increased. Despite my own limitations, I have always felt able to contribute to MDT discussions.

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

43.1 Yes, my views were sought by clinicians on proposed patient care pathways. The MDT setting facilitated/allowed my contribution, and during any clinical encounter, my views on proposed patient care pathways were actively listened to. Where for example the Chair of MDT was not familiar with the patient, they would have sought clarity from the CNS regarding for example the patient's performance status and any relevant challenges the patient may have disclosed which could influence their decision-making in relation to treatment choice. An example was some patients who lived in rural areas expressed concern regarding their access to public transport. This may have been so troublesome for them they would have considered declining treatment in centres which required daily attendance over a lengthy period.

For those living in rural Fermanagh, travelling for radiotherapy necessitated a daily commute of several hours to and from treatment centres for period of up to four weeks.

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

44.1 Yes, I did feel able to contribute to MDT discussions if I did not agree with the proposed plan for the patient. An example would be if I felt the patient's performance status would not be optimal for the proposed treatment option. I would have explained the challenges shared with me by the patient. Another example was a patient who disclosed a likely inability to commit, at that time, to the proposed treatment plan as they were struggling with addiction at the time.

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 Yes, differing views on proposed patient care pathways were discussed among all core participants of the MDT, including Consultant Urologists, Oncologists, Radiologists, Histopathologists and CNSs. The very purpose of MDT is to bring together the expertise and skills of all participants to assess, plan and manage care to meet the needs of the patient.

45.2 A combination of guidelines such as the NICAN Urology Cancer Guidelines 2016 were applied to assist with decision making.

45.3 Alongside these guidelines, examples of recent research papers were shared in an attempt to resolve differing views. On occasions, where a consensus on the treatment pathway or an agreed conclusion was not reached, these cases were added to the Regional Urology Specialty meeting which occurred every

Thursday afternoon and to which the local MDT linked into virtually. This was not a frequent requirement.

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

46.1 The MDT co-ordinator recorded the patient outcome, and at a time suitable to the Chair for that MDM the minutes and outcomes were checked for accuracy and agreed. It was the responsibility of the MDT co-ordinator to upload the outcomes to NIECR and post a hard copy to the GP. The outcomes were emailed from the MDT co-ordinator to all core members of MDT and the Consultant secretaries to prompt the planning of reviews in the outpatient department. The patient was then appointed to a secured/protected slot as explained in my answer to question 36.

46.2 More recently, there has been a concerted effort to appoint the patient to the most appropriate Consultant following the MDT discussion. This means that while one Consultant may have assessed the patient, organised their scans and listed the patient for MDT discussion another Consultant reviewed them following MDT if that was their area of specialism. Examples of this would include patients who required a Nephrectomy were reviewed by Mr Glackin or Mr Haynes, while those considered for primary cystectomy were reviewed by Mr Haynes as he was one of a team of three who offered this surgery on the Belfast City Hospital site. At this review, the Consultant would detail specific information regarding for example the proposed length of in-patient stay, the potential complications and recovery timeframes. During this review, the CNS used the opportunity to discuss a variety of issues for example optimising performance status as a means to improve operative outcome and recovery. The outcomes and decisions made at MDT were acted upon by the Consultant Urologist who reviewed them post MDT.

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 Nowhere in the SHSCT Operational Policy for Urology MDT or NICAN Urology Cancer Guidelines (2016) does it state that the CNS has a responsibility to ensure that MDT decisions regarding patient care and treatment are followed through.

47.2 This would have been the role of the Consultant, facilitated and assisted by their secretary. The secretary appointed the patient to a protected slot within the review clinic. The Consultant communicated the MDT decision to the patient, dictated a letter to the GP and completed onward referral letters to appropriate specialties. The secretary then typed and forwarded the dictated letters.

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 My view is that there was healthy discussion regarding patient care and care planning. Professional opinion was valued as indicated in my answer to question 45. Where there was differing opinions a combination of guidelines such as NICAN Urology Cancer Guidelines 2016 were applied to select appropriate treatment pathways.

48.2 These guidelines along with examples of recent research papers were applied to resolve the differing opinions. Where an agreed conclusion was not achieved, these cases were added to the Regional Urology Specialty meeting, which the local MDT team linked into virtually on a weekly basis. This was not a frequent occurrence.

48.3 Increased use of Zoom for MDT meetings has helped with minimising the numbers in the meeting room; however, this method of communication

presented its own challenges such as poor broadband connection. If this occurs when the Chair is attempting to link into the regional meeting from an off-site location, a colleague will present the cases to avoid unnecessary delays.

48.4 In the main, communications were courteous in nature. Only on a few occasions have I ever felt a little ill at ease. One example I can recall was when Mr O'Donoghue was Chair of MDT. The meeting commenced a few minutes ahead of the agreed start time of 14:15pm. Mr O'Brien joined the meeting at the agreed time or a few minutes later, I cannot be sure. Mr O'Brien expressed his dissatisfaction that the meeting had commenced ahead of schedule. He directed his dissatisfaction toward the Chair, his voice was raised and tone forceful in nature. Mr O'Donoghue apologised that the meeting had commenced ahead of time, and after approximately five minutes during which time Mr O'Brien expressed his discontent, the MDT continued to a conclusion. As none of the content of the communication was directed towards me, I did not dwell on this encounter, though at the time I felt embarrassed for Mr O'Donoghue. I thought the encounter was unnecessary, as the discussion and outcomes up to that point could have been recapped. At no time did I feel that patient care or care planning were impacted upon.

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 From MDT commenced in 2010 until 2012, the meeting would have regularly overrun significantly, delaying the end of the working day for those present. Not all participants could remain for the entirety of the MDT on these occasions. Reasons for this would have included for example childcare responsibilities.

49.2 In 2022, an MDT proforma was introduced to ensure that the locally agreed minimum dataset is available for each patient being discussed at the MDT. The minimum dataset includes patient details, referring Consultant, clinical details,

co-morbidities, staging and results to date and the question for the MDT. The number of patient discussions is capped at 40 to facilitate adequate time for discussion and to ensure that the meeting ends promptly. Protocoled care contained within the Urology MDT Operational Policy is applied alongside discussion on the patients performance status to determine outcomes. The chair of MDT for the incoming month is emailed in advance, and preparation time is secured within the Consultant job plan.

49.3 The introduction of an MDT proforma, the capping of numbers to 40, and the application of protocoled care has improved the efficiency of this meeting.

49.4 There were occasional glitches with IT issues.

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 I would not have considered that communication was difficult with some Consultants. There were many competing challenges within the service and the availability of a CNS at every results clinic was not possible. The information below details the challenges within the service, and how the CNS role has evolved over the years, particularly the improved access to a CNS following additional appointments. I provided information previously through the questionnaire, and have inserted this again with some amendments for clarity. (page 19 in section relating to concerns)

50.2 In the early years of the CNS role, I made available information packs on urological cancers and provided a contact number for patients and families. At that time, I would have been involved in the clinical activity within the unit and would not have been in the room with any Consultant when a cancer

diagnosis was discussed. The Consultant would have come out of the room and stated the information required. I may have briefly entered the room to introduce myself and provide the information and a contact number. If I were on leave or absent for any reason, this information and a contact number for me was provided by my colleague Jenny McMahon or a Staff Nurse.

50.3 When the Urology MDT was established in 2010, the post MDT results clinics were provided within the modular build of Thorndale Unit. This was the first time that I can recall being present with Consultants during results consultations. There were three Consultants in position at that time, Mr O'Brien, Mr Young and Mr Akhtar, and I would have been able to provide support to these clinics except when on leave. Appointment to Consultant roles increased over the next few years, as did clinical activity within the unit and therefore my availability to every Consultant clinic became limited. When Thorndale Unit moved into the Outpatient unit within the hospital and "one-stop clinics" were established this limited my input further. In addition, at this time I undertook a training programme to develop the skill of undertaking prostate biopsy. My performing of prostate biopsies assisted in facilitating the majority of diagnostics being performed on the day, reducing unnecessary delay for the procedure.

50.4 With additional Consultants in place, the demand for Keyworker input increased, as there were more Consultants and therefore more patients to be seen at results clinics. While still the sole CNS with Oncology focus, as a team we were conscious that I was unable to commit to providing a CNS to every Consultant clinic. Where one-stop clinics ran in parallel to Consultant results clinics this restricted my Keyworker input further. At the start of any results clinic, it would have been my practice to inform the Consultant of my availability or otherwise for the duration of the session. This combination of clinical activity and the necessity to perform the Keyworker role meant that:

(a) Where possible I would be available during the Consultant/patient consultation and was present throughout the consultation.

(b) More often (though not always) I was invited in at the end of the encounter to provide information, support and a contact number. This was not unique to any single Consultant.

(c) If I had a biopsy clinic, patient notes would have been set on a work counter with a request for me to meet the patient (located in the waiting area) and provide keyworker support in the form of written information, support and a contact number as soon as I was free.

(d) On occasions when I had not met the patient, I would have received phone calls over the following days from patients seeking clarification of the diagnosis/treatment plan which had been provided by the Consultant.

(e) At no time was there an expectation that I would attend any satellite sites where cancer diagnosis may also have been discussed (Banbridge Polyclinic, Armagh Community Hospital, South Tyrone Hospital or South West Acute Hospital SWAH). In recent times we have been able to provide a CNS to support the clinic at Armagh Community Hospital

(f) Nor was there an expectation that the CNS/Keyworker had the responsibility to ensure that scans were requested or onward referrals completed

50.5 Consultants managed the above challenges differently. For example, if I were not available Mr Glackin may have given out the pack with the contact number himself, Mr Haynes generally requested that the patient wait until I was available, while Mr O'Brien may only have invited me into the room if the patient required nursing intervention for example a dressing change, or for referral onto other services such as the community continence team or the palliative team. I cannot determine if Mr O'Brien gave the pack or contact number to the patient in my absence. This meant that, on occasions, I would have been involved periodically throughout the clinic and on other occasions, I would not have been involved at all. I am unable to explain the reasons as to why the Consultants adopted various approaches to this particular clinic. The time constraints of a clinic and competing challenges for the Consultant (needing to undertake another clinic or theatre session) may have contributed to these various approaches. At no stage did any of the nursing team within Thorndale Unit recognise or raise a concern that CNSs

were not invited to be present at uro-oncology consultations in general or by any particular Consultant.

50.6 On occasions, a patient would randomly contact the unit to explain they had an appointment a day or two previously with a Consultant and they wanted to clarify a specific issue or were unsure of the next plan in their pathway. I would have used these opportunities to speak with the Consultants directly to explain the benefit of being present during the consultation. I can recall conversations with Mr Glackin, Mr Suresh and Mr O'Brien in relation to this. While they all acknowledged what I said, I cannot recall any of them expressing any particular view in relation to the subject. These were occasional phone calls and conversations. Being present, for me, provides an understanding of how much information was provided and how well it was absorbed. Opportunities to clarify issues at the time of the encounter can be addressed in real time.

50.7 In my answer to question 7 I provided information regarding the delays linked to the appointment of additional CNS's.

50.8 By 2019 two Urology CNS's were appointed (one of which was to have a cancer focus, Leanne McCourt). From this time onwards, in addition to providing support and information, completing a permanent record of management and providing a contact number, we would have recorded a brief summary of the patient interaction on progress notes on the NIECR system. In August 2020 a third CNS with a cancer focus Patricia Thompson was appointed, which provided further assistance with the above clinics.

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?

50.9 From my appointment to the CNS role in 2005 until 2019, I remained the only CNS with an Oncology focus. This resulted in the issues discussed above. The inability to provide CNS access to all Consultant clinics, and the competing

challenges in parallel clinics were discussed with the HoS and Lead Nurse with a desire to find a solution. Consultant colleagues were aware of this situation through conversations in the clinical setting and at Departmental meetings. The HoS held meetings at which only the Consultants were present, I cannot determine if this issue was discussed in that forum.

50.10 When the CNS team returned from redeployment during Covid in April 2021, and when the Outpatient Ward Manager acquired managerial responsibility for Thorndale Unit (except in periods of leave/sickness) it became more manageable for a CNS to be available to support uro-oncology clinics. This is as direct result of the recruitment of two additional CNS's with an Oncology focus, and the CNS not having to undertake managerial duties within Thorndale Unit.

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 can only recall meeting resistance in relation to my role in performing prostate. This resistance was from Mr Young who appeared reluctant to refer patients into the nurse-led prostate biopsy service. I feel it is necessary to give some background as to how this nurse-led service came to be established.

51.2 Shortly after my appointment to the CNS role, I absorbed the management of the prostate biopsy service. At that time, there was an excessive waiting period (several years) for this procedure, which was provided on an ad hoc basis, by a Consultant Radiologist within the radiology department setting. With the support of management, I established a weekly clinic within our unit where two Radiologists would attend to perform four biopsies on an alternate weekly basis. In addition, we established a waiting list initiative to clear the backlog by undertaking evening clinics. One of the Radiologists became unavailable long term to commit to his weekly session, in I believe 2014 and later left the Trust. This left a deficit, which was filled on alternate weeks by one of two Consultant

Urologists, Mr Glackin and Mr Haynes. Given my interest in this service, I undertook additional training under direct supervision of the two Urologists and competencies were met/achieved, resulting in the establishment of the only nurse led prostate biopsy clinic in NI commencing in July 2015. In addition to a once weekly nurse-led clinic, and in an attempt to shorten the diagnostic pathway, I would have performed biopsies at the new one-stop clinics as well as in sessions where any other activity was cancelled and nursing staff were available to provide support. This activity kept waiting times to a minimum. I continued to provide the one Consultant Radiologist's secretary the names of patients for their ongoing lists. These lists would have included those patients who were determined as either having significant complex medical issues or those who were discussed at MDT and identified as appropriate for the Radiologist list.

51.3 If I had any queries or concerns regarding any patients such as their co-morbid issues or performance status, I would have discussed the plan of care with their Consultant directly. Throughout this time, I would have noted one Consultant in particular, Mr Young, when listing a patient for prostate biopsy almost always verbalised a reason as to why he felt the patient should be appointed to the Radiologist list. Examples given by Mr Young would include the prostate is small, the patient has co-morbidities or is frail. The remaining Consultants throughout this time would have referred similar patients into the nurse-led service for prostate biopsy; therefore, I could not understand why Mr Young adopted this approach. As time passed, I presented audits demonstrating the outcomes from the nurse led biopsy service at Departmental and Patient Safety Meetings. I was able to demonstrate that my service was safe and the outcomes were comparable to national data. I believe that these presentations and the availability of prostate biopsy at one-stop clinics removed this barrier and from approximately 2019, resulted in more referrals from Mr Young.

51.4 Otherwise, I have always felt that all Consultants readily engaged with, supported and accommodated nurse-led services.

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 Yes, I share the view that nurse-led procedures and prescribing has released pressure on medical teams. I wish to clarify that I am not a non-medical prescriber. Nurse-led prostate biopsy sessions directly removed the need for Consultants to provide this service on one session per week, releasing them to undertake other work.

52.3 One-stop clinics offering nurse-led flexible cystoscopy and prostate biopsy directly contributed to an increase in the capacity of Consultants to see additional new patients within the session.

52.4 These clinics were undertaken within a supportive/safe environment, where the patients' privacy and dignity were paramount. Nurse-led procedures in this setting shortened the diagnostic pathway, provided clarity for the review process, established patient/practitioner relationships, provided a contact number for the unit and offered an opportunity for emotional support.

52.5 In relation to general outcomes patients have verbalised positive experiences while attending nurse-led clinics, and the presence of nurse-led clinics have gone some way in assisting with demand/capacity pressures.

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 With the recruitment of two additional CNS's with an Oncology focus, the team of three from 2021/2022 offer a range of services including Transperineal Prostate Biopsy, Prostate Cancer Review, Renal Cancer Review and Holistic Needs Assessment, which has increased urology capacity through releasing Consultants to undertake other activity.

53.2 The two CNS's with a benign focus have a variety of new referrals directly triaged to their services avoiding the necessity for the Consultant to see them in the outpatient setting until a later stage in their pathway, if at all.

53.3 Collectively, management continue to engage in a supportive manner with the CNS team to explore more nurse-led services for development in the future should further CNS appointments occur. As stated previously, administrative support remains challenging.

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 I was appointed to the CNS role in 2005 and the first two years were spent planning service development and the design of a modular build to accommodate urology clinics. Thorndale Unit opened in 2007. From 2007, Mr O'Brien would have undertaken review clinics in the unit, though as I was involved in nurse-led activity I would not have been present with him in clinic. This was also the case for Mr Young.

54.2 In 2010, when MDT was established by Mr Akhtar, in discussion with the Consultants and the HoS, and in the background of having additional Staff Nurses assigned to the unit I became more involved in results clinics. For all three Consultants where possible, and except during periods of leave I would have been in the consultation room along with the Consultant, patient and family. Here I would have provided information booklets specific to their condition and provided a contact number.

54.3 When the Consultant team expanded further and we moved to the current Thorndale Unit within the footprint of the main hospital, it became impossible to be present for every Consultant clinic in the capacity of keyworker. This resulted

in the concerns raised in question 50 relating to the CNS not invited into the uro-oncology consultation, and I have provided a reply as to how Consultants managed this challenge differently.

54.4 I never felt that Mr O'Brien prevented/obstructed CNS involvement in his clinic, nor did my colleague Jenny McMahon or Staff Nurse Dolores Campbell who would both have deputised for me on occasions, ever raise this as an issue. My job plan meant that I was generally available for uro-oncology clinics with Mr Glackin, Mr O'Donoghue and Mr Haynes but to a lesser extent, Mr O'Brien and Mr Young. This meant that I would see much fewer patients with Mr O'Brien and Mr Young. I do recall Mr O'Brien introducing me to patients to either plan prostate biopsy for them, engage or signpost to other services (such as Palliative Care Team) or for the provision of information. On those occasions I felt that I was able to offer information, support and a contact number. On occasions I would have received phone calls from patients seeking clarity regarding their consultation with any of the Consultants. Had I not been present during the consultation the patient was referring to, I would have viewed the dictated letter from NIECR for clarity in relation to their questions, or sought clarity from their Consultant. For many years, I have worked a four-day week, Monday- Thursday, except with the occasional half day on a Friday. I would have spent this session preparing/organising the prostate biopsy service. In my absence for whatever reason, in the majority of these situations a colleague would have been available to support the clinic where necessary to provide documentation/contact numbers. There may have been a wait involved for the member of staff to become available, due to parallel activity, and this may have been a Staff Nurse. At no time did they ever raise a concern in relation to this activity.

54.5 Mr O'Brien was aware of the keyworker role given his involvement in Peer Review and MDT. He would have involved me in keyworker activity from time to time, but as stated previously it was not common for me to be available when his clinic took place. My job plan meant that I had much more keyworker activity with other Consultants. I contacted the entire Consultant team via email on several occasions explaining the role of the keyworker and the information to be provided

to all patients with a new cancer diagnosis. The details of which have been provided in reply to questions 24 and 56.

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?

55.1 I have provided a detailed response in relation to a lack of CNS involvement in Mr O'Brien's clinics and my experience of this in reply to question 54. I was not aware that Mr O'Brien had adopted an approach not to engage routinely with CNSs for service provision to patients with a cancer diagnosis. As no-one had raised this as a concern with me, and I was not aware of it, I did not escalate this issue at any time. . Information packs were readily available within each consultation room in the Thorndale Unit. The packs contained a contact number, and had they been provided (in the absence of the CNS), this would potentially have opened an avenue for the patient/family to engage with the CNS.

55.2 I have provided detail earlier in my reply to question 7 in relation to the timetable of appointment of additional CNSs to urology services. These appointments contributed to improved availability within the job plans to allow a CNS to be allocated to each uro-oncology results clinic from April 2021 onwards, except in times of unexpected leave, or when a clinic was built at short notice and nurse-led clinical commitment had already be allocated.

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 Yes, having had the overarching report in relation to the 9 SAI's shared with me (via egress access) in March 2021, I am now aware of governance concerns in relation to urology services These include:

(a) Delay in triage of letters – I would have heard all Consultants on occasion discuss issues related to the challenges of completing triage during busy on-call rotas among themselves and with the HoS. Until e-triage was introduced (cannot be sure when) the hard copies of GP referrals for triage were brought to the office in Thorndale Unit and placed in a tray. While on call the Consultants collected the triage from here, usually on a daily basis for processing. I had no knowledge of the depth of the problem or the fact that the issue was investigated through a Root Cause Analysis of Serious Adverse Incidents (SAI's) in 2016. I was shocked to read the extent of this issue through an article in the local press in June 2021 stating that greater than 700 referral letters were found in a filing cabinet which had not been triaged. The possibility of CNSs undertaking triage was discussed on several occasions with the HoS, the Consultant team and the CNSs, though no decision ever concluded that nurses would undertake this role. At no time would I have had any managerial responsibility in relation to triage.

(b) **Access to a CNS** – I was not aware of this issue until the report of the SAI's was made available to me in March 2021. I have provided information in relation to Mr O'Brien's involvement with CNS's in my reply to questions 54 and 55. I have previously provided email evidence to the USI. These included an email dated 18/05/2015 entitled Involvement of Keyworker and provision of patient information and a further email dated 16/06/2017 entitled Issue raised at the Thorndale Unit Meeting today, asking all Consultant colleagues that all patients who require the input of a keyworker would be offered the opportunity to meet with the appropriate member of staff on the day. I have attached this email as evidence. While competing demands in the clinic setting are acknowledged, had I known that this was as issue, I

would have engaged with the HoS, Consultant and nursing colleagues in order to seek a solution, to ensure that a CNS, where possible, was allocated to every uro-oncology results clinic. *Please see:*

20. Email correspondence Kate O'Neill

(c) **Backlog review** – I was aware of the general backlog review situation since it was identified during the Review of Urology Services in 2009, an issue which may have arisen from a demand/capacity position. It was not specific to one Consultant. I have provided information in reply to question 24 outlining my input in 2009/2010 to assist with the backlog review problem. I have also located an email dated 11th August 2017 from Martina Corrigan asking my colleague Leanne McCourt and I to assist with validating Mr O'Brien's review backlog in relation to uro-oncology patients. Corresponding emails in relation to this activity have been added as evidence. At no time would I have access to exact figures relating to the backlog review, nor was I in a position to provide a resolution to this problem as I had no managerial responsibility in relation to backlog reviews. *Please see:*

21. Email AOB review

(d) **Delay in dictation of letters/onward referral/ordering of scans** – I was aware of delays in dictation of letters in real time at clinics. The HoS was aware that Mr O'Brien regularly dictated letters in the evening of a clinic or in the days that followed completion of a clinic. On occasions, dictation may not have taken place for several weeks. I first became aware of delays in dictation affecting onward referrals or ordering of scans in 2019 through patient enquiries in my role as Keyworker. I previously supplied examples of this through the email search process. Emails relating to delays in dictation, onward referral have been attached as evidence. An example was an email I sent to Mr O'Brien's secretary on 17/09/2019 asking if dictation had been completed from Mr O'Brien's clinic on 03/09/2019 as a patient had phoned

in stating he had not received any appointments in Belfast and was concerned regarding this. In reply from the secretary I was advised that the patient was attending for Urodynamic studies on 20th September 2019. On 09/12/2019 the same patient contacted me again asking if he had been referred to Belfast for Brachytherapy – on this occasion I emailed Mr O'Brien directly and copied his secretary into the email. From the introduction of MDT in 2010 onwards, following MDT, it was my practice to keep a hard copy of the outcomes for each patient until I knew they had been appointed to a uro-oncology review clinic. From time to time, when I became aware of a delay in first review following MDT, I would have discussed these with Mr O'Brien (or any Consultant) directly in order to seek resolution. This was not a frequent occurrence, nor was it related to any one Consultant in particular. I cannot recall escalating this as an issue to anyone else. On discussing the outcome of the SAI report in March 2021, Martina Corrigan informed me that the issue of dictation was investigated by the Trust and an action plan put in place. I did not know the extent of this issue and would not have been in a position to provide a solution, however in hindsight had I know the extent of the problem I would have escalated it to the HoS. *Please see:*

22. Email re dictation

23. Email to Leanne McCourt re patient query

(e) **Delay in sign off or acting upon results** - I became aware there was an issue in relation to the sign off and acting upon results in August/September 2020. Martina Corrigan and Mr Haynes approached Leanne McCourt CNS and I to check a database from histopathology and radiological results to determine if patients had been communicated with and onward referrals completed. Together Leanne McCourt and I completed this task in relation to histopathology results but expressed our concern to both Martina Corrigan and Mr Haynes regarding the expectation placed upon us for this role, This related to the risk of us overlooking something of importance. We detailed our concerns in an email dated 22/09/2020 which is attached as evidenced . In this email we informed Martina Corrigan and Mr Haynes we

did not wish to undertake checking whether radiological results had been actioned. We felt the number of radiological results was overwhelming and the checking of radiological results did not sit with ease in our role and responsibility as a CNS. Martina Corrigan and Mr Haynes accepted that we did not undertake this task. Prior to August/September 2020 I was not aware this was a significant issue. I would have no managerial responsibility in relation to the sign off or acting upon results. *Please see*

24. Attachment results
25. Email from Leanne McCourt re results

(f) Prescribing issues – I first became aware of prescribing issues during Autumn/Winter of 2020 when I was asked by Martina Corrigan and Mr Haynes to provide CNS input at review clinics to be held in Ramone outpatient building. It is my understanding that these patients with prostate cancer, were identified during a Lookback exercise, where it became apparent that patients had been prescribed a dosage of Bicalutamide by Mr O'Brien, which did not reflect the NICAN Urology Cancer Guidelines (2016). I was not aware of the extent of this issue until the report of the SAIs was made available in March 2021. I cannot recall if this matter was raised at MDT, which would have been the appropriate setting for which to raise this concern had it been known. I am not a non-medical prescriber, nor would I have any managerial responsibility in relation to the prescribing practices of Medical colleagues.

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

57.1 I do not have an explanation as to what went wrong within urology services but the following may have been contributing factors. There are a number of questions I would have to which I am unable to provide an answer to as I did not have any managerial responsibility for Medical colleagues or the planning of urology services other than at a nursing level.

57.2 I am unable to clarify the attempts that were made to meet or resolve the following:

(a) Implementation of Team South plan following the Regional Review of Urology Services. How serious were the recommendations taken? Were all efforts to address recruitment and retention issues for Consultants and CNSs exhausted?

(b) The decision made by the Surgical Reconfiguration Group in 2009 to close the Urology ward appeared to have a significant effect on the stability of urology staff. Despite the regional review of urology services stating that a dedicated urology in-patient unit would remain at Craigavon Hospital, the above group decided to close the ward. This resulted in urology staff with specialised skills being redeployed throughout all surgical wards. By the time this decision was reversed in 2010, some staff had already left the service, relocated to work in other sites of the Trust, while others remained in their newly deployed areas. This depleted the urology nursing skill set significantly, and for many years after there was difficulty in retaining a Ward Manager for the new ward.

(c) Were all efforts exhausted to resolve the critical quoracy issues within MDT? By this I mean was there engagement with Urology MDT, SHSCT Cancer Service managers and tertiary service providers, particularly in relation to Oncology.

(d) My understanding is that there was a limit to the tracking of the patient pathway within Urology MDT, meaning that the patient journey was only tracked up to the point of the first definitive treatment. An example would be the patient was tracked up to the point they had their first surgical procedure or the recommendation was made in MDT to commence on medication and refer for Radiotherapy. There was no tracking beyond this point and I would suspect that this is likely not unique to Urology services.

57.3 On further reflection, when the Mandeville Unit opened to deliver cancer services in CAH there was no urological footprint within the unit. Did this contribute to a disconnect through lack of regular contact and access to those in management

roles within the Cancer Directorate, or was there regular contact with Consultant Urologists at meetings I may not have known about? Could this have contributed to any isolation of the Urological service?

57.4 My experience to date is that as a CNS. I had sufficient access to the HoS and Lead Nurse through meetings and on an ad hoc basis and I felt that collectively we worked well together. Despite the lack of adequate CNS resources, we continued to plan out new services such as Prostate and Renal cancer follow up and Holistic Needs Assessment to assist with capacity and demand issues to allow us to be in a state of readiness when appointments were secured.

57.5 Beyond HoS and Lead Nurse level of management, within nursing structures visibility, accessibility and engagement with the Assistant Director and Director of Nursing was limited This however did not have an impact on my role as a CNS, nor do I feel it contributed to the concerns within urology services as I understood that the HoS and Lead Nurse had regular meetings with higher management and would have escalated any necessary concerns such as CNS vacancies to them.

57.6 For me personally, it has been disappointing to learn that investigations had occurred within the Urology Service over a period of time leading up to and during a time when our work was recognised through the awarding of Frontline Team of the Year and Overall Winner of the Trust Excellence Awards in 2016.

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 In my role as a CNS, I did not have any managerial responsibility in relation to Mr O'Brien. My understanding is that operational issues were managed by the HoS and professional issues within the senior management structure

58.2 I consider that both Medical and Nursing workforce issues appear to be a predominant contributory factor in relation to the concerns that arose within the Urology services. It was not possible for a single Oncology focussed CNS to offer an adequate resource to every patient with a urological cancer. Given competing pressures, this CNS could not be available to support every Consultant led

results clinic and this was the position from MDT commenced in 2010, and while the appointment of an Oncology CNS in 2019 and a further one in 2020 have helped, a deficit remains. There is clear need for adequate CNS resource to ensure that scheduling of a CNS to each results clinic is achievable. . A shortage of Consultants within the SHSCT was identified during the Regional Review of Adult Urology Services in 2009. From that point forward until the present, there have been lengthy periods of absence of the full quota of whole time equivalent Consultant Urologists. A shortage of Consultants created challenges to fulfilling the needs of the service, and an over reliance on Locum Consultants.

58.3 There appears to have been a lack of oversight in relation Mr O'Brien's approach to administrative issues. This meant that opportunities to identify delays in for example the completion of triage, dictation and sign off of results were missed. Had these issues been identified at an earlier point perhaps some of the SAI's could have been avoided. Triage is now an electronic process and therefore delays in triage and who is accountable should be easier to monitor and address. I am unsure of the processes in place currently for internal Trust referrals from one specialty to another.

58.4 In relation to the prescribing of Bicalutamide, if this issue was known to Consultant colleagues within the SHSCT it should have been escalated at the earliest opportunity. Furthermore, if prescribing issues were identified upon the patients referral for Oncology input it should also have been escalated formally. This may have limited the number of patients affected by these prescribing errors. I am not aware if there is a feedback process in place to allow regional services to report back to SHSCT Cancer Services issues such as delayed referral or prescribing discrepancies. If there were no formal process in place, would it be useful to consider this going forward?

58.5 During periods where Consultant vacancies were/remain an issue, the Consultant on-call commitment for all the Consultants in post appeared to be frequent and lengthy which limited ability to offer for example out-patient new and review clinics as often as required. On-call periods meant that priority was given to managing in-patient care pathways for all urological patients, who may have

been located over many wards throughout the hospital. In-patient ward rounds occurred at least once a day. Emergency theatre space required negotiation. In addition urgent referrals within the ED or internal across specialty referrals in various ward settings in the Trust were to be assessed. This workload may have presented challenges to completing triage promptly.

58.6 The lookback exercise has highlighted the need for improvement to or extension of the cancer tracking role within the MDT setting as a means to determine have outcomes been actioned as agreed. If patients were tracked beyond the point of first intervention such as the prescribing of medication perhaps mechanisms could be built into this service to identify prescribing discrepancies in the future. In addition, a mechanism could be applied to check that onward referral has taken place.

58.7 In relation to learning, I would have several questions to which I do not have the answer. These include:

(a) Where investigations relating to Mr O'Brien's practice during his time within the SHSCT have taken place and action plans put in place, was there a robust process in place for dealing with non-compliance and to what level of senior management was this issue escalated and addressed?

(b) I am not familiar with the appraisal structure applied to medical staff. If appraisal was with a peer within the urology specialty was this appropriate, or should appraisal involve someone neutral to the specialty/ or indeed from outside the Trust?

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 As stated previously I do not work within the management structure, and therefore do not know the levels to which concerns were raised or discussed.

59.2 The Medical and Nursing recruitment issue and the critical quoracy issues within MDT in my view had a direct impact on patient care and care planning. The need to resolve the above challenges sat with the Senior Management Team, Cancer Services and Urology Services. I would not be in a position to clarify the level of engagement that these teams undertook to resolve the problems.

59.3 The internal review relating to triage, that took place in 2016 and was signed off in 2020 indicates that there were issues dating back possibly decades. Did management structures take cognisance of the cumulative effect of the various issues identified within the report? I am unaware of the structures for raising concerns to the highest level within the medical management structure or what has to be raised to highest level – when 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?

60.1 I believe that the information I have provided within this document demonstrates that throughout my career, where I identified concerns within the urology service, I escalated them promptly in order to seek resolution.

60.2 An article that appeared in local press in 2021 stated that concerns about “difficult colleagues” and “difficult issues” were not passed up the line. If this Inquiry finds that this was the case, were the appropriate support structures in place to facilitate this process? If the triage issues were decades old could this have been handled any better at an earlier stage?

60.3 Specifically in relation to MDT quoracy issues, every effort was made to progress the patient pathway. On reflection, if a cease-and-desist approach had been taken would this have added any strength or impetus to resolve this problem?

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?

60.4 I am unable to state if governance arrangements were utilised to maximum effect in my role as a CNS. The investigation into delayed triage in 2016 demonstrated that an action plan was agreed, however following periods of compliance there was a slip back to non-compliance again. I would not have access to information to determine that this issue was addressed robustly.

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 Only upon reading the SAI report shared with me in March 2021, can I say that it would appear to me that governance arrangements were not fit for purpose. For example the findings within this report indicate a disconnect between the Urology MDT and Cancer Services Management. They also concluded that leadership focused on service delivery, with limited processes in place to benchmark quality, identify deficiencies and escalate concerns.

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 do not have anything additional to add which I 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.

Statement of Truth

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

Signed: __ Personal Information redacted by the USI **_____**

Date: _____28.10.22_____

Section 21 Notice Number 71 of 2022

Witness Statement: Kate O'Neill

Index

Attachment	Document name
1	Radical Laparoscopic keyhole Nephrectomy
2	20160401 Urology
3	clinicalnursespecialistsanevidencereview2012
4	prostate-cancer-a-guide-for-men-who've-just-been-diagnosed
5	PDP Paula McKay 2022
6	PDP Sarah Ward 2019
7	Rough notes from 2010
8	Thorndale department meeting question
9	Minutes of meetings with HoS MC, Kate and Jenny Thorndale 03 04 2015
10	Dawn Connolly Governance meeting
11	Dawn Connolly Governance meeting 2
12	Supporting Nurses in Difficulty Question 21
13	Nursing and Midwifery Accountability and Assurance Framework
14	Response for Trusts proposals for Ward reconfiguration
15	Email involvement pathway recording form
16	Email involvement
17	Action plan form
18	CNS proforma
19	Permanent record of management
20	Email correspondence Kate O'Neill
21	Email AOB review
22	Email re dictation
23	Email to Leanne McCourt re patient query
24	Attachment results
25	Email from Leanne McCourt re results

RADICAL LAPAROSCOPIC (KEYHOLE) NEPHRECTOMY (REMOVAL OF A KIDNEY FOR SUSPECTED CANCER)

Information about your procedure from
The British Association of Urological Surgeons (BAUS)

This leaflet contains evidence-based information about your proposed urological procedure. We have consulted specialist surgeons during its preparation, so that it represents best practice in UK urology. You should use it in addition to any advice already given to you.

To view the online version of this leaflet, type the text below into your web browser:

http://www.baus.org.uk/_userfiles/pages/files/Patients/Leaflets/Radical nephrectomy lap.pdf

Key Points

- The aim of laparoscopic nephrectomy is to remove a tumour-bearing kidney, using a telescopic (keyhole) technique through several small incisions in your abdomen
- In some patients, the adrenal gland and nearby lymph nodes are also removed
- One of the keyhole incisions needs to be enlarged to remove your kidney
- The procedure is normally well-tolerated with an average length of stay of around three days
- Recovery normally takes four to six weeks, but it can be longer
- Regular, long-term follow-up with scans is required after removal of a kidney tumour

What does this procedure involve?

Removal of your tumour-bearing kidney through three or four keyhole incisions, using a telescope and operating instruments put into your abdominal (tummy) cavity. One incision will need to be enlarged to remove the kidney.

What are the alternatives?

- **Observation alone** – leaving the tumour in your kidney and observing it carefully for any signs of enlargement

- **Open radical nephrectomy** – removing the whole kidney and its surrounding tissues through an abdominal or loin incision
- **Open partial nephrectomy** – removing only the part of the kidney containing the tumour, through an abdominal or loin incision
- **Robotic-assisted partial nephrectomy** – removing part of the kidney containing the tumour using a keyhole technique with robotic asistance

What happens on the day of the procedure?

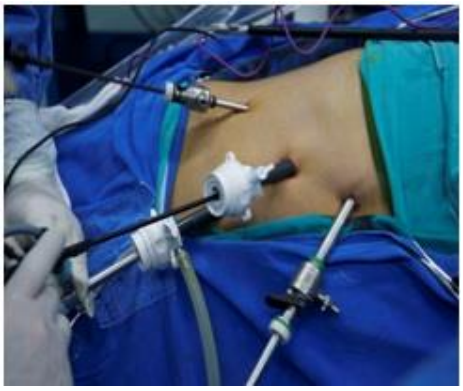
Your urologist (or a member of their team) will briefly review your history and medications, and will discuss the surgery again with you to confirm your consent.

An anaesthetist will see you to discuss the options of a general anaesthetic or spinal anaesthetic. The anaesthetist will also discuss pain relief after the procedure with you.

We may provide you with a pair of TED stockings to wear, and we may give you a heparin injection to thin your blood. These help to prevent blood clots from developing and passing into your lungs. Your medical team will decide whether you need to continue these after you go home.

Details of the procedure

- we carry out the procedure under a general anaesthetic meaning that you will be asleep throughout
- we may give you an injection of antibiotics before the procedure, after you have been checked for any allergies
- we inflate your abdominal (tummy) cavity by injecting carbon dioxide gas using a special needle
- we place a telescope & operating instruments into your abdominal cavity through three or four small incisions (pictured)



- we free your kidney and its surrounding fat using these instruments, and extract the kidney from your abdomen by enlarging one of the port incisions
- we close the wounds with absorbable stitches or clips which normally disappear within two to three weeks and inject local anaesthetic into the wounds for pain relief

- we put a catheter in your bladder to monitor your urine output; this is removed as soon as you are mobile
- we sometimes put a drain down to the area where the kidney was removed, to prevent fluid accumulation; this is removed when it stops draining
- the procedure takes from one to three hours to complete, depending on complexity
- you can expect, on average, to be in hospital for three days

Following major abdominal surgery, some urology units have introduced Enhanced Recovery Pathways. These actually start before you are admitted to hospital. After your surgery, they are designed to speed your recovery, shorten your time in hospital and reduce your risk of re-admission.

We will encourage you to get up and about as soon as possible. This reduces the risk of blood clots in your legs and helps your bowel to start working again. You will sit out in a chair shortly after the procedure and be shown deep breathing/leg exercises. We will encourage you to start drinking and eating as soon as possible.

Are there any after-effects?

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
Pain or discomfort at the incision site	 Almost all patients
Shoulder tip pain due to irritation of your diaphragm by the carbon dioxide gas	 Between 1 in 2 & 1 in 10 patients
Temporary abdominal bloating (gaseous distension)	 Between 1 in 2 & 1 in 10 patients

Bleeding, infection, pain or hernia at the incision site requiring further treatment		1 in 33 patients (3%)
Recognised (or unrecognised) injury to organs/blood vessels requiring conversion to open surgery (or deferred open surgery)		Between 1 in 10 & 1 in 50 patients
Bleeding requiring transfusion or conversion to open surgery		Between 1 in 10 & 1 in 250 patients
Entry into your lung cavity requiring insertion of a temporary drainage tube		Between 1 in 50 & 1 in 250 patients
Anaesthetic or cardiovascular problems possibly requiring intensive care (including chest infection, pulmonary embolus, stroke, deep vein thrombosis, heart attack and death)		Between 1 in 50 & 1 in 250 patients (your anaesthetist can estimate your individual risk)
Involvement or injury to nearby local structures (blood vessels, spleen, liver, lung, pancreas & bowel) requiring more extensive surgery		Between 1 in 50 & 1 in 250 patients
The abnormality in the kidney may turn out not to be cancer		Between 1 in 50 & 1 in 250 patients
Dialysis may be required to stabilise your kidney function if your other kidney does not function well		Between 1 in 50 & 1 in 250 patients

What is my risk of a hospital-acquired infection?

Your risk of getting an infection in hospital is between 4 & 6%; this includes getting *MRSA* or a *Clostridium difficile* bowel infection. This figure is higher if you are in a "high-risk" group of patients such as patients who have had:

- long-term drainage tubes (e.g. catheters);
- bladder removal;
- long hospital stays; or
- multiple hospital admissions.

What can I expect when I get home?

- you will get some twinges of discomfort in your incisions which may go on for several weeks; this can used be controlled by simple painkillers such as paracetamol
- you should have recovered completely after 10 to 14 days
- most people can return to work after two to four weeks
- you will be given advice about your recovery at home
- you will be given a copy of your discharge summary and a copy will also be sent to your GP
- any antibiotics or other tablets you may need will be arranged & dispensed from the hospital pharmacy
- the pathology results on your kidney will be discussed in a multi-disciplinary team (MDT) meeting
- you and your GP will be informed of the results at the earliest possible opportunity
- we normally arrange a follow-up appointment for you once the pathology results are available

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 (e.g. warfarin, aspirin, clopidogrel, rivaroxaban, 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).

Questions you may wish to ask

If you wish to learn more about what will happen, you can find a list of suggested questions called "Having An Operation" on the website of the Royal College of Surgeons of England. You may also wish to ask your surgeon for his/her personal results and experience with this procedure.

For several years, BAUS has collected data from urologists undertaking this surgery. You can view these data, by unit and by Consultant, in the Surgical Outcomes Audit section of the BAUS website.

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 surgeon 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.

Smoking and surgery

Ideally, we would prefer you to stop smoking before any procedure. Smoking can worsen some urological conditions and makes complications more likely after surgery. For advice on stopping, you can:

- contact your GP;
- access your local NHS Smoking Help Online; or
- ring the free NHS Smoking Helpline on **0300 123 1044**.

Driving after surgery

It is your responsibility to make sure you are fit to drive after any surgical procedure. You only need to contact the DVLA if your ability to drive is likely to be affected for more than three months. If it is, you should check with your insurance company before driving again.

What should I do with this information?

Thank you for taking the trouble to read this information. Please let your urologist (or specialist nurse) know if you would like to have a copy for your own records. If you wish, the medical or nursing staff can also arrange to file a copy in your hospital notes.

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.

Disclaimer

We have made every effort to give accurate information but there may still be errors or omissions in this leaflet. BAUS cannot accept responsibility for any loss from action taken (or not taken) as a result of this information.

PLEASE NOTE

The staff at BAUS are not medically trained, and are unable to answer questions about the information provided in this leaflet. If you do have any questions, you should contact your urologist, specialist nurse or GP.

Prostate cancer

A guide for men who've just been diagnosed

PROSTATE CANCER UK

About this booklet

This booklet is for anyone who's recently been diagnosed with prostate cancer. Your partner, family or friends might also find it helpful. We explain what prostate cancer is, the tests you may have to diagnose it, and the treatment options available. There's also information about where you can get support if you need it.

Each hospital will do things slightly differently. Use this booklet as a general guide to what to expect and ask your doctor or nurse for more details about your care and the support available to you. You can also speak to our Specialist Nurses, in confidence, on 0800 074 8383 or chat to them online.

This booklet is also available in large print.

The following symbols appear throughout the booklet:

Our Specialist Nurses

Our publications

Sections for you to fill in

Watch online at **prostatecanceruk.org**

You can use this booklet as your personal guide and write down any information that might be helpful to you in the blue shaded areas towards the back.

Contents

Sections for you to fill in

If you've just been diagnosed with prostate cancer

If you've just been diagnosed with prostate cancer, you might feel scared, worried, stressed or even angry. Your feelings may change over time. There's no right way to feel and everyone reacts in their own way.

When you're told you have cancer, it can be a shock and you might find it difficult to take everything in. Thinking about your cancer and possible treatments can be stressful and you may have lots of questions. You may also feel anxious about the future and how having prostate cancer will affect your life and your loved ones.

There are people who are there to support you as well as things you can do to help yourself. You might find it helpful to read about prostate cancer and treatment options. And you can read more about getting support on page 44, or speak to our Specialist Nurses.

Families can also find this a difficult time and they may need support and information too. They may want to read our booklet, **When you're close to someone with prostate cancer: A guide for partners and family.**

I called the Specialist Nurses on the day I was diagnosed. They talked me through the scenarios and possible treatments.

A personal experience

What is the prostate?

The prostate is a gland. It is usually the size and shape of a walnut and grows bigger as you get older. It sits underneath the bladder and surrounds the urethra, which is the tube that carries urine (wee) out of the body. The prostate's main job is to help make semen – the fluid that carries sperm.

Who has a prostate?

The following people have a prostate:

- men
- trans women*
- non-binary people who were assigned male at birth**
- some intersex people.***

Trans, non-binary or intersex?

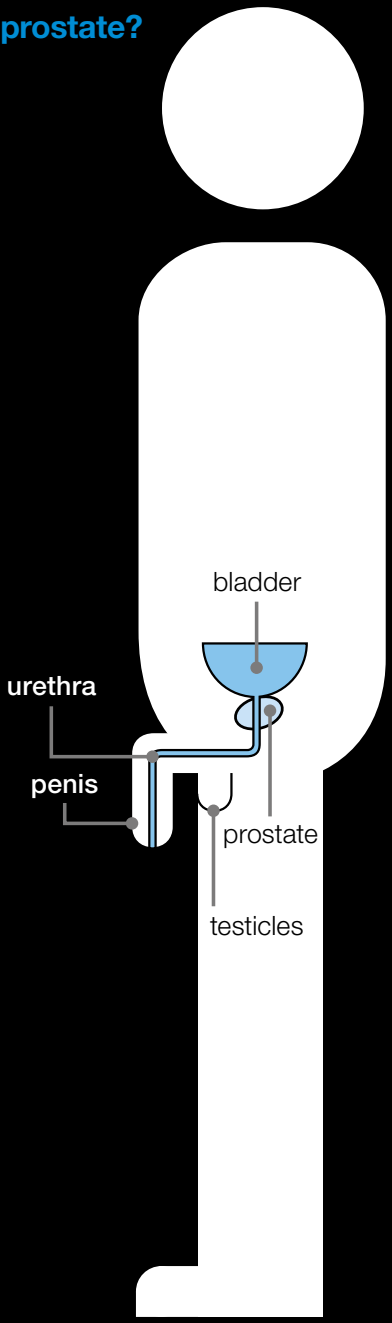
The information in this booklet has been developed based on guidance and evidence in men. If you are a trans woman, male-assigned non-binary or intersex, some of this information is still relevant to you – but your experience may be slightly different. For more information visit **prostatecanceruk.org/trans-women**

* A trans woman is someone who was assigned male at birth but identifies as a woman. Trans women can develop prostate problems, even if they have taken hormones. The prostate is not removed during genital reconstructive surgery.

** A non-binary person may not identify as a man or a woman.

*** An intersex person may have both male and female sexual characteristics and so might have a prostate.

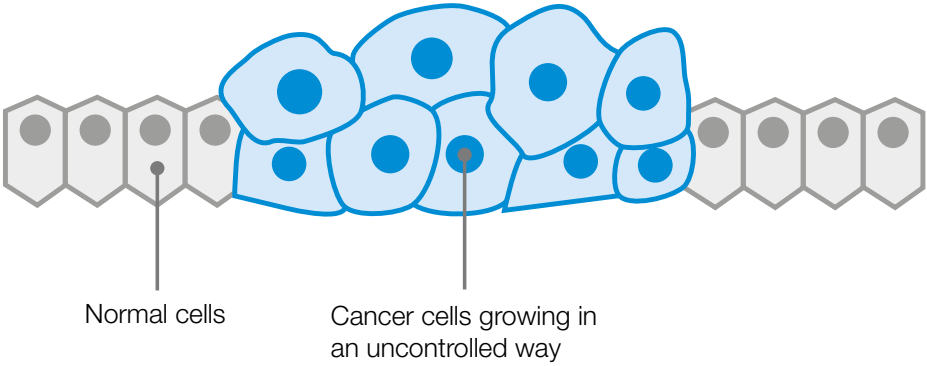
Where is the prostate?



What is prostate cancer?

Normally, the growth of all cells is carefully controlled in the body. As cells grow old and die, new cells take their place. Cancer can develop when cells start to grow in an uncontrolled way. If this happens in your prostate, you have prostate cancer.

How cancer develops



Prostate cancer is the most commonly diagnosed cancer in the UK. About 1 in 8 men in the UK will be diagnosed with prostate cancer at some point in their lives.

Most prostate cancer grows slowly or doesn't grow at all. It may never cause any problems or shorten a man's life. But some prostate cancer does grow quickly and is more likely to spread to other parts of the body and cause problems. This needs treatment to help prevent it spreading.

Most men with early prostate cancer don't have any symptoms. One reason for this is the way the cancer grows. You'll usually only get early symptoms if the cancer grows near the tube you urinate through (the urethra) and presses against it, changing the way you urinate (wee). But because prostate cancer usually starts to grow in a different part of the prostate, early prostate cancer doesn't often press on the urethra and cause symptoms.

Some men have tests for prostate cancer because they had urinary problems. But urinary problems are usually caused by other things that aren't cancer.

Find out more about prostate cancer by watching our online video, **Understanding your prostate cancer** at **prostatecanceruk.org/just-diagnosed-video**

How is prostate cancer diagnosed?

Prostate cancer is diagnosed using a number of tests, which we describe on the following pages. You might have already had some of these, but you may need further tests to find out whether the cancer has spread and how aggressive it is (how likely it is to grow and spread). You may not need to have all of these tests, and you might not have them in this order.

Read more about these tests in our fact sheet, **How prostate cancer is diagnosed**.

PSA test

This is a blood test that measures the amount of prostate specific antigen (PSA) in your blood. PSA is a protein produced by normal cells in your prostate and also by prostate cancer cells. It's normal to have a small amount of PSA in your blood, and the amount rises as you get older. Read more in our booklet, **Understanding the PSA test: A guide for men concerned about prostate cancer**.

Digital rectal examination (DRE)

This is where the doctor or nurse feels your prostate through the wall of the back passage (rectum). They'll wear gloves and put some gel on their finger to make it more comfortable. They'll feel your prostate for any hard or lumpy areas and to get an idea of its size.

MRI (magnetic resonance imaging) scan

This creates a detailed picture of your prostate and the surrounding tissues. You may have had an MRI scan to help your doctor decide whether you needed a biopsy (see page 10), or to decide which

areas of the prostate to take the biopsy samples from. An MRI scan may also be used after a biopsy has found cancer, to see if the cancer has spread outside the prostate.

Prostate biopsy

This involves using a thin needle to take small pieces of tissue from the prostate. The tissue is then looked at under a microscope to check for cancer.

CT (computerised tomography) scan

This can show whether the cancer has spread outside the prostate, for example to the lymph nodes or nearby bones. Lymph nodes are part of your immune system and are found throughout your body.

Bone scan

This can show whether any cancer cells have spread to your bones. A small amount of a safe radioactive dye is injected into a vein in your arm before you have the scan. If there is any cancer in the bones, the dye will collect in these areas and show up on the scan.

PET (positron emission tomography) scan

At some hospitals, you may be offered a PET scan. This can be used to check if cancer has spread to the bones, lymph nodes and other tissues. But it's more commonly used to see if your cancer has come back after treatment, rather than when you are first diagnosed.

What do my test results mean?

Your doctor will use all your test results to find out if the cancer has spread and how quickly it is growing. Ask your doctor or nurse to explain your test results if you don't understand them. You can also read more in our fact sheet, **How prostate cancer is diagnosed**, or speak to our Specialist Nurses.

PSA level

It's normal to have a small amount of PSA in your blood, and the amount rises as you get older. Other things can raise your PSA level, including prostate cancer. But not all men with prostate cancer have a raised PSA level. You may have had a PSA test showing your PSA was raised, and then had other tests to diagnose your prostate cancer.

MRI scan results

A specialist called a radiologist looks at your MRI scan images. They specialise in diagnosing health problems using X-rays and scans. Your results will be used to decide if you need a biopsy and can help your doctor to decide what areas of the prostate to take biopsy samples from. If you have an MRI scan after a biopsy, the images will be used to see if your cancer has spread outside your prostate.

Biopsy results

Biopsy samples are looked at under a microscope to check for any cancer cells. Your doctor will be sent a pathology report with the results. The results will show if any cancer was found. They'll also show how many biopsy samples contained cancer and how much cancer was in each sample.

You might be sent a copy of the pathology report. And you can ask to see copies of letters between the hospital and your GP. If you have trouble understanding any of the information, ask your doctor to explain it or speak to our Specialist Nurses.

Your biopsy results will show how aggressive the cancer is (how likely it is to grow and spread). You might hear this called your Gleason grade, Gleason score or grade group.

Gleason grade

Prostate cells seen under the microscope have different patterns, depending on how quickly they're likely to grow. The pattern is given a grade from 1 to 5 – this is called the Gleason grade. Grades 1 and 2 are no longer included on pathology reports, as they are similar to normal cells. If you have prostate cancer, you will have Gleason grades of 3, 4 or 5. The higher the grade, the more likely the cancer is to grow and spread.

Gleason score

There may be more than one grade of cancer in the biopsy samples. Your Gleason score is worked out by adding together two Gleason grades.

The first is the most common grade in all the samples. The second is the highest grade of what's left. When these two grades are added together, the total is called the Gleason score.

Gleason score = the most common grade + the highest other grade in the samples

For example, if the biopsy samples show that:
- most of the cancer seen is grade 3, and
- the highest grade of any other cancer seen is grade 4, then
- the Gleason score will be 7 (3 + 4).

A Gleason score of 4 + 3 shows the cancer is more aggressive than a score of 3 + 4 as there is more grade 4 cancer. If your Gleason score is made up of two of the same Gleason grades, such as 3 + 3, this means that no other Gleason grade was seen in the biopsy samples.

If you have prostate cancer, your Gleason score will be between 6 (3 + 3) and 10 (5 + 5).

Grade group

Your doctor might also talk about your 'grade group'. This is a newer system for showing how aggressive your prostate cancer is likely to be. Your grade group will be a number between 1 and 5 (see table on page 14).

What does the Gleason score or grade group mean?

The higher your Gleason score or grade group, the more aggressive the cancer and the more likely you are to need treatment to stop the cancer spreading. The table on page 14 describes the different Gleason scores and grade groups that can be given after a prostate biopsy. This is just a guide. Your doctor or nurse will talk you through what your results mean.

Grade group	Gleason score	Description
1	6 (3 + 3)	All of the cancer cells found in the biopsy look likely to grow very slowly, if at all.
2	7 (3 + 4)	Most of the cancer cells found in the biopsy look likely to grow very slowly. There are some cancer cells that look likely to grow at a moderately quick rate.
3	7 (4 + 3)	Most of the cancer cells found in the biopsy look likely to grow at a moderately quick rate. There are some cancer cells that look likely to grow very slowly.
4	8 (3 + 5)	Most of the cancer cells found in the biopsy look likely to grow very slowly. There are some cancer cells that look likely to grow quickly.
	8 (4 + 4)	All of the cancer cells found in the biopsy look likely to grow at a moderately quick rate.
	8 (5 + 3)	Most of the cancer cells found in the biopsy look likely to grow quickly. There are some cancer cells that look likely to grow very slowly.
5	9 (4 + 5)	Most of the cancer cells found in the biopsy look likely to grow at a moderately quick rate. There are some cancer cells that look likely to grow quickly.
	9 (5 + 4)	Most of the cancer cells found in the biopsy look likely to grow quickly. There are some cancer cells that look likely to grow at a moderately quick rate.
	10 (5 + 5)	All of the cancer cells found in the biopsy look likely to grow quickly.

What type of prostate cancer do I have?

Your doctor will look at your biopsy results to see what type of prostate cancer you have.

For most men who are diagnosed, the type of prostate cancer is called adenocarcinoma or acinar adenocarcinoma – you might see this written on your biopsy report. There are other types of prostate cancer that are very rare. If you're told you have a rare type of prostate cancer, read more on our website at **prostatecanceruk.org/rare** or speak to our Specialist Nurses.

What stage is my cancer?

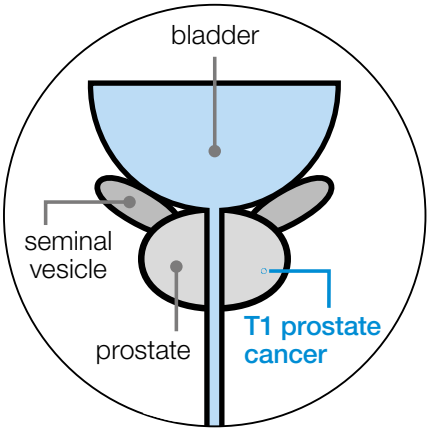
You may need scans to find out the stage of your cancer – in other words, how far it has spread. Your doctor or nurse will let you know about any scans you need to have. The results should help you and your doctor decide which treatments might be suitable for you.

You might not need any further scans if your PSA is low and your previous results suggest that the cancer is unlikely to have spread.

The most common way to record the stage of your cancer is the TNM (Tumour-Nodes-Metastases) system.

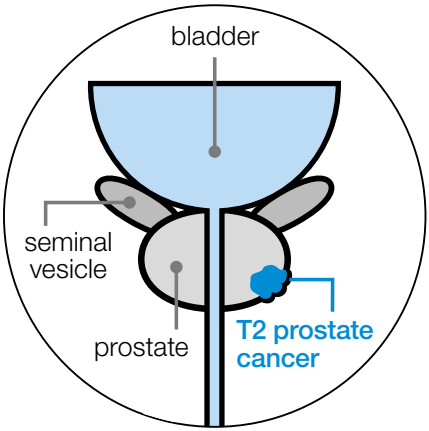
T stage

The T stage shows how far the cancer has spread in and around the prostate. A DRE or MRI scan is usually used to find out the T stage, and sometimes a CT scan.



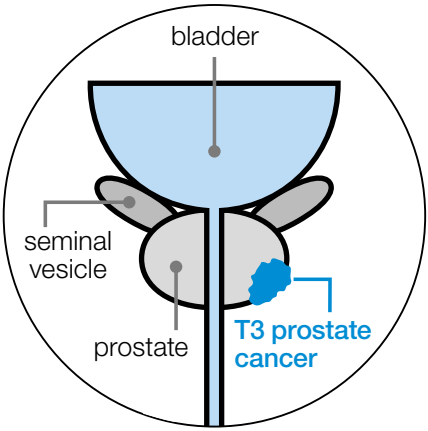
T1

The cancer can't be felt during a DRE or seen on scans, and can only be seen under a microscope.

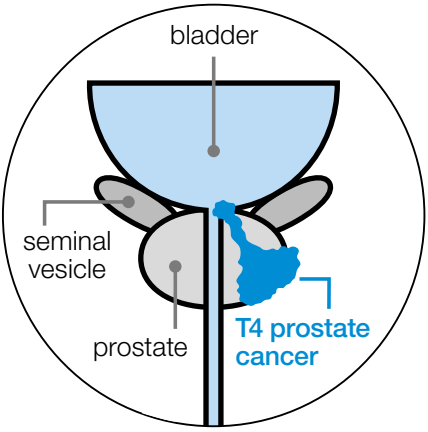


T2

The cancer can be felt during a DRE or seen on scans, but is still contained inside the prostate.



T3
The cancer can be felt during a DRE or seen breaking through the outer layer (capsule) of the prostate. It may also have spread to the seminal vesicles.



T4
The cancer has spread to nearby organs, such as the bladder, back passage or pelvic wall.

N stage

The N stage shows whether the cancer has spread to the lymph nodes near the prostate. The lymph nodes near your prostate are a common place for prostate cancer to spread to. An MRI or CT scan is used to find out your N stage.

The possible N stages are:

NX The lymph nodes were not looked at, or the scans were unclear.
N0 No cancer can be seen in the lymph nodes.
N1 The lymph nodes contain cancer.

M stage

The M stage shows whether the cancer has spread (metastasised) to other parts of the body, such as the bones. A bone scan is usually used to find out your M stage.

The possible M stages are:

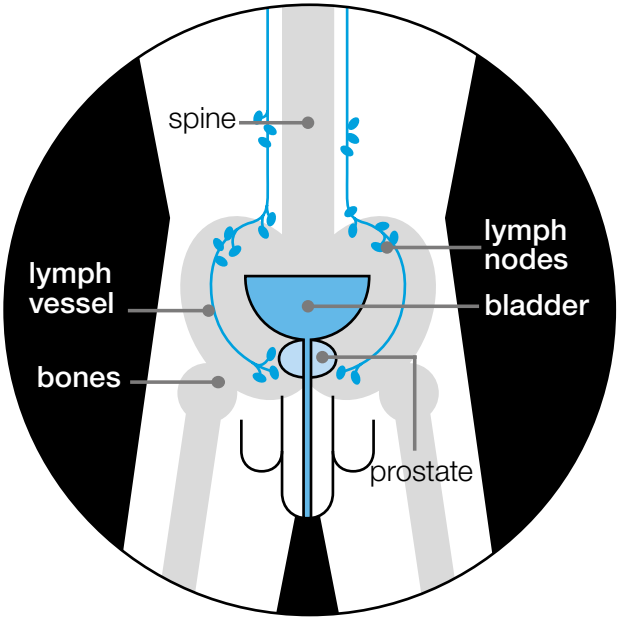
MX The spread of the cancer wasn't looked at, or the scans were unclear.

M0 The cancer hasn't spread to other parts of the body.

M1 The cancer has spread to other parts of the body.

How prostate cancer spreads

Prostate cancer cells can move to other parts of the body through the blood. Or they can spread to nearby lymph nodes and then travel through lymph vessels. Lymph nodes and lymph vessels are part of your lymphatic system, and are found throughout your body.



What does my stage mean?

Your TNM stage is used to work out if your cancer is localised, locally advanced or advanced.

Stage	Description	T stage	N stage	M stage
Localised (early)	Cancer that's contained inside the prostate.	T1 or T2	N0 or NX	M0 or MX
Locally advanced	Cancer that's started to break out of the prostate, or has spread just outside it.	T1 or T2	N1	M0
		T3 or T4	N0 or N1	M0
Advanced (metastatic)	Cancer that's spread from the prostate to other parts of the body.	Any T stage	Any N stage	M1

Localised prostate cancer

Localised prostate cancer is cancer that hasn't spread outside the prostate. You may also hear it called early prostate cancer. Many localised cancers are not aggressive and grow slowly or not at all. They may not cause any problems or shorten your life.

Slow-growing localised prostate cancer may not need to be treated and can often be monitored instead. But some localised cancers may grow more quickly and spread to other parts of the body. These cancers are more likely to cause problems and need to be treated. Treatments for localised prostate cancer usually aim

to get rid of the cancer. What you are offered will depend on how likely your cancer is to grow and spread outside your prostate (see below).

Locally advanced prostate cancer

Locally advanced prostate cancer is cancer that's started to break out of the prostate, or has spread to the area just outside it. It can spread to the seminal vesicles, bladder, back passage, pelvic wall or lymph nodes near your prostate. You might have treatment to get rid of the cancer or to keep it under control. Your treatment options will depend on how far the cancer has spread. Read more in our fact sheet, **Locally advanced prostate cancer**.

If you have localised or locally advanced prostate cancer, your doctor may talk to you about the risk of your cancer spreading outside the prostate. To work out your risk, your doctor will look at your PSA level, your Gleason score and the T stage of your cancer. These three factors will place you in one of five categories that form the **Cambridge Prognostic Group (CPG)**. This helps your doctor decide which treatment options are suitable for you, based on your risk.

The five CPG categories are described below. If you are have any questions about your GPG speak to your doctor or specialist nurse.

CPG 1

- Gleason score 6 (grade group 1), **and**
- PSA less than 10 ng/ml, **and**
- T stage of 1 or 2.

This means your cancer is likely to grow very slowly and very unlikely to spread. Your treatment options may include active surveillance, surgery, or radiotherapy with hormone therapy.

CPG 2

You will be in this group if you have a T stage of 1 or 2 and **one** of the following:

- Gleason score of 3 + 4 = 7 (grade group 2), **or**
- PSA 10 to 20 ng/ml.

This means your cancer is likely to grow slowly and unlikely to spread. Your treatment options may include active surveillance, surgery, or radiotherapy with hormone therapy.

CPG 3

- Gleason score 3 + 4 = 7 (grade group 2), **and**
- PSA 10 to 20 ng/ml, **and**
- T stage of 1 or 2.

You will also be in this group if you have:

- Gleason 4 + 3 = 7 (grade group 3), **and**
- T stage of 1 or 2.

This means there is a medium (intermediate) risk of your cancer growing and spreading. Your treatment options may include surgery, or radiotherapy with hormone therapy. Active surveillance may also be an option if you don't want or can't have treatment.

CPG 4

You will be in this group if you have only one of the following:

- Gleason score 8 (grade group 4), **or**
- PSA more than 20 ng/ml, **or**
- T stage 3.

This means that there is a high risk of your cancer growing quickly and spreading out of your prostate. Treatment options may include surgery, or radiotherapy with hormone therapy.

CGP 5

You will be in this group if you have two or more of the following:

- Gleason score 8 (grade group 4), **and**
- PSA more than 20 ng/ml, **and**
- T stage 3.

You will also be in this group if you have **one** of the following:

- Gleason score 9 to 10 (grade group 5), **or**
- T stage 4.

This means that there is a high risk of your cancer growing quickly and it's very likely to spread. Treatment options may include surgery, or radiotherapy with hormone therapy.

Low, medium or high risk prostate cancer

When talking to your doctor about the risk of your cancer spreading, they may use the old system, and refer to your cancer as being low, medium or high risk. You should ask your doctor about your CPG category and what this means in terms of your treatment options.

Advanced prostate cancer

Advanced prostate cancer is cancer that has spread from the prostate to other parts of the body. It's also called metastatic prostate cancer. Prostate cancer can spread to any part of the body, but it most commonly spreads to the bones and lymph nodes.

It's not possible to cure advanced prostate cancer, but treatments can keep it under control, sometimes for several years.

Advanced prostate cancer can cause symptoms, such as fatigue (extreme tiredness), pain in the back, hips or pelvis, and problems urinating. There are treatments available to help manage these symptoms. Read more in our fact sheet, **Advanced prostate cancer**.

What are my treatment options?

Your treatment options will depend on a number of things, including:

- the stage of your cancer (whether it is localised, locally advanced or advanced) (see page 19)
- how likely your cancer is to grow and spread
- your general health.

We've included a summary of the main treatments for prostate cancer on the next page. Some of these treatments may not be suitable for you, so talk to your doctor or nurse about which ones you can have. There's more information about choosing a treatment on page 34.

Ask your doctor or nurse to mark which treatments might be suitable for you. Read more about all of the available treatments on the following pages.

I'm pretty sure I would have had this treatment anyway, but I think I would have benefited from learning more about the options available.

A personal experience

Most common treatment options

Localised prostate cancer

- ☐ Active surveillance
- ☐ Watchful waiting
- ☐ Surgery (radical prostatectomy)
- ☐ External beam radiotherapy
- ☐ Brachytherapy (either permanent seed or high dose-rate)
- ☐ High-intensity focused ultrasound, but this isn't very common
- ☐ Cryotherapy, but this isn't very common

Locally advanced prostate cancer

- ☐ External beam radiotherapy with hormone therapy (and sometimes with brachytherapy)
- ☐ Hormone therapy alone
- ☐ Surgery (radical prostatectomy), usually with radiotherapy or hormone therapy, and sometimes with both
- ☐ Watchful waiting

Advanced prostate cancer

- ☐ Chemotherapy with hormone therapy
- ☐ Hormone therapy alone
- ☐ Further treatments to control advanced prostate cancer
- ☐ Treatments to manage the symptoms of advanced prostate cancer

Active surveillance

This is a way of monitoring localised prostate cancer that's likely to be slow-growing. The aim is to avoid or delay unnecessary treatment in men with localised prostate cancer that is unlikely to spread. This means you can avoid or delay the side effects of treatment.

Active surveillance involves monitoring your cancer with regular tests, including PSA tests, MRI scans and biopsies, rather than treating it straight away. Ask your doctor or nurse what to expect. The tests aim to find any changes that suggest the cancer is growing. If any changes are found, you'll be offered treatment that aims to get rid of the cancer completely, such as surgery, external beam radiotherapy or brachytherapy.

Active surveillance is only an option for men with CPG 1 or 2 localised prostate cancer. It's also sometimes suitable for men with CPG 3 localised prostate cancer, who want to avoid or delay treatment. Read more in our fact sheet, **Active surveillance**.

Watchful waiting

This is a different way of monitoring prostate cancer that isn't causing any problems. The aim is to monitor the cancer and avoid or delay treatment and its side effects.

If you do get symptoms, such as problems urinating or bone pain, you'll be offered hormone therapy to control the cancer and help manage your symptoms, rather than treatment to get rid of the cancer.

Watchful waiting involves having fewer tests than active surveillance. Ask your doctor or nurse what to expect. It's generally suitable for men with other health problems who aren't fit enough

for treatments such as surgery or radiotherapy. It might also be suitable if your prostate cancer isn't likely to cause problems during your lifetime or shorten your life.

Monitoring your cancer

If you're offered active surveillance or watchful waiting, make sure you know which one your doctor is talking about. There are key differences between them. These terms aren't always used in the same way, and some doctors use different names such as 'active monitoring' and 'wait and see'. Ask your doctor to explain exactly what they mean if you're not sure.

Surgery (radical prostatectomy)

This is an operation to remove the whole prostate, including the cancer inside it. Your surgeon will also remove the seminal vesicles – two glands that lie behind the prostate and produce some of the fluid in semen. They may also remove nearby lymph nodes if there is a risk that the cancer has spread there.

There are three types of operation:

- keyhole (laparoscopic) surgery by hand
- robot-assisted keyhole surgery (da Vinci® robot)
- open surgery.

Surgery is usually offered to men with localised prostate cancer who are generally fit and healthy. It may also be an option for some men with locally advanced prostate cancer if the surgeon thinks it's possible to remove all the cancer that has spread outside the prostate. You may also need to have external beam radiotherapy after your surgery.

Side effects can include leaking urine and erection problems. Side effects may improve over time but some men have side effects for longer. There are treatments available to help manage them.

After surgery, you won't be able to ejaculate any semen. But you can still feel the sensation of orgasm. Surgery will affect your ability to have children (fertility). If you're planning on having children, you may be able to store your sperm before the operation for use in fertility treatment.

Read more about surgery, including the side effects, in our fact sheet, **Surgery: radical prostatectomy**.

External beam radiotherapy

This uses high-energy X-ray beams to destroy cancer cells from outside the body. These beams damage the cells and stop them from dividing and growing. External beam radiotherapy treats the whole prostate, and sometimes the area around it.

Radiotherapy is suitable for men with localised prostate cancer, who will often have it with hormone therapy. Radiotherapy with hormone therapy is also the standard treatment for men with locally advanced prostate cancer. You may have hormone therapy for six months if you have localised prostate cancer, and for up to three years if you have locally advanced prostate cancer.

Radiotherapy isn't a standard treatment for men with advanced prostate cancer. But if you've just been diagnosed with advanced prostate cancer, you may be offered external beam radiotherapy alongside your main treatment. This isn't suitable for all men and will depend on how far your cancer has spread. Read more in our fact sheet, **Radiotherapy for advanced prostate cancer**.

Side effects can include problems urinating, bowel problems such as passing loose or watery bowel movements (diarrhoea), erection problems, and extreme tiredness (fatigue). Side effects can develop during treatment and may get better with time. But for some men they can be long-term. And some men may develop side effects several months or years after having radiotherapy. There are treatments available to help manage side effects.

Read more about external beam radiotherapy, including the side effects, in our fact sheet, **External beam radiotherapy**.

Brachytherapy

This is a type of internal radiotherapy. There are two types of brachytherapy – permanent seed brachytherapy and high dose-rate brachytherapy.

- **Permanent seed brachytherapy**, also called low dose-rate brachytherapy, involves putting tiny radioactive seeds into the prostate. The seeds release radiation for 8 to 10 months but stay in the prostate forever. This may be an option for men with localised prostate cancer.

- **High dose-rate (HDR) brachytherapy**, also called temporary brachytherapy, involves putting thin, hollow needles into the prostate. A source of radiation is then passed down the needles into the prostate for a few minutes to destroy cancer cells. The source of radiation is then removed, so no radiation is left inside your body. It's less common than permanent seed brachytherapy but can be used to treat localised prostate cancer that is likely to grow quickly, and sometimes locally advanced prostate cancer.

If you have localised or locally advanced prostate cancer, you may have brachytherapy together with external beam radiotherapy to give an extra dose of radiation to the prostate.

You might have hormone therapy to shrink the prostate for a few months before starting brachytherapy.

Side effects can include problems urinating, erection problems, and extreme tiredness (fatigue). Men who have brachytherapy may also get bowel problems, although these tend to be mild. There are treatments available to help manage these side effects.

Read more about brachytherapy, including the side effects, in our fact sheets, **Permanent seed brachytherapy** and **High dose-rate brachytherapy**.

High-intensity focused ultrasound (HIFU)

HIFU uses ultrasound to heat and destroy cancer cells in the prostate. It is newer than some other treatments for prostate cancer, so we don't know how well it works in the long term (after 10 years). Because of this, it's only available in specialist centres in the UK or as part of a clinical trial.

HIFU can be used to treat localised prostate cancer. It may also be used to treat locally advanced prostate cancer that has only just started to break out of the prostate, but this is less common. It can also be used to treat cancer that has come back after external beam radiotherapy.

Side effects can include urinary problems and erection problems. These side effects may improve over time, and there are ways to manage them.

Read more about HIFU, including the side effects, in our fact sheet, **High-intensity focused ultrasound (HIFU)**.

Cryotherapy

Cryotherapy uses extreme cold to freeze and destroy cancer cells. It's newer than some of the other treatments for prostate cancer, so we don't know as much about the risk of side effects and how well it works in the long term. Because of this, it's only available in specialist centres in the UK or as part of a clinical trial.

Cryotherapy can be used to treat localised prostate cancer and, less commonly, locally advanced prostate cancer that has only just started to break out of the prostate. It can also be used to treat prostate cancer that has come back after treatment with external beam radiotherapy or brachytherapy.

Side effects can include urinary problems and erection problems. These side effects may improve over time, and there are ways to manage them.

Read more about cryotherapy, including the side effects, on our website. Visit **prostatecanceruk.org/cryotherapy**

Hormone therapy

Prostate cancer cells usually need the hormone testosterone to grow. Hormone therapy works by either stopping your body from making testosterone, or by stopping testosterone from reaching the cancer cells.

It will treat all prostate cancer cells, wherever they are in the body. Hormone therapy won't get rid of your prostate cancer, but it can keep the cancer under control, sometimes for several years.

Hormone therapy is often used with external beam radiotherapy to treat localised prostate cancer. It can also be used with external beam radiotherapy to treat locally advanced prostate cancer. Hormone therapy is a standard treatment for advanced prostate cancer. If you've just been diagnosed with advanced prostate cancer, you may be offered chemotherapy and sometimes external beam radiotherapy at the same time as your hormone therapy.

There are three main ways to have hormone therapy for prostate cancer:

- injections or implants
- tablets
- surgery (orchidectomy) to remove the testicles or the parts of the testicles that make testosterone.

The side effects of hormone therapy are usually caused by low testosterone levels. They can include:

- hot flushes
- loss of desire for sex
- problems getting or keeping an erection
- extreme tiredness (fatigue)
- breast swelling or tenderness (gynaecomastia)
- weight gain.

The chances of getting each side effect depend on the type of hormone therapy you're having and how long you have it for. There are ways to manage side effects.

Read more about hormone therapy, including the side effects, in our publications, **Hormone therapy** and **Living with hormone therapy: A guide for men with prostate cancer**.

Chemotherapy

Chemotherapy uses anti-cancer drugs to kill prostate cancer cells, wherever they are in the body. It doesn't get rid of prostate cancer, but it aims to shrink it and slow down its growth.

Chemotherapy is usually only used to treat advanced prostate cancer. It can be used at the same time as hormone therapy in men who have just been diagnosed with advanced prostate cancer. It can also be given to men whose cancer has stopped responding to hormone therapy (see below).

You need to be quite fit to have chemotherapy because the side effects can be harder to deal with if you have other health problems. Side effects include extreme tiredness (fatigue), feeling and being sick, loss of appetite, hair loss, bowel problems, a sore mouth, and being less able to fight off infections. These side effects usually gradually improve after you finish treatment.

Read more about chemotherapy, including the side effects, in our fact sheet, **Chemotherapy**.

Further treatments to control advanced prostate cancer

Hormone therapy, often with chemotherapy, is the standard first treatment for advanced prostate cancer. Over time, it may become less effective, but there are other treatments available that can help control the cancer and help men live longer.

- **More hormone therapy** can help control your cancer. You might be offered types called abiraterone (Zytiga®), enzalutamide (Xtandi®) or apalutamide (Erleada®).
- **More chemotherapy** might be an option if your hormone therapy is no longer working so well.

- **Radium-223 (Xofigo®)** is a type of internal radiotherapy. It can help some men whose cancer has spread to the bones to live longer, and can also help reduce bone pain.
- **Steroids** can stop the body from producing as much testosterone. They may also help improve your appetite and energy levels, and can treat pain.
- **Olaparib (Lynparza®)** is a drug used to treat men who are known to have a BRCA1 or BRCA2 gene change (mutation), and whose hormone therapy is no longer working so well.

Read more in our fact sheet, **Treatment options after your first hormone therapy**.

Treatments to manage the symptoms of advanced prostate cancer

If you've been diagnosed with advanced prostate cancer and have symptoms such as bone pain, there are treatments to manage these.

- **Pain-relieving drugs** can help manage any pain.
- **Radiotherapy** can slow down the growth of the cancer and control symptoms.
- **Drugs called bisphosphonates** can strengthen the bones in men whose bones have been weakened by their prostate cancer or by hormone therapy. Bisphosphonates are also sometimes used to help relieve and prevent further bone pain.

Read more about these in our fact sheets, **Managing pain in advanced prostate cancer**, **Radiotherapy for advanced prostate cancer** and **Bisphosphonates for advanced prostate cancer**.

Clinical trials

A clinical trial is a type of medical research. Clinical trials aim to find new and improved ways of preventing, diagnosing, treating and managing illnesses. You can ask your doctor or nurse if there are any clinical trials you could take part in, or speak to our Specialist Nurses. You can also find details of some clinical trials for prostate cancer at **www.cancerresearchuk.org/trials**

Read more on our website at **prostatecanceruk.org/clinical-trials**

Choosing a treatment

Depending on how far your cancer has spread, you may have a choice of treatments. If so, your doctor or nurse will talk you through your treatment options and help you choose the right type of monitoring or treatment for you. You might not be able to have all of the treatments listed in this booklet. Ask your doctor or nurse which ones are suitable for you.

It's not always easy to make a decision about treatment and there are lots of things to think about. These include:

- how far your cancer has spread (its stage)
- how quickly your cancer may be growing
- the advantages and disadvantages of each treatment, including the possible side effects
- what each treatment involves
- practical things, such as how often you would need to go to hospital, or how far away your nearest hospital is
- your own thoughts about different treatments
- how the treatment you choose now could affect your treatment options in the future, if your cancer comes back or spreads (see page 36)

- your general health
- how long you're expected to live for.

All treatments can have side effects. These will affect each man differently, and you might not get all the possible side effects. It's important to think about how you would cope with the different side effects when choosing a treatment.

Make sure you have all the information you need, and give yourself time to think about which treatment is right for you. Your doctor or nurse can help you think about the advantages and disadvantages.

It can be hard to take everything in when you've just been diagnosed. And you may forget exactly what was said. It can help to write down any questions you might want to ask at your next appointment. And to take someone with you to appointments, such as your partner, friend or family member.

It can also help to write down or record what's said to help you remember it. You have the right to record your appointment because it's your personal data. Let your doctor or nurse know why you are recording them, as not everyone is comfortable being recorded.

Support when choosing a treatment

There should be a clinical nurse specialist (CNS) in the room when you get your test results. You should be given their name and telephone number to get in touch if you have any questions.

You can also call our Specialist Nurses on 0800 074 8383. They can help with any questions you have, or put you in touch with other men who have been diagnosed with prostate cancer. Page 44 has more information on these and other support services available to you and your loved ones.

I think the most confusing bit was being given a choice of treatments – you sort of expect to be told what the treatment will be, not have to decide yourself. It's a lot to take in.

A personal experience

If you need further treatment

If your cancer comes back after treatment that aimed to get rid of it, the first treatment you have had may affect which treatments you can have in the future.

Some of these treatments may not be suitable for you, so speak to your doctor or nurse about your own situation.

The table below shows which treatments may be possible after your first treatment. You might hear these called second-line treatments.

First treatment for prostate cancer	Second-line treatments that may be available
Surgery (radical prostatectomy)	• Radiotherapy to the prostate bed (with or without hormone therapy) • Hormone therapy alone
External beam radiotherapy	• Hormone therapy • High-intensity focused ultrasound (HIFU) • Cryotherapy • Brachytherapy • Surgery
Permanent seed brachytherapy or high dose-rate (HDR) brachytherapy	• Hormone therapy • External beam radiotherapy • More brachytherapy • Surgery • Cryotherapy • HIFU, but this is rare and only offered in specialist centres
High-intensity focused ultrasound (HIFU)	• More HIFU • External beam radiotherapy • Cryotherapy • Hormone therapy • Surgery, but this is rare
Cryotherapy	• More cryotherapy • HIFU • External beam radiotherapy • Hormone therapy • Very rarely, surgery

If your prostate cancer has spread to other parts of your body, you might be offered chemotherapy at the same time as hormone therapy. See page 31 for more information.

Read more about treatments that are available if your cancer comes back in our booklet, **If your prostate cancer comes back: A guide to treatment and support**.

Dealing with prostate cancer

Some men say being diagnosed with prostate cancer changes the way they think and feel about life. You might feel scared, worried, stressed, helpless or even angry.

At times, lots of men with prostate cancer get these kinds of thoughts and feelings. But there's no 'right' way to feel and everyone reacts in their own way.

This section suggests some things you can do to help yourself and people who can help. Families can also find this a difficult time and they may need support and information too. They may want to read our booklet, **When you're close to someone with prostate cancer: A guide for partners and family.**

> Everyone's experience of cancer, whether you are the patient or the carer, is very, very unique and I don't think anybody can tell you how you should behave.
>
> A personal experience

Am I going to die?

You might want to know how prostate cancer will affect you and whether you are likely to die from prostate cancer. This is sometimes called your outlook or prognosis. Most prostate cancer grows slowly

and may never cause any problems or shorten a man's life. So having prostate cancer doesn't necessarily mean that you'll die from it.

No one can tell you exactly what will happen, as this will depend on many things, including the following.

- **Your stage.** If you are diagnosed with localised prostate cancer, you may not need treatment or you will have treatment that aims to get rid of the cancer. If you are diagnosed with locally advanced prostate cancer, you may have treatment that aims to get rid of the cancer or keep it under control. If you are diagnosed with advanced prostate cancer, the treatment won't cure your cancer but it can help to keep it under control.
- **Your Gleason score or grade group.** The higher your Gleason score or grade group, the more aggressive the cancer, and the more likely it is to spread (see page 12).
- **Your PSA level.** After you've been diagnosed, PSA tests are a good way of monitoring your prostate cancer and seeing how you're responding to treatment.
- **Your treatment options.** You may be able to have treatment aimed at getting rid of the cancer. Or you may be able to have treatment to keep the cancer under control.
- **How successful your treatment is.** Your treatment may be successful at getting rid of your cancer or keeping it under control. But for some men, treatment may not work as well as expected.
- **Your health.** If you have other health problems, you may have fewer treatment options. And other health conditions may cause more problems than your prostate cancer.

Most men are diagnosed at a stage where treatment can either get rid of their cancer, or keep it under control. But a small number of men are diagnosed with cancer that is already very advanced. If your doctor has explained that this is the case you may want to read our information on what to expect at **prostatecanceruk.org/advanced-prostate-cancer**

For more information about the outlook for men with prostate cancer, visit **www.cancerresearchuk.org**. The figures they provide are a general guide and they cannot tell you exactly what will happen to you. Speak to your doctor or nurse about your own situation.

Talking to your family

You might be worried about telling your friends and family that you have cancer. You might be concerned about how they'll react or if you'll upset them.

It can be difficult to know how to start a conversation. Try to find a quiet place and explain to them that you have prostate cancer. You might find it helpful to show them this booklet.

Ask them if they have any questions. If you don't know the answers, you could write down their questions and ask your doctor or nurse at your next appointment.

If you don't feel able to tell your friends and family, you could ask someone you trust to tell people for you.

Macmillan Cancer Support have information that can help you work out where to start and make these conversations a bit easier. It includes information about talking to children.

Talking to male family members about their own risk of prostate cancer

If you have brothers or sons, you might want to talk to them about their own risk of prostate cancer. This is because men are two and a half times more likely to get prostate cancer if their father or brother has had it, compared to someone who doesn't have any relatives who have been diagnosed with prostate cancer. They might want to talk to their doctor or nurse about their situation, particularly if they are 45 or over. Read more about this in our booklet, **Know your prostate: A guide to common prostate problems**.

How can I help myself?

Everyone has their own way of dealing with prostate cancer, but you may find some of the following suggestions helpful.

Look into your treatment options

Find out about the different treatments you could have. Bring a list of questions to your doctor or nurse. And ask about any side effects so you know what to expect and how to manage them. This will help you decide what's right for you.

Talk to someone

Share what you're thinking – find someone you can talk to. It could be someone close or someone trained to listen, like a counsellor or your doctor or nurse. People involved in your care should be able to help with any questions or concerns you might have.

Set yourself some goals

Set yourself goals and plan things to look forward to – even if they're just for the next few weeks or months.

Look after yourself

Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like breathing exercises or listening to music. If you're having difficulty sleeping, talk to your doctor or nurse.

Eat a healthy, balanced diet

We don't know for sure whether any specific foods have an effect on prostate cancer. But eating well can help you stay a healthy weight, which may be important for men with prostate cancer. It's also good for your general health and can help you feel more in control. Certain changes to your diet may also help with some side effects of treatment. For more information, read our fact sheet, **Diet and physical activity for men with prostate cancer**.

Be as active as you can

Keeping active can improve your physical strength and fitness, and can lift your mood. We don't know for sure if physical activity can help slow the growth of prostate cancer. But it can help you stay a healthy weight, which may help to lower your risk of advanced prostate cancer. Physical activity can also help with some side effects of treatment. Even a small amount can help. Take things at your own pace. Read more in our fact sheet, **Diet and physical activity for men with prostate cancer**.

Get more tips on how to look after yourself from Macmillan Cancer Support, Maggie's, Penny Brohn UK, or your nearest cancer support centre. You can also find more ideas in our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**.

Check out our online 'How to manage' guides
Our interactive guides have lots of practical tips to help you manage symptoms and side effects. We have guides on fatigue, sex and relationships, urinary problems, and advanced prostate cancer. Visit **prostatecanceruk.org/guides**

Who else can help?

Your medical team

It could be useful to speak to your nurse, doctor, GP or someone else in your medical team. They can explain your diagnosis, treatment and side effects, listen to your concerns, and put you in touch with others who can help.

Trained counsellors

Many hospitals have counsellors or psychologists who specialise in helping people with cancer. You can also refer yourself for counselling on the NHS, or you could see a private counsellor. To find out more, visit **www.nhs.uk/counselling** or contact the British Association for Counselling & Psychotherapy.

Spiritual support

You might begin to think more about spiritual beliefs as a result of having prostate cancer. You could get spiritual support from your friends, family, religious leader or faith group.

"I found talking on the phone to an experienced Prostate Cancer UK nurse very helpful.

A personal experience

Our Specialist Nurses

Our Specialist Nurses can help with any questions and explain your diagnosis and treatment options. They have time to listen, in confidence, to any concerns you or those close to you have.

Our one-to-one support service

This is a chance to speak to someone who's been there and understands what you're going through. They can share their experiences and listen to yours. You can discuss whatever's important to you. We'll try to match you to someone with similar experiences.

Our online community

Our online community is a place to talk about whatever's on your mind – your questions, your ups and your downs. Anyone can ask a question or share an experience.

Support groups

At support groups, men get together to share their experiences of living with prostate cancer. Many groups also hold meetings online. Some groups are run by health professionals, others by men themselves.

> **There is nothing like talking to someone who has been there.**
>
> A personal experience

Our fatigue support

Fatigue is a common symptom of prostate cancer, and a side effect of some treatments. Our Specialist Nurses can talk to you in depth about your experiences of fatigue, and the impact it's having on your day-to-day life. They can also discuss ways to help you better manage your fatigue, such as behaviour and lifestyle changes.

To find out more about any of these services, visit **prostatecanceruk.org/get-support** or call our Specialist Nurses on 0800 074 8383.

Practical issues

You might need to make decisions about things like work and money. Read more about this in our booklet, **Living with and after prostate cancer: A guide to physical, emotional and practical issues**.

Free prescriptions

If you live in England and are having treatment for cancer, including treatments for symptoms or side effects, you are entitled to free prescriptions. You'll need to apply for a medical exemption certificate. Ask your doctor for an FP92A form. Once you have filled out the form, your doctor will need to sign it, and the certificate will be sent to you. You will need to take the certificate with you whenever you collect a prescription. You can find out more about free prescriptions on the NHS website.

If you live in Scotland, Wales or Northern Ireland, all prescriptions are free.

List of medical words

Gleason grade

When prostate cells are seen under the microscope, they have different patterns, depending on how quickly they're likely to grow. The pattern is given a grade from 1 to 5 – this is called the Gleason grade. If you have prostate cancer, you will have Gleason grades of 3, 4 or 5 (see page 12).

Gleason score

This is worked out by adding together two Gleason grades. The first is the most common grade in all the samples. The second is the highest grade of what's left. If you have cancer, the higher the Gleason score, the more likely the cancer is to grow and spread outside the prostate (see page 12).

Lymph nodes

These are part of your immune system and are found throughout your body. Lymph nodes are sometimes called lymph glands. The lymph nodes near the prostate are a common place for prostate cancer to spread to.

Metastasis

The spread of prostate cancer cells from the prostate to other parts of the body. Cancer that has spread may be called advanced cancer, metastases, mets, secondary cancers, or secondaries. A cancer that has spread is said to have metastasised.

Oncology department

The hospital department that deals with the diagnosis and treatment of cancer. An oncologist is a doctor who specialises in cancer treatments other than surgery, such as radiotherapy or chemotherapy. There will usually be an oncologist in your team of health professionals.

Prostate specific antigen (PSA)

A protein produced by normal cells in the prostate, and also by prostate cancer cells. It's normal for all men to have a small amount of PSA in their blood. A raised PSA level can be caused by a number of things including age, a urine infection, an enlarged prostate and prostate cancer.

Seminal vesicles

Two glands located behind the prostate and bladder that produce some of the fluid in semen.

Urology department

The hospital department that deals with the diagnosis and treatment of diseases of the urinary system, including prostate cancer. Urologists are surgeons who operate on the prostate. There will usually be a urologist in your team of health professionals.

Uro-oncology

The diagnosis and treatment of cancers of the urinary system, including prostate cancer.

What are my test results?

Use this section with your doctor or nurse to write down your test results and appointment dates.

PSA level at diagnosis:

Number of biopsy samples taken:

Number of biopsy samples that contain cancer:

Gleason score:

Grade group:

T stage at diagnosis (if known):

N stage at diagnosis (if known):

M stage at diagnosis (if known):

Date of MRI scan (if needed):

Results of MRI scan:

Date of CT scan (if needed):

Results of CT scan:

Date of bone scan (if needed):

Results of bone scan:

My cancer is (tick one):

- ☐ **localised** – contained inside the prostate
- ☐ **locally advanced** – starting to break out of the prostate or spread to the area just outside it
- ☐ **advanced** – spread from the prostate to other parts of the body

Treatment plan:

My next appointments are with my (tick those that apply):

- ☐ urologist
- ☐ specialist nurse
- ☐ oncologist
- ☐ other.

You can write down details of future appointments on page 56.

Contact your doctor or nurse at any time if you have any questions or concerns. There will usually be one person who is your main contact – you might hear them called your key worker. You can also speak to our Specialist Nurses.

When I was first diagnosed I found it extremely helpful to fill in the details of the diagnosis. It also helped me to ask the right questions.

A personal experience

Who are my team members?

Use this space to write down the names and contact details of the health professionals who will be involved in your care. You may hear them called your multi-disciplinary team (MDT). They will discuss your individual diagnosis and agree on which treatment options would be suitable for you.

We've listed the health professionals who are likely to be most involved in your care, but you might not see all of them. You're likely to meet more of them later on when you begin treatment or have check-ups.

Specialist nurse

You may have a urology, uro-oncology or prostate cancer specialist nurse. You may hear them called a clinical nurse specialist (CNS). They can answer any questions you may have, and might carry out some of your tests, treatments and follow-up care.

Name:

Telephone:

Notes:

Main contact (key worker)

Your main point of contact might be called your key worker. This could be your specialist nurse or another health professional. They will help to co-ordinate your care, guide you to the appropriate team member and help you get information.

Name:

Telephone:

Notes:

Consultant urologist

This type of doctor specialises in the urinary and reproductive systems. Urologists are surgeons.

Name:

Telephone:

Notes:

Consultant oncologist

This type of doctor specialises in cancer treatments other than surgery, such as radiotherapy.

Name:

Telephone:

Notes:

Other health professionals

You can write down contact details of other health professionals in the space below.

General practitioner (GP):

Practice nurse:

Other health professionals:

Our Specialist Nurses: 0800 074 8383

Your nearest local support group:

You can find out about your nearest local support group from your nurse, or on our website at **prostatecanceruk.org/support-groups**

Questions to ask your doctor or nurse

Which treatments are available to me?

Are there any clinical trials I could take part in?

How long do I have to decide on my treatment?

Will my treatment aim to get rid of the cancer or to control it?

What are the side effects of the treatment?

What support is available if I do get side effects?

What are the chances of the treatment being successful?

What happens if the cancer comes back again?

What check-ups will I have after treatment?

Who can I contact if I have questions or concerns?

Appointment diary

You can fill in this diary before and after your appointments, to help you get the most out of them. You might want to photocopy these pages so you have enough copies to last you for a while.

Date of appointment:

Fill in before your appointment

How I've been feeling – you can include physical things (for example, side effects of treatment) as well as emotional things.

Things I want to talk about at my appointment:

- ☐ urinary problems
- ☐ sexual problems
- ☐ bowel problems
- ☐ fatigue problems
- ☐ emotional or mood problems
- ☐ diet
- ☐ physical activity
- ☐ work and finances

Your doctor or nurse may not have time to talk about all of these things, so think about what is most important to you. You can also call our Specialist Nurses in confidence.

Fill in during or after your appointment

My questions or concerns

Answers to my questions or concerns

Advice from my doctor or nurse

PSA level

Date and time of next appointment

More information from us

The Tool Kit

The Tool Kit information pack contains fact sheets that explain how prostate cancer is diagnosed, how it's treated and how it may affect your lifestyle. Each treatment fact sheet also includes a list of suggested questions to ask your doctor. Call our Specialist Nurses for a personally tailored copy.

Leaflets and booklets

We have a range of other leaflets and booklets about prostate cancer and other prostate problems.

To order publications:

All our publications are free and available to order or download online. To order them:

- call us on **0800 074 8383**
- visit our website at **prostatecanceruk.org/publications**

Call our Specialist Nurses

If you want to talk about prostate cancer or other prostate problems, call our Specialist Nurses in confidence. You can also text NURSE to 70004, or you can email or chat online with our nurses on our website. Visit **prostatecanceruk.org/get-support**

Speak to our Specialist Nurses
0800 074 8383*
prostatecanceruk.org

*Calls are recorded for training purposes only. Confidentiality is maintained between callers and Prostate Cancer UK.

Other useful organisations

British Association for Counselling & Psychotherapy

www.bacp.co.uk
Telephone: 01455 883 300
Information about counselling and details of therapists in your area.

Cancer Research UK

www.cancerresearchuk.org
Telephone: 0808 800 4040
Information about prostate cancer and clinical trials.

Citizens Advice

www.citizensadvice.org.uk
Telephone: 0800 144 8848 (England), 0800 702 2020 (Wales), 0800 917 2127 (Scotland)
Advice on a range of issues including financial and legal matters. Find your nearest Citizens Advice in the phonebook or online.

Macmillan Cancer Support

www.macmillan.org.uk
Telephone: 0808 808 0000
Practical, financial and emotional support for people with cancer, their family and friends.

Maggie's

www.maggies.org
Telephone: 0300 123 1801
Drop-in centres for cancer information and support, and online support groups.

NHS 111 Wales
www.111.wales.nhs.uk
Telephone: 0845 46 47
Provides health advice 24 hours a day, and lists local health services in Wales.

NHS Inform
www.nhsinform.scot
Telephone: 0800 22 44 88
Health information and details of NHS and other support services in Scotland.

NHS website
www.nhs.uk
Information about conditions, treatments and lifestyle.
Support for carers and a directory of health services in England.

nidirect
www.nidirect.gov.uk
Information about government services in Northern Ireland, including health services.

Penny Brohn UK
www.pennybrohn.org.uk
Telephone: 0303 3000 118
Courses and physical, emotional and spiritual support for people with cancer and their loved ones.

Samaritans
www.samaritans.org
Telephone: 116 123
Confidential, judgement-free emotional support, 24 hours a day, by telephone, email, letter or face to face.

About us

Prostate Cancer UK has a simple ambition: to stop men dying from prostate cancer – by driving improvements in prevention, diagnosis, treatment and support.

At Prostate Cancer UK, we take great care to provide up-to-date, unbiased and accurate facts about prostate diseases. We hope these will add to the medical advice you have had and help you to make decisions. Our services are not intended to replace advice from your doctor.

References to sources of information used in the production of this booklet are available at **prostatecanceruk.org**

This publication was written and edited by
our Health Information team.

It was reviewed by:

- Manit Arya, Consultant Urological Surgeon, University College Hospital, London
- Zoe Storton, Uro-oncology Clinical Nurse Specialist, Bradford Teaching Hospitals NHS Foundation Trust
- Alastair Thomson, Consultant Clinical Oncologist, Royal Cornwall Hospitals NHS Trust
- Karen Wilkinson, Uro-oncology Clinical Nurse Specialist, University College Hospital, London
- Our Specialist Nurses
- Our volunteers.

Donate today – help others like you

Did you find this information useful? Would you like to help others in your situation access the facts they need? Every year, over 47,000 men face a prostate cancer diagnosis. Thanks to our generous supporters, we offer information free to all who need it. If you would like to help us continue this service, please consider making a donation. Your gift could fund the following services:

- £10 could buy a Tool Kit – a set of fact sheets, tailored to the needs of each man with vital information on diagnosis, treatment and lifestyle.
- £25 could give a man diagnosed with prostate cancer unlimited time to talk over treatment options with one of our Specialist Nurses.

To make a donation of any amount, please call us on **0800 082 1616**, visit **prostatecanceruk.org/donate** or **text PROSTATE to 70004**†. There are many other ways to support us. For more details please visit **prostatecanceruk.org/get-involved**

† You can donate up to £10 via SMS and we will receive 100% of your donation. Texts are charged at your standard rate. For full terms and conditions and more information, please visit prostatecanceruk.org/terms

Registered with FUNDRAISING REGULATOR

Tell us what you think

If you have any comments about our publications, you can email: **yourfeedback@prostatecanceruk.org**

Speak to our Specialist Nurses
0800 074 8383*
prostatecanceruk.org

Trusted Information Creator
Patient Information Forum

Like us on Facebook: **Prostate Cancer UK**
Follow us on Twitter: **@ProstateUK**

To be reviewed September 2022

Call our Specialist Nurses from Monday to Friday 9am 5pm, Wednesday 10am 5pm
* Calls are recorded for training purposes only.
Confidentiality is maintained between callers and Prostate Cancer UK.

Prostate Cancer UK is a registered charity in England and Wales (1005541) and in Scotland (SC039332). Registered company number 02653887.

6679 DIA/AUG22

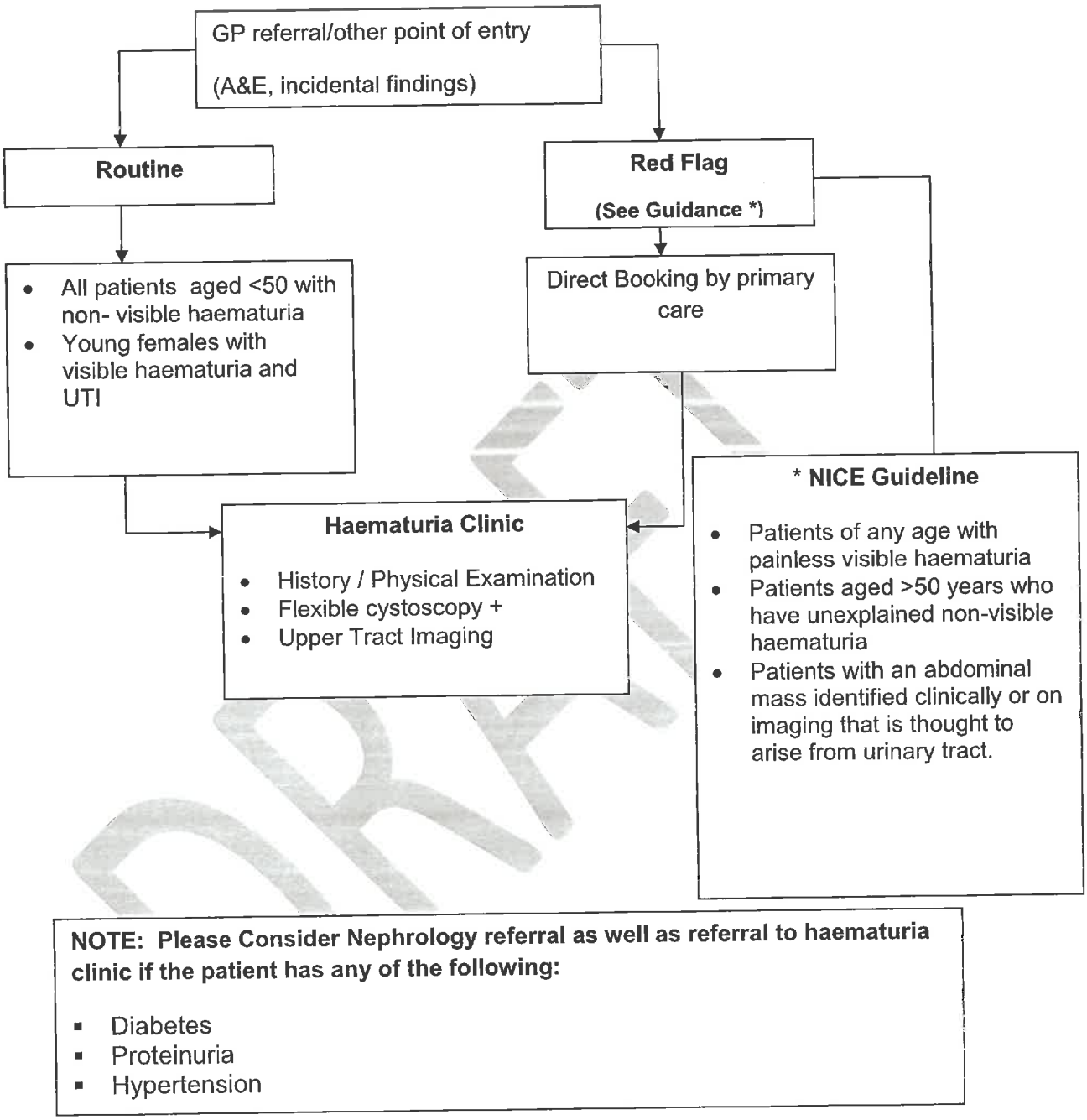
NICaN
Northern Ireland Cancer Network

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).

Haematuria Referral Guideline

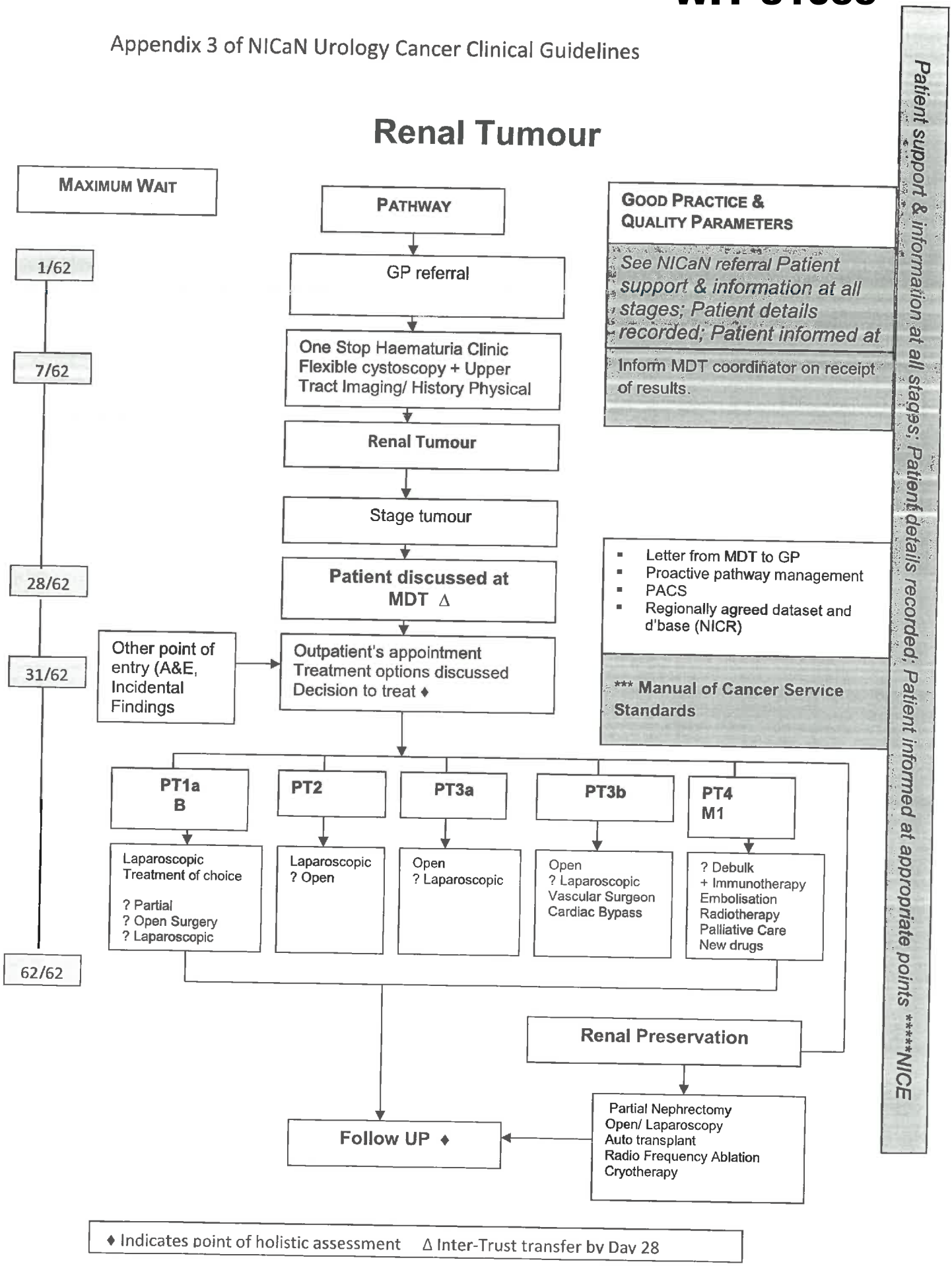


NOTE: Please Consider Nephrology referral as well as referral to haematuria clinic if the patient has any of the following:

- Diabetes
- Proteinuria
- Hypertension

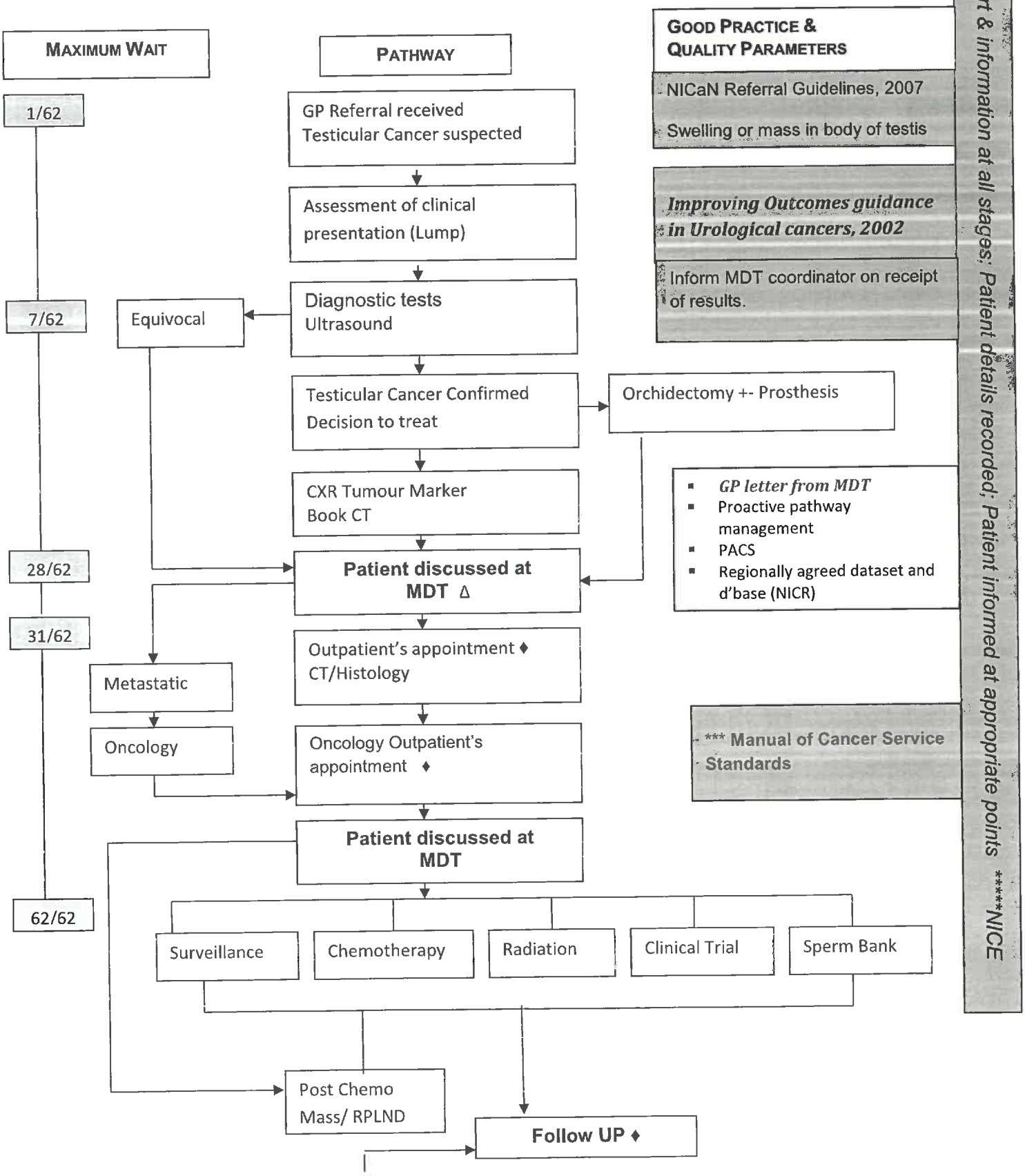
Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Renal Tumour



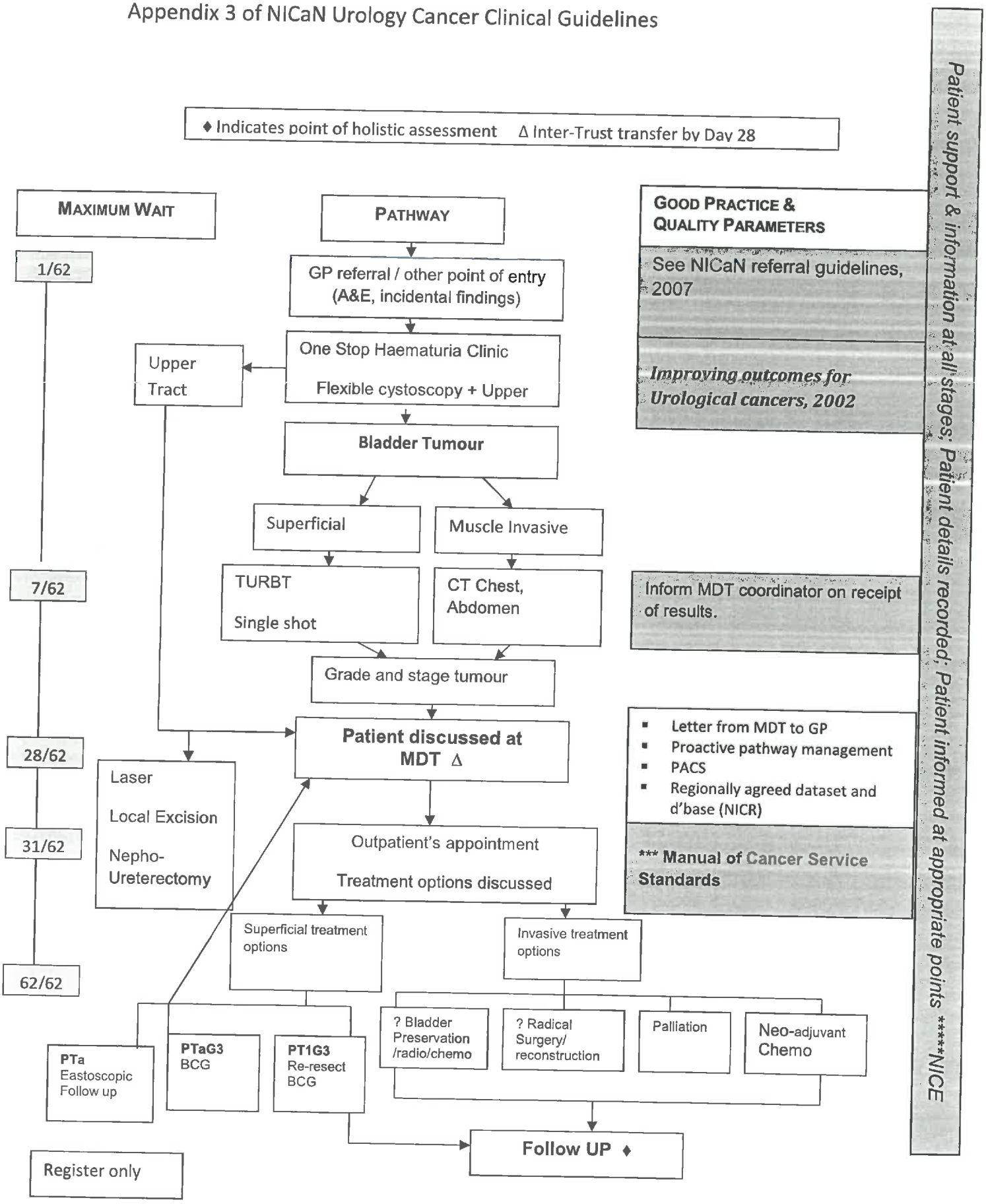
Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Testicular Cancer Pathway



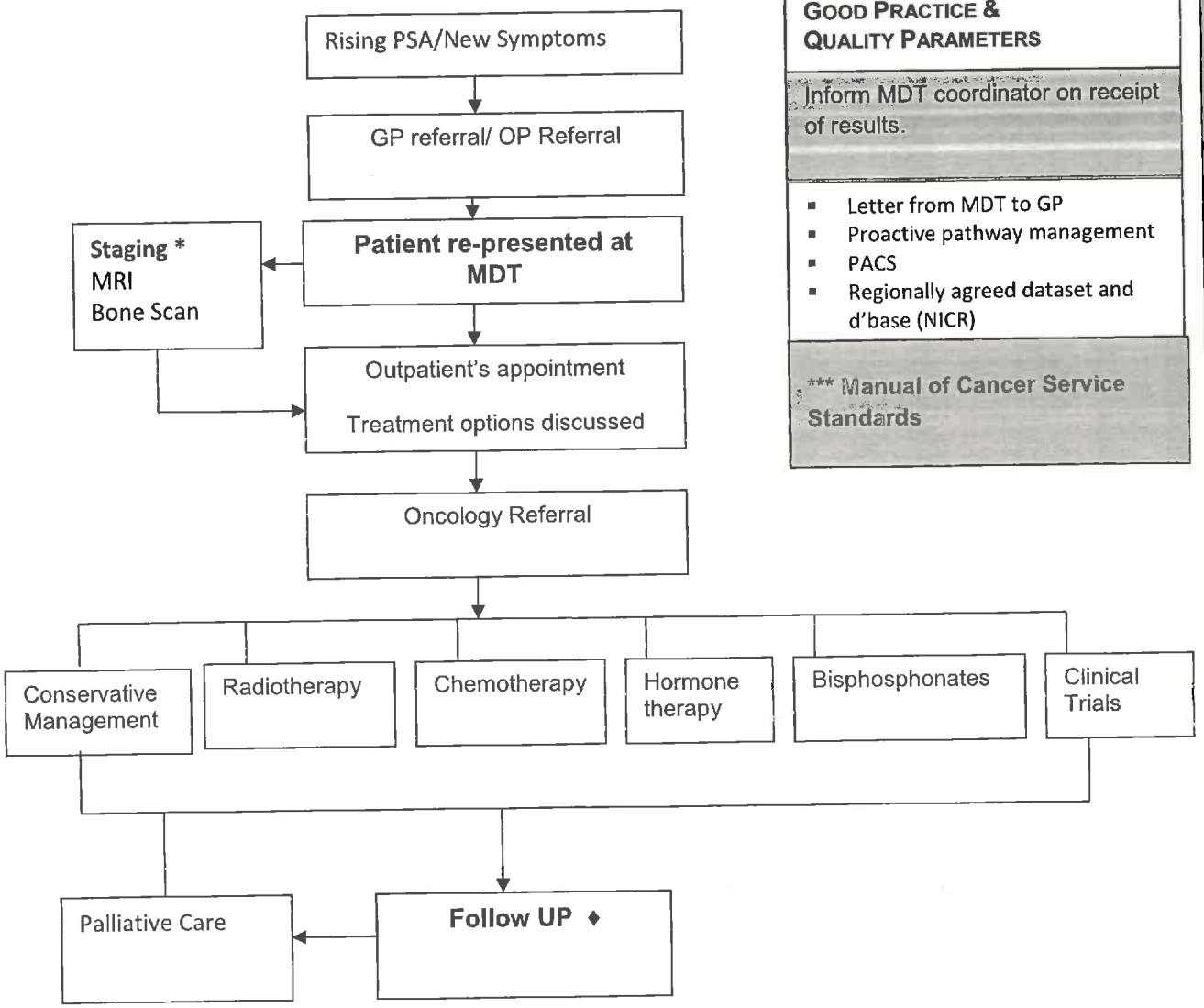
Appendix 3 of NICaN Urology Cancer Clinical Guidelines

♦ Indicates point of holistic assessment Δ Inter-Trust transfer by Day 28



Appendix 3 of NICaN Urology Cancer Clinical Guidelines

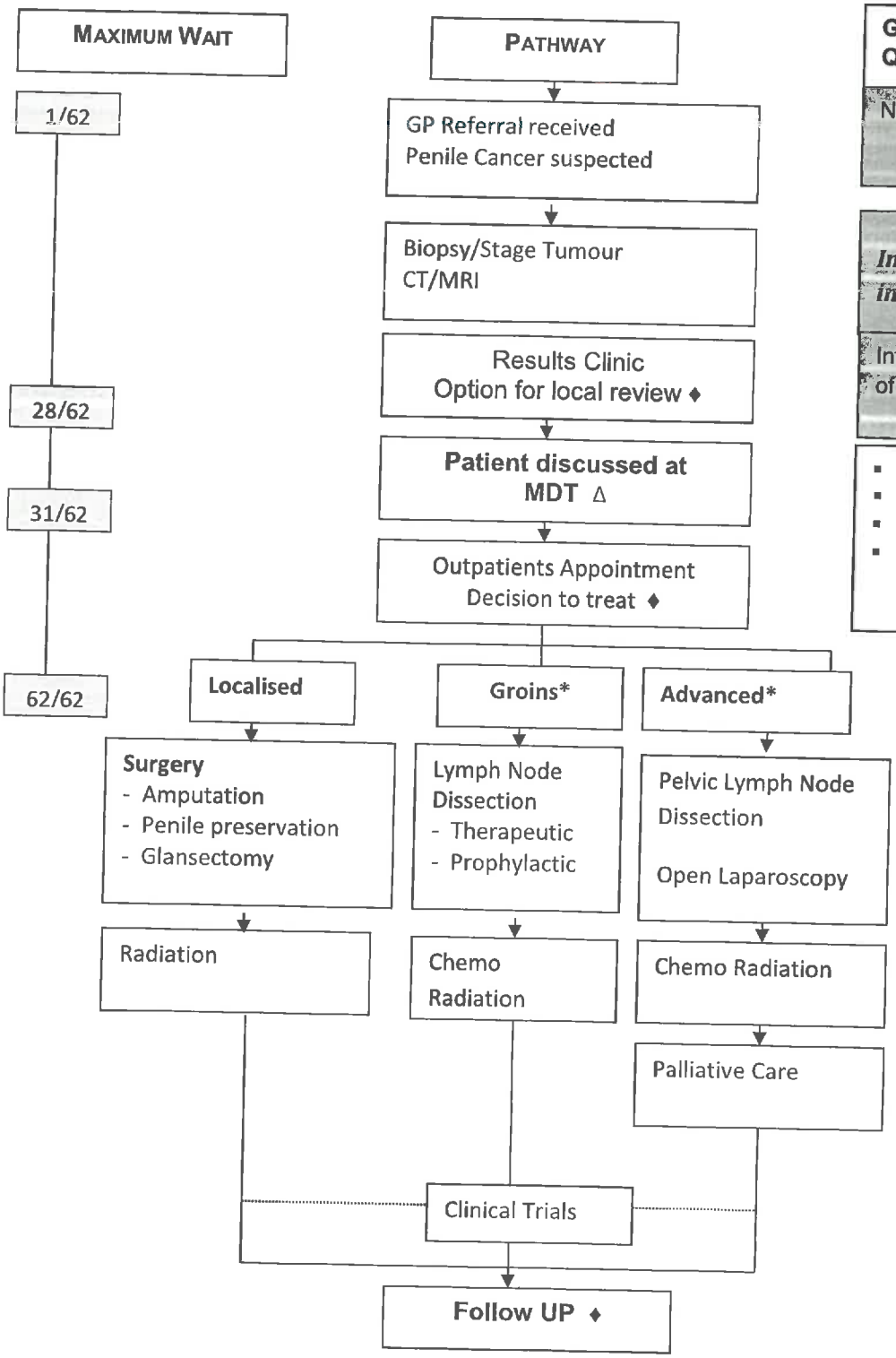
Castration Resistant Prostate Cancer



* MRI/Bone Scan as clinically indicated

Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Penile Cancer Pathway (Currently Under Review as part of development of local penile service 2019)



GOOD PRACTICE & QUALITY PARAMETERS

NICaN Referral Guidelines, 2007

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)

*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

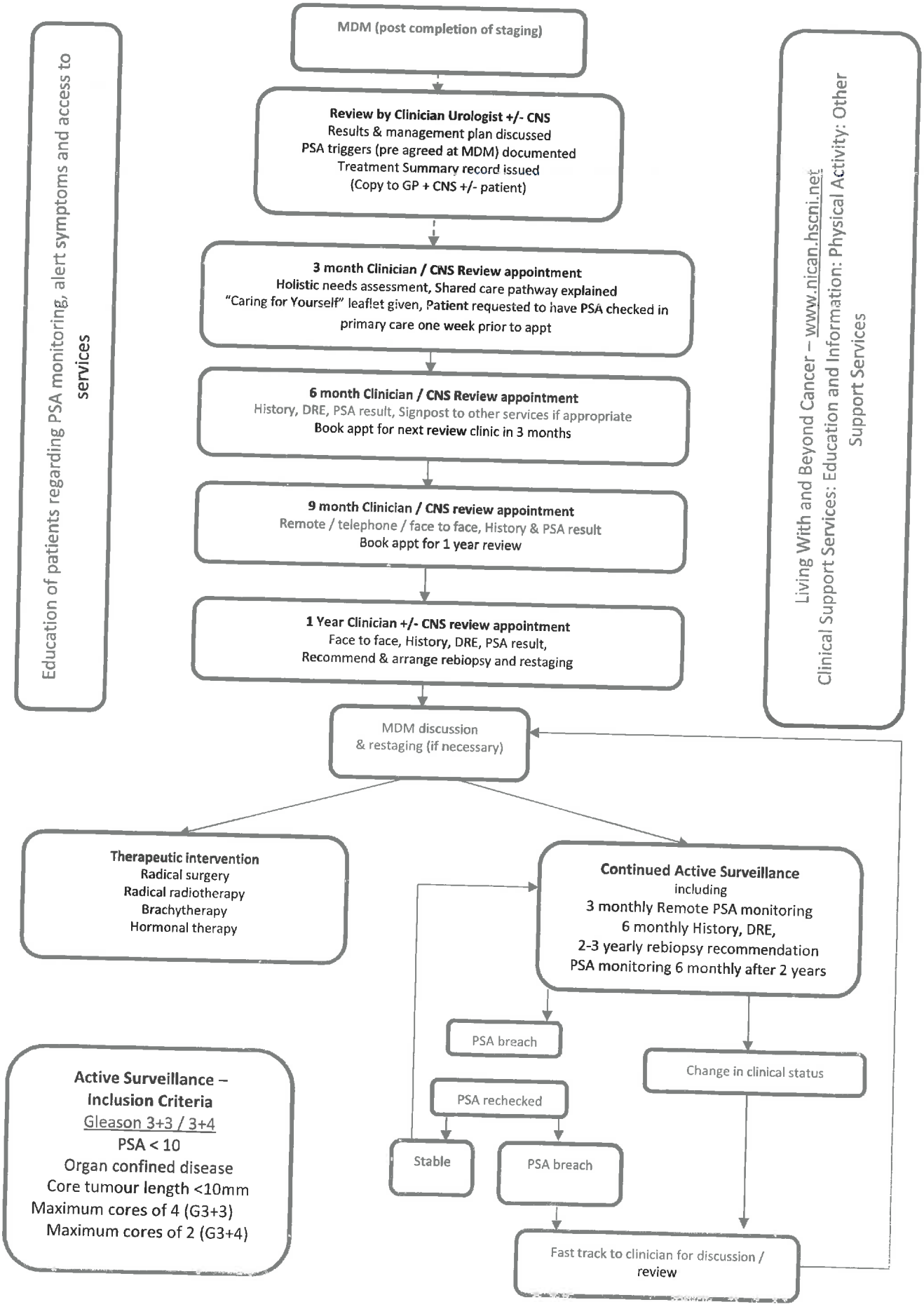
Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Policy Code / Reference No:

Trust Logo

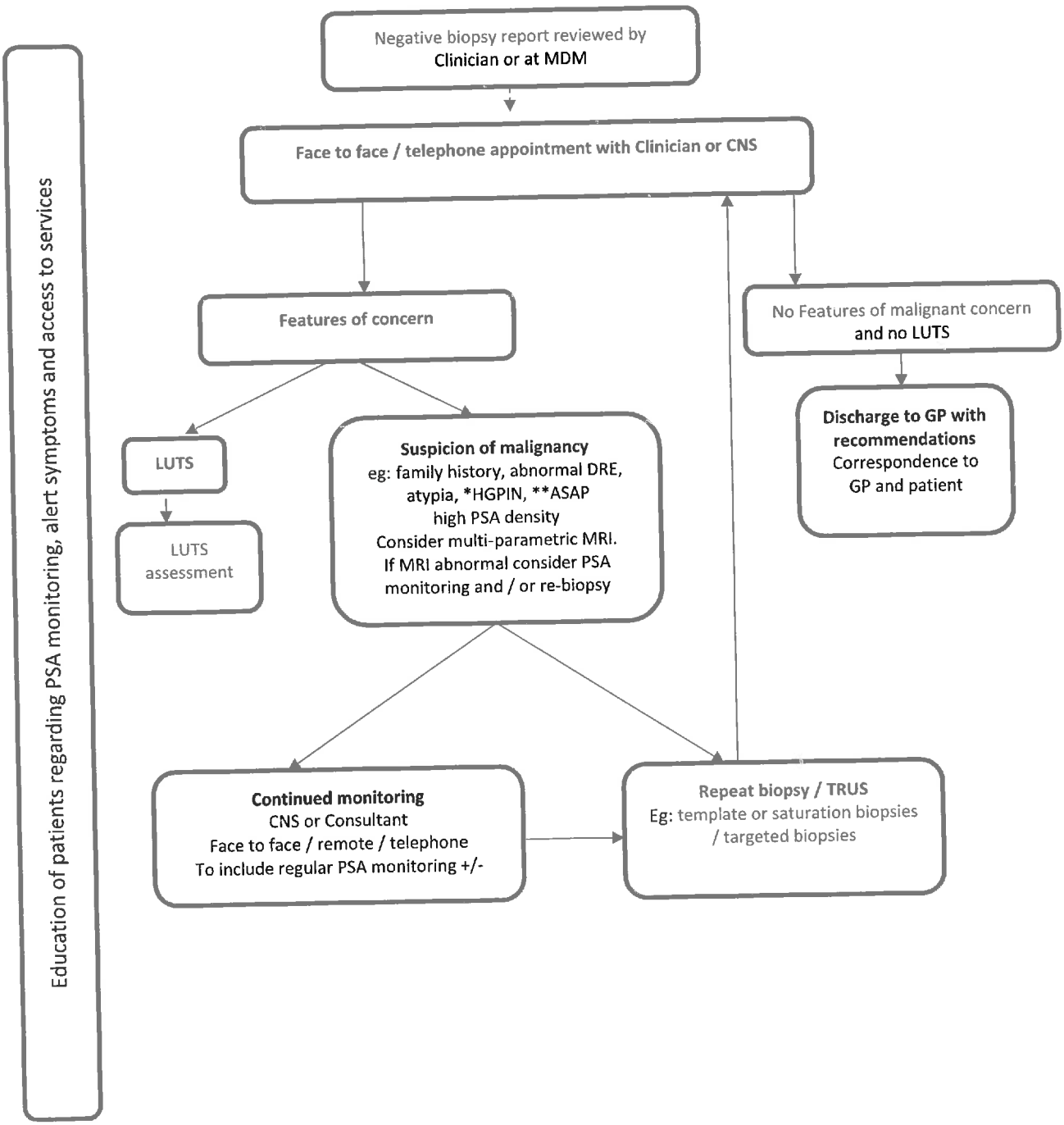
Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 2 **Prostate Cancer: Active Surveillance**



Appendix 3 of NICaN Urology Cancer Clinical Guidelines

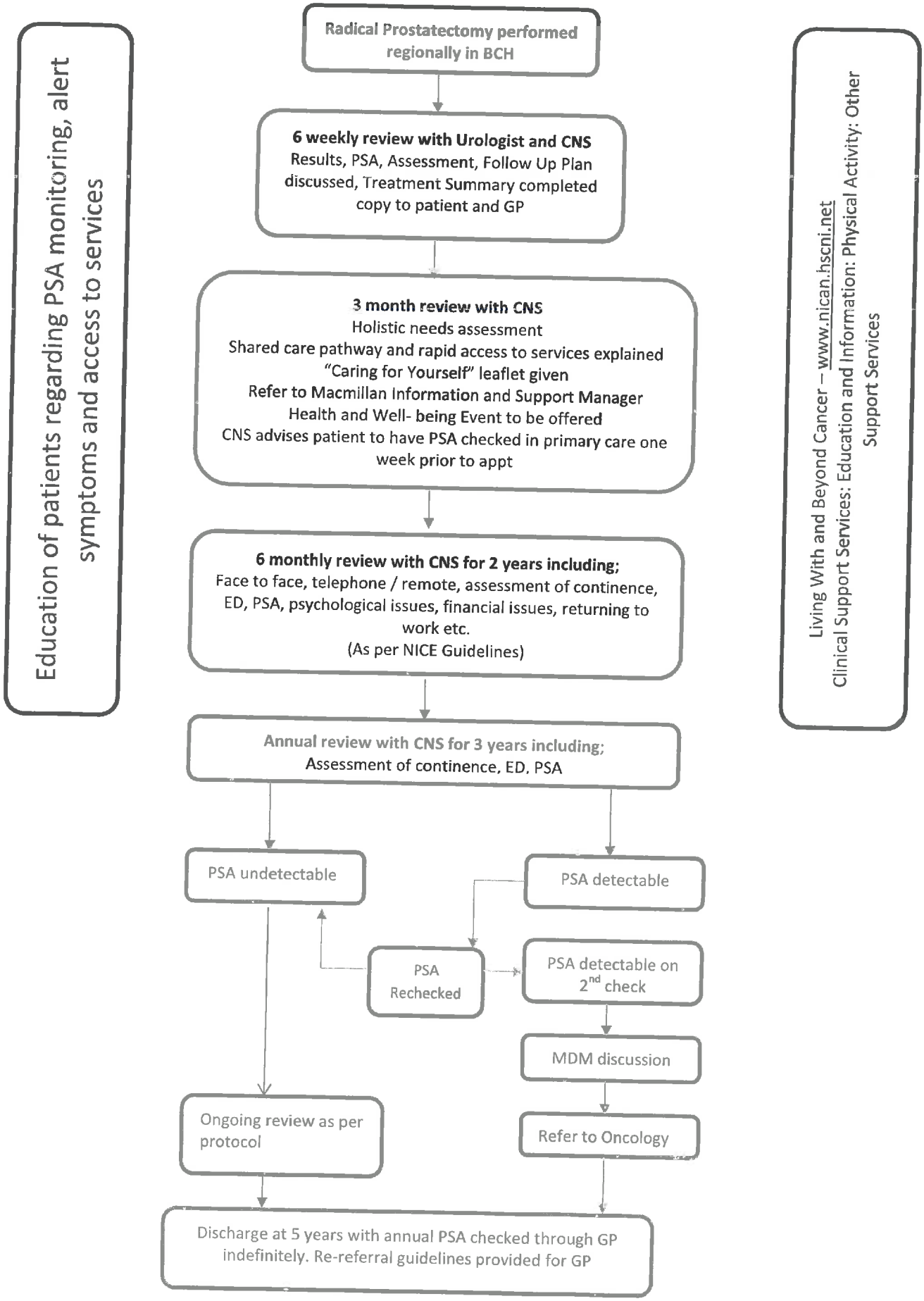
Pathway 3 **Raised PSA & Negative Biopsy**



*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**



Appendix 3 of NICaN Urology Cancer Clinical Guidelines

Pathway 5 Prostate Cancer: Permanent Prostate Brachytherapy (LDR)

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

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

Education of patients regarding PSA monitoring, alert symptoms and access to services

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

Living With and Beyond Cancer – www.nican.hscni.net
Clinical Support Services: Education and Information: Physical Activity: Other Support Services

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

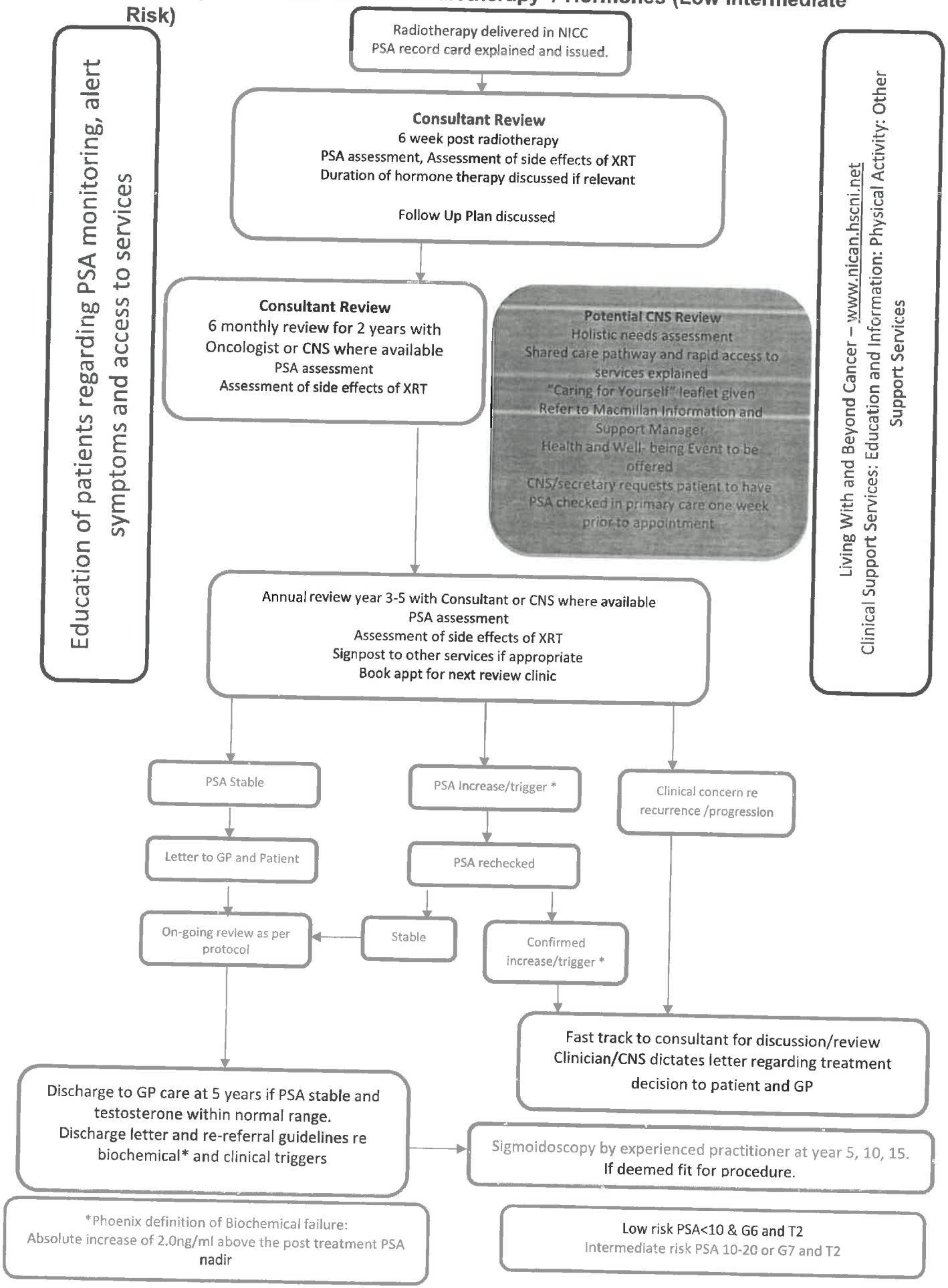
Clinical exclusion criteria for brachytherapy:
Prostate volume >50ml (> 65ml prior to hormonal cytoreduction)
IPSS >9. (Would consider for implant is <15 & Qmax >12ml/sec)
Life expectancy <5years
Large or poorly healed TURP defect
Unacceptable operative risk
Relative contraindications for brachytherapy:
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)



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 two 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 to 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]

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]

'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

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]:

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 a 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.

REFERENCES

1 Macmillan Cancer Support. Postcount data 2014. UK.
2 Office for National Statistics. Registrations of cancer diagnosed in 2012, England http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--43--2012/stb-cancer-registrations-2012.htm. 2014 (accessed August 2014).
3 Wales - Welsh Cancer Intelligence and Surveillance Unit. Official Statistics - Trends. http://www.wcisu.wales.nhs.uk/officical-statistics-exel-files-of-trend (accessed July 2014).
4 N. Ireland - Northern Ireland Cancer Registry. Online Statistics. http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/ (accessed July 2014).
5 Scotland - ISD Scotland. Cancer Incidence in Scotland 2012. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233 (accessed July 2014).
6 J Maddams J et al. Cancer prevalence in the United Kingdom: Estimates for 2008. 2008. British Journal of Cancer.
7 Macmillan Cancer Support. Internal analysis by Intelligence & Research, Corporate Development Directorate. Macmillan Statistics Factsheet. 2010.
8 Department of Health. National Cancer Survivorship Initiative Vision. 2010.
9 Macmillan Cancer Support, Department of Health and NHS Improvement. National Cancer Survivorship Initiative (NCSI) Living with and Beyond Cancer: Taking Action to Improve Outcomes.
10 Campbell J. Macmillan Cancer Voice Summer edition. 2010.
11 Department of Health. Cancer Reform Strategy. 2007.
12 Brookes J. A Patients Journey: living with breast cancer. BMJ. 2006; 333(7557): 31–33.
13 National Cancer Action Team. Excellence in cancer care: the contribution of the clinical nurse specialist.. http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/ExcellenceinCancerCaretheContributionofth eClinicalNurseSpecialist.pdf (accessed September 2014).
14 HSJ Workforce. Time For some Advanced Thinking? The Benefits of Specialist Nurses. An HSJ Supplement. 2015. (accessed April 2015).
15 NHS England. National Cancer Patient Experience Survey 2013.
16 NHS England. National Cancer Patient experience Survey 2014.
17 The Prostate Cancer Charity. Response to the call for evidence on cancer inequalities from the APPG on cancer. 2009.
18 UK Lung Cancer Coalition. Experts call for more lung cancer nurses. 2008.
19 NCAT Cancer. CNS Survey 2011.
20 UK Lung Cancer Coalition. Putting_patients_first_-_Understanding_what_matters_most_to_lung_cancer_patients_and_carers http://www.uklcc.org.uk/files/pdf/UKLCC_-_Putting_patients_first_-_Understanding_what_matters_most_to_lung_cancer_patients_and_carers.pdf. (accessed August 2013)
21 Royal College of Nursing (RCN). Specialist Nurses: Changing lives, saving money. 2010.
22 Royal College of Nursing (RCN). Guidance of Safe Nurse Staffing Levels in the UK. http://www.rcn.org.uk/__data/assets/pdf_file/0005/353237/003860.pdf (accessed August 2013)
23 Secondary Breast Cancer Taskforce Breast Cancer Care. Guide for commissioners meeting the nursing needs of metastatic breast cancer patients. 2008.
24 Macmillan Cancer Support. The Reach of Macmillan's Services fact sheet. 2015.
25 Macmillan Cancer Support. Macmillan Clinical Nurse Specialists: http://www.macmillan.org.uk/Aboutus/Healthprofessionals/Macmillan_Clinical_Nurse_Specialists/How_to_become_a_Macmillan_Nurse.aspx (accessed August 2014)
26 Adapted by Macmillan Cancer Support from Frontier Economics. One to one support for cancer patients. 2010. A report prepared for the Department of Health. London. UK.
27 Department of Health. Improving Outcomes – A Strategy for Cancer. 2011.
28 Thornton et al. Hard choices: a qualitative study of influences on the treatment decisions made by advanced lung cancer patients. International Journal of Palliativet Nursing. 2011. 17(2):68-74. UK
29 The NHS Information Centre. National Lung Cancer Audit. 2010.
30 The Prostate Cancer Charity. Access to Clinical Nurse Specialists for men with prostate cancer.(2009)
31 Corner J et al. Exploring nursing outcomes for patients with advanced cancer following intervention by Macmillan specialist palliative care nurses. 2003. Blackwell Publishing.
32 Moore et al. BMJ. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. 2002.
33 NHS Information Centre. National Lung Cancer Audit. 2010.
34 Royal College of Nursing (RCN.) Clinical nurse specialists: adding value to care. 2010.
35 Macmillan Quotation Library. Updated 2008.
36 NCAT. Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist.UK. 2010.

37 Trevatt P, Petit J, Leary A. Cancer Nursing Practice. Mapping the English cancer clinical nurse specialist workforce. 2008.
38 National Patient Safety Agency. How do staffing levels impact on patient safety? 2009.
39 Pollard et al. Justifying the expense of the cancer Clinical Nurse Specialist. 2010. European Journal of Cancer Care.
40 Department of Health Vital role of Clinical Nurse Specialists. 2010.
41 CHKS. http://www.chks.co.uk/assets/files/Published%20articles/NT_290311.pdf.
42 NursingTimes.net. Powerful evidence' of growing role of specialist nurses revealed. http://www.nursingtimes.net/nursing-practice/clinical-specialisms/practice-nursing/powerful-evidence-of-growing-role-of-specialist-nurses-revealed/5027698.article.
43 Vidall C et al. Clinical nurse specialists: essential resource for an effective NHS. British Journal of Nursing. 2011.
44 Frontier Economics. One to one support for cancer patients. A report prepared for the Department of Health. 2010 London. UK.
45 Baxter J et al Productivity gains by specialist nurses. Nursing Times. 2011.
46 Beaver et al. Colorectal cancer follow-up: patient satisfaction and amenability to telephone after care. European Journal of Oncology Nursing. 2011. 15 (1): 23-30.
47 Leary A, Bell N, Darlison L, Guerin M. An analysis of Lung Clinical Nurse Specialist workload and value. Cancer Nursing Practice. 2008.
48 Macmillan Cancer Support. Demonstrating the economic value of co-ordinated cancer services. An examination of resource utilisation in Manchester. March 2010.
49 Breast cancer care. Secondary breast cancer task force. Improving the care of people with metastatic breast cancer. UK. 2008.

50 Macmillan Cancer Support. The Cost of Macmillan's Services fact sheet. 2015.
51 Sheppard E. What value do specialist nurses add to care of patients in your ward, department or team? Nursing Times. 2011.
52 Sullivan A, Elliot S. Assessing the value of a cancer clinical nurse specialist on patient outcomes. Cancer Nursing Practice. 2007.
53 Moore et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. BMJ. 2002.
54 Davies N and Bateup L. NCSI. Cancer follow-up: Towards a personalised approach to aftercare services. 2009.
55 Sheppard C et al. Breast cancer follow up: a randomised controlled trial comparing point of need access versus routine 6-monthly clinical review. European Journal of Oncology Nursing. 2009.

Part A

KSF PERSONAL DEVELOPMENT REVIEW FORM

Post Title, Pay Band: Urology CNS Band 8a **Staff Number:** [redacted]

Is Professional Registration up to date? _____

KEY ISSUES & OUTCOMES	COMMENTS
Have you read and understood your Post Outline? Post Outlines can be accessed via Trust Intranet (KSF link) YES ☑ NO ☐ **Have Post Outline levels been achieved:** YES ☑ NO ☐ **If no, record below what action to be taken:**	**Staff members comments on his/her performance over past year:** [redacted] **Line Manager's Feedback on staff members performance over past year:** [redacted]
Objectives for Next Year: [redacted]	

Reviewee Staff Name (Print) K O'NEILL Signature [redacted] Date 25/7/22

Reviewer Manager/Supervisor (Print) PAULA McKay. Signature [redacted] Date 25th July 2022.

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

Part A

KSF PERSONAL DEVELOPMENT REVIEW FORM

Post Title, Pay Band: Urology Nurse Specialist. **Staff Number:** [redacted]

Is Professional Registration up to date? Yes

KEY ISSUES & OUTCOMES	COMMENTS
Have you read and understood your Post Outline? **Post Outlines can be accessed via Trust Intranet (KSF link)** YES ☑ NO ☐ **Have Post Outline levels been achieved:** YES ☑ NO ☐ **If no, record below what action to be taken:** [redacted]	**Staff members comments on his/her performance over past year:** [redacted] **Line Manager's Feedback on staff members performance over past year:** [redacted]
Objectives for Next Year: [redacted]	

Reviewee Staff Name (Print) Kowell Signature [redacted] Date 3/4/19

Reviewer Manager/Supervisor (Print) SARAH WARD Signature [redacted] Date 3.4.19

28 May 10

Mr Young & Mr O'Brien informed of concerns & that we had spoken to Noleen & Martine given our serious concern about personal health + potential impact on himself, patients + service. Informed of behaviours displayed, rocking, smoking, pacing, inappropriate questions, seeking reassurance anxiety (out of perspective) presentation. Also impact on SVCS - undue anxiety for patients - ordering unnecessary investigations, unable to make clinical decision without continual reassurance or advice from colleagues, unable to trust own judgement.

Outcome - Mr Young to discuss c X about occupational health.

No contact made with OHD / X. Unable day as long Bank Holiday due (isolation)

3/6/10 - Martine informed Kate that She had informed Eamon Mackle as her clinical lead.

25th May 10

- Noleen informed re: our concerns on personal level as well as clinical & service performance issues. Advised d/w Martine re: operational level as well as all 3 consultants.

26th May 10

- Martine Coulgan informed re concerns + operational impact - Reviews
  - Parallel clinic
  - Staff

27th May 10

- Mr Akhtar informed of concerns. as he was unable to attend meeting planned with all 3 Consultants for 28/5/10

4/6/10

Jenny informed by Mr Young over phone that following fork discussion held between My + Dr X - had requested occup. health not be contacted at this stage. My will reassess [redacted] hols - planned

10/6/10

Further discussion with Mr O'Brien that X:. unchanged & behaviour inappropriate, agitated at times. We stated that we felt more was needed to support Dr X / health status & that we did not feel a holiday would change behaviour considerably. Mr O'Brien to discuss situation again c Mr Young.

Martina Corrigan & Heather Monaghan informed of details to date re: Consultants & Martina stated that Eamon Mackle & My had met to discuss the situation

Aug & Sept 10 - further conversations with Heather, Martina + Catriona re: inappropriate behaviour
pacing floor
unkempt (wearing same clothes all week + sweat stains apparent)
unable to make decisions re: patients
constantly seeking reassurance
constantly asking for opinions of everyone in unit regarding clinical matters + how to manage clinical problems

22 Oct 10

Discussion re Alison Porter regarding MDM matters + ongoing difficulties re: radiology input, cancer waiting times ie to Hexi. Conversation turned to Dr X + Alison informed of previous performance issues, difficulty discharging pts, eg of reviewing same pt 7 times in 2 yrs while cance pts waiting 2 yrs for results appts!

Thorndale Consultant Departmental Meeting
3rd June 2021 at 12:45

AGENDA

1. Apologies
2. Actions from previous meeting
    a. Taster week
    b. CNS medical mentorship
    c. Catheter Changes
    d. DHH paed patients review
    e. Scheduling
3. Staffing
    a. Trainees (Aug 21 intake)
    b. Clinical Fellow interviews
4. Elective/Outpatient activity update
    a. Scheduling
    b. Haematuria clinic
5. CNS policies
6. Any other business

Southern Health and Social Care Trust

Quality Care - for you, with you

[redacted]

Present: **Martina Corrigan, Kate O'Neill, Jenny McMahon**

Ref	Issue	Discussion	Owner/Date
1.	**Precarious Liability**	Letter to be done for Kate and Jenny in respect of Removal of Stents/Prostate and Flexi's	Martina
2.		Access to A&E for ill patients	Kate and Mary Burke
3.	**Governance**	We discussed the format and Martina to see if a previous format is still used within SEC	Martina
		Trus Biopsies/Urodynamic/Flexi SOP's and what information is needed from the patient including – clinical obs, NEWS charts to be completed etc…..	Jenny
		Jenny to email specific questions…..	Martina
		Latex free policy how long latex free environment – Advise needed.	Martina/Kate/Jenny
		Look at all documentation with Dawn Connolly Control of documents and are they still ok.	Martina/Kate/Jenny
		Standard Operational Policies within the unit are done but some will need changed whilst others need done, at the moment none are signed off but this will be part of the new process.	

Ref	Issue	Discussion	Owner/Date
4.	**Operational** **Staffing**	It was agreed that we would take one policy at a time – starting with Urodynamics and work thorough and then discuss with Consultant and get their signature that they are happy with them. Scopes issues to continue to work on getting this resolved Clarification of an outpatients with procedure and what should be recorded as a Day case • Radiology Biopsies – the future management of these • How are the biopsies captured Martina advised that she was not in a position to extend the temporary staff beyond April as the meeting with HSCB has not taken place, but she will keep them informed and once funding is in place the jobs will be advertised on a permanent basis **Date and Time of Next Meeting: no meeting next Friday 10th and next meeting will be at 11:30pm with Katherine Robinson/Sharon Glenny to discuss Nurse-led clinics**	Martina

Southern Health and Social Care Trust

Surgery and Elective Care Division
Nursing Governance Action Plan as at 7 September 2010
Urology Nurse Specialists: Jenny McMahon & Kate O'Neill

Nursing Governance Issue	Action	By when
Staffing	Gain clarification in relation to who is the operational manager / professional line manager for staff working in the Thorndale Unit that are not managed by the Urology Nurse Specialists (Doctors, Nurses, Clerical staff). For example, who is responsible for ensuring mandatory training is up-t-date, validation of registration, nurse supervision etc	End of September 2010
Validation of nursing registration	Local process for checking validation of nursing registration includes: ▪ 2 USN Band 7 – check with each other ▪ 3 Band 5 staff nurses - Registered Nurses show new PIN Expiry date to Urology Specialist Nurse. PIN Expiry is recorded on KSF annual appraisal document Ensure new expiry dates are forwarded to Nursing Administration for input onto HRMS. HRMS reviewed and corrections identified as part of the Trust-wide validation of HRMS. A number of corrections need to be made and USN will talk to Lead Nurse (Noleen O'Donnell) to make arrangements to ensure HRMS system is updates. Ensure that the HRMS system for the Thorndale is kept accurate. Be in a position at the end of each month to give verbal / written assurances at the Surgery and Elective Nursing Governance Forum that all RN working in the Thorndale Unit (managed by UCNs) have a valid registration.	Ongoing September 2010 Commencing September 2010
Nursing Supervision	Facilitate one-to-one nurse supervision sessions by end of August.	One Group session with the three RNs was held in August. Individual nurse supervision sessions have been booked with each SN for Feb / March.

Southern Health and Social Care Trust

Surgery and Elective Care Division
Nursing Governance Action Plan as at 7 September 2010
Urology Nurse Specialists: Jenny McMahon & Kate O'Neill

Nursing Governance Issue	Action	By when
	Commence peer supervision: Urological Nurse Specialists; Continence Nurse Specialists Complete Nurse Registration Form and forward to Dawn Ensure supervision sessions are recorded on the Trust database by completing monthly return form.	Peer supervision booked for 14/9/10 End of September After each session
KSF appraisals and Personal Development Plans	Complete KSF appraisals (including Personal Development Plan) with staff August / September 2010 (2 staff August, 2 staff September 2010)	Completed August / September Mid-year check planned for Feb / March 11
Learning needs assessment / training	Identify core training for registered nurses and non registered nursing staff (see attached pro forma). Agree any additional training that specifically related to nursing staff working in Thorndale Unit and add to training matrix. Ensure that statutory training (dates are populated on the training matrix database. Work out percentage of nursing staff that have attended each. Ensure that each member of nursing staff is facilitated to attend statutory training.	September 2010
Induction	Finalise induction programmes for (a) Registered Nurses (b) Nursing Auxiliaries	Two staff nurses are in the process of putting the induction programmes together. Completion date???

Southern Health and Social Care Trust

Surgery and Elective Care Division
Nursing Governance Action Plan as at 7 September 2010
Urology Nurse Specialists: Jenny McMahon & Kate O'Neill

Nursing Governance Issue	Action	By when
Preceptorship	No newly qualified nurses work in the Thorndale Unit.	No action
NMC standards for learning and assessment in practice	Not applicable – no students	No action
Nursing policies and procedures	Map relevant procedures in the Royal Marsden to practice in the Thorndale Unit to ensure practice is up-to-date. Scope if specific clinical procedures need to be developed in line with Southern Trust Clinical Procedure template. Ensure clinical procedures are uploaded onto Southern Trust section of Royal Marsden	Still difficulty accessing the Royal Marsden (very slow to access on-line). Four procedures still to be checked.
Audits	Hand Hygiene – commencing in September 2010	Liaise with Dorothy Sharpe to commence audits.

Southern Health and Social Care Trust

Surgery and Elective Care Division
Nursing Governance Action Plan as at 7 September 2010
Urology Nurse Specialists: Jenny McMahon & Kate O'Neill

Nursing Governance Issue	Action	By when
Patient Group Directions	No PGDs in use in the Thorndale Unit	N/A
Risk Register	Risk assessments are up-to-date.	No further action
Adverse Incidents	No active action plans at present	No further action
Complaints	No active complaints at present	No further action

Nursing Governance Baseline	
Directorate: Acute	PSGL: Dawn Connolly
Division: Surgery and Elective Care	Ward Manager: Jenny McMahon & Kate O'Neill
Date as at: 29 June 2010	Thorndale Unit
Brief description of ward Urology Out-Patient Unit Assessment and Diagnostic procedures 5 day service 8am – 5.30pm; evening clinics; occasional Saturday clinics Integrated Clinical Assessment and Treatment Services (ICATS)	

Nursing staff			
Grade	**Number (Headcount)**	**Actual WTE**	**Funded WTE**
Urology Nurse Specialists (Band 7)	2	1.86	Martina is working to establish funded establishment
Ward Sister (Band 6)	-	-	
Staff Nurses (Band 5)	3	2.23	
Nursing Auxiliaries (Band 3)	-	-	
Nursing Auxiliaries (Band 2)	1	0.8	
Total	**6**	**4.89**	

Skill Mix ratio (% Registered Nurses : Nursing Auxiliaries)	**%**
Actual establishment (WTE) • RN 4.09 wte (5 registered nurses) • NA 0.8 wte (1 Nursing Auxiliary)	83%
Comments (vacant post, maternity leave etc) Lecturer Practitioner Urological Nursing 1 session per week (9am – 1pm) in andrology	

Staffing	**Yes / No**	**Comment / Action**
Have you any concerns in relation to your current staffing levels?	Yes	As Urology Nurse Specialists Band & we have managerial responsibility for 3 Band 5 nurses and 1 Band 2 Nursing Auxiliaries. We do not have managerial responsibility for other staff within the unit i.e. GPNSI (Line Manager: Mr Young); Clerical staff (Line Manager: Judith Anderson); Lecturer/Practitioner (??).
Validation of nursing registration	**Yes / No**	**Comment / Action**
Do you have a procedure for checking the validity of nurse registrations? If Yes, what is it?	Yes	Process for nurses that USNs manage: ▪ 2 USN Band 7 – check with each other ▪ 3 Band 5 staff nurses Registered Nurses show new PIN Expiry date to Urology Specialist Nurse. PIN Expiry is kept on KSF annual appraisal document HRMS reviewed and corrections identified as part of the Trust-wide validation of HRMS.
Do you have a record of expiry dates of nursing registrations of all nurses who you manage? If Yes, where do you record this?	Yes	PIN Expiry date recorded on annual KSF appraisal document
Do you know which nurse's registration are due to expire at the end of June 2010.	Yes	No registration due for renewal
Do you know if the HRMS system is up-to-date in relation to your ward?	No	Ask Elizabeth to forward a print out of Thorndale Unit
Can you give verbal assurance today that all nurses who you manage have a valid nursing registration?	Yes	All registrations are valid (staff that are managed by USNs).
Nursing Supervision	**Yes / No**	**Comment / Action**
Do you have enough trained nurse supervisors? How many & who?	Yes	Jenny McMahon Kate O'Neill

Do any more nurses need to attend nurse supervision training? How many and who?	No	
Are nurse supervisors registered on the Trust database?	Yes	Training just completed on 17 June 2010
Do you have a process in place to ensure that nurses receive a minimum of two supervision sessions per year?	No	Plan to have one to one nurse supervision carried out by end of summer. Plan to recommence peer supervision
How many nurses received supervision during the month of April?	0	
KSF appraisals and Personal Development Plans	**Yes / No**	**Comment / Action**
Do you have enough nurses trained to carry out KSF & PDPs? How many and who?	Yes	Jenny McMahon Kate O'Neill
Do any more nurses need to attend KSF & PDP training? How many and who?	No	
Do you have a process in place to ensure that all registered nurses and HCAs / NAs have KSF appraisal & PDP on an annual basis?	Yes	KSF & PDPs will be completed by end of September.
How many nurses and HCAs / NAs received KSF and PDP during June?	None	
Learning needs assessment	**Yes / No**	**Comment / Action**
Do you have a process in place to identify learning needs of nurses and HCAs / NAs whom you manage?	Yes	KSF Appraisal and development of a PDP will highlight learning needs. Also, training matrix for statutory, mandatory and best practice provides guidance for training needs analysis. As new services develop training needs are identified
Have you an agreed training matrix for NA Band 2? *(Statutory / Mandatory/ Best Practice DHSSPS / Best Practice Trust)*	No	Group set up to consider core training for nursing staff working in the SEC division. Each ward to identify specific requirements thereafter (see attached pro forma)
Have you an agreed training matrix for HCA / NA Band 3? *(Statutory / Mandatory/ Best Practice DHSSPS / Best Practice Trust)*	No	

Have you an agreed training matrix for Band 5 nurses? *(Statutory / Mandatory/ Best Practice DHSSPS / Best Practice Trust)*	No	Advised that a short life working group is being set up (chaired by Jacqueline Clarke) to review and refine training matrix for nursing staff.
Have you an agreed training matrix for Band 6 nurses? *(Statutory / Mandatory/ Best Practice DHSSPS / Best Practice Trust)*	No	
Have you an agreed training matrix for yourself, ward manager, Band 7? *(St atutory / Mandatory/ Best Practice DHSSPS / Best Practice Trust)*	No	
Are statuatory, mandatory and best practice training (as outlined in training matrices for Band 2,3,5,6 & 7) up-to-date?	No	Majority of training up-to-date. Difficulty getting booked onto ILS course. Had to cancel due to activity in clinics and difficult to get rebooked
Have you a robust learning needs assessment process for courses commissioned through the DHSSPS Education Commissioning Plan and BMC service level agreement?	No	No ECG Courses commissioned this year Specialist Practice in Urological Nursing – 1 module to complete (Kate)
Do you have a robust process to record training undertaken by nurses and HCAs / NAs? If Yes, is it up-to-date?	No	Training matrix database up-to-date
Induction	**Yes / No**	**Comments / Action**
Do you have a ward induction programme for: • Student nurses • Registered Nurses • HCAs / NAs	 N/A Yes Yes	Induction programmes almost ready
Preceptorship	**Yes / No**	**Comments / Action**
Do you have a process in place for preceptorship?	N/A	
NMC standards for learning and assessment in practice	**Yes / No**	**Comments / Action**
Do you have enough mentors? How many?		No students
Do you have enough 'sign off' mentors? How many?		
Do you need any more registered nurses to be trained as:		

(a) mentors (b) 'sign off' mentors		
Have mentors and sign off mentors access to an annual update?		
Is an up-to-date register of mentors available?		
Are mentors supported in their role? How?		
Nursing policies	**Yes / No**	**Comments / Action**
Do you have any specific nursing policies relating to your area of practice? If yes, are they up-to-date?	NO	
Do you have a process in place to ensure that all registered nurses are aware of the nursing policies posted on the intranet?	Yes	All staff know how to access the intranet.
Nursing procedures (evidence based)	**Yes / No**	**Comments / Action**
Are nursing procedures as outlined in the Royal Marsden (7th Edition) carried out by nurses in your ward?	Unsure	Not possible to give assurance that all clinical procedures are carried out in line with Royal Marsden. Ask registered nurses to map relevant procedures to their practice.
Have all nurses access to the online version of the Royal Marsden (7th Edition)	Yes	
Do you have any specific procedures relating to your area of practice those are not included in the Royal Marsden? If Yes, are they up-to-date?	Yes	Identify clinical procedures that may require to be written in new Trust procedural template and uploaded onto Southern Trust section of the Royal Marsden
Audits	**Yes / No**	**Comments / Action**
See pro-forma		None
Patient Group Directions	**Yes / No**	**Comments / Action**
See pro-forma		No PGDs in use in Thorndale Unit
Risk Register	**Yes / No**	**Comments / Actions**
Have relevant nurses been trained in risk management / development of a risk register? (Ward manager and ward sisters)	Yes	Jenny McMahon and Kate O'Neill

		(Beatrice Moonan provided update)
Do you have a process in place to manage the risk register?	Yes	All risk assessments are up-to-date
Do you have any active action plans in place to reduce the risk of items identified on the risk register?	No	
Adverse Incidents		
Have all registered nurses been trained in reporting of adverse incidents?	Yes	All RN have attended Training
Do you have any active action plans in relation to adverse incidents that have occurred in your ward?	No	
Do you have a process in place to share the learning from adverse incidents that have happened in your ward?	Yes	Ward sisters meeting
Do you have a process in place to share the learning from adverse incidents that have happened in others wards?	Yes	As above
Complaints		
Have all registered nurses been trained in complaints?	No	
Do you have any active action plans in relation to complaints that have occurred in your ward?	No	
Do you have a process in place to share the learning from complaints that have occurred in your ward?	Yes	Ward sisters meeting
Do you have any active action plans in relation to complaints that have occurred in others wards / departments (i.e. sharing the learning)?	No	

Supporting Nurses in Difficulty

Key Aims

Learning opportunity

- To review the Trust's internal Fitness to Practice process
- To review the NMC Fitness to Practise referral process

Collaborative working

- Role of Corporate Nursing Team
- Role of Directorate Nurse Lead/Professional Head of Service
- Role of HR

Streamlining the process

- Internal Nurses in Difficulty referral form
- Monthly Directorate Nurses in Difficulity 'clinics'

Internal Fitness to Practice process

PURPOSE

- Escalation/ radar
- Support/Challenge
- 2 way mechanism for assurance/good governance
- Live document –tracking progress

12 NMC Policy Principles Code of Practice

1) Person centred approach
2) FTP –managing risk , not punitive
3) Time limited –swift decision
4) Local resolution in the first instance
5) NMC will take regulatory action if there is a risk employers are not taking effective action
6) Context in which the registrant is practicing
7) Promote a culture of learning from mistakes
8) Deliberate cover ups regulatory action
9) NMC role not to punish about past events, but are required to know
10) Concerns raised about non clinical practise e.g. dishonesty, harassment
11) Regulatory concerns not remedied and require restrictive practise/ suitability to remain on the register
12) Full public hearings not always required, labour intensive, negative impact

Internal Fitness to Practice

WHO?

Any Band (Band 2 or above), within the nursing and midwifery workforce

WHEN? –criteria

Acted in such a way that brings the profession into disrepute or is in any way seen to put patients at risk
Is part of the formal Capability Procedure.
Received a precautionary suspension by the Trust.
Received a final warning.
Is under investigation by the PSNI
In breech of the NMC Code of Practice and is being considered for referral to the NMC

Guiding principles of a good local investigation into concerns about someone's practice

1. Promote a just culture
2. Have clear policies and procedures and follow best practice guidance
3. Have a clear plan and terms of reference
4. Start as early as possible
5. Be objective
6. Listen to people who use services and families, keep them informed, and take their information and views into account
7. Support staff and encourage openness without blame
8. Take equality, diversity and inclusion into account
9. Keep records of all evidence and decisions
10. Avoid delays and stick to a reasonable timeframe

NMC Fitness to Practice Referral

WHO ?

Any Substantive Band (Band 5 or above), within the nursing and midwifery workforce

WHEN ? –refer to Code Of Practice

- *Misconduct, for example physical abuse, neglect, adult safe guarding issues*
- *Lack of competence, for example persistent failure to deliver appropriate care*
- *Bad character, for example a serious legal conviction, dishonesty*
- *Poor health, for example a neglected or untreated addiction issues*
- *Not having the necessary knowledge of English*
- *Failure to maintain adequate records*
- *Misappropriation of medication*
- *Access Illegal Pornography*

NMC Fitness to Practice Self Referral

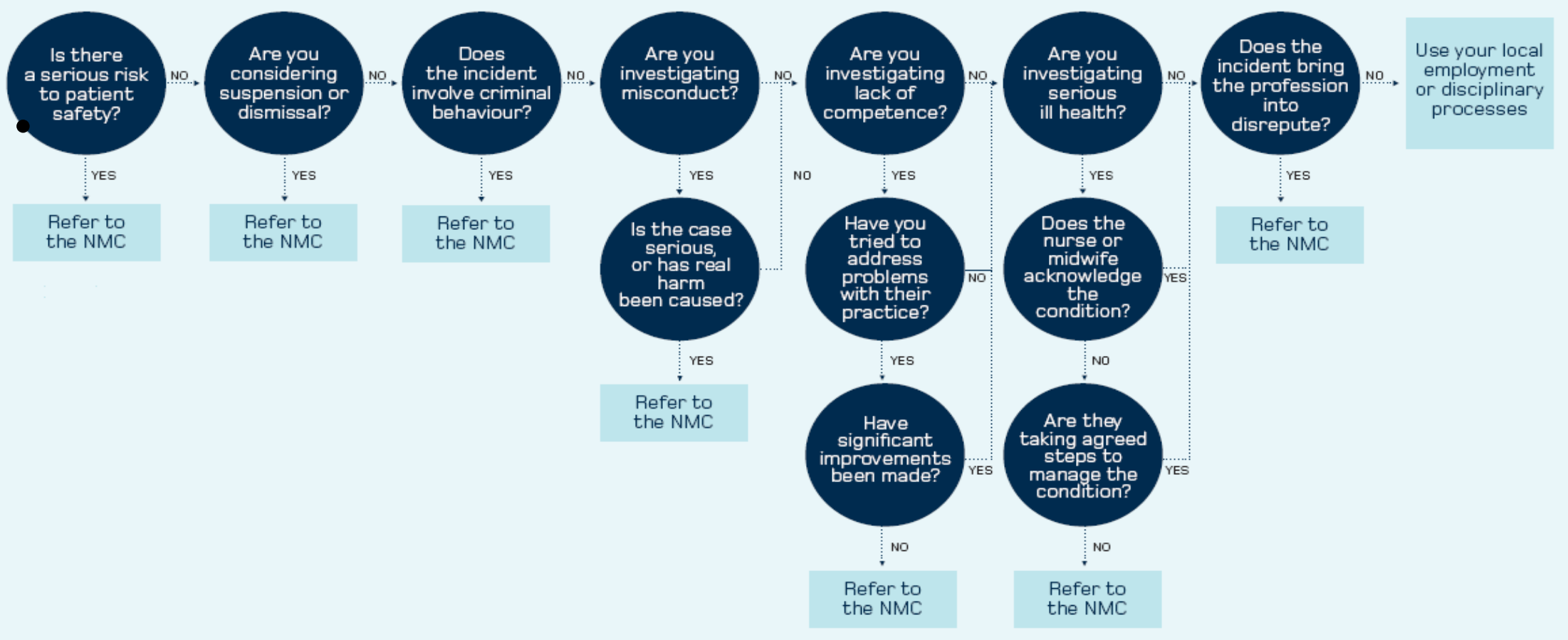
When not to self refer

- Minor offences or penalties
- Protected cautions
- Managed health conditions
- Locally managed concerns

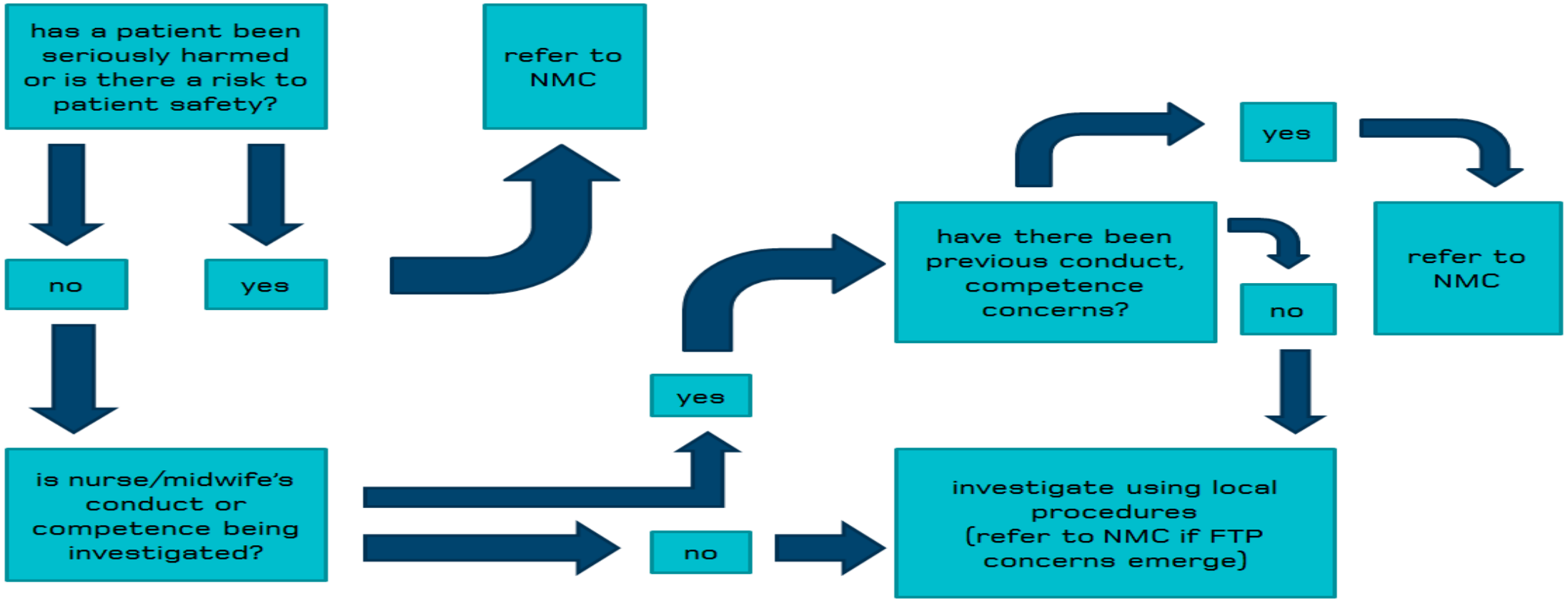
When to self refer

- If you've received a caution or been charged with an offence
- If you've received a conditional discharge about or have been found guilty of a criminal offence that isn't a protected caution or conviction
- If you've been disciplined by another regulatory or licencing organisation

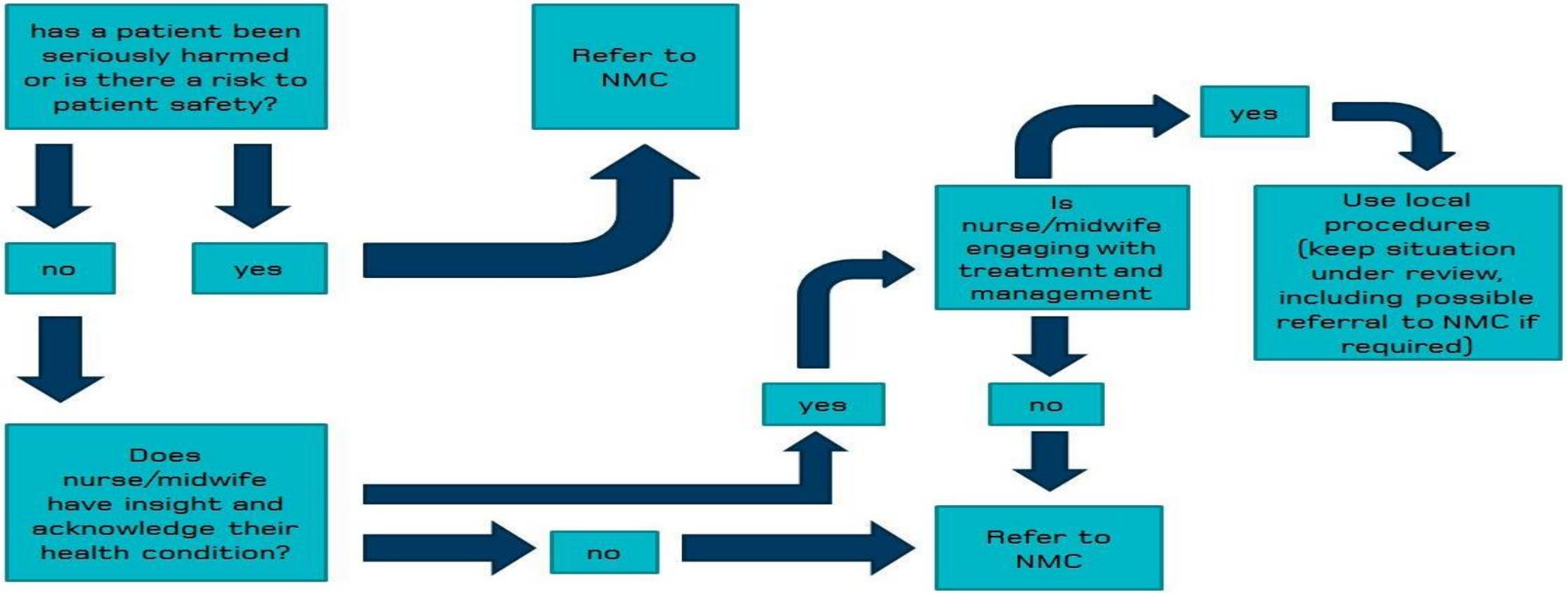
NMC Decision Tree



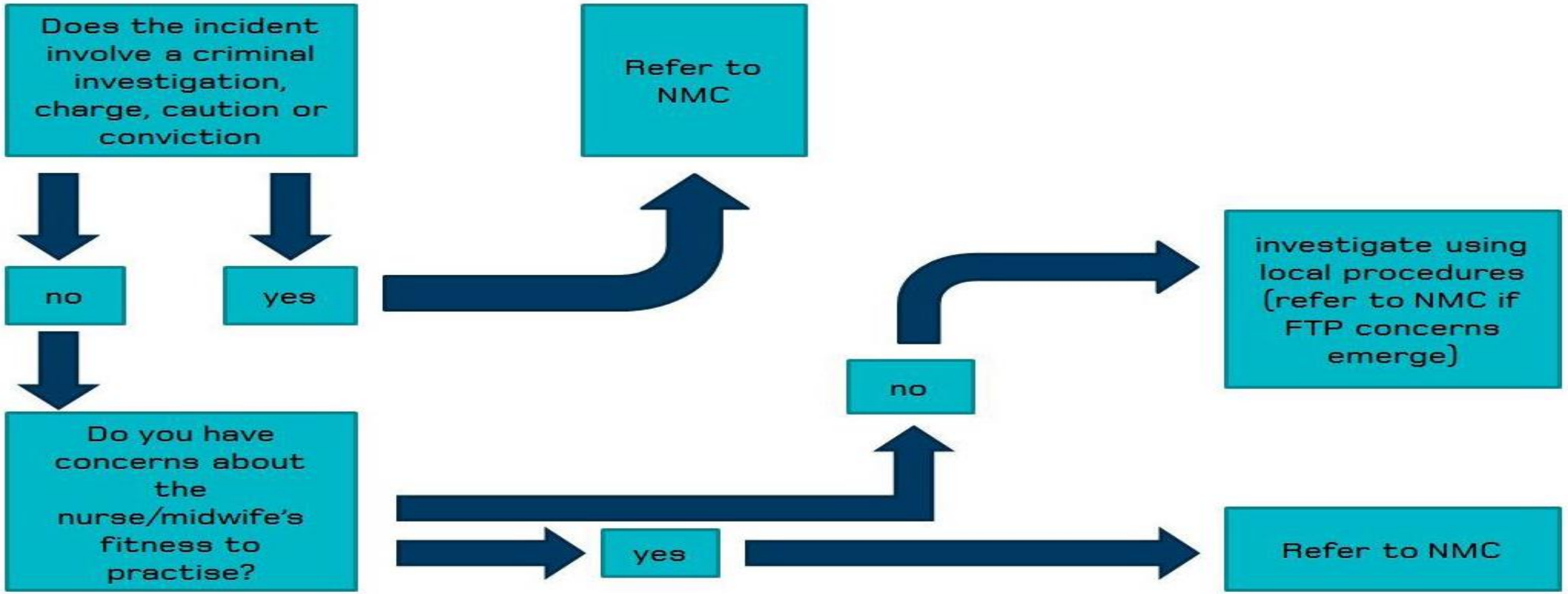
Misconduct and lack of competence



Serious ill health



Character



Challenges with current process

- Silos
- Undefined roles and responsibilities
- Information/email heavy
- Prolonged timeframes
- Person dependent
- Needs streamlined

How do you feel?

Role of Corporate Nursing

- Works in collaboration with Directorates/Divisions
- Provides support and expert advice relating to professional nursing and midwifery issues
- Ensures good governance arrangements are in place relating NMC FTP referrals
- Works closely with NMC and Senior Specialist Advisor
- Liaises with CNO, completes alert and continues to follow up
- Learning from poor practice -closing the loop to ensure safe practice and improved patient experience

Role Of Employment Law Team /HR

- Co-ordinates the administration of Internal FTP and NMC FTP referrals in conjunction with professional guidance/advice
- Provides professional advice, guidance, support to management and staff in line with Trust policies and HR best practice
- Proactive approach –management and resolution of disciplinary, grievance, capability, harassment and working well together
- Resolution methods –mediation and informal grievance solution
- Management of all Industrial/Fair Employment Tribunal application
- Completion of Statutory Questionnaires/consultation with legal advisors and statutory agencies
- Works collaboratively with HR teams e.g. Adult safe guarding team, GMC, NMC, NI Social Care Council, legal services, PSNI, Office of Industrial Tribunal and Fair employment Tribunals, complaints, Agencies and Enforcement Agencies

Role of Directorate Nurse Lead/Professional Head of Service

- Governance role -Assurance and oversight of all Internal FTP and NMC FTP Referrals Cases. Quality assure all referrals
- Provide clinical expertise
- Supportive role to staff
- Ensure correct HR processes are followed
- Embed learning/change practice
- Timely response
- Work in collaboration with Corporate Nursing team to seek advice / clarification in cases of complex / serious.

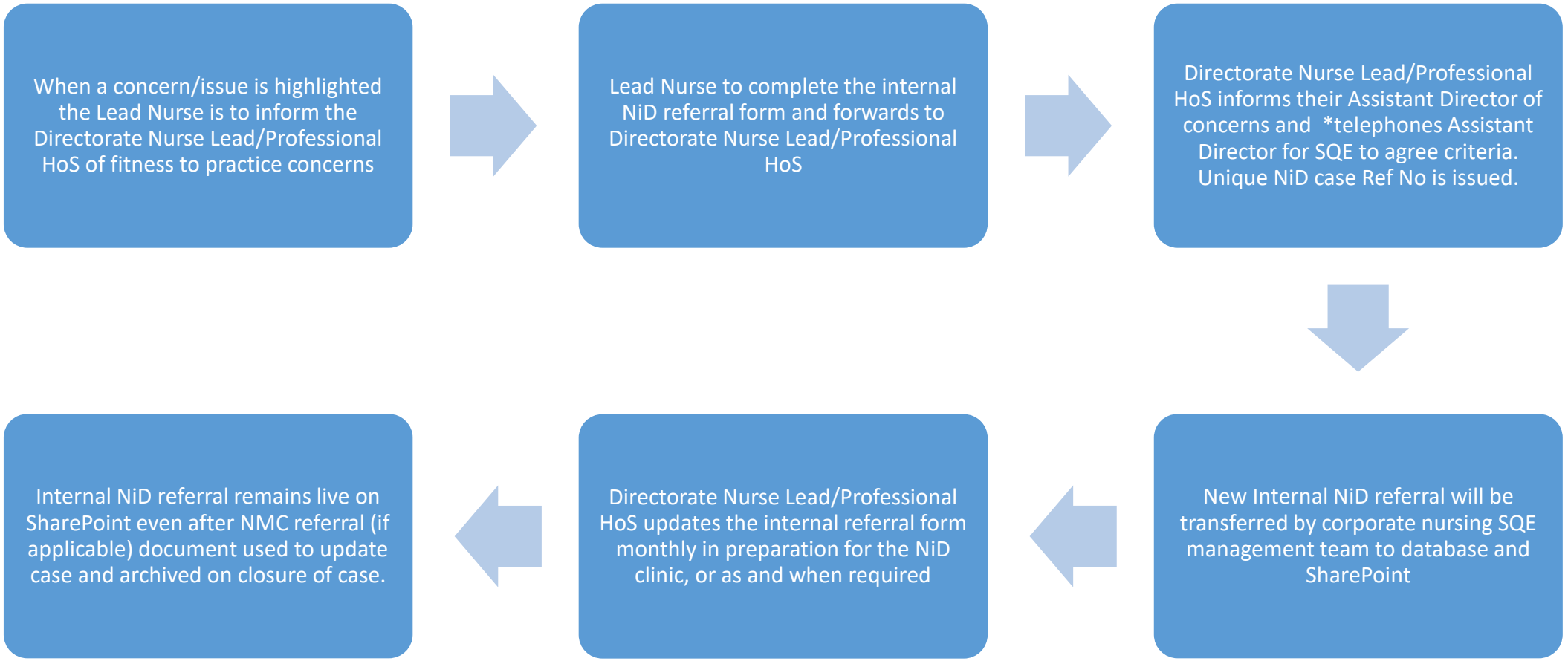
Discussion

Streamlining our processes
Internal Fitness to Practice

Proposed New arrangements

- Completion of NiD forms by Directorate Nurse Lead /Professional Head of Service
- Monthly NiD clinics to raise concerns, seek advice and provide support to NiD and managers
- Dedicated one hour slot for each directorate
- Need to attend or send representative
- HR present
- First clinics to be allocated in April 2022
- Evaluate after 6 months

Proposed Pathway



Agreed actions

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

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

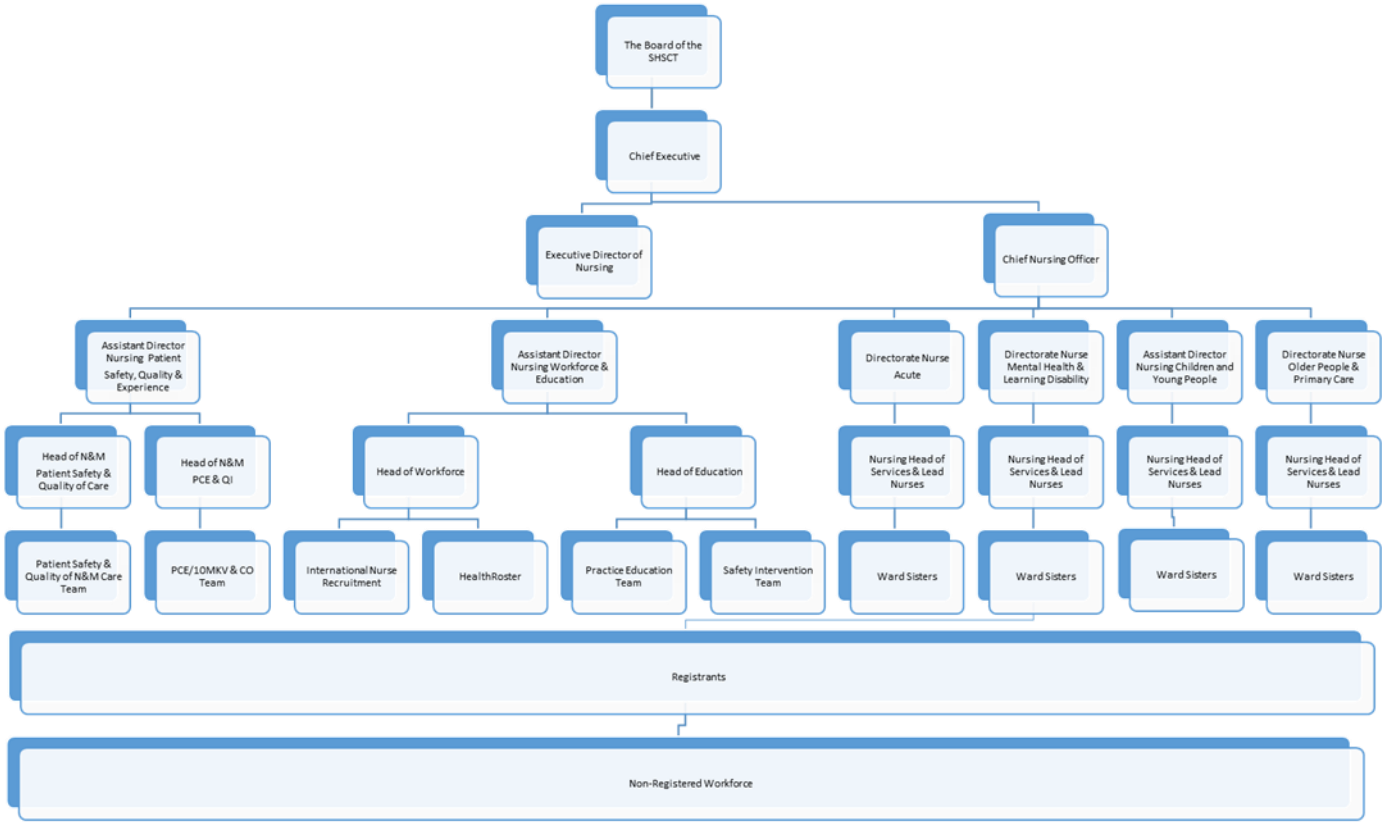
The Trust has a range of mechanisms in place to support assurance and accountability of the Nursing and Midwifery workforce.

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

Department of Health Social Services and Public Safety and Northern Ireland Practice Education Council (2013) Preceptorship Framework for Nursing, Midwifery and Specialist Community Public Health Nursing in Northern Ireland, Belfast: NIPEC.

Department of Health, Social Services and Public Safety (2014) Delivering Care: Nurse Staffing in Northern Ireland

Department of Health (2018) *Standards for Nursing Assistants employed in HSC Trusts by Northern Ireland*. Belfast: DoH

NIPEC (2019) *Deciding to delegate: a decision support framework For nursing and midwifery.* http://nipec.hscni.net/download/projects/current_work/provide_adviceguidanceinformation/delegation_in_nursing_and_midwifery/documents/NIPEC-Delegation-Decision-Framework-Jan-2019.pdf

Nursing and Midwifery Council (2008) Standards to Support Learning and Assessment in Practice Retrieved from https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-to-support-learning-assessment.pdf

Nursing and Midwifery Council (2015) The Code for Nurses and Midwives Retrieved from www.http//nmc.org.uk/standards/code

Nursing and Midwifery Council (2016) *Revalidation* Retrieved from http://revalidation.nmc.org.uk/welcome-to-revalidation

Southern Health and Social Care Trust (no year) *Management Guidance Note: EER 05, Trust's procedure for probationary periods* (SHSCT).

Southern Health and Social Care Trust (2010) *Recruitment and Selection*

Southern Health and Social Care Trust (20211~~13~~) *Corporate Mandatory Training Policy*

Southern Health and Social Care Trust (2016~~3a~~) *Trust Induction Policy*

Southern Health and Social Care Trust (2015) *Policy for the Management of Complaints (Working Draft)*

Southern Health and Social Care Trust (2015a) *Capability Procedure*

Southern Health and Social Care Trust (2015b) *Disciplinary Procedure*

Southern Health and Social Care Trust (2015c) *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*

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

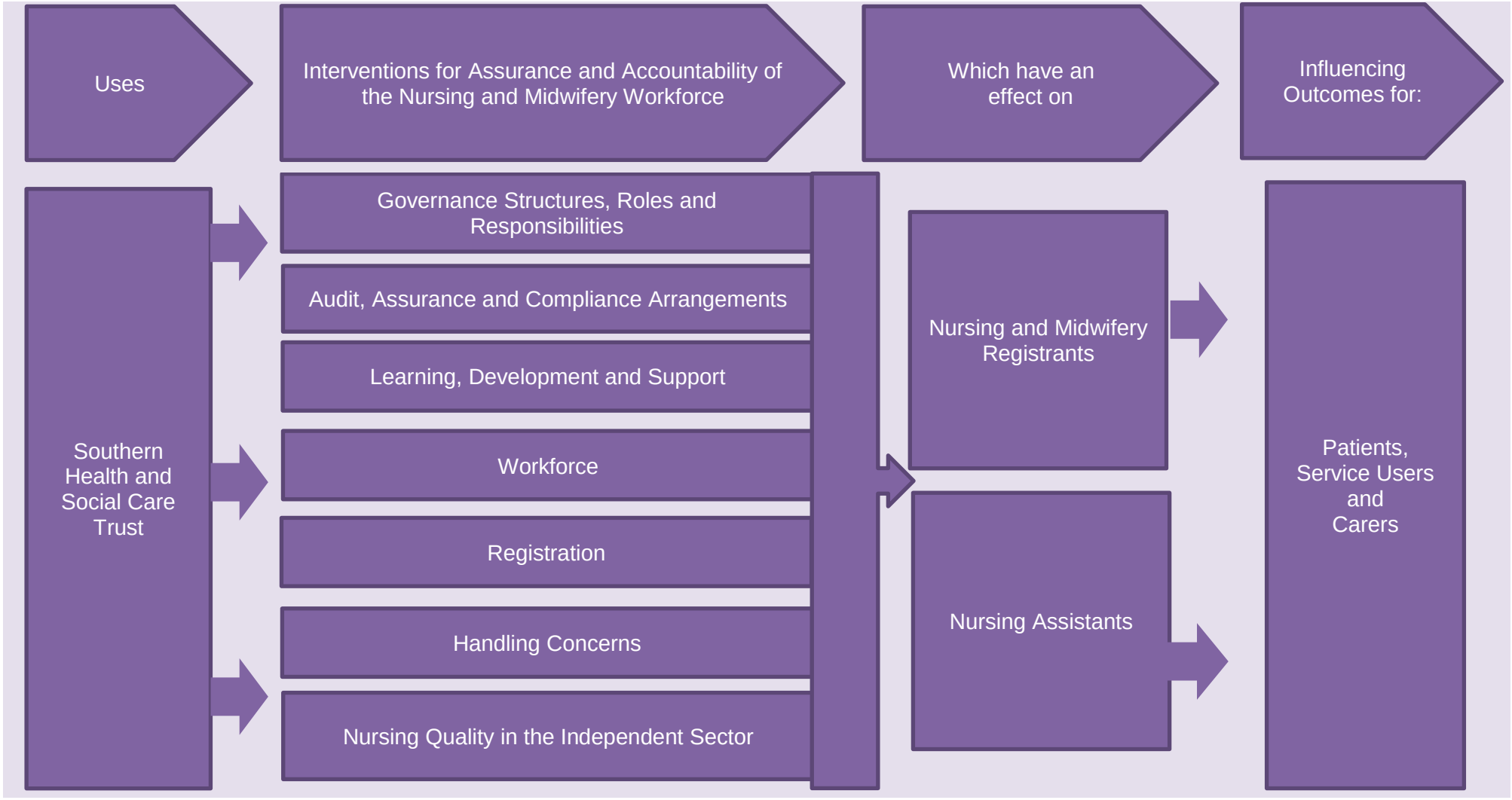
Nursing and Midwifery Accountability and Assurance

Logic Models

Southern Health and Social Care Trust

Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

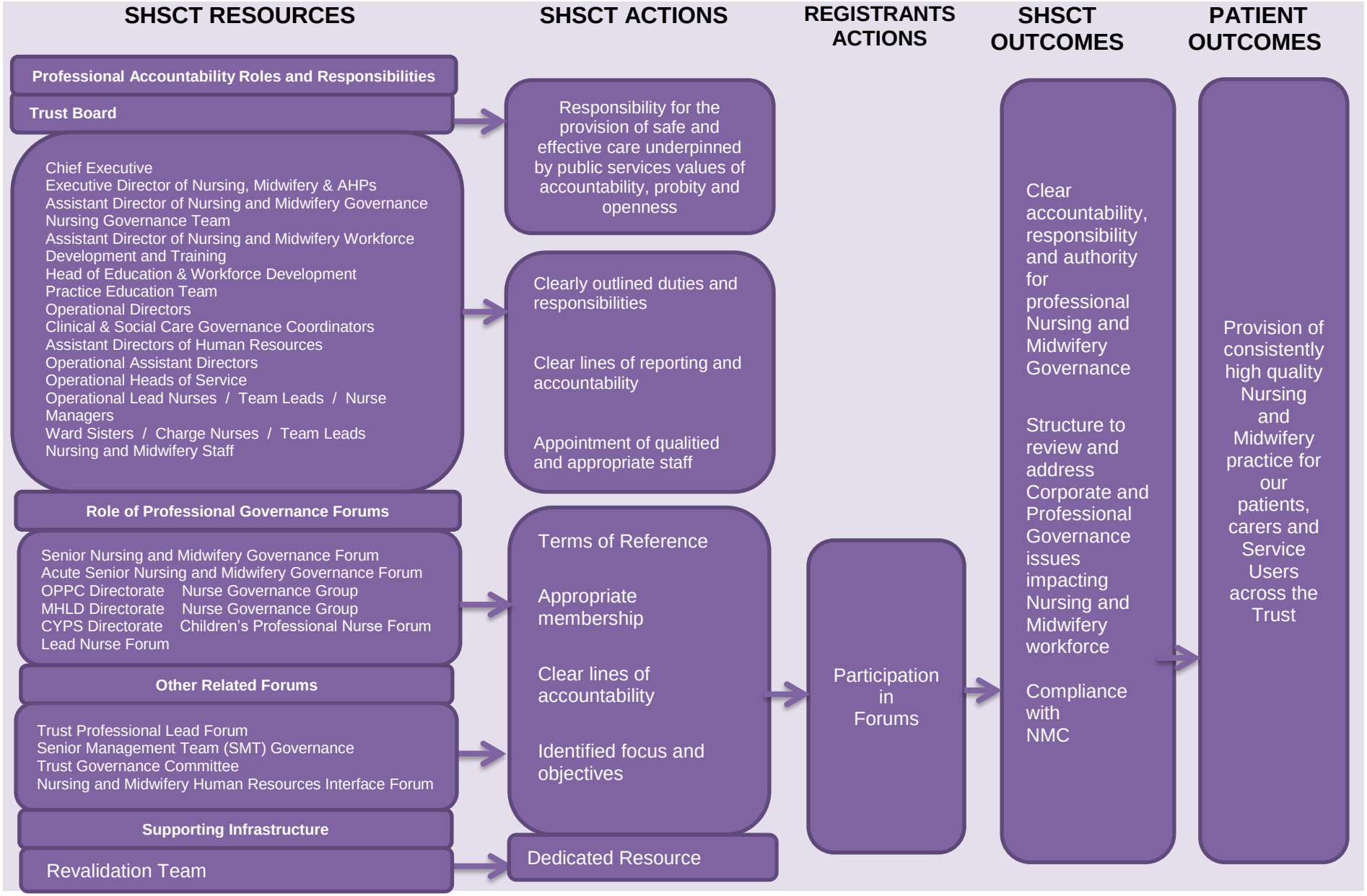


Southern Health and Social Care Trust

Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

Governance Structures, Roles and Responsibilities

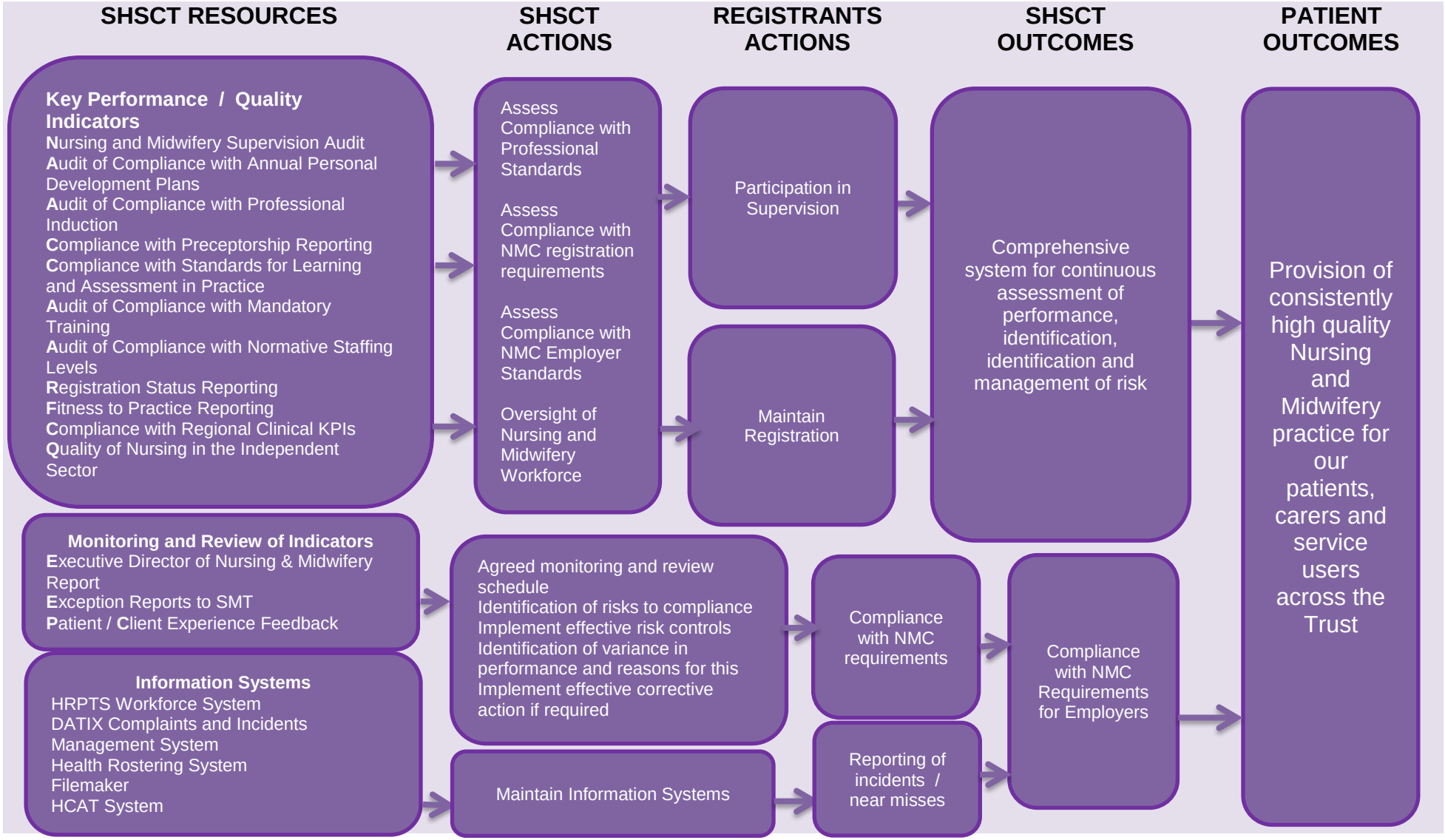


Southern Health and Social Care Trust

Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

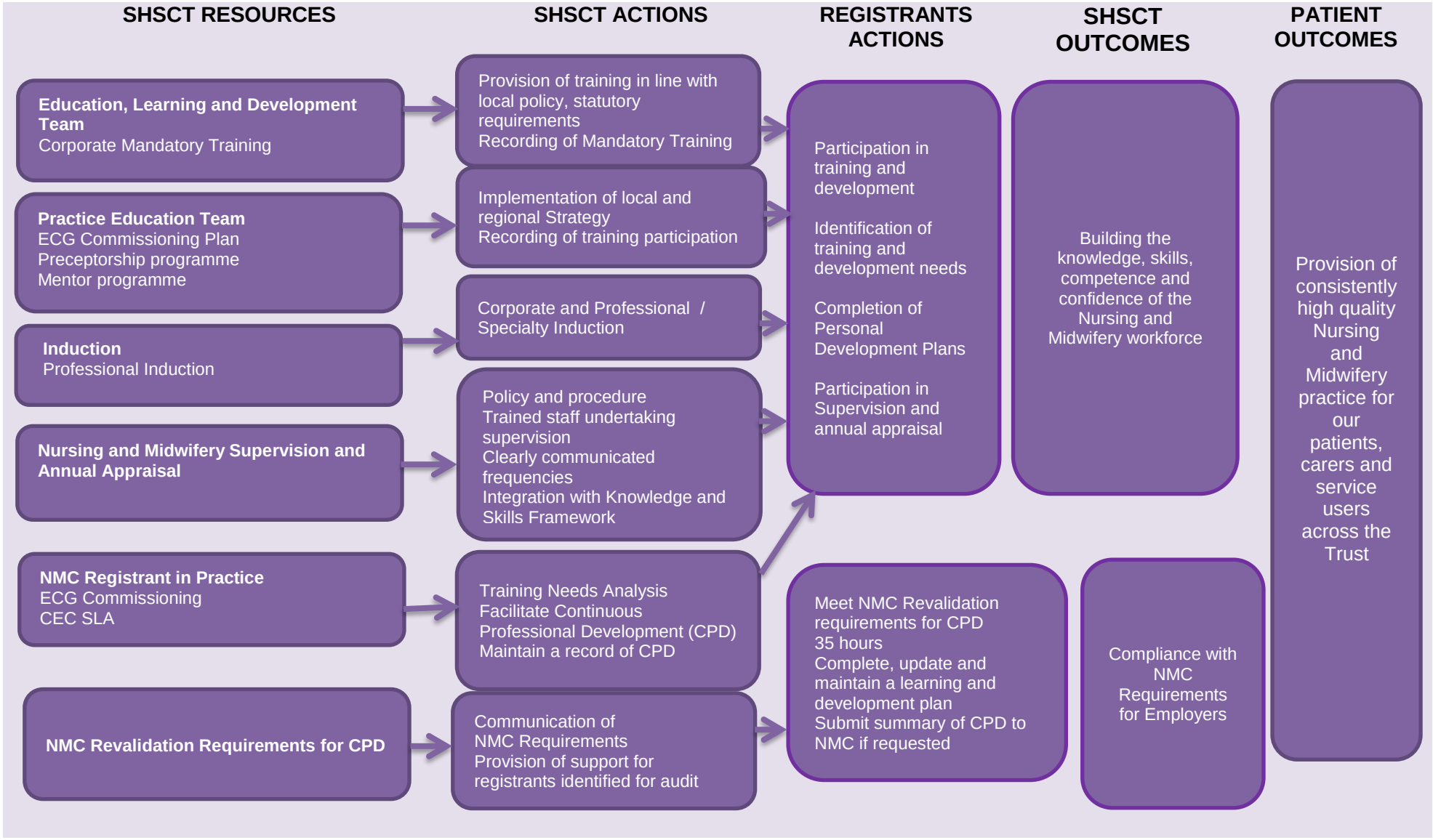
Audit, Assurance and Compliance Arrangements



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

Accountability and Assurance Framework
Nursing and Midwifery

Learning, Development and Support

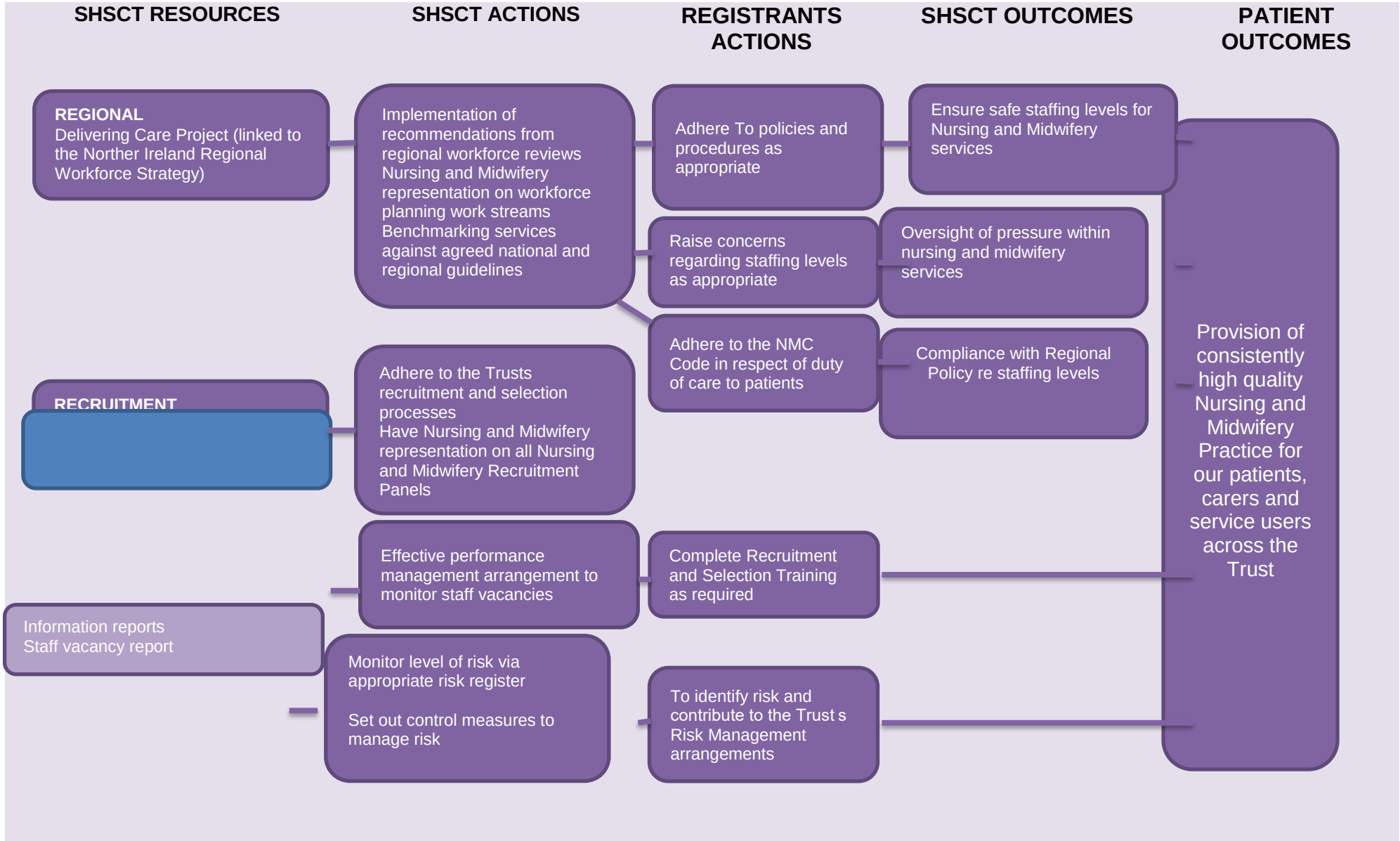


Southern Health and Social Care Trust

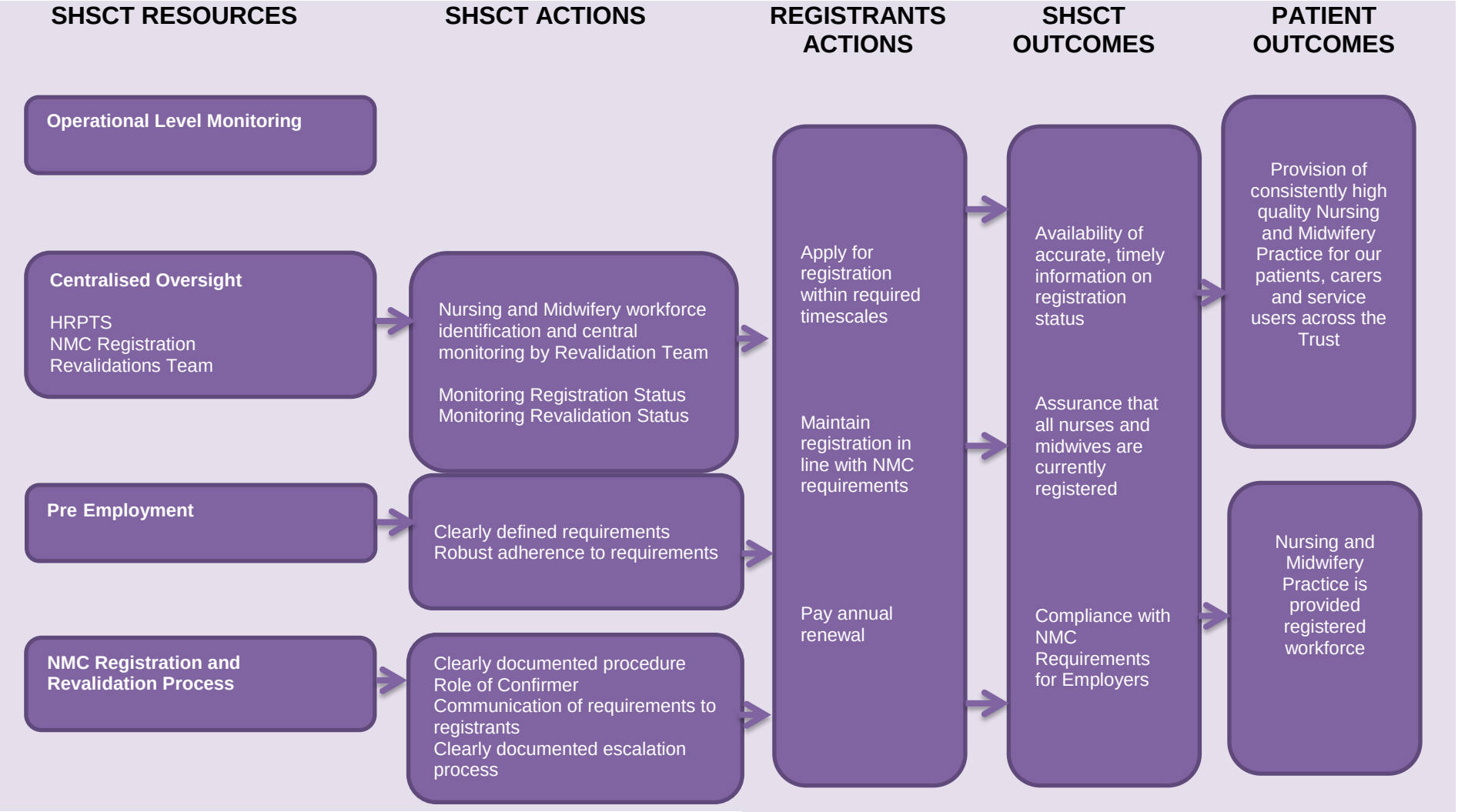
Quality Care - for you, with you

Accountability and Assurance Framework
Nursing and Midwifery

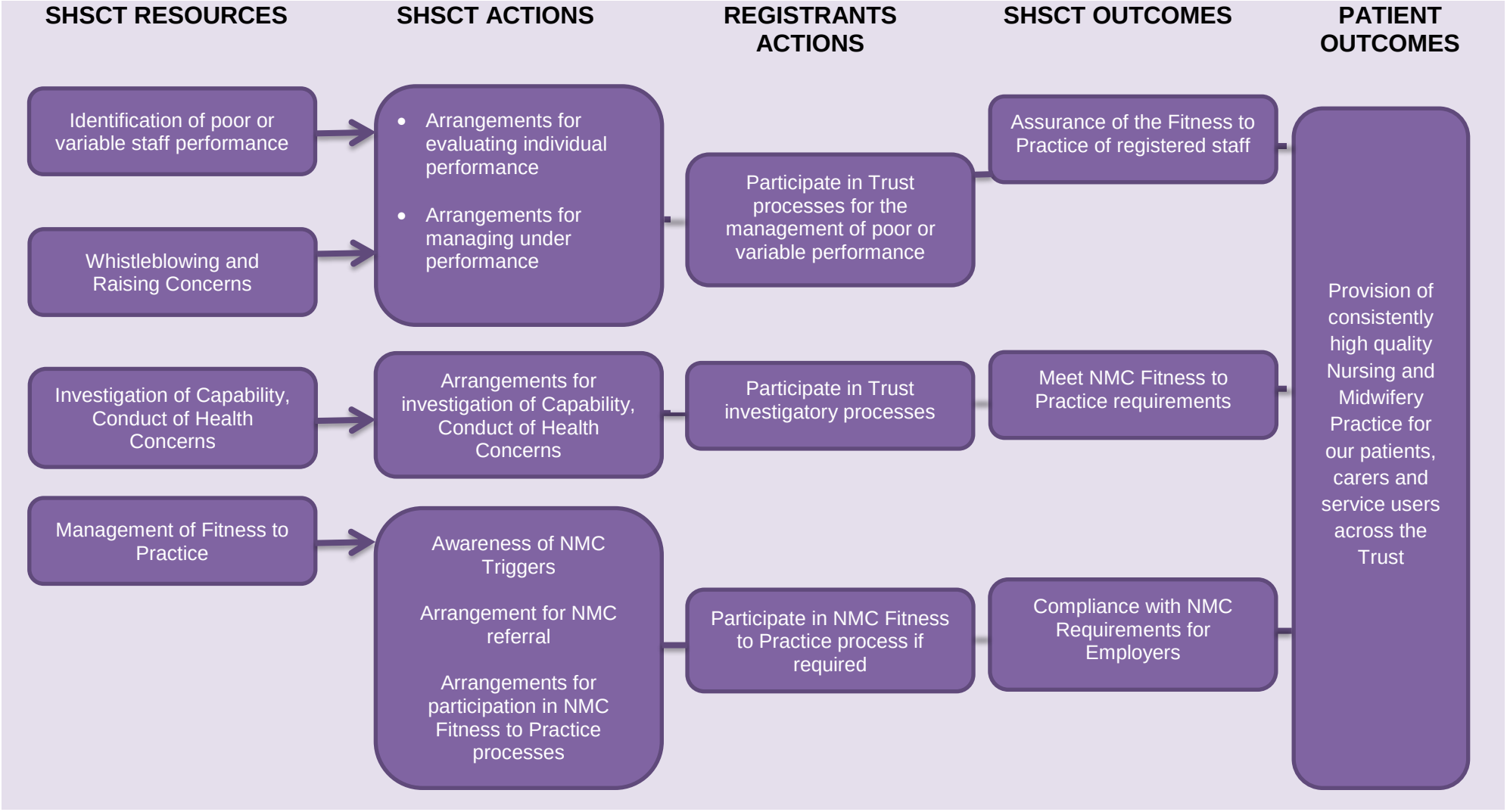
Workforce



Registration



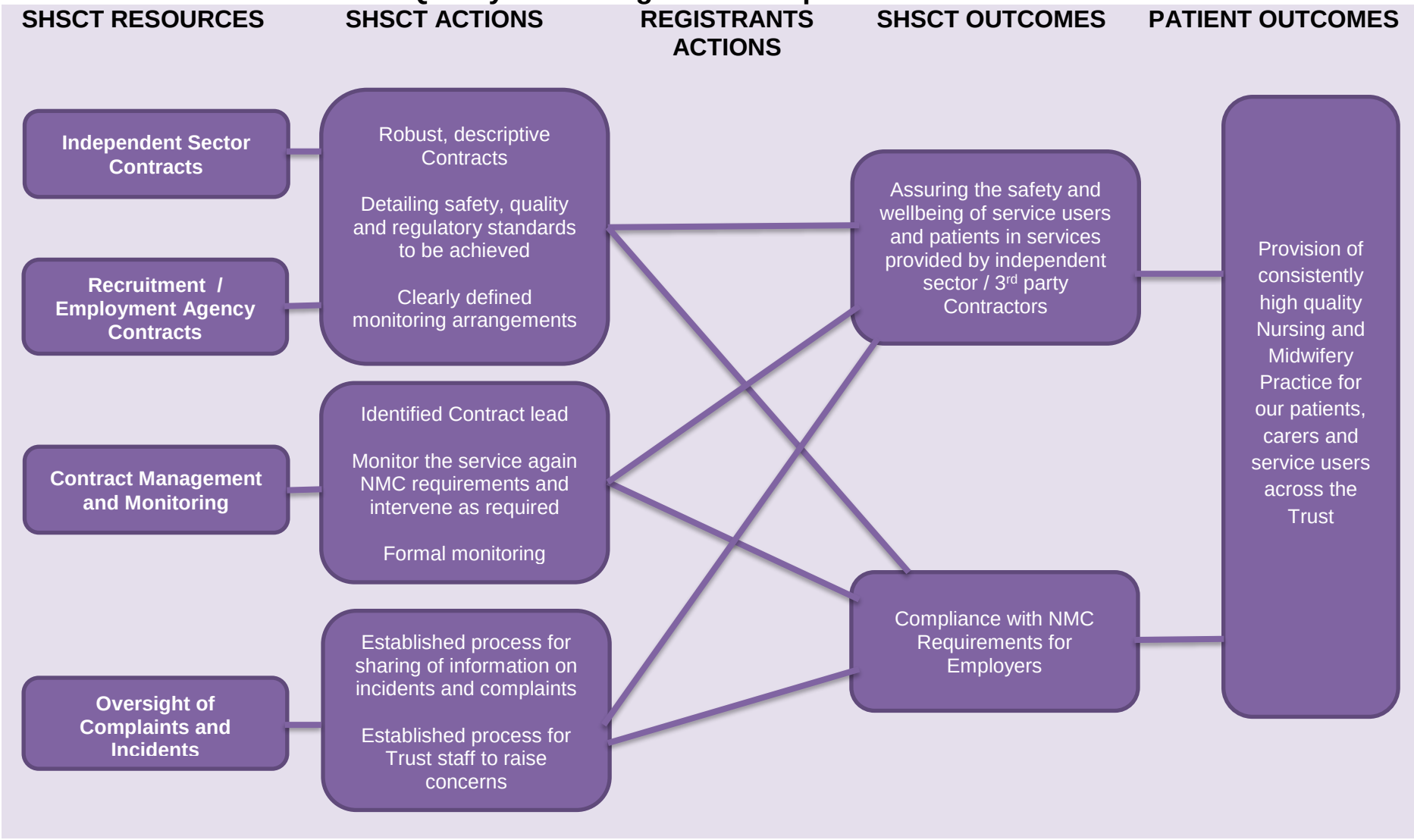
Handling Concerns



Accountability and Assurance Framework

Nursing and Midwifery

Quality of Nursing in the Independent Sector



Response To
Trust's Proposals for Ward Reconfiguration

Department of Urology
Craigavon Area Hospital

May 26th, 2009

The members of the Department of Urology in attendance at the meeting of the Clinical Forum of Tuesday 12 May 2009 were invited to consider the Trust's initial proposals for Ward Reconfiguration in conjunction with the discussions which took place at that meeting, with a view to returning to the next meeting of the Clinical Forum on Tuesday 26 May 2009 with their own reflections and/or proposals for the way forward.

Those members have met with others on two occasions since then. Arising from those meetings, this paper attempts to encapsulate our understanding of the challenges faced by the Trust in the future delivery of surgical services in general, in additional to the challenges faced by the Trust and our Department in implementation of the recommendations of the Regional Review of Urology Services in Northern Ireland. It seeks to articulate core values and principles which we believe should be safeguarded in meeting those challenges. It details proposals which we believe are constructive and essential if the challenges are to be met with success. Lastly, they are proposals to which all members of our Department would be wholly committed, in partnership with the Trust, in ensuring that success.

Challenge facing the Trust

It is our understanding that the Trust is presented with the need to deliver surgical services during the current financial year with a reduced budget. It is also our understanding that it is anticipated that the Trust will be required to deliver surgical services during coming years with possibly more stringent budgetary conditions.

We also understand that the Trust is required to comply with the Elective Reform Program (ERP), Developing Better Services (DBS), and the Integrated Elective Access Protocol (IEAP). We appreciate that the Trust is required to implement the measures recommended by the Scheduled Care Reform Program (SCRP), including

- Preoperative assessment, to facilitate
- Admission on day of surgery, and
- Increased day surgery rates, and
- Reduction of cancelled operations
- Maximising use and productivity of theatres

We appreciate that the Trust will be expected to benchmark their performance in these areas.

Lastly, it is our understanding that Trust management have concluded that introduction and implementation of these measures would enable the Trust to comply with HSC expectations and to remain within imposed budgetary constraints, while continuing to provide quality elective and non-elective surgical services with such capacity as to meet demand.

Regional Review of Urology Services in Northern Ireland

A regional review of Urology Services in Northern Ireland was established in September 2008 and reported in March 2009. The stated purpose was to '*develop a modern, fit for purpose in 21st century, reformed service model for Adult Urology Services which takes account of relevant guidelines (NICE, Good Practice, Royal Colleges, BAUS, BAUN). The future model should ensure quality services are provided in the right place, at the right time by the most appropriate clinician through the entire pathway from primary care to intermediate to secondary and tertiary care.'*

The report of the review presented a modernisation and invested plan. It presented 26 recommendations to be implemented by all Trusts and Departments of Urology in Northern Ireland. Fundamental to all is the recommendation that all Urological services in Northern Ireland should be reconfigured into a 3 Team model (known as Team North, Team East and Team South), to achieve long term stability and viability. Each Team is to have '*main, acute, elective and non-elective, inpatient unit'.*

Team South is to provide Urological services to the southern third of the current Western Trust area (County Fermanagh, population circa 61,000), in addition to all of the current population of the Southern Trust area (342,754): an increase of approx. 20%. Team South will require 5 Consultant Urologists and will have its main, acute, elective and non-elective, inpatient unit at Craigavon Area Hospital. Day surgery will be conducted at Craigavon Area, Daisy Hill, South Tyrone Hospitals. Outpatient clinics will be conducted at Craigavon Area, Daisy Hill, South Tyrone and Armagh Community Hospitals as well as Banbridge Polyclinic, as at present. In addition, it is recommended that Team South may wish to consider the provision of outreach clinics and/or day case diagnostics at the Erne Hospital, Enniskillen.

Therefore, the Review has established that its purpose requires the reconfiguration of Urological Service provision in Northern Ireland by three Teams, and that each Team requires a Urology Unit in its main, acute hospital.

Non-elective Urological Services

There are approx. 2,500 non-elective urological admissions per annum in Northern Ireland (Report 3.18). There are only two Urology Units (at Belfast City and Craigavon Area Hospitals) to which acute admissions are admitted directly or subsequently transferred, if required (Report 3.22). Team North should also have a *'main acute unit'* for non-elective admissions (Report 9.6). The Report's Recommendations 7 and 8 state that Urologists *'should develop and implement clear protocols and care pathways for Urology patients requiring admission to an acute hospital which does not have an acute Urology Unit…and for those requiring direct transfer and admission to an acute Urology Unit'.* With specific relevance to Team South, Recommendation 9 states that *'Trusts should ensure arrangements are in place to proactively manage and provide equitable care to those patients admitted under General Surgery in hospitals without Urology Units (e.g., Daisy Hill, Erne). Arrangements should include 7 day week notification of admissions to the appropriate Urology Unit, and provision of Urology advice/care by telephone, electronically or in person, also 7 days a week'.*

Therefore, the Review has emphasised the need for each Team to have a Urology Unit to which acute urological admissions can be admitted directly or transferred, and from which the care of those admitted elsewhere can be advised, monitored, supervised. Moreover, with the implementation of Development of Better Services (DBS) in future years, increasing proportions of acute urological admissions will be admitted directly to Urology Units.

Reducing Length of Stay (LOS)

The Review's recommendations 13 and 14 states that *'Trusts should implement the key elements of the elective reform program… and should participate in a benchmarking exercise of a set number of elective (procedure codes) and non-elective (diagnostic codes) patients…with a view to agreeing a target length of stay for these groups of patients'.*

In doing so, the Review acknowledged that some hospitals would expect to have longer than average LOS if they undertake more complex operations, treat patients with greater comorbidity and patients with higher levels of social deprivation (Report 5.14).

The Review also stated that ERP will require Urology Services to be creative in the development of day and short stay surgery, *'ensuring the provision of a safe model of care that provides a quality service to patients'* (Report 5.22).

Therefore, the Review requires a benchmarked reduction in Length of Stay whilst ensuring a safe, quality service to patients.

Day Surgery

The Review noted the implications of the Audit Commission recommendations for day surgical rates across a number of surgical specialties, and the more specific recommendations of the British Association of Day Surgery (BADS) for day surgical rates for 31 urological procedures (Report 5.19). Review recommendation 15 states that *'Trusts will be required to include in their implementation plans, an action plan for increasing the percentage of elective operations undertaken as day surgery…'.*

Importantly, the Review states that Trusts will need to *'consider procedures currently undertaken using theatre / day surgery facilities, and the appropriateness of transferring this work to procedure / treatment rooms, thereby freeing up valuable theatre space to accommodate increased day surgery'* (Report 5.23).

Therefore, the Review wholly requires Trusts and Urology Teams to maximise day surgery rates and to be creative in that endeavour.

Values and Principles

With all of the relentless challenges that we all have to face and for which we will be held accountable, whether collectively or individually, whether manager, doctor or nurse, we believe that it is critically important to reflect upon and to redefine our *raison d'etre.* In the context of considering ward reconfiguration, *we are a hospital.*

Several of the component activities of an integrated Urology Service detailed in the Review Report (some, such as ICATS, not referred to above) need not be conducted in a hospital at all, though for several reasons, we believe that it is preferable. However, the one component that can only be conducted in a hospital is the care of those so ill, or requiring management so significant, as to require inpatient care.

We believe that urological inpatient care can only best be provided by doctors and nurses fully trained, qualified, competent and experienced in urological inpatient care. This belief is wholly and unreservedly supported by the British Associations of Urological Surgeons and Nurses, in recent publications and communications.

Therefore, we believe that it is self-evident that the only manner in which such urological inpatient care can possibly be provided is in a distinct, dedicated, inpatient Urology Unit.

The provision of such a Urology Unit is compliant with the Recommendations of the Regional Review.

We believe that it is equally self evident that all urological inpatients should be managed in the Urology Unit, whether elective or non-elective, and irrespective of their length of stay.

We believe that elective, urological, day surgery should be provided in adequately resourced units which do not compromise the ability to maximise inpatient care.

Lastly, we assert that it is incumbent upon all to have robust evidence to support any claim that any different model proposed for urological inpatient care provides for a quality of care and clinical outcomes superior to that above.

Department of Urology Proposals

1. The Trust should firstly explore the possibility of moving all elective flexible cystoscopies out of day surgical theatres and into outpatient procedure rooms. This would be particularly worthwhile at CAH, moving flexible cystoscopies from DSU to the Thorndale Unit. This alone would free up six theatre sessions per month for elective day surgical procedures. Similar possibilities should be explored at STH and DHH.
2. The Trust should maximise the provision of adequately resourced, elective, day surgical facilities at all sites, so as to minimise the inappropriate use of inpatient beds for day surgery.
3. With concerns regarding continuity of care, we commit, where necessary, to having elective, short stay patients admitted on the day of surgery to that elective admissions ward, but only on condition that they return postoperatively to the Urology Unit.
4. All longer stay, elective admissions will be admitted to the Urology Unit, and remain there until discharge.
5. All non-elective admissions will be admitted directly to, or transferred to, the Urology Unit.
6. The Urology Unit will be singular and distinct. Any compromise of its integrity would disable implementation of the Regional Review.

Southern Health and Social Care Trust

Cancer information pathway recording form

Version 1 February 2015

Place addressograph here

Assessment and provision codes:

P	Patient accepted paper copy		D	Patient declined information
DC	Patient declined, carer accepted		NA	Information not relevant
S	Patient was signposted and assisted to seek own copy		O	Other; you may wish to write a note

KEY WORKER DETAILS:	

Information Given	**Code**	**Date**	**Completed by**
CNS contact details			
Macmillan Cancer Guide			
Macmillan CAB Flyer			
Cancer Survivorship website flyer			
Information for you & About this pack			

Site specific information for patients

ONeill, Kate

From: ONeill, Kate <[redacted]>
Sent: 15 May 2015 15:32
To: Young, Michael; O'Brien, Aidan; Glackin, Anthony; Haynes, Mark; Suresh, Ram; ODonoghue, JohnP
Cc: McMahon, Jenny; Corrigan, Martina
Subject: RE: Involvement of Key Worker & Provision of Patient Information
Attachments: Recording form Generic Feb 2015.doc

Dear Gentlemen,

In keeping with Peer Review we plan to keep a record of information provided to all patients diagnosed with a cancer.

At the point of diagnosis after seeing the Consultant/with the Consultant (whichever is appropriate), we would hope to have a member of the nursing team available to meet with the patient/family.

The above document will be completed to record:

- Core Macmillan information provided
- Site specific information provided
- The name of the Key Worker

The above document will then be filed in the patient's medical notes as a permanent record. We shall also record if the patient chooses to decline the information, bearing in mind they can always be offered an opportunity at a later date.

If we work in collaboration with this we should continue to improve our service to the patients.

Regards,
Kate

Appendix 4: Service Improvement Action plan based on patient feedback 2016/17

Area	Lead responsibility	Date	Update
Appointment of two extra nurses to the Thorndale Unit	Martina Corrigan /Kate O'Neill	Dec 2016	Two new clinical sisters have been appointed and will take up post early 2017
Allocation of Clerical staff to the Thorndale Unit	Martina Corrigan	Dec 2016	New clerical staff member appointed to the unit
Allocation of named Key Worker to all newly diagnosed patients	Urology consultants / CNS's	Dec 2016	All newly diagnosed patients are allocated a key worker and contact details provided to the patient along with the core information pack and site specific information
Ensure a Holistic Needs Assessment is completed for all newly diagnosed patients	Kate O'Neill / CNS's	Ongoing	Due to appointment of new staff, work is ongoing to ensure that an assessment is being completed for all newly diagnosed patients
Pilot a Permanent Record of Management for all newly diagnosed patients.	Urology consultants / nurses	Oct-December 2016	Permanent record of management form developed and implemented for 3 months. Patient evaluation to be completed and results shared with Urology team for further consideration.

Pilot a community prostate review clinic	Martina Corrigan / urology team / Mary Haughey	June 2017	Steering group established to take forward community based review clinics for stable prostate cancer patients

CNS Proforma

CANCER CNS PROFORMA

Form will be emailed to admin.cancersupportworkers@southerntrust.hscni.net

PATIENT DETAILS

Name: *

DOB: *

H+C: *

Tumour Site: Choose an Item *

Date of Referral:

Date of 1st Contact:

Date of MDM:

Type of Contact: Choose an Item.

Reason for Contact: Choose an Item.

CNS (Please choose your name): Choose an Item.

Consultant:

Hospital Site: Choose an Item.

Treatment Intent: Curative ☐ Palliative ☐

Patient Type: New ☐ Recurrence ☐ Benign ☐

CNS Email

Diagnosis:

Staging:

Treatment Received

Chemotherapy ☐ Radio ☐ Surgery ☐ Supportive Care ☐ A/S ☐ W/W ☐ Other:

Reason for referral to service

Breaking bad news: ☐

Pain Management: ☐

Other Symptom Management: ☐

Holistic Needs Assessment: ☐

Rapid Access: ☐

Inpatient: ☐

Newly Diagnosed: ☐

Disease Progression: ☐

Pathway (if applicable)

Shared Care: ☐

Consultant Led: ☐

Contact info given: Choose an Item.

Core info pack given: Choose an Item.

HNA

HNA Status: Choose an Item.

HNA to be booked: Yes ☐ No ☐

If yes, when:

Additional Info:

H+WB Event: Choose an Item.

Relevant Information:

Referrals to other services

Move more: ☐

Hospice: ☐

Charis: ☐

Community Macmillan Team: ☐

Smoking cessation: ☐

Counsellor/Psychologist: ☐

CAB referral: ☐

Macmillan Information Support Services: ☐

SDA Patients: ☐

Other, Please Specify:

CAPPS updated: Yes ☐ No ☐

Date of Death (if applicable):

Send to Admin Cancer Support Workers

Southern Health and Social Care Trust

Department of Urology

Addressograph label or patient details

Patient Name

DOB

H&C Number

Permanent Record Of Management

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

Contact Number for Keyworker: [redacted]

Davis, Anita

From: ONeill, Kate
Sent: 16 June 2017 11:52
To: Holloway, Janice; Campbell, Dolores; McCreesh, Kate; Leonard, Mairead; Mulholland, Nuala
Cc: McCourt, Leanne; Young, Jason; McMahon, Jenny
Subject: FW: RE: Issue raised at the Thorndale Unit Meeting today

Please see email which has been forwarded to all consultants following our meeting this morning.

Thanks,
Kate

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

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

Davis, Anita

From: ONeill, Kate
Sent: 16 December 2021 10:39
To: Clayton, Wendy
Subject: FW: AOB reviews for validation
Attachments: AOB reviews.xlsx

From: Corrigan, Martina
Sent: 11 August 2017 14:49
To: McCourt, Leanne; ONeill, Kate
Subject: AOB reviews for validation

Hi Kate and Leanne

Very difficult to find actual prostate patients in the review backlog so for now I have pulled down all of those on his uro-oncology review waiting list.

If you could use NIECR in the first instance to see if there was an inpatient episode for them and then take it from there.

Remember I have secured additional funding for this, so if you decide to stay on in an evening or come in on a Saturday, just record the time you start and then the time you finish and the casenote numbers of all the patients you check and then I will do the rest.

Thanks so much for agreeing to do this and happy to discuss in detail

Martina

Martina Corrigan
Head of ENT, Urology, Ophthalmology and Outpatients
Craigavon Area Hospital

Changed My Number

INTERNAL: EX Personal Information redacted by the USI ***if dialling from Avaya phone. If dialling from old phone please dia*** Personal Information redacted by the USI
EXTERNAL : Personal Information redacted by the USI
Mobile: Personal Information redacted by the USI

Davis, Anita

From: Clayton, Wendy
Sent: 16 December 2021 12:31
To: Davis, Anita
Subject: FW: RE: Dictation

Follow Up Flag: Follow up
Flag Status: Flagged

Sharepoint

From: ONeill, Kate
Sent: 16 December 2021 12:17
To: Clayton, Wendy
Subject: FW: RE: Dictation

From: Elliott, Noleen
Sent: 17 September 2019 13:50
To: ONeill, Kate
Subject: RE: RE: Dictation

Kate,

Mr O'Brien has not dictated this clinic as yet, however, Patient 148 is attending on Friday 20th September 2019 for Urodynamic studies under AOB.

Noleen

Noleen Elliott
Mr A. O'Brien's Secretary
Level 2 (Beside Bed Lifts)
CRAIGAVON AREA HOSPITAL

INTERNAL: EXT Personal Information redacted by the USI ***if dialling from Avaya phone. If dialling from old phone please dial*** Personal Information redacted by the USI
EXTERNAL Personal Information redacted by the USI

From: ONeill, Kate
Sent: 17 September 2019 12:08
To: Elliott, Noleen
Subject: RE: Dictation

Hi Noleen,

Do you know has dictation been done from AOB clinic Tues 3rd Sept, a patient has been phoning in as he has received no appointments in Belfast yet.

Patient 148 Personal Information redacted by the USI

Thanks,
Kate

Davis, Anita

From: ONeill, Kate
Sent: 12 December 2019 15:42
To: McCourt, Leanne
Subject: FW: RE: Patient Query

From: ONeill, Kate
Sent: 09 December 2019 09:47
To: O'Brien, Aidan
Cc: Elliott, Noleen
Subject: RE: Patient Query

Morning Aidan/Noleen,

RE: Personal Information redacted by the USI Patient 148 (Male / Personal Information)

This patient phoned in this morning. He had missed several calls on Friday and was concerned that either of you may have been trying to contact him. His mobile number is Personal Information redacted by the USI. I was able to update him in relation to his most recent PSA result.

Aidan – he also asked had a referral been sent to BCH as yet in relation to Brachytherapy.

Thank you,
Kate

Histopathology results requested by Mr O'Brien but not signed off on NIECR from January 2019 until 4 August 2020

HCN	Surname	Forename	EXAM DATE	TIME REPORTED	REQUESTED FROM	DESCRIPTION	REQUESTED BY	Comments	Needs followed up
[redacted]	[redacted]	[redacted]	10-Feb-16	12/11/2019 09:13	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURBT 2016 & 2019 - BCG completed & CTU planned	No
			18-Dec-18	02/01/2019 11:49	CAH/OPD	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	B-cell lymphoma referred to Haem	No
			19-Dec-18	03/01/2019 18:26	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Benign TURP was r/v & discharged	No
			03-Jan-19	07/01/2019 13:32	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	G6 (PSA 9.08)Jan 19 PSA now 10.2 MDT 27/08/20 JOD requested MRI	No
			08-Jan-19	22/01/2019 08:52	CAH/CDSU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Benign mucoid cyst excised - no planned r/v	No
			09-Jan-19	15/01/2019 11:14	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Benign TURP - pt aware	No
			09-Jan-19	16/01/2019 16:32	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pTaG2 treated with MMC - flexi July 20	No
			09-Jan-19	16/01/2019 16:29	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	G7 (2013) Many TURBT's & MMC - flexi Aug 20	No
			09-Jan-19	14/01/2019 09:19	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Benign TURP - discharged	No
			16-Jan-19	21/01/2019 17:27	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	G8 (3+5) 2005 EBRT, TURP 2019 Benign	No

Personal Information redacted by the USI			16-Jan-19	05/02/2019 08:01	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Benign TURP	Pt cancelled r/v appt may not know histology result
			16-Jan-19	19/01/2019 14:52	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Benign bladder biopsy - treated for cystitis	No
			16-Jan-19	18/01/2019 16:05	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Bladder biopsy benign MDM r/v to reassure and repeat PSA	Patient aware but PSA not performed
			23-Jan-19	31/01/2019 10:08	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Urothelial tumour treated with EBRT	No
			30-Jan-19	20/02/2019 08:32	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Benign TURP, patient aware	No
			31-Jan-19	06/02/2019 16:24	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	G7 (4+3)bx 2017 TURP 2019 Benign	Could he be changed to LHRHa
			31-Jan-19	06/02/2019 16:39	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	G7 Dublin 2003 G9 TURP 2019 Known to Oncology	No
			06-Feb-19	11/02/2019 18:07	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Bladder bx benign TURP G6	No
			06-Feb-19	11/02/2019 12:26	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pTaG3/TURP benign Flexi Aug 20	No
			06-Feb-19	13/02/2019 16:04	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pTaG3 CIS BCG Neph tube	No
			10-Feb-19	18/02/2019 10:20	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	G(4+5=9) RIP Personal Information redacted by the USI expected	No

Personal Information redacted by the USI			19-Feb-19	28/02/2019 16:00	CAH/CDSU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Scrotal cyst benign patient aware	No
			19-Feb-19	25/02/2019 08:27	CAH/CDSU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Atrophic testis - benign patient aware	No
			20-Feb-19	25/02/2019 09:32	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Atrophic testis - benign, patient aware	No
			20-Feb-19	22/02/2019 18:25	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Urothelial tumour - check flexi's	No
			27-Feb-19	01/03/2019 15:37	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	H/O G6 TURP 2017 Benign on bx	No
			06-Mar-19	13/03/2019 15:43	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	IR1- ongoing Aug 2020	IR1- ongoing Aug 2020
			06-Mar-19	15/03/2019 15:03	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Gleason 3+3 CaP 2013. TURP 2019 to relieve bladder outlet obstruction. Pt aware.	overdue PSA re A/S
			13-Mar-19	22/03/2019 17:17	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Urothelial Ca- RIP Personal Information redacted by the USI - Personal Informati on	No
			13-Mar-19	21/03/2019 13:29	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Known Gleason 10 PC (2018) pT3 N1 M1.. Channel TURP (2019)- Gleason 5+5=10 prostatic adenocarcinoma. RIP Personal Information redacted by the USI	No
			02-Apr-19	08/04/2019 10:17	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pTaG2 - on w/l flexi	No
			02-Apr-19	09/04/2019 11:48	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Known Prostate Ca (intermediate risk - JOD 2016) TURBT 04/19- pT1 G3 TCC. TURP 04/19 showed 3+4 = 7.- WW. Pt aware. Currently having BCG	No

Personal Information redacted by the USI			03-Apr-19	08/04/2019 12:25	CAH/DCC	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Metastatic renal Ca- known to oncology	No
			09-Apr-19	14/04/2019 13:20	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TCC Bladder pTa Grade 2- second induction MMC	No
			09-Apr-19	18/04/2019 12:00	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Squamous cell ca penis. MDM 18/04/19- advises CT CAP. Review 24/05/19, dictated 08/07/19, CT requested 08/07/19 and performed 26/07/19- rec lymph node bx.*** also see later entry on spreadsheet- Oct 19- Lymph node bx showed mets	review timelines - also see entry on spreadsheet Oct 19 re metastatic disease
			09-Apr-19	18/04/2019 09:32	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Gleason 5 + 5 prostatic carcinoma diagnosed January 2019. On androgen blockade since then. Prostate resected to relieve bladder outlet obstruction. MDM Feb 19- c/o LHRHa. 01/03/2019- hot flushes - on medroxy and deferred	review timelines
			09-Apr-19	15/04/2019 16:17	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	h/o TCC bladder. TURBT 09/04/19- no CIS or invasive malignancy. TURP- nodular hyperplasia. MDM for maint BCG- same carried out	No
			09-Apr-19	18/04/2019 12:39	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	bladder biopsy- inflammation and ulceration. Pt aware	No
			16-Apr-19	29/04/2019 13:43	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP benign. Pt aware	No
			16-Apr-19	30/04/2019 16:38	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP benign. No record of histo apt	Unsure if pt aware of pathology
			16-Apr-19	30/04/2019 16:38	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP benign. Pt aware	No
			29-Apr-19	04/05/2019 15:45	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Gleason 4+3 =7 ? Single nodal met on 30/04/19. MDM 09/05/20- c/o LHRHa + refer oncol. C/o bicalutamide 150 mg and tamoxifen 09/04/19. no oncology referral letter, but was seen by oncology 18/10/19	medication deviation and timeline review
			30-Apr-19	03/05/2019 16:37	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pT1 G2/3 2011, EBXRT for Gleason 7 2015. Ongoing surveillance flexis BCH	No

[redacted]			02-May-19	13/05/2019 16:44	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	urothelial Ca.. pt aware. Surveillance flexis	No
			05-May-19	10/05/2019 17:44	CAH/CPB	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	orchidectomy- testicular torsion	No
			14-May-19	21/05/2019 16:53	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Clinical and biochemical diagnosis of advanced PrCa. TURP- benign. Known to oncology. RIP [redacted]	No
			14-May-19	22/05/2019 13:52	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP- Benign. Pt aware	No
			20-May-19	31/05/2019 16:08	CAH/CDSU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Orchidectomy- atrophy	No
			21-May-19	28/05/2019 12:58	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	urothelial Ca- MMC and surveillance flexi	No
			22-May-19	29/05/2019 18:10	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURBT 23/05/19- pTa (gd2). MDM - MMC and surveillance flexi. Pt aware - declined MMC and opted for flexi	No
			28-May-19	12/06/2019 12:45	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP- benign. No evidence of pt being aware	Unsure if pt aware of pathology
			28-May-19	31/05/2019 15:54	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	29/05/20 pTa Gd 3 bladder .MDM re-resection July 19. pt aware and outcome actioned	No
			10-Jun-19	13/06/2019 12:10	CAH/DCC	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	left renal biopsy- no malignancy. For CT- surveillance. Actioned	No
			11-Jun-19	19/06/2019 15:35	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	IR1 ongoing	IR1 ongoing

Personal Information redacted by the USI			11-Jun-19	14/06/2019 17:25	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Left orchidopexy- hydatid of Morgagni	No
			11-Jun-19	14/06/2019 16:22	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Urothelial ca - MDM MMC and flexis- actioned	No
			11-Jun-19	17/06/2019 10:39	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	see entry above	No
			18-Jun-19	26/06/2019 13:55	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP Gleason 6. MDM - A/S- pt awareRIP Personal Information redacted by the USI - Personal Information redacted by the USI	No
			18-Jun-19	28/06/2019 16:15	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP- Gleason 10. MDM actioned RIP Personal Information redacted by the USI	No
			25-Jun-19	04/07/2019 18:12	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP- Gleason 3+3. MDM A/S. Actioned pt aware	No
			25-Jun-19	02/07/2019 09:56	CAH/CEAU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURBT pT1 Gd3. MDM cystect vs BCG and surv. Pt opted for BCG- actioned	No
			25-Jun-19	03/07/2019 18:55	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Testicular Ca. MDM- actioned	No
			01-Jul-19	13/07/2019 17:40	CAH/CDSU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Vasectomy.	No
			02-Jul-19	05/07/2019 15:19	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Resectiom n of stenosed urostomy- no dysplasia or malignancy. Pt aware	No
			02-Jul-19	09/07/2019 09:36	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP 03/07/19 Gleason 4+3 MDM 11/07/19 - assess fitness- WW vs EBRT. Deviation from MDM decision and review timeline.	Deviation from MDM decision and review timeline.

Personal Information redacted by the USI			09-Jul-19	24/07/2019 13:24	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	seminoma- delayed referral to oncology	delayed referral to oncology
			09-Jul-19	15/07/2019 08:48	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Prev CIS and BCG tx. TURBT 10/07- inflammation. MDM 18/07- c/w maint BCG and MRI renal.	No
			10-Jul-19	09/08/2019 18:07	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP 11/07/19- Gleason 3+4 MDM 15/08/19- MRI and repeat PSA	review timeline re ordering of MRI
			10-Jul-19	05/08/2019 16:29	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP 11/07/19 Gleason 4+3 MDM 08/08/19- A/S- pt informed but no PSA since Aug 19	deviance from A/S
			16-Jul-19	30/07/2019 14:47	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP 17/07/19- benign. Pt aware	No
			17-Jul-19	01/08/2019 16:20	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP 18/07/19- benign. Pt aware	No
			17-Jul-19	19/07/2019 15:55	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pTa G2 - for flexi Nov/Dec 19- no record of having flexi	Yes. Email to secretary to arrange flexi
			23-Jul-19	28/07/2019 15:10	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	bladder bx- squamous metaplasia. Pt aware	No
			23-Jul-19	29/07/2019 16:39	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Bladder bx- inflammation . MDM 15/08/19 - CT . Apt 3/09- dictated 27/10. CT 15/11/19	Review timelines. Also needs stent change- secretary emailed (on JOD w/l)
			23-Jul-19	05/08/2019 13:24	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP- Benign. Pt aware	No
			23-Jul-19	29/07/2019 16:38	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pTa g3 MDM 01/08/19- BCG- actioned	No

[redacted] Personal Information redacted by the USI			23-Jul-19	30/07/2019 13:57	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	***see second entry also**** TURP 24/07/19 and further resection 31/07/19. both benign. no record of pt being aware of result	Unsure if pt aware of pathology
			25-Jul-19	29/07/2019 13:11	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	pTa G2. MDM 01/08/19- MMC and CT . Actioned	No
			26-Jul-19	14/08/2019 18:14	CAH/CPB	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	? Torsion. Patho 27/07/19- HYDATID CYST OF MORGAGNI. No evidence pt ware	Unsure if pt aware of pathology
			29-Jul-19	02/08/2019 12:16	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Gleason 7. MDM 08/08/19- all options. Significant LUTS- declined investigations. On maximum androgen blockade - no onward oncology referral	Deviation from MDM . Of note PSA from 15/09/20 has risen to 15
			29-Jul-19	05/08/2019 10:23	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TRUS 30/07/19 3+4=7 (4/10 cores). MDM 08/08/19- rec tx with curative intent. Apt 03/09- LUTS management. Not referred to oncology until 09/02/20	review timelines
			30-Jul-19	14/08/2019 17:19	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	****see previous entry******	Unsure if pt aware of pathology
			30-Jul-19	03/08/2019 15:56	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP benign July 2019, patient made aware Dec 2019	No
			13-Aug-19	15/08/2019 15:45	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Urothelial cancer - MMC & Flexi	No
			13-Aug-19	23/08/2019 08:41	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP G7 1% of tissue - MDM watchful waiting & stop Bicalutamide - patient aware	No
			13-Aug-19	16/08/2019 16:42	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Umbilical lesion - endometriosis - patient aware	No
			20-Aug-19	28/08/2019 15:57	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Orchidectomy - Epidermoid cyst patient aware MDM recommended **MRI Liver**	**USS Abdomen** requested 31/03/20 and remains vetted on system

[redacted]	[redacted]	[redacted]	21-Aug-19	28/08/2019 13:21	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	H/O pTa G2 - benign on this occasion patient aware - follow up flexi	No
			22-Aug-19	29/08/2019 08:45	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Gleason (3+4=7) 6/17cores MDM 29/08/19 refer for radical treatment. Referral sent 20/11/2019	Review timelines
			26-Aug-19	29/08/2019 11:47	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Urothelial cancer - MMC & Flexi	No
			26-Aug-19	29/08/2019 11:36	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP benign, patient aware also H/O pTaG3 ongoing flexi	No
			27-Aug-19	05/09/2019 10:00	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Joint surgery with gynae - Nephrectomy clear cell renal cell ca has since undergone adjuvant chemotherapy	No
			27-Aug-19	03/09/2019 10:34	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	Bladder biopsies & TURP benign, patient aware	No
			27-Aug-19	06/09/2019 14:56	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	TURP 28/08/19 Benign- pt aware	No
			02-Sep-19	16/09/2019 17:02	CAH/CDSU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	03/09/19 - epidymal cystectomy- benign	Unsure if pt aware of pathology
			03-Sep-19	11/09/2019 10:46	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	04/09/19- TURP (BOO) Gleason 9 (first diagnosed 2014) under care of oncology- pt aware	No
			10-Sep-19	17/09/2019 08:45	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/09/19 TURP - benign- pt aware	No
			24-Sep-19	09/10/2019 09:58	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	25/09/2019 TURP- Gleason 6. MDM A/S - pt informed. RIP- subdural haemorrhage .	No

[redacted]			25-Sep-19	30/09/2019 16:30	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	26/09/19- TURBT- recurrence pTa G2 (multifocal. MDM - MMC- pt aware and outcome actioned	No
			25-Sep-19	27/09/2019 16:09	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	26/09/19 TURBT- no recurrence of high risk NMI bladder Ca. pt aware - maintenance BCG and surveillance flexi	No
			07-Oct-19	10/10/2019 17:13	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	08/10/19 TRUS- benign. MDM PSA monitoring. Pt aware and outcome actioned	No
			08-Oct-19	16/10/2019 11:52	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	***also see entry for April 19*** 09/10/19- lymph node bx - metastatic disease. MDM rec LN dissection. Actioned 13/10. pt aware.	review timelines
			15-Oct-19	21/10/2019 15:28	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	known met prostate Ca- ADT and Docetaxol in 2018 . 16/10/19- TURP for LUTS Gleason 8. MDM ongoing review by AOB (also under care of oncology). Outcome actioned	No
			15-Oct-19	04/11/2019 17:27	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	16/10/20- TURP- benign.	Unsure if pt aware of pathology
			18-Oct-19	28/10/2019 14:57	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	19/10/19- TURBT and TURP- pT2 G3- recuurent tumour post XRT. Bilateral nephrostomies on 24/10/19. MDM 31/10- change of nephrostimes and ongoing care - known to pallitive care team. RIP [redacted] - expected death	No
			22-Oct-19	25/10/2019 16:48	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	23/10/19 TURBT- pTa G2 (low) MDM 07/11- flexi 3/12. pt aware. Outcome actioned	No
			28-Oct-19	31/10/2019 12:41	CAH/OPD	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	28/10/19- renal bx- clear cell. MDM 31/10- metastatic renal cell- consideration of fitness for systemic tx vs best supportive care and XRT. Referred to BCH. RIP [redacted] - expected death	No
			30-Oct-19	17/11/2019 17:02	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	30/10/19 TURP benign. Readmitted 24/11/19 with haematuria. No letter to inicated pt aware of results ? Informed during 2nd admission- medical notes need reviewed. No OPD review since surg.	unsure if pt aware of pathology
			30-Oct-19	31/10/2019 16:21	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	30/10/19- bladder bx - benign(H/O high risk non muscle invasive bladder ca- previous reaction to induction BCG)MDM 07/11/19- surveillance flexi 3/12 (07/02/2020)- pt aware and outcome actioned. Next surveillance flexi overdue- secretary emailed	No. Next surveillance flexi overdue (May 20)- secretary emailed. Booked for 21/09/20

Personal Information redacted by the USI							
		31-Oct-19	12/11/2019 09:43	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	31/10 TURBT pTa Gd 3 + CIS. MDM 7/11- refer to Central. 21/11/19- Central MDM not discussed . BCG and surveillance flexi. Pt aware	No
		05-Nov-19	12/11/2019 18:21	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	05/11/19- TRUS- Gleason 6. MDM 14/11/19- A/S- pt informed	No
		05-Nov-19	07/11/2019 09:51	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	05/11/19- TRUS Gleason 9 MDM 14/11/19- initiate androgen blockade and for bone scan and CT . Pt seen 20/12/19 and c/o bicalutamide 150mg and tamoxifen 10 mg OD. Scans ordered 10/02/20 and carried out end of Feb 20 . Pt informed of results 14/03/20	review timeline re scans. No onward to oncology
		06-Nov-19	23/11/2019 14:27	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	06/11/19- TURP- benign. Pt aware	No
		06-Nov-19	11/11/2019 14:23	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	06/11/2019 TURP- benign (H/O Gleason 6). MDM 28/11/19- c/w AS. Pt aware	No
		06-Nov-19	25/11/2019 09:15	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	06/11/19- TURP- benign. Pt aware	No
		13-Nov-19	21/11/2019 10:23	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	13/11/19- circumcison- Squamous cell pT1b. MDM 21/11/19- refer to Altnagelvin. Pt aware and outcome actioned	No
		14-Nov-19	15/11/2019 16:41	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	14/11/19 TURBT pT1 g2 (high). Pt aware MDM 21/11/19- re-resection- actioned, CTU-performed 29/02/20, CT chest 29/02/20	review radiology timeline
		15-Nov-19	20/11/2019 17:03	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	15/11/19 Redo TURP Gleason 7. MDM 28/11 staging MRI and back to MDM. Pt informed. AOB letter for UDS and if no further BOO surgery required then for MRI. UDS 07/02/20- detrusor overactivity. MRI 01/04/20- rT3a N0.- high risk disease	review radiology timeline
		19-Nov-19	22/11/2019 12:12	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	19/11/19 TRUS Gleason 7. MDM 28/11/19 curative tx vs watchful waiting. Pt aware	No
		19-Nov-19	21/11/2019 16:43	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	19/11/19 TRUS Gleason 7 PSA 79. bone scan no mets. MDM 28/11 for CT CAP and consider early referral to oncology. Apt 20/12/19 -c/o bicalutamide 150 mg with tamoxifen. Not referred to oncology until 11/07/2020	Deviation from MDM decision- review timeline

[redacted]			20-Nov-19	26/11/2019 14:20	CAH/UOP	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	20/11/19- lung biopsy- no diagnosis. MDM 05/12/19- review and further discussion with radilogy re repat bx. Pt aware. Outcome actioned	No
			22-Nov-19	26/11/2019 17:13	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	22/11/19 TURBT- pTa (g2 low). MDM 05/12/19- CTU and endoscopic surveillance. CTU ordered 06/12 to be completed in March 20 (performed 05/03/20)Endoscopic surveillance actioned	review timeline for CTU
			27-Nov-19	29/11/2019 17:45	CAH/3ESU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	27/11/19- renal biopsy. No malignancy evident. Limited tissue. MDM 12/12/19- review and order renal MRI. Pt aware outcome actioned	No
			27-Nov-19	05/12/2019 12:07	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	27/11/19- resection of bladder mucosa and posterior bladder outlet - BPH. MDM 05/12- defer for expert opinion on pathalogy. *** see below***	No
			27-Nov-19	16/12/2019 09:11	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	BPH MDM 12/12/19- benign pt aware.	No
			29-Nov-19	03/12/2019 17:08	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	29/11/19-TURBT PT2 Gd 3 MDM 05/12/19- now muscle invasive. Staging CT CAP, Bone Scan and rediscuss. Pt aware. Outcome actioned	No
			11-Dec-19	03/01/2020 11:43	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/12/19 TURP- benign. unsure if pt aware- nil on ECR	unsure if pt aware of pathology
			11-Dec-19	16/12/2019 13:07	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/12/19 TURBT pTa Gd 2 (high)multifocal. MDM 19/12/20- early re-resection . Pt informed 03/01/20 and booked at that time for cystoscopy +_ TURBT March 20	review timeline for early re-resection
			11-Dec-19	17/12/2019 09:56	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/12/19- bladder biopsy- inflammation. MDM 19/12/19- surveillance flexi March 20. pt aware, outcome actioned	No
			19-Dec-19	07/01/2020 17:01	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	19/12/19 TURP Gleason 6. 06/02/20 MDM- PSA surveillance . Pt aware	No
			03-Jan-20	10/01/2020 11:53	CAH/OPD	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	03/01/20- USS guided renal bx- inadequate for diagnosis ***see entry below***	No

[redacted] Personal Information redacted by the USI							
	03-Jan-20	09/01/2020 09:02	CAH/OPD	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	03/01/20 CT guided renal bx- eosinophillic renal cell. MDM 23/01/20 - review re cytoreductive lap neph and refer for systemic tx	No
	07-Jan-20	11/01/2020 15:06	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	07/01/20- TRUS Gleason 7 MDM 23/01/20- Bobe scan and MDM. Patient aware. Outcome actioned	No
	08-Jan-20	17/01/2020 15:56	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	08/01/20- right orchidectomy- pT1 seminoma. 30/01/20 MDM refer to testicular MDM and oncology. Mr Hayne's pt- outcomes actioned	
	14-Jan-20	17/01/2020 16:26	CAH/CPB	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	14/01/20- left orchidectomy- necrosis. No record of pt being aware of pathology.	Unsure if pt aware of pathology
	22-Jan-20	24/01/2020 16:53	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	22/01/20- TURP (known Gleason 6)- benign. 30/01 MDM continue with PSA surveillance . Pt aware	No
	22-Jan-20	24/01/2020 17:17	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	22/01/20 TURBT pTa Gd2 (low) MDM 06/02/20- flexi 3/12. pt aware. Flexi delayed - COVID . Has had flexi as of Sept 20	No
	22-Jan-20	29/01/2020 15:32	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	22/01/20 TURP Gleason 8 (previously Gleason 7), prostatatic urethra bx - inadequate for diagnosis. 13/02/20 MDM addition of bicalutamide 50 mg and flexi 3/12. Pt aware outcome actioned	No
	22-Jan-20	24/01/2020 16:56	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	22/01/20 bladder bx- no evidence of malignancy (h/o low risk bladder Ca) no MDM discussion. Pt aware of pathology- for flexible cystoscopy July 20. Secretary emailed as has not had flexi to date.	Secretary emailed as has not had flexi to date. Booked for 21/09/20
	29-Jan-20	16/02/2020 12:54	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	29/01/2020 TURP Gleason 6 - no MDM discussion. No evidence pt was aware	Mr Haynes has discussed pt at MDM 10/09/20 and reviewed the patient with results and plan
	04-Feb-20	14/02/2020 15:46	CAH/CDSU	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	04/02/20- right orchidectomy- Pt2 adenocarcinoma. MDM 20/02- review and refer oncology. Pt aware . Outcome actioned	No
	04-Feb-20	11/02/2020 16:08	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	04/02/20 TRUS Gleason 9. MDM 20/02/20- review and refer oncoloy. Pt ware, outcome actioned	No

Personal Information redacted by the USI							
	05-Feb-20	11/02/2020 15:22	CAH/UOP	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	05/02/20 repeat lung biopsy- hamartoma possible diagnosis. MDM 13/02/20- current bx may not be represenative of lesion. Review and consider referral to cardiothoracics for surgical biopsy . Pt aware 13/03/20. AOB spoke with respiratory colleagues - due to COVID	review time line for referral to thoracics. However delay may be due to COVID
	11-Feb-20	14/02/2020 18:14	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/02/20 TRUS Gleason 7. 20/02/20- MDM - high risk. Review, order bone scan and back to MDM. Reviewed 09/03/20. C/o bicalutamide 150 and tamoxifen. Bone scan ordered 27/07 and performed 05/05. not rediscussed at MDM until 02/07/20- JOD has taken over his care	review time lines re ordering of radiology
	11-Feb-20	13/02/2020 17:22	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/02/2020. TURBT pTa Gd3. 20/02 MDM - BCG and surveillance flexi. Pt aware. Due to COVID, BCG induction not started. Due surveillance flexi Aug 20 - not yet done	I have emailed secretary and RF team to prioritise for flexi as high risk and no BCG tx . Booked for 21/09/20
	11-Feb-20	13/02/2020 17:22	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	as above	
	13-Feb-20	19/02/2020 12:05	CAH/OPD	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	13/02/20 kidney bx- clear cell. 27/02/20 MDM- suitable for cryo.delays due to COVID. Now under care of MDH and referred for cryo	No
	18-Feb-20	19/02/2020 17:49	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	RIP Personal Information redacted by the USI GI bleed. 18/02/20 TRUS- Gleason 7. 27/0/20 MDM review and recommend WW or ADT. Pt aware, outcome actioned	No
	18-Feb-20	24/02/2020 12:23	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	18/02/20 TRUS gleason 7 MDM 27/02/20- high risk , review, order bone scan and back to MDM. Reviewed 18/03- c/o bicalutamide 150mg and tamoxifen. Bone scan ordered 10/05/20 and performed 15/05/20. referred to oncology 10/07/20	review time lines re ordering of radiology
	18-Feb-20	20/02/2020 16:58	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	18/02/20 TRUS Gleason 7 MDM 27/02/20- high risk. For bone scan and discussion of radical tx vs WW. Review 18/04- c/o bicalutamide 150 and tamoxifen . Letter mentions ordering of bone scan deferred due to COVID. Performed 22/06	review time lines re ordering of radiology
	18-Feb-20	21/02/2020 12:48	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	18/02/20- circumcision - balanitis. No evidence patien t is aware (also under care of dermatology and no evidence that he has been informed via this route either)	Unsure if pt aware of pathology
	21-Feb-20	25/02/2020 08:34	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	prev high risk NMIBC. TURBT 25/02/20- pTa G2 (low)MDM 05/03/20 BCG vs cystectomy and surveillance of lung nodule. Reviewed 18/03/20. BCG not commenced until 01/07/20 due to suspension of service (COVID). On w/l for check flexi.	No
	21-Feb-20	25/02/2020 15:28	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	21/02/20 TURP- benign - pt aware	No

Personal Information redacted by the USI			22-Feb-20	18/03/2020 18:03	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	22/02/20 TURP- benign - no evidence pt aware of pathology	Unsure if pt aware of pathology
			22-Feb-20	26/02/2020 15:02	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	22/02/20- TURBT pTa g2 (high)(prev MIBC- XRT 2019) TURBT performed by AOB when an inpt, but pt under care of MDM. Unable to attend for results- GP aware. Mutiple admissions - MDM best supportive care. RIP Personal Information redacted by the USI	No
			25-Feb-20	27/02/2020 10:10	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	25/02/20 TRUS - benign MDM 05/03/20- PSA monitoring. Pt aware, outcome actioned	No
			26-Feb-20	04/03/2020 14:41	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	26/02/20 TURBT pTa Gd2 (low) (prev pTa G2 Nov 19) MDM 05/03- CT chect and CTU and refer to MDH/Glackin for lap N/U. pt aware. Outcome actioned	No
			28-Feb-20	04/03/2020 14:49	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	28/02/20 TURBT and prostatic urethral bx- pT1 G3 (h/o PrCA and bladder CA 19/03/20 MDM BCG reractory but not fif for cystectomy. For reinduction BCG. Delayed due to COVID- received July/Aug 20. on W/L for flexi	No
			03-Mar-20	09/03/2020 11:51	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	03/03/20 TRUS 5+4 12/03/20 metastatic,consider referral to oncology. On LhRH. Referred to oncology 03/07/20- is on their W/L for apt October	review referral time line
			05-Mar-20	12/03/2020 13:34	CAH/UOP	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	05/03/20 sacral bx- metastatic renal cancer. 12/03+19/03 MDM palliative XRT. Referred to oncology	No
			10-Mar-20	18/03/2020 17:13	CAH/THO	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	10/03/20 TRUS Gleason 8. MDM 19/03 - for bone scan, c/o ADT and refer oncology. Pt aware. Outcome actioned	No
			11-Mar-20	03/04/2020 15:03	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/03/20 TURP- benign unsure if pt aware	Unsure if pt aware of pathology
			11-Mar-20	02/04/2020 14:26	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/03/20 TURP- benign unsure if pt aware	Unsure if pt aware of pathology
			11-Mar-20	02/04/2020 14:27	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/03/20 circumcision- inflammation. Unsure if pt aware	Unsure if pt aware of pathology

Personal Information redacted by the USI			11-Mar-20	03/04/2020 15:04	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/03/20 TURP- benign unsure if pt aware	Unsure if pt aware of pathology
			11-Mar-20	16/03/2020 18:57	CAH/1W	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	11/03/20 TURBT pTa G2 (high) recurrence. MDM 19/03/20- telephone pt and recommend MMC. No record of pt being contacted until letter dictated 28/06/20- explaining MMC not offered due to COVID impact	review timeline
			20-Mar-20	07/04/2020 13:24	CAH/3S	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	20/03/20 TURP- benign. Pt aware as per letter 11/07/20	ensure on w/l for stent removal . Secretary emailed
			18-Jun-20	23/06/2020 16:01	CAH/1E	Histopathology	&CAH/AOB - Belfast HSC Trust Lab	19/06/20 TURBT pT2 Gd 3. MDM 02/07+16/07- referral to oncology. Pt aware. Outcome actined	No

ONeill, Kate

From: McCourt, Leanne <[redacted]>
Sent: 23 September 2020 11:07
To: ONeill, Kate
Subject: FW: CONFIDENTIAL
Attachments: Results Sign Off - AOB histopathology only.xlsx

From: McCourt, Leanne
Sent: 22 September 2020 15:08
To: Corrigan, Martina; Haynes, Mark
Subject: CONFIDENTIAL

Afternoon Martina 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