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

Patricia Thompson
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

<u>Provision of a Section 21 Notice requiring the provision of evidence in the form of a written statement</u>

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 [redacted].

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

Yours faithfully

Personal Information redacted by the USI [redacted]

Anne Donnelly
Solicitor to the Urology Services Inquiry

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

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

Chair's Notice

[No 75 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:

Patricia Thompson
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: Personal Information redacted by the USI [redacted]

Christine Smith QC
Chair of Urology Services Inquiry

SCHEDULE
[No 75 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 as full as answers as possible to this Notice, including further details or information not contained in your questionnaire.

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

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

Your role

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

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

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

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

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

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

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

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

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

Electronic systems for communication

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

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

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

Staff Performance Reviews

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

Concerns

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

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

Weekly meetings with Head of Service

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

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

(ii) How were topics identified for discussion?

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

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

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

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

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

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

(i) If so, what was your involvement?

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

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

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

Concerns and Risks identified

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

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

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

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

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

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

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

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

Patient Experience Surveys

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

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

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

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

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

Secured slots for patient discussions following MDT meetings

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

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

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

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

Attendance at MDTs

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

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

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

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

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

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

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

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

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

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

Uro-oncology consultations

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

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

Nurse-led services

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

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

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

Involvement of the CNS

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

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

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

Learning

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

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

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

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

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

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

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

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

NOTE:

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

UROLOGY SERVICES INQUIRY

USI Ref: Section 21 Notice No 75 of 2022

Date of Notice: 20th September 2022

Witness Statement of: Patricia Thompson

I, Patricia Thompson, 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 as full as answers as possible to this Notice, including further details or information not contained in your questionnaire.

1.1 I commenced my employment with the Southern Trust in August 2020. In 1999 I was first introduced into the specialty of Urology when I took a post in the Surgical Operating Theatre Department at Belfast City Hospital. During that time I did work in different specialities but progressed to specialising in Urology and Gynaecology. In 2002 I took up a senior staff Nurse position in Urology Theatres and Urology Day Care in Belfast City Hospital. In 2005 I applied for a Macmillan

Clinical Nurse specialist in Urology post at the South Eastern Trust in which I commenced employment in October 2005. I left the South Eastern Trust in July 2020 to take up a position at the Southern Trust as this [redacted] and involved less travelling time. Please see:

1. Band 7 – Urology Nurse Specialist JD

1.2 I will answer this statement since my tenure at a Urology Nurse Specialist at the Southern Trust from August 2020. I will however will mention my previous employment at the South Eastern Trust in Question 31.

1.3 I never had any concerns with any Urology colleagues in my 23 years working in Urology. I never worked with Mr O'Brien and I cannot comment on his practice. The dealings I had with Mr O'Brien were attending a NiCAN meeting when he was chair at that time. I found Mr O'Brien to be professional and he never disagreed with another professional's opinion at these meetings. I was only made aware of concerns relating to Mr O'Brien's practice when I was asked to be on the review group of the 9 SAIs by Martina Corrigan which progressed to the lookback exercise. I will answer this statement and hope this will help with the Inquiry.

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

2.1 Any documents referenced in this statement can be located in folder S21 75 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?

<u>Communication between the patient and Urology CNS:</u>

4.1 I would be available at the consultants' results clinic when I would introduce myself as the Urology Nurse Specialist and my role of key worker. I would explain that the role of the key worker is a supportive role and a point of contact if the patient or relatives have any concerns or further questions. I provide my contact details with written information on their diagnosis, e.g., Prostate cancer booklet from prostate cancer UK. Advice is relayed to patients to make contact if any concerns or information on their diagnosis and treatment needs to be discussed.

4.2 I receive a letter of referral in relation to patients who have been referred to the nurse led clinic by the consultant. These clinics are either by telephone or face to face. For the telephone review clinic which can also be known as virtual clinic, patients receive an appointment letter with information of their upcoming telephone review and the expected time of their telephone call. I do take into account any barriers such as language or sensory deficit and I ensure that this clinic appointment is face to face with an interpreter if there is a language barrier. As a Urology Nurse Specialist I would send a letter to patients informing them of recent results of investigations, e.g., blood. My name and job title are on the letter, I would put the department telephone number of the Thorndale unit on the letter.

4.3 I completed the Advance Communication skills training between 6th-8th October 2010. This training is essential for any clinician, e.g., Consultant, CNS, GPs or Allied Health Professional whose role involves working with patients who have a cancer diagnosis. This course helped me as a Urology Nurse to communicate effectively and be sensitive to patients who have a cancer diagnosis. This is a 2 day course provided by the trusts in Northern Ireland. *Please see:*

2. *Advance communication Skills Certificate*

<u>Communication between Urology CNS and Consultant</u>

4.4 I have no difficulty with communication with my urology consultant colleagues. We have access to communicating with them via availability at consultant clinics, Multidisciplinary team meetings and Patient Safety Meetings. During working hours (8.00am – 17.30) I have access to urology consultants' telephone numbers. I can email my consultant colleagues with queries or updates as it may not be appropriate to phone, especially if they are in consultations or theatre sessions. If there are any nurse led clinic patients that may require to be brought to a consultant's attention, I ensure that they are and that the consultant is copied into the letter of the consultation.

4.5 I have no concerns in relation to how to communicate with the consultants and patients. However on occasions, there has been no administration staff available, in the Thorndale Unit. This can be frustrating as I may be in clinic or in Day surgery and patients may be trying to ring the unit resulting in no availability to receive calls. This can be distressing for any patients or relatives trying to make contact. However, I do feel that an answering service for patients to leave voicemails would be of benefit.

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 only been employed with the Southern Trust since 3rd August 2020. My initial Operational line Manager was Martina Corrigan until November 2020 and my clinical manger was Sarah Ward until June 2021.

5.2 Both Martina Corrigan and Sarah Ward were supportive and I had a very good professional working relationship with both of them. When I started the Southern Trust both made me feel very welcome. I did not have any concerns with management nor did management have any concerns with my practice or patient care.

5.3 From November 2020 until present my operational manager has been Wendy Clayton and from June 2021 my clinical manger has been Paula McKay. Again, both have been supportive and there has been no concerns or difficulties in relation to my practice or patient care. I praise the management at Southern Trust since my employment and have had no incidents that I had to report. .

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 started my job with the SHSCT as a Urology Nurse Specialist in August 2020 which was a challenging time, as it was during the first wave of the Covid-19 pandemic resulting in services being reduced. From July 2021, services have now returned to pre covid. My current job plan is structured and my roles specialise in cancer liaison (key worker), nurse led renal cancer review and flexible cystoscopy service for patients with red flag symptoms of bladder cancer and cancer surveillance with patients with known bladder cancer. If I had any concerns with fulfilling my role or in regards to patient safety, I can speak to both Paula McKay and Wendy Clayton. *Please see:*

3. *Flexible cystoscopy certificate*
4. *Excellence in Cancer Care the contribution of clinical nurse specialists*

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 Since I started my employment at the Southern Trust in August 2020, I can say that I have never reported any problems. If I had an issue to discuss for example if a patient's review was delayed and this would have an impact on their treatment pathway I would report this to both Wendy Clayton or Paula McKay and I am happy to say I would feel that this would be addressed. I do feel that currently both Wendy Clayton and Paula McKay would handle any issues effectively.

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 No I don't have adequate administrative support for my role as a urology nurse specialist. The support I do have consists of:

(a) Administrative support of 18 ½ hours a week for five Urology Nurse Specialists. The specific role of the administrative support is to appoint patients for the nurse specialists at the nurse led clinics. My clinic is a virtual renal cancer review clinic 1-2 times a week. I would provide dates of availability within an adequate period of 4-6 weeks. Initially the administrative support role was to type clinic letters for the nurse specialist clinics. However as the support is 18 ½ hours a week for five full time nurse specialists each working 37 ½ hours this has been a challenge. The admin support is excellent at their job, but one concern has been that there is no cover in times of sick leave, study leave and annual leave. As mentioned, part of their role is to type letters for nurse led clinics and there has been a significant 8 week backlog of letters awaiting to be typed. This can result in delays of information being provided to GPs or other specialities relating to the patient's recent consultation. This has been brought to their management's attention Matthew McAlinden. I have been informed by Matthew McAlinden that there has been a problem with staff recruitment and absenteeism and this has been the reason for letters not being typed in an appropriate timeframe. The consultant secretaries can DARO (discharge awaiting results – outpatients). If a consultant's patient is awaiting results prior to a decision regarding follow up treatment being made, they must be recorded as a discharge (DIS) and not added to the OP Waiting List for review. Unfortunately the CNSs administrative support does not provide this facility, therefore we have to keep a database of patients awaiting results. *Please see*

5. *Discharge Patient Awaiting Results (DARO)*

8.2 Macmillan administrative support 7 hours a week for the 3 urology nurse Specialists (Cancer). This administrative support works alongside the cancer CNSs. Initially they were to deal with patients who have less complex needs, to signpost patients who had completed their cancer treatment to the Macmillan Move More physical rehabilitation scheme or to refer patients to the Macmillan Benefits and to offer support. Unfortunately, due to the 7 hours allocated to 3 urology CNSs (cancer) our support worker appoints patients for Holistic Needs Assessment and sets up their online concerns checklist.

8.3 Support from Consultant secretaries

(b) This support is given at the flexible cystoscopy service. The consultant secretaries appoint patients who are due their routine flexible cystoscopy (cancer surveillance). I am provided with a list of patients attending prior to the clinic. I dictate my findings and letters to the appropriate consultant secretary. Communication is excellent and if there are any queries that need brought to my attention such as a date for surgery or patients who have been in contact with the secretary with concerns, I am emailed promptly by the secretaries. The concern I would have is the backlog of letters being typed. On occasions my letters for flexible cystoscopy may not be typed for a number of weeks (4 weeks). This is due to recruitment. The consultant secretaries' number is not adequate to support the CNSs as they have their own duties, being responsible for the consultants' administration. However, I ensure that letters that need urgent attention are typed in an appropriate timeframe by marking G2 a dictation system which is a speech report for letters to be transcribed as Urgent or Cancer letter. I can also email the audio typist requesting for a letter to be typed urgently.

8.4 Appointments booking team (medical records, red flag booking team)

(c) The appointments and red flag booking team are two teams that are responsible for booking routine, urgent or red flag appointments. They help me in my role, as they are responsible for appointing new patients who are attending my red flag flexible cystoscopy service (patients who have a suspected cancer). I have a good relationship with both teams and can email if I have any queries with appointments or cancellations. If I did not have this support, I would not have new patients appointed to my red flag clinic

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

9.1 I do feel supported in my role. As a team of 5 Urology CNSs we work very well together and help each other in any times of difficulty. We have very good team dynamics and I have had no issues. Management is supportive, again I have had no issue.

9.2 There are good opportunities for development. I have had opportunities for development. I have attended a recent 2 day oncology conference between 16th June-17th June 2022. My recent appraisal with Paula McKay discussed applying through agenda for change to up band my role from Band 7 to Band 8A. *Please see:*

6. *Oncology conference*
7. *KSF*

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

10.1 I do feel that the introduction of nurse led activities has improved patient care. The nurse led services were being introduced when I first started with the Southern Trust. The implementation of nurse led services provides a good continuity of care for the patient and autonomy for myself. Nurse led activities also give me job satisfaction and improves the patient/nurse relationship. Nurse led activities contribute to waiting time reduction and to satisfaction from both the patients and clinicians on patients' quality of life and control of symptoms. Patients are kept more informed of their condition and choices of treatment. As previously mentioned, I would see the patient from diagnosis to follow up, for example patients with newly diagnosed bladder cancer, I would meet at the results clinic and be involved in their follow up resulting in continuity of care.

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 The information which has made references to the terms stated above refers to the one role of the Urology CNS. A Urology CNS can sub specialise in cancer or benign. As a cancer CNS we focus on the patients who have been diagnosed with a urological cancer. Our role provides support as the key worker to patients and their families. We are with the patient from diagnosis, through their pathway of holistic needs assessment and cancer surveillance.. The benign Urology CNS follows up the patients with urological conditions such as renal calculi or enlarged prostates or dysfunctional bladder. They also can be seen as a key worker for these patients as many are living with chronic conditions that have an impact on their day-to-day life.

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 will discuss the electronic system that I use. I will address if this differs from other clinicians and if there is any built in system that alerts staff, if follow up of investigations are outstanding.

12.2 The Patient Centre system would provide me with information in regards to patients who are currently on waiting lists for procedures, inpatients and any upcoming hospital appointments in the Southern Trust. Patients' letters can be viewed on this system. This system does not have the facility to alert staff of any outstanding tasks or investigations. However administration staff and consultants' secretaries mainly use the Patient Administration System (PAS) and can use the DARO facility which alerts administrative staff of outstanding investigations.

12.3 Electronic Care Record (ECR) – this system I would avail of the most. This provides information on hospital attendances, inpatient, outpatient or emergency department within the trust and of other trusts. ECR enables me to review a patient's progress such as when a patient has been referred to oncology from MDT, we can see if they have an upcoming appointment and letters from any recent consultations. We can have access to view laboratory results such as clinical biochemistry, microbiology and histopathology and the advantage of viewing radiology results. I would make referrals to community services and can view if a patient's referral has been actioned and reviewed. I can send and receive messages on ECR, for example I have received messages from my consultant colleagues with any recent investigations that I have requested. The only criticism I have is that the system does not notify me if results are available and the named consultant gets notified regardless of who requested the investigation. This is a regional issue not a trust issue and this is why consultants notify me of results.

12.4 Cancer Patient Pathway System (CAPPS) – is a regional cancer care information system to monitor cancer waiting times and to assure the timeliness of access to diagnosis and treatment services for cancer patients in accordance with the access standards. This is used at cancer multidisciplinary meetings to aid decisions on a patient's treatment pathway. I can use this system to view MDT decisions and patients due for discussion at upcoming MDTs. There is a section on CAPPs for specialist nurses to record any encounters or consultations with patients and it is recorded on the MDT outcome report that the patient has been seen by a specialist nurse. The MDT report from CAPPS is uploaded onto ECR and patients' GPs receive a copy of the outcome of the MDT.

12.5 Microsoft email – I keep in contact with my urology colleagues and other staff who would be involved within the team I work with, e.g., community service, cancer trackers and administrative staff. It is also an excellent form of communication to keep staff informed. When sending emails I adhere to trust policy to keep the title confidential especially if this is about a patient. If I need an email to be marked urgent attention, I mark this on the email. I have not received any emails that I would be concerned about. We adhere to the trust's policy on confidentiality when emailing. This does not alert staff of any outstanding tasks but I can flag emails that I have received to deal with urgently.

12.6 Sectra ordering system- this is another system that I can use to request radiological investigations which is useful if I am unable to access ECR. For example due to technical issues ECR may be down for a period for a period of time and if so, I can access. Sectra which is useful as this can prevent delays in requests or viewing recent radiological investigations. Again, I am not notified when results are available.

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

13.1 I don't use any other method of communication. However I do not have a work mobile phone or bleep which may be of benefit especially if another specialty needs to make contact.

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 In my role as a Urology Nurse Specialist, I request imaging for patients who are currently under surveillance for bladder cancer surveillance, renal cell cancer review and for any patients presenting with symptoms suspicious of cancer. As previously mentioned, I request these investigations through Sectra or ECR. However, when the examination has been completed and reported I do not be notified but the consultants are informed. The consultant would write to me or notify me of the completed investigation. This is not an issue with the Southern Trust but is a regional issue. However, I can see if a result is available and this has been signed off and actioned by a consultant.

14.2 In the G2 dictation system as previously stated some typing is delayed due to low staffing levels. I don't get notified if letters are not typed in a specific timescale. Again as previously mentioned I can place the letter as urgent or email the secretary or audio typist. I find out if letters have not been typed by looking into the G2 system to view my dictation.

14.3 DARO - At the end of an outpatient clinic all attendances and discharges must be recorded on PAS. Recording "Attendances and Disposals" is an essential part of the outpatient flow and is required for statistical analysis of clinic outcomes and activity and can be used for future planning of services and determining capacity and demand. Patients who are awaiting results prior to a decision regarding follow up are recorded as Discharged Awaiting Results. This is recorded by consultant secretaries and patients are so recorded if investigations and tasks are outstanding. This is excellent and is a fail-safe mechanism but the again the Urology CNSs administration support does not have access to this service and this would improve follow ups if they had access to this. *Please see*

5. Discharge Patient Awaiting Results (DARO)

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 Since commencing my employment at the Southern Trust in August 2020 I have not completed any staff performance reviews on other colleagues. I have had my own staff appraisals since I started at the Southern Trust with Sarah Ward. My first appraisal was on the 27th November 2020 as part of my 3 month induction and then on 25th February 2021 as my 6 months' induction period when starting new employment. I had my Revalidation as part of the NMC registration with Paula McKay on 7th February 2022. My appraisal which is known as KSF was also with Paula McKay on 30th September 2022. My understanding of KSF is that it enables staff to be clear about the knowledge and skills they need to apply in their posts, promoting equality for all. This provides support and guidance to staff and encourages a culture of on-going development and career progression and what to work towards to for their next appraisal. I have never identified any problems or concerns via this route or been informed of any concerns. My view is that staff performance appraisals should not be an opportunity to be critical to a clinician, as this is a review of what a member of staff has achieved in the year and to set out goals for them to work towards for the following year. Any concerns about a clinician should be addressed at the time they have been raised and should not wait to when their appraisal is due which could be in 6 months' time. *Please see 7. KSF*

8. *Appraisal 1*
9. *Appraisal 2*

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 Since I started in the Southern Trust in August 2020, I have had no concerns with any practitioner. During my past employment in urology services within the Belfast City Hospital from February 1999 until September 2005 and the South Eastern Trust from October 2005 until July 2020, I cannot say I had any concerns with any practitioner.

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 During my tenure in the Southern Trust, I have never raised a concern so I cannot answer this question. I am aware of the procedures and would expect to be informed of how my concerns were managed.

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 Since I started my employment in Southern Trust my current operational manger Wendy Clayton schedules weekly departmental meetings. This meeting is for the urology team. The meeting is attended by Urology CNS's, Consultants, the Outpatients manager and the Administration manager.

18.2 There is an agenda to the meeting, which is decided by the Wendy Clayton and the topics for discussion are set and include:

(a) Apologies
(b) Covid update
(c) Public Inquiry update
(d) Staffing
(e) Elective/outpatients update
(f) Governance
(g) Service development
(h) CNS update
(i) Any other business

18.3 The topics discussed at the meeting are ongoing issues, such as the number of Covid cases in Southern Trust, staff recruitment or any new initiative for the urology service. The minutes of the meeting are recorded and are forwarded to the team. With regards to outstanding issues we are kept up to date either via email or discussed at the following week's meeting.

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 Since I started employment at Southern Trust in August 2020, in my experience the CNS and clinicians meet weekly at the Urology MDT to discuss patient care. This meeting is very beneficial for Urology CNSs to attend as many have established a rapport with patients and their families and can contribute to these meetings. The CNS is a core member of the MDT and is important that we are available at these meetings. I would also be in attendance at the consultant clinic as support to patients who are receiving pathology results. This gives me an opportunity to discuss with the consultant patient care and the pathway.

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 Governance meetings I have attended:

(a) Policy writing. New nurse led services were being set up and as a group we arranged a meeting with Senior Nurse Lisa Houlihan on 5th May 2021 to discuss guidance on writing policies. I was starting a nurse led renal cancer review clinic and a policy was written by myself for this service on evidence based guidance. This meeting was beneficial however; we are still waiting for our policies to be signed and agreed by senior management. A lot of time and effort was put into writing these policies. *Please see:*

10. DRAFT Corporate Policy Template NURSE LED RENAL CELL CANCER FOLLOW UP v3

(b) CNS Nurse forum is regional meeting facilitated by Nican. When I first started as a Urology CNS in South Eastern Trust in 2005, Urology CNS's from each trust met every three months to discuss their service and any new developments. Unfortunately this did not continue due to poor attendance. In 2021, NiCan started a CNS forum for Urology CNS's in all trusts in Northern Ireland. We met via zoom on 30th September 2021 and 28th April 2022. The aim is for these meetings to be held six monthly. The topics of discussion at these meetings relate to finalising nurse led pathways so that all trusts work together. I have attached agenda and minutes of these meeting in my documents. *Please see:*

11. CNS forum Minutes

(c) The weekly departmental meetings with Wendy Clayton are also governance meetings I would attend. Any issues such as complaints or audits are discussed at the meeting.

(d) SAI Meetings – when I started my employment at the Southern Trust, Martina Corrigan asked me to be part of a review group for the nine SAIs. These meetings commenced on 10th September 2020 and I have attached a list of the frequency of these meetings. I was unsure of what the SAIs were until I attended the first meeting. I was unaware of issues related to Mr O'Brien. This group has published recommendations of the outcome of the nine SAIs. I have attached this in my documents. *Please see:*

12. *SAI overarching report*

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 In my experience since starting in Southern Trust in August 2020, the efficiency and effectiveness of governance processes is to ensure good polices and guidance are in place. For my renal cancer follow up clinic as this was a new service, policies and procedures had to be written. During my previous employment in South Eastern Trust I had written policies for nurse led services for Prostate Cancer Review, Renal Cell Cancer Review and the administration of Intravesical Treatments to patients with bladder cancer. Policies provide guidance and ensures the patient a safe delivery of care. Rigorously developed evidence based guidelines minimise the potential harms and can improve the quality of care. As I was part of the group that reviewed the 9 SAIs this has highlighted that not adhering to guidelines can lead to harm. These SAIs have improved my view. Guidelines offer a remedy, making it more likely that patients will be cared for in the same manner regardless of where or by whom they are treated.

21.2 For any procedure or assessment that has an impact on patients, each practitioner would need required training and sign off competencies and to attend regular updates. The British Association of Urological Nurse (BAUN) have yearly workshops on flexible cystoscopy, TP biopsy Urodynamics etc. Unfortunately, these workshops have not been in place since 2019 due to covid measures

21.3 The Royal Marsden Manual of Clinical Nursing Procedures has been the market-leading guide to clinical nursing skills. This indispensable guide sets the gold standard for nursing care, providing the procedures, rationale, and guidance required by qualified nurses to deliver clinically effective, patient-focused care with expertise and confidence. This manual reflects urology nursing procedures and updates in any changes in modern practice. This manual is on the trust's intranet.

21.4 Each nurse needs to ensure they have revalidated every three years as set out by the Nursing Midwifery Council (NMC). They need to meet specific requirements of practice, study and reflection. It is important for managers to be aware of nurses who are due for revalidation and have been revalidated. *Please see:*

13. *Revalidation*

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

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

(i) If so, what was your involvement?

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

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

22.1 I was not employed by the Southern Trust during the time of the Regional Review of Urology Services, Team South. I cannot answer this question. I was not involved in any meetings or discussions relating to implementing and or monitoring the Regional Review of Urology Services, Team South, published on 14 June 2010. I cannot give any views on the matter.

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

23.1 I was not employed at the Southern Trust during the time of Regional Review of Urology Services, Team South. However prior to commencing employment at Southern Trust in August 2020 3 Urology CNSs were in post. Since September 2020 there are 5 CNSs and I do feel we are resourced properly. The team is made up of 3 Urology CNS dealing with oncology which does provide better key worker support and 2 benign nurses who are there to enhance the benign side of the service. More staff currently has a better impact on the urology nursing service.

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 I will answer this question since my tenure as a CNS in Southern Trust from August 2020. When I first started there was adequate CNS provision, with 5 Urology Nurse Specialists. However from 14th November 2021 until 17th January 2022 I had a period of [redacted] leave, [redacted]. I am sure this was difficult for my colleagues. We have had one of our CNSs retire in October and we are awaiting an appointment for her replacement. We ensure there is adequate CNS attendance at the MDT meetings. Previously as a team of 3 Urology Nurse Specialists in Oncology, we ensured this meeting had CNS attendance, however in January 2021 as a team of 3 cancer CNSs we were re-deployed during the third wave of the Covid pandemic. I was re-deployed to Theatres for a period of 6 weeks and I can say at the time there was no CNS provision.

24.2 I do not see routine referrals. My group of patients are cancer review patients, bladder cancer surveillance for flexible cystoscopy, patients who have red flag symptoms and renal cancer review patients. New routine referrals do not be referred to me.

24.3 Since I have started at Southern Trust there is a locum consultant currently working with the urology team (Mr Khan). There has been difficulty in regards to recruitment of Urology Consultants, this is due to training and who is available to apply for such positions.

24.4 During my tenure with the Southern Trust the MDT meetings have not been quorate. This was due to when on occasions no radiologist was present and imaging reviews had to be carried forward to the next week's meeting when a radiologist would be in attendance. This was due to only one radiologist being available to discuss imaging. However, this is not a concern at present as there are two radiologists present at MDT. Both would be present at MDT at the same time and provide cover in times of annual leave. I have not been present when there has been no histopathologist.

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 This is my view from August 2020.

25.2 Lack of CNS provision at the time when CNSs were re-deployed in January 2021 for a period of 6 weeks meant that the meeting was not quorate. Systems should have been in place for a CNS to be available to be present such as a rota to attend MDT.

25.3 The locum consultant has been in post since November 2020 and is still working within the urology service at the Southern Trust. I have no concerns with his practice. I had no concern with the other consultants' practices. This is due to difficulty in recruitment.

25.4 No radiologist presence at the MDT meant delays in patients being discussed. Again there were difficulties in the recruitment of a radiologist. However cover should have been available to deal with this if no radiologist was to be present.

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

26.1 I cannot comment prior to August 2020 but in my experience the impact of the issues outlined can result in a delay in the patient's treatment pathway. Lack of CNS provision means no CNS input for a patient's preference for treatment, patients' discussions at MDT have been delayed due to lack of radiological input and patients would have to be discussed at a later date, leading to delays in decisions and delays in starting cancer treatment. To address these issues would be funding to recruit and the training of specialist roles and systems to be in place to cover staff if not available to be at MDT meetings.

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

27.1 As of writing, I do not see the concerns and risks existing at present. However when I first started at the Southern Trust there was an issue with radiology. The MDT had only one radiologist and when they were not available cases had to be discussed at another date. As previously mentioned since May 2020, there are now two radiologists present at the MDT meeting at the same time so this issue does not happen.

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 I have not needed to speak or complain to anyone about any matters impacting on my role or on patient care. The only occasion when I had concerns as did my colleagues was when we were re-deployed during the third wave of the Covid-19 pandemic. We were informed by management (Wendy Clayton, Sarah Ward and Ronan Carrol) that we were being asked to be deployed to another ward (I was deployed to Theatres). I felt patients who needed Urology CNS input were missing out, as we were not available to provide this. At that time CNS provision was not present at MDTs which therefore could not have been quorate.

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 Concerns would be raised via the Departmental meeting, and discussion with management. I have had no concerns to raise. However the trust has a whistleblowing policy for staff for guidance if they wish to raise a concern. I have attached a flow chart as one of my documents for nurses and midwifes to raise a concern. Nurses can document in patients' medical notes if they have a concern and who they raised the concern to. Datix is another form that can report and record if staff have a concern about patient care and safety. *Please see:*

14. Guide to support Nurses and Midwifes in Raising a Concern March 2022

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 Raising a concern can be difficult. I believe that a personal grievance may arise from raising a concern but nonetheless but the focus should be on patient safety. A record of the concern is important and any steps that have been taken to deal with it. Staff should be encouraged to speak up if concerned and ask for feedback on their concern. The trust has sessions on duty of candour, having this as mandatory training could be of use.

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 As mentioned, I came into employment with the Southern Trust in August 2020. In my previous job, at the South Eastern Trust my Manager Mary Jo Thompson informed us of CEPS 2018, which was a follow on report from PHA and Macmillan. This report did show a regional issue of access to a CNS, not only in urology but also in other cancer specialties. The urology CNS model at South Eastern Trust was different to that of the Southern Trust in that we were a team of 3 nurses and there was no specific solely cancer nurse and benign nurse. Our job plans dealt both with benign and cancer. However we looked at job plans and to see if areas could be improved such as delegating tasks so one nurse could be benign and another a cancer nurse being the keyworker . In 2019 funding became available for another Urology CNS which was to be specifically for benign. A CNS was appointed in January 2020 and took up post in May 2020. However I left my post in South Eastern Trust in July 2020. *Please see:*

15. Northern Ireland Cancer Patient Experience Survey 2018

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

32.1 I was not in post during that time. I cannot recall any internal survey in my previous post. However recently in conjunction with Macmillan a patient engagement report was carried out on 30 patients in 3 tumour groups, prostate, renal and bladder on their experience of their cancer journey. Macmillan Peer Facilitators were invited to support the review through one to one conversations with patients of the Urology Cancer Service. The report is currently out for consultation. *Please see:*

16. Patient Engagement Report Urology Cancer Service SHSCT

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

33.1 Any feedback I would receive first and foremost is compliments from patients. This could be either from a card or a patient stating they are happy with my care. Emails to state good practice are also received. Our weekly meetings manager would keep me up to date on feedback. Appraisals are also a good source of feedback. I have not received any negative feedback or complaints since starting my post in August 2020.

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 I do believe that CNS support is important to enhance the patient's journey through their care pathway such as having contact details and access to speak to a Urology CNS/Keyworker if there are any concerns. Urology CNS can re-emphasise information on their treatment pathway. In my experience patients feel happier to contact CNS for any queries. CNS support should not be seen as a failsafe mechanism but can be a link if the patient is concerned about tests to highlight to a practitioner or consultant.

34.2 Communication breakdown can develop if patients have no access to a CNS. At clinics without a CNS patients may have difficulty absorbing information and appropriate written information. CNS support re-emphasises information and ensures patients receive site specific information along with their cancer core information packs. Patients who have no CNS support find they contact secretaries for information. The secretarial support are excellent at their role but they may not provide specific medical information. Without nurse led clinics patients may not be fully aware of their treatment pathway.

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 Patient satisfaction surveys are a meaningful and essential source of information for identifying gaps in service provision and patient experience with a view to auctioning a plan for quality improvements in healthcare. I have not carried out a satisfaction survey since commencement in the Southern Trust. However I do plan to carry out a satisfaction survey on my renal cancer review clinic. I have not been informed of any satisfaction survey since I have started in the Southern Trust.

Secured slots for patient discussions following MDT meetings

36. The 2015 National Peer Review Report: Northern Ireland 2015 also identified good practice within urology Southern Trust (TRU 84717), including having Secured slots in clinic following MDT meeting for patient discussion (Southern). Please explain, as relevant, your experience of how

these slots for patient meetings operated, who attended, the effectiveness of these slots, and whether they were a regular post MDT feature and remain so? If these slots no longer operate, why not and what, if anything, replaced this system?

36.1 My knowledge of the secured slots in clinic following MDT meeting for patient discussion is:

(a) The consultant secretaries and booking centre ensure that these slots are available. Patients are identified following MDT by the MDT coordinator and secretaries are emailed to book the patient into the appropriate slot. The secretary would advise the patient to bring a relative or friend along to the appointment. This is the consultant led clinic. As a team of 3 cancer Urology Nurse Specialists we ensure that one of us is available to be present at these meetings. These secured slots continue and have not changed since I started my employment at the Southern Trust.

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

37.1 Since I commenced my employment at the Southern Trust in August 2020 information is given by the consultant urologist to the patient of their diagnosis and what has been discussed at the MDT. Patients are provided with site-specific cancer information.

37.2 Examples of the information given to patients would be:

(a) Prostate cancer booklets from Prostate cancer UK, with information on prostate cancer treatments for example radiotherapy, surgery, active surveillance and hormone treatment.

(b) Macmillan booklet on bladder cancer with the types of treatment available.

(c) Kidney cancer booklet form Kidney Cancer UK.

(d) British Association of Urological Surgeons (BAUS) information is available for all treatment either cancer related or benign.

(e) We ensure that all information is available for each patient with contact details being provided.

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

38.1 Since I started in August 2020 these meetings are recorded in patients' medical notes. A letter is dictated and typed by the consultant's secretary detailing the consultation and who attended. The Urology CNS detailing a brief description of what has been discussed completes a record of the consultation, a copy of this record is filed in the patient's medical notes, and a copy is given to the patient. Another form of what information has been given, e.g., cancer specific information given to the patient is also filed in the medical notes. At present the Urology CNS records their meeting with the patient on progress notes on ECR and on CAPPS.

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 These meeting slots are very effective. From my experience patients are seen within 7 days following MDT which reduces anxiety for both patients and their relatives. Patients want to know their treatment plan and prompt appointments reduce patient anxiety and results in patients being better informed.

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 I cannot account for both figures from 2016 and 2019 for MDT attendance. However as previously mentioned when I first came into post there were a number of weeks radiology attendance was not available and this resulted in delays in treatment pathway decision making. I'm not aware if this had an impact on patient outcome but did increase anxiety. However since 2021 the MDT attendance now has 2 radiologists and both medical and clinical oncology which has improved decision making and ensures the patient pathway is not delayed. There is both clinical and medical oncology present at these meetings and pathology is also present.

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

41.1 I do believe the role of the Urology CNS is valued within the MDT. They are a core member of the multidisciplinary team (MDT), and as such, each MDT is required to have a Clinical Nurse Specialist in order to meet accepted MDT peer review standards. The CNS knows the patient holistically such as their physical, psychological, social and performance status. The team will ask the CNS about their views on a patient's preference for treatment. We would have contact with patients and their families and be aware of their preference for treatment.

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

42.1 I do contribute to MDT discussions. My role involves cancer follow up and I have had to refer patients to be discussed at MDM. An example would be part of my bladder cancer surveillance pathway where I would ask patients to be discussed at MDT if they are due to be discharged of the pathway. This ensures the patient has had a group decision to be discharged safely. I have had no issues with contributing and cannot say if anything inhibits myself from contributing.

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

43.1 At the MDT my views are asked by clinicians. As a Urology CNS, we establish a rapport with patients by the key worker role. We would be aware of the patient's preference for their treatment pathway and I would bring this information to the meeting. The chair of the MDT would review each patient to be discussed and ask the CNSs for their input. I believe my input and opinion at the MDT is valued.

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

44.1 I have no issues with contributing at the MDT discussions. As previously mentioned, I have added patients to the MDT list who are on the bladder cancer pathway. In particular if a patient had a recurrence, I would have knowledge of their previous adjuvant treatments and the patient's performance status and of their suitability for further adjuvant treatment.

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 I have heard differing views on a patient's plan of care at MDTs. However, these discussions were a "healthy debate" discussing the latest guidance and evidence base. The MDT quoracy is of different specialities and they will always discuss their professional opinion. Patients care is protocol driven. I have never been in the MDT meeting since I started in August 2020 where a view on treatment had to be resolved. If there needs to be clarity on a patient's treatment this can be discussed at the regional or specialist MDT at Belfast.

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

46.1 At the MDT the Chair leads the discussion on each patient. After each patient has been discussed and a treatment pathway has been agreed, the chair liaises with the cancer MDT co-ordinator, who records the outcome on the Cancer Patient Pathway System (CAPPs). This system records the date of the meeting and what treatment was agreed. As mentioned previously this system records all investigations. This is uploaded onto ECR and the GP is sent a copy of the outcome. The system also records previous MDTs and the outcomes decided. The consultant who is in charge the patient's care is responsible to ensure that the decision is acted on. For example a patient with prostate cancer, decision at MDT for consultant to review and refer to oncology for radiotherapy. The consultant reviews the patient following this meeting and refers to the oncologist.

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 It is not the Urology CNS role to ensure that MDT decisions regarding care and treatment are followed through. However as we have established a rapport with patients as their keyworker, I would contact the patients updating them that they have been discussed at the MDT meeting and they will receive an appointment to see their consultant. I would ensure that myself or one of my colleagues would be available at the consultant's post MDT clinics. The consultant would be responsible for ensuring patient care and treatment were followed through. In my experience, I have not been in the situation when an MDT decision was not discussed with the patient, but if this did happen, I would have no problem with questioning this.

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 In my view and experience, the CNSs and other professionals never had any difficulty communicating within an MDT. However, I believe, there has been debates on decisions on deciding patients' pathways. MDT meetings can result at times in a healthy debate on decision making and the latest guidance and evidence base literature being discussed.

48.2 Some members of the MDT may link into the meeting virtually and at times there has been IT issues. For example, the Chair of the MDM may be linking in from another site but due to IT difficulties cannot link into the regional meeting and patient information will have to be discussed by another consultant. This has had no impact on patient care or decisions.

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

49.1 As stated in my answer to the previous question other professionals did have IT issues linking into the meeting. The MDT proforma has to be completed which has its advantages such as relevant information being recorded on this. There are a limit of 35 patients to be discussed at the meeting. Therefore at times if the limit is exceeded patients needing to be discussed may have to wait longer. This has not had an impact but increased anxiety.

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?

50.1 Since I have commenced employment with the Southern Trust, I have been present and invited at uro-oncology consultations. As a team, we review our rota to ensure availability at these consultations. I do not have first-hand experience.

Nurse-led services

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

51.1 I have never met any resistance from medical staff in relation to nurse led services since starting employment at the Southern Trust. My 2 colleagues Kate

O'Neill and Leanne McCourt could answer this question. However I cannot account for the period prior to August 2020.

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 do believe that nurse led procedures has released pressure on the medical teams. This has improved some of the waiting times for flexible cystoscopy, cancer review and transperineal biopsy. I can give an example of patients who have high risk non muscle invasive bladder cancer who receive maintenance BCG intravesical treatment to prevent recurrence. Prior to starting my surveillance flexible cystoscopy service, these patients were waiting for a timescale of 6 months for their surveillance cystoscopy, instead of 3 months resulting in delays of their maintenance treatment. Now these patients are having their check cystoscopies in the 3 months' timeframe needed for their treatment. Patients on the renal cancer follow up pathway only contact was having their annual CT or ultrasound scan and receiving a letter informing them of their results. Now this group of patients are having a contact with a CNS who can discuss their pathway, symptoms of disease recurrence and have a point of contact if they have issues with pain or weight loss. I can look into expediting their scan or arrange an appointment with the consultant.

52.2 The Holistic Needs assessment clinic gives both the CNS and the patient time to discuss their pathway and diagnosis. The luxury of this nurse led service allows the patient to be signposted to services such as counselling, benefits check and the Move More programme which is a rehabilitation service for patients recovering from cancer treatment.

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 Yes, I do agree that CNS carrying out nurse-led roles and procedures has increased capacity. A Macmillan report in 2012 described the CNS as managing the health concerns of patients and working to promote health and wellbeing in the patients they care for. CNSs use their skills and expertise in cancer care to provide physical and emotional support, to coordinate care services and to inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes. As CNS, we can reduce treatment costs by providing nurse led services, which reduces consultant waiting times to ensure patients are seen in a robust timeframe. We are supported by management in fulfilling our role. Our nurse led clinics are added to the monthly rota along with the consultant's rota.

53.2 However as previously answered at Question 8 administrative support is an issue. As mentioned, their weekly hours are 18 ½ per week which is not enough for 5 Urology Nurse Specialists. Macmillan administrative support is of 7 hours per week for 3 Cancer Urology Nurse Specialists. The delay in typing is a further issue mentioned. We are fulfilling our role ourselves with our skills. Due to administrative issues which we have addressed with their management we feel we are getting nowhere. Our operational manger is Wendy Clayton. Management does support us to carry out these nurse led services but you need the administrative resources to make this work effectively.

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 Mr O'Brien retired prior to the commencement of my employment with the Southern Trust. Therefore I find this question difficult to answer.

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 was personally involved with the patients in the 9 SAIs as part of the review team. In each of the SAIs there was no evidence that these patients were introduced to a Urology Nurse Specialist. Having read patients records, no documentation of CNS support was recorded. This was not my CNS colleagues fault in my view. I do believe if CNSs had been present or had the opportunity to be a key worker for these patients, they would have been better supported. As part of the review group we discussed this. However, this does not persist today and we do ensure that all patients have support and have access to a Urology Nurse Specialist. *Please see:*

12. SAI overarching report

Learning

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

56.1 I am now aware of governance concerns since having commenced my employment with the Southern Trust in August 2020. I was made aware of these concerns when I was part of the review group for the nine SAIs. Such governance concerns include the prescribing of Bicalutamide, delay in dictation of clinics, the lack of engagement of the Urology Nurse Specialist at the results clinic, results not being signed off on ECR and actioned and medical notes being removed from trust property. I was not employed at the time and these concerns were highlighted after I started my employment when the SAIs were being investigated. *Please see:*

12. SAI overarching report

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 have been a Urology CNS since 2005. Over fourteen years of my time as a CNS was at the South Eastern Trust. I love my job; I would not have been a urology CNS so long if I was not passionate about it. The reason I left to work in the Southern Trust was for travelling as it is [redacted]. In addition, the team are so dedicated and I can say I feel privileged to work with such a great team. I was so excited when I took up my post in the Southern Trust. I feel for my colleagues, management, medical and nursing. . It is difficult for me to answer as to what went wrong with the Urology service.

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

58.1 I consider the learning from a governance perspective regarding the issues of concern within Urology services and regarding the concerns involving Mr O'Brien to be strong leadership. A manger or leader needs to have a skill to ensure staff don't overstep boundaries that can have an impact on the service. These need to be addressed however strong personalities can be difficult if issues have to be addressed by managers. I have mentioned issues in my answer to Question 56. There was no capability process in place. I am aware that nursing staff go through a capability procedure if there have been concerns with their performance. Do procedures exist in this case for medical staff underperforming? There needs to be learning from this such as the use of the whistle blowing. Each trust has a policy on whistle blowing but unfortunately, staff are reluctant to use this, as they do not want to be seen as a troublemaker.

58.2 The nine SAIs yes, this system is relevant if something goes wrong. This looks at what happened and put systems in place to prevent the incident from re-occurring. I was unaware of concerns until I was part of the review group. I agree that you do need to adhere to guidance for prescribing, the need for CNS support and to escalate if administrative support or delays impact on patient care. I am aware following the review of the SAIs, this involved the look back exercise and the public inquiry. *Please see:*

12. SAI overarching report

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

59.1 I cannot say who I consider failed to engage fully with the concerns within Urology Services as I was not part of the urology team during that time. Stronger management should address issues that were raised. Staff should be given feedback on how issues were addressed and what systems have been put in place. Owning up to mistakes can prevent concerns escalating. A practitioner may recognise the mistake, rectify this and put a system in place to prevent this reoccurring.

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 was not in post when the concerns were identified so this is difficult for me to answer. As part of the 9 SAI group we reviewed each case. I am very confident that if I had a concern, I would discuss it with current management. I would feel confident that they would handle this effectively. *Please see:*

12. SAI overarching report

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?

60.2 Again, this is difficult to answer. Current management would handle any concerns effectively. As part of the SAI group we met regularly to review each case. I can confirm the SAIs would not have been done differently.

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 This is difficult to answer, as I was not in post at the time of concerns. I am sure governance was fit for purpose and following on from being part of the SAI group, this resulted in a look back exercise which led to the public inquiry.

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

62.1 I have nothing further to add to the information available to me.

NOTE:

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

<u>Statement of Truth</u>

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

Signed: Patricia Thompson

Date: 14/11/2022

S21 75 of 2022

Witness statement of: Patricia Thompson

Table of Attachments

Attachment	Document Name
1	Band 7 – Urology Nurse Specialist JD
2	Advance communication Skills Certificate
3	Flexible cystoscopy certificate
4	Excellence in Cancer Care the contribution of clinical nurse specialists
5	Discharge Patient Awaiting Results (DARO)
6	Oncology conference
7	KSF
8	Appraisal 1
9	Appraisal 2
10	DRAFT Corporate Policy Template NURSE LED RENAL CELL CANCER FOLLOW UP v3
11	CNS forum Minutes
12	SAI overarching report
13	Revalidation
14	Guide to support Nurses and Midwifes in Raising a Concern March 2022
15	Northern Ireland Cancer Patient Experience Survey 2018
16	Patient Engagement Report Urology Cancer Service SHSCT

Southern Health and Social Care Trust

Quality Care - for you, with you

JOB DESCRIPTION

Title of Post: Urology Clinical Nurse Specialist x 2 posts

Grade of Post: Band 7

Reports to: Lead Nurse – Surgery and Elective Care

Accountable to: Head of ENT, Urology, Ophthalmology and Outpatients

Initial Location: Southern Health and Social Care Trust

Hours of Work: 37.5 hours

Job Purpose

In order to meet the overall mission of the Trust, the post holder will:

- Plan to deliver effective patient focused services which meet local, regional and national requirements

- Provide clinical expertise within the specialist area of urological benign and cancer conditions by working closely with Consultants, Nursing and the wider multidisciplinary team.

- Lead by example in promoting and delivering high standards of evidence based clinical treatment and sharing clinical expertise.

- The post holder will work closely with the in-patient ward staff, Oncology teams and Palliative Care teams to ensure holistic assessment and management.

Main Responsibilities

The postholder will focus and lead on the following key areas within the organisation's framework

1. Clinical/Professional/Specific Managerial Responsibilities

1.1 *Professional, ethical and legal*

- Adhere to DHSSPS and NMC Guidelines for practice requirements and standards for example, safe handling , administration, storage and custody of medicinal products
- Adhere to Trust guidelines, policies and procedures and comply with nursing strategy. Ensure that organisational goals are reflected in own and service objectives
- Contribute to the development of the Trusts policies and strategies where appropriate
- Maintain own professional and personal development in accordance with the NMC Codes (2008), standards and professional guidelines
- Establish and maintain relationship based on mutual respect communicating on a regular basis with the patient, relatives and carers in the provision of care and services, providing timely information at all stages of the patient pathway ensuring that individual needs are met and addressing any issues identified. Ensure appropriate systems are developed and operational to facilitate the dissemination of information within the team
- Adhere to the Data Protection Act (1998)

1.2 *Evidence-based practice*

- To act as a role model to promote a culture of research and reflective practice within the department to enhance person-centred care.
- Ensure evidence-based care is provided to agreed standards within the ward / department for patients with urological conditions.
- Assist in developing, implementing and monitoring policies, procedures and protocols.
- Create an environment which supports a culture of learning and reflective practice for all staff.
- Assist the line manager to ensure that systems and processes are in place to support effective mentoring of relevant staff.

1.3 *Environment*

- To maintain a safe and clean environment for staff, patients / clients and visitors by ensuring compliance with legislation, policies and protocols including health and safety, healthcare associated infection, risk management and critical incident reporting.
- Ensure staff awareness of environmental issues and take appropriate action as per HSC Trust policy.
- Assist the line manager with the analysis, assessment and management of actual and potential risks to health and well-being.
- Ensure safe and effective use of equipment as per HSC Trust policy.
- Ensure near misses, incidents, accidents and faulty devices are recorded, reported, investigated and learning disseminated as per HSC Trust policy.

1.4 *Multi-professional working*

- Contribute to the establishment of systems and processes to ensure effective communication and continuity of patient / client care, liaising with multi-disciplinary / multi-agency teams and community services.

2. Enhance the patient/client experience

2.1 *Person-centred care*

- Develop and maintain a culture of person-centred care within the service.
- Promote a caring environment where equality and diversity issues are respected and patients/clients and their carers are enabled to be partners in their care.
- Develop strategies for communication between staff, patients/clients, relatives and their carers, showing awareness of barriers to understanding.
- Facilitate communication between all members of the multi-disciplinary/multi-agency team, and across care settings.
- Enhance the patient experience through the provision of information and support throughout the patient journey.
- Act as the patient’s advocate, providing education and information, which enables the patient to make informed choices.
- Provide advice on palliative symptom control as required.
- Develop and promote post treatment recovery programmes as required.
- Ensure signposting and referral to health and well-being services.

2.2 *Coordination of the patient/client journey*

- Ensure the safety and quality of the patient's/client's journey by effective planning and co-ordination at all stages of the pathway.
- Support development of a patient centred service, within the multidisciplinary team, that provides specialist nursing care and support to patients and their families/carers.
- Arrange and coordinate investigations in a timely manner
- Be responsible for and positively influence the assessment, planning, delivery and evaluation of nursing care, establishing mechanism by which each patient has a coherent and comprehensive management plan. These plans will be developed with the patients and carers according to their needs and included referral to other disciplines and services observing the principles of holistic care
- Co-ordinate effective and holistic nursing care in a multi professional setting
- Provide nurse led clinics as deemed appropriate to the service needs.
- Monitor and report on patient's/client's progress and maintain contemporaneous records
- Make decisions based on professional knowledge and experience
- Assess both the physical and psychological needs of the patient and act as a resource to all disciplines involved in the delivery of care to the client group.

2.3 *Patient/client involvement*

- Identify opportunities for meaningful involvement of patients and carers in relation to the development of care and services.
- Ensure effective systems are in place to gain patient and carers feedback on their experience of care.
- Ensure patient involvement in the design and redesign of services
- Ensure compliments and complaints are managed in line with HSC Trust policy including the dissemination of shared learning.

3. Provide effective leadership and management

3.1 *Role model*

- Act as a visible leader within the service.
- Provide leadership that enables professional decision making and effective team working.
- Empower and enable staff to contribute to the delivery of high quality person-centred care.

- Provide professional leadership and expert nursing advice and support to the MDT and other care professionals across the Trust and actively support their professional development.
- Attend and contribute to Departmental, Directorate and other meetings on a regular basis as required.
- Undertake delegated responsibilities from the Service Manager.

3.2 Develop team performance

- Promote, develop and facilitate a learning culture within the service.
- Promote equality of opportunity for all, in accordance with HSC Trust Equality Opportunity Policy.
- Lead and participate in annual staff appraisal/development review, ensuring effective implementation of the Knowledge and Skills Framework (DH, 2004).
- Lead and participate in learning needs analysis and facilitate annual personal development plans for the nursing team as required.
- Lead and participate in orientation and induction programmes for staff within the department.
- Promote a person-centred culture to facilitate good staff relationships and morale among staff.
- Contribute to the education commissioning process for nursing staff as required.
- Manage poor performance and practice of staff in line with HSC Trust policies as required.

3.3 Effective use of resources

- Deliver a safe and effective service within allocated resources, ensuring the resources are used to maximum effect.
- Adhere to financial policies and procedures, particularly Standing Financial Instructions, Authorisation Frameworks, Procurement Legislation and associated processes, and Prompt Payment Code.
- Adhere to HSC Trust financial controls and fraud awareness principles (e.g. verification of authenticity / accuracy of the Staff-in-Post records).
- Adhere to HSC Trust systems for effectively managing stock and safeguarding fixed assets.
- Promote the principles of good governance and protect the department from financial risk, particularly in respect of patient/client monies and property and charitable funds.
- Display managerial and organisational skills to ensure that products required for patient/client care/treatment are procured in timely fashion and demonstrate value for money.

- Show a commitment to effectively manage resources and achieve statutory financial targets.

4. Contribute to the delivery of the organisation's objectives

4.1 Continuous quality and improvement

- Promote a culture of continuous quality improvement through the use of audit, patient/client feedback and reflection on practice by self and other members of the team.
- Deliver and promote evidence based practice and agreed care pathways for patients with Cancer

4.2 *Service improvement, development and modernisation*

- Work in partnership with a range of clinicians and managers in the planning or development of own service promoting the involvement of patients and carers.
- Review processes /practices including those within the department to support patients/clients to improve their own health and well-being.
- Review processes/practices to ascertain if there are better ways of working within the service to enhance patient/client care, service delivery and deliver required efficiencies
- Liaise with NICaN in the development of regional and local services
- Collate and analyse statistical data for the service.
- Lead on business planning for development of the service.
- Actively promote new ways of working and models of service delivery to improve services for Cancer patients

4.3 Nursing

- Liaise with nursing managers and heads of nursing on all professional nursing issues.
- Ensure staff are aware of and act in accordance with all relevant policies, procedures, guidelines, protocols, codes of conduct and nursing strategy.
- Ensure processes are in place to manage sickness/absenteeism and take appropriate action in line with HSC Trust policies.
- Promote the health and well-being of staff and observe for any signs of ill health or stress factors in staff assigned to the area and take appropriate action in line with HSC Trust policies and NMC guidelines.

5. General Responsibilities

The post holder will be required to:

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

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

iii. The HSC Code of Conduct for Employees sets out the standards of conduct expected of all staff in the Southern Health & Social Care Trust and outlines the standards of conduct and behaviours required during and after employment with the Trust. Professional staff are expected to also follow the code of conduct for their own professions.

iv. Adhere at all times to all Trust policies/codes of conduct, including for example:

    a. Smoke Free policy
    b. IT Security Policy and Code of Conduct
    c. Standards of attendance, appearance and behaviour

v. Contribute to ensuring the highest standards of environmental cleanliness within your designated area of work.

vi. Co-operate fully with regard to Trust policies and procedures relating to infection prevention and control.

vii. All employees of the Trust are legally responsible for all records held, created or used as part of their business within the Trust including patients/clients, corporate and administrative records whether paper-based or electronic and also including emails. All such records are public records and are accessible to the general public, with limited exception, under the Freedom of Information act 2000 the Environmental Information Regulations 2004, the Data Protection Act 2018 and General Data Protection Regulations. Employees are required to be conversant with the Trusts policy and procedures on records management and to seek advice if in doubt.

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

ix. Represent the Trust's commitment to providing the highest possible standard of service to patients/clients and members of the public, by treating all those with whom he/she comes into contact in the course of work, in a pleasant, courteous and respectful manner. Seek to engage and involve service users and members of the public in keeping with the Trust's Personal and Public Involvement Strategy and as appropriate to the job role.

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

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

SOUTHERN HEALTH & SOCIAL CARE TRUST

PERSONNEL SPECIFICATION

Title of Post: Urology Clinical Nurse Specialist

Grade of Post: Band 7

HOURS 37.5 per week

Notes to applicants:

1. *You must clearly demonstrate on your application form under each question, how you meet the required criteria as failure to do so may result in you not being shortlisted. You should clearly demonstrate this for both the essential and desirable criteria.*
2. *Shortlisting will be carried out on the basis of the essential criteria set out in Section 1 below, using the information provided by you on your application form. Please note the Trust reserves the right to use any desirable criteria outlined in Section 3 at shortlisting. You must clearly demonstrate on your application form how you meet the desirable criteria.*
3. *Proof of qualifications and/or professional registration will be required if an offer of employment is made – if you are unable to provide this, the offer may be withdrawn.*
4.

ESSENTIAL CRITERIA		
SECTION 1: The following are **ESSENTIAL** criteria which will initially be measured at shortlisting stage although may also be further explored during the interview/selection stage. You should therefore make it clear on your application form whether or not you meet these criteria. Failure to do so may result in you not being shortlisted. The stage in the process when the criteria will be measured is stated below.		
Factor	**Criteria**	**Method of Assessment**
Experience / Qualifications/ Registration	Currently a Registered Nurse Level 1, (Adult) on the Live NMC Register. **AND** University degree or relevant health/social care qualification plus at least 2 years' experience within the last 6 years at Band 6 in a hospital or community environment delivering health or social care service and people with urological conditions **AND** Have completed or be willing to undertake specialist nursing practice in Urology **OR** Have worked for at least 5 years in a senior role[1]	Shortlisting by Application Form
Other	Hold a current full driving licence which is valid for use in the UK	Shortlisting by

	and have access to a car on appointment. This criteria will be waived in the case of applicants whose disability prohibits driving but who have access to a form of transport approved by the Trust which will permit them to carry out the duties of the post flexible with regards to working arrangements to meet the needs of the service	Application Form
Factor	**Criteria** *Ideally no more than 6-8 criteria in this section*	**Method of Assessment**
Skills / Abilities	1. Ability to influence and manage change, including the promotion of evidence based practice. 2. Have effective communication skills to meet the needs of the post in full. 3. Ability to work independently within protocols and, where appropriate, Patient Care Directives, providing agreed standards of patient care 4. Demonstrate ability to work effectively as part of a multi-disciplinary team while managing a busy caseload 5. Ability to actively engage in research and audit processes 6. Ability to teach colleagues and patients using a range of media 7. Competent IT skills	Interview
Knowledge	8. Current evidence of informed nursing practices and treatment modalities in both oncological and general aspects of urology care. 9. Awareness of the national urological nursing agenda	Interview

[1] *"senior role" is defined as experience gained at Band 6 or above*

<u>Vetting</u>
As part of the Recruitment and Selection process, it may be necessary for the Trust to carry out an Enhanced Disclosure Check through Access NI before any appointment to this post can be confirmed.

Canvassing either directly or indirectly will be an absolute disqualification for appointment.

Additional Information:
Candidates shortlisted for interview will be required to produce original certificates and photocopies of the same.

If successful staff will be required to produce documentary evidence that they are legally entitled to live and work in the UK eg P45, payslip, National Insurance Card, Birth Certificate. Failure to do so will result in a non appointment.

The Trust is an Equal Opportunities Employer.

WE ARE
MACMILLAN.
CANCER SUPPORT

NICaN
Northern Ireland
Cancer Network

This is to certify that

Patricia Thompson

attended a three day

Advanced Communication Skills Training Course

6th 7th and 8th October 2010

Dunadry Hotel, Templepatrick

Course Facilitators

Dr Susie Wilkinson

Personal information redacted by USI

Dr Bernie Corcoran

Personal information redacted by USI

The Royal Surrey County Hospital & Frimley Park Hospital

This is to certify that

Patricia Thompson

attended the

Flexible Cystoscopy Course

at the Postgraduate Medical School of
The University of Surrey

Personal information redacted by USI

n Friday 8 December 2006

Personal information redacted by USI

Stephen Langley
Course Director

Date 8/12/06

Bruce Montgomery
Course Director

Date 8th DEC 06

This course is recognised by the Raven Department of Education at The Royal College of Surgeons of England

Ensuring Better Treatment

National Cancer Action Team
Part of the National Cancer Programme

Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist

WE ARE MACMILLAN.
CANCER SUPPORT

Contents

Foreword

Together we share an ambition to achieve the best cancer outcomes for patients in the UK, recognising that, at a time of tightened budgets, it is critical that NHS resources are deployed to best effect. Now more than ever, clinical nurse specialists (CNSs) have a vital role to play in delivering high quality and compassionate care, including care closer to home, and supporting a drive for efficiency that improves health outcomes and maximises resources.

Cancer CNSs have played an important role in the successful implementation of initiatives to improve NHS cancer services. Despite an increasing incidence of the disease and an ageing population, death rates from many cancers are dropping, survival rates are improving and many patients' experiences of care have been enhanced. CNSs are at the front line of cancer care; they are the main point of contact for patients and as a result help to shape services for each patient according to need and patient choice, which contributes to wider cancer priorities. For example, CNSs play an important role in enabling care to be delivered closer to home and in improving patients' and their families' ability to self-manage symptoms and side-effects of treatment.

CNSs contribute to increasing the quality of care provided by the NHS; indeed, in the face of rising patient expectations, more patients report being treated with dignity and respect and having trust and confidence in their care team. Increasingly, they have an ongoing role in supporting cancer survivors as well as cancer patients. Overall it is estimated that there are now 2 million people living with cancer and this is set to rise to 4 million by 2030.[1]

For people affected by cancer, the effective management of their care pathway is essential to maintain quality of life. People whose care is unplanned and un-coordinated are more likely to be high users of health and social care services, including emergency care. CNSs work closely with patients and with their clinical colleagues to adapt to patients' emerging needs thus reducing the need for unplanned care.

This short guide is designed to support clinical teams, commissioners, employers and managers to understand and evaluate the contribution of CNSs in cancer as they plan their local workforce and service improvement strategies. With examples drawn from front-line services across a range of cancers, this guide sets out how effective CNS deployment drives innovation, reduces inefficiency and improves the quality of cancer care across the UK.

We still have further to go if we are to improve outcomes for all cancers, with the aim of bringing us in line with the best in Europe. Ensuring provision of CNSs where they are needed, coupled with effective use of their skills and expertise will enable us to move faster towards this goal.

Professor Sir Mike Richards
National Cancer Director

Mike Richards

Ciarán Devane
Chief Executive
Macmillan Cancer Support

Ciarán Devane

Dame Christine Beasley DBE
Chief Nursing Officer (England)
Department of Health

CBeasley

The role of the Clinical Nurse Specialist in cancer care

The roles undertaken by Clinical Nurse Specialists (CNSs) are many and varied; however, there are core clinical practice functions and a level of practice that could be reasonably expected of all CNSs in cancer care.

CNSs in cancer care can be described as registered nurses, who have graduate level nursing preparation and who would usually be expected to be prepared at Master's level. They are clinical experts in evidence-based nursing practice within a specialty area. The specialty may be focused on a population (e.g. young people), type of care (e.g. palliative care), type of problem (e.g. lymphoedema), type of treatment (e.g. chemotherapy) or tumour type (e.g. lung cancer).

CNSs treat and manage the health concerns of patients and work to promote health and wellbeing in the patients they care for. CNSs in cancer care practice autonomously and integrate knowledge of cancer and medical treatments into assessment, diagnosis, and treatment of patients' problems and concerns.[2] Whilst many specialist nurses may function at an advanced level, this level of practice is not common to all, thus the title Clinical Nurse Specialist does not in itself indicate that the nurse is an 'advanced practitioner'.

The high-level activities of CNSs can be separated into four main functions.[3] In the context of cancer care these consist of:

1. 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
2. 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
3. Using empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines as appropriate
4. Using technical knowledge and insight from patient experience to lead service redesign in order to implement improvements and make services responsive to patient need

Furthermore, some cancer CNSs have developed their roles to include technical elements, for example: physical examinations and diagnostic tests; and insertion of central venous lines for the delivery of chemotherapy or for nutritional purposes.

Many cancer CNSs work as part of a tumour specific team, whereas others may work across more than one service or setting. Although many are based within acute trusts, post-holders are also located in primary care and community settings or private and voluntary sector organisations. They may be responsible for whole client groups, or for episodes of care and nursing services more widely. They are also typically core members of a multidisciplinary team.[4]

Key contributions that CNSs make to cancer care

Clinical Nurse Specialist

- Acting as a key worker across the whole care pathway
- Advanced clinical / diagnostic skills
- In depth knowledge of a tumour area
- Ability to assess patients' holistic needs
- Advanced communication and advocacy skills
- Empathy for patients and their families
- Excellent decision making abilities
- Leadership within the MDT and wider cancer team
- Innovation, project management and change management

The cost of managing cancer

The cost to the NHS in England of patient care for cancer in 2007/8 was £5 billion.[5] Department of Health figures for 2007-08 showed that:

- Over half (i.e. over £2 billion) of the total expenditure on cancer in England went on inpatient care[6]
- Inpatient care for cancer patients accounted for 12% of all inpatient beds in England[6]
- The number of emergency admissions for cancer increased by 47% in the past 8 years[6]
- 4.7 million bed days were cancer related[6]

Statistics from 2006-07 for England show:

- 417,646 emergency inpatient admissions for cancer representing 2,963,987 bed days[6]
- 339,038 elective inpatient admissions for cancer representing 1,750,223 bed days[6]

Reducing the financial burden of cancer – the potential of the CNS

The specialist nature of the cancer CNS and their role as key worker to individual patients means that they can quickly identify emerging issues that might require medical attention, enabling care to be planned and emergency admissions averted. CNSs also support enhanced recovery after surgery – equipping patients to manage their recovery at home and reducing the need for lengthy hospital stays. These two important contributions help the NHS to improve patient experience and safety.

There are also sound economic arguments for supporting patients to manage their care at home and helping them through the complex systems of health care provision.

The National Audit Office's End of Life Care report estimated £104m savings by reducing emergency admissions by 10 per cent, and reducing the length of stay by 3 days.[7]

An economic modelling analysis by Macmillan Cancer Support in 2009[8], 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. This related only to breast and lung patients admitted through the two week wait system in one health economy. If extrapolated to a national level then the economic benefits could be significant.

CNSs: leading quality and productivity in cancer care

Patients rightly expect high quality, effective healthcare and CNSs have an important role to play in meeting their needs and expectations.

The proposed NHS Outcomes Framework[9] is structured around five high level outcome domains. These are intended to cover everything the NHS is there to do. These five outcome domains are:

- Preventing people from dying prematurely
- Enhancing the quality of life for people with long-term conditions
- Helping people to recover from episodes of ill health or following injury
- Ensuring people have a positive experience of care
- Treating and caring for people in a safe environment and protecting them from avoidable harm

As practitioners and partners at the heart of multidisciplinary teams, CNSs have influence and credibility across the care pathway. They are increasingly taking a leadership role in refining systems and smoothing care pathways, making a demonstrable contribution to effectiveness, patient experience and safety.

Experience from the front line – CNSs transforming cancer care

Impact of key CNS-led activites

Improving quality and experience of care

- Managing complex, individual and changing information and support needs of patients and carers
- Supporting patients in choices around treatment and care
- Enhancing recovery and delivering care flexibly and closer to home
- Facilitating set up of support groups

Reinforcing safety

- Delivering safe, nurse-led services
- Using vigilance of symptoms and drug toxicity to trigger rescue work
- Identifying and taking action to reduce risks
- Facilitating rapid re-entry into acute services, if appropriate

Increasing productivity and efficiency

- Intervening to manage treatment side effects and/or symptom control, preventing unplanned admissions
- Providing nurse-led services that free up consultant resource
- Empowering patients to self-manage their condition

Demonstrating leadership

- Educating the wider healthcare team and acting as a mentor
- Identifying and implementing service improvement and efficiencies
- Determining measurable outcomes, auditing practice, and sharing good practice and innovation

CNSs across the country are already transforming patients' experiences of cancer care. The following case studies provide a flavour of the kinds of initiatives that CNSs are leading – highlighting their pivotal role in maximising resource and benefitting patients.

Case Studies

Innovation, project management, change management

Lesley Barnett, Macmillan Lead Cancer Nurse, Doncaster
Gina Wibberley, Macmillan Lung CNS, Lincoln

CNSs in Doncaster and Lincolnshire have implemented rapid alert systems to ensure that they are immediately informed when one of their patients enters hospital with an unplanned admission. Using mobile technology and integrated IT systems, a text message and email is sent to the CNS who can immediately attend the patient or discuss the case with the treating clinicians.

Using their specialist knowledge in lung cancer, and their understanding of individual patients' needs, CNSs in Lincolnshire use this as an opportunity to re-assess the patient's cancer pathway outside of scheduled patient planning, or identify where a quick specialist intervention can turn around an inappropriate admission. The nurses in Doncaster have identified length-of-stay reductions of one to two days per patient, they work to ensure that the patient is admitted to the correct ward and in some cases prevent admission altogether. Added to these productivity benefits is the increased quality of care experienced by patients who report feeling completely supported, knowing that they are receiving coordinated care.

Empathy for patients and their families

Frances McKay, Macmillan Mesothelioma and Lung CNS, Medway

Frances, and her colleagues Caroline Williams and Pat Cameron, run the only lung cancer and mesothelioma support group in their Cancer Network. Up to 28 people each month attend the group.

The CNSs work in collaboration with a local hospice to facilitate the monthly group meetings with a hospice volunteer managing the meeting practicalities. A successful buddy system has been established for patients and carers who face the challenging and complex issues of a terminal disease.

The group also enables the CNSs to identify emerging health issues, including helping patients to self-manage symptoms such as shortness of breath, reducing anxiety and maintaining quality of life. Importantly, the CNSs are able to mediate between patients and hospital services and quickly address any issues of concern raised by patients and their families.

Advanced clinical and diagnostic skills

Sharon McGeary and Amanda Gerrard, Paediatric Oncology Outreach Network CNSs, Newcastle Upon Tyne

Nurses from the children s oncology outreach service in Newcastle work with children and young people throughout their cancer journeys. Using specialist knowledge of symptom management, palliative and complex care, the nurses work a 24/7 on call system, allowing for timely, effective interventions which maximise care delivery. The nurse team are trained as non medical prescribers, and more than half are practising prescribers.

Working in a large geographical region, the nurses have developed effective collaborative working practices with local primary care service providers. This is particularly important in enabling children and young people with progressive disease to be cared for, and die, in their preferred place of choice, often their home.

The nurses are leading the way in the implementation of new technologies in their hospital trust. Smart Pump technology, considered to be the next generation of ambulatory infusion devices, allows the release of medication over seven days maximising symptom management and minimising hospital attendance. Corresponding drug libraries, managed by the nurses, help to improve safety by reducing drug errors, improving workflow and providing a new source of data for continuous quality improvement.

Acting as key worker across the whole care pathway

Tina Lightfoot, Lead Specialist Nurse for GI services (surgery), Chester

Tina and the colorectal specialist nurses provide quality services to enhance recovery for patients with colorectal cancer at the Countess of Chester Hospital. Through a pre operative counselling initiative, patients and carers have an increased understanding of recovery and discharge expectations, helping them to make plans for managing care at home. In addition, patients who are expected to have a stoma are visited at home by the stoma nurse for a dummy’ teaching session, reducing the time it takes to become self-sufficient in stoma management.

Patients on the enhanced recovery programme are discharged as early as two days after surgery, and there is evidence that this is significantly reducing care costs. The colorectal specialist nurses contact the patient daily after discharge for up to 10 days to assess their progress. This vigilance ensures that complications are picked up early enabling timely intervention, and patients report feeling supported through their recovery.

Excellent decision making abilities

Debbie Fitzgerald, Gynaecology CNS, Torbay

Debbie has developed an innovative early-alert service for women with ovarian cancer who suffer from a painful and distressing build up of fluid in the abdominal area.

Patients are alerted to the possibility of fluid build-up, and encouraged to phone her if they begin to experience symptoms. When contacted, Debbie makes a clinical assessment, organising an abdominal scan if required and booking blood tests pre-admission. The drainage can then be done as a day patient, preventing emergency admission to A&E and lengthy inpatient stays as well as improving patients’ quality of life.

The CNS’s coordinating role ensures that phlebotomists, radiographers, and the medical team are all available at the right time. Debbie has developed this into a protocol - now widely used.

Advanced communication and advocacy skills

Judith Clarke, Surgical Breast Care CNS, Coventry

Judith has developed an innovative system to monitor and best manage anxiety among patients recalled to the breast screening clinic for further assessment following attendance to the NHS breast screening programme. Judith devised a simple tool that encourages patients to reflect on their anxiety and prompt them to seek additional support from the breast care nurse (BCN). It also promotes greater collaboration with radiographers and a more coordinated patient-centred experience.

Designed to look like a thermometer, the assessment tool asks women to score themselves from 0 10 (low to high anxiety) enabling BCNs to triage the more vulnerable women (scoring 5 and above) and ensure they are offered a BCN consultation before being re screened. Radiographers also use the self-assessment to ensure more patient-focused care, taking into account women s concerns. Feedback from patients shows that women find this activity useful and many have commented on how it helped to reduce their anxiety.

Case Studies (continued)

Demonstrating Leadership

Catherine Oakley, Nurse Consultant, London

Catherine and the team of chemotherapy nurse specialists at Guy’s and St Thomas’ Hospital have been working together to redesign the way chemotherapy is delivered. Nurses in the chemotherapy unit now work in four specialised teams according to tumour types to improve consistency for patients and maximise the nurses’ clinical expertise.

Catherine piloted an intervention in urology in which a specialist nurse and pharmacist delivered an improved pre-treatment consultation. The key to its success is structuring the consultation to ensure that patients’ educational and supportive care needs are met to optimise safety and empower patients to actively participate in their treatment plan. Additionally, CNSs proactively call patients to monitor their progress during the course of their treatment. Closely monitoring patients in this way ensures that any side-effects can be quickly managed and that patients are supported through this sometimes difficult part of their cancer journey.

In-depth knowledge of tumour area

Tessa Fitzpatrick, Macmillan Lung CNS, North Tees

Analysis of patient experience at University Hospital of North Tees suggests that lung cancer patients and carers can encounter problems following admission to the Emergency Assessment Unit (EAU). These include unnecessary investigations, poor symptom management, lack of recognition of end of life, delays in discharge and inadequate communication. This has a negative impact on patients’ confidence in the service and also on the length of stay which has a cost implication.

The CNSs at North Tees use their specialist knowledge of lung cancer to support patients who are admitted as emergency cases, reducing inpatient stays and helping patients and carers to understand and manage symptoms. University Hospital of North Tees examined a total of 94 inpatient episodes resulting in 964 bed days. The average length of stay for those patients not referred to the lung CNS was 10.8 days however there was a reduction in length of stay to 9.7 days for those patients who had lung CNS input during their admission.

Ability to assess patients' holistic needs

Anita Pabla, Sarcoma CNS, Leicester

Anita works with patients throughout their cancer journey but has particularly focussed on supporting survivorship and smoothing the transition from secondary to primary care.

Six to eight weeks post-treatment, she provides patients with detailed and individual end of treatment’ summaries within the context of a holistic consultation. This captures their initial diagnosis and treatment history, medication and follow up schedule   incorporating the wider services they have accessed, such as limb fitting and support groups. The summary also acts as an important communication tool for their GP, enabling greater integration between different parts of the patient pathway.

The summary and assessment has proved valuable to patients increasing their confidence and ability to self-manage   as well as to primary care   improving appropriate referral if and when needed.

Delivering the future for cancer patients

The NHS White Paper, Equity and Excellence: Liberating the NHS, puts patients and clinicians at the heart of decision-making in the NHS. The phrase "no decision about me without me" is used in the White Paper to emphasise patients' involvement in their own care.[10] CNSs are often the main point of contact for cancer patients and their families, and work closely with colleagues throughout the patient's cancer journey. As a result, they are well placed to support patients at each stage and to promote integration within care teams.

Equity and Excellence proposes a shift away from measuring clinical inputs and processes in favour of achieving improved clinical outcomes and higher quality patient experience. Here too, CNSs already demonstrate their skills in assessing and putting in place interventions to achieve these.

The Cancer Reform Strategy (2007) stated that: "Commissioners and providers should ensure that the critical roles of clinical nurse specialists in information delivery, communication and coordination of care are supported".[11] This remains essential to achieving safe and high quality cancer care and we expect to see this reflected in the refreshed Cancer Reform Strategy.

Nursing is changing, reflecting and rewarding the skills and expertise of its workforce. Career pathways have been updated and transferable skills identified to enable nurses to shape their careers within and across different care pathways.[12] Embracing new models of care, the CNS role extends beyond the hospital setting into local community and specialist settings and increasingly includes informed individual care planning that enables patients to self-manage their condition where possible.

There is wide variation in the types of tasks that CNSs are carrying out. While some of these make good use of their skills, there is evidence that CNSs are also being diverted into general ward duties and tied up in administrative tasks. This does not represent good value to the NHS. Commissioners, employers and managers therefore need to consider whether CNSs are being deployed to best effect.

Matching workforce planning to patient need

Clinical teams will be considering whether provision of CNSs in their local area is sufficient to meet need. Understanding the patterns of access is fundamental to being able to match the CNS workforce to patients' needs. Despite the expansion in overall CNS numbers since the 1980s, workforce shortages are still an issue.[13]

The best available data indicates that not every cancer patient has access to a CNS, despite the recommendations made in the Improving Outcomes Guidance. The National Cancer Action Team's Workforce Review Team 2010 census demonstrates significant variation in provision of cancer CNSs in England, which cannot be accounted for by geographical differences in cancer incidence or in patient flows.[14] Since the last census in 2008,[15] there appears to have been an increase in CNS posts in rarer cancers, but the 2010 census revealed no significant growth in other tumour groups despite increasing cancer prevalence. Inequities remain across England and also between different tumour types. Patient advocacy groups have argued that in some cancers - notably lung and urological cancers - CNS provision falls significantly short of patient need and that CNSs face variable case-loads.

Issues for Employers and Managers to consider

CNSs provide quality care and contribute to improved outcomes for cancer patients. They lead innovation, and can drive efficiency in their teams. They also contribute to the delivery of health strategies and policy guidance including:

- Cancer Reform Strategy
- Improving Outcomes
- Quality, Innovation, Productivity and Prevention Challenge
- High Impact Actions for nursing and midwifery
- Equity and Excellence: Liberating the NHS
- Chemotherapy Services in England
- Vital Signs
- End of Life Care Strategy

Employers and managers may wish to ask the following questions when considering their cancer services and assessing their CNS provision, to identify to what extent cancer services are configured to maximise the safety, quality and productivity of care:

Your community

- What is the all-age, all-cause cancer incidence rate in your PCT?
- What are the demographics of your PCT in terms of: age; socioeconomic and deprivation factors; prevalence of risk factors; ethnicity?
- Are there communities with particular unmet needs?
- What priority issues for cancer have been identified through the Joint Strategic Needs Assessment?
- How have you reflected these in the selection of local priorities and incentives for health care providers e.g CQUINs? QOF?
- How do you plan to measure and improve outcomes in these areas?

Provision and capacity

- How many whole-time equivalent CNSs posts are there in your PCT?
- What is the distribution of these across different cancers?
- How does this compare to patterns in neighbouring areas and to the national picture?
- Does each specialist team dealing with a particular cancer type have at least one CNS member?
- How good is CNS attendance at MDT meetings for each team?
- How many new patients does each CNS see each year?
- Have you considered using the expertise of the Macmillan Cancer Support Service Development Team to redesign CNS roles and services should you have concerns that CNSs may not be working to the best potential of their roles?

Where can CNSs make most impact?

- How many unplanned admissions are there for cancer each year in your PCT? And how does this vary by cancer type?
- Do audited records demonstrate that at least 80% of patients receive information about their diagnosis, treatment and care plan?
- Can it be demonstrated that care is effectively coordinated across boundaries?
- Are CNSs working in roles that reflect and demand their knowledge and skills or are they undertaking general ward duties?

Further sources of information

- Cancer Commissioning Guidance
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110115
- Cancer Commissioning Toolkit
  https://www.cancertoolkit.co.uk
- Cancer Reform Strategy and Annual Reports
  http://www.dh.gov.uk/en/Healthcare/Cancer/ReformStrategy
- National Cancer Intelligence Network
  http://www.ncin.org.uk
- Association of Public Health Observatories
  http://www.apho.org.uk/
- Public Health Observatory Handbook of Health Inequalities Measurement
  http://www.sepho.org.uk/viewResource.aspx?id=9707
- Guidance on Joint Strategic Needs Assessment
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081097
- The Operating Framework for the NHS in England, 2010/11 (December 2009)
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110107
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- National Audit Office, End of Life Care, November 2008 available here:
  http://www.nao.org.uk/publications/0708/end_of_life_care.aspx
- Department of Health, Equity and excellence: Liberating the NHS, July 2010
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- To download this publication go to:
  http://ncat.nhs.uk/our-work/ensuring-better-treatment/quality-in-nursing

Acknowledgments

The Department of Health, National Cancer Action Team and Macmillan Cancer Support would like to thank all those who have contributed to the development of this publication, in particular the Clinical Nurse Specialists who provided examples of good practice, and the members of the National Quality in Cancer Nursing Steering Group for their advice and guidance.

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10 Department of Health, Equity and excellence: Liberating the NHS, July 2010

11 Department of Health, Cancer Reform Strategy, December 2007

12 Department of Health, Towards a framework for post-registration nursing careers - consultation response report, July 2008

13 National Cancer Action Team, National Cancer Peer Review Programme 2004 – 2007. An overview of the findings from the second national round of peer reviews of cancer services in England, June 2008

14 National Cancer Action Team Workforce Review Team, Census of Cancer Specialist Nurses in English Cancer Networks, 2010

15 Trevatt, P., Leary, A., A Census of the advanced and specialist cancer nursing workforce in England, Northern Ireland and Wales, European Journal of Oncology Nursing (2009) 14:1 (68-73)

Endorsements

The content of this publication is endorsed
by the following organisations:

BRAIN TUMOUR UK

BREAKTHROUGH BREAST CANCER

breast cancer care

Kidney Cancer UK
SUPPORTING PATIENTS & CARERS

Blood and Lymphatic cancers
Leukaemia CARE
supporting a quality of life

Ovarian cancer action

PANCREATIC CANCER UK
Striving for Survival

THE PROSTATE CANCER CHARITY

RCF RARER cancers FOUNDATION
incorporating Rarer Cancers Forum

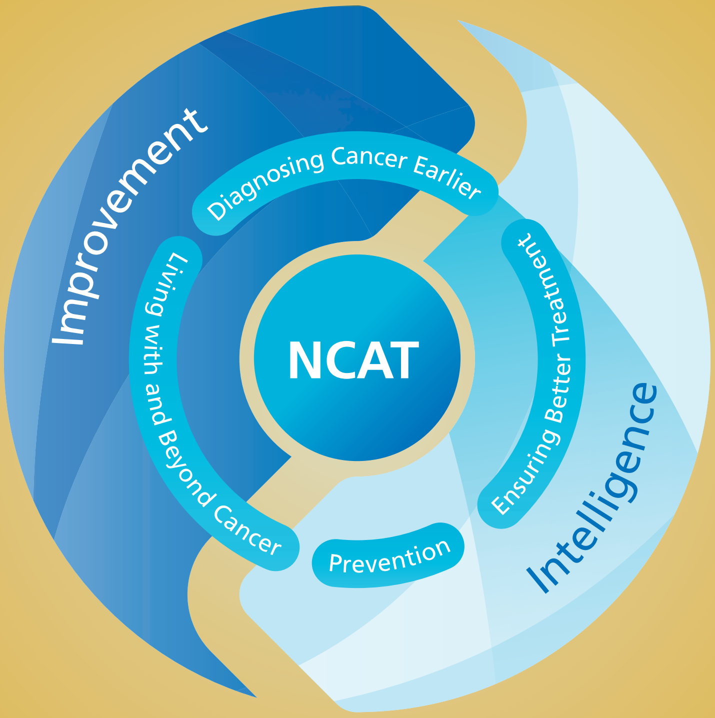
Royal College of Nursing

TARGET OVARIAN CANCER
For every woman. For life.

UKONS
Oncology Nursing Society

DH Department of Health

Gateway Number: 14851



WE ARE MACMILLAN. CANCER SUPPORT

NHS

Southern Health
and Social Care Trust

Quality Care - for you, with you

DRAFT

ADMINISTRATIVE & CLERICAL
Standard Operating Procedure No.

Title	Discharge Awaiting Results – Outpatients (DARO)	
S.O.P. Number		
Version Number	v1.0	**Supersedes:** v0.1
Author	Operational Support Leads	
Page Count	9	
Date of Implementation	November 2010	
Date of Review	November 2011	**To be Reviewed by: OSL's**
Approved by		

Standard Operating Procedure (S.O.P.)
Discharge Awaiting Results (DARO)

At the end of an outpatient clinic all attendances and disposals (AADs) must be recorded on PAS. Recording “Attendances and Disposals” is an essential part of the outpatient flow, and is required for statistical analysis of clinic outcomes and activity, and can be used for future planning of services and determining capacity & demand. Using “AAD” can also be used as a “failsafe mechanism” by secretarial staff, so as to ensure that all patients who were booked to a specific clinic have had their attendance recorded; to ensure that letters have been dictated and typed for each patient; to ensure that the correct outcome is recorded for each patient – i.e. to ensure that patients are not “lost” in the system and that patients are added to WL for procedures or added for further OP review in the future.

If a patient has attended a clinic and is awaiting results before a decision is made regarding further treatment, the following process must be followed:

Recording Clinic Disposals on PAS

1) ensure all attendances for the clinic have been recorded on PAS using function “AAD” (Attendances and Disposals) – if function “ATT” (Appointment Attendance) has been used by reception staff to record the attendances immediately after the clinic, the attendance codes will default in (i.e. ATT, DNA, CND, WLK)
2) ensure all disposals are now recorded for each patient - the disposal codes which are used within the Trust are shown below:

```
              D i s p o s a l   C o d e   M a s t e r   F i l e
     Maintenance Details                                   09/11/10 09:01 CAH
+--------------------------------------+-----------------------------------------+
|  Command        :LIST                |Code  Description                        |
|                                      +-----------------------------------------+
|  Disposal Code  :                    |ADM   ADMIT DIRECT FROM O.P.D            |
|                                      |BKD   DATE GIVEN AT OPD TO COME IN       |
|  Description    :                    |DIS   DISCHARGE                          |
|                                      |DNA   DNA - NO FURTHER APPOINTMENT       |
|                                      |DNAR  DNA - APPOINTMENT REBOOKED         |
|                                      |REV   REVIEW APPOINTMENT                 |
|                                      |RVL   REVIEW AT A LATER DATE             |
|                                      |TRT   ADDED WAIT. LIST FOR OP TREAT      |
|                                      |WL    ADDED TO WAITING LIST              |
|                                      |                                         |
|  Enter?         :                    |                                         |
|                                      +-----------------------------------------+
|                                                                                |
+--------------------------------------------------------------------------------+
```

3) If a patient is awaiting results prior to a decision regarding follow up treatment being made, they must be recorded as a discharge (DIS) **and not** added to the OP Waiting List for review.

4) All outcomes/disposals should be recorded on PAS for each patient. For those patients who have had a disposal code of DIS, WL, BKD, DNA or WL recorded, you will then be prompted to select each patient individually for discharge (when you enter “Yes” – when using AAD function).

```
          R e c o r d   A t t e n d a n c e   a n d   D i s p o s a l
       Outpatients                                         09/11/10 09:12 CAH
+--------------------------------------------------------------------------------+
| Clinic: CS1      Doctor:    CS1      Date: 25/10/2010  Session: 08:00-13:00   |
|                                                                                |
|Time  Status   Case Note No Name                 Attd      Disp Grade          |
|08:45 OP REG   CAH12345     BLOGGS, J             ATT      :REV :              |
|08:45 OP DSCH  CAH23456     GREEN, J             :ATT      :WL  :              |
|08:45 OP DSCH  CAH10000     SMIITH, M            :ATT      :DIS :              |
|09:00 OP DSCH  CAH45678     THOMPSON, P          :ATT      :DIS :              |
|09:00 OP REG   CAH56789     BROWN, C             :ATT      :REV :              |
|09:15 OP REG   CAH67890     WEIR, M              :ATT      :RVL :              |
|09:15 OP REG   CAH78900     MACKLE, C            :ATT      :RVL :              |
|09:15 OP DSCH  CAH54321     SLOAN, E             :ATT      :WL  :              |
|09:20 OP REG   CAH43210     MCKEOWN, G           :ATT      :REV :              |
|09:25 OP REG   CAH10101     CLARKE, J            :ATT      :RVL :              |
|09:25 OP REG   CAH10000     BLACK, N             :ATT      :REV :              |
|09:30 OP DSCH  CAHE0000     WHITE, D             :ATT      :WL  :              |
|                                                                                |
|                                                                                |
+--------------------------------------------------------------------------------+
```

For those patients who require test results before a decision is made regarding follow-up treatment:

Record using function “AAD” on PAS –

- Record “Discharge On” (discharge date) as the date of the clinic.
- Record Disposal “Reason Code” as ***DARO (Discharge Awaiting Results - Outpatients)***
- Record an appropriate comment in the “Reason Text” field – for example:
  - Await MRI results
  - Await CT scan/x-rays/barium enema/ultrasound etc.
  - Await injection
  - Await blood results
  - Await urodynamics
  - Await histology results
  - Await physiotherapy treatment
  - Await Anaesthetic Assessment

Recording an appropriate comment is vital, so that the reason for discharge and what results are awaited for the patient are known to relevant staff.

Example:

```
               D W   O u t p a t i e n t   D i s c h a r g e
     Referral Details                                      09/11/10 09:23 CAH
 ++Name+---------------------------------------------------------------------+
++ SMITH, MARY                                         Casenote CAH10000      ++
|+--------------------------------------------------------------------------+|
|  Consultant          :GENS       A GENERAL SURGEON                          |
|  Specialty           :GSUR       GENERAL SURGERY(C)                         |
|                                                                             |
|  Category            :NHS        NHS not formal                             |
|  Ref By              :GPR        GP ROUTINE REFERRAL (N)                    |
|  Referral Date       :24/10/2008                                            |
|  Ref comment         :SG OPD 28.10.08                                       |
|  Reason for Ref      :ADV        ADVICE AND CONSULTATION                    |
|                                                                             |
|  Priority Type       :1          Routine                                    |
|                                                                             |
|                                                                             |
|  Discharge Date/Time :25/10/2010 12:42                                      |
|  Reason Code         :DARO    DCHARGED AWAITING RESULTS OUTPTS              |
|  Reason Text         :AWAIT ULSTRASOUND RESULTS                             |
|                                                                             |
+-----------------------------------------------------------------------------+
```

<u>UPDATING PAS AS PER CONSULTANT DECISION -</u>
<u>*Add patient to Inpatient/Day Case Waiting List*</u>

When the results are returned to the secretary, and the Consultant has determined that the patient needs to be added to the WL (inpatient or daycase) for a procedure, the OP DSCH **must** be updated:

1) Use function "ODD" (Outpatient Delete Discharge)
2) Type in the casenote number, and ensure the correct patient has been selected.
3) Select the correct OP episode.
4) The discharge details will be displayed for the patients (as shown below).
5) At the prompt ***"Are you sure you want to delete?"*** type in "Yes".

The OP episode will now be re-opened.

6) Now use function "OD" (Outpatient Discharge) and select the now re-opened OP REG.
7) Record "Discharge On" (discharge date) as the date the tests were carried out.
8) Record Disposal "Reason Code" as ***WL***
9) Record a comment in the "Reason Text" field, "added to WL"

10) Enter “Yes”
11) This OP episode will now have the status of “OP Dsch”.

****This will ensure that the patient is removed from your DARO list.****

Example:

```
              D W   O u t p a t i e n t   D i s c h a r g e
    Referral Details                                        09/11/10 09:23 CAH
 ++Name+---------------------------------------------------------------------+
++ SMITH, MARY                                       Casenote CAH10000      ++
|+-----------------------------------------------------------------------+|
|  Consultant          :GENS       A GENERAL SURGEON                         |
|  Specialty           :GSUR       GENERAL SURGERY(C)                        |
|                                                                            |
|  Category            :NHS        NHS not formal                            |
|  Ref By              :GPR        GP ROUTINE REFERRAL (N)                   |
|  Referral Date       :24/10/2008                                           |
|  Ref comment         :SG OPD 28.10.08                                      |
|  Reason for Ref      :ADV        ADVICE AND CONSULTATION                   |
|                                                                            |
|  Priority Type       :1          Routine                                   |
|                                                                            |
|                                                                            |
|  Discharge Date/Time :01/11/2010 15:42                                     |
|  Reason Code         :WL    ADDED TO WAITING LIST                          |
|  Reason Text         :ADDED TO WL PER MR MACKLE                            |
|                                                                            |
+----------------------------------------------------------------------------+
```

UPDATING PAS AS PER CONSULTANT DECISION - *Patient can be discharged – review not required:*

When the results are returned to the secretary, and the Consultant has determined that the results are normal and the patient does not require further investigation/review, the OP DSCH **must** be updated:

1) Use function “ODD” (Outpatient Delete Discharge)
2) Type in the casenote number, and ensure the correct patient has been selected.
3) Select the correct OP episode.
4) The discharge details will be displayed for the patients (as shown below).
5) At the prompt ***“Are you sure you want to delete?”*** type in “Yes”.

The OP episode will now be re-opened.

6) Now use function “OD” (Outpatient Discharge) and select the now re-opened OP REG.
7) Record “Discharge On” (discharge date) as the date the tests were carried out.
8) Record Disposal “Reason Code” as ***DGP – Discharge to GP***

9) Record a comment in the "Reason Text" field, e.g., "per Mr Murnaghan 22/11/10"
10) Enter "Yes"
11) This OP episode will now have the status of "OP Dsch".

****This will ensure that the patient is removed from your DARO list. ****

Example:

```
               D W   O u t p a t i e n t   D i s c h a r g e
    Referral Details                                        09/11/10 09:23 CAH
 ++Name+-----------------------------------------------------------------------+
++ SMITH, MARY                                         Casenote CAH10000      ++
|+-----------------------------------------------------------------------------+|
|  Consultant          :GENS       A GENERAL SURGEON                            |
|  Specialty           :GSUR       GENERAL SURGERY(C)                           |
|                                                                               |
|  Category            :NHS        NHS not formal                               |
|  Ref By              :GPR        GP ROUTINE REFERRAL (N)                      |
|  Referral Date       :24/10/2008                                              |
|  Ref comment         :SG OPD 28.10.08                                         |
|  Reason for Ref      :ADV        ADVICE AND CONSULTATION                      |
|                                                                               |
|  Priority Type       :1          Routine                                      |
|                                                                               |
|                                                                               |
|  Discharge Date/Time :01/11/2010 15:42                                        |
|  Reason Code         :DGP    DISCHARGED TO GP                                 |
|  Reason Text         :OP DSCH PER MR MACKLE                                   |
+---------------------------------------+---------------------------------------+
```

UPDATING PAS AS PER CONSULTANT DECISION – *Review patient at outpatient clinic*

If, following the test results, the Consultant determines that the patient is to be reviewed at the outpatient clinic; the secretary must delete the original discharge episode using ODD.

1) Use function "ODD" (Outpatient Delete Discharge)
2) Type in the casenote number, and ensure the correct patient has been selected.
3) Select the correct OP episode.
4) The discharge details will be displayed for the patient (as shown below).
5) At the prompt ***"Are you sure you want to delete?"*** type in "Yes".

```
                 D W   O u t p a t i e n t   D i s c h a r g e
     Referral Details                                       09/11/10 09:23 CAH
 ++Name+-----------------------------------------------------------------------+
++ SMITH, MARY                                        Casenote CAH10000      ++
|+----------------------------------------------------------------------------+|
|  Consultant          :GENS       A GENERAL SURGEON                           |
|  Specialty           :GSUR       GENERAL SURGERY(C)                          |
|                                                                              |
|  Category            :NHS        NHS not formal                              |
|  Ref By              :GPR        GP ROUTINE REFERRAL (N)                     |
|  Referral Date       :24/10/2008                                             |
|  Ref comment         :SG OPD 28.10.08                                        |
|  Reason for Ref      :ADV        ADVICE AND CONSULTATION                     |
|                                                                              |
|  Priority Type       :1          Routine                                     |
|                                                                              |
|                                                                              |
|  Discharge Date/Time :01/11/2010 15:42                                       |
|  Reason Code         :DGP    DISCHARGED TO GP                                |
|  Reason Text         :OP DSCH PER MR MACKLE                                  |
+---------------------------------------+                                      |
|Are you sure you want to delete? :     |                                      |
+---------------------------------------+--------------------------------------+
```

****The OP episode will now be re-opened.****

You must now add the patient onto the OPWL for their review appointment (if review is required more than 6 weeks later).

6) Use function set "DWA" (District Wide Access)
7) Select function "OWL" (Waiting List Add/Revise/Del/List) and select the re-opened episode. Then you will see the following screen (which showed the last time the patient attended the clinic):

```
             D W   O P   W L   A d d / R e v / D e l / L i s t
     Existing Appointments                                  09/11/10 09:45 CAH
 ++Name+-----------------------------------------------------------------------+
++ SMITH, MARY                                         Casenote CAHB10000     ++
+------------------------------------------------------------------------------+
|    Status Department    Date      Day  Time   Clinic  Appt With Type         |
|    Site               (*Breach)  By  Date/Time         Rev Date/Time         |
+------------------------------------------------------------------------------+
|    OP WLB: CEMN      Con: EM        Spec: GSUR  Date Reqd:             REV   |
|    (NR) PB1D 23/08/10 CS1 BOOK SEPT                 DC6 07/09/10 14:15   |
|                                                                              |
|    ATT                 25/10/2010 MON  08:45  CS1      CS1       NR          |
|           Bk from WL : CEMN       DC6 07/09/10 14:15                          |
|                          ** End of List **                                   |
|                                                                              |
|                                                                              |
|                                                                              |
|                                                                              |
+------------------------------------------------------------------------------+
   PRESS ENTER
```

8) then you must add the patient to the waiting list for their review appointment.
9) Enter the relevant Waiting List code. (then the Consultant and specialty codes will default in).
10) "Date Required" must be the timeframe the patient is to be reviewed in – this is now a mandatory field and cannot be by-passed.
11) Enter "Appointment Type" as Review.
12) In accordance with the new Regional PAS Technical Guidance, you must enter the Date Required in the "Comment" field – i.e if a patient requires an appointment in December 2010, you must enter ***"DR 12/10"*** (as shown below)
13) Record appropriate comment in the "Procedure Type" field, so that the reason for review can be ascertained (please see screen dump below):

Examples
- "cancer monitoring – patient must be seen Dec 2010"
- "cancer patient – must be seen by EM in Dec 2010"
- "review with results of MRI"
- "review with histology results"
- "Anaesthetic Assessment complete – review to discuss surgery" etc.

Recording an appropriate comment can also assist in determining whether the appointment is an urgent or routine review.

14) Enter "Date on List" – this should be recorded as the date the test was carried out, and not "T" for today.

Please see screen dump below to illustrate the steps to be taken:

```
               D W   O P   W L   A d d / R e v / D e l / L i s t
     Appointment Pending Details                            09/11/10 09:45 CAH
 ++Name+-------------------------------------------------------------------+
++ SMITH, MARY                                    Casenote CAH10000   ++
|+---------------------------------------------------------------------+|
|                                                                        |
| Command       :ADD                                                     |
|                                                                        |
| WL Code       :CEMR                                                    |
| Consultant    :EM                                                      |
| Specialty     :GSUR                                                    |
|                                                                        |
| Date Required   : 12/2010                                              |
| Appointment type  :REV  REVIEW APPOINTMENT                             |
| Transport code  :                                                      |
| Comment         :DR 12/10                                              |
| Procedure Type  :**CANCER MONITORING - PT MUST BE SEEN IN DEC 2010**   |
| Category        :NHS  NHS not formal                                   |
| Date on List    :01/11/2010         Short Notice  :NO                  |
|                                                                        |
|                                                                        |
| Enter?          :                                                      |
+------------------------------------------------------------------------+
```

Please Note – a patient must not be added to the OP Waiting List if they are awaiting results and no decision has been made regarding their review date.

Management & Monitoring

A list of all patients who have been discharged using the reason code DARO can be produced by the OSL's/ Service Administrators and used as a failsafe mechanism for checking that all results are returned and that all charts taken are returned.

ONCOLOGY FORUM

2022 UK Oncology Forum

A Special Invitation

Register ASAP - avoid disappointment

Date:	Thu 16h & Fri 17th June 2022
Venue:	ICC in Belfast
Registration:	Registration open now!
Website:	www.oncology-forum.co.uk

The UK Oncology Forum Faculty are pleased to announce that the 2022 UK Oncology Forum registration is open soon! There is NO fee to attend the UK Oncology Forum and the meeting is CME accredited. The ACP, BASO, BTOG, BCTRCG, BOPA, NOTCH, Macmillan, UKONS, UKOMiC and SABR will all be collaborating and exhibiting at the meeting. Post ASCO highlights will feature.

@OncologyForum #OF22 Please follow the twitter feed.

Thursday 16th June 10:30 - 11:45	**2022 UK Oncology Forum Day 1** Rapid Diagnostic Services (RDS) Special inaugural session Chaired by Dr Saoirse Dolly. ALL welcome.
Friday 17th June Programme to be confirmed shortly	**2022 UK Oncology Forum Day 2**

NO sponsors have had any input to the programme or speaker choices. The programme is wholly designed by the Faculty. The meeting will run strictly to the ABPI code of practice, with full disclosure. The meeting is CME accredited. Please arrange your travel to be at the venue no later than 12 noon.

Southern Health
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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:**	**Staff members comments on his/her performance over past year:** I have now a Job Plan that identifies my role + Responsibilities ie Flexible Cystoscopy, renal cell followup, HNA **Line Manager's Feedback on staff members performance over past year:** Patricia is a valuable member of the CNS team working in the Thorndale unit. Patricia is working towards her new banding of 8A- She hopes over the next year to research regionally & nationally a service for CNS to cystodiathermy +/- oblate small bladder lesions as a CNS.

Objectives for Next Year:

To start training for Nurse led Cystodiathermy +/- Laser to Small bladder tumours.

To work towards Agenda for change to Band 8A.

Reviewee Staff Name (Print) ____ Signature ____ Date ____

Reviewer Manager/Supervisor (Print) PAULA McKay Signature [redacted] Date 30.09.22

HSC Southern Health and Social Care Trust
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Part B

ANNUAL PERSONAL DEVELOPMENT PLAN

For training requirements specific to your staff group refer to Trust Intranet Training Link

Staff Number: ____________________

Training type	Identified learning need	Date Training Completed	Agreed Action
Corporate Mandatory Training ALL STAFF	Corporate Induction once only: covid online [redacted]	6/8/20	
	Departmental Induction/Orientation (once only)	6/8/20	
	Control of Substances Hazardous to Health (COSHH) (every 3 years)	3/9/20	(45 mins)
	Display Screen Equipment programme (every 3 years)		(20 mins)
	Equality, Good Relations and Human Rights: Making a Difference (every 3 years)	15/9/20	(45 mins)
	Fire Safety (Pharmacists DNFO) face to face (yearly)	10/5/22	
	Fraud Awareness (every 3 years) Currently unavailable	19/8/20	
	Clinical trials GCP training to be completed every 3 years as organised by Clinical Trials Pharmacist		
	SOP for the Emergency Un-blinding of a Clinical Trial Treatment (Code-break) to be read & signed off at induction		
	Hyponatraemia Training (every 3 years)		
	Fluid Management Case Study Tool (every 3 years)		
	Cyber Security Awareness previously ICT security (every 3 years)	29/9/22	(60 mins)
	Infection Prevention Control Tier 2 (every 2 years)	3/9/20 / 5/8/22	(30 mins)
	Information Governance Awareness (every 3 years)	3/9/20	(60 mins)
	Manual Handling Awareness (every 3 years)	28/7/21	(45 mins)
	Adult Safeguarding (every 3 years)	29/12/20	
	Towards Zero Suicide (once only)		
	Deprivation of Liberty		
	Waste Management (3 yearly)	27/8/20	(45 mins)
Corporate Mandatory Training ROLE SPECIFIC	MAPA level 2 in face to face in Non Covid times Or Level 1 in Covid times MOVA strategy 1-8 [redacted]		

	[redacted]		
	Pre – Registration Pharmacist Tutor		
	Recruitment and Selection (yearly)		
Essential for Post	**PSNI registration/CPD submission (yearly)**		
	Independent Prescribing Qualification	August 2016	

Best practice/ Development (Coaching/Mentoring) (Relevant to current job role)	**Effective Mentoring e-learning NICPLD**		
	Workplace Training e-learning NICPLD		

Reviewee Staff Name (Print) ________ Signature ________ Date ________

Reviewer Manager/Supervisor (Print) PAULA ~~Coffey~~ McKay Signature [redacted] Date 30-09-22.

PLEASE SEND ENTER IN STAFF PROFILE ON HRPTS DATE OF COMPLETION

Appendix 1

PROBATIONARY REPORT (3 MONTHS)

Commenced:

NAME: Patricia Thompson.	**POST:** Urology Nurse Specialist
DEPT: Thorndale	**STAFF No:**

DATE OF APPOINTMENT	**PERIOD COVERED BY REVIEW**	**ABSENCES DURING REVIEW PERIOD AND REASONS**
3.8.2020.	3months	[redacted]

TRAINING UNDERTAKEN DURING REVIEW PERIOD ~~Madc~~ mandatory training upto date.	Online training for xrays/ scans ordering. Non medical prescrption isdone – need to get on register.
RESPONSE TO TRAINING Satisfactory.	

PERFORMANCE DURING REVIEW PERIOD

MAIN TASKS UNDERTAKEN	**ACHIEVEMENTS/COMMENTS RE: PERFORMANCE**
Oncology – renal ca follow up Keyworker role urodynamics + flex cyst.	Nil concerns @ present. Has fitted well into the team, feels supported and aware when clinic returns to normal more opportunities my arise.

ARE YOU SATISFIED WITH EMPLOYEE'S PROGRESS TO DATE: [✓ YES]/NO

ADDITIONAL COMMENTS/ACTION TO BE TAKEN TO IMPROVE PERFORMANCE (3 MONTHS)

[redacted]

Signed: [redacted] **(Manager)** **Date:** 27-11.2020

Signed: [redacted] **(Probationer*)** **Date:** 27/11/2020

* **Signature confirms that the above review has been discussed with you.**

Copy to: Probationer and Employee Engagement and Relations – HR Department

Appendix 2

PROBATIONARY REPORT (6 MONTHS)

Commenced:

NAME: Patricia Thompson.	**POST:** B7 CNS Urology
DEPT: Thorndale	**STAFF No:**

DATE OF APPOINTMENT	PERIOD COVERED BY REVIEW	ABSENCES DURING REVIEW PERIOD AND REASONS
3.8.2020	6 months.	As per 3 month probation (Nil further).

TRAINING UNDERTAKEN DURING REVIEW PERIOD

ANP - transcript obtained from course. Wendy to sign off.

All up to date. MTH / BLS outstanding (MTH booked).

RESPONSE TO TRAINING

Nil concerns raised.

PERFORMANCE DURING REVIEW PERIOD

MAIN TASKS UNDERTAKEN	ACHIEVEMENTS/COMMENTS RE: PERFORMANCE
Has been redelployed to theatre - so role specific tasks have been limited due to surge 3 + downturn of outpatient activity.	Nil concerns Eager to get going with clinics / Thorndale services.

ARE YOU SATISFIED WITH EMPLOYEE'S PROGRESS TO DATE: [✓ YES]/NO

RECOMMENDATION REGARDING CONFIRMATION OF APPOINTMENT (6 MONTHS)

ongoing SAI - support offered from Lead Nurse @ anytime.

Signed: Personal Information redacted by the USI ______(Manager) **Date:** 25.2.2021.

Signed: Personal Information redacted by the USI ______(Probationer*) **Date:** 25/2/2021

* Signature confirms that the above review has been discussed with you.

Copy to: Probationer and Employee Engagement and Relations – HR Department

Southern Health and Social Care Trust
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The Management of Nurse Led Clinics for patients with renal cell carcinoma following nephrectomy, ablation and on active surveillance pathway

Lead Policy Author & Job Title:	Patricia Thompson Clinical Nurse Specialists in Urology
Directorate responsible for document:	Acute
Issue Date:	01 July 2021
Review Date:	01 July 2023

Working together Excellence Openness & Honesty Compassion

Policy Checklist

Policy name:	The Management of Nurse Led Clinics for patients with renal cell carcinoma following nephrectomy, ablation and on active surveillance pathway
Lead Policy Author & Job Title:	**Patricia Thompson Clinical Nurse Specialist in Urology**
Director responsible for Policy:	Melanie McClements ????
Directorate responsible for Policy:	Acute
Equality Screened by:	Click here to enter text.
Trade Union consultation?	Yes ☐ No ☒
Policy Implementation Plan included?	Yes ☐ No ☐
Date approved by Policy Scrutiny Committee:	Click here to enter a date.
Date approved by SMT:	Click here to enter a date.
Policy circulated to:	Eg Directors, Assistant Directors, Heads of Service for onward distribution to line managers, Global email, Staff Newsletter
Policy uploaded to:	Eg SharePoint, Trust website

Version Control

Version:	**Version 1.0**		
Supersedes:	**N/A**		
Version History			
Version	**Notes on revisions/modifications and who document was circulated or presented to**	**Date**	**Lead Policy Author**
Eg Version 1_0	Click here to enter text	Click here to enter a date.	Click here to enter text
Eg Version 2_0	Click here to enter text	Click here to enter a date.	Click here to enter text

Contents

1.0 INTRODUCTION

1.1. Renal cancer follow up forms a substantial part of the urology outpatient workload. On average there were 206 male and 114 female cases of kidney cancer diagnosed in Northern Ireland each year between 2014 and 2018 (NI Cancer Registry 2018). Surveillance after surgery or ablation allows the monitoring for complications, renal function, local recurrence, recurrence in the contralateral kidney and development of metastasis.

1.2. This document outlines the policy principles for nurse led renal cell carcinoma follow up and in accordance with the Trusts Key Principles for Policy development.

1.3. However this policy is only a foundation and it is recommended that nurses maintain their continuing education in this specialist area of care.

2.0 PURPOSE AND AIMS

The NHS is undergoing radical changes particularly in its approach to cancer. Nurse led clinics are becoming increasingly common, offering patients an alternative method of follow up. By developing these new roles and services, nurses are playing a key role in reducing waiting times, expanding accessibility to services and improving the quality of care.

The aim of this policy is to set a minimum standard for nurse led follow up of patients with renal cell carcinoma

- ✓ Monitor patient progress, identify and monitor postoperative complications, renal function and detect local recurrence to include recurrence in the contralateral kidney and / or detection of progression and refer promptly to MDT
- ✓ Enable holistic assessment
- ✓ Identify late effects of treatment quickly; provide support and signpost to the appropriate service if necessary
- ✓ Inform patients about specialists services that can help with their medical, practical, emotional and rehabilitation needs and refer
- ✓ Support patients living with and beyond cancer
- ✓ To identify the need for additional supportive interventions and to refer onto other members of the multidisciplinary team as necessary

3.0 OBJECTIVES OF THIS POLICY

The objectives of this policy are to improve and maintain standards of clinical practice and quality of care to patients. These are:

- ✓ Providing evidence for establishing and maintaining a nurse led clinic for renal cancer follow up, promoting excellence in the care that is delivered.
- ✓ Reduce variation in clinical practice and encouraging uniformity of practice.
- ✓ Providing a framework from which individual practitioners can apply their own level of clinical expertise and to identify competencies.
- ✓ To ensure that all patients entering the renal cancer follow up service are on the appropriate risk stratified pathway.
- ✓ Helping nurses and health care providers to make informed decisions, aiding the education process and reducing the risk of clinical negligence.
- ✓ Identifying competencies for nursing care.
- ✓ Aiding development of a locally agreed policy.
- ✓ Establish a yearly audit cycle.

4.0 POLICY STATEMENT

The purpose of the nurse led clinic is to enhance the quality of care and to promote the health and wellbeing of patients who are living with renal cancer or have been treated for renal cancer. The clinic will also facilitate the provision of emotional support for patients and their families/carers requiring the opportunity to discuss treatment or care options

A risk stratified model of aftercare in line with the National Cancer Survivorship Initiative will be utilised and patients will be stratified in their follow up pathway according to their staging and personal characteristics by the Consultant.

Risk stratified means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease, (what type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short term and long term) and the person (whether they have other illnesses or conditions, and how much support that they feel they need). This will include the on-going follow up of patients who are clinically stable and are stratified into the relevant pathway

5.0 SCOPE OF POLICY

This policy applies to all Clinical Nurse Specialists in Urology who are employed within the Southern Trust.

6.0 ROLES AND RESPONSIBILITIES

The SHSCT Trust Chief Executive as ‘Accountable Officer’ has overall responsibility for ensuing that the aims of this policy are met and has a responsibility to invest in training and education for all health care professionals.

Within the Acute directorate, the Director, Assistant Director, Head of Service and Lead Nurse have responsibility for the effective application of this policy.

The Lead Nurse has a responsibility to ensure that appropriate systems are in place to monitor and review staff performance, registration and training requirements.

It is the responsibility of the Urology Consultant to determine suitability and referral to this service as per the MDM outcome.

It is the responsibility of the Urology CNS team to be familiar with and adhere to this policy and followed agreed processes.

6.1 *Rapid Access Protocol*

All patients should be able to access the Consultant responsible for their care through the Urology CNS. Any patient that contacts the Urology CNS with worrying symptoms will be seen by a Consultant promptly. If necessary, their case should be discussed by the MDT.

Each patient will be able to contact the Urology CNS outside of scheduled follow up appointments The Urology CNS will triage the patient on their concerns/issues to the most appropriate member of the Urology team or refer on to other agencies accordingly. Outcomes may include:

- Face to face consultant appointment promptly
- Face to face Nurse led clinic (where appropriate)
- Advised to contact GP

- Advised to attend the emergency department

Only clinical issues will result in a clinical appointment.

6.2 *Radiological/imaging referral*

It is the responsibility of the referrer to follow up imaging requests. Letter should be dictated to patient and consultant informing them of results and further management. Imaging results that needs reviewed should have rapid access to MDT for discussion.

7.0 Legislative Compliance, Relevant Policies, Procedures and Guidance

This policy has been developed in accordance with the following list of legislation, guidance and standards:

1. https://www.baus.org.uk/_userfiles/pages/files/professionals/surg/TJW-Kidney-Cancer.pdf
2. https://uroweb.org/guideline/renal-cell-carcinoma
3. Azawi NH, Fode M, Boesen L, Joensen UN (2016) Comparison of the Outcome between the Mayo Clinic Stage, Size, Grade, and Necrosis (SSIGN) Score and the Leibovich Score in Non-Metastatic Renal Cancer. J Urol Res 3(7): 1074.
4. Nursing and Midwifery Council (NMC): The Code: Standards of conduct, performance and ethics for nurses and midwives (2015)
5. Department of Health (2007) Cancer Reform Strategy
6. National Institute for Health and Care Excellence Renal Cancer Overview http://pathways.nice.org.uk/pathways/renal-cancer
7. Northern Ireland Cancer Registry (2020) www.qub.ac.uk

8.0 EQUALITY AND HUMAN RIGHTS CONSIDERATIONS

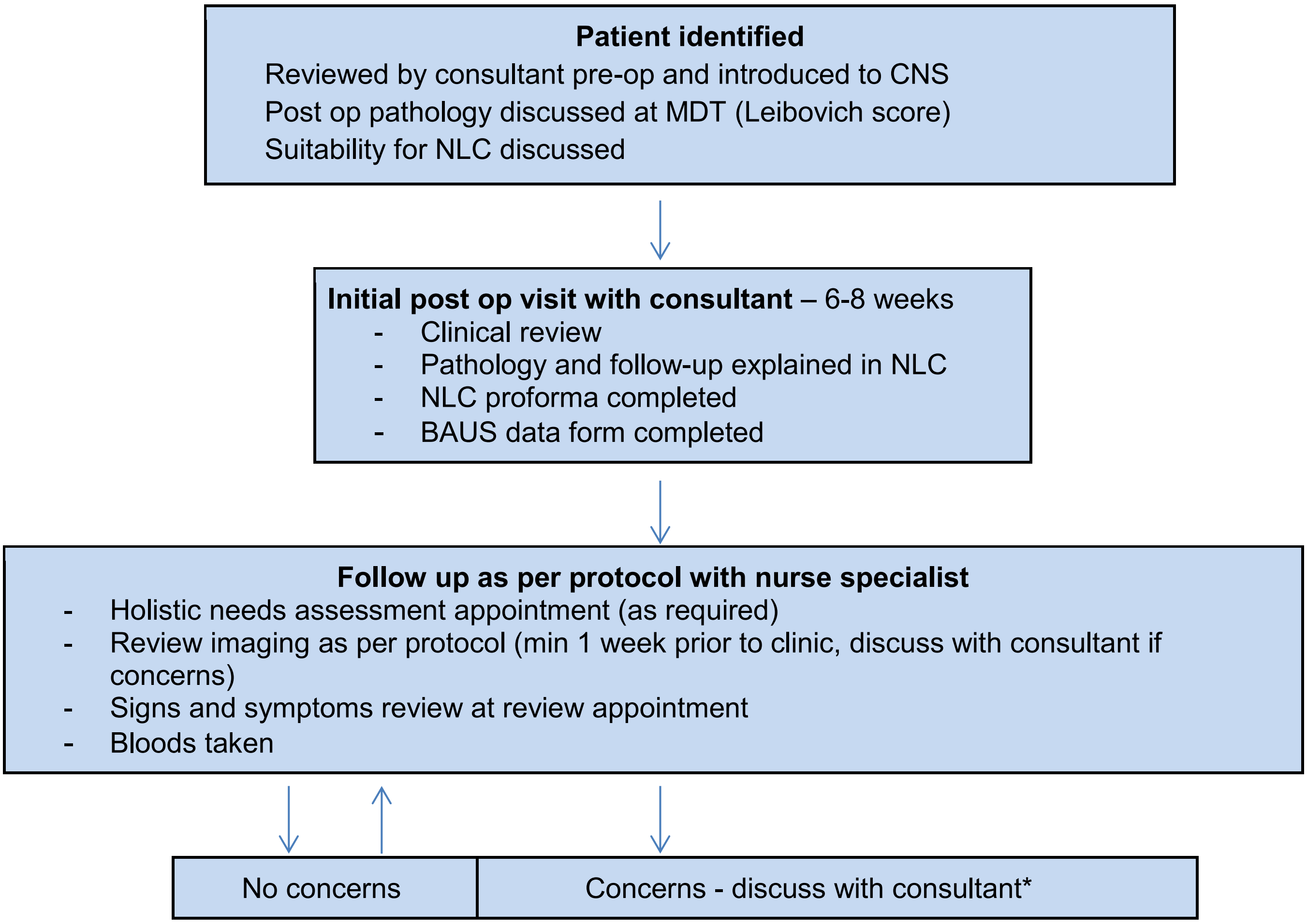
This policy has been screened for equality implications as required by Section 75 and Schedule 9 of the Northern Ireland Act 1998. Using the Equality Commission's screening criteria; no significant equality implications have been identified. Similarly, this procedure has been considered under the terms of the Human Rights Act 1998 and was deemed compatible with the European Convention Rights contained in the Act.

9.0 SOURCES OF ADVICE AND FURTHER INFORMATION

This policy should be read in conjunction with related policies and procedures.

Appendix 1

Flow Chart for referral/ patient pathway into Nurse Led Clinic



Patient identified

Reviewed by consultant pre-op and introduced to CNS
Post op pathology discussed at MDT (Leibovich score)
Suitability for NLC discussed

Initial post op visit with consultant – 6-8 weeks

- Clinical review
- Pathology and follow-up explained in NLC
- NLC proforma completed
- BAUS data form completed

Follow up as per protocol with nurse specialist

- Holistic needs assessment appointment (as required)
- Review imaging as per protocol (min 1 week prior to clinic, discuss with consultant if concerns)
- Signs and symptoms review at review appointment
- Bloods taken

No concerns

Concerns - discuss with consultant*

*Discussion or referral back to consultant:

1. Any signs/ symptoms or results from investigations that are indicative of disease progression or relapse
2. Haematuria requiring cystoscopy
3. Any deterioration in renal function
4. At the request of the patient
5. Any question the nurse specialist is unable to answer

Appendix 2

Post nephrectomy follow-up schedule for RCC

Craigavon Area Hospital

Background:

- Cell type

Conventional clear cell	75%
Papillary	12%
Chromophobe	4%
Collecting duct	1%
Unclassified	3-5%

- Peak age 60 – 70
- M2:F1
- RFs: smoking, obesity, HTN, dialysis, heredity (2% of all RCC)[1]
- More than 50% of RCCs are detected incidentally by non-invasive imaging investigating various non-specific symptoms and other abdominal diseases[2]
- The classic triad of flank pain, visible haematuria, and palpable abdominal mass is rare (6-10%) and correlates with aggressive histology and advanced disease[2]
- CT contrast of abdomen and chest appropriate for diagnosis and staging. Bone scan, brain CT, or MRI may be used in the presence of specific clinical or laboratory signs and symptoms[2]
- Patient identified and referred to MDT for imaging review and decision regarding treatment.
- Leibovich score calculated for patient at MDT and decision made if appropriate for Nurse Led Clinic (NLC) for follow-up.
- The Leibovich score is a scoring algorithm to predict cancer specific survival rates. It assesses the risk of recurrence/metastatic disease.[3]
- Most important **prognostic** factors according to Leibovich score:
  - T stage (T)
  - Fuhrman grade (G)
  - Tumour Size <5cm or ≥5cm
  - Necrosis present or absent
  - Lymph node involvement

2017 TNM classification system

T – Primary tumour
TX Primary tumour cannot be assessed T0 No evidence of primary tumour T1 Tumour < 7 cm or less in greatest dimension, limited to the kidney T1a Tumour < 4 cm or less T1b Tumour > 4 cm but < 7 cm T2 Tumour > 7 cm in greatest dimension, limited to the kidney T2a Tumour > 7 cm but < 10 cm T2b Tumour > 10 cm, limited to the kidney T3 Tumour extends into major veins or perinephric tissues but not into the ipsilateral adrenal Adrenal gland not beyond T3a Tumour extends into the renal vein or its segmental branches, or invades the Pelvicalyceal system or invades perirenal and/or renal sinus fat, but not beyond Gerota fascia T3b Tumour grossly extends into the vena cava below diaphragm T3c Tumour grossly extends into vena cava above the diaphragm or invades the wall of the Vena cava T4 Tumour invades beyond Gerota fascia (including contiguous extension into the ipsilateral adrenal gland

N - Regional Lymph Nodes	
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis in regional lymph node(s)

M - Distant Metastasis	
M0	No distant metastasis
M1	Distant metastasis

pTNM stage grouping			
Stage I	T1	N0	M0
Stage II	T2	N0	M0
Stage III	T3	N0	M0
	T1, T2, T3	N1	M0
Stage IV	T4	Any N	M0
	Any T	Any N	M1

Leibovich Score

Feature	**Score**
Primary tumour/ T-stage	
T1a	0
pT1b	2
pT2	3
pT3 – pT4	4
Tumour Size	
<10cm	0
>10cm	1
Regional lymph node status	
pNx/ pN0	0
pN1- pN2	2
Nuclear grade	
Grade 1-2	0
Grade 3	1
Grade 4	3
Tumour Necrosis	
No necrosis	0
Necrosis	1

Risk groups can be stratified by the scoring system:

Low risk	**0-2**
Intermediate risk	**3-5**
High risk	**≥6**

Appendix 3

Post nephrectomy followup schedule for non-metastatic RCC

Surveillance after treatment for RCC allows the urologist to monitor or identify:

- Post-operative complications;
- Renal function;
- Local recurrence;
- Recurrence in the contralateral kidney;
- Distant metastases;
- Cardiovascular events.

Risk Profile (*)	Oncological follow up after date of surgery								
	3 mon	6 mon	12 mon	18 mon	24 mon	30 mon	36 mon	➢ 3 yr	➢ 5yr
Low risk For ccRCC Leibovich Score 0- 2 For non-ccRCC: pT1a-T1b pNx-0 M0 and histological grade 1 or 2.	HNA Bloods	CT Bloods	-	CT Bloods	-	CT Bloods		CT once every 2 years	
Intermediate risk For ccRCC: Leibovich Score 3-5 For non-ccRCC: pT1b pNx-0 and/or histological grade 3 or 4	HNA Bloods	CT	CT	-	CT	-	CT	CT once a year	CT once every 2 years
High risk For ccRCC: Leibovich Score ≥ 6 For non-ccRCC: pT2-pT4 with any histological grade or pT any, pN1 cM0 with any histological grade	CT HNA Bloods	CT	CT	CT	CT	-	CT	CT once a year	CT once every 2 years

Post ablation follow-up schedule for non-metastatic RCC

Post ablation oncological follow up								
3 months	6 months	12 months	18 months	24 months	30 months	36 months	4 yr	5 yr
CT Scan Bloods HNA	CT Scan Bloods	Bloods	CT Scan Bloods	Bloods	CT Scan Bloods	Bloods	CT Bloods	CT Bloods

- *Bloods including FBC, LFTs, calcium and U&Es
- Individually tailored follow up for Bilateral and Familial disease
- The metastatic risk may differ with histology other than clear cell
- ~S&S:
  - Otherwise unexplained signs and symptoms:
    - Weight loss
    - Shortness of breath
    - Pain/weakness
    - Haematuria
    - Night sweats
    - Fatigue

Appendix 4

Nurse Led Clinic planning

Low risk

- Patient reviewed every 6-12months at NLC (nurse led clinic)
- Bloods and appropriate imaging booked to precede next appointment
- At 5 years post operatively with no recurrence, patient discharged to GP

Intermediate risk

- Patient reviewed every 6 months until 2 years post operatively at NLC then every 12 months
- Bloods and appropriate imaging booked to precede next appointment
- At 10 years post operatively with no recurrence, consider patient being discharged to GP

High risk

- Patient reviewed every 6 months until 2 years post operatively at NLC then every 12 months
- Bloods and appropriate imaging booked to precede next appointment

If abnormalities are detected on imaging, bloods or clinical assessment then the patient is for discussion with doctor/ unit and consider further discussion at MDT.

Appendix 5

Competencies for Nurse-led Follow-up

Competencies required assessing patients with stable renal cancer include:

- Advanced nurse practitioner/clinical nurse specialist having been employed for a minimum of twelve months working with a urologist/oncologist in the follow up setting
- Demonstrate a full understanding of the network site specific group pathways for renal cancer. As agreed by the local tumour network
- To be enrolled in or be undertaking, a programme of study in their specialist area of nursing practice which has been accredited for at least 20 CAT points at level 3 (DH2004) e.g. Health Assessment module
- Have advanced communication skills – to have enrolled in, or be undertaking a recognised course/module in communication skills
- In order to run a clinic the individual must be a core member or extended member of the urology multidisciplinary team
- To be able to demonstrate knowledge of the disease trajectory in Renal Cancer
- To be able to demonstrate knowledge of risk stratified pathways
- To have competent consultation and symptom analysis skills. To have worked under supervision for a minimum of six months and have been deemed competent by the consultant urologist/oncologist
- To be able to demonstrate knowledge of the tests and investigation required during follow up of renal cancer patients
- To have IMER training and deemed competent by the relevant specialist for organising radiology imaging
- Demonstrate knowledge of drugs and treatments used in renal cancer including side effect

Appendix 6

Nurse Led Assessment Procedure

Referral process

- The Urologist must provide written or online referral to Urology CNS clearly detailing expectations on patients who are deemed suitable for nurse led follow up.
- These patients who have had surgery, ablation or on the surveillance pathway and have been discussed at MDT or reviewed at consultants clinics.
- The Leibovich score should be stated in the referral as this will risk stratify the selection on imaging at review.
- Each referral must be sent to booking centre and placed on the appropriate waiting list with specific code.

Recommended exclusion criteria

- Patients who do not want to be followed up by a nurse
- Patients who have metastatic disease.
- Patients with metastatic disease who are under the care of the oncologist
- Patients deemed unsuitable for review at a nurse led clinic by the consultant in charge

Actions

Discuss
- Nurse led clinic
- History/treatment to date
- Timeline for routine follow up such as CT Chest Abdomen Pelvis renal function tests, FBP.

Symptoms

Is the patient experiencing any symptoms .
- Ask about pain – any new pain lasting more than a week (use locally agreed pain scale)
- Weight loss/gain
- Fatigue
- Neurological symptoms – Numbness, tingling or odd sensations in limbs
- Lower Urinary tract symptoms
- Haematuria
- Deterioration in renal function

Is the patient experiencing any symptoms suggestive of local or metastatic disease

- Abdominal /Pelvic /Skeletal pain
- Weight loss
- Anorexia
- Nausea or vomiting

Ask about any other symptoms/concerns

Urology CNS Meeting		
Date: Thursday 28th April 2022	**Time:** 10am – 12 .20pm	**Venue**: By Zoom

Time	**Agenda Items**	**Notes**
10am	**Welcome**	**Participants present:** Kerry Chambers (Chair), Hazel Templeton, Patrick Rooney, Naomi Casson, Lorna Nevin, Rachel Patton, Leanne McCourt, Shelley Mooney, Kirsty McKay, Patricia Thompson, Paula Ryan, Moyra Mills, Karen Kelly, Olivia, Pamela Neill **Apologies:** Eimear McLaughlin, Samantha McBeigh, Kate O'Neill All members welcomed by Kerry Chambers. Each member introduced themselves. Advised that all minutes would be put on sharepoint so that they could be shared with CNS team
1	**Review of minutes of last meeting**	Nothing to add from previous minutes
2	**Update from each trust provided**	**WHSCT** – New band 6 uro-oncology nurse, Naomi Casson in post. There is stall a backlog of patients requiring review but work is ongoing to attend to this. Most reviews remain virtual although face to face reviews are arranged as required – this includes histology review and patients needing LUTS assessment. An audit was undertaken to assess patients' views regarding virtual review and the majority of patients reported that they prefer this approach. There is also still a backlog with intravesical treatment but work is also ongoing addressing this. The regional penile cancer service is now based at the WHSCT. It is hoped that with the new band 6 appointment that this service will be developed. Aim is to have nurses taking the lead for each tumour group. There is also a back log with eHNA. At present eHNA are only being done with the prostate cancer patients but this will be rolled out to the other tumour groups. Access to surgical slots is still an issue and there is little theatre capacity. **Belfast Trust:** Surgery is returning to the new normal. They currently have around 2 cystectomies, 3 prostatectomies and 2-3 nephrectomies per week. All nurse-led clinic remain virtual. They are attempting to restart clinics for cystectomy patients face to face. Pre-operative prostatectomy clinics are again running. Intravesical treatments are delivered in urology day care and there are no delays with these. **SHSCT:** Nurse-led review clinics are running to schedule. Intravesical treatments are delivered by a band 6 nurse and are also on schedule with no delays. There is a waiting list for patients awaiting check flexible cystoscopies which is having an effect on the maintenance regime. Access has been lost for urology services at the Thorndale Unit. This has caused a 12 week wait for Transperineal prostate biopsies so help has been provided by Lagan Valley and Kingsbridge to

		address this. Leanne McCourt, Uro-oncology Nurse Specialist is almost trained regarding TP biopsies and Patricia Thompson undertakes flexible cystoscopies. It is hoped that these will be moved back to Thorndale unit. **NHSCT:** There has been a massive increase in the number of patients requiring chemotherapy which has an effect on service delivery. Kirsty McCay also contacts the patients on systemic treatments on a 4 weekly basis. Nurse-led review clinics are also carried out for prostate cancer patients post-radiotherapy and stable relapsed patients. PSA tracking is also carried out by Uro-oncology nurses in the NHSCT. **SEHSCT:** While intravesical treatment are on schedule here, there is a backlog of patients awaiting check flexible cystoscopies. Nurse-led clinics continue virtually for the review of prostate and renal cancer patients.
3	**Holistic needs assessments (HNA)**	Kerry told us that in the WHSCT eHNAs were currently being undertaken for patients with prostate cancer following completion of treatment. It is hoped that this would be rolled out so that eHNA were carried out with all tumour groups in the WHSCT. It was noted that eHNAs are quite time consuming. Patrick Rooney (WHSCT) explained that some patients may note that they have many concerns but may have to discuss the key concerns during the allocated review appointment time. Shelley Mooney advised that they had lost their support worker and administration support so eHNAs were currently not happening in the Belfast Trust until this was re-established. Paula noted that they also had no support worker so were unable to do eHNAs at present. Prior to the pandemic, they had been doing these face to face by the uro-oncology specialist nurse. Kerry explained that in the WHSCT, the support worker would set up the eHNA and the appointment are put on PAS by partial booking so that as CNS, recognition for this work is recorded. Leanne stated that the careplan in the SHSCT is uploaded to ECR by the support worker. The eHNA in the SHSCT is carried out at diagnosis for prostate cancer patients and post-surgery for the renal cancer patients. In the SEHSCT, eHNA are carried out 3 months from diagnosis with prostate cancer patients. Again there is no support worker so a letter is dictated for ECR. Shelley explained that they previously had used an 'opt in' option, where patients opted in to having a HNA. If they did not opt in, it was presumed they had no needs that required a HNA. Lorna Nevin commented and thanked the team regarding their openness regarding issues relating to HNA. She appreciated the challenging particularly without a support worker. She stressed that HNA is here to stay. She also noted it might be useful to try standardise how we carried out HNA within the various trusts.

4	**Lorna Nevin – CNS workforce planning**	Presentation by Lorna Nevin regarding the project she was involved in regarding CNS workforce planning. Lorna recognised that she wants to be open and transparent in communication with the CNS workforce. Phase 1 of this work began in 2016. £18.250 million will be invested in this. KPIs have also been developed and such data will help us provide evidence to support the difference that CNS's are making. Succession planning is critical but has been difficult. It is fundamental that we are role models as CNS's. Timely course commissioning is also required. The NI Cancer Strategy was launched in March 2022. Action 39 is directed at the Cancer CNS's. All patients diagnosed with cancer must have access to a CHS throughout their entire care pathway. This recommendation provides the premise for Phase 2 of this work. Lorna emphasised that when looking at the CNS expansion it is necessary to consider incidence, prevalence, recovery and death/palliative care. The 3 cancer group method was used and 5 year survival needed to be carefully considered. It was reported by Lorna that at • **0-1 year from diagnosis** – 100% of urology patients should be seen by CNS • **Yr 1-2 if complex –** 1/5 of patients should be considered as complex and need CNS input • **Yr 1-2 if non complex –** 20% of the remaining 4/5 of these patients will need CNS input • **Yrs 2-5 post diagnosis -** 10% of these patients will require CNS support. This data was supported by the work of White and Goodchild (2019). Kerry noted that this data does not take account the input that is required from CNS's for many patient groups accurately. The renal cancer patients are reviewed for 10 years. Also many prostate cancer patients such as those on hormone therapy may be under review for many years. Lorna advised that they also looked at how many new patients is to possible for a CNS to manage and the figures of 1 nurse to every 145 patients was provided. There are currently 15.26 whole time equivalent (WTE) uro-oncology CNS in Northern Ireland but it is predicted that by 2025 an additional 9.75 WTE would be required, equating to an increase of 64%. This information was shared in the NI Cancer Strategy with regards to workforce planning. Lorna concluded that while the Cancer Strategy is published, there is no promise as yet regarding funding. Assurances of funding is needed and allocation processes required. We also need to ensure that commissioning of courses and negotiation of places occurs in a timely

		manner. This needs to be formalised with NIPEC in a more robust structure. The need for extra administration and support staff but also be included in this. Lorna stated that she has regular meeting with all Cancer managers but is aware that some participants of this meeting have managers that are not under cancer services. **Lorna has asked if these participants could forward contact details of these relevant managers to her so she can make contact with them.** Shelley noted that they lost many of their support workers as they had to undertake a mainly administrative role. These roles need to be clearly identified. It has been difficult during the pandemic for support workers to get involved face to face with patients. Kerry noted it would be useful to develop this as there is great potential here for developing the support worker role.
4	**Leanne McCourt – Prostate Cancer Pathway**	Leanne asked if any changes needed to the current version of the Prostate Cancer Pathways that had been sent by email. Many participants had not been able to open the attachment. **Leanne will resend the Prostate cancer Pathways Kerry who will forward to all participants.** The main changes that had been made were regarding the Active Surveillance Pathway. MRI in this section had been changed to 18 months but it was felt that 12-18 months may be more appropriate. **Could all participants please read these and send comments back so that these pathways can be finalised. Please get back to Leanne directly with any final comments.**
5	**AOB**	No other issues identified
6	**Dr Jane Frankland**	**Enabling risk stratified follow-up for care for men with prostate cancer: True NTH UK- supported Self management and follow-up Care programme.** This presentation was recorded and slides can be sent to participants if required. **Kerry will share Dr Frankland's email address with participants.** She can be contacted directly with any relevant queries.
7	**Next meeting**	It was agreed that this meeting will take place on a 6 monthly basis and the next meeting will be arranged for September/October 2022. Dates will be sent out nearer the time.

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

Organisation's Unique Case Identifier:

Personal information redacted by USI

[redacted]

Date of Incident/Event: Multiple dates

HSCB Unique Case Identifier:

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

Responsible Lead Officer: Dr Dermot Hughes

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

Report Author: The Review Team

Date report signed off: 26 February 2021

Date submitted to HSCB: 1 March 2021

1.0 EXECUTIVE SUMMARY

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

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

2.0 THE REVIEW TEAM

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

3.0 SAI REVIEW TERMS OF REFERENCE

The aims and objectives of this review are to:

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

3.0 SAI REVIEW TERMS OF REFERENCE

quality care.

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

4.0 REVIEW METHODOLOGY

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

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

5.0 DESCRIPTION OF INCIDENT/CASE

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

Causal deficits in their care and contributory factors were identified.

Service User A

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

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

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

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

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

5.0 DESCRIPTION OF INCIDENT/CASE

Service User B

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

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

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

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

Service User C

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

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

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2019 by Dr 1 who arranged for a repeat CT scan to be performed on 17 December 2019 with a plan for review in January 2020. This did not happen.

The CT scan report was available on 11 January 2020 which showed a possible sclerotic metastasis in a vertebral body which had not been present on the previous CT scans. This report was not actioned until July 2020 when a new consultant reviewed the care. Service User C was subsequently diagnosed with prostate cancer.

The Review Team find that the treatment and care in relation to management of the renal tumour was of a high standard. High-risk surgery was performed successfully following informed consent as to the risks and benefits of the surgery. A urology review was planned for July 2019 following the CT scan report in June but this didn't happen. Service User C appeared to be lost to review. The scan performed in December 2019 with a plan to review in January was not actioned and the plan for review did not happen. This resulted in a delay of 6 months in diagnosis of a prostate cancer from the scan result. This would be approximately a delay of 18 months from his first presentation in ED in November 2018.

Service User D

Service User D attended ED on 24 December 2018 with retention of urine. A urinary catheter was inserted, and a urology consultant review was planned to coincide with a trial removal of catheter with a specialist nurse. Service User D was placed on the waiting list for a TURP. A normal PSA result (2.79 ng/l) was noted.

On 19 June 2019 Service User D underwent a TURP. The procedure notes describe the prostate tissue as having "endoscopic appearances of prostatic carcinoma". Histology confirmed adenocarcinoma (Gleason score 5+5) in 90% of the resected tissue. His case was discussed at MDM on 25 July 2019 who noted there was no evidence of metastases on a CT abdomen and pelvis. It recommended a CT scan of chest and a bone scan to check for spread outside the prostate. Further, a LHRH agonist as ADT should be commenced. In August 2019 a bone scan and CT scan were requested together with an ultrasound scan of the urinary tract to assess bladder emptying. Doctor 1 prescribed Bicalutamide (50mgs once daily), in order to 'assess its tolerability in a generally frail man' and in the 'light of the low presenting PSA'.

The Review Team could not locate any record in the medical notes of a digital rectal examination being performed at any point during this patient's medical treatment. This may well have provided evidence to support the malignant nature of the prostate gland prompting a swifter biopsy.

The patient was discussed at MDM on 25 July 2019 when the recommendation for ADT (a LHRH analogue) was made. He should have been started on this hormonal therapy to achieve "castration testosterone levels" as soon as the diagnosis of poorly differentiated prostate cancer was made. Instead he was started on an inadequate dose of a drug (bicalutamide) which was not licensed for the treatment of prostate cancer and was contrary to the recommendations at MDM. This therapy was not in adherence with the Northern Ireland Cancer Network (NICAN) Urology Cancer Clinical Guidelines (2016) which were signed off by the Southern Health and Social Care Trust (SHSCT) Urology Multi-disciplinary Team, as their standard of care for Cancer Peer Review (2017). This guidance was issued when Dr 1 was the regional

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

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

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

Service User E

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

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

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

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

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

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

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as an MDM administration tracker, was not in place.

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

Service User F

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

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

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

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

Service User G

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

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

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

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

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

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

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

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

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

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

Service User H

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

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

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

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

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

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

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

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

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

Service User I

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

A letter dated 11 November 2016 Service User I's General Practitioner asked for Service User I TURP to be expedited.

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

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

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

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

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than surveillance with PSA monitoring.

6.0 FINDINGS

Diagnosis and Staging

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

Targets

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

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Multidisciplinary Meeting

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

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for initial biopsy.

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

<u>Multidisciplinary working and referral</u>

- The review team noted repeated failure to appropriately refer patients
- Service User A should have been referred to oncology initially and then to palliative care as his disease progressed.
- Service User B should have had an earlier diagnosis and referral to oncology.
- Service User D should have been referred to oncology and palliative care.
- Service User E should have been referred to oncology for time critical care.
- Service User F should have been referred to oncology.
- Service User G should have been referred to the Small Renal Mass Team.
- Patient H should have been referred to the Regional / Supra-Regional Penile Cancer Network according to NICAN Urology cancer guidelines 2016 but a

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

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

Patient Support and Experience

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

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

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

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

Affects of Covid

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

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

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

Governance / Leadership

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

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to know about the issue and address it.

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

7.0 CONCLUSIONS

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

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

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

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

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

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

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

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

8.0 LESSONS LEARNED

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

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

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

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

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

9.0 RECOMMENDATIONS AND ACTION PLANNING

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

Recommendation 1.

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

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

Timescale – Immediate and ongoing

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

Recommendation 2.

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

9.0 RECOMMENDATIONS AND ACTION PLANNING

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

Timescale - Immediate and ongoing

Assurance - Comprehensive Cancer Pathway audit and Patient experience.

Recommendation 3.

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

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

Timescale – Immediate and ongoing

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

Recommendation 4.

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

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

Timescale - 3 months and ongoing

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

Recommendation 5.

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

This will be achieved by - Appropriate resourcing of the MDM tracking team to encompass a new role comprising whole pathway tracking, pathway audit and pathway assurance. This should be supported by a safety mechanisms from laboratory services and Clinical Nurse Specialists as Key Workers. A report should

9.0 RECOMMENDATIONS AND ACTION PLANNING

be generated weekly and made available to the MDT. The role should reflect the enhanced need for ongoing audit / assurance. It is essential that current limited clinical resource is focused on patient care.

Timescale - 3 months

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

Recommendation 6.

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

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

Timescale - 3 months

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

Recommendation 7.

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

Timescale - 3 months

Recommendation 8.

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

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

Timescale – Immediate and ongoing

Assurance - Variance from accepted Care Guidelines and MDM recommendations

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

9.0 RECOMMENDATIONS AND ACTION PLANNING

Recommendation 9.

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

Timescale - 3 months

Recommendation 10.

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

Recommendation 11

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

References:

1. Hoffmann, R., et al. Innovations in health care and mortality trends from five cancers in seven European countries between 1970 and 2005. Int J Public Health, 2014. 59: 341.
2. Oliver, R.T., et al. Radiotherapy versus single-dose carboplatin in adjuvant treatment of stage I seminoma: a randomised trial. Lancet, 2005. 366: 293.
3. Laguna M.P., et al EAU Guidelines: testicular cancer. https://uroweb.org/guideline/testicular-cancer/note_127-129 (accessed 26/02/2021)
4. Peer review Self-Assessment report for NICaN 2017
5. Northern Ireland Cancer Network (NICAN) Urology Cancer Guidelines (2016)
6. EAU guidelines for penile cancer: section 6.2.1 (2019)
7. NICE improving outcomes in urological cancer (2002)
8. NICAN Urology Cancer Clinical Guidelines (March 2016), Penile Cancer treatment Section 9.3 (3).

9.0 RECOMMENDATIONS AND ACTION PLANNING

10.0 DISTRIBUTION LIST

Mr Shane Devlin – Chief Executive SHSCT

Mrs Melanie McClements – Director of Acute Services SHSCT

Dr Maria O'Kane – Medical Director SHSCT

Mrs Heather Trouton Executive Director of Nursing, Midwifery and AMPs

PHA

HSCB

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

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

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

SECTION 1

INFORMING THE SERVICE USER[1] / FAMILY / CARER

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

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

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

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

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

---

[1] *Service User or their nominated representative*

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

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

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

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

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

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

SECTION 2

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

(complete this section for all death related SAIs)

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

DATE CHECKLIST COMPLETED	**1.3.2021**

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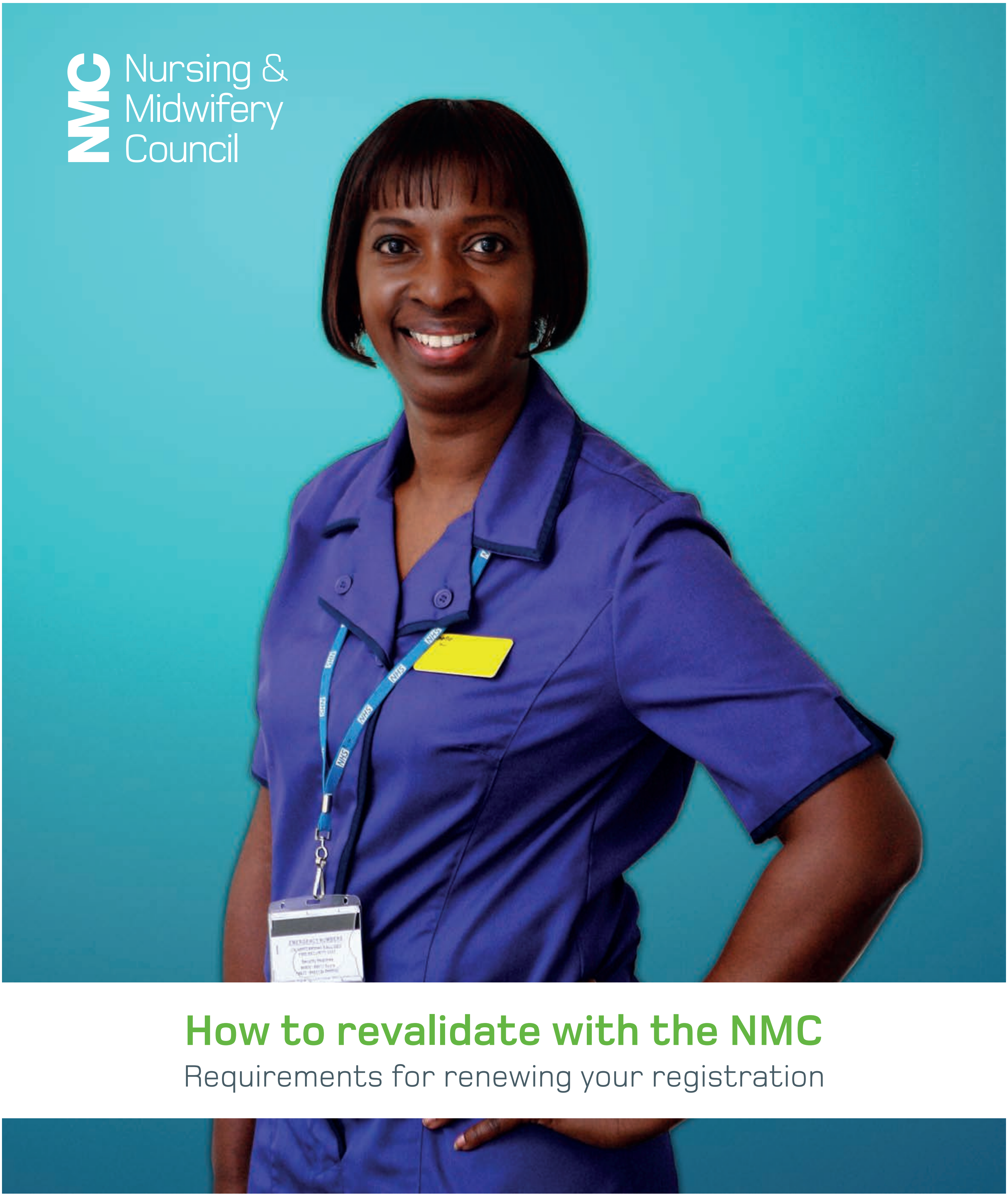
[1] *Service User or their nominated representative*

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

REVALIDATION



How to revalidate with the NMC

Requirements for renewing your registration

CONTENTS

This updated document was updated in May 2019

WHAT DOES THIS DOCUMENT DO?

This document is for nurses, midwives and nursing associates who are registered with the NMC. It sets out how to renew your registration with the NMC through revalidation every three years.

The requirements for revalidation are either prescribed in the Nursing and Midwifery Order 2001 (the Order)[1] and the Education, Registration and Registration Appeals Rules (the Rules)[2], or are standards set by the NMC for revalidation and readmission.[3]

About the NMC

We're the independent regulator for nurses and midwives in the UK and nursing associates in England.

Better and safer care for people is at the heart of what we do, supporting the healthcare professionals on our register to deliver the highest standards of care.

How to use this document

This document gives an overview of the revalidation requirements which you will have to meet every three years in order to renew your registration. It also sets out how you should collect the required information and approach the process, including suggested templates which you can use as well as mandatory forms which you must complete as part of your revalidation application.

This document includes a checklist of the revalidation requirements and the supporting evidence for each requirement.

Each requirement is presented on pages 18-37 followed by information about:

- the purpose of the requirement
- how to meet the requirement
- the recommended or mandatory approach to collecting and recording the required information, and
- how to demonstrate to us that you have met the requirement in your online application.

You should read this document in conjunction with the Code[4] and other guidance on our website. We have published a range of resources that you might find helpful in preparing for revalidation, including completed templates and case studies. We have also provided information for confirmers, which you should ensure that your confirmer has read, as well as information for employers, which we recommend you encourage your employer (if applicable) to read.

Please note that you must still pay your annual registration fee every year to retain your registration with the NMC.

How the NMC will use your information

As part of the revalidation process you are required to submit information about yourself to the NMC. We will only process your personal data, as permitted by the Data Protection Act 2018 ('DPA').

Details of our data protection policy are included in our privacy notice at:
www.nmc.org.uk/privacy

We will use your personal data for the purposes of administering and assessing your revalidation application and any subsequent verification of that application. We may also use information obtained through the revalidation process for research, and for the purpose of maintaining and improving our internal systems and processes.

Your responsibility

You are responsible for your revalidation application. You need to sufficiently plan to ensure, to the best of your ability, that you will meet the requirements within your three year renewal period. If you require support from us to help you revalidate, please see our support to help you revalidate guidance sheet.

We expect you to complete your revalidation application on NMC online. This should not be delegated to someone else unless we have granted you an adjustment. You must provide accurate information in your online application.

You must adhere to the conditions we set out in this guidance and in the guidance we provide for confirmers and employers (if appropriate). Examples of these conditions include (but are not limited to) avoiding conflicts of interest and having your reflective discussion with a person on the NMC register.

If there are grounds for believing that you have not met these conditions, and/or that you have made a false declaration as part of your revalidation application, we will investigate and your registration could be at risk. Information supplied by you may be used to investigate any alleged breach of the Code and for the purpose of any subsequent fitness to practise proceedings.

Equality, diversity and inclusion

We value the diversity of the people on our register, and the wider community we serve. We are dedicated to ensuring revalidation is supportive and fair.

The Equality Act 2010 ('the Act') is legislation that applies in England, Wales and Scotland.[5] This Act protects people from discrimination, harassment or victimisation by specifying a number of 'protected characteristics':

- age
- gender reassignment
- being married or being in a civil partnership
- being pregnant or in the maternity period
- disability[6]
- race, including colour, nationality, ethnic or national origin
- religion, belief, or lack of religion or belief
- sex
- sexual orientation.

We expect all employers of nurses, midwives and nursing associates to meet their legal duty in the Equality Act 2010. We expect them to support you based on your individual needs and remove any unnecessary barriers to help you meet the revalidation requirements.

We cannot change the revalidation requirements as they are competence standards that demonstrate that you can practise safely and effectively. However, we can support you to renew your registration by providing adjustments that help you revalidate. For example, we can provide you with a short extension to your application date so you have more time to meet the revalidation requirements or give you a paper application form.

You can find further information on the support we offer on our website.

How to contact the NMC

For more information please see the revalidation section of the NMC website at: **www.nmc.org.uk**. If you are unable to find the information you need and you still require further help you can email us at: **revalidation.escalation@nmc-uk.org**.

If you wish to make a complaint or provide feedback about the standard of our service, please visit the 'Contact us' pages of our website at **www.nmc.org.uk/contact-us/complaints-about-us**.

WHAT IS REVALIDATION?

Revalidation

- is the process that allows you to maintain your registration with the NMC
- demonstrates your continued ability to practise safely and effectively, and
- is a continuous process that you will engage with throughout your career.

Revalidation is your responsibility. You are the owner of your own revalidation application. We recommend that you work towards meeting the revalidation requirements throughout the three year revalidation period so you are prepared when your application is due.

Revalidation is not

- an assessment of your fitness to practise
- a new way to raise fitness to practise concerns (any concerns about a nurse, midwife or nursing associate's practice should be raised through the existing fitness to practise process), nor
- an assessment against the requirements of your current/former employment.

Purpose of revalidation

- to raise awareness of the Code and professional standards expected of you
- to provide you with the opportunity to reflect on the role of the Code in your practice as a nurse, midwife or nursing associate and demonstrate that you are 'living' these standards
- to encourage you to stay up to date in your professional practice by developing new skills and understanding the changing needs of the public and fellow healthcare professionals
- to encourage a culture of sharing, reflection and improvement
- to encourage you to engage in professional networks and discussions about your practice, and
- to strengthen public confidence in the nursing and midwifery professions.

Revalidation and the Code

One of the main strengths of revalidation is that it reinforces the Code by asking you to use it as the reference point for all the requirements, including your written reflective accounts and reflective discussion.

This should highlight the Code's central role in the nursing and midwifery professions and encourage you to consider how it applies in your everyday practice.

The Code (paragraph 22) requires you to fulfil all registration requirements. To achieve this you must:

- meet any reasonable requests so we can oversee the registration process (22.1)
- keep to our prescribed hours of practice and carry out continuing professional development (CPD) activities (22.2), and
- keep your knowledge and skills up to date, taking part in appropriate and regular learning and professional development activities that aim to maintain and develop your competence and improve your performance (22.3).

Revalidation and the standards of proficiency

One purpose of revalidation is to help you to maintain safe and effective practice. Revalidation does this by encouraging you to update your knowledge and develop new skills. The NMC publishes and regularly updates standards of proficiency for everyone on our register. These set out what we expect students to know, understand and be able to do to apply to join our register and to practise safely and effectively. It is important for you to become familiar with the most recent standards, identify which ones relate to your scope of practice and identify your training needs. This will help you to advance your practice and also means that you will be equipped to supervise and assess students if this is part of your role.

It is important that you speak to your employers about the types of continuous professional development that will help you achieve this.

Overall, revalidation should lead to improved practice and therefore public protection benefits.

Confirmation: provides assurance, increases support and engagement between nurses,midwives, nursing associates and their confirmers.

Practice hours: helps you maintain safe and effective practice while keeping your skills up to date.

CPD: reduces professional isolation through engagement while increasing skills and awareness.

Professional indemnity arrangement: is a legal requirement for all healthcare professionals

Safe and effective practice in line with the Code

Practice-related feedback: helps you become more responsive to the needs of patients, colleagues and service users which will improve practice.

Health and character: satisfies the Registrar that you are capable of safe and effective practice.

Reflective discussion: cultivates a sharing reflective culture that focuses on improvement.

Written reflective accounts: helps you identify changes or improvements to make and embed the Code in your practice.

CHECKLIST OF REQUIREMENTS AND SUPPORTING EVIDENCE

These are all of the requirements that you must meet in order to complete your revalidation and renew your registration every three years with the NMC.

Requirements	Supporting evidence
450 practice hours for each registration. **Dual registration (e.g. nurse and midwife) requires 900 practice hours[7]**	Maintain a record of practice hours you have completed, including: • dates of practice • the number of hours you undertook • name, address and postcode of the organisation • scope of practice (see tip box on page 22) • work setting (see tip box on page 22) • a description of the work you undertook, and • evidence of those practice hours should be recorded. See our practice hours requirements guidance sheet and suggested template at guidance and information.
35 hours of continuing professional development (of which 20 must be participatory)	Maintain accurate and verifiable records of your CPD activities, including: • the CPD method (examples of 'CPD method' are self-learning, online learning, course) • a brief description of the topic and how it relates to your scope of practice • dates the CPD activity was undertaken • the number of hours and participatory hours • identification of the part of the Code most relevant to the CPD, and • you should record evidence of the CPD activity. See our guidance sheet and suggested template at guidance and information
Five pieces of practice-related feedback	Notes on the content of the feedback and how you used it to improve your practice. This will be helpful for you to use when you are preparing your reflective accounts. Make sure your notes do not include any personal data (see the section on non-identifiable information on pages 15-17).

Requirements	Supporting evidence
Five written reflective accounts	Five written reflective accounts that explain what you learnt from your CPD activity and/or feedback and/or an event or experience in your practice, how you changed or improved your work as a result, and how this is relevant to the Code. You must use the NMC form on page 47 and make sure your accounts do not include any personal data (see the section on non-identifiable information).
Reflective discussion	A reflective discussion form which includes the name and NMC Pin of the NMC-registered nurse, midwife or nursing associate that you had the discussion with as well as the date you had the discussion. You must use the NMC form on page 48 and make sure the discussion summary section does not contain any personal data (see the section on non-identifiable information).
Health and character	You must make a declaration as to your health and character as part of your online revalidation application. You can find more information in our guidance on health and character.
Professional indemnity arrangement	Evidence to demonstrate that you have an appropriate indemnity arrangement in place. You must tell us whether your indemnity arrangement is through your employer, membership of a professional body or through a private insurance arrangement. If your indemnity arrangement is provided through membership of a professional body or a private insurance arrangement, you will need to record the name of the professional body or provider.
Confirmation	A confirmation form signed by your confirmer. You must use the NMC form on pages 49-51.

THE REVALIDATION PROCESS

During the three years since your last renewal/you joined the register

You need to meet a range of revalidation requirements to show that you are keeping your skills and knowledge up to date and maintaining safe and effective practice	▶ See pages 18–37: for details of the requirements

In the 12 months before your renewal date

Once you have met the requirements, you will need to discuss your revalidation with a confirmer. As part of this confirmation discussion, you will demonstrate that you have complied with all of the revalidation requirements, except having a professional indemnity arrangement and meeting the requirements of health and character.	▶ See pages 35–37: 'Confirmation'

At least 60 days before your revalidation application date

Every three years you will be asked to apply for revalidation using NMC Online. We will notify you at least 60 days before your application is due, either by email if you have set up an NMC Online account, or by letter sent to your registered address.	▶ See pages 38–40: The application process'

In the 60 days before your revalidation application date

Once you receive your notification you will need to go online and complete the application form. As part of that application, you need to declare to the NMC that you have complied with the revalidation requirements.	▶ See pages 38–40: The application process'

Following submission of your revalidation application

Each year we will select a sample of revalidation applications and ask those professionals to provide us with further information so we can verify the declarations they made as part of their revalidation application. If you are selected your registration will be held effective until the verification process is complete and you can continue to practise as normal during this time. Your registration will only renew if the verification is completed successfully.	▶ See pages 41–42: 'Verification of your application'

HOW TO APPROACH REVALIDATION

Understand key terms

1. The registration process: Every three years from when you join (or re-join) the register you will need to renew your registration by revalidating. Every year you will also need to retain your registration by paying an annual registration fee. If you don't complete these processes on time your registration will expire.
2. Fee expiry date: The deadline for paying your annual registration fee in order to retain your registration.
3. Revalidation application date: The deadline for submitting your revalidation application. It is the first day of the month in which your registration expires, so if your renewal date is 30 April, your revalidation application date will be 1 April.
4. Renewal date: The date on which your registration will be renewed if you have successfully completed your revalidation application. It is the last day of the month in which your registration expires.

Keep a portfolio

5. We strongly recommend that you keep evidence that you have met the revalidation requirements in a portfolio. This does not necessarily need to be an e-portfolio; please see our guidance sheet on e-portfolios at **revalidation.nmc.org.uk/download-resources/guidance-and-information** for further information. We have provided forms you must use and templates you may like to use to record your evidence for each requirement; these are available at the end of this document and on our website at **revalidation.nmc.org.uk/download-resources/forms-and-templates,** where you will also find examples of completed forms and templates for you to refer to.
6. We expect any evidence to be kept in English, and nurses, midwives and nursing associates must submit their revalidation application, and any subsequent requested verification information in English.
7. The portfolio will be helpful for the discussion you have with your confirmer (see pages 35-37). You will also need to have this information available in case we request to see it to verify the declarations you made as part of your application (see pages 41-42).
8. You may already keep a professional portfolio. If so, you do not need to maintain a separate portfolio but you might like to add to it.

The NMC recognises the culture and linguistic needs of the Welsh speaking public (for further information please see **www.nmc.org.uk/about-us/our-equality-and-diversity-commitments/welsh-language-scheme**). We have published Welsh language versions of our guidance for nurses and midwives, confirmers and employers, as well as our templates and forms, on our website at **revalidation.nmc.org.uk/download-resources/guidance-and-information**.

9. You can use the checklist on page 9 to make sure that all of the information is in your portfolio before you have your confirmation discussion with your confirmer or submit your revalidation application.

10. We recommend that you keep your portfolio until after you complete your next revalidation. For example, if you revalidated in 2016, we suggest that you should keep your portfolio until after you have revalidated again in 2019.

11. Your portfolio must not record any information that might identify an individual, whether that individual is alive or deceased. This means that all information must be recorded in a way that no patient, service user, colleague or other individual can be identified from the information. The section on non-identifiable information on pages 15-17 provides guidance on how to make sure that your portfolio does not contain any information that might identify an individual.

12. During your revalidation application we will not request that you upload your evidence or submit your portfolio to the NMC. However, each year we will select a sample of revalidation applications and request further information from you to verify your revalidation application via NMC online. In some cases, we may request further evidence, so it is important that you keep all of your revalidation evidence safe.

Conflicts of interest and perceptions of bias

13. A conflict of interest is a situation that has the potential to undermine the impartiality and objectivity of decision making within the revalidation process. Conflicts of interest can arise when an individual's judgement is influenced subjectively through association with colleagues out of loyalty to the relationship they have, rather than through an objective process.

14. Conflicts of interest can occur because of personal or commercial relationships.

15. You need to be mindful about any personal or commercial relationship between you, your confirmer and your reflective discussion partner. You may not choose a family member or person with whom you have a close personal relationship, such as a close friend to undertake either of these roles

16. You, your confirmer and reflective discussion partner will need to take responsibility for deciding whether there is any conflict of interest or perception of bias to ensure that the confirmation process and reflective discussion retains credibility and remains objective. If you think that there is a risk there might be a conflict of interest you should use a different person as your confirmer and reflective discussion partner.

Appraisals

17. Many nurses, midwives and nursing associates have an employer. It is important for their employers to be aware of the Code and the standards expected of people on our register in their professional practice. See our Employers guide to revalidation at **revalidation.nmc.org.uk/download-resources/guidance-and-information**.

18. Appraisals are a way for employers to assess the performance of their employees against the requirements of their role and identify areas for improvement and development.

19. The revalidation process is designed so that it can be undertaken as part of a regular appraisal. If you are an employee who does not have a regular appraisal you could consider asking your employer to arrange an appraisal for you in advance of your revalidation application date.

20. The confirmation discussion has a different purpose from an appraisal, as it is about demonstrating to an appropriate confirmer that you have met the revalidation requirements, not the requirements of your employment (please see the section on Confirmation on pages 35-37 for more details). However, it can be incorporated into an appraisal, and we recommend that, where possible, your confirmation discussion forms part of an annual appraisal, if you have one.
21. If your line manager is also registered with the NMC, you might like to have both your reflective discussion and your confirmation discussion as part of an annual appraisal, if you have one. You might find it helpful to have a discussion with your confirmer every year as part of an annual appraisal, so that you can keep them updated on your revalidation.
22. If you are not an employee, or if you are an employee who has been unable to arrange an appraisal in advance of your revalidation application date, you will still be able to renew your registration by meeting the revalidation requirements. You are not required to arrange for another person or organisation to conduct an appraisal for the purposes of revalidation, but you will still need to arrange a reflective discussion and confirmation discussion.

NON-IDENTIFIABLE INFORMATION

23. You are likely to process personal data as part of your day to day role. If you are employed, you are likely to be covered by your employer's registration under data protection legislation. If you are practising as an independent or self-employed nurse, midwife or nursing associate you are already likely to be registered under data protection legislation in your capacity.
24. This section sets out your obligations in relation to confidentiality and data protection in relation to meeting the revalidation requirements. It does not cover your existing obligations in relation to data protection legislation.

Personal data means data which identifies an individual.
Section 1(1) of the Data Protection Act 1998.

Your obligations in relation to confidentiality under the Code

25. The Code sets out the professional standards that you must uphold in order to be registered to practise in the UK. Standard 5 of the Code states:

Respect people's right to privacy and confidentiality

- As a nurse, midwife or nursing associate you owe a duty of confidentiality to all those who are receiving care. This includes making sure that they are informed about their care and that information about them is shared appropriately.

To achieve this, you must:

- respect a person's right to privacy in all aspects of their care (5.1)
- make sure that people are informed about how and why information is used and shared by those who will be providing care (5.2)
- respect that a person's right to privacy and confidentiality continues after they have died (5.3)
- share necessary information with other health and care professionals and agencies only when the interests of patient safety and public protection override the need for confidentiality, and (5.4)
- share with people, their families and their carers, as far as the law allows, the information they want or need to know about their health, care and ongoing treatment sensitively and in a way they can understand. (5.5)

Making sure that your evidence does not include any personal information

26. In meeting the revalidation requirements and keeping your evidence, you must not record any information that might identify an individual, whether that individual is alive or deceased. This means that all information recorded must be recorded in a way that no patient, service user, colleague or other individual can be identified from the information.

27. For example, any notes or reflections must not include:
    - the name of any individual
    - the date of any incident or event referred to
    - the particular ward or place where the event occurred, or
    - descriptions of unique circumstances where an individual could be identified from the circumstances.

28. Any information extracted from employer data (such as complaints logs) must be extracted in a way that no information identifying an individual is obtained, used or recorded. For example, you must not forward work emails to your personal account, or download and take copies of employer records. You must seek consent to access or use your employer's information.

Example scenarios

29. You will already be aware of the importance of keeping personal information confidential, and not processing personal information outside of your employment or work settings. However, we have provided some simple examples below to demonstrate how an instance of feedback could be recorded in a way that no individual can be identified.

Scenario 1

In January 2015 Mrs Jones was in ward 8 with a broken hip. She made a complaint about lack of hydration. You want to use this feedback in one of your reflections as an example of where you put in place a new process to make sure all patients were offered water on a regular basis.

In your reflective account you could say: 'A patient with a serious injury made a complaint about lack of hydration.'

No dates, names or wards have been included in the record, and the type of injury has also been omitted, so Mrs Jones cannot be identified from this information. You can then explain what you did, what improvement you made and how this is related to the Code.

Scenario 2

In reviewing the complaints log held by the maternity unit where you work, you noticed a complaint made by Mrs Smith in relation to a lack of continuity of care and handover between midwives at the end of a shift on 12 January 2015. You were one of the midwives involved, along with your colleague Sarah. You discussed this with your colleagues and have made improvements in the way you handover at the end of shifts. You want to use this feedback in one of your reflections.

Before writing your reflective account, you need to check with your employer that you can use information from the complaints log. In your reflective account you could say: 'A complaint was received about the lack of continuity of care and handover between myself and a colleague at the end of a shift'.

No information identifying any individual, including both Mrs Smith and your colleague, has been included in this record. You can then explain what you did, what improvement you made and how this is related to the Code.

Storing your reflective accounts form, reflective discussion form and confirmation form

30. You are not required to submit your reflective accounts form, reflective discussion form and confirmation form to the NMC at any point in the revalidation application. There is no requirement to store them electronically or upload them into NMC Online as part of your application, or provide them if you are selected so we can verify your evidence.

31. Your 'reflective discussion form' and 'confirmation form' contain personal data about another person. This means that there are data protection implications for nurses, midwives and nursing associates completing these forms, when they are processing electronic records. There is not an exemption under Data Protection legislation which applies to personal data processed by our registrants, as part of the reflection and discussion elements of revalidation. However, the Information Commissioner's Office (ICO) have recognised that it would be highly disproportionate to expect our registrants to have to register with them as data controllers when processing electronic records, or to pay a fee. The ICO has confirmed that it does not plan to take any action against any of our registrants for failing to register with them.

32. You may choose to store your completed reflective discussion and confirmation forms in either paper or electronic format. You should still respect the fact that these forms contain personal data about your reflective discussion partner and confirmer. Please see our guidance sheet on e-portfolios for further information at guidance and information.

The Information Commissioner's Office has published a guide to data protection legislation at **ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/**

PRACTICE HOURS

The requirements

33. You must have practised as a registered nurse, midwife or nursing associate for a minimum number of hours over the three year period since your registration was last renewed or you joined the register.[8]

Registration	Minimum total practice hours required
Nurse	450 practice hours required
Midwife	450 practice hours required
Nursing associate	450 practice hours required
Nurse and SCPHN	450 practice hours required
Midwife and SCPHN	450 practice hours required
Nurse and midwife (including Nurse/SCPHN and Midwife/SCPHN)[9] Or Nursing associate and nurse	900 practice hours required (to include 450 hours for nursing, 450 hours for midwifery, 450 hours for nursing associate)

A specialist community public health nurse (SCPHN) means a registered nurse, midwife or nursing associate who is also registered in the Specialist Community Public Health Nurses' part of the register.

34. If you have practised for fewer than the required number of hours in the three year period since your registration was last renewed or you joined the register, then you must successfully complete an appropriate return to practice programme approved by the NMC before the date of your application for renewal of registration.[10]

35. Registered nurses, midwives or nursing associates who are admitted to another part of the register since their registration was last renewed or they joined the register only need to meet the practice hours requirement for their initial registration. They will need to meet the practice hours requirements for registration in both parts in subsequent three year renewal periods.[11]

The purpose of these requirements

36. The practice hours requirements are designed to help you to maintain safe and effective practice, and keep your skills up to date.

How to meet the requirements

37. You can only count practice hours that you undertook while you were registered with the NMC. You cannot count unregistered practice or hours completed when working in an entirely different regulated profession such as a paramedic or medical doctor.

38. Practice hours should reflect your current scope of practice. You must comply with The Code: professional standards of practice and behaviour for nurses, midwives and nursing associates at all times. This includes the duty to recognise and work within the limits of your competence.

39. You must meet your practice hours in a role where you rely on your skills, knowledge and experience of being a registered nurse, midwife or nursing associate.

    This includes:

    - practice as a nurse, midwife, SCPHN and nursing associate, in roles that are likely to require registration
    - practice in roles where your employment contract does not expressly require you to be registered with us but you rely on your skills, knowledge and experience of being a registered nurse, midwife or nursing associate. For example, this could include roles in public health or nursing, midwifery, management, commissioning, policy and education

40. The following activities cannot be counted towards the practice hours requirement: hours undertaken in a healthcare, nursing or midwifery assistant or support worker role cannot be counted towards practice hours as a registered nurse, midwife or nursing associate.

    - Hours completed when working in a separate regulated profession for example when working as a paramedic or medical doctor.
    - Nurses undertaking an 18-month midwifery programme cannot use their midwifery training hours in order to maintain their registration as a nurse. They will be able to use any practice hours undertaken as a nurse, either before or after their midwifery course, during the three-year period.
    - Hours undertaken in any healthcare, nursing or midwifery assistant or support worker roles cannot be counted towards practice hours.

41. If you are working overseas (or have worked overseas for part of your three year renewal period) as a nurse, midwife or nursing associate you can count these hours towards the practice hours requirements for revalidation. Where possible, you should always register with the appropriate regulator in the country in which you are practising.

42. If you have had a career break, you will still be able to meet the practice hours requirement if you have completed the required hours of registered practice during your three year renewal period.

43. We have produced a guidance sheet for people with multiple registrations and additional qualifications. Please see our guidance and information on our website.

Further information on working outside the UK and returning to practice can be found on our website **www.nmc.org.uk/registrations**

44. If you have not undertaken any type of work where you relied on your skills, knowledge or experience as a registered nurse, midwife or nursing associate, or if you are unable to meet the practice hours requirement, you have two options:
    - you can successfully complete an appropriate NMC-approved return to practice programme before the date of your revalidation application. These programmes are designed to allow you to renew your registration and return to practice after a break in practice. Further information about return to practice programmes is available on our website or
    - you can cancel your registration. You will continue to hold a nursing and/or midwifery qualification, but will not be registered with the NMC. You can apply for readmission to the register in future if you wish to practise as a registered nurse, midwife or nursing associate. Information on cancelling registration and seeking readmission to the register is available on our website.
45. If you do not renew your registration, you will lapse from the register. You will not be able to practise in the capacity of a registered nurse, midwife or nursing associate. You cannot rely on any hours of work you undertake when you were not registered with the NMC as part of any application for readmission to the register.

How to record practice hours

46. We strongly recommend that you maintain a record of practice hours you have completed.
47. This will form part of the discussion you have with your confirmer, and you will also need to have this information available in case we request to see it for verification of your application. We have provided a guidance sheet on practice hours and have a suggested template to help you record your practice hours. Your records should include:
    - dates of practice
    - the number of hours you undertook
    - name, address and postcode of the organisations
    - scope of practice
    - work setting
    - a description of the work you undertook, and
    - evidence of those practice hours, such as timesheets, job specifications and role profiles.
48. You do not necessarily need to record individual practice hours. You can describe your practice hours in terms of standard working days or weeks.

What you need to tell us in your online application

49. When you apply for revalidation, you need to declare that you have met the practice hours requirement during the three year period since your last registration renewal or initial registration. You only need to tell us about the most recent hours you have undertaken to meet the minimum requirement for your registration(s). If you are currently practising in more than one setting, provide details of your main setting first.

50. You will also be asked to enter the following details:

    - whether you are currently practising
    - if you are currently in practice, where you undertake that practice, including details of your scope of practice and work setting, and
    - if you are not currently in practice, where you undertook your most recent practice, including details of your scope of practice and work setting.

51. To help you prepare for your online application we have listed the scope of practice and work setting options in the tip box below. These were designed to capture the wide breadth of types of practice that people on our register can undertake, and as such they will not apply to all roles.

52. If you have completed a return to practice course or been admitted to another part of the register since you last renewed your registration or joined the register, your practice hours declaration will be as follows:

    - If you have recently completed an approved return to practice course since you last renewed your registration or joined the register, you will be able to meet the practice hours requirement for that registration.
    - If you have been admitted to another part of the register since you last renewed your registration or joined the register (for example you are a nurse who has undertaken training as a midwife and gained a second registration as a midwife), you only need to meet the practice hours requirement for your initial registration. Please note that next time you apply for revalidation, if you wish to renew your registration on both parts of the register and continue practising as both a nurse and a midwife, you will need to meet the practice hours requirements for both registrations.
    - For further information about multiple registrations and additional qualifications please see our guidance sheet at guidance and information.

Scope of practice

Direct clinical care or management: adult and general care nursing; children's and neo-natal nursing; mental health nursing; learning disabilities nursing; midwifery; health visiting; occupational health; school nursing; public health; other. Commissioning, Education, Policy, Quality assurance or inspection, Research, other.

Work setting

Ambulance service, Care home sector, Community setting (including district nursing and community psychiatric nursing), Consultancy, Cosmetic or aesthetic sector, Governing body or other leadership, GP practice or other primary care, Hospital or other secondary care, Inspectorate or regulator, Insurance or legal, Maternity unit or birth centre, Military, Occupational health, Police, Policy organisation, Prison, Private domestic setting, Public health organisation, School, Specialist or other tertiary care including hospice, Telephone or e-health advice, Trade union or professional body, University or other research facility, Voluntary or charity sector, other.

CONTINUING PROFESSIONAL DEVELOPMENT

The requirements

53. You must have undertaken 35 hours of continuing professional development (CPD) relevant to your scope of practice as a nurse, midwife or nursing associate, in the three year period since your registration was last renewed or you joined the register.[12]

54. Of those 35 hours of CPD, at least 20 must have included participatory learning.[13]

55. You must maintain accurate records of the CPD you have undertaken. These records must contain:
    - the CPD method
    - a description of the topic and how it related to your practice
    - the dates on which the activity was undertaken
    - the number of hours (including the number of participatory hours)
    - the identification of the part of the Code most relevant to the activity, and
    - evidence that you undertook the CPD activity.[14]

The purpose of these requirements

56. As a professional, you have a duty to keep your professional knowledge and skills up to date through a continuous process of learning and reflection.

57. The CPD requirements are designed to help you to maintain safe and effective practice, to improve practice or develop new skills where a gap has been identified and to respond to changes and advances in nursing and midwifery.

58. The participatory requirement also helps to challenge professional isolation by requiring learning through engagement and communication with others.

How to meet the requirements

59. CPD is a learning activity that you undertake separately from your normal practice. This is different from the everyday learning that all healthcare professionals will engage in as part of their ongoing practice.

60. Any learning activity you participate in should be relevant to your scope of practice as a nurse, a midwife or a nursing associate. When you plan, undertake and record your CPD you should focus on what you are learning, how it is linked to your scope of practice and how you can apply it to your practice.

61. We do not prescribe any particular type of CPD. We think that you are better placed to decide what learning activities are the most suitable and beneficial to your individual scope of practice. We have produced a guidance sheet that suggests some individual and participatory CPD activities that you can undertake, which includes many activities other than training courses (see guidance and information). It is not an exhaustive list and we have only provided it as an example.

62. We know that many organisations require their staff to undertake mandatory training. You should not include mandatory training that is not directly related to your practice (for example, fire training or health and safety training) as part of your 35 hours of CPD. However, if you undertake any mandatory training that is necessary to your scope of practice and professional development, for example, mandatory training on equality legislation if you are in a policy role, you could include that.

63. Participatory learning includes any learning activity in which you personally interact with other professionals, including professionals working outside healthcare. It can be an activity undertaken with one or more professionals or in a larger group setting. The group does not always need to be in a common physical environment, such as a study group or conference. It could be a group in a virtual environment (such as an online discussion group).

64. The NMC publishes and regularly updates standards of proficiency for everyone on our register. These set out what we expect students to know, understand and be able to apply to join our register and practise safely and effectively. When you are considering what CPD to undertake we recommend that you review the latest standards of proficiency for your part of the register and reflect on how your scope of practice relates to the standards and consider CPD activities that would help you to develop your skills. This is particularly important if you supervise and/or assess students as part of your role.

How to record CPD

65. You must maintain accurate records of your CPD activities, and we have provided a template to help you with this. This will form part of the discussion you have with your confirmer. You will need to have this information available in case we request to see it for verification of your application. Your records should include:

- the CPD method
- a brief description of the topic and how it relates to your practice
- dates the CPD activity was undertaken
- the number of hours and participatory hours
- identification of the part of the Code most relevant to the CPD, and
- evidence of the CPD activity.

What you need to tell us in your online application

66. You need to declare that you have met the CPD requirement.

PRACTICE-RELATED FEEDBACK

The requirement

67. You must have obtained five pieces of practice-related feedback in the three year period since your registration was last renewed or you joined the register.[15]

The purpose of this requirement

68. The practice-related feedback requirement is intended to encourage you to be more responsive to the needs of patients and service users and those who care for them. You need to seek feedback from people you work with and care for and importantly you need to use the feedback that you receive to assess and make improvements to you practice.

How to meet the requirement

69. We recommend that you try to obtain feedback from a variety of sources, for example:
    - feedback from patients, service users, carers or students as part of your day to day practice
    - feedback from colleagues such as nurses, midwives, nursing associates and other healthcare professionals
    - feedback from colleagues in management, on reception, in assistant positions, as well as fellow teachers, researchers, academics or policy colleagues
    - complaints
    - team performance reports
    - serious event reviews, and
    - feedback received through your annual appraisal.
70. Types of feedback:
    - feedback can be about your individual practice or about your team, ward, unit or organisation's practice (you should be clear about the impact the feedback had on your practice)
    - formal or informal
    - written or verbal, and
    - positive or constructive.

71. It's likely that you will already receive a range of feedback. In many organisations, feedback is already collected in a variety of ways. You must seek consent to access or use your employer's information. Any information must be extracted in a way that no information identifying an individual is obtained, used or recorded. For example, you must not forward work emails to your personal accounts, or download and take copies of employer records. See the section on non-identifiable information on pages 15-17 for more information.

72. Should you choose to solicit feedback directly from colleagues, patients or service users, you must make clear in your request that no information identifying individuals should be included in any feedback provided. You should also inform them how you intend to use their feedback, and reassure patients and service users that any feedback they give will not affect the care they receive.

How to record feedback

73. We recommend that you keep a note of the content of any feedback you obtain, including how you used it to improve your practice. This will be helpful for you to use when you are preparing your reflective accounts. We have provided a template to help you record your feedback.

74. You may choose to collect more feedback but to meet the revalidation requirement you only need to note the details of five pieces of feedback.

75. In any note you keep, you must not record any information that might identify an individual, whether that individual is alive or deceased. The section on non-identifiable information on pages 15-17 provides guidance on how to make sure that your notes do not contain any information that might identify an individual.

What you need to tell us in your online application

76. You need to declare that you have met the feedback requirement.

WRITTEN REFLECTIVE ACCOUNTS

The requirement

77. You must have prepared five written reflective accounts in the three year period since your registration was last renewed or you joined the register. Each reflective account must be recorded on the approved form and must refer to:

    - an instance of your CPD and/or
    - a piece of practice-related feedback you have received and/or
    - an event or experience in your own professional practice

    and how this relates to the Code.

The purpose of this requirement

78. We want you to engage in reflective practice so that you identify any changes or improvements you can make to your practice based on what you have learnt.

79. This requirement should also raise awareness of the Code and encourage you to consider the role of the Code in your practice and professional development.

How to meet the requirement

80. Each reflective account can be about an instance of your CPD, feedback, an event or experience in your practice as a nurse, midwife or nursing associate, or a combination of these. Both positive and negative experiences should be reflected on. Any experience, including a conversation with a colleague, a significant clinical or professional event, or a period of time can generate meaningful reflections, insights and learning. For example, you could create a reflective account on a particular topic which may have arisen through some feedback your team received following an event, such as consent and confidentiality and identify how that relates to the Code.

How to record your reflective accounts

81. We have provided a form that you must use to record your reflective accounts. You must explain what you learnt from the CPD activity, feedback, event or experience, how you changed or improved your practice as a result, and how this is relevant to the Code.

82. This form can be hand written, typed or, if necessary, dictated.

83. Your reflective accounts must not include any information that might identify an individual whether that individual is alive or deceased. The section on non-identifiable information on pages 15-17 provides guidance on how to make sure that your reflective accounts do not contain any information that might identify an individual.

84. You do not need to submit a copy of the reflective accounts to the NMC for the purpose of revalidation. However, you should retain these as a record to inform your reflective discussion and to show your confirmer.

What you need to tell us in your online application

85. You need to declare that you have met the requirement for written reflective accounts.

REFLECTIVE DISCUSSION

The requirement

86. You must have had a reflective discussion with another NMC registrant, covering your five written reflective accounts on your CPD and/or practice-related feedback and/or an event or experience in your practice and how this relates to the Code.[16]

87. You must ensure that the NMC registrant with whom you had your reflective discussion signs the approved form recording their name, NMC Pin, email, professional address and postcode, as well as the date you had the discussion.[17]

The purpose of this requirement

88. This requirement will encourage a culture of sharing, reflection and improvement. It does this by requiring you to discuss your professional development and improvement, and by ensuring that you do not practise in professional isolation.

How to meet the requirement

89. You must discuss your five written reflective accounts with another person on our register as part of a reflective discussion. In the discussion you and your reflective discussion partner will be linking your reflective accounts to the Code, so it is important that both of you are familiar with, and working to, the professional standards presented in the Code.

90. The reflective discussion partner:

- must be a nurse, midwife or nursing associate with an effective registration with the NMC, by which we mean they cannot be subject to any kind of suspension, removal or striking-off order at the time of having the discussion
- could be someone you frequently work with or someone from a professional network or learning group
- does not need to be someone you work with on a daily basis
- does not need to undertake the same type of practice as you, and
- does not need to be on the same part of the register as you (so a nurse can have a reflective discussion with a midwife and vice versa).

91. If you practise in a setting with few or no nurses, midwives or nursing associates, you can reach out to peers, who are registered with the NMC, from your wider professional or specialty network in order to have your reflective discussion.

92. It is for you to decide the most appropriate person for you to have this conversation with, including whether they are senior or junior to you.

93. If your confirmer is on our register, your reflective discussion can form part of the confirmation discussion. If your confirmer is not on our register, you will need to have your reflective discussion with an NMC-registered nurse, midwife or nursing associate before your confirmation discussion with your confirmer.

94. We expect the discussion to be a face-to-face conversation in an appropriate environment. If for some reason you cannot have a face-to-face discussion, then you could arrange a video conference.

95. During your discussion you should not discuss patients, service users or colleagues in a way that could identify them unless they expressly agree. For further information on reflective discussions please guidance and information.

How to record your reflective discussion

96. We have provided an NMC form that you must use to record your discussion. You must make sure that the nurse, midwife or nursing associate with whom you had your reflective discussion signs the form and records their name, NMC Pin, email, professional address including postcode, contact number and the date you had the discussion and a summary of the discussion.[18] You should keep the completed and signed form.

97. The discussion summary section of the form must not include any information that might identify an individual, whether that individual is alive or deceased. The section on non-identifiable information on pages 15-17 provides guidance on how to make sure that your notes do not contain any information that might identify an individual.

What you need to tell us in your online application

98. You need to declare that you have had a reflective discussion with another NMC-registered nurse, midwife or nursing associate.

99. You will also need to enter the name, NMC Pin, email, professional address including postcode and contact number of your reflective discussion partner, as well as the date you had the reflective discussion.

HEALTH AND CHARACTER

The requirements

100. You must provide a health and character declaration.[19]

101. You must declare if you have been convicted of any police charge, police caution, conviction or conditional discharge.[20]

102. You will be asked to declare if you have been subject to any adverse determination that your fitness to practise is impaired by a professional or regulatory body (including those responsible for regulating or licensing a health and social care profession).[21]

The purpose of these requirements

103. These requirements will help to satisfy the Registrar that you are capable of safe and effective practice.

How to meet the requirements

104. You will need to complete these declarations as part of your revalidation application.

105. When making these declarations please refer to our guidance on health and character for nurses, midwives and nursing associates.

106. Your character is important and is central to the Code because nurses, midwives and nursing associates must be honest and trustworthy. Your character is based on your conduct, behaviour and attitude. When declaring that you are of good character you should consider whether you have been involved in conduct which would breach the requirements of the Code. You can read the Code on our website: **www.nmc.org.uk/standards/code**. See our guidance on health and character for further information.

107. You will also be asked to declare if you have been subject to any determination by a professional or regulatory body (including those responsible for regulating or licensing a health or social care profession) to the effect your fitness to practise is impaired.[22]

108. In accordance with the Code, we expect you to declare any police charges, cautions, convictions and conditional discharges to the NMC immediately, not wait until revalidation. [23] A caution or conviction includes a caution or conviction you have received in the UK for a criminal offence, as well as a conviction received elsewhere for an offence which, if committed in England and Wales, would constitute a criminal offence.[24] Please do not notify the NMC of motoring offences unless it led to a disqualification of driving or offences that have previously been considered by the NMC. See our guidance on health and character for further information.

109. We need to know that people applying to renew their registration meet our requirements for health to ensure they can practise safely and effectively.

110. It's important to remember that when we talk about 'good health' we mean that you are capable of safe and effective practice as a nurse, midwife or nursing associate either with or without reasonable adjustments and adjustments which your employer has made.

111. Our focus is whether you have a health condition and/or disability which may affect your practice. This is because we need to be able to assess whether it may place at risk the safety of people in your care

112. It doesn't mean the absence of a health condition and/or disability. Many people with disabilities and health conditions are able to practise with or without adjustments put in place by their employer to support them.

113. It is up to you to decide whether your health allows you to be capable of safe and effective practice. If you are satisfied with your decision then you do not need to provide us with any further information apart from your declaration (see section below).

How to record health and character declarations

114. If your health and character enable you to practise safely and effectively in accordance with the Code, and you do not have any charges, cautions, convictions, conditional discharges or determinations to declare, you do not need to keep any information as part of this requirement. Your confirmer does not need to check that you have met this requirement.

115. If you do need to declare any charges, cautions, convictions, conditional discharges or determinations you will need to keep evidence of these to provide us with further information.

Paragraph 23.2 of the Code states that you must inform us and any employers you work for as soon as you can of any caution or charge against you, or if you have received a conditional discharge in relation to, or have been found guilty of, a criminal offence (other than a protected caution or conviction).

What you need to tell us in your online application

116. You need to declare that your health and character enable you to practise safely and effectively in accordance with the Code. See our guidance on health and character.

117. You will be asked to declare if you have a charge, caution, conviction or conditional discharge other than those which are protected. You do not have to tell us about protected cautions and convictions. These are minor offences that will not be disclosed on a Disclosure and Barring Service (DBS) check. Listed offences are never protected and must always be declared to us. See the full list from the DBS for England, Wales and Northern Ireland. In Scotland, the checking and barring service is operated by Disclosure Scotland.

PROFESSIONAL INDEMNITY ARRANGEMENT

The requirement

118. You must declare that you have, or will have when practising, appropriate cover under an indemnity arrangement.[25]

The purpose of this requirement

119. By law, you must have in place an appropriate indemnity arrangement in order to practise and provide care. While the arrangement does not need to be individually held by you, it is your responsibility to ensure that appropriate cover is in place.

How to meet the requirement

120. You will need to complete this declaration as part of your revalidation application.

121. Most employers provide appropriate indemnity cover for their employees. If you are employed you should check this with your employer(s). Further information is available from the NHS Employer's website.

122. Please refer to our information on professional indemnity arrangements when making this declaration This document defines 'appropriate cover' and sets out information for those who are employed, self-employed or undertake work in both employed and self-employed roles. It also sets out information for those who work in education, undertake voluntary work, or are having a break in their practice.

123. If it is discovered that you are practising as a nurse, midwife or nursing associate without an appropriate indemnity arrangement in place, you will be removed from the NMC register and unable to practise as a nurse, midwife or nursing associate.

How to record your professional indemnity arrangement

124. Your declaration will be made as part of your revalidation application.

125. We strongly recommend that you retain evidence that you have an appropriate arrangement in place.

126. If your arrangement is provided through membership of a professional body or a private insurance arrangement, your declaration should be based on having an indemnity arrangement in place which provides 'appropriate cover' in relation to your individual scope of practice, as explained on our website and in the professional indemnity arrangement guidance. Please note that you will need to justify decisions on cover you put in place or rely on, if we request you to do so. Your confirmer does not need to check that you have met this requirement.

127. Your confirmer does not need to check that you have met this requirement.

What you need to tell us in your online application

128. You need to inform the NMC whether your indemnity arrangement is through your employer, membership of a professional body, or a private insurance arrangement. Alternatively, you will be able to inform us that you are not practising at this time but that you intend to have appropriate cover in place before you practise.

129. You are required to have appropriate cover in place for all of your current practice settings. If you are currently practising in more than one setting, please tell us first about your arrangement in relation to your main practice setting. Please then add other arrangements to cover all your current practice settings.

130. If your indemnity arrangement is provided through membership of a professional body or a private insurance arrangement, you will be asked to provide the name of the professional body or provider.[26]

CONFIRMATION

The process

131. We will ask you for information for the purpose of verifying the declarations you have made in your application.[27]

132. This will be a declaration that you have demonstrated to an appropriate confirmer that you have complied with the revalidation requirements. We have provided a form for you to use to obtain this confirmation.

133. We will ask you to provide the name, NMC Pin or other professional identification number (where relevant), email, professional address and postcode of the confirmer.

The purpose of confirmation

134. Confirmation encompasses several benefits for you. It will provide assurance, increase support and engagement between you and your confirmer, and make you more accountable for your own practice and improvement. It should support you by increasing access to appraisals.

135. The interactive nature of the confirmation process should reduce professional isolation and encourage a culture of sharing, reflection and improvement.

136. Ultimately, the confirmation process is designed to increase professionalism by making nurses, midwives and nursing associates more accountable for their practice and improvement. This requirement also gives us an additional layer of assurance that nurses, midwives and nursing associates are complying with the revalidation requirements.

137. Confirmation is not a new way for employers to raise fitness to practise concerns. Confirmation is not about employers judging whether a nurse, midwife or nursing associate is fit to practise or an assessment against the requirements of their current or former employment. Raising a concern about a nurse, midwife or nursing associate's fitness to practise should be raised promptly through our fitness to practise procedures. Information on our website about our fitness to practise processes.

How to obtain confirmation

138. The confirmation process involves having a discussion about your revalidation with an appropriate confirmer. We recommend that you obtain confirmation through a face-to-face discussion or video conference.

139. As part of that discussion, you will demonstrate to that confirmer that you have complied with all of the revalidation requirements, except those related to a professional indemnity arrangement and health and character, as set out in this guidance.

140. We recommend that you obtain your confirmation during the final 12 months of the three year renewal period to ensure that it is recent. If you obtain confirmation earlier, we may ask you to explain why.

141. If your confirmer is a NMC-registered nurse, midwife or nursing associate, your reflective discussion can form part of the confirmation discussion. If your confirmer is not on the NMC register, you will need to have your reflective discussion with an NMC-registered nurse, midwife or nursing associate before you have your confirmation discussion with your confirmer.

142. We have provided further information about the role of confirmers in our guidance document Information for confirmers, which you should ensure your confirmer has read.

An appropriate confirmer

143. Your line manager is an appropriate confirmer, and we strongly recommend that you obtain confirmation from your line manager wherever possible. A line manager does not have to be an NMC-registered nurse, midwife or nursing associate. For example they could be a GP practice manager or care home manager at your place of work.

144. If you do not have a line manager, you will need to decide who is best placed to provide your confirmation. Wherever possible we recommend that your confirmer is an NMC-registered nurse, midwife or nursing associate. It is helpful if they have worked with you or have a similar scope of practice, but this is not essential.

145. If that is not possible, you can seek confirmation from another healthcare professional that you work with and who is regulated in the UK. For example, you could ask a doctor, dentist or a pharmacist. You will need to record their profession and professional Pin or registration number.

146. If you do not have a line manager, or access to someone on the NMC register or another healthcare professional, please check our online confirmation tool for further guidance as to who can act as a confirmer in this situation at **revalidation.nmc.org.uk/what-you-need-to-do/confirmation**.

147. If your confirmer is an NMC-registered nurse, nursing associate, midwife, they must have an effective registration with the NMC. We will not be able to verify your application if your confirmation was provided by a person who was subject to any kind of suspension, removal or striking-off order at the time of making the confirmation.

Obtaining confirmation if you work wholly overseas

148. If you work wholly overseas, you can seek confirmation from your line manager where you undertake your work.

149. If you do not have a line manager, you will need to decide who is best placed to provide your confirmation. Wherever possible we recommend that your confirmer is a nurse, midwife or nursing associate regulated where you practise, or another regulated healthcare professional. Our online confirmation tool provides further guidance as to who can act as a confirmer in this situation.

Obtaining confirmation if you have more than one line manager

150. If you have more than one employer or undertake more than one role, you only need to obtain one confirmation. You will need to decide which line manager is most appropriate to provide confirmation that you have met the revalidation requirements.
151. We recommend that you have your revalidation discussion and obtain confirmation through the line manager where you undertake the majority of your work. You may choose to have a revalidation discussion with each of your line managers, and bring the outputs of those discussions to the line manager you think is most appropriate to be your confirmer.

Confirmation and appraisals

152. The revalidation process is designed so that it can form part of an appraisal process, and where possible we recommend that you use your annual appraisal to have your revalidation discussion and obtain confirmation.
153. If your line manager is an NMC-registered nurse or midwife, you might like to have your reflective discussion at the same time as your confirmation discussion as part of your annual appraisal.
154. However, it is not a requirement of revalidation that you obtain your confirmation as part of an appraisal.

How to record confirmation

155. You must use the NMC form to record your confirmation. Your confirmer will need to complete and sign this form.
156. You should keep the completed and signed form.

What you need to tell us in your online application

157. You will be asked to enter the name, NMC Pin or other professional identification number (where relevant), email, professional address including postcode and contact number of your confirmer. If your confirmer is not your line manager or an individual on the NMC register, you will also need to provide details of their profession and regulation.
158. We will also ask you whether you have a regular appraisal and whether you have a line manager who is an NMC-registered nurse, midwife or nursing associate so that we understand what level of support was available to you in completing your revalidation application.

THE APPLICATION PROCESS

Before you apply

159. **Set up an NMC Online account.**
You will need to submit your application through NMC Online. You can also check your renewal date and revalidation application date on NMC Online. We have published a step-by-step guide to registering for NMC Online at **www.nmc.org.uk/registration/nmc-online**.

> Once you have set up your online account, you will receive all subsequent notifications by email. Please add the NMC as a safe sender and check your email (including any junk email folder) regularly during the revalidation process.

160. **Keep your contact details up to date so that we can notify you when your revalidation application is due.**
The most common reason for someone failing to revalidate is a failure to keep the NMC updated on your contact details.

161. **Make sure you know when your revalidation application is due.**
You must submit your application by the date we specify. You may affect our ability to process your revalidation application if you do not submit your application by this date, and the renewal of your registration may be at risk as a result.

162. **Make sure that you have all your supporting evidence to hand when you start your online application.**
Please contact the NMC well in advance of your revalidation application date if you require an adjustment for using NMC Online (see Support to help you revalidate section below).

The online application

163. Your online application opens 60 days before your revalidation application date.

164. During this 60 day period you will need to log into your application via NMC Online and address each of the requirements.

165. Do not submit your application until you have met all the revalidation requirements.

Contacting your employer or any other relevant third party

166. As part of your application process we may need to contact your employer or any other relevant third party who can verify the information that you have provided in your application.[28]

167. In your online application you will be asked to provide consent for this purpose.

Equality and diversity information

168. As part of the online application process you will be asked to supply some equality and diversity information. We use this data to monitor our services so that we can support you and make sure we are treating everyone in a fair and equal way. The questions have been designed to gather data about our service users in relation to the characteristics protected by the law under the Equality Act 2010.

169. We will keep the information from this questionnaire confidential and store it in line with the Data Protection Act 2018 and the NMC's Data Protection Policy. By submitting this sensitive personal information to us, you explicitly consent to the collection and processing of your sensitive personal information in accordance with the NMC's Data Protection Policy.

170. Providing this information is optional and will not affect your revalidation application or registration renewal. If you would prefer not to disclose this information you can select the 'prefer not to say' option for any or all of the questions.

Details of our Data Protection Policy are included in our privacy notice at **www.nmc.org.uk/privacy.**

Paying your fee

171. Alongside your revalidation application you need to pay your annual registration fee every year to maintain your registration with the NMC. Your registration will not be renewed until we have received your payment.

172. Please refer to our guidance on paying your fees at **www.nmc.org.uk/registration/staying-on-the-register/paying-your-fee**. This sets out the different ways that you can pay, including by direct debit and by debit or credit card, as well as how to pay your fee in four quarterly instalments.

173. As a registered UK tax payer you can claim tax relief on the NMC registration fees. HM Revenue and Customs (HMRC) allows individuals to claim tax relief on professional subscriptions or fees which have to be paid in order to carry out a job. The registration fee you pay to us is included in this category. Please refer to our guidance on how to claim tax relief on your fee at **www.nmc.org.uk/registration/staying-on-the-register/tax-relief**.

After you have completed your application

174. After you have completed your online application you will be offered the option of printing a paper copy of your application for your records.

175. Once your application has been successfully processed and your payment has been received we will send you an email confirming that your registration has been renewed.

176. We advise you to search the register on our website at to double check your status.

Support to help you revalidate

177. We understand that there may be circumstances that make it more difficult for you to meet the revalidation requirements. This may be as a result of a disability, an illness, pregnancy, a maternity period or any other life event that impacts on your ability to meet the revalidation requirements.

178. We can support you to meet the revalidation requirements in several ways, for example by:
    - helping you to use NMC Online, or
    - providing a short extension to your application date.[29]

For further information on the support we can offer and how to apply for this support please see our support to help you revalidate guidance sheet.

VERIFICATION OF YOUR APPLICATION

179. Each year we will select a sample of revalidation applications and request further information so we can verify the information provided.[30] Such a request does not necessarily mean that there are any concerns about your application and you can continue to practise while we review the information that you provide.

180. We will contact you by email within 24 hours of you submitting your revalidation application if you have been selected to provide further information and where possible we will notify you immediately after you have submitted your application through NMC online. Please make sure to check your email during this time, including junk email folders.

181. If you are selected to provide further information, you will need to complete an online form where you will be asked to provide further information. We may also request further evidence. We will ask you to provide this information within 21 days of receiving your notice that you have been selected for verification.

182. Your registration will not lapse during the verification process, even if the process extends past your renewal date. We will hold your registration effective until the verification process is complete, and you can continue to practise as normal during this time.

183. The table below sets out the information that you will need to provide if you are selected to provide further information. You should already have this information so you should not need to seek any additional information.

184. We will contact your confirmer to request further information using the email address you provided in your application. Please contact us if your confirmer requires adjustments in the way we contact them. Please ensure that your confirmer is aware that if they do not respond to our request for verification they may put your registration at risk. We may also contact your employer and reflective discussion partner.

185. If we identify that you have not met the revalidation requirements, or you have submitted fraudulent information, your registration might be at risk. Please note that if you do not engage fully with the verification process your registration could lapse and you would have to apply for readmission.

186. The verification process will be completed within three months of your renewal date.

Verification information

Practice hours

You will need to provide the following information, starting with your most recent practice until you demonstrate the minimum number of practice hours during the three year revalidation period:

- dates of practice
- the number of hours you undertook
- name, address and postcode of the organisations
- scope of practice and work setting (see tip box on page 22)
- a description of the work you undertook, and
- if practising overseas, whether you are registered with the appropriate regulating body.

We may contact your employer for further information, and you may also be asked to provide further evidence of practice hours and how this relied on your knowledge, skills and experience as a nurse, midwife or nursing associate.

If you are using a completed return to practice course for your practice hours requirement, or you have been admitted to another part of the register since you last renewed your registration or joined the register, please see our guidance sheet on return to practice and new registration at **revalidation.nmc.org.uk/download-resources/guidance-and-information** for further information.

Continuing professional development

You will need to provide the following information:

- the CPD method
- a brief description of the topic and how it relates to your practice
- the dates the CPD activity was undertaken
- the number of hours and participatory hours, and
- identification of the part of the Code most relevant to the CPD.

You may also be asked to provide evidence of the CPD activity.

Reflective discussion

We will not ask you to upload a copy of the signed reflective discussion form; however, we may contact your reflective discussion partner about your discussion.

Professional indemnity arrangement

You are required to have appropriate cover in place for all of your current practice settings. If your arrangement is provided through membership of a professional body or a private insurance arrangement you will be asked to confirm a) that you have read and understood our information on professional indemnity arrangements; b) that you have in place an indemnity arrangement which provides "appropriate cover" in relation to your individual scope of practice, as explained in our guidance, Professional indemnity arrangements; and c) that you understand that you will need to justify decisions on cover you put in place or rely on, if we request you to do so. If you are currently practising in more than one setting, please tell us first about your arrangement in relation to your main practice setting, followed by any other arrangements to cover all your current practice settings.

Confirmation

We will not ask you to upload a copy of the signed confirmation form; however, we will contact your confirmer using the contact details you provided to us in your initial application so please ensure these are accurate. Please ensure that your confirmer is aware that if they do not respond to our request for verification they may put your registration at risk.

REVALIDATION AND NMC FITNESS TO PRACTISE PROCESSES

187. If an employer, a nurse, midwife or nursing associate, or any other individual becomes aware of a serious concern about the fitness to practise of a nurse, midwife or nursing associate they should raise it promptly through our fitness to practise procedures. All nurses, midwives and nursing associates have a professional duty to raise a concern about the practice of a person on our register either through their employer or directly with us.

188. Revalidation does not create a new way of raising a fitness to practise concern about a nurse , midwife or nursing associate. You should not wait until a nurse, midwife or nursing associate's renewal is due before raising a concern.

For more information on how to raise a fitness to practice concern see www.nmc.org.uk/concerns-nurses-midwives/concerns-complaints-and-referrals/

189. The confirmation stage of revalidation is not for the confirmer to make a judgment as to whether a nurse, midwife or nursing associate is fit to practise but rather to confirm that they have met the revalidation requirements.

190. If you are subject to an NMC investigation, condition(s) of practice order or a caution, you are still required to apply to renew your registration as long as you fulfil all the requirements for renewal. However, You will remain subject to NMC fitness to practise processes and the outcome of those processes.

191. If you have been struck off the register, you are not able to revalidate because you are no longer on the register. You will need to apply for restoration to the register.

For more information on restoration please see www.nmc.org.uk/concerns-nurses-midwives/information-under-investigation/restoration

192. If you are suspended from the register, you are not able to revalidate during your suspension. At the end of your suspension, if your registration is effective, you will need to comply with the revalidation requirements at the time that your registration is due to be renewed. If your registration is not effective following the end of your period of suspension, you will need to follow the readmission process.

CANCELLING YOUR REGISTRATION

193. You may not want to retain one or all your registrations with us.
    - For example you may wish to cancel all of your registrations with us if you have moved abroad, have retired from practice, changed career or wish to take a break from practice due to your current health.
    - Alternatively you may wish to cancel one of your registrations if you wish to continue practising in one but not the other. For example if you are registered as both a nurse and a midwife but only wish to continue practising as a midwife you may want to cancel your nursing registration.

Please note that if you are receiving pay as a nurse, midwife or nursing associate whilst on maternity leave, sick leave or annual leave you may need to maintain your registration with us throughout this period in order to receive it. Please speak to your employer about this.

194. If you want to cancel your registration at the time of your revalidation application, you can do this online through the online revalidation application.

195. If you want to cancel your registration when you are not due to revalidate, you must submit an 'application to lapse your registration' form.

196. You will need to provide your NMC Pin, full name, contact address, the reason for cancelling and a declaration stating that you are not aware of any matter which could give rise or has given rise to a fitness to practise allegation being made against you.

Information on cancelling your NMC registration is available on our website at **www.nmc.org.uk/registration/leaving-the-register/cancelling-registration/**

197. You will not be able to practise or present yourself as a registered nurse or midwife in the UK or nursing associate in England if you are no longer registered with the NMC. It is a criminal offence if with intent to deceive (whether expressly or by implication), you falsely represent yourself as being on the register, or on part of it, possess qualifications in nursing or midwifery or to use a title to which you are not entitled.[31]

198. If you choose to cancel your registration, and later wish to resume practising as a nurse or midwife in the UK, please refer to our guidance on readmission to the register at **www.nmc.org.uk/registration/returning-to-the-register**.

199. If you apply for readmission within six months of lapsing your registration when your revalidation was due, you will have to meet some of the revalidation requirements in addition to the usual readmission requirements, unless you are able to demonstrate that exceptional circumstances apply. These additional revalidation requirements are:

- 20 of your 35 CPD hours must be participatory
- Five pieces of practice related-feedback
- Five written reflective accounts
- Reflective discussion

200. For further details of the revalidation readmission requirements and process please see **www.nmc.org.uk/registration/returning-to-the-register/readmission-register/details-of-the-requirements**.

Failure to revalidate and appeals

201. If you cannot meet the revalidation requirements, you can cancel your registration with us. By cancelling your revalidation and providing us with a reason for doing so, you are showing insight and it demonstrates to us that you are managing your situation in a responsible way. You will continue to hold a nursing, midwifery or nursing associate qualification, but will not be a registered nurse, midwife or nursing associate. When you are ready to practise again, you can apply for readmission. Information on cancelling registration and seeking readmission to the register is available on our website at **www.nmc.org.uk/registration**.

202. If you do not cancel your registration, but you fail to submit your revalidation application before the end of your three year renewal period, your registration will lapse (automatically expire). You will need to apply for readmission if you want to come back on to the register.

203. If your application for revalidation is refused because a decision is made that you have not met the revalidation requirements, you may appeal this decision within 28 days of the date on your decision letter.[32]

204. A notice of appeal should be sent to **registrationinvestigations@nmc-uk.org** made in writing and include:

- your name, address and NMC Pin
- the date, nature and other relevant details of the decision against which the appeal is brought
- a concise statement of the grounds of the appeal
- the name and address of your representative (if any) and a statement as to whether the NMC should correspond with that representative concerning the appeal instead of you
- a statement that the notice is a notice of appeal
- a signature by or on behalf of you, and
- a copy of any documents that you propose to rely on for the purposes of your appeal.[33]

Please contact us if you require support or assistance in completing this notice.

205. You do not have the right of appeal if you fail to pay the registration fee or submit a revalidation application form within the required timescale and your application to renew your registration is refused as a result.[34]

206. If your registration is not renewed because you cancelled your registration, did not complete your revalidation application, did not submit your application in time or your application for revalidation is refused, you will not be able to practise as a registered nurse, midwife or nursing associate. It is a criminal offence if you knowingly falsely represent yourself as being on the register, or on part of it or you use a title to which you are not entitled.

REFLECTIVE ACCOUNTS FORM

You **must** and/or an event or experience in your practice and how this relates to the Code. Please fill in a page for each of your reflective accounts, making sure you do not include any information that might identify a specific patient, service user, colleague or other individuals. Please refer to our guidance on preserving anonymity in the section on non-identifiable information in *How to revalidate with the NMC*.

Reflective account:
What was the nature of the CPD activity and/or practice-related feedback and/or event or experience in your practice?
What did you learn from the CPD activity and/or feedback and/or event or experience in your practice?
How did you change or improve your practice as a result?
How is this relevant to the Code? **Select one or more themes: Prioritise people – Practise effectively – Preserve safety – Promote professionalism and trust**

REFLECTIVE DISCUSSION FORM

You **must** use this form to record your reflective discussion with another NMC-registered nurse, midwife or nursing associate about your five written reflective accounts. During your discussion you should not discuss patients, service users, colleagues in a way that could identify them unless they expressly agree, and in the discussion summary section below make sure you do not include any information that might identify an individual. Please refer to the section on non-identifiable information in *How to revalidate with the NMC* for further information. For more information about reflective discussion, please refer to our guidance sheet on reflective practice for revalidation.

To be completed by the nurse, midwife or nursing associate:

Name:	
NMC Pin:	

To be completed by the nurse, midwife or nursing associate with whom you had the discussion:

Name:	
NMC Pin:	
Email address:	
Professional address including postcode:	
Contact number:	
Date of discussion:	
Short summary of discussion:	
I have discussed five written reflective accounts with the named nurse, midwife or nursing associate as part of a reflective discussion. **I agree to be contacted by the NMC to provide further information if necessary for verification purposes.**	**Signature:** **Date:**

CONFIRMATION FORM

You **must** use this form to record your confirmation.

To be completed by the nurse, midwife or nursing associate:

Name:	
NMC Pin:	
Date of last renewal of registration or joined the register:	

I have received confirmation from (select applicable):

- ☐ A line manager who is also an NMC-registered nurse, midwife or nursing associate
- ☐ A line manager who is not an NMC-registered nurse, midwife nursing associate
- ☐ Another NMC-registered nurse, midwife or nursing associate
- ☐ A regulated healthcare professional
- ☐ An overseas regulated healthcare professional
- ☐ Other professional in accordance with the NMC's online confirmation tool

To be completed by the confirmer:

Name:	
Title:	
Email address:	
Professional address including postcode:	
Contact number:	
Date of confirmation discussion:	

If you are an NMC-registered nurse, midwife or nursing associate please provide:

NMC Pin:

If you are a regulated healthcare professional please provide:

Profession:

Registration number for regulatory body:

If you are an overseas regulated healthcare professional please provide:

Country of practice:

Profession:

Registration number for regulatory body:

If you are another professional please provide:

Name of regulating body:

Registration number for regulatory body:

Confirmation checklist of revalidation requirements

Practice hours

☐ You have seen written evidence that satisfies you that the nurse, midwife or nursing associate has practised the minimum number of hours required for their registration

Continuing professional development

☐ You have seen written evidence that satisfies you that the nurse, midwife or nursing associate has undertaken 35 hours of CPD relevant to their practice as a nurse, midwife or nursing associate

☐ You have seen evidence that at least 20 of the 35 hours include participatory learning relevant to their practice as a nurse, midwife or nursing associate.

☐ You have seen accurate records of the CPD undertaken.

Practice-related feedback

☐ You are satisfied that the nurse, midwife or nursing associate has obtained five pieces of practice-related feedback.

Written reflective accounts

☐ You have seen five written reflective accounts on the nurse, midwife or nursing associate's CPD and/or practice-related feedback and/or an event or experience in their practice and how this relates to the Code, recorded on the NMC form.

Reflective discussion

☐ You have seen a completed and signed form showing that the nurse, midwife or nursing associate has discussed their reflective accounts with another NMC-registered individual(or you are an NMC-registered individual who has discussed these with the nurse, midwife or nursing associate yourself).

I confirm that I have read *Information for confirmers*, and that the above named NMC-registered nurse, midwife or nursing associate has demonstrated to me that they have met all of the NMC revalidation requirements listed above during the three years since their registration was last renewed or they joined the register as set out in *Information for confirmers*.

I agree to be contacted by the NMC to provide further information if necessary for verification purposes. I am aware that if I do not respond to a request for verification information I may put the nurse, midwife or nursing associate's registration application at risk.

Signature:

Date:

PRACTICE HOURS LOG TEMPLATE

Guide to completing practice hours log

To record your hours of practice as a registered nurse, midwife and nursing associate, please fill in a page for each of your periods of practice. Please enter your most recent practice first and then any other practice until you reach 450 hours. You can only count practice hours during the three year period since your last registration renewal or initial registration. You do not necessarily need to record individual practice hours. You can describe your practice hours in terms of standard working days or weeks. For example if you work full time, please just make one entry of hours. If you have worked in a range of settings please set these out individually. You may need to print additional pages to add more periods of practice. If you are both a nurse and a midwife or a nursing associate and nurse you will need to provide information to cover 450 hours of practice for each of these registrations.[33]

Work setting

- Ambulance service
- Care home sector
- Community setting (including district nursing and community psychiatric nursing)
- Consultancy
- Cosmetic or aesthetic sector
- Governing body or other leadership
- GP practice or other primary care
- Hospital or other secondary care
- Inspectorate or regulator
- Insurance or legal
- Maternity unit or birth centre
- Military
- Occupational health
- Police
- Policy organisation
- Prison
- Private domestic setting
- Public health organisation
- School
- Specialist or other tertiary care including hospice
- Telephone or e-health advice
- Trade union or professional body
- University or other research facility
- Voluntary or charity sector
- Other

Scope of practice

- Direct clinical care or management
- Commissioning
- Education
- Policy
- Quality assurance or inspection
- Research
- Other

Registration

- Nurse
- Midwife
- Nurse/SCPHN
- Midwife/SCPHN
- Nurse and Midwife (including Nurse/SCHPN and Midwife/SCPHN) Nurse and nursing associate (including Nurse/SCPHN

Dates	**Name and address of organisation**	**Your work setting** (choose from list above)	**Your scope of practice** (choose from list above)	**Number of hours**	**Your registration** (choose from list above)	**Brief description of your work**

CONTINUING PROFESSIONAL DEVELOPMENT (CPD)

LOG TEMPLATE

Guide to completing CPD record log

Examples of learning method

- Online learning
- Course attendance
- Independent learning

What was the topic?

Please give a brief outline of the key points of the learning activity, how it is linked to your scope of practice, what you learnt, and how you have applied what you learnt to your practice.

Link to Code

Please identify the part or parts of the Code relevant to the CPD

- Prioritise people
- Practise effectively
- Preserve safety
- Promote professionalism and trust

Please provide the following information for each learning activity, until you reach 35 hours of CPD (of which 20 hours must be participatory).
For examples of the types of CPD activities you could undertake, and the types of evidence you could retain, please refer to our guidance sheet at **www.revalidation.nmc.org.uk/download-resources/guidance-and-information**.

Dates	**Method** Please describe the methods you used for the activity.	**Topic(s)**	**Link to Code**	**Number of hours**	**Number of participatory hours**
				Total	**Total**

FEEDBACK LOG TEMPLATE

Guide to completing a feedback log

Examples of sources of feedback

- Patients or service users
- Colleagues – nurses, midwives, nursing associates other healthcare professionals
- Students
- Annual appraisal
- Team performance reports
- Serious event reviews

Examples of types of feedback

- Verbal
- Letter or card
- Survey
- Report

Please provide the following information for each of your five pieces of feedback. You should not record any information that might identify an individual, whether that individual is alive or deceased. The section on non-identifiable information in How to revalidate with the NMC provides guidance on how to make sure that your notes do not contain any information that might identify an individual.

You might want to think about how your feedback relates to the Code, and how it could be used in your reflective accounts.

Date	**Source of feedback** Where did this feedback come from?	**Type of feedback** How was the feedback received?	**Content of feedback** What was the feedback about and how has it influenced your practice?

ENDNOTES

[1] SI 2002/253 as amended.

[2] SI 2004/1767 as amended.

[3] The standards for revalidation are made under Article 19(1) of the NMC Order 2001.

[4] The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates, NMC, 2018.

[5] The Equality Act 2010 does not apply to Northern Ireland. Where the legislation is spread across several pieces of legislation, with some differences. For example Section 75 of the Northern Ireland Act 1998 also includes consideration of 'political opinion' as a protected characteristic.

[6] Disability is defined in the Act as a physical or mental impairment that has a substantial or long-term negative effect on a person's ability to do normal daily activities.

[7] Triple registration for nurse, midwife and nursing associate is also possible; this would require 1,350 practice hours.

[8] Article 10(2)(c) of the Order, Rule 13(1)(b)(ii) of the Rules.

[9] Triple registration for nurse, midwife and nursing associate is also possible; this would require 1,350 practice hours.

[10] Standards set under Article 19(3) of the Order.

[11] Standards set under Article 19(3) of the Order.

[12] Standards set under Article 19(1) of the Order.

[13] Standards set under Article 19(1) of the Order.

[14] Standards set under Article 19(1) of the Order and under rule 13(1)(b)(i) of the Rules.

[15] Standards set under Article 19(1) of the Order.

[16] Standards set under Article 19(1) of the Order.

[17] Standards set under Article 19(1) of the Order.

[18] Rule 13(1)(b)(i).

[19] Rule 13(1)(a) of the Rules.

[20] Rule 13(1)(a) and paragraph 2 of Schedule 4 of the Rules.

[21] Rule 13(1)(a) and Rules 6(6)(d) and 6(6)(e).

[22] Rule 6(6)(c).

[23] Rule 6(6)(c).

[24] Rule 6(6)(c) of the Rules.

[25] Article 10(2)(aa) of the Order and Rule 13(1)(aa) of the Rules.

[26] Paragraph 1(h)(ii) of Schedule 4 of the Rules.

[27] Rule 13(1)(d) of the Rules.

[28] We cannot extend any application beyond three months. Rule 14(5) of the Rules.

[29] Rule 13(1)(d).

[30] Article 44 of the Nursing and Midwifery Order 2001.

[31] Article 37(1)(a) of the Order.

[32] Article 37(1)(a) of the NMC Order 2001 and the Rules 19, 20 and 21 of the Registration Rules.

[33] Article 37(2) of the Order.

[34] Article 44 of the Nursing and Midwifery Order 2001.

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The nursing and midwifery regulator for England, Wales, Scotland and Northern Ireland
Registered charity in England and Wales (1091434) and in Scotland (SC038362)

NMC Nursing & Midwifery Council

Guide to support Registered Nurses and Midwifes in Raising Concerns

This document has been produced to support Nurses and Midwives in the Southern Health and Social Care Trust to Raise Concern's.

NMC

Raising and escalating concerns is a central clause in the Nursing and Midwifery Council (NMC) Code, which states nurses must *act without delay if you believe that there is a risk to patient safety or public protection* (NMC, 2018).

TRUST

The Southern Health and Social Care Trust (the Trust) wants you to feel able to raise your concerns about any issue troubling you with your managers at any time.

Step 1

- If there is immediate risk of harm, **report immediatley**
- Raise concern with your Line Manager, you can do this verbally or in writing.
- Be clear, honest and objective.

Step 2

- If unable to raise concern with Line Manager, you should rasie your concern with a designated person in your organistion.
- Make yorself aware of the Trust policy - (see link below).

Step 3

- Timescales and confidentiality agreed between yourself and manager.
- Prompt investigation takes place, which is objective and involves communication with yourself.
- Action taken as approproiate.
- Investigation manager feeds back to senior manager.

Step 4

- If appropriate ensure learning is shared
- Remember : **If in doubt, please raise it.**

'YOUR RIGHT TO RAISE A CONCERN' (WHISTLEBLOWING)

March 2022: Final

Contents

1. Foreword

We are delighted to launch the results of the second NI Cancer Patient Experience Survey (CPES). This survey asked people diagnosed with cancer and who were treated as an inpatient or a day-case between May and October 2017, about their experience of the treatment and care they received. We acknowledge the time that many patients and their families have taken to complete the survey and thank them for their valuable feedback.

We also wish to acknowledge Macmillan Cancer Support's generosity in part-funding CPES, alongside the Health and Social Care Board and the Public Health Agency, enabling us to undertake this important work and deliver a statistical analysis against the results of the 2017 Cancer Patient Experience Survey in England.

The key findings of the survey will help the Board, Agency and Trusts plan and structure future services. The survey respondents rated their care overall as 8.97 out of 10 and this provides explicit reassurance of the high-quality services provided across Northern Ireland.

However, we must not be complacent. The survey responses indicate several areas where there is room for improvement, including patients feeling they have someone to talk to about their worries and fears when they are in hospital, being provided with appropriate information regarding side effects of treatment and access to clinical trials and research. These have been identified as priorities for service development.

The Cancer Patient Experience Survey 2018 provides important information and feedback to all of those working within the health and social care sector. It enables us to understand the impact of patient care initiatives and gain insight into the improvements required in patient care. The importance of CPES as an opportunity to benchmark our service against other areas of the UK, and as a vehicle to drive service improvement, cannot be underestimated and underlines its importance and relevance as an approach, now and in the future.

We extend our gratitude to all who helped administer the survey and collect responses and most importantly, to every individual who took the time to respond. We greatly appreciate your time, commitment and honest feedback which will help us to improve the standard of cancer care provided in Northern Ireland.

Valerie Watts

Ms Valerie Watts

Heather Monteverde

Ms Heather Monteverde

2. Executive summary

Within the Health and Social Care sector the provision of high-quality cancer care is a priority. Among all providers, there is a clear focus on the provision of patient-centred services and on improving the patient experience of care. The Northern Ireland Cancer Patient Experience Survey (NI CPES) 2018 follows on from the successful delivery of the survey in Northern Ireland in 2015, and similar surveys in England, Scotland and Wales. The NI CPES 2018 gave patients the opportunity to give detailed confidential feedback on their experience of care across the five Health and Social Care Trusts in Northern Ireland, allowing comparison with the experience of cancer care in the England CPES 2017, enabling local monitoring of progress on cancer care, and providing evidence that can be used to drive quality improvements.

As with the 2015 survey, the NI CPES 2018 shows that the experience of cancer patients in Northern Ireland is generally very positive. There are encouraging improvements in a number of areas; however, there are also several areas where further work is needed to continue to improve patients' experience of cancer care in Northern Ireland. To this end, the survey provides rich data which will help to shape the future direction of cancer services in Northern Ireland.

This report provides a regional perspective on the results of the survey. Alongside this, a local report has been produced for each Trust, comparing individual Trusts' results to other Trusts and to the regional scores for Northern Ireland. Detailed survey data – including response data broken down by Trust, cancer type and different demographic and clinical variables – are also available in the NI CPES 2018 data tables.

Headline Findings

The average score for overall rating of care was 8.97 (out of a maximum of 10), significantly higher than the most recent CPES carried out in England in 2017 (8.80)[1].

Scores across many other survey questions also compared favourably to those for England in 2017. Of the 28 questions with significant differences between scores:

- NI 2018 scores were significantly higher than England 2017 scores on 20 questions;
- NI 2018 scores were significantly lower than England 2017 scores on 8 questions.

Comparing scores over time within NI also shows a generally positive picture, though these scores are not statistically comparable[2]. Of the 36 questions which were asked in both the NI CPES 2015 and the NI CPES 2018:

- On 21 questions, scores had improved between 2015 and 2018;
- On 15 questions, scores had declined between 2015 and 2018.

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[1] Comparison of this score to the previous NI CPES is not possible due to differences in how the question was asked.

[2] Due to changes in the survey questionnaire since NI CPES 2015, it has not been possible to test the statistical significance of changes in scores over time.

Areas with Strong Performance

Clinical Nurse Specialist (CNS) Provision

The most increased score since NI 2015 was regarding CNS provision. The percentage of respondents stating that they had been given the name of a CNS who would support them through their treatment increased from 72% in 2015 to 82% in 2018. However, this remains significantly lower than England 2017 (91%).

It is important to note that respondents with access to a CNS had significantly higher scores than those without on 47 of the 48 comparable questions.

Being offered a needs assessment and care plan

The proportion of patients being offered a needs assessment and care plan increased from 21% in NI 2015 to 28% in NI 2018, which is encouraging.

As with CNS provision, respondents who were offered a needs assessment and care plan reported significantly higher scores than those who were not on 46 of the 50 comparable questions.

Provision of written information

A higher proportion of patients received written information about the type of cancer they had in 2018 compared to 2015 (from 64% to 69%), but this is significantly lower than England 2017 (73%).

Being asked preferred name

The proportion of patients being asked by doctors and nurses what name they preferred to be called by had increased from 59% in NI 2015 to 69% in NI 2018. The England 2017 score was also 69%.

Enough nurses being on duty

The proportion of patients who thought there were enough nurses on duty to care for them increased from 60% in NI 2015 to 67% in NI 2018. The England 2017 score was 66%.

Other aspects of inpatient experience

On several other questions, many relating to inpatient care, scores were significantly higher than England 2017 and higher than NI 2015:

- Patients being given information about how to get financial help or benefits: 66% in NI 2015, 58% in England 2017 and 68% in NI 2018;
- Patients having confidence and trust in the ward nurses treating them: 78% in NI 2015, 76% in England 2017 and 81% in NI 2018;
- Patients' families or someone close to them being able to talk to a doctor if they wanted to: 69% in NI 2015, 73% in England 2017 and 76% in NI 2018.

Areas for Improvement

While findings indicate a positive overall picture of cancer patient experience in Northern Ireland, there are some clear areas where there is scope for improvement.

Finding someone in hospital to talk to about worries and fears

Despite increasing CNS provision and strong performance across other aspects of inpatient care, there was a reduction in scores between 2015 and 2018 in people finding someone on the hospital staff to talk to about their worries and fears during their hospital visit(s) (from 70% to 53%). However, the NI 2018 score is the same as England 2017.

Side effects

The proportion of patients who felt that potential side effects had been adequately explained to them was lower than England 2017 and had decreased within NI since 2015:

- Patients having possible side effects of treatment explained to them in an understandable way: 78% in NI 2015, 73% in England 2017 and 72% in NI 2018;
- Patient being told about possible future side effects of treatment (late effects): 58% in NI 2015, 56% in England 2017 and 54% in NI 2018.

Cancer research / clinical trials

Fewer patients reported being asked about taking part in cancer research / clinical trials in 2018 (15%) than in 2015 (18%). This is a concern and, notably, the equivalent – though not directly comparable – score in the England CPES 2017 was also markedly higher at 31%.

Primary care

There was a considerable drop in the proportion of patients who felt that primary care staff did everything that they could to support them while they were having their cancer treatment: 77% in NI 2015, 60% in England 2017 and 71% in NI 2018.

The Way Forward

Within cancer services there is ongoing work taking place looking at the delivery of non-surgical oncology treatments, in line with the regional transformation agenda and there has been significant patient engagement throughout this project. The NI CPES 2018 results will also contribute to influencing how these services can be delivered more effectively with continued patient centred care.

The NI 2015 survey highlighted the importance of the CNS role within patient experience.

Since 2014 we have seen an additional 60 CNS recruited across NI, largely supported by the CNS workforce expansion plan, supported by the Health and Social Care Board and Macmillan Cancer Support.

The expansion plan is ongoing with further CNS recruitment planned through to 2021.

There is recognition that there needs to be increased engagement between primary care and secondary care to enhance care for patients with cancer. The NI Cancer Network in conjunction with Macmillan Cancer Support have appointed a Primary Care Director in December 2018 to progress work in this area.

Furthermore, as a result of the NI CPES 2018 survey, there will be an overarching regional action plan and local Trust action plans to address:

- Finding someone in hospital to talk to about worries and fears;
- The provision of information on side effects and late effects;
- Increasing the numbers of patients being offered to take part in clinical trials.

3. Methodology

3.1. Fieldwork

Survey packs (including cover letter, questionnaire, and information sheet) were sent by post in June 2018, with two reminder letters sent during July 2018 to those who had yet to respond. Survey packs included an option to complete online, and details of a free telephone line which patients could call to ask questions, complete the questionnaire verbally, or to access an interpreting service. Survey packs were prepared by Quality Health, couriered to Trust staff and posted to patients.

The inclusion criteria were that patients had to:

- Be 16 or over
- Have a confirmed primary diagnosis of cancer, with an International Classification of Disease (ICD10) code of C00-C99 or D05;
- Have been discharged from a hospital within the Trust (inpatient or day case) between 1st May and 31st October 2017.

Patients were excluded if they:

- Had a primary diagnosis of ICD10 code C44 or C84;
- Were deceased at the time of posting surveys;
- Received their treatment privately;
- Were current inpatients at the time of posting surveys;
- Only attended as an outpatient during the sample period;
- Did not have a valid Northern Ireland postal address.

The survey population included all those with rarer cancers as well as patients in the "Big 4" cancer groups – i.e. breast, prostate, lung, and colorectal/lower GI.

Patients eligible for the survey were identified from the Trusts' Patient Administration Systems. Trust samples and patient lists were then checked rigorously for duplicates to ensure that patients did not receive multiple copies of the questionnaire.

Deceased checks on Trust samples were carried out on at least three occasions during the fieldwork, to ensure that the numbers of deceased patients receiving survey packs or reminder letters was reduced to an absolute minimum. This process was undertaken by the Business Services Organisation.

3.2. Response rates

The response rate to the NI CPES 2018 (57% or almost 3,500 people), while lower than the rate for the NI CPES in 2015 (62%), compares favourably with the response rate for other NHS surveys and is similar to the rate achieved in the 2017 CPES in England (63%).

It is also encouraging that a high proportion of respondents (72% or almost 2,300 people) have again indicated that they would be willing to be contacted about participating in further surveys designed to understand their experiences of cancer services.

3.3. Analysis

Percentage scores

The findings from the survey have been summarised as the percentage of patients who reported a positive experience in response to each question. For example, the percentage scores represent the proportion of patients who were given information about support or self-help groups for people with cancer by staff or the proportion of patients who said that groups of doctors and nurses did NOT talk in front of them as if they were not there. Neutral responses, such as “Don’t know / can't remember” and “I did not need an explanation” have not been included in the denominator when computing scores.

The higher the score the better the performance. Some scores relate only to one care setting (e.g. acute) but others represent performance across a pathway involving primary and community care in addition to acute care.

Scoring for question 62 - in which patients were asked to give an 'overall rating' of their cancer care - is based on an average score out of 10, rather than a ‘percentage positive’.

Most of the questions in the NI CPES 2018 are in the same format as and have similar wording to the 2017 CPES for England, and the scoring system for them is identical, thus enabling robust comparisons to be made.

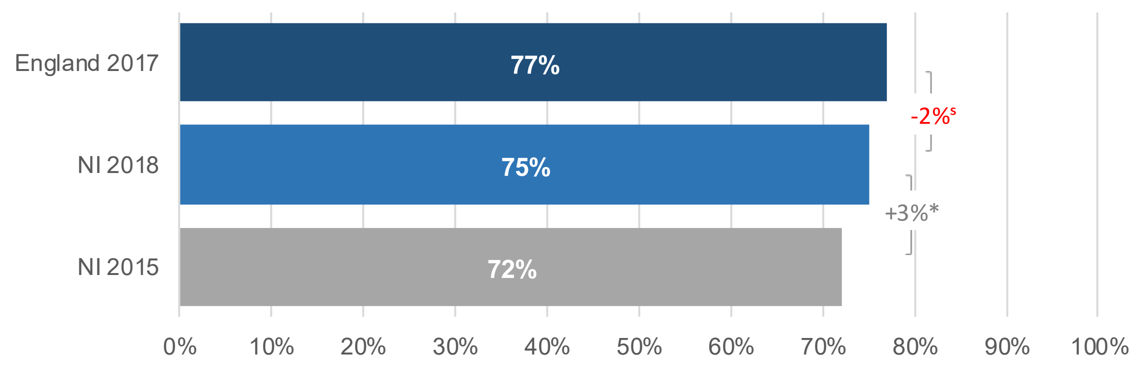
Only questions that have been designated a score have been included in this report. Questions which aim only to clarify the respondent's treatment pathway or to direct them through the questionnaire (for example, question 5 “Did the test(s) take place at the hospital named on the letter that came with this questionnaire?”) are not included in the report.

Significance tests

Significance tests have been used to establish whether there are statistically significant differences between responses from different groups of respondents on a particular question.

In this report, we have tested the significance of differences between scores on the NI CPES 2018 and the England CPES 2017. Among respondents to the NI CPES 2018, significance has also been tested for between different groups of patients based on demographic factors (gender, age, ethnicity, deprivation and employment status) and clinical factors (cancer type, cancer status, co-morbidities, access to Clinical Nurse Specialists and access to needs assessment/care plan) – see Chapter 6.

3.4. Sample Chart



+%^{s} / -%^{s} *Indicates a positive or negative significant difference between the NI 2018 and England 2017 scores*

* *NI 2015 scores provided for information only, comparison not statistically valid*

In the chart above the top line represent the score for the England 2017 survey, the middle line is the score for the Northern Ireland 2018 survey and the bottom line is the score for the Northern Ireland 2015 survey. The score for each survey is shown on the relevant bar, and where there is no comparable question there will be a placeholder graphic stating this:

No comparable England data

No comparable 2015 data

To the right of each bar is an indicator of the difference in scores between the relevant surveys, where applicable.

When comparing the England 2017 survey to the Northern Ireland 2018 survey:

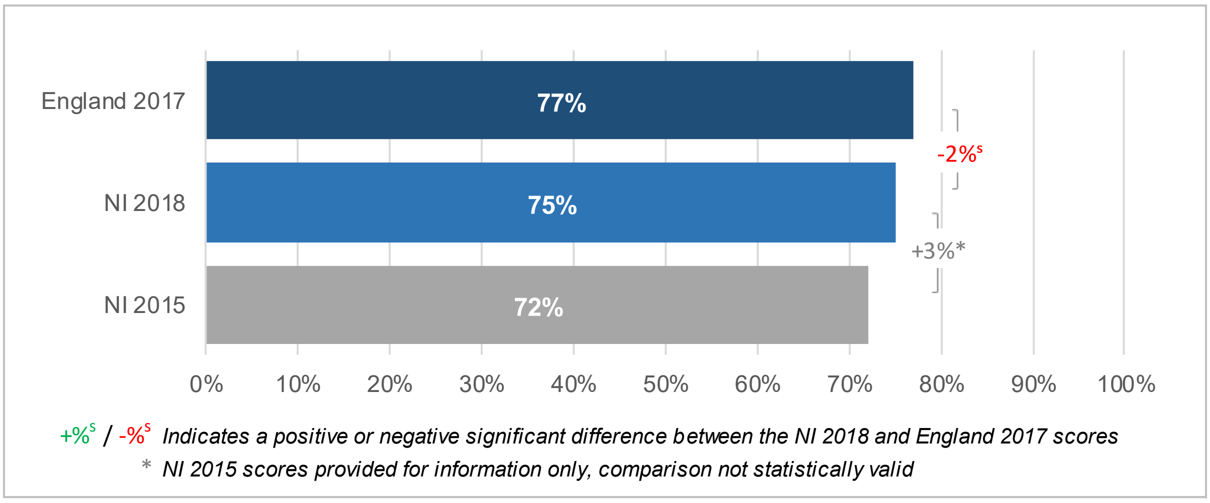
- if this indicator is coloured green, it means that the Northern Ireland 2018 score is significantly more positive than the England 2017 score.
- if this indicator is coloured red (as per the example above) it means that the Northern Ireland 2018 score is significantly more negative than the England 2017 score.
- if this indicator is coloured grey, it means that the Northern Ireland 2018 score is neither significantly more positive nor negative than the England 2017 score.

Please note that Northern Ireland 2015 scores are not comparable to Northern Ireland 2018 scores, due to changes in the sampling timeframe and questionnaire design. Northern Ireland 2015 scores are therefore shown for information purposes only.

4. Survey results

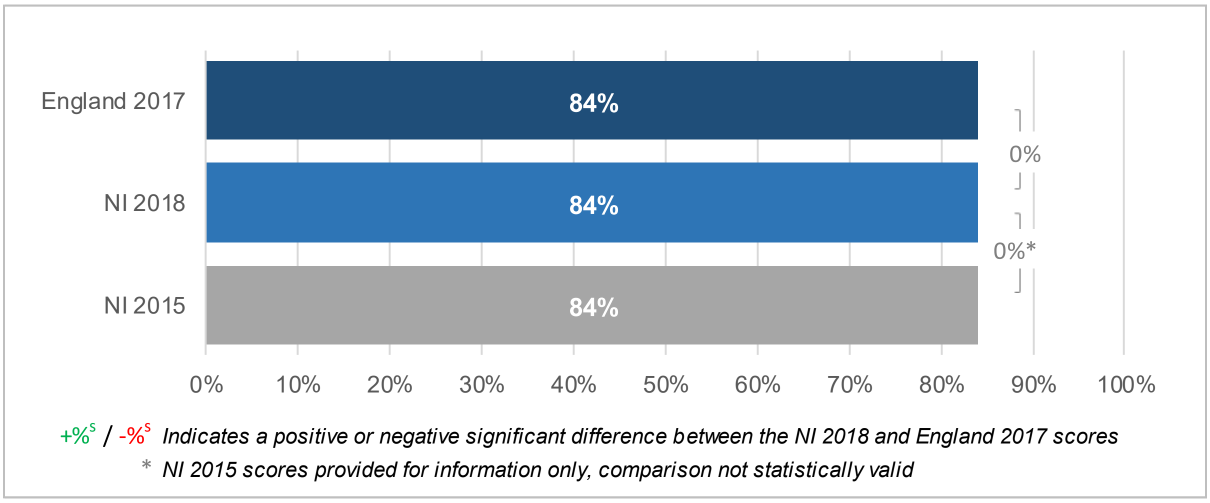
4.1. Before Your Diagnosis

Q1. Patient saw GP once or twice before being told they had to go to the hospital



75% of patients saw their GP either once or twice before being told they needed to go to the hospital about their cancer. This is significantly lower than the England 2017 score of 77%. However, it is an improvement of 3% on the Northern Ireland 2015 score of 72%.

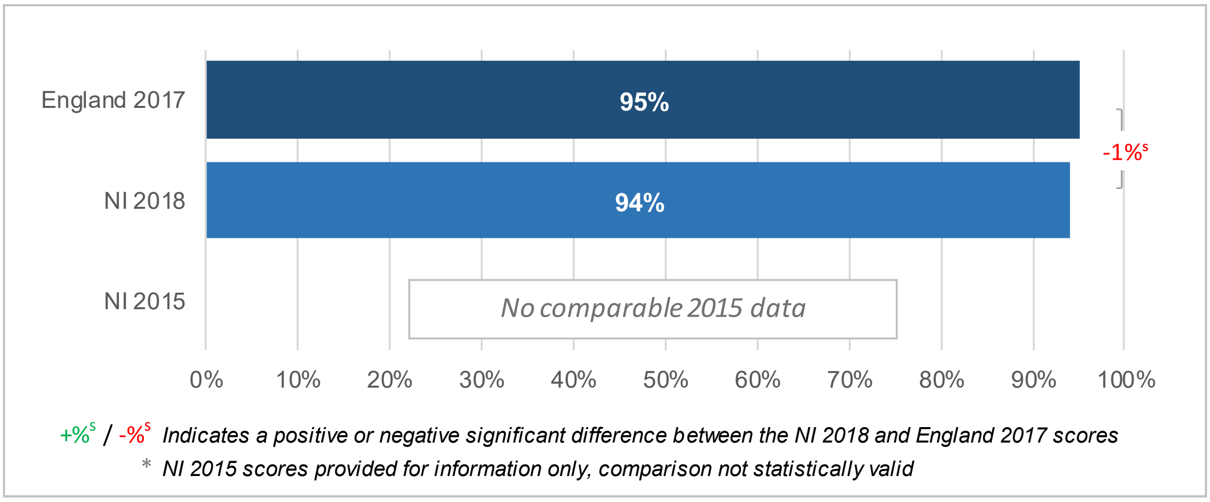
Q2. Patient thought they were seen as soon as necessary for their first appointment



84% of patients felt they were seen for their first appointment with a hospital doctor as soon as they thought necessary. This is the same as the England 2017 score of 84%. It is also the same as the Northern Ireland 2015 score of 84%.

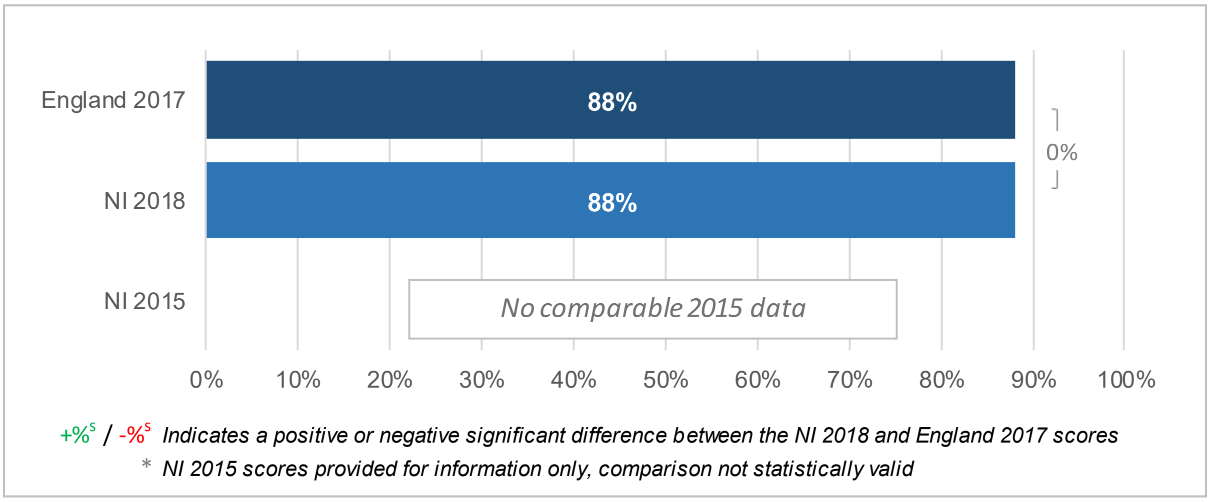
4.2. Diagnostic Tests

Q6. Patient had all the information needed about their test beforehand



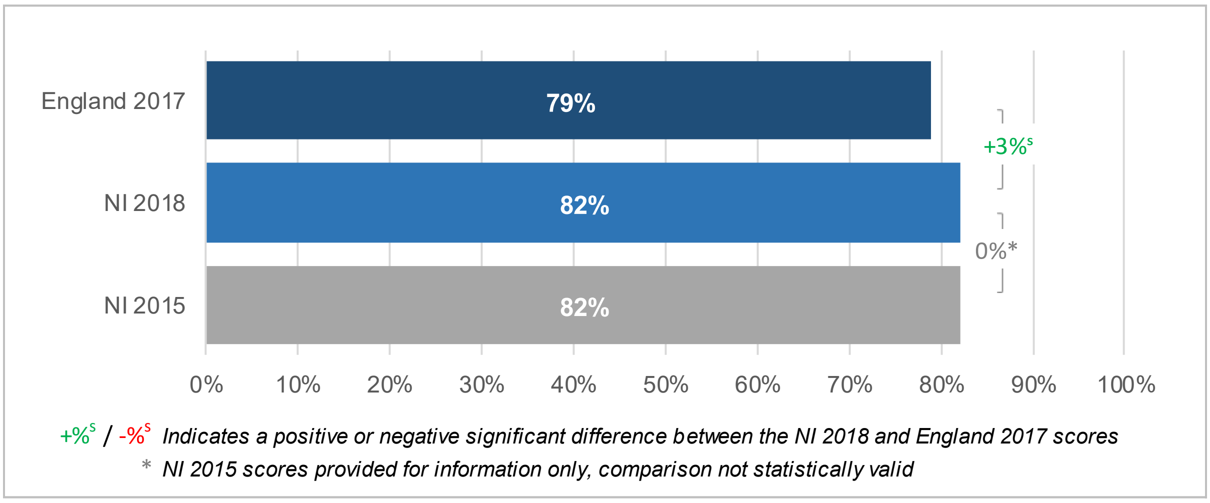
94% of patients had all the information they needed about their test before it took place. This is significantly lower than the England 2017 score of 95%. This was not a question asked on the Northern Ireland 2015 survey.

Q7. Patient thought length of time for test to be done was about right



88% of patients thought the length of time they had to wait for their test to be done was about right. This is the same as the England 2017 score of 88%. This was not a question asked on the Northern Ireland 2015 survey.

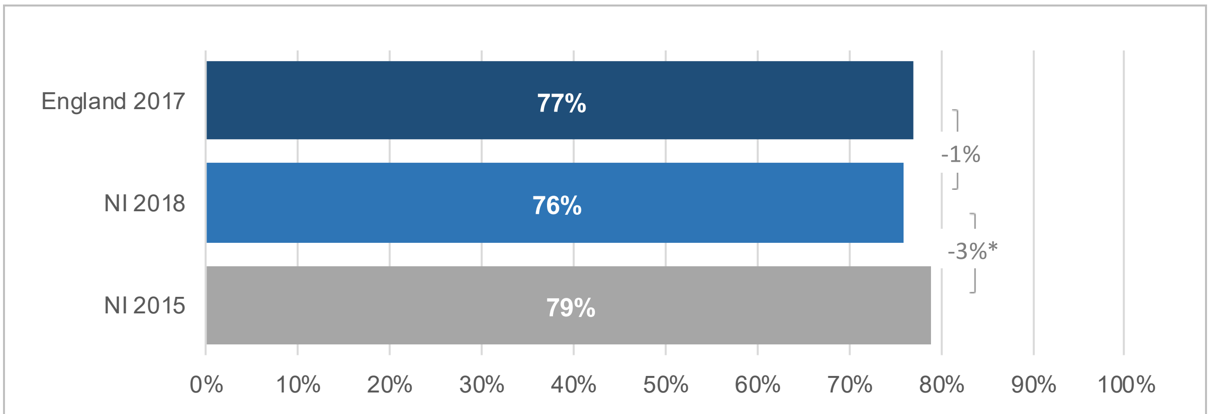
Q8. Results of test were explained in a way the patient completely understood



82% of patients thought the results of their tests were explained in a way they could completely understand. This is significantly higher than the England 2017 score of 79%. It is the same as the Northern Ireland 2015 score of 82%.

4.4. Finding Out What Was Wrong with You

Q9. Patient had been told they could bring a family member or friend when they were first told about cancer

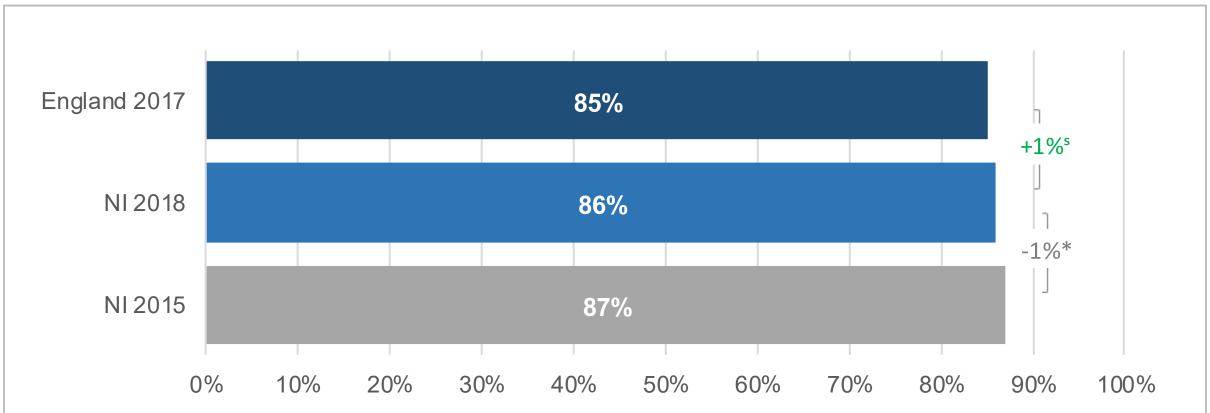


+%ˢ / -%ˢ *Indicates a positive or negative significant difference between the NI 2018 and England 2017 scores*

* *NI 2015 scores provided for information only, comparison not statistically valid*

76% of patients were told they could bring a family member or friend with them when they were first told they had cancer. This is lower than the England 2017 score of 77%. Additionally, it is a decrease of 3% on the Northern Ireland 2015 score of 79%.

Q10. Patient thought they were told they had cancer in a sensitive manner



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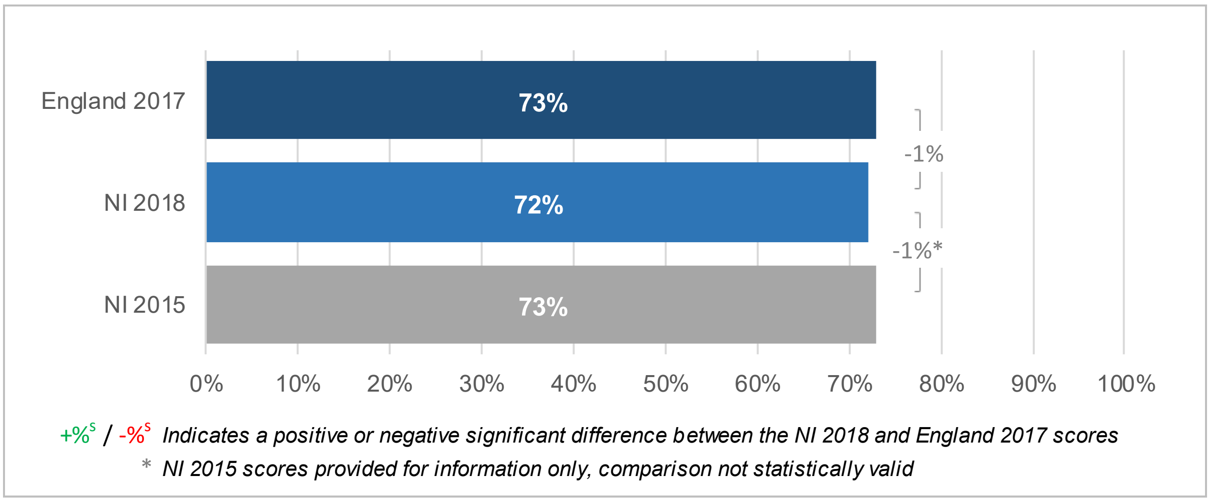
* *NI 2015 scores provided for information only, comparison not statistically valid*

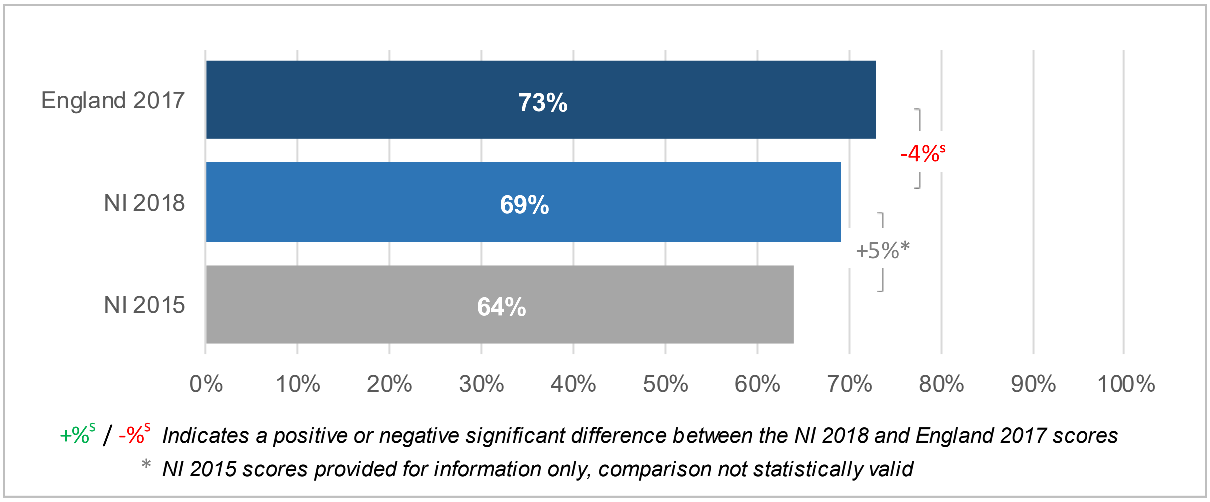
86% of patients thought that they had been told they had cancer in a sensitive manner. This is significantly higher than the England 2017 score of 85%. However, it is a decline of 1% on the Northern Ireland 2015 score of 87%.

Q11. Patient completely understood the explanation of what was wrong with them



72% of patients completely understood the explanation of what was wrong with them. This is lower than the England 2017 score of 73%. Additionally, it is a decrease of 1% on the Northern Ireland 2015 score of 73%.

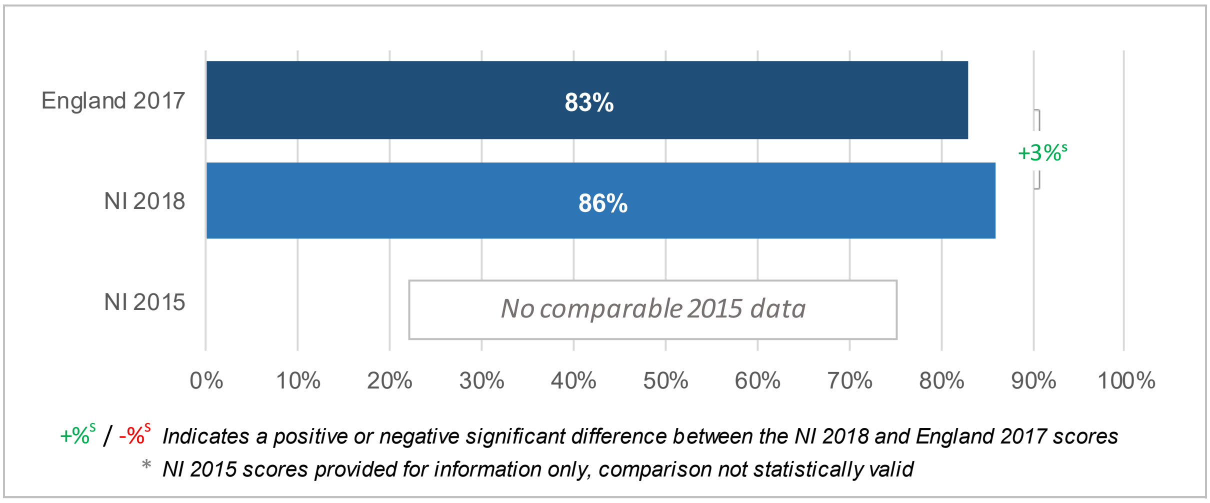
Q12. Patient was given easy to understand written information about the type of cancer they had when they were first told they had cancer



69% of patients were given written information about the type of cancer they had and found it easy to understand. This is significantly lower than the England 2017 score of 73%. However, it is an improvement of 5% on the Northern Ireland 2015 score of 64%.

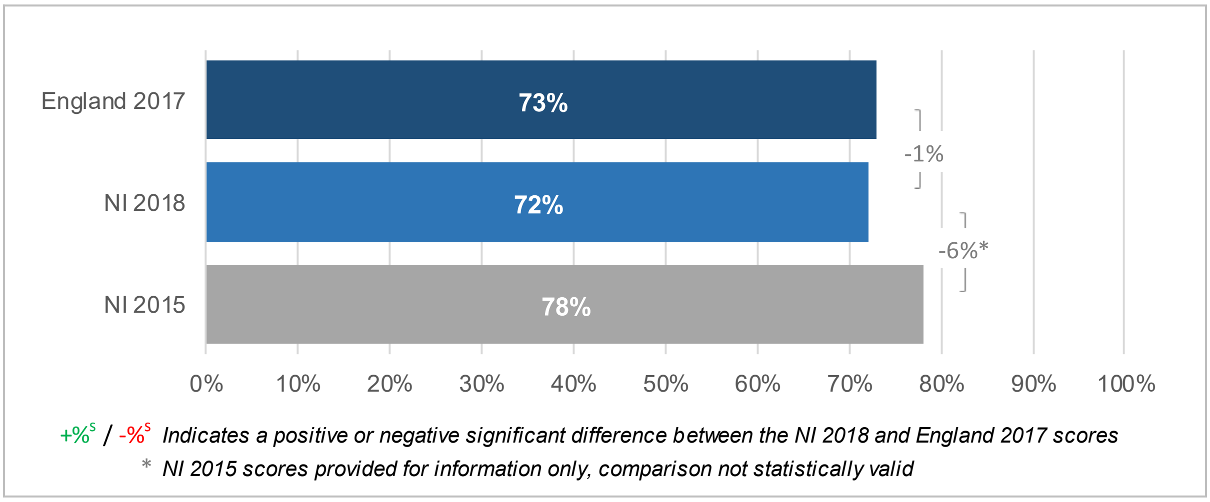
4.6. Deciding the Best Treatment for You

Q13. Treatment options were completely explained to patient before treatment started



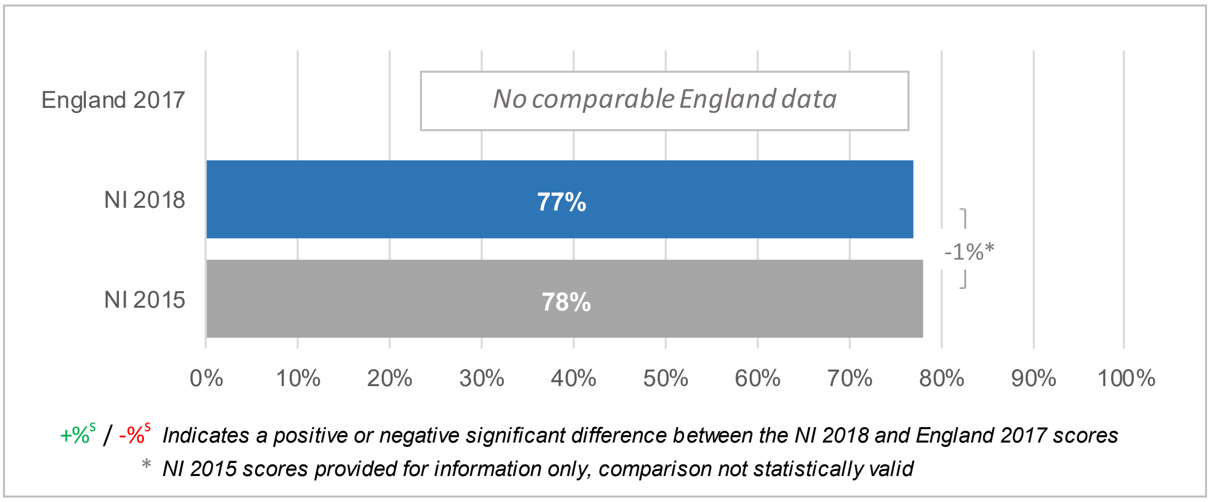
86% of patients felt the options for treatment were completely explained to them, before treatment started. This is significantly higher than the England 2017 score of 83%. This was not a question asked on the Northern Ireland 2015 survey.

Q14. Side effects of treatment were definitely explained in a way the patient could understand



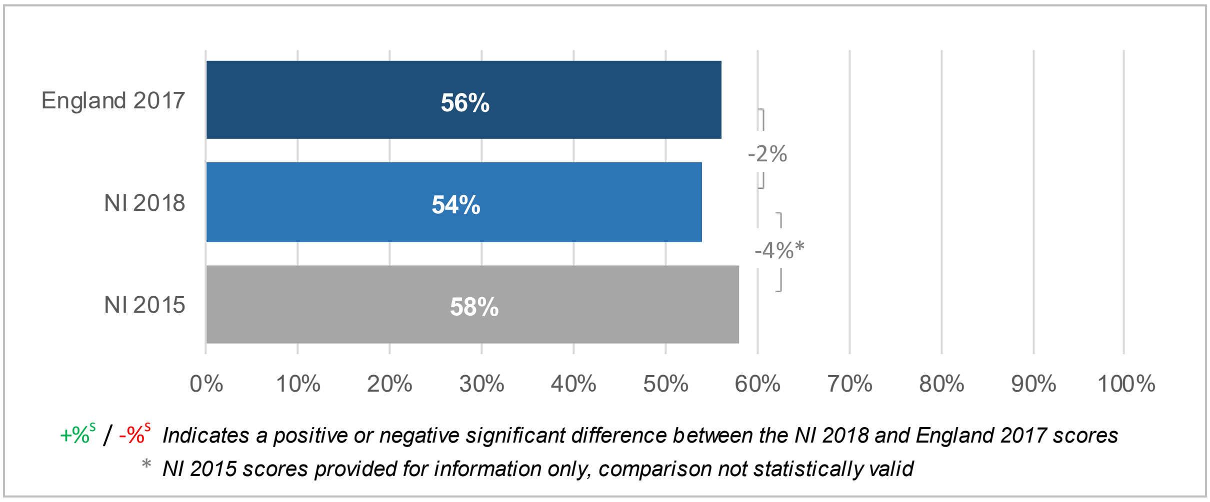
72% of patients definitely felt the possible side effects of treatment(s) were explained in a way they could understand. This is lower than the England 2017 score of 73%. Additionally, it is a decrease of 6% on the Northern Ireland 2015 score of 78%.

Q15. Patient was given easy to understand written information regarding side effects



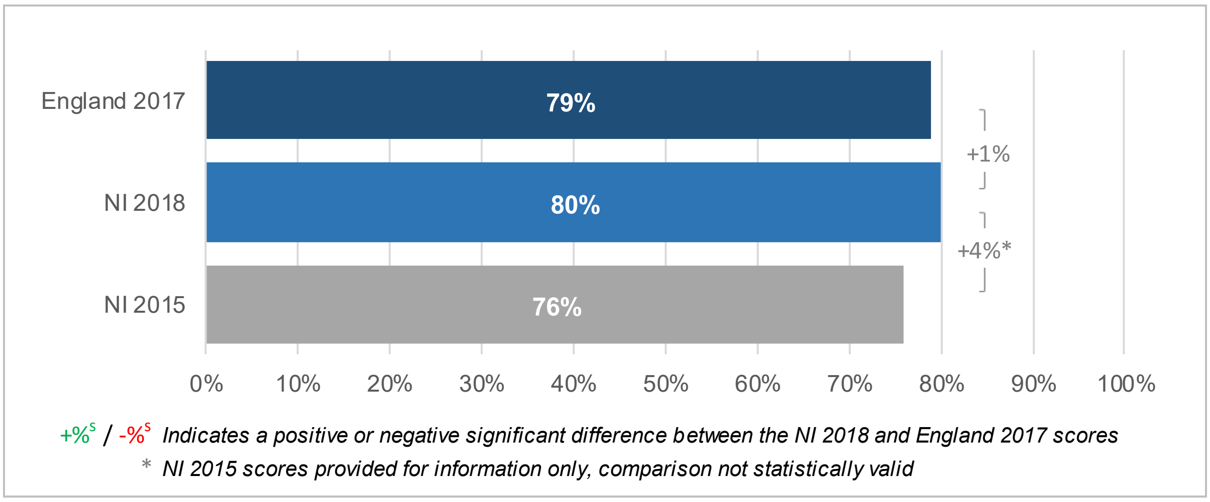
77% of patients were given written information about the side effects of treatment(s) before treatment started and found it easy to understand. This was not a question asked on the England 2017 survey. However, it is a decline of 1% on the Northern Ireland 2015 score of 78%.

Q16. Patient was definitely told about future side effects before treatment



54% of patients were definitely told before treatment about any side effects of treatment(s) that could affect them in the future. This is lower than the England 2017 score of 56%. Additionally, it is a decrease of 4% on the Northern Ireland 2015 score of 58%.

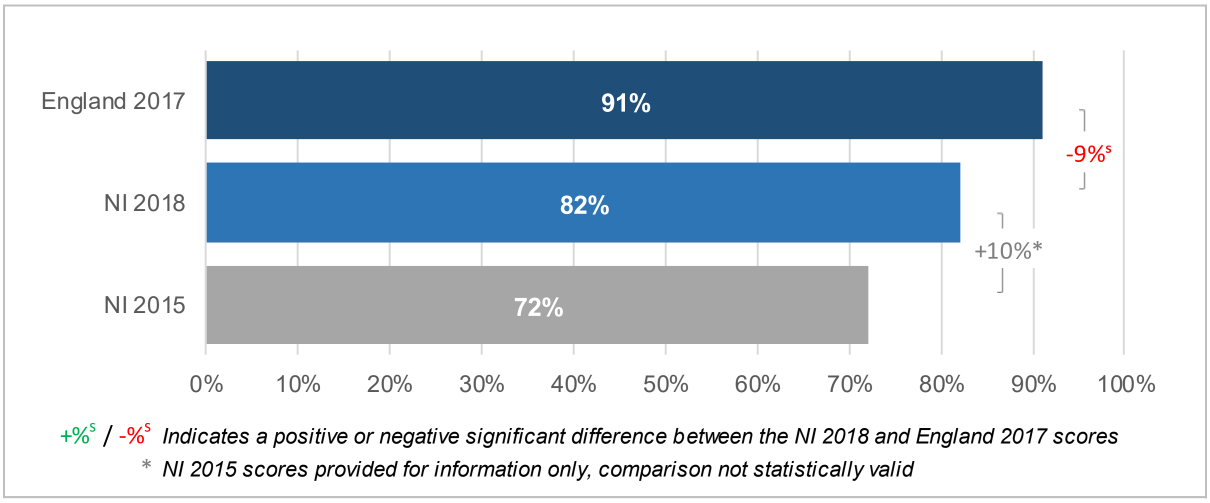
Q17. Patient was definitely involved as much as they wanted to be in decisions about their care



80% of patients felt they were definitely involved as much as they wanted to be in decisions about their care and treatment. This is higher than the England 2017 score of 79%. Additionally, it is an improvement of 4% on the Northern Ireland 2015 score of 76%.

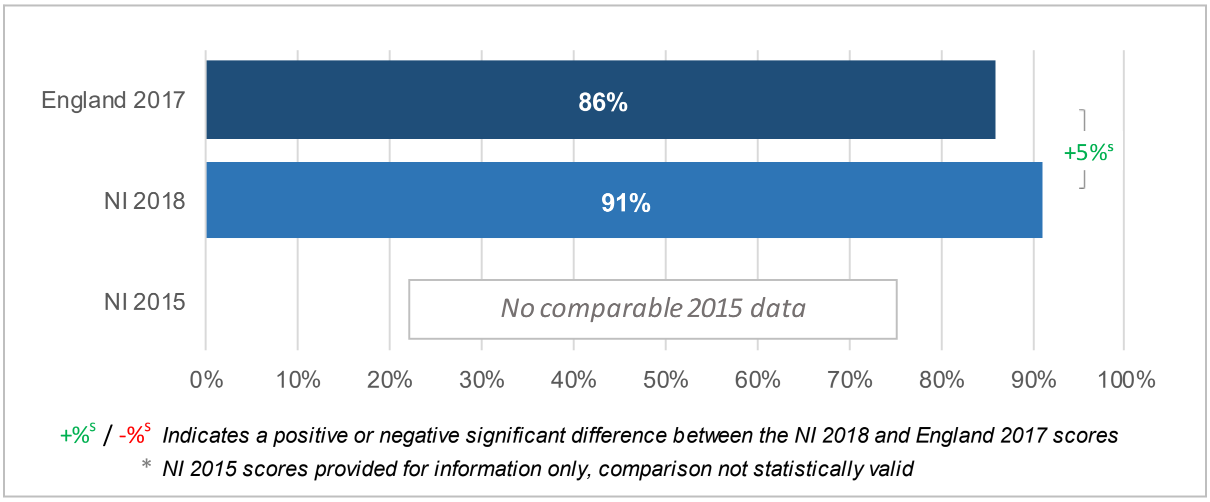
4.7. Clinical Nurse Specialist

Q18. Patient was given the name of a Clinical Nurse Specialist who would support them through treatment



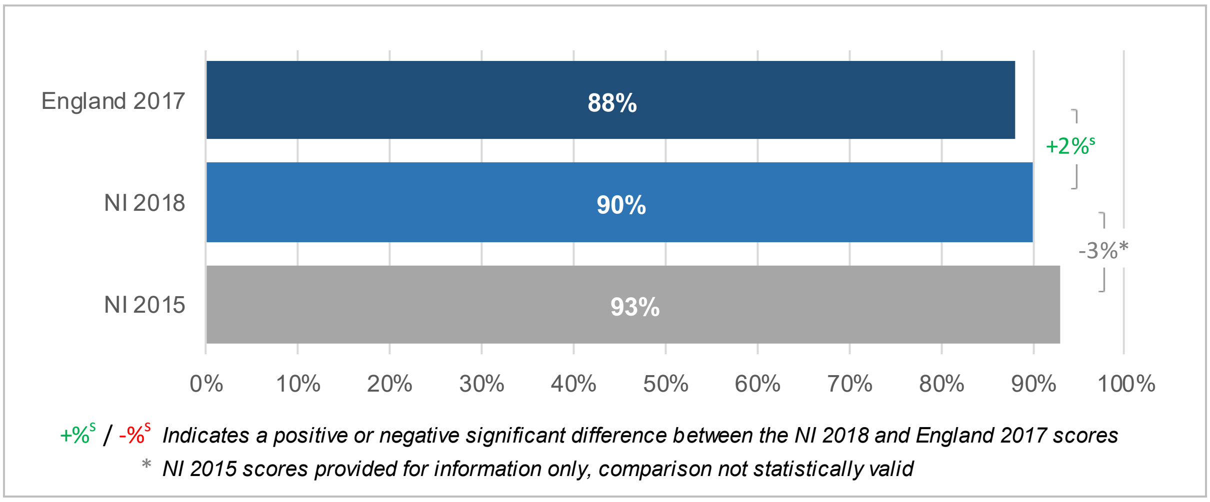
82% of patients were given the name of a Clinical Nurse Specialist. This is significantly lower than the England 2017 score of 91%. However, it is an improvement of 10% on the Northern Ireland 2015 score of 72%.

Q19. Patient found it very easy or quite easy to contact their Clinical Nurse Specialist



91% of patients found it either 'Quite easy' or 'Very easy' to contact their Clinical Nurse Specialist when required. This is significantly higher than the England 2017 score of 86%. This was not a question asked on the Northern Ireland 2015 survey.

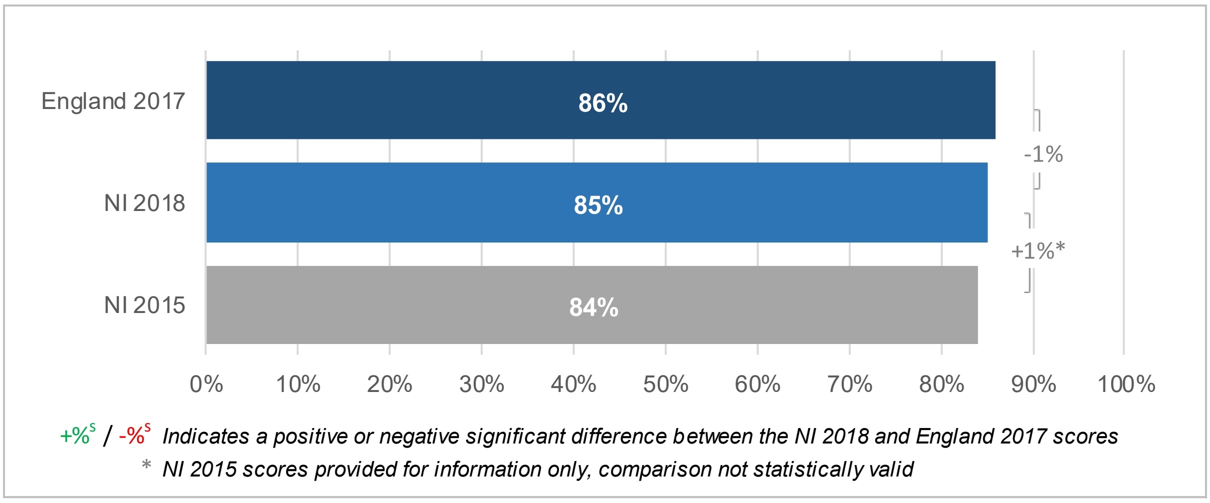
Q20. Patient was able to get answers they could understand from their Clinical Nurse Specialist all or most of the time



90% of patients felt they got answers they could understand all or most of the time, when they had an important question for their Clinical Nurse Specialist. This is significantly higher than the England 2017 score of 88%. However, it is a decline of 3% on the Northern Ireland 2015 score of 93%.

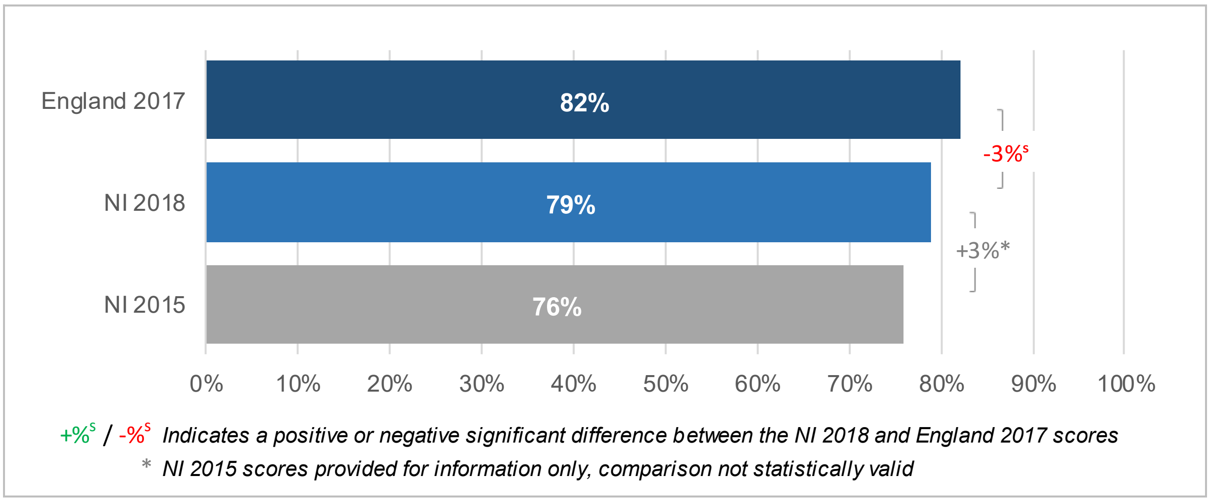
4.8. Support for People with Cancer

Q21. Patient was given information by hospital staff about support or self-help groups



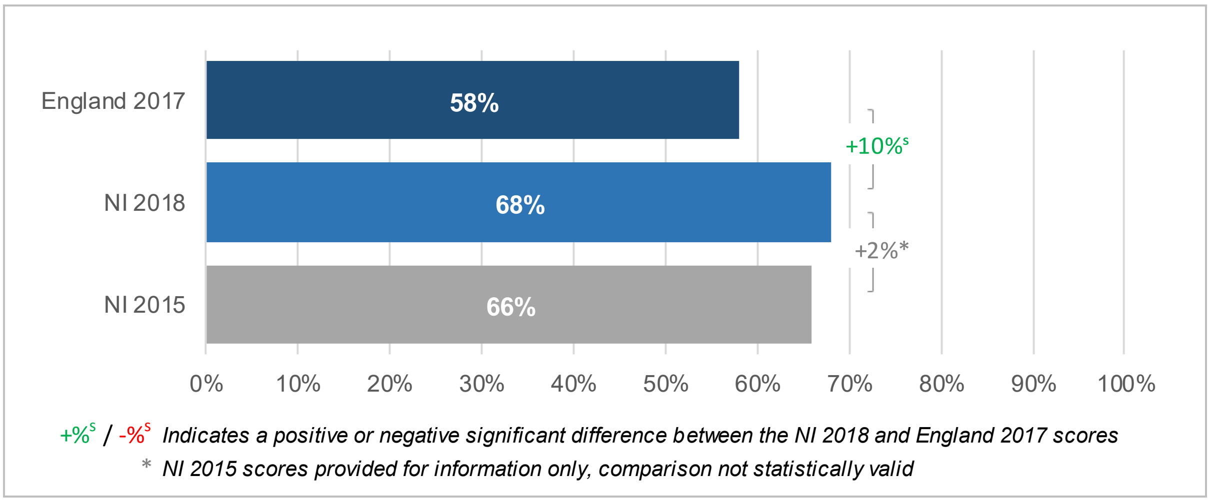
85% of patients were given information about support or self-help groups for people with cancer by hospital staff. This is lower than the England 2017 score of 86%. However, it is an improvement of 1% on the Northern Ireland 2015 score of 84%.

Q22. Staff discussed / gave patient information about the impact cancer could have on their work-life or education



79% of patients either discussed with hospital staff or were given information about the impact cancer could have on their work-life or education. This is significantly lower than the England 2017 score of 82%. However, it is an improvement of 3% on the Northern Ireland 2015 score of 76%.

Q23. Hospital staff gave patient information about financial help and benefits available



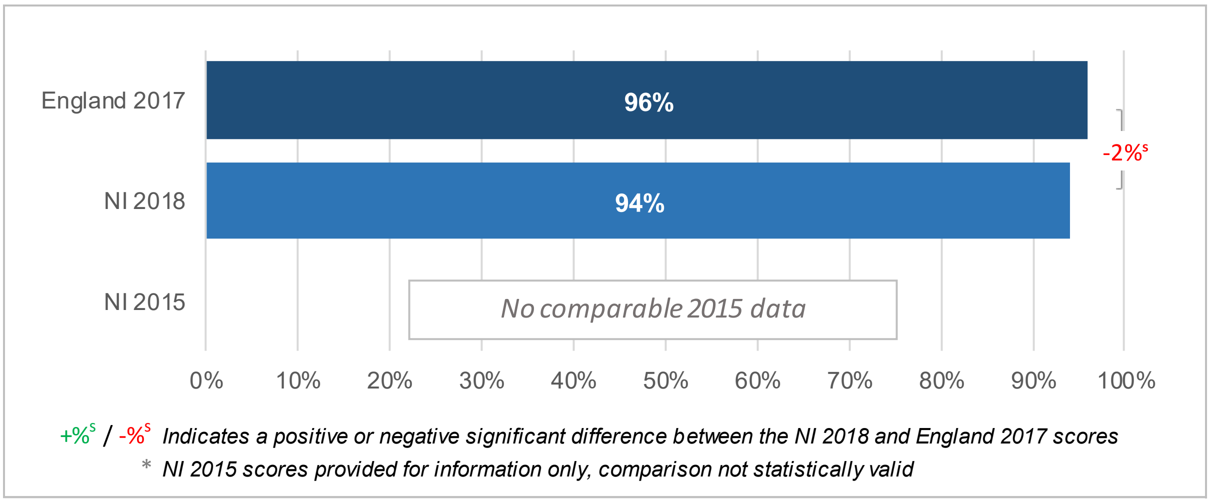
+%^{s} / -%^{s} *Indicates a positive or negative significant difference between the NI 2018 and England 2017 scores*

* *NI 2015 scores provided for information only, comparison not statistically valid*

68% of patients were given information by hospital staff about how to get financial help or benefits they may be entitled to. This is significantly higher than the England 2017 score of 58%. Additionally, it is an improvement of 2% on the Northern Ireland 2015 score of 66%.

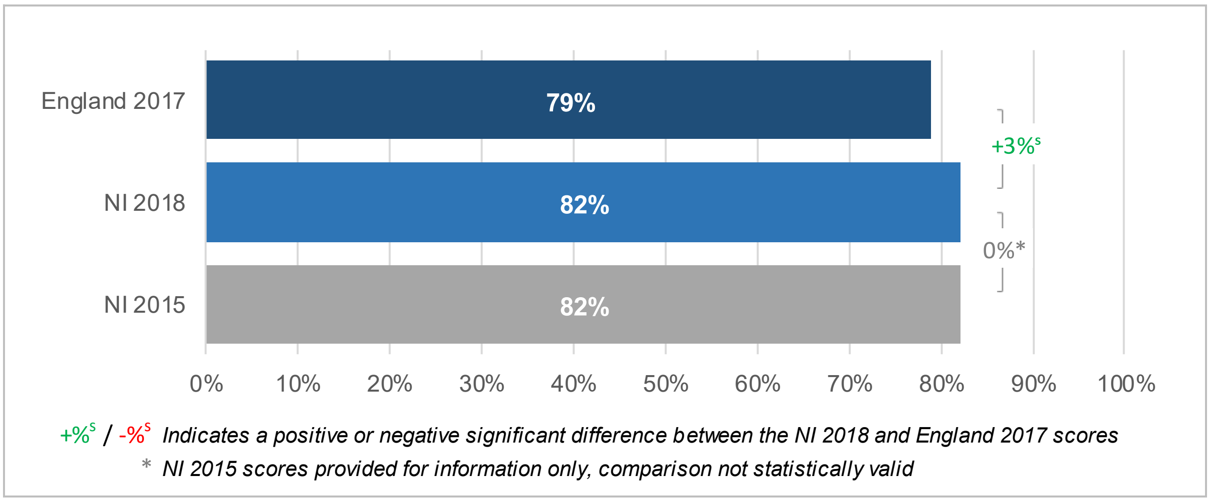
4.9. Operations

Q26. Patient had all the information they needed about their operation beforehand



94% of patients were given all the information required about their operation, before their operation. This is significantly lower than the England 2017 score of 96%. This was not a question asked on the Northern Ireland 2015 survey.

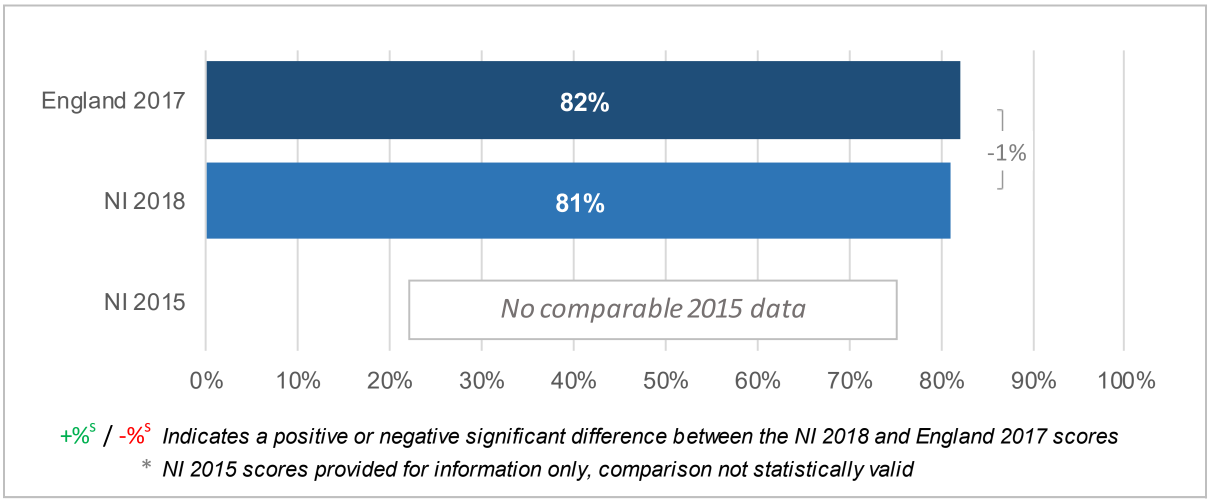
Q27. A member of staff completely explained outcome of the operation to the patient in a way they could understand



82% of patients completely understood the explanation given by a member of staff about how their operation had gone. This is significantly higher than the England 2017 score of 79%. It is the same as the Northern Ireland 2015 score of 82%.

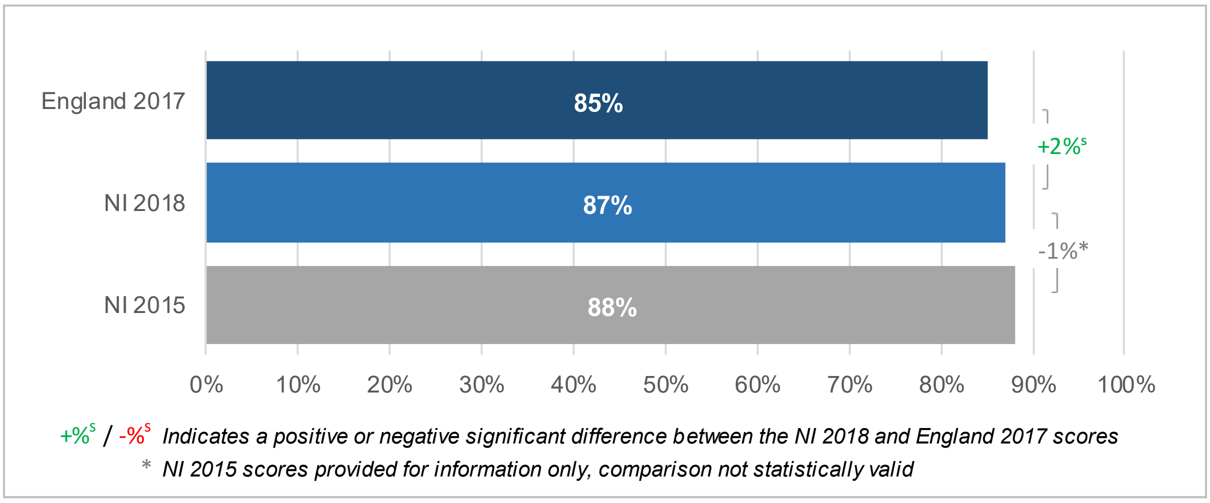
4.10.Hospital Care as An Inpatient

Q30. Patient thought no doctors or nurses talked in front of them as if they weren't there



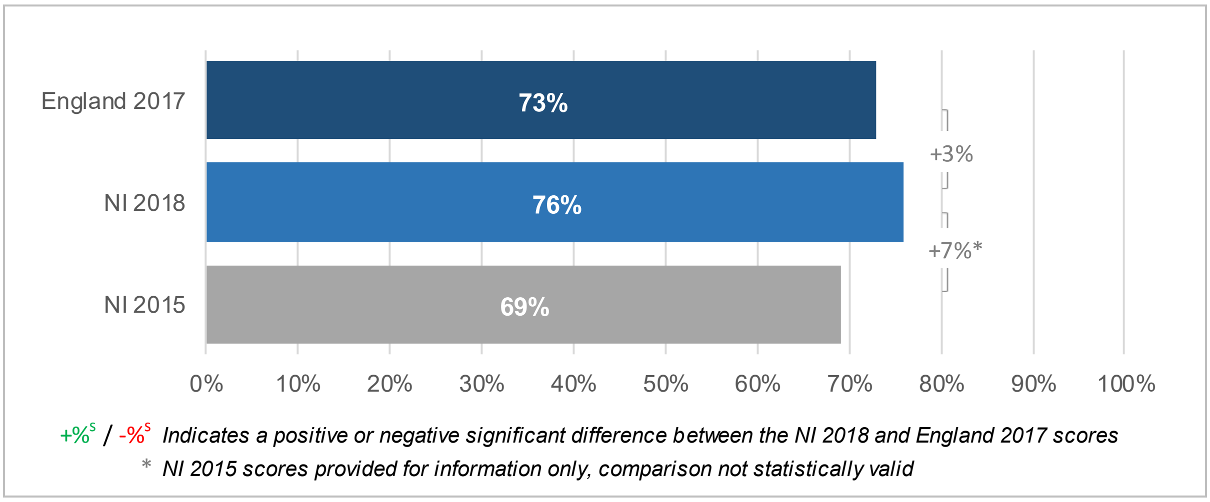
81% of patients said that no groups of doctors or nurses ever talked in front of them as if they weren't there. This is lower than the England 2017 score of 82%. This was not a question asked on the Northern Ireland 2015 survey.

Q31. Patient had confidence and trust in all of the doctors treating them



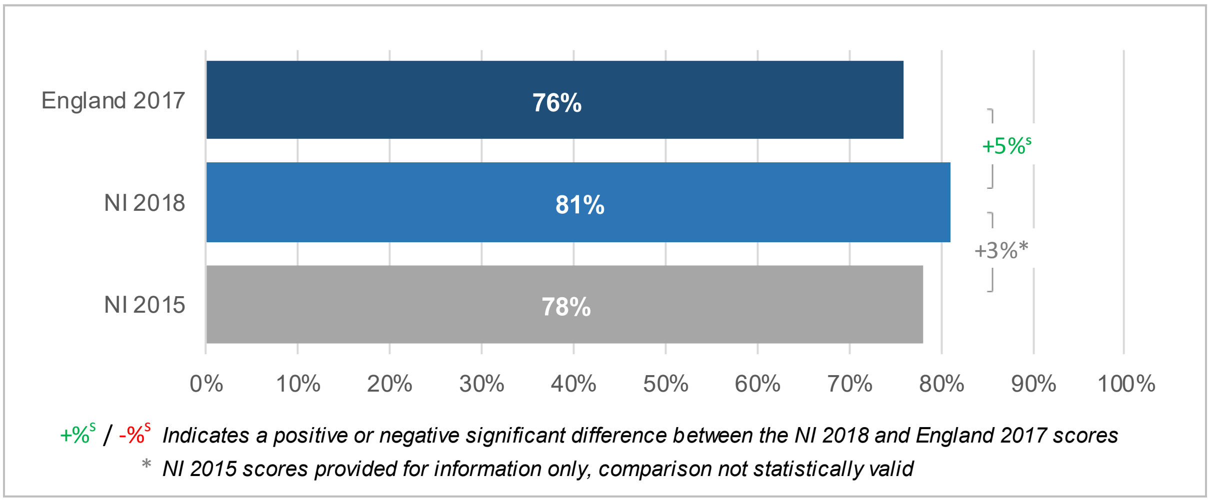
87% of patients had confidence and trust in all the doctors who treated them. This is significantly higher than the England 2017 score of 85%. However, it is a decline of 1% on the Northern Ireland 2015 score of 88%.

Q32. Family or friends of the patient were definitely able to talk to a doctor if they wanted to



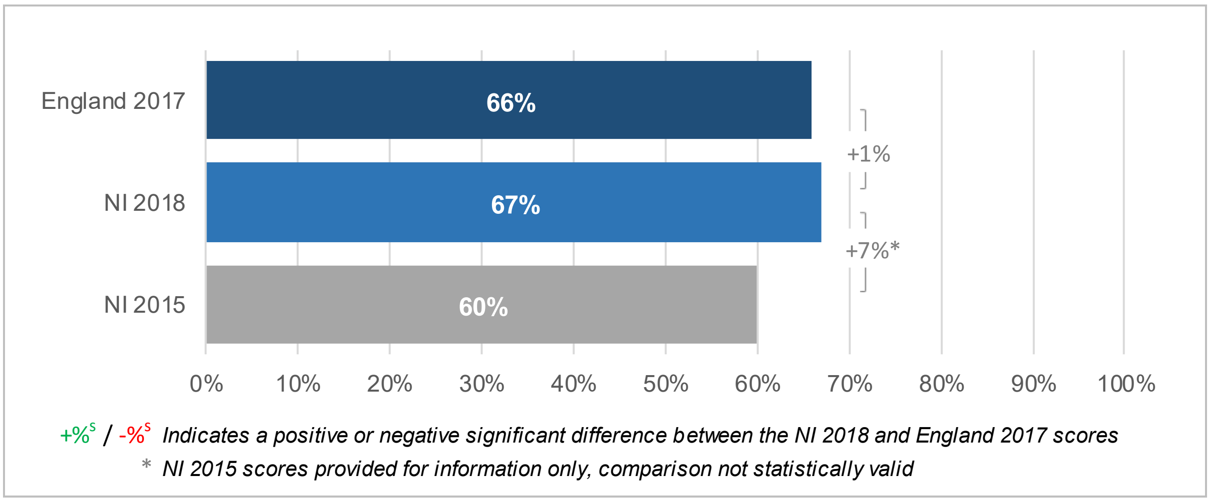
76% of patients said that if their family or someone else close to themselves wanted to talk to a doctor, they were definitely able to. This is higher than the England 2017 score of 73%. Additionally, it is an improvement of 7% on the Northern Ireland 2015 score of 69%.

Q33. Patient had confidence and trust in all of the nurses treating them



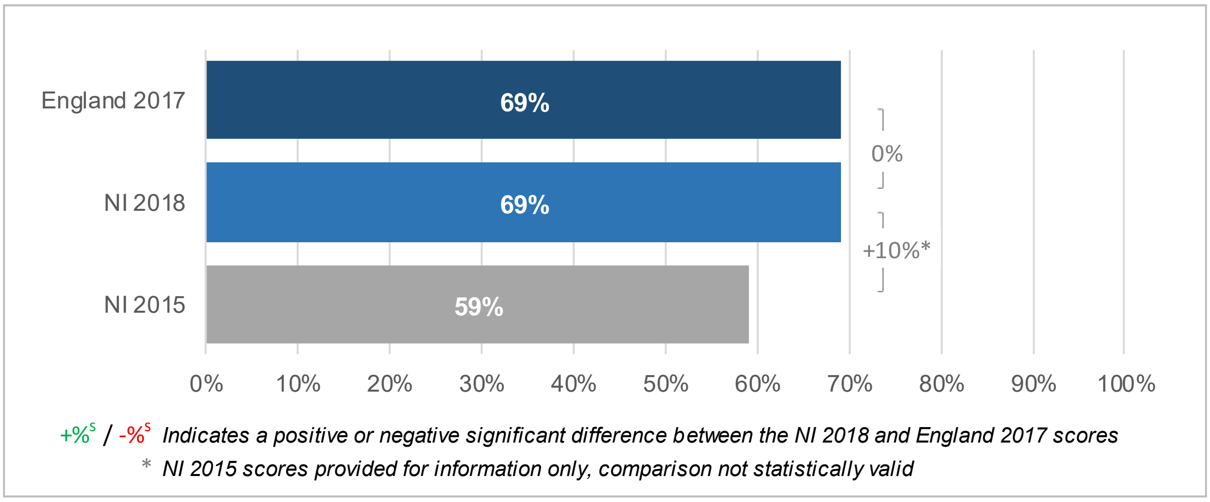
81% of patients had confidence and trust in all of the ward nurses who treated them. This is significantly higher than the England 2017 score of 76%. Additionally, it is an improvement of 3% on the Northern Ireland 2015 score of 78%.

Q34. Patient thought there were always or nearly always enough nurses on duty to care for them in hospital



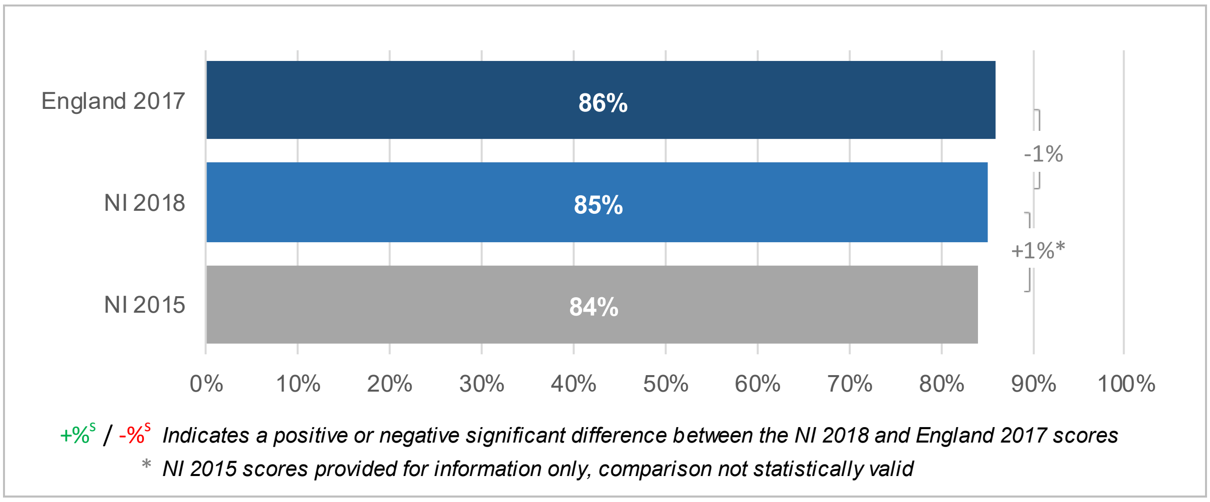
67% of patients thought that there were always or nearly always enough nurses on duty to care for them in hospital. This is higher than the England 2017 score of 66%. Additionally, it is an improvement of 7% on the Northern Ireland 2015 score of 60%.

Q35. Patient was asked which name they prefer to be called by all doctors and nurses



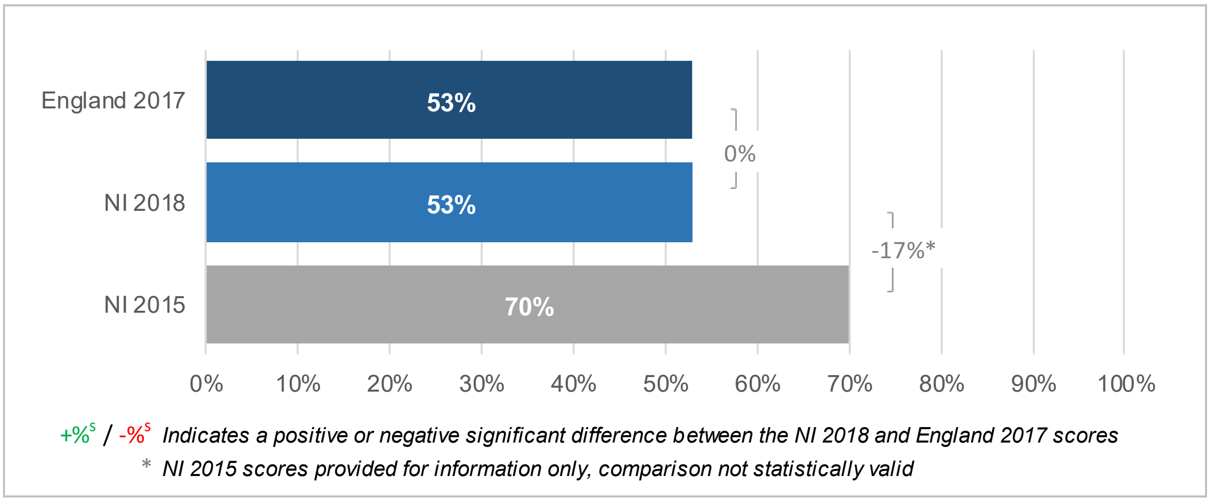
69% of patients said all of the doctors and nurses they saw asked which name they prefer to be called by. This is the same as the England 2017 score of 69%. It is an improvement of 10% on the Northern Ireland 2015 score of 59%.

Q36. Patient was always given enough privacy when discussing their condition or treatment



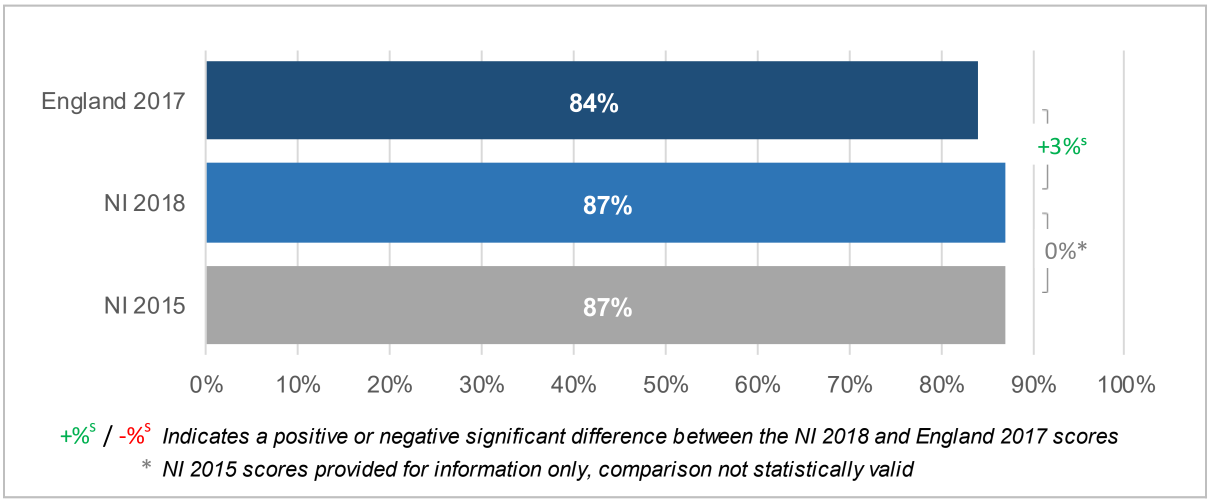
85% of patients were always given enough privacy when discussing their condition or treatment. This is lower than the England 2017 score of 86%. However, it is an improvement of 1% on the Northern Ireland 2015 score of 84%.

Q37. As an inpatient, patient was definitely able to find a member of hospital staff to talk to about their worries and fears



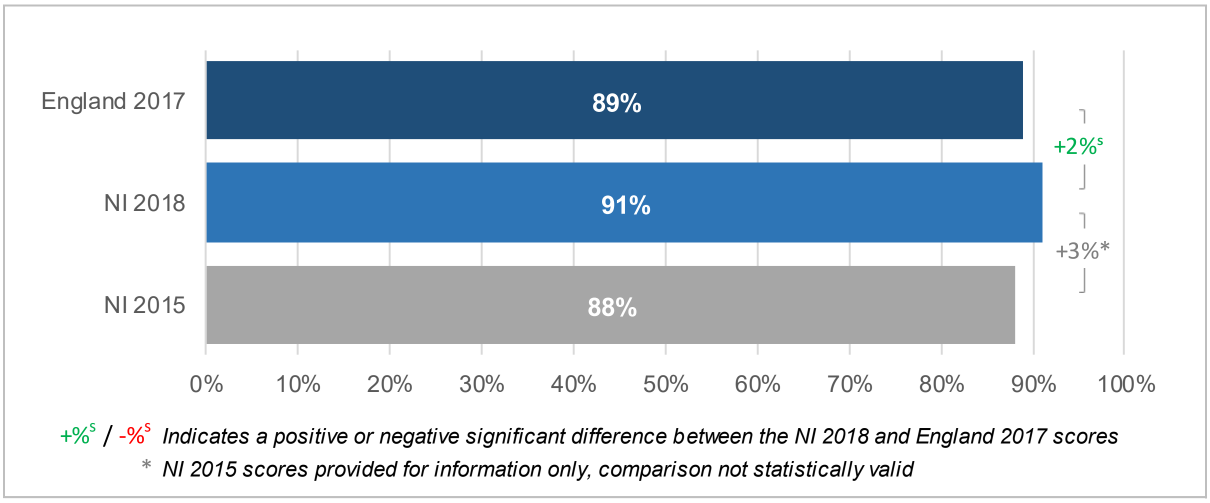
53% of patients definitely found someone on the hospital staff to talk to about their worries and fears during their hospital visit as an inpatient. This is the same as the England 2017 score of 53%. However, it is a decrease of 17% on the Northern Ireland 2015 score of 70%.

Q38. Patient thought staff definitely did all they could to help control their pain



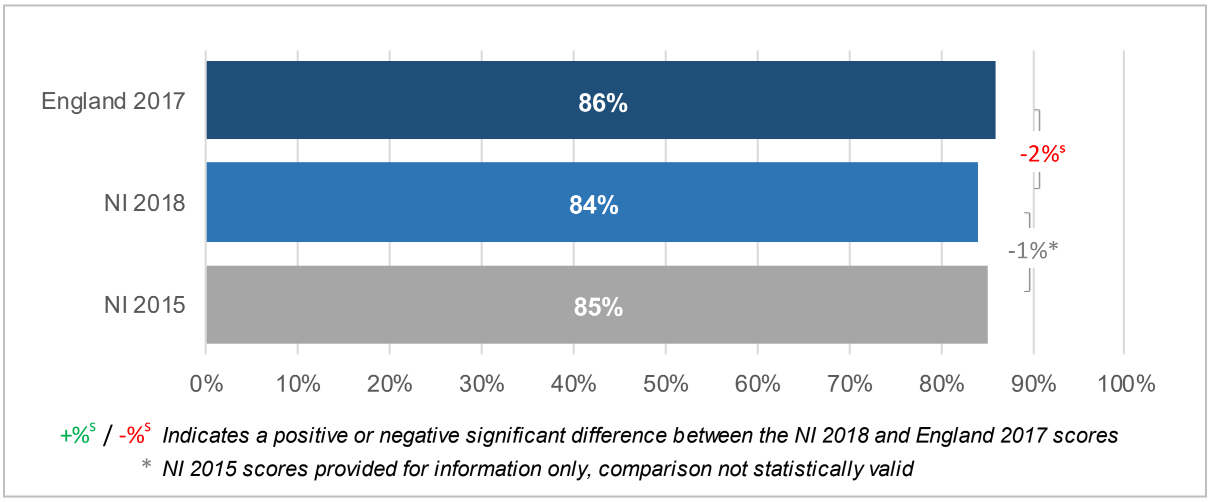
87% of patients definitely thought that hospital staff did everything they could to help control their pain. This is significantly higher than the England 2017 score of 84%. It is the same as the Northern Ireland 2015 score of 87%.

Q39. Patient thought they were always treated with respect and dignity while in hospital



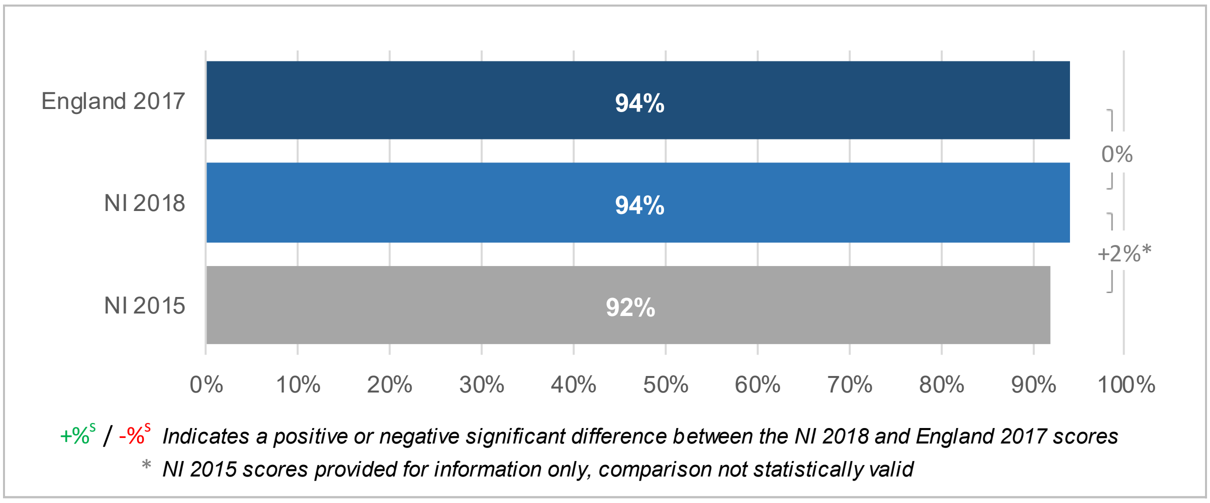
91% of patients felt like they were always treated with respect and dignity whilst in hospital. This is significantly higher than the England 2017 score of 89%. Additionally, it is an improvement of 3% on the Northern Ireland 2015 score of 88%.

Q40. Patient was given clear written information about what they should or should not do after leaving hospital



84% of patients were given clear written information about what they should or should not do after leaving hospital. This is significantly lower than the England 2017 score of 86%. Additionally, it is a decrease of 1% on the Northern Ireland 2015 score of 85%.

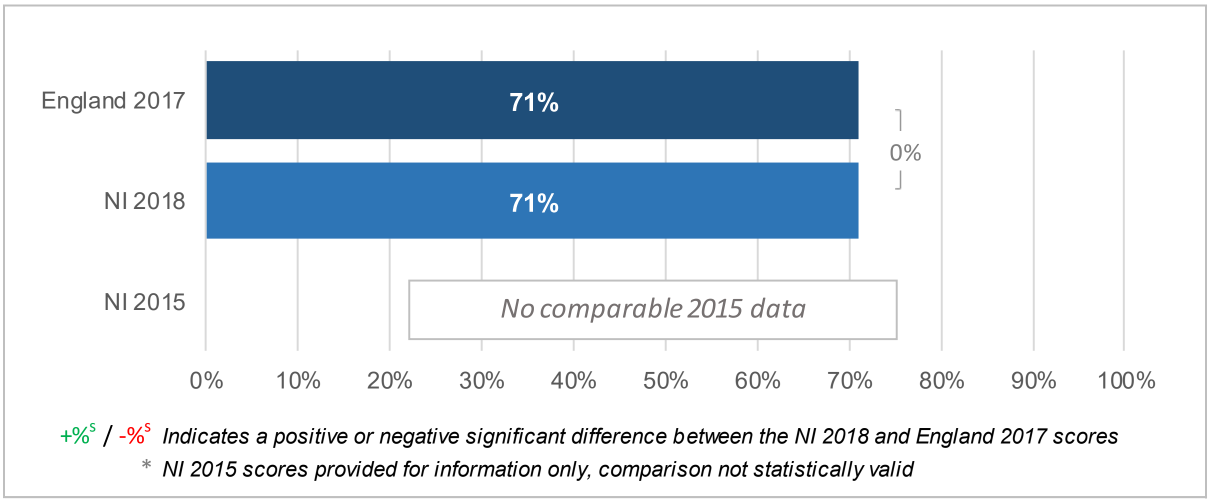
Q41. Patient was told who to contact if they were worried about their condition or treatment after leaving hospital



94% of patients were told by hospital staff who to contact if they were worried about their condition or treatment after leaving hospital. This is the same as the England 2017 score of 94%. Additionally, it is an improvement of 2% on the Northern Ireland 2015 score of 92%.

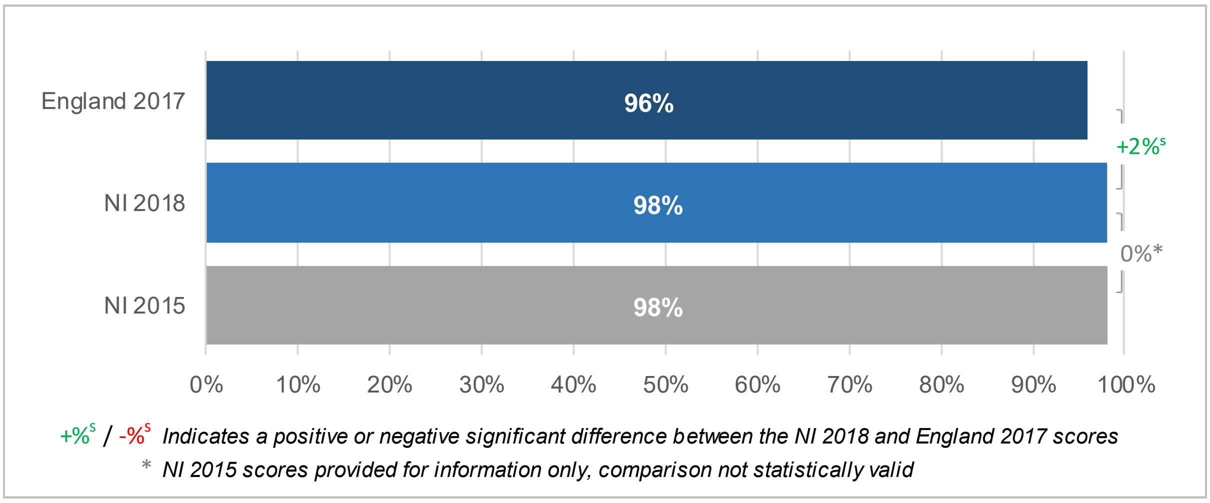
4.11.Hospital Care as A Day Patient / Outpatient

Q44. As an outpatient, patient was able to find a member of hospital staff to talk to about their worries and fears



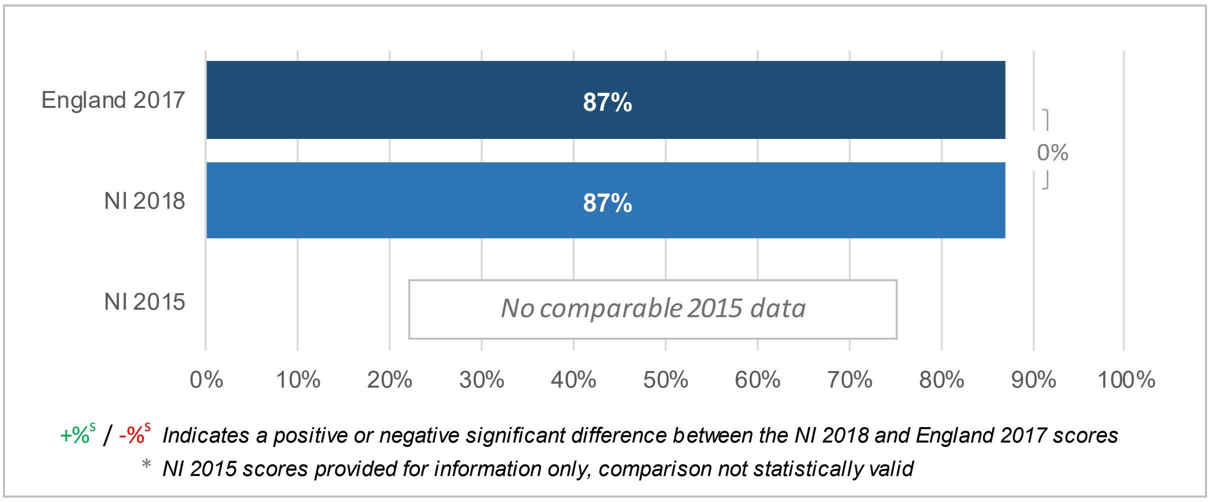
71% of patients were definitely able to find someone on the hospital staff to talk to about their worries and fears, whilst being treated as an outpatient or day case. This is the same as the England 2017 score of 71%. This was not a question asked on the Northern Ireland 2015 survey.

Q45. Cancer doctor had the right documents during patient's last outpatient appointment



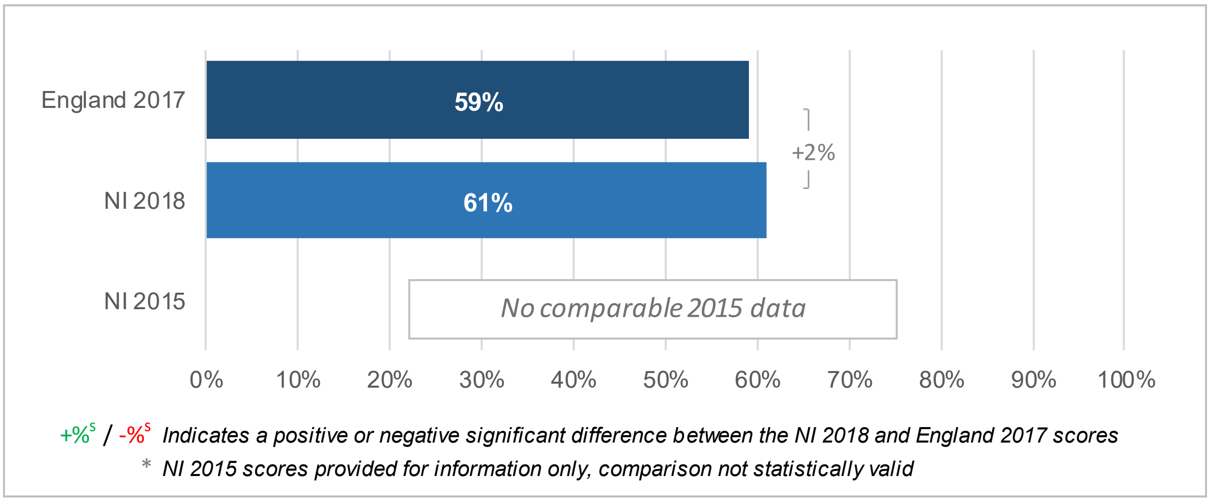
98% of patients said that the last time they had an outpatients appointment with a cancer doctor, the doctor had all the right documents. This is significantly higher than the England 2017 score of 96%. It is the same as the Northern Ireland 2015 score of 98%.

Q47. Patient had all the information they needed about their radiotherapy beforehand



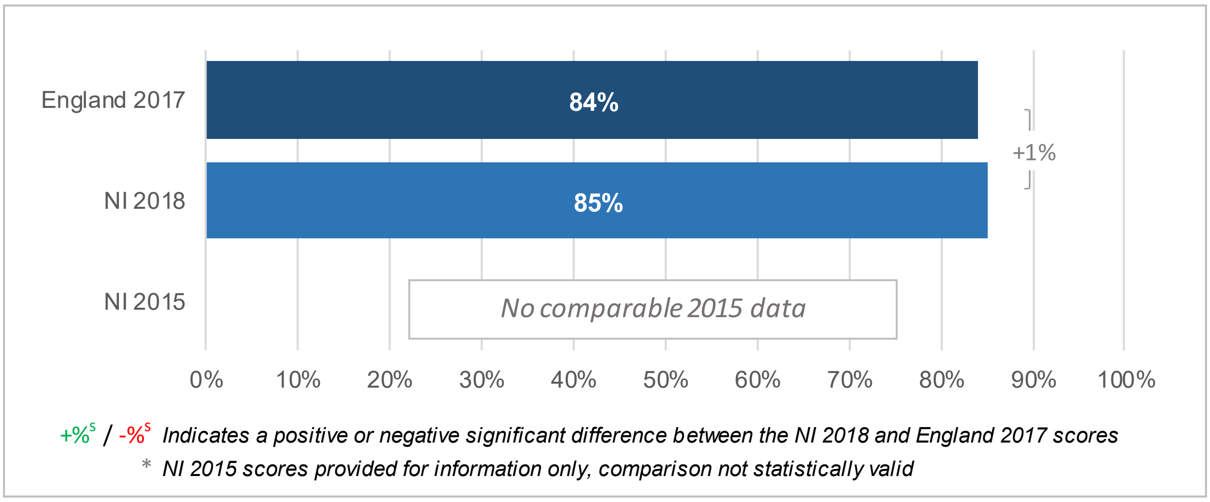
87% of patients were given all the information they needed about their radiotherapy treatment before the treatment started. This is the same as the England 2017 score of 87%. This was not a question asked on the Northern Ireland 2015 survey.

Q48. Patient was given enough information about whether their radiotherapy was working, in a way they could completely understand



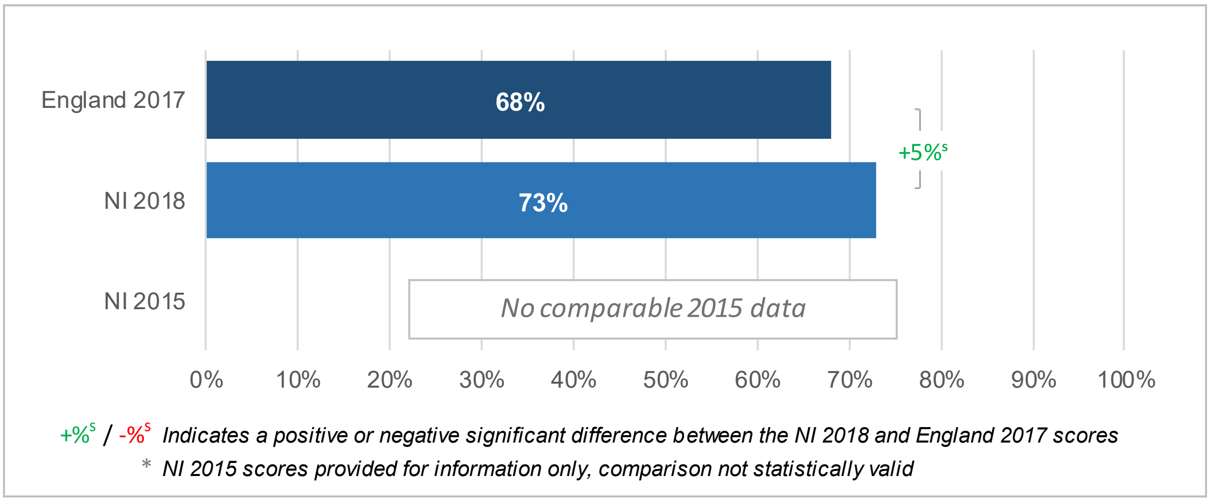
61% of patients felt they were given enough information about whether or not their radiotherapy was working, in a way they understood. This is higher than the England 2017 score of 59%. This was not a question asked on the Northern Ireland 2015 survey.

Q50. Patient had all the information they needed about their chemotherapy beforehand



85% of patients were given all the information they needed about their chemotherapy treatment before the treatment started. This is higher than the England 2017 score of 84%. This was not a question asked on the Northern Ireland 2015 survey.

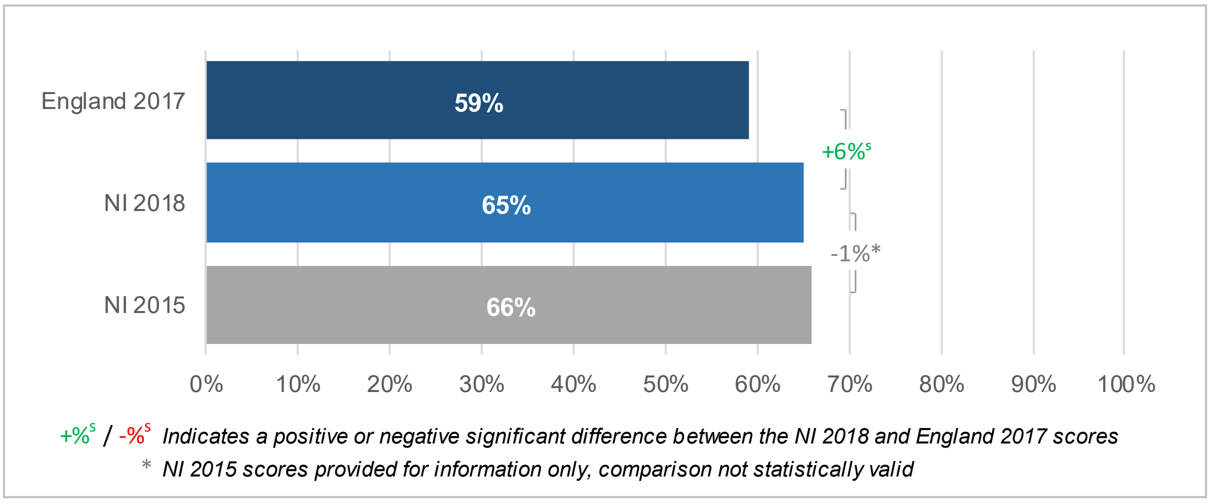
Q51. Patient was given enough information about whether their chemotherapy was working, in a way they could completely understand



73% of patients felt they were completely given enough information about whether or not their chemotherapy was working in a way they understood. This is significantly higher than the England 2017 score of 68%. This was not a question asked on the Northern Ireland 2015 survey.

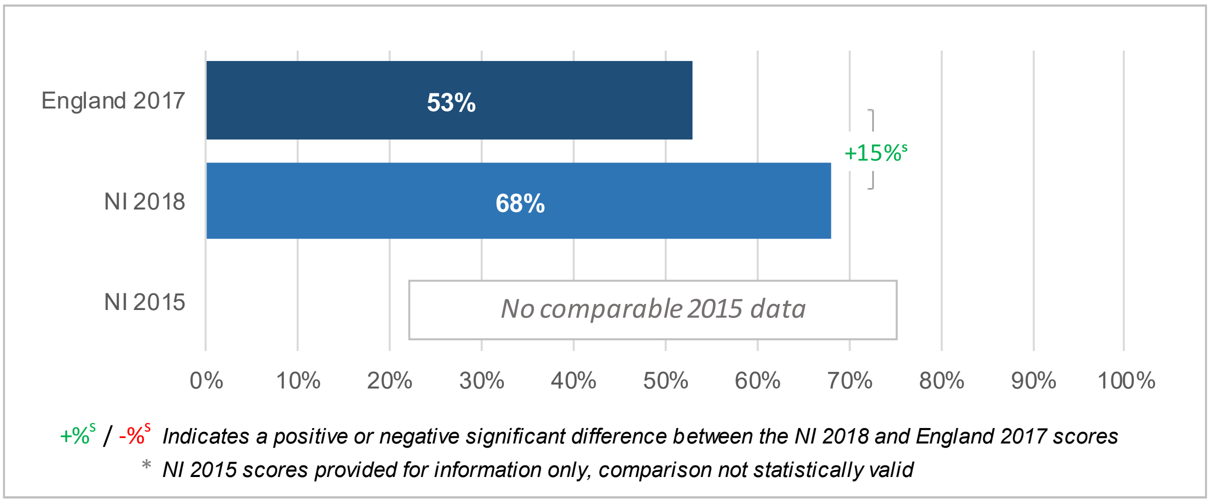
4.12.Home Care and Support

Q52. Doctors or nurses definitely gave the patient's family or friends all the information they needed to help care for them at home



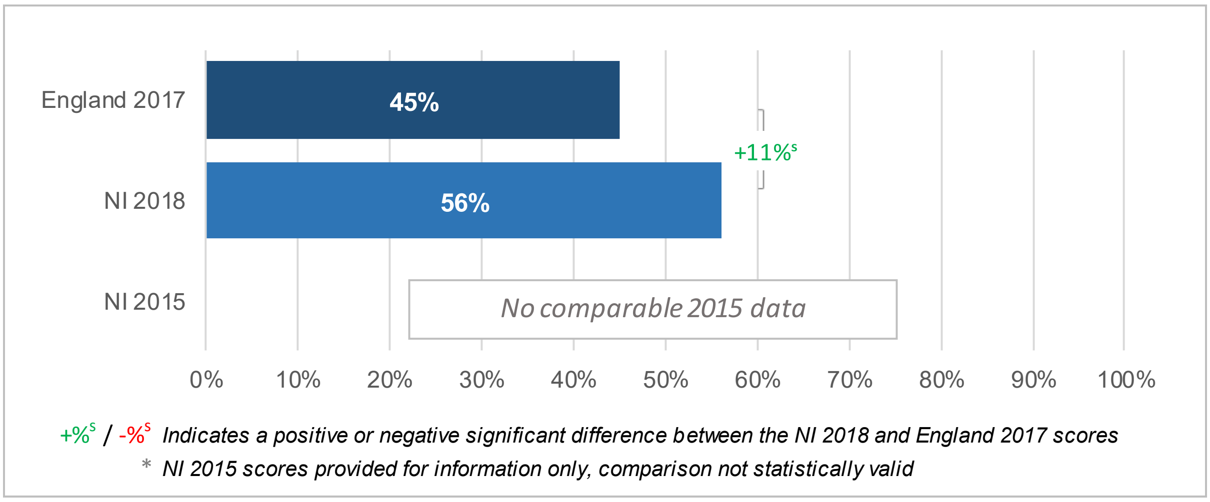
65% of patients said the doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home. This is significantly higher than the England 2017 score of 59%. However, it is a decline of 1% on the Northern Ireland 2015 score of 66%.

Q53. Patient was definitely given enough care and support by health or social services during treatment



68% of patients definitely felt they were given enough care and support from health or social services during their cancer treatment. This is significantly higher than the England 2017 score of 53%. This was not a question asked on the Northern Ireland 2015 survey.

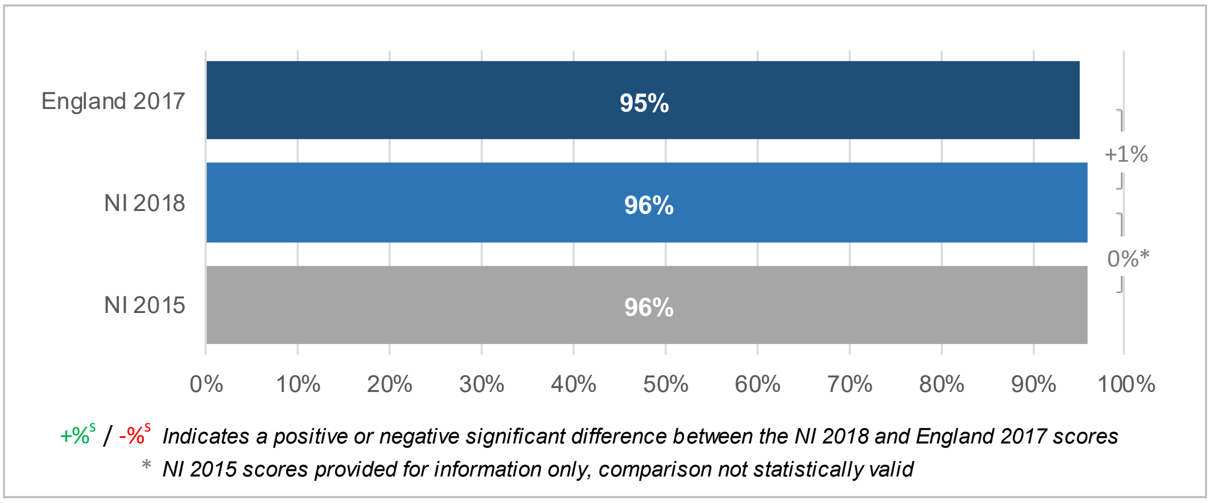
Q54. Patient was definitely given enough care and support by health or social services after treatment



56% of patients definitely felt they were given enough care and support from health or social services once their cancer treatment finished. This is significantly higher than the England 2017 score of 45%. This was not a question asked on the Northern Ireland 2015 survey.

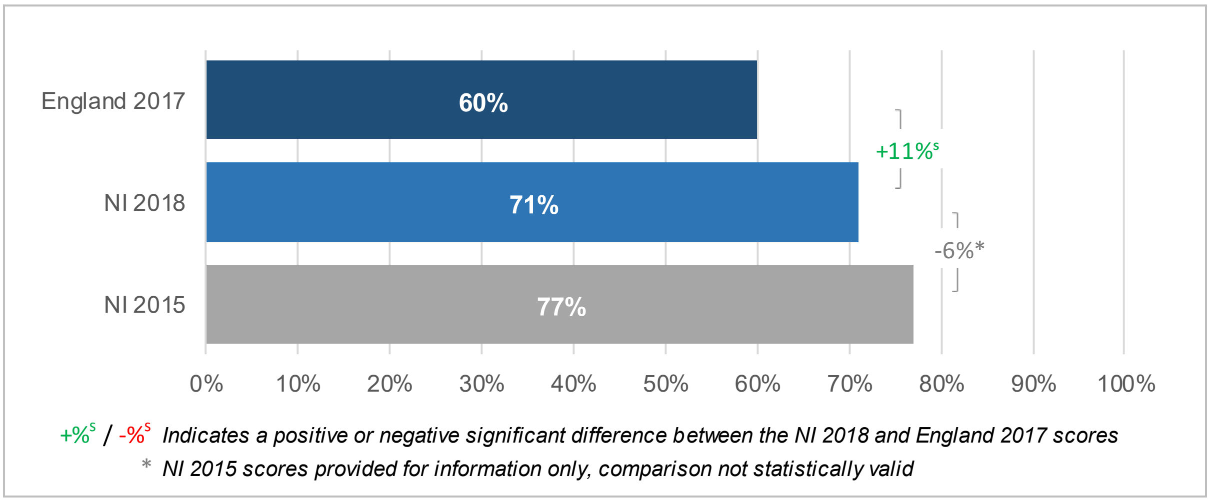
4.13. Care from Your General Practice

Q55. Patient thought their GP was given enough information about their condition and treatment



96% of patients said that their GP was given enough information about their condition and the treatment they had at the hospital. This is higher than the England 2017 score of 95%. It is the same as the Northern Ireland 2015 score of 96%.

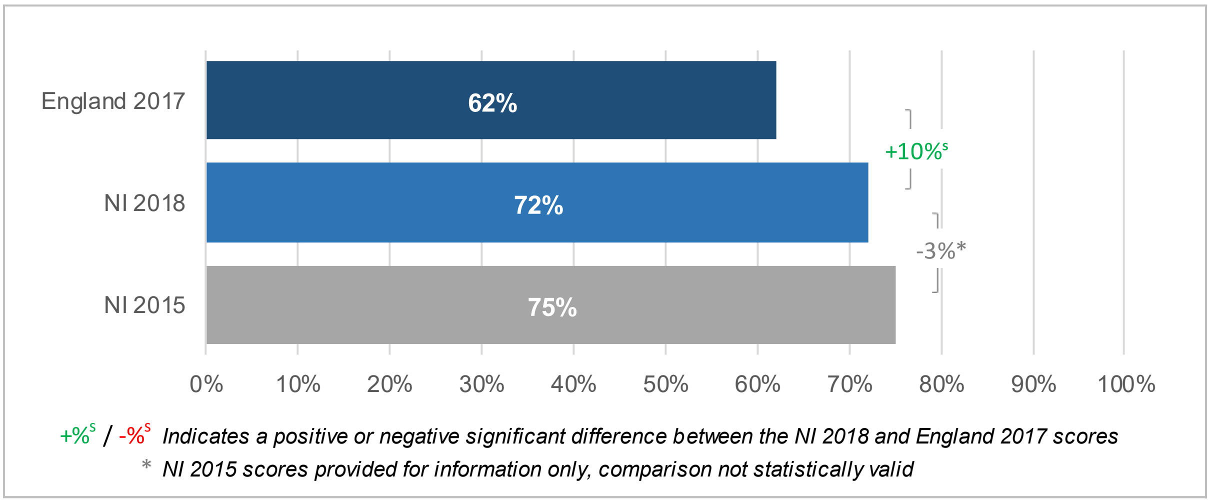
Q56. Patient thought GP staff definitely did everything they could to support them during treatment



71% of patients definitely felt that the GPs and nurses at their general practice definitely did everything they could to support them during their cancer treatment. This is significantly higher than the England 2017 score of 60%. However, it is a decline of 6% on the Northern Ireland 2015 score of 77%.

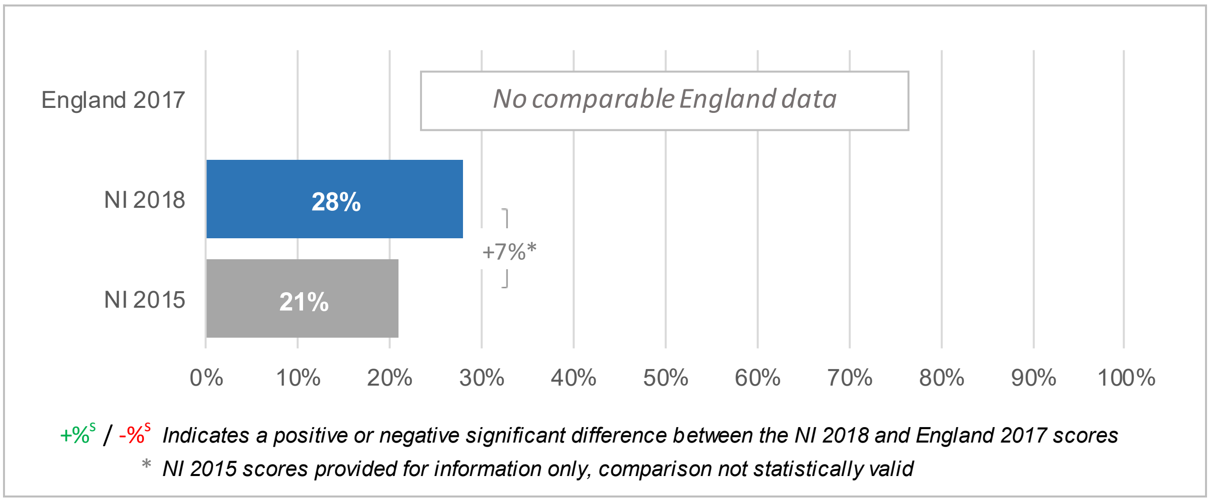
4.14. Your Overall Care

Q57. Patient thought all the different people treating and caring for them always worked well together



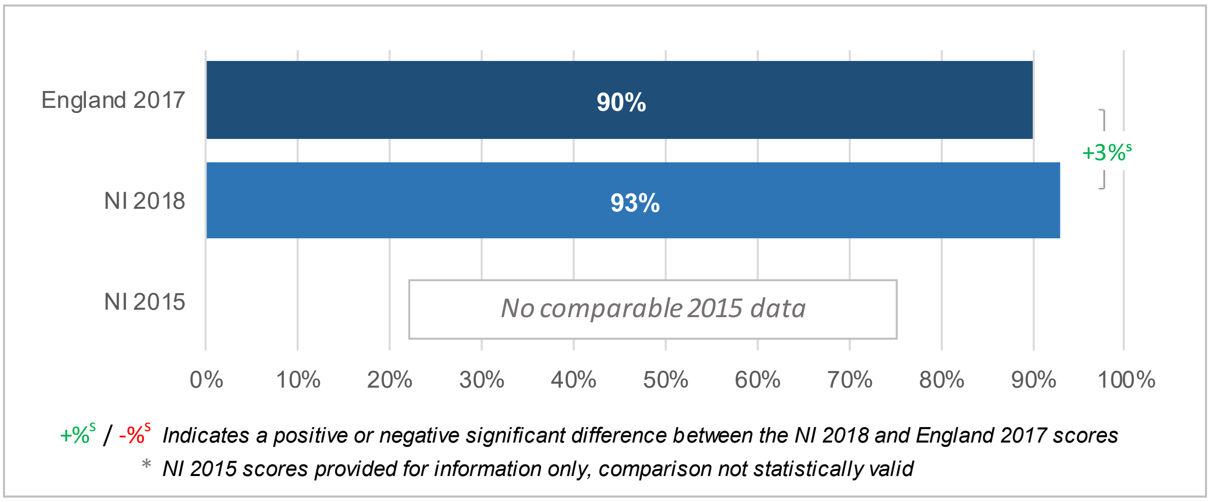
72% of patients always felt that the different people treating and caring for them worked well together to provide the best possible care. This is significantly higher than the England 2017 score of 62%. However, it is a decline of 3% on the Northern Ireland 2015 score of 75%.

Q58. Patient was offered a needs assessment and care plan



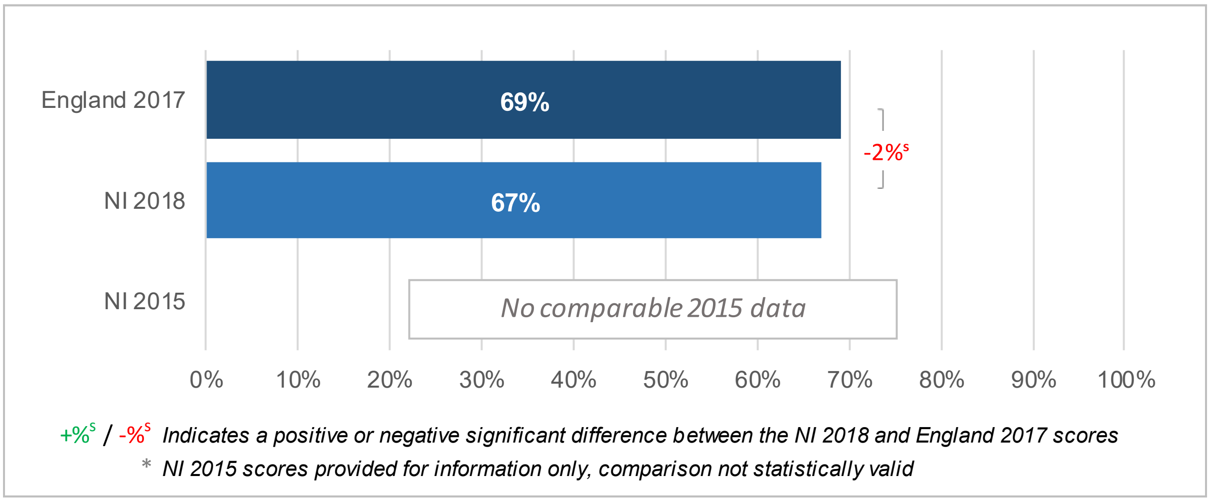
28% of patients have been offered a needs assessment and care plan. This was not a question asked on the England 2017 survey. However, it is an improvement of 7% on the Northern Ireland 2015 score of 21%.

Q59. Patient thought the administration of their care was either good or very good



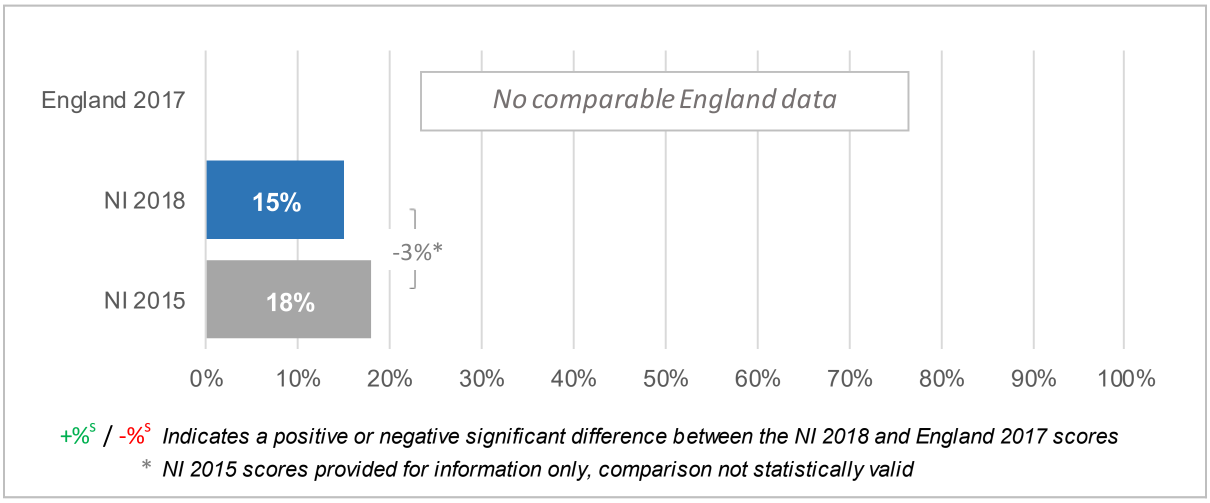
93% of patients rated the administration of their overall care as either 'Good' or 'Very good'. This is significantly higher than the England 2017 score of 90%. This was not a question asked on the Northern Ireland 2015 survey.

Q60. Patient thought the wait time when attending clinics for treatment was about right



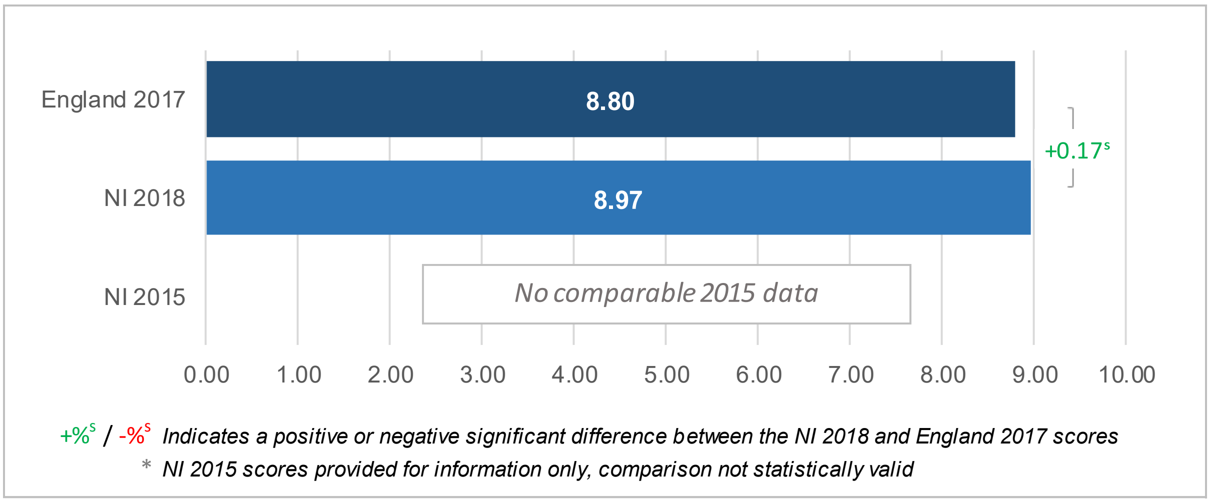
67% of patients felt the length of time they had to wait whilst attending clinics and appointments for their cancer treatment was about right. This is significantly lower than the England 2017 score of 69%. This was not a question asked on the Northern Ireland 2015 survey.

Q61. Patient was asked whether they would like to take part in cancer research



15% of patients had, since diagnosis, had someone discuss with them whether they would like to participate in cancer research. This was not a question asked on the England 2017 survey. However, it is a decline of 3% on the Northern Ireland 2015 score of 18%.

Q62. Overall rating patient gave for care received



Patients for Northern Ireland 2018 gave an average overall rating of 8.97 for their care, on a scale of 0 (Very Poor) to 10 (Very Good). This is significantly higher than the England 2017 score of 8.80. This was not a question asked on the Northern Ireland 2015 survey.

5. Variation in scores across Trusts

In this section, we highlight the survey questions with the greatest variation between the highest lowest scores by Trust. For any questions where the difference between the scores for the highest and lowest scoring Trusts was 10% or more, the table below shows the highest score, the lowest score and the difference between these scores.

		Highest	***Lowest***	***Difference***
Q23	Hospital staff gave patient information about financial help and benefits available	81.7%	62.5%	19.2%
Q60	Patient thought the wait time when attending clinics for treatment was about right	74.6%	56.8%	17.9%
Q36	Patient was always given enough privacy when discussing their condition or treatment	95.6%	80.1%	15.5%
Q61	Patient was asked whether they would like to take part in cancer research	21.5%	8.6%	12.9%
Q50	Patient had all the information they needed about their chemotherapy beforehand	91.8%	79.2%	12.6%
Q54	Patient was definitely given enough care and support by health or social services after treatment	64.4%	52.1%	12.3%
Q53	Patient was definitely given enough care and support by health or social services during treatment	75.3%	63.5%	11.8%
Q30	Patient thought no doctors or nurses talked in front of them as if they weren't there	86.5%	74.9%	11.6%
Q38	Patient thought staff definitely did all they could to help control their pain	89.8%	79.1%	10.7%
Q51	Patient was given enough information about whether their chemotherapy working, in a way they could completely understand	79.1%	68.8%	10.4%
Q37	As an inpatient, patient was definitely able to find a member of hospital staff to talk to about their worries and fears	61.3%	51.1%	10.2%
Q33	Patient had confidence and trust in all of the nurses treating them	86.8%	76.7%	10.1%
Q58	Have you been offered a needs assessment and care plan?	33.6%	23.6%	10.0%

6. Comparison between different groups of cancer patients

6.1. Demographics

For this section, we have tested for differences in patient experience between different cohorts of patients, by dividing respondents into groups based on gender, age, cancer type, etc. and then testing for significant differences between the scores for different groups across all questions. This allows us to highlight any statistically significant inequalities in cancer patient experience in Northern Ireland based on patients' demographic characteristics or clinical factors

For more detail on the methods used, see Appendix 1. For more detailed results from the analysis presented here, please view the NI CPES 2018 data tables at this link:

https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey-2018/northern-ireland-cancer-patient-experience-survey-reports-2018

There are significant differences between **genders** on 19 questions (men higher on 14 questions, women on 5).

There are significant differences between **ethnic groups** on only 5 questions.

There are significant differences between **age groups** on 35 questions.

On most questions, there is at least one **cancer type** that has significantly higher or lower scores than the others.

There are significant differences between **deprivation quintiles** 1 and 5 on only 6 questions. On all of these, respondents from the most deprived quintile report a more positive score than those from the least deprived.

6.2. Impact of a CNS

There is a statistically significant association between being given the name of a CNS (question 18) and positive scores elsewhere in the survey.

Those who answer 'Yes' to question 18 have statistically higher scores on 47 of the other 48 questions.

6.3. Impact of a care plan

There is a statistically significant association between being offered a needs assessment and care plan (question 58) and positive scores elsewhere in the survey.

Those who answer ‘Yes’ to question 58 have significantly higher scores on 46 of the other 50 questions.

6.4. Cancer status

There are some differences in responses between those whose cancer remained after treatment and those whose cancer had been successfully treated or removed.

Those whose cancer remained score significantly lower on 18 questions; and significantly higher on none.

6.5. Comorbidities

There are some differences in responses between those with comorbidities and those without.

Those with comorbidities score significantly lower on 26 questions; and significantly higher on only two.

6.6. Unemployment

There are some differences in responses between who were employed at the time of diagnosis and those who weren’t.

Those who were unemployed score significantly lower on 19 questions; and significantly higher on only three.

APPENDIX 1

How to interpret the results

The significance level was set at $p<0.05$ for all comparisons. The combined Northern Ireland 2018 score was compared, where applicable, to the England 2017 survey score with the significance noted. There is no comparability between the 2018 & 2015 Northern Ireland surveys due to changes in the sampling timeframe and questionnaire design and so the difference in score is only shown for information purposes and is in no way statistically significant.

Methodology

In order to establish whether differences between groups of respondents on a particular question are statistically significant, two standard tests of significance have been used:

- A test of proportion (Stata's prtest) to test whether there is a significant difference between the scores of two groups (e.g. gender)

- A chi-squared test, to test whether there are significant differences in scores across multiple patient sub-groups (e.g. across ethnic groups, or across age bands).

Both tests examine, for any particular question, differences in the proportion of 'positive' responses across the various sub-groups, e.g. age bands. If there were no differences, the proportion of 'positive' responses would be constant across all sub-groups (and equal to the overall proportion).

Question 62 (overall rating of care)

For question 62, an average score is calculated (rather than a "percentage positive"). Significance Testing for this question takes two forms:

1. For the gender breakdown, a t-test compares the average scores for males and females. Similarly, for deprivation, a t-test compares the average scores for the 1st and 5th deprivation quintiles
2. For cancer type, age band and ethnic group, t-tests compare each sub-group to the national score.

Stata 14 was used for the statistical analysis. The immediate form of the pr-test and t-test was used for the comparison between NI CPES 2018 and England CPES 2017.

Urology Cancer Service

Patient Engagement

Report

Maura McClean, Macmillan Engagement Lead

September 2022

Acknowledgements

This report has only been possible due to the invaluable contributions of patients in the Urology Cancer Service in the Southern Trust and the involvement of Macmillan Peer Facilitators. We would like to acknowledge their willingness to engage in the meaningful discussions, and thank the participants for sharing their lived experiences.

Introduction and context

As part of a review of the Urology Cancer Service in the Southern Health and Social Care Trust, nursing staff wanted to engage directly with patients of the service, so that their experience of the service would provide authentic feedback and reflection, and help inform any future service improvements or developments.

To enable this to happen, Macmillan Peer Facilitators were invited to support the review through one to one conversations with patients of the Urology Cancer Service.

Peer Facilitators

Peer facilitators are people affected by cancer who have been recruited by Macmillan in a voluntary capacity and who have undertaken bespoke facilitation and safeguarding training to enable them to engage with their peers around specific issues and feed back their findings to Macmillan and their partners. Peer led engagement is based on the principles of shared understanding, empathy and respect for each individual's cancer experience, resulting in meaningful conversations about 'what matters'.

Methodology

Initial engagement with staff team

The Macmillan Engagement Lead met with key members of the Urology Team in the Southern Trust, Mary Haughey (Service Improvement Lead), Leanne McCourt (CNS) and Patricia Thompson (CNS) to determine the purpose and focus of the engagement with patients, agree methodology, sample size, tumour groups and key areas where insight was required.

The Engagement Lead designed an information leaflet which staff could use when inviting patients to be part of the engagement process. The Engagement Lead and team of facilitators then designed a conversation guide to support the patient interviews based on the key areas of interest outlined by the Urology Team and also to ensure consistency across the interviews.

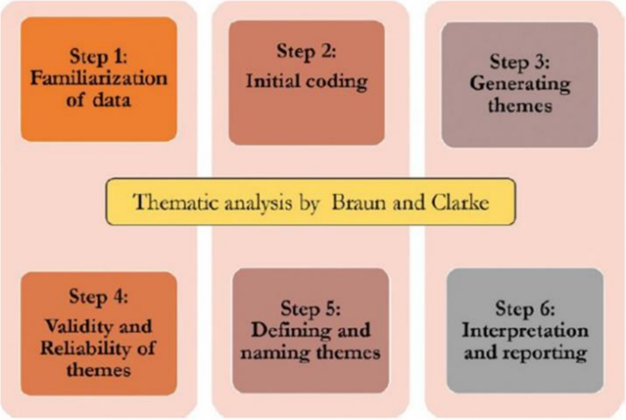
Patients

A total of 30 patients were identified from 3 tumour groups – renal, bladder and prostate (10 from each group). The Urology team contacted patients by letter initially, enclosing the patient information leaflet, and then followed up by telephone to confirm if they wanted to take part. Out of the 30 identified patients, a total of 12 patients agreed to take part in the engagement process.

Interviews

Peer facilitators carried out the interviews either by telephone or over video conference, depending on the preference of the participant. Due to Covid restrictions, no face to face interviews were carried out. The peer facilitators carried out each interview directed by the agreed conversation guide, which ensured consistency and comparability across all 12 interviews. After each interview, peer facilitators completed a feedback report and submitted to the Macmillan Engagement Lead. All reports were completed on an anonymous basis, and therefore no patients were identified in the process.

Analysis



The Macmillan Engagement Lead analysed the data from each of the peer facilitator reports. Braun and Clarke's six-step thematic analytical method was chosen to review the data collected by the peer facilitators from their conversations with Urology patients. From this data, a set of key themes emerged and each theme is presented in turn in this report, qualified by the use of participant's own words in the form of quotes.

Peer facilitators were involved in the review of the report, ensuring that it is reflective of their conversations with patients, and that it depicts their authentic voice and experience.

Findings by theme

Role of Clinical Nurse Specialist (CNS)/Key Worker

All patients were asked about their contact with their CNS or key worker, with the aim of understanding how well patients understood the role, and in what ways they benefited from their support. Insight has been organised according to the following categories:

Presence/Availability

The majority of patients stated that they had been given contact details for their CNS and knew they could contact them at any time,

"He knew if he had any questions he could phone her"

"She was there to help me at all times..just lift the phone and ring"

In most cases patients reported that the majority of interaction with CNS staff has been via telephone. Some stated they 'felt comfortable' talking to the CNS and that a good rapport had been established. Others described their CNS as 'caring' and 'supportive'.

One patient described how the CNS was present at the very first consultation with the Urologist and at every consultation thereafter, prior to, during and after treatment. The CNS was also with the patient at the point of admission to Craigavon Hospital and was always there in support during the week long stay in hospital. The patient's appreciation of the support given by the CNS was summed up as follows,

"She (CNS) is one of the reasons everything went so well. She phoned me at home 5 or 6 times before I went in for the operation to remove the tumour..I was treated impeccably.."

Providing clarity in times of uncertainty

One patient talked about the CNS as someone who provided great clarity at a time when they had experienced a possible misdiagnosis and felt confused and in the dark,

"At the start it was a bit of a mess, there was possibly a misdiagnosis. I had an eight week wait after tests and then got a letter to go to Dungannon to see (I thought) my consultant, but it was a different person. I was expecting to hear all was fine and this was the first time I was told I had cancer – I met my CNS a good while after diagnosis, but everything was fine from there"

Practical Support

One patient detailed how the CNS had been supportive in a number of practical ways, including help to obtain a Blue Badge by completing the necessary paperwork, and that this help and support had been greatly appreciated by the patient. Another described getting help with a referral to a hospital in Dublin,

" My case was referred to the Mater in Dublin and the CNS was brilliant at talking me through how to contact them. What to ask them etc, and contacted me again to make sure I did this. She was a great help at all times"

Uncertainty around terms 'CNS/Key Worker'

Whilst the majority of patients interviewed stated they knew their CNS or key worker (CNS was the term mostly used), a small number of patients were unclear about who this was,

" I don't know what a Cancer Nurse Specialist is, or any key worker other than my consultant. Nobody identified themselves as a key worker or specialist, but the staff I did have contact with were great and I was happy with everything.."

One patient was unsure because they relied on their daughter for all aspects of their care,

"A lady who might have been a CNS gave my daughter a folder with all the details. My daughter might have made contact with her, but I didn't.."

A third patient referred to their CNS as a 'Macmillan Nurse' and seemed unsure of what their role entailed.

Receiving 'bad news'

A small number of patients indicated that the presence of a CNS in the room when they were getting their diagnosis indicated to them that they would be getting 'bad news'

"I had a CNS present on the day I was told I had cancer..I saw her with a box of tissues so I guessed she was the comfort of bad news"

"On the day I was told I had cancer, as soon as I saw the nurse in the room I knew it wasn't going to be good news.."

Involvement in decision making

Patients were asked to comment on their level of understanding about decisions being made about their care, and to what extent they felt involved and that their preferences were taken into account. Insight is organised according to the themes below.

Choice and control

The predominant emerging theme in this section is one of choice and control offered to patients at different stages in their cancer pathway. Most patients described feeling 'fully involved' in decisions about their care, as well as being offered a range of options to choose from in some cases. It is important to note the involvement of the CNS in some instances, in supporting patients to 'make sense' of the information, enabling them to come to a decision about their care.

A strong sense of a joint and collaborative decision making ethos is also clear from patient's experiences,

"I have a great relationship with the consultant and his team. He is open about everything and I was given options..I told him what I preferred and then we discussed the treatment plan together. By doing this, it helped me come to the right decision for me."

"My consultant met me face to face, which he didn't have to do, in South Tyrone Hospital. He offered me 3 options – monitor, oblate, or deal with it quickly; I felt I really only had one choice, but I'm sure my consultant would have supported me whichever I chose..I felt the only choice I had was to deal with it quickly.."

Others talked about liking the 'matter of fact' approach of the consultant, enabling a good understanding of what would happen,

"The consultant was straight to the point, very matter of fact and explained everything carefully..diagnosis, treatment plan and surgery. He gave me options and choices, carefully explaining the effects of each treatment. I understood everything and I was able to contact the CNS to clarify any questions I had. At no point did I feel under any pressure to make an immediate choice..I was given time to think"

One patient described feeling content at being offered choices and options, but was more than happy to follow the recommendations of the consultant,

"..the feeling was always one of choice rather than coercion in significant matters such as the prostate biopsy, the colonoscopy and the hormone injections. I was willing to follow the consultant's advice and recommendations, but I was pleased to be involved in the discussions and offered choices"

Even in situations where outcomes may not be as good as others, patients were still given the choice to make the decisions they felt were right for them at the time. One patient described how after their first round of chemotherapy was not successful, removal of the bladder was recommended. However, the final choice was still left with the patient,

"The consultant said it looked like the cancer had come back again and seemed to be gearing me towards removal..but I didn't want to go straight to that option. I asked what the potential success rate might be for a further round of chemo, and was told 10 – 15%, but that if I wanted to go that route, they would give it a go. I chose to have a further round of chemo, which in the end did not work.."

Deferring to the 'expert'

Whilst the majority of patients expressed satisfaction with the level of involvement in decision making in relation to their care, a small number were happy to defer to the medical staff looking after them,

" I listened to everything the medics told me, I just let them do their job but they were very clear in all they were doing and would talk to me and let me know everything. I didn't disagree with them at all as I was letting them get on with things...sure they know what they are doing"

Rapid diagnosis and treatment

In some cases where cancer was discovered and rapid treatment needed, there may not have been as much time for involvement in the decision making process,

"It all happened so quick, my husband was getting a chest scan for COPD and that's when they found the cancer, next thing he was on the operating table, everything was so quick, but the staff always chatted through everything with me"

Awareness of treatment plan

Patients were invited to comment on their awareness and knowledge of the treatments and processes they had been through in the course of their cancer pathway, and also about the level of information they received in relation to the timelines involved and when everything would happen. Insight is organised below according to the following themes.

Good understanding and knowledge of treatment plan

Some patients stated they had clear and detailed treatment plans which were well explained to them and accurately carried out. This brought them a sense of reassurance and clarity about what was going to happen and when,

"My treatment plan is discussed regularly and I have felt involved at all times..I had a plan for hospitalisation, a plan for 3-monthly blood tests and a plan for a CT scan after 3 months"

"I always knew what to expect before it happened"

Role of Support Staff

The role of supporting staff including the CNS and Consultant's Secretary were also deemed important, in cases where the patient was unable to contact the consultant directly,

" I understand everything, and anything I am not sure about I contact the Consultant's Secretary who I find very helpful"

Another patient who had been referred to Dublin for treatment said they were unclear about what treatment they would be getting there, and without the help of the CNS would not have had any information about their treatment plan,

"I really didn't have a clue what to expect, so I rang the Macmillan CNS and she gave some really helpful direction about contacting the Mater, exactly what to ask and how to ensure all the questions were dealt with. This was a great help because without the CNS I wouldn't have had any idea about where to start"

Waiting times

One patient said that although their treatment plan was well explained, and they knew exactly what was going to happen, waiting times between procedures was long, and they found themselves having to make enquiries and follow up at different stages, *"All the information was given to me, but timelines are long between appointments and follow ups and I have had to ring the CNS to check on various results and appointments"*

Little awareness of treatment plan

A small number of patients reported not being aware of their treatment plan, and in some cases resorting to the internet to look up treatments and what they entailed,

"..much of what I learned about the operation I picked up online which was scary.."

"...I didn't know a lot – I didn't know what to expect from the first course of chemo..."

Impact of treatment and follow up

One patient reported difficulties coming to terms with what had happened to them. Even though they reported that their treatment plan was explained, they said that they were still in shock and still dealing with the fact that they have cancer, which indicates this patient may have benefitted from follow up support post treatment,

"*Now that I have had treatment I have been left to deal with a lot on my own...*"

Type of support provided

Patients were asked to comment on the ways they were comforted, assisted or supported by staff within the Urology Cancer Service, and in particular to reflect on how that support made them feel. Insight is organised according to the themes below.

✓ Excellent levels of support

One patient has been particularly appreciative of the support given by the nursing staff during chemotherapy sessions. At the start of the treatment process, great care was taken to ease their understandable concerns regarding the side-effects of chemotherapy, such as sickness and hair loss. These reassurances helped reinforce the patient's very positive attitude, although, as it turned out, they experienced neither sickness nor hair loss:

"Everybody is very professional and helpful. They go out of their way to help – even down to the tea and toast afterwards".

The patient was also impressed at receiving an unexpected telephone call from the consultant's secretary the day after receiving the first hormone injections, to enquire if there had been any adverse effects. Coordination between the Urology Service at Craigavon Area Hospital and local Health and Social Care would appear to be working efficiently. The day after each chemotherapy treatment, the District Nurse visits the patient at home to administer a stomach injection. The patient also visits the local Health Centre on a 4-weekly basis to receive further follow-up treatment,

"all of these things have happened like clockwork"

Patients described receiving support both in a hospital ward setting as well as in general from the urology service. Significantly, each patient spoke highly of the support received, using works like 'reassurance', 'comfort' and 'great care' to describe their experiences.

The role of the CNS was again noted as important right through all stages of the cancer pathway,

"My CNS was a big support after diagnosis, right through the treatment. My partner or I could ring her 2 or 3 times a week and she would always have time for us., or get back to us as soon as she could"

Support in hospital

Several of the patients interviewed stated they had spent time in hospital as part of their treatment pathway, and some praised the support of staff on the ward,

"I was in hospital and felt the nurses gave great care and attention and through lots of embarrassing situations they made me feel at ease and my care was excellent. At times I was scared and I felt that the nursing staff helped to reassure me."

Another patient referred to the fact that whilst their treatment in hospital was good, it did seem that staff were under pressure, and indeed that there was a shortage in staff. They reflected that perhaps this was caused by the pandemic,

"I did feel a lack of support from the staff during that time, however I thought it was down to the pandemic and that it normally wouldn't be like that"

Support from Urology Department in general

The support received from the Urology Service pre-treatment, during treatment as an in-patient, and now during aftercare was, in one patient's words "second to none". This patient was particularly impressed by the fact that the word "cancer" was kept to a minimum during discussions up until completion of the hospital procedure, in order, it was thought, to minimise stress levels.

"The ability of the urologist and the CNS to display such levels of sensitivity was much appreciated."

Several patients praised the support they received from the consultant,

"My consultant met me face to face – probably because of the 'C' word. I didn't think he needed to, but it shows how much he cares. This would be really important for others if not for me.."

On the other hand, some patients noted some difficulty in getting in touch with the consultant, and that this was due to the fact that they were incredibly busy. This, according to one patient, made the role of the CNS even more critical.

Impact of Covid and telephone consultations

Patients were asked to reflect on their experiences during the pandemic, to determine what impact this period had on patient care. Staff in the Urology team were also keen to understand patient experience of telephone appointments and consultations; as a result of the Covid pandemic, many interactions have taken place by telephone, and staff were keen to gain a greater insight into whether patients had a preference for this means of contact or face to face appointments. Insight is organised according to the themes below

Impact of Covid

Overwhelmingly, no patients reported any major impact on their care owing to Covid. Several reported that appointments had continued in a face to face setting where required, with some telephone conversations in between appointments,

" Most of my treatment was pre-covid, however all my check-ups have still been face to face. I have had a couple of phone calls, but not ones replacing hospital visits"

One patient reported that Covid did not in any way delay the period from diagnosis to the start of chemotherapy treatment, nor did it disrupt the original treatment plan, including the periods between chemotherapy sessions.

Another patient reflected on the prompt timing of their treatment during the pandemic, firstly to see the Urologist (2 months after initial diagnostic scan organised by GP), and then to have the hospital procedure,

"I just don't know how I got the operation so quickly"

For those patients that required hospital visits for appointments, or hospital stays, again Covid 19 did not appear to have caused any significant issues. It appeared that patients were understanding of the protocols, and happy to accept these in situations where treatment was planned,

" *We went to the hospital together and I sat in the car and he went in for his checks..that's the way it was during Covid, those of us that went with someone sat out in the car. I got used to that"*

"All my appointments were face to face, and apart from having to wear masks, I wasn't affected at all"

Telephone appointments

Again, in relation to the increased use of telephone for appointments and consultations, patients appeared to favour this means of communication where necessary.

One patient related an instance shortly after diagnosis when a consultant from Belfast City Hospital got in touch to arrange an initial telephone consultation. The patient stated that a face to face conversation would be preferable, particularly considering that this was at the early stages of the whole process. The consultant was happy to arrange a face to face meeting, which turned out to be very helpful to the patient, who felt their preferences had been taken into account. In relation to the Urology Service at Craigavon, the same person noted that all contact with the CNS had been by telephone, as has any contact with the Consultant at Craigavon, and the patient did not believe these appointments had any adverse effect on treatment or timing.

Some other patients stated a preference for telephone appointments where appropriate. One patient noted that they had been updated via telephone on 5 or 6 occasions by the CNS via certain procedures. After treatment they are also given blood test results and CT scan results by telephone, *"As I work full-time, I'd much prefer to be given a clear blood test result (Or CT scan result) by telephone, rather than having to take half a day (or a day) off work to travel to Craigavon Hospital, just to be told my bloods are ok. This also must be more efficient from the hospital's point of view"*

Suggestions for improvement

Patients were invited to reflect on any areas, however small, they could identify for improvement.

As was evident throughout this report, the overall feeling is one of satisfaction and indeed praise for the care and treatment received by patients of the Urology Service in the Southern Trust. This was borne out by the words of one patient,

"I can't think of anything more they could have done for me. All the examinations and procedures were well handled and efficient. The chemo nurses were just great. The District Nurse always arrives the day before chemo to give the stomach injections. The visit to my health centre every 4 weeks happens with no problems."

Another patient talked about their satisfaction of the service,

"The service provided, right from diagnosis, through treatment and beyond has been, and still is second to none"

In relation to being referred to other services, one patient felt they would have had a much longer waiting time had they not been directly referred by their Consultant,

"If I had to arrange my cardiologist myself I think I would still be waiting for treatment if they hadn't done that for me"

There were nonetheless, a few suggestions from patients resulting from experiences they had during their cancer journey.

One patient, being very careful to praise staff for the care they received, nevertheless, wanted to talk about **waiting times**,

"I had a positive experience, but I have waited a long time at various stages, especially for scans and then results.."

Another talked about **pressures facing staff**, particularly in their view in relation to hospital staff,

"Although I have had good care, the hospital staff do appear under stress, I could almost sense it in the air…if I could change anything it would be to give them more staff"

A further patient talked about their **experience at diagnosis**, where they had initially been given the 'all clear' and subsequently then told they had cancer,

"There was a big issue with my diagnosis – to this day I still don't know why they were looking at my results 10 weeks after I was given the all clear. My CNS told me I could complain, but I didn't want to go a formal complaint route. I have no complaints about my CNS and Consultant (although he is hard to get hold of)"

Finally one patient touched upon the importance of **follow up contact**, just to keep them informed about progress/their situation,

"The only change I'd mention is about the frequency of contact, maybe even a telephone call monthly to update me on what is happening etc. I do understand that the CNS is under a lot of pressure…."

Conclusion and key messages

As the above report clearly demonstrates, patient feedback in relation to their experiences in the care of the Urology Cancer Service in the Southern Trust, have been overwhelmingly positive, with patients feeling well informed about treatment plans and timings, included in decision making and given options in relation to treatment as well as being well supported by the staff team.

It would appear, from patient experience and insight that there is an ethos of person centred care across the service. The prevalent culture, based on the majority of conversations would seem to be one in which the patient is valued, and this culture pervades from initial diagnosis right through the treatment process to aftercare.

None of the patients who took part in the conversations reported disruption because of Covid, and there was a sense that even though precautions meant that they had to attend appointments alone or wear masks, they were accepting of this and grateful that treatment could continue.

A significant number of people expressed a preference for telephone consultations or appointments *where appropriate.* Especially for patients who worked, they deemed it preferable to receive results by telephone rather than taking time off to travel to receive the results in person.

Nevertheless, some of the patient insight indicated areas for improvement, some relating to the service itself, and others which might be deemed as out of the remit of the service. Not every patient interviewed, for example was aware of the terms 'CNS' or 'Key Worker' and there appeared to be some confusion with the term 'Macmillan Nurse'

Whilst the majority of patients were aware of their treatment plan and informed about timings and processes, a small number reported that they had little or no awareness of it, and instead resorted to the internet to look for information on what various treatments entailed.

The impact on the patient of undergoing cancer diagnosis and treatments cannot be underestimated and a small number of patients said that some form of follow up after treatment finished would provide much needed reassurance and support.

Although not an area for improvement as such, it is worth nothing that several of the patients were quite content to let staff 'get on with it' and did not actively seek to be involved in their care as a result.

In conclusion, based on key insights gathered by peer facilitators, key messages can be summarised as follows:

- The role of the Clinical Nurse Specialist (CNS) is crucial, this has been evident throughout the report, with patients reporting that the CNS provides high level care, continuity and reassurance. Even when other staff members cannot be reached, it is the CNS who provides essential support.
- There is a lack of awareness in some patients of the CNS/Key Worker role, with some patients referring to 'Macmillan Nurses' instead, or in a small number of cases not having any contact with a CNS at all
- Involvement of the patient in decisions about their care matters. Patients have reported a greater sense of choice and control in their care, indicating that they felt listened to and their choices respected, even if it may not have been the option preferred by the professional.
- Some patients are content to defer to the 'experts' and do not seek to be involved in decisions about their care.
- Providing the patient with information about their treatment plan is important, including details about timings and stages of treatment, so that the

patient knows what to expect and when. Patients said that if they were aware of everything in advance, this helped them prepare for what was to come.

- Lack of information about treatment or lack of a treatment plan, can lead to greater levels of uncertainty or even fear, with some patients resorting to the internet to search for information.
- Telephone appointments and consultations are preferred by a significant number of patients where appropriate.
- Patients reported an awareness of pressures on staff, especially in hospitals and it was thought that the pandemic has had an impact in this regard
- Waiting times between appointments can be long for some patients, and when treatment finishes, patients can be left feeling insecure and in some cases scared of what the future might bring. In such cases, follow up support between appointments or after treatment finishes could bring a greater sense of reassurance to the patients concerned.