

Manuscript Details

Manuscript number	YEJON_2016_32
Title	Aiming for a holistic integrated service for men diagnosed with prostate cancer – Definition of standards and skill sets for nursing and allied healthcare professionals.
Article type	Full Length Article

Abstract

Objectives -To establish a comprehensive set of recommendations for the service structure and skill set of nurses and allied healthcare professionals in prostate cancer care. **Methods** -Using components of formal consensus methodology, a 33-member multidisciplinary panel produced 53 items for discussion relating to the provision of care for prostate cancer patients by specialist nurses and allied healthcare professionals. -Items were developed by two rounds of email correspondence in which, first, items were generated and, second, items refined to form the basis of a consensus meeting which constituted the third round of review. The fourth and final round was an email review of the consensus output. **Results** -The panel agreed on 33 items that were appropriate for recommendations to be made. These items were grouped under categories of “Environment” and “Patient Pathway” and included comments on training, leadership, communication and quality assessment as well as specific items related to prostate diagnosis clinics, radical treatment clinics and follow-up survivor groups. **Conclusions** - Specialist nurses and allied healthcare professionals play a vital role alongside urologists and oncologists to provide care to men with prostate cancer and their families. -We present a set of standards and consensus recommendations for the roles and skill-set required for these practitioners to provide gold-standard prostate cancer care. -These recommendations could form the basis for development of comprehensive integrated prostate cancer pathways in prostate cancer centres as well as providing guidance for any units treating men with prostate cancer.

Keywords	Prostate cancer; Patient care pathway; Allied Health Personnel; Holistic health;
Taxonomy	Prostate Cancer, Care, Integrated Care Pathway, Allied Health Professionals, Nursing
Corresponding Author	Alastair D G Lamb
Order of Authors	Alastair D G Lamb, Sue Thompson, Netty Kinsella, Ingmar Gerbitz, Elaine Chapman, Lisa Putt, Sophie Bennett, Vineetha Thankappannair, Lisa Geoghegan, Naomi Wright, Alison Stirton-Croft, Penny Nixon, Andrew Styling, Diane Whitney, Lindsay Hodgson, Lisa Punt, Jenny Longmore, Mike Carter, Bill Petch, Siimon Russell, Luke Hughes-Davies, Danish Mazhar, Nimish Shah, Vincent Gnanapragasam, Andrew Doble, Ola Bratt, Christof Kastner
Suggested reviewers	Declan Murphy, Kathryn Chatterton

Submission Files Included in this PDF

File Name [File Type]

TUF Pathway - Cover letter.docx [Cover Letter]

AUTHOR DECLARATION.docx [Conflict of Interest]

Lamb Prostate Pathway Consensus - manuscript.docx [Manuscript File]

HIGHLIGHTS.docx [Highlights]

To view all the submission files, including those not included in the PDF, click on the manuscript title on your EVISE Homepage, then click 'Download zip file'.

Saturday 17th December 2016

Professor Alex Molassiotis

Editor, European Journal of Oncology Nursing

alex.molassiotis@polyu.edu.hk

Dear Professor Molassiotis,

We have great pleasure in submitting our manuscript entitled "**Aiming for a holistic integrated service for men diagnosed with prostate cancer – Definition of standards and skill sets for nursing and allied healthcare professionals.**" Further to your discussions with Netty Kinsella we believe that European Journal of Oncology Nursing would be the ideal place to disseminate this work.

In brief, we gathered together a network of experts involved in provision of nursing and medical prostate cancer care to agree on key recommendations for clinical nurse specialists and AHPs providing a gold-standard prostate cancer pathway. We present here the results of that consensus meeting and the attendant rounds of review with the intention of providing a framework for such care provision in similar centres.

We believe this is a timely report given the recent European Prostate Cancer Unit Initiative publications (Valdagni et al) and that it will be of interest to the wider prostate cancer and urological community. In fact, developing such an integrated service may make a significant difference to cancer related outcomes, side-effects, quality of life and patient experience. We also believe this work is likely to be highly cited, being the first time that such a consensus report has been produced.

We are pleased to submit this manuscript for review at European Journal of Oncology Nursing and look forward to hearing from you.

Kind regards,

Alastair Lamb and Christof Kastner on behalf of the authors.

AUTHOR DECLARATION TEMPLATE

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome. We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us.

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

We understand that the Corresponding Author is the sole contact for the Editorial process (including Editorial Manager and direct communications with the office).

He is responsible for communicating with the other authors about progress, submissions of revisions and final approval of proofs. We confirm that we have provided a current, correct email address which is accessible by the Corresponding Author and which has been configured to accept email from

Signed by corresponding author on behalf of all authors:

A handwritten signature in blue ink, appearing to read 'Alastair DG Lamb', with a long horizontal stroke extending to the right.

Alastair DG Lamb

Peter MacCallum Cancer Centre, Melbourne, Australia

& Christof Kastner

Addenbrooke's Hospital, Cambridge, UK

**Aiming for a holistic integrated service for men diagnosed with prostate cancer –
Definition of standards and skill sets for nursing and allied healthcare professionals.**

Alastair D Lamb¹, FRCS(Urol), PhD, Sue Thompson², RN, Netty Kinsella³, RN, PhD, Ingmar Gerbitz⁴, RN(Germ), Elaine Chapman¹, RN, Lisa Putt¹, RN, Sophie Bennett¹, RN, Vineetha Thankappannair¹, RN, Lisa Geoghegan¹, RN, Naomi Wright¹, RN, Alison Stirton-Croft¹, RN, Penny Nixon¹, Andrew Styling¹, Diane Whitney¹, Lindsay Hodgson¹, Lisa Punt⁵, Jenny Longmore¹, Mike Carter⁶, Bill Petch⁶, Yvonne Rimmer¹, FRCP, PhD, Simon Russell¹, FRCP, PhD, Luke Hughes-Davies¹, FRCP, PhD, Danish Mazhar¹, FRCP, PhD, Nimish C Shah¹, FRCS(Urol), Vincent J Gananapragasam¹, FRCS(Urol), PhD, Andrew Doble¹, FRCS(Urol), Ola Bratt^{1,7}, MD, PhD, Christof Kastner,¹ FRCS(Urol)

¹CampPARI Clinic, Cancer Directorate, Addenbrooke's Hospital, Cambridge, UK

²Peterborough City Hospital, Peterborough, Cambridgeshire, UK

³Royal Marsden Hospital, Fulham Rd, London, UK

⁴Martini-Klinik, Martinistraße 52, 20246 Hamburg, Germany

⁵Maggies Wallace, Long Road, Cambridge, UK

⁶Patient representatives

⁷Department of Translational Medicine, Division of Urological Cancer, Lund University, Sweden

Corresponding Author:

Mr Christof Kastner. Email: Christof.Kastner@addenbrookes.nhs.uk

Keywords:

Prostate cancer; Patient care pathway; Allied Health Personnel; Holistic health;

Word Count: 3560 words

Structured Abstract

Objectives

-To establish a comprehensive set of recommendations for the service structure and skill set of nurses and allied healthcare professionals in prostate cancer care.

Methods

-Using components of formal consensus methodology, a 33-member multidisciplinary panel produced 53 items for discussion relating to the provision of care for prostate cancer patients by specialist nurses and allied healthcare professionals.

-Items were developed by two rounds of email correspondence in which, first, items were generated and, second, items refined to form the basis of a consensus meeting which constituted the third round of review. The fourth and final round was an email review of the consensus output.

Results

-The panel agreed on 33 items that were appropriate for recommendations to be made. These items were grouped under categories of "Environment" and "Patient Pathway" and included comments on training, leadership, communication and quality assessment as well as specific items related to prostate diagnosis clinics, radical treatment clinics and follow-up survivor groups.

Conclusions

- Specialist nurses and allied healthcare professionals play a vital role alongside urologists and oncologists to provide care to men with prostate cancer and their families.

-We present a set of standards and consensus recommendations for the roles and skill-set required for these practitioners to provide gold-standard prostate cancer care.

-These recommendations could form the basis for development of comprehensive integrated prostate cancer pathways in prostate cancer centres as well as providing guidance for any units treating men with prostate cancer.

Introduction

Prostate cancer is a common disease that, on current statistics, will be diagnosed in 12.5% percent of the male population in the UK with current life expectancy projections.(1) While much focus in the field has been on improving diagnosis and treatment of prostate cancer, there has been little attention as yet to the role played by allied healthcare professionals and nursing colleagues in developing gold standards of care along the entire pathway, from first contact with a prostate cancer service through to follow up after treatment. Recently, attention has focussed on the interdisciplinary and multiprofessional nature of prostate cancer care with proposals for European Prostate Cancer Units.(2) In addition, some units internationally have sought to define standards for nurse-led care in specific treatment domains, for example Robocare(3). We sought to establish a comprehensive set of recommendations for the service structure and skill set of nurses and allied healthcare professionals in prostate cancer care in a referral centre.

Receiving a cancer diagnosis has a big impact on any person and their family. From the point when patients 'walk through the door of the clinic' they should come into contact with staff who have been well trained to sensitively offer support, provide accurate and comprehensive information and easy access to services such as counselling and support groups.

The prostate cancer journey involves a great variety of specialisms and, in general, nurses need to be 'upskilled' to provide this wide ranging support. There is no standard for advanced or specialist practice within the UK for nurses or allied health professionals. The Nursing & Midwifery Council (NMC) do not legislate a level or standard of skill or competence but rather require the individual practitioner to "work within limits of your competence".(4) Such training is not standard within the NHS. The majority of specialist nurses gain their experience through longevity of role, ad hoc training and self-funded courses. Nursing and allied health professional activity (and therefore patient care and flow) are often determined by the traditional boundaries of specialties and disciplines. These specialty boundaries need to be dissolved to open gaps in education and professional development for nurses who are adopting such a cross-discipline approach. The urology work force survey (Prostate Cancer UK 2014) collated additional levels of qualification that nursing staff desire. This report examined the needs of the workforce and training requirements. The British Association of Urology Nurses (BAUN) is currently working to establish the definition of a prostate cancer nursing specialist (CNS) skill set.

Due to recent changes in prostate cancer diagnostics and management, for example minimally invasive treatments, or the use of multiparametric magnetic resonance imaging (mpMRI) early in assessment and during active surveillance, there is a natural trend towards an integrated interdisciplinary prostate cancer service. In larger centres prostate cancer professionals are making the ambitious step to grow together as an Integrated Practice Unit (IPU). European networks have proposed specialist multidisciplinary prostate cancer units to better organise prostate cancer care.(2, 5) In such units, the intention is that specialties and practitioners involved in prostate cancer care and research shape their practice together around the patient's journey. The overarching ambition is to provide the best prostate care from screening, diagnosis, treatment and patient support. This can be achieved by embracing quality-focused team working, with the patient and improved outcomes as the focus.

The formation of the IPU with a single team made of those from prostate radiology, pathology, urology and oncology and the related allied disciplines has already begun in Cambridge with development of a vision and strategy involving all disciplines and specialties as well as external expertise. During this process and discussions, it became apparent that growing an integrated nursing and allied healthcare professional service is a key strategic pillar to these efforts.

In this study we describe a process leading to recommendations and standards for nurses and allied healthcare professionals as part of a comprehensive integrated prostate cancer pathway for implementation in a large UK cancer centre. We gathered evidence, expertise and opinions by using a semi-structured approach with components of formal consensus methodology. The aim was to provide a summary of the process as guidance for our own and others' development.

Methods

Although publications and opinions from professional bodies relating to such integrated services exist in the literature, we felt that a semi-structured consensus methodology was important to allow transparency. We adopted a modified version of the Nominal Group process(6) and Delphi method(7). The Nominal Group process is a recognised approach to structured meetings that provides an orderly procedure for obtaining qualitative information from target groups. The Delphi method consists of several rounds of contributions from a defined panel with review led by a facilitator leading to convergence of opinion.(8) While using these approaches, it was felt that the process must not be restrictive and therefore the methodology was only used as a guide for discussion and documentation.

Panel

Individuals were invited to the discussion panel based on specialist expertise in their own hospital (external members) or local experience in the centre of interest (local members). This 31-member panel consisted of six local clinical nurse specialists and their leaders, four external clinical nurse specialists (three from UK, one from Germany), two physiotherapists, one advanced practitioner therapeutic radiographer, two brachytherapy physicists, two patient representatives, one trial co-ordinator, one psychologist, five oncologists and six urologists, one of whom was from Sweden.

Process

The 31-member panel were invited to suggest items relating to key stages of the patient pathway or questions (in PICO format(9)) as part of the first stage of the process. This first round was conducted by e-mail, with items of interest and relating statements collated and in a second stage by email further comments were invited.

The third round of discussion took place at a meeting convened at Addenbrooke's Hospital, Cambridge. The items of interest were presented in tabular format with comments summarised where agreement was obvious or diverging opinions highlighted. This table was used as an agenda for the discussions of the day and minutes were taken by the two chairs whilst discussions were taking place.

The fourth round involved the collation of this summary from the documentation of all stages by the chairs with subsequent input from all members to finalise the document.

Results

Items for discussion

There were 53 items tabled for discussion, which were distilled to 33 items on final round reporting that fell into two broad categories of “Environment” and “Patient Pathway”. The Environment category included items concerning infrastructure and activities that facilitate the work of health care professionals, promote their performance and outcomes and support their personal work experience - these items are globally relevant across the whole pathway (**Table 1**). The Patient Pathway category was divided into 11 subsections pertaining to each step along the prostate cancer care pathway (**Table 2**).

Environment

A functional and dynamic working environment is of key importance to the provision of any healthcare service,(10) providing the framework and philosophy in which patients are managed and healthcare delivered. The group identified three broad areas under which items were discussed including a general area of ‘Quality, Leadership & Training’, as well as ‘Communication’ and ‘Assessment’.

Generally the group were in strong agreement that practitioners should share experience in order to learn from one another and that care should be taken to avoid a blame culture (**Table 1**). Styles of leadership were discussed and broad agreement that a ‘flat hierarchy’ is preferable with a strong emphasis of integration of nursing and allied health practitioners into the overall leadership structure. There was general consensus that this is what patients want, although establishing such structures can be time-consuming and needs buy-in from various stakeholders.

Role development and training were discussed with general consensus that those with skills and experience should be given the mandate and resource to train others with less experience in that area. During the preparation and consensus meeting it became apparent that allied healthcare professionals (AHPs) in different disciplines have varying competencies, formal training and development. The role of the Advanced Practitioner Therapeutic Radiographer (APTR) was identified as a role with the most formalised and defined training and certification process, and was highlighted as a representative model for other practitioners (**Table 3**). In discussion of training in general, emphasis was placed on ‘local’ training with external courses being attended where possible while recognising that such courses are few and over-subscribed.(11) It was highlighted that only 2% of the current specialist nursing workforce are prostate-specialist trained which is similar to ‘rare’ cancers.(12) There was agreement that clinical nurse specialists involved in prostate cancer care should be ‘specialists’.

The group focussed on modes of communication and interaction, and agreed that printed literature and electronic forms of communication should be employed in addition to conventional face-to-face interactions. Such additional forms of communicating important details about the disease, department and treatment pathway were felt to be important in allowing the patients to review information in the comfort of their own surroundings. Discussion groups and psychological support were recommended. Very high attendance and satisfaction rates for such groups were reported (unpublished evidence) from Guys’ Hospital (prostate cancer) and from Maggie’s Wallace in

Cambridge (breast cancer). In terms of timing, patient representatives led the group in recommending that information be restricted to a bare minimum prior to diagnosis, with follow-on information and the option for further discussion being given between diagnosis and decision making appointment. The provision of a keyworker as a contact point for information was felt to be mandatory(13)(www.nationalpeerreview.nhs.uk; www.cquins.nhs.uk) but, interestingly, while the CNS is the person charged with this role in UK hospitals (Addenbrooke's, Guys, Royal Marsden) and throughout Sweden, the surgeon is the key-worker at the Martini-Klinik. Patients emphasised the importance of having a single point of contact and of meeting this person no later than diagnosis. Private rooms should be provided for confidential consultations and care should be taken to ensure consistency in communication by all staff.

Finally, under discussion of environment, the group recommended establishing a culture of continual assessment both of patient satisfaction and medical outcomes. Questionnaires were recommended (e.g. CARE Measure(14) or National Cancer Patient Experience Survey(15)) to audit the patient experience and emphasis was placed on the importance of adequate and comprehensive information management systems with staff employed or time allocated to permit accurate recording and data management.

Patient Pathway

The group identified 11 separate areas for discussion relating to essential aspects along the prostate cancer patient's pathway, under which all items were listed (**Table 2**). Under preparatory items identified in advance of entry to the prostate cancer service the group recognised the importance of effective information exchange and education with primary care practitioners. In addition patients should be given the option of contact with a CNS prior to their clinic attendance, something that is already offered at Guys Hospital and Imperial. At entry to the service, call centre or reception staff should be given training to include some basic prostate cancer knowledge and empathic communication, although it was recognised that such training would need to be adapted to the local setting.

The prostate diagnostic clinic is the workhorse of any prostate cancer service, seeing the most patients and at the earliest point in their journey. Recommendations here included the designated CNS keyworker hosting the patient through the process (described as a 'guest' at the Martini-Klinik), and patient representatives emphasised keeping information exchange to a 'minimum required' at this stage. The basic set of assessments were discussed and comprehensive evaluation of lower urinary tract symptoms (LUTS), sexual function and bowel function, as well as a Quality of Life and a Holistic Needs Assessment were recommended, with these assessments serving both as a screening tool but also to inform subsequent treatment options. Nonetheless it was recognised that practice differs at different sites, for example the Martini-Klinik only routinely perform urinary flow studies on those who wish to undergo brachytherapy, while the Royal Marsden Hospital offers all of the above and, where appropriate, urodynamic studies. Prostate biopsy was discussed at length, including review of available literature on skill sets and training which has been defined by the British Association of Urological Nurses (BAUN).(16, 17) The group recommended that any practitioner who meets such training criteria and works within a clinical team and environment providing governance can perform prostate biopsies and that biopsy results should be collected personally and reviewed for quality control. Patients must be counselled appropriately regarding the potential side

effects of biopsy, especially given that this is the point of entry to the service for many men and the experience here will determine compliance with future treatment and trial participation.

Multidisciplinary Team (MDT) meetings should be the focal point for treatment decision in prostate cancer(18) and the group felt that all staff involved in the patient's care should be invited to attend, including referring urologists. The CNS keyworker should be designated as the patient's advocate and responsible for communicating the result of discussions to the patient. Those presenting the case should ideally have met the patient and essential LUTS, bowel and sexual function assessments should be available at this meeting to ensure accurate treatment decision making. The MDT-Fit model was seen as a useful tool for continuous improvement in team working at MDT.(19)

Several items were discussed relating to the 'results clinic' including some recommendations that were deemed 'essential' in this category. An essential requirement on delivery of bad news was the presence of the CNS in the room, giving a one patient to two practitioners ratio (on inclusion of the urologist). Indeed, it was felt that when notifying the prostate cancer diagnosis the doctor is the dispensable practitioner, although careful MDT governance would be needed if this were to be led by CNS alone. A CNS in this setting in the UK must be Band 7(20, 21) or above (see **Table 1** for detailed CNS description) and have received Advanced Communication Skills training. An Holistic Needs Assessment should be done early at diagnosis if possible or within 6 weeks of diagnosis. The Group recommended that a personal phone call from a CNS and attendance at a support group (for example, Maggie's Centre) should be offered after receiving diagnosis. The role of psychological support workers was recognised at this stage and some hospitals (for example Guy's Hospital) have an established tariff for groups of this nature. The decision-making aspect of the results clinic should involve all relevant specialist practitioners but be CNS-led. All practitioners should aim for equipoise(22) while acknowledging treatment-specific expertise. Interaction should involve, where relevant, use of videos, diagrams and information sheets as adjuncts, possibly shared beforehand with the patient, for example in the form of an electronic tablet.

The distinction between 'Results clinic' and 'Treatment clinic' varies across institutions but, for discussion, these were considered separately by the Group. The recommendation was that a single practitioner (CNS or AHP) act as the point of contact for an individual from the time of treatment decision through treatment and follow up, recognising that this practitioner may change from the keyworker allocated at diagnostic visit. The scope of practice for the CNS and AHP was considered and the Advanced Practitioner Therapeutic Radiographer (APTR) role used to demonstrate the potential for independent pre-treatment, on-treatment and post-therapy management.

Further treatment-related items included the Pre-Assessment Clinic at which the Group felt that patients should be given a choice whether to attend an appointment on the same day as discussion of treatment options or at a later date. The Martini-Klinik have a dedicated CNS who undertakes pre-operative assessments in the treatment clinic while at other institutions this service is provided by a different team, often led by anaesthetic staff. All patients should be pre-assessed to streamline the treatment process and timing of surgery should be discussed.

Physiotherapy assessment and training for pelvic floor exercises should be offered to all men undergoing radical treatment.(23, 24) The Group recommended that this be offered in a group setting and by a trained physiotherapist. Such group sessions can also be used to brief patients on their upcoming admission and inform expectations. It was recognised that visual feedback for pelvic

floor training can be useful, especially for those who do not find the concept of PFEs straightforward, but that further evidence is awaited from randomised trials. Ongoing assessment of patient satisfaction and outcomes should take place. The Royal Marsden hospital offers “pr-hab” seminars to all men with upcoming radical treatment alongside You-Tube videos(25, 26) and apps such as “Squeezy(27)”. In the Martini Klinik these sessions are delivered one-to-one by a specialist nurse.

Finally, the ‘follow-up clinic’ was considered. The Group recognized that follow-up could be provided by a range of individuals (medical, nursing or AHP). The consensus was that CNS representatives should be present for aftercare counselling and that such practitioners should be equipped to handle the continued basic management and information needs of the patient post-therapy. Again, the Advanced Practitioner Therapeutic Radiographer (APTR) model was highlighted (**Table 3**) as an example with APTRs running follow up clinics for initial assessment of side-effects after radiotherapy and onward referral for rehabilitation as needed followed by a telephone review service.(28, 29) Emphasis was placed on the need for first post-treatment review to be face-to-face wherever possible but that there is a place in the longer term for telephone, online (e.g. PSA Tracker(30)) or questionnaire-based assessment (e.g. SurveyMonkey). The Martini-Klinik sends out 20,000 questionnaires per annum (all living men treated at the clinic), with most men being managed by local urologists, reflecting the nature of the Klinik’s referral practice. However, they also offer face-to-face follow-up. The concept of ‘Survivorship clinics’ was discussed. At the Royal Marsden Hospital these are provided face-to-face on first assessment by an andrologist, an advanced nurse practitioner and a nurse to include assessment of PSA, erectile function and continence (with pad weights when necessary). Subsequent assessments are managed with SurveyMonkey. Funding for such clinics varies with the Group noting, for example, that Mt Vernon Hospital is funded by MacMillan, while others obtain hospital funding.

Discussion

The ultimate goal was to improve care of patients by producing a consensus of opinion on gold-standard nursing and allied healthcare roles in management of prostate cancer in large tertiary centres. The preparatory work for this meeting, in addition to discussions face-to-face, was revelatory for all involved. Although many of our results and recommendations are based on best practice experience rather than scientific evidence, there was genuine consensus for the respective proposals. This in itself was an encouragement to the members involved as they were affirmed in their individually developed practice.

Without question we agreed that the patient has to be at the centre of the service and of the interactions of all groups and individuals involved. We concluded that an integrated team environment with a flat hierarchy is most desirable. Other key pillars include establishing a culture of leadership without blame, sharing experience and learning based on an outcome based quality management.

One of the reasons to embark on this exercise was the absence of standardisation of training and of day-to-day practice. However, having engaged in this process, we have learnt that good models do exist. The advanced radiotherapy practitioner training and job description already is structured in detail and should be used as a template for nursing or AHP equivalents. Evidence shows that “where these roles have been introduced they have demonstrated the potential to drive efficiency, reduce waiting times and refocus radiotherapy services around the needs of patients.”(31) In the development of these standardised models the relevant bodies should indeed ignore boundaries and aim for an integrated approach.

Our consensus discussions have been systematically presented. We do not claim that they are the ultimate solution. Rather we want to progress the development and optimisation of care of prostate cancer patients by encouragement of practitioners to proceed in their good practice or by initiating further thought and discussions.

We recognise the limitations of this approach given that this is a report of recommendations made by a consensus group where the evidence incorporates opinion, published literature, experience and practice. This, of course, introduces bias and can produce recommendations that reflect the opinions of certain individuals who dominate a discussion. We have sought to mitigate this by drawing together a broad group of representatives, carefully preparing items for discussion from all participants, impartial chairing of the discussion on the day, and ensuring that all members of the group were given the chance to reflect on the final items of recommendation with time to amend and propose changes to the group as necessary. Another limitation is that the views expressed here inevitably tend towards the practice (or desired practice) of a few large UK centres. This has been mitigated by invited representatives from the Martini-Klinik in Germany and care has also been taken to define UK specific terms. In addition, we have not sought to cover metastatic prostate cancer or end-of-life care as we did not feel that this fell within the scope of this consensus group.

In conclusion, specialist nurses and allied healthcare professionals play a vital role alongside urologists and oncologists to provide care to men with prostate cancer and their families. We present a consensus of recommendations and standards developed using components of formal consensus methodology, for the desired role and skill-sets of these practitioners addressing both the

specific elements of the prostate cancer patient pathway and the general environment in which such gold-standard care can be provided.

Acknowledgements

Thank you to The Urology Foundation (Small Project Award 2015) for their support in funding the consensus meeting.

References

1. Cancer Research UK 2016. Lifetime risk of prostate cancer. Website: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/incidence#heading-Four>. Accessed: 28/3/2016. [cited 2016 28th March]; Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/incidence#heading-Four>.
2. Valdagni R, Van Poppel H, Aitchison M, Albers P, Berthold D, Bossi A, et al. Prostate Cancer Unit Initiative in Europe: A position paper by the European School of Oncology. Critical reviews in oncology/hematology. 2015;95(2):133-43. Epub 2015/06/21.
3. Birch E, van Bruwaene S, Everaerts W, Schubach K, Bush M, Krishnasamy M, et al. Developing and evaluating Robocare; an innovative, nurse-led robotic prostatectomy care pathway. European journal of oncology nursing : the official journal of European Oncology Nursing Society. 2016;21:120-5. Epub 2016/03/10.
4. The Code for Nurses and Midwives. Nursing & Midwifery Council. . <https://www.nmc.org.uk/standards/code/>: Jan 2015.
5. Valdagni R, Albers P, Bangma C, Drudge-Coates L, Magnani T, Moynihan C, et al. The requirements of a specialist Prostate Cancer Unit: a discussion paper from the European School of Oncology. European journal of cancer. 2011;47(1):1-7. Epub 2010/12/04.
6. Van de Ven A, Delbecq A. The nominal group as a research instrument for exploratory health studies. Am J Public Health. 1972;62:337-42.
7. Pill J. The Delphi method: substance, context, a critique and an annotated bibliography. Socio-Econ Plan Sci. 1971;5:57-71.
8. Fink A, Kosecoff J, Chassin M, Brook RH. Consensus methods: characteristics and guidelines for use. Am J Public Health. 1984;74(9):979-83. Epub 1984/09/01.
9. Richardson WS, Wilson MC, Nishikawa J, Hayward RS. The well-built clinical question: a key to evidence-based decisions. ACP journal club. 1995;123(3):A12-3. Epub 1995/11/01.
10. Franco LM, Bennett S, Kanfer R. Health sector reform and public sector health worker motivation: a conceptual framework. Social science & medicine. 2002;54(8):1255-66. Epub 2002/05/07.
11. <http://prostatecanceruk.org/for-health-professionals/education/courses/urological-nursing-courses>. 2016.
12. Specialist nursing workforce UK Research Report 2014. http://prostatecanceruk.org/media/2491517/2631-urology-nurse-workforce-research-report_web.pdf: 2014.
13. Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist. National Cancer Action Team; 2010 [cited <http://www.macmillan.org.uk/documents/aboutus/commissioners/excellenceincancercaretheco ntributionoftheclinicalnursespecialist.pdf>].
14. CARE. Consultation and Relational Empathy (CARE) Measure. <http://www.caremeasure.org/>; Nursing, Midwifery and Allied Health Professions Research Unit (NMAHP-RU); 2016 [31/08/2016]; Available from: <http://www.caremeasure.org/>.

15. National Cancer Patient Experience Survey. <http://www.ncpes.co.uk/index.php>: Quality Health; 2016 [09/09/2016].
16. Greene D, Ali A, Kinsella N, Tuner B. TRANSRECTAL ULTRASOUND AND PROSTATIC BIOPSY: GUIDELINES & RECOMMENDATIONS FOR TRAINING. http://www.baus.org.uk/_userfiles/pages/files/Publications/Transrectal%20Ultrasound%20%20Prostatic%20Biopsy%20FINAL.pdf: www.baus.org.uk, April 2015.
17. Turner B, Aslet P. Nurse practitioner-led prostate biopsy in the United Kingdom. *Urologic nursing*. 2011;31(6):351-3. Epub 2012/01/24.
18. Lamb BW, Brown KF, Nagpal K, Vincent C, Green JS, Sevdalis N. Quality of care management decisions by multidisciplinary cancer teams: a systematic review. *Annals of surgical oncology*. 2011;18(8):2116-25. Epub 2011/03/29.
19. MDT-Fit: Briefing Note. http://www.nhs.uk/media/2444565/mdt-fit_briefing_note_sept_2013.pdf: 2013.
20. Minimum Core Job Description for Band 7 CNS. http://www.macmillan.org.uk/documents/aboutus/health_professionals/cnsband7jd.pdf: Macmillan Cancer Support; 2016.
21. RCN Factsheet: Specialist nursing in the UK. https://www2.rcn.org.uk/_data/assets/pdf_file/0018/501921/4.13_RCN_Factsheet_on_Specialist_nursing_in_UK_-_2013.pdf: Royal College of Nursing; 2014.
22. Mills N, Donovan JL, Smith M, Jacoby A, Neal DE, Hamdy FC. Perceptions of equipoise are crucial to trial participation: a qualitative study of men in the ProtecT study. *Controlled clinical trials*. 2003;24(3):272-82. Epub 2003/05/22.
23. Chang JI, Lam V, Patel MI. Preoperative Pelvic Floor Muscle Exercise and Postprostatectomy Incontinence: A Systematic Review and Meta-analysis. *European urology*. 2016;69(3):460-7. Epub 2015/11/28.
24. Centemero A, Rigatti L, Giraudo D, Lazzeri M, Lughezzani G, Zugna D, et al. Preoperative pelvic floor muscle exercise for early continence after radical prostatectomy: a randomised controlled study. *European urology*. 2010;57(6):1039-43. Epub 2010/03/17.
25. Darshpreet K. Pelvic Floor Muscle Exercises. <https://www.youtube.com/watch?v=7lqrHYRQOas>
accessed 09/09/2016.
26. David H. Pelvic Floor Exercises. https://www.youtube.com/watch?v=QHwVglPQR_w.
27. Squeezy App. The NHS Physiotherapy App for Pelvic Floor Muscle Exercises. <https://itunes.apple.com/au/app/squeezy-nhs-physiotherapy/id700740791?mt=8>.
28. Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient education and counseling*. 2005;57(3):250-61. Epub 2005/05/17.
29. Verma R, Treasure P, Hughes R. Development and evaluation of radiographer led telephone follow up following radical radiotherapy to the prostate. A report of a Macmillan Cancer Support Sponsored Pilot project at Mount Vernon Hospital. *Radiography*. 2015;21(1):16-24.
30. Hennessey DB, Lynn C, Templeton H, Chambers K, Mulholland C. The PSA tracker: a computerised health care system initiative in Northern Ireland. *The Ulster medical journal*. 2013;82(3):146-9. Epub 2014/02/08.
31. National Radiotherapy Advisory Group. 2007. Radiotherapy: developing a world class service for England. http://www.axrem.org.uk/radiotherapy_papers/DH_Radiotherapy_developing_first_class_service_NRAG.pdf2007.
32. Department of Health Learning and Personal Development Division (2003). *Radiography Skills Mix: A report on the four-tier service delivery model*. London: Department of Health. 2003.

33. College of Radiographers (2005) Implementing Radiography Career Progression: Guidance for Managers. London: The College of Radiographers. 2005.
34. Holland J, Rowland J, eds. Handbook of Psycho-oncology: Psychological Care of the Patient with Cancer. . Oxford: Oxford University Press; 1990. 1990.
35. Egan G. The Skilled Helper: A Problem-Management Approach to Helping 7th edn. . Pacific Grove, CA: Brooks/Cole; 2002. 2002.
36. Rees CE, Bath PA, Lloyd-Williams M. The information concerns of spouses of women with breast cancer: patients' and spouses' perspectives. Journal of advanced nursing. 1998;28(6):1249-58. Epub 1999/01/15.
37. Silverman J, Kurtz S, Draper J. Skills for Communicating with Patients Oxford: Radcliffe Publishing; 2005. 2005.
38. McGregor S. Information on video format can help patients with localised prostate cancer to be partners in decision making. Patient education and counseling. 2003;49(3):279-83. Epub 2003/03/19.
39. Calman K, Hine D. A Policy Framework for Commissioning Cancer Services. London: The Stationery Office; 1995. 1995.
40. Department of Health. Cancer Reform Strategy.
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf2007.

Table 1. Definitions & “Environment” consensus recommendations.

Definitions	Clinical/Cancer Nurse Specialist	CNS	<ul style="list-style-type: none"> • A nurse with specialist knowledge and practice in a specific area of disease management. • Holder of a degree (BSc) with 5 years of experience of urology nursing or can demonstrate competency and potential to transition from a Band 6 post(20, 21). • Attended Counselling/communication skills training.
Definitions	Allied Healthcare Professional	AHP	<ul style="list-style-type: none"> • Health care practitioners, exclusive of physicians and nurses, with formal education and clinical training who are credentialed through certification and registration with the Health Care Professions Council; these may include physiotherapists, radiographers, counsellors and psychologists. • They collaborate with physicians and other members of the health care team to deliver high quality patient care services.

Category	Item	Personnel	Comments & Recommendations
Quality, Leadership & Training	Senior staff to establish an environment of mutual learning	Consultants Senior nurses	<ul style="list-style-type: none"> • Practitioners to share experience with each other** • Willingness to learn from those who are 'better' at something. • Ongoing assessment of data towards continuous improvement.
Quality, Leadership & Training	Performance & Quality	All staff	<ul style="list-style-type: none"> • Focus on continuous quality improvement • Aim to establish individual employee strengths • Take care to avoid blame culture** • Attention to approach and attitude so that results can be shared without blame.
Quality, Leadership & Training	Leadership	All staff	<ul style="list-style-type: none"> • Importance of selection of leaders who will act as role models, provide vision, and also have experience on shop-floor. • Flat hierarchy. Example of grass-roots football team with 10 players on a level and one captain (model used for consultant specialists in Martini-Klinik). • Importance of integrating nursing team into overall leadership structure. • Avoid separation of nursing and medical hierarchies which can lead to different agendas. • Experience isn't everything - focus should be on requirements of a role / skills needed rather than length of time spent in a job. This should be stated clearly in job description, especially for leadership roles. • Establishing horizontal leadership hierarchies takes time and needs 'buy-in' from all stakeholders. • Patients have indicated that they want this.
Quality, Leadership & Training	Training	All staff	<ul style="list-style-type: none"> • Emphasis on local training and training on the job • Those with skills/experience in a specific area (e.g. Outpatient clinic) to be tasked with and provisioned for training less experienced staff in the same area. • Concept of coaching each other. • Avoid thinking of oneself as an isolated worker.
Quality, Leadership & Training	CNS/ AHP Role Development	CNS, AHPs	<ul style="list-style-type: none"> • Importance of prostate cancer specific roles and training • Only 2% of specialist nursing workforce currently prostate specific which is similar to 'rare' cancers.* • Clinical nurse specialists should aim to be 'specialists'

			<ul style="list-style-type: none"> • Individuals should be empowered to identify areas of skills need and given resource/opportunity to acquire skills in those areas. • External courses should be attended (e.g. PCUK Masterclass) - although it was recognised that these are few and over-subscribed. • The highly defined role of Advanced Practitioner Therapeutic Radiographer can be a valuable guide for the development of skill set and job description. The meeting felt that this is supported with sufficient evidence to be used as a model for the specialist Nurse/AHP role development (see TABLE 3)
Communication	Medium for communication	All staff	<ul style="list-style-type: none"> • Aim for combination of face-to-face, printed literature and electronic. • Electronic information could take the form of an iPad/tablet or reference to website for further information. • Videos of clinician/nurse/physio discussing options allow patients to review information in comfort of own surroundings and to 'meet' their treating team in advance. • Psychological support centres can provide invaluable support. • Treatment decision webinar or seminar for men is another option. • Should not take away from value of face-to-face meetings. • Importance of individualising information as well as treatment.
Communication	Timing of information	All staff	<ul style="list-style-type: none"> • Importance of restricting information to bare minimum at diagnosis to maximise likelihood of retention. • Follow-on information should be available with option to talk further with someone after diagnosis. • Bulk of information should be given between diagnostic and treatment decision appointment (N.B. not before diagnosis which simply causes sleepless nights).
Communication	Timing of face-to-face contact	CNS	<ul style="list-style-type: none"> • Each patient should have a designated key worker.(13)** • CNS should meet the patient for the first time face-to-face at time of diagnosis. • Patients emphasise the need for a single point of contact (nurse or surgeon) and the availability of someone to speak to. • Call centres are dependent on staff having extensive experience and adequate training in actioning 'red flag' issues.
Communication	Privacy	All staff	<ul style="list-style-type: none"> • Importance of provision of private rooms for confidential conversations with sufficient space for both patient and relatives.
Communication	Consistency	All staff	<ul style="list-style-type: none"> • All practitioners should receive formalised training in advanced communication for cancer patients • Emphasis to be placed on consistent message to be communicated by all staff. • All to attend MDT planning meetings to facilitate this. • De-briefing for staff should be offered.
Assessment	Patient satisfaction		<ul style="list-style-type: none"> • Questionnaires recommended by patients and other units. • Findings should be collated and areas needing change identified and implemented

** = strong recommendations.

Table 2. "Patient Pathway" consensus recommendations.

Category	Item	Personnel	Comments & Recommendations
Preparatory	General Practitioner role at referral	GP CNS Management	<ul style="list-style-type: none"> • Recommend referring practitioners give explanatory information about why referral necessary. • GP websites available include ProsDex • Give patient the option of contacting CNS prior to appointment. • CNS and consultants to play active role in primary care education (for both early referral and post-treatment follow up care)
Entry to Service	Registration Process	Management Reception staff CNS	<ul style="list-style-type: none"> • Call centre or reception team need specialist training including prostate cancer know-how and empathy
Prostate diagnostic clinic	Specialist nurse contact	CNS	<ul style="list-style-type: none"> • CNS keyworker to meet patient at this stage as contact point for further information and questions • Information to be kept to minimum necessary at this stage
Prostate diagnostic clinic	Assessment of Erectile function and Lower urinary tract symptoms	CNS Urologist	<ul style="list-style-type: none"> • A basic set of information should be collected at this stage including: IPSS, Flow studies, PVR, IIEF, QoL questionnaire, holistic needs assessment. **
Prostate diagnostic clinic	TRUS Biopsy - skill set required	CNS Urologist	<ul style="list-style-type: none"> • Emphasis should be on skill set and training • Training has been defined (BAUS/BAUN guideline, Kinsella et al) • Any practitioner who meets training criteria can perform procedure • Biopsy results should be collected personally and reviewed to establish quality control. • Patients must be counselled appropriately regarding side-effects.
MDT	Who should attend?	All staff	<ul style="list-style-type: none"> • Referring urologists should be invited as well as all unit staff • CNS staff are personal contact point with patient and can communicate results of discussion to patient after meeting. • CNS to play role of patient advocate • Ideally, individual who presents case should know patient • LUTS and sexual function assessment need to be known at this stage to permit accurate treatment decision making.
Results clinic	Who should deliver news?	CNS Urologist	<ul style="list-style-type: none"> • Essential requirement is for one to two appointments (with Urologist and CNS key worker). • The presence of the CNS in the room at time of delivery of bad news is non-negotiable. ** • CNS in this setting must be Band 7 or above and have received Advanced Communication Skills training.
Results clinic	Holistic needs assessment	CNS Counsellor	<ul style="list-style-type: none"> • This should be done early, at diagnosis if possible. • Must be completed within 6 weeks of diagnosis. <p>The holistic needs assessment includes documentation of symptoms, support structure and a "thermometer" of the patient's level of distress.</p>

Results clinic	Support after diagnosis	CNS Counsellor Psychologist	<ul style="list-style-type: none"> • Recommend a phone call by CNS to be patient and attendance at a support group or seminar should be offered.** • Patients consider a phone call from a CNS to be desirable, especially if there's an interval between diagnosis and treatment decision clinic appointment • There is a role for psychological support workers at this stage (e.g. Maggie's Centre)
Results clinic	Decision-making	CNS Urologist Oncologist Counsellor Psychologist	<ul style="list-style-type: none"> • CNS-led but all practitioners contributing. • All practitioners to aim for equipoise while acknowledging the treatment-specific expertise of specialist treatment providers. • Use of videos, tablets, diagrams or information sheets as adjuncts to communication.
Treatment Clinic (Radiotherapy, Brachytherapy, Prostatectomy, Surveillance, other treatment)	Specialist nurse/AHP for specialist treatments	CNS/AHP	<ul style="list-style-type: none"> • Single practitioner to take responsibility and act as point of contact for all men choosing specific treatment from treatment decision through after care and follow up.
Treatment Clinic (Radiotherapy, Brachytherapy, Prostatectomy, Surveillance, other treatment)	Scope of practice	CNS/AHP	<ul style="list-style-type: none"> • Pre-treatment review with patient exploring treatment options, and understanding the side-effects associated with these (Rutten 11) • Fully independent practice during on-treatment review • Management of patients post-therapy (within a clinical team) to provide for the continued need for information regarding treatment, side-effects, and rehabilitation (Rutten) • Refer patients for consideration of onward care if indicated.
Pre-Assessment clinic	Pre-admission planning	CNS Management	<ul style="list-style-type: none"> • Patient should be given the choice whether to have the pre-treatment briefing and pre-operative assessment on the day of clinic to discuss treatment options or at a later date. • Timing of surgery should be discussed
Physio / Briefing session	Pelvic Floor Exercise (PFE) training	Physio CNS	<ul style="list-style-type: none"> • Training in pelvic floor exercises should be provided to all men awaiting radical prostatectomy.** • This is best offered in a group setting and by a trained physiotherapist** • This session is also an opportunity to brief patients on upcoming inpatient admission and inform expectations
Physio / Briefing session	Should ultrasound be used in PFE training?	Physio	<ul style="list-style-type: none"> • Visual feedback can be important and reinforce training and education. Some men find this straightforward, others benefit from additional feedback. • Recommend that the man be offered the physio service required to achieve maximal continence for him as an individual.
Physio / Briefing session	Assessing outcomes of Pre-op training	Physio CNS	<ul style="list-style-type: none"> • Assessment of patient satisfaction and continence outcomes is essential to quality improvement. • This can be offered as a face-to-face assessment or questionnaire.

Inpatient Ward	Presence of CNS	CNS	<ul style="list-style-type: none"> • CNS should be present or available through stages of inpatient care to provide continuity and ongoing source of information and support. • Set and manage patient expectations, enabling the patient.
Psychological support	Timing and Provision	Psychologist CNS Physio	<ul style="list-style-type: none"> • Should be offered to all men after prostate diagnosis clinic • Includes pre-operative counselling as well as post-operative survivorship
Follow up clinic	Who should be present?	CNS AHP APTR Urologist	<ul style="list-style-type: none"> • CNS should be present for aftercare counselling and support • NURSE/AHP management of patients post-therapy (within a clinical team) to provide for the continued need for information regarding treatment, side-effects, and rehabilitation.(28) refer patients for consideration of onward care if indicated • follow up clinic is run by the same Radiographers (or AHP) who review patients during treatment • continuity of care from treatment into follow up • patients usually know the follow up radiographer prior to entering the telephone follow up service
Follow up clinic	Mode of follow up	CNS AHP APTR Urologist	<ul style="list-style-type: none"> • First post-treatment review should be face-to-face if possible • Place for phone, online and questionnaire-based approaches with ongoing assessment (e.g. PSA Tracker, SurveyMonkey) • Phone follow-up evidence
Follow up clinic	Survivorship	CNS Psychologist	<ul style="list-style-type: none"> • Consider multidisciplinary survivorship clinics.

** = strong recommendations.

Table 3. Advanced Practitioner Therapeutic Radiographer (APTR) role description.

Definition	<ul style="list-style-type: none"> • autonomous in oncological clinical practice • defines the scope of practice of others • continuously develops clinical practice within a defined field.(32, 33)
Training	<ul style="list-style-type: none"> • Specialised first degree in Radiotherapy and Oncology • Master's degree in Radiotherapy and Oncology including: <ul style="list-style-type: none"> ○ Psychology of Cancer Care(34) ○ Counselling Skills(35, 36) ○ Contemporary Issues in Radiotherapy, Research Methods • Additional MSc modules in: <ul style="list-style-type: none"> ○ Expert Practice (On-treatment review & informed consent) ○ Prostate cancer • Advanced Communication Skills training(37, 38) • GCP training.
Skill Set	<ul style="list-style-type: none"> • on-treatment review (Advanced Practitioner-developed PGDs) • requisite professional experience and knowledge to discuss all aspects of scanning, planning, treatment delivery, and hormone manipulation at an appropriate level for the individual (laymen, clinicians or physicists), including Radiation biology/physics if required (imaging (kilovoltage/megavoltage, target volumes, doses and potential clinical implications related to side-effects) • Development of guidance/protocols to address toxicity caused by radiation therapy potential to become a non-medical prescribing body
Job description	<ul style="list-style-type: none"> • work in a specific area of expert clinical practice • delivery of specialist care to patients(39) • contribution to the evidence base (data collection for VoxTox for example) and to the development of other staff • presentation of obtained evidence/research in local, regional and national/international meetings • acts as an expert resource for their particular field of practice and demonstrates team leadership.(33) • pre-treatment review with patient exploring treatment options, and understanding the side-effects associated with these (Rutten et al(28)) • fully independent practice during on-treatment review • bleep carrier as first point of contact for triaging and managing patients with acute treatment-related toxicity within the radiotherapy department • management of patients post-therapy (within a clinical team) to provide for the continued need for information regarding treatment, side-effects, and rehabilitation(28, 29) • refer patients for consideration of onward care if indicated
Overview	<ul style="list-style-type: none"> • Addenbrooke's is the national lead for Radiographer Advanced Practice, and is a guide for other hospitals in the UK and overseas.(40) • NRAG3 statement: "... where these roles have been introduced they have demonstrated the potential to drive efficiency, reduce waiting times and refocus radiotherapy services around the needs of patients."(31)

HIGHLIGHTS

- To our knowledge this is the first consensus report on provision of gold-standard prostate cancer care by nursing and allied healthcare professionals in a dedicated prostate cancer unit.
- A group of 33 individuals, including patients, nurses, physiotherapists, radiotherapists, psychologists, researchers, oncologists and surgeons, produced a set of recommendations and guidelines.
- The process involved several rounds of review and centred on a face-to-face round-table meeting.
- The recommendations covered the entire prostate cancer care pathway from entry to the prostate clinic to end-stage care as well as more general aspects of care provision such as leadership styles, communication and assessment.
- These recommendations could form a model for similar care to be provided in other institutions.