



Policy Challenges in Prostate Cancer

Updated May 2022

The following policy challenges have been collated and written up by the Policy and Health Influencing team. It by no means represents the entirety of the challenges and issues we are engaged with. However, as a resource for recognising the priorities and providing a brief overview of our activities within prostate cancer treatment, care and support we hope it is useful.

If you think there are any policy challenges or issues missing from this document, that we should be pursuing, please get in touch with the Policy & Health Influencing team via:

campaigns@prostatecanceruk.org

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Workforce

The challenge:

There are well known workforce issues within the NHS across primary and secondary care. An existing shortfall in staff is negatively impacting patient outcomes and with increasing cancer incidence the shortfall is set to widen as the need grows.

A report by Cancer Research UK found that a 45% staff increase is needed across all seven cancer related professions to meet Health Education England's (HEE) aim to provide world class services for cancer patients by 2029.

The workforce areas we focus on are Clinical Nurse Specialists (CNSs), Radiologists, Clinical Oncologists, and Pathologists as those within the prostate cancer pathway which have the greatest relevance to patient outcomes.

Clinical Nurse Specialists (CNSs)

Men who have access to a CNS are more likely to be positive about their care and treatment. CNSs provide cost-effective, high quality and consistent care across the entire patient pathway, reducing appointment cancellations, unnecessary hospital admissions, and alleviating doctor contact. There are not enough CNSs specialising in urology which has the fewest dedicated CNSs per patient of any cancer type.

Radiologists

Multi-parametric MRI (mpMRI) scans are now built into the prostate cancer diagnosis pathway. Until recently, the only way to investigate suspected localised prostate cancer and determine whether it needs treating was based on the results of a biopsy.

mpMRI is significantly better at identifying clinically significant prostate cancer compared to biopsy alone. It also the case that as treatment options and survivability of PrC improves, recurrence monitoring becomes increasingly important. This relies on PSMA-PET scans and additional radiology resource.

The NHS radiologist workforce is short-staffed by 33% and needs at least another 1,939 consultants to keep up with pre-COVID-19 levels of demand for scans. This shortfall is forecast to hit 44% (3,613 consultants) by 2025. Already, more than half (58%) of radiology leaders say they do not have enough diagnostic and interventional radiologists to keep patients safe.

Moreover, there are significant regional variations in workforce shortages across England. Clinical radiology workforce shortages are highest in the East Midlands and the Northeast. The East

Midlands also has the lowest number of radiologists (whole-time equivalent) per 100,000 population, currently at 6.8 – the European average is 12.8 radiologists per 100,000.

Oncologists

Clinical oncologists deliver non-surgical cancer treatment including brachytherapy, radiotherapy, and chemotherapy. All essential treatment modalities for prostate cancer. The NHS needs at least another 189 (17% of the workforce) clinical oncologists to meet rising demand, and more than half of UK cancer centre clinical directors (52%) say oncologist shortages are negatively impacting patient care. If nothing is done to retain exhausted staff and expand the workforce by 2025 the shortfall of clinical oncology consultants in the NHS will be between 21–29%.

There are also large regional variations in workforce shortages for the clinical oncology workforce across England. While a quarter of cancer centres reported average annual workforce growth of 6% or more per year, another quarter reported no gain or a decline in their workforce. Regional variation in workforce has a direct impact on the care that patients receive. In areas that have severe staff shortages, access to services is likely to be more difficult and there is no time to implement treatment innovations, potentially adversely affecting patient outcomes.

Pathologists

Cancer Research UK's report, [Estimating the cost of growing the NHS cancer workforce in England by 2029](#) shows that without targeted action and investment, the number of histopathologists is forecast to reduce from the existing shortfall by an additional 2% by 2029. The Royal College of Pathologist workforce census, [Meeting Pathology Demand](#) found that just 3% of histopathology departments have enough staff to meet clinical needs.

This workforce is also an ageing one; a quarter of all histopathologists are aged 55 or over. This means that when most senior consultants retire in the next five to ten years, there will not be enough trainee doctors to replace them in numbers, let alone in knowledge and expertise. The introduction of new targets for cancer diagnosis and treatment leads to further pressure on reporting turnaround times, compounded by the now well documented COVID-19 backlog.

What are we doing about the issues?

- We campaign as part of One Cancer Voice on workforce (as most issues are pan-cancer rather than prostate cancer specific)
- Campaigning and influencing for increased recruitment of a larger prostate specific CNS workforce, while helping with the retention and development of the existing workforce through their career pathway to becoming a CNS. This is currently in development with multiple healthcare stakeholders.
- Continue to highlight workforce issues with political stakeholders highlighting and amplifying relevant reports, recommendations, and solutions to addressing those issues.

Contact: Joe Woollcott / Marion Thorpe / Andrew Seggie

Further references: See submission to the [10 Year Plan](#) and [CNS Plan](#)

<https://prostatecanceruk.org/for-health-professionals/making-the-case-for-clinical-nurse-specialists>

<https://www.rcpath.org/uploads/assets/fcb04da2-89d4-425f-8da2f12db2be18b8/HEE-Strategic-Framework-Call-for-Evidence-2021-RCPath-summary-response.pdf>

<https://www.rcpath.org/discover-pathology/public-affairs/the-pathology-workforce.html>

<https://www.rcr.ac.uk/press-and-policy/policy-priorities/workforce/radiology-workforce-census>



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Access to new drugs and treatments

As new treatments come onto the market and lead to improved outcomes for patients, in terms of longer survival and reduced side effects, we work to ensure equal access, availability and best practice in their delivery and pathway. In terms of priorities this currently includes, olaparib, lutetium and abiraterone. Each of which have specific policy challenges.

Olapraib

Olaparib is a precision medicine treatment called a PARP inhibitor, it inhibits poly (ADP-ribose) polymerase enzymes. PARP helps with DNA repair and some cancer cells rely heavily on PARP to repair their DNA.

Cancer cells with *BRCA1/2* mutations rely on PARP to help with their DNA repair, olaparib prevents this process causing cancer cells that carry the mutation to die.

Olaparib is for use in patients who have metastatic castration-resistant prostate cancer and also have a *BRCA1/2* mutation. These patients will have stopped responding to hormone treatments such as enzalutamide or abiraterone when they start taking Olaparib.

Access to Olaparib is currently still being negotiated by NICE and AstraZeneca, but the decision should be made soon.

The challenge:

Once drugs are approved by NICE/SMC patients should have timely and easy access.

One issue is that newly approved drugs are not put onto local formularies fast enough, therefore slowing down the process and ultimately taking time away from patients.

Another more specific issue for olaparib is procuring the genetic test that determines its suitability. We have had patients in Scotland tell us they have had to procure their own genetic test to know whether they may receive olaparib, which should not be the case.

This test is required to determine whether a patient has a *BRCA1/2* mutation which would then allow for them to receive treatment with this drug. The infrastructure within pathology is not robust enough currently to withstand the new influx of men coming through the pipeline in Scotland. We believe should olaparib be approved by NICE in England and Wales we may face the same issues here.

What are we doing about the issues?

We have worked to raise this with the Scottish Government and held a meeting with the health minister outlining the situation. See briefing below for more details.

In England, NICE and AstraZeneca are in discussions surrounding approval, although we foresee many similar issues arising in England/Wales as in Scotland. We are in the process of raising issues with access to newly approved medicines (with some focus on olaparib) with Anne Marie Morris MP, chair of the APPG on access to medicines and medical devices. We are also working with AZ to share our learning and insight into this issue.

The move towards more precision medicine is growing across cancer treatments. However current services for genomics and molecular pathology are not arranged in such a way to cope with the influx of demand and expense. We intend to raise this with all engaged stakeholders.

Contact: Joe Woollcott / Lizzie Ellis

Further references: [Scottish Health Minister Briefing](#) olaparib [internal briefing](#)

Lutetium

Lutetium-177 (Lu-177) PSMA-617 is used to treat metastatic castration resistant prostate cancer. The treatment is the first of its kind for prostate cancer in that it falls within the radio-ligand therapy (RLT) modality. RLT delivers radiation specifically targeting cancer cells with very little exposure to other parts of the body unlike other radiation therapies which carry a significant burden in terms of side-effects.

The challenge:

The main challenges (among many) are typically around workforce, logistics and infrastructure. If these issues are not addressed well in advance, patients will not be able to access this treatment if it is granted NICE approval.

- There are concerns around the diagnostic provision required to determine whether a patient is suitable for lutetium (177Lu). For example, some centres do not have sufficient physical facilities to perform PSMA theragnostics for numerous reasons including lack of radio-pharmacy space, PET/CT or SPECT/CT scanning capacity or room in which to give PSMA therapy.
- Centres are just in the stage of planning PSMA imaging and setting up new imaging sites is complex. Subsequently, some centres will need to rely on other hospitals/ trusts to perform PSMA imaging, potentially leading to bottle necks in the patient pathway.
- Some centres do have the environment agency authorisation for holding and disposing of lutetium.
- Additional staff will be required to provide PSMA theragnostic services.
- There is limited training specific to RLT which may also lead to insufficient numbers of trained healthcare professionals having licences to administer the treatment.
- The decline in radionuclide supply following the UK's exit from the EU which may be further compromised by the Russian war in Ukraine.
- Awareness and understanding of RLT is insufficient among people with cancer who could benefit from it.
- Equitable access/ postcode lottery concerns.

What are we doing about the issues?

We are working with the manufacturer (AAA/Novartis), stakeholder groups, and experts as well as NHS England, to raise awareness and action in a bid to ease these issues in anticipation of approval. We are also submitting information to NICE to demonstrate the clinical need for this treatment.

Contact: Marion Thorpe

Further references:

<https://prostatecanceruk.org/about-us/news-and-views/2021/6/behind-the-headlines-lutetium-therapy>

https://www.rcr.ac.uk/system/files/publication/field_publication_files/review-molecular-radiotherapy-services-uk.pdf

<https://www.healthpolicypartnership.com/app/uploads/Radioligand-therapy-realising-the-potential-of-targeted-cancer-care.pdf>

Off label Abiraterone

Abiraterone is a type of hormone therapy treatment for advanced prostate cancer. It will be coming off patent in October 2022. This will have price implications for the current and potential new indications this drug can be used in, which could in turn affect the decision as to whether it can be used in a new indication.

Abiraterone is currently recommended for treatment of metastatic hormone-relapsed prostate cancer before or after chemotherapy, however clinicians are calling for a new approved use of this drug in the non metastatic setting.

This call is for the off-label use of abiraterone (plus prednisolone) in addition to current standard of care – long-term androgen deprivation therapy and radiotherapy – based on the recent publication from the STAMPEDE study, the results of which are compelling.

What are our thoughts?

Having access to abiraterone at this point in the pathway would not only allow for a choice of treatment options which we anecdotally know improves a patient's stress levels towards their diagnosis, allowing for conversations with their clinician to decide whether abiraterone with hormone therapy would be right for them.

In this instance it allows a patient to feel more in control of their treatment regimen, and therefore quality of life, by enabling the clinician and the patient to make a shared decision based on the patient's best options and potential outcome.

Based on the trial results we also know that having abiraterone earlier enables patients to have a greater benefit than later on in the pathway. Results show the number of patients who died from prostate cancer reduced within six years by more than half (from 15% to 7%).

The potential for abiraterone to give a significant increase in progression-free survival, whilst simultaneously allowing the patient to feel that they are proactively treating their cancer would increase a patient's quality of life considerably.

What are we doing about the issues?

Scotland: Prostate Cancer UK submitted a response to the National Cancer Medicines Advisory Group (NCMAG) appraisal for the use of abiraterone in high-risk non-metastatic hormone sensitive prostate cancer. We also took part in the Council meeting held on 9 June 2022. The decision for abiraterone in this indication will be released under embargo on the 8th July.

England: We have heard anecdotally that clinicians are confident that abiraterone in this indication will be made available across the NHS post October. However, this isn't for certain. Prostate Cancer UK are working in collaboration with pharma companies who have an interest in taking abiraterone on once the patent has expired. We also have been working with clinicians to understand the benefits in this indication and to draw up the next steps in obtaining approval across England and Wales.

What does this mean for future drugs we want to use for different indications of prostate cancer?

Currently off label prescribing is a regular part of medical practice and clinicians must follow what is called a "prescribing hierarchy". At their own discretion clinicians can therefore make a decision to prescribe off-label on a patient-by-patient basis, if they are satisfied that an alternative licenced medicine would not meet the patient's needs as well as the off-label indication.

However, this system leads to variation in practice due to the lack of a set protocol for administration of a drug in a new indication. Some clinicians are not willing to take the risk at all which leaves some patients missing out entirely where they could benefit.

Scotland: The NCMAG programme has been developed with the help of the SMC to deliver advice to support the equitable access to safe and effective off-label and off-patent uses of cancer medicines to improve outcomes for cancer patients across NHS Scotland.

England: NHS commissioners (typically clinical commissioning groups (CCGs) or NHS England in one of its national direct commissioning roles, such as specialised commissioning) hold the responsibility for making decisions on which treatments are made available (and funded) within the NHS, including off-label medicines. Decisions will be based on the available evidence of relative clinical benefit and relative cost.

NICE has been asked to consider whether it could pilot an adapted approach (much like the NCMAG) for off-label medicines so that high quality guidelines can be produced to better inform commissioning decisions.



Health Inequalities

The challenge:

Issues surrounding access to treatments is made more acute through a disproportionate impact on older men, Black men and men in more deprived areas. Inequalities such as this persist throughout the prostate cancer pathway.

The National Prostate Cancer Audit reports on the determinants of potential under-treatment that “Men were more likely to receive radical treatment if they were less deprived, had fewer comorbidities and were of non-Black ethnicity. [...]

“Importantly, 40% of the men of Black ethnicity were from the most deprived group compared to 23%, 22% and 12% of the men of Asian, Other and White ethnicity indicating a disparity between deprivation status and ethnicity.”

This takes on added urgency when we consider that Black men are twice as likely to be diagnosed with prostate cancer than other ethnic groups. Health inequalities is thus a key policy challenge for Prostate Cancer UK.

What are we doing about the issues?

We work with cancer alliances and health boards to deliver risk awareness campaigns designed specifically to encourage Black men to come forward and engage with healthcare.

We campaign and influence to raise these issues through consultations, working groups and reports with key stakeholders including the APPG on Cancer, DHSC, NHS E among others.

With the recent recruitment of a Health Inequalities Manager this activity is set to increase in scope and ambition.

Contact: Lubna Latif-Curtis / Marion Thorpe / Paul Munim

Further references: <https://www.npca.org.uk/reports/npca-short-report-2020/>



Earlier Diagnosis, risk awareness and PSA tests

The challenge:

The Covid-19 pandemic meant fewer people were seeing their GPs, and NHS referrals for suspected cancer crashed as a result – an estimated 430,000 fewer people than normal were on an urgent suspected cancer referral. NHS England launched initiatives such as ‘Help us help you’ to get people talking to their GPs again, targeting other cancers.

14,000 men are missing from the prostate cancer treatment pathways.

Prostate cancer – the most common cancer in men – is a special challenge for public health campaigns. It clashes with what everyone thinks they already know about cancer: check yourself, watch for symptoms, and go for screening.

You can't check yourself; it often doesn't have symptoms until it's already spread; and it's the biggest cancer with no national screening programme. There's a blood test, but asymptomatic men probably won't get one unless they ask. And we can't tell you to ask for one, because there are pros and cons and it's not right for all men. Clinical standards say that asymptomatic men must make their own *informed decision* about whether or not to have the test, based on an understanding of their own risk and the pros and cons of the PSA test.

What are we doing about the issues?

- S&I and the Comms teams are working collaboratively to deliver national risk awareness campaigns. These campaigns will generally link to key moments throughout the year – for example, hooking on to major stories in relation to the men who have yet to come forwards for a diagnosis.
- Specific focus on awareness raising in Black men who have double the risk of being diagnosed with prostate cancer (1 in 4 compared to 1 in 8 in the general population)
- Specific focus on men with a family history (father or brother diagnosed) who are 2.5 times more likely to be diagnosed.
- Continue to support NHS stakeholders to develop and deliver regional awareness campaigns.
- Continue to look for opportunities to work in partnership with NHSE to deliver mass public awareness campaigns.

Contact: Andrew Seggie

Further references: <https://prostatecanceruk.org/prostate-information/risk-campaign>



Challenges within the Prostate Cancer pathway

Active Surveillance

The challenge:

Active surveillance is a way of managing men with low and intermediate-risk, localised prostate cancer. Men assigned to active surveillance can avoid radical treatments (surgery and radiotherapy) and the associated side-effects. Active surveillance comes with its own side-effects, namely anxiety and stress related to concerns that the cancer could spread whilst being monitored.

What are we doing about the issues?

We aim to understand the support needs of men on active surveillance, the support that will help reduce anxiety and hopefully keep men on active surveillance for as long as its clinically safe to do so. Once we know men's support needs, we'll look to develop a support package, addressing any gaps along the way. We'll continue to promote our active surveillance best practice consensus and associated healthcare professional resources. We'll develop healthcare professional education resources that highlight the support needs of men and how those needs can be met.

Contact: Andrew Seggie

Hormone Therapy

Androgen Deprivation Therapy (ADT) and Cardiovascular (CV) risk

ADT reduces the amount of testosterone the body produces, therefore slowing the growth of cancer or shrinking the cancer temporarily and is a common treatment for prostate cancer. Cardiovascular disease is prevalent in the UK with 4 million men living with a heart or circulatory disease.

The Knowledge team carried out an evidence review and found that it points to an increased CV mortality risk as a result of ADT for prostate cancer treatment.

The challenge:

The link between ADT and CV risk is not something that is covered in NICE guidelines. We have the following questions that need to be answered:

- Is there awareness of CV mortality risk associated with ADT amongst clinicians?
- Are CV risk assessments routinely performed in patients requiring ADT (particularly, outside of the "best practice" centres)?
- Does prescribing ADT vary in practice depending on the outcome of the CV risk assessment?

What are we doing about the issues?

Carrying out a project investigating the understanding of the link between ADT and Cardiovascular risk amongst clinicians. Once that understanding has been confirmed and outlined clearly actions and projects will be developed.

Contact: Tayla Maloney

Further references:

<https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/hormonal-therapy-for-prostate-cancer>

<https://www.bhf.org.uk/what-we-do/news-from-the-bhf/contact-the-press-office/facts-and-figures>



End of life care for men with prostate cancer

Please note our work, scoping and understanding the challenges regarding end of life and palliative care are in the early stages. The below represents the desk research carried out by our team and will be updated as we continue to work with experts and clinicians in this field.

Overview:

Anyone with advanced prostate cancer may be offered palliative care, sometimes called supportive care, which aims to manage pain and other symptoms. It can also provide emotional, physical, practical and spiritual support. Men with advanced prostate cancer might receive palliative care for many months or years, or as end-of-life care.

Palliative and end of life care can include treating and managing pain and other symptoms, talking about feelings, relaxation services, social groups, financial and practical support and support for family members. Treatment can be offered in a hospice, hospital, care home, own home, nursing home or residential home.

The challenge:

Early intervention - Trusts are facing difficulties understanding when is the right time to put an individual on the palliative care pathway. Questions arise regarding if they can or should, be put on to it sooner. The conversations between patients and healthcare professionals about their needs and how their needs might change are all live and subject to interpretation and variation.

Pain management - prostate cancer typically metastasises into the bones causing excruciating pain. There is no consistent approach to managing metastatic bone pain. Education is needed to inform men that pain from prostate cancer can be experienced anywhere and can be an indication of metastatic cancer. Healthcare professionals should be prepared to refer patients to pain review clinics to investigate their pain.

Communication - There can be a misunderstanding of the word 'palliative' and the difference between palliative and curative care amongst men. Men need a key contact when receiving end of life and palliative care, however those with prostate cancer are looked after by an MDT team and there is a lack of culture of communicating amongst peers, leaving men without a key person who understands their holistic needs. Men should understand that they can make informed choices about their treatments and should share their wishes during the end of life and palliative pathway and that they can change their mind during this time.

What are we doing about the issues?

We are in conversation with Phillipa Aslet Director of Nursing at St Michaels Hospice, a former BAUN president and Urology CNS. This may lead to co-production of different resources and innovations.

We have received educational talks from the charity Compassion in Dying to inform our specialist nurses and wider team on how to talk to men about end of life. This includes information on how to help people prepare for end of life and record their wishes, support to make decisions around treatment, protection from DNACPR, information on Advance Decision Forms/Power of Attorney/Advance statement.

Our Improvement Programmes team are currently developing a short course on educating healthcare professionals and patients on challenges such as communication, pain management, early intervention and understanding what palliative care means.

We provide information on our website about end-of-life care and where/how to access it.

Opportunities: There isn't much specific information about end of life and palliative care for prostate cancer patients, there should be research into the way that inequalities and access impact PrC patients in particular.

Work with Marie Curie/Hospice UK/Compassion in Dying and other charities to explore our part in improving access/quality of care/funding

Contact: Tayla Maloney (tayla.maloney@prostatecanceruk.org)

Further references:

<https://prostatecanceruk.org/prostate-information/advanced-prostate-cancer/dying-from-prostate-cancer/thinking-and-planning-ahead>

<https://professionals.hospiceuk.org/what-we-offer/publications?kwrd=hospice%20care%20in%20the%20uk>

<https://professionals.hospiceuk.org/what-we-offer/hospice-finance/benchmarking>

Marie Curie- Dying to Care: A report into social care at the end of life (2016)

Compassion in Dying talk (15th June 2022) from senior information and support nurse

<https://prostatecanceruk.org/prostate-information/advanced-prostate-cancer/dying-from-prostate-cancer/thinking-and-planning-ahead>

<https://prostatecanceruk.org/prostate-information/advanced-prostate-cancer/dying-from-prostate-cancer/thinking-and-planning-ahead>

<https://www.nhs.uk/service-search/other-services/Palliative-care/Location/Places/A/1822><https://www.nice.org.uk/guidance/ng31/ifp/chapter/About-this-information>

<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life><https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/End-of-life-care/End-of-life-care.aspx><https://lwdwtraining.uk/>



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Other policy questions

Bins in male toilets – the Boys Need Bins campaign – this campaign is centred around asking for mandatory provision of bins in men’s toilets so men who suffer from incontinence or bowel problems can dispose of their sanitary products cleanly and discreetly.

Contact: Lubna Latif-Curtis

Travel Insurance – accessing travel insurance for cancer patients is notoriously difficult and takes on additional aspects for PrC patients given the frequent longevity of their condition and treatment.

Contact: Joe Woollcott / Tayla Maloney