

2024

Policy challenges in prostate cancer



**PROSTATE
CANCER UK**

2024

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The following policy challenges have been collated and written up by Prostate Cancer UK's Policy and Health Influencing team. It by no means represents the entirety of the challenges and issues with which our team are engaged. This resource aims to recognise the policy challenges in the prostate cancer pathway but also provides a brief overview of our activities within prostate cancer diagnosis, treatment, care and support.

Please also note that throughout this document, we refer to Black men, in describing the experiences of Black African and Black Caribbean men. We recognise that there are diverse aspects within and between these groups and that this should be taken into consideration when developing policies. For the purposes of this document, we are using the collective term of Black men.

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**

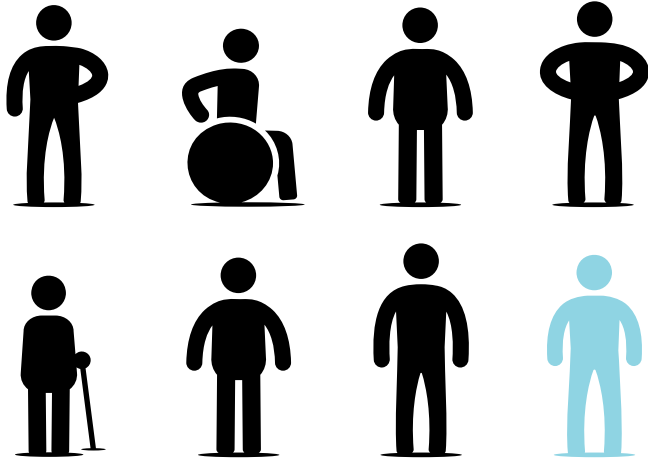
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Earlier diagnosis, risk awareness and PSA blood tests

The challenge:



1 in 8 men

will be diagnosed with prostate cancer in their lifetime in the UK. To save lives, we need to stop men from being diagnosed too late.

1 in 8 of all stage 4 cancers in England (those most likely to be deadly) are prostate cancer. It is the only major cancer without a screening programme, and while an early prostate cancer diagnosis is very curable, it often has no symptoms.

The PSA blood test is the first step to diagnose prostate cancer. It is a cheap, safe, and effective way to identify men who would benefit from further testing – the first of which is an MRI scan.

The men at highest risk of prostate cancer are Black men, men with a family history of prostate cancer, and men with genetic risk factors (e.g. BRCA2 positive, a genetic mutation which increases men's risk of developing prostate cancer). Black men have double the risk of death from prostate cancer, while men with a family history are 2 to 4 times more likely to be diagnosed. They all tend to develop the disease at a younger age – from 45 – potentially losing decades of their life and leaving them and their families dealing with the emotional hardship of losing a loved one.

Our analysis suggests that of men aged 60 or under are diagnosed with incurable prostate cancer.

33%



Late diagnosis will also be more expensive for the NHS, as treatments for advanced cancer, are much more expensive than treating the disease through surveillance, surgery or radiotherapy.

The current system is failing men who are at the highest risk, as it is based on historical trials that do not reflect the modern diagnostic pathway and that underrepresent Black men. It benefits the most health-literate, who will actively seek testing, while compounding the inequalities that affect other men. It also burdens an already stretched primary care system – unlike all other major cancer types that have funded access to early detection.

Earlier diagnosis, risk awareness and PSA blood tests

What are we doing about the issues?

- Health influencing – in the absence of screening, we focus on strategies such as stratified awareness raising, to achieve early detection and also tackle health inequalities.
- Risk awareness – campaigns aimed at raising awareness for men aged 50+ on their risk of prostate cancer and targeted campaigns towards men with high risk (Black men, men with family history, and men with genetic risk factors, e.g. BRCA2 positive).
- Advocating for continued implementation of best practice from the NHS early detection pilots.



- Strengthening our position on the optimal use of the PSA blood test through a robust consensus process of men with lived experience, clinicians and academics. This will inform:
 - our messaging towards men, i.e. how we communicate with men about the PSA blood test
 - our education and training offer for healthcare professionals – focusing on primary care
 - our policy and health influencing activity, and
 - gaps in research and evidence which need to be addressed.
- Supporting the NHS to deliver on initiatives to increase the early detection rates of prostate cancer.
- Working within England, Northern Ireland, Scotland and Wales with key political, public health, NHS and community stakeholders to deliver targeted awareness campaigns and initiatives in areas where late-stage diagnosis rates are highest.

Further references:

Prostate Cancer UK - risk campaign

Prostate Cancer UK - PCN DES resources

Health Inequalities

The challenge:

In line with one of Prostate Cancer UK's key objectives to

Reduce health inequalities and become more relevant to the communities most impacted, starting with Black men.

- we aim to investigate the health inequalities that exist at every point of the prostate cancer pathway for Black men. This forms part of our wider health inequalities workstream, which seeks to improve our understanding of the health inequalities in prostate cancer diagnosis and treatment.

We know that the life-time risk of being diagnosed with and dying from prostate cancer have previously been shown to be disproportionate between Black (1 in 4 and 1 in 12 respectively) and White men (1 in 8 and 1 in 24 respectively.) Moreover, the African-Caribbean population have been reported to have the highest rate of prostate cancer mortality in the world - 26.3 per 100,000. Past studies have investigated whether the incidence of prostate cancer seen in Black men was due to biological reasons or differences in testing rates caused either by healthcare access issues or increased testing of Black men (detection bias).

Furthermore, *The National Prostate Cancer Audit* which reports on the determinants of potential under-treatment, stated that "men were more likely to receive radical treatment if they were less deprived, did not have any other diseases or conditions at the time of their diagnosis 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 Caucasian, indicating a disparity between deprivation status and ethnicity.

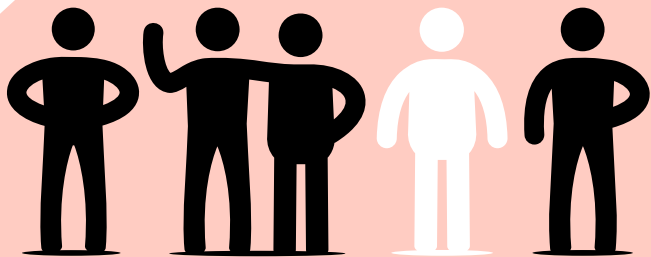
The experience of Black men must be addressed, recognising the health inequalities and unequal access to healthcare that exists for Black communities. Improving health outcomes and tackling health inequalities are therefore key policy challenges for Prostate Cancer UK.

The NHS Confederation shows that for every £1 invested in community and primary care brings back £14 to the economy, compared to £11 per £1 for acute services such as Accident and Emergency (A&E) departments. It is through working for a healthier population that the pressure will be lifted off the NHS, and the opportunity to address health inequalities will be realised.

Health Inequalities

What are we doing about the issues?

Prostate cancer is, for many men, asymptomatic until it has reached the later stages. So unlike other cancers, where there are national campaigns focussing on symptoms, we have to take a different approach. Prostate Cancer UK recently conducted research speaking to 2,000 men about what they know about prostate cancer. There is a worrying lack of knowledge about risk factors.



For example, **4 out of 5 men** did not know that being Black was a risk factor of prostate cancer.

This is why risk awareness campaigns are key to help raise awareness and empower men to make informed decisions about their health. We work with cancer alliances, integrated care boards, primary care colleagues as well as health boards to deliver risk awareness campaigns designed specifically to encourage Black men to come forward and engage with healthcare.

The Government needs to take positive action and invest to address the health inequalities that exist for Black men as well as those living in deprived communities. The National Institute of Health note that there is a higher incidence of disease, associated with deprivation, and that it channels deprived populations into categories of increased likelihood of multiple conditions and diseases with a greater prevalence of depression and higher mortality. This has implications for the way that resources are allocated in England's NHS.

We continue to campaign and influence government to raise these issues through consultations, working groups and reports with key stakeholders including the All-Party Parliamentary Group (APPG) on Cancer, DHSC, NHS, among others.

New approaches, guidelines and interventions that work with and are co-designed by Black and deprived communities must be developed. In doing so, this work needs to increase the access and uptake of prostate cancer diagnoses, treatments and care for men. This will improve experiences and outcomes and reduce the health inequalities that persist in the UK.

Further references:

National Prostate Cancer Audit (2020)

National Library of Medicine - Impact of deprivation on occurrence, outcomes and health care costs of people with multiple morbidity (2013)

The primary and secondary care 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 resulting in increased waiting times along the prostate cancer pathway. With prostate cancer to become the most common cancer in the UK by 2030, the shortfall is set to widen as the need grows. We need to improve workforce capacity in primary and secondary care to support men who have been diagnosed, and those who will be diagnosed in the future, with prostate cancer.

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 have a positive care and treatment experience. 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.

England

The number of urology CNSs is lower than other cancer types. In 2017, the *Macmillan Census* reported that 12% of CNSs in England are specialised in urology, compared with 18% in breast cancer. Based on cancer prevalence, that suggests that each breast cancer CNS in England has a caseload of approximately 160 patients, whereas for urological cancers, the caseload is around 795 cases per urology CNS. We want to see more CNSs specialised in prostate cancer care to give men the care they deserve.

Scotland

8.54% of filled CNS posts have urology as an area of practice. This is lower than other areas, for example, breast CNSs equates to 17.8% of the workforce and colorectal CNSs 12.6%. In Scotland, there were 4,066 cases of prostate cancer and 4,895 cases of breast cancer. Each urology CNS in Scotland in 2019 would have an average of 116 urology patients, compared to each breast CNS with an average of 67 breast cancer patients.

Northern Ireland

12% of CNSs had urology as an area of practice compared to 19% for breast and 14% for haematology. According to the *Northern Ireland Cancer Registry*, there are on average 1,259 prostate cancer patient cases each year (2016-2020). And on average there are 1,490 breast cancer patients per year (2017-2021). This means each urology CNS in Northern Ireland in 2021 had an average caseload of 70 patients. Compared to each breast CNS with an average case load of 48 patients.



The primary and secondary care workforce

Radiologists

MRI 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.

MRI is significantly better at identifying clinically significant prostate cancer compared to biopsy alone. Also, as treatment options and survivability of prostate cancer improves, recurrence monitoring becomes increasingly important. This relies on PSMA-PET scans, a type of scan commonly used to see if prostate cancer has come back. As such, the radiology workforce is crucial to the prostate cancer pathway.

However, 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.

The Royal College of Radiologists Clinical Radiology Workforce Census in 2022 found that the average growth of oncological radiologists over the past five years has been 1% compared to 11% for neuroradiologists.

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%.

Similar to radiologists, there are large regional variations in workforce shortages for the clinical oncology workforce across England. While a quarter of cancer centres reported an 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.

The primary and secondary care workforce

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 issues (as many 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.
- We continue to highlight workforce issues with political stakeholders by responding to consultations and amplifying relevant reports, recommendations, and solutions to addressing those issues.

Further references:

Prostate Cancer UK - Making the case for clinical nurse specialists

The Royal College of Pathologists - HEE Strategic Framework Call for Evidence (2021)

The Royal College of Pathologists - The pathology workforce

Macmillan - Cancer workforce in England (2017)

Macmillan - Cancer workforce in Scotland (2019)

Public Health Scotland - Cancer Incidence and Prevalence in Scotland (2021)

Macmillan - Cancer workforce in Northern Ireland (2021)

Queen's University Belfast - Northern Ireland Cancer Registry (prostate cancer)

Queen's University Belfast - Northern Ireland Cancer Registry (breast cancer)

Artificial Intelligence (AI)

AI has the potential to provide the medical community with much needed additional support. It could help mitigate against current workforce challenges by reducing reporting times, improving analysis, and diagnostic accuracy. Research on AI within the prostate cancer space is rapidly evolving and has the potential to speed up aspects of the current standard diagnostic pathway.

AI and Magnetic Resonance Imaging

We are funding a project led by Dr Tristian Barrett to develop and test a software tool which uses AI to measure and assess the quality of MRI images. The team will be supported by Lucida Medical, an AI software company that specialises in the analysis of MRI for prostate cancer. Alongside prostate cancer MRI experts, Dr Tristian Barrett and his team aim to develop a scoring system by examining MRI scans that have already been taken. They'll set up a scoring scale from 1-5, with 5 being a good quality image and 3 being acceptable.

AI for Biopsy

Over recent years, there has also been noticeable potential for AI to assist in spotting cancer in prostate biopsies, potentially making diagnosis quicker and more accurate through Digital Pathology (DP). Currently, when a man has a biopsy for prostate cancer, a histopathologist will place the tissue samples onto a glass slide and look under a microscope to see what the cells look like. However, with DP, the glass slide is scanned and the whole slide image is examined on a computer screen instead of a microscope.

A study which we are supporting in this area is the *ARTICULATE PRO (artificial Intelligence for Cellular Pathology Transformation in Prostate Practice)*.

The project aims to investigate whether a recent AI tool called Paige Prostate can help pathologists analyse prostate biopsies.

The challenge:

There are generic data and digital health considerations such as:

- data sharing and privacy,
- the secondary uses of healthcare data,
- patient consent,
- the definitions and ownership of health and care data,
- the digital divide/eHealth literacy among those less digitally engaged,
- ensuring that there is evidence of efficacy.

Specific Algorithmic Considerations:

- AI algorithm biases - as AI technologies gain their insights from the existing structures and dynamics of the societies they analyse, this can cause them to unintentionally reproduce, and perpetuate existing patterns of marginalisation, inequality, and discrimination. Similarly, because many of the features and analytic structures of the models are chosen by the people building them, these technologies may also copy their designers' biases. This in turn can lead to misdiagnoses and loss of trust.

If we do not think about transparency, accountability, liability, explicability, and bias, and put appropriate governance systems and frameworks in place, it is possible that increasing the use of data-driven technologies, including AI, within the health and care system could cause unintended harm.

What are we doing about the issues?

We will continue to support and fund research in this space, while taking the above considerations and challenges into consideration when it comes to our campaigning and lobbying work around this issue.

Access to treatments

Access to precision treatments

Now that the first precision medicine has become available for metastatic patients, it's more pertinent that they know their status. It specifically targets BRCA gene variants, called olaparib. However, since *Olaparib monotherapy was made available in Scotland in September 2021 followed by England, Wales and NI in May 2023*, we still do not have an official national policy and pathway on BRCA variant testing for diagnosed men.

For those with a diagnosis of prostate cancer

It should be noted that despite risk factors such as a family history of prostate or breast cancer, men who have a diagnosis of prostate cancer should have access to a BRCA test at a timely point in their own prostate cancer pathway. This will allow them to commence treatment with olaparib should they be eligible.

It is imperative that

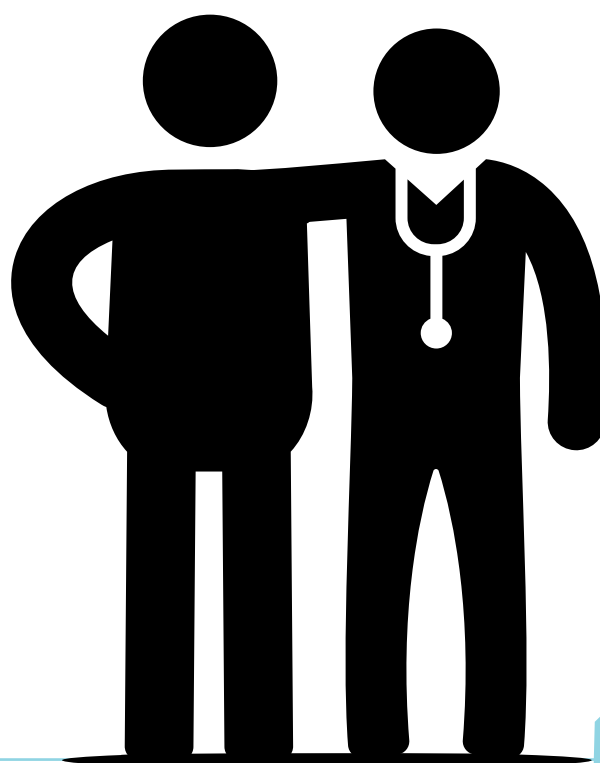
BRCA positive men

should be able to access and commence treatment with olaparib as soon as they become metastatic hormone resistant and have progressed onto a novel hormonal agent.

Testing therefore must be achieved in advance of this point in the man's prostate cancer journey.

We know currently in the UK that despite BRCA 1 and 2 variants for inherited prostate cancer being added to the national genomic test directory (including the ATM variant and others associated with homologous recombination repair like BRCA1 and 2), testing is not routinely undertaken and sometimes not even understood by the clinical community. This leads to patients receiving sub-optimal or inappropriate treatments for their particular prostate cancer, having unnecessary side effects and potentially worse outcomes.

With new precision medicines coming through the pipeline for prostate cancer (for example the clinical trial Talopro 2 which looks at the use of talozoparib with enzalutamide in prostate cancer patients with an "Homologous Recombination Repair (HRR) mutation", we need a comprehensive, clear and robust testing system which will encompass all the current and potential gene variants which could have an affect on a man's prognosis.



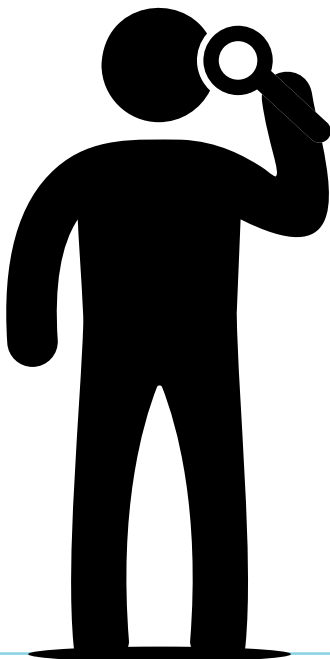
Access to treatments

What is happening currently?

In England, the *NHS Genomic Medicine Service* was introduced in 2018 to help embed genomics into routine NHS care. This service focuses on enabling faster diagnoses and tailoring treatments through harnessing the power of genomic technology and science.

This service is delivered through seven hubs called genomic laboratory hubs (GLHs) across England, each responsible for organising services for a particular part of the country. Aligned to these hubs are NHS Genomic Medicine Services Alliances (GMSAs). Each GMSA has a critical role in collaborating across the alliances, providing clinical leadership and working with the public to build trust in genomics.

GLHs and GMSAs together provide the new national NHS genomic medicine service supposedly delivering equitable and consistent access to genomic testing and end-to-end care pathways across the country.



We are now aware of genomic prostate cancer testing pathways within some of these GMSAs, such as the *South West Hub* (SW GMSA PPT). We do not know if similar pathways for prostate cancer are being developed/used in other GMSAs.

However, despite the progress mentioned above, we know anecdotally and from research:

- Clinicians are confused about the process/when to test. Some clinicians have limited awareness of the role of testing. Education on biomarkers and genomics for the clinical workforce is limited .
- There are inefficiencies in the ordering and reporting systems.
- Many of the assays are poor and accessibility is limited.
- Historical biopsy tissue is often of poor quality and cannot be used.
- Many men do not have biopsy tissue available for testing (men who were diagnosed metastatic often do not need a biopsy).
- There are significant issues with workforce numbers which limits capacity to test.
- Those who are tested may have long waits for a genetic counselor.

Short term recommendations should include, a more standardized and equitable approach to testing across the country for prostate cancer patients. Drug companies should work with experts in the clinical community to educate about precision medicines, testing protocols and how to interpret results. Patients who are recommended to have a test for a BRCA variant should easily be able to access genetic counselling alongside their test.

Active surveillance

The challenge:

Active surveillance is a way of managing localised prostate cancer in men with low and some intermediate risk. 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 concerns that the cancer could spread whilst being monitored.

Although thousands of men are eligible and are on active surveillance, there are no national standard protocols, quality assurance, audit or KPIs relating to active surveillance. Men do not always have a clear surveillance plan and are often left feeling anxious and worried.

Men are not put onto the pathway according to their cancer, leading to the overuse of resources such as PSA, MRI and biopsy.

Active surveillance is considered to be an important aspect of the prostate cancer pathway in relation to screening and the overall reduction of overtreatment in men with prostate cancer that is not lethal.

What are we doing about the issues?

We've improved our *health information and resources* for men and their loved ones. This ensures they have access to the best evidence and information whilst they are deciding about active surveillance, and beyond.

We have produced a *suite of education resources for healthcare professionals* to support them in implementing evidence-based best practice. We'll continue to engage with healthcare professionals through our improvement programmes and education workstreams to support them in the implementation of examples of good practice.

Next steps – priority action

Through the delivery of activity in 2022-23, we have understood there are some key areas within active surveillance which need to change, here's how we can support that change:

- The priority will be to collaborate with clinicians to influence changes to national guidelines on active surveillance.
- We think this can be achieved through co-producing with key stakeholders a standardised protocol to include, but not limited to, some of the following aspects: risk-stratified follow-up, quality assurance and audit processes, and examples of IT systems that can support the Active Surveillance pathway.
- The output from this work will form the basis of our influencing activity to change NICE guidelines, develop our healthcare professional resources and patient facing health information and support offers.

Continued support and education for men, their loved ones and healthcare professionals.

Whilst the co-producing activity is being delivered, we will also aim to develop a support package for healthcare professionals and system leads who wish to implement active surveillance protocols and risk-stratified follow-up, using examples of good practice we have now.

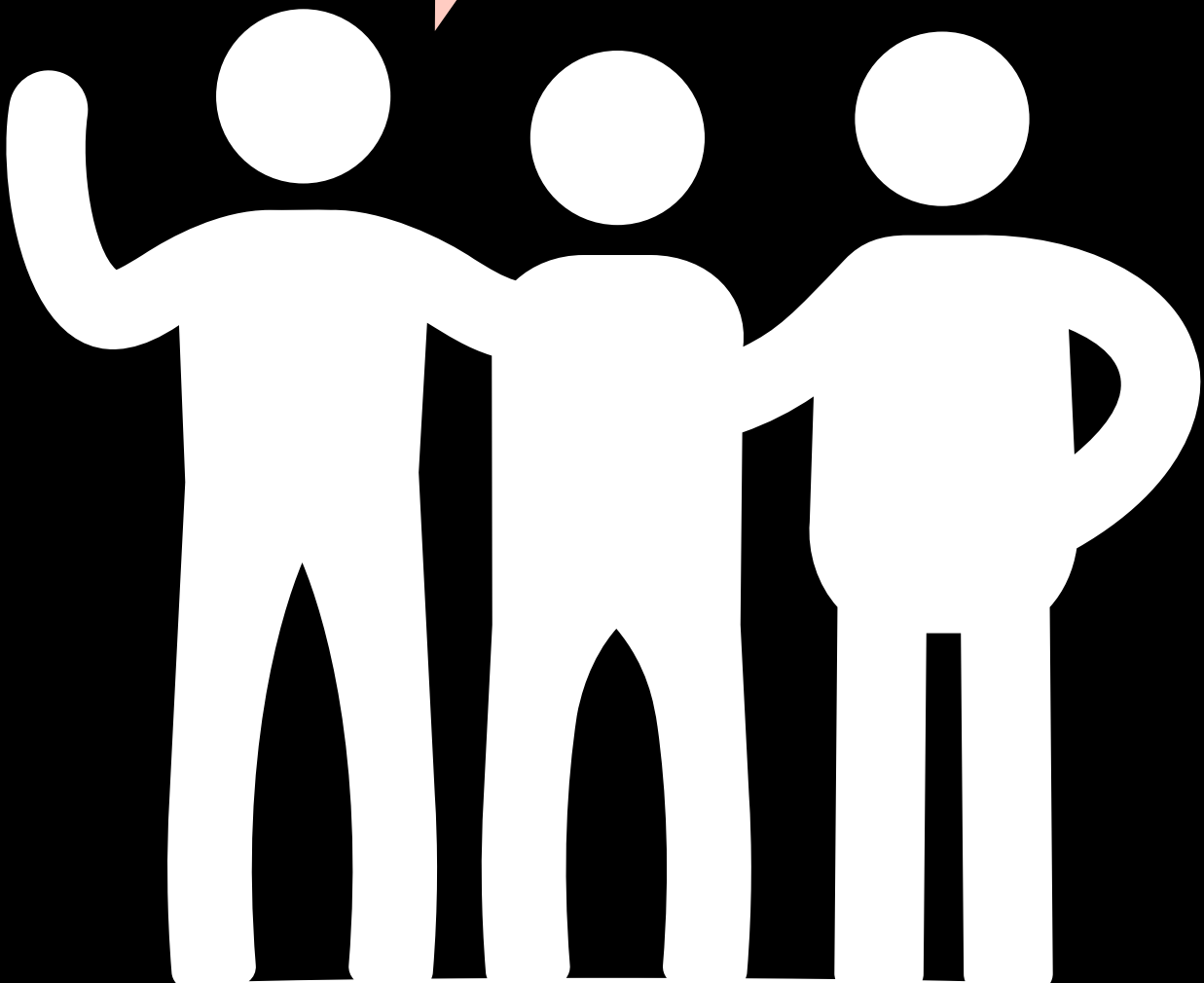
This will include some of the education resources already developed and sharing of impact assessments from our Improvement Programmes: Active Surveillance short-course cohort.

Additionally, we'll continue to develop and promote our health information and support resources to men and their loved ones.

Support for men

At Prostate Cancer UK we want to ensure that men and their loved ones are receiving the best possible support.

There are several challenges around support for men in the following areas: Psychological Wellbeing, Sexual Wellbeing, Incontinence care and Palliative and End of Life care. We recognise the importance of these areas and the impact it has on men's lives and so we want the best support possible to be available for all men.



Support for men

Psychological Wellbeing

The challenge:

Receiving a prostate cancer diagnosis and subsequently living with the cancer, or its side-effects from treatment, can be difficult to deal with. Not only does this affect men physically, but also mentally and emotionally. It can also have an impact on men's partners or loved ones.

The introduction of PSA blood testing has increased the number of prostate cancer diagnoses being made, which, despite favourable prognoses, has consequently had a significant impact on men's mental health. This highlights a key challenge as more and more men receive a prostate cancer diagnosis but may not yet need treatment. Indeed, being put on **active surveillance** – a form of prostate cancer care that monitors early, localised, prostate cancer, rather than treating it straight away – can also lead to adverse psychological consequences and requires high-quality, personalised psychological support.

Whilst the psychological impact of prostate cancer diagnosis can already be harmful for patients, the aftermath of treatment can disadvantage patients further. Many men will live for years following diagnosis, but the **side-effects** from treatment may reduce the **quality of life** and can force lifestyle changes and lead to psychological distress.

Treatment regret for localised prostate cancer patients can also play into this.

As the *2022 NPCA Audit states*, patients should be empowered to ask to be **referred to specialist support services** if they are experiencing psychological side-effects during or following prostate cancer treatment. This is something that should be offered to men at the beginning of their cancer journey and on an ongoing basis. Additionally, healthcare professionals should be continuously referring their patients to mental health professionals after their diagnosis.

Men with prostate cancer will often need psychological support, in a study of 94 men,



reported psychological distress as a result of their prostate cancer diagnosis.

There is a lack of data, but our understanding is that men feel there is a lack of mental health support following a diagnosis of prostate cancer. A more proactive approach to these issues is necessary to prevent men who do not feel comfortable asking about their mental health concerns from being overlooked.

Further references:

- National Library of Medicine - Psychological adjustment of men with prostate cancer: a review of the literature (2007)*
- Wiley Online Library - Why do patients regret their prostate cancer treatment? A systematic review of regret after treatment for localized prostate cancer (2015)*
- Science Direct - Prostate cancer diagnosis: The impact on patients' mental health (2006)*
- British Journal of Cancer - Anxiety and depression after prostate cancer diagnosis and treatment: 5-year follow-up (2006)*
- Science Direct - Best Current Practice and Research Priorities in Active Surveillance for Prostate Cancer – A Report of a Movember International Consensus Meeting (2023)*
- National Library of Medicine - Prostate Cancer: Quality of Life, Psychosocial Implications and Treatment Choices (2019)*

Support for men

Sexual Wellbeing

The challenge:

Since the prostate is an inherently sexual organ, treatment against prostate cancer will inevitably affect sexual function and can impact overall sexual wellbeing. Because of this, sexual wellbeing treatment, care and support should be included and well-integrated in the prostate cancer pathway. Unfortunately, this isn't the case, with most men **not being offered helpful intervention or support** regarding their sexual wellbeing, or not even having the sexual side-effects of prostate cancer treatment discussed within consultations, leaving men, as well as their partners, behind.

Part of the reason for this can be attributed to the lack of consensus amongst healthcare professionals around who should take responsibility for the

management of this aspect of health (Kinnaird et al., 2021), leaving a gap in treatment and care.

Similarly, to the section on psychological wellbeing, there are issues in referral. Whilst some patients may be referred onto specialist services such as erectile dysfunction clinics, this is not a given. Men may often have to be proactive and persistent about their sexual wellbeing to receive the treatment and care they deserve.

The power of psychosexual support must be recognised.

This is perhaps one of the most important areas of specialist care that a patient can be referred on to for their sexual wellbeing as it can crucially help men, as well as their partners, adjust to the side-effects of prostate cancer treatment and still live a satisfying sex life.

Incontinence care

Urinary incontinence is experienced **by as many as 60% of men** who have a radical prostatectomy.

We surveyed men and workplaces about their understanding and experience of male incontinence to gain insights. Men have told us that they feel isolated, stressed and anxious due to their incontinence and so there needs to be support for men to mitigate these experiences. Whilst workplaces have told us that they are unaware of the needs of men. We call upon the Government to raise awareness of male incontinence to help break this silence and to normalise the experience for men.



References:

Science Direct - Prevalence of Urinary Incontinence in Men, Women, and Children— Current Evidence: Findings of the Fourth International Consultation on Incontinence (2019)
Prostate Cancer UK - Incontinence Hub

Support for men

Palliative and end of life care

While some men will die from their prostate cancer, many will die from other diseases whilst they have prostate cancer. The effective management of symptoms at the end of life, in all care settings, is supported by the use of palliative and end of life care that facilitate the quality of care at the end of life.

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.

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 the right time is 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 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.

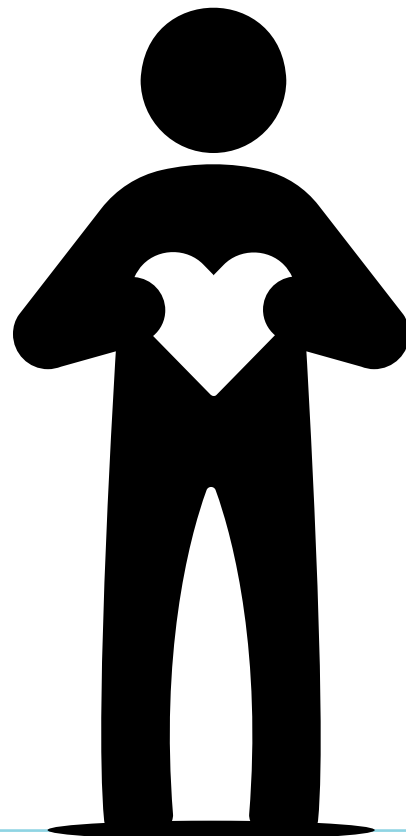
Healthcare professionals should be prepared to refer patients to pain review clinics to investigate their pain.

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 a Multi Disciplinary Team (MDT) 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 decisions 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.

Health professional resources for prostate cancer

Health professionals have expressed that they had limited resources around palliative and end of life care, such as financial advice, to share with men with prostate cancer and their families.



Support for men

What are we doing about the issues?

Psychological Wellbeing:

Our Senior Health Information Officer is currently working on a prostate cancer and psychological wellbeing project that will explore the emotional and psychological impact of a prostate cancer diagnosis on men and their loved ones.

Sexual Wellbeing:

In April of this year, we published a *Sexual Wellbeing Hub* for healthcare professionals.



which will help healthcare professionals to gain confidence in approaching the topic with patients as well as highlight best practice in this space, in line with the Movember Clinical Guidelines for Sexual Health and Prostate Cancer. This work will continue to improve the standard of care men receive in this area. Increased use of comprehensive guidelines as such will undoubtedly improve patient, as well as partner(s) sexual wellbeing and overall quality of life.

Incontinence:

There is an existing *incontinence hub* which includes our incontinence campaigning activity and resources for men who experience incontinence.

Palliative and end of life care:

Men with prostate cancer and their loved ones may want to know how long they have left to live and what to expect at the end of life. Although it may be difficult to give precise timeframes, some idea of where the cancer has spread to and what problems it may cause may mean that men can be better prepared. Men can be referred to Prostate Cancer UK's information on what to expect.

We are producing a Palliative and End of Life Care Signposting Library for health professionals to use when having conversations with men and their families on a palliative and end of life pathway. This was produced with support and guidance from Prostate Cancer UK's Specialist Nurses' team and health professionals from our Improvement Programme.

Within the library topics such as finance and welfare, complementary therapies, hospice care, and bereavement support will be covered. Along with many other aspects of the palliative and end of life pathway.

It will be available on Prostate Cancer UK's website in 2024.

Support for men

Further references:

Prostate Cancer UK - Dying from prostate cancer

Hospice UK - Innovation Hub

Marie Curie - Dying to Care

Compassion in Dying

NHS - Find palliative care services

National Institute for Health Care Excellence - Care of dying adults in the last days of life (2015)

Skills for care - End of life care

Marie Curie - A guide to end of life services

Cruse bereavement support

NHS - Palliative and end of life care: Statutory guidance for integrated care boards (ICBs)

Marie Curie: The Grief Toolkit



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