

Health and Social Care Committee: Men's Health Inquiry

Evidence submission, September 2023

About Prostate Cancer Research (PCR)

Prostate Cancer Research (PCR) is a research and information provision charity that is dedicated to improving and saving the lives of people with prostate cancer. Patients are central to everything we do and drive our work. Our work covers three key areas:

- Academic and social research – We fund novel and innovative research projects at world-leading institutions that are working towards breakthroughs in the prevention, diagnosis and treatment of advanced prostate cancer, and better quality of life outcomes for patients. We ensure that our research is targeted to address patient need and research gaps to maximise our impact and reach better treatments for patients sooner.
- Translational research – Proven Connect is the translational research arm of PCR focused on ensuring more promising treatments get from lab to patient through bridging the gap between industry, investors, health providers and patients.
- Patient information and empowerment – We acknowledge that research alone is not enough to achieve our vision. We involve, educate, and empower people affected by prostate cancer to enable them to play a more active role in driving forward changes in research, treatment and care.

What factors drive lower, and falling, male life expectancy and what action would have the biggest impact on addressing this?

Prostate cancer is the 2nd most common cause of cancer death in men in the UK, accounting for 14% of all male cancer deaths (ONS data 2019) and 22% of all deaths among Black men. Deaths from prostate cancer are increasing (reflective of aging population). Prostate cancer has extremely high one year survival rates (around 100%) if caught early (in stages 1, 2, or 3) falling to 87.6% if detected in stage 4. By the 5-year mark survival rates for stage 4 metastatic disease fall to 50%, as opposed to 100% in stages 1 and 2 and 95% in stage 3. Prostate cancer is not a disease of old men; just under 50% of diagnoses each year are in men under the age of 70 years. Men diagnosed at a younger age, and those with a family history have a higher mortality rate than older men. Amongst men with more advanced and more aggressive prostate cancer, those diagnosed at a young age have a higher cause-specific mortality than men diagnosed at an older age, except those over age 80 years.¹

¹ <https://www.esmo.org/oncology-news/archive/prostate-cancer-in-young-men>



There is also a link between prostate cancer mortality and deprivation, being 14% higher for males living in the most deprived areas (48 per 100,000 people) when compared to males living in the least deprived areas (43 per 100,000 people).²

Partly as a result of covid-19, the number of men who present with stage 4 metastatic disease at first diagnosis has risen to 17%. For these men, their chance of survival has dropped considerably due to their late diagnosis. This average rate hides the sizeable disparity between different parts of the country too. In some parts of the country, such as parts of the north-east of England, men are 5-6 times more likely to receive a diagnosis of stage 4 prostate cancer than in the best performing parts of the country. In North Tees and South Tees, the diagnosis is 29%, compared with parts of the South and London where only 5% are diagnosed with stage 4.³

The action that would have the biggest impact in the case of prostate cancer would be access to earlier diagnosis, potentially via a universal screening offer from 50 years. Equity of access to earlier diagnosis, potentially via a universal screening offer from 50 years (45 for Black men and men with a family history) with a view to reducing rates of metastatic diagnoses. Timely review of the evidence, and investment in /support for new technologies to augment or replace PSA will be key.

Provision of more and better diagnostic machinery (MRI scanners in particular) would go some way to bringing down the number of men diagnosed late with stage 4 disease and improving equity of access to earlier diagnosis. In 2019, the NHS had 16.1 CT and MRI scanners per million head of population, compared to Canada with 24.7, France 33.6 and Germany at 69.8.⁴

Equity of access to treatment is an equally important factor. For example, a minority of hospitals provide both surgery and radiotherapy and more advanced and accessing more sophisticated technologies and targeted treatments may require travelling substantial distances.⁵ Choice of treatment should not be determined by local availability and measures should be considered to overcome the impact of distance or lack of local access.

What is known about why men have a higher risk of dying from cancer and how can this risk be reduced.

There is a direct link between late diagnosis and elevated risk of dying from prostate cancer, and therefore a link between access to early diagnosis and risk. Young men with more advanced, aggressive disease have a higher cause-specific mortality than men diagnosed at an older age, except those over age 80 years. This suggests biological differences exist between prostate cancer which affects younger men. There are certain groups that have a higher risk of contracting and dying from prostate cancer, specifically men with a family history, Black men and young men with advanced, aggressive disease.

² [https://digital.nhs.uk/data-and-information/publications/statistical/cancer-registration-statistics/england-2020/deaths-from-cancer-increased-with-deprivation#:~:text=The%20mortality%20rate%20for%20prostate,\(43%20per%20100%2C000%20people\).](https://digital.nhs.uk/data-and-information/publications/statistical/cancer-registration-statistics/england-2020/deaths-from-cancer-increased-with-deprivation#:~:text=The%20mortality%20rate%20for%20prostate,(43%20per%20100%2C000%20people).)

³ <https://www.npca.org.uk/provider-results/>

⁴ https://www.kingsfund.org.uk/sites/default/files/2023-06/How_NHS_compare_2023.pdf

⁵ <https://www.theinfopool.co.uk/local-services>



Men with a family history have a 2-3 times greater chance of being diagnosed with prostate cancer, a risk that rises higher the more relatives they have affected by the disease. For Black men, they have a 2 times higher risk of being diagnosed compared to White men, and 3 times that of men of other ethnicities in the UK.

Other risk factors for prostate cancer diagnosis and worse outcomes are social and environmental factors, particularly poor diet and lifestyle factors relating to obesity. Men who are overweight or obese are at greater risk of developing an aggressive form of prostate cancer. A Cancer Research UK study funded by Oxford Population Health found that greater body fat may increase the risk of dying from prostate cancer by up to 10%, with every five-point increase in BMI increasing the risk of dying by 10%. Similarly, risk of death was found to be increased by increases in waist to hip ratio.⁶

What action is needed to improve early detection of cancers specific to men, for example around awareness of symptoms, issues with screening and encouraging men to come forward?

More needs to be done to improve awareness of prostate cancer and its symptoms; in September 2021 we and cancer care provider GenesisCare polled 2,000 people and found that 51% of adults in the UK are unaware of where the prostate is and 79% don't know what it does. It is not uncommon for men to ignore symptoms for several months before consulting their GP. According to the NHS National Cancer Patient Experience Survey, more than 63% of men had to see their GP more than once before referral, with 1 in 20 men having to visit their GP five or more times. In addition to encouraging men to come forward, GP awareness relating to symptoms and factors elevating the risk of prostate cancer need to be improved.

Including a discussion in GP health checks intended to elicit reporting of possible symptoms of prostate cancer or factors suggestive of elevated prostate cancer risk for those over 50 (45 for Black men), and, as appropriate, an offer of PSA testing would be a step forward.

With nearly half a million men living with or after prostate cancer, how well does aftercare support ongoing symptoms of male specific cancers and how could this be improved?

Many men find it difficult to access adequate support to live better with prostate cancer. The support that is provided with respect to sexual services continues to be a postcode lottery. A UK study published in 2021 found significant shortcomings in the support offered to UK men with sexual dysfunction following diagnosis and treatment for prostate cancer. The findings indicate that more than half of men reporting poor sexual function were not offered any intervention.⁷

Some men can access support from psychosexual nurses, whilst others are not able to. Some men can easily access important aides and devices, such as penis pumps, while

⁶ <https://www.ndph.ox.ac.uk/news/greater-adiposity-linked-to-increased-risk-of-fatal-prostate-cancer>

⁷ <https://pubmed.ncbi.nlm.nih.gov/33642238/>



others end up having to fight to get something that is given freely elsewhere. Such disparity is common also in mental health support and access to continence services. National Prostate Cancer Audit data in 2022 showed that the number of trusts in the UK with sexual function services was 73%, specialist continence services was 81% and psychological services was only 66%.⁸ We need to be providing these services to all men so they can be better supported post treatment. Most men with prostate cancer report fatigue, which can be so severe as to be debilitating. Providing interventions and support targeting fatigue could have a profound impact on a man's ability to engage with social activities and to manage activities of daily living.

What role do community and sport-based projects play in reaching men at high risk of isolation or poor mental health, and how can it be ensured that this support is spread equitably across the country?

Community and sports-based projects can play an important role in reaching men with prostate cancer at risk of isolation and poor mental health. Some studies have found that men with prostate cancer who exercise, live longer than those who do not, possibly due to the combination of positive physical benefits of weight lost, increased fitness and stamina with social and emotional wellbeing and mental health benefits. It is important that the opportunities to engage in sports and exercise are varied to ensure that there are appropriate opportunities for all. For example, there are tens of thousands of men on hormone therapy that suffer weight gain, and potentially incontinence, factors that might make participation in certain sports or types of activity difficult for an individual. It is likely that targeted interventions aimed at meeting the needs of men with prostate cancer are not equitably spread across the country. Targeted investment coupled with evaluation would be welcome.

What are the challenges in delivering health equity across different population groups among men and how best can they be addressed?

In 2021, we conducted research that found:

- 1 in 4 people diagnosed with prostate cancer felt they were not given enough information to make informed treatment decisions.
- Only 38% said they made treatment decisions with their healthcare team.
- People wanted a more patient-centred approach and not to feel like 'just a number'.
- In the Black and South Asian communities there were feelings of being treated differently due to their ethnicity and a power dynamic, with many saying their healthcare team did not like being questioned or challenged.

The quality and value of interactions between patients and their healthcare team is variable across patients particularly in Black and South Asian communities and those from lower socioeconomic groups. Amongst the Black community in particular there is an historic lack of trust, in healthcare institutions, healthcare professionals and in research. This has led to growing disparities which need to be addressed by working with community organisations to rebuild trust and provide tailored support and

⁸ <https://www.npca.org.uk/reports/npca-annual-report-2022/>



resources. Best practice includes programmes of work like our Health Equity programme which combines a research focus (grant rounds focused specifically on addressing racial disparities in prostate cancer), with relevant patient involvement and with resources co-developed with and for the Black community that are relevant and culturally accessible. Prostate Cancer Research have co-developed an online resource - “the infopool” – to support patients access the right information at the right time, thereby allowing them to be more active partners in shared decision-making and reducing treatment regret in these communities.⁹ We believe that signposting patients to the infopool could help to address some of the challenges in delivering health equity.

Furthermore, BAME populations around the world are under-represented in clinical trials [as well as in the preclinical research that shapes clinical research]. Black/African American representation in clinical trials across therapeutic areas reveals a wide range of inclusiveness with oncology phase II and III trial inclusion being the lowest, with only 2.8% Black/African American patients in trials run in 2020–2022, 80% below their 2019 U.S. cancer incidence of 13.8%.¹⁰ What this means is that future medicines will not be proven to work on these populations, thereby continuing the inequity that currently exists. We need to increase levels of diversity in trials now in order to break this cycle. This requires investment in research, provision of specifically targeted resources – both the message and the delivery are important – as well as removal of barriers to participation, such as provision of travel grants and other financial support to help those who are unemployed or who work on zero hours contracts to participate in research.

Public campaigns specifically addressing the myths and misconceptions around trials and to increase awareness of trials as BAME communities are needed not least because these communities are often presumed to be uninterested and so not targeted (a vicious cycle). We also need to ensure more research is being led by members of these communities to help overcome the trust deficit that exists right now, and work on better communication to those with lower levels of health literacy. Trusted patient advocacy organisations have a vital role to play in this arena, acting as a bridge between institutions and communities, to help reverse this decline.

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⁹ <https://www.theinfopool.co.uk>

¹⁰ Global Oncology Trends 2023, IQVIA Institute (<https://www.iqvia.com/insights/the-iqvia-institute/reports/global-oncology-trends-2023>)