

Introduction

At the start of 2014, Prostate Cancer UK launched Men United v Prostate Cancer - a campaign to create a movement for change in the battle against the most common cancer in men. By July, 185,000 people throughout the UK had signed for Men United to help us drag the issue of prostate cancer into the spotlight.

At the heart of this campaign is the issue of inequalities faced by men with, and at risk of, prostate cancer. These inequalities exist within Scotland, between the nations of the UK, and at different stages of a man's prostate cancer experience.

This document summarises the five key inequalities, each with a call to action for MSPs to help us tackle these.

Men United v Prostate Cancer – We can win this

Five inequalities, five solutions

Awareness Inequality

Prostate cancer is the most common male cancer in Scotland, and has the fourth highest rate of cancer mortality (1). Despite this, the Scottish Government's Detect Cancer Early initiative doesn't include awareness raising related to prostate cancer and the available diagnostic tests. Prostate cancer is often symptomless until the disease is at an advanced stage, and any symptoms that do materialise may indicate benign disease rather than cancer. Therefore an awareness initiative based on risk factors (such as age, ethnicity and family history) rather than symptoms would be more effective for early detection of prostate cancer (2).

Our call

The Scottish Government should include prostate cancer in the next phase of the Detect Cancer Early initiative to raise awareness of prostate cancer risk factors. The Prostate Cancer Risk Management Programme (PCRMP) (3) should be better communicated and used in primary care, ensuring that GPs and patients are aware that all men over the age of 50 have a right to a Prostate Specific Antigen (PSA) test (4) once they have been informed of its pros and cons.

Treatments and support Inequality

The full range of treatments and aftercare support for prostate cancer are not always available for men in Scotland. For example, men in Scotland do not have access to robotic surgery on the NHS, which is now widely available in England and soon to be available in Wales*. Furthermore, a 2013 survey showed that 46% of Scottish prostate cancer patients were not told about treatment side effects that could affect them in the future (5).

Our call

The Scottish Government should ensure that the best treatments and aftercare are available throughout the country. This should include: at least one specialist centre for robot-assisted surgery for men requiring a radical prostatectomy (6)* and the development of national guidelines on the management of life-changing side effects such as erectile dysfunction (7).

Geography Inequality

Scotland is the only part of the UK with no plans for a National Cancer Patient Experience Survey (NCPES).** The introduction of a NCPES in Scotland would allow an unparalleled insight into Scottish men's quality of life following a diagnosis of prostate cancer, as well as their experiences of treatment and their support needs. A regular survey would help to identify areas of good quality treatment and care, as well as gaps in support or poor patient experience outcomes.

Our call

The Scottish Government must introduce a National Cancer Patient Experience Survey which includes regional analysis, to help drive improvements in the experiences and care of people being treated for all cancers in Scotland (8).**

Age Inequality

Although no Scotland specific statistics are available, UK-wide data indicates that older men have fewer treatment options offered to them than younger men, and that decisions regarding older people's treatment lacks fairness and transparency (9). It is not clear that treatment pathways are currently based on a person's fitness and preferences rather than their age alone.

Our call

The Scottish Government and NHS Scotland must ensure that older men are not denied treatments on the basis of their age, and that all men are given information about all available treatments and their side effects. The Scottish Government must introduce a comprehensive National Cancer Patient Experience Survey which includes analysis by age, to identify specific issues faced by men of different ages with prostate cancer.**

Ethnicity Inequality

1 in 4 Black men will be diagnosed with prostate cancer in their lifetime - double the average risk (10). Black men may also be more likely to be diagnosed with prostate cancer at an average of 3-5 years younger than White men (11-13), with mortality rates being 30% higher in Black men than White men (14).

Our call

The Scottish Government should ensure future awareness programmes on prostate cancer, such as Detect Cancer Early, place due emphasis on the higher risks in Black communities, and encourage more comprehensive collection and reporting of ethnicity data to ensure equality for all aspects of prostate cancer treatment and support.

What can MSPs do to help?

You can pledge to work with us to tackle these inequalities today.

Having pledged your support, Prostate Cancer UK will be in touch to provide you with the materials you need, at the time you need them, to help us make these inequalities a thing of the past.

Example follow up actions include:

- publicly backing our campaign in traditional, online and social media by issuing photo and template press release
- writing to the Health Secretary and the Chief Medical Officer calling for:
 - introduction of robot assisted surgery in Scotland*
 - introduction of a National Cancer Patient Experience Survey**
 - inclusion of prostate cancer in the Detect Cancer Early initiative
 - development of guidelines on erectile dysfunction
 - improved awareness of the PCRMP
- tabling parliamentary questions and tabling/signing parliamentary motion on issues highlighted above.

**Men United v Prostate Cancer
we can win this**



* Shortly after Prostate Cancer UK's Holyrood Campaigning Day on 7 August the Scottish Government announced that robot assisted surgery was to be introduced on NHS Scotland. The first robot is to be available in Aberdeen Royal Infirmary from the beginning of 2015, with another to be brought to the central belt within the next three years. (Scottish Government press release, 19 August 2014).

** The Scottish Cancer Taskforce agreed to introduce a National Cancer Patient Experience Survey for Scotland at its 3 October meeting. The survey is expected to be available by the end of 2015. (Written answer S4W-22756)

References and notes

1. ISD Scotland. Cancer in Scotland. 2014. Available from: https://isdscotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2014-04-29/Cancer_in_Scotland_summary_m.pdf
2. YouGov. Figures from YouGov Plc. Total sample size was 504 Scottish adults. Fieldwork was undertaken between 13 January and 4 February 2014. The survey was carried out online. The figures have been weighted and are representative of all Scottish adults (aged 18+). 2014.
A survey conducted by YouGov earlier this year shows that almost nine in ten men (86%) in Scotland at higher risk of prostate cancer are unaware of their increased vulnerability and are therefore not having the vital conversations with GPs that could save their lives. We also know that 50% of Scottish men over 50 have never heard of the PSA test. These survey findings highlight the importance of increasing awareness of risk factors of prostate cancer.
3. Burford D, Kirby M, Austoker J. Prostate Cancer Risk Management Programme information for primary care; PSA testing in asymptomatic men. Evidence document. NHS Cancer Screening Programmes. 2010. Available from: <http://www.cancerscreening.nhs.uk/prostate/pcrmp-guide-2.html>
The Prostate Cancer Risk Management Programme (PCRMP) is backed by the Scottish Government and supports GPs to give clear and balanced information about the advantages and disadvantages of the PSA test to men who are concerned about their risk of prostate cancer. It aims to help men to decide whether they want to have the test. Any man over the age of 50 who asks for a PSA test after careful consideration of the implications should be given one. Copies of the PCRMP have been issued to general practitioners across NHS Scotland, urologists and histopathologists working in Scottish hospitals and also those working in Scottish PSA testing laboratories.
4. The PSA test is a blood test that measures the total amount of prostate specific antigen (PSA) in the blood. A raised PSA level may indicate a problem with a man's prostate. However, high PSA level does not always indicate prostate cancer, and low PSA does not always mean that cancer is absent. The PSA test may help pick up more aggressive forms of the disease at an early stage, but could also lead to treatment for cancers that may not affect men during their lifetime. For these reasons, men need to make a decision about whether the PSA test is right for them based on their circumstances and risk factors.
5. Quality Health. Prostate Cancer UK Survey: The Views of Prostate Cancer Patients in Scotland. Sample size for quantitative survey was 225 Scottish men with prostate cancer. Sample size for in-depth interviews was 12 Scottish men with prostate cancer. Fieldwork was undertaken between February 2013 and May 2013. 2013.
6. Robotic surgery should be conducted by clinicians trained in the technique and conducting the procedure regularly. Clinical guidelines now suggest that robotic surgery should take place in specialist centres that are expected to perform at least 150 procedures a year. Men requiring surgery should be able to make an informed choice about whether they wish to undergo robot-assisted surgery or not.
7. Prostate Cancer UK. Men's views on quality care in prostate cancer: What does good quality care mean for men with prostate cancer? 2012. Available from: http://prostatecanceruk.org/media/1559431/prostate_cancer_uk_quality_care_survey_report_june_2012.pdf
A Prostate Cancer UK survey undertaken in 2012 showed that 76% of men who experience treatment side effects suffer from erectile dysfunction, with 79% of these men saying they found it very difficult or difficult to deal with. Yet Scotland has no national guidelines on the management of erectile dysfunction – and these are needed to ensure that men can recover from this life-changing condition.
8. The use of the NCPES in England has acted as an important driver for service and care improvement in individual trusts. Without a similar resource in place for Scotland, variations in care around the country cannot be identified, let alone addressed.
9. brap for Macmillan Cancer Support. 'Walking into the unknown' - Survivors and carers speak out on discrimination and inequality in cancer care services. 2011. Available from: http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/OlderPeoplesProject/Walkingintotheunknown.pdf
10. Prostate Cancer UK. Working out the risk of prostate cancer in Black men. 2013 [cited 2013 Oct 30]. Available from: <http://prostatecanceruk.org/we-can-help/african-caribbean-communities/1-in-4-stat-explained>
11. Ben-Shlomo Y, Evans S, Ibrahim F, Patel B, Anson K, Chinegwundoh F, et al. The risk of prostate cancer amongst black men in the United Kingdom: the PROCESS cohort study. *Eur Urol*. 2008 Jan;53(1):99–105.
12. Karami S, Young HA, Henson DE. Earlier age at diagnosis: another dimension in cancer disparity? *Cancer Detect Prev*. 2007;31(1):29–34.
13. Metcalfe C, Evans S, Ibrahim F, Patel B, Anson K, Chinegwundoh F, et al. Pathways to diagnosis for Black men and White men found to have prostate cancer: the PROCESS cohort study. *Br J Cancer*. 2008 Oct 7;99(7):1040–5.
14. National Cancer Intelligence Network. Mortality from Prostate Cancer: Urological Cancers SSCRG [Internet]. 2012. Available from: <http://www.ncin.org.uk/view?rid=1701>

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