

NHS England Cancer Taskforce call to evidence

Tackle Prostate Cancer evidence submission : Five-year strategy for cancer

Introduction

Tackle Prostate Cancer welcomes NHS England's announcement of the establishment of a new cancer taskforce to develop a five-year strategy for cancer.

We believe that to improve outcomes for patients in the UK, a clear strategy should be in place to allow the cancer community to work together to help reduce variations in practice and ensure that high quality and timely care is delivered in a consistent manner.

We are pleased to be able to submit evidence to the taskforce in order to inform the content of this strategy, particularly as we represent what is the most common cancer in men in this country. Further information is available at www.tackleprostate.org or by emailing roger.wotton@tackleprostate.org

Submission Overview

The three commitments that you would like to see in a new cancer strategy that would significantly improve cancer services for patients/the health of the public, referencing any relevant evidence and costing information.

1. Risk Assessment and Referral - for men over 50 (or black men over 45)
2. Diagnosis – receiving the most effective diagnostic options irrespective of geography
3. Access to treatment – having access to treatments of choice

Examples of good practice in cancer services that you would like to see replicated across the country.

1. Ready access to Clinical Nurse Specialists
2. Greater use of hospice services integrated with primary/secondary care
3. Availability of supported self management
4. Access to specialist services post-treatment
5. Linking hospitals with support groups

The biggest barrier to improving cancer services.

Integrated and seamless support across the NHS

Tackle Prostate Cancer evidence submission

“The three commitments that you would like to see in a new cancer strategy that would significantly improve cancer services for patients/the health of the public, referencing any relevant evidence and costing information”

Commitment 1 : Risk Assessment and Referral

The Commitment : Men over 50 or (or black men over 45) requesting a PSA test or presenting in primary care with symptoms suggesting prostate cancer are risk assessed, counselled and offered a PSA test. If considered appropriate they should be referred to a specialist centre.

What it means for the patient : Assurance that symptoms and concerns have been taken seriously, and if the patient is at risk of prostate cancer it will be diagnosed sufficiently early to give them the best possible outcome.

Rationale : The high death rate from prostate cancer (25-30% of those diagnosed¹) is to a large extent due to the fact that in too many cases it is not diagnosed until it has progressed beyond the curable stage. The high death rate represents not only a personal disaster for over 10,000 men who die every year, but also a great burden on the Health Service in terms of palliative care costs (e.g. long term hormone treatment and chemotherapy).

There is often increased anxiety amongst men with risk factors, particularly those with a family history of prostate cancer. If these men present in primary care, it is important that they receive the best available information and support to assist them in the decision of whether or not to have a PSA test.

Men often present to their GP with increased urinary frequency with no other signs or symptoms unless the cancer is metastatic. Patients raise concern that GPs are reluctant to offer a PSA (prostate specific antigen) test if patient presents with no symptoms. Prostate cancer can grow slowly or very quickly. Most prostate cancer is slow-growing to start with and may never cause any symptoms or problems in a man's lifetime. However, some men will have cancer that is more aggressive or 'high risk.' This needs treatment to help prevent or delay it spreading outside the prostate gland.

Black men (irrespective of Black-African or Black-Caribbean origin) have a 3-fold higher risk of developing prostate cancer than white men [1] whilst Asian and Oriental men have the lowest incidence [2,3]. Despite the higher risk of prostate cancer, awareness of prostate cancer is low amongst Black men. Anecdotal reports also indicate low awareness amongst some GPs, with some Black men being refused a PSA test [4]. The combination of lack of cancer awareness in the Black community, and lack of cultural competence amongst health professionals, is almost certainly contributing to poorer outcomes from prostate cancer [4].

Clinical experience points to regular PSA testing for asymptomatic men from age 45 if Black and age 50 if White. Most Primary Care teams (including Practice Nurses /Nurse Practitioners) are not provided with the necessary education and knowledge around PSA testing, leading to patients having a PSA test without being adequately informed or offered relevant counselling (in some instances a PSA test is offered to patients presenting with UTI). Not enough men are informed about availability of the test. Research carried out by Prostate Cancer UK shows that two thirds of men

¹ <http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/prostate-cancer/>

over 50 do not even know that the test exists. Awareness on PSA testing needs to be improved amongst men and they should be given adequate information about the PSA blood test, the digital rectal examination (DRE) and biopsies, with the opportunity to discuss the pros and cons of the tests with a doctor or nurse. Access to local support groups should be made available to help men improve awareness on signs and symptoms and when to access their GP for further investigations.

The Prostate Cancer Risk Management Programme (PCRMP) [5] aims to help the primary care team give clear and balanced information to men who request details about testing for prostate cancer. Any man over the age of 50 who asks for a PSA test after careful consideration of the implications should be given one. However, there are growing signs that some GPs are ignoring the PCRMP, and following instead, informal “guidance” published in the BMJ [6], that recommends “Physicians can improve the health of their male patients by recommending against PSA screening for prostate cancer.” This is a dangerous trend, which will only result in more men being diagnosed late with advanced, incurable prostate cancer that is likely to kill them.

According to NICE clinical guideline 27 ‘Referral for suspected cancer’ (June 2005), in a male patient with or without lower urinary tract symptoms and in whom the prostate is normal on DRE but the age-specific PSA is raised or rising, an urgent referral should be made [7]. If there is doubt about whether to refer an asymptomatic male with a borderline level of PSA, the PSA test should be repeated after an interval of 1 to 3 months [7]. If the second test indicates that the PSA level is rising, the patient should be referred urgently.

Commitment 2 : Diagnosis

The Commitment: Men referred with suspected prostate cancer are offered the full range and access to the most up to date and clinically effective diagnostic technologies.

What it means for the patient: Assurance that they will receive the most effective diagnostic options for their condition to be accurately graded and staged no matter where they live.

Rationale: For a patient, being informed of a suspected cancer can be a traumatic and difficult time. This is further confounded by the choice of diagnostic procedures available. Some patients have experience of being offered procedures that are deemed the ‘preferred option’ of the healthcare professional and others speak about requesting specific procedures based on personal information and knowledge they had gained from doing their own research. It is important for the healthcare professional to take into consideration the patient’s lifestyle, personal preferences, and any co-morbidities they may have when making decisions about which diagnostic technologies are to be used.

The Trans Rectal Ultrasound prostate biopsy (TRUS) procedure can cause significant anxiety and most men describe the biopsy as an embarrassing, uncomfortable experience, and some describe it as painful. In addition, if the cancer lesions are small, biopsy may not reveal them. [8-10].

An increasing number of centres are able to offer transperineal template prostate biopsy [11]. Clinical experience is that the diagnostic accuracy is double that of TRUS biopsy and the sepsis rate

very much lower. It is also the case that Transperineal biopsy is reserved for men with rising PSA and one or more negative TRUS biopsies, however it is now extended to first time biopsies, especially if the MRI pre biopsy suggests an anteriorly located cancer. In a British Association of Urological Surgeons (BAUS) session (June 2014), almost all urologists said that they would personally prefer a transperineal prostate biopsy rather than TRUS given the choice, although they recognised the current challenge of limited theatre capacity.

There is growing evidence that multiparametric (mpMRI) (using a 1.5T or 3T machine) by an experienced team of radiographers and radiologists before a prostate biopsy can provide more information by which to identify prostate cancer and thus reduce the false-negative rate [12]. An on going, large-scale trial (the PROMIS trial) is looking at mpMRI. It has been running since 2012, and is also looking at the cost-effectiveness of using mpMRI before biopsy, which is vital information if it is to become part of standard practice in the UK. The PROMIS trial finishes in 2015.

NICE guidelines recommend that, when a patient has been diagnosed as having prostate cancer, they have access to imaging techniques such as magnetic resonance imaging (MRI), computerised tomography (CT) scans and radioisotope bone scans to assess the extent of cancer and whether or not that has spread beyond the prostate [13].

Commitment 3 : Access to Treatment

The Commitment: Men with prostate cancer (regardless of stage of disease) have access to their treatment of choice, including clinical trials if deemed clinically appropriate, regardless of geographical location.

What it means for the patient: Assurance that they will have access to treatments offering them the best chance of controlling their cancer and that gives them the best quality of life regardless of where they live.

Rationale: Prostate cancer is unique in that, without solid evidence of the best treatment option, personal choice (e.g. of surgery versus radiation) becomes an important element in selecting treatment options. In the latest national cancer patient experience survey (October 2014) 73% of prostate cancer patients felt their views were taken into consideration when discussing treatment options.

The NHS Constitution sets out patients' right to treatment, right to NICE approved drugs and right to complain about their care [14]. The constitution gives the patient the right to ask their doctor and hospital for the right care. For cancer drugs that have not been approved by the National Institute for Health and Care Excellence (NICE) the Government has set up the Cancer Drugs Fund (CDF) to pay for cancer drugs that haven't been approved and aren't available within the NHS in England. There is a national list of drugs available through the Fund and if a patient meets the conditions for a drug that is on the list, he should be able to have it on the NHS regardless of geographical location within England (this is currently under review by NHS England).

Patients should also have the opportunity to speak to their specialist about whether there are any other treatments they can access such as trials of new experimental treatments going on and their eligibility to take part in one of them. Cancer Research UK publishes a clinical trials database (<http://www.cancerresearchuk.org/about-cancer/trials/>) listing trials both open and closed.

“Examples of good practice in cancer services that you would like to see replicated across the country”

Uniformity in diagnosis and treatment of prostate cancer is an area of concern, but there are emerging good practices that ought to be promoted as examples of possible best practice. These include:

1. Ready access for all patients to a Clinical Nurse Specialist attached to a urology or oncology centre in England. These individuals provide a valuable service to patients, particularly in reassuring newly diagnosed patients and their families and dealing with the side effects of treatment. They take a lot of weight from the shoulders of consulting staff. [15,16]
Examples of good practice are : **University Hospitals of Leicester ; Birmingham QE Hospital ; Tameside General Hospital**
2. Greater use of hospice facilities, not restricted to ‘end of life care’ . Non-curative care can be offered following treatment , or in the early stage of illness, as witnessed by a number of leading hospice organisations. This extends to counselling, wellness programmes, social activities and is integrated with primary and secondary care pathways. Examples of good practice are: **Blythe House Hospice, Chapel-en-le-Frith, Derbyshire; LOROS Hospice, Leicester; Cynthia Spencer Hospice, Northampton; Hospice of St. Francis, Berkhamsted, Herts**
3. Availability of supported self-management of the side effects of treatment. Some patients welcome the opportunity to self-manage their condition, and the side effects, under the guidance of their clinician. This requires a personalised care plan, possibly remote monitoring with an alert system to prompt screening investigations. [17,18] Example of good practice is the **Macmillan Recovery Package**. See www.macmillan.org.uk
4. Some Trusts have a pro-active approach in providing access to specialists to support the prevention and management of complications due to prostate cancer disease, be they physical, social, emotional, sexual or psychological. Erectile dysfunction, urinary problems and bone health complications are critically important issues for some men. It is vitally important these patients are aware of the issues and treatment options available. [19,20]
An example of good practice is **High Peak Prostate Cancer Support Group**
5. A number of urology centres in England have close relationships with local support groups. This is a vital connection for patients who would like to talk to other patients and their partners. It also offers an opportunity for men to realise there is life after prostate cancer and to discuss problems with fellow sufferers. Many support groups also have a regular

presence at urology clinics to promote this relationship for mutual benefit [21]. Examples of good practice are : **Droylsden Prostate Cancer Support Group and Tameside General Hospital ; Chiltern Prostate Cancer Support Group and Wycombe General Hospital**

“The biggest barrier to improving cancer services”

In our experience the biggest single barrier to improving services for prostate cancer patients is a weakness in the structure of the NHS itself. A lack of ‘joined-up thinking’ in ongoing support and advice is a frequent cause for complaint. Men living with prostate cancer should benefit from an integrated and seamless approach to their care and wellbeing appropriate to their stage of their disease for the rest of their lives. This includes clear accountability and responsibility across primary and secondary care.

From a patient perspective this should show consistent thinking in the support and advice given, irrespective of who the patient needs to contact. This will enable the patient to benefit from a holistic approach to all aspects of their care and there will be no risk of ‘falling between the cracks’ of specialisations.

Integrated care means all health and social care services working together across organisational and professional boundaries to ensure individual patients get the care, information, support and treatment they need, when they need it [22]. It is clear that primary care providers should play a bigger role, as it is they who inevitably care not only for prostate cancer survivors, but all those affected by prostate cancer. In order to ensure men are adequately supported to manage these needs there must be a seamless integration of well co-ordinated cancer care across primary (GP), secondary (hospital), and social care. This includes clear lines of responsibility and accountability with staff provided with the necessary training and links to resources.

Furthermore, in health and social care policy, addressing wellbeing needs is becoming a growing priority. However, despite this growing emphasis, provision of wellbeing services for men with prostate cancer appears to be highly inconsistent. Recent research commissioned by Prostate Cancer UK put this down to lack of resources; low awareness (of the problem and / or support services) among clinicians; over-concentration on ‘the cancer’ relative to ‘the man’; and lack of local strategic direction [19]. The manner / type of referral makes a difference to the take-up of support services – integration of wellbeing into standard pathways (through a holistic needs assessment, for example) is important. The extent of local clinical engagement in the ‘wellbeing agenda’ is therefore an important determining factor in the support men receive.

APPENDIX

Tackle Prostate Cancer Submission

This submission has been made by the Board of Trustees of the Prostate Cancer Support Federation (Tackle Prostate Cancer), supported by clinical advisors Professor Frank Chinegwundoh MBE, Consultant Urological Surgeon Barts Health NHS and representing Cancer Black Care, and Dr Chris Booth, Clinical Director CHAPS – The Men’s Health Charity

Source Guidance

1. 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; 53:99–105.
2. Parkin D, Whelan S, Ferlay J, Raymond LYJ. Cancer Incidence in Five Continents. Lyon: IARC Scientific Publications No. 143, 1997. Report No. V11.
3. Parker SL, Davis KJ, Wingo PA, Ries LA, Heath CW Jr. Cancer statistics by race and ethnicity. *CA Cancer J Clin* 1998; 48:31–48.
4. Hear me now: the uncomfortable reality of prostate cancer in black African-Caribbean men. A report by Rose Thompson, BME Cancer Communities, February 2013.
<http://www.nbpa.co.uk/wp-content/uploads/2014/04/Hear-me-now.pdf>.
5. NHS Cancer Screening Programmes. An easy reference to assist primary care teams in providing asymptomatic men with information on the benefits, limitations and implications of having a PSA test for prostate cancer. (2009). Available from:
<http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf>.
6. Wilt and Ahmed – “Prostate cancer screening and the management of clinically localized disease” - published in *BMJ* 19th January 2013
7. National Institute for Health and Care Excellence. Referral guidelines for suspected cancer. NICE clinical guideline 27(2005). Available from:
<http://www.nice.org.uk/guidance/cg27/resources/guidance-referral-guidelines-for-suspected-cancer-pdf>.
8. Loch T, Eppelmann U, Lehmann J, Wullich B, Loch A, Stockle M. Transrectal ultrasound guided biopsy of the prostate: random sextant versus biopsies of sono-morphologically suspicious lesions. *World J Urol*. 2004;22:357–360.
9. Wefer AE, Hricak H, Vigneron DB, Coakley FV, Lu Y, Wefer J, et al. Sextant localization of prostate cancer: comparison of sextant biopsy, magnetic resonance imaging and magnetic resonance spectroscopic imaging with step section histology. *J Urol*. 2000;164:400–404.
10. Hricak H, Choyke PL, Eberhardt SC, Leibel SA, Scardino PT. Imaging prostate cancer: a multidisciplinary perspective. *Radiology*. 2007;243:28–53.
11. NICE interventional procedures guidance (IPG364). Transperineal template biopsy and mapping of the prostate. October 2010
12. Myung Sun Choi, Yong Sun Choi, Byung Il Yoon et al. The Clinical Value of Performing an MRI before Prostate Biopsy. *Korean J Urol*. Aug 2011; 52(8): 572–577.

13. Men referred for suspected prostate cancer, in accordance with NICE clinical guideline 27, recommendations 1.8.2 – 1.8.8 are offered a transrectal ultrasound (TRUS) guided biopsy, in accordance with NICE clinical guideline 175, recommendation 1.2.4.
14. The NHS Constitution:
<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf>
15. Cancer Patient Experience Survey 2014. <http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>
16. 2011 CNS Census
http://www.bdn.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf (page 10)
17. Macmillan cancer support, Self-management support for cancer survivors: guidance for developing interventions: An update of the evidence (March, 2010). <http://www.ncsi.org.uk/wp-content/uploads/Guidance-for-Developing-Cancer-Specific-Self-Management-Programmes.pdf>.
18. DH, Macmillan Cancer Support & NHS Improvement. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). March 2013.
19. Prostate Cancer UK. Research into wellbeing services for men with prostate cancer –final report. August 2014
20. National Institute for Health and Care Excellence. Prostate cancer: Diagnosis and treatment. NICE clinical guideline 175 (2014). Available from:
<http://www.nice.org.uk/nicemedia/live/14348/66232/66232.pdf>
21. See the list of support groups available to prostate cancer patients at
<http://www.tackleprostate.org/>
22. Patients' experience of integrated care: A report from the Cancer Campaigning Group. November 2012