25th January 2013

To whom it may concern,


Prostate Cancer UK welcomes the opportunity to respond to the NHS Commissioning Board’s standard contract ‘Urological cancers – kidney, bladder and prostate cancer’.

Prostate Cancer UK is the UK’s leading charity for men with prostate cancer and prostate problems. We support men and provide information, find answers through funding research and lead change to raise awareness and improve care. The charity is committed to ensuring the voice of people affected by prostate cancer is at the heart of all we do.

About Prostate Cancer

Prostate cancer is the most common form of cancer in men in England. Nearly 35,000 men are diagnosed with prostate cancer every year and 215,000 men are currently living with the disease.

In the UK, 1 in 8 men will get prostate cancer at some point in their lives. Older men, men with a family history of prostate cancer and men of black African and black Caribbean descent are more at risk.

We have chosen to provide a general response to the sections most relevant to prostate cancer.

Information regarding prostate cancer

We are concerned that the wording used to describe prostate cancer is out of date and does not provide more detail. We would suggest the following wording:

‘Prostate cancer is a form of cancer that develops in the prostate. Advanced prostate cancer is prostate cancer that has spread out of the prostate to other parts of the body. In 2010 there were 34,892 newly diagnosed cases of prostate cancer in England, with a crude incidence rate of 135 cases per 100,000 population. One year relative survival estimates in England in 2005-2009 are very high at 93.5%.’

We believe this section should add ‘prostate cancer is the most common form of cancer in men in England. Currently over 215,000 men are living with prostate cancer and 1 in 8 men will get it at some point in their lives.’ Finally, mortality rates for men with prostate cancer have decreased for all age groups apart from men aged 85 and over.’
Referencing all current clinical and commissioning documents

We are concerned that the standard contract refers to documents which have since been updated and does not reference important prostate cancer guidance. We feel that the most up to date information should be used to set out the best possible framework for commissioning urological cancers. We are very concerned there is no reference to the 2008 National Institute for Health and Clinical Excellence (NICE) clinical guideline on prostate cancer [CG58]. Although the guidance is currently being partially updated the existing version should be referenced. Clinical guidelines are important as they aim to improve the quality of care, improve the relationship between healthcare professionals and patients and help patients make informed decisions. The clinical guideline for prostate cancer is important to reference as we are still awaiting a quality standard for prostate cancer. Prostate cancer is currently the most common cancer not to have a quality standard, with publication not due until late 2014.

Patient information

We feel this section could be strengthened by adding in sources of external information for patients regarding prostate cancer. For example, Prostate Cancer UK produces a range of balanced information publications on prostate cancer for men and their families, which have been certified by the Information Standard. They are free to download and order and have been reviewed by both experts and people affected by prostate cancer. Furthermore, Prostate Cancer UK provides support services, such as our helpline, staffed by clinical specialist nurses and peer support, which we believe should be highlighted to future commissioners. More information can be found at www.prostatecanceruk.org

Prostate Cancer UK has recently published our ‘Quality checklist: Your standards of care’ which details the standards of support and care that men should expect to receive from a cancer diagnosis through to end of life care. This is a patient led and patient driven document that is based on the views of hundreds of men with prostate cancer and has been endorsed by, Prostate Cancer Research Centre, Royal College of General Practitioners, Royal College of Nurses, The Society of Radiographers, British Uro-oncology Group and The British Association of Urological Nurses. In the absence of a quality standard from NICE on prostate cancer we believe it is vitally important that men are made aware of their rights as patients and what to expect. This should inform quality commissioning for prostate cancer.

Treatment for prostate cancer

We have some suggested additions to this section. First, in this section on surgery there is no mention of robotic surgery. This is now available in some parts of England and as such should be included. We know the outcomes for both hand and robot assisted laparoscopic prostatectomies are similar but we want to ensure that men with prostate cancer have the option of either. We are concerned that men will not have the freedom of choice when it comes to deciding on which treatment is best for them. It is important that men across England are able to access robotic surgery if they and their doctors feel it is right for them, therefore including robotic surgery in this commissioning document will help to ensure this happens. We also feel the lack of inclusion of robotic surgery is in conflict with the Government’s ‘choice’ agenda.
Second we feel there should be a greater focus on radiotherapy services. Information from our helpline tells us that radiotherapy is currently not widely available locally and patients often have to travel considerable distances to access the treatment. With the Radiotherapy Innovation Fund and a pledge from the Prime Minister to improve and increase radiotherapy services we feel this needs to have a greater emphasis in the commissioning guidance. There needs to be an inclusion of the growing numbers of different types of radiotherapy treatments which are now available. Intensity modulated radiotherapy and image guidance radiotherapy is increasing and this should be reflected in the commissioning guidance.

**Key service outcomes for prostate cancer**

We welcome the fact that urologists will now be collecting statistics regarding which type of treatment men opt for, something Prostate Cancer UK has been advocating for some time. We know that men want this information (we often get asked for it through our dedicated helpline) so they can make an informed choice about their treatment. We feel the embedding of this information into standard commissioning practice is a positive step in the right direction.

We want a range of treatment options available for men with prostate cancer as currently there is no evidence that any one treatment is better. At present there is too much variation in the type of treatment for prostate cancer available across the UK. Therefore the standardisation of practice is to also be welcomed.

Finally, the section detailing advanced disease needs to include the addition of new drugs, such as abiraterone (brand name Zytiga). We want all men with prostate cancer to have access to clinically effective treatments; therefore this contract should act as a guide to address regional variation.

**General**

**Third sector support services**
Organisations such as Prostate Cancer UK are in an excellent position to provide good quality information and support to men with prostate cancer. The NHS Commissioning Board must ensure it has a positive impact on the lives of men with prostate cancer by detailing all care and support services available, particularly those services, such as ours, that can be used at little or no cost.

**National clinical audit**
From 2013, a national clinical audit will be undertaken for prostate cancer. Currently, we still do not know the best way to treat the majority of men diagnosed with early forms of the disease. As well as giving clinicians the opportunity to learn more from one another and compare their performance, this clinical audit will allow us to better understand the long-term outcomes of the different treatments available for the disease. This will help clinicians and men make informed decisions about the best treatment options for them, and will lead to vital improvements in the quality of care men with prostate cancer receive.

We know from the success of previous audits for other common cancers that improvements in the quality of services and care for men with prostate cancer should not be far behind. We look forward to actively supporting the implementation of this audit over the next three years. The results from the clinical audit should provide detailed evidence on how services can be improved and therefore commissioners need to take this into account.
Thank you for taking the time to read Prostate Cancer UK’s response. If you would like more information on any aspect of our response please contact the Policy & Campaigns team by email at policy@prostatecanceruk.org or telephone 0208 222 7622.

Yours sincerely,

Holly Mitchell
Policy Officer

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1 Cancer Research UK http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/
3 National Institute of Health and Clinical Excellence http://guidance.nice.org.uk/CG58
4 Prostate Cancer UK http://prostatecanceruk.org/media/1620003/a_quality_checklist_-_your_standards_of_care.pdf
6 The Department of Health http://mediacentre.dh.gov.uk/2012/10/08/eight-thousand-patients-to-benefit-from-advanced-cancer-treatment/