

## Patient Summary 2017 – Third Year Annual Report



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The glossary at the end of this report gives further explanations of the clinical terms used in this report.

## Prostate Cancer: Facts & Figures

Prostate cancer is the most common cancer in men with over 46,000 new cases diagnosed each year in the United Kingdom. One in eight men will get prostate cancer in their lifetime and over 330,000 men are living with prostate cancer.

### What is the National Prostate Cancer Audit?

This is a national clinical audit assessing the quality of services and care provided to men with prostate cancer in England and Wales. The National Prostate Cancer Audit collects clinical information about the treatment of all patients newly diagnosed with prostate cancer in England and Wales and about their outcomes. The Audit's findings will give us a better understanding of how patients are being looked after. This will help NHS hospitals to improve the care they provide to prostate cancer patients.

The National Prostate Cancer Audit started on the 1st April 2013. Collection of clinical information for all men diagnosed with prostate cancer started on 1st April 2014 in England and one year later, on 1st April 2015, in Wales.

### Who is undertaking the National Prostate Cancer Audit?

The Audit is run by a team of clinicians, audit experts and cancer information specialists based at the Royal College of Surgeons of England, the British Association of Urological Surgeons, the British Uro-oncology Group, and the National Cancer Registration and Analysis Service.

### How is data collected for the Audit?

- NHS hospitals provide information about the diagnosis, treatment and outcomes of patients with prostate cancer to the National Cancer Registration and Analysis Service and to NHS databases, such as the Hospital Episode Statistics.
- The Audit receives anonymised clinical information on a range of different data items, which are combined for analysis. The Audit also mails a survey questionnaire to some patients. The anonymised answers to this patient survey are also combined with the clinical data.
- The Audit works within strict rules covering data protection and confidentiality. Individual patients are never identified.
- It is important to note that the Audit uses anonymised clinical data from multiple sources. The data we receive is therefore very complex and can produce inconsistencies with respect to some crucial data items. Further development of the approach taken to resolve these inconsistencies is a priority area for the Audit.

## What data is in the 2016 Annual Report?

The 2016 Annual Report is the third report produced by the National Prostate Cancer Audit. It has 3 main components:

1. A clinical audit in England: This has collected data on over 35,000 men diagnosed with prostate cancer between 1st April 2014 and 31st March 2015.
2. A clinical audit in Wales: This contains preliminary data on over 800 men diagnosed between 1st April 2015 and 31st September 2015.
3. A patient survey of men undergoing radical treatment in England: This is a comprehensive collection of self-reported patient experience and outcome data from over 6,000 men who completed a survey questionnaire 18 months after their prostate cancer diagnosis and its subsequent treatment.

## Clinical audit in England: Key Findings

### How many Trusts are participating?

- 138 of 139 NHS Hospital Trusts in England that provide prostate cancer services submitted data for the National Prostate Cancer Audit.
- Data items related to the stage of prostate cancer are well completed but other data items, such as those related to patients' health and type of treatment received, are currently not well completed.

### What techniques are being used for diagnosis?

- The commonest method used to take samples of the prostate for diagnosis is **transrectal ultrasound biopsy**. This accounts for 85% of all prostate biopsies carried out.
- **Multiparametric MRI** was used in 44% of men and was performed before biopsy in over half of these (55%).

### What treatments are patients receiving?

- Most men with **low-risk prostate cancer** (prostate cancer unlikely to spread beyond the prostate) can be managed with active surveillance, a treatment programme that includes careful monitoring in order to detect disease progression early. A key concern is the possibility that these patients are "**over-treated**" if they undergo early and potentially unnecessary radical therapies. This can result in avoidable side-effects of treatment.
  - ➔ Approximately 1 in 8 men with low-risk prostate cancer received radical treatment. This is similar to the number of men being treated in this way between 2010 and 2013.

- Men with **high-risk locally advanced prostate cancer** (prostate cancer that is likely to, or that already has spread beyond the prostate), particularly in healthy older men, may be “**under-treated**” by the failure to use radiotherapy or in some circumstances, surgery to the prostate. The most common form of “under-treatment” is the use of hormonal treatments alone without the additional radiotherapy or surgery.

→ There has been a reduction in potential “under-treatment” of locally-advanced disease from 53% (2010-13 data) to 39% in 2016.

## Clinical audit in Wales: Key Findings

### How many Health Boards are participating?

- All six Health Boards that provide prostate cancer services in Wales submitted data to the National Prostate Cancer Audit
- Each key Audit data item was completed well by all six Health Boards in Wales.

### What techniques are being used for diagnosis?

**Transrectal ultrasound biopsy** of the prostate was the most commonly used technique in Wales (92% of men).

**Multiparametric MRI** was used in 65% of patients and just over one in five of these men received it before biopsy.

## Patient outcomes and experience survey in England: Key Findings

### How many patients responded to the survey?

- This was one of the largest individual patient treatment surveys undertaken in the UK with an excellent response rate (73% of all men who were diagnosed between 1st April and 31st October 2014 and underwent radical treatment).

### What were the main findings regarding outcomes reported by patients?

- Men who received either radical surgery or external beam radiotherapy reported that **problems with having erections** was the side-effect of treatment that affected them most severely. However, they reported good **urinary function** and **bowel function**.

### What were the main findings reported by patients about their experience?

The **overall picture regarding men’s experience** of care is very positive, with 90% of men receiving radical treatment for prostate cancer rating their care as 8 or above on the scale of 0 (‘very poor’) to 10 (‘very good’).

### Do men with prostate cancer receive support from a clinical nurse specialist?

In keeping with recommended standards<sup>1</sup> the majority of men were given the name of a **clinical nurse specialist** to provide support throughout their treatment (83% of radical prostatectomy patients and 85% of radiotherapy patients).

## Recommendations for patients

- All men undergoing surgery or radiotherapy should be made aware that they may experience significant side-effects including problems having erections and urinary incontinence. They should have early and ongoing access to support services that can help with these side-effects in keeping with national recommendations<sup>2</sup>.
- Men with prostate cancer are encouraged to see clinical nurse specialists and other allied health professionals who can provide support with their condition.
- There are many sources of further information and support available for prostate cancer patients and carers. These are accessible via GP services and from prostate cancer charities including Prostate Cancer UK ([www.prostatecanceruk.org](http://www.prostatecanceruk.org)) and Tackle Prostate Cancer ([www.tackleprostate.org](http://www.tackleprostate.org)). Both of these charities operate nationwide support networks.

<sup>1</sup> NICE, 2015. Prostate Cancer. NICE Quality Standard 91. Quality statement 1: “Men with prostate cancer have a discussion about treatment options and adverse effects with a named nurse specialist”

<sup>2</sup> NICE, 2015. Prostate Cancer. NICE Quality Standard 91. Quality statement 4: “Men with adverse effects of prostate cancer treatment are referred to specialist services”

## Annual Report

The National Prostate Cancer Audit released the Third Annual Report in December 2016. This provides a more in-depth analysis of the Audit's findings. This report, as well as previous Annual and Patient Reports, can be accessed on the website ([www.npca.org](http://www.npca.org)).

## The Future of the Audit

- The National Prostate Cancer Audit will continue to engage with NHS Hospital Trusts in England and NHS Health Boards in Wales to improve completeness of all data items required by the National Prostate Cancer Audit.
- Better completeness of these data items will allow the Audit to perform a fair comparison of how well each NHS provider of prostate cancer care is doing compared with others and to make recommendations of where change is needed.

**The next results will be published in the Audit's Annual Report and Patient Summary in November 2017.**

## Glossary

### Active Surveillance

This treatment is a way of monitoring prostate cancer that has low risk features and is contained within the prostate. Doctors monitor your cancer closely and they can initiate active treatment with surgery or radiotherapy if the cancer starts to grow.

### Clinical Nurse Specialist (CNS)

These are experienced senior nurses who have undergone specialist training. They play an essential role in improving communication with cancer patients, and that are first point of contact for the patient, coordinating and facilitating the patient's treatment.

### External Beam Radiotherapy (EBRT)

The use of high energy X-ray beams directed at the prostate from outside the body to kill cancer cells. It can be used to treat localised or locally advanced prostate cancer.

### Health Board

A local health organisation that is responsible for delivering all healthcare services within a regional area in Wales. Currently, there are seven Health Boards in Wales and six of these provide prostate cancer services.

### Magnetic Resonance Imaging (MRI)

A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

### Multiparametric MRI (mpMRI)

A special type of Magnetic Resonance Imaging Scan (MRI) that provides detailed images of the prostate.

### NHS Hospital Trust

An NHS organisation that provides acute care services in England. A trust can include one or more hospitals.

### Radical treatment

Treatment aimed at curing prostate cancer (getting rid of all cancer tissue). These treatments include radical prostatectomy and radiotherapy (including brachytherapy).

### Radiotherapy

The use of radiation to destroy cancer cells. There are different types of radiotherapy, including external beam radiotherapy and brachytherapy.

### Transrectal Ultrasound (TRUS) Biopsy

This involves using thin needles put in to the prostate after "freezing" the area with local anaesthetic to take around 10-12 small samples of tissue. The biopsy is done through the rectum (back passage). The placement of these needles precisely is enabled by use of an ultrasound scanner in the rectum to guide the biopsy.