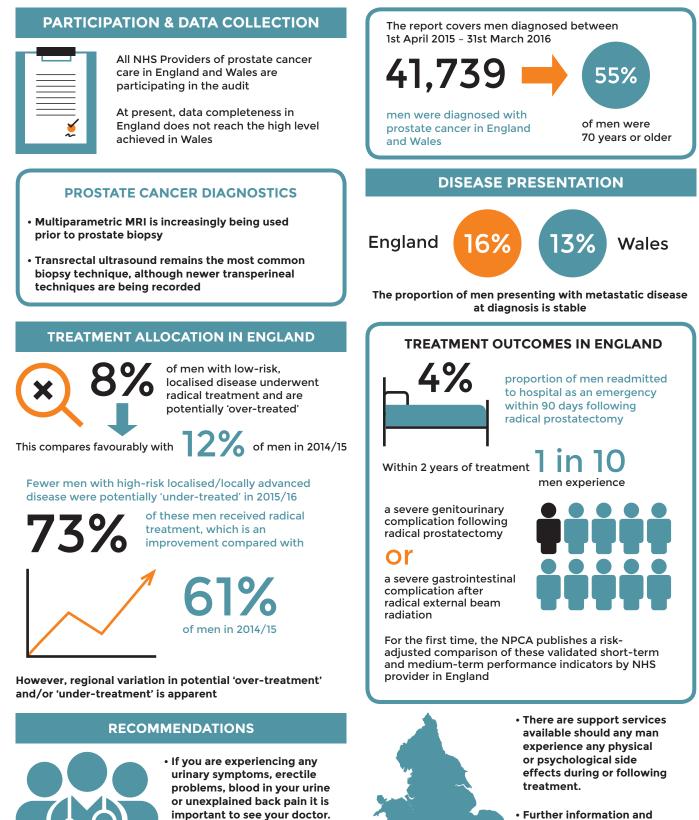


# Patient Summary 2018 – Fourth Year Annual Report



## **NPCA Patient Summary 2018**



 Further information and support are accessible via GP services and from prostate cancer charities including Prostate Cancer UK (www.prostatecanceruk.org) and Tackle Prostate Cancer (www.tackleprostate.org).

References NICE, 2014. Prostate Cancer. Clinical Guideline 175. https://www.nice.org.uk/guidance/cg175; NICE, 2015. Prostate Cancer. NICE Quality Standard 91. https://www.nice.org.uk/guidance/cg175; NICE, 2015.

that they may experience.

• It is important that all men having treatment for

prostate cancer are aware of the significant side effects

## Patient Summary 2018 - Fourth Year Annual Report

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 47,000 new cases diagnosed each year in the United Kingdom. 1 in 8 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 and outcomes of all patients newly diagnosed with prostate cancer in England and Wales. It uses this information to help to define standards for diagnosis and treatment outcomes. The Audit's findings will give us a better understanding of how patients are being looked after. This will help NHS Hospital Trusts to improve the care they provide to prostate cancer patients.

The National Prostate Cancer Audit started on 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 Hospital Trusts 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 Hospital Episode Statistics.
- The Audit receives anonymised clinical information on a range of different data items, which are combined for analysis. The Audit also sends a questionnaire to all men who are on active surveillance or who underwent radical treatment. We will present information on these patientreported measures in a future report when we have the results from additional surveys.
- The Audit works within strict rules covering data protection and confidentiality. Individual patients are never identified.

#### What data is in the 2016 Annual Report?

The 2017 Annual Report is the fourth report produced by the National Prostate Cancer Audit. We report on 2 main parts of the Audit:

- 1. A clinical audit in England: This has collected data on over 39,000 men diagnosed with prostate cancer between 1st April 2015 and 31st March 2016.
- 2. A clinical audit in Wales: This has collected data on over 2,000 men diagnosed between 1st April 2015 and 31st March 2016.

### **Clinical audit in England: Key Findings**

#### How many Trusts are participating?

- All 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 filled out by hospitals. This information is vital for the Audit so that we can display information according to risk.
- Other data items, such as those related to patients' health and type of treatment received, are less complete. In the next audit cycle we aim to help hospitals to improve the quality of this information.

## What techniques are being used for diagnosis?

- Trans-rectal ultrasound (TRUS) guided biopsy is the most common method used to take samples of the prostate for diagnosis. This accounts for almost 9 out of every 10 prostate biopsies carried out. This type of biopsy involves using needles to take small samples and is done through the rectum (back passage). An ultrasound scanner in the rectum is used to guide the biopsy.
- 12 in every 100 biopsies were performed via the perineum (trans-perineal biopsy) and this technique is increasing year on year (11 in every 100 in 2014/15). This method is able to target specific areas of the prostate more accurately but is only used in a proportion of men as it is more complicated for patients. This method usually requires a general anaesthetic and can have more side effects in men with large prostates.
- Multiparametric Magnetic Resonance Imaging (MRI) of the prostate (a scanning technique that combines different types of image to look at the prostate in detail) was used for half of the men. This method showed an increase from 2014/15 where it was used for 44 in every 100 patients who were diagnosed. Three-quarters of these MRI scans were performed before a prostate biopsy, which is also an improvement on last year's results, when just over half of the men had this. Having an MRI before the biopsy helps the doctors to plan more effectively and target specific areas of the prostate.

#### How do men present at diagnosis?

- More than half of the men diagnosed with prostate cancer were 70 years or older. 36 in every 100 men were aged between 70 and 80 years of age and just under one-fifth of men were older than 80 years. Just over 1 in every 10 men diagnosed were under 60 years old.
- Approximately 1 in 4 men were from the least deprived areas of the country as measured by the Index of Multiple Deprivation (IMD), in contrast to only just over 1 in 10 men who were from the most deprived group.
- 93 in every 100 men were of white ethnic origin.
- 16 in every 100 men with prostate cancer presented with advanced (metastatic) disease and 35 in every 100 men had disease which was high-risk or locally advanced (prostate cancer that had spread just outside the prostate but not to other areas of the body). Just under 1 in 10 men presented with low-risk localised disease and 4 in 10 men had intermediate-risk localised disease.

#### 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 to detect disease progression early. A key concern is the possibility that patients with low-risk localised prostate cancer may be potentially "over-treated" if they have early and potentially unnecessary radical therapies (i.e. treatments that aim to cure the cancer). This can result in avoidable side-effects of treatment.
  - → Approximately 1 in 12 men with low-risk prostate cancer received radical treatment. This is less than the number of men being treated in this way in 2014/15 (1 in 8 men). This finding is particularly encouraging, as it means fewer men are having potentially unnecessary treatment.
- Men with locally advanced prostate cancer, particularly 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 "undertreatment" is the use of hormonal treatments alone without additional radiotherapy or surgery.
  - → There has been a continued reduction in potential "under-treatment" of locally advanced disease from 4 in 10 men (2014/15) to less than 3 in 10 men.

## What are the outcomes for men having treatment?

- For the first time, the National Prostate Cancer Audit compared the performance of NHS Hospital Trusts to identify any differences and areas where improvements may be needed.
- Of all the men who had surgery for their prostate cancer in 2015/16, only 4 in every 100 men were readmitted back to hospital within 90 days of their operation. This is consistent across all NHS Hospital Trusts in England which perform surgery after adjusting for differences in case-mix (see Glossary). One hospital was flagged as a potential 'outlier', meaning their results looked noticeably different to other hospitals. But further analysis showed that this hospital's readmission rates were similar to those in the rest of the country.
- Our results show that the rate of experiencing a severe urinary complication following prostate cancer surgery is low. 1 in 10 men who had surgery experienced this type of complication. This was defined as a patient needing a further procedure within two years of their operation. This proportion is consistent across all NHS Hospital Trusts in England which perform surgery.
- Our results show that the rate of experiencing a severe bowel side effect following radiotherapy is low. 1 in 10 men who had radiotherapy in 2014/15 experienced these side effects. This was defined as a patient needing a further procedure within two years of their radiotherapy. This proportion is consistent across all NHS Hospital Trusts in England which perform radiotherapy.

### 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 well filled out by all six Health Boards in Wales.

## What techniques are being used for diagnosis?

- Trans-rectal ultrasound (TRUS) guided biopsy of the prostate was the most commonly used technique in Wales (96 in every 100 men).
- Multiparametric MRI was used in just over half of the patients and just over 1 in 4 of these men received it before their prostate biopsy. More men are now receiving this type of MRI scan before their biopsy than in 2014/15.

#### How do men present at diagnosis?

- More than half of the men diagnosed with prostate cancer were 70 years or older. Just under 4 in every 10 men were aged between 70 and 80 years of age and just under 2 in every 10 men were older than 80 years. Just over 1 in every 10 men diagnosed were under 60 years old.
- Over half of men diagnosed were otherwise in very good health and less than 1 in 20 men were in very poor health.
- 13 in every 100 men with prostate cancer presented with advanced (metastatic) disease and 34 in every 100 had locally advanced disease. 1 in 10 men presented with low-risk localised disease and 4 in 10 men had intermediate-risk disease.

### **Recommendations for patients**

- More than 1 in 10 men who are diagnosed with prostate cancer present with advanced (metastatic) disease. If you are experiencing any urinary symptoms, erectile problems, blood in your urine or unexplained back pain it is important to see your doctor so that any problems can be picked up early.
- 1 in 10 men will need a further procedure following either surgery or radiotherapy due to developing treatment side effects. It is important that all men having treatment for prostate cancer are aware of the significant side effects that they may experience. These include problems getting or keeping erections, loss of ejaculatory function, drop in sexual pleasure, urinary incontinence and/or bowel side effects.
- There are support services available should any man experience any physical or psychological side effects during or following treatment and there should be early and ongoing access to these services, in keeping with national recommendations.<sup>1</sup>
- 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) and Tackle Prostate Cancer (www.tackleprostate.org). Both of these charities operate nationwide support networks.

### **Annual Report**

The National Prostate Cancer Audit released the Fourth Annual Report in November 2017. This provides a more indepth 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.uk).

### The Future of the Audit

- The National Prostate Cancer Audit will continue to work with NHS Hospital Trusts in England and NHS Health Boards in Wales to improve completeness of all data required by the National Prostate Cancer Audit.
- Better completeness of these data allows the Audit to compare how well each NHS Hospital Trust is doing compared with others, and to make recommendations of where change is needed.
- The Audit will continue to analyse patient outcomes to compare NHS Hospital Trusts' performance in England. We aim to start to perform similar comparisons with Welsh data in the next Annual Report.
- The Audit will publish results as part of the Clinical Outcomes Programme where patients can access information specific to their local hospital and treatment centre via the NHS Choices website.
- Further patient surveys are currently being sent out to patients to look at patient-reported outcomes and experiences. This will give the Audit additional information on the benefits and side effects of treatment for men diagnosed with prostate cancer in England and Wales.
- As more data becomes available we will start to look at other areas of prostate cancer management. This will include outcomes following multiple treatments, complications of different methods of prostate biopsy and the potential causes of under-treatment.

#### The next results will be published in the Audit's fifth Annual Report in December 2018 and the corresponding Patient Summary in February 2019.

1 NICE, 2015. Prostate Cancer. NICE Quality Standard 91. Quality statement 4: "Men with adverse effects of prostate cancer treatment are referred to specialist services"

### Glossary

#### **Active Surveillance**

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

## British Association of Urological Surgeons (BAUS)

A dedicated professional association for urological surgeons. Registered charity no: 1127044.

#### British Uro-oncology Group (BUG)

Dedicated professional association for clinical and medical oncologists specialising in the field of urology. Registered charity no: 1116828.

#### Case-mix

Refers to different characteristics of patients seen in different hospitals (for example age, sex, disease stage, social deprivation and general health). Knowledge of differing casemix enables a more accurate method of comparing quality of care (case-mix adjustment).

#### **Clinical Outcomes Programme (COP)**

An NHS initiative, managed by the Healthcare Quality Improvement Partnership (HQIP), to publish quality measures at the level of each individual consultant, team and unit using national clinical and administrative data.

#### **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.

#### **Hospital Episode Statistics (HES)**

A database that contains data on all inpatients treated within NHS hospitals in England. This includes details of admissions, diagnoses and treatments.

#### **Localised Disease**

When cancer is confined within the prostate.

#### **Locally Advanced Disease**

When cancer has spread outside the prostate and potentially into surrounding lymph nodes in the pelvis.

#### **Metastatic Disease**

When cancer has spread away from the prostate to distant areas of the body, mainly to the bones.

#### Multiparametric MRI (mpMRI)

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

## National Cancer Registration and Analytical Service (NCRAS)

A national body which collects, analyses and reports on cancer data for the NHS population in England.

#### **NHS Trust**

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

#### Radiotherapy

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

#### **Royal College of Surgeons of England (RCS)**

An independent professional body committed to enabling surgeons to achieve and maintain the highest standards of surgical practice and patient care. As part of this it supports audit and the evaluation of clinical effectiveness of surgery.

#### **Trans-rectal Ultrasound (TRUS) Guided Biopsy**

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

#### **Trans-perineal biopsy**

Taking biopsies of the prostate through the perineum (the area between the testicles and the rectum). This is performed under general anaesthetic and needle placement can be more precise than trans-rectal ultrasound guided biopsies.