NPCA
National Prostate Cancer Audit

Patient Summary of Annual Report 2018 (Published May 2019)

Results of the NPCA Prospective Audit in England and Wales for men diagnosed from 1 April 2016 to 31 March 2017

National Prostate Cancer Audit

Patient Summary of Annual Report 2018 (Published May 2019)

London: The Royal College of Surgeons of England, 2019.

The Royal College of Surgeons of England (RCS) is 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 for surgery.

The NPCA is based at the The Clinical Effectiveness Unit (CEU). The CEU is an academic collaboration between The Royal College of Surgeons of England and the London School of Hygiene and Tropical Medicine, and undertakes national clinical audits and research. Since its inception in 1998, the CEU has become a national centre of expertise in methods, organisation, and logistics of large-scale studies of the quality of surgical care. The CEU managed the publication of the NPCA Annual Report, 2015.

Registered Charity No: 212808

In partnership with:

The British Association of Urological Surgeons (BAUS) was founded in 1945 and exists to promote the highest standards of practice in urology, for the benefit of patients, by fostering education, research and clinical excellence. BAUS is a registered charity and qualified medical practitioners practising in the field of urological surgery are eligible to apply for membership. It is intended that this website will be a resource for urologists, their patients, other members of the healthcare team and the wider public.

The British Uro-oncology Group (BUG) was formed in 2004 to meet the needs of clinical and medical oncologists specialising in the field of urology. As the only dedicated professional association for uro-oncologists, its overriding aim is to provide a networking and support forum for discussion and exchange of research and policy ideas.

National Cancer Registration and Analysis Service (NCRAS), Public Health England collects patient-level data from all NHS acute providers and from a range of national data feeds. Data sources are collated using a single data processing system ('Encore') and the management structure is delivered through eight regional offices across England.

The NCRAS is the data collection partner for the NPCA.

Commissioned by:

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the National Clinical Audit Programme, comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual audits, also funded by the Health Department of the Scottish Government, DHSSPS Northern Ireland and the Channel Islands.

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Annual Report 2018

Diagnosis

42,975

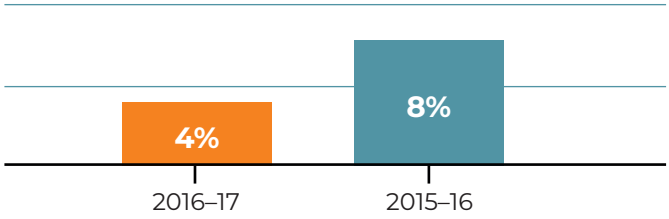
men were diagnosed with prostate cancer in England and Wales between 1st April 2016 and 31st March 2017

	England	Wales	
	80%	41%	of men had a pre-biopsy multiparametric MRI
	12%	4%	of men had a transperineal biopsy

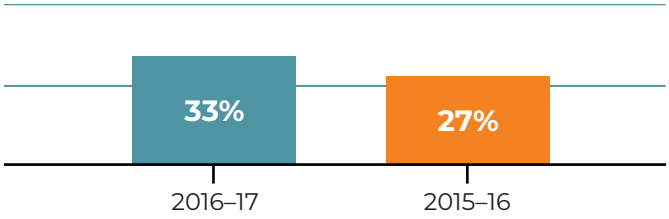
55% of men were 70 years or older

16% of men presented with advanced (metastatic) disease – no change from 15/16

Treatment allocation



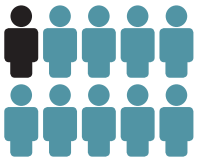
Fewer men with low-risk, localised disease had radical treatments and were potentially 'over-treated'



Slightly more men with locally-advanced disease did not have radical treatments and were potentially 'under-treated'

Treatment outcomes

13% of men were **readmitted** within 3 months **following surgery**



Within **2 years of treatment** 1 in 10 men experienced a **severe urinary complication after surgery** or a **severe bowel complication after external beam radiation**

After surgery, men reported their **sexual function** to be **23** and **urinary continence** to be **71** on a scale of 1 to 100

After external beam radiation, men reported their **sexual function** to be **17** and **bowel function** to be **85** on a scale of 1 to 100 (with 1 being the lowest)

Experience of care

90% of men said they were **given the 'right amount' of information**

83% of men said they were **'given the name of a clinical nurse specialist'**

72% of men said they were **involved as much as they wanted to be in treatment decision making**

89% of men rated their care as 8/10

Patient Summary 2018 – Fifth 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

Over 47,000 men are diagnosed with prostate cancer each year in the UK and over 11,000 men die because of the disease. This makes prostate cancer the second most common cause of cancer-related death for men in the UK. 1 in 8 men will develop prostate cancer in their lifetime and approximately, 400,000 men are now living with the disease.

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 (NPCA) collects clinical information about the treatment and outcomes (what happens after treatment) of all patients newly diagnosed with prostate cancer in England and Wales. This includes information collected from hospital records and directly from patients diagnosed with prostate cancer. The Audit then uses this information to help define new standards for diagnosis and treatment outcomes. The Audit's findings will give us a better understanding of how people are being looked after. This will help NHS Hospital Trusts to improve the care they provide to patients with prostate cancer.

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 and the British Uro-oncology Group.

How is data collected for the Audit?

- NHS Hospital Trusts and Health Boards provide information about the diagnosis, treatment and outcomes of patients with prostate cancer to national organisations in England and Wales. These include the National Cancer Registration and Analysis Service and the Wales Cancer Network. These organisations are allowed to collect data on patients diagnosed with cancer. Information on how to opt out of data collection is provided here.
- The Audit collects anonymised clinical information on a range of different data items, from multiple hospital data sources, which are then combined for analysis.
- The Audit also sends out a questionnaire to all men who are on active surveillance or have undergone radical treatment to capture information on any side effects they might be experiencing (functional outcomes.)
- The Audit works within strict rules covering data protection and confidentiality and therefore individual patients are never identified.

Which patients are included in the NPCA?

The NPCA started on the 1st April 2013. Collection of clinical information for all men diagnosed with prostate cancer has been ongoing since 1st April 2014 in England and since 1st April 2015 in Wales.

What is the NPCA Patient Survey?

The NPCA Patient Survey aims to find out patients' views of their experience of care and their specific treatment outcomes.

Patients are asked questions about their quality of life, side effects (particularly sexual/urinary/bowel complications), the information they received at diagnosis and how treatment decisions were made.

Men with localised prostate cancer who receive radical treatment, either surgery or radiotherapy, usually survive for many years. This is why potential side effects following these treatments are particularly important to monitor.

What data is in the 2018 Annual Report?

The 2018 Annual Report is the fifth report produced by the National Prostate Cancer Audit. We report on all aspects of the care pathway for men with prostate cancer in England and Wales. We also compare the performance of NHS Hospital Trusts to identify any differences and areas where improvements may be needed.

We report on data from the following sources:

1. The clinical audit in England and Wales: We have collected data on 42,975 men diagnosed with prostate cancer between 1st April 2016 and 31st March 2017.
2. The patient survey in England and Wales: A questionnaire was sent to 35,162 men diagnosed with prostate cancer between 1st April 2015 and 30th September 2016 who underwent radical treatment. Just under 25,490 men (7 in every 10 men) returned a completed questionnaire.

Key Findings in England and Wales

How many Trusts are participating?

- All 139 NHS Hospital Trusts in England and 7 Health Boards in Wales that provide prostate cancer services submitted data for the National Prostate Cancer Audit.

- Data on the stage of prostate cancer has been well recorded by hospitals across England and Wales. This means the Audit can accurately measure and display information relating to the risks associated with having prostate cancer, depending on the stage of the disease.

- Some data such as information related to the patients' health and the type of treatment received, remain less complete in England, although improvements from our last report have been observed. In Wales all data items were well filled out by all Health Boards. We are continuing to work closely with hospitals to find the best ways to help improve the quality of this information.

What techniques are being used to diagnose prostate cancer?

- Trans-rectal ultrasound (TRUS) guided biopsy remains the most common method used to take samples of the prostate. It is used in 9 in every 10 patients having prostate biopsies. This type of biopsy uses a needle to take small samples and is performed through the rectum (back passage) with the aid of an ultrasound scanner.

- 12 in every 100 patients in England and 4 in every 100 patients in Wales had biopsies performed via the perineum (trans-perineal biopsy). In previous years this method of taking biopsies has been increasing, although this year's results have observed no increase in the uptake of this technique. This method is able to target specific areas of the prostate more accurately but it is more complicated for patients with more side effects for men with large prostates. It usually requires a general anaesthetic and this may explain why uptake at hospitals has not continued to increase.

- Multiparametric magnetic resonance imaging (MRI) of the prostate (a non-invasive scanning technique that combines different types of image to look at the prostate in detail) shows encouraging development. From 2016/2017 in England, 58 in every 100 patients were scanned for prostate cancer using this approach compared to 51 in 100 patients in 2015/2016 and only 44 in every 100 in 2014/15. In Wales the technique is also being used in over half of patients.

- In England 8 in every 10 MRI scans were performed before a prostate biopsy, as recommended, although in Wales more than half were not. However, these figures are both improvements on previous year's results. 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?

- The numbers of men diagnosed with prostate cancer remains stable and it remains very much a disease of older men. At the time of diagnosis over one-third of men are aged between 70 and 80 and one-third are aged between 60 and 70. Approximately 1 in 6 men were older than 80 and approximately 1 in 10 men were younger than 60.

- Two thirds of men diagnosed in England, and over half of men diagnosed in Wales, were otherwise in very good health. In both nations only 2 in every 100 men were in very poor health.

- 16 in every 100 men in England and 12 in every 100 men in Wales presented with advanced (metastatic) disease. 39 in every 100 men in England and 33 in every 100 men in Wales 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). 35 in every 100 men in England and 44 in every 100 men in Wales had intermediate-risk localised disease. 7 in every 100 men in England and 8 in every 100 men in Wales presented with low-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 prostate cancer may be potentially "over-treated" if they have early and potentially unnecessary treatment. This can result in avoidable side-effects of treatment.

    - Less than 1 in 20 men with low-risk prostate cancer received radical treatment. This is a reduction in the number of men being treated in this way from 1 in every 12 men in 2015/16. 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 "under-treatment" is the use of hormonal treatments alone without additional radiotherapy or surgery.

    - Unfortunately there has been a slight increase in potential "under-treatment" in men with locally advanced prostate cancer. This report identifies patients from 2016-2017 and demonstrates that 33 in every 100 patients are potentially being "under-treatment" compared with 27 in every 100 men patients observed in 2015-2016.

- With the accuracy of pre-treatment investigations improving, fewer men are receiving treatment unnecessarily. However, men with locally advanced disease appear to be at slightly higher risk of not receiving the recommended treatment than those observed in last year's report.

What are the outcomes for men having treatment?

- Just over 1 in 10 men who had surgery for their prostate cancer in 2016/17 needed readmission to hospital within 90 days of their operation. All surgical centres had similar readmission rates.

- Our results show that the rate of experiencing a severe urinary complication (side-effect) following prostate cancer surgery is low. 1 in 10 men who had surgery in 2015 experienced this type of complication. This was defined as a patient needing a further procedure within two years of their operation. Examples of urinary complications include bleeding, infection, narrowing or blockage of the urinary tract.

- The types of procedures used to treat these side effects include insertion of a urinary catheter, bladder washouts or further surgery. The proportion of side effects and secondary procedures is consistent across all NHS Hospital Trusts in England and Wales which perform surgery.

- The rate of experiencing a severe bowel side effect following radiotherapy is also low. 1 in 10 men who had radiotherapy in 2015 experienced these side effects. This was defined as a patient needing a further procedure within two years of their radiotherapy. Examples of side effects to the bowel include bleeding, infection, ulceration, fistula formation or strictures.

- The procedures used to treat these side effects include a camera test, known as an endoscopy, or bowel surgery. The proportion of side effects and secondary procedures is consistent across all NHS Hospital Trusts in England and Wales which perform radiotherapy.

What are the outcomes reported by men after treatment?

- We asked men about their views on their side effects (functional outcomes) after radical treatment in the patient survey.

- Men who received either surgery (radical prostatectomy) or external beam radiotherapy reported that problems with having erections was very common.

- Patients were asked to rate their sexual function after treatment on a scale from 0-100. A score of 0 was associated with complete loss of sexual function and a score of 100 was associated with unaffected sexual function.

- Patients reported poor sexual function scores following radiotherapy aimed at curing the prostate cancer, with an average score of 17 out of 100.

- Sexual function scores following surgery to remove the prostate were also poor, with patients reporting an average score of 23 out of 100.

How do men report their experience of care?

- We also asked men about their views on their experience of care since they received a diagnosis of prostate cancer in the patient survey.

- The overall picture regarding men's experience of care is very positive.

- 9 in every 10 men said they were given 'the right amount' of information about their condition and treatment.

- 8 in every 10 men were given the name of a clinical nurse specialist.

- 7 in every 10 men were involved as much as they wanted to be in decisions about their treatment and care.

- 8 in every 10 men rated their overall care as 8 or above on the scale of 0 ('very poor') to 10 ('very good').

Recommendations for patients

1. Seek medical advice if you are experiencing any urinary symptoms, erectile problems, blood in your urine, unexplained back pain or have a family history of prostate cancer or breast cancer so that any potential prostate cancer related problems can be picked up early.

2. If you're having treatment for prostate cancer you may experience significant side effects. These include problems getting or keeping erections, not being able to ejaculate, urinary incontinence and/or bowel side effects.

3. You should have appropriate counselling before treatment about the likelihood of experiencing a loss of sexual function.

4. There are support services available for men experiencing physical or psychological side effects during or following treatment. These services are available straight away and at any point after treatment, including being provided with a named clinical nurse specialist, in keeping with national recommendations.[1]

5. There are many sources of further information and support available. 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 Fifth Annual Report in Feb 2019. 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.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.

- Working directly with individual care providers will help improve data quality and completeness to ensure the reliability of all the results we present.

- We will continue to publish our findings and highlight areas for improvement to clinicians, stakeholders, patients and the wider public to offer a benchmark of care for those receiving treatment for prostate cancer.

- Our plans are to continue to report on all our current performance indicators, which will hopefully include further patient surveys to capture men's views on their experience of care and their functional outcomes following treatment.

- As more data becomes available the Audit will aim to develop new methods to measure additional performance indicators from individuals with prostate cancer. These will include looking at disease progression, the risks of recurrence and assessing the outcomes from alternative treatments. As the data matures this will also include the reporting of mortality rates from prostate cancer, which will require at least 5 years of follow-up.

[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 case-mix enables a more accurate method of comparing quality of care (case-mix adjustment).

Clinical Nurse Specialist (CNS)
These are experienced senior nurses who have undergone specialist training in Urology. They play an essential role in improving communication with cancer patients. They act as the first point of contact for the patient following prostate cancer diagnosis, coordinating and facilitating the patient's treatment.

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.

Fistula
An abnormal opening between organs or other structures in the body. Fistulas are more common in the pelvic area but can happen in different parts of the body.

Functional Outcomes
How a patient's sexual function, urinary continence and bowel function is effected by treatment.

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.

Patient-reported outcome measures (PROMs)
Selected questions designed to measure prostate cancer related quality of life in five domains (urinary incontinence, urinary irritation/obstruction, bowel function, sexual function, hormonal disturbance).

Patient-reported experience measures (PREMs)
Selected questions from the National Cancer Patient Experience to determine patients' views of their experience of care.

Radical treatment
Any treatment aimed at getting rid of the disease completely, for example surgery or external beam radiotherapy for prostate cancer.

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.