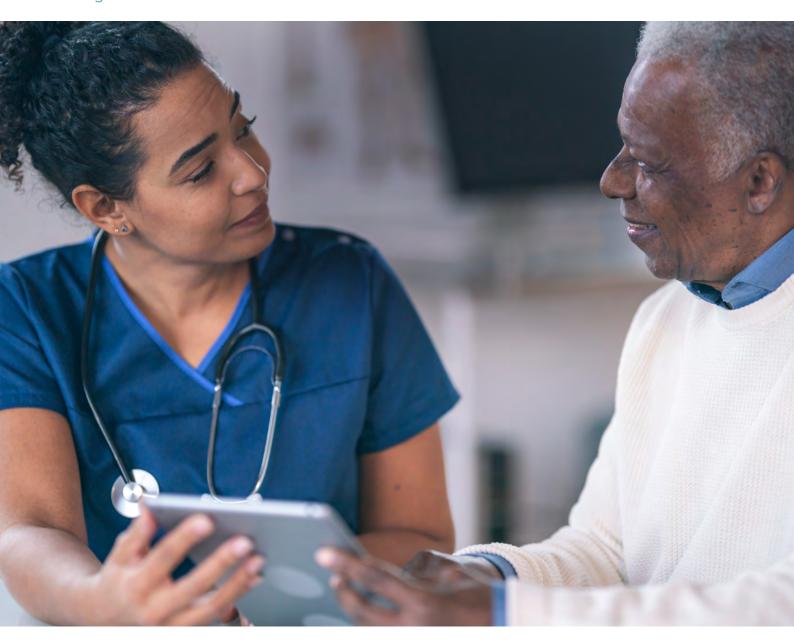


# Patient Summary of Annual Report 2022 (Published June 2023)

Results of the NPCA Prospective Audit in England and Wales for men diagnosed from 1 April 2020 to 31 March 2021 and the impact of COVID-19 in England and Wales during 2020 and 2021



## **National Prostate Cancer Audit**

Patient Summary of Annual Report 2022 (Published June 2023)

London: The Royal College of Surgeons of England, 2023.



Registered Charity No: 212808

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 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, 2022.

## 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), NHS Digital 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 in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering 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 projects, other devolved administrations and crown dependencies www.hqip.org.uk/national-programmes

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## Part 1: Patient Summary: NPCA Annual Report 2022

## Diagnosis & staging

For men diagnosed in England and Wales April 2020 - March 2021:

men were diagnosed with prostate cancer 32,426 in England and Wales between 1st April 2020 and 31st March 2021



decrease compared with 45,885 men in 2019-2020\*

\*this may be explained by the reporting period being pre-COVID-19 in last year's report



of men were 70 years or older



of men presented with metastatic disease

## **Treatment outcomes**

For men undergoing surgery in England and Wales between April 2020 - March 2021:

of men were readmitted within 3 months following surgery



Decreased compared with 13% in 2019-2020

For men undergoing radical treatment between October 2018 and September 2019:



experienced at least one **genitourinary** complication requiring a procedural/surgical intervention within two years after radical prostatectomy



experienced at least one gastrointestinal complication requiring a procedural/surgical intervention within two years after radical radiotherapy

Stable compared with 7% in last year's report

Decrease compared with 11% in last year's report

## Treatment allocation

For men diagnosed in Wales April 2020 - March 2021:

Low-risk, localised disease

High-risk/locally advanced disease

of men had radical treatments and were potentially 'over-treated' -10% in 2019-2020

of men did not have radical treatments and were **potentially** 'under-treated' - 40 % in 2019-2020





## **Foreword**

Thank you for reading the Patient Summary of the 9th Annual Report from the National Prostate Cancer Audit. This 2022 NPCA report has been produced as services have been moving back to 'normality' but still with added pressures and the aftermath of an extremely difficult period. The pandemic has continued to challenge the collection of data for this report. As a result, this year we have continued to use the Rapid Cancer Registration Dataset (RCRD) for England. We have also received the standard (i.e. 'usual') dataset for Wales despite considerable ongoing pressures.

The RCRD for England provided quick access to information which would otherwise have been inaccessible, but because of its rapid acquisition, without having the comprehensive range of data available for previous reports, there was inevitably some missing detail that would usually be included in a 'normal' year. This has meant that, as in last year's report, we were again able to report on four of our usual indicators for both England and Wales and a further two for Wales alone.

This 9th NPCA Annual Report covers the diagnostic period between 1st April 2020 and 31st March 2021 in order to bring clinicians and patients up to date with the prostate cancer landscape as it stood during the pandemic in England and Wales. It also covers the period, for England, up to the end of December 2021 and for Wales, up to the end of March 2021, giving an insight into the effect of the pandemic on prostate cancer diagnosis and treatment. We explore the impact of COVID-19 in the second part of this document.

The NPCA Quality Improvement (QI) Programme will continue to bring together key stakeholders to improve prostate cancer patient care. We recently (Feb 2023) hosted a QI workshop featuring thought-provoking and lively discussions. We have a dedicated QI section on the NPCA website (https://www.npca.org.uk/quality-improvement/) so please look at it if you are interested! The NPCA is also going to have more of a focus on quality improvement and closing the audit cycle as it becomes part of the National Cancer Audit Collaborating Centre (NATCAN) from 1st July 2023. More information about this can be found in The Future of the Audit section below.

Finally, we would like to express our great thanks to the members of the NPCA Patient and Public Involvement (PPI) Forum and patient organisations, including Tackle Prostate Cancer and Prostate Cancer UK, for their support. The PPI Forum continues to be at the forefront of all that we do at the NPCA. Our regular meetings with our PPI members allow us to ensure that the work that we are doing at the audit is relevant and important to the patient population. The members review and advise on the appropriateness of our patient information displayed on our website and the members are co-authors on some of the upcoming publications from the NPCA. We look forward to working together this year to further improve the audit and how it can be accessed by prostate cancer patients.



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Noel Clarke Urological Clinical Lead representing the British Association of Urological Surgeons



Header Payre

Heather Payne Oncological Clinical Lead representing the British Uro-oncology Group

## **Prostate Cancer: Facts & Figures**

Normally, over 52,000 men are diagnosed with prostate cancer each year in the UK and around 475,000 men are living with and beyond prostate cancer. Around 1 in 8 men will be diagnosed with prostate cancer in their lifetime. About 1 in 4 black men will get prostate cancer in their lifetime. Men whose father or brother has had prostate cancer are two and a half times more likely to get it, compared to a man who has no relatives with prostate cancer. Over 12,000 men die as a result of the disease each year and this makes prostate cancer the second most common cause of cancer-related death for men in the UK.

## **What is the National Prostate Cancer Audit?**

The National Prostate Cancer Audit (NPCA) is a Clinical Audit of the quality of services and care provided to men with prostate cancer in England and Wales.

The aim of the NPCA is to assess the process of care and its outcomes in men diagnosed with prostate cancer in England and Wales. The NPCA determines whether men's prostate cancer care is consistent with current recommended practice and promotes consistency in treatments across all treatment centres. It provides information to healthcare providers, commissioners, regulators, patient groups and patients to support the improvement of prostate cancer diagnosis and treatment.

In this report we again make use of the Rapid Cancer Registration Dataset for England that was collated and provided more quickly than usual as well as the standard or 'usual' dataset from Wales (i.e. data from the same source as in previous reports) to describe aspects of the care pathway for men with prostate cancer.

## Data sources used

- National Cancer Registration Dataset (NCRD)
- Rapid Cancer Registration Dataset (RCRD)

## **Advantages of RCRD:**

- 1. It is collated and provided more quickly, which creates opportunity for more frequent reporting.
- 2. When compared, there is good agreement between the RCRD and NCRD data.

## **Disadvantages of RCRD:**

1. The main limitation of the RCRD is that there is a large amount of missing staging (TNM) data and no Gleason score is provided, which makes it difficult to assign prostate cancer risk groups for reporting.

## 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 (RCS), the British Association of Urological Surgeons (BAUS) and the British Uro-oncology Group (BUG).

## What data is reported in the 2022 Annual Report?

The National Prostate Cancer Audit has been reporting annually for nine years, developing and adding relevant measures year-on-year. Although the NPCA still covers the whole patient care pathway from diagnosis through to treatment and treatment-related outcomes, the unprecedented circumstances of the pandemic mean that data capture, collection and collation has been impacted in England. We are fortunate to be able to report as usual for Wales and in addition, we have been able to access a Rapid Cancer Registration Dataset (RCRD) linked to treatment information for England.

- We report on several key indicators relating to diagnosis, staging and treatment during the period of the COVID-19 pandemic.
- We describe the impact of COVID-19 on diagnosis and treatment services during 2021 in England.
- In this year's report we are able to describe the impact of COVID-19 on diagnosis and treatment services up to March 2021 in Wales.
- The Audit works within strict rules covering data protection and confidentiality. The data we collect on individuals is anonymised and individual patients are not identifiable in the information provided to us.

## Which patients are included in the NPCA?

The NPCA was established on the 1st April 2013. All men diagnosed with prostate cancer have been included since 1st April 2014 in England and since 1st April 2015 in Wales. In the current summary report, we present the results for men diagnosed with prostate cancer between 1st April 2020 and 31st March 2021. This includes over 30,000 men diagnosed in England, and over 1,500 men diagnosed in Wales during this time period.

## **Annual Report 2022**

The National Prostate Cancer Audit released the 9th Annual Report in January 2023. This provides an in-depth analysis of the Audit's findings. This report, as well as previous Annual and Patient Reports, can be accessed here.

## **Key Findings in England and Wales**

## **Data quality**

- Data completeness of key information necessary to determine which risk group men are in remains high for Wales (PSA, Gleason score and TNM variables; 83%, 83% and 70%, respectively). We were unable to assign a risk group for patients in England this year as information on Gleason score was unavailable.
- Data completeness of performance status reached 100% in Wales and increased in England compared with the previous report (66% versus 61%).
- Please refer to Table 4 (Patient and diagnostic characteristics for men newly diagnosed with prostate cancer in England and Wales over the period of 1 April 2020 and 31 March 2021) in the Annual report for further information. Annual report accessible at https://www. npca.org.uk/reports/npca-annual-report-2022/

## What are the characteristics of men who were diagnosed with prostate cancer in England and Wales?

- The number of men diagnosed with prostate cancer, in the pandemic period covered by this report (1st April 2020 to 31st March 2021), is 32,426. This is a decrease on the number (45,885) reported in last year's report which covered the period 1st April 2019 to 31st March 2020.
- The proportion of men presenting with metastatic disease at diagnosis in England and Wales is 17%, an increase from 13% in last year's report.
- Over a third of men diagnosed were aged between 70 and 80 (41% for England and 40% for Wales) and another third were aged between 60 and 70.
- Prostate cancer is a disease of the older man as is shown by the significant proportion being diagnosed above 70 years old (59% and 54% in England and Wales, respectively).
   This is consistent with last year's report.
- In England and Wales, most men had no other medical conditions recorded (81% and 82%).

## What treatments are patients receiving in Wales?

(Some indicators could not be presented for England due to data not being available. We expect these data to be available in future reports.)

- 9% of men with low-risk disease had radical treatments and were potentially "over-treated" in Wales. They were classified as "over-treated" as radical treatments aren't generally advised for low-risk prostate cancer patients.
  - o This represents a decrease from 2019-2020 when 10% of men were potentially "over-treated" in Wales.
- 28% of men with high-risk disease did not have radical treatments and were potentially "under-treated" in Wales. They were classified as "under-treated" as radical treatments are generally advised for high-risk prostate cancer patients.
  - This has decreased from 2019-2020 when 40% of men were potentially "under-treated" in Wales.

## What are the rates of the possible complications of radiotherapy or surgery in England and Wales?

- The proportion of men recorded as having an emergency readmission within 90 days of radical prostate cancer surgery is 12%, which is a slight reduction compared to the 13% reported last year.
- Genitourinary complications following radical prostatectomy have remained stable since last year's report. 7% of men experienced at least one genitourinary complication within two years of their prostatectomy.
- Gastrointestinal complications following radical radiotherapy reduced slightly: 10% of men experienced a gastrointestinal complication within two years of their radiotherapy, compared to 11% in the previous year.

## The Future of the Audit

The National Prostate Cancer Audit (NPCA) is going to become part of the National Cancer Audit Collaborating Centre (NATCAN) from 1st July 2023. The NPCA will continue to use existing, routine national data to report key performance indicators for all prostate cancer service providers in England and Wales each year as well as produce patient summaries and peer-reviewed publications. The NPCA will benefit from several NATCAN innovations such as:

- More timely and more frequent reporting on a quarterly basis (using 'rapid cancer registration' data).
- Instead of a detailed annual report, the NPCA will develop a concise 'State of the Nation' report (limited to 10 pages and 5 recommendations).
- Greater focus on quality improvement and closing the audit cycle.
- Closing the audit cycle means measuring to what extent recommendations from NPCA audits are implemented in cancer services and their impact on outcomes.

#### The NPCA will continue to:

- Work with NHS Trusts in England and NHS Health Boards in Wales to improve completeness of all the data it requires.
- Investigate the data gathered in our organisational audit, which gives a current overview of the organisation of prostate cancer services delivered in England and Wales, in particular the provision of support services.
- Strengthen our collaborations with existing partners such as the British Association of Urological Surgeons, the British Uro-oncology Group, and NHS Improvement's Getting it Right First Time programme in England, whilst reaching out to other groups to use the power of the NPCA prostate cancer data resource to monitor and improve the quality of care.

As more data becomes available the Audit will aim to develop new methods to measure additional performance indicators for individuals with prostate cancer. These will include looking at metastatic disease, disease progression, the risks of recurrence and assessing the outcomes from newer treatments. As we start to have increasingly longer follow up of patients this will also include the reporting of mortality rates from prostate cancer.

When full data availability returns, the NPCA audit will
use an updated, widely-accepted risk stratification score
(the Cambridge Prognostic Grouping¹) which will give
more detail about treatment allocation for different risk
groups, in particular whether men with low risk disease
are potentially receiving treatment unnecessarily.

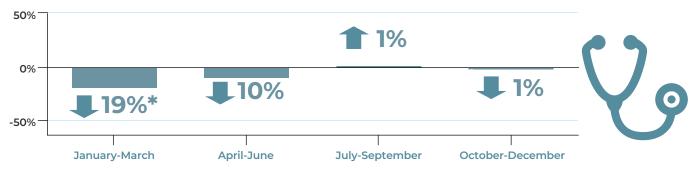
Parry MG, Cowling TE, Sujenthiran A, et al. Risk stratification for prostate cancer management: value of the Cambridge Prognostic Group classification for assessing treatment allocation. BMC Med. 2020;18(1):114.

## **Part 2: Patient Summary**

## Impact of COVID-19 in England in 2021

## Impact on **Diagnosis**

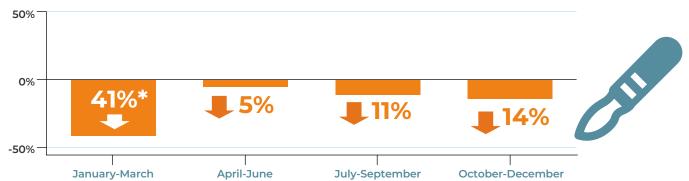
Number of patients newly diagnosed with prostate cancer in 2021 (compared to same period in 2019)



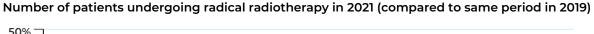
<sup>\*</sup> There was a 19% reduction in the number of men diagnosed between January-March 2021 compared with same period in 2019

## Impact on Radical treatment received

Number of patients undergoing radical prostatectomy in 2021 (compared to same period in 2019)



<sup>\*</sup> There was a 41% reduction in the number of men undergoing prostatectomy between January-March 2021 compared with same period in 2019

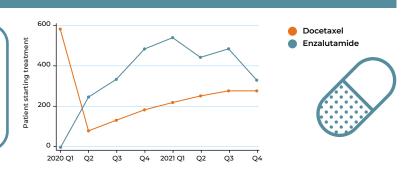




<sup>\*</sup> There was a 31% reduction in the number of men undergoing radiotherapy between January-March 2021 compared with same period in 2019

## Impact on systemic therapy

There has been a dramatic shift in utilisation rates of **Docetaxel** and **Enzalutamide** during 2020 and 2021.



Note: Q1 Jan-Mar, Q2 Apr-Jun, Q3 Jul-Sep, Q4 Oct-Dec

## Impact of COVID-19 in Wales in 2020 and 2021

## Impact on Diagnosis

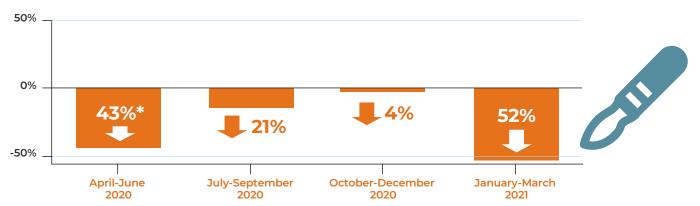
Number of patients newly diagnosed with prostate cancer in 2020 or 2021 (compared to same period in 2019)



<sup>\*</sup> There was a 52% reduction in the number of men diagnosed between April - June 2020 compared with same period in 2019

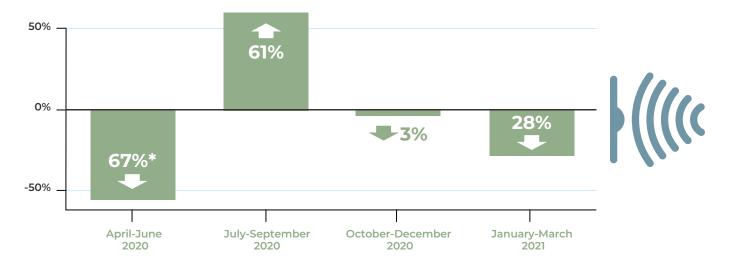
## Impact on Radical treatment received

Number of patients undergoing radical prostatectomy in 2020 or 2021 (compared to same period in 2019)



<sup>\*</sup> There was a 43% reduction in the number of men undergoing prostatectomy between April - June 2020 compared with same period in 2019

## Number of patients undergoing radical radiotherapy in 2020 or 2021 (compared to same period in 2019)



<sup>\*</sup> There was a 67% reduction in the number of men undergoing radiotherapy between April - June 2020 compared with same period in 2019

## Introduction

Welcome to the 'Impact of COVID-19 in England and Wales' patient summary. This special report covers the period, for England, up to the end of December 2021 and for Wales, up to the end of March 2021, giving an insight into the effect of the pandemic on prostate cancer diagnosis and treatment.

The COVID-19 pandemic has had an impact on the care provided to patients with cancer, with delays in diagnosis and treatment due to the steps taken to control spread of the virus, changes to the provision of services due to pressure on hospitals and patients being reluctant to seek care.

This year, for the first time, we report on the impact of COVID-19 in Wales in 2020 and early 2021. We found the patterns of change in diagnoses and treatment rates are similar to those we reported for England last year. For England this year, we report on the impact of COVID-19 throughout 2021 and we can see a recovery in many regions for diagnoses and treatment services during this year.

## Impact of the COVID-19 pandemic in England

In this section we focus on the diagnosis and treatment of patients with prostate cancer during 2021 in England. We describe the activity of prostate cancer services over time (from 1st January 2021 - 31st December 2021) and compare this with the 'usual' activity during 2019, before the COVID-19 pandemic in England. In last year's report, we reported on the impact of the COVID-19 pandemic during 2020 in England. This year, we report on the impact of further waves of the pandemic and the move towards recovery during 2021.

Here we also report regional variation in the patterns of diagnostic and treatment activity (surgery, radiotherapy and chemotherapy) over each quarter of 2021 compared to the same periods in 2019.

As highlighted in the Annual Report 2022, the NPCA used the Rapid Cancer Registration Dataset (RCRD) again, which is collated and provided more quickly than the dataset usually used for the Annual report (National Cancer Registration Dataset), creating an opportunity for more frequent reporting.

## **Key findings**

## **Diagnosis**

- Overall, there was a 19% reduction in the number of men diagnosed in January to March 2021 compared to the same period in 2019 (range across seven NHS regions: 12% to 31% decrease).
- By October to December 2021, the number of men diagnosed had returned to the levels of 2019 (range: 5% increase to 16% decrease).

Please refer to Table 7 (Patient and diagnostic characteristics for men newly diagnosed with prostate cancer in England over the period of 1st January - 31st December in 2019 and 2020 and up to 31st December 2021 in England) in the annual report for further information. Annual report accessible at https://www.npca.org.uk/reports/npca-annual-report-2022

## **Surgery**

- Between January and March 2021 there was a 41% reduction overall in the number of men undergoing radical prostatectomy compared to 2019.
- Surgical activity increased for most regions from Jan-Mar 2021 to Oct-Dec 2021 and in some, rose higher than in the same quartiles of 2019.
- Overall, however, the number of procedures in October to December 2021 was 14% lower than in 2019, varying by

## Radiotherapy

- During January to March 2021 there was a 31% reduction in radiotherapy compared to the same period in 2019.
- Despite some recovery, particularly in certain regions, in October to December 2021 the number of men starting radiotherapy remained lower than the same period in 2019. A reduction in activity was observed in all seven regions by the end of the year.
- The use of a hypofractionated radiotherapy regimen in 2021 was similar to the levels of use seen in 2019 for most regions with standard radiotherapy being used less than in 2019 in all regions during 2021.

## **Systemic treatment**

In 2021, there was evidence of a steadily increasing use of docetaxel, but the level of usage remained relatively low. The utilisation of enzalutamide continued to increase during 2021. Docetaxel is a type of chemotherapy whereas enzalutamide is an anti-androgen treatment.

## Impact of the COVID-19 pandemic in Wales in 2020 and 2021

In this section, we report for the first time on the impact of COVID-19 in Wales in 2020 and early 2021. We describe the activity of prostate cancer services over the period from 1st January 2020 to 31st March 2021 including diagnosis and treatment. We used the standard dataset for Wales (the same dataset the NPCA has used before and throughout the COVID-19 pandemic) and compare this with what can be considered the 'baseline' activity during 2019.

For Wales we also report regional variation in the patterns of diagnostic and treatment activity (surgery and radiotherapy) over each quarter of 2020 and the first quarter of 2021 compared to the same periods in 2019.

## **Key findings**

## **Diagnosis**

- During the first 'lockdown period' April June 2020, there was a 52% reduction overall in the number of patients newly diagnosed with prostate cancer compared to the same period in 2019 (range across the four specialist multidisciplinary teams [SMDTs]: 34% to 75% decrease).
- By October December 2020 there was a 25% reduction overall in the number of patients newly diagnosed with prostate cancer compared to the same time periods in 2019 (range: 47% decrease to 24% increase).

#### **Surgery**

- There was a 43% reduction in the number of men undergoing radical prostatectomy in April to June 2020 compared to 2019 which varied by SMDT (range: 16% to 67% decrease).
- During October to December 2020 there was a 4% reduction in surgical activity compared to 2019 (range: 67% decrease to 50% increase).

## Radiotherapy

- During April to June 2020 there was a 67% reduction in patients received radiotherapy compared to 2019 (range: 50% to 83% decrease). By October to December 2020, there was an overall 3% reduction in the number of men starting radical radiotherapy compared to 2019.
- Increasing use of a hypofractionated regimen was evident across Wales and by July - September of 2020 all radiotherapy was performed using a hypofractionated

## Recommendations for patients and healthcare professionals

## **Recommendations for patients**

- 1. Seek advice from a doctor if any of the following new symptoms are experienced: urinary symptoms, erectile problems, blood in urine or unexplained back pain, as early diagnosis improves outcomes.
- 2. Ensure that a family history of prostate, breast or ovarian cancer is reported to a healthcare provider as it should precipitate a genetic counselling referral.
- 3. If you have low-risk prostate cancer, discuss with your clinical specialist the option of disease monitoring with active surveillance in the first instance.
- 4. Discuss with your clinical specialist the radical treatment options available for men with high-risk/locally advanced

## **Recommendations for healthcare** professionals

- 1. Ensure that men who are offered prostate cancer treatment are made aware of the side effects including: loss of libido, problems getting or keeping erections, loss of ejaculatory function, a worsening of sexual experience, urinary incontinence and/or bowel side effects.
- 2. Empower patients to ask to be referred to specialist support services if they are experiencing physical or psychological side effects during, or following, prostate cancer treatment. These should be offered early and on an ongoing basis, in keeping with national recommendations.
- 3. Make available sources of further information and support for men with prostate cancer 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.

## **Glossary**

## **Anti-androgen Treatment**

This is a type of hormone therapy. Prostate cancer cells are encouraged to divide and grow by testosterone attaching to prostate cancer cell receptors. To stop testosterone from attaching to these receptors, anti-androgen drugs attach themselves to the prostate cancer cell receptors instead. Examples include enzalutamide, bicalutamide, flutamide, apalutamide and cyproterone acetate.

#### **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 with scans and PSA measurements, and they can begin active treatment with surgery or radiotherapy with or without hormone therapy if the cancer starts to grow.

## **Brachytherapy**

A treatment for prostate cancer using either the placement of permanent radioactive seeds into the prostate (termed low dose rate brachytherapy) or the temporary insertion of a source of radiation through needles temporarily placed in the prostate (termed high dose rate brachytherapy). Brachytherapy can deliver a high radiation dose to the prostate gland whilst avoiding radiation to the surrounding healthy tissue. This treatment can be used as the sole treatment but it is used more commonly in combination with conventionally delivered external beam radiotherapy in higher risk disease, known as a "brachytherapy boost".

## **Cambridge Prognostic Group Classification**

The Cambridge Prognostic Group (CPG) classification provides a five-tiered prostate cancer risk classification for non-metastatic prostate cancer. This is in contrast to the traditional three-tiered risk classification. In order to classify a cancer to one of the 5 CPG groups (CPG1 to CPG5), doctors will take into account: Gleason score or Grade Group, prostate specific antigen (PSA) level and tumour stage.

## Chemotherapy

A type of anti-cancer drug treatment, also known as "cytotoxic chemotherapy". These drugs act throughout the body (systemically) to target and kill the cancer cells. The cytotoxic drug used most commonly and effectively in prostate cancer is Docetaxel.

## **Clinical Nurse Specialist (CNS)**

These are experienced senior nurses who have undergone specialist training in urology. They help to administer treatment and 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 Audit**

Clinical audit is a method that healthcare professionals use to look at and improve patient care by comparing how patients are treated and studying the outcomes of care against set accepted standards and guidelines. In a clinical audit, information on the care received by patients is collected and analysed to see if individual clinicians and hospitals are following national clinical standards, such as those published by the National Institute for Health and Care Excellence (NICE). These audits also produce information for hospitals to compare their outcomes with other hospitals. The aim is to allow quality improvement to take place where it will be most helpful and will potentially improve outcomes for patients.

#### **External Beam Radiotherapy (EBRT)**

The use of high energy X-ray beams directed at the prostate to kill cancer cells. It is used to treat localised disease or locally advanced prostate cancer. It may be Hyperfractionated or Hypofractionated Radiotherapy (see below).

## **Fistula**

An abnormal opening between organs or other structures in the body. Fistulas are rare in prostate cancer treatment. If they occur, they are usually in the pelvic area.

#### **Functional Outcomes**

How a patient's sexual function, urinary continence, bowel function and overall well-being is affected by treatment.

#### **Gleason Score**

The grade of the cells in the prostate tissue (how they look under the microscope) and the pattern of the cells. The Gleason score makes up part of the risk profile that helps to inform treatment decisions.

## **Hypofractionated Radiotherapy**

Radiotherapy delivered using a regime of treatment during which a smaller number of high-intensity radiotherapy treatments (fractions) are administered over a shorter period of time. It is used to treat intermediate risk localised prostate

## **Hyperfractionated Radiotherapy**

Radiotherapy with a longer regime of treatment during which radiotherapy treatments (fractions) are administered at a lower dose and on more visits. It is used to treat localised disease or locally advanced prostate cancer, usually in combination with hormone treatment.

#### **Localised Disease**

When cancer is contained within the prostate gland and has not spread to any other parts of the body. Localised prostate cancer is classed into 3 risk groups depending on how likely it is that the cancer will grow quickly or spread. These risk groups depend on the following:

- the tumour distribution in the prostate (T stage)
- the grade of the cells in the prostate tissue (how they look under the microscope) (Gleason Score)
- the Prostate Specific Antigen blood test (PSA) blood test

## **Locally Advanced Disease**

When cancer has spread to areas immediately outside the prostate. This may also be associated with early spread of cancer to surrounding lymph nodes in the pelvic region close to the prostate gland itself.

#### **Metastatic Disease**

When cancer has spread away from the prostate to distant areas of the body, mainly to the bones and lymph nodes outside the pelvic region.

## Multiparametric MRI (mpMRI)

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

#### **Performance status**

A measure of how well a patient is able to perform ordinary tasks and carry out daily activities (e.g. eating, bathing, dressing themselves, cleaning their house).

## **Prostate Specific Antigen blood test (PSA)**

PSA is a protein that is produced by prostatic tissue. The blood test determines the level of PSA in the blood. This indicates if further investigations are needed and makes up part of the risk profile that helps to inform treatment decisions.

## **Radical Prostatectomy**

The surgical removal of all the prostate gland and the associated seminal vesicles. The latter are structures integrally associated with the prostate. Their function is to produce and store fluid which sustains the viability of sperm when it leaves the prostate.

#### **Radical Treatment**

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

## **Radiotherapy**

The use of radiation to destroy cancer cells. There are different ways in which radiotherapy can be delivered, including external beam radiotherapy and brachytherapy.

## **Risk profiles:**

## Low risk prostate cancers

- are unlikely to grow or spread for many years and have all of the following:
  - o a T stage of T1 to T2a
  - a Gleason score no higher than 6
  - a Prostate Specific Antigen blood test (PSA) level less than 10 ng/ml

## Medium (intermediate) risk prostate cancers

- may grow or spread but many do not do so for some years.
   The Gleason score is the most important determinant of this.
  - ° a Gleason score of 7 (Gleason 3+4 is less aggressive than Gleason 4+3)
  - a Prostate Specific Antigen blood test (PSA) level between 10 and 20 ng/ml

## **High-risk prostate cancers**

- might grow or spread within a few years and have one of the following:
  - o a T stage of T2c or above
  - o a Gleason score between 8 and 10
  - a high Prostate Specific Antigen blood test (PSA) level is usually but not always associated with this

## **Specialist Multidisciplinary Team (SMDT)**

A team of specialists who coordinate the specialist treatment of men with prostate cancer. The SMDT enables local cancer units to access specialist prostate cancer services which may not be locally available. Specialist services include prostatectomy and radiotherapy.

## Staging/stage

The anatomical extent of a cancer, in other words, how far it has spread within and around the prostate and in metastatic cases, where the disease is elsewhere in the body.

T1 means the cancer is too small to be seen on a scan, T2 means the cancer is completely inside the prostate gland, T<sub>3</sub> means the cancer has broken through the capsule (covering) of the prostate gland and T4 means the cancer has spread into other body organs nearby, such as the back passage, bladder, or the pelvic wall.

No means that the nearby lymph nodes do not contain cancer cells and N1 means there are cancer cells in lymph nodes near the prostate.

Mo means the cancer has not spread to other parts of the body and M1 means the cancer has spread to other parts of the body outside the pelvis

## **Treatment-related bowel (gastrointestinal)** complications

E.g. diarrhoea, bleeding, infection, ulceration, and rarely, fistula formation or strictures in the bowel.

## **Treatment-related genitourinary** complications

E.g. leaking urine, difficulty urinating, infection, and rarely, narrowing or blockage of the urinary tract.

## **Organisations**

## **British Association of Urological Surgeons** (BAUS)

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

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

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

## **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.

## Healthcare Quality Improvement Partnership (HQIP)

The Healthcare Quality Improvement Partnership (HQIP) aims to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP is led by a group of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices.

## 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 (usually a hospital) that provides acute care services in England. A Trust can include one or more hospitals.

## National Institute for Health and Care Excellence (NICE)

An organisation responsible for providing national guidance on the promotion of good health, and the prevention and treatment of ill health.

## **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. Registered charity no: 212808.

## **Wales Cancer Network**

Wales Cancer Network (WCN) is an organisation that has evolved from the merger of the two Cancer Networks in Wales and the Cancer National Specialist Advisory Group (NSAG) and is designed to collect cancer-specific information in Wales.