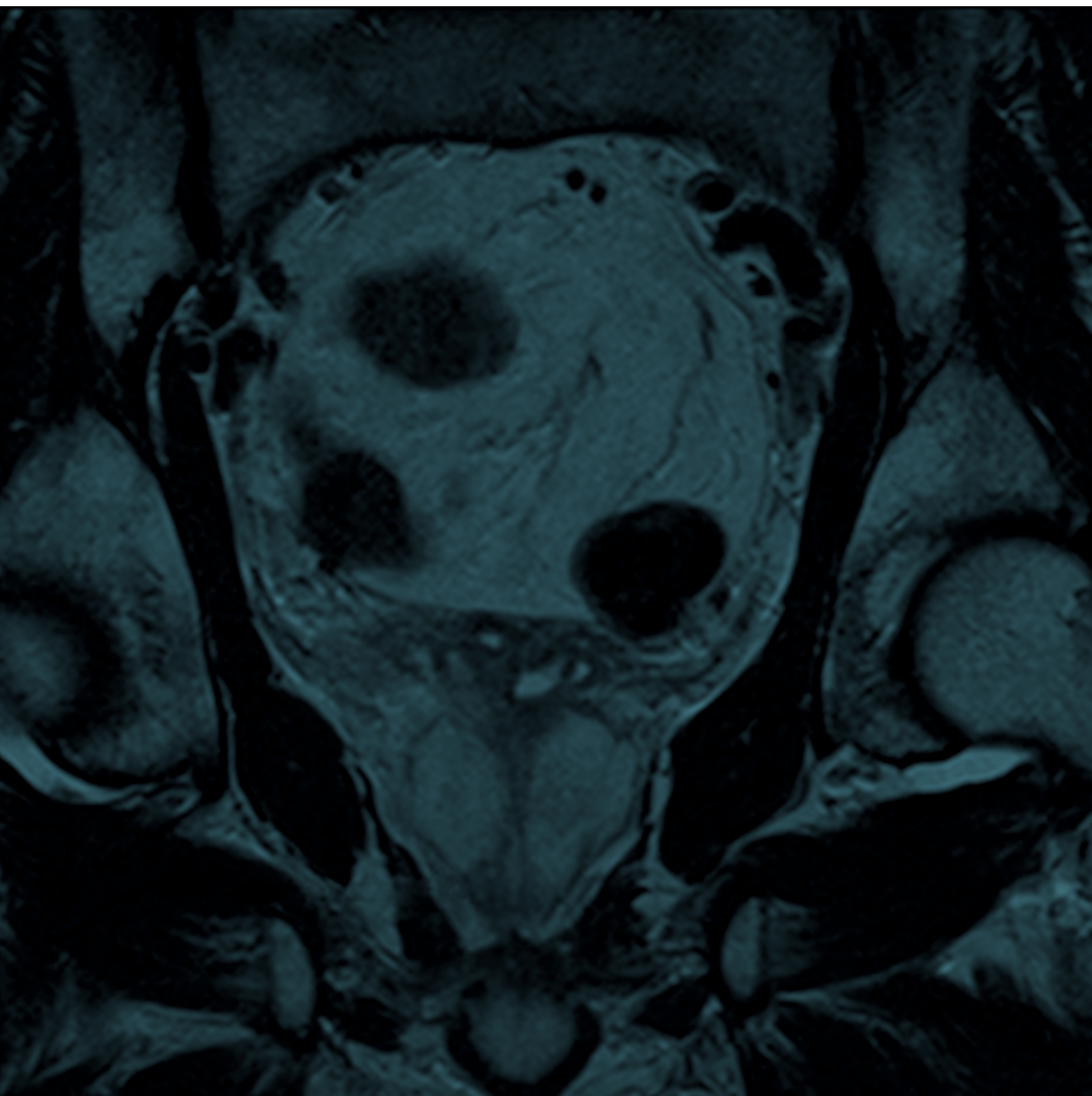


Annual Report 2018

Results of the NPCA Prospective Audit in England and Wales for men diagnosed from 1 April 2016 to 31 March 2017 (published February 2019).



National Prostate Cancer Audit

Fifth Year Annual Report – Results of the NPCA Prospective Audit in England and Wales for men diagnosed 1 April 2016 – March 2017

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



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 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.

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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.

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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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Published February 2019 by the National Prostate Cancer Audit

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Acronym list

British Association of Urological Surgeons (BAUS)	National Cancer Registration and Analysis Service (NCRAS)
British Uro-Oncology Group (BUG)	National Clinical Audit and Patient Outcomes Programme (NCAPOP)
Cancer Network Information System Cymru (CaNISC)	National Clinical Audit Benchmarking (NCAB)
Cancer Outcomes and Services Dataset (COSD)	National Health Service (NHS)
Clinical Effectiveness Unit (CEU)	National Institute for Care Excellence (NICE)
Clinical Nurse Specialist (CNS)	National Prostate Cancer Audit (NPCA)
Clinical Outcomes Programme (COP)	National Radiotherapy Data Set (RTDS)
Clinical Reference Group (CRG)	Office for National Statistics (ONS)
Expanded Prostate Cancer Index Composite 26-item (EPIC-26)	Office of Population Censuses and Surveys (OPCS)
External Beam Radiation Therapy (EBRT)	Patient Episode Database for Wales (PEDW)
Gastrointestinal (GI)	Patient-Reported Experience Measure (PREM)
General Practitioner (GP)	Patient-Reported Outcome Measure (PROM)
Genitourinary (GU)	Prostate Specific Antigen (PSA)
Healthcare Quality Improvement Partnership (HQIP)	Public Health England (PHE)
Hospital Episode Statistics (HES)	Radical Prostatectomy (RP)
Intensity Modulated Radiation Therapy (IMRT)	Royal College of Surgeons (RCS)
International Classification of Disease (ICD)	The Index of Multiple Deprivation (IMD)
Magnetic Resonance Imaging (MRI)	Tumour, Nodes, Metastases (TNM)
Minimum Data Set (MDS)	Wales Cancer Network (WCN)
Multi-Disciplinary Team (MDT)	Welsh Cancer Intelligence and Surveillance Unit (WCISU)
National Cancer Patient Experience Survey (NCPES)	

Acknowledgements

The National Prostate Cancer Audit (NPCA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP)¹ and funded by NHS England and the Welsh Government as part of the National Clinical Audit and Patient Outcomes Programme. The audit is a collaboration between the Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England (RCS), the British Association of Urological Surgeons (BAUS) and the British Uro-oncology Group (BUG).

The NPCA Project Team would like to thank all men in England and Wales who have completed the NPCA Patient Survey and for sharing their views on the quality of care and the impact of radical treatment on their daily lives.

The Project Team would like to thank all urological and uro-oncological colleagues, and their clinical and non-clinical teams at NHS Trusts in England and Health Boards in Wales who collected and submitted data for the audit. Your support is key to enabling the NPCA to evaluate the care that men receive following a diagnosis of prostate cancer in England and Wales and whether this care reflects recommended guidelines and quality standards. For the first time, the NPCA compares NHS Providers in England identifying any potential outlying performance related to both short-term and medium-term treatment outcomes following radical treatment.

A report summarising the key results in a patient friendly format will be published in Spring 2019.

We are grateful to the NPCA data collection partners including the National Cancer Registration and Analysis Service (NCRAS), Public Health England (PHE)² and the Wales Cancer Network, Public Health Wales for supporting NPCA data submissions from Trusts and Health Boards and for supplying data for this report.

We would like to thank BAUS and BUG for their continued professional guidance and for raising awareness amongst urological and uro-oncological colleagues.

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¹The NPCA is commissioned by the ©2018 Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). 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 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

²Data for the NPCA in England is based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data is collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England.

Foreword

This is the fifth Annual Report from the National Prostate Cancer Audit (NPCA) and presents current data regarding prostate cancer care in England and Wales for men diagnosed between 1st April 2016 and 31st March 2017. This is the first national audit which is able to report on process and outcome measures from all aspects of the care pathway for men with prostate cancer. This has not been achieved anywhere else in the world and the NPCA is very proud of the progress that has been made in its first five years. This provides us with a platform to robustly compare NHS cancer providers across England and Wales and lead to substantial improvement in the delivery of care.

The NPCA uses solely routine data sources and patient-reported measures to compare providers and we now report on 14 performance indicators. This not only takes account of patient voices but ensures that clinician reported outcomes are not used. This is only possible due to the collaborative process of the NPCA with our data collection partners, all Trusts and Health Boards in England and Wales and the goodwill of thousands of patients filling out questionnaires. This process has also allowed us to combine English and Welsh data and allow for a comparison across both countries.

Encouragingly we are seeing continuing trends in terms of the use of multiparametric MRIs pre-biopsy but the use of trans-perineal biopsies has appeared to plateau. Specialist MDTs should aim to ensure that multiparametric MRI and transperineal biopsies are continuing to be utilised in the diagnostic pathway. Differing results have also been observed in terms of under- and over-treatment where a trend towards active surveillance for low-risk men is continuing, however the proportion of men with high-risk and locally advanced disease has reduced. It must be stressed that the importance of appropriate treatment allocation, especially with an aging population, is paramount for regional prostate cancer teams.

The NPCA are now able to report on treatment-specific complications in two distinct ways using both hospital routine data and patient-reported outcome measures (PROMs). Urinary continence following radical prostatectomy is generally consistent, as is bowel function following radical radiotherapy. We show that one in ten men experience at least one severe genitourinary or bowel-related complication within two years. The identification of treatment-specific issues need to be flagged as early as possible so that the morbidity of treatment can be minimised.

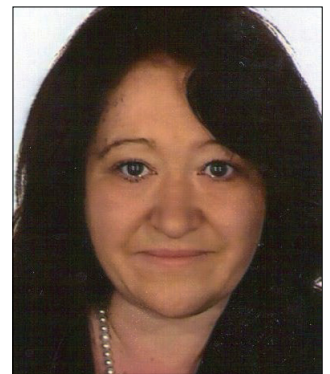
A novel finding with this year's Annual Report is the ability to report on sexual function from the PROMs survey. On average sexual function scores following both radical radiotherapy and prostatectomy were generally poor with men reporting scores of lower than 25 out of 100, at least 18 months after diagnosis. It is imperative that patients are appropriately counselled as to the likelihood of having a deterioration in their function, and for clinicians to enquire about post-treatment sexual function.

Lastly, the success of the Audit is reliant on the data quality and the involvement of both patients and clinicians alike. As we enter the second Audit term we hope that all colleagues can continue to improve their data completeness so that the NPCA can continue to be an impressive and incredibly useful national source of prostate cancer information.



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Executive Summary

The National Prostate Cancer Audit (NPCA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England and the Welsh Government to support improvement in the quality and outcomes of care for men with prostate cancer in England and Wales.

The NPCA is a collaboration between the Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England, the British Association of Urological Surgeons (BAUS) and the British Uro-Oncology Group (BUG). The National Cancer Registration and Analysis Service (NCRAS), Public Health England, and the Wales Cancer Network (WCN), Public Health Wales, act as the Audit's data collection partners.

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 the care received by men diagnosed with prostate cancer in England and Wales is consistent with current recommended practice, such as those outlined in the National Institute for Care Excellence (NICE) Guidelines and Quality Standards^{3,4} and provides information to support healthcare providers, commissioners and regulators in helping improve care for patients (see box). This is the first national audit which is able to report on process and outcome measures from all aspects of the care pathway for men with prostate cancer.

Data collection and analysis

This report presents results from the prospective audit for men diagnosed with prostate cancer between 1st April 2016 and 31st March 2017 in England and Wales. The basis of the audit is the bespoke NPCA dataset which is combined with other data sources. In England these are Cancer Registry data, which also includes the Cancer Outcomes and Services Dataset (COSD), Hospital Episode Statistics (HES), the Office for National Statistics (ONS) death data and the National Radiotherapy Data Set (RTDS). In Wales these are Cancer Network Information System Cymru (CaNISC) data, the Patient Episode Database for Wales (PEDW) and ONS death data.

We report on specific diagnostic, staging and treatment information as well as core performance indicators in order to compare diagnostic specialist MDTs or treatment centres. This is the first report which combines English and Welsh data as well as using patient-reported experience (PREMs) and outcome measures (PROMs) as performance indicators. The survey for the PROMs/PREMs used the National Cancer Patient Experience Survey (NCPES), the Expanded Prostate Cancer Index Composite 26-item version (EPIC-26) and the EuroQol. We used surveys collected at least 18 months after diagnosis for men diagnosed between 1st April 2015 and 30th September 2016.

In total we report on 14 performance indicators:

1. Proportion of men presenting with metastatic disease at diagnosis.
2. Proportion of men with low-risk localised prostate cancer undergoing radical prostate cancer therapy.
3. Proportion of men with locally advanced disease receiving radical prostate cancer therapy.
4. Proportion of patients who had an emergency readmission within 90 days of radical prostatectomy.
5. Proportion of patients experiencing at least one severe genitourinary (GU) complication within 2 years of radical prostatectomy.
6. Proportion of patients experiencing at least one severe gastrointestinal (GI) complication within 2 years of radical external beam radiotherapy.
7. Proportion of patients who were given the 'right amount' of information about their condition and treatment.
8. Proportion of patients who were involved as much as they wanted to be in decisions about their treatment and care.
9. Proportion of patients who were given the name of a clinical nurse specialist.
10. Proportion of patients rating their overall care as at least 8 out of 10.
11. Mean urinary incontinence score after radical prostatectomy.
12. Mean sexual function score after radical prostatectomy.
13. Mean bowel function score after radical external beam radiotherapy.
14. Mean sexual function score after radical external beam radiotherapy.

³ NICE, 2014: <https://www.nice.org.uk/guidance/cg175>

⁴ NICE, 2015: <https://www.nice.org.uk/guidance/qs91>

NICE Quality Standards, 2015

1. QS 1: men with prostate cancer have a discussion about treatment options and adverse effect with a named nurse specialist.
2. QS2: men with low-risk prostate cancer for whom radical treatment is suitable are also offered the option of active surveillance.
3. QS3: men with intermediate- or high-risk localised prostate cancer who are offered non-surgical radical treatment are offered radical radiotherapy and androgen deprivation therapy in combination.
4. QS4: men with adverse effects of prostate cancer treatment are referred to specialist services.
5. QS5: men with hormone-relapsed metastatic prostate cancer have their treatment options discussed by the urological cancer MDT.

Although the NPCA started prior to the publication of the NICE Quality Standards, the Audit provides results that can be used to evaluate to what extent prostate cancer care providers meet most of these standards.

The NPCA patient survey asks about how men were informed about their treatment options, how treatment decisions were made and to what extent they had access to a named clinical nurse specialist (CNS) (QS1).

We also present results for indicators of possible over-treatment in men with low-risk disease and under-treatment in men with locally advanced disease (QS2 and QS3).

In our organisational survey, originally performed in 2014 and updated each year (see NPCA website), we describe whether providers of cancer services have specialist services on-site (QS4).

Prostate cancer has a protracted natural course and with further follow-up of patients in later years, the NPCA will assess to what extent the treatment options of men with hormone-relapsed metastatic cancer have been discussed at an MDT (QS5). This will be included in the update of the organisational survey (first quarter of 2019) and reported in next year's Annual Report.

In addition to the results directly linked to the NICE Quality Standards, the NPCA reports on aspects of care that capture ongoing developments in the way men with prostate cancer are being assessed and treated. The Audit also provides evidence on the adoption of newer technologies (use of multiparametric MRI scanning before the prostate biopsy and the type of biopsy used) and treatments (robotic-assisted prostatectomy and intensity-modulated radiotherapy) as well as the impact on patient outcomes.

Key Messages

1. Data completeness in England is still not comparable with that of Wales but it is possible to stage a high proportion of men in both countries (94% and 98%, respectively).
2. The proportion of men presenting with metastatic disease at diagnosis is stable.
3. The use of multiparametric MRI is increasing (58% in England; 59% in Wales), with also an increase in its use prior to biopsy, which is preferable, but the majority of MRI scans are still being performed after initial biopsy in Wales.
4. The use of transperineal biopsies has remained static with last year, despite its more precise diagnosis, but its use in England is higher than that of Wales.
5. Slightly more men are being diagnosed with locally advanced disease in England compared to last year, with a reduction in the proportion of men with both low- and intermediate-risk disease. Further analysis will explore reasons for this finding.
6. Performance indicators now apply to all Trusts in England and all Health Boards in Wales as, given the NPCA started a year later in Wales, we now have appropriately mature data.
7. The potential “over-treatment” of men with low-risk disease is continuing to decline.
8. The potential “under-treatment” of men with locally advanced disease has increased slightly despite an increase in the proportion of men diagnosed with locally advanced disease.
9. The majority of patients are given the amount of information that they feel is appropriate. They also feel they are involved with their care, are given the name of a CNS and are happy with their overall care.
10. Genitourinary complications following radical prostatectomy are generally stable and consistent with last year. One in ten men experience at least one severe genitourinary complication within two years of their prostatectomy.
11. The rate of bowel dysfunction following radical radiotherapy is stable and consistent with that reported last year. One in ten men experience a severe gastrointestinal complication within two years of their radiotherapy.
12. Sexual function scores following radical radiotherapy were generally poor at 17 on a scale of 0-100.
13. Sexual function scores following radical prostatectomy were generally poor at 23 on a scale of 0-100.
14. For all but one of the performance indicators there was significant variation between specialist MDTs or treatment centres with potential outlying performance. The specific measures reporting outcomes for the surgical and radiotherapy centres are involved in the full outlier process.

Recommendations

For prostate cancer teams (local and specialist MDTs) within NHS Trusts/Health Boards

1. Increase the use of pre-biopsy multiparametric MRI and avoid its use post biopsy.
2. Increase the use of transperineal prostate biopsy where necessary to reduce the risk of post-biopsy sepsis and to maximise diagnostic accuracy and risk stratification.
3. Advocate active surveillance in the first instance for men with low risk prostate cancer.
4. Investigate why men with locally advanced disease are not considered for radical local treatment.
5. Use data on side effect prevalence from this report to ensure appropriate counselling and management for all patients.
6. When outlying performance is confirmed, engage with partners, including the NPCA, to review practice urgently and instigate quality improvement measures.
7. Engage with the NPCA Quality Improvement initiatives planned for 2019 (see Future Plans).
8. Review and improve data completeness focussing particularly on performance status, use of multiparametric MRI and biopsy route.

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. Patients having treatment for prostate cancer should be aware of the significant side effects that they may experience. These include problems getting or keeping erections, loss of ejaculatory function, urinary incontinence and/or bowel side effects.
3. It is important that patients are appropriately counselled prior to treatment regarding the likelihood of a deterioration in their sexual function.
4. Patients should be aware of all the support services that are 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 CNS, in keeping with national recommendations.⁵
5. Patients and carers should be aware of the 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.

For commissioners and health care regulators

1. Review the performance indicators for your region to identify shortfalls in resources, service provision and to identify areas where improvements can be made.
2. Work with local NHS providers to develop strategies to reduce variation in the care provided.
3. Enact plans and make resources available for the development and implementation of standardised diagnostic pathways. These should aim to shorten diagnostic timings and improve the diagnostic accuracy and disease risk stratification of prostate cancer with use of pre-biopsy multiparametric MRI and transperineal biopsies.

Future Plans for the NPCA

The contract period for the NPCA has been renewed by HQIP for work to continue at the Royal College of Surgeons of England for a further three years. Our plans are to continue to report on all of our performance indicators, which will hopefully include PROMs and PREMs from further patient surveys in 2020. The NPCA will continue to develop new and important performance indicators. We will also initiate a programme to develop methods to measure disease progression, recurrence and its treatment. Also, as the data matures we will be able to report on mortality which will require at least 5 years of follow-up.

We shall continue to publish data as part of the Clinical Outcomes Programme (COP) and the National Clinical Audit Benchmarking (NCAB) to enable dissemination of our findings to clinicians, stakeholders, patients and the wider public. We will also update and improve our NPCA cross-sectional data on provision of services by conducting annual organisational surveys. This will enable accurate reporting of the current structure and services of providers of prostate cancer care in England and Wales and compare this with our previous data of service provision.

The success of the NPCA relies solely on the quality of the data received from Trusts and Health Boards across England and Wales. Our data collection partners (NCRAS and WCN) will continue to work directly with individual care providers to help improve data quality. This will ensure the reliability of all the results we present and the reporting of outliers.

The NPCA will continue to use our outlier policy to notify outlying providers and specialist MDTs for each performance indicator. This will enable the data to be checked and changes implemented to improve patient outcomes.

⁵ NICE, 2015. Prostate Cancer. NICE Quality Standard 91. Quality statement 4: "Men with adverse effects of prostate cancer treatment are referred to specialist services"

DIAGNOSIS AND STAGING

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

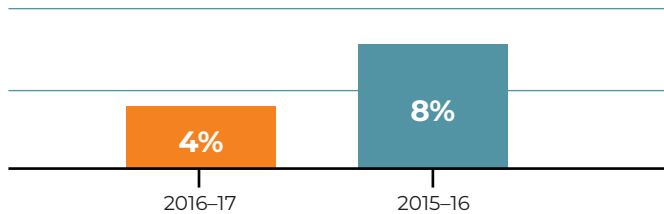
55%

of men were 70 years or older

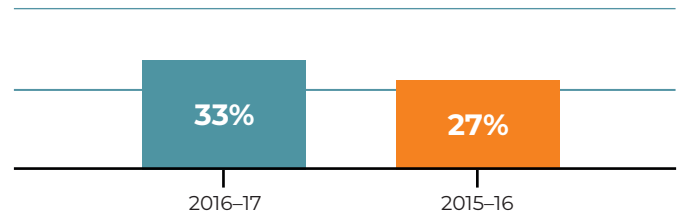
16%

of men presented with metastatic disease – no change from 15/16

TREATMENT ALLOCATION



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

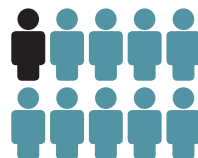


Slightly more men with locally-advanced disease did not have radical treatments and were potentially 'under-treated'

TREATMENT OUTCOMES

13%

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



Within **2 years of treatment** 1 in 10 men experienced a **severe genitourinary complication after surgery** or a **severe gastrointestinal 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

PATIENT 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**

1. The National Prostate Cancer Audit (NPCA): Introduction

1.1 Background

There are over 40,000 new diagnoses of prostate cancer every 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. The Government has therefore promised more funding for prostate cancer with an investment of £75 million pounds aimed at developing innovative new diagnostic and treatment approaches with a view to improving survival.

Prostate cancer is highly heterogenous with disease ranging from indolent, low-risk tumours to very aggressive tumours with a high risk of progressing. The dilemma is effectively diagnosing these high-risk patients so that treatments can be started early whilst at the same time, preventing men with low-risk disease from undergoing unnecessary treatment. A key objective of the National Prostate Cancer Audit (NPCA) is to report on the potential 'under-treatment' of men with high-risk disease and the potential 'over-treatment' of men with low-risk disease. Encouragingly, since the start of data collection for the NPCA in 2014 these respective numbers have shown improvements year on year.

Although treatment is often a necessity for prostate cancer this can lead to important side effects which can have a significant impact on the quality of life that men experience. These side effects include erectile dysfunction, urinary incontinence, urethral strictures and gastrointestinal side effects (for example pain, bloating, urgency, diarrhoea and rectal bleeding). Limiting the impact of these radical treatments is therefore another priority area for the audit. We have developed validated performance indicators which can identify men experiencing severe genitourinary (GU) complications following surgery (radical prostatectomy) and external beam radiation therapy (EBRT), and severe GI toxicity following EBRT.^{6,7} These indicators are used by the NPCA to compare surgical and radiotherapy providers. We hope that this process can drive quality improvement as sites across the country aim to reach the highest standards possible.

The National Prostate Cancer Audit (NPCA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England and the Welsh Government to support improvement in the quality and outcomes of care for men with prostate cancer in England and Wales. The NPCA is a collaboration between the Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England, the British Association of Urological Surgeons (BAUS) and the British Uro-Oncology Group (BUG). The National Cancer Registration and Analysis Service (NCRAS), Public Health England, and the Wales Cancer Network, Public Health Wales, act as the Audit's data collection partners.

1.2 Aim and objectives

The aim of the NPCA is to assess the process of care and treatment outcomes in men diagnosed with prostate cancer in England and Wales.

The key objectives of the Audit are to investigate:

- Service delivery and organisation of care in England and Wales.
- The characteristics of men newly diagnosed with prostate cancer.
- The diagnostic and staging process and planning of initial treatment.
- The initial treatments that men received.
- The experiences of men receiving care and their health outcomes 18 months after diagnosis
- Overall and disease-free survival

The NPCA determines whether the care received by men diagnosed with prostate cancer in England and Wales is consistent with current recommended practice and provides information to support healthcare providers, commissioners and regulators in helping improve care for patients. With the introduction of new performance indicators in this year's Annual Report, the NPCA is now the first national audit which is able to report on process and outcome measures from all aspects of the care pathway for men with prostate cancer.

⁶ Sujenthiran A, Charman S et al. Quantifying severe urinary complications after radical prostatectomy: the development and validation of a surgical performance indicator using hospital administrative data. *BJU int* (2017); 120:219-225

⁷ Sujenthiran A, Nossiter J et al. National population-based study comparing treatment-related toxicity in men who received Intensity-modulated versus 3D-Conformal Radical Radiotherapy for prostate cancer. *Int J Radiat Oncol Biol Phys*. (2017); 99: 1253-1260

1.3 Previous Annual Reports

Previous NPCA Annual Reports

The 2016 Annual Report⁸ reported on prostate cancer services provided by individual NHS providers to men diagnosed between 1st April 2014 to 31st March 2015 in England and 1st April to 30th September in Wales. Key findings include:

- Increases in the use of multiparametric MR imaging and new biopsy methods.
- Considerable variation among NHS providers in the level of potential over-treatment of patients with low-risk disease and under-treatment of those with high-risk / locally advanced disease.
- Variation among providers in short-term outcomes after radical prostatectomy in terms of length of stay and emergency readmission within 90 days.
- Variation among providers in occurrence of a urinary complications one year after radical prostatectomy.

In addition, this report presented patient-reported outcome measures (PROMs) and experiences measures (PREMs) reported by men diagnosed in the English NHS between April and October 2014 who had radical treatment.

- A high response rate was achieved indicating successful engagement of patients with the patient survey (77%).
- Most men reported a very positive experience of care after radical prostate cancer treatment in England with 90% rating their care as 8 or above on a scale ranging from 0 ('very poor') to 10 ('very good'), with limited variation among providers.
- 85% of patients were given the name of a clinical nurse specialist.

The 2017 Annual Report⁹ reported on prostate cancer services provided by individual NHS providers to men diagnosed between 1 April 2015 to 31 March 2016 in England and Wales. Key findings include:

- The proportion of men presenting with metastatic disease at diagnosis remains stable.
- Changes in diagnostic and staging practice over time are apparent with increasing use of multiparametric MRI prior to biopsy and transperineal biopsies.
- The potential 'over-treatment' of men with low-risk disease is reducing.
- The potential 'under-treatment' of men with locally advanced disease is reducing.
- The emergency 90-day readmission rate following radical prostatectomy is stably low.
- 1 in 10 men experience at least one severe genitourinary complication, after a radical prostatectomy, or severe gastrointestinal complication, after radical radiotherapy.
- Risk-adjustment was used for the first time to compare providers with regard to treatment outcomes.

⁸ NPCA Annual Report 2016. Download from: <http://www.npca.org.uk/reports/>

⁹ NPCA Annual Report 2017. Download from: <http://www.npca.org.uk/reports/>

2. Methods

2.1 Inclusion criteria & prospective audit period

Patients are eligible for inclusion in the prospective audit if they are newly diagnosed with prostate cancer using the ICD-10 diagnostic code of “C61” (malignant neoplasm of the prostate). Men with a diagnosis of bladder cancer “C67” were excluded. The data collection period reported here includes men diagnosed between 1st April 2016 and the 31st March 2017 in England and Wales, which allows an assessment of all short-term indicators.

Medium-term indicators require longer follow-up (up to two years post-treatment) so the cohort reported for these indicators are patients diagnosed between 1st January and 31st December 2015.

PROMs and PREMs indicators also require longer follow-up with surveys being completed at least 18 months after diagnosis. In this report we present PREMs for all men who underwent or were candidates for radical treatment, and PROMs for all men who underwent either a radical prostatectomy, or radical radiotherapy. The cohort reported for these indicators are patients diagnosed between 1st April 2015 to 30th September 2016.

2.2 Routine data collection

In England the NPCA works with the National Cancer Registration and Analysis Service (NCRAS), Public Health England, as a data collection partner. NCRAS collects patient-level data from all NHS acute providers using a range of national data-feeds. This includes the Cancer Outcomes and Services Dataset (COSD), which specifies the data items that need to be submitted. Data is submitted to the National Cancer Data Repository (NCDR) on a monthly basis via MDT electronic data collection systems. Clinical sign-off of data submitted to NCRAS is not mandated in England.

The NPCA's data collection partner in Wales is the Wales Cancer Network (WCN), Public Health Wales. The NPCA dataset (section 2.3) is captured through a national system, Cancer Information System for Wales (CaNISC), after identification by hospital cancer services and uploaded via electronic MDT data collection systems. Prior to submission of NPCA data to the WCN each patient record is validated, frequently by an MDT coordinator, and signed off by a designated clinician. Patient records are signed off when all key data items have been completed.

2.3 NPCA dataset

The audit collects data on the diagnosis, management and treatment of every patient newly diagnosed with prostate cancer and discussed at an MDT meeting in England and Wales. In addition to the routine datasets described above, the NPCA collects a specific dataset which comprises three broad categories:

1. NPCA Minimum data set 1 (MDS-1): The first category of data items are collected for **all men newly diagnosed with prostate cancer** during the initial phase of management.
2. NPCA Minimum data set 2 (MDS-2): The second category of data items are collected for all patients who have **undergone radical prostatectomy**.
3. NPCA Minimum data set 3 (MDS-3): The third category of data items are collected for **all men for whom external beam radiation therapy or brachytherapy is planned, with or without hormone deprivation therapy**.

A summary of the NPCA dataset collected for patients diagnosed between 1st April 2016 and 31st March 2017 can be found on the website.¹⁰ These data are linked to other national datasets to provide extra information. In England these supplementary datasets are Cancer Registry data, Hospital Episode Statistics (HES) data, the Office for National Statistics (ONS) dataset and the National Radiotherapy Dataset (RTDS).

In Wales, NPCA data are linked to additional data items from the Patient Episode Database for Wales (PEDW), ONS and CaNISC. The NPCA dataset is captured through CaNISC, which also provides information regarding radiotherapy intent, site and dosing. The radiotherapy centres are currently implementing the collection of the RTDS, which will be available to the NPCA in the near future.

¹⁰ <http://www.npca.org.uk/prospective-audit-tools/>

2.4 Patient-reported outcome and experience measures (PROMs/PREMs)

The NPCA Patient Survey was designed by the NPCA Project Team following review of current literature/guidelines and in consultation with clinical and patient representatives in the Audit's Clinical Reference Group. The questionnaire includes PROMs and PREMs including:

- Selected questions from the National Cancer Patient Experience Survey (NCPES) – a national survey commissioned by NHS England to determine patients' views of their experience of care.
- The Expanded Prostate Cancer Index Composite 26-item version (EPIC-26) – a validated instrument to measure prostate cancer related quality of life in five domains (urinary incontinence, urinary irritation/obstruction, bowel function, sexual function, hormonal disturbance).

The mechanism for data collection has been described previously.^{11,12} In summary, further to identification of the patient cohort by the NPCA team, the NPCA data collection partners in England (NCRAS, PHE) and Wales (WCN, PHW) securely transferred the relevant identifiable patient data (name, address, date of birth, NHS number and NPCA identifier) to Quality Health, the NPCA's survey provider. Before sending out the surveys, Quality Health used NHS Digital's list-cleaning service to remove men who had raised a type-II objection, to determine a current address and whether a patient had died. Questionnaires were mailed to the homes of all identified men ≥ 18 months after diagnosis. Two reminders were sent to non-responders with the final reminder ≤ 8 weeks after the first mail out.

De-identified survey response data was securely transferred to the NPCA team for linkage to de-identified patient-level clinical data and analyses.

2.5 Level of reporting

It is recommended that the care of patients eligible for radical prostate cancer treatments should be coordinated by specialist MDTs.¹³ These hubs are made up of one or more specialist cancer centres coordinating services for referring local Trust MDTs.

Results are presented at the level of the specialist MDT except for treatment specific outcomes which are reported at the level of the surgical or radiotherapy centre. The arrangement of NHS Providers, both local and specialist MDTs, and the range of services they provide for the staging and management of prostate cancer was determined by the NPCA Organisational Audit.¹⁴ This survey will be updated each year.

2.6 Patient inclusion and data quality

A patient is included in the prospective audit in England if they have a record of newly diagnosed prostate cancer in the English Cancer Registry. The proportion of new diagnoses captured in the Cancer Registry is close to 100% and we therefore do not report case ascertainment with regard to the NPCA dataset.

A patient is included in the prospective audit in Wales if a completed NPCA record was submitted and the Wales Cancer Network (WCN) can assign that record to a diagnosing Health Board. The total expected number of cases was determined from the number of men newly diagnosed with prostate cancer in the Welsh Cancer Intelligence and Surveillance Unit (WCISU) in 2015. WCISU were not able to provide exact numbers for the time frame of NPCA data collection and so figures from 2015 were used as the closest approximation. As only data for men with an NPCA record is available for analysis, case ascertainment for the Health Boards in Wales is presented and defined as the proportion of the expected number of newly diagnosed men present in the WCISU dataset for whom an NPCA record was submitted which contained at least one NPCA tumour staging data item.

The completeness of five key data items (prostate specific antigen (PSA), Gleason score, TNM, performance status and multiparametric MRI performed) in England and Wales provided a marker of data quality.

2.7 Definition of disease status and risk stratification

In England, men were assigned to a disease status category according to their TNM stage, Gleason score and PSA using a previously developed algorithm.¹⁵ TNM and Gleason score are received from the Cancer Registry. PSA is collected from the COSD dataset as it is not routinely collected within the Cancer Registry.

In Wales, cancer stage was defined using "T category (pre-treatment)", "N category (pre-treatment)" and "M category (pre-treatment)". Where pre-treatment information was missing for T or N, the corresponding pathological staging items were used if available. All men were assigned to a disease status category in the same way as the English men. All data items were collected as part of the NPCA dataset in Wales.

¹¹ NPCA Annual Report 2016. Download from: <https://www.npca.org.uk/reports/npca-annual-report-2016/>

¹² Nossiter J, Sujenthiran A et al. Robot-assisted radical prostatectomy vs laparoscopic and open retropubic radical prostatectomy: functional outcomes 18 months after diagnosis from a national cohort study in England. *Br J Cancer* (2018); 118: 489–494

¹³ NICE 2002. Improving outcomes in urological cancer.

¹⁴ Aggarwal A, Nossiter J et al. Organisation of Prostate Cancer Services in the English National Health Service. *Clin Oncol (R Coll Radiol)* 2016;28:482–9

¹⁵ NPCA Annual Report 2016. Download from: <https://www.npca.org.uk/reports/npca-annual-report-2016/>

2.8 Definition of radical prostate cancer treatment

A patient was considered to have undergone radical prostate cancer therapy if he was identified as having undergone a radical prostatectomy, or received radical external beam radiotherapy or brachytherapy within 12 months of their diagnosis date.

HES and PEDW records, for England and Wales respectively, were used to identify patients who had undergone a radical prostatectomy using the OPCS-4 procedure code “M61”. For England the RTDS data-item “treatment modality” was used to identify men who received external beam radiotherapy and/or brachytherapy. Men receiving radiotherapy for metastases or radiotherapy with palliative intent were excluded. For Wales, CaNISC was used in a similar way to the RTDS to identify men receiving curative radiotherapy and to exclude those receiving palliative radiotherapy. HES and PEDW records were also used to identify brachytherapy patients using OPCS-4 procedure codes (“M706” + “X653” + “Y363 / M706 + “X653/ M712” + “X653”).

2.9 NPCA performance indicators

2.9.1 Definition

The NPCA initially reported on six performance indicators. These performance indicators have now been supplemented with PROMs and PREMs. The NPCA determines whether the care received by men diagnosed with prostate cancer in England and Wales is consistent with current recommendations and practice, such as those outlined in the NICE Quality Standards,¹⁶ which are summarised below:

NICE Quality Standards 2015

1. QS1: men with prostate cancer have a discussion about treatment options and adverse effects with a named nurse specialist.
2. QS2: men with low-risk prostate cancer for whom radical treatment is suitable are also offered the option of active surveillance.
3. QS3: men with intermediate- or high-risk localised prostate cancer who are offered non-surgical radical treatment are offered radical radiotherapy and androgen deprivation therapy in combination.
4. QS4: men with adverse effects of prostate cancer treatment are referred to specialist services.
5. QS5: men with hormone-relapsed metastatic prostate cancer have their treatment options discussed by a urological cancer MDT.

The performance indicators are summarised here and, where applicable, references which NICE Quality Standard it applies to:

Disease presentation

- **Performance indicator 1: Proportion of men presenting with metastatic disease at diagnosis.**

This process indicator provides information on the potential late diagnosis of prostate cancer. Men assigned to the mixed, locally advanced or metastatic groups were excluded.

Treatment allocation

- **Performance indicator 2: Proportion of men with low-risk localised prostate cancer undergoing radical prostate cancer therapy (QS2).**

This process indicator provides information about the potential “over-treatment” of men with low-risk prostate cancer.

- **Performance indicator 3: Proportion of men with locally advanced disease receiving radical prostate cancer therapy (QS3).**

This process indicator provides information about potential “under-treatment” of men with locally advanced disease.

Performance indicators 1-3 are presented at the level of the specialist MDT and men who could not be allocated to a specific Trust at diagnosis were excluded.

Outcomes of treatment: short-term

- **Performance indicator 4: Proportion of patients who had an emergency readmission within 90 days of radical prostatectomy.**

This outcome indicator was derived from linkage with HES/ PEDW admissions. Emergency readmission may reflect that patients experienced a complication related to radical prostate cancer surgery after discharge from hospital.

Outcomes of treatment: medium-term

- **Performance indicator 5: Proportion of patients experiencing at least one severe genitourinary (GU) complication within 2 years of radical prostatectomy.**

We used a coding-framework based on OPCS-4 procedure codes to capture genitourinary complications severe enough to require an intervention.¹⁷ These included complications of the urinary tract as opposed to those related to sexual dysfunction. Men with an associated diagnosis of bladder cancer (ICD-10 “C67” code) or who received post-operative radiotherapy were excluded.

¹⁶ NICE prostate cancer quality standards. Download from: <https://www.nice.org.uk/guidance/qs91>

- **Performance indicator 6: Proportion of patients experiencing at least one severe gastrointestinal (GI) complication within 2 years of radical external beam radiotherapy.**

We used a coding-framework based on OPCS-4 procedure codes to capture interventions required to treat GI toxicity. The indicator also required the presence of specific ICD-10 diagnosis codes relating to GI toxicity.¹⁸ This combination approach allowed us to exclude the men who had GI interventions for reasons unrelated to radiotherapy, such as part of a screening programme. Men with an associated diagnosis of bladder cancer, those who received additional brachytherapy and those who had received a radical prostatectomy prior to radiotherapy were excluded.

Performance indicators 4-6 are presented at the level of the surgical or radiotherapy centre. Treatment centres which performed less than 10 procedures per year were excluded.

Patient-reported experience measures (PREMs)

- **Performance indicator 7: Proportion of patients who were given the ‘right amount’ of information about their condition and treatment.**
- **Performance indicator 8: Proportion of patients who were involved as much as they wanted to be in decisions about their treatment and care.**
- **Performance indicator 9: Proportion of patients who were given the name of a clinical nurse specialist (QS1).**
- **Performance indicator 10: Proportion of patients rating their overall care as eight or above (on a scale of 0 – 10, where 0 = ‘very poor’ and 10 = ‘very good’).**

Performance indicators 7-10 are presented at the level of the specialist MDT and men who could not be allocated to a specific Trust at diagnosis were excluded. All these PREMs were derived from selected NCPES questions in the NPCA Patient Survey.

Patient-reported outcome measures (PROMs)

- **Performance indicator 11: Mean urinary incontinence score after radical prostatectomy**
- **Performance indicator 12: Mean sexual function score after radical prostatectomy**

- **Performance indicator 13: Mean bowel function score after radical external beam radiotherapy**
- **Performance indicator 14: Mean sexual function score after radical external beam radiotherapy**

Performance indicators 11-14 are presented at the level of the surgical or radiotherapy centre. The same exclusions used for performance indicators 5 and 6 were also applied. Treatment centres which performed less than 10 procedures per year were excluded. These performance indicators present the validated summary score for each EPIC-26 domain, which ranges from 0 to 100 with higher scores representing better function.

2.9.2 Funnel plots

Funnel plots were generated for all performance indicators using control limits defining differences corresponding to two standard deviations (inner limits) and three standard deviations (outer limits) from the national average population.

Multivariable logistic regression was carried out with adjustment for patient age, socio-economic status and comorbidity to determine adjusted outcomes for performance indicators 2 and 3. Comorbidity was captured using the Royal College of Surgeons (RCS) Charlson comorbidity score¹⁹ using ICD-10 diagnosis codes in HES/PEDW. The Index of Multiple Deprivation (IMD) was used to categorise patients into five socioeconomic groups (1=least deprived; 5=most deprived) based on the areas in which they lived. The five categories were fifths of the national IMD ranking of these areas. Stage was included in the adjustment model for all treatment outcomes (performance indicators 4-6) including patient-reported outcomes (performance indicators 11-15).

Surgical and radiotherapy treatment centres outside the outer funnel for the adjusted performance indicators (4, 5, 6, 11, 12, 13 and 14) were considered as potential ‘alarm’ outliers and contacted according to the NPCA Outlier Policy.²⁰ Provider responses during the Outlier Process can be found in Appendix 1.

¹⁷ Sujenthiran A, Charman S et al. Quantifying severe urinary complications after radical prostatectomy: the development and validation of a surgical performance indicator using hospital administrative data. *BJU int* (2017); 120:219-225

¹⁸ Sujenthiran A, Nossiter J et al. National population-based study comparing treatment-related toxicity in men who received Intensity-modulated versus 3D-Conformal Radical Radiotherapy for prostate cancer. *Int J Radiat Oncol Biol Phys.* (2017); 99: 1253 -1260

¹⁹ Armitage JN, et al. Identifying co-morbidity in surgical patients using administrative data with the Royal College of Surgeons Charlson Score. *Br J Surg* 2010; 97:772-81

²⁰ <https://www.npca.org.uk/resources/npca-outlier-policy/>

3. Results

3.1 Audit participation

Prostate cancer services are provided at 139 NHS Trusts across 47 specialist MDTs in England and 7 Health Boards across 5 specialist MDTs in Wales. All NHS Trusts and Health Boards participated in the NPCA from 1st April 2016 to 31st March 2017. In this time period we received Cancer Registry records of 40,948 newly diagnosed men from England who could be assigned a valid NHS provider.

In Wales we received a total of 2,027 NPCA records of newly diagnosed men who could be assigned to a valid NHS provider. The number of prostate cancer diagnoses appearing in WCISU for 2015 was 2,434 resulting in approximate case ascertainment of 83%.

3.2 Data completeness

Completeness of pre-treatment data items

Data completeness is extremely high for Wales with key variables reaching completeness of at least 89% (performance status, biopsy type, multiparametric MRI performed, PSA and Gleason score; Table 1). TNM-stage is only partially complete at 70%. With the ability to place 98% of Welsh men into a risk category the quality of the Welsh data is extremely high and similar to last year.

Data completeness in England remains low. Performance status and multiparametric MRI are 51% complete. However, the diagnostic information is substantially better with completeness for PSA, Gleason score and TNM reported as 71%, 83% and 76%, respectively. It is possible to place 94% of English men into a risk category showing that the data quality is very good and continues to improve.

Completeness of radical prostatectomy data items

Given the poor completeness of prostatectomy information (MDS-2) in England the NPCA now uses solely HES and PEDW to identify surgical data for England and Wales, respectively. These data sources identify the men who undergo a radical prostatectomy, the type of prostatectomy received (open, laparoscopic or robotic) and whether a lymphadenectomy was performed. Completeness therefore relies on the presence, or absence, of specific procedure codes and so completeness is reported as 100%. Data on margin status and whether nerve sparing surgery was performed is now being collected as part of COSD and as such we will be able to report on these variables in future reports.

Completeness of radical radiotherapy and brachytherapy data items

In the same way, radiotherapy information (MDS-3) is also poorly completed in England. This information is now collected through the RTDS in England and CaNISC in Wales, respectively. These data sources can identify men who undergo radical radiotherapy (EBRT) or brachytherapy. The RTDS in England can provide information on radiotherapy modality (IMRT or 3D-conformal) and relies on the code for Intensity Modulated Radiation Therapy (IMRT) being correct. Completeness is therefore reported as 100%. Treatment region is also extremely high at 98%. Wales are currently transitioning onto collecting the RTDS and so we are still reporting these variables from the NPCA planned radiotherapy variables. As with the rest of the Welsh NPCA, completeness of the radiotherapy variables is extremely high at above 98%.

Overall data completeness can be seen in Table 1 and completeness of all data items by diagnosing Trust, specialist MDT, surgical centre and radiotherapy centre can be found on our website <https://www.npca.org.uk/provider-results/>

Table 1. Data completeness for selected data items for men newly diagnosed with prostate cancer in England and Wales over the period of 1 April 2016 and 31 March 2017.

Data variable	England		Wales	
	N	%	N	%
Diagnostic and staging variables				
No. of men with new diagnosis of prostate cancer	40,948 [CR]		2,027 [NPCA]	
Performance status completed	20,938 [COSD]	51%	2,027 [NPCA]	100%
mpMRI performed completed	20,837 [NPCA]	51%	1,993 [NPCA]	98%
PSA completed	29,270 [COSD]	71%	1,808 [NPCA]	89%
Gleason score completed	33,916 [CR]	83%	1,808 [NPCA]	89%
TNM completed	30,988 [CR]	76%	1,416 [NPCA]	70%
Radical prostatectomy variables				
No. of men who underwent a radical prostatectomy	6,462 [CR-HES]		270 [CR-PEDW]	
Prostatectomy type completed	6,462 [HES]	100%	270 [PEDW]	100%
Lymphadenectomy performed completed	6,462 [HES]	100%	270 [PEDW]	100%
Radical radiotherapy variables				
No. of men who underwent a radical radiotherapy	13,341 [CR-RTDS]		595 [NPCA]	
Radiotherapy modality completed	13,341 [RTDS]	100%	587 [NPCA]	99%
Radiotherapy region completed	13,053 [RTDS]	98%	583 [NPCA]	98%

3.3 Audit findings

Patient and diagnostic characteristics are summarised in Table 2.

Patient characteristics

Over one-third of men are aged between 70 and 80 (37% and 41% for England and Wales, respectively). One-third are also aged between 60 and 70. Prostate cancer is very much a disease of the elderly shown with a high number being diagnosed when they are over 80 years old (17% and 14% in England and Wales, respectively). This remains consistent with last year's report. In England two thirds of the men had a performance status of 0 versus only 56% for Wales, again consistent with last year's report. However to note, this measure is reported only for patients for whom data has been submitted. Whilst performance status was completed for all patients in Wales; completeness in England is low at 51%

Diagnostic investigations

Transrectal ultrasound guided prostate biopsy remains the most common biopsy technique at 88%, with the remainder undergoing a transperineal biopsy (12%). Significantly more men are undergoing a transrectal ultrasound guided biopsy in Wales at 96%, versus the transperineal route (4%). This is consistent with last year's results. It is important to note that this measure is reported only for patients for whom data has been submitted. Whilst the data on route of biopsy was completed for all patients in Wales the completeness in England was low at 54%.

By contrast, the use of multiparametric MRI has increased from 51% to 58% in England, and from 54% to 59% in Wales. The use of pre-biopsy multiparametric MRI is also increasing and is up to 80% (from 74%) in England, and 41% (from 27%) in Wales, but this does indicate that the use of post-biopsy multiparametric MRI is still high. Again, these results need to be interpreted alongside the high level of incompleteness of this variable in England (51%).

PSA, tumour grade, tumour stage and disease status at presentation

The distribution of PSA, Gleason score and TNM staging is shown in Table 2 and has remained consistent with last year's results. The proportion of men presenting with metastatic prostate cancer at diagnosis is stable in England (16%). However, it appears that more men are now being diagnosed with locally advanced disease, which has risen from 35% to 39%. The proportions of low and intermediate risk disease have both dropped to 7% (2,837) and 35% (13,424), respectively. The presentation of Welsh men at diagnosis appear to be generally consistent with last year's results but with only 2,027 men the sample size is too small to effectively comment on disease trends.

Table 2. Patient and diagnostic characteristics for men newly diagnosed with prostate cancer in England and Wales over the period of 1 April 2016 and 31 March 2017.

Data variable	England		Wales	
	N	%	N	%
No. of men with new diagnosis of prostate cancer	40,948		2,027	
Age				
<60	5,085	12%	226	11%
60-70	13,443	33%	677	33%
70-80	15,350	37%	832	41%
≥80	7,070	17%	292	14%
Total	40,948	100%	2,027	100%
Missing	0		0	
Performance status				
0	14,042	67%	1,138	56%
1-2	6,461	31%	852	42%
≥3	435	2%	37	2%
Total	20,938	100%	2,027	100%
Missing	20,010		0	
Charlson score				
0	28,893	72%	1,628	80%
1	7,117	18%	223	11%
≥2	4,299	11%	103	9%
Total	40,309	100%	1,954	100%
Missing	639		73	
Biopsy performed				
Transrectal sampling	15,112	85%	1,682	96%
Transrectal saturation	476	3%	6	0%
Perineal sampling	1,057	6%	2	0%
Perineal template	1,179	7%	60	3%
Other	983		60	
None	3,143		217	
Total	21,950	100%	2,027	100%
Missing	18,998		0	

Data variable	England		Wales	
	N	%	N	%
mpMRI performed				
No	8,777	42%	825	41%
Yes - Before biopsy	9,642	46%	478	24%
Yes - After biopsy	2,418	12%	690	35%
Total	20,837	100%	1,993	100%
Missing	20,111		34	
PSA value				
<10	13,558	46%	939	52%
10-20	6,446	22%	459	25%
>20	9,266	32%	410	23%
Total	29,270	100%	1,808	100%
Missing	11,678		219	
Gleason score				
≤6	7,501	22%	655	36%
7	16,348	48%	748	41%
≥8	10,067	30%	405	22%
Total	33,916	100%	1,808	100%
Missing	7,032		219	
T stage				
T1	6,097	17%	350	18%
T2	15,130	43%	949	48%
T3	12,472	35%	539	27%
T4	1,827	5%	132	7%
Total	35,526	100%	1,970	100%
Missing	5,422		57	
N stage				
No	28,684	88%	1,679	92%
N1	3,732	12%	155	8%
Total	32,416	100%	1,834	100%
Missing	8,532		193	
M stage				
M0	29,222	83%	1,307	85%
M1	6,103	17%	239	15%
Total	35,325	100%	1,546	100%
Missing	5,623		481	

Data variable	England		Wales	
	N	%	N	%
Risk group				
Metastatic	6,103	16%	239	12%
Locally advanced	14,881	39%	657	33%
Mixed (advanced/locally advanced)	1,185	3%	52	3%
Intermediate	13,424	35%	883	44%
Low risk	2,837	7%	163	8%
Total	38,430	100%	1,994	100%
Insufficient	2,518		33	

Treatment Information

Treatment characteristics are summarised in Table 3.

6,462 men underwent a radical prostatectomy (RP) in England and the vast majority were robotically assisted (81%), with the remainder performed laparoscopically (9%) or open (10%). The frequency of robotic prostatectomies is continuing to rise, up from 74% last year. Robotic prostatectomies were performed less frequently in Wales at 63% with a significantly higher proportion being performed open (23%). One-third of the prostatectomies were performed with a lymphadenectomy in England (33%) and slightly more in Wales (39%).

13,341 men underwent radical radiotherapy in England and the vast majority of treatments were delivered with IMRT (89%), an increase on the figure reported last year (82%; Table 3). Only 13% received radiotherapy to the pelvic lymph nodes (18% for high-risk cases), as well as the prostate, with the vast majority receiving radiotherapy to the prostate +/- seminal vesicles. Wales appears to be using IMRT routinely and more men appear to be having radiotherapy to the pelvic lymph nodes (22%) – (25% in high-risk cases). At present the Welsh and English use different data sources for radiotherapy information but once Wales has transitioned onto using the RTDS a better comparison between countries will be possible. Also of note is that some high-volume radiotherapy centres appear to have lower annual numbers than expected which may contribute to a degree of misclassification.

Table 3. Treatment characteristics for men receiving radical radiotherapy or prostatectomy in England and Wales over the period of 1 April 2016 and 31 March 2017.

Data variable	England		Wales	
	N	%	N	%
Radical prostatectomy information				
No. of men undergoing radical prostatectomy	6,462		270	
Prostatectomy type				
Robotic	5,229	81%	171	63%
Open	652	10%	63	23%
Laparoscopic	581	9%	36	13%
Total	6,462	100%	270	100%
Missing	0		0	
Lymphadenectomy performed				
No	4,339	67%	164	61%
Yes	2,123	33%	106	39%
Total	6,462	100%	270	100%
Missing	0		0	
Radical radiotherapy information				
No. of men undergoing radical radiotherapy	13,341		595	
Radiotherapy modality				
IMRT	11,911	89%	585	100%
3D conformal	1,430	11%	2	0%
Total	13,341	100%	587	100%
Missing	0		8	
Planned radiotherapy region				
Prostate and/or seminal vesicles	11,415	87%	453	78%
Whole pelvis incl. lymph nodes	1,638	13%	130	22%
Total	13,053	100%	583	100%
Missing	288		12	

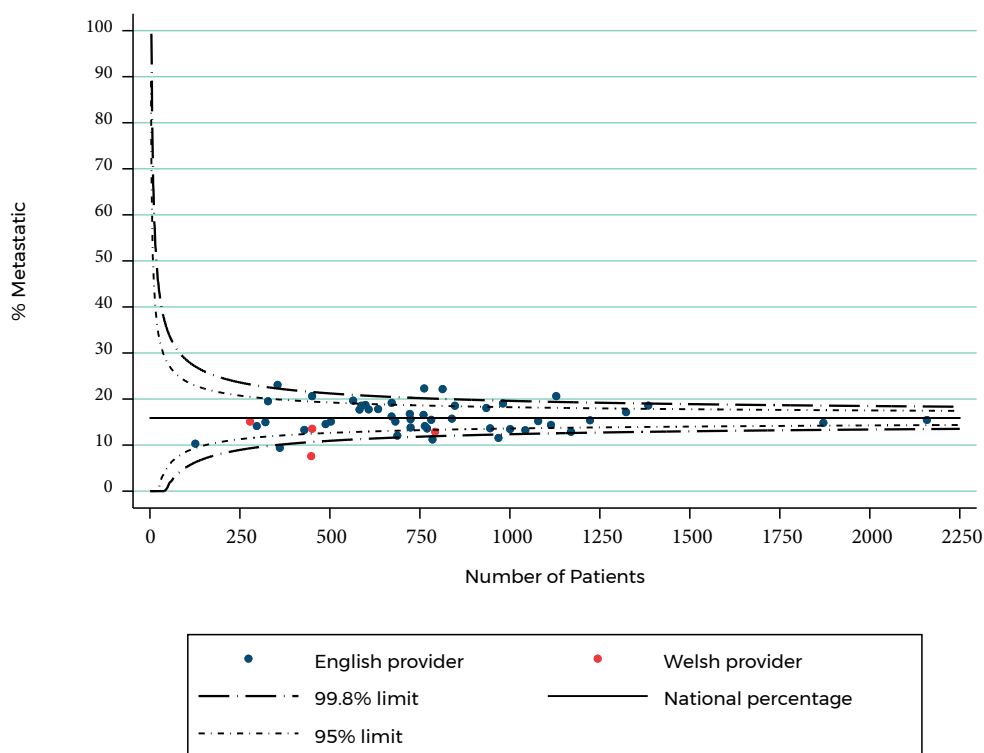
3.4 NPCA 'short-term' performance indicators

Performance indicators 1-3 and 7-10 were applied to men with a record containing information about the diagnosing Trust. We were able to determine disease status and allocate a provider to 38,430 patients in England (94%) and 1,994 in Wales (98%). Performance indicators 4-5 and 11-13 were applied to men who could be linked to a surgical centre where their radical prostatectomy was performed. Performance indicator 6 and 14-15 were applied to men who could be linked to a radiotherapy centre.

Performance indicator 1: Proportion of men presenting with metastatic disease at diagnosis

Overall 16% of men presented with metastatic disease at diagnosis (range: 8% - 23%). The incidence is stable when compared to that reported by the NPCA report in 2017. An adjusted funnel plot demonstrates that there were four specialist MDTs with a significantly higher proportion of men presented with metastatic disease than the others (negative outlier), and four specialist MDTs with a significantly lower level (good outlier) (Figure 1).

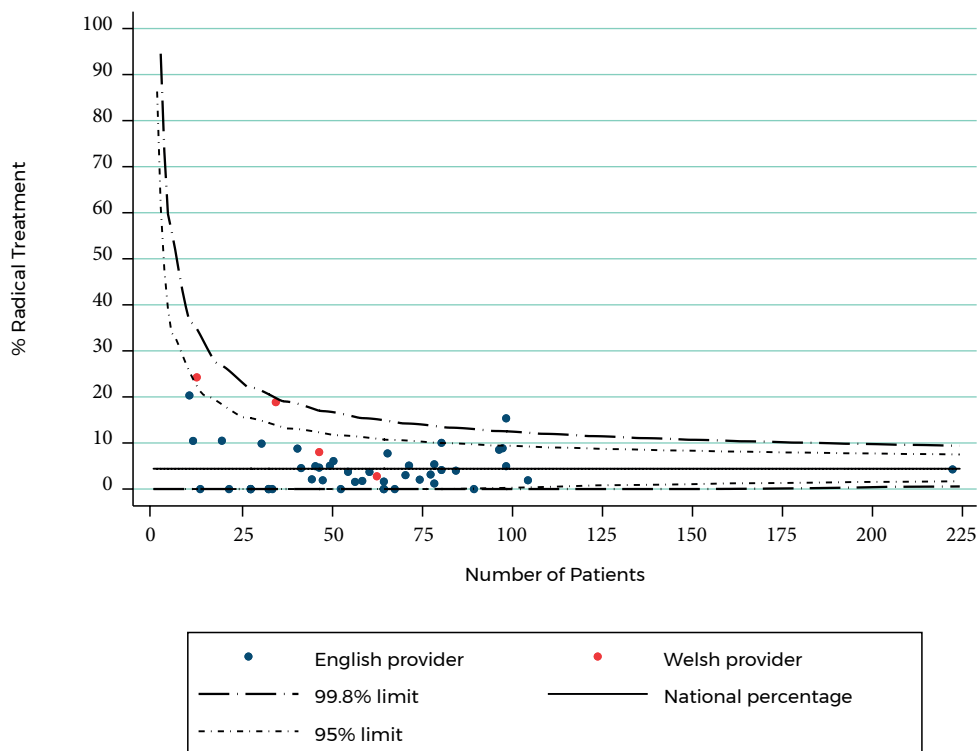
Figure 1. Unadjusted funnel plot for the proportion of patients with metastatic disease at diagnosis across the specialist MDTs in England and Wales



Performance indicator 2: Proportion of men with low-risk localised cancer undergoing radical prostate cancer treatment

Overall, 4% of men diagnosed with low-risk localised cancer underwent radical prostate cancer therapy within 12 months of diagnosis (range: 0% - 24%). 2.6% of men received radiotherapy, 1.7% underwent a prostatectomy and 0.1% received brachytherapy. An adjusted funnel plot demonstrates that there was one specialist MDT which had a significantly worse level of over-treatment compared to the others (negative outlier), and no specialist MDT had a significantly better level of over-treatment (good outlier) (Figure 2). Out of 51 specialist MDTs, one does not feature in the funnel plot as this MDT did not report treating any patients with low-risk disease.

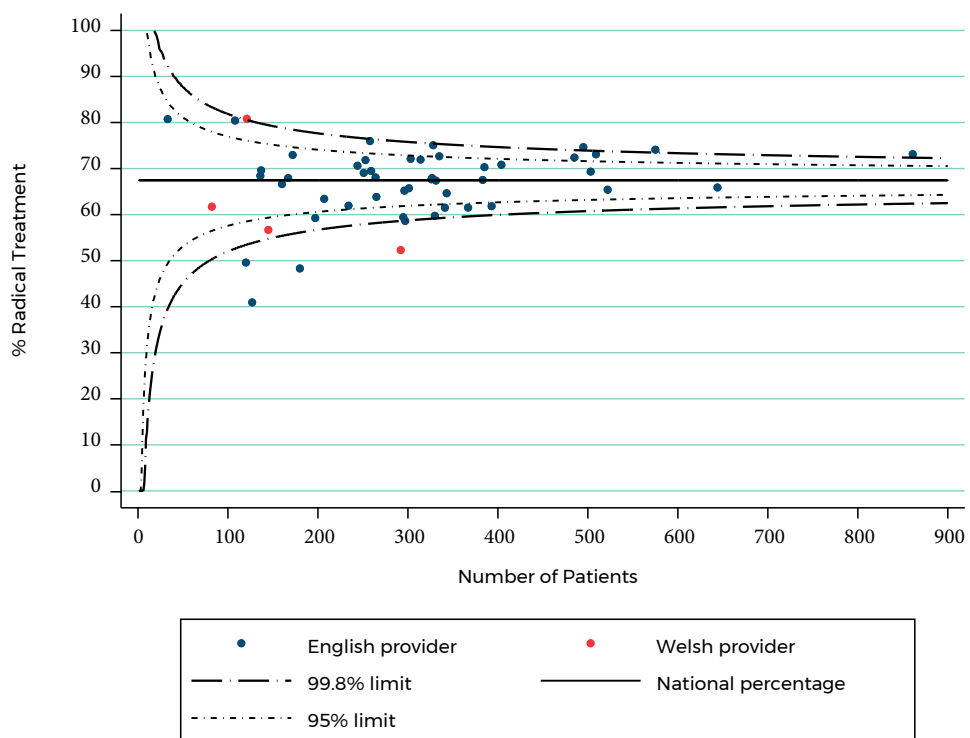
Figure 2. Adjusted funnel plot for the proportion of patients with low-risk prostate cancer undergoing radical treatment by specialist MDTs in England and Wales.



Performance indicator 3: Proportion of men with locally advanced disease undergoing radical prostate cancer treatment

67% of men diagnosed with locally advanced prostate cancer were found to have undergone some form of radical therapy within 12 months of diagnosis (range: 41% - 81%). 48% received radiotherapy, 20% underwent a radical prostatectomy and 0.1% underwent brachytherapy. An adjusted funnel plot demonstrates that out of 51 specialist MDTs there were five which had significantly worse levels of under-treatment compared to the others (negative outliers), and four which had significantly better rates of under-treatment (good outliers) (Figure 3).

Figure 3. Adjusted funnel plot for the proportion of patients with high-risk or locally advanced prostate cancer undergoing radical treatment by specialist MDTs in England and Wales.

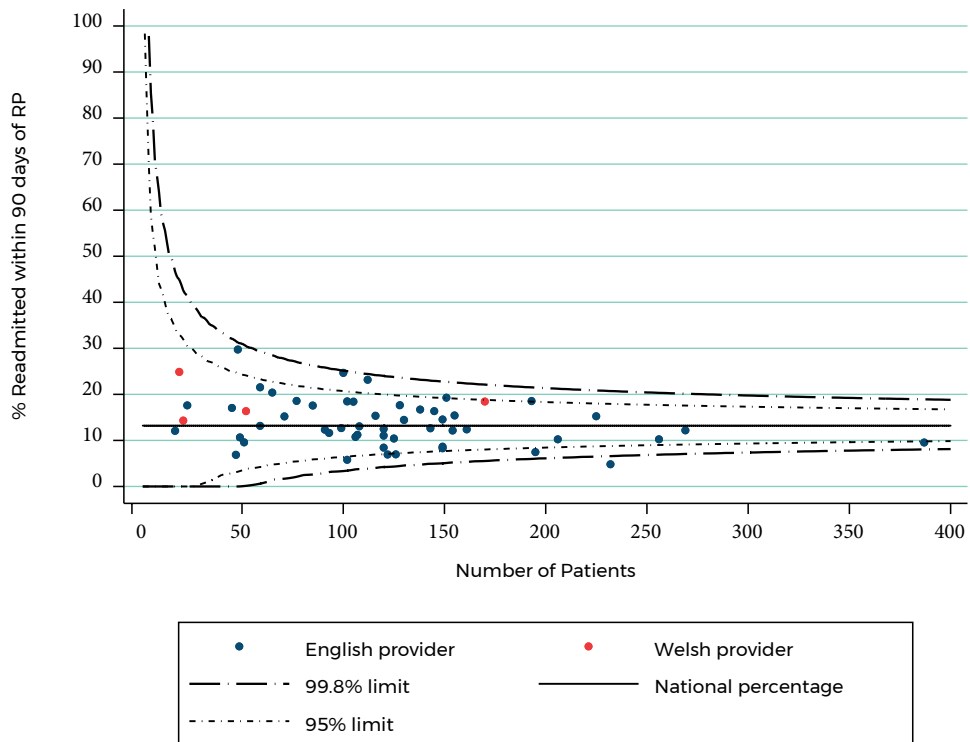


The results for each specialist MDT can be found on our website <https://www.npca.org.uk/provider-results/>

Performance indicator 4: Proportion of patients readmitted as an emergency within 90 days of radical prostatectomy

6,647 men underwent a radical prostatectomy at 55 Trusts between 1st April 2016 and 31st March 2017. The 90-day emergency readmission rate following radical prostatectomy was 13%. Following adjustment, no surgical centre had a significantly worse readmission rate than the others (negative outlier), and one centre had a significantly better rate (good outlier) (Figure 4).

Figure 4. Adjusted funnel plot for the proportion of patients readmitted as an emergency within 90 days of radical prostatectomy by surgical centres in England and Wales.



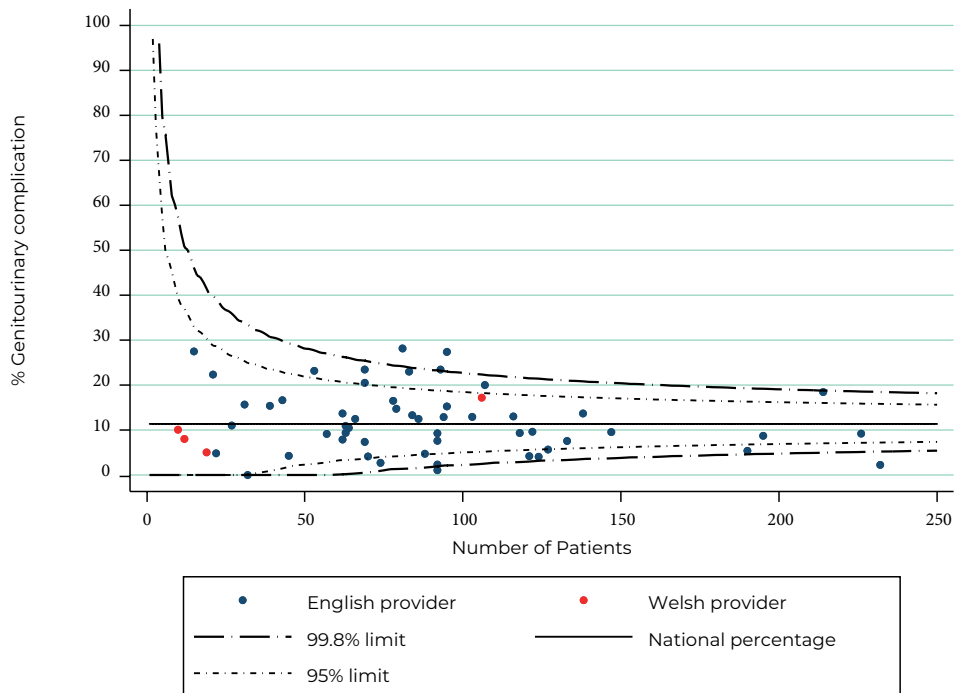
Individual provider results can be found on our website
<https://www.npca.org.uk/provider-results/>

3.5 NPCA 'medium-term' performance indicators

Performance indicator 5: Severe genitourinary toxicity following radical prostatectomy

5,000 men underwent a radical prostatectomy at 57 Trusts during 2015. Overall 11% of men experienced at least one severe treatment-related GU complication within two years following surgery. Following adjustment, there were three surgical centres which had significantly worse rates of severe GU complications than the others (negative outliers), and two centres with significantly better rates of complications (good outliers) (Figure 5).

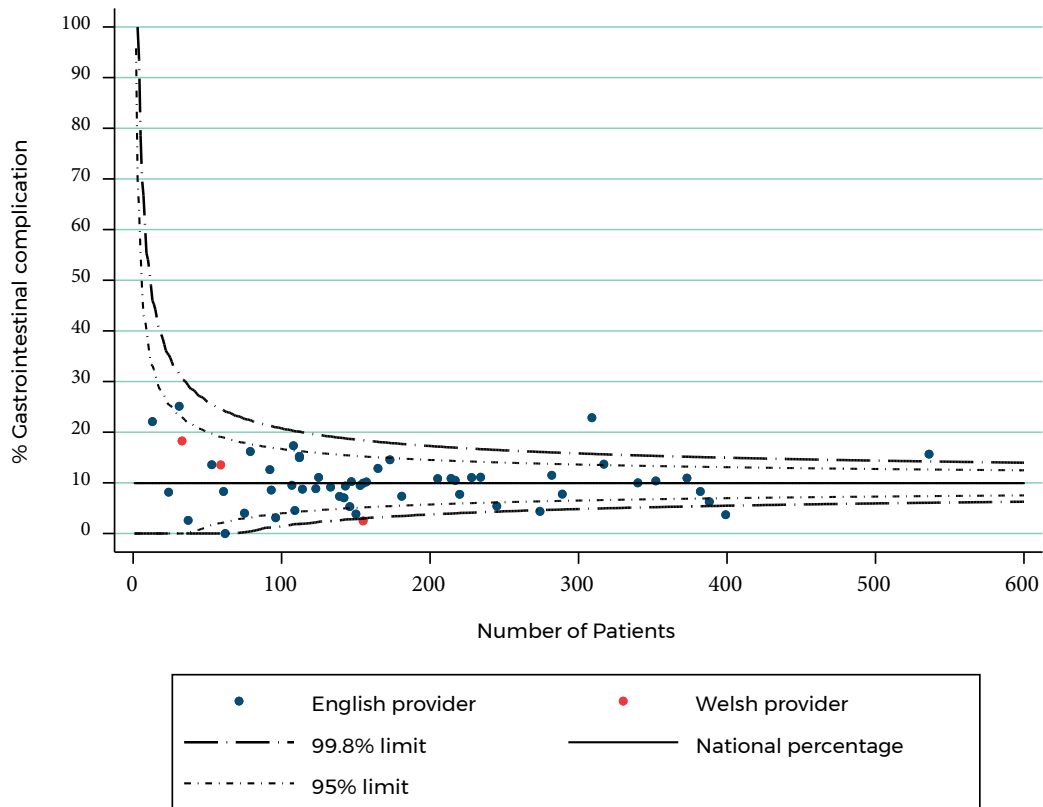
Figure 5. Adjusted funnel plot for the proportion of patients who experienced a severe genitourinary complication with 2 years of radical prostatectomy by surgical centres in England and Wales.



Performance indicator 6: Severe toxicity following radical radiotherapy (external beam [EBRT])

9,661 men received EBRT at 55 Trusts during 2015. Overall 10% experienced at least one severe bowel complication within two years of radiotherapy. Following adjustment, there were two centres with significantly worse rates of severe GI toxicity than the others (negative outliers), and three centres with significantly better rates of complications (good outliers) (Figure 6).

Figure 6. Adjusted funnel plot for the proportion of patients who experienced a severe gastrointestinal complication with 2 years of radical radiotherapy by radiotherapy centres in England and Wales.



Individual provider results can be found on our website
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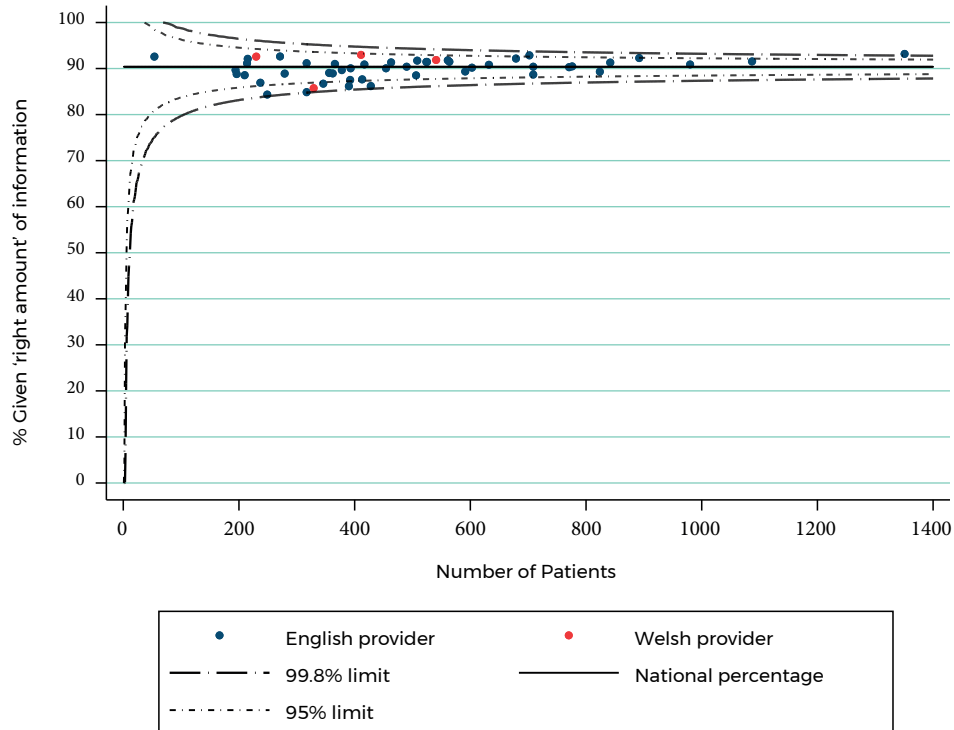
3.6 NPCA patient-reported experience measures (PREMs)

The NPCA Patient Survey was sent to 35,162 men who were diagnosed with prostate cancer from 1st April 2015 to 30th September 2016 in England and Wales. 25,490 responded resulting in a response rate of 73%.

Performance indicator 7: Proportion of patients who were given the 'right amount' of information about their condition and treatment, prior to treatment.

Overall, 90% of men diagnosed with prostate cancer were given the right amount of information about their condition and treatment (range: 84% - 93%). An unadjusted funnel plot demonstrates that out of 51 specialist MDTs there were no negative outliers, but one specialist MDT had a significantly higher proportion of patients rating the information they received as the 'right amount' compared with the national average (good outlier) (Figure 7).

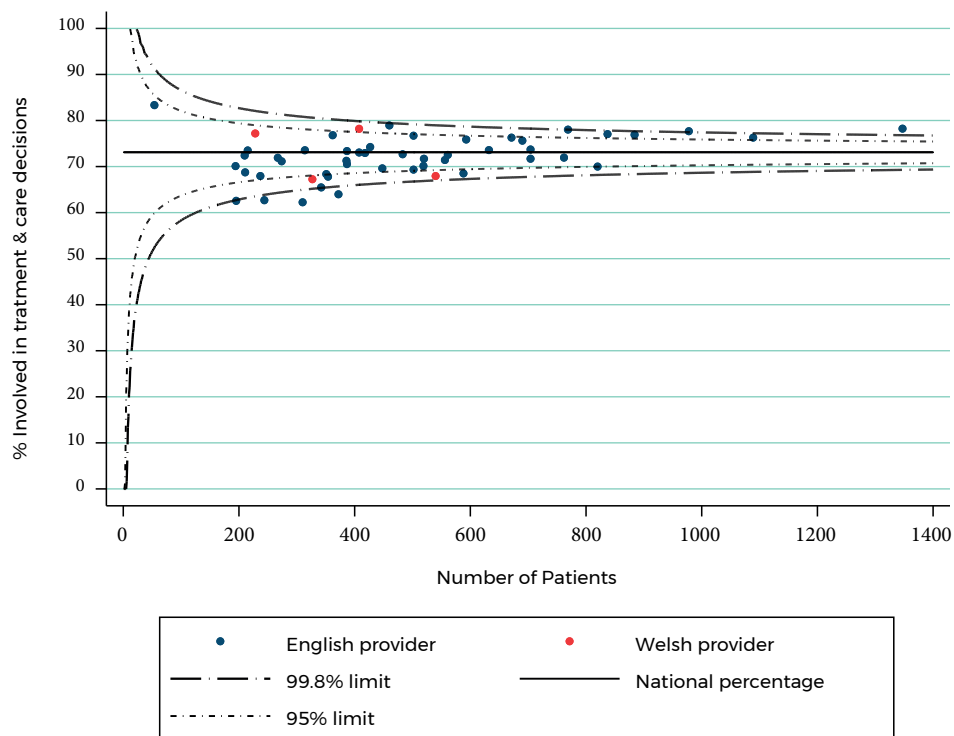
Figure 7. Adjusted funnel plot for the proportion of patients who were given the 'right amount' of information about their condition and treatment by specialist MDTs in England and Wales.



Performance indicator 8: Proportion of patients who were involved as much as they wanted to be in decisions about their treatment and care.

Overall, 72% of men diagnosed with prostate cancer felt they were involved as much as they wanted to be in decisions about their treatment and care (range: 62% - 83%). An unadjusted funnel plot demonstrates that out of 51 specialist MDTs, four had a significantly lower proportion of patients stating they were happy with their involvement (negative outliers). Three specialist MDTs had a significantly higher proportion of patients who were happy with their involvement in the treatment decision making process (good outliers) (Figure 8).

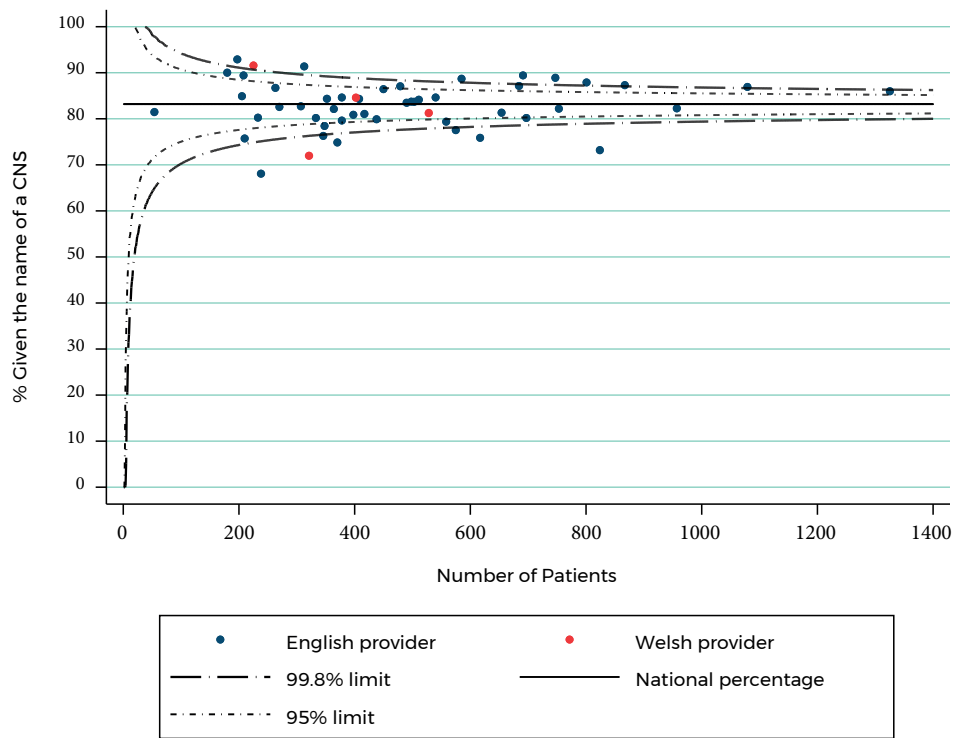
Figure 8. Adjusted funnel plot for the proportion of patients who were involved as much as they wanted to be in decisions about their treatment and care by specialist MDTs in England and Wales.



Performance indicator 9: Proportion of patients who were given the name of a clinical nurse specialist (CNS).

Overall, 83% of men diagnosed with prostate cancer were given the name of a CNS (range: 68% - 93%). An unadjusted funnel plot demonstrates that out of 51 specialist MDTs, seven had a significantly lower proportion of patients who were given the name of a CNS (negative outliers), and nine had a significantly higher proportion of patients (good outliers) (Figure 9).

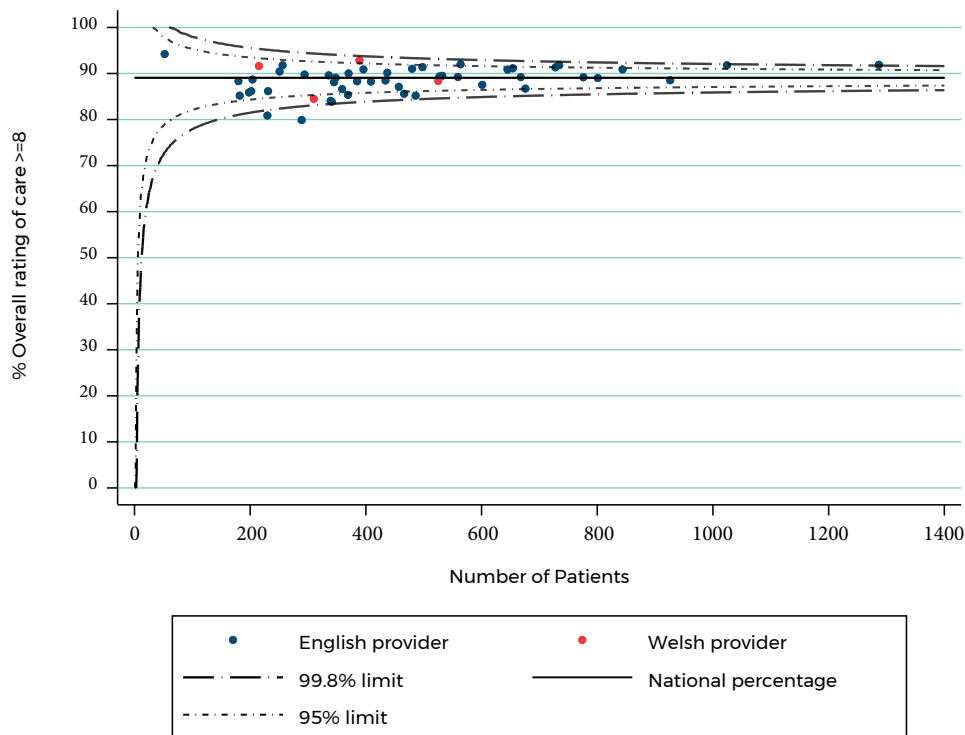
Figure 9. Adjusted funnel plot for the proportion of patients who were given the name of a clinical nurse specialist by specialist MDTs in England and Wales.



Performance indicator 10: Proportion of patients rating their overall care as eight or above (on a scale of 0 – 10, where 0 = ‘very poor’ and 10 = ‘very good’)

Overall, 89% of men diagnosed with prostate cancer rated their overall care as eight or above (range: 80% - 94%). An unadjusted funnel plot demonstrates that out of 51 specialist MDTs, two had a significantly lower proportion of patients who rated their care as eight or above (negative outliers), and one had a significantly higher proportion of patients rating their care as eight or above (good outliers) (Figure 10).

Figure 10. Adjusted funnel plot for the proportion of patients rating their overall care as eight or above (on a scale of 0 – 10, where 0 = ‘very poor’ and 10 = ‘very good’) by specialist MDTs in England and Wales.



The results for each specialist MDT can be found on our website <https://www.npca.org.uk/provider-results/>

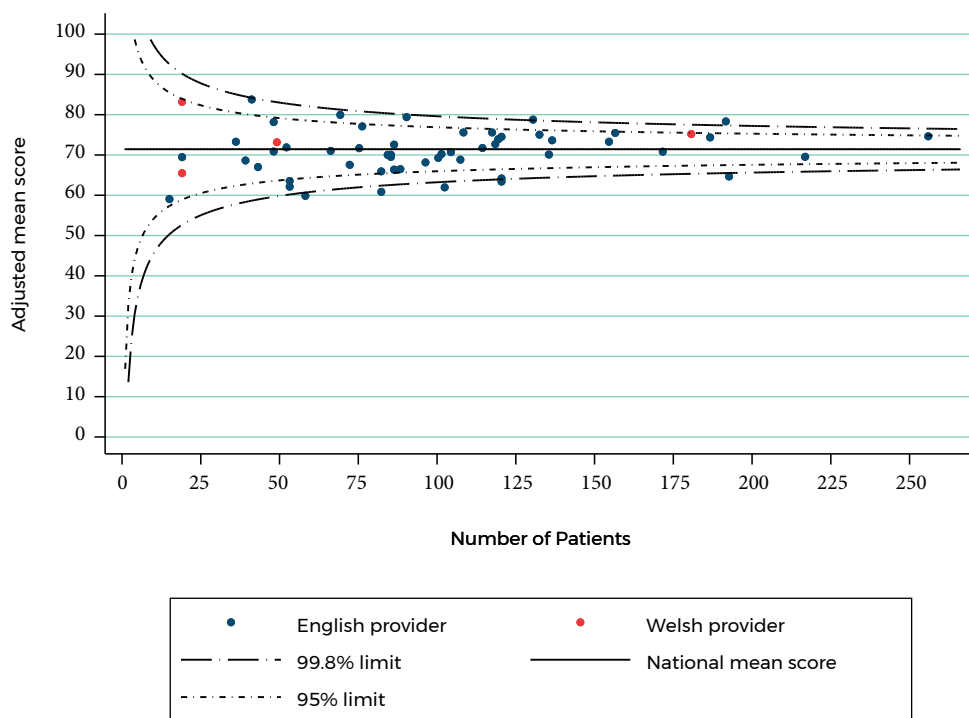
3.7 NPCA patient-reported outcome measures (PROMs)

Of the 25,490 men diagnosed with prostate cancer from 1st April 2015 to 30th September 2016 in England and Wales who responded to the NPCA Patient Survey, 5,732 (23%) had a radical prostatectomy at 56 surgical centres and 11,161 (44%) had EBRT at 55 radiotherapy centres. The following performance indicators use results from the EPIC-26 questionnaire which ranks patient function on a scale of 0 to 100 representing bad to good function.

Performance indicator 11: Mean urinary incontinence score after radical prostatectomy

5,505 men (96%) who had radical surgery completed sufficient information to be assigned an EPIC-26 urinary incontinence score. Overall, the mean urinary incontinence score after a radical prostatectomy was 70.9 (range: 59.0 – 83.8). An adjusted funnel plot demonstrates that out of 56 surgical centres, five had significantly worse scores (negative outliers),* and two had significantly better scores than the national average (good outliers) (Figure 11).

Figure 11. Adjusted funnel plot for the mean urinary incontinence score after radical prostatectomy by surgical centres in England and Wales.

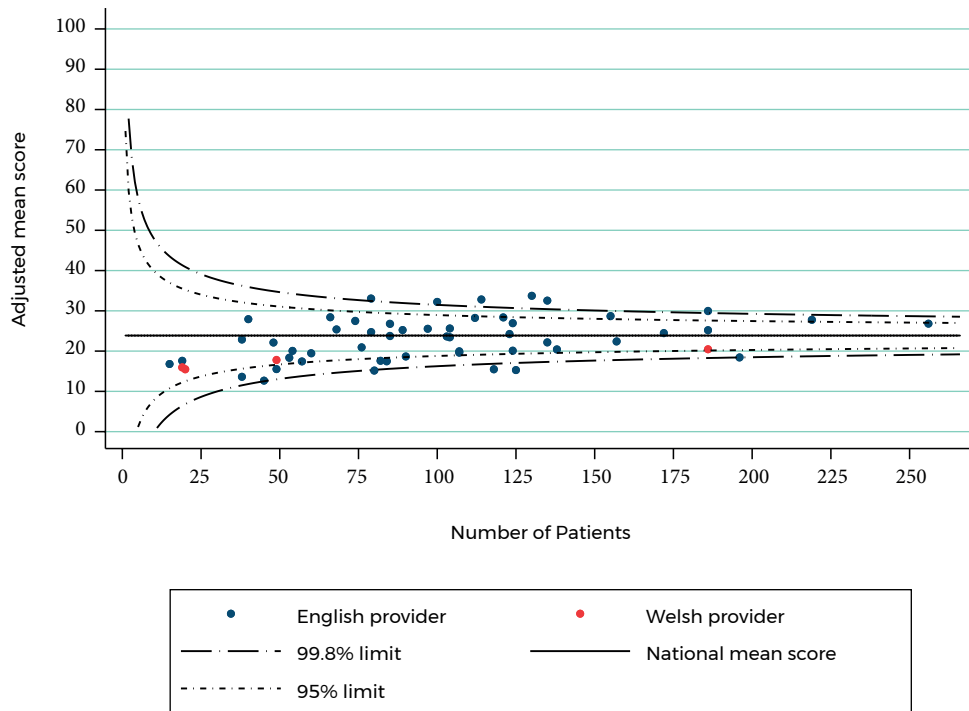


* Four out of five surgical centres remained a negative outlier on conclusion of the outlier process.

Performance indicator 12: Mean sexual function score after radical prostatectomy

5,583 men (97%) completed sufficient information to be assigned an EPIC-26 sexual function score. Overall, the mean sexual function score after a radical prostatectomy was 22.7 (range: 12.7 - 33.7). An adjusted funnel plot demonstrates that out of 55 surgical centres, three had significantly worse scores (negative outliers), and six had significantly better scores than the national average for this domain (good outliers) (Figure 12).

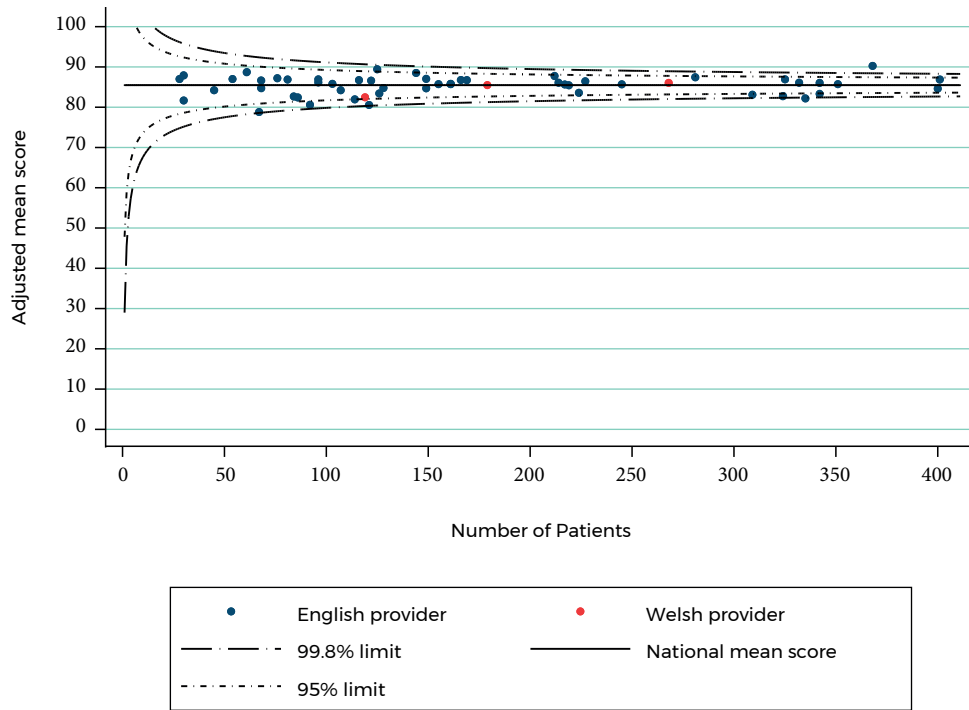
Figure 12. Adjusted funnel plot for the mean sexual function score after radical prostatectomy by surgical centres in England and Wales.



Performance indicator 13: Mean bowel function score after radical radiotherapy

All men who had EBRT completed sufficient information to be assigned an EPIC-26 bowel function score. Overall, the mean bowel function score after radical radiotherapy was 85.3 (range: 78.8 - 90.3). An adjusted funnel plot demonstrates that out of 55 radiotherapy centres, one had a significantly worse score (negative outliers), and one had a significantly better score than the national average (good outliers) (Figure 13).

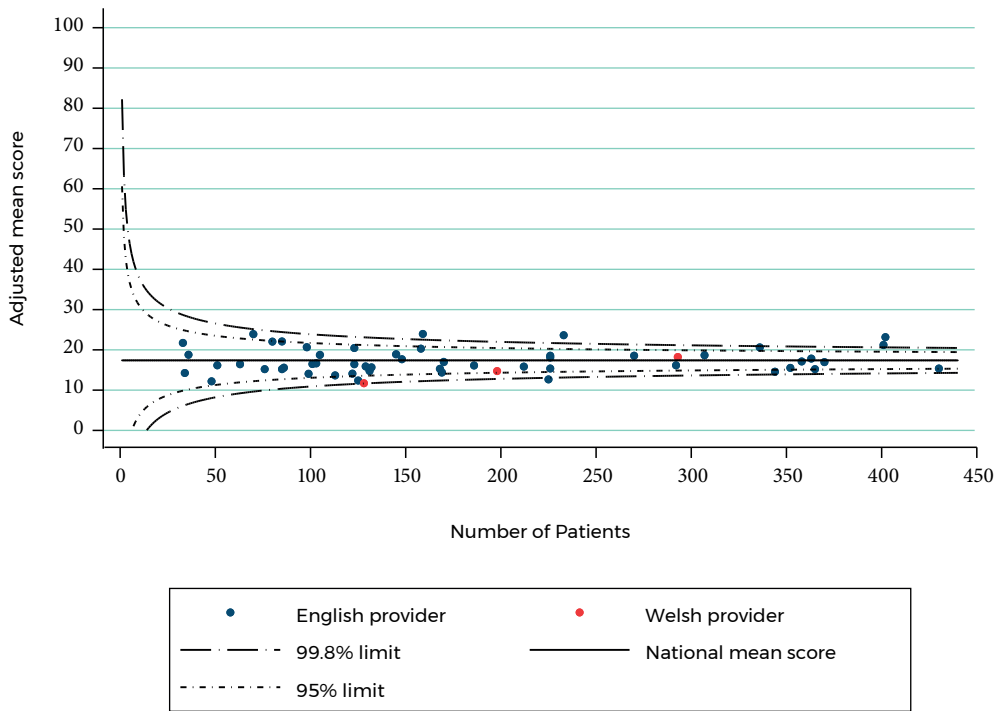
Figure 13. Adjusted funnel plot for the mean bowel function score after radical radiotherapy by radiotherapy centres in England and Wales.



Performance indicator 14: Mean sexual function score after radical radiotherapy

10,147 men (91%) who had EBRT completed sufficient information to be assigned an EPIC-26 sexual function score. Overall, the mean sexual function score after radical radiotherapy was 17.2 (range: 11.7 - 24.0). An adjusted funnel plot demonstrates that out of 55 radiotherapy centres, one had significantly worse scores (negative outliers), and four had significantly better scores than the national average for this domain (good outliers) (Figure 14).

Figure 14. Adjusted funnel plot for the mean sexual function score after radical radiotherapy by radiotherapy centres in England and Wales.



Individual provider results can be found on our website
<https://www.npca.org.uk/provider-results/>

4. Discussion

4.1 Participation and data completeness

This is the first national audit which is able to report on process and outcome measures from all aspects of the care pathway for men with prostate cancer. This has not been achieved anywhere else in the world and the NPCA, and all its contributors, can be very proud of the progress that has been made in its first five years. This provides us with a platform to robustly compare NHS cancer providers across England and Wales and lead to substantial improvement in the delivery of care.

The NPCA uses only routine data sources and patient-reported measures to compare providers. This not only takes account of patient voices but ensures that clinician reported outcomes are not used. This is only possible due to the collaborative process of the NPCA with our data collection partners in England (NCRAS) and Wales (WCN), the involvement of all Trusts and Health Boards and the participation of patients. This process has also allowed us to combine English and Welsh data and allow for a comparison across both countries.

Data completeness of staging items has continued to improve in England and Wales. As a result we were able to determine disease status in 94% of men in England and 98% of men in Wales. The completeness of the Welsh data remains consistently high due to the mandated “sign off” of NPCA records by clinicians. English data is improving year on year but there is still a need for improvement. Regarding pre-treatment data items, such as performance status and multiparametric MRI performed, completeness was close to 100% in Wales, but remained poor in England (both 51%). MDTs should be encouraged to ensure these data items are appropriately filled in where possible.

The NPCA relies on routinely collected data to report on surgical and radiotherapy data items. As such, completeness is very high. These variables do rely on specific procedure codes for prostatectomy, surgical access (robotic or laparoscopic), lymphadenectomy, IMRT and radiotherapy treatment region. Treatment centres should therefore continue to monitor that these codes are being used correctly. In Wales there is a transition onto collection of the RTDS and so the NPCA will begin to use this data as it becomes available.

4.2 Diagnostics and staging

Prostate cancer is very much a cancer of the older man with the majority being aged over 70. With an ageing population this is set to increase and has specific decision making implications for the elderly so as to avoid the under-treatment of this patient cohort. The expected survival is benchmarked at 10 years in order to justify radical treatment and this will have to be carefully considered given that men are now living longer.

The use of transperineal biopsies has remained static compared to last year's results (12% in England and 4% in Wales). Transrectal ultrasound guided biopsy is still the dominant biopsy technique being used (88% in England and 96% in Wales). Encouragingly the use of multiparametric MRI is continuing to rise year on year and is close to 60% in both England and Wales. Equally the use of pre-biopsy MRI is also increasing and is now up to 80% (from 73%) in England although far too many scans are carried out after, rather than before, biopsy. Although there was also an increase in the use of pre-biopsy MRI in Wales the majority are seemingly being performed after biopsy (59%). These results need to be interpreted with caution given that the completeness of this variable remains quite poor in England (51%).

Compared to last year it appears that in England more men are being diagnosed with locally advanced disease with a reduction in the proportion of low-risk men. Specialist MDTs should aim to ensure that multiparametric MRI is continuing to be utilised in the diagnostic pathway. There has been recent development of an optimum prostate cancer diagnostic pathway by NHS England which promotes pre-biopsy multiparametric MRI and transperineal biopsy. The NPCA will continue to monitor how these techniques are being increasingly utilised.

4.3 Treatment characteristics

The use of robotic prostatectomy continues to rise, although more so in England than Wales. A significant number of prostatectomies are still being performed open in Wales at 23%. Lymphadenectomy is used in roughly one-third of operations. This appears to be consistent with the number of lymphadenectomies performed last year (33% in England and 39% in Wales).

IMRT is now the dominant radiotherapy technique for localised prostate cancer treatment in England and Wales. Although the use of IMRT continues to increase in England (80% to 89%), it is now used universally in Wales, with <1% of patients being treated using 3D conformal techniques. Different data sources were used for the radiotherapy information in England (RTDS) and Wales (CaNISC) but better comparisons will be able to be made once all radiotherapy centres in Wales are using the RTDS. Some high-volume radiotherapy centres appear to have lower annual numbers than expected in the RTDS. We will work closely with these centres to make sure that all radiotherapy patients are being captured routinely.

4.4 Performance indicators

Diagnosis and treatment selection

The proportion of men presenting with metastatic disease at diagnosis has remained consistent with that seen last year (16%). There is minimal variation across specialist MDTs in England and Wales. Encouragingly only 4% of men with low-risk disease are being potentially “over-treated”, a further reduction from the figure reported last year (8%). The proportion of men with locally advanced disease receiving treatment is less than last year’s report²¹ (73% to 67%) and so it is important for specialist MDTs to ensure that all men with locally advanced disease are considered for radical treatment to continue the previously seen trend of decreasing rates of “under-treatment” in previous Audit reports. This is especially important given the ageing population and an increasing proportion of men being diagnosed at this stage.

Patient-reported experience measures

The high response rate (73%) achieved demonstrates that patients in England and Wales have continued to engage successfully with the NPCA Patient Survey. The results of the PREMs are encouraging, with 89% rating their overall care as at least eight out of ten (where ten represents ‘very good’ care). The majority of men feel that they were given the right amount of information about their condition and treatment (90%), and were involved as much as they wanted to be in decisions about their care (72%). An important NICE quality

standard is the involvement of a named CNS and this became an important measure for our PREMs survey. 83% of patients stated they were given a named CNS although we have no indication as to whether this translated into use of specific nurse-led services.

We found significant variation in patient-reported measures between specialist MDTs (except for receipt of information). This suggests that improvements could be made in the future to improve the patient experience of care. Diagnosing Trusts and specialist MDTs should aim to make sure that appropriate information is given to patients to ensure that they feel involved with treatment decisions. Potential areas for improvement would be the use of patient-information leaflets, direction to appropriate websites (e.g. Prostate Cancer UK, Tackle Prostate Cancer) and to ensure the involvement of a CNS for every new diagnosis of prostate cancer.

Treatment-related outcome measures

Our algorithm for identifying readmissions has been strengthened and so comparison with previous years was not possible. The national average for readmissions is now 13%. The variation was contained within a relatively narrow range and no surgical centre had more 90 day readmissions than expected. The proportion of men experiencing a severe treatment-related GU complication within two years of surgery remained consistent with that reported last year (11%) but there were three centres with significantly more men requiring a procedure within two years. Regarding PROMs, the mean urinary incontinence score was 71 out of 100 (a higher score represents better function). There was significant variation between centres and five potential outlying centres.

The proportion of men experiencing a severe treatment-related GI complication within two years of radiotherapy remained consistent with last year at 10%, but there were two centres with higher than expected complication rates after PROMs based assessments. The mean bowel function score overall was 85 out of 100 (higher score represents better function). There was significant variation between radiotherapy centres with one provider having significantly worse bowel function and a different centre having worse sexual function.

PROMs reported sexual function scores were much lower than is generally reported in the published urological literature following both surgery and radiotherapy. The mean sexual function scores following both surgery and radiotherapy was 23 and 17 (out of 100), respectively. There was also significant variation between providers with three surgical providers and one radiotherapy provider having significantly worse sexual function than the others. It is important that this information is used to recognise the fact

²¹ NPCA Annual Report 2017. Download from: <https://www.npca.org.uk/reports/npca-annual-report-2017/>

that patients and clinicians view and report clinical outcomes, such as sexual function and incontinence, very differently. It is therefore important that patients are counselled appropriately and honestly regarding their likelihood of experiencing urinary and/or sexual dysfunction in the post-treatment period, whether they are treated using surgery or radiotherapy. Centres should also consider whether their survivorship programmes are sufficiently robust to deal with these post-treatment problems which may need physical or pastoral help.

Wales and England

This is the first time that data from Welsh and English men have been combined to report NPCA performance indicators. All outcomes measured show that Welsh treatment centres are performing consistently with the English centres, and significantly better for one radiotherapy centre in terms of radiotherapy-related GI toxicity.

Key Messages

1. Data completeness in England is still not comparable with that of Wales but it is possible to stage a high proportion of men in both countries (94% and 98%, respectively).
2. The proportion of men presenting with metastatic disease at diagnosis is stable.
3. The use of multiparametric MRI is increasing (58% in England; 59% in Wales), with also an increase in its use prior to biopsy, which is preferable, but the majority of MRI scans are still being performed after initial biopsy in Wales.
4. The use of transperineal biopsies has remained static with last year, despite its more precise diagnosis, but its use in England is higher than that of Wales.
5. Slightly more men are being diagnosed with locally advanced disease in England compared to last year, with a reduction in the proportion of men with both low- and intermediate-risk disease. Further analysis will explore reasons for this finding.
6. Performance indicators now apply to all Trusts in England and all Health Boards in Wales as, given the NPCA started a year later in Wales, we now have appropriately mature data.
7. The potential “over-treatment” of men with low-risk disease is continuing to decline.
8. The potential “under-treatment” of men with locally advanced disease has increased slightly despite an increase in the proportion of men diagnosed with locally advanced disease.
9. The majority of patients are given the amount of information that they feel is appropriate. They also feel they are involved with their care, are given the name of a CNS and are happy with their overall care.
10. Genitourinary complications following radical prostatectomy are generally stable and consistent with last year. One in ten men experience at least one severe genitourinary complication within two years of their prostatectomy.
11. The rate of bowel dysfunction following radical radiotherapy is stable and consistent with that reported last year. One in ten men experience a severe gastrointestinal complication within two years of their radiotherapy.
12. Sexual function scores following radical radiotherapy were generally poor at 17 on a scale of 0-100.
13. Sexual function scores following radical prostatectomy were generally poor at 23 on a scale of 0-100.
14. For all but one of the performance indicators there was significant variation between specialist MDTs or treatment centres with potential outlying performance. The specific measures reporting outcomes for the surgical and radiotherapy centres are involved in the full outlier process.

Recommendations

For prostate cancer teams (local and specialist MDTs) within NHS Trusts/Health Boards

1. Increase the use of pre-biopsy multiparametric MRI and avoid its use post biopsy.
2. Increase the use of transperineal prostate biopsy where necessary to reduce the risk of post-biopsy sepsis and to maximise diagnostic accuracy and risk stratification.
3. Advocate active surveillance in the first instance for men with low risk prostate cancer.
4. Investigate why men with locally advanced disease are not considered for radical local treatment.
5. Use data on side effect prevalence from this report to ensure appropriate counselling and management for all patients.
6. When outlying performance is confirmed, engage with partners, including the NPCA, to review practice urgently and instigate quality improvement measures.
7. Engage with the NPCA Quality Improvement initiatives planned for 2019 (see Future Plans).
8. Review and improve data completeness focussing particularly on performance status, use of multiparametric MRI and biopsy route.

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. Patients having treatment for prostate cancer should be aware of the significant side effects that they may experience. These include problems getting or keeping erections, loss of ejaculatory function, urinary incontinence and/or bowel side effects.
3. It is important that patients are appropriately counselled prior to treatment regarding the likelihood of a deterioration in their sexual function.
4. Patients should be aware of all the support services

that are 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 CNS, in keeping with national recommendations.²²

5. Patients and carers should be aware of the 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.

For commissioners and health care regulators

1. Review the performance indicators for your region to identify shortfalls in resources, service provision and to identify areas where improvements can be made.
2. Work with local NHS providers to develop strategies to reduce variation in the care provided.
3. Enact plans and make resources available for the development and implementation of standardised diagnostic pathways. These should aim to shorten diagnostic timings and improve the diagnostic accuracy and disease risk stratification of prostate cancer with use of pre-biopsy multiparametric MRI and transperineal biopsies.

²² NICE, 2015. Prostate Cancer. NICE Quality Standard 91. Quality statement 4: "Men with adverse effects of prostate cancer treatment are referred to specialist services"

Future Plans for the NPCA

The contract period for the NPCA has been renewed by HQIP for work to continue at the Royal College of Surgeons of England for a further three years. Our plans are to continue to report on all of our performance indicators, which will hopefully include PROMs and PREMs from further patient surveys in 2020. The NPCA will continue to develop new and important performance indicators. We will also initiate a programme to develop methods to measure disease progression, recurrence and its treatment. Also, as the data matures we will be able to report on mortality which will require at least 5 years of follow-up.

We shall continue to publish data as part of the Clinical Outcomes Programme (COP) and the National Clinical Audit Benchmarking (NCAB) to enable dissemination of our findings to clinicians, stakeholders, patients and the wider public. We will also update and improve our NPCA cross-sectional data on provision of services by conducting annual organisational surveys. This will enable accurate reporting of the current structure and services of providers of prostate cancer care in England and Wales and compare this with our previous data of service provision.

The success of the NPCA relies solely on the quality of the data received from Trusts and Health Boards across England and Wales. Our data collection partners (NCRAS and WCN) will continue to work directly with individual care providers to help improve data quality. This will ensure the reliability of all the results we present and the reporting of outliers. The NPCA will continue to use our outlier policy to notify outlying providers and specialist MDTs for each performance indicator. This will enable the data to be checked and changes implemented to improve patient outcomes.

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 the cancer closely and can initiate active treatment with surgery or radiotherapy if the cancer starts to grow.

Androgen Deprivation Therapy (ADT)

The use of drugs or surgery to block or lower the level of testosterone (the main male hormone) as part of treatment of prostate cancer treatment.

ASA score

The American Society of Anaesthesiologists (ASA) classification is a scoring system based on the perioperative health and co-morbidities of a surgical patient. A high ASA score denotes a higher risk of perioperative complications in the short and long term. For the NPCA, an ASA score is assigned to all patients regardless of treatment.

Brachytherapy

A technique which involves the placement of a radioactive source directly into the prostate. This can either be with radioactive seeds (seed implant brachytherapy used only for low-risk disease) or High Dose-Rate Brachytherapy (HDR brachytherapy) which is used either alone or more commonly as a supplement to external beam radiation therapy.

British Association of Urological Surgeons (BAUS)

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

British Uro-oncology Group (BUG)

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

Cancer Network Information System Cymru (CaNISC)

An online computer system that provides information for health professionals on cancer patients across Wales.

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).

Case-mix adjustment

A statistical method of comparing quality of care between organisations that takes into account important and measurable characteristics (also see risk-adjustment).

Care Quality Commission (CQC)

Independent regulator of health and adult social care in England. The CQC makes sure that health and social care services provide people with safe, effective, compassionate and high-quality care.

Clinical Effectiveness Unit (CEU)

An academic collaboration between the Royal College of Surgeons (RCS) of England and the London School of Hygiene and Tropical Medicine (LSHTM). The Clinical Effectiveness Unit (CEU) carries out national surgical audits, develops audit methodologies and produces evidence on clinical and cost effectiveness.

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 Publication (COP)

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

Co-morbidity

Medical condition(s) or disease process(es) that are additional to the disease under investigation (in this case, prostate cancer).

Cancer Outcomes and Services Dataset (COSD)

The national standard for reporting of cancer in the NHS in England. Trusts submit a data file to the National Cancer Registration and Analysis Service (NCRAS) every month.

Charlson Co-morbidity Score

A commonly used scoring system for medical co-morbidities. The score is calculated based on the absence and presence of specific medical problems in the Hospital Episode Statistics (HES) database.

External Beam Radiotherapy (EBRT)

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

Gleason Score

The Gleason score is a measure of how aggressive the prostate cancer is and is graded up to nine. Along with PSA and TNM, the Gleason score can be used to risk stratify patients, in other words, to make an assessment of how cancer is likely to behave in the future.

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)

It aims to promote quality improvement in healthcare and increase the impact of clinical audit on the services provided by the NHS and independent healthcare organisations.

Hospital Episode Statistics (HES)

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

Intensity-modulated Radiotherapy (IMRT)

IMRT is a type of conformal radiotherapy. Conformal radiotherapy shapes the radiation beam to closely fit the area of the cancer more closely in order to avoid affecting healthy tissue with excess ionising radiation. The benefit over 3-dimensional conformal radiotherapy is that a higher dose can be given to the prostate while limiting the radiation dose to the surrounding tissues.

International Classification of Diseases, Tenth Revision (ICD-10)

This is the World Health Organisation international standard diagnostic classification, and is used to code diagnoses and complications within the Hospital Episode Statistics database of the English NHS.

Localised Disease

When cancer is confined within the prostatic capsule.

Locally Advanced Disease

When cancer has spread outside the prostatic capsule (T3 or T4) and potentially into surrounding lymph nodes in the pelvis (N1).

Lymphadenectomy

The surgical removal of one or more groups of lymph nodes. In prostate cancer this almost always relates to lymph nodes in the pelvis.

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.

Margin Status

Once the prostate has been removed during surgery, the margin status indicates if the edge of the specimen contains cancer cells or not. A positive margin status would indicate that residual prostate cancer cells may have been left behind, although this does not necessarily mean that an individual's disease will relapse at the site of surgery or elsewhere.

Metastatic Disease

When cancer has spread away from the prostate to distant sites of the body, most commonly to the bones and/or lymph nodes outside the pelvic region.

Multidisciplinary Team (MDT)

A team of specialist health care professionals from various backgrounds (e.g. doctors, nurses, administrative staff) who collaborate to organise and deliver care for patients with a specific condition (e.g. prostate cancer).

Multimodal Therapies

The use of multiple treatments for use against prostate cancer. This may be a combination of radiotherapy, hormones, chemotherapy and/or surgery.

Multiparametric MRI (mpMRI)

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

National Cancer Data Repository (NCDR)

The NCDR comprises a merged dataset of English cancer registration data, linked to further national datasets including Hospital Episode Statistics (HES), the radiotherapy dataset (RTDS) and Office of National Statistics data (ONS).

National Cancer Registration and Analytical Service (NCRAS)

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

Nerve-sparing Surgery

During a prostatectomy the surgeon may avoid the nerves surrounding the prostate in order to preserve erectile function after the operation. This is not always possible if the cancer has spread outside of the prostatic capsule.

NHS Digital

The provider of professional IT services to the NHS. Their goal is to improve health and social care in England by making better use of technology, data and information.

NHS Hospital Trust

An NHS organisation 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.

Office for National Statistics (ONS)

Government department responsible for collecting and publishing official statistics about the UK's society and economy. This includes cancer registration data.

Patient Episode Database for Wales (PEDW)

A database that contains all inpatient and day case activity undertaken in NHS Wales hospitals. This includes details of admissions, diagnoses and the treatments undergone.

Performance Status (WHO/ECOG)

The World Health Organisation (WHO)/Eastern Cooperative Oncology Group (ECOG) performance status indicator is a measure of how disease(s) impacts a patient's ability to manage on a daily basis. It was initially developed in the research setting to standardise the reporting of chemotherapy toxicity and the response of cancer patients in clinical trials. However, it is now in the public domain and is routinely used in other research and clinical settings.

Prostate Specific Antigen (PSA)

A protein produced by the cells of the prostate gland. A high PSA may indicate prostate cancer or prostate cancer recurrence but it also may indicate benign conditions such as an enlarged prostate or infection.

Prostatectomy

The surgical removal of the prostate gland.

Radical treatment

Treatment aimed at curing prostate cancer (removing cancer tissue). These treatments include radical prostatectomy and radiotherapy (including brachytherapy) with or without the use of ADT before and after treatment.

Radiotherapy Data Set (RTDS)

A database that contains standardised data from all NHS Trust providers of radiotherapy services in England.

Radiotherapy

The use of radiation to destroy cancer cells. There are different types of radiotherapy, including external beam radiotherapy, which delivers the radiation in a targeted way from outside the body (telepathy) or by delivering the radiation from a source inside the prostate itself (brachytherapy).

Risk Stratification

Men with prostate cancer are classified according to their risk profile. This is assessed by taking into account how aggressive the cancer is and how far it has spread. Tools such as Gleason grade, PSA levels and different scans are usually used to make this assessment.

Risk-adjustment

A statistical method of that takes into account important and measurable characteristics (also see case-mix adjustment).

Robotic-assisted Prostatectomy

A laparoscopic (key-hole) operation that uses a robot console to help the operating surgeon. The robot allows for more controlled and precise movements during the operation. Advantages over traditional open surgery include less blood loss, less post-operative pain, a shorter hospital stay, smaller scars and a greater likelihood of sparing the nerves and blood vessels attached to the prostate.

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. It is responsible for surgical training and examinations and it supports audit and the evaluation of the clinical effectiveness of surgery.

Specialist Multidisciplinary Team (sMDT)

An sMDT coordinates 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.

TNM stage

This is a classification that describes how advanced a cancer is. Tumour (T), Node (N) and Metastasis (M). T describes the size and extent of the tumour, N describes the involvement of lymph nodes away from the primary cancer site and M describes whether the cancer has spread to a different part of the body.

Transrectal Ultrasound (TRUS) Biopsy

This involves using thin needles to take tissue samples from the prostate after numbing the area with local anaesthetic. The biopsy is done through the rectum (back passage). The placement of these needles is enabled by use of an ultrasound scanner in the rectum to guide the biopsy and the administration of antibiotics to reduce the risk of infection after the procedure.

Transperineal biopsy

Taking biopsies of the prostate through the perineum (the area of skin between the back of the scrotum and the front of the anus). This is usually performed under general anaesthetic. Needle placement can be more precise than transrectal ultrasound biopsies and it can be used to sample tissue from areas of the prostate which are not accessible using TRUS based methods.

Treatment-related Toxicity

This relates to complications following radical treatment. Genitourinary and gastrointestinal complications can be expected following radiotherapy and surgery.

Wales Cancer Network (WCN)

A new 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 collate cancer-specific information in Wales.

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

A new 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 collate cancer-specific information in Wales.

Appendix 1 – Outlier Communications

Introduction to the NPCA Outlier Process 2018

In this 2018 report the NPCA “potential outlier” process reporting treatment-specific complications using both hospital routine data and patient-reported outcome measures has been introduced for the first time in England and Wales. The information used herein has been derived from data sources which are completely independent of the medical teams involved in diagnosis and treatment and by this means, we believe that the information shown is as free as it can be from any potential clinical prejudice or bias.

The report details key indicators which are validated measures of outcome both for radical prostate surgery and radiotherapy. “Potential outliers” are highlighted if their cumulative results differ significantly from those of most of the teams carrying out treatment of a similar type. This information is then fed back to the clinicians in units highlighted, affording the opportunity for those individual groups to look at their data as reported, establish its veracity and respond in writing, setting out potential causes for their negative outlier status and where necessary, putting in place mechanisms to correct problems where they exist.

It is important to recognise that this is not a “name and shame” exercise. Rather, it encourages treating clinicians to look carefully at their practice when their data suggests that their results lie outside the norm. The responses shown confirm that this endeavour has been successful, as evidenced by the careful scrutiny of practice initiated by most groups following notification. In the majority, there was a rational explanation for “potential outlier” status and where there was an identifiable problem, modifications to process and/or treatment have been made. We believe that this method is both fair and open, addressing problems where they exist and explaining unusual results when they do not. The NPCA team are grateful to the clinicians identified for their willingness to comply so readily and promptly and for making this process a success.

Professor Noel Clarke

NPCA Urological Clinical Lead representing the British Association of Urological Surgeons

Professor Heather Payne

NPCA Oncological Clinical Lead representing the British Uro-oncology Group

Surgical centres

Performance indicator 5: Proportion of patients experiencing at least one severe genitourinary (GU) complication within 2 years of radical prostatectomy.

Gloucestershire Hospitals NHS Foundation Trust
Oxford University Hospitals NHS Foundation Trust
University Hospitals Coventry and Warwickshire NHS Trust

Performance indicator 11: Mean urinary incontinence score after radical prostatectomy.

East and North Hertfordshire NHS Trust
Lancashire Teaching Hospitals NHS Foundation
Sheffield Teaching Hospitals NHS Foundation Trust
Stockport NHS Foundation Trust

Performance indicator 12: Mean sexual function score after radical prostatectomy.

Gloucestershire Hospitals NHS Foundation Trust
Heart of England NHS Foundation Trust
Worcestershire Acute Hospitals NHS Trust

Radiotherapy centres

Performance indicator 6: Proportion of patients experiencing at least one severe gastrointestinal (GI) complication within 2 years of radical external beam radiotherapy.

Norfolk and Norwich University Hospitals NHS Foundation Trust
The Christie NHS Foundation Trust

Performance indicator 13: Mean bowel function score after radical external beam radiotherapy.

Norfolk and Norwich University Hospitals NHS Foundation Trust

Performance indicator 14: Mean sexual function score after radical external beam radiotherapy.

Hull and East Yorkshire Hospitals NHS Trust

Response from Gloucestershire Hospitals NHS Foundation Trust

Performance indicator 5: Proportion of patients experiencing at least one severe genitourinary (GU) complication within 2 years of radical prostatectomy.

Performance indicator 12: Mean sexual function score after radical prostatectomy

25.01.19

1. 'the mean sexual function EPIC-26 domain score'

We acknowledge that our patient cohort, from the time period audited, have not recovered the level of sexual function we would like to see.

Our main deficiency has been in pre and post-operative penile rehabilitation. This has been the result of the lack of availability of erectile dysfunction clinics and thus lack of capacity to see the patients pre-operatively and then offer the level of support they need post-operatively to enhance the recovery of sexual function.

Since the audit results we have addressed this short fall, we are in the process of setting up additional clinics and have appointed a new consultant urologist who is leading the re-configuration of the service.

We are looking at pre-operative assessment of sexual function in patients undergoing RALP and initiating treatment pre-operatively where appropriate. Post-operative rehabilitation is also being reviewed.

We are confident we will see an improvement in sexual function moving forward and will be auditing pre and post-operative sexual function closely.

2. 'the percentage of men who experienced at least one genitourinary complication within 2 years'

During the time period audited we experienced an increased rate of development of urethral stricture post-operatively. This increase resulted in the complication rate highlighted.

The strictures occurred across all 4 surgeons performing the operation. We reviewed the entire process of surgery to try and identify any causative factors. Discussion with other departments highlighted similar problems in the units.

Following our review we have changed the skin prep used at surgery, we have also shortened the time a catheter may be put on gentle traction during surgery.

Since the changes the stricture rate has diminished to acceptable levels and thus our post-operative complication rate has fallen.

Response from Oxford University Hospitals NHS Foundation Trust

Performance indicator 5: Proportion of patients experiencing at least one severe genitourinary (GU) complication within 2 years of radical prostatectomy.

25.01.19

Thank you for bringing these 26 men from 2015 to our attention. We have inspected the outcome data on these men and found that, for 22 of these men, the GU complication in question was a urethral stricture. All of these urethral strictures were bulbar rather than anastomotic indicating issues related to positioning or the catheter or both rather than technical skill at the anastomosis. Since this time we have, as a unit, changed our catheters and modified the amount of traction used during the apical stages of the procedure and had a marked reduction in our stricture rate.

Please note that, from our audit of data from 2016, the stricture rate had fallen to 2%, and at most recent audit of 2017 data last month, we noted that this low stricture rate has fallen further to 1.6%.

We hope that this is a satisfactory explanation for the unexpectedly high GU complication rate in 2015 and our successful efforts to address the issue.

Response from University Hospitals Coventry and Warwickshire NHS Trust

Performance indicator 5: Proportion of patients experiencing at least one severe genitourinary (GU) complication within 2 years of radical prostatectomy.

02.11.18

The higher than expected incidence of severe urinary complications after radical prostatectomy was identified by our internal quality assurance program in 2015. As soon as this was identified we modified our surgical technique. Performing the same analysis on the 2016 cohort of patients showed 4.6% patients affected. When comparing this to the data in Sujenthiran et al 2017 our current data would make us one of the best performing institutions in the UK.

Response from East and North Hertfordshire NHS Trust

Performance indicator 11: Mean urinary incontinence score after radical prostatectomy

07.11.18

Firstly, I would like to thank the NPCA team for all the help over the last four weeks both by phone and email. We have been impressed with the level of commitment to help us make sense of the NPCA data.

We have analysed both the NPCA data, specifically the 120 EPIC-26 forms submitted to your dataset and compared them to the total 355 robotic prostatectomies that have been done at the Lister in the same surgical time frame.

We have three comments which we would be grateful if you could consider with regards to our unit being a potential outlier

1: Adjustments

The adjustment for SE group disadvantages us at the Lister a little as does the 27% locally advanced disease.

We feel our more favourable SE group doesn't impact on continence results in our dataset and we also feel that we have much more T3 disease in our 355 cases than our trust uploaded NPCA data.

We are actually much closer to the 41% mean and may have been adjusted to a degree that pushes us in the wrong direction as a result of this

2: Secondly, we have carefully analysed our 355 patients and compared them to the 120 entered in the NPCA.

The pad free and security pad rates in our 355 patients do appear to be better than those 120 patients that were looked at in the NPCA and this data is potentially not a true representation of our unit.

3: Thirdly, and most importantly we have been a Royal College of Surgeons of England Accredited Robotic Training Centre for 7 years and produced 6 consultants all performing robotics now. We are well known for this hands-on robotic training scheme which is important in producing tomorrows surgeons. The data from the NPCA and our own data set highlights an opportunity to adjust this modular training program to improve results for the future.

Response from Lancashire Teaching Hospitals NHS Foundation

Performance indicator 11: Mean urinary incontinence score after radical prostatectomy

08.11.18

We have now reviewed the case records of patients undergoing radical prostatectomy diagnosed between 1 April 2015 and 30 September 2016. We have identified 116 patients . 3 surgeons performed laparoscopic radical prostatectomies during this time period.

58 out of these 116 patients responded to the NCPA patient survey.

We have carefully reviewed the case records of these 58 patients.

46 out of these 58 patients have reported full continence or use a small pad for protection (occasional leak).

Therefore our records are at variance with the NCPA patient survey findings. We believe our records unambiguously confirm that our outcomes are satisfactory.

We have transitioned to robotic surgery and since May 2017 all prostatectomies are being performed robotically with a robust mentorship programme that includes operative videos review.

We are prospectively auditing our outcomes. We will constantly strive to achieve outcomes comparable to centres of excellence.

Response from Sheffield Teaching Hospitals NHS Foundation Trust

Performance indicator 11: Mean urinary incontinence score after radical prostatectomy

27.11.18

We thank the NPCA team for undertaking this work and appreciate the value of this audit. We note that a separate, larger and more detailed audit (Life and Prostate Cancer) examining men over a longer time period (18-42 months after diagnosis) found better data for STH. For example, overall health was scored 76.5/100 for Sheffield and 76.9 for England, and 94.4% of men in Sheffield 'agreed'/'strongly agreed' that their treatment had been the right decision for themselves (92.8% in England for comparison). With regards to incontinence, 70.3% of Sheffield patients leaked urine either 'never' or 'once per week' (versus 71.3% for England). These data are encouraging as completion rates were high in this audit (419/648 men invited replied (64.7%)). In addition, many of our patients are recruited into multicentre clinical trials (for example, we were high volume recruiters for ProtecT, PART, TOOKAD and VANCEo1 randomised trials) that include Radical Prostatectomy and longitudinal surveys of recovery after treatment [e.g. *Patient-Reported Outcomes after Monitoring, Surgery, or Radiotherapy for Prostate Cancer. N Engl J Med. 2016 375: 1425-37*]. Sheffield men were not outliers in these studies.

Regardless, we are disappointed by the NPCA findings and hope that these do not reflect current or overall outcomes in Sheffield. Firstly, our robotic surgery programme was in development during recruitment for this study (NPCA men were diagnosed from April 2015-September 2016 and STH robotic surgery started late 2013). As such, outcomes were maturing during this audit period. Secondly, these findings are from half our population (52%: 179 of 346 men undergoing surgery) and may reflect those most unhappy with recovery. Finally, our region has poor survival from prostate cancer (reflecting many factors including low rates of PSA testing, late presentation and higher than average social deprivation). This affects our radical treatment patterns. For example, our rates of surgery in men aged 70-80 were higher than national average (21% vs. 13% in NPCA: of note, older men have more incontinence than younger men [e.g. *J Urol 1997; 158(5): 1733-7*]) and we treat many locally advanced cancers (Radical treatment rate for T₃ disease in NPCA 2017 audit was 72%; these men may have no or only partial nerve sparing (degree of nerve sparing strongly associated with continence).

Going forward we will endeavour to measure outcomes using prospective in house monitoring of performance (using the same Tool as used in this audit) to understand if (and why) these findings are still present. We will also encourage all our patients to return NPCA questionnaires, so that findings represent our entire population.

Response from Stockport NHS Foundation Trust

Performance indicator 11: Mean urinary incontinence score after radical prostatectomy

28.11.18

We welcome the feedback we have received from the NPCA in terms of our continence rates at 18 months after surgery. We have looked at these results and compared them to the data we have on our system. We do as a trust recognise the need to constantly improve our patient outcomes.

This data represents the start of our robotic programme and although we had a recognised mentoring system in place there was clearly a variation in the patient experience in terms of this particular outcome measure. Part of our IOG compliant network at this time contained an in-reach element which we felt made it more difficult to run a unified service and to keep a close eye on outcomes. This has been changed to an outreach service in the past 18 months which we feel will improve audit / feedback and therefore our outcomes.

We would like to thank you for providing the first epic data which will be an invaluable baseline for our planned prospective audit using this tool which we will be planning to share annually both as part of the NPCA but also on our hospital website to help with patient counselling.

Response from Heart of England NHS Foundation Trust

Performance indicator 12: Mean sexual function score after radical prostatectomy

14.12.2018

Re: Potential 'outlier' status for sexual function domain of EPIC-26 patient-related outcome measure

Many thanks for your letter alerting us to our potential status as an 'outlier' for sexual function EPIC-26 domain score as assessed >18 months following prostate cancer diagnosis of patients at (formerly) Heart of England NHS Foundation Trust for the period April 2015 - September 2016. We were undoubtedly disappointed to learn of this result given the dedication and hard work of our clinical team.

We are sorry to learn that you have sent several communications in writing on 4th October, 19th October, and 27th November 2018 but did not receive any response. I would like to notify you that [the previous Clinical Lead] has retired from the Trust on 30th September 2018 and this may explain the lack of response. This has been brought to my attention as Clinical Service Lead for the first time on 3rd December 2018 as a result of notification sent to the Trust Chief Executive Officer.

We have reviewed the aggregate information included in the notification letter. As per your advice, we have also requested the patient-level data from NCRAS for those Trust patients who contributed to the NPCA survey for the period in question (n = 125 patients). Once we had received the data on 5th December 2018, we embarked on reviewing the clinical records for some of these patients (80 patients) to investigate possible reasons, limitations, or inaccuracies that could explain the findings in question. Given the limited timeframe available and to ensure that we meet the response deadline of 14th December 2018, we were unable to review all the records. We have summarised our conclusions in the following points.

Review of aggregate data

We understand the sexual function scores were adjusted for age, comorbidities, cancer risk status, and socioeconomic deprivation. The aggregate data indicate that, whilst most patient characteristics included are similar to the national data, we have treated a higher proportion of patients of age 70-80 years (27% vs 13%) and from a lower socioeconomic status (class 5 was 26% vs national of 11%).

Our EPIC-26 score for sexual function domain was 15.3 vs a national average of 22.7. The literature classifies EPIC-26 sexual function scores of <40 as poor function (Vertosick et al, J Urol 2017). Therefore, whilst statistically we would be categorised as an 'outlier', it is unclear whether the numerical values mentioned are of any meaningful clinical significance.

The Charlson score indicates similar comorbidity profile to the national data, however, to our knowledge, the Charlson Comorbidity index has not been validated or correlated with sexual function scores. The Massachusetts Male Aging study indicated that erectile function is worse in patients at age 70 years. Since we are treating an older cohort of patients, it is likely that some of the results could be explained by this difference.

Review of patient-level data

On reviewing patient records, we found that data pertaining to measurement of pre- and postoperative sexual function (eg the use of standardised patient-completed questionnaires) is limited and of poor quality in general. As a result, we were unable to assess whether the treatment these patients had received for prostate cancer (i.e. radical prostatectomy) may have contributed to the low scores of the EPIC-26 sexual function domain.

All our patients underwent open radical prostatectomy. This is in contrast to the national context which indicates that robotic surgery was used for almost 75% of patients according to NPCA 2017 report. Whilst the literature is controversial with regards to impact of robotic surgery on functional outcomes, there is supporting evidence that clearly indicates that sexual function is better if robotic technology is used.

Our 'nerve-sparing' prostatectomy rates are generally low (approximately 25%) compared to the national average (overall 53% according to NPCA 2017 report). This may also explain the difference in sexual function scores compared to the national average.

One patient had radical prostatectomy over 18 months following diagnosis as he was initially on 'active surveillance' for prostate cancer. It is unclear from the aggregate data and the methodology of the PROM survey whether the latter may have taken place before or after this patient received treatment.

Four patients had adjuvant treatment within 12 months of radical prostatectomy including radiotherapy +/- ADT. The latter may have impacted on their sexual function scores.

One patient developed Peyronie's disease following radical prostatectomy and eventually underwent insertion of penile prosthesis. This may have impacted on their sexual function scores.

Action plan

Despite our disappointment with the results and the limitations above, we have found this exercise very helpful to benchmark our results against the national outcomes. As a result, we had extensive internal discussions about how we could improve these in the future. We have identified the following objectives for our unit:

- Improve documentation of pre- and postoperative functional measures using standardised validated patient-completed questionnaires (eg SHIM, ICIQ, or EPIC-26). This would allow us to assess the impact of treatment of prostate cancer on our patient population.
- Improve our 'nerve sparing' surgical rates by adopting robotic surgery and 'joint consultant' operating.
- Continue to contribute to national audits such as NPCA and BAUS and regularly monitor our clinical outcomes. We are already undertaking these in our unit.

Response from Worcestershire Acute Hospitals NHS Trust

Performance indicator 12: Mean sexual function score after radical prostatectomy

05.12.18

Following various communications with the NPCA project team to fully understand the methodology used by the NPCA particularly in relation of using the “EPIC” instrument for PROMS for the 1st time and the fact that the statistical analysis of one of the domains (mean sexual function domain 18 months following surgery) has shown that Worcestershire results show a statistically significant difference (albeit clinically non meaningful difference) from the national mean.

I consulted with my colleagues, and studied the cohort of patients and we came up with the following conclusions and action points.

There is no base line assessment of the patients prior to the intervention, which makes it impossible to know how much this had an impact on their perception of erectile function 18 months following surgery.

There is a huge difference between Worcestershire patients and the national aggregate, with 32% of our patients aged between 70 and 80 compared to only 13% nationally. This also means that they are likely to have more comorbidities and a lower base line score.

Despite the attempts of NPCA to correct for the comorbidities (using the Charlson score as calculated from the HES data base) this is highly likely to under-estimate the comorbidities (as evidenced in our cohort of patients) and consequently disproportionately dis-advantage services like ours dealing with an older more co-morbid population.

We operate on a large number of locally advanced disease, with aggressive extended lymphadenectomy techniques (as evidenced by the lymph node yield), sometimes with elective sacrifice of the neurovascular bundles, for oncological expedience and these facts have not been accounted for during the analysis.

Our request to have access to the patient level responses to be able to conduct these analyses ourselves to inform our service development was turned down on information governance basis?

We will be looking forwards to continue co-operating with the NPCA to improve data capture in the future and to ensure that “clinically meaningful variations” can be identified and acted upon to continually improve services.

Response from Norfolk and Norwich University Hospitals NHS Foundation Trust

Performance indicator 6: Proportion of patients experiencing at least one severe gastrointestinal (GI) complication within 2 years of radical external beam radiotherapy.

Performance indicator 13: Mean bowel function score after radical external beam radiotherapy.

04.12.18

Thank you very much for informing us that NNUH is a potential outlier for rectal toxicity for prostate cancer. We have looked at all of the patient level data and the radiotherapy plans that patients received in the period 2015-2016. We agree that we treated 309 patients and have checked all of the diagnosis codes from subsequent colonoscopy for radiation toxicity. We were unable to check the data for patients who subsequently underwent colonoscopy at the James Paget Hospital (JPH) or the Queen Elizabeth Hospital (QEH) following radiotherapy treatment at NNUH. We agreed that the NNUH patients who were given a diagnosis of radiation proctitis did indeed have this complication and that these patients were either referred for GI investigation either via the 2 week wait pathway or due to rectal symptoms via their attending oncologist. Only a very small minority of patients had presented incidentally via the screening programme. We have no reason to think the colonoscopy diagnosis codes for QEH or JPH will be any different. We have come to the conclusion that our rate of 23 % for radiation proctitis is real, and that we are an outlier for this complication. This conclusion is based on the assumption that endoscopy units nationwide apply WHO ICD-10 coding to all of their procedures such that there are no "unreported" instances of radiation proctitis.

We have looked very carefully at all of the patients that we have treated in this period to try and find reasons for our radiation proctitis rate.

Most of the patients we treated in that period either had high or very high risk prostate cancer. Standard treatment at NNUH at that time involved rapid arc radiotherapy. Those patients that received radiotherapy to the prostate and seminal vesicle received 66Gy/37 fractions to the prostate and seminal vesicles and 74Gy/37 fractions to the prostate alone. The treatment was given concomitantly. Our standard PTV margins at that time were 1cm on the prostate and seminal vesicles and 1cm/0.5cm on the prostate alone. CHHIP dose constraints were used to assess urinary, rectal and bowel DVHs.

Our very high risk patients received nodal irradiation in addition with 55 Gy 37 fractions to the pelvic nodes, 66 Gy to prostate and seminal vesicles and 74gy to the prostate alone. The treatment was delivered concomitantly. Volumes were based on the original Pivotal trial. Our CTV to PTV nodal expansion was 0.5cm. Prostate and seminal vesicle expansions were as above. We used the Pivotal dose constraints to assess bowel, bladder and rectal DVH's. Many of our patients had rectal preparation prior to treatment. At this time all patients had daily cone beams to assess prostate position with bony matching and movement if the CTV was not covered adequately. Only 10 patients failed the rectal DVH constraints and then only at one level.

We have not found any significant difference in radiation proctitis rate between those that received pelvic radiotherapy (14 of 77 patients, 18%) radiation proctitis rate) to those treated with radiotherapy to the prostate alone (55 of 231 patients 23%).

We have compared our practice to other hospitals in our region and do not believe that the margins we used at that time were out of keeping with these centres. We note that there is great heterogeneity between prostate cancer treatment protocols in different centres.

We have changed our margins following analysis of our set up errors and our standard margins are now 0.6/0.5cm on the prostate and 1cm on the seminal vesicles. We now match the treatment field directly to the prostate and seminal vesicles.

In summary although we accept that we do have an increased rate of radiation proctitis we have not yet clearly established the cause of this. We note 71 % of our patients had locally advanced disease. It appears that the CHHIP trial dose constraints were falsely reassuring for this group of patients.

Going forward we have already reduced our margins for the PTV's and our matching process has changed. We have moved to 60 Gy in 20 fractions for the majority of our patients and are reviewing our dose levels with a view to reducing the prostate and seminal vesicle dose. We have established an HDR brachytherapy service for our high risk/locally advanced patients with the first patient treated on the 29th November 2018. We will also prospectively audit our prostate radiotherapy patients going forward.

Response from The Christie NHS Foundation Trust

Performance indicator 6: Proportion of patients experiencing at least one severe gastrointestinal (GI) complication within 2 years of radical external beam radiotherapy.

10.12.18

We thank you for your letter of 30 November informing us that that the Christie is a potential outlier in data recorded within the NCPA in respect of gastrointestinal toxicity in patients who had received radical radiotherapy for prostate cancer.

We are grateful for this notification and have taken this signal seriously. As you are aware we have a strong interest in toxicity associated with radiation therapy and have published extensively on the assessment of this and indeed have presented and published toxicity following modifications in our radiation techniques and fractionation which have led to the current protocol within which this patient group were treated(Appendix 1). Our own analysis of this patient recorded data has not flagged any concern that our toxicity was out with the range recorded within National and International trials. For completeness we have requested that the toxicity data of patients treated within the CHHiP trial at our centre be compared with patient groups receiving radiotherapy in other centres. This request has been made to Professor David Deamaley and Emma Hall . We have been assured that this will be made available to us by 18 December 2018 and will be shared with the NCPA.

We have had an opportunity to review the patient group that has been identified by the OPCS 4 and ICD-10 codes.

We can verify that the OPCS codes correctly indicate that this patient group did have per rectal endoscopic procedures. This has led to the correct labelling K627; Radiation proctitis in the majority of patients although review of our individual notes indicates that a significant minority were identified with non-radiotherapy related problems.

All patients had documented follow up; the vast majority within Oncology clinics. The main reason for referral for endoscopy was rectal bleeding, and it appears that we have a low threshold for referring patients for investigations.

We have conducted an initial analysis of this data; the time frame has not allowed greater investigation and in particular we have not had the opportunity to review the patients to allow patient reported data to be analysed. We intend to analyse this patient set more thoroughly and believe this will be helpful to us but also to interrogate the validity of the metrics that you have recorded.

From this analysis we have found that the patients fall into the following categories

Patients correctly identified with self-limiting radiation proctitis	50%
Patients diagnosed with non-radiation related pathology	14%
Patients correctly identified with ongoing radiation proctitis (GI/G2)	36%

As indicated we will in time be able to provide a more robust analysis of this data and in addition provide patient recorded data.

We will also have information from the CHHiP trial which will shed further light on our toxicity outcomes.

We thank you for sharing this with us and providing the opportunity to comment on this. We believe that the tools used in identifying patients within this audit have been proven to be robust.

We do however have concerns that the use of endoscopy as a measure of toxicity in a group of patients where NICE guidelines encourage the use of this investigation is a poor measure of toxicity which is relevant to the patient . Although this does clearly identify patients with significant toxicity the overall figure recorded is more indicative of the threshold of referral of patients to exclude other malignancy as a cause of rectal bleeding.

We understand that you are looking to introduce patient reported data and are supportive of this to finesse the important data currently captured in NCPA

Patient-reported outcomes and health-related quality of life in prostate cancer treated with a single fraction of high dose rate brachytherapy combined with hypofractionated external beam radiotherapy. Choudhury A; Arthur C; Malik J; Mandall P; Taylor C et at. Clinical oncology (Royal College of Radiologists (Great Britain)); Oct 2014; vol. 26 (no. 10); p. 661-667

Dose-escalated hypofractionated intensity-modulated radiotherapy in high-risk carcinoma of the prostate: outcome and late toxicity. Thomson D; Merrick S; Swindell R; Coote I; Kelly. K; Stratford J; Wylie J; Cowan R; Elliott T; Logue J; Choudhury A; Livsey J .Prostate cancer; 2012; vol. 2012 ; p. 450246

Efficacy of data capture for patient-reported toxicity following radiotherapy for prostate or cervical cancer. Farnell DJ; Routledge J; Hannon R; Logue JP; Cowan RA et al. Famell DJ; Routledge J; Hannon R; Logue JP; Cowan RA; Wylie JP; Barraclough LH; Livsey JE; Swindell R; Davidson SE. European journal of cancer (Oxford, England : 1990); Feb 2010; vol. 46 (no. 3); p. 534-540

Response from Hull and East Yorkshire Hospitals NHS Trust

Performance indicator 6: Proportion of patients experiencing at least one severe gastrointestinal (GI) complication within 2 years of radical external beam radiotherapy.

15.01.2019

Many thanks for informing that the sexual function domain score of the patients treated in Hull with external beam radiotherapy, based on the EPIC -26 questionnaire, lies outside the expected limit around the national mean score.

As per the NPCA EPIC-26, the mean sexual score of 225 patients who received external beam radiotherapy for the prostate cancer between 1st April 2015 – 30th September 2016 in our trust was 12.7.

Whereas, the mean national score of this domain was 17.2 (with a funnel limit 13.1).

I have discussed with our clinical cancer lead and cancer lead manager.

There is currently ED clinic run by a specialist urology nurse. Probably, patients having radiotherapy are not well informed thus not utilizing this service optimally.

I have decided following action plan:

1) Improving awareness of availability of existing service:

We are having a local meeting on 23rd of January where we would be discussing and sharing our own 6-month PROMs prospective study results (including EPIC score) with nursing, oncology and radiographer team. I would discuss the data provided by NPCA and measures to improve it including to promote increase referral to available ED clinics and to encourage discussion around the sexual functions during consultation (perhaps, we, in radiotherapy, are focused-on bowel functions only).

2) Engaging with living with and beyond survivorship team to include patients with prostate cancer in their service to assess the patients about the sexual function's rehabilitation.

3) Involving ED services at district general hospitals and in the community.

4) Analysing the patient level data to identify any other factors not taken into account – such as changes from the baseline sexual functional score and duration and types of hormones (antiandrogen vs LHRH agonist)

Incidentally, I am doing a prospective study to assess the patients reported outcomes in the patients receiving radiotherapy (IRAS Project-216169) employing same tools those used in the CHHiP trial including EPIC to generate 'real-word' data in patients receiving hypofractionation (60/20).

We started it last year. About 150 patients have been entered so far (Target 250). Forty-nine patients have completed more than 6 months follow up.

Our radiographer has pulled out this data.

Hull PROMs in Prostate cancer having radiotherapy: EPIC- results for the first 49 patients that have a 6 month Follow up completed.

	Baseline Mean score	6 Month Mean Score
Overall Sexual Score	17.16	27.8
Sexual Function Score	7.54	4.48
Sexual Bother Score	39.81	78.86

In this cohort of 49 patients, even baseline sexual function score is very low -7.54- which has, as expected, deteriorated further at 6 months (mostly would be on hormones) to 4.48.

Strangely, the patients are not bothered at this stage thus overall sexual score improved. We would keep analysing the data.

It would be interesting to know how these scores would change at 18 months follow-up.