

First Year Annual Report – Organisation of Services and Analysis of Existing Clinical Data



National Prostate Cancer Audit

First Year Annual Report – Organisation of Services and Analysis of Existing Clinical Data.

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The NCRS is the data collection partner for the NPCA.

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Foreword

Completion of the 1st Annual Report of the National Prostate Cancer Audit (NPCA) for England and Wales is an important milestone for men diagnosed with prostate cancer and the professionals responsible for their care. It contains the key results of the organisational audit, which provide an invaluable insight into the availability of essential diagnostic, staging and therapeutic facilities, how prostate cancer services are organised and delivered, and the functioning of local and specialist MDTs. You will also find a description of how we developed the minimum dataset that is now being used for the prospective audit.

It has been a pleasure and privilege to work as the Clinical Leads for this project and the first year has been both exciting and productive. We are grateful to all contributors to this important and large-scale initiative. We know that great efforts have been made to make this project work. Special thanks to all who provided clinical, logistical and administrative support, without whom this audit would not be possible. We are pleased that we can benefit from the expertise of staff of the National Cancer Registration Service in England and Public Health Wales who will be supporting the data collection for the prospective audit.

We also extend our thanks to Professor David Neal for his vision in helping to develop this important multidisciplinary audit and guiding it through its crucial first year.

We have come a long way but there is still a lot to do. The prospective audit has now started in England which will enable us to determine the care that individual men with prostate cancer receive. We hope that the NPCA will help to improve our current standards of care and facilitate the development of better means for diagnosis, treatment and support of patients and their families. Keep sending in your data!



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



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Executive Summary

The first National Prostate Cancer Audit (NPCA) was commissioned by the Healthcare Quality Improvement Partnership (HQIP)* as part of the National Clinical Audit Programme with the aim of assessing the process of care and its outcomes in men diagnosed with prostate cancer in England and Wales.

The NPCA started on 1st April 2013 and will continue for a minimum of five years. The audit is based at the Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England and is managed in partnership with the British Association of Urological Surgeons (BAUS), the British Uro-Oncology Group (BUG) and the National Cancer Registration Service (NCRS).

The NPCA consists of the following components:

- 1. An organisational audit of service delivery and prostate cancer care in England and Wales
- 2. An analysis of existing datasets to provide comparative baseline data for the prospective audit
- 3. A prospective audit of all men newly diagnosed with prostate cancer in England and Wales
- 4. An audit of patient-reported outcome and experience measures for all patients with localised prostate cancer who are candidates for radical treatment
- 5. An evaluation of the feasibility of a PSA testing audit in primary care

The first annual report covers the work undertaken since April 2013. It includes a preliminary analysis of the NPCA's organisational audit, an analysis of existing data sets including patients with prostate cancer in England, and the design of the NPCA's prospective audit dataset.

Organisational audit

All NHS providers of prostate cancer services in England and Wales were surveyed to determine the availability of essential diagnostic, staging and therapeutic facilities, how prostate cancer services are organised and delivered, and the functioning of local and specialist multidisciplinary teams (MDTs). The report presents key findings at a national level.

All providers of prostate cancer services in England and Wales participated. In England, 143 NHS trusts in England provide prostate cancer services with 131 local and 48 specialist MDTs coordinating patient management. In Wales, 10 NHS hospitals provide prostate cancer services in Wales with six local and four specialist MDTs.

Diagnostic access

142 (99%) of trusts in England and all NHS hospitals providing prostate cancer services in Wales have access to onsite MRI imaging. 75% of NHS providers in England and 60% in Wales have access to multiparametric MRI, which has been recommended for men who have a negative transrectal biopsy to determine if a second biopsy if necessary and for men with a positive histological diagnosis to get further information about T and N staging.¹

92% of English trusts and 100% of relevant Welsh hospitals have isotope bone scanning facilities on site. All specialist MDTs have access to this staging modality in keeping with recommendations.¹

Radical treatment

Surgical treatment for prostate cancer is centralised in line with national guidelines with 61 NHS trusts in England and five NHS hospitals in Wales offering radical surgical treatments for prostate cancer. Of these, 43% in England and 20% in Wales offer robot-assisted laparoscopic prostatectomy. NICE recommend that this technique should be based at only those centres performing ≥150 procedures/year.¹

Radiation services are also centralised for prostate cancer with 54 English centres and three Welsh centres offering radical radiotherapy. 91% of centres in England and all centres in Wales can offer Intensity modulated radiotherapy (IMRT), increasingly considered to be the new standard.² High-dose rate brachytherapy in combination with external beam radiotherapy is recommended as a means of dose escalation for men with intermediate and high-risk localised or locally advanced prostate cancer,¹ but this is being provided only by 11 (20%) of the 54 radiation centres in England. At present, high-dose brachytherapy is not offered at centres in Wales.

Support Services

50% of NHS trusts in England and 60% of hospitals in Wales can provide the full array of personal support services including cancer advisory centres, sexual function and continence services, and psychological/counselling services.

Urological clinical nurse specialists (CNS) are available at most NHS trusts in England (97%) and NHS hospitals in Wales (90%) providing prostate cancer care in keeping with national recommendations.³ However, patients have access to oncological CNSs in less than half of the same NHS providers in England (46%) and Wales (40%).

15% of the local MDTs in England are attended by a member of the palliative care team. However, lack of

^{*} 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 produce 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. www.hqip.org.uk

attendance at meetings of the MDT does not reflect the potential involvement in the extended multidisciplinary team. 83% of local MDTs in Wales are attended by a member of the palliative care team. In addition, 24-hour access to specialist advice on palliative care is available in 78% of English NHS trusts and 80% of Welsh Hospitals providing prostate cancer care.

Clinical infrastructure: specialist clinics

54% of specialist MDTs in England and 50% in Wales offer specialist clinics that allow patients a joint consultation with a surgeon, oncologist and a CNS. Almost all specialist MDTs in England have consultant-led follow-up clinics after radical treatment (post-surgery, 96% and post-radiotherapy, 98%). The corresponding figures for Wales are lower (post-surgery, 75% and post-radiotherapy 50%).

Duration of follow-up after radical treatment according to specialist MDTs in England and Wales

Approximately 30% of prostate cancer patients with low-risk disease who receive radical treatment are currently expected by specialist MDTs in England to be followed up for longer than 5 years, despite the low risk of relapse. The number of specialist MDTs in Wales is too low to investigate the impact of disease risk on the follow-up duration.

Encouragingly, the results from the organisational audit indicate that, overall, NHS providers in England and Wales are following guidelines for the management of prostate cancer services.

Analysis of existing datasets including patients with prostate cancer in England

It was not possible to carry out the planned analysis of 2008-2010 Urological Cancer Registry data linked to the English Hospital Episode Statistics (HES) as the linkage could not be carried out by the Health and Social Care Information Centre in time for this report. Welsh data was unavailable whilst an appraisal was undertaken of data release regulations and procedures.

To minimise the impact on the audit's progress, alternative analyses were carried out using an earlier extract of Cancer Registry data linked to HES (patients diagnosed between April 2006 and March 2008) and a later extract of unlinked Cancer Registry data (patients diagnosed in 2012). The report presents an analysis of data completeness among the 28 English Cancer Networks that existed at the time these data were collected to determine data completeness and disease status and to introduce key performance indicators.

The completeness of recording cancer stage and tumour grade varied markedly across the Cancer Networks. At national level, cancer grade and tumour stage was available for only 53% of patients diagnosed between 2006 and 2008. However, there was a considerable improvement in the most recently available Cancer Registry data (corresponding percentage was 71% for patients diagnosed in in 2012). The analysis demonstrated that English Cancer Registry records can be linked to the HES database and used to provide a comparative baseline dataset for the prospective audit. Six key performance indicators were introduced, which will be used in the NPCA's prospective audit. These indicators reflect indicators of stage at diagnosis (proportion of men diagnosed with locally advanced and proportion with advanced disease), indicators of possible over- and under-treatment (proportion with low-risk localised cancer undergoing radical prostate cancer treatment and proportion with locally advanced disease undergoing radical prostate cancer treatment), and indicators of short-term outcome after radical surgery (proportion with an inhospital length of stay longer than 3 days or proportion readmitted as an emergency within 90 days of radical prostate cancer surgery).

NPCA Prospective Audit

The NPCA prospective audit has started to collect the following data on men who were diagnosed with prostate cancer from 1st April 2014:

- The characteristics of the prostate cancer, how it was detected, and the referral pathway.
- The crucial steps in the diagnostic and staging process.
- The planning of initial treatment.
- Initial treatments that were planned (e.g. active monitoring/surveillance, surgery, radiotherapy, hormonal therapy, and novel treatments including cryotherapy and HIFU).

The NPCA is the first national cancer audit to work with the NCRS as data collection partner in England. A guiding principle of the NPCA's prospective audit design was to keep the burden of data collection on staff and patients to a minimum. The mechanism for data collection and submission of prospective data for the NPCA in England mirrors that in place within each trust for the Cancer Outcomes and Services Dataset (COSD) with a continuous monthly flow of data to local NCRS offices.

The NPCA dataset is a true 'minimum dataset' consisting of three categories with only 50 data items in total (20 of which are new NPCA data items, one is part of the BAUS dataset and the rest are part of COSD). The first category concerns initial diagnosis, staging, and planned treatment. These items should be collected for **all men with newly diagnosed prostate cancer** at meeting(s) of the MDT during the initial phase of management.

The second focuses on surgery for prostate cancer and includes method of surgery and pathological outcome of surgery. These data items are only collected for patients who have **undergone radical prostatectomy**.

The third concerns planned radiotherapy. These items are only collected for men for whom **external beam radiation therapy or brachytherapy, is planned with or without hormone deprivation therapy**. Data items should be collected before actual treatment takes place.

The mechanism for data collection in Wales is currently in development and is anticipated to commence in 2015.

Recommendations

On the basis of this first Annual Report, we have the following recommendations for providers of prostate cancer services in England and Wales:

With respect to the delivery and organisation of prostate cancer services:

- NHS providers should ensure that multiparametric MRI is more widely available to decrease the likelihood of unnecessary re-biopsy and to improve staging and treatment decision making for patients with potentially curable disease where indicated.
- The availability of high-dose rate brachytherapy should be increased for men with intermediate and high-risk localised or locally advanced prostate cancer.
- The availability of personal support services including cancer advisory centres, sexual function and continence advice, and psychological counselling should be improved.
- Patients with prostate cancer should have access to a CNS with an appropriate background in uro-oncology.
- NHS providers should ensure that patients have access to a joint clinic with a surgeon, an oncologist and a CNS to discuss their treatment options.

With respect to data collection for the prospective audit:

• Senior clinicians and other members of the MDT should ensure that complete and accurate data can be submitted to the NPCA for every patient with newly diagnosed prostate cancer, including data on cancer stage and tumour grade.

1. The National Prostate Cancer Audit (NPCA)

1.1 Background

Prostate cancer is the most frequently diagnosed solid cancer in men and the third most common cause of cancer-related mortality in the United Kingdom (UK)⁴ with about 40,000 new cases each year resulting in 10,000 deaths. It is mainly a disease of older men and most prostate cancer-related deaths (70%) occur in men aged 75 years or older.⁵

Prostate cancer follows a variable course in different patients as a result of its highly heterogeneous nature. This ranges from slow-growing tumours that are unlikely to cause any symptoms or problems (clinically insignificant disease) to aggressive, fast-growing tumours that if left untreated may seriously impact on a man's quality of life and lead to death (clinically significant disease).

PSA testing, digital rectal examination (DRE) and transrectal ultrasound (TRUS) are the key diagnostic tools for prostate cancer, although a definitive diagnosis depends on histological verification following prostate biopsy (which is commonly TRUS-guided).⁶

An increasing number of men are living with a diagnosis of low-risk localised disease without evidence of spread beyond the prostate, which might not become clinically evident in their lifetime. A key concern is the potential for patients with low-risk disease to undergo unnecessary radical treatments. Men older than 70 years with low-risk prostate cancer, comorbidities and a relatively short life expectancy are at particular risk of overtreatment.⁵ Active surveillance, a treatment program for monitoring low-risk prostate tumours over time for progression, has been recommended in the National Institute for Health and Care Excellence (NICE) clinical guidelines on the management of patients with prostate cancer (Figure 1).¹ Men with high-risk localised or locally advanced disease are more likely to develop progression and to die of their disease. There is evidence that multimodal treatment with external beam radiotherapy (EBRT) and hormones or combined treatment with surgery, EBRT and hormone therapy achieves favourable outcomes. ⁷⁻⁹ However, this group of men may be placed on hormonal treatments alone denying them the radical treatment that gives them a chance of long-term cure. Healthy older men in particular are at risk of undertreatment.⁵

The variable nature of prostate cancer and the availability of multiple treatment options including active surveillance, surgery, radiotherapy in all its forms, with or without hormonal therapy provides a real challenge for clinical management and requires a multidisciplinary approach with a team of clinical specialists being responsible for the diagnosis, staging and optimisation of treatment. Shared decision making with a fully informed patient is of particular importance for providing the highest quality of prostate cancer care.

All patients with a new diagnosis of prostate cancer should be discussed at a multidisciplinary team (MDT) meeting in line with NICE guidance on improving the organisation and delivery of cancer services in urological cancers.³ This guidance sets out the minimum requirements on membership of an MDT, their roles, training and how the team should organise its work, and the standards by which MDTs are peerreviewed and accredited.^{3,10}



* High-risk localised prostate cancer is also included by NICE for the same therapy options as locally advanced prostate cancer.

1.2 Introduction to the NPCA

The National Prostate Cancer Audit (NPCA) has been commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme in response to the need for better information about the quality of prostate cancer services and care provided in England and Wales. The NPCA was established to determine whether the care received by patients with prostate cancer is consistent with recommended practice, including the recently updated NICE guideline covering the diagnostic procedures, treatments, care and support that men who have suspected or diagnosed prostate cancer should be offered,¹ and to identify areas where improvements can be made.

The audit started on the 1st April 2013 and will continue for a minimum of 5 years. The NPCA is based at the Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England and is managed as a partnership between a team of clinical, cancer information, and audit experts from the British Association of Urological Surgeons, the British Uro-Oncology Group, the National Cancer Registration Service and the RCS.

1.3 Aims and objectives of the audit

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 principal audit questions will examine:

- service delivery and organisation of care in England and Wales
- 2. characteristics of newly-diagnosed prostate cancer, how the cancer was detected and the referral pathway
- 3. diagnostic and staging process and planning of initial treatment
- 4. initial treatments received
- 5. patient experience and health outcomes 18 months after diagnosis
- 6. overall and disease-free survival
- 7. feasibility of a PSA testing audit in primary care

The NPCA consists of the following components:

- 1. An *organisational audit of service delivery and prostate cancer care* in England and Wales to determine the current infrastructure of prostate cancer services including the functioning of multidisciplinary teams (MDTs), the regional coordination of specialised services, and the availability of diagnostic, staging and therapeutic facilities.
- 2. An analysis of *existing datasets* to provide comparative baseline data for the prospective audit including information on trends in patient characteristics in men diagnosed with prostate cancer prior to the audit, the treatments they received and their outcomes in terms of complications, readmissions and mortality.
- 3. A *prospective audit of all men with newly diagnosed prostate cancer* in England and Wales to examine patients' demographic characteristics, routes to diagnosis, tumour characteristics, diagnostic and staging investigations, treatment choices and patient outcomes, in addition to adherence to national guidelines.
- 4. An *audit of patient-reported outcome and experience measures* for all patients with localised prostate cancer who are candidates for radical treatment 18 months after diagnosis. Patients will be asked questions on the information they received about their prostate cancer diagnosis and treatment options, the treatment options offered, how the decision for their initial treatment was made, further treatments, quality of life, side effects and sexual/urinary/bowel complications.
- 5. An additional element of the NPCA will evaluate the *feasibility of a PSA testing audit in primary care* and will provide information about the "use" of PSA in men who are suspected to have prostate cancer (in contrast to use of PSA to monitor response to treatment or cancer progression), the "yield" of PSA testing (proportion of test that result in a prostate cancer diagnosis, and the "timeliness" of the diagnostic process (time between initial test and the actual cancer diagnosis date).

1.4 NPCA activity timeframe

In year 1:

- carry out an organisational audit of prostate cancer care in England and Wales
- analyse existing data to provide comparative background data for NPCA
- develop a national data collection system for a prospective audit that can collect complete and accurate data in a timely fashion with minimum burden to staff
- design a short and simple minimum dataset for the prospective audit that will be incorporated into MDT information systems
- carry out a scoping exercise for the feasibility study of PSA testing in primary care

From year 2 onwards:

• prospective data will be collected from each newlydiagnosed patient discussed at an MDT meeting and will continue throughout the audit

From year 3 onwards:

- collect patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) from all patients with localised prostate cancer who are candidates for active monitoring or radical treatment 18 months after diagnosis
- carry out a feasibility study for an audit of PSA testing in primary care

1.5 Audit reporting

The NPCA will publish an annual report each year describing its findings, which will be available on the audit website www. npca.org.uk.

This **first annual report** covers the work undertaken since April 2013 and includes:

- 1. A preliminary analysis of the NPCA's organisational audit carried out in 2013 and 2014 in England and Wales
- 2. An analysis of existing data sets including patients with prostate cancer in England.
- 3. Design of the prospective audit minimum dataset.
- 4. An update on a feasibility study of PSA testing in primary care.

The second annual report will be published in **October 2015** and will describe the initial results of the prospective audit, which will be reported at national, Strategic Clinical Network and provider (NHStrusts in England) level.

The third annual report, in **October 2016**, will describe further results from the prospective audit in England (including data from Wales, which will be reported at National, Cancer Network and Health Board level) and an analysis of patient-reported outcome and experience measures, in addition to results from the PSA testing feasibility study. This type of annual report will be continued in later years.

1.6 What improvements are anticipated?

- Appropriate use of active surveillance for men with lowrisk prostate cancer based on patient choice
- Appropriate use of multimodality treatment for men with high-risk or locally advanced disease
- Improved safety and toxicity profile of prostate cancer therapy
- Reduced variation in prostate cancer diagnosis and therapy across NHStrusts and Health Boards

2. The organisation of prostate cancer services in England and Wales: results from the organisational audit

2.1 Introduction

An organisational audit was carried out of all NHS providers of prostate cancer services in England and Wales. The aim of this organisational audit was to collect information about the availability of essential diagnostic, staging and therapeutic facilities and how prostate cancer services are organised and delivered. Topics of special interest were the functioning of the local and specialist Multidisciplinary Teams (MDTs) and the regional coordination of specialised services.

The results of this organisational audit are important as they will strengthen the interpretation of the findings of the management of individual patients, based on information derived from existing data (cancer registry data linked to HES), and the prospective audit data collection that is the core of the NPCA.

In this chapter, we present selected key findings. The results of a more detailed analysis, especially analysing the regional coordination, will be reported in a separate paper.

2.2 Methods

Two questionnaires were developed for the organisational audit. The first questionnaire was directed at individual NHS providers in England and Wales, including local MDTs, with a focus on prostate cancer service provision. Specific questions related to availability of diagnostic and therapeutic facilities, availability of supportive services and palliative care, specialist nurse provision, and longer followup. The second questionnaire was directed at specialist MDTs. This questionnaire looked at regional service coordination of radical treatments (e.g. the link with local NHS providers) and the availability of specialist expertise for the treatment of patients eligible for radical treatment or those requiring complex treatments. The questionnaires are available on our website:

http://www.npca.org.uk/organisational-audit-nhs-trustsproviding-prostate-cancer-services-england-wales-nowprogress/

Both questionnaires were devised with reference to recommendations about the management of prostate cancer. ${}^{_{1-3,6,10}}$

It is recommended that the care of patients eligible for radical prostate cancer treatments should be coordinated by specialist MDTs and radical surgery for prostate and bladder cancer should concentrated in centres that carry out at least 50 surgical procedures year.³ Each member of a specialist MDT should have a specialist interest in urological cancer and attend the majority of meetings. The local MDT leads are represented at the specialist MDTs that they are linked to.

A list of all NHS providers of prostate cancer services in England and Wales was prepared from various sources and the prostate cancer lead for each provider was identified. The local and specialist MDT leads were contacted by email and the survey was delivered electronically in October 2013. Nonresponders were followed up by email and telephone until a 100%-response rate was achieved.

All providers of prostate cancer services in England and Wales participated in the organisational audit (Appendix 3). 145 responses were received for all 143 NHS trusts in England currently providing prostate cancer services. The extra two responses reflected more than one specialist prostate cancer unit being present at an individual trust. Two NHS trusts were identified to have specialist prostate cancer units present at different hospital sites. Each of these NHS trusts accessed two different local MDTs. The responses indicate that there are 131 local MDTs (some local MDTs serve more than one NHS provider) and 48 specialist MDTs.

Secondary care cancer services in Wales are provided by six Health Boards. Health Boards serve a distinct geographical area and include two or more individual hospitals. Within these six Health Boards, there are nine centres providing prostate cancer services. In addition, the Velindre NHS trust's Cancer Centre based in Cardiff provides non-surgical oncological services. As a result, the survey describes the care provided by the ten Welsh NHS providers. There are six local MDTs (one per Health Board) and four specialist MDTs (covering one or more Health Boards). Patients resident in a seventh Health Board (Powys Teaching Health Board) are managed by MDTs in the surrounding Health Boards or in England dependent on location. Given the unique configuration of prostate cancer services in Wales, we present the results of the Welsh survey information separately.

2.3 Key Findings

2.3.1 Diagnostic access: availability of MRI

NICE guidelines advise that multiparametric MRI should be considered for men with a negative transrectal ultrasound core biopsy to determine whether another biopsy is needed.¹ The guidelines also indicate that this staging modality should be considered for men with histologically proven prostate cancer if knowledge of the T or N stage could affect management.

142 out of the 143 trusts surveyed have onsite MRI imaging. 75% of the NHS trusts providing prostate cancer services in England provide multiparametric MRI (Table 1). Availability of 3-Tesla MRI and image registration is lower, but both modalities are not part of standard care according to currently available recommendations. 14% of trusts do not have any of these specific MRI modalities. In Wales, 60% of the NHS hospitals providing prostate cancer services have access to multiparametric MRI (Table 1). These MRI modalities are not available in 20% of the hospitals.

Table 1 – Provision of diagnostic and staging investigations in NHStrusts in England and NHS hospitals in Wales									
	MRI Modality								
	Multiparametric MRI	3-Tesla MRI	Image registration	Standard MRI					
England (n=142)	107 (75%)	44 (31%)	27 (19%)	20 (14%)					
Wales (n=10)	6 (60%)	4 (40%)	1 (10%)	2 (20%)					
	Isotope bone scan a	vailable							
England (n=143)	131 (92%)								
Wales (n=10)	10 (100%)								

2.3.2 Diagnostic access: availability of isotope bone scan

Isotope bone scans are an important staging modality, particularly in patients with PSA concentrations above 20mg/ ml.^{1,6} Bone scans should also be offered if hormonal therapy for prostate cancer is being deferred when watchful waiting is offered to asymptomatic men who are at high risk of developing bone complications.

The results of our survey demonstrate that 131 (92%) out of 143 NHS trusts in England have isotope bone scanning available onsite and it is available in all ten NHS hospitals in Wales (Table 1). 100% of Specialist MDTs have access to isotope bone scanning.

The survey also found that all 48 prostate cancer SMDTs (100%) in England and Wales had agreed policies detailing appropriate staging investigations for suspected prostate cancer patients.

2.3.3 Radical treatment: availability of surgical techniques

The provision of surgical treatment for prostate cancer has undergone a process of centralisation to ensure its quality and efficiency.^{1,3} Currently, 61 (43%) of 143 NHS trusts in England carry out radical prostatectomy for prostate cancer patients (Table 2). Of these 61 NHS trusts, 26 (43%) use robotassisted laparoscopic prostatectomy. Open radical retropubic prostatectomy is carried out in 37 (61%) and standard laparoscopic prostatectomy in 53 (46%) surgical centres.

In Wales, currently five centres perform radical prostatectomy (Table 2). One (20%) of these surgical centres uses robotassisted laparoscopic surgery, three (60%) use standard laparoscopic and all use open retropubic surgery.

	Radical Prostatectomy									
	Robot-assisted laparascopic	Standard Iaparascopic	Perineal	Open radical retropubic						
England (n=61)	26 (43%)	34 (56%)	2 (3%)	37 (61%)						
Wales (n=5)	1 (20%)	3 (60%)	0	5 (100%)						
	External Beam Radiotherapy									
	3D Conformal	IMRT*	Arcing IMRT	Stereotactic body irradiation						
England (n=54)	40 (74%)	49 (91%)	18 (33%)	4 (7%)						
Wales (n=3)	2 (67%)	2 (67%) 3 (100%) 3 (100%)								
	Brachytherapy									
	High-dose rate									
England (n=54)	11 (20%)									
Wales (n=3)	0									

2.3.4 Radical treatment: Availability of radiotherapy modalities

The provision of radiotherapy has also been centralised. The organisational audit found that of the 143 NHS trusts involved in delivering prostate cancer services, 55 (38%) carry out radiotherapy (Table 2), providing all specialist MDTs in England with access to external beam radiotherapy.

The organisational audit demonstrated that 91% of radiotherapy centres routinely use IMRT to treat prostate cancer patients. 3D conformal radiotherapy is still being used in 74% of trusts. However, it is important to note that the external beam radiotherapy modality is likely to vary depending on grade and stage of the tumour, the intent of treatment (e.g. as primary therapy or as adjuvant or salvage therapy following surgery), or whether it is used in combination with other radiation modalities such as brachytherapy. Another important finding is that five trusts (9%) in England still use 3D conformal radiotherapy alone for prostate cancer patients.

High-dose rate brachytherapy in combination with external beam radiotherapy as a means of dose escalation is recommended for men with intermediate and high-risk localised or locally advanced prostate cancer,¹ but this is being provided only by 11 (20%) of the 54 radiotherapy centres in England.

In Wales, three centres provide radical radiotherapy for prostate cancer patients (Table 2). All three centres provide IMRT or arcing IMRT but 3D conformal radiotherapy is also still being used in two (66%) centres. No centres in Wales currently provide high-dose brachytherapy.

2.3.5 Support services: availability of personal support

The provision of personal support to patients at all stages of the cancer management pathway is an essential part of patient-centred prostate cancer care.^{1-3,6,10} This ranges from providing support for making a decision on the initial treatment to helping patients and their partners with managing the impact of treatment and problems arising as a consequence of progressing prostate cancer, including urinary continence, rectal problems, skeletal / pain problems, and sexual functioning.

In England, support services, including a cancer advisory centre (e.g. Macmillan Centre), sexual function and continence services, and psychological and counselling services are being provided in at least 80% of the 143 NHS trust providing prostate cancer services in England (Table 3). 71 (50%) trusts indicated that they can provide all four of these services and 128 (90%) can provide at least three.

Nine (90%) of the ten NHS hospitals providing prostate cancer services in Wales can provide sexual function and continence services (Table 3) but only six (60%) have a cancer advisory centre or can provide psychological and counselling services.

Table 3 – Availability of personal support services in NHS trusts in England and NHS hospitals in Wales									
	Cancer Advisory Centre (e.g. Macmillan Centre	Sexual Function Services	Specialist Continence Services	Psychological / counselling services					
England (n=143)	114 (80%)	129 (90%)	129 (90%)	112 (78%)					
Wales (n=10)	6 (60%)	9 (90%)	9 (90%)	6 (60%)					
	Clinical Nurse Special	lists							
	Urology	Oncology							
England (n=140)	136 (97%)	65 (46%)							
Wales (n=10)	9 (90%)	4 (40%)							

2.3.6 Support services: specialist nurses

It is recommended that every new cancer patient should have access to a named clinical nurse specialist (CNS) who can provide information, support decision making, and deliver psychological and emotional support throughout the treatment pathway.³ These specialist nurses play a critical role in coordinating patient care and can act as the central contact point for patients, partners and carers on the one hand and the team of clinicians on the other.

Specialist nurses can have a background in urology, oncology or both. It is important to distinguish these backgrounds as they come with different expertise and experience.

Almost all (97%) NHS trusts in England (136 of the 140 trusts that responded to this question) have a – full or part-time – CNS with a urological background. The corresponding percentage for NHS trusts that have a CNS with an oncological background is 46% (65 of 140 trusts).

A similar pattern exists in Wales with nine (90%) of the ten hospitals providing prostate cancer services having urological CNS and only four (40%) oncological CNS capacity.

2.3.7 Support services: palliative care

It has been recommended that a member of the palliative care team is present at both the local and specialist MDT meetings³ or that they should be part of the "extended team".¹⁰ Also, systems should be in place to permit 24-hour access to specialist advice on palliative care.

Of the 131 local MDTs in England, only 19 (15%) are attended by a palliative care physician or CNS in palliative care (Table 4a). Only five (10%) of the 48 specialist MDTs had palliative care representation. 111 (78%) of the 143 NHS trusts had 24hour access to palliative care advice (Table 4b).

In Wales, five (83%) of the six local MDTs and all four (100%) of the specialist MDTs are attended by either a physician or CNS of the palliative care team (Table 4a). Of the ten hospitals providing prostate cancer services, 8 (80%) had 24-hour access to palliative care advice (Table 4b).

Table 4a – Attendance of palliative care specialist at local MDT meetings in England and Wales

	Local MDT
	Palliative care representation
England (n=131)	19 (15%)
Wales (n=6)	5 (83%)
	Specialist MDT
	Specialist MDT Palliative care representation
England (n=48)	Specialist MDT Palliative care representation 43 (90%)

Table 4b – 24-hour access to advice on palliative care in NHS trusts in England and NHS hospitals in Wales

	24-hour access to advice on palliative care
England (n=143)	111 (78%)
Wales (n=10)	8 (80%)

2.3.8 Clinical infrastructure: specialist clinics in England and Wales

Specialist clinics (defined as a clinic where patients are referred to discuss radical prostate cancer treatment options) are the cornerstone of "integrated care". In the initial phase of prostate cancer management, specialist MDTs should have an agreed policy enabling patients with early (organ-defined) prostate cancer to have access to a joint clinic with a surgeon, an oncologist and a CNS where therapeutic options can be discussed before a final treatment decision is made.¹⁰ In England, 26 (54%) of the 48 specialist MDTs offer these specialist clinics. In Wales, the corresponding figures are two (50%) out of four.

Almost all (96%) of the 48 specialist MDTs in England have consultant-led follow-up clinics to monitor the impact of radical surgical treatment (Table 5). However, alternative models to provide follow-up clinics are also being used. 37 (77%) of the 48 specialist MDTs report to have CNS-led clinics, 19 (40%) have telephone clinics, and 5 (10%) have community-based clinics. The numbers that were reported for the follow-up clinics after radical radiotherapy treatment are very similar: 47 (98%) specialist MDTs have consultant-led follow-up clinics, 32 (67%) CNS-led clinics, 16 (33%) telephone clinics, 2 (4%) community-based clinics, and in addition 3 (6%) radiographer-led clinics.

Table 5 – Follow-up modalities after radical treatment according to specialist MDT									
	After Radical Prostatectomy								
	Consultant-led clinic	CNS-led clinic	:	Telephone o	clinic	Commun specialist	ity-based follow-up		
England (n=48)	46 (96%)	37 (77%)	37 (77%)		19 (40%)				
Wales (n=4)	3 (75%)	2 (50%)		0		0			
	After Radical Rad	2 (50%) 0 0 ter Radical Radiotherapy							
	Consultant-led clinic	CNS-led clinic	Tele clini	phone c	Comm based follow	unity- specialist -up	Radiographer- led clinic		
England (n=48)	47 (98%)	32 (67%)	16 (33	3%)	2 (4%)		3 (6%)		
Wales (n=4)	4 (100%)	2 (50%)	0		0				

In Wales, three (75%) of the four specialist MDTs have consultant-led follow-up clinics and two (50%) have CNSled clinics after radical surgical treatment (Table 5). All four specialist MDTs have consultant-led clinics and two (50%) have CNS-led clinics after radical radiotherapy.

2.3.9 Duration of follow-up after radical treatment according to specialist MDTs in England and Wales

The survey asked the clinical leads of the specialist MDTs about the duration of clinical follow up for prostate cancer patients after radical surgery and radiotherapy. The duration was stratified according to D'Amico risk classification to account for its impact on prognosis.¹¹

There is an overall trend towards a longer follow-up duration for patients with higher risk disease who are at a greater risk of disease progression (Table 6). NICE guidelines¹ advocate follow-up outside hospital for at least two years for men with a stable PSA who have no significant treatment complications. The number of specialist MDTs in England that indicate that they expect the follow-up after a radical prostatectomy to be longer than 5 years increases from 16 (33%) for patients with low-risk localised disease to 29 (61%) for patients with higher risk disease.

A similar pattern was seen for patients who had radical radiotherapy. The number of specialist MDTs in Wales is too low to investigate the impact of disease risk on the follow-up duration.

 Table 6 - Duration of follow-up longer than 5 years after radical treatment according to prostate cancer risk*

 reported by specialist MDTs in England and Wales

	After Radical Prostatectomy Low-risk Intermediate risk High risk 16 (33%) 20 (42%) 29 (61%) 3 (75%) 3 (75%) 4 (100%) After Radical Radiotherapy Intermediate risk High risk Low-risk Intermediate risk High risk 14 (29%) 17 (35%) 26 (54%)							
	Low-risk	Intermediate risk	High risk					
England (n=48)	16 (33%)	20 (42%)	29 (61%)					
Wales (n=4)	3 (75%)	3 (75%)	4 (100%)					
	After Radical Radiotherapy	fter Radical Radiotherapy						
	Low-risk	Intermediate risk	High risk					
England (n=48)	14 (29%)	17 (35%)	26 (54%)					
Wales (n=4)	2 (50%)	3 (75%)	4 (100%)					
* D'Amico risk classification	on:	·	·					

Low-risk – PSA <10ng/ml, Gleason Grade ≤6, Clinical Stage T1-T2a Intermediate Risk – PSA 10-20ng/ml, Gleason Grade 7, Clinical Stage T2b

High-risk - PSA >20ng/ml, Gleason Grade 8-10, Clinical Stage ≥T2c

2.3 Summary

This chapter describes how prostate cancer services are organised in England and Wales and documents the current availability of diagnostic, staging and therapeutic facilities. We found that:

- 143 NHS trusts in England provide prostate cancer services with 131 local and 48 specialist MDTs coordinating patient management. 10 NHS hospitals provide prostate cancer services in Wales with six local and four specialist MDTs.
- 75% of English NHS trusts can provide multiparametric MRI onsite and this is available in 60% of the Welsh hospitals.
- 92% of the English NHS trusts and 100% of the Welsh hospitals have isotope bone scanning facilities on site.
- 61 English trusts and five Welsh hospitals offer radical surgical treatments for prostate cancer. 43% of these English trusts and 20% of these Welsh hospitals offer robot-assisted laparoscopic prostatectomy.
- 54 English centres and three Welsh centres offer radical radiotherapy. 49 (91%) of the English centres and all of the Welsh centres can provide IMRT or arcing IMRT. Only 11 (20%) of the English radiotherapy centres and none of the centres in Wales provide high-dose rate brachytherapy
- 50% of English trusts and 60% of Welsh hospitals can provide the full array of personal support services (cancer advisory centre, sexual function and continence services, and psychological and counselling services).
- 97% of English NHS trusts and 90% of Welsh hospitals have CNS staff with a urological background. 46% of English trust and 40% of Welsh hospitals have CNS capacity with an oncological background.
- 15% of local MDTs in England and 83% of local MDTs in Wales are attended by a palliative care physician or CNS. 78% of English NHS trusts and 80% of Welsh hospitals have 24-hour access to palliative services.
- 54% of specialist MDTs in England and 50% in Wales provide specialist clinics that allow patients a joint consultation with a surgeon, an oncologist and a CNS.
- 33% of specialist MDTs in England expects to follow up patients with low-risk localised disease longer than 5 years duration after a radical treatment.

In conclusion, NHS providers of prostate cancer services in England and Wales are following national and international recommendations about the management of prostate cancer services. However, the organisational audit demonstrates that for a number of providers the delivery of multiparametric MRI, robot-assisted prostatectomy, IMRT, personal support, palliative services and the availability of specialist MDT clinics can be further improved.

3. Analysis of existing data sets including patients with prostate cancer in England

3.1 Introduction

An analysis of the most recent Cancer Registry data linked at patient level to the administrative English Hospital Episode Statistics (HES) and Patient Episode Data for Wales (PEDW) was planned as a key component of the first year of the NPCA. This analysis would have provided a comparative background for the prospective audit as well as information on time trends in the patients' characteristics and cancer stage at diagnosis, treatments and outcomes. It was expected that it would also improve our understanding of the value of existing cancer registry and administrative data for the evaluation of prostate cancer services.

However, the original plan could not be completed as the required linkage of recent Cancer Registry data to HES could not be achieved in time. The Health and Social Care Information Centre (HSCIC) was expected to provide the HES data and to carry out the actual record linkage as a "trusted third party".¹² Triggered by concerns that data had been inappropriately released in the past by the NHS Information Centre, the HSCIC's predecessor organisation, it stopped processing requests for data release and record linkage in 2013. From January 2014, a formal review was carried out of all data and information released by the NHS Information Centre, which resulted in a moratorium on handling all requests for data.¹³⁻¹⁵

At the same time, an appraisal was taking place of the regulations and procedures for the release of existing health data in Wales, which also led to a stop of all data release procedures. As a consequence, the audit did not receive any Welsh data either.

To minimise the impact of these data issues on the audit's progress, we carried out analyses of alternative data sets:

- An analysis of less recent English Cancer Registry data linked to HES, including men diagnosed with prostate cancer between April 2006 and March 2008.
- An analysis of English Cancer Registry data of men diagnosed with prostate cancer in 2012 not linked to HES.

In this chapter, we present key findings of these alternative analyses. We describe the success of the linkage and data completeness as well as the patients' disease status and cancer treatments. Furthermore, we present preliminary findings for six performance indicators derived from the 2006-2008 Cancer Registry data linked to HES. Given the fact that prostate cancer services are regionally managed, we present these results for the 28 regional Cancer Networks that were in place until 2013 to coordinate prostate cancer services at the time these men were diagnosed. From July 2014, the HSCIC has restarted its data release activities after having implemented revised data release procedures and data sharing agreements. Also, we understand that the Welsh government has recently decided that the release of data for the evaluation of cancer services will be a future priority. Therefore, we expect that we can report the results of the originally planned analyses in the Audit's second annual report.

3.2 Methods

3.2.1 Data collection

We used data collected by the eight regional Cancer Registries of all men diagnosed with prostate cancer in England (CD-10 code "C61"). A dataset containing records of all men diagnosed between 2006 and 2008 was linked at patient level by the NHS Information Centre to corresponding HES records and to mortality records provided by the Office for National Statistics (ONS).

We also used more recent English Cancer Registry dataset of all men diagnosed with prostate cancer in 2012 that was not linked to HES or mortality records, provided to us by Public Health England's Office of Data Release.

3.2.2 Analysis of the linked 2006-2008 Cancer Registry HES data

The Cancer Registry data included 94,166 men diagnosed with prostate cancer between 1 April 2006 and 31 March 2008 (Figure 2). Linkage to at least one HES record was achieved for 89,214 patients (95%). A further 966 (1%) were excluded because they could not be placed within a regional Cancer Network. Sufficient information to determine disease status (staging and / or Gleason grade) was not available for 47,248 (53%) men. As a result, 40,995 patients (46%) could be included in the analysis.

3.2.3 Level of reporting

All data presented in this chapter are reported at national level and at the level of the regional Cancer Networks. While the Cancer Networks have been abolished due to the introduction of Strategic Clinical Networks in April 2013, we felt it was appropriate to report at Cancer Network given that our data relate to men diagnosed between 2006 and 2008. The HES data item that uniquely identifies the NHS provider nearest to the date of cancer diagnosis was used to determine the Cancer Network within which patients were managed.



3.2.4 Definition of disease status, disease risk stratification, and prostate cancer treatment received

Disease status

Cancer stage was identified using two Cancer Registry data items: "T_CLIN" (assigned by a clinician who examined the patient) and "T_PATH" (refers to pathological stage following radical prostatectomy). Where T_CLIN was missing, the Cancer Registry data item T_PATH was used. If the Cancer Registry data items "NODES" or "METASTASES" did not contain a "flag" or if these items were missing it was assumed that patients did not have nodal involvement or metastases.

All included men were assigned to a prostate cancer disease status category according to their cancer stage and Gleason score. Serum Prostate Specific Antigen (PSA) could not be used as a component in this classification as the Cancer Registries had not collected PSA data. Disease status category was allocated using the following steps:

- select all patients with a metastasis (irrespective of whether or not information is available on tumour stage, Gleason grade or nodes) and label these as "advanced disease"
- 2. select all remaining patients with positive nodes (irrespective of whether or not information is available on tumour stage and Gleason score) and label these as **"locally advanced disease"**
- 3. select all remaining patients with Gleason grade of 8 or above (irrespective of whether or not information on tumour stage is available) and label these as **"locally advanced disease"**
- 4. select all remaining patients with tumour stage T₃ or T₄ (irrespective of whether or not Gleason grade is available) and label these as **"locally advanced disease"**
- select all remaining patients with tumour stage T2 and (Gleason grade 6 or 7) and label these as "intermediaterisk localised disease"
- 6. select all remaining patients with tumour stage T1 and Gleason grade 7 and label these as **"intermediate-risk localised disease"**
- 7. select all remaining patients with tumour stage T1 and Gleason 6 grade or lower and label these as "low-risk localised disease"
- 8. consider all other patients as having insufficient information about disease status

Capturing cancer treatment received

A patient was considered to have undergone radical prostate cancer therapy if they were identified as having received radical prostatectomy radiotherapy, brachytherapy, highintensity focused ultrasound (HIFU) or cryotherapy. HES records were used to identify patients who had undergone either **radical prostatectomy**, **brachytherapy**, **HIFU** or **cryotherapy** using the following OPCS-4 procedure codes ("M61" for radical prostatectomy; "M7o6" + "X653" + "Y363 / M7o6 + "X653/ M712" +"X653" for brachytherapy; "M711" for HIFU; "M7o8" + "Y132" + "Y532" + "Z422"for cryotherapy). HES records also provided the procedure date. Patients were only considered to have undergone radical treatment as **primary prostate cancer treatment** if this procedure date was within 12 months of the diagnosis date.

Cancer Registry records were used to identify patients who had received **radiotherapy** using a "radiation therapy" data item. Cancer Registry records also provided the start date of the radiotherapy. Patients were only considered to have undergone radiotherapy as **primary prostate cancer treatment** if this start date was within 12 months of the diagnosis date.

3.2.5 Definition of performance indicators

We defined six performance indicators that can all be derived from Cancer Registry data linked to HES and ONS mortality relating to disease presentation, treatment allocation, and treatment outcomes.

Disease presentation

The first two performance indicators are the **proportion of men diagnosed with advanced disease and the proportion of men diagnosed with locally advanced disease**. These indicators were chosen as they provide information on prostate cancer stage at diagnosis.

Treatment allocation to evaluate over and undertreatment

The third indicator is the **proportion of men with low-risk localised prostate cancer undergoing radical prostate cancer therapy**. This indicator was chosen as it may provide information about the potential "overtreatment" of men with low-risk prostate cancer.

The fourth indicator was **proportion of men with locally advanced disease receiving radical prostate cancer therapy.** This indicator was chosen as it may provide information about potential "undertreatment".

Outcomes of treatment

The fifth indicator was **length of hospital stay for radical prostate cancer surgery**. Length of stay was derived from HES as the difference between the dates of admission and discharge. This indicator is being used as it may reflect the occurrence of complications of surgery in hospital. Length of in-hospital stay was considered to be "prolonged" if it was longer than 3 days.

The sixth indicator was the **proportion of patients who had an emergency readmission within 90 days of radical prostate cancer surgery.** This indicator was derived from HES admissions. Emergency readmission may reflect that patients experienced a complication after discharge from hospital.

3.3 2006-2008 Cancer Registry data linked to Hospital Episode Statistics and Mortality data

3.3.1 Completeness of information on disease status

There was marked variation in the completeness of information to determine disease status (Figure 3). Overall, completeness was 43%, ranging from 20% in the Cancer Network with the lowest and to 78% in the Cancer Network with the highest rate of completion.

3.3.2 Distribution of cancer stage, tumour grade and disease status

Among the 38,005 patients with information about tumour stage, 35% were staged as having stage T1 disease, 35% T2, 24% T3 and 6% T4 (Figure 4). Gleason score was available for 51,406 men, of whom 38% had a Gleason score of 6 or below, 37% a score of 7 and 25% a score of 8 or higher.





3.3.2 Distribution of cancer stage, tumour grade and disease status

Among the 38,005 patients with information about tumour stage, 35% were staged as having stage T1 disease, 35% T2, 24% T3 and 6% T4 (Figure 4). Gleason score was available for 51,406 men, of whom 38% had a Gleason score of 6 or below, 37% a score of 7 and 25% a score of 8 or higher.

3.3.3 <u>Performance indicators 1 and 2</u>: proportion of men diagnosed with locally advanced disease and proportion of patients diagnosed with advanced disease

Large variation existed among Cancer Networks in the proportion of patients with locally advanced cancer and with advanced disease at the time of diagnosis (Figure 5). Overall, 61% of men had locally advanced disease, varying from 42% to 86% across the Networks. The overall proportion of men with advanced disease was 6%, ranging from 0% to 19%.

3.3.4 Performance indicator 3: proportion of men with low-risk localised cancer undergoing radical prostate cancer treatment

Overall, 28% of men diagnosed with low-risk prostate cancer underwent radical prostate cancer therapy within 12 months of their diagnosis (Figure 6). The majority had either a prostatectomy (13%) or external beam radiation therapy (13%). Very few patients received brachytherapy (1%), HIFU (<1%) or cryotherapy (0%).

There was considerable variation among Cancer Networks in the treatments that men with low-risk prostate cancer received. The proportion of men with low-risk disease undergoing any form of radical treatment varied from 11 to 53% with the proportion of men undergoing surgery varying from 4% to 31% and the corresponding proportion for external beam radiation therapy varying from 2% to 33%.



Figure 6. Proportion of patients with cancer therapy (men diagnosed betw	low-ri veen 2	sk ri 006	sk loca and 20	alised p 008)	prostate	cancer ι	Indergo	oing ra	dical p	rostate	
Anglia (N=608)											
Arden (N=44)											
Avon, Somerset & Wiltshire (N=183)											
Central South Coast (N=162)											
Dorset (N=224)											
East Midlands (N=149)											
Essex (N=329)											
Greater Manchester & Cheshire (N=136)											
Greater Midlands (N=38)											
Humber & Yorkshire Coast (N=71)											
Kent & Medway (N=133)											
Lancashire and South Cumbria (N=91)											
Merseyside & Cheshire (N=163)											
Mount Vernon (N=173)											
North East London (N=19)											
North London (N=282)											
North Trent (N=35)											
North West London (N=36)											
North of England (N=458)											
Pan Birmingham (N=172)											
Peninsula (N=159)											
South East London (N=158)											
South West London (N=94)											
Surrey, West Sussex & Hampshire (N=147)											
Sussex (N=158)											
Thames Valley (N=58)											
Three Counties (N=139)											
Yorkshire (N=102)											
Overall (N=4,521)											
0%	10	%	20%	30%	40%	50%	60%	70%	80%	90%	100%
	Noi	ne					Radioth	erapy			
	HIF	U					Brachyt	herapy:	,		
	Pro	state	ctomy								

3.3.5 <u>Performance indicator 4</u>: proportion of men with locally advanced disease undergoing radical prostate cancer treatment

Overall, 27% of patients with locally advanced prostate cancer underwent radical therapy within 12 months of diagnosis, which varied from 12% to 41% among the Cancer Networks (Figure 7).

Patients undergoing treatment had either external beam radiation therapy (17%) or radical surgery (10%). Brachytherapy (<1%) and HIFU (<1%) were rarely used.

3.3.6 <u>Performance indicator 5</u>: Proportion of patients with a length of hospital stay for radical prostate cancer surgery longer than 3 days

Overall, 53% of the patients who underwent a radical prostatectomy stayed longer than 3 days in hospitals (Figure 8). This proportion varied greatly between Cancer Networks, ranging from 23% to 82% of patients.

3.3.7 <u>Performance indicator 6</u>: Proportion of patients readmitted as an emergency within 90 days of radical prostate cancer surgery

The emergency readmission rate was relatively low with overall 7% of patients being readmitted within 90 days. The emergency readmission rate varied from 3% to 22%.

Figure 7. Proportion of patients with therapy (men diagnosed between 20	locally 06 and	advanced 2008)	prosta	te cance	r under	going ra	adical p	rostate	cancer	
Anglia (N=1,414)										
Arden (N=762)										
Avon, Somerset & Wiltshire (N=825)										
Central South Coast (N=1,579)										
Dorset (N=697)										
East Midlands (N=1,725)										
Essex (N=1,224)										
Greater Manchester & Cheshire (N=1,324)										
Greater Midlands (N=796)										
Humber & Yorkshire Coast (N=641)										
Kent & Medway (N=825)										
Lancashire and South Cumbria (N=876)										
Merseyside & Cheshire (N=1,322)										
Mount Vernon (N=659)										
North East London (N=434)										
North London (N=619)										
North Trent (N=801)										
North West London (N=425)										
North of England (N=840)										
Pan Birmingham (N=931)										
Peninsula (N=1,290)										
South East London (N=761)										
South West London (N=616)										
Surrey, West Sussex & Hampshire (N=505)										
Sussex (N=606)										
Thames Valley (N=1,149)										
Three Counties (N=664)										
Yorkshire (N=764)										
Overall (N=25,074)										
0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
	None	e				Radioth	erapy			
	HIFU	I				Brachyt	herapy			
	Pros	tatectomy								

Figure 8. Proportion of patients with 3 days (men diagnosed between 200	a lengt 06 and 2	h of hos 2008)	pital st	ay for ra	adical p	orostate	cancer	surgery	longer	than
Anglia (N=400)										
Arden (N=110)										
Avon, Somerset & Wiltshire (N=246)										
Central South Coast (N=265)										
Dorset (N=171)										
East Midlands (N=270)										
Essex (N=143)										
Greater Manchester & Cheshire (N=164)										
Greater Midlands (N=118)										
Humber & Yorkshire Coast (N=100)										
Kent & Medway (N=315)										
Lancashire and South Cumbria (N=147)										
Merseyside & Cheshire (N=162)										
Mount Vernon (N=144)										
North East London (N=162)										
North London (N=153)										
North Trent (N=72)										
North West London (N=189)										
North of England (N=270)										
Pan Birmingham (N=327)										
Peninsula (N=154)										
South East London (N=206)										
South West London (N=101)										
Surrey, West Sussex & Hampshire (N=103)										
Sussex (N=151)										
Thames Valley (N=199)										
Three Counties (N=112)										
Yorkshire (N=177)										
Overall (N=5,131)										
0%	10%	, 20%	30%	6 40%	509	% 609	6 70%	80%	90%	100
	read	mission w	vithin 90	days afte	r surger	y				

length of stay > 3 days

3.4 Cancer Registry data 2012

3.4.1 Completeness of information on disease status

The completeness of information on disease status has considerably improved (Figure 9). This information was complete in 71% of the 36,883 men who were diagnosed with prostate cancer in 2012 compared to 53% in the 2006 – 2008 data.

3.4.2 Distribution of cancer stage and tumour grade

Among the 25,151 men diagnosed in 2012 with staging information, 26% had stage T1 disease, 36% T2, 33% T3, and 5% T4. Of the 22,593 who had information on tumour grade, 29% of patients had a Gleason score of 6 or less, 44% a score of 7 and 26% a score of 8 or higher. A comparison with the results based on 2006-2008 Cancer Registry data demonstrates that men diagnosed in 2012 had more advanced disease: fewer were diagnosed at stage T1 (26% compared to 35%) and with Gleason score of 6 (29% compared 38%).

3.4.3 Performance indicators 1 and 2: proportion of men diagnosed with locally advanced disease and proportion of patients diagnosed with advanced disease.

The proportion of men diagnosed in 2012 who had locally advanced disease was 46%, compared to 61% in men diagnosed between 2006 and 2008. The proportion of men with advanced disease was 4% compared to 6% in men diagnosed between 2006 and 2008.

Figure 9. Completeness of information for men diagnosed in 2012	n to det	ermine	disease	status b	y Cance	r Network			
Anglia (N=2,467)									
Arden (N=670)									
Avon, Somerset & Wiltshire (N=1,559)									
Central South Coast (N=1,614)									
Dorset (N=942)									
East Midlands (N=2,854)									
Essex (N=1,047)									
Greater Manchester & Cheshire (N=2,025)									
Greater Midlands (N=1,620)									
Humber & Yorkshire Coast (N=823)									
Kent & Medway (N=1,208)									
Lancashire and South Cumbria (N=1,102)									
Merseyside & Cheshire (N=1,570)									
Mount Vernon (N=931)									
North East London (N=870)									
North London (N=763)									
North Trent (N=1,279)									
North West London (N=776)									
North of England (N=2,037)									
Pan Birmingham (N=1,420)									
Peninsula (N=1,426)									
South East London (N=967)									
South West London (N=824)									
Surrey, West Sussex & Hampshire (N=864)									
Sussex (N=1,009)									
Thames Valley (N=1,596)									
Three Counties (N=909)									
Yorkshire (N=1,711)									
Overall (N=36,883)									
0%	10%	20%	30%	40%	50%	60%	70% 80%	o 90%	10

3.5 Summary

This chapter describes findings of a preliminary analysis of English Cancer Registry data linked to HES. We present data completeness and introduce six performance indicators. The full analysis could not be carried out because the HSCIC was not able to provide up-to-date HES data and to carry out linkage of 2012 Cancer Registry data to HES.

Alternative analyses were carried out of 2006-2008 Cancer Registry data linked to HES and an analysis of 2012 Cancer Registry data not linked to HES. We found that:

- Of the 94,116 men diagnosed with prostate cancer between 2006 and 2008, 95% could be linked to HES but only 43% could be included in the analyses with sufficient information to determine disease status.
- Between 2006 and 2008, 61% presented with locally advanced disease (performance indicator 1) and 6% with advanced disease (performance indicator 2).
- 28% of men diagnosed between 2006 and 2008 with low-risk (localised) disease underwent radical treatment (performance indicator 3).
- 27% of men diagnosed between 2006 and 2008 with locally advanced disease underwent radical treatment (performance indicator 4).
- 53% of men diagnosed between 2006 and 2008 who underwent a radical prostatectomy had a hospital stay longer than 3 days (performance indicator 5).
- 7% of men diagnosed between 2006 and 2008 who had a radical prostatectomy were readmitted as an emergency within 90 days of surgery (performance indicator 6).
- Of men diagnosed in 2012, 71% had sufficient information to determine disease status.
- Men diagnosed in 2012 were less likely to be diagnosed with locally advanced disease in 2012 than men diagnosed with prostate cancer between 2006 and 2008 (46% versus 61%).

In conclusion, we have demonstrated that records of the English Cancer Registry can be successfully linked to the HES database. The completeness of recording of cancer stage and tumour grade in Cancer Registry data is rapidly improving. These findings demonstrate the feasibility of using existing data to provide a comparative background for the prospective audit of prostate cancer patients in England and Wales.

A number of questions remain unanswered which need to be addressed as a priority as soon as the 2012 Cancer Registry can be linked to HES data. First, there is uncertainty about the completeness of the recording of the radiotherapy in Cancer Registry data. Second, we did not explore how strongly the length of hospital stay for prostate cancer surgery depends on the surgical approach. Third, it is unclear to what extent the low percentage of men recorded as having advanced disease is due to poor data completeness.

4. NPCA Prospective Audit

4.1 Introduction

The NPCA's prospective audit was designed to address two specific areas of concern. Firstly, the management of patients with low-risk disease ('are we over-treating patients that could be appropriately managed by active surveillance?'), in addition to the availability and provision of multimodality therapy for patients with advanced disease ('are we undertreating patients with locally advanced or high-risk disease?').

From the 1st April 2014 the NPCA initiated prospective data collection about the diagnosis, management and treatment of every patient newly diagnosed with prostate cancer and discussed at a multi-disciplinary (MDT) meeting in England. The NPCA prospective audit collects data on:

- The characteristics of all men with newly diagnosed prostate cancer, how their cancer was detected, and the referral pathway.
- The crucial steps in the diagnostic and staging process.
- The planning of initial treatment.
- Initial treatments given (e.g. active monitoring/ surveillance, surgery, radiotherapy, hormonal therapy, and novel treatments including cryotherapy and HIFU).

The NPCA will also will provide detail on early complications, longer-term survival and quality of life.

NICE has recently updated its guidance on the diagnosis and management of men with prostate cancer and has previously produced national guidance on urological cancer services.^{1,3} In addition, NICE is developing a Quality Standard for prostate cancer that will be used to monitor NHS commissioning. This standard will set out evidence-based characteristics of a high quality service.

The NPCA's prospective audit will provide key information on current practice and outcomes that will be compared against these criteria, in addition to evidence-based, measurable Quality Performance Indicators (QPIs) that will be developed as part of the audit.

4.2 A new generation of national cancer audit in England

The NPCA is the first national cancer audit to work with the newly established NCRS as data collection partner, which collects patient-level data from all NHS acute providers and from a range of national data feeds. In addition, the NPCA is the first cancer audit to utilise the Cancer Outcomes and Services Dataset (COSD) as its main source of data, the new standard for reporting cancer, which has been mandated since January 2013. COSD replaces the National Cancer Dataset and the Cancer Registration Dataset, and specifies the items to be submitted routinely by service providers via MDT electronic data collection systems to the NCRS on a monthly basis, for example clinically-relevant site-specific data items. Unlike previous national cancer audits, which frequently include 100+ items, the dataset for the NPCA is a true 'minimum dataset'. The NPCA dataset consists of only 50 data items in total: 29 items are part of the COSD dataset, one item is part of the BAUS dataset (which is collected by all urologists as part of surgeon level reporting), and 20 new items, each of which is essential for answering the key questions that the audit was commissioned to address (which includes two existing items from the Royal College of Pathologists' dataset).

The mechanism for collection and submission of prospective data for the NPCA mirrors that in place within each trust for COSD. Data are collected during meetings of the MDT, which are subsequently exported from MDT software systems and submitted directly to local NCRS offices along with each trust's routine COSD submission on a monthly basis. In this way, data collection and submission for the NPCA is a continuous flow rather than the majority of data being submitted close to the annual data submission deadline as experienced in other national cancer audits.

Figure 10 provides an overview of prospective audit data collection for the NPCA.

In order to keep the number of items in the NPCA dataset to a minimum and to streamline data collection (thereby limiting the burden of data collection on patients and staff), additional data items beyond the NPCA minimum dataset (which includes both COSD and NEW NPCA data items), will be collated by the NCRS for the NPCA. This will include existing electronic data including imaging records, pathology results, radiotherapy and chemotherapy data, in addition to information on future hospital use from the Hospital Episode Statistics and survival data obtained from the Office for National Statistics.

An anonymised copy of the audit's data set will be transferred to the NPCA's Project Team at 3-monthly intervals for analysis.

The mechanism for data collection in Wales is currently in development and is anticipated to commence in 2015.



4.3 Development of the NPCA Prospective audit dataset

4.3.1 Design principles

The design of the audit's minimum dataset was based on the following principles:

- All men with newly diagnosed prostate cancer should be included.
- Data on their diagnosis, staging, and initial treatment should be collected based on information available at meetings of the multidisciplinary team (MDT) during the initial phase of management.
- The burden of data collection on patients and staff should be kept to a minimum.
- The audit data items need to be available soon after they are generated in clinical practice, given that the relevance of audit data decays with time.

4.3.2 Design of the NPCA prospective audit dataset

A summary of the NPCA dataset is shown in Appendix 2. The detailed dataset specification, accompanying detailed data dictionary and FAQs are published on the NPCA website.

http://www.npca.org.uk/audit-tools/

The NPCA dataset comprises three broad categories:

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

All men with newly diagnosed prostate cancer: NPCA Minimum data set 1

The first category of data items concerns initial diagnosis, staging, specialist referral and planned treatment.

Differences in case mix

To ensure that the assessment of NHS providers and clinicians who treat patients with prostate cancer is fair and to avoid those who treat more difficult cases being unfairly penalised, the NPCA will take account of differences in mix of patients between providers e.g. age and ethnicity, socioeconomic status, overall physical condition, comorbidity, and preexisting urinary symptoms.

Method of diagnosis

Currently, approximately a quarter of patients with cancer in the UK are first diagnosed after an emergency admission to hospital.¹⁶ Early detection of cancer is an important determinant of the outcome of cancer treatment and late presentation is associated with lower survival rates.

The NPCA will determine the extent of variation in the way the prostate cancer was diagnosed. The audit will collect information on the reporting of symptoms by men prior to their initial assessment for prostate cancer. The NPCA will determine to what extent the method of diagnosis varies geographically and the relationship with disease stage at presentation, treatment allocation and ultimately treatment outcomes.

Risk stratification

The NPCA will collect information on a patient's definitive diagnosis of prostate cancer including the histology of the prostate biopsy cores. Although the standard diagnostic approach is a transrectal ultrasound (TRUS)-guided prostate biopsy taking 10-12 cores,^{1,17} this data item will future proof the NPCA as men are increasingly undergoing more intensive prostate biopsies, often via the perineal route. Risk stratification will be in line with the D'Amico risk stratification on the basis of PSA level, Gleason score and TNM staging. The audit will also include data items from the Royal College of Pathologists dataset to describe the results of the pathological examination of the prostate biopsy.

Multiparametric MRI

A data item was included to monitor if a multiparametric MRI was used as it is anticipated that men will increasingly undergo multiparametric MRI before prostate biopsy as an initial step in the diagnostic pathway.

Patient pathways and planned treatments

Determining treatment pathways following diagnosis is essential for the evaluation of patient outcomes. The audit will therefore identify '*specialist referral appointments*' and the type/s of clinical specialist men with newly diagnosed prostate cancer are seen by and in what clinical setting. Information on '*planned prostate cancer treatment*' will demonstrate the treatment/s agreed with the patient. Primary treatment received will be determined by utilising the '*cancer treatment modality*' data item from COSD, which is not an item in the current NPCA dataset.

All men undergoing radical prostatectomy: NPCA minimum dataset 2

The second category focuses on surgery for prostate cancer and includes data items concerning:

- 1. date of surgery to determine variation in the time from diagnosis to treatment for NHS providers
- method of surgery new NPCS data item '*Type of Radical Prostatectomy*, which includes Robotic prostatectomy (NICE guidelines recommend that commissioners should consider providing this surgical approach to treat localised prostate cancer)
- 3. pathological outcome of surgery utilising the existing COSD Urology items: '*T* and *N* category, Organ confined, Seminal Vesicles invasion, Number of nodes examined and Number of nodes positive'.

Surgeon-level reporting

To ensure that the NPCA can provide outcomes that reflect the performance of individual urologists involved in the treatment of prostate cancer patients, the GMC number of the consultant urologist responsible for the radical prostatectomy will be collected and a new data item capturing '*margin status after radical prostatectomy*' has been included. This data item has also been included in the British Association of Urological Surgeons (BAUS) dataset. Similarly, the NPCA has incorporated the BAUS data item '*procedure – nerve sparing*'. BAUS will report on surgeon-level outcomes for radical prostatectomy in 2014/15.

All men for whom external beam radiation or brachytherapy is planned with or without androgen deprivation therapy: NPCA minimum dataset 3

The majority of new data items included within the NPCA concern external beam radiation therapy (EBRT) and brachytherapy as current COSD data items are limited for both therapies. As all NPCA data are due to be collected following MDT discussion, all new data items in this category concern '*planned therapy' e.g.* '*planned radiation total dose*' as the actual treatment is being decided at a later stage when the result of the MDT meeting is being discussed with the patient. Also, it may take many months following diagnosis and discussion at MDT before the radiotherapy will start. Men with intermediate and high-risk prostate cancer can receive up to 6 months of androgen deprivation therapy before radical external beam radiotherapy.'

The item *'planned radiotherapy intent'* will capture treatment intent including primary radical (sole or multimodal therapy), adjuvant (following radical prostatectomy) or palliative. The precise treatment intent will depend on the tumour characteristics including stage and grade, as well as the general health of the patient, which in turn influence the choice of *'planned radiotherapy field'*. *'Planned radiotherapy type'* includes new radiation technologies that are increasingly being utilised in the management of prostate cancer in order to reduce damage to surrounding tissue and structures.

As the optimal image guidance strategy remains undefined in this setting and to evaluate the variation across specialist centres the NPCA will capture *'planned type of image guidance for EBRT'*, again as precise targeting of the tumour will facilitate dose escalation and potentially reduce treatment toxicity. The NPCA will also capture androgen deprivation details including neoadjuvant hormone therapy prior to commencement of EBRT or adjuvant hormone therapy following completion of EBRT, the duration of which is defined by a patient's risk stratification.

New NPCA items also include *'planned brachytherapy type'*, *'total dose'* and *'total fractions'*. This will seek to ascertain the modality of brachytherapy (low or high dose).

5. Feasibility study of PSA testing in primary care

5.1 Scoping exercise

The aim of the feasibility study is to provide information about the variation in the "use" of PSA in men who are suspected to have prostate cancer irrespective of whether or not they have symptoms (in contrast to the use of PSA to monitor response to treatment or cancer progression), the "yield" of PSA testing (proportion of PSA tests that result in a prostate cancer diagnosis), and the "timeliness" of the diagnostic process (time between initial test and the actual cancer diagnosis date).

During the initial phase of the scoping exercise the Project Team identified and liaised with key informers (for example, members of the National Pathology Programme) in order to canvass opinions and determine the availability of suitable data sources. Intelligence received informed the Project Team that the HSCIC, on behalf of NHS England and Public Health England, has launched the Primary Care Pathology (PCP) Project to investigate both the feasibility of primary care pathology data collection and linkage to other data sources such as HES, as part of the care.data programme.

Subsequent to discussions between the NPCA and HSCIC, it was agreed that the NPCA's proposal to determine the feasibility of linking PSA data from primary care feeds to Cancer Registry data would be a key case study as part of the PCP project. The HSCIC anticipate that the PCP project will progress in the final quarter of 2014 and the NPCA's scoping exercise is currently on-hold until this time.

Appendix 1: Project Board and Clinical Reference Group

Membership of the Project Board			
Name	Representing		
Derek Alderson	Trustee of RCS		
Noel Clarke	Lead Urologist, Project Team		
Heather Payne	Lead Oncologist, Project Team		
Jem Rashbass	Lead Cancer Registration, Project Team		
Jan van der Meulen	Lead Methodologist, Project Team		
Roger Kockelbergh	NCIN Urology CRG, NCPA CRG Chair		
Simon Russell	BUG		
Howard Kynaston	BAUS		
Sarah Cant	Prostate Cancer UK		
Yvonne Silove	HQIP		
Julie Nossiter	Project Manager, Project Team		

Membership of the Clinical Reference Group				
Name	Representing			
Roger Kockelbergh (Chair)	NCIN			
Howard Kynaston	BAUS Wales			
Raj Persad	BAUS			
Simon Russell	BUG			
Philippa Aslet	BAUN			
Michael Kirby	RCGP			
Sandy Tyndale-Biscoe	Tackle Prostate Cancer			
Sarah Mee	Prostate Cancer UK			
Mick Peake	NCIN			
Julietta Patnick	NHS Cancer Screening Programmes			
Adam Glaser	UK Cancer survival initiative			
Julia Verne	Public Health Observatories			
Sean Duffy	National Commissioning Board			
Julia Hill	National Cancer Peer Review			
Vijay Sangar	Specialised Urology CRG, NHS England			
All members of the Project Tea	m			

Appendix 2: Summary of the dataset for the prospective audit

The detailed NPCA dataset specification, accompanying data dictionary and frequently asked questions can be found on our website.

http://www.npca.org.uk/audit-tools/

www.npca.org.uk e-mail:npca@rcseng.ac.uk	PCA Larce
Version 1.1, 15th October 2014 Nationa	al Prostate Cancer Audit
Summary of clinical data items for collection is arranged into three sections. The first secti prostate cancer, the second focuses on men concerns all men where external beam radiat therapy, is planned.	from 1st April 2014 in England and Wales. The data set ion will be collected from all men with newly diagnosed who have undergone radical prostatectomy and the third ion therapy or brachytherapy, with or without hormone
NPCA MINIMUM DATA SET 1: To be completed for meeting(s) of the multidisciplinary team (MDT) do	all men with newly diagnosed prostate cancer. To be completed a uring the initial phase of management.
Patient Characteristics	
1. Date of diagnosis (clinically agreed)//	
2. Symptoms prior to diagnosis	None Lower Urinary Tract Symptoms (LUTS)
Symptoms possibly linked to metastasis (e.g. pain) General symptoms weight loss letharc	(e.g. Not known
3. Performance status (adult)	<i>///</i>
Able to carry out all normal activity without restriction.	Restricted in physically strenuous activity, but able to walk and do light work
Able to walk and capable of all self care, but unable to care work. Up and about more than 50% of waking bours.	ry out any Capable of only limited self care, confined to bed or chair more that 50% of waking hours.
Completely disabled. Cannot carry out any self care. Totall to bed or chair.	y confined Not recorded
4. ASA score – prostate (collect from ALL patients whether s	urgery is planned or not)
A normal healthy patient.	A patient with mild systemic disease.
A patient with severe systemic disease that limits function incapacitating.	but is not A patient with severe systemic disease that is a constant threat to life.
E Source of referral for out patients	Enllowing an amazzaney admirsion
Referral from a consultant other than in an accident	Other
6. PSA (diagnosis)	(na/ml)
7. Prostate biopsy technique No Biopsy done	Transrectal sampling biopsy
Perineal Template Perineal Template N	
biopsy biopsy	
Gleason Score of Biopsy	
1. Gleason grade (primary)	2. Gleason grade (secondary)
3. Gleason grade (tertiary)	
Magnetic Resonance Imaging of Prostate	
1. Multiparametric MRI performed	
Einal Pre-Treatment Tumour Characteristics	
1. T category (final pre-treatment)	2. N category (final pre-treatment)
3. M category (final pre-treatment)	
4. Perineural invasion Yes	No Not Assessable
5. Number of positive cores	6. Total number of cores
7. Greatest percentage of cancer in single most involved core	(%)
Treatment	
1. Specialist referral appointments	Urologist only Oncologist only
Specialist prostate cancer surgeon and oncologist separat	tely Specialist prostate cancer surgeon and oncologist in joint speciali

2. Planned prostate cancer treatn	ient		
Watchful waiting	Active surveillance	Radical Prostatectomy	Transurethral Resection of Prostate (TURP)
Bilateral Orchidectomy	Cryotherapy	High Intensity Focused	Focal Therapy (any modality)
Radical External Beam	Low Dose Rate Brachytherapy	High Dose Rate Brachytherapy	Continuous Androgen
Radiotherapy Intermittent Androgen	Neoadjuvant hormone		Deprivation Therapy Characteristics
Deprivation Therapy	therapy		
Palliative Radiotherapy	Specialist palliative care	Other – active	
NPCA MINIMUM DATA SET To be completed at the MD	2: Data items to be collected f r meeting following radical su	or all men who have undergon rgery.	e a radical prostatectomy.
Radical prostatectomy deta	ils		
1. Organisation site code - cancer		2. Consultant code (treatment)	
3. Type of radical prostatectomy (actual)		
Open prostatectomy	Robotic prostatectomy	Laparoscopic prostatectomy	Not known
4. Procedure date//			
5. Procedure - nerve sparing		□	
Bilateral	Unilateral	None	
6. T category (pathological)		7. N category (pathological)	
8. Organ confined	Yes	No	Not Applicable
9. Seminal vesicles invasion	Yes	No	Not Applicable
10. Radical prostatectomy margin	status	Negative Margins	length
- Desitive assessments as 2 areas in	B		
length □	unknown	Not known	
Positive margins 2 3 mm in length	unknown	Not known 12. Number of nodes positive	
Positive margins 2 s mm in length 11. Number of nodes examined _ NPCA MINIMUM DATA SET brachytherapy is planned w treatment is planned (befor Radiotherapy details	Positive margins, length unknown S: Data items to be collected fr ith or without androgen depri e actual treatment takes place	Not known 12. Number of nodes positive or all men for whom external b vation therapy. To be complet e).	beam radiation or ed at the MDT meeting wher
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Positive margins 2 s mm in length II. Number of nodes examined NPCA MINIMUM DATA SET brachytherapy is planned w treatment is planned (befor Radiotherapy details I. Planned radiotherapy intent (p Palliative Planned radiotherapy type	Positive margins, length unknown S: Data items to be collected frith or without androgen depri e actual treatment takes place rostate) Other	Not known 12. Number of nodes positive or all men for whom external b vation therapy. To be complet b). Primary radical intent Not known 3D conformal	Deam radiation or ed at the MDT meeting when Adjuvant
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Positive margins 2 s mm in length In Number of nodes examined _ NPCA MINIMUM DATA SET brachytherapy is planned w treatment is planned (befor Radiotherapy details I. Planned radiotherapy intent (p Palliative Arcing IMRT S. Planned type of image-guidan Combined come for with	Positive margins, length unknown S: Data items to be collected fi ith or without androgen depri e actual treatment takes place rostate) Other SBRT Se for external beam radiotherapy	Not known 12. Number of nodes positive or all men for whom external b vation therapy. To be complet b) Primary radical intent Not known 3D conformal Other Cone beam CT	Deam radiation or ed at the MDT meeting wher Adjuvant IMRT Not known
Positive margins 2 s mm in Positive margins 2 s mm in II. Number of nodes examined	Positive margins, length unknown	Not known 12. Number of nodes positive or all men for whom external bration therapy. To be completed by the completed by t	Deam radiation or ed at the MDT meeting when Adjuvant IMRT Not known Fiducial markers Not known
		Not known 12. Number of nodes positive or all men for whom external bration therapy. To be completed by the completed by t	Deam radiation or ed at the MDT meeting when Adjuvant IMRT Not known Fiducial markers Not known Prostate, seminal vesicles and Iymph nodes
Positive margins 2 s min in length In Number of nodes examined _ NPCA MINIMUM DATA SET brachytherapy is planned w treatment is planned (befor Radiotherapy details I. Planned radiotherapy intent (p Palliative Palliative Arcing IMRT Gombined cone beam CT with fiducial markers Planned radiotherapy field Prostate Bed		Not known 12. Number of nodes positive or all men for whom external bracket in the apy. To be complete in the apy. To be complete in the applet in the appl	Deam radiation or ed at the MDT meeting when at the MDT meeting when Adjuvant IMRT Not known Fiducial markers Not known Prostate, seminal vesicles and Iymph nodes Not known
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		Not known 12. Number of nodes positive or all men for whom external bration therapy. To be completed by the second secon	Deam radiation or ed at the MDT meeting when a Adjuvant Adjuvant IMRT Not known Fiducial markers Not known Prostate, seminal vesicles and lymph nodes Not known
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Appendix 3: Participants in the Organisational Audit

All NHS providers of prostate cancer services in England and Wales participated in the organisational audit.

England	
Airedale NHS Trust	Isle of Wight NHS Trust
Aintree University Hospital NHS Foundation Trust	Lancashire Teaching Hospitals NHS Foundation Trust
Ashford & St Peter's NHS Trust	Leeds Teaching Hospitals NHS Trust
Barking, Havering & Redbridge University Hospitals NHS Trust	Lewisham & Greenwich NHS Trust
Barnet & Chase Farm Hospitals NHS Trust	Luton & Dunstable University Hospital NHS Foundation Trust
Barnsley Hospital NHS Foundation Trust	Maidstone and Tunbridge Wells NHS Trust
Barts Health NHS Trust	Medway NHS Foundation Trust
Basildon & Thurrock University Hospitals NHS Foundation Trust	Mid Cheshire Hospitals NHS Foundation Trust
Bedford Hospital NHS Trust	Mid Essex Hospital Services NHS Trust
Blackpool, Fylde & Wyre Hospitals NHS Foundation Trust	Mid Staffordshire NHS Foundation Trust
Bolton NHS Foundation Trust	Milton Keynes Hospital NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust	Mount Vernon Cancer Centre
Brighton & Sussex University Hospitals NHS Trust	Newcastle upon Tyne Hospitals NHS Foundation Trust
Buckinghamshire Healthcare NHS Trust	Norfolk & Norwich University Hospitals NHS Foundation Trust
Burton Hospitals NHS Foundation Trust	North Bristol NHS Trust
Calderdale & Huddersfield NHS Foundation Trust	North Cumbria University Hospitals NHS Trust
Cambridge University Hospitals NHS Foundation Trust	Northern Lincolnshire and Goole NHS Foundation Trust
Central Manchester University Hospitals NHS Foundation Trust	North Middlesex University Hospital NHS Trust
Chelsea & Westminster Hospital NHS Foundation Trust	Northampton General Hospital NHS Trust
Chesterfield Royal Hospital NHS Foundation Trust	Northern Devon Healthcare NHS Trust
City Hospitals Sunderland NHS Foundation Trust	Northumbria Healthcare NHS Foundation Trust
Colchester Hospital University NHS Foundation Trust	Nottingham University Hospitals NHS Trust
Countess of Chester Hospital Foundation NHS Trust	North Tees & Hartlepool NHS Foundation Trust
County Durham & Darlington NHS Foundation Trust	Oxford University Hospitals NHS Trust
Croydon Health Services NHS Trust	Pennine Acute Hospitals NHS Trust
Dartford & Gravesend NHS Trust	Peterborough & Stamford Hospitals Trust
Derby Hospitals NHS Foundation Trust	Plymouth Hospitals NHS Trust
Doncaster & Bassetlaw Hospitals NHS Foundation Trust	Poole Hospital NHS Foundation Trust
Dorset Country Hospital NHS Foundation Trust	Portsmouth Hospitals NHS Trust
East & North Hertfordshire NHS Trust	Princess Alexandra Hospital NHS Trust
East Cheshire NHS Trust	Royal Berkshire NHS Foundation Trust
East Kent Hospitals University NHS Foundation Trust	Royal Cornwall Hospitals NHS Trust
East Lancashire Hospitals NHS Trust	Royal Devon & Exeter NHS Foundation Trust
East Sussex Healthcare NHS Trust	Royal Free London NHS Foundation Trust
Epsom & St Helier University Hospitals NHS Trust	Royal Surrey County Hospital NHS Foundation Trust
Frimley Park Hospital NHS Foundation Trust	Royal United Hospital Bath NHS Trust
Gateshead Health NHS Foundation Trust	Salford Royal NHS Foundation Trust
George Eliot Hospital NHS Trust	Salisbury NHS Foundation Trust
Gloucestershire Hospitals NHS Foundation Trust	Sandwell & West Birmingham Hospitals NHS Trust
Great Western Hospitals NHS Foundation Trust	Sheffield Teaching Hospitals NHS Foundation Trust
Guy's and St Thomas' NHS Foundation Trust	Sherwood Forest Hospitals NHS Foundation Trust
Hampshire Hospitals NHS Foundation Trust	South Devon Healthcare NHS Foundation Trust
Harrogate and District NHS Foundation Trust	South Tees Hospitals NHS Foundation Trust
Heart of England NHS Foundation Trust	South Tyneside NHS Foundation Trust
Heatherwood and Wexham Park Hospitals NHS Foundation Trust	South Warwickshire NHS Foundation Trust
Hinchingbrooke Health Care NHS Trust	Southend University Hospital NHS Foundation Trust
Homerton University Hospital NHS Foundation Trust	Southport & Ormskirk Hospital NHS Trust
Hull and East Yorkshire Hospitals	St George's Healthcare NHS Trust
Imperial College Healthcare NHS Trust	St Helens & Knowsley Teaching Hospitals NHS Trust
James Paget University Hospitals NHS Foundation Trust	Stockport NHS Foundation Trust
Kettering General Hospital NHS Foundation Trust	Surrey and Sussex Healthcare NHS Trust
Kingston Hospital NHS Foundation Trust	Tameside Hospital NHS Foundation Trust

England continued	Wales
Taunton and Somerset NHS Foundation Trust	North Network
The Christie NHS Foundation Trust	Western - Betsi Cadwaladr University Health Board
Clatterbridge Cancer Centre NHS Foundation Trust	Central - Betsi Cadwaladr University Health Board
The Dudley Group NHS Foundation Trust	Eastern - Betsi Cadwaladr University Health Board
The Hillingdon Hospitals NHS Foundation Trust	South Network
The Ipswich Hospital NHS Trust	Aneurin Bevan Health Board
The Mid Yorkshire Hospitals NHS Trust	Cardiff and Vale University Health Board
The North West London NHS Trust	Cwm Taf Health Board
The Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust	Velindre NHS Trust
The Rotherham NHS Foundation Trust	Abertawe Bro Morgannwg University Health Board - Swansea
The Royal Bournemouth and Christchurch Hospitals NHS	Abertawe Bro Morgannwg University Health Board – Neath Port
Foundation Trust	Talbot
The Royal Liverpool & Broadgreen University Hospitals NHS Trust	Hywel Dda Health Board
The Royal Marsden NHS Foundation Trust	
The Royal Wolverhampton Hospitals NHS Trust	
The Shrewsbury & Telford Hospital NHS Trust	
The Whittington Hospital NHS Trust	
University Hospitals Birmingham NHS Foundation Trust	
United Lincolnshire Hospitals NHS Trust	
University College London Hospitals NHS Foundation Trust	
University Hospital of South Manchester NHS Foundation Trust	
University Hospital Southampton NHS Foundation Trust	
University Hospitals Coventry and Warwickshire NHS Trust	
University Hospital of North Staffordshire NHS Trust	
University Hospitals of Leicester NHS Trust	
University Hospitals of Morecambe Bay Foundation NHS Trust	
Walsall Healthcare NHS Trust	
Warrington and Halton Hospitals NHS Foundation Trust	
West Hertfordshire Hospitals NHS Trust	
West Middlesex University Hospital NHS Trust	
West Suffolk NHS Foundation Trust	
Western Sussex Hospitals NHS Foundation Trust	
Weston Area Health NHS Trust	
Wye Valley NHS Trust	
Wirral University Teaching Hospitals NHS Foundation Trust	
Worcestershire Acute Hospitals NHs Trust	
Wrighton, Wigan & Leigh NHS Foundation Trust	
Yeovil District Hospital NHS Foundation Trust	
York hospitals NHS Foundation Trust	

References

- 1. NICE, 2014. Prostate cancer: diagnosis and treatment.
- 2. EAU, 2014. Guidelines on Prostate Cancer 2014
- 3. NICE, 2002. Improving outcome in urological cancer.
- 4. Ferlay et al. 2013. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. Eur J Cancer; 49: 1374-403.
- 5. Droz et al. 2014. Management of prostate cancer in older patients: updated recommendations of a working group of the International Society of Geriatric Oncology. Lancet; 15: e404-14.
- 6. BUG and BAUS, 2013. MDT guidance for managing prostate cancer.
- Dall'Era MA et al 2012. Active surveillance for prostate cancer: a systematic review of the literature. Eur Urol: 62:976-83.
- 8. Bolla M et al. 2002. Long-term results with immediate androgen suppression and external irradiation in patients with locally advanced prostate cancer (an EORTC study): a phase III randomised trial. Lancet; 360: 103-6.
- 9. Bolla M et al. 2012. Postoperative radiotherapy after radical prostatectomy for high-risk prostate cancer: longterm results of a randomised controlled trial (EORTC trial 22911). Lancet; 380: 2018-27.

- 10. National Cancer Peer Review Programme (England). 2013. Urology Specific Measures. London: NHS.
- 11. D'Amico AV et al. Biochemical outcome after radical prostatectomy, external beam radiation therapy, or interstitial radiation therapy for clinically localized prostate cancer. Jama. 1998;280(11):969-74
- 12. www.hscic.gov.uk/dars
- 13. <u>http://www.theguardian.com/society/2014/jan/19/nhs-</u> patient-data-available-companies-buy
- 14. http://www.bmj.com/content/bmj/348/bmj.g2702.full.pdf
- 15. <u>http://www.hscic.gov.uk/media/14244/Sir-Nick-</u> <u>Partridges-summary-of-the-review/pdf/Sir_Nick</u> <u>Partridge's summary of the review.pdf</u>
- 16. Department of Health, 2014 CCG Outcomes Indicator Set 2014/15:technical guidance. Available at: <u>http://www.england.nhs.uk/wp-content/uploads/2013/12/ccg-ois-1415-tech-guid.pdf</u> (last accessed 22/08/2014)
- Heidenreich A et al 2014. EAU guidelines on prostate cancer.
 Part 1: screening, diagnosis, and local treatment with

curative intent-update. Eur Urol; 65:124-37.

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