NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Prostate cancer

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 20 October 2014

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for prostate cancer. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Prostate cancer: diagnosis and treatment. NICE clinical guideline 175 (2014)

2 Overview

2.1 Focus of quality standard

This quality standard will cover diagnosis and treatment of prostate cancer. It will cover the care of men referred to secondary care with suspected or diagnosed prostate cancer, including follow-up in primary care for men with diagnosed prostate cancer. It will not cover men with an abnormal prostate-specific antigen (PSA) level detected in primary care who have no symptoms and are not referred for subsequent investigation.

2.2 Definition

The prostate is a gland of the male reproductive system which produces fluid to create semen. Prostate cancer usually develops slowly, so there may be no clinical signs for many years. Symptoms often become apparent when the prostate is large enough to affect the urethra. When this happens, the man may notice things like an increased need to urinate, straining while urinating and a feeling that their bladder has not fully emptied.

2.3 Incidence and prevalence

Prostate cancer is the most common cancer in men and makes up 26% of all male cancer diagnoses in the UK. In 2008, 34,335 men were diagnosed with prostate cancer and there were 9376 deaths from prostate cancer in England, Wales and Northern Ireland. This figure increased to 9632 deaths in 2010. Incidence of prostate cancer has increased worldwide since the 1960s due to improved diagnosis and an aging population.

Prostate cancer is predominantly a disease of older men (aged 65–79 years) but around 25% of cases occur in men younger than 65.

Family history has been shown to be a risk factor for prostate cancer; approximately 5-10% of cases are thought to have a substantial inherited component. It has been established that strong predisposing genes could be responsible for up to 40% of cases in younger men up to the age of 55. The relative risk to a patient increases with increasing numbers of first-degree relatives diagnosed and the father-to-son relative risk is increased 2.5-fold whilst the relative risk between brothers is increased 3.4-fold. Patients with hereditary prostate cancer are often diagnosed 6-7 years prior to spontaneous cases.

Ethnicity has been shown to be a risk factor for prostate cancer. The lowest incidence rates of prostate cancer are observed in Asian men, particularly in India, China and Japan. South Asian men living in England have a lower incidence of prostate cancer than their white counterparts (relative risk of 0.8). Higher rates are seen in Black men; African-American men are thought to have 1.3-2.0 times the risk of developing prostate cancer than Caucasian men, and black men (irrespective of black-African or black-Caribbean origin) have been shown to have a 3-times higher risk of developing prostate cancer than white men.

The patient-reported outcome measures (PROMs) study of cancer survivors 1-5 years following diagnosis reported that 38.5% of prostate cancer respondents had some degree of urinary leakage, 12.9% reported difficulty controlling their bowels, and 58.4% were unable to have an erection. A further 11.0% reported significant difficulty in having or maintaining an erection. The presence of urinary leakage was found to be significantly associated with lower quality of life scores. The PROMs study also found that patients with two or more long-term conditions or who were in the most deprived quintile (based on the IMD) were significantly associated with lower quality of life scores and increased social distress and difficulties.

The impact of prostate cancer in an aging population is expected to increase, even if the incidence rate were to remain constant. The financial burden of treatment will therefore increase as a higher number of patients is diagnosed with the disease. There will also be an increased need for resources such as treatment facilities and trained specialists. The mean direct costs per patient for initial treatment for prostate cancer have been estimated at around £2,505 in the UK. The total estimated costs for all patients in the first year from diagnosis were estimated to be £94.1 million in the UK. However, this does not include indirect costs, such as time and productivity lost through cancer-related illnesses, the impact of the physical and mental suffering of both patients and relatives during diagnosis and follow-up, or end-of-life costs.

Prostate cancer patients have also been shown to have more emergency than elective admissions during their last year of life (National End of Life Care Intelligence Network 2012). In those dying from prostate cancer, the average final admission cost is nearly half (47%) of the average total last year of life cost (National End of Life Care Intelligence Network 2012). The estimated total cost of inpatient care per person during their last year of life is reported to be £6,931 for prostate cancer.

2.4 Management

The most commonly used procedures as diagnostic tests for prostate cancer are digital rectal examination (DRE), the PSA blood test, transrectal ultrasound (TRUS), and needle biopsy. A suspect DRE is usually an indication for prostate biopsy which commonly involves needle biopsy in conjunction with TRUS. Radiological screening, including computerised tomography (CT) and magnetic resonance imaging (MRI) are also often used to aid diagnosis and staging.

A number of treatments are available for localised disease, including: active surveillance, radical prostatectomy, external beam radiotherapy and brachytherapy. Hormone therapy (androgen deprivation or anti-androgens) is the usual primary treatment for metastatic prostate cancer, but is also increasingly being used for men with locally advanced, non-metastatic disease.

2.5 National Outcome Frameworks

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 The Adult Social Care Outcomes Framework 2014–15

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	***Overarching measure*** 1A Social care-related quality of life* ***Outcome measures*** **People manage their own support as much as they wish, so that are in control of what, how and when support is delivered to match their needs.** 1B Proportion of people who use services who have control over their daily life **Carers can balance their caring roles and maintain their desired quality of life.** 1C Proportion of people using social care who receive self-directed support, and those receiving direct payments 1D Carer-reported quality of life*(NHSOF 2.4)
2 Delaying and reducing the need for care and support	2B Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services**(NHSOF 3.6i)
3 Ensuring that people have a positive experience of care and support	***Overarching measure*** **People who use social care and their carers are satisfied with their experience of care and support services.** 3A Overall satisfaction of people who use services with their care and support. 3B Overall satisfaction of carers with social services 3E Improving people's experience of integrated care **(NHSOF 4.9) ***Outcome measures*** **Carers feel that they are respected as equal partners throughout the care process** 3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help.** 3D The proportion of people who use services and carers who find it easy to find information about support **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of the individual**

4 Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm	***Overarching measure*** 4A The proportion of people who use services who feel safe * (PHOF 1.19) ***Outcome measures*** **Everybody enjoys physical safety and feels secure** **People are free from physical and emotional abuse, harassment, neglect and self-harm.** **People are protected as far as possible from avoidable harm, disease and injuries.** **People are supported to plan ahead and have the freedom to manage risks the way that they wish** 4B The proportion of people who use services who say that those services have made them feel safe and secure 4C Proportion of completed safeguarding referrals where people report they feel safe
Aligning across the health and care system * Indicator complementary ** Indicator shared	

Table 2 NHS Outcomes Framework 2014–15

Domain	**Overarching indicators and improvement areas**
1 Preventing people from dying prematurely	**Overarching indicator** 1B Life expectancy at 75 i Males ***Improvement areas*** **Reducing premature mortality from the major causes of death** 1.4 Under 75 mortality rate from cancer*
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** (ASCOF 1A) ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition** **Improving functional ability in people with long-term conditions** 2.2 Employment of people with long-term conditions***(ASCOF 1E PHOF 1.8) **Reducing time spent in hospital by people with long-term conditions** **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers** (ASCOF 1D)

3 Helping people to recover from episodes of ill health or following injury	***Overarching indicators*** 3a Emergency admissions for acute conditions that should not usually require hospital admission
4. Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care i GP services ii GP Out of hours services 4b Patient experience of hospital care 4c Friends and family test ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving hospitals' responsiveness to personal needs** 4.2 Responsiveness to in-patients personal needs **Improving people's experience of of accident and emergency services** 4.3 Patient experience of A&E services **Improving access to primary care services** 4.4 Access to i GP services **Improving the experience of care for people at the end of their lives** 4.6 Bereaved carers' views on the quality of care in the last 3 months of life **Improving people's experience of integrated care** 4.9 People's experience of integrated care***(ASCOF 3E)
Alignment across the health and social care system * Indicator shared with Public Health Outcomes Framework (PHOF) ** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF) *** Indicator shared with Adult Social Care Outcomes Framework	

Table 3 Public health outcomes framework for England, 2013–2016

Domain	**Objectives and indicators**
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities ***Indicators*** 4.5 Mortality from cancer

3 Summary of suggestions

3.1 Responses

In total 15 stakeholders responded to the 2-week engagement exercise 26/08/14-09/09/14. This includes 2 stakeholders that had no suggestions for quality improvement.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 5 for further consideration by the Committee.

NHS England's patient safety division did not submit any data for this topic.

Full details of all the suggestions provided are given in appendix 4 for information.

Table 5 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Information & decision support	
• Access to a clinical nurse specialist (MDT member)	CBC, TPC, WM, I Ltd, PCUK, SCM
• Patient decision aids	TPC, WM, I Ltd
• Discuss the options in an unbiased manner	CBC, SCM
• Offer men a personalised care plan	CBC, I Ltd, J, TPC, WM
Assessment and diagnosis	
• Offer a man with a raised PSA a biopsy only after multiple risk factors are taken into account	SCM
• Consider multiparametric MRI to determine whether a biopsy is needed	CBC, TPC, WM, I Ltd, SCM, PCUK
• Accreditation for undertaking and reporting mpMRI studies	SCM
• Consider transperineal template prostate cancer biopsy	CBC, TPC, WM, RCP, I Ltd
Localised and locally advanced prostate cancer	
• Active surveillance for low risk prostate cancer as an initial treatment strategy	SCM, BAUS, SCM
• Robotic radical prostatectomy should be performed in centres where more than 150 cases per year are performed	SCM, BAUS
• Positive surgical margin rate	BAUS
• Offer men undergoing radical external beam radiotherapy for localised prostate cancer a minimum dose of 74 Gy to the prostate at no more than 2 Gy per fraction	BAUS
• Use androgen deprivation therapy with radiotherapy in advanced prostate cancer	SCM
• Patients with higher cardiovascular risk should not be given androgen deprivation therapy	FP
• Timely referral of patients with disease progression following androgen deprivation therapy	J
• Use state of the art technology	SCR
Managing adverse effects of treatments	
• Sexual dysfunction & urinary incontinence (All treatments)	SCM, PCUK
• Radiation-induced enteropathy (All treatments)	SCM
• Sexual dysfunction (Hormone therapy)	FP, SCM, PCUK
Metastatic prostate cancer	
• Men with newly diagnosed prostate cancer metastatic to bone should be seen in a specialist clinic	BAUS, J, SCM
• Number of castration refractory patients offered systemic treatment (e.g. Docetaxel, Abiraterone)	NUH NHS TRUST
Areas not covered	
• PSA testing	CBC, TPC, WM, I Ltd, SCM, NUH NHS Trust
• Audit & development of metrics	SCM, PCUK, J
• Equality issues	TLGF,TPC, WM, I Ltd
	ACPOPC, CBC,

Suggested area for improvement	Stakeholders
• Role of the radiographer	SCR

ACPOPC, Association of Chartered Physiotherapists in Oncology and Palliative Care
BAUS, British Association of Urological Surgeons
CBC, Cancer Black Care
FP, Ferring Pharmaceuticals
I Ltd, Ipsen Ltd
J, Janssen
NUH NHS Trust, Nottingham University Hospital NHS Trust
PCUK, Prostate Cancer UK
RCP, Royal College of Pathologists
SCM, Special Committee Member
SCR, Society & College of Radiologists
TLGF, The Lesbian & Gay Foundation
TPC, Tackle Prostate Cancer
WM, Wicked Minds

4 Suggested improvement areas

4.1 Information and decision support

4.1.1 Summary of suggestions

Access to a clinical nurse specialist

Stakeholders highlighted that having a key clinical contact such as a clinical nurse specialist are more likely to have a positive experience as they can discuss any concerns they may have. A clinical nurse specialist can also play a key role in signposting to support services and better integration of care.

Patient decision aids

Stakeholders suggested the use of patient decision aids which are specially designed information resources and help patients make decisions about difficult treatment options.

Discuss the options in an unbiased manner

Stakeholders stated that patients should have an unbiased discussion with an MDT member about their treatment options so that they can make an informed decision.

Offer men a personalised care plan

Stakeholders suggested that men should be offered a personalised care plan as it offers the opportunity to discuss and ensure the patient is aware of the treatment options and consequences as well as the support they should receive as part of the care plan.

4.1.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee’s discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	**Suggested source guidance recommendations**
Access to a clinical nurse specialist (MDT member)	**Information & decision support** NICE CG175 Recommendation 1.1.2
Patient decision aids	**Information & decision support** NICE CG175 Recommendation 1.1.6
Discuss the options in an unbiased manner	**Information & decision support** NICE CG175 Recommendation 1.1.10
Offer men a personalised care plan	No recommendations

Access to a clinical nurse specialist (MDT member)

NICE CG175 – Recommendation 1.1.2

Offer men with prostate cancer individualised information tailored to their own needs. This information should be given by a healthcare professional (for example, a consultant or specialist nurse) and may be supported by written and visual media (for example, slide sets or DVDs). [2008]

Patient decision aids

NICE CG175 – Recommendation 1.1.6

Use a validated, up-to-date decision aid[i] in all urological cancer multidisciplinary teams (MDTs). Healthcare professionals trained in its use should offer it to men with localised prostate cancer when making treatment decisions. [2008]

Discuss the options in an unbiased manner

NICE CG175 – Recommendation 1.1.10

Tell men:

- about treatment options and their risks and benefits1 in an objective, unbiased manner and
- that there is limited evidence for some treatment options. [new 2014]

4.1.3 Current UK practice

Access to a clinical nurse specialist (MDT member)

The Cancer Patient Experience Survey (2013) demonstrates that patients with a clinical nurse specialist are more likely to report a positive experience of their care than patients without a clinical nurse specialist[ii]. However, according to the National Cancer Action Team (2011) there is variability in access to a specialist nurse specialist across the country[iii].

Patient decision aids

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

Discuss the options in an unbiased manner

A recent survey by Prostate Cancer UK has revealed that 1 in 4 men felt that they received 'too little' information from the NHS when they were diagnosed.[iv]

Offer men a personalised care plan

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

4.2 Assessment and diagnosis

4.2.1 Summary of suggestions

Biopsy

Stakeholders suggested that a man with a raised PSA should be offered a biopsy only after multiple risk factors are taken into account in order to reduce the number of unnecessary biopsies and therefore lower the risk of potential over diagnosis of clinically insignificant prostate cancer

Multiparametric MRI

Stakeholders highlighted the use of multiparametric MRI in determining whether a biopsy is needed.

Accreditation for undertaking and reporting mpMRI studies

Stakeholders suggested that staff should be accredited for the undertaking and reporting mpMRI as it is a complex and technically demanding test to perform and report. Its benefits can be reduced if it is not performed to the minimum standards.

Transperineal template

Stakeholders suggested the use of transperineal template prostate biopsy which they state as having higher diagnostic accuracy than transrectal ultrasound guided biopsy. However, NICE recommends transperineal template biopsy for patients with suspected prostate cancer who have had a negative or inconclusive transrectal biopsy (IPG354, 2010)

4.2.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 7 to help inform the Committee’s discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Biopsy	**Assessment & diagnosis** NICE CG175 Recommendations 1.2.1 and 1.2.5
Multiparametric MRI	**Assessment & diagnosis** NICE CG175 Recommendations 1.2.6 & 1.2.11
Accreditation for undertaking and reporting mpMRI studies	No recommendations
Transperineal template prostate cancer biopsy	No recommendations

Biopsy

NICE CG175 Recommendation 1.2.1

To help men decide whether to have a prostate biopsy, discuss with them their prostate-specific antigen (PSA) level, digital rectal examination (DRE) findings (including an estimate of prostate size) and comorbidities, together with their risk factors (including increasing age and black African-Caribbean family origin) and any history of a previous negative prostate biopsy. Do not automatically offer a prostate biopsy on the basis of serum PSA level alone. [2008]

NICE CG175 Recommendation 1.2.5

A core member of the urological cancer MDT should review the risk factors of all men who have had a negative first prostate biopsy, and discuss with the man that:

- there is still a risk that prostate cancer is present and
- the risk is slightly higher if any of the following risk factors are present:
  - the biopsy showed high-grade prostatic intra-epithelial neoplasia (HGPIN)
  - the biopsy showed atypical small acinar proliferation (ASAP)
  - abnormal digital rectal examination

Multiparametric MRI

NICE CG175 Recommendation 1.2.6

Consider multiparametric MRI (using T2- and diffusion-weighted imaging) for men with a negative transrectal ultrasound 10–12 core biopsy to determine whether another biopsy is needed. [new 2014]

NICE CG175 Recommendation 1.2.11

Consider multiparametric MRI, or CT if MRI is contraindicated, for men with histologically proven prostate cancer if knowledge of the T or N stage could affect management. [new 2014]

4.2.3 Current UK practice

Biopsy

Stakeholders highlighted that there is great inconsistency between urologists and centres on the threshold for biopsy.

Multiparametric MRI

Multiparametric MRI can improve diagnosis and reduce the need for biopsies[v] However, stakeholders have highlighted access inequalities to MRI.

Accreditation for undertaking and reporting mpMRI studies

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

Transperineal template prostate biopsy

An increasing number of centres are able to offer transperineal template prostate biopsy as it has double diagnostic accuracy than transrectal ultrasound guided biopsy and lower sepsis rate(CBC, TPC, WM, Ipsen Ltd). However, NICE recommends transperineal template biopsy for patients with suspected prostate cancer who have had a negative or inconclusive transrectal biopsy (IPG354, 2010)

4.3 Localised and locally advanced prostate cancer

4.3.1 Summary of suggestions

Active surveillance

Stakeholders suggested active surveillance for low risk prostate cancer as an initial treatment strategy. This can a) reduce overtreatment of low risk disease b) improve capacity for rapid treatment of high risk disease and c) decrease costs associated with treatment and management of side effects of radical treatment.

Radical prostatectomy

Stakeholders highlighted that robotic radical prostatectomy should be performed in centres where more than 150 cases per year are performed to achieve better outcomes for the men and more effective use of robotic systems.

Positive surgical margin rate

A stakeholder suggested the positive surgical margin rate for pT2 prostate cancer <20% which may be used as a good surrogate for quality of surgery.

Radiotherapy

Stakeholders suggested that men undergoing radical external beam radiotherapy for localised prostate cancer should be offered a minimum dose of 74 Gy to the prostate at no more than 2 Gy per fraction.

Stakeholders suggested the combined use of androgen deprivation therapy with radiotherapy in advanced prostate cancer.

Hormone therapy

Stakeholders emphasised that patients with higher cardiovascular risk should not be given androgen deprivation therapy.

Timely referral of patients with disease progression following androgen deprivation therapy

Stakeholders highlighted that delays in referral can lead to disease progression and affect the patient’s ability to access optimal treatment which could impact on survival and quality of life. Also, poor access to care for radiation enteropathy.

State of the art technology

Stakeholders suggested use of state of the art technology for improved tumour targeting and side effect management

4.3.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Active surveillance	**Localised and locally advanced prostate cancer** NICE CG175 Recommendation 1.3.7 & 1.3.8
Robotic radical prostatectomy	**Localised and locally advanced prostate cancer** NICE CG175 Recommendation 1.3.15 & 1.3.16
Positive surgical margin rate	No recommendations
Radiotherapy	**Localised and locally advanced prostate cancer** NICE CG175 Recommendation 1.3.17 & 1.3.19
Hormone therapy	No recommendations
Timely referral of men with disease progression	No recommendations
State of the art technology	No recommendations

Active surveillance

NICE CG175 Recommendation 1.3.7

Offer active surveillance (in line with recommendation 1.3.8) as an option to men with low-risk localised prostate cancer for whom radical prostatectomy or radical radiotherapy is suitable. [new 2014]

NICE CG175 Recommendation 1.3.8

Consider using the protocol in table 2 for men who have chosen active surveillance [new 2014]

Radical prostatectomy

NICE CG175 Recommendation 1.3.15

Commissioners of urology services should consider providing robotic surgery to treat localised prostate cancer. [new 2014]

NICE CG175 Recommendation 1.3.16

Commissioners should ensure that robotic systems for the surgical treatment of localised prostate cancer are cost effective by basing them in centres that are expected to perform at least 150 robot-assisted laparoscopic radical prostatectomies per year. [new 2014]

Radiotherapy

NICE CG175 Recommendation 1.3.17

Offer men undergoing radical external beam radiotherapy for localised prostate cancer a minimum dose of 74 Gy to the prostate at no more than 2 Gy per fraction. [2008]

NICE CG175 Recommendation 1.3.19

Offer men with intermediate- and high-risk localised prostate cancer a combination of radical radiotherapy and androgen deprivation therapy, rather than radical radiotherapy or androgen deprivation therapy alone. [new 2014]

4.3.3 Current UK practice

Active surveillance

Active surveillance is recommended as an option for men with low risk disease in whom surgery/radiotherapy is suitable but stakeholders reported there are differences in practice across the country that means not all men are offered active surveillance.

Robotic radical prostatectomy

Robotic radical prostatectomy is growing in popularity. Evidence demonstrates better outcomes in higher volume centres and more cost effective use of robotic systems.

Radiotherapy

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

Hormone therapy

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

Timely referral of men with disease progression

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

State of the art technology

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

4.4 Managing adverse effects of prostate cancer

4.4.1 Summary of suggestions

Managing adverse effects of treatments

Stakeholders highlighted the importance of managing the adverse effects of treatments.

Managing adverse effects of hormone therapy

Stakeholders highlighted the importance of managing the adverse effects of hormone treatment.

4.4.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
	Managing Adverse effects of radical treatment
Sexual dysfunction & urinary incontinence	NICE CG175 Recommendation 1.3.31 & 1.3.32
Radiation-induced enteropathy	NICE CG175 Recommendation 1.3.37
	Managing adverse effects of hormone therapy
Sexual dysfunction	NICE CG175 Recommendation 1.4.6, 1.4.7, 1.4.8 & 1.4.9

Managing adverse effects of treatments

<u>NICE CG175 Recommendation 1.3.31</u>

Ensure that men have early and ongoing access to specialist erectile dysfunction services. [2008, amended 2014]

<u>NICE CG175 Recommendation 1.3.32</u>

Offer men with prostate cancer who experience loss of erectile function phosphodiesterase type 5 (PDE5) inhibitors to improve their chance of spontaneous erections. [2008]

<u>NICE CG175 Recommendation 1.3.37</u>

Ensure that men with signs or symptoms of radiation-induced enteropathy are offered care from a team of professionals with expertise in radiation-induced enteropathy (who may include oncologists, gastroenterologists, bowel surgeons, dietitians and specialist nurses). [new 2014]

Managing adverse effects of hormone therapy

NICE CG175 Recommendation 1.4.6

Before starting androgen deprivation therapy, tell men and, if they wish, their partner, that long-term androgen deprivation will cause a reduction in libido and possible loss of sexual function. [new 2014]

NICE CG175 Recommendation 1.4.7

Advise men and, if they wish, their partner, about the potential loss of ejaculation and fertility associated with long-term androgen deprivation and offer sperm storage. [new 2014]

NICE CG175 Recommendation 1.4.8

Ensure that men starting androgen deprivation therapy have access to specialist erectile dysfunction services. [new 2014]

NICE CG175 Recommendation 1.4.9

Consider referring men who are having long-term androgen deprivation therapy, and their partners, for psychosexual counselling. [new 2014]

4.4.3 Current UK practice

Managing adverse effects of treatments

Men can experience significant side effects following treatment. Prostate Cancer UK's 2012 survey found that 1 in 5 men described the care and support they received for the side effects they experienced as 'bad' or 'very bad'. After completing treatment, 1 in 3 men said that they received 'too little' after care for the treatment of side effects[vi].

Managing adverse effects of hormone therapy

Men can experience significant side effects following treatment. Prostate Cancer UK's 2012 survey found that 1 in 5 men described the care and support they received for the side effects they experienced as 'bad' or 'very bad'. After completing treatment, 1 in 3 men said that they received 'too little' after care for the treatment of side effects.

4.5 Metastatic prostate cancer

4.5.1 Summary of suggestions

Specialist clinic

Stakeholders highlighted that men with newly diagnosed prostate cancer metastatic to bone should be seen in a specialist clinic where consideration should be given to bone mineralisation assessment and bone protection. This can prevent skeletal-related events during treatment of the cancer.

Systemic treatment

Stakeholders suggested systemic treatment for castration refractory patients.

4.5.2 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 10 to help inform the Committee's discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Specialist clinic	**Metastatic prostate cancer** NICE CG175 Recommendation 1.5.1
Systemic treatment	**Metastatic prostate cancer** No recommendations

Specialist clinic

NICE CG175 Recommendation 1.5.1

Offer men with metastatic prostate cancer tailored information and access to specialist urology and palliative care teams to address the specific needs of men with metastatic prostate cancer. Offer them the opportunity to discuss any significant changes in their disease status or symptoms as these occur. [2008]

4.5.3 Current UK practice

Specialist clinic

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

Systemic treatment

Stakeholders highlighted that systemic therapy prolongs survival in stage 4 castration refractory prostate cancer but utilisation of these treatments has been variable across the country.

4.6 Areas not covered

4.6.1 Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise however they were felt to be outside the remit of quality standards or are addressed by other NICE quality standard topics.

This quality standard will cover the care of men referred to secondary care with suspected or diagnosed prostate cancer, including follow-up in primary care for men with diagnosed prostate cancer.

There will be an opportunity for the QSAC to discuss these areas at the end of the session.

PSA testing

Stakeholders suggested the use of PSA testing for high risk men who present to primary care. This is to aid diagnosis in asymptomatic men. This area of quality improvement refers to the initial assessment in primary care and is addressed in NICE clinical guideline 27: referral guidelines or suspected cancer.

Audit & development of metrics

Stakeholders suggested the use of audit to better understand current pathways and establish a baseline before setting standards. They also suggested the development of metrics for metastatic disease. This is not in the remit of this quality standard.

Equality issues

Stakeholders highlighted the care needs of black men and gay, bisexual and transgender patients. Those groups of men will be considered in the diversity, equality and language section of the quality standard.

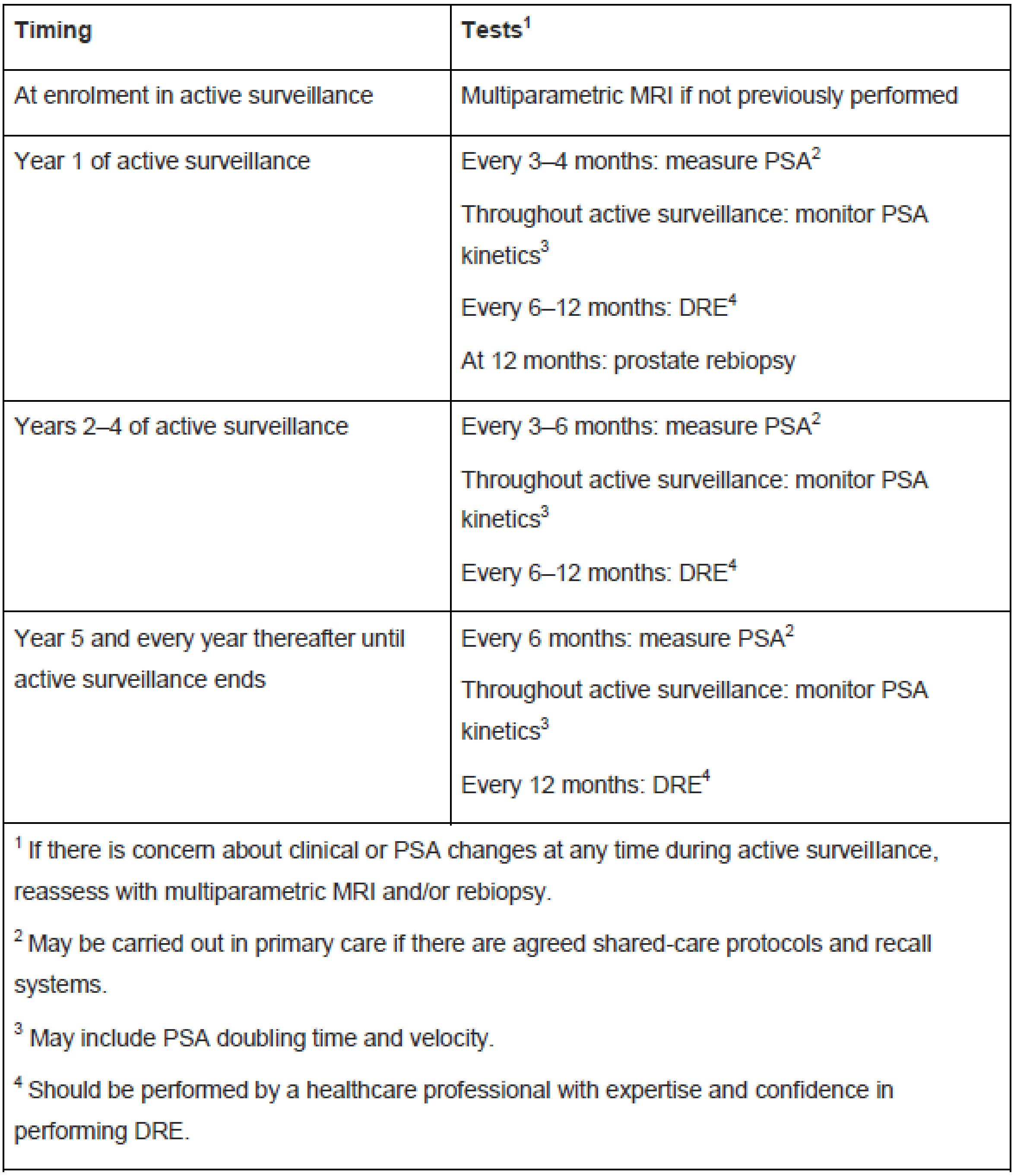
Stakeholders highlighted that all men should access to treatment but there are variations in patient experience and mortality across the UK. Those variations will be considered in the diversity, equality and language section of the quality standard.

Role of the radiographer

A stakeholder highlighted the role of the radiographer as part of the multidisciplinary team. This is not in the remit of the quality standard.

Appendix 1: Additional information

Table 2 Protocol for active surveillance



Timing	**Tests**[1]
At enrolment in active surveillance	Multiparametric MRI if not previously performed
Year 1 of active surveillance	Every 3–4 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3] Every 6–12 months: DRE[4] At 12 months: prostate rebiopsy
Years 2–4 of active surveillance	Every 3–6 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3] Every 6–12 months: DRE[4]
Year 5 and every year thereafter until active surveillance ends	Every 6 months: measure PSA[2] Throughout active surveillance: monitor PSA kinetics[3] Every 12 months: DRE[4]

[1] If there is concern about clinical or PSA changes at any time during active surveillance, reassess with multiparametric MRI and/or rebiopsy.

[2] May be carried out in primary care if there are agreed shared-care protocols and recall systems.

[3] May include PSA doubling time and velocity.

[4] Should be performed by a healthcare professional with expertise and confidence in performing DRE.

Appendix 2: Key priorities for implementation (CG175)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

Information and decision support for men with prostate cancer, their partners and carers

Decision support

Discuss all relevant management options recommended in this guideline with men with prostate cancer and their partners or carers, irrespective of whether they are available through local services. [2008] [recommendation 1.1.9]

Assessment

Magnetic resonance imaging for rebiopsy

Consider multiparametric MRI (using T2- and diffusion-weighted imaging) for men with a negative transrectal ultrasound 10–12 core biopsy to determine whether another biopsy is needed. [new 2014] [recommendation 1.2.6]

Staging

Consider multiparametric MRI, or CT if MRI is contraindicated, for men with histologically proven prostate cancer if knowledge of the T or N stage could affect management. [new 2014] [recommendation 1.2.11]

Low-risk localised prostate cancer

Active surveillance

Offer active surveillance (in line with recommendation 1.3.8) as an option to men with low-risk localised prostate cancer for whom radical prostatectomy or radical radiotherapy is suitable. [new 2014] [recommendation 1.3.7]

Consider using the protocol in table 2 for men who have chosen active surveillance. [new 2014] [recommendation 1.3.8]

Intermediate- and high-risk localised prostate cancer

Active surveillance

Consider active surveillance (in line with recommendation 1.3.8) for men with intermediate-risk localised prostate cancer who do not wish to have immediate radical prostatectomy or radical radiotherapy. [new 2014] [recommendation 1.3.11]

Radical treatment

Offer men with intermediate- and high-risk localised prostate cancer a combination of radical radiotherapy and androgen deprivation therapy, rather than radical radiotherapy or androgen deprivation therapy alone. [new 2014] [recommendation 1.3.19]

Managing adverse effects of radical treatment

Sexual dysfunction

Ensure that men have early and ongoing access to specialist erectile dysfunction services. [2008, amended 2014] [recommendation 1.3.31]

Radiation-induced enteropathy

Ensure that men with signs or symptoms of radiation-induced enteropathy are offered care from a team of professionals with expertise in radiation-induced enteropathy (who may include oncologists, gastroenterologists, bowel surgeons, dietitians and specialist nurses). [new 2014] [recommendation 1.3.37]

Men having hormone therapy

Consider intermittent therapy for men having long-term androgen deprivation therapy (not in the adjuvant setting), and include discussion with the man, and his partner, family or carers if he wishes, about:

- the rationale for intermittent therapy and
- the limited evidence for reduction in side effects from intermittent therapy and
- the effect of intermittent therapy on progression of prostate cancer. [new 2014] [recommendation 1.4.1]

Appendix 3: Glossary

Active surveillance

This is part of a „curative‟ strategy and is aimed at men with localised prostate cancer who are suitable for radical treatments, keeping them within a “window of curability” whereby only those whose tumours are showing signs of progressing, or those with a preference for intervention are considered for radical treatment. Active surveillance may thus avoid or delay the need for radiation or surgery.

Androgen deprivation

A treatment that lowers testosterone levels, that is, bilateral orchidectomy or treatment with LHRH agonists (e.g. goserelin).

Biopsy

Removal of a sample of tissue from the body to assist in diagnosis of a disease.

Decision aids

Booklets or videos/DVDs that provide information about the disease, treatment options and outcomes, and help patients to explore how their individual values impact on their treatment decision.

Hormonal therapy

Treatment of cancer by removing and/or, blocking the effects of hormones which stimulate the growth of prostate cancer cells.

Magnetic resonance imaging (MRI)

A non-invasive method of imaging using fluctuating high magnetic fields to depict tissues and organs (also known as nuclear magnetic resonance).

Multiparametric MRI

Magnetic Resonance Imaging study that incorporates anatomical and functional information about a body part. The functional information may include one or more sequences based on diffusion weighted imaging, dynamic contrast enhanced imaging or magnetic resonance spectroscopy.

Metastatic prostate cancer

Cancer which has spread from the primary site in the prostate to the lymph nodes, bones or other parts of the body.

Multi Disciplinary Team (MDT)

A team with members from different health care professions (e.g. urology, oncology, pathology, radiology, nursing).

Prostate Specific Antigen (PSA)

A protein produced by the prostate gland and identified in the blood. Men with prostate cancer tend to have higher levels of PSA in their blood (although most men with prostate cancer have normal PSA levels). PSA levels may also be increased by conditions other than cancer and levels tend to increase naturally with age.

Radiation induced enteropathy

Gastrointestinal problems arising a result of radiation treatment. Although both acute and late side effects may occur, this usually refers to chronic problems such as bleeding, stricture, ulceration, flatulence, pain and change in bowel habit.

Radical treatment

Treatment given with the aim of cure, rather than just improving symptoms.

Radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill tumour cells. This can either be EBRT or brachytherapy.

Appendix 4: Suggestions from stakeholder engagement exercise

[Include all stakeholder comments and all SCM comments (labelled SCM1, SCM2, SCM3...)]

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
001	Cancer Black Care	Information and support	Providing people on treatment for their prostate cancer with a personalised care plan offers the opportunity to discuss and ensure the patient is aware of all treatment expectations, consequences of treatment such as erectile dysfunction, incontinence, and bone health, and access to care and support they should receive as part of their care plan. In addition, having the opportunity to meet with other people living with prostate cancer through support groups can offer an immense sense of support and relief that they are not alone. The Cancer Patient Experience Survey demonstrates that patients with a CNS are more likely to report a positive experience of their care than patients without a CNS. Therefore having a key clinical contact such as a clinical nurse	The 2012/13 Cancer Patient Experience Survey demonstrated that 87% of people diagnosed with prostate cancer were given the name of a CNS compared to 93% of people diagnosed with breast cancer. The reason may be reflected by the 2011 CNS Census which showed that urology CNS's have a caseload of 176 new patients per year compared to breast cancer CNS's with a case load of 79 per annum. The National Cancer Survivorship Initiative (NCSI) highlights a number of key interventions that could make an immediate difference, including the introduction of an integrated recovery package of: • Structured holistic needs assessment and care planning • Treatment summaries (linking up primary and secondary care) • Patient education and support events (Health and Wellbeing Clinics) • Advice about, and access to, schemes that support people to undertake physical activity and healthy	1. Cancer Patient Experience Survey 2013. http://www.healthwatchbathnes.co.uk/sites/default/files/Cancer%20Report%202013%20Final%20-%20embargoed%20until%201100%2030.8.13.pdf 2. 2011 CNS Census http://www.bdng.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf (page 10) 3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf 4. The hidden price of getting treatment. Macmillan Cancer Support. June 2006. http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pd

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			specialist is vital to ensure that the patient and their carer/family members are able to speak to a single point of contact to discuss any questions or concerns they may have during the course of their care.	weight management. Many cancer patients and their families are dealing with a huge financial burden as a result of their illness. According to research conducted by Macmillan 9 out of 10 cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer. It also highlights that far too many cancer patients are not made aware of the help that may be available to them, such as through the Hospital Travel Costs Scheme or the NHS Low Income Scheme. It is therefore important to also provide financial and other social care related support available to patients and their families as part of the information and support included in their personalised care plan.	
002	Cancer Black Care	Integrated care	With more and more people becoming long term survivors of prostate cancer there is an urgent need for essential follow up care to deliver timely access to treatments as and when necessary and	Many men with prostate cancer have concerns whether their primary care provider has the ability to provide care that is specific to their needs. There needs to be a clearer definition as to who is responsible for the management of the side effects of	1 Living with and beyond cancer: taking action to improve outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). March 2013. http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			the alleviation of suffering whilst ensuring that no one falls through the cracks. In particular integration of services should support proactive management of side effects, long-term surveillance, re-activate care (if there is recurrence), survivorship, and access to palliative care. People living with prostate cancer would benefit from an integrated approach to their care, managed by the healthcare professional that is appropriate to their stage of disease for the rest of their lives.	prostate cancer treatment. It is clear that primary care should take a bigger role as it is they who inevitably care not only for prostate cancer survivors but all those affected by prostate cancer. The link between primary care and the prostate cancer specialists' team needs to be seamless. In order to ensure people are adequately supported to manage these we believe that there must be a seamless integration of well co-ordinated cancer care across primary (GP), secondary (hospital), and social care. This includes clear lines of responsibility and accountability with staff provided with the necessary training and links to resources. Integrated care means all health and social care services working together across organisational and professional boundaries to ensure individual patients get the care, information, support and treatment they need, when they need it. This includes ensuring people are informed about their particular condition, treatment	2 Patients' experience of integrated care: A report from the Cancer Campaigning Group. November 2012

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				options, side effects and care pathway. Care is best integrated when patients have access to a specialist nurse or other key worker, when they are actively involved in decisions about their treatment, when referrals across care services are efficient and when information is shared amongst relevant professionals involved in a person's treatment and care. This requires clear accountability and responsibility across the primary and secondary care interface with clear links to social services.	
003	Tackle prostate cancer (Prostate Cancer Support Federation)	Integrated care	With more and more people becoming long term survivors of prostate cancer there is an urgent need for essential follow up care to deliver timely access to treatments as and when necessary and the alleviation of suffering whilst ensuring that no one falls through the cracks. In particular integration of services should support proactive management of side effects, long-term surveillance, re-activate care (if there is recurrence),	Many men with prostate cancer have concerns whether their primary care provider has the ability to provide care that is specific to their needs. There needs to be a clearer definition as to who is responsible for the management of the side effects of prostate cancer treatment. It is clear that primary care should take a bigger role as it is they who inevitably care not only for prostate cancer survivors but all those affected by prostate cancer. The link between primary care and the prostate cancer specialists' team needs to be seamless.	1 Living with and beyond cancer: taking action to improve outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). March 2013. http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf 2 Patients' experience of integrated care: A report from the Cancer Campaigning Group. November 2012

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			survivorship, and access to palliative care. People living with prostate cancer would benefit from an integrated approach to their care, managed by the healthcare professional that is appropriate to their stage of disease for the rest of their lives	In order to ensure people are adequately supported to manage these we believe that there must be a seamless integration of well co-ordinated cancer care across primary (GP), secondary (hospital), and social care. This includes clear lines of responsibility and accountability with staff provided with the necessary training and links to resources. Integrated care means all health and social care services working together across organisational and professional boundaries to ensure individual patients get the care, information, support and treatment they need, when they need it. This includes ensuring people are informed about their particular condition, treatment options, side effects and care pathway. Care is best integrated when patients have access to a specialist nurse or other key worker, when they are actively involved in decisions about their treatment, when referrals across care services are efficient and when information is shared amongst relevant professionals involved in a person’s treatment and care. This	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				requires clear accountability and responsibility across the primary and secondary care interface with clear links to social services.	
004	Wicked Minds		Providing people on treatment for their prostate cancer with a personalised care plan offers the opportunity to discuss and ensure the patient is aware of all treatment expectations, consequences of treatment such as erectile dysfunction, incontinence, and bone health, and access to care and support they should receive as part of their care plan. In addition, having the opportunity to meet with other people living with prostate cancer through support groups can offer an immense sense of support and relief that they are not alone. The Cancer Patient Experience Survey demonstrates that patients with a CNS are more likely to	The 2012/13 Cancer Patient Experience Survey demonstrated that 87% of people diagnosed with prostate cancer were given the name of a CNS compared to 93% of people diagnosed with breast cancer. The reason may be reflected by the 2011 CNS Census which showed that urology CNS's have a caseload of 176 new patients per year compared to breast cancer CNS's with a case load of 79 per annum. The National Cancer Survivorship Initiative (NCSI) highlights a number of key interventions that could make an immediate difference, including the introduction of an integrated recovery package of: • Structured holistic needs assessment and care planning • Treatment summaries (linking up primary and secondary care) • Patient education and support	1. Cancer Patient Experience Survey 2013. http://www.healthwatchbathnes.co.uk/sites/default/files/Cancer%20Report%202013%20Final%20-%20embargoed%20until%201100%2030.8.13.pdf 2. 2011 CNS Census http://www.bdng.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf (page 10) 3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf 4. The hidden price of getting treatment. Macmillan Cancer Support. June 2006. http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pd

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			report a positive experience of their care than patients without a CNS. Therefore having a key clinical contact such as a clinical nurse specialist is vital to ensure that the patient and their carer/family members are able to speak to a single point of contact to discuss any questions or concerns they may have during the course of their care.	events (Health and Wellbeing Clinics) • Advice about, and access to, schemes that support people to undertake physical activity and healthy weight management. Many cancer patients and their families are dealing with a huge financial burden as a result of their illness. According to research conducted by Macmillan 9 out of 10 cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer. It also highlights that far too many cancer patients are not made aware of the help that may be available to them, such as through the Hospital Travel Costs Scheme or the NHS Low Income Scheme. It is therefore important to also provide financial and other social care related support available to patients and their families as part of the information and support included in their personalised care plan.	
005	Wicked	Integrated care	With more and more people	Many men with prostate cancer have	1. Living with and beyond cancer: taking action

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Minds		becoming long term survivors of prostate cancer there is an urgent need for essential follow up care to deliver timely access to treatments as and when necessary and the alleviation of suffering whilst ensuring that no one falls through the cracks. In particular integration of services should support proactive management of side effects, long-term surveillance, re-activate care (if there is recurrence), survivorship, and access to palliative care. People living with prostate cancer would benefit from an integrated approach to their care, managed by the healthcare professional that is appropriate to their stage of disease for the rest of their lives.	concerns whether their primary care provider has the ability to provide care that is specific to their needs. There needs to be a clearer definition as to who is responsible for the management of the side effects of prostate cancer treatment. It is clear that primary care should take a bigger role as it is they who inevitably care not only for prostate cancer survivors but all those affected by prostate cancer. The link between primary care and the prostate cancer specialists' team needs to be seamless. In order to ensure people are adequately supported to manage these we believe that there must be a seamless integration of well co-ordinated cancer care across primary (GP), secondary (hospital), and social care. This includes clear lines of responsibility and accountability with staff provided with the necessary training and links to resources. Integrated care means all health and social care services working together across organisational and professional boundaries to ensure individual	to improve outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). March 2013. http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf 2. Patients' experience of integrated care: A report from the Cancer Campaigning Group. November 2012

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				patients get the care, information, support and treatment they need, when they need it. This includes ensuring people are informed about their particular condition, treatment options, side effects and care pathway. Care is best integrated when patients have access to a specialist nurse or other key worker, when they are actively involved in decisions about their treatment, when referrals across care services are efficient and when information is shared amongst relevant professionals involved in a person's treatment and care. This requires clear accountability and responsibility across the primary and secondary care interface with clear links to social services.	
006	Tackle Prostate Cancer	Information and support	Providing people on treatment for their prostate cancer with a personalised care plan offers the opportunity to discuss and ensure the patient is aware of all treatment expectations, consequences of treatment such as erectile dysfunction, incontinence, and bone health, and access to care	The 2012/13 Cancer Patient Experience Survey demonstrated that 87% of people diagnosed with prostate cancer were given the name of a CNS compared to 93% of people diagnosed with breast cancer. The reason may be reflected by the 2011 CNS Census which showed that urology CNS's have a caseload of 176 new patients per year compared to breast cancer CNS's with a case load	1. Cancer Patient Experience Survey 2013. http://www.healthwatchbathnes.co.uk/sites/default/files/Cancer%20Report%202013%20Final%20-%20embargoed%20until%201100%2030.8.13.pdf 2. 2011 CNS Census http://www.bdng.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf (page 10) 3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			and support they should receive as part of their care plan. In addition, having the opportunity to meet with other people living with prostate cancer through support groups can offer an immense sense of support and relief that they are not alone. The Cancer Patient Experience Survey demonstrates that patients with a CNS are more likely to report a positive experience of their care than patients without a CNS. Therefore having a key clinical contact such as a clinical nurse specialist is vital to ensure that the patient and their carer/family members are able to speak to a single point of contact to discuss any questions or concerns they may have during the course of their care.	of 79 per annum. The National Cancer Survivorship Initiative (NCSI) highlights a number of key interventions that could make an immediate difference, including the introduction of an integrated recovery package of: • Structured holistic needs assessment and care planning • Treatment summaries (linking up primary and secondary care) • Patient education and support events (Health and Wellbeing Clinics) • Advice about, and access to, schemes that support people to undertake physical activity and healthy weight management. Many cancer patients and their families are dealing with a huge financial burden as a result of their illness. According to research conducted by Macmillan 9 out of 10 cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer. It also highlights that far too many cancer patients are not made aware of the help that may be available to them, such as through the Hospital Travel	National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf 4. The hidden price of getting treatment. Macmillan Cancer Support. June 2006. http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pd

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				Costs Scheme or the NHS Low Income Scheme. It is therefore important to also provide financial and other social care related support available to patients and their families as part of the information and support included in their personalised care plan.	
007	Ipsen Limited	Information and support	Providing people on treatment for their prostate cancer with a personalised care plan offers the opportunity to discuss and ensure the patient is aware of all treatment expectations, consequences of treatment such as erectile dysfunction, incontinence, and bone health, and access to care and support they should receive as part of their care plan. In addition, having the opportunity to meet with other people living with prostate cancer through support groups can offer an immense sense of support and relief that they are not alone.	The 2012/13 Cancer Patient Experience Survey demonstrated that 87% of people diagnosed with prostate cancer were given the name of a CNS compared to 93% of people diagnosed with breast cancer. The reason may be reflected by the 2011 CNS Census which showed that urology CNS's have a caseload of 176 new patients per year compared to breast cancer CNS's with a case load of 79 per annum. The National Cancer Survivorship Initiative (NCSI) highlights a number of key interventions that could make an immediate difference, including the introduction of an integrated recovery package of: • Structured holistic needs	1. Cancer Patient Experience Survey 2013. http://www.healthwatchbathnes.co.uk/sites/default/files/Cancer%20Report%202013%20Final%20-%20embargoed%20until%201100%2030.8.13.pdf 2. 2011 CNS Census http://www.bdng.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf (page 10) 3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf 4. The hidden price of getting treatment. Macmillan Cancer Support. June 2006. http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pd

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			The Cancer Patient Experience Survey demonstrates that patients with a CNS are more likely to report a positive experience of their care than patients without a CNS. Therefore having a key clinical contact such as a clinical nurse specialist is vital to ensure that the patient and their carer/family members are able to speak to a single point of contact to discuss any questions or concerns they may have during the course of their care.	assessment and care planning • Treatment summaries (linking up primary and secondary care) • Patient education and support events (Health and Wellbeing Clinics) • Advice about, and access to, schemes that support people to undertake physical activity and healthy weight management. Many cancer patients and their families are dealing with a huge financial burden as a result of their illness. According to research conducted by Macmillan 9 out of 10 cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer. It also highlights that far too many cancer patients are not made aware of the help that may be available to them, such as through the Hospital Travel Costs Scheme or the NHS Low Income Scheme. It is therefore important to also provide financial and other social care related support available to patients and their families as part of the information and support included in their personalised	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				care plan.	
008	Ipsen Limited	Integrated care	With more and more people becoming long term survivors of prostate cancer there is an urgent need for essential follow up care to deliver timely access to treatments as and when necessary and the alleviation of suffering whilst ensuring that no one falls through the cracks. In particular integration of services should support proactive management of side effects, long-term surveillance, re-activate care (if there is recurrence), survivorship, and access to palliative care. People living with prostate cancer would benefit from an integrated approach to their care, managed by the healthcare professional that is appropriate to their stage of disease for the rest of their lives.	Many men with prostate cancer have concerns whether their primary care provider has the ability to provide care that is specific to their needs. There needs to be a clearer definition as to who is responsible for the management of the side effects of prostate cancer treatment. It is clear that primary care should take a bigger role as it is they who inevitably care not only for prostate cancer survivors but all those affected by prostate cancer. The link between primary care and the prostate cancer specialists' team needs to be seamless. In order to ensure people are adequately supported to manage these we believe that there must be a seamless integration of well co-ordinated cancer care across primary (GP), secondary (hospital), and social care. This includes clear lines of responsibility and accountability with staff provided with the necessary training and links to resources. Integrated care means all health and social care services working together	1. Living with and beyond cancer: taking action to improve outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). March 2013. http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf 2. Patients' experience of integrated care: A report from the Cancer Campaigning Group. November 2012

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				across organisational and professional boundaries to ensure individual patients get the care, information, support and treatment they need, when they need it. This includes ensuring people are informed about their particular condition, treatment options, side effects and care pathway. Care is best integrated when patients have access to a specialist nurse or other key worker, when they are actively involved in decisions about their treatment, when referrals across care services are efficient and when information is shared amongst relevant professionals involved in a person's treatment and care. This requires clear accountability and responsibility across the primary and secondary care interface with clear links to social services.	
009	Prostate Cancer UK	Specialist support for side effects following treatment	Many men experience life-changing side effects from prostate cancer treatment and require support from healthcare professionals for some time after treatment has finished.	Not all men with prostate cancer are receiving information, care and support for the life changing side effects that result from their treatment. The 2013 NCPES in England (8) found that: - 36% of prostate cancer patients were not told about treatment	1. Mills ME, Sullivan K. The importance of information giving for patients newly diagnosed with cancer: a review of the literature. J Clin Nurs. 1999 Nov;8(6):631–42. 2. Fallowfield L, Ford S, Lewis S. No news is not good news: information preferences of patients with cancer. Psychooncology. 1995 Oct;4(3):197–202. 3. Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, et al. Information needs of cancer

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			A 2012 survey of 866 prostate cancer survivors in England showed that on average 58% of prostate cancer patients were unable to have an erection 1-5 years after treatment, with a further 11% having significant difficulty in having or maintaining an erection, 13% having difficulty controlling their bowels, and 39% having some degree of urinary leakage (17,18). The presence of urinary leakage was significantly associated with poorer quality of life. Men often have particular wellbeing needs following active treatment. Psychological distress, depression and anxiety are particularly present, and debilitating, among men no longer being treated (25). Research has shown that 72% of men reported a need for psychological care and 82% reported some	side effects that could affect them in the future - 26% of prostate cancer patients did not have possible side effects explained in an understandable way - 17% of prostate cancer patients were not given written information about side effects Prostate Cancer UK's 2012 survey found that 1 in 5 men (19%) described the care and support they received for the side effects they experienced as 'bad' or 'very bad'. After completing treatment, 1 in 3 men (31%) said that they received 'too little' aftercare for the treatment of side effects (11). Although there is emerging evidence that men have significant wellbeing needs, service provision can be patchy at best (10,28). The CNS plays an important role in signposting to relevant support services; however, there is variability in access to CNSs (8,9).	patients in west Scotland: cross sectional survey of patients' views. BMJ. 1996 Sep 21;313(7059):724–6. 4. Ream E, Richardson A. The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. Eur J Cancer Care (Engl). 1996 Sep;5(3):132–8. 5. Department of Health. Improving Outcomes: A Strategy for Cancer [Internet]. 2011. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf 6. Department of Health. National Cancer Patient Experience Survey Programme: 2010 National Survey Report [Internet]. 2010. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216682/dh_122520.pdf 7. Department of Health. National Cancer Patient Experience Survey 2011/12 - National Report [Internet]. 2012. Available from: https://www.wp.dh.gov.uk/publications/files/2012/08/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf 8. Quality Health. Cancer Patient Experience Survey 2012-13 National Report [Internet]. 2013. Available from: http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file 9. National Cancer Action Team. Clinical Nurse Specialists in Cancer Care; Provision, Proportion and

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			depression or anxiety (26). This high level of reported distress is particularly significant given the general under-reporting of psychological distress by men (27).	New research has shown the importance of early intervention in treating erectile dysfunction (29) – access to early treatment and nerve sparing surgery needs to be improved to better preserve sexual function.	Performance. A census of the cancer specialist nurse workforce in England 2011 [Internet]. 2012. Available from: http://webarchive.nationalarchives.gov.uk/20130513211237/http:/ncat.nhs.uk/sites/default/files/NCAT%20Census%20of%20the%20Cancer%20Specialist%20Nurse%20Workforce%202011.pdf 10. BritainThinks for Prostate Cancer UK. Findings from qualitative research carried out by BritainThinks. Total sample size was 53 adults affected by prostate cancer across the UK (including 8 partners of men with prostate cancer). Fieldwork was undertaken between 5th February and 13th March 2014, comprising telephone interviews, focus groups and online qualitative research. 2014. 11. Prostate Cancer UK. Men's views on quality care in prostate cancer: What does good quality care mean for men with prostate cancer? [Internet]. 2012. Available from: http://prostatecanceruk.org/media/1559431/prostate_cancer_uk_quality_care_survey_report_june_2012.pdf 12. National Institute for Health and Care Excellence. Prostate cancer: Diagnosis and treatment. NICE clinical guideline 175 [Internet]. 2014 [cited 2013 Apr 25]. Available from: http://www.nice.org.uk/nicemedia/live/14348/66232/66232.pdf 13. Department of Health. Our health, our care, our say: a new direction for community services [Internet]. 2006. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272238/6737.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					14. Cancer Care Review « National Cancer Survivorship Initiative [Internet]. [cited 2014 Sep 5]. Available from: http://www.ncsi.org.uk/what-we-are-doing/cancer-care-review/ 15. Clark JA, Wray NP, Ashton CM. Living with treatment decisions: regrets and quality of life among men treated for metastatic prostate cancer. J Clin Oncol Off J Am Soc Clin Oncol. 2001 Jan 1;19(1):72–80. 16. Steer AN, Aherne NJ, Gorzynska K, Hoffman M, Last A, Hill J, et al. Decision regret in men undergoing dose-escalated radiation therapy for prostate cancer. Int J Radiat Oncol Biol Phys. 2013 Jul 15;86(4):716–20. 17. Glaser AW, Fraser LK, Corner J, Feltbower R, Morris EJA, Hartwell G, et al. Patient-reported outcomes of cancer survivors in England 1-5 years after diagnosis: a cross-sectional survey. BMJ Open. 2013;3(4). 18. Department of Health. Quality of Life of Cancer Survivors in England - Report on a pilot survey using Patient Reported Outcome Measures (PROMS) [Internet]. Department of Health; 2012. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/267042/9284-TSO-2900701-PROMS-1.pdf 19. Prostate Cancer UK. Men United v Prostate Cancer: Five inequalities, five solutions [Internet]. 2014. Available from: http://prostatecanceruk.org/media/2339836/inequalities-report.pdf 20. Moore CM, Robertson NL, Arsanious N, Middleton T, Villers A, Klotz L, et al. Image-guided prostate biopsy using magnetic resonance imaging-derived targets: a systematic review. Eur Urol. 2013

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					Jan;63(1):125–40. 21. National Health Service. The NHS Constitution: the NHS belongs to us all [Internet]. 2013. Available from: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf 22. National Institute for Health and Care Excellence. Costing statement: prostate cancer: diagnosis and treatment: Implementing the NICE guideline on prostate cancer (CG175) [Internet]. 2014. Available from: http://www.nice.org.uk/guidance/cg175/resources/cg175-prostate-cancer-costing-statement2 23. National Cancer Intelligence Network. Treatment Routes in Prostate Cancer Urological Cancers SSCRG [Internet]. 2012. Available from: http://www.ncin.org.uk/view?rid=1260 24. MRC Clinical Trials Unit. PROMIS - Prostate MRI Imaging Study: Evaluation of Multi-Parametric Magnetic Imaging in the Diagnosis and Characterisation of Prostate Cancer [Internet]. [cited 2014 May 22]. Available from: http://www.ctu.mrc.ac.uk/research_areas/study_details.aspx?s=126 25. Eton DT, Lepore SJ. Prostate cancer and health-related quality of life: a review of the literature. Psychooncology. 2002 Aug;11(4):307–26. 26. Ream E, Quennell A, Fincham L, Faithfull S, Khoo V, Wilson-Barnett J, et al. Supportive care needs of men living with prostate cancer in England: a survey.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					Br J Cancer. 2008 Jun 17;98(12):1903–9. 27. Bloch S, Love A, Macvean M, Duchesne G, Couper J, Kissane D. Psychological adjustment of men with prostate cancer: a review of the literature. Biopsychosoc Med. 2007;1:2. 28. ICF International for Prostate Cancer UK. Research into wellbeing services for men with prostate cancer. 2014. 29. Kirby MG, White ID, Butcher J, Challacombe B, Coe J, Grover L, et al. Development of UK recommendations on treatment for post-surgical erectile dysfunction. Int J Clin Pract. 2014 May;68(5):590–608. 30. Cancer Campaigning Group & Prostate Cancer UK. Patients' experience of integrated care. 2012.
010	Prostate Cancer UK	Information provision	Although some aspects of communication are addressed in the Quality Standard for patient experience in adult NHS services, men with prostate cancer have very specific information needs that should be addressed through this quality standard – just as information provision is highlighted in the prostate cancer clinical guideline (CG 175) in addition to CG 138 on patient experience in adult NHS services.	• The National Cancer Patient Experience Survey (NCPES) (8) and Clinical Nurse Specialist (CNS) audit (9) indicate variability in the provision of information and access to a CNS. • We know that men often feel that they were not provided with adequate information on which to make a decision, or about issues such as financial help and side effects (8,10,11) • Information provision is highlighted in several points in Clinical Guideline 175 (12), which refers to the need for high quality, individualised	See ID 009

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Providing patients with information about their condition and health needs plays an essential role in ensuring a positive care experience. Information is particularly important for men diagnosed with localised prostate cancer due to both the complex nature of the disease and the wide range of treatment options and related side effects. Previous research has shown that the majority of people diagnosed with cancer want as much information about their condition as possible, irrespective of whether this is good news or bad (1,2). People with cancer want information: - to help them understand their diagnosis, their chance of successful treatment, and the potential side effects of treatment (3)	information; and the importance of informing men about the effects that prostate cancer and treatment options will have on their masculinity. Information following diagnosis Over 1 in 5 men with prostate cancer (19%) in England who took part in the NCPES said that they weren't given written information about the type of cancer they had (8). Furthermore, more than a quarter of the men who responded to our quality care survey in 2012 told us that they did not receive enough information when they were diagnosed (11). Information about treatment and care options Treatment decisions can be very difficult for men with prostate cancer. However, a quarter of men (27%) who took part in our quality care survey told us that they had not received enough information in order to make an informed choice about what treatment to have (11). The same	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			- to reduce anxiety, promote their psychological well-being and increase their sense of control (4) - to create realistic expectations of treatment outcomes (1) - to provide knowledge to enable meaningful participation in treatment decision-making (5) Providing men with easy to understand, written information following face-to-face consultations along the care pathway is important because it gives them something to consider in their own time. It can be difficult for patients to take in all of the information provided during a consultation, particularly around the stressful time of diagnosis. Friends and relatives play an important part in helping men being treated for prostate cancer so it is important that	number of men (27%) also said that they hadn't been given enough information about what side effects they might experience after treatment (11). The latest NCPES also found that almost 1 in 5 men with prostate cancer in England (17%) are not given written information about side effects (8). The Department of Health white paper 'Our health, our care, our say' set out the NHS's commitment to offer a care plan to everyone with a long term condition by 2010 (13). However at present, according to the NCPES, over three quarters of English men with prostate cancer (78%) are not given a written assessment and care plan (8). Information for partners and carers Although the support of a partner can be very important to men with prostate cancer, not enough emphasis is placed on providing support to partners. One in 5 men (22%) surveyed by us thought the support their partner received was 'very bad' or 'bad', and some men reported that	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			their information needs are also adequately addressed. Men should be given the opportunity to bring a friend or family member with them to face-to-face consultations. Access to a CNS can facilitate a balanced discussion about prostate cancer, different treatment choices and their impacts. Each NCPES undertaken in England to date has highlighted the importance of CNSs, as patients who had access to a CNS were more likely to report a positive experience of care, information provision and treatment choice (6–8). During treatment, the type of support required varies and a man may see many different healthcare professionals including GPs, urologists, oncologists and specialist nurses. It is therefore	their partners had not been offered any support or given information about prostate cancer (11). The NCPES found that nearly three quarters (71%) of men with prostate cancer were told they could bring a friend with them when first told they had cancer (8). This is lower than the figure for some other cancers (by comparison, 81% of people with breast cancer were told that they could bring a friend with them) (8). Information about financial help and benefits The NCPES reported that in 2013 only 2 in 5 (41%)prostate cancer patients were given information by hospital staff on getting financial help (8). This is much lower than the 83% who were given information about support groups and the nearly three quarters (73%) who were told they could get free prescriptions (8). The National Cancer Survivorship Initiative (NCSI) tells us that over three quarters (77%) of all cancer patients receive no information about welfare benefits yet nearly all (92%) of people affected by	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			essential that men are given a detailed, written care plan that sets out the follow-up tests and care they should expect to receive from these healthcare professionals.	cancer have suffered a loss of income and/or higher costs as a result (14). Regional differences in access to information In addition to providing information on the overall levels of information provided to men, the NCPES also gave an insight into the significant regional variations that exist. In South London, for example, almost half of men with prostate cancer (45%) aren't given written information about the side effects they might experience after their treatment. In Dudley, however, only 1 in 20 (5%) men fail to get this information (8).	
011	Prostate Cancer UK	Integrated care	It is essential to men with prostate cancer that interactions between primary and secondary, and health and social care, are seamless in order to ensure they receive the best possible care. We know from men with	There is currently no national dataset that collates information on whether patients had an integrated experience of care, where by they felt that services were joined up, flexible and seamless. However, findings from a report published by the Cancer Campaigning Group in November 2012 found that 43% of cancer patients surveyed said they had not	See ID 009

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			prostate cancer that they value the one-to-one support and information they receive from their specialist nurse throughout their prostate cancer journey. Over three quarters of men in our 2012 'Men's views of Quality Care' survey stated that being given the name and contact details of a specialist nurse was "very important" to them (11); while in each NCPES undertaken in England since 2010, cancer patients who had a nurse specialist were significantly more positive about their experience of care than those without (6–8).	experienced integrated care (30). On average, 87% of men with prostate cancer in England reported that they were given the name of the CNS in charge of their care, with the poorest scoring Trust reporting only 64% of men. Only 5 Trusts across England reported that 100% of men with prostate cancer were given the name of the CNS in charge of their care (8). Men have told us that they feel there is a gap in support following active treatment, particular with regard to unmet emotional news (10). From the 2013 NCPES, only 68% of men with prostate cancer thought that hospital and community staff caring for them always worked well together (8).	
12	Prostate Cancer UK	Supported decision-making	Treatment decision-making for men with prostate cancer is complex, particularly for men with localised cancer, and cancer of an intermediate risk. There is a lack of data on treatment outcomes	Supported decision making is covered in CG 175 (12), however there is strong evidence that this is a particular issue for men with prostate cancer. Levels of decision regret, defined as a feeling of loss or distress over an	See ID 009

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			specific to the circumstances of sub-groups of men (for example, outcomes by treatment, stage at diagnosis and co-morbidities combined), and prognosis can be difficult to predict for early stage cancers. Men, therefore, need to be equipped to make a decision about treatment that is appropriate to their values and circumstances, and in order to do this, they must be able to have a balanced conversation with a healthcare professional about the options available to them. Where radical treatment is clinically indicated, men will need particular support to understand the side effects of all the options available to them. This should take the form of written information and the opportunity to have a balanced discussion about their options.	action or inaction made under conditions of uncertainty, can be high for men with prostate cancer (15) – particularly in men with localised prostate cancer who are often faced with the difficult task of choosing between several very different management options (16). The importance of involving patients in decisions about their treatment became particularly apparent during the development of Prostate Cancer UK's Quality Checklist where over a quarter of men (27%) said they had not received enough information for them to make an informed choice about what treatment to have or the potential side effects (11). We know from qualitative research that we have commissioned that men often feel like they have either received insufficient guidance and were left with full autonomy in deciding from an overwhelming range of treatment options, or they felt that specialists would lean toward recommending treatment that they themselves could provide rather than providing objective	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Friends and relatives play an important part in supporting men with prostate cancer. It can, therefore, also be important for men to involve family or friends in their decision making process, and they should be enabled to do so.	advice (10). As the proportion of men experiencing side effects following treatment is high (17,18), discussion of these should be an important part of the decision making process. We have particular concerns that some groups of men, for example older men, may be less likely to be given information on side effects of treatment (19) There is variation in access to a CNS, which is an obvious route to enable supported decision making (8,9).	
013	SCM		Men with newly diagnosed prostate cancer are given access to a named cancer nurse specialist		
014	Tackle prostate cancer (Prostate Cancer Support Federation)	Shared decision making	Prostate cancer is unique in that, without solid evidence of the best treatment option, personal choice (e.g. of surgery versus radiotherapy) becomes an important element in selecting treatment options. It is essential that patients are provided with the most up to	Healthcare professionals should be encouraged to use Patient Decision Aids which are specially designed information resources that help people make decisions about difficult healthcare options. They will help patients think about why one option is better than another. It is also important to bear in mind that people's views change over time	1. The Right Care Shared Decision Making Programme aims to embed Shared Decision Making in NHS care. This is part of the wider ambition to promote patient centred care, to increase patient choice, autonomy and involvement in clinical decision making and make “no decision about me, without me” a reality. http://sdm.rightcare.nhs.uk 2. NICE clinical guideline 175 recommendations 1.1 Information and decision

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			date information and opportunity to speak to each member of their MDT to discuss the pros and cons of all available treatment options in order to help aid their decision on treatment choice. People with prostate cancer should have the opportunity to talk through all available treatment options and are provided with comprehensive information on their risks and benefits by members of their multi-disciplinary team (MDT) in order to make an informed decision.	depending on their experiences and who they talk to. The shared decision making conversation also needs both the patient and professional to understand the other's point of view and agree the reasons why the treatment chosen was the best one for the patient. The reason may be that it was the best medical option or it was the best option for that patient's life. Part of the shared decision making may also include involving the patient's partner, family members, and carer (if requested by the patient).	support for men with prostate cancer, their partners and carers.
015	Wicked Minds	Shared decision making	Prostate cancer is unique in that, without solid evidence of the best treatment option, personal choice (e.g. of surgery versus radiotherapy) becomes an important element in selecting treatment options. It is essential that patients are provided with the most up to date information and	Healthcare professionals should be encouraged to use Patient Decision Aids which are specially designed information resources that help people make decisions about difficult healthcare options. They will help patients think about why one option is better than another. It is also important to bear in mind that people's views change over time depending on their experiences and	1. The Right Care Shared Decision Making Programme aims to embed Shared Decision Making in NHS care. This is part of the wider ambition to promote patient centred care, to increase patient choice, autonomy and involvement in clinical decision making and make "no decision about me, without me" a reality. http://sdm.rightcare.nhs.uk 2. NICE clinical guideline 175 recommendations 1.1 Information and decision support for men with prostate cancer, their partners

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			opportunity to speak to each member of their MDT to discuss the pros and cons of all available treatment options in order to help aid their decision on treatment choice. People with prostate cancer should have the opportunity to talk through all available treatment options and are provided with comprehensive information on their risks and benefits by members of their multi-disciplinary team (MDT) in order to make an informed decision.	who they talk to. The shared decision making conversation also needs both the patient and professional to understand the other's point of view and agree the reasons why the treatment chosen was the best one for the patient. The reason may be that it was the best medical option or it was the best option for that patient's life. Part of the shared decision making may also include involving the patient's partner, family members, and carer (if requested by the patient).	and carers.
016	Ipsen Limited	Shared decision making	Prostate cancer is unique in that, without solid evidence of the best treatment option, personal choice (e.g. of surgery versus radiotherapy) becomes an important element in selecting treatment options. It is essential that patients are provided with the most up to date information and opportunity to speak to each	Healthcare professionals should be encouraged to use Patient Decision Aids which are specially designed information resources that help people make decisions about difficult healthcare options. They will help patients think about why one option is better than another. It is also important to bear in mind that people's views change over time depending on their experiences and who they talk to. The shared decision	1. The Right Care Shared Decision Making Programme aims to embed Shared Decision Making in NHS care. This is part of the wider ambition to promote patient centred care, to increase patient choice, autonomy and involvement in clinical decision making and make "no decision about me, without me" a reality. http://sdm.rightcare.nhs.uk 2. NICE clinical guideline 175 recommendations 1.1 Information and decision support for men with prostate cancer, their partners and carers.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			member of their MDT to discuss the pros and cons of all available treatment options in order to help aid their decision on treatment choice. People with prostate cancer should have the opportunity to talk through all available treatment options and are provided with comprehensive information on their risks and benefits by members of their multi-disciplinary team (MDT) in order to make an informed decision.	making conversation also needs both the patient and professional to understand the other's point of view and agree the reasons why the treatment chosen was the best one for the patient. The reason may be that it was the best medical option or it was the best option for that patient's life. Part of the shared decision making may also include involving the patient's partner, family members, and carer (if requested by the patient).	
017	Cancer Black Care	Shared decision making	Prostate cancer is unique in that, without solid evidence of the best treatment option, personal choice (e.g. of surgery versus radiotherapy) becomes an important element in selecting treatment options. It is essential that patients are provided with the most up to date information and opportunity to speak to each member of their MDT to	Healthcare professionals should be encouraged to use Patient Decision Aids which are specially designed information resources that help people make decisions about difficult healthcare options. They will help patients think about why one option is better than another. It is also important to bear in mind that people's views change over time depending on their experiences and who they talk to. The shared decision making conversation also	1. The Right Care Shared Decision Making Programme aims to embed Shared Decision Making in NHS care. This is part of the wider ambition to promote patient centred care, to increase patient choice, autonomy and involvement in clinical decision making and make "no decision about me, without me" a reality. http://sdm.rightcare.nhs.uk 2. NICE clinical guideline 175 recommendations 1.1 Information and decision support for men with prostate cancer, their partners and carers.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			discuss the pros and cons of all available treatment options in order to help aid their decision on treatment choice. People with prostate cancer should have the opportunity to talk through all available treatment options and are provided with comprehensive information on their risks and benefits by members of their multi-disciplinary team (MDT) in order to make an informed decision.	needs both the patient and professional to understand the other's point of view and agree the reasons why the treatment chosen was the best one for the patient. The reason may be that it was the best medical option or it was the best option for that patient's life. Part of the shared decision making may also include involving the patient's partner, family members, and carer (if requested by the patient).	
18	SCM	MDT	This does not refer to just the MDT meeting but to the whole team in all areas and aspects of prostate cancer management.	The MDT meeting is a vital cog in decision making for patients and allows access to all specialists for all patients if arranged to be discussed and if meeting delivered appropriately to allow this to happen. As per previous key area though, MDT also refers to all health care and tertiary services. Eg-advanced nursing practice, GP, District Nurses, practice Nurses, non – NHS support.	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
19	SCM	Provision of unbiased information	For localised prostate cancer, majority of men have more than one option of treatment but the actual treatment given/advised/encouraged can depend upon the clinician/specialist who reviews patient.	For localised prostate cancer, there is usually a multiple of treatment options. There is no quality evidence to advise 1 treatment over another in most cases but yet this is often the case. All treatments including surveillance should be discussed without bias.	NICE 175 update CMG
020	SCM	Provision of unbiased information and decision support on treatment options for men with localised prostate cancer	There are a number of treatment options available for men with localised prostate cancer but no good evidence on which specific treatment would most benefit an individual man. The updated NICE clinical guidelines for prostate cancer (CG175) highlight that these patients should choose treatment based on an unbiased discussion of all possible options with a clinician, including information on the relevant side effects.	We know from feedback from men that this does not always happen, leading to them being uncertain and anxious about choosing a treatment option and also causing treatment regret in some men. Although the Quality Standard for patient experience in adult NHS services (QS15) includes a standard on Understanding treatment options, there is a need to specifically highlight this as an area for improvement in prostate cancer care.	NICE CG175 Prostate Cancer UK. Men's views on quality care in prostate cancer: What does good quality care mean for men with prostate cancer? [Internet]. 2012. Available from: http://prostatecanceruk.org/media/1559431/prostate_cancer_uk_quality_care_survey_report_june_2012.pdf Findings from qualitative research carried out by BritainThinks for Prostate Cancer UK. Total sample size was 53 adults affected by prostate cancer across the UK (including 8 partners of men with prostate cancer). Fieldwork was undertaken between 5th February and 13th March 2014, comprising telephone interviews, focus groups and online qualitative research. 2014.
021	SCM		Men with raised PSA are given clear and balanced		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			information before considering prostate biopsy		
022	The Lesbian & Gay Foundation	Options for investigation (screening vs. biopsy)	We are aware of recommendations for future screening over regular biopsy but at the current point in time we hear from many men who are either choosing not to have biopsy because of the fear of how this will affect them or men who are having the side effects of biopsies underestimated. It is essential that the options are fully discussed with the patient and their particular needs taken into account.	Patient-centred, holistic care is a cornerstone of the NHS service model and NHS constitution. Providing information and treatment that is responsive to patient need will be more effective in the long term and lead to better patient outcomes.	We recommend the resource published by Prostate Cancer UK and Stonewall on meeting the needs of gay and bisexual men: http://prostatecanceruk.org/news/2013/2/stonewall-meeting-the-needs-of-gay-and-bisexual-men
023	Janssen	Involvement of patients in their care	Like any other patients, those with prostate cancer should be fully involved in their care	The NHS Mandate states that one of the NHS objectives is to help patients have better control over the care they receive and to empower patients to manage and make decisions about their own care and treatment. The National Cancer Patient Experience Survey identifies areas where patients believe they do not receive adequate explanations of their diagnostic test and treatment options.	NHS Mandate 2014/15 'It's time for quality care. Everywhere.' Report by Prostate Cancer UK http://prostatecanceruk.org/media/2105544/2298-its-time-for-quality-care-everywhere_full-2-.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				This is linked to their access to support from a CNS who can explain treatment side effects and the (long and short term) benefit of alternative treatment options. The NHS five year forward view (5YFV) plan looks to address how best to support patients to be more active and engaged in their own health, and how the NHS can improve its responsiveness when patients are ill. Improving access to CNS support at all stages of the cancer journey is important, with equal emphasis placed on improving access for patients with or without metastatic disease.	The NHS 5YFV Plan http://www.england.nhs.uk/2014/08/15/5yfv/
024	SCM	Diagnosis – decision to biopsy patient with raised PSA	NICE CG175 states that the decision to undertake a biopsy in a man with a raised PSA should take into account multiple risk factors, and not all men with a raised PSA should proceed to biopsy. Men should have time to decide, and understand risks	Decreasing the number of unnecessary biopsies is a key component to reducing the risk of potential 'overdiagnosis' of clinically insignificant prostate cancer. There is great inconsistency between urologists and centres on the threshold for biopsy, and often the patient is not given enough information to fully engage in this	http://www.prostatecancer-riskcalculator.com/seven-prostate-cancer-risk-calculators

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			and benefits.	decision making process. The use of computerised risk calculators such as that produced by the ERSPC should be encouraged.	
025	Cancer Black Care	Diagnosis	For a patient being informed of a suspected cancer can be a traumatic and difficult time. This is further confounded by the choice of diagnostic procedures available. At this stage patients tend to be guided by the recommendation of their healthcare professional. It is important therefore for the healthcare professional to discuss all options and to take into consideration the patient's lifestyle and personal preferences when making decisions about which diagnostic technologies are to be used. People referred with suspected prostate cancer should be offered the full choice and access to the	An increasing numbers of centres are able to offer transperineal template prostate biopsy. The diagnostic accuracy is double that of TRUS biopsy and the sepsis rate very much lower. In a BAUS session (June 2014), not a single urologist said that they would offer a TRUS biopsy if they could offer a transperineal biopsy, albeit under general anaesthesia. There is also growing evidence that multiparametric MRI (using a 1.5T or 3T machine) by an experienced team of radiographers and radiologists before a prostate biopsy can provide more information by which to identify prostate cancer and thus reduce the false-negative rate. NICE Guidelines recommends that, when a patient has been diagnosed as having prostate cancer, they have access to imaging techniques such as magnetic resonance imaging (MRI), computerised tomography (CT) scans	1. NICE interventional procedures guidance (IPG364). Transperineal template biopsy and mapping of the prostate. October 2010 2. Myung Sun Choi, Yong Sun Choi, Byung Il Yoon et al. The Clinical Value of Performing an MRI before Prostate Biopsy. Korean J Urol. Aug 2011; 52(8): 572–577. 3. People referred for suspected prostate cancer, in accordance with NICE clinical guideline 27, recommendations 1.8.2 – 1.8.8 are offered a transrectal ultrasound (TRUS) guided biopsy, in accordance with NICE clinical guideline 175, recommendation 1.2.4. 4. People should be provided with comprehensive information about the biopsy procedure, in accordance with the Prostate Cancer Risk Management Programme (PCRMP) Guide No 1. 5. NICE clinical guideline 175 recommendations 1.2.6 (key priority for implementation) and 1.2.7 are followed in cases of rebiopsy. 6. NHS Cancer Screening Programmes. Undertaking a transrectal ultrasound guided biopsy

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			most up to date and clinically effective diagnostic technologies.	and radioisotope bone scans to assess the extent of cancer and whether it has, or how far it may have, spread.	of the prostate (2006). Available from: http://www.cancerscreening.nhs.uk/prostate/pcrmp01.pdf
026	Tackle prostate cancer (Prostate Cancer Support Federation)	Diagnosis	For a patient being informed of a suspected cancer can be a traumatic and difficult time. This is further confounded by the choice of diagnostic procedures available. At this stage patients tend to be guided by the recommendation of their healthcare professional. It is important therefore for the healthcare professional to discuss all options and to take into consideration the patient's lifestyle and personal preferences when making decisions about which diagnostic technologies are to be used. People referred with suspected prostate cancer should be offered the full	An increasing numbers of centres are able to offer transperineal template prostate biopsy. The diagnostic accuracy is double that of TRUS biopsy and the sepsis rate very much lower. In a BAUS session (June 2014), not a single urologist said that they would offer a TRUS biopsy if they could offer a transperineal biopsy, albeit under general anaesthesia. There is also growing evidence that multiparametric MRI (using a 1.5T or 3T machine) by an experienced team of radiographers and radiologists before a prostate biopsy can provide more information by which to identify prostate cancer and thus reduce the false-negative rate. NICE Guidelines recommends that, when a patient has been diagnosed as having prostate cancer, they have access to imaging techniques such as magnetic resonance imaging (MRI), computerised tomography (CT) scans	1. NICE interventional procedures guidance (IPG364). Transperineal template biopsy and mapping of the prostate. October 2010 2. Myung Sun Choi, Yong Sun Choi, Byung Il Yoon et al. The Clinical Value of Performing an MRI before Prostate Biopsy. Korean J Urol. Aug 2011; 52(8): 572–577. 3. People referred for suspected prostate cancer, in accordance with NICE clinical guideline 27, recommendations 1.8.2 – 1.8.8 are offered a transrectal ultrasound (TRUS) guided biopsy, in accordance with NICE clinical guideline 175, recommendation 1.2.4. 4. People should be provided with comprehensive information about the biopsy procedure, in accordance with the Prostate Cancer Risk Management Programme (PCRMP) Guide No 1. 5. NICE clinical guideline 175 recommendations 1.2.6 (key priority for implementation) and 1.2.7 are followed in cases of rebiopsy. 6. NHS Cancer Screening Programmes. Undertaking a transrectal ultrasound guided biopsy

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			choice and access to the most up to date and clinically effective diagnostic technologies.	and radioisotope bone scans to assess the extent of cancer and whether it has, or how far it may have, spread.	of the prostate (2006). Available from: http://www.cancerscreening.nhs.uk/prostate/pcrmp01.pdf
027	Wicked Minds	Diagnosis	For a patient being informed of a suspected cancer can be a traumatic and difficult time. This is further confounded by the choice of diagnostic procedures available. At this stage patients tend to be guided by the recommendation of their healthcare professional. It is important therefore for the healthcare professional to discuss all options and to take into consideration the patient's lifestyle and personal preferences when making decisions about which diagnostic technologies are to be used. People referred with suspected prostate cancer should be offered the full	An increasing number of centres are able to offer transperineal template prostate biopsy. The diagnostic accuracy is double that of TRUS biopsy and the sepsis rate very much lower. In a BAUS session (June 2014), not a single urologist said that they would offer a TRUS biopsy if they could offer a transperineal biopsy, albeit under general anaesthesia. There is also growing evidence that multiparametric MRI (using a 1.5T or 3T machine) by an experienced team of radiographers and radiologists before a prostate biopsy can provide more information by which to identify prostate cancer and thus reduce the false-negative rate. NICE Guidelines recommends that, when a patient has been diagnosed as having prostate cancer, they have access to imaging techniques such as magnetic resonance imaging (MRI), computerised tomography (CT) scans	1. NICE interventional procedures guidance (IPG364). Transperineal template biopsy and mapping of the prostate. October 2010 2. Myung Sun Choi, Yong Sun Choi, Byung Il Yoon et al. The Clinical Value of Performing an MRI before Prostate Biopsy. Korean J Urol. Aug 2011; 52(8): 572–577. 3. People referred for suspected prostate cancer, in accordance with NICE clinical guideline 27, recommendations 1.8.2 – 1.8.8 are offered a transrectal ultrasound (TRUS) guided biopsy, in accordance with NICE clinical guideline 175, recommendation 1.2.4. 4. People should be provided with comprehensive information about the biopsy procedure, in accordance with the Prostate Cancer Risk Management Programme (PCRMP) Guide No 1. 5. NICE clinical guideline 175 recommendations 1.2.6 (key priority for implementation) and 1.2.7 are followed in cases of rebiopsy. 6. NHS Cancer Screening Programmes. Undertaking a transrectal ultrasound guided biopsy

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			choice and access to the most up to date and clinically effective diagnostic technologies.	and radioisotope bone scans to assess the extent of cancer and whether it has, or how far it may have, spread.	of the prostate (2006). Available from: http://www.cancerscreening.nhs.uk/prostate/pcrmp01.pdf
028	Ipsen Limited	Diagnosis	For a patient being informed of a suspected cancer can be a traumatic and difficult time. This is further confounded by the choice of diagnostic procedures available. At this stage patients tend to be guided by the recommendation of their healthcare professional. It is important therefore for the healthcare professional to discuss all options and to take into consideration the patient's lifestyle and personal preferences when making decisions about which diagnostic technologies are to be used. People referred with suspected prostate cancer should be offered the full	An increasing number of centres are able to offer transperineal template prostate biopsy. The diagnostic accuracy is double that of TRUS biopsy and the sepsis rate very much lower. In a BAUS session (June 2014), not a single urologist said that they would offer a TRUS biopsy if they could offer a transperineal biopsy, albeit under general anaesthesia. There is also growing evidence that multiparametric MRI (using a 1.5T or 3T machine) by an experienced team of radiographers and radiologists before a prostate biopsy can provide more information by which to identify prostate cancer and thus reduce the false-negative rate. NICE Guidelines recommends that, when a patient has been diagnosed as having prostate cancer, they have access to imaging techniques such as magnetic resonance imaging (MRI), computerised tomography (CT) scans	1. NICE interventional procedures guidance (IPG364). Transperineal template biopsy and mapping of the prostate. October 2010 2. Myung Sun Choi, Yong Sun Choi, Byung Il Yoon et al. The Clinical Value of Performing an MRI before Prostate Biopsy. Korean J Urol. Aug 2011; 52(8): 572–577. 3. People referred for suspected prostate cancer, in accordance with NICE clinical guideline 27, recommendations 1.8.2 – 1.8.8 are offered a transrectal ultrasound (TRUS) guided biopsy, in accordance with NICE clinical guideline 175, recommendation 1.2.4. 4. People should be provided with comprehensive information about the biopsy procedure, in accordance with the Prostate Cancer Risk Management Programme (PCRMP) Guide No 1. 5. NICE clinical guideline 175 recommendations 1.2.6 (key priority for implementation) and 1.2.7 are followed in cases of rebiopsy. 6. NHS Cancer Screening Programmes. Undertaking a transrectal ultrasound guided biopsy

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			choice and access to the most up to date and clinically effective diagnostic technologies.	and radioisotope bone scans to assess the extent of cancer and whether it has, or how far it may have, spread.	of the prostate (2006). Available from: http://www.cancerscreening.nhs.uk/prostate/pcrmp01.pdf
029	SCM	Diagnosis: MRI prior to rebiopsy	NICE CG175 recommends offering men with raised PSA but negative initial biopsy an MRI scan to determine whether rebiopsy is needed. This potentially reduces the numbers of biopsies performed, reducing risk of significant complications such as sepsis, whilst targeting biopsy at the highest risk patients.	This recommendation is inconsistently applied, leading to many men having repeated Transrectal Ultrasound guided biopsy without the offer of other pathways that may carry less risk.	NICE CG175
030	SCM	Use of imaging to aid in diagnosis and staging	There is a growing body of evidence that MRI can improve a number of different aspects of prostate cancer diagnosis and treatment, including for men with negative initial transrectal ultrasound core biopsies, in staging and as part of the active surveillance protocol. Men tell us that there is not equal access to MRI for these uses.	A quality standard focussing on this area would help to reduce inequalities and ensure all men are able to experience the best possible care.	CG 175 National Health Service. The NHS Constitution: the NHS belongs to us all [Internet]. 2013. Available from: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
031	Prostate Cancer UK	Access to treatments and diagnostic and prognostic tools	It is important that men are able to access the treatments and diagnostic and prognostic tools as soon as there is good evidence of their efficacy. There is an emerging body of evidence about the diagnostic benefits of using multiparametric MRI (magnetic resonance imaging) for ruling some men out of needing unnecessary biopsies (20). Where robust clinical trial data is published between reviews of clinical guidance, it is important that the necessary steps are taken to ensure that men everywhere can benefit. This may require consideration of training, infrastructure and equipment. Access to treatments is particularly important given that, according to the NHS Constitution, NHS service	Robotic surgery is listed as an option in CG 175 (12), however we understand that effective access to this type of surgery varies due to the location of the required infrastructure. As of January 2014, we were aware of the da Vinci system having been installed in 23 NHS Trusts in England and Wales. A clinical trial is underway that will further explore the diagnostic benefits of using multiparametric MRI (24), but in the meantime there is variation in clinical practice (12). This may also apply to other diagnostic and treatment modalities, and we hope that the forthcoming results of the first year of the National Prostate Cancer Audit (NCPA) will be used to inform the selection of priority topics for the Quality Standard. Older men diagnosed with prostate cancer may be offered fewer treatment options than younger men (23). Men must not be denied quality care on the basis of their age. It is not	See 009

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			users have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if their doctor deems them clinically appropriate (21). It is also important that men have access to trained surgeons, with the appropriate level of skills and expertise. For example, while NICE has recognised the benefits of setting up high volume, multi-disciplinary centres with surgeons performing robot-assisted surgery (12,22).	clear that current treatment pathways are based on a person's fitness and preferences rather than their age alone.	
032	Royal College of Pathologists	Access and funding for template prostate biopsies	The increase use of MRI in prostate cancer has lead to an increase in template biopsies. These biopsies increase the workload of the laboratory and the pathologist, and normally require a general anaesthetic. These biopsies improve the pick up rate for prostate cancer in comparison to	Patients should have access to template prostate biopsies and this service needs to be funded to include the extra theatre, laboratory and pathology time.	http://www.nice.org.uk/guidance/IPG364/chapter/1-guidance See graph below showing rapid increase in number of specimens per patient due to affect of template biopsies in our trust.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			standard TRUS biopsies as they sample the anterior prostate, which is difficult to sample with standard TRUS biopsies. There needs to be access to this technique and there needs to be funding for this process as centres have taken on this activity without correct funding.		
033	SCM		Use of fMRI at diagnosis of prostate cancer and in men who have negative biopsies	Enables selection of men with negative biopsies at risk of having significant prostate cancer in whom further biopsies are needed; fMRI at diagnosis provides accurate staging which improves management decisions	NICE guidelines Jan 2014
034	SCM	mpMRI	Accreditation for undertaking and reporting mpMRI studies	mpMRI features strongly in the NICE guidance, yet it is a complex and technically demanding test to perform and to report. Its benefits are at risk of being diminished if not performed/reported to minimum standards. These have been set out in ESUR 2012 consensus paper and are in the process of being updated. The training time to become competent to report the studies is approximately 1	www.esur.org

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				year. RCR accreditation or other system of quality assurance/governance should be considered	
035	SCM	mpMRI	As part of Key area 1 above, establish registry of mpMRI pre biopsy predictions vs subsequent prostatectomy AND ALSO vs biopsy records (template, targeted)	The NPV, PPV, accuracy of mpMRI as it moves out from specialist centres should be determined. NHS in UK provides opportunity to do this on a scale impossible elsewhere. The information will inform on standards but also give isight in to modifying sequences timings and other parameters to make mpMRI better. Likewise, opportunity to assess new biopsy techniques	
036	SCM	mpMRI	Establish concept of regional centres of formal mpMRI-TRUS fusion biopsy	Mirroring the surgical model of concentrating intervention to regional centres (in pelvic surgery, 50 cases per year minimum), offer centres of excellence for dedicated formal fusion of mpMRI and TRUS. This concentrates complex technique requiring specialist knowledge and equipment to ensure highest standards and best patient outcomes	IOG Urology (concept specialist centres) 66. Marks L, Young S, Natarajan S. MRI-ultrasound fusion for guidance of targeted prostate biopsy. Current opinion in urology. 2013 Jan;23(1):43-50. PubMed PMID: 23138468. 67. Hadaschik BA, Kuru TH, Tulea C, Rieker P, Popeneciu IV, Simpfendorfer T, et al. A novel stereotactic prostate biopsy system integrating pre-interventional magnetic resonance imaging and live ultrasound fusion. J Urol. 2011 Dec;186(6):2214-20. PubMed PMID: 22014798. 68. Vourganti S, Rastinehad A, Yerram NK, Nix J, Volkin D, Hoang A, et al. Multiparametric

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					magnetic resonance imaging and ultrasound fusion biopsy detect prostate cancer in patients with prior negative transrectal ultrasound biopsies. J Urol. 2012 Dec;188(6):2152-7. PubMed PMID: 23083875. 69. Durmus T, Stephan C, Grigoryev M, Diederichs G, Saleh M, Slowinski T, et al. [Detection of Prostate Cancer by Real-Time MR/Ultrasound Fusion-Guided Biopsy: 3T MRI and State of the Art Sonography.]. RoFo : Fortschritte auf dem Gebiete der Rontgenstrahlen und der Nuklearmedizin. 2013 Feb 18. PubMed PMID: 23420313. Detektion des Prostatakarzinoms durch Echtzeit-MRT/US-Fusionsbiopsie: 3T MRT und moderne Ultraschalltechnik. 70. Rud E, Baco E, Eggesbo HB. MRI and ultrasound-guided prostate biopsy using soft image fusion. Anticancer research. 2012 Aug;32(8):3383-9. PubMed PMID: 22843919.
037	SCM	Active surveillance protocols	As set out in CG175, men with low- and intermediate-risk localised prostate cancer, for whom radical prostatectomy or radiotherapy is suitable, should also be offered active surveillance as a treatment option. This will provide men with the opportunity to	We know from men that different active surveillance protocols have been followed by different clinical teams. A consistent protocol would ensure that all men have access to the best quality care, and that uncomfortable procedures such as biopsies are conducted at the appropriate frequency.	NICE CG175 National Prostate Cancer Audit

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			choose a treatment option that can delay, or possibly even prevent, the need for other treatments (such as surgery or radiotherapy) that have significant physical side effects. The active surveillance protocol suggested in CG175 was developed through a Delphi consensus process and should be adopted.		
038	SCM	Active surveillance	Variable practice across the country means not all men are offered AS and the schedule for AS varies considerably.		NICE guidelines Jan 2014
039	SCM	Active Surveillance for low risk prostate cancer	AS is recommended as an option for men with low risk disease in whom surgery / radiotherapy is suitable. A clear protocol for AS is detailed in CG175.	Consistent application of this recommendation across the country will: Reduce overtreatment of low risk disease Improve capacity within the system for rapid treatment of high risk disease Decrease costs associated with treatment and management of side effects of radical treatment	NICE CG175

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				But, quality information and support of men for whom AS is considered an option is vital.	
040	British Association of Urological Surgeons, Section of Oncology	Men with low risk prostate cancer are offered active surveillance as an initial treatment strategy	Recommended in NICE Guideline	To ensure that active surveillance is offered to appropriate patient groups.	
041	SCM	Active surveillance is offered to all men with low risk localised prostate cancer	Active surveillance has been shown to be safe and reduces overtreatment low risk prostate cancer. Active surveillance is recommended within NICE guidance	Active surveillance eligibility criteria and management protocols vary widely in various centres	
042	SCM	Radical prostatectomy	To ensure those patients undergoing radical prostatectomy do so in units with sufficient experience and throughput to achieve best results.		NICE guidelines Jan 2014
043	SCM	Robotic surgery	Robotic radical prostatectomy (RRP) is growing in popularity throughout the UK and is recommended as a potential treatment option in CG175 –	This is a key area of quality control to ensure patient safety – evidence clearly demonstrates better outcomes in higher volume centres with these procedures.	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			however, it is recommended that this is only performed in centres performing >150 of these procedures per annum.		
044	British Association of Urological Surgeons, Section of Oncology	Where robotic prostatectomy is offered this should be undertaken in centres where more than 150 cases are performed per year	Recommended in NICE Guideline	Evidence demonstrates better outcomes in high volume centres and more cost effective use of robotic systems	
045	British Association of Urological Surgeons, Section of Oncology	Positive surgical margin rate for pT2 prostate cancer <20%	The PSM rate may be used as a good surrogate for quality of surgery for prostate cancer.	Quality of surgery relates to both functional and oncological outcomes following surgery and is therefore of great importance to the patient.	Van Poppel, EJSO (2005) 31, 650-655
046	British Association of Urological Surgeons, Section of	When offering external beam radiotherapy offer a minimum dose of 74 Gy at no more than 2	Recommended in NICE Guideline	Evidence available for better outcomes at this minimum dose regimen.	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Oncology	Gy per fraction			
047	SCM		Use of ADT with radiotherapy in advanced prostate cancer	New trial evidence which shows improved outcome using combined ADT and RT in this patient group compared to either RT alone or ADT alone.	NICE guidelines Jan 2014 PR07
048	SCM	Treatments for men with intermediate- and high-risk localised prostate cancer	These men should be offered radical radiotherapy in combination with androgen deprivation therapy, rather than either alone. This has been shown to significantly increase survival.	A quality standard would ensure that all men have access to the best possible treatment and therefore reduce variations in access and outcomes.	CG 175 National Health Service. The NHS Constitution: the NHS belongs to us all [Internet]. 2013. Available from: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf
049	SCM			Men having long-term androgen deprivation therapy are given written information about potential side effects and considered for intermittent therapy	
050	Ferring Pharmaceuticals	Form of Androgen Deprivation Therapy (ADT) and cardiovascular (CV) risk.	There is evidence that the rates of CV events are increased in patients exposed to LHRH agonists compared those receiving other forms of ADT, such as bilateral orchidectomy or GnRH antagonists.	When ADT is recommended, alternative forms of ADT should be considered in patients at higher risk of CV events.	Please see: • Gandaglia et al. BJU 2014; Mar 10. Doi: 10.1111/bju. 12732. [Epub aahead of print] • Albertsen et al. Eur Urol 2014; 65: 565-73

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
051	Janssen	Timely referral of patients with disease progression after treatment with ADT	Without timely referral, some patients could be lost to follow-up. Delay in referral from urologist to oncologist may also lead to disease progression and affect patient's ability to access optimal treatment, which could impact on survival and quality of life.	Currently, cancer waiting time targets only apply to the timeliness from referral and diagnosis to first and subsequent treatment of patients at the initial phases of their cancer journey. There are no targets for the management of recurrent disease. For patients progressing after ADT, it is important to ensure timely referral from urologist to oncologist to optimise their treatment options. The NICE clinical guideline for prostate cancer (CG175) highlights that multi-disciplinary team case study review meetings and 62 day waiting time to treatment are key quality indicators, but this is not explicitly stated for metastatic or progressive disease. For metastatic prostate cancer, a referral time between functions for second line treatment following ADT failure is not stated. Statement 11 of the NICE quality standard for breast cancer (QS12) refers to metastatic disease being discussed by an MDT. Statement 12 also refers to recurrence and	Improving Outcomes: A Strategy for Cancer (January 2011) Waiting Times for Suspected and Diagnosed Cancer Patients 2012-13 annual report http://www.england.nhs.uk/statistics/2013/07/19/cancer-waiting-times-annual-report-2012-13/ NICE Clinical Guideline - Prostate Cancer (CG175) NICE QS12 for Breast Cancer

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				continued care being offered within breast cancer. This demonstrates a level of inequality between the two cancers.	
052	Society and College of Radiographers	State of the art technology	Use of state of the art technology Use of VMAT and IGRT IGBRT	Improved tumour targeting and side effect management Use of MRI	We thought this would have been in the overview but it is probably quoted in the general cancer management documents
053	SCM	Management of side effects of treatment / Survivorship	The numbers of men living with prostate cancer as a ‘chronic disease’ are increasing year on year – it is estimated that by 2022 in the US, 45% of male cancer survivors will be prostate cancer patients. Long term effects of treatment such as erectile dysfunction, continence, osteoporosis, cardiovascular risk, cognitive impairment, fatigue etc are increasingly managed in the community, and many men are discharged from secondary care for long term follow up including PSA surveillance in primary care.	NICE CG175 recommends that all men have access to specialist erectile dysfunction services, men commencing androgen deprivation therapy should be offered supervised exercise regimes to reduce fatigue etc – but the various recommendations are inconsistently applied – this means many men are unsupported in the community with the long term impact of their treatment. The QS should clearly specify the basic standards that should be achieved consistently for these men.	American Cancer Society. Cancer Treatment and Survivorship Facts & Figures 2012-2013. Atlanta: American Cancer Society; 2012 Projections of cancer prevalence in the UK 2010-2040. Br J Cancer 2012; 107: 1195 - 1202

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
054	SCM	Managing adverse effects of treatments	Prostate cancer treatments are associated with a range of significant side effects, including erectile and sexual dysfunction, urinary incontinence, bowel incontinence, hot flushes, fatigue and problems with mental wellbeing. The exact side effects a man may experience will depend on the treatment/s he has. Many men tell us that the side effects they are experiencing are not being managed effectively and are therefore having a significant impact on their quality of life.	Support and care for men with prostate cancer should not only be focussed on active treatment or surveillance, the after effects must be managed too. This would help to improve the quality of life for many men with prostate cancer.	CG175 Glaser AW et al. Patient-reported outcomes of cancer survivors in England 1-5 years after diagnosis: a cross-sectional survey. BMJ Open. 2013;3(4). Department of Health. Quality of Life of Cancer Survivors in England - Report on a pilot survey using Patient Reported Outcome Measures (PROMS) [Internet]. Department of Health; 2012. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/267042/9284-TSO-2900701-PROMS-1.pdf Ream E, et al. Supportive care needs of men living with prostate cancer in England: a survey. Br J Cancer. 2008 Jun 17;98(12): 1903–9. Prostate Cancer UK. Men’s views on quality care in prostate cancer: What does good quality care mean for men with prostate cancer? [Internet]. 2012. Available from: http://prostatecanceruk.org/media/1559431/prostate_cancer_uk_quality_care_survey_report_june_2012.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					Quality Health. Cancer Patient Experience Survey 2012-13 National Report [Internet]. 2013. Available from: http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file
055	SCM		Men with troublesome urinary symptoms after treatment have access to specialist continence services for assessment, diagnosis and treatment		
056	SCM	Radiation enteropathy		Variable and generally poor access to specialist care across the country.	NICE guidelines Jan 2014
057	SCM	Radiation enteropathy		Men with signs or symptoms of radiation-induced enteropathy are offered care from a team of professionals with expertise in radiation-induced enteropathy	
058	SCM		Men with prostate cancer undergoing treatment are given early and ongoing access to specialist erectile dysfunction services		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
059	Prostate Cancer UK	Specialist support for side effects following treatment	Many men experience life-changing side effects from prostate cancer treatment and require support from healthcare professionals for some time after treatment has finished. A 2012 survey of 866 prostate cancer survivors in England showed that on average 58% of prostate cancer patients were unable to have an erection 1-5 years after treatment, with a further 11% having significant difficulty in having or maintaining an erection, 13% having difficulty controlling their bowels, and 39% having some degree of urinary leakage (17,18). The presence of urinary leakage was significantly associated with poorer quality of life. Men often have particular wellbeing needs following active treatment.	Not all men with prostate cancer are receiving information, care and support for the life changing side effects that result from their treatment. The 2013 NCPES in England (8) found that: - 36% of prostate cancer patients were not told about treatment side effects that could affect them in the future - 26% of prostate cancer patients did not have possible side effects explained in an understandable way - 17% of prostate cancer patients were not given written information about side effects Prostate Cancer UK's 2012 survey found that 1 in 5 men (19%) described the care and support they received for the side effects they experienced as 'bad' or 'very bad'. After completing treatment, 1 in 3 men (31%) said that they received 'too little' aftercare for the treatment of side effects (11). Although there is emerging evidence	See ID 009

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			Psychological distress, depression and anxiety are particularly present, and debilitating, among men no longer being treated (25). Research has shown that 72% of men reported a need for psychological care and 82% reported some depression or anxiety (26). This high level of reported distress is particularly significant given the general under-reporting of psychological distress by men (27).	that men have significant wellbeing needs, service provision can be patchy at best (10,28). The CNS plays an important role in signposting to relevant support services; however, there is variability in access to CNSs (8,9). New research has shown the importance of early intervention in treating erectile dysfunction (29) – access to early treatment and nerve sparing surgery needs to be improved to better preserve sexual function.	
060	British Association of Urological Surgeons, Section of Oncology	All men with newly-diagnosed prostate cancer metastatic to bone should be seen in a specialist clinic		Consideration should be given to bone mineralisation assessment and bone protection in order to prevent skeletal-related events during treatment of the cancer.	
061	SCM			Men with metastatic prostate cancer are given tailored information and have access to specialist urology and palliative care teams	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
062	Janssen	Management of metastatic prostate cancer	Patients with metastatic prostate cancer have worse prognosis than those with non-metastatic disease. However, they can still benefit from high quality management of their disease (particularly with the new treatment options now available for this stage of disease), which aims to extend their lives while maintaining reasonable quality of life.	Preventing premature death, enhancing quality of life for people with long term conditions and improving the experience of care are three of the five domains in the NHS Outcomes Framework where there is particular relevance to metastatic prostate cancer. Whilst there is evidence that one-year survival for prostate cancer is improving, survival is linked to stage of disease. For disease which is confined to the prostate, five-year relative survival for patients in England in 1999-2002 is 90% or more, but, if the disease is metastatic at presentation, five-year relative survival is lower at around 30%. Improving functional ability in people with long-term conditions sits within the NHS Mandate. It also states that empowering patients to manage and make decisions about their own care and treatment is an objective for NHS England. There are treatment options now available that offer life extension whilst maintaining a reasonable quality of	NHS Mandate 2014/15 Cancer Survival in England by Stage: https://www.gov.uk/government/publications/cancer-survival-in-england-by-stage Cancer survival statistics http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/survival/prostate-cancer-survival-statistics

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				life.	
063	Nottingham University Hospital NHS Trust		Number of castration refractory patients offered systemic treatment. (eg Docetaxel, Abiraterone)	Systemic therapy prolongs survival in stage 4 CRPC but utilisation of these treatments has been variable across the country.	Docetaxel for the treatment of hormone-refractory metastatic prostate cancer (NICE technology appraisal guidance 101). Abiraterone for castration-resistant metastatic prostate cancer previously treated with a docetaxel-containing regimen. NICE technology appraisals [TA259] NICE: Prostate cancer pathway http://pathways.nice.org.uk/pathways/prostate-cancer
064	Cancer Black Care	High risk groups	Not enough people are being offered a PSA (prostate specific antigen) test or informed about availability of the test and research carried out by Prostate Cancer UK shows that two thirds of men over 50 do not even know that the test exists. There is often increased	Patients we have spoken to have raised concerns that GPs were reluctant to offer a PSA test if patient presents with no symptoms. The fact that many men do not get early symptoms appears under accepted and underplayed, in some cases resulting in treatment coming too late to help. Patients also commented that most	1. Ben-Shlomo Y, Evans S, Ibrahim F, Patel B, Anson K, Chinegwundoh F, et al. The risk of prostate cancer amongst black men in the United Kingdom: the PROCESS cohort study. Eur Urol 2008; 53:99–105. 2. Parkin D, Whelan S, Ferlay J, Raymond LYJ. Cancer Incidence in Five Continents. Lyon: IARC Scientific Publications No. 143, 1997. Report No. V11.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			anxiety amongst men with risk factors, particularly those with a family history of prostate cancer. If these men present in primary care, it is important that they receive the best available information and support to assist them in the decision of whether or not to have a PSA test. We would recommend regular PSA testing for asymptomatic men from age 45 if black and age 50 if white. People identified as high risk should be offered a tailored risk assessment and regular PSA testing with appropriate counselling.	primary care teams (including Practice Nurses/Nurse Practitioners) were not provided with the necessary education and knowledge around PSA testing, leading to patients having a PSA without being adequately informed or offered relevant counselling. Black men (irrespective of black-African or black-Caribbean origin) have a 3-fold higher risk of developing prostate cancer than white men [1] whilst Asian and Oriental men have the lowest incidence [2,3]. Despite the higher risk of prostate cancer, awareness of prostate cancer is low amongst black men. Anecdotal reports also indicate low awareness amongst some GPs, with some black men (who may be at an increased risk of prostate cancer) being refused a PSA test [4]. The combination of lack of cancer awareness in the black and other BME communities, and lack of cultural competence amongst health professionals, is almost certainly contributing to poorer outcomes from	3. Parker SL, Davis KJ, Wingo PA, Ries LA, Heath CW Jr. Cancer statistics by race and ethnicity. CA Cancer J Clin 1998; 48:31–48. 4. Hear me now: the uncomfortable reality of prostate cancer in black African-Caribbean men. A report by Rose Thompson, BME Cancer Communities, February 2013. http://www.nbpa.co.uk/wp-content/uploads/2014/04/Hear-me-now.pdf 5. NHS Cancer Screening Programmes. An easy reference to assist primary care teams in providing asymptomatic men with information on the benefits, limitations and implications of having a PSA test for prostate cancer. (2009). Available from: http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				prostate cancer [4].	
065	Tackle prostate cancer (Prostate Cancer Support Federation)	High risk groups	Not enough people are being offered a PSA (prostate specific antigen) test or informed about availability of the test and research carried out by Prostate Cancer UK shows that two thirds of men over 50 do not even know that the test exists. There is often increased anxiety amongst men with risk factors, particularly those with a family history of prostate cancer. If these men present in primary care, it is important that they receive the best available information and support to assist them in the decision of whether or not to have a PSA test. We would recommend regular PSA testing for asymptomatic men from age 45 if black and age 50 if white.	Patients we have spoken to have raised concerns that GPs were reluctant to offer a PSA test if patient presents with no symptoms. The fact that many men do not get early symptoms appears under accepted and underplayed, in some cases resulting in treatment coming too late to help. Patients also commented that most primary care teams (including Practice Nurses/Nurse Practitioners) were not provided with the necessary education and knowledge around PSA testing, leading to patients having a PSA without being adequately informed or offered relevant counselling. Black men (irrespective of black-African or black-Caribbean origin) have a 3-fold higher risk of developing prostate cancer than white men [1] whilst Asian and Oriental men have the lowest incidence [2,3]. Despite the higher risk of prostate cancer, awareness of prostate cancer is low	1. Ben-Shlomo Y, Evans S, Ibrahim F, Patel B, Anson K, Chinegwundoh F, et al. The risk of prostate cancer amongst black men in the United Kingdom: the PROCESS cohort study. Eur Urol 2008; 53:99–105. 2. Parkin D, Whelan S, Ferlay J, Raymond LYJ. Cancer Incidence in Five Continents. Lyon: IARC Scientific Publications No. 143, 1997. Report No. V11. 3. Parker SL, Davis KJ, Wingo PA, Ries LA, Heath CW Jr. Cancer statistics by race and ethnicity. CA Cancer J Clin 1998; 48:31–48. 4. Hear me now: the uncomfortable reality of prostate cancer in black African-Caribbean men. A report by Rose Thompson, BME Cancer Communities, February 2013. http://www.nbpa.co.uk/wp-content/uploads/2014/04/Hear-me-now.pdf 5. NHS Cancer Screening Programmes. An easy reference to assist primary care teams in providing asymptomatic men with information on the benefits, limitations and implications of having a PSA test for prostate cancer. (2009). Available from:

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			People identified as high risk should be offered a tailored risk assessment and regular PSA testing with appropriate counselling.	amongst black men. Anecdotal reports also indicate low awareness amongst some GPs, with some black men (who may be at an increased risk of prostate cancer) being refused a PSA test [4]. The combination of lack of cancer awareness in the black and other BME communities, and lack of cultural competence amongst health professionals, is almost certainly contributing to poorer outcomes from prostate cancer [4].	http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf
066	Wicked Minds	High risk groups	Not enough people are being offered a PSA (prostate specific antigen) test or informed about availability of the test and research carried out by Prostate Cancer UK shows that two thirds of men over 50 do not even know that the test exists. There is often increased anxiety amongst men with risk factors, particularly those with a family history of prostate cancer. If these men	Patients we have spoken to have raised concerns that GPs were reluctant to offer a PSA test if patient presents with no symptoms. The fact that many men do not get early symptoms appears under accepted and underplayed, in some cases resulting in treatment coming too late to help. Patients also commented that most primary care teams (including Practice Nurses/Nurse Practitioners) were not provided with the necessary education and knowledge around PSA testing,	1. Ben-Shlomo Y, Evans S, Ibrahim F, Patel B, Anson K, Chinegwundoh F, et al. The risk of prostate cancer amongst black men in the United Kingdom: the PROCESS cohort study. Eur Urol 2008; 53:99–105. 2. Parkin D, Whelan S, Ferlay J, Raymond LYJ. Cancer Incidence in Five Continents. Lyon: IARC Scientific Publications No. 143, 1997. Report No. V11. 3. Parker SL, Davis KJ, Wingo PA, Ries LA, Heath CW Jr. Cancer statistics by race and ethnicity. CA Cancer J Clin 1998; 48:31–48.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			present in primary care, it is important that they receive the best available information and support to assist them in the decision of whether or not to have a PSA test. We would recommend regular PSA testing for asymptomatic men from age 45 if black and age 50 if white. People identified as high risk should be offered a tailored risk assessment and regular PSA testing with appropriate counselling.	leading to patients having a PSA without being adequately informed or offered relevant counselling. Black men (irrespective of black-African or black-Caribbean origin) have a 3-fold higher risk of developing prostate cancer than white men [1] whilst Asian and Oriental men have the lowest incidence [2,3]. Despite the higher risk of prostate cancer, awareness of prostate cancer is low amongst black men. Anecdotal reports also indicate low awareness amongst some GPs, with some black men (who may be at an increased risk of prostate cancer) being refused a PSA test [4]. The combination of lack of cancer awareness in the black and other BME communities, and lack of cultural competence amongst health professionals, is almost certainly contributing to poorer outcomes from prostate cancer [4].	4. Hear me now: the uncomfortable reality of prostate cancer in black African-Caribbean men. A report by Rose Thompson, BME Cancer Communities, February 2013. http://www.nbpa.co.uk/wp-content/uploads/2014/04/Hear-me-now.pdf 5. NHS Cancer Screening Programmes. An easy reference to assist primary care teams in providing asymptomatic men with information on the benefits, limitations and implications of having a PSA test for prostate cancer. (2009). Available from: http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf
067	Ipsen Limited	High risk groups	Not enough people are being offered a PSA (prostate specific antigen) test or	Patients we have spoken to have raised concerns that GPs were reluctant to offer a PSA test if patient	1. Ben-Shlomo Y, Evans S, Ibrahim F, Patel B, Anson K, Chinegwundoh F, et al. The risk of prostate cancer amongst black men in the United

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			informed about availability of the test and research carried out by Prostate Cancer UK shows that two thirds of men over 50 do not even know that the test exists. There is often increased anxiety amongst men with risk factors, particularly those with a family history of prostate cancer. If these men present in primary care, it is important that they receive the best available information and support to assist them in the decision of whether or not to have a PSA test. We would recommend regular PSA testing for asymptomatic men from age 45 if black and age 50 if white. People identified as high risk should be offered a tailored risk assessment and regular PSA testing with appropriate	presents with no symptoms. The fact that many men do not get early symptoms appears under accepted and underplayed, in some cases resulting in treatment coming too late to help. Patients also commented that most primary care teams (including Practice Nurses/Nurse Practitioners) were not provided with the necessary education and knowledge around PSA testing, leading to patients having a PSA without being adequately informed or offered relevant counselling. Black men (irrespective of black-African or black-Caribbean origin) have a 3-fold higher risk of developing prostate cancer than white men [1] whilst Asian and Oriental men have the lowest incidence [2,3]. Despite the higher risk of prostate cancer, awareness of prostate cancer is low amongst black men. Anecdotal reports also indicate low awareness amongst some GPs, with some black men (who may be at an	Kingdom: the PROCESS cohort study. Eur Urol 2008; 53:99–105. 2. Parkin D, Whelan S, Ferlay J, Raymond LYJ. Cancer Incidence in Five Continents. Lyon: IARC Scientific Publications No. 143, 1997. Report No. V11. 3. Parker SL, Davis KJ, Wingo PA, Ries LA, Heath CW Jr. Cancer statistics by race and ethnicity. CA Cancer J Clin 1998; 48:31–48. 4. Hear me now: the uncomfortable reality of prostate cancer in black African-Caribbean men. A report by Rose Thompson, BME Cancer Communities, February 2013. http://www.nbpa.co.uk/wp-content/uploads/2014/04/Hear-me-now.pdf 5. NHS Cancer Screening Programmes. An easy reference to assist primary care teams in providing asymptomatic men with information on the benefits, limitations and implications of having a PSA test for prostate cancer. (2009). Available from: http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			counselling.	increased risk of prostate cancer) being refused a PSA test [4]. The combination of lack of cancer awareness in the black and other BME communities, and lack of cultural competence amongst health professionals, is almost certainly contributing to poorer outcomes from prostate cancer [4].	
068	SCM	Risk based assessment	Decisions to refer men to secondary care with raised PSA are currently based purely on age specific reference ranges, There is growing evidence to support better targeting of higher risk men – e.g. those with positive family history of prostate cancer, afro-caribbean men and those with 'baseline PSA levels' above the median at a young age.	A clear statement recommending targeting of PSA tests at these higher risk men in primary care, in the absence of a formal national screening programme, would at least enable us to improve the current ad hoc testing regime based on patient demand and inconsistent application of the Prostate Cancer Risk Management Programme.	
069	Nottingham University Hospital NHS Trust		Detailed information about pros and cons of PSA testing in asymptomatic men.	PSA screening can be harmful in some while benefitting a few. Provision of detailed information to patients by trained health professionals before testing in primary care would help patients make an informed choice about PSA testing.	NHS: Prostate Cancer Risk Management Programme. http://www.cancerscreening.nhs.uk/prostate/ NHS choices website: Should I have a PSA test? http://www.nhs.uk/Livewell/Prostatehealth/Pages/ps

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					a-test.aspx
070	SCM	Establishing an understanding of current pathways to provide a baseline and differences within the UK	To audit current practice and initiate a more uniform approach and set guidelines/standards	In order to realise the issues we have to have a baseline to then develop. We also must set standards and review competencies.	NPCA (England and Wales) QPI's (SCOTLAND)
071	Prostate Cancer UK	Data collection Pre-biopsy MRI	Data collection is essential for enabling men to make informed decisions about care and treatment. Robust data collection and reporting allows us to improve our knowledge and understanding of a disease and how it affects different demographics. It also enables us to identify areas of best practice and areas for improvement in NHS provision. Improved knowledge, understanding and services are important because this will reduce variations and inequalities and drive better outcomes for	As highlighted above, there are key areas in which enhanced data collection may enable men to make more informed decisions about their treatment options – for example, information about outcomes broken down by stage at diagnosis and other factors. Data are needed on treatment outcomes broken down by combinations of: • Stage at diagnosis • Gleason score • Ethnicity • Co-morbidities • Specific types of treatment (eg	See ID 009

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			patients. As highlighted in an earlier section, we also expect important evidence on the use of pre-biopsy MRI to emerge from the PROMIS clinical trial.	at the level of type of surgery conducted) This is currently an area of variation in clinical practice. If supported by the evidence from PROMIS (24), pre-biopsy MRI could hold value in ruling men out of needing a biopsy, thus reducing the risk of infection from biopsy, and of subsequent treatment side effects.	
072	Janssen	Development of metrics for CG175 (prostate cancer), particularly for patients with metastatic disease	Metrics need to be developed in order to ensure that recommendations in CG175 are properly implemented	Metrics for patients with metastatic disease have not been fully developed for the following recommendations in CG175: • Improve communication with men receiving treatment including their partners and carers • Increase communication between GPs and hospital specialists • Effective monitoring and managing side effects designed to identifying complications earlier and increase QoL • Shared care protocols between primary and secondary care • Tracking software to ensure	NICE CG175

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				effective recall	
073	The Lesbian & Gay Foundation	Increased awareness among healthcare staff of the potential impacts of prostate cancer on gay, bisexual and other men who have sex with men	Gay, bisexual and other men who have sex with men are more likely than heterosexual men or women to have to deal with prostate cancer in their lifetime, as both partners will have a prostate gland. The main treatments available for prostate cancer can have significant side effects such as incontinence, infertility and erectile dysfunction. These side effects can affect gay and bisexual men differently to heterosexual men, particularly in relation to how they see themselves and their sexuality. Healthcare staff are often unaware of the needs of gay, bisexual and other men who have sex with men, and receive limited training on the health of this group. As a consequence, these needs go unmet in treatment and	Patient-centred, holistic care is a cornerstone of the NHS service model and NHS constitution. Providing information and treatment that is responsive to patient need will be more effective in the long term and lead to better patient outcomes. Patient sexual orientation monitoring across the healthcare system would contribute to increased quality of care as healthcare staff would be better aware of their patients' needs and better able to meet them. Men using our services say that healthcare staff usually assume that they are heterosexual and have a female partner, which makes it more difficult to come out about their sexual orientation. In some cases this results in the wrong information being given to patients or treatment options suggested which are not appropriate. Healthcare professionals receive limited training on the health of gay and bisexual men, and limited training on equality and diversity including trans* awareness training. A possible	We recommend the resource published by Prostate Cancer UK and Stonewall on meeting the needs of gay and bisexual men: http://prostatecanceruk.org/news/2013/2/stonewall-meeting-the-needs-of-gay-and-bisexual-men

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			patient engagement.	solution to be investigated is developing a training package for oncologists and wider cancer support health professionals on sexual orientation equality (and possibly other equality and diversity issues).	
074	The Lesbian & Gay Foundation	Address the psychosexual needs of gay, bisexual and other men who have sex with men diagnosed with prostate cancer	Men who use our services say that as men who have sex with men their psychosexual needs are not addressed by the NHS. The main treatments available for prostate cancer can have significant side effects such as incontinence, infertility and erectile dysfunction. These side effects can affect gay and bisexual men differently to heterosexual men, particularly in relation to how they see themselves and their sexuality.	Patient-centred, holistic care is a cornerstone of the NHS service model and NHS constitution. Providing information and treatment that is responsive to patient need will be more effective in the long term and lead to better patient outcomes. The side effects of treatment for prostate cancer can affect gay and bisexual and other men who have sex with men differently to heterosexual men, particularly in relation to how they see themselves and their sexuality. Often they tell us that there concerns are not addressed in the quest to deal with their cancer or remove their prostate and whenever a question is raised about issues such as incontinence, or erectile dysfunction e.g.: they are told that the most important thing is that their cancer has been dealt with. This often	We recommend the resource published by Prostate Cancer UK and Stonewall on meeting the needs of gay and bisexual men: http://prostatecanceruk.org/news/2013/2/stonewall-meeting-the-needs-of-gay-and-bisexual-men

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				leaves these men to become very isolated and withdrawn and affects their personal relationships as well as their self-esteem.	
075	The Lesbian & Gay Foundation	Hormone therapy (discussing options with patients)	Hormone therapy for prostate cancer stops the testis from producing testosterone, which stimulates the growth of prostate cancer. This slowly switches off libido causing men great distress. Hormone therapy for the treatment of prostate cancer also has a historical significance for some older gay and bisexual men (regarding how some male same sex sexual orientation was treated before the decriminalisation of homosexuality in 1967). This may need to be taken into account by health professionals when counselling this group of patients.	Patient-centred, holistic care is a cornerstone of the NHS service model and NHS constitution. Providing information and treatment that is responsive to patient need will be more effective in the long term and lead to better patient outcomes.	
076	The Lesbian & Gay	HIV & prostate cancer	Some medicines used to treat conditions associated with HIV can interact with	Some medicines used to treat conditions associated with HIV can interact with medicines to treat cancer	We recommend the resource published by Prostate Cancer UK and Stonewall on meeting the needs of gay and bisexual men:

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Foundation		medicines to treat cancer. Approximately 1 in 10 MSM is living with HIV (Dodds et al., 2007), so this should be properly considered by healthcare professionals.	so it is vital for an open discussion about treatment with those affected by both HIV and cancer	http://prostatecanceruk.org/news/2013/2/stonewall-meeting-the-needs-of-gay-and-bisexual-men
077	Janssen	Equality	Patients should receive high quality care regardless of their characteristics such as age, ethnicity or fitness for chemotherapy	There is evidence that from the 'Hear me Now' report that Black African Caribbean men have a three-fold greater risk of developing prostate cancer and are more likely to present with prostate cancer at a younger age. The death rate from prostate cancer is 30% higher in black men compared to their white counterparts. The National Cancer Patient Experience Survey highlights variation in patient's experience of care, some of which is documented in the Prostate Cancer UK report 'It's time for quality care everywhere'. The suggested quality check list is a step in the right direction. However, this still does not sufficiently address the specific needs of men with metastatic disease nearing the end of their life. According to the current NICE	Hear Me Now Report 2013 (attached) 'It's time for quality care. Everywhere.' Report by Prostate Cancer UK http://prostatecanceruk.org/media/2105544/2298-its-time-for-quality-care-everywhere_full-2-.pdf NICE TA259 for abiraterone NICE TA316 for enzalutamide

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				guidance, no novel therapy for metastatic hormone-relapsed prostate cancer is recommended when a patient is not deemed fit for chemotherapy. This is unfair for such patients and, since fitness to chemotherapy is often associated with a patient's age, there is a risk of age discrimination.	
078	Cancer Black Care	Access to treatment	The NHS Constitution sets out patients' right to treatment, right to NICE approved drugs and right to complain about their care. The constitution gives the patient the right to ask their doctor and hospital for the right care. The patient and his partner, family and/or other carers (if appropriate) should be able to make appropriate decisions based upon the choices offered by their healthcare professionals. For example, the choice between radical treatment and active surveillance may be	All men with prostate cancer have a right to have the best possible care and support regardless of where they live. According to a report by Prostate Cancer UK, unfortunately, there are significant variations in prostate cancer incidence, patient experience, mortality and survival across the UK. The decisions taken about treatment options may impact upon quality of life long after treatment has finished. The National Cancer Survivorship Initiative (NCSI) suggests offering patients support in making the decisions that best reflect their individual priorities. This quality improvement should seek	1. Quality care. Everywhere? An audit of prostate cancer services in the UK. http://prostatecanceruk.org/media/1818657/1772-day-of-action-report_for-web.pdf 2. The NHS Constitution: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf 3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			influenced by a patient's desire to retain sexual activity, physical energy and quality of life. It is important that people with prostate cancer (regardless of stage of disease) have access to their treatment of choice, (including access to clinical trials) and clinical expertise regardless of geographical location.	to give patients a more powerful voice and active involvement in setting priorities for service improvement and in improving access to cutting edge diagnostics, innovative treatments and clinical trials.	
079	Tackle prostate cancer (Prostate Cancer Support Federation)	Access to treatment	The NHS Constitution sets out patients' right to treatment, right to NICE approved drugs and right to complain about their care. The constitution gives the patient the right to ask their doctor and hospital for the right care. The patient and his partner, family and/or other carers (if appropriate) should be able to make appropriate decisions based upon the	All men with prostate cancer have a right to have the best possible care and support regardless of where they live. According to a report by Prostate Cancer UK, unfortunately, there are significant variations in prostate cancer incidence, patient experience, mortality and survival across the UK. The decisions taken about treatment options may impact upon quality of life long after treatment has finished. The National Cancer Survivorship Initiative	1. Quality care. Everywhere? An audit of prostate cancer services in the UK. http://prostatecanceruk.org/media/1818657/1772-day-of-action-report_for-web.pdf 2. The NHS Constitution: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf 3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			choices offered by their healthcare professionals. For example, the choice between radical treatment and active surveillance may be influenced by a patient's desire to retain sexual activity, physical energy and quality of life. It is important that people with prostate cancer (regardless of stage of disease) have access to their treatment of choice, (including access to clinical trials) and clinical expertise regardless of geographical location.	(NCSI) suggests offering patients support in making the decisions that best reflect their individual priorities. This quality improvement should seek to give patients a more powerful voice and active involvement in setting priorities for service improvement and in improving access to cutting edge diagnostics, innovative treatments and clinical trials.	with-and-beyond-2013.pdf
080	Wicked Minds		The NHS Constitution sets out patients' right to treatment, right to NICE approved drugs and right to complain about their care. The constitution gives the patient the right to ask their doctor and hospital for the right care. The patient and his partner,	All men with prostate cancer have a right to have the best possible care and support regardless of where they live. According to a report by Prostate Cancer UK, unfortunately, there are significant variations in prostate cancer incidence, patient experience, mortality and survival across the UK.	1. Quality care. Everywhere? An audit of prostate cancer services in the UK. http://prostatecanceruk.org/media/1818657/1772-day-of-action-report_for-web.pdf 2. The NHS Constitution: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			family and/or other carers (if appropriate) should be able to make appropriate decisions based upon the choices offered by their healthcare professionals. For example, the choice between radical treatment and active surveillance may be influenced by a patient's desire to retain sexual activity, physical energy and quality of life. It is important that people with prostate cancer (regardless of stage of disease) have access to their treatment of choice, (including access to clinical trials) and clinical expertise regardless of geographical location.	The decisions taken about treatment options may impact upon quality of life long after treatment has finished. The National Cancer Survivorship Initiative (NCSI) suggests offering patients support in making the decisions that best reflect their individual priorities. This quality improvement should seek to give patients a more powerful voice and active involvement in setting priorities for service improvement and in improving access to cutting edge diagnostics, innovative treatments and clinical trials	3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf
081	Ipsen Limited	Access to treatment	The NHS Constitution sets out patients' right to treatment, right to NICE approved drugs and right to complain about their care. The constitution gives the patient the right to ask their	All men with prostate cancer have a right to have the best possible care and support regardless of where they live. According to a report by Prostate Cancer UK, unfortunately, there are significant variations in prostate cancer incidence, patient experience,	1. Quality care. Everywhere? An audit of prostate cancer services in the UK. http://prostatecanceruk.org/media/1818657/1772-day-of-action-report_for-web.pdf 2. The NHS Constitution:

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			doctor and hospital for the right care. The patient and his partner, family and/or other carers (if appropriate) should be able to make appropriate decisions based upon the choices offered by their healthcare professionals. For example, the choice between radical treatment and active surveillance may be influenced by a patient's desire to retain sexual activity, physical energy and quality of life. It is important that people with prostate cancer (regardless of stage of disease) have access to their treatment of choice, (including access to clinical trials) and clinical expertise regardless of geographical location.	mortality and survival across the UK. The decisions taken about treatment options may impact upon quality of life long after treatment has finished. The National Cancer Survivorship Initiative (NCSI) suggests offering patients support in making the decisions that best reflect their individual priorities. This quality improvement should seek to give patients a more powerful voice and active involvement in setting priorities for service improvement and in improving access to cutting edge diagnostics, innovative treatments and clinical trials.	http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf 3. Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). http://www.ncsi.org.uk/wp-content/uploads/Living-with-and-beyond-2013.pdf
82	Society and	Key area for quality	Expert radiographer	This role completes the MDT and offers a support role available to the	Cost effectiveness

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	College of Radiographers	improvement 1	practitioner Advanced knowledge of the management of prostate cancer and treatment side effects	patient 1. Decision making Information for treatment option particularly radiotherapy (EBRT and BRT) 2. Support through the pathway to follow up 3. Undertaking telephone follow up 4. Named individual for patients receiving radiotherapy	Improved patient experience Side effect management We suspect there isn't any formal study but there may be something in the National Cancer Patient Experience Survey
83	Association of Chartered Physiotherapists in Oncology and Palliative Care	Access to information and support for exercise and physical activity	Physical activity is recommended by NICE to help fatigue issues but also recommended for reducing risk of disease progression in survivorship stage	DOH recommendations regarding exercise for health of the nation 5 x week – 30 mins http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx#muscle	Erin et al (2011) Physical Activity after diagnosis and risk of prostate cancer progression : data from the cancer research urologic research endeavour. Can Research Dr. Stacey Kenfield,,Journal of Clinical Oncology 2011 that looked at physical activity and outcomes for men in the Health Professionals Follow-up Study diagnosed with prostate cancer. That study found that: • Men who walked briskly for 90 minutes or more per week lower their risk of death from any cause by 46% compared to men who men who walked less quickly and less often. • Men who exercised vigorously (e.g., biking, tennis, jogging, swimming) three or more hours per week had a 61% lower risk of death from prostate cancer compared to men who exercised vigorously less than one hour per week.

ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
					• Both non-vigorous and vigorous activity lowed men’s risk of death from any cause. Journal of Physical Activity & Health, found that men diagnosed with cancer who burned 12,600 kilojoules (kJ) or more a week doing physical exercise (such as walking or stair climbing) cut their risk of death from any cause by half, compared to men whose weekly exercise burns only added up to 2,100 kilojoules a week. (12,000 kJ converts to 3,011 calories.) Physical activity and survival after cancer diagnosis in men. Lee IM, Wolin KY, Freeman SE, Sattlemair J, Sesso HD (2014) J Phys Act Health 11(1):85-90
084	British Association of Urological Surgeons, Section of Oncology	Key area for quality improvement 1 Ensure men with localised prostate cancer have the opportunity to meet with a surgical and clinical oncologist	Recommended in NICE Guideline	In the absence of evidence of superiority of one treatment it is important that all men at least have the opportunity to discuss their treatment choice with a surgical and clinical oncologist,	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
085	Ferring Pharmaceuticals	Additional developmental areas of emergent practice – where guidance is expected during the consultation and development period prior to publication	To ensure guidance is contemporaneous – a statement placing potential therapies under consideration is required	To ensure there is no timelag to inclusion of newer therapies	This is standard practise in SIGN guidance. NICE reference newer therapies in the index alongside older guidance where there is potential for it to be missed.
086	Royal College of Pathologists	Key area for quality improvement 1 All prostate core biopsies reported to follow standard of Royal College of pathologists Cancer dataset	In order to assign a risk category for a patient a prostate biopsy pathology report needs to provide a Gleason score (unless there has been previous therapy), the amount of tumour present (number of cores involved, percentage of tumour) and the presence or absence of perineural invasion. A proforma report is ideal for data extraction.	Stratifying risk is essential for patient management. Data extraction for cancer registries provides population statistics for service planning - this is facilitated by the use of proforma pathology reports.	http://www.rcpath.org/publications-media/publications/datasets/prostate.htm Please note that this dataset is due to be updated in the next 6 months.
087	SCM	Patient self-empowerment	Do we need to review patients as often. Under guidelines can we empower patients to be self	The MDT meeting is a vital cog in decision making for patients and allows access to all specialists for all patients if arranged to be discussed	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			empowered.	and if meeting delivered appropriately to allow this to happen. As per previous key area though, MDT also refers to all health care and tertiary services. Eg-advanced nursing practice, GP, District Nurses, practice Nurses, non – NHS support.	
088	SCM		How and by whom prostate cancer patients are reviewed throughout the pathway.	Volume of prostate cancers increasing exponentially and reportedly as much as 28% over next 5 years. Patient management more complex and requiring long-term follow up. Follow-up requires many areas of resource. Wider aspects of care need managed along with clinical treatment.	We are already struggling to manage this. We need to have a “joined-up” team approach throughout all aspects planned now.
089	SCM		Counselling and assessment prior to investigations that lead to a prostate cancer diagnosis	Screening for prostate cancer is currently not advocated in the UK. However, many men appear with concerns of a diagnosis having presented with other complaints to GP. Also, this is often only from a single finding (ie PSA) and usually there is very little if any counselling as to implications. This leads to overdiagnosis but more importantly patients being ill/poorly informed.	To prevent overdiagnosis but more importantly have patients better prepared/informed about implications. Need for patient information and counselling but also clinician education and resource to provide this.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
090	SCM			Men with localised prostate cancer who are candidates for radical treatment have the opportunity to discuss their treatment options with a specialist surgical oncologist and a specialist clinical oncologist	
091	SCM			Men with localised prostate cancer receiving radical external beam radiotherapy with curative intent are offered planned treatment techniques that optimise the dose to the tumour while minimising the risks of normal tissue damage	
092	SCM		Conformity of MDM discussion	Important aspect of NICE guidance, the MDM format needs to be standardised. There wil be resource implications and need to seek agreement from NHS care facilities to alter job plans. However, as the MDM is the ultimate point of patient discussion and management formulation, it is in some ways the key point of the pathway, with risk of discarding any excellence in the diagnostic work up and so less beneficial treatment and poorer patient experience.	
093	SCM			Men with prostate cancer are given opportunity to participate in research	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				and trials where appropriate	
094	SCM			Additional evidence sources for consideration	
095	Tackle prostate cancer (Prostate Cancer Support Federation)	In addition to the comments provided above Tackle Prostate Cancer wish to highlight to the Quality Standard Advisory Committee (QSAC) that we have been chairing a working group made up of members from Tackle Prostate Cancer, Prostate Cancer UK, Macmillan Cancer Support, patient representatives, urologists, oncologists, clinical nurse specialists, cancer commissioners, and Ipsen Limited. These organisations have pooled resources to develop a set of quality statements that best represents the quality of care for patients with prostate cancer with a particular focus on the quality and service requirements from the perspective of a patient. Over the last 3 months the working group has identified 10 areas, where, based on actual experiences of patients with prostate cancer, improvements are most needed. These are listed below. Although the NICE engagement exercise has asked for only 5 key areas and one emerging area, we would like to press that we strongly believe that the following areas all warrant quality improvement in order to ensure the best experience and outcomes for the patient. We will be submitting our formal report to the QSAC in time for their first meeting in October, in which of the areas below will be fully detailed. Key quality areas as agreed by working group of patients and HCPs: 1. Risk assessment and referral 2. High risk groups 3. Diagnosis 4. Shared decision making 5. Access to treatment 6. Information and support 7. Access to specialist multidisciplinary teams 8. Self management			

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		9. Integrated care 10. Palliative care			
096	Wicked Minds	In addition to the comments provided above Wicked Minds wish to highlight to the Quality Standard Advisory Committee (QSAC) that we have been facilitating and sipporting a working group made up of members from Tackle Prostate Cancer, Prostate Cancer UK, Macmillan Cancer Support, patient representatives, urologists, oncologists, clinical nurse specialists, cancer commissioners, and Ipsen Limited. These organisations have pooled resources to develop a set of quality statements that best represents the quality of care for patients with prostate cancer with a particular focus on the quality and service requirements from the perspective of a patient. Over the last 3 months the working group has identified 10 areas, where, based on actual experiences of patients with prostate cancer, improvements are most needed. These are listed below. Although the NICE engagement exercise has asked for only 5 key areas and one emerging area, we would like to press that we strongly believe that the following areas all warrant quality improvement in order to ensure the best experience and outcomes for the patient. We will be submitting our formal report to the QSAC in time for their first meeting in October, in which the areas below will be fully detailed. Key quality areas as agreed by working group of patients and HCPs: 1. Risk assessment and referral 2. High risk groups 3. Diagnosis 4. Shared decision making 5. Access to treatment 6. Information and support 7. Access to specialist multidisciplinary teams 8. Self management 9. Integrated care			

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		10. Palliative care			
097	NHS England	I wish to confirm that NHS England has no substantive comments to make regarding this consultation.			
098	Royal College of Nursing	This is just to let you know that there are no comments to submit on behalf of the Royal College of Nursing in relation to the stakeholder engagement exercise for the prostate cancer quality standard.			

---

[i] http://sdm.rightcare.nhs.uk/pda/

[ii] Cancer Patient Experience Survey 2013. http://www.healthwatchbathnes.co.uk/sites/default/files/Cancer%20Report%202013%20Final%20-%20embargoed%20until%201100%2030.8.13.pdf

[iii] National Cancer Action Team. Clinical Nurse Specialists in Cancer Care; Provision, Proportion and Performance. A census of the cancer specialist nurse workforce in England 2011 [Internet]. 2012. Available from file:///X:/Users/KAngeloudis/Downloads/CNS%20census%202011%20-%20NCAT%20Census%20of%20the%20Cancer%20Specialist%20Nurse%20Workforce%202011.pdf

[iv] Prostate Cancer UK. Men’s views on quality care in prostate cancer: What does good quality care mean for men with prostate cancer? 2012 Available from: http://prostatecanceruk.org/media/1559431/prostate_cancer_uk_quality_care_survey_report_june_2012.pdf

[v] Willis S, Ahmed H, Moore C, Donaldson I. Multiparametric MRI followed by targeted prostate biopsy for men with suspected prostate cancer: a clinical decision analysis. British Medical Journal. 2014 June 15;4(6). Available from: http://bmjopen.bmj.com/content/4/6/e004895.full

[vi] Prostate Cancer UK. Men’s views on quality care in prostate cancer: What does good quality care mean for men with prostate cancer? 2012 Available from: http://prostatecanceruk.org/media/1559431/prostate_cancer_uk_quality_care_survey_report_june_2012.pdf