More to do

Identifying and tackling the unmet need in prostate cancer care

The writing of this report was undertaken by Orchid Cancer Appeal with support from Janssen.[†]

ORCHID
FIGHTING MALE CANCER

[†]The writing of this report was undertaken by Orchid Cancer Appeal. The report was commissioned by Janssen, a pharmaceutical company of Johnson & Johnson, with research and project management support from Incisive Health, a communications consultancy. Janssen has provided funding for Incisive Health's support and the printing of the report.

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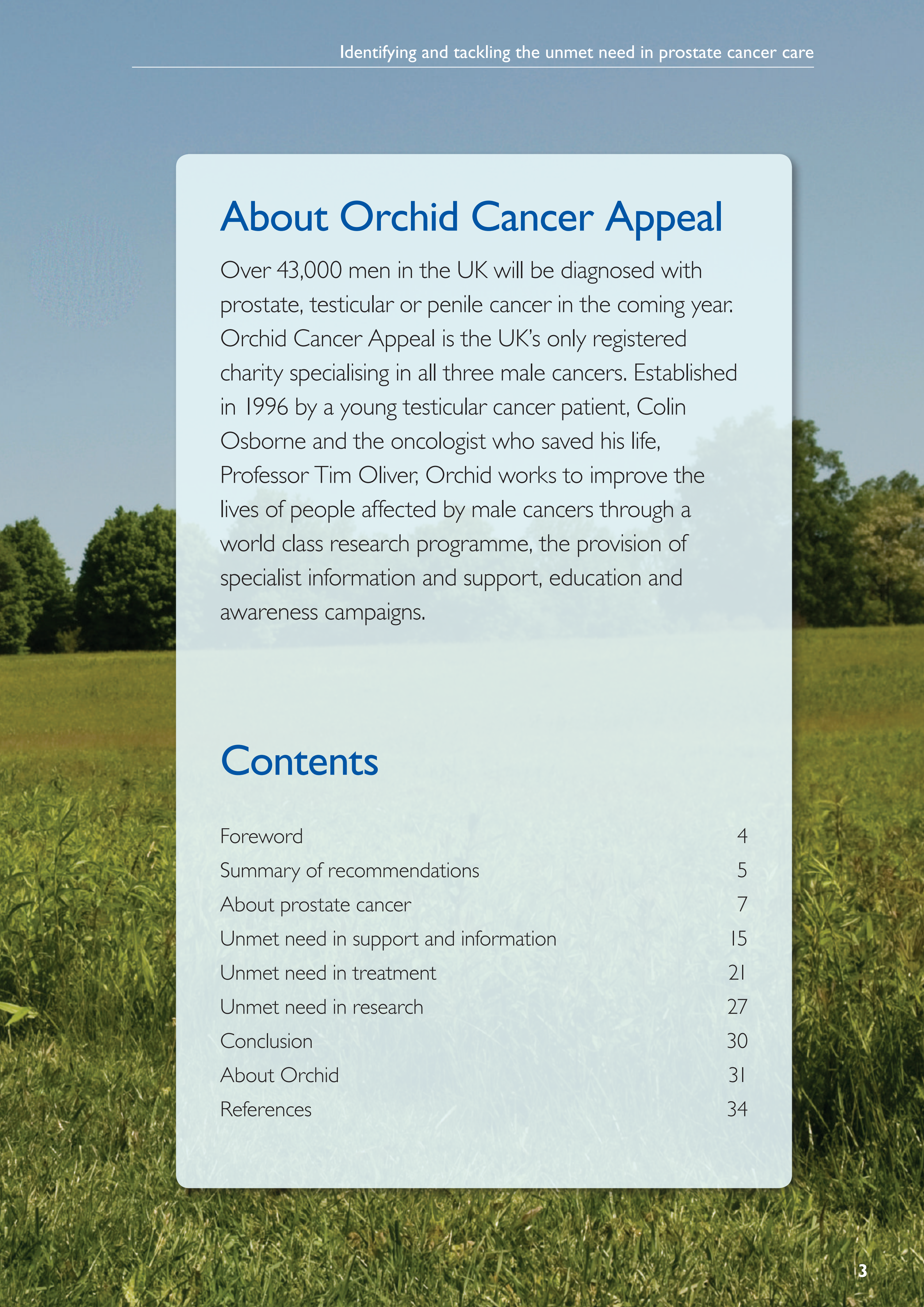

About Orchid Cancer Appeal

Over 43,000 men in the UK will be diagnosed with prostate, testicular or penile cancer in the coming year. Orchid Cancer Appeal is the UK's only registered charity specialising in all three male cancers. Established in 1996 by a young testicular cancer patient, Colin Osborne and the oncologist who saved his life, Professor Tim Oliver, Orchid works to improve the lives of people affected by male cancers through a world class research programme, the provision of specialist information and support, education and awareness campaigns.

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Foreword

Orchid is the UK's leading registered charity dedicated to male-specific cancers: prostate, testicular and penile cancer. Established in 1996 by a cancer patient, Colin Osborne and the oncologist who saved his life, Professor Tim Oliver, Orchid works to improve the lives of people affected by male cancers through a world-class research programme, the provision of specialist information and support, and education and awareness campaigns.

Amongst all those male-specific cancers, prostate cancer is a particular success story of recent years. New treatments have been introduced, new investment has been made, and research into new tests and technologies offer hope that the condition can be treated even more effectively in the near future than it is today.

However, that success should not breed complacency. As this report shows, there are significant areas of unmet need which need to be addressed by the NHS, by policymakers and by politicians. These areas of unmet need fall into three broad categories: the support and information which patients receive about their condition; the treatments that are made available to them; and the level of access they have to research and clinical trials.

Our objectives in developing this report have therefore been three-fold:

- To show just how far patient outcomes have been improved in the prostate cancer community over the last few decades
- To ensure that politicians and policymakers understand the steps which need to be taken to improve prostate cancer services today
- To make recommendations which will drive change in these areas

We want this report to shine a light on the unmet need in current prostate cancer care, and to quantify the level of improvement which now needs to be made. We intend to use the findings of this report to affect the policy change we wish to see.

We do hope you find the report interesting and of use in your work. Our thanks go in particular to the Rt Hon Paul Burstow MP who assisted us so ably in some of our investigations and to Janssen for supporting the research underpinning the production of this report.

Our thanks go above all to all the prostate cancer patients, their carers, and their families, who responded to our call for evidence. Without their assistance, this report would not have been possible.

Rebecca Porta
Chief Executive, Orchid

Summary of recommendations

Support and information

Recommendation 1: NHS England should take action to ensure that the care of all prostate cancer patients is coordinated and planned by an appropriately established multidisciplinary team (MDT), which includes a surgeon, and medical and clinical oncologists.

Recommendation 2: NHS England – as the commissioner of specialist prostate cancer treatment services – and local commissioners should ensure that NHS services treating patients implement NICE guidance and guidelines, including by providing sufficient information for patients to understand the risks and benefits of all treatment options to enable them to make informed decisions.

Recommendation 3: the Department of Health should review the operation of its 'integration pioneers' to see whether any lessons can be learned with respect to driving improvements in the delivery of integrated prostate cancer care.

Recommendation 4: in the next annual report on improving progress in cancer services, NHS England should detail in specific terms the exact steps and timelines it is taking to improve the experience of patients living with prostate cancer.

Recommendation 5: NHS-funded providers of prostate cancer services should ensure that their staff are directing patients with prostate cancer to a range of specialist support services – including charities, helplines and support groups – when it is appropriate to do so.

Recommendation 6: the Government should reinforce the need for Trusts to ensure patients have access to a Clinical Nurse Specialist (CNS), and in particular uro-oncology CNSs, at all stages of their cancer journey. Trusts should review the caseload of CNSs to ensure that there are adequate numbers and that cover arrangements are in place for all newly diagnosed cases as well as metastatic patients.

Recommendation 7: the Care Quality Commission (CQC), in its inspection of healthcare providers, should ensure they are compliant with National Cancer Peer Review measures, which include the provision of CNSs at a level sufficient to deliver the required standard of care and support to patients living with prostate cancer.

Access to treatment

Recommendation 8: the Department of Health should expedite the implementation of Systemic-Anti Cancer Therapy (SACT) and ensure that data are used to help determine whether unwarranted variations in access to prostate cancer treatments exist.

Recommendation 9: the CQC should set out how it intends to honour the spirit of the commitment made by the Health Minister in October 2013 that it will examine levels of access to NICE-approved medicines in the NHS-funded services it inspects.

Recommendation 10: the Department of Health should ensure a sufficient number of clinical/medical oncologists are available to support local and specialist multidisciplinary teams (MDTs). Consideration should be given to allowing urologists working in collaboration with oncologists through a MDT to make applications to the Cancer Drugs Fund.

Recommendation 11: the Government should work with NICE to ensure the original aims of 'value-based pricing' – and, in particular, the Coalition's commitment to ensure all patients access the drugs and treatments their doctors think they need – are delivered through meaningful reform, therefore helping to reduce demand on the Cancer Drugs Fund for prostate cancer treatments.

Recommendation 12: the Government and NICE should work with charities such as Orchid and with our partners in the prostate cancer community to ensure that there are clear opportunities to improve the evaluation of new treatments within current NICE processes – and, as a result, to improve access to treatment for patients.

Access to research and clinical trials

Recommendation 13: the Department of Health should take steps to continue to ensure high participation rates in prostate cancer clinical trials.

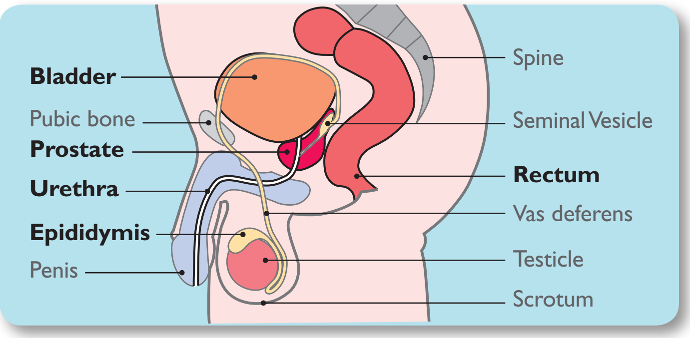
Recommendation 14: providers of prostate cancer care who perform significantly worse than their peers on the question of patients being asked to participate in cancer research, including in clinical trials in the National Cancer Patient Experience Survey, should undertake an internal audit of the reasons for their poor performance and take steps to improve their performance over time.

Recommendation 15: providers of prostate cancer services should take steps to ensure that their employees are aware of the actions they should take when asked about prostate cancer clinical trials, and the information they should provide.

About prostate cancer

General information

Where is the prostate gland and what does it do?



The prostate gland is located just below the bladder. It is only found in men and is responsible for helping to produce the fluid found in semen (sperm). The gland is tiny at birth, but grows in size after puberty due to rising levels of the male hormone, testosterone. The prostate is surrounded by a thin capsule and is situated in the pelvis, the lower part of the trunk between the abdomen and the thighs. The prostate also has structures called the seminal vesicles attached to it (see diagram above) which secrete around 60% of the fluid that ultimately becomes semen.

The cancer and its symptoms

The growth of all cells is normally carefully controlled: as cells die, they are replaced in an orderly fashion. Cancer can develop when cells start to grow in an uncontrolled way. If this happens in the prostate gland, prostate cancer can develop. The prostate is a gland in the male reproductive system – so only men can get prostate cancer.

Most prostate cancer is slow-growing and may never cause any problems or symptoms. Possible symptoms may include:

Some possible symptoms of prostate cancer[1]

- An increased need to urinate
- Straining while urinating
- A feeling that the bladder has not fully emptied
- Weak flow
- Needing to rush to the toilet

Causes and risk factors

The causes of prostate cancer are multifactorial. The proportion of cases attributable to genetic factors appears low (although research is ongoing):[2] it is certainly the case that men who have had a father or brother affected by prostate cancer are at an increased risk. For reasons not yet understood, prostate cancer is more common in men of African-Caribbean or African descent, and less common in men of Asian descent.[1]

The strongest risk factor for prostate cancer, however, is age.[3] It is relatively uncommon in men under 45 but becomes more common with advancing age. In England in 2010, for example, 75% of new cases occurred in men aged 65 and over with the largest number of new cases among those aged 70-74.[4]

Diagnosis

There is no definitive test for prostate cancer, but a GP is likely to:[1]

- Ask for a urine sample to rule out infection
- Take a blood sample to test the level of prostate-specific antigen (PSA) –a protein produced by the prostate gland, which may be produced in greater levels when prostate cancer is present (although PSA is non-specific and can be raised in other conditions, such as urinary or prostate infection)
- Examine the prostate (through a digital rectal examination)

If a GP feels that further tests are necessary, he may refer the man to a hospital. Tests at the hospital may involve a biopsy (where tissue samples of the prostate are taken), and – if there is a chance the cancer has spread – an MRI and / or bone scan (among others).[8]

Treatment

For many men with prostate cancer, treatment is not immediately necessary.
If the cancer is at an early stage and not causing symptoms, a policy of 'active surveillance' may be adopted – or if men feel that they would not ultimately benefit from treatment, be medically fit enough or have no symptoms, a policy of 'watchful waiting' may be employed.

Active surveillance involves more regular check-ups at hospital, and includes tests (such as prostate biopsies and specialist MRI scans). The aim is to treat the cancer promptly if it shows signs of progression, or if an individual wishes to have treatment with the intent of cure.

Watchful waiting involves check-ups at a GP surgery or hospital clinics, with the aim of treating the symptoms of cancer, usually with palliative intent, if they begin to cause problems. However, some men will have cancer that is more aggressive or 'high risk'. This will need treatment to cure it, or delay it spreading to other parts of the body.

Many cases of prostate cancer can be cured if treated in the early stages: treatment options include removing the prostate (prostatectomy), and radiotherapy (with the addition of adjuvant or neo-adjuvant hormone therapy). When the cancer spreads to other parts of the body, however – typically the bones – it cannot be cured and treatment is focused on prolonging life and relieving symptoms.

All treatment options carry the risk of potential side effects, on urinary and sexual function. For this reason, some men choose to delay treatment until there is a risk the cancer might spread.

Types of treatment for prostate cancer

- **Radical prostatectomy.** A radical prostatectomy is the surgical removal of a man's prostate gland. Although, for many men, having a radical prostatectomy will get rid of the cancer cells, the surgery may have serious long-term side effects – including stress, urinary incontinence and erectile dysfunction.
- **Radiotherapy.** Radiotherapy is used both to cure localised prostate cancer and locally-advanced prostate cancer. As well as short-term side effects, radiotherapy can also cause urinary symptoms after treatment, and occasionally bowel damage, as well as erectile dysfunction. A form of radiotherapy – brachytherapy – is delivered through tiny radioactive seeds implanted into the tumour site. In addition many units are using IMRT (Intensity Modulated Radiotherapy) which may prevent damage to surrounding tissue and help reduce these complications.
- **Hormone therapy.** Prostate cancer needs the hormone testosterone to grow. Hormone therapy is used to reduce the production of testosterone. (A surgical alternative to hormone therapy is an orchidectomy – removal of the testicles.) Side effects are mainly caused by reduced testosterone levels (such as lack of sex drive and erectile dysfunction) which should improve once treatment is stopped.
- **Chemotherapy.** Chemotherapy is used to treat metastatic prostate cancer which has become resistant to hormone therapy. Chemotherapy destroys cancer cells by interfering with the way cells multiply: it does not cure prostate cancer, but can keep it under control. Side effects of chemotherapy are caused by the impact the treatment has on healthy cells – and include tiredness, nausea and hair loss.
- **Other treatments.** Other treatments – such as cryotherapy or High-Intensity Focused Ultrasound (HIFU) – are used as 'salvage treatments' after radiotherapy treatment and are not recommended for men as a first line treatment other than in the context of controlled clinical trials. A range of other treatments including anti androgens and steroidal blockade along with novel, newer treatments may be used when hormonal therapy no longer works.

Current situation

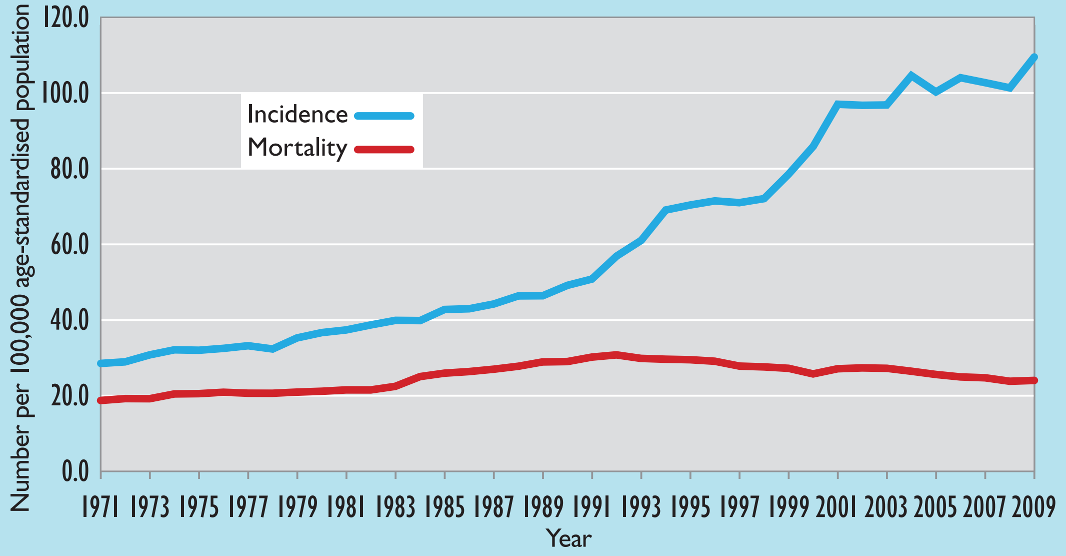
Prostate cancer is the most common male cancer in England, accounting for a quarter of all newly diagnosed cases of cancer among men in 2011.[5] Just over 41,700 new cases of prostate cancer were diagnosed in England in 2011,[5] and it is estimated that one in eight men will develop prostate cancer at some point in their lives.[3]

In 2011, just under 10,800 men died from prostate cancer in England, accounting for 13% of all male cancer deaths.[6] Around a quarter of a million men are living with or after prostate cancer.[7]

Changes over time

Figure 1 shows how the incidence of, and mortality arising from, prostate cancer has changed in England since 1971:[4]

Figure 1: Incidence and mortality from prostate cancer



The chart, which controls for age by using age-standardised measures, shows two clear trends:

- A sharp increase in the recorded incidence of prostate cancer since the 1980s
- A steady increase in mortality between 1971 and 1992 (with the increase partly tracking the rise in incidence) followed by a gradual decline since then

The reasons for these trends are complex, and we consider each in turn.

Incidence

The increase in incidence since 1971 can be broken down into two parts:

- The increase in the 1980s, which is believed to be due to detection of more prostate cancer in men after their deaths (i.e. they died with prostate cancer, rather than from it, and the cancer was subsequently diagnosed)[2]
- The very sharp increase since the early 1990s, which is largely due to the discovery and use of the PSA test (see box)

About prostate cancer testing

"If someone ever invents a method of screening apparently healthy men for prostate cancer, the apparent incidence rates may be expected to rise quite quickly by several hundred percent."[9]

Doll R and Peto R, The Causes of Cancer, 1981

The PSA test began to be widely used in England in the early 1990s. Its use is, however, controversial. PSA is non-specific and can be raised in other conditions e.g. benign prostatic hypertrophy. Furthermore, it can result in treatment for cases, which do not need to be treated i.e. a slow growing cancer which does not cause any symptoms and does not shorten life-expectancy. Treatments for prostate cancer – as stated above – can have significant and adverse side effects and impact on quality of life. No randomised trial has yet shown a reduction in mortality from use of the PSA test.[2]

The UK National Screening Committee reviewed the evidence for introducing a screening programme in 2009 and 2010 and concluded, as a result of the lack of evidence of benefit, that men should not be routinely invited for PSA testing.[10] However, the Prostate Cancer Risk Management programme – which was introduced in 2002 in response to demand for the PSA test among men worried about prostate cancer – continues to operate. The programme provides information to men on the risks and benefits of the PSA test, to enable them to decide whether or not to have the PSA test.

The 'holy grail' of a prostate cancer test is one which can differentiate between aggressive cancers that could go on to kill, and cancers that may never cause any harm. At present, no evidence-based tests exist.

The increase in diagnosis set out in **Figure 1**– and particularly, the diagnosis of 'latent' tumours, which do not progress far enough to cause problems or become life-threatening – has been key to the large improvements in survival from prostate cancer over recent years. For men diagnosed with prostate cancer in 2006-2010 and followed up to 2011, the five year survival estimate was 80%, compared with 75% for men diagnosed between 1999 and 2003 and followed up to 2004.[11, 4]

It is also one of the reasons for the unusual shape of the survival curve from prostate cancer (which is similar to that seen in breast cancer in women[2]): whereas survival of most cancers is generally higher among younger patients than older ones, for prostate cancer the reverse is true: survival is slightly lower for men aged 15–49 years (90 per cent) than for those aged 50–69 years (92 per cent).[4] Higher survival among men aged 50-69 is likely to be due to PSA testing in this age group.[12]

Mortality

Although the absolute number of deaths from prostate cancer has increased – from around 9,500 deaths in the early 1990s to around 10,800 today[13] – this is largely due to the ageing population. When controlling for age as the chart in **Figure 1** shows, the age-standardised mortality rate has declined from 30.7 per 100,000 men in 1992 to 23.8 in 2010 (a reduction of more than 20%).[4]

This welcome downward trend can be attributed to three reasons:

- The use of new treatments for prostate cancer (and in particular the more widespread use of hormone therapy, radical surgery and radiotherapy)[13]
- The earlier diagnosis of some aggressive prostate cancers – linked to improved awareness of the disease and the use of the PSA test[13]
- A range of improvements in NHS services over recent years, set out in more detail in the section below

Policy improvements

The past 15 years have witnessed significant progress in improving cancer services in general, and prostate cancer services have been part of that progress.

- **Investment in capacity.** Triggered by the NHS Cancer Plan of 2000, the 2000s saw large-scale investment in cancer services – with additional funds of £640 million over the term of the Cancer Plan, and an increase in the number of consultants with a specialty in cancer of over 36% between 2000 and 2006. The Plan also established cancer networks and made use of the extra capacity to introduce waiting times standards for the diagnosis and treatment of cancer.[14]
- **Improvement in service delivery.** Building on the improvements in capacity, the Department of Health published its *Cancer Reform Strategy* in 2007 to make further progress – particularly in the outcomes of patients living with cancer (both in terms of the effectiveness of treatments delivered and in terms of patient's experience of their care), and to facilitate the introduction of new service models to deliver this progress.[15] New service models for prostate cancer services – which recommended (among other steps) that men with prostate cancer had access to a 'Clinical Nurse Specialist' (CNS) from the time of diagnosis – were set out in *Improving Outcomes Guidance* of September 2002.[16] The Strategy resulted in the introduction of a Cancer Patient Experience Survey, and in an increase in the use of clinical audit in cancer care.[15] Building on this, *Improving Outcomes a Strategy for Cancer* was published by the coalition Government in January 2011 setting the ambition that cancer outcomes are comparable with the best in Europe, along with a set of levers and measures to help commissioners and service providers help deliver this.[54]
- **Improvements in access to treatment.** A range of new treatments – and, in particular, hormone therapies – have been brought into use in the NHS over the last few years, supported by policies such as NICE's 'end-of-life' criteria and the Cancer Drugs Fund. These have ensured that effective treatments for prostate cancer have been made available to patients on the NHS even before they have been approved by NICE.[17]

- **Improving quality of life for people living with and beyond cancer.** Today over 1.6 million people are living with and beyond cancer, a figure which is set to rise to 3 million by 2030.[18] The National Cancer Survivorship Initiative (NCSI) published its vision in 2010, which identified the unmet needs of cancer survivors.[18] In its latest report, *Living with and beyond cancer: taking action to improve outcomes*, the NCSI set out how it planned to improve care and support. Amongst other things, it identified that the NHS should be encouraged to commission innovative treatments which minimise the risk of long-term consequences, such as laparoscopic surgery and intensity-modulated radiotherapy (IMRT) to help improve quality of life for people with cancer.[56]

About this report

The context for men living with prostate cancer is therefore positive, with the last twenty years having witnessed significant improvements in standards of care.

Despite this positive story, however, there is both empirical and anecdotal evidence of weaknesses in existing prostate cancer services. For example:

- Men with prostate cancer continue to report a worse experience of NHS care compared with other cancer patients[19]
- Reports of the National Cancer Peer Review Programme found that there continue to be cases of prostatectomies happening inappropriately outside of agreed specialist centres[20]
- An analysis of variations in drug usage across a number of different countries shows that the UK has a low rank for the most recently licensed cancer drugs[21]

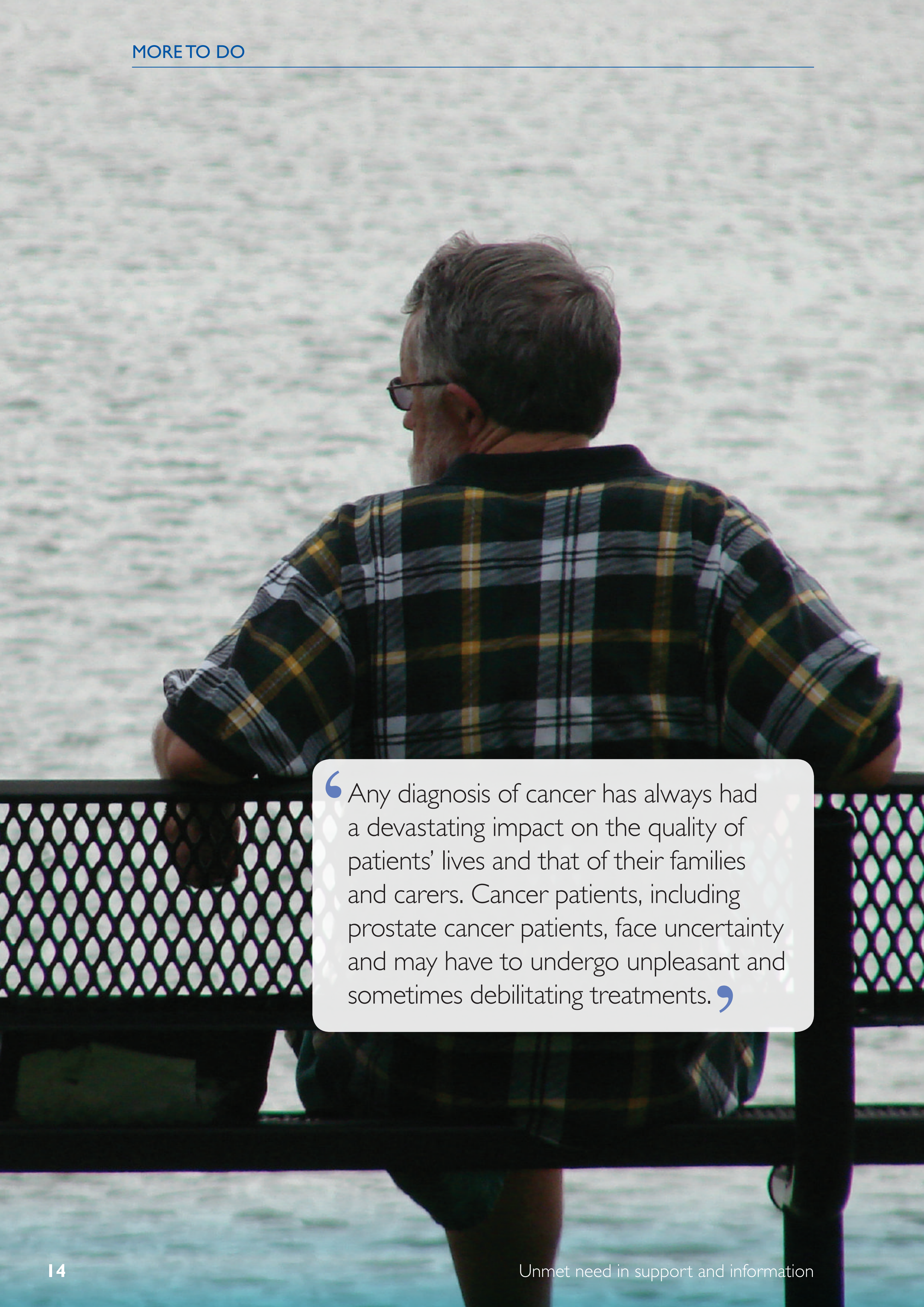
In addition, much anecdotal evidence of weaknesses continues to be reported to Orchid. These include challenges in access to CNSs, and in accessing the support and information needed to participate in clinical trials.

The purpose of this report is to:

- Explore available evidence, and identify new evidence on the quality of prostate cancer services
- Use the evidence explored to demonstrate where there is an unmet need in prostate cancer services
- Make recommendations to policymakers to meet the unmet need

In producing this report, we have taken a broad approach to capturing new evidence. This involves:

- Interviews with clinicians involved in prostate cancer services
- Analyses of publicly available sources of data, including the National Cancer Patient Experience Survey
- Investigations through questions in Parliament, which we are grateful to the former Cancer Minister Paul Burstow MP for assisting us with.



‘Any diagnosis of cancer has always had a devastating impact on the quality of patients’ lives and that of their families and carers. Cancer patients, including prostate cancer patients, face uncertainty and may have to undergo unpleasant and sometimes debilitating treatments.’

Unmet need in support and information

In recent years, the significant progress in the outcomes delivered for prostate cancer patients set out above has been achieved in part through the development of more comprehensive pathways of care.

- Care for prostate cancer today can often involve many different healthcare professionals, working in community, secondary care or specialist centres. Prostate cancer care is now delivered through multidisciplinary teams (MDTs) of those best-equipped to help tackle what can be a multi-faceted condition – such as surgeons, oncologists, urologists, radiotherapists and nurse specialists (among others). Evidence uncovered in the course of developing this report confirms that nearly all areas of the country are now caring for prostate cancer patients through MDTs, with 88 local urological MDTs and 49 specialist urological MDTs currently in place. However, despite this welcome progress, it is not known if all patients with prostate cancer are cared for through MDTs.[22]

Recommendation 1: NHS England should take action to ensure that the care of all prostate cancer patients is coordinated and planned by an appropriately established multidisciplinary team (MDT), which includes a surgeon, and medical and clinical oncologists.

- Prostate cancer can be treated in a number of ways – as set out on page 9 – and the various treatment options have very different side effects. For some patients, the treatments which will deliver the best possible outcomes, are either watchful waiting or active surveillance – treatments which do not immediately attempt to cure the cancer, even though the possibility of this cure exists. NICE's most recent guidance on prostate cancer recommended these options for those groups in which it is suitable and for patients to have sufficient information be involved in treatment decisions.[23]

Recommendation 2: NHS England – as the commissioner of specialist prostate cancer treatment services – and local commissioners should ensure that NHS services treating patients implement NICE guidance and guidelines, including by providing sufficient information for patients to understand the risks and benefits of all treatment options to enable them to make informed decisions.

Prostate cancer has therefore always been a condition requiring an exceptional level of support for patients – but it is also a condition which now demands effective systems of coordination to be put in place to ensure that truly integrated care is delivered to patients as seamlessly as possible. It is also a condition, which places exceptional burden on patients' carers and families – all of whom need to be offered appropriate levels of care and support.[15]

Fourteen areas of the country were selected last year as 'integration pioneers'. These pioneers are developing innovative ways of creating and spreading change across health and social care to help deliver more integrated care for patients. There may be lessons on how more integrated care in prostate cancer can be delivered from the work these pioneers are undertaking.

Recommendation 3: the Department of Health should review the operation of its 'integration pioneers' to see whether any lessons can be learned with respect to driving improvements in the delivery of integrated prostate cancer care.

Patient experience

A measure of integration – from the patient's perspective – is whether they experience a good standard of care. However, patients living with prostate cancer have historically had amongst the poorest experience of their care when compared to patients living with other common cancers, with the National Audit Office reporting in 2005 that, "prostate cancer patients continued to have a worse experience than those with other cancers".[19]

Although in some areas patient experience of prostate cancer care has improved in recent years, there is still room for improvement, as the figures in **Table 1** show:[57]

Table 1: Patient experience of men with prostate cancer compared to patients with other cancers

	Patients with prostate cancer	Patients with breast cancer
Written information on side effects not given	17%	11%
Staff not doing everything they could to help control pain	22%	17%
Patient felt care was neither very good nor excellent	13%	10%
Patient's family did not have opportunity to talk to a doctor	34%	30%
Patient not told they could bring a friend when first told they had cancer	28%	19%
Hospital staff did not give information about support groups	17%	12%

Recommendation 4: in the next annual report on improving progress in cancer services, NHS England should detail in specific terms the exact steps and timelines it is taking to improve the experience of patients living with prostate cancer.

Recommendation 5: NHS-funded providers of prostate cancer services should ensure that their staff are directing patients with prostate cancer to a range of specialist support services – including charities, helplines and support groups – when it is appropriate to do so.

Clinical nurse specialists

Given the complexity of the prostate cancer care pathway – and the resultant possibilities of patients experiencing disjointed care – the many roles of CNSs in improving the experience of people living with and surviving prostate cancer care (set out in detail in the box below) assume a critical importance.

The role of clinical nurse specialists

The Department of Health's Cancer Reform Strategy of 2007 set out in detail the hugely valuable role played by CNSs across many different elements of cancer patient management and support. The Strategy set out a range of the technical, informational, emotional and coordination functions carried out by CNSs, including:[15]

- Familial risk assessment
- Communication and information
- Delivering some forms of treatment
- Psychological and emotional support for patients and families
- Providing continuity of care
- Supporting and advising patients' families and carers
- Developing a post treatment plan

A more recent evidence review of cancer CNSs carried out by Macmillan Cancer Support identified some of the tangible improvements in outcomes which CNSs have delivered – both for patients and for society in general, including:[25]

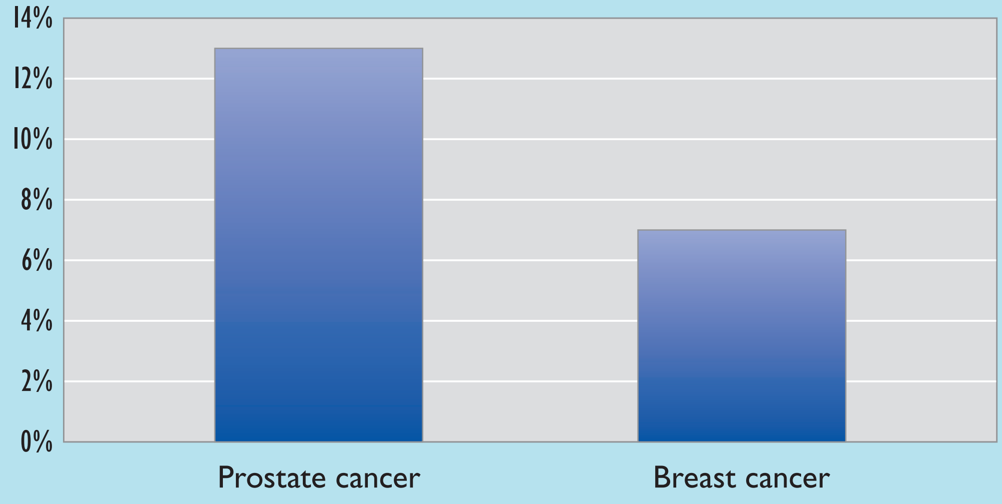
- Better quality and experience of care for patients
- Improvements in patient safety
- Increased productivity and efficiency
- Fewer emergency admissions
- Reduced length of hospital stay

However, despite the clear benefits which CNSs can deliver, prostate cancer patients have historically experienced poorer levels of access to CNSs than patients living with other cancers:

- A 2007 study by the Prostate Cancer Charter for Action, for example, identified a significant variation in provision of CNSs between different tumours, resulting in significant variations in the average caseload for a CNS[26]
- A 2011 study found significant regional variation for CNSs in uro oncology with one cancer network having 30 Whole Time Equivalent (WTE) CNSs and another cancer network having just one WTE CNS[27]

Findings from the most recent National Cancer Patient Experience Survey suggest that – half a decade after these studies were undertaken – prostate cancer patients continue to experience a worse provision of CNSs than other patients, as the following chart shows:[24]

Figure 2: Patient not given name of clinical nurse specialist in charge of their care



During the course of developing our report, Orchid also heard particular concerns that investment in CNSs was at risk as a result of the significant financial pressures facing the NHS – as well as healthcare services around world. An editorial in the International Journal of Urological Nursing, published in 2013, noted that:[28]

"Across the globe, nurses are reporting a negative revising of the care offered to patients as governments and local health providers struggle to provide health and social care from ever decreasing economic resources… This revision of services, sometimes labelled as 'efficiency savings', is increasingly turning into job cuts and it is often nurses, in particular specialist nurses, who find themselves having to justify their existence."

Despite these concerns, our research suggested that the Government had little appetite to investigate what changes had taken place in the provision of CNSs over the last five years – with a Health Minister stating recently that:[29]

"The current number of specialist clinical and urological clinical nurses employed by the NHS in England is not included in the annual NHS workforce census and they are not identified separately…

"The Department has no plans to conduct an audit of the number of specialist clinical and urological nurses working in the NHS in England."

Recommendation 6: the Government should reinforce the need for Trusts to ensure patients have access to a CNS, and in particular uro-oncology CNSs, at all stages of their cancer journey. Trusts should review the caseload of CNSs to ensure that there are adequate numbers and that cover arrangements are in place for all newly diagnosed cases as well as metastatic patients.

The Care Quality Commission (CQC) – which inspects NHS-funded services and rates the quality of care they deliver – is currently developing a new inspection regime to ensure that patients have good quality care. A Health Minister recently stated in Parliament that:[30]

"The CQC is increasingly incorporating information from accreditation and peer review programmes into its assessments of NHS trusts' services for the treatment of prostate cancer. This includes the national cancer peer review programme, which encompasses prostate cancer. The cancer patient survey also asks specific questions on having a specialist nurse. The CQC also intends to use data from the national clinical audit which is being developed for prostate cancer."

Although this step is a welcome one, it is important that the CQC includes – in addition to assessments of patient experience – an assessment of staffing levels, particularly in relation to clinical nurse specialists.

Recommendation 7: the CQC, in its inspection of healthcare providers, should ensure they are compliant with National Cancer Peer Review measures, which include the provision of CNSs at a level sufficient to deliver the required standard of care and support to patients living with prostate cancer.

> The outlook for men with advanced prostate cancer – where the cancer has spread beyond the prostate – is significantly poorer than for those whose cancer has not spread.[31]

Unmet need in treatment

For men with advanced prostate cancer, the goal is to extend and improve their lives rather than to 'cure' their disease. However, in recent years, a number of treatments have been developed which have given men with advanced prostate cancer hope, including:

- Docetaxel, which was recommended by NICE in June 2006 for use in men with hormone-refractory prostate cancer[32]
- Abiraterone, which was recommended by NICE in June 2012 for use in men with prostate cancer following treatment with docetaxel[58]
- Enzalutamide, which is currently (as of June 2014) being appraised by NICE for use in men with prostate cancer following treatment with docetaxel[33]

Treatments such as those listed above have improved outcomes for men with prostate cancer markedly. As understanding of new treatments increases, so their uses in helping men with advanced prostate cancer improve. For example, abiraterone has been shown to be clinically effective when used before chemotherapy.[34]

However, despite the progress that has been made in recent years in developing new treatments, evidence suggests that the needs of patients for these treatments are not being met:

- First, there is evidence that even drugs which have been approved by NICE are not being made available across the NHS in an equitable manner[35]
- Second, the level of applications for treatment for prostate cancer to NHS England's Cancer Drugs Fund – which makes available funding for cancer treatments which have not yet been approved or been rejected by NICE – are consistently high, indicating that NICE processes are frustrating the availability of prostate cancer treatments for routine use on the NHS [37]

We explore the evidence for each in turn.

Delay in implementing NICE-approved medicines

The NHS is under a legal duty to make available treatments recommended by NICE within three months. However, an analysis last year of statistics produced by the Health and Social Care Information Centre (HSCIC) on the uptake of NICE-approved medicines found an unexplained variation in usage of NICE-approved cancer medicines between hospitals.[38]

In order to tackle the unwarranted variation in access, NHS England implemented a set of policies to drive up compliance with NICE guidance. These included:[39]

- Introducing clauses in the NHS Standard Contract that require all providers of NHS services to comply with NICE guidance, and to publish their formularies so that anyone can see which medicines and technologies are being made available locally
- Taking steps to establish a 'whistleblower hotline' to report on cases of organisational non-compliance
- Establishing a NICE implementation collaborative – bringing together the NHS, members of the pharmaceutical industry, and clinicians – working to accelerate the implementation of NICE guidance

Although these steps are welcome, measuring the adherence to NICE guidance of NHS organisations is challenging given the limitations of existing datasets:

- Data collected by hospitals on their levels of usage of cancer treatment have historically not been collected on a comparable basis[15]
- Where comparable data on the hospital-level use of medicines has been obtained in the past, it has had to be sourced from manufacturers themselves or external suppliers[35]
- Many cancer treatments can be used in multiple indications, meaning that even if the volume of a cancer treatment being used can be identified, the specific cancer in which that treatment can be used is not

In addition, and for prostate cancer specifically, many of the latest treatments are taken orally (and can thus be supplied by homecare or community routes outside of hospital) – meaning that hospital-level data is unable to provide a comprehensive picture on levels of access.[35]

Many of the limitations in existing datasets stand to be resolved through the development of the new Systemic Anti-Cancer Therapy dataset (or SACT), which will capture comprehensive and accurate data on cancer treatment usage – both in hospital and community settings – and link that information to data on the specific diagnosis in which that treatment is being used. The HSCIC has noted the potential benefit that this dataset could deliver in terms of analysing adherence to NICE-approved medicines[35] - thus helping to shine a light on where variations exist. In the last year information on 16,364 courses of treatment for urological cancers has been submitted.[40]

However, despite the National Audit Office having criticised the implementation of SACT for being two-and-a-half years behind schedule in 2010,[14] progress in ensuring full implementation of the programme remains frustratingly slow. For example, only 6% of submissions included a completed treatment outcome summary.[41]

Recommendation 8: the Department of Health should expedite the implementation of SACT and ensure that data are used to help determine whether unwarranted variations in access to prostate cancer treatments exist.

Even if robust data are collected, there continue to be concerns that the steps taken by the NHS to ensure NHS bodies adhere to NICE guidance – some of which are set out above – are insufficient to ensure patients have access to NICE-recommended treatments, and that stronger safeguards are needed. During the passage through Parliament of the Care Act 2014, these concerns were raised and it was suggested that the CQC should play a stronger role. In response to these concerns, a Health Minister said:[42]

> *"The issues raised… are important: namely, how providers deal with the most commonly recurring conditions in specific settings, and how hospitals are implementing NICE guidance on the use of medicines. I do not argue that the CQC should not consider these issues. It has made clear in its consultation document, A New Start, that NICE guidance will play an integral role in its new performance-assessment methodology."*

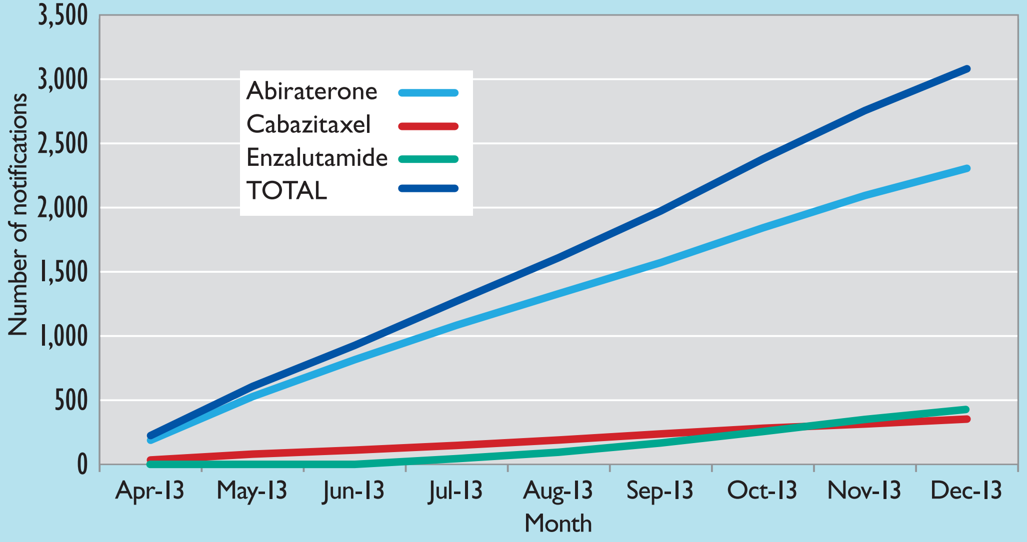
However, despite the Health Minister's commitment, the CQC's *A New Start* consultation document makes no reference to NICE guidance on the use of medicines – referring instead only to the quality standards which are developed by NICE.[43]

Recommendation 9: the Care Quality Commission should set out how it intends to honour the spirit of the commitment made by the Health Minister in October 2013 that it will examine levels of access to NICE-approved medicines in the NHS-funded services it inspects.

Level of applications for non-NICE approved prostate cancer treatments

The Cancer Drugs Fund was established in April 2011 in order to meet the demand for treatments which had not yet been approved, or had been rejected, by NICE. Data published on the use of the Cancer Drugs Fund indicate significant demand for drugs for the treatment of prostate cancer, as follows:[37]

Figure 3: Cumulative number of notifications to the Cancer Drugs Fund in each month of 2013-14 (to December) for treatment of prostate cancer



The Cancer Drugs Fund was established only as an interim measure: it was originally intended to close to new patients in January 2014 (although it has now been extended until 2016), upon the introduction of a new 'value-based pricing' system for appraising new medicines.[59] This value-based pricing system was intended to help ensure drugs which addressed areas of significant unmet need were reimbursed on the NHS.[44] The Coalition Programme of 20 May 2010, for example, promised that the new system of value-based pricing would ensure that, "all patients can access the drugs and treatments their doctors think they need".[45]

The Cancer Drugs Fund has benefitted large numbers of prostate cancer patients, as **Figure 3** shows. It has also had an indirect benefit due to its positive impact on NICE's processes: in March 2012, for example, NICE decided to apply its more generous 'end-of-life' criteria to assessing the treatment abiraterone, when data obtained from the Cancer Drugs Fund suggested that it should be appraised through this process.[46]

Today, treatments for prostate cancer are amongst those most applied for through the Cancer Drugs Fund: by way of example, abiraterone is the second most requested drug through the fund.[37] As well as indicating that existing NICE processes fail to capture the need for prostate cancer treatments, this high level of applications is concerning because it is occurring despite urologists – who deliver care for prostate cancer patients – being unable to apply for treatments from the fund.[47] For as long as oncology clinicians alone can make applications to the Cancer Drugs Fund, there remains a risk that some men living with prostate cancer who might benefit are not able to do so because urologists, who may want to prescribe treatment in the pre-chemotherapy setting, cannot apply for treatment.

Recommendation 10: the Department of Health should ensure sufficient numbers of clinical/medical oncologists are available to support local and specialist MDTs. Consideration should be given to allowing urologists working in collaboration with oncologists through a MDT to make applications to the Cancer Drugs Fund.

As stated above, the original purpose of the Cancer Drugs Fund was to act as a 'pressure valve' for those treatments which NICE was not making available, pending the development of value-based pricing. The Government has since amended its focus from developing value-based pricing to asking NICE to develop a new 'value-based assessment' process, which NICE has recently indicated it does not favour.[48,49]

However, given the high levels of demand on the Cancer Drugs Fund for prostate cancer treatment, it is imperative that any future changes to NICE processes for evaluating medicines act to address the long-term challenges which prostate cancer treatments in particular are encountering. This will help to relieve pressure on the Cancer Drugs Fund, allowing it once again to act as a 'pressure valve' for those treatments which NICE has not yet appraised but for which demand from doctors exists.

Recommendation 11: the Government should work with NICE to ensure the original aims of 'value-based pricing' – and, in particular, the Coalition's commitment to ensure all patients access the drugs and treatments their doctors think they need – are delivered through meaningful reform, therefore helping to reduce demand on the Cancer Drugs Fund for prostate cancer treatments.

Prostate cancer charities have been amongst those most vocal in articulating the tests which reforms to NICE must pass to be judged a success. These are set out in the box below.

Prostate Cancer UK's 5 key policy recommendations for value-based pricing[50]

Reform of the current system must lead to significant improvements in access to effective drugs... People affected by cancer and the organisations that represent them will not support a system which cannot be shown to improve and promote timely and equitable access to the best possible medicines.

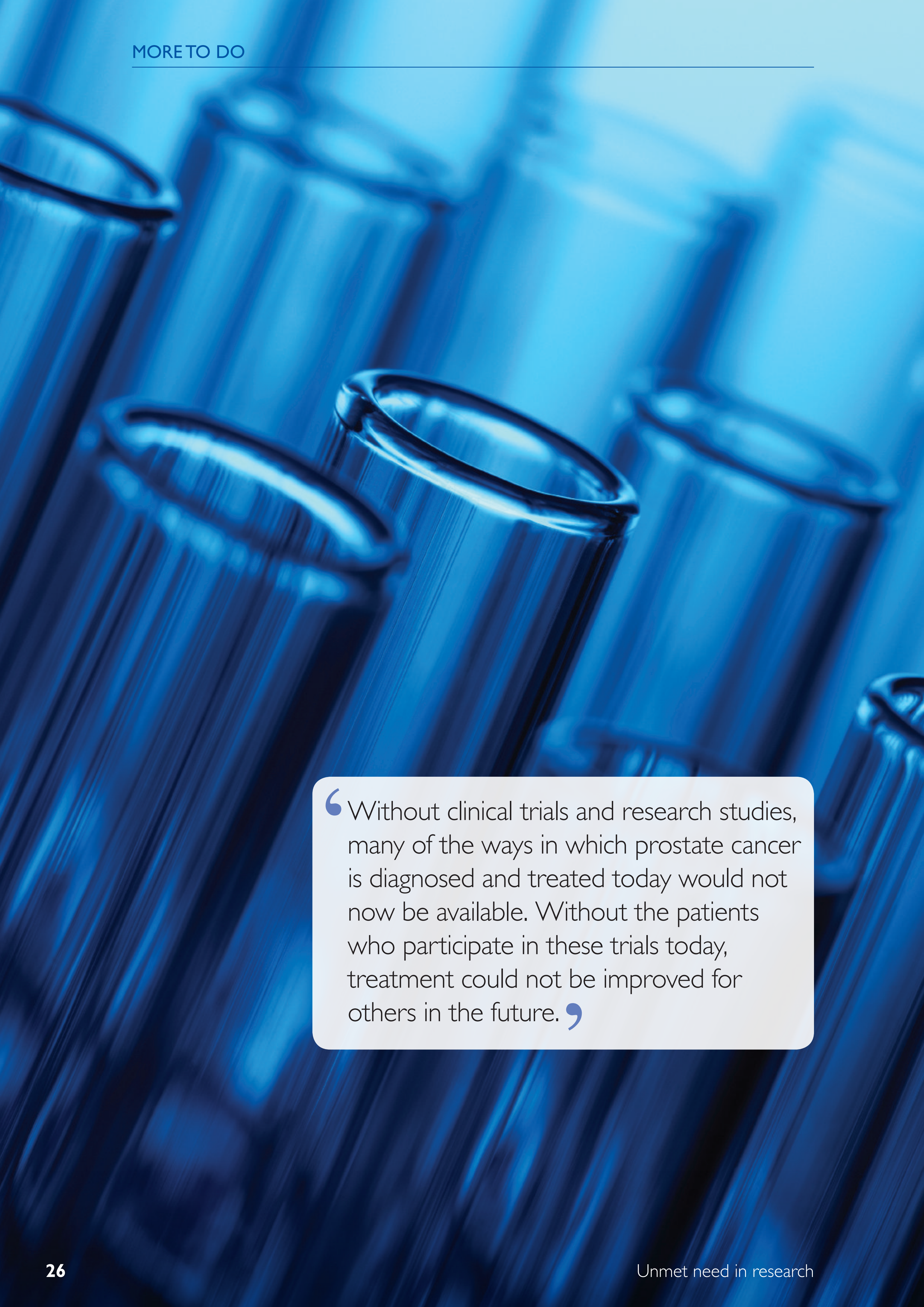
People affected by cancer must have an equal role in the design of the Value Based Pricing (VBP) system... People affected by cancer and the organisations that represent them deserve an equal role in the design of VBP. The DH must commit to involving them in this process.

A new method for involving people affected by cancer in the process of appraising individual drugs should be introduced... The current processes for involving people affected by cancer in individual drug appraisals do not allow their views to be heard sufficiently. A new method is needed.

Drugs that improve people's quality of life should be given the greatest value... The value of drugs that can give people approaching the end of their lives precious extra time with friends and family should not be forgotten.

The wider societal benefits of drugs should be carefully considered... If the new system prioritises drugs aimed at helping people back to work, then there's a grave risk that many people affected by cancer will lose out. It's vital that VBP does not lose sight of the contribution that many of these people have already made to our economy and society or the role that younger people will play in the future.

Recommendation 12: the Government and NICE should work with charities such as Orchid and with our partners in the prostate cancer community to ensure that there are clear opportunities to improve the evaluation of new treatments within current NICE processes – and, as a result, to improve access to treatment for patients.



> ‘Without clinical trials and research studies, many of the ways in which prostate cancer is diagnosed and treated today would not now be available. Without the patients who participate in these trials today, treatment could not be improved for others in the future.’

Unmet need in research

The role of research in developing a prostate cancer test

The key improvement that can be made on existing tests for prostate cancer is to find a test which can differentiate between high-risk and low-risk prostate cancer.

In a recent positive step, scientists at the Institute of Cancer Research in London, who have been screening men from families with a history of prostate cancer, established that 14 mutations in known cancer genes might be able to predict life-threatening disease.

The results of the investigation, which were published in the British Journal of Cancer in February 2014, mean that men with prostate cancer in the family might one day be screened to assess their risk, in the same way that women with a family history of breast cancer can be screened for the BRCA1 and BRCA2 genes.[51]

The UK has a long history of research into cancer, with the first specialist cancer research charity having been set up well over 100 years ago.[52] As well as its role in promoting awareness, Orchid itself plays a leading role in the fight against prostate cancer through its support for world-class research.

There are many ways through which patients can benefit from participating in clinical trials, including:[53]

- Having access to newer and perhaps more effective treatments which are not available outside the trial
- Having more regular check-ups, tests and support from doctors and nurses than usual

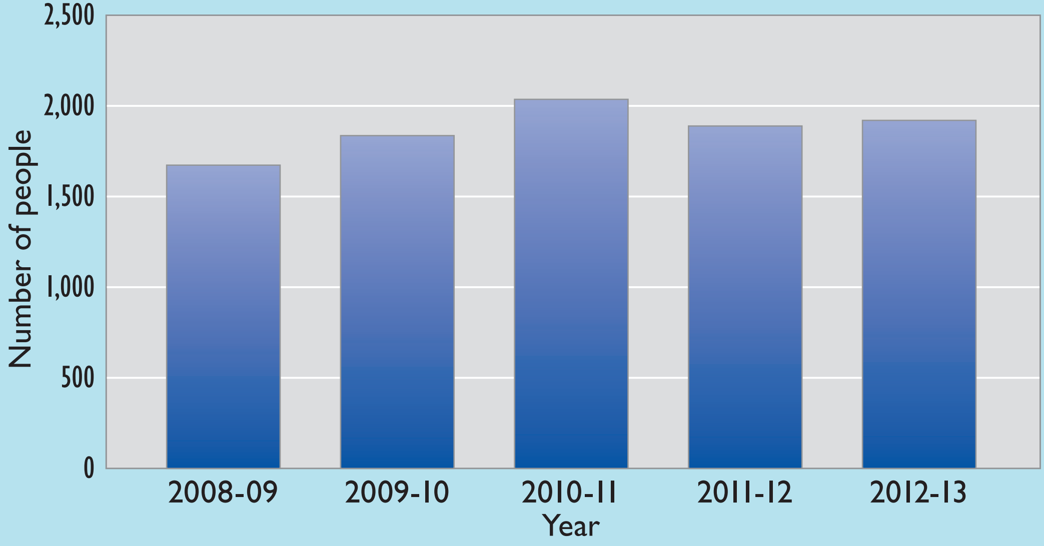
As with any clinical trial, however, it may be possible that the treatment causes side effects which even the researchers are not aware of – or that the treatment does not help the patient in the trial (even if it may help others in the future).[53]

For these reasons, it is imperative that patients:

- Receive information about the clinical trials which are available and which they might benefit from participating in
- Are supported in understanding the nature of the clinical trial, what it may involve and what the benefits and drawbacks may be
- Receive sufficient information and support to determine whether to participate

Cancer research in the UK is built on firm foundations. For example, to avoid duplication in research efforts, all key partners in cancer research – from government, industry and the charitable sector – are now brought together in the National Cancer Research Institute, which coordinates research initiatives on prevention, awareness and early diagnosis, survivorship and radiotherapy.[54] This helps ensure that research spending delivers the maximum benefit possible for patients. These policies have helped ensure that well over 1,500 prostate cancer patients are consistently recruited into clinical trials, as depicted below in **Figure 4**.[55]

Figure 4: Number of people recruited to prostate cancer treatment trials by the National Institute for Health Research Clinical Research Network

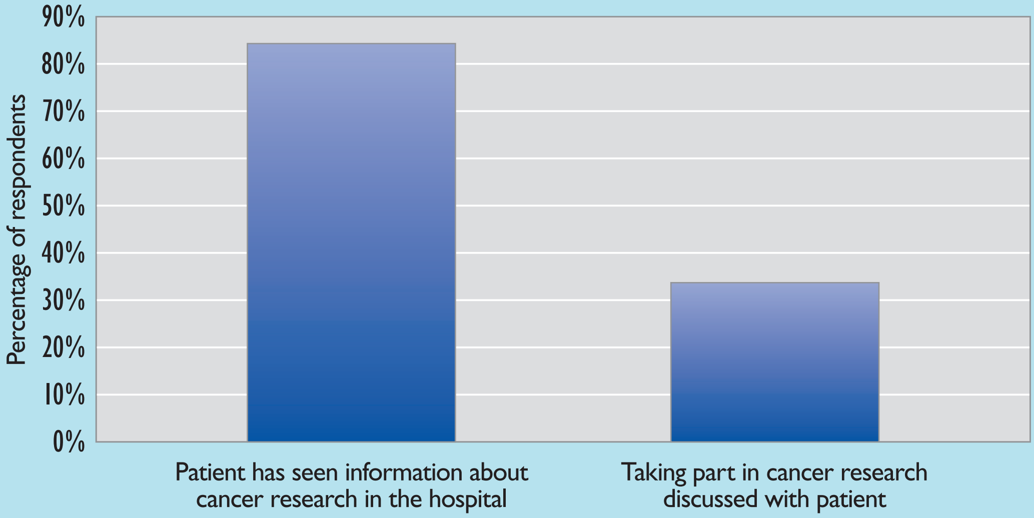


It has also helped ensure that a wide range of hospitals and other sites participate in prostate cancer clinical trials: for example, there are, as at March 2014, 74 prostate cancer clinical studies recruiting patients in the UK, in a total of 274 locations.[55]

Recommendation 13: the Department of Health should take steps to continue to ensure high participation rates in prostate cancer clinical trials.

However, for prostate cancer patients, there is also evidence that patients are not being supported to participate in clinical trials. As the following chart shows, figures from the National Cancer Patient Experience Survey show that, although patients see information about cancer research at the hospital, very few patients then recall a discussion they had on taking part in cancer research.[24]

Figure 5: Prostate cancer patients' experience of information regarding cancer research



Recommendation 14: providers of prostate cancer care who perform significantly worse than their peers on the question of patients being asked to participate in cancer research, including clinical trials in the National Cancer Patient Experience Survey, should undertake an internal audit of the reasons for their poor performance and take steps to improve their performance over time.

Recommendation 15: providers of prostate cancer services should take steps to ensure that their employees are aware of the actions they should take when asked about prostate cancer clinical trials, and the information they should provide.

Conclusion

The recent history of prostate cancer care and treatment is one of continual improvement. Although prostate cancer is the most common male cancer in England, the prospect for men diagnosed with advanced and aggressive prostate cancer is now better than ever.

This success has been brought about by a number of developments over the last fifteen years, including:

- Investment in extra capacity to improve NHS cancer services
- Improvements in service delivery, including through investment in clinical nurse specialists
- Improvements in treatment – both in greater access to treatment and through the invention and availability of new treatments

However, despite this progress, improvements can still be made. This report makes 15 recommendations to improve prostate cancer services further still.

These recommendations relate, in particular to:

- Ensuring that variations in access to treatment – and outcomes – are understood by NHS England and acted upon
- Continuing to invest in the uro-oncology clinical nurse specialist workforce
- Supporting services which ensure patients have a good experience of their care
- Facilitating the availability of access to the latest treatments for patients, both through ensuring high levels of uptake of NICE-approved medicines and through ensuring that the Cancer Drugs Fund supports access to the prostate cancer treatments which it funds
- Encouraging participation in high quality clinical trials for prostate cancer patients

We are confident in the ability of the NHS to consider and act on these recommendations. We look forward to working with the NHS – and all those with an interest in improving prostate cancer services – to implement the recommendations we have made.

About Orchid

Orchid is the UK's leading charity working on behalf of anyone affected by or interested in male cancer – prostate, testicular and penile cancer. Established in 1996 by testicular cancer patient, Colin Osborne MBE and the oncologist who saved his life, Professor Tim Oliver, Orchid exists to save men's lives from male cancer through a range of support services, education and awareness campaigns and a pioneering research programme.

Support services

Orchid offers everyone affected by or interested in male cancer an extensive range of services led by Male Cancer Information Nurse Specialists. The services include a dedicated freephone National Male Cancer Helpline, a portfolio of publications including a series of specialist factsheets, research updates, an interactive microsite **www.yourprivates.org.uk**, an award winning DVD *'Know Your Balls…Check Em Out'*, resource packs, a dedicated website **www.orchid-cancer.org.uk** and newsletter *low-down.*

Staff also run Roadshows across the UK offering support and information in the heart of the community. All services are free of charge. Demand for these services continues to increase - last year Orchid launched twelve new publications and distributed over 370,000 items of information, an increase of 48% on the previous year.

Education and awareness campaigns

On a national level Orchid raises awareness of male cancer and educates men in the signs and symptoms of cancer. The Orchid Male Cancer Information Nurses and volunteers work closely with health and social care professionals, other voluntary organisations, community groups and support networks, schools, universities and local companies to deliver education and health awareness programmes and wellness sessions thereby ensuring men of all ages are well informed.

In 2011 the Orchid Community Golf Programme was launched as part of the continuing commitment to education programmes for young people. This is a unique, exciting opportunity to bring golf to young people. Using specialist SNAG (Starting New at Golf) equipment, the programme is designed to encourage young people to keep fit and healthy whilst promoting good citizenship, community sport and learning about male cancer and the work of Orchid. The programme has already attracted over 13,000 participants and over 16,000 adults have learnt about the charity's work.

Throughout the year Orchid runs campaigns on a range of issues. The annual Orchid Male Cancer Awareness Week has quickly become a recognised campaign in the healthcare diary and is featured in national, regional, local and trade media.

A pioneering, world class research programme

Funding of innovative research in the cancer field remains a key focus of Orchid's work. The research programme aims to encourage, support and fund research into the causes, prevention and treatment of male cancers. It has identified new ways to treat male cancers and improved understanding of how these cancers behave. The four programmes of research include molecular biology and cancer genetics, histopathology, cancer epidemiology and clinical trials. In December 2011 Orchid announced the appointment of Professor John Kelly as the Orchid Chair in Male Genito-urinary Oncology. Professor Kelly is a Consultant Urological Surgeon, Professor of Uro-Oncology and Clinical Lead of Uro-Oncology based at University College Hospital, London.

Alongside existing research commitments Orchid approved an exceptional grant in March 2013 for an exciting new global research study led by Professor Tom Powles, a leading expert in the field of testicular cancer. The aim of the study is to improve the understanding of the development and progression of testicular cancer and to offer the possibility of new treatment and management techniques for men with testicular cancer that has returned and spread beyond the testis - these patients are currently likely to die from the disease. The study will involve collaborations with researchers across the United States, Germany, Italy, UK, France, Denmark and Ireland placing Orchid firmly on the global map.

Building on these many achievements, the implementation of the new Orchid Research Strategy 2013 - 2016 promises to make a real, tangible difference through supporting research which will improve the understanding of the risk, diagnosis and treatment of male cancers. Ultimately Orchid's aim is to promote, support and accelerate step change in cancer management thereby improving the outlook for men and their families.

Working in partnership with the business community to make a difference

In recent years Orchid has enjoyed a number of successful partnerships with the business community including Paperchase, King Sturge, Next, Bath Rugby Club, Brooks Brothers, The Bluebeards Revenge, GCS Recruitment, Easy As HGV and Raging Bull. Orchid were chosen as a beneficiary of ICAP Charity Day 2011 to support the Orchid Tissue Bank and are the Charity of the Year for ASDA Distribution in 2013. Orchid's work with their UK depots, their 15,000 colleagues and the local community is helping to ensure they can support even more people affected by or interested in male cancer.

Working in partnership with other organisations to make a difference

Orchid works in partnership with other voluntary organisations and networks to campaign for improved services for men and their families including Cancer Research UK, Network for Patients, Macmillan Cancer Support, Teenage Cancer Trust, British

Association of Urological Nurses, British Association of Urological Surgeons and the Penile Cancer Supra-networks. Orchid is a member of the Helplines Partnership and NCVO (National Council for Voluntary Organisations) and plays a full part in the Cancer Campaigning Group and Cancer52, an equivalent collaborative concerned with less common cancers (i.e. all those except prostate, lung, breast and bowel disease) that together account for around 52% of all cancer deaths in the UK.

In 2012-2013 Orchid took part in a number of important projects. The charity was invited to join an advisory panel for PEPC, a www.HealthTalkOnline.org.uk project on penile cancer funded by the Research for Patient Benefit programme of the National Institute for Health Research. The penile cancer site was launched on the 23rd October 2012 at a Reception at the Royal Society. The site is an important source of support and information for men and their families and has been featured in national media including Radio 4 and The Guardian.

Orchid was also invited to join the National Cancer Intelligence Network - Urology Site Specific Clinical Reference Group (NCIN Urology SSCRG). NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.

Orchid has taken part in several roundtable policy discussions to examine variations in prostate cancer care and to campaign for improved services. Two new reports were launched: in February 2012 ***The Forgotten 10,000: Getting it right for men with prostate cancer*** was launched with support from Ian Liddell-Grainger MP. ***Prostate Cancer in BME Communities Raising Awareness and Improving Outcomes*** was launched at the end of November 2012 with support from Paul Uppal MP Vice-Chair of the All-Party Parliamentary Group on Men's Health.

Meeting commitments

Orchid relies on voluntary income to meet its commitments to supporting men, their families and those with an interest in male cancer. Funds are raised through individuals, events, the business community, trusts and foundations.

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