PROSTATE CANCER

BRITAIN'S GROWING PROBLEM

ORCHID
FIGHTING MALE CANCER

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FOREWORD

REBECCA PORTA, CHIEF EXECUTIVE, ORCHID

As our population continues to live longer into old age, the number of men suffering and living with prostate cancer continues to grow too. In fact, so much so that it is predicted to become the most common cancer in the UK by 2030. If we are to be ready to deal with this number of prostate cancer patients and to deliver positive outcomes for these men, it is now the time to assess, plan and prepare for what lies ahead.

In this report, we draw together the expert knowledge and experience of a number of the UK's leading experts working across the clinical spectrum in prostate cancer. We set out what we believe are the main challenges for the future of prostate cancer care and aim to offer some guidance on the priorities for action.

The first task of all of us, in the NHS, the charitable sector, public health and indeed friends and families, is to raise awareness of signs and symptoms and tackle head on the 'man problem' that stops men recognising their symptoms and taking early action to see their GP.

GPs have a key role to play, not only in improving patient awareness but also when it comes to alerting men to hereditary risk. Once men are identified as being at a higher risk or are exhibiting worrying systems, we must be able to provide a diagnostic test that commands the confidence of clinicians and patients. We need a unified, efficient and effective diagnostic test and we must ensure that once men present, they will be definitively diagnosed within 28 days if we are to deliver the best care options.

Throughout the whole process, from presentation of symptoms through to diagnosis and treatment, we must give men the support they need. Prostate cancer and its treatment can result in a number of significant changes for men, so they should be well informed of their treatment options If they are to make informed decisions about their own care. When healthcare professionals recommend care and treatment options, they must do so with the patient in mind and ensure that the patient is assigned to a specialist nurse to help provide clear information and professional support.

Currently, the number of clinical nurse specialists working in prostate cancer is low, relative to those working in colorectal cancer or breast cancer, and this must be rebalanced. Across the board, we need more funding, recruitment and training of specialist nurses to ensure men have access to the information and emotional and psychological support they need.

As we move patients from the hospital to the community, we need to ensure that GP and community nursing is set up to offer men the support they need. Community follow-up care is an excellent way of reducing the cost burden of prostate cancer on the NHS but it will require upskilling of primary and community care providers if it is to be done effectively and with due regard to patients.

Finally, as the prostate cancer population grows, it is inevitable that the number of men suffering advanced prostate cancer will also grow. While the NHS should be commended for looking to drive down the costs of drugs, the new NHS drug cap could present a real problem when it comes to the treatment of men with advanced prostate cancer and we must ensure that access to those drugs is available and equitable.

With added support, a refocus on patient needs and a willingness to accept that prostate cancer will become the UK's most prevalent cancer, together we can make sure we are skilled and ready to tackle this growing cancer, save lives and deliver better outcomes for men.

01 PROSTATE CANCER
THE STATE OF THE NATION

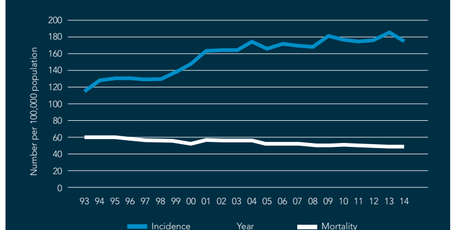
THE CURRENT POSITION

Prostate cancer is the most common cancer in men in the UK[1] and it is estimated that one in eight men in the UK will develop prostate cancer at some point in their lives[2]. For the African-Caribbean community the figure is higher, with prostate cancer affecting one in four.

In 2014, 46,690 new cases of prostate cancer were diagnosed, with the cancer taking the lives of 11,287 men, accounting for 13% of all male cancer deaths[3] and second only to lung cancer. However, recent advances in the diagnosis and treatment of prostate cancer has resulted in a more positive survival rate with 84% of men now surviving 10 years or more.

For men in their 70's though, the prognosis is less favourable with survival rates at one year falling well below the European average, highlighting the need for increased awareness and an earlier diagnosis to improve one year survival rates in this age group.

Incidence and Mortality of Prostate Cancer (UK, 1993-2014)[4,5]



INCIDENCE[6]

2ND MOST COMMON CANCER

BASED ON INCIDENCE RATES IN 2014, PROSTATE CANCER IS THE SECOND MOST COMMON CANCER IN THE UK

130 NEW CASES EVERY DAY

ON AVERAGE, THERE ARE 130 NEWLY DIAGNOSED CASES OF PROSTATE CANCER IN THE UK EVERY DAY

INCIDENCE RATES **+44%**

AGE-STANDARDISED INCIDENCE RATES OF PROSTATE CANCER HAVE INCREASED BY 44% IN THE UK SINCE THE EARLY 1990S

OVER HALF DIAGNOSED **70+**

MORE THAN HALF (54%) OF CASES IN THE UK BETWEEN 2012-2014 WERE DIAGNOSED IN MALES AGED 70 AND OVER, WITH THE HIGHEST RATES IN MEN OVER THE AGE OF 90

INCIDENCE RATES **+6%**

OVER THE LAST DECADE, PROSTATE CANCER INCIDENCE RATES HAVE INCREASED BY 6%

MORE COMMON IN BLACK MALES

PROSTATE CANCER IS MOST COMMON IN BLACK CARIBBEAN AND BLACK AFRICAN MALES AND LEAST COMMON IN ASIAN MALES

MORTALITY[6]

31

PROSTATE CANCER CLAIMS THE LIVES OF 31 MEN EVERY DAY IN THE UK

↑21%

PROSTATE CANCER MORTALITY RATES HAVE INCREASED BY 21% SINCE THE EARLY 1970S

4TH

PROSTATE CANCER IS THE 4TH MOST COMMON CAUSE OF CANCER DEATH IN THE UK

43% UNDER EIGHTY

ALMOST HALF OF PROSTATE CANCER DEATHS ARE IN MALES UNDER THE AGE OF 80

GOVERNMENT POLICY

Whilst there is no specific government policy for prostate cancer, the NHS Cancer Strategy is an initiative that has a direct impact on prostate cancer patients and their care, both now and over the next few years.

NHS Cancer Strategy

In 2016, NHS England produced a five-year forward view on achieving world class cancer outcomes entitled 'Achieving World-Class Cancer Outcomes: Taking the strategy forward'. The strategy document sets out a commitment to six key workstreams to achieve the very best cancer outcomes for everyone in England:

— A radical upgrade in prevention and public health
— A national ambition to achieve earlier diagnosis
— Establish patient experience on par with clinical effectiveness and safety
— Transform the support of people living with and beyond cancer
— Investments to deliver a modern, high-quality service
— Ensure commissioning, provision and accountability processes are fit-for-purpose

"The Cancer Strategy is relevant to addressing the current state of prostate cancer care in the UK and, as a male cancer charity, we are involved in helping to deliver against some of the workstreams. However, we have concerns as to whether the proposed deliverables are sustainable over the next 20 years to meet the significant growth in prostate cancer patients."

Rebecca Porta
Chief Executive, Orchid

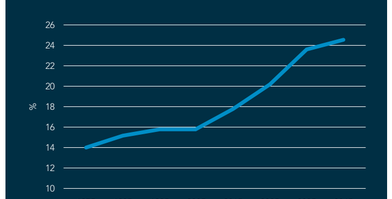
PROSTATE CANCER — THE FUTURE

The ageing population crisis has been well documented in terms of its impact on future healthcare service provision but with the average age for men to be diagnosed with prostate cancer being between 65 and 69 years, and the risk increasing with age, there is a 'ticking time bomb' in terms of prostate cancer provision.

↑ 6%

INCIDENCE OF PROSTATE CANCER HAS INCREASED BY 6%[8] OVER THE LAST DECADE, IN PART DUE TO AN AGEING POPULATION BUT THE MAJOR CONCERN IS THAT PROSTATE CANCER IS ESTIMATED TO BE THE MOST COMMON FORM OF CANCER BY 2030[9]

Percentage of population aged 65 and over[10]



AGEING POPULATION

1/2 OVER SEVENTY

AS OVER HALF OF PROSTATE CANCER CASES WERE DIAGNOSED IN MEN OVER THE AGE OF 70, THE RISE IN INCIDENCE RATES SINCE THE EARLY 1990S IS STRONGLY RELATED TO THE UK'S AGEING POPULATION[11]

OVER SIXTY +29%

24.2% IN 2015 TO OVER 29% IN 2035 - THE PERCENTAGE OF THE TOTAL POPULATION WHO ARE OVER THE AGE OF 60[12]

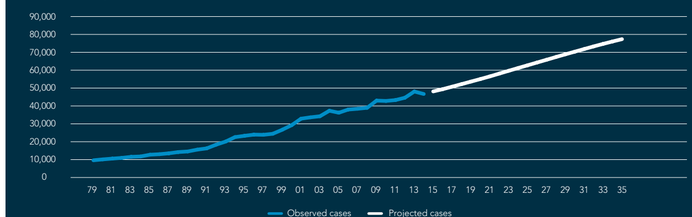
MEDIAN AGE 40

BETWEEN 1974 AND 2014, THE MEDIAN AGE OF THE UK POPULATION HAS INCREASED FROM 33.9 YEARS TO 40.0 YEARS[13]

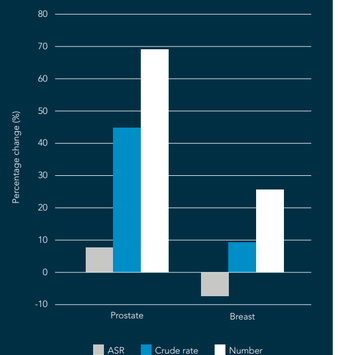
PREDICTION

In light of the future predictions relating to the ageing population and the associated rise in prostate cancer incidence, there are significant concerns that the UK healthcare system is not prepared for this kind of increase and the pressures that it will bring. To address this, there is an urgent requirement for the government, health policy makers and healthcare providers to review service provision and funding for prostate cancer.

Observed and Projected Prostate Cancer Cases (1979-2035)[14]



Projected change in cancer incidence between 2007-2030[15]



PREDICTION

↑ 12%

WITH INCIDENCE RATES FOR PROSTATE CANCER ESTIMATED TO RISE BY 12% ACROSS THE UK BETWEEN 2014 AND 2035, IT IS EXPECTED THAT THERE WILL BE 233 CASES PER 100,000 MALES BY 2035[16]

↓ 16%

PROSTATE CANCER MORTALITY RATES ARE EXPECTED TO FALL BY 16% IN THE UK BETWEEN 2014 AND 2035, TO 48 DEATHS PER 100,000 MALES BY 2035[17]

↑ 20M

THE NUMBER OF PEOPLE AGED OVER 60 IS EXPECTED TO RISE TO 20 MILLION BY 2030[18]

↑ X2

THE POPULATION OVER 75 IS EXPECTED TO DOUBLE IN THE NEXT 30 YEARS[19]

02 DIAGNOSIS

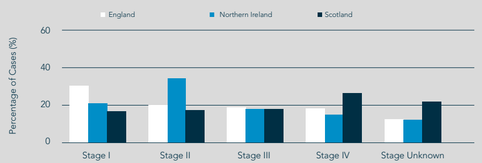
With an ageing population and a predicted increase in prostate cancer incidence, is the current diagnostic environment equipped to improve early detection rates, offer more effective treatment planning and deliver a reduction in the proportion of men diagnosed with incurable advanced prostate cancer?

RECOGNISING THE SYMPTOMS

The majority of deaths from prostate cancer occur because men present with symptoms too late. Currently as many as 23% of all cancer cases in the UK are diagnosed through A&E[20] and these patients are less likely to survive a year than those who present at their GP practice as the disease is often at a more advanced stage.

Symptom awareness is recognised as the leading factor in the early diagnosis of prostate cancer and, once diagnosed, it is critical that men are made aware of the symptoms of advancing prostate cancer such as extreme tiredness, bone pain and problems urinating.

Proportion of Cases Diagnosed at Each Stage, All Ages[21]



"Men need to have a much better understanding of their risk and the symptoms of prostate cancer and be encouraged to visit their GP whenever they suspect anything unusual."

Katherine Mutsvangwa
Orchid Male Cancer Information Nurse and Oncology Nurse in genito-urinary cancer at Bart's and The London NHS Trust

SYMPTOM AWARENESS[22]

46%

ONLY 46% OF THE UK COULD IDENTIFY WHERE THE PROSTATE IS

12%

ONLY 12% OF THE UK KNOW WHAT THE PROSTATE DOES

47%

ONLY 47% OF THE UK KNOW THAT HAVING A FAMILY HISTORY OF PROSTATE CANCER INCREASES A MAN'S RISK OF DEVELOPING PROSTATE CANCER

40%

ONLY 40% OF THE UK KNOW THAT BEING AGED 50 AND OVER INCREASES A MAN'S RISK OF DEVELOPING PROSTATE CANCER

45%

45% OF UK MEN (AND 63% OF UK BLACK MEN) WOULD LIKE TO KNOW MORE ABOUT PROSTATE CANCER RISK FACTORS

83%

83% OF UK MEN AT HIGHER THAN AVERAGE RISK OF PROSTATE CANCER DO NOT CLASSIFY THEIR OWN RISK OF BEING DIAGNOSED WITH PROSTATE CANCER AS 'HIGHER THAN AVERAGE'

5%

ONLY 5% OF THE UK KNOW THAT BLACK ETHNICITY INCREASES A MAN'S RISK OF DEVELOPING PROSTATE CANCER

SEEKING HELP

It has been well documented that men are much less likely than women to visit their GP with early medical symptoms and there is no new evidence to suggest that men's attitudes are changing and this is true for prostate cancer patients too.

Men still turn a blind eye to symptoms and risk factors and this is well illustrated in a number of studies. The recent National Cancer Patient Experience Survey 2016[23] indicates that a large number of men are still not responding quickly to symptoms, with 11.7% waiting between 3 and 6 months before seeing a GP, 4.8% 6-12 months and 3.7% more than 12 months. This compares to breast cancer patients, 87.7% of whom will see their GP within 3 months of experiencing symptoms. A Prostate Cancer UK study shows that 75% of UK men at higher than average risk of prostate cancer say that even if they were aware that they were at a higher than average risk of cancer, but didn't have any symptoms, they wouldn't speak to their GP about it.[24]

A further survey, conducted by Bayer Healthcare, highlighted that 7 in 10 men were shown to ignore or under report symptoms of advanced prostate cancer.[25]

> We need to break down the barriers that prevent men seeking help. For many, it is counter-intuitive to engage with healthcare providers and many men report being anxious about prostate examinations.

Katherine Mutsvangwa
Orchid Male Cancer Information Nurse and Oncology Nurse in genito-urinary cancer at Bart's and The London NHS Trust

DIAGNOSTIC TESTS

Diagnostic testing for prostate cancer has advanced in recent years, resulting in earlier diagnosis and improved survival rates with 8 in 10 now surviving beyond five years compared to 2 in 10 in the 1970's[26] PSA testing and early diagnostic procedures in primary care can alleviate the burden on the NHS and may help reduce the 25% of prostate cancer cases diagnosed at an advanced stage through A&E attendance.

PSA testing

According to The European Randomised study of Screening for Prostate Cancer (ERSPC), evaluating prostate-specific antigen (PSA) testing in eight European countries, screening can reduce mortality by over 25%.[27]

The prostate specific antigen (PSA) test is available free to any man aged 50 or over who requests it. However, according to Dr Jonny Coxon, GP Partner and Secretary of the Primary Care Urology Society, "this creates inequity as if a man does not know about the availability of the test he does not know he can ask for it, and so does not have it. This system of screening leads to PSA tests being taken up by more highly educated men in more affluent areas". Men concerned about the risk of prostate cancer should receive clear and balanced information about the advantages and disadvantages of the PSA test, biopsy and treatments for prostate cancer enabling them to make an informed decision about whether or not to have the test.

Informed decision making and earlier diagnosis may be improved by better use of algorithms that take into account factors like age, family history, prostate size, as well as PSA. Such algorithms exist but according to Dr Jonny Coxon "seem too difficult to easily access in routine care and, in a similar vane, we eagerly await a simple system that could advise GPs who have checked a man's PSA what the individual risk is, and when or if the test should be repeated".

Confusion continues to surround the use of PSA testing. Benefits include identifying prostate cancer before symptoms present and early identification of advanced disease whilst controversy exists over the numbers of mis-diagnosed cases, missed diagnoses and large numbers of men diagnosed with a slow-growing form of prostate cancer that may never progress, causing unnecessary distress and potentially resulting in unnecessary treatment.

As Professor Frank Chinegwundoh MBE, Consultant Urological Surgeon, Bart's Health NHS Trust explains; "Controversy remains regarding the efficacy of PSA testing as a means of prostate cancer screening and Public Health England has argued that many men are overtreated for their prostate cancer, which may never have caused a problem had it been undetected. However, it is still vital that patients are diagnosed early to assess if they need treatment or not as advanced prostate cancer is incurable".

For prostate cancer patient Andrew Richardson, there is no debate surrounding the value of a PSA test and early diagnosis; "I didn't really notice any symptoms apart from blood in my urine and after a PSA test and biopsy, underwent a prostatectomy. The most overwhelming time for me was after the surgery as I was expecting the cancer to be removed and I woke up to see the urologist who told me that the tumour had already spread to my bones and it was too dangerous to remove it. I then had a bone scan which showed I had advanced prostate cancer and it had spread. I believe that screening for prostate cancer should be as widely available as breast and cervical cancer screening enabling early diagnosis"

Whilst patients are vocal about the benefits of PSA testing, many clinicians remain cautious.

Currently the serum PSA test is the most widely used prostate cancer biomarker, although in the recent Stockholm Study (STHLM3) a combination of biomarkers were found to perform significantly better than PSA alone for the detection of cancers with a Gleason score of at least 7. "This advance could potentially reduce the number of biopsies by 32% and avoid 44% of benign biopsies and is a significant step towards personalised risk-based prostate cancer diagnostic programmes," Greg Shaw, Consultant Urological Surgeon, University College London Hospitals.

> More evidence about the benefits of PSA testing would be helpful — although we have been waiting for this for 20 years.

Dr Michael Harding
Primary Care Physician

DIAGNOSTIC TESTS

MRI imaging

For any positive PSA test there are now more effective MRI imaging techniques which help assess which cases have tumours that need further treatment and which can be monitored. This level of screening is much more cost-effective for the NHS, as many men can avoid unnecessary surgical treatment while those with aggressive cancer can also be treated sooner and avoid complications, thus vastly improving the outcome for them and their families.

One of the main difficulties with prostate cancer diagnosis is the unnecessary treatment of indolent tumours. However, as Greg Shaw points out; "MRI scanning before biopsy increases detection of aggressive cancers so that radical treatment can be applied appropriately. MRI will increasingly play a role in selecting the men who have high PSA levels who need biopsy and directing the areas from where those biopsies are taken."

> There is an urgent need for better tests to define how aggressive a prostate cancer is from the outset, building on diagnostic tests like MRI scans and new biopsy techniques which help to more accurately define the extent of the prostate cancer. This would enable us to counsel patients with more certainty whether the prostate cancer identified is suitable for active surveillance or requires urgent surgery and treatment.

Mr Greg Shaw
Consultant Urological Surgeon University College London Hospitals

New Tests

There are a number of trials currently under-way that could dramatically improve diagnosis. For example, patients who have aggressive prostate cancer could be identified by a highly accurate and simple blood test according to an early study by Queen Mary University of London. The research discovered rare cells in the blood that could be used to identify patients who are 10 times more likely to die of their prostate cancer.

Rebecca Porta, CEO of Orchid – Fighting Male Cancer, the main funder of the study comments "this is a very promising study for patients and has the potential to significantly increase the ability of clinicians to act earlier to treat those who are at a higher risk of dying earlier from their cancer"

New Diagnostic Centres

Rapid diagnostic and assessment centres are designed for patients with suspected cancer to ensure they receive the very best diagnostic tests and care without delay. Identifying cancer earlier with better diagnostic tests like MRI scans and new biopsy techniques to help more accurately define the extent of the prostate cancer, is critical to improving survival rates.

The NHS's Five Year Forward View includes plans to speed up and improve diagnosis by opening new Rapid Diagnostic and Assessment Centres.

As part of the national Accelerate, Coordinate, Evaluate (ACE) Programme a variety of pilots models are running across London to access patients with symptoms such as abdominal pain or weight loss. These centres offer a one-stop shop service offering appropriate diagnostic tests enabling a faster diagnosis for the patient and the GP.

GP INTERVENTION

Healthcare professionals need to be more proactive about discussing symptoms with their patients, especially their at-risk patients and care givers.

One of the primary risk factors in prostate cancer is hereditary risk, with a two-fold increased risk of prostate cancer if a father or brother has had it, compared to a man who has no relatives with prostate cancer.[28] However, a recent Prostate Cancer UK study shows that only 1-in-10 GPs are likely to always ask a man whether any close relatives have had the disease.[29] The National Cancer Patient Experience Survey 2016[30] also highlights that 42.6% of prostate cancer patients saw their GP two or more times with symptoms before they were referred to hospital (compared to just 9.4% of breast cancer patients). Worryingly, 6% of prostate cancer patients saw their GP 5 or more times prior to referral.

GP intervention is therefore vital not only in early detection of at risk patients but also in encouraging men to talk about and recognise the symptoms of prostate cancer.

There is currently a trial under way to develop a new risk assessment tool for GPs that should indicate the presence of cancer far more accurately than the current PSA test. The research project – involving scientists from around the world – will not only help GPs and men understand their risk of aggressive prostate cancer, but also what to do about it.[31]

ACTION ON DIAGNOSIS

One man every hour dies from prostate cancer although it is one of the more treatable types of cancer if diagnosed early. To ensure we reduce this level of prostate cancer mortality in the UK, the following needs to be addressed:

Public awareness
Public Health England and local authorities must invest in campaigns to improve symptom awareness, encourage a much better understanding of prostate cancer and empower men to visit their GP at the earliest opportunity

Referral to treatment standards
Healthcare professionals must adhere to the current standards and embrace the new 2020 standard that is currently being piloted to give patients a definitive diagnosis within 28 days

Improved diagnostic tests
NHS England must introduce a unified, efficient and effective testing programme for those at high risk and those with worrying symptoms

Research
The Department of Health, National Institute for Health Research, academic institutions, charities and health organisations must continue to invest and develop new funding streams for research into diagnostic testing and patient risk profiling

"There are no life saving new treatments in the pipeline in the foreseeable future for advanced prostate cancer so early diagnosis is key. The ideal scenario would be to ensure patients are all diagnosed early and then we would never see cases of advanced prostate cancer. We need to raise awareness of the benefits of earlier diagnosis but there is still a long way to go regarding having the optimum diagnostic services available across the UK."

Professor Frank Chinegwundoh MBE
Consultant Urological Surgeon, Bart's Health NHS Trust

03 TREATMENT

Is there sufficient investment and funding for new treatment options and information support services to enable the increasing number of men with prostate cancer to make an informed choice and access the best possible treatment?

LOCALISED PROSTATE CANCER TREATMENTS

For the six in ten men[32] diagnosed with localised prostate cancer there is a wide range of treatment options available including:

Active surveillance
Active surveillance involves a strict regime of PSA blood tests every 3 months and a DRE of the prostate every 6 months. A multiparametric MRI may be used to identify specific areas of cancer before active surveillance commences and a further scan may then be performed at a later stage. Further biopsies may be recommended after 12-18 months to monitor

Watchful waiting
Watchful waiting is an option for men who do not have obvious symptoms and who want to avoid radical treatment and associated side-effects. Reviews should include regular PSA tests

Surgery (radical prostatectomy)
Removal of the prostate gland as well as surrounding seminal vesicles is considered a major operation with side effects including urinary incontinence and erectile dysfunction

External beam radiotherapy
Radiotherapy uses radiation beams to treat and destroy cancer cells and involves treatment for 10 minutes a day, 5 days a week for 6–7 weeks

Brachytherapy
Brachytherapy is a form of radiotherapy where a sealed radiation source is placed inside or next to the area requiring treatment

High Intensity Frequency Ultrasound (HIFU)
HIFU is a treatment that uses ultrasound (high-energy sound waves) to destroy cancer cells. HIFU is usually used to treat prostate cancer that has returned after an initial treatment such as radiotherapy

Cryotherapy
Cryotherapy is a way of killing cancer cells by freezing them. It is also called cryoablation or cryosurgery. Cryotherapy is usually used to treat prostate cancer that has returned after an initial treatment such as radiotherapy

> We need to educate men about the benefits of active surveillance. They need to feel assured in the knowledge that they can simply be observed and monitored and may not ever need treatment. It is obviously far better to be monitored and observed at the earliest stage rather than to present with metastasised incurable prostate cancer later.

Professor Frank Chinegwundoh MBE
Consultant Urological Surgeon,
Bart's Health NHS Trust

LOCALLY ADVANCED PROSTATE CANCER TREATMENTS

Cancer that has started to break out of the prostate can be treated with a range of options including:

External beam radiotherapy with hormone therapy
This is sometimes administered with high dose-rate brachytherapy

Hormone therapy alone
Prostate cancer growth is often driven by male sex hormones called androgens, which include testosterone, and hormone drugs can stop the testicles from making androgens or block how they affect the body. This type of treatment is called hormone therapy or androgen-deprivation therapy

Surgery
Radical prostatectomy is a major operation to remove the prostate gland and the surrounding seminal vesicles. Sometimes an orchidectomy may be performed to prevent the production of androgens and may be considered for locally advanced disease with the possibility of adjuvant treatment

Watchful waiting
Watchful waiting is an option for men who want to avoid radical treatment and associated side-effects

ADVANCED PROSTATE CANCER TREATMENTS

When prostate cancer has spread to other areas of the body (metastatic) such as lymph nodes and bones, it is at the advanced stage where a curative treatment is not possible.

> Too many prostate cancer cases in the UK are diagnosed at an advanced stage, lagging someway behind the United States, where there is greater public awareness of prostate cancer and greater screening via the PSA test.

Professor Frank Chinegwundoh MBE
Consultant Urological Surgeon, Bart's Health NHS Trust

There have been a number of breakthroughs in advanced treatment options in recent years that can help slow the progression and manage the symptoms including:

New hormone therapies
Enzalutamide and abiraterone, which can be administered once the cancer is no longer responding to first-line hormone therapy, could extend life expectancy by up to 40%

Chemotherapy
Cabazitaxel is a newer type of chemotherapy for use when the prostate cancer has stopped responding to hormone therapy and the chemotherapy drug docetaxel

Targeted therapy
Radium-223 is a radioactive drug, to treat castration-resistant prostate cancer, which targets tumours which have metastasised to the bones and blasts them with alpha particles helping to delay bone fractures and reduce bone pain

TREATMENT DECISION MAKING

Informed Patient Choice
According to the 2014 NICE guidelines on Prostate Cancer, men should be offered individualised prostate cancer information tailored to their own needs and be given the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professional. However, there are so many potential types of treatment available, some with varying degrees of side effects, that it can be overwhelming for men to decide which, if any, they should have.

Which prostate cancer treatment a patient chooses often depends on their general awareness of prostate cancer, their personal circumstances as well as their ability to cope with active surveillance and potential treatment side effects. Long-term side effects as a result of a prostatectomy, including chronic fatigue, incontinence and impotence, can have a significant psychological, physical and emotional impact on men and have a dramatic impact on quality of life.

> For many men, incontinence can come as a huge shock as it increases anxiety levels and affects erectile dysfunction, which then becomes a vicious circle. The consequences of impotence and incontinence cannot be underestimated and many men, particularly younger men, become extremely depressed and can't function in their daily lives. So any treatment which carries impotency as a side effect is an extremely difficult decision and warrants considerable discussion and support.

Katherine Mutsvangwa
Orchid Male Cancer Information Nurse and Oncology Nurse in genito-urinary cancer at Bart's and The London NHS Trust

Although men now have access to much more information upon diagnosis, once they are told they have cancer, it can be very difficult to absorb the relevant practical information. At this life-changing moment, it is therefore vital that men have access to clinical specialists who can explain the treatment options, side effects and pathway available to them in order that they can make an informed choice.

Recommendations for treatment will be made based on individual circumstances but many men may get confused if they are offered a choice of active surveillance, surgery or radiotherapy. One of the roles of a clinical nurse specialist (CNS) is to discuss all these potential options and likely side-effects, provide information and be a point of contact during the treatment pathway. It is especially important for men from black and ethnic minority communities to have this support as cultural differences or understanding may vary, as Orchid Nurse, Katherine Mutsvangwa explains; "A patient can often simply choose the treatment option that they understand the most about or feel more confident with, which isn't always the right decision. They also make decisions based on what they can handle within their life situation. Specialist support is therefore vital in helping the patient overcome these concerns, as well as any fears about rectal examinations, so that they can make an informed choice and get the best treatment for them as quickly as possible."

> The most difficult part of the diagnosis for me was trying to decide what was the best treatment option. It would certainly have helped at that stage to have a specialist nurse to talk through all the options and consequences to help me choose which one would suit my situation the best.

Andrew Richardson
Prostate cancer patient

> Future advanced prostate cancer care pathways are going to require a more diverse and multispecialty workforce, which may not be deliverable in all centres and may require increased collaborative working between units.

Mr William Cross
Consultant Urologist, St James's University Hospital

LOCAL SUPPORT & GUIDANCE

NICE guidelines state that men with prostate cancer should be offered advice on how to access information and support from websites, local and national services, as well as access to support groups, such support groups are not widely available.

Charities, such as the male cancer charity Orchid, provide extensive support through its nurse helpline and online resources and can help patients with treatment choices, referrals to local services and support groups, as well as psychological support but the NHS is moving to a point where it over-relies on charities providing these services and concerns are being raised about the sustainability of this model.

> After a urology nurse suggested I talk to other patients and put me in touch with support groups, I found it invaluable being able to share my experience face to face with other sufferers who completely understood what I was going through and helped me to provide a better perspective on the treatments available. Every man should have access to a local group to help him deal with his side effects and treatment.

Andrew Richardson
Prostate cancer patient

HEALTHCARE PROFESSIONAL RECOMMENDATION

Recommending treatments for prostate cancer is also not always straight forward for healthcare professionals as there are so many psychological as well as physical factors to take into consideration. For example, treatment recommendation can depend on how patients cope with active surveillance and regular monitoring as Katherine Mutsvangwa explains; "Different patients experience different levels of anxiety at different times of their cancer journey. For those who get very stressed at every appointment that the disease may be developing, I would recommend that they have treatment to reduce the risk of disease development, if the option is available, rather than active surveillance"

Treatment recommendations are normally made by a multidisciplinary team of clinical specialists (MDT) but these work in different ways across the country, which can make access to treatment and the decision making process for clinicians and patients complex. However, Pauline Bagnall of BAUN has concerns over a nurse's role in a MDT, as she explains; "Nurses advocate on behalf of their patients within the multidisciplinary team meeting. However, research shows that not all nurses are active participants in the MDT meeting and many would benefit from training to enable them to make their voices heard and facilitate their role as advocates. Many Trust managers also do not see the value of the MDT in determining the optimal treatment plan and would rather their consultants and nurse specialists are either operating on patients or seeing them in outpatients than sitting in a meeting."

A further issue with treatment recommendation lies in the need to improve the grading and staging of prostate cancer. A recent study shows that tests to grade and stage prostate cancer underestimated the severity of the disease in half of men whose cancers had been classified as 'slow growing.'[33]

Such difficulties with MDTs and staging can make the choice of treatment difficult for specialists and this can be further compounded by difficulties surrounding patient choice.

NEW TREATMENTS

> The reality is that it takes 17 years from innovation to treatments being available in practice and we need a top down approach to change this and speed up the process, as well as for consultants to be more open to change, to maximise patient outcomes sooner.

Professor Frank Chinegwundoh MBE
Consultant Urological Surgeon, Bart's Health NHS Trust

Advanced Prostate Cancer — new treatments
There are a number of new treatment options in development for advanced prostate cancer but according to Professor Chinegwundoh the time it takes for research results to be implemented and new treatments to be made available is just taking too long as he highlights; "According to the recent ASCENDE study, seed brachytherapy boost with external radiotherapy and hormone treatment should be the standard treatment for locally advanced prostate cancer due to proven survival benefits. However, 39% of patients are still just given hormone treatment and not offered radiotherapy, let alone with a seed brachytherapy boost. It is hard, therefore, to effect change and for best practice to be disseminated in spite of research providing the evidence of survival benefits."

Personalised Treatment
There has also been extensive research into individual genetic mutations which will help to provide more effective personalised treatments in the future. Trials at The Royal Marsden and Institute of Cancer Research have already shown that prostate cancer patients with BRCA mutations can benefit from drugs called Parp inhibitors which disrupt cancer cells' DNA repair mechanism. Such research helps scientists to better understand how prostate cancer develops, which will make it easier to design drugs to target those changes, providing more effective treatments.

Delaying Disease Progression
An exciting new clinical study called PROVENT is also underway to evaluate the ability to delay progression of early prostate cancer using vitamin D3 and aspirin. "These well-known drugs are both cheap and generally safe. If a delay in progression is seen, these drugs will likely be very cost-effective and widely available," explains Greg Shaw.

DRUG FUNDING

Despite the predictions that prostate cancer will be the most common form of cancer by 2030, prostate cancer is 20th in the league of research funding, receiving half the funding of breast cancer.

Whilst the majority of existing drugs for prostate cancer are routinely available through the NHS, the reforms to the Cancer Drugs Fund could result in innovative new prostate cancer treatments being restricted due to price.

In addition, the newly introduced NHS England £20 million annual cap for new drugs could further restrict access to new prostate cancer treatments. Effectively penalising breakthrough drugs that could benefit large patient populations, such as prostate cancer, the cap has been widely criticised. Drugs approved by NICE that may exceed the cap will be subject to price negotiations between the NHS and the drugs manufacturers - a process which could take up to three years therefore delaying access to patients who may die before they could benefit.

To ensure that the increasing population of prostate cancer patients will benefit from the breadth of research and treatment developments in the pipeline, it is vital that the funding issues are resolved to allow greater access to new breakthrough treatments that could improve the quality and quantity of life.

> For prostate cancer care to remain financially sustainable whilst avoiding unnecessary delay in introducing the latest therapies, I believe that there is need to address the following;
>
> —Improved health-economic modelling specific to the NHS within large-scale drug trials
>
> —Industry must make its new treatments and technologies affordable to the NHS
>
> —Explore alternative funding models, such as reimbursement based on therapeutic performance/benefit
>
> —Identifying cost saving opportunities earlier in the prostate cancer pathway may release funding for the newer life-extending novel therapies

Mr William Cross
Consultant Urologist, St James's University Hospital

NEW TREATMENT CENTRES

By March 2018, 10 new multi-disciplinary Rapid Diagnostic and Assessment Centres will be introduced across England and by March 2019, there are plans to have Centres in each of the 16 cancer alliances.[25]

At these new centres, patients will have access to state of the art new and upgraded linear accelerators, a device most commonly used for external radiation treatments and designed to destroy the cancer cells while sparing the surrounding normal tissue.[34] The aim is for patients to have access to radiotherapy treatments wherever they live and this plan is the largest radiotherapy upgrade programme in 15 years.

NEW SURGICAL TECHNIQUES

> Using current treatments and surgical techniques in a smarter way to minimise side-effects is the priority.

Mr Greg Shaw
Consultant Urological Surgeon University College London Hospitals

75% of prostate cancers are now removed with robotic surgery in the UK and its increased precision allows the surgeon to spare the nerves which run within the coverings of the prostate, promoting potency and continence, as Greg Shaw observes; "Modern surgery, using robotic assistance, where the surgeons image is at 10x magnification with 3D enhancement, allows more precise sparing of the important structures around the prostate with faster recovery and less side effects than surgery where the tissues surrounding the prostate are destroyed."

There are now 4-5 centres offering specialised fellowship training in robotic surgery which usually consists of a committed year of intensive training following completion of a standard urological surgery training program. Robotic surgery is relatively expensive but in time improved cost-effectiveness will be achieved through shortening length of stay in hospitals and decreasing the number of complications and requirement for extra adjuvant cancer treatment. Funding for further centres offering training will also significantly improve patient outcomes and minimise any side-effects associated with prostatectomies.

Further surgical advances, resulting in less surgery related side-effects, could also be just a few years away, as Greg Shaw explains; "I am leading a clinical study called NeuroSAFE PROOF to evaluate the effects of a new technique designed to encourage surgeons to spare nerves without detriment to cancer control. Nerve sparing decreases the side effects of surgery and this study will progress to a randomised controlled multicentre trial designed to generate conclusive evidence within 5 years, about who should receive this technique and whether it is cost effective."

ACTION ON TREATMENT

A range of treatments exist for men with prostate cancer which are currently well funded by the NHS.

However, with a projected increase in people over 75 in the UK of 89.3% by 2035[35], additional funds and resources will be required to meet the needs of the growing population of men with prostate cancer. Funding is required for:

Research
An increase in government, industry and charity funding for research into new drug therapies and surgical techniques

Specialist support
Funding for recruitment and training of specialist nurses and GPs to enable men to make informed choices about their treatment options

04 PATIENT CARE

Could an increase in clinical nurse specialists and primary care support help reduce the increasing burden of prostate cancer and improve patient care and experience?

GENERAL PRACTITIONERS

For many men, their prostate cancer journey starts with a visit to their GP and ease of access to this service is key to early identification of the disease

GPs can also play a major role in patient support pre and post treatment but, according to Dr Jonny Coxon "this would benefit from more guidance for GPs on advice to patients regarding the PSA test and its potential consequences and improved locally commissioned services in primary care, with specifications that include prompts for GPs to ask about and provide emotional support following treatment".

However, the current shortage of GPs combined with a predicted increase of those living with cancer from 2.5 million people to 4 million by 2030[36], could potentially impact on GP support for those men, particularly the rising population of ageing men, who present with early symptoms of prostate cancer.

> There is marked variation across the country in terms of access to the formal help that is outlined in the guidance for prostate cancer care and whilst GPs and Practice Nurses play a valuable role there is still so much to improve upon.
>
> **Dr Jonny Coxon**
> GP Partner and Secretary of the Primary Care Urology Society

To avert a breakdown in primary care support for men with prostate cancer it is important that commissioners and providers plan for the future when addressing GP shortages, taking into account the ageing population and increased burden of cancer.

NURSE SPECIALISTS

Shortage of Nurse Specialists

Although considerable evidence strongly suggests that clinical nurse specialists make a significant impact on the quality of patient care and demonstrate cost effectiveness,[37] there still remains a worrying shortage and not every person with prostate cancer in the UK has access to a clinical nurse specialist.

The number of nurse specialists for men with prostate cancer is not proportionate to disease incidence and there is insufficient and varied access across the UK. According to the national cancer nursing census, only 2% of the specialist nursing workforce in England is prostate specific,[38] compared with 18% specialising in breast cancer care and 12% for colorectal cancer. Additionally, due to high and increasing survival rates for prostate cancer, the number of patients per specialist nurse grows with each year.

Despite prostate cancer cases more than tripling in the UK over the last 40 years, recruitment and training of nurse specialists has not kept pace. With prostate cancer estimated to be the most common form of cancer globally by 2030, the huge inequality in specialist nurse provision needs urgent action to address the current shortage and to plan for an increasing population of men with prostate cancer.

Adding to the crisis, a new survey revealed that many nurse specialists plan to leave their role in the next decade, with no plans in place to develop a new specialist workforce.[39]

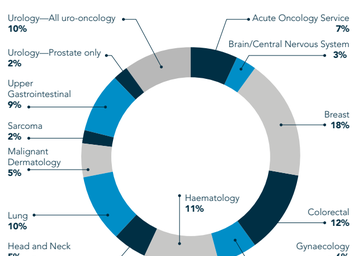
> Compared to other specialities, urology specialist nurses are one of the smallest in number yet have one of the biggest workloads. Many men with prostate cancer are missing out on this vital support.
>
> **Rob Cornes**
> Orchid Male Cancer Information Nurse

Funding isn't the only reason for specialist nursing shortages as there are also considerable disparities regarding training provision and accessibility at a local level, as Katherine Mutsvangwa explains; "The GP Federation needs to consider the provision of more nurse specialists within primary care as the existing charity funded model is simply not sustainable. It would also help to address the shortfall if training was available in more local hospitals and made more appealing to nurses through study days and fully funded, rather than self-funded, training for nurses wishing to up-skill."

Experts support a call for further investment and the need to urgently plan and develop the specialist nursing workforce in prostate cancer care so that men, wherever they live, get the support they need throughout their diagnosis and treatment, to minimise the impact on their lives as much as possible.

> You only need to talk to clinical nurse specialists to hear how over-worked they are and how they regularly have to discharge patients earlier than they would wish, or see them less frequently.
>
> **Dr Jonny Coxon**
> GP Partner and Secretary of the Primary Care Urology Society

Total specialist adult cancer nursing workforce by area of practice, WTE, England 2014[40]



NURSE SPECIALISTS

The Role of the Clinical Nurse Specialist

Nurses specialising in the care of patients with prostate cancer have a varied and crucial role to play including:

Supporting patients post PSA test
NICE guidelines recommend nurse follow-up for men with a stable PSA and no significant treatment complications

Performing biopsies and urological procedures
Uro-oncology nurse specialists can perform these procedures thus reducing the burden on other clinicians

Performing Holistic Needs Assessments (HNA)
Aiding men to identify any issues or problems that they may need support with enabling self-management and effective monitoring of disease progression by nurses and GPs

Emotional support and advice before, during and after treatment
The positive effect of specialist nurse support on the patients experience and disease outcome is well documented

Post-surgery care
Clinical nurse specialists support enhanced recovery after surgery, reducing the need for lengthy hospital stays. The recent Prostate Testing for Cancer and Treatment (ProtecT) trial, assessing the benefits of nurse-led active surveillance care comprising an explicit nurse-led protocol with support from urologists, verified that a nurse-led model of care was acceptable to men with localised prostate cancer, as well as clinical specialists in urology[41]

Palliative care
Patients enrolled in nurse-supported palliative care programmes early after diagnosis have been shown to experience significant improvements in their quality of life and mood, survived longer and had lighter symptom burden at the end-of-life than patients receiving standard care[42]

> A lack of nurse specialists means many hospitals are unable to meet their HNA targets resulting in patients missing out on a self-management plan.
>
> **Katherine Mutsvangwa**
> Orchid Male Cancer Information Nurse

> It is so important that specialist nurses are where patients need them, whether that be in primary, secondary or palliative care. We need more prostate cancer and uro-oncology nurses now. However, with funding as short as it is currently and unlikely to change over the next few years, I am not hopeful that we will see a sufficient increase in specialist nurse provision to provide a nurse for each patient across the whole pathway any time soon.
>
> **Pauline Bagnall**
> Uro-oncology nurse specialist and council member of the British Association of Urological Nurses (BAUN)

FOLLOW UP SHIFTING TO PRIMARY CARE

The traditional follow up model follows a standard regime of hospital outpatient appointments and surveillance tests over several years. However, both patients and professionals have identified that many appointments are unnecessary and incur unnecessary costs for patients and the NHS and, with recurrence usually detected through PSA monitoring, follow up care could be conducted in a primary care setting.

Primary care is now a suitable alternative to provide long term support for people affected by cancer. Primary care teams play a key role in earlier diagnosis in symptomatic patients and accessing treatment after diagnosis. Evidence suggests that as patients want proactive cancer care in a primary care setting,[43] primary care led and supported self-management pathways are recommended as a preferred future option for prostate cancer follow up.

An economic analysis of primary care and secondary care follow up pathways also shows that there could be a 57% cost saving[44], if stable prostate cancer patients are transferred and followed-up in the community. A further review also showed that patients prefer their care being delivered by their GP practice where they can receive comprehensive information and access to relevant support services.[45]

However, with increased survival rates, the numbers being cared for in primary care will continue to rise, putting further pressure on already stretched resources. Addressing the current pressures on GP's and nurses and staffing shortages are clearly a priority if patients are to receive optimal care in the primary care setting and the nursing profession has some serious reservations about the sustainability of primary care-led provision.

> "I am concerned that we are discharging patients into primary care and with GP's stretched already, we are simply adding to their workloads without providing any additional support. In addition, prostate cancer treatment is changing so rapidly. Urology specialists can keep abreast of new developments as this is our specialist interest but GP's will not be able to keep up to date to the extent that we do and patient care may be compromised as a result."
>
> **Pauline Bagnall**
> Uro-oncology nurse specialist and council member of BAUN

TRANSFER OF CARE

Improved communication and information at the point of transfer of care, including a welcome appointment with the GP or practice nurse to discuss a patient's needs and templates to standardise a holistic approach to follow up appointments, were key recommendations to improve primary care follow up.

The project also identified that nurses are now taking a lead role in a patient's follow up and more training is needed to educate GP's and nurses about PSA referral thresholds, red-flag signs and symptoms as well as safety-net protocols to comply with clinical governance and ensure that transfers back to secondary care were as quick as possible when required.

The project also makes recommendations to address patients' needs and it identified that patients did want more information at the point of transfer of care and they also wanted the opportunity to have face-to-face consultations and to discuss their wider needs, specifically erectile dysfunction, bladder issues, psychological and social needs.

SELF MANAGEMENT PATHWAYS

There is a strong justification for self-management pathways and the National Cancer Survivorship Initiative and NHS Improvement recently developed and tested a series of principles to assess alternative pathways for follow up treatment as well as to determine the level of care a patient needs and their ability to self-manage.[46]

Although stratified pathways, offering alternative routes for patients with cancer, have been developed over the past five years, most pathways in primary care-based services are still secondary care-led, with remote monitoring and nurse-led telephone follow up. With more men living with prostate cancer than ever before, it was concluded that a re-design of services is urgently needed to promote faster and more comprehensive recovery, fewer patients in routine follow up, increased self-management and better access to services.

Studies within NHS Improvement test sites and elsewhere have found that with appropriate investment in quality initiatives such as needs assessments and care plans, information and education, up to 44% of prostate patients were found to be suitable for a supported self-management pathway,[47] bringing care closer to home.

ACTION ON PATIENT CARE

With an increasing prostate patient population, the following needs to be addressed:

Care closer to home

Ministers and CCGs need to call for an urgent review of the role of primary care in prostate cancer patient management, with the aim of reducing the burden on secondary care and offering patients care and support closer to home

Clinical Nurse Specialists

NHS Trusts and CCGs need to take urgent action on the shortage of Urology Clinical Nurse Specialists in prostate cancer and develop and implement a long-term plan to recruit, train and fund additional nurses to provide adequate support for prostate cancer patients

05 | SUMMARY

With prostate cancer due to be the most prevalent cancer in the UK by 2030, we are facing a potential crisis in terms of diagnostics, treatment and patient care. Urgent action needs to be taken now if we are to be in a position to deliver world class outcomes for prostate cancer patients and their families in the future.

Whilst Orchid supports the government's cancer strategy, and initiatives to deliver against it, we have grave concerns about whether there is sufficient immediate positive action to ensure the proposed strategy will meet the huge demands of a growing prostate cancer population at a time when healthcare professional resources and funding are considerably stretched.

Our recommendations, as set out in this report, are based upon the opinions of a range of experts working in prostate cancer together with our own experience of working with patients, healthcare professionals and policy makers over the past 21 years. We want to ensure that prostate cancer receives a proportionate share of voice when it comes to implementing the cancer strategy and we, together with our charity and patient organisation partners, will continue to push for the best possible outcomes for prostate cancer patients now and in the future.

Rebecca Porta
Chief Executive, Orchid

> "There is an opportunity for interested national groups and charities to engage with clinicians and patients to highlight the clinical challenges and identify service gaps, but also promote the wider adoption of novel care pathways and services."

Mr William Cross
Consultant Urologist, St James's University Hospital

ORCHID'S RECOMMENDATIONS FOR URGENT ACTION BY POLICY MAKERS TO ADDRESS BRITAIN'S GROWING PROSTATE CANCER PROBLEM:

ACTION ON DIAGNOSIS

Public awareness
Public Health England and local authorities must invest in campaigns to improve symptom awareness, encourage a much better understanding of prostate cancer and empower men to visit their GP at the earliest opportunity

Referral to treatment standards
Healthcare professionals must adhere to the current standards and embrace the new 2020 standard that is currently being piloted to give patients a definitive diagnosis within 28 days

Improved diagnostic tests
NHS England must introduce a unified, efficient and effective testing programme for those at high risk and those with worrying symptoms

Research
The Department of Health, National Institute for Health Research, academic institutions, charities and health organisations must continue to invest and develop new funding streams for research into diagnostic testing and patient risk profiling

ACTION ON TREATMENT

Research
An increase in government, industry and charity funding for research into new drug therapies and surgical techniques

Specialist support
Funding for recruitment and training of specialist nurses and GPs to enable men to make informed choices about their treatment options

ACTION ON PATIENT CARE

Care closer to home
Ministers and CCGs need to call for an urgent review of the role of primary care in prostate cancer patient management, with the aim of reducing the burden on secondary care and offering patients care and support closer to home

Clinical Nurse Specialists
NHS Trusts and CCGs need to take urgent action on the shortage of Urology Clinical Nurse Specialists in prostate cancer and develop and implement a long-term plan to recruit, train and fund additional nurses to provide adequate support for prostate cancer patients

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