

# Achieving the best possible outcomes for men with prostate cancer in Northern Ireland



**PROSTATE  
CANCER UK**

## Context

In 2017, over 1,100 men were diagnosed with prostate cancer in Northern Ireland, and around 300 died from the disease.<sup>(2)</sup> Of those diagnosed with prostate cancer between 2013 and 2017, the majority had stage I and II cancer (53 per cent per year), which is localised within the prostate.<sup>(2)</sup> Yet, 38 per cent of men were diagnosed with advanced disease, meaning that the cancer had spread outside the prostate where treatment is more complex and survival rates are lower. The stage at diagnosis of the remaining nine per cent was not recorded.<sup>(2)</sup>

Northern Ireland currently has over 10,000 men living with and beyond prostate cancer.<sup>(2)</sup> But Northern Ireland's population is ageing and as men live longer, their risk of prostate cancer increases. In 2016, there were 303,000 men aged 50 and older; when age becomes a significant risk factor for prostate cancer. The Office for National Statistics (ONS) estimates that there will be a 21.5 per cent increase from 2016 to 2030, which means that there will be 368,000 men aged 50 or older living in Northern Ireland by 2030. Using ONS population statistics from 2016, Prostate Cancer UK estimates that there will be over 13,000 men living with and beyond prostate cancer by 2028.

## Executive summary

Prostate cancer is set to become the most commonly diagnosed cancer in the UK by 2030.<sup>(1)</sup> It is important that these men are diagnosed early and accurately, to give them the greatest chance of survival. It is also important to make sure that these men have access to the latest cost-effective treatments. As treatments improve, we can expect a greater proportion of men to live longer with and beyond prostate cancer. These men will require support to monitor their condition, manage the risk of recurrence and manage any consequences, symptoms or side-effects they experience.

With the number of men living with and beyond prostate cancer set to grow, this report highlights the new technologies and service improvements that can be introduced to make sure these men can continue to achieve improving outcomes. This report also provides advice on how to tackle the increasing burden on healthcare services from this growing prostate cancer population.



## Summary of proposals

### Better diagnosis

- Using the Prostate Cancer UK clinical consensus on PSA testing to make sure the PSA test is used as effectively as possible.
- Supporting all centres to:
  - make sure they are delivering pre-biopsy MRI to a high standard, maximising diagnostic accuracy
  - plan for future increases in demand for diagnostic capacity.
- Reviewing patient access to local anesthetic transperineal biopsy and how hospitals can be supported to improve provision.
- Making sure there is parity with the rest of the UK in access to PSMA-PET scans for recurrence after treatment for localised prostate cancer.

### Access to effective treatments

- Highlighting the important role that best practice active surveillance can play in allowing men to avoid or delay the consequences of radical treatment.
- Parity of access to new cancer treatments and technologies, including those on the new Cancer Drugs Fund.

### Support for every man

- Rolling out the digital supported self-management tool in Northern Ireland.
- Meeting NICE guidelines in support for men experiencing erectile dysfunction or incontinence following radical treatment.
- Exploring how men with advanced prostate cancer can be supported to deal with the symptoms of their cancer and side-effects of their treatment.

### Workforce

- Putting in place measures to make sure that hospitals in Northern Ireland have the staff and equipment they need to provide prostate cancer diagnosis both now and, in the future.
- Assessing the clinical nurse specialist workforce across Northern Ireland to make sure workforce numbers are sufficient to provide support throughout the cancer pathway.

### Data collection and monitoring

- Considering how data collection can be expanded to provide information to drive improvements in cancer service delivery.

## Introduction

Our ambition at Prostate Cancer UK is to save and extend the lives of men with prostate cancer. We are working to achieve this by:

- investing in the medical research and NHS pathway transformation that can provide men at higher than average risk of prostate cancer with an earlier and more accurate diagnosis
- triaging these men to identify those with clinically significant disease
- and streamlining the diagnostic pathway so that they receive faster access to the most effective treatments.

The more men that can be diagnosed when their prostate cancer is still contained within the prostate, the more likely we are to see them cured. The provision of advanced imaging to stage men who experience recurrence after treatment for localised disease will mean the potential for curative treatment can be increased.

At the same time, the treatment landscape for advanced prostate cancer is constantly changing as new evidence demonstrates the clinical benefit of re-purposed and new treatments. Additional months of life for men diagnosed at this stage is increasingly becoming the norm. The first personalised prostate cancer treatment is also imminent. The more treatments that become available to men, the longer they will live. This will need new and innovative mechanisms that enable cost-effectiveness for hospitals, while meeting the needs of the pharmaceutical industry.

When we achieve our ambition, more men will live with and beyond prostate cancer. These men need to be empowered, through supported self-management programmes to access the breadth of support they need to have a good quality of life.



## Reducing the burden of prostate cancer

### I. Better diagnosis

#### I.1 Achieving earlier and more accurate diagnosis

As the population of men with prostate cancer is set to grow in Northern Ireland, it is important that prostate cancer is diagnosed at an early stage, when curative treatment is still an option. Northern Ireland's strategic approach to cancer recognises the value of early diagnosis and a focus on cancer awareness raising and early detection. To truly achieve this strategic approach there will need to be a reduction in the number of men who are diagnosed with prostate cancer at a late stage of the disease.

##### I.1.1 Better use of the PSA test

For asymptomatic men at higher than average risk of prostate cancer (men aged 50 and over, black men and men with a family history of the disease),<sup>(3,4)</sup> the PSA test is currently the best first step for early detection of prostate cancer. A clinical consensus involving hundreds of clinicians was facilitated by Prostate Cancer UK to outline ways that the PSA test can be delivered optimally and in combination with awareness raising of prostate cancer risk factors.<sup>(5)</sup> For example, one of the recommendations of the consensus is that GPs and practice nurses should know what may increase a man's risk of getting prostate cancer, and that all men should be able to have a PSA test if they are over 50, or over 45 if they have a higher risk of prostate cancer. We recommend use of this consensus across Northern Ireland, while we continue to fund research to find a new and more effective testing approach.

In addition, the introduction of a pre-biopsy triage in the form of mpMRI before biopsy and an increased use of active surveillance for low risk localised prostate cancer has the potential to reduce the harms currently associated with PSA testing. The GP community can be reassured that initiatives to drive consistent use of the PSA test for men at increased prostate cancer risk can be delivered with a lower likelihood of resultant over-diagnosis.

**Prostate Cancer UK advises the use of our clinical consensus to make sure the PSA test is used as effectively as possible.**

##### I.1.2 Prostate mpMRI before biopsy

Equally important is to make sure men receive an accurate diagnosis with minimal side-effects. The introduction of mpMRI before biopsy makes this possible. The PROMIS(6) trial (2017) showed that giving men with suspected prostate cancer an MRI scan as their first-line diagnostic investigation upon referral can reduce the number who need to undergo a biopsy by 27 per cent and almost double the detection of clinically significant cancer. Ruling men out of immediate biopsy saves men the possibility of biopsy-related side effects and reduces the burden on histopathology services. The PRECISION(7) trial (2018) supported these findings, showing that risk assessment combined with pre-biopsy MRI and targeted biopsy reduces the number of clinically insignificant cancers diagnosed.

Prostate Cancer UK has been working to support the rollout of mpMRI before biopsy across the UK, including in Northern Ireland. Our aim is that all eligible men have access to this technique. This includes men with an elevated PSA level of  $\geq 3\text{ng/ml}$ .<sup>(8)</sup>

Further, we are working to help centres provide mpMRI to high quality standards, as used in PROMIS, so that the technique can provide maximum benefit to men and health services. Quality standards were agreed in a UK consensus meeting in 2018<sup>(9)</sup> and included in the updated NICE Guidelines for prostate cancer in 2019.<sup>(10)</sup>

Data from a Freedom of Information request run by Prostate Cancer UK in early 2018 showed that, of the five Health and Social Care Boards in Northern Ireland, three were providing bi-parametric MRI (bpMRI) before biopsy, and therefore only using three of the four sequences needed for mpMRI. Two were not providing any pre-biopsy MRI, though had arrangements in place to either begin this service or refer men to other areas for pre-biopsy MRI.

We recognise that there is clinical debate around the use of the fourth mpMRI sequence, which involves dynamic contrast enhancement (DCE). However, without it, mpMRI is not being made available, bpMRI is. Prostate Cancer UK recommends the use of DCE because it is supported by the level 1 evidence provided by the PROMIS trial and we have no similar evidence to enable us to support bpMRI. To this extent, we uphold the recommendations in the UK clinical consensus and NICE Guidelines.

DCE provides an additional image of the prostate which makes it easier to read scans and identify potential prostate cancer. Therefore, it is particularly important for centres that are new to using pre-biopsy MRI, or with radiologists who have reported fewer than 500 scans to improve their accuracy. It is also particularly important to have this additional scan in centres with poor image quality. Poor image quality may be due to older or weaker MRI scanners, or due to those scanners' calibration.

We understand that DCE can have additional resource implications. Before centres consider pre-biopsy MRI without DCE, we believe it is necessary that an audit of image quality is undertaken, and radiologists' reporting is validated by biopsy results, so that there is no reduction in diagnostic accuracy.

Understanding the resource implications that providing pre-biopsy MRI can have, we recommend plans to make sure that MRI scanner capacity and radiologist numbers keep pace with the increased demand anticipated from a growing prostate cancer population. Prostate Cancer UK has population and demand modelling that can help to determine likely radiologist and MRI capacity requirements for pre-biopsy MRI in future. We would be happy to share this work to help hospitals in Northern Ireland plan for future diagnostic capacity requirements.

**Prostate Cancer UK advises that support should be offered to all centres to:**

- **make sure they are delivering pre-biopsy MRI to a high standard, maximising diagnostic accuracy**
- **plan for future increases in demand for diagnostic capacity.**



**When you're faced with a prostate cancer diagnosis, there are so many uncertainties, but if mpMRI was available when I was diagnosed we would have instantly known what we were up against. mpMRI scans must be made available to all men across Northern Ireland so that all men can benefit from the most accurate diagnosis it can provide.**

Raymond McKee from Newtownards

### 1.1.3 Biopsy options

For men who have to undergo a biopsy due to positive findings on an MRI scan, there are newer biopsy techniques which have the potential to reduce the risk of sepsis.<sup>(11)</sup>

A sample of the prostate can be taken either through the rectal wall or through the skin of the perineum. The latter is called 'transperineal' biopsy, which is the newer technique and can be performed under local anaesthetic. The potential saving for hospitals comes from the reduction in sepsis cases which a study in 2012 estimated cost £4,260 per patient.<sup>(12)</sup>

The technique is already being provided in hospitals in the Belfast, Southern and Western Health and Social Care Trusts. However, some of these hospitals have retrofitted older technology to deliver the technique and other areas face issues with training. A small capital investment would allow more hospitals to offer this technique to a high standard so that all men in Northern Ireland undergoing biopsy have the option of benefitting from the reduced risk of sepsis that transperineal biopsy provides.

**Prostate Cancer UK advises a review of patient access to local anaesthetic transperineal biopsy and how hospitals can be supported to improve provision.**

### 1.2 Effective staging for bio-chemical relapse

CT and bone scans are currently used to stage men experiencing biochemical relapse after treatment for localised prostate cancer. However, they can often provide sub-optimal images that can result in patients being under-treated. This can result in poorer patient outcomes, especially for men with low-volume metastases. The earlier these men are treated, the better their outcomes.

The improved diagnostic accuracy provided by Prostate-Specific Membrane Antigen Positron Emission Tomography-Computed Tomography (PSMA PET-CT) scans for staging recurrent prostate cancer makes it possible to accurately determine which area of the body the recurrence has appeared in. For instance, it is possible to tell if the recurrence is situated in the local prostate, regional prostate (lymph nodes) or in other parts of the body. As the treatments currently considered the most effective for these different sites vary significantly, the right treatment choice is only possible when using the most effective diagnostic tool. This is critical for making the best use of finite resources.

Additionally, PSMA-PET enables the identification of disease sites at the lowest possible PSA level in men with biochemical recurrence. This provides an optimal chance to receive salvage treatment, which has the potential to save lives, while limiting the future use of expensive late stage treatment management.

PSMA-PET scans also offer the potential to deliver the clinical trials needed to better understand which treatments in the future can provide the most effective outcomes for various stages of recurrent prostate cancer.

**Prostate Cancer UK advises Northern Ireland health authorities to make sure there is parity with the rest of the UK in access to PSMA-PET scans for recurrence after treatment for localised prostate cancer.**

## 2. Accessing effective treatments

### 2.1 Localised prostate cancer

Historically, overdiagnosis has been a problem in prostate cancer. This was a result of the diagnostic pathway relying on TRUS biopsy (Transrectal ultrasound) which would diagnose more low-risk cancers (five per cent more) than is currently the case with mpMRI before targeted biopsy.<sup>(15)</sup> Many of these men would be offered or choose radical treatments and often experience life changing side-effects for a cancer that would likely not have done them any harm.

#### 2.1.1 Active surveillance

Active surveillance is the monitoring of localised (early) prostate cancer that may be growing slowly – if at all – and have a low risk of spreading. It is a treatment option that allows men to avoid or delay the consequences of more radical treatment. This has the potential to reduce overtreatment, while still leaving radical treatment as an option.

In March 2019, a consensus guideline for health professionals was published following work by Prostate Cancer UK's Expert Reference Group on active surveillance.<sup>(16)</sup> This included guidelines suggesting that men with a Gleason score of  $\leq 6$  should be offered active surveillance and active surveillance may be suitable for men whose cancer has other characteristics including a Gleason score of  $\leq 3+4$ . This consensus guideline was largely replicated by NICE in its updated 2019 guidelines for prostate cancer.

Some men will not opt for active surveillance, or will switch to radical treatment, due to the fear of disease progression. Alongside active surveillance, consideration should be given to providing supportive and educational interventions to reduce the risk of psychological distress.<sup>(17)</sup>

There is good provision of active surveillance in Northern Ireland. In a Freedom of Information request that Prostate Cancer UK ran in 2018, all four of the trusts that responded reported using an active surveillance protocol.

**Prostate Cancer UK advises highlighting the important role that best practice active surveillance can play in allowing men to avoid or delay the consequences of radical treatment.**

## 2.2 Advanced prostate cancer

The treatment landscape for prostate cancer is constantly changing as new evidence demonstrates the clinical benefit of re-purposed and new treatments. The first personalised prostate cancer treatment is imminent. Making sure that men get access to these treatments will need new and innovative mechanisms that enable cost-effectiveness, while meeting the needs of industry. This will require, for example, facilitating flexible pricing systems that draw on real-world data to establish a long-term price. It may also include opportunities for multi-indication pricing.

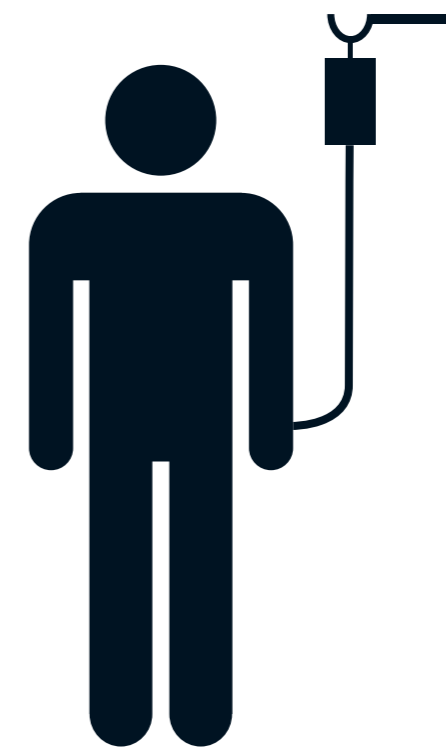
### 2.2.1 Cancer Drugs Fund

In 2016, the Cancer Drugs Fund (CDF) was redesigned and is now a managed access fund for cancer drugs.<sup>(18)</sup> This allows NICE to give conditional approval to cancer drugs, making the drugs available to patients while more data is collected to better determine their clinical cost-effectiveness. Before this, and currently for all non-cancer drugs, NICE was only able to give a positive or negative recommendation.

Northern Ireland previously relied on NICE recommendations to determine which treatments it makes available to patients in Northern Ireland. When drugs enter the Cancer Drugs Fund, NICE defers a final decision, this meant that patients in Northern Ireland would have had to wait up to two years to access new treatments entering the CDF.

Thankfully, in 2018, the Department of Health announced that patients in Northern Ireland now receive parity of access to those drugs that have conditional approval through the Cancer Drugs Fund.<sup>(19)</sup> This has been fantastic so far and has the potential to continue to benefit patients in Northern Ireland. We hope that this parity continues, and future funding is made available to achieve this.

**Prostate Cancer UK welcomes parity of access to new cancer treatments and technologies, including those on the new Cancer Drugs Fund, and hopes this continues.**



## 2.2.2 Personalised medicine

We are seeing a new age of personalised medicine, with treatments that are only suitable for smaller patient populations but that are more likely to work for those populations. One treatment for prostate cancer is the PARP-inhibitor Olaparib. This treatment is made complicated by the need for genomic diagnostic testing to determine whether patients are eligible to receive it. How these tests are factored into cost-effectiveness, and how they are made equitably available to the specific patient population, is a challenge that needs to be overcome to make sure that men with advanced prostate cancer in Northern Ireland are able to benefit from these new treatments. Northern Ireland could either form links with Genomics England or forge a new and innovative mechanism to make these tests available. We also recommend that men identified with a somatic BRCA mutation (where the mutation is identified in the tumor) are germline tested. Families of men who receive a positive germline test should be able to access genetic counselling and make an informed choice about undertaking genetic testing, with regular PSA testing available to any men identified with a germline BRCA mutation.

**Prostate Cancer UK advises that systems are in place to commission diagnostic testing for personalised cancer treatments. Additionally, provide genetic counselling and germline genomic testing for the family members of those with identified genomic mutations.**

## 3. Support

With an ageing population, more men diagnosed with prostate cancer and better treatment, there will be more men living with and beyond prostate cancer who require support. This includes men who have received curative treatment and may be suffering the consequences of that treatment along with needing to be monitored for cancer recurrence. It also includes men with advanced prostate cancer, for whom there is no curative treatment available. These men need support with the symptoms of advanced prostate cancer and the side-effects of their treatment.

### 3.1 Supported Self-Management

Problems with the consequences of treatment and the risk of prostate cancer recurrence mean that men will need to continue to be monitored after radical curative treatment. The most effective, and cost-effective, way to do this is through Supported Self-Management.

This is a digital system developed by Movember and Prostate Cancer UK that enables remote monitoring. Eligible men are empowered to detail their PSA test results, side-effects and symptoms through the system, and can be triaged according to the support needs they self-identify. To be effective, men need to be supported to complete regular holistic needs assessments (HNA) that include consideration of side-effects specific to prostate cancer, including fatigue and erectile dysfunction. It also enables them to be referred to secondary care should PSA results indicate recurrence.

Supported Self-Management has been successfully rolled out in various locations around the UK and Prostate Cancer UK can support its roll-out in Northern Ireland.

**Prostate Cancer UK recommends the roll out of Supported Self-Management and follow-up care in Northern Ireland.**

## 3.2 Post radical treatment

Following radical prostate cancer treatment, the most common side effects are problems with getting or keeping an erection (erectile dysfunction) and leaking urine (urinary incontinence). Up to 85 per cent of men can suffer with erectile dysfunction after radical treatment (20) and incontinence can affect up to 40 per cent of men.<sup>(21)</sup> In Northern Ireland, men 18-42 months after diagnosis also reported significantly more urinary irritation/obstruction, significantly poorer bowel function and reduced vitality/hormone function.<sup>(22)</sup>

NICE Guidelines include recommendations on the services that should be offered to men following radical prostate cancer treatment suffering with erectile dysfunction or urinary incontinence. This includes access to specialist services, medication for erectile dysfunction and access to intraurethral inserts, penile injections, vacuum erection devices and prosthesis if medication fails.

**Prostate Cancer UK would like to see all Health and Social Care Trusts meet NICE guidelines in their support for men experiencing erectile dysfunction or incontinence following radical treatment.**

### 3.4 Advanced prostate cancer

Men with advanced prostate cancer will experience the disease differently depending on where in their bodies the cancer has spread, the extent of that spread, whether the cancer still responds to hormone therapy and which treatments they are taking.

Some of the symptoms that patients experience include fatigue, urinary problems, bowel problems, lymphoedema, anemia and hypercalcemia.

Advanced prostate cancer and hormone therapy can both change the structure of bones leaving them weak. Bisphosphonates are a treatment that can help to avoid the breakdown of bones and so reduce the chance of fractures or breaks due to osteoporosis.

Men with advanced disease can develop metastatic spinal cord compression if the cancer spreads to the spine. This can lead to symptoms including pain, weakness and numbness of the limbs, or loss of bladder and bowel control. Radiotherapy and surgery are options that can be considered to help treat metastatic spinal cord compression.

Many of the treatments for advanced prostate cancer also have side-effects that will need to be managed, these can include fatigue and hot flushes.

All of these different symptoms can create a complicated patchwork of different patient needs, which are made more complicated by comorbidities. With an ageing population and a rising population of men diagnosed with prostate cancer, it will be important that adequate support is in place for men with advanced prostate cancer.

**Prostate Cancer UK suggests exploring how men with advanced prostate cancer can be supported to deal with the symptoms of their cancer and side-effects of their treatment.**

## 4. Workforce

Key to delivering better diagnosis, better treatment and better support for patients is the cancer workforce. In this section we highlight two professions, radiologists and cancer nurse specialists, which we believe require particular attention for adequate staffing levels in the future.

### 4.1 Radiology

Radiologists are fundamental to delivering pre-biopsy prostate MRI. However, Northern Ireland is facing a shortage of radiologists. The Royal College of Radiologists' 2018 census suggested there are 27 unfilled clinical radiologist posts in Northern Ireland, this is an 18 per cent vacancy rate which compares to a UK average vacancy rate of nine per cent.<sup>(23)</sup>

Furthermore, in response to predicted population changes Prostate Cancer UK estimates that by 2030, to deal with prostate MRIs alone, Northern Ireland will require at least an additional 0.2 scanners worth of capacity and require an additional 17 hours of radiologist reporting time per week.

**Prostate Cancer UK recommends measures be put in place to make sure that hospitals in Northern Ireland have the staff and equipment they need to provide prostate cancer diagnosis both now and, in the future.**

### 4.2 Clinical nurse specialists

Clinical nurse specialists (CNS) have a positive impact on patient experience and outcomes. It has been proven that the work of clinical nurse specialists is more cost-effective for the system as it reduces treatment costs and increases the efficiency of care delivery. However, Northern Ireland has the lowest number of CNSs per head of population in the UK. Without parity in numbers, this could risk leaving patients with poor experience and outcomes.

The Macmillan census in 2014 suggests the specialist adult cancer nursing workforce in Northern Ireland makes up one per cent for prostate cancer which equals one nurse practitioner for the entire population. For all uro-oncology cancers, including prostate cancer, the number is seven per cent which compares poorly with breast cancer (34 per cent).<sup>(24)</sup>

The census also showed that except for the one cancer specialist nurse in Belfast, no Trust has any prostate cancer specific CNSs. The Northern Ireland Cancer Patient Experience Survey from 2015 showed significant variation in the proportion of patients saying they had access to a nurse specialist. For prostate cancer, it was only 70 per cent, compared to 94 per cent in breast cancer. Furthermore, 30 per cent of the total specialist cancer nurses are over the age of 50.<sup>(24)</sup>

**Prostate Cancer UK advises an assessment of clinical nurse specialists capacity across Northern Ireland to make sure workforce numbers are sufficient to provide support throughout the cancer pathway.**



**As a Clinical Nurse Specialist I'm in a unique position to provide men with prostate cancer with the specific individual support that they need. Unfortunately, the number of men being diagnosed with prostate cancer is increasing, but the number of Clinical Nurse Specialists isn't. In Northern Ireland our service operation is reliant upon every member of our team. Succession planning is essential to make sure the service can continue.**

Samantha Thompson, Clinical Nurse Specialist

## 5. Data collection and monitoring

Effective data collection is an important tool in assessing performance and identifying potential issues and priorities. The more we know about the impact of cancer on our health services and our communities, the better we can plan those services and make improvements to better meet patient needs.

At present, the Northern Ireland Cancer Registry (NICR) collates key data for a number of cancer sites, including prostate cancer. This is a valuable function. As part of any review of cancer services, a review of current data collection should be considered to determine the scope for expanding data collection around cancer performance in Northern Ireland.

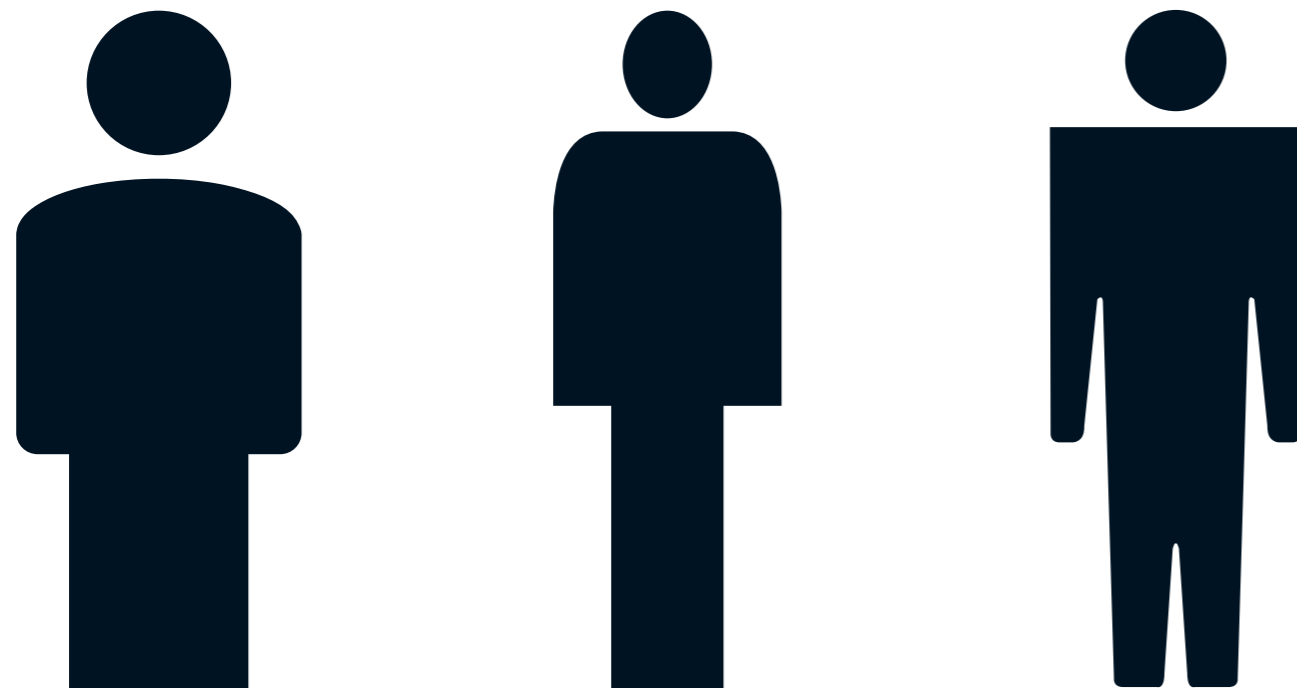
**Prostate Cancer UK believes it would be helpful to consider how data collection can be expanded to provide information to drive improvements in cancer service delivery.**



## In summary

**With prostate cancer expected to rise over the coming years and be the most commonly diagnosed cancer by 2030 – we need to act now. There have been a number of changes to prostate cancer care in Northern Ireland in recent years. By continuing to work together we can make change happen in the areas highlighted in this report, so that we continue to improve the prostate cancer care men receive.**

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