THE RICH PICTURE

PEOPLE WITH PROSTATE CANCER

WE ARE MACMILLAN. CANCER SUPPORT

Simon, 46, living with prostate cancer

Understanding the numbers, needs and experiences of people affected by cancer

About this ‘Rich Picture’

This document is a collation of the key available evidence about the numbers, needs and experiences of people affected by cancer.

Our aim is that the insight within this document will summarise the numbers, needs and experiences of people affected by cancer for Macmillan staff, cancer care professionals, volunteers and other interested parties. It includes data specific to the particular group who are the focus of this Rich Picture, as well as more generic information about all people affected by cancer where specific data are not available or where the information applies to all groups of people with cancer.

The Rich Picture is intended to be accessible to both clinical and non-clinical cancer support staff. Therefore the language and facts included are intended to cater for information needs of both groups. We have included references to other documents to help with interpretation of some facts included, and a Jargon Buster of some technical terms is included in Appendix A.

The information could be valuable in many ways:

- Adding weight and evidence to negotiations with partners and commissioners
- Providing evidence to support campaigning
- Enabling more effective marketing
- Inspiring and engaging supporters to give and do more
- Providing some insight into the lives of people with cancer

This document is not intended to

- Be a comprehensive collation of all evidence on the group affected by cancer who are the focus of this Rich Picture
- Suggest or recommend that specific action should be taken

For simplicity, the year to which the data in this document relate and the sample size is not always shown in the main sections, however this is shown in the original data linked from the references section.

If you are short on time, a quick read of the summary on pages 2 and 3 will give you a brief outline of the rest of the content of this comprehensive document.

This ‘Rich Picture’ is one of a suite of documents. To access these documents please visit http://www.macmillan.org.uk/Richpictures or for further information please contact evidence@macmillan.org.uk

The legal bit

The information contained in this document is a summary of selected relevant research articles, papers, NHS data, statistics and Macmillan-funded research.

This document intends to summarise in a broad sense the numbers, needs and experiences of people with cancer, it is not an exhaustive systematic review that follows strict scientific community rules governing such types of review. However we have compiled the information using broad quality assessment criteria to ensure that the information presented in this document is largely representative and unbiased. It is worth noting that people with cancer have a very wide range of experiences; therefore the information presented here may not reflect the experiences or profile of everyone within the category presented.

Macmillan or any other organisation referenced in this document claim no responsibility for how third parties use the information contained in this document. We have endeavoured to include all the major data available to us as of July 2014, but a document of this nature (essentially a summary of a large body of evidence) inevitably goes out of date. Macmillan has sought external validation of this document from clinical experts and we aim to regularly update the content of this document.

There may be data that have been released that does not appear in this document and Macmillan is under no obligation to include any particular data source. Any medical information referred to in this document is given for information purposes only and it is not intended to constitute professional advice for medical diagnosis or treatment. Readers are strongly advised to consult with an appropriate professional for specific advice tailored to your situation.

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Guidance on referencing this document

You are free to use any of the data contained in this document, however when quoting any factual data that do not belong to Macmillan, it is best practice to make reference to the original source – the original sources can be found in the References section at the back of this document on page 58.

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklets more helpful:

Understanding early (localised) prostate cancer
MAC11639

Understanding locally advanced prostate cancer
MAC11685

Understanding advanced (metastatic) prostate cancer
MAC11686

All these titles are available in hard-copy by calling our Macmillan Support Line free on **0808 808 00 00** (Monday to Friday, 9am–8pm), or by ordering online at **www.be.macmillan.org.uk**.

A wealth of other resources are also available, all produced by Macmillan Cancer Support and available free of charge.

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

Macmillan staff may also wish to use this Rich Picture document in combination with other connected documents, such as the Impact Briefs or the Macmillan Communications Platform. You may wish to select evidence from more than one source to build a case for support, add weight to your influencing, or to engage and inspire Macmillan's supporters. A range of evidence that may be helpful to you is summarised here. Please note that any hyperlinks active below may not work for non-Macmillan staff.

Case Study Library

People affected by cancer
Contains stories and quotes from real-life examples of people affected by cancer who have been helped by Macmillan.

Professionals/Services
Contains specific examples of our services across the UK, and the impact they are having.

Comms Platform
Describes how to communicate with people affected by cancer.

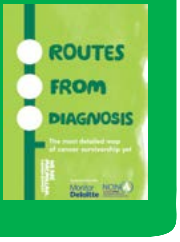

Summary of key issues on the cancer journey

Rich Pictures
Describe the numbers, needs and experiences of key groups within the 2.5 million people with cancer.

Impact Briefs
Generically describe what our services do, and the impact they have on people affected by cancer.

Local Cancer Intelligence
A local overview of the essential data on the changing burden of cancer in your area, including prevalence, survival, patient experience and comparisons across clinical commissioning groups.

Routes from Diagnosis
Results from the first phase of the Routes from Diagnosis study, including outcome pathways, survival rates, inpatient costs and morbidities associated with breast, lung, prostate and brain cancers.



For further information about any of the above, please contact a member of **Macmillan's Evidence Department**, or contact **evidence@macmillan.org.uk**.

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SUMMARY OF PEOPLE LIVING WITH PROSTATE CANCER

Key stats

Prostate cancer is the **most common cancer in men.** A quarter of all new cases of cancer diagnosed in men are prostate cancers, with **119 men diagnosed every day** in the UK.(6,7,8,9)

Prostate cancer is the second most common cause of cancer death in men in the UK, and around **30 men die every day** from prostate cancer.(10,11,12)

Three-quarters of prostate cancer cases are diagnosed in men aged **over 65 years.**(53)

Survival rates for prostate cancer have been improving over the last 30 years, and now **80% of men in England live for more than five years** after their prostate cancer diagnosis.(2)

Prostate cancer is the most common cancer in men.

Diagnosis

The most common symptoms of prostate cancer include, having to **rush to the toilet to pass urine, difficulty in passing urine** and **passing urine more often than usual,** especially at night. (see page 24)

Men with early prostate cancer are **unlikely to have any symptoms**, as these only occur when the cancer is large enough to put pressure on the urethra.(1)

First-degree relatives of men with prostate cancer have a **higher risk** of being diagnosed with prostate cancer than men without a family history.(see page 17)

There is currently **no national screening programme** in the UK for prostate cancer.(see page 24)

Men with relatives who have had prostate cancer have a slightly higher risk of being diagnosed.

Treatment

Treatment options will depend on whether the cancer is contained within the prostate gland (localised), has spread just outside of the prostate (locally advanced) or has spread to other parts of the body (advanced).(40)

10% of prostate cancer patients have a record of a **major surgical resection** as part of their treatment.(39)

26% of prostate cancer patients feel that the **side effects of treatment** are **not explained well**, which is below average for all cancer types.(47)

There is an **under provision of Clinical Nurse Specialists** for men with prostate cancer which means some prostate cancer patients are missing out on valuable information and support.(46)

26% of prostate cancer patients felt that the side effects of treatment were not explained.

Survivorship

People living with prostate cancer have reported feelings of **depression, anxiety, stress, fatigue, and pain** following their initial treatment, and side effects such as **impotence, erectile dysfunction, sexual issues and incontinence.**(63)

43% of men with prostate cancer are **not given enough care** and help from health and social care professionals **once they are at home.**(76)

Prostate cancer patients may suffer a **loss of self confidence**, which may be a particular issue in the period shortly after completion of primary treatment and this loss of self-confidence may be a significant barrier to accessing support.(66)

Many prostate cancer patients **feel abandoned by the healthcare system** once their initial treatment has been completed.(76)

Long term side effects are often not dealt with.

End of Life

Prostate cancer patients who are at end of life report negative symptoms of **pain, drowsiness, fatigue, depression, loss of sleep and anxiety.**(87)

For people with prostate cancer who are at end of life, **palliative care can help alleviate symptoms and side-effects.**(90)

Patients with prostate cancer who receive earlier palliative care have a better quality of life, longer survival and less aggressive care at the end of life compared to those receiving standard care.(4)

According to a 2004 Macmillan report, **54%** of all people with terminal cancer **do not claim the benefits they are entitled to**. This amounts to £126.5m.(92)

54% of all people with terminal cancer do not claim the benefits they are entitled to.

Lifestyle & perceptions

People living with prostate cancer can come from all parts of society. **Prostate cancer is the most common cancer in men and three quarters are diagnosed over the age of 65.**(53)

Active elderly people living in pleasant retirement locations are well-represented amongst people being treated for prostate cancer.(see page 48)

Prostate cancer is a **well-known and highly publicised cancer type** and articles on prostate cancer are often found in UK national newspapers. (see page 56)

Contents

INTRODUCTION TO PROSTATE CANCER

What is prostate cancer?(1)

Prostate cancer is a malignant tumour that occurs in the prostate gland, which is found only in men. The prostate gland is the size of a walnut and surrounds the first part of the urethra which carries urine from the bladder to the penis.

Early cancer of the prostate gland (early prostate cancer) is when the cancer is only in the prostate and has not spread into the surrounding tissues or to other parts of the body. It is also called localised prostate cancer.

Locally advanced prostate cancer is cancer that has spread into the tissues around the prostate gland.

Advanced or metastatic cancer of the prostate gland is when the cancer has spread beyond the prostate gland to other parts of the body.

Want to know more?

Macmillan produces a wealth of information about what prostate cancer is, its causes, symptoms and treatment. Macmillan staff can refer to reference (1) on **page 58** for where you can find this information, or if you're affected by cancer, call our Macmillan team on the number below, or visit our website.

Almost one in two of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way. Call the Macmillan team free on **0808 808 0000** (Monday to Friday, 9am-8pm) or visit **www.macmillan.org.uk**

> ‘I was diagnosed with prostate cancer in 2005… I’d noticed something wasn’t right and went to my GP. Nobody expected it to be cancer as I was so young – only 37 years old, so it was a big shock to everyone. Because of my age, the treatment options available to me were limited and after 14 months of appointments and tests I finally gave in and had keyhole prostatectomy.
>
> I have now been cancer free for 5 years, and face the daily challenge of living with the side effects of treatment. My life has changed utterly, in many unexpected ways, but not all bad. I now live a much less stressful and quieter existence, enjoying more those things that matter and make me happy, and letting go of those things that do not.’

Simon, 46

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people with prostate cancer

The estimated total number of people living with cancer in the UK in 2015 is almost 2.5 million. Assuming that all existing trends in incidence and survival continue cancer prevalence is projected to increase to **4 million** in 2030. Particularly large increases are anticipated in the oldest age groups and in the number of long term survivors. By 2040 77% of all cancer survivors will be at least 65 years old and 69% of cancer survivors will be at least 5 years from diagnosis.(58)

Macmillan's ambition is to reach all of these people and help improve the set of **9 Outcomes** you can see opposite. Remember, certain groups will identify more or less strongly with the various Outcomes.

Around 330,000 men were living with prostrate cancer in the UK in 2015.(3)

How is this different for men with prostate cancer?

Macmillan is carrying out work internally to 'baseline' the 9 Outcomes, and we hope to be able to show how the 9 Outcomes vary for different groups. This document will be updated when this work is complete.

The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

I get the treatment and care which are best for my cancer, and my life

Those around me are well supported

I am treated with dignity and respect

I know what I can do to help myself and who else can help me

I can enjoy life

I feel part of a community and I'm inspired to give something back

I want to die well

THE FACTS ON PROSTATE CANCER

This section presents some of the key stats and facts relating to men with prostate cancer. You may benefit from referring to the jargon buster on page 64 for details on some of the terms used in this section.

119

men are diagnosed with prostate cancer every day in the UK(6,7,8,9)

330,000

men were living with prostrate cancer in the UK in 2015(3)

93%

of men in England live for more than one year after their prostate cancer diagnosis(2)

82%

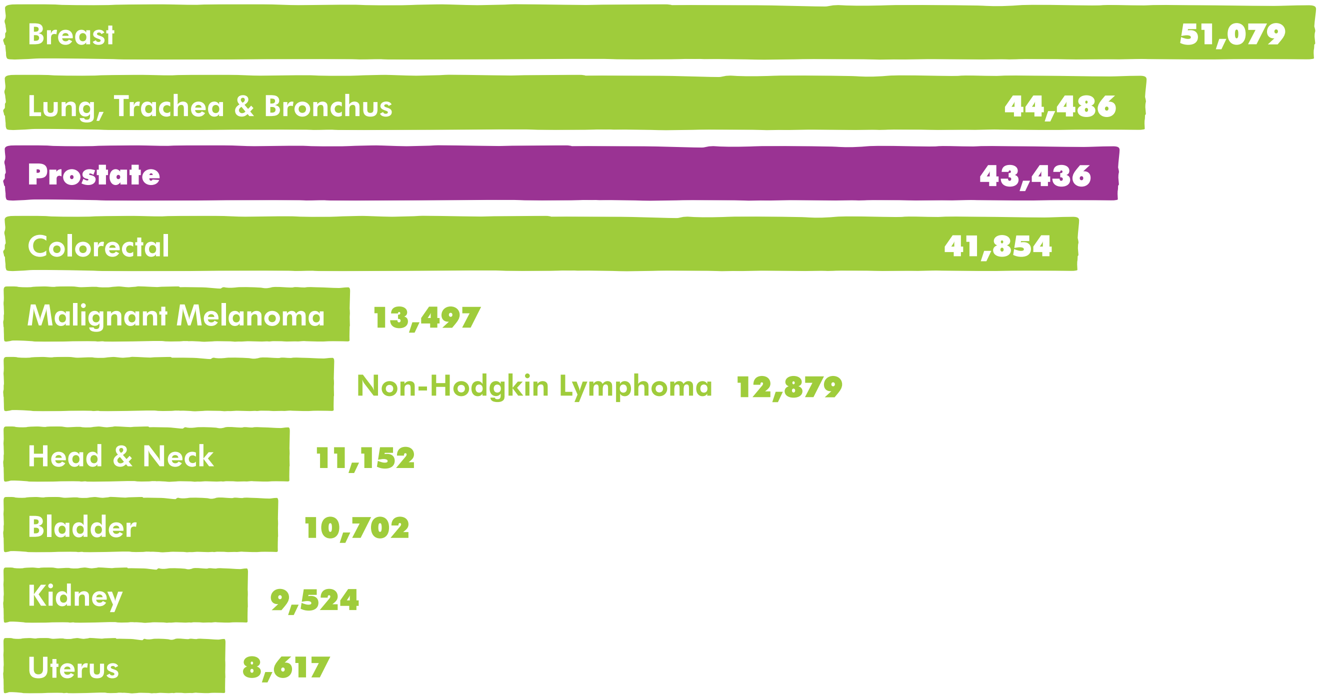
of men in England live for more than five years after their prostate cancer diagnosis(2)

30%

men die every day of prostate cancer in the UK(9,10,11)

How many men get prostate cancer per year (incidence)(6,7,8,9)

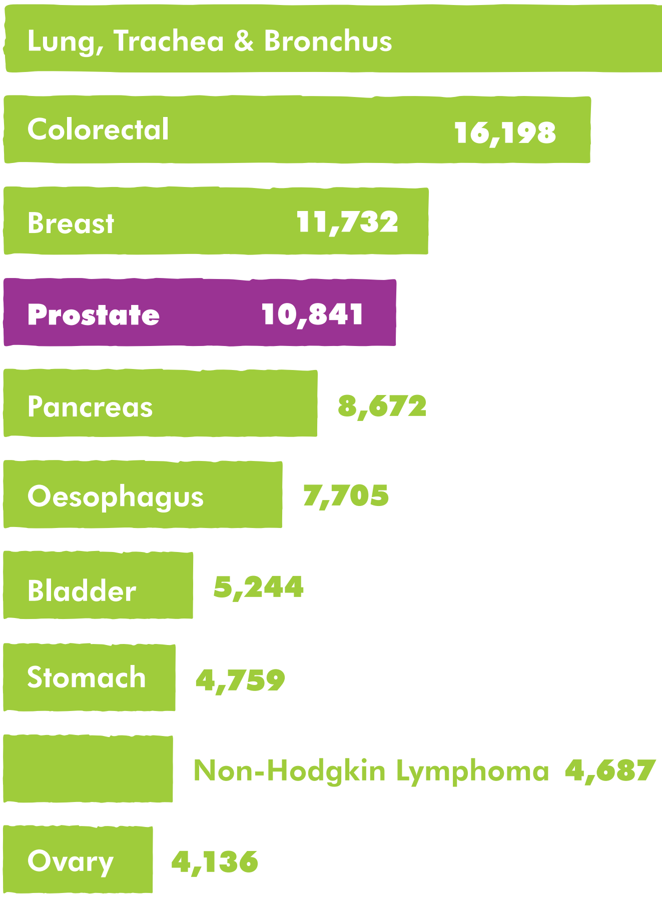
Cancer incidence, UK, 2012, top 10 cancer sites



Prostate cancer is the most common cancer in men in the UK. A quarter of all new cases of cancer diagnosed in men are prostate cancers.

How many men die from prostate cancer per year? (mortality)(10,11,12)

Cancer mortality, UK, 2012, top 10 cancer sites



Prostate cancer is the second most common cause of cancer death in men in the UK, after lung cancer. Around 10,800 men die from prostate cancer each year in the UK, that's around 30 every day.

How many men are currently living with prostate cancer? (prevalence)

Men living with prostrate cancer in the UK in 2015(3)

330,000

Prostate cancer is the most common cancer in men. Survival rates have been improving over the last 30 years, partly due to the detection of a greater proportion of latent, earlier, slow-growing tumours.

What are the key stats for England?

See data on incidence, mortality and prevalence for England

*Age-Standardised Rates are used to eliminate the variation in the age structures of populations to allow for fairer comparisons between incidence and mortality rates in different areas (in this case in the four different UK nations). The Age-Standardised Rate is a rate that has been weighted using a standard population (in this case the European Standard Population) to control for differences in populations. Age-Standardised incidence and mortality rates have been expressed here as rates per 100,000 head of population.

How many men get prostate cancer per year in England? (incidence)(6)

37,136

new cases of prostate cancer diagnoses in England in 2012.

How many men die from prostate cancer per year in England? (mortality)(10)

9,142

prostate cancer deaths in England in 2012.

How many men are living with prostate cancer in England? (prevalence)(2)

Around 280,000

men were living with prostrate cancer in England in 2015

What is the age-standardised* rate of incidence of prostate cancer in men in England?(13)

107

new cases of prostate cancer diagnoses in England in 2011 per 100,000 heads of population

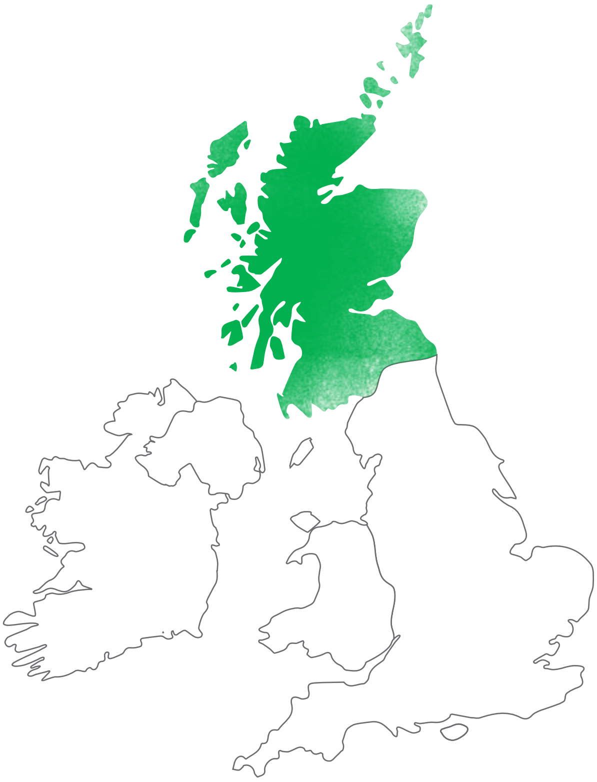
What is the age-standardised* rate of mortality from prostate cancer in men in England?(5)

24

cases of prostate cancer deaths in England in 2011 per 100,000 heads of population

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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How many men get prostate cancer per year in Scotland? (incidence)(7)

2,857

new cases of prostate cancer diagnoses in Scotland in 2012.

How many men die from prostate cancer per year in Scotland? (mortality)(11)

881

prostate cancer deaths in Scotland in 2012.

How many men are living with prostate cancer in Scotland? (prevalence)(12)

Around 25,000

men were living with prostrate cancer in Scotland in 2015.

What is the age-standardised* rate of incidence of prostate cancer in men in Scotland?(13)

82

new cases of prostate cancer diagnoses in Scotland in 2011 per 100,000 heads of population

What is the age-standardised* rate of mortality from prostate cancer in men in Scotland?(5)

25

cases of prostate cancer deaths in Scotland in 2011 per 100,000 heads of population

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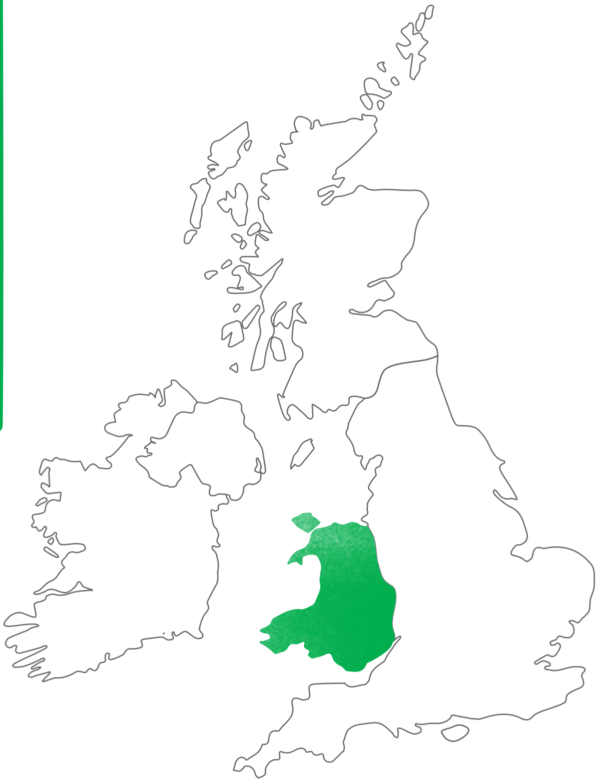
What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



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How many men get prostate cancer per year in Wales? (incidence)(8)

2,419

new cases of prostate cancer diagnoses in Wales in 2012.

How many men die from prostate cancer per year in Wales? (mortality)(10)

556

prostate cancer deaths in Wales in 2012.

How many men are living with prostate cancer in Wales? (prevalence)(12)

Around 17,000

men were living with prostrate cancer in Wales in 2015

What is the age-standardised* rate of incidence of prostate cancer in men in Wales?(13)

107

new cases of prostate cancer diagnoses in Wales in 2011 per 100,000 heads of population

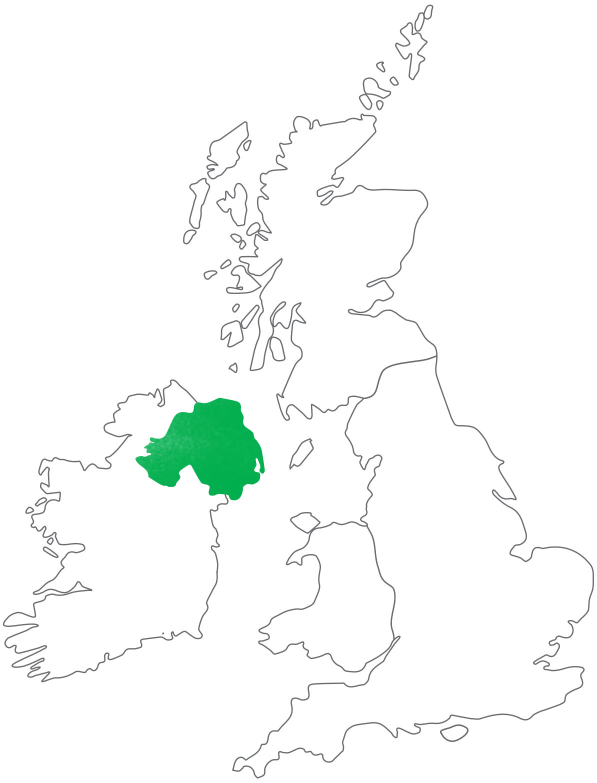
What is the age-standardised* rate of mortality from prostate cancer in men in Wales?(5)

22

cases of prostate cancer deaths in Wales in 2011 per 100,000 heads of population

What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



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How many men get prostate cancer per year in Northern Ireland? (incidence)(9)

1,024

new cases of prostate cancer diagnoses in Northern Ireland in 2012.

How many men die from prostate cancer per year in Northern Ireland? (mortality)(9)

262

prostate cancer deaths in Northern Ireland in 2012.

How many men are living with prostate cancer in Northern Ireland? (prevalence)(12)

Around 7,000

men were living with prostrate cancer in Northern Ireland in 2015

What is the age-standardised* rate of incidence of prostate cancer in men in Northern Ireland?(13)

101

new cases of prostate cancer diagnoses in Northern Ireland in 2011 per 100,000 heads of population

What is the age-standardised* rate of mortality from prostate cancer in men in Northern Ireland?(5)

22

cases of prostate cancer deaths in Northern Ireland in 2011 per 100,000 heads of population

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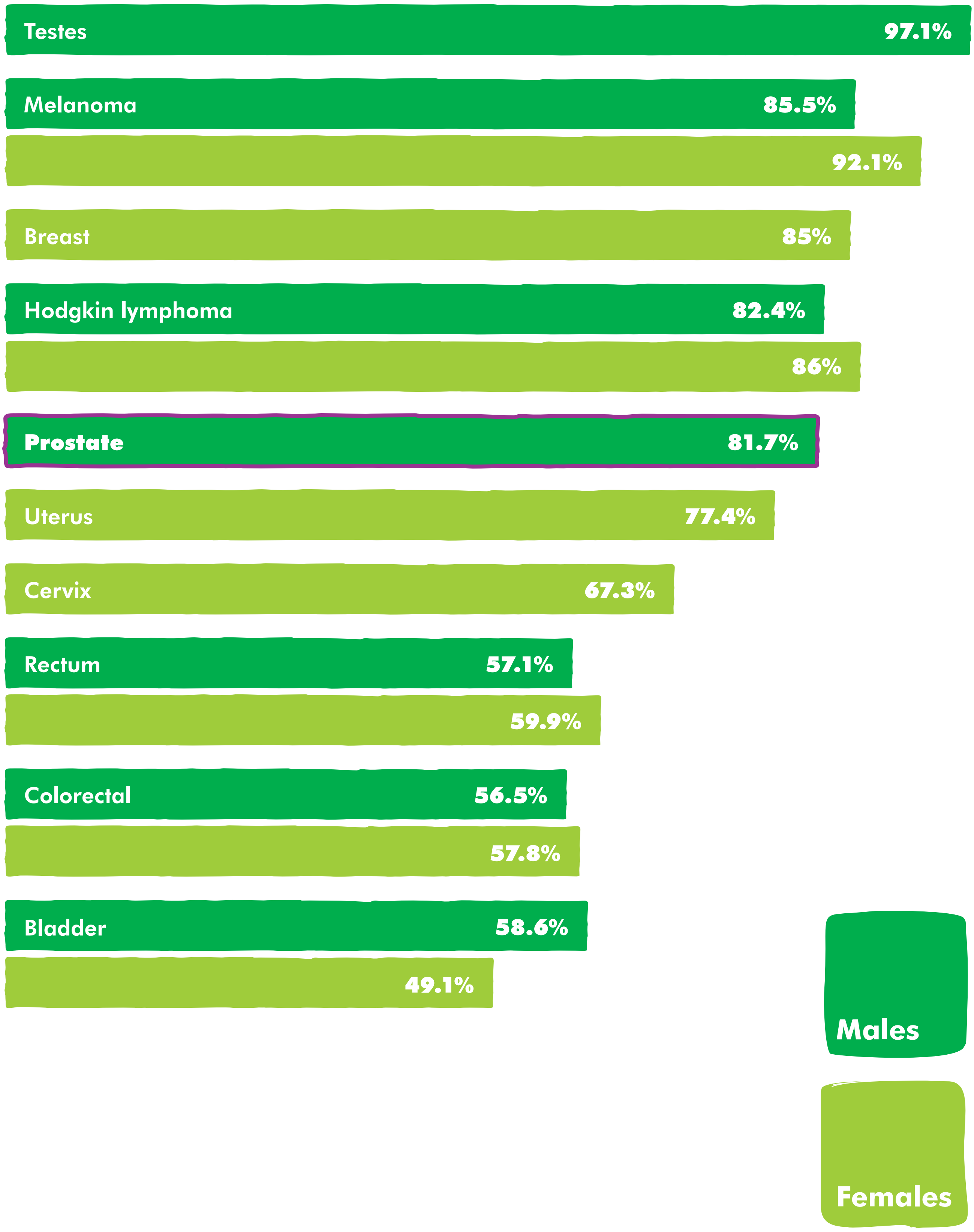
What proportion of men survive prostate cancer? (survival)(2)

Relative 5 year survival estimates, 2007-2011, by gender, England.

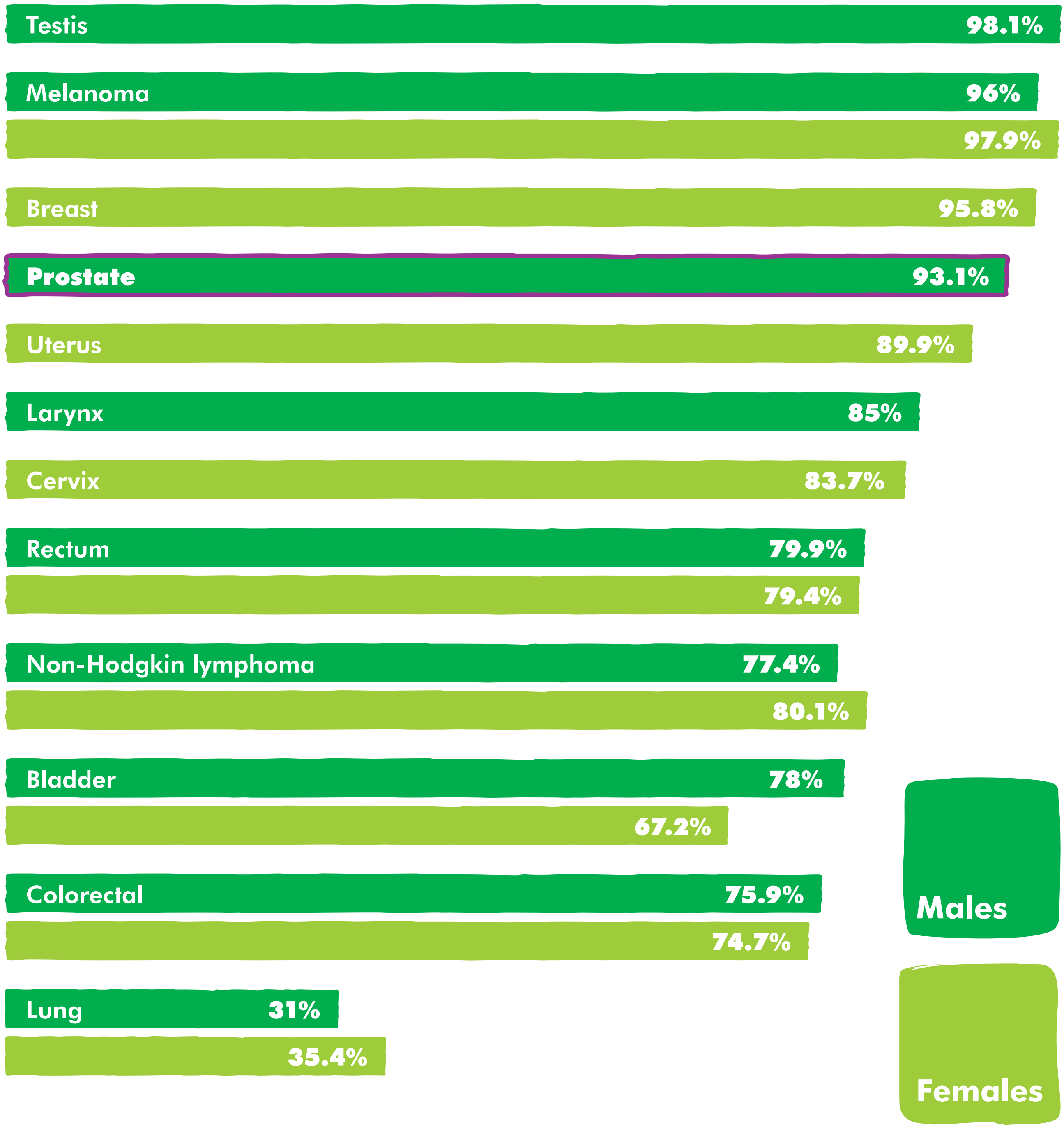


Prostate cancer has one of the highest 5 year survival rates of all cancers for men (81.7% of men are alive 5 years after their diagnosis).

This puts prostate cancer at number 5 out of 22 in the rankings of 5 year survival.

How many men live beyond one year of their prostate cancer diagnosis?(14)

Relative 1 year survival estimates, 2007-2011, by gender, England



An estimated 93.1% of men are alive one year after their prostate cancer diagnosis.(2)

What is the median prostate cancer survival time since diagnosis?

Overall median survival time 40 years ago for all cancers was one year. These latest figures predict median survival time is now nearly six years. High prostate cancer survival rates are due, in part, to the detection of a greater proportion of latent, earlier, slow-growing tumours via transurethral resection of the prostate (TURP), and Prostate Specific Antigen (PSA) testing.(13) However due to the introduction of PSA testing and subsequent increase in incidence of low stage tumours trends in median survival times for prostate cancer cannot be accurately measured.(15)

How do UK survival rates compare internationally?

Cancer survival rates in the UK are improving overall, but international comparisons show that the UK still has worse cancer survival rates than many countries, including Canada, Australia, Sweden and Norway.(25)

Before PSA testing became widespread in the late 1980s, the average 5-year survival rate in England and Wales was just over 40%, well below the European average of 56%. Survival rates were markedly higher in the USA though, at 86%.(16)

What are the major demographic variations in incidence, mortality, prevalence and survival for prostate cancer?

Age

Age is the strongest risk factor for developing prostate cancer. Prostate cancer generally affects men over 50, and is rarely found in younger men.

Approximately one half of all men in their fifties have some cancer cells within their prostate and 8 out of 10 men (80%) over the age of 80 have a small area of prostate cancer. Most of these cancers grow extremely slowly and so, particularly in elderly men, may never cause any problems.(1)

Family history

A small number of prostate cancers (5-10% of cases) are thought to be due to an inherited faulty gene in the family.

A specific gene linked to prostate cancer has not yet been identified but men who have close relatives (a father, brother, grandfather or uncle) who have had prostate cancer are slightly more likely to develop it themselves. It is thought that a man's risk of developing prostate cancer is more likely if:

- their father or brother developed prostate cancer at or under the age of 60
- more than one man on the same side of the family has had prostate cancer.

If several women in a family have had breast cancer (especially before the age of 40), it could also indicate that a faulty gene may be present. This gene may increase the risk of men in the family getting prostate cancer.(1)

Ethnic background

Some ethnic groups have a higher chance of developing prostate cancer than others. In the UK, Black Caribbean and Black African men are approximately two to three times more likely to be diagnosed or die from prostate cancer than White men. Asian men generally have a lower risk than the national average.(17)

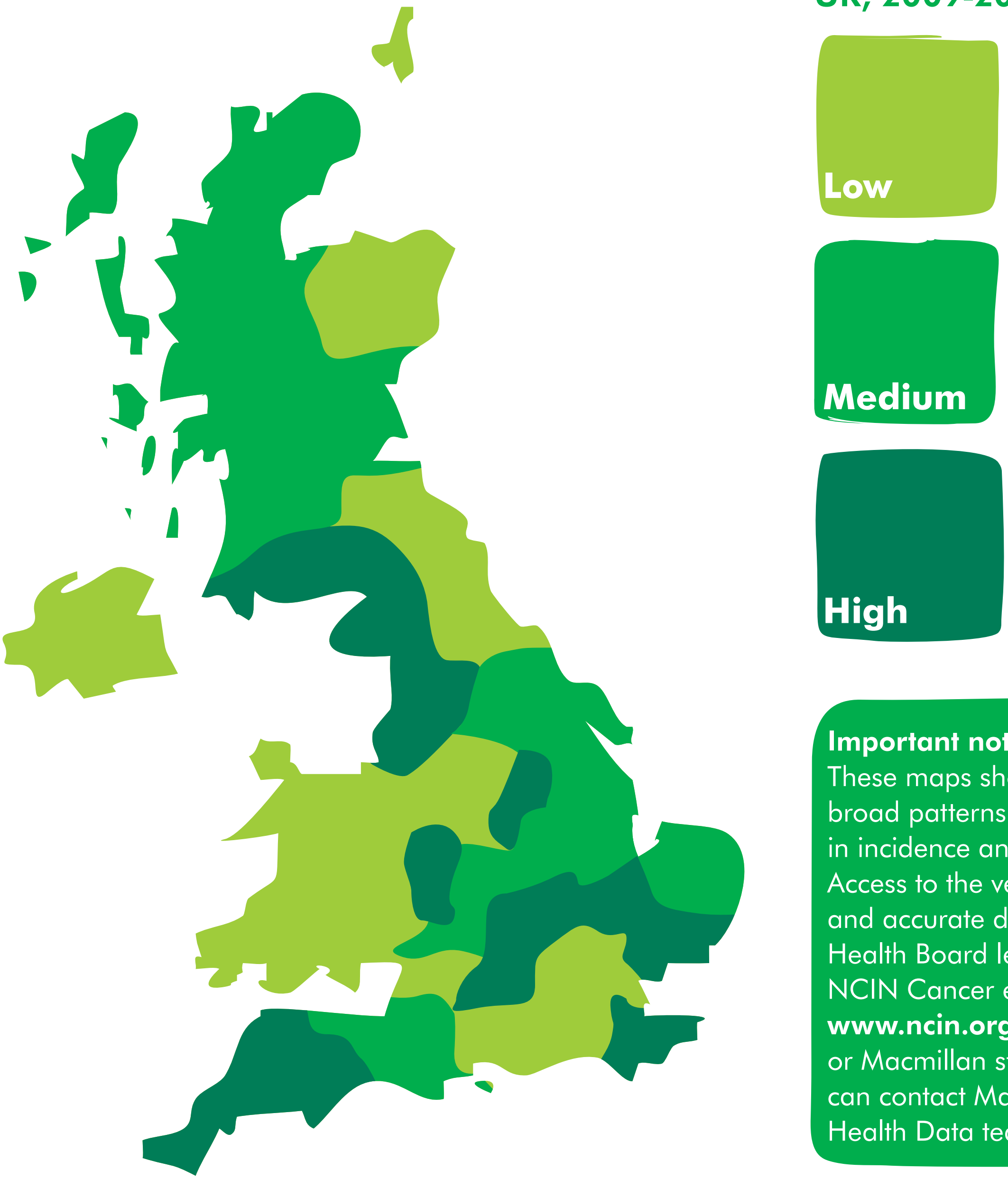
What are the geographical 'hotspots' for prostate cancer incidence, mortality and survival?(18)

Prostate cancer incidence UK, 2008-2010

Important note
These maps show only the broad patterns of variation in incidence and mortality. Access to the very detailed and accurate data at the PCT/Health Board level is via the NCIN Cancer e-atlas website, **www.ncin.org.uk/eatlas**, or Macmillan staff members can contact Macmillan's Health Data team.

Prostate cancer incidence rates are higher in Wales and parts of Southern England, and lower in Scotland, Northern Ireland and the North. It is possible this is linked to variations in use of PSA testing.

Prostate cancer mortality UK, 2009-2011



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Prostate cancer mortality rates are higher in the South East and Devon, and lower in Scotland, Northern Ireland and the North.

Survival
At present there does not appear to be much variation in prostate cancer survival rates according to where men live in the UK.

Trends in the data

What are the major trends? (Incidence/mortality/prevalence or survival)(17)

Prostate cancer is the most common cancer in men in the UK, and generally affects those over 50.

Aside from age, family history and ethnicity are thought to the strongest risk factors for developing prostate cancer.

By 2040 the total number of prostate cancer survivors is projected to have more than trebled to around 830,000 accounting for approximately 2–3% of the male population.(2)

Prostate cancer mortality rates are decreasing:

Prostate cancer mortality rates have decreased by around a fifth since the early 1990s. Between 1990-92 and 2008-2010, age standardised mortality rates decreased by 21% in men aged 45–54 years, 25% in 55–64 year-olds, 29% in 65–74 year-olds, and 25% in 75–84 year-olds. Overall mortality rates have increased by 2% for men aged 85+ in this period. It is thought this could be due to older men being less likely to receive radical treatment.(5)

Survival rates are improving:

Survival rates for prostate cancer have been improving for 30 years. Earlier detection of slow growing tumours via TURP and PSA testing (introduced in the late 1980s) has been linked to the increase in survival rates – by detecting tumours well before they might have been detected without screening. More effective treatment for early, aggressive and advanced prostate cancers is also thought to have contributed to the improvement in survival rates.(4)

> **‘Both my father and uncle had died from prostate cancer and so I asked for a PSA test. I had no other common symptoms of a diseased prostate, other than perhaps more frequent daytime urination.’**
>
> Alistair, 63

Contents

THE CANCER JOURNEY

We know that everyone with cancer has different experiences at different times of their cancer journey. However most people will go through one or more of the four stages of the ‘cancer journey’.

The following pages summarise what we currently know about the needs and experiences of people living with prostate cancer at these stages.

A typical 'cancer journey' showing four key stages:

1 Diagnosis

What happens to me when I'm diagnosed with cancer?

- People often **show signs and symptoms** that may be caused by cancer, and a GP can refer patients for tests to find out more.
- **Screening** aims to detect cancer at an early stage or find changes in cells which could become cancerous if not treated. However screening is not yet available routinely for head and neck cancer.
- However screening can only pick up some cancers, and we know that some people have their cancer **diagnosed at a late stage** – this can have a huge effect on their chances of survival.

2 Treatment

What can I expect when I'm being treated for cancer?

- Cancer can be **treated** in different ways depending on what type of cancer it is, where it is in the body and whether it has spread.
- Different cancer types can have **varying treatment regimes**, and treatment is personalised to each patient.

3 Survivorship*

If I complete my treatment for cancer, what next?

- An increasing number of people **survive** their initial (or subsequent) cancer treatments, and often have **rehabilitation** and **other needs** post-treatment.
- We also know they need support to be able to **self-manage**.
- Many people in this stage experience **long-term or late effects** of their cancer, and/or their cancer treatment.

4 Progressive illness and end of life

If my cancer is incurable, what might I experience?

- Progressive illness includes people with **incurable cancer**, but not those in the last year of life. Many of these people have significant treatment-related illnesses.
- End of life generally means those in the **last year of life**. Needs often get greater as the person moves closer to death.

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*While Survivorship relates to the time both during and post-treatment, as illustrated by the Recovery Package (p39), this section largely highlights the post-treatment needs and experiences of people living with cancer.

NEEDS AND EXPERIENCES

DIAGNOSIS

What are the top 3 signs and symptoms of prostate cancer?

1. Having to rush to the toilet to pass urine
2 Difficulty in passing urine
3. Passing urine more often than usual, especially at night

How good are we at early diagnosis? How aware are people of signs and symptoms? How aware are GPs of signs and symptoms?

Men with early prostate cancer are unlikely to have any symptoms, as these only occur when the cancer is large enough to put pressure on the urethra. In men over 50, the prostate gland often gets larger due to a non cancerous condition known as benign prostatic hyperplasia (BHP).(1)

The symptoms of both benign enlargement of the prostate gland and malignant tumours are similar.(1)

Patients with cancer in the UK tend to present with more advanced disease and have poorer survival rates than many of their European counterparts. The most likely explanations are either late presentation by patients or late onward referral by GPs.(19)

Four out of five men at higher than average risk of prostate cancer are not aware of their risk. In addition, three quarters (75%) of men at greater risk admit that, even if they were aware but didn't have any symptoms, they wouldn't go and speak to their GP about it.(101)

The most commonly endorsed barriers to seeking medical help with potential cancer symptoms are; difficulty making an appointment, worry about wasting the doctor's time and worry about what would be found. Emotional barriers are more prominent in lower socio-economic groups and practical barriers (eg 'too busy') are more prominent in higher socio-economic groups.(19)

How well does screening work for prostate cancer?

There is currently no national screening programme in the UK for prostate cancer.

Prostate specific antigen (PSA) was introduced as a diagnostic test for prostate cancer more than 20 years ago. However, there is continuing debate regarding its utility in diagnosis for prostate cancer. PSA is a protein produced by the prostate and men with prostate cancer tend to have more PSA in their blood, however, PSA levels get higher as men get older.(20)

Mass testing is costly and may result in unnecessary diagnosis and treatment. The evidence of a subsequent reduction in mortality is also inconclusive. Although the evidence is contradictory, PSA is still an important tool for monitoring patient progression following treatment of definitive localized prostate cancer.(20)

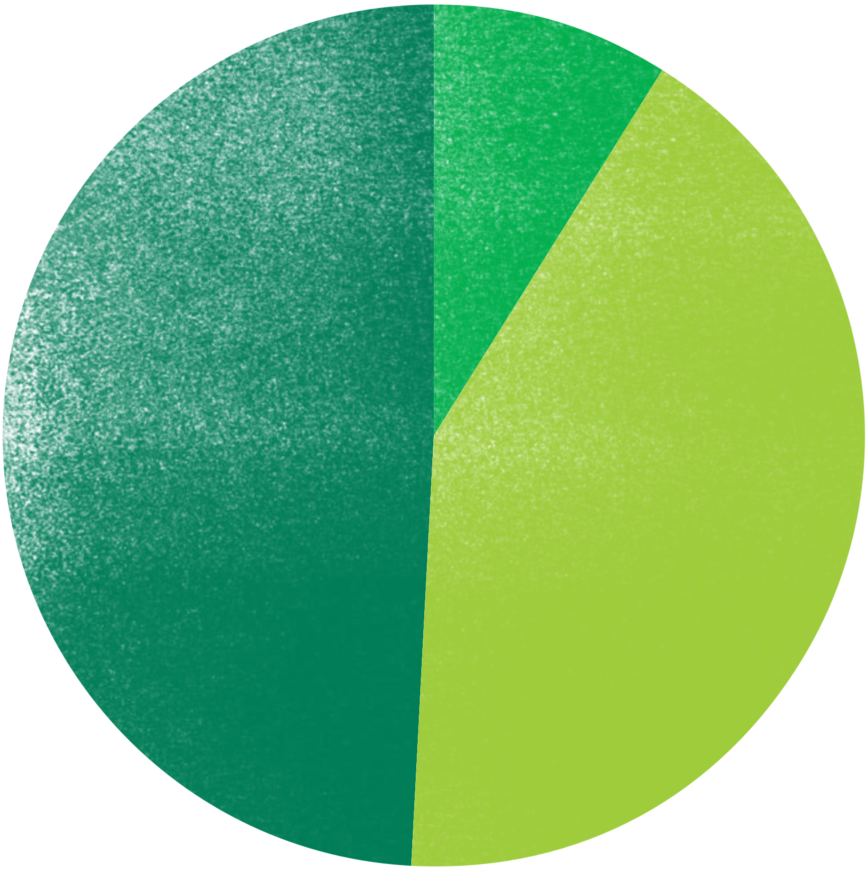
Also, many men diagnosed with prostate cancer have very slow growing cancers that will never cause any symptoms or problems in their lifetime. Unnecessary cancer treatment can cause side effects such as impotence and incontinence that may greatly reduce their quality of life.(21)

Despite there being no national screening programme, there is a Prostate Cancer Risk Management Programme organised by the NHS, whose aim is to ensure that men who are concerned about prostate cancer receive clear and balanced information about the advantages and disadvantages of the PSA test.(22)

‘After moaning to my wife about the need to go to the loo as much as three or four times an hour, and getting up during the night as often, I decided it was time to see the Doctor. I set off on a path that would go on for almost a year.’

Daniel, 62

How is prostate cancer diagnosed? (Routes to diagnosis)(23)



Emergency

9%

GP

42%

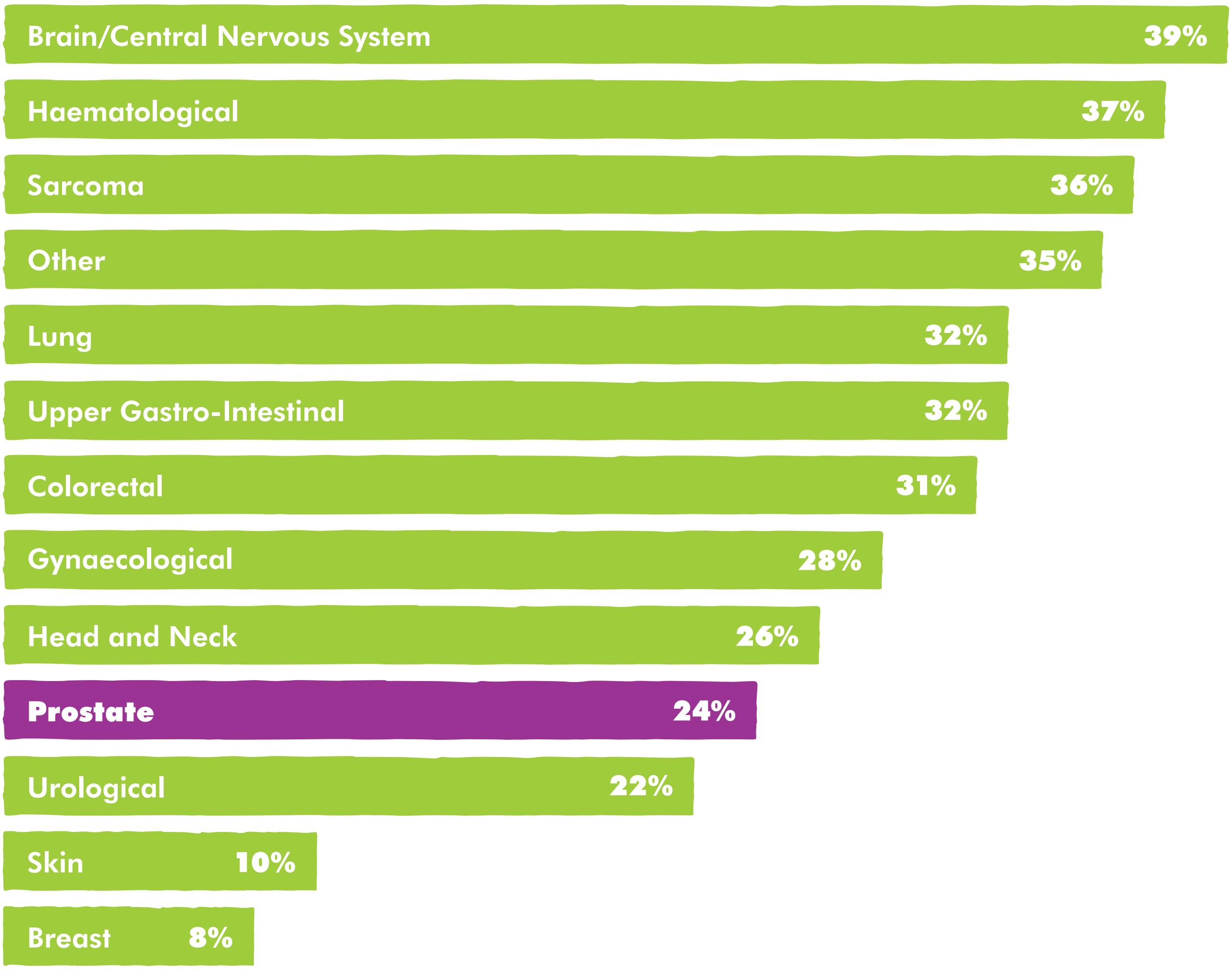
Other

49%

‘Other’ includes screening, 2 week wait GP referrals where there is a suspicion of cancer, in-patient and out-patient routes, ‘death certificate only’ diagnoses, and ‘unknown’ routes.

10% of people newly diagnosed with prostate cancer were diagnosed via the emergency route. This is significantly lowers than the average for all cancers (23%). This is indicative of increased detection of abnormalties through the widespread use of the PSA test.

How many prostate cancer patients had to see their GP more than twice before they were diagnosed?(24)



24% of people newly diagnosed with prostate cancer had to see their GP more than twice before they were diagnosed. Although better than most, there is still significant room for improvement.

How does stage at diagnosis relate to probable survival rates?(25)

The impact of Stage at Diagnosis on Survival – prostate cancer

NB: This data reflects 5 year survival rates.

The later the stage at diagnosis, the poorer the chances of survival – in other words early diagnosis and treatment of prostate cancer saves lives.

How long do people with prostate cancer have to wait to be referred?(26)

According to recent data, 95% of patients with suspected prostate cancer were seen by a specialist within 2 weeks of referral. This is relatively good performance; however patients with suspected breast cancer and lung had a slightly stronger performance.

PHYSICAL AND MEDICAL NEEDS

Not specific to people with prostate cancer

Often at diagnosis men experience few physical or medical needs. Prostate cancer differs from other cancers in the body as small areas of cancer within the prostate are common and may stay dormant for many years. **Approximately half of men in their fifties have some cancer cells** within their prostate. Most of these cancers grow extremely slowly and so, particularly in old men, may never cause any problems.(1)

Diagnosis is sometimes delayed because people are **uncertain about what is 'normal'** and may delay seeking medical advice.(27)

FINANCIAL NEEDS

Not specific to people with prostate cancer

According to a 2013 Macmillan report, **four in five (83%) people are, on average, £570 a month worse off** as a result of a cancer diagnosis.(51)

Reduced income is a major factor of financial hardship It is estimated that 30% of people with cancer **experience a loss of income as a result of their cancer**, with those affected losing, on average £860 a month. Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families.(107)

Amongst households which do suffer a loss of income, **the average drop in income is 50%**. This shows the financial strain that a cancer diagnosis can place on many families.(28)

In a 2013 survey, of the people with prostate cancer who said they wanted it, **only 40% of them were given information on financial help or benefits by hospital staff**, compared to an average (for all cancers) of 54%.(24)

Over two-fifths (42%) of people with cancer did not receive money or debt advice following their diagnosis.(107)

PRACTICAL AND INFORMATION NEEDS

A 2013 survey found that **78% of people with prostate cancer said they received a completely understandable explanation of their test results**. This is comparable to other cancer types. This however suggests that 22% of prostate cancer patients do not receive a completely understandable explanation of their test results.(24)

In the same survey **81% of people with prostate cancer received written information about their cancer**. This was the highest for all cancer types, with the average for all cancer types being 71%.(24)

Not specific to people with prostate cancer

88% of cancer patients said that they were given the right amount of information about their condition and treatment; 10% said they were not given enough and 2% said they were given too much.(24)

Many people affected by cancer (not just people affected by prostate cancer) are **frustrated at being unaware of support until late into their illness** and information on how to deal with emotions, relationships and social situations is the hardest to find.(32)

Information needs at diagnosis are extensive and include side effects of treatments, impact on family and friends, altered body image, self care and risks of family developing the disease.(35)

The strongest preference for information at diagnosis is **information about prognosis**.(35)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Not specific to people with prostate cancer

15% of prostate cancer patients report **feeling lonely, or more lonely than they felt before their diagnosis**.(50)

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, around half of all people with cancer (all cancer types) experience levels of **anxiety and depression** severe enough to adversely affect their quality of life.(36)

58% of people diagnosed with cancer (all cancer types, not just prostate cancer) feel their emotional needs are not adequately looked after. **75% suffer anxiety** and **85%** of these **do not receive any advice or support**.(31)

More than four in ten (45%) people with cancer say that the **emotional aspects** of cancer are the **most difficult to cope with**, as compared to practical and physical effects.(31)

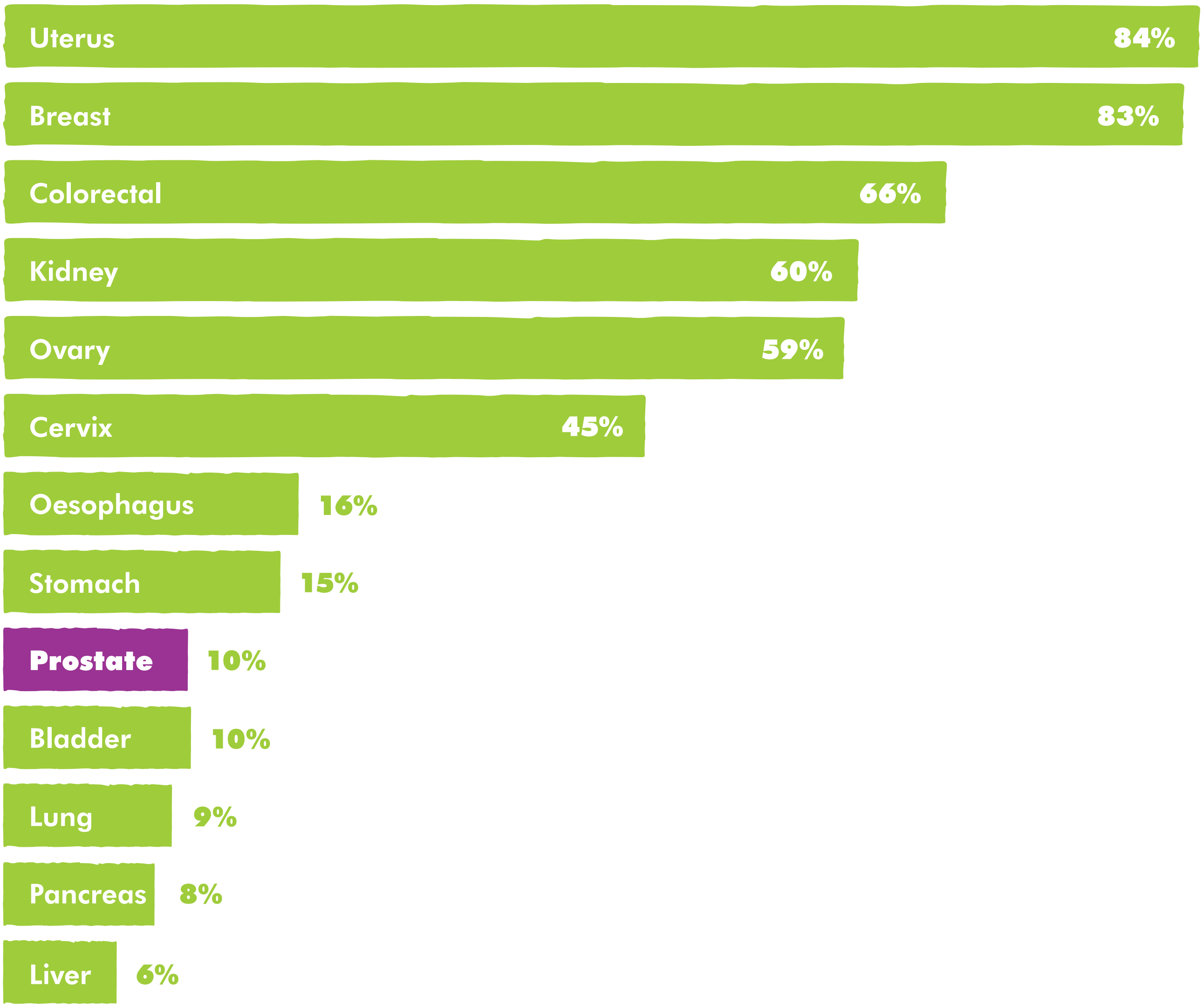
For prostate cancer patients **psychosexual issues are not always addressed at the appropriate time** for the patient. Older patients are often too **embarrassed** to raise psychosexual concerns as they feel they would be considered 'too old' to be worried about the loss of sexual function.(37)

The psychosocial impacts of a cancer diagnosis include **reduced quality of life, poorer inter-personal relationships, hopelessness** and **mental illness**.(38)

NEEDS AND EXPERIENCES

TREATMENT

Percentage of patients who had major surgical resection, 2004-2006 (39)



10% of prostate cancer patients had a record of a major surgical resection as part of their treatment.

What treatments do prostate cancer patients get?(40)

Treatment options depend on whether the cancer is contained within the prostate gland (localised), has spread just outside of the prostate (locally advanced) or has spread to other parts of the body (advanced).

Active surveillance/'Watchful waiting'

Prostate cancer often grows very slowly and may never cause harm within a man's lifetime. Active surveillance is a way of monitoring prostate cancer that is not causing any symptoms or problems, in order to avoid or delay unnecessary treatment in men with less aggressive cancer.

Surgery: radical prostatectomy

Radical prostatectomy is an operation to remove the prostate gland and the cancer contained within it.

Between 2004 and 2006, around 1 in 10 men in received major surgical resection for their prostate cancer.(39)

Radiotherapy

External beam radiotherapy uses high energy X-ray beams to damage the cancer cells and stop them growing.

Men with advanced prostate cancer may have radiotherapy to help relieve symptoms (palliative radiotherapy). Palliative radiotherapy does not get rid of the cancer but it can help to slow down its growth. There are two types of palliative radiotherapy: external beam radiotherapy (EBRT) and internal radiotherapy (radioisotopes).

Permanent seed brachytherapy (low dose rate brachytherapy) is a form of radiotherapy which involves having tiny radioactive seeds implanted into the prostate gland to destroy destroys cancer cells in the prostate.

High dose rate (HDR) brachytherapy, (temporary brachytherapy), involves inserting a source of high-dose radiation into the prostate gland for a few minutes at a time to destroy cancer cells.

Hormone therapy

Hormone therapy helps control prostate cancer by stopping the production of testosterone or stopping testosterone reaching the prostate cancer cells. It is the main treatment for men with advanced prostate cancer.

Abiraterone (Zytiga®) is a new type of hormone therapy for men whose prostate cancer has spread to other parts of the body (advanced prostate cancer) and has stopped responding to other hormone therapy treatments. It is used to help control symptoms and not to cure prostate cancer.

Bisphosphonates

Bisphosphonates are drugs that do not actually treat prostate cancer but relieve pain when prostate cancer has spread to the bones and is no longer responding to hormone therapy.

Chemotherapy

Chemotherapy uses anti-cancer drugs to kill cancer cells. It is used to help control symptoms and not to cure prostate cancer.

Cabazitaxel (Jetvana®) is a new type of chemotherapy treatment for men with advanced prostate cancer that has stopped responding to hormone therapy and the chemotherapy medicine docetaxel (Taxotere®). Cabazitaxel is licensed for use in the UK but is not yet widely available on the NHS.(40)

Cryotherapy

Cryotherapy treats prostate cancer by using freezing and thawing to kill the cancer cells in the prostate gland. Cryotherapy is most commonly an option for men whose prostate cancer has come back after treatment with radiotherapy or brachytherapy.

How many prostate cancer admissions are there and how many prostate cancer patients stay in hospital (and for how long)?

Just over 10% of prostate cancer patients spent up to 10% of their time in hospital.(41)

Contents

Those who are newly diagnosed or near end of life are much more likely to spend time in hospital.(41)

In total, there were over 56,656 admissions to NHS Hospitals in England for prostate cancer during 2012–13.(42)

Around 10% of prostate cancer patients were admitted through the emergency route. This is similar to the average for all cancers.(42)

The median length of stay for prostate cancer patients who were admitted to hospital was 2 days in 2011–2012.(42)

What can a person with prostate cancer expect, therefore, from a typical treatment regime?

If the cancer is contained within the prostate gland then there are treatments available that aim to get rid of the cancer completely, such as surgery to remove the prostate or radiotherapy. If the cancer has spread outside of the prostate gland then treatment is usually aimed at controlling the cancer or managing symptoms.(40)

How many people with prostate cancer have access to a prostate CNS?

There are around 280 prostate cancer clinical nurse specialists (includes data for all Urology cancer patients).(44)

Modelling work by Frontier Economics has indicated that a further 209 prostate CNSs are required to fully meet the demand in England.(45)

What does this mean for patients?

Currently, there is under provision of CNSs for men with prostate cancer compared to some other common cancers, this means some prostate cancer patients are missing out on valuable information and support.(46)

87% of prostate cancer patients were given the name of a CNS, compared to 93% of breast cancer and 91% of lung cancer patients. This is below average for all cancer types (88%).(42)

CNSs provide patients with essential care and support including the provision of comprehensive information, support with making complex treatment decisions, advice on managing side effects, and emotional and psychological support.(46)

A survey on prostate cancer patients experiences of CNSs indicated that patients who saw a specialist nurse had more positive experiences of receiving written information about tests and treatment, and about sources of advice and support, and were more likely to say they made the treatment decision themselves. Two key aspects of the specialist nurse role were seen as important: their availability to the patient, and their ability to liaise between the patient and the medical system.(48)

What other health conditions do people with prostate cancer have? How does this affect their treatment, survival, long term effects or experiences?

Just under half (49%) of all people living with cancer (of all cancer types) have at least one other chronic condition. This includes 15% who have two, and 6% who have three other chronic conditions.(49)

Many of the treatments for prostate cancer have significant side effects that have a long term impact on quality of life. For example the most common side effects of treatment include urinary incontinence, bowel incontinence, erectile dysfunction, loss of sex drive, fatigue, and depression. Side effects such as these have a considerable impact on quality of life and can make decisions about treatments difficult.(46)

Macmillan has produced an 'Impact Brief on Clinical Nurse Specialists'. This is an evidence review, which more fully sets out how our CNSs use their skills and expertise in cancer care to provide technical and emotional support, coordinate care services and to inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes. The paper, along with other Impact briefs, is available via the Macmillan website, at **www.macmillan.org.uk/servicesimpact**

‘Before all this, I didn’t even know what the prostate was. I was plunged into a world of treatment: three months of hormone therapy, five and a half weeks of radiotherapy, a brachytherapy operation, and then a further nine months of hormone treatment.’

James

PHYSICAL AND MEDICAL NEEDS

Not specific to people with prostate cancer

A 2009 report found that experiences of patients with prostate cancer tend to be **less positive** than the other patient groups. They have longer waits for treatment, are more likely to have first appointments postponed or cancelled, and to report that their carers have not been involved or given the right amount of information.(43)

However prostate cancer patients on average have the **greatest choice of treatment (90%)** in comparison to all other cancers.(50)

Around **26%** of men with prostate cancer report some or **extreme pain and 22% report problems with mobility**. Treatment is significantly associated with **both problems**.(78)

A 2013 survey found that 27% of people with prostate cancer thought **GPs and nurses** at their local practice **could have done more** to support them while they were having their treatment.(24)

The same survey found that **confidence in ward nurses** was relatively **high** amongst prostate cancer patients (74%) however, this implies that 26% of patients did not have confidence in the ward nurse who treated them.(24)

FINANCIAL NEEDS

Not specific to people with prostate cancer

Some of the **additional costs** incurred at treatment stage for cancer patients and their carers is **travel** to and from hospital. The average number of trips is 53 at a cost of £325 per trip in 2006 prices.(54)

A recent Macmillan report on the financial burden of cancer, found that costs related directly to treatment, notably **hospital travel/parking** were a **particular burden** to those with long journeys and/or on low incomes.(107)

A 2013 survey found that **27% of prostate cancer patients** who wanted to know were not informed of free prescriptions.(24)

PRACTICAL AND INFORMATION NEEDS

Men with prostate cancer report a **worse experience of NHS** care compared with other cancer patients in terms of level and quality of information provided and support given.(46)

Misunderstandings regarding methods of diagnosis and treatment are widespread, especially amongst ethnic minority groups.(53)

20% of prostate cancer patients **would have preferred** more information on how their treatment had gone compared to 13% of patients with other common cancers.(56)

In a 2013 survey **26%** of prostate cancer patients felt that the **side effects of treatment were not explained** well.(24)

In the same survey **84%** of prostate cancer patients were given **information on support and self help groups**, this is lower than breast cancer patients of which 88% received information on support groups. This shows that prostate cancer patients have fewer options to share their experience with other patients.(24)

16% of prostate cancer patients felt that they were **given conflicting information** regarding their treatment which resulted in **confusion and uncertainty**.(59)

Older men in particular report not understanding how the treatment for prostate cancer will **impact on their quality of life.**(24

EMOTIONAL AND PSYCHOLOGICAL NEEDS

In a 2013 survey **27%** of prostate cancer patients felt they **did not receive adequate emotional support.**(24)

Some men with prostate cancer regret taking the decision to have surgery because of **increased pain and financial difficulty** and **decreased sexual function**. They report feeling less masculine, having less sexual enjoyment, difficulty in getting and maintaining an erection, and discomfort when being sexually intimate after surgery.(62)

Anxiety may exist both before testing and while awaiting test results. **Confusion** over choosing from various interventions often adds to **anxiety and depression** in prostate cancer patients.(63)

The side effects of treatments can also have an emotional impact. Hormone therapy **lowers testosterone levels**, and this can contribute to a **low mood**.(64)

A 2011 report found that African Caribbean prostate cancer patients face specific problems when it comes to communication with professionals, **stereotyping and insensitivity of some staff**. Lack of coordination between services and agencies also adversely affects the well-being of frail men and widowers of men with prostate cancer.(65)

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

Why are cancer survivors (all cancer survivors; not just cervical cancer survivors) not catered for properly by the current system?

The current system for cancer patients after the end of treatment concentrates on medical surveillance, and looking for recurrence. However we know that this does not address people's needs:

- Some feel a sense of abandonment after treatment.(43)
- **39%** who completed treatment in 2009/10 say that **no health or social care professional talked them through the needs they might have.** (37)
- **94%** experience **physical health condition problems** in their first year after treatment. (62)
- **78%** of people with cancer have experienced **at least one physical health condition** in the last 12 months which can occur as a result of cancer or its treatment.(62)
- **62%** of people with cancer have experienced **at least one of the psychological conditions** that can occur as a result of cancer and its treatment.(62)
- **40%** with emotional difficulties had **not sought medical help** or other support. (43)
- **23% lack support from friends and family** during treatment and recovery (67)
- **One in six people (17%)** who were diagnosed with cancer more than 10 years ago have **not been visited at home by a friend or family member for at least six months.** (67)

Cancer survivors have greater health needs than the general population

- **90%** of cancer survivors have visited their GP and **45%** visited a specialist doctor in the last 12 months. This compares with **68%** and **15%** of the wider population.(106)
- In a recent survey, **80%** of gynaecological cancer patients, and 78% of all cancer patients, said that they were not offered a written assessment or care plan. These are essential in providing personalised care for cancer patients and their carers. (3)

Macmillan and NHS England are working to implement personalised support for all cancer survivors

The National Cancer Survivorship Initiative (NCSI) was a partnership between the Department of Health, Macmillan and NHS Improvement. NCSI reports were produced in 2013, including **'Living with and beyond cancer: Taking Action to Improve Outcomes'**, which informs the direction of survivorship work in England, to support commissioners, health service providers and others to take the actions necessary to drive improved survivorship outcomes.

Contents

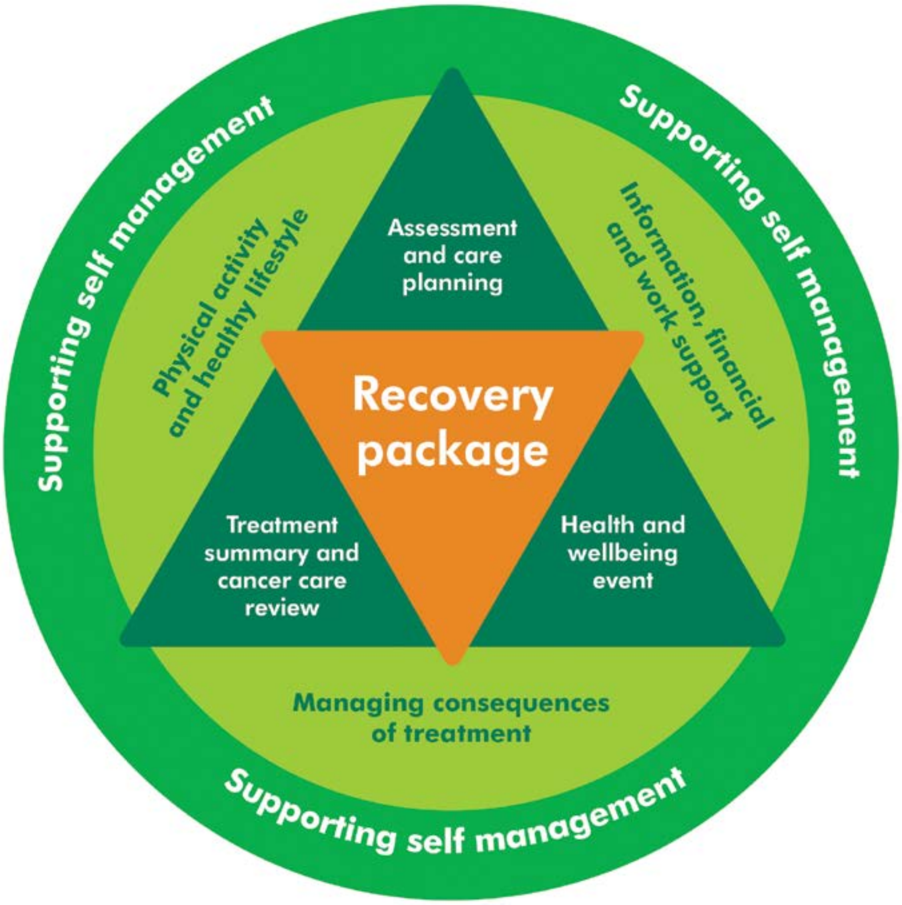
The document was followed by: **'Innovation to implementation: Stratified pathways of care for people living with or beyond cancer: A "how to' guide"'**.

The documents set out what has been learned about survivorship, including interventions that have been tested and are ready to be spread across England, and could make an immediate difference to people affected by cancer. These include:
A key intervention which is the 'Recovery Package' consisting of:

- Structured Holistic Needs Assessment and care planning,
- Treatment Summary to provide good communication to primary care including information about treatment, and the potential short- and long-term consequences.
- Education and support events, such as Health and Wellbeing Clinics, which give patients information about lifestyle choices, signs and symptoms of recurrence, getting back to work, benefits and financial support.
- The Cancer Care Review carried out by the GP six months following a diagnosis of cancer

Further key interventions include:

- Offering appropriate information including information about work support needs onwards referral to specialist vocational rehabilitation services and financial support
- Offering advice on physical activity, weight management and how to access appropriate programmes.



PHYSICAL AND MEDICAL NEEDS

Men living with prostate cancer report high levels of **unmet sexuality-related need. Younger men** with a good prognosis following curative treatment **are more greatly affected**.(78)

Many people living with prostate cancer feel that there is little their GP could do for them as they were too 'generalist' and feel that there is a **lack of continuity of care**.(67)

Older people living with prostate cancer **(over 75 years)** have a **greater hospital use**.(66)

A 2010 report found that men are rarely invited to discuss psychosexual side effects within follow up appointments and lack of rapport with health care professionals make it **difficult to raise problems** themselves.(37)

Not specific to people with prostate cancer

Although people living with cancer (not prostate specific) describe ongoing needs for information and support that could potentially be provided by GPs, they report **little involvement by GPs in their care**. In addition, GPs are perceived by patients as lacking the necessary expertise in cancer management.(66)

A recent survey revealed relatively **poorer health** and **well-being** and relatively **higher use of hospital services** among individuals who had a former cancer diagnosis when compared with individuals who had no cancer diagnosis.(66)

FINANCIAL NEEDS

60% of prostate cancer patients were not given information on financial help or benefits by hospital staff. (110)

Some cancer patients (not just prostate cancer specific patients) do **not know that they can claim benefits**, even at a time when they have completed initial treatment and may feel more able to deal with their financial issues.(69)

Not specific to people with prostate cancer

Some people affected by cancer (not just people affected by prostate cancer) find benefits claim forms complicated. **Benefits advice is also not always offered** in a timely fashion and they are ashamed to seek advice, even those who are seriously ill, and lifetime tax payers feel stigma in claiming financial help.(69)

Although cancer results in substantial increase in sick leave, a substantial number of prostate cancer patients **return to work** within 1 year after the cancer diagnosis.(70)

A 2009 report found that of those who were the main income earners in their households prior to a cancer diagnosis, **(26%) were no longer the main earners after treatment.**(71)

PRACTICAL AND INFORMATION NEEDS

Not specific to people with prostate cancer

Many people feel **abandoned by the healthcare system** once their initial treatment for cancer has been completed. 43% of prostate cancer patients are not given enough care or support once they are at home from health and social care professionals.(76)

The need for information post treatment may not be as great as it was during diagnosis and treatment for some.(72)

However people living with cancer (not prostate cancer specific) would **like to have a more active role in their health care** and to know how to look after themselves after diagnosis, including what diet and lifestyle changes they should make.(73)

For those experiencing a recurrence, only half of those surveyed said that they received supported information, suggesting there is **unmet need at recurrence.**(72)

Many of the men with recurrent disease (not prostate cancer specific) were **dissatisfied with the information** they received about their medical condition and possible side effects.(74) Other areas of complaint are the lack of genetic information and information about lifestyle changes, and help with worries about spread or recurrence.(75)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Psychological distress is currently not being assessed or managed well in men living with prostate cancer, despite just under a third of men reporting **moderate or extreme anxiety or depression**.(78)

Depression, anxiety, stress, fatigue, pain and psychosocial factors can affect patients with prostate cancer. These factors can occur as a result of impotence, erectile dysfunction, sexual issues and incontinence.(63)

Compared to colorectal cancer patients, people living with prostate cancer **are more likely to receive a prescription for an antidepressant**. Those nearing the end of life receive the highest volume of prescriptions.(77)

Prostate cancer patients may also suffer a **loss of self confidence**, which may be a particular issue in the period shortly after completion of primary treatment and this loss of self-confidence may be a significant **barrier to accessing support**.(66)

Not specific to people with prostate cancer

30% of people with cancer report **five or more unmet needs after finishing treatment**. The most frequently reported unet needs are **psychological needs and fear of recurrence**. For **60%** of these patients the situation does not **improve even six months later**.(79)

NEEDS AND EXPERIENCES

PROGRESSIVE ILLNESS AND END OF LIFE

How many prostate cancer patients are at End of Life?

Approximately 10,000 prostate cancer patients are at end of life, and 2,600 are within one year of diagnosis.(80)

What health data do we have on prostate cancer patients with progressive illness?

It is estimated that around 1 in 220 new cancer diagnoses in the UK are associated with radiotherapy for a previous cancer.(81)

It is estimated that around 5% of these radiotherapy related second cancers follow a prostate cancer diagnosis.(81)

What is the impact of giving patients palliative care? Where do people with cancer die?

Palliative care provision for cancer patients can improve quality of life and reduce health care costs. As cancer is detected earlier and its treatments improve, palliative care is increasingly playing a vital role in the oncology population. Palliative care entails an expert and active assessment, evaluation and treatment of the physical, psychological, social and spiritual needs of patients and families with serious illnesses. It provides an added layer of support to the patient's regular medical care.(82)

A recent study found that home, hospital, and inpatient specialist palliative care significantly improved patient outcomes in the domains of pain and symptom control, anxiety, and reduced hospital admissions.(29)

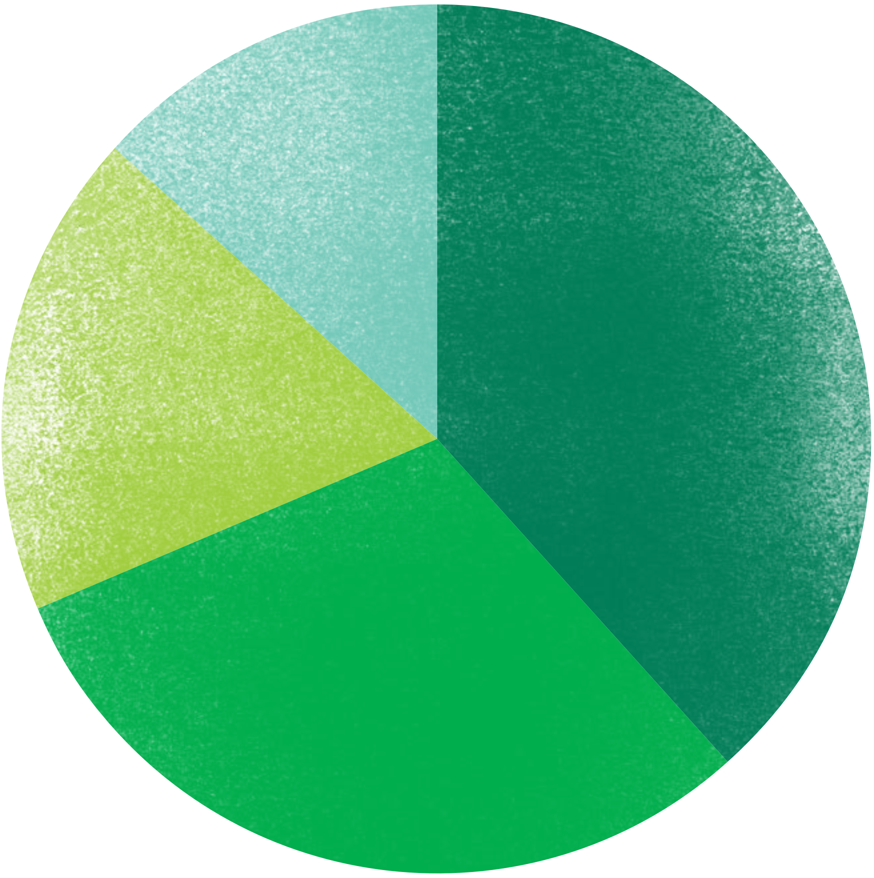
The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life-threatening condition: Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Where do people with cancer die?(83)

Data on place of death is not available broken down by cancer type. However for all cancers, we know that cancer deaths in England & Wales account for 90% of all deaths in hospices, 39% of all deaths at home, 23% of all deaths in hospital, 18% of all deaths occur in care homes, 19% of all deaths in communal establishments and 23% of all deaths elsewhere.

For further information, visit the National Council for Palliative Care website, **www.ncpc.org.uk**

Where did people with cancer die in 2011?* (83)



Hospital
38%

Home (own residence)
30%

Hospice
18%

Care and nursing home
13%

* Does not add up to 100% due to rounding.

To what extent do prostate cancer patients die in the place of choice?

A recent survey found that 73% of people who died from cancer would have liked to have spent the last weeks and days of their life at home.(34) However, only 30% of those who die from cancer actually die at their home or own residence.(33)

In terms of dying in the place of choice, only around one in five people (or fewer in many local authorities) are supported to die in their own home. If these trends are to continue over 500,000 people in England will die in a place other than their own home by 2015, suggesting that more needs to be done to ensure that people's wishes about where they want to die are met.(85)

‘I keep wondering what will happen to me when I’m left behind, what’s going to happen to me? But we are doing as much as we can together to enjoy our time while he is still here.’

Marilyn, 67, wife of Phillip
living with prostate cancer.

PHYSICAL AND MEDICAL NEEDS

Metastatic prostate cancer is incurable, and the disease and other co-morbidities, as well as side effects from treatments, can be very **disabling** for patients, particularly the elderly.(86)

Advanced prostate cancer patients report negative symptoms of **pain, drowsiness, fatigue, depression, loss of sleep and anxiety**.(87)

A recent study found that **53% of men with prostate cancer at the end of life used a hospice** for a median of 24 days. Hospice care has been found to **improve symptom management**, quality of death and quality of life. Men who enrolled in a hospice are also less likely to receive high-intensity care, including intensive care unit admissions, inpatient stays, and multiple emergency department visits.(88)

Not specific to people with prostate cancer

More than **one-quarter** of patients with cancer (not prostate specific) experience **serious pain 3 to 6 months before death** and more than 40% were in serious pain during their last 3 days of life.(91)

Various symptoms are very common in advanced cancer (not prostate specific), with patients having a median of **11 symptoms** on admission to palliative care.(90)

Pain relief is not dealt with very effectively at home. 37% of cancer carers felt that **pain was only partially relieved in the last three months of their loved ones lives** whilst at home.(83)

FINANCIAL NEEDS

Not specific to people with prostate cancer

According to a 2004 Macmillan report, **54%** of all people with terminal cancer (not specifically prostate cancer) did **not claim the benefits they were entitled to.** This amounts to £126.5m.(92)

A recent study found that advanced stage at diagnosis, being older at diagnosis, and higher comorbidity were associated with **increased costs**. The financial burden is also highest around two events, cancer diagnosis and death.(93)

PRACTICAL AND INFORMATION NEEDS

Men with prostate cancer have distinct information needs and information-seeking behaviours throughout their cancer journey, and the **partners** of men with prostate cancer also have needs for information, yet these **needs are often unmet.**(94)

Not specific to people with prostate cancer

A recent study into advanced cancer (not prostate specific) found that patients identified the greatest areas of need in relation to psychological and medical communication/information domains. Patients' specific needs were highest in dealing with a **lack of energy and tiredness**, coping with **fears** about the cancer spreading, and coping with **frustration** at not being able to do the things they used to do.(95)

Those who are older, male, from ethnic minorities, not married, lacking in home care or socio-economically disadvantaged are all less likely to access **community palliative care services.**(96)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Not specific to people with prostate cancer

Amongst all cancer patients (not prostate specific) the overall prevalence of **psychological distress** is 25% among those who are undergoing, or have just finished, cancer treatment. This rises to 59% amongst those receiving palliative care.(97)

A study of men with progressive illness highlighted particular problems with side-effects of treatment, anger and pain. Although they received help for their pain, healthcare professionals did **not satisfy their needs to talk** with someone about their cancer.(43)

Men with greater spirituality trended toward more hospice use, suggesting that they redirected the focus of their care from curative to palliative goals.(98)

Contents

LIFESTYLE AND PERCEPTIONS

This section attempts to give an indication of the typical profile of people living with prostate cancer, however we know that there is huge variation within the population. This section also provides insight into perceptions about prostate cancer.

What is the profile of the average person living with prostate cancer?

- Prostate cancer is the most common cancer in men. A quarter of all new cases of cancer diagnosed in men are prostate cancers.(53)

- The majority of prostate cancer patients are White however Black Caribbean and African men are approximately two to three times more likely to be diagnosed than White men.(53)

- Three quarters of prostate cancer cases are diagnosed in men aged over 65 years.(53)

What is the demographic breakdown/ market segmentation of the over 330,000 people living with prostate cancer in the UK?(3)

We have analysed England hospital episode statistics and compared this to the general population to see which MOSAIC* groups and types are more prevalent amongst prostate cancer patients attending hospital. We believe the correlations seen in England will be broadly similar to those seen in the other three UK nations, and so this insight could be applied UK-wide.

Amongst prostate cancer patients, the following MOSAIC* group shows significantly greater than average representation:

Group E: Active Retirement (active elderly people living in pleasant retirement locations): People in Group E are mostly people aged over 65 whose children have grown up and who, on retirement, have decided to move to a retirement community among people of broadly similar ages and incomes. Most of these people have paid off their mortgages on their family home and now live in a bungalow or country cottage.

For some, the move to a rural or coastal location is an opportunity to make a new start and explore new places. Most people in this group will have the benefit of a company pension and many will have access to savings. Others may be on lower state pensions, and may struggle with rising utility bills.

In addition to Group E, the following MOSAIC* groups shows greater than average representation amongst prostate cancer patients:

Group C: Rural Solitude (residents of isolated rural communities): People in Group C tend to live in small villages or in isolated farmhouses and cottages where farming and tourism drives the local economy. These are places where residents still value a traditional country way of life characterised by a strong sense of community spirit. The group includes a mix of farmers, people who work for businesses that provide services to the farming industry, people who have deliberately retired to a community with a slower pace of life and locally born people who work in low and middle income jobs in local market towns. A high proportion of the population is married or, if single, widowed. Most of them own their homes.

Group B: Professional Rewards (successful professionals living in suburban or semi-rural homes): People in Group B are generally executive and managerial classes who have worked hard to build up a comfortable lifestyle and a significant financial asset base. Often in their 40s, 50s or 60s, and can be in successful careers. Most are married and living in a spacious family home. Many have children who are at university or starting their careers.

Group L: Elderly Needs (elderly people reliant on state support): People in Group L are usually pensioners who may be struggling with the responsibility of looking after the family house and garden. Most of these people are in their 70s, 80s or 90s. Most of them are on low pension incomes. They tend to live in various types of home, including nursing homes, sheltered accommodation, their own family home, or a down-sized property.
In addition to the above Groups, there are two Types within **Group D (Small Town Diversity) and one Type within Group M (Industrial Heritage)** who are also well-represented amongst prostate cancer patients:

- Group D, Type 18: Hardworking Families
- Group D, Type 19: Innate Conservatives
- Group M, Type 54: Clocking Off

What are the typical leisure activities/ where do they shop/what media they consume/what do they do?[103]

- **Group E:** Active Retirement. Holidays, cruises and dining out for those who are well-off. Reading books, doing crosswords, knitting and looking after grandchildren are also popular activities. They tend to read national daily newspapers every day.

- **Group C:** Rural Solitude: Many people within this group may spend time in their gardens, or growing fruit and vegetables. There is less frequent visiting of theatres and cinemas than other groups. Many people in this group enjoy outdoor pursuits such as fishing, walking, etc.

- **Group B:** Professional Rewards: Holidays, cruises and day trips are popular activities, as is going to the theatre and to concert halls. People in this group tend to read the broadsheet newspapers, particularly The Daily Telegraph and the Sunday Times.

- **Group L:** Elderly Needs: People in this group tend to be less physically active. Watching TV is popular as is shopping in charity shops. They tend to lack familiarity with IT, so most of the people in this group receive information from watching TV and daily newspapers, and most are not using the internet.

*For more detail and definitions see **www.experian.co.uk/business-strategies/mosaic-uk-2009.html**

What are people affected by prostate cancer saying about their lives both before and after a cancer diagnosis?

Before:

'I'd had symptoms for around five years but I wouldn't talk about it and I certainly didn't go to my GP, men have a fear of being examined. In the end, it was feeling a lump that forced me to make an appointment.'

Sam, 41

'I didn't have the guts to talk to my GP. I felt I had an old man's cancer and there was no one of my age to talk to.'

Rodger, 37

After:

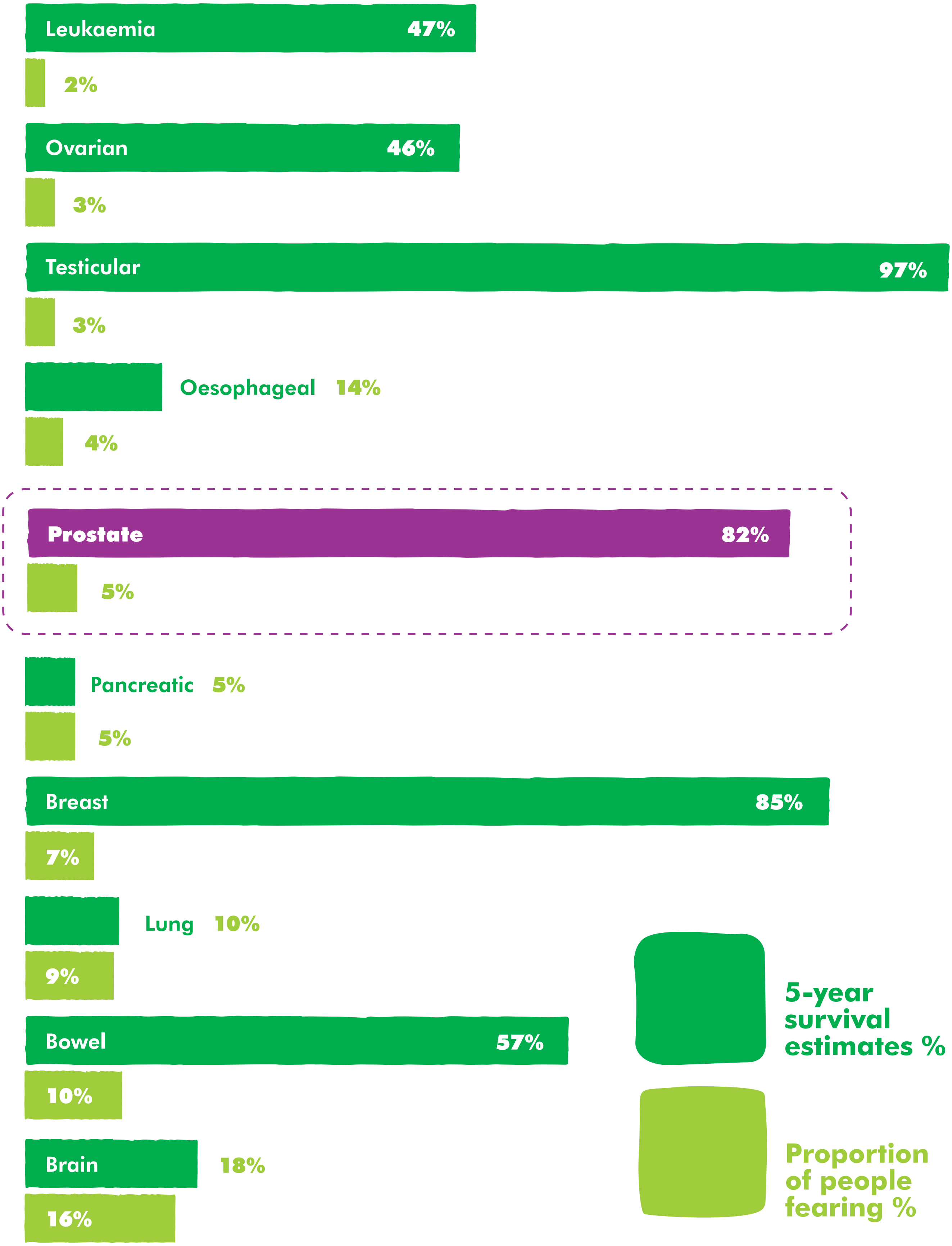
‘I had to stop work when I was diagnosed with prostate cancer. It was a shock dropping from a good income onto DLA. There was no early retirement cushion and it’s hard to accept that I’m not entitled to other benefits, not even the Winter Fuel Payment as I’m a year too young. When I phoned the benefits office they just asked me when I’m expected to die. It will be money hardship until I do die.’

Peter

‘The side effects of cancer have been a big surprise. The inconvenience is much worse than my cancer. The treatment is over but the after effects aren’t. No one warned me about the downside of being a cancer survivor.’

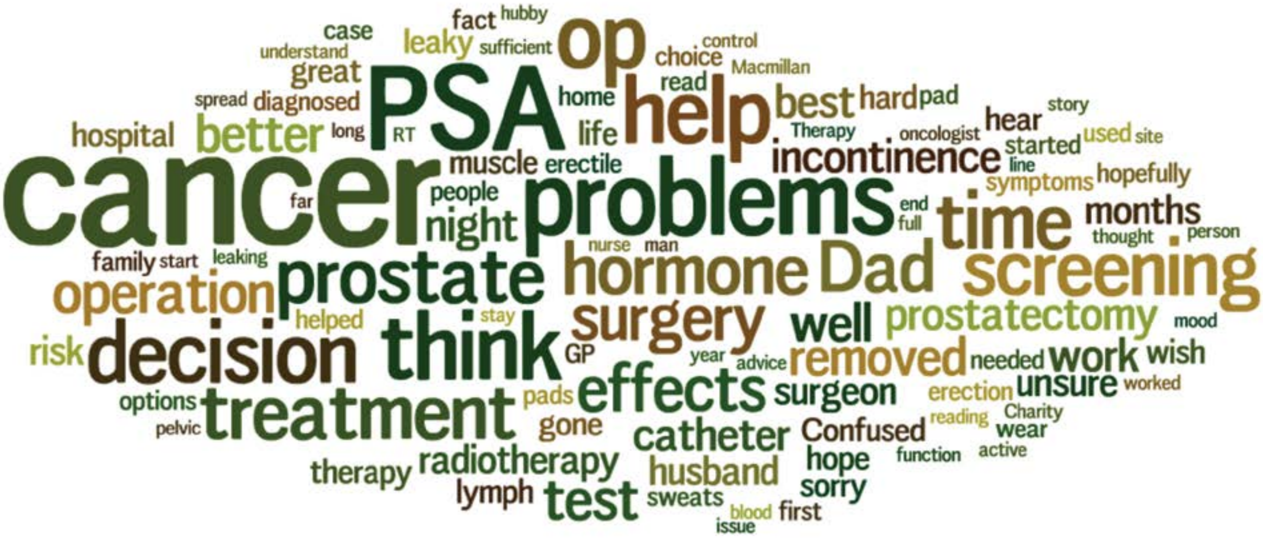
Oliver

How does people's fear of prostate cancer compare to actual survival rates?(99,100)

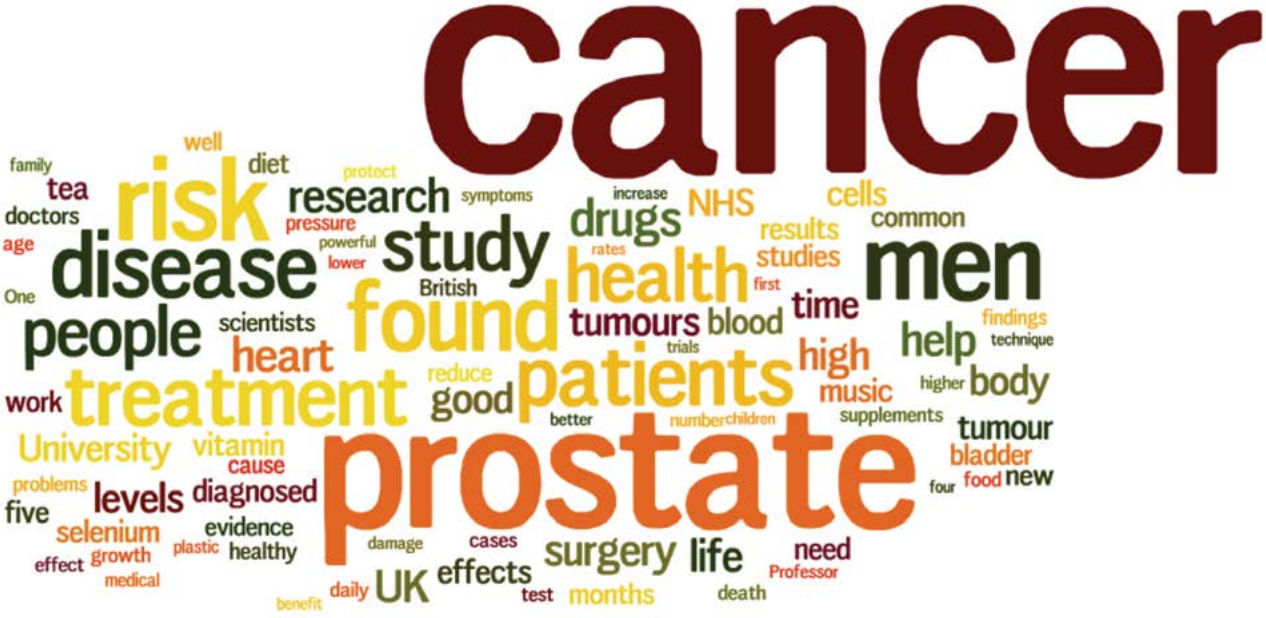


Fear of prostate cancer is fairly low amongst the general public, both lung and brain cancer are feared by more people. This is possibly linked to the fact that people are aware that the 5-year survival rate for prostate cancer is higher than for the majority of other cancers.

What our prostate cancer online Macmillan Community members are saying...(76)



How the media* portrays prostate cancer...(68)



*UK national daily newspapers

Note: These 'word clouds' give greater prominence to words that appear more frequently in the source text.

What does this mean? What do we want to change in terms of people's perceptions?(76)(68)

Macmillan hosts online discussions on its website; we have analysed the frequency of words used in the discussions relating to prostate cancer compared to the frequency of words used in UK media articles where prostate cancer is the subject. The results are summarised here:

- The words 'dad', 'husband' and 'family' feature prominently in the online community discussions, probably referring to parents and partners who have prostate cancer. The online community may include many family members who are carers, and rely on this community for support that is not readily available elsewhere.
- References to treatment and the subsequent results of treatment, both physically and emotionally, feature predominantly within the online community as those going through treatment use the community as a form of support and advice, with the terms 'decision', 'radiotherapy' and 'surgery' illustrating the concerns of prostate cancer patients.
- The media however, tend to focus more upon the causes and diagnosis of prostate cancer and those at risk, as opposed to the personal journey which the patients undertake. Common words include 'risk', 'pressure' and 'diet'.
- There is more technical terminology in the online discussions than in the media: eg 'prostatectomy', 'PSA', 'lymph', suggesting that those affected by cancer are sufficiently knowledgeable to be comfortable with such terms. Terms in the media are simple, to reach a non-specialist audience.
- The terms 'confused', 'unsure' and 'hopefully' in the online community discussions emphasise the confusion and emotional difficulties experienced by prostate cancer patients. The media includes none of those types of words, focusing instead on the use of words such as, 'tumours', 'cancer' and 'disease'.

REFERENCES,

SOURCES, NOTES AND CAVEATS

Quotes

The quotes on pages 23, 27, 37, 47, 52 and 53 are real quotes from people with prostate cancer or their carers, however we have changed their names to protect their identity. The quote and photo on page 5 is from a Macmillan prostate case study who has kindly agreed to be featured in this publication.

References

1. Macmillan Cancer Support. Cancer information section on prostate cancer. http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Prostate/Aboutprostatecancer/Theprostate.aspx (Accessed July 2014)
2. Office for National Statistics – Cancer survival rates, Cancer survival in England, patients diagnosed 2007–2011 and followed up to 2012. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-320365 (accessed July 2014)
3. Prevalence in 2015 estimated from Maddams et al. (2012). Prevalence in 2030 and 2040 taken directly from Maddams J, Utley M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. British Journal of Cancer. 2012; 107: 1195-1202. (Scenario 1 presented here)
4. Cancer Research UK. Prostate cancer – survival statistics http://info.cancerresearchuk.org/cancerstats/types/prostate/survival/ (Accessed July 2014)
5. Cancer Research UK. Prostate cancer – UK mortality statistics. http://info.cancerresearchuk.org/cancerstats/types/prostate/mortality/ (Accessed July 2014)
6. England – Office of National Statistics. Cancer Registration Statistics, England, 2012. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-352128 (accessed July 2014)
7. Scotland – ISD Scotland. Cancer Incidence in Scotland 2012. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233 (accessed July 2014)
8. Wales – Welsh Cancer Intelligence and Surveillance Unit. Official Statistics – Trends. http://www.wcisu.wales.nhs.uk/officical-statistics-exel-files-of-trend (accessed July 2014)
9. N. Ireland – Northern Ireland Cancer Registry. Online Statistics. http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/ (accessed July 2014)
10. England and Wales – Office of National Statistics. Mortality Statistics: Deaths Registered in England and Wales, 2012. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-325289 (accessed July 2014)
11. Scotland – ISD Scotland. Cancer Mortality in Scotland 2012. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233 (accessed July 2014)
12. Cancer Research UK. Prostate cancer statistics – Key Facts. http://info.cancerresearchuk.org/cancerstats/keyfacts/prostate-cancer/ (Accessed July 2014)

Contents

13. Cancer Research UK. Prostate Cancer – UK Incidence Statistics http://info.cancerresearchuk.org/cancerstats/types/prostate/incidence/ (Accessed July 2014)

14 Office for National Statistics – Cancer survival rates, Cancer survival in England, patients diagnosed 2007–2011 and followed up to 2012. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-320365 (accessed July 2014)

15. Macmillan Cancer Support identified median survival times based on research by the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine. 2012. Macmillan. London.

16. Quinn M. and Babb P. (2002), Patterns and trends in prostate cancer incidence, survival, prevalence and mortality. Part I: international comparisons. BJU International, 90: 162–173.

17. Cancer Research UK. Prostate Cancer – Risk Factors. http://info.cancerresearchuk.org/ cancerstats/types/prostate/riskfactors/ (Accessed July 2014)

18. NCIN. Cancer e-Atlas: NHS Health boundaries. http://www.ncin.org.uk/cancer_information_tools/eatlas/default.aspx (accessed July 2014)

19. Robb K, et al. Public awareness of cancer in Britain: a population-based survey of adults. British Journal of Cancer. 2009. 101:518-23

20. Payne, H, Cornford, P. Prostate-specific antigen: An evolving role in diagnosis, monitoring, and treatment evaluation in prostate cancer. Urologic Oncology-Seminars and Original Investigations. 2011. 29: 593-601

21. Cancer Research UK. Prostate cancer screening. http://www.cancerscreening.nhs.uk/prostate/index.html (accessed July 2014)

22. NHS – Prostate Cancer Risk Management Programme http://www.cancerscreening.nhs.uk/prostate/index.html (Accessed July 2014)

23. National Cancer Intelligence Network. Routes to Diagnosis. http://www.ncin.org.uk/search/routes+to+diagnosis+2014 (accessed July 2014)

24. NHS England. The Cancer Patients Experience Survey 2013. http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file (accessed July 2014)

25. Kings Fund. How to improve cancer survival: Explaining England's relatively poor rates. www.kingsfund.org.uk/document.rm?id=9149 (accessed July 2014)

26. NHS England. Provider based Cancer Waiting Times for Q4 2013/14. http://www.england.nhs.uk/statistics/2014/05/30/provider-based-cancer-waiting-times-for-q4-2013-14/ (accessed July 2014

27. Corner J, et al. Experience of health changes and reasons for delay in seeking care: a UK study of the months prior to the diagnosis of lung cancer. Social Science and Medicine. 2006.62:1381-91

28. Macmillan Cancer Support/YouGov online survey of 1,495 UK adults living with cancer. Fieldwork conducted 1-16 August. Survey results unweighted.

29. Higginson I J, Evans C J. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer Journal. 2010. 16:423-435

30. Wilson K, et al. 'A qualitative exploration of financial concerns, advice, support and coping in people diagnosed with cancer and their carers'. 2010. University of Manchester for Macmillan Cancer Support. UK.
31. Cardy P, et al. Worried Sick: The Emotional Impact of Cancer. Research for Macmillan Cancer Support conducted by Opinion Leader Research. 2006. Macmillan Cancer Support, London
32. Heron P, et al. Information for people living with conditions that affect their appearance. 2007. Picker Institute Europe, Oxford.
33. Office for National Statistics. Mortality statistics. Deaths registered in England and Wales 2011. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-277727 (accessed July 2014)
34. Macmillan Cancer Support. February 2010 online survey of 1,019 UK adults living with cancer. Survey results have not been weighted.
35. Carlyle R, et al. Cancer information pathways literature review. 2011. Macmillan Cancer Support, London
36. National Cancer Survivorship Initiative. Supportive and Palliative care: The manual. http://guidance.nice.org.uk/CSGSP (accessed July 2014)
37. O'Brien, R et al."I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. Patient education and counselling. 2011. 84:200-207
38. Dale H L et al. Systematic review of post-treatment psychosocial and behaviour change interventions for men with cancer. Psycho-oncology. 2010.19:227-237
39. NCIN. Major surgical resections, England, 2004-2006. 2011. NCIN, London
40. Prostate Cancer UK. Treatment options. http://prostatecanceruk.org/information/prostate-cancer/treatment (accessed July 2014)
41. Maddams, J et al. Levels of acute health service use among cancer survivors in the United Kingdom. European Journal of Cancer, 2011. 47, 14: 2211-2220,
42. Health and Social Care Information Centre: Hospital Episode Statistics. http://www.hscic.gov.uk/searchcatalogue?productid=13264&q=title%3a%22Hospital+Episode+Statistics%2c+Admitted+patient+care+-+England%22&sort=Relevance&size=10&page=1#top (accessed July 2014)
43. Sinfield P, et al. Men's and carers' experiences of care for prostate cancer: a narrative literature review. Health expectations. 2009. 12: 301-312
44. NCAT Cancer CNS survey. 2011. http://ncat.nhs.uk/sites/default/files/NCAT%20Census%20of%20the%20Cancer%20Specialist%20Nurse%20Workforce%202011.pdf (accessed July 2012)
45. Frontier Economics. One to one support for cancer patients. December 2010
46. The Prostate Cancer Charity. Access to clinical nurse specialists for men with prostate cancer. 2009. The Prostate Cancer Charity, London.
47. Prostate Cancer UK. Emotional Impact. http://prostatecanceruk.org/information/livingwithprostate- cancer/emotional-impact (accessed July 2014)
48. Tarrant C, et al. Is seeing a specialist nurse associated with positive experiences of care? The role and value of specialist nurses in prostate cancer care. BMC Health Services Research. 2008. 8:65
49. Elliot J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. British Journal of Cancer. 2011. 105:511-20.

Contents

50. Macmillan Cancer Support. Isolation amongst people affected by cancer. Results not published. 2014.
51. Macmillan Cancer Support/RBS Group. Cancer's Hidden Price Tag: Revealing the Costs behind the Illness. 2013. http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf (accessed July 2014)
52. Prostate cancer UK. Day of Action. http://prostatecanceruk.org/dayofaction (accessed October 2014)
53. Cancer Research UK. Prostate cancer statistics – UK http://info.cancerresearchuk.org/cancerstats/types/prostate/ (Accessed July 2014)
54. Macmillan Cancer Support/RDSi. Telephone survey of 1,137 people affected by cancer: 942 patients, 195 carers. Fieldwork conducted Nov 2005-Feb 2006
55. Bungay H, Cappello R. 'As long as the doctors know what they are doing': trust or ambivalence about patient information among elderly men with prostate cancer? European Journal of Cancer Care. 2009. 18:470-476
56. NAO Report: Tackling Cancer: Improving the Patient Journey. http://www.nao.org.uk/wp-content/uploads/2005/02/0405288.pdf (Accessed July 2014)
57. National Cancer Survivorship Initiative. Assessment and care planning. http://www.ncsi.org.uk/what-we-aredoing/assessment-care-planning/ (accessed August 2014)
58. Prevalence in 2015 estimated from Maddams et al. (2012). Prevalence in 2030 and 2040 taken directly from Maddams J, Utley M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. British Journal of Cancer. 2012; 107: 1195-1202. (Scenario 1 presented here)
59. Macmillan Cancer Support analysis, July 2012. Data was extracted from Hospital Episode Statistics (HES) database for the NHS financial year 2010/11 at episode level for all types of cancer, excluding C44 (other malignant neoplasms of skin). The data covers England only, but it is assumed that the patterns seen in England will be broadly similar in the other UK nations. The earliest hospital admittance was taken for each person within the NHS 2010/11 financial year. MOSAIC UK profiles were created for hospital admittances for people living with each of the top 10 cancer types (and a further profile for all other cancers combined, ie the rarer cancers) and compared to the base population. Base population (ie population of England) was population at the end of December 2008. HES records where the age of the patient was not recorded were removed from all analyses. Only records with a valid MOSAIC Type were analysed, however the number of these was small, and limited largely to data on people aged 0-14. MOSAIC profiles are built from 440 data elements, collated by Experian Ltd. For further details, visit www.experian.co.uk/business-strategies/mosaic-uk-2009.html
60. Wong F, et al. Men with prostate cancer: influence of psychological factors on informational needs and decision making. Journal of Psychosomatic Research. 2000. 49: 13-19
61. Department of health. Cancer Patient Experience Survey 2011.Q59. https://www.wp.dh.gov.uk/publications/files/2012/08/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf (accessed July 2014)
62. Davison B J, et al. Quality of Life, sexual function and decisional regret at 1 year after surgical treatment for localised prostate cancer. BJU International. 2007. 100: 780-785
63. De Sousa A, et al. Psychological aspects of prostate cancer: a clinical review. Prostate cancer and prostatic diseases. 2012. 15: 120-127
64. Fitch M I, et al. Travelling for radiation cancer treatment: patient perspectives. Psycho-Oncology. 2003. 12:664-674

Contents

65. Nanton V, Dale J. 'It don't make sense to worry too much': the experience of prostate cancer in African-Caribbean men in the UK. European Journal of Cancer Care. 2011. 20:62-71
66. Richards M, et al. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. British Journal of Cancer. 2011. 105: 1-4
67. Khan N F, et al. A qualitative study of unmet needs and interactions with primary care among cancer survivors. British Journal of Cancer. 2011. 105: p46–p51
68. Macmillan Cancer Support/Factiva. 2011. Word cloud formed from analysis on 18 July 2012 using www.wordle.net of the 100 most recent UK national daily newspaper articles where the key words of “prostate cancer” appeared at least once. Frequency of the most frequent words are shown in larger fonts than less frequent words. Dates ranged from 19 April 2012 to 17 July 2012. UK national daily newspapers included: The Express, The Guardian, The Independent, The Daily Mail, The Metro, The Mirror, The Star, The Sun, The Telegraph and The Times.
69. Chapple A, et al. Lung cancer patient’s perception of access to financial benefits: a qualitative study. British Journal of General Practice. 2004. 54(505):589-94
70. Sjovall K, et al. Sickness absence among cancer patients in the pre-diagnostic and the postdiagnostic phases of five common forms of cancer. Supportive Care in Cancer. 2012. 20: 741- 747
71. Bennett J A, et al. Changes in employment and household income during the 24 months following a cancer diagnosis. Supportive Care in Cancer. 2009. 17:1057-1064
72. Macmillan survey of Cancer Voices: exploring information and support needs. 2010. Macmillan Cancer Support, London.
73. Davies N, et al. The role of diet and physical activity in breast, colorectal, and prostate cancer survivorship: a review of the literature. British Journal of Cancer. 2011. 105:52-73
74. Fitch M I, et al. Men’s perspectives on the impact of prostate cancer: implications for oncology nurses. Oncology Nursing Forum, 2000; 27: 1255–1263
75. (Morrison V, et al. Common, important, and unmet needs of cancer outpatients. European Journal of Oncology Nursing. 2012. 16(2):115-123)
76. Macmillan Cancer Support. 2012. Word cloud created on wordle.net from Macmillan’s online community from the 30 most recent posts listed under ‘recent group activity for the Prostate Cancer group, on 18 July 2012
77. Khan, et al. Consulting and prescribing behaviour for anxiety and depression in long-term survivors of cancer in the UK. European Journal of Cancer. 2010. 46. 3339-3344
78. Ream E, et al. Supportive care needs of men living with prostate cancer in England: a survey. British Journal of Cancer. 2008. 98:1903-1909
79. Armes J, et al. Patients’ supportive care needs beyond the end of cancer treatment: A prospective, longitodical survey. Journal of Clinical Oncology. 2009. 27:6172-6179
80. Maher J, et al. How many people need expert symptom assessment but are not in the last year of life? 2012 Macmillan, London
81. Maddams J, et al. The cancer burden in the United Kingdom in 2007 due to radiotherapy. International Journal of Cancer. 2011. 192(12):2885-93
82. Temel J, et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine.* 2010. 363(8):733-42)
83. National Bereavement Survey (VOICES) 2012. http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2012/stb---national-bereavement-survey-2012.html#tab-Place-of-Death (accessed July 2014)

84. Macmillan Feb 2010 online survey of 1,019 people living with cancer. Respondents were sourced from Macmillan's database of people affected by cancer in the UK who have agreed to take part in research. Survey results are unweighted
85. MHP Health Mandate. An Atlas of Variations in Social Care. June 2012. http://www.mhpc.com/sites/default/files/pictures/An%20atlas%20of%20variations%20in%20social%20care%20June%202012.pdf (accessed July 2014)
86. Kaya E, Feuer D. Prostate Cancer: Palliative Care and Pain Relief. Prostate cancer and prostatic diseases. 2004. 27:311-315
87. Yennurajalingam, S et al. The impact of an outpatient palliative care consultation on symptom burden in advanced prostrate cancer patients. Journal of Palliative medicine. 2012. 15:20-24
88. Bergman J, et al. Hospice use and high-intensity care in men dying of prostate cancer. Archive of internal medicine. 2011. 171:204-210
89. Bergman J, et al. Quality of End-of-Life Care in Low-Income, Uninsured Men Dying of Prostate Cancer. Cancer. 2010. 116:2126-2131
90. Tsai J, et al. Symptom patterns of advanced cancer patients in a palliative care unit. Palliative Medicine. 2006. 20(6):617-22
91. McCarthy E, et al. Dying with cancer: patients' function, symptoms, and care preferences as death approaches. Journal of the American Geriatrics Society. 2000. 48:5110-21
92. Macmillan Cancer Support. Unclaimed Millions Report. http://www.macmillan.org.uk/documents/getinvolved/campaigns/campaigns/the_unclaimed_millions.pdf (accessed July 2014)
93. Krahn M D, et al. Healthcare costs associated with prostate cancer: estimates from a population-based study. BJU International. 2010. 105: 338-346
94. Adams E, et al. The information needs of partners and family members of cancer patients: A systematic literature review. Patient Education and Counselling. 2009. 77:179-186
95. Rainbird K, et al. The needs of patients with advanced, incurable cancer. British Journal of Cancer. 2009. 101:759-764
96. Walshe C, et al. Patterns of Access to Community Palliative Care Services: A Literature Review. Journal of Pain and Symptom Management. 2009. 37(5): 884-912
97. Gao W, et al. Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications. European Journal of Cancer. 2010. 46 (11): 2036-2044
98. Bergman J, et a. Spirituality and end of life care in disadvantaged men dying of prostate cancer. World journal of urology. 2011. 29:43-49
99. Cancer Research UK. People Fear Cancer More Than Other Serious Illnesses. http://www.cancerresearchuk.org/about-us/cancer-news/press-release/people-fear-cancer-more-than-other-serious-illness (accessed July 2014)
100. Cancer Research UK. Survival stats for the most common cancers. http://www.cancerresearchuk.org/cancer-info/cancerstats/survival/common-cancers/ (accessed July 2014) Note: 'all people' figures for cancers affecting both men and women were estimated by taking the mean average of the survival rate for men and women combined.

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APPENDIX A JARGON BUSTER

Not sure of some of the terms used in this document? Our handy jargon buster should help you out.

(i) Health data terms

Incidence: When we talk about 'cancer incidence' we mean the number of people who are newly diagnosed with cancer within a given time-frame, usually one calendar year. The data can be 'cut' in a number of ways, for example by cancer type (breast, prostate, lung, colorectal, etc) or by gender, age, etc. The latest data we have is for 2012, and we know that over 300,000 people are newly diagnosed with cancer in the UK every year. Incidence can sometimes be given as a rate (per head of population).

Mortality: When we talk about 'cancer mortality' mean the number of people who die from cancer within a given time-frame, usually one calendar year. The latest data we have is for 2012, and we know that over 150,000 people die from cancer in the UK every year. Mortality can sometimes be given as a rate (per head of population).

Prevalence: When we talk about 'cancer prevalence' we mean the number of people who are still alive and who have had, within a defined period, a cancer diagnosis. It equates to the number of people living with cancer. Any prevalence figure is for a snapshot (set point in time). The latest snapshot we have was made in 2015, and we estimate that there are 2.5 million people living with cancer in the UK. Some data are only available and presented for 20-year prevalence (i.e. anyone with a cancer diagnosis within a 20 year period). Prevalence can sometimes be given as a rate (per head of population).

Survival: When we talk about 'cancer survival' we mean the percentage of people who survive a certain type of cancer for a specified amount of time.

Cancer statistics often use one-year or five-year survival rates. Relative survival (the standardised measure used) is a means of accounting for background mortality and can be interpreted as the survival from cancer in the absence of other causes of death. Survival rates do not specify whether cancer survivors are still undergoing treatment after the time period in question or whether they are cancer-free (in remission).

(ii) Other terms

Co-morbidities: This means either the presence of one or more disorders (or diseases) in addition to a primary disease or disorder, or the effect of such additional disorders or diseases.

Curative treatment: When we talk about curative treatment for someone with cancer, we talk about treatments intended to cure the cancer; this usually mean the removal of a cancerous tumour. It works best on localised cancers that haven't yet spread to other parts of the body, and is often followed by radiotherapy and/or chemotherapy to make sure all cancerous cells have been removed.

Palliative treatment: Palliative treatment is only used to ease pain, disability or other complications that usually come with advanced cancer. Palliative treatment may improve quality of life and medium-term survival, but it is not a cure or anti-cancer treatment. However palliative treatment can be given in addition to curative treatment in order to help people cope with the physical and emotional issues that accompany a diagnosis of cancer.

For further support, please contact
evidence@macmillan.org.uk

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NOTES

Full suite of the Rich Pictures

This document is one of the twenty in the full suite of Rich Pictures summarising the numbers, needs and experiences of people affected by cancer. See a full list below:

Overarching Rich Picture

The Rich Picture on people with cancer	(MAC15069)

The Rich Pictures on cancer types

The Rich Picture on people living with cervical cancer	(MAC13846_11_14)
The Rich Picture on people living with breast cancer	(MAC13838_11_14)
The Rich Picture on people living with prostate cancer	(MAC13839_11_14)
The Rich Picture on people living with lung cancer	(MAC13848_11_14)
The Rich Picture on people living with cancer of the uterus	(MAC13844_11_14)
The Rich Picture on people living with non-Hodgkin lymphoma	(MAC13843_11_14)
The Rich Picture on people living with rarer cancers	(MAC13847_11_14)
The Rich Picture on people living with malignant melanoma	(MAC13841_11_14)
The Rich Picture on people living with head & neck cancer	(MAC13845_11_14)
The Rich Picture on people living with colorectal cancer	(MAC13840_11_14)
The Rich Picture on people living with bladder cancer	(MAC13842_11_14)

The Rich Pictures on age groups

The Rich Picture on people of working age with cancer	(MAC13732_14)
The Rich Picture on children with cancer	(MAC14660_14)
The Rich Picture on older people with cancer	(MAC13668_11_14)
The Rich Pictureon teenagers and young adults with cancer	(MAC14661_14)

Other Rich Pictures

The Rich Picture on people at end of life	(MAC13841_14)
The Rich Picture on carers of people with cancer	(MAC13731_10_14)
The Rich Picture on people with cancer from BME groups	(MAC14662_14)
The Emerging Picture on LGBT people with cancer	(MAC14663_14)

All these titles are available in hard-copy by calling our Macmillan Support Line free on **0808 808 00 00** (Monday to Friday, 9am–8pm), or by ordering online at **www.be.macmillan.org.uk**.

A wealth of other resources are also available, all produced by Macmillan Cancer Support and available free of charge.

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. How to talk to those close to you. What to do about work. How you'll cope with the extra costs.

At Macmillan, we know how a cancer diagnosis can affect everything. So when you need someone to turn to, we're here, because no one should face cancer alone. We can help you find answers to questions about your treatment and its effects. We can advise on work and benefits, and we're always here for emotional support when things get tough.

Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support to help you feel more in control of your life.

We are millions of supporters, professionals, volunteers, campaigners and people affected by cancer. Together we make sure there's always someone here for you, to give you the support, energy and inspiration you need to help you feel more like you. We are all Macmillan.

For support, information or if you just want to chat, call us free on 0808 808 00 00 (Monday to Friday, 9am–8pm) or visit macmillan.org.uk

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CANCER SUPPORT

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