THE RICH PICTURE

PEOPLE WITH BLADDER CANCER

WE ARE MACMILLAN. CANCER SUPPORT

Steve, 52, living with bladder 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.

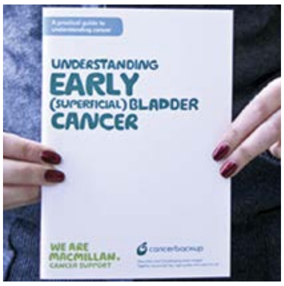
There may be data that have been released that does not appear in this document and Macmillan is under no obligation to include any particular data source. Any medical information referred to in this document is given for information purposes only and it is not intended to constitute professional advice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

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 booklet 'Understanding Early (Superficial) Bladder Cancer' (MAC11683) more helpful:



Understanding Early (Superficial) Bladder Cancer
MAC11683

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.

Rich Pictures

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

Impact Briefs

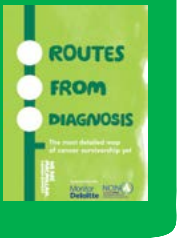
Generically describe what our services do, and the impact they have on people affected by cancer.

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**.

CONTENTS

SUMMARY OF PEOPLE LIVING WITH BLADDER CANCER

Key stats

Bladder cancer is the eighth most **commonly diagnosed cancer,** and an average of **29 people** receive a bladder cancer diagnosis **every day in the UK.**(5)(6)(7)(8)

Bladder cancer is the seventh most common cause of cancer death in the UK, with over **5,000 people dying every year** from bladder cancer in the UK.(9)(10)(20)

Around **8 in 10** of all bladder cancer cases are diagnosed in people **aged 65 and over.**(3)

Survival rates for bladder cancer are improving, with around **59% of men and 49% of women** living for more than five years after their bladder cancer diagnosis.(4)

Bladder cancer is the eighth most commonly diagnosed cancer in the UK.

Diagnosis

Bladder cancer patients have a significantly better chance of survival if they are referred to hospital **within 14 days of the onset of symptoms.**(28)

Around **45%** of patients diagnosed with bladder cancer experience **psychological distress** prior to their surgery.(35)

Bladder cancer is the **second most common tobacco-related cancer.**(19)(33)

There is **no screening currently available for bladder cancer in the UK,** however a programme may become available in the future. (see page 24)

People with bladder cancer are more likely to survive their illness if they are referred to hospital within two weeks.

Treatment

People with bladder cancer who are **aged 80 or older** are **less likely to be treated with radical surgery** than younger people, despite the fact that such surgery has the greatest risk reduction in death from bladder cancer.(54)

21% of people with urological cancers (including bladder cancer) are **not given a choice of different types of treatment.**(55)

Radiotherapy to the pelvic region can sometimes cause **painful cracks in the pelvic bones** called pelvic insufficiency fractures.(53)

Patients who are aged 80 years or older may not be offered curative treatments because of their age.

Survivorship

30% of people with urological cancers (including bladder cancer) feel that they are **not given enough emotional support by hospital staff** when they return as outpatients.(75)

Only **52% of people with urological cancers** (including bladder cancer) feel that they are given **enough care and help from health or social services** once they leave hospital.(68)

Many people who have bladder cancer state that their **psychological welfare is largely affected by health-related quality of life.**(77)

Health-related quality of life affects the psychological welfare of many people with bladder cancer.

End of Life

457,000 people (not just those with cancer) need good palliative care services every year in England, but around **92,000 people are not being reached.**(88)

More than one quarter of patients with all forms of cancer **experience serious pain 3 to 6 months before death** and **more than 40% are in serious pain during their last 3 days of life.**(90)

Widows who lose their husbands to bladder cancer have an increased risk of experiencing **feelings of guilt if their spouse does not get enough pain relief** compared to widows who feel that their husbands have adequate pain relief.(97)

92,000 people do not have access to effective palliative care.

Lifestyle & perceptions

People from the **most deprived socio-economic groups are 1.3 times more likely to get bladder cancer** compared to people from the most affluent groups.(101)

Amongst people with bladder cancer, **people who are aged over 65** and are retired are well represented. (see page 50)

In articles published about bladder cancer, the media tend to focus upon **the causes and diagnosis of cancer and those at risk,** as opposed to the personal journey which the patients undertake.(see page 56)

INTRODUCTION TO BLADDER CANCER

What is bladder cancer?

The majority of bladder cancers present at a non-invasive stage involve only the inner lining of the bladder – this is early (superficial) bladder cancer. Some non-invasive cancers develop into invasive bladder cancer. Around a third are muscle invasive at diagnosis.

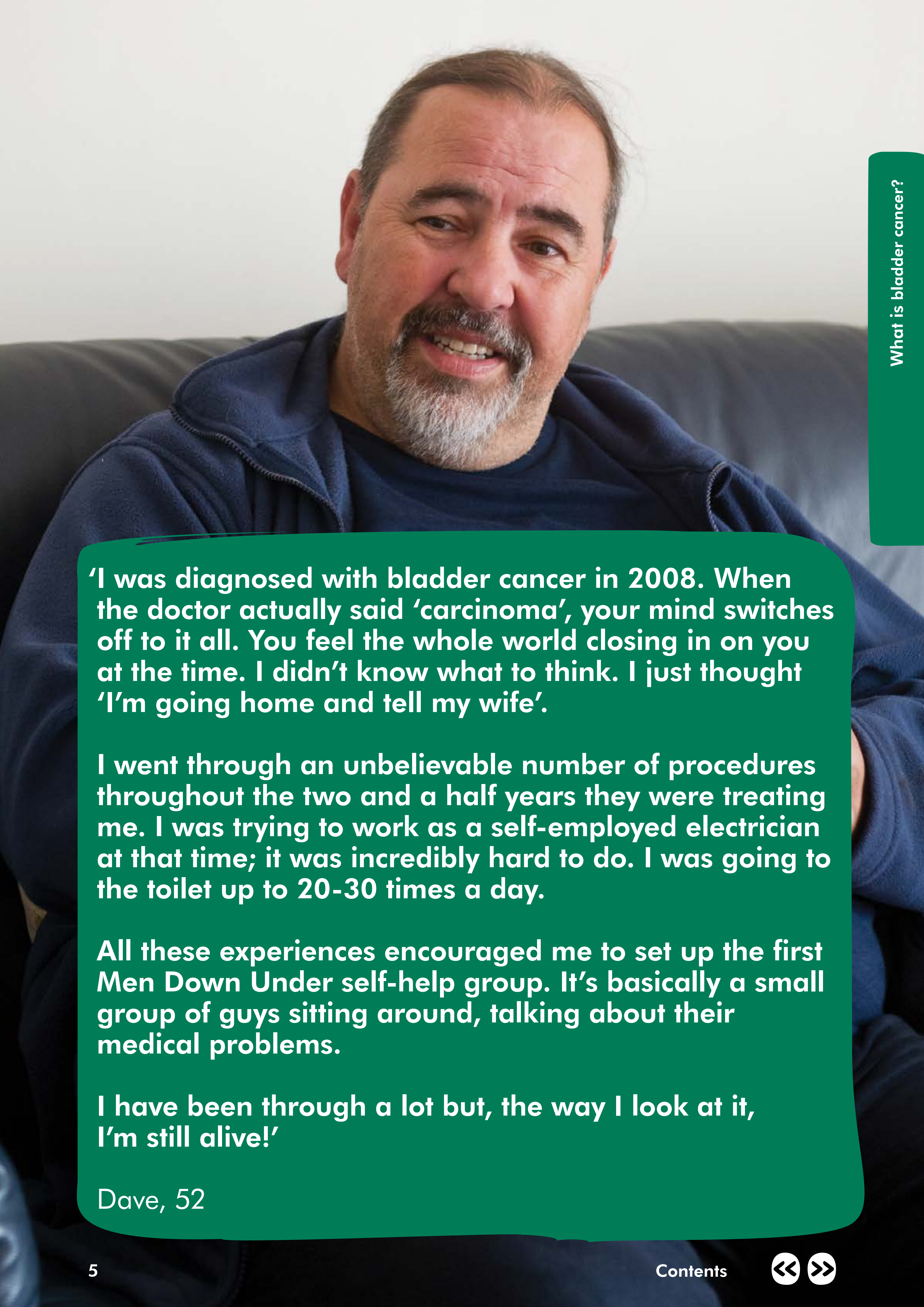
Bladder cancer may appear in different forms:

- Transitional cell bladder cancer (TCC) – the most common type of bladder cancer. The cancer starts in cells in the bladder lining (urothelium).
- Carcinoma in situ (CIS) – a non-invasive bladder cancer that appears as a flat, red area in the bladder. CIS can grow quickly, and if it is not treated effectively, there is a high risk that CIS will develop into an invasive bladder cancer.
- Papillary cancer – a form of early bladder cancer. Some people may have both papillary cancer and CIS.
- Rarer types of bladder cancer – these include squamous cell cancer and adenocarcinoma. Both of these types of bladder cancer are usually invasive.

Want to know more?

Macmillan produces a wealth of information about what bladder 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 bladder cancer in 2008. When the doctor actually said ‘carcinoma’, your mind switches off to it all. You feel the whole world closing in on you at the time. I didn’t know what to think. I just thought ‘I’m going home and tell my wife’.

I went through an unbelievable number of procedures throughout the two and a half years they were treating me. I was trying to work as a self-employed electrician at that time; it was incredibly hard to do. I was going to the toilet up to 20-30 times a day.

All these experiences encouraged me to set up the first Men Down Under self-help group. It’s basically a small group of guys sitting around, talking about their medical problems.

I have been through a lot but, the way I look at it, I’m still alive!’

Dave, 52

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people with bladder 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.(121)

Macmillan's ambition is aim 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 69,115 people were living with bladder cancer in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.(122)

How is this different for people with bladder 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.

*Please note that the prevalence figures have been estimated by Macmillan Cancer Support using best available data and are indicative only

Contents

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 BLADDER CANCER

This section presents some of the key stats and facts relating to people with bladder cancer. You may benefit from referring to the Jargon Buster on page 69 for details on some of the terms used in the section. Please note that incidence and mortality data on all cancers exclude non-melanoma skin cancer.

*Please note that the prevalence figures have been estimated by Macmillan Cancer Support using best available data and are indicative only.

29

people are diagnosed with bladder cancer every day.(5,6,7,8,9)

69,115

people were living with bladder cancer in the UK in 2010, based on people living up to 20 years post diagnosis.(122)

78%

of men and 67% of women live for more than one year after their bladder cancer diagnosis. (4)

59%

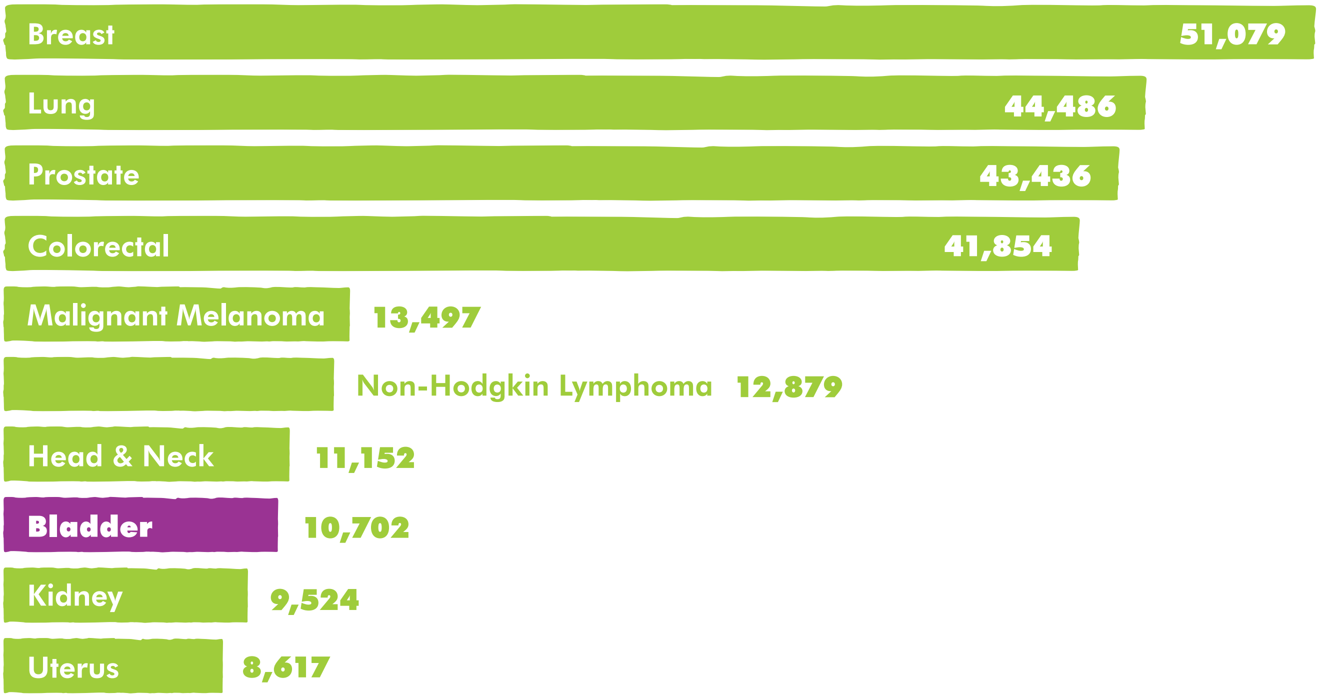
of men and 49% of women live more than five years after their bladder cancer diagnosis. (4)

101

people die every week of bladder cancer in the UK. (9,10,20)

How many people get bladder cancer per year? (incidence)(5)(6)(7)(8)

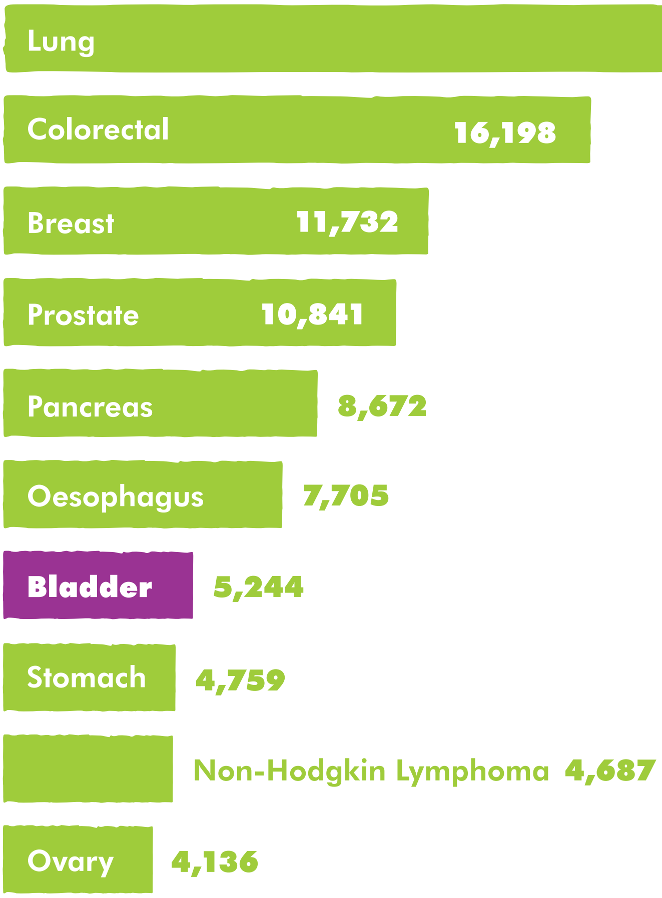
Cancer incidence, UK, 2012, top 10 cancer sites



Bladder cancer is the eighth most commonly diagnosed cancer. Around 10,702 people are diagnosed every year in the UK, which is around 29 people every day.

How many people die from bladder cancer per year? (mortality)(9)(10)(20)

Mortality, UK, 2012, top 10 cancer sites



Bladder cancer is the seventh most common cause of cancer death in the UK. Over 5,000 people die from bladder cancer every year in the UK, which is around 101 people per week.

How many people are currently living with bladder cancer? (prevalence)(122)

People were living with bladder cancer in the UK in 2010, bases on people living up to 20 years post diagnosis.

69,115

The prognosis for people with bladder cancer is relatively good. Since the early 1990s, bladder cancer death rates in the UK have decreased by around a third for men and by around a quarter for women.(3)

What are the key stats for England?

See data on incidence, mortality and prevalence for England

How many people get bladder cancer per year in England? (incidence)(5)

9,124

new cases of bladder cancer diagnoses in England in 2012.

How many people die from bladder cancer per year in England? (mortality)(9)

4,382

bladder cancer deaths in England in 2012.

How many people are living with bladder cancer in England? (prevalence)(122)

57,296

people were living with bladder cancer in England in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).

What is the age-standardised* rate of incidence of bladder cancer in people in England?(18)

11

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

What is the age-standardised* rate of mortality from bladder cancer in people in England?(18)

5

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

*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.

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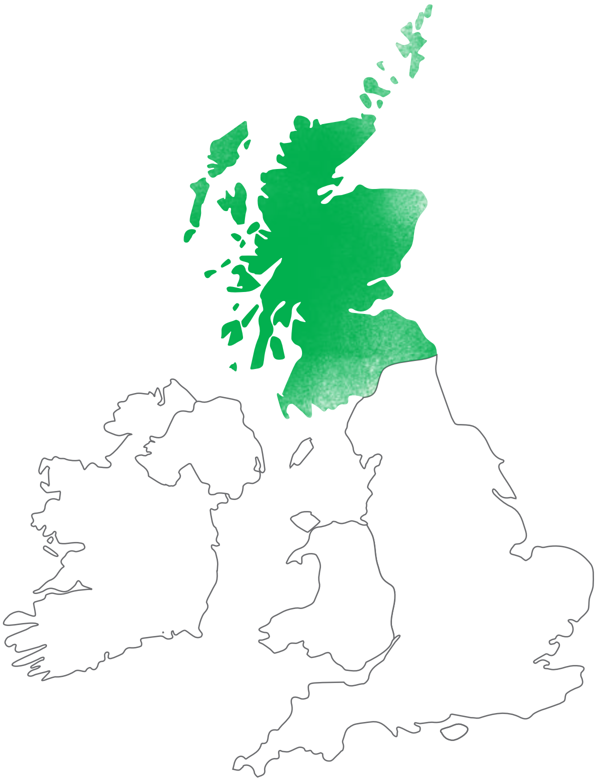
What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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How many people get bladder cancer per year in Scotland? (incidence)(6)

832

new cases of bladder cancer diagnoses in Scotland in 2012.

How many people die from bladder cancer per year in Scotland? (mortality)(10)

482

bladder cancer deaths in Scotland in 2012.

How many people are living with bladder cancer in Scotland? (prevalence)(122)

4,978

people were living with bladder cancer in Scotland in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).

What is the age-standardised* rate of incidence of bladder cancer in people in Scotland?(18)

10

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

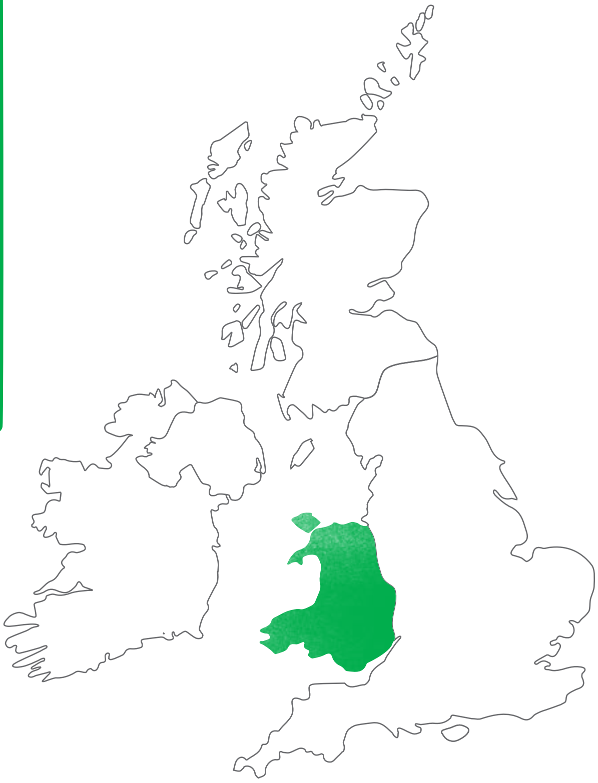
What is the age-standardised* rate of mortality from bladder cancer in people in Scotland?(18)

5

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

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



*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 people get bladder cancer per year in Wales? (incidence)(7)

550

new cases of bladder cancer diagnoses in Wales in 2012.

How many people die from bladder cancer per year in Wales? (mortality)(9)

264

bladder cancer deaths in Wales in 2012.

How many people are living with bladder cancer in Wales? (prevalence)(122)

5,546

people were living with bladder cancer in Wales in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).

What is the age-standardised* rate of incidence of bladder cancer in people in Wales?(18)

11

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

What is the age-standardised* rate of mortality from bladder cancer in people in Wales?(18)

5

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

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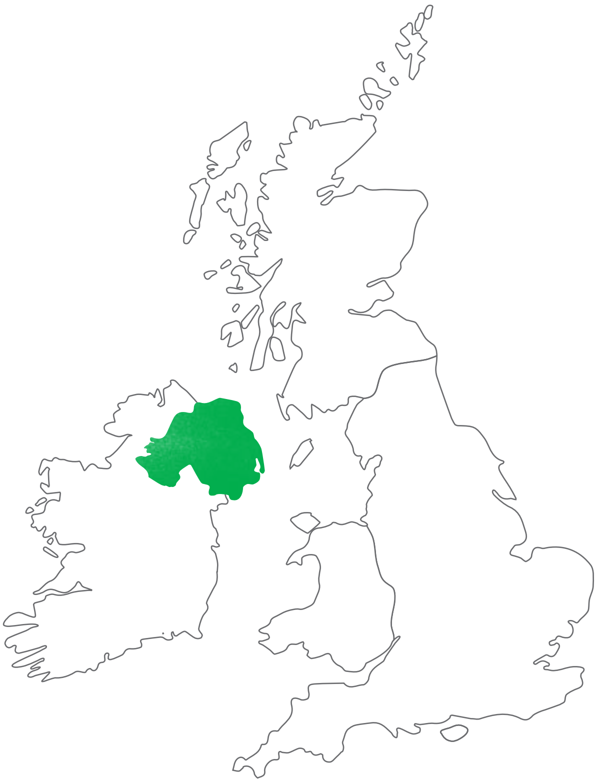
What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



How many people get bladder cancer per year in Northern Ireland? (incidence)(8)

196

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

How many people die from bladder cancer per year in Northern Ireland? (mortality)(8)

116

bladder cancer deaths in Northern Ireland in 2012.

How many people are living with bladder cancer in Northern Ireland? (prevalence)(122)

1,295

people were living with bladder cancer in Northern Ireland in 2010, based on people living up to 20 years post a cancer diagnosis (1993 and 2010).

What is the age-standardised* rate of incidence of bladder cancer in people in Northern Ireland?(11a)

11

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

What is the age-standardised* rate of mortality from bladder cancer in people in Northern Ireland?(11b)

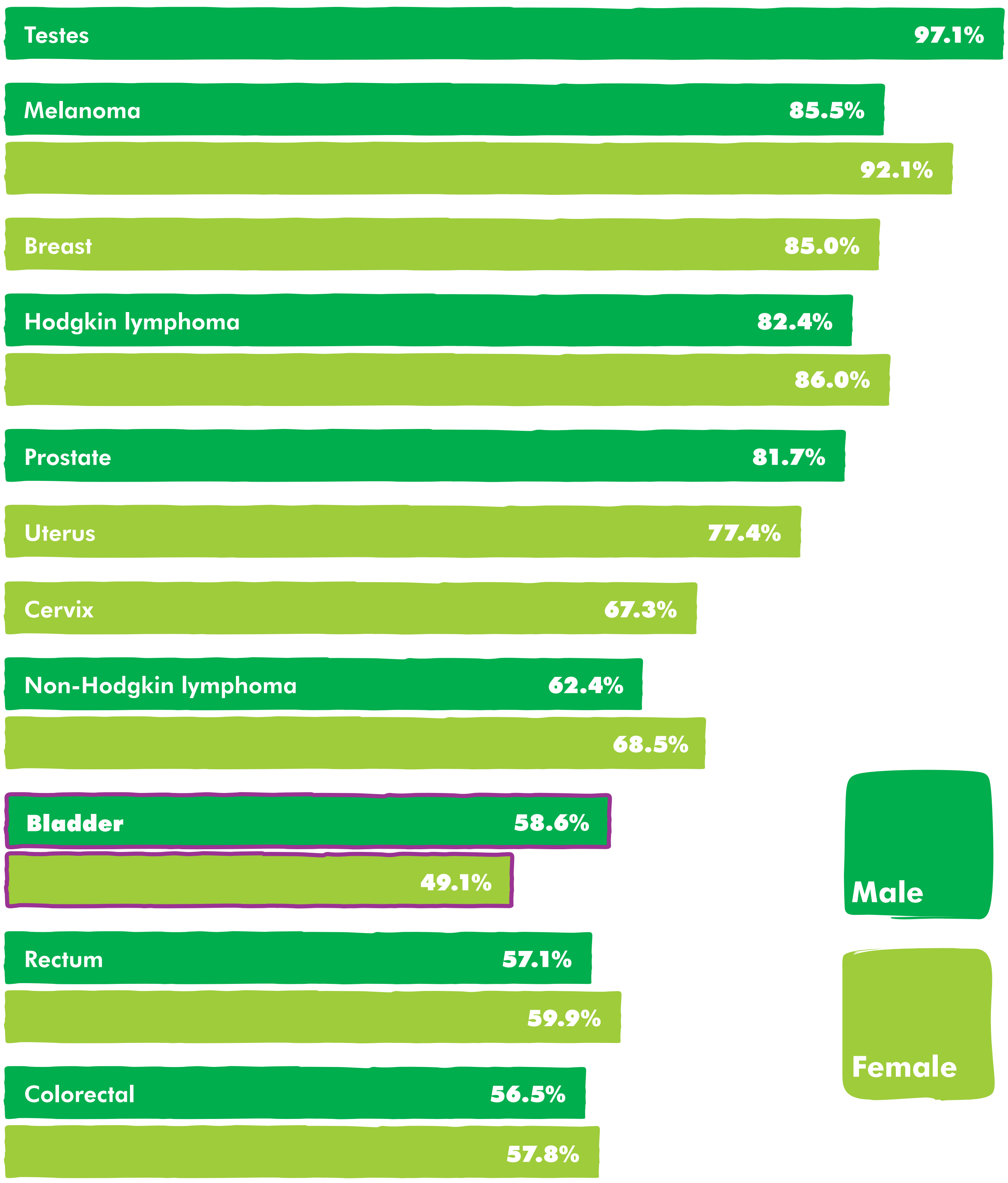
4

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

**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.

What proportion of people survive bladder cancer? (survival) (4)

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

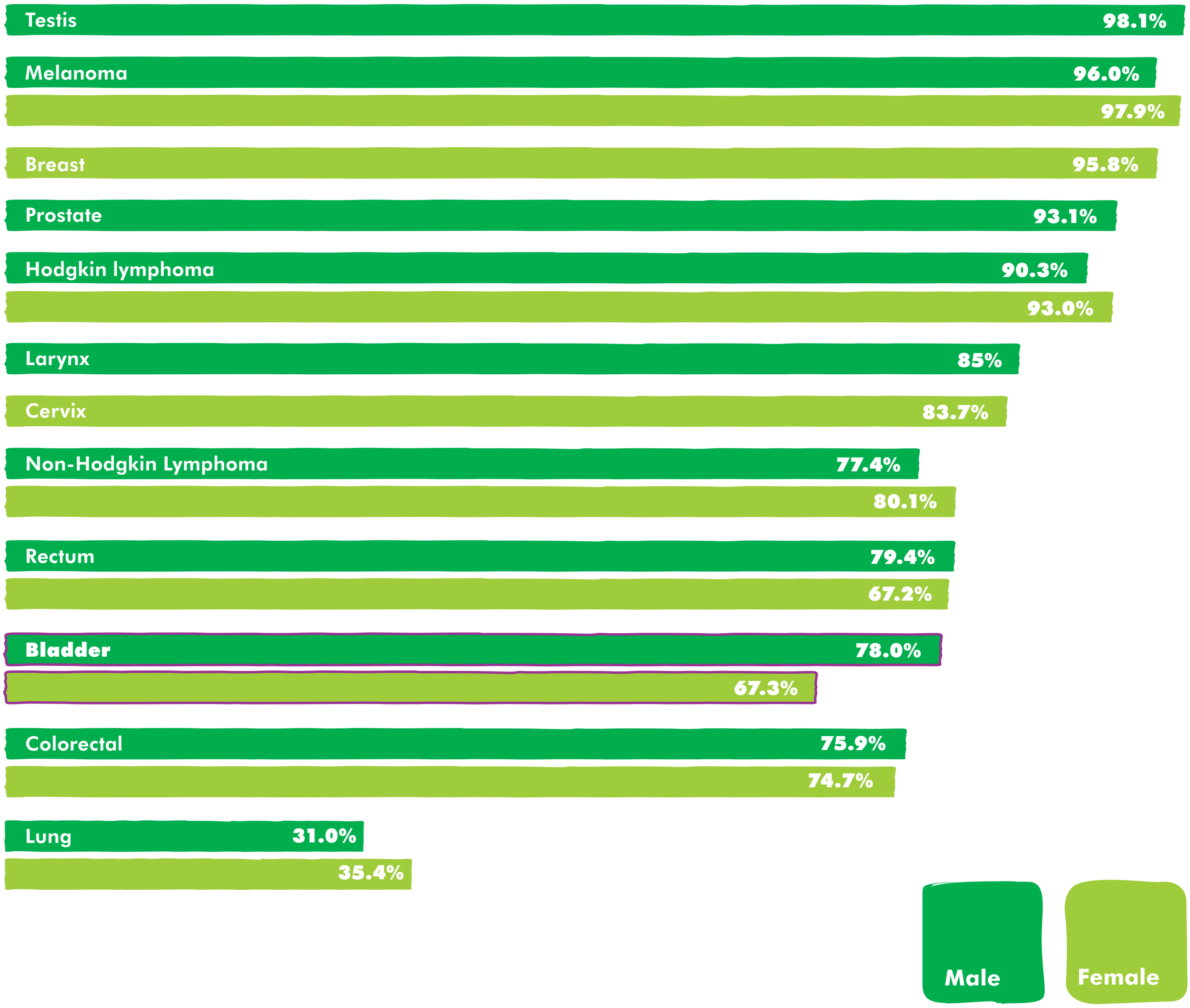


When compared to other cancers, bladder cancer has a relatively low 5 year survival rate (59% of men and 49% of women are alive 5 years after their diagnosis).

One reason for this is that many people are diagnosed too late for curative treatment. Earlier diagnosis would improve survival.

How many people live beyond one year of their bladder cancer diagnosis? (4)

Age-standardised relative survival estimates, 2007-2011, by gender, England.(108)



The estimated proportion of people living more than one year after their bladder cancer diagnosis is 78% for men and 67% for women. This is relatively low compared to the other most common cancers in England.

How have median survival times changed for bladder cancer?

Overall median survival time 40 years ago for all cancers was one year. The latest figures predict median survival time is now nearly six years. Over the last 20 years, the median survival time for bladder cancer has remained relatively static at around 9-10 years. (13)

How do UK survival rates compare internationally?

Specific data is not available on bladder cancer survival rates in the UK compared to internationally. However, for all cancers (not just bladder cancer), cancer survival rates in England are improving overall, but the most up-to-date international comparisons show that England still has worse 1- and 5-year cancer survival rates than many countries, including Canada, Australia, Sweden and Norway. This suggests there is more we can do to improve survival for people with cancer in the UK. (14)

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

Gender

There are more than twice as many cases of bladder cancer in men compared with women.

Bladder cancer is the fourth most common cancer in males in the UK, however for females it is the eleventh most common cancer, with a male:female ratio of 5:2.

It has been estimated that the lifetime risk of developing bladder cancer is approximately 1 in 40 for men and approximately 1 in 110 for women in the UK. (11)

Bladder cancer is the sixth most common cause of cancer death in UK men and the eleventh in women. (12)

Ethnic background

Incidence rates amongst Asian men are significantly lower compared to the incidence for White men. Incidence rates for Black people are also significantly lower in comparison to White men, with Black men having about half the risk of bladder cancer of White men.

For females there is a similar pattern whereby Black women have about two thirds the risk of getting bladder cancer in comparison to White women. This risk is significantly lower for Asian females. (11)

Age

The risk of getting bladder cancer increases with age, with around 8 in 10 cases of bladder cancer occurring in people aged 65 and over. (3)

Almost nine in ten deaths occur from bladder cancer in people aged 65 and over. (3)

Bladder cancer survival rates are higher for patients diagnosed at a younger age. The reasons for this are likely to include a combination of better general health, more effective response to treatment and earlier diagnosis in younger people overall. (3)

The five-year relative survival rates for bladder cancer in men in England during 2005-2009 ranged from 71% in 15-49 year olds to 41% in 80-99 year olds. Relative survival was lower in women for all of the age groups, ranging from 53% in 15-49 year olds to 34% in 80-99 year olds. (15)

Social background

Incidence data has found that the lowest bladder cancer incidence rates were recorded for the most affluent and the highest incidence rates were recorded for the most deprived groups. (11)

People from the most deprived socio-economic groups are 1.3 times more likely to get bladder cancer compared to people from the most affluent groups. (16)

The two main risk factors for bladder cancer are smoking and exposure to chemicals at work, which again suggests strong associations with socio-economic deprivation. (17)

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

Bladder cancer incidence, UK, 2008-2010

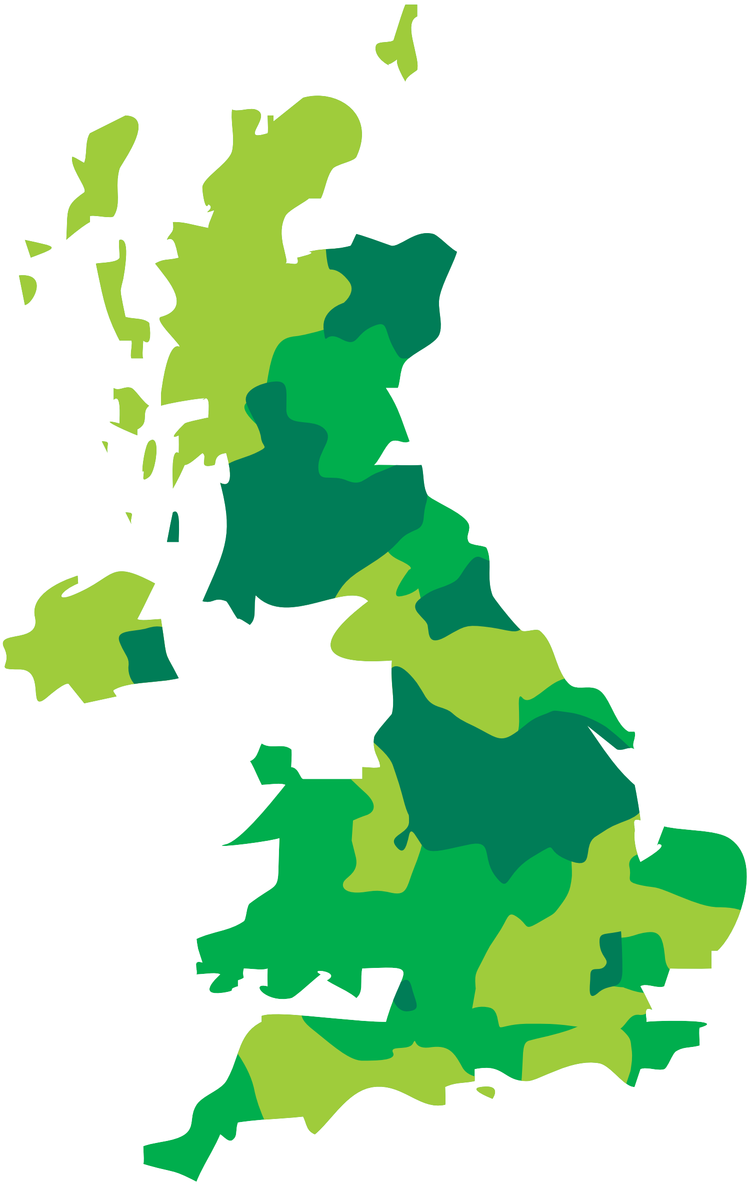
Low

Medium

High

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.

Bladder cancer incidence rates are higher in Northern England and Wales, and lower in Southern England and the North of Scotland.



Bladder cancer mortality, UK, 2009-2011

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.

Bladder cancer mortality rates are generally higher in the West of Scotland and the North East of England compared with the rest of the UK.

Trends in the data

What are the major trends?

Incidence rates are decreasing…

In the UK, incidence rates rose throughout the 1970s and 1980s, reaching a peak in the early 1990s. Since then male rates have fallen by more than a third (42%). For females rates have decreased by 38% since then.(11)

The decreasing incidence rates may be because of avoidable risk factors. Bladder cancer is the second most common tobacco-related cancer, and people who smoke are more likely to be diagnosed with bladder cancer (19) (33). A study published in December 2011 estimated that 38% of bladder cancer cases in men and 34% in women in the UK in 2010 were caused by smoking(32).

Exposure to environmental tobacco smoke during childhood may also increase the risk of bladder cancer.(19)

Additionally, around 7% of male bladder cancer cases in the UK are linked to occupational exposure to certain chemicals.(19)

People with a first-degree relative who has been diagnosed with bladder cancer have a higher risk of developing the disease.(3)

The age-specific bladder cancer incidence rates in the UK show a consistent decrease since the early 1990s for all age-groups under age 85. Reductions in smoking and exposure to occupational carcinogens may have played a role in the decrease, especially as the mortality rates have also decreased.(11)

Mortality rates are decreasing…

Generally there has been little change in female bladder cancer mortality rates although overall rates have fallen slightly from around 3.5 per 100,000 of the population in the late 1970s/early 1980s to 2.8 in 2012. In contrast, the male rates have shown a consistent fall since 1992 from 12.2 to 7.7 per 100,000 in 2012, a fall of 37%.(12)

Between 1971 and 2008 the mortality rates for men aged 45-64 fell by more than 60%. For females, the largest overall fall in bladder cancer mortality since 1971 has been in the 45-64 age-group. Rates have fallen from 3.8 per 100,000 in the early 1970s to 2.0 in 2008, a fall of almost 50%, but this data is masked by the all-ages rates.(12)

Overall survival rates are increasing…

Bladder cancer statistics should be interpreted with caution. This is because of different and changing classification/coding practices.

Relative survival for bladder cancer improved through the 1970s, 1980s and early 1990s. But since the late 1990s relative survival has decreased. Some of this decrease is likely to be due to different classification/coding practices, with an increasing proportion of bladder tumours now being coded as in situ or uncertain.

In men, five-year relative survival rates for bladder cancer increased from 44.0% in England and Wales during 1971-1975 to 58.2% in England during 2005-2009, having risen as high as 64.2% during 1991-1995. In women, five-year relative survival rates increased from 42.0% in 1971-1975 to 50.2% in 2005-2009, having risen as high as 59.0% during 1991-1995.(15)

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> **‘I believe that some of the chemicals I used frequently when in the Royal Navy may have played a contributory factor in the cancer; these carcinogenic chemicals are now banned by the Montreal Protocol.’**
>
> Joseph, 52, South-West

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 with bladder 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 routinely available for bladder 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 (p41), 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 bladder cancer?

1. Blood in the urine (haematuria)
2. Bladder changes
3. Pain in the lower part of the stomach or back

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

Data is not currently available on how many cases of bladder cancer are diagnosed early in the UK.

Low cancer awareness (for all cancers, not just bladder cancer) contributes to delay in presentation for cancer symptoms and may lead to delay in cancer diagnosis.(21)

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.(22)

No specific research into GP awareness of bladder cancer has yet been carried out.

General awareness of cancer signs and symptoms is lower in men, those who are younger, and from lower socio-economic status groups or ethnic minorities.(22)

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.(22)

However one study suggest that patients with bladder cancer were more likely to see the doctor promptly with the onset of symptoms.(119)

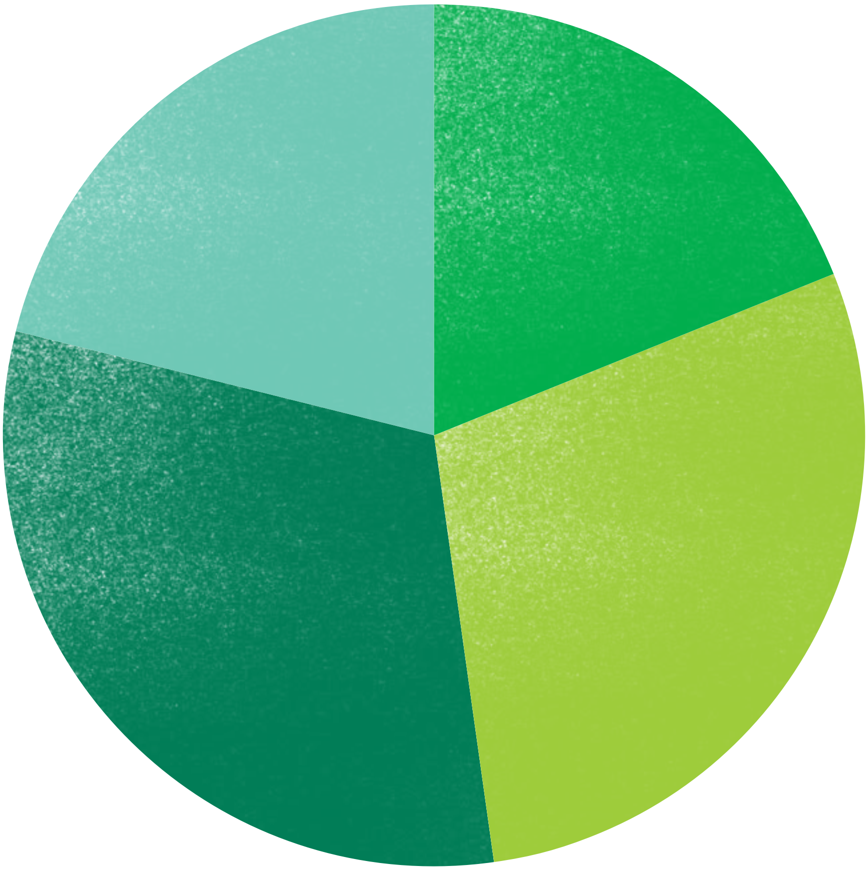
How well does screening work for bladder cancer?

There is currently no screening programme for bladder cancer.

‘It hit me pretty hard when I got the diagnosis but I took it on the chin. I take the attitude, if you succumb to it, it will drag you down. You have to keep your sense of humour.’

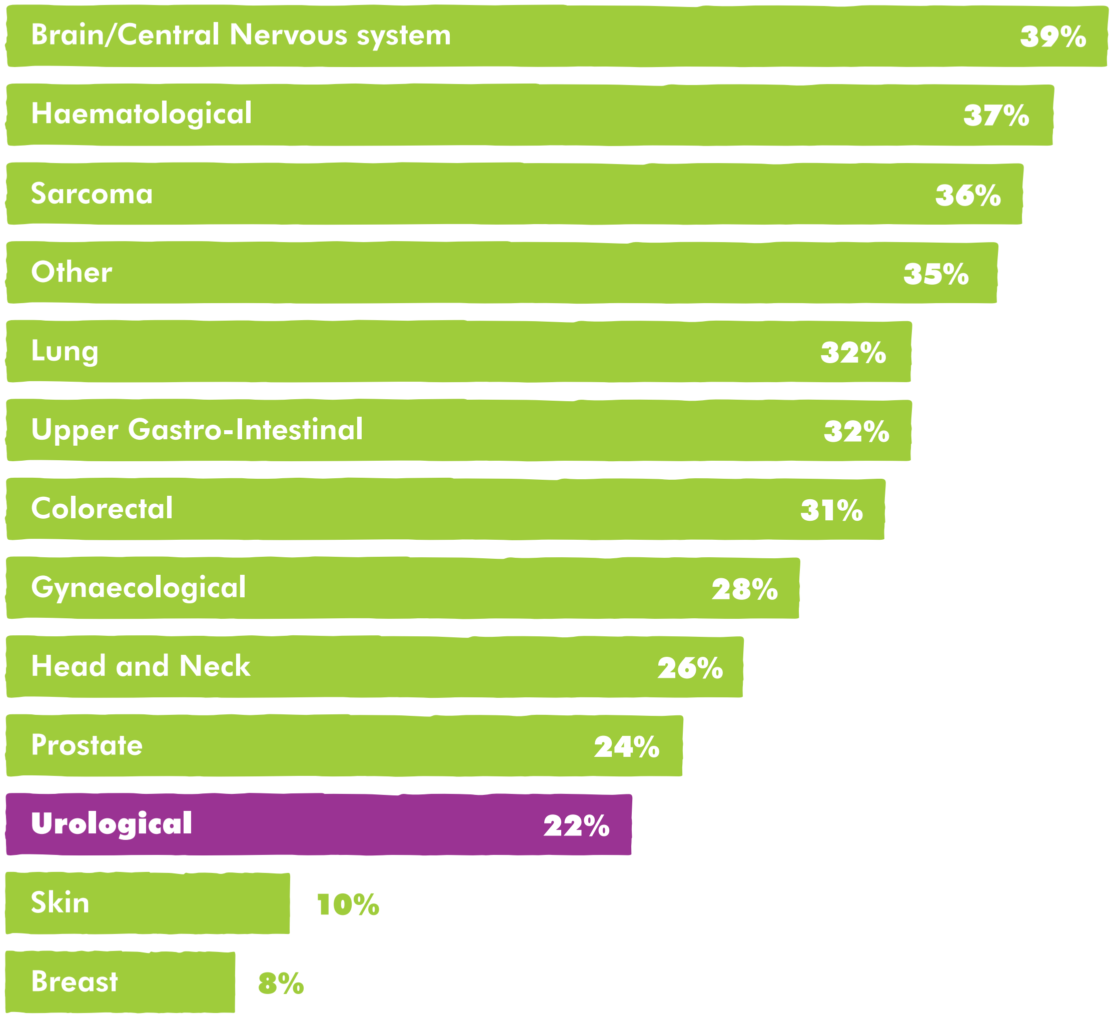
Sue, 60, North East

How is bladder cancer diagnosed? (Routes to diagnosis)[(23)]



19% of people newly diagnosed with bladder cancer were diagnosed via the emergency route, this is lower than the average for all cancers (23%). This suggests high rates of early presentation of signs and symptoms.

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



22% of people newly diagnosed with urological cancer (which includes bladder cancer) had to see their GP more than twice before they were diagnosed, compared with only 8% of breast cancer patients and 10% skin cancer patients.

How does stage at diagnosis relate to probable survival rates?

There is limited available data from the UK on the stage at diagnosis on survival for bladder cancer.

A cancer's stage describes its size and whether it has spread. A commonly used staging system for bladder cancer is the TNM system:

- T is the size of the tumour (cancer).
- N is whether it has spread to the nearby lymph nodes (sometimes called glands).
- M is whether the cancer has spread to other parts of the body (metastases)(109).

Another common staging system uses numbers to indicate the stage of the cancer(109):

Stage 0a	**Stage 0is or CIS (carcinoma in situ)**	**Stage 1**	**Stage 2**	**Stage 3**	**Stage 4**
There is a small area of cancer only in the bladder lining.	This is sometimes described as a flat tumour. The cancer cells are confined to the inside layer of the lining of the bladder.	The cancer has grown into the layer of connective tissue beneath the bladder lining.	The cancer has grown into the muscle of the bladder wall under the connective tissue layer.	The cancer has grown through the muscle of the bladder and into the fat layer surrounding it. It may have spread to the prostate, womb or vagina.	The cancer has spread to the wall of the abdomen or pelvis, the lymph nodes or to other parts of the body. If bladder cancer spreads to other parts of the body, it will most likely go to the lungs, liver or bones.

Anecdotal evidence from both the UK and US suggests that the later the stage at diagnosis (110,111), the poorer the chances of survival – in other words early diagnosis and treatment of bladder cancer saves lives.

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

According to recent data, over 95.6% of patients with suspected urological cancer (including bladder cancer) were seen by a specialist within 2 weeks of referral.

This is relatively good performance, comparable to an average of 95.6% for all cancers, and is higher than the operational standard of 93%.(106)

PHYSICAL AND MEDICAL NEEDS

There is **no screening currently available for bladder cancer.** However, research has shown that even if a screening programme were to be developed people may be prevented from taking part by co-morbidities, worry that screening would find bladder cancer and ease of arranging schedules. Another reason to avoid screening is social influence.(27)

Bladder cancer patients have a significantly better chance of survival if they are referred to hospital within 14 days of the onset of symptoms. The relationship between delay and survival in bladder cancer is complex, however, **and hospital delays may be influenced more by co-morbidity than by the characteristics of a tumour in the bladder.**(28)

Most bladder cancers are diagnosed on the early side while they are still only in the bladder lining. Between 80% to 90% with this stage of bladder cancer live for more than 5 years.75% to 85% of bladder cancers are this early type. These early bladder cancers can often be cured or controlled with minor surgery or treatment into the bladder.(25)

Smokers with a new diagnosis of bladder cancer are almost **five times as likely to quit** smoking as smokers in the general population.(33)

FINANCIAL NEEDS

Not specific to people with bladder cancer

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 a different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families.(29)

According to a 2013 Macmillan report, **83%** of people are, on average, **£570 a month worse off** as a result of cancer diagnosis.(112)

PRACTICAL AND INFORMATION NEEDS

32% of people living with bladder cancer **did not receive any written information** about the type of cancer they had.[113]

People living with bladder cancer are **more likely to be aware that smoking is a risk factor for bladder cancer if their urologist is the source of their understanding.** Therefore, urologists can play an integral role in affecting the patterns of tobacco use of those newly diagnosed.[33]

Not specific to people with bladder cancer

The strongest preference for information at diagnosis is information about prognosis. However, there are also many other information needs such as side effects of treatment, impact on family and friends, altered body image, self care and risks of family developing the disease.[31]

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Not specific to people with bladder cancer

The **preoperative prevalence of psychological distress** in patients diagnosed with bladder cancer is around 45%.[35]

67% of people with urological cancer (including bladder cancer) are given information about available **support groups** for people with their disease. **This is the lowest of any cancer group:** the second lowest, sarcoma, was 78%.[36]

Of the half of patients who want information, advice and support about the emotional aspects of cancer, **41% are not able to get it.**[30]

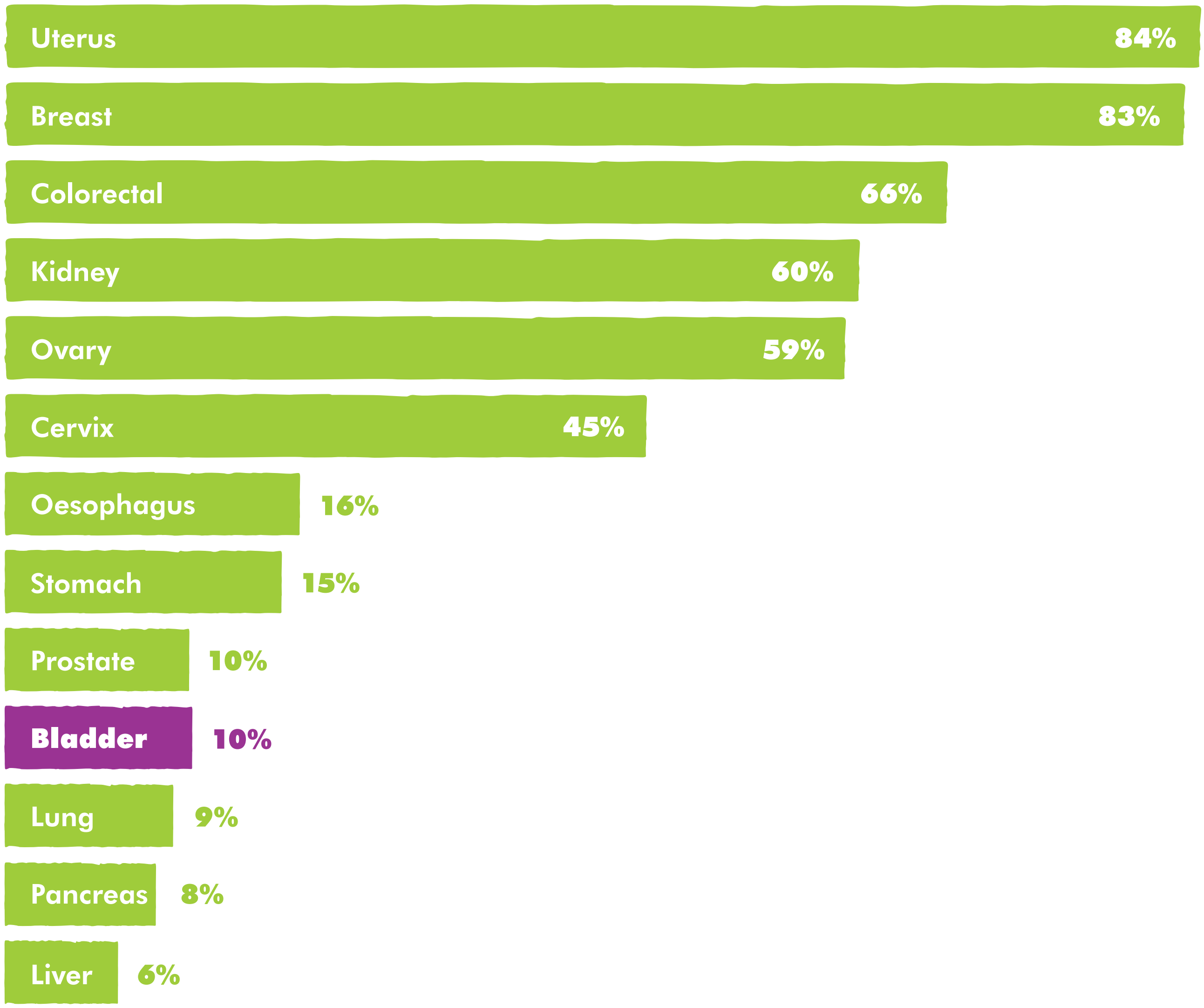
75% of people with cancer experience anxiety as a result of their cancer diagnosis. **Anxiety** is more common among women than men (79% of women compared with 66% of men).[30]

56% of cancer patients who experience anxiety **do not receive information, advice, support or treatment** for this.[30]

NEEDS AND EXPERIENCES

TREATMENT

Percentage of patients who had major surgical resection, 2004-2006 (37)



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

What treatments do bladder cancer patients get?

Surgery

For early stage bladder cancer the tumours are removed surgically using a cystoscope. Removing the whole bladder (radical cystectomy) is more common for invasive bladder cancer and involves taking out the whole bladder and the nearby lymph nodes. (38) However, radiotherapy is typically as effective as surgery in treating bladder cancer.

Chemotherapy

Chemotherapy before surgery or radiotherapy can shrink the tumour, aiming to make the treatment work better. Clinical trials have shown that chemotherapy before surgery, or before or during radiotherapy, can lower the risk of bladder cancer coming back in the future. Chemotherapy given after surgery may help to stop the cancer coming back and is called adjuvant chemotherapy. Usually a combination of drugs is used. (39)

BCG

Bacillus Calmette-Guerin (BCG) is usually given to people with early bladder cancer who have a high risk of the cancer coming back and growing into the muscle (becoming invasive). BCG is a type of immunotherapy. Immunotherapy stimulates the body's immune system to destroy cancer cells. (40)

Radiotherapy

For many people with invasive bladder cancer, radiotherapy works as well as surgery at curing it. Chemotherapy can be used at the same time as the radiotherapy. This is called con-commitant chemoradiation. (41)

Urological cancers (including bladder cancer) accounted for 19% of all radiotherapy episodes in England in 2011-2012. There were 25,366 radiotherapy episodes and 459,117 radiotherapy attendances. (42)

How many bladder cancer admissions are there and how many bladder cancer patients stay in hospital (and for how long)? (43)

In total, there were over 101,800 admissions to NHS hospitals in England (emergency and non-emergency) for bladder cancer during 2009-10.

The median length of stay for bladder cancer patients who were admitted was 2 days in 2011-12.

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

For early bladder cancer surgery is the main treatment. However, early bladder cancer can recur. In order to reduce the chances of this happening, further treatment can be undertaken. This can involve chemotherapy or the BCG vaccine.

People with bladder cancer at stage 2 or stage 3 are usually given treatment with the aim of curing the cancer or controlling it for a long time.

Surgery or radiotherapy are the main treatments that are used. Surgery usually involves removing the bladder, which can have some adverse side effects for some patients. Radiotherapy uses high-energy rays to destroy the cancer cells, and can mean that the bladder is not removed. Radiotherapy also causes side effects, and some people may have long-term side effects. (44)

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

There are currently 280 Urology Clinical Nurse Specialists (CNSs) in England(46)

Macmillan's internal data suggests that we had (as of June 2013) 137 Uro-Oncology/ Urology Macmillan nurse posts across the whole of the UK.(45)

What does this mean for patients?

76% of people with urological cancer (including bladder cancer) report that they have been given the name of a CNS.(47)

The uro-oncology clinical nurse specialist's role is to provide support and information, and act as a link between all the staff involved in the patient's care.(48)

Patients with access to a CNS report a better experience in relation to other aspects of their care, particularly regarding information about diagnosis and treatment, financial help, support and self help groups, and the availability of free prescriptions.(49)

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 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**

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

Bladder cancer patients are, together with lung cancer patients, most likely to have serious chronic cardiovascular and respiratory co-morbidity that often limit their fitness for major interventions.(34)

Just under half (47%) 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.(50)

Understanding other health conditions cancer patients may have can help to predict or explain decisions to treat, outcomes and longer term complications, as well as ensure care and support are tailored to the individual.

There is mounting evidence that co-morbidity affects the risk, disease progression and treatment of people with cancer.(51)

‘I did not have my bladder removed because I was deemed too old. Instead I have been on an immuna treatment for 2 years, a system I may have to live with for 10 years. In honesty the decision about my treatment was a bit rushed.’

Lincoln, 86, Midlands

PHYSICAL AND MEDICAL NEEDS

Radiotherapy to the stomach area can cause **side effects such as diarrhoea, nausea and tiredness,** as well as more specific side effects such as **inflammation of the bowel or bladder lining.** These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of treatment.(52)

In some people, the **bowel or bladder may be permanently affected by the radiotherapy.** If this happens, increased bowel motions and diarrhoea may continue, or the patient may need to pass urine more often than before, and blood may appear in the urine or in bowel movements.(52)

Radiotherapy to the pelvic region can sometimes cause **painful cracks in the pelvic bones** called pelvic insufficiency fractures. It is more likely to happen in people who have general weakening of their bones as they get older (osteoporosis). It is also more likely in people who are taking hormone therapies or steroids.(53)

People with bladder cancer aged **80 years or older** are **less likely to be treated with radical surgery** than young people. However, among patients aged 80 or older, such surgery had the greatest risk reduction in death from bladder cancer.(54)

21% of people with urological cancers (including bladder cancer) are **not given a choice of different types of treatment.**(55)

FINANCIAL NEEDS

Only **31%** of people with urological cancer (including bladder cancer) are given information about how to claim **financial help or benefits** by hospital staff. This is lowest of any cancer type, and can be compared to prostate cancer (40%) and lung cancer (70%).(58)

Not specific to people with bladder cancer

Many cancer patients experience **extra costs due to treatment.** Low income, younger age, chemotherapy and living rurally can lead to greater financial hardship.(56)

Recent research found **additional costs caused by cancer treatment include fuel charges** which arise from transporting cancer patients and their carers to and from appointments. This affects 69% of cancer patients and costs them, on average, £170 a month.(29)

Over a fifth of those surveyed by Macmillan were **affected by costs for over-the-counter or prescription medicines**, costing on average £8 a month.(29)

Contents

PRACTICAL AND INFORMATION NEEDS

17% of people with urological cancers (including bladder cancer) are given conflicting information during their stay in hospital.(60)

A recent German study of people with breast and urological cancers (including bladder cancer) has shown that during the first week of radiotherapy, patients rate **patient-doctor interaction and communication on treatment and disease** as important factors for their satisfaction.(61)

A Canadian study showed that information, open communication and support from family and friends are seen as the most important factors in helping patients adjust after surgery for bladder cancer. Patients require **clear, concise and consistent information about their cancer,** treatment options and care, in order to feel secure.(62)

Only **69% of people with urological cancers** (including bladder cancer) feel that the **possible side effects of treatment are explained to them** in a way that they understand. This compares to 78% of people with breast cancer and 76% of people with lung cancer.(63)

Not specific to people with bladder cancer

10% of people with cancer are **not given enough information** about their condition and treatment, but 2% feel that they are given too much.(59)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

One study into the emotional and psychological effects of bladder cancer shows that **family, relationships, health, and finance** are the most important determinants of quality of life during treatment, whereas **body image is not mentioned** by anyone. It also found that there is no difference in quality of life of patients before and after surgery.(65)

Not specific to people with bladder cancer

Amongst all cancer patients the **overall prevalence of psychological distress is 25%** among those who are undergoing, or have just finished, cancer treatment.(64)

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

Why are cancer survivors (all cancer survivors; not just bladder 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:

- **39%** who completed treatment in 2009/10 say that **no health** or **social care professional** talked them through the needs they might have.(121)
- **94%** experience **physical health condition problems** in their first year after treatment.(50)
- **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.(50)
- **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.(50)
- **40%** with **emotional difficulties** had not sought medical help or other support.(122)
- **23%** lack **support from friends and family** during treatment and recovery.(114)
- **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.(116)

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.(107)
- Currently only **25%** of cancer patients are receiving a holistic needs assessment and a care plan – both of these are essential in providing personalised care for cancer patients and their carers.(107)

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.

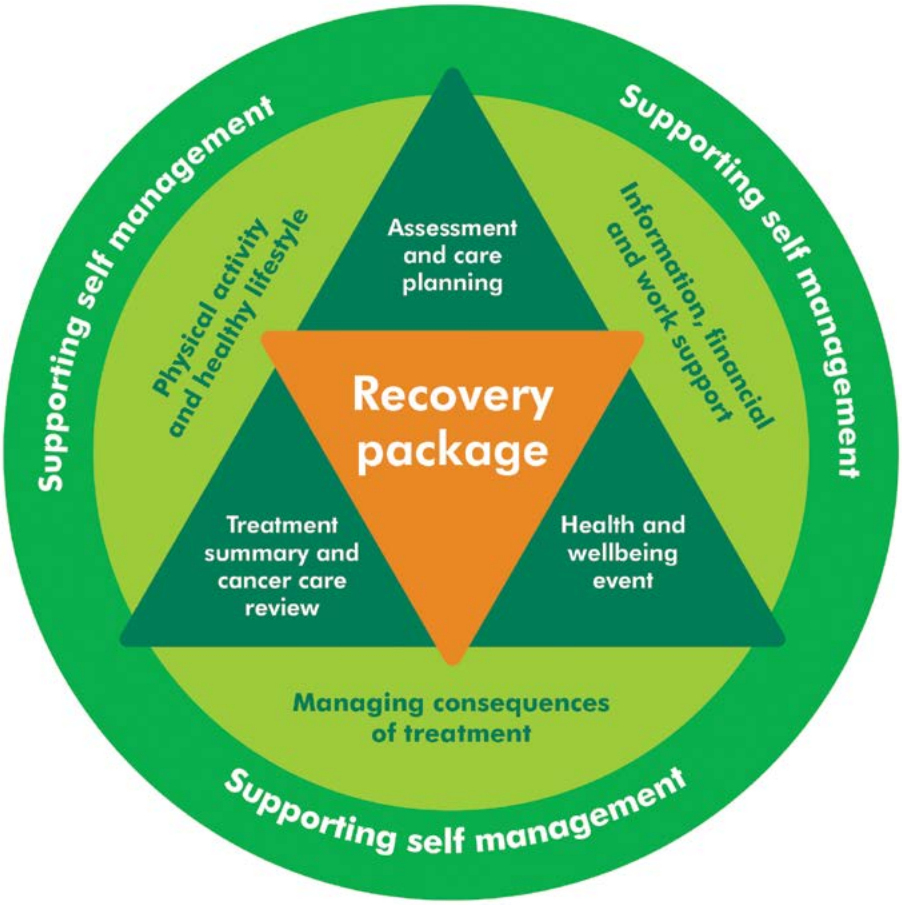
The document was followed by: **'Innovation to implementation: Stratified pathways of care for people living with or beyond cancer: A "how to' guide"'**.

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

Bladder cancer survivors who meet recommended daily exercise guidelines are **more likely to have better functional well-being, sexual function and body image than those who don't,** as well as experiencing less fatigue.(66)

A survey of bladder cancer survivors showed that **many are interested in receiving exercise counselling** and would prefer exercising at home, walking and moderate intensity exercise.(67)

Only **52% of people with urological cancers** (including bladder cancer) feel that they are given **enough care and help from health or social services** once they leave hospital. This is the lowest of any cancer group.(68)

The prevalence of **sexual dysfunction in patients with bladder cancer is very high** (54%) compared with an age- and gender-matched healthy population (20-45%). These patients and partners would benefit from proper sexual information in the outpatient clinic.(69)

Not specific to people with bladder cancer

However, 33% of all cancer survivors find **participation in vigorous activities very difficult** or report not being able to do them at all, while 16% find performing physical activities very difficult.(50)

FINANCIAL NEEDS

Not specific to people with bladder cancer

Among cancer patients the **main barrier to accessing benefits is a lack of knowledge about benefit entitlement.** This outweighs factors such as the perceived stigma of benefits and concerns about benefit fraud. Some people affected by cancer do not know that they can claim benefits even when they have completed initial treatment.(70)

The cancer journey – Survivorship

PRACTICAL AND INFORMATION NEEDS

82% of people with urological cancer (including bladder cancer) said they had **not been offered a written assessment and care plan.**(115)

Patients with bladder cancer need to be counselled not only about their predicted surgical risks and survival but also about the **impact their disease will have on their longer-term quality of survival.** Factors such as stoma maintenance, catheter use, urinary incontinence, body image and sexual side effects are potentially different for each major type of surgery for bladder cancer.(72)

Not specific to people with bladder cancer

Many cancer outpatients feel that their **information needs are not being met.** The most common areas of complaint are the lack of genetic information and information about lifestyle changes, and help with worries about spread or recurrence.(71)

If recurrence occurs, people with cancer generally express a renewed need for information and support. However, a survey of **patients suffering from a recurrence** showed that **only half of those asked had received adequate information.**(73)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

30% of people with urological cancers (including bladder cancer) feel that they are **not given enough emotional support by hospital staff** when they return as outpatients.(75)

Many people who have bladder cancer state that their psychological welfare is largely affected by health related quality of life. **The largest causes of concern are urinary and sexual health concerns.**(77)

Not specific to people with bladder cancer

23% of cancer survivors report **poor emotional well-being.**(74)

33% of people living with cancer **say a lack of support has caused them stress or anxiety** and more than 28% say they have experienced depression.(116)

All cancers including bladder cancer can have a long term effect on mental health. **Around 240,000 people** living with cancer are living with a **mental health problem** which can include **moderate depression to severe anxiety, and post-traumatic stress disorder (PTSD).**(76)

NEEDS AND EXPERIENCES

PROGRESSIVE ILLNESS AND END OF LIFE

What health data do we have on bladder 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, however, the number of people diagnosed with bladder cancer as a result of previous radiotherapy is extremely small.(79)

How many bladder patients are at the end of life?

Specific data for bladder cancer is not available, but for all cancers around 7% of patients are in the last year of life.(78)

What is the impact of giving patients palliative care?

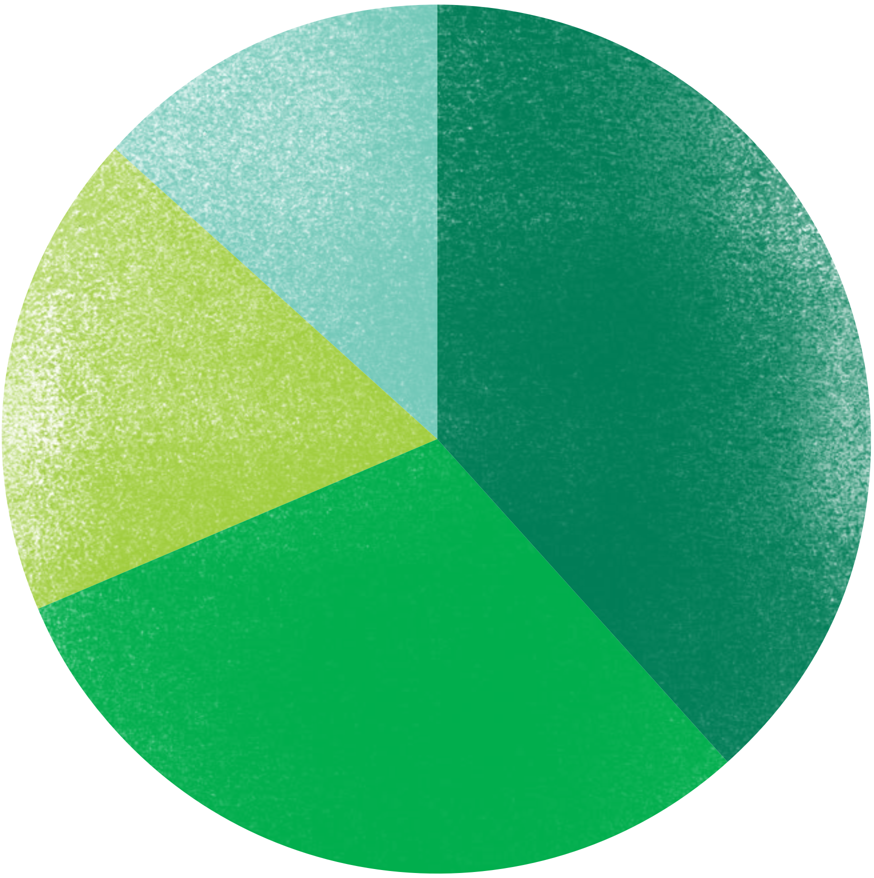
The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life-threatening condition: “Palliative care is the active holistic care of patients with advanced progressive 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.”

How many cancer deaths there are in each setting?

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 do people with cancer die?*(85)



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 bladder 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.(117) However, only 30% of those who died from cancer actually die at their home or own residence.(118)

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.(87)

‘He has doubts sometimes, but I think he’s coping very well. If he’s getting a bit maudlin, I take him out for a cup of tea at the local garden centre! We’re on a cancer journey and I don’t really know where it’s going to lead.’

Lorna, 66, wife of
bladder cancer patient.

PHYSICAL AND MEDICAL NEEDS

Not specific to people with bladder cancer

457,000 people (not just those with cancer) need good palliative care services every year in England, but around **92,000 people are not being reached.**(88)

Various symptoms are very common in advanced cancer, with **patients having a median of 11 symptoms on admission to palliative care.**(89)

More than one quarter of patients with all forms of cancer **experience serious pain 3 to 6 months before death** and **more than 40% were in serious pain during their last 3 days of life.**(90)

Amongst carers who have supported someone with cancer in the last 12 months, 27% are no longer providing this care because the person has since died – from this we estimate there are around **2.1 million people in the UK who have cared for someone with cancer in the last 12 months who are now bereaved.**(91)

The majority of people requiring palliative care will not receive specialist palliative care: they are cared for by the generalist workforce such as district nurses, GPs, and generalist hospital staff.(83)

FINANCIAL NEEDS

Not specific to people with bladder cancer

In 2010 Macmillan reported that **36% of people with a terminal cancer diagnosis did not claim the benefits they were automatically entitled to.** This amounts to over £90m.(92)

People with a terminal diagnosis who wish to travel may have their **travel insurance cover refused** by insurance companies, or be offered cover at prohibitively high premiums, stopping them from fulfilling their wishes.(93)

Death of a partner has been shown to be a **trigger for claiming income support.**(94)

A study on the financial impact of a death of a partner has revealed that on average, **widows' incomes fell to around 61% of their previous incomes,** compared with a drop to 74% of pre-bereavement incomes for widowers.(94)

Contents

PRACTICAL AND INFORMATION NEEDS

Not specific to people with bladder cancer

Cancer patients and their families often want information about how long they may have to live after hearing that their cancer is terminal. However **doctors tend to over-estimate the survival times of terminally ill cancer patients.** Results from a systematic review suggest that actual survival time is typically **30% shorter than predicted.**(95)

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

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Widows who lost their husbands to bladder cancer had an increased risk of experiencing **feelings of guilt if their spouse did not get enough pain relief compared** to widows who felt that their husbands had adequate pain relief. If a widow considered her husband had experienced poor care of treatment, she had an almost two-fold increased relative risk of feeling guilty. Therefore, feelings of guilt after bereavement may occur in response to the perception of inadequate health care.(97)

Not specific to people with bladder cancer

Cancer patients approaching death suffer more **psychological distress.**(98)

Amongst all cancer patients the **overall prevalence of psychological distress during or soon after treatment is 25%. For patient receiving specialist palliative care, the overall prevalence of psychological distress is 59%.**(99)

83% of people say they are scared of dying in pain, while 67% say they are scared of dying alone, and 52% are scared of being told they are dying.(99)

A survey by Macmillan of people who have received a cancer diagnosis found that **57% would like to spend the last weeks and days of their life at home**(79)**.** This rose to 73% if all their concerns, which included access to round the clock care, about dying at home were addressed. Only 1% of respondents would choose to die in hospital.(100)

LIFESTYLE AND PERCEPTIONS

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

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

- There are more than twice as many cases of bladder cancer in men compared with women.(11)
- People from the most deprived socio-economic groups are 1.3 times more likely to get bladder cancer compared to people from the most affluent groups.(102)
- Incidence rates amongst Asian men are significantly lower compared to the incidence for White men. Incidence rates for Black people are also significantly lower in comparison to White men, with Black men having about half the risk of bladder cancer of White men.(11)
- The risk of getting bladder cancer increases with age, with around 8 in 10 cases of bladder cancer occurring in people aged 65 and over.(11)

What is the demographic breakdown/ market segmentation of the 69,115 bladder cancer patients?

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

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.

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 Groups E and L, the following MOSAIC* groups shows greater than average representation amongst bladder cancer patients:

Group D: Small Town Diversity (Residents of small and mid-sized towns with strong local roots): People in Group D are most likely to be in their retirement years, although they can be quite diverse in terms of age distribution and type of household. A key characteristic is that they often live in communities small enough for houses of different ages and styles to exist in close proximity. Incomes are usually restricted by the relatively low wage rates offered by employers situated in small towns.

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. They are 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.

In addition to the above Groups, there are Types within Groups who are also well-represented amongst bladder cancer patients:

Group M (Industrial Heritage)
- Type 54: Clocking Off

Group C (Rural Solitude)
- Type 12: Country Loving Elders

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

- 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.

- 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 D: Small Town Diversity: The focus of many people's leisure is on home improvement and meeting up with friends in homes and gardens, in pubs at meetings of local associations and sharing trips to visit local sites of historical or environment distinction. Many people in this group read the Daily Telegraph or Daily Express.

- 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.

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

Contents

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

Before:

> **‘The doctor said I couldn’t have an operation, but I had to have a special treatment. It was all a bit vague and nobody explained what the pros and cons were, or offered me a second opinion.’**
>
> Winston, 86, North-East

> **‘My only criticism was in the lead up to the diagnosis of bladder cancer. A urine test was taken and this came back negative, I was then investigated for kidney problem and was only diagnosed with bladder cancer by accident.’**
>
> Matthew, 74, South-West

After:

‘I’ve stopped treatment now, as the effects aren’t good. They said from the start that the treatment wasn’t a cure, but they initially led me to believe that I’d be all right for the next 10 years.’

Nelson, 86, Midlands

‘I try to keep fit, but I’m worn out after five minutes. Has it all been worth it? I don’t know – I don’t seem to have got much advantage out of this extra life.’

Nigel, 86, Midlands

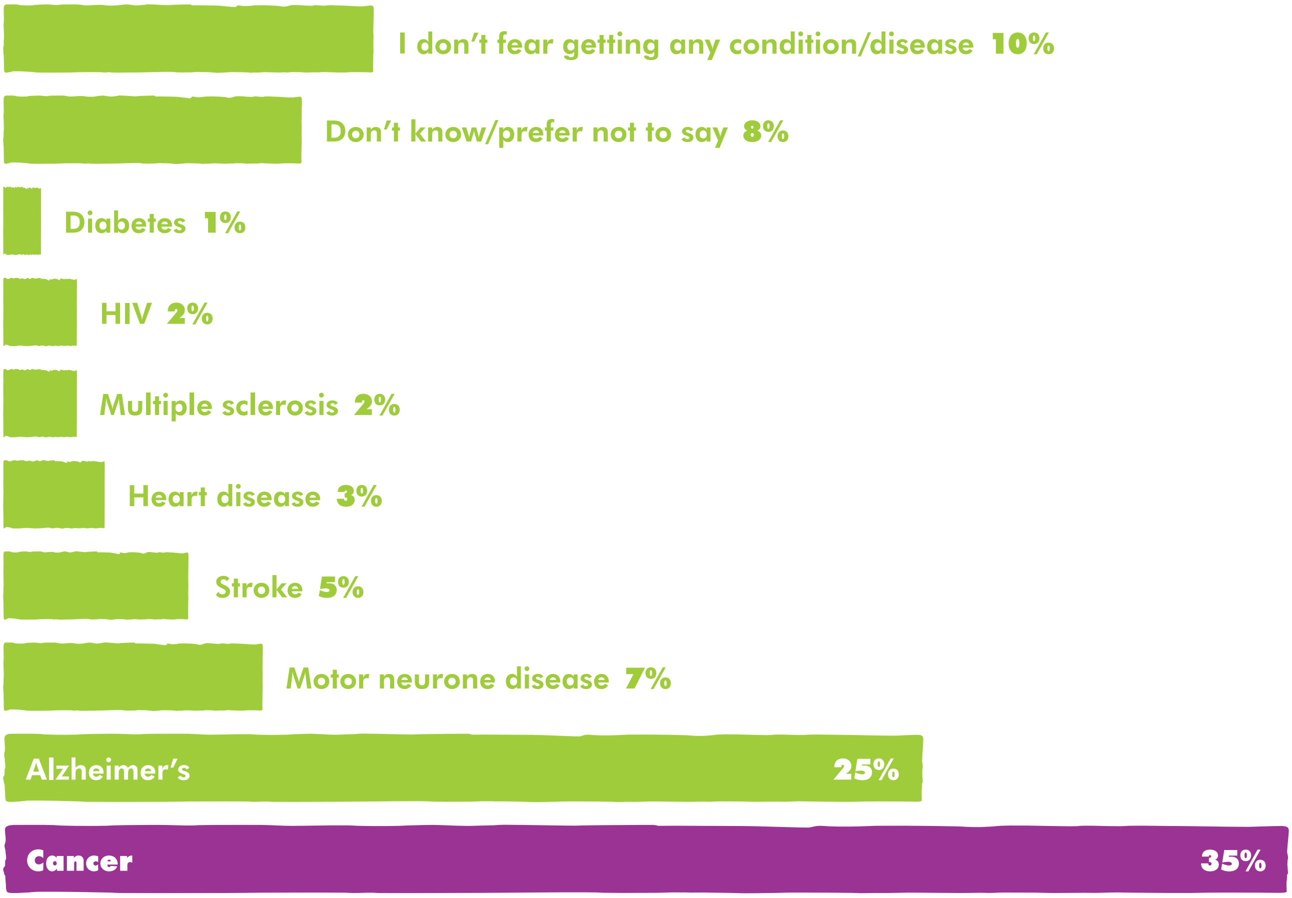
‘I’ve found that after each operation for my bladder cancer, gradually increasing walking and then gradually increasing the amount of golf has been beneficial.’

Sam, 74, Midlands

How does people's fear of bladder cancer compare to actual survival rates?

A 2011 study by Cancer Research UK surveyed people's fear of certain cancer types. However bladder cancer was not included in the research. Instead of showing the results of that research, we devote this page instead to a different set of results from the same survey which examined how people's fear of cancer compares to other feared diseases.(103)

How much do people fear cancer?(103)



35% of people in the UK fear cancer more than other life-threatening conditions – such as Alzheimer’s, stroke and heart disease.

What our bladder cancer online Macmillan Community members are saying...(104)

How the media* portrays bladder cancer...(105)

*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?

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

- The word 'dad' and 'mum' feature very prominently in the online community discussions, probably referring to parents who have bladder cancer. The online community may include many adult sons and daughters who are carers, and rely on this community for support that is not readily available elsewhere.

- There is more technical terminology in the online discussions than in the media: 'BCG', 'lymph', 'cystectomy' and 'nodes' 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 media however, tend to focus more upon the causes and diagnosis of cancer and those at risk, as opposed to the personal journey which the patients undertake, such as the emphasis upon 'risk', 'diet', and 'drugs'.

- The terms 'positive', 'hope', 'worried' and 'tough' in the online community discussions emphasise the physical and emotional difficulties experienced by bladder cancer patients. The media includes none of those, focusing instead on 'disease', 'cancer', 'pain'.

Contents

REFERENCES, SOURCES, NOTES AND CAVEATS

Quotes

The quotes on pages 23, 27, 37, 47, 52 and 53 are real quotes from people with bladder 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 Case Study who has kindly agreed to be featured in this publication.

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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

Code: MAC13842_11_14

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