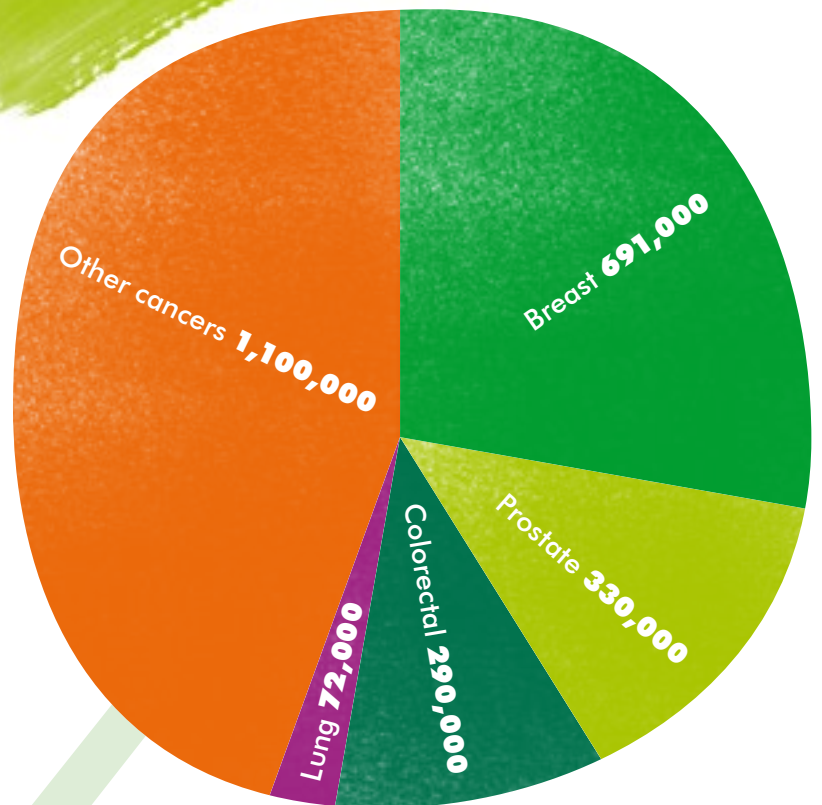


THE RICH PICTURE

PEOPLE WITH CANCER

WE ARE
MACMILLAN.
CANCER SUPPORT

Around
340,000
getting cancer
for the first time



2.5m

Living with cancer

66% aged 65+

Around
163,000
dying from
cancer

over
94,000
dying of other
causes



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 generic information about all people affected by cancer where the information applies to all groups of people with cancer and data specific to the particular groups where the need is significantly different and/or higher from the general population of people living 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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conditions set out in the Creative Commons licence.

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 73.

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 'The Cancer Guide' (MAC5765) more helpful:



The Cancer Guide
MAC5765

This title is 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.

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SUMMARY OF PEOPLE LIVING WITH CANCER

Key stats

More than 2.5 million people are living with or beyond cancer in the UK, rising to 4 million by 2030.⁽⁷⁾

In 2012 almost 340,000 people were diagnosed with cancer in the UK and over 160,000 people died of cancer.^(2, 3, 4, 5, 6)

By 2020 almost 1 in 2 people in the UK will develop some form of cancer during their lifetime.⁽³²⁾

Over half of people living with or beyond cancer have had the diagnosis for over 5 years.⁽⁹⁾

UK cancer survival rates are worse than the European average rate.⁽¹⁰⁾ Cancer survival in the UK has doubled in the last 40 years: overall median survival time 40 years ago was one year, whereas half of people diagnosed with cancer now survive their disease for a decade.⁽¹¹⁾

More than 2.5 million people are living with or beyond cancer in the UK.

Diagnosis

Breast, lung, prostate and bowel cancers together account for over half of all new cancers each year in the UK.⁽¹⁾

Four in five people with cancer are affected by the financial impact of cancer, on average incurring costs of £570 a month.⁽¹²⁾

The strongest preference for information at diagnosis is information about prognosis.⁽¹³⁾

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, around half of all people with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life.⁽¹⁴⁾

Breast, lung, prostate and bowel cancers together account for over half of all new cancers each year.

Treatment

The effects of cancer and its treatment can impact people's lives in many different ways. Fatigue is a very common and frustrating problem, with 65% of cancer survivors saying that they have to deal with fatigue following treatment.⁽¹⁵⁾

Costs associated with outpatient appointments affect almost three-quarters (71%) of people living with cancer, and over a quarter (28%) incur costs for inpatient admissions.⁽¹²⁾

In a 2010 survey around a quarter of cancer patients said they received no information from health and social care professionals about their condition, its treatment and effects, or support services available in their local area.⁽¹⁶⁾

Half of people with cancer want information, advice and support about the emotional aspects of cancer, of whom 41% are not able to get it.⁽¹⁷⁾

The effects of cancer and its treatment can impact people's lives.

Survivorship

At least 500,000 people in the UK are facing poor health or disability after treatment for cancer – approximately one in four (25%) of those diagnosed with cancer.⁽¹⁸⁾

Some people affected by cancer 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.⁽¹²⁾

Around 240,000 cancer survivors are living with mental health problems, which can include moderate to severe anxiety or depression, and post-traumatic stress disorder (PTSD).⁽¹⁸⁾

At least 500,000 people in the UK are facing poor health or disability after treatment for cancer.

End of life

73% of people who died from cancer would have liked to have spent the last weeks and days of their life at home.⁽²⁰⁾ However, only 30% of those who die from cancer actually die at their home or own residence.⁽⁶⁾

A number of symptoms are very common in advanced cancer, with patients having an average of 11 symptoms on admission to palliative care. Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common, occurring in some combination in virtually all patients.^(21, 22)

More than £90 million in disability benefits is unclaimed by people diagnosed with terminal cancer in the UK.⁽²³⁾

Cancer patients approaching end of life have increased levels of psychological distress.⁽²⁴⁾

Cancer patients approaching end of life have increased levels of psychological distress.

Specialist themes

Nearly six in ten (58%) people with cancer feel their emotional needs are not looked after as much as their physical needs.⁽¹⁷⁾

Just under half (47%) of all people living with cancer 1-5 years post treatment have at least one other chronic condition. This includes 15% who have two, and 6% who have three other chronic conditions.⁽²⁵⁾

63% of people with cancer living with one or more other chronic conditions report general health problems. This is 30% higher than people with cancer but no other chronic conditions and 46% higher than 'healthy people'.⁽²⁶⁾

58% of people with cancer feel their emotional needs are not looked after as much as their physical needs.

INTRODUCTION TO CANCER

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Cancer is not a single disease with a single cause and a single type of treatment.

Although cells in different parts of the body may look different and work in different ways, most repair and reproduce themselves in the same way. Normally, cells divide in an orderly and controlled way. But if for some reason the process gets out of control, the cells carry on dividing, and develop into a lump called a tumour. Tumours can be either benign (noncancerous) or malignant (cancerous). Doctors can tell whether a tumour is benign or malignant by removing a piece of tissue (biopsy) and examining a small sample of cells under a microscope.

In a benign tumour, the cells do not spread to other parts of the body and so are not cancerous. However, they may carry on growing at the original site, and may cause a problem by pressing on surrounding organs.

In a malignant tumour, the cancer cells have the ability to spread beyond the original area of the body. If the tumour is left untreated, it may spread into surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system. When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a secondary cancer or a metastasis.⁽²⁷⁾

What is included in this document?

We know that while the cancer journey is different for every person there are nevertheless common themes shared by many people living with cancer. This Rich Picture document is intended to tell the unique story of living with cancer. Its purpose is to show who is affected by cancer, how this experience typically varies across stages of a cancer journey and how it compares to the general population and people living with cancer in other European countries.

'The Rich Picture on people with cancer' is intended to be the 'master document' in a suite of other similar documents produced by Macmillan's Evidence Department. Please see the full list of all the Rich Pictures on the document's inside back cover. This document aims to summarise key figures and common themes of need and experiences with references to other Rich Pictures in the suite and related Macmillan publications. Green panels below different sections provide details for further information.

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 want to help other people with cancer by telling them that the diagnosis of cancer is not always doom and gloom, that there is light at the end of the tunnel, and that sometimes cancer can be a life changing experience for the better.'

Rebecca, 54

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people with 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.⁽⁷⁾

To help support every person with cancer, Macmillan has developed the 'Nine Outcomes' - nine statements that people with cancer have told us they want to be able to say about their cancer experience. It is our vision that by 2030, every person living with cancer will be able to say that the Nine Outcomes are true for them.

More than 2.5 million people are living with or beyond cancer in the UK, rising to 4 million by 2030.

How is this different for people with 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, and the information used to help focus our efforts to reach those most in need of support.

To read more about the state of cancer in the UK in terms of Macmillan's Nine Outcomes you can access our '**Cancer in the UK 2014**' report.

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

KEY STATISTICS ON PEOPLE WITH CANCER

This section presents some of the key stats and facts relating to people with cancer. You may benefit from referring to the jargon buster on page 82 for details on some of the terms used in this section. Please note that prevalence, incidence and mortality data on all cancers exclude non-melanoma skin cancer.

1,000

people will be diagnosed with cancer every day in the UK by the end of 2016.^(2, 3, 4, 5)

442

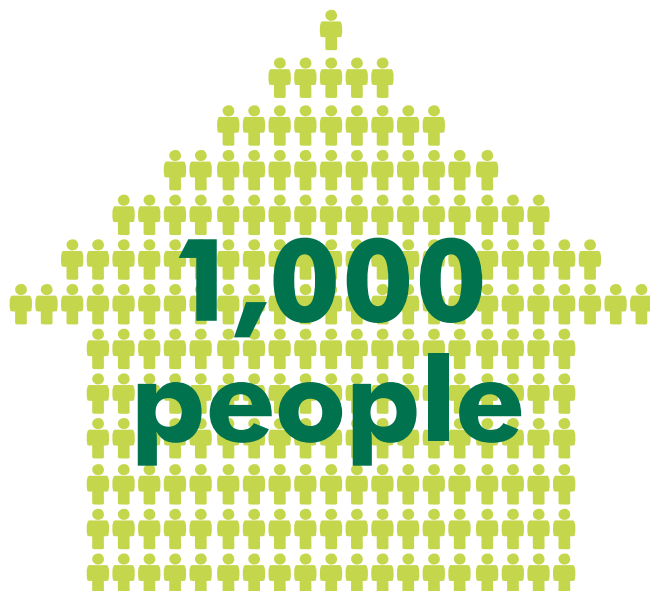
people die of cancer every day in the UK.⁽⁴⁻⁶⁾

2.5 million

people are living with or beyond cancer in the UK, rising to 4 million by 2030.⁽⁷⁾

Cancer: A colossal change⁽¹²⁵⁾

Cancer incidence, 1996 – 2016, UK



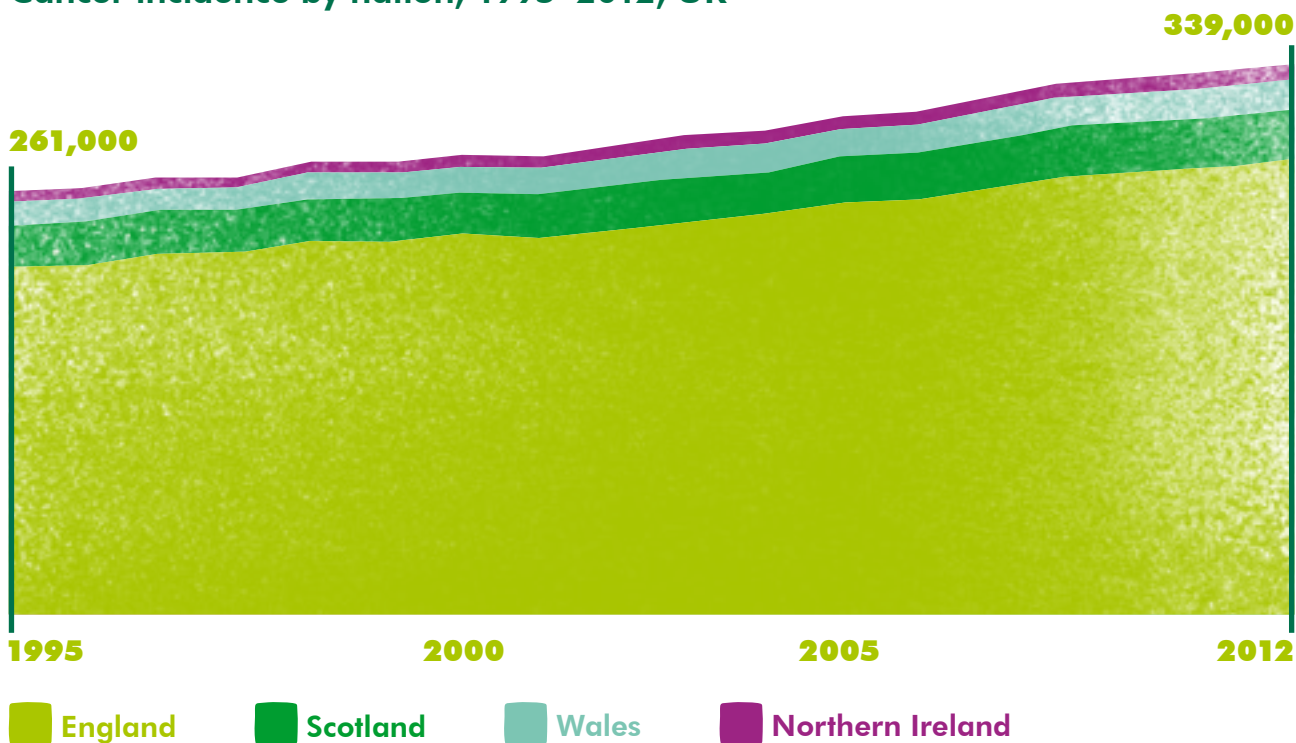
By the end of 2016, there will be more than 1,000 people diagnosed with cancer every day in the UK.



That's an extra 100,000 people diagnosed in a year compared with 20 years ago.

Are more people getting cancer?^(2, 3, 4, 5)

Cancer incidence by nation, 1995–2012, UK



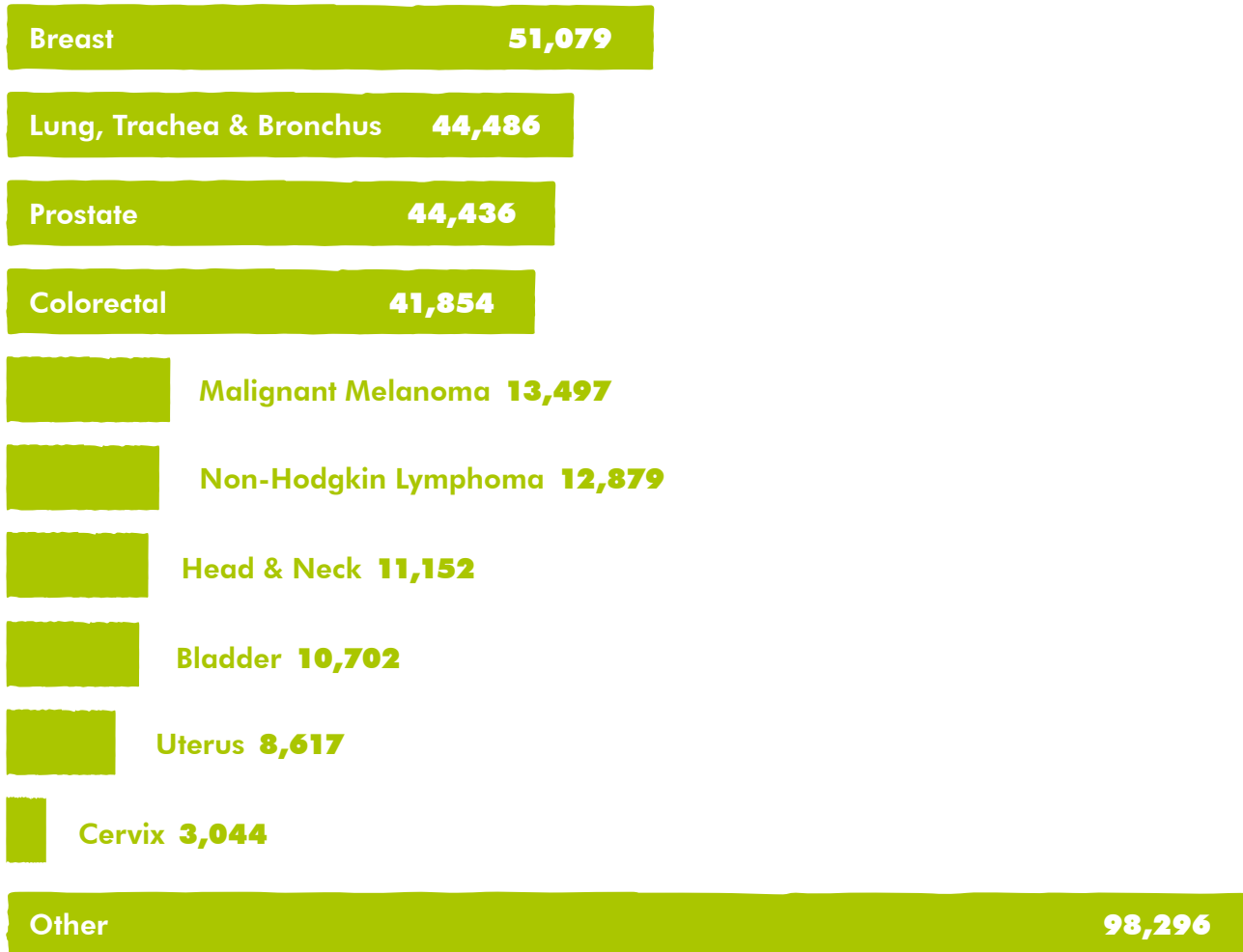
The number of new cases of cancer diagnosed every year has grown from 261,000 in 1995 to 339,000 in 2012. This is partly due to the growth in the UK population, partly due to the population ageing and partly due to the cancer incidence rate rising in the last decades. This may be related to many factors, including increased uptake of screening programmes, better diagnosis and rise in risky lifestyle factors.

There have been large increases in the incidence of many cancers strongly linked to lifestyle, such as kidney, liver, skin (malignant melanoma), oral and uterine (womb).⁽¹⁾

Age-standardised cancer incidence (and mortality) rates in 2012 were higher in Scotland, when compared to other UK nations.⁽²⁹⁾

How many people get cancer per year?⁽²⁻⁵⁾

Cancer incidence by cancer type, 2012, UK



In total almost 340,000 people were diagnosed with cancer in the UK in 2012.

Are people now more likely to survive cancer?⁽¹⁾

Cancer survival, 1970-2012, England and Wales

1970s:
Cancer is mostly about dying from cancer

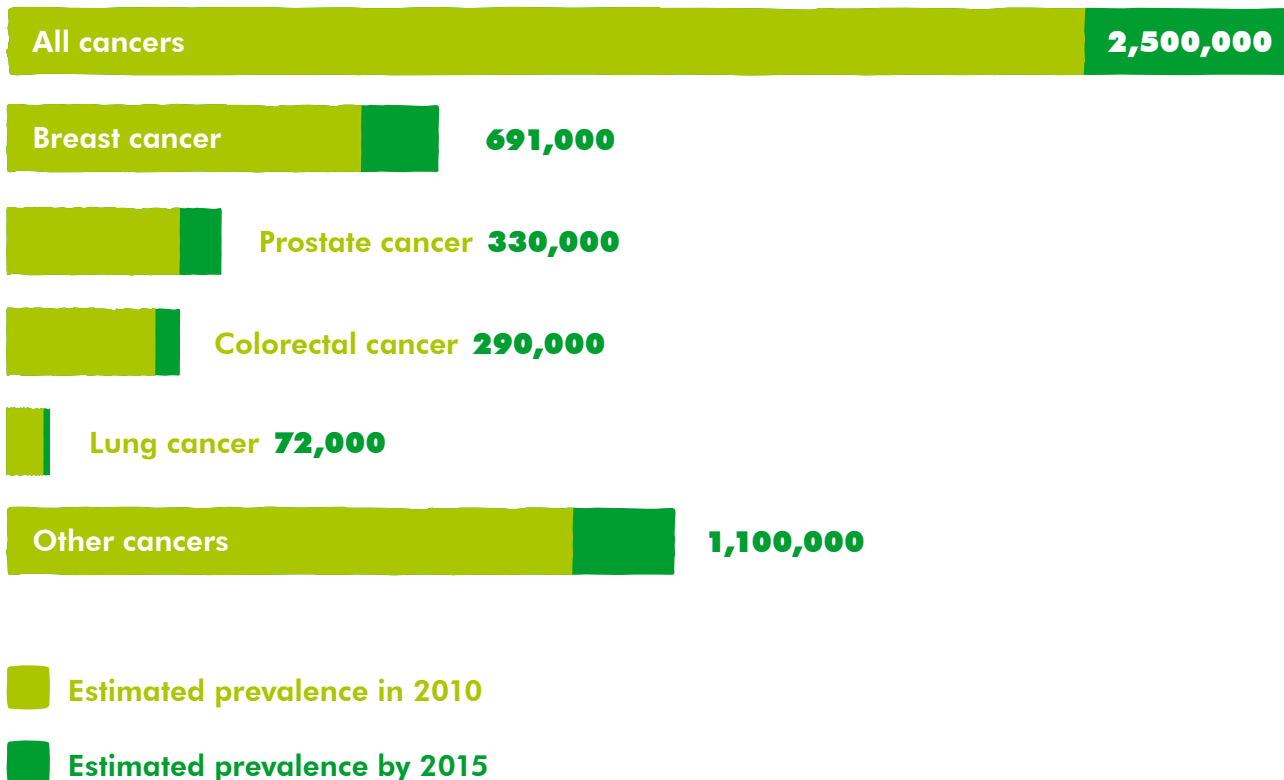
2010 onwards:
Cancer is increasingly about living with cancer



Half of people diagnosed with cancer in England and Wales survived their disease for at least ten years in 2010-2011.⁽¹⁾

How many people live with cancer?⁽³⁰⁾

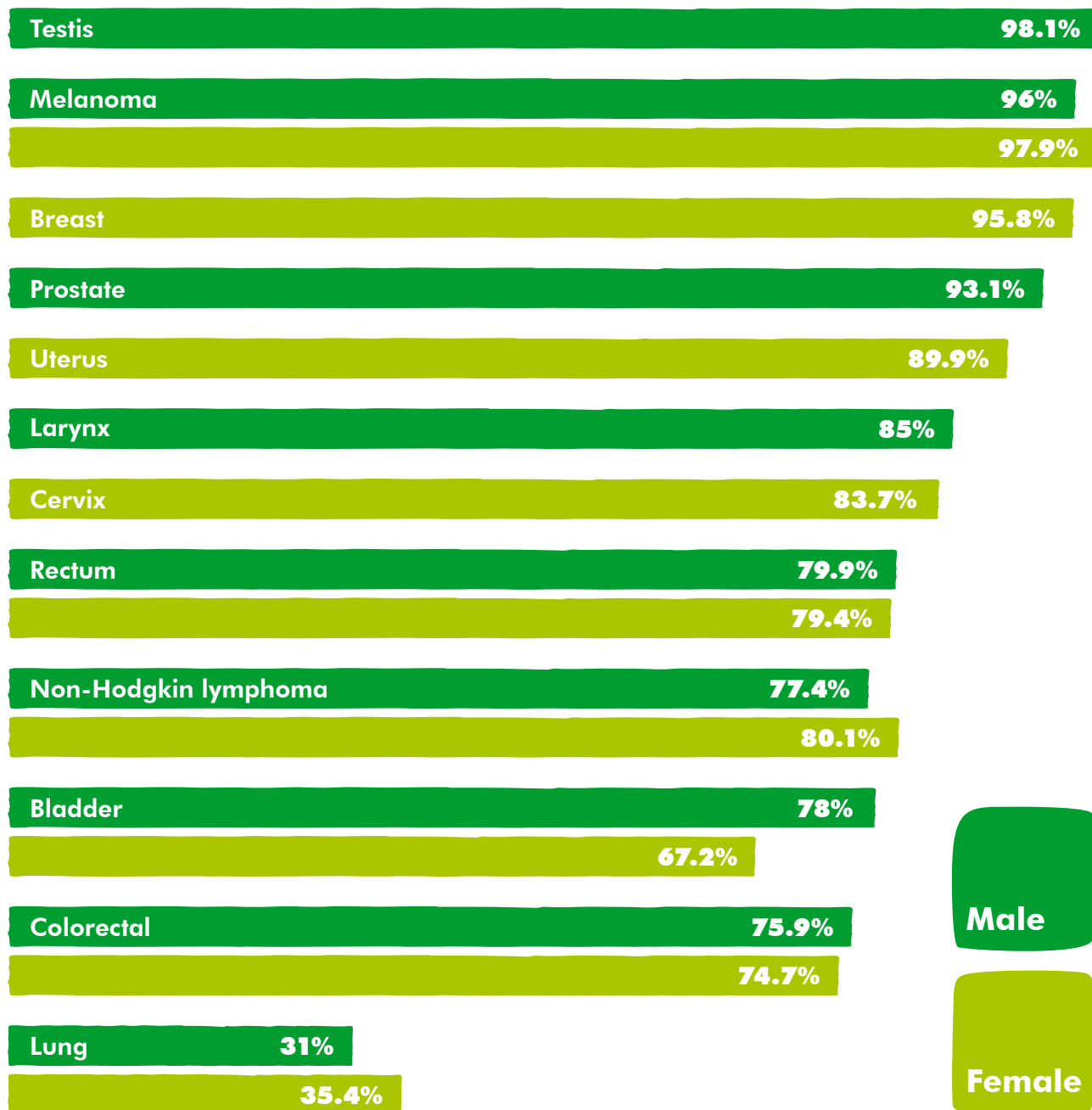
Estimated cancer prevalence (all cancers combined and four most commonly diagnosed), 2010-2015, UK



There are an estimated 2.5 million people living with cancer in the UK in 2015. The number has grown by over 400,000 since 2010. The increase has varied significantly by cancer type. For example, there was an estimated 11% increase in the number of people with lung cancer, compared with a 27% increase in the number of men with prostate cancer.

How many people survive cancer beyond 1 year (1-year survival)?⁽³⁵⁾

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



Over 70% of people diagnosed with cancer are still alive at least a year after their diagnosis in England.⁽³⁵⁾ For Wales specifically the one-year survival is 70%.⁽³⁷⁾

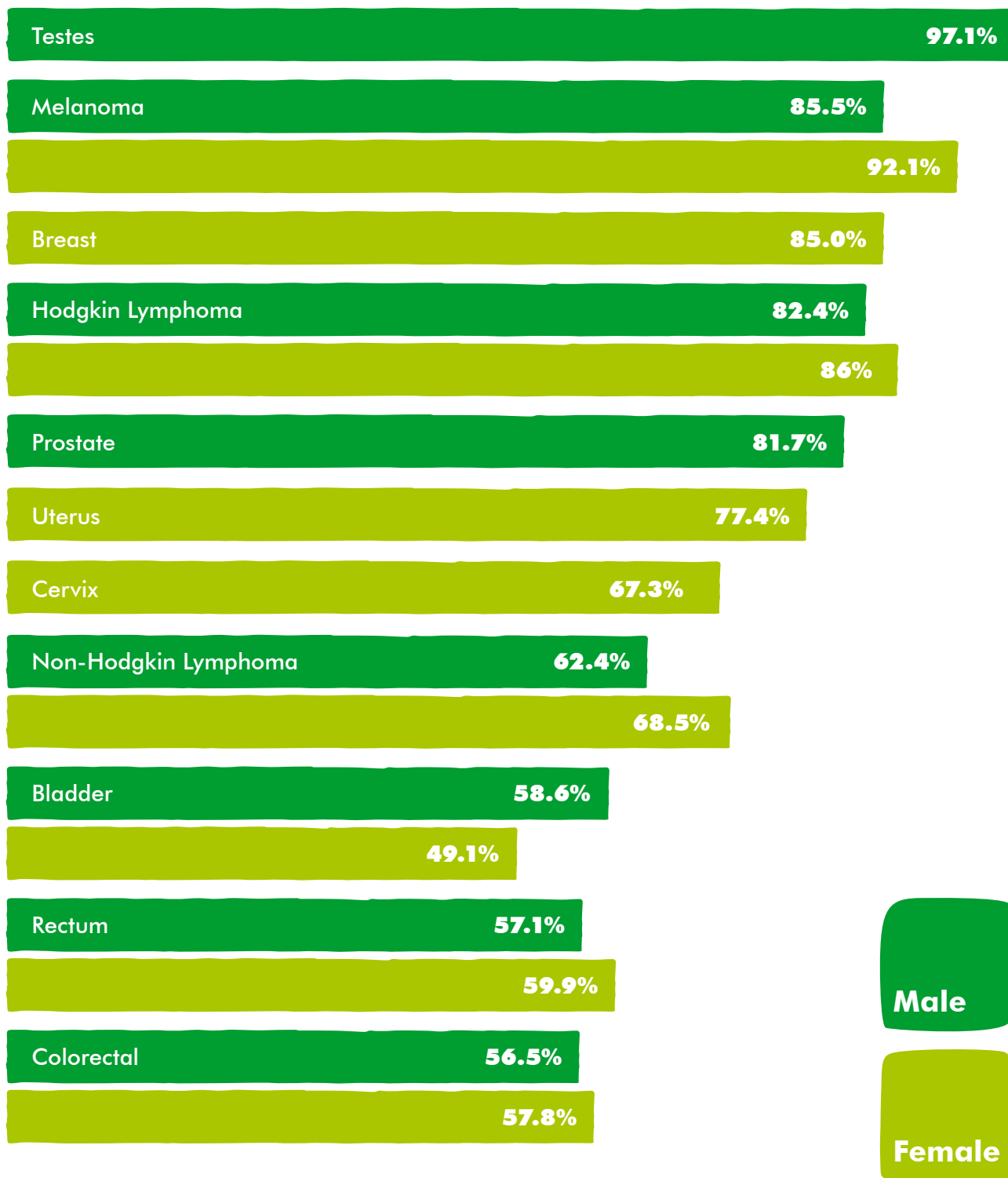
In Northern Ireland the age-standardised estimate of one-year survival for all cancers is 70%.⁽⁴⁾

In Scotland the age-standardised one-year cancer survival in 2003-2007 was 44% in males and 51% in females.⁽³⁶⁾

Please note that due to differences in methodologies cancer survival rates are not comparable between the nations.

How many people survive cancer beyond 5 years (5-year survival)?⁽³⁵⁾

Relative 5-year survival rates by gender, 2007–2011, England



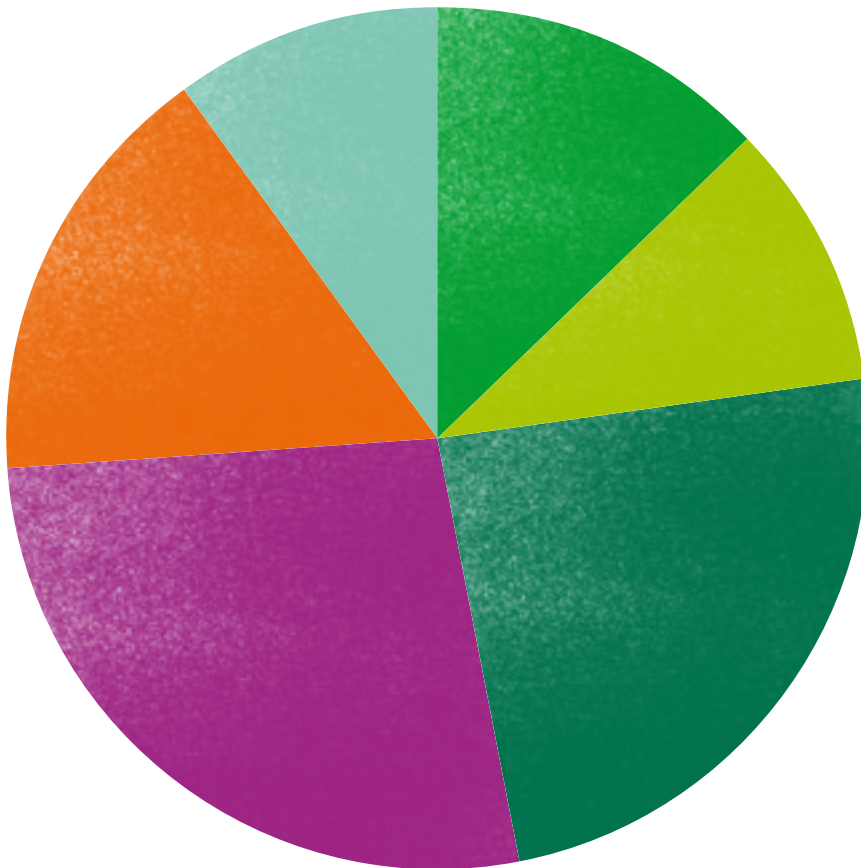
On average (across all cancers) 54% people living with cancer are likely to live five or more years after their diagnosis in England. This varies for different cancer types.⁽¹⁾

In Northern Ireland the age-standardised five-year survival in 2003-2007 for all cancers was 50%.⁽⁴⁾

Please note that due to differences in methodologies cancer survival rates are not comparable between the nations.

How does time since diagnosis vary among people living with cancer?⁽⁹⁾

Time since diagnosis in people diagnosed with cancer between 1991 and 2010, UK



0-1 years

13%

1-2 years

10%

2-5 years

24%

5-10 years

27%

10-15 years

16%

15-20 years

10%

Over half of people living with cancer are long-term cancer survivors (at least five years from diagnosis).

To find out more about the people living with cancer see Macmillan funded work with National Cancer Intelligence Network (NCIN) on **'Cancer prevalence'**

What are the survivorship outcomes of people with cancer?⁽⁴¹⁾

Limited survival

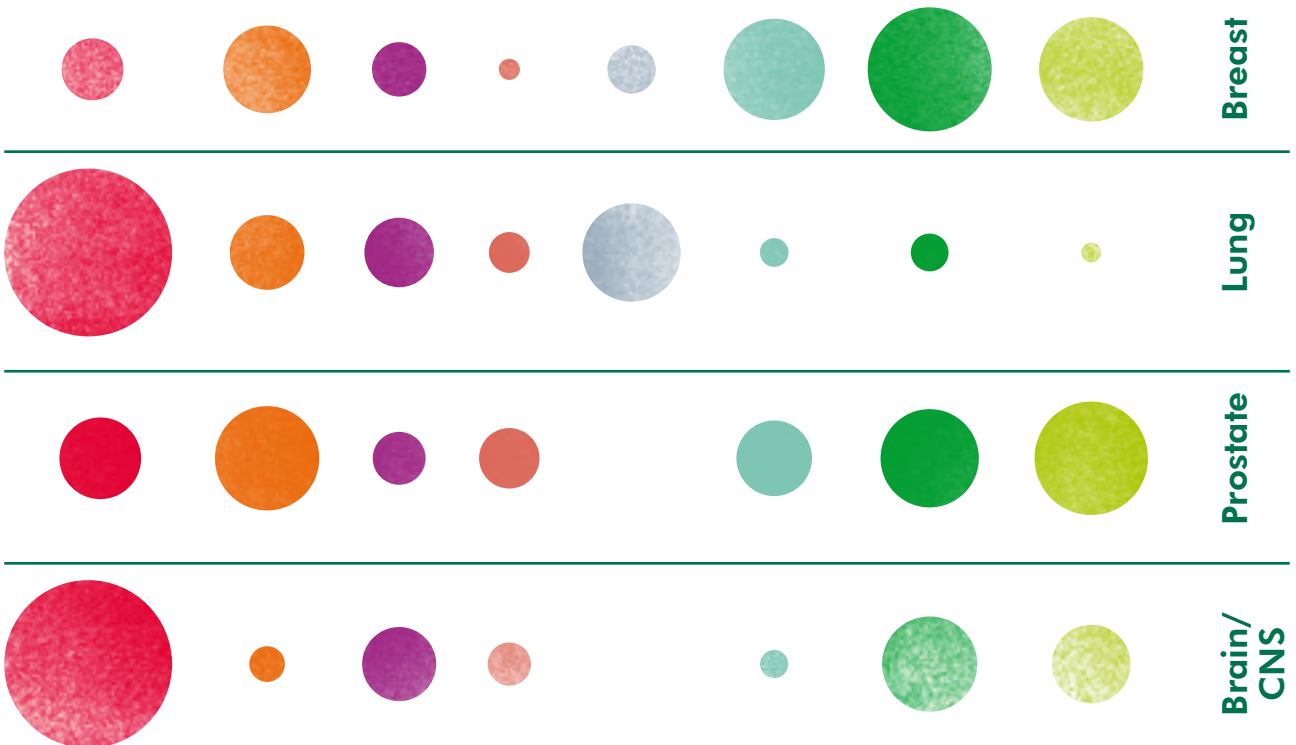
- **Group 1**
Limited survival
- **Group 2**
More aggressive complications/recurrence

Limited–moderate survival

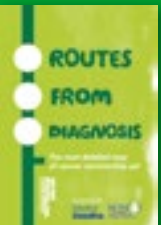
- **Group 3**
Patients with other inpatient diagnoses
- **Group 4**
Limited intervention
- **Group 5**
Less aggressive complications/recurrence

On-going survival

- **Group 6**
Living with or beyond cancer
- **Group 7**
Living with or beyond other inpatient diagnoses
- **Group 8**
Living beyond cancer



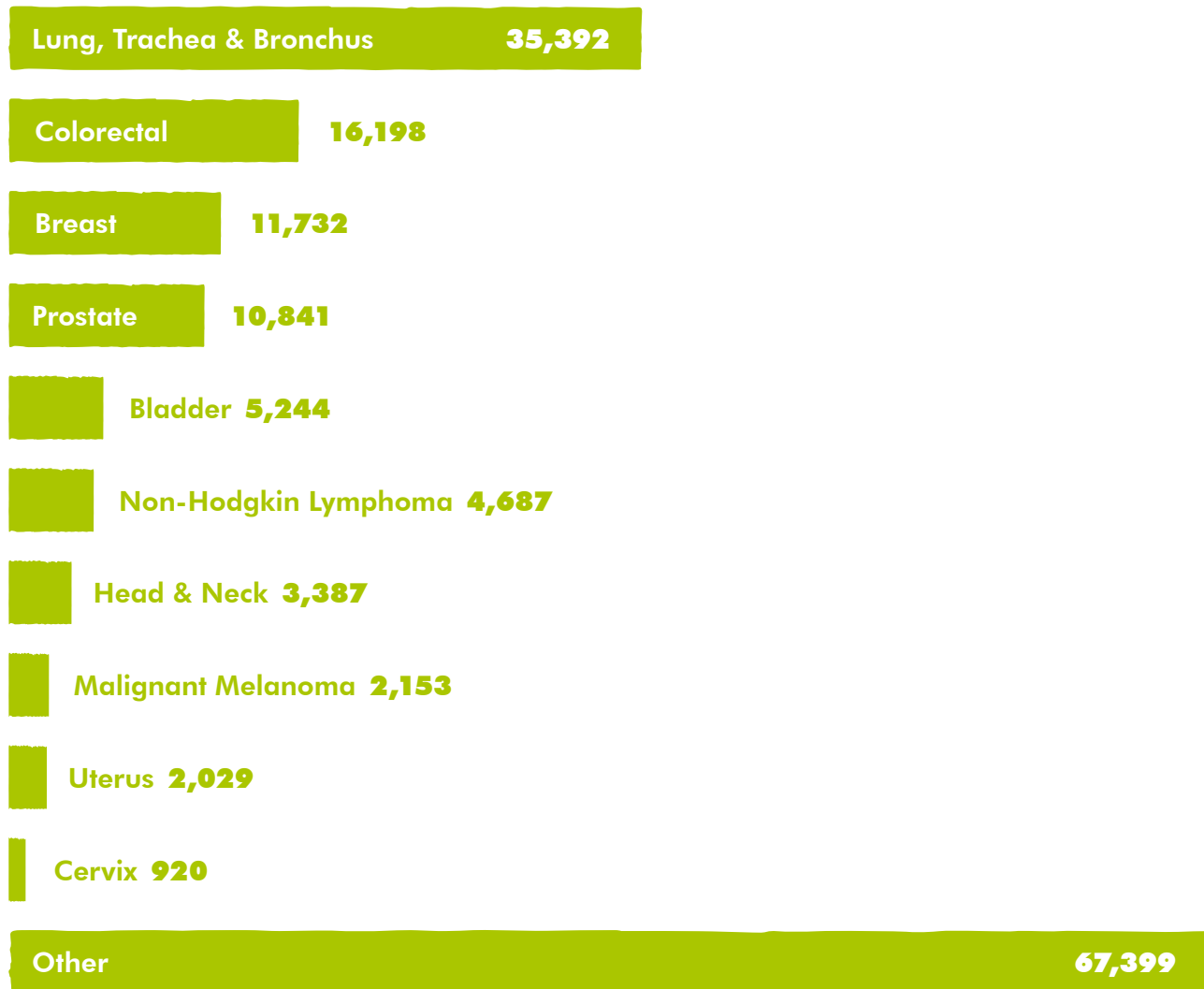
Surviving cancer does not always mean living well. There is a significant variation in health outcomes of cancer survivors.



To find out more about the survivorship outcomes please read the Macmillan report **Routes from Diagnosis. The most detailed map of cancer survivorship yet**

How many people die of cancer per year? ⁽⁴⁻⁶⁾

Cancer mortality by cancer type, 2012, UK



Cancer is the most common cause of death in the UK, causing more than one in four of all deaths. In 2012, over 160,000 people died of cancer in the UK. Lung, colorectal, breast and prostate cancers (the four most common cancers) together account for almost half of all cancer deaths.

However, cancer death rates in the UK have fallen by around a fifth over the last thirty years and by a tenth over the last decade.⁽¹⁾

Four in 10 people (38%) who have had cancer will die from another cause.⁽³²⁾ The most common causes (based on data for Scotland) are ⁽³¹⁾:

- One in five (20%) who do not die of cancer die from ischaemic heart disease
- Another one in five (20%) die from respiratory disease such as pneumonia
- Around one in eight (12%) die from cerebrovascular disease such as stroke

The proportion of people in the UK who get cancer and who do not die from the disease has increased by around 70% over the past 20 years.⁽³²⁾

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 1976 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. We used the 2011 rates as the changes to how these are calculated in 2012 resulted in the rates not being comparable between the nations.

How many people get cancer per year in England? (incidence)⁽²⁾

281,118

new cases of cancer diagnoses in England in 2012.

How many people die from cancer per year in England? (mortality)⁽⁶⁾

132,911

cancer deaths in England in 2012.

How many people are living with cancer in England? (prevalence)⁽³³⁾

2,000,000

people are living with cancer in England in 2015.

What is the age-standardised* rate of incidence of cancer in England?⁽²⁹⁾

393

new cases of cancer diagnoses in England in 2011 per 100,000 people, compared to the UK average of 396 people per 100,000 of the population.

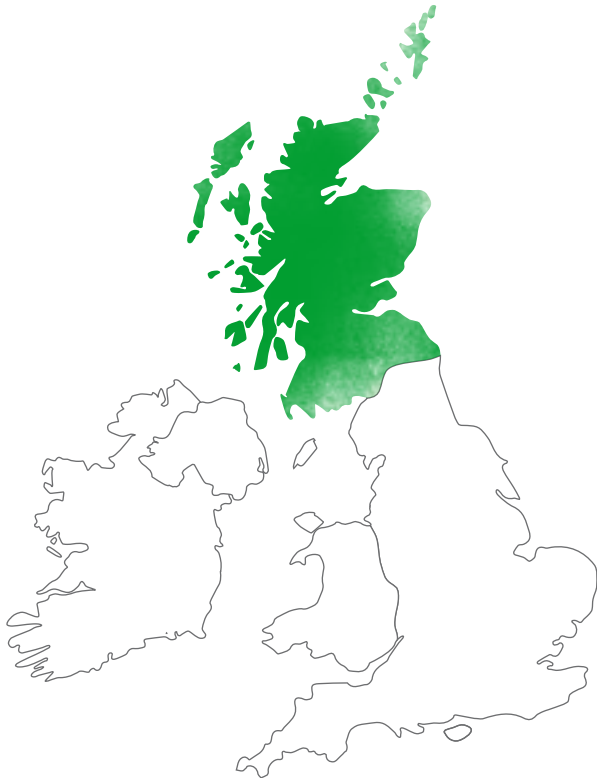
What is the age-standardised* rate of mortality of cancer in England?⁽²⁹⁾

166

cases of cancer deaths in England in 2011 per 100,000 people, compared to the UK average of 170 people per 100,000 of the population.

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



*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 1976 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. We used the 2011 rates as the changes to how these are calculated in 2012 resulted in the rates not being comparable between the nations.

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

30,450

new cases of cancer diagnoses in Scotland in 2012.

How many people die from cancer per year in Scotland? (mortality)⁽⁵⁾

15,787

cancer deaths in Scotland in 2012.

How many people are living with cancer in Scotland? (prevalence)⁽³⁴⁾

220,000

people are living with cancer in Scotland in 2015.

What is the age-standardised* rate of incidence of cancer in Scotland?⁽²⁹⁾

421

new cases of cancer diagnoses in Scotland in 2011 per 100,000 people, compared to the UK average of 396 people per 100,000 of the population.

What is the age-standardised* rate of mortality of cancer in Scotland?⁽²⁹⁾

194

cases of cancer deaths in Scotland in 2011 per 100,000 people, compared to the UK average of 170 people per 100,000 of the 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 1976 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. We used the 2011 rates as the changes to how these are calculated in 2012 resulted in the rates not being comparable between the nations.

How many people get cancer per year in Wales? (incidence)⁽³⁾

18,029

new cases of cancer diagnoses in Wales in 2012.

How many people die from cancer per year in Wales? (mortality)⁽⁶⁾

8,654

cancer deaths in Wales in 2012.

How many people are living with cancer in Wales? (prevalence)⁽³⁴⁾

130,000

people are living with cancer in Wales in 2015.

What is the age-standardised* rate of incidence of cancer in Wales?⁽²⁹⁾

411

new cases of cancer diagnoses in Wales in 2011 per 100,000 people, compared to the UK average of 396 people per 100,000 of the population.

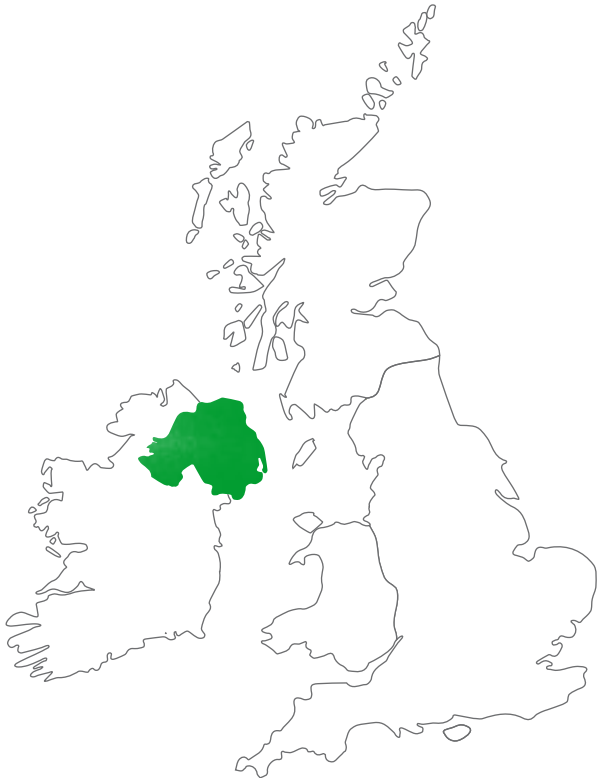
What is the age-standardised* rate of mortality of cancer in Wales?⁽²⁹⁾

172

cases of cancer deaths in Wales in 2011 per 100,000 people, compared to the UK average of 170 people per 100,000 of the population.

What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



*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 1976 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. We used the 2011 rates as the changes to how these are calculated in 2012 resulted in the rates not being comparable between the nations.

How many people get cancer per year in Northern Ireland? (incidence)⁽⁴⁾

9,034

new cases of cancer diagnoses in Northern Ireland in 2012.

How many people die from cancer per year in Northern Ireland? (mortality)⁽⁴⁾

4,027

cancer deaths in Northern Ireland in 2012.

How many people are living with cancer in Northern Ireland? (prevalence)⁽³⁴⁾

63,000

people are living with cancer in Northern Ireland in 2015.

What is the age-standardised* rate of incidence of cancer in Northern Ireland?⁽²⁹⁾

401

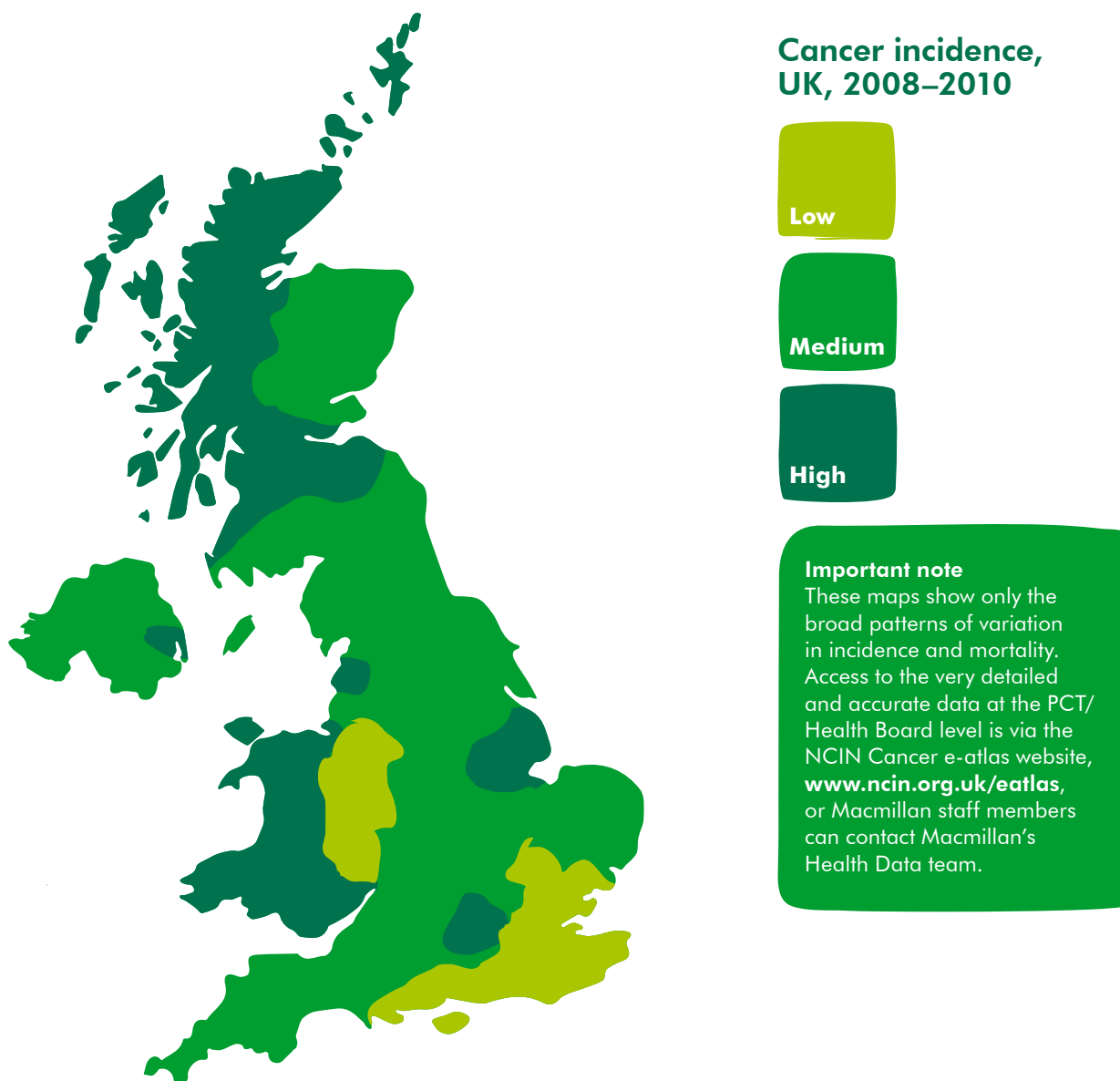
new cases of cancer diagnoses in Northern Ireland in 2011 per 100,000 people, compared to the UK average of 396 people per 100,000 of the population.

What is the age-standardised* rate of mortality of cancer in Northern Ireland?⁽²⁹⁾

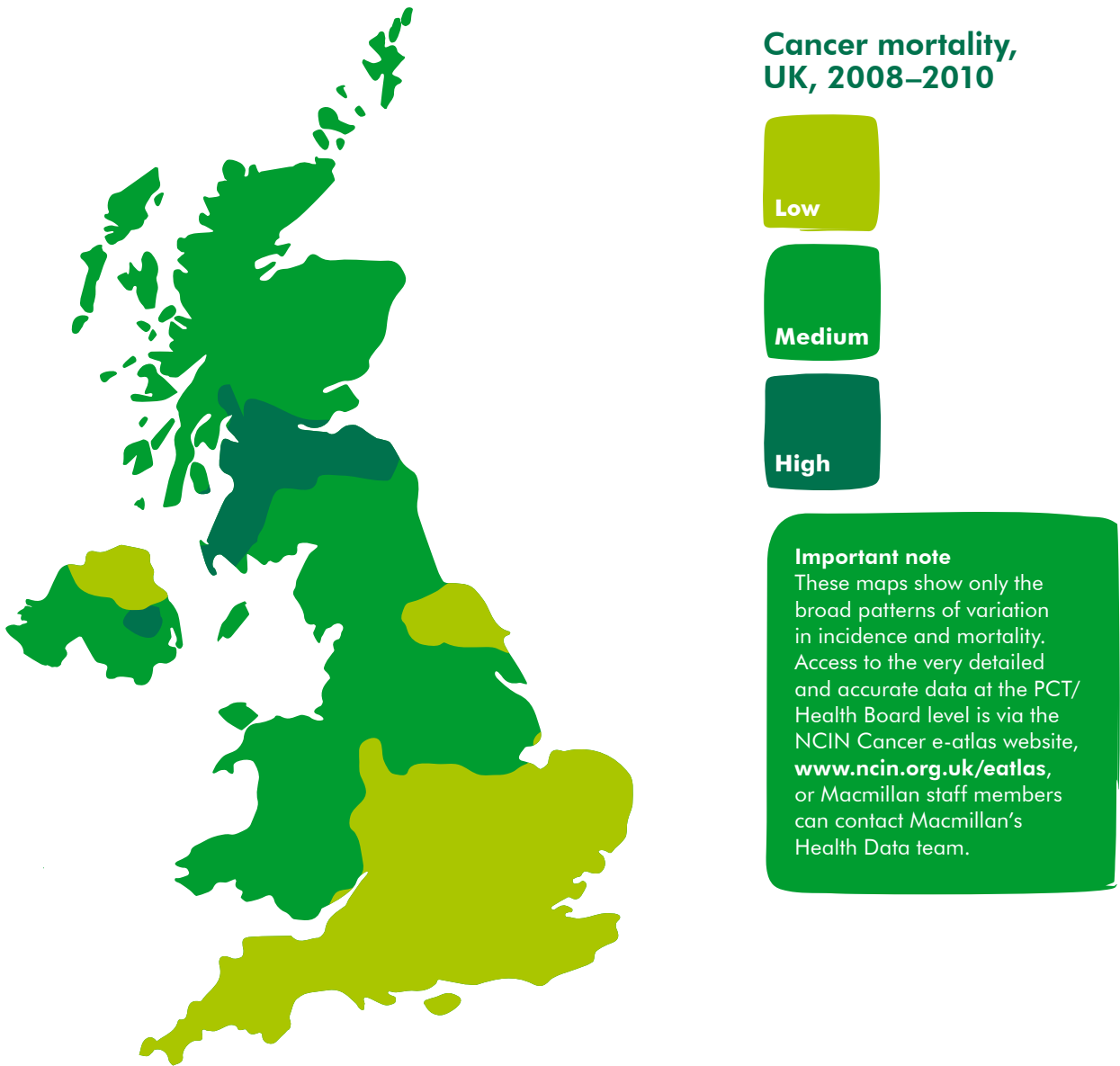
172

cases of cancer deaths in Northern Ireland in 2011 per 100,000 people, compared to the UK average of 170 people per 100,000 of the population.

How does cancer incidence and mortality vary across the UK?⁽⁴²⁾



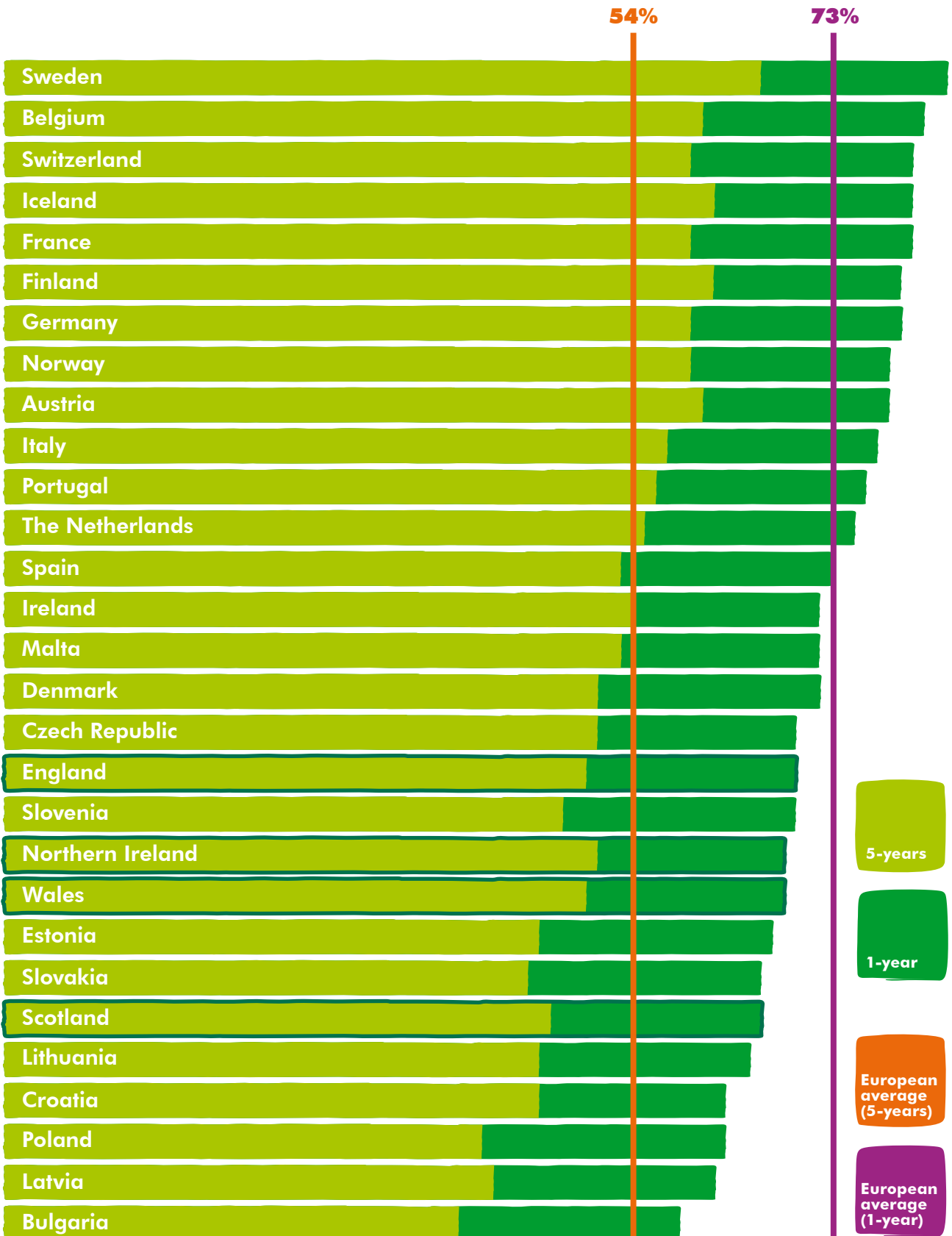
Cancer incidence rates are generally higher in Wales and in the north of Scotland, and lower in Southern England.



Cancer mortality rates are generally higher in Scotland, and lower in Southern England.

How does cancer survival in the UK compare across Europe?⁽³⁸⁾

Age-standardised survival rate for all cancers in 2000–2007



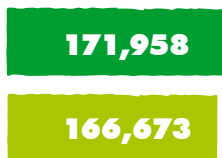
Data from the European cancer survival study suggest that many countries in Europe have better survival rates than the four nations in the UK. England has a slightly higher cancer survival rate than Wales, Scotland and Northern Ireland.⁽³⁸⁾

Understanding variation in survival rates between the UK and other nations is a key priority for the UK. The International Cancer Benchmarking Partnership was purposely set up to explore in more detail how and why cancer survival varies between countries and jurisdictions.⁽³⁹⁾ **Some of the possible reasons for better cancer survival rates in countries such as Sweden include solutions like nurse led clinics or coordination of care in primary care centers.**⁽⁴⁰⁾

What are the major demographic variations in cancer incidence, mortality, prevalence and survival?^(2, 3, 4, 5, 6, 7)

Cancer incidence, prevalence and mortality by gender, UK

Cancer incidence (2012)



20-year cancer prevalence (2010)



Cancer mortality (2012)



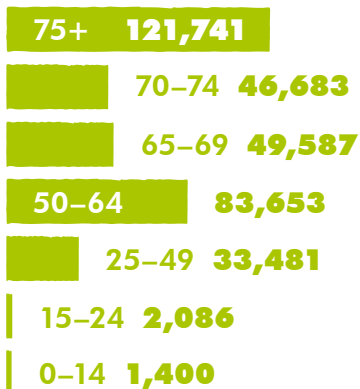
Slightly more men than women get cancer and die of cancer each year, however there are more women living with and beyond cancer up to 20 years after diagnosis. This may be related to the relatively high survival rates for breast cancer, which is the most common cancer in women.

Cancer incidence rates in the UK have risen by a quarter in males and by almost half in females since the mid-1970s.

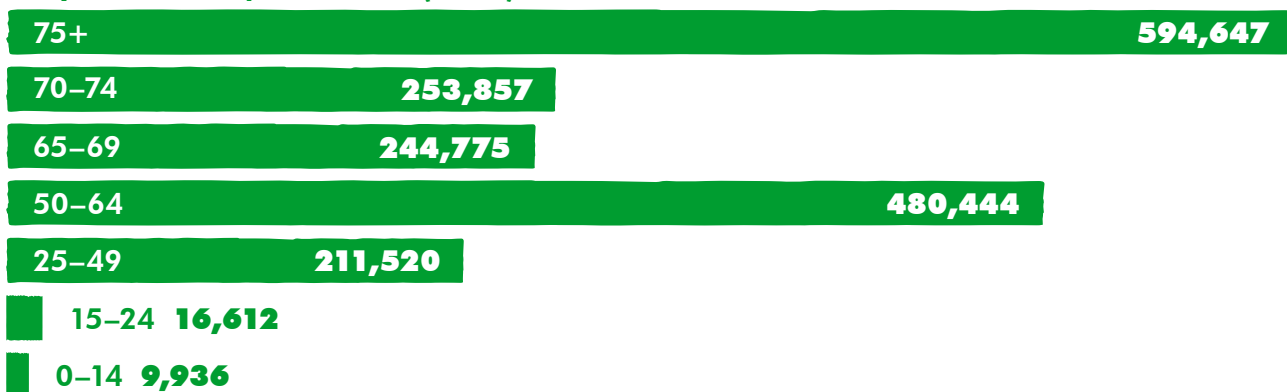
What is the age variation in incidence, mortality and prevalence of cancer?^(2, 3, 4, 5, 6, 9)

Cancer incidence, prevalence and mortality by age, UK

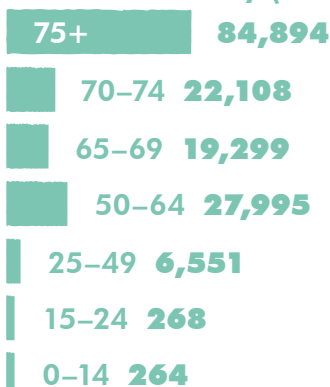
Cancer incidence (2012)



20-year cancer prevalence (2010)



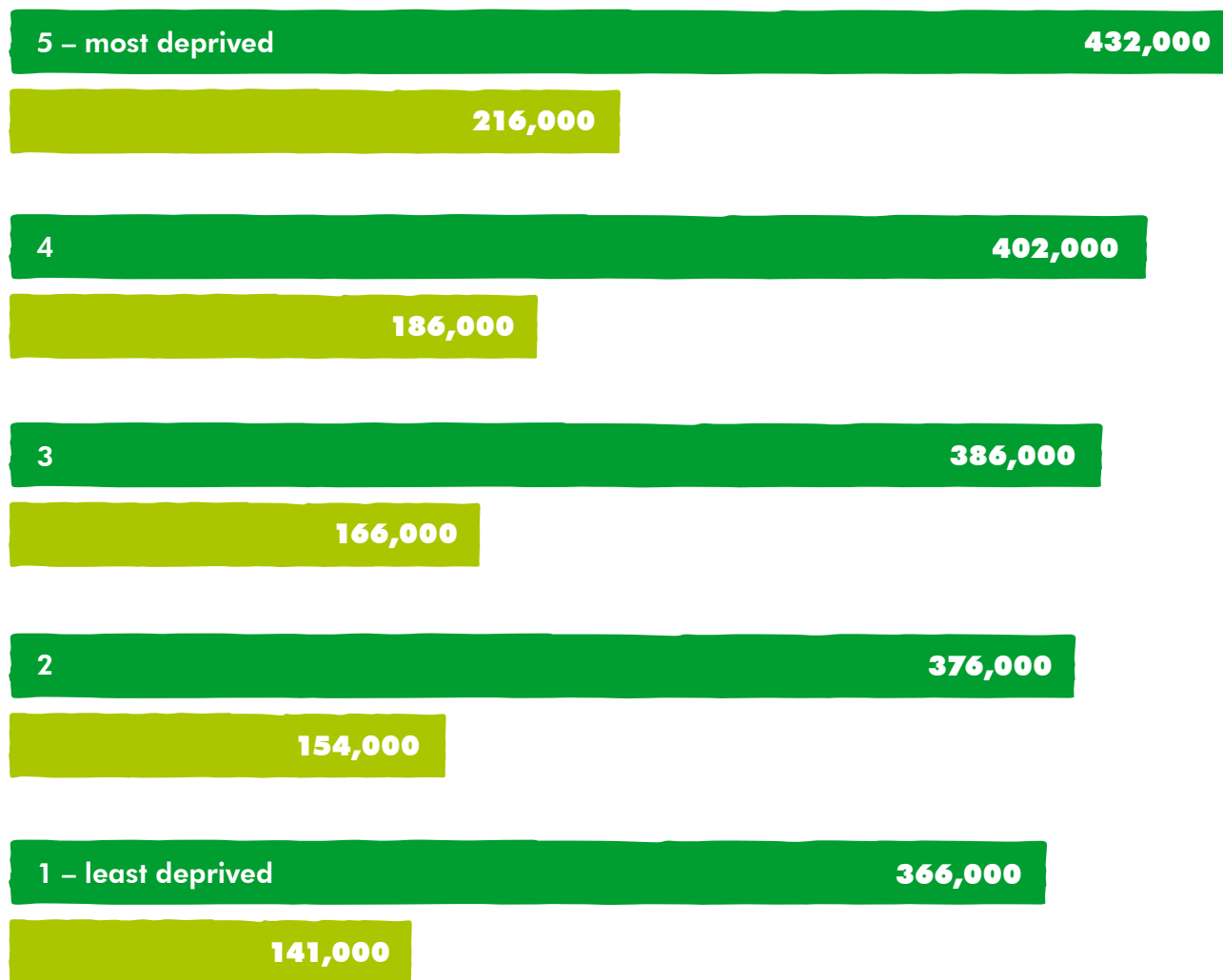
Cancer mortality (2012)



The biggest group of people getting cancer, living with cancer and dying of cancer are people aged over 75.^(2, 3, 4, 5, 6, 9)

What is the variation in incidence, mortality and prevalence of cancer by deprivation?⁽⁴³⁾

Cancer incidence and mortality by deprivation quintile, England



Cancer incidence*



Cancer mortality**

*Age-standardised rate per 100,000 people (2006–2010)

**Age-standardised rate per 100,000 people (2007–2011)

Cancer patients in England are 33% less likely to be alive five to ten years after diagnosis if they are from the most deprived areas than the least deprived. Incidence and mortality for all cancers combined are higher in more deprived groups than the least deprived. If rates for the more deprived groups had been the same as the least deprived in England:

- **around 15,300 fewer cancers would have been diagnosed per year (2006–2010)**
- **around 19,200 fewer deaths from cancer would have occurred per year (2007–2011)**

In general, differences in cancer incidence and mortality by deprivation have not improved over time. Lung cancer has by far the strongest association with deprivation. Other smoking-related sites, such as larynx and oral cavity, also have strong associations between deprivation and cancer incidence or mortality due to higher prevalence of smoking among people from deprived areas.⁽⁴³⁾ Incidence of skin, breast, prostate and testicular cancers is lower in people from deprived areas.⁽⁴³⁾

What is the ethnic variation in incidence and mortality of cancer?

Cancer incidence by ethnicity, England⁽⁴⁴⁾



Note: The bars represent how the risk of getting cancer in people from BME communities compared to the White population. The numbers in the bars show the estimated upper end of the risk range in each ethnic group compared to White people. The risk in the White population is the baseline, therefore it has a value of 1. Green border indicate values that are not significantly different to the White population.

People from Asian and Mixed communities are 30%-40% less likely to get cancer than people from the White population. In Black men the risk of getting cancer (except for prostate cancer) is comparable to men from the White population (not statistically different). The majority of BME groups also have a lower mortality from cancer than the national average.⁽⁴⁴⁾



To find out more about the differences in numbers, needs and experiences of cancer journey in different ethnic groups please read Macmillan's 'The Rich Picture on people with cancer from BME groups'

'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, 59, North East

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 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 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.

*While Survivorship relates to the time both during and post-treatment, as illustrated by the Recovery Package (p51), this section largely highlights the post-treatment needs and experiences of people living with cancer.

NEEDS AND EXPERIENCES DIAGNOSIS

What are the general signs and symptoms of cancer?

Reporting symptoms to a GP early can help ensure that if cancer is diagnosed, then it is **diagnosed as early as possible** and improves later survivorship outcomes.

Some common types of cancer have common signs and symptoms:

- a lump (breast, colon)
- a cough, breathlessness or hoarseness that doesn't go away (lung)
- changes in bowel habit (colorectal)
- abnormal bleeding (colorectal, cervical)
- changes in a mole (skin)
- unexplained weight loss (many types of cancer)
- pain

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

Over **338,000 people** are diagnosed with cancer each year in the UK.^(2, 3, 4, 5) **Patients with cancer in the UK** tend to present with more advanced disease and **have poorer survival rates** than many of their European counterparts.⁽⁴⁵⁾

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**.⁽⁴⁵⁾ The most common **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.⁽⁴⁶⁾ Emotional barriers are more prominent in lower socio-economic groups and practical barriers (e.g. 'too busy') are more prominent in higher socio-economic groups.⁽⁴⁵⁾

GPs typically consider cancer a priority, partly because of its profile in the public mind and partly because of its importance in the QOF (Quality and Outcomes Framework) process. Many GPs, however, **feel that they have little time to improve their understanding of cancer** in general and about new treatments in particular.⁽⁴⁷⁾

Of the cancer patients of all ages in England who saw their GP before going to hospital, **74% said that they saw their GP either once (53%) or twice (21%) before they were told they needed to go to hospital**.⁽⁴⁸⁾

What cancer screening programmes are available in the UK?

There are national screening programmes for breast, cervical and bowel cancer that monitor people regularly. Bowel cancer screening is the only national cancer screening programme which applies both to men and women. Uptake rates vary by screening centre.⁽⁴⁹⁾

Women between the ages of 50 and 70 are invited for breast screening every 3 years under national programmes. This is intended to detect breast cancer at an early stage. In England of women aged 53-70 who were eligible in 2013, 77% were recorded as having undergone screening in the past 3 years. Women under 50 are not currently offered routine screening. Research has shown that **routine screening in the 40–50 age group is less effective.**⁽⁵⁰⁾

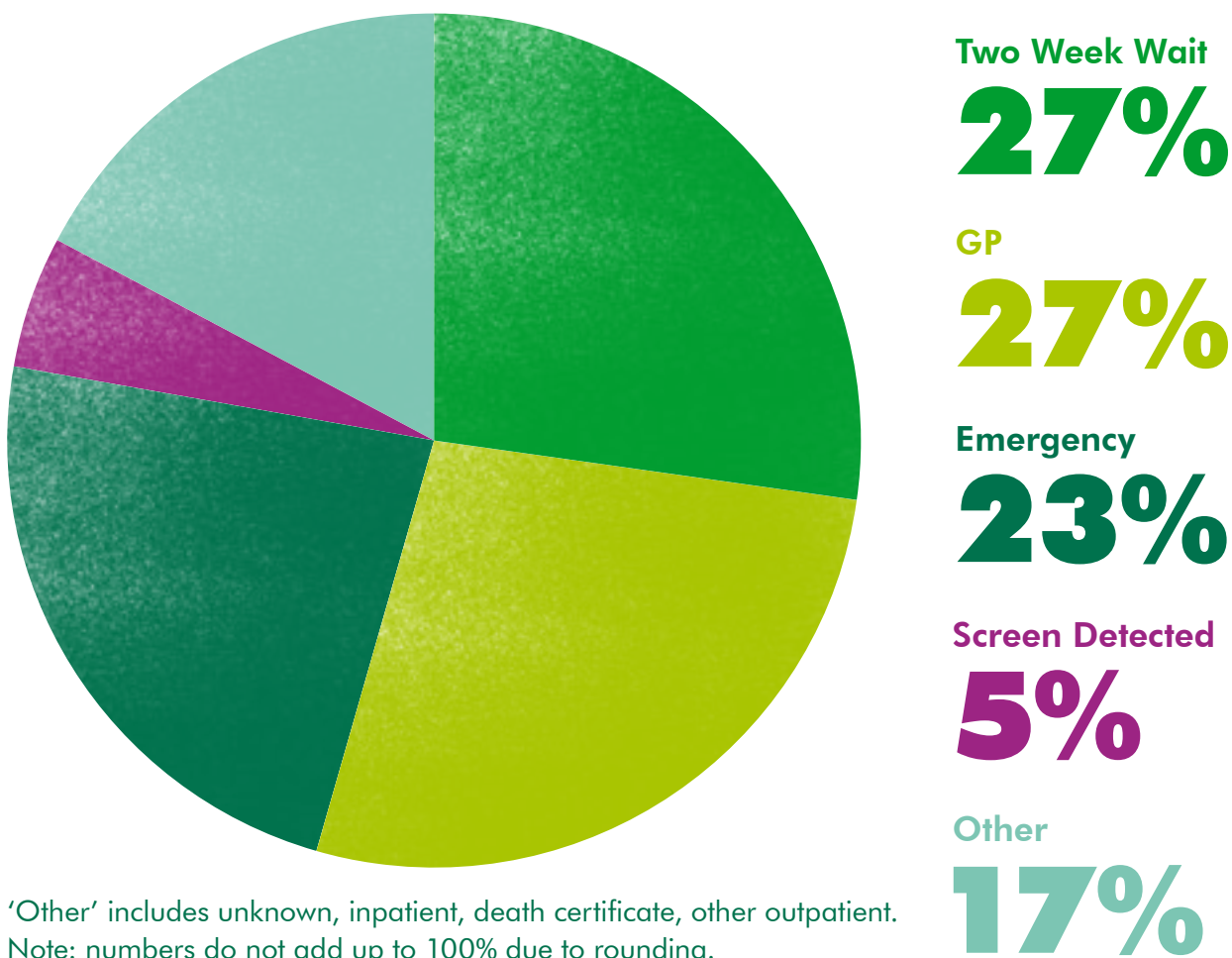
There is a **variation in the recommended age groups for cervical cancer screening in the different nations of the UK:**

- In England, Wales, and Northern Ireland, women aged between 25 and 49 years are invited to a screening every 3 years, while women aged between 50 and 64 years are invited every 5 years.
- In Scotland, women aged between 20 and 60 years are invited to a screening every 3 years.⁽⁵¹⁾

Figures for 2012–13 show **that 78% of eligible women (aged 25–64) were recorded as screened for cervical cancer** at least once in the previous 5 years.⁽⁵¹⁾

The NHS Bowel Screening Programme began in England in 2006, Scotland in 2007, Wales in 2008 and in Northern Ireland in 2010. The eligibility ages for screening are 60-69 in England, 60–74 in Wales, 60–71 in Northern Ireland and 50–74 in Scotland.⁽⁵²⁾ 54% of those invited completed bowel screening in the first two years. Men had lower uptake than women (51% and 56% respectively).⁽⁵³⁾

How is cancer diagnosed? (Routes to diagnosis)



In England, most people are diagnosed with cancer through GP referral (27%) and the “two-week wait” (27%). These two routes have some of the highest survival rates.⁽⁵⁴⁾ However, around one in four people are diagnosed via an emergency presentation, which is associated with much poorer survival. There is a large variation by cancer type in the proportion of cancer cases diagnosed via each route and the survival rates.



To find out more about early diagnosis of cancer please read Macmillan’s ‘Cancer in the UK 2014’ report.

How does stage at diagnosis relate to probable survival rates?⁽⁵⁵⁾

Most types of cancer have 4 stages, numbered from 1 to 4

Stage 1	Stage 2	Stage 3	Stage 4
Usually means a cancer is relatively small and contained within the organ it started in.	Usually means the cancer has not started to spread into surrounding tissue, but the tumour is larger than Stage 1. Sometimes Stage 2 means that cancer cells have spread into lymph nodes close to the tumour. This depends on the type of cancer.	Usually means the cancer is larger. It may have started to spread into surrounding tissues and there are cancer cells in the lymph nodes in one area.	Means the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

What are the variations in survival by stage?

Being diagnosed with cancer when it is still at an early stage greatly improves people's chances of survival. For breast, prostate, and colorectal cancer age standardised one-year survival is above 90% for stage 1 to 3 tumours with substantially lower survival only for stage 4. However, for lung and ovarian tumours there is a marked drop in survival with each increase in stage.⁽⁵⁶⁾

There are sociodemographic differences in cancer survival. For example one-year survival for all stages for lung cancer is 43% for females compared to 36% for males. For colorectal cancer all-stage survival is higher in males than females (81% compared to 79%). This variation is seen for each stage for lung but only stage 3 for colorectal.⁽⁵⁶⁾

There are also differences by age. Both increasing age and stage result in lower survival, and these factors exacerbate each other with the oldest age group with most advanced stage having the poorest survival.⁽⁵⁶⁾

Finally, all-stage survival for breast, colorectal, lung and ovarian cancer is lower in more deprived groups.⁽⁵⁶⁾



PHYSICAL AND MEDICAL NEEDS

The top four cancer types (breast, lung, colorectal and prostate) **account for over half of the cancer cases** in the UK, and medical needs for all cancer types will vary for each patient.⁽⁵⁷⁾



Symptoms of cancer in children are often vague and non-specific **making it harder for GPs to know when to refer children for further tests.** This can result in delays in diagnosis and explain why the majority of cancers in children are diagnosed through emergency presentation.⁽⁵⁴⁾



Even when corrected for tumour characteristics and co-morbidities, studies indicate that **older people are less likely to receive intensive investigation and treatment** and are more likely to be admitted as emergencies.⁽⁵⁸⁾



FINANCIAL NEEDS

Four in five (83%) people are, on average, **£570 a month worse off** as a result of a cancer diagnosis.⁽¹²⁾

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 people and their families.⁽¹²⁾



A cancer diagnosis as a teenager or young adult often disrupts educational or vocational goals and can result in more of a reliance on family during a time when other teenagers and young adults are gaining more independence.⁽⁶⁰⁾



PRACTICAL AND INFORMATION NEEDS

A significant proportion of newly-diagnosed patients undergoing cancer treatment have unmet needs. The most common needs include information needs, physical needs and psychological needs. **The level of unmet needs is highest after diagnosis and at the start of treatment**, and decreases over time.⁽⁶¹⁾

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.⁽¹³⁾



In one survey almost half of people living with cancer who were in work when diagnosed (**47%**) said their **employer did not discuss sick pay entitlement, flexible working arrangements or workplace adjustments** when they informed them of their diagnosis.⁽¹⁶⁾



Older cancer patients are less likely to seek additional information to that provided by their healthcare professionals, with many older patients with breast cancer saying that they would prefer to receive information face-to-face from healthcare professionals rather than from leaflets or websites.⁽⁶³⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, around **half of all people with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life**.⁽¹⁴⁾

75% of people with cancer have anxiety and 56% of these do not receive any advice or support.⁽¹⁷⁾



Teenage and young adult patients can find it emotionally hard to deal with their cancer diagnosis, particularly as they view their whole life still ahead of them. This is in contrast to some older people who may view their future differently and be better able to emotionally cope with illness.⁽⁶⁴⁾



Generally cancer patients are **less well equipped in dealing with the physiological and physical challenges associated with cancer**, while there is also some **lack of ability from line managers in dealing with the impact upon or attitudes of other employees**, and the stress and emotional challenges associated with cancer in the workplace.⁽⁶⁵⁾

NEEDS AND EXPERIENCES TREATMENT

What treatments do people with cancer get?

A number of factors affect the treatment a cancer patient may receive, including the type and stage of cancer, where in the body the cancer started, where the cancer has spread and the general health of the patient.

Surgery

The use of surgery as a treatment for cancer varies between cancer types. A report for the National Cancer Intelligence Network (part of Public Health England) in England showed that for liver cancer 6% of all patients were recorded as having undergone a major surgical resection within NHS hospitals, while for breast cancer the proportion reached 83%.⁽⁶⁶⁾

Chemotherapy

Chemotherapy is a very effective cancer treatment, and there are more than 100 different chemotherapy drugs.⁽⁶⁷⁾ Chemotherapy can cause side effects, which vary in severity. Most side effects are short-term, begin to improve once the treatment has finished and can be reduced by other medicines. Some chemotherapy treatments can cause long-term effects, such as cardiac problems or peripheral neuropathy (i.e. damage to the peripheral nervous system). A doctor or chemotherapy nurse can advise patients about the likely effects of the chemotherapy being undertaken.⁽⁶⁷⁾

Radiotherapy

Four out of ten of all people with cancer (40%) have radiotherapy as part of their treatment. Radiotherapy affects people in different ways, so it is difficult to predict exactly how a given patient will react. Some people have only mild side effects can be more severe, for example for people who have pelvic radiotherapy. For many people the side effects of radiotherapy wear off within a few weeks of the treatment ending and they can go back to a normal life.⁽⁶⁸⁾

Bone marrow transplants

A bone marrow transplant is a procedure used when people with cancer have very-high-dose chemotherapy, sometimes with whole-body radiotherapy as well. Because cancer patients are able to tolerate higher doses of chemotherapy with this treatment, there may be a better chance of curing the cancer than with standard treatment. High doses of chemotherapy drugs kill off bone marrow, meaning blood cells cannot be made. So doctors can take bone marrow from a donor or from the patient before chemotherapy. After the high dose chemotherapy healthy bone marrow is injected into the bloodstream through a drip.⁽⁶⁹⁾

Donor stem cell transplant

Stem cell transplants are more common than bone marrow transplants as part of very-high-dose chemotherapy, sometimes with whole body radiotherapy as well. This has a good chance of killing the cancer cells but also kills the stem cells in the bone marrow. Stem cells are very early blood cells in the bone marrow that develop into red blood cells, white blood cells and platelets. So after the high dose treatment stem cells are injected into a vein through a drip to replace those that the cancer treatment has killed.⁽⁷⁰⁾

Immunotherapy

Immunotherapy drugs target specific cancer cells. Because they target specific cells, other parts of the body are less affected and the side effects are usually mild. Immunotherapy is only suitable for certain types of cancer. It is usually given with chemotherapy.⁽⁷¹⁾

What are clinical trials?

In order to push the boundaries of cancer treatment forward, clinical trials need to be carried out. A clinical trial is a medical research study that compares a newer treatment with the standard treatment or a placebo (a dummy treatment). The aim is to find out whether the newer treatment works, or works better than standard treatment. In cancer research, clinical trials will usually compare a newer treatment with the standard one because it would be unethical to give someone who could benefit from standard treatment a dummy treatment instead. One group of people is given the established treatment and the other is given the newer one, with the results studied in terms of their benefits and drawbacks, such as side effects. All clinical trials are strictly controlled, and the drugs will have been tested fully in the laboratory, and often on other people already.⁽⁷³⁾ If a patient agrees to take part in one, and it becomes clear before it is over that one treatment is definitely better than the other, it will be stopped and the more effective treatment will be given to everyone.⁽⁷³⁾

Does treatment vary by age?

Treatment received varies by age.⁽⁶³⁾ More older patients than younger patients receive neither surgery nor chemotherapy, whilst more young people received chemotherapy alone. Far fewer older patients received both surgery and chemotherapy.⁽⁷²⁾

How many people with cancer have a Clinical Nurse Specialist?

People aged 16–64 are more likely to have access to a Clinical Nurse Specialist (CNS) than those aged over 65, with 90% of those of working age confirming that they had received the name of a CNS, compared to 86% amongst those aged 65 and over.⁽⁴⁸⁾

Macmillan’s internal data suggests that there were 4,149 Macmillan nurse, not only CNS, posts across the UK (as of June 2014).⁽⁷⁴⁾

What does this mean for cancer patients?

CNSs improve experience of care for patients, reinforce patient safety, demonstrate leadership and increase productivity and efficiency. CNSs also coordinate ward admissions for unwell patients, expedite outpatient clinic appointments, reorganise reviews to minimise cancelled procedures or operations and give advice on managing medication, pain and cancer symptoms throughout the cancer journey. This enables patients to move through the system as smoothly as possible and diverts pressure away from other professionals such as doctors and the ward nursing team.⁽⁷⁵⁾

Without CNSs the cancer journey can be complex and disjointed, often leaving the patient with unmet needs, increasing the risk of emergency admissions and avoidable costs for the health service.

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/impactbriefs

Cancer care teams

NHS guidelines state that anyone diagnosed with cancer should be under the care of a multidisciplinary team, which includes professionals such as surgeons, oncologists, doctors who specialise in symptom control, radiologists, specialist cancer nurses, physiotherapists, occupational therapists, psychologists, social workers and dieticians. However we know that many people do not benefit from the full range of support that could be available.⁽⁷⁶⁾

What other health conditions do people with cancer present at diagnosis?

Understanding the 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 disease progression and treatment of people with cancer. To read more about cancer and other conditions go to the Specialist Theme on page 65.

‘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



PHYSICAL AND MEDICAL NEEDS

The effects of cancer and its treatment can impact people's lives in many different ways, and can affect them for weeks, months or even years after treatment has ended. Fatigue is a very common and frustrating problem, with **65% of cancer survivors saying that they have to deal with fatigue following treatment.**⁽¹⁵⁾

Other significant effects caused by cancer and treatment can include **pain, reduced freedom of movement and reduced ability to process information and apply knowledge.**⁽⁷⁷⁾

Recent Macmillan research shows that **patients want more opportunity to talk to a health or social care professional** about their condition, its treatment and effects, particularly long-term effects.⁽¹⁶⁾



For many people a diagnosis of cancer, treatment and living with cancer will involve **significant time for treatment, check-ups and associated activities** usually fitted around the schedule of the health system and care providers. For those who work this can often require taking time off work.⁽⁷⁷⁾



FINANCIAL NEEDS

The most common additional cost people living with cancer face is **getting to and from hospital, or making journeys to other healthcare appointments.**⁽¹²⁾

Costs associated with outpatient appointments affect almost three-quarters (71%) of people living with cancer, and over a quarter (28%) incur costs for inpatient admissions.⁽¹²⁾

The proportion of patients who said they received or accessed financial advice decreases significantly with the time since diagnosis, with 35% of those still undergoing treatment seeking financial advice, dropping to just 17% of those diagnosed more than 10 years ago.⁽⁷⁹⁾



Disability Living Allowance (DLA) is the main source of additional financial support for young people and their families with one survey reporting that 88% of families with a child or young person (aged 16-24) with cancer had applied for DLA. Treatment for young people with cancer usually starts immediately after diagnosis but under proposed benefit reforms **many will not receive any financial support until at least six months after diagnosis.**⁽⁸⁰⁾



Of cancer patients aged 18-65 who faced increased costs or lost income, a recent Macmillan survey found that **20% returned to work sooner than they should have**, while 13% stayed in work when they should have been off, 33% used savings and 14% borrowed money, primarily in the form of credit card/overdrafts or family and friends.⁽⁷⁹⁾



PRACTICAL AND INFORMATION NEEDS

Around **40% of patients** completing cancer treatment in 2010 said they **received no information from health and social care professionals about their condition**, its treatment and effects, or support services available in their local area.⁽¹⁶⁾

40% of all cancer survivors are unaware of the long-term side effects of cancer and its treatment.⁽²⁵⁾



Whilst many professionals do recognise that in theory they could have more detailed discussions with cancer patients about work, they often do not wish to do so. **Healthcare professionals in particular feel that they do not have the time to talk about patient's work** and do not see it as their role.⁽⁸¹⁾



More vulnerable, **older cancer patients may not ask for help when necessary** and often need guidance in asking for and receiving help.⁽⁶⁴⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

One in four of all people (**23%**) diagnosed with cancer in the UK lack support from family or friends during their treatment and recovery – that represents more than 70,000 people each year.⁽⁸²⁾

In one survey **49% of people with cancer reported experiencing depression** as a result of their cancer, of whom 60% said they did not receive any information, advice support or treatment.⁽¹⁷⁾

43% of patients want information, advice and support about the impact a cancer diagnosis can have on their relationships, of whom 49% are not able to get it.⁽¹⁷⁾

There are often many **visible side effects of cancer treatment** such as **hair loss and weight gain** due to steroid treatment that can result in low self-esteem.⁽⁸³⁾



Older people with cancer frequently reported that they are concerned that decisions regarding their treatment lack fairness and transparency. They frequently feel that they are made excessively aware of the costs of treatment and whether they merit the expense of such treatments which could lead to psychological distress.⁽⁸⁴⁾

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

How well does the current follow-up system work for people with cancer?

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% of people with cancer who completed treatment in 2009/10 say that no health or social care professional talked them through the needs they might have.⁽¹⁶⁾
- 94% of people with cancer experience physical health problems in their first year after treatment.⁽²⁵⁾
- 23% of people with cancer lack support from friends and family during treatment and recovery.⁽⁸²⁾
- 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.⁽⁸²⁾

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

Physical side effects of cancer and its treatment can include **fatigue, weight gain and obesity, nerve damage, swelling around the arms, lymphoedema, blood clots, hot flushes, night sweats, impotence, and urinary and bowel problems.**⁽¹⁸⁾

500,000 people in the UK face poor health or disability after cancer treatment. **350,000** people living with and beyond cancer experience chronic fatigue.⁽¹⁸⁾

Some cancer survivors have specific emotional and physical needs that could benefit from input from their primary care team, but not all cancer survivors look to their GP for their long-term cancer-related care. Better information care planning is required from specialists in order to identify those who would benefit most.⁽⁸⁵⁾



Recent evidence suggests that work can be good for physical and mental health and well being, reversing the harmful effects of long-term unemployment and prolonged sickness absence. Yet much of the current approach to the treatment of people of working age, including the sickness certification process, reflects **an assumption that illness is incompatible with being in work.**⁽⁸⁶⁾



FINANCIAL NEEDS

Some people affected by cancer 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.⁽⁴⁸⁾

Cancer patients often express **worry about their ability to repay money borrowed from parents or family members** due to the negative impact of cancer when treatment has ended.⁽⁸⁸⁾



6% of the childhood cancer survivors in one study **had never been employed** compared to 1.2% of children who had not had cancer.⁽⁸⁹⁾



One fifth of people with cancer in work before cancer diagnosis returned to work and reported **deterioration in job satisfaction and career prospects.**⁽⁹⁰⁾



PRACTICAL AND INFORMATION NEEDS

19% of cancer patients report that the **future side effects were not explained to them at all.**⁽⁴⁸⁾

For some people their cancer can come back (recur). **If recurrence occurs, a renewed need for information and support is generally expressed by people with cancer.** For those experiencing a recurrence, only half of those surveyed said that they received supported information, suggesting a major unmet need at this stage.⁽⁹¹⁾



Young adult cancer survivors (aged 20-39) have been found to be **in need of further information about managing late effects after treatment.**⁽⁹²⁾



Illness trajectories and treatment regimes in cancer can be more difficult to predict than in other health conditions, and ascertaining whether a patient can return to work lies in identifying the physical, cognitive and psychological demands of the workplace, and matching these to the patient's capacity.⁽⁹³⁾



Many older people with cancer felt that professionals did too little to 'uncover' information from them which would have helped in planning follow-on care, neglecting to ask important information about the type of support network the patient had.⁽⁸⁴⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Although psychological issues, such as depression, anxiety, memory problems, difficulty concentrating, sexual problems and a lack of confidence in engaging socially are more common in the first year after treatment, one third of people continue to report significant levels of distress well after treatment has been completed. Even **10 years on 54% of cancer survivors still suffer from at least one psychological issue.**⁽¹⁸⁾

More than four in ten (45%) of people with cancer say the emotional effects of cancer are the most difficult to cope with, compared to the physical and practical aspects. Nearly six in ten (58%) of people with cancer feel their emotional needs are not looked after as much as their physical needs.⁽¹⁷⁾



83% of young people with cancer (aged 16-24) that responded to a survey **felt that their quality of life had been affected by cancer.**⁽⁸⁰⁾



Older people with cancer can be less likely to have a support system in place, often because they have lost close family members or do not live close to them.⁽⁹⁵⁾

NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

What is palliative care?

The National Institute for Health and Care 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 are there in each setting?

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 in care homes, 19% of all deaths in communal establishments and 23% of all deaths elsewhere.⁽⁶⁾

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

To what extent do people with cancer die in their place of choice?

Where people living with cancer want to die, with the right support:



Where they actually die:



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.⁽²⁰⁾ However, only 30% of those who die from cancer actually die at their home or own residence.⁽⁶⁾



To find out more about the choice at the end of life please read the Macmillan 'Cancer in the UK 2014' report.



PHYSICAL AND MEDICAL NEEDS

Various symptoms are very common in advanced cancer, with patients having an average of 11 symptoms on admission to palliative care. Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common, occurring in some combination in virtually all patients.⁽²¹⁾

Symptoms such as pain, fatigue and shortness of breath, may be caused by co-morbid conditions and not the cancer.⁽⁹⁶⁾



People with cancer from **BME groups are less likely to complete an advance care plan, more likely to desire more active treatment and report lower quality of care**

in care homes or even under-treatment of pain or poor communication.⁽⁹⁸⁾



FINANCIAL NEEDS

More than **£90 million in disability benefits is going unclaimed by people diagnosed with terminal cancer** in the UK.⁽²³⁾



According to one study, **73% of bereaved parents said that they were given the option for their child to return to or continue at school after they had stopped receiving curative treatment.** Those that had taken up the offer felt that they had received sufficient support from the school and that by allowing their child to return to school they were able to maintain as normal a life as possible, which was particularly important for many families.⁽⁸³⁾



PRACTICAL AND INFORMATION NEEDS

Cancer patients and their families often want **information about how long they may have to live** after hearing that their cancer is terminal. However, 31% of doctors tend to **over-estimate the survival times** of terminally ill cancer patients.⁽¹²⁴⁾



There is often **poor awareness of palliative care services for children by families and professionals**. It has also been reported that there is sometimes a lack of co-ordination between those involved in delivering children's palliative care. This can result in many children and families not receiving information about appropriate palliative care or having access to the right services.⁽⁹⁹⁾



One study found that many **teenagers and young adults** (aged 16-28) with life-threatening conditions (including cancer) **want to be involved in decisions about the kind of medical care they receive and be able to choose what information is given to their family and friends**, as well as how they would like to be remembered.⁽¹⁰⁰⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Cancer patients approaching end of life have **increased levels of psychological distress**.⁽²⁴⁾

Amongst older carers of people with advanced cancer satisfaction is reported particularly in being able to **provide love and care** to the person diagnosed with cancer and **enabling them to have a 'good' death**. However, the majority of older carers find the **main challenges to be due to miscommunication, disorganisation, lack of services, lack of information and over-reliance on informal carers**. These factors contributed to crisis admissions to hospital, poor pain control for the patient, carers feeling overwhelmed and residual feelings of anxiety and guilt in bereavement.⁽¹⁰¹⁾



A recent study on small-medium sized enterprises found that when an employee has been too ill to attend work for some time **the knowledge that they are in the final stages of their illness can be difficult for close colleagues to deal with**.⁽¹⁰³⁾



Two-thirds (66%) of women with advanced breast cancer, or their carers, believe **life-extending treatment to be important so that they can spend more time with family and friends**, and 67% say that the treatment was worthwhile, despite potential associated side effects.⁽¹⁰⁴⁾

LIFESTYLE AND PERCEPTIONS

This section attempts to give an indication of the typical profile of people living cancer, although we know that there is huge variation within the population.

What lifestyle factors can cause cancer?⁽¹⁰⁵⁾

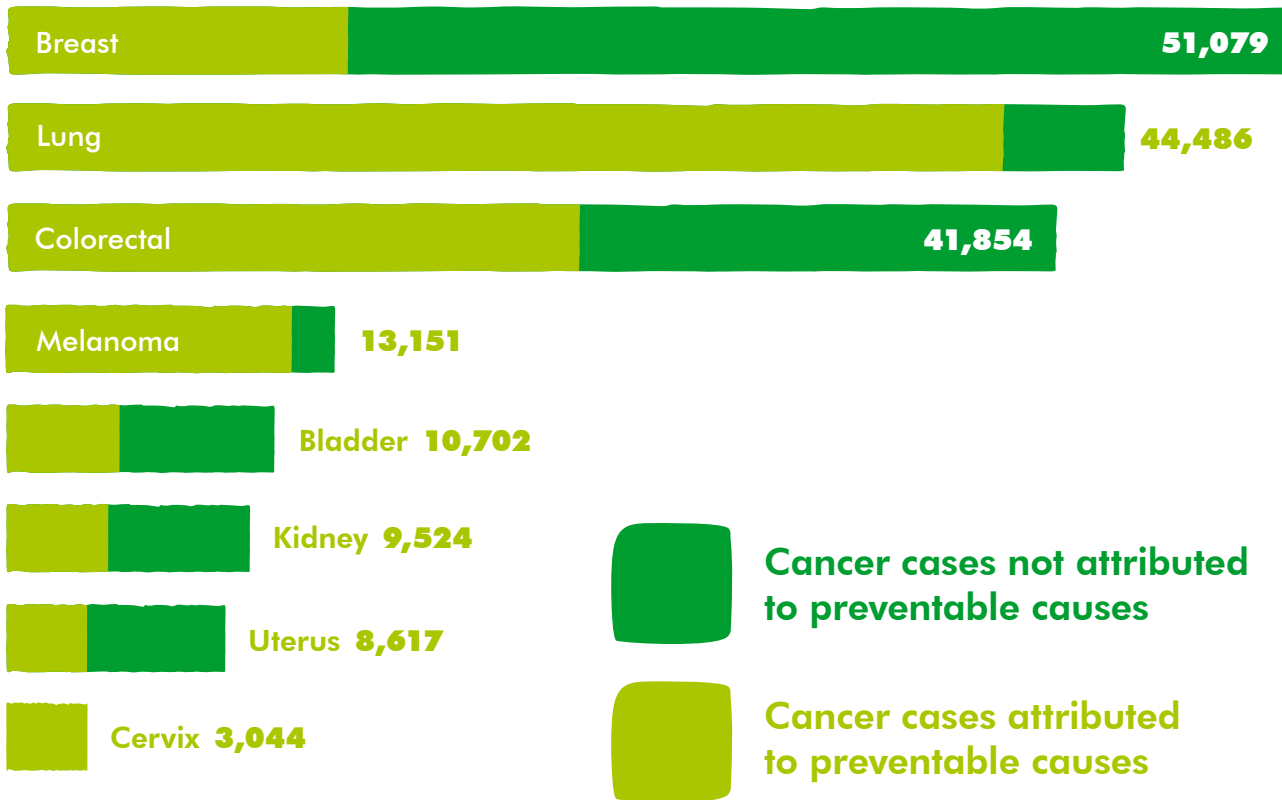
Developing cancer depends on many factors, including age, lifestyle and genetics. More than 40% of all cancers in the UK are linked to lifestyle factors, including tobacco, alcohol, diet, being overweight, inactivity and others. This results, among other things, in:

- Over 60,000 new cases each year of cancer in the UK caused by cigarette smoking.
- Around 17,000 new cases each year of cancer linked to being overweight or obese.
- Around 12,500 new cases each year of cancer linked to consumption of alcohol.
- Nearly 4% of cancers in the UK linked to exposures at work.

We also know that:

- Physical activity protects against several cancer types, independently of its effect on body weight.
- A few infectious agents, especially certain viruses, play a key role in causing certain types of cancer, for example cervical cancer and head and neck cancers.
- Reproductive factors such as the age at which a woman has her first child, the number of children she has and whether or not she breastfeeds, affect risk of the most common female cancers, for example breast cancer.

Number of cancer cases attributable to lifestyle risk factors, by cancer type (selected cancers)⁽¹⁰⁶⁾



To find out more about the importance of physical activity in cancer prevention and recovery please read the Macmillan's report **'The importance of physical activity: a concise evidence review'**

What is the demographic breakdown/ market segmentation of people with cancer?

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 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 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.

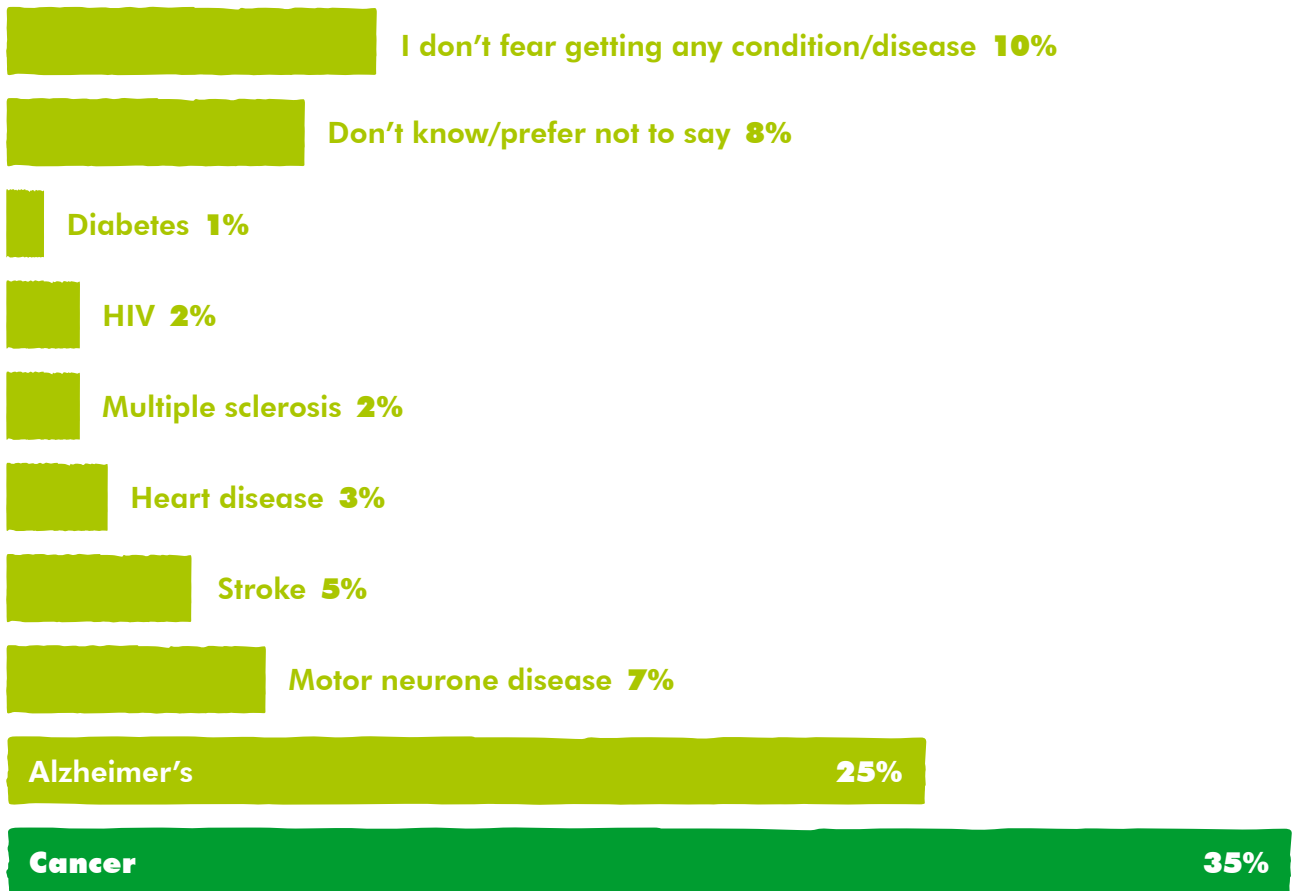
What are the typical leisure activities/ where they shop/what media they consume/what they do?

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.

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

What are people's perceptions of cancer?



People in the UK fear cancer more than other life-threatening conditions such as Alzheimer's, stroke and heart disease.⁽¹⁰⁷⁾

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

- In the media, the word “cancer” itself dominates the discussion, followed by “treatment”. In contrast, on the online community, cancer and its treatment takes a back seat to more personal and emotional aspects. The word “feel” is the most commonly used word, highlighting the emotional impact that cancer can have, and the importance of talking about it.
- The online community also has a more positive and personal side; members frequently use words such as “good”, “well”, “best”, “life” and “magic”. The importance of support from the other members of the community also stands out, as “everyone”, “sorry” and “thanks” feature prominently. This forms a sharp contrast to the more clinical and fact-driven approach of the media, which focuses on “risk”, “disease” and “patients”. The emotional side of cancer is not entirely overlooked by the media however, as “family”, “mother” and “support” form part of the media discussion.
- The media has an in-depth focus on research into cancer treatments and the business-related aspects, as demonstrated by the presence of the names of several large pharmaceutical companies. “Research” is not featured in the online community cloud; the members show almost as much interest in the “side effects” as in the treatment or cancer itself.
- Words like “hard”, “struggle”, and “concern” emphasise the difficulties experienced by people living with cancer. One concern of people living with cancer that can be identified in the online community word cloud is the importance of information. The word “know” stands out in particular, as well as “questions”, “guess”, and “understand”. Receiving the right amount of information at the right time is an important part of the cancer journey. Another issue is that of “work” and “cost”; cancer often makes it difficult for people to continue to work and support themselves.

SPECIALIST THEME: MENTAL HEALTH PROBLEMS AND NEEDS OF PEOPLE LIVING WITH CANCER

Although measures differ, there is a growing body of evidence that suggests that low level **anxiety and emotional problems are more prevalent among people who have had cancer than those who have not.**⁽¹¹⁰⁾ They also often report not receiving the appropriate support for their problems.⁽¹⁹⁾ This section presents what is currently known on people living with cancer who have mental health problems.

What are mental health problems?

The language around mental health and mental wellbeing can be difficult to navigate and the definitions can hinder as much as they can help. Having a clearly defined problem facilitates access to relevant support. However, being diagnosed with a mental health problem can have highly loaded connotations. There are some differences between the language used to describe mental health problems by clinicians and people living with cancer.

Having full mental health as conceived by the World Health Organisation suggests more than an absence of mental disorders:

“a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.”⁽¹¹¹⁾

This definition emphasises **the holistic nature of mental health and the importance of being able to interact with the wider environment.**

In the meantime, being diagnosed with cancer is a life-changing experience for most people. Cancer can have a huge effect on person’s emotions, as well as on other aspects of life. The most common feelings that people living with cancer may feel are⁽¹¹²⁾:

- Shock
- Anxiety
- Panic attacks
- Loss of control and independence
- Anger and resentment
- Sorrow and sadness
- Denial
- Withdrawal

These feelings may occur at the time of diagnosis, during treatment, recovery and adjusting to life after treatment. Their long-term impact on one’s life and the ability to manage them vary from person to person.

While it is generally considered that having poor mental health and having poor mental wellbeing are distinct states, there is a relationship between the two. **A mere presence of these feelings does not mean that a person has mental health problems.** However, they may prompt a requirement for support in maintaining or regaining full mental health.

How many people living with cancer have mental health problems and how does it compare to other groups?

Analysis of data from the World Mental Health Surveys showed that twelve-month **prevalence rates of common mental health disorders were higher among active cancer than cancer-free respondents**, even when adjusted for sociodemographic and other lifetime chronic conditions. Common mental health disorders rates are higher among cancer survivors compared to cancer-free respondents.⁽¹¹³⁾

This is an **experience that cancer survivors share with others who live with long-term conditions**⁽¹¹⁴⁾ It is estimated that **240,000 people living with and beyond cancer have mental health problems.**⁽¹⁸⁾ The measure looks at the prevalence of depression and anxiety only. The total prevalence of mental health needs among people living with cancer is likely to be higher. Even 10 years on, 54% of cancer survivors still suffer from at least one psychological issue.⁽¹⁸⁾

The prevalence of mental health problems differs significantly in different groups. In one study cancer type was the best predictor for psychological distress in both specialist palliative care (prostate cancer much higher than other cancers) and general community samples (lung cancer much higher than other cancers).⁽²⁴⁾ An analysis of data on patients attending cancer clinics in Scotland found that major depression was most common in patients with lung cancer (13%) and lowest in those with genito-urinary cancer (6%).⁽¹¹⁵⁾

People living with cancer aged between 16 and 54 are twice as likely as people over 65 years to report that cancer made them feel depressed and anxious. **One in three (34%) 16–54 year olds living with cancer also say they do not have enough or have no moral support**, compared with one in five (19%) people aged 65 or over.⁽⁸²⁾

One study of colorectal cancer patients looked into the predictors of anxiety and depression in people living with cancer. **Self-reported history of anxiety/depression predicted anxiety but not depression after cancer diagnosis.**⁽¹¹⁶⁾ However, **the evidence on the root causes of mental health problems of people with cancer is still patchy.** One evidence review showed that 80% of research papers are concerned with the effects of cancer on mental health rather than the reverse. There is also an imbalance of cancer types looked at: breast dominated (21%), followed by prostate (5%). The area of mental health most studied in cancer was unipolar depression.⁽¹¹⁷⁾

What are the mental health problems most commonly reported by people living with cancer?

Due to the definitional issues described above the estimates of prevalence of different mental health problems vary slightly between different sources. The list below describes the most commonly listed mental health problems of people living with cancer:

- Between 49% and 75% of people living with cancer feel depressed or anxious.⁽¹⁷⁾
- 57% of Patient-Reported Outcomes Measurement (RPOMs) respondents report fear of the cancer coming back and 45% of them are worried about the cancer spreading.⁽¹¹⁸⁾
- One third (32%) of people living with cancer have relationship problems.⁽⁸²⁾
- Around a third of people with cancer have body image problems (31%), report mood swings (31%) and irritability (30%) or fears about dying (28%).⁽¹¹⁸⁾
- The estimates of prevalence of isolation and loneliness among people with cancer suggest that around a third may experience these states.⁽¹¹⁸⁾

How well are people with cancer and mental health problems supported?

In the **Scottish study nearly three quarters (73%) of depressed cancer patients were not receiving treatment.**⁽¹¹⁵⁾ **Nearly six in ten (58%) of people with cancer feel their mental health needs are not looked after as much as their physical needs.** This breaks down as follows⁽¹⁷⁾:

- 60% of people with cancer who report depression say they do not receive any information, advice support or treatment.

- Half of cancer patients want information, advice and support about the emotional aspects of cancer, of whom 41% are not able to get it.
- 43% of cancer patients want information, advice and support about the impact a cancer diagnosis can have on their relationships, of whom 49% are not able to get it.

There are differences in what mental health needs are met across cancer the journey:

- At diagnosis most unmet needs around mental health are concerns about the disease spread and recovery.⁽⁶¹⁾
- Emotional closeness with family and reassurance from family are the most met mental health needs in people with cancer during the first year since diagnosis.⁽¹¹⁹⁾
- Some cancer survivors have more than one moderate or severe unmet need, mainly around psychological support and coping with the fear of recurrence.⁽¹²⁰⁾
- Issues with access to appropriate emotional support are commonly mentioned at the end of life.⁽²⁴⁾

Unmet mental health needs may have long-term impact on the quality of life and other needs. In one study of multiple myeloma patients, anxious/depressed patients had more than double unmet needs than non-anxious/depressed patients. The patients complained of several symptoms, including tiredness (41%), pain (36%), insomnia (32%), peripheral neuropathies (28%) and memory problems (22%). 41% were worried about their health in the future.⁽¹²¹⁾

'My fear is for my children. I worry that my partner won't cope and I worry that they worry. I feel sad that I might not see their milestones and angry that it's all happened to me.'

Sarah, 39

SPECIALIST THEME: PEOPLE LIVING WITH CANCER AND OTHER HEALTH CONDITIONS

Why are other health conditions of people living with cancer important?

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

There is mounting evidence that **multi-morbidity affects disease progression and treatment of people with cancer**. In the meantime living with multiple conditions is the norm rather than the exception for many people with cancer. It is associated with **poorer quality of life, more hospital admissions and higher mortality**. This may be partially because health services are largely organised to provide care for single diseases.⁽¹²²⁾

How many people living with cancer live with other health conditions?

The estimated prevalence of people living with cancer living with other health conditions varies depending on what other health conditions are looked at. One study reported that just under **half (47%) of all people living with cancer have at least one other chronic condition**. This includes 15% who have two and 6% who have three other chronic conditions.⁽²⁵⁾

Macmillan's 'Routes from Diagnosis' database captures a more detailed description of a patient's survivorship through the identification of 'inpatient morbidities',⁽⁴¹⁾ The clinical advisory group identified what they believed were clinically important inpatient morbidities during the survivorship phase for each index tumour.

These were defined as:

- Common morbidities likely to be more prevalent for the tumour type population than a general population;
- Common morbidities likely to affect treatment decisions;
- Common complications of the cancer or cancer treatment.

Even though the data is limited only to inpatient episodes, it shows that in some tumour groups the prevalence of other morbidities can be much higher:

- 67% of people with breast cancer
- 77% of people with lung cancer
- 60% of people with prostate cancer
- 66% (depending on type of cancer) of people with brain or CNS tumours.

To find out more about the survivorship outcomes of people with cancer please read the Macmillan's report '**Routes from Diagnosis. The most detailed map of cancer survivorship yet**'

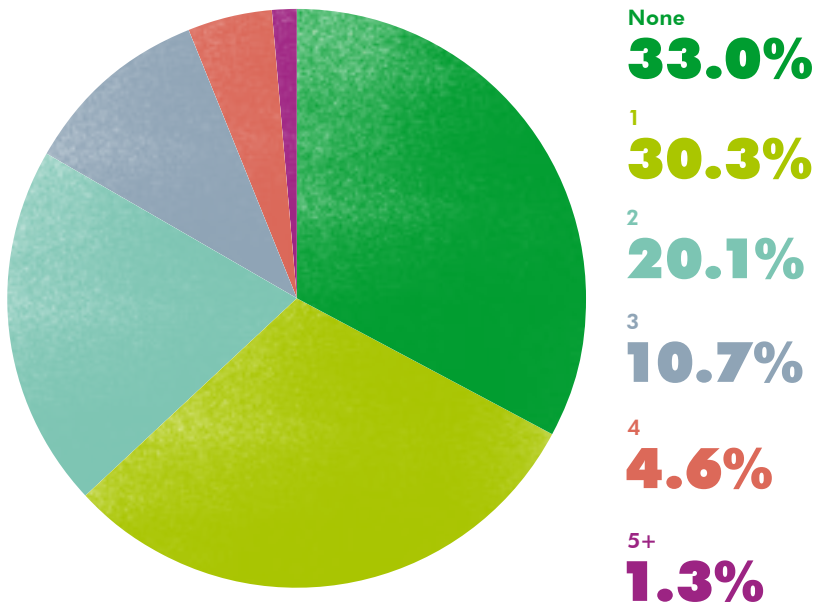
The prevalence of inpatient morbidities varies significantly by age. Around a third of people living with cancer have no record of post-diagnosis morbidity in an inpatient setting (33% for studied in 'Routes from Diagnosis' combined). The proportion ranges from 23% of people with lung cancer to 40% of people with prostate cancer.

The percentage of people who are free of post-diagnosis inpatient morbidities declines with age for all cancers combined and for each cancer separately⁽⁷²⁾:

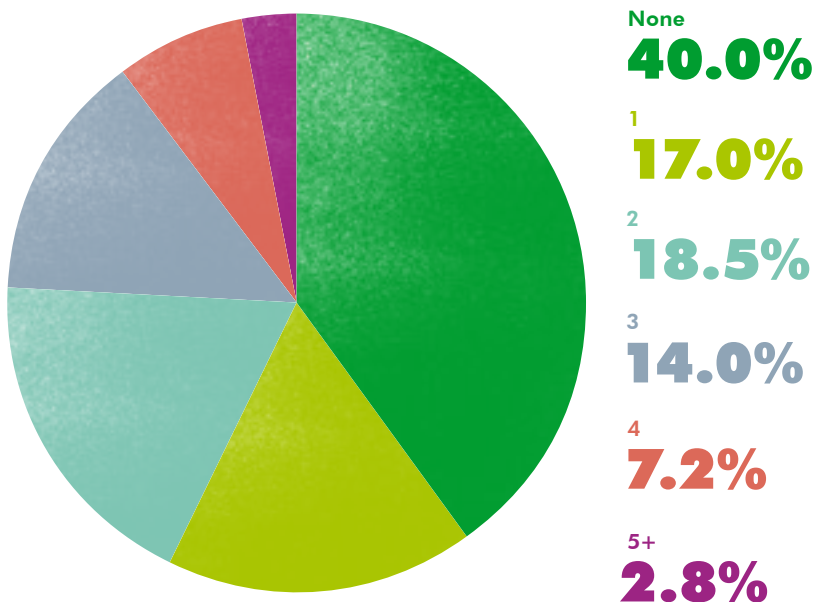
- The proportion for all four cancers combined ranges from 42% among 18-24 year-olds to 27% in people aged 75 years or over.
- The differences are most striking among people living with breast cancer (from 41% in 18-64-year-olds to 16% of those aged 75+).
- The differences are smallest among people living with prostate cancer (from 47% in 18-64-year-olds to 35% of those aged 75+).

How many people living with cancer have inpatient morbidities?

Percentage of breast cancer population by number of inpatient morbidities taken over the seven year survivorship period



Percentage of prostate cancer population by number of inpatient morbidities taken over the seven year survivorship period



Only 33% of people with breast cancer and 40% with prostate cancer are not living with inpatient morbidities up to 7 years after their diagnosis. For both cancers, over a third of people live with multiple morbidities after they are diagnosed.

What other health conditions do people with cancer live with?

The Scottish School of Primary Care's Multimorbidity Research Programme looked at clinical data from 310 Scottish general practices. It showed that in the group of people with cancer the prevalence of other conditions was high, including⁽¹²²⁾:

- 34% with hypertension
- 19% with 'painful conditions'
- 14% with coronary heart disease
- 14% with depression
- 10% with diabetes

How do needs of people with cancer and other conditions differ for other groups?⁽¹²²⁾

In a study of over 3,000 GP consultations, **patients with multi-morbidity** (all including combinations of conditions with and without cancer) **had more problems to discuss, which were more often complex (a mix of physical, psychological, and social) when compared to those without multi-morbidity**. However, the consultations were not longer for people with multi-morbidity and patient enablement was lower. These findings were worse in deprived areas, and GPs in deprived areas reported more stress in and after the consultations.

A study looking at people living with and beyond cancer reported that **63% of people with cancer and one or more chronic condition report general health problems**. This is 30% more than people with cancer but no other chronic conditions and 46% more than 'healthy people'. People with cancer and other chronic conditions are also more likely to report:

- difficulties with vigorous activities (56% compared to 27% of those without)
- aches and pains (76% compared to 55% of those without)
- problems with work or physical activities (27% and 23%, respectively, compared to a tenth of those without chronic conditions).

They are also more likely to need medical attention. 25% of people with cancer and other chronic conditions reported visiting a doctor or other healthcare professional more than ten times over the past year.⁽²⁶⁾

One study of non-small cell lung cancer patients showed that **severe comorbidity** (three or more conditions) in that cohort **was independently associated with significantly higher death rates**. Stage-specific 5-year survival in patients with severe comorbidity was significantly lower than in patients without comorbid disease.⁽¹²³⁾

'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,
living with prostate cancer

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References for the figures on the cover

People living with cancer:

Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. *Br J Cancer*. 2012;107: 1195-1202. (Projections scenario 1). 2015 data is based on 2010 and 2020 rate. The percentage aged 65+ in 2015 based on trend between 2010 and 2020 forecast .

People dying from cancer:

Macmillan Cancer Support estimates cancer mortality trends to 2015 assuming trends from 2002 to 2012, continue at the same rate. 2002 to 2012 data are provided by Welsh Cancer Intelligence and Surveillance Unit, Scottish Cancer Registry, Health and Social Care Information Centre (England) & Northern Ireland Cancer Registry. See references 2, 3, 4, 5.

People dying of other causes:

Macmillan broad estimate, of the number of people with a cancer diagnosis dying from cause other than cancer, using data on prevalence trends (see reference for ‘People living with cancer’), incidence projections (see reference for ‘People getting cancer for the first time’), and people dying from cancer (see reference ‘People dying from cancer’) along with all causes- mortality data from Office for National Statistics principal population projection - UK Summary.

People getting cancer for the first time:

Estimated based on the assumption that age-specific all-cancer incidence rates remain constant at 2012 rates for the next few years (as per Mistry et al. 2011). The UK 2012 incidence rates for five-year age groups from Office of National Statistics, Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, the Information Services Division Scotland and the Northern Ireland Cancer Registry.

This is applied to the ONS’s 2012 UK population projections. We also assume 5% of people get two or more primary diagnoses of cancer as noted in (Sasieni P.D, et al. 2011)

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 340,000 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’ we 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 160,000 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

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 Picture on 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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