

A man with a serious expression, wearing a black puffer jacket and a black cap, stands on a city street. The background is slightly blurred, showing other pedestrians and urban structures.

THE RICH PICTURE

**PEOPLE WITH
LUNG
CANCER**

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Lloyd, 48, living with lung cancer

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



About this 'Rich Picture'

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

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

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

The information could be valuable in many ways:

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

This document is not intended to

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

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

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

This 'Rich Picture' is one of a suite of documents. To access these documents please visit

<http://www.macmillan.org.uk/Richpictures> or for further information please contact evidence@macmillan.org.uk

The legal bit

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

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

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

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



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Guidance on referencing this document

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

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklet 'Understanding Lung Cancer' (MAC11632) more helpful:



**Understanding
Lung cancer**
MAC11632

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

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

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

Case Study Library

People affected by cancer

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

Professionals/Services

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



Comms Platform

Describes how to communicate with people affected by cancer.



Rich Pictures

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



Impact Briefs

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



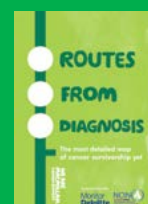
Local Cancer Intelligence

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



Routes from Diagnosis

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



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

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SUMMARY OF PEOPLE LIVING WITH LUNG CANCER

Key stats

Lung cancer is the second most commonly diagnosed cancer, and an average of **122 people** receive a lung cancer diagnosis every day in the UK.^(2a,2b,2c,2d)

Lung cancer is the **biggest killer** of all cancers, with over **35,000 people** dying **every year** from lung cancer in the UK.^(3a,3b,3c)

Survival rates are generally **poor**, however lung cancer doesn't have to be a death sentence – if **caught early** enough, it can be **treated**.⁽⁴¹⁾

Lung cancer is the biggest killer of all cancers.

Diagnosis

There is a clear link between the prevalence of **smoking** and **lung cancer** and smoking is linked to up to **86% of lung cancer cases**. This of course means that a significant proportion lung cancers (over **1 in 10** cases) are not linked to smoking.⁽¹⁵⁾

Some of the most **common signs and symptoms** of lung cancer include a **persistent cough**, changes in cough patterns, **coughing up blood** and **chest pains**.⁽⁶⁾

38% of people newly diagnosed with lung cancer were diagnosed via the **emergency route**, this is significantly **higher** than the average for all cancers.⁽²²⁾

Over 1 in 10 cases are not linked to smoking.

Treatment

Chemotherapy, radiotherapy and surgery are all used to treat **lung cancer**, however only **16%** of lung cancer patients receive surgery in England (in some countries this is well over **20%**, and there is large variation across the UK). Surgery can cure cancer, however many patients are not being offered surgery that could help **save their lives**.⁽³⁹⁾

People with lung cancer have many **symptoms and side-effects**, including cough, **tiredness**, shortness of breath, **depression and anxiety**, and many of these symptoms are not alleviated as well as they should be.⁽⁵⁶⁾

Only 16% of lung cancer patients receive surgery.

Survivorship

For those that do **survive** their **lung cancer**, their needs after initial treatment (survivorship needs) are often unmet – the most common unmet need is around lack of energy and tiredness. People often feel **abandoned** by the health system after their treatment has finished, and many people do not get **information** about recurrence.⁽⁶⁹⁾

There are some cancers with **better** survival rates that are more **feared** than **lung cancer**, which has a **relatively poor survival** rate.^(99–100)

People often feel abandoned by the health system.

End of Life

For people with **lung cancer** who are at **end-of-life**, palliative care can help alleviate symptoms and side-effects. Evidence shows that patients with **lung cancer** who receive **earlier palliative care** have a better quality of life and less aggressive care at the end of life but longer survival, compared to those receiving standard care.⁽⁸⁴⁾

People with **lung cancer** at end-of-life generally experience **greater isolation** and physical **dependency** than people with other types of cancer.⁽⁵³⁾

People with lung cancer at end-of-life generally experience greater isolation.

Lifestyle & perceptions

Over **80%** of people with lung cancer are **over 60 years old**. Incidence rates are highest in Scotland, then Wales, and lowest in Northern Ireland and England.^(94–98)

Macmillan hosts **online discussions** on its website; amongst those taking part in the lung cancer discussions, **references** to the word '**smoking**' are **less frequent** than articles feature in the **UK media** (UK national newspapers). The UK media widely report the links between **smoking** and **lung cancer**. This suggests that people affected by **lung cancer** don't find this issue important to discuss. Instead, words used by our online communities such as '**hugs**', and '**support**' suggest people affected by **lung cancer** are more **focussed** on **immediate needs**.^(104–105)

INTRODUCTION TO LUNG CANCER

What is lung cancer?

- Lung cancer is usually defined as a collection of cancers of the lung, bronchi (air passages in the lungs) and trachea (windpipe).
- There are two main types of primary lung cancer: **small cell lung cancer** (about 15% have this more aggressive form) and **non-small cell lung cancer** (about 85% have this less aggressive form). This document's focus is on people with these cancer types.
- **Mesothelioma** is a less common type of cancer that can affect the covering of the lungs, but it is not classified as lung cancer.
- **Secondary cancer in the lung** describes the situation where cancer cells have spread to the lungs from a cancer that began elsewhere in the body.
- There are also other rarer types of cancer which can occur in the lungs, eg **carcinosarcoma**, **carcinoid tumours**.

Want to know more?

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

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

'I was diagnosed with lung cancer in 2009. It's probably the worst feeling in the world. I was quite numb and when I was diagnosed I was on my own and I remember being on the train home and fighting back tears. I was completely in another world. Being self-employed I was reliant on my income to live and I was worried about missing my mortgage payments. I even contemplated not having the surgery that was being recommended. If someone tells you, you have cancer you shouldn't be debating whether or not you should have the operation. I had surgery which involved removing the lower lobe of my lung on the right hand side. I have now been clear of cancer for three years and have returned to work. I feel like my business has actually got better.'

Lloyd, 48

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people with lung 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.⁽⁵⁶⁾

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

**Around 72,000 people
were living with lung
cancer in the UK in 2015.**⁽⁵⁶⁾

How is this different for people with lung 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 our support.

The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

THE FACTS ON LUNG CANCER

This section presents some of the key stats and facts relating to people with Lung cancer. You may benefit from referring to the Jargon Buster on page 65 for details on some of the terms used in the section. Please note that incidence and mortality data on all cancers exclude non-melanoma skin cancer.

122

people are diagnosed with lung cancer every day in the UK

72,000

people were living with lung cancer in the UK in 2015⁽⁵⁶⁾

33%

of people in England live for more than one year after their lung cancer diagnosis

9.7%

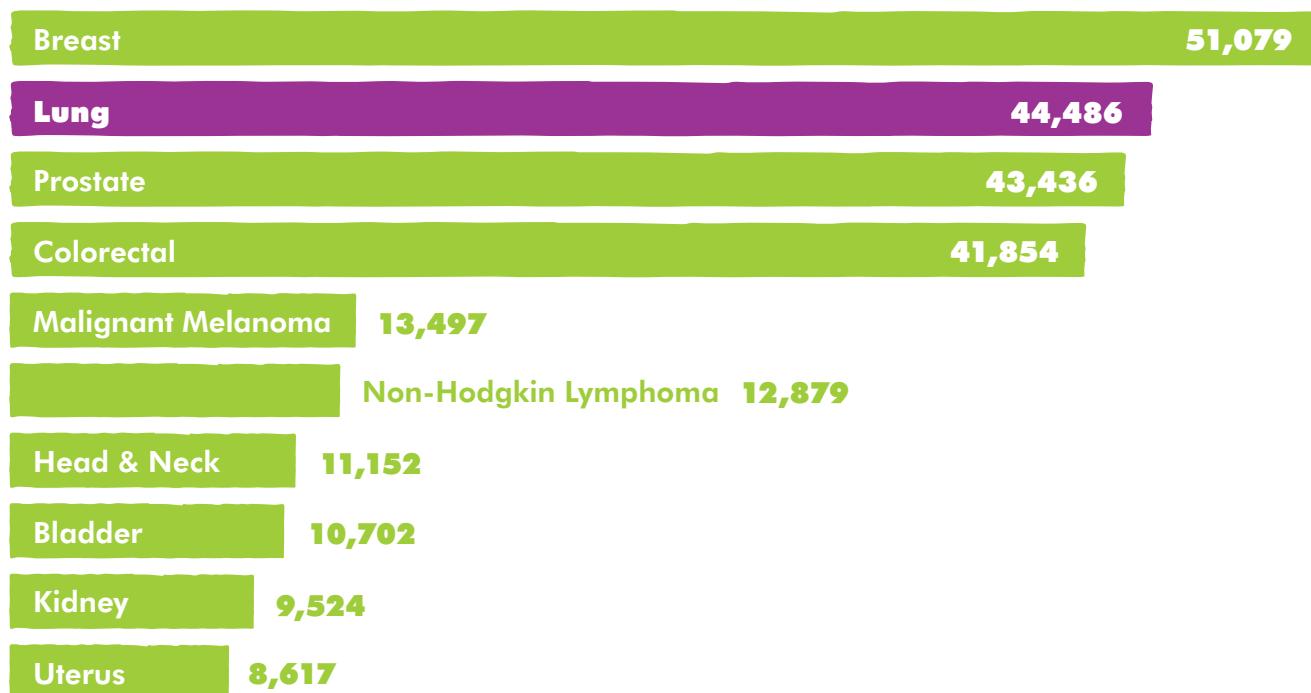
of men (12.5% of women) in England live more than five years after their lung cancer diagnosis

97

people die every day of lung cancer in the UK

How many people get lung cancer per year? (incidence)^(2a,2b,2c,2d)

Cancer incidence, UK, 2012, top 10 cancer sites

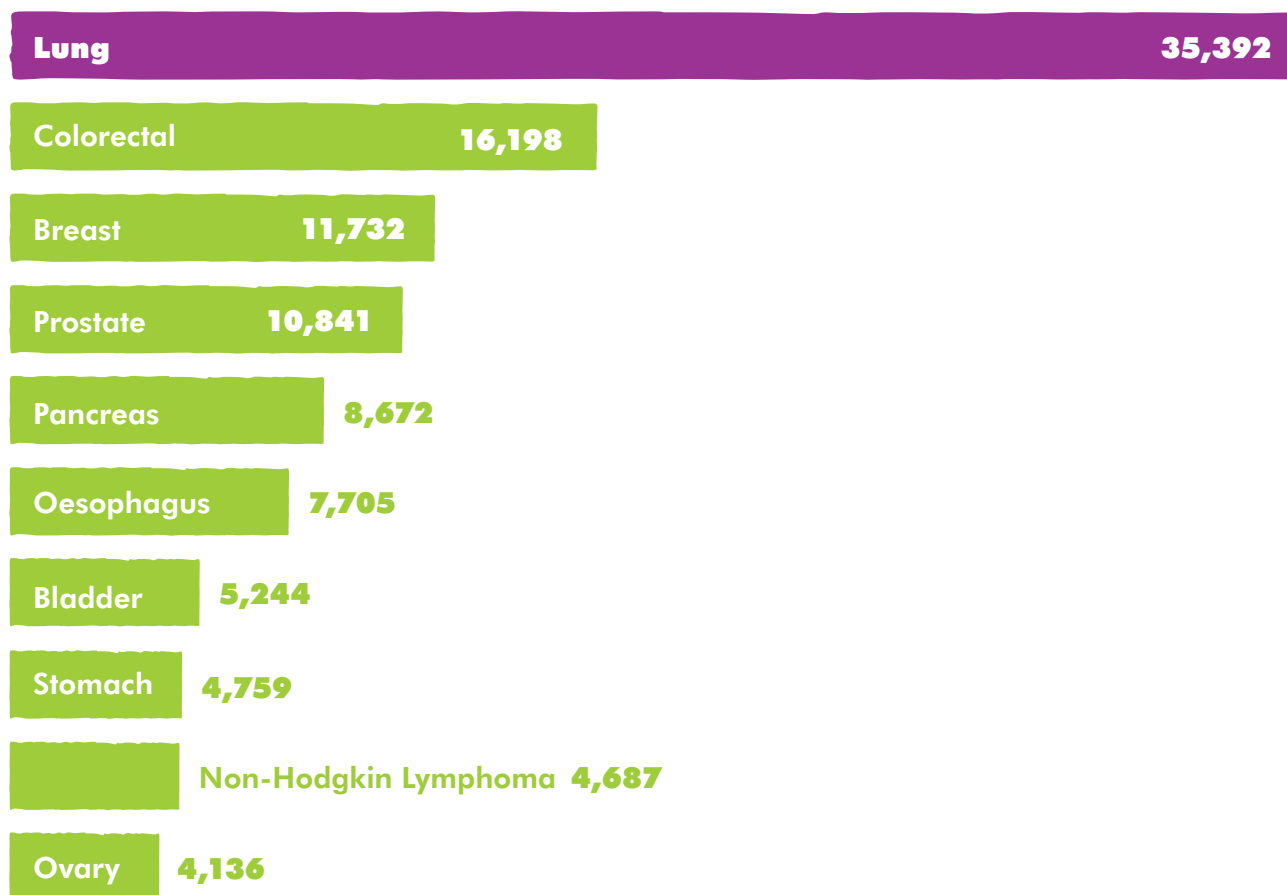


Lung cancer is the second most commonly diagnosed cancer.

Over 40,000 people are diagnosed with lung cancer every year in the UK; that's 122 people every day.

How many people die from lung cancer per year? (mortality)^(3a,3b,3c)

Mortality, UK, 2012, top 10 cancer sites



Lung cancer is the biggest killer of all cancers.

Over 35,000 people die from lung cancer every year in the UK; that's 97 people every day.

How many people are currently living with lung cancer? (prevalence)⁽⁵⁶⁾

People were living with lung cancer in the UK in 2015

72,000

Lung cancer is the most common cause of death from cancer and the prognosis for people with lung cancer is often poor.

What are the key stats for England?

See data on incidence, mortality and prevalence for England



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

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

35,903

new cases of lung cancer diagnoses in England in 2012.

How many people die from lung cancer per year in England? (mortality)^(3a)

28,379

lung cancer deaths in England in 2012.

How many people are living with lung cancer in England? (prevalence)⁽⁴⁾

58,000

People living with lung cancer in England in 2015.

What is the age-standardised* rate of incidence of lung cancer in people in England?^(11a)

47

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

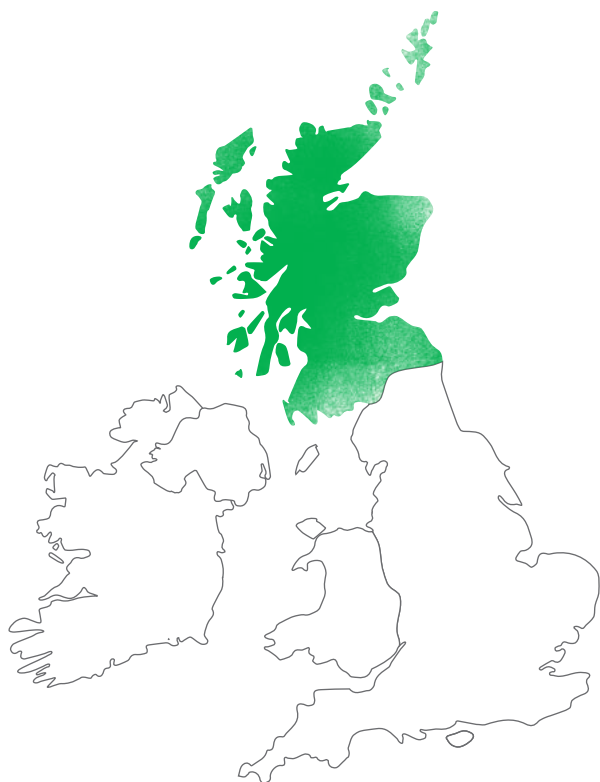
What is the age-standardised* rate of mortality from lung cancer in people in England?^(11b)

37

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

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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

How many people get lung cancer per year in Scotland? (incidence)^(2a)

5,070

new cases of lung cancer diagnoses in Scotland in 2012.

How many people die from lung cancer per year in Scotland? (mortality)^(3b)

4,189

lung cancer deaths in Scotland in 2012.

How many people are living with lung cancer in Scotland? (prevalence)⁽⁴⁾

8,000

People living with lung cancer in Scotland in 2015

What is the age-standardised* rate of incidence of lung cancer in people in Scotland?^(11a)

66

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

What is the age-standardised* rate of mortality from lung cancer in people in Scotland?^(11b)

53

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

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



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

How many people get lung cancer per year in Wales? (incidence)^(2b)

2,370

new cases of lung cancer diagnoses in Wales in 2012.

How many people die from lung cancer per year in Wales? (mortality)^(2b)

1,894

lung cancer deaths in Wales in 2012.

How many people are living with lung cancer in Wales? (prevalence)⁽⁴⁾

4,000

People living with lung cancer in Wales in 2015

What is the age-standardised* rate of incidence of lung cancer in people in Wales?^(11a)

50

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

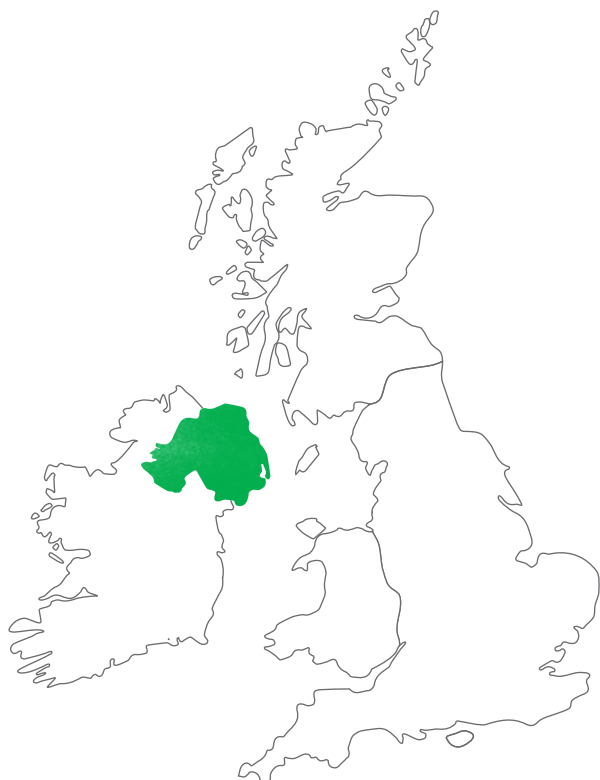
What is the age-standardised* rate of mortality from lung cancer in people in Wales?^(11b)

39

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

What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



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

How many people get lung cancer per year in Northern Ireland? (incidence)^(2c)

1,143

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

How many people die from lung cancer per year in Northern Ireland? (mortality)^(3c)

930

lung cancer deaths in Northern Ireland in 2012.

How many people are living with lung cancer in Northern Ireland? (prevalence)⁽⁴⁾

2,000

People living with lung cancer in Northern Ireland in 2015

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

49

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

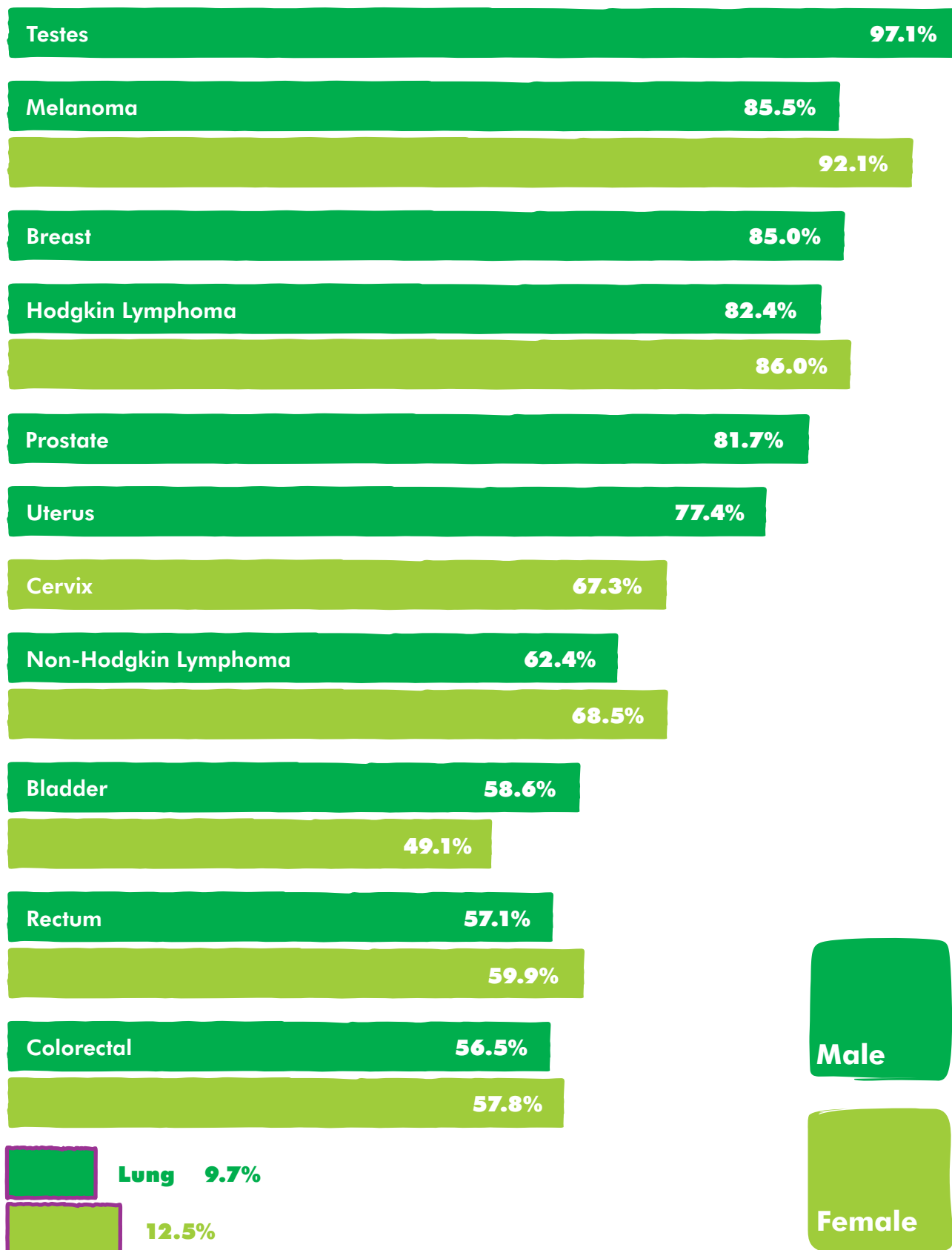
What is the age-standardised* rate of mortality from lung cancer in people in Northern Ireland?^(11b)

40

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

What proportion of people survive lung cancer? (survival)⁽⁵⁾

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

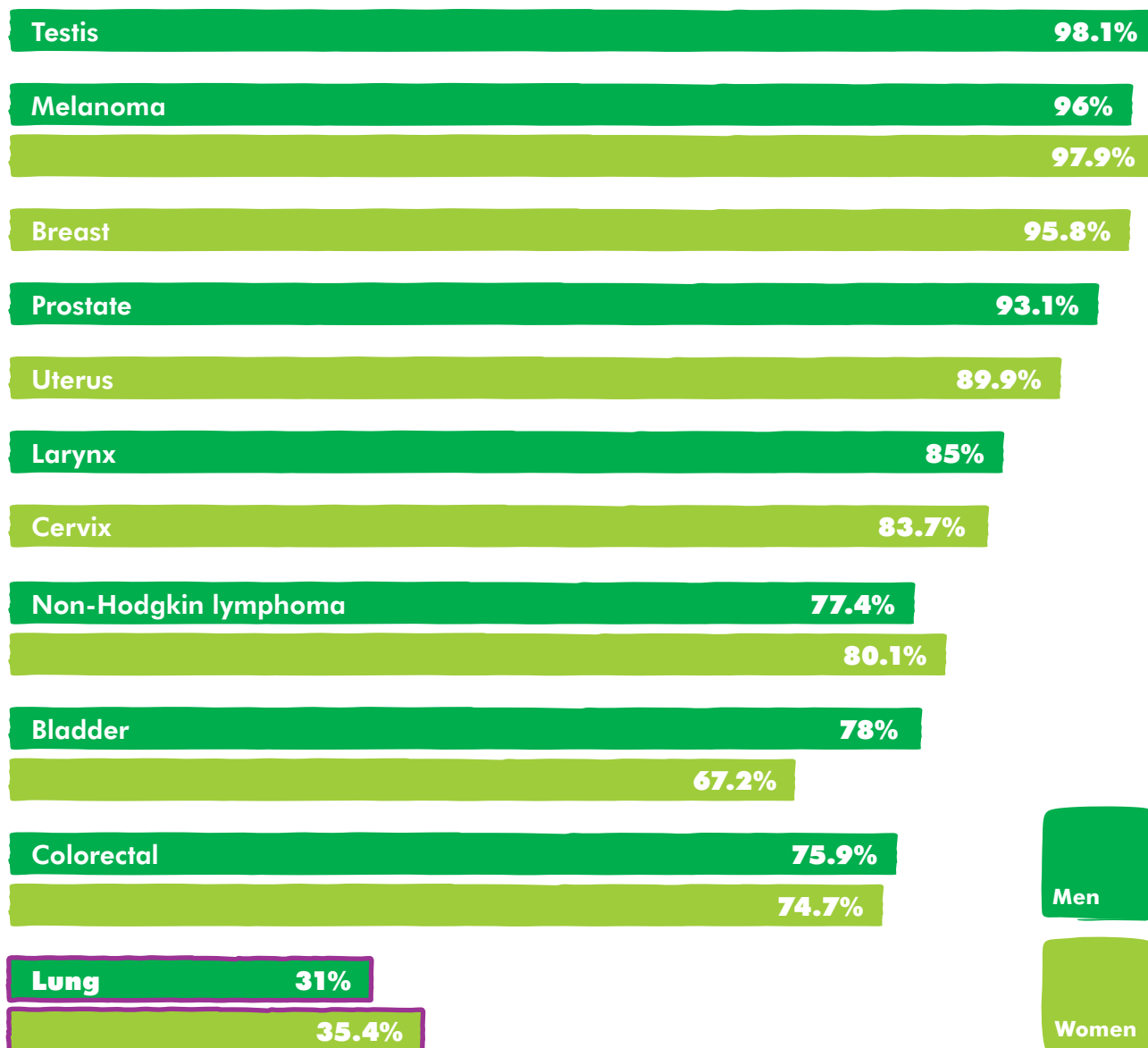


Lung cancer has one of the lowest 5 year survival rates of all cancers (9.7% of men and 12.5% of women are alive 5 years after their diagnosis).

This puts lung cancer at number 21 out of 22 in the rankings of 5 year survival. One reason for this is that many people are diagnosed too late for curative treatment. Earlier diagnosis would improve survival.⁽⁸⁶⁾

How many people live beyond one year of their lung cancer diagnosis?⁽⁵⁾

Age-standardised relative survival estimates, 2007-2011, by gender, England



The estimated proportion of people living more than one year after their lung cancer diagnosis is around 33% as the prognosis for lung cancer is often poor.

How do UK survival rates compare internationally?⁽⁷⁾

In the UK we perform worse on both one and five year survival when compared to other similar countries. For 2000-07, 1-year survival was around 30% in the UK nations, 34% in Denmark, and 37-43% in Norway, Sweden, France and Germany. The European average was 39%. 5-year survival was comparatively low at 9–10% in the UK and Denmark versus 13-16% in the other 4 countries, while the average for Europe was 13%. This suggests there is more we can do to improve survival for people with lung cancer in the UK.

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

Gender

The latest data we have shows that there are 4-10 new lung cancer cases in women for every 12 new cases in men.⁽⁸⁾

Survival rates for lung cancer are, on average, worse for men than for women, with a 3 to 7 percentage point difference in 5-year survival rate in the age brackets between 15-69, but only around 2 percentage points or less difference for men and women aged 70+.⁽⁹⁾

Ethnic background

White women are almost **three** times as likely to get lung cancer compared to women from the Asian, Black and Mixed groups, and White men are more than 1.5 times more likely to get lung cancer compared to people from Asian groups.⁽¹⁰⁾

Age

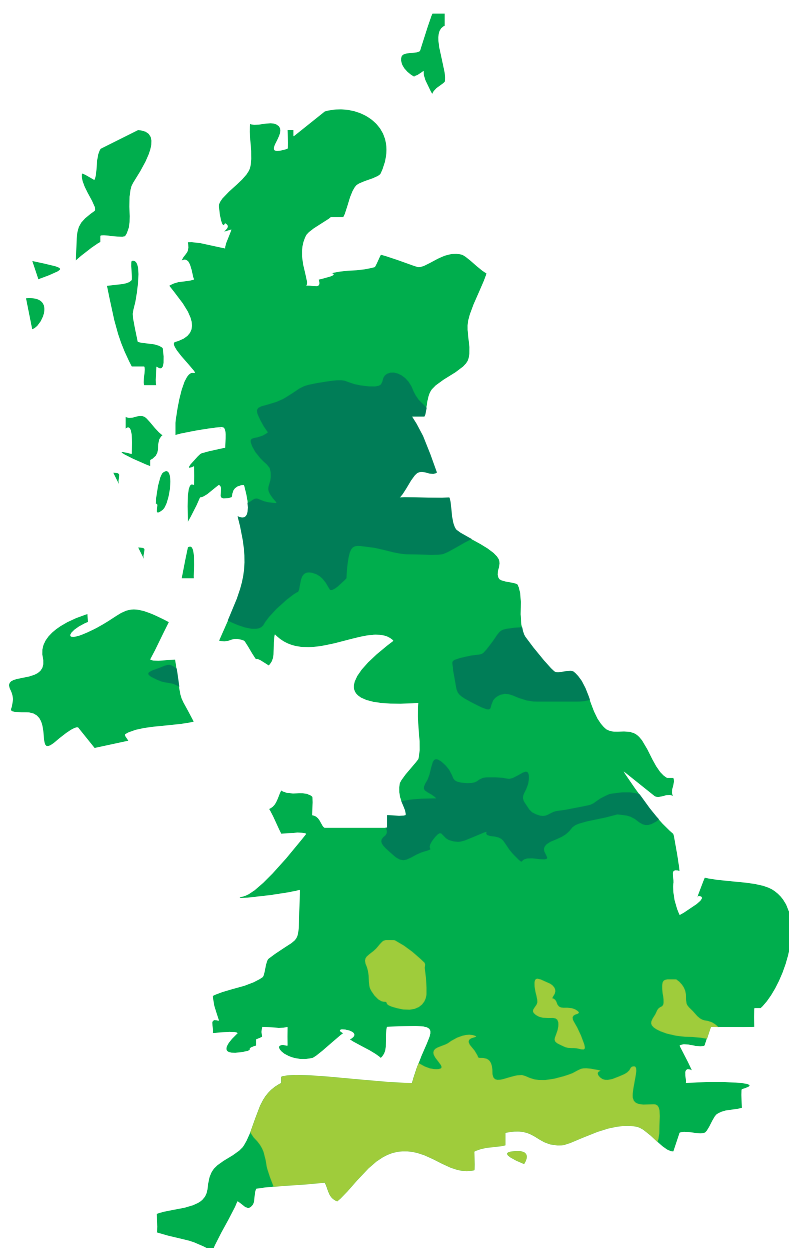
Three quarters of people diagnosed with lung cancer are 65+ years. Lung cancer is rarely diagnosed in people younger than 40, but incidence rises steeply thereafter peaking in people aged 80-84 years.^(11a)

More than three quarters of all lung cancer deaths in the UK occur in people aged 65+ years.^(11b)

Social background

People from the most deprived socio-economic groups are 2.5 times more likely to get lung cancer compared to people from the most affluent groups.⁽¹⁰⁾

What are the geographical 'hotspots' for lung cancer incidence, mortality and survival?⁽¹³⁾



Lung cancer incidence, UK, 2008-2010

Low

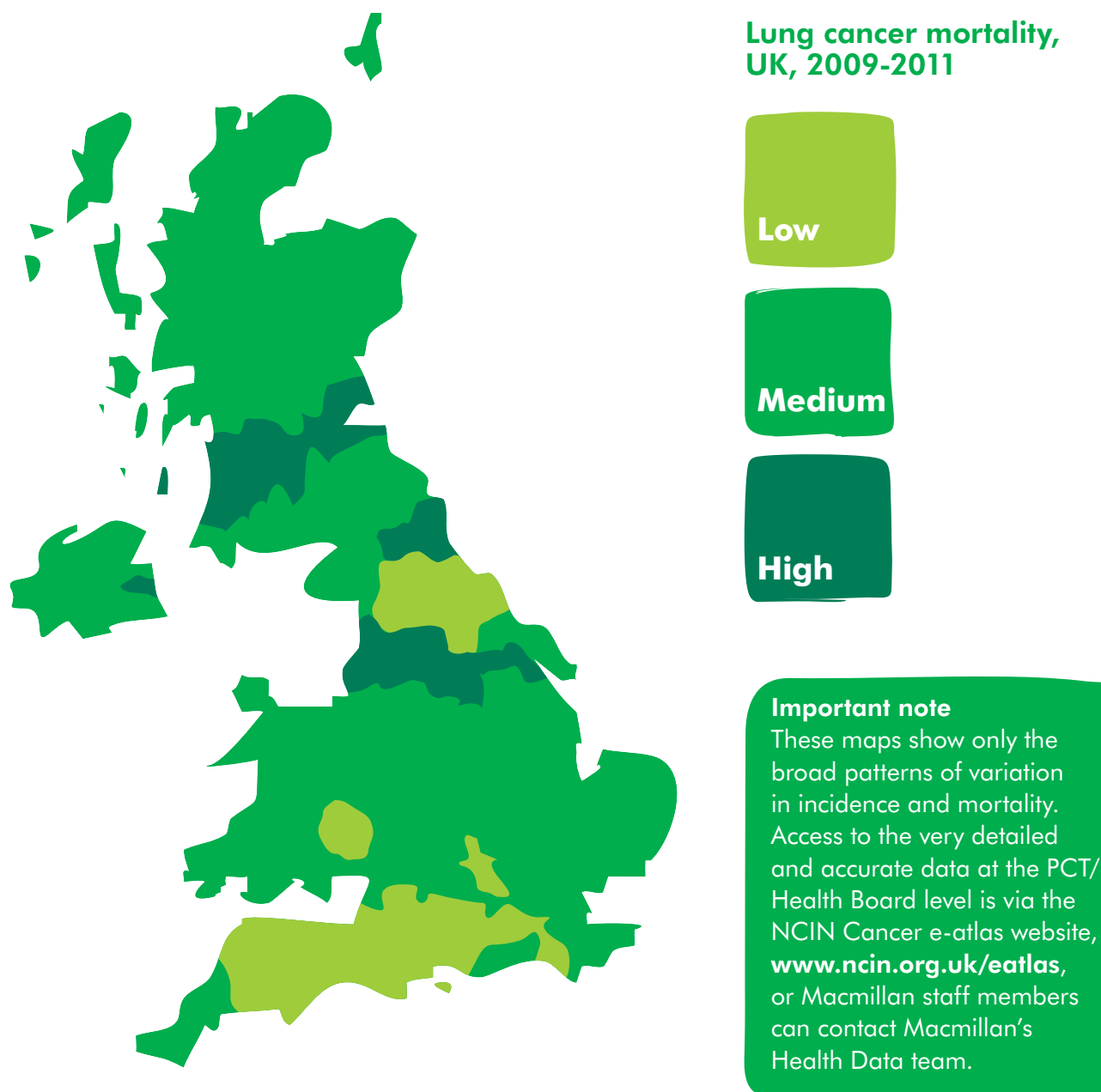
Medium

High

Important note

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

Lung cancer incidence rates are higher in the north (Scotland and Northern England) and lower in southern England



Lung cancer mortality rates are generally higher in Scotland compared with the rest of the UK

Survival

At present there is massive variation in survival rates according to where people live in the UK – for example, the 1 year survival rates for lung cancer ranges from just 20% in Medway PCT to 45% in Westminster PCT (based on 2009 data).⁽¹⁴⁾

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

There is a clear link between the prevalence of smoking and lung cancer – smoking is linked to up to 86% of cases of lung cancer. However not all people who are diagnosed with lung cancer are smokers, or have ever been smokers.⁽¹⁵⁾

The trends seen in lung cancer rates reflect historical (and projected) smoking habits:

Between 1993 and 2010 lung cancer incidence rates for males decreased by a third (33%) in the UK. Over the same period (1993 to 2010) there was an increase in the female rates (14%). For males and females combined, the lung cancer incidence rate decreased by 15%.^(11a)

In 1948 over two-thirds of men and more than two-fifths of women smoked in Great Britain. By the mid-1970s around half of men smoked and in 2012 this had more than halved to 22%. For British women, however, the same proportion smoked in 1974 as in 1948 (41%), though by 2012 only 19% of women smoked.⁽¹⁰³⁾

Female smoking rates have always been lower than male rates but, today, the gap between the sexes has narrowed considerably. The gap has fallen from 24% in 1948 to just 3% in 2012. As male smoking prevalence has fallen sharply, male lung cancer rates are set to reach a more comparable level with those of females.⁽¹⁰³⁾

Mortality rates for lung cancer are decreasing:

Lung cancer mortality decreased by a third (-36%) for all persons from 1979 (59 per 100,000) to 2011 (38 per 100,000) in the UK.^(11b)

Survival rates for lung cancer are improving:

In terms of survival, 1-year lung cancer survival rates for men in England and Wales have risen from 15% to 31% and for women they have risen from 13% to 35% diagnosed between 1971-75 and 2007-11.^(5,18)

5-year lung cancer survival rates over the same period have more than doubled but still remain low at around 11%. The latest figures show a continued upward trend in survival.^(5,18)

'A lot of people think, 'oh, did you smoke? Ah well, it's self-inflicted, isn't it'. I think that's the view people have of lung cancer, but I've never smoked.'

Bob, Scotland

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 lung 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 (p41), this section largely highlights the post-treatment needs and experiences of people living with cancer.

NEEDS AND EXPERIENCES DIAGNOSIS

What are the top 3 signs and symptoms of lung cancer?⁽⁶⁾

1. Persistent cough/change in cough pattern
2. Coughing up blood
3. Chest pain

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

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

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

In a recent study of the general population 30% did not recognise a persistent cough or hoarseness as a warning sign that might indicate lung cancer. Awareness of lung cancer signs and symptoms is lower in men, those who are older, and from less-educated groups or ethnic minorities.⁽²⁰⁾

Another study showed that among lung cancer patients, 75% had unrecognised symptoms prior to their diagnoses.⁽¹²⁾

There is a reluctance among people to seek help because they are unsure what is normal and what is not. Individuals often fail to recognise symptoms over many months prior to lung cancer diagnosis because they attribute them to everyday causes – even when severe.⁽²¹⁾ 50% of lung cancer patients had symptoms for more than 14 weeks before seeking medical advice. In particular, smokers tended to wait longer, possibly because they regard the symptoms as normal for smokers.⁽¹²⁾

How well does screening work for lung cancer?

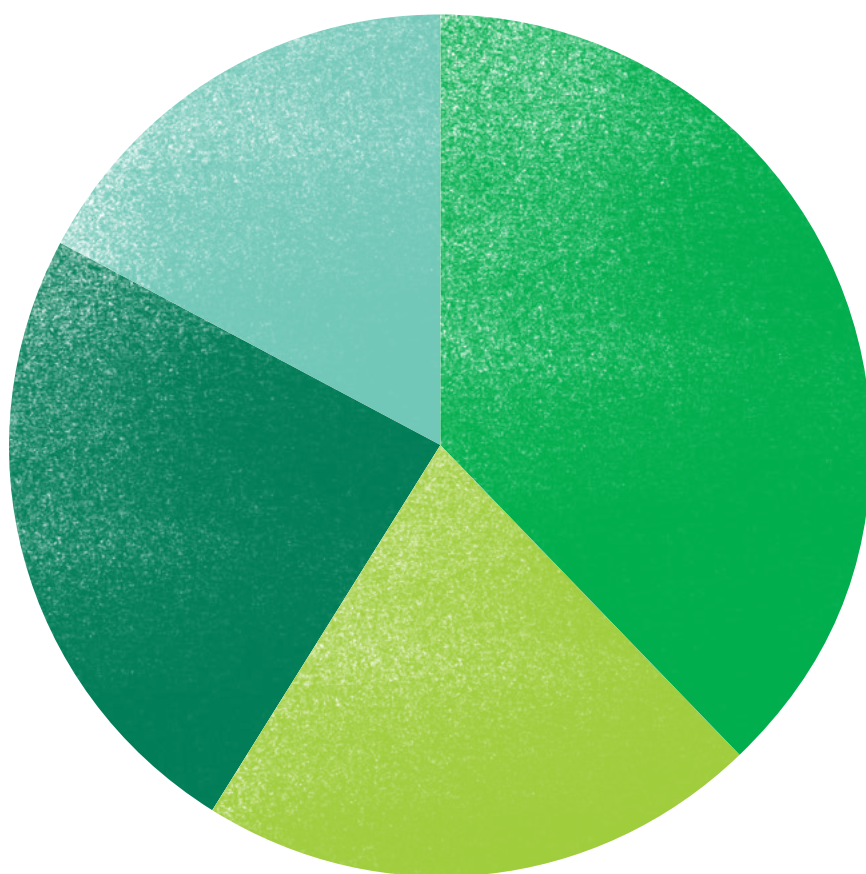
There is currently no screening test routinely available for lung cancer. At present, patients have to recognise signs and symptoms, refer themselves to their GP, and their GP must also have the ability to recognise signs and symptoms and refer the patient for tests in order to diagnose lung cancer as early as possible.

Novel research is being developed that may lead to new lung cancer screening tests being introduced, for example research into low-dose CT scanning and breath samples where lung cancer might be detected. The research is in the early stages of development, so any new screening test is unlikely to be introduced in the near future.⁽¹⁶⁾

**‘It was only the cough at first
and that’s why I had the X-ray.
I did have a bad cough and I
couldn’t seem to get rid of it.’**

David, North West

How is lung cancer diagnosed? (Routes to diagnosis)⁽²²⁾



Emergency

38%

GP referral

21%

Two Week Wait

24%

Other

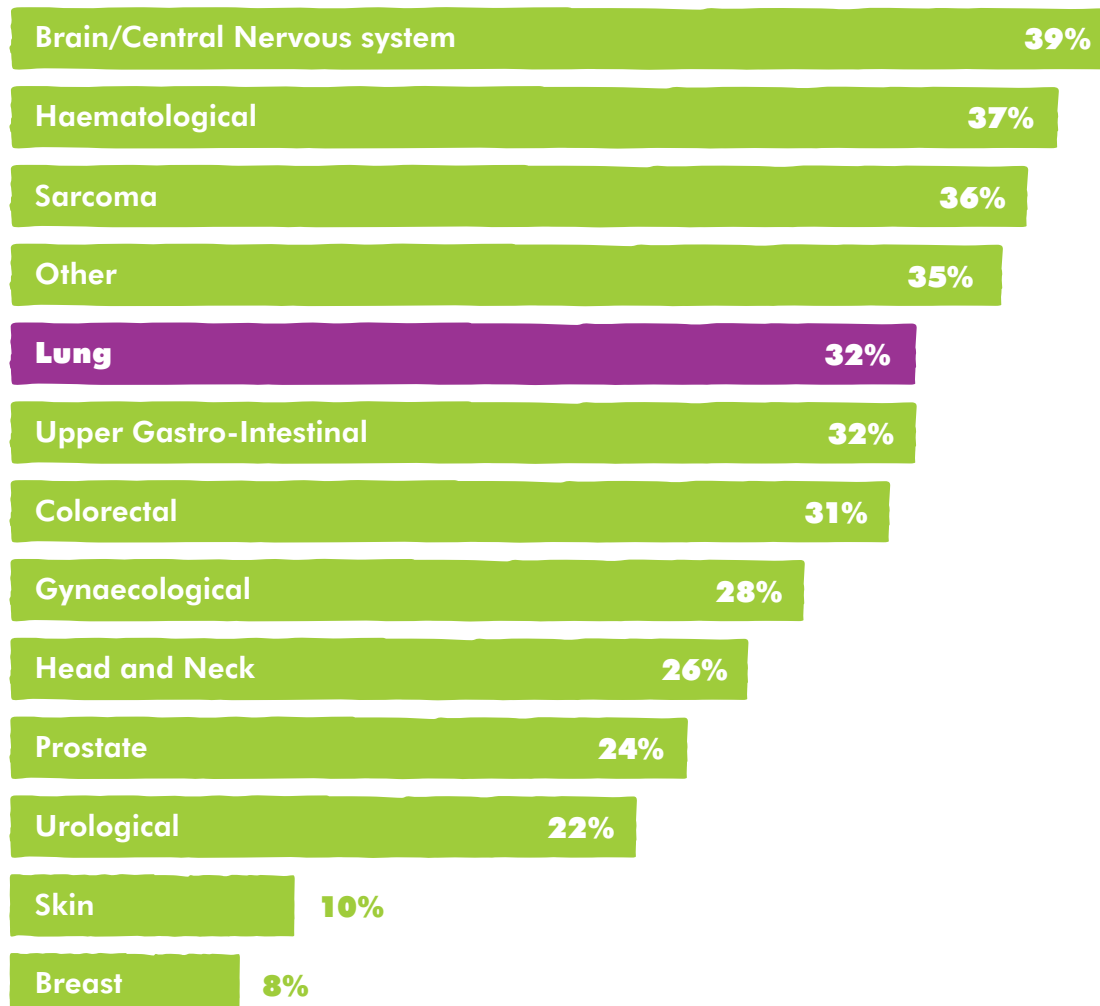
17%

'Other' includes screening, in-patient and out-patient routes, 'death certificate only' diagnoses, and 'unknown' routes.

2 week wait GP referrals occur where there is a suspicion of cancer.

38% of people newly diagnosed with lung cancer were diagnosed via the emergency route; this is significantly higher than the average for all cancers (23%). This is indicative of higher rates of late presentation of signs and symptoms which often leads to poor prognosis.

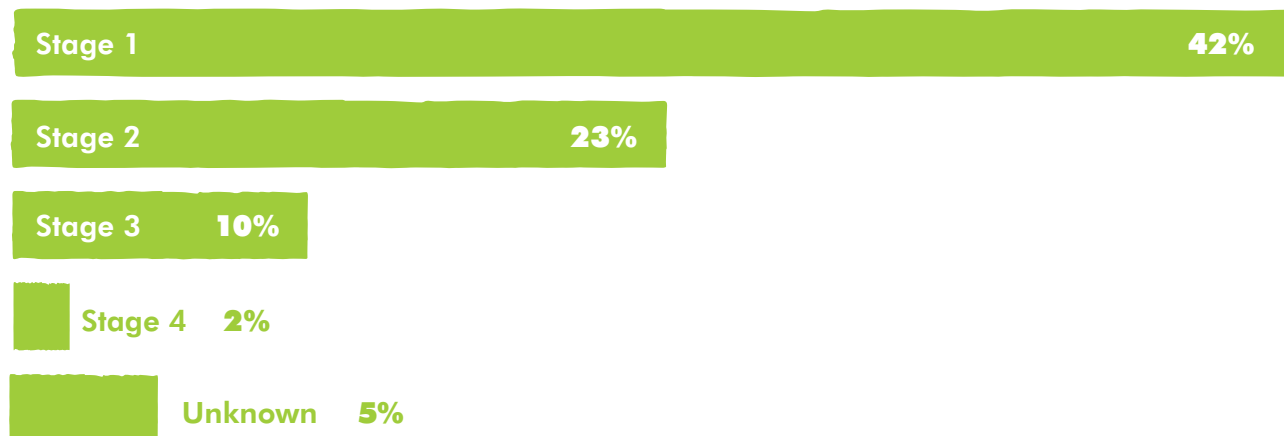
How many lung cancer patients had to see their GP more than twice before they were referred to hospital?⁽²³⁾



32% of people newly diagnosed with lung cancer had to see their GP more than twice before they were diagnosed compared with only 8% of breast cancer patients, 24% of prostate cancer patients and 10% skin cancer patients.

How does stage at diagnosis relate to probable survival rates?⁽²⁴⁾

The impact of stage at diagnosis on 5-year survival – lung cancer



5-year survival rates (%)

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

How long do people with lung cancer have to wait to be referred?⁽²⁵⁾

According to recent data, just over 97% of patients with suspected lung cancer were seen by a specialist within 2 weeks of referral.

This is a relatively good performance, well above the average for all cancers of just over 95%. Patients with suspected testicular cancer, leukemia, and haematological malignancies showed a slightly stronger performance.



PHYSICAL AND MEDICAL NEEDS

Diagnosis of lung cancer is difficult because its symptoms are similar to COPD (chronic obstructive pulmonary disease), which is the co-occurrence of chronic bronchitis and emphysema – a long-term, progressive disease of the lungs that causes shortness of breath. Many people with lung cancer will have co-morbidities (see Jargon buster on page 65) like COPD – this makes it particularly hard to diagnose lung cancer.

National guidelines in the UK recommend that patients with cancer have their care needs assessed at key points, including at the time of diagnosis. One survey in Nottingham found that in 650 people with thoracic cancer (mainly lung cancer) soon after diagnosis, **tiredness** and **shortness of breath** were the commonest issues causing distress or bother, present in about 50%.⁽¹⁰⁶⁾

As described on page 28, an average of 38% of lung cancer patients were diagnosed via the emergency admission route. In a review of patients in Exeter, 23% of lung cancer patients were admitted to hospital as an emergency. In the same review **11%** of these patients had **no respiratory symptoms**. This suggests that for some patients, the 'usual' signs and symptoms are not always apparent.⁽²⁶⁾

Delays in seeking medical advice may be due to **uncertainty amongst people about what is 'normal'** leading to delays in diagnosis.⁽²¹⁾



FINANCIAL NEEDS

Of the people with lung cancer who said they wanted it, **30%** of them were **not given information on financial help** or benefits by hospital staff, compared to an average (for all cancers) of 46%.⁽²⁸⁾

Not specific to people with lung cancer

According to a 2013 Macmillan report, **83%** of people are, on average, **£570 a month worse off** as a result of a cancer diagnosis.⁽²⁷⁾



PRACTICAL AND INFORMATION NEEDS

78% of people with lung cancer said they received a completely understandable explanation of their test results. This is comparable to other cancer types. This of course suggests **that 22% of lung cancer patients do not receive a completely understandable explanation of their test results.**⁽³²⁾

Only **65% of people with lung cancer received written information about their type of cancer** compared to 81% of prostate and skin cancer patients. The average for all cancer types was 71%.⁽³³⁾

In a 2013 survey, **25% of lung cancer patients said they did not completely understand the explanation of what was wrong with them.** For some other cancer types, this is even more of a problem, such as haematological cancer (42%).⁽¹⁷⁾

Not specific to people with lung cancer
Information needs at diagnosis are extensive and include prognosis, side effects of treatments, impact on family and friends, altered sexual attractiveness, self care and risks of family developing the disease.⁽³⁴⁾

The strongest preference for information at diagnosis is **information about prognosis.**⁽³⁴⁾

Many people affected by cancer (not just people affected by lung cancer) are frustrated at being **unaware of support** until late into their illness and information on how to deal with **emotions, relationships and social situations** is the hardest to find.⁽³¹⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

People with lung cancer often experience **higher levels of distress** than some other cancers.⁽³⁶⁾

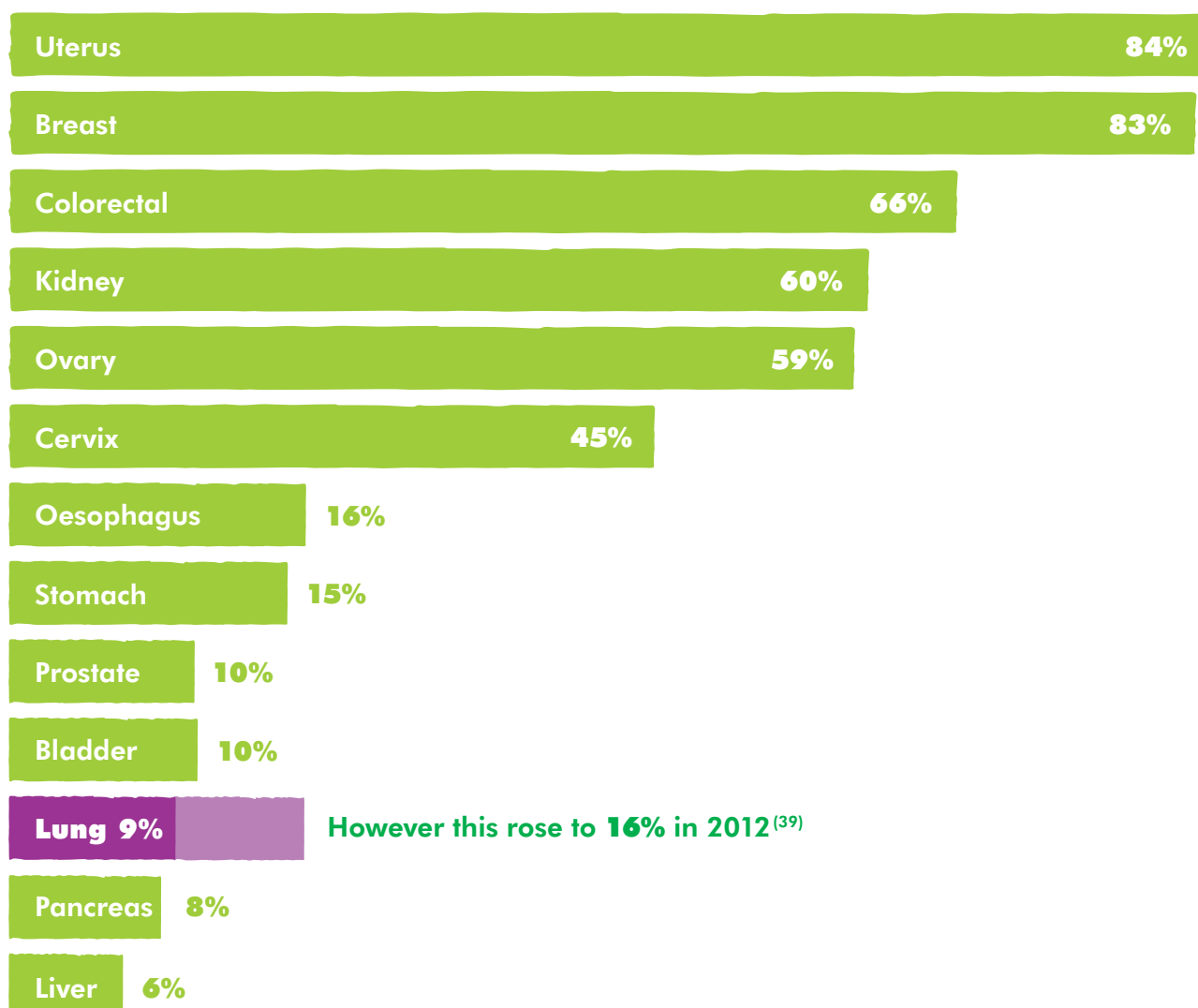
Depression is common and persistent amongst people with lung cancer, possibly due to the frequency of severe symptoms, medical comorbidities, and poor prognoses.⁽³⁷⁾

Not specific to people with lung cancer
One in four people (23%) diagnosed with cancer in the UK will **lack support from family or friends** during their treatment and recovery – that represents more than 70,000 people each year.⁽⁸³⁾

62% of all cancer patients in a survey had experienced **at least one psychological condition** that can occur as a result of cancer and its treatment in previous 12 months. Such conditions include **depression, anxiety and sexual problems.** However, 40% of them **had not sought help** from healthcare professionals.⁽³⁰⁾

NEEDS AND EXPERIENCES TREATMENT

Percentage of patients who had major surgical resection,
England 2004-2006⁽³⁸⁾



In 2012, 16% of lung cancer patients had a record of a major surgical resection as part of their treatment.

What treatments do lung cancer patients get?

Any active treatment

Around 20,000 people with lung cancer received active treatment in England and Wales in 2012, this represents **61%** of the total number of cases.⁽³⁹⁾

Chemotherapy

68% of people with small cell lung cancer received chemotherapy, but only **57%** of people with non-small cell lung cancer received chemotherapy in England and Wales in 2012.⁽³⁹⁾

Radiotherapy

Around 9,900 people with lung cancer received radiotherapy; **30%** of the total lung cancer cases.⁽³⁹⁾

Lung cancer accounts for **14%** of all the radiotherapy episodes in England (2011-12). There were 17,736 radiotherapy episodes and 141,890 radiotherapy attendances for lung cancer.⁽⁴⁰⁾

Surgery

Lung cancer has a relatively poor 5-year survival rate, but the one treatment that can cure non-small cell lung cancer is the removal of the tumour with surgery. As shown in the chart, left, only **around 9%** of these patients are treated with surgery in the UK in 2004-2006, but this rose to 16% in 2012, compared with around 20% in other countries. If you look within the UK cancer networks it varies from between 20% down to just 4%.^(38,41)

For 2008-2012, the surgical resection rate for lung cancer patients aged over 75 was only 14%, compared to around 21% for those under 75.⁽³⁹⁾ Recent research has found that a lung cancer patient aged 75+ is around **five times less likely to receive surgery** than a younger patient.⁽²⁹⁾

Biological therapy

Biological therapies use substances that occur naturally in the body to destroy cancer cells. There are two types of biological therapy that can be used for lung cancer; cancer growth inhibitors and monoclonal antibodies (eg Avastin). Side effects of biological therapies can include nausea, tiredness, diarrhoea and lowered resistance to infection.

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

More than a quarter (26%) of the 64,000 people living with lung cancer spend some time in hospital for cancer-related treatment, this compares to 10% of women living with breast cancer.⁽⁴²⁾

Those who are newly diagnosed or near end of life are much more likely to spend time in hospital.⁽⁴²⁾

In total, there were just over 85,000 admissions to NHS hospitals in England (emergency and non-emergency) for lung cancer during 2012-13.⁽⁴³⁾

Twice as many lung cancer patients were admitted through an emergency route compared to all cancers (19% for lung cancer compared to 9% for all cancers).⁽⁴³⁾

The median length of stay for patients who were admitted in 2012-13 was 6 days for lung and bronchus cancer patients and 3 days for trachea cancer patients.⁽⁴³⁾

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

The two main types of primary lung cancer are treated differently; chemotherapy and radiotherapy are usually used for small cell lung cancer. Surgery, chemotherapy and radiotherapy can all be used for non-small cell lung cancer.⁽⁴⁴⁾

Other treatments for people with lung cancer that can sometimes be used to treat symptoms include laser therapy (to remove blockages in the airway which can create breathlessness), and airway or blood vessel stents (to keep airways or blood vessels open if they are closed due to external pressure on them).⁽⁴⁵⁾

NHS guidelines state that anyone diagnosed with lung cancer should be under the care of a multi-disciplinary team, which includes professionals such as surgeons, oncologists, doctors who specialise in symptom control, radiologists, specialist lung cancer nurses, physiotherapists, occupational therapists, psychologists, social workers and dietitians. However we know that many people do not benefit from the full range of support that could be available.⁽⁴⁶⁾

How many people with lung cancer have access to a lung CNS? ⁽⁴⁷⁾

As of 2010, there were **252 lung cancer clinical nurse specialists** (CNSs) in England.

In 2012, **82%** of lung cancer patients in England and Wales **were seen by a lung CNS**, and 61% had the nurse present at the time of diagnosis. This is an improvement on previous years.⁽³⁹⁾

Recent modelling work carried out by Frontier Economics has indicated that **a further 179 lung CNSs are required to fully meet the demand** in England. Macmillan has estimated the total UK-wide requirements and continues work with local partners to support people living with cancer.⁽⁴⁸⁾

Macmillan's internal data suggests that we had (as of June 2013) **255 lung and thoracic Macmillan Nurse posts** across the whole of the UK.⁽⁴⁹⁾

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

What does this mean for patients

In 2009 65% of people with lung cancer seen by a lung CNS received cancer treatment compared to 30% of those who did not see a lung CNS.⁽⁵⁰⁾

91% of people with lung cancer reported that they had been given the name of a CNS. People with a CNS responded far more positively than those without on a range of items related to information, choice and care.⁽⁵¹⁾

Lung cancer CNSs have a positive contribution for patient outcomes along all stages of the cancer pathway and perform a wide range of interventions.⁽⁵²⁾

CNSs shift the emphasis of care from focusing solely on the physical aspects of lung cancer management to include also the emotional and social needs of their patients.⁽⁵²⁾

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

Just under half (49%) of all people living with cancer (of all cancer types) have at least one other chronic condition. This includes 15% who have two, and 6% who have three other chronic conditions.⁽⁵⁴⁾

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

A Spanish study has found that 49% of lung cancer patients had no co-morbidity, 32% had one, and 19% had two or more. The most common co-morbidities were COPD (30%), cardiovascular disease (15%) and diabetes (9%).⁽⁵⁵⁾

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

‘One hospital I went to for lung cancer treatment told me exactly what was being done, why it was being done and what my problem was. Another hospital that I went to wouldn’t tell you anything.’

Peter, North West



PHYSICAL AND MEDICAL NEEDS

People with lung cancer have **many symptoms** including cough, tiredness, shortness of breath, depression and anxiety, and many of these symptoms are not alleviated as well as they should be.⁽⁵⁶⁾

31% of people with lung cancer thought **GPs and nurses** at their local practice **could have done more** to support them while they were having their treatment.⁽⁵⁷⁾

Pain intensity and **depression levels** tend to be higher for people with lung cancer compared to cancer patients with other cancer types.⁽⁵⁸⁾

A recent review found that patients with lung cancer living in **more socioeconomically deprived** circumstances are **less likely to receive any type of treatment**, surgery, and chemotherapy. Combined with the socioeconomic inequalities in incidence due to the prevalence of smoking in deprived areas, this partly explains the variations in survival for people with lung cancer.⁽⁵⁹⁾



FINANCIAL NEEDS

Not specific to people with lung cancer

It is estimated that **30% of people with cancer** (not just lung cancer) **experience a loss of income** as a result of their cancer, with those affected losing, on average **£860 a month**.⁽²⁷⁾

Some of the additional costs incurred at **treatment stage** for cancer patients and their carers is **travel to and from hospital**. This affects 67% of cancer patients and costs them, on average, £170 a month.⁽²⁷⁾



PRACTICAL AND INFORMATION NEEDS

In a 2008 report on **information recall amongst people with lung cancer** the recall of a cancer diagnosis was relatively high however only 49% of those with lung cancer **could recall whether their treatment was curative or palliative**. (See Jargon buster on page 65 for definitions of these terms).⁽⁶²⁾

85% of people with lung cancer **were given a choice about treatment** compared to 92% prostate cancer patients and 89% breast cancer.⁽⁶³⁾

24% of people with lung cancer were **not told about treatment side effects** in a way in which they could understand. This is similar for patients with other cancer types.⁽⁶⁴⁾

Lung cancer can **affect your ability to drive**. People who have had lung cancer and are driving with a large goods or passenger-carrying driving licence should notify the DVLA if they have been diagnosed with lung cancer in the last 5 years.⁽⁶⁵⁾

Not specific to people with lung cancer

10% of people with cancer (not lung-cancer-specific) were **not given enough information** about their condition and treatment, 2% were given too much.⁽⁶¹⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Depression levels tend to be higher for people with lung cancer compared to cancer patients with other cancer types.⁽⁵⁸⁾

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

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

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

- Some feel a sense of abandonment after treatment.⁽⁷⁷⁾
- **39%** who completed treatment in 2009/10 say that **no health or social care professional talked them through the needs they might have.**⁽³⁷⁾
- **94%** experience **physical health condition problems** in their first year after treatment.⁽⁶⁶⁾
- **78%** of people with cancer have experienced **at least one physical health condition** in the last 12 months which can occur as a result of cancer or its treatment.⁽⁶⁶⁾
- **62%** of people with cancer have experienced **at least one of the psychological conditions** that can occur as a result of cancer and its treatment.⁽⁶⁶⁾
- **40%** with emotional difficulties had **not sought medical help** or other support.⁽⁷⁷⁾
- **23%** **lack support from friends and family** during treatment and recovery.⁽⁸³⁾

- **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.**⁽⁸³⁾

Cancer survivors have greater health needs than the general population

- **90%** of cancer survivors have visited their GP and **45%** visited a specialist doctor in the last 12 months. This compares with **68%** and **15%** of the wider population.⁽⁶⁸⁾
- In a recent survey, **78%** of lung cancer patients said that they were **not offered a written assessment or care plan.** These are essential in providing personalised care for cancer patients and their carers.⁽⁸⁵⁾

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.

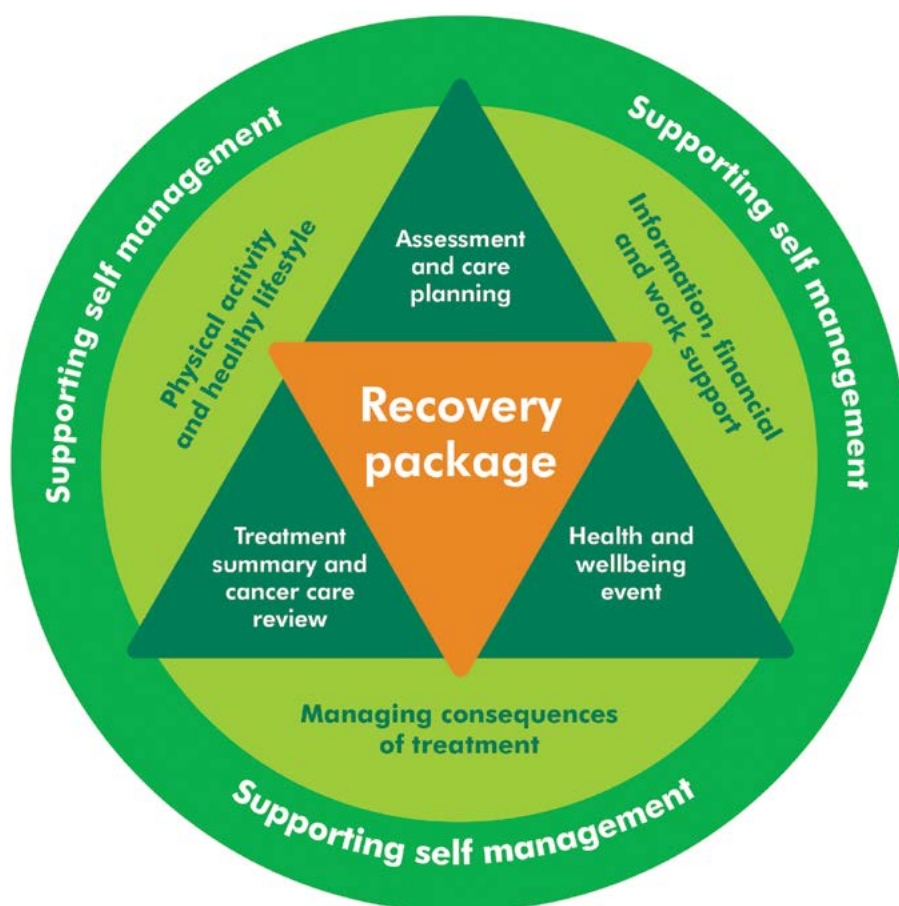
The document was followed by: **‘Innovation to implementation: Stratified pathways of care for people living with or beyond cancer: A “how to” guide’**.

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

The **greatest unmet needs** for people with lung cancer are **physical needs** followed by psychological needs. The most common unmet need is around a **lack of energy** and **tiredness**.⁽⁶⁹⁾

Self reported **sexual concerns** are common in people with lung cancer and are related to shortness of breath and emotional distress.⁽⁷⁰⁾

An American study found that people with lung cancer experience **higher levels of pain** compared with patients with other types of cancer.⁽⁵⁸⁾

In lung cancer survivors, **fatigue** is usually the symptom with the most significant effect on quality of life.⁽⁷¹⁾

Not specific to people with lung cancer

Amongst many people with cancer (not just lung) **social distress** usually follows reduced physical functioning, and **psychological and spiritual distress** is greatest at key transitions: diagnosis, discharge after treatment, disease progression and end of life.⁽⁷²⁾



FINANCIAL NEEDS

18% of people with lung cancer who wanted to know were **not told about free prescriptions**. Even fewer patients with cancer types other than lung were told about free prescriptions.⁽⁷³⁾

Not specific to people with lung cancer

Some people affected by cancer (not just people affected by lung cancer) **are not aware that they can claim benefits**. 61% of a recent survey did not receive health-related benefits.⁽²⁷⁾

Some people affected by cancer (not just people affected by lung cancer) find the **benefits system complex and difficult to navigate**. Benefits advice is also not always offered in a timely fashion. 42% of people with cancer did not receive money or debt advice following their diagnosis.⁽²⁷⁾

There is also a **lack of support for** cancer patients who wish to **remain in or return to work**. There are over 700,000 people of working age living with cancer across the UK, but research has shown less than 2% of people with cancer (roughly 40,000) access specialist return-to-work services.⁽⁶⁰⁾



PRACTICAL AND INFORMATION NEEDS

43% of people with lung cancer were **not given enough care** and help from health and social care professionals **once they were at home**.⁽⁷⁵⁾

Not specific to people with lung cancer

Many people **feel abandoned** by the healthcare system once their initial treatment for cancer has completed.⁽⁷⁸⁾

Post-treatment information needs are also reported by people with cancer, although comparatively speaking **the need may not be as great** as it was during diagnosis and treatment for some.⁽⁷⁶⁾

If **recurrence** occurs, a **renewed need for information & support** is generally expressed by people with cancer.⁽⁷⁶⁾

For those experiencing a **recurrence**, only **half of those surveyed said that they received supported information**, suggesting there is unmet need at recurrence.⁽⁷⁶⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

People with lung cancer have the **highest number of unmet needs** out of all cancer patients. This is mainly due to **higher psychological support and physical/daily living support needs**.⁽⁷⁹⁾

28% of people with lung cancer were **not given enough emotional support** from hospital staff when being treated as an outpatient.⁽⁸⁰⁾

15% of people with lung cancer were **not given information about self help and support groups**.⁽⁸¹⁾

Among lung cancer survivors, **never smokers tend to experience better spiritual well-being** than former or current smokers. Spiritual well-being covers aspects such as peace of mind and concepts of faith.⁽¹⁰⁰⁾

Not specific to people with lung cancer

Although psychological issues are more common in the first year after **treatment one third of people** (of all cancer types) **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 emotional issue.⁽⁷⁷⁾

NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

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

It is estimated that around 1 in 220 new cancer diagnoses in the UK were associated with radiotherapy for a previous cancer.⁽⁸²⁾ Nearly a quarter (24%) of these radiotherapy related second cancers were lung cancer.⁽⁸²⁾

Evidence of palliative care provision for cancer patients indicate that it improves quality of life and reduces health care costs.⁽⁸⁴⁾

How many lung cancer patients are at End of Life?

Due to its poor prognosis more than a fifth of people living with lung cancer are in their last year of life (13,700), and nearly two-thirds of these (9,000) were diagnosed in the same year they died.⁽⁴²⁾

What is the impact of giving lung cancer patients palliative care*?

Evidence suggests that compared to patients receiving standard care, those receiving regular palliative care input from the time of diagnosis had a better quality of life, received less aggressive treatments close to death, and survived longer.⁽⁸⁴⁾

*The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life-threatening condition: "Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is 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."

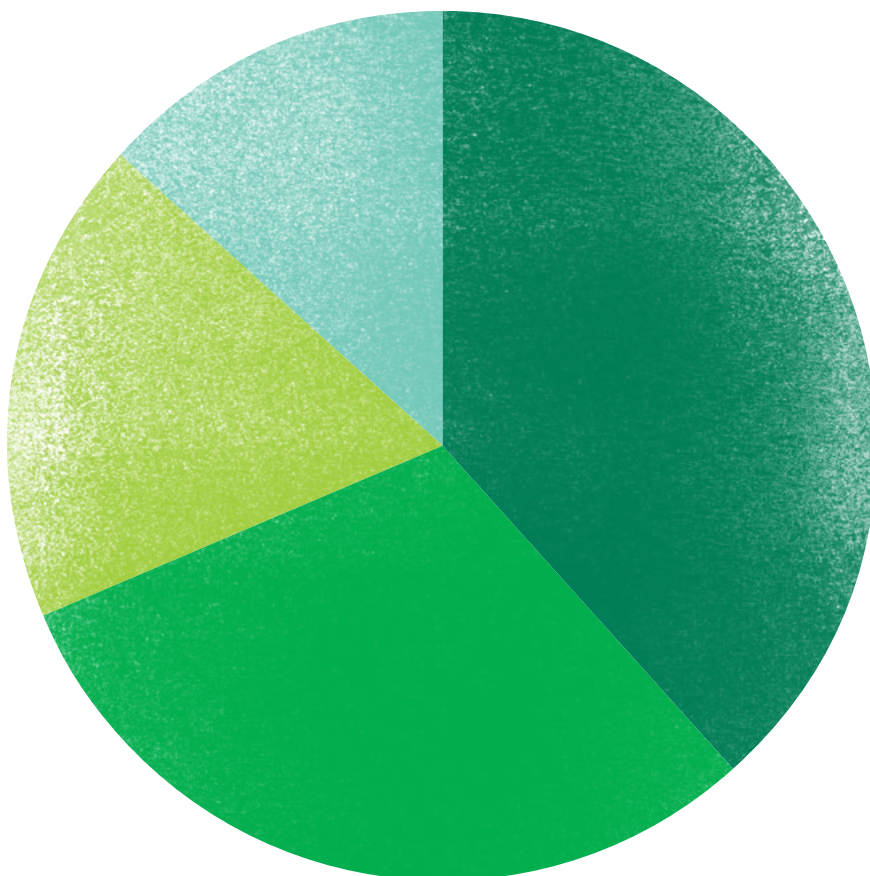
How many cancer deaths are there in each setting?

Data on place of death is not available broken down by cancer type. However for all cancers, we know that cancer deaths in England & Wales account for 90% of all deaths in hospices, 39% of all deaths at home, 23% of all deaths in hospital, 19% of all deaths occur in care homes, 18% of all deaths in communal establishments and 23% of all deaths elsewhere.^(3a)

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

Where did people with cancer die⁽¹⁰²⁾

Place of death, England, 2012



Hospital

38%

Home
(own residence)

30%

Hospice

18%

Care and
nursing home

13%

*Excludes deaths that occur elsewhere. Does not add up to 100% due to rounding.

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

A recent survey found that 73% of people who died from cancer, as well as 73% of all people who died, would have liked to have spent the last weeks and days of their life at home.⁽¹⁰²⁾ However, only 30% of those who die from cancer actually die at their home or own residence.⁽¹⁰²⁾

If people who have (or have had) cancer but don't die of cancer, what do they die of and how many of them die of other causes?

42% of people who die in the UK will have had a cancer diagnosis.

And for most of them it is cancer which causes their death (64% of cases).⁽⁸⁷⁾

**‘As someone with lung cancer,
you can either die on your
knees or die standing up.
I intend to die standing up.’**

Simon, Midlands



PHYSICAL AND MEDICAL NEEDS

Palliative care introduced **early after diagnosis** for patients with incurable cancer can **improve quality of life**. It can also lead to less aggressive care at the end of life and **longer survival**.⁽⁸⁴⁾

Not specific to people with lung cancer

The reported prevalence of **moderate to severe pain in advanced cancer** is approximately 64%, with a sharp increase to as high as **80-90% at the end of life**.⁽⁸⁸⁾

Various symptoms are **very common in advanced cancer**, with patients having an average of 6 uncontrolled symptoms on admission to palliative care.⁽⁸⁹⁾

Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; they occur in some combination in virtually all patients.⁽⁹⁰⁾



FINANCIAL NEEDS

Lung cancer often progresses rapidly and prognosis is usually poor. This often means that **many people with lung cancer** (especially those with the more aggressive small cell lung cancer) **will qualify for benefits under special social security rules (DS1500)** because they have a terminal illness and are unlikely to live 6 months.⁽⁷⁴⁾

Not specific to people with lung cancer

In 2010 Macmillan reported that **36% of people with a terminal cancer diagnosis** (all cancer types, not specifically lung cancer) **did not claim the benefits they were automatically entitled to**. This amounts to over £90m.⁽⁹¹⁾



PRACTICAL AND INFORMATION NEEDS

People with lung cancer experienced **greater isolation** and **physical dependency** towards End of Life, and were particularly aware of the lack of coordination of supportive care.⁽⁵³⁾

Only **27%** of lung cancer patients said that they **received information** about services offering psychological/emotional support in one study of lung and breast cancer patients in a UK cancer centre.⁽⁹²⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

As lung cancer progresses, patients have to contend with **worsening symptoms** including adverse psychological and social effects.⁽⁵³⁾

Not specific to people with lung cancer
Emotional and psychological support needs for carers, family members, and other loved ones are very high at the point of death, and can continue for a long time after death. We believe that adequate **bereavement support** is not always in place for those who really need it.

Cancer patients (all cancer types, not just lung cancer) **approaching death suffer more psychological distress**.⁽⁹³⁾

LIFESTYLE AND PERCEPTIONS

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

What is the profile of the average person living with lung cancer?^(2a-d,94-98)

- It is rare for a lung cancer patient to be under 40 years old. Over 80% of lung cancer patients are over 60 years old.
- 23% of people living with lung cancer are of working age (under 65).
- Slightly more men are diagnosed than women – 54% diagnosed in 2012 were men.
- Incidence rates are highest in Scotland, then Wales, and lowest in Northern Ireland and England.
- Male lung cancer patients are 2.5 times more likely to be in the most deprived groups, and female lung cancer patients are 3 times more likely to be in deprived groups.
- 90% of lung cancers in men and 83% in women are estimated to have been caused by smoking. Over 10% of those with lung cancer have never smoked.
- Lung cancer patients are more likely than breast or prostate cancer patients to report internal causal attributions for their cancer, suggesting that the link between smoking and lung cancer is generally well understood.

What is the demographic breakdown/ market segmentation of the 72,000 lung cancer patients?

Lung cancer is more prevalent among older people, those living in Scotland and the north, and slightly more prevalent amongst deprived groups, the **MOSAIC* group L, 'Elderly Needs'** is likely to be particularly prominent amongst people with lung cancer:

- This group features many retired people on low incomes, concentrated in Scotland, northern industrial cities, coastal retirement destinations.
- Likely to rely on support, perhaps the basic state pension or specialist accommodation.
- Most would have left school at or before 16.
- Often widowed.

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

The following are a selection of typical characteristics for MOSAIC group L:

- Preference for visiting independent grocery shops, libraries, charity shops, and cafes, near to their home.
- Main interests are family and food, reading, and walking pet dogs.
- Prefer familiar brands like M&S.
- Main spend is on housing (including utilities) and alcohol and tobacco.
- A lack of familiarity with IT, relying on TV and papers for information and not the internet, and preferring to communicate by post.

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

What are people affected by lung cancer saying about their lives both before and after their cancer diagnosis?⁽⁹⁸⁾

Before:

'My dad was a non-smoker, always had been which is something I'm always desperate to stress, very fit and agile man, and he developed a limp. And I thought it was psychosomatic...'

Joyce, carer, South

'He was complaining bitterly about pain in his back. And I'd noticed he coughed a lot. He was supposed to have given up (smoking)... he'd lost a lot of weight and I thought he's not eating any less'

Dawn, carer, South

After:

'I'm still working, I'm not a defeatist, I think positive, that's what keeps me going... I've wanted to work because I didn't want it to get to me'

Brenda, North

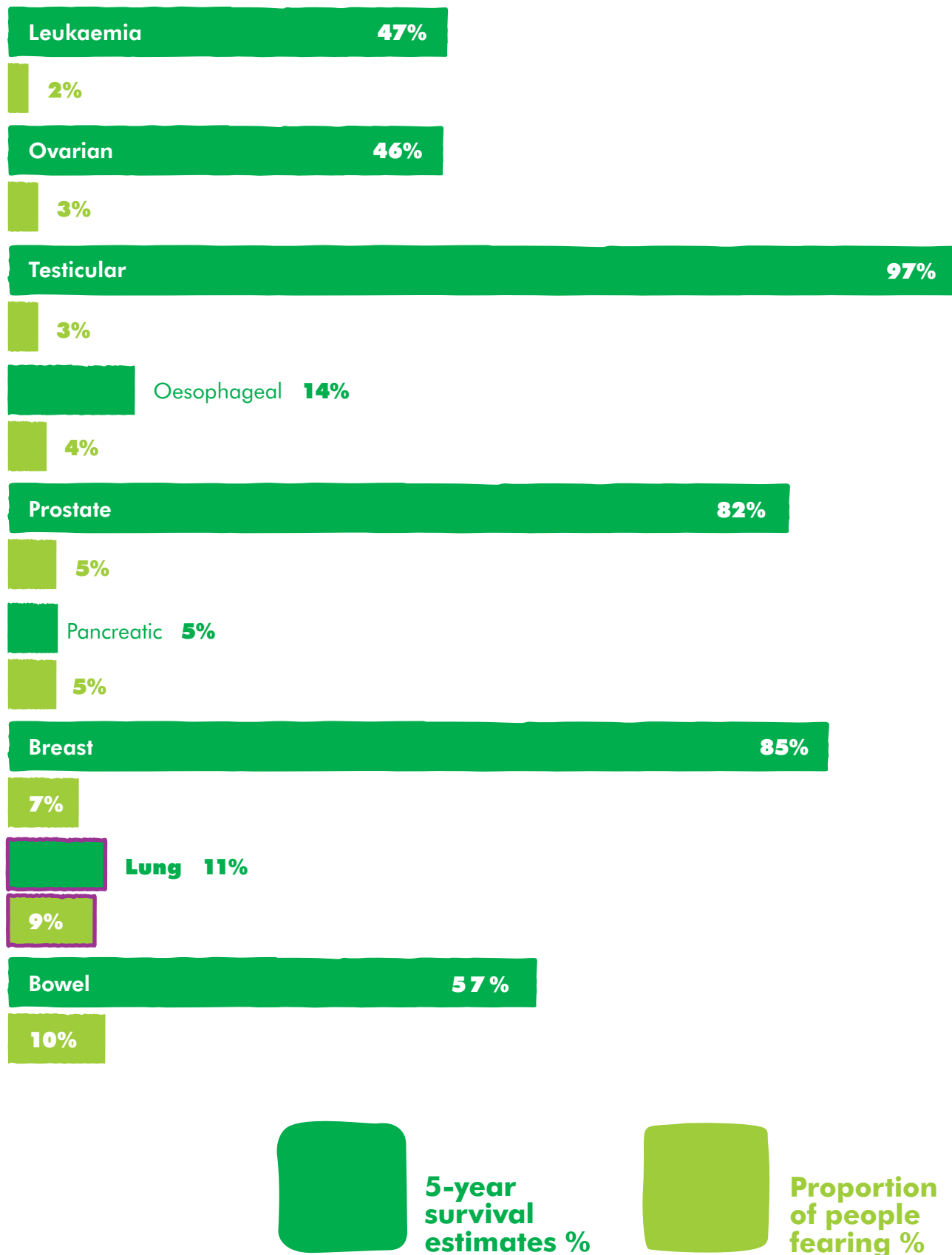
'Once a fortnight she goes to this spa place for a half day. It's a sort of pampering day – she can get her hair done, manicure, pedicure, beauty treatments, that sort of thing'

Keith, carer, North West

'I'm not able to do things I used to do. I was out there the other day and it took me 3 hours to saw some wood, which a couple of years back would have taken me about 15 minutes'

George, North East

How does people's fear of lung cancer compare to actual survival rates?^(99, 5)



Fear of lung cancer is fairly high amongst the general public, and with good reason – the 5-year survival rates for lung cancer are fairly low.

Both bowel and brain cancer are more feared than lung cancer but show better survival patterns, and breast cancer is almost as feared but has dramatically better survival estimates.

Given such poor survival estimates, it is surprising that lung cancer is not more feared.

[illegible][illegible]

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

What does this mean? What do we want to change in terms of people's perceptions?⁽¹⁰⁴⁻¹⁰⁵⁾

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

- The word 'dad' and 'mum' feature very prominently in the online community discussions, probably referring to parents who have lung cancer. The online community may include many adult sons and daughters who are carers, and rely on this community for support that is not readily available elsewhere.
- References to smoking do not appear at all in the online community word cloud, but are present in the media. The relationship between smoking and lung cancer is clearly being widely reported in the media, whereas people affected by lung cancer don't find it important to discuss. Instead, words like 'hugs' and 'support' suggest a focus on immediate needs over possible causes or past behaviour.
- There is more technical terminology in the online discussions than in the media: 'nodes', 'nslc', 'lymph', suggesting that those affected by cancer are sufficiently knowledgeable to be comfortable with such terms. Terms in the media are simple, to reach a non-specialist audience.
- The words 'pain', 'hope', 'pathetic', 'scared' in the online community discussions emphasise the physical and emotional difficulties experienced by lung cancer patients. The media includes none of those, focusing instead on 'drugs', 'cases', 'death'.

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SOURCES, NOTES AND CAVEATS

Quotes

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

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APPENDIX A

JARGON BUSTER

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

(i) Health data terms

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

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

Prevalence: When we talk about 'cancer prevalence' we mean the number of people who are still alive and who have had, within a defined period, a cancer diagnosis. It equates to the number of people living with cancer. Any prevalence figure is for a snapshot (set point in time). The latest snapshot we have was 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

NOTES

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

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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