

# THE RICH PICTURE

WE ARE  
MACMILLAN.  
CANCER SUPPORT.

# PEOPLE WITH RARE CANCERS



Paul, 51, living with oesophageal 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](mailto: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 October 2013, 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 wide range of information booklets more helpful; a selection of which are shown below:



**Understanding  
Acute Lymphoblastic  
Leukaemia**  
MAC11612



**Understanding  
Kidney Cancer**  
MAC11629



**Understanding  
Stomach Cancer**  
MAC11641



**Understanding  
Cancer of the  
Pancreas**  
MAC11638

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](http://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.



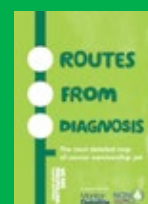
### Local Cancer Intelligence

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](mailto:evidence@macmillan.org.uk).

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# SUMMARY OF PEOPLE LIVING WITH RARER CANCERS

## Key stats

'Rarer cancers' has been defined by us in this document as all cancers **outside the top ten most common** types of cancer.

(see page 4)

There are around **444,000** people living with rarer cancers in the UK.<sup>(12)</sup>

Around **67,000** people died from rarer cancers in 2012.<sup>(11)(13)(14)</sup>

In general, rarer cancers have **poorer 1 and 5-year survival rates** than any of the top ten most common cancers, with the exception of lung cancer.<sup>(15)</sup>

**67,000 people died from rarer cancers in 2012.**

## Diagnosis

For many patients with rarer cancers, the **vague nature of their symptoms**, and GPs initially suspecting more obvious causes, mean they **do not consider that they have cancer**. Therefore, they can be extremely shocked when informed of their diagnosis.<sup>(41)</sup>

Rarer cancers are **more likely to be diagnosed through emergency presentation** than the 10 most common types of cancer.<sup>(37)</sup>

**20%** of patients with cancers outside the 12 most common cancers are **not given information about support or self-help groups** for people with cancer by hospital staff.<sup>(45)</sup>

**Rarer cancers are more likely to be diagnosed through emergency presentation.**

## Treatment

**Patients with rarer cancers** may feel a greater sense of **isolation** because so little is known about their disease.<sup>(65)</sup>

25% of people with cancers outside the 12 most common cancers are **given conflicting information about their illness and its treatment** whilst in hospital.<sup>(66)</sup>

NHS patients in England with rarer cancers are over **three times more likely** to gain access to **newer cancer drugs** than they are in Scotland.<sup>(61)</sup>

**Additional costs caused by cancer treatment include fuel charges** which arise from transporting cancer patients and their carers to hospital.<sup>(63)</sup>

**Rarer cancer patients in England have better access to newer cancer drugs than patients in Scotland.**

## Survivorship

**Patients with rarer cancers** often feel **abandoned and isolated** after discharge from hospital.<sup>(41)</sup>

**23%** of people living with cancer (not just rarer cancers) report **poor emotional well-being**.<sup>(70)</sup>

Among cancer patients (not just those with rarer cancers) the **main barrier to accessing benefits is a lack of knowledge about benefit entitlement**.<sup>(72)</sup>

**Living with the aftermath** of cancer can be **challenging for many rarer cancer patients**. For example, oesophageal cancer patients can have problems with reduced appetite, nausea and acid reflux.<sup>(41)</sup>

**Nearly a quarter of people living with cancer report poor emotional well being.**

## End of Life

For some types of rarer cancers services appear to be patchy, and to **fall short of recommendations for best practice in supportive and palliative care**.<sup>(41)</sup>

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

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**.<sup>(88)</sup>

Death of a partner has been shown to be a **trigger for claiming income support**.<sup>(93)</sup>

**Services for some people with rarer cancer fall short of best practice in palliative care.**

## Lifestyle & perceptions

The incidence of most cancer types increases with age and **77% of all cancer deaths in the UK are amongst the 65+** age group. However, although **young people** may be less likely to develop cancers overall, those who do get cancer **are more likely to develop rarer forms** of the disease.<sup>(23)(5)</sup>

**Elderly people reliant on state support** are well-represented amongst people being treated for rarer cancers.<sup>(see page 51)</sup>

A Macmillan online community discussion shows the **uncertainty** which being diagnosed with a rarer cancer may bring.<sup>(see page 56)</sup>

# INTRODUCTION TO RARER CANCERS

## What are rarer cancers?

There are several definitions of rarer cancers, used by different organizations and jurisdictions. Some define rarer cancers as:

- All cancers outside the top four most common cancers (lung cancer, breast cancer, colorectal cancer and prostate cancer).<sup>(1)</sup>
- All cancers that have fewer than 2 cases diagnosed each year per 100,000 people.<sup>(2)</sup>
- A cancer that affects an unusual site in the body, or a cancer that is an unusual type, or requires special treatment.<sup>(3)</sup>
- All tumours whose incidence is less than 6 per 100,000 people.<sup>(30)</sup>

However, for the purposes of this document we use the following definition:

- All cancers outside the top ten most common types of cancer (listed by prevalence).

### Top 10 cancer types (by prevalence)<sup>(12)</sup>

- Breast cancer
- Prostate cancer
- Colorectal cancer
- Malignant Melanoma
- Bladder cancer
- Non-Hodgkin Lymphoma
- Cancer of the uterus
- Head and Neck cancers
- Lung cancers
- Cervical cancer

There are more than 200 different kinds of cancer, each with its own name and treatment. Our chosen definition of rarer cancers for the purposes of this document includes a variety of these conditions, including some relatively better known cancers such as leukemia and pancreatic cancer, as well as much less reported illnesses such as cancer of the appendix and cancer of the gall bladder.<sup>(4)</sup>

Rarer cancers, such as types of the disease which affect the blood system or bones, may be more common in younger people such as children and adolescents. However, this is not true of all rarer cancers.<sup>(5)</sup>

## Want to know more?

Macmillan produces a wealth of information about what cancer is, its causes, symptoms and treatment. Macmillan staff can refer to reference 6 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](http://www.macmillan.org.uk)**



**'I think it is a battle. You know there's something in your body and you want to get rid of it. You think, 'why has it happened to me?' Initially cancer takes control away from you and you can feel very vulnerable. But eventually you've got to take back control. I'm only on this planet once and there are lots of things I want to do. I do have my bucket list, so I've got to keep ticking things off. So yes, there'll be a few more challenges.**

**I think a lot of people feel sorry for me because I can't eat. But, the way I look at it, I went to such a bad place, I'm just grateful to be alive and coming out the other side. If my disability is I can't eat, that's a small price to pay for living a full life.'**

**Paul, 51, living with oesophagael cancer**

# MACMILLAN'S AIMS AND OUTCOMES

## Macmillan's aims and outcomes – and how they are different for people with rarer cancers

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.<sup>(7)</sup>

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.

**There are around 444,000 people living with rarer cancers in the UK.**<sup>(12)</sup>

## How is this different for people with rarer cancers?

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

## The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

# THE FACTS ON RARER CANCERS

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

**269**

people are diagnosed with rarer cancers\* very day in the UK<sup>(8)(9)(10)(11)</sup>

**444,000**

people are living with rarer cancers in the UK<sup>(12)</sup>

**184**

people die every day of rarer cancers in the UK.<sup>(11)(13)(14)</sup>

**20%**

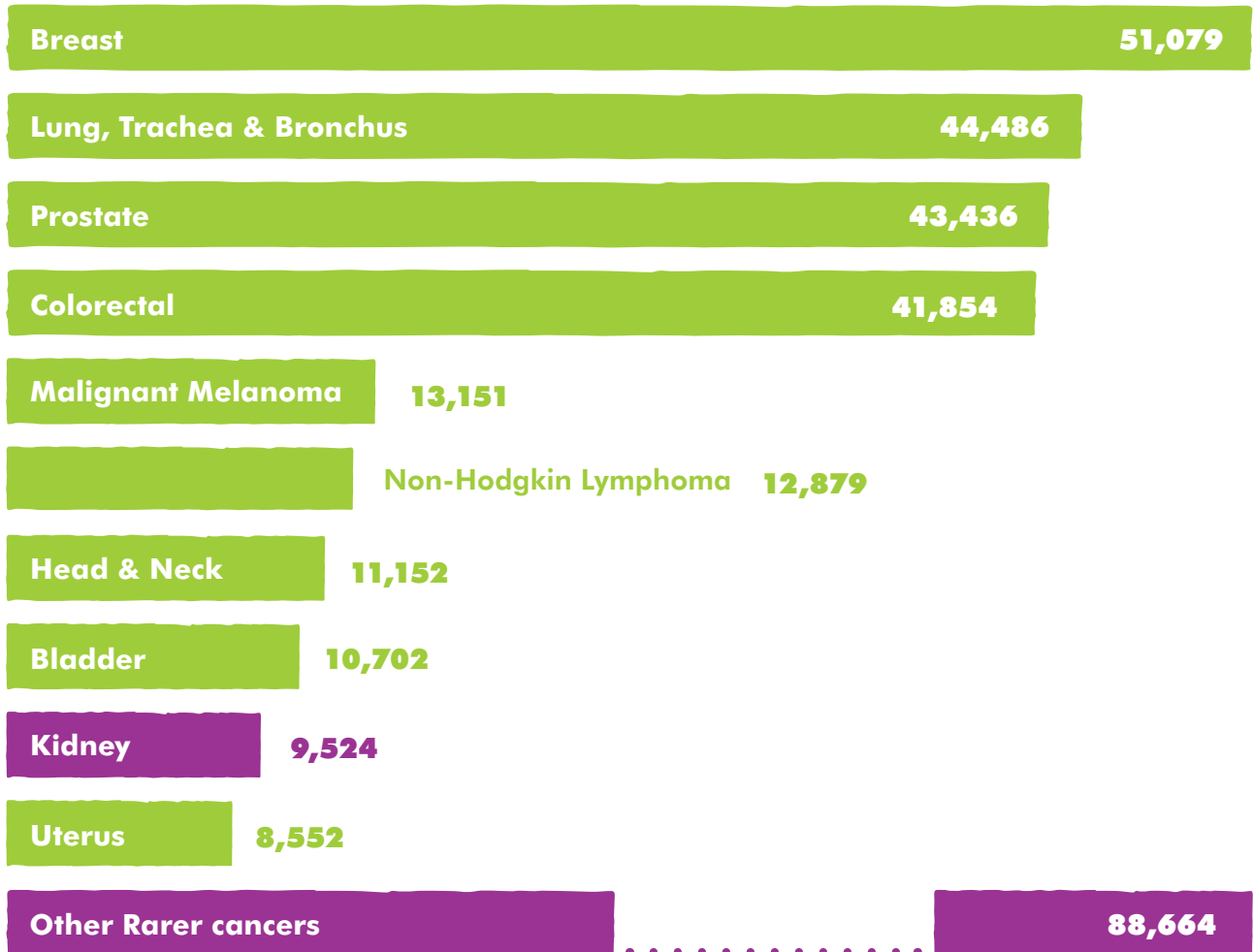
of people in England survive pancreatic cancer, a rare form of cancer for more than 1 year.<sup>(15)</sup>

\*Defined as those cancers outside the 10 most common cancers by prevalence.



## How many people get rarer cancers per year? (incidence)<sup>(8,9,10,18)</sup>

### Cancer incidence, UK, 2012, top 10 cancer sites

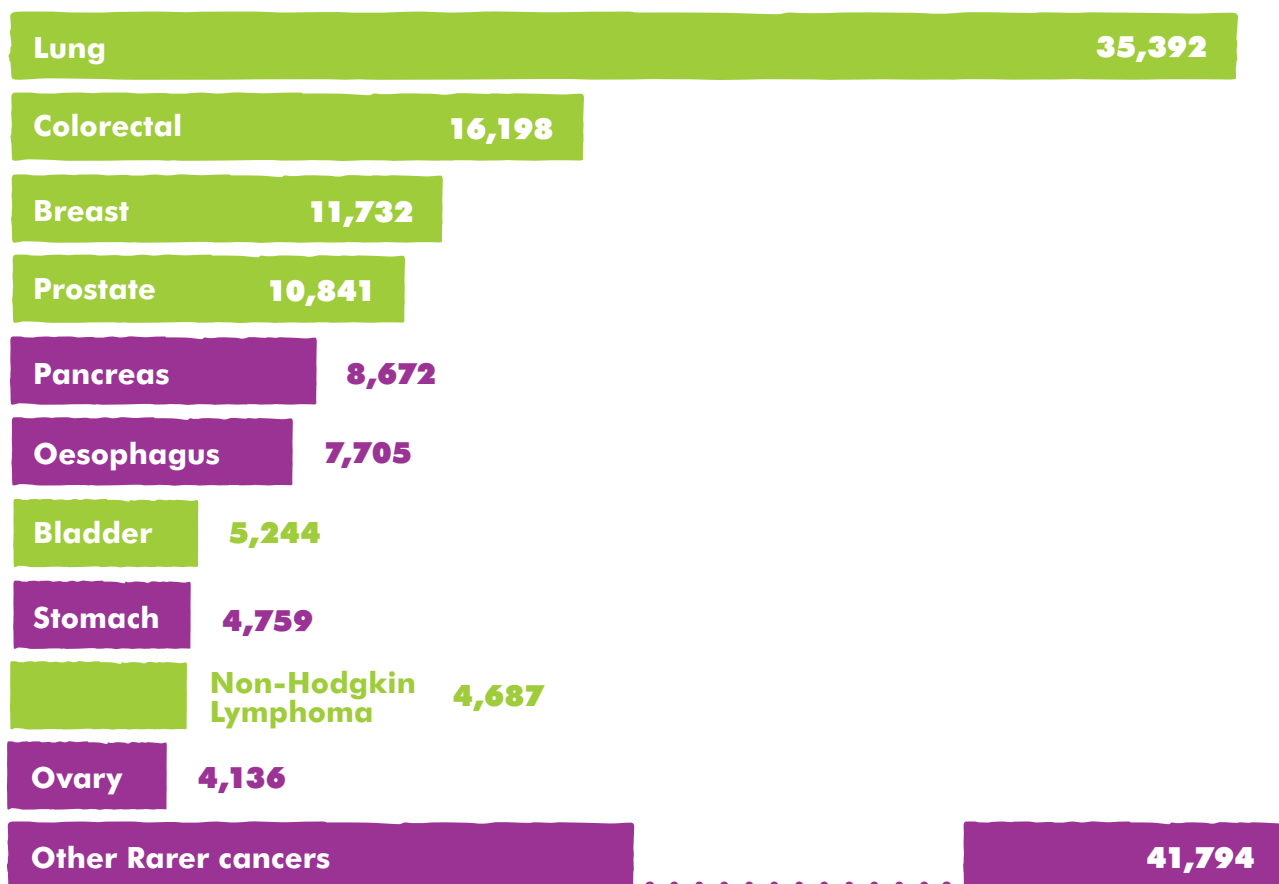


**Almost 98,200 people were diagnosed with cancers that were not one of the 10 most prevalent cancers in 2012.**

 Rarer Cancer

## How many people die from rarer cancers per year? (mortality)<sup>(11,13,14)</sup>

### Mortality, UK, 2012, top 10 cancer sites



**Around 68,000 people died from cancers that were not one of the top 10 most prevalent cancers in 2012. Although each individual form of cancer is rare, this group is significantly larger than any site-specific cancer.**

 Rarer Cancer

## How many people are currently living with rarer cancers? (prevalence)\*<sup>(12)</sup>

People living with rarer cancers in the UK

**444,000**

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

## What are the key stats for England?

See data on incidence, mortality and prevalence for England



How many people get rarer cancers per year in England? (incidence)<sup>(8)</sup>

**81,132**

new cases of rarer cancers were diagnosed in England in 2012.

How many people die from rarer cancers per year in England? (mortality)<sup>(13,10)</sup>

**57,168**

rarer cancers deaths in England in 2012.

How many people are living with rarer cancers in England? (prevalence)<sup>\*(12)</sup>

**Around 371,000**

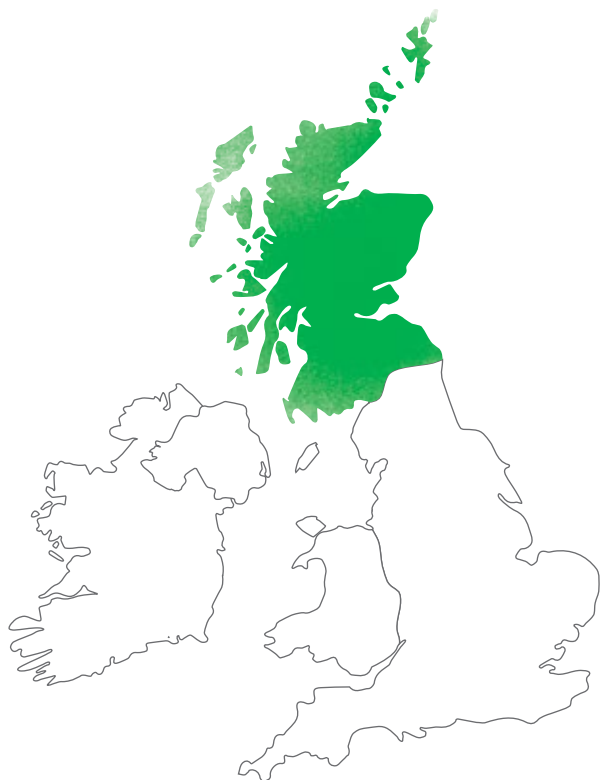
people are living with rarer cancers in England in 2010.

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



## What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



### How many people get rarer cancers per year in Scotland? (incidence)<sup>(9)</sup>

**8,640**

new cases of rarer cancers were diagnosed in Scotland in 2012.

### How many people die from rarer cancers per year in Scotland? (mortality)<sup>(14)</sup>

**4,477**

rarer cancers deaths in Scotland in 2012.

### How many people are living with rarer cancers in Scotland? (prevalence)<sup>\*(12)</sup>

**Around 38,700**

people are living with rarer cancers in Scotland in 2010.

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

## What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



How many people get rarer cancers per year in Wales? (incidence)<sup>(10)</sup>

**5,371**

new cases of rarer cancers were diagnosed in Wales in 2012.

How many people die from rarer cancers per year in Wales? (mortality)<sup>(10)</sup>

**3,712**

rarer cancers deaths in Wales in 2012.

How many people are living with rarer cancers in Wales? (prevalence)<sup>\*(12)</sup>

**Around 22,800**

people are living with rarer cancers in Wales in 2010.

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

## What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



### How many people get rarer cancers per year in Northern Ireland? (incidence)<sup>(11)</sup>

**3,045**

new cases of rarer cancers were diagnosed in Northern Ireland in 2012.

### How many people die from rarer cancers per year in Northern Ireland? (mortality)<sup>(18)</sup>

**1,709**

rarer cancers deaths in Northern Ireland in 2012.

### How many people are living with rarer cancers in Northern Ireland? (prevalence)<sup>\*(12)</sup>

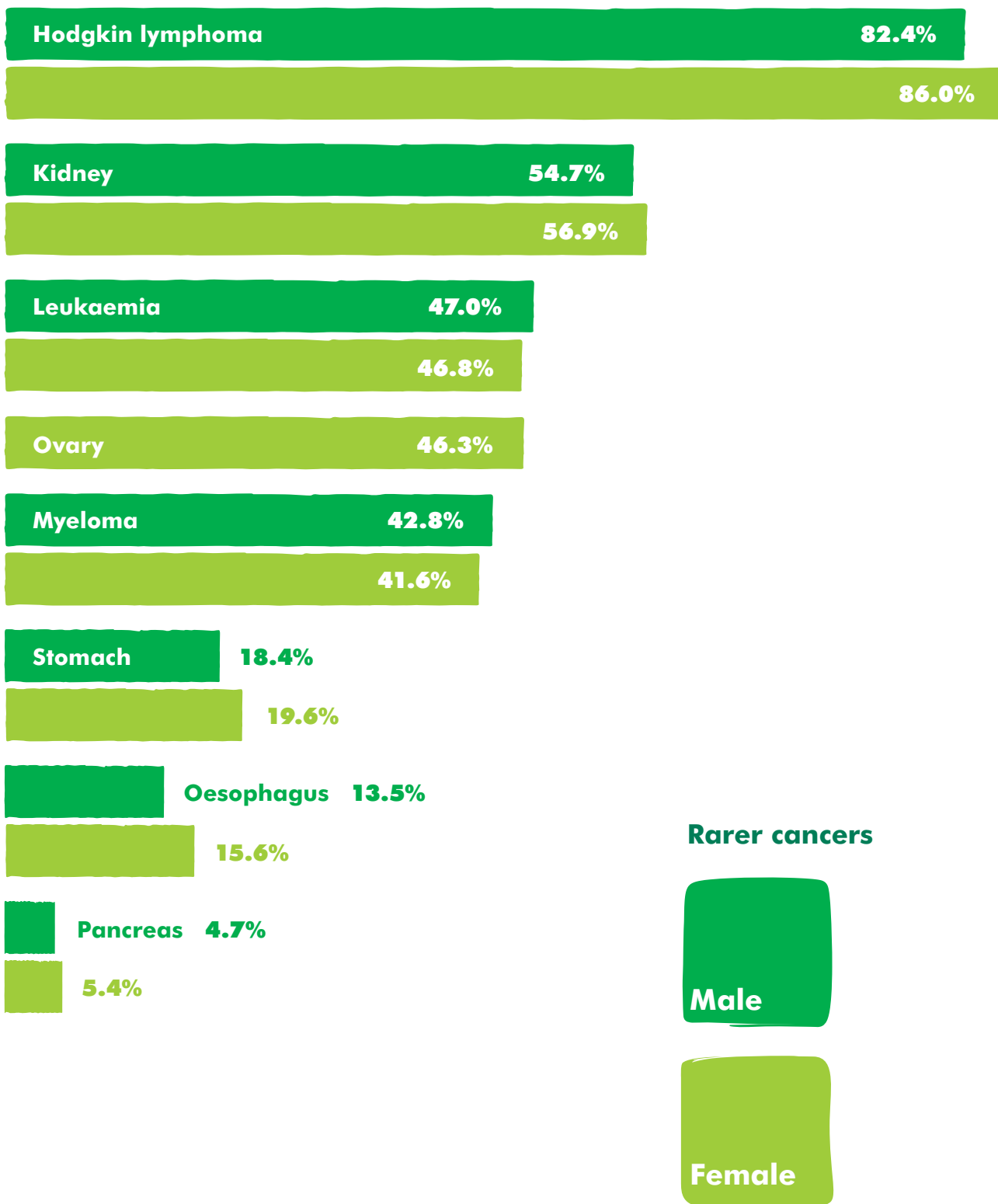
**Around 12,300**

people are living with rarer cancers in Northern Ireland in 2010.

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

## What proportion of people survive rarer cancers? (survival) <sup>(15)</sup>

Relative 5 year survival estimates for a selection of rarer cancers, 2007–2011, by gender, England.



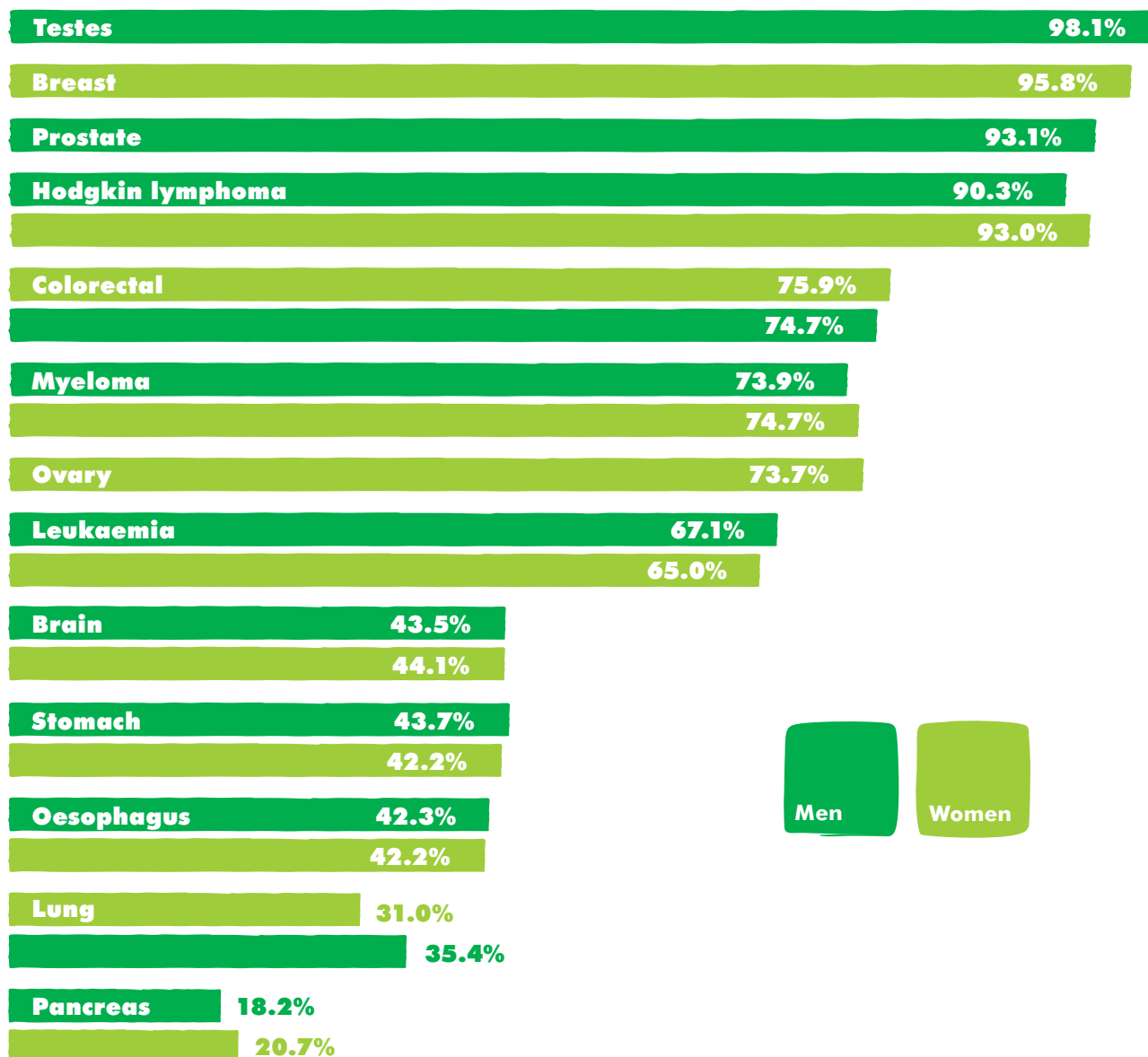


**There is significant variation between the survival rates of rarer cancers, but in general they tend to have a poorer survival rate than more common types of cancer, with the exception of Hodgkin lymphoma which has a relatively high survival rate.**

**However, lung cancer (which is one of the top 10 most common cancers in terms of prevalence) has a 5 year survival rate of 10.9%. This is much lower than a number of rarer cancers with, of the rarer cancers listed, only pancreatic cancer having a lower survival rate.**

## How many people live beyond one year of their rarer cancer diagnosis?<sup>(15)</sup>

Relative 1 year survival estimates for the top 4 most common cancers and a selection of rarer cancers, by gender, 2007-2011, England.



Although testicular cancer has the highest 1-year survival rate and lung cancer has the second lowest, in general rarer cancers tend to show significantly worse 1-year survival rates than the top 4 most common cancers.

## How have median survival times changed for rarer cancers?

Over the last 35 years median survival time for all cancers has increased from 1 year to 6 years. Amongst rarer cancers the changes in median survival times have varied greatly, reflecting the diversity of cancer types that make up the definition of 'rarer cancers' in this rich picture. For example, pancreatic cancer median survival time has constantly remained low at 0.7 years; similarly brain cancer survival time has remained low, slowly increasing from 0.3 years in 1971–72 to 0.5 years in 2007. By contrast, survival time for leukaemia has jumped from 0.3 years in 1971–72 to 3.0 years in 2007, and ovary cancer has jumped from 0.7 years in 1971–72 to 3.1 years in 2007.<sup>(16)</sup>

## How do UK survival rates compare internationally?

Survival rates for all types of cancer in the UK are improving overall. However, the most up-to-date international comparisons show that the UK has performed worse on both 1 and 5-year survival rates when compared to other countries, including Germany, France, Sweden and Norway. This suggests more can be done to improve survival for people living with cancer in the UK.<sup>(17)</sup>

## What are the major demographic variations in incidence, mortality, prevalence and survival for rarer cancers?

Because of the diversity of types of cancer which make up Macmillan's definition of rarer cancers it is hard to state the major demographic variations in people affected by just these cancers types. Therefore, the data below refers to all types of cancer, unless stated otherwise.

### Gender

In 2012, there were 171,958 new cancers diagnosed in men (excluding non-melanoma skin cancer). A very similar number of new cancers were diagnosed in women in the UK (166,673).<sup>(11,13,14)</sup>

The gender difference in mortality is reflected in certain rarer cancers, for example there were 1,950 deaths from mesothelioma in males in the UK in 2011, compared to 360 deaths in females. However, research has also shown that there were more deaths from cancers outside the 20 most common cancers amongst females (10,932) than males (9,139), in the UK in 2011.<sup>(19)</sup>

### Ethnic background

Males and females in the Asian, Chinese and Mixed ethnic groups all had a significantly lower risk of getting cancer than White people. Across both age groups and for all ages, people from these three ethnic groups were between 20% and 60% less likely to get cancer than those from the White ethnic group.<sup>(20)</sup>

However, these trends can differ for particular rarer cancers. For example, myeloma is almost twice as common in Black people as in White and Asian people. This difference is evident in both men and women.<sup>(21)</sup>

### Age

77% of all cancer deaths in the UK are amongst the 65+ age group.<sup>(23)</sup>

However, young people who are diagnosed with cancer are more likely to develop rarer forms of the disease. The most common cancer in young men in the UK (15-24 year olds) is testicular cancer (27%) and the most common cancer in young women is carcinomas (31%).

### Social background

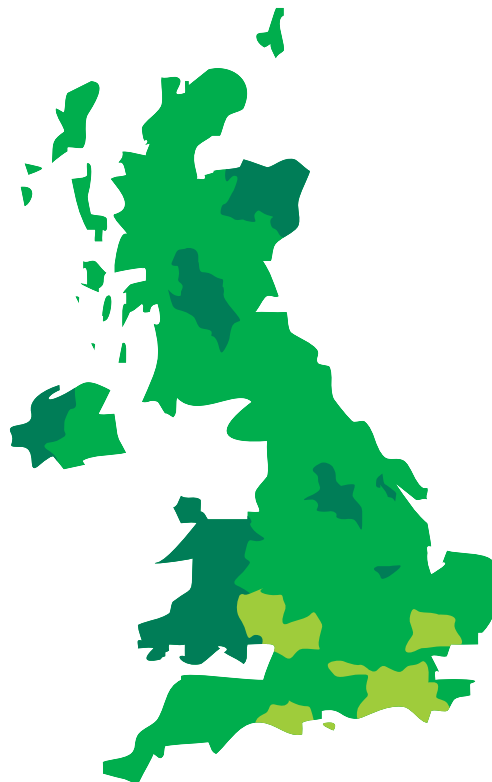
The incidence and mortality of cancer is higher in deprived groups compared with more affluent groups.<sup>(24)</sup>

For some cancers, patients from socioeconomically deprived groups tend to present symptoms later than others and thus tend to have more advanced disease and a worse prognosis, while the excess mortality may also be linked to later presentation and later diagnosis in more deprived groups.<sup>(25)</sup>

### What are the geographical 'hotspots' for stomach and pancreatic cancer, as representative of rarer cancers, incidence, mortality and survival\*? (26)



Pancreatic cancer incidence, UK, 2008-2010



Stomach cancer incidence, UK, 2008-2010



**Pancreatic cancer incidence rates are highest in some parts of Scotland and Northern England as well as areas of South East England including London.**

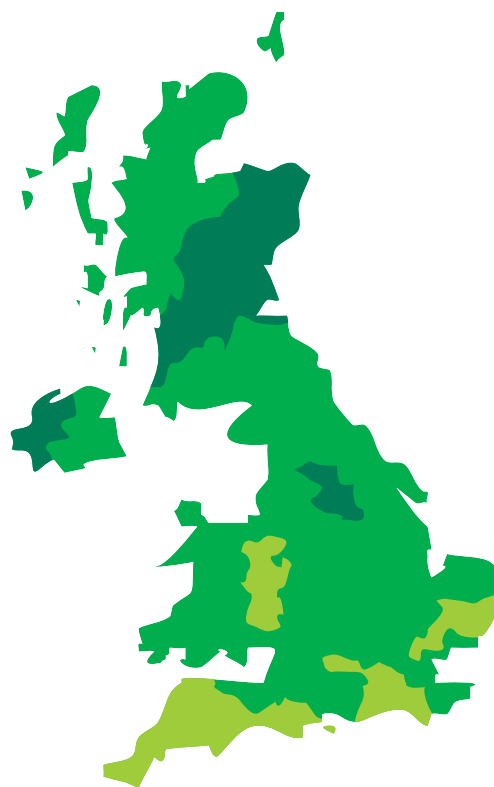
**Stomach cancer incidence is highest in parts of Scotland and Northern England with Northern Ireland and Wales also showing higher incidence.**

\*Data on incidence for all rarer cancers combined are not available to create a single geographic hotspot map, but instead we have shown the geographical hotspots for two of the more common rarer cancers. For geographical hotspot maps for other rarer cancers, please contact the Health Data team at Macmillan.





Pancreatic cancer mortality, UK, 2009-2011



Stomach cancer mortality, UK, 2009-2011



**Pancreatic cancer mortality rates are generally quite evenly spread throughout the UK. Stomach cancer mortality rates appear to be higher in some parts of Scotland, Northern Ireland and the Midlands.**

### Survival

At present there is a considerable variation in survival rates for stomach cancer according to where people live in the UK. For example, the 5-year survival rates for stomach cancer are 22.4% in London and 12.1% in Durham, Darlington and Tees. The 1-year survival rates are 43.7% in Wessex and 35.3% in South Yorkshire and Bassetlaw.<sup>(94)</sup>

\*Data on mortality for all rarer cancers combined are not available to create a single geographic hotspot map, but instead we have shown the geographical hotspots for two of the more common rarer cancers. For geographical hotspot maps for other rarer cancers, please contact the Health Data team at Macmillan.

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

The European age-standardised incidence rates for all cancers in the UK during the period between 1975 and 2011 increased by 21% in males (from 351.1 per 100,000 to 426.1 per 100,000), and by 43% in females (from 262.7 per 100,000 to 376.4 per 100,000). Most of this rise occurred before the late 1990s. Over the last ten years in the UK (between 2001 and 2011) the incidence rates have increased by just 1% and 7%, respectively.<sup>(27)</sup>

In the UK over the last decade there have been large increases in the incidence, in both males and females, of certain rarer cancers which are strongly linked to lifestyle choices. This includes kidney cancer (linked to excessive alcohol consumption), liver cancer (linked to cigarette smoking and obesity) and oral cancer (linked to smoking and alcohol consumption).<sup>(28)</sup>

Mortality for all cancers combined in the UK started to fall in the early 1990s, with the European age-standardised mortality rates decreasing by 27% in males and 20% in females during the period between 1991 and 2011.<sup>(29)</sup>

The rate of decrease has slowed down over the last ten years, with the age-standardised mortality rates in the UK decreasing by 14% in males and 10% in females during the period between 1991 and 2011. This is despite a small increase in cancer incidence during the last decade.<sup>(29)</sup>

Since the early 1970s in the UK, the male age-standardised mortality rate has been consistently higher than the rate for females. However, since the male rate has declined more quickly than the female rate, the gap between the sexes has decreased considerably; over the last twenty years (from 1991 to 2011) the difference in age-standardised mortality rates between the sexes has decreased by 41%.<sup>(29)</sup>

The largest fall in mortality in the last decade in the UK has occurred for stomach cancer (35% and 31% decreases in the male and female rates, respectively). This reflects the falling incidence of stomach cancer, which may be linked to greater awareness of lifestyle factors such as smoking or alcohol consumption.<sup>(19)</sup>

**‘We navigated through an extremely political and complex process in order to get him treatment on the NHS. The National Commissioning Group funded the treatment and it was provided abroad due to the lack of provision in this country. Living abroad while on treatment and trying to keep a family together brings its own challenges, let alone language and cultural differences.’**

Gemma, 37, whose 6 year old son has a cancer of the muscle tissue

# THE CANCER JOURNEY

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

The following pages summarise what we currently know about the needs and experiences of people living with rarer cancers 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 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. There are some common signs and symptoms for most cancers: <sup>(31)</sup>

- a lump
- a cough, breathlessness or hoarseness that doesn't go away
- changes in bowel habit
- abnormal bleeding
- changes in a mole
- unexplained weight loss

Rarer cancers may present more unusual symptoms. For example, people with liver or pancreatic cancer may appear jaundiced, while those with bone cancer may experience soreness in their limbs which are similar to growing pains. It is important that any persistent symptoms are examined by a GP. <sup>(32) (33) (34)</sup>

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

A 2009 survey suggests that amongst the general public 68% of people remembered, unprompted, the classic cancer symptom of feeling a lump or swelling. However, for all other symptoms, which may be more prominent in rarer cancers, unprompted recall was less than 30%. <sup>(35)</sup>

The NHS Cancer Patient Experience Survey has shown that patients with some rarer cancers are more likely to have visited their GP more than two times before being referred to secondary care than those patients with one of the more common cancers. This suggests that GPs are less aware of the symptoms associated with rarer cancers. <sup>(38)</sup>

GPs may take longer to diagnose rarer cancers for a number of reasons: <sup>(1)</sup>

- GPs are less likely to see cases of rarer cancers than more common cancers or conditions, making it more difficult for them to recognise the symptoms.
- There are hundreds of different types of rarer cancers with varying symptoms, which makes it very difficult for GPs to be aware of the symptoms of every cancer type.
- The wide variety of symptoms, many of which can be non-specific and can initially indicate more common benign conditions.

## How well does screening work for rarer cancers?

At present there are no screening programmes available for rarer cancers. However, research is being carried out into the possibility of screening some high-risk individuals for some forms of rarer cancers, particularly pancreatic cancer. <sup>(36)</sup>

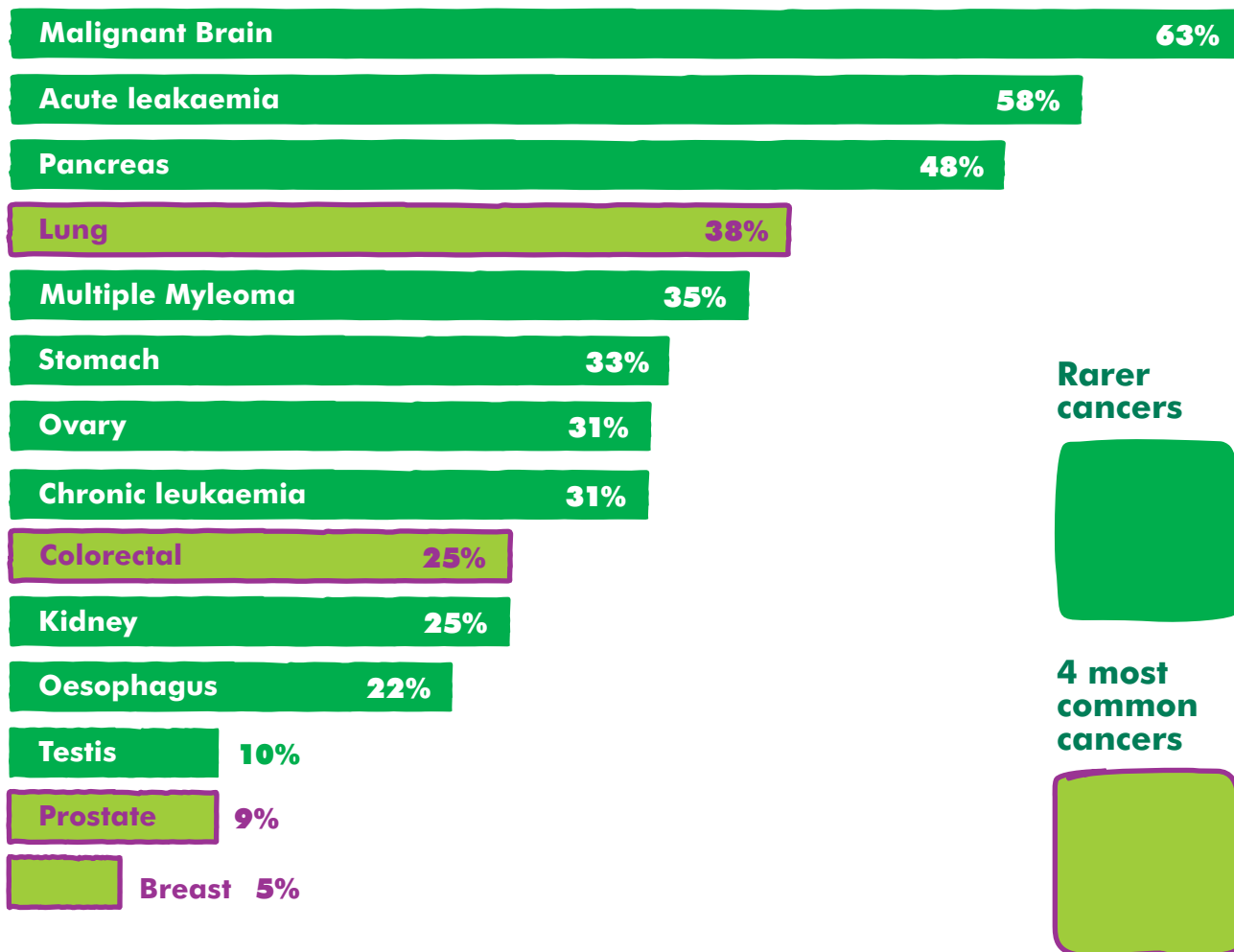
Screening is also offered to individuals with hereditary conditions that increase their risk of some rarer cancers including kidney and womb cancers. <sup>(105, 106)</sup>



**‘It turned out that I had PMP, which is cancer of the appendix and really rare – apparently, there are only about 50 people in the UK diagnosed with this every year. And there are only two centres that specialise in it, both a long way away. The consultant didn’t really explain things – I think they only tell you things if you ask, and I didn’t really know what to ask, although I wanted to know everything about it.’**

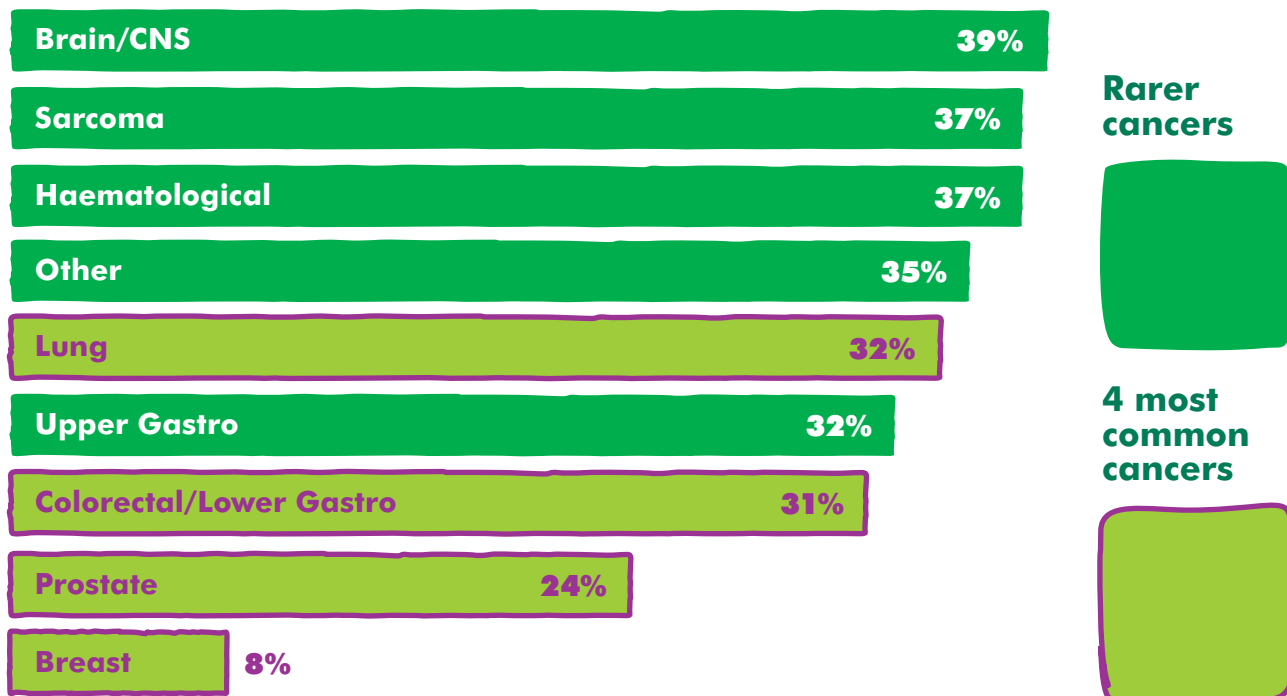
Janet, 66, living with cancer of the appendix

## What percentage of rarer cancer patients were diagnosed through emergency presentation? (Routes to diagnosis, 2006-2010) <sup>(37)</sup>



Rarer cancers are much more likely to be diagnosed through emergency presentation than the top 4 most common types of cancer, with the exception of lung cancer. Only 2 of the rarer types of cancers shown above fall below the national average of 23% of cancers being diagnosed through emergency presentation.

## How many rarer cancer patients had to see their GP more than twice before they were diagnosed? <sup>(38)</sup>

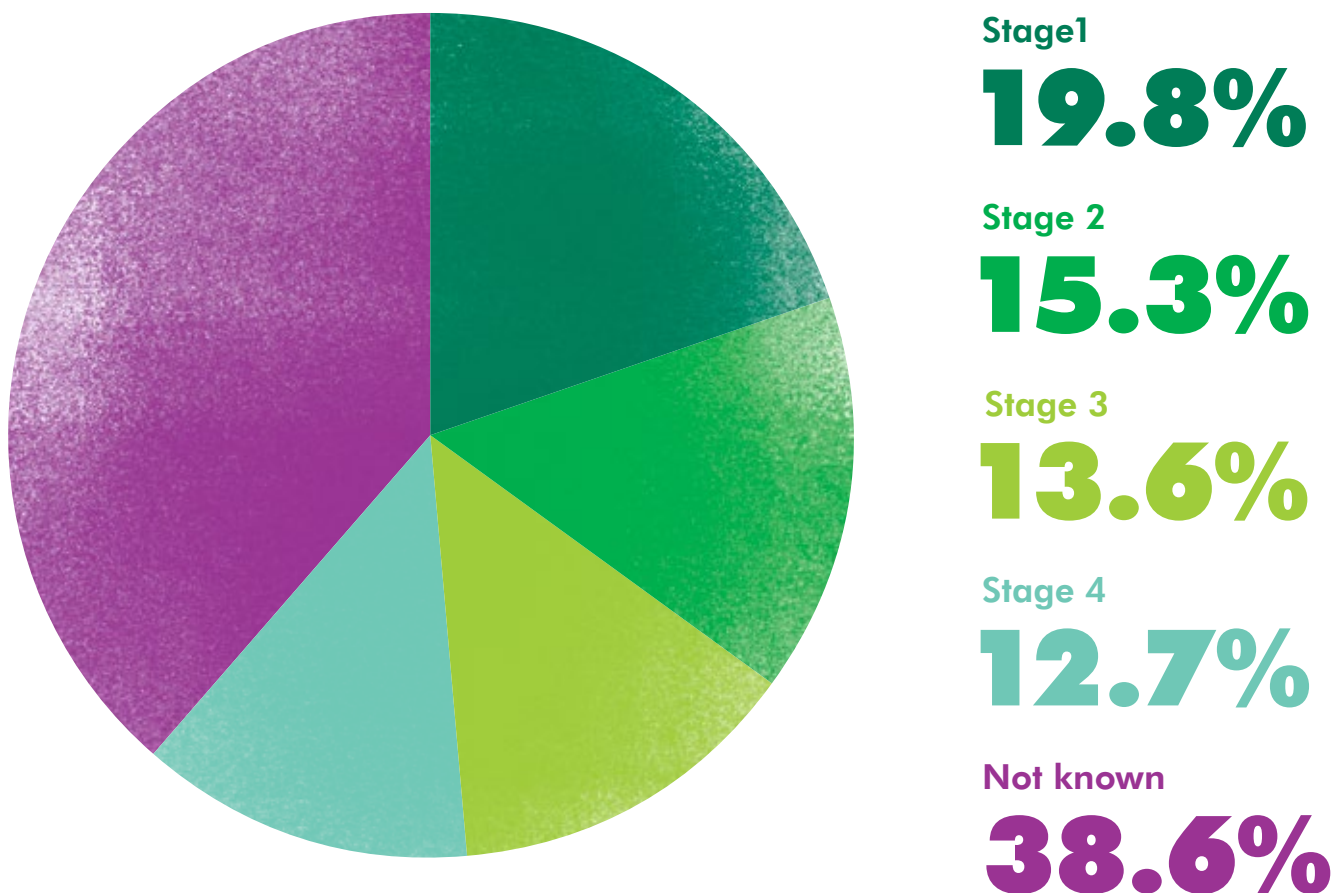


People with certain types of rarer cancers are more likely to see their GP more than twice when compared to people with the 4 most common types of cancer. This is especially true of cancer of the brain or central nervous system, sarcoma and haematological cancers (although this latter group includes non-Hodgkin lymphoma which is a more common form of cancer).

## How does stage at diagnosis relate to probable survival rates?

As there are so many types of rarer cancers, it is difficult to state how the survival of each one is affected by stage of diagnosis. However, in general, the earlier the stage at diagnosis, the better the chance of survival.

### The stage of cancer at point of diagnosis for all rarer cancers<sup>(1)</sup>



The chart shows the stage of diagnosis of cancers apart from the top four most common cancers in 2011, including a wide array of rarer cancers such as liver cancer, sarcomas and kidney cancer. Less than 20% of people with rarer cancers were diagnosed in the first stage of their cancer.

## Most types of cancer have 4 stages, numbered from 1 to 4.<sup>(39)</sup>

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 in stage 1. Sometimes stage 2 means that cancer cells have spread into lymph nodes close to the tumour. This depends on the particular 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 the area.	Means the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

### How long do people with rarer cancers have to wait to be referred?<sup>(1)</sup>

**A 2011 survey carried out by the Rarer Cancer Foundation suggests that 67.4% of people with cancers outside the four most common cancers (lung, breast, prostate and colorectal) were seen within 2 weeks of referral.**

**In comparison, according to a 2012-13 NHS England report, 95.5% of all cancer types were seen within 2 weeks of referral.**



## PHYSICAL AND MEDICAL NEEDS

**Rarer cancers may be caused by a variety of reasons.** The fact that they are uncommon does not mean that they affect people randomly; for example, several risk factors have been reported regarding the development of pancreatic cancer. These risk factors include family history, accompanying diseases, and lifestyle/personal habits.<sup>(40)</sup>

Patients with many types of rare cancer often experience vague, but nevertheless debilitating symptoms which could be attributed to causes other than cancer. They may therefore **put off seeking help from their GP** for some time and **may not suspect cancer as a possible cause** of their problems.<sup>(41)</sup>

### Not specific to people with rarer cancers

**Late diagnosis of cancer** is a major explanation for **poor outcomes**. By contrast, if a person is diagnosed with cancer at an early stage, then they will have a greater range of treatment options which are often less invasive and offer a better chance of a positive long term outcome.<sup>(1)</sup>



## FINANCIAL NEEDS

Just under half (**50%**) of patients with “less common cancers\*” were **not given information about how to access financial help or benefits** by hospital staff. This is compared to 42% of gynaecological cancer patients.<sup>(42)</sup>

### Not specific to people with rarer cancers

It is estimated that thirty per cent of people with cancer **experience a loss of income as a result of their cancer**, with those affected losing, on average £860 a month. Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families.<sup>(107)</sup>

\* ‘Less common cancers’ refers to people with cancers outside the 12 most common cancers, according to a 2012/2013 Department of Health survey.





## PRACTICAL AND INFORMATION NEEDS

80% of patients with “less common cancers\*” were **given information about support or self-help groups** for people with cancer by hospital staff. This is compared to 88% of breast cancer patients and 85% of people with skin cancer.<sup>(45)</sup>

44% of people with “less common cancers\*” **do not receive written information about their condition or would like to receive more**, compared to 19% of prostate or skin cancer patients.<sup>(46)</sup>

### Not specific to people with rarer cancers

**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.<sup>(48)</sup>

The strongest preference for information at diagnosis is **information about prognosis**.<sup>(48)</sup>

Many people affected by cancer **are dissatisfied with the information they receive**. In a study of older people living with cancer, between 10% and 60% had not received the information they wanted. Most of them needed information on treatment, lifestyle and social functioning.<sup>(47)</sup>

\* ‘Less common cancers’ refers to people with cancers outside the 12 most common cancers, according to a 2012/2013 Department of Health survey.



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

A report by Macmillan suggests that for many patients with a rare cancer, the vague nature of their symptoms, and GPs initially suspecting more obvious causes, mean they **do not consider that they have cancer**. Therefore, they can be **extremely shocked when informed of their diagnosis**.<sup>(41)</sup>

Amongst **people with brain cancer**, which is classified by Macmillan as a rare cancer, **48% of patients experience depression and anxiety**. A significant cause of such psychological problems is dissatisfaction with health care provider communication and information. It is likely that the lack of information is caused by the rare nature of the illness, as doctors are likely to treat fewer patients with brain cancer than other forms of cancer.<sup>(49)</sup>

### Not specific to people with rarer cancers

Although a certain amount of **emotional distress** is common, particularly around the time of a diagnosis, around half of all people with cancer (all cancer types) experience levels of anxiety and depression severe enough to adversely affect their quality of life.<sup>(50)</sup>

62% of 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.<sup>(77)</sup>

# NEEDS AND EXPERIENCES TREATMENT

**As rarer cancers come in so many different forms, it is impossible to estimate how many patients will undergo surgery. Surgery is a very important part of treatment for some forms of rarer cancer such as bone cancer and brain cancer,<sup>(51)(52)</sup> however, others such as myeloma (cancer of the plasma cells) are almost never treated with surgery.<sup>(53)</sup>**

## What treatments do rarer cancer patients get?

People living with different types of rarer cancers will get different types of cancer treatment, specifically designed for their cancer. Below, some examples of the different treatments available for rarer cancers are summarised.

### Surgery

Surgery is common for some types of rarer cancers. People with bone cancers will often have the section of bone containing a tumour removed. In other cancers, such as brain cancer, kidney cancer and gall bladder cancer surgery is also common if the cancer has not yet spread to other locations.<sup>(6)</sup>

60% of patients with kidney cancer undergo a major surgical resection, compared to 8% of patients with pancreatic cancer. This shows the diversity that is present in the treatment of rarer cancers and reflects the complexity of the treatment.<sup>(54)</sup>

### Chemotherapy

Chemotherapy may be used to treat rarer cancers both as a curative treatment, and to provide palliative care. In the case of some rarer cancers, such as Leukaemia and Myeloma, chemotherapy can be used to destroy bone marrow cells in order to prepare for a stem cell transplant.<sup>(6)</sup>

Nearly all cases of Ewing's sarcoma, a bone cancer, are treated with chemotherapy and the treatment can often be used alongside surgery. Chemotherapy may also be given after surgery to try to reduce the chance of the cancer coming back. This is known as adjuvant chemotherapy.<sup>(6)</sup>

### Radiotherapy

Radiotherapy is an important part of the treatment for soft tissue sarcomas, particularly those affecting the arms or legs. It is usually given after surgery to destroy any remaining cancer cells. It is also common for patients with brain cancer to undergo radiotherapy following surgery. This is known as adjuvant radiotherapy.<sup>(6)</sup>

Because it is slow-growing and generally doesn't cause any problems, classic Kaposi's sarcoma (a cancer of the skin and internal organs) does not usually need to be treated. Therefore, radiotherapy is sometimes used to treat large or very visible lesions.<sup>(6)</sup>

### How many rarer cancer hospital admissions are there?

In total, there were over 665,000 admissions to NHS hospitals in England (emergency and non-emergency) for rarer cancers during 2012–13.<sup>(55)</sup>

### How many nurses are there for people with rarer cancers?

Although it is not clear how many Macmillan nurses specialise in rarer cancers, our internal data suggests that we had (as of June 2014) 4,149 Macmillan nurse posts across the UK.<sup>(56)</sup>

### What does this mean for patients?

In a recent survey the Department of Health reported that **82%** of people with cancers outside the 12 most common cancers said that they had been **given the name of a clinical nurse specialist** (CNS). People with a CNS responded far more positively than those without on a range of items related to information, choice and care.<sup>(57)</sup>

Patients with access to a CNS report a better experience in relation to other aspects of their care, particularly regarding information about diagnosis and treatment, financial help, support and self help groups, and the availability of free prescriptions.<sup>(58)</sup>

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 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. **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.<sup>(59)</sup>

### **What other health conditions do people with rarer cancers 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.<sup>(60)</sup>

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.

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](http://www.macmillan.org.uk/servicesimpact)

**‘I’d been told I needed eight weeks of radiotherapy but was going to turn it down because it just didn’t seem possible to manage without earning a living. I was afraid to lose the house if I couldn’t afford to keep up the mortgage. My Macmillan nurse produced all the benefits forms, helped me fill them in and sent them off.’**

Sarah, 52, living with sarcoma



## PHYSICAL AND MEDICAL NEEDS

The experience of **treatment and care in primary care reported by patients with rarer cancers tends to be poorer** than those with common cancers.<sup>(1)</sup>

**The type and stage of cancer generally dictates the type of treatment used.** For example, patients with oesophageal cancer sometimes undergo chemotherapy to reduce tumour size prior to extensive surgery intended to cure the cancer. In contrast, patients with multiple myeloma typically embark on a protracted course of chemotherapy, followed by radiotherapy and then stem cell transplantation in order to induce remission.<sup>(41)</sup>

Patients undergoing **major surgery** typically have no choice but **admission to hospital followed by several months at home to recuperate**, whereas patients having **chemotherapy** often continue to **work during treatment**, although occasionally needing to take time off if they develop an infection. The desire to continue working during treatment can be a way for patients to cope with what is happening to them.<sup>(41)</sup>

In 2011 a report by the Rarer Cancers Foundation revealed that **NHS cancer patients in England are more than three times as likely to gain access to newer cancer drugs** than they are in Scotland.<sup>(61)</sup>



## FINANCIAL NEEDS

**Patients with rarer cancers who are undergoing treatment have found gaining access to financial support problematic.** Patients often found other people with cancer were more helpful than professionals in providing advice about financial assistance.<sup>(41)</sup>

**75%** of people with “less common cancers\*” were **told that they were entitled to free prescriptions by hospital staff.** This is roughly equal to the average for all cancer types.<sup>(62)</sup>

### Not specific to people with rarer cancers

The most common cost that people living with cancer face is getting to and from their hospital appointments. The cost of **getting to and from appointments affects 69% of people with cancer** and costs them, on average, **£170 a month.**<sup>(107)</sup>

\* ‘Less common cancers’ refers to people with cancers outside the 12 most common cancers, according to a 2012/2013 Department of Health survey.



## PRACTICAL AND INFORMATION NEEDS

Patients with rarer cancers may feel a sense of **isolation** because **so little is known about their disease**. A 2011 study of women with vulval cancer found that there was a lack of knowledge and understanding about this condition, both in their social world, and the healthcare system in which they received treatment, leading to feelings of seclusion.<sup>(65)</sup>

**25%** of people with “less common cancers\*” were given **conflicting information about their illness and treatment whilst in hospital**. This is compared to 13% of people with skin cancer and 17% of people with urological cancers.<sup>(66)</sup>

**78%** of patients with “less common cancers\*” were **given a choice about the treatment** for their illness. This is compared to an average for all cancers of 85%.<sup>(67)</sup>

### Not specific to people with rarer cancers

**10% of people with cancer** (not just rarer cancers) are **not given enough information** about their condition and treatment, but 2% feel that they are given too much.<sup>(64)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

**64%** of people with rarer cancers felt that they were **given enough emotional support from hospital staff** whilst being treated as an outpatient or day case. This is lower in comparison to 74% of skin cancer patients and 72% of lung cancer patients.<sup>(68)</sup>

### Not specific to people with rarer cancers

Amongst all cancer patients (not just rarer cancers) the **overall prevalence of psychological distress is 25%** among those who are undergoing, or have just finished, cancer treatment.<sup>(69)</sup>

\* ‘Less common cancers’ refers to people with cancers outside the 12 most common cancers, according to a 2012/2013 Department of Health survey.



# NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

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

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

- **39%** who completed treatment in 2009/10 say that **no health or social care professional talked them through the needs they might have.**<sup>(44)</sup>
- **94%** experience **physical health condition problems** in their first year after treatment.<sup>(60)</sup>
- **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.<sup>(60)</sup>
- **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.<sup>(60)</sup>
- **40%** with emotional difficulties had not sought **medical help** or other support.<sup>(77)</sup>
- **23%** **lack support from friends and family** during treatment and recovery.<sup>(43)</sup>

- **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.**<sup>(43)</sup>

## 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.<sup>(71)</sup>
- Currently only **19%** of people with cancers outside the 12 most common cancers said that they had received a written assessment and care plan - both of these are essential in providing personalised care for cancer patients and their carers.<sup>(86)</sup>

## 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

**Living with the aftermath of cancer can be challenging** for many rarer cancer patients. For example, oesophageal cancer patients can have problems with **reduced appetite, nausea and acid reflux**, whilst in vulval cancer patients, **constant pain, leg numbness and difficulty with walking** are common.<sup>(41)</sup>



## FINANCIAL NEEDS

People with primary bone cancer, a rare form of the disease, are **typically young and undergo arduous treatments, which often result in significant disabilities**. This often comes at a time when patients are choosing career paths, establishing their independence and embarking on new roles. A recent Canadian study showed that patients re-entered the work place with a different sense of themselves, and found **re-adjustment to work difficult**.<sup>(73)</sup>

### Not specific to people with rarer cancers

61% of cancer patients in a recent survey did not receive health-related benefits.<sup>(107)</sup> The **main barrier to accessing benefits is a lack of knowledge about benefit entitlement**. Some people affected by cancer are not aware that they can claim benefits, even when they have completed their initial treatment.<sup>(72)</sup>

Some people affected by 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.<sup>(107)</sup>

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.<sup>(104)</sup>



## PRACTICAL AND INFORMATION NEEDS

In a study by Macmillan about rarer cancers, some patients suggested that they felt **abandoned and isolated after discharge from hospital**. This sense of abandonment was linked to hospital nurses omitting to refer them to primary care services or other agencies such as hospice or support groups.<sup>(41)</sup>

**60%** of patients with “less common cancers\*” were **not given enough care and help** from health and social care professionals once they were at home. This compares with 66% of colorectal cancer patients and 57% of prostate cancer patients.<sup>(75)</sup>

\* ‘Less common cancers’ refers to people with cancers outside the 12 most common cancers, according to a 2012/2013 Department of Health survey.



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

Some rarer cancer patients, regardless of whether they are disease free or living with disease, say that **knowledge that the cancer could return or remission end is never far from their thoughts**.<sup>(41)</sup>

### Not specific to people with rarer cancers

**23%** of people living with cancer (not just rarer cancers) report **poor emotional well-being**.<sup>(70)</sup>

Emotional and psychological long-term side effects of cancer and its treatment include **depression, anxiety, memory problems, difficulty concentrating, sexual problems and a lack of confidence in engaging socially**.<sup>(77)</sup>

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 people living with cancer still suffer from at least one psychological issue**.<sup>(77)</sup>

# NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

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

Specific data for rarer cancers are not available.

## How many rarer cancer patients are at End of Life?

Specific data for rarer cancers are not available, but for all cancers around 7% of patients are in the last year of life.<sup>(78)</sup>

It is estimated that on average **1 in 220** new cancer diagnoses in the UK are associated with radiotherapy for a previous cancer. However the number of people diagnosed with rarer cancers as a result of previous radiotherapy is extremely small.<sup>(79)</sup>

## What is the impact of giving patients palliative care?

Palliative care is the active holistic care of patients with advanced progressive illness.<sup>(80)</sup>

It provides an added layer of support to the patient's regular medical care.<sup>(81)</sup>

A recent study found that home, hospital, and inpatient specialist palliative care significantly improved patient outcomes in the domains of pain and symptom control, anxiety and reduced hospital admissions.<sup>(82)</sup>

The majority of people requiring palliative care will not receive specialist palliative care. It is usually only when a patient's symptoms become complex that they are referred for specialist palliative care.<sup>(83)</sup>

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'.<sup>(80)</sup>

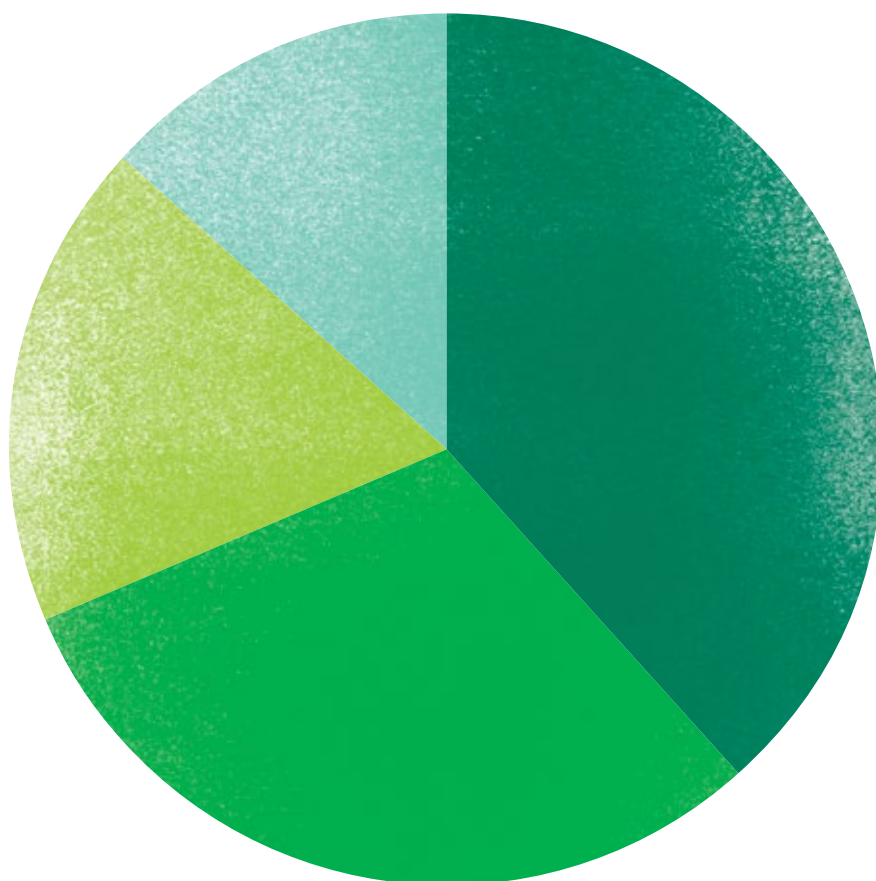
## Where do people with cancer die?<sup>(85)</sup>

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

For further information, visit the National Council for Palliative Care website, [www.ncpc.org.uk](http://www.ncpc.org.uk)



## Where do people with cancer die?\* (84)



Hospital

**38%**

Home  
(own residence)

**30%**

Hospice

**18%**

Care and  
nursing home

**13%**

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

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

Note: not specific to people with rarer cancers

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.<sup>(93)</sup> However, only 30% of those who die from cancer actually die at their own home or own residence.<sup>(85)</sup>



**‘I suppose I have settled down towards a more accepting state of mind regarding both cancers. The leukaemia is incurable but my last haematology check up indicated that it is still progressing slowly albeit steadily. For me the worst part was having to tell my children.’**

Simon, 56, living with kidney cancer and leukaemia



## PHYSICAL AND MEDICAL NEEDS

For some patients with brain tumours referral to specialist palliative care services occur late in the illness trajectory. This means that patients and carers may not be able to access the full range of supportive care services available.<sup>(90)</sup>

### Not specific to people with rarer cancers

An estimated 457,000 people (not just those with rarer cancers) need good palliative care services every year in England, but around **92,000 people are not being reached.**<sup>(87)</sup>

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

Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; they occur in some combination in virtually all patients.<sup>(108)</sup>

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.**<sup>(88)</sup>



## FINANCIAL NEEDS

### Not specific to people with rarer cancers

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

People with a terminal diagnosis who wish to travel may have their **travel insurance cover refused** by insurance companies, or be offered cover at prohibitively high premiums, stopping them from fulfilling their wishes.<sup>(92)</sup>

Death of a partner has been shown to be a trigger for claiming **income support.**<sup>(93)</sup>



## PRACTICAL AND INFORMATION NEEDS

### Not specific to people with rarer cancers

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

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

A study of people with advanced cancer found that the greatest areas of need are psychological and medical communication/information domains. Patients' **specific needs were highest in dealing with a lack of energy and tiredness, coping with fears about the cancer spreading, and coping with frustration at not being able to do the things they used to do**.<sup>(63)</sup>

**Access to community nursing at any time of the day or night is essential** to support those who wish to die at home. Where these wishes are not met in can lead to traumatic experiences for patients and their families.<sup>(22)</sup> Freedom of Information requests placed on England Primary Care Trusts (PCTs) by Macmillan in 2010 indicated that 24/7 **community nursing** is available for all end of life patients **in only 56% of PCTs that responded**.<sup>(74)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

Amongst pancreatic cancer patients only 10–15% are diagnosed at a stage where the tumor is resectable. Thus, **most pancreatic cancer patients are treated with a palliative intention at first diagnosis** and the median survival of patients with metastatic pancreatic cancer is three to six months. This very **short space of time between diagnosis and death can be very emotionally difficult for patients and their family**.<sup>(98)(99)</sup>

### Not specific to people with rarer cancers

Cancer patients (all cancer types, not just rarer cancers) approaching death suffer more **psychological distress**.<sup>(69)</sup>

Amongst all cancer patients (not just rarer cancers) the **overall prevalence of psychological distress is 59% amongst those receiving palliative care**.<sup>(69)</sup>

**83% of people say they are scared of dying in pain**, while 67% say they are scared of dying alone, and 62% are scared of being told they are dying.<sup>(97)</sup>

**Depression** is an **under recognized condition** experienced by a significant number of palliative care patients. It contributes to considerable **distress in patients and families**.<sup>(76)</sup>

# LIFESTYLE AND PERCEPTIONS

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

## **What is the profile of the average person living with a rarer cancer?**

Because of the diversity of the types of cancer which make up Macmillan's definition of rarer cancers it is hard to state what the average person affected by these cancers types is like.

However, for all cancers people in the Asian, Chinese and mixed ethnic groups all had significantly lower risk of getting cancer than White people across the majority of cancer types.<sup>(20)</sup>

The incidence of most cancer types increases with age and 77% of all cancer deaths in the UK are amongst the 65+ age group. However, although young people may be less likely to develop cancers overall, those who do get cancer are more likely to develop rarer forms of the disease.<sup>(23)(5)</sup>

## **What is the demographic breakdown/ market segmentation of 422,400 rarer cancer patients?<sup>(100)</sup>**

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.

Given the diversity of people with rarer cancers it is difficult to analyse their demographic breakdown. However amongst cancer patients in general the following MOSAIC\* groups show significantly greater than average representation

**Group L: Elderly Needs (elderly people reliant on state support):** People in Group L are usually pensioners who may be struggling with the responsibility of looking after the family house and garden. Most of these people are in their 70s, 80s or 90s. Most of them are on low pension incomes. They tend to live in various types of home, including nursing homes, sheltered accommodation, their own family home or a down-sized property.

**Group E: Active Retirement (active elderly people living in pleasant retirement locations):** People in Group E are mostly people aged over 65 whose children have grown up and who, on retirement, have decided to move to a retirement community among people of broadly similar ages and incomes. Most of these people have paid off their mortgages on their family home and now live in a bungalow or country cottage. For some, the move to a rural or coastal location is an opportunity to make a new start and explore new places. Most people in this group will have the benefit of a company pension and many will have access to savings. Others may be on lower state pensions, and may struggle with rising utility bills.

In addition to the above Groups, there are two types within **Group C (Rural Solitude)** and two within **Group B (Professional Rewards)** which are also well-represented amongst rarer cancer patients:

**Group C, Type 15: Upland Struggle**  
**Group C, Type12: Country Loving Elders**

**Group B, Type 06: Yesterday's Captain**  
**Group B, Type10: Parish Guardians**

## What are the typical leisure activities/where they shop/ what media they consume/ what they do?<sup>(100)</sup>

**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 do not use 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.

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

### Before:

**'Diagnosis was difficult for me and my family. I was fit and in my mid-thirties; it was utterly unexpected.'**

Max, 38, living with Leukaemia

**'I kept telling my GP I didn't feel well – I was desperately tired, in a lot of pain and breathless. But I had existing problems and he told me it might be something to do with those, or it was just my age.'**

Pam, 61, living with an adrenal tumour

**After:**

**'I want to be an inspiration for other people with cancer, especially teenagers. Firstly because I am really meant to be dead and I'm still here, and secondly because I'm supposed to be disabled but I'm fine. To look at me you'd never think I had cancer.'**

Juliet, 23, living with Ewing's sarcoma

**'I've learned to live with the "new normal" of post cancer fatigue, vitamin deficiencies, bowel spasms and the quite severe pain. The last three problems have all been caused by the pelvic radiotherapy damage. I have got some control through following a careful diet. It doesn't always work, though, and stress can lead to flare ups. A particularly busy week is often followed by a week in bed.'**

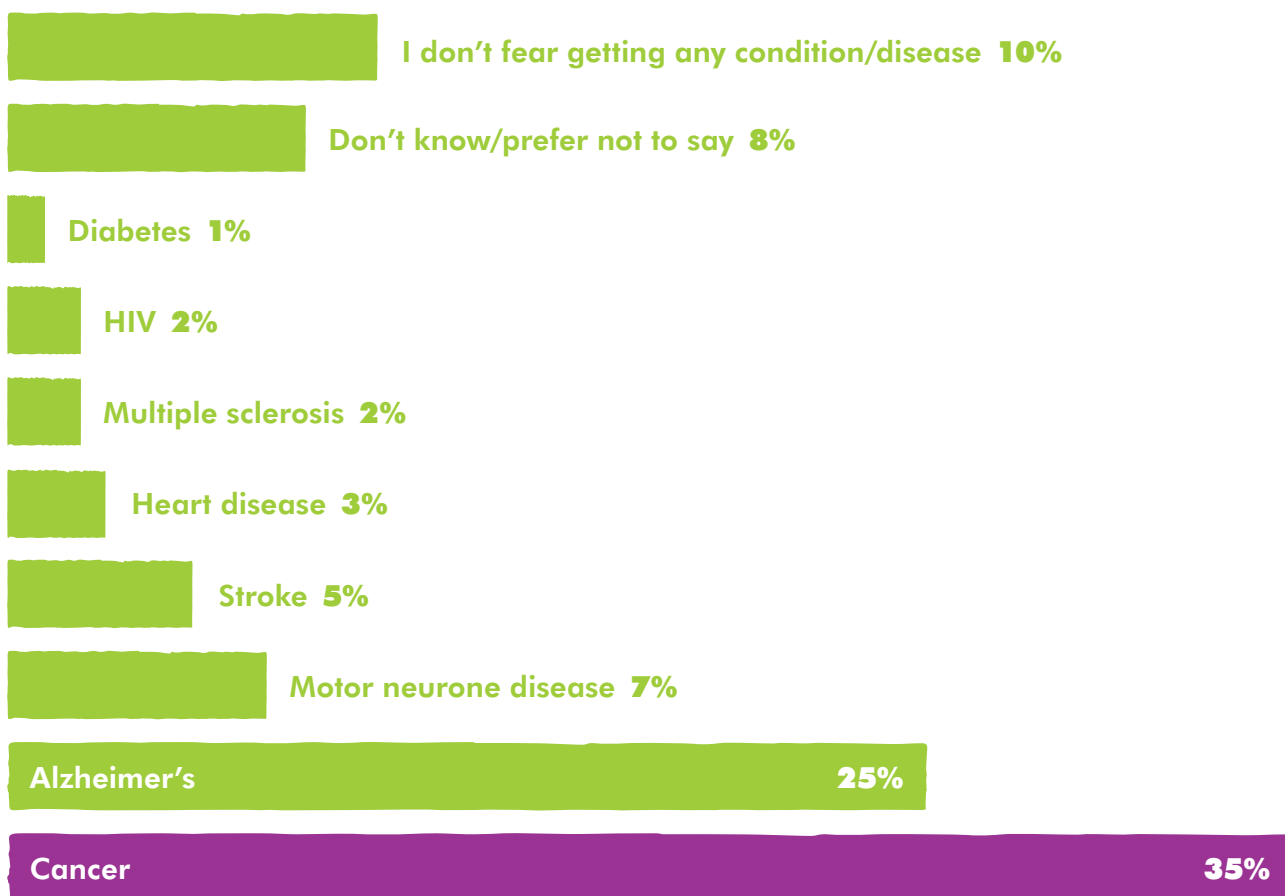
Jane, 54, living with anal cancer



## How does people’s fear of rarer cancer compare to actual survival rates?

A 2011 study<sup>(101)</sup> by Cancer Research UK surveyed people’s fear of certain cancer types. However rarer cancers were not included in the research. Instead of showing the results of that research, we devote this page instead to a different set of results from the same survey which examined how people’s fear of cancer compares to other feared diseases.

### How much do people fear cancer?<sup>(101)</sup>



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



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

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

The online community discussion shows the uncertainty which being diagnosed with a rarer cancer may bring. This is noticeable in words such as "information", "odd", "waiting" and "advice".

The online community concentrates on the emotional and physical side effects of rarer cancers and its treatment. Words such as 'shock', 'waiting' and 'worried' show something of the emotional rollercoaster which faces people living with cancer. However, the media also focuses on the effects of cancer, with words such as "children", "family" and "mum" showing that articles have been written about cancer and how this affects relationships

The media demonstrates much more of an interest into cancer research and the hospital system than the online rarer cancers group. This is clear from words such as 'research' and 'NHS'.

# REFERENCES, SOURCES, NOTES AND CAVEATS

## Quotes

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

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# APPENDIX A

# JARGON BUSTER

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

## (i) Health data terms

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

**Mortality:** When we talk about ‘cancer mortality’ 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 150,000 people die from cancer in the UK every year. Mortality can sometimes be given as a rate (per head of population).

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

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

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

## (ii) Other terms

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

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

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

For further support, please contact  
[evidence@macmillan.org.uk](mailto: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

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

### The Rich Pictures on age groups

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

### Other Rich Pictures

<b>The Rich Picture on people at end of life</b>	(MAC13841_14)
<b>The Rich Picture on carers of people with cancer</b>	(MAC13731_10_14)
<b>The Rich Picture on people with cancer from BME groups</b>	(MAC14662_14)
<b>The Emerging Picture on LGBT people with cancer</b>	(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](http://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](http://macmillan.org.uk)**

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