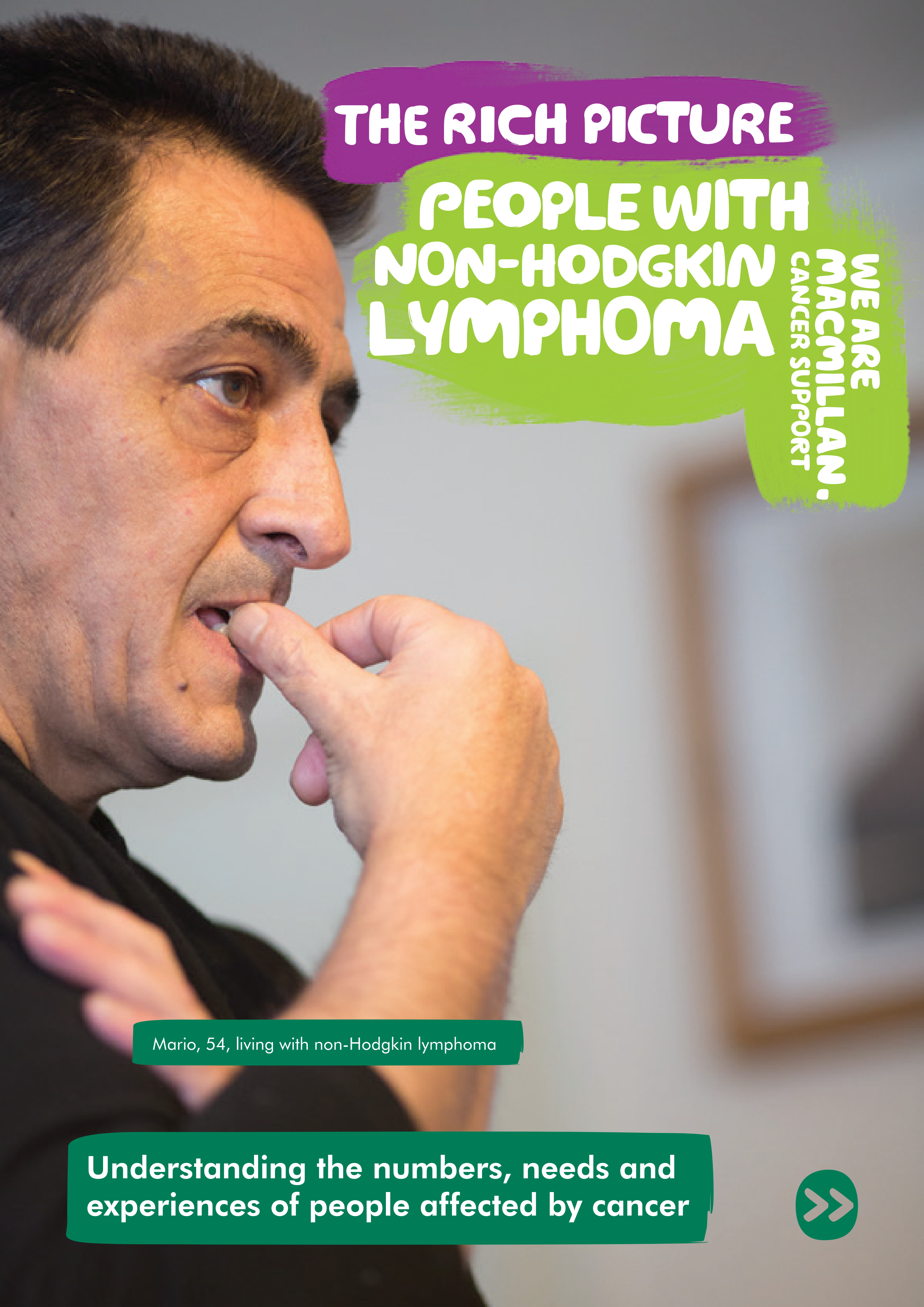


THE RICH PICTURE

PEOPLE WITH NON-HODGKIN LYMPHOMA

WE ARE MACMILLAN.
CANCER SUPPORT

Mario, 54, living with non-Hodgkin lymphoma

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

About this 'Rich Picture'

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

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

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

The information could be valuable in many ways:

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

This document is not intended to

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

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

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

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

The legal bit

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

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

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

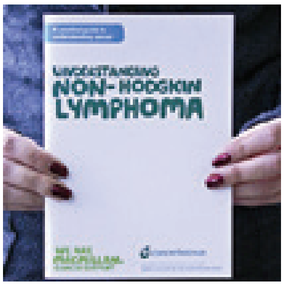
There may be data that have been released that does not appear in this document and Macmillan is under no obligation to include any particular data source. Any medical information referred to in this document is given for information purposes only and it is not intended to constitute professional advice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

Guidance on referencing this document

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

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklet 'Understanding non-Hodgkin lymphoma' (MAC11635) more helpful:



Understanding non-Hodgkin lymphoma
MAC11635

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

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

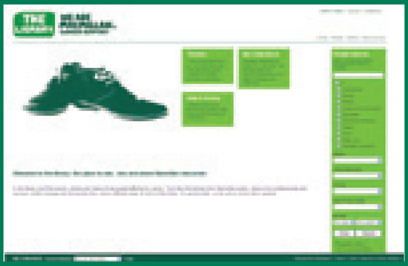
OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

Case Study Library

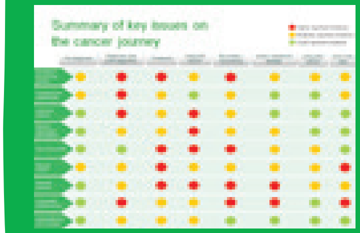
People affected by cancer
Contains stories and quotes from real-life examples of people affected by cancer who have been helped by Macmillan.

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



Comms Platform

Describes how to communicate with people affected by cancer.

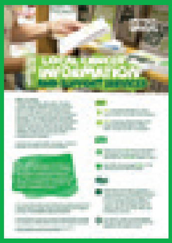


Rich Pictures

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

Impact Briefs

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



Local Cancer Intelligence

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

Routes from Diagnosis

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

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

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CONTENTS

SUMMARY OF PEOPLE LIVING WITH NON-HODGKIN LYMPHOMA

Key stats

Non-Hodgkin lymphoma is the **sixth most commonly diagnosed cancer** in the UK, and an average of **35 people** receive a non-Hodgkin lymphoma diagnosis **every day in the UK.**(5, 6, 7, 8)

Non-Hodgkin lymphoma is the ninth most common cause of cancer death in the UK, with around **4,700 people dying every year** from non-Hodgkin lymphoma in the UK.(8, 9, 10)

Around **7 in 10** of all non-Hodgkin lymphoma cases are diagnosed in people **aged 60 and over.**(11)

Survival rates for non-Hodgkin lymphoma are improving, with **62% of men and 69% of women** living for **more than 5 years** after a diagnosis.(90, 91)

Non-Hodgkin lymphoma is the sixth most commonly diagnosed cancer in the UK.

Diagnosis

Lymphoma sub-type is a major factor determining the **rate of progress** from presentation to the start of treatment.(25)

People who have indolent (low grade or non-aggressive) non-Hodgkin lymphoma may not begin treatment immediately, but **many are still unable to work following diagnosis.**(28)

Only **58% of people** with haematological cancers (which includes non-Hodgkin lymphoma) felt that they **fully understood the explanation** of what was wrong with them.(33)

Many people living with non-Hodgkin lymphoma do not fully understand the explanation of their illness.

Treatment

46% of carers of people with non-Hodgkin lymphoma reported having at least **one personal expense** and **52%** experienced at least **one financial impact** during treatment.(52)

The **needs of adolescent patients with non-Hodgkin lymphoma are often unmet** because medical oncologists and paediatric oncologists sometimes disagree over treatment plans.(47)

26% of people with haematological cancers (including non-Hodgkin lymphoma) were given **conflicting information** whilst in hospital.(56)

Around half of carers of people with non-Hodgkin lymphoma experience financial issues during treatment.

Contents

Survivorship

35% of survivors of childhood lymphoma (including both the Hodgkin and non-Hodgkin forms of the disease) **experience side effects as adults.**(62)

Among long term survivors of non-Hodgkin lymphoma **41%** reported **problems with work, 15%** with obtaining **life insurance** and **22%** with obtaining a **mortgage.**(66)

Around **37%** of non-Hodgkin lymphoma survivors experience persistent or worsening symptoms of **post-traumatic stress disorder.**(69)

Non-Hodgkin lymphoma survivors can experience difficulties with returning to work, insurance and other financial issues, and post-traumatic stress.

End of life

Patients with haematological cancers (including non-Hodgkin lymphoma) are **less likely to receive care from specialist palliative or hospice services** compared to other cancers.(78)

Adolescents with haematological cancers (including non-Hodgkin lymphoma) are **more likely to die in an intensive care unit** than those with other cancers and **end of life discussions** are more likely to occur in the **last 7 days of life,** which can be very distressing.(89)

Patients with haematological cancers are less likely to receive palliative care than people with other types of cancer.

Lifestyle & perceptions

People living with non-Hodgkin lymphoma can come from all parts of society; it mostly affects **older people**, however lymphomas are common amongst the relatively small number of **adolescents** who are diagnosed with cancer.(47)

Active elderly people living in pleasant retirement locations and **elderly people reliant on state support** are well-represented amongst people being treated for non-Hodgkin lymphoma.**(see page 49)**

Non-Hodgkin lymphoma is **not a particularly well-known type of cancer,** with much less media reporting about it in comparison to other cancers.**(see page 53)**

INTRODUCTION TO NON-HODGKIN LYMPHOMA

What is Non-Hodgkin lymphoma? (2)

- Non-Hodgkin lymphoma is a **cancer of the lymphatic system** and is the most common blood cancer.

There are many sub-types of non-Hodgkin lymphoma (sometimes abbreviated to NHL), but they can all be put into one of two broad categories:

- **High-grade non-Hodgkin lymphoma,** where the cancer develops quickly and aggressively. Diffuse large B-cell lymphoma is the most common type of aggressive lymphoma.

- **Low-grade or indolent non-Hodgkin lymphoma,** where the cancer develops slowly and there may be no symptoms for many years. Follicular lymphoma is the most common type of indolent non-Hodgkin lymphoma.

- Lymphomas are often described as **B-cell lymphomas or T-cell lymphomas** according to whether they began in B-cell lymphocytes or T-cell lymphocytes. **B-cell lymphomas are much more common** than T-cell lymphomas. About 9 in 10 people diagnosed with non-Hodgkin lymphoma have a B-cell lymphoma.

- In non-Hodgkin lymphoma, **blood cells called lymphocytes become abnormal**. These abnormal lymphocytes (lymphoma cells) keep dividing and grow out of the body's control. Over time, the number of lymphoma cells increases and they form a lump called a tumour.

- Lymphoma cells generally **start to grow in lymph nodes,** which are part of the lymphatic system. Usually non-Hodgkin lymphoma affects groups of lymph nodes in one area of the body. However, the **lymphoma cells can sometimes spread through the lymphatic system** to lymph nodes in other parts of the body. They can also go into the bloodstream, which may carry them to other organs. When the cells reach a new area they may go on dividing and form a new tumour.

- Lymphoma that grows outside the lymph nodes is called **extranodal lymphoma**.

Want to know more?

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

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

‘I was diagnosed with Non-Hodgkins Lymphoma in 2006. When I was diagnosed I had everything ripped away from me. I lost my business, I lost my home, I was getting divorced. It was quite difficult for the first few months as I was really poorly and I was living alone. Emotionally, I was at one of the lowest points of my life. I felt like I was falling from a great height but Pat, my Macmillan nurse, was there to catch me.’ She helped me through a lot of difficult times.

Because of what Pat did for me, I wanted to give something back to Macmillan and volunteer at my local Macmillan information and support centre. When I finished treatment, I felt alone because I was so used to the routine it gives you, but volunteering has given me a new purpose.’

Mario, 54

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people with non-Hodgkin lymphoma.

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.(108)

Around 76,840 people were living with non-Hodgkin lymphoma in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.(3)

How is this different for people with non-Hodgkin lymphoma?

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.

Contents

The 9 Outcomes for people living with cancer

- I was diagnosed early
- I understand, so I make good decisions
- I get the treatment and care which are best for my cancer, and my life
- Those around me are well supported
- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- I can enjoy life
- I feel part of a community and I'm inspired to give something back
- I want to die well

THE FACTS ON NON-HODGKIN LYMPHOMA

This section presents some of the key stats and facts relating to people with non-Hodgkin lymphoma cancer. You may benefit from referring to the Jargon Buster on page 66 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.

35

Around 35 people in the UK are diagnosed with non-Hodgkin lymphoma every day. (5, 6, 7, 8)

76,840

People were living with non-Hodgkin lymphoma in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.(3)

77%

of men (80% of women) live for more than one year after their non-Hodgkin lymphoma diagnosis. (4)

69%

of men (67% of women) live for more than five years after their non-Hodgkin lymphoma diagnosis. (4)

13

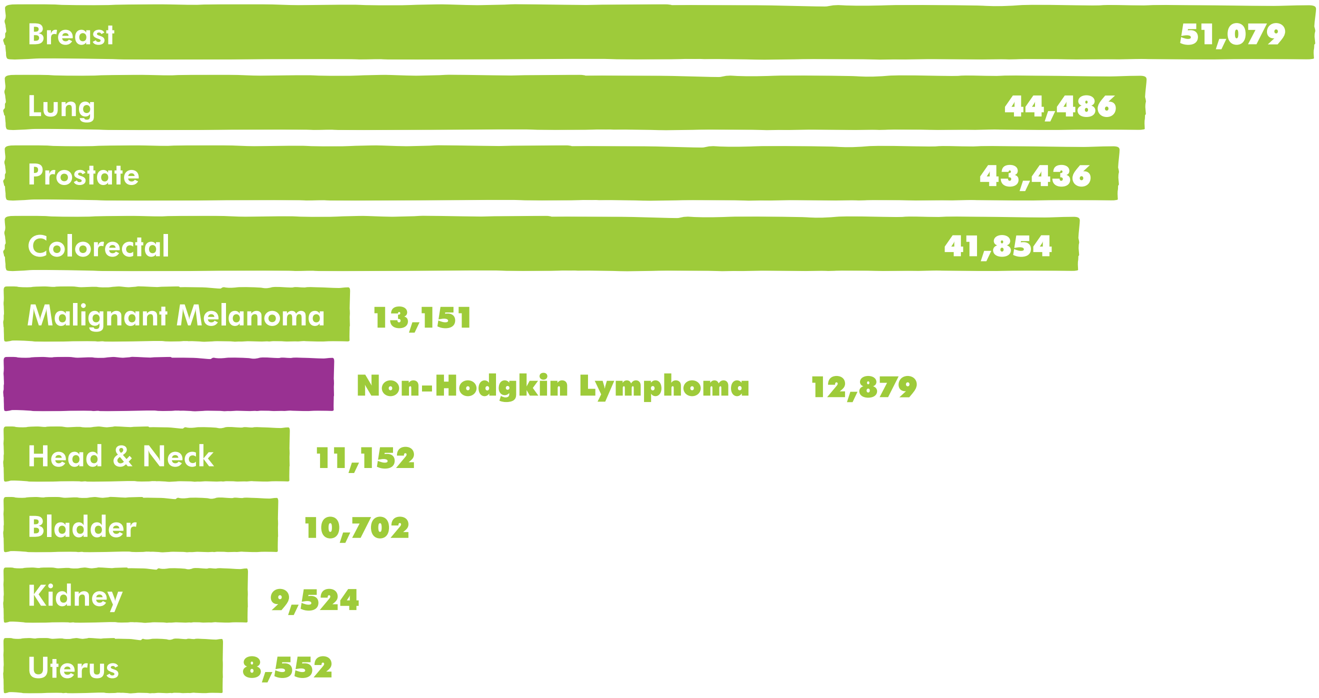
Around 13 people die every day of non-Hodgkin lymphoma in the UK. (5, 6, 7, 8)

*Please note that the prevalence figures have been estimated by Macmillan Cancer Support using best available data and are indicative only. Refer to reference 3 for more information.

Contents

How many people get non-Hodgkin lymphoma per year (incidence)

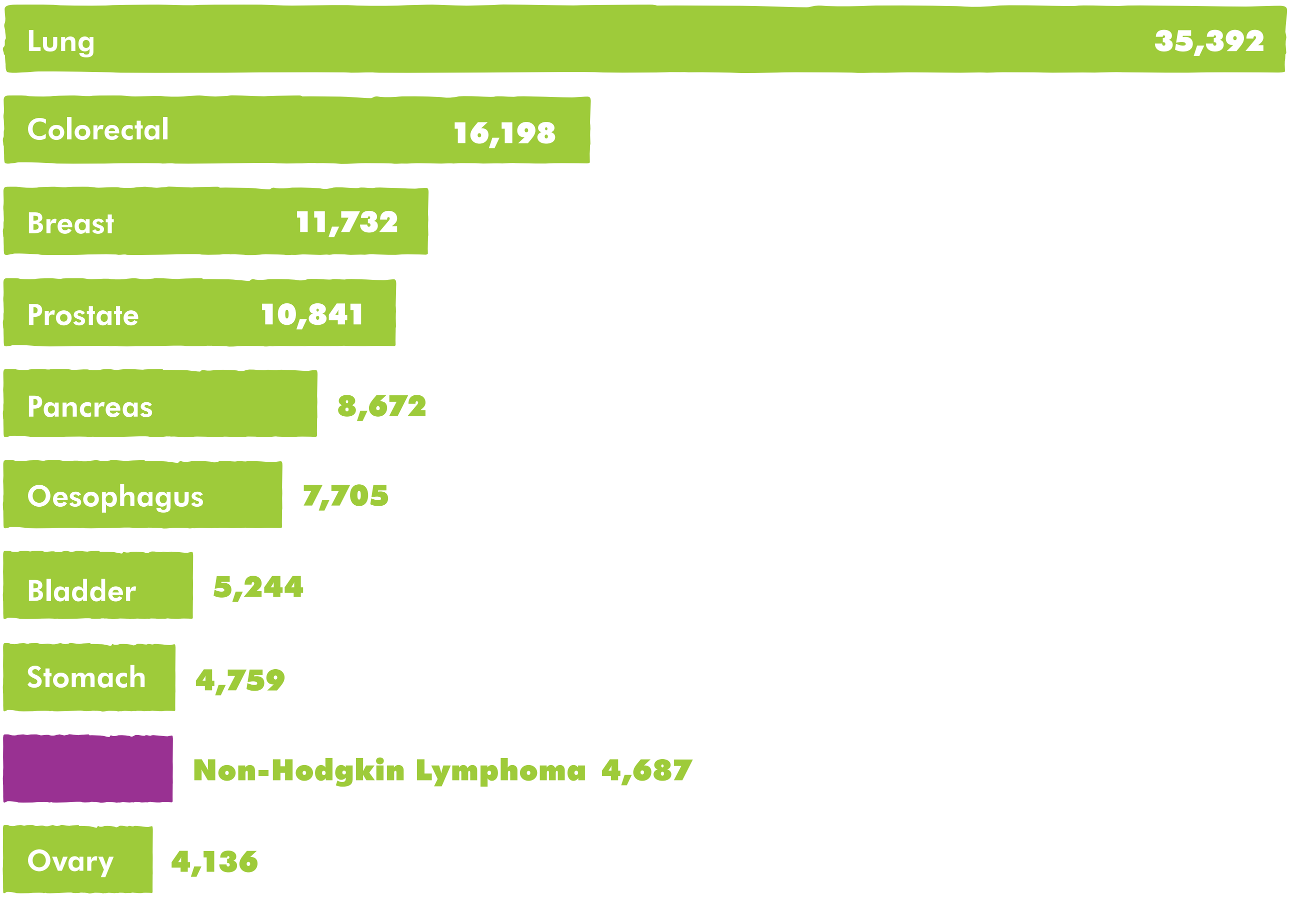
Cancer incidence, UK, 2012, top 10 cancer sites



Non-Hodgkin lymphoma is the sixth most commonly diagnosed cancer. Over 12,500 people are diagnosed every year in the UK, that's around 35 people every day. (5, 6, 7, 8)

How many people die from non-Hodgkin lymphoma per year? (mortality)

Mortality, UK, 2012, top 10 cancer sites



Non-Hodgkin lymphoma is the ninth most common cause of cancer death in the UK. Around 4,700 people die from non-Hodgkin lymphoma every year in the UK, that's around 13 people every day.(8, 9, 10)

How many people are currently living with non-Hodgkin lymphoma? (prevalence)(3)

People were living with non-Hodgkin lymphoma in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.

76,840

Non-Hodgkin lymphoma is the ninth most common cause of death from cancer(8, 9, 10) and the prognosis for people with non-Hodgkin lymphoma is relatively good. Non-Hodgkin lymphoma patients are now twice as likely to survive their disease for at least 10 years compared to those diagnosed in the early 1970s.(2)

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 non-Hodgkin lymphoma per year in England? (incidence)(5)

10,857

new cases of non-Hodgkin lymphoma diagnoses in England in 2012.

How many people die from non-Hodgkin lymphoma per year in England? (mortality)(9)

3,882

Non-Hodgkin lymphoma deaths in England in 2012.

How many people are living with non-Hodgkin lymphoma in England? (prevalence)(3)

64,389

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

What is the age-standardised* rate of incidence of non-Hodgkin lymphoma in people in England?(11)

16

new cases of non-Hodgkin lymphoma diagnoses in England in 2011 per 100,000 heads of population

What is the age-standardised* rate of mortality from non-Hodgkin lymphoma in people in England?(12)

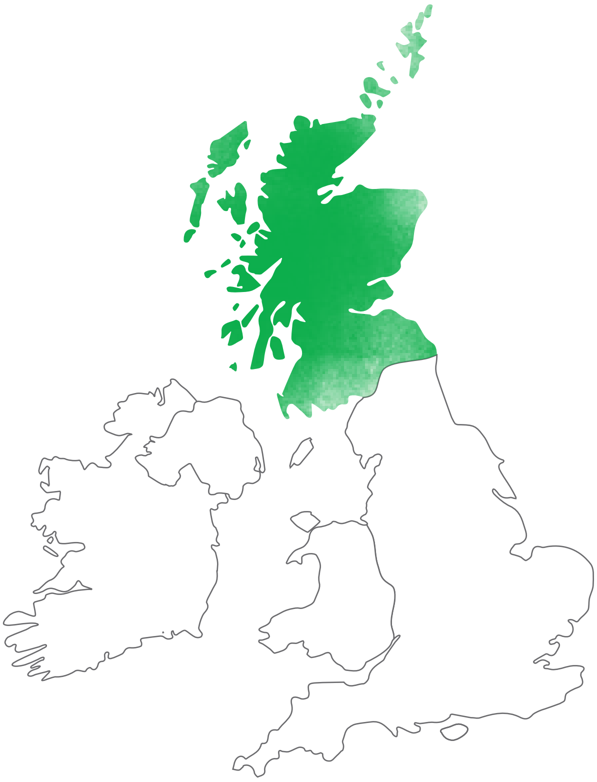
4.9

cases of non-Hodgkin lymphoma deaths in England in 2011 per 100,000 heads of population

Contents

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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How many people get non-Hodgkin lymphoma per year in Scotland? (incidence)(6)

1,068

new cases of non-Hodgkin lymphoma diagnoses in Scotland in 2012.

How many people die from non-Hodgkin lymphoma per year in Scotland? (mortality)(10)

418

Non-Hodgkin lymphoma deaths in Scotland in 2012.

How many people are living with non-Hodgkin lymphoma in Scotland? (prevalence)(3)

6,743

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

What is the age-standardised* rate of incidence of non-Hodgkin lymphoma in people in Scotland?(11)

14

new cases of non-Hodgkin lymphoma diagnoses in Scotland in 2011 per 100,000 heads of population

What is the age-standardised* rate of mortality from non-Hodgkin lymphoma in people in Scotland?(12)

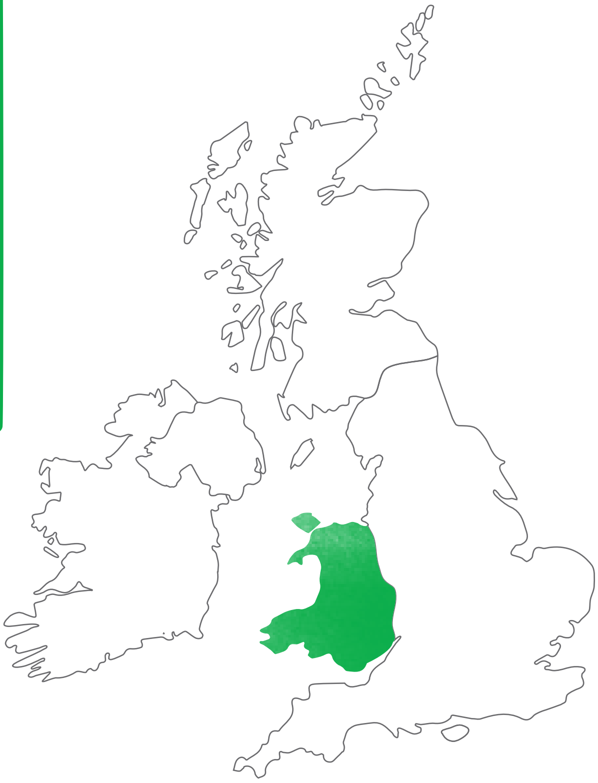
4.6

cases of non-Hodgkin lymphoma deaths in Scotland in 2011 per 100,000 heads of population

Contents

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



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How many people get non-Hodgkin lymphoma per year in Wales? (incidence)(7)

578

new cases of non-Hodgkin lymphoma diagnoses in Wales in 2012.

How many people die from non-Hodgkin lymphoma per year in Wales? (mortality)(9)

257

Non-Hodgkin lymphoma deaths in Wales in 2012.

How many people are living with non-Hodgkin lymphoma in Wales? (prevalence)(3)

3,677

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

What is the age-standardised* rate of incidence of non-Hodgkin lymphoma in people in Wales?(11)

15

new cases of non-Hodgkin lymphoma diagnoses in Wales in 2011 per 100,000 heads of population

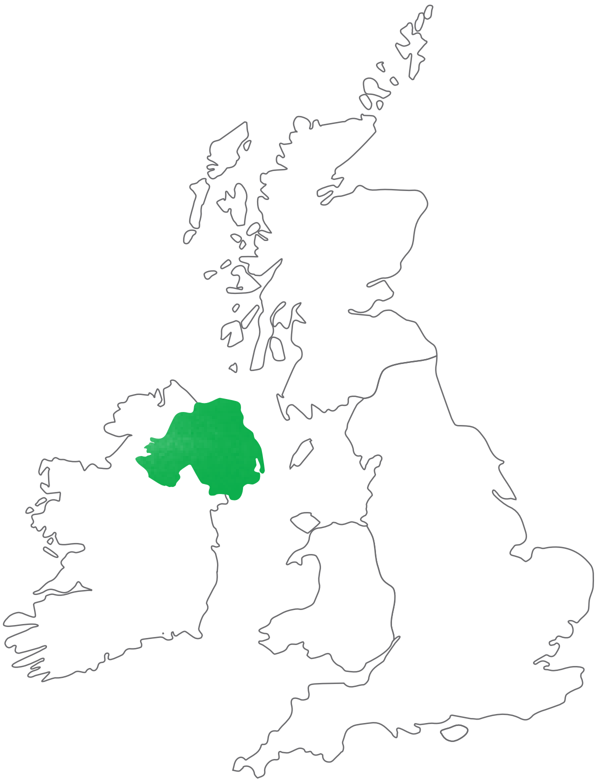
What is the age-standardised* rate of mortality from non-Hodgkin lymphoma in people in Wales?(12)

4.5

cases of non-Hodgkin lymphoma 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 non-Hodgkin lymphoma per year in Northern Ireland? (incidence)(6)

376

new cases of non-Hodgkin lymphoma diagnoses in Northern Ireland in 2012.

How many people die from non-Hodgkin lymphoma per year in Northern Ireland? (mortality)(10)

130

Non-Hodgkin lymphoma deaths in Northern Ireland in 2012.

How many people are living with non-Hodgkin lymphoma in Northern Ireland? (prevalence)(3)

2,034

people were living with non-Hodgkin lymphoma in Northern Ireland in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).

What is the age-standardised* rate of incidence of non-Hodgkin lymphoma in people in Northern Irealand?(11)

16

new cases of non-Hodgkin lymphoma diagnoses in Northern Ireland in 2011 per 100,000 heads of population

What is the age-standardised* rate of mortality from non-Hodgkin lymphoma in people in Northern Ireland?(12)

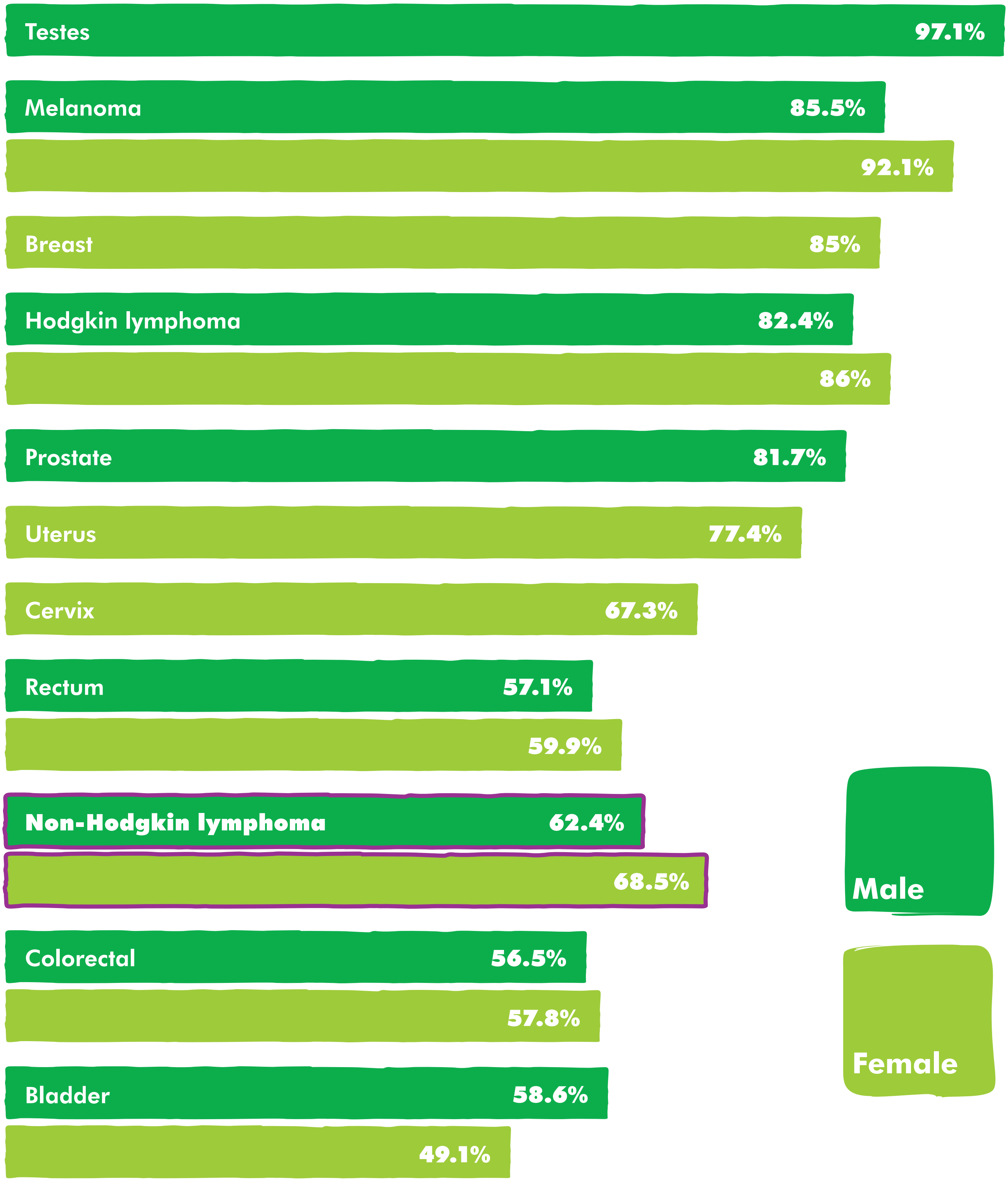
5.5

cases of non-Hodgkin lymphoma deaths in Northern Ireland in 2011 per 100,000 heads of population

Contents

What proportion of people survive non-Hodgkin lymphoma? (survival) (4)

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

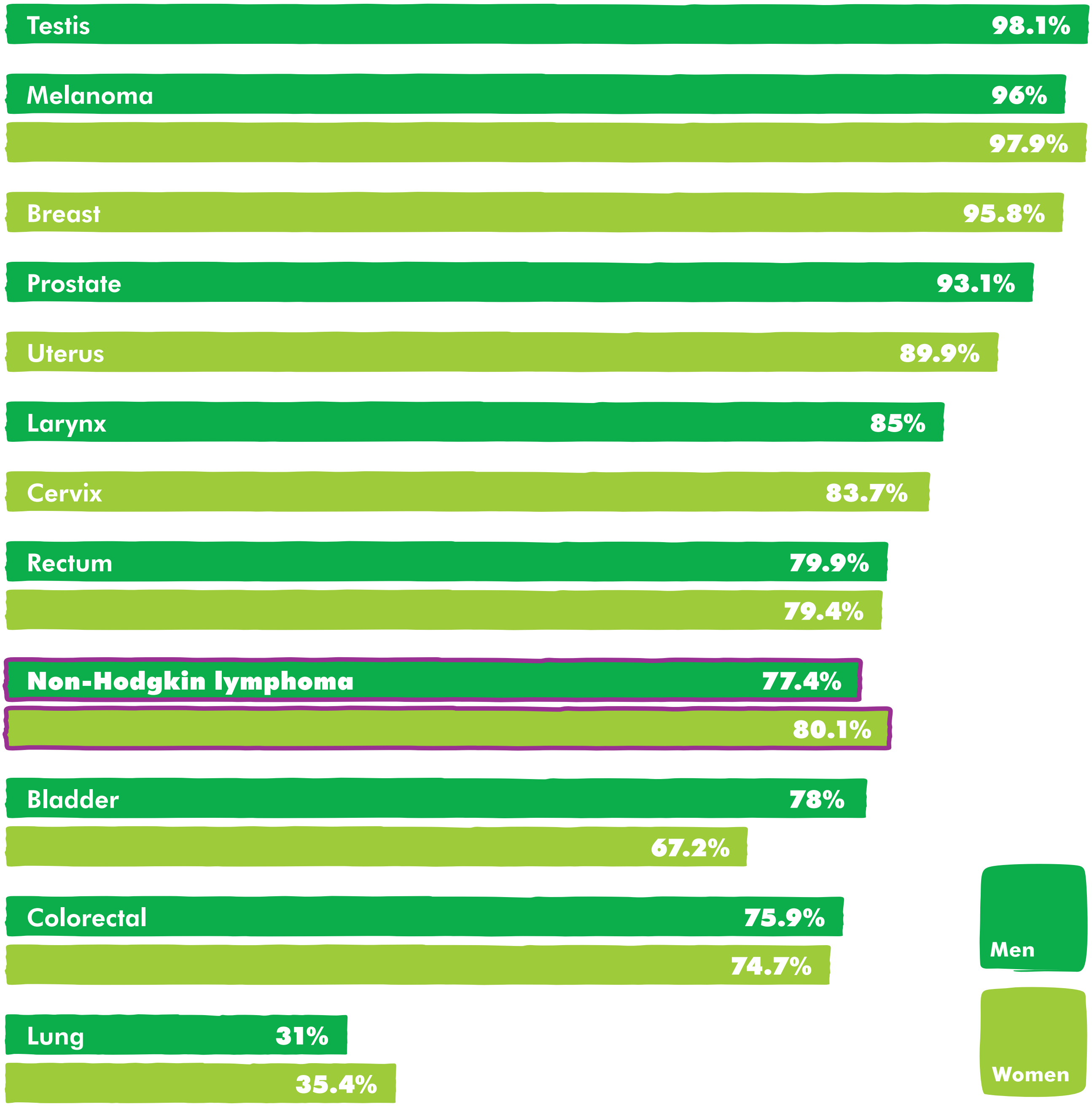


When compared to other cancers, Non-Hodgkin lymphoma has relatively low 5 year survival rates (62.4% of men and 68.5% of women are alive 5 years after their diagnosis). It is ranked at number 8 in the rankings of 5-year survival.

Survival rates for non-Hodgkin lymphoma are increasing; this can generally be attributed to faster diagnosis and improvements in treatment.

How many people live beyond one year of their non-Hodgkin lymphoma diagnosis? (4)

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



The estimated proportion of people living more than one year after their non-Hodgkin lymphoma diagnosis is 79%.

How have median survival times changed for non-Hodgkin lymphoma?(13)

Over the last 40 years, the median survival time for non-Hodgkin Lymphoma has increased by 10-fold, from 1 year in 1970–71 to 10 years in 2007.

How do UK survival rates compare internationally?

The most recent 5-year survival data for 1995–1999 for non-Hodgkin lymphoma show England is slightly below the average for Europe (55%). Scotland, Wales and Northern Ireland were also lower than the European average. Across the European countries, 5-year survival rates range from 44% to 63%.(14)

What are the major demographic variations in incidence, mortality, prevalence and survival for non-Hodgkin lymphoma?

Gender

Incidence rates are higher for males than females, with 6,998 males and 5,880 females diagnosed in the UK in 2011. This gap is widest in the 5–9 and 10–14 age groups, when the male:female incidence ratios of age-specific rates are around 38:10 and 25:10, respectively. The ratio is lowest in the 85 and over age group, at around 13:10.(5)

Amongst women, non-Hodgkin lymphoma is the seventh most common cause of cancer death in the UK whereas for men non-Hodgkin lymphoma is the eight most common cause of cancer death in the UK. In 2012 in the UK, around 2,130 females died from non-Hodgkin lymphoma, and 2,557 males died from non-Hodgkin lymphoma showing that the mortality rates are similar for both genders.(8, 9, 10)

In men, 5-year relative survival rates for non-Hodgkin lymphoma increased from 27% in England and Wales during 1971–1975 to 61.5% during 2005–2009 and in women, 5-year relative survival rates increased from 31% to 65.7% during the same time periods.(14)

Ethnic background

There appears to be no significant variation in Non-Hodgkin lymphoma incidence by ethnicity in the UK.

Age-standardised rates for White males with Non-Hodgkin lymphoma range from 15.7 to 16.5 per 100,000. Rates for Asian males are similar, ranging from 10.3 to 16.9 per 100,000 and the rates for Black males are also similar, ranging from 11.4 to 19.6 per 100,000. For females there is a similar pattern - the age-standardised rates for White females range from 11.2 to 11.8 per 100,000 and 8.7 to 15.1 per 100,000 respectively.(11)

Age

Non-Hodgkin lymphoma incidence is strongly related to age, with the highest incidence rates being in older patients, with incidence rates rising steeply from around age 50–54, peaking in the 80–84 age group for both men and women.(11)

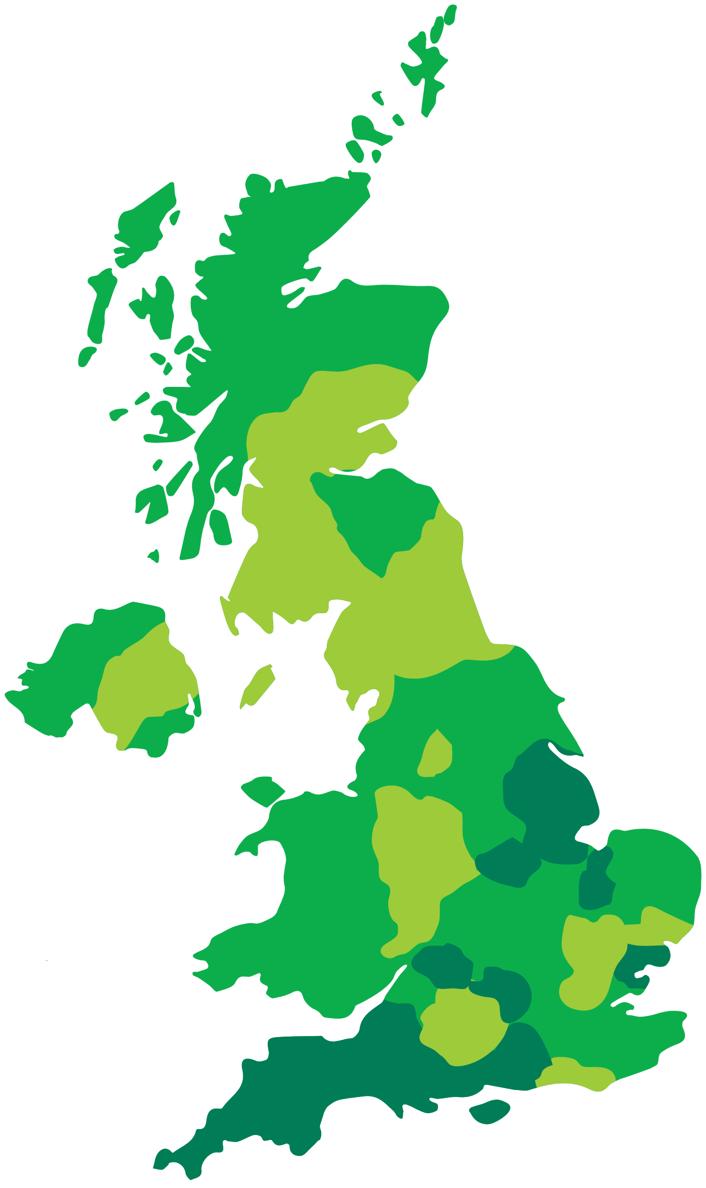
In the UK between 2009 and 2011, an average of 34% of cases were diagnosed in men and women aged 75 and over, although around 1 in 7 (14%) were diagnosed in the under-50s. Age-specific incidence rates rise steeply from around age 50-54, reaching an overall peak in the 80-84 age group for both men and women. Incidence rates are higher for males than females for almost all age groups, though the sex ratios vary between age groups.(8)

In England in 2013, around 60% of males diagnosed with Non Hodgkin lymphoma were aged 65 and over with only around 1 in 7 (14%) of men being under 50. For women, around 66% of those newly diagnosed were over 65 and 12% of women being under 50.(8)

Social background

For most cancers, survival is worse for deprived groups and this gap has tended to increase as survival rates have increased overall. Non- Hodgkin lymphoma incidence does not show an association with measures of social class, such as area-based deprivation. These results are perhaps unsurprising since there are no known causal links between deprivation and Non-Hodgkin lymphoma.(11)

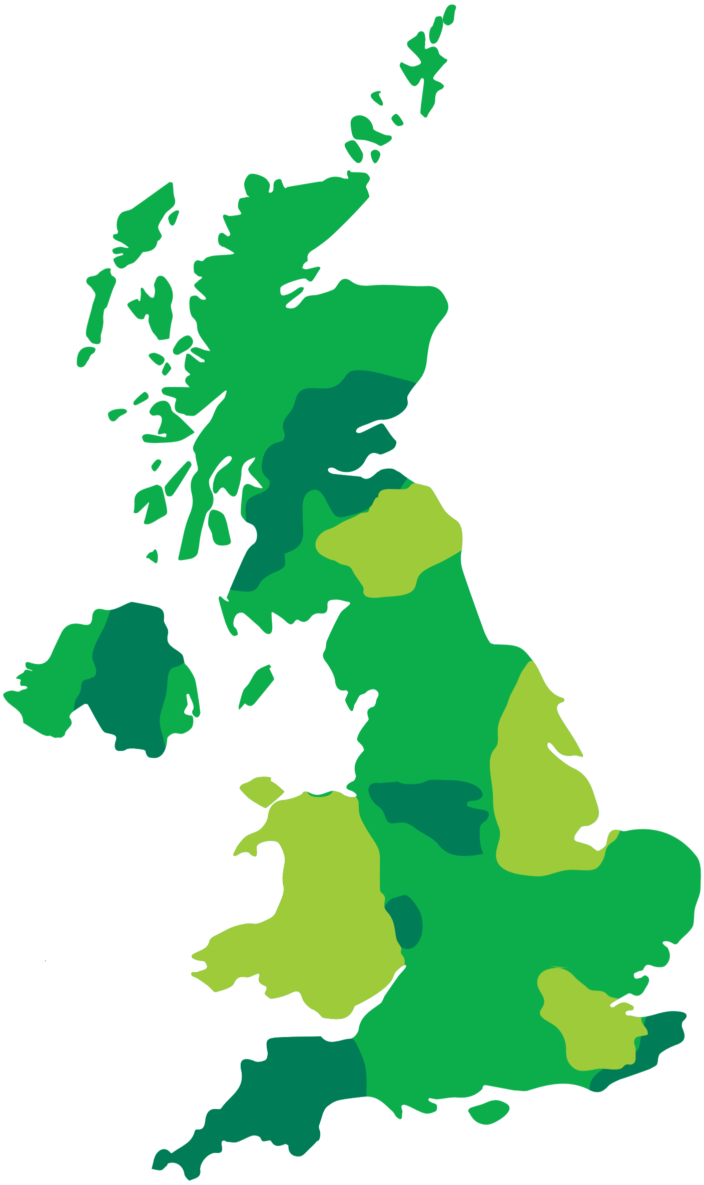
What are the geographical 'hotspots' for non Hodgkin lymphoma incidence, mortality and survival? (17)



Non-Hodgkin lymphoma incidence, UK, 2008-2010

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

Non-Hodgkin lymphoma incidence rates are generally higher in the South West and East of England, and lower in Northern England and Scotland.



Non-Hodgkin lymphoma mortality, UK, 2009-2011

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

Non-Hodgkin lymphoma mortality rates are generally higher in South West England and Northern Ireland, and lower in Wales.

What are the major trends?

Incidence

Non-Hodgkin lymphoma is the sixth most common cancer in the UK (2010). (5) (6) (7) (8)

Non-Hodgkin lymphoma incidence rates in Britain are more than two and a half times higher now than they were in the mid 1970s and incidence rates of non-Hodgkin lymphoma in people aged 50 and over have increased more than four-fold since the mid-1970s. (11)

Non-Hodgkin lymphoma incidence is strongly related to age, with the highest incidence rates being in older men and women. In the UK between 2008 and 2010, an average of 60% of cases were diagnosed in people aged 65 and over. (11)

For most patients, the cause of non-Hodgkin lymphoma is unknown, although a weakened immune system and previous cancer treatments, along with age and family history are thought to the strongest risk factors for developing non-Hodgkin lymphoma. (1)

Non-Hodgkin lymphoma mortality rates are decreasing…

After mortality rates peaked in 1990, from then on mortality rates have been decreasing.

In the UK between 2009 and 2011, an average of 54% of NHL deaths were in men and women aged 75 years and over, and around 1 in 20 were in people aged under 50. (12)

Survival rates are increasing…

Relative survival for non-Hodgkin lymphoma is improving. This can generally be attributed to faster diagnosis and improvements in treatment. (14)

These relatively high survival rates can be attributed in part to the effectiveness of chemotherapy against some subtypes, and the indolent nature of others. (14)

Non-Hodgkin lymphoma patients are now twice as likely to survive their disease for at least 10 years compared to those diagnosed in the early 1970s and half of all non-Hodgkin lymphoma patients will survive their disease for at least ten years. (14)

The five-year relative survival rates in NHL in men in England during 2005-2009 range from 80% in 15-39 year olds to 34% in 80-99 year olds. A similar pattern is seen in women with relative survival rates ranging from 82% in 15-39 year olds to 36% in 80-99 year olds. (14)

Contents

‘Some people describe feeling numb or disbelieving when they are diagnosed with cancer; I felt like I was in a bubble for several days. I then had a full-on two days of abject fear and then after meeting with the Consultant and Specialist Nurse I have moved forward with the treatment feeling completely confident.’

Paula, 41

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 non-Hodgkin lymphoma at these stages.

A typical 'cancer journey' showing four key stages:

1 Diagnosis

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

- People often **show signs and symptoms** that may be caused by cancer, and a GP can refer patients for tests to find out more.

- **Screening** aims to detect cancer at an early stage or find changes in cells which could become cancerous if not treated. However screening is not yet available routinely for non-Hodgkin lymphoma.

- 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 signs and symptoms of non-Hodgkin lymphoma?

The most common early symptoms are one or more painless swellings in the lymph nodes in one area of the body, such as:
- Neck
- Armpit
- Groin

There are other general symptoms such as:
- Heavy sweating at night
- Temperatures that come and go with no obvious cause
- Losing a lot of weight (more than one tenth of your total weight)

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

There is currently no data on how many cases of non-Hodgkin lymphoma are diagnosed early in the UK. Patients with non-Hodgkin lymphoma in the deeper lymph nodes often initially present with non-specific symptoms (such as abdominal discomfort or a persistent cough) which can be mistaken for common minor ailments, leading to potential delays in diagnosis. This is particularly the case where a lump is not palpable, for example where a lump is in the abdomen, pelvis or chest.

However, patients with all cancer types 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)

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

Low cancer awareness contributes to delay in presentation for cancer symptoms and may lead to delay in cancer diagnosis. (20)

How well does screening work for non-Hodgkin lymphoma?

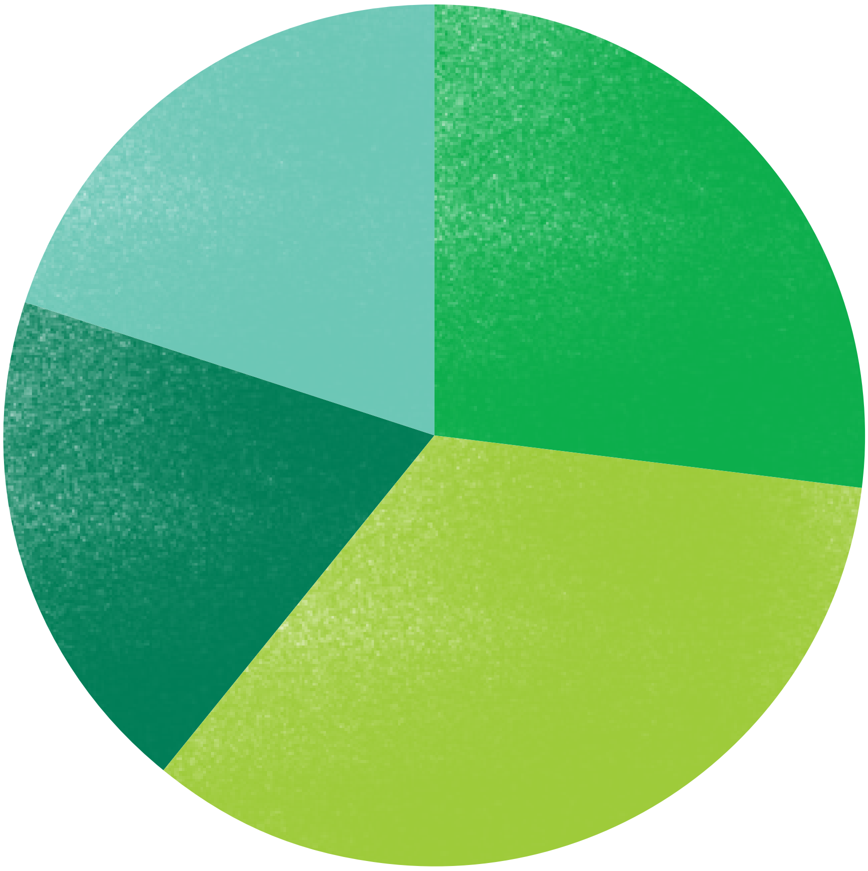
There are currently no screening programmes for non-Hodgkin lymphoma.

Contents

‘I’d been feeling very sluggish and had a lump by my ear. My GP sent me away with antibiotics. My wife wasn’t convinced and nagged me to return. I saw a different doctor, after feeling my neck, he instantly made an appointment with a haematological specialist, who correctly diagnosed non-Hodgkin lymphoma.’

Nick, 65

How is non-Hodgkin lymphoma diagnosed? (Routes to diagnosis)(18)



Emergency

27%

GP referral

34%

Two Week Wait

19%

Other

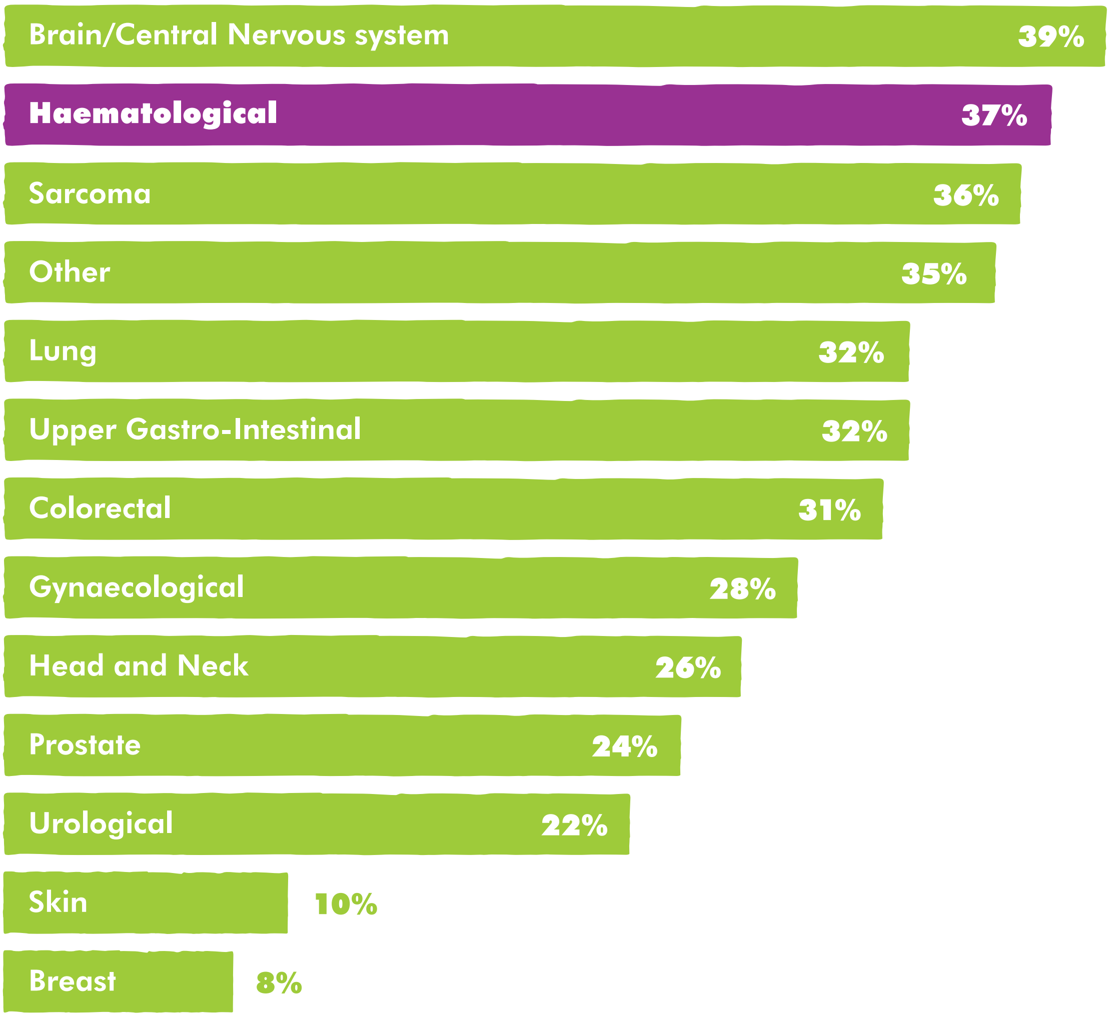
20%

'Other' includes 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.

27% of people newly diagnosed with non-Hodgkin lymphoma were diagnosed via the emergency route, this is higher than the average for all cancers (24%). This is indicative of higher rates of late presentation of signs and symptoms which often leads to poor prognosis.

How many non-Hodgkin lymphoma patients had to see their GP more than twice before they were diagnosed?(21)



37% of people newly diagnosed with haematological cancers (which includes non-Hodgkin lymphoma) 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? (23)

The impact of stage at diagnosis on 5 year survival – follicular non-Hodgkin lymphoma

There are 4 stages of non-Hodgkin lymphoma:

Stage 1 – the patient has one group of lymph nodes affected or lymphoma just in one organ of the body.

Stage 2 – the patient has two or more groups of lymph nodes affected. They are on the same side of your diaphragm.

Stage 3 – the patient has lymph nodes affected on both sides of the diaphragm.

Stage 4 – the patient's lymphoma has spread outside the lymph nodes, for example, to the liver, bones or lungs. (22)

The later the stage at diagnosis, the poorer the chances of survival. For example, the 5-year survival rate for follicular lymphoma diagnosed at stage 1 is 91% yet this falls to 79% at stages 3 and 4; in other words early diagnosis and treatment of non-Hodgkin lymphoma saves lives.(23)

Contents

How long do people with non-Hodgkin lymphoma have to wait to be referred? (24)

According to recent data, nearly 95% of patients with suspected cancer (not just non-Hodgkin lymphoma) were seen by a specialist within 2 weeks of referral.

PHYSICAL AND MEDICAL NEEDS

Lymphoma sub-type is a major factor determining the rate of progress from presentation to the start of treatment. Patients with Hodgkin lymphoma tend to be younger, more likely to receive urgent referral and have a diagnosis made from neck node biopsy than those with non-Hodgkin lymphoma. Patients with non-Hodgkin lymphoma however, have the shortest interval between presentation and the start of treatment. (25)

32% of people with haematological cancers (which includes non-Hodgkin lymphoma patients) felt that **their health worsened in the time that they waited for their first hospital appointment.** This is compared to 6% of breast cancer patients. (26)

FINANCIAL NEEDS

92% of people diagnosed with lymphoma, leukaemia or myeloma are exposed **some degree of negative financial impact** as a result of their diagnosis. (97)

People who have indolent (low grade or non-aggressive) non-Hodgkin lymphoma **may not begin treatment immediately,** but many are still **unable to continue employment** following diagnosis, need to miss days from work, or impose a significant burden on caregivers. The greatest impact on activity is apparent in patients who rate their health status as poor and in those who receive systemic therapy. (28)

Not specific to people with non-Hodgkin lymphoma

88% of cancer patients suffer **loss of income and/or increased costs** as a direct result of their cancer diagnosis. (27)

It is estimated that **30% of people with cancer experience a loss of income as a result of their cancer,** with those affected losing, on average **£860 a month.** Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families. (27)

PRACTICAL AND INFORMATION NEEDS

Patients who are newly diagnosed with lymphoma (of both the non-Hodgkin and Hodgkin sub-types) **report an extremely wide range of symptoms which are not always interpreted as serious or potentially caused by cancer.** This, in association with a clear lack of knowledge about lymphoma, often led to help seeking being deferred. Therefore, if more information is available about non-Hodgkin lymphoma and its symptoms, there could be more early diagnoses. **(31)**

Only **58% of people with haematological cancers** (which includes non-Hodgkin lymphoma) felt that they **fully understood the explanation of what was wrong with them.** This is the lowest of any cancer group and is noticeably smaller than skin cancer, which had the highest percentage of patients understanding their diagnosis (81%). **(33)**

Not specific to people with non-Hodgkin lymphoma

16% of people with cancer **do not receive any information about their condition** and **43%** would like to receive more. **(29)**

The strongest preference for information at diagnosis is information about prognosis. However, there are also many other information needs such as side effects of treatment, impact on family and friends, altered body image, self care and risks of family developing the disease. **(30)**

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Patients with non-Hodgkin lymphoma **need tailored information** to deal with the uncertainty of their situation at key points during their pre-diagnosis journey. This is especially because **they can have diverse symptom presentation over long periods of time, which may lead to greater uncertainty and anxiety. (34)**

Not specific to people with non-Hodgkin lymphoma

Of the half of cancer patients of all cancer types who want information, advice and support about the emotional aspects of cancer, **41% are not able to get it. (29)**

75% of people with **cancer experience** anxiety as a result of their cancer diagnosis. Anxiety is more common among women than men (79% of women compared with 66% of men). **(29)**

56% of cancer patients who experience anxiety **do not receive information, advice, support or treatment** for this. **(29)**

NEEDS AND EXPERIENCES
TREATMENT

What treatments do non-Hodgkin lymphoma patients get? (35)

Surgery

Surgery is rarely used to treat non-Hodgkin lymphoma as most people need a treatment that can work in several areas of their body at once, such as chemotherapy.

If the lymphoma is in just one part of the body, it may be treated with an operation. There seems to be a lack of overall data on the proportion of patients who have a surgical intervention for non-Hodgkin lymphoma.

Watch and wait

Some types of non-Hodgkin lymphoma grow very slowly and may not cause troublesome symptoms for a long time. Because of this, some people do not need to start treatment straight away. Instead, they see their specialist for regular check-ups and only begin treatment if they develop troublesome symptoms. This approach is called 'watch and wait' or active surveillance.

Chemotherapy

Chemotherapy, a combination of anti-cancer drugs, is the main form of treatment for non-Hodgkin lymphoma. These drugs need to be taken in a precise sequence, called a protocol, to have the best effect. Patients may be given different protocols according to the type and stage of their lymphoma.

Radiotherapy

Radiotherapy is sometimes used on its own, or with chemotherapy, to treat patients with early stage non-Hodgkin lymphoma. Radiotherapy is an intensive form of treatment that uses high-energy rays to kill cancer cells. Non-Hodgkin lymphoma accounts for around 4% of all radiotherapy episodes in England (2009-2010). There were 5,811 radiotherapy episodes and 52,621 radiotherapy attendances for haematological cancers. (36)

Monoclonal antibodies

Monoclonal antibodies are a relatively non-toxic form of treatment that target the cancer cells directly. They work by attaching to and 'labelling' cancer cells so that they are recognised and destroyed by the patient's own immune system. Most patients with B-cell non-Hodgkin lymphoma are treated with a drug combination plus a monoclonal antibody called rituximab. Rituximab binds to a target which is only found on B-cells so it cannot be used for other types of lymphoma.

Stem cell transplant

Stem cell transplant is an intensive form of treatment and is only feasible for patients who are in good general health and whose lymphoma is difficult to treat with chemotherapy alone. This includes some patients with indolent lymphoma and those whose disease has come back after treatment.

How many non-Hodgkin lymphoma admissions are there and how many non-Hodgkin lymphoma patients stay in hospital (and for how long)?

Those who are newly diagnosed or near end of life are much more likely to spend time in hospital. (37)

In total, there were over 90,960 admissions to NHS hospitals in England (emergency and non-emergency) for non-Hodgkin lymphoma during 2012–13.

The median length of stay for:
- Diffuse non-Hodgkin lymphoma patients who were admitted was 5 days in 2012–13.
- Follicular non-Hodgkin lymphoma patients who were admitted was 1 day in 2012–13.(38)

What can a person with non-Hodgkin lymphoma expect, therefore, from a typical treatment regime? (39)

Treatment options for a non-Hodgkin lymphoma patient would depend upon the type of lymphoma that the patient has and whether it is an aggressive high-grade lymphoma (diffuse) or an indolent low-grade lymphoma (follicular).

The most common treatment for early-stage indolent lymphoma is radiotherapy to the affected lymph nodes. This usually makes the lymphoma disappear completely and many people are cured. If the lymphoma comes back, it can be treated with chemotherapy and can often be controlled for many years. Indolent lymphoma is often very slow-growing, so some people do not need to start treatment straight away and a process of ‘watch and wait’ is undertaken. This avoids the inconvenience and side effects of treatment until it is really needed.

For a more advanced indolent lymphoma, the most likely treatment is chemotherapy, either on its own or with a monoclonal antibody. After the lymphoma has gone into remission, some people have a further course of treatment with a monoclonal antibody. This is called maintenance treatment.

Aggressive lymphomas however, are usually fast-growing and need treatment soon after diagnosis. The most common treatment is chemotherapy given into a vein. This is often given in combination with a monoclonal antibody. Most people have their treatment as outpatients.

Radiotherapy can sometimes be used after chemotherapy, especially if the lymphoma is in just one area of the body, or if the lymph nodes were very enlarged (bulky) before chemotherapy was given.

Some types of aggressive lymphoma may spread to the brain. If there is lymphoma in the brain or a high risk of it spreading there, the patient may be given additional treatments. These may include having chemotherapy directly into the fluid in the spine (intrathecal chemotherapy) or having chemotherapy to treat the lymphoma in the brain.

How many haematological nurses are there?

Non-Hodgkin lymphoma is a haematological cancer. There are currently **230 haematological nurses in England.** These nurses specialise in leukaemia and Hodgkin and non-Hodgkin lymphoma. This makes up 10% of all Clinical Nurse Specialists (CNSs) in England. (40)

Macmillan's internal data suggests that we had (as of July 2014) **128 haematology cancer nurse posts** across the UK. (41)

85% of people with haematological cancers were given the name of a Clinical Nurse Specialists who would be in charge of their care. This is compared to 93% of people with breast cancer. (42)

What does this mean for patients?

There are many different types of non-Hodgkin lymphoma, and Clinical Nurse Specialists play an important role in the **education of patients** regarding the type of lymphoma they have and the steps necessary to make an accurate diagnosis, which is important in determining the appropriate treatment. (43)

Clinical Nurse Specialists can also help with the non-Hodgkin lymphoma specific **side effects** which may result from treatment, such as weight loss and night sweats. (44)

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

Non-Hodgkin lymphoma is one of the diseases considered to **define the transition from being infected with HIV to having AIDS.** The increased risk of non-Hodgkin lymphoma in people with HIV is probably a consequence of immuno-suppression. (45)

HIV-related lymphomas tend to be more aggressive than lymphomas in people who are HIV negative and HIV-infected patients tend to have a worse overall quality of life and chance of survival than uninfected patients. However, research has shown that treatment for HIV (HAART) has helped improve survival in people with HIV-related lymphomas. (1) (46)

Immuno-suppressed patients develop non-Hodgkin lymphoma at a much higher rate than the general population. Although still uncommon, non-Hodgkin lymphoma is seen significantly more often in patients who are receiving drugs to prevent rejection of a transplanted organ. (45)

Several other autoimmune disorders, including rheumatoid arthritis, Sjogren's syndrome (which causes dry eyes and a dry mouth), and Hashimoto's thyroiditis (which causes inflammation of the thyroid gland) can increase the risk of developing non-Hodgkin lymphoma.(1)

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**

‘The way the medical team handled everything gave me great confidence. I was quickly given chemotherapy followed by radiotherapy and I am now on a two year maintenance programme – rituximab.’

Oliver, 77

PHYSICAL AND MEDICAL NEEDS

Lymphoma is the most common cancer among adolescents, and around 33% of such cancers are non-Hodgkin lymphomas. However, sometimes the needs of patients are unmet because adolescent lymphoma often shares features with both childhood and adult lymphoma. As medical oncologists and paediatric oncologists often follow divergent treatment plans, **disagreements may arise between doctors as to how best treat the adolescent group, resulting in complications within treatment plans.** (47)

During chemotherapy for non-Hodgkin lymphoma among elderly patients, **physical functioning and quality of life deteriorate and fatigue increases in groups with a poor prognosis,** whereas quality of life in those with earlier detection remains stable. During follow-up, quality of life is significantly better for patients in complete response or partial remission than for patients with a progression or relapse. (49)

FINANCIAL NEEDS

Not specific to people with non-Hodgkin lymphoma

Many cancer patients experience **extra costs due to treatment.** Low income, younger age, chemotherapy and living rurally can lead to greater financial hardship. (50)

Additional costs caused by cancer treatment include fuel charges which arise from transporting cancer patients and their carers to hospital. The average number of trips is 53 at a cost of £325 in 2006 prices. (51)

In a recent survey of carers for haematological cancer patients (including people with non-Hodgkin lymphoma) **46% of carers reported having at least one personal expense and 52% experienced at least one financial impact.** Male carers and carers of patients undergoing active treatment had the most significant personal expenses. (52)

46% of patients with haematological cancer (including people with non-Hodgkin lymphoma) **were not given information about how to get financial help or benefits** by hospital staff. This is compared to 30% of lung cancer patients. (53)

PRACTICAL AND INFORMATION NEEDS

When asked about the process of being given information regarding their illness and treatment, patients with haematological cancers (including non-Hodgkin lymphoma) stated that the areas most in need of improvement were the **amount of emphasis placed on their illness journey, the doctor's ability to adapt to their emotional needs, language used, information leaflets and personalising the approach used.** (55)

25% of people with haematological cancers (including non-Hodgkin lymphoma) were **given conflicting information** whilst in hospital. (56)

18% of people with haematological cancers (including non-Hodgkin lymphoma) were **not given a choice of different types of cancer treatment before their treatment started** and 20% were not given easy to understand written information about the side effects of treatment. (98)

Not specific to people with non-Hodgkin lymphoma

10% of people with cancer (not just those with non-Hodgkin lymphoma) **were not given enough information** about their condition and treatment. (54)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

73% of people living with haematological cancers (including non-Hodgkin lymphoma) felt that they **received enough emotional support from hospital staff** during their treatment. (58)

Not specific to people with non-Hodgkin lymphoma

Amongst all cancer patients the **overall prevalence of psychological distress is 25%** among those who are undergoing, or have just finished, cancer treatment. (57)

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

Why are cancer survivors (all cancer survivors; not just non-Hodgkin lymphoma 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. (102)
- **94%** experience **physical health condition** problems in their first year after treatment. (61)
- **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. (61)
- **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. (61)
- **40%** with **emotional difficulties** had not **sought medical help or other support**. (101)
- **23%** lack **support from friends and family during treatment** and recovery. (100)
- 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**. (100)

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. (96)
- Currently only **25%** of cancer patients are receiving a holistic needs assessment and a care plan – both of these are essential in providing personalised care for cancer patients and their carers. (96)

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

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

Contents

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

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

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

Further key interventions include:

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

PHYSICAL AND MEDICAL NEEDS

Most people living with non-Hodgkin lymphoma can participate in sexual activity after treatment; however, **more than half are dissatisfied with their sex life.** (59)

Among people with non-Hodgkin lymphoma who **do not meet public exercise guidelines** quality of life is relatively low, but improves with increased physical activity. (60)

A recent Norwegian study has suggested that around **35% of people who had childhood lymphoma** (including both the Hodgkin and non-Hodgkin forms of the disease) **experience side effects as adults,** eg infertility, heart-problems, impaired dental status, hypothyroidism, breast cancer, reduced muscle growth, fatigue and reduced memory or concentration. (62)

There are **variations in the physical needs of people living with different types of non-Hodgkin lymphoma.** Physical function in survivors of indolent (non-aggressive) non-Hodgkin lymphoma is significantly better than that in survivors of aggressive non-Hodgkin lymphoma. (63)

Not specific to people with non-Hodgkin lymphoma

However, **33% of all people living with cancer** (not just non-Hodgkin lymphoma) find **participation in vigorous activities very difficult** or report not being able to do them at all. (61)

FINANCIAL NEEDS

People who are living with non-Hodgkin lymphoma are most likely to show **problems in physical functioning, appetite loss, vitality** and **financial problems.** This shows that behind the physical symptoms caused by cancer and its treatment, financial issues are deemed to be the most important problem that non-Hodgkin lymphoma can cause. (65)

Among people living with non-Hodgkin lymphoma who **were involved in a recent Dutch study (2007), 41%** reported **problems with work, 15%** with obtaining **life insurance** and **22%** with obtaining a **mortgage.** (66)

Not specific to people with non-Hodgkin lymphoma

Among cancer patients the **main barrier to accessing benefits is a lack of knowledge about benefit entitlement.** (64)

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. (27)

There is also a lack of support for cancer patients who wish to remain in or return to work. Research has shown less than 2% of people with cancer (roughly 40,000) access specialist return-to-work services. (104)

PRACTICAL AND INFORMATION NEEDS

35% of patients with haematological cancers (which includes non-Hodgkin lymphoma) **have had to wait more than 30 minutes for a scheduled outpatient appointment** to begin. This is compared to 23% of urological cancer patients. (67)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

An American study has shown that around 37% of people living with non-Hodgkin lymphoma experience persistent or worsening symptoms of **post traumatic stress disorder.** The average time since treatment had ended for the participants in this study was 13 years. (69)

People living with non-Hodgkin lymphoma who experience **negative feelings about their health and treatment intensity** tend to report **worse physical and mental health** than those who do not. After controlling for demographic and clinical characteristics, younger patients report better physical health but poorer mental health and quality of life. (70)

Not specific to people with non-Hodgkin lymphoma

23% of all cancer survivors report **poor emotional well being.** (61)

Many cancer outpatients (not just those with non-Hodgkin lymphoma) feel that their **information needs are not being met.** The most common areas of complaint are the lack of genetic information and information about lifestyle changes, and help with worries about spread or recurrence. (68)

NEEDS AND EXPERIENCES

PROGRESSIVE ILLNESS AND END OF LIFE

What health data do we have on non Hodgkin lymphoma 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. (71)

Non-Hodgkin lymphoma is slightly more common in people who have been treated for cancer before. Treatment with radiotherapy, or with some chemotherapy drugs, can increase a person's risk of developing non-Hodgkin lymphoma many years later. However, the risk is very small compared to the benefit of having the treatment in the first place. (1)

Palliative care for non-Hodgkin lymphoma is likely to include either chemotherapy or low dose radiotherapy. In 2011 an American study demonstrated that more than 80% of patients who receive such palliative radiotherapy have consistently reported local control of lymphoma for at least 2 years. (72)

How many non Hodgkin lymphoma patients are at the end of life?

There is currently no specific data on how many non-Hodgkin lymphoma patients are at end of life.

What is the impact of giving people palliative care?

Palliative treatment is important for all patients with untreatable disease. Pain relief forms a central part of palliative care. (105)

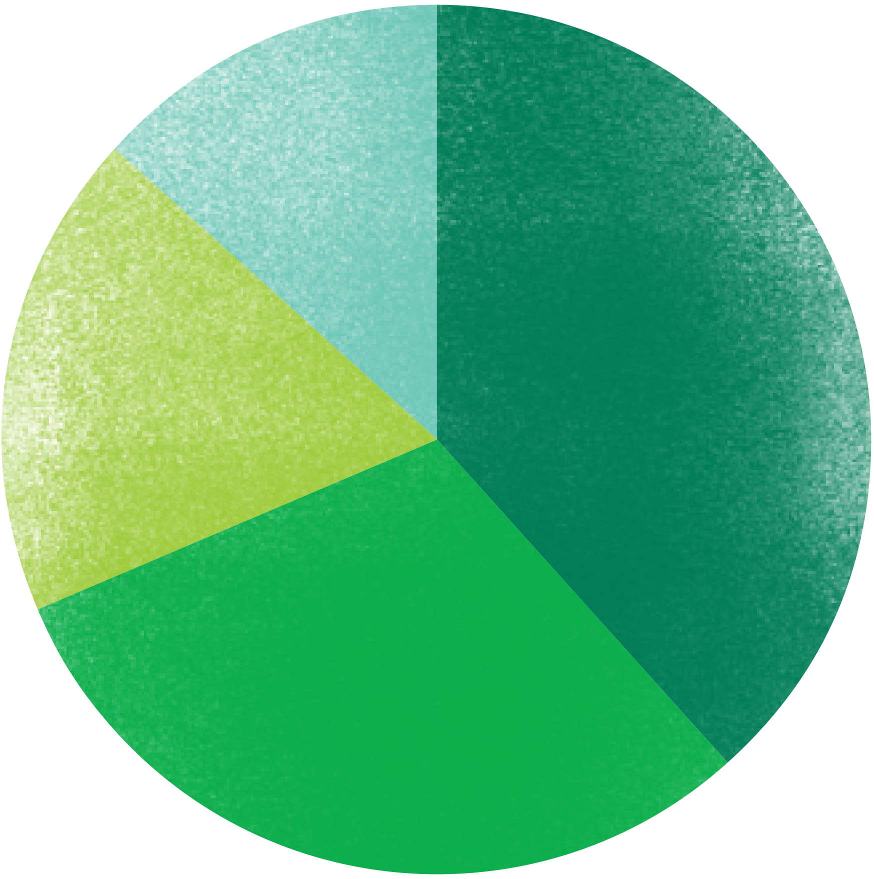
Palliative care is increasingly playing a vital role in the oncology population. Palliative care entails an expert and active assessment, evaluation and treatment of the physical, psychological, social and spiritual needs of patients and families with serious illnesses. It provides an added layer of support to the patient's regular medical care. (106)

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. (107)

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.

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

Where do people with cancer die? (75)



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 non-Hodgkin lymphoma patients die in the place of choice?(76).

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.(103)

However, only 30% of those who die from cancer actually die at their home or own residence.(9)

‘I had radiotherapy and chemotherapy treatment. Now, I’ve been told they can do no more for me.’

Jack, 65

PHYSICAL AND MEDICAL NEEDS

Patients with haematological cancers (including non-Hodgkin lymphoma) are **less likely to receive care from specialist palliative or hospice services** compared to other cancers. There are several possible explanations for this finding, including: ongoing management by the haematology team and consequent strong bonds between staff and patients; uncertain transitions to a palliative approach to care; and sudden transitions, leaving little time for palliative input. (78)

Not specific to people with non-Hodgkin lymphoma

457,000 people need good palliative care services every year in England, but around **92,000 people are not being reached.** (77)

Various symptoms are very common in advanced cancer, with **patients having a median of 11 symptoms on admission to palliative care.** (79)

More than one-quarter of patients with all forms of cancer **experience serious pain 3 to 6 months before death and more than 40% were in serious pain during their last 3 days of life.** (80)

Amongst carers who have supported someone with cancer in the last 12 months, 27% are no longer providing this care because the person has since died – from this we estimate there are around **2.1 million people in the UK who have cared for someone with cancer in the last 12 months who are now bereaved.** (81)

FINANCIAL NEEDS

Not specific to people with non-Hodgkin lymphoma

In 2010 Macmillan reported that **36% of terminally ill cancer patients did not claim benefits they were entitled to. This amounts to £90m.** Reasons for low take-up included people not knowing they were eligible, the perceived stigma and the confusing claiming process. (82)

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. (83)

The **widow's or survivor's pension** payable on a spouse's previous employment is around **70% of the amount payable when the spouse was still alive.** (85)

A study on the financial impact of a death of a partner has revealed that on average, **widows' incomes fell to around 61% of their previous incomes,** compared with a drop to 74% of pre-bereavement incomes for widowers. (85)

PRACTICAL AND INFORMATION NEEDS

Not specific to people with non-Hodgkin lymphoma

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. (86)

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.** (87)

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Not specific to people with non-Hodgkin lymphoma

Cancer patients approaching death suffer increasing **psychological distress.** (57)

Amongst all cancer patients the **overall prevalence of psychological distress is 59% amongst those receiving palliative care.** (57)

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. (88)

A survey by Macmillan of people who have received a cancer diagnosis found that **57% would like to spend the last weeks and days of their life at home.** This rose to 73% if all their concerns, which included access to round the clock care, about dying at home were addressed. Only 1% of respondents would choose to die in hospital. (76)

Adolescents with haematological cancers are **more likely to die in an intensive care unit** than those with other cancers and end of life discussions are more likely to occur in the last 7 days of life, allowing **very little time to psychologically prepare for death.** (89)

LIFESTYLE AND PERCEPTIONS

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

What is the profile of the average person living with non-Hodgkin lymphoma?

- Incidence rates for non-Hodgkin lymphomas are marginally higher for males than for females. (5)
- Non-Hodgkin lymphoma incidence is strongly related to age, with the highest incidence rates being in older patients. (11)
- However, lymphomas are a common cancer amongst the relatively small number of adolescents who are diagnosed with cancer. (47)

What is the demographic breakdown/ market segmentation of the 76,840 non-Hodgkin lymphoma patients? (3)

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

Amongst non-Hodgkin lymphoma patients, the following MOSAIC* groups show significantly greater than average representation:

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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.

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.

What are the typical leisure activities/ where they shop/what media they consume/what they do? (95)

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

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

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

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What are people living with non-Hodgkin lymphoma saying about their experiences, in their own words? (94)

‘I found a lump in my groin and my GP referred me to a surgeon who removed the lymph node. The biopsy showed this to be a follicular lymphoma.’

Christopher, 77

‘When you don’t know anything it’s very scary. You feel like you have no control over your life.’

Julie, 52

‘My Macmillan nurse is brilliant. When she saw our financial difficulties she got someone to help us fill in a benefits form, and explain what we were entitled to.’

Joe, 66

‘The treatment I received was six cycles of CHOP chemotherapy followed by high dose chemotherapy and a stem cell transplant. I found that with the last two or three cycles I was very shivery after my treatment and found it quite difficult to get warm.’

Nancy, 61

‘I put on a lot of weight and all of a sudden I had no hair or eye brows and felt like I had lost control.’

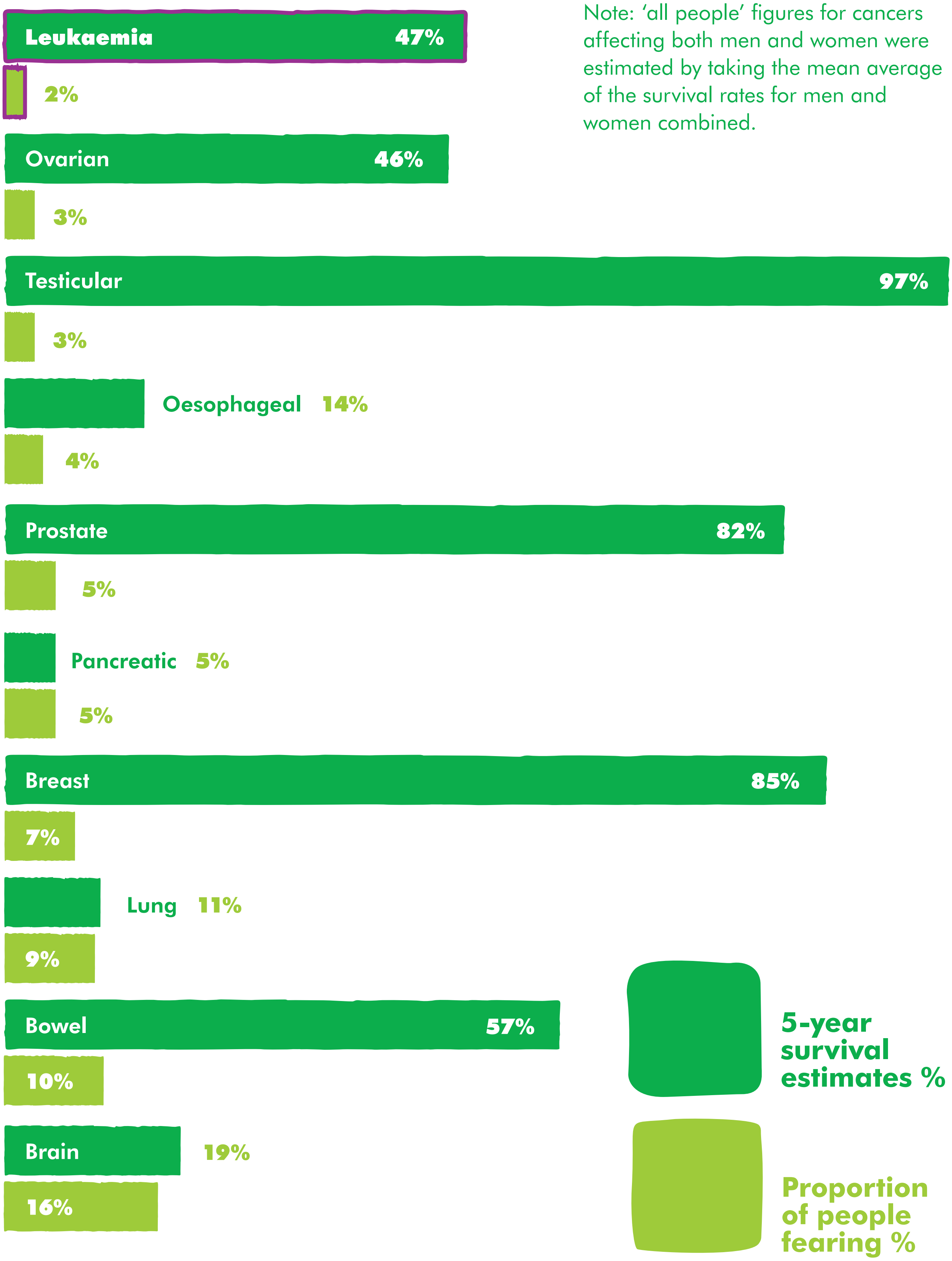
Lucy, 62

‘I was put on chemo tablets for 6 months but, on advice, continued them for 11 months. Three weeks after I came off them, my stomach swelled, it looked like I was carrying twins, and I’d put a stone on.’

Laura, 65

How does people's fear of haematological cancers (eg leukaemia, non-Hodgkin lymphoma) compare to actual survival rates? (90) (91)

Note: 'all people' figures for cancers affecting both men and women were estimated by taking the mean average of the survival rates for men and women combined.



Fear of leukaemia is low which is relatively surprising as the 5-year survival rates are 47% for men and women. 5-year survival for non-Hodgkin lymphoma is higher, at 62% for men and 69% for women.

This suggests that little is known about haematological cancers publicly, especially when compared with breast cancer which receives a lot of media attention and as such there is a strong public awareness of it which leads to increased fear.*

*Data for non-Hodgkin lymphoma was not included in this research, however leukaemia (a different haematological cancer) was included, so we have commented on this in place of being able to comment specifically on non-Hodgkin lymphoma.

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What our non-Hodgkin lymphoma online Macmillan Community members are saying… (92)

How the media* portrays non-Hodgkin lymphoma… (93)

*UK national daily newspapers

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

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

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

- Non-Hodgkin lymphoma is not a particularly well known cancer, as such, there is much less media reporting about it in comparison to other well known cancers such as breast or lung cancer which have a much greater public awareness. As such the media tend to focus on individual stories, as seen by the references to 'mother', 'children', 'family' and 'parents'.

- Additionally, the terms 'husband' and 'kids' feature prominently in the online community discussions, probably referring to family members affected by non-Hodgkin lymphoma. The online community may include many relatives and partners who are carers, and rely on this community for support that is not readily available elsewhere.

- References to treatment and the subsequent results of treatment, both physically and emotionally, feature predominantly within the online community, emphasised by the terms 'advice', 'support' and 'cope', as those going through treatment use the community as a form of support and advice.

- The media however, tend to focus more upon the causes and diagnosis of cancer and those at risk, as opposed to the personal journey which the patients undertake, such as the emphasis upon 'risk', 'nuclear', and 'meat'.

- There is more technical terminology in the online discussions than in the media: 'R-DHAP', 'chemo', 'lymphoma', suggesting that those affected by cancer are sufficiently knowledgeable to be comfortable with such terms. Terms in the media are simple, to reach a non-specialist audience.

- The terms 'positive', 'hope' and 'worry' in the online community discussions emphasise the emotional difficulties experienced by non-Hodgkin lymphoma patients. The media includes none of those types of words, focusing instead on the use of words such as, 'risk', 'died' and 'disease'.

REFERENCES,
SOURCES, NOTES AND CAVEATS

Quotes

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

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APPENDIX A
JARGON BUSTER

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

(i) Health data terms

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

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

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

Survival: When we talk about 'cancer survival' we mean the percentage of people who survive a certain type of cancer for a specified amount of time. Cancer statistics often use one-year or five-year survival rates. Relative survival (the standardised measure used) is a means of accounting for background mortality and can be interpreted as the survival from cancer in the absence of other causes of death. Survival rates do not specify whether cancer survivors are still undergoing treatment after the time period in question or whether they are cancer-free (in remission).

(ii) Other terms

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

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

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

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

Full suite of the Rich Pictures

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

Overarching Rich Picture

The Rich Picture on people with cancer	(MAC15069)

The Rich Pictures on cancer types

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

The Rich Pictures on age groups

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

Other Rich Pictures

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

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

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

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

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

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

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

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

Code: MAC13843_11_14

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