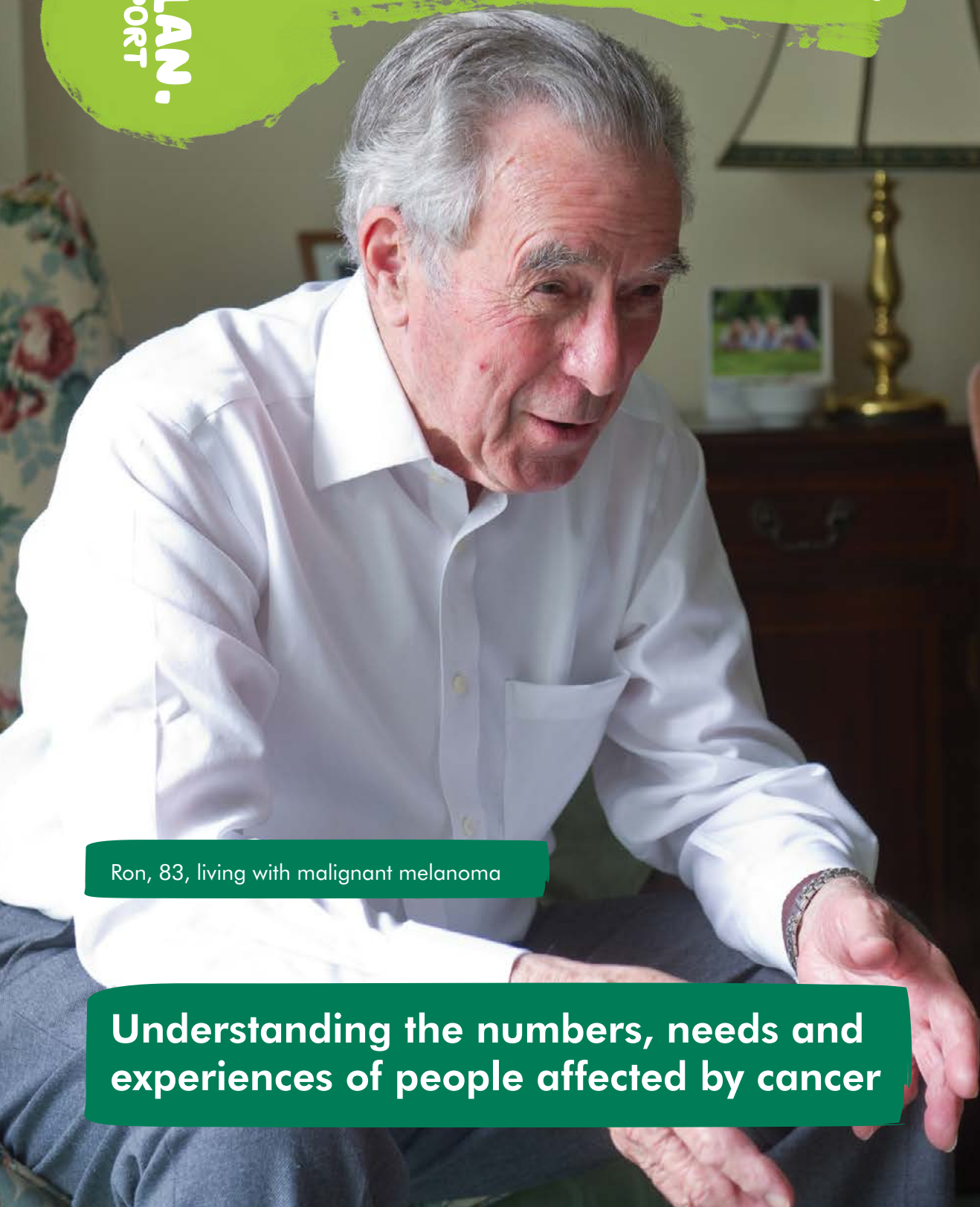


THE RICH PICTURE

**PEOPLE WITH
MALIGNANT
MELANOMA**

**WE ARE
MACMILLAN.
CANCER SUPPORT**



Ron, 83, living with malignant melanoma

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



About this 'Rich Picture'

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

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

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

The information could be valuable in many ways:

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

This document is not intended to

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

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

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

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

The legal bit

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

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

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

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



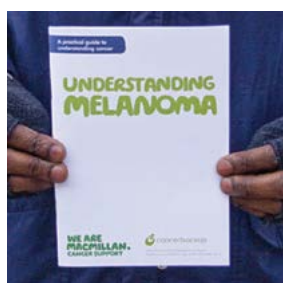
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Guidance on referencing this document

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

Other related information for people affected by cancer

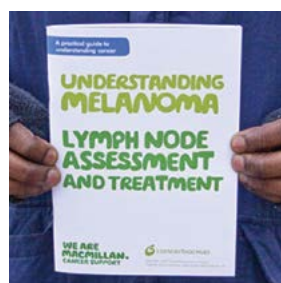
This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our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



Understanding Melanoma
MA12174



Understanding Melanoma – Adjuvant Treatments After Surgery
MAC12177



Understanding Melanoma – Lymph Node Assessment and Treatment
MAC11686



Understanding Melanoma – That Has Come Back in the Same Area
MAC12178

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

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

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

Case Study Library

People affected by cancer

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

Professionals/Services

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



Comms Platform

Describes how to communicate with people affected by cancer.



Rich Pictures

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



Impact Briefs

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



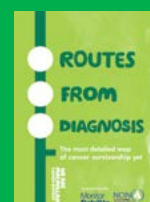
Local Cancer Intelligence

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



Routes from Diagnosis

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



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

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SUMMARY OF PEOPLE LIVING WITH MALIGNANT MELANOMA

Key stats

Malignant melanoma is the **fifth most commonly diagnosed cancer**, with around 37 people being diagnosed every day.^(6,7,8,9)

Around 110,330 people were living with malignant melanoma in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.⁽³⁾

Malignant melanoma is the eleventh most common cause of cancer death in the UK. Over **2,150 people die from malignant melanoma every year in the UK.**^{(8)(9)(10) (11)}

However, **86% of men and 92% of women live for more than five years** after their malignant melanoma diagnosis.⁽⁴⁾

Malignant melanoma is the fifth most common cancer in the UK.

Diagnosis

If a mole has turned to melanoma, **pain and itching may be experienced.**⁽²³⁾

Patient understanding and awareness of malignant melanoma is influenced by **personal, family and friends' experiences of melanoma and other cancers, and the media.**⁽²⁸⁾

48% of people diagnosed with malignant melanoma are **not given information on financial help or benefits** by hospital staff.⁽²⁵⁾

Women with malignant melanoma have reported **higher levels of anxiety, depression, tiredness and sleep disturbance** than men.⁽³²⁾

Pain and itching may be experienced by people who have been diagnosed with malignant melanoma.

Treatment

Melanomas are commonly treated with local surgery, known as a **wide local excision.**⁽³⁵⁾

Surgery for malignant melanoma **nearly always leaves some type of scar.**⁽⁴⁵⁾

25% of people with malignant melanoma are **not told about treatment side effects** in a way in which they can understand.⁽⁵⁰⁾

Travelling to and from frequent appointments is an **additional cost** for patients undergoing treatment. This affects **69%** of cancer patients and costs them, on average **£170 a month.**⁽⁹⁵⁾

Melanomas are often treated with surgery, which nearly always leaves a scar.

Survivorship

44% of people with malignant melanoma who want to know are **not told about free prescriptions.**⁽⁵⁴⁾

People who have had melanoma have an increased risk of developing a new melanoma. This **fear of recurrence may leave them with emotional and psychological needs.**⁽⁵⁸⁾

61% of people with malignant melanoma felt that they were **given enough care and help from health or social services** after their treatment was completed.⁽⁵³⁾

Psychological and social long-term side effects of cancer and its treatment include **depression, anxiety, problems with memory and concentration, lack of confidence, sexual problems and isolation.**⁽¹⁰⁷⁾

Patients with malignant melanoma have an increased risk of a cancer recurrence.

End of Life

Terminal cancer patients and their families often want information about how long they may have to live. However, **31% of doctors tend to over-estimate the survival times** of terminally ill cancer patients.⁽⁷⁵⁾

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.**⁽⁶⁹⁾

In 2010, **36% of people with a terminal cancer diagnosis did not claim the benefits they were automatically entitled to.** This amounts to over £90m.⁽⁷¹⁾

People with a terminal diagnosis who wish to travel **may have their travel insurance cover refused** by insurance companies.

92,000 people who require good palliative care are not being reached.

Lifestyle & perceptions

White people are significantly **more likely to get malignant melanoma** than people of other races. This difference is because the majority of malignant melanomas are caused by **heavy sun exposure in white-skinned populations.**⁽¹⁴⁾⁽³⁰⁾

Active elderly people living in pleasant retirement locations are well-represented amongst people being treated for malignant melanoma.⁽⁷⁸⁾

Media reports on malignant melanoma clearly focus on the causes of malignant melanoma. They frequently include words such as “sun bed”, “UVA” or “burn”.⁽⁸⁰⁾

INTRODUCTION TO MALIGNANT MELANOMA

What is malignant melanoma?⁽¹⁾

Melanoma is a cancer that usually starts in the skin, either in a mole or in normal looking skin. Although melanoma is a type of cancer of the skin, it is not exactly the same as skin cancer. The term 'skin cancer' can also refer to non-melanoma cancers including basal cell carcinoma and squamous cell carcinoma.

Malignant melanoma begins in the melanocyte cells, which are the cells that produce pigment. Non-melanoma skin cancers tend to start in the others cells which make up the epidermis (skin).

There are four main types of skin (cutaneous) melanoma:

- **Superficial spreading melanoma** is the most common type of skin melanoma. In women the most common place for it to start is on the legs; in men it's on the chest and the back. Usually the melanoma cells grow slowly at first, spreading out across the surface of the skin.
- **Nodular melanoma** is the second most common type. It can grow more quickly than other melanomas and is usually found on the chest, back, head or neck.
- **Lentigo maligna melanoma** is usually found in older people in areas of skin that have had a lot of exposure to the sun over many years (most often the face and neck). It develops from a slow-growing precancerous condition called a lentigo maligna or Hutchison's freckle, which looks like a stain on the skin.

- **Acral melanoma** is the rarest type and is usually found on the palms of the hands, soles of the feet, or under fingernails or toenails. It's more common in people with black or brown skin and isn't thought to be related to sun exposure.

Occasionally, melanoma can start in parts of the body other than the skin. It can start in the eye (ocular melanoma) or in the tissues that line the inside of the body, such as the nose, mouth, lung, and digestive tract (mucosal melanomas).⁽¹⁾

Most statistics in this rich picture refer to malignant melanoma. However for some data, where malignant melanoma data was not available, we have commented on skin cancer instead.

Want to know more

Macmillan produces a wealth of information about what malignant melanoma 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 noticed some rough dark skin on my right heel. I finally decided to see my doctor who immediately referred me to the skin clinic. A series of tests were carried out culminating in a biopsy, referral to a consultant and a diagnosis confirming a melanoma.

The melanoma was removed but a skin graft to cover the wound did not take. My treatment at the hospital was first class (and so was the food). I had a follow-up appointment for six months later when a large lump was discovered in the groin. My doctor arranged for me to attend The Royal Marsden. All of the concerns that have arisen from time to time have been addressed by the doctors and nurses there and I cannot speak highly enough of them, they have been fantastic.

I have been doubly lucky in having the support of my wife and a wonderful family. My grandchildren try to keep me up to date with social media and modern technology. I have a smartphone, all I have got to do is learn to use it! Very early advice given to me was 'take each day as it comes'. This was good advice. I am now 83, 58 years married, and looking forward to tomorrow.'

Ron, 83

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people with malignant melanoma.

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.⁽⁸³⁾

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

Around 110,330 people were living with malignant melanoma 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 malignant melanoma?

Macmillan is carrying out work internally to 'baseline' the 9 Outcomes, and we hope to be able to show how the 9 Outcomes vary for different groups. This document will be updated when this work is complete, and the information used to help focus our efforts to reach those most in need of our support.

The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

THE FACTS ON MALIGNANT MELANOMA*

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 66 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.

37

people are diagnosed with malignant melanoma every day^(6,7,8,9)

110,330

people were living with malignant melanoma in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.⁽³⁾

96%

of men and 98% of women live for more than one year after their malignant melanoma diagnosis⁽²⁾

86%

of men and 92% of women live for more than five years after their malignant melanoma diagnosis in England⁽²⁾

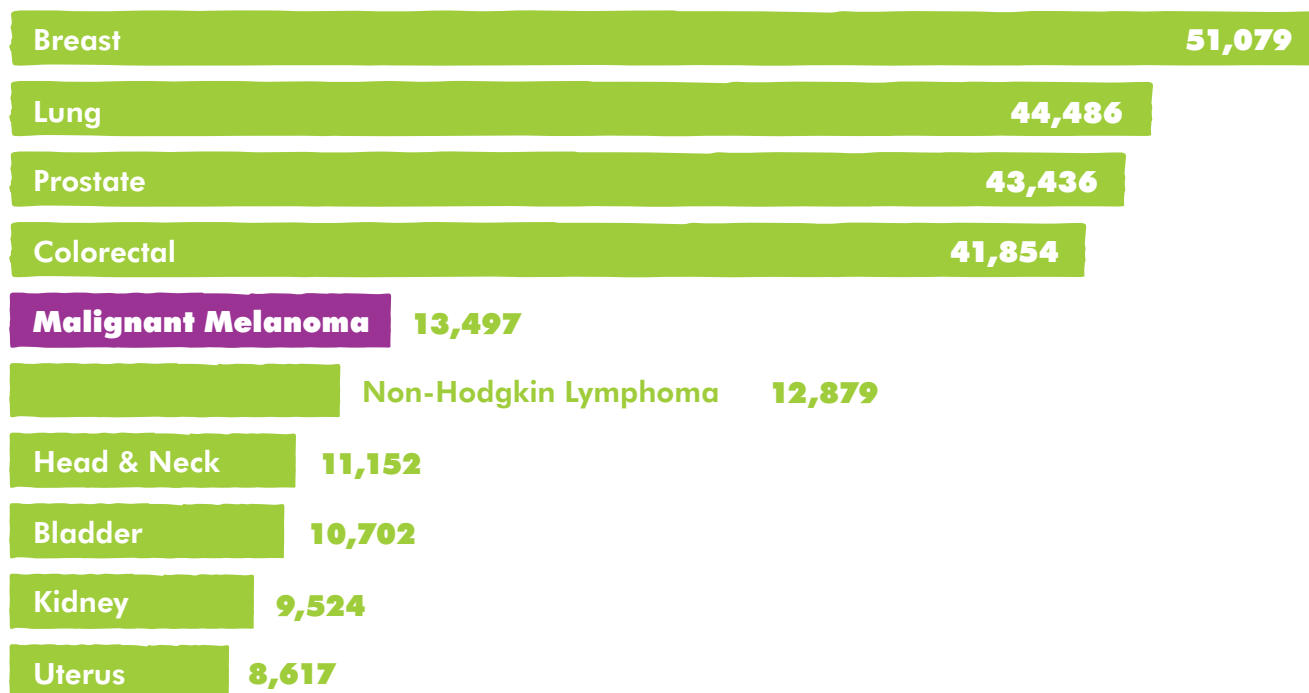
6

people die every day from malignant melanoma in the UK^(10,11,85)

* 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.

How many people get malignant melanoma per year? (incidence)^(6,7,8,9)

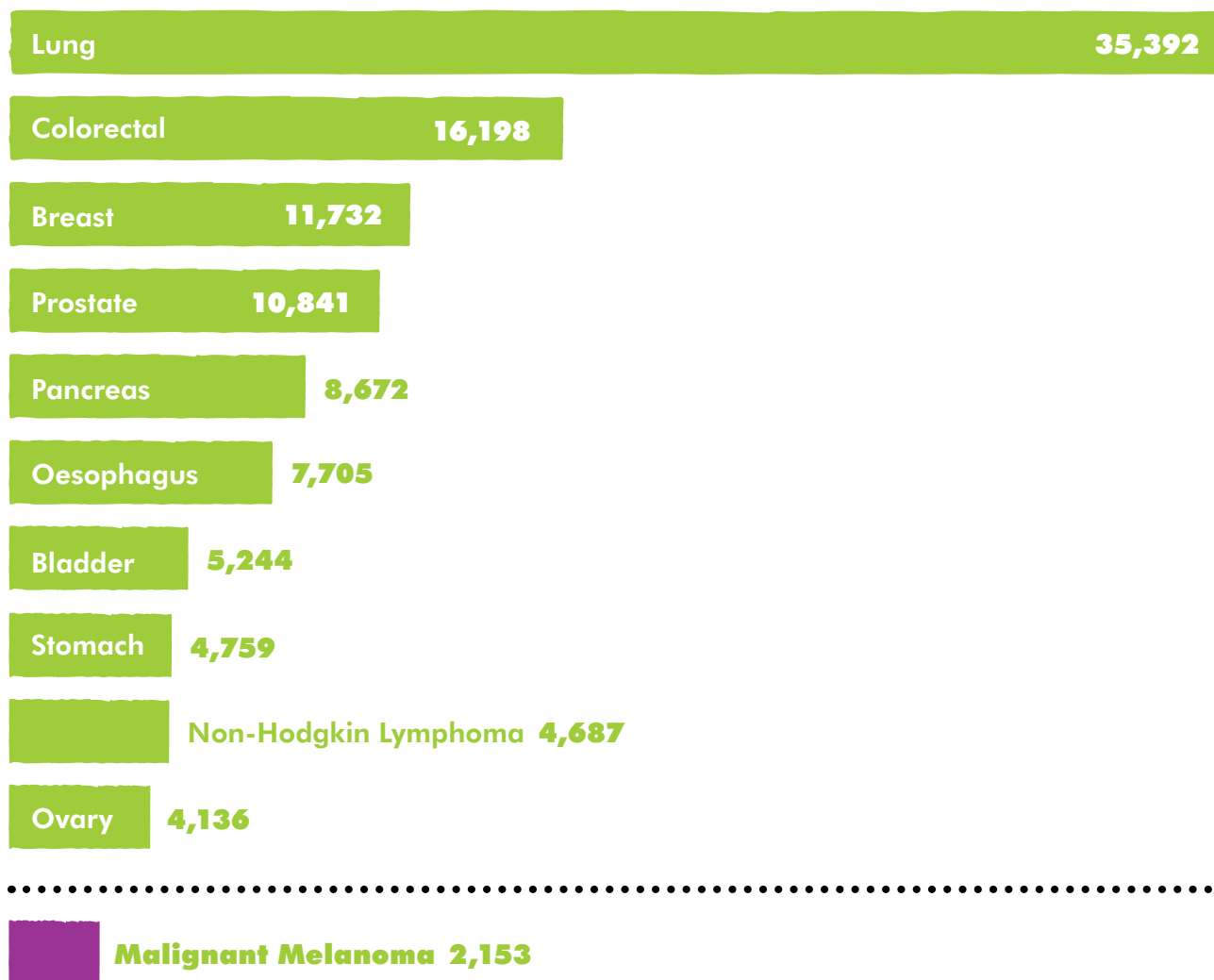
Cancer incidence, UK, 2012, top 10 cancer sites



Malignant melanoma is the fifth most commonly diagnosed cancer. Around 13,500 people are diagnosed every year in the UK; that's almost 37 people every day.

How many people die from malignant melanoma per year? (mortality)^(8,9,10,11)

Mortality, UK, 2012, top 10 cancer sites



Malignant melanoma is the twelfth most common cause of cancer death in the UK. 2,153 people die from malignant melanoma every year in the UK, which is around 6 people every day.

How many people are currently living with malignant melanoma? (prevalence)*⁽³⁾

People were living with malignant melanoma in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.

110,330

* 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.

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 malignant melanoma per year in England? (incidence)⁽⁶⁾

11,281

new cases of malignant melanoma diagnoses in England in 2012.

How many people die from malignant melanoma per year in England? (mortality)⁽¹⁰⁾

1,787

malignant melanoma deaths in England in 2012.

How many people are living with malignant melanoma in England? (prevalence)

Around 91,320

People were living with malignant melanoma in England in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).⁽³⁾

What is the age-standardised* rate of incidence of malignant melanoma cancer in women in England?⁽⁴⁾

17

new cases of malignant melanoma cancer diagnoses in England in 2012 per 100,000 heads of population.

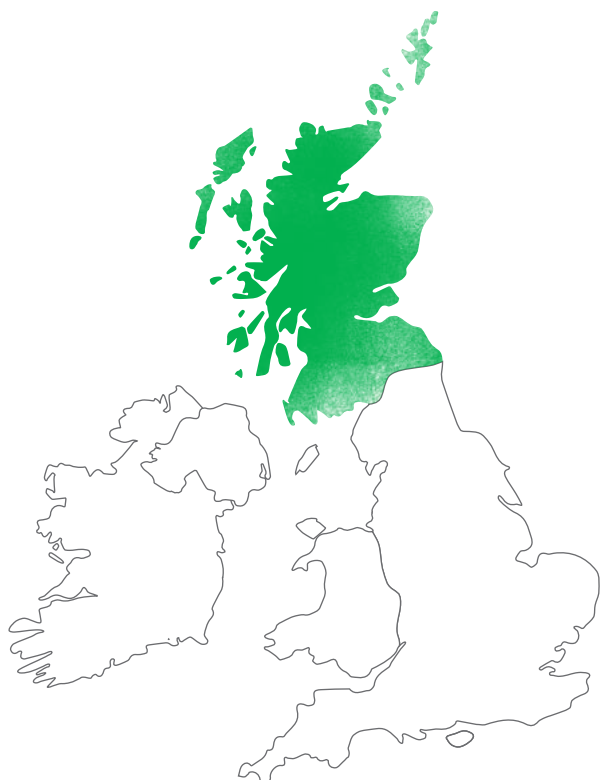
What is the age-standardised* rate of mortality from malignant melanoma cancer in women in England?⁽⁶⁾

3

cases of malignant melanoma cancer deaths in England in 2012 per 100,000 heads of population.

What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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

How many people get malignant melanoma per year in Scotland? (incidence)⁽⁸⁹⁾

1,177

new cases of malignant melanoma diagnoses in Scotland in 2012.

How many people die from malignant melanoma per year in Scotland? (mortality)⁽⁸⁶⁾

190

malignant melanoma deaths in Scotland in 2012.

How many people are living with malignant melanoma in Scotland? (prevalence)

Around 11,030

People were living with malignant melanoma in Scotland in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).⁽³⁾

What is the age-standardised* rate of incidence of malignant melanoma cancer in women in Scotland?⁽⁴⁾

18

new cases of malignant melanoma cancer diagnoses in Scotland in 2012 per 100,000 heads of population.

What is the age-standardised* rate of mortality from malignant melanoma cancer in women in Scotland?⁽⁶⁾

2

cases of malignant melanoma cancer deaths in Scotland in 2012 per 100,000 heads of population.

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



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

How many people get malignant melanoma per year in Wales? (incidence)⁽⁹⁰⁾

693

new cases of malignant melanoma diagnoses in Wales in 2012.

How many people die from malignant melanoma per year in Wales? (mortality)⁽⁹²⁾

133

malignant melanoma deaths in Wales in 2012.

How many people are living with malignant melanoma in Wales? (prevalence)

Around 5,120

People were living with malignant melanoma in Wales in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).⁽³⁾

What is the age-standardised* rate of incidence of malignant melanoma cancer in women in Wales?⁽⁴⁾

19

new cases of malignant melanoma cancer diagnoses in Wales in 2012 per 100,000 heads of population.

What is the age-standardised* rate of mortality from malignant melanoma cancer in women in Wales?⁽⁶⁾

3

cases of malignant melanoma cancer deaths in Wales in 2012 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 malignant melanoma per year in Northern Ireland? (incidence)⁽⁹¹⁾

346

new cases of malignant melanoma diagnoses in Northern Ireland in 2012.

How many people die from malignant melanoma per year in Northern Ireland? (mortality)⁽⁸⁵⁾

43

malignant melanoma deaths in Northern Ireland in 2012.

How many people are living with malignant melanoma in Northern Ireland? (prevalence)

Around 2,850

People were living with malignant melanoma in Northern Ireland in 2010, based on people living up to 20 years post a cancer diagnosis (1991 and 2010).⁽³⁾

What is the age-standardised* rate of incidence of malignant melanoma cancer in women in Northern Ireland?⁽⁴⁾

15

new cases of malignant melanoma cancer diagnoses in Northern Ireland in 2012 per 100,000 heads of population.

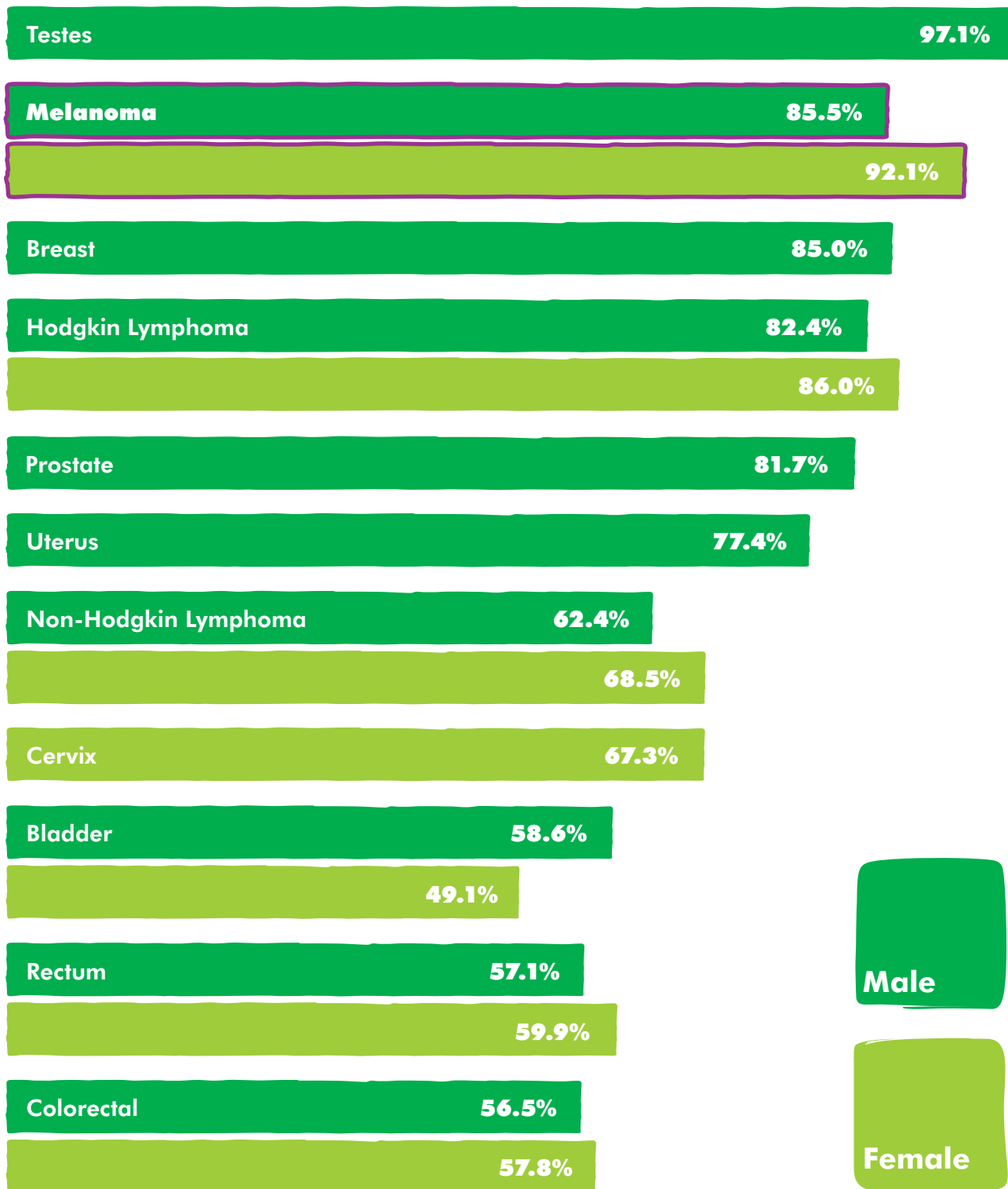
What is the age-standardised* rate of mortality from malignant melanoma cancer in women in Northern Ireland?⁽⁶⁾

2

cases of malignant melanoma cancer deaths in Northern Ireland in 2012 per 100,000 heads of population.

What proportion of people survive malignant melanoma? (survival)⁽²⁾

Relative 5 year survival estimates, 2007–2011, by gender, England.

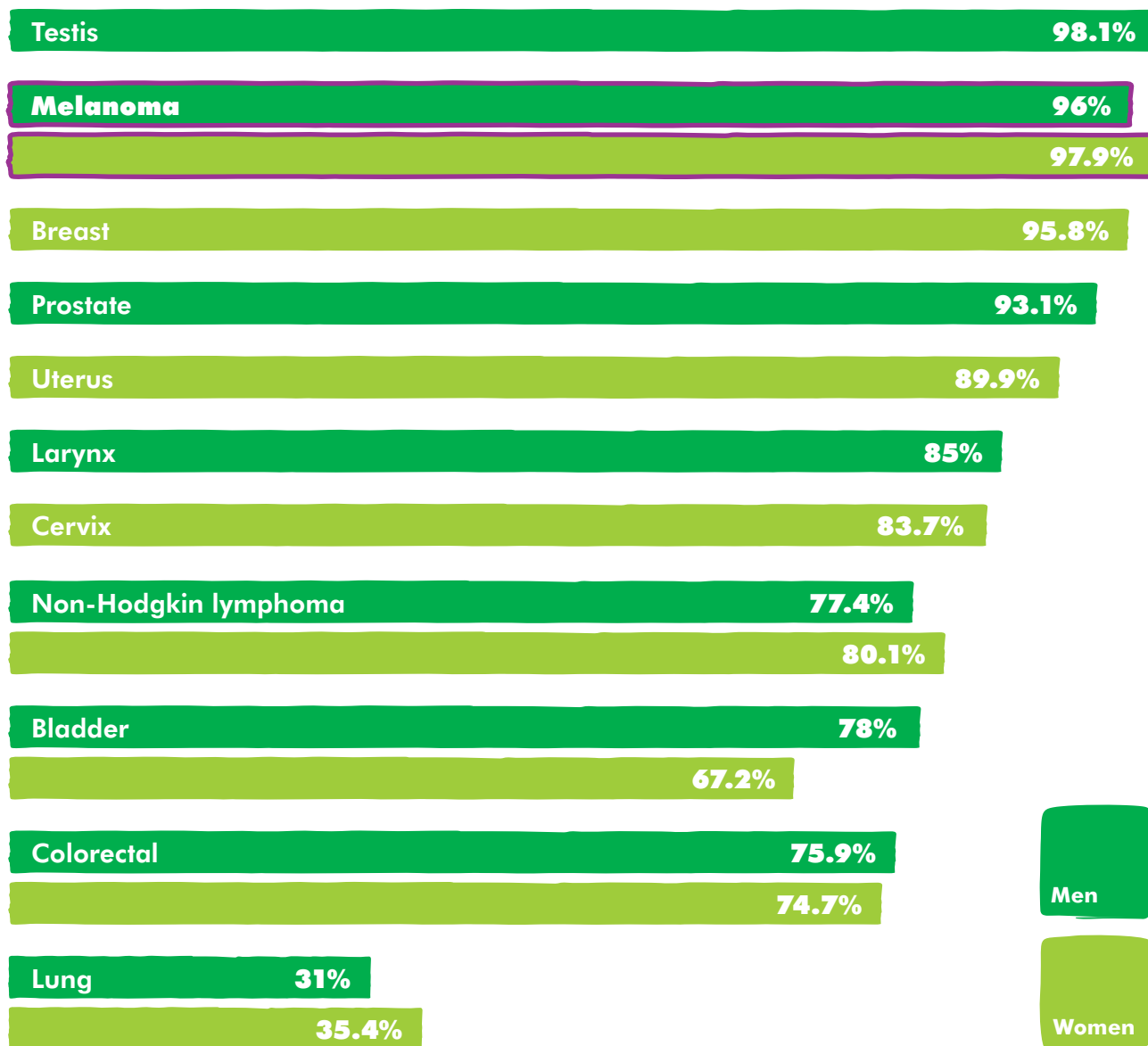


Malignant melanoma has one of the highest survival rates of all cancers (86% of men and 92% of women are alive 5 years after their diagnosis).

This puts malignant melanoma at number 2 out of 22 in the rankings of 5 year survival.

How many people live beyond one year of their malignant melanoma diagnosis?⁽²⁾

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



The estimated proportion of people living beyond 1 year of their malignant melanoma diagnosis is 97% which shows that the initial prognosis for many people with malignant melanoma is very good.

How have median survival times changed for malignant melanoma?

Over the last 40 years median survival time has increased from 1 to 6 years for all cancer types. However, since the early 1970s median survival time has been more than 10 years for malignant melanoma.⁽¹²⁾

How do UK survival rates compare internationally?

Survival rates for all types of cancer in the UK are improving overall.⁽¹³⁾ 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. Although this suggests more can be done to improve survival for people living with malignant melanoma in the UK, survival rates are relatively high, and higher than the European average.⁽⁴⁾

What are the major demographic variations in incidence, mortality, prevalence and survival for malignant melanoma?

Gender

Incidence rates of malignant melanoma are slightly higher for females than males. In 2012, 6,896 new cases were diagnosed in women, compared to 6,601 among men.^(6,7,8,9)

However, men are more likely than women to die from malignant melanoma. In 2012, 1,247 men died from malignant melanoma compared to 906 women.^(9,10,11)

Ethnic background

White people are significantly more likely to be diagnosed with malignant melanoma than people in other ethnic groups. The Age-Standardised rate in the White ethnic group ranged from 14.7 to 13.1 per 100,000 but only 0.2 to 1.1 per 100,000 and 1.0 to 0.6 per 100,000 in the Asian and Black ethnic groups respectively.⁽³⁰⁾

This difference may be because the majority of malignant melanomas are caused by heavy sun exposure in white-skinned populations.⁽²⁾

Age

Malignant melanoma incidence is related to age, but it has an unusual pattern when compared with most other cancer sites. An average of 25% of new malignant melanoma cases diagnosed in the UK in 2012 were in those aged under 50 years. This is in contrast to all cancers combined where in 2012, just 11% of cases were diagnosed in those aged under 50.^(6, 7, 8, 9)

Relative survival rates for malignant melanoma are higher in young men and women. In 2012, 82 people under the age of 40 died from malignant melanoma and over half of all deaths were in people aged under 70.^(8, 9, 10, 11, 12)

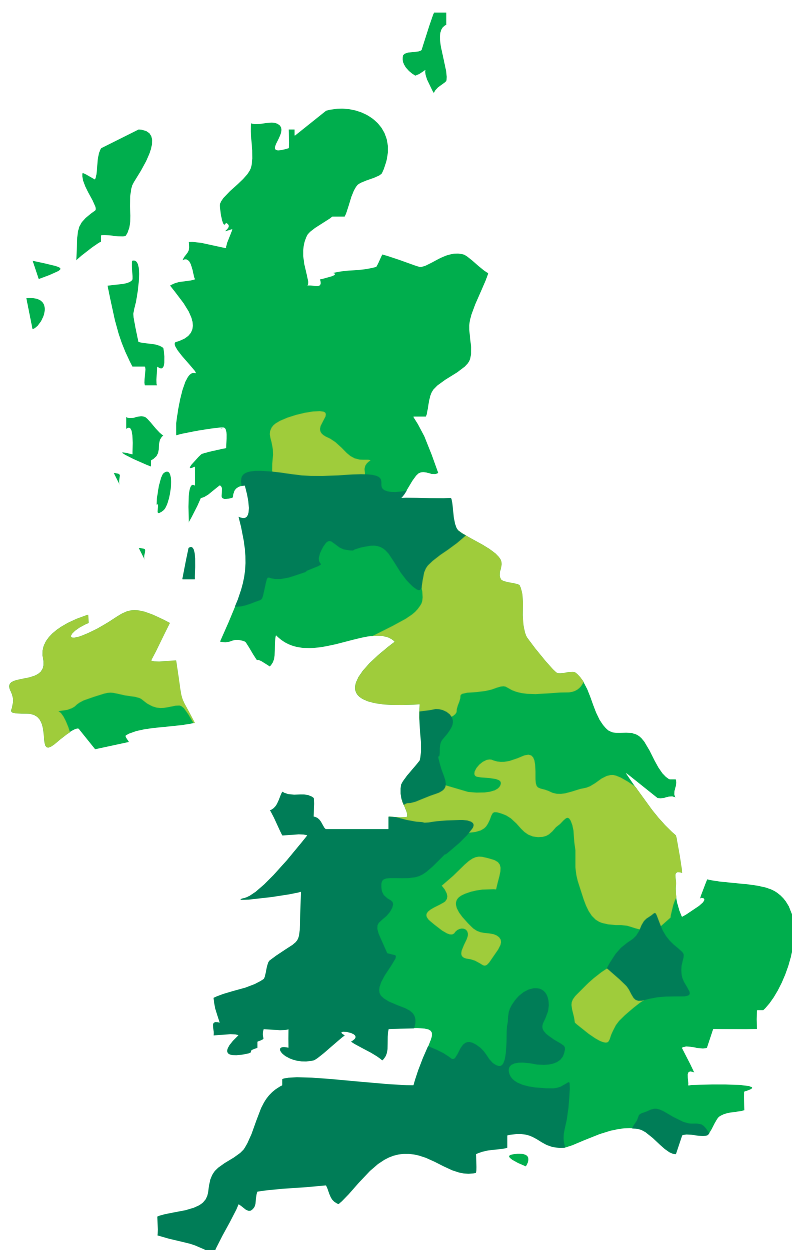
The mortality rate in persons aged 75 and over dying from malignant melanoma has almost quadrupled in the last 30 years in the UK. In contrast, the death rate for people aged 15-49 has remained stable over the same period.⁽⁵⁾

Social background

Malignant melanoma incidence is inversely related to deprivation. Incidence rates increase as deprivation decreases, meaning that the affluent are more likely to get melanoma. This is likely to be because the affluent are able to afford more frequent holidays abroad, or have a higher usage of sunbeds. It has been estimated that there would have been an additional 2,000 new malignant melanoma cancer cases each year in England during 2000-2004 if all men and women had experienced the same rates as the most affluent.⁽³⁰⁾

A study in Scotland for 2005-2009 showed that although there is still a gap between the affluent and the deprived for malignant melanoma, it is slightly smaller than that seen for England. Similar associations with deprivation have also been reported in Wales and Northern Ireland.⁽³⁰⁾

What are the geographical 'hotspots' for malignant melanoma incidence, mortality and survival?⁽¹⁵⁾



Malignant melanoma incidence, UK, 2008-2010

Low

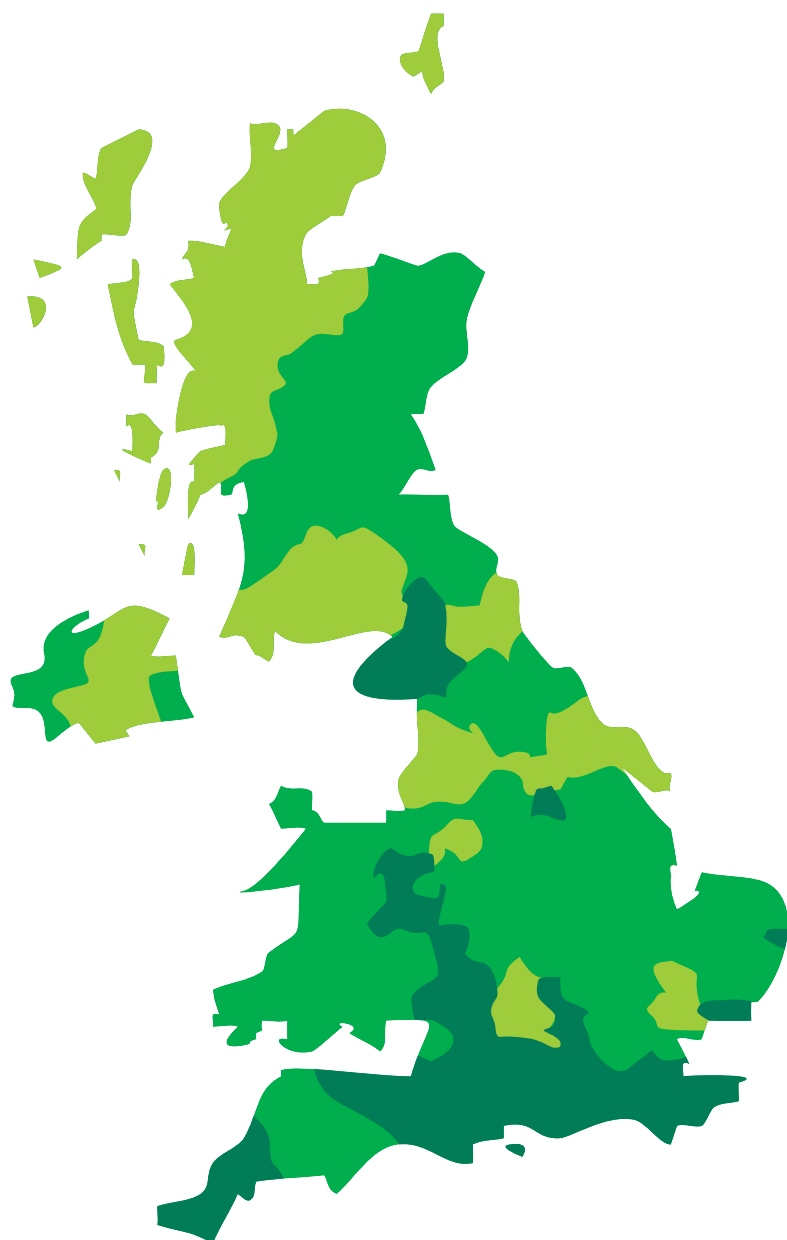
Medium

High

Important note

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

Malignant melanoma incidence rates are higher in Scotland and the South West, and lower in Northern Ireland and Northern England.



Malignant melanoma mortality, UK, 2009-2011

Low

Medium

High

Important note

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

Malignant melanoma mortality rates are generally higher in the south of England than elsewhere in the UK.

Trends in the data

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

Incidence rates are increasing:

Malignant melanoma incidence rates have overall increased in Great Britain since the mid 1970s. For men, European age standardised incidence rates were almost seven times higher in 2009–2011 than in 1975–1977. For women the increase is smaller but rates have quadrupled between 1975–1977 and 2009–2011. During this thirty year period, incidence rates of malignant melanoma in Great Britain have increased more rapidly than any of the current ten most common cancers in males and females.⁽⁸⁷⁾

The increase may be partly due to increased surveillance and early detection as well as changes in diagnostic criteria. However it is mostly considered to reflect actual increases in incidence rather than detection, and is linked to changes in sun-related behaviour such as an increase in frequency of holidays abroad over time. A study published in December 2011 estimated that around 86% of malignant melanomas in the UK in 2010 were linked to exposure to UVR from the sun and sunbeds.⁽⁴⁶⁾

A study in 2012 estimated that 99 deaths a year in the UK from malignant melanoma can be linked to the use of sunbeds.⁽¹⁰⁸⁾

Survival rates are increasing:

As with the majority of cancers, relative survival for malignant melanoma is improving. This can generally be attributed to faster diagnosis and improvements in treatment.⁽⁶⁵⁾

One-year relative survival rates have been used as an indicator of early diagnosis, since death before one year may be due to the disease being diagnosed at a late stage. In men, one-year relative survival rates for malignant melanoma increased from 79% in England and Wales during 1971–1975 to 96% in England during 2007–2011. In women, one-year relative survival rates increased from 89% to 98% during the same time periods, respectively.⁽⁶⁵⁾

In men, five-year relative survival rates for malignant melanoma increased from 47% in England and Wales during 1971–1975 to 86% in England during 2007–2011. In women, five-year relative survival rates increased from 65% to 92% during the same time periods, respectively. This increased survival rate has contributed to an increase in the prevalence of malignant melanoma, as people are living with the disease for longer.⁽⁶⁵⁾

Mortality rates are also increasing:

For men, European age-standardised mortality rates increased by 185% between 1971–1973 and 2009–2011 in the UK. For women, the rise was smaller with rates increasing by 55% over the same time period.

Increases in mortality reflect increases in incidence but are much less pronounced due to the effects of earlier diagnosis and improving treatment. The lower mortality rates since the mid-1980s for women compared with men, despite the higher female incidence, is a reflection of the better female survival rates.⁽⁵⁾ This is partly the result of the fact that skin lesions (the areas of tissue abnormality that create melanomas) tend to be less thick in women compared with men.⁽⁶⁷⁾

'I used to play out in the sun when I was a kid and my mum says that no-one really used sun cream in those days. I also used sunbeds occasionally before my diagnosis.'

Georgia, 39, North East.

THE CANCER JOURNEY

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

The following pages summarise what we currently know about the needs and experiences of people living with malignant melanoma 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 signs and symptoms of malignant melanoma?^(88, 93)

About half of all melanomas start with **a change in previously normal looking skin**. This usually looks like a dark area or an abnormal new mole.

Other melanomas start from a **mole or freckle** that the patient already has.

The following general symptoms of advanced melanoma are also common:

- Weight loss
- Loss of appetite
- Extreme tiredness

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

In the UK, most melanomas are found at an early stage when the chance of cure is very high.⁽¹⁶⁾

94% of respondents in a UK survey say that they would recognise the change in appearance of a mole as a warning sign of cancer.⁽¹⁸⁾

Patients with cancer in the UK tend to present with more advanced disease and have poorer survival rates than many of their European counterparts. The most likely explanations are either late presentation by patients or late onward referral by GPs.⁽¹⁸⁾

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.⁽¹⁸⁾

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.⁽¹⁸⁾

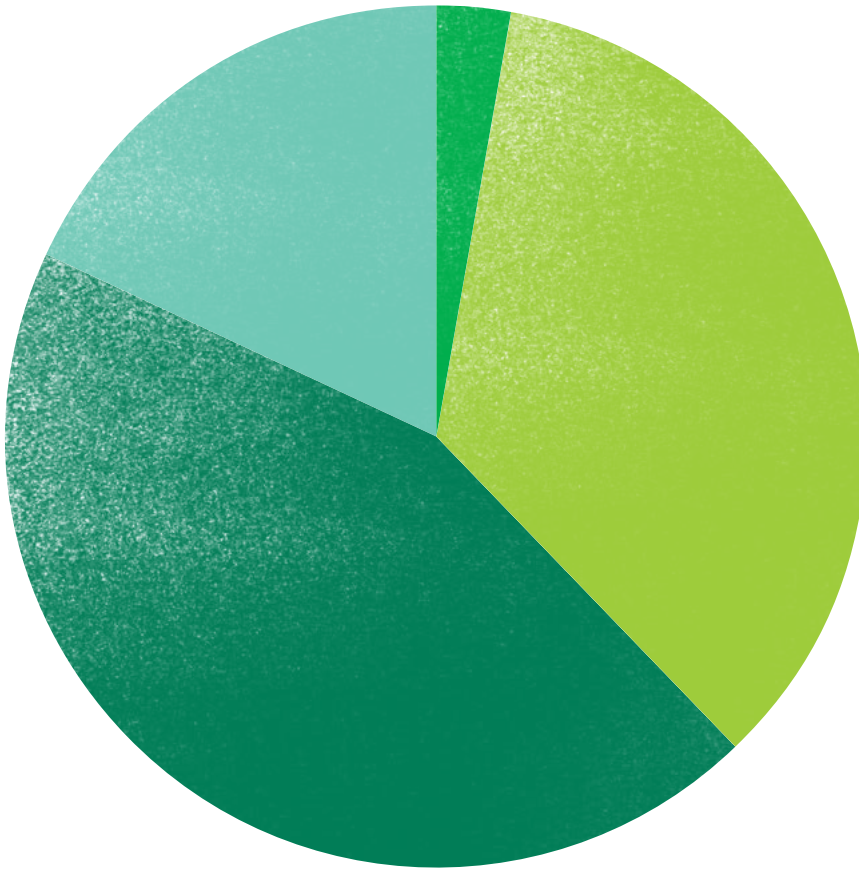
How well does screening work for malignant melanoma?

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

'I went to see my GP in April last year for something different, and had 3/4 length trousers on. When I jumped on her couch for an examination she noticed this mole. She referred me and... it was malignant melanoma at 1.2mm deep.'

Anne, 34, London.

How is malignant melanoma diagnosed? (Routes to diagnosis)⁽¹⁹⁾



Emergency

3%

GP referral

35%

Two Week Wait

44%

Other

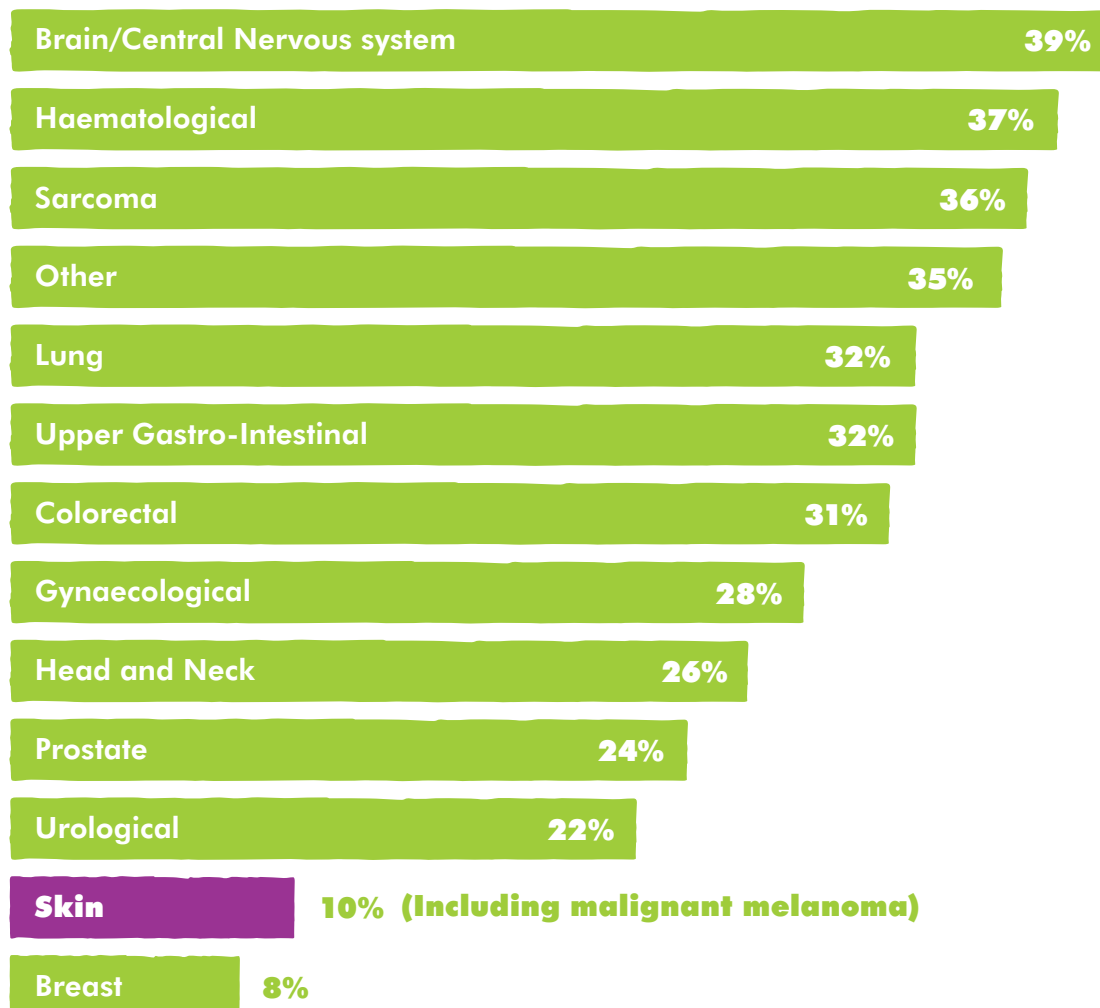
18%

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

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

3% of people newly diagnosed with malignant melanoma were diagnosed via the emergency route, this is significantly lower than the average for all cancers (23%). This is likely to be because the majority of patients with malignant melanoma are the first to recognize their symptoms, in the form of a change to the appearance of a mole or their skin.

How many malignant melanoma patients had to see their GP more than twice before they were diagnosed?⁽²⁰⁾

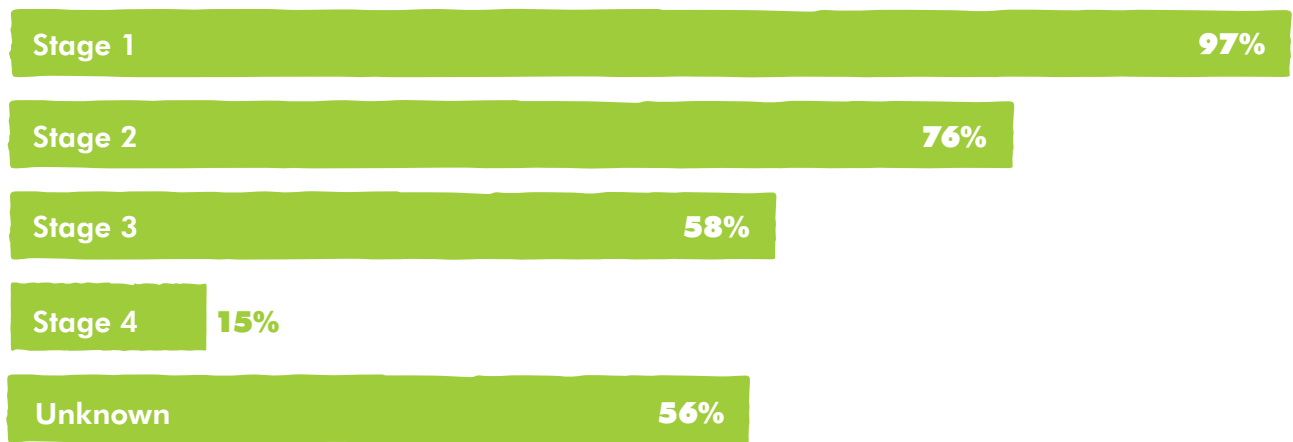


10% of people newly diagnosed with malignant melanoma had to see their GP more than twice before they were diagnosed compared with only 8% of breast cancer patients, 24% of prostate cancer patients and 32% of lung cancer patients.

How does stage at diagnosis relate to probable survival rates?

There is a specific form of staging for malignant melanoma which combines factors such as how far the melanoma has spread with the thickness (depth) of the original melanoma. Generally cancers at Stage 1 are small and localized, Stage 2 may be thicker but remain localized, Stage 3 have spread to the lymph nodes or lymphatic tubes closest to the melanoma and Stage 4 have spread to distant areas of skin or distant lymph nodes, or to other organs.⁽²¹⁾

The impact of stage at diagnosis on 5-year survival – Malignant melanoma⁽¹³⁾



5-year survival rates (%)

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

How long do people with malignant melanoma have to wait to be referred?⁽²²⁾

According to recent data just over 95% of patients with suspected skin cancer (including malignant melanoma) are seen by a specialist within 2 weeks of referral. This is roughly the same as the average for all suspected cancers, which is around 95% and is higher than the operational standard of 93% average for all cancer types.



PHYSICAL AND MEDICAL NEEDS

If a mole has turned to melanoma, **pain, change of colour and itching may be experienced.**⁽²³⁾



FINANCIAL NEEDS

Of people with skin cancer (all skin cancers, not just malignant melanoma) who said they wanted **information on financial help or benefits** from the hospital staff, **48% were not given it**, compared to an average of 46% for all cancers.⁽²⁵⁾

Not specific to people with malignant melanoma

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.⁽⁹⁵⁾



PRACTICAL AND INFORMATION NEEDS

Patient understanding and awareness of malignant melanoma is **influenced by personal, family and friends' experiences of moles, malignant melanoma and other cancers, knowledge of risk factors and the lay media.**⁽²⁸⁾

People who have had **sunburn are twice** as likely to get melanoma as those who have not⁽⁸¹⁾. However **public awareness** of how to avoid sunburn is quite low in the UK; more than **one in five UK adults (22%)** do not believe they can get sunburnt if they already have a tan.⁽⁷⁶⁾

In 2013 81% of people with skin cancer (all skin cancers, not just malignant melanoma) **received written information** about their cancer compared to 81% of prostate cancer patients and 76% of breast cancer patients. The average for all cancer types was 71%.⁽²⁶⁾

85% of people with skin cancer (all skin cancers, not just malignant melanoma) say they **receive a completely understandable explanation of their test results**. This is the highest of any cancer type, and compares favourably to an average of 78% for all cancers.⁽²⁷⁾

Not specific to people with malignant melanoma

Information needs at diagnosis are extensive and include prognosis side effects of treatments, impact on family and friends, sexual attractiveness, self care and risks of family developing the disease.⁽³¹⁾

The strongest preference for information at diagnosis is information about prognosis.⁽³¹⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Research has found that patients newly diagnosed with malignant melanoma exhibit levels of **psychological distress** similar to those reported by other cancer patients.⁽³²⁾

The **psychosocial issues** around the diagnosis and treatment of malignant melanoma have **received scant attention from healthcare professionals.**⁽³²⁾

Women with malignant melanoma have reported **higher levels of anxiety, depression, tiredness and sleep disturbance** than men.⁽³²⁾

Not specific to people with malignant melanoma

Although a certain amount of **emotional distress** is common, particularly around the time of a diagnosis, around half of all people with cancer (all cancers, not just malignant melanoma) experience levels of anxiety and depression severe enough to adversely affect their quality of life.⁽³³⁾

Recent research found that **1 in 14 people (7%) diagnosed with cancer** (all cancers, not just malignant melanoma) – representing around 20,000 people in the UK each year – **receive no help whatsoever, facing cancer completely alone.**⁽⁹⁶⁾

58% of people diagnosed with cancer (all cancers, not just malignant melanoma) **feel their emotional needs are not adequately looked after**. 75% suffer anxiety and 85% of these do not receive any advice or support.⁽⁶¹⁾

NEEDS AND EXPERIENCES TREATMENT

Malignant melanoma is usually treated by surgery. There seems to be a lack of overall data on the proportion of patients who have a surgical intervention for malignant melanoma.

What treatments do malignant melanoma patients get?

Surgery

Melanomas are commonly treated with local surgery, known as a wide local excision.⁽³⁵⁾

For early stage melanomas, surgery is usually the only treatment that is needed.⁽³⁵⁾

Sometimes a melanoma can spread to nearby lymph nodes. If this is the case, these lymph nodes can be removed during a surgical operation known as a lymph node dissection.⁽³⁵⁾

Chemotherapy

Chemotherapy may be offered as a treatment for advanced melanoma that has spread to another part of the body.⁽³⁶⁾

Chemotherapy is sometimes used to try to stop melanoma coming back after it has been removed, if melanoma cells are found in the lymph nodes. Chemotherapy used in this way is called adjuvant chemotherapy.⁽³⁶⁾

Radiotherapy

Radiotherapy may be used for advanced melanoma to shrink melanoma tumours and help to control symptoms. Some people have it as a treatment after surgery to remove the melanoma, to try to lower the chance of the melanoma coming back, but this is not common.⁽³⁷⁾

Skin cancer (including malignant melanoma) accounts for **5%** of all the radiotherapy episodes in England (2011–12). There were 6,411 radiotherapy episodes and 54,032 radiotherapy attendances for malignant melanoma.⁽³⁸⁾

Biological therapy

Biological therapies use substances that occur naturally in the body to destroy cancer cells. Vemurafenib is a type of biological therapy drug that can be used for malignant melanoma. Side effects include joint pain, tiredness, skin rash, skin sensitivity to sunlight, feeling sick, hair loss and itching.⁽³⁹⁾

Occasionally, biological therapy is used after surgery if there is a risk that the melanoma could come back.⁽⁴⁰⁾

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

In total, there were almost 14,200 admissions to NHS hospitals in England (emergency and non-emergency) for malignant melanoma during 2012–13.⁽⁴¹⁾

Roughly **3%** of malignant melanoma patients were admitted through an emergency route, compared to **9%** of all cancers.⁽⁴¹⁾

The median length of stay for malignant melanoma patients who were admitted was 1 day in 2012–13.⁽⁴¹⁾

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

What can a person with malignant melanoma expect, therefore, from a typical treatment regime?

Local surgery to remove a melanoma is the most common treatment. If the melanoma is at an early stage, this is usually the only treatment that's needed and the chances of being cured are high.⁽⁴⁰⁾

The whole mole will be removed during a procedure called an excision biopsy. After the entire mole has been removed and the biopsy results show that it was a melanoma, the specialist may advise a wide local excision, in which the surgeon removes a small amount of normal-looking tissue from all around the area where the melanoma was, in order to ensure that all cancerous cells are removed.⁽⁴⁰⁾

How many malignant melanoma nurses are there?⁽⁴³⁾

Macmillan's internal data suggests that we had (as of June 2014) 97 skin cancer Macmillan nurse posts across the whole of the UK.

What does this mean for patients?

84% of people in 2013 with skin cancer (all skin cancers, not just malignant melanoma) reported 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.⁽⁴⁴⁾

In 2011 there were 129 Whole Time Equivalent (WTE) malignant dermatology CNS posts in England.⁽⁹⁷⁾

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

Just under half (49%) of all people living with cancer (all cancers, not just malignant melanoma) have at least one other chronic condition. This includes 15% who have two, and 6% who have three other chronic conditions.⁽⁶⁰⁾

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.

Studies have shown up to a 7 times increased risk of melanoma for people with Parkinson's disease.⁽⁸¹⁾

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

‘I am very happy with the treatment I received throughout the process and am keen to repay the NHS for the skillful and timely treatment I received.’

Ross, 71, Scotland



PHYSICAL AND MEDICAL NEEDS

The time it takes to heal after surgery is different for each person. **Pain may be felt for the first few days after surgery.**⁽⁴⁵⁾

Surgery nearly always leaves some type of scar. The size and colour of the scar depend on the size of the cancer, the type of surgery, skin colour, and how the skin heals.⁽⁴⁵⁾



FINANCIAL NEEDS

Not specific to people with malignant melanoma

Additional costs caused by cancer treatment include fuel charges which arise from transporting cancer patients and their carers to and from appointments. **These travel costs affect 69% of cancer patients** and cost them on average, **£170 a month.**⁽⁹⁵⁾



PRACTICAL AND INFORMATION NEEDS

87% of people with skin cancer (all skin cancer not just malignant melanoma) believe that it was **never the case that one doctor or nurse said one thing about their condition or treatment and another said something different.** This is the highest of any cancer type.⁽⁴⁸⁾

88% of people with skin cancer (all skin cancers, not just malignant melanoma) **are given a choice about treatment** compared to 92% with prostate cancer patients and 89% with breast cancer.⁽⁴⁹⁾

25% of people with skin cancer (all skin cancers, not just malignant melanoma) are **not told about treatment side effects** in a way in which they can understand. This is compared to 22% of people with breast cancer and 23% of people with colorectal cancer.⁽⁵⁰⁾

Not specific to people with malignant melanoma

10% of people with cancer (all cancers, not just malignant melanoma) are **not given enough information** about their condition and treatment, while 2% are given too much.⁽⁴⁷⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

While being treated as an outpatient or day case **74%** of malignant melanoma patients say they **are given enough emotional support** from hospital staff.⁽⁵²⁾

Not specific to people with malignant melanoma

Amongst all cancer patients (all cancers, not just malignant melanoma) the **overall prevalence of psychological distress is 25%** among those who are undergoing, or have just finished, cancer treatment.⁽⁵¹⁾

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

Why are cancer survivors (all cancer survivors not just malignant melanoma) 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.⁽²⁴⁾
- **94%** experience **physical health condition problems** in their first year after treatment.⁽⁶⁰⁾
- **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.⁽⁶⁰⁾
- **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.⁽⁶⁰⁾
- **25%** people living with cancer say they would have found it helpful to have had more advice on the **emotional effects of cancer**.⁽⁶¹⁾
- **23%** **lack support** from **friends and family** during treatment and recovery.⁽¹⁰³⁾

- **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**.⁽¹⁰³⁾

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.⁽⁸⁴⁾
- Currently only **20%** of skin cancer patients (including malignant melanoma) are offered a written assessment and care plan – both of these are essential in providing personalised care for cancer patients and their carers.⁽¹⁷⁾

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”’**.

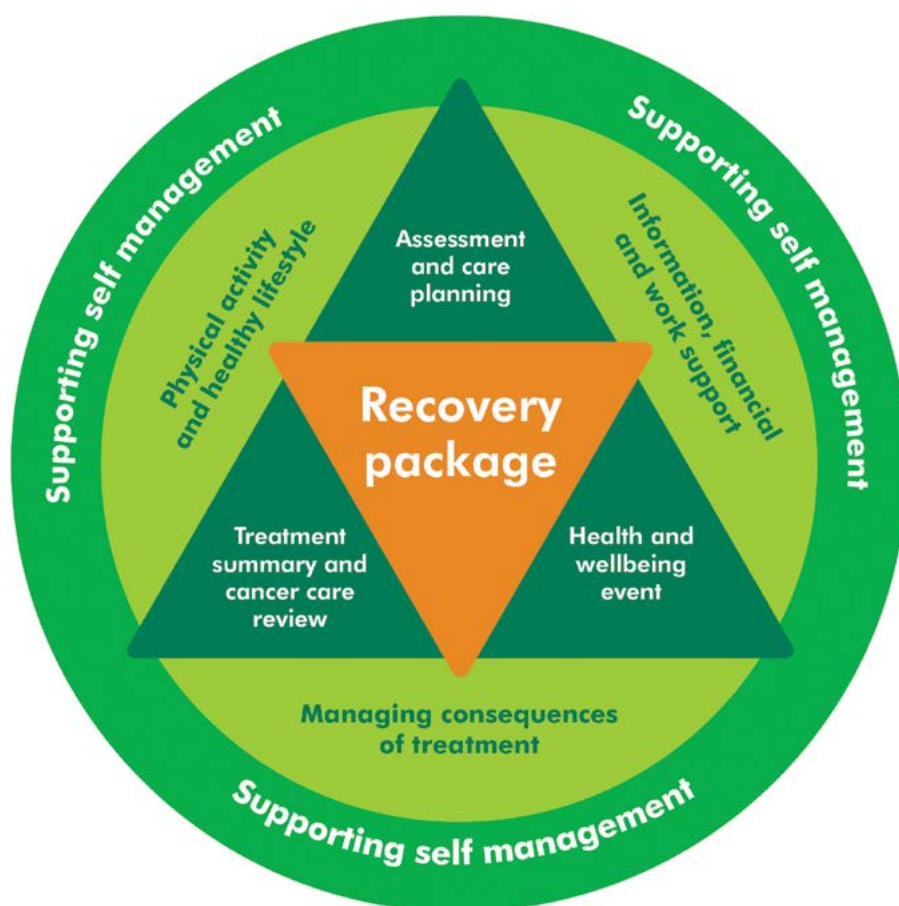
The documents set out what has been learned about survivorship, including interventions that have been tested and are ready to be spread across England, and could make an immediate difference to people affected by cancer. These include: A key intervention which is the ‘Recovery Package’ consisting of:

- 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

61% of people with skin cancer (all skin cancers, not just malignant melanoma) **felt that they were given enough care and help from health or social services** after their treatment was completed. This is compared to 66% of people with colorectal cancer and 57% of people with prostate cancer.⁽⁵³⁾

'I have a passionate reminder in the form of a large unsightly scar on my arm which 8 weeks later is still painful. The area under my arm where my lymph glands were removed have a permanently numb area.'

Andrew, 38, South West



FINANCIAL NEEDS

44% of people with skin cancer (all skin cancers, not just malignant melanoma) who want to know **are not told about free prescriptions**. This is significantly above the average for all cancer types of 24%.⁽⁵⁴⁾

Not specific to people with malignant melanoma

Some people affected by cancer **are not aware that they can claim benefits**. 61% of those questioned in a recent survey did not receive health-related benefits.⁽⁹⁵⁾

Some people living with cancer find the **benefits system complex and difficult to navigate**. Benefits advice is also not always offered in a timely fashion.⁽⁹⁵⁾

Personal Independence Payment (PIP), the successor benefit to Disability Living Allowance (DLA), was introduced across Great Britain in June 2013. However there are **significant delays** in the new system – 60% of claimants have waited on average just under four and a half months for a response, while 25% have been waiting at least six months.⁽²⁹⁾

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.⁽⁹⁴⁾



PRACTICAL AND INFORMATION NEEDS

Not specific to people with malignant melanoma

Many people **feel abandoned by the healthcare system** once their initial treatment for cancer has completed.⁽¹⁰⁶⁾

Many cancer outpatients (all cancers, not just malignant melanoma) 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.⁽⁵⁶⁾

If **recurrence** occurs, a **renewed need for information & support** is generally expressed by people with cancer (not just those with malignant melanoma).⁽⁵⁷⁾

However, for those experiencing a recurrence, **only half of those surveyed said that they received supported information**, suggesting there is unmet need at recurrence.⁽⁵⁷⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

People who have had melanoma have an increased risk of developing a new melanoma. This **fear of recurrence may leave them with emotional and psychological needs**.⁽⁵⁸⁾

Not specific to people with malignant melanoma

Recent research found **37% of healthcare professionals do not always ask if a cancer patient has support from family or friends**; this increases to almost half (47%) of GPs.⁽⁹⁶⁾

23% of people living with cancer (all cancers, not just malignant melanoma) report **poor emotional well-being**.⁽⁹⁵⁾

Psychological and social long-term side effects of cancer and its treatment include **depression, anxiety, problems with memory and concentration, lack of confidence, sexual problems and isolation**. Around 240,000 people living with and beyond cancer are living with mental health problems.⁽¹⁰⁷⁾

33% of people living with cancer (all cancers, not just malignant melanoma) say **a lack of support has caused them stress or anxiety**, and more than 28% say they have experienced depression⁽⁹⁶⁾

NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

How many malignant melanoma patients are at End of Life?

Specific data for malignant melanoma is not available, but for all cancers around 7% of patients are in the last year of life.⁽⁴²⁾

What is the impact of giving patients palliative care?

The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life threatening condition: "Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is 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."⁽¹⁰⁴⁾

Palliative care aims to:

- Affirm life and regard dying as a normal process.
- Provide relief from pain and other distressing symptoms.
- Integrate the psychological and spiritual aspects of patient care.

- Offer a support system to help patients live as actively as possible until death.
- Offer a support system to help the family cope during the patient's illness and in their own bereavement.⁽¹⁰⁴⁾

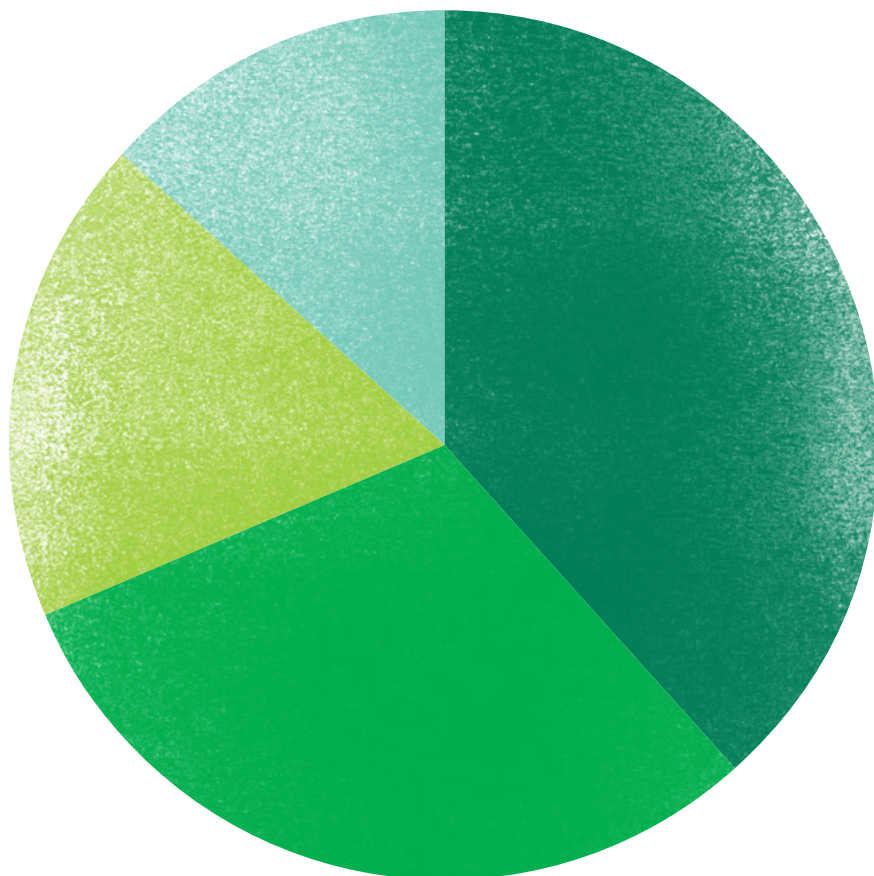
The majority of people requiring palliative care will not receive specialist palliative care: they are cared for by the generalist workforce such as district nurses, GPs, and generalist hospital staff. It is usually only when a patient's symptoms become complex that they are referred for specialist palliative care.⁽⁶³⁾

How many cancer deaths are there in each setting?

Data on place of death is not available broken down by cancer type. However for all cancers, we know that cancer deaths in England & Wales account for 90% of all deaths that occur in hospices, 39% of all deaths at home, 23% of all deaths in hospital, 18% of all deaths in care homes, 19% of all deaths in communal establishments and 23% of all deaths elsewhere.⁽¹⁰⁾

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

Where do people with cancer die?*(102)



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 malignant melanoma cancer patients die in the place of choice?

Not specific to people with malignant melanoma

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.⁽¹⁰⁵⁾ However, only 30% of those who die from cancer actually die at their home or own residence.⁽¹⁰⁾

In terms of dying in the place of choice, only around one in five people (or fewer in many local authorities) have access to homecare, supporting them to die in their own home.⁽⁶⁶⁾ If these trends are to continue, approximately 222,000 people in England will die in hospital in 2020, having said that they wished to die at home. This suggests that more needs to be done to ensure that people's wishes about where they want to die are met.⁽⁹⁹⁾

‘We tried to prepare ourselves for the fact that he was going to need chemo or radiotherapy. We were thinking: ‘We can get through that...’ so when the doctor said: ‘There’s no easy way to tell you, but we can’t do anything,’ it was an absolute bombshell.’

Sarah, 38, who cared for her husband until his death, South West



PHYSICAL AND MEDICAL NEEDS

Not specific to people with malignant melanoma

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.**⁽⁶⁹⁾

Various symptoms are **very common in advanced cancer**, with patients having an average of **6 uncontrolled symptoms** on admission to palliative care.⁽⁷⁰⁾

Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; they occur in some combination in virtually all patients.⁽⁷³⁾



FINANCIAL NEEDS

Not specific to people with malignant melanoma

In 2010 Macmillan reported that **36% of people with a terminal cancer diagnosis** (all cancer, not just malignant melanoma) **did not claim the benefits they were automatically entitled to.** This amounted to over £90m in 2010.⁽⁷¹⁾

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.⁽⁷²⁾

A study found that **advanced stage at diagnosis, being older at diagnosis, and higher comorbidity were associated with increased costs.** The financial burden is highest around cancer diagnosis and end of life.⁽¹⁰¹⁾



PRACTICAL AND INFORMATION NEEDS

Not specific to people with malignant melanoma

Cancer patients and their families often want information about how long they may have to live after hearing that their cancer is terminal. However, **31% of doctors tend to over-estimate the survival times** of terminally ill cancer patients.⁽⁷⁵⁾

A study into advanced cancer (not malignant melanoma specific) found that patients identified the greatest areas of need in relation to 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.⁽⁷⁴⁾

More than one in four people living with cancer say they would have found it helpful to have had more advice or information on the physical long-term effects of cancer.⁽⁶¹⁾

Research has found that **older patients with cancer are often under-treated**. This under-treatment is present in palliative care. Older people with cancer are more likely to receive less social and practical support, which suggests that they are not getting the adequate care and services they need at end of life.⁽¹⁹⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Cancer patients (all cancer types, not just malignant melanoma) approaching death suffer more **psychological distress**.⁽⁵¹⁾

Amongst all cancer patients (not just malignant melanoma) the **overall prevalence of psychological distress is 59% amongst those receiving palliative care**.⁽⁵¹⁾

83% of people say they are scared of dying in pain, while 67% say they are scared of dying alone, and 52% are scared of being told they are dying.⁽⁷⁷⁾

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 it can lead to traumatic experiences for patients and their families.⁽³⁴⁾

LIFESTYLE AND PERCEPTIONS

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

What is the profile of the average person living with malignant melanoma?

Malignant melanoma is slightly more common in women than men. In 2012, 6,896 new cases were diagnosed in women, compared to 6,601 among men.^(6,7,8,9)

White people are significantly more likely to get malignant melanoma than people of other races. This difference is because the majority of malignant melanomas are caused by heavy sun exposure in white-skinned populations.^(2,14)

Malignant melanoma affects people of many different ages. An average of 25% of new malignant melanoma cases diagnosed in the UK in 2012 were in those aged under 50 years, with an average of 49% of cases diagnosed in people aged 65 years and over.^(6, 7, 8, 9)

What is the demographic breakdown/market segmentation of the 110,330 malignant melanoma 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 malignant melanoma cancer patients attending hospital. We believe the correlations seen in England will be broadly similar to those seen in the other three UK nations, and so this insight could be applied UK-wide.

Amongst malignant melanoma patients, the following MOSAIC* group shows significantly greater than average representation:

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 Group E, the following MOSAIC* groups shows greater than average representation amongst malignant melanoma cancer patients:

Group C: Rural Solitude (residents of isolated rural communities): People in Group C tend to live in small villages or in isolated farmhouses and cottages where farming and tourism drives the local economy. These are places where residents still value a traditional country way of life characterised by a strong sense of community spirit. The group includes a mix of farmers, people who work for businesses that provide services to the farming industry, people who have deliberately retired to a community with a slower pace of life and locally born people who work in low and middle income jobs in local market towns. A high proportion of the population is married or, if single, widowed. Most of them own their homes.

Group B: Professional Rewards (successful professionals living in suburban or semi-rural homes): People in Group B are generally executive and managerial classes who have worked hard to build up a comfortable lifestyle and a significant financial asset base. They are often in their 40s, 50s or 60s, and can be in successful careers. Most are married and living in a spacious family home. Many have children who are at university or starting their careers.

Group D: Small Town Diversity (residents of small and medium sized towns)

People in Group D are generally mature people who have strong roots in their local community. They may be on lower incomes than other people their age in more urban parts of the country. People in this group tend to be skilled workers, such as craft workers, and many may live in a bungalow or a semi-detached property.

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.

In addition to the above Groups, there is one Type within **Group M (Industrial Heritage)** which is also well-represented amongst malignant melanoma patients:

- **Group M, Type 54: Clocking Off.**

What are the typical leisure activities/ where they shop/what media they consume/what they do?⁽⁷⁸⁾

- **Group E:** Active Retirement. Holidays, cruises and dining out for those who are well-off. Reading books, doing crosswords, knitting and looking after grandchildren are also popular activities. They tend to read national daily newspapers every day.
- **Group C:** Rural Solitude: Many people within this group may spend time in their gardens, or growing fruit and vegetables. There is less frequent visiting of theatres and cinemas than other groups. Many people in this group enjoy outdoor pursuits such as fishing, walking, etc.
- **Group B:** Professional Rewards: Holidays, cruises and day trips are popular activities, as is going to the theatre and to concert halls. People in this group tend to read the broadsheet newspapers, particularly The Daily Telegraph and The Sunday Times.
- **Group D:** The focus of leisure is on home improvement and meeting up with friends in homes and gardens, in pubs, at meetings of local associations and sharing trips to visit local sites of historical or environment distinction.
- **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.

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

Before:

'I wasn't a massive sunbather, but when I went abroad I would lie in the sun. When I went away with my parents I used to take care, but when I went with my friends, I was less careful, and was more likely to use oil than lotion.'

Amy, 23, South East.

'It's a male thing to be reluctant to go to the doctor and not get checked out but, if I hadn't gone as soon as I did, it could have so easily been a different outcome for me.'

Michael, 51, Wales.

After:

'I would love to feel pretty again. I have had so many medicines, and still do, that over the last year I have gone from a size 10 to size 16/18. Nothing I own flatters my figure.'

Rachel, 36, South East.

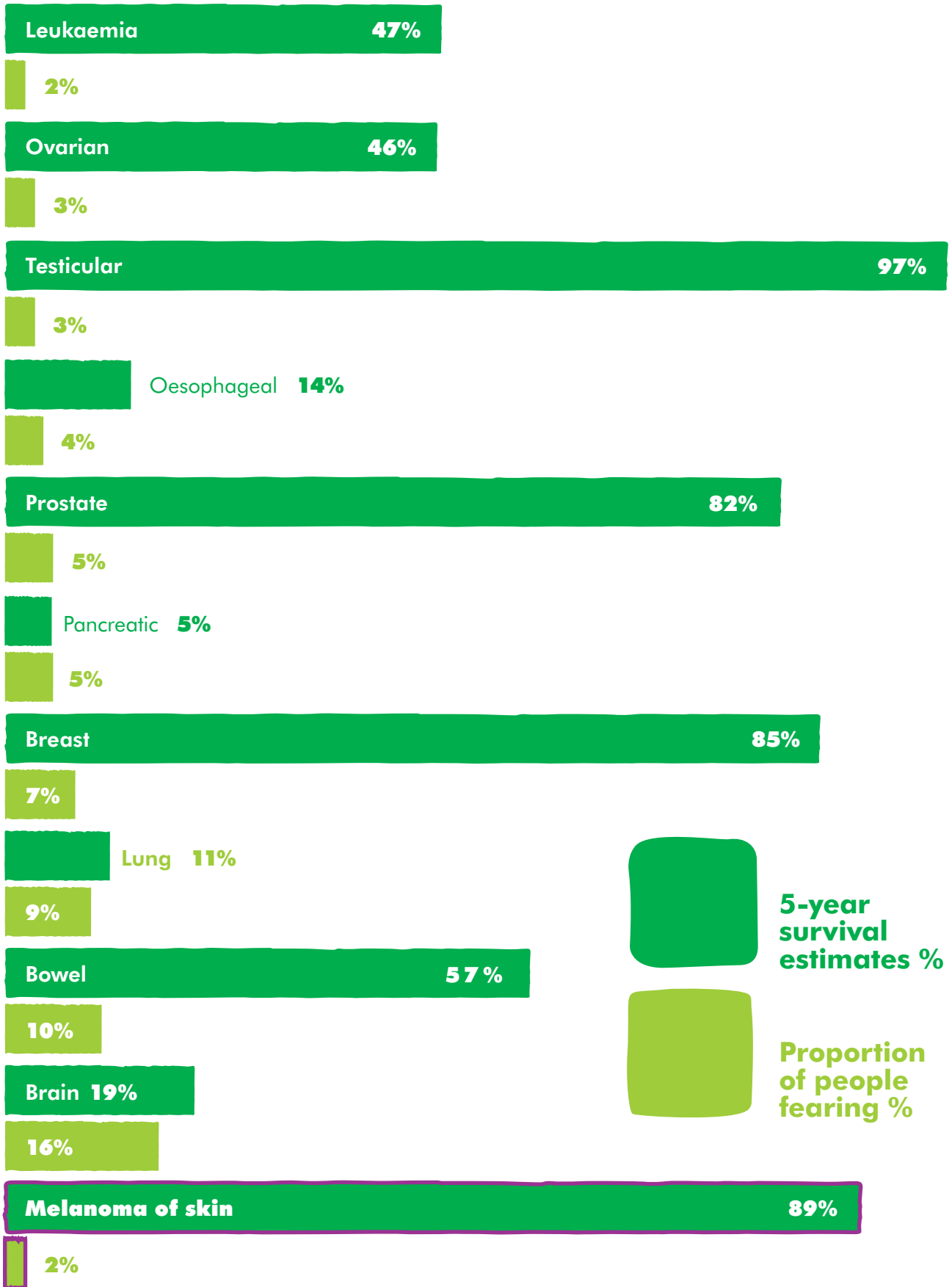
'I don't think there has been anywhere near enough publicity about melanoma, and people really do need to know how easy it is to get, and how hard to get rid of. Friends of mine just think they have to cut away the "skin cancer" they really haven't got a clue, and I know that I didn't either until it was too late.'

Sally, 38, North West.

'I may have cancer, but I used to run my own business, I've not lost my brains.'

Tessa, 71, North West.

How does people's fear of malignant melanoma compare to actual survival rates?^(2,82)



Fear of malignant melanoma is extremely low amongst the general public. This may be because the 5-year survival rates for malignant melanoma are very high. The low fear rate may also reflect low public awareness of the risks of malignant melanoma.

Malignant melanoma is the jointly least feared cancer, along with leukaemia, and its 5-year survival rates are the second highest of all cancers, behind testicular.

What does this mean? What do we want to change in terms of people's perceptions?^(79,80)

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

- The media reports on malignant melanoma clearly focus on the causes of malignant melanoma. The most frequent words include 'sun', 'tan', 'sunbeds' and 'UVA'. Interestingly, none of these words appear in the online community word cloud.
- The online community instead concentrates on the emotional and physical side effects of malignant melanoma and its treatment. Words such as 'feeling', 'hope' and 'normal' are prominent, showing that people who have malignant melanoma are looking forward to the end of treatment, and possible remission.
- In the online community word cloud, the word 'cancer' does not appear, despite usage of words such as 'oncologist' and 'radiotherapy', whilst in media representations of malignant melanoma 'cancer' is the most frequently used term. This suggests that perhaps people with the disease wish to use more technical terms when dealing with their cancer, as malignant melanoma is more precise than skin cancer.

REFERENCES,

SOURCES, NOTES AND CAVEATS

Quotes

The quotes on pages 23, 27, 37, 42, 47, 52 and 53 are real quotes from people with malignant melanoma or their carers, however we have changed their names to protect their identity. The quote and photo on page 5 is from a Macmillan malignant melanoma case study who has kindly agreed to be featured in this publication.

References

1. Cancer Research UK. Types of melanoma. <http://www.cancerresearchuk.org/cancer-help/type/melanoma/about/types-of-melanoma> (accessed August 2014)
2. Office for National Statistics. Cancer survival rates, Cancer survival in England, patients diagnosed 2007–2011 and followed up to 2012. <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-320365> (accessed August 2014)
3. Personal Communication: NCIN. 2014. Macmillan-NCIN work plan. Segmenting the cancer survivor population: by cancer type, 20-year prevalence at the end of 2010, UK. Data sourced and presented in collaboration with the Welsh Cancer Intelligence and Surveillance Unit, Health Intelligence Division, Public Health Wales, the Information Services Division Scotland and the Northern Ireland Cancer Registry. The analysis is based on patients diagnosed with cancer between 1991 and 2010 in England, Wales and Scotland, and between 1993 and 2010 in Northern Ireland. To ensure that patients, rather than tumours, were counted, only the first diagnosed tumour (excluding non-melanoma skin cancer) of each cancer type in each patient was included in the analysis. The numbers in this analysis may not agree with those published elsewhere due to slight differences in methodologies, periods of observation, datasets, and rounding.
4. Eurocare. Eurocare-5 Database, Survival Analysis 2000-2007. <http://www.eurocare.it/Database/tabid/77/Default.aspx> (accessed July 2014)
5. Cancer Research UK. Skin cancer mortality statistics. <http://info.cancerresearchuk.org/cancerstats/types/skin/mortality/> (accessed August 2014)
6. England – Office of National Statistics. Cancer Registration Statistics, England, 2012. <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-352128> (accessed August 2014)
7. Scotland – ISD Scotland. Cancer Incidence in Scotland 2012. <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233> (accessed August 2014)
8. Wales – Welsh Cancer Intelligence and Surveillance Unit. Official Statistics – Trends. <http://www.wcisu.wales.nhs.uk/offical-statistics-exel-files-of-trend> (accessed August 2014)
9. N. Ireland – Northern Ireland Cancer Registry. Online Statistics. <http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/> (accessed August 2014)

10. Office for National Statistics and London School of Hygiene and Tropical Medicine. Mortality statistics. Deaths registered in England and Wales 2012. <http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/dr-tables-2012.xls> (accessed August 2014)
11. Scotland – ISD Scotland. Cancer Mortality in Scotland 2012. <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233> (accessed August 2014)
12. Macmillan Cancer Support. Living after diagnosis. Median cancer survival times. <http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/LivingAfterCancerMedianCancerSurvivalTimes.pdf> (accessed August 2014). Macmillan Cancer Support identified median survival times based on research by the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine.
13. Kings Fund. How to improve cancer survival: Explaining England’s relatively poor rates. <http://www.kingsfund.org.uk/publications/how-improve-cancer-survival> (accessed August 2014)
14. NCIN. Cancer Incidence and Survival by Major ethnic group. England, 2002-2006. 2009. <http://www.ncin.org.uk/view?rid=75> (accessed August 2014)
15. NCIN. Cancer e-Atlas: NHS Health Boundaries. http://www.ncin.org.uk/cancer_information_tools/eatlas/ (accessed August 2014)
16. Cancer Research UK. Stages of melanoma. <http://cancerhelp.cancerresearchuk.org/type/melanoma/treatment/stages-of-melanoma> (accessed August 2014)
17. NHS England. Cancer Patient Experience Survey 2013. Q68. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
18. Robb K, et al. Public awareness of cancer in Britain: a population-based survey of adults. *British Journal of Cancer*. 2009. 101:518-23)
19. Macmillan Cancer Support. Age Old Excuse. 2012. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/AgeOldExcuse/AgeOldExcuseReport-MacmillanCancerSupport.pdf> (accessed July 2014)
20. NHS England. Cancer Patient Experience Survey 2013. Q1. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
21. Macmillan Cancer Support. Staging and grading of melanoma. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Symptomsanddiagnosis/Stagingandgrading.aspx> (accessed August 2014)
22. NHS England. Provider-based Cancer Waiting Times for Q4 2013-14. <http://www.england.nhs.uk/statistics/2014/05/30/provider-based-cancer-waiting-times-for-q4-2013-14/> (accessed August 2014)
23. Cancer Research UK. Melanoma symptoms. <http://cancerhelp.cancerresearchuk.org/type/melanoma/about/melanoma-symptoms> (accessed August 2014)
24. Macmillan Cancer Support/YouGov online survey of 1,495 UK adults living with cancer. Fieldwork conducted 1-16 Aug 2011. Survey results are unweighted.

25. NHS England. Cancer Patient Experience Survey 2013. Q27 <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
26. NHS England. Cancer Patient Experience Survey 2013. Q14. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
27. NHS England. Cancer Patient Experience Survey 2013. Q9. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
28. Walter et al. Patient understanding of moles and skin cancer, and factors influencing presentation in primary care: a qualitative study. *BMC Family Practice*. 2010.
29. Macmillan Cancer Support. Waiting to Benefit. 2014. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/WelfareReform/Waiting-to-benefit-report.pdf> (accessed July 2014)
30. Cancer Research UK. Skin Cancer Statistics Report. 2013. http://publications.cancerresearchuk.org/downloads/Product/CS_CS_SKIN.pdf (accessed August 2014)
31. Tariman J, et al. Information needs priorities in patients diagnosed with cancer: a systematic review. *Journal of the Advanced Practitioner in Oncology*. 2014. 5(2): 115-122.
32. Al-Shakhli, H. Harcourt D, Kenealy J. Psychological distress surrounding diagnosis of malignant and non malignant skin lesions at a pigmented lesion clinic. *Journal of Plastic, Reconstructive & Aesthetic Surgery*. (2006). 59, 479–486.
33. National Cancer Survivorship Initiative. Supportive and Palliative care: The manual. <http://guidance.nice.org.uk/CSGSP> (accessed July 2013)
34. Macmillan Cancer Support. Always there? The impact of the end of life care strategy on 24/7 community nursing in England. 2010. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/AlwaysThere.pdf> (accessed August 2014)
35. Macmillan Cancer Support. Treatment overview for melanoma. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Treatingmelanoma/Treatmentoverview.aspx> (accessed August 2014)
36. Cancer Research UK. Chemotherapy for melanoma. <http://cancerhelp.cancerresearchuk.org/type/melanoma/treatment/chemotherapy-for-melanoma> (accessed August 2014)
37. Cancer Research UK. Radiotherapy for melanoma. <http://cancerhelp.cancerresearchuk.org/type/melanoma/treatment/radiotherapy-for-melanoma> (accessed August 2014)
38. Department of Health. Radiotherapy Services in England 2012. <http://www.natcansat.nhs.uk/dlhandler.ashx?d=pubs&f=Radiotherapy-Services-in-England-2012.pdf> (accessed July 2014)
39. Cancer Research UK. Biological therapy for melanoma. <http://cancerhelp.cancerresearchuk.org/type/melanoma/treatment/biological-therapy-for-melanoma> (accessed August 2014)
40. Macmillan Cancer Support. Treatment for melanoma. <http://www.macmillan.org.uk/Cancerinformation/teensandyoungadults/Cancertypes/Melanoma/Treatmentformelanoma.aspx> (accessed August 2014)

41. The Health and Social Care Information Centre. Hospital Episode Statistics, Admitted Patient Care, England 2012-13. <http://www.hscic.gov.uk/article/2021/Website-Search?productid=13264&q=hospital+episode+statistics+admitted&sort=Relevance&size=10&page=1&area=both#top> (accessed July 2014)
42. Maddams, J et al. Levels of acute health service use among cancer survivors in the United Kingdom. 2011. <http://www.ncbi.nlm.nih.gov/pubmed/21592781> (accessed August 2014)
43. Macmillan Cancer Support. Internal PS@Mac data.
44. NHS England. Cancer Patient Experience Survey 2013. Q21. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
45. National Cancer Institute. What you need to know about melanoma and other skin cancer. <http://www.cancer.gov/cancertopics/wyntk/skin.pdf> (accessed August 2014)
46. Parkin DM, Mesher D, Sasieni P. 13. Cancers attributable to solar (ultraviolet) radiation exposure in the UK in 2010. *Br J Cancer* 2011;105 Suppl 2:S66-9.
47. NHS England. Cancer Patient Experience Survey 2013. Q67. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
48. NHS England. Cancer Patient Experience Survey 2013. Q46. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
49. NHS England. Cancer Patient Experience Survey 2013. Q15. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
50. NHS England. Cancer Patient Experience Survey 2013. Q17. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
51. Gao W, et al. Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications. *European Journal of Cancer*. 2010. 46(11): 2036-2044
52. NHS England. Cancer Patient Experience Survey 2013. Q60. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
53. NHS England. Cancer Patient Experience Survey 2013. Q56. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
54. NHS England. Cancer Patient Experience Survey 2013. Q28. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed August 2014)
55. Moffatt S, et al. "Done more for me in a fortnight than anybody done in all me life." How welfare rights advice can help people with cancer. *BMC Health Services Research*. 2010. 10:259)

56. Morrison V, et al. Common, important, and unmet needs of cancer outpatients. *European Journal of Oncology Nursing*. 2012. 16(2):115-123
57. Macmillan Cancer Support. *Macmillan survey of Cancer Voices: exploring information and support needs*. 2010. Macmillan Cancer Support, London.
58. Cancer Research UK. *Skin Cancer- Risk Factors* <http://cancerhelp.cancerresearchuk.org/type/melanoma/about/melanoma-risks-and-causes> (accessed July 2013).
59. Mitchell J. *Having your say about cancer in Wales*. 2009. Macmillan Cancer Support. http://www.macmillan.org.uk/Documents/GetInvolved/CancerVoices/cancerVoices/Cancervoicesconference/have_your_say.pdf (accessed July 2013)
60. Elliott J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer*. 2011. 105: S11-S20
61. Macmillan Cancer Support. *Cured – but at what cost? Long-term consequences of cancer and its treatment*. 2013. <http://www.macmillan.org.uk/Documents/Cancerinfo/Livingwithandaftercancer/Consequences/Cured-but-at-what-cost-report.pdf> (accessed September 2014)
62. Maddams J, et al. The cancer burden in the United Kingdom in 2007 due to radiotherapy. *International Journal of Cancer*. 2011. 192(12):2885-93.)
63. Macmillan Cancer Support. *Palliative and End of Life Care Framework*. Macmillan Cancer Support, London. (accessed May 2012)
64. Office for National Statistics. *Mortality statistics. Deaths registered in England and Wales 2011*. <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcM%3A77-277727> (accessed July 2013)
65. Cancer Research UK. *Skin Cancer Survival Statistics*. <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/skin/survival/#trends> (accessed August 2014)
66. MHP Health Mandate. *An Atlas of Variations in Social Care*. June 2012. <http://www.mhpc.com/health/atlas-of-variations-in-social-care/> (accessed July 2013)
67. NCIN. *Mortality, Incidence and Gender: Malignant Melanoma - NCIN Data Briefing*. London: NCIN. 2012. <http://www.ncin.org.uk/view?rid=1386> (accessed August 2014)
68. Boniol, M. et al. Cutaneous melanoma attributable to sunbed use: systematic review and meta-analysis. *British Medical Journal*. 2012. 345:e4757.
69. Gao et al. *Managing Cancer Pain at the End of Life with Multiple Strong Opioids: A Population-Based Retrospective Cohort Study in Primary Care*. *PloS One*. 2014. 9(1): e79266
70. de Santiago A et al. *A new palliative care consultation team at the oncology department of a university hospital: an assessment of initial efficiency and effectiveness*. *Support Cancer Care*. 2012. 20(9):2199-203.
71. Macmillan Cancer Support. *Cancer Patients Lose Out on Millions of Unclaimed Benefits*. 2010. http://www.macmillan.org.uk/Aboutus/News/Latest_News/CancerPatientsLoseOutOnMillionsOfUnclaimedBenefits.aspx (accessed August 2014)
72. Macmillan Cancer Support. *Getting travel insurance when you have been affected by cancer*. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Practicalissues/Travel/Gettingtravelinsurance.aspx> (accessed August 2014)

73. Higginson I, Constantini M. Dying with cancer, living well with advanced cancer. *European Journal of Cancer*. 2008. 44(10):1414-24
74. Rainbird K, et al. The needs of patients with advanced, incurable cancer. *British Journal of Cancer*. 2009. 101:759-764
75. Gwilliam B, et al. Prognosticating in patients with advanced cancer – observational study comparing the accuracy of clinicians’ and patients’ estimates of survival. *Ann Oncol*. 2013. 24(2): 482-488.
76. Macmillan Cancer Support/YouGov online survey of 2,250 UK adults aged 18+. Fieldwork conducted 6-7th August 2014. Survey results are weighted to be nationally representative of all UK adults.
77. NHS National End of Life Care Programme. What do we know now that we didn’t know a year ago? <http://www.endoflifecare-intelligence.org.uk/view?rid=464> (accessed August 2014)
78. Macmillan Cancer Support analysis, July 2012. Data was extracted from Hospital Episode Statistics (HES) database for the NHS financial year 2010/11 at episode level for all types of cancer, excluding C44 (other malignant neoplasms of skin). The data covers England only, but it is assumed that the patterns seen in England will be broadly similar in the other UK nations. The earliest hospital admittance was taken for each person within the NHS 2010/11 financial year. MOSAIC UK profiles were created for hospital admittances for people living with each of the top 10 cancer types (and a further profile for all other cancers combined, ie the rarer cancers) and compared to the base population. Base population (ie population of England) was population at the mid-point of 2010. HES records where the age of the patient was not recorded were removed from all analyses. Only records with a valid MOSAIC Type were analysed, however the number of these was small, and limited largely to data on people aged 0-14. MOSAIC profiles are built from 440 data elements, collated by Experian Ltd. For further details, visit www.experian.co.uk/business-strategies/mosaic-uk-2009.html
79. Macmillan Cancer Support. 2012. Word cloud created on wordle.net from Macmillan’s online community from the 30 most recent posts listed under “recent group activity for the malignant melanoma group, on 31 July 2012)
80. Macmillan Cancer Support/Factiva. 2012. Word cloud formed from an analysis on 31 July 2012 using www.wordle.net of the 100 most recent UK national daily newspaper articles where the key words of “malignant melanoma” appeared at least once. Frequency of the most frequent words are shown in larger fonts than less frequent words. Dates ranged from 11 August 2011 to 31 July 2012. UK national daily newspapers included: The Metro, The Times, The Daily Mail, The Mirror, The Sun, The Daily Express, The Guardian, The Telegraph and The Independent.
81. Cancer Research UK. Melanoma risks and causes. <http://cancerhelp.cancerresearchuk.org/type/melanoma/about/melanoma-risks-and-causes> (accessed August 2014)
82. Cancer Research UK. People Fear Cancer More Than Other Serious Illnesses. <http://www.cancerresearchuk.org/cancer-info/news/archive/pressrelease/2011-15-08-fear-cancer-more-than-other-diseases> (accessed August 2014)
83. Prevalence in 2015 estimated from Maddams et al. (2012). Prevalence in 2030 and 2040 taken directly from Maddams J, Utey M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*. 2012; 107: 1195-1202. (Scenario 1 presented here)

84. National Cancer Survivorship Initiative. Assessment and care planning. <http://www.ncsi.org.uk/what-we-are-doing/assessment-care-planning/> (accessed July 2013).
85. Northern Ireland Cancer Registry. Malignant Melanoma Mortality 1993-2012. <http://www.qub.ac.uk/research-centres/nicr/FileStore/Excel/Mortality/Filetoupload,439607,en.xlsx> (accessed August 2014)
86. ISD Scotland. Skin Cancer Mortality 2012. https://isdscotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2013-11-26/sm_cancer_skin.xls?9069461 (accessed August 2014)
87. Cancer Research UK. Skin cancer incidence statistics. <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/skin/incidence/> (accessed August 2014)
88. Macmillan Cancer Support. Symptoms of melanoma. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Symptomsanddiagnosis/Symptomsofmelanoma/Symptomsofmelanoma.aspx> (accessed August 2014)
89. ISD Scotland. Skin Cancer Incidence in Scotland 2012. https://isdscotland.scot.nhs.uk/Health-Topics/Cancer/Publications/2014-04-29/si_cancer_skin.xls?9069461 (accessed August 2014)
90. Welsh Cancer Intelligence and Surveillance Unit. Skin cancer incidence in Wales 1985-2012. <http://www.wcisu.wales.nhs.uk/opendoc/238721> (accessed August 2014)
91. Northern Ireland Cancer Registry. Malignant Melanoma Incidence and Survival 1993-2012. <http://www.qub.ac.uk/research-centres/nicr/FileStore/Excel/Filetoupload,431454,en.xls> (accessed August 2014)
92. Welsh Cancer Intelligence and Surveillance Unit. Skin cancer mortality in Wales 1985-2012. <http://www.wcisu.wales.nhs.uk/opendoc/238745> (accessed August 2014)
93. Macmillan Cancer Support. Symptoms of advanced melanoma. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Symptomsanddiagnosis/Symptomsofmelanoma/Symptomsofadvancedmelanoma.aspx> (accessed August 2014)
94. Macmillan Cancer Support. Making the Shift. 2013. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/WorkingThroughCancer/Making-the-shift-specialist-work-support-for-people-with-cancer.pdf> (accessed July 2014)
95. Macmillan Cancer Support/RBS Group. Cancer's Hidden Price Tag: Revealing the Costs behind the Illness. 2013. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf> (accessed August 2014)
96. Macmillan Cancer Support. Facing the Fight Alone: Isolation among Cancer Patients. 2013. http://www.macmillan.org.uk/Documents/AboutUs/MAC13970_Isolated_cancer_patients_media_reportFINAL.pdf (accessed July 2013)
97. NCAT. Clinical Nurse Specialists in Cancer Care. 2011. http://www.bdng.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf (accessed July 2014)
98. Department of health. Cancer Patient Experience Survey 2011.Q68. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212860/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf (accessed July 2013)
99. Macmillan Cancer Support. Can we live with how we're dying? 2014. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/EndofLifereport-June2014.pdf> (accessed July 2014)

100. Office for National Statistics. 2013. National Bereavement Survey (VOICES) 2012 Statistical Bulletin. <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2012/stb---national-bereavement-survey-2012.html> (accessed July 2013).
101. Krahn MD, et al. Healthcare costs associated with prostate cancer: estimates from a population-based study. *BJU International*. 2010. 105: 338-346
102. Office for National Statistics. National Bereavement Survey (VOICES) 2012 <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2012/stb---national-bereavement-survey-2012.html#tab-Place-of-Death> (accessed August 2014)
103. Macmillan Cancer Support. Facing the Fight Alone. 2013. http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Isolated_cancer_patients_media_report.pdf (accessed August 2014)
104. NCCPC. Palliative Care Explained. <http://www.nccpc.org.uk/palliative-care-explained> (accessed August 2014)
105. Macmillan Cancer Support. February 2010 online survey of 1,019 UK adults living with cancer. Survey results have not been weighted.
106. Macmillan Cancer Support. Cancer in the UK 2014. <http://www.macmillan.org.uk/Documents/AboutUs/WhatWeDo/CancerintheUK2014.pdf> (accessed September 2014)
107. Macmillan Cancer Support. Throwing the light on the consequences of cancer and its treatment. 2013. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Throwinglightontheconsequencesofcanceranditstreatment.pdf> (accessed September 2014)

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 Picture on teenagers and young adults with cancer	(MAC14661_14)

Other Rich Pictures

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

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

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

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

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

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

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

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

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