

Diane, 49, living with breast cancer

**THE RICH PICTURE**  
**PEOPLE WITH**  
**BREAST**  
**CANCER**

**WE ARE**  
**MACMILLAN.**  
**CANCER SUPPORT**

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

**2017 update**

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# 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 the 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 [www.macmillan.org.uk/Richpictures](http://www.macmillan.org.uk/Richpictures) or for further information please contact [evidence@macmillan.org.uk](mailto:evidence@macmillan.org.uk)

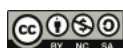
## The legal bit

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

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

Macmillan or any other organisation referenced in this document claim no responsibility for how third parties use the information contained in this document. We have endeavoured to include all the major data available to us as of July 2017, 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 68.

## 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 breast cancer**  
MAC11616



**Understanding breast reconstruction**  
MAC11660



**Understanding breast cancer in men**  
MAC11915



**Managing the late effects of breast cancer treatment**  
MAC12161



**Understanding secondary breast cancer**  
MAC11617



**Understanding risk-reducing breast surgery**  
MAC11680

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

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

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# Find out more about cancer: what Macmillan can offer

Macmillan's own evidence has revealed the story of cancer is changing. We produce a variety of evidence that helps us, and others, understand the needs, numbers and experiences of people affected by cancer.



## Our research publications

### Our reports and posters

Published Macmillan research and evaluation reports, as well as summaries of commissioned research and research posters, produced either by Macmillan or our partners.

### Rich Pictures

Our suite of Rich Pictures describe the needs, numbers and experiences of key groups within the 2.5 million people living with cancer.

### Impact Briefs

Our suite of Impact Briefs describe what some of our services do and the impact they have on people affected by cancer.

## Our cancer intelligence

### Local Cancer Intelligence tool (LCI)

Combining local cancer population data with insight from Macmillan and other sources, LCI is an online tool designed to help you use data as evidence to plan services and influence decisions.

### Routes from Diagnosis

Results from first phase of the Routes from Diagnosis study, including outcome pathways, survival rates, inpatient costs and comorbidities associated with some cancers.

### Cancer Patient Experience Survey

Macmillan's partnership work to gain insight on how patients feel about their care, what's working and what could be done better.

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# SUMMARY OF PEOPLE LIVING WITH BREAST CANCER

## Key stats

**Breast cancer is the most common cancer in the UK**, with an average of around 150 cases diagnosed every day. Breast cancer in men is very rare – less than 1% of cases are amongst males.<sup>(3,4,5,6)</sup>

The lifetime risk of being diagnosed with breast cancer is **1 in 8 for women** in the UK.<sup>(12)</sup>

Breast cancer is now the **second most common cause of death** from cancer in women, with just over **11,400** women dying from breast cancer in the UK every year.<sup>(9,10,11)</sup>

Survival rates for breast cancer are generally high due to early diagnosis and treatment – **around 96% of women in England survive their cancer at least one year after diagnosis.**<sup>(8)</sup>

## Diagnosis

Around **3%** of new breast cancer cases are thought to be caused by an **inherited gene** which can increase the risk of breast cancer.<sup>(55)</sup>

Over **20,000** people were diagnosed with breast cancer following routine screening in 2015-16 in the UK.<sup>(42,43,44,45)</sup>

The most common symptoms of breast cancer are **lumps in the breast**, or other changes to its appearance. The majority of breast cancer cases are diagnosed after women notice unusual changes.<sup>(1)</sup>

## Treatment

The most common form of treatment for breast cancer is surgery. Around **74% of all patients in England will have surgery** to either remove part, or all, of their breast. However, this procedure is not as common in older patients with only **25% of those aged 85+** receiving resections.<sup>(29,65)</sup>

Some of the most common side effects during breast cancer treatment are **fatigue, hot flushes, numbness and cognitive impairment.**<sup>(78,140,79,80)</sup>

Drugs can be prescribed to treat pain, nausea and osteoporosis but they may lead to other side effects themselves.<sup>(81,82,83)</sup>

Increased **household fuel bills** and the **cost of travel** to and from appointments lead to extra costs during the treatment period.<sup>(76)</sup>

## Survivorship

Regular interactions with professionals are important as they could address any clinical issues arising after treatment.<sup>(132)</sup> **12% of breast cancer patients in England felt that they were not given enough care and support** from health or social care services once they finished their treatment.<sup>(26)</sup>

Some **breast cancer treatments can affect women's fertility** which can be a source of concern. Although younger women are more likely to not experience these problems, it is important that doctors communicate these issues with patients prior to treatment.<sup>(97)</sup>

Breast cancer survivors have an **increased risk of bone thinning** due to the effects of hormonal therapy and going through early menopause. Physical activity such as walking, dancing and resistance training can help keep bones strong.<sup>(133)</sup>

## End of Life

Nearing death, cancer patients may experience **difficulty sleeping, tiredness, breathlessness and difficulty eating.**

<sup>(111)</sup> Opioids are sometimes prescribed at the end of life to help alleviate pain experienced by cancer patients.<sup>(106)</sup>

Approximately **70%** of all cancer patients prepare their will but only **11%** prepare what kind of care they would like at the end of life.<sup>(110)</sup>

## Lifestyle & perceptions

**Almost all people diagnosed with breast cancer are women**, and over **80% of them are aged 50 or over.**<sup>(3,4,5,6)</sup>

**Fear of breast cancer is fairly high** amongst the general public.<sup>(39)</sup> This can be attributed to the high profile and public awareness of breast cancer.

Perceptions of breast cancer vary across the population. Some evidence suggests that feelings of **blame** and **fatalistic beliefs** can sometimes be present in the breast cancer population.<sup>(46,143)</sup>

# INTRODUCTION TO BREAST CANCER

## What is breast cancer?

Breast cancer is a predominantly female cancer, and so the majority of statistics and information relate to female patients, however men can also be diagnosed with breast cancer. Breast cancer is a malignant tumour that starts in the cells of the breast. A malignant tumour is a group of cancer cells that can grow into surrounding tissues or spread to distant areas of the body. Breast cancer that has spread to another part of the body is called secondary breast cancer.

## What types of breast cancer are there?<sup>(2)</sup>

There are several types of breast cancer.

**Ductal carcinoma in situ (DCIS)** is the earliest form of breast cancer. DCIS is a non-invasive form of breast cancer, which means that cancer cells are in the ducts of the breast, but have not started to spread into the surrounding breast tissue. DCIS is usually diagnosed when women go for breast screening.

If cancer cells have spread outside the lining of the ducts or lobules (the glands that produce milk when breast feeding) into surrounding breast tissue, it is called invasive breast cancer. There are several different types of invasive breast cancer:

- **Invasive breast cancer (NST)** – this is the most common type of breast cancer. NST stands for 'No Special Type', which means that cancer cells do not have any special features. It is sometimes called NOS (Not Otherwise Specified) or ductal carcinoma.
- **Invasive lobular breast cancer** – happens when the cancer starts in cells that line the lobules (the glands that produce milk when breast feeding) and spreads into the surrounding tissue. About 1 in 10 breast cancers are of this type.
- **Inflammatory breast cancer** – the breast can become swollen, red and inflamed. The cancer cells block the lymph vessels and this blockage causes these symptoms. This cancer is rare, with 1 in 10,000 diagnosed breast cancers being this type.

- **Paget's disease of breast** – this is a condition where people develop an eczema-like rash around the nipple. 9 out of 10 people with Paget's disease of the breast have an underlying breast cancer. Only around 1% to 4% of diagnosed breast cancers are this type.

Breast cancer can also be classified by receptor status. Breast cancer cells often have receptors (proteins) that hormones or other proteins can attach to and stimulate the cancer to grow. Based on this a breast cancer can be:

- **ER-positive (oestrogen receptor positive)** – about 80% of cancers are ER-positive. The cancer has receptors for the hormone oestrogen and grow in response to oestrogen.
- **Triple negative** – these cancers do not have receptors for either oestrogen, progesterone or the protein HER2. Around 15% of diagnosed breast cancers are triple negative.
- **HER2 positive** – these cancers have a large number of receptors for the protein HER2, which stimulates the cancer cells to divide and grow. About 15% to 25% of breast cancers are HER2 positive.

## Want to know more?

Macmillan produces a wealth of information about what breast cancer is, its causes, symptoms and treatment. To find out more, call our Macmillan team on the number below, or visit our website.

You may have cancer, but you are still you. Macmillan is here to help you live life no matter what. We'll give you the support you need to hold on to who you are and what's important to you.

From the moment you're diagnosed, for as long as you need us, you can lean on Macmillan. Call us free on **0808 808 00 00** or visit **macmillan.org.uk**

Life with cancer is still life – we'll help you live it.



**'I was diagnosed with breast cancer at the beginning of August 2015.**

**It was a real shocker as I was a runner with couple of half marathons under my belt. I also love to garden and grow my own veg and no one in my family has had breast cancer despite there being hundreds of us.**

**I was distraught when I was told as we'd lost a friend, Rachel, to breast cancer a couple of years before, so in my mind I couldn't get my head round that it would be ok.'**

**Diane**

# KEY FACTS AND STATS ON BREAST CANCER

This section presents some of the key stats and facts relating to people with breast cancer. You may benefit from referring to the jargon buster on page 77 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.

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**150**

cases of breast cancer diagnosed on average everyday in the UK<sup>(3,4,5,6)</sup>

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**691,000**

women estimated to be living with breast cancer in the UK in 2015<sup>(7)</sup>

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**96%**

of women in England survive their breast cancer at least one year after diagnosis<sup>(8)</sup>

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**86%**

of women in England survive their breast cancer at least five years after diagnosis<sup>(8)</sup>

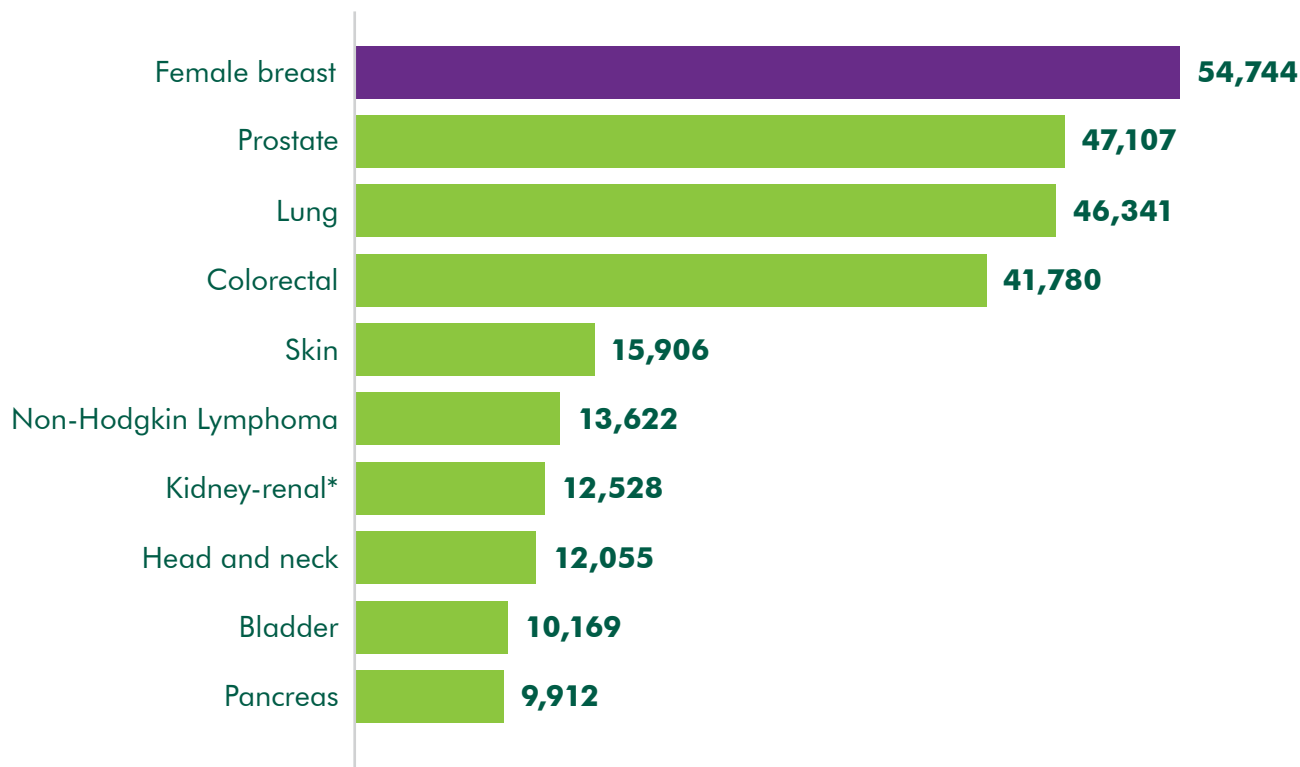
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**30**

women, on average, die every day of breast cancer in the UK<sup>(9,10,11)</sup>

## How many people get breast cancer per year? (incidence)<sup>(3,4,5,6)</sup>

### Cancer incidence, UK, 2015, top 10 sites, all genders



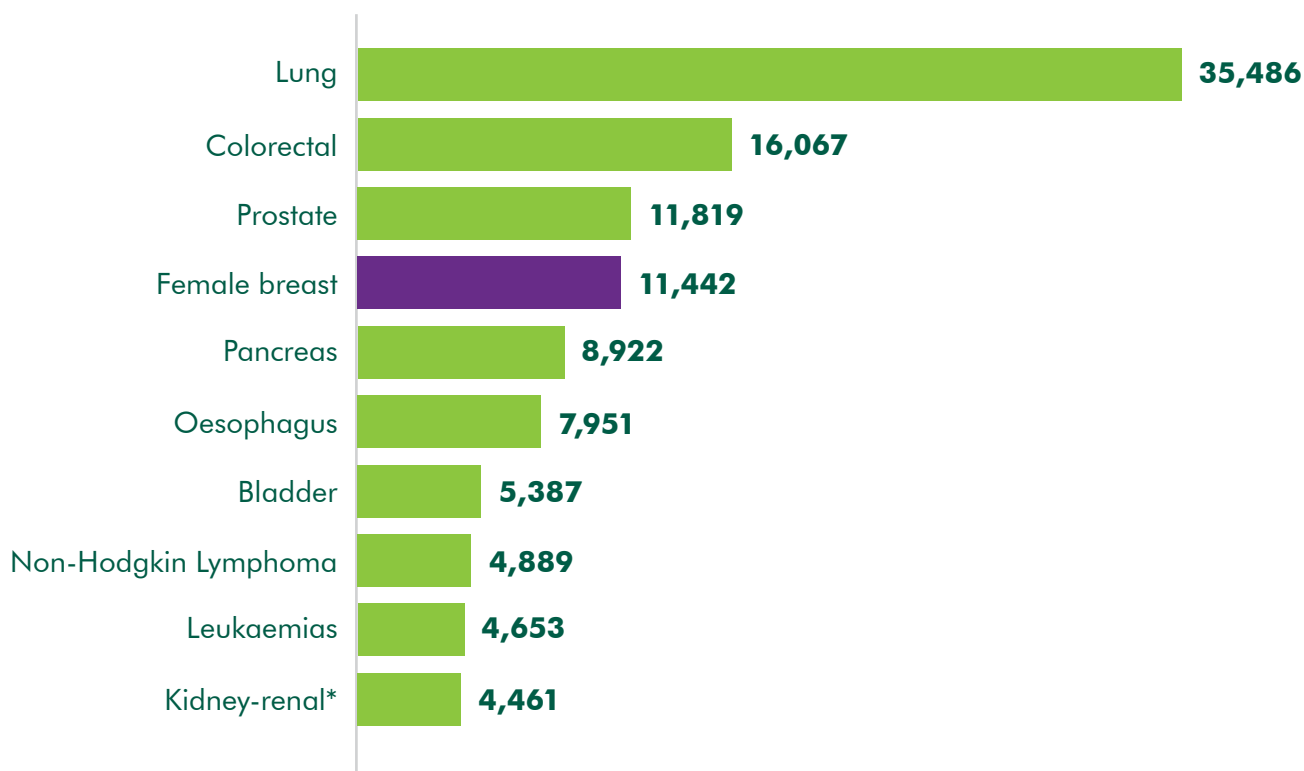
\*calculated using ICD-10 codes C64-C66, C68.

**Breast cancer is the most commonly diagnosed cancer in the UK, with a lifetime risk of being diagnosed for women of 1 in 8.<sup>(12)</sup>**

**Almost 55,000 women are diagnosed every year in the UK, that's around 150 women every day.**

## How many people die from breast cancer per year? (mortality)<sup>(9,10,11)</sup>

### Cancer mortality, UK, 2015, top 10 sites



\*calculated using ICD-10 codes C64-C66, C68.

**In 2015, over 11,400 women died from breast cancer; around 30 every day.**

**In the UK, breast cancer is now the fourth most common cause of death from cancer for all genders and second if considering women only.**

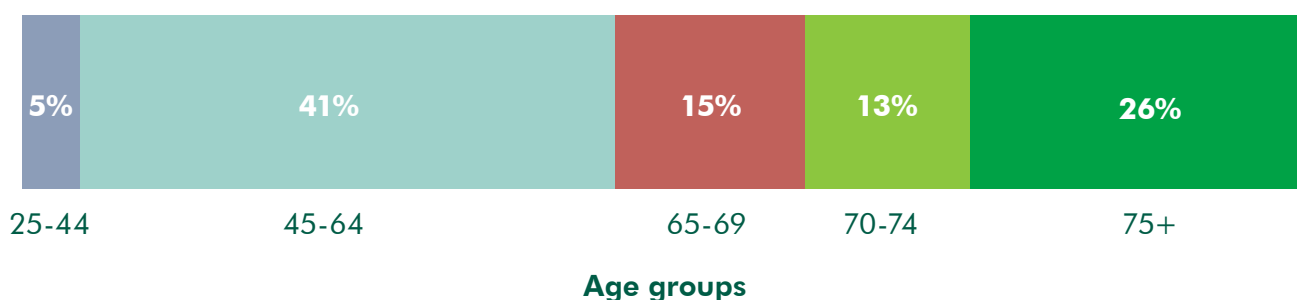
## How many people are living with breast cancer? (prevalence)

### Prevalence, UK, 2015<sup>(7)</sup>

Women estimated to be living with breast cancer in the UK

# 691,000

### 20-year breast cancer prevalence in 2010 by age (based on diagnosis between 1991-2010), England<sup>(24)\*</sup>



\*The percentages cannot be applied to the overall prevalence figure of 691,000 as they were calculated using different prevalence data sets – see references.

**Looking at age distribution, over half of the female breast cancer population is aged 65 or over.**

## 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 2013) 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 women get breast cancer per year in England?<sup>(3)</sup>**

**45,764**

new diagnoses in England in 2015.

**How many women die from breast cancer per year in England?<sup>(9)</sup>**

**9,556**

deaths from breast cancer in England in 2015

**How many women are living with breast cancer in England?<sup>(13)</sup>**

**579,000**

women were estimated to be living with breast cancer in 2015

**What is the age-standardised\* rate of female breast cancer incidence in England?<sup>(14)</sup>**

**170.2**

new cases of breast cancer per 100,000 women in 2015

**What is the age-standardised\* rate of female breast cancer mortality in England?<sup>(18)</sup>**

**34.3**

deaths from breast cancer per 100,000 women in 2015

## 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 2013) 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 women get breast cancer per year in Scotland?<sup>(4)</sup>**

**4,738**

new diagnoses in Scotland in 2015

**How many women die from breast cancer per year in Scotland?<sup>(10)</sup>**

**989**

deaths from breast cancer in Scotland in 2015

**How many women are living with breast cancer in Scotland?<sup>(13)</sup>**

**58,000**

women were estimated to be living with breast cancer in 2015

**What is the age-standardised\* rate of female breast cancer incidence in Scotland?<sup>(15)</sup>**

**168.8**

new cases of breast cancer per 100,000 women in 2015

**What is the age-standardised\* rate of female breast cancer mortality in Scotland?<sup>(19)</sup>**

**34.7**

deaths from breast cancer per 100,000 women in 2015

## 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 2013) 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 women get breast cancer per year in Wales?<sup>(5)</sup>**

**2,786**

new diagnoses in Wales in 2015

**How many women die from breast cancer per year in Wales?<sup>(11)</sup>**

**612**

deaths from breast cancer in Wales in 2015

**How many women are living with breast cancer in Wales?<sup>(13)</sup>**

**38,000**

women were estimated to be living with breast cancer in 2015

**What is the age-standardised\* rate of female breast cancer incidence in Wales?<sup>(16)</sup>**

**170.0**

new cases of breast cancer per 100,000 women in 2015

**What is the age-standardised\* rate of female breast cancer mortality in Wales?<sup>(20)</sup>**

**35.5**

deaths from breast cancer per 100,000 women in 2015



## 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 2013) 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 women get breast cancer per year in Northern Ireland?<sup>(6)</sup>**

**1,456**

new diagnoses in Northern Ireland in 2015

**How many women die from breast cancer per year in Northern Ireland?<sup>(12)</sup>**

**285**

deaths from breast cancer in Northern Ireland in 2015

**How many women are living with breast cancer in Northern Ireland?<sup>(13)</sup>**

**16,000**

women were estimated to be living with breast cancer in 2015

**What is the age-standardised rate of female breast cancer incidence in Northern Ireland?<sup>(17)</sup>**

**169.6**

new cases of breast cancer per 100,000 women in 2015

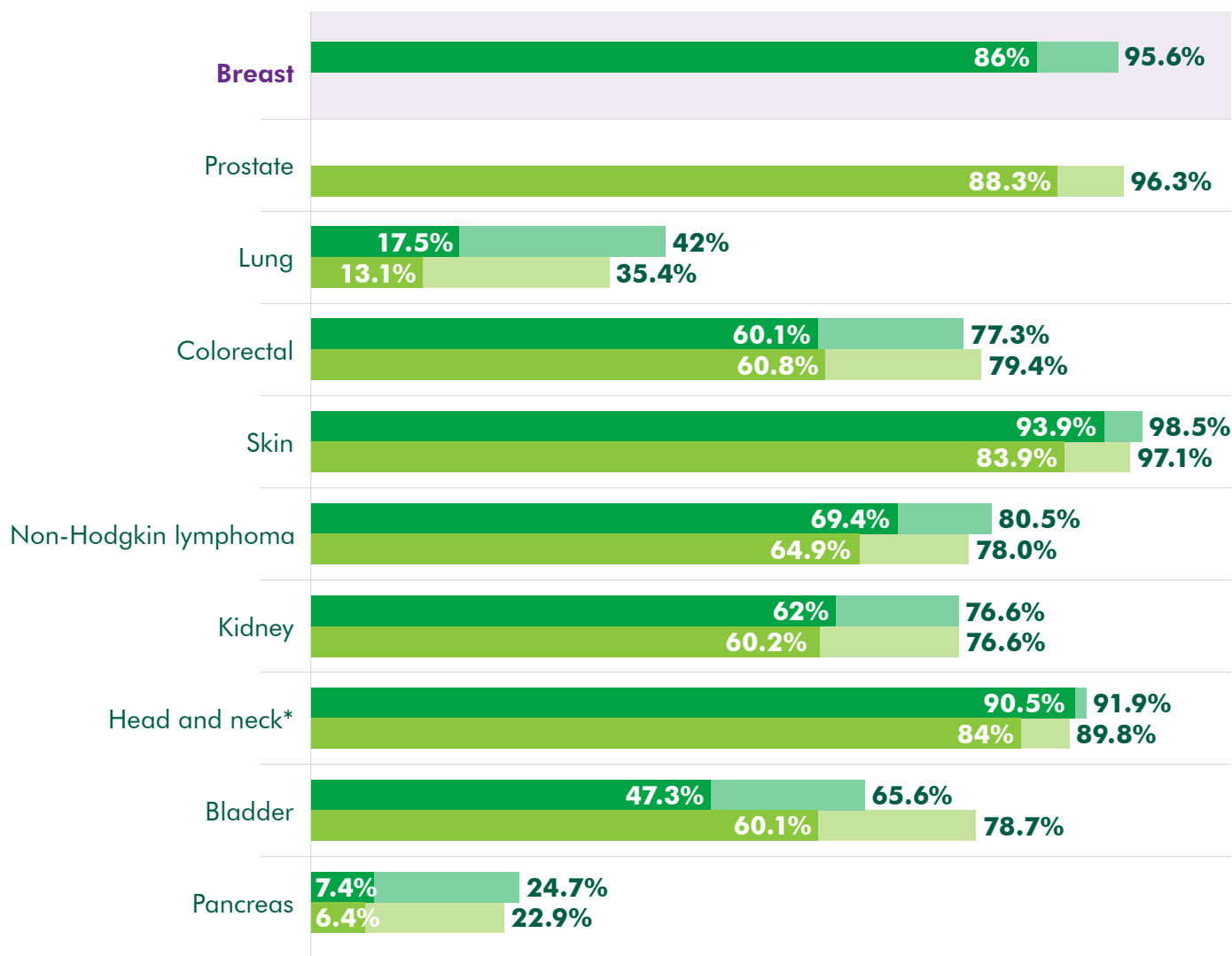
**What is the age-standardised rate of female breast cancer mortality in Northern Ireland?<sup>(21)</sup>**

**33.2**

deaths from breast cancer per 100,000 women in 2015

## How many people survive at least one and five years after their breast cancer diagnosis? (survival)<sup>(22)</sup>

1-year and 5-year age-standardised net survival rates, for the top 10 most commonly diagnosed cancers, England, 2011-2015



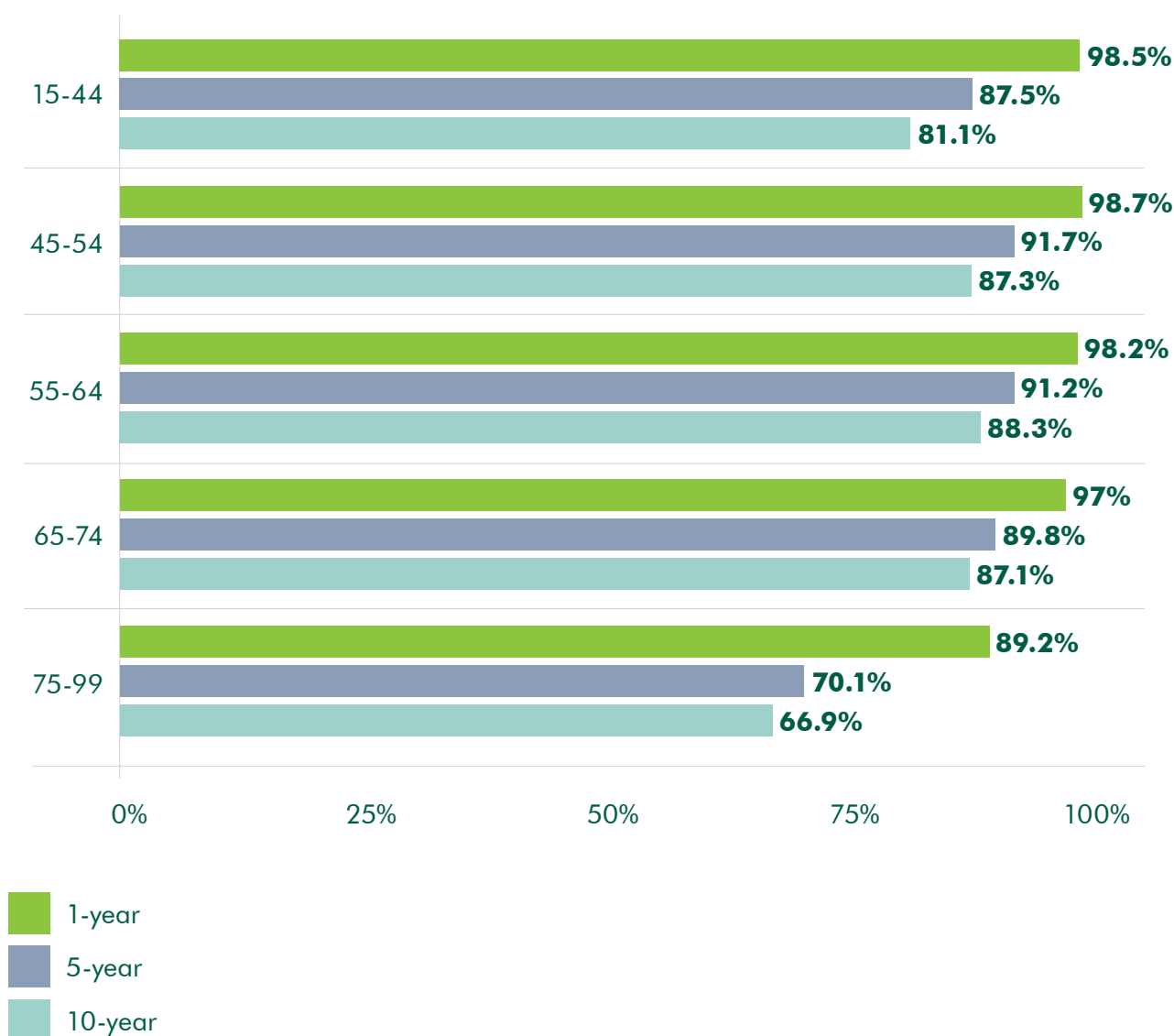
\*Thyroid cancer only



**Almost 96% of women in England survive their breast cancer one year after diagnosis – one of the highest 1-year survival rates of all cancers for females. This can be seen as the result of several different factors including improved detection through screening, increasing specialisation of care, and better access to more effective treatments.**

## How does survival vary with age?<sup>(22)</sup>

1-, 5- and 10-year age-standardised predicted net survival (%) for women (aged 15 to 99 years) who would be diagnosed in 2016 with breast cancer, England

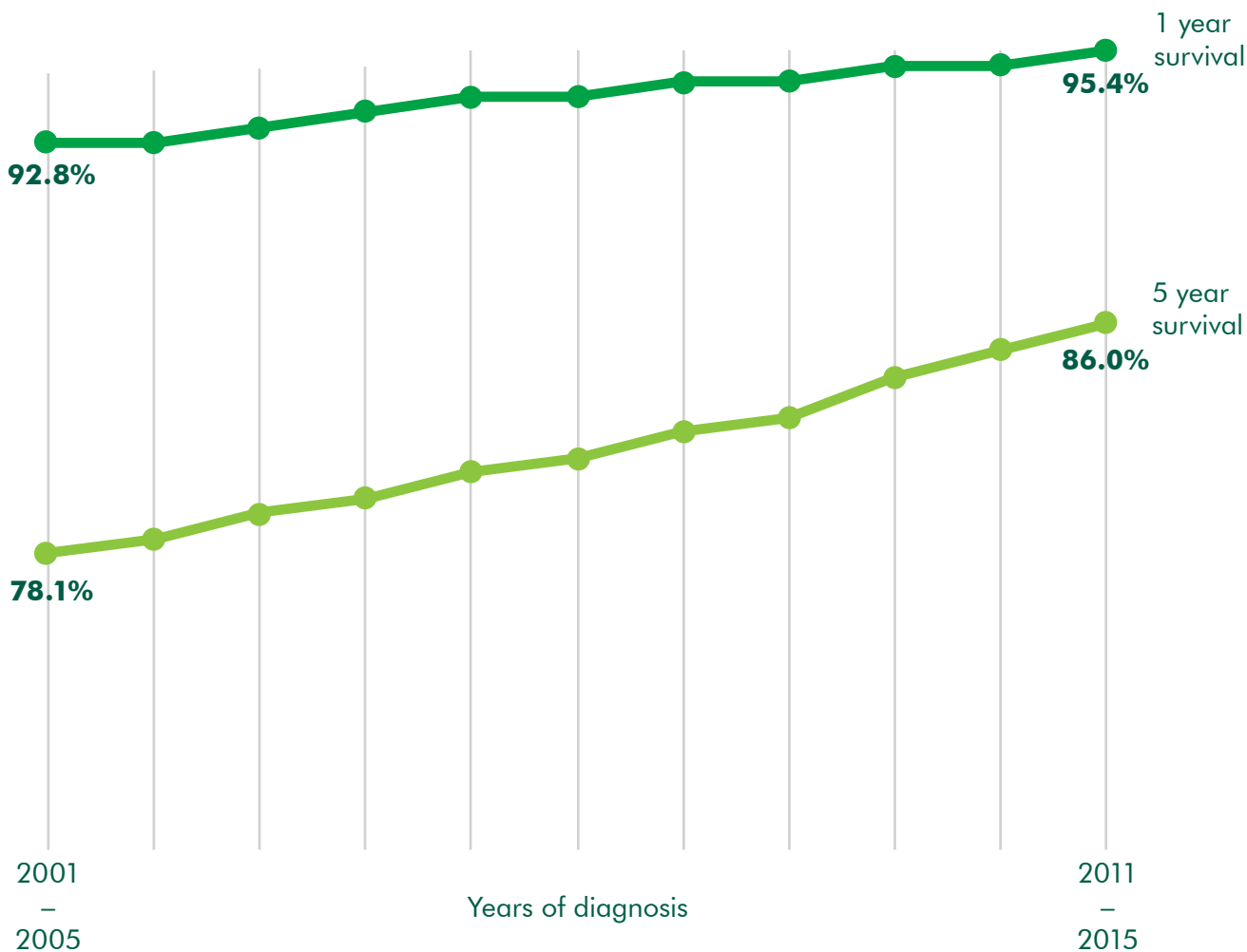


**Predicted survival rates by age show that, whilst breast cancer survival is generally high, 5- and 10-year rates decline sharply for older patients.**

**Interestingly, both 5- and 10-year survival rates are higher for women aged 45-54 than for younger patients (aged 15-44).**

## How has breast cancer survival changed over time?<sup>(22)</sup>

1-year and 5-year age-standardised net survival rates between women diagnosed in 2001-2005 and 2011-2015, England



**In general, both 1-year and 5-year survival rates have increased for breast cancer over the years. 86% of women diagnosed between 2011 and 2015 now survive their breast cancer five years after diagnosis. This is higher than for women diagnosed between 2001-2005 (78%).**

## International comparisons

### What are the global statistics on incidence, mortality and prevalence of breast cancer in women?

In 2012, it was estimated that there were 6.3 million women living with breast cancer globally. There were over 1.6 million cases of female breast cancer diagnosed, making up around 25% of all new cases of cancer in women. In the same year, there were just over 520,000 deaths from breast cancer.<sup>(130)</sup>

### How do UK breast cancer survival rates compare internationally?

The UK performs worse on both 1 and 5-year survival when compared to other developed countries. For 2005-2009, 5-year survival was around 81% in the UK nations, 82% in Denmark, 86% in Norway, Australia, Canada and Sweden.<sup>(131)</sup> This suggests there is more we can do to improve survival for people with breast cancer in the UK.

However, survival has improved in the UK, which is possibly due to diagnosis at an early stage, including through effective screening programmes, access to optimal treatment and improvements in the management of older people with cancer.<sup>(33)</sup>

## Demographic comparisons

### How do incidence, mortality and prevalence vary by gender?

Breast cancer is a predominantly female cancer, but a small number of men also get breast cancer. In 2015, 54,744 women and 359 men were diagnosed with breast cancer in the UK.<sup>(3,4,5,6)</sup>

In the same year, 11,442 women and 77 men died from breast cancer in the UK.<sup>(9,10,11)</sup>

Among men, breast cancer is the 26th most common cancer, accounting for less than 1% of male cancer cases, whereas breast cancer accounts for around 46% of cancer prevalence amongst women in the UK.<sup>(7)</sup>

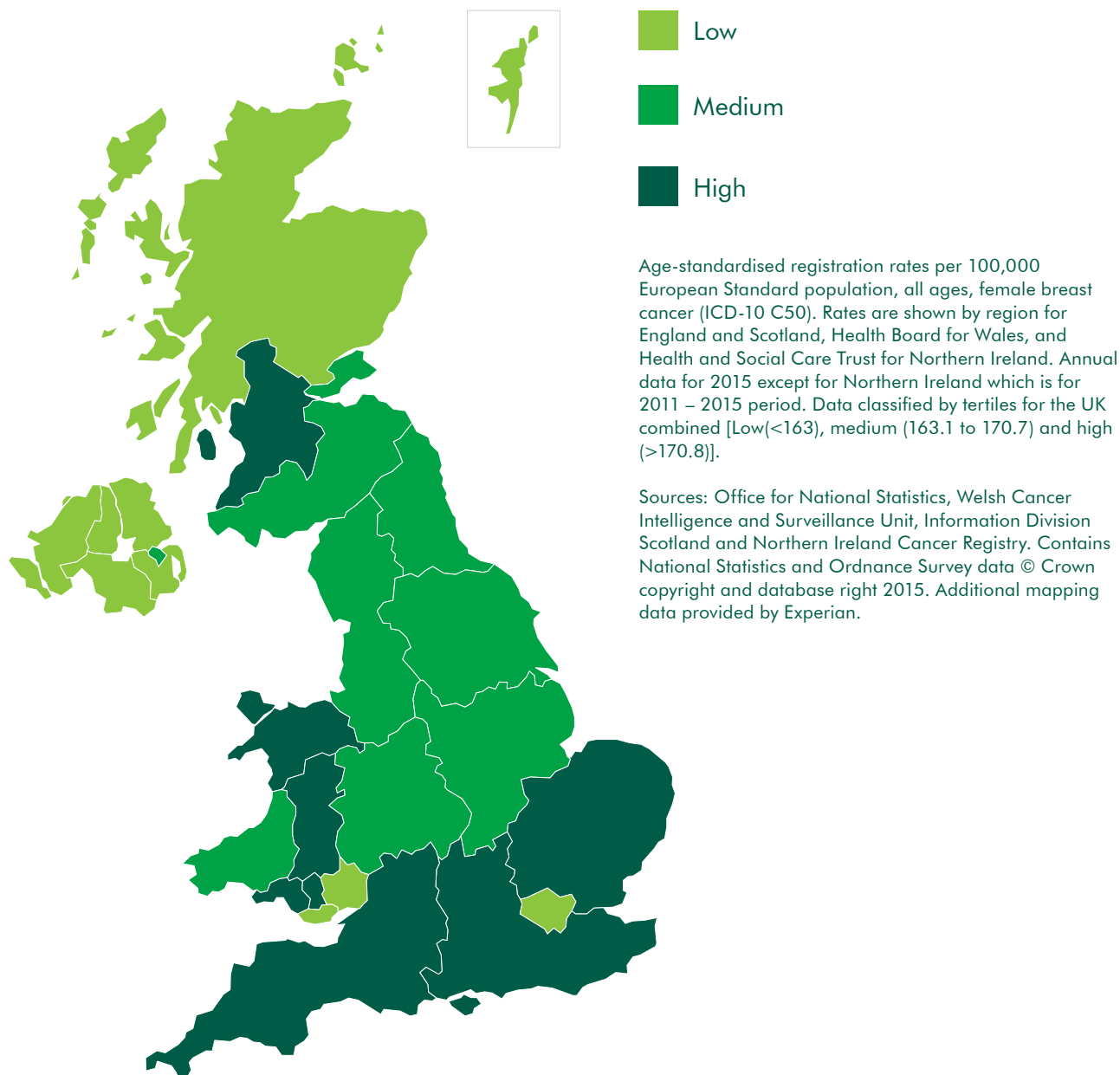
### How do incidence and survival vary by ethnic background?

90% of breast cancer patients in England are White women.<sup>(149)</sup> Looking at deprivation, 75% of women with breast cancer known to be Black and 62% of women known to be Asian were in the two most deprived quintiles. This compares to just 33% of White women with breast cancer.<sup>(34)</sup>

46% of Black people with breast cancer were diagnosed under 50 and had tumours which were significantly larger and of a higher grade in comparison to White patients. Additionally, only 20% of Black patients had screen-detected breast cancers compared with 33% and 31% of women known to be White or Asian, respectively.<sup>(34)</sup>

## Thematic maps – distribution of breast cancer incidence in the UK

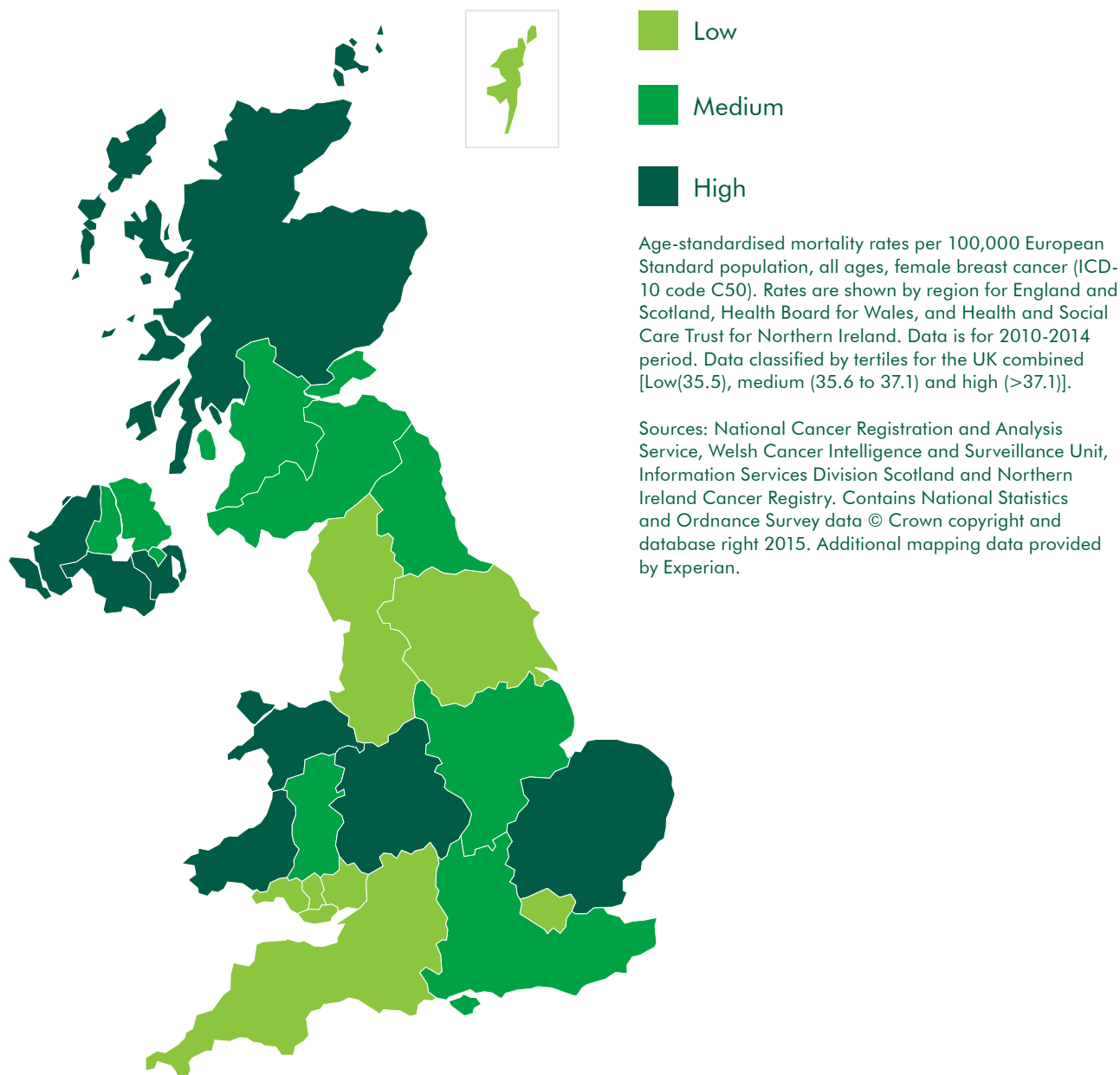
### Female breast cancer incidence, UK, 2015



**Breast cancer incidence rates are generally higher in Southern England and lower part of Scotland and Northern Ireland.**

## Thematic maps – distribution of breast cancer mortality in the UK

### Female breast cancer mortality, UK, 2010-2014



**Some areas of England appear to have lower mortality rates, but in general no clear pattern emerges.**

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

Although more women are being diagnosed with breast cancer than in previous years, improvements in treatment mean that they are living for longer.

Hereditary factors explain only around a quarter of breast cancer risk. However, there is a clear link between the incidence of breast cancer and a family history of breast cancer as women with a mother, sister or daughter diagnosed with breast cancer have around twice higher risk of being diagnosed with breast cancer themselves. Over 85% of women with a first-degree relative with breast cancer will never develop breast cancer themselves. 87% of women with breast cancer have no first-degree relatives with the disease.<sup>(36)</sup>

There are currently around 691,000 women living with breast cancer in the UK.<sup>(7)</sup>

## Female breast cancer mortality rates are decreasing:

Female breast cancer mortality rates decreased overall for most of the broad adult age groups in the UK since the early 1970s, but have increased overall in females aged 80+. The largest decrease has been in females aged 25-49, with rates falling by 55% between 1971-1973 and 2012-2014.<sup>(37)</sup>

## Survival rates are improving:

Breast cancer survival rates have been improving for 40 years and more women are surviving breast cancer than ever before.

In the 1970s around 5 out of 10 women with breast cancer survived the disease beyond five years. Now it is more than 8 out of 10.

This can generally be attributed to faster diagnosis due to improvements in treatment, raised awareness and screening programmes.<sup>(38)</sup>



**'When I was diagnosed I did think  
"oh god I should've gone earlier"...  
I wish now as soon as I'd found it  
I thought I'll go and get it checked.  
But I think sometimes you're just  
like "I don't want to make a fuss"'**

Diane

# 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 breast cancer at these stages.**

## A typical 'cancer journey' showing four key stages:

### 1 Diagnosis

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

This stage of the cancer journey can include different elements, such as:

- Being concerned about health and going for tests
- Receiving a cancer diagnosis
- Cancer coming back – when people are diagnosed with a new cancer after surviving a previous cancer

### 2 Treatment

#### What can I expect when I'm being treated for cancer?

This stage of the cancer journey can include different elements, such as:

- Starting and going through treatment
- Finishing treatment and recovering from cancer

### 3 Life after treatment\*

#### If I complete my treatment for cancer, what next?

This stage of the cancer journey can include different elements, such as:

- Living with consequences of cancer and/or its treatment
- Living well after cancer

### 4 Progressive illness and end of life

#### If my cancer is incurable, what might I experience?

This stage of the cancer journey can include different elements, such as:

- Cancer that is treatable but not curable
- End of life

\*This is often referred to as 'survivorship' or 'Living with and beyond cancer'. While Survivorship relates to the time both during and post-treatment, as illustrated by the Recovery Package (p43), this section largely highlights the post-treatment needs and experiences of people living with cancer.

# NEEDS AND EXPERIENCES: DIAGNOSIS

## What are the top 3 signs and symptoms of breast cancer?<sup>(1)</sup>

- A lump in the breast or armpit
- A change in the size or shape of the breast
- Dimpling of the skin or thickening in the breast tissue

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

According to recent data, 52% of breast cancer patients in England saw their GP once before referral to hospital and around 29% of breast cancer patients went straight to hospital following a cancer screening appointment. This was higher than most other cancer patients.<sup>(26)</sup>

In addition to this, the majority of breast cancer cases are diagnosed after women notice unusual changes, take the initiative and visit their doctor. This suggests that there is a relatively high level of awareness about breast cancer symptoms.<sup>(23)</sup>

However, there is evidence that breast cancer awareness varies widely in different ethnic groups in the UK. Therefore, further education is needed, particularly among ethnic minorities.<sup>(41)</sup>

GPs follow guidelines to decide whether or not to send patients to a breast clinic. They usually will if there are changes in the breast such as a definite lump, puckering or dimpling, changes to the nipple, including a rash or discharge, or severe and persistent breast pain.<sup>(40)</sup>

## How well does screening work for breast cancer?

There is a successful screening process in place for breast cancer. The NHS screening programme ensures that all women aged 50-70 in the UK are invited for screening every 3 years. As of 2010 this programme is extending the age range of women entitled to screening to those aged 47 to 73.<sup>(25)</sup> Between 2014-2015, 1.8 million women, aged 50-70 had undergone screening in England.<sup>(141)</sup>

Around 2.5 million women were screened by the UK NHS breast screening programme in England, Wales, Northern Ireland and Scotland between 2015-2016, with 20,737 cancers (invasive and non-invasive) detected.<sup>(42,43,44,45)</sup>

However, given that over 55,000 new cases of breast cancer (invasive) were reported in 2015 there is still room for improvement in the screening process.<sup>(46,47,48,49)</sup>

Some women are deemed to be at 'high risk' of a breast cancer diagnosis, often because of their family history. The Cancer Reform Strategy 2007 recommended that all women identified as being at higher risk (for example, because of their family history) should be offered the opportunity to have their risk formally assessed. As of 2011, the NHS Breast Screening Programme is also working to meet the needs of these women.<sup>(50)</sup>

## How is breast cancer diagnosed?<sup>(25)</sup>

Routes to diagnosis, England, 2006-2014, breast cancer\*

Emergency

4%



GP referral

11%



2-week wait

48%



Screening

29%



Other

7%

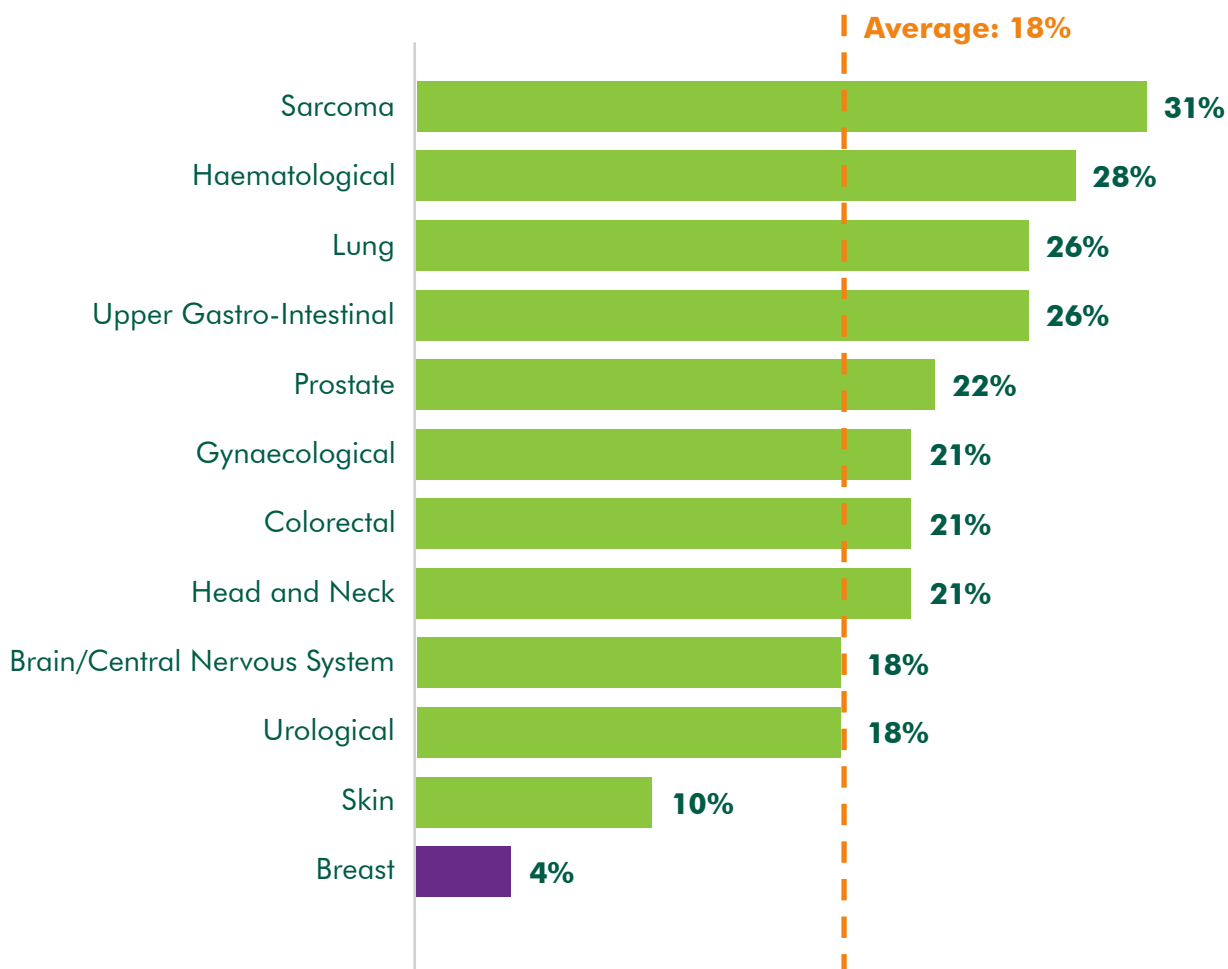
'Other' includes in-patient and out-patient routes, 'death certificate only' diagnoses, and 'unknown' routes.

\*invasive breast cancer only

**Only 4% of people newly diagnosed with breast cancer were diagnosed via the emergency route; this is significantly lower than the average for all cancers (22%). This is indicative of higher rates of early diagnosis through NHS screening programmes, in addition to increased public awareness regarding checking for symptoms.**

## How many breast cancer patients had to see their GP more than twice before they were diagnosed?<sup>(26)</sup>

More than two GP visits, England, 2016

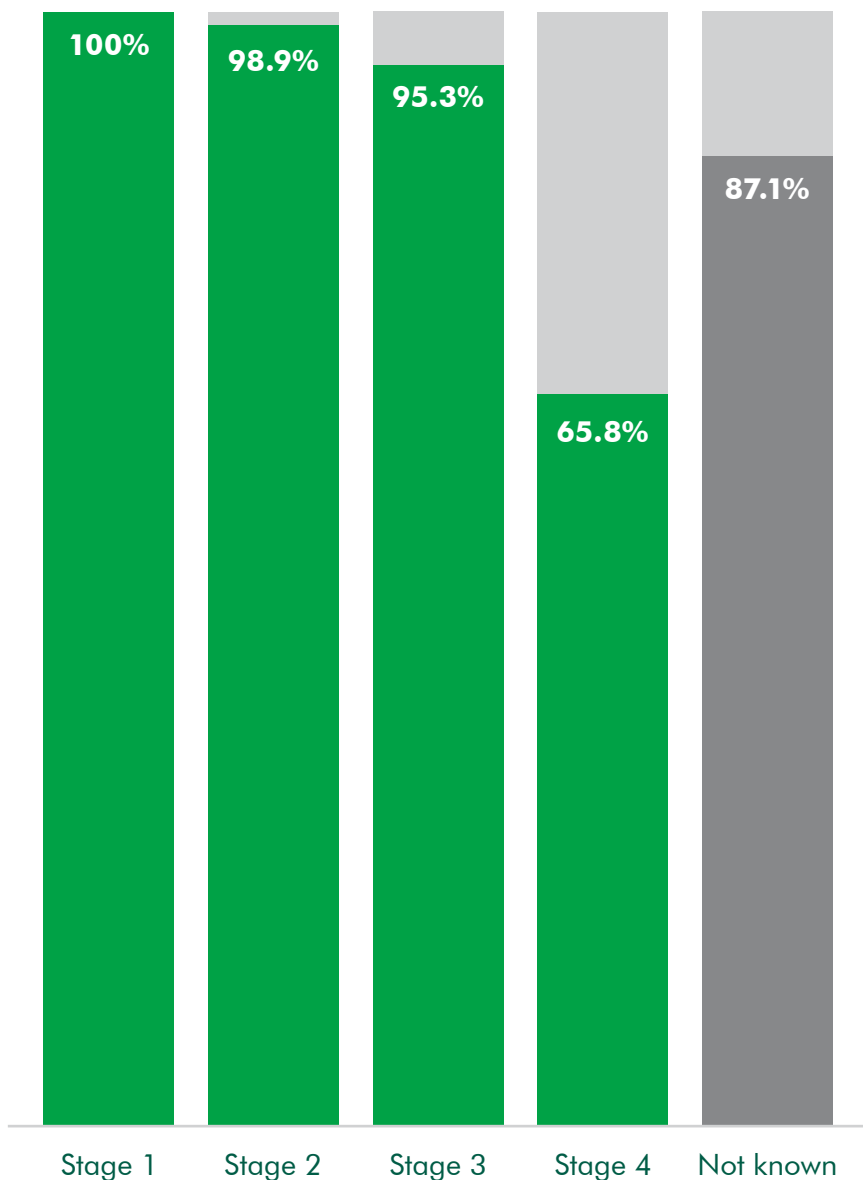


**Only 4% of people newly diagnosed with breast cancer in England had to see their GP more than twice before they were diagnosed compared with 26% of lung cancer patients, 22% of prostate cancer patients and 21% of colorectal cancer patients.**

**This shows how the general awareness of breast cancer is high, leading to a quicker diagnosis when compared to other cancers.**

## How does stage at diagnosis relate to probable survival rates?<sup>(22)</sup>

1-year age-standardised net survival rates by stage, female breast cancer only, England, 2015



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

## What are the national targets for urgent cancer referrals and treatment?

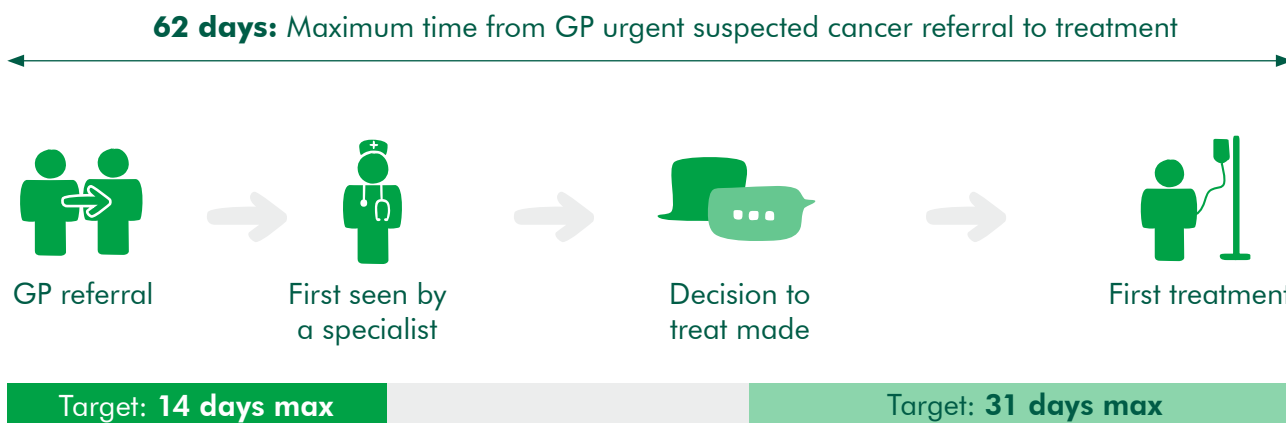
The two-week wait is the route to diagnosis for urgent GP referrals, and is one of many routes to diagnosis including emergency admission and screening.

For England, the NHS aims for maximum a two week wait for patients to be seen by a specialist, after urgent referral for suspected cancer by the GP. For breast symptoms, there should be a maximum of a two-week wait, even if cancer is not initially suspected.

Patients should experience a maximum wait of one month (31 days) between receiving their diagnosis and the start of first definitive treatment, for all cancers.

Following a diagnosis of cancer, patients should wait a maximum of two months (62 days) to begin their first definitive treatment, following an urgent referral for suspected cancer from their GP (therefore via the two week wait).

The exact targets vary across the each of the four nations.<sup>(96)</sup>





## How long do people with breast cancer have to wait to be referred?<sup>(28)</sup>

### Waiting times for breast cancer, England only, 2016-2017



**According to recent data, waiting times for breast cancer meet the national performance standards.**

**95% of suspected breast cancer cases were seen by a cancer specialist within 14 days of referral. This is higher than the average for all cancer types.**

**99% of people began first definitive treatment within 31 days of the decision to treat being made, which is higher than the operational standard of 96% average for all cancer types.**

# Needs at diagnosis



## Physical needs

Women diagnosed with breast cancer express that they have significant needs around sexual health. Worries about physical limitations and pain influences patients' sexual experience.<sup>(60)</sup>



## Clinical needs

1 in 7 women aged 50-70 who attend routine mammograms never check their breasts for signs of cancer outside these appointments.<sup>(53)</sup>

Four main breast cancer genes have been identified. If there's a fault in one of them, the risk of breast cancer is higher. Having a fault in one of the high-risk breast cancer genes raises the risk of developing breast cancer to between 40% and 85%. It is estimated that 3% of breast cancer cases are caused by an inherited faulty gene.<sup>(54,55)</sup>

88% of breast cancer patients in England say they were seen by a hospital doctor within 3 months of thinking something might be wrong.<sup>(26)</sup>

A small study found that some women from lower educational backgrounds tend to attribute their breast cancer symptoms to trivial factors and were reticent in using the word 'cancer'. Women with higher education were more confident about interpreting symptoms, looking for information online, and seeking medical help when needed.<sup>(56)</sup>



## Practical needs

### **Not specific to people with breast cancer**

Cancer patients are found to have mild to moderate concern about cancer affecting their parental role. Cancer symptoms and treatment side effects can sometimes make it very difficult to keep up a normal daily routine, especially for those who have children.<sup>(57,58)</sup>

Social difficulties are common among cancer patients, as a result of their cancer diagnosis. Advanced disease, younger age, lower income and poor psychological well-being emerge as some of the factors that make cancer have a stronger impact on the social life of patients.<sup>(57)</sup>



## Financial needs

Only 33% of breast cancer patients in England were given advice on how to claim financial aid and benefits by hospital staff. This compared to 48% of lung cancer patients.<sup>(26)</sup>

### **Not specific to people with breast cancer**

83% of cancer patient households suffer a loss of income and/or increased costs as a direct result of cancer.<sup>(76)</sup>

Loss of income alone is experienced by 30% of cancer patients, with those affected losing, on average £860 a month. Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families.<sup>(76)</sup>

According to a 2013 Macmillan report, 83% of people are, on average, £570 a month worse off as a result of a cancer diagnosis.<sup>(76)</sup>

The most common additional cost people living with cancer face is getting to and from hospital, or making other healthcare visits.<sup>(76)</sup>

Costs associated with outpatient appointments hit almost three-quarters (71%) of people living with cancer, and over a quarter (28%) incurred costs for inpatient appointments.<sup>(76)</sup>

## Information needs

Information is amongst the highest needs for breast cancer patients, with 70% expressing unmet needs in health information.<sup>(59)</sup>

### **Not specific to people with breast cancer**

The strongest preference for information at diagnosis is information about prognosis. However, there are also many other information needs such as side effects of treatment, impact on family and friends, altered body image, self care and risks of family developing the disease.<sup>(60)</sup>

## Emotional needs

An Australian study found that rates of anxiety and depression in women with breast or gynaecological cancer were higher at diagnosis than in other stages. These disorders were more severe in patients with a pre-existing history of similar mental health issues.<sup>(61)</sup>

A study found that in the early stages after diagnosis and before treatment, some patients (including those diagnosed with breast cancer) considered their emotional distress as a temporary and understandable reaction. Some were reluctant to acknowledge or address emotional needs, although they valued knowing that support was available.<sup>(63)</sup>

Interestingly, a study reports that mothers with breast cancer had an immediate desire to receive psychosocial support regarding the worry about their own children from the very early stages of the disease.<sup>(139)</sup>

### **Not specific to people with breast cancer**

Receiving psychosocial support emerges as very important for those patients experiencing multiple sources of stress associated with their cancer diagnosis.<sup>(62)</sup>

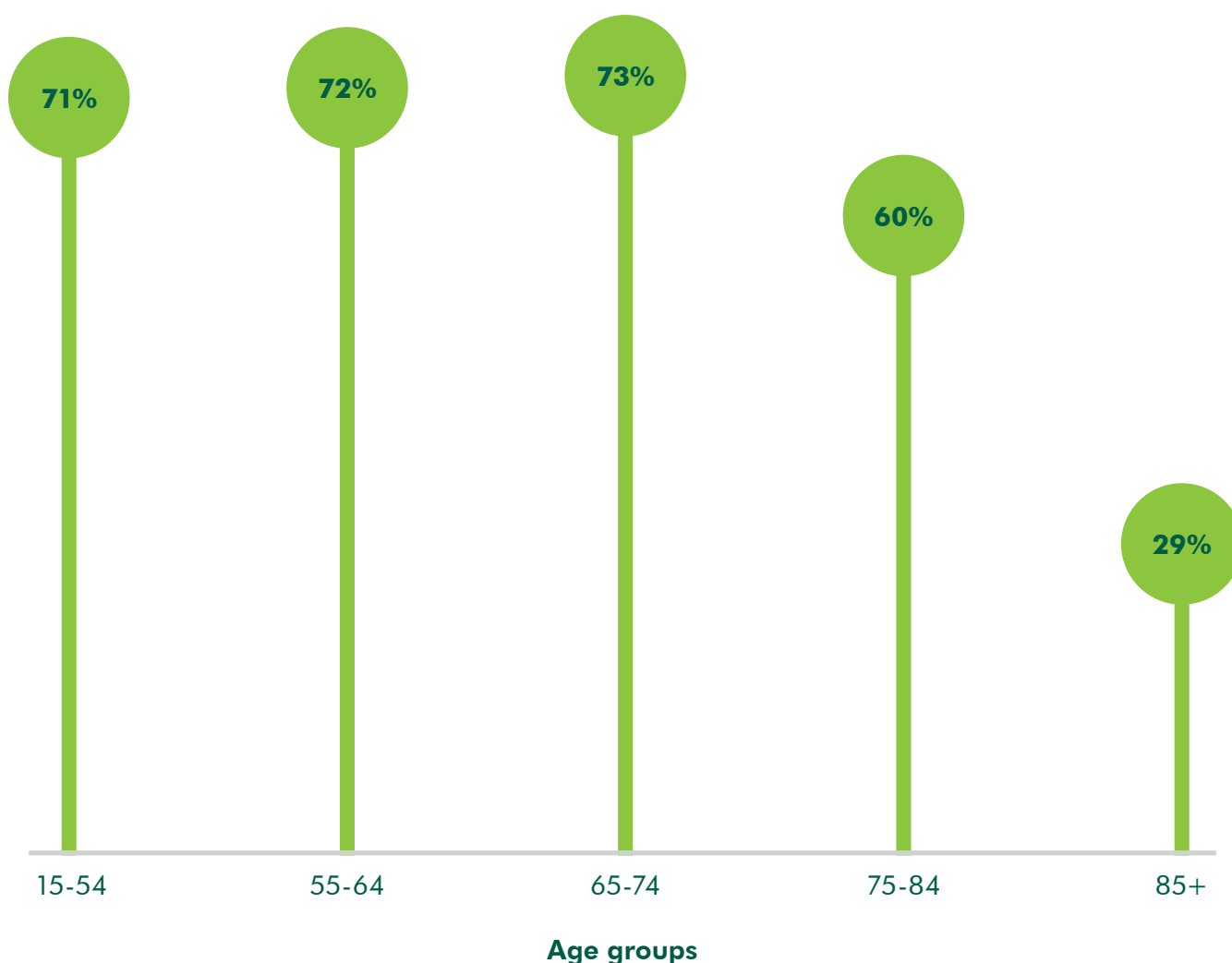
**'All I heard was aggressive and rapid. And I just went down this downward spiral of "this isn't good". And I just couldn't see any positivity in it.'**

Diane

# NEEDS AND EXPERIENCES: TREATMENT

## How often do breast cancer patients have surgical resection?

Percentage of major surgical resection for breast cancer patients by age, female breast cancer only, England, 2006-2010<sup>(29)</sup>



**The percentage of patients having a major surgical resection remains above 70% for patients aged up to 74. With older age (75+), the number of patients undergoing this type of treatment decreases rapidly.**

## How many admissions due to breast cancer are there (and for how long)?

In total, there were over 201,000 admissions to NHS hospitals in England due to breast cancer during 2015-2016. Of these, over 4,500 were emergency cases.<sup>(68)</sup> The median length of stay for people admitted due to breast cancer was 1 day in 2015-2016.<sup>(68)</sup>

## What can a person with breast cancer expect from a treatment regime?

There are various treatments for breast cancer. Doctors work with the patient in coming up with a specialist treatment plan which would be based on what stage the cancer was diagnosed and other patient health information. Patients would typically undergo a combination of the following treatments.<sup>(144)</sup>

### Surgery

For most women, the first stage of treatment for breast cancer is surgery to remove the tumour. 74% of breast cancer patients had a record of a major surgical resection as part of their treatment. The proportion of breast cancer patients receiving a resection varies with age, with fewer resections in the older patients (29% in those aged 85+) compared with the younger patients (71% in those aged 15-54).<sup>(29,65)</sup>

The surgeon often tries to keep as much of the lump as possible, which can be achieved using a lumpectomy, in which only the lump or areas of cancer is removed. However, sometimes women will choose or be advised to have the whole breast removed (mastectomy). Some breast cancer patients may choose to have a double mastectomy where both breasts are removed in order to prevent a reoccurrence of the cancer. Breast reconstruction can be done at the same time as this or later.<sup>(66,67,47)</sup>

### Chemotherapy

Chemotherapy involves the circulation of anti-cancer (cytotoxic) drugs in the blood stream to kill cancer cells. This can be administered through various methods including intravenous drip, oral chemotherapy and intramuscular chemotherapy. There are many drugs used for chemotherapy and typically a patient will

be given a combination of 2 or 3 drugs. The type of drugs given will depend on how aggressive the cancer is and other health conditions the patient may have.<sup>(145,146)</sup> Patients normally undergo chemotherapy after surgery to reduce the risk of the cancer coming back. However, if the tumour is large, patients may undergo chemotherapy before surgery to reduce the tumour.<sup>(147)</sup>

### Radiotherapy

Radiotherapy kills cancer cells by using high energy x-rays and may also be used as part of the treatment regime if there is a likelihood of the cancer coming back after surgery or if the surgeon removed cancerous lymph nodes from the armpit.<sup>(64)</sup> Breast cancer accounts for 28% of all radiotherapy episodes in England (2011-2012). In 2012, there were 37,132 radiotherapy episodes and 510,076 radiotherapy attendances for breast cancer.<sup>(49)</sup> But careful planning and newer ways of giving radiotherapy have reduced the risk of damage to healthy tissue and nearby organs. Cancer cells cannot repair themselves after radiotherapy, but normal cells usually can.<sup>(64)</sup>

### Biological Therapy

Biological therapies use substances that occur naturally in the body to destroy cancer cells. The most common form of biological therapy for breast cancer involves the use of the drug Herceptin. Herceptin is used to reduce the risk of breast cancer coming back in women whose breast cancer cells have a large number of HER2 receptors on their surface. It works by attaching to HER2 receptors (proteins) on the surface of breast cancer cells. This stops the cancer cells from dividing and growing. The side effects of Herceptin are usually mild. They include flu-like symptoms, such as headache, high temperature (fever) and chills, or feeling sick.<sup>(47)</sup>

### Hormonal therapy

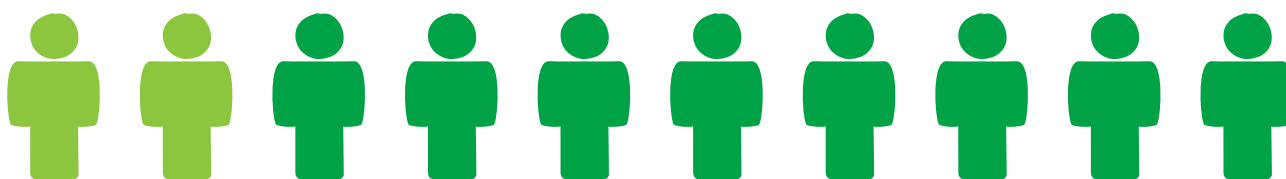
Some women have oestrogen-positive breast cancers and hormonal therapy can be used to reduce the levels of oestrogen in the body and reduce the risk of the cancer coming back. This is normally taken after surgery and chemotherapy. Women who have been through menopause are normally given aromatase inhibitors (AIs) whereas younger women usually take Tamoxifen which itself can cause an early onset of menopause.<sup>(148)</sup>

## What is Lymphoedema?

Lymphoedema is swelling that develops because of a build-up of fluid in the body's tissues. This happens when the lymphatic system, which normally drains the fluid away, isn't working properly. It can occur in any part of the body, but is most likely to affect an arm or a leg. It is a chronic condition that never goes away because the causes can't be reversed. However, the swelling can be reduced in most people, particularly when it's diagnosed early. Specialists in lymphoedema can assess and treat lymphoedema.<sup>(69)</sup>

Lymphoedema can be caused by cancer itself or develop as a side effect of its treatment. It is a condition that can appear months or years after cancer treatment. It can be the result of surgery to remove the lymph nodes, radiotherapy and cancer that has spread to the lymph nodes or that presses on the lymph vessels.<sup>(70)</sup>

Primary lymphoedema is rare and is thought to affect around 1 in every 6,000 people. Secondary lymphoedema is much more common, and affects around 2 in 10 women with breast cancer.<sup>(71)</sup>



**Secondary lymphoedema affects around 2 in 10 women with breast cancer.<sup>(71)</sup>**



## CNS treatment

### How many people with cancer have access to a breast CNS?

In 2014, breast cancer clinical nurse specialists (CNSs) in England accounted for 18% of the CNS total. This is the largest proportion of any specialised nurses.<sup>(72)</sup>

92% of people with breast cancer in England were given the name of a CNS, in 2016. This is one of the highest for all cancer types.<sup>(26)</sup>

Having access to a CNS is very important for cancer patients. A 2015 study identified CNSs as increasing the chances of a patient receiving chemotherapy and helping to reduce emergency admissions and inpatient stays.<sup>(73)</sup>

In England, of those patients who said that they asked their CNS questions, 78% said that they got understandable answers all or most of the time.<sup>(26)</sup>

### How do other health conditions affect people with cancer (all cancers)? How does this affect their experiences?

A review of evidence suggests that cancer patients with co-morbidities have poorer survival than those without co-morbidities. In general, co-morbidities do not appear to be associated with more aggressive types of cancer or other differences in tumour biology.<sup>(74)</sup>

Presence of specific severe co-morbidities or psychiatric disorders were found to be associated with delayed cancer diagnosis in some studies, while chronic diseases requiring regular medical visits were associated with earlier cancer detection in others.<sup>(74)</sup>

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

# Needs during treatment

## Physical needs

A US study found that people living with breast cancer reported higher unmet needs than other cancer patients post-treatment, with physical problems being the most frequently recorded.<sup>(77)</sup>

Fatigue is one of the most common symptoms among cancer patients. A study found that, post-treatment, patients living with breast and colorectal cancer are more likely to report higher rates of fatigue, compared with prostate cancer patients.<sup>(78)</sup>

Hot flushes are a common side effect of treatment, experienced by 70% of women with breast cancer. Some treatments may also cause an early onset of menopause, particularly for those women who are closer to menopause. This can also cause hot flushes and heighten feelings of discomfort.<sup>(140)</sup>

Chemotherapy drugs can cause nerve damage (peripheral neuropathy), with symptoms including pins and needles, numbness and pain. Nerves may recover after completion of initial treatment but in some women nerve damage is permanent.<sup>(79)</sup>

Evidence suggests that breast cancer patients that had undergone chemotherapy and radiotherapy had more problems in retaining memory and scored lower than average on neuropsychological tests.<sup>(80)</sup>

## Clinical needs

During and after treatment, the quality of life for breast cancer patients is negatively impacted by experiencing pain. Opioids (such as morphine) can be prescribed to reduce pain, but they can lead to side effects, including constipation and nausea.<sup>(81)</sup>

Cancer treatments can cause nausea which can be treated by anti-sickness medication in the form of tablets, skin patches and injections. These treatments may cause other side effects themselves including constipation, headaches and tiredness.<sup>(82)</sup>

A common side effect of chemotherapy for breast cancer patients is osteoporosis where bones become frail and brittle and lead to significant risk of fractures. Joint pain may also be a side effect of specific hormonal therapies, leading to a significantly increased risk of bone fractures.<sup>(83)</sup>



## Practical needs

### Not specific to people with breast cancer

75% people with cancer who have practical or personal needs say these are caused by their cancer or cancer treatment.<sup>(87)</sup>

Help with mobility and practical tasks is reported as crucial for some patients during and after treatment. On average, 1 in 3 people with cancer need help with getting out of bed and using transport. 31% of cancer patients also need assistance in tasks around the house and grocery shopping.<sup>(87)</sup>

Approximately 31% of patients who have practical needs say they do not get enough support. Around 1 in 7 patients had an emergency hospital visit due to lack of social and practical support.<sup>(87)</sup>

The majority of people with practical needs receive support from their friends and family, but around 3 in 10 receive formal support through their local authority or the NHS.<sup>(87)</sup>



## Financial needs

A study suggests that breast cancer patients might be facing higher overall costs as a consequence of their cancer, compared to prostate cancer patients. This was mainly due to increased use of non-prescription drugs, childcare costs and increased NHS costs.<sup>(75)</sup>

48% of breast cancer patients in England were told by hospital staff that they were eligible for free prescriptions.<sup>(26)</sup>

### Not specific to people with breast cancer

33% of people with cancer spend an additional £24 a month on household fuel bills as a result of their cancer and/or its treatment.<sup>(76)</sup>

The cost of travel to and from appointments affects 69% of people with cancer and costs them, on average, £170 a month.<sup>(76)</sup>

A quarter of patients incur costs for help around the home or garden due to experiencing fatigue during treatment. This adds up to around £34 a month.<sup>(76)</sup>

Some patients who have recently undergone chemotherapy or surgery would like to take time off work, which could accentuate the effect of increased costs during treatment.<sup>(76)</sup>

## Information needs

Evidence shows that information needs are frequent amongst breast cancer patients. Commonly reported unmet needs in this area include receiving timely and understandable information on disease stage, treatment options (including risks and benefits of treatment), test results and information on managing consequences of cancer treatment (including complementary therapies).<sup>(60,84)</sup>

A qualitative study on information needs of older women with breast cancer suggests that tailored information on treatment options are valued by patients, especially as some of the participants report preferring to avoid surgery, due to perceived risks associated with their older age.<sup>(86)</sup>

In England, only 3% of people with breast cancer did not feel that the possible side effects of treatment were explained to them in a way that they could understand.<sup>(26)</sup>

In England, approximately 10% of breast cancer patients say they were not given sufficient updates on whether their chemotherapy was working. For radiotherapy, this was slightly higher at 13%.<sup>(26)</sup>

## Emotional needs

A study found that patients undergoing treatment (including those diagnosed with breast cancer) were more likely to be open to seek help to deal with emotional issues, compared to those who hadn't undergone treatment yet.<sup>(63)</sup>

A qualitative study suggests that some breast cancer patients report experiencing a 'loss of self' and decreased self-confidence after treatment, particularly due to body changes. Isolation and challenges around communicating post-treatment issues with partners, friends and family members also emerged as common for many women with breast cancer.<sup>(88)</sup>

12% of people with breast cancer in England felt that they were not given enough care and support from health or social services during their treatment.<sup>(26)</sup>

### **Not specific to breast cancer**

Approximately 45% of people with cancer have emotional needs but do not get enough support for them.<sup>(87)</sup>

**'Every morning when I woke up the first thing I thought was cancer'**

Diane

# NEEDS AND EXPERIENCES: LIFE AFTER TREATMENT

## Are cancer survivors receiving adequate support by the health and social care system?

Cancer often has an impact on the lives of people affected by it even after treatment ends. The consequences of cancer and its treatment – which can include issues such as fatigue, mental health problems and pain – can persist long after treatment. These can also impact other aspects of people's lives, including their social life and family relationships.<sup>(91)</sup>

Maintaining their personal identity and adjusting to life as cancer survivors is very important for people living with and after cancer. Evidence shows that breast cancer survivors can perceive an inadequate level of support from oncology teams, as well as deterioration of support from personal support networks after their treatment ends.<sup>(89)</sup>

GPs play a very important part in the experience of cancer survivors, as they are a key point of contact for them. Evidence suggests that cancer survivors seek different types of support from their GPs, such as psychological support, discussing the impact of their disease, medical help (also for non-cancer related problems), and getting general information about their disease.<sup>(90)</sup>

12% of breast cancer patients in England felt that they were not given enough care or support from health and social services once they finished their treatment.<sup>(26)</sup>

## What is the survivorship experience of people from BME groups?

Some evidence suggests that cancer survivors from BME groups might have different experiences, compared to white British population. Higher levels of anxiety and depression, as well as poorer quality of life and stronger fatalistic beliefs are reported as tendentially more common in South Asian breast cancer survivors. Religion also appears to be a stronger source of support for breast cancer survivors from some minority groups.<sup>(92)</sup>

## Macmillan and NHS England are working to implement improved aftercare for people with cancer.

The National Cancer Survivorship Initiative (NCSI) was a partnership between the Department of Health, Macmillan and NHS Improvement. In 2013, NCSI published documents to support commissioners and the health system to deliver services to improve the long-term quality of life of cancer patients. This included tested interventions which can address the needs of people after cancer treatment, including the Recovery Package.

In 2015, an Independent Cancer Taskforce published 'Achieving world-class cancer outcomes: a strategy for England 2015-2020'. The strategy recommended that everyone with cancer has access to personalised care and support after their treatment ends. To help achieve this, it recommends that NHS England commission services 'for patients living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020'.



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The Government and NHS England have since committed to delivering on these recommendations. The provision of the Recovery Package for cancer patients was included in the 'NHS Five Year Forward View', and reiterated in the 'Next Steps on the Five Year Forward View', published in 2017. To help deliver these commitments, the NHS Operational Planning and Contract Guidance for 2017-2019 included commissioning all elements of the Recovery Package within its 'must-dos' for cancer.

### The Recovery Package consists of:

**Holistic Needs Assessment (HNA) and Care Plan** – HNA identifies the holistic needs and concerns people with cancer have at a particular time, considering the patient as a whole person rather than just focusing on their cancer. The HNA can be administered at any time during the cancer journey. The responses to the HNA inform the 'Care Plan', which captures a record of what needs are most important to the person and how they are going to be addressed, as well as providing the foundation for future re-assessment as needs change along the pathway.

**Treatment Summary** – sent to the patient and the GP after at the end of each stage of active treatment, it serves as a record of the treatment the patient received that can be looked back on and used to inform conversations around recovery, side effects of treatment, and possible future courses of treatment.

**Cancer Care Review (CCR)** – triggered by the completion of the treatment summary and carried out by the GP, the CCR encourages conversations between patients and professionals about any issues related to cancer or its treatment – whether clinical or non-clinical – and the impact they have on patients' quality of life or wellbeing.

**Health and Wellbeing events** – semi-structured education events that offer relevant support and information to people living with cancer in order to help them become more able to self-manage. Health and wellbeing events can be big or small, based on working with groups or individuals, and are highly flexible depending on the needs or means of the community setting in which they are held.

## What is Routes from Diagnosis?

Routes from Diagnosis is a programme of research performing retrospective analysis of almost 85,000 cancer patients' interactions with the NHS in England over seven years. It allows us to understand survival patterns and just how many people affected by cancer are living with serious long-term conditions.

## How long do breast cancer patients typically live after their cancer treatment?

### Simplified survivorship outcomes framework for breast cancer<sup>(30)</sup>

#### Limited survival



**6.5%** 0-12 months survival



**13.8%** 1-5 years survival with cancer complications

#### Limited to moderate survival



**5.5%** 1 - 7 years survival with other inpatient diagnoses



**0.9%** 1 - 7 years survival with no other inpatient diagnoses

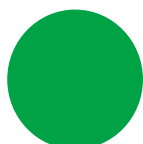


**4.5%** 5-7 years survival with cancer complications

#### On-going survival



**19.2%** 7+ years survival with cancer complications



**29.1%** 7+ years survival with other inpatient diagnoses



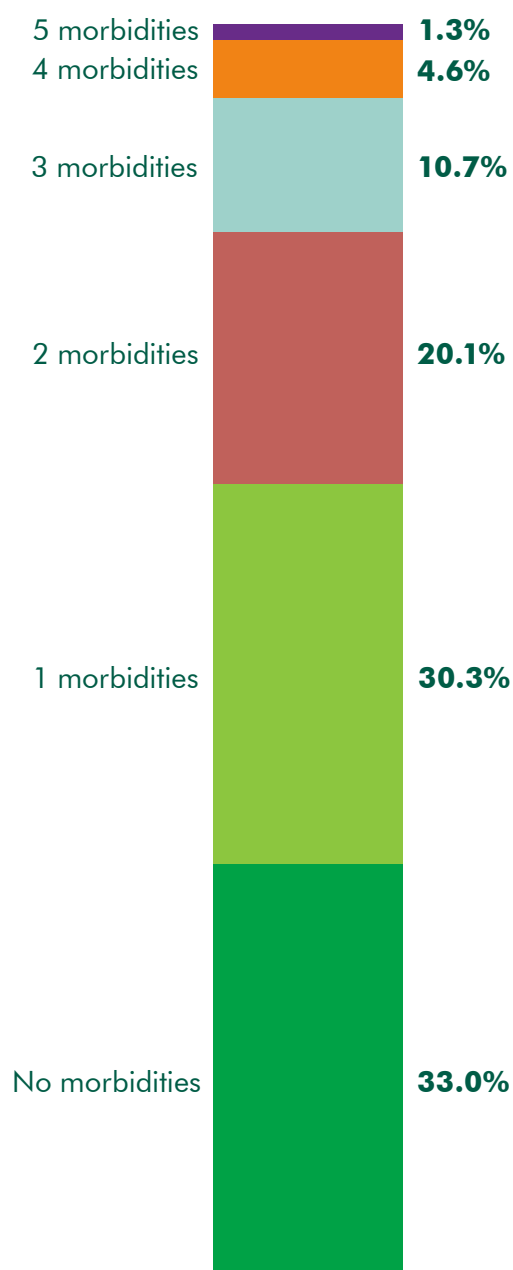
**20.5%** 7+ years survival with no other inpatient diagnoses

**More than two thirds of breast cancer survivors live over 7 years after their diagnosis, although many of them experience either cancer complications or other inpatient morbidities. This tells us that the journey for breast cancer patients can be long and complex.**



## How many morbidities do people living after breast cancer treatment have?

Percentage of breast cancer population by number of inpatient morbidities (taken over a seven-year survivorship period)<sup>(30)</sup>



**The majority of breast cancer patients experience at least one inpatient morbidity after their diagnosis. Just under 40% experience 2 or more morbidities. This is lower than for prostate and lung cancer (43% and 47% respectively).**

# Needs after treatment

## Physical needs

Fatigue is the biggest post-treatment problem for women with breast cancer. Although fatigue is often acute and tends to last only a relatively short amount of time, a study suggests that around 30% of breast cancer survivors may experience long-term fatigue even years after treatment.<sup>(138)</sup>

Some breast cancer treatments can affect women's ability to have children. Whilst some women, particularly at a younger age, do not experience issues around fertility, this can be a major source of concern for many breast cancer survivors.<sup>(97)</sup>

A study on the experience of older women with breast cancer shows that survivors may experience a range of long-term physical problems resulting from surgical treatment. These include both cosmetic issues and restricted joint movements. The study found that breast reconstruction was rarely discussed post-treatment, although most participants would have liked to discuss this option.<sup>(98)</sup>

Hormonal therapies for breast and early menopause due to cancer treatments can increase the risk of bone thinning. Weight-bearing exercises such as walking, dancing or resistance training, can help keep bones strong.<sup>(133)</sup>

## Clinical needs

A study found that breast cancer survivors in Scotland report the need to be better informed when their cancer is under control or in remission.<sup>(93)</sup>

Breast cancer treatment can have an impact on the life of cancer survivors. Regular interactions with professionals (including check-ups and mammographs) are important, to address any clinical issues arising after treatment.<sup>(132)</sup>

### **Not specific to people with breast cancer**

A US study identified the need to be informed about and receive clinical support for possible late effects of treatments as important for cancer survivors.<sup>(94)</sup>

Cancer survivors can experience treatment-related pain long after treatment and during survivorship. In these cases, prolonged pain is likely to have effects on the psychological wellbeing of cancer survivors. Reducing pain becomes crucial to help alleviating other symptoms.<sup>(95)</sup>



## Practical needs

Evidence suggests that breast cancer survivors seek information and tools to allow them to regain control of themselves, their bodies and their lives after treatment. The main issues identified are around general functioning, going back to work and maintaining a good social life.<sup>(88)</sup>

### **Not specific to people with breast cancer**

A study of cancer patients after treatment found that cancer patients felt the need for more community based programmes and better linking and partnership between community teams, secondary, primary and social care as well as voluntary sectors.<sup>(134)</sup>

Evidence shows that older people tend to have high needs at transition from treatment to survivorship. Key concerns are around rehabilitation and maintaining independence.<sup>(101)</sup>



## Financial needs

In England, 21% of breast cancer patients said they had not been given information on how to get financial help or benefits by staff, but they would have liked to.<sup>(26)</sup>

### **Not specific to people with breast cancer**

Financial difficulties following treatment are widely recognised as a major worry for cancer survivors. These are linked to concerns around adjusting back to normal life, as well as readjustments of life standards for themselves and their partners or dependents.<sup>(99,100)</sup>

## Information needs

### **Not specific to people with breast cancer**

People living with cancer acknowledged the need for trusted sources of information and many would attend a hospital-based education programme.<sup>(85)</sup>

The top three patient information priorities were related to prognosis, diagnosis, and treatment options. Being able to prioritise the most-needed information can make patient encounters more meaningful and useful.<sup>(60)</sup>

## Emotional needs

Breast cancer survivors can experience severe psychological problems even years after finishing treatment. Depression, anxiety and fear of cancer coming back are reported as particularly frequent issues for many breast cancer survivors.<sup>(138)</sup>

A high percentage (61%) of breast cancer survivors with children claim they need support on dealing with worries about children. Fear of dying, having children at home and financial worries are the main causes related to this worry.<sup>(139)</sup>

### **Not specific to people with breast cancer**

Cancer survivors can experience a variety of long-term emotional and psychological side effects of cancer and its treatment. These can include depression, anxiety and, in some cases, symptoms of post-traumatic stress disorder (PTSD).<sup>(135)</sup>

**'You kind of think chemotherapy,  
that's important. A little achy arm?  
Let's not worry about that'**

Diane

# NEEDS AND EXPERIENCES: PROGRESSIVE ILLNESS AND END OF LIFE

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

The National Institute for Clinical Excellence (NICE) has defined palliative care for people with cancer. With some modifications, the definition can be used for people with any life-threatening condition: palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

## How many cancer deaths are there in each setting? To what extent do cancer patients die in their place of choice?

Data on place of death is usually not available broken down by cancer type. However, for all cancer types, 64% of people with cancer in the UK would like to die at home, and only 1% would prefer to die in hospital.<sup>(102)</sup>

Contrary to what people living with cancer wish, figures show that deaths in hospital are very frequent. In 2015 in England and Wales, 37% of people who died from cancer died in an NHS hospital, 30% died at home or a private address, 17% died in a hospice, 14% died in a care home and 2% died elsewhere.<sup>(103)</sup>

In 2015 in Scotland, 43% of people who died from cancer died in a hospital, 30% died at home, 19% died in a hospice and 8% died in a care home or elsewhere.<sup>(104)\*</sup>

\*Equivalent information not available for Northern Ireland.

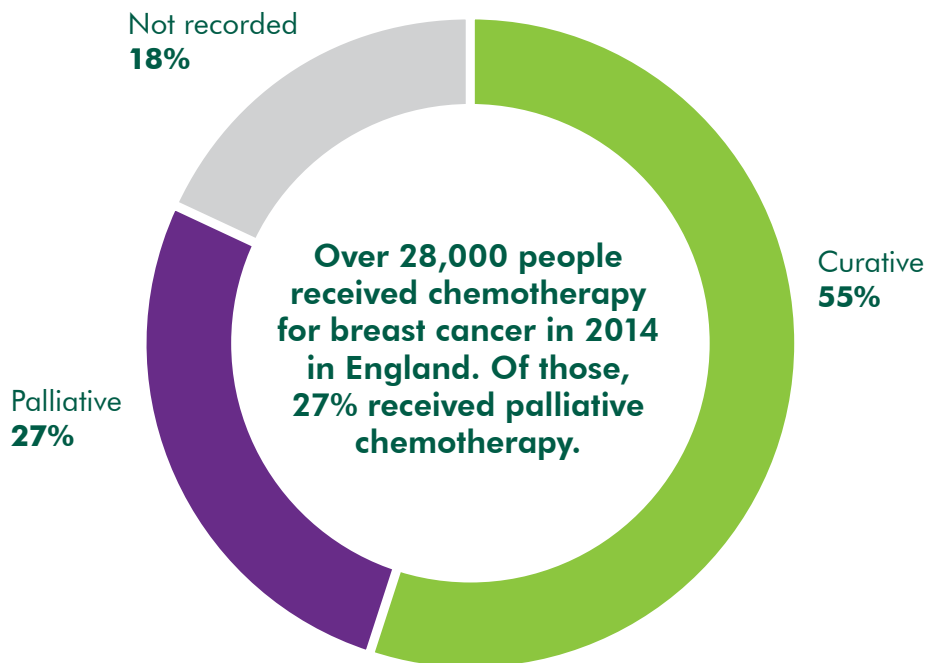
## What health data do we have on breast cancer recurrence related to radiotherapy?

It is estimated that around 1 in 220 new cancer diagnoses in the UK were associated with radiotherapy for a previous cancer.<sup>(82)</sup>

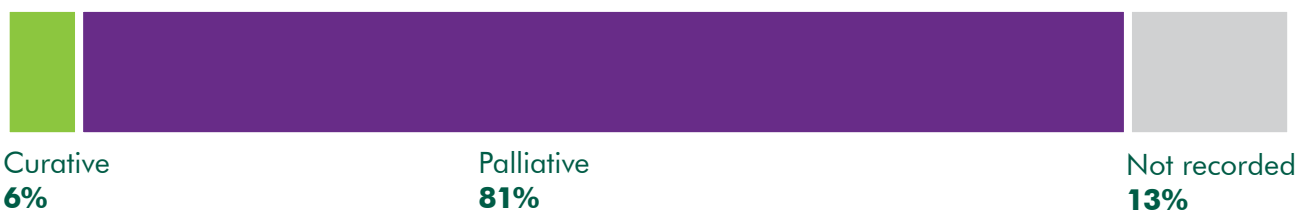
Over a tenth (10.6%) of these radiotherapy – related second cancers were breast cancer.<sup>(82)</sup>

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

### How many people receive palliative chemotherapy?<sup>(31)</sup>



### How many people die receiving palliative chemotherapy?<sup>(31)</sup>



Looking at deaths within 30 days of chemotherapy administration, 81% of deaths are for breast cancer patients who were receiving palliative chemotherapy.

# Needs at end of life

## Physical needs

### **Not specific to people with breast cancer**

Cancer patients at end of life tend to show a rapid deterioration of physical functioning, alongside issues with prolonged fatigue and pain. A US study suggests that patient-reported outcomes can help provide further insight to understand trajectories and needs at end of life.<sup>(108)</sup>

Nearing death, cancer patients can experience a variety of physical symptoms, such as difficulty sleeping, tiredness and lack of energy, breathlessness, difficulty eating or a sore mouth.<sup>(111)</sup> The most common symptoms experienced by more than half of people during their last two weeks of life include shortness of breath, pain, and confusion.<sup>(137)</sup>

## Clinical needs

### **Not specific to people with breast cancer**

Opioids are often prescribed to patients at end of life to keep pain under control. Some evidence suggests that opioids tend to be given to patients at end of life on the basis of professionals' prescribing behaviours rather than individual patient needs.<sup>(106)</sup>

1 in 10 patients dying from cancer experience poor care at the end of their life.<sup>(107)</sup>





## Practical needs

### Not specific to people with breast cancer

A study showed that the main priority for cancer patients nearing end of life was to improve the quality of life over extending life. In this international study, having pain and discomfort relieved was the highest priority for patients in England (cancer and non-cancer).<sup>(109)</sup>

Cancer patients vary in the level of planning they make around their death. Approximately 70% of people with cancer have prepared their will. However, only 11% of people with cancer have prepared what kind of care they would like at the end of life.<sup>(110)</sup>



## Financial needs

### Not specific to people with breast cancer

For someone at the end of life, putting their affairs in order can spare family or friends painful decisions and even financial difficulties that could happen if the person living with cancer's wishes are not clear. It may also help alleviate worries, leaving them free to concentrate on the present.<sup>(128)</sup>

Patients and families may have concerns about income, additional costs or managing finances at end of life. Access to financial information is crucial, as some may be entitled to benefits in the last months of life to help with care.<sup>(129)</sup>

According to a 2010 Macmillan report, 36% of all people with terminal cancer did not claim the benefits they were entitled to. This amounts to over £90m.<sup>(105)</sup>

## Information needs

### **Not specific to people with breast cancer**

Effective communication with healthcare professionals at end of life is a highly reported unmet need, the lack of which negatively impacts on the care received by patients and carers. Many people with cancer are not communicating their preferences for end of life medical care, either through written documents or discussions with loved ones.<sup>(112,113)</sup>

Clear communication with home care services is a key need identified by multiple studies for people at end of life.<sup>(113)</sup>

A European study shows how the majority of cancer patients would want to be informed when they have limited time left to live. The importance of clear communication between clinicians and patients emerges as crucial.<sup>(114)</sup>

Cancer patients and their families often want information about how long they may have to live after hearing that their cancer is terminal. However, some evidence suggests that 31% of doctors tend to overestimate the survival times of terminally ill cancer patients.<sup>(136)</sup>

## Emotional needs

### **Not specific to people with breast cancer**

A study comparing hospital-based non-cancer patients with terminal cancer and home care residents shows existential problems tend to be common among cancer patients at the end of life. Concerns around quality of life and depression were also high.<sup>(115)</sup>

Psychological distress, particularly in the form of anxiety and depression, is particularly common for cancer patients at end of life. A German study found that half of the surveyed cancer patients receiving palliative care presented clinically significant scores of depression.<sup>(116)</sup>

**'We've all got loved ones, nobody wants to lose a loved one earlier than they should.'**

Diane

# LIFESTYLE AND PERCEPTIONS

**This section provides insight into perceptions about breast cancer. Evidence for this section is gathered from a variety of sources, including social media. Please note that this section includes only some examples, but we know that there is huge variation within the population.**

## What is the profile of the average person living with breast cancer?

- Almost all people living with breast cancer are women – although men can also get breast cancer; less than 1% of breast cancer cases are amongst men.<sup>(3,4,5,6)</sup>
- 75% of breast cancer patients in England are White, and 25% from other non-White ethnic groups<sup>(34)</sup>
- More than 8 in 10 of female breast cancers are diagnosed in women aged 50 and over.<sup>(48)</sup>

## What do people living with breast cancer think about their cancer?

Perceptions of breast cancer vary across the population, but some evidence can provide a useful indication of potential themes in this area.

A US study shows that amongst patients with metastatic breast cancer, feelings of blame and regret are very common. Many of those interviewed tended to look for someone to blame for their cancer diagnosis – typically either themselves or doctors.<sup>(46)</sup>

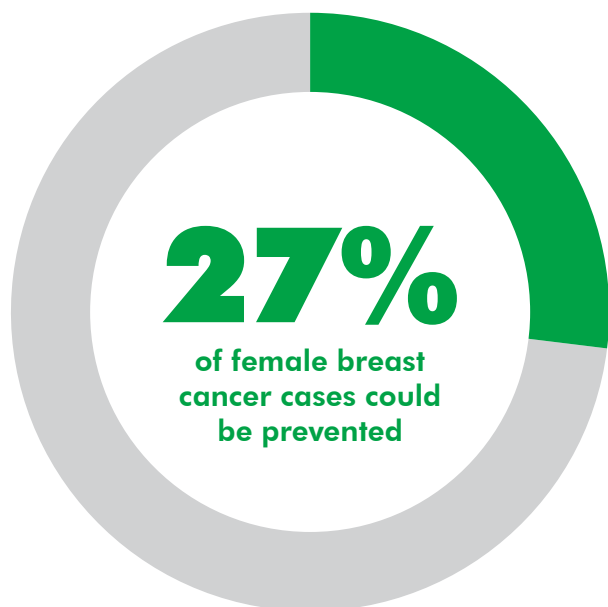
Fatalistic beliefs are also sometimes present amongst breast cancer patients. A study looking at the experience of Black and South Asian women with breast cancer found that some of the participants, particularly those with strong religious beliefs, considered cancer as punishment and/or due to forces beyond their control.<sup>(143)</sup>

A small study of 24 women with breast cancer also found that for many participants there was a strong association of cancer diagnosis with death, with a resulting potential for a stigmatised identity.<sup>(47)</sup>

However, the study found a much more positive discourse around cancer survivorship, associated with campaigning and a push towards positive thinking. Sometimes, though, women played down their private suffering as they were afraid of alienating public support.<sup>(47)</sup>

## Can breast cancer be prevented?

Percentage of preventable breast cancer cases, UK, 2011<sup>(32)</sup>



This includes

**9%**

could be prevented by keeping a healthy weight

**6%**

could be prevented by drinking less alcohol

**5%**

could be prevented by minimise risk at work (e.g. asbestos)

**3%**

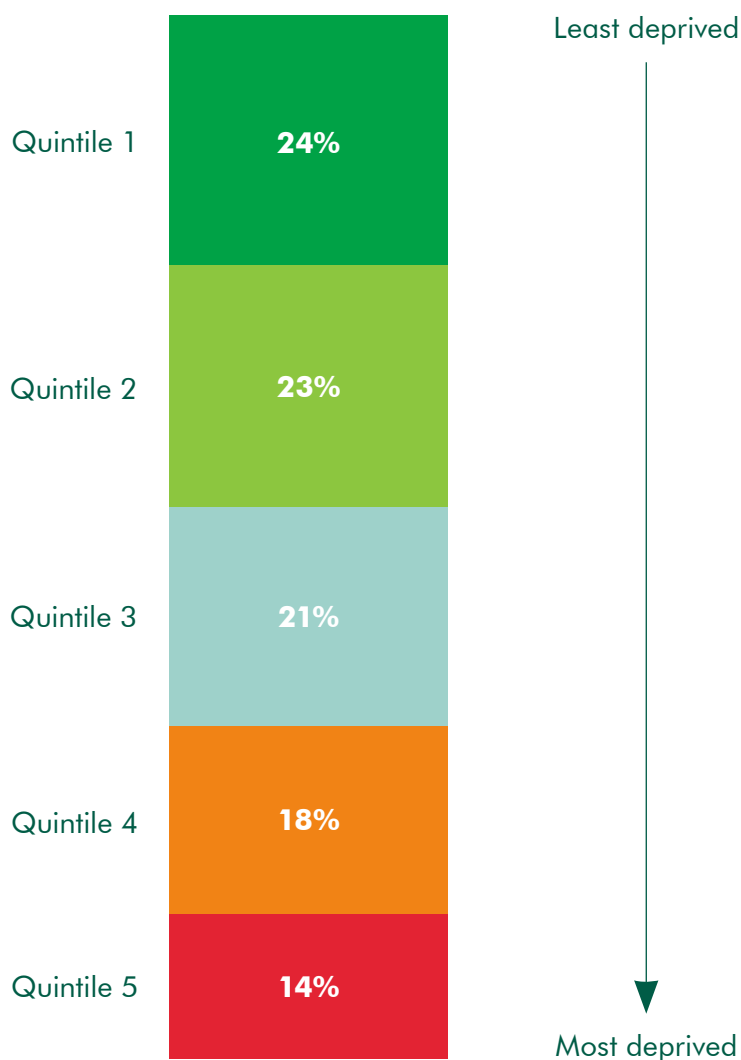
could be prevented by being active

**27% of breast cancer cases in the UK are considered to be preventable, as they are linked with modifiable lifestyle factors.**

**Some of these preventable cases of breast cancer are linked to being overweight (9%) and excessive alcohol consumption (6%).**

## How does prevalence vary according to deprivation?

20-year breast cancer prevalence in 2010 (based on diagnosis in 1991-2010) by deprivation quintile, England<sup>(24)\*</sup>



\*Based on the Income Domain of the Index of Multiple Deprivation at time of diagnosis.

**The levels of deprivation are usually split into quintiles, going from least deprived (quintile 1) to most deprived (quintile 5).**

**Breast cancer prevalence decreases with the level of deprivation. Of all women with breast cancer, 14% are in the most deprived quintile, compared to 24% in the least deprived quintile.**

**'Talking to people who've been diagnosed you know they get it, you know they're having the same feelings as you'**

Diane

## What are people living with cancer saying about their lives with cancer?

### Diagnosis and treatment

**'It's a scary time. I think the worst part of it is waiting, not knowing and "What ifing". What if it's spread more, what if I have chemo, what if and on and on. Our emotions and thoughts go on rampages that we just don't seem to be able to control.'**

Dottie

**'All the waiting has been so difficult! Carrying on with normal life, not feeling ill or looking ill but knowing you have this cancer, it's so weird. I'm generally feeling positive although do have my down days. Everyone keeps telling me to stay strong, but some days it's hard!'**

Moira

**'My chemotherapy nurses keep drumming into me that I should not suffer in silence in any way. If I have a problem then they can usually find a cure.'**

Gill

**'At every stage [of treatment], I've only ever been treated with dignity and courtesy, whether it's the consultant remembering to look me in the eye, even though I'm standing half naked in front of him, or the nurse holding my hand at a scan.'**

Zena



## Life after treatment

**'After active treatment stopped, I thought that it was a case of getting off the roller coaster ride. I don't think it is the case. We are still on it – I think that for a while there will be ups and downs as you adjust back to real life.'**

Gaynor

**'I think we all worry about the cancer coming back one day. The hardest part is when you finish treatment so no longer have regular visits to the hospital. I felt so alone and worried.'**

Sue

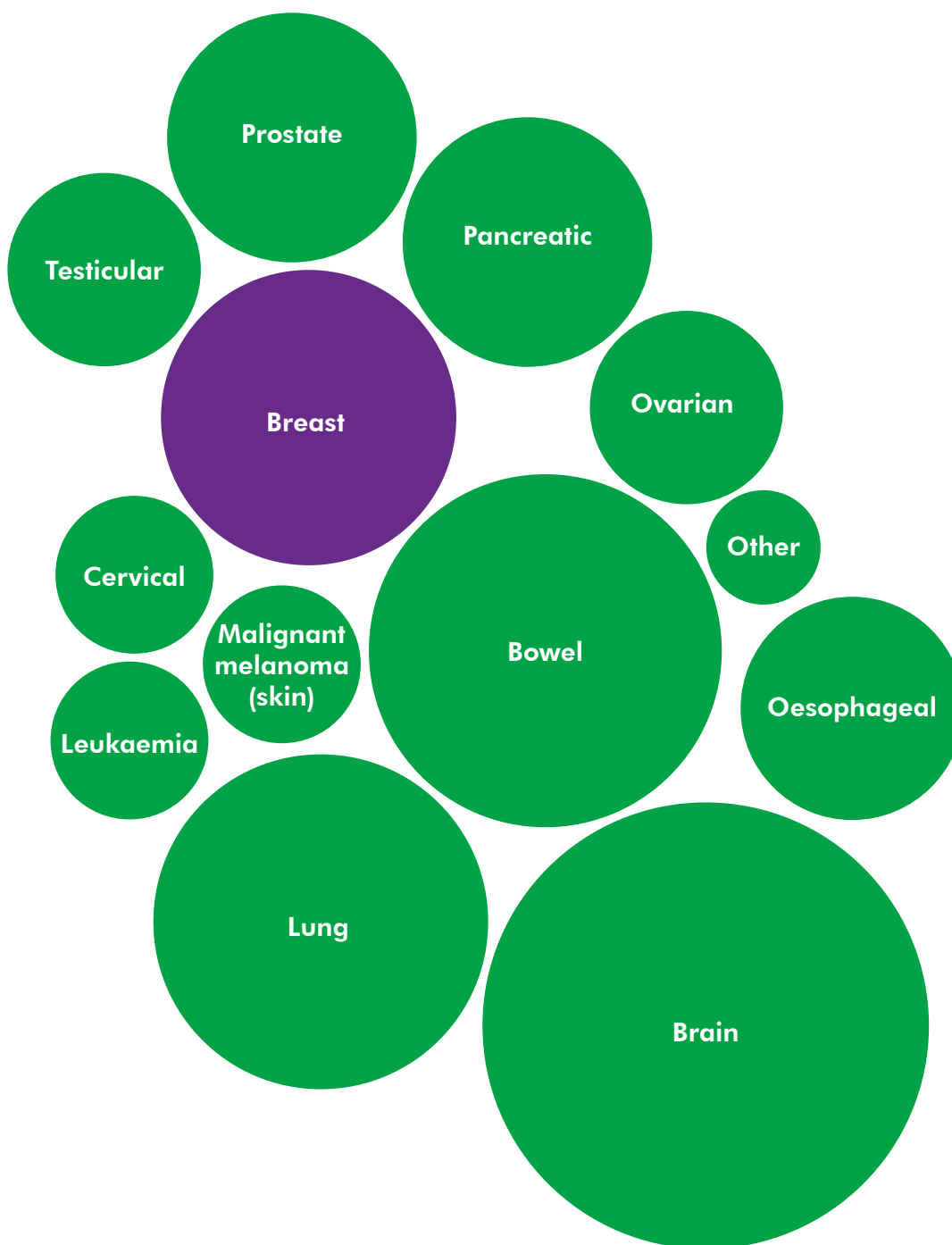
**'None of it is pleasant but now I've completely finished treatment and beginning to get my life back again it is all beginning to fade.'**

Jo

**'When I first went back to my tai chi class [...] the memories flooded back and I felt very emotional. I'm now prepared to accept this will happen as I venture back to the things I used to do. It's all a healing process that takes time. I try to pat myself on the back as I venture forth and try not to give myself a hard time when I don't always succeed!'**

Diana

### How does fear of cancer vary by cancer type?<sup>(39)</sup>



**35% of people said cancer is the illness they most fear getting.**

**When looking at individual cancer types, fear of breast cancer is fairly high amongst the general public. This can be attributed to the high profile and public awareness of breast cancer.<sup>(39)</sup>**

## The Macmillan website hosts guest blog posts from Online Community members, which are a great source of information on the different experiences of people living with cancer.

The post below was written by Anna. Anna was diagnosed with breast cancer when she was 34. She is a proud mum of two boys and lives with them and her partner, Eddie, in the Yorkshire Dales. She is a photographer, blogger, and digital marketing manager.

### Feeling feminine during chemo

Chemotherapy was a massive learning curve. I didn't know much about it – anything, in fact. I soon learnt that 'chemotherapy' isn't just one thing. There are over 100 different chemo drugs, and these can be given in many different ways. You effectively get your own 'cocktail' tailored to your specific cancer needs. Cancer is a disease caused by rapidly dividing abnormal cells. Chemotherapy destroys any of these cells. Unfortunately, it isn't quite clever enough to distinguish between healthy, rapidly dividing cells (like hair follicles) and unhealthy ones, so it can kill the lot! And there lies the problem, chemo can kill the good stuff too and leave you feeling so far from your normal self.

The common misconception about chemo is that just the hair on your head will fall out, but actually it ALL can! And I mean all! I lost my nose hair, arm hair, eyelashes, eyebrows ... I very quickly realised why hair is so essential. Regulating body temperature, keeping dirt out of our bodies, not to mention helping us look top-notch. Also, it's crazy how much your nose and eyes run when there's nothing there to stop it! Nails can also be affected; chemo can make them weak and brittle and mine ended up looking pretty awful. With these things taken away, it was hard for me to find a way to feel feminine. I felt completely stripped back.

Once I'd grudgingly accepted that I was soon to be hair-free, I went on a mission to figure out how on earth I could combat this issue in an effort to cling on to the little bit of confidence I had left, and thank goodness I did! The internet is riddled with useful sites, tutorials, and advice on how to deal with hair loss and other side effects of chemo. Gone are the days of covering up under a hat and riding it out!

Here are a few ways that helped me to feel feminine during chemo:

Embrace it – It's horrible, but we know it's for the best, so use it to your advantage. Think ahead about the style you would go for throughout your treatment time if you lost your hair. Would you go for scarves, hats, a wig, or rock the bald look?

Girly time – Get the girls involved! I gathered my girlfriends and we went wig shopping. Make it a fun event; we had fun trying different wig styles.

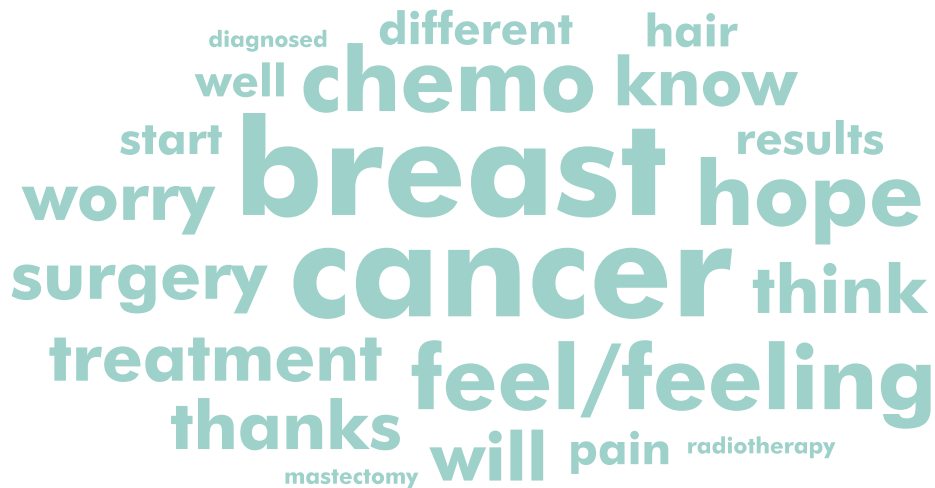
Accept any offers – Friends and family rally round at times like this. I had offers of massages, manicures and make-up help. When I was feeling low and needed a boost, these were all perfect remedies.

Learn to fake it – You can fake pretty much anything these days. Not just the hair, but eyelashes, brows, the lot! So ask a friend or search the internet for the best way. Even if it's just for special occasions, it can help you feel a whole lot more like yourself.

An excuse to shop – You may not need an excuse, but if you do then a bit of TLC for yourself during treatment is the perfect one.

Accentuate other areas – For me, I wore big earrings to distract from the lack of hair, but you could also choose bright lip, snazzy shoes, or brightly coloured clothes. Emphasising other areas to draw people's attention can really help.

## What our breast cancer online Macmillan Community members are saying...<sup>(97)</sup>



## How the media\* portrays breast cancer...<sup>(98)</sup>



\*UK national daily newspapers

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

## What does this tell us about people's perception of breast cancer?

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

References to treatment and the subsequent results of treatment feature predominantly within the online community, with the use of terms such as 'chemo', 'results', 'surgery' and 'mastectomy'. Also, the presence of terms such as 'hope', 'worry' and 'feeling' shows how the emotional impact of cancer and its treatment is a key topic of conversation for the online community members.

However, the media tend to focus more upon the medical aspects of cancer care, using often words such as 'drug', 'treatment', 'research' and 'risk'. Also, the media appear to be drawing the attention on the healthcare system, with words such as 'NHS', 'charity' and 'business' featuring quite prominently.

# SPECIALIST THEME: MALE BREAST CANCER

## What is male breast cancer? What are the key statistics for male breast cancer?

Similar to women, most men first notice their breast cancer as a painless lump near the nipple or armpit. Other notable symptoms include changes in the appearance of the nipple or areola as well as nipple discharge or sores.<sup>(111)</sup>

In 2015, around 359 men in the UK (excluding Northern Ireland) were diagnosed with breast cancer – compared to approximately 54,621 women in the whole of the UK<sup>(3,4,5,6)</sup>, which accounts for less than 1% of breast cancer cases. This shows that while breast cancer is the most common type of cancer in the UK, men are rarely affected.

As with women, age presents the greatest risk factor for developing breast cancer in men<sup>(117)</sup>, with 79% of cases diagnosed in men aged 60 and over.<sup>(3,4,5)</sup>

Inherited genes can also increase risk; about 1 in 5 men with breast cancer (20%) have a close relative who has had breast cancer.<sup>(117)</sup> There are different types of breast cancers (see page 4), but invasive ductal breast cancer – when cancer cells have spread into surrounding tissue – is the most common type seen in men. It accounts for about 80-90% cases of male breast cancers.<sup>(119)</sup>

## What information on breast cancer is specific to men?

Information on breast cancer is usually aimed at women rather than men. However, typical symptoms of breast cancer, the route to diagnosis, as well as treatment options are similar for both men and women.

In contrast to women, no standard breast cancer screening programmes exist for men, irrespective of risk factors and age.

With respect to risk factors, men born with two or more X chromosomes, known as the rare genetic condition 'Klinefelter syndrome', are at increased risk of developing breast cancer than the average man. While the lifetime risk is about 1 in 1,000 for men in general, the risk for those with Klinefelter syndrome is around 1 in 25.<sup>(117)</sup>

Regarding treatment, the most common form of breast cancer treatment for women as well as men is surgery, which usually involves the removal of the whole breast including the nipple. Breast reconstruction can be carried out in women to match the shape and appearance of the new breast to the other breast as closely as possible.<sup>(120)</sup> For men, however, implants to reconstruct the correct shape of the breast are not currently available, though it is possible to improve chest appearance by creating a new nipple.<sup>(121)</sup>

A large proportion of male breast cancer cases are oestrogen positive. These can be treated using hormone therapy, which can specifically block oestrogen receptors.<sup>(122)</sup> These drugs have side effects such as decreased libido, hot flushes, weight gain and changes in mood.<sup>(123)</sup>

## What are the specific issues facing men with breast cancer?

Many people are unaware that men can develop breast cancer since they are not thought of as having breasts, but men do have a small amount of breast tissue in which the cancer can develop.<sup>(124)</sup> A recent review highlighted that, perhaps due to poor awareness of male breast cancer and delays in diagnosis, men are more likely to be diagnosed at advanced stages of cancer, with poorer prognosis.<sup>(118)</sup>

As breast cancer is seen as primarily a female disease, diagnosis of breast cancer in men could have psychological effects including anxiety and emasculation. Men are also less informed than women on how their appearance will change after a mastectomy as many of the available resources are targeted towards women.<sup>(125)</sup>

As a result, feelings of embarrassment and isolation are reported to be common, and men may feel particularly self-conscious when waiting to be seen in their breast clinic. Some men also report feelings of anger and frustration about repeatedly having to explain that men can get breast cancer and that they were indeed affected by the disease.<sup>(126)</sup>

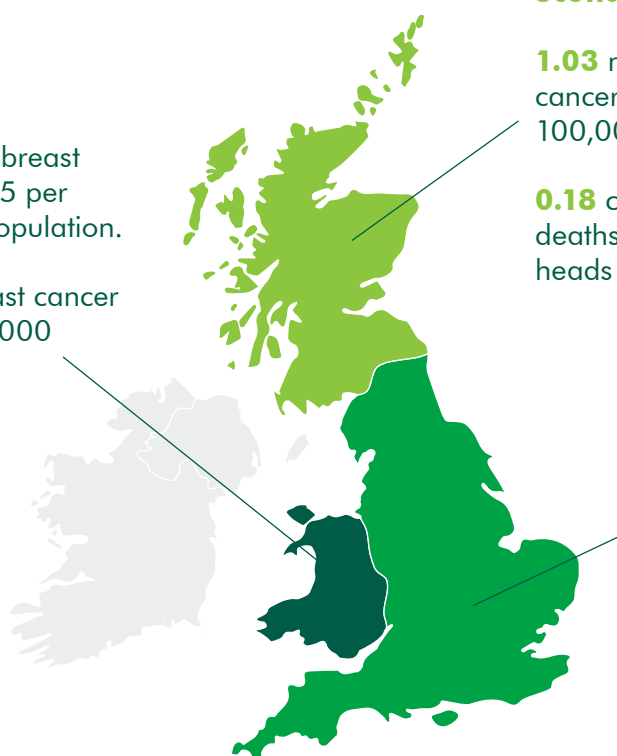
A US study shows that male breast cancer patients may benefit from access to male breast cancer support networks, social workers and psychologists where open discussions about the side effects of treatment, loss of libido and isolation were amongst the many topics discussed. This pilot scheme had a high approval rating and 75% of the participants reported to have gained new information and connected with other individuals in a similar situation.<sup>(127)</sup>

## Age-standardised incidence and mortality rates of male breast cancer in England, Scotland and Wales, 2015.\*<sup>(33)</sup>

### Wales

**1.15** new cases of male breast cancer diagnoses in 2015 per 100,000 heads of the population.

**0.28** cases of male breast cancer deaths in 2015 per 100,000 heads of population.



### Scotland

**1.03** new cases of male breast cancer diagnoses in 2015 per 100,000 heads of the population.

**0.18** cases of male breast cancer deaths in 2015 per 100,000 heads of population.

### England

**1.40** new cases of male breast cancer diagnoses in 2015 per 100,000 heads of the population.

**0.30** cases of male breast cancer deaths in 2015 per 100,000 heads of population.

\*No data available for Northern Ireland

# References, sources, notes and caveats

## Photo and quotes

The photo on the front cover and quotes on pages 5, 21, 33, 41, 49, 55 and 59 are from our cover star Diane, who has kindly agreed to be featured in this publication.

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# Appendix A: Jargon Buster

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

## (i) Health data terms

**Incidence:** When we talk about ‘cancer incidence’ we mean the number of people who are newly diagnosed with cancer within a given time-frame, usually one calendar year. The data can be ‘cut’ in a number of ways, for example by cancer type (breast, prostate, lung, colorectal, etc) or by gender, age, etc. The latest data we have is for 2015, and we know that over 350,000 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 2015, and we know that over 160,000 people die from cancer in the UK every year. Mortality can sometimes be given as a rate (per head of population).

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

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

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

## (ii) Other terms

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

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

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

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



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# 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_14
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## 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 (2017 update)	MAC13838_17
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 (2017 update)	MAC13845_17
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 (2017 update)	MAC13732_17
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 (2017 update)	MAC13841_17
The Rich Picture on carers of people with cancer (2016 update)	MAC16275_10_16
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 [be.macmillan.org.uk](https://www.be.macmillan.org.uk)

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

You may have cancer, but you are still you with a life to lead, friends to see, family who need you and people to love.

Macmillan is here to help you get on with your life no matter how cancer affects you. We can give you the practical, emotional and genuinely personal support you need to hold on to who you are and what's important to you.

We can be there for you during treatment, help with work and money worries and give you the time you need to talk about your feelings or whatever's troubling you. Whether it's everyday things like the cost to park at hospital during treatment or big stuff like explaining cancer to your children, we'll do all we can to support you.

We'll be honest: cancer can be tough. But we've helped millions of people through it and we can do the same for you. To us you're always a person, never a patient. Life with cancer is still your life and we will help you live it.

From the moment you're diagnosed, for as long as you need us, you can lean on Macmillan. Call us free on **0808 808 00 00** or visit **macmillan.org.uk**

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