# THE RICH PICTURE

# PEOPLE WITH CERVICAL CANCER

WE ARE MACMILLAN. CANCER SUPPORT

Kate, 34, living with cervical cancer

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

# About this 'Rich Picture'

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

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

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

The information could be valuable in many ways:

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

This document is not intended to

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

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

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

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

## The legal bit

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

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

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

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

# Guidance on referencing this document

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

# Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklet 'Understanding Cervical Cancer' (MAC11648) more helpful.

**Understanding Cervical Cancer**
MAC11648

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

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

# OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

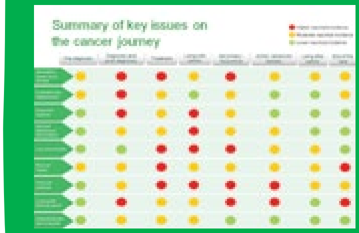
## Case Study Library

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

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

## Comms Platform

Describes how to communicate with people affected by cancer.


Summary of key issues on the cancer journey

## Rich Pictures

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


THE RICH PICTURE
PEOPLE WITH CERVICAL CANCER
Understanding the numbers, needs and experiences of people affected by cancer

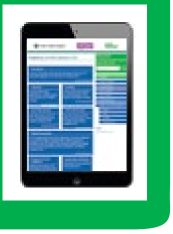
## Impact Briefs

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


LOCAL CANCER INFORMATION

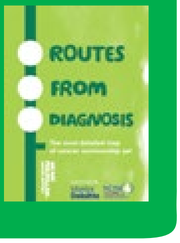
## Local Cancer Intelligence

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



## Routes from Diagnosis

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


ROUTES FROM DIAGNOSIS

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

Contents

# CONTENTS

# SUMMARY OF PEOPLE LIVING WITH CERVICAL CANCER

## Key stats

Cervical cancer is the fifteenth most commonly diagnosed cancer in the UK. More than 8 women are diagnosed every day.(4)(5)(6)(7)

Infection with the human papillomavirus (HPV) is the main risk factor and cause of cervical cancer.(1)

Cervical screening can prevent 45% of cervical cancer cases in women in their 30s, rising to 75% in women in their 50s and 60s.(9)

Survival rates are generally good with two thirds of women living for 5 or more years after their diagnosis.(16)

**More than 8 women are diagnosed with cervical cancer a day in the UK.**

## Diagnosis

Screening programmes have **reduced the overall incidence of cervical cancer;** they have also led to a disproportionate rise in the incidence of early-stage disease due to early detection.(23, 34)

The most common symptoms of cervical cancer are **bleeding from the vagina,** a **vaginal discharge that smells unpleasant** and **pain or discomfort during sex.**(25)

The NHS National Cervical Screening programme **screens over 3 million women** in England each year.(28)

**Screening programmes have reduced the overall incidence of cervical cancer.**

## Treatment

**45%** of cervical cancer patients have a record of a **major surgical resection** as part of their treatment.(48)

Radiotherapy and surgical treatment for cervical cancer can **compromise fertility.**(30)

**24%** of people with cervical cancer are **not told about treatment side effects.**(70)

**33%** of people with cervical cancer think **GPs and nurses at their local practice could have done more** to support them while they were having their treatment.(63)

**Radiotherapy and surgical treatment for cervical cancer can compromise fertility.**

## Survivorship

Cervical cancer and its treatment can produce short- and long-term side effects, such as **sexual dysfunction, infertility, or lymphoedema that can adversely affect quality of life.**(74)

Many people feel **abandoned by the healthcare system** once their initial treatment for cancer has completed.(80)

**42%** of people with cervical cancer are **not given enough care and help from health and social care professionals** once they are at home.(80)

**Cervical cancer and its treatment can produce negative side-effects especially related to fertility and sexual functioning.**

## End of Life

According to a 2010 Macmillan report, **36%** of all people with terminal cancer **do not claim the benefits they are entitled to.** This amounts to over £90m.(94)

Cervical cancer patients who are at end of life report symptoms of pain, anorexia, vaginal bleeding, psychological problems, weight-loss and physical deterioration.(91)

For people with cervical cancer who are at end of life, **palliative care can help alleviate symptoms and side-effects.**(92)

**36% of all people with terminal cancer do not claim the benefits they are entitled to.**

## Lifestyle & perceptions

Although women living with cervical cancer can come from all parts of society, the majority tend to come from lower middle class or deprived areas and over **60% of them are under the age of 50.**(9)(101)

**Elderly women reliant on state support and younger women reliant on benefits** are well-represented amongst people being treated for cervical cancer.(101)

Cervical cancer is a **well-known and highly publicised cancer type** and articles on cervical cancer are often found in UK national newspapers.(104)

Contents

# INTRODUCTION TO CERVICAL CANCER

## What is cervical cancer? (1)

The cervix is the lower part of the womb (uterus) and is often called the neck of the womb. It joins the womb to the top of the vagina.

There are two main types of cervical cancer:

- Squamous cell carcinoma – This is the most common type of cervical cancer. It develops from the flat cells which cover the outer surface of the cervix at the top of the vagina.
- Adenocarcinoma – This type develops from the glandular cells which line the cervical canal (endocervix). As adenocarcinoma starts in the cervical canal it can be more difficult to detect with cervical screening tests.

Cancer of the cervix can take many years to develop. Before it does, changes occur in the cells of the cervix. These abnormal cells are not cancerous, and are called cervical intra-epithelial neoplasia however these cells can develop into cancer in some women if they are not treated.

Cervical cancer is usually caused by a common infection called the human papilloma virus (HPV); however, most women who have HPV will not get cervical cancer.

The cervical smear can detect changes in the cells of the cervix caused by HPV infection.

## Want to know more?

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

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

‘When I was diagnosed it wasn’t the shock of having cancer that upset me the most it was that I was told the treatment plan would leave me infertile and take me into an early menopause – I was only 30 years old with plans of a family.

My treatment started fast and the staff around me were amazing, but the treatment didn’t stop it spreading. I was heading for a second course of radiotherapy in 6 months. The chemo was ok but I found the radiotherapy hard going, simple tasks became difficult and life became frustrating.

Treatment is over for now but the lasting effects stay with me. I can honestly say the cancer journey, despite being terrible has in some ways changed my life for the better, it certainly makes you realise what’s important.’

Kate, 34

# MACMILLAN'S AIMS AND OUTCOMES

## Macmillan's aims and outcomes – and how they are different for people with cervical cancer

The estimated total number of people living with cancer in the UK in 2015 is almost 2.5 million. Assuming that all existing trends in incidence and survival continue cancer prevalence is projected to increase to 4 million in 2030. Particularly large increases are anticipated in the oldest age groups and in the number of long term survivors. By 2040 77% of all cancer survivors will be at least 65 years old and 69% of cancer survivors will be at least 5 years from diagnosis.

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

**Around 34, 850 women were living with cervical cancer in the UK in 2010, based on women living up to 20 years post a cancer diagnosis.(3)**

## How is this different for people with cervical cancer?

Macmillan is carrying out work internally to 'baseline' the 9 Outcomes, and we hope to be able to show how the 9 Outcomes vary for different groups. This document will be updated when this work is complete. (3)

## The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

# THE FACTS ON CERVICAL CANCER

**This section presents some of the key stats and facts relating to people with cervical cancer. You may benefit from referring to the Jargon Buster on page 66 for details on some of the terms used in the section. Please note that incidence and mortality data on all cancers exclude non-melanoma skin cancer.**

**8**

women are diagnosed with cervical cancer in the UK every day. (4) (5) (6) (7)

**Around 34,850**

women were living with cervical cancer in the UK in 2010, based on women living up to 20 years post a cancer diagnosis.

**84%**

of women in England live for more than one year after their cervical cancer diagnosis. (8)

**67%**

of women live more than five years after their cervical cancer diagnosis. (8)

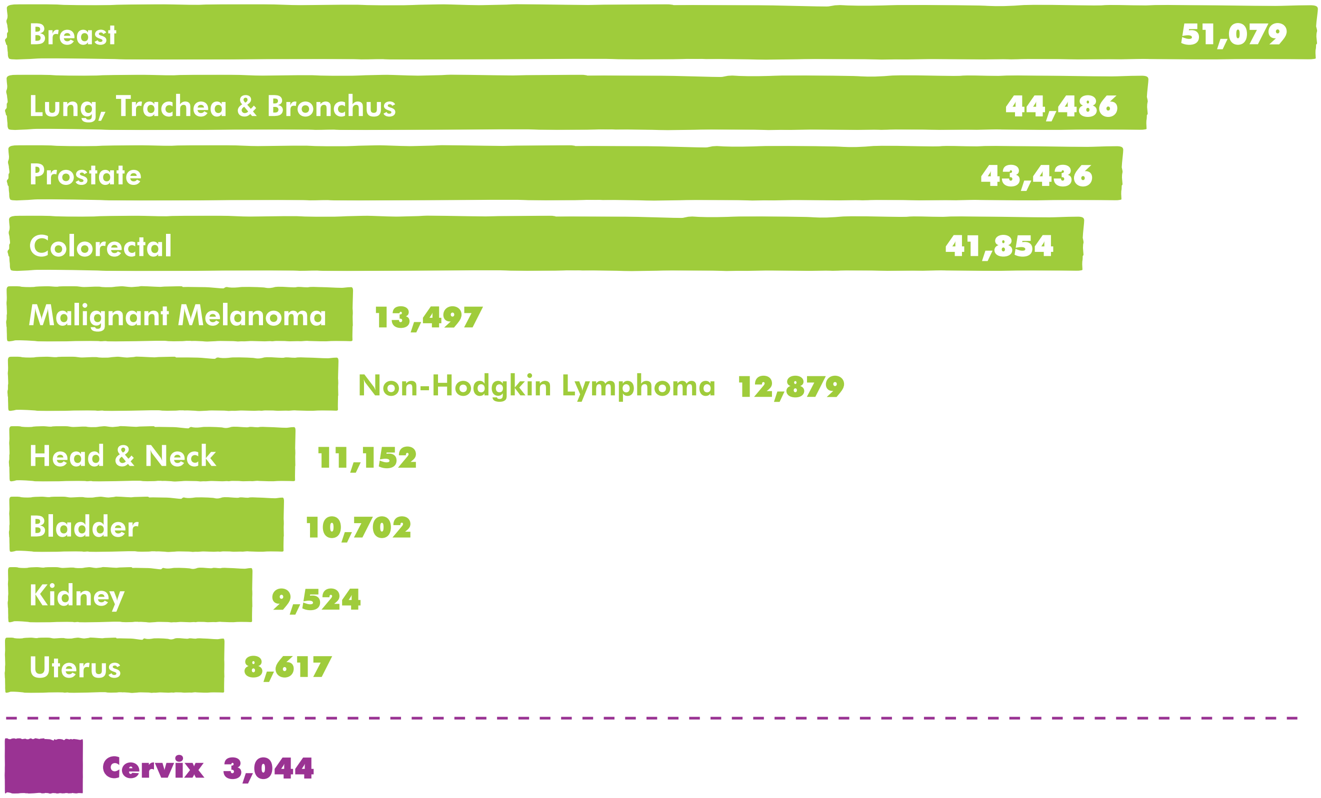
**3**

women die every day of cervical cancer in the UK. (9)

Contents

## How many people get cervical cancer per year (incidence) (4) (5) (6) (7)

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



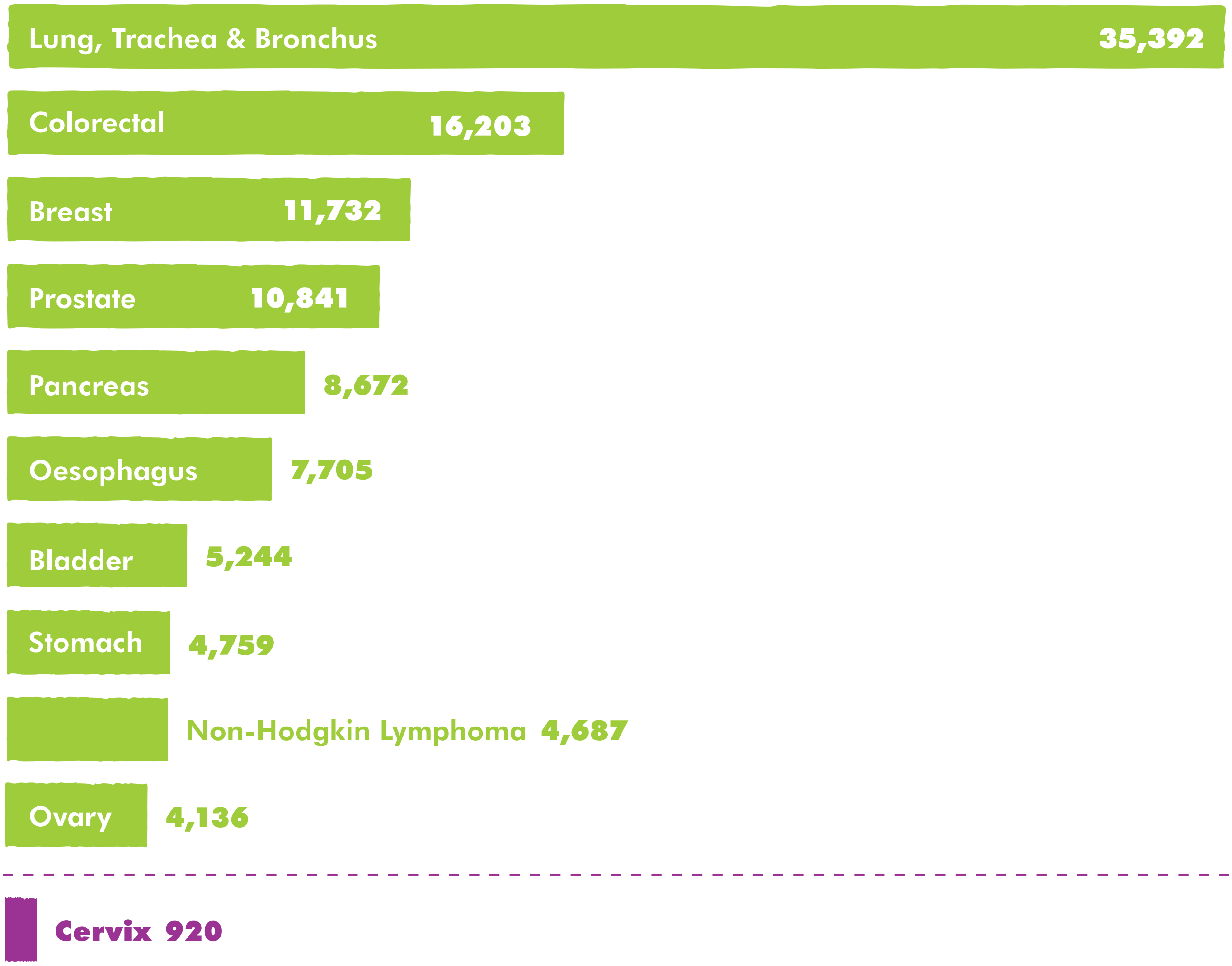
**Cervical cancer is the fifteenth most commonly diagnosed cancer. Over 3,000 women are diagnosed every year in the UK; that’s more than 8 women every day.**

**Over 17% of second cancers that occurred among survivors of cervical cancer are estimated to be associated with radiotherapy for the first cancer.** (10)

Key facts and stats

## How many people die from cervical cancer per year? (mortality) (11) (12) (13)

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



**Cervical cancer is the twentieth biggest killer of all cancers. 920 women die from cervical cancer every year in the UK; that's around 3 every day.**

## How many people are currently living with cervical cancer? (prevalence) (3)

Women living with cervical cancer in the UK in 2010, based on women living up to 20 years post a cancer diagnosis.

**34,850**

**Although the prognosis for people with cervical cancer is often good, incidence is relatively low so the overall proportion of people living with cervical cancer in the UK is small.**

## What are the key stats for England?

See data on incidence, mortality and prevalence for England

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

### How many people get cervical cancer per year in England? (incidence)(4)

**2,482**

new cases of cervical cancer diagnoses in England in 2012.

### How many people die from cervical cancer per year in England? (mortality)(11)

**743**

cervical cancer deaths in England in 2012.

### How many people are living with cervical cancer in England? (prevalence)(3)

**Around 28,600**

women were living with cervical cancer in England in 2010, based on women living up to 20 years post diagnosis (1991 and 2010).

### What is the age-standardised* rate of incidence of cervical cancer in women in England?(14)

**8.7**

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

### What is the age-standardised* rate of mortality from cervical cancer in women in England?(116)

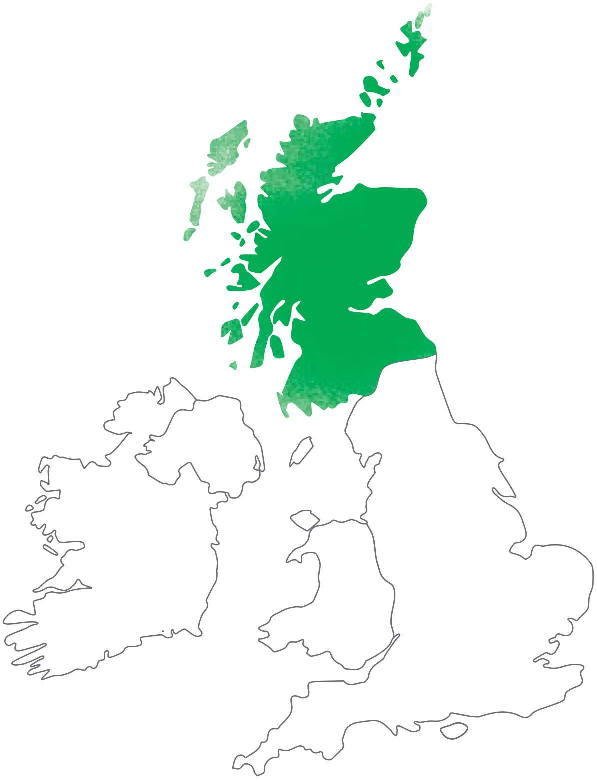
**2.2**

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

Contents

# What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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## How many people get cervical cancer per year in Scotland? (incidence)(4)

**295**

new cases of cervical cancer diagnoses in Scotland in 2012.

## How many people die from cervical cancer per year in Scotland? (mortality)(11)

**112**

cervical cancer deaths in Scotland in 2012.

## How many people are living with cervical cancer in Scotland? (prevalence)(3)

**Around 3,500**

women were living with cervical cancer in Scotland in 2010, based on women living up to 20 years post diagnosis (1991 and 2010).

## What is the age-standardised* rate of incidence of cervical cancer in women in Scotland?(2)

**10.7**

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

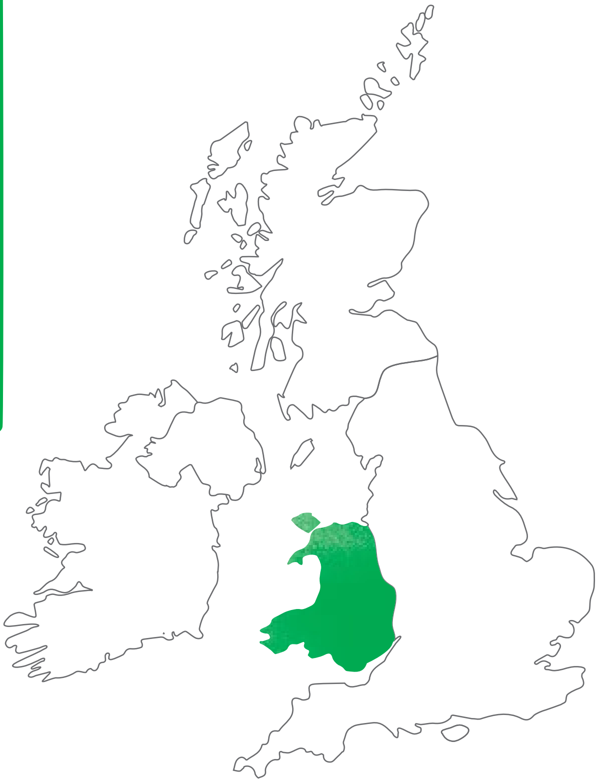
## What is the age-standardised* rate of mortality from cervical cancer in women in Scotland?(116)

**3.1**

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

# What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales



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## How many people get cervical cancer per year in Wales? (incidence)(4)

**174**

new cases of cervical cancer diagnoses in Wales in 2012.

## How many people die from cervical cancer per year in Wales? (mortality)(11)

**43**

cervical cancer deaths in Wales in 2012.

## How many people are living with cervical cancer in Wales? (prevalence)(3)

**Around 1,710**

women were living with cervical cancer in Wales in 2010, based on women living up to 20 years post diagnosis (1991 and 2010).

## What is the age-standardised* rate of incidence of cervical cancer in women in Wales?(14)

**7.8**

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

## What is the age-standardised* rate of mortality from cervical cancer in women in Wales?(116)

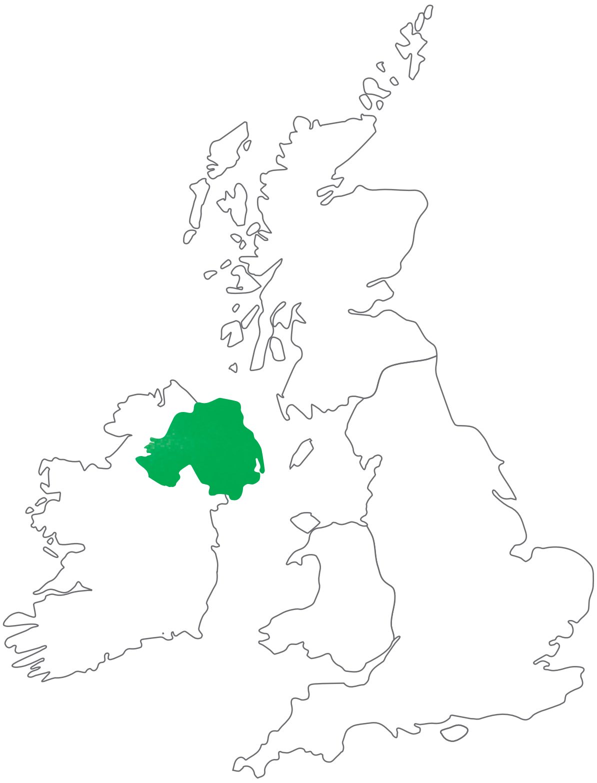
**2.9**

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

Contents

# What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



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## How many people get cervical cancer per year in Northern Ireland? (incidence)(4)

**93**

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

## How many people die from cervical cancer per year in Northern Ireland? (mortality)(11)

**22**

cervical cancer deaths in Northern Ireland in 2012.

## How many people are living with cervical cancer in Northern Ireland? (prevalence)(3)

**Around 1,030**

women were living with cervical cancer in Northern Ireland in 2010, based on women living up to 20 years post diagnosis (1991 and 2010).

## What is the age-standardised* rate of incidence of cervical cancer in women in Northern Ireland?(2)

**11.1**

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

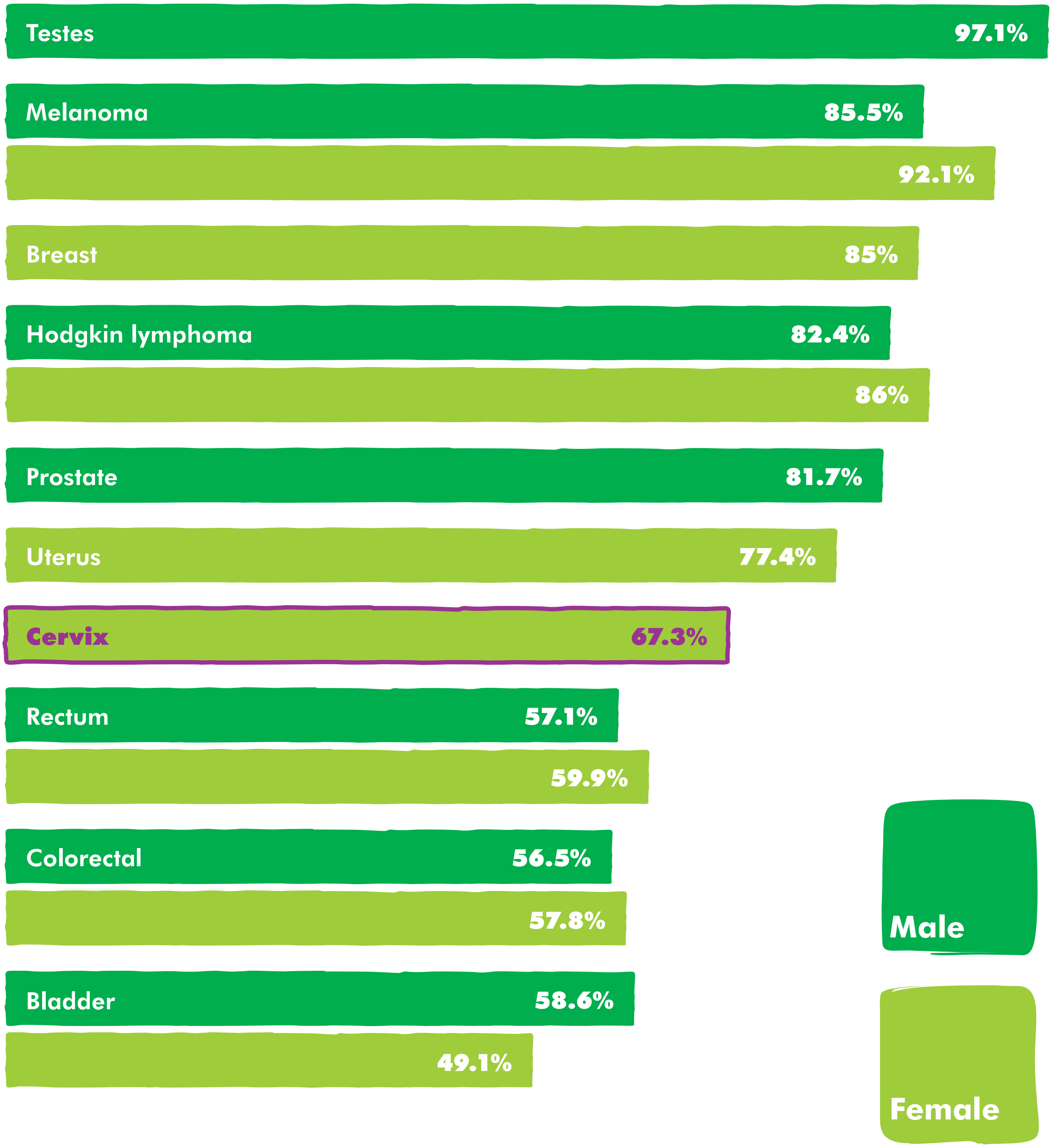
## What is the age-standardised* rate of mortality from cervical cancer in women in Northern Ireland?(116)

**2.1**

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

## What proportion of people survive cervical cancer? (survival) (16)

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

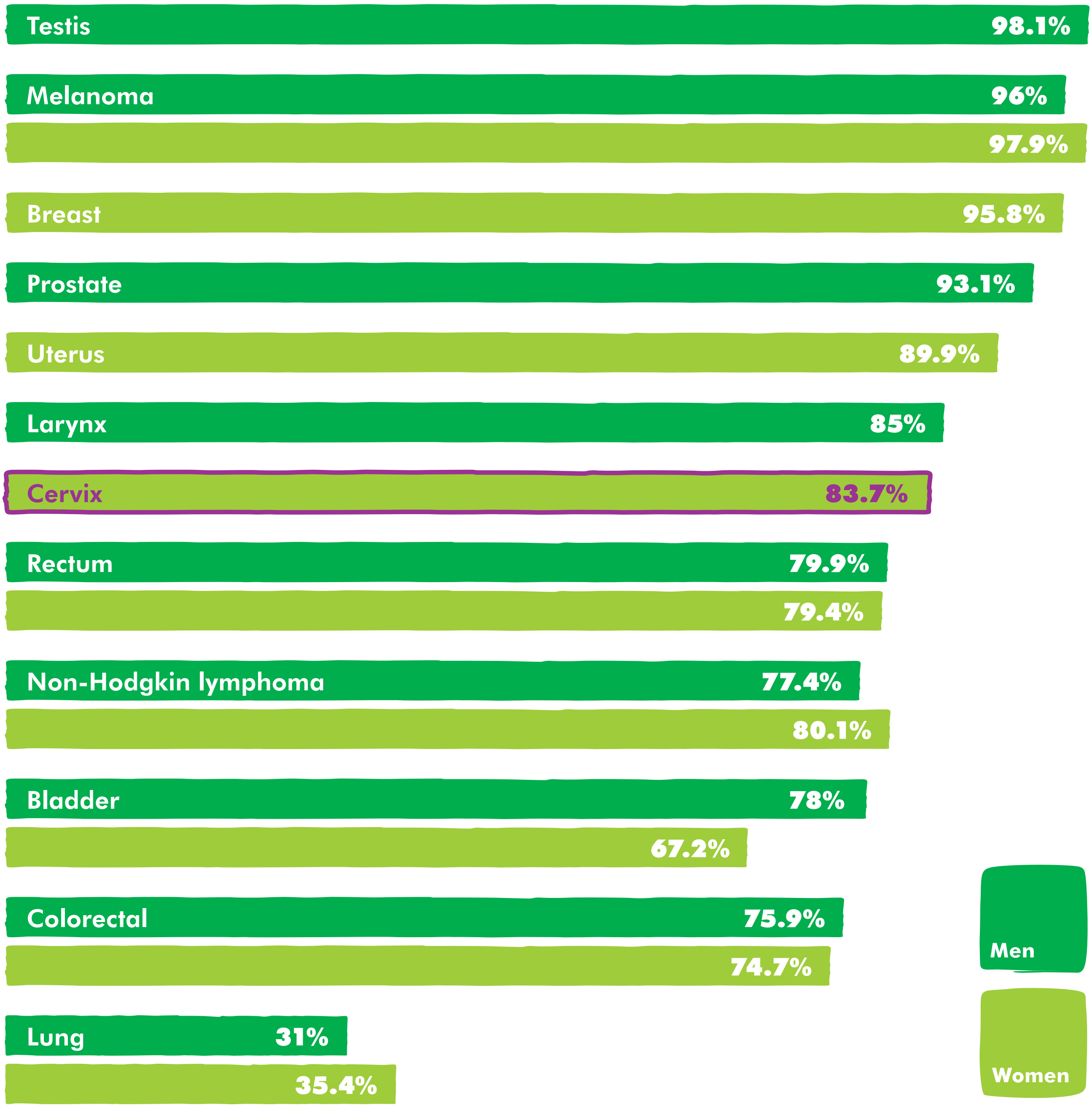


**Cervical cancer has the fifth highest survival rate of all cancers in women (two thirds of women are alive 5 years after their diagnosis).**

**One reason for these relatively high survival rates is the NHS Cervical Screening Program, introduced in the 1980s. Screening can detect cervical cancers at an early stage when treatment is most likely to be successful.(8)**

## How many people live beyond one year of their cervical cancer diagnosis? (17)

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



**The proportion of people living more than one year after their cervical cancer diagnosis is estimated to be almost 84% – in other words the prognosis, especially for younger women, is often good.**

## How have median survival times changed for cervical cancer?

Overall median survival time 40 years ago for all cancers was one year. These latest figures predict median survival time is now nearly six years. The biggest improvement in median survival time has been for colon cancer with a 17-fold increase from around seven months to ten years. In 1971-72 median survival time for cervical cancer was 7.7 years, since when it has increased to more than 10 years, and as a result no data at a more specific level are available. (18)

However we do know that five year relative survival rates for cervical cancer increased from 52% to 67% from 1971-75 to 2007-11 in England and Wales and ten year relative survival rates have improved from 46% to 64% for the same period. (8)

## How do UK survival rates compare internationally?

Survival rates for cervical cancer are slightly worse in the UK and Ireland than on average in Europe. In 2000-07, one year survival for cervical cancer was 80% in the UK and Ireland but 84% on average in Europe. Five year survival was 59% in the UK and Ireland but 62% on average in Europe. (19)

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

### Gender

As men do not have a cervix they are unable to develop cervical cancer.

### Ethnic background

Women in developing countries have a higher cervical cancer risk. This is partly because developing countries don't have screening. It is also because women in developing countries are more likely to have large families. Women who have had 7 or more children have double the risk of women with only 1 or 2 children. (20)

In England, Black and Asian females aged 65 years and over, are at higher risk of cervical cancer compared to White females.(113)

### Age

Cervical cancer incidence is related to age but it is unusual as it does not follow the same pattern of increasing incidence with age seen for most cancers. There are two peaks in the age-specific incidence rates: the first in women aged 25–29, (possibly related to many women becoming sexually active in their late teens/early twenties giving rise to the increase of the HPV), and the second in women aged 85-89 (due to increasing cancer incidence with age). (4)

Four in five (78%) of cervical cancer cases occur in 25-64 year olds. (4)

As with nearly all cancers, relative survival for cervical cancer is higher in younger women, even after taking account of the higher background mortality in older people. (8)

### Social background

Women living in the most deprived areas have cervical cancer incidence rates more than three times as high as those in the least deprived areas. (21)

Smoking, HIV/AIDS and prolonged use of the oral contraceptive pill are also linked to higher incidence rates of cervical cancer. (21)

### LGBT

HPV can be transmitted via skin to skin contact during sexual activity between two women. However research shows that around 40% of women who have sex with women have previously been erroneously advised that they do not need smear tests, either by healthcare professionals or by members of the community. (114) 15% of lesbian and bisexual (LB) women over 25 years old have never had a cervical screen, compared to 7% of the general female population over 25 years old. (115)

## What are the geographical 'hotspots' for cervical cancer incidence, mortality and survival? (14)

Cervical cancer incidence, UK, 2008-2010

🟩 Low

🟩 Medium

🟩 High

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

## Cervical cancer incidence rates are higher in North East England, Wales and Northern Ireland and lower in the south of the UK (southern England and the Midlands).

Much of the variation in incidence can be attributed to geographical differences in deprivation, population prevalence of HPV, and other co-factors such as oral contraceptive use and smoking. (23)

**Cervical cancer mortality, UK, 2009-2011**

- 🟩 Low
- 🟩 Medium
- 🟩 High

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

## Cervical cancer mortality is higher in Scotland and Wales than the South of England and the Midlands.

# Trends in the data

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

The introduction of the national NHS cervical screening programmes across the UK in the late 80’s saw a significant decrease in cervical cancer incidence rates. This is because cervical cancer screening detects and treats abnormal cells preventing many cases of cervical cancer from ever developing. (23)

Cervical cancer mortality rates in 2009-2011 were 71% lower than they were nearly 40 years earlier. This is predominantly due to earlier diagnosis as a result of the introduction of the national screening programme. (17)

Risk of cervical cancer is almost doubled in women with a mother or sister who has been diagnosed with the disease, due to similarity of lifestyles or genetic factors. Cervical cancer is not hereditary. (21)

**‘I suppose the only difficult thing about it is that because of my age I was the youngest in the ward and you do feel like, why I’m here I’m only 30 I’m too young. Even now when I go up for my check-ups I feel odd that I know my way round a hospital because I don’t think of myself as a sick person at all. The nurses say you were ill but I’ve always been so fit and active it doesn’t feel real.’**

Clara, Scotland

# THE CANCER JOURNEY

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

**The following pages summarise what we currently know about the needs and experiences of people with head and neck cancer at these stages.**

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

## 1 Diagnosis

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

- People often **show signs and symptoms** that may be caused by cancer, and a GP can refer patients for tests to find out more.
- **Screening** aims to detect cancer at an early stage or find changes in cells which could become cancerous if not treated.
- However screening can only pick up some cancers, and we know that some people have their cancer **diagnosed at a late stage** – this can have a huge effect on their chances of survival.

## 2 Treatment

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

- Cancer can be **treated** in different ways depending on what type of cancer it is, where it is in the body and whether it has spread.
- Different cancer types can have **varying treatment regimes**, and treatment is personalised to each patient.

## 3 Survivorship*

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

- An increasing number of people **survive** their initial (or subsequent) cancer treatments, and often have **rehabilitation** and **other needs** post-treatment.
- We also know they need support to be able to **self-manage**.
- Many people in this stage experience **long-term or late effects** of their cancer, and/or their cancer treatment.

## 4 Progressive illness and end of life

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

- Progressive illness includes people with **incurable cancer**, but not those in the last year of life. Many of these people have significant treatment-related illnesses.
- End of life generally means those in the **last year of life**. Needs often get greater as the person moves closer to death.

*While Survivorship relates to the time both during and post-treatment, as illustrated by the Recovery Package (p41), this section largely highlights the post-treatment needs and experiences of people living with cancer.

Contents

# NEEDS AND EXPERIENCES
# DIAGNOSIS

## What are the top 3 signs and symptoms of cervical cancer? (25)

1. The most common symptom of cervical cancer is bleeding from the vagina:
   - Between periods
   - After or during sex
   - At any time if you are past your menopause
2. A vaginal discharge that smells unpleasant
3. Discomfort or pain during sex

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

Declining rates in cervical screening, particularly in younger women, have prompted renewed interest in raising awareness of signs and symptoms to lead towards earlier diagnosis. (26)

The most commonly endorsed barriers to seeking help were difficulty making an appointment, worry about wasting the doctor's time and worry about what would be found. (27)

## How well does screening work for cervical cancer?

There is a variation in the recommended age groups for screening in the different nations of the UK:

- In England, Wales, and Northern Ireland, women aged between 25 and 49 years are invited to a screening every 3 years, while women aged between 50 and 64 years are invited every 5 years. (28, 24, 15)
- In Scotland, women aged between 20 and 60 years are invited to a screening every 3 years. (22)

The most up to date figures for 2012–13 show that the percentage of eligible women (aged 25 to 64) who were recorded as screened at least once in the previous 5 years was 78%. The trend over the last 10 years has shown a gradual and slight decrease in coverage; excluding a slight increase in 2009, it has either fallen or remained unchanged each year since 2003, when it was 81.2 per cent. (29)

Screening programmes have reduced the overall incidence of cervical cancer; however, this has led to a disproportionate rise in the incidence of early-stage disease. (30)

Cervical screening can prevent 45% of cervical cancer cases in women in their 30s, rising to 75% in women in their 50s and 60s. (9)

The English guidelines recommend screening every 3 years for women if they are between 25 and 50. It is acceptable and safe for women of 50 or more to be screened every 5 years. For women under 25, it is thought that screening would do more harm than good; incidence is very low for this age bracket, while abnormalities that will later resolve themselves are common. Screening can therefore cause unnecessary anxiety. (31)

Currently the only UK nation that does not follow these guidelines is Scotland; however this is in the process of being changed. From 2015, the lower age limit will be raised to 25 and women between 50 and 64 will be screened every 5 years. (117)

Contents

**‘Knowing I’m a bit of a hypochondriac, I just laughed at myself and thought, no its not that, you don’t have cervical cancer when you are 30. When I was given the diagnosis, I was shell shocked. I didn’t think it was happening to me.’**

Sophie, 33

## How is cervical cancer diagnosed? (Routes to diagnosis) (32)

**Emergency**

**11%**

**GP**

**32%**

**Two Week Wait**

**16%**

**Screen Detected**

**24%**

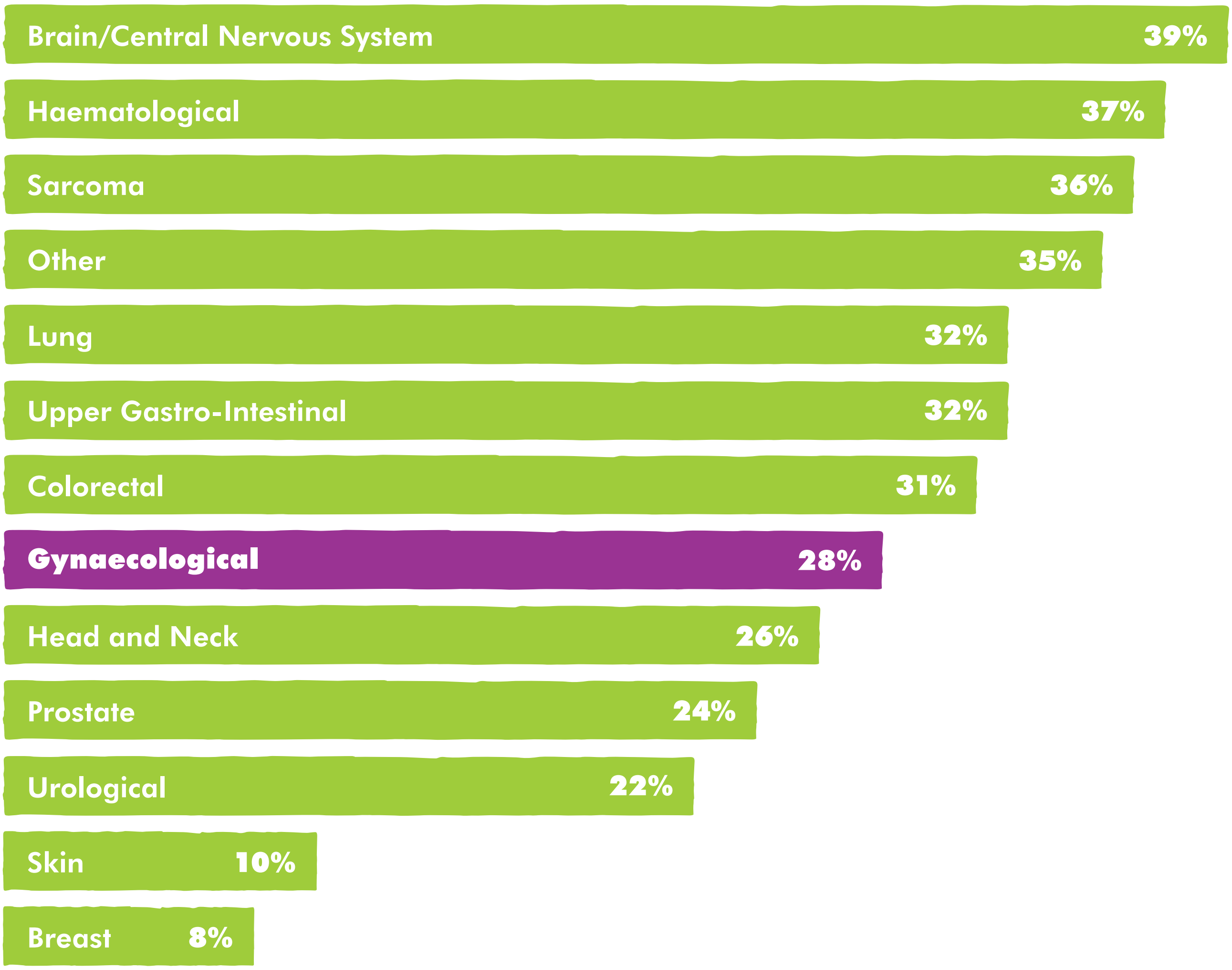
**Other**

**17%**

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

**11% of people newly diagnosed with cervical cancer were diagnosed via the emergency route, which is significantly lower than the average for all cancers (23%). This is indicative of a high uptake of the cervical screening programme and detection at an earlier stage.**

## How many cervical cancer patients had to see their GP more than twice before they were diagnosed? (33)



**28% of people newly diagnosed with gynaecological cancers (including cervical cancer) had to see their GP more than twice before they were diagnosed compared with only 8% of breast cancer patients, 10% of skin cancer patients and 22% of urological cancers.(33)**

## How does stage at diagnosis relate to probable survival rates? (34)

### The impact of stage at diagnosis on survival* – cervical cancer

*For stage 1, the cure rate is given. For stages 2-4, the rate refers to the percentage alive 5 years later.

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

## How long do people with cervical cancer have to wait to be referred? (35)

**According to recent data, around 96% of patients with suspected gynaecological cancer (including cervical cancer) were seen by a specialist within 2 weeks of referral.**

**This is a relatively good performance although patients with other suspected cancers, such as breast and lung, showed a slightly stronger performance with 98%.**

# PHYSICAL AND MEDICAL NEEDS

**Diagnosis of cervical cancer can occur during pregnancy or in young women who wish to preserve their fertility.** Unless the cancer is diagnosed at a very early stage, any treatment will result in infertility, so a discussion about this at the diagnosis stage is very important.(110)

**Different options of fertility-sparing treatment can be considered on the basis of several factors** such as the stage of the tumour and the patient's desire regarding future family plans. The **type of treatment offered during pregnancy is also dependent upon gestational age.**(36) If the pregnancy is within the second or third trimester then usually the patient will be able to continue with the pregnancy before starting treatment.(110)

# FINANCIAL NEEDS

Of the people with gynaecological cancer (including cervical cancer) who said they wanted it, **42%** of them were **not given information on financial help or benefits by hospital staff,** compared to an average (for all cancers) of 46%. **(38)**

The mean travel costs in the UK per attendance at a smear test and at a colposcopy appointment were estimated to be £9.20 and £27.40, respectively (valued at 2002 prices). **(39)**

## Not specific to people with cervical cancer

It is estimated that **30% of people with cancer experience a loss of income as a result of their cancer, with those affected losing, on average £860 a month.** Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families. (109)

# PRACTICAL AND INFORMATION NEEDS

**In a 2013 survey 76%** of people with gynaecological cancers (including cervical cancer) said they **received a completely understandable explanation of their test results.** This suggests that **27% of gynaecological cancer patients do not receive a completely understandable explanation of their test results.** There was significant variation in the number of patients saying they had a completely understandable explanation of their tests results. Scores ranged from 85% (skin cancer) to 71% (brain / CNS). (41)

Only **65%** of people with gynaecological cancers (including cervical cancer) **received written information about the type of cancer that they had and said that it was easy to understand** compared to 81% of prostate cancer patients and 76% of breast cancer patients. The average for all cancer types is 71%. (42)

## Not specific to people with cervical cancer

The **strongest preference for information** at diagnosis is information about **prognosis**. (40)

# EMOTIONAL AND PSYCHOLOGICAL NEEDS

**Fear, self-blame, distress, and anxiety** about cervical cancer are common in women who receive abnormal screening results. Such results **impact body image, self-esteem and relationships with partners.** (44)

At preoperative assessment, women choosing a radical hysterectomy report greater **concern about cancer recurrence** than women choosing a radical trachelectomy (removal of the cervix). Both groups demonstrated s**igns of depression and distress preoperatively.** (47)

## Not specific to people with cervical cancer

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, around **half of all people with cancer (all cancer types) experience levels of anxiety and depression** severe enough to adversely affect their quality of life. (45)

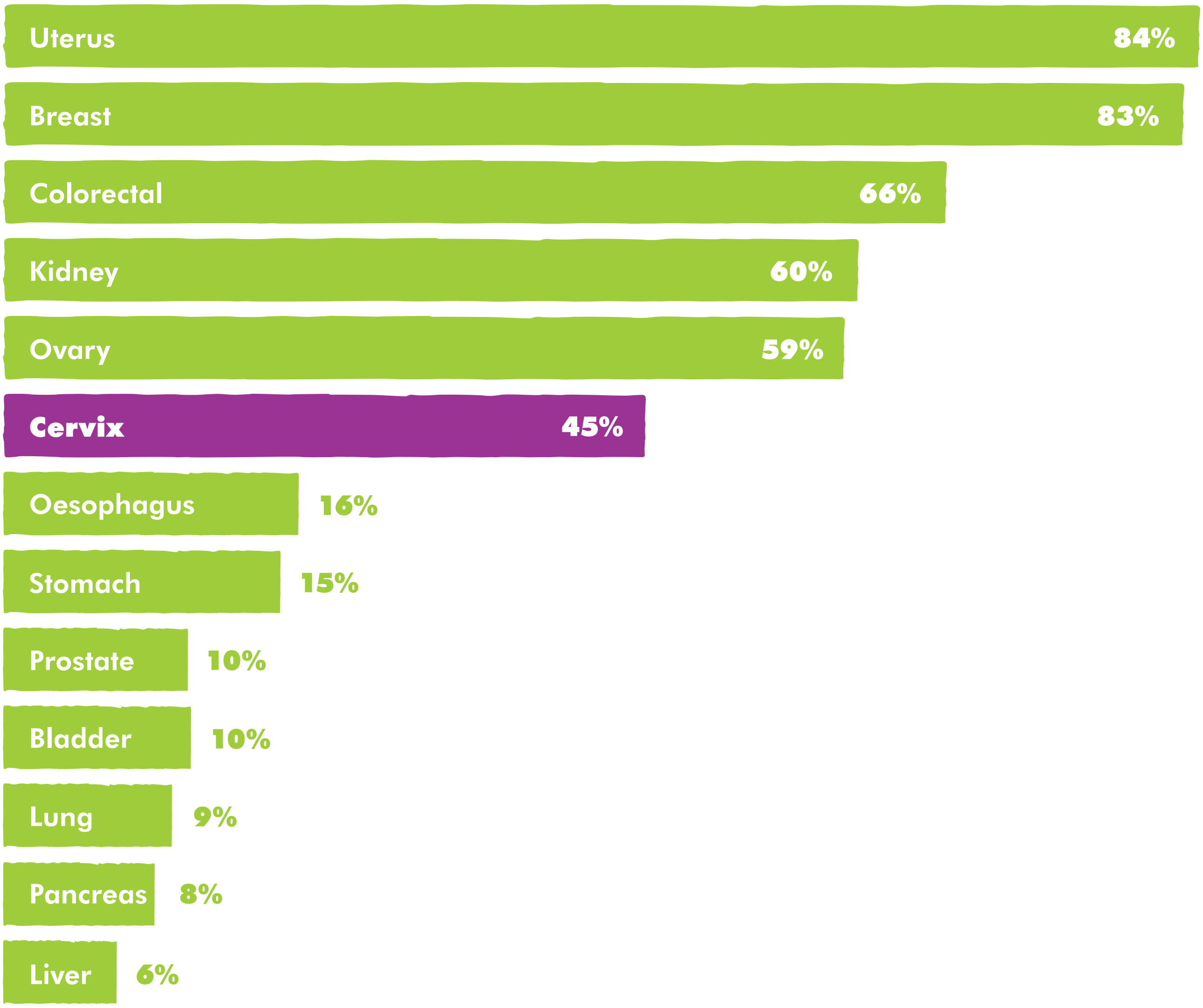
**62% of cancer patients in a survey had experienced at least one psychological condition** that can occur as a result of cancer and its treatment in previous 12 months. Such conditions include depression, anxiety and sexual problems. However, 40% of them had not sought help from healthcare professionals. (43)

Contents

## NEEDS AND EXPERIENCES

# TREATMENT

Percentage of patients who had major surgical resection, 2004-



**45% of cervical cancer patients had a record of major surgical resection as part of their treatment.**

## What treatments do cervical cancer patients get?

**Surgery**
Radical trachelectomy - This operation can only be done for small stage 1 cervical cancer. The aim is to remove all the cancer and leave the internal opening of the cervix. This is a fertility-sparing option.

Hysterectomy - A hysterectomy involves removal of the womb and can sometimes be done using keyhole surgery.

For advanced cervical cancer, a pelvic exenteration is undertaken which involves removing the womb, cervix, top of the vagina and lymph nodes as well as other organs. (49)

45% of NHS treated cervical cancer patients have a record of a major resection. The percentage of patients with major resection decreases with age. For patients aged under 40, around 60% have
a record of a major resection. In patients aged 60-69, 31% have a record of a major resection and for patients aged 80 and over, 10% have a record of a major resection. (48)

**Radiotherapy**
Gynaecological cancer (which includes cervical cancer) accounts for 4% of all radiotherapy episodes in England (2011-2012). There were 5,388 radiotherapy episodes and 87,895 radiotherapy attendances for gynaecological cancer. (50)

In 2007, 43% of cervical cancer patients underwent radiotherapy. (10)

**Chemotherapy**
There are several chemotherapy drugs which can be used to treat cervical cancer. The most commonly used is cisplatin. Chemotherapy is commonly combined with radiotherapy to make the radiotherapy more effective. (51)

Chemoradiotherapy can cure 80-95% of women with early stage disease (stages I and II) and 60% with stage III disease. (52)

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

In total, there were just under 8,800 NHS admissions to hospitals in England (emergency and non-emergency) for cervical cancer during 2012-13.

The median length of stay for cervical cancer patients who were admitted was 2 days in 2012-13. (53)

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

The standard treatment for cervical cancer compromises fertility. Whilst screening programmes have reduced the overall incidence of cervical cancer, they have led to an increase in demand for fertility-sparing techniques to be developed, as more women are diagnosed at a young age and early stage. (30)

For early stage cervical cancer surgery is often the main treatment when the cancer is only in the cervix. (54)

Radical trachelectomy is a fertility-sparing procedure, for the treatment of early invasive cervical cancer, with the aim to provide adequate oncological safety to patients with cervical cancer whilst preserving their fertility. (55)

For locally advanced cancer, radiotherapy is usually given in combination with chemotherapy rather than surgery. Chemotherapy may be given to women whose cancer has spread to other parts of the body or if the cancer comes back after radiotherapy. It is used to try to shrink and control the cancer and relieve symptoms. (54)

Contents

## How many people with cervical cancer have access to a cervical CNS? (57)

There are currently 174 Clinical Nurse Specialists (CNSs) in England.

Macmillan's internal data suggests that we had (as of June 2012) 106 Gynae/Oncology Macmillan nurse posts across the whole of the UK. (56)

## What does this mean for patients?

In a 2013 survey 91% of women with gynaecological cancers (including cervical cancer) reported that they had been given the name of their clinical nurse specialist. This is slightly higher than the average for all cancers (86%). People with a CNS respond far more positively than those with regards to information, choice and care. (58)

Sensitive, appropriate patient information is considered to be an important element in the psychological support of patients. CNSs are seen to have a key responsibility for this work. (90)

Women who have initial support from a CNS at the time of diagnosis experience a clinically significant reduction in their level of psychological distress 6 months from diagnosis. This suggests that support from a CNS may be able to assist psychological recovery. (59)

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 to inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes. The paper, along with other Impact briefs, is available via the Macmillan website, at **www.macmillan.org.uk/servicesimpact**

The CNS is in a key position to be able to address the complex and sensitive issues such as the patients' psychological, social and sexual rehabilitation following treatment. The successful development of medical/nursing partnerships enables women with cervical cancer to gain proper access to essential expert knowledge and information and thereby to make informed decisions. (60)

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

More people with cervical cancer are living long enough to develop chronic treatment-related conditions. (61)

## Not specific to people with cervical cancer

Just under half (47%) of all people living with cancer (of all cancer types) have at least one other chronic condition. This includes 15% who have two, and 6% who have three other chronic conditions. (62)

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

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

Contents

**‘They told me I could not have infertility treatment because I was single, and didn’t even have a partner at the time. I felt discriminated against. I was ignorant about having smears done and the importance of having a smear!’**

Kim, 31

Contents

# PHYSICAL AND MEDICAL NEEDS

**33%** of people with gynaecological cancers (including cervical cancer) thought **GPs and nurses at their local practice could have done more to support them** while they were having their treatment. (63)

Only those with **very early stage cancer** are eligible for the fertility-sparing surgical options. (64)

Pregnancy following fertility-sparing surgery, such as a radical trachelectomy can have a variety of **adverse pregnancy outcomes,** such as second-trimester loss and pre-term delivery. (65)

**Cervical cancer patients treated with radiotherapy have worse sexual functioning** when compared with patients treated with radical hysterectomy. (66)

The proportion of older patients who complete treatment for cervical cancer is lower than that of younger patients, although it is unknown whether this is due to treatment not being offered or treatment being refused. Older patients are also more likely to be given palliative rather than curative radiation therapy. (112)

# FINANCIAL NEEDS

**Women who have surgery in combination with radiotherapy** experience more **financial difficulties** due to their **physical condition** compared with women who have surgery alone, or surgery combined with adjuvant chemotherapy. (66)

## Not specific to people with cervical cancer

The **cost of travel to and from appointments affects 69% of people with cancer** and costs them, on average, **£170 a month**. (109)

# PRACTICAL AND INFORMATION NEEDS

In a 2013 survey **83%** of people with gynaecological cancers (including cervical cancer) were **given a choice of treatment** compared to 92% of prostate cancer patients and 89% of breast. (68)

**33%** of gynaecological cancer (including cervical cancer) patients did **not have trust and confidence in their ward nurses.** (71)

## Not specific to people with cervical cancer

**10%** of people with all cancers (not just cervical cancer) were **not given enough information about their condition and treatment,** 2% were given too much. (69) 24% of people with gynaecological cancers (including cervical cancer) were **not told about treatment side effects** in a way in which they could understand. This is around comparable with other cancer types. (70)

# EMOTIONAL AND PSYCHOLOGICAL NEEDS

Patients who are treated surgically display significantly higher levels of **anxiety** than in patients treated with radiotherapy. Patients cite **pain** and **irregular menstrual bleeding** as the main factors in the development of anxiety. (72)

**Psychosexual dysfunction** (sexual difficulties not directly due to physical factors) is a common complication of treatment for gynaecological cancers and has a considerable impact on the quality of life for the increasing number of women who are survivors of gynaecological cancer. (73)

Treatment for cervical cancer such as **radiotherapy often results in infertility** (110). This can be very distressing for those women who had wanted to have children and are unable to as a result of their treatment.

# NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

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

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

- Some feel a sense of abandonment after treatment.(43)
- **39%** who completed treatment in 2009/10 say that **no health or social care professional talked them through the needs they might have.** (37)
- **94%** experience **physical health condition problems** in their first year after treatment. (62)
- **78%** of people with cancer have experienced **at least one physical health condition** in the last 12 months which can occur as a result of cancer or its treatment.(62)
- **62%** of people with cancer have experienced **at least one of the psychological conditions** that can occur as a result of cancer and its treatment. (62)
- **40%** with emotional difficulties had **not sought medical help** or other support. (43)
- **23% lack support from friends and family** during treatment and recovery (67)
- **One in six people (17%)** who were diagnosed with cancer more than 10 years ago have **not been visited at home by a friend or family member for at least six months.** (67)

## Cancer survivors have greater health needs than the general population

- **90%** of cancer survivors have visited their GP and **45%** visited a specialist doctor in the last 12 months. This compares with **68%** and **15%** of the wider population.(106)
- In a recent survey, **80%** of gynaecological cancer patients, and 78% of all cancer patients, said that they were not offered a written assessment or care plan. These are essential in providing personalised care for cancer patients and their carers. (3)

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

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

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

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

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

Further key interventions include:

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

# PHYSICAL AND MEDICAL NEEDS

Regardless of cancer origin or age of onset, cervical cancer and its treatment can produce side-effects, such as **sexual dysfunction, infertility, or lymphoedema that can adversely affect quality of life.** (74)

Recent findings found that many women report significantly **worse sex lives and a significantly lower frequency of sexual relations** following gynaecological cancer treatment. (75)

Many cervical cancer patients report **pain on vaginal penetration.** They also often feel uncomfortable discussing their **sexual difficulties** with their oncologist. (75)

**Fertility is an important issue** for women living with cervical cancer. A recent survey found that the majority of women who attempt to conceive after a radical trachelectomy are successful, and most of their pregnancies result in full-term births. However, it seems that they are at highter risk of premature delivery for their second baby. (76)

# FINANCIAL NEEDS

In a 2013 survey **25%** of people with gynaecological cancers (including cervical cancer) who wanted to know were **not told about free prescriptions.** (77)

## Not specific to people with cervical cancer

Some people affected by cancer (not just people affected by cervical cancer) **are not aware that they can claim benefits.** 61% of a recent survey did not receive health-related benefits. (78)

Some people affected by cancer (not just people affected by cervical cancer) find the **benefits system complex and difficult to navigate**. Benefits advice is also not always offered in a timely fashion. 42% of people with cancer did not receive money or debt advice following their diagnosis. (78)

There is also a lack of support for cancer patients who wish to remain in or return to work. **There are over 700,000 people of working age living with cancer across the UK**, but research has shown less than 2% of people with cancer (roughly 40,000) access specialist return-to-work services. (119)

# PRACTICAL AND INFORMATION NEEDS

Young adult cancer survivors are often **unaware of their fertility status and uninformed regarding their fertility and fertility preservation options.** This suggests that young women could benefit from improved information regarding their fertility and parenthood options throughout survivorship. (79)

They could also benefit from emotional and practical support around issues that arise when considering their reproductive and parenthood options. (79)

Many people feel **abandoned by the healthcare system** once their initial treatment for cancer has completed. In a 2013 survey **42%** of people with gynaecological cancers (including cervical cancer) were **not given enough care and help from health and social care professionals** once they were at home. (80)

# EMOTIONAL AND PSYCHOLOGICAL NEEDS

In a 2013 survey **31%** of people with gynaecological cancers (including cervical cancer) were **not given enough emotional support from hospital staff** when being treated as an outpatient. (81)

**17%** of people with gynaecological cancers (including cervical cancer) were **not given information about self help and support groups.** (82)

There are five main areas of need following treatment of cervical cancer. These include **emotional needs and life interruption/return to normality.** (83)

## Not specific to people with cervical cancer

Women who view themselves as infertile following treatment for cancer report **lower sexual and relationship satisfaction** than women who believe they have normal fertility. (64)

# NEEDS AND EXPERIENCES
# PROGRESSIVE ILLNESS AND END OF LIFE

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

The prospect of a complete cure is usually good for stage one cervical cancer. It is moderate for stage two cervical cancer. A complete cure is less likely for stage three cervical cancer, and very unlikely for stage four cervical cancer. For advanced stage four cancer chemotherapy, radiotherapy and possibly surgery is used to provide palliative care. (84)

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

Palliative treatment is important for all patients with untreatable disease. Pain relief forms a central part of palliative care. (85)

Palliative care is increasingly playing a vital role in the oncology population. Palliative care entails an expert and active assessment, evaluation and treatment of the physical, psychological, social and spiritual needs of patients and families with serious illnesses. It provides an added layer of support to the patient's regular medical care. (86)

A recent study found that home, hospital, and inpatient specialist palliative care significantly improved patient outcomes in the domains of pain and symptom control, anxiety, and reduced hospital admissions. (87)

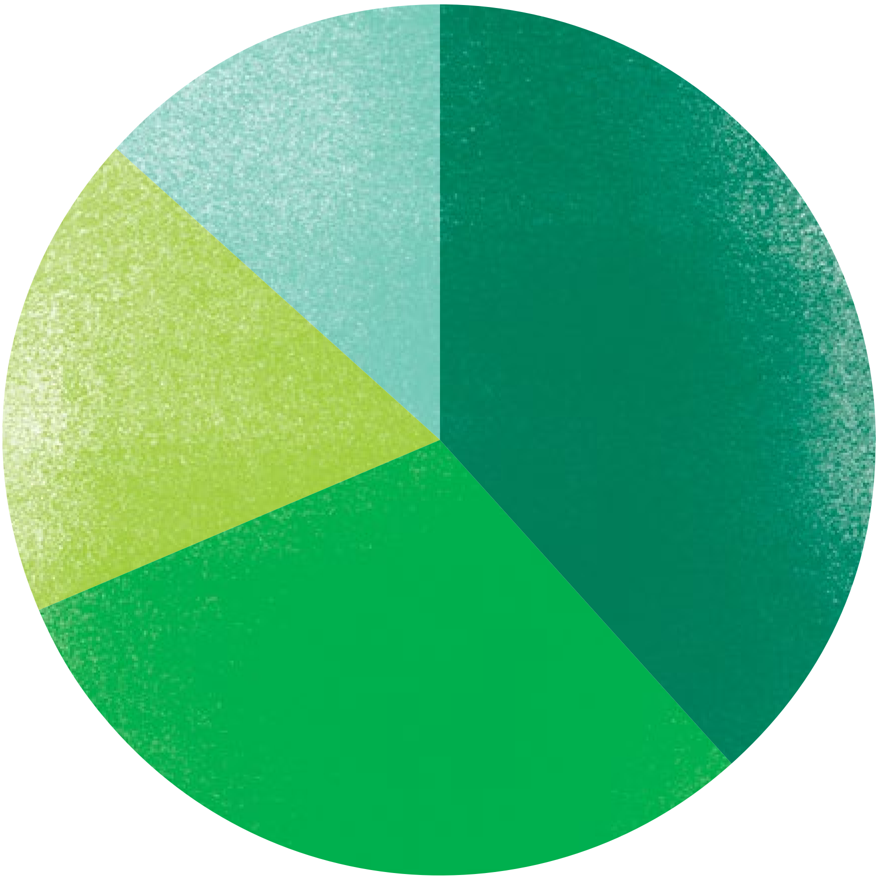
The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life-threatening condition: 'Palliative care is the active holistic care of patients with advanced progressive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

## How many cancer deaths there are in each setting? (88)

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

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

## Where do people in England with cancer die?* (108)



**Hospital**

**38%**

**Home (own residence)**

**30%**

**Hospice**

**18%**

**Care and nursing home**

**13%**

* Does not add up to 100% due to rounding.

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

### Not specific to people with cervical cancer:

A recent survey found that 73% of people who died from cancer, and 81% of all people who died, would have liked to have spent the last weeks and days of their life at home. (108, 111) However, only 29% of those who die from cancer actually die at their home or own residence (88).

**‘My fear is for my children. I worry that my partner won’t cope and I worry that they worry. I feel sad that I might not see their milestones and angry that it’s all happened to me.’**

Sarah, 40

# PHYSICAL AND MEDICAL NEEDS

Most patients presenting in late stages of disease will experience a recurrence of cancer. The **prognosis of recurrent disease is very poor and treatment options are limited.** For patients with recurrences of cervical cancer, the roles of second-time radiotherapy or post-radiation chemotherapy are very limited. (85)

Patients with cervical cancer may develop pelvic recurrence, distant metastases, or a combination of both. A **10%-20% recurrence rate** has been reported following primary surgery or radiotherapy in women with stage IB-IIA cervical tumors. (91)

Patients with **recurrent/metastatic cervical cancer may experience a variety of symptoms** including pain, vaginal bleeding, psychological problems, weight loss and physical deterioration among others. (91)

Research has found that **older patients with cervical cancer are often under treated.** This under treatment is present in palliative care. Older people with cancer are more likely to receive less social and practical support, which suggests that they are not getting the adequate care and services they need at end of life. (46)

# FINANCIAL NEEDS

## Not specific to people with cervical cancer

In 2010 Macmillan reported that **36% of people with a terminal cancer diagnosis** (all cancer types, not specifically cervical cancer) **did not claim the benefits they were automatically entitled to.** This amounts to over £90m. (94)

A study found that **advanced stage at diagnosis, being older at diagnosis, and higher comorbidity were associated with increased costs.** The financial burden is highest around cancer diagnosis and end of life. (95)

People with a terminal diagnosis who wish to travel may have their **travel insurance cover refused** by insurance companies, or be offered cover at prohibitively high premiums, stopping them from fulfilling their wishes. (105)

# PRACTICAL AND INFORMATION NEEDS

## Not specific to people with cervical cancer

Cancer patients and their families often want information about how long they may have to live after hearing that their cancer is terminal. However **doctors tend to over-estimate the survival times of terminally ill cancer patients.** Results from a systematic review suggest that actual survival time is typically **30% shorter** than predicted. (96)

A study into advanced cancer (not cervical specific) found that patients identified the greatest areas of need in relation to psychological and medical communication/information domains. Patients' **specific needs were highest in dealing with a lack of energy and tiredness,** coping with **fears** about the cancer spreading, and coping with **frustration** at not being able to do the things they used to do. (97)

A third of people who have had cancer didn't have all the information they needed, including knowledge of how to self-manage conditions or guidance on when and how they should contact healthcare professionals in the future. (43)

A study into end of life care found that **older patients** are associated with **lower use of services,** such as receiving a home care visit and receiving a physician house call. Women living in lower income neighbourhoods were also found to receive lower physician home visits. (93)

# EMOTIONAL AND PSYCHOLOGICAL NEEDS

## Not specific to people with cervical cancer

Cancer patients (all cancer types, not just cervical cancer) approaching death suffer **more psychological distress than those not approaching death.** (98)

**Depression** is an **under recognized condition** experienced by a significant number of palliative care patients. It contributes to considerable **distress in patients and families** and can become yet another terminal illness for the patient to endure. (99)

Access to community nursing at any time of the day or night is essential to support those who wish to die at home. Where these wishes are not met in can lead to traumatic experiences for patients and their families. (100)

Freedom of Information requests placed on England Primary Care Trusts (PCTs) by Macmillan in 2010 indicated that 24/7 community nursing is available for all end of life patients in only 56% of PCTs that responded. (118)

# LIFESTYLE AND PERCEPTIONS

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

## What is the profile of the average person living with cervical cancer? (9)

- Worldwide, cervical cancer is the fourth most common cancer in women. Women with a sister or mother who has had cervical cancer are at increased risk of developing it themselves.
- For women under the age of 35 in the UK, it is the most common cancer.
- Cervical cancer is the most common cancer diagnosed in women in Southern Africa and Central America.
- Cervical cancer is associated with younger women with 6 out of 10 women diagnosed under the age of 50.

## What is the demographic breakdown/market segmentation of the 34,850 people living with cervical cancer in the UK? (3)

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

Amongst cervical cancer patients, the following MOSAIC* group shows significantly greater than average representation:

**Group I: Ex-Council Community (low levels of education but sufficient incomes).** People in group I have created a comfortable lifestyle despite low levels of formal education. They tend to live in owner occupied council houses well equipped with appliances and modern comforts, albeit basic models or discounted brands. This group are more commonly found in the South East of England or Scotland.

**Group J: Claimant Culture (families reliant on benefits in council estates).** People in this group are amongst the most deprived in the UK. They often live in undesirable council estates with high levels of antisocial behaviour, robbery and burglary. They tend to have high levels of unemployment and few own cars. Families often have disproportionate numbers of children and parents are often in unstable relationships.

**Group K: Upper Floor Living (young, single people on low incomes).** Group K tend to be young single people or adults sharing a flat. They are most commonly found in inner city London and Scotland and tend to have low levels of income. Neighbourhoods tend to be blighted with unemployment, alcohol and drug abuse however areas which have received investment are now attracting young professionals seeking cheaper housing.

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

In addition to the above Groups, there are two Types within **Group C (Rural Solitude)** and **Group O (Liberal Opinions)** who are also well-represented amongst cervical cancer patients:

- Group C, Type 15: Upland Struggle
- Group O, Type 65: Anti-Materialists

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

- Group I: Ex-Council Community: People in this group tend to enjoy watching TV especially phone in celebrity shows. They enjoy home DIY and online gambling but tend not to bank or purchase goods over the internet. They also tend not to be very health conscious.

- Group J: Claimant Culture: People in this group tend to have little, if any disposable income. They spend disproportionate amounts on alcohol and tobacco whilst their diet is poor. They enjoy watching TV but are not generally internet users. They also tend to shop in charity or second hand shops.

- Group K: Upper Floor Living: Few have much disposable income or own a car. Many households do not own a computer, although a sizeable number are internet savvy. Alcohol and tobacco are widely consumed along with ready meals, and purchases are generally made with cash.

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

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

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

**Before:**

**‘Being told I’d need a radical hysterectomy when I was still in my 20s was devastating and on top of that knowing I’d now never have children. But when you’re faced with a life or death situation, you take life for the sake of your family.’**

Jenny, 30, Northern England

**‘As a gay female, I did not go for smear tests which most likely would have diagnosed the problem a lot earlier and prevented me losing my bladder.’**

Laura, 42, Midlands

Contents

**After:**

**‘I’m now going through the menopause – even before my mum. I have lost touch with some friends too as we lead such different lives.’**

Shazia, 28, London

**‘If I tell people I went back to work, they are surprised – it doesn’t seem to be the norm. It makes me feel as if I’ve done something wrong and that maybe I shouldn’t be there.’**

Tracey, 38, South East

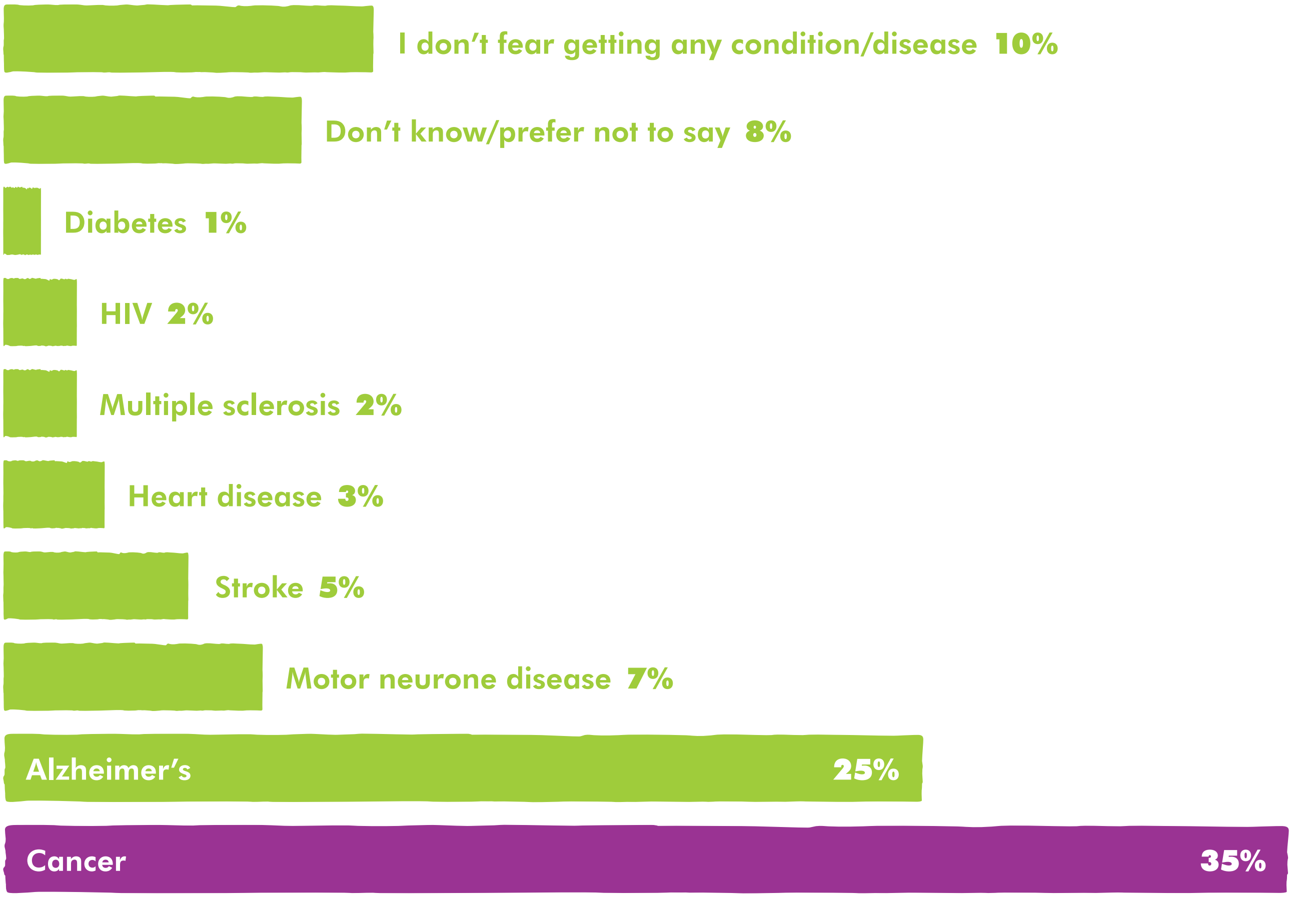
**‘I was lucky in the end as I was able to attend counselling sessions which helped me to re-evaluate my perceptions of being a woman.’**

Kerri, 29, Scotland

## How does people’s fear of cervical cancer compare to actual survival rates? (102)

A 2011 study by Cancer Research UK surveyed people’s fear of certain cancer types. However cervical cancer was not included in the research. Instead of showing the results of that research, we devote this page instead to a different set of results from the same survey which examined how people’s fear of cancer compares to other feared diseases.

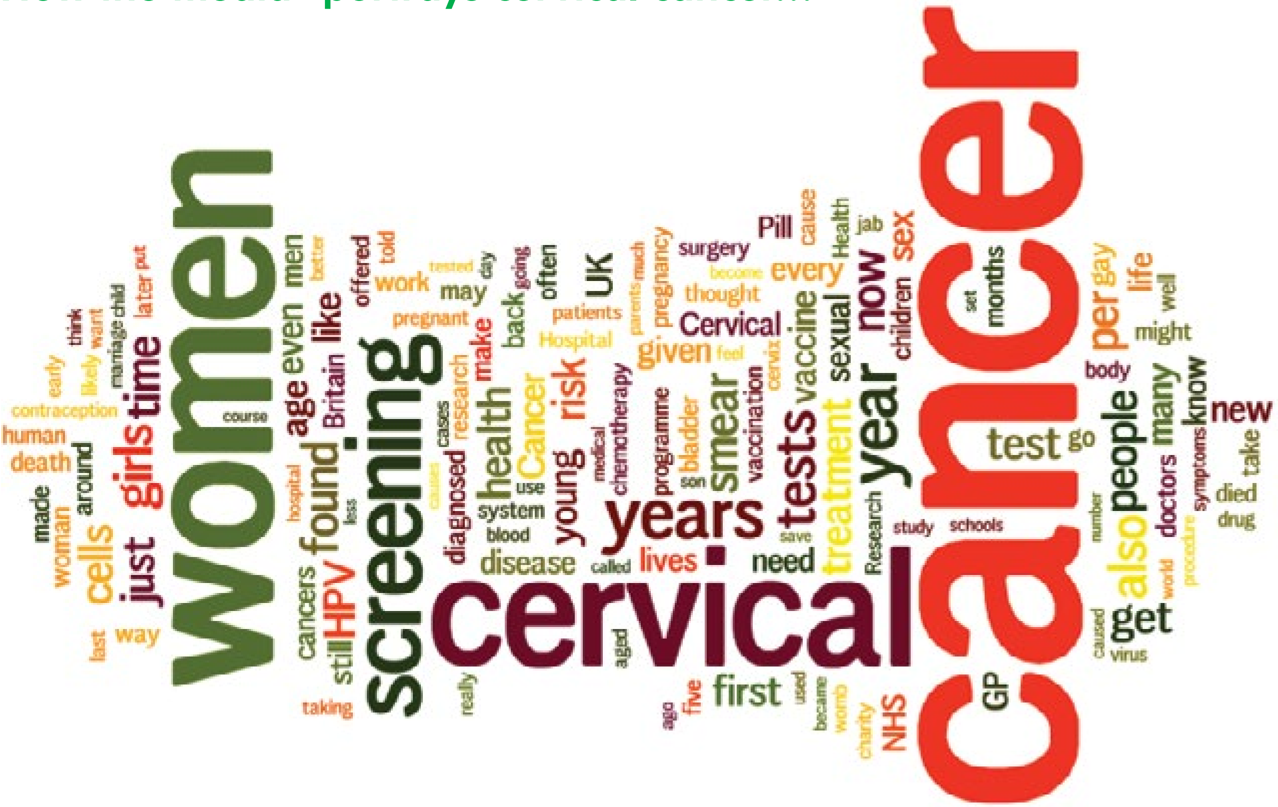
### How much do people fear cancer?



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

## What our cervical cancer online Macmillan Community members are saying… (103)

## How the media* portrays cervical cancer… (104)



*UK national daily newspapers

Note: these ‘word clouds’ give greater prominence to words that appear more frequently in the source text.

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

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

- Cervical cancer is a well known and highly publicised cancer. It has recently received a high profile in the press as a result of the introduction of the HPV vaccine in 2008 for girls aged 12-13 and the death of the celebrity Jade Goody from the disease in 2009. It is likely this is why there are no major differences between reporting in the media and Macmillan's online community.

- References to tests and the subsequent results of tests, both physically and emotionally, feature predominantly within the online community as those going through diagnosis and treatment use the community as a form of support and advice at this time.

- There are also a number of positive words within the online community discussions such as 'hope', 'optimistic', 'good' and 'great', which may reflect the fact that if diagnosed early, cervical cancer has a relatively good prognosis compared to other cancers.

- The media however, tend to focus more upon the risk factors and prevention of cervical cancer as opposed to the personal journey which the patients undertake, such as the emphasis upon 'pill', 'sexual', 'virus' and 'HPV.'

- The terms 'worrying', 'stress' and 'problems' in the online community discussions emphasise the emotional difficulties experienced by cervical cancer patients. The media includes none of those types of words, focusing instead on the use of words such as, 'screening', 'smear' and 'vaccine'.

# REFERENCES,

## SOURCES, NOTES AND CAVEATS

### Quotes

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

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Contents

# APPENDIX A
# JARGON BUSTER

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

## (i) Health data terms

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

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

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

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

## (ii) Other terms

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

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

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

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

# Full suite of the Rich Pictures

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

## The Rich Pictures on cancer types

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

## The Rich Pictures on age groups

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

## Other Rich Pictures

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

## Overarching Rich Picture

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|---|---|
| **The Rich Picture on people with cancer** | (MAC15069) |

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

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

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

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

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

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

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

Code: MAC13846_11_14