THE RICH PICTURE

PEOPLE WITH UTERUS CANCER

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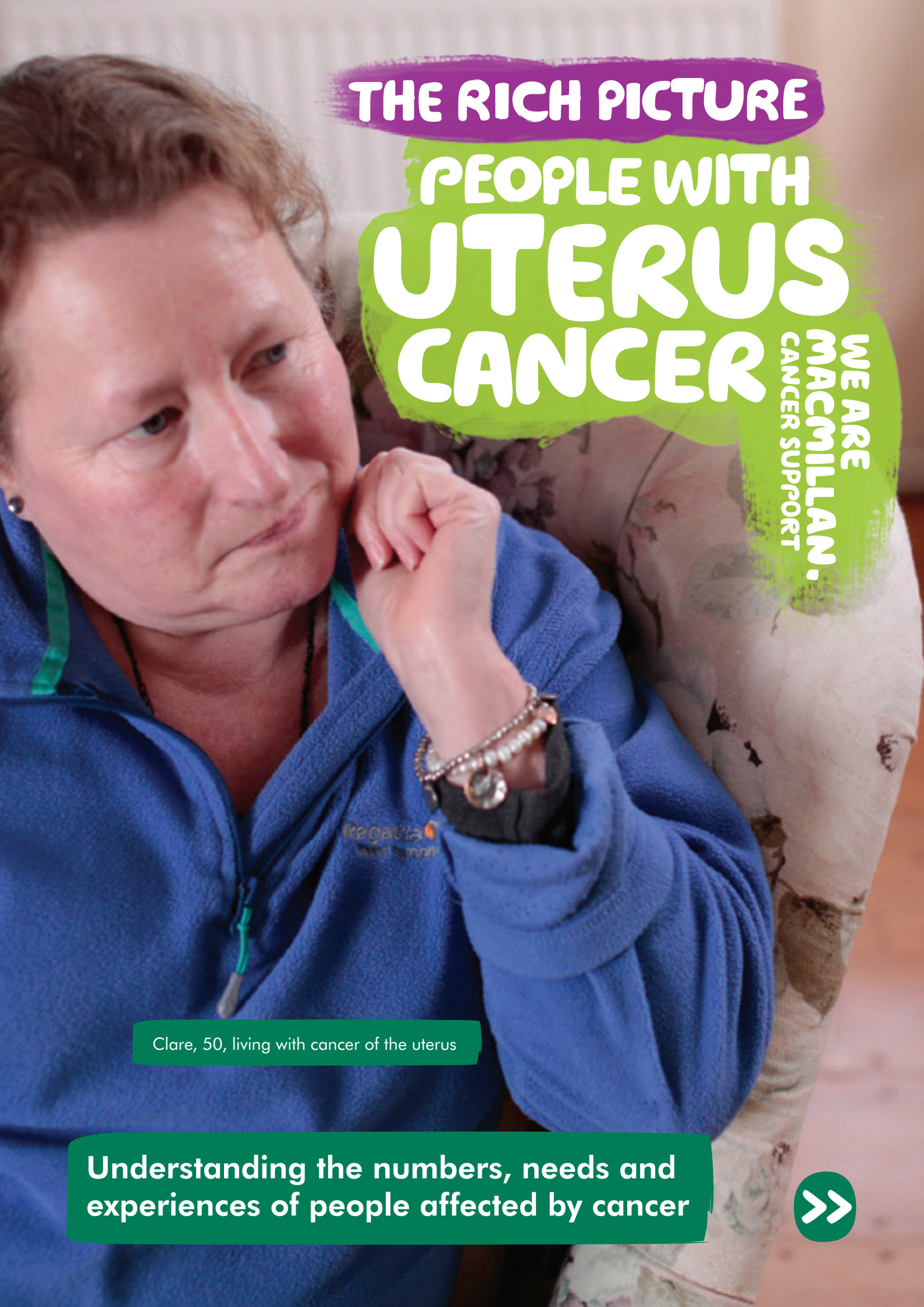

Clare, 50, living with cancer of the uterus

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 August 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 Womb (Endometrial) Cancer' (MAC11656) more helpful:

Understanding Womb (Endometrial) Cancer
MAC11656

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

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

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

Case Study Library

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

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

Comms Platform

Describes how to communicate with people affected by cancer.

Rich Pictures

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

Impact Briefs

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

Local Cancer Intelligence

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

Routes from Diagnosis

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

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

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SUMMARY OF PEOPLE LIVING WITH UTERUS CANCER

Key stats

Uterine cancer is the **fourth most commonly diagnosed cancer** amongst women in the UK, with an average of **23 people** receiving a uterine cancer diagnosis every day.[7,8,9,10]

Cancer of the uterus is the **eighth biggest killer** of all cancers among women in the UK, with almost **1,700 people dying every year.**[2b, 10, 11, 12]

Survival rates for uterine cancer are relatively **good** if it is **caught early** enough. The five-year relative survival rates are among the highest of the 21 most common cancers in England.[13]

Cancer of the uterus is the fourth most commonly diagnosed cancer amongst women in the UK.

Diagnosis

The **most common symptom of uterine cancer is abnormal vaginal bleeding**. Post-menopausal bleeding is the most common symptom of cancer of the uterus. All women with post-menopausal bleeding should be referred urgently.[110]

A significant proportion of newly-diagnosed patients of all cancer types had **unmet psychological and information needs.**[33]

28% of people newly diagnosed with gynaecological cancers (including cancer of the uterus) **had to see their GP more than twice** before they were diagnosed.[22]

The most common symptom of uterine cancer is abnormal vaginal bleeding.

Treatment

Radiotherapy and **surgical treatment** for cancer of the uterus **compromises fertility.**[80]

On average **84%** of women with cancer of the uterus have a record of a **major surgical resection (normally a hysterectomy)** as part of their treatment.[36]

24% of people with gynaecological cancers (including uterine cancer) were **not told about treatment side effects in a way that they could understand.**[60]

33% of women with gynaecological cancer (including cancer of the uterus) thought **GPs and nurses at their local practice could have done more to support them** whilst they were having their treatment.[53]

24% of people with gynaecological cancers (including uterine cancer) were not told about treatment side effects.

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Survivorship

Cancer of the uterus and its treatment can produce short and long-term side-effects, such as **sexual dysfunction, infertility or lymphoedema, which can adversely affect quality of life**.[54]

42% of people with gynaecological cancers (including uterine cancer) were not **given enough care and help from health and social care professionals** once they were at home.[74]

25% of people with gynaecological cancers (including cancer of the uterus) who wanted to know were **not told about free prescriptions.**[72]

31% of people with cancer of the uterus were **not given enough emotional support from hospital staff** when being treated as an outpatient.[77]

Cancer of the uterus and its treatment can produce negative side-effects, including infertility.

End of Life

Women with cancer of the uterus who are at end of life report **negative symptoms** of pain, vaginal bleeding, psychological problems and physical deterioration.[111]

For women with cancer of the uterus who are at end of life, **palliative care can help alleviate symptoms and side-effects**.[83]

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.[93]

Evidence shows that **patients with uterine cancer who receive earlier palliative care have a better quality of life, longer survival and less aggressive care at the end of life**, compared to those receiving standard care.[114]

People with uterine cancer at the end of life who receive earlier palliative care have a better quality of life.

Lifestyle & perceptions

People living with cancer of the uterus can come from all parts of society, but all of them are women, and over **94% of them are aged 50 or over.**[7]

Active elderly women living in retirement are well-represented amongst people being treated for cancer of the uterus.[99]

In articles published about uterine cancer, the media tend to focus upon **the causes and diagnosis of cancer and those at risk**, as opposed to the personal journey which the patients undertake.[101, 102]

Obesity is a **key risk factor** for developing uterine cancer.[104]

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INTRODUCTION TO UTERUS CANCER

What is cancer of the uterus?

The womb, or uterus, is the place in a woman's body where a baby grows before being born. The lining of the womb is called the endometrium and is shed each month as a period. Cancer that starts in the lining of the womb is known variously as:

- Endometrial cancer
- Uterus cancer
- Womb cancer
- Cancer of the uterus
- Uterine cancer

For consistency, we have used the latter two terms throughout this document.

Cancer that starts in the muscle layers of the womb is called uterine sarcoma; this type of cancer is rare with only 700 people diagnosed every year, and will be covered within the "Rich picture on people living with rarer cancers" (MAC13847_11_14).

The lower part of the womb is called the cervix, or sometimes 'the neck of the womb'. Although the cervix is part of the womb, cervical cancer is very different from womb cancer. For more information on cervical cancer, please refer to the "Rich picture on people living with cervical cancer" (MAC13846_11_14).

What is Gynaecological cancer?

The term 'gynaecological cancer', which at times is used throughout this document, refers to the five cancers that start in the female reproductive system. They are:

- Cervical
- Ovarian
- Vaginal
- Vulval
- Cancer of the uterus, or uterine cancer. [108]

Want to know more?

Macmillan produces a wealth of information about what cancer of the uterus 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 are 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**

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‘When I was diagnosed it was New Year’s Eve. The consultant phoned me and said she was 99% sure that it was cancer. But I didn’t understand all the jargon. My brother-in-law’s a dentist and knows all those medical words. So then she rang him and confirmed the diagnosis with him.

I had quite a lot of chemo before they could do the hysterectomy. I felt quite numb during that time. I didn’t really feel upset or depressed. It was good to talk about it – I found that helped. And when you’re having chemo, you talk to other people who are going through the same thing. From the time you’re diagnosed to going into remission, you always need that support. It’s really good to get talking – without that I think you’d go mad. It’s always on your mind

Clare, 50

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes – and how they are different for people with cancer of the uterus.

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.[2]

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

Around 70,190 people were living with cancer of the uterus in the UK in 2010, based on people living up to 20 years post a cancer diagnosis.[3]

How is this different for people with uterine 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.

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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

Contents

THE FACTS ON UTERUS CANCER

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

23

people are diagnosed with uterine cancer every day [7, 8, 9, 10]

70,190

people were living with cancer of the uterus in the UK in 2010, based on people living up to 20 years post a cancer diagnosis[3]

90%

of people in England live for more than one year after their uterine cancer diagnosis[5]

77%

of people in England live more than five years after their uterine cancer diagnosis[5]

6

people die every day of uterine cancer in the UK[6]

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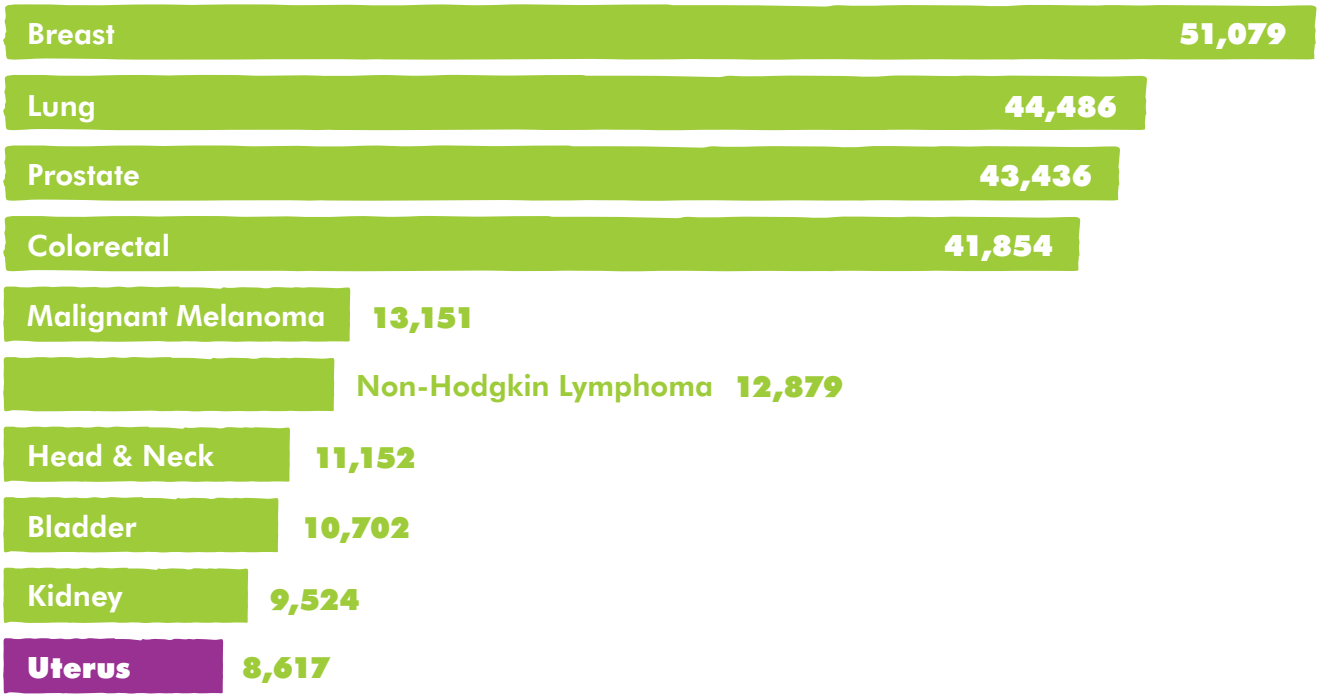
How many people get cancer of the uterus per year? (incidence)[7,8,9,10]

Cancer incidence, UK, 2012, top 10 cancer sites



Cancer of the uterus is the tenth most commonly diagnosed cancer. Over 8,600 people are diagnosed every year in the UK; that's 24 people every day.

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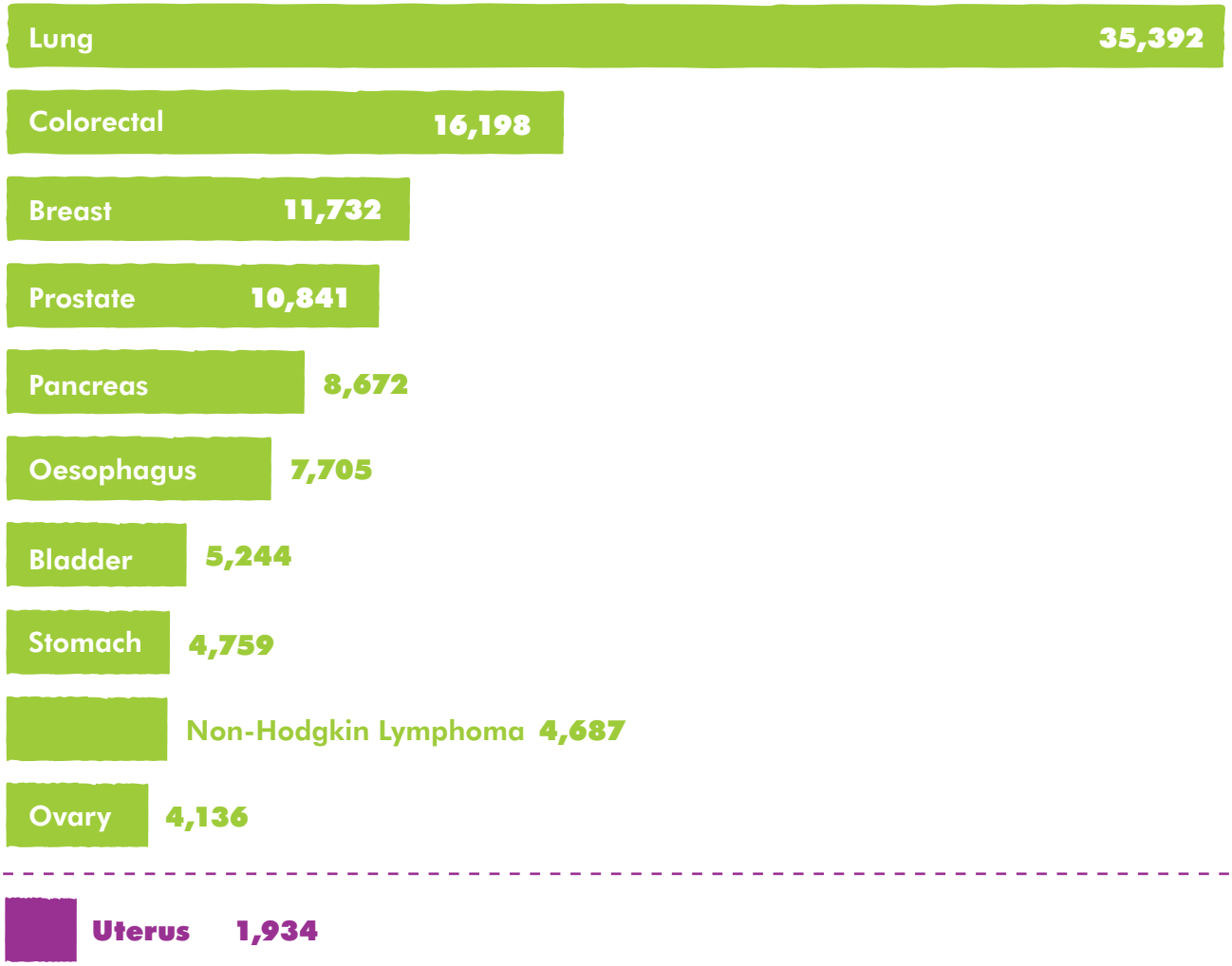
How many people die from cancer of the uterus per year? (mortality)[2b,10,11,12]

Cancer mortality, UK, 2012, top 10 cancer sites



Uterine cancer is the thirteenth biggest killer of all cancers. Amongst women specifically, cancer of the uterus is the eighth biggest killer, with over 2,000 people dying every year in the UK; that's 6 people every day.

How many people are currently living with cancer of the uterus? (prevalence)[3]

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

70,190

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 cancer of the uterus per year in England? (incidence)[7]

7,192

new cases of uterine cancer were diagnoses in England in 2012.

How many people die from cancer of the uterus per year in England? (mortality)[11]

1,683

uterine cancer deaths in England in 2012.

How many people are living with cancer of the uterus in England? (prevalence)[3]

58,323

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

What is the age-standardised* rate of incidence of uterine cancer in women in England?[4]

20.4

new cases of uterine cancer diagnoses in England in 2012 per 100,000 heads of population

What is the age-standardised* rate of mortality from uterine cancer in women in England?[6]

3.8

cases of uterine cancer deaths in England in 2012 per 100,000 heads of population

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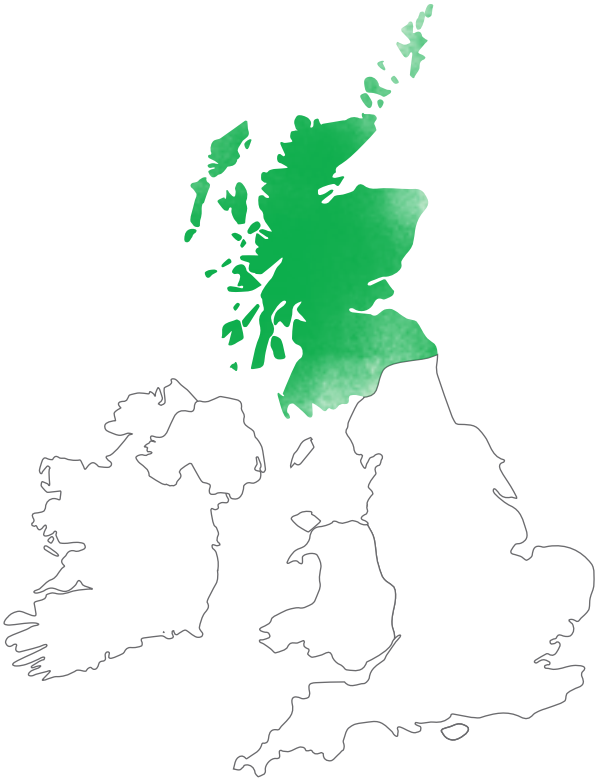
What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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How many people get cancer of the uterus per year in Scotland? (incidence)[8]

724

new cases of uterine cancer were diagnoses in Scotland in 2012.

How many people die from cancer of the uterus per year in Scotland? (mortality)[12]

194

uterine cancer deaths in Scotland in 2012.

How many people are living with cancer of the uterus in Scotland? (prevalence)[3]

5,936

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

What is the age-standardised* rate of incidence of uterine cancer in woment in Scotland?[4]

18.8

new cases of uterine cancer diagnoses in Scotland in 2012 per 100,000 heads of population

What is the age-standardised* rate of mortality from uterine cancer in women in Scotland?[6]

3.5

cases of uterine cancer deaths in Scotland in 2012 per 100,000 heads of population

What are the key stats for Wales?

See data on incidence, mortality and prevalence for Wales

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

How many people get cancer of the uterus per year in Wales? (incidence)[9]

458

new cases of uterine cancer diagnoses in Wales in 2012.

How many people die from cancer of the uterus per year in Wales? (mortality)[9]

120

uterine cancer deaths in Wales in 2012.

How many people are living with cancer of the uterus in Wales? (prevalence)[3]

4,154

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

What is the age-standardised* rate of incidence of uterine cancer in women in Wales?[4]

22.2

new cases of uterine cancer diagnoses in Wales in 2012 per 100,000 heads of population

What is the age-standardised* rate of mortality from uterine cancer in women in Wales?[6]

3.7

cases of uterine cancer deaths in Wales in 2012 per 100,000 heads of population

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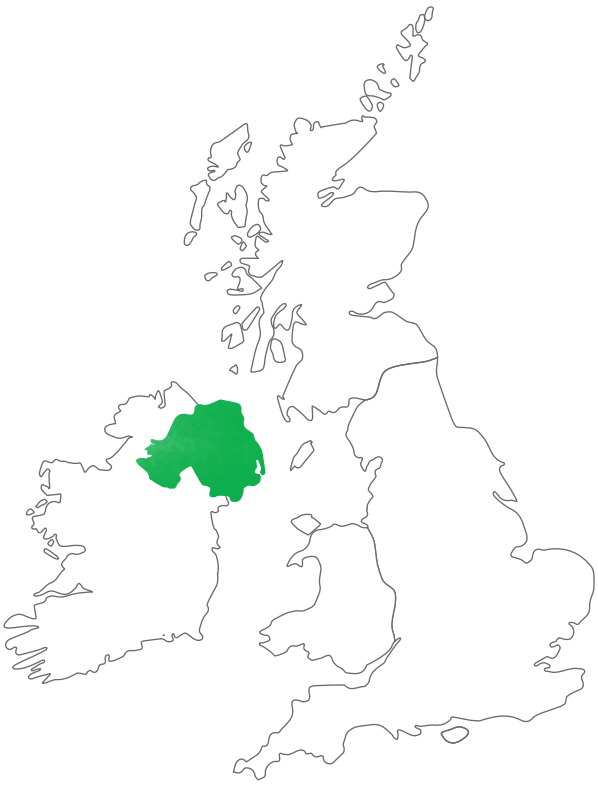
What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



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How many people get cancer of the uterus in Northern Ireland? (incidence)[10]

243

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

How many people die from cancer of the uterus per year in Northern Ireland? (mortality)[10]

32

uterine cancer deaths in Northern Ireland in 2012.

How many people are living with cancer of the uterus in Northern Ireland? (prevalence)[3]

1,779

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

What is the age-standardised* rate of incidence of uterine cancer in women in Northern Ireland?[4]

20.7

new cases of uterine cancer diagnoses in Northern Ireland in 2012 per 100,000 heads of population

What is the age-standardised* rate of mortality from uterine cancer in women in Northern Ireland?[6]

3.5

cases of uterine cancer deaths in Northern Ireland in 2012 per 100,000 heads of population

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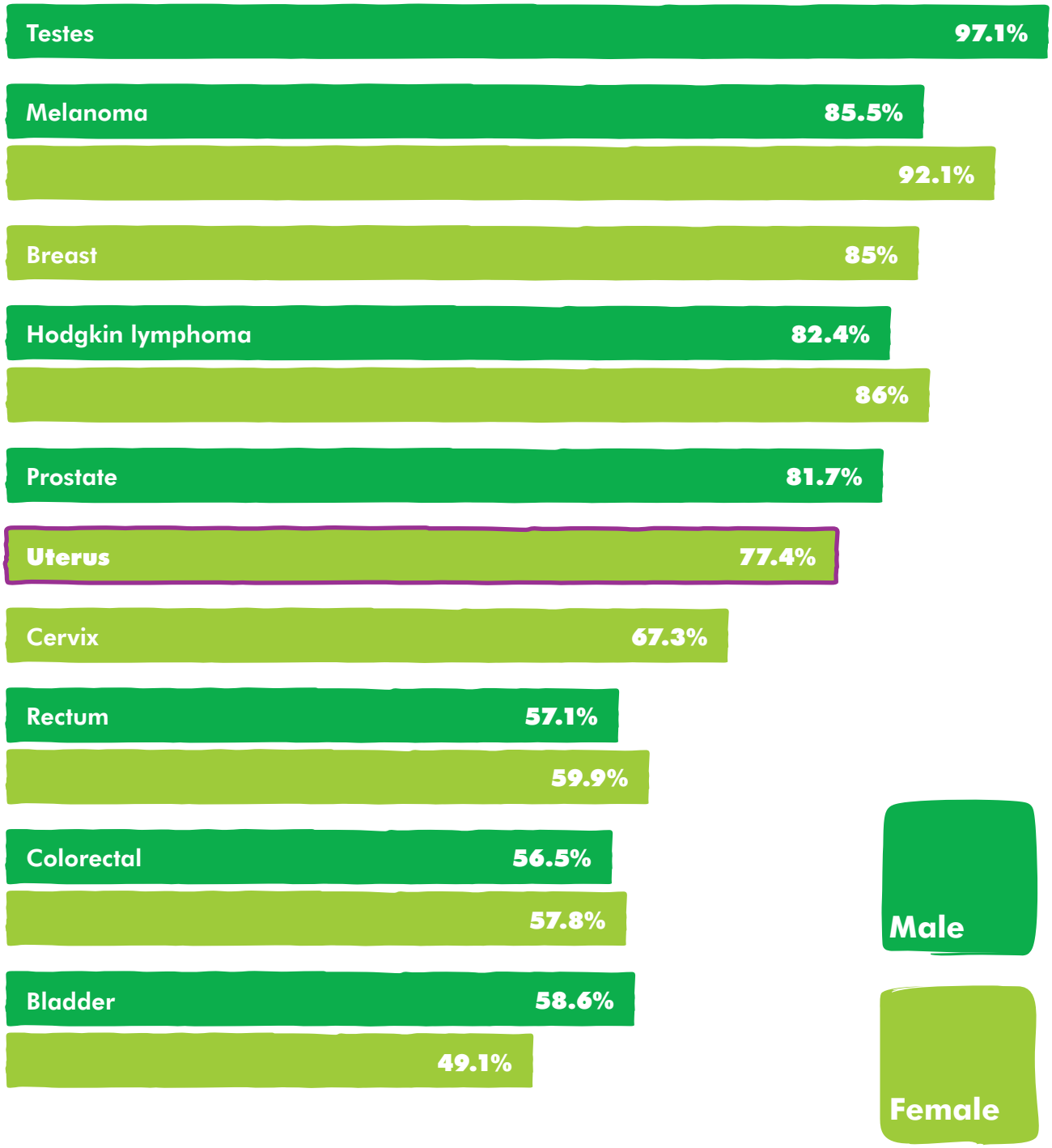
What proportion of people survive cancer of the uterus? (survival)[13]

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

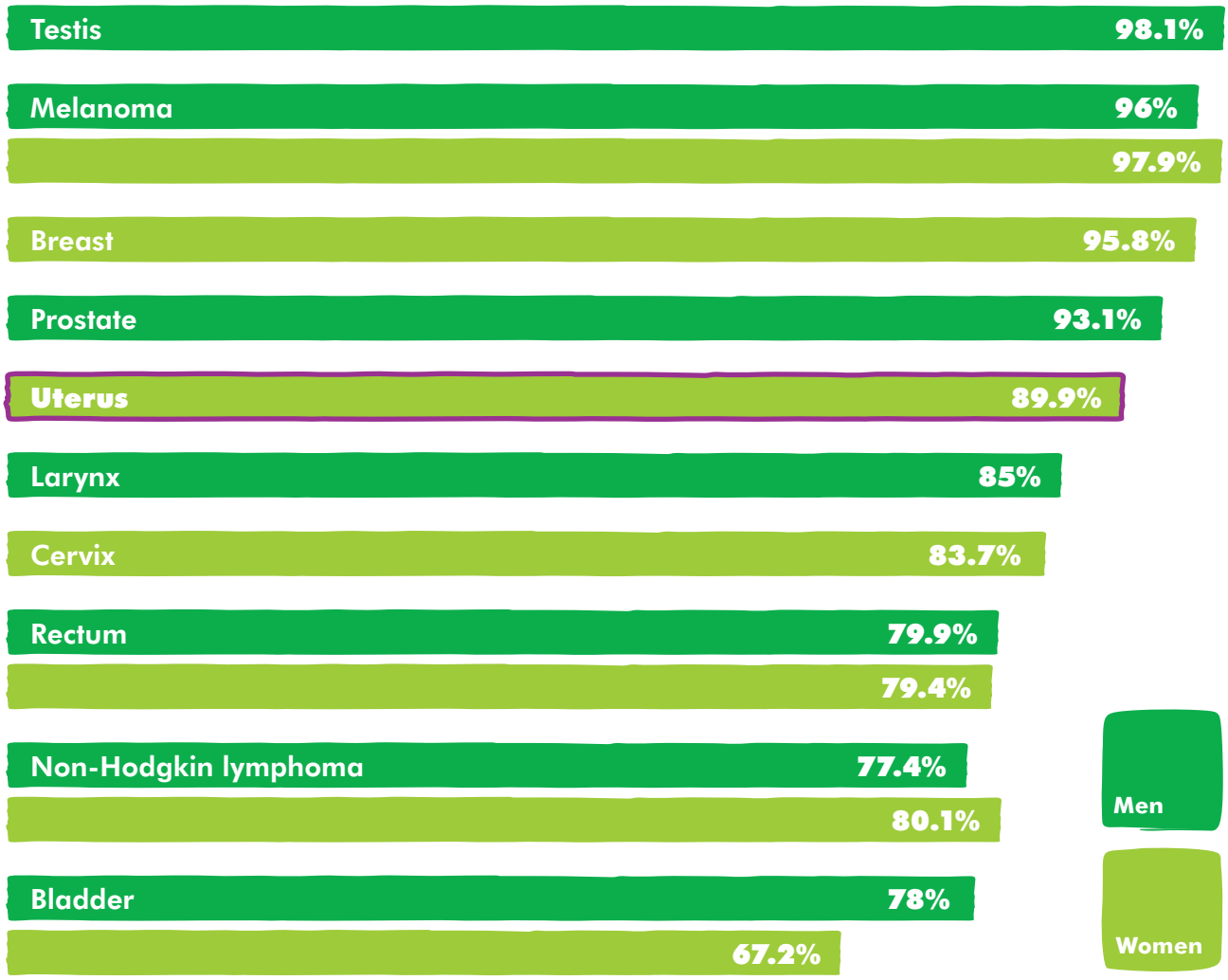


Uterine cancer has one of the highest 5-year survival rates of all cancers with 77% of patients surviving the period. This puts cancer of the uterus at number 6 in the rankings of 5-year survival.

A study in Canada suggests that these high survival rates are due in large part to that fact that approximately 75% of all patients with uterine cancer present with early stage disease.[14]

How many people live beyond one year of their uterine cancer diagnosis?[13]

Relative-1 year relative survival estimates, 2007-2011, by gender, Englands



The estimated proportion of people living more than one year after uterine cancer diagnosis is 90% – in other words the prognosis for cancer of the uterus is often good.

How do UK survival rates compare internationally?

In the UK we perform slightly worse on both one- and five-year survival when compared to other similar countries. For 2000–07, 1-year survival was 89% in the UK and Ireland, 90% in Denmark, and 93-94% in Norway, Sweden, and Germany. The European average was 90%. 5-year survival was 76% in the UK and Ireland and 78% in Denmark, compared to 81-85% in Norway, Sweden and France. While the gap between European and UK survival rates is not as large as for some other cancer types, this suggests there is still more we can do to improve survival for people with cancer of the uterus in the UK.[17]

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

Gender

As men do not have wombs they cannot have cancer of the uterus.

Ethnic background

White females over 65 are statistically significantly more likely to get uterine cancer than Asian populations[15]. This could be explained by larger family sizes in Asian communities, as pregnancy and childbirth reduce the risk of developing uterine cancer. The risk is reduced by 30% for a woman's first brith, and by 25% for each successive birth.[104]

Estimated European age-standardised rates of cancer incidence by major ethnic group show that the White ethnic group ranged from 16.9 to 17.7 per 100,000 for all ages. Rates for the Asian ethnic group ranged from 10.7 to 18.0 per 100,000. Rates for the Black ethnic group ranged from 13.7 to 23.6 per 100,000 for all ages.[15]

In the United States there are significant differences in survival between African American women and White women. Whilst this could partly be due to differences in treatment between the two groups, African American women are significantly more likely to get high-grade tumours and to present at a later stage.[5]

Age

In 2012 in England, 94% of uterine cancer cases are diagnosed in women aged 50 years and over. The highest incidence rate was for women in their late sixties.[7]

As with nearly all cancers, relative survival for uterine cancer is higher in younger women, even after taking account of the higher background mortality in older people. The reasons for this are likely to include a combination of better general health, more effective response to treatment and earlier diagnosis in younger people overall.[5]

Social background

Data shows that there is no correlation between the incidence of uterine cancer and degree of social deprivation.[16]

Lifestyle

The risk of uterine cancer is 32% higher in overweight women and 154% higher in obese women.[109]

Diabetes is also a risk factor although it is difficult to determine the risk independently, as diabetes is closely linked to obesity.[104]

Women who are physically active have a 23%-27% reduced risk of uterine cancer. Women taking the combined oral contraceptive pill also have a lower risk of developing the disease.[104]

What are the geographical 'hotspots' for uterine cancer incidence, mortality and survival?[15]

Uterine 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.

Uterine cancer incidence rates are generally lower in the North-East and South-East of England, and higher in Scotland and Wales.

Uterine 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.

Uterine cancer mortality rates vary across the UK. They are generally higher in Scotland than the rest of the UK.

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

Incidence rates are increasing:

The age-standardised incidence rates of uterine cancer remained stable between the mid–1970s and early 1990s in Great Britain; since then, however, rates have increased by around 40%.[4]

There are important variations in the trends of uterine cancer incidence by age. The largest increases in rates are seen in those aged between 65 and 74, rising from around 45 women in every 100,000 in the mid–1970s to 88 in every 100,000 in 2009-2011. For those aged under 55 incidence rates have remained largely stable.[4]

Survival rates for cancer of the uterus have increased:

The relative survival for cancer of the uterus is improving. One-year relative survival rates for uterine cancer increased from 78% in England and Wales during 1971–1975 to 90% in England during 2007–2011 and five-year relative survival rates for uterine cancer increased from 61% in England and Wales during 1971–1975 to 77% in England during 2007–2011.[5,13]

The mortality rate for cancer of the uterus has increased:

The amount of deaths from uterine cancer has risen by nearly 20% in the last decade.

In the period from 1971 to 1999, mortality rates fell from 4.7 to 3.0 per 100,000 people. However, since then, the mortality rate has risen to 3.7 per 100,000 in the UK in 2011. Mortality rates have increased for almost all age groups in the last 10 years with the largest rises in those aged 65-79.[6]

The rise in deaths follows a steep increase in the number of women being diagnosed with uterine cancer since the mid 1990s. This in turn most likely caused by an increase in risk factors, such as more women being overweight or obese and women having fewer or no children.[4]

‘I want to help other people with cancer by telling them that the diagnosis of cancer is not always doom and gloom, that there is light at the end of the tunnel, and that sometimes cancer can be a life changing experience for the better.’

Rebecca, 55

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 cancer of the uterus at these stages.

A typical 'cancer journey' showing four key stages:

1 Diagnosis

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

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

2 Treatment

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

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

3 Survivorship*

If I complete my treatment for cancer, what next?

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

4 Progressive illness and end of life

If my cancer is incurable, what might I experience?

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

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

NEEDS AND EXPERIENCES DIAGNOSIS

What are the top signs and symptoms of cancer of the uterus?[110]

1. The most common symptom is abnormal vaginal bleeding, such as:

- Bleeding that starts after the menopause
- Bleeding between periods
- Heavier periods than normal (in pre-menopausal women)
- Abnormal vaginal discharge.

2. There are other general symptoms such as:

- Pain in the lower abdomen (tummy), back or legs
- Swelling in the abdomen or legs
- A loss of appetite and weight
- Constipation
- Being sick (vomiting)
- Passing urine more than usual
- Tiredness and weakness.

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

There are currently little data available on how many cases of cancer of the uterus are diagnosed early in the UK.

There are delays in all stages of the uterine cancer pathway. 52% of women waited more than a month and 12% waited more than 6 months to see their GP from the onset of symptoms. Almost half the cases said they were unaware that abnormal bleeding was a symptom of cancer.[18]

However they often do recognise that this is abnormal and seek help, which is why endometrial cancer is often diagnosed early.[103]

Patients with cancer in general in the UK tend to present with more advanced disease and have poorer survival rates than many of their European counterparts. The most likely explanations are either late presentation by patients or late onward referral by GPs.[19]

The most commonly endorsed barriers to seeking medical help with potential cancer symptoms are: difficulty making an appointment, worry about wasting the doctor's time and worry about what would be found. Emotional barriers are more prominent in lower socio-economic groups and practical barriers (eg 'too busy') are more prominent in higher socio-economic groups.[19]

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

How well does screening work for cancer of the uterus?

There is currently no screening programme for cancer of the uterus.

Contents

‘I’d suffered a couple of years of abnormal bleeding but put it down to going back onto the pill in my mid 40s. I was totally shocked when they told me I had cancer. Looking back, I knew something was wrong and perhaps should have pushed for tests to happen faster.’

Clare, 51

How is cancer of the uterus diagnosed? (Routes to diagnosis)[21]

Emergency
8%

GP referral
37%

Two Week Wait
40%

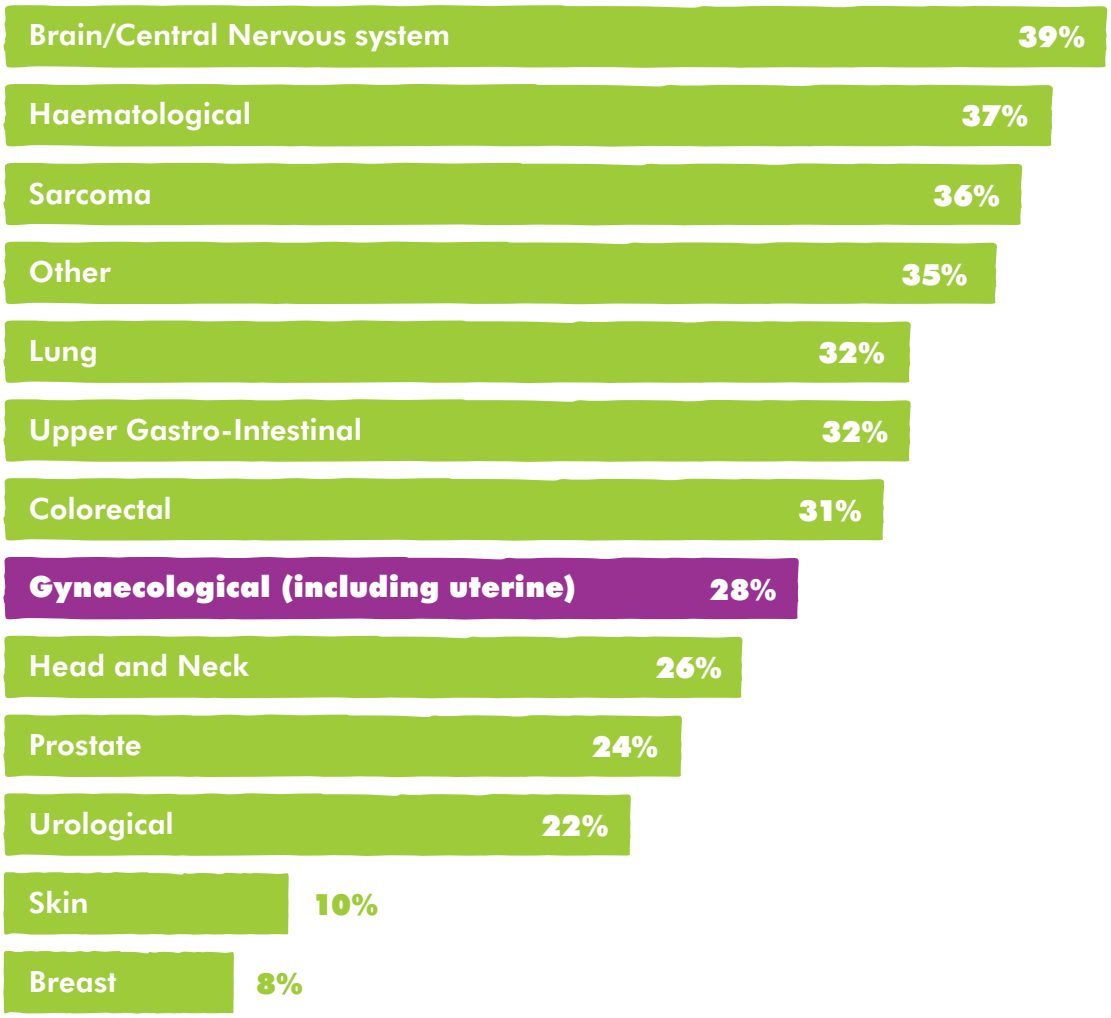
Other
15%

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

8% of people newly diagnosed with cancer of the uterus were diagnosed via the emergency route, this is significantly lower than the average for all cancers (23%). This is indicative of higher rates of early presentation of signs and symptoms which often leads to a better prognosis.

Contents

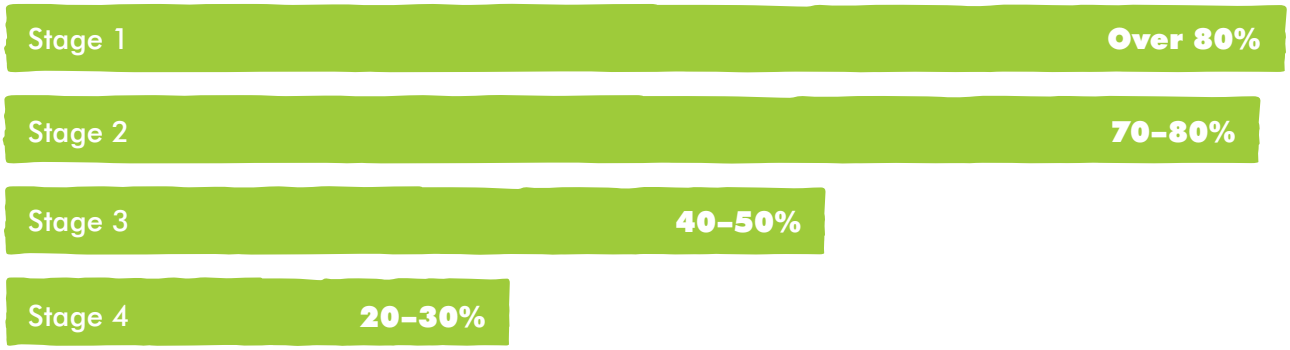
How many patients with cancer of the uterus had to see their GP more than twice before they were diagnosed?[22]



28% of people newly diagnosed with gynaecological cancers (including cancer of the uterus) had to see their GP more than twice before they were diagnosed, compared with only 8% of breast cancer patients, 24% of prostate cancer patients and 10% of skin cancer patients.

How does stage at diagnosis relate to probable survival rates?[23]

The impact of stage at diagnosis on survival – cancer of the uterus



Rate refers to the 5-year survival rate.

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

How long do people with cancer of the uterus have to wait to be referred?[24]

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

This is a relatively good performance although patients with other suspected cancers, such as lung and testicular, showed a slightly stronger performance at 97-98%.

PHYSICAL AND MEDICAL NEEDS

Post-menopausal bleeding is the most common symptom of cancer of the uterus. It occurs in up to 10% of women aged over 55 years and all women with **post-menopausal bleeding should be referred urgently unless they are receiving hormone replacement therapy**. Research has shown that women are not often aware of the association to cancer of the uterus and post-menopausal bleeding.[26]

Not specific to people with cancer of the uterus

Young adult cancer patients (of all cancer types) are often **unaware of their fertility status and uninformed regarding their fertility and fertility preservation options**. This suggests that younger patients could benefit from improved information regarding their fertility and parenthood options throughout diagnosis, better coordination of medical care, and support navigating many emotional and practical issues that arise when considering their reproductive and parenthood options.[27]

FINANCIAL NEEDS

Not specific to people with cancer of the uterus

83% of cancer patient households (not specifically cancer of the uterus) suffer a **loss of income and/or increased costs** as a direct result of cancer.[25]

According to a 2013 Macmillan report, **four in five (83%) people are, on average, £570 a month worse off as a result of a cancer diagnosis**. Reduced income is a major factor of financial hardship.[25]

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.[25]

Over two-fifths (42%) of people with cancer did not receive money or debt advice following their diagnosis.[25]

PRACTICAL AND INFORMATION NEEDS

In a 2013 survey 76% of people with gynaecological cancers (including cancer of the uterus) said they received a completely understandable explanation of their test results. This is slightly lower than the average result for all cancer types (78%).This suggests that **24% of gynaecological cancer patients do not receive a completely understandable explanation of their test results.**[30]

Only **65%** of people with gynaecological cancers (including cancer of the uterus) **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 was 71%.[31]

Not specific to people with cancer of the uterus

Information needs at diagnosis are extensive and include prognosis, side effects of treatment, altered sexual attractiveness, self care and risks of family developing the disease.[40]

The **strongest preference for information** at diagnosis is information about **prognosis**.[40]

A recent study has found that a significant proportion of newly-diagnosed patients undergoing cancer treatment had **unmet needs**. The most common needs included psychological needs, information needs, and needs in the physical domain. Most studies showed that the **level of unmet needs was highest after diagnosis and start of treatment** and decreased over time.[33]

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Not specific to people with cancer of the uterus

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.[34]

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 the previous 12 months. Such conditions included **depression, anxiety and sexual problems**. However, 40% of them **had not sought help** from healthcare professionals.[79]

Women living with cancer are **more likely to say they lack support from family and friends during treatment and recovery**, which can have negative impacts on both their emotional well-being and medical care.[105]

For some people, isolation is a direct result of their cancer diagnosis – just over one in six (18%) of those who lack support say they lost touch with family or friends because of their diagnosis.[105]

Women are more likely than men to be have family or friends with them when they are told they have cancer – only one in five men (22%) have a family member or friend present when they hear their diagnosis, compared with almost two in five women (37%). Almost half of women who received their diagnosis alone would have preferred to have someone with them, compared with just 15% of men.[105]

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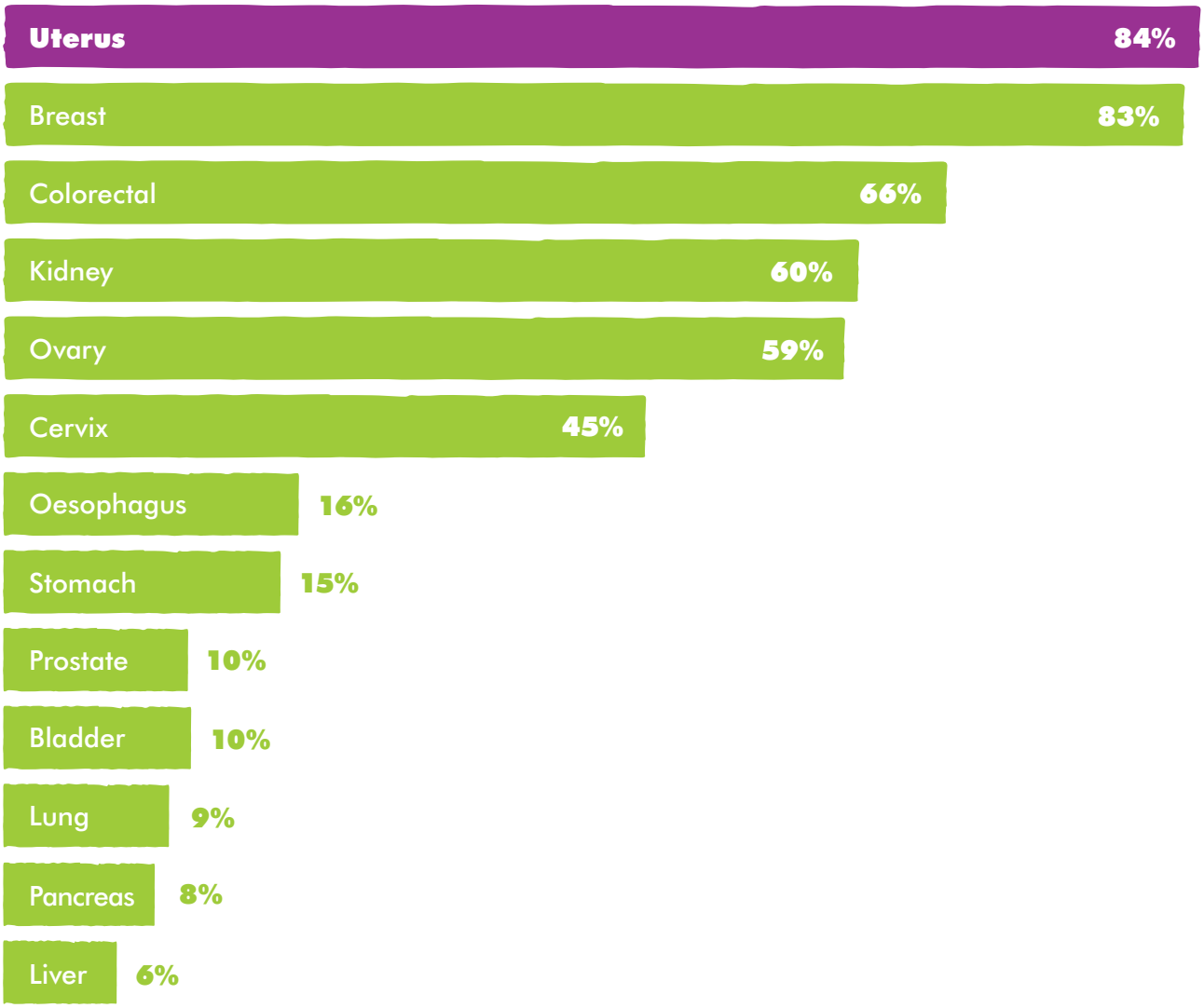
NEEDS AND EXPERIENCES TREATMENT

Percentage of patients who had major surgical resection 2004–2006[36]



84% of uterine cancer patients had a record of a major surgical resection as part of their treatment.

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What treatments do uterine cancer patients get?

Surgery

Most women will be advised to have a total hysterectomy, which involves removing the womb, the fallopian tubes and both ovaries. This operation is sometimes called a **total hysterectomy with bilateral salpingo-oopherectomy.**[37]

On average 84% of NHS treated uterine cancer patients have a record of a major resection. The percentage of patients receiving a major resection (normally a hysterectomy) decreases with age.[36]

Radiotherapy

Gynaecological cancers (which include cancer of the uterus) account for 4% of all radiotherapy episodes in England (2011–2012). There were 5,388 radiotherapy episodes and 87,895 radiotherapy attendances for gynaecological cancers (including cancer of the uterus).[38]

In 2007, **40%** of cancer of the uterus patients **underwent radiotherapy**.[39]

Hormonal treatment

Progesterone treatment is the most common form of hormonal treatment for uterine cancer and may shrink the cancer and control symptoms. Progesterone is available as tablets or by injection and can be administered by a GP.[40]

Chemotherapy

Chemotherapy may be used to treat some types of uterine cancer. It is **mainly used if the cancer comes back**, or has spread to other parts of the body, and doesn't respond to hormonal treatment.[41]

How many cancer of the uterus admissions are there and how many cancer of the uterus patients stay in hospital (and for how long)?

In total, there were over **15,700** admissions to NHS hospitals in England (emergency and non-emergency) for all forms cancer of the uterus during 2012–13.[42]

The median length of stay for uterine cancer patients who were admitted was **3-4 days** in 2012–13.[42]

What can a person with cancer of the uterus expect, therefore, from a typical treatment regime?

Surgery is the main treatment but radiotherapy and, increasingly, chemotherapy are used to treat women with advanced disease and those at high risk of recurrence.[43]

For early stage cancer of the uterus, a hysterectomy is the main treatment option and further treatment is not normally necessary.[44]

If the cancer cannot be completely removed, radiotherapy may be recommended after surgery. Even if the whole tumour has been removed, radiotherapy is sometimes given to reduce the chance of the cancer coming back. Radiotherapy can also be used instead of surgery if the cancer cannot be removed surgically, or if the patient is not well enough to have an operation.[82]

For advanced cancer of the uterus, a female hormone called progesterone may be able to shrink the cancer and help control symptoms. Chemotherapy can also help to shrink the cancer and control its growth for a time.[44]

Adjuvant (post-operative) chemotherapy improves survival from cancer of the uterus and is associated with a small benefit in progression-free survival and overall survival irrespective of radiotherapy treatment. It reduces the risk of developing a metastasis, could be an alternative to radiotherapy and has added value when used with radiotherapy.[45]

Surgery is less often used if a person has advanced uterine cancer, although there is some evidence that removing as much of the cancer as possible can help to slow it down.[44]

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How many people with cancer of the uterus have access to a Gynaecological CNS?

Macmillan's internal data suggests that we had (as of June 2014) **123 Gynae/Gynae Oncology Macmillan nurse posts** across the whole of the UK.[46]

In 2011 there were **174 Gynaecology Clinical Nurse Specialists** (CNSs) in England.[47]

What does this mean for patients?

91% of women with gynaecological cancers (including uterine cancer) reported that they had been **given the name of their clinical nurse specialist**. This is slightly higher than the average for all cancers (88%). People with a CNS responded far more positively than those without on a range of items related to information, choice and care.[48]

Sensitive, appropriate patient information is considered to be an important element in the psychological support of patients. Clinical nurse specialists are seen to have a key responsibility for this work.[33]

The **clinical nurse specialist** 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 cancer of the uterus to gain proper access to essential **expert knowledge and information** and thereby to make informed decisions.[50]

Women who had initial **support from a clinical nurse specialist** at the time of diagnosis of gynaecological cancer experienced a clinically significant **reduction in their level of psychological distress** 6 months from diagnosis. This shows that support from a clinical nurse specialist may be able to assist psychological recovery.[49]

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

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.[51]

In a study of morbidly obese women who underwent a total laparoscopic hysterectomy bilateral salpingo-oophorectomy (TLHBSO), co-morbidities were present in 76% of women. 29% had a single comorbid condition, and 26% had two. A further 21% had more than two.[52]

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

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

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**

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'The medical profession are now doing hysterectomies via keyhole surgery, which leaves less of a scar, and the recovery time after the operation is quicker with some patients being discharged the following day. Do not think of a hysterectomy as being the end of being a woman; embrace your hysterectomy as the new beginning of your womanhood.'

Sarah, 54

PHYSICAL AND MEDICAL NEEDS

33% of people with gynaecological cancer (including cancer of the uterus) thought **GPs and nurses at their local practice could have done more to support them** whilst they were having their treatment.(53)

Regardless of the cancer origin or age of onset, gynaecological cancer and its treatment can produce **short and long-term effects that adversely affect quality of life**. These include issues around sexual functioning, reproductive issues and lymphoedema.(54)

Radiotherapy and surgical treatment for cancer of the uterus **compromises fertility**. While the majority of women with cancer of the uterus are over the age of 50, it does affect younger women for whom this may be a concern.(80)

The **role of radiotherapy,** both pelvic external beamradiotherapy (EBRT) and vaginal intracavity brachytherapy (VBT), in stage 1 uterine cancer following a hysterectomy remains controversial as it can have **adverse side effects** for patients. It is associated with significant morbidity and a reduction in quality of life, and bladder and rectal function.(56)

Not specific to people with cancer of the uterus

Fatigue is one of the most common symptoms of cancer and its treatment. This compromises the patient's quality of life, but also diminishes their chances of physical activity, resulting in limited treatment and increased morbidity.(55)

FINANCIAL NEEDS

Of the people with gynaecological cancer (including cancer of the uterus) 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%.(58)

Not specific to people with cancer of the uterus

A recent Macmillan report on the financial burden of cancer, found that **costs related directly to treatment,** notably hospital travel/ parking were a particular burden to those with long journeys and/or on low incomes.(25)

The **most common additional cost people living with cancer face is getting to and from hospital, or making other healthcare visits.** 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.(25)

The **cost of travel to and from appointments affects 69% of people with cancer** and costs them, on average, £170 a month. Parking for outpatient appointments affects 38% of people with cancer and costs them, on average, £37 a month. Over a quarter (28%) of people with cancer incur costs for inpatient appointments. On average, this amounts to £20 a month for those affected.(25)

PRACTICAL AND INFORMATION NEEDS

83% of people with gynaecological cancers (including uterine cancer) were **given a choice about treatment** compared to 92% of prostate cancer patients and 89% of breast.[59]

24% of people with gynaecological cancers (including uterine cancer) were **not told about treatment side effects** in a way in which they could understand. This is comparable with other cancer types.[60]

33% of gynaecological cancer (including uterine cancer) patients did **not have trust and confidence in their ward nurses**.[61]

10% of people with gynaecological cancers (including uterine cancer) were **not given enough information about their condition and treatment**, 2% were given too much.[63]

EMOTIONAL AND PSYCHOLOGICAL NEEDS

A recent survey found that women undergoing chemotherapy (for breast, ovarian, cervical or uterine cancer) expressed an average of **10 concerns**, of which **80%** of these concerns were **not identified by the nurses**. Lack of identification of concerns leads to unmet needs, increased psychological distress, dissatisfaction with care and complaints.[64]

Treatment for cancer of the uterus in young women can cause sudden onset of **intense menopausal symptoms**, such as emotional disorders, hot flushes, and sexual dysfunction. In order to overcome these unpleasant and sometimes severe symptoms, hormone replacement therapy (HRT) has proven to be very effective [65].However there could be risks, especially if the tumour is oestrogen stimulated.[103]

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.[66]

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NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

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

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

- **39%** of people living with cancer who completed treatment in 2009/10 say that **no health or social care professional** talked them through the needs they might have.[29]
- **94%** of people living with cancer experience **physical health condition problems** in their first year after treatment.[51]
- **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.[51]
- **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.[51]
- **40%** of people living with cancer with **emotional difficulties** had not sought medical help or other support.[79]
- **23%** of people living with cancer **lack support from friends and family** during treatment and recovery.[105]
- **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.[105]

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.[67]
- 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.[62]

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.

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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

With improving survival rates for most gynaecologic malignancies, survivorship issues are becoming increasingly important. The impact on **sexual functioning** is becoming especially important for cancers with **effective treatment regimes affecting younger women**.[69]

Recent findings found that many women reported significantly **worse sex lives and a significantly lower frequency of sexual relations** following gynaecological cancer treatment.[68]

Many gynaecological cancer patients also reported **pain** on vaginal penetration and feeling uncomfortable in discussing their **sexual difficulties** with the oncologist.[68]

Female sexual morbidity after pelvic radiotherapy remains a neglected aspect of routine follow-up and cancer survivorship, in addition to the fact that sexual issues are only being explored in 25% of consultations.[70]

A recent study found that patients who received **external beam pelvic radiotherapy (EBRT)** reported higher levels of bowel symptoms and other limitations in daily activities with lower social functioning 5 years after treatment. Negative sexual symptoms were more frequently reported by all treatment groups.[71]

FINANCIAL NEEDS

25% of people with gynaecological cancers (including cancer of the uterus) who wanted to know were **not told about free prescriptions**.[72]

Not specific to people with cancer of the uterus

Some people affected by cancer **are not aware that they can claim benefits**. 61% of those questioned in a recent survey did not receive health-related benefits.[25]

Some people living with cancer find the **benefits system complex and difficult to navigate**. Benefits advice is also not always offered in a timely fashion.[25]

Personal Independence Payment (PIP), the successor benefit to Disability Living Allowance (DLA), was introduced across Great Britain in June 2013. **However there are significant delays** in the new system – 60% of claimants have waited on average just under four and a half months for a response, while 25% have been waiting at least six months.[113]

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.[73]

Contents

PRACTICAL AND INFORMATION NEEDS

42% of people with gynaecological cancers (including uterine cancer) were **not given enough care and help from health and social care professionals** once they were at home.[74]

Following treatment for cancer of the uterus, patients may experience **difficulties returning to work**, due to residual symptoms, such as continuing fatigue, or as a result of unrealistic expectations about returning to full employment soon after treatment has completed. This highlights the need for ongoing support and information following cancer treatment.[75]

Not specific to people with cancer of the uterus

Many people feel **abandoned by the healthcare system** once their initial treatment for cancer has completed.[79]

If recurrence occurs, a **renewed need for information & support** is generally expressed by people with cancer.[76]

For those experiencing a recurrence, only **half of those surveyed said that they received supported information**, suggesting there is unmet need at recurrence.[76]

EMOTIONAL AND PSYCHOLOGICAL NEEDS

31% of people with gynaecological cancers (including cancer of the uterus) were **not given enough emotional support from hospital staff** when being treated as an outpatient.[77]

17% of people with gynaecological cancers (including uterine cancer) were **not given information about self help and support groups.**[78]

Not specific to people with cancer of the uterus

Although psychological issues are more common in the first year after treatment one third of people (of all cancer types) continue to report significant levels of distress well after treatment has been completed. Even 10 years on **54% of cancer survivors still suffer from at least one psychological issue.**[79]

One in three people with cancer (33%) who have experienced isolation say a **lack of support has caused them stress or anxiety.**[105]

NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

What health data do we have on cancer of the uterus patients with progressive illness?

It is estimated that around **1 in 220** new cancer diagnoses in the UK (all cancer types, not just cancer of the uterus) are associated with radiotherapy for a previous cancer.[81]

How many uterine cancer patients are at the end of life?

We currently have no data on how many cancer of the uterus patients are at end of life.

What is the impact of giving patients palliative care?

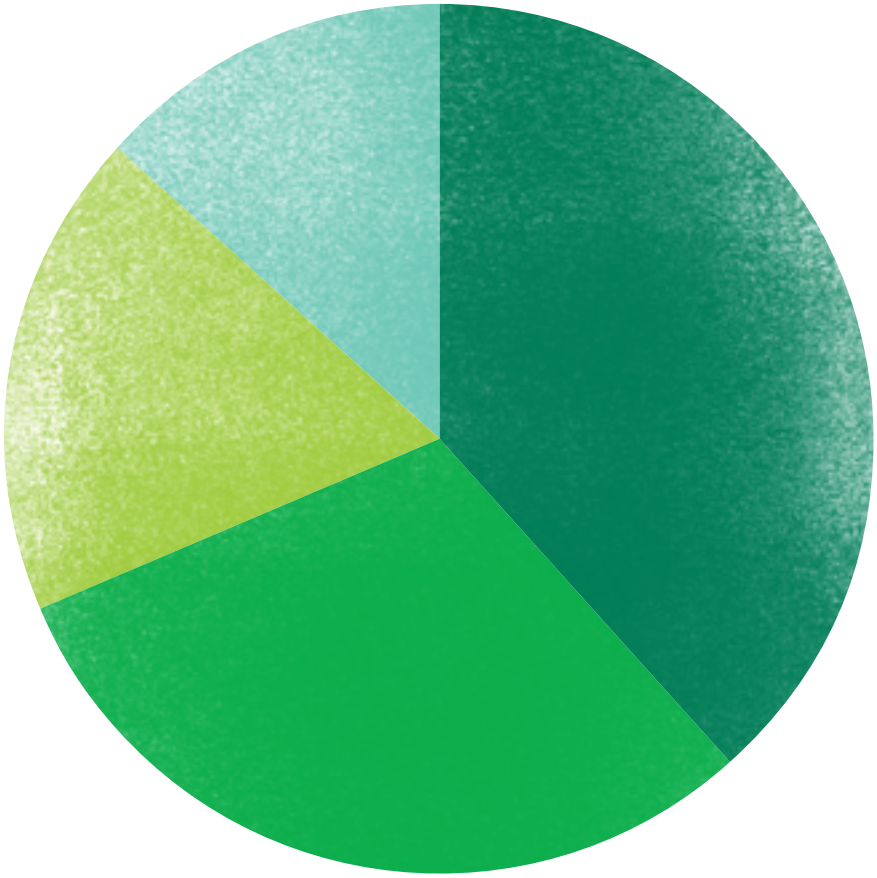
The National Institute for Clinical Excellence (NICE) has defined supportive and palliative care for people with cancer. With some modification the definition can be used for people with any life-threatening condition: 'Palliative care is the active holistic care of patients with advanced progressive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

How many cancer deaths are there in each setting?[11]

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 occur 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 with cancer die?*[85]



Hospital
38%

Home (own residence)
30%

Hospice
18%

Care and nursing home
13%

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

To what extent do patients with cancer of the uterus die in their place of choice?

Not specific to people with cancer of the uterus:

A recent survey found that 73% of people who died from cancer would have liked to have spent the last weeks and days of their life at home.[106] However, only 30% of those who die from cancer actually die at their home or own residence.[85]

In terms of dying in the place of choice, only around one in five people (or fewer in many local authorities) are supported to die in their own home.[87] If these trends are to continue, approximately 222,000 people in England will die in hospital in 2020, having said that they wished to die at home. This suggests that more needs to be done to ensure that people's wishes about where they want to die are met.[112]

‘We held onto hope, even as the diagnosis and prognosis got steadily worse. Then one day it broke, and she died. That day we had to let go of hope and face a new reality.’

Ian, 55, bereaved husband

PHYSICAL AND MEDICAL NEEDS

Common symptoms of gynecological cancers (including cancer of the uterus) that need symptom management towards the end of life are pain, vaginal bleeding, psychological problems and physical deterioration.[111]

Not specific to people with cancer of the uterus

The reported prevalence of **moderate to severe pain in advanced cancer** is approximately **64%**, with a sharp increase to as high as **80–90% at the end of life**.[90]

Various symptoms are very common in advanced cancer, with patients having an average of 6 uncontrolled symptoms on admission to palliative care.[91]

Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; they occur in some combination in virtually all patients.[92]

Evidence shows that **patients with cancer who receive earlier palliative care have a better quality of life**, longer survival and less aggressive care at the end of life compared to those receiving standard care.[114]

FINANCIAL NEEDS

Not specific to people with cancer of the uterus

In 2010 Macmillan reported that **36% of people with a terminal cancer diagnosis** (all cancer types, not specifically uterine cancer) **did not claim the benefits they were automatically entitled to**. This amounts to over £90m.[93]

A recent study found that advanced stage at diagnosis, being older at diagnosis, and higher comorbidity were associated with **increased costs**. The financial burden is also highest around two events, cancer diagnosis and cancer death.[94]

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.[107]

PRACTICAL AND INFORMATION NEEDS

A study into end of life care found that **older gynaecological cancer 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 fewer physician home visits.[35]

Not specific to people with cancer of the uterus

A recent study into advanced cancer 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.[95]

A third of people who have had cancer **did not 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.[79]

Research has found that **older patients with cancer are often under-treated**. This under-treatment is present in palliative care. Older people with cancer are more likely to receive less social and practical support, which suggests that they are not getting the adequate care and services they need at end of life.[89]

EMOTIONAL AND PSYCHOLOGICAL NEEDS

Not specific to people with cancer of the uterus

Cancer patients (all cancer types, not just cancer of the uterus) approaching death suffer more **psychological distress**.[96]

Access to community nursing at any time of the day or night is essential to support those who **wish to die at home**. Where these wishes are not met it can lead to traumatic experiences for patients and their families.[97]

Depression is an under-recognised 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. **More than one in four** (28%) of people living with cancer say they have **experienced depression.**[98]

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LIFESTYLE AND PERCEPTIONS

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

What is the profile of the average person living with cancer of the uterus?

- Uterine cancer is a female-specific cancer, so all people with cancer of the uterus are women.
- The vast majority (94%) of uterine cancer cases are diagnosed in women aged 50 years and over.[7]
- Incidence of uterine cancer is positively correlated to obesity. The more overweight or obese a women is, the more likely they will be diagnosed with cancer of the uterus (and vice versa).[104]
- Incidence rates amongst Asian women are significantly lower compared to the incidence for White females, but there is evidence that black females are more likely to get cancer of the uterus than white females.[15]

What is the demographic breakdown/ market segmentation of the 70,190 women living with cancer of the uterus?[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 uterine 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 patients with cancer of the uterus, the following MOSAIC* groups show significantly greater than average representation:

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

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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 Groups E and L, the following MOSAIC* groups shows greater than average representation amongst patients with cancer of the uterus:

Group D: Small Town Diversity (Residents of small and mid-sized towns with strong local roots): People in Group D are most likely to be in their retirement years, although they can be quite diverse in terms of age distribution and type of household. A key characteristic is that they live in communities small enough for houses of different ages and styles to exist in close proximity and where council estates, if they do exist, are small in scale and their residents well integrated with the rest of the population. Incomes are restricted by the relatively low wage rates offered by employers situated in small towns. This is a group who are almost exclusively white.

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

In addition to the above Groups, there are Types within Groups who are also well-represented amongst uterus cancer patients:

Group M (Industrial Heritage)
- Type 54: Clocking Off.

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

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

- **Group 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.

- **Group D: Small Town Diversity:** The focus of many people's leisure is on home improvement and meeting up with friends in homes and gardens, in pubs at meetings of local associations and sharing trips to visit local sites of historical or environment distinction. Many people in this group read the Daily Telegraph or Daily Express.

- **Group B: Professional Rewards:** Holidays, cruises and day trips are popular activities, as is going to the theatre and to concert halls. People in this group tend to read the broadsheet newspapers, particularly The Daily Telegraph and the Sunday Times.

What are people affected by cancer of the uterus saying about their lives both before and after a cancer diagnosis?

Before:

'As long as I can remember I have what is termed as "woman problems" and from the onset of puberty I was suffering severe painful periods and heavy blood loss each month. Sometimes the symptoms were so severe that I would be so ill that I had to lie in bed for days.'

Michelle, 54

'I had no time to think about my operation as the same day I was diagnosed, I had to go for the pre-operation tests, such as blood tests, chest X-ray, urine test, and temperature, blood pressure, and heart rate tests, and fortunately I was fit enough to have the operation.'

Jane, 54

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After:

'I had a hysterectomy, then six chemotherapy sessions, and finally, radiotherapy. Initially, I returned to work two half days a week between chemo and radio. I just wanted some sort of normality, but the radiotherapy had a big cumulative impact. I had to stop.'

Eve, 51

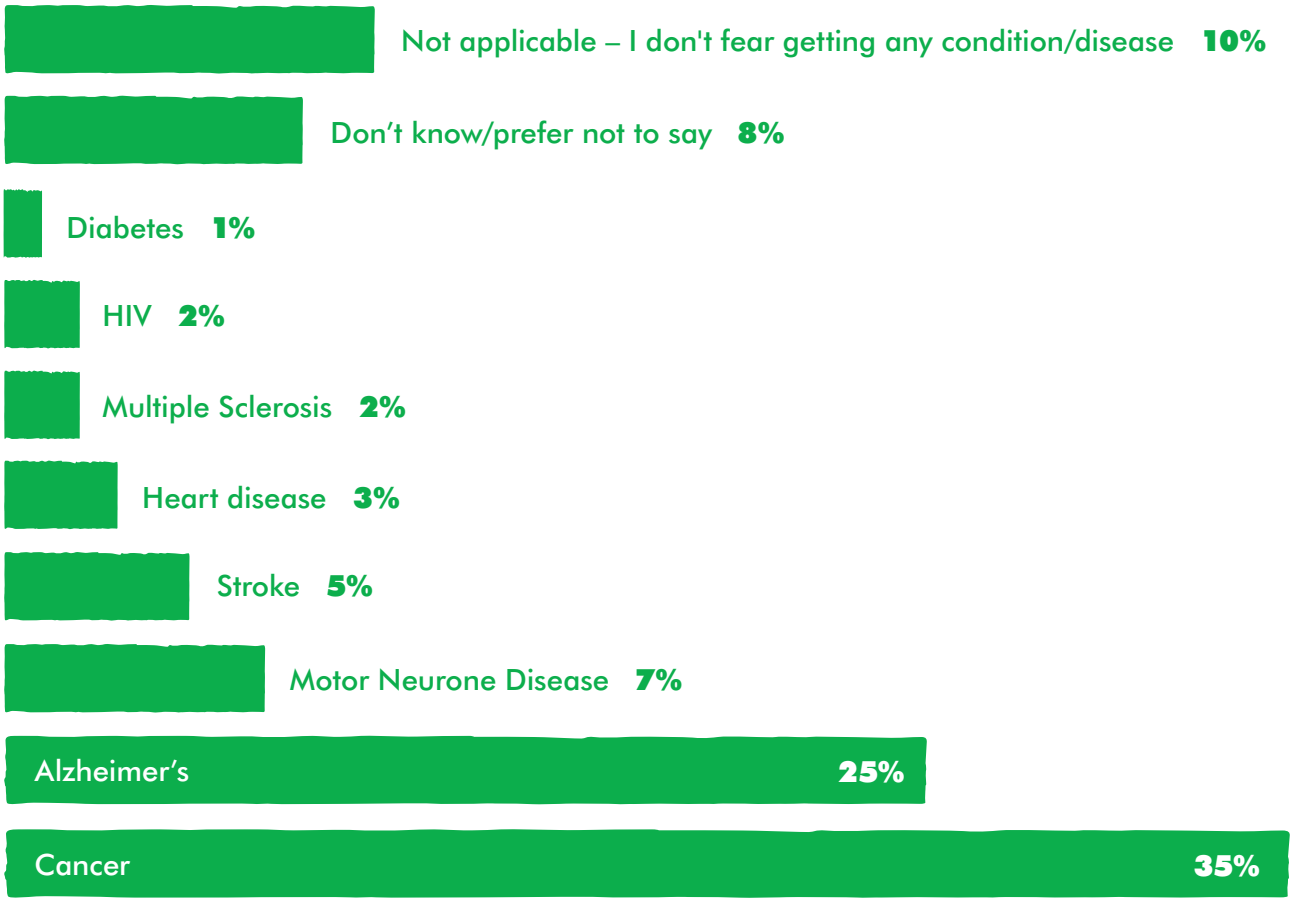
'After six months my health began to improve and I felt like a new woman and I began to recognise that having a hysterectomy has it's advantages especially for younger women who do not want any more babies, no more periods and not having the worry about birth control. Hysterectomies have saved the lives of many women and may have ended their years of suffering due to female related problems.'

Julie, 54

How does people's fear of cancer of the uterus compare to actual survival rates?[100]

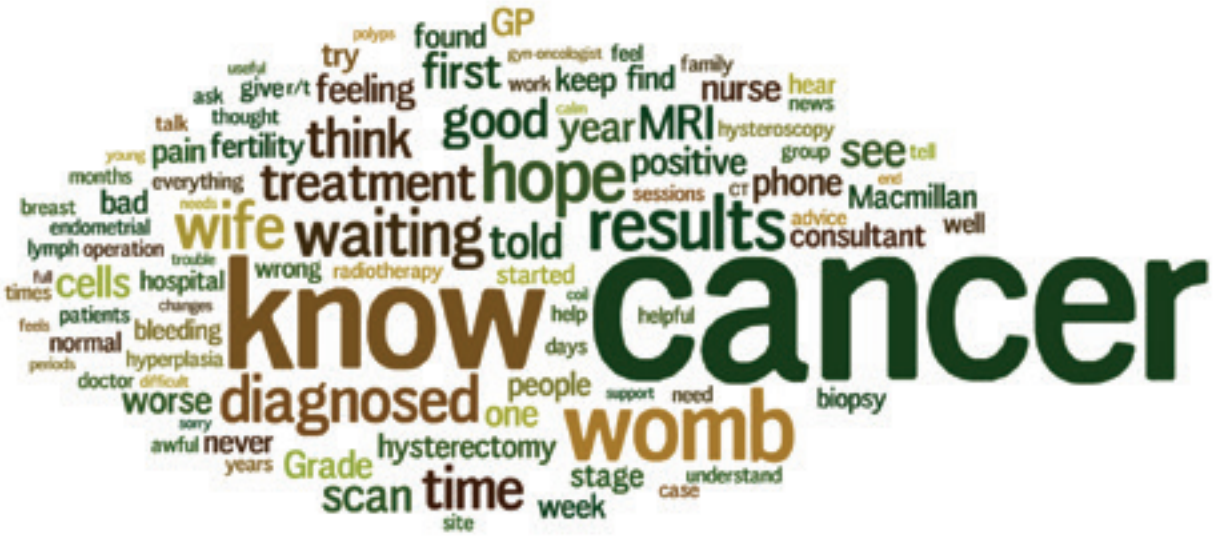
A 2011 study by Cancer Research UK surveyed people's fear of certain cancer types. However cancer of the uterus was not included in the research. Instead of showing the results of that research, we devote this page instead to a different set of results from the same survey which examined how people's 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, a stroke and heart disease.

What our uterine cancer online Macmillan Community members are saying...[101]



How the media* portrays cancer of the uterus...[102]

*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 cancer of the uterus compared to the frequency of words used in UK media articles where womb cancer (i.e. cancer of the uterus) is the subject. The results are summarised here:

- The terms 'wife' and 'family' feature prominently in the online community discussions, probably referring to a partner or family member who has cancer of the uterus. The online community may include many family members and partners who are carers, and rely on this community for support that is not readily available elsewhere.

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

- The media also tend to focus more upon the causes and diagnosis of cancer and those at risk, as opposed to the personal journey that the patients undertake, such as the emphasis upon 'risk', 'menopause', 'HRT' and 'lifestyle.'

- The terms 'positive' and 'hope' in the online community discussions emphasise the emotional difficulties experienced by women with cancer of the uterus. The media includes none of those types of words, focusing instead on the use of words such as, 'risk', 'death' and 'disease'.

REFERENCES, SOURCES, NOTES AND CAVEATS

Quotes

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

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APPENDIX A JARGON BUSTER

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

(i) Health data terms

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

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

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

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

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

(ii) Other terms

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

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

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

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

Full suite of the Rich Pictures

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

Overarching Rich Picture

The Rich Picture on people with cancer	(MAC15069)

The Rich Pictures on cancer types

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

The Rich Pictures on age groups

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

Other Rich Pictures

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

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

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

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

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

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

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

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

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