

# THE RICH PICTURE

WE ARE  
MACMILLAN.  
CANCER SUPPORT

# PEOPLE WITH COLORECTAL CANCER



Thom, living with colorectal 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](mailto:evidence@macmillan.org.uk)

## The legal bit

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

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

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



The Rich Pictures are licenced under a Creative Commons Attribution-NonCommercial-Share Alike 4.0 International Licence. Users are welcome to download, save, or distribute this work and make derivative works based on it, including in foreign language translation without written permission subject to the conditions set out in the Creative Commons licence.

# Guidance on referencing this document

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

## Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklets Understanding Colon Cancer (MAC12474) and Understanding Rectal Cancer (MAC12475) more helpful.



**Understanding  
Colon Cancer**  
MAC12474



**Understanding  
Rectal Cancer**  
MAC12475

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](http://www.be.macmillan.org.uk)**.

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

# 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.



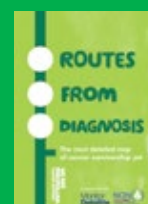
### Local Cancer Intelligence

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](mailto:evidence@macmillan.org.uk).

# CONTENTS

Summary of people living with colorectal cancer	2
What is colorectal cancer?	4
Macmillan's aims and outcomes	6
Key facts and stats	8
The cancer journey	24
Needs and experiences – Diagnosis	26
Needs and experiences – Treatment	34
Needs and experiences – Survivorship (post-treatment)	40
Needs and experiences – Progressive illness and end of life	44
Lifestyle and perceptions	50
References	58
Appendix A – Jargon buster	66



# SUMMARY OF PEOPLE LIVING WITH COLORECTAL CANCER

## Key stats

An average of around **115 people** are diagnosed with colorectal cancer every day.<sup>(8, 9, 10, 11)</sup>

Colorectal cancer is the second most common cause of cancer death in the UK after lung cancer. Around **16,200 people** died of colorectal cancer in 2012 in the UK.<sup>(11, 12, 13, 14)</sup>

Around 290,000 people were living with colorectal cancer in the UK in 2015.

**73%** of colorectal cancer cases were diagnosed in people **aged over 65 years old between 2009-2011.**<sup>(4)</sup>

**Colorectal cancer in the third most prevalent cancer in the UK and second only to lung cancer in terms of mortality rates.**

## Diagnosis

The two principal symptoms for bowel cancer, **rectal bleeding** and **change in bowel habit**, are very similar to other, much less serious problems with the bowel.<sup>(93)</sup>

One of the difficulties with bowel cancer is that **often there are no symptoms until quite late.**<sup>(32)</sup>

The NHS Bowel Screening Programme aims to **save over 2,000 lives each year by 2025.**<sup>(26)</sup>

The **leading barrier to colorectal cancer screening is fear**, while other barriers include **embarrassment, lack of knowledge and pain.**<sup>(43)</sup>

In the general UK population, **knowledge of colorectal cancer warning signs is low.**<sup>(134)</sup>

**Often there are no bowel cancer symptoms until quite late.**

## Treatment

**Surgery is the main treatment** for colorectal cancer.<sup>(32)</sup>

**Colorectal cancer can be successfully treated in over 90% of cases**, if it is diagnosed at an early stage.<sup>(1)</sup>

For those that receive it, radiotherapy to the bowel area can cause **side effects such as diarrhoea, nausea and tiredness**, as well as more specific side effects such as **inflammation of the bowel or bladder lining.**<sup>(49)</sup>

Colorectal cancer patients who have a **colostomy bag** report **lower self-image and poorer social confidence.**<sup>(74)</sup>

**Colorectal cancer can be successfully treated in over 90% of cases if diagnosed early.**

## Survivorship

Survivors of colorectal cancer **may experience the effects of cancer and its treatment up to 10 years after diagnosis.**<sup>(75)</sup>

**Higher physical activity levels** are associated with higher physical health-related quality of life in colorectal cancer survivors.<sup>(77)</sup>

**Only 51% of colorectal cancer patients** said they have been **given information about how to get financial help or benefits** by hospital staff.<sup>(36)</sup>

**82%** of colorectal cancer patients have been **given information about support or self-help groups for people with cancer** by hospital staff.<sup>(85)</sup>

**The effects of colorectal cancer treatment may be felt up to 10 years after diagnosis.**

## End of life

The most common symptoms experienced by more than half of people **during their last two weeks** of life include **shortness of breath, pain, and confusion.**<sup>(99)</sup>

**Chemotherapy has been shown to prolong survival** amongst metastatic colorectal cancer patients **by an average of 9 months.**<sup>(92)</sup>

**36% of all people with terminal cancer did not claim the benefits they were entitled to.**<sup>(101)</sup>

**Psychological distress is common** amongst patients and their carers at end of life.<sup>(71, 100)</sup>

**Chemotherapy prolongs survival amongst metastatic colorectal cancer patients by 9 months.**

## Lifestyle & perceptions

Colorectal cancer affects both men and women, with a **slightly higher level of diagnosis amongst men.**<sup>(8, 9, 10, 11)</sup>

Amongst those with colorectal cancer, **a large number are aged over 65**, who on retirement have decided to move to a retirement community among people of broadly similar ages and incomes.<sup>(118)</sup>

**Fear of bowel cancer is high amongst the general public, which suggests that awareness is fairly strong, possibly because of screening campaigns.**

# INTRODUCTION TO COLORECTAL CANCER

## What is colorectal cancer?

**Colorectal cancer** is also referred to as **bowel or colon cancer**. The term bowel cancer may also refer to cancer of the small bowel – this is incredibly rare and only 700 people are diagnosed with this cancer every year. We will be looking at rarer cancers in greater detail in the rarer cancers Rich Picture. This Rich Picture focuses on colorectal cancers. These are cancers which can develop in the **large bowel or rectum**. Around two-thirds of colorectal cancers appear in the large bowel and one-third in the rectum. <sup>(1)</sup>

More than 95% of colorectal cancers diagnosed are **adenocarcinomas**. This means that the cancer started in the gland cells in the lining of the colorectal wall. The gland cells normally produce mucus. Mucus is a slimy substance that makes it easier for the stool to pass through the bowel. <sup>(123)</sup>

Most colorectal cancers start as benign **innocent growths** – called **polyps** – on the wall of the bowel. Polyps are like small spots and most do not cause any symptoms. Polyps are common in older people and most are not pre-cancerous, however, a specific type of polyp called an **adenoma** can become cancerous. <sup>(2)</sup>

## Want to know more?

Macmillan produces a wealth of information about what colorectal cancer is, its causes, symptoms and treatment. Macmillan staff can refer to reference 3 on **page 58** for where you can find this information, or if you're affected by cancer, call our Macmillan team on the number below, or visit our website.

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



**I thought I'd contracted some sort of stomach bug and it was persisting and persisting.**

**I was meant to come in to get my results and they went "Yes, it's not good. You've been diagnosed with colon cancer and now you're going into surgery."**

**It was a big thing for me personally, but then when you have to deal with that on an emotional level, deal with all of the symptoms and all of the actual medical side of things, I think that's why Macmillan do such a fantastic job.**

**I've got this phrase: from your darkest hour comes your greatest power.**

**Thom, living with colorectal cancer**



# MACMILLAN'S AIMS AND OUTCOMES

## Macmillan's aims and outcomes – and how they are different for people with colorectal 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 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 290, 000 people were living with colorectal cancer in the UK in 2015.**

## How is this different for people with colorectal 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, and the information used to help focus our efforts to reach those most in need of support.

## The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

# THE FACTS ON COLORECTAL CANCER

This section presents some of the key stats and facts relating to people with colorectal cancer. 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.

**115**

people are diagnosed with colorectal cancer every day <sup>(8, 9, 10, 11)</sup>

**290,000**

people were living with colorectal cancer in the UK in 2015.<sup>(19)</sup>

**75%**

of people live for more than one year after their colorectal cancer diagnosis <sup>(6)</sup>

**16,198**

people died of colorectal cancer in 2012 in the UK, which is equivalent to 44 people every day <sup>(11, 12, 13, 14)</sup>

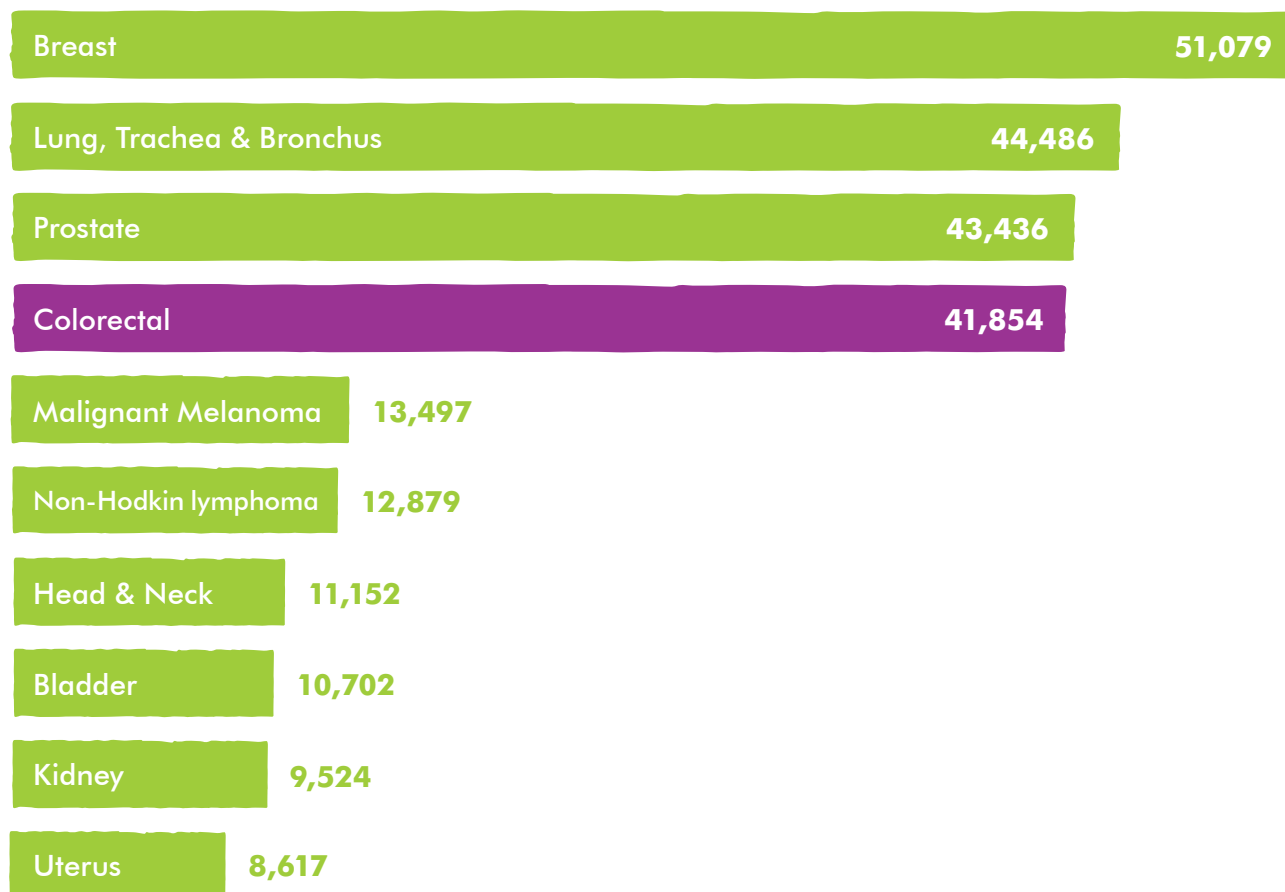
**58%**

of women and 57% of men live for more than five years after their colorectal cancer diagnosis <sup>(6)</sup>

## How many people get colorectal cancer per year? (incidence)

(8, 9, 10, 11)

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

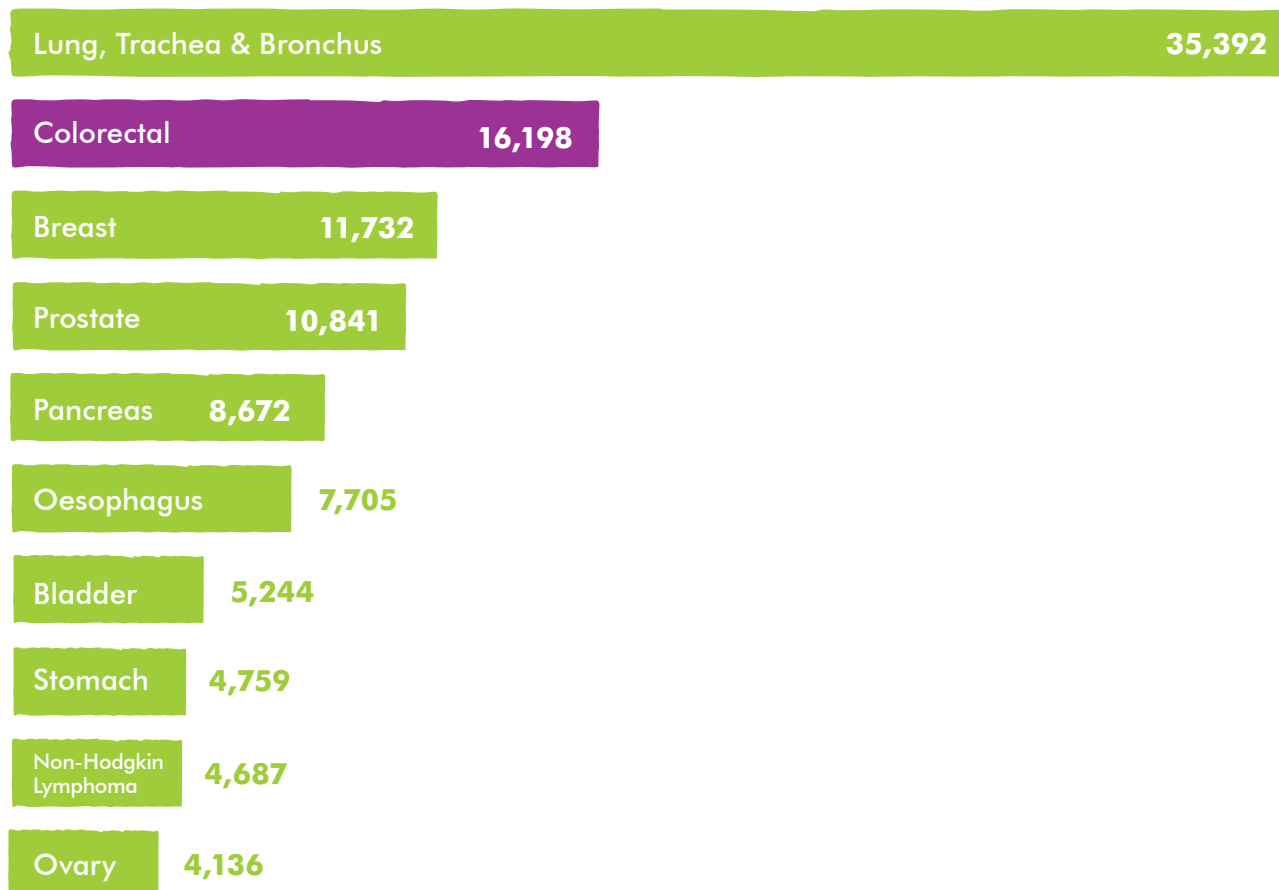


**It is estimated that around 1 in 222 new colorectal cancer diagnoses in the UK are associated with radiotherapy for a previous cancer. <sup>(91)</sup>**

## How many people die from colorectal cancer per year? (mortality)

(11, 12, 13, 14)

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



**Colorectal cancer is the second most common cause of cancer death in the UK after lung cancer. Numbers are proportionally higher than breast and prostate cancers when compared to incidence, possibly due to later diagnostics.**

## How many people are currently living with colorectal cancer? (prevalence) <sup>(119)</sup>

**290,000**

People were living with colorectal cancer in the UK in 2015.

**Colorectal cancer death rates have been falling since the 1970s, dropping by around 16% in the last decade.**

**This, combined with an aging population means the overall proportion of people living with colorectal cancer in the UK is increasing.**

## 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 colorectal cancer per year in England? (incidence) <sup>(8)</sup>

**34,322**

New cases of colorectal cancer diagnosed in England in 2012.

### How many people die from colorectal cancer per year in England? (mortality) <sup>(12, 14)</sup>

**13,254**

Colorectal cancer deaths in England in 2012.

### How many people are living with colorectal cancer in England? <sup>(5)</sup>

**240,000**

People were living with colorectal cancer in the UK in 2015.

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

**46.0**

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

### What is the age-standardised\* rate of mortality from colorectal cancer in England? <sup>(116)</sup>

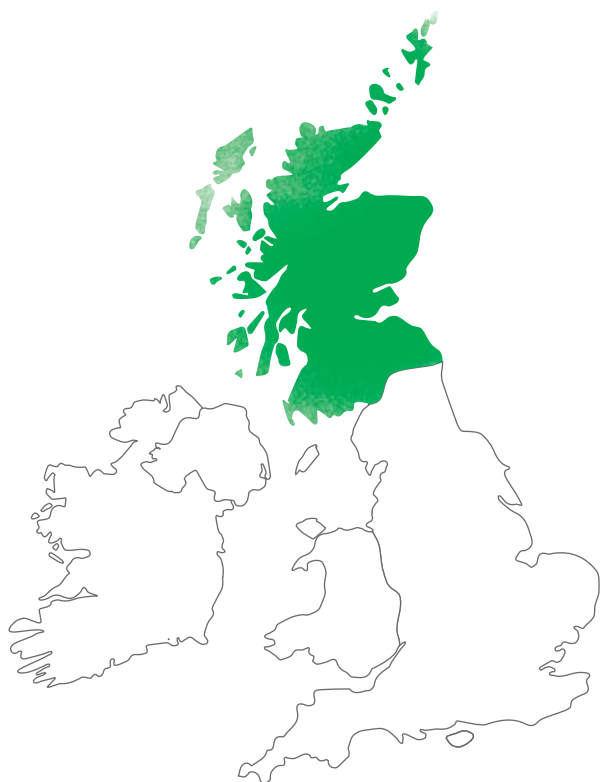
**15.7**

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



## What are the key stats for Scotland?

See data on incidence, mortality and prevalence for Scotland



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

### How many people get colorectal cancer per year in Scotland? (incidence) <sup>(9)</sup>

**3,849**

New cases of colorectal cancer diagnosed in Scotland in 2012.

### How many people die from colorectal cancer per year in Scotland? (mortality) <sup>(13)</sup>

**1,621**

Colorectal cancer deaths in Scotland in 2012.

### How many people are living with colorectal cancer in Scotland? (prevalence) <sup>(5)</sup>

**28,000**

People were living with colorectal cancer in Scotland in 2015.

### What is the age-standardised\* rate of incidence of colorectal cancer in Scotland<sup>(14)</sup>

**53.3**

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

### What is the age-standardised\* rate of mortality from colorectal cancer in Scotland?<sup>(116)</sup>

**18.7**

cases of colorectal 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



\*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 colorectal cancer per year in Wales? (incidence) <sup>(10)</sup>

**2,444**

New cases of colorectal cancer diagnosed in Wales in 2012.

### How many people die from colorectal cancer per year in Wales? (mortality) <sup>(14)</sup>

**912**

Colorectal cancer deaths in Wales in 2012.

### How many people are living with colorectal cancer in Wales? (prevalence) <sup>(5)</sup>

**16,000**

People were living with colorectal cancer in Wales in 2015

### What is the age-standardised\* rate of incidence of colorectal cancer in Wales?<sup>(14)</sup>

**49.6**

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

### What is the age-standardised\* rate of mortality from colorectal cancer in Wales?<sup>(116)</sup>

**16.4**

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

## What are the key stats for Northern Ireland?

See data on incidence, mortality and prevalence for Northern Ireland



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

### How many people get colorectal cancer per year in Northern Ireland? <sup>(11)</sup>

**1,239**

New cases of colorectal cancer diagnosed in Northern Ireland in 2012.

### How many people die from colorectal cancer per year in Northern Ireland? (mortality) <sup>(11)</sup>

**411**

Colorectal cancer deaths in Northern Ireland in 2012.

### How many people are living with colorectal cancer in Northern Ireland? (prevalence) <sup>(5)</sup>

**9,000**

People were living with colorectal cancer in Northern Ireland in 2015.

### What is the age-standardised\* rate of incidence of colorectal cancer in Northern Ireland?<sup>(14)</sup>

**53.5**

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

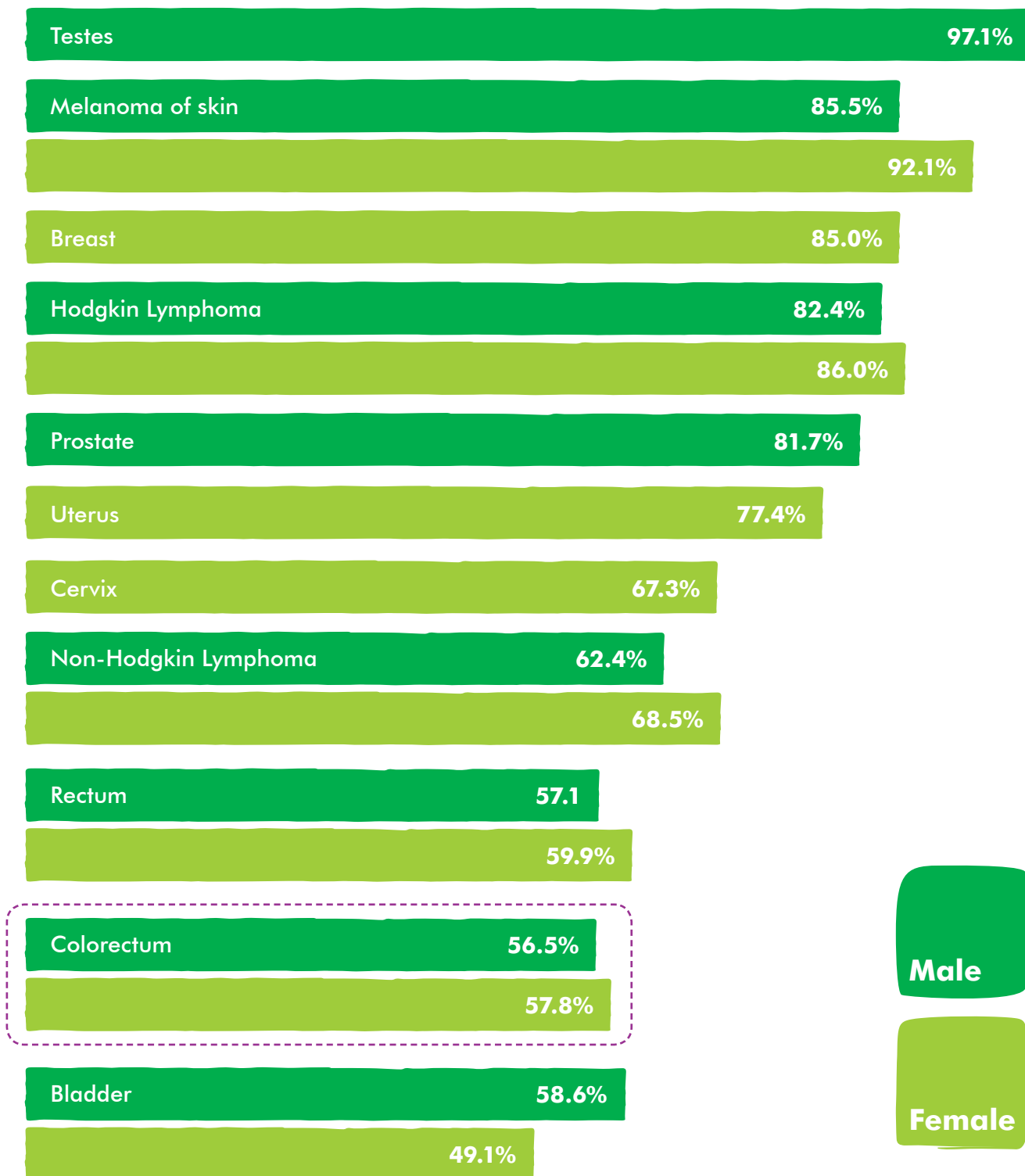
### What is the age-standardised\* rate of mortality from colorectal cancer in Northern Ireland?<sup>(116)</sup>

**16.9**

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

## What proportion of people survive colorectal cancer? (survival) <sup>(6)</sup>

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

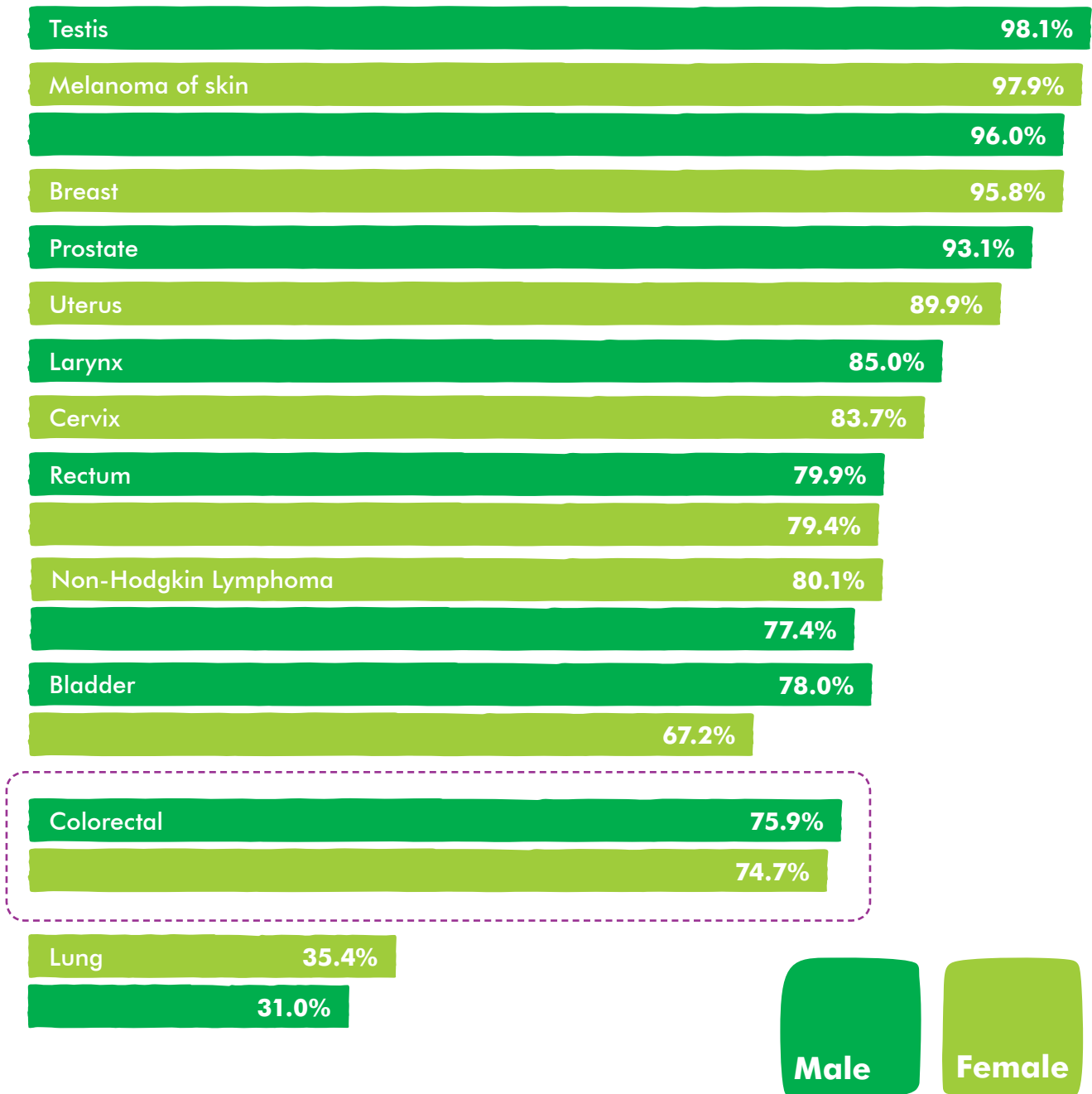


**Colorectal cancer has a poor 5-year survival rate, in comparison to some other cancers. 57% of men and 58% of women are alive 5 years after their diagnosis.**

**This puts colorectal cancer at number 10 out of 22 in the rankings of 5-year survival.**

## How many people live beyond one year of their colorectal cancer diagnosis? <sup>(6)</sup>

Age-Standardised relative survival estimates, 2007-2011, by gender, England



The estimated proportion of men living more than one year after their colorectal cancer diagnosis is 76%, while the proportion of women is 75%. The earlier the cancer is diagnosed the greater the survival rate.

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

Over the last 40 years median survival time has increased from 1 year to 6 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. <sup>(114)</sup>

## How do UK survival rates compare internationally? <sup>(15)</sup>

Cancer survival rates in England are improving overall. However, the most up-to-date international comparisons show that England still has worse cancer survival rates than many countries, including Canada, Australia, Sweden and Norway. In relation to colorectal cancer, in the period 2005-2007, the UK's 5-year survival rate was around 54% , compared to 62% in Norway, 63% in Sweden and 66% in Australia. This strongly suggests that more can be done to improve the chances of survival for people with colorectal cancer in the UK.

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

### Gender

Colorectal cancer affects both men and women, with a slightly higher level of incidence and mortality amongst men. <sup>(8-14)</sup>

### Ethnic background

Uptake for colorectal screening programmes is generally lower in minority ethnic groups than in the population as a whole. <sup>(16)</sup>

White people are significantly more likely to be diagnosed with colorectal cancer. For example, the age-standardised rate in the White ethnic group ranges from 34.0 to 34.8 per 100,000 for all ages, but in the Asian ethnic group ranges from 11.3 to 17.5 per 100,000. This difference does not affect the likelihood of survival though, as there were no significant differences in age-standardised relative

survival between White, Asian and Black ethnic groups either at one or three years post-diagnosis. <sup>(17)</sup>

### Age

While colorectal cancer affects people of all ages, it is strongly related to age. In the UK between 2009 and 2011, 73% of colorectal cancer cases were diagnosed in people aged 65 years and over. Age-specific incidence rates increase sharply from around age 50, peaking in the over 70s. <sup>(4)</sup>

Between 2010 and 2012, 81% of colorectal cancer deaths were in people aged 65 years and over. <sup>(7)</sup>

There can be slight differences caused by the site of colorectal cancer. Rectal cancer patients are more likely to be male and tend to be younger. Rectal cancer patients also tend to have a lower stage of cancer than patients with colon cancer; specifically they are more likely to have a cancer that is confined to the wall of the bowel. In 2012-13, of 31,723 patients diagnosed with colorectal cancer in England and Wales, the highest proportion of colon cancer cases (32%) were observed in the 75-84 age group, while the highest proportion of rectal cancer cases (33%) was seen in patients aged 65 and under. <sup>(51)</sup>

### Social background

There is evidence for a small association between colorectal cancer incidence and deprivation in England for males. The most recent studies show incidence rates are higher for men living in more deprived areas compared with the least deprived, though no significant differences are reported for women. <sup>(4)</sup>

Previous studies have shown that people from more deprived areas are more likely to smoke, be very overweight, have heavy alcohol consumption and poor low fibre diets. All factors which can greatly increase the risk of colorectal cancer. <sup>(19)</sup>

People from more deprived areas are also less likely to take up screening initiations. The most ethnically diverse areas also had lower uptake than other areas, especially amongst men. <sup>(20)</sup>

## What are the geographical 'hotspots' for colorectal cancer incidence, mortality and survival? <sup>(21)</sup>



Colorectal 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](http://www.ncin.org.uk/eatlas), or Macmillan staff members can contact Macmillan's Health Data team.

**Colorectal cancer incidence rates are higher in the north (Scotland and Northern England) and Northern Ireland and lower in the south of the UK (southern England and the Midlands)**



### Colorectal 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](http://www.ncin.org.uk/eatlas), or Macmillan staff members can contact Macmillan's Health Data team.

**Colorectal cancer mortality rates are generally higher in Scotland, Wales, Northern Ireland and the North of England compared with the rest of the UK.**

## Trends in the data

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

Colorectal cancer incidence rates have overall increased in Britain since the mid-1970s. Between 2006 and 2008, colorectal cancer incidence for people aged 60-69 increased by more than 13% in the UK. This rise is almost certainly due to the roll out of colorectal cancer screening and the higher detection rates this has led to. The screening programme started in England for 60- to 69-year olds in 2006, and has now been introduced across the whole of the UK. Since 2008, there has been very little change in incidence rates for this age group in the UK. <sup>(4)</sup>

People who have a close member of their family with colorectal cancer have an increased likelihood of developing colorectal cancer themselves. <sup>(110)</sup>

Colorectal cancer mortality rates overall have decreased in the UK since the early 1970s. European age-standardised mortality rates in 2012 were 39% lower for men and 50% lower for women than in 1971-1973. There are probably a combination of reasons for the decline in colorectal cancer mortality rates, including earlier detection and better treatment. <sup>(7)</sup>

Colorectal screening has been shown to reduce the risk of dying from colorectal cancer by a quarter in people who are screened in England. A similar risk reduction has recently been observed in a study in Scotland<sup>(108)</sup>. There are also screening programmes in Northern Ireland and Wales, but no studies have yet been conducted into their effectiveness. <sup>(7)</sup>

**'I was diagnosed with bowel cancer through the national screening. I feel so incredibly lucky that it was picked up because I had no idea: I felt incredibly well.'**

Helen, 69, North West

# 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 colorectal 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.

# NEEDS AND EXPERIENCES DIAGNOSIS

## What are the top signs and symptoms of colorectal cancer?

1. Bleeding from the rectum or blood in the bowel motion
2. Persistent change in bowel habit

Other symptoms include abdominal pain, a lump in the abdomen and unexplained tiredness, dizziness or weight loss (signs of anaemia).

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

Patients with cancer in the UK **tend to present with more advanced disease and have poorer survival rates** than many of their European counterparts. The most likely explanations are either late presentation by patients or late onward referral by GPs. <sup>(22)</sup>

**Knowledge of colorectal cancer warning signs is low.** A 2011 survey found that **respondents, on average, named less than one sign of colorectal cancer** when they were not prompted about specific symptoms. The most commonly recalled warning signs included change in bowel habit (23%) and blood in stools (15%). <sup>(134)</sup>

When respondents were asked about specific symptoms, however, **78% agreed that changes in bowel habit posed a warning sign and 87% were aware that blood in stools could be a symptom** of colorectal cancer. Women, older people and knowing someone who had been diagnosed with cancer were also associated with higher awareness. <sup>(134)</sup>

**Diagnosis begins with a visit to a GP**, who could perform a rectal examination and blood test. **This may lead to a hospital referral**, where a range of tests can follow examining the colon or rectum. If cancer is detected, **further tests will find out the size and position of the cancer, and whether it has spread.** <sup>(24)</sup>

In 2004 a full-time GP in the UK would only be likely to encounter one new patient each year with colorectal cancer. <sup>(25)</sup>

Rectal bleeding is a frequent first symptom of colorectal cancer. However, it is also a symptom of haemorrhoids, inflammatory bowel disease and many other non-malignant conditions, and only a small proportion of people consult their GP each year with this symptom. **Change in bowel habit is as important a symptom<sup>(93)</sup> as rectal bleeding, but is the symptom most associated with patient delay in colorectal cancer presentation.** Diarrhoea is the symptom most associated with doctor delay. <sup>(25)</sup>

## How well does screening work for colorectal cancer?

**The NHS Bowel Screening Programme began in England in 2006, Scotland in 2007, Wales in 2008 and in Northern Ireland in 2010.** The eligibility ages for screening are 60-69 in England, 60-74 in Wales, 60-71 in Northern Ireland and 50-74 in Scotland. <sup>(26)</sup>

**Over 2,000 lives could be saved each year** in the UK by 2025 if just 60% of those eligible took up the invitation for bowel screening. <sup>(26)</sup>

**54% of those invited completed bowel screening** in the first two years of the colorectal screening programme. Men had lower uptake than women (51% and 56% respectively). <sup>(20)</sup>

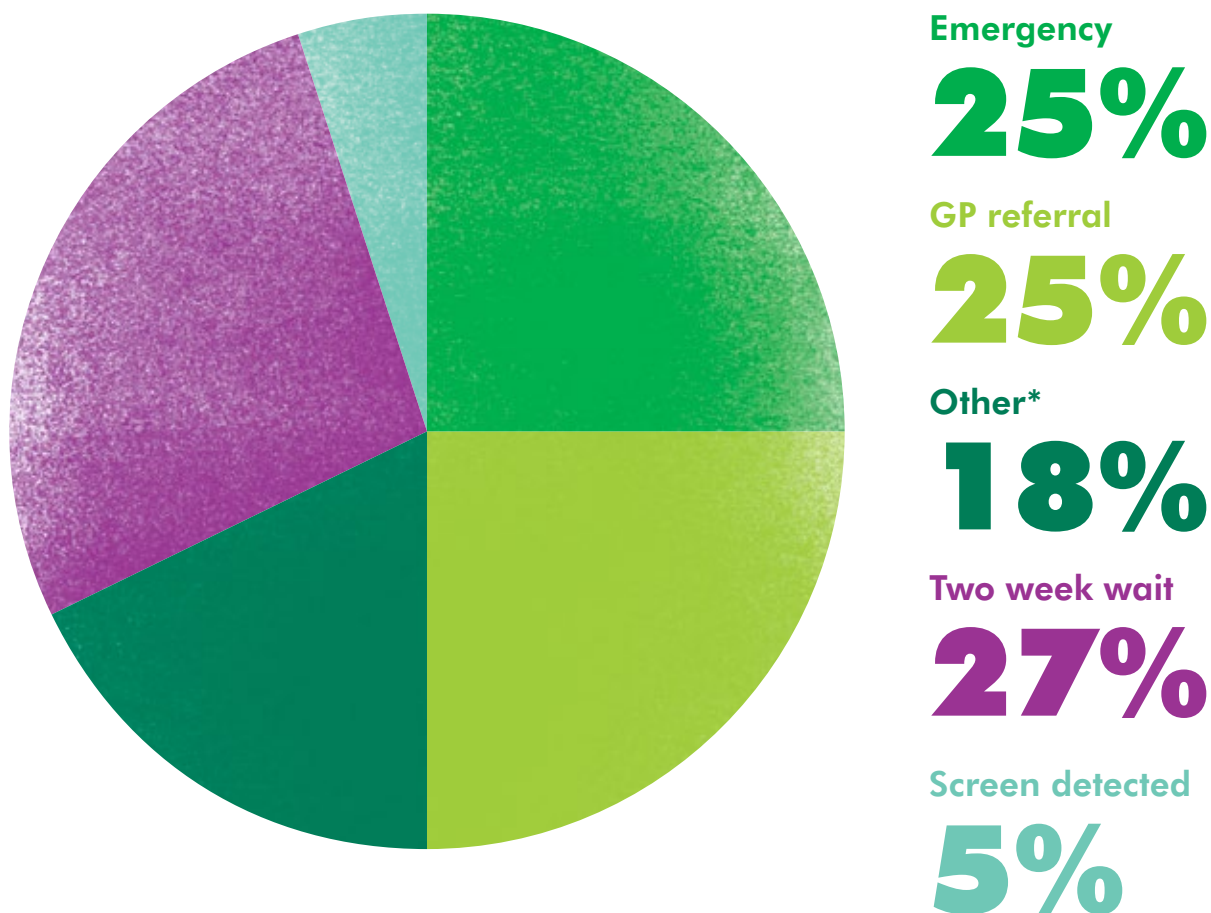
Regular bowel cancer screening has been shown to **avoid approximately 1 in 6 colorectal cancer deaths.** <sup>(27)</sup>

**‘The results from the test showed I had a tumour but cancer still didn’t come into my mind. I knew a tumour meant a mass or a lump but the realisation of a cancer diagnosis didn’t come until later.’**

Matt, 28, South West

## How is colorectal cancer diagnosed? (Routes to diagnosis) <sup>(28)</sup>

Routes to diagnosis, England, 2006-2010



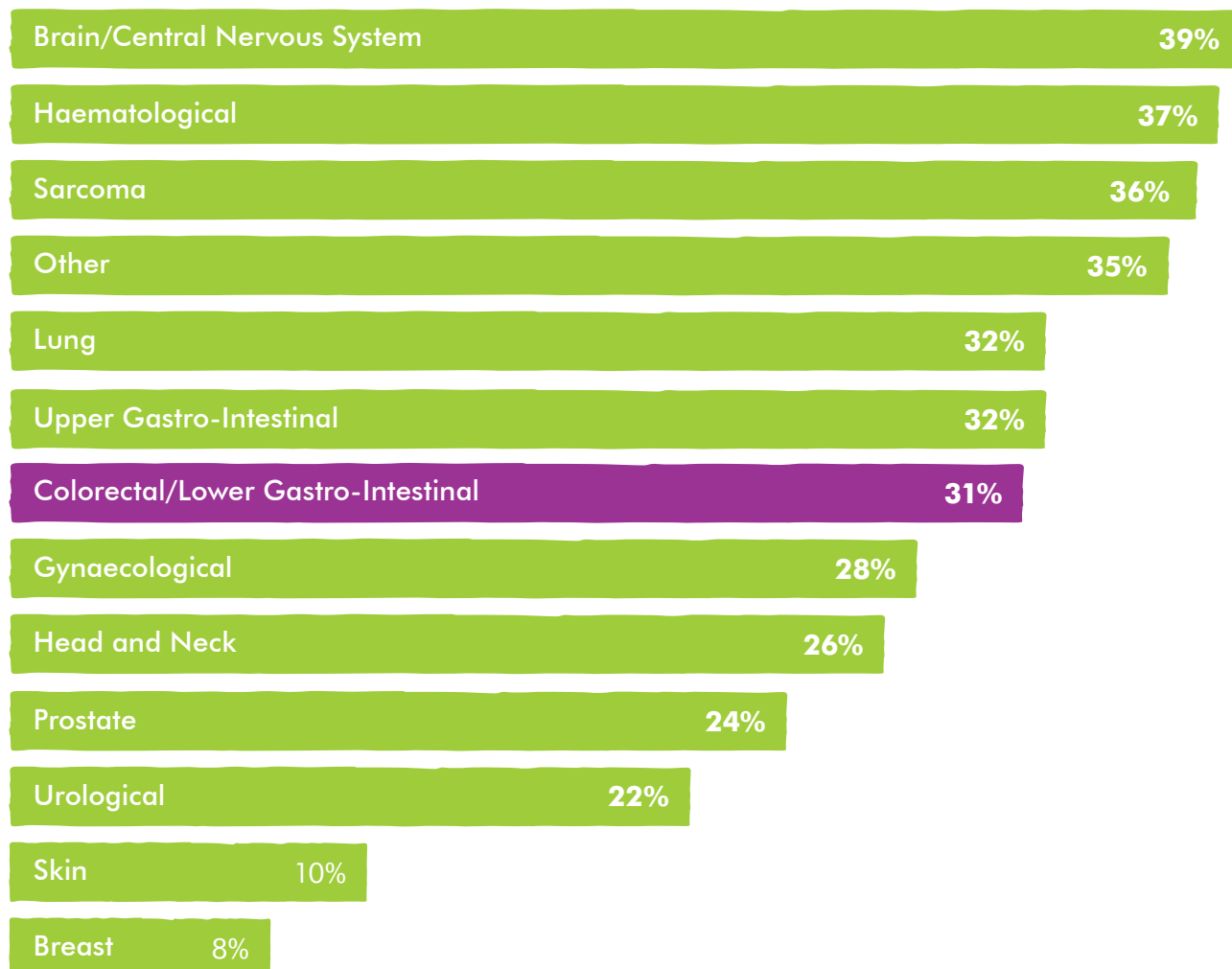
\* 'Other' includes inpatient, outpatient, and unknown routes.

**25% of people newly diagnosed with colorectal cancer were diagnosed via the emergency route. This is slightly higher than the average for all cancers (23%).**



## How many colorectal cancer patients had to see their GP more than twice before they were diagnosed? <sup>(29)</sup>

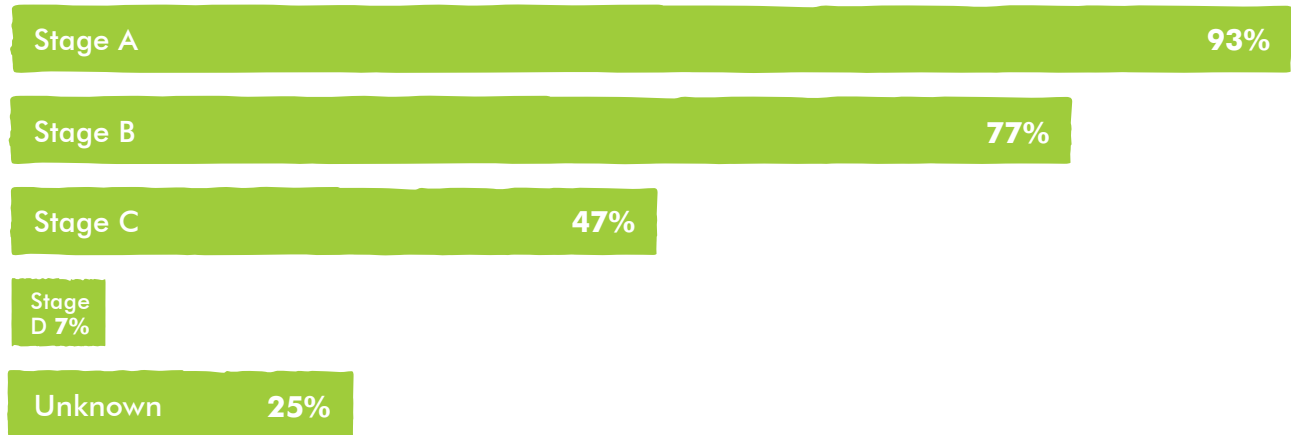
### More than two GP visits, UK, 2013



**31% of people newly diagnosed with colorectal cancer had to see their GP more than twice before they were diagnosed compared with only 8% of breast cancer patients, 24% of prostate cancer patients and 10% skin cancer patients.**

## How does stage at diagnosis relate to probable survival rates? <sup>(15)</sup>

### The impact of Stage at diagnosis on 5-year survival – colorectal cancer



**Colorectal cancer uses slightly different stages** than traditional cancer diagnosis, known as the Dukes' stages<sup>(128)</sup>:

- **Dukes' A:** the cancer is only in the innermost lining of the colon or rectum or slightly growing into the muscle layer;
- **Dukes' B:** the cancer has grown through the muscle layer of the colon or rectum;
- **Dukes' C:** the cancer has spread to at least one lymph node close to the colon or rectum;
- **Dukes' D:** the cancer has spread to somewhere else in the body such as the liver or lung.

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

**How long do people with colorectal cancer have to wait to be referred? <sup>(30)</sup>**

**79% of all cancer patients (not only colorectal) waited less than three months from the time they first thought something might be wrong with them until they first saw a hospital doctor.**

**19% of colorectal cancer patients did not feel that they were seen as soon as necessary and 24% said that their health worsened during the wait to see a hospital doctor.**



## PHYSICAL AND MEDICAL NEEDS

The two principal symptoms for bowel cancer, **rectal bleeding and change in bowel habit, are very similar to other, much less serious problems with the bowel.** Rectal bleeding is also a symptom of haemorrhoids, inflammatory bowel disease and many other non-malignant conditions. <sup>(93) (31) (25)</sup>

One of the difficulties with bowel cancer is that **often there are no symptoms until quite late.** <sup>(32)</sup>

A study of 136 colorectal cancer patients found that **those who experienced rectal bleeding showed longer delays in reporting their symptom** compared to those who did not experience rectal bleeding. <sup>(133)</sup>



## FINANCIAL NEEDS

**Only 51% of colorectal cancer patients were given advice on how to claim financial aid and benefits** by hospital staff. This is compared to 70% of lung cancer patients. <sup>(36)</sup>

**Providing screening free of charge** encourages people to attend. For example, a study in China found that between **82% and 87% of people were willing to attend screening if the colonoscopy was free**, but only between **53% and 56% were willing if they had to pay.** <sup>(37)</sup>

### Not specific to people with colorectal cancer

83% of people with cancer are **financially worse off** because of their diagnosis. <sup>(64)</sup>

Cancer patients are, on average, **£570 a month worse off.** This figure is made up of reduced income and increased costs across the following categories: inpatient and outpatient costs, other healthcare costs, clothing, equipment for and modifications to the home and day-to-day living costs. <sup>(64)</sup>

An estimated **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. <sup>(64)</sup>



## PRACTICAL AND INFORMATION NEEDS

**71% of people with colorectal cancer receive written information about their cancer.**<sup>(40)</sup>

In a 2013 survey, of those colorectal cancer patients who said they needed an explanation of their test results, **80% said they received a completely understandable explanation**, compared to an average of 78% for all cancer patients.<sup>(41)</sup>

**80% of colorectal cancer patients were told that they could bring a family member or friend** with them when they received their diagnosis. This is higher than the average for all cancer patients (74%).<sup>(23)</sup>

### Not specific to people with colorectal cancer

The strongest preference for **information at diagnosis is information about prognosis, disease stage, and treatment options.**<sup>(39)</sup>

A significant proportion of newly-diagnosed patients undergoing cancer treatment have unmet needs. The **most common needs include information needs, physical needs and psychological needs.** The **level of unmet needs is highest after diagnosis** and at the start of treatment, and decreases over time.<sup>(38)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

There are **psychological needs which must be overcome** in order for colorectal cancer screening to be fully effective. Many people **suffer from a large amount of embarrassment** regarding the screening process, both due to the rectal nature of the screening, and from the possibly intimate nature of examinations following the screening.<sup>(42)</sup>

The **leading barrier to colorectal cancer screening is fear.** This could include fear of cancer, an invasive procedure, complications, test results, detected colorectal cancer being too advanced for a favourable prognosis, requirement of a colostomy, belief that colorectal cancer is incurable or family ramifications. **Other leading barriers to colorectal cancer screening are apprehension about bowel preparation, lack of knowledge and pain.**<sup>(43)</sup>

In general after a colorectal cancer diagnosis, men appear more accepting of their diagnosis, whilst the majority of females seem more emotional and more affected by physical side effects. However, in private consultations with nurses, men are more likely to discuss their needs. This suggests that **many men may have been experiencing side effects** and/or psychological distress that **they are reluctant to discuss publicly.**<sup>(44)</sup>

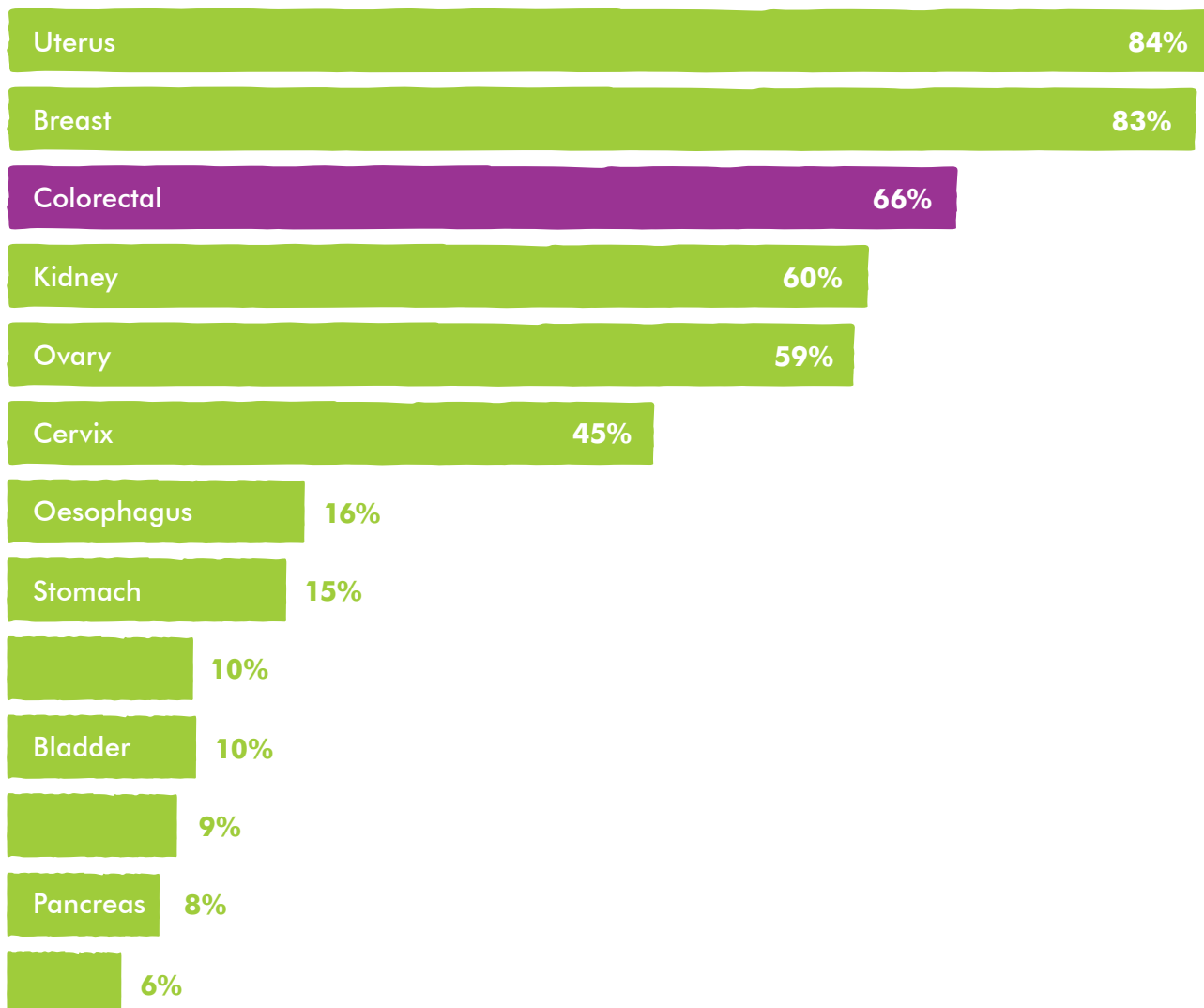
### Not specific to people with colorectal cancer

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, **around half of all people with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life.**<sup>(109)</sup>

# NEEDS AND EXPERIENCES TREATMENT

Percentage of patients who had major surgical resection. <sup>(45)</sup>

Major surgical resection, England, 2004-2006



**66% of colorectal cancer patients had a record of a major surgical resection as part of their treatment.**

## What treatments do colorectal cancer patients get?

**Colorectal cancer can be successfully treated in over 90% of cases, if it is diagnosed at an early stage, before it has had a chance to grow and spread.** <sup>(26)</sup>

### Any active treatment

There are three main types of treatment for colorectal cancer, based on surgery, chemotherapy and radiotherapy techniques. Depending on the stage and location of the cancer, the patient will usually receive one or a combination of these treatments. Colorectal cancer patients may also receive monoclonal antibody treatments if the cancer has spread to other parts of the body. <sup>(46)</sup>

### Surgery

Surgery is the only cure for bowel cancer. Unfortunately almost half of those diagnosed with large bowel cancer are detected too late and the disease has spread too far for surgical cure. <sup>(32)</sup>

In 2012-13, of 31,723 patients diagnosed with colorectal cancer in England and Wales, 64% had a major surgical resection. <sup>(51)</sup>

To be successful, an operation must remove all cancer tissue in the body. However, it is extremely difficult to know if this has been achieved as microscopic amounts can lead to recurrence if left behind. Many people are offered chemotherapy and radiotherapy as well as an operation, with an aim to destroy any cancer not removed by the operation. <sup>(32)</sup>

Traditionally, surgery to remove the very low rectum has often required patients to live with a colostomy (bag) for the rest of their lives. According to HES (Hospital Episode Statistics) 14,064 individuals underwent excision of the rectum in UK hospitals in 2012-13. <sup>(47)</sup>

### Chemotherapy

In colon cancer, chemotherapy is mainly used after surgery. Its aim is to get rid of any remaining cancer cells and reduce the chance of

the cancer coming back in the future (adjuvant chemotherapy). However, it is sometimes given before an operation (neo-adjuvant chemotherapy) or for palliative purposes to patients with metastatic disease. The aim of the treatment is to reduce the size of the cancer, to make it easier to remove during surgery. This may make it possible to avoid having a permanent colostomy. <sup>(48)</sup>

### Radiotherapy

Radiotherapy is often given in combination with chemotherapy, which is called chemoradiotherapy. The chemotherapy makes the cancer cells more sensitive to radiotherapy. <sup>(49)</sup>

Colorectal cancer accounted for 6% of all radiotherapy episodes in England in 2009-10. There were 8,039 radiotherapy episodes and 126,501 radiotherapy attendances for colorectal (lower gastrointestinal) cancer. <sup>(50)</sup>

### Biological Therapy

Biological therapies use substances that occur naturally in the body to destroy cancer cells. Colorectal cancer patients may receive monoclonal antibody treatments if the colorectal cancer has spread to other parts of the body. <sup>(129)</sup>

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

In total there were over 140,000 admissions to NHS hospitals in England (emergency and non-emergency) for colorectal cancer during 2012-13. <sup>(52)</sup>

In 2012-13, of 31,723 patients diagnosed with colorectal cancer in England and Wales, 80% of those who underwent rectal cancer surgery and 65% of those who underwent colon cancer surgery stayed in hospital for longer than five days after their procedure. <sup>(51)</sup>

In 2012-13, emergency admission for patients with colorectal cancer accounted for 36% of all cases. <sup>(52)</sup>

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

Overall the majority receive a combination of surgery and either chemotherapy or radiotherapy.

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

There are currently 274 colorectal cancer clinical nurse specialists (CNSs) in England. This was the second largest proportion of any specialised nurses at 12% of the CNS total, only behind breast cancer at 19%.<sup>(53)</sup>

The percentage of patients seen by a CNS is difficult to determine as a quarter of patients did not have this information recorded. Amongst patients where this information was available, just above 87% of colon cancer patients and 90% of rectal cancer patients were seen by a clinical nurse specialist.<sup>(51)</sup>

Modelling work carried out by Frontier Economics has estimated that 155 additional cancer nurse specialists are needed in England to provide one to one support to all colorectal cancer patients and survivors.<sup>(54)</sup>

Macmillan's internal data suggests that we have (as of June 2014) 121 colorectal cancer Macmillan nurse posts across the UK.<sup>(116)</sup>

Macmillan has produced an 'Impact Brief on Clinical Nurse Specialists'. This is an evidence review, which more fully sets out how our CNSs use their skills and expertise in cancer care to provide technical and emotional support, coordinate care services and 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](http://www.macmillan.org.uk/servicesimpact)

## What does this mean for patients?

Having a CNS available can lead to the detection of cancer recurrence. Nurse-led clinics for colorectal cancer follow-up can achieve the same detection rates of recurrent or metastatic disease as a consultant follow-up, and this prevents consultant colorectal surgical clinic practices from becoming overwhelmed, allowing more focus on patients.<sup>(55)</sup>

People who have undergone bowel surgery often have specific information needs, particularly in relation to living with altered bowel function. Recent research has shown the importance of specialist colorectal cancer nurses in providing information and support; in particular, nurse-led clinics provided continuity of care and information that was tailored to individual need.<sup>(56)</sup>

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

Just under half (47%) of all cancer survivors (all cancer types) have at least one other chronic condition.

Almost a quarter of people living with colorectal cancer experience intestinal problems including hernias and colitis. Around 13% of patients survive between 1 and 5 years post diagnosis but still suffer from additional co-morbidities including intestinal morbidities and heart disease. Only 14% of patients survive for greater than 7 years post diagnosis with no identified medical issues.<sup>(117)</sup>

For colorectal cancer patients, co-morbid conditions diagnosed during the period 6 to 18 months before the diagnosis of colorectal cancer are strongly associated with lower survival at 1 year.<sup>(58)</sup>

Colorectal cancer patients can also have an increased risk of dementia, diabetes and osteoporosis. In some cases this may be caused by cancer treatment, but there is also a link to underlying lifestyle.<sup>(59)</sup>



**‘My cancer treatment involved chemotherapy and surgery. The former continues to affect my life... Feeling weak, sick and achey continues even during the off periods.’**

Sam, 62, South West



## PHYSICAL AND MEDICAL NEEDS

Radiotherapy to the bowel area can cause **side effects such as diarrhoea, nausea and tiredness**, as well as more specific side effects such as **inflammation of the bowel or bladder lining**. These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of treatment. In some people, the bowel or bladder may be permanently affected by the radiotherapy. If this happens, the increased bowel motions and diarrhoea may continue, or they may need to pass urine more often than before, and blood may appear in the urine or in bowel movements.<sup>(49)</sup>

Radiotherapy to the pelvic region can also sometimes cause **painful cracks in the pelvic bones** called pelvic insufficiency fractures. It is more likely to happen in people who have general weakening of their bones as they get older (osteoporosis). It is also more likely in people who are taking hormone therapies or steroids.<sup>(60)</sup>

In an interview study with colorectal cancer patients who needed a colostomy bag, commonly reported side effects included **skin irritation around the stoma and noise from the appliance**.<sup>(62, 74)</sup>

### Not specific to people with colorectal cancer

In a 2013 survey, **79% of cancer patients who had radiotherapy felt staff did everything they could to control side effects** compared to **81% of patients who had chemotherapy**.<sup>(61)</sup>



## FINANCIAL NEEDS

Of those patients who said it was necessary, **80% of colorectal cancer patients said that hospital staff had told them that they could get free prescriptions**, compared to an average of 76% for all cancers.<sup>(65)</sup>

In a recent survey of patients undergoing chemotherapy for colorectal cancer (as well as breast cancer and lymphoma), it was shown that whilst **64% of patients were working when diagnosed, this fell to 29% as treatment progressed**. The most important influencing factor when making decisions about work was the need to concentrate on looking after oneself. If someone with colorectal cancer is unable to work because of their illness, it is extremely likely that their finances will suffer.<sup>(66)</sup>

### Not specific to people with colorectal cancer

Many cancer patients experience **extra costs due to treatment**. Low income, younger age, chemotherapy and living rurally can lead to greater financial hardship.<sup>(63)</sup>

The most common cost that people living with cancer face is getting to and from their hospital appointments. The **cost of getting to and from appointments affects 69% of people with cancer** and costs them, on average, **£170 a month**.<sup>(64)</sup>

**Over a fifth of cancer patients** said that they were affected **by costs for over-the-counter or prescription medicines** despite prescription medicines being free for cancer patients.<sup>(64)</sup>



## PRACTICAL AND INFORMATION NEEDS

83% of colorectal cancer patients were given a choice of different types of treatment before their cancer treatment started. **17% were not given a choice but would have liked one.**<sup>(69)</sup>

**28%** of colorectal cancer patients said that their views about treatment were either only **partly taken into account or not taken into account** at all.<sup>(122)</sup>

Of those colorectal cancer patients saying they needed an explanation, **77% said possible side effects of treatment were definitely explained to them in a way they could understand**, more than most other types of cancer. 84% said that they had received written information about the side effects of treatment and that it was easy to understand.<sup>(70)</sup>

Interviews with colorectal cancer patients who required a colostomy bag showed that many patients identified the period before surgery as crucial to their experience. Those who knew what to expect because they had received good information prior to their procedure were better prepared to deal with the situation afterwards.<sup>(132)</sup>

### Not specific to people with colorectal cancer

**10% of people with cancer were not given enough information** about their condition and treatment, but 2% felt that they were given too much.<sup>(67)</sup>

**83% of cancer patients** who had important question to ask doctors said that they **received answers they could understand all or most of the time**<sup>(68)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

**29%** of people with colorectal cancer **did not feel that they were given enough emotional support** by staff during treatment.<sup>(72)</sup>

A 2014 study found that colorectal cancer patients had **increased levels of depression**, particularly in those who had received neo-adjuvant radiotherapy (radiotherapy treatment prior to surgery).<sup>(131)</sup>

The preoperative experience for patients waiting to undergo surgery for colorectal cancer is often characterised by fear, questions, isolation and uncertainty. Some believe that cancer is 'their problem' and that no-one can help them with it.<sup>(73)</sup>

A common side effect of colorectal cancer treatments is the need for a colostomy bag. Interviews with people with colorectal cancer showed that **patients who had a colostomy bag reported lower self-image and poorer social confidence.**<sup>(74)</sup>

Many colorectal patients require emotional support immediately after their cancer treatment. **Traditional hospital follow-up appointments do not always address patients' psychological, social and information needs**, and many people say that they would prefer to speak to a cancer nurse rather than a consultant.<sup>(56)</sup>

### Not specific to people with colorectal cancer

Amongst all cancer patients the **overall prevalence of psychological distress is 25%** among those who are undergoing, or have just finished, cancer treatment.<sup>(71)</sup>

# 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.<sup>(43)</sup>
- **39%** who completed treatment in 2009/10 say that **no health or social care professional talked them through the needs they might have.** <sup>(37)</sup>
- **94%** experience **physical health condition problems** in their first year after treatment. <sup>(62)</sup>
- **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.<sup>(62)</sup>
- **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. <sup>(62)</sup>
- **40%** with emotional difficulties had **not sought medical help** or other support. <sup>(43)</sup>
- **23%** **lack support from friends and family** during treatment and recovery <sup>(67)</sup>
- **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.** <sup>(67)</sup>

## 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.<sup>(106)</sup>
- 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. <sup>(3)</sup>

## 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

Survivors of colorectal cancer **may experience the effects of cancer and its treatment up to 10 years after diagnosis.** Fatigue and bowel problems such as diarrhea and constipation are particularly noted. <sup>(75)</sup>

In a 2013 survey, of those patients who said they needed it, **66% of colorectal cancer patients said they were definitely given enough care and help from health or social services after leaving hospital,** more than for any other cancer type. <sup>(76)</sup>

Colorectal cancer survivors may have a slightly **lower physical quality of life** than the general population. However, higher levels of physical activity can improve this. <sup>(77)</sup>

A recent Canadian study has shown that only **34% of younger people with colorectal cancer have a discussion with a specialist regarding possible changes to their fertility** following treatment. This is in spite of the fact that recent advances in fertility treatment mean that, with adequate fertility counselling and preparation, **many colorectal cancer patients (in particular women) could preserve their fertility.** <sup>(33) (34)</sup>

### Not specific to people with colorectal cancer

**33% of all cancer survivors find participation in vigorous activities very difficult** or report not being able to do them at all. <sup>(78)</sup>



## FINANCIAL NEEDS

A 2011 study found that long-term survivors of colorectal cancer report financial difficulties up to 10 years after diagnosis. <sup>(80)</sup>

American research suggests that **17% of people who have colorectal cancer are unable to return to work** due to their illness. <sup>(82)</sup>

A recent study has shown how **helpful specialist advice can be to colorectal cancer patients who wish to return to work.** This research involved giving participants an educational leaflet and a face-to-face consultation which included advice and guidance on managing symptoms at work, communication with employer, and information on work ability during and after treatment. Most participants found this intervention useful. In particular, **information and advice on the impact of treatment upon work ability were considered valuable.** <sup>(83)</sup>

### Not specific to people with colorectal cancer

Among cancer patients the **main barrier to accessing benefits is a lack of knowledge about benefit entitlement.** This outweighs factors such as the perceived stigma of benefits and concerns about benefit fraud. Some people affected by cancer do not know that they can claim benefits even when they have completed initial treatment. <sup>(81)</sup>



## PRACTICAL AND INFORMATION NEEDS

Of those patients who said it was necessary, **82% of colorectal cancer patients have been given information about support or self-help groups for people with cancer by hospital staff.** <sup>(85)</sup>

### Not specific to people with colorectal cancer

Many cancer outpatients feel that their **information needs are not being met.** The most common areas of complaint are the lack of genetic information and information about lifestyle changes, and help with worries about spread or recurrence. <sup>(84)</sup>

If recurrence occurs, people with cancer generally express a renewed need for information and support. However, a survey of **patients suffering from a recurrence** showed that only **half of those asked had received adequate information.** <sup>(86)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

After a colostomy reversal, there is often a temporary alteration in bowel function, which can impact on colorectal cancer patient's **physical, social and psychological health** for several months. There is possibility of permanent difficulties for some, significantly affecting their quality of life if left untreated. These effects can lead to more negative post-operative experiences than expected. <sup>(88)</sup>

After 5 years most survivors reach overall quality of life levels comparable with the general population and can identify positive benefits arising as a result of their cancer experience. Despite this, an **increased awareness regarding chronic and late effects of colorectal cancer like bowel problems, depression and distress** is essential to overcome existing shortcomings in cancer care of long-term survivors. <sup>(79) (89)</sup>

### Not specific to people with colorectal cancer

23% of cancer survivors report **poor emotional well-being.** <sup>(78)</sup>

Emotional and psychological long-term side effects of cancer and its treatment include **depression, anxiety and post-traumatic stress disorder (PTSD).** <sup>(87)</sup>

# NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

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

For colorectal cancer patients in particular, the most common form of palliative treatment is chemotherapy, but surgery is also often offered. Chemotherapy has been shown to prolong survival by an average of 9 months. In patients undergoing chemotherapy, surgery did not prolong survival, whereas in patients not undergoing chemotherapy, it improved prognosis by 5 months.<sup>(92)</sup>

## How many colorectal patients are at the end of life?

Macmillan have estimated that around 16,000 colorectal cancer patients are at end of life. Of these, 11,000 were diagnosed less than a year before their disease became terminal.<sup>(90)</sup> Around 20% of people within 6 months of their diagnosis.<sup>(117)</sup>

## 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 the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.”

## How many cancer deaths there are in each setting?

Data on place of death is not available broken down by cancer type. However for all cancers, we know that cancer deaths in England & Wales account for 90% of all deaths 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.<sup>(94)</sup>

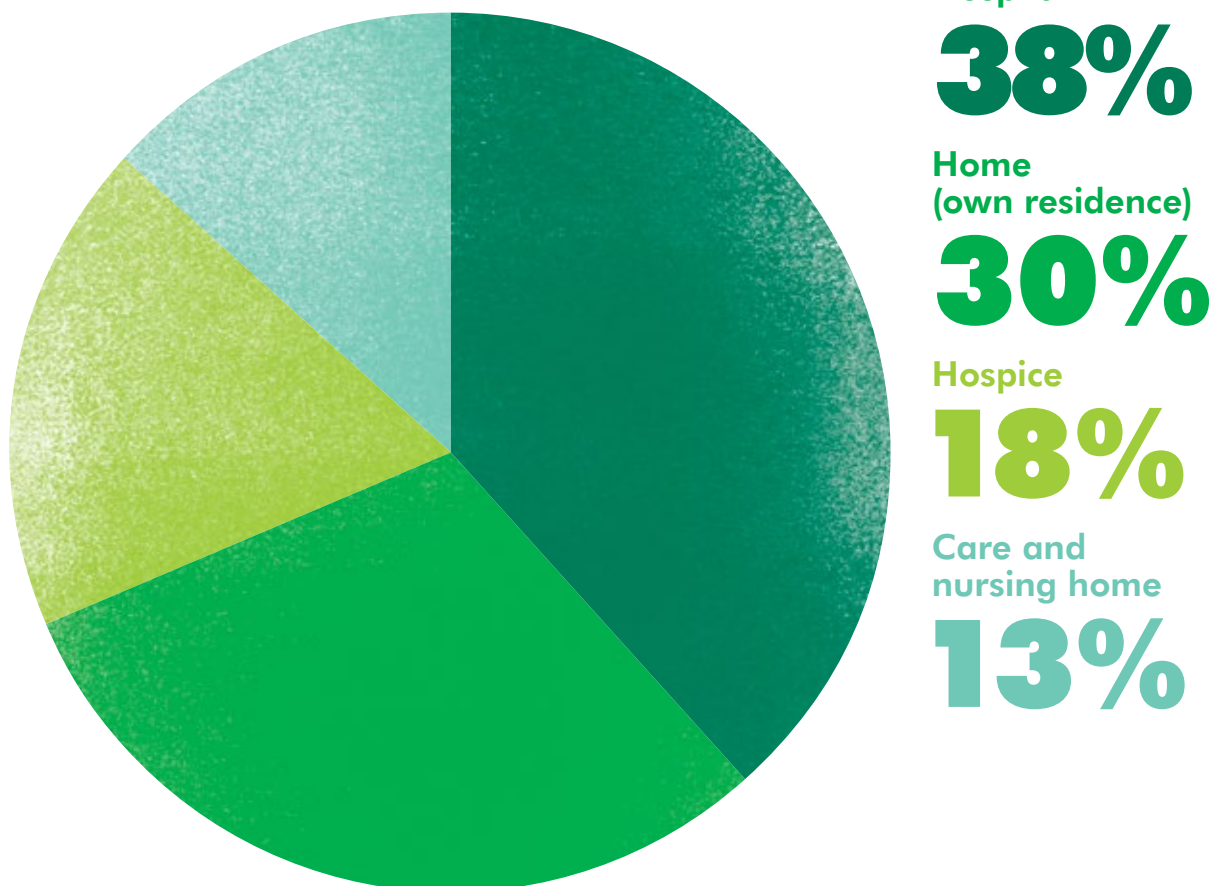
For further information, visit the National Council for Palliative Care website, [www.ncpc.org.uk](http://www.ncpc.org.uk)



## How many cancer deaths there are in each setting?\*

(94)

### Place of death, England, 2012



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

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

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 <sup>(125)</sup>. However, only 30% of those who die from cancer actually die at their home or own residence <sup>(94)</sup>.

In terms of dying in the place of choice, only around one in five people in the general population (or fewer in many local authorities) are supported to die in their own home. If these trends are to continue, over 500,000 people in England will die in a place other than their own home by 2015, suggesting that more needs to be done to ensure that people's wishes about where they want to die are met. <sup>(96)</sup>

**‘On a couple of occasions I was on the verge of phoning the hospice and saying I couldn’t cope and could she go back to the hospice. But I didn’t. Sometimes she would stir from her fitful sleep and she would seem calm and coherent and all she wanted me to do was hold her. How hard was that?’**

William, carer for his wife who died of colorectal cancer, 58, North East



## PHYSICAL AND MEDICAL NEEDS

**Chemotherapy has been shown to prolong survival** in metastatic colorectal cancer patients by an average of 9 months.<sup>(92)</sup>

### Not specific to people with colorectal cancer

457,000 people (not just those with cancer) need good palliative care services every year in England, but around **92,000 people are not being reached.**<sup>(97)</sup>

**Various symptoms are very common in advanced cancer**, with patients experiencing an average of 13 symptoms on admission to hospital.<sup>(98)</sup>

The most common symptoms experienced by more than half of people **during their last two weeks of life include shortness of breath, pain, and confusion.**<sup>(99)</sup>



## FINANCIAL NEEDS

### Not specific to people with colorectal cancer

According to a 2010 Macmillan report, **36% of all people with terminal cancer did not claim the benefits they were entitled to.** This amounts to over £90m.<sup>(101)</sup>

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.<sup>(115)</sup>

**Death of a partner** has been shown to be a **trigger for claiming** income support.<sup>(102)</sup>

**Anxiety about financial insecurity is common in the days and weeks after a partner has died**, but uncertainties can extend into the first or second year after death.<sup>(130)</sup>

A study on the financial impact has revealed that, after a partner's death, the **number of women feeling financially worse off doubled** from 24% to 48%. The **number of men who felt worse off also increased** from 19% to 30% as a result of their partner's death.<sup>(103)</sup>



## PRACTICAL AND INFORMATION NEEDS

A recent US study of colorectal and lung cancer patients at end of life has shown that **although most patients discuss end of life care planning with doctors before death, many discussions occur during acute hospital care**, with providers other than oncologists, and late in the course of illness.<sup>(106)</sup>

### Not specific to people with colorectal 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, **31% of doctors tend to over-estimate the survival times of terminally ill cancer patients.**<sup>(104)</sup>

Those who are **older, male, from ethnic minorities, not married, lacking in home care or socioeconomically disadvantaged** are all **less likely to access community palliative care services.**<sup>(105)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

### Not specific to people with colorectal cancer

Cancer patients approaching death suffer more **psychological distress.**<sup>(71)</sup> This is also a highly distressing time for carers.<sup>(100)</sup>

For cancer patients the **overall prevalence of psychological distress is 59% amongst those receiving palliative care.**<sup>(71)</sup>

**83%** of people say they are scared of dying in pain, while **67%** say they are scared of dying alone, and **62%** are scared of being told they are dying.<sup>(107)</sup>

### Not specific to people with colorectal cancer

A survey by Macmillan of people who have received a cancer diagnosis found that **57% would like to spend the last weeks and days of their life at home.** This rose to 73% if all their concerns, which included access to round the clock care, about dying at home were addressed. Only 1% of respondents would choose to die in hospital.<sup>(95)</sup>

# LIFESTYLE AND PERCEPTIONS

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

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

- Colorectal cancer affects both men and women, with a slightly higher level of diagnosis amongst men. <sup>(8) (9) (10) (11)</sup>
- White people are significantly more likely to be diagnosed with colorectal cancer than people in Asian, Black, Chinese or mixed ethnic groups. <sup>(17)</sup>
- In the UK between 2010 and 2012, an average of 81% of colorectal cancer deaths were in people aged 65 years and over. <sup>(7)</sup>

## **What is the demographic breakdown/market segmentation of the 290,000 people living with colorectal cancer in the UK?** <sup>(119)</sup>

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 colorectal 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 colorectal cancer patients, the following MOSAIC\* group shows significantly greater than average representation:

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

**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 homes, 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 show greater than average representation amongst colorectal cancer patients:

**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. Often in their 40s, 50s or 60s, and can be in successful careers. Most are married and living in a spacious family home. Many have children who are at university or starting their careers.

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

**Group D (Small Town Diversity):** People in Group D typically live in medium sized and smaller towns in neighbourhoods of older housing. These are people who tend to have strong roots in their local community, whose friends and family live nearby. Incomes are restricted by the relatively low wage rates offered by employers situated in small towns. A significant number are self-employed.

## What are the typical leisure activities/where do they shop/what media they consume/what do they do? <sup>(118)</sup>

- 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 B: Professional Rewards: Holidays, cruises and day trips are popular activities, as is going to the theatre and to concert halls. People in this group tend to read the broadsheet newspapers, particularly *The Daily Telegraph* and the *Sunday Times*.
- Group C: Rural Solitude: Many people within this group may spend time in their gardens, or growing fruit and vegetables. There is less frequent visiting of theatres and cinemas than other groups. Many people in this group enjoy outdoor pursuits such as fishing, walking, etc.
- Group D: Small Town Diversity: People in this group may focus their leisure time on home improvement, or meeting up with friends in homes and gardens, and in pubs at meetings of local associations. Many share trips to visit local sites of historical or environment distinction.

\*For more detail and definitions see [www.experian.co.uk/business-strategies/mosaic-uk-2009.html](http://www.experian.co.uk/business-strategies/mosaic-uk-2009.html)

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

### Before:

**'It was the shock of my life. I'm the sort of person who has always eaten healthily, I was jogging two-and-a-half miles Monday to Friday. Even the doctors were surprised.'**

Evelyn, 69, North West.

**'I was a total idiot for ignoring my health. I honestly think I was trying to be the big man and shirk it off as nothing important... My stubbornness could have cost me my life.'**

Ejike, 32, South East.



**After:**

**'Now and again, the little demon tries to create doubt and negativity, with negative thoughts such as... it'll come back with a vengeance... it'll get you, you're going to die, so what's the point.'**

Meg, 31, North West

**'After my experiences of the last 18 months or so, issues at work seem so trivial and insignificant that I now find it hard to be interested in what I do.'**

James, 43, Scotland

**'Since his death I have been filling in forms and trying to get so many things sorted out. It is just awful what is expected of people when they are dealing with loss and bereavement.'**

Emily, South East

## How does people's fear of cancer compare to actual survival rates? <sup>(6, 111)</sup>

**Leukaemia 47%**

2%

**Ovarian 46%**

3%

**Testicular 97%**

3%

**Oesophageal 15%**

4%

**Prostate 82%**

5%

**Pancreatic 5%**

5%

**Breast 85%**

7%

**Lung 11%**

9%

**Bowel 57%**

10%

**Brain 19%**

16%

Note: Five-year survival figures for cancers affecting both men and women were estimated by taking the mean average of the survival rates for men and women combined.



**5-year survival estimates %**



**Proportion of people fearing %**

**Fear of bowel cancer is fairly high amongst the general public: it is the second most feared cancer after brain cancer.**

**It is more feared than both lung cancer and leukaemia which have worse survival patterns.**

**This could be because of increased awareness as a result of screening campaigns.**



## What does this mean? What do we want to change in terms of people's perceptions? <sup>(112)</sup> <sup>(113)</sup>

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

- The media show more focus on the causes and pre-diagnosis stage of the colorectal cancer journey, with an emphasis on words such as 'aspirin', 'IBS' and 'screening'. The online community features more words about cancer treatment. 'Chemo' is prominent, as are 'effects', 'hair' and 'tiredness'.
- The words such 'hoping', 'trying' and 'anxious' in the online community discussions reveals the emotional toll of a colorectal cancer diagnosis. The media focuses more on the practical side of cancer through the use of words such as 'NHS', 'patients' and 'department'.
- Both word clouds contain words relating to time, with 'months' and 'years' featuring in both. However, although in the online community discussions words relating to the short term such as 'days', 'tomorrow' and 'week' appear with greater frequency. This suggests that colorectal cancer patients are most concerned with their immediate treatment.
- The media demonstrates much more of an interest into cancer research than the online colorectal cancer group. This is clear from words such as 'research', 'university' and 'published', none of which are present in the community support group.

# REFERENCES, SOURCES, NOTES AND CAVEATS

## Quotes

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

## References

1. Bowel Cancer UK. *What is bowel cancer?* <http://www.bowelcanceruk.org.uk/understanding-bowel-cancer/what-is-bowel-cancer/> (Accessed September 2014)
2. Beating Bowel Cancer. *What is bowel cancer?* <http://www.beatingbowelcancer.org/what-bowel-cancer> (Accessed September 2014)
3. Macmillan Cancer Support. *Colon and rectal cancer.* <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Colonandrectum/Colonandrectalcancer.aspx> (Accessed September 2014)
4. Cancer Research UK. *Bowel Cancer Incidence Statistics.* <http://info.cancerresearchuk.org/cancerstats/types/bowel/incidence/> (Accessed September 2014)
5. UK prevalence in 2015 estimated from Maddams J, Utley M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer.* 2012; 107: 1195-1202. (Scenario 1 presented here) Split by nation estimated from Maddams J., Thames Cancer Registry, personal communication. See also Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer.* 2009. 101: 541-547
6. Office for National Statistics. *Cancer Survival in England: Patients diagnosed 2007–2011 and followed up to 2012.* <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-320365> (Accessed September 2014)
7. Cancer Research UK. *Bowel Cancer mortality statistics.* <http://info.cancerresearchuk.org/cancerstats/types/bowel/mortality/> (Accessed September 2014)
8. Office for National Statistics. *Cancer Registration Statistics England 2012.* <http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--43--2012/rft-cancer-registration-statistics.xls> (Accessed September 2014)
9. ISD Scotland. *Cancer Incidence in Scotland 2012.* <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233> (Accessed September 2014)
10. Welsh Cancer Intelligence and Surveillance Unit. *Incidence Trends.* <http://www.wcisu.wales.nhs.uk/official-statistics-exel-files-of-trend> (Accessed September 2014)
11. Northern Ireland Cancer Registry. *Cancer Data 2012.* <http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/> (Accessed September 2014)
12. Office for National Statistics and London School of Hygiene and Tropical Medicine. *Mortality statistics. Deaths registered in England and Wales 2012.* <http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/dr-tables-2012.xls>
13. ISD Scotland. *Cancer mortality in Scotland 2012.* <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233> (Accessed September 2014)
14. Welsh Cancer Intelligence and Surveillance Unit. *Mortality Trends.* <http://www.wcisu.wales.nhs.uk/official-statistics-exel-files-of-trend> (Accessed September 2014)

15. The King's Fund. *How to improve cancer survival: Explaining England's relatively poor rates*. [www.kingsfund.org.uk/document.rm?id=9149](http://www.kingsfund.org.uk/document.rm?id=9149) (Accessed September 2014)
16. NCIN. *Evidence to March 2010 on cancer inequalities in England*. <http://www.ncin.org.uk/view?rid=169> (Accessed September 2014)
17. NCIN. *Cancer Incidence and Survival by Major Ethnic Group, England, 2002-2006*. <http://www.ncin.org.uk/view?rid=75> (Accessed September 2014)
18. National Institute for Health and Care Excellence. *Referral Guidelines for Suspected Cancer*. <https://www.nice.org.uk/guidance/CG27/chapter/1-Guidance> (Accessed September 2014)
19. Cancer Research UK. *Poor men more likely to die from bowel cancer*. <http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2011-11-06-poor-men-more-likely-to-die-from-bowel-cancer> (Accessed September 2014)
20. Von Wagner C, et al. Inequalities in participation in an organized national colorectal cancer screening programme: results from the first 2.6 million invitations in England. *Int J Epidemiol*. 2011. 40: 712-718
21. NCIN. *Cancer e-Atlas: NHS Health Boundaries*. [http://www.ncin.org.uk/cancer\\_information\\_tools/eatlas/network/atlas.html?select=Eav&indicator=i0](http://www.ncin.org.uk/cancer_information_tools/eatlas/network/atlas.html?select=Eav&indicator=i0) (Accessed September 2014)
22. Robb K, et al. Public awareness of cancer in Britain: a population-based survey of adults. *Brit J Cancer*. 2009. 101:518-23
23. NHS England. *Cancer Patient Experience Survey 2013*. Q11. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
24. Macmillan Cancer Support. *How colon and rectal cancers are diagnosed*. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Colonandrectum/Symptomsdiagnosis/Diagnosis.aspx> (Accessed September 2014)
25. Hamilton W, et al. Diagnosis of colorectal cancer in primary care: the evidence base for guidelines. *Fam Pract*. 2004. 21(1):99-106.
26. Cancer Research UK. *Bowel Cancer Key Stats*. <http://info.cancerresearchuk.org/cancerstats/keyfacts/bowel-cancer/cancerstats-key-facts-on-bowel-cancer> (Accessed September 2014)
27. Hewitson P, et al. Screening for colorectal cancer using the faecal occult blood test, Hemoccult. *Cochrane Database of Systematic Reviews*. Updated 2010. doi:10.1002/14651858.CD001216.pub2
28. NCIN. *Routes to diagnosis 2006-2010*. <http://www.ncin.org.uk/view?rid=2645> (Accessed September 2014)
29. NHS England. *Cancer Patient Experience Survey 2013*. Q1. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
30. NHS England. *Cancer Patient Experience Survey 2013*. Q2 and Q4. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
31. Beating Bowel Cancer. *Bowel Cancer Symptoms*. <http://www.beatingbowelcaneacer.org/bowel-cancer-symptoms> (Accessed September 2014)
32. Bowel & Cancer Research. *Bowel (colorectal) cancer*. <http://www.bowelcancerresearch.org/bowel-problems/bowel-cancer/> (Accessed September 2014)
33. Kumar A, et al. Fertility risk discussions in young patients diagnosed with colorectal cancer. *Curr Oncol*. 2012. 19(3):155-159
34. O'Neill M T, et al. Topic Update: Effects of Colorectal Cancer Treatments on Female Fertility and Potential Methods for Fertility Preservation. *Dis Colon Rectum*. 2011. 54:(3) 363-369
35. Macmillan Cancer Support/YouGov online survey of 1,740 UK adults living with cancer. Fieldwork conducted 26 July-9 August 2010. Survey results unweighted.

36. NHS England. *Cancer Patient Experience Survey 2013*. Q27. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
37. Chan-Rong C, et al. Barriers to colorectal cancer screening: A case-control study. *World J Gastroenterol*. 2009. 15(20): 2531-2536
38. Puts MTE, et al. A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. *Support Care Cancer*. 2012. 20:1377-1394.
39. Tariman J, et al. Information needs priorities in patients diagnosed with cancer: a systematic review. *J Adv Pract Oncol*. 2014. 5(2): 115-122.
40. NHS England. *Cancer Patient Experience Survey 2013*. Q14. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
41. NHS England. *Cancer Patient Experience Survey 2013*. Q9. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
42. Consedine NS, et al. The many faeces of colorectal cancer screening embarrassment: Preliminary psychometric development and links to screening outcome. *Brit J Health Psychol*. 2011. 16: 559 – 579
43. Jones RM, et al. Patient-Reported Barriers to Colorectal Cancer Screening: A Mixed Methods Analysis. *Am J Prev Med*. 2010. 38(5) 508-516.
44. McCaughan E, et al. Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer at diagnosis and during surgery. *J Adv Nurs*. 2011. 67 (7): 1591-1600.
45. NCIN. *Major surgical resections, England, 2004-2006*. 2011. [www.ncin.org.uk/view?rid=540](http://www.ncin.org.uk/view?rid=540) (Accessed September 2014)
46. Beating Bowel Cancer. *What Happens Now?* <http://www.beatingbowelcancer.org/what-happens-now> (Accessed September 2014)
47. Health and Social Care Information Centre. *Hospital Episode Statistics, Admitted Patient Care England, 2012-13*. <http://www.hscic.gov.uk/catalogue/PUB12566/hosp-epis-stat-admi-proc-2012-13-tab.xlsx> (Accessed September 2014)
48. Macmillan Cancer Support. *Chemotherapy for rectal cancer*. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Colonandrectum/Treatingrectalcancer/Chemotherapy/Chemotherapy.aspx> (Accessed September 2014)
49. Macmillan Cancer Support. *Radiotherapy side effects*. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Colonandrectum/Treatingrectalcancer/Radiotherapy/Radiotherapysideeffects.aspx> (Accessed September 2014)
50. National Cancer Action Team. *RTDS Annual Report 2009-2010*. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215528/dh\\_128868.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215528/dh_128868.pdf) (Accessed September 2014)
51. Health and Social Care Information Centre. *National Bowel Cancer Audit Progress Report*. 2014. <http://www.tripartite2014.org/content/uploads/2013/05/NBOCAP-2014-Progress-Report.pdf> (Accessed September 2014)
52. Health and Social Care Information Centre. *Hospital Episode Statistics, Admitted Patient Care England, 2012-13*. <http://www.hscic.gov.uk/searchcatalogue?productid=13264&q=title%3a%22Hospital+Episode+Statistics%2c+Admitted+patient+care+-+England%22&sort=Relevance&size=10&page=1#top> (Accessed September 2014)
53. NCAT. *Cancer CNS census*. 2011. [www.cfwi.org.uk/2014-adult-cancer-specialist-nurse-census/at\\_download/attachment4](http://www.cfwi.org.uk/2014-adult-cancer-specialist-nurse-census/at_download/attachment4) (Accessed September 2014)
54. Frontier Economics. *One to one support for cancer patients*. 2010. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216683/dh\\_122521.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216683/dh_122521.pdf) (Accessed September 2014)



55. McFarlane K, et al. The process and outcomes of a nurse-led colorectal cancer follow-up clinic. *Colorectal Dis.* 2012. 14(5):245-249.
56. Beaver K, et al. An exploratory study of the follow-up care needs of patients treated for colorectal cancer. *J Clin Nurs.* 2010. 19 (23-24):3291-3300
57. Elliot J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *Brit J Cancer.* 2011. 105:511-20.
58. Shack LG, et al. Does the timing of co-morbidity affect colorectal cancer survival? A population based study. *Postgrad Med J.* 2010. 86 (1012): 73-78.
59. Khan N F, et al. Long-term health outcomes in a British cohort of breast, colorectal and prostate cancer survivors: a database study. *Brit J Cancer.* 2011. 105(1): 29-37.
60. Cancer Research UK. *Abdominal or pelvic radiotherapy side effects: pain.* <http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/radiotherapy/side-effects/abdominal/stomach-or-pelvic-radiotherapy-side-effects-pain> (Accessed September 2014)
61. NHS England. *Cancer Patient Experience Survey 2013. Q57 and Q58.* <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
62. Healthtalkonline.org. *Learning to manage a stoma.* <http://healthtalkonline.org/peoples-experiences/cancer/colorectal-cancer/learning-manage-stoma> (Accessed September 2014)
63. Brooks J, et al. Additional financial costs borne by cancer patients: A narrative review. *Eur J Oncol Nurs.* 2011. 15(4):302-310
64. Macmillan Cancer Support. *Cancer's Hidden Price Tag: Revealing the Costs Behind the Illness.* 2013. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Costofcancer/Cancers-Hidden-Price-Tag-report-England.pdf> (Accessed September 2014)
65. NHS England. *Cancer Patient Experience Survey 2013. Q28.* <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
66. Shewbridge A, et al. Working while receiving chemotherapy: a survey of patients' experiences and factors that influence these. *Eur J Cancer Care.* 2012. 21(1):117-123.
67. NHS England. *Cancer Patient Experience Survey 2013. Q67.* <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
68. NHS England. *Cancer Patient Experience Survey 2013. Q37.* <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
69. NHS England. *Cancer Patient Experience Survey 2013. Q15.* <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
70. NHS England. *Cancer Patient Experience Survey 2013. Q17 and Q18.* <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
71. Gao W, et al. Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications. *Eur J Cancer.* 2010. 46 (11): 2036-2044
72. NHS England. *Cancer Patient Experience Survey 2013. Q60.* <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
73. Worster B, Holmes S. The preoperative experience of patients undergoing surgery for colorectal cancer: A phenomenological study. *Eur J Oncol Nurs.* 2008. 12(5): 418-424.

74. Healthtalkonline.org. *Feelings about stomas*. <http://healthtalkonline.org/peoples-experiences/cancer/colorectal-cancer/feelings-about-stomas> (Accessed September 2014)
75. Caravati-Jouvencaux A, et al. Health-Related quality of life among long-term survivors of colorectal cancer: a population-based study. *Oncologist*. 2011. 16 (11): 1626-1636
76. NHS England. *Cancer Patient Experience Survey 2013*. Q56. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
77. Buffart M L, et al. Self-Reported Physical Activity: Its Correlates and Relationship with Health- Related Quality of Life in a Large Cohort of Colorectal Cancer Survivors. *PLoS One*. 2012. 7(5) e361-64.
78. Elliott J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *Brit J Cancer*. 2011. 105: S11-S20.
79. Jansen L, et al. Quality of life among long-term ( $\geq 5$  years) colorectal cancer survivors – Systematic review. *Eur J Cancer*. 2010. 46: 2879-2888.
80. Jansen L, et al. Health-related quality of life during the 10 years after diagnosis of colorectal cancer: a population-based study. *JCO*. 2011. 29(24): 3263-3269.
81. Moffatt S, et al. “Done more for me in a fortnight than anybody done in all me life.” How welfare rights advice can help people with cancer. *BMC Health Serv Res*. 2010. 10:259.
82. Earle CC, et al. Employment Among Survivors of Lung Cancer and Colorectal Cancer. *J Clin Oncol*. 2010. 28(10):1700-1705.
83. Bains M, et al. Return-to-Work Guidance and Support for Colorectal Cancer Patients: A Feasibility Study. *Cancer Nurs*. 2011. 34 (6):1-12.
84. Morrison V, et al. Common, important, and unmet needs of cancer outpatients. *European J Oncol Nurs*. 2012. 16(2):115-123
85. NHS England. *Cancer Patient Experience Survey 2013*. Q25. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
86. Macmillan Cancer Support. *Macmillan survey of Cancer Voices: exploring information and support needs*. 2010. Macmillan Cancer Support, London.
87. Macmillan Cancer Support. *Throwing light on the consequences of cancer and its treatment*. 2013. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Throwinglightontheconsequencesofcanceranditstreatment.pdf> (Accessed September 2014)
88. Taylor C, et al. Quality of life following reversal of temporary stoma after rectal cancer treatment. *Eur J Oncol Nurs*. 2011. 15(1):59-66
89. Jansen L, et al. Benefit finding and post-traumatic growth in long-term colorectal cancer survivors: prevalence, determinants, and associations with quality of life. *Brit J Cancer*. 2011. 105: 1158–1165.
90. Maher J, et al. How many people need expert symptom assessment but are not in the last year of life? *BMJ Support Palliat Care*. 2012. 2: 8
91. Maddams J, et al. The cancer burden in the United Kingdom in 2007 due to radiotherapy. *Int J Cancer*. 2011. 192(12):2885-93.
92. Costi R, et al. Impact of Palliative Chemotherapy and Surgery on Management of Stage IV Incurable Colorectal Cancer. *Ann Surg Oncol*. 2010. 17(2): 432-440
93. Beating Bowel Cancer. What else could it be? <https://www.beatingbowelcancer.org/what-else-could-it-be> (Accessed September 2014)
94. Macmillan Cancer Support. February 2010 online survey of 1,019 UK adults living with cancer. Survey results have not been weighted.

95. Macmillan Feb 2010 online survey of 1,019 people living with cancer. Respondents were sourced from Macmillan's database of people affected by cancer in the UK who have agreed to take part in research. Survey results are unweighted.
96. MHP Health Mandate. *An Atlas of Variations in Social Care*. 2012. <http://www.mhpc.com/sites/default/files/pictures/An%20atlas%20of%20variations%20in%20social%20care%20June%202012.pdf> (Accessed September 2014)
97. Hughes-Hallett T, et al. Independent Palliative Care Funding Review. 2011. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215107/dh\\_133105.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf) (Accessed September 2014)
98. Spichiger E, et al. Symptom prevalence and changes of symptoms over ten days in hospitalized patients with advanced cancer: A descriptive study. *EJON*. 2011. 15(2): 95-102.
99. Kehl KA, et al. A Systematic Review of the Prevalence of Signs of Impending Death and Symptoms in the Last 2 Weeks of Life. *Am J Hosp Palliat Care*. 2013. 30(6): 601-616.
100. Macmillan Cancer Support/Ipsos MORI. *More than a Million: Understanding the UK's carers of people with cancer*. 2011. [http://www.macmillan.org.uk/Documents/Cancerinfo/Ifsomeoneelsehascancer/More\\_than\\_a\\_million.pdf](http://www.macmillan.org.uk/Documents/Cancerinfo/Ifsomeoneelsehascancer/More_than_a_million.pdf) (Accessed September 2014).
101. Macmillan Cancer Support. *Cancer patients lose out on millions of unclaimed benefits*. [http://www.macmillan.org.uk/Aboutus/News/Latest\\_News/CancerPatientsLoseOutOnMillionsOfUnclaimedBenefits.aspx](http://www.macmillan.org.uk/Aboutus/News/Latest_News/CancerPatientsLoseOutOnMillionsOfUnclaimedBenefits.aspx) (Accessed September 2014)
102. Shaw A, et al. *Moving Off Income Support: Barriers and bridges*. <http://webarchive.nationalarchives.gov.uk/20130314010347/http://research.dwp.gov.uk/asd/asd5/rrep053.pdf> (Accessed September 2014)
103. Corden A, et al. Death of a partner. *Bereavement Care*, 2010. 29(1): 23-28.
104. Gwilliam B, et al. Prognosticating in patients with advanced cancer – observational study comparing the accuracy of clinicians' and patients' estimates of survival. *Ann Oncol*. 2013. 24(2): 482-488.
105. Walshe C, et al. Patterns of Access to Community Palliative Care Services: A Literature Review. *J Pain Symptom Manage*. 2009. 37(5): 884-912
106. Mack JW, et al. End-of-Life Care Discussions Among Patients With Advanced Cancer A Cohort Study. *Ann Intern Med*. 2012. 156 (3): 204-65
107. National End of Life Care Programme. *What do we know now that we didn't know a year ago?* [http://www.endoflifecare-intelligence.org.uk/resources/publications/what\\_we\\_know\\_now.aspx](http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx) (Accessed September 2014)
108. Wise J. Population screening in Scotland reduces bowel cancer deaths. *BMJ*. 2011. 343: d7304.
109. National Institute for Clinical Excellence. *Supportive and Palliative care: The manual*. <http://www.nice.org.uk/guidance/csgsp/resources/supportive-and-palliative-care-the-manual-2> (Accessed September 2014)
110. Beating Bowel Cancer UK. *Causes of bowel cancer*. <http://www.beatingbowelcancer.org/causes-bowel-cancer> (Accessed September 2014)
111. Cancer Research UK. *People Fear Cancer More Than Other Serious Illnesses*. <http://info.cancerresearchuk.org/news/archive/pressrelease/2011-15-08-fear-cancer-more-than-other-diseases> (Accessed September 2014)
112. Macmillan Cancer Support. 2012. Word cloud created on wordle.net from Macmillan's online community from the 30 most recent posts listed under "recent group activity for the Colorectal Cancer group, on 29 June 2012)
113. Macmillan Cancer Support/Factiva. 2012. Word cloud formed from an analysis on 09 July 2012 using [www.wordle.net](http://www.wordle.net) of the 100 most recent UK national daily newspaper articles where the key words of "colorectal cancer" appeared at least once. The most frequent words are shown in larger fonts than less frequent words. Dates ranged from 20 March 2012 to 07 July 2012. UK national daily newspapers included: *The Metro, The Times, The Daily Mail, The Mirror, The Sun, The Daily Express, The Guardian, The Telegraph and The Independent*.

114. Macmillan Cancer Support. *Living after diagnosis: Median cancer survival times*. <http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/LivingAfterCancerMedianCancerSurvivalTimes.pdf> (Accessed September 2014)
115. Macmillan Cancer Support. *Getting travel insurance when you have been affected by cancer*. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Practicalissues/Travel/Gettingtravelinsurance.aspx> (Accessed September 2014)
116. Macmillan Cancer Support. Internal PS@Mac data.
117. Wells J., et al. *Using clinical attendance patterns to determine likely survivorship journey in England*. NCIN Conference 2011. Data are for patients in England with a diagnosis of colorectal cancer in quarter 2 2001, followed up to the end of 2007. A sample of nearly 6,000 people were taken from the National Cancer Data Repository (NCDR). These data relate to health problems as identified by NHS inpatient hospital activity. Through the NCDR patients' registry data are linked to NHS inpatient hospital activity data to ascertain if patients are admitted to hospital and for what condition. Data are being prepared for academic publication – paper in preparation.
118. Macmillan Cancer Support analysis, July 2012. Data was extracted from Hospital Episode Statistics (HES) database for the NHS financial year 2010/11 at episode level for all types of cancer, excluding C44 (other malignant neoplasms of skin). The data covers England only, but it is assumed that the patterns seen in England will be broadly similar in the other UK nations. The earliest hospital admittance was taken for each person within the NHS 2010/11 financial year. MOSAIC UK profiles were created for hospital admittances for people living with each of the top 10 cancer types (and a further profile for all other cancers combined, ie the rarer cancers) and compared to the base population. Base population (ie population of England) was population at the mid-point of 2010. HES records where the age of the patient was not recorded were removed from all analyses. Only records with a valid MOSAIC Type were analysed, however the number of these was small, and limited largely to data on people aged 0-14. MOSAIC profiles are built from 440 data elements, collated by Experian Ltd. For further details, visit [www.experian.co.uk/business-strategies/mosaic-uk-2009.html](http://www.experian.co.uk/business-strategies/mosaic-uk-2009.html)
119. Prevalence in 2015 estimated from Maddams et al. (2012). Prevalence in 2030 and 2040 taken directly from Maddams J, Utley M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. *British Journal of Cancer*. 2012; 107: 1195-1202. (Scenario 1 presented here)
120. National Cancer Survivorship Initiative. *Assessment and care planning*. <http://www.ncsi.org.uk/what-we-are-doing/assessment-care-planning/> (Accessed September 2014)
121. NHS England. *Cancer Patient Experience Survey 2013*. Q20. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
122. NHS England. *Cancer Patient Experience Survey 2013*. Q16. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/> (Accessed September 2014)
123. Cancer Research UK. *Types of bowel cancer*. <http://www.cancerresearchuk.org/cancer-help/type/bowel-cancer/about/types-of-bowel-cancer> (Accessed September 2014)
124. Cancer Research UK. *Bowel Cancer – survival statistics*. <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/survival/> (Accessed July 2013).
125. Office for National Statistics. *Additional analysis from the National Bereavement Survey (VOICES), 2012*. 2013. <http://www.ons.gov.uk/ons/about-ons/business-transparency/freedom-of-information/what-can-i-request/published-ad-hoc-data/health/september-2013/cancer-deaths-2012.xls> (Accessed September 2014)
126. Macmillan Cancer Support. *Facing the Fight Alone*. 2013. [http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Isolated\\_cancer\\_patients\\_media\\_report.pdf](http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Isolated_cancer_patients_media_report.pdf) (Accessed September 2014)
127. Macmillan Cancer Support. *Symptoms of colon and rectal cancer*. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Colonandrectum/Symptomsdiagnosis/Symptoms.aspx> (Accessed September 2014)

128. Cancer Research UK. *Dukes' stages of bowel cancer*. <http://www.cancerresearchuk.org/about-cancer/type/bowel-cancer/treatment/dukes-stages-of-bowel-cancer> (Accessed September 2014)
129. Beating Bowel Cancer. *Targeted therapies*. <https://www.beatingbowelcancer.org/targeted-therapies> (Accessed September 2014)
130. Corden A, et al. Economic components of grief. *Death Studies*. 2013. 37(8): 725-749
131. Gray NM, et al. Predictors of anxiety and depression in people with colorectal cancer. *Support Care Cancer*. 2014. 22: 307-314.
132. Healthtalkonline.org. *Information and support about colostomy or ileostomy*. <http://healthtalkonline.org/peoples-experiences/cancer/colorectal-cancer/information-and-support-about-colostomy-or-ileostomy> (Accessed September 2014)
133. Pedersen AF, et al. Patient Delay in Colorectal Cancer Patients: Associations with Rectal Bleeding and Thoughts about Cancer. *PLoS ONE*. 2013. 8(7): e69700.
134. Power E, et al. Assessing awareness of colorectal cancer symptoms: Measure development and results from a population survey in the UK. *BMC Cancer*. 2011. 11: 366
135. Macmillan-NCIN work plan. *Segmenting the cancer survivor population*. [www.ncin.org.uk/view?rid=2493](http://www.ncin.org.uk/view?rid=2493) (Accessed September 2014). The analysis is based on patients diagnosed with cancer between 1991 and 2010 in England, Wales and Scotland, and between 1993 and 2010 in Northern Ireland. To ensure that patients, rather than tumours, were counted, only the first diagnosed tumour (excluding non-melanoma skin cancer) in each patient was included in the analysis. Anyone who died or left the country in the period, or were aged over 99 at diagnosis or over 105 at the end of 2010, were removed from the study. The numbers in this analysis may not agree with those published elsewhere due to slight differences in methodologies, periods of observation, datasets, and rounding.

# 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 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](mailto: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

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

### The Rich Pictures on age groups

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

### Other Rich Pictures

<b>The Rich Picture on people at end of life</b>	(MAC13841_14)
<b>The Rich Picture on carers of people with cancer</b>	(MAC13731_10_14)
<b>The Rich Picture on people with cancer from BME groups</b>	(MAC14662_14)
<b>The Emerging Picture on LGBT people with cancer</b>	(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](http://www.be.macmillan.org.uk).

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

**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](https://www.macmillan.org.uk)**

Code: MAC13840\_11\_14

©Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

