

THE RICH PICTURE

WE ARE
MACMILLAN.
CANCER SUPPORT

PEOPLE WITH
CANCER FROM
BME
GROUPS

Gee, living with breast cancer

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



About this 'Rich Picture'

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

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

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

The information could be valuable in many ways:

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

This document is not intended to

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

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

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

This 'Rich Picture' is one of a suite of documents. To access these documents please visit

<http://www.macmillan.org.uk/Richpictures> or for further information please contact evidence@macmillan.org.uk

The legal bit

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

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

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



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Guidance on referencing this document

You are free to use any of the data contained in this document, however when quoting any factual data that do not belong to Macmillan, it is best practice to make reference to the original source – the original sources can be found in the References section at the back of this document on page 44.

Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experiences of BME people with cancer. It is designed for a broad audience of health and social care professionals, commissioners, influencers and staff or volunteers working with (or for) cancer patients. BME people affected by cancer may find wide our wide set of information booklets more helpful, including our main booklet “The Cancer Guide”, suitable for everyone affected by cancer.



The Cancer Guide
MAC5765

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

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

OTHER RELATED INFORMATION FOR MACMILLAN STAFF

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

Case Study Library

People affected by cancer

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

Professionals/Services

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



Comms Platform

Describes how to communicate with people affected by cancer.



Rich Pictures

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



Impact Briefs

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



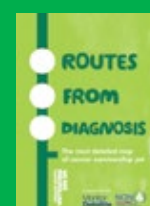
Local Cancer Intelligence

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



Routes from Diagnosis

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



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

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SUMMARY OF PEOPLE WITH CANCER FROM BME GROUPS

Key stats

13% of people living in the UK describe themselves as belonging to a BME (non-White) group.^(14,16,15)

15% of people living in England are non-White, compared to **2%** of people living in Northern Ireland and **4%** of the Welsh and Scottish populations.^(14,15,16)

The proportion of people belonging to a BME group living in England and Wales is projected to increase to **20%** in **2026**.⁽¹⁷⁾

People from Asian and Mixed communities are **20%-60% less likely to get cancer** than the White population. In **Black men** the risk of getting cancer is **comparable** to White men.⁽⁷⁾

People living in the UK who were born in the East African and Indian subcontinent have a **lower mortality** from cancer than the national average.⁽¹⁹⁾

Diagnosis

23% of all newly diagnosed cases of cancer are detected through an **emergency route**. There are no major differences between BME and White ethnic groups.⁽⁷⁴⁾

Cancer awareness and help seeking behaviours among people from BME groups are **low** across all minority ethnic groups.⁽³⁰⁾

Uptake of cancer screening invitations is generally **lower** in people from BME groups than people from the White population.⁽³¹⁾

Four in five (83%) people are **affected financially** by a cancer diagnosis.⁽³⁵⁾ The effects are starker in people from BME communities because there tend to be higher levels of poverty among these groups.⁽³⁷⁾

British South Asian patients report **significantly higher rates of depressive symptoms** following a recent cancer diagnosis, compared with White British patients.⁽³⁹⁾

Treatment

Participants in clinical cancer trials have better outcomes than are reported in the population at large, but **people from BME groups are less likely to participate**. Barriers to participation include:⁽⁷⁵⁾

- Cultural factors (such as fear and cancer stigma)
- Lack of knowledge regarding clinical trials
- Mistrust of the medical system.

Survivorship

Around 50% of those diagnosed with cancer will live for at least ten years after diagnosis. There are some **differences in survival rates** between people from BME groups and White cancer patients.⁽³⁾

Cancer survivors from **White communities** are **more likely to receive follow-up screening** than cancer survivors from BME communities.⁽⁵⁰⁾

Around **20–30%** of people living with cancer (of all ethnicities) **consistently report long-term psychological problems** including depression and anxiety.⁽⁴⁹⁾

End of Life

There is a **low uptake of palliative and end of life care** amongst people from BME groups. This may be because of⁽⁴³⁾:

- A **lack of referrals**
- A **lack of knowledge** of hospice/ palliative care
- **Location of hospices**
- Cultural perceptions and preferences around death and dying
- **Poor communication** between healthcare professionals and the BME patients

People from BME groups are **less likely to complete advance care planning** documents⁽⁸⁸⁾ and **more likely** to want active **treatment**⁽⁴³⁾ to continue until the end of life, compared with White people.

Some BME groups have a **strong reliance on spiritual belief and practice**, this has important implications for the way that they want to be cared for at the end of life.⁽²⁰⁾

Specialist themes

- People with cancer from Gypsy and Traveller communities in the UK

There are examples of **lack of understanding** of Gypsy and Traveller culture in hospitals, resulting in ill-treatment of these groups.⁽⁷⁸⁾

- Polish economic migrants living with cancer

There are **shortages of translators and printed information in Polish** affecting Polish people in the UK's access to cancer care.⁽⁶³⁾

- Spiritual needs of people with cancer from BME groups

In one US study of advanced cancer patients, more African Americans (89%) and Hispanics (79%) reported religion to be very important compared with Whites (59%).⁽¹⁰⁾

INTRODUCTION TO BLACK AND MINORITY ETHNIC (BME) GROUPS

What is ethnicity?

There is no single definition of ethnicity and no single approach to capture it. Many definitions highlight its **multifaceted and changing** nature, and a sense of **belonging** to a group.⁽¹⁾ Ethnicity can be described as “the social group a person belongs to as a result of a mix of cultural and other factors including **language, diet, religion, ancestry and physical features**”.⁽²⁾

How is ethnicity captured in health data?

To harmonise data collection and to enable consistency and comparability of data it has been agreed that ethnicity should be categorised into groups of common characteristics.⁽¹⁾ The most common grouping in the UK health data context relates to five categories: White, Asian, Black, Mixed and Other, with further breakdowns, depending on the data source.

Ethnicity data has been collected through the Census since 1991. The latest release of the Census from 2011 brought in some changes. Traveller and Gypsy as well as Arab categories were added, and the Chinese category was repositioned from ‘Other’ to ‘Asian’. This has resulted in more detailed information to analyse the needs in key ethnic groups, but also a lack of comparability when looking at time trends.

Who is included in the Black and Minority Ethnic (BME) group?

Just as it is with the notion of ethnicity itself, the definition of BME is open to interpretation. In the UK context it is most often described as people of non-White ethnic decent. Some sources narrow it down further to **non-White British**.⁽⁴⁾ As there are differences in cancer journey experience and mortality within the White group, for the purposes of this report we will talk about BME communities in the context of non-White British people, unless otherwise specified. We have profiled two White non- British groups (Gypsy and Travellers and Polish) in a special ‘Spotlight on’ section on page 38.

Ethnic group	Definition
White	People who describe their ethnicity as British, Irish or from other European ancestral origins who identify themselves as White
Asian	People who identify themselves as having Asian or Asian British ethnicity, including Indian, Pakistani, Bangladeshi, Chinese* or other Asian ethnicities
Black	People identifying themselves as Black British, African, Caribbean or other ethnicities with African ancestral origins
Mixed	People who identify themselves as belonging to an ethnic group that has a mix of ancestral origins, for example White and Black African, White and Black Caribbean, White and Asian or any other mix of ethnic groups
Other	All people who identify themselves as having any other ethnicity that is not one of the above definitions

*In some groupings Chinese people can also be added to category ‘Other’ or separated out.

AVAILABILITY OF DATA ON PEOPLE WITH CANCER FROM BME GROUPS

Data used for this Rich Picture

Some data presented in this document come from local and national datasets and may not be representative of the whole UK population. For further information on limitations to the analysis in the reports used please refer to the source. Despite the limitations, including various levels of ethnicity and country of birth recording, and regional focus, this document provides a good first look at the overall pattern of cancer incidence and mortality by ethnicity. No data on prevalence of cancer in people from BME communities are available.

The 'Cancer Journey' section collates for the first time a wealth of information on experiences of people living with cancer from BME communities. However, here too there are some gaps in data on the effects of cancer and its treatment on people from the BME groups, specifically around financial and physical needs.

What is the problem?

There is a great need for more robust cancer data on ethnicity as **the quality of ethnicity recording in routinely collected health data remains poor.**⁽⁵⁾ This raises **concerns around completeness and accuracy of analysis** when using existing data, with the main area of concern being primary care.⁽⁵⁾

The National Cancer Intelligence Network (NCIN), which collates and coordinates data and information on cancer patients reported that the **recording of ethnicity** in data on hospital admissions for cancer has **improved**, reaching 95% completeness in 2013 in comparison to 86% in 2008-2010.⁽⁷⁾ Ethnicity assigned to a hospital admission is used to populate cancer registrations in the **National Cancer Data Repository**, an important source of insight on cancer outcomes for commissioners.

Why is it a problem?

Poor quality healthcare data on ethnicity may lead to **inadequate resource and service commissioning**, as it is needed to assist with the design of appropriate interventions, target resources and education to high risk populations, and then evaluate these interventions.⁽⁵⁾ This becomes especially crucial with the changes to healthcare commissioning introducing **locally conducted allocations**. The process depends heavily on up to date, robust information from population needs assessment. However, as the data on ethnicity are available mostly on a national level, and even then are quite limited. This increases the chances of not meeting needs appropriately. As a result, experiences of the cancer journey can continue to be worse in people from BME communities.⁽⁸⁾

What is being done to improve data quality?

Software to identify distinct names in subpopulations of South Asian (the largest minority group) has been one of the first attempts to overcome the absence of robust self-assigned ethnicity data. However, the use of the software is still limited, particularly for other ethnic groups, and does not provide sustainable and comprehensive solutions to the problem.⁽⁹⁾ Similarly, there is limited information on the uptake of the 2005 NHS 'practical guide to ethnic monitoring in the NHS and social care' and their applicability to local contexts.⁽¹¹⁾

National Cancer Action Team (NCAT), now transferred to NHS Improving Quality, leads on a number of initiatives to collect new data on cancer in BME communities, and improve the quality of existing resources:

- The **BME Cancer Voice** panel was set up to provide BME patients and carers with an opportunity to voice their experiences of cancer services and change the way that cancer services are delivered in England.
- In 2009 NCAT conducted a **BME Audit Project** and contacted all NHS trusts and Cancer Networks in England asking them about their policy and services relating to BME communities. As a result NCAT shared best practices and created guidelines for delivery of culturally sensitive services.

The National Cancer Intelligence Network (NCIN) in collaboration with Macmillan are funding two data fellows over three years who will analyse large scale data sets on survivorship. The analysts are known as the **Macmillan-NCIN Data Fellows**. One of the dimensions included in the analysis will be ethnicity.⁽¹²⁾

'I was diagnosed with cancer in 2007. In 2006 I had a mammogram and the result came back and everything was fine. But a year later I found a lump. So if I wasn't examining myself and was instead leaving it thinking I would be fine, I wouldn't be here today. I'm not sure if anybody has been down that avenue like I have but for me it was quite frightening.

I find making cards for me makes me use my brain, my mind, and my hands. I don't get too depressed because I've found something to do. I think there's something for all of us; a little thing that we do. I make cards and I knit instead of sitting down and feeling sorry for myself. I find something active to do.'

Gee, London

MACMILLAN'S AIMS AND OUTCOMES

Macmillan's aims and outcomes

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.⁽¹³⁾

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.

How is this different for people with cancer from BME groups?

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

The 9 Outcomes for people living with cancer

I was diagnosed early

I understand, so I make good decisions

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

Those around me are well supported

I am treated with dignity and respect

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

I can enjoy life

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

I want to die well

THE FACTS ON PEOPLE WITH CANCER FROM BME GROUPS

This section presents some of the key stats and facts relating to people from BME groups and measures of cancer in the groups. You may benefit from referring to the Jargon Buster on page 50 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.

Due to the lack of data on prevalence of cancer in people from BME groups this section presents ethnic breakdown across the UK population as a whole.^(14,15,16) The information is important to understand differences in cancer incidence (age breakdowns and lifestyles) and different needs and experiences on cancer journey (proficiency in English and religion).

Please note there are some gaps around knowledge about the cancer experiences of people from BME communities affecting the robustness of data presented in this document. To read more on the extent and impact of the availability of data on our understanding of cancer in this group see our specialist section on page 5.

13% of people living in the UK are non-White*:

15% of people living in England

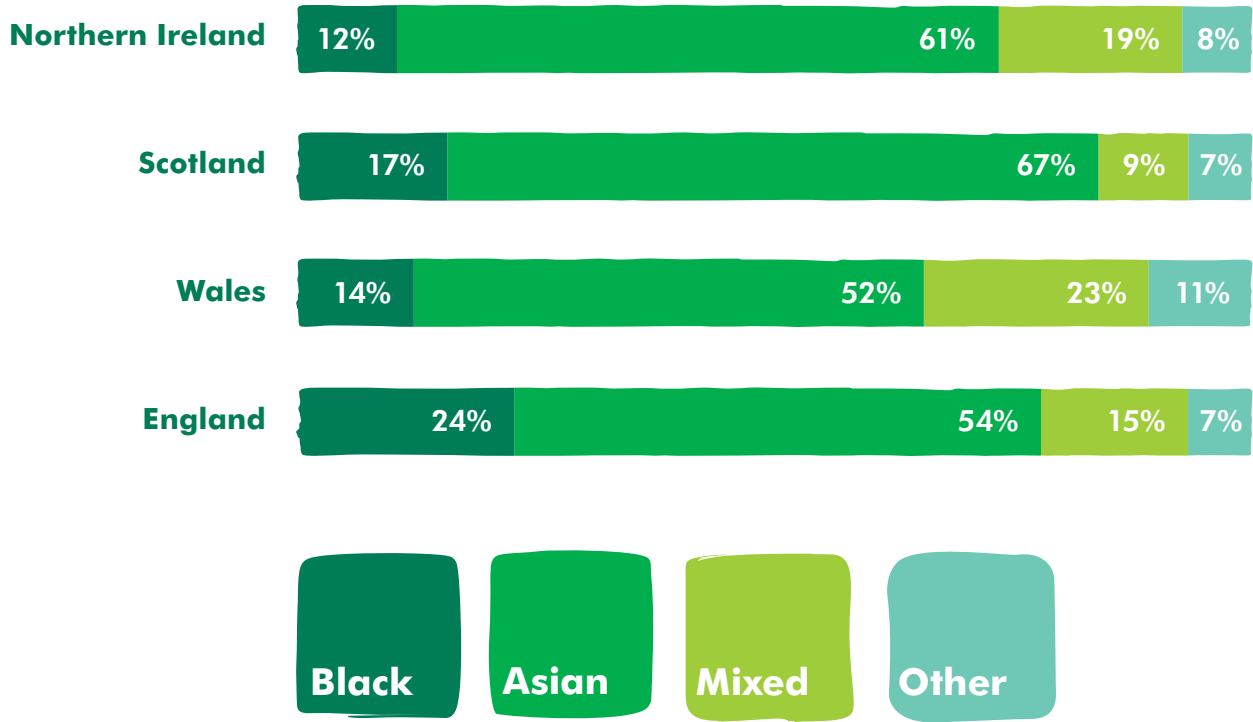
4% of the Welsh and Scottish population

2% of people living in Northern Ireland

13% of people in England and Wales were born outside of the UK.

7% of people in Scotland and Northern Ireland were born outside of the UK.

What is the breakdown of BME groups in the UK nations?^(14,15,16)

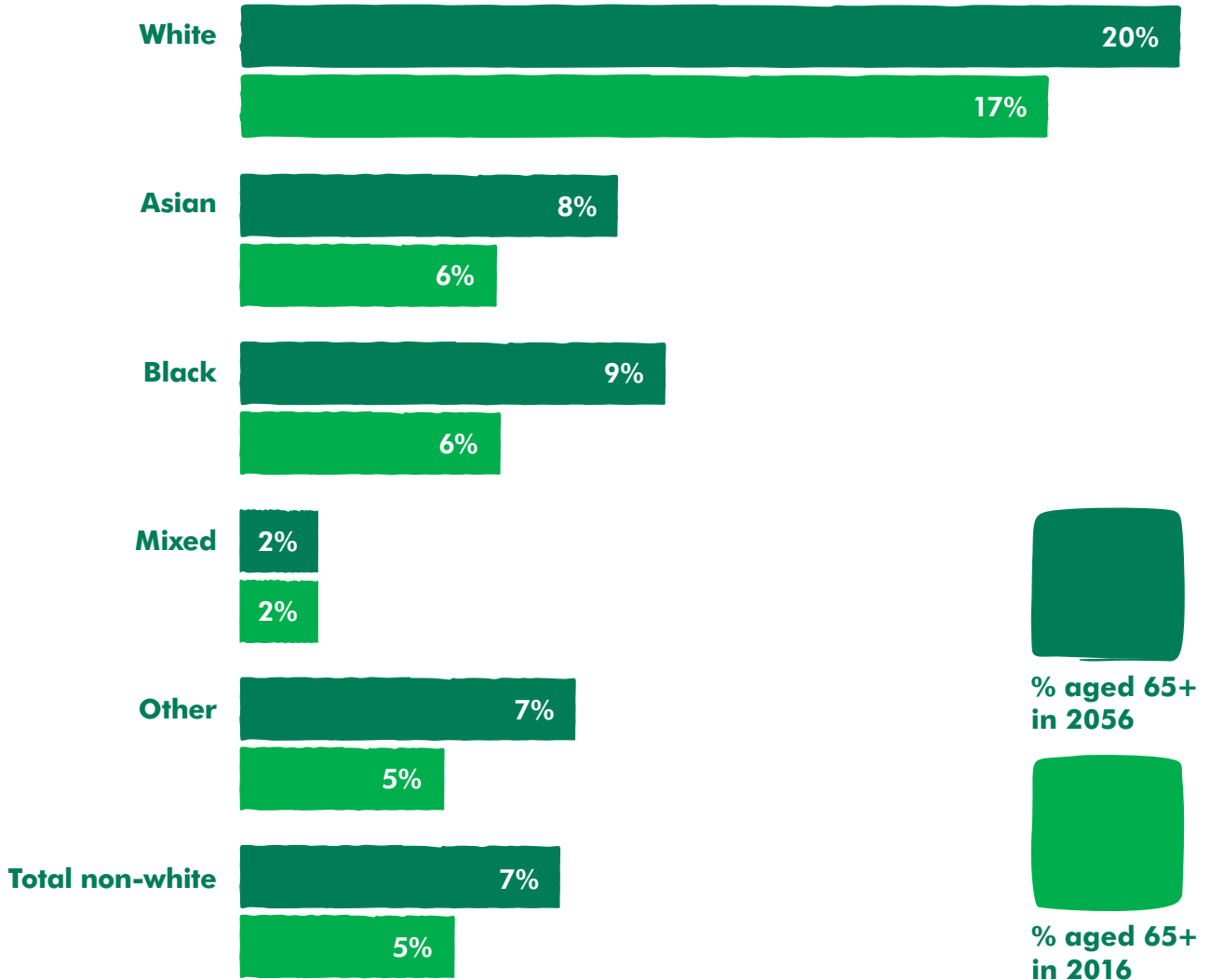


8% of people living in England and Wales do not have English as their first language.

21% of these cannot speak English at all or cannot speak it proficiently.

79% of BME people in England and Wales are reported to follow a religion, compared to 65% of White British people.

How will the age structure change in ethnic groups in England and Wales?⁽¹⁷⁾



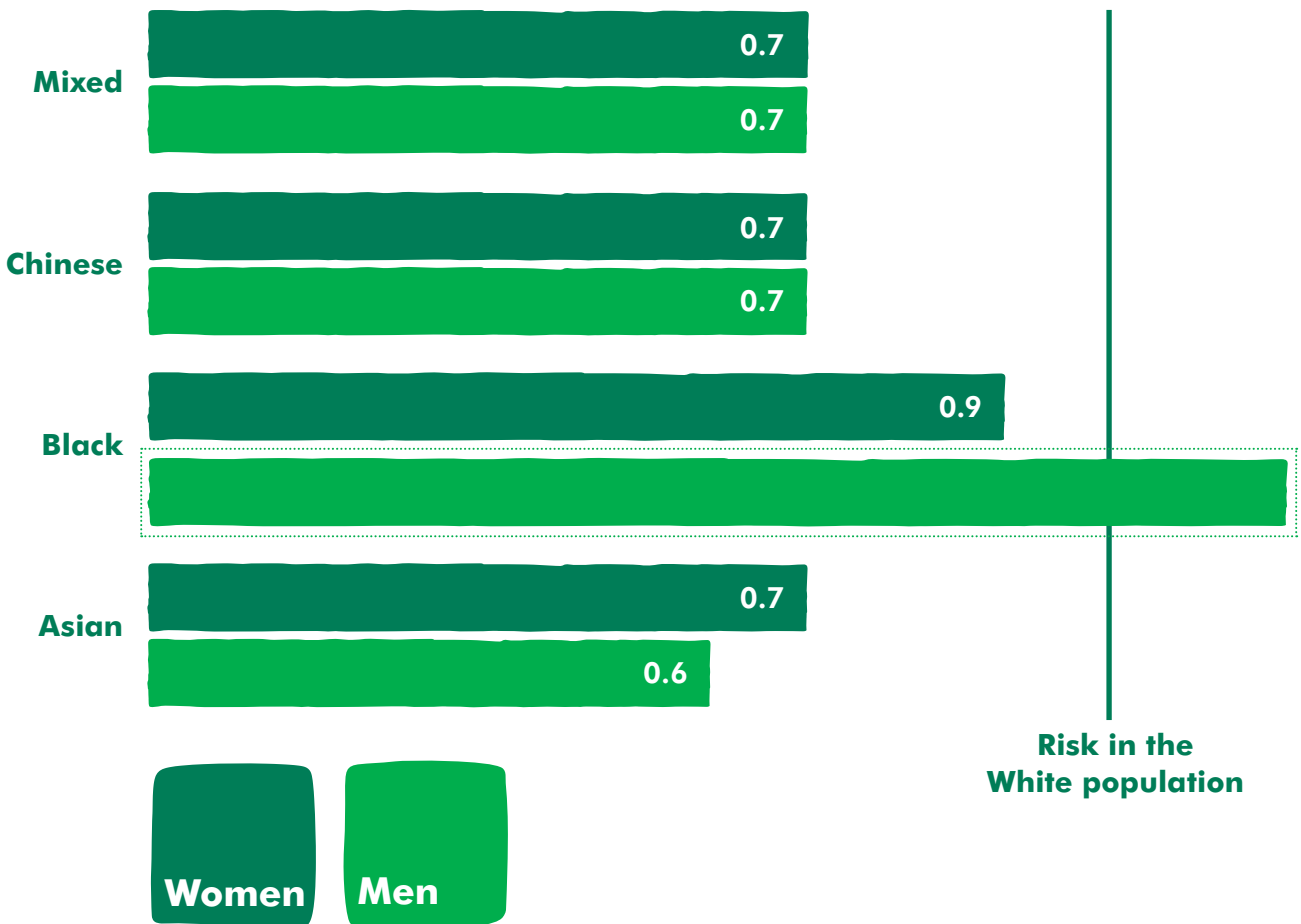
The BME population in England and Wales is younger than the White population. Nearly all ethnic groups will have a larger proportion of people aged over 65 by 2056.

'I felt it was a white person's disease. No one of my ethnicity is ever shown as a cancer patient. I was ignorant about cancer. In Nigeria, people who have cancer just die from it. I appeared on a TV programme out there and they asked me whether I'd survived because I lived in the UK!'

Della, London

How does the risk of getting cancer vary by UK ethnic group?⁽³⁾

Age standardised cancer incidence rate ratios by site and ethnic group, England, 2004-2006



Note: The bars represent how the risk of getting cancer in people from BME communities compared to the White population. The numbers in the bars show the estimated upper end of the risk range in each ethnic group compared to White people. The risk in the White population is the baseline, therefore it has a value of 1. Dotted lines indicate values that are not significantly different to the White population.

People from Asian and Mixed communities are 20%-60% less likely to get cancer than people from the White population. In Black men the risk of getting cancer is comparable to men from the White population.

How does the risk of getting cancer in BME groups vary by cancer site?

Overall, and for many individual cancer sites, people from BME groups are less likely to get cancer than White people. E.g.

Asian and Black women are **between 80% and 60% less likely** to get lung cancer than White females in England.⁽³⁾

The risk of getting **bowel cancer** in the **Asian** community is **around half that** of the White population.⁽³⁾

However, there are a few exceptions:

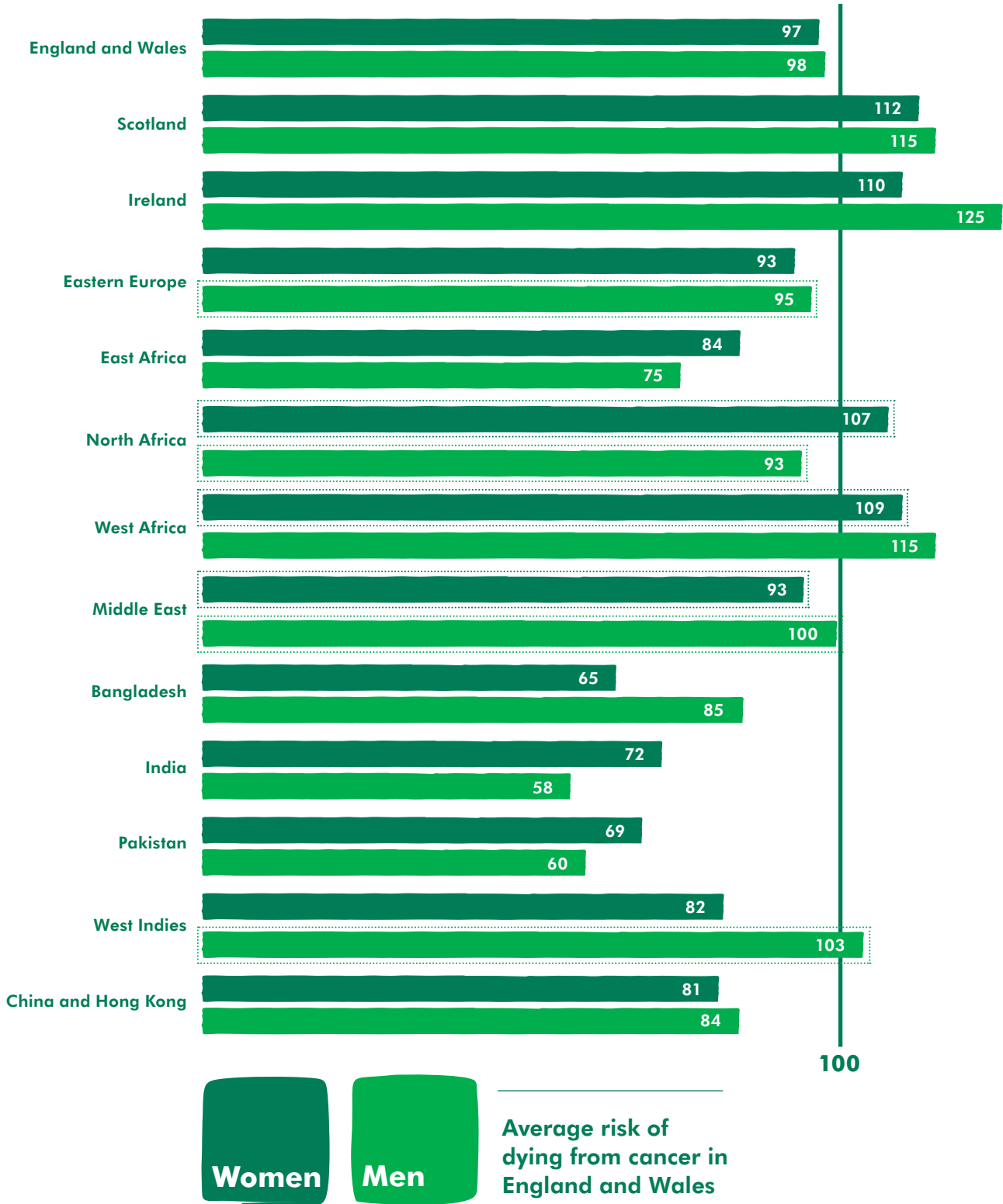
Black men are around twice as likely to get **prostate cancer** than White men in England.⁽³⁾

Asian people are **between 1.5 and 3 times more likely** to get **liver cancer** than the White population in England.⁽³⁾

Black and Asian females aged 65 years and over, are at **higher risk of cervical cancer** compared to White females in England.⁽³⁾

Incidence of oral cancer **among South Asians** is higher than any other ethnic group.⁽¹⁸⁾

What are the differences in the risk of dying from cancer amongst people living in the UK by country of birth?⁽¹⁹⁾



Note: The graph shows risk index. 100 is average for England and Wales. Dotted lines indicate values that are not significantly different to the national average. 'Ireland' relates to people born in the Republic of Ireland and Northern Ireland.

How does the risk of dying from cancer in BME groups vary by cancer site?

Breast cancer

Breast cancer deaths in women born in **West Africa** and living in England and Wales are **30% higher** than the average for England and Wales.⁽¹⁹⁾

Women born in **Bangladesh** and living in England and Wales have rates of breast cancer deaths **70% lower** than the average for England and Wales.⁽¹⁹⁾

Lung cancer

People living in England and Wales who were born in the Indian subcontinent have 15% to 40% lower rates of lung cancer than the overall population in England and Wales.⁽¹⁹⁾

Bowel cancer

Pakistani men have rates of bowel cancer deaths **around 70% below** the overall population of England and Wales.⁽¹⁹⁾

Prostate cancer

Prostate cancer mortality rates for men **born in West Africa and the West Indies** living in England and Wales are **two to three times higher** than the overall population of England and Wales.⁽¹⁹⁾

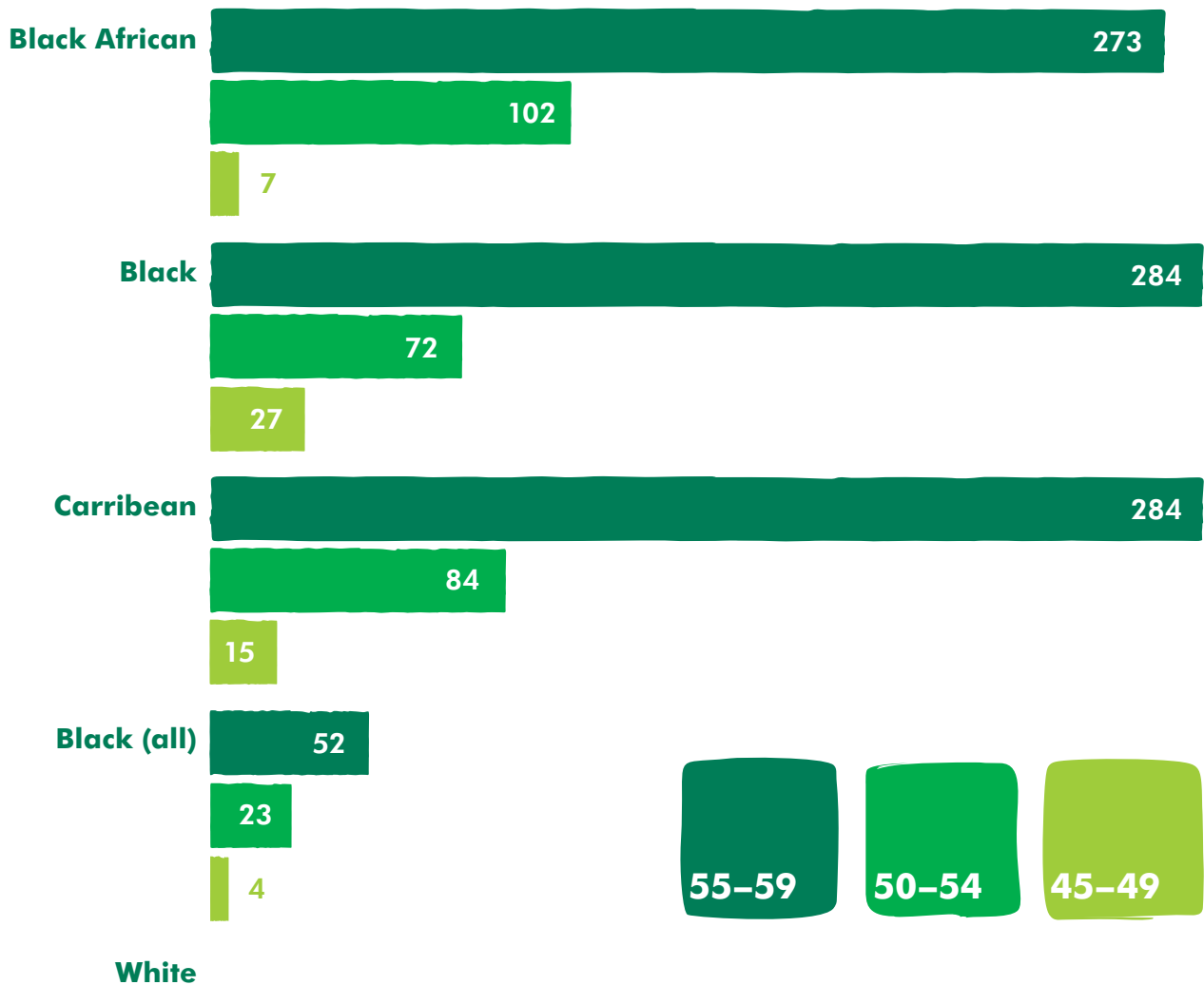
Men living in England and Wales who were born in the **Indian subcontinent** have **30% to 80% lower** rates of prostate cancer deaths than the overall population in England and Wales.⁽¹⁹⁾

What are the ethnicity specific cancer issues?

Breast and prostate cancer are among the top three most commonly diagnosed cancers in the UK. There are stark differences in incidence and mortality from these cancers between ethnic groups.

Prostate cancer in Black men⁽⁸⁾

Rate per 100,000 of men with prostate cancer by ethnic group



Black men are three times more likely to have prostate cancer compared to White men.⁽⁸⁾
Prostate cancer appears to progress more rapidly in Black men and death rates from prostate cancer are 30% higher in Black men than White men living in England.^(96,22)

Breast cancer in South Asian women

Incidence of breast cancer in South Asian women is **half** that of the whole population of England and Wales⁽²³⁾ and breast cancer **mortality** in Bangladeshi women is **70% lower than the average** mortality experienced by the overall female population of England and Wales⁽¹⁹⁾. Breast cancer remains the most common cancer that women of this ethnic group are likely to develop. **21% of all cancer deaths in South Asian women** (compared to 18% in non-South Asian women) are due to breast cancer.⁽²⁴⁾

Note: The data in this section comes from regional and nation databases. Please go to section 'Availability of data on people with cancer from BME communities' to read about implications for interpretation.

What are the time trends in cancer mortality in BME communities?

Despite overall lower prevalence of cancer in BME communities compared to the White population, there is some evidence that **cancer rates in this group are on the rise**.⁽²⁴⁾

This may be because of the changes to both incidence and mortality patterns. There are stark differences within the BME population in both.

Between 1989 and 2003 **mortality rates from all cancers**, lung cancer and colon cancer **fell by around a quarter** in men born in England and Wales.⁽⁹⁵⁾ Of those now living in England and Wales, men born in **India** experienced a similar drop in rates for all cancers, while men born in **Jamaica** saw a **20% increase**. **20% to 30% drop** in mortality rates from **lung cancer** between 1989 and 2003 occurred in men born in the **Caribbean (excluding Jamaica), East Africa, India and Bangladesh**. Men born in **Jamaica**, on the other hand, experienced an **increase** in mortality rates for the same cancer by **30%**.⁽⁹⁵⁾

In **women** living in England and Wales, large decreases in mortality rates between 1989 and 2003 due to all cancers occurred in those born in **West Africa (-34%), India (-21%)** and the **Caribbean (except for Jamaica, -15%)**.⁽⁹⁵⁾

Women born in **Pakistan** experienced an **increase** in mortality rates by **13%**. In that same period **breast cancer mortality** dropped most significantly in women born in **West Africa (-27%)**. **Lung cancer mortality fell by a third** between 1989 and 2003 in women born in **India**.⁽⁹⁵⁾

In spite of general declines in cancer death rates, inequalities in migrant mortality remain. Compared with the declines for those born in England and Wales, smaller or non-significant declines in groups with historically low mortality resulted in alignment of rates with those for England and Wales (e.g. breast cancer among women from the Caribbean or East Africa). However, for migrant groups with historically higher rates of cancer mortality this lead to either maintaining or widening the gap (e.g. lung cancer among men from Jamaica).

Why do incidence and mortality change?

There are many theories on the changing incidence of cancer in people from BME communities. One of which is that the lower rates of cancer in many BME communities may be partially explained by a combination of the effects of the country of origin and young age at the time of migration. This has been referred to as the **'healthy migrant effect'**.⁽²⁵⁾

This then can be replaced by the so called **'migrant effect'** over time, the health influence of the **country of origin is replaced by that of the host country** and the cancer figures for BME communities align with the rest of the UK population.⁽²⁶⁾ This may impact both incidence and mortality. The changes can occur due to many factors **ageing** of the population⁽²⁷⁾, **lifestyle**, diet, smoking and other forms of tobacco consumption, as well as **living conditions**.⁽²⁸⁾

How do lifestyles of people from BME communities affect their risk of getting cancer?

Depending on the type of cancer, the risk of getting it can be related to environment, lifestyle and/or genetic risk factors.

Although people from BME groups are less likely to get cancer, certain lifestyle factors can increase the risk of cancer. Higher rates of **smoking** in Bangladeshi men may cause higher rates of lung cancer incidence. Similarly, higher rates of oropharyngeal cancers in that group can be caused by **chewing betel** and other products containing tobacco.⁽²⁸⁾

It has been suggested that the **traditional diet** of some ethnic migrant groups (rich in fruits and vegetables and with generally lower red meat consumption) is a likely reason for lower rates of some diet related cancers in the first generation of migrants.⁽²⁴⁾

Living conditions of certain groups, for example Gypsies and Travellers who lack a permanent address, can cause difficulties in access to and use of health care.⁽²¹⁾

The impact of genetics on getting cancer by BME groups living in Europe is often less important than environmental and lifestyle aspects.⁽²⁷⁾

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 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 (p33), this section largely highlights the post-treatment needs and experiences of people living with cancer.

NEEDS AND EXPERIENCES DIAGNOSIS

What are the general signs and symptoms of cancer? ⁽⁶⁾

Reporting symptoms to a GP early can help ensure that **cancer is diagnosed as early as possible**. There are some common **signs** and **symptoms** for most cancers:

- a lump
- a cough, breathlessness or hoarseness that doesn't go away
- changes in bowel habit
- abnormal bleeding
- changes in a mole
- unexplained weight loss

How good are we at early diagnosis?

Patients with cancer in the **UK** tend to present with **more advanced** disease and have poorer survival rates than many of their European counterparts. ⁽²⁹⁾ The most likely explanations for this are either **late presentation** by patients or **late onward referral** by general practitioners.

How aware are people from BME groups of cancer signs and symptoms?

Awareness of cancer signs is **lower** in those who are male, younger, and from lower socio-economic or BME groups. ⁽²⁹⁾

A recent study looking at **cancer awareness and challenges seeking help** among BME groups found awareness and help seeking behaviour low across all minority ethnic groups, with the **lowest** awareness in the **Black African** group. ⁽³⁰⁾ The biggest **challenge** in people being able to seek help was **emotional**, with 41% of respondents

stating they were worried about what the doctor might find. 40% had **difficulty making an appointment** and 37% stated they had too many other things to worry about.

How well does screening work for people with cancer from BME groups?

Screening is a way of testing people to pick up a disease early, when it has the best chance of being cured. A number of international studies have highlighted that uptake of **cancer screening invitations is generally lower in BME groups**, which can lead to later presentation and poorer outcomes.

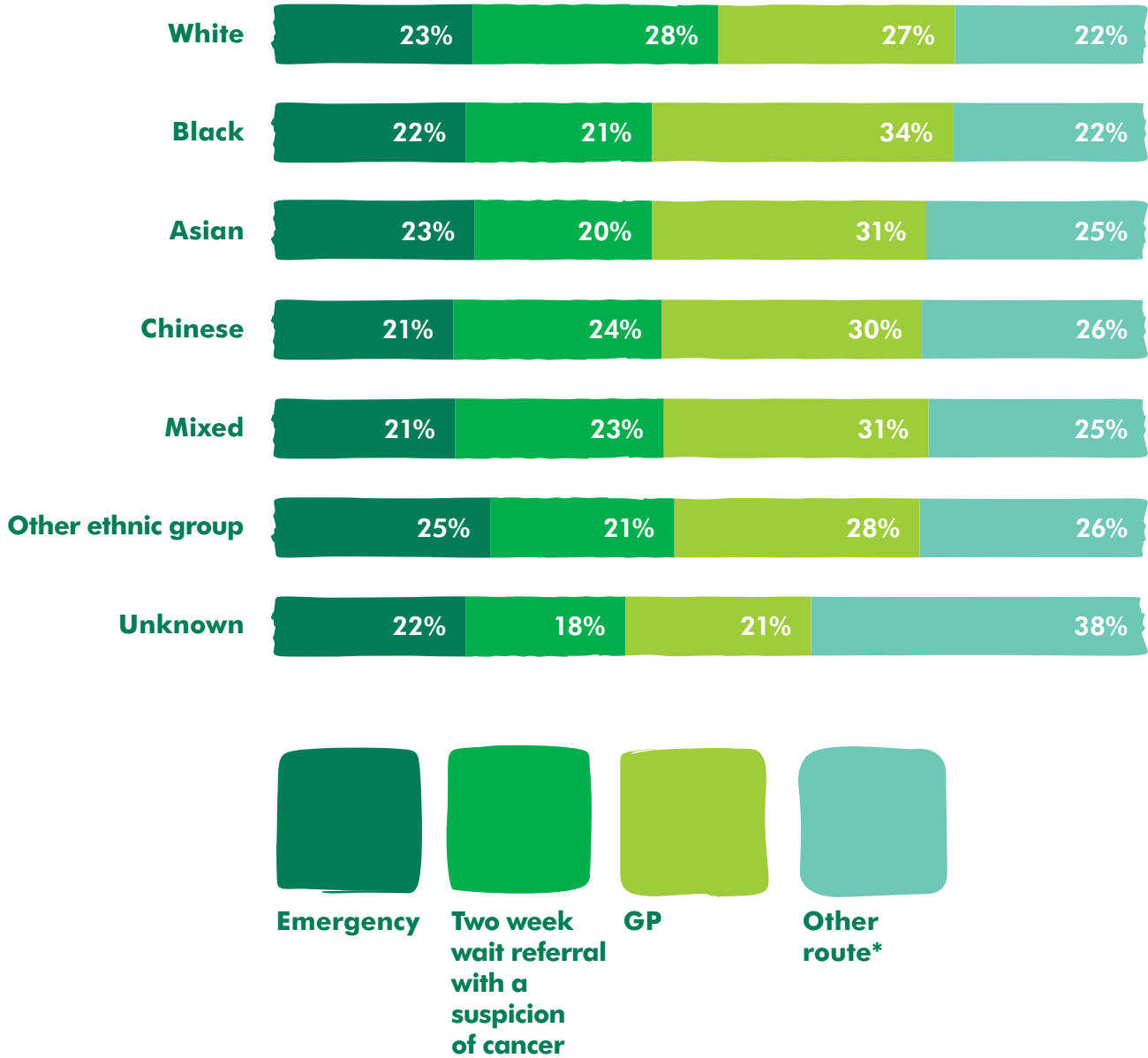
A study analysing patterns in the uptake of breast and bowel cancer screening programmes in the UK found **South Asians** demonstrated **significantly lower bowel screening uptake**; 33% vs. 61% for non-Asians. ⁽³¹⁾ For breast cancer screening, a smaller difference was observed between South Asians and non-Asians; 61% vs. 75%, respectively. ⁽³¹⁾

5% of cancers are screen detected in White people, compared to 6% in Asian and Chinese people and 3% in Black people. ⁽⁷⁴⁾

Cultural beliefs and **preferences around gender or religion of the practitioner** delivering screening, as well as protection of virginity in unmarried women were listed among other reasons affecting uptake of cervical screening in Arabic communities. ⁽³²⁾

People from **ethnic minority groups** with, or at risk of, **family linked cancer** appear less **likely to access screening** and other services to assess and address this risk. This may be because of a **difficulty discussing cancer** and genetic risk with their family. Other challenges may include language barriers and cultural sensitivity of cancer including **stigma**. ⁽³³⁾

How is cancer diagnosed in BME groups? ⁽⁷⁴⁾



*Other routes include screening, inpatient and outpatient routes, death certificate only diagnosis and unknown routes.

23% of all newly diagnosed cases of cancer are detected through an emergency route. The proportion is similar in all ethnicities.



PHYSICAL AND MEDICAL NEEDS

National guidelines in the UK recommend that patients with cancer have their care needs assessed at all key points, including at the time of diagnosis. The most recent Cancer Patient Experience Survey found that people from BME groups were **more likely to receive an assessment and care plan** in comparison to their White counterparts.⁽³⁴⁾

Amongst the factors which inhibit initial presentation of symptoms by BME groups, **difficulty in making an appointment** is one of the most common, with 42% of Chinese women participating in one study stating this as a reason for putting off going to the doctor with a potentially serious symptom.⁽³³⁾ Nevertheless, BME communities, with the exception of the Chinese ethnic group appear to have similar or higher GP consultation rates in comparison to their White counterparts.⁽²⁶⁾ This highlights that there may be factors embedded in healthcare systems that inhibit their use by BME groups. **Lack of cultural awareness** among staff is often quoted as a reason for worse access to diagnostics and care in cancer in BME communities.⁽²⁶⁾



FINANCIAL NEEDS

Following a cancer diagnosis, people are exposed to a wide range of potential new or increased costs, relating to different areas of expenditure, as well as a potential reduction in income through, for example, loss of earnings.

Demographic characteristics play only a small role in determining which types of people are at risk of incurring any added expense. However, overall ethnicity has been found to be a factor in predicting extra expense.⁽³⁶⁾

The financial impact of a cancer diagnosis may be starker in people from BME groups as some experience **higher rates of poverty**. Around 40% of Black, Asian and other ethnic groups, and 35% of mixed ethnic groups live in low income households, compared to less than 20% of the White population.⁽³⁷⁾

Not specific to people from BME groups living with cancer

Four in five (83%) people from all ethnicities in the UK are affected financially following a cancer diagnosis, and on average **£570 a month** worse off because of their cancer diagnosis. People may stop working and face loss of income whilst having to cope with additional costs.⁽³⁵⁾



PRACTICAL AND INFORMATION NEEDS

Evidence suggests that the gap in provision of cancer information is especially high in people from BME groups, potentially resulting in **lower awareness of cancer risk factors, signs and symptoms and cancer services among people from BME communities.**⁽⁴⁰⁾

In one cancer study people from BME communities were found to have **less knowledge about cancer screening services** and a lack of understanding about the recommended frequency for the tests, affecting their uptake of screening services.⁽³²⁾

Language can be a significant barrier to people from BME communities accessing health information and services. Studies have shown that among those with additional language needs a high proportion do **not have access to a translator** when visiting the GP and that BME cancer patients were less likely to understand their treatment options and diagnosis.⁽⁴⁰⁾

Not specific to people from BME groups living with cancer

22% of all cancer patients (of all ethnicities) who need **written information** about their type of cancer **do not receive it.** A further 8% are given written information but find it difficult to understand.⁽⁸⁰⁾ These barriers are even more prominent in older members of BME groups with low English literacy as many **hospitals outside of urban areas do not provide written information in other languages.**⁽⁴⁰⁾ **27% of cancer patients** (of all ethnicities) **do not fully understand** the explanation of **what is wrong** with them.⁽³⁸⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

A recent study found that **British South Asians** reported **significantly higher rates of symptoms associated with depression** compared with White British patients following a cancer diagnosis 35.1% vs. 16.8%.⁽³⁹⁾

The lack of conversations about cancer in certain BME communities has had an adverse effect on their likelihood of engaging in cancer screening practices.⁽³²⁾

Not specific to people from BME groups living with cancer

Around 240,000 people living with and beyond cancer are **living with mental health problems**, including anxiety and depression. (81) 25% people living with cancer say they would have found it helpful to have had more advice on the emotional effects of cancer.⁽⁴¹⁾

NEEDS AND EXPERIENCES TREATMENT

What treatments do people from BME groups get?

A number of factors affect the treatment a patient may receive, including the type and grade of cancer, where in the body the cancer started, where the cancer has spread and the general health of the patient.⁽⁴²⁾

There are also stark differences in access to treatment in different ethnic groups. Patients from BME groups often report poorer experiences of the cancer services than White patients.

Data currently available focuses on two types of needs BME patients have during their cancer treatment, physical/medical needs and practical/information needs.

'The NHS supplied me with one free wig. It wasn't at all suitable for me as a black woman as the style and texture was all wrong. I didn't want to stick out like a sore thumb. I had always been experimental with my hair and so started making wigs in styles that I had used to style my own hair. With my new wigs, if you saw me and didn't know I was going through chemo I didn't look any different which was exactly what I wanted.'

Kewcha, London



PHYSICAL AND MEDICAL NEEDS

Participants in clinical cancer trials have better outcomes than are reported in the population at large, but people from BME groups are less likely to participate. **Barriers to participation include cultural factors** (such as fear and cancer stigma), **lack of knowledge** regarding clinical trials, and **mistrust** of the medical system.⁽⁷⁵⁾

A recent study found that Black men with prostate cancer were **less likely to proactively ask healthcare professionals about their treatment and condition**, suggesting more should be done to facilitate the conversations by healthcare professionals.⁽⁸⁾

There is evidence of a **lack of understanding** by hospital staff of certain BME cultures. Negative experiences can then lead to avoidance of certain services.⁽⁷⁶⁾



PRACTICAL AND INFORMATION NEEDS

Language can be a significant barrier to people from BME communities accessing health information and services. Studies have shown that among those with additional language needs a high proportion do not have access to a translator when visiting the GP and that BME cancer patients were less likely to understand their treatment options and diagnosis.⁽⁷⁷⁾

English literacy may also be a barrier to accessing information among members of BME communities. Due to high levels of **illiteracy in Gypsy and Travellers** groups, once admitted for diagnosis or treatment, many of the elderly patients are **unable to fill in forms**; but reluctant to admit this, they experience frustration and obstacles accessing relevant services.⁽⁷⁸⁾

NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

Why are cancer survivors not catered for properly in the current system?

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

- 39% who completed treatment in 2009/10 say that no health or social care professional talked them through the needs they might have.⁽⁸²⁾
- 94% experience physical health condition problems in their first year after treatment.⁽⁷⁹⁾
- 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.⁽⁷⁹⁾
- 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.⁽⁷⁹⁾
- 25% people living with cancer say they would have found it helpful to have had more advice on the emotional effects of cancer.⁽⁸³⁾
- 23% lack support from friends and family during treatment and recovery.⁽⁸⁴⁾
- 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.⁽⁸⁴⁾

Differences in cancer survival

For many patients (for all cancer patients not just those from BME groups), treatment is very successful. Around 50% of those diagnosed with cancer will live for at least ten years after diagnosis. However, for some cancers there are **differences in survival rates** between BME cancer patients and White cancer patients:

- **Black women** have significantly poorer **survival from breast cancer** at both one and three years since diagnosis than White women (85% compared with 91% at three years)⁽³⁾
- **Black men aged 65-99 with lung cancer** have **better survival** than White men at both one and three years since diagnosis (13% compared with 8% at three years).⁽³⁾

Cancer patients have greater health needs than the general population

Many cancer patients will complete primary treatments and return to the same level of health and wellbeing before diagnosis. However, a significant proportion will experience a wide range of distressing long term problems such as bowel and urinary incontinence, crippling fatigue, sexual difficulties, heart or bone problems, or a second cancer. Many of these problems can persist for at least ten years after treatment.

‘I think Nigerians just need to be educated about cancer. They need to know it does exist, but that it can be treated. I take things back with me to raise awareness – Macmillan leaflets, booklets, and other things. I’ve even been on TV over there. So I’m just telling people about cancer and what helped me.’

Della, London



PHYSICAL AND MEDICAL NEEDS

Evidence regarding ethnicity and uptake of follow-up surveillance found that cancer survivors from **White communities** were **more likely to receive follow-up** than survivors from BME communities.⁽⁵⁰⁾



FINANCIAL NEEDS

Less developed health information seeking behaviours⁽³⁰⁾ and linguistic barriers mean that some people from BME communities may have problems accessing relevant cancer information, and that often professionals cannot communicate with them in a way that is understandable.⁽⁸⁶⁾

Not specific to people from BME groups living with cancer

26% of cancer patients (from all ethnic groups) report they are only told to some extent about the long term side effects of their treatment and 19% report that the future side effects were not explained to them at all.⁽⁸⁵⁾



EMOTIONAL AND PSYCHOLOGICAL NEEDS

Receiving a cancer diagnosis or treatment for cancer can affect emotional state. A recent study found that **British South Asians** reported significantly **higher rates of depressive symptoms** compared with White British patients following a cancer diagnosis.⁽³⁹⁾ Some people develop long lasting mental health problems such as anxiety and depression.

Not specific to people from BME groups living with cancer

The emotional impacts of cancer diagnosis and treatment remain for a long time. More than 5 years after diagnosis with cancer, around **20–30%** of people living with cancer (of all ethnicities) **consistently report long-term psychological problems** including depression and anxiety.⁽⁴⁹⁾

Improving the health and wellbeing of cancer survivors

Some long term consequences of cancer and its treatment can be reduced with simple interventions, while more complex issues will require specialist services.

Ways to improve the lives of those affected by cancer (from all ethnic groups) and its treatment include the National Cancer Survivorship Initiative (NCSI) Recovery Package, specialist late-effects services and help lines, physical activity programmes, improving patient information, and improved data collection, coding and research.

The NCSI is partnership between the Department of Health and Macmillan and is supported by NHS improvement.

For more information about the initiative, please visit the NCSI website at www.ncsi.org.uk

NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

Current evidence shows that palliative and end of life care provision for people from BME communities may be inadequate. As the number of people from BME groups increases, there is a greater need for culturally sensitive end of life care.⁽⁴³⁾

Access to palliative and end of life care⁽⁴³⁾

There is a **low uptake of palliative and end of life care** amongst people from BME groups. There are many potential reasons for this:

- A **lack of referrals** because of an assumption that family members would provide care at home.
- A **lack of knowledge** of what hospice/palliative care settings involve or how they work, partially due to a lack of information on relevant services in different languages and formats across care settings.
- **Location of hospices** with many inpatient hospices located in areas with low proportions of BME residents, or services unavailable in more rural remote areas.
- **Poor communication** between healthcare professionals and BME patients in receipt of palliative or end of life care.

Where do people with cancer die?

A recent survey found that 73% of people who died from cancer (not just those from BME groups) would have liked to have spent the last weeks and days of their life at home.⁽⁴⁴⁾ However, only 30% of those who die from cancer actually die at their home or own residence.⁽⁴⁵⁾

38% of all cancer deaths take place in hospital, 30% at home, 13% in care and nursing homes and 18% in hospices.⁽⁴⁶⁾

Where do people with cancer from BME communities die?

Although data on place of cancer deaths by ethnicity is not available, research has found **Black and Chinese men** in South East England are **less likely to die at home** in comparison to White patients and significantly more likely to die in hospital.⁽⁸⁾

The research also found that **Black Caribbean bereaved carers** were more likely to report that the deceased was **not given adequate choice regarding their place of death**, in comparison to their White counterparts.⁽⁸⁾

‘You have to be a White, articulate, middle class person to be taken seriously. I had no support caring for a loved one who was dying. My family were ignored and made to feel stupid for wanting to know basic information’

Cancer patient quoted in ‘Walking into the unknown’⁽⁵¹⁾



PHYSICAL AND MEDICAL NEEDS

A US study found **that only 47% of Black or Hispanic people have an advanced care plan**, compared to 80% of White people.⁽⁸⁸⁾

People from BME groups are **more likely** to desire **more active treatment** at the end of life.⁽⁴³⁾

People from BME groups also report **lower quality of care in care homes**, individual suffering, poorer experiences of hospice care compared to other groups and **under treatment for pain** or inadequate pain relief.⁽⁴³⁾

Some BME groups have strong spiritual beliefs which are likely to impact on the way that they would like to be cared for at the end of life.⁽²⁰⁾

Not specific to people from BME groups living with cancer

Various symptoms are very common in advanced cancer, with patients having an average of 6 uncontrolled symptoms on admission to palliative care.⁽⁴⁷⁾

Pain, breathlessness, fatigue, anorexia, constipation and insomnia are especially common; they occur in some combination in virtually all patients.⁽⁸⁷⁾



PRACTICAL AND INFORMATION NEEDS

Poor communication between healthcare professionals and the patient is often reported when people from BME communities are at the end of life care stage of their cancer journey.⁽⁴³⁾

Frequent **generalisations and stereotyping** around lifestyle and spiritual preferences in people from BME communities by service providers can lead to further mismatches between needs and services.⁽⁵¹⁾

'As a part of the Asian Women's Breast Cancer Group I have come across members who say they felt there has been a lack of compassion when they have been spoken to by healthcare professionals. The use of technical terms is also not helpful, and it is important that treatment is explained in a clear way that people can understand. There is also a further question of care after treatment, people need to be able to be supported after their treatment stops.'

Bhari, London

SPOTLIGHT ON

People with cancer from gypsy and traveller communities

The UK is home to one of the largest Roma populations in Western Europe. There are an estimated 200,000 to 300,000 indigenous Gypsies and Travellers living in the UK. Combined with the migrant Roma population, the figure is around **400,000 – 500,000**.⁽⁵²⁾

However, we know surprisingly little about their health. Nonetheless, some strong and persistent themes around access and provision of healthcare, including cancer care, emerge.

What issues affect access to cancer care for Gypsies and Travellers?

Lack of understanding

There are examples of **a lack of understanding** of Gypsy and Traveller culture in hospitals, resulting in ill-treatment of these groups.⁽⁷⁸⁾ As a result, many Gypsies and Travellers avoid particular services where negative experiences affected them or their families previously.⁽⁷⁶⁾

Housing

25,000 Travellers have been displaced and are therefore forced to **stop in illegal or unsafe places** which are exposed to poor conditions of roadside camps⁽⁵²⁾; this has a direct bearing on their health. **Lack of permanent address** makes it difficult to register with a GP practice.⁽²¹⁾ This causes an **overdependence on A&E** and late presentations, with many Travellers accessing health only at the point of crisis.⁽⁷⁶⁾

Information

According to estimates, as many as two thirds of Gypsies and Travellers living in the UK have literacy levels that mean they have **difficulty completing forms**.⁽⁵³⁾ This makes it difficult for them to access information about available services, including hospices⁽⁷⁸⁾, but also symptoms of cancer. Similarly, once admitted for diagnosis or treatment, many of the older patients are unable to fill in forms, but reluctant to admit this, they experience frustration and obstacles to access relevant services.⁽⁷⁸⁾

Perception of health

Self-reliance is common among Gypsies and Travellers.⁽⁷³⁾ This can result in strong reactions when presented with life threatening diagnosis with one study reporting "no evidence of any acceptance of life-threatening diagnoses or the experience of dying" in the community.⁽⁷³⁾ Self-reliant attitudes towards health are expressed on many levels. **Mental health issues** resulting from being diagnosed with and treated for cancer, such as stress, anxiety and depression can also often be left unaddressed.⁽⁷⁶⁾ As a result, some people living with cancer from Gypsy and Traveller communities will require more support from the social and healthcare professionals to engage in available support services.

What are the needs of Gypsies and Travellers in provision of cancer care?

There is a need for cultural education of staff and flexibility in models of service provision to accommodate for specific preference resulting from '**brick and mortar**' syndrome – an aversion to being in a contained environment. This has been put forward as an explanation for high rates of early discharges from hospital in Travellers (not cancer specific).⁽⁷⁸⁾

As **healthcare** in many Gypsy and Traveller communities is largely **delivered within families**, more needs to be done to promote early cancer symptom detection and presentation to healthcare specialists. Family involvement can also create tensions with the professionals by **interference** from a large number of unofficial carers and **lack of privacy** to discuss health issues.⁽⁷⁶⁾ Nonetheless, the importance of family in Gypsy and Traveller communities as a **support network**, especially at the end of life, should not be underestimated. Provision of **personal care** at home is often not only an option, but also a preference in this group.⁽⁷⁸⁾

Finally, it is important to bear in mind strong **gender divide** in the community, making it sometimes inappropriate to discuss health issues with a person of the opposite sex.⁽⁷⁸⁾

What are the changes to the data on health in Gypsy and Traveller communities?

Even though Gypsies and Travellers are an ethnic minority group under UK law and were included in the 2011 Census, The Department of Health have made **no commitment** to include them as one of the 16 **ethnic minority categories monitored by the NHS**.⁽⁵⁴⁾ As a result, there is no centralised dataset making it difficult for health service providers to effectively address poor health outcomes in these communities.⁽⁵⁴⁾

SPOTLIGHT ON

Polish economic migrants living with cancer

Spotlight on people with cancer from Polish communities living in the UK

There is a large number of young Polish immigrants in the UK and a great need for support in provision of cancer services in the community. This section presents the specific needs in that group.

Since 2004 there has been a significant increase in the number of economic migrants to the UK from new EU member countries.⁽⁵⁶⁾ In **2013** there were an estimated **679,000** Polish people in the UK. Polish migrants are now the second largest non-UK born group in the country.⁽⁹⁷⁾

Although Polish migrants are a highly heterogeneous group, the majority of them have come to the UK mainly for **economic reasons**.⁽⁵⁸⁾ Not surprisingly then, as many as **86%** of Poles living in the UK are of **working age** (16-64).⁽⁵⁷⁾

What are the risks of getting cancer in the group before and after migration?

Cancer incidence in Poland is lower than in the UK, particularly so in the case of women. However **mortality** from all cancers is comparable in women in both countries, but **higher in Polish men**.^(59, 90)

There is evidence to suggest that **low rates of cancer in Polish women are likely to align with those of the UK** with time, partially because of lifestyle changes.⁽²⁸⁾ Even though levels of obesity in Poland are lower than in the UK,⁽⁵⁵⁾ and alcohol consumption is roughly comparable,⁽⁸⁹⁾ there is anecdotal evidence of **increased alcohol consumption** in the group following migration.⁽⁶⁰⁾ Moreover, a survey of the Polish population in Ireland indicated that as many **61% of men and 47% of women smoke**.⁽⁶¹⁾ This compares with 33% in Poland and 22% in the UK.^(91,92)

High prevalence of cancer in Polish men is likely to persist after arrival to the UK. There is also evidence to suggest that **low rates of cancer in women are likely to align with those of the UK** with time, partially because of lifestyle changes.⁽²⁸⁾ Even though levels of obesity and alcohol consumption in Poland are lower than in the UK,⁽⁵⁹⁾ there is anecdotal evidence of **increased alcohol consumption** in the group following migration.⁽⁶⁰⁾ Moreover, a survey of the Polish population in Ireland indicated that as many **61% of men and 47% of women smoke**.⁽⁶¹⁾ This compares with 32% in Poland and 27% in the UK.⁽⁵⁹⁾

What issues affect access to cancer care for Polish migrants?

Limited knowledge of English is one of the challenges faced by Polish migrants when it comes to access and benefit from healthcare services.⁽⁶²⁾ Even though the public sector bodies in the UK, including medical centres, have been responding to communication problems by **producing information in Polish** and recruiting **translators**⁽⁶³⁾, there is still evidence of **shortages** in both areas, partially because of the ethnicity coding in the systems. With the group being described as **White Other** it is hard to pick up on the need for a translator.⁽⁶²⁾

There is a clear need for lifestyle and health promotion interventions in the Polish community living in the UK, but there is also strong evidence suggesting this group is **less likely to engage in primary and preventative care**⁽⁶⁴⁾ There is **lower uptake of cancer screening programmes** in Polish women in the UK compared to White British women.⁽⁶²⁾ There have been many explanations for this situation. Confusion resulting from **differences in recommendations** for screening age and intervals⁽⁶⁶⁾, as well as wider **problems accessing the information, understating healthcare** and lack of prior experience of the NHS are among many on the list.⁽⁶⁷⁾

What are the needs of Polish migrants in provision of cancer care?

As a **young, transient population** moving frequently, screening information and **invites sent in letter often do not reach them**. Optional routes of staying in touch and reaching the group should be considered. **Preferences** around the provision of screening (interval and staff involved) also play an important role in their likelihood to engage in the screening programme and should be taken into account when delivering services.⁽⁶²⁾ Availability of cancer service **information in Polish and translators** supporting cancer patients alongside cancer pathway is crucial for provision of effective care in the group in the later stages of person's cancer journey.

SPIRITUAL NEEDS OF PEOPLE WITH CANCER FROM BME GROUPS

What are spiritual needs?

“Spiritual needs” can be **both religious and non-religious**, depending on personal beliefs.⁽⁶⁸⁾ In one US study of advanced cancer patients, more African Americans (89%) and Hispanics (79%) reported religion to be very important compared with Whites (59%).⁽¹⁰⁾

Rephrasing spiritual support to **‘lifting spirits’** highlights new meanings of having someone to talk to about concerns and **fears for the future** and coming up with coping strategies despite the circumstances and the prognosis. What distinguishes emotional support from spiritual support is its source. Whereas the first one depends largely on friends and family, spiritual support is often seen as **delivered by professionals and networks outside**, including religious figures and groups, but not exclusively.⁽⁹⁴⁾

Focus on the unknown aspects of the future places spiritual support at the core of treatment of progressive conditions such as cancer when considering spiritual care for many people with cancer from BME communities.⁽²⁰⁾ Some people from BME groups have a **strong reliance on spiritual belief** and practice, with strong variations between the groups in the form and extent of spiritual or religious practices.⁽²⁰⁾

What are the positive impacts of spiritual support in cancer care?

A study found over 40% of one ethnically diverse group of cancer patients indicated a need for help finding hope and meaning of life following their cancer diagnosis.⁽⁶⁹⁾ More precisely, religious faith and spiritual belief have been identified as important **copied resources**.⁽⁷⁰⁾

African-American participants talked about **increased faith and church attendance** after diagnosis, and used church, faith and church families for coping and receiving support. Participants in six of seven African-American focus groups spoke about **the significance of prayer in helping them cope** with their cancer diagnosis, treatment and recovery.⁽⁶⁷⁾

Involvement of **key religious figures**, for example Imams and Pastors, into **delivery of health promotion messages** increases their strength through linking them to the Qur’an or Bible.⁽³²⁾ These messages could help promote early detection of cancer in some BME groups.

What are the possible challenges around spirituality in cancer care?

Spirituality can have an impact on engagement in healthcare.⁽⁷¹⁾ This can be seen clearly in the end of life care, as **religion** has been shown to have a **fundamental influence in shaping treatment decisions**.⁽⁷²⁾ This also applies to making decisions about cancer treatment.

People from BME groups have also been found to be **more anxious about talking about death** and dying.⁽⁴³⁾ This has implications for the healthcare providers in terms of how they engage with people from BME communities facing terminal illness.

Frequent **generalisations and stereotyping** around lifestyle and spiritual preferences in BME groups by service providers was shown to lead to further mismatches between needs and services.⁽⁵¹⁾ In the meantime, simple solutions can mitigate the risk of delivering services inappropriately. Incorporating a **multicultural calendar** into the appointment-booking system, for example taking into consideration the holy month of Ramadan or religious holidays in planning screening or appointment times, could increase the uptake of those services in Muslim communities.⁽³²⁾ Asking people what their fears and anxieties are and what support they would like in a timely and appropriate way and in an appropriate setting, would help to identify if they have any spiritual support needs. Similarly, accommodating for spiritual needs such as prayer rooms in hospitals can have a positive impact on people's experience of their cancer journey.

REFERENCES, SOURCES, NOTES AND CAVEATS

Quotes

The quotes on pages 13, 28, 31 and 35 are real quotes from people with malignant melanoma or their carers, however we have changed their names to protect their identity. The quote on page 7 is from a Macmillan case study who has kindly agreed to be featured in this publication.

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APPENDIX A

JARGON BUSTER

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

(i) Health data terms

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

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

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

Survival: When we talk about ‘cancer survival’ we mean the percentage of people who survive

a certain type of cancer for a specified amount of time.

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

(ii) Other terms

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

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

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

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

Full suite of the Rich Pictures

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

Overarching Rich Picture

The Rich Picture on people with cancer

(MAC15069)

The Rich Pictures on cancer types

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

The Rich Pictures on age groups

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

Other Rich Pictures

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

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

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

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

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

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

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

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

Code: MAC14662_14
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