

THE EMERGING PICTURE

# LGBT PEOPLE WITH CANCER

WE ARE  
MACMILLAN.  
CANCER SUPPORT



Karen, 44, living with cancer

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



# About this 'Emerging 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, and particularly the 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 Emerging 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.

As there are limited data specifically about lesbian, gay, bisexual or transgender people (LGBT – for full definitions of these terms please see page 4) people with cancer we are focusing more on the needs and experiences of this group; in time, as robust data becomes available about LGBT people with cancer we hope to turn this 'Emerging Picture' into a 'Rich Picture', covering more comprehensively the numbers, as well as the needs and experiences, of LGBT people with cancer.

This Emerging 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
- Help those working with LGBT people with cancer to understand better the specific needs of this group

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 Emerging Picture
- Suggest or recommend that specific action should be taken

For simplicity, the year to which the data in this document relates 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 'Emerging Picture' is part of a suite of Rich Picture documents. To access these documents please visit <http://www.macmillan.org.uk/Richpictures>. 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.



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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 52.

## Other related information for people affected by cancer

This document is designed to summarise the numbers, needs and experience of people with cancer. It is not designed specifically with people affected by cancer in mind, although some people within this latter group may find the information contained here helpful. People affected by cancer may find our information booklet 'The Cancer Guide' (MAC5765) more helpful:



**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](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 Emerging 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).

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# SUMMARY OF LGBT PEOPLE WITH CANCER

## Key stats

Treasury actuaries estimate that **5%-7% of the population in the UK are lesbian, gay or bisexual**, which equates to **approximately 3.6 million people\***.<sup>(6)</sup>

In 2009 the **number of people in the UK who had sought gender reassignment treatment was estimated at 12,500**, out of a subset of **300,000 people in the UK who were transgender**.<sup>(9)</sup>

**338,631 people in the UK were diagnosed with cancer in 2012**.<sup>(12)</sup>

Around **22,000 LGBT people die in the UK each year, from all causes**.<sup>(14)</sup>

**6% of the population in the UK are LGBT, according to treasury estimates\***

\*However it is widely acknowledged that these data lack robustness.

## Diagnosis

LGB people with cancer are **more likely to receive an assessment and care plan** in comparison to their heterosexual counterparts.<sup>(35)</sup>

Oestrogen may **increase the risks of breast cancer for male to female transgender individuals** depending on the amount taken over the person's entire life.<sup>(31)</sup>

LGB people with cancer are **less likely than heterosexual people** with cancer to be given **written information** about the type of cancer they have.<sup>(35)</sup>

LGB people with cancer are **less likely than heterosexual people with cancer** to receive information from hospital staff about **self help and support groups** for people with cancer.<sup>(35)</sup>

**LGB people with cancer are less likely than heterosexual people with cancer to be given written information about the type of cancer they have**

## Treatment

LGB people with cancer are **less likely than heterosexual people with cancer** to say that they believe that **hospital staff always did everything they could to control their pain**.<sup>(35)</sup>

**Gay men have lower levels of sexual functioning** than heterosexual men **after prostate cancer surgery and during hormone therapy treatment**.<sup>(52)</sup>

**LGB people with cancer are more likely** than heterosexuals to say that they were **given enough information about their condition and treatment for cancer**.<sup>(35)</sup>

**LGB people with cancer are less likely than heterosexual people with cancer to be given written information about the type of cancer they have**

## Survivorship

Some **lesbian and bisexual women** report feeling **excluded from support groups** because the environments are not sufficiently comfortable for them to feel able to come out.<sup>(62)</sup>

**500,000 people** in the UK (not just LGBT people) are **facing poor health or disability after cancer treatment**.<sup>(57)</sup>

**350,000 people** living with and beyond cancer (not just LGBT people) are **experiencing sexual difficulties**.<sup>(57)</sup>

58% of people with cancer (not just LGBT people) feel their **emotional needs are not looked after** as much as their physical needs.<sup>(34)</sup>

**500,000 people in the UK are facing poor health or disability after cancer treatment**

## End of life

**93% of LGBT specialists and service-users** consider that more work needed to be done to ensure **end of life services are improved for LGBT people**.<sup>(71)</sup>

It can be a **concern for LGBT people being treated in hospital that someone close to them will be denied visiting rights and information** because they are not seen as the 'next of kin'.<sup>(72)</sup>

**77% of people who died from cancer** (all people not just LGBT people) **would have liked to have spent the last weeks and days of their life at home**. However, only 30% of those who die from cancer actually die at their home or own residence.<sup>(65, 66)</sup>

**93% of LGBT specialists and service-users** consider that more needs to be done to ensure end of life services are improved for LGBT people

## Lifestyle & perceptions

LGB people are significantly **more likely to smoke** than heterosexuals. Smoking accounts for one in four UK cancer deaths.<sup>(92)</sup>

LGBT communities appear to **consume higher rates of alcohol** when compared to the general population. Drinking alcohol regularly can increase the risk of a number of cancers included breast, mouth and bowel cancer.<sup>(95)</sup>

Among gay men there is evidence of **higher rates of eating disorders**, such as **bulimia**, compared to heterosexual men.<sup>(95)</sup>

LGB people are **more likely to take recreational drugs** than heterosexuals.<sup>(98)</sup>

**LGBT communities appear to consume higher rates of alcohol when compared to the general population**

# INTRODUCTION TO LGBT PEOPLE WITH CANCER

## Who are LGBT people with cancer?

The term 'LGBT' refers to lesbian, gay, bisexual or transgender people.

There are a range of understandings of the terms 'lesbian', 'gay', 'bisexual' and 'transgender', and not all LGBT people openly identify with the terms used, so it is therefore difficult to arrive at definitive terms. However it is important that the language, definitions and categories used to describe LGBT people are considered in terms of how they impact on the person themselves.

### Gay and Lesbian

'Gay' or 'lesbian' refers respectively to a man or a woman who is attracted to people of the same gender.

Women can also identify as gay as well as lesbian; it is a generic term for lesbian and gay sexuality.<sup>(1)</sup>

### Bisexual

'Bisexual' is an umbrella term for people who are attracted to more than one gender.<sup>(2)</sup>

### Transgender<sup>(3, 4)</sup>

'Transgender' is a more complex term to define.

'Trans' can be an umbrella term inclusive of anyone whose gender identity differs from the gender they were assigned at birth, and this is the definition of 'trans' that we will use in this document.

Trans men are those who were assigned female at birth, but who identify as men. Trans women are those who were assigned male at birth, but who identify as women. By contrast, 'cisgendered' refers to people who self-identify with their birth gender.

However, definitions can vary as trans people often have complex gender identities, so the terms we use in this Emerging Picture are intended to provide a basic overview.

'Transgender' is a broad term, that can refer to a person whose gender identity differs to a greater or lesser degree from the gender they were assigned at birth.


'Transsexual' typically refers to the subset of transgender people who have hormone therapies or gender reassignment surgeries to change their gender from that they were assigned at birth.

The Gender Recognition Act (2004) means a transgender person can apply for a gender recognition certificate, which allows the person to have a new birth certificate and be treated, for legal purposes, as a person in their gender.

Lesbian, gay and bisexual labels essentially relate to sexual orientation, whereas the term transgender addresses gender identity and may encompass people who are heterosexual as well as those who identify as lesbian, gay or bisexual.

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





**'I was diagnosed with stage 3 cervical cancer at the age of 37. I went through five and a half weeks of chemo and radiotherapy, then had internal radiotherapy, and then more radio and chemo. Luckily, this cured me but damage was done to my bowel and bladder and last year I had a hysterectomy, and, after several cystoscopies and being told I had bladder cancer, my bladder was removed.**

**As a gay female, I did not go for smear tests which most likely would have diagnosed the problem a lot earlier and prevented me losing my bladder. My treatment was done at the cancer centre, Queen Elizabeth Hospital Birmingham, and I cannot thank the nurses and my consultants enough for saving my life. I am now in remission, and getting on with my life – I have even written a novel called 'The Knowing', which has recently been published.'**

Karen, 44

# AVAILABILITY OF DATA ON LGBT PEOPLE WITH CANCER

As there are limited data available specifically about LGBT people with cancer we are focusing more on the needs and experiences of this group; in time, as robust data becomes available about LGBT people with cancer we hope to turn this 'Emerging Picture' into a 'Rich Picture', covering more comprehensively the numbers, as well as the needs and experiences, of LGBT people with cancer.

This Emerging Picture will focus on the **needs and experiences** of LGBT people with cancer, more than the numbers. This is because there are **significant limits to the amount of robust data that is available on LGBT people in general, and specifically LGBT people with cancer, both in the UK and internationally.**

While we aim to be inclusive in this document we are drawing upon external resources, and these sometimes conflate terminology, so that some data claims to refer to LGBT people when in fact they only refer to subsets of this group.

In addition, 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 relevant source.

Although data gaps exist, this Emerging Picture attempts to pull together the evidence that is available around numbers, needs and experiences of LGBT people with cancer. The sections 'Cancer journey' and 'Lifestyle and perceptions' collate for the first time such comprehensive information on experiences of LGBT people living with cancer, across the whole cancer pathway.

At the same time, by acknowledging that in some areas robust evidence is not yet available, we hope to highlight the need for greater research to be undertaken into LGBT people with cancer, in order to understand and support this group better. We have explicitly indicated the areas where data are lacking.

In order for this Emerging Picture to progress to a Rich Picture sexual orientation and gender identity need to be monitored at every point of the cancer journey, to identify prevalence and start to raise awareness, as the introduction of monitoring often starts to raise these conversations. More work needs to be done around raising the fact that people of different sexual orientations and gender identities might have different needs.

## What is the problem?

There is a need for more robust data on LGBT people with cancer, as **the quality of sexual orientation recording in routinely collected health data remain poor.** This raises **concerns around completeness and accuracy of analysis** when using existing data.

The relatively small numbers of gay, lesbian and bisexual women in research studies and the lack of health-related data collected for this group mean that statistically significant and widely meaningful results can be difficult to obtain.

Fear of discrimination can mean people are cautious about being open about sexual orientation or gender identity, so accurate statistics are difficult to achieve.<sup>(72)</sup>

**In particular, the figures around bisexual and trans people affected by cancer are limited,** and there is little representation or research around bisexual and trans people affected by cancer.

Even when reports and publications claim to cover the LGBT community it is not uncommon for far greater focus to be placed on gay and lesbian people, and for bisexual and trans people to be less well represented. However it is important to realise that bisexual and trans people's experiences can differ significantly from those of lesbian and gay people, and that it is therefore not always accurate to group them together.

### Why is it a problem?

Poor quality healthcare data on sexuality may lead to **inadequate resource and service commissioning**, as it is needed to identify health issues, assist with the design of appropriate interventions, target resources and education to high risk populations, and then evaluate these interventions. This can also result in a **lack of guidance for healthcare professionals**, which may dissuade LGBT people from seeking the care they need.

### What is being done to improve data quality?

It is to be hoped that this Emerging Picture will lend weight to the importance of collecting data around sexual orientation, not least by highlighting the gaps that currently exist in data collection, and various other organisations are undertaking work to improve data quality.

The National LGB&T Partnership is working with NHS England, Public Health England and Department of Health around the issue of sexual orientation monitoring, with a view to **ensuring that it is possible for commissioned services to capture sexual orientation data (from an IT point of view)**, and ensuring that **the reasons are understood why collecting data is so important**. The three system leaders are being lobbied to create a **sexual orientation monitoring task force**, and for **the monitoring of sexual orientation to be made mandatory** as a result.

The National LGB&T Partnership and the Gender Identity Research and Education Society (GIRES) have produced **guides to the monitoring of sexual orientation and gender identity** respectively, and Stonewall has produced a **guide to the use of sexual orientation data**. Such initiatives can potentially help to address the problem of poor quality sexual orientation recording in routinely collected health data, and ultimately help to improve data collection around LGBT people with cancer.

Regarding LGBT people with cancer, Public Health England's 2013 report, 'The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document' recommends that **sexual orientation and gender identity monitoring should be encouraged in the national cancer registry and national cohort studies relating to cancer**.<sup>(81)</sup>

The National LGB&T Partnership is also **lobbying on a local level regarding the importance of knowing the population being treated or worked with**, and there are a number of instances of good practice around this. For example, in London, Manchester and Birmingham local LGB&T charities are developing Community Champion/Leader programmes, to raise awareness of the issues faced by, and the needs of, LGB&T patients, including raising awareness of the importance of recording their sexual orientation and gender identity.

# 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.<sup>(5)</sup> Particularly large increases are anticipated in the oldest age groups and in the number of long term survivors. 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.

At present there are limited robust data on the numbers of LGBT people living in the UK, and therefore there is also a lack of robust information on the number of LGBT people living with cancer in the UK.

Treasury actuaries have estimated that 5% to 7% of the UK population is LGBT, which equates to approximately 3.6 million people.<sup>(6)</sup> Stonewall (a UK lesbian, gay and bisexual charity), has regularly cited the 5% to 7% figure, based on the same data.<sup>(7)</sup> However, although commonly cited, and although there is little alternative data available, this estimate is based on the findings in a number of different studies, from both the UK and internationally. It is therefore widely acknowledged that this methodology could be improved, and that additional data must be collected to provide a more accurate indication of the LGBT population in the UK. In this Emerging

Picture we will use the 6% figure, based on the Treasury estimates, purely as an indicative figure.

A 2010 Office of National Statistics (ONS) survey indicated that just under 1% of the UK population identified as gay/lesbian and 0.5% as bisexual; in other words, over 750,000 adults (over 16) in the UK. However, 3.2% were recorded as "Don't know/refusal" and 0.6% were recorded as "Non-response", as well as which there would be some who choose not to be open or do not identify with L, G, or B.<sup>(8)</sup> It is therefore widely acknowledged that, while these data are also commonly cited, the methodology for this estimate could also be improved, and more robust data must be collected.<sup>(103)</sup>

A 2013 survey of cancer patients provided similar proportions, with 0.7% identifying as gay/lesbian and 0.2% as bisexual, while 3.4% preferred not to answer (a specific response option) and 6.2% did not answer the question at all.<sup>(35)</sup>

Fear of discrimination can mean people are cautious about being open about sexual orientation or gender identity, so accurate statistics are difficult to achieve.<sup>(72)</sup>

In 2009 the number of people in the UK who had sought gender reassignment treatment was estimated at 12,500, with the expectation that this figure will grow as more transgender people feel able to seek increasingly available support. This figure was a subset of an estimated 300,000 people in the UK who were transgender. However, while these are commonly cited data, it is widely acknowledged that more robust data are needed in this area. It is also worth noting that this figure does not represent the true extent of people who identify as trans, as there will be many who have not come forward for treatment.<sup>(9)</sup>

## 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 LGBT PEOPLE WITH CANCER

This section presents some of the key stats and facts relating to LGBT people with cancer. You may benefit from referring to the Jargon Buster on page 61 for details on some of the terms used in the section. Please note that incidence and mortality data on all cancers exclude non-melanoma skin cancer.

## 6%?

of the UK population are LGB people, according to Treasury estimates of 5% to 7%, and 1.5% of the UK population are LGB according to ONS data. However it is widely acknowledged that these methodologies could be improved, and that additional data must be collected to provide a more accurate indication of the LGB population in the UK.<sup>(6, 105)</sup>

## 12,500

people in the UK presented for gender reassignment in 2009.<sup>(9)</sup>

## 2.5 million

people in the UK are currently living with cancer.<sup>(5)</sup>

## 90%

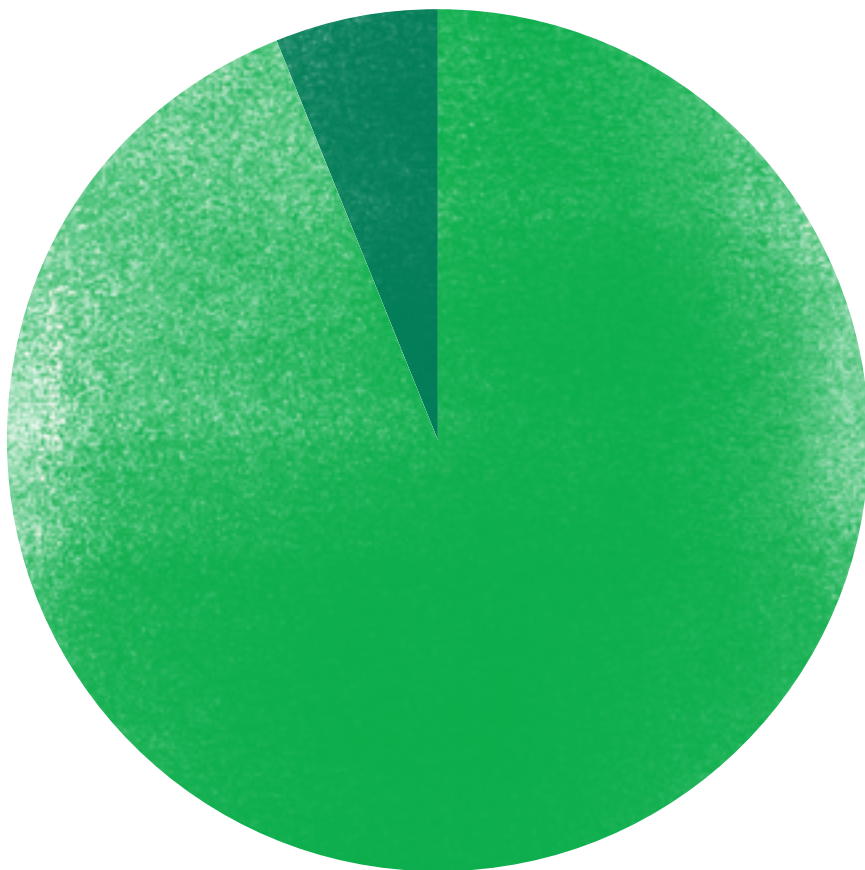
of gay and bisexual men in the UK have never talked with a healthcare professional about prostate cancer, the most common cancer in men in Britain.<sup>(10)</sup>

## 18%

of lesbian and bisexual women of an eligible age have never had a cervical screening test, compared with 7% of women in general.<sup>(11)</sup>

## How many LGBT people live in the UK?<sup>(6, 7)</sup>

Sexuality of UK population, 2009



UK heterosexual  
population

**94%?**

UK LGB  
population

**6%?**

**Treasury actuaries estimate that 6% of the population is LGB, which equates to approximately 3.6 million people, but it is commonly acknowledged that the methodology used to arrive at this figure could be improved.<sup>(6)</sup> An estimated 300,000 people in the UK are transgender.<sup>(9)</sup>**

## How many people get cancer per year? (incidence)<sup>(12)</sup>

Cancer incidence, UK, 2012

**338,600**

people in the UK were diagnosed with cancer in 2012



**At present there are limited robust data, so it is not currently known how many LGBT people are living with cancer in the UK.**



## How many LGBT people die from cancer per year?

There is limited available data on the number of LGBT people who die from cancer per year.

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**Around**  
**22,000**

LGBT people die in the UK each year, from all causes.<sup>(14)</sup>  
This compares to around 570,000 deaths of all people in the UK, in 2012.<sup>(13)</sup>



**At present there are limited robust data, so it is not currently known how many LGBT in the UK die from cancer.**

## How many LGBT people are currently living with cancer?

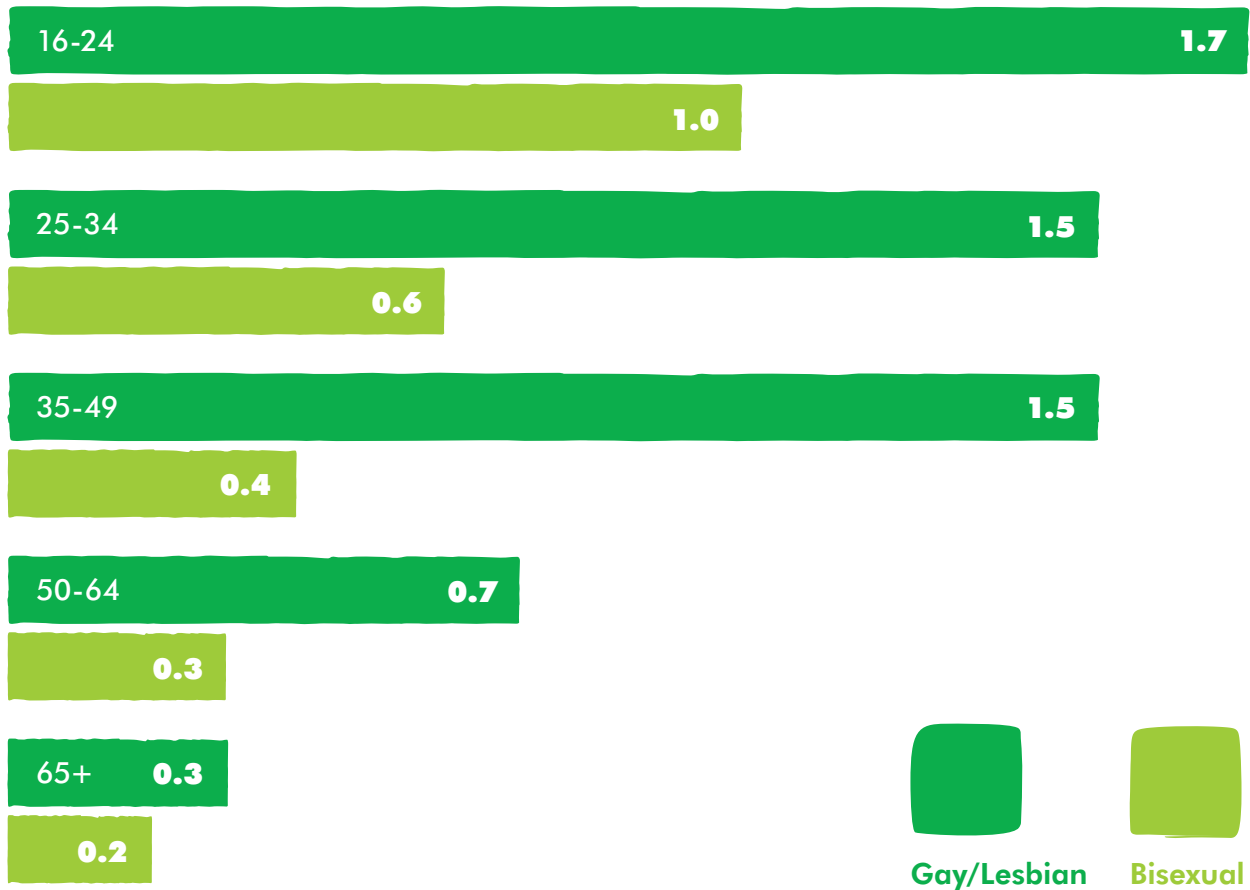


**At present there are limited available robust data on the number of LGBT people who are living with cancer in the UK.**

**2.5 million people in the UK are currently living with cancer.**

## What are the age breakdowns of the UK population who identify themselves as lesbian, gay and bisexual?

### Sexual orientation by age group<sup>\*(15)</sup>



\*These ONS data estimate that just under 1% of the UK population identifies as gay/lesbian and 0.5% as bisexual, whereas we believe that the actual figure is much higher (eg Treasury actuaries estimate that around 6% of the population are LGB).<sup>(103)</sup> However, robust data are not available.

**!** There is a lack of robust data on the age breakdowns of the UK population who identify themselves as trans.

## What are the major demographic variations for LGBT people with cancer?



Data are not generally available that show the characteristics of LGBT people with cancer, and data for the LGBT population overall is limited. However, some data which are available by sexual orientation for the overall population are shown below.

### Age

A 2007 UK survey of the health needs of 6,178 lesbian and bisexual women found that respondents came from a wide age-range. The youngest female respondent was 14 and the oldest was 84.<sup>(17)</sup>

A 2011 UK survey of the health needs of 6,861 gay and bisexual men's health needs found that the youngest participant was 16 and the oldest was 85.<sup>(10)</sup>

'Coming out' can particularly affect older LGB people, some of whom are not as open about their sexuality as younger people. A 2003 survey of people aged over 50 found that 37% of male and 23% of female respondents had concealed their sexual orientation throughout their lives.<sup>(16)</sup>

### Ethnic background

The aforementioned 2007 UK survey of lesbian and bisexual women found that 82% of respondents were white British, and the rest were from ethnic minorities, which is comparable with the general population.<sup>(17)</sup>

The aforementioned 2011 UK survey of gay and bisexual men's health needs found that 95% of male respondents were white and 5% were black or minority ethnic.<sup>(10)</sup>

### Social background

Studies in the US have documented the low social and economic status of some trans people. Socially and economically disadvantaged groups are at increased risk of cancer of the lung, cervix, stomach, oesophagus, larynx, liver, and bladder. The links between poverty, social marginalization, and cancer are not well understood, but are believed to be connected to stresses on marginalized people (including social isolation, often a problem for trans people), lack of access to good quality food, and marketing of cigarettes and alcohol to people living in poverty.<sup>(18)</sup>

## How does the UK compare internationally for LGBT people with cancer?

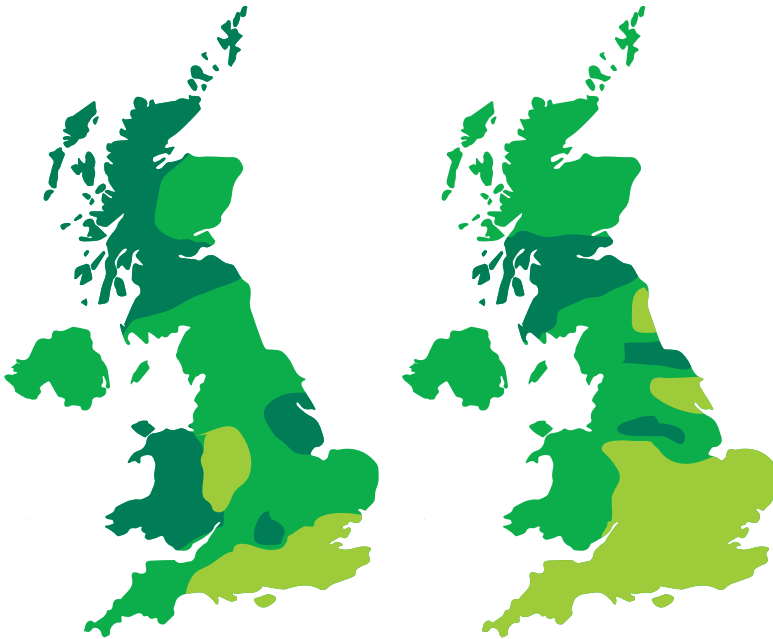
There is more information on cancer within the LGBT community in the US than there is in the UK, but there are limited robust sources of international comparison. For example an American Cancer Society study has found that, at a conservative estimate, tobacco use takes the lives of 30,000 LGBT individuals each year, but we do not know the equivalent for the UK.<sup>(19)</sup>

While in both the UK and the US LGBT people are more likely to be smokers than heterosexual people (increasing their risk of some cancers), evidence suggests that the proportion of LGBT people who smoke is greater in the US. In the UK, 26% of gay and bisexual men currently smoke compared to 22% of men in general.<sup>(10)</sup> More than a quarter of lesbian and bisexual women in the UK currently smoke.<sup>(17)</sup> The differences in the United States are more marked, where in 2009–2010, the prevalence of cigarette smoking among LGBT individuals was 33%, compared with 20% among heterosexual individuals.<sup>(20)</sup>

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



There are limited available data around the geographical spread of cancer incidence and mortality rates amongst LGBT people. The maps on these pages show the broad variations across the UK in terms of cancer incidence and cancer mortality for all new cases and all cancer deaths, and for people of all sexual orientations.



Incidence

Mortality



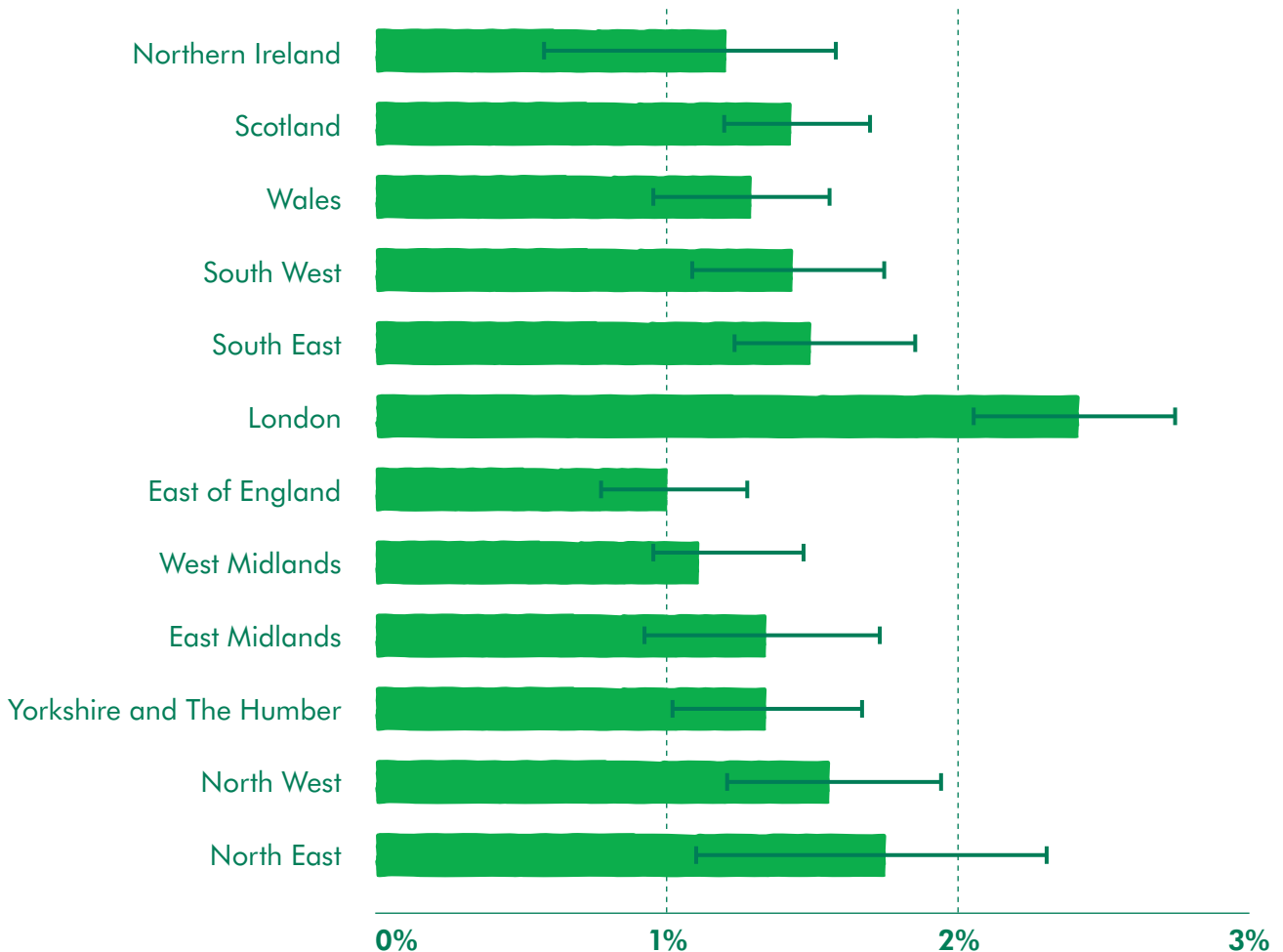
### Important note

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, [http://www.ncin.org.uk/cancer\\_information\\_tools/eatlas/](http://www.ncin.org.uk/cancer_information_tools/eatlas/), or Macmillan staff members can contact Macmillan's Health Data team.

**Cancer incidence rates are higher in Scotland and Wales, and lower in Southern England. Cancer mortality rates are generally higher in Scotland, Wales and parts of Northern England.**

## What are the geographical ‘hotspots’ for LGBT people living in the UK?<sup>(15)</sup>

Percentage of gay, lesbian, and bisexual adults by region, January 2012–December 2012



The whisker bars on top of the bar chart show confidence intervals for each estimate, ie they indicate the level of uncertainty surrounding each percentage. These ONS data estimate that just under 1% of the UK population identifies as gay/lesbian and 0.5% as bisexual, whereas we believe that the actual figure is much higher (e.g. Treasury actuaries estimate that around 6% of the population are LGB).<sup>(103)</sup>

**There may be significant LGBT populations in urban as opposed to rural areas, and within particular areas within cities, so some areas may have more LGBT people affected by cancer simply because there are more LGBT people living there.**

# 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 LGBT people living with 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 (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?<sup>(22)</sup>

Reporting symptoms to a GP early can help ensure that if cancer is diagnosed, then it is diagnosed as early as possible. There are some common signs and symptoms for most cancers, though each cancer type has different signs and symptoms. Common signs and symptoms (for many cancer types) are:

- 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? 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 for this are either **late presentation** by patients or **late onward referral** by general practitioners.<sup>(23)</sup>

**23% of all newly diagnosed cancers** in 2006–2010 (excluding non-melanoma skin cancer) first presented into secondary care as an emergency. The **emergency presentation** route includes A&E attendance, emergency GP referrals to an inpatient setting and emergency admissions to either an inpatient or outpatient setting. Relative survival estimates for emergency presentations were significantly lower than for other routes across all sites.<sup>(24)</sup>

Young gay and bisexual men have a slightly higher awareness overall of cancer signs and symptoms than young heterosexual men.<sup>(25)</sup>

Among younger women, bisexual women and lesbians seemed to have slightly more recall of signs and symptoms, but heterosexual women scored slightly higher on recognition of signs and symptoms. In the older age group however, lesbians seemed to have the most awareness overall.<sup>(25)</sup>

### What are the variations in screening for LGBT people with cancer?

A UK study of over 6,000 LGB women in 2007 highlighted that 15% of LGB women over the age of 25 had never had cervical cancer screening test. This is compared to 7% of women in the general population.<sup>(17)</sup>

Of those women who had never been for a cervical screening test, one in five had been told by a health professional that they are not at risk and one in fifty had said that they had been refused a test based on their sexual orientation.<sup>(17)</sup>

Around 20% LGB women who have not attended a cervical screening test did not think that they were at risk of cervical cancer.<sup>(17)</sup>

Screening may be particularly challenging for trans and non-gendered individuals as the service is by nature gendered and literature and imagery often assumes a heterosexual biological female status of the patient.<sup>(27)</sup>

Some cancer screening programmes are gender-specific based on assumptions about what body parts men and women have (e.g., screening for cancer of the breast and cervix). It may be difficult for health professionals to know what to recommend for trans people.<sup>(28)</sup>

An American study found that many lesbians have a history of delaying or avoiding check-ups and cancer screenings due to previous negative experiences in healthcare and/or because they feared discrimination.<sup>(29)</sup>



**'I am an 'out' lesbian woman and have found that the medical staff I have had to deal with have taken this fact in their stride without any awkwardness. I have not knowingly been discriminated against during my treatment as a result of my sexuality.**

**I think that is partly because I attend a specialist unit that seem to have an excellent level of staff training, and also partly because I have the confidence to present my domestic situation in such a way that everyone (that needs to be) is aware of my sexuality and so don't make any embarrassing 'slip ups' or assumptions.'**

Jean, 47

## How is cancer diagnosed? (Routes to diagnosis)<sup>(30)</sup>



Data is not generally available that shows routes to diagnosis split by sexual orientation. However the routes to diagnosis for people of all sexual orientations is shown below.



Emergency  
**23%**

GP referral  
**27%**

Two Week Wait  
**27%**

Other  
**23%**

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

**The number of diagnoses made via the emergency route is lower than the number made via the GP route.**

**‘There was one occasion that I went to the oncology hospital and the consultant was condescending and patronising. I remember how, when speaking to me (as a gay person) he referred to me as ‘people like you...’**

Paul, 47



## 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 Cancer Patient Experience Survey found people in the LGBT group were **more likely to receive an assessment and care plan** in comparison to their heterosexual counterparts.<sup>(35)</sup>

**Oestrogen may increase the risks of breast cancer for trans women** depending on the amount taken over the person's entire life. Transwomen who never take oestrogen or progestin have the same low breast cancer risks as cisgendered men.<sup>(31)</sup>

**Trans men who do not take hormones or have surgery have the same risks for breast cancer as cisgendered women.** There is no clear evidence that testosterone increases or decreases breast cancer risk. Chest reconstruction reduces but doesn't totally eliminate the risk of breast cancer, as microscopic breast tissue cells remain even after surgery.<sup>(31)</sup>

**Trans women who have not had a vaginoplasty (surgical creation of a vagina)** do not have a cervix so are **not at risk of cervical cancer.** Some types of vaginoplasty use the head of the penis to form a cervix; in these cases there is a risk of cervical cancer.<sup>(31)</sup>

**Trans women who are not taking hormones** are at the **same risk for prostate cancer as cisgendered men.** Feminising hormones cause the prostate to shrink, which reduces the risk of cancer, but it is not known how much the risk is reduced.<sup>(31)</sup>



## FINANCIAL NEEDS



**At present there are limited robust data on the financial needs of LGBT people at the Diagnosis stage of their cancer journey.**

There is **no available evidence** to suggest that **people from LGBT communities experience substantially different financial effects of their cancer** than non LGBT people living with cancer.

**Not specific to LGBT people with cancer**  
Four in five (83%) people are, on average, **£570 a month worse off as a result of a cancer diagnosis** (all people, not specifically LGBT people).<sup>(32)</sup>

It is estimated that **30% of people with cancer experience a loss of income as a result of their cancer**, with those affected losing, on average £860 a month. Additional costs and loss of income arise at different points in the cancer journey, but these figures show the financial strain that a cancer diagnosis can place on many families.<sup>(32)</sup>



## PRACTICAL AND INFORMATION NEEDS

**Prejudice, poor access to health care and several other risk factors** add to a **growing concern about cancer in the LGBT community.** A study in America found that insensitive treatment is fairly common, even from well intentioned doctors, so lesbians and gay men may avoid the medical system completely. Many lesbians have anticipatory fears, so they may not feel comfortable with coming out.<sup>(33)</sup>

LGB people with cancer are **less likely than heterosexuals to say that they were seen as soon as necessary** by a hospital doctor.<sup>(35)</sup>

LGB people with cancer are **less likely than heterosexual people to be given written information about the type of cancer** they have.<sup>(35)</sup>



**At present there are limited robust data on the practical and information needs of bisexual and trans people at the Diagnosis stage of their cancer journey.**



## EMOTIONAL AND PSYCHOLOGICAL NEEDS



**At present there are limited robust data on the emotional and psychological needs of LGBT people at the Diagnosis stage of their cancer journey.**

LGBT people with cancer were **less likely than heterosexuals to report that they were told sensitively** that they had cancer.<sup>(35)</sup>

LGBT people with cancer were **less likely than heterosexuals to believe they have been treated with dignity and respect** by hospital staff.<sup>(35)</sup>

**Not specific to LGBT people with cancer** **62%** of cancer patients in a survey had experienced **at least one psychological condition** that can occur as a result of cancer and its treatment in the previous 12 months. Such conditions included **depression, anxiety and sexual problems.** However, 40% of them had not sought help from healthcare professionals.<sup>(34)</sup>

**Women** living with cancer are **more likely to say they lack support from family and friends during treatment and recovery,** which can have negative impacts on both their emotional well-being and medical care.<sup>(53)</sup>

# NEEDS AND EXPERIENCES TREATMENT

## What treatments do LGBT 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.<sup>(36)</sup>



There are very limited data on specific cancer treatments across the UK and their effects on people from LGBT communities. However, we know that patient experience in cancer care may be poorer in the LGBT community.<sup>(35)</sup>

### Surgery

The use of surgery as a treatment for cancer varies between cancer types. A report for the National Cancer Intelligence Network in England showed that for cancers of the oesophagus, stomach, bladder, prostate, lung, pancreas and liver, less than 16% had a record of a major resection as part of their treatment. For liver cancer, only 6% of all patients were recorded as having undergone a major resection within NHS hospitals.<sup>(38)</sup>

### Chemotherapy

Chemotherapy is a very effective cancer treatment, and there are more than 100 different chemotherapy drugs.<sup>(36)</sup> Chemotherapy can cause side effects, which vary in severity. Most side effects are short term, begin to go once the treatment has finished and can be reduced through medicines. A doctor or chemotherapy nurse may be able to advise patients about the likely effects of the chemotherapy being undertaken.<sup>(36)</sup>

### Radiotherapy

Four out of ten of all people with cancer (40%) have radiotherapy as part of their treatment.<sup>(40)</sup> Radiotherapy affects people in different ways, so it is difficult to predict exactly how a given patient will react. Some people have only mild side effects but for others the side effects are more severe. For many people the side effects of radiotherapy wear off within a few weeks of the treatment ending and they can go back to a normal life.

## How many LGBT people with cancer have access to a Clinical Nurse Specialist (CNS)?



Currently, data are not widely collected on the numbers of LGBT individuals who have access to a CNS. Access to CNSs varies both geographically and by tumour site, which may lead to inequalities in patient experience. On average there is only one lung cancer nurse in England for every 161 people diagnosed with lung cancer, compared to one breast cancer nurse per 117 people diagnosed with breast cancer.<sup>(41)</sup>

Macmillan's internal data suggests that we had (as of June 2014) 4,149 Macmillan nurse posts across the UK.<sup>(42)</sup>

## What does this mean for LGBT cancer patients?

CNSs improve quality and experience of care for patients, reinforce patient safety, demonstrate leadership and increase productivity and efficiency. CNSs also coordinate ward admissions for unwell patients, expedite outpatient clinic appointments, reorganise reviews to minimise cancelled procedures or operations and give advice on managing medication throughout the cancer journey. This enables patients to move through the system as smoothly as possible and diverts pressure away from other professionals such as doctors and the ward nursing team.<sup>(43)</sup>

Without CNSs the cancer journey can be complex and disjointed, often leaving the patient with unmet needs, increasing the risk of emergency admissions and avoidable costs for the health service. The 2013 Cancer Patient Experience Survey found that, of those who disclosed their sexuality, LGB individuals were not significantly less likely than heterosexuals to be given the name of a CNS who would be in charge of their care.<sup>(35)</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 other health conditions do LGBT people with cancer have? How does this affect their treatment, survival, long term effects or experiences?

### Mental Health

The available evidence suggests that LGBT people have a higher risk of experiencing suicidal feelings, self-harm, drug or alcohol misuse and mental health problems such as depression and anxiety.<sup>(44)</sup>

Evidence indicates that the increased risk of mental disorder in LGB people is linked to experiences of discrimination. LGB people are more likely to report both daily and lifetime discrimination than heterosexual people.<sup>(45)</sup>

In a 2011 survey of 6,861 gay and bisexual men in Britain, Stonewall claimed that:

- 13% of respondents were experiencing moderate to severe levels of mixed depression and anxiety, while suggesting that this compared to 7% of men in general.<sup>(10)</sup>
- 3% of gay men and 5% of bisexual men surveyed had attempted to take their own life in the previous year, while suggesting that just 0.4% of men in general attempted to take their own life in the same period.<sup>(10)</sup>
- 1 in 14 (7%) gay and bisexual men deliberately harmed themselves in the previous year, while claiming that this compared to 1 in 33 men in general.<sup>(10)</sup>

In a 2007 survey of 6,178 lesbian and bisexual women in Britain, Stonewall claimed that:

- 5% of lesbians and bisexual women surveyed say they have attempted to take their own life. This increases to 7% of bisexual women.<sup>(17)</sup>
- 1 in 5 (20%) lesbian and bisexual women surveyed have deliberately harmed themselves compared to 0.4% of the general population.<sup>(17)</sup>

- 79% of lesbian and bisexual women surveyed say they have had a spell of sadness, felt miserable or felt depressed. This increases to 84% of bisexual women and 86% of black and minority ethnic lesbian and bisexual women.<sup>(17)</sup>
- 74% of lesbian and bisexual women surveyed say they felt anxious or nervous, this increases to 78% of bisexual women and 81% of black and minority ethnic lesbian and bisexual women.<sup>(17)</sup>

### Sexual health

Anyone can get HIV if they have unprotected sex, but gay men are one of the highest risk groups. Women who have only ever had sex with women are at low risk.<sup>(46)</sup>

At the end of 2012, there were an estimated 41,000 gay men and men who have sex with men (MSM) living with HIV of whom 18% were undiagnosed. That means over 7,000 MSM may be undiagnosed, not on treatment and therefore potentially infectious. The prevalence of HIV in MSM is around 1 in 20 with nearly 1 in 12 in London.<sup>(47)</sup>

MSM account for:

- 41% of people living with HIV in the UK<sup>(47)</sup>
- 51% of all new HIV diagnoses in 2012 were among MSM<sup>(47)</sup>

3 in 10 gay and bisexual men have never had an HIV test in spite of early diagnosis now being a public health priority.<sup>(10)</sup>

HIV attacks cells which help the immune system respond to infections. This makes people with the virus more prone to developing serious infections and different types of cancer, including lymphoma and anal cancer.<sup>(48,75)</sup>

1 in 4 gay and bisexual men have never been tested for any sexually transmitted infection.<sup>(49)</sup>



**'Most questions were directed at my partner though I was included in the process, but not necessarily as my girlfriend's partner, but as a "close friend". It isn't questioned, but it is assumed you are heterosexual until you choose to make them aware of what you thought should be obvious. We didn't always do this as this might add to what was a stressful event by itself. However, the times we did bring it up, it helped us relax and approach the situation in a much more together way.'**



## PHYSICAL AND MEDICAL NEEDS

LGBT people with cancer are **less likely** than heterosexuals to say **that they believe that hospital staff always did everything they could to control their pain.**<sup>(35)</sup>

Two studies have shown that **gay men have lower levels of sexual functioning than heterosexual men after prostate surgery** and during hormone therapy treatment.<sup>(52)</sup>

### Not specific to LGBT people with cancer

The effects of cancer and its treatment can impact people's lives in many different ways, and can affect them for weeks, months or even years after treatment has ended. **Fatigue** is a very common and frustrating problem, with **75% of cancer** survivors saying that they have to deal with fatigue following treatment.<sup>(57)</sup>

Other significant effects caused by cancer and treatment can include **pain, reduced freedom of movement and reduced ability to process information and apply knowledge.**<sup>(51)</sup>



## FINANCIAL NEEDS



**At present there are limited robust data on the financial needs of LGBT people at the Treatment stage of their cancer journey.**

### Not specific to LGBT people with cancer

The most common additional cost people living with cancer face is getting to and from hospital, or making other healthcare visits.<sup>(32)</sup>

Costs associated with outpatient appointments hits almost **three-quarters** (71%) of people living with cancer, and **over a quarter** (28%) incur costs for inpatient admissions.<sup>(32)</sup>



## PRACTICAL AND INFORMATION NEEDS

Half of around 6,000 lesbian and bisexual women in one UK survey (all LGBT people, not specifically those affected by cancer) had **negative experiences in the health service** in 2007.<sup>(17)</sup>

A small qualitative study revealed that **health professionals seem to struggle more frequently with LGBT patients, carers and partners than any other group** to “get the basics right” regarding respect for family life, sexual orientation, partner status etc.<sup>(53)</sup>

A 2012-13 survey suggested that LGB people with cancer are **more likely** than heterosexuals to say that their doctors **talked in front of them as if they were not there.**<sup>(35)</sup>

LGB people with cancer are **less likely** than heterosexuals to say that they were **given enough information about their condition and treatment.**<sup>(35)</sup>

The language in most printed materials **assumes marriage and heterosexuality**, making the information less accessible to some LGB people living with cancer.<sup>(37)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

LGBT people have reported high levels of isolation in the health system. They reported feeling **alone, lost** and **unsupported.**<sup>(53)</sup>

In a recent survey of trans people, **21% had experienced discrimination, transphobia, homophobia or unfair treatment based on their gender identity** from their GP or another member of staff at the GP surgery.<sup>(85)</sup>

LGBT people with cancer were **more likely** than heterosexuals to say that they were not **given enough privacy when discussing their condition and treatment and being examined or treated.**<sup>(35)</sup>

It is not uncommon for LGBT people to be alienated from their family of origin because of their gender identity and/or sexual orientation. **Healthcare professionals may not know how to ask about or recognise alternative support systems**, and these supportive others may be excluded from providing care or assisting with medical decision making.<sup>(37)</sup>

LGBT patients and carers report **persistent insensitivities** regarding their domestic and family life and status of partners.<sup>(53)</sup>

**Not specific to LGBT people with cancer**  
**One in four** of all people (23%) diagnosed with cancer in the UK will **lack support** from family or friends during their treatment and recovery – that represents more than **70,000 people** each year.<sup>(54)</sup>

# NEEDS AND EXPERIENCES SURVIVORSHIP (POST-TREATMENT)

## Why are cancer survivors (all cancer survivors; not just LGBT 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 all 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.**<sup>(26)</sup>
- **94%** experience **physical health condition problems** in their first year after treatment.<sup>(55)</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>(55)</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>(55)</sup>
- **25%** people living with cancer say they would have found it **helpful to have had more advice on the emotional effects of cancer.**<sup>(57)</sup>
- **23%** **lack support from friends and family** during treatment and recovery.<sup>(54)</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>(54)</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>(56)</sup>
- Currently only **22%** of cancer patients are receiving a written needs assessment and a care plan – both of these are essential in providing personalised care for cancer patients and their carers.<sup>(56)</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



At present there are limited robust data on the physical and medical needs of LGBT people at the Survivorship stage of their cancer journey.

Much of the research around **erectile dysfunction** assumes that men are in long-term, monogamous relationships and doesn't address issues that single men may experience. Stonewall's research shows that **older gay men are more likely to be single than older heterosexual people.**<sup>(49)</sup>

A study in California showed that there was **no significant difference in prevalence of cancer among women of different sexual orientations**, although lesbian and bisexual female cancer survivors are 2 and 2.3 times respectively more likely to report fair or poor health compared with heterosexual female cancer survivors.<sup>(58)</sup>

**Not specific to LGBT people with cancer**  
**500,000** people in the UK are facing **poor health or disability** after cancer treatment.<sup>(57)</sup>

**350,000** people living with and beyond cancer are experiencing **chronic fatigue.**<sup>(57)</sup>

**350,000** people living with and beyond cancer are experiencing **sexual difficulties.**<sup>(57)</sup>



## FINANCIAL NEEDS



At present there are limited robust data on the financial needs of LGBT people at the Survivorship stage of their cancer journey.

### Not specific to LGBT people with cancer

Long term consequences of cancer treatment can include financial worries caused by the **disruption to work** and the potential **impact on education and future prospects** for those who are treated for cancer as young adults.<sup>(57)</sup>



## PRACTICAL AND INFORMATION NEEDS



At present there are limited robust data on the practical and information needs of LGBT people at the Survivorship stage of their cancer journey.

While lesbian and bisexual women affected by cancer have many of the same information needs as heterosexual women, research indicates that **some would like to receive more information relevant to their sexuality**. This applies to the diagnosis and treatment stages of the cancer journey, as well as survivorship.<sup>(81)</sup>

### Not specific to LGBT people with cancer

A Macmillan survey showed that a third of people who have had cancer **did not have all the information they needed**, and were not aware that it could be more important for them to adopt a healthy lifestyle. Respondents said they would like more information on diet and nutrition, weight management, genetics, stress and exercise.<sup>(34)</sup>

26% of cancer patients (from all sexual orientations) 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**.<sup>(60)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS



At present there are limited robust data on the emotional and psychological needs of LGBT people at the Survivorship stage of their cancer journey.

In an American study, 43% of LGBT cancer survivors and caregivers were **not offered referrals to LGBT support groups**.<sup>(61)</sup>

In a UK study of 13 lesbian and bisexual women with breast cancer, respondents reported feeling **excluded from support groups because the environments are not sufficiently comfortable for them to feel able to come out**. Some of the women felt that they were unable to access existing support groups: they felt excluded by topics of conversation or by the environment of the group.<sup>(62)</sup>

### Not specific to LGBT people with cancer

Receiving a cancer diagnosis or treatment for cancer can affect one's emotional state. Some people develop long lasting mental health problems such as **anxiety** and **depression**.

More than four in ten (45%) of all people with cancer say the **emotional effects of cancer are the most difficult to cope with**, compared to the physical and practical aspects. Nearly six in ten (58%) of all people with cancer feel their emotional needs are not looked after as much as their physical needs.<sup>(34)</sup>

# NEEDS AND EXPERIENCES PROGRESSIVE ILLNESS AND END OF LIFE

## Are LGBT people getting the end of life care that they need?

LGBT people and their families may not be getting the dignified, pain-free end of life care that everyone deserves.

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

Evidence suggests that compared to patients given standard care, those given regular palliative care input from the time of diagnosis had a better quality of life, received less aggressive treatments close to death, and survived longer.<sup>(63)</sup>

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

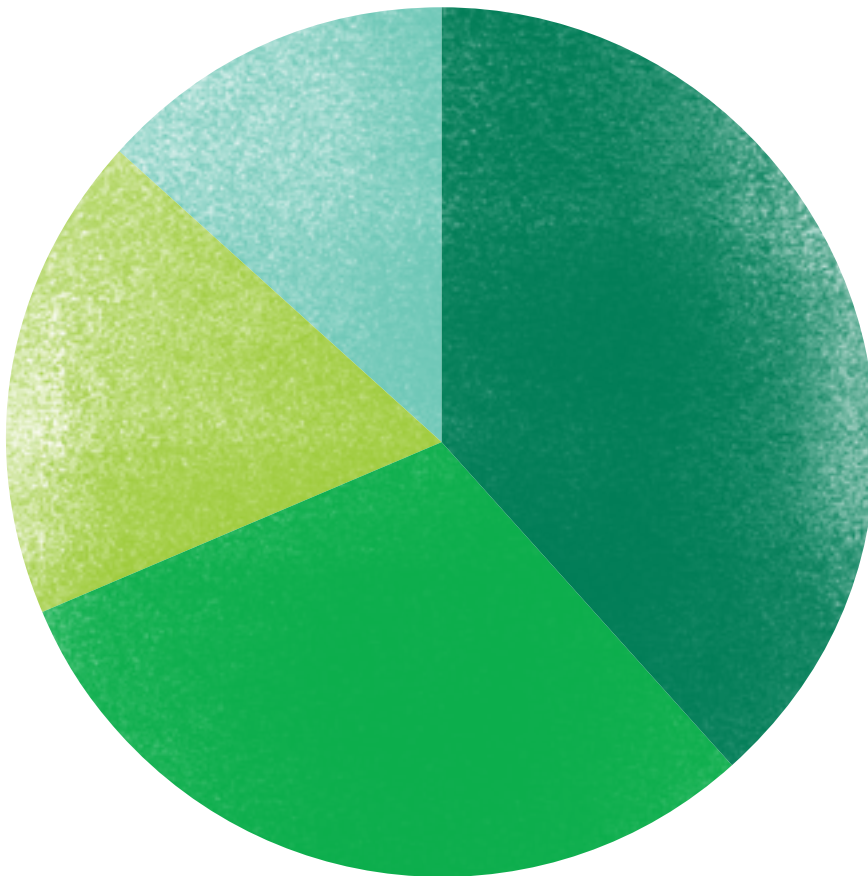
For further information, visit the National Council for Palliative Care website, [www.ncpc.org.uk](http://www.ncpc.org.uk)



## Where do people with cancer die?\*(65)



Data are currently not available breaking down place of death for LGBT people who die from cancer. However, information about place of death for all cancer patients is presented below.



Hospital

**38%**

Home  
(own residence)

**30%**

Hospice

**18%**

Care and  
nursing home

**13%**

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

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



Robust data on place of death specifically for LGBT people with cancer are not readily available.

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>(64)</sup> However, only 30% of those who died from cancer actually die at their home or own residence.<sup>(13)</sup>

**'I have had long term male and female partners in my life. I don't identify as any particular sexuality, as it seems to change throughout my life, and hormone status seems to play a role (my cancer was hormone sensitive). I was particularly preoccupied about the effects of surgery and radiotherapy on my future sexual relationships. It was exceptionally difficult to get information and support on this topic, and I felt it was impossible to ask questions that probed further into same sex relationships.'**

Vanessa, 43



## PHYSICAL AND MEDICAL NEEDS



At present there are limited robust data on the physical and medical needs of LGBT people at the Progressive Illness and End of Life stage of their cancer journey.

**Not specific to LGBT people with cancer**  
**Appropriate palliative care introduced early after diagnosis can improve quality of life.**

It can also lead to less aggressive care at the end of life and longer survival.<sup>(67)</sup>

Various symptoms are very common in advanced cancer, with patients having an **average of 6 uncontrolled symptoms on admission to palliative care.**<sup>(59)</sup>

**Pain, breathlessness, fatigue, anorexia, constipation and insomnia** are especially common; they occur in some combination in virtually all patients.<sup>(63)</sup>



## FINANCIAL NEEDS



At present there are limited robust data on the financial needs of LGBT people at the Progressive Illness and End of Life stage of their cancer journey.

**Not specific to LGBT people with cancer**

In 2010, Macmillan reported that **36%** of terminally ill cancer patients **did not claim benefits they were entitled to.** This amounted to over £90 million. Reasons for low take up included people not knowing they were eligible, the perceived stigma and the confusing claiming process.<sup>(69)</sup>



## PRACTICAL AND INFORMATION NEEDS

70% lesbian, gay and bisexual people **do not think they would be able to maintain a comfortable degree of privacy in a residential care home**; 61% of heterosexual people say the same.<sup>(72)</sup>

**22% of lesbian, gay and bisexual people say they would need to turn to social services** if they were ill and needing help around the home compared to 13% of heterosexual people. However, **61% are not confident that social care and support services**, like paid carers, would be able to understand and meet their needs; 51% of heterosexual people feel the same.<sup>(72)</sup>

**A similar amount of lesbian, gay and bisexual people** and heterosexual people currently have wills.<sup>(70)</sup>



## EMOTIONAL AND PSYCHOLOGICAL NEEDS

A recent survey of LGBT specialists and service-users found that **70% disagreed that current end of life services use language that is appropriate to LGBT people**, and 93% considered that more work needed to be done to ensure end of life services were improved for LGBT people.<sup>(71)</sup>

It can be a concern for LGBT people that someone close to them will be **denied visiting rights and information** because they are not seen as the 'next of kin'. Issues of confidentiality and information sharing may arise, especially if tensions exist within the person's network as a person is approaching the end of life.<sup>(72)</sup>

There is a **common misunderstanding** that **"next of kin"**, refers to and needs to be a person related by blood or marriage.<sup>(72)</sup> This could also be the case whilst an individual is going through treatment.

LGBT individuals and their family may feel **particularly vulnerable**, not only due to deterioration of health but also due to the fears about their personal situation, family network and lifestyle being misunderstood or not acknowledged.<sup>(72)</sup>

# SPECIALIST THEME

## PROSTATE CANCER AND GAY AND BISEXUAL MEN

**Prostate cancer is the most common cancer in men in the UK, but the main body of research into prostate cancer has tended to focus on the experiences of heterosexual men.**<sup>(49)</sup>

Differences in the incidence of prostate cancer in gay and bisexual men from the general population is not known.<sup>(49)</sup>

Prostate cancer mainly affects men over the age of 50 and risk increases with age. Gay men with prostate cancer may have social support, but this support may be different from heterosexual men. For example, older gay and bisexual people are more likely to live alone and less likely to have children.<sup>(73)</sup>

### Support

90% of gay and bisexual men in the UK have never talked with a healthcare professional about prostate cancer, the most common cancer in men in Britain. More than two thirds (68%) of gay and bisexual men aged over 50 have not had a discussion.<sup>(10)</sup>

Some research suggests than men with prostate cancer may not disclose their sexuality to health care professionals because they are worried about negative reactions; or that when they do let them know they are gay, this may then be ignored.<sup>(49)</sup>

As gay men with prostate cancer are typically older, they may have more concerns about disclosing their sexuality to healthcare providers than younger gay men who may feel more comfortable being open about their sexuality. Older gay men might also be less likely than younger gay men to insist on including partners in consultations.<sup>(49)</sup>

Specific issues for gay men may not be addressed in standard advice and information. During anal sex, the prostate gland can be an area of sexual pleasure, and it may therefore be that prostate cancer carries a particular significance to gay men and their sense of sexuality.<sup>(49)</sup>

### Effects of treatment

Radiotherapy to the prostate and the surrounding area can cause bowel problems such as diarrhoea, pain in the back passage, or, more rarely, bleeding from the back passage. Gay men who receive anal sex need to be made aware in a sensitive way of these side effects, not only after treatment, but before treatment during decision-making.<sup>(76, 77)</sup>

Gay men had lower levels of functioning than heterosexual men after prostate surgery and during hormone therapy treatment.<sup>(78, 79)</sup>

In one study, gay men with cancer acknowledged an interaction with the effect of cancer on the body and the importance placed on physical appearance for some gay and bisexual men.<sup>(49)</sup>

Information on trans women and prostate cancer can be found on page 24.

# SPECIALIST THEME

## BREAST CANCER AND LESBIAN AND BISEXUAL WOMEN

**Being a lesbian is not a risk factor for breast cancer, but some lifestyles issues that may increase their risk, can be more prevalent in (although not exclusive to) lesbian communities. These include being more likely to be overweight, being more likely to drink alcohol and smoke, and a reduced likelihood of having children and breastfeeding.**<sup>(80, 81)</sup>

It may be that since lesbian and heterosexual women are not different physiologically or genetically, any variations in breast cancer rates may result from the stress and stigma of living in societies where homophobia and discrimination continue to impact, as these may prompt the behaviours that can increase cancer risk, such as smoking and alcohol consumption.<sup>(82)</sup>

### **Awareness of breast cancer amongst lesbian and bisexual women**

Many breast health awareness messages are delivered to women when they attend surgeries and clinics for contraceptive advice or smear tests. Because lesbians are less likely to attend these, they may be less aware of them.<sup>(81)</sup>

Three in ten lesbian and bisexual women check their breasts for lumps or changes every month and half every few months.<sup>(17)</sup>

### **Experiences with healthcare professionals**

There is no evidence of any clinical differences among women of different sexual orientations diagnosed with breast cancer. However, research suggests certain behaviours are beneficial, such as when healthcare professionals and others delivering cancer services are sensitive to the needs and experiences of lesbian and bisexual women, do not assume a patient is heterosexual, and use images and language inclusive of lesbian and bisexual women.<sup>(81)</sup>

A 2010 UK study of lesbian and bisexual women revealed that 70% had come out to their families and 90% had come out to friends, but it was much less likely (44%) that they had come out to their GP or other health professional.<sup>(83)</sup>

### **Breast cancer in older lesbian and bisexual women**

One in twelve lesbian and bisexual women aged between 50 and 79 have been diagnosed with breast cancer, compared to one in twenty women in general.<sup>(17)</sup>

Four in five lesbians over the age of 50 have been screened for breast cancer, which is similar to women in general.<sup>(17)</sup>

A 2010 UK cancer awareness measure survey of 600 lesbian and bisexual women found that amongst older women (40+) 75% of lesbians said they would present to a doctor within a week of finding a lump, compared to 68% of bisexual women and 80% of heterosexual women.<sup>(81)</sup>

Information on trans men and breast cancer can be found on page 24.

# SPECIALIST THEME

## CERVICAL CANCER AND LESBIAN AND BISEXUAL WOMEN

**Women who are diagnosed with cancer are not monitored by the NHS on the grounds of sexual orientation therefore it is impossible to conclude that lesbians have a decreased risk of cervical cancer.<sup>(17)</sup>**

### **Cervical cancer risk factors amongst lesbian and bisexual women**

Lesbian and bisexual women may contract human papilloma virus (HPV – the major cause of the main types of cervical cancer) through their own previous sexual behaviour with men, through sex with a female partner who has had previous heterosexual sex, through vaginal penetration with fingers and skin to skin contact, and through the use of sex toys.<sup>(86)</sup>

There is a common misconception that, because lesbians usually do not have sex with men, lesbian and bisexual women are at no risk or substantially lower risk of cervical cancer than heterosexual women – lesbians' risk status and sexual behaviours have often been compared to those of virgins or celibate women. However, studies have suggested that up to four-fifths of lesbians have previously had sex with men in their lifetime.<sup>(86)</sup>

In addition to sexual behaviour, lesbians may be subject to other risk factors for cervical cancer, specifically smoking.<sup>(86)</sup>

Information on trans women and cervical cancer can be found on page 24.

### **Cervical cancer screening for lesbian and bisexual women**

National and international research shows that lesbian and bisexual women are significantly less likely to attend routine screening for cervical cancer.<sup>(84)</sup>

18% of lesbian and bisexual women of an eligible age have never had a cervical screening test, compared with 19% of BME lesbian and bisexual women and 7% of women in general.<sup>(11,74)</sup>

Women's screening behaviour differs significantly according to whether they report having had sex with men. 42% of lesbians who had never had sex with men report no prior screening, compared to 12% of those who had been sexually active with men.<sup>(86)</sup> Lesbian and bisexual women who have never had sex with men are also more likely to have longer intervals between tests.<sup>(87, 88)</sup>

However, participation rates in cervical screening increase with age among lesbian and bisexual women.<sup>(86)</sup>



## Barriers to screening for cervical cancer:

As well as misconceptions about the need for lesbian and bisexual women to attend cervical screening there are a number of other reasons why lesbian and bisexual women perceive barriers to cervical screening. Four of these barriers are:

### Misinformation

41% of respondents to a 2012 survey of lesbian and bisexual women in the UK had been told by someone (a friend, nurse, GP, family member etc) that they did not need a test. Attitudes of and a lack of guidance for medical staff have a huge influence on testing behaviour with 46% of lesbian and bisexual women of an eligible screening age saying that being told they didn't need a test directly influenced their screening behaviour. Nearly 1 in 5 had been discouraged or refused a screen test by a health professional.<sup>(89)</sup>

### Negative healthcare experiences

Lesbian and bisexual women's reduced participation in cervical screening may be partly attributable to their experiences of smear tests. Healthcare providers may sometimes be uncomfortable with providing care to lesbian and bisexual patients and may have difficulties in establishing effective communication. In a 2005 study of 22 GPs in Sheffield, UK, sexual orientation formed a barrier to discussion about sexual health matters for almost half the GPs surveyed. Difficulties related to ignorance of lesbian lifestyles, use of appropriate language and, amongst a minority, homophobic attitudes.<sup>(86)</sup>

## Concerns about disclosing sexual orientation to the healthcare provider

Some lesbian and bisexual women choose not to disclose their sexual orientation to healthcare providers. In cervical screening, failure to disclose sexual orientation may mean that healthcare workers may assume that the woman is heterosexual and are therefore unable to elicit a relevant sexual history. The risks of non-disclosure are that health may be negatively affected: lesbians and bisexual women who hide their sexual orientation may be subject to inappropriate questioning, inaccurate diagnoses, irrelevant health information and they may experience anxiety about inadvertently revealing (or avoiding questions about) their sexual identity in the health encounter.<sup>(86)</sup>

### Assumptions of heterosexuality

The presumption of heterosexuality means that unless a healthcare professional is explicitly told about a woman's sexual orientation, the discussion is likely to be framed by these assumptions. Questions asked during sexual history taking may be problematic for lesbians, for example, the question 'what contraception do you use?' implicitly assumes the woman is heterosexual; lesbians mostly, do not need to control their fertility because sex is not linked to reproduction.<sup>(86)</sup>

Screening may be particularly challenging for trans and non-gendered individuals as the service is by nature gendered and literature and imagery often assumes a heterosexual biological female status of the patient.<sup>(90)</sup>

# LIFESTYLE AND PERCEPTIONS

**This section attempts to give an indication of the typical profile of people from LGBT groups living with cancer and lifestyle factors affecting their risk of getting cancer, however, we know that there is a huge variation within the group.**



**At present there are limited robust data on the lifestyles of LGBT people, and particularly about the lifestyles of bisexual and trans people. This section is a collation of what evidence does exist.**

It is estimated that around half of all cancers could be prevented by changes to lifestyle.<sup>(91)</sup> For many LGBT people, behaviours and lifestyles (e.g. drug and alcohol use, obesity, etc), which can have a significant impact on physical and mental health and well-being, are often linked to 'minority stress' (i.e. the cumulative effects of marginalised identities). Minority stress can include experiences of stigma, marginalisation or discrimination. Because of their impact on the physical and mental health and well-being of LGBT people, these experiences of minority stress are now acknowledged as social determinants of health.<sup>(101, 102, 103)</sup>

## **LGBT people and smoking**

- Lesbian, gay and bisexual (LGB) people are significantly more likely to smoke than heterosexuals.<sup>(92)</sup>
- An estimated 25% of lesbians are smokers, compared with 15% of heterosexual women.<sup>(93)</sup>
- 33% of gay men are smokers, compared with 21% of heterosexual men.<sup>(93)</sup>
- Young people (aged 18-19) who identify as lesbian, gay or bisexual are twice as likely to have smoked than their heterosexual peers.<sup>(94)</sup>
- One study has found that lesbian and bisexual women as a combined group had higher rates of smoking, drinking alcohol and recreational drug use than the general population.<sup>(17)</sup>
- A Canadian study has suggested that many trans people use smoking and alcohol to cope with the stress of living in a transphobic society.<sup>(18)</sup>
- A recent survey found that 27% of gay and bisexual men are ex-smokers compared to 29% of men generally, while 32% of lesbian and bisexual women are ex-smokers compared to 23% of women generally.<sup>(39)</sup>

### LGBT people and alcohol consumption

- LGBT communities appear to consume higher rates of alcohol when compared to the general population. One widely-cited UK survey found that around 37% of lesbians drank over the recommended level compared to 11% of women in the general population.<sup>(95)</sup>
- Binge drinking (ie drinking more than 6 units on the heaviest drinking day) at least once a week is around twice as common in lesbian, gay and bisexual females as compared to the wider population. 34% of males and 29% of females surveyed in a 2009-11 survey of over 4,000 gay, lesbian and bisexual people reported binge-drinking at least once a week, compared to 19% of males and 15% of females in a 2010 ONS survey of the wider population.<sup>(96)</sup>
- Young lesbian and gay people (aged 18-19) are also more likely to drink alcohol frequently.<sup>(94)</sup>
- Older LGB people drink alcohol more often than heterosexuals, with 45% drinking alcohol at least 'three or four days' a week compared to just 31% of heterosexual people.<sup>(97)</sup>

### Lesbian and gay people and body weight

- Among lesbians there is mixed evidence relating to overweight and obesity, with a number of studies finding increased rates within this group.<sup>(95)</sup>
- Among gay men there is evidence of higher rates of eating disorders, such as bulimia, compared to heterosexual men. These differing health issues illustrate the need to tailor information to meet the needs of diverse communities and groups.<sup>(95)</sup>

### LGBT and recreational drugs

- A 2010 UK study estimated that about 75% of non-heterosexual individuals had taken recreational drugs during their lifetime while between 30% and 50% had used drugs in the preceding year. Respondents who identified themselves as LGB were about 3 times more likely to report having taken illicit drugs compared to heterosexual respondents.<sup>(98)</sup>
- This trend is true for older LGB people, who are also more likely than the heterosexual peers to take drugs. 1 in 11 have taken drugs within the last year compared to 1 in 50 heterosexual people.<sup>(97)</sup>
- A recent US study found that bisexual men were more likely than gay and heterosexual men to use recreational drugs.<sup>(65)</sup>

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

### Before:

'I found the lump in my breast one evening whilst going to bed. I felt tender as I turned over and pressed where it hurt and found that I had a large lump there. I was surprised how I had not found it before and was pretty scared. I left it for about a week before I made an appointment with the Doctor. Luckily I only had to wait a few days before seeing the Doctor.

The Consultant who saw me did an ultrasound, mammogram and a core biopsy. His gut feeling was that it was not cancerous and that it was an old injury with trapped blood inside, as when he took the biopsy I spurted blood and he felt that this was old blood trapped inside the lump. I felt confident that he was right, so when I got my results two weeks later and was told it was cancer, I was very shocked and couldn't quite take it in.'

Amanda, 39

'After I was diagnosed with prostate cancer and had keyhole surgery I lost any sexual function. I feel I had to keep a brave face and I didn't even have the confidence to ask for help. Being gay, I didn't have the guts to talk to my GP. I felt I had an old man's cancer and there was no one of my age to talk to. Being gay made it even tougher.'

Simon, 38

**After:**

**'As a lesbian with cancer, my journey's been no different to anyone else. I've always been very open about my sexuality and don't see it as a problem but I know others may find it more difficult.'**

Vicky, 48

**'I had been very open and upfront about sex before this cancer, but the experience of the cancer made me suddenly very protective of my sexual identity, of my body, and fearful of speaking about sex.'**

Sam, 53



## What does this mean?

Macmillan hosts online discussions on its website; we have analysed the frequency of words used in the discussions relating to LGBT people and cancer, compared to the frequency of words used in UK media articles where cancer and L, G, B or T people is the subject. The results are summarised here:

- Within the online community word cloud several of the most prominent words are personal and supportive, such as 'feel', 'like', and 'group', suggesting that conversations within the online community are focused upon offering warmth and a welcoming environment. The impact of such supportive terminology is heightened given that the online community is a forum for people who are not acquainted but are, effectively, strangers.
- By contrast the vocabulary in the media word cloud is more fact-driven, with the most prominent words including 'men', 'women', 'health' and 'gay'. These may reflect that the principal focus within the media is to communicate the context and subject matter of cancer within the LGBT community, above any emotive message.
- Within the online community informal words such as 'really' and 'just' are prominent, reflecting a relaxed and friendly forum which allows participants to be themselves. By contrast such informal vocabulary is not prominent within the media word cloud, reflecting a tone of communication that is, fairly understandably, more formal.
- There is more health-related terminology within the media word cloud, including words such as 'health', 'healthcare', 'HIV' and 'HPV'. Such terms are absent from the online community word cloud, but instead terms such as 'together', 'support', 'love' indicate that emotional care is a greater issue than clinical and healthcare within this forum.

# REFERENCES, SOURCES, NOTES AND CAVEATS

## References, sources, notes and caveats

The quotes on pages 21, 23, 29, 39 and 48 are real quotes from LGBT people with 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 cancer case study who has kindly agreed to be featured in this publication.

1. Stonewall. What is sexual orientation? [http://www.stonewall.org.uk/at\\_home/sexual\\_orientation\\_faqs/2695.asp](http://www.stonewall.org.uk/at_home/sexual_orientation_faqs/2695.asp) (accessed September 2014)
2. Stonewall. Bisexuality and biphobia. [http://www.stonewall.org.uk/at\\_home/sexual\\_orientation\\_faqs/2696.asp](http://www.stonewall.org.uk/at_home/sexual_orientation_faqs/2696.asp) (accessed September 2014)
3. Definitions adapted from following source. Age UK. Transgender issues in later life. 2011. [http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS16\\_Transgender\\_issues\\_in\\_later\\_life\\_fcs.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS16_Transgender_issues_in_later_life_fcs.pdf?dtrk=true) (accessed September 2014)
4. Definitions adapted from: National End of Life Care Programme. The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people. 2012. <http://www.nhs.uk/nhsq.nhs.uk/download.ashx?mid=8301&nid=8300> (accessed September 2014)
5. 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)
6. The Department for Business, Enterprise and Regulatory Reform. <http://webarchive.nationalarchives.gov.uk/20090609003228/http://www.berr.gov.uk/files/file23829.pdf> (accessed September 2014). The report acknowledges that there is very little reliable data about the size of the LGB population, and indicates that the 5% - 7% figure is based on the findings in a number of different studies, from both the UK and internationally: "The National Survey of Sexual Attitudes and Lifestyles (NATSAL 2000) of 16-44 year olds, found that 5.4% of men and 4.9% of women had ever had a same sex partner compared to just 2.6% of both genders who had had recent experience in Johnson et al, Sexual behaviour in Britain: Partnerships, Practices and HIV Risk Behaviours, *The Lancet*, Volume 358, Number 9296, Dec 1, 2001, pp 1835-42. About 5% of those questioned in exit polls identified themselves as 'gay' in US Voter News Service exit polls 1996 and 2000. Plug, E and Berkhout, P (2001) found that about 5% of their Dutch sample had gay, lesbian or bisexual sexual preferences in *Effects of Sexual Preferences on Earnings in the Netherlands*. About 6% of a national sample of Americans identified as gay or lesbian in Yankelovich Monitor Research (1994). Laumann et al found the incidence of homosexual desire was just over 7% of both men and women in the USA. Janus and Janus (1993) found that 9% of men and 5% of women identified as gay or lesbian. Some studies have found higher estimates, such as Kinsey (1948) and Sell et al (1995), whilst others using estimates of cohabiting same-sex couples have found much lower estimates, for example the Labour Force Survey finds just 0.2% of UK households consist of same-sex couples."



7. Stonewall. How many lesbian, gay and bisexual people are there? [http://www.stonewall.org.uk/at\\_home/sexual\\_orientation\\_faqs/2694.asp](http://www.stonewall.org.uk/at_home/sexual_orientation_faqs/2694.asp) (accessed September 2014)
8. Office for National Statistics. Measuring Sexual Identity: Evaluation Report. 2010. <http://www.ons.gov.uk/ons/rel/ethnicity/measuring-sexual-identity---evaluation-report/2010/sexual-identity.pdf> (accessed September 2014)
9. Gender Identity Research and Education Society. Gender Variance in the UK: Prevalence, Incidence, Growth and Geographic Distribution. 2009. <http://www.gires.org.uk/assets/Medpro-Assets/GenderVarianceUK-report.pdf> (accessed September 2014)
10. Stonewall. Gay and bisexual men's health survey. Survey of 6,861 gay and bisexual men across Britain. 2012. [http://www.stonewall.org.uk/documents/stonewall\\_gay\\_mens\\_health\\_final.pdf](http://www.stonewall.org.uk/documents/stonewall_gay_mens_health_final.pdf) (accessed September 2014)
11. The Lesbian & Gay Foundation. Cervical Screening Sample Taker Online Toolkit. <http://www.lgf.org.uk/screeningtoolkit> (accessed September 2014)
12. England: Office of National Statistics. Cancer Registration Statistics, England, 2012. <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-352128> (accessed July 2014); Scotland: ISD Scotland. Cancer Incidence in Scotland 2012. <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables.asp?id=1233#1233> (accessed July 2014); Wales: Welsh Cancer Intelligence and Surveillance Unit. Official Statistics - Trends. <http://www.wcisuwales.nhs.uk/offical-statistics-exel-files-of-trend> (accessed July 2014); Northern Ireland: Northern Ireland Cancer Registry. Online Statistics. <http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/> (accessed July 2014)
13. England and Wales: Office for National Statistics. Deaths Registered in England and Wales, 2012. 2013. <http://www.ons.gov.uk/ons/rel/vsobl/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/stb-deaths-registered-in-england-and-wales-in-2012-by-cause.html#tab-Key-findings> (accessed September 2014); Scotland: General Registrar Office for Scotland. Scotland's Population 2012. 2013. <http://www.gro-scotland.gov.uk/files2/stats/annual-review-2012/rgar-2012.pdf> (accessed September 2014); Northern Ireland: Northern Ireland Statistics and Research Agency. Registrar General Northern Ireland Annual Report 2012. 2013. [http://www.nisra.gov.uk/archive/demography/publications/annual\\_reports/2012/RG2012.pdf](http://www.nisra.gov.uk/archive/demography/publications/annual_reports/2012/RG2012.pdf) (accessed September 2014)
14. Dying Matters. LGBT people 'let down' by end of life care services. <http://dyingmatters.org/page/lgbt-people-let-down-end-life-care-services> (accessed September 2014)
15. Office for National Statistics. Integrated Household Survey 2012. [http://www.ons.gov.uk/ons/dcp171778\\_329407.pdf](http://www.ons.gov.uk/ons/dcp171778_329407.pdf) (accessed September 2014)
16. National Council for Palliative Care. Open to all? 2012. National Council for Palliative Care, London. Survey of 266 LGB people aged over 50.
17. Stonewall. Prescription for change. 2008. 2007 survey of 6,178 lesbian and bisexual women across Britain. [http://www.stonewall.org.uk/documents/prescription\\_for\\_change.pdf](http://www.stonewall.org.uk/documents/prescription_for_change.pdf) (accessed September 2014)

18. Transcend Transgender Support & Education Society. Trans people and cancer. 2006. [http://www.cancer-network.org/media/pdf/Trans\\_people\\_and\\_cancer.pdf](http://www.cancer-network.org/media/pdf/Trans_people_and_cancer.pdf) (accessed September 2014)
19. The DC Center. Smoking and the LGBT community. [http://www.thedccenter.org/facts\\_smoking.html](http://www.thedccenter.org/facts_smoking.html) (accessed September 2014)
20. Fiore MC, et al. Treating Tobacco Use and Dependence: 2008 Update – Clinical Practice Guidelines. <http://www.ncbi.nlm.nih.gov/books/NBK63952/> (Accessed September 2013)
21. NCIN. Cancer e-Atlas: NHS Health Boundaries. [http://www.ncin.org.uk/cancer\\_information\\_tools/eatlas/](http://www.ncin.org.uk/cancer_information_tools/eatlas/) (Accessed July 2013)
22. Macmillan Cancer Support. Signs and Symptoms of Cancer. <http://www.macmillan.org.uk/Cancerinformation/Aboutcancer/Signssymptoms.aspx> (accessed September 2014)
23. Robb K, et al. Public awareness of cancer in Britain: a population-based survey of adults. *British Journal of Cancer*. 2009. 101:518-23
24. NCIN. Routes to Diagnosis. [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis) (accessed September 2014)
25. YouGov. Cancer awareness: the impact of sexual orientation. [http://www.cancerni.net/files/dh\\_115244.pdf](http://www.cancerni.net/files/dh_115244.pdf) (accessed September 2014)
26. Macmillan Cancer Support/YouGov online survey of 1,495 UK adults living with cancer. Fieldwork conducted 1-16 Aug 2011. Survey results are unweighted.
27. Public Health England. The LGB&T Public Health Outcomes Framework Companion Document. <http://www.lgf.org.uk/policy-research/the-lgbt-public-health-outcomes-framework-companion-document/> (accessed September 2014)
28. Transcend Transgender Support & Education Society. Trans people and cancer. [http://www.cancer-network.org/media/pdf/Trans\\_people\\_and\\_cancer.pdf](http://www.cancer-network.org/media/pdf/Trans_people_and_cancer.pdf) (accessed September 2014)
29. Harris Interactive Poll. New National Survey Shows Top Causes for Delay by Lesbians in Obtaining Health Care. Rochester, NY: Harris, March 11, 2005.
30. National Cancer Intelligence Network. Routes to Diagnosis, 2006-2010 NCIN information Supplement. [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis) (Accessed October 2013)
31. Transcend Transgender Support & Education Society. Trans people and cancer. [http://www.cancer-network.org/media/pdf/Trans\\_people\\_and\\_cancer.pdf](http://www.cancer-network.org/media/pdf/Trans_people_and_cancer.pdf) (accessed September 2014)
32. 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)

33. American Cancer Society. Sexual orientation and cancer. [http://www.cancer-network.org/media/pdf/Sexual\\_Orientation\\_and\\_Cancer.pdf](http://www.cancer-network.org/media/pdf/Sexual_Orientation_and_Cancer.pdf) (accessed September 2014)
34. Macmillan Cancer Support. It's no life. 2009.
35. NHS England. Cancer Patient Experience Survey 2013. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed September 2014)
36. Cancer Research UK. About Cancer, Chemotherapy and Cancer. <http://www.cancerresearchuk.org/cancer-help/about-cancer/treatment/chemotherapy/about/chemotherapy-and-cancer> (accessed September 2014)
37. Margolies L. The Psychosocial Needs of Lesbian, Gay, Bisexual or Transgender Patients with Cancer. *Clinical Journal of Oncology Nursing*. 2014. 18(4) 462-464.
38. NCIN. Major surgical resections, England 2004–06. [www.ncin.org.uk/view.aspx?rid=540](http://www.ncin.org.uk/view.aspx?rid=540) (accessed September 2014)
39. Lesbian and Gay Foundation. Findings from the “I Exist” survey of lesbian, gay and bisexual people in the UK. 2012. <http://www.lgf.org.uk/downloads/159> (accessed September 2014)
40. Cancer Research UK. What Radiotherapy is. <http://www.cancerresearchuk.org/cancer-help/about-cancer/treatment/radiotherapy/about/what-radiotherapy-is> (accessed September 2014)
41. NCAT. Clinical Nurse Specialists in Cancer Care. 2011. [http://www.bdnng.org.uk/documents/NCAT\\_Census\\_of\\_the\\_Cancer\\_Specialist\\_Nurse\\_Workforce\\_2011.pdf](http://www.bdnng.org.uk/documents/NCAT_Census_of_the_Cancer_Specialist_Nurse_Workforce_2011.pdf) (accessed September 2014)
42. Macmillan Cancer Support. Internal UK.PS@Mac data.
43. Macmillan Cancer Support. Cancer Clinical Nurse Specialists – An evidence review. 2011. <http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/ClinicalNurseSpecialistsAnEvidenceReview2012.pdf> (accessed September 2014)
44. Mind. Sexuality and mental health. <http://www.mind.org.uk/information-support/guides-to-support-and-services/sexuality-and-mental-health/> (accessed September 2014)
45. Department of Health. Mental health issues within lesbian, gay and bisexual (LGB) communities. 2007. [www.pinktherapy.com/Portals/0/Downloadables/Health/NHS\\_LGB\\_Mental\\_Health.pdf](http://www.pinktherapy.com/Portals/0/Downloadables/Health/NHS_LGB_Mental_Health.pdf) (accessed September 2014)
46. NHS Choice. HIV and AIDS. <http://www.nhs.uk/Livewell/LGBhealth/Pages/HIV.aspx> (accessed September 2014)
47. Terrence Higgins Trust. Men who have sex with men. <http://www.tht.org.uk/our-charity/Facts-and-statistics-about-HIV/Men-who-have-sex-with-men> (accessed September 2014)

48. Macmillan Cancer Support. HIV related Lymphoma. <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Lymphomanon-Hodgkin/TypesofNHL/HIVrelatedlymphoma.aspx> (accessed September 2014)
49. Prostate Cancer UK & Stonewall. Exploring the needs of gay and bisexual men dealing with prostate cancer. [http://prostatecanceruk.org/media/1798529/gay\\_and\\_bisexual\\_men\\_dealing\\_with\\_pc\\_report.pdf](http://prostatecanceruk.org/media/1798529/gay_and_bisexual_men_dealing_with_pc_report.pdf) (accessed September 2014)
50. Research-Live. Out Now Consulting calls for withdrawal of 'flawed' ONS sexual identity study. 2010. <http://www.research-live.com/news/news-headlines/out-now-consulting-calls-for-withdrawal-offlawed-ons-sexual-identity-study/4004028.article> (Accessed December 2013)
51. Macmillan Cancer Support. Making it Work. 2010. <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/WorkingThroughCancer/MakingitWorkPolicyPage.pdf> (accessed September 2014)
52. Susman E. Gay Men Face Extra Burden Coping with Prostatectomy. *Oncology Times*. 2011 Jun;33(11):23, and Motofei IG, et al. Preliminary study with bicalutamide in heterosexual and homosexual patients with prostate cancer: a possible implication of androgens in male homosexual arousal. *BJU Int*. 2011 Jul;108(1):110–5.
53. Macmillan Cancer Support. Walking into the unknown. [http://www.macmillan.org.uk/Documents/AboutUs/Health\\_professionals/OlderPeoplesProject/Walkingintotheunknown.pdf](http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/OlderPeoplesProject/Walkingintotheunknown.pdf) (accessed September 2014)
54. Macmillan Cancer Support. Facing the Fight Alone. 2013. [http://www.macmillan.org.uk/Documents/AboutUs/MAC13970\\_Isolated\\_cancer\\_patients\\_media\\_reportFINAL.pdf](http://www.macmillan.org.uk/Documents/AboutUs/MAC13970_Isolated_cancer_patients_media_reportFINAL.pdf) (accessed September 2014)
55. Elliott J, et al. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer*. 2011. 105: 11-20
56. NHS England. Cancer Patient Experience Survey 2013. Q68. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed September 2014)
57. Macmillan Cancer Support. Cured – but at what cost? 2013. [http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Consequences\\_of\\_Treatment\\_June2013.pdf](http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Consequences_of_Treatment_June2013.pdf) (accessed September 2014)
58. Cancer Research UK. Cancer survivorship 'varies by sexual orientation'. <http://www.cancerresearchuk.org/cancer-info/news/archive/cancernews/2011-05-09-Cancersurvivorship-varies-by-sexual-orientation> (accessed September 2014)
59. de Santiago A et al. A new palliative care consultation team at the oncology department of a university hospital: an assessment of initial efficiency and effectiveness. *Support Cancer Care*. 2012. 20(9):2199-203.

60. NHS England. Cancer Patient Experience Survey 2013. Q19. <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports> (accessed September 2014)
61. National LGBT cancer network. LGBT patient-centered outcomes – Cancer survivors teach us how to improve care for all. <http://www.cancer-network.org/downloads/lgbt-patient-centered-outcomes.pdf> (accessed September 2014)
62. Fish, J. 2010. Coming out about Breast Cancer – Research Report February 2010. Lesbian and Bisexual Women’s experiences of breast cancer. [http://www.sabp.nhs.uk/aboutus/equality/index\\_html/Coming%20out%20about%20breast%20cancer.pdf](http://www.sabp.nhs.uk/aboutus/equality/index_html/Coming%20out%20about%20breast%20cancer.pdf) (accessed September 2014)
63. Higginson I, Constantini M. Dying with cancer, living well with advanced cancer. *European Journal of Cancer*. 2008. 44(10):1414-24
64. Macmillan Cancer Support. February 2010 online survey of 1,019 UK adults living with cancer. Survey results have not been weighted.
65. Miller M, et al. Bisexual health: An introduction and model practices for HIV/STI prevention programming. 2007. National Gay and Lesbian Task Force Policy Institute, the Fenway Institute at Fenway Community Health, and BiNet USA.
66. 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> (accessed July 2014)
67. Temel J, et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine*. 2010. 363(8):733-42
68. Tsai J, et al. Symptom patterns of advanced cancer patients in a palliative care unit. *Palliative Medicine*. 2006. 20:617.
69. 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)
70. Stonewall. Lesbian, gay and bisexual people in later life. [http://www.stonewall.org.uk/documents/lgb\\_in\\_later\\_life\\_final.pdf](http://www.stonewall.org.uk/documents/lgb_in_later_life_final.pdf) (accessed September 2014)
71. National Council for Palliative Care. Open to all? 2012. National Council for Palliative Care, London.
72. National End of Life Care Programme. The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people. 2012. <http://www.nhs.uk/resource-search/publications/eolc-rts-lgbt.aspx> (accessed September 2014)

73. Department of Health. Briefing 4: Older lesbian, gay and bisexual (LGB) people. <http://www.openingdoorslondon.org.uk/resources/Reducing%20health%20inequalities%20for%20lesbian,%20gay,%20bisexual%20and%20trans%20people,%20breifing%20for%20health%20and%20social%20care%20staff.pdf> (Accessed August 2013)
74. Light, B et al. Lesbian, gay and bisexual women in the North West: a multi-method study of cervical screening attitudes, experiences and uptake. 2011. [http://usir.salford.ac.uk/16596/5/LGF\\_Final\\_Report3.pdf](http://usir.salford.ac.uk/16596/5/LGF_Final_Report3.pdf) (accessed September 2014)
75. Silverberg M. J. et al. Risk of Anal Cancer in HIV-Infected and HIV-Uninfected Individuals in North America. *Clinical Infectious Diseases*. 2012. 54(7):1026–34
76. Blank TO. Gay men and prostate cancer: invisible diversity. *J. Clin. Oncol.* 2005 Apr 20;23(12):2593–6.
77. Cornell D. A Gay Urologist's Changing Views on Prostate Cancer. *Journal of Gay & Lesbian Psychotherapy*. 2005;9(1-2):29–41.
78. Susman E. Gay Men Face Extra Burden Coping with Prostatectomy. *Oncology Times*. 2011 Jun. 33(11):23.
79. Motofei IG, et al. Preliminary study with bicalutamide in heterosexual and homosexual patients with prostate cancer: a possible implication of androgens in male homosexual arousal. *BJU Int.* 2011 Jul; 108(1):110–5.
80. Williams, H., et al. The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document. The Lesbian & Gay Foundation, 2013.
81. Breast Cancer Care. Lesbian and bisexual women and breast cancer. [http://www.stonewall.org.uk/documents/lesbian\\_and\\_bisexual\\_women\\_and\\_breast\\_cancer\\_1.pdf](http://www.stonewall.org.uk/documents/lesbian_and_bisexual_women_and_breast_cancer_1.pdf) (accessed September 2014)
82. Medical News Today. Why are lesbians apparently at higher risk of developing breast cancer? <http://www.medicalnewstoday.com/articles/235878.php> (accessed September 2014)
83. DeMontfort University, National Cancer Action Team. Coming Out About Breast Cancer. <https://www.dora.dmu.ac.uk/bitstream/handle/2086/4744/Fish%20Coming%20out%20about%20breast%20cancer.pdf?sequence=1> (accessed September 2014)
84. Kerker, B. D et al. Health care access and utilization among women who have sex with women: Sexual behavior and identity. *Journal of Urban Health*. 2006. 83(5), 970-979
85. The Lesbian & Gay Foundation. Trans\* Patients' Experiences of their GP surgery – Annual Survey 2013. <http://www.lgf.org.uk/policy-research/building-health-partnerships/lgb-and-t-patient-insight-surveys-and-focus-groups/> (accessed September 2014)
86. Fish J. Cervical screening in lesbian and bisexual women: a review of the worldwide literature using systematic methods. <https://www.dora.dmu.ac.uk/xmlui/bitstream/handle/2086/4743/Fish%20cervical%20screening.pdf?sequence=1> (accessed September 2014)

87. Bailey, J. V et al. Lesbians and Cervical Screening. *British Journal of General Practice*. 2000. 50, 481-482.
88. Marrazzo, J et al. Papanicolaou test screening and prevalence of genital human papillomavirus among women who have sex with women. *American Journal of Public Health*. 2001. 91(6); 947-952.
89. The Lesbian & Gay Foundation. New Survey Highlights Lack of Knowledge Around Cervical Screening for Lesbian and Bisexual Women. 2012. <http://www.lgf.org.uk/news-articles/new-survey-highlights-lack-of-knowledge-around-cervical-screening-for-lesbian-and-bisexual-women/> (accessed September 2014)
90. Public Health England. The LGBT Public Health Outcomes Framework Companion Document. <http://www.lgf.org.uk/policy-research/the-lgbt-public-health-outcomes-framework-companion-document/> (accessed September 2014)
91. Cancer Research UK. Can cancer be prevented? <http://www.cancerresearchuk.org/cancer-info/healthyliving/introducingcancerprevention/can-cancer-be-prevented> (Accessed October 2013)
92. Department of Health. Healthy lifestyles for lesbian, gay, bisexual and trans (LGBT) people. [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_078345.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_078345.pdf) (accessed September 2014)
93. Tang, H, et al. Cigarette smoking among lesbians, gays, and bisexuals: How serious a problem? *Cancer Causes and Control*. 2004. 15(8): 797–803.
94. Hagger-Johnson G, et al. Sexual orientation identity in relation to smoking history and alcohol use at age 19/19: cross-sectional associations from the Longitudinal Study of Young People in England (LSYPE). *BMJ Open*. 2013. 3, 8.
95. Cancer Research UK. Health inequalities in cancer and Lesbian, Gay, Bisexual, Transgender (LGBT) communities. [http://www.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@pol/documents/generalcontent/crukmig\\_1000ast-3350.pdf](http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/crukmig_1000ast-3350.pdf) (accessed September 2014)
96. The Lesbian & Gay Foundation. Part of the picture: lesbian, gay and bisexual people's alcohol and drug use in England (2009-2011). Survey of 4,206 gay, lesbian and bisexual people in England, 2009-2011.
97. Stonewall. LGB in later life. [http://www.stonewall.org.uk/documents/lgb\\_in\\_later\\_life\\_final.pdf](http://www.stonewall.org.uk/documents/lgb_in_later_life_final.pdf) (accessed September 2014)
98. The UK Drug Policy Commission. The Impact of drugs on different minority groups. A review of the literature. Part 2: Lesbian, Gay, Bisexual and Transgender groups. 2010. [http://www.ukdpc.org.uk/wp-content/uploads/Evidence%20review%20-%20The%20impact%20of%20drugs%20on%20different%20minority%20groups\\_%20LGBT%20groups.pdf](http://www.ukdpc.org.uk/wp-content/uploads/Evidence%20review%20-%20The%20impact%20of%20drugs%20on%20different%20minority%20groups_%20LGBT%20groups.pdf) (accessed September 2014)

99. Macmillan Cancer Support. Word cloud reflecting Macmillan’s online community constructed from analysis on 7 November 2013, from a selection of the 20 most recent posts listed under “gay”, “lesbian”, “bisexual”, “transgender” or “LGBT”, then using [www.wordle.net](http://www.wordle.net) to create the word cloud image.
100. Macmillan Cancer Support/Factiva. 2013. Word cloud formed from on an analysis on 8 November 2013 using [www.wordle.net](http://www.wordle.net) of the 100 most recent UK national daily newspaper articles where the key words of “cancer” and “gay”, “lesbian”, “bisexual” or “transgender” appeared at least once. The most frequently used words are shown in larger fonts than less frequent words. Dates ranged from 9 November 2012 to 8 November 2013. 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.
101. Mulé, N et al. Promoting LGBT health and wellbeing through inclusive policy development. *International Journal for Equity in Health*. 2009. 8(18).
102. Williams H et al. The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document. 2013. National LGB&T Partnership, Public Health England, Department of Health.
103. Witten T et al. *Gay, Lesbian, Bisexual and Transgender Aging: Challenges in Research, Practice and Policy*. 2012. Johns Hopkins University Press, Baltimore MA.



# APPENDIX A

# JARGON BUSTER

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

## **(i) Health data terms**

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

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

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

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

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

## **(ii) Other terms**

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

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

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

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

# NOTES

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## Full suite of the Rich Pictures

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

### Overarching Rich Picture

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

### 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](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](http://macmillan.org.uk)**

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