No one overlooked: Experiences of LGBT people affected by cancer
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INTRODUCTION

One of the core principles underpinning the health and social care system in the UK is that access to – and appropriate delivery of – the best quality care services is available to everyone. This applies irrespective of race, age, sexual orientation, gender or gender identity, income, disability or religion. And yet, health consistently remains one of the great focal points of inequality and a central concern in public health policy, especially when it comes to cancer.

In 2015 the estimated number of people living with cancer in the UK is almost 2.5 million. Assuming that all existing trends in incidence and survival continue, cancer prevalence is projected to increase to four million by 2030. Considering this, it is vital that the experiences of everyone living with and affected by cancer are taken into consideration so that no one is overlooked, ignored or poorly treated. Robust data about these experiences, therefore, is crucial.

Current methods for data collection about patient experience often target people living with cancer who are easily accessible. The analysis rarely stretches far enough to uncover hidden or latent needs as experienced by ‘too-frequently-ignored’ communities.

What’s more, such quantitative methods only provide a descriptive snapshot without explanations. The drivers of inequalities are likely to be complex and difficult to articulate, resulting in needs that are hidden. By definition, surveys only capture recognised current needs, not hidden or future needs.

Such a lack of evidence into people’s experiences will limit our ability to deliver services which truly reach every person living with or affected by cancer. The knock-on effects will include a lower take-up of services, later diagnosis, and an exacerbation of existing health inequalities.
However, what we do know is that successive Cancer Patient Experience Survey (CPES) reports have shown that LGB cancer patients have poorer experiences of cancer services than their heterosexual counterparts. For instance, the recent 2014 CPES revealed that LGB patients have showed statistically significant differences to their heterosexual counterparts in respect of 24 dimensions of experiences. These include communication, the management of pain, and access to adequate practical and emotional support (from healthcare professionals in primary and secondary care, but also from self-help groups for people with cancer).

The Public Health Outcomes Framework LGBT Companion Document highlights health inequalities experienced by LGBT people across the life course, including cancer risk factors such as smoking, alcohol use and obesity, suggesting important inequalities in cancer care. However, more research is necessary to fully understand what lies at the root of these results and how to identify ways of addressing poorer experiences and outcomes.

Due to a lack of consistent sexual orientation and gender identity monitoring across the healthcare system it is not known how many LGBT people are diagnosed with cancer or what their outcomes are. This increases the risk of not meeting needs appropriately for LGBT people affected by cancer. As a result, experiences of the cancer journey can continue to be worse for people in the LGBT community, and resource and service commissioning may be inadequate.

At present there is limited robust data on the numbers of lesbian, gay, bisexual and transgender people living in the UK, and there is also a lack of robust information on the number of LGBT people living with cancer.
WHAT WE'RE DOING: MACMILLAN’S ENGAGEMENT APPROACH

There are several broad principles to our engagement approach aimed at tackling health inequalities:

• To understand the complex issues driving health inequalities and to identify hidden needs, we need more qualitative research that targets specific seldom-heard-from groups of people affected by cancer.

• People affected by cancer are the experts in their experience, and should be equal partners in shaping the future of cancer care. We will support people affected by cancer to prioritise what the most important issues are, identify and test possible solutions, and influence decisions that lead to improvements.

• We will work with a range of partners (including people living with and affected by cancer, researchers, community partners, service providers, and policy makers) to understand needs and co-design solutions that work.

The research reported in this document is the first part of this engagement approach for LGBT people affected by cancer. It builds on Macmillan’s report, The Emerging Picture: LGBT people with cancer5 (a document that collated the key available evidence about the numbers, needs and experiences of this community).

In this report, we look in depth, in a qualitative way, at the experiences of a sample of LGBT people living with cancer at different points of the cancer journey. Following this, we plan to work with people affected by cancer, policymakers, commissioners and service providers to develop recommendations and develop interventions that will drive improvements in patient experience and reduce inequalities.
To explore the experiences of LGBT cancer patients, the study was carried out using a bespoke online engagement forum. It brought together a sample of 21 LGBT people living with cancer with 24 healthcare professionals, diversity specialists and academics with an interest in equality, diversity and cancer.

The sample of participants with cancer included nine gay participants, eight lesbian participants, three bisexual participants and one male-to-female transgender participant. They were aged between 18 and 65, and the majority (13) of the participants were married or in long-term relationships, while eight lived alone. Nearly everyone had completed their treatment so could comment on all aspects of the cancer journey. With respect to the specific cancers they had, 12 participants were diagnosed with one of the ten most common cancers and nine had rarer cancers.

Over a period of eight weeks, two professional researchers involved participants in 70 qualitative research and engagement tasks (see Appendix 1). Our main aim was to give a genuine voice to participants, and allow them to define and discuss the issues in their own terms.
The findings are presented under the following headings: emotional and psychological needs, physical needs, practical needs (including financial and information needs), and underlying assumptions and perceptions.

We have presented the findings in this way as the boundaries between treatment (be it curative or palliative), recovery and post-treatment can sometimes be very fluid. Indeed, most of the experiences the participants living with and beyond cancer in our sample discussed (such as not feeling treated like ‘whole people’, lacking knowledge and information, poor communications, not feeling involved in decision making) were not confined to specific stages. The participants’ experiences also pertained to both primary and secondary care services, as well as to post-treatment and survivorship. Additionally, the same participant could have more than one cancer or have a recurrence, therefore they could be at different stages of the cancer journey simultaneously.

a. Emotional and psychological needs

The Emerging Picture: LGBT people with cancer highlighted a number of emotional and psychological needs, including:

- LGBT people with cancer were less likely than heterosexual people to report that they were told sensitively that they had cancer.7
- LGBT people with cancer were less likely than heterosexual people to believe they have been treated with dignity and respect by hospital staff.8
- LGBT people have reported high levels of isolation in the health system. They reported feeling alone, lost or unsupported.9 For example, 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.10
- 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.11
- A recent survey of LGBT specialist and service users found that 70% disagreed that current end of life services use language that is appropriate to LGBT people. 93% considered that more work needed to be done to ensure end of life services were improved for LGBT people.12
Disclosure and identity

Most of the participants within the sample talked of the stresses of having to weigh the risk of disclosing their sexual orientation or gender identity to each and every one of the many health professionals involved in their care. Common questions they asked themselves included, ‘Is this relevant?’, ‘What kind of reaction will I get?’ and ‘Will this impact on my care?’

LGBT participants resented having to worry about these additional stresses because of the lack of sensitivity and assumptions of health professionals, at a time when they were already feeling highly vulnerable because of their cancer diagnoses.

‘Post cancer, I mentioned to my GP that I am gay but I thought it may embarrass the breast care nurses. And with my daughter or sister going with me to appointments, I felt it would be even more confusing for them. I didn’t have the energy to deal with it at the time.’

(Lesbian woman affected by cancer, 65–79)

The implications of such heteronormative assumptions for both the treatment and care of cancer patients were manifold. Many of the negative experiences of the LGBT participants at various points in their cancer journey were a direct consequence of these professional ‘blind spots’. By contrast, the feeling of inclusion, recognition and normalisation was very potent.

‘Today I met a fabulous nurse who welcomed me and my wife, and asked several times where my wife was? Was she okay? And did my wife want to join me? It is the first time in my 42 years of life that I felt completely normal and absolutely accepted unconditionally.’

(Lesbian woman affected by cancer, 35–64)

In contrast to this, some within the sample reported instances where partners attending medical appointments were ‘mistaken’ for being parents, children, ‘friends’, or simply not acknowledged. This negation of the role of partners was offensive to the participants and their partners and carers.

‘No one spoke to my partner at all about anything. She felt totally left out of the equation. When she tried to get answers she was told to speak to me. We are each other’s next of kin as we have had a civil partnership, [but] some of the hospital staff didn’t seem to accept this.’

(Lesbian woman affected by cancer, 35–64)

‘My partner became acutely aware of her standing in relation to my family and the medical profession. Basically that she was a ‘nobody’. In her words, “like someone you had met the week before”. When I was in theatre and she would go to ask for an update, the staff were guarded with giving information as they assumed she was a friend. Basically the behaviour of the staff was heteronormative; nobody offered any support or asked if she had any questions or concerns.’

(Lesbian woman affected by cancer, 35–64)

Support needs

For some participants within the sample whose families had never been supportive of their sexual orientation
or gender identity, a cancer diagnosis could bring to the fore a complex mix of guilt, shame, sadness, anger and loneliness.

‘Was I really being punished for being gay? Were my family right? Would everyone be better off without me? This was the worst day of my life. When you have had your parents and sister telling you for years how bad you are, it is very difficult not to think that cancer may be a punishment. They were ashamed of me and wouldn’t tell anyone I was a lesbian. My parents are dead now and I am free of their hatred, but I had a letter from my sister hoping I didn’t recover from my cancer.’

(Lesbian woman affected by cancer, 35–64)

‘I emailed [my brother] to let him know of my diagnosis so that his children would have the information as family medical history. He emailed me back to wish me well, but that’s been the last contact. We were never close! I am not in touch with any other members of my birth family.’

(Bisexual woman affected by cancer, 35–64)

‘I was left in an isolation room in hospital for three months and my family never visited. We have complicated family dynamics.’

(Trans woman affected by cancer, 35–64)

‘At our support group, one man brought his partner along once. I remember thinking at the time that, as a carer, he seemed to get a lot from attending the meeting and certainly had a lot of stories to tell about looking after his partner who unfortunately had metastatic bowel cancer, as well as having been treated for prostate cancer. At the time, the support group was the only one of its kind in the country and they both travelled all the way up from London to attend the meeting in Manchester, and were both very thankful for being able to do so.’

(Health practitioner, community and voluntary sector)

‘My partner would have liked advice on how she could help me best. She should have had more support with nursing care at home. We didn’t have any nurses call to help with bandaging and cleaning my wounds. She had to hope she was doing it right. Nobody would speak to her at the hospital unless she was with me.’

(Lesbian woman affected by cancer, 35–64)

The participants with cancer, healthcare professionals, diversity specialists and academics all reported the near total absence of offline or online support, and support groups in particular, specifically for LGBT carers. As a result, LGBT partners and carers were missing out on much needed support.
'We would have liked more support during the worst times but it’s only looking back now that we’ve both realised how very little there has been for my partner. When I was not able to do much at all, both before and after diagnosis and treatment, he took on the role of full-time carer for months. This was new to us both and an offer of some practical support would have gone a long way. He picked up tips on things, like how to get me to eat from neighbours, rather than finding things out from healthcare professionals. He would have benefitted from some one-to-one chats and a carers’ group, but that would have required someone to keep an eye on me for a few hours for him to be able to take part. He’d also have benefitted from a whole day off every so often but he couldn’t leave me because I was so ill.’

(Gay man affected by cancer, 35–64)

Support is needed not only in relation to the medical or practical dimensions of care. Carers also need support during periods of stress and uncertainty for their loved ones, as well as for themselves.

‘Technically and medically, my partner was well informed and I could share information that I was given and gained as I continued my treatment and care. But there was no support for him emotionally or how to deal with my changing emotions, fears and frustrations. The lack of support and understanding at work, where it was ‘so inconvenient’ when I or he would ring in and say I would not be in work on Monday as I was being readmitted to hospital again.’

(Gay man affected by cancer, 35–64)

Finally, participants remarked that it is important for healthcare professionals to be aware that LGBT people may have a broader definition of ‘family’. They may have a loose network of trusted loved ones, eg partners, ex-partners or close friends, who may be all the more important when tensions within the patient’s birth family means they cannot rely on them for emotional or practical support.

‘Many LGBT people have a strong support network of partners and friends, some of whom will be willing to provide on-going care. This may be because LGBT people tend to create their own families, owing to the fact that sometimes their birth families are not quite so accepting of their sexual orientation and relationships.’

(Academic/researcher)

b. Physical needs

The Emerging Picture: LGBT people with cancer highlighted a number of physical needs, including:

• Oestrogen may increase the risks of breast cancer for male to female trans individuals depending on the amount taken over the person’s entire life.13

• Gay men may have lower sexual functioning than heterosexual men after prostate cancer surgery and during hormone therapy treatment.14

• LGBT people with cancer are less likely than heterosexuals to say they believe that hospital staff always did everything they could to control their pain.15
Within the sample, all gay and bisexual men with prostate cancer were dissatisfied with the clinical aspects of their treatment. They specifically mentioned the lack of timely information on the possible side effects of various prostate cancer treatment options that might have informed their choices.

The treatment of prostate cancer can have well-known side effects. These include a lower libido, difficulty reaching and maintaining an erection, loss of penile or rectal sensitivity, urinary incontinence, loss of ejaculation, lower fertility, changes in body image, fatigue, and pain. Regardless of sexual orientation or gender identity, these common side effects can have debilitating effects for cancer patients and undermine men’s self and sexual confidence.16

Our research suggests the same cancer treatment can have a disproportionate impact on gay and bisexual men. Participants reported that anal sex requires a more erect penis for the man ‘on top’ than vaginal sex; erectile dysfunction therefore makes anal penetration especially difficult. Damage to the lining of the rectum also limits the sexual enjoyment of men who receive anal sex.

‘Erectile dysfunction is a common side effect of treatments for prostate cancer and might be more difficult to manage for gay men who practice anal sex, as a penis needs to be more rigid for anal sex than vaginal sex. Radiotherapy can also damage the lining of the rectum and surgical removal or irradiation of the prostate will affect the enjoyment received when engaging in anal sex. So the same treatment can have more of an impact psychosexually for gay men because their sexual practice is different, not necessarily because sexuality is more important.’
(Health practitioner, community and voluntary sector)

‘My sex life is much worse. There’s no such thing as spontaneity any more. As a gay man, I identified more as a ‘top’ before. I’m not able to be a ‘top’ any more, even with the help of pills. There’s little understanding among health professionals of what is needed for sex between men. Pills and pumps might be sufficient for vaginal sex but not for anal sex. In the gay community, there’s also a lot of importance attached to actually seeing the ‘cum’. I am no longer able to ejaculate, so that’s gone, too.’
(Gay man affected by cancer, 35–64)

Gay and bisexual men in the sample were particularly upset by the fact that the potential side effects of each treatment option (for their cancer and for their life) were never discussed with healthcare professionals. They therefore undertook treatment without a full understanding of the consequences of their treatment.

‘Two years on, I get the occasional incontinence, stress leakage. I am on daily 5mg Cialis and 100mg Viagra but erections haven’t fully come back. It has destroyed whatever emotional or sex life I may have had. No one really went into the detail of this with me at the time. We were just focused on curing the cancer without considering the impact on my life.’
(Bisexual man affected by cancer, 35–64)

**During conversations within the forum, there was insufficient data on physical needs for lesbian or bisexual women, or those from the trans community.**
c. Practical needs

The Emerging Picture: LGBT people with cancer highlighted a number of practical needs, including:

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

- LGB people with cancer are less likely than heterosexual people with cancer to receive information from the hospital ward about self-help and support groups for people with cancer.

- 41% of respondents in 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 cervical cancer screening.

Finances

The economic cost of cancer is documented for cancer patients in general, but there is no published evidence on the financial impact of cancer on LGBT patients and their loved ones. In our sample, LGBT participants with cancer rarely reported acute financial hardship. Many could afford to pay for treatment and care not covered by the NHS, to travel abroad and to attend fitness and wellbeing classes, for instance. Nevertheless, participants experienced a range of significant negative impacts. These included losing or having to give up their job, taking early retirement (with reduced pensions thereafter), having to cut down on their work commitment and income, struggling to pay their mortgage, losing their home and having to live on benefits.

‘I think we all need some financial support. This is an expensive business and we all adjust lives to our earnings, but because I have a reasonable job, I receive no help financially. Last month alone, we paid out £350 in train fees. It’s really upsetting and means we have to adjust food bills and other things to accommodate. It is appalling that patients with long-term illnesses are not supported regardless of their income. I have also felt I had to work throughout my treatment as we cannot afford for me to financially go onto half-pay. This has only added to the stress. What I find incredulous is that the first hospital I attended made absolutely no concessions for patients with long-term illnesses and those required to attend appointments. At the second hospital I attended, there was a voucher issued to cancer patients and a lesser payment charge, which seemed fairer.’

(Lesbian woman affected by cancer, 35–64)

Data collection

A major barrier in the treatment and care of LGBT cancer patients is the fact that cancer registries do not consistently collate information on the sexual orientation and gender identity of their patients. The absence of systematic monitoring of cancer, cancer treatment, experiences and outcomes by sexual orientation, means that all key stakeholders (public health bodies, clinical commissioning groups, healthcare professionals and charities) do not have the information they need.
to devise interventions or provide tailored support to meet the needs of LGBT cancer patients.

‘LGBT patients are essentially invisible due to lack of monitoring. We cannot therefore analyse cancer registries to see which cancers, if any, affect LGBT people more or less than heterosexual people or if they are presenting at a later stage and have worse outcomes. Until sexual orientation monitoring is widely used across the cancer centres in the UK, trying to identify inequalities will continue to be a guessing game.’

(Health practitioner, community and voluntary sector)

Where information on sexual orientation is gathered, it does not always seem to be used by healthcare professionals to improve their services or to feed into their interactions with cancer patients.

‘I did not realise that the information we give on the sexual orientation monitoring form is not used by the medical staff ... Silly mistake, really. I thought that, having been brave enough to tick a box, that would be looked at by staff and someone would ask the question of how I want this to be addressed. It would have been amazing. I would have explained that it would be very helpful to talk to a gay woman if possible throughout the whole diagnosis/treatment process. It would have made the whole thing easier.’

(Lesbian woman affected by cancer, 65–79)
There were also some concerns about the potential uses of monitoring data among some LGBT participants, including negative targeting and unwitting breaches of confidentiality as personal information is shared among professionals. Healthcare professionals, LGBT people and the general public all need to understand why sexual orientation monitoring is important to develop fair services.

Besides poor experiences (real or anticipated), lack of awareness of the relevance of disclosing their sexual orientation to their clinical teams was an important factor that explained why some LGBT patients never broached the subject. They did not always realise that their treatment options could be different or that tailored support may be available to them.

‘LGBT people will not necessarily know how their sexual orientation might be relevant to their cancer treatment. It is beholden upon us as healthcare experts and patient advocates to explain this to patients.’
(Health practitioner, community and voluntary sector)

‘It was the support group ‘Out With Prostate Cancer’ in Manchester that talked me through things and gave me the courage to talk privately with my urologist and surgeon. He was really amazing when I told him and immediately changed my treatment. He had been thinking I was a married man with an understanding wife. When he knew the truth, he changed the meds to suit a gay man and his needs.’
(Bisexual man affected by cancer, 35–64)

Information

While there is a growing amount of information for gay men with prostate cancer, healthcare professionals, diversity specialists and academics said there remains a real dearth of resources elsewhere. For example, there is a lack of information for lesbian and bisexual women with breast or cervical cancer, for gay or bisexual men with anal cancer, and for trans people with any type of cancer at all.

‘There is very little information for LGBT people. The only serious piece of work that I am aware of is from Prostate Cancer UK… I’ve struggled to find any information on anal cancer, for example. Likewise, very little information for breast and cervical cancers.’
(Health practitioner, community and voluntary sector)

Most LGBT participants within the sample were happy to read generic information about their cancer and its treatment, to contact mainstream helplines, to join any online forum, or to receive counselling from a straight, cis-gendered person, etc. However, at times when they felt at their most vulnerable, they would have liked to feel at ease discussing their experiences. This was especially the case when these experiences concerned their body image, their relationships, the questions that cancer has raised for their self-identity, and their relationships with family members, etc. They would have liked to be able to share with people who had similar experiences to their own, who could understand their views and needs, who could offer relevant advice, and who would accept them without judgement.
‘My partner and I attend the London-based prostate cancer group for gay and bisexual men that started at the beginning of 2014. We’ve been to most of the monthly meetings and we both get a lot from them. We all chat, we all mix, we all get on and we all accept one another as people. There are no holds barred on subjects discussed and there are no judgments made.’
(Gay man affected by cancer, 35-64)

Gay and bisexual men within the sample strongly felt that they needed more information on the consequences of various treatments for prostate cancer. This information must be communicated clearly to patients before treatment begins so that it can inform treatment decisions. Decisions must be based not merely on clinical assessments but on in-depth discussions with each patient of their own lifestyle, priorities, goals, needs, and tolerance of risk, etc.

**d. Underlying assumptions and perceptions**

The Emerging Picture: LGBT people with cancer highlighted a number of underlying assumptions and perceptions including:

- It can be a concern for LGBT people being treated in hospital that someone close to them will not be seen as their next of kin, and be denied visiting rights and information.
- Fear of discrimination can mean people are cautious about being open about sexual orientation or gender identity, so accurate statistics are difficult to achieve.

- Some cancer screening programmes are gender specific, based on assumptions about what body parts men and women have. Health professionals aren’t always aware of what to recommend for trans people.
- Screening may be particularly challenging for trans men and women as the service is by nature gendered, and literature and imagery often assumes a heterosexual biological female status of the patient.
- 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.
- LGBT patients and carers report persistent insensitivities regarding their domestic and family life and status of partners.
- The language in most printed materials assumes marriage and heterosexuality, making the information less accessible to some LGB people living with cancer.

**Disclosure of sexuality and gender identity**

A number of LGBT participants within the sample reported being very guarded about their personal life with their doctors. Some (especially, but not exclusively, those who were not ‘out’) did not wish to disclose their sexual orientation because they feared discrimination or lack of confidentiality that could then impact on their care and other aspects of their life (e.g., their work, family, or insurance).
‘A problem living a life in a closet is that you can’t take your guard down to the medical profession as you can’t trust that your records will be kept confidential. In essence you have to manage your own health and use medical professionals almost like subcontractors, telling them just enough to do their job for you.’
(Bisexual man affected by cancer, 35–64)

Some participants simply limited contact with their GP. This does not seem to be particularly because of difficulties with specific GPs, but more because of historical and structural concerns about lack of confidentiality over HIV and AIDS.

‘I have been a very private person medically over the years and hardly ever had to go visit my GP. My cancer was diagnosed from a private wellbeing test, where things are confidential and they don’t let your GP know. I don’t have an opportunity to sit down and talk with anyone about my needs and wishes. That was not a problem before I had cancer but now it is.’
(Bisexual man affected by cancer, 35–64)

‘LGBT people clearly perceive barriers to accessing primary care when they suspect symptoms of cancer. This is published in the literature and also reflected in our own LGBT cancer patient survey.’
(Health practitioner, community and voluntary sector)

In rare cases, participants reported instances where nurses laughed at their sexual orientation, held stereotypical views of LGBT people, offered to pray for them (implicitly, to ‘cure’ their homosexuality), disrespected their right to privacy, or assumed that they may be HIV positive.

‘The nurse asked who was taking me home. When I said [male partner’s name], she asked if he was my partner. Initially I agreed, but then, not wanting to be perceived as straight, I went on to say he was one of my partners, that I have two but the other one was at work. She looked a bit surprised and said something about greed and wasn’t it a bit naughty or some such. I told her: “No, it wasn’t naughty. We all live together and there’s nothing naughty about it!”’
(Bisexual woman affected by cancer, 35–64)
‘I didn’t disclose my sexuality during my care. Even though I’ve worked in healthcare myself and advocated the importance of disclosure, I chose not to. During previous surgery, I was asked bluntly “if I preferred to sleep with men or women” in front of my parents, in A&E, then overheard the A&E doctor on the phone disclosing, “We have a homosexual with cardiac fibrulation in the cubicle here”, leading to an assumption that I must be HIV positive, which delayed a more thorough examination of my condition. I was under intense pressure to undertake an HIV test, despite my risk activity being minimal – but my doctors didn’t ask me about that. They just assumed that a gay man with a heart condition must be HIV positive.’

(Gay man affected by cancer, 35–64)

Fears of discrimination, and concerns over confidentiality and privacy, were understandably more intense whenever participants with cancer discussed being treated or cared for in communal areas, such as a hospital ward, care home or hospice. Those who were more guarded about their sexuality feared that they may be ‘outed’ by circumstances and against their will. Those who were open about their sexuality and wanted to be visited by their partner(s) still felt more self-conscious. They felt that they had, or would have, to curtail normal signs of affection, and therefore lack the comfort of these gestures.

‘Would I have been as comfortable and relaxed about showing my feelings when surrounded by other patients in a ward, some of whom may not have been particularly tolerant?’

(Gay man affected by cancer, 35–64)

‘Some people worry about being nursed in an open ward where they feel their affectionate greetings and goodbyes for their same-sex partner may be looked upon unfavourably by other patients or visitors.’

(Academic/researcher)

The perceptions and concerns reported by LGBT participants with cancer, healthcare professionals, diversity specialists and academics find echoes in a new report that states LGBT people feel let down by end of life care services (in general, not specifically cancer related). The report draws on a survey of more than 700 hospices, care homes and hospitals, as well as clinicians and service users.

**Heteronormative assumptions**

Much more commonly, however, participants described what they refer to as ‘heteronormative assumptions’ among healthcare professionals: the unquestioned idea that all patients are straight or cis-gendered. This was by far the most common source of frustration and upset among LGBT participants with cancer. This makes it impossible for patients to feel treated as ‘a whole person’, rather than a set of symptoms, and to feel that they are afforded respect and dignity. All sexual orientations and gender identities need to be recognised as equally valid by everyone involved in care, and not ‘default’ to heterosexual and/or cis-gendered. It is also essential that, for those who choose to disclose their sexual orientation or gender identity, this remains confidential.
On several occasions, members of staff have quite happily ‘outed’ people: “Oh, Fred’s gay.” What right have they to ‘out’ someone? When people are ill themselves, or worried about someone who is ill, the last thing they need is to be put yet again in the situation of having to explain a part of their life which really shouldn’t be an issue.’

(Health practitioner, community and voluntary sector)

Heteronormative assumptions underpin the absence of sexual orientation monitoring and the lack of targeted public health cancer campaigns. But they also manifest in clinical encounters in a variety of ways. LGBT participants with cancer reported that their partners may be ignored or excluded altogether, referred to as ‘friends’ (even after they have been introduced as ‘partners’), or as the patient’s mother, daughter, father or son. This was especially likely when there was a significant age gap between partners, but occurred even in the absence of any age difference between partners.

‘DO NOT refer to a patient’s partner as a ‘friend’ in letters. DO NOT only inform my parents of what is happening because you are not clear who the other person is, even though my partner had been introduced when we arrived.’

(Lesbian affected by cancer, 35–64)

‘I’ve had to explain and repeat several times to the same people that, “No, my wife will not be picking me up after treatment; my male partner will”. Assumptions of any sort being made are bad enough, but when the same people I’ve already told I’m gay insist on referring to my non-existent wife, it becomes very trying, to say the least.’

(Gay man affected by cancer, 35–64)

We discussed above the fact that, if partners do attend medical appointments, they may be ‘mistaken’ for being parents, children, ‘friends’, or simply not acknowledged. This negation of the role of partners was offensive to participants with cancer and their partners and carers.

No one spoke to my partner at all about anything. She felt totally left out of the equation. When she tried to get answers she was told to speak to me. We are each other’s next of kin as we have had a civil partnership, [but] some of the hospital staff didn’t seem to accept this.’

(Lesbian affected by cancer, 35–64)

‘My partner became acutely aware of her standing in relation to my family and the medical profession. Basically that she was a ‘nobody’. In her words, “like someone you had met the week before”. When I was in theatre and she would go to ask for an update, the staff were guarded with giving information as they assumed she was a friend. Basically the behaviour of the staff was heteronormative; nobody offered any support or asked if she had any questions or concerns.’

(Lesbian affected by cancer, 35–64)

Perceptions and misconceptions

Participants told us it is often assumed – both by LGBT people themselves and by healthcare professionals – that sexual orientation and gender identity have no relevance to cancer. Prior to their diagnosis, all patients in the sample were aware of cancer as a condition, could recognise many of the signs and symptoms of the disease, and knew some of the main lifestyle-related risk factors.
However, even those who were familiar with cancer did not consider themselves to be at risk.

‘I knew nothing of risk factors or anything to do with prostate cancer.’
(Bisexual man affected by cancer, 35–64)

LGBT participants with cancer, healthcare professionals, diversity specialists and academics within the sample all commented on the paucity of health education and promotion campaigns targeting the LGBT community. This dearth of information comes despite the fact that LGBT people in general are more likely to smoke, drink alcohol and take recreational drugs, and that lesbians are less likely to benefit from the protective impacts of parity, breastfeeding or taking contraceptive pills, for instance. They felt that all public health efforts focused on sexual health, and failed to encourage LGBT people to recognise the lifestyle risks of cancer. They also reported time and again that the imagery used in health education materials (websites, leaflets, posters, etc) failed to include LGBT people.
This report provides a lot of food for thought, and we hope that it is just the start of the conversation. With this in mind, we would like to invite LGBT people living with and affected by cancer, as well as health and social care professionals, to join an LGBT taskforce. This taskforce will aim to produce recommendations arising from this report, prioritise the issues that the members want to address, and co-design and prototype solutions.

If you would like to get involved and help shape the future of cancer care for people from the LGBT community, please contact us at researchlearning@macmillan.org.uk

In order for this work to continue to explore and understand the needs of LGBT people with cancer, Macmillan wants to:

- work with LGBT people living with and affected by cancer, using their experience to identify health inequalities and variation in experience. Together, we aim to co-design solutions, and influence decision-makers at local, regional, and national levels to tackle health inequalities.
- work with multiple partners and stakeholders within the LGBT community to develop and strengthen our knowledge around the experiences of those within the LGBT community who are living with and affected by cancer.
- provide support for LGBT people living with and affected by cancer to develop their skills, resources, and confidence to self-organise and use their experiences to influence decision-makers.

We know that this is only part of a much bigger story around the experiences of LGBT people living with and affected by cancer.
Acknowledgements

We’re deeply grateful and would like to thank each of the participants on the online engagement forum for their contributions, openness and honesty. We would also like to thank Forum for their design, moderation and analysis of the research. We would also like to thank Frontline for their evaluation of the research.

Forum would like to express their gratitude to all the participants, to Frontline for a formative and summative evaluation; and to the three community managers (for working sensitively with the participants and providing rich input at all stages of the research process): Cynthia Amorim, Rhonda Senior and Deborah Simmons.
References


2. The Cancer Patient Experience Survey monitors experiences by sexual orientation but not by gender identity, so there is no information on trans cancer patients specifically.

3. Cancer inequalities are ‘the differences between individuals’ cancer experience or outcome which result from their social-economic status, race, age, gender, disability, religion or belief, sexual orientation, cancer type or geographical location.’ (Report of the All Party Parliamentary Group on Cancer’s Inquiry into Inequalities in Cancer, 2009)


6. The sample includes patients with breast, prostate, colorectal, malignant melanoma, non-Hodgkin lymphoma, head and neck, lung, and cervical cancer.


8. Ibid


29. See: http://www.stonewall.org.uk/documents/stonewall_gay_mens_health_final.pdf. This survey of 6,861 LGBT people carried out by Stigma Research for Stonewall in 2011 provides hard evidence that gay, lesbian, bisexual and trans men and women nationwide are more likely to smoke, drink and take illegal drugs. A number of scientific articles show that lesbian and bisexual women are at greater risk of some cancers than heterosexual women because they are more likely to smoke, drink, have a higher BMI, and are less likely to be protected against cancer by parity, breastfeeding and the use of birth control pills. See for instance: Dible, S.L.; Roberts, S.A.; Robertson, P.A. and Paul, S.M. (2002) ‘Risk factors for ovarian cancer: lesbian and heterosexual women’. Oncology Nursing Forum. Jan-Feb; 29(1): E1-7.
Below is an overview of the engagement exercises that participants took part in.

**Final Task Plan**

*Macmillan research into inequalities in experiences of cancer services*

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<tr>
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<th>RESPONSES</th>
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<tr>
<td>Wk 1.2</td>
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</tr>
<tr>
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</tr>
<tr>
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<tr>
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</tr>
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</tr>
<tr>
<td>Wk 4.4</td>
<td>Involvement in decisions about care: survey</td>
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<tr>
<td>Wk 4.5</td>
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<td>Wk 4.6</td>
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<tr>
<td>Wk 4.7</td>
<td>Thank goodness …</td>
<td>PLWC only</td>
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<tr>
<td>Week 4.1</td>
<td>Holistic approach to individual needs</td>
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<tr>
<td>Week 4.2</td>
<td>Information and resources for patients</td>
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<td>Involvement in decisions about care</td>
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<td>In segment</td>
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<tr>
<td>Week 4.4</td>
<td>Case study: Susan</td>
<td>Professionals only</td>
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</tr>
<tr>
<td>WEEK</td>
<td>TASK TITLES</td>
<td>ALLOCATION</td>
<td>RESPONSES</td>
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<tr>
<td>Wk 5.1.</td>
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<td>Wk 5.2.</td>
<td>Support for people who care about you</td>
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<td>In segment</td>
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<tr>
<td>Wk 5.3.</td>
<td>Adjusting to life once treatment is over</td>
<td>PLWC only</td>
<td>In segment</td>
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<tr>
<td>Wk 5.4.</td>
<td>Being active in the community</td>
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<td>In segment</td>
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<tr>
<td>Wk 5.5.</td>
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<tr>
<td>Wk 5.6.</td>
<td>On balance, I feel ...</td>
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</tr>
<tr>
<td>Wk 5.7.</td>
<td>Bin it!</td>
<td>PLWC only</td>
<td>In segment</td>
</tr>
<tr>
<td>Week 5.1.</td>
<td>The impact of cancer on people around older cancer patients</td>
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<td>In segment</td>
</tr>
<tr>
<td>Week 5.2.</td>
<td>Support for people who care for cancer patients</td>
<td>Professionals only</td>
<td>In segment</td>
</tr>
<tr>
<td>Week 5.3.</td>
<td>Adjusting to life once treatment is over</td>
<td>Professionals only</td>
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<tr>
<td>Week 5.4.</td>
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<td>In segment</td>
</tr>
<tr>
<td>Wk 6.1.</td>
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</tr>
<tr>
<td>Wk 6.2.</td>
<td>Discrimination based on age</td>
<td>PLWC and Professionals</td>
<td>In segment</td>
</tr>
<tr>
<td>a)  What else could explain poorer experiences or outcomes?</td>
<td></td>
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<tr>
<td>b)  What else could explain poorer experiences or outcomes?</td>
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<tr>
<td>c)  What else could explain poorer experiences or outcomes?</td>
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</tr>
<tr>
<td>Wk 6.3.</td>
<td>Your public health campaign</td>
<td>PLWC only</td>
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</tr>
<tr>
<td>Wk 6.4.</td>
<td>Why do perceived inequalities exist?</td>
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<td>In segment</td>
</tr>
<tr>
<td>Managing difficult situations</td>
<td>Professionals only</td>
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<td></td>
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<tr>
<td>Wk 6.5.</td>
<td>Your public health campaign</td>
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<td>Open</td>
</tr>
<tr>
<td>Wk 7.1.</td>
<td>Your shout</td>
<td>PLWC and Professionals</td>
<td>Open</td>
</tr>
<tr>
<td>Wk 7.2.</td>
<td>Top three lessons</td>
<td>PLWC and Professionals</td>
<td>Open</td>
</tr>
<tr>
<td>Wk 7.3.</td>
<td>A cup of tea with your doctor</td>
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</tr>
<tr>
<td>Wk 7.4.</td>
<td>Message in a bottle</td>
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<tr>
<td>Wk 7.5.</td>
<td>I pledge ...</td>
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</tr>
<tr>
<td>Wk 7.6.</td>
<td>The last word</td>
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<td>Open</td>
</tr>
<tr>
<td>Week 7.3.</td>
<td>Professional engagement and capacity building</td>
<td>Professionals only</td>
<td>Open</td>
</tr>
</tbody>
</table>

‘Open’ means that all participants assigned this activity can see and comment on other participants’ posts.

‘In segment’ means that if participants share a segment, they can see and comment on other participants’ posts.

‘In private’ means that no one apart from the posting participant can see the answer. Some tasks can ONLY be set as private (such as ‘Mark Up’ tasks or surveys).
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. Whether it’s concerns about who you can talk to, planning for the extra costs or what to do about work, at Macmillan we understand how a cancer diagnosis can affect everything.

No one should face cancer alone. So when you need someone to turn to, we’re here. Right from the moment you’re diagnosed, through your treatment and beyond, we’re a constant source of support, giving you the energy and inspiration to help you take back control of your life.

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