

# “More than a diagnosis”

Promoting Good Outcomes in  
Lesbian, Gay and Bisexual Cancer Care.



Promoting good outcomes in Lesbian, Gay and Bisexual cancer care:  
a qualitative study of patients' experiences in clinical oncology.

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## **FORWARD**

**By Lord Michael Cashman**

Cancer has intimately touched my life, and in so many ways.

When my late husband, Paul, was diagnosed with cancer it was a huge shock, as it is for so many others. Initially we felt alone in a sea of specialists and appointments. However, as the process and the professionals took over, we were very fortunate with the treatment and care that he received from everyone. He was treated as a whole person, and that meant including me in his life, and in his care. Sometimes this meant having to remind people that we were a couple, a committed relationship, sometimes explaining why I was in the room with him, and often discussing his treatment together.

Paul and I took the decision to accept that cancer had come into our life as a teacher. But it was a teacher that we wanted to depart very quickly. We quickly learnt the lessons on how to value life itself, and how priceless love is. We learnt too that we had to fight. And fight hard.

We were lucky that we had each other, and though it is painful to be the powerless observer, we knew that together we could get through it, even through to the end. Some people face cancer alone, particularly older people, and sometimes without support within their wider families or communities.

The battle is even harder when other issues arise, ever more so when one is a part of a minority, and often a misunderstood minority.

Not once was our relationship an issue, but that is not always the case. Having to declare one's sexual orientation or relationship when we are feeling vulnerable can be challenging and intimidating. In fact it can have a negative effect on the outcomes.

And that is why I embrace this study and its recommendations. It is the first study conducted in a hospital setting of any health condition, apart from important research on HIV/AIDS. It looks at our experiences as members of Lesbian, Gay and Bisexual communities, and asks the serious questions about the care, understanding and treatment that we receive, and whether we are treated differently because of our sexual orientation.

The recommendations are simple, effective and cost efficient. Their aim is stunning: to improve our lives and wellbeing at every point of care and interaction, and to ensure that we never feel unwelcome or alone in the journey through the cancer care landscape.

A handwritten signature in blue ink that reads "Michael Cashman". The signature is written in a cursive style and is underlined with a single horizontal line.

Lord Cashman CBE.

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# EXECUTIVE SUMMARY

Cancer inequalities, including differences in cancer outcomes and patient satisfaction, affect a range of groups including lesbian, gay and bisexual (LGB) people. In its strategy to reduce these inequalities, the Department of Health commissioned the Cancer Patient Experience Survey (CPES) providing baseline data in which LGB patients were more likely to say their experiences were less positive than those of heterosexual patients. These differences included accessible information, psychosocial support and the human rights concerns of dignity and respect. The CPES, which was carried out in four successive years (2010-2014), suggesting that these are intractable problems, found that LGB patients were more likely to disagree with statements such as they 'never felt treated as a set of cancer symptoms rather than as a whole person' or the 'doctor never talked about me as if I wasn't there'. The CPES did not collect qualitative data and consequently the reasons for these differences were not known. This De Montfort University study, funded by Macmillan, illuminates some of the reasons for these survey findings as we were able to gather people's accounts of their treatment and care. This report identifies key moments in the cancer journey where care provided for LGB cancer patients can contribute to their recovery and well-being.

Alongside this evidence of unmet need, NHS England (2017) has recently issued guidance to support the introduction of mechanisms for recording sexual orientation across all health services in England for patients over 16. It recommends that sexual orientation monitoring occurs at every face to face contact with the patient. The collection of this monitoring data has implications; not only for cancer professionals, but also that patients themselves understand why this information is being requested. The report draws on LGB cancer patients' motivations and methods for disclosing their sexual orientation and the perceived benefits of doing so for their quality of life. The findings will contribute to understanding the health benefits of coming out and how disclosure might be facilitated in hospital settings.

This study provides compelling data about some of the factors underpinning inequalities in the experiences and, potentially, cancer outcomes for LGB patients. Managing the worry about whether it is safe to disclose their sexual orientation to professionals and the uncertainty about how this will be received presents an additional burden for LGB people with cancer. Participants in this study were sometimes hesitant to disclose because the opportunity did not arise or they were uncertain about its relevance. The report identifies some moments that matter in the care relationship where professionals could seek to facilitate disclosure thus contributing to Achieving World Class Cancer Outcomes (Department of Health, 2015) for LGB patients.

In addition, the findings point to the importance of creating an inclusive care environment; participants noted that even in the Cancer Centres of Excellence, there were few visible signs of inclusion for LGB cancer patients. Steps to promote inclusion may entail a diversity policy statement, imagery on walls or the display of a LGB staff network on a hospital notice-board. participants also shared experiences where they were accepted in an everyday manner by hospital staff. They often talked about a whole hospital approach where they were acknowledged by staff from porters, health care assistants, nurses and consultants.

These cancer narratives also highlight the need for LGB cancer support groups and tailored resources. The lack of LGB support groups in the UK mean that some participants were coping with their cancer with few forms of social and emotional support and they found few sources of information which addressed their needs. There was a clear demand for a greater range of LGB support resources that were relevant to the challenges and concerns of specific cancer types and reports of rather patchy provision in this regard, with differences influenced primarily by geographic location and cancer type.

Finally, our findings suggest that participants had heterogeneous expectations of cancer care requiring complex skills from professionals. Yet there is little or no curricula content in university programmes of Medicine or Nursing. This might suggest a lack of recognition of distinctive cancer care needs and may explain why participants reported different patient experiences even within the same hospital. The inclusion of research with LGB patients alongside heterosexual populations and relevant case studies to underpin Learning and Development and Continuous Professional Development to inform understanding of patient experience, psychosocial concerns and cancer risk is urgently needed.





# Recommendations

## For NHS Trusts

- Include images that reflect the diversity of the UK population in health promotion and other resources including LGB communities;
- Display equality & diversity policies for patients;
- Work alongside LGB voluntary sector organisations to offer to offer after care support;
- Undertake training for staff across the hospitals from consultants to hospital porters so that they are confident and comfortable providing care for LGB patients.

## For the General Medical Council

- Ensure that undergraduate medical and nursing curricula include appropriate case studies and discussion relevant for LGB communities.

## For Cancer Charities

- Undertake Public and Patient Involvement work with LGB patients with cancer and their carers to complete the feedback loop for this research ensuring that the recommendations and key findings reflect their concerns;
- Develop the patient resource which builds on the specific findings of this study;
- Develop information resources to address the support needs of LGB patients with less common forms of cancer and those living in geographic regions with no access to support;
- Widely share good practice examples of inclusive care.

# BACKGROUND AND CONTEXT



Across Europe, cancer is a key public health concern with 2.6 million people diagnosed each year. In the UK, 250,000 people are newly diagnosed with cancer and approximately 130,000 people die from the disease (Department of Health (DH), 2013). Although deaths from cancer have fallen in recent years, the UK lags behind other European nations in reducing mortality. While there are multiple contributory risk factors, social characteristics may mitigate cancer survivorship in the two million people living with cancer. Analysis of existing US cancer surveillance data has inferred that 36 720 cancer deaths (43% of all cancer deaths) in men aged 25–64 years in 2007 could have been avoided if educational and racial disparities were eliminated (Boehmer et al. 2012). This burden, where some groups of people have different experiences or outcomes for cancer, is recognised in UK cancer policy as a cancer inequality and includes lesbian, gay and bisexual (LGB) people (DH, 2011).

## *Estimating incidence, risk and prevalence for LGB people with cancer*

Statistics about cancer incidence, mortality and patterns of risk among LGB people are not available because the National Cancer Intelligence Network does not collect data on sexual orientation. In the absence of such data, the task of estimating risk and prevalence rates specifically for LGB people has been undertaken, only recently, through large-scale surveys. Among GB men, research has found differences in cancer prevalence with gay men having almost twofold odds of reporting a cancer diagnosis, partly attributable to the increased risk of anal cancer, compared with heterosexual men (Boehmer et al. 2011); among HIV positive GB men, the incidence is 9 times higher than for other GB men (Quinn et al. 2015a). Some evidence suggests that LGB people are diagnosed with cancer at a younger age (Boehmer et al. 2011). The latter study revealed differences in quality of life: lesbian and bisexual (LB) breast cancer survivors were twice as likely to report fair or poor health compared with heterosexual women. It also found that bisexual women report cervical cancer at more than twice the rate of other women. LB breast cancer patients have higher stress associated with the diagnosis, lower satisfaction with the doctor's care and with the perceived availability of emotional support (Quinn et al. 2015a).

### ***LGB patient satisfaction with cancer services***

To develop evidence about social inequalities in cancer, the Department of Health introduced the Cancer Patient Experience Survey (CPES), its flagship assessment of patient satisfaction in 2014 (CPES, 2014). Among the 67,000 respondents and in comparison to heterosexual respondents, LGB people reported less positive patient experiences, in relation to: accessible information, psychosocial support and the human rights concerns of dignity and respect. The survey, which was carried out in four successive years, suggesting that these are intractable problems, found that LGB patients were more likely to disagree with statements such as they never felt treated as a set of cancer symptoms rather than as a whole person or the doctor never talked about me as if I wasn't there.

### ***Professional and patient communication for LGB people in cancer care***

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## Rationale

The purpose of this study is to understand the barriers and facilitators to sexual orientation disclosure and how disclosure can be facilitated and responded to. Encouraging higher rates of disclosure is a means of improving the patient experience for lesbian, gay and bisexual people with cancer (if the interaction is a positive one) and will provide more robust data to monitor patient experience. But we are also aware that for some patients their privacy is paramount. We aim also to understand what patients perceive as the benefits or obstacles to their use or access to cancer support groups, who they turn to for support and their information needs.

## AIMS

To conduct qualitative research with lesbian, gay and bisexual people affected by cancer to:

1. Identify the patient-reported issues that facilitate disclosure of sexual orientation throughout the cancer journey by understanding:
  - a. What are the (systems and interpersonal) barriers to disclosure of sexual orientation and what can be done to make disclosure easier?
  - b. What are the 'moments that matter' in clinical interactions for LGB people affected by cancer?
2. Understand the complexity of disclosure; how professionals can appropriately respond to it; and any evidence that could help efforts to improve the consistent, inclusive monitoring of the sexual orientation of patients across the healthcare system.

# METHODOLOGY

## *Public and Patient Involvement (PPI) undertaken in the design of this study*

We have undertaken substantial PPI work, funded by De Montfort University, in developing this research. Although few mainstream avenues exist through which to contact LGB patients, we used our extensive networks to engage patients' views in designing this study. We have had strong support from the Macmillan inclusion team who held a PPI event in Manchester. As part of this day, 11 LGB patients were recruited and using social media we received 5 additional surveys. Participants were provided with a research summary and completed a short survey, in which five open questions were asked, about the proposed design. Participants were subsequently telephoned for a detailed response. We then presented a written and verbal summary to a lively workshop held in Leicester with 9 LGB people with cancer. This approach allowed collective reflection on perspectives gathered individually.

## *Participants*

Fifteen participants took part in the study. The inclusion criteria were that participants had been diagnosed with any form of cancer within the past five years and self-identified as a lesbian, gay man or bisexual person.

## *Design*

This is the first study to be conducted in hospital settings of any health condition among LGB people apart from HIV research. Following ethical approval, Research & Development (R&D) approval was obtained from five NHS hospitals. In depth qualitative interviews were conducted using an interview topic schedule.

The justification for the size of the sample is that data saturation can be reached in the first 12 interviews (Guest et al. 2006). The population is one that is sometimes described as 'hard to reach' due to the lack of traditional avenues of recruitment; it comprises a relatively small community within the general population thus necessitating the collaboration of 5 hospital sites for a small study. The sample size was also constrained by the time period post R&D.

## *Procedure*

The study was funded as a 10 month project by Macmillan Cancer Support. Study materials were prominently displayed in clinic waiting rooms and an appointed member of staff facilitated recruitment in each site. Visits were made to each site and regular contact was maintained. To publicise the study we used social media, conducted a radio interview and a blog was placed on Macmillan online community by one of the participants who had participated at the PPI design stage.

Potential participants contacted the research assistant by email and an initial discussion took place about the aims and purpose of the study. Participants were sent a participant information sheet, provided informed consent and gave brief demographic information before taking part in the study. Semi-structured interviews with 15 LGB people with cancer lasting between 1-2 hours took place in a location of participants' choice, mainly their own homes or in university or other private offices, and were conducted by one of four experienced interviewers, who had received good clinical practice training, in the team between April and December 2017. The interviews were digitally recorded and transcribed verbatim.

### **Ethics**

Ethical approval (#1538) was given by De Montfort University, Health and Life Sciences, Research Ethics Committee in February 2017. NHS IRAS was obtained in February 2017 (#180271) and R&D for each hospital site was approved by the end of May 2017. All data were securely stored and participants' names and other details are appropriately anonymised.

The study was conducted in accordance with the British Psychological Society (BPS), Code of Research Ethics (BPS, 2010). Participants were provided with full information to enable them to take part and we obtained written informed consent. To ensure confidentiality and privacy, participants were allocated a pseudonym; a distress protocol was implemented and participants had the right to pause, reconvene or terminate the interview.

### **Method of analysis**

Our analytical approach is informed by thematic analysis (Braun and Clarke, 2006); this is a method which is commonly used in psychological research. We paid attention to the meaning-making of participants in an iterative process. At phase one, at a very early stage in the data-collection, four of the research team independently read a subset of transcripts. We met together to discuss our individual interpretations of the data and this immersive reading involved the identification of patterns in the data. Our initial theme categories were: managing the etiquette of disclosure, person-centred care, routine acceptance and emotional affects, support networks and the hospital environment. Through discussion we amended the theme titles to more accurately reflect the data generated. At phase two, two researchers used a template to identify these recurring themes and produced an overarching framework. The analysis was undertaken over a period of seven months.

# FINDINGS AND DISCUSSION

## 1. Understanding disclosure decision-making

Disclosure, or the decision about whether to come out, is part and parcel of the lives of lesbian, gay bisexual people. A positive and open LGB identity is seen to constitute an authentic sense of self. In previous studies, (Durso and Meyer, 2013) disclosure is associated with health benefits.



Our findings suggest that participants made decisions about disclosure which were based on inter-personal relationships: the interaction with the cancer professional was pivotal to their decision-making. Nadia describes the initial consultation in which the consultant performed a biopsy and despite being 'out' in her everyday life, she made a strategic decision not to disclose:

*And she said oh I am sure you two are really good friends, but if you wouldn't mind stepping behind the curtain, to my partner. So that was a bit just a bit unfortunate... It just jars when that kind of thing happens you are already in quite a vulnerable place and it makes you feel a bit self-conscious. And you don't know whether to make a big deal out of it and say hang on a minute actually it's my partner...And I decided not to at that point, because I don't know, I knew I probably wasn't going to see her again  
(Nadia, lesbian, breast cancer).*

By contrast, in a similar circumstance, Julian made the decision to disclose.

*But this appointment he called me in from the waiting room and we went into this room I sat down, the doctor is there, I am here and Chris is to my right. And the doctor kept on looking up and I knew he was thinking who the hell is this guy but he never asked. So after about a minute and a half I thought I suppose I had better tell him I said he is with me. Oh, oh, I did wonder, is he your brother. I said no he is my partner (Julian, gay man, prostate cancer).*

In this instance, the consultant might have asked an open question: 'who is this?' or 'what is the relationship between you?' an opportunity was presented for the clinician to ask a simple open question. In their accounts, Nadia, Julian and Lou spoke about their partner being mistaken for a sibling, parent or friend and because of this they felt that their intimate relationships were accorded lesser value.

Two of the bisexual men in the study felt that they did not have an opportunity to disclose their sexual orientation even though they wished to do so. Robert felt that despite having several operations and a hospital stay, all of those involved in his care had avoided the use of pronouns (in reference to his partner) and he was unable to correct the assumption that his primary partner is female. He also wanted a one-to-one consultation where he could ask about the impact of treatment on his sexual relationships but felt inhibited by the presence of a nurse:



*The only time it's come up (his sexual orientation) was in the last meeting I had with my oncologist ..and there were questions I wanted to ask him that I couldn't or wouldn't or didn't feel comfortable asking him because he is always chaperoned by a female nurse. And I think if I had been talking about sex with a woman I think I would have been more comfortable, .... Whereas if I am talking about sex with a guy and that's what I wanted to ask him about, I would feel, I did feel uncomfortable and I didn't ask him about that*  
(Robert, bisexual man, prostate cancer).





Similarly, because Daniel had attended his first appointment with his wife, the consultant assumed that he was heterosexual (other bisexual men in the study also attended the first appointment with their wives). Previously, for a sexual health concern, he attended a clinic in a distant town to avoid anyone he knew. When he asked about their computer records, he was reassured that they asked only for the first three digits of his postcode. For his prostate cancer, Daniel had treatment at several different hospitals and only at the private hospital was he asked about his sexual orientation where one of the forms asked a question about sex with men. This gave him the opportunity to disclose and he subsequently confided in the nurse. Mostly, Daniel kept his bisexuality private and talked about the legal penalties historically associated with sex with men.

Cancer is a disease which predominantly affects older people. Despite wider social and legislative changes, LGB older people may continue to limit the number of others they trust with the knowledge of their sexual orientation because they have lived their lives under less supportive social conditions (Fish and Karban, 2015). Their perceptions about social attitudes affected their cancer journey throughout their treatment, care and recovery. For Robert, his fear about being accepted meant that he was not able to access a cancer support group:

*And I certainly wouldn't be open with them... generally speaking the older people are the less open minded they are. So I wouldn't go there  
(Robert, bisexual man, prostate cancer).*

The relevance to his care of being out is articulated by Tim who had come out to his GP ten years previously and throughout his treatment and care he was open about his sexual orientation:

*And all the way through it I have made a point of making sure they know I am gay...I made sure all the way through this process, where-ever appropriate, that they knew I was gay because I think it's important for me to be open and it's important for them to know. And I do think that gay men have different relationships with their bodies than perhaps straight men  
(Tim, gay man, prostate cancer).*

Many of the participants in the study talked about looking for opportunities to come out to cancer professionals or drew attention to the barriers to disclosure. For a small number of participants in the study, their sexual orientation is more peripheral to their sense of self (e.g. it's only a small part of whom I am) and they are less likely to come out in cancer care. This perspective was articulated by Bob:

*So it just seemed right, and I have to say it is the first meeting of all gay people I have ever been to, I am not outwardly gay, I don't wear my sexuality on my sleeve it's a very small part of who I am so I don't particularly mix with gay people. I have got a few gay friends, I have got a lot of straight friends, it doesn't matter*  
(Bob bisexual man, prostate cancer).

His account draws attention to the probability that some patients will continue to hide their sexual orientation and it points to the need to actively promote a safe and supportive environment whether or not LGB patients decide to disclose.

In this theme, we have outlined some of the enablers and barriers to disclosure for LGB cancer patients. The data here suggest that participants made situated and contingent decisions based on a risk-benefit analysis: does the benefit of disclosure outweigh the potential risks of a negative reaction? As illustrated in the narrative provided by Nadia, LGB people are often attuned to verbal and non-verbal cues and make fairly quick decisions about disclosing based on their perceptions of the likely response or whether they are likely to have continued contact with the cancer professional. The initial consultation then, provides an important arena where the oncologist or other cancer professional can signal the inclusivity of the hospital environment and its commitment to inclusive care for LGB patients. In this study, participants frequently talked about the lack of opportunity to disclose. For one of the participants, this meant that he had previously chosen to receive care at a distant town in order to keep his identity confidential. Disclosure is an interactional process; patients will consider the terminology used by professionals (such as 'friend' used to refer to their partner) and their body language. Coming out should not be an additional burden when patients are faced with a life-threatening condition; instead, as part of a commitment to inclusive care, the hospital should consider ways to facilitate it. This is the focus of the following theme.

## 2. Creating Safe LGB-Affirmative Clinical Spaces



In this theme, we outline some of the concerns participants had about being open about their LGB identity in clinical spaces and the lack of visible LGB equality indicators in many of these settings.

In this theme we outline some of these experiences and their effects and also discuss how more visible markers of LGB equality in clinical oncology spaces could help to mitigate some of them.

Alongside some of the interactions noted previously where long-term partners were excluded from consultations and presumed to be relatives or friends, a number of participants described actually feeling threatened in clinical environments. These included a few accounts of witnessing explicitly homophobic discourse. These events were noted but typically minimised and ‘normalised’ by participants. For example Julian described a number of staff as making ‘a few throwaway remarks just generally about gay blah blah blah’ but downplayed them noting ‘they weren’t directed at me’.

However more common, was a sense of anticipation of threat. This was most commonly noted by gay and bisexual men in the study who described feeling vulnerable on male wards:

*On the ward was six people and some of the, it was a male ward... And there was a couple of guys who had girlfriends or wives and I think one with kids as well. And certainly... I wouldn't have felt comfortable about being intimate with hugging a boyfriend or you know in that environment. It felt quite macho and I would have felt, I wouldn't have felt comfortable doing that (Daniel, bisexual man, prostate cancer).*

*And so they put me in the orthopaedic ward and I felt really, really threatened by being with a whole load of extremely macho men... I didn't like that at all and so I went back into the closet straight away. And so it led to things like I said to Mark (partner) don't kiss me. And ...I even encouraged him...you needn't bother to come and visit  
(Rudy, gay man, breast cancer).*

The second of these quotations is particularly salient as it comes from a participant who earlier in his interview described coming out to his healthcare team as an act of activism. A similar view is offered by (Julian, gay man, prostate cancer) who experienced a lengthy in-patient stay after contracting sepsis relating to his cancer treatment:



*I ended up at the hospital and I can remember feeling really it was fearful because I didn't want to come out. I was in this strange alien environment is how I viewed it there was nothing there to reassure me that I would be OK being myself. I am out in every other aspect of my life I went back in the closet for this  
(Julian, gay man, prostate cancer).*

Another prostate cancer patient, Tom, disclosed that he felt that both his surgeons and doctors operated in a very 'macho' style and, whilst arguably alienating rather than threatening, showed no appreciation that treatments are difficult and distressing:

*they forget that you are going through a complete and utter nightmare  
(Tom, gay man, prostate cancer).*

A number of both female and male participants offered examples of spaces being less inclusive and welcoming to LGB people and their partners than to heterosexual couples. In another extract from Julian's interview he describes a sense of exclusion for him and his partner during his lengthy chemotherapy sessions:

*And my partner came with me to every one of those, he sat there with me every three weeks for a couple of hours and not once did anyone say who he is he, or involve him. But there were straight couples there where the partner was being involved. It just seemed why can't they be more friendly, they should know better*  
(Julian, gay man, prostate cancer).

Although she didn't recall direct negative experiences, Corinne also felt uncomfortable in continued proximity with other participants citing perceptions of a heterosexist environment in waiting rooms and chemotherapy suites:

Corinne potentially explains her anticipation of prejudice as potentially representing her own internalised homophobia, which has been defined by Williamson (2000, p. 97) as 'the negative and distressing thoughts and feelings experienced by lesbians and gay men about their sexuality, and which are attributed to experiences of cultural heterosexism and victimization'. However as Williamson (2000) argues such explanations position the LGB individual as lacking resilience and suggest individual interventions rather than structural or institutional changes are required. As noted previously by Fish & Williamson (2016) LGB patients who might routinely tackle prejudice in other contexts often feel diminished in their resources because of pain and fatigue relating to their cancer or treatment. In this situation, and like many other participants, Corinne often scanned the environment for visible clues about the hospital ethos, looking for a noticeable sign of its commitment to equality and diversity:

*But there would be couples male and female... but I think it was often felt, you know I didn't want to go into my sexuality with anybody there. And I think what could happen... It's stressful enough going in there and I didn't want to meet homophobia in that way Maybe I am doing them a disservice, but I did feel that the waiting room really was the place that I felt a little bit, I felt my sexuality in the sense of I don't want to discuss it*  
(Corinne, lesbian, breast cancer).



*P: But I think something, ...not OTT but something that says it's OK to be, just to be. And there is nothing around if you notice, there is nothing that says anything. But I was expecting...*

*I: You were expecting something?*

*P: Yes which is the worse thing really isn't it? So is it my internalised homophobia or is it just my? ... I think it's more my defence mechanism that I am just being, I want to recover and I don't want the issues. So there just needs to be something around, it is weird isn't it? Maybe I am the only one who thinks that having a little rainbow flag matters but it does, you to go B&Bs and you see a little rainbow flag in the window and you think oh great I am not going to have to give a thought about this. And I think those sorts of things need to be addressed... What would be really helpful at Hospital X is something on the rolling information thing or whatever, cancer doesn't discriminate neither should you. Or a rainbow flag or something that suggests not everybody is in a heterosexual relationship and it felt more of an issue there*

*(Corinne, lesbian, breast cancer)*

It can be seen in Corinne's account that the presence of a sign or symbol acts as a visual reassurance that they would not encounter poor reactions from staff and it meant that they could then focus on their treatment and recovery. It arguably should give pause for thought that a large cancer centre serving a city noted for its large LGB community displayed no materials (that the participant was aware of) to indicate its policy on inclusivity; perhaps it has not been considered or might be seen as offensive to the larger population of patients.

Some participants interacted with staff who were openly LGB or who displayed markers of LGB equality and advocacy. Even if these interactions were transient, they typically had a significant effect on boosting our participants' sense of safety:

*Whilst I was in hospital there was a girl there who had a rainbow tie attached to her trouser belt, this was in intensive care, and I thought that's really good. It made me feel quite at ease because there was somebody who was working on the ward who was obviously identifying as lesbian and she was working with these people so it was, that made me feel quite at ease. So I think yes it would have been nice I think to have had more things around that were identifiable as lesbian or gay or LGBT*

*(Ellie, lesbian, breast cancer).*

As well as visible markers of LGB equality, for other participants it was the way that staff engaged with them that created a sense that they were safe and accepted and their care and support would not be affected by their sexuality. This generally involved attributes such as having some literacy about LGB culture and legitimising same-sex relationships. As in the previous extract, these were typically small actions but they had considerable significance to the recipient.

*'And she [nurse] said 'you get your wife to make you an Ovaltine in the evening and get her to bring it up to you in bed. And the way that she so naturally said that, it was absolutely lovely, it was moving because we never really had an explicit conversation about it'*  
(Nadia, lesbian, breast cancer).

What is notable about these encounters is that they are both mundane, but also powerful ways of demonstrating inclusion and a holistic understanding of the patient.

*Actually the doctor who did the ultra sound I went back to him again for the scan like a year later and he remembered me and he did say how is everything, you were getting married weren't you. And I said yes and he remembered that and it wasn't like, yes, he knew I was getting married to a woman so he was quite positive about it and it was nice that he remembered*  
(Steph, queer, breast cancer).

*One of the radiotherapy staff said as she was preparing me have you got anything planned this weekend and I said its gay pride in Margate. Oh really my daughter went to gay pride or was in Amsterdam when it was on or something like that. So that was just an ordinary conversation that took place a sort of acceptance that this discourse was the sort of discourse that any one might have. It could have been I am going to decorate the house I am going to Gay Pride*  
(Rudy, gay man, breast cancer).

Furthermore, perceptions of safety and acceptance in the hospital environment were key in some of the treatment decisions made by some patients and affect the potential holistic and patient-centred care that most hospitals claim to provide. Daniel moved his care because of concerns around how his bisexuality would be received and concerns over confidentiality at his nearest hospital describing the town he lived in as being part of a 'very homophobic area' Another participant with prostate cancer elected to have his blood-tests carried out at a hospital which involved a round trip of 128 miles because he found the environment much more 'compassionate...softer,

warmer and more friendly' compared to 'the harsh, hard and business-like' environment of the local hospital where he was much more guarded about disclosing his bisexuality.

*I don't get my bloods done here  
I go over there to get them  
done. It's kind of a safe place  
(Robert, bisexual man, prostate  
cancer).*



In this theme we have outlined the way that some clinical environments were perceived as being either overtly or more commonly potentially heterosexist or homophobic. This often meant that patients were 'out' in all other aspects of their lives, but not in hospitals. Some of the gay and bisexual men expressed fear at being placed on all male wards. We have also outlined the ways in which visual markers of LGB(T) equality (discrete symbols such as the rainbow) are viewed as important in providing reassurance to LGB patients that their care will be as good as that provided to heterosexuals and their rights will be upheld. We also look at how staff, individually and collectively create a culture in which LGB patients feel comfortable and in which they may be more likely to invite their LGB partners and friends for support, and to disclose their identity. Their narratives gave examples of small acts of commitment to inclusive principles which could make a large impact on them feeling safe and comfortable. Their resilience in tackling heterosexist behaviour is diminished for patients undergoing treatment; visual cues of inclusion can make people feel less anxious.

These findings confirm very recent work from the USA that has identified barriers to LGB-affirmative practice and advocates for interventions to support LGB 'cultural competence' (Radix & Maingi, 2018).



### 3. Addressing social isolation through appropriately tailored health information

In this theme we consider the social isolation and impoverished social support experienced by some LGB people with cancer, and highlight the lack of appropriately tailored LGB-community support resources especially in relation to specific cancers. We lobby for both increased understanding of the social support needs of LGB patients and for further resources to address some of these needs.

Social support is associated with both reduced cancer mortality and improved outcomes for members of sexual and gender-identity minorities (Boehmer, 2018; Kamen et al., 2015). Previous research has shown that LGB people with cancer, particularly sexual minority men, are more likely to report social isolation and attend consultations alone (Baughman et al. 2017; Hulbert-Williams et al 2016).

A number of our participants reported a sense of isolation or abandonment especially when attending treatment or during long spells of rest and recovery at home. For several months Steph's main social interaction involved the 'casual chats' she had when out walking her dog:

*P: I was off for about 6 months so it just gets you out the house and you talk to people on the park that you see.*

*I: Other dog walkers?*

*P: Yes, so it was good to, I could imagine myself just being quite isolated and off work and not really speaking to anybody, but it got me out and about and just chatting with people, just casual chat. I think if I wasn't doing that I would probably have needed some counselling just to get myself, force myself to go out and about, you get quite isolated when you are off work not really seeing many people... if you have not got the support from your family then it's going to be really difficult to get through stuff  
(Steph, queer, breast cancer).*



Some of the participants attended unpleasant and fatiguing treatments alone, resulting in both physical and psychological exhaustion. Following a break-up with his male partner Robert reported significant distress at having to make an almost three-hour round trip alone to attend regular outpatient treatment sessions:

*I was really suffering last year when I was going through radiotherapy especially with quite strong depression, it was very difficult. I was driving there every day on my own... it's a full day, every day, five days a week. And it's exhausting*  
(Robert, bisexual man, prostate cancer).

Although heterosexual individuals undergoing testing and treatment for cancer are not immune from lacking adequate social support, a body of research suggests that LGB individuals are more likely to attend procedures alone and to feel isolated (Hulbert-Williams et al., 2017). Whilst this was more frequently true of our single participants, as will be

discussed further in the final theme, those in long-term relationships may also feel poorly supported because they are wary in asking partners to attend appointments or visit them during inpatient stays for anxieties about anticipated stigma in what they perceive to be heterosexist environments.

In keeping with previous research (Fish, 2010), most of our participants felt they lacked access to more specific LGB-attuned resources, both in terms of information and support. However, participants had varying views about the extent to which they wanted cancer 'foregrounded' in those resources. One of the gay men who had experienced prostate cancer eschewed the idea of a support group housed indoors and expressed a desire to be part of a therapeutic walking group:

*I think really what you do need... is taking out of yourself, you don't want to go and be in a cancer environment at least I don't...I would like to be with people who recognise me as a person the fact that I am a patient or an ex patient is quite incidental. I don't need emotional support I don't need propping up I don't want 'oh isn't he doing well, he is lovely isn't it?' I don't need all that business thank you very much...A walking club that would be good, and you are distracted because you are looking at things ...But in a building no thank you*  
(Jeremy, gay man, prostate cancer).

Recent research (e.g. Fischer et al., 2017) has shown the benefits of such interventions. However it must be noted that other men who had had prostate cancer preferred groups where the focus was more directly on discussing and addressing the psychosocial and psychosexual needs of gay and bisexual men with the condition, especially around body image and sexual functioning. Arguably because of the nature of the men's concerns, as reported in a previous study (Fish & Williamson, 2016) more general groups aimed at prostate cancer survivors were not seen as helpful.

Indeed although he had no significant knowledge of the members or their views, Robert presumed that if he attended the nearest group he would face a heterosexist environment where he would not feel comfortable discussing his concerns:

*There are no prostate cancer support groups for men here, there is one further down the coast that I have never been to... I wouldn't go because I think it's a room full of seventy year old guys....If there was a LGBT group I would check it out*  
(Robert, bisexual man, prostate cancer).

Most of the men in our study had experienced prostate cancer and several had accessed information through the website of Prostate Cancer UK and found support through one of the three prostate cancer support groups in England for gay and bisexual men. They reported a spirit of camaraderie, openness to discussion and a belief that they were able to ask any question without fear of discomfort or embarrassment.

*So it's that kind of thing that is to me what a support group is about. ... You go in (to hospital) and have stuff done and you go out. It takes the support groups to give you that, I think because we are such an open group there is not a subject that is not on the agenda. So you can ask anything, I could go next month and ask a question and by the following month there would be answers, it might be by emails*  
(Robin, gay man, prostate cancer).

Many of these participants appeared knowledgeable about treatment options, the impact of particular treatments on sexual functioning and a small number had become involved in wider campaigns. Some of these support groups were co-ordinated through voluntary sector organisations on very tight budgets and were threatened by a withdrawal of funding due to austerity measures. Despite the positive experiences of these men, in relation to most other cancers participants, they struggled to access the specific information and support that many of them desired. For example, Rudy felt very isolated as a gay man who had experienced breast cancer despite creating a blog which he hoped would help connect him to other sexual minority men who had experienced this form of cancer. Although aware of more general cancer information

and supported targeted at LGB people with cancer he didn't find these resources very helpful to his particular situation:

*I feel I might be the only gay man in the country that has breast cancer... I don't find the LGBT forum in Macmillan very useful  
(Rudy, gay man, breast cancer).*



Perhaps more surprisingly given its much greater prevalence, and despite a considerable amount of research in the area (e.g. Fish, 2016; Wandrey et al., 2016), there also appeared to be very little breast-cancer specific support available for lesbian and bisexual women with breast cancer:

*I did look on the internet and found some information online but didn't find much in terms of support locally  
(Nadia, lesbian, breast cancer).*

In the absence of local tailored support, Nadia had connected with other lesbian breast cancer survivors through increased participation on Twitter but would have welcomed more 'in person' support. Other women talked positively about utilising their own existing support networks who provided some of the needed informal care:

*in [Northern City] we have got a group of lesbians who really do look after each other, a lot of us are single and we understand that sometimes you know you need a bit of support because you don't have a partner there making your dinner for you or bringing your food up when you are poorly. So yes we do that for each other.... But if it hadn't been for the community it would have been really hard work  
(Ellie, lesbian, breast cancer)*

However, although Ellie was very involved in a number of LGBT networks in her everyday life, she drew attention to the lack of signposting to existing networks, support groups and resources and despite feeling well-supported by her friendship

group she expressed a regret that the support of a more specific group of women who could empathise specifically with her situation had not been available to her especially when she was adapting to her diagnosis.

*I would have liked to have had an LGBT support group (for breast cancer survivors)... I was on my own and it would have been nice to have been able to talk with other people, like-minded people  
(Ellie, lesbian, breast cancer).*



The findings outlined in this theme demonstrate that some LGB people with cancer may lack key social support both at home and when attending hospitals to experience clinical procedures. In the past few years, three or more groups for gay and bisexual men with prostate cancer had been set up by GB men themselves in large cities; some of these groups were supported by local voluntary sector organisations who provided co-ordination and hosted online resources. Men attending these groups largely felt that they had aftercare support to promote their recovery. But there was also a clear demand for a greater range of LGB support resources, that were relevant to the challenges and concerns of specific cancer types, and reports of rather patchy provision in this regard, with differences influenced primarily by geographic location and cancer type. Participants with other forms of cancer (than prostate), those living alone or those living outside of the three cities which hosted support groups, felt a lack of aftercare support and pointed to a lack of a co-ordinated package of care which addressed their needs as LGB cancer patients.

## **Study limitations**

This study has some limitations. Because this patient group is sometimes described as 'hard to reach' by virtue of its relative size in the general population, it is likely that participants are more open about their sexual orientation than is the case in the wider LGB population. The sample does not reflect the ethnic diversity of LGB communities in the UK. The study recruited people with a relatively narrow range of cancer types.

# CONCLUSIONS

This study provides compelling data about some of the factors underpinning inequalities in the experiences and, potentially, cancer outcomes for LGB patients. Managing the worry about whether it is safe to disclose their sexual orientation to professionals and the uncertainty about how this will be received presents an additional burden for LGB people with cancer. Participants in this study were sometimes hesitant to disclose because the opportunity did not arise or they were uncertain about its relevance. The report identifies some moments that matter in the care relationship where professionals could seek to facilitate disclosure thus contributing to Achieving World Class Cancer Outcomes (Department of Health, 2015) for LGB patients.

In addition, the findings point to the importance of creating an inclusive care environment; participants noted that even in the Cancer Centres of Excellence, there were few visible signs of inclusion for LGB cancer patients. Steps to promote inclusion may entail a diversity policy statement, imagery on walls or the display of a LGB staff network on a hospital notice-board. Participants shared experiences where they were accepted in an everyday manner by hospital staff. They often talked about a whole hospital approach where they were acknowledged by staff from porters, health care assistants, nurses and consultants.

These cancer narratives also highlight the need for LGB cancer support groups and tailored resources. The lack of LGB support groups in the UK mean that some participants were coping with their cancer with few forms of social and emotional support and they found few sources of information which addressed their needs. There was a clear demand for a greater range of LGB information resources and sources of support that were relevant to the challenges and concerns of specific cancer types, and reports of rather patchy provision in this regard, with differences influenced primarily by geographic location and cancer type.

Finally, our findings suggest that participants had heterogeneous expectations of cancer care requiring complex skills from professionals. Yet there is little or no curricula content in university programmes of Medicine or Nursing. This might suggest a lack of recognition of distinctive cancer care needs and may explain why participants reported different patient experiences even within the same hospital. The inclusion of LGB research to inform understanding of patient experience, psychosocial concerns and cancer risk is urgently needed in health curricula.

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