Supporting Lesbian, Gay and Bisexual People in Healthcare

A Practitioner Guide

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Summary

This guide has been produced as an output of research undertaken at Queen Margaret University, Edinburgh, exploring the experiences of Lesbian, Gay and Bisexual (LGB) people affected by cancer. The lives and health of LGB people have in recent times become more of a focus of attention as societal attitudes have changed. However, despite the recent legal reform and the advances that have been made in UK society, LGB communities still cannot be fully assured that their specific health needs are being addressed and that healthcare is delivered in non-judgemental ways. The guide is aimed at providing practitioners with a series of recommendations to consider in their practice in order to ensure they are delivering inclusive healthcare. In keeping with the principles of the underpinning research, the guide has been devised in collaboration with the participants and their individual voices are present in the recommendations.

Foreword

For the Chair of the College of Radiographers Board of Trustees, there is no task more satisfying than seeing the work of a recipient of a College Doctoral Fellowship gaining their PhD. Dr Gareth Hill was a recipient of our Research Fellowships in 2018 and I am honoured to be asked to write the foreword to this guidance document developed from the outcomes of their research.

This guidance document is unique and inspirational. There is a dearth of research into the experiences of members of the LGB community when they receive healthcare. The focus of this work was to establish how cancer care and treatment impact upon their identity and, in addition, to enable the participants to creatively explore how their support needs and experiences had affected their cancer pathway.

Throughout the research, Dr Hill used innovative participatory research methods to enable us, the readers, to hear the participants' voices, and be informed about what is important to them. Their voice is heard loud and clear, and we as practitioners must listen, learn and react in order to work with them to provide person-centred care.

At the conclusion of the research, the participants were contacted and asked if they were satisfied with the guidance created by their participation, and if in their eyes the guidance was fit for purpose. The participants endorsed the recommendations as true outcomes of what they had described. Furthermore, 43 organisations – including those who advocate for the rights of LGB people, and charities including cancer charities – have ratified the recommendations.

This guidance document has the potential to be of great importance not only to radiographers but to all health professionals who wish to provide person-centred care. In addition, I believe this guidance should be used to improve the care of LGB communities not just nationally but also internationally.

Therefore, I strongly recommend this guide to you all. And I finish with the words of one of the participants:

"Looking at the recommendations, they seem extremely sensible and helpful and will steer services towards better practice."

Sandie A Mathers FCR, MSc, DCR

Chair of the College of Radiographers Board of Trustees (UK)

Background research

Despite recent legal reforms and advancements in UK society, the LGB community still cannot be assured that healthcare will be delivered in non-judgemental ways, nor that will fully address their specific health needs. Some research has been undertaken to examine the needs of LGB persons with specific cancers, revealing that they have distinctive experiences and needs of cancer services (Hill et al 2021; Doran et al 2018; Fish and Williamson 2018).

The research that underpins this practitioner guide was undertaken by Hill et al (2021) to develop the evidence base specifically examining the effects of cancer treatment on personhood. As there is a general trend towards more person-centred care, it has become necessary to understand that sexual orientation in the context of personhood should be taken into consideration when planning services, treatment and care provision. Ultimately, there is a need to ensure that health services are meeting the needs of all users, including persons who identify as LGB, and radiographers are well placed in their roles as health professionals to address this. The guide within this document provides information for practitioners to consider in their practice, and advice on how they can improve the care that they provide in a more inclusive manner. It is derived from research undertaken by the Centre for Person-Centred Research Practice at Queen Margaret University and was part-funded by the College of Radiographers' Doctoral Fellowship. The underpinning research fits within the Society and College of Radiographers (SCoR) key research priorities (SCoR 2017) in the area of Public and Patient Experience. Survivorship in Oncology was investigated by developing an understanding of how LGB persons adjust following their experience of cancer care. The research achieved its aim of establishing UK national practitioner guidance focused on improving the experiences of LGB persons affected by cancer. The guide ensures that the participant's voice is clear in demonstrating the importance of the recommendations, by providing targeted information and real-life accounts with the aim of improving patient choice and communication. The research adds to the understanding of how LGB persons interact with services, providing an evidence base to better develop cultural humanity within the profession of Radiography and, more broadly, Oncology services. Many of the participants had very positive experiences of the services they accessed and this has been taken into account when creating the recommendations for practitioners to follow.

Drawing on critical and person-centred theories, an adapted participatory inquiry (Heron and Reason 1997) methodology was used to explore in-depth, with nine participants, their experiences of cancer treatment in Scotland. The focus of the work was to establish how cancer treatment impacts on the identity of LGB persons and to enable participants to creatively explore how their support needs and experiences had affected their cancer care pathways. This offered insight into the perceptions, feelings and life events of participants, and LGB persons were found to have distinct care experiences and needs related to cancer across a variety of areas and services. The main findings of the research provided an evidence base for this assertion and were then used to develop a co-created national practitioner guide with the participants and key stakeholders. Extracts of research transcripts were used to support the recommendations and provide the participants' voices to add weight to the guidance.

It was deemed appropriate and consistent to go back and seek the views of key stakeholders and participants involved in the earlier aspects of the inquiry, rather than just devise the guidance without any feedback from those who had supported the research. Further, it was important to ensure that the participants, as people who were directly affected by the issues, were satisfied with any guidance created from this research and that it was deemed fit for purpose in their eyes. This approach is consistent with person-centred principles and having respect for the community involved in the research. In addition to the nine inquiry participants, 43 feedback replies were received from representatives and employees of the following organisations to ratify the guide:

- Maggie's Cancer Centres
- MacMillan Cancer Support

- Prostate Cancer UK
- Out With Prostate Cancer Support Group (Manchester)
- Lesbian Gay Foundation Manchester
- SCoR professional officers
- SCoR Council representatives
- LGBT cancer academics employed at universities in the UK and Canada
- Eighteen NHS-employed oncology professionals from eight different trusts and boards, including therapeutic and diagnostic radiographers, health managers and policy makers, oncologists, specialist oncology nurses, counsellors and psychologists
- Four members of the public who had cancer and identified as Lesbian, Gay or Bisexual, but who were not in themselves participants in the research inquiry
- LGBT Health Edinburgh
- The Equality Network Scotland

The guide now raises awareness of the needs of LGB persons affected by cancer and is aimed at improving the care experience for all.

It must be noted that the research undertaken to develop this guide did not recruit any members of the transgender or intersex community. It is known that the transgender cancer experience has been far from ideal. Many transgender persons have faced issues of discrimination when accessing care (Braun et al 2017, Ingham et al 2018), and also have specific medical needs related to gender reassignment and cancer. This guide should also be considered alongside the inclusive pregnancy checking guidance issued by the SCoR.

From the outset, the researcher sought to work with people directly affected by the issues and stakeholders in healthcare, in order to establish a set of practitioner guidelines that would develop and improve person-centred cancer care for persons identifying as LGB. The principal investigator in the research was Dr Gareth Hill, a Registered Therapeutic Radiographer based within the Centre for Person-centred Practice Research within Queen Margaret University. The research received full ethical clearance from the University Ethics Committee.

Practitioner guide recommendations

1. Practitioners should support disclosure of sexual orientation in a non-judgemental way.

"I would like to come out gracefully, just drop it into the conversation, but make it just seem the most natural thing in the world, so there's no awkwardness about it" – Susy

Practitioners need to avoid practising in a heteronormative way and making assumptions about someone's sexual orientation. LGB people are more likely to come out to staff if they feel comfortable and safe in doing so. Education in non-judgemental, relationship-based working is key. Asking questions about people's circumstances without the use of assumptions or gender can help LGB people to disclose rather than correct a practitioner. Staff should recognise the diversity of the people they meet, and should use open and neutral conversations such as "Do you have a partner?" or "Have you someone at home that looks after you?" In addition, relevant healthcare documentation should include options such as civil partnerships.

2. Practitioners should always be cautious of asking leading questions and reacting to people's responses in a negative or surprised way.

"I'm forever asked if I could possibly be pregnant – every time I'm scanned, for example. Only once have I jokingly said that would be impossible as I'm a lesbian (as well as the fact I have had my ovaries removed!). The woman I was speaking to didn't laugh or make any further comments. Anyway, I just answer, 'No' now" – Tate

Practitioners should avoid asking people questions that are presumptive and based on what they anticipate someone may say, such as questions regarding pregnancy status. It is recognised that staff will have to ask people about their pregnancy status, for example, under their responsibilities outlined in the Ionising Radiation (Medical Exposure) Regulations. However, it is also important to be non-judgemental in reactions to responses that practitioners do not expect. Negative and surprised reactions from can undermine LGB people's confidence in the ability to provide non-judgemental care. Having knowledge of clinical facts in advance of discussions, where possible, and using neutral professional responses is important for preventing misunderstandings in care.

3. Practitioners should know where to signpost LGB people who need mental health support.

"I felt worthless because I was gay, I had cancer and nobody really cared. I felt that my parents and family would be better off without me and they as kids would come to terms easier with a dead dad than one who was gay and had cancer" – Lewis

LGB people can be signposted to local cancer support through Macmillan and Maggie's Centres. Both are committed to supporting all persons affected by cancer, no matter what their sexual orientation is. In addition, most large NHS Trusts and Boards have Equality and Diversity Champions and LGBTQ+ forums that can also signpost to more specialist support.

4. Practitioners should be mindful of how LGB people may be feeling about appointments and the healthcare environment.

"I don't express affection, physical affection with my partner, very much in public. The reason for that is that's quite loaded, I think to do with LGBT history and the social acceptability" – Evan

"Not only am I waiting to find out if I have cancer or not, I'm also worrying about the people in the waiting area – are they thinking that I'm weird...? I am thinking about that... It's like just another thing" – Tate

Many LGB people do not feel comfortable showing physical affection in public or in front of people they do not know. This includes hand-holding and comfort they may express when supporting someone close to them who is affected by cancer. Departments are encouraged to use posters and encourage teams to wear Rainbow NHS badges to promote diversity and inclusion, and to foster an environment that reaches out and endorses people's individuality and identity.

5. Practitioners must recognise that LGB people have next-of-kin with the same status as those of heterosexual people.

"She came back, actually quite discreetly, managed to say 'ooh, you know, your form says you were widowed, but then you said you were lesbian', and then I had to say, well actually, it was my civil partner that died, and I ticked the widowed box. That was horrible" – Susy Some LGB people find that their doctor, nurse, radiographer or other health professionals assume they are heterosexual and/or do not think beyond the label. Practitioners need to be mindful that LGB people have relationships with the same status as straight persons and that these relationships are just as meaningful and legally equitable.

6. Practitioners devising health information targeted at LGB populations need to be cautious when using labels.

"Queer, don't get that. Don't ever, ever, call me queer, to me that's such an insult. I don't get that word, I think it's appalling, it's one of the worse things you could ever call someone when I was a kid. Why would you want to own that?!" – Lewis

Many LGB people have uncomfortable associations with specific labels, especially those that have been used in a derogatory sense, or as a means of previous discrimination or abuse. Opportunities should be sought to include representation of LGB people on patient information groups and when designing LGB literature. In addition, Equality and Diversity Champions and LGBTQ+ forums can assist in feeding back when developing information.

7. Practitioners should be prepared to discuss the effects of cancer on physical intimacy.

"When we got to the point of being intimate for the first time, I mean, I think my girlfriend had no idea what to expect, she wasn't even clear at that point if I'd had a mastectomy" – Susy

"After treatment I was very tired, we couldn't be physically intimate. I just stopped having sex with him a long time ago, and it was over" – Drew

LGB people may feel more unconformable about talking about the effects of cancer on physical intimacy. Practitioners should approach these conversations sympathetically and, where needed, seek additional support for themselves and the LGB person. In addition, written advice and support should be created to be inclusive of people who engage in same-sex activity. Further signposting to LGB-specific advice and support is contained in the additional resources section of this document.

Additional resources

- Prostate Cancer UK provides a wealth of information designed to support gay and bisexual people with prostate cancer: <u>www.prostatecanceruk.org</u>
- Out with Prostate Cancer support group is based in Manchester, but can offer online support to persons across the UK and overseas: <u>www.outwithprostatecancer.org.uk</u>
- Live Through This is a patient-led support group for those who have felt on the outside of the usual support options: www.maggies.org/about-us/news/online-lgbtqi-support-in-partnership-with-live-through-this/
- The Gay and Lesbian Medical Association, Cancer in Our Lives: <u>www.glma.org</u>
- Queering Cancer provides online resources of information and stories aimed at supporting LGBTQ2+ community with cancer: <u>www.queeringcancer.ca</u>
- Centers for Disease Control and Prevention, Lesbian, Gay, Bisexual, and Transgender Health: <u>www.cdc.gov/lgbthealth</u>
- Simms/Mann-UCLA Integrative Oncology Program: <u>www.simmsmanncenter.ucla.edu</u>
- CancerCare's LGBTQ+ Program: <u>https://www.cancercare.org/tagged/lgbtq+</u>
- National Coalition for LGBTQ Health: <u>https://healthlgbt.org</u>
- LGBT Foundation: <u>www.lgbt.foundation</u>
- Macmillan's Supporting LGBT people with cancer provides guidance on facilitating the disclosure of sexual orientation as well as other more general support: <u>www.dmu.ac.uk/documents/</u> <u>research-documents/health-and-life-sciences/msrc/supporting-lgbt-people-with-cancer.pdf</u>
- Society and College of Radiographers, Inclusive pregnancy status guidelines for ionising radiation: Diagnostic and therapeutic exposures: <u>Inclusive pregnancy status guidelines for</u> <u>ionising radiation: Diagnostic and therapeutic exposures | SoR</u>
- Live Through This is a cancer support and advocacy charity for the LGBTIQ+ community, based within the UK. <u>https://livethroughthis.co.uk/</u>

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