

Gareth Hill

College of Radiographers Doctoral Fellowship 011

£24,957 awarded

Title: The impact of cancer treatment on LGB people's identity

Aims:

1. Explore with LGB persons with cancer, their experiences throughout the cancer care pathway.
2. Work with LGB people, their support persons and key stakeholders to develop guidelines for best practice for cancer services and LGB people
3. Influence education of radiography professionals through developing an evidence-based curriculum
4. Contribute theoretically to knowledge of personhood/person-centeredness.

Objectives:

1. Find out with LGB people, any distinct aspects of their treatment and care.
2. Contribute to the evidence base of cancer treatment and care for persons identifying as LGB.
3. Develop a best practice guideline for hospital-based oncology services and LGB people.
4. Embed the research findings within professional education
5. Make a theoretical contribution to person-centred practice research, specifically personhood in the context of LGB persons

Outcomes:

1. Positive engagement experience for all participants
2. Contribution to the evidence base and cancer care for persons identifying as LGB through best practice guidelines for hospital-based oncology services
3. Development of materials for teaching and learning in QMU and other universities
4. Increased awareness of LGB people's care needs and improved cultural competence within the radiography profession
5. Theoretical contribution to person-centred practice research, specifically on personhood in the context of LGB persons
6. Minimum, one 3* publication in an international peer reviewed journal, UK and international conference presentation, plus other user-friendly research summaries.

Background to the Project:

Person-centred care is becoming the norm in terms of policy directing the planning and provision of healthcare in many Western countries (McCormack 2015, The Scottish Government 2010); and is supported by WHO policy (WHO 2015). In addition, The Society and College of Radiographers stipulate that radiographers must provide the best compassionate care for patients based on current evidence (SoR 2013). The lives and health of LGB people have in recent times gained increased attention as societal attitudes change and recognition of likely inequalities grows. Despite recent legal reform and advancements in UK society, the LGB community still cannot be assured that their healthcare needs are fully recognised and met and that treatment and care are delivered in non-judgmental ways (Stonewall 2015). Recent research undertaken by Hill and Holborn (2016) supports this claim. A recent review of the worldwide literature revealed that LGB people have distinctive experiences and needs relating to cancer care, particularly when attempting to access specific psychosocial and psychosexual support. Although attitudes towards homosexuality differ vastly throughout the world, only two studies have been conducted in the UK examining LGB experiences of cancer care (Doran and Beaver 2015; Fish and Williamson 2016). These studies have started to portray a picture of some issues from an English perspective, with no participants from Scotland. Neither study explored the effects of cancer treatment experience on LGB personhood. Further, literature on person-centeredness in general, does not address sexual diversities, which warrants attention.

Research for my Master's degree and subsequent publications have fuelled my interest in i) what the experiences of LGB persons are when they and their support givers are in hospital settings for cancer treatments and ii) what the longer term impact is on personhood, including identity. I have a longstanding interest in social justice and equality issues; as an oncology healthcare professional, and as a person who identifies as a homosexual, I believe that persons should have access to the same level and continuity of care regardless of social background, race, or sexuality or other 'special characteristics'. I argue that currently, the experiences of LGB persons in Scotland in relation to cancer are not fully understood and it is necessary to establish any deficiencies that might affect care/treatment. As there is also a general trend towards more person-centred care in cancer services, I argue that person's sexual orientation should be considered as core to personhood and be given consideration when reviewing the services and support that they use.

Preliminary data:

Her Majesties Treasury Department of Business (2015) estimates that 5–7% of the population in the UK is Lesbian, Gay or Bisexual (LGB), which equates to approximately 370,000 LGB persons living in Scotland. Macmillan (2015) also estimates that there are approximately 220,000 people living with cancer in Scotland, and this will include approximately 15,400 persons that will identify as LGB. Reports released by Macmillan (2013) and Cancer Research UK (2008) discuss the increased need of LGB persons affected by cancer to have specialised support services. Progress has been made with the recent introduction of gay cancer support groups in England and the formation of organisations such as the LGB Cancer Alliance (Out with Prostate Cancer 2014; The Lesbian Gay Foundation 2015). The cultural context is, however, different in Scotland. Homosexuality (for men) was not decriminalised in Scotland until 1980, compared with 1967 in England. This may give rise to a difference in social acceptability of LGB persons and a different experience of cancer treatment. It is important to note that as cancer has a peak incidence between ages 65-75 years, many members of this demographic group will have lived as adults in Scotland at a time when homosexuality was illegal. This may contribute to people being less vocal about their needs. My person-centred approach is underpinned by a fundamental belief that no facet of social phenomena can be fully understood unless it is connected to its historical and structural context (Parlour and McCormack 2011).

Two previous UK-based studies in this area have reported a nuance of discrimination and raised levels of apprehension and anxiety experienced by LGB persons using oncology specialist services (Fish and Lockley 2015; Doran and Beaver 2015). Fish and Williamson (2016) conceptualise this as an 'awkward

choreography around disclosure' manifested through micro-aggressions and heteronormative care systems and practices, contributing to the nuance of discrimination. Neither study recruited participants in Scotland, which raises a gap in the literature, due to the cultural specificity of experiences of LGB persons. In addition, these two novel studies did not take a person-centred perspective which prioritises what matters to the person and mutual respect (McCormack et al 2010). Person-centred care goes beyond the clinical to also address wider social, financial, emotional, practical, psychological and spiritual concerns. It is likely that further valuable insights will result from explicitly exploring experiences from a person-centred perspective (Macmillan 2013). This is in line with international prioritisation of person-centred practice, now health care policy within Scotland (McCormack et al 2015). Therefore, the main focus of my research is to explore how the experiences of LGB persons affected by cancer treatment impact on personhood. As a result, my research will increase awareness and understanding of LGB social issues and will ensure that the views and experiences of people who may not usually be listened to are represented.

Detailed plan of investigation:

The study will follow the stages of a participatory inquiry underpinned by values derived from person-centred research and critical social theory. The aim of the research is to explore with participants the effects of cancer treatment on personhood and therefore focus on possible or actual points of transformation as a result of healthcare experiences. My theoretical framework is illustrated in Figure 1, and is adapted from the cooperative inquiry paradigm devised by Heron and reflective processes developed by Mezirow (Mezirow 1991, Heron and Reason 1997). The framework proposes that cooperative inquiry can offer participants an opportunity to 'process' and learn (further) from their experiences of cancer treatment and reflect on how the learning has been or can be absorbed into personhood.

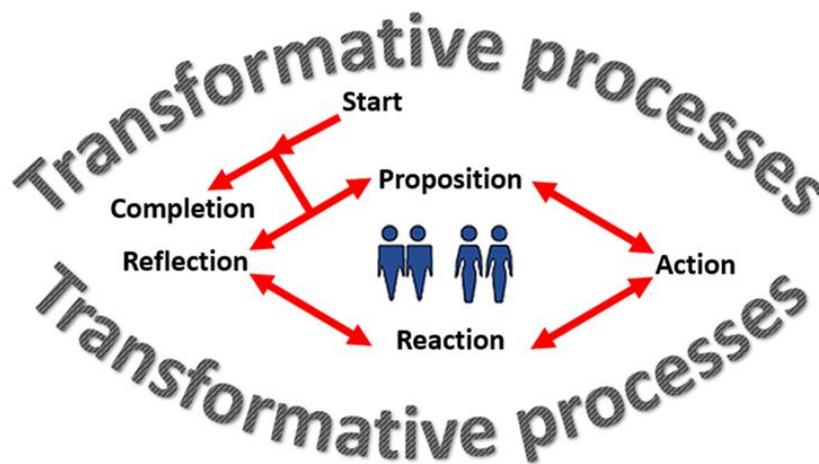


Figure 1. Theoretical framework to the research

The research participants in this study are LGB persons who have undergone primary treatment for cancer and their key support person (if available) and will need to meet the following criteria:

Inclusion Criteria

- People who self-identify as LGB and are aged 18 or over
- LGB people who live in Scotland and have received treatment for cancer, including radiotherapy, in the past 5 years
- People who are able to sufficiently speak and understand English
- People who can participate in the sessions

Exclusion Criteria

- People under the age of 18
- People that identify as heterosexual
- People who cannot speak and understand English sufficiently
- People who are currently undergoing or about to undergo invasive treatments such as surgery, radiotherapy, brachytherapy and chemotherapy or have undergone treatment during the past three months.

Participants should be in the follow-up stages of the cancer treatment pathway (see figure 2). In addition key support persons will be appropriate for inclusion if they are also able to independently consent to the study, able to sufficiently speak and understand English, and are over the age of 18. Support persons are included because they can have a view on the impacts of cancer treatment. However, I am not specifically seeking to explore their personhood.

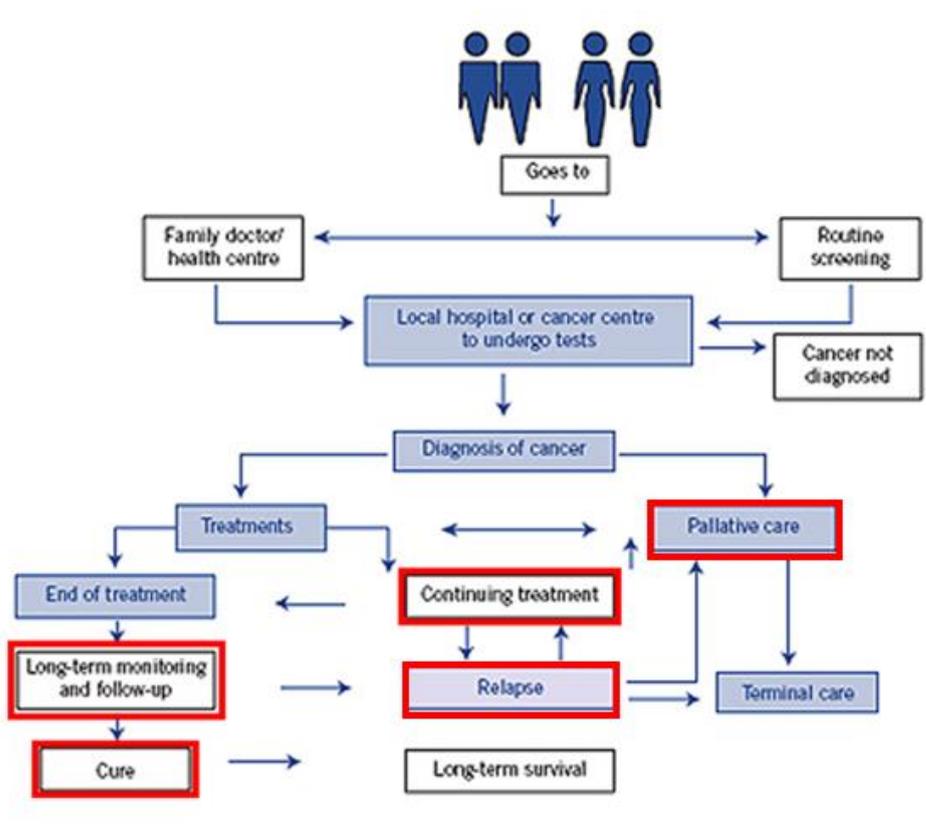


Figure 2. Participants for the research will be recruited from the areas on the pathway highlighted in red. Adapted from Baker and Schwartz (2005).

Participants will be recruited via my local and national networks. Targeted recruitment using purposeful and snowball sampling will be focused on voluntary sector organisations working in the LGB communities and LGB cancer support groups in Scotland. Publicity materials will be designed and distributed to LGB groups, support agencies, individuals, twitter feeds, and Scottish LGB venues to ensure maximum possibilities for recruitment into the study. A contact number and email address will be established at QMU for potential participants to contact and obtain further details of the study.

Participants will be provided with full information to enable them to take part; confidentiality, privacy and informed consent will be assured. Potential participants will be provided with an information sheet prior to arranging a face-to-face meeting and given at least 48 hours to decide if they want to participate. They will be given the name and contact details of an independent staff member within QMU to be able to discuss the study.

Face-to-face inquiry sessions with the participant and their key support person, if available, will take place in an agreed venue. Prior to each session, participants will be sent information setting out how the sessions are constructed and the sorts of activities that I hope to engage them in. The first meeting will focus on personhood and identity with participants asked to construct their personhood mapping. This will be achieved using a creative method that is acceptable to the participant e.g. using existing objects and artefacts, photograph of personal significance, using creative expression such as painting, music, craft, etc. The materials will then be used as a trigger and basis for conversation exploring its meaning in relation to self as a person who identifies as LGB. The conversation will be transformed during the interaction into an identity map that the participants feel reflects important aspects of personhood.

The second meeting will use a process of critical reflection to focus on how experiences of cancer treatment have impacted on participants' personhood. In the sessions I will draw on the 10 steps of Mezirow's (1997) transformative learning model to assist us. Questions will focus on the personhood map, using this to trigger critical reflections on how different aspects of their being have been impacted on, positively or negatively, through experiences of cancer care. Participants will use the 'creative map' to help structure and theme their thoughts about any impacts on personhood. A third session can be organised if required.

The sessions require one-to-one negotiation with participants about how best to record them. This could make use of digital recording, video, photography, use of creative products and flow charts, or a combination. Participants will be offered an opportunity to take part in the thematic analysis of their inquiry session. Again, I will draw on the 10 steps of Mezirow's (1997) transformative learning model to assist us in theming and to gain a new perspective on the participants' experience. The next step will be a participatory synthesis of the combined themes from different participants. It is anticipated that this will be done at a distance through the use of private social media or other web-based technology. Figure 3 demonstrates the likely trajectory of the research and participant's pathway.

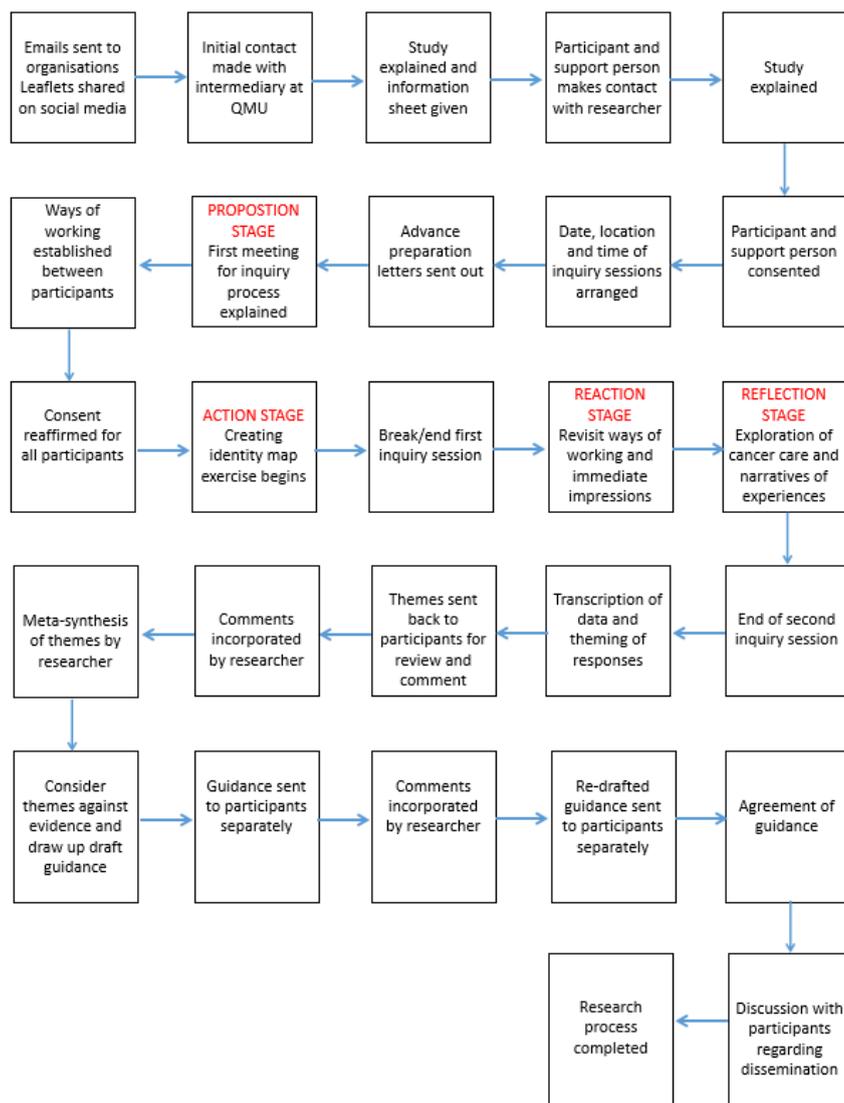


Figure 3. Likely stages of the research process.

Some participants will then be invited to share the draft findings in a stakeholder workshop to assist in the formulation of professional guidance. Stakeholders such as Macmillan, Maggie’s cancer charity, local cancer centres, Stonewall, and The Society and College of Radiographers will be invited to take part in a half day event that will focus on ratifying and agreeing the final set of guidance. Research participants will be able to attend if they wish. Funding for the stakeholder aspect of the research is not included in this proposal and will be sought from elsewhere.

A consensus agreement from within the group will be established at the start of the inquiry session on how to record the session and group rules. It is anticipated that the draft guidance will be a key output from this workshop.

It is key that throughout the research process that I as the initiator of the research and the other participants continue to be committed to the methodological principles of engaging in partnership and collaborative working. This will be achieved by continually reflecting on each stage of the inquiry process to ensure that all participants are at ease with the research and providing opportunities to seek shared understandings and new knowledge generation that is key to the research process. I will use reflection techniques and my research supervision to facilitate this. At all times, participants will understand that they can withdraw from the research should they wish. It is my goal that participants have the opportunity to develop an enhanced understanding of their own transformational experience of cancer treatment by engaging in the research.

Potential problems and contingency plans

I have identified eight main risks that may occur and have devised a risk reduction plan. See attached appendix two.

User Involvement plans

To date, an information sheet has been prepared to brief anyone who may wish to be involved informally in the development of the research and its methods, or lend support in raising awareness of the study in accordance with principles of community based participatory research. Contact has been established with Out with Prostate Cancer support group, the LGBT Cancer Alliance, Edinburgh LGB Health Centre and The LGBT and Cancer Staffordshire Project and this has led to several informal contacts who identify as LGB and have cancer who have provided informal feedback on the design of the research.

There will be opportunity for participants to participate as little or as much as they wish across the research process. Participants may wish to engage with the study at the start by providing insight into their experiences and stop at that stage, whereas other participants may then want to become more involved in the final development of national guidance, input into the curriculum, and at key stakeholder events. Participants will be asked throughout the research if they are happy to continue and areas for potential involvement will be highlighted in the information provided when initial contact is made and throughout the research.

Dissemination Strategy

Prior to the research commencing, awareness of the study through the use of social and online media will be needed and will be targeted at voluntary sector organisations working in LGB communities and LGB cancer support groups in Scotland. Publicity materials will be designed and distributed to LGB groups, support agencies, individuals, twitter feeds, and Scottish LGB venues to ensure maximum possibilities for recruitment into the study.

During the research project, participants, supporters and other LGB and cancer organisations will be updated through plain English briefings, social media tweets, and press releases.

At the end of the research we aim to present at the Annual Radiotherapy Conference and submit a publication to the Radiography Journal and International Practice Development Journal. We will also work with our local and national networks established throughout this study to promote the dissemination of research among non-academic audiences, including the stakeholder workshop.

Integration of this project into the ongoing work of the group/department and into patient care:

This research is being undertaken as part of a much larger multi-professional research and development programme in the Centre for Person-Centred Practice Research at QMU. (<https://www.qmu.ac.uk/research-and-knowledge-exchange/research-centres-institutes-and-groups/centre-for-person-centred-practice-research/>). A key aspect of the Centre is that we ensure our research impacts on the way healthcare services are delivered and in particular, on the lives of vulnerable persons and groups. This includes, amongst others, those affected by cancer and those who belong to the LGB community and as such this project aligns well within the Research Centre's goals. Within the Centre there is a focus on doing research that 'humanises healthcare' by keeping the person at the centre of care, as well as promoting new methodologies for person-centred research that influence international developments in this field. My research draws on this approach, influencing my choice to undertake a participatory research design, keeping my participants at the centre.

Ultimately, the Centre's research aims to enhance people's experiences of care, wellbeing and flourishing; making a difference to people's lives locally, nationally and internationally. This project fits very well into this agenda by ensuring that LGB people can have a direct influence on development of support offered by cancer services. This will have a direct impact on patient care by enhancing the experiences of LGB people when accessing cancer services, informing the teaching

and learning of future radiographers, and transferring learning beyond Radiography in its impact on cancer support services more broadly.

Potential impact of the project:

This project will seek to inform professional practice and patient care within Radiography. Evidence will be collected to demonstrate breadth and nature of its impact. There is potential to inform national policy of the College of Radiographers when interacting with LGB people and provide valuable information to other key stakeholders and organisations.

Potential impacts of this project should be evidenced across Scotland through strategic involvement of key-stakeholders who are placed at the heart of policy-making and development of cancer services.

I aim to build on this research at post-doctoral level.

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Appendix 2 – Risk table

Potential Problems	Actions taken to mitigate risk
Research Administrator recruitment may be not be timely.	In the event of successful award, finalising the research agreement will be prioritised and administrative processes relating to the approval and advertisement of related research posts will be expedited through close inter-departmental working at QMU. Advertisements relating to these posts will be disseminated widely through the research team networks.
It is possible that participants may find it difficult to attend face-to-face meetings, particularly those with demanding caring and leadership and management roles.	In order to optimise face-to-face meetings: we will plan meetings well ahead with administrative support from the research administrator; costs are included to reduce the impact, including for the time of carer representatives. To mitigate for inability to attend face-to-face: the team will book the video-conferencing suite at QMU and discuss different ways of attending remotely if necessary. Technological support will be available and planned ahead for those at a distance.
Delay to ethical approval	In order to reduce the likelihood of the ethical review process delaying recruitment and data collection, this will be sought from the start of the project. Any changes will be discussed with the sponsor for research ethics application and if they are viewed to represent substantive changes, an amendment will be submitted. A time period has been included in the Gantt Chart for this.
Difficulties recruiting nationally	The recruitment plan for Edinburgh and Glasgow is well developed and supported through local contacts. The national recruitment plan will be developed in an ongoing way. During the stage of grant development networking has been prioritised, which will continue and be supported through the wider network of the supervisory team. Further networking will take place while searching for grey literature and contacting relevant organisations and services. While this can be seen as a risk as it is iterative, it also enables the ongoing development of the impact strategy and recruitment of people to participate in the Stakeholder Workshop or receive updates afterwards.

Appendix 2 – Risk table *cont.*

Potential Problems	Actions taken to mitigate risk
Difficulty recruiting people to the Stakeholder Workshop with roles that would facilitate impact of project outcomes	Networking and promotion of the project through different routes including social media will be a specific work stream in the project design and management. This will form an agenda item at a regular meeting between the Principal Investigator and the employed research administrator to ensure that activities are coordinated and strategic. As the project develops, a specific strategic plan will be developed for who to invite to the Stakeholder Workshop, to include people who can impact on policy, practice and research in Scotland and across the UK.
Physical threat or abuse, being in a compromising situation	I have established lone worker arrangement through carrying a mobile phone, ensuring my location and activities are known, and will ensure that I maintain contact with my supervisory team during the inquiry sessions.
Psychological harm for participants	To minimise the risk of causing psychological harm I will ensure that contact details of local cancer support and LGBT services are provided to participants in case they wish to discuss any matters that arise as a result of the research.
Psychological harm for researcher	To reduce the risk of causing psychological to myself from potentially distressing conversation topics I will ensure that I debrief with the supervisory team, complete a reflective diary, and ensure that if necessary that I use the occupational health and psychological support mechanisms available through QMU.