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# Improving the cancer journey for lesbian, gay and bisexual people living with cancer

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#### Introduction

Every year in the UK, 250,000 people are newly diagnosed with cancer while more than two million people are living with the disease. Although there are multiple risk factors, there is increasing recognition that people's social characteristics play a part in quality of life and survivorship, where some groups of people have different experiences or outcomes for cancer. These differences are known as cancer inequalities and they include lesbian, gay, bisexual people and trans people. Estimates suggest that there may be 40,000 LGBT people living with cancer in the UK; yet relatively little is known about their experiences of care and support.

International studies suggest that LGB people have higher risks and increased prevalence of some cancers in comparison to the general population. Among gay and bisexual men, studies indicate they have twofold odds of reporting a diagnosis of anal cancer; while rates of cervical cancer among bisexual women are more than twice that of other women. Some research reveals higher mortality from breast cancer among lesbian and bisexual women; they are also twice as likely to report fair or poor health compared with heterosexual women. Due to the lack of formal support groups and targeted health information, LGB people may have a poorer post-diagnosis experience and lower quality of life with cancer. Few international studies have considered the cancer care needs of trans people.

Alongside these international findings, the Department of Health, Cancer Patient Experience Survey (CPES) has revealed some differences in the quality of care and in the interactions of LGB patients with cancer professionals in the NHS. In comparison to the heterosexual survey respondents, LGB people reported less positive patient experiences in relation to four over-

arching domains: accessible information, psychosocial support, the human rights concerns of dignity and respect, and management of pain. Sexual minority patients in the survey were more likely to disagree with statements including: they never felt treated as a set of cancer symptoms rather than as a whole person; hospital staff did everything they could to control pain; the doctor never talked in front of them as if they were not there; and the patient was given information about support or self-help groups. The survey did not comprise a qualitative component and consequently it is not known what factors give rise to these different experiences. No previous qualitative research has been conducted in the UK with LGB cancer service users, to our knowledge, making this study a unique opportunity to investigate whether there are distinct issues and concerns in their cancer patient experience, quality of life and survivorship. The study seeks to understand the nature of LGB patients' support networks, their need for appropriate information and their experience through the cancer pathway. We know from the CPES that LGB people regard research more positively and are more likely to wish to take part in studies than other patient groups.

#### Aims

The study aims to improve the health and well-being of LGB people during treatment for cancer and contribute to their quality of life in survivorship.

# **Objectives**

- To establish a stakeholder steering group of professionals working in the NHS,
  hospice care, voluntary sector organisations providing support for LGB people, and
  cancer service users;
- To provide qualitative data about the experience of diagnosis; beliefs and attitudes
  about cancer prevention; experiences of treatment and care; formal support
  structures and informal support networks; quality of life and survivorship; access to
  information;
- 3. To disseminate the findings through a public engagement event;
- 4. To present the findings to professionals and policymakers.

## Methods

We sought to use participatory approaches in conducting this research to make sure that the questions asked, and the analysis undertaken, reflect the concerns of service users. To this end, a stakeholder steering group was set up within two weeks of the appointment of the researcher. The participants of this group included representatives from LOROS; Leicester LGBT Centre; Trade Sexual Health; University Hospitals of Leicester NHS Trust and cancer service users. A discussion took place around the aims of the study, the recruitment of research participants, publicity materials and participants' experiences either as a patient or medical professional. Stakeholders were also issued with a draft outline of the research

questions and encouraged to make comments and suggest additions or amendments to the interview schedule.

The data was collected via one-to-one interviews, with the researcher either meeting face-to-face with the study participant or undertaking a prior arranged telephone interview. An in depth, semi-structured interview schedule was used, which provided the opportunity for the researcher to ask supplementary questions, and the interviews were digitally recorded. This ensured that rich data about participants' experiences and feelings were gathered.

Once the interviews were completed and transcribed, the researcher used thematic analysis to identify themes emerging from participants' experiences of, and feelings about, the care and treatment they had received for their cancer. Once the themes were identified and analysed, conclusions could be drawn and recommendations made for improved practice in the future.

# Challenges for research with LGB communities

LGB people with cancer comprise a *hard to reach group*. This is partly attributable to the fact that older people constitute the group most affected by cancer and this group have lived during a social era when legislation and public attitudes required that sexual orientation remained a private concern. They are also a hard to reach group because, until recently, few health surveys included sexual orientation as a demographic characteristic and consequently LGB people are not used to being asked to disclose their sexual orientation in research. In practical terms, this meant that it was far more challenging than anticipated to make contact with people to take part. For example, we contacted 17 Leicester,

Leicestershire and Rutland cancer support groups, but this did not lead to any participants taking part in the study.

In light of the dearth of research on trans people and cancer, the intention was to recruit a sub-sample of trans study participants. Although efforts were made through social media and through relevant groups and organisations, we were not able to encourage any trans people to take part in the study. This is a limitation of the study; it is evident that a different and more focussed approach to recruiting trans people with cancer is needed.

# Recruitment and publicity for the study

We developed a comprehensive sampling strategy to let people know we were conducting this study. We gave radio interviews; used social media setting up Facebook pages and a Twitter account; and placed articles in local publications. We targeted recruitment among voluntary sector organisations working in the LGBT communities and LGB cancer support groups. Publicity materials were designed, and the resulting flier was distributed to over 150 LGBT groups, support agencies, individuals, twitter feeds, and to local and national LGBT venues.

# The sample

Seventeen LGB people with cancer took part in the study, two of whom were carers whose partners had a cancer diagnosis. Seven lesbians, nine gay men and one bisexual man were interviewed and the most common cancer was prostate cancer. The age range of the participants was early forties to seventy years and the majority lived in either Leicestershire or the North West of the UK. For brief details of participants see appendix 1.

# Developing links with other agencies

Links were developed with other agencies working in the field of LGB cancer. Meetings were held with LGBT Cancer Support, a UK wide social media support group based in Manchester; North West and West Midlands' Out With Prostate Cancer groups; the Manchester Lesbian and Gay Foundation; and contact was made with the Manager of the Macmillan Survivorship Network at the Christie Hospital NHS Foundation Trust in Manchester.

# Disseminating the findings

The project findings were disseminated through a number of seminars, conferences and public engagement events. Please see appendix 2 for details.

#### **Ethics**

Ethical approval was given by De Montfort University's HLS Research ethics committee in December 2013. The study was conducted in accordance with the Code of Ethics for Social Work (Butler, 2002). Participants were provided with full information to enable them to take part, confidentiality, privacy and informed consent were assured; a distress protocol was implemented and participants had the right to pause, reconvene or terminate the interview. All data were securely stored and anonymised to protect confidentiality.

# Findings and discussion

The following three main themes emerged from the data gathered from the research interviews:

# i) Disclosing sexual orientation to medical professionals

Previous research suggests that the decision of whether or not to disclose one's sexual orientation in the healthcare setting has consequences for lesbian, gay and bisexual people's health. There are benefits and risks associated with both disclosure and non-disclosure.

The main drawbacks of non-disclosure, in the case of treatment for cancer, are known to be that lesbian, gay and bisexual people's health may be negatively affected; they may be subject to inappropriate questioning; irrelevant health information may be provided; and they may experience anxiety about inadvertently revealing their sexual orientation in the healthcare setting.

Disclosure on the other hand is seen to be associated with health benefits, lesbian, gay and bisexual patients are likely to be more satisfied and comfortable with the care they receive, they experience greater ease in communicating with their doctor and, by disclosing, they allow for the possibility of including their same-sex partner in treatment decisions.

Nine of the 17 participants in this study disclosed their sexuality, explicitly, to medical or nursing staff during the consultative or investigative period of their treatment for cancer. A significant number of those participants expressed the feeling that disclosing their sexual orientation led to a more positive experience. Of interest in the data were instances of

participants saying that they came out, not necessarily to make themselves feel comfortable but to smooth the relationship with the cancer professional or remove doubt about their sexual orientation (with the outcome presumably of a better relationship with the clinicians):

'It wasn't a case of us being asked...I think we volunteered the information because it makes other people feel at ease' (Participant 05 p3).

'Well there is no need to be apologetic and I think if you are out front with it, it doesn't give people any cause for ambiguity' (Participant 16 p5).

Others said that by coming out they had experienced a 'smoother journey', although this insight appears to be retrospective:

'I can see this now' (Participant 13 p5).

Also, in relation to treatment for prostate cancer, some men felt that disclosing their sexual orientation might lead to some consideration of their specific needs when treatment options were being considered:

'...because prostate cancer affects you so much sexually, if they know that you're gay then they might take that into account when deciding on treatment options...'(Participant 08 p3).

It is evident that having a partner, and particularly a partner who attends medical appointments, makes it easier for participants to disclose their sexual orientation, in some cases their partner's presence obliges the patient to disclose their orientation. The partner's presence also provides the opportunity to disclose without having to make a bald statement about oneself, when there is no other context in which to place such a

statement. This appeared particularly so for lesbians, although a small number of gay mean also expressed this sentiment:

'I took F with me and I introduced her as my partner and everybody was very nice'.

(Participant 03 p5)

"I said, "This is my partner D" (Participant 06 p2)

'I think going along to your appointments with a partner and introducing him, it's kind of like wearing the badge -I'm gay, you know. Which in one way does make everything easier.' (Participant 12 p5)

There were more examples of gay men disclosing their sexual orientation as a statement solely about themselves, rather than in the context of explaining the presence of a partner and thereby disclosing their sexual orientation by default. Perhaps, because in the study, gay men appeared to be more likely to attend appointments alone and thus were more likely to make a statement about themselves:

'...and I said "Well, I want to tell you that I'm a gay man" (Participant 12 p5)

'... I talk about my partner quite openly...I am not shy about being who I am. ...it's the way I am and the things I say...' (Participant 10 p3)

Some of the most positive descriptions of the issue of sexual orientation being introduced are those where the clinical practitioner raises the question of the patient's orientation without waiting for the patient to disclose, or where the clinical practitioner also discloses their own sexual orientation:

'They...said "oh you're missing...Pride...aren't you because you're in here? So they obviously picked up the fact that I was gay but the response was just brilliant, there was no nastiness, no animosity. It was really open and it was good...I was really feeling at ease with it.' (Participant 14 p8)

'...pushed me down to the theatre and she went "have you been together long?" and I said- oh 22 years... and she went "good lord that's longer than me and my husband-you deserve a medal". So, perfectly accepting and perfectly friendly.' (Participant 15 p5)

'But there was another lady who came out to us on that second appointment, the day after T got his diagnosis; she came out to us then. So we felt comfortable talking to her...She instantly became a friend if that makes sense' (Participant 05 p5)

Of the eight participants who did not explicitly disclose their sexual orientation during the consultative or investigative period of their treatment; one gay man said he did not have to

'as they would have known, it's the way I am and the things I say' (Participant 10 p3).

A lesbian said: 'I didn't think it was relevant.

'I don't expect someone to say oh I am straight, when you are talking about something else that's nothing to do with it' (Participant 11 p4).

Others said that they disclosed later in the process, when their partner attended for the first time or when treatment options were being discussed.

In this small study, more than half (12) of the participants came out to a cancer professional at some point during their treatment. In disclosing their sexual orientation, only one gay man experienced explicit hostility or animosity from one doctor. For some, their reasons for coming out were to put the professional at ease, others benefited by the professional facilitating the disclosure.

# ii) The nuanced nature of discrimination in the hospital environment

The introduction of the Equality Act in 2006 prohibited discrimination on the grounds of sexual orientation in public services, including health, for the first time. Alongside this legislation, there has been a transformation in social attitudes, where people are much more accepting of same sex relationships and tolerant towards LGB people. Not surprisingly then, in the interviews, there were few examples of direct discrimination. Rather, participants anticipated that they might be treated differently from heterosexual patients, and planned how they might respond in this eventuality. Some participants experienced mundane incidents where, when they reflected upon their interactions with health professionals, they were often not sure whether the care they had received was different to that provided to other patients with cancer.

In some of the data extracts, participants said that their sexual orientation became visible if their partner was present in the consultation. In one example, a lesbian whose partner did not accompany her for chemotherapy talked about sensing an apparent lack of interest in her relationship status and wondered whether every other patient experienced the same lack of interest, or whether it was because it was a same-sex partner she was mentioning.

'I suppose what I don't know is...they are very non-committal...or non-interested in that way with everybody, or whether as soon as I mention a partner then that shuts the conversation down. I don't know that, because I am not sitting there with my husband'. (Participant 02 P9)

In another interview, a participant stated that she felt very comfortable about her sexual orientation and felt able to relate normally to her partner in the hospital environment.

However, later in her interview she declared (almost without reflecting on what she said) that she was not going to get 'bothered' by concerns about what staff and other patients on the ward might think about her sexual orientation, which she refers to as 'this'. It is clear from her extract that she felt more comfortable off the ward, outside with her partner and dog:

'I thought I am just not going to let this bother me. So we would greet and say goodbye to each other in a normal way. But when I started to get better she would bring in a wheel chair and she would take me out of the ward so I could get some fresh air and... obviously that was much better' (Participant 06 p4)

How a patient is perceived by medical staff also became a matter of concern when questions about the impact of treatment arose. One gay man talked about being concerned about what the reaction might be if he asked about the impact of prostate cancer treatment upon his sexual function as a gay man; his concerns about the response he might receive meant that he did not ask those questions:

'I didn't feel comfortable asking all the ins and outs about the sexual side of things...as far as me as a gay man was concerned...I think if I'd have known...that the consultant sitting in front of me was gay I would have been completely open but I suppose really I didn't want any negative reaction' (Participant 08 p4).

In another interview, a gay man explained that non-verbal disapproval is very quickly understood:

'I think you learn, as a gay couple. About who approves of you and who doesn't and it may not necessarily be a spoken disapproval, it can be non-verbal and most of our communication is non-verbal. So you pick up very quickly that you are deemed not to be approved of, for want of a better term. And we picked that up straight way'

(Participant 01 p8).

One participant talked about processes being followed, in relation to filling out patient intake forms, with no acknowledgement that LGB people may have specific experiences or concerns:

'...your treatment...could render you infertile ...And her words were "well, I knew you were together but I have to ask the questions because I have to make sure that the form is completed...". We weren't given an option of...do you want to talk about fertility? It was "I need to ask you about this because it's on the form"

(Participant 05 p4)

In this instance, it appears that the intake form determined what questions were asked, rather than the interview being patient-led. It is not clear whether the nurse completing the form felt uncomfortable adapting the questions about fertility to embrace the possible circumstances of a gay couple, or whether she was unable to adapt her approach to take account of new or unanticipated information, and thus needed to rely on the form to guide the interview questions.

One participant spoke about some comments made by staff being due to a lack of awareness, rather than explicit homophobic attitudes:

'I think it's prejudices of staff. And I'm not saying prejudices as in from a hate perspective, but from ignorance, they just put their foot in it without meaning to. Like

I've got children, so people automatically make assumptions that I am married to a man' (Participant 07 p6).

Participants spoke about the fact that anticipating such discriminatory or uninformed comments had an effect upon their approach to engagements with staff, when they, by right, should have been concentrating on their health and treatment concerns. One lesbian talked about having to prepare in advance for what might be said to them as a couple:

'So I think you have to go in on the offensive, which is counterproductive if you are not feeling well...you are battling your own illness but you think "right what are we going to face today". So there is that huge barrier of an extra tension of...how are we going to be received.' (Participant 04 p10)

As a counter to this, there were examples of hospital staff being aware of issues relating to sexual orientation and being able to discuss such issues with participants in a supportive and sensitive manner:

'everybody that I've had contact with...other than that one doctor- by coming out to them I've had, well...normal reactions. I mean some of them were very supportive, particularly the ... nurse specialist I had at the lymphoma clinic, and she was very good. Like every time I went there for appointments with the doctor she...always come over spoke to us both and... really empathetic.' (Participant 12 p7)

It would seem that if LGB people are not reasonably confident that they are being positively acknowledged, they can have no certainty that healthcare professionals' responses are not driven by prejudice, rather than perhaps a lack of awareness. It is apparent that the anticipation of potentially negative responses to the disclosure of sexual orientation, and

second guessing about the intent of any comments and interactions, adds another layer of stress to LGB people's interactions with medical staff. There is the possibility that this could affect LGB patients' sense of wellbeing at a time when they need to be focusing their attention on their health and treatment, and could negatively impact upon their experience of the care provided to them.

# iii) Finding benefit from the experience of having cancer

All 15 of the participants who had been diagnosed with and treated for cancer could describe, when asked, at least one positive effect of having been diagnosed with, and treated for, cancer. Of the eleven participants who had a partner at the time of their diagnosis, eight of them described their experience of cancer as having improved their relationship or of bringing them closer:

'I'm more committed to my relationship than I've ever been-we've been together for 20 years and he went through hell really, with my diagnosis and treatment, and has been a complete rock throughout and I'll never be able to repay that debt to him, on an emotional level' (Participant 01 p15)

'Yes, in a positive way...Because we have been through such a lot together she is very, very supportive...And she is more forgiving of what I can and can't do, I think more tolerant...' (Participant 04 p12)

Others described the positive impact of people they had met along the cancer journey:

'I think the most positive thing, the shining star, is the super people that you meet on your cancer journey, both the professionals and the people in the support groups and fellow patients. There is a lot that restores your faith in human nature.' (Participant 16 p6)

Other participants described a positive effect upon their self-knowledge, and their desire

to live and enjoy the things they loved doing:

'...not having the cancer but the experience of dealing with it and stuff like that, has really been quite positive. Which might sound a bit crazy but I got to learn a lot more about myself and other people going along the line. Again, I'm certainly a lot more confident' (Participant 12 p9).

'I think it's just sort of reinforced I suppose the things that I love doing and they're really active things and it's been nice to be able to get back to them' (Participant 09 p11).

One man, who had experienced the most severe impact upon his sexual function, after treatment for prostate cancer, found a benefit even in the midst of his loss of his previous function:

'I discovered sensuality, it's like shit I can have better sex without my cock getting in the way, I have never experienced that before.' (Participant 17 p6)

It would appear that despite a diagnosis of cancer being a negative and often frightening and challenging life event, there is the potential for patients to experience beneficial effects.

These beneficial effects are experienced both on an individual level and within partnerships and relationships with other people.

## **Practice and policy recommendations**

## For oncology services and services for other long term conditions in the NHS

Conduct equality monitoring for sexual orientation and gender identity in defined services. Create health care environments where LGBT people with cancer feel safe to come out (if they choose to do so). Services can signal that they promote equality and diversity through patient information materials, the inclusion of positive imagery of LGBT people in clinic waiting rooms and the implementation of changes to read codes, intake and other forms.

## For Health Education England

Ensure that Education providers demonstrate how they promote LGBT equality in the Education Outcomes Framework including specific indicators for patient experience and treatment. Provide training for health professionals so that there is particular understanding of the cancer care and support needs of LGBT people. Medical, nursing and allied health education should include issues relevant for lesbian, gay, bisexual and trans patients in pre and post-qualifying curricula. Education and training should support the development of effective communication skills among professionals in delivering cancer care. Workforce training should be rolled out to ensure that training is provided for reception, administrative and auxiliary staff.

## For the NHS leadership academy

Ensure that better leadership leads to better patient care for LGBT people. Future leaders within the NHS can influence the culture and ethos in hospital settings to achieve better outcomes for all.

## For the National Institute of Health Research

Ensure that, where relevant, funded studies include a sample of LGBT people and ensure that studies do not pathologise LGBT patients.

## For the Department of Health

Ensure that cancer policy and other initiatives include LGBT people with cancer. Where action plans have been identified, these should be reviewed annually to monitor and evaluate progress.

Actively include LGBT people in consultations about the design and delivery of services. Disseminate good practice and make good practice easily accessible, for example, through a dedicated website or a similar initiative to the NHS ethnicity library. This should be easy to navigate and freely available.

Prioritise the establishment of a data standard for the collection of information and statistics relating to sexual orientation and gender identity.

Recognise the additional work needed to embed equality and diversity in relation to LGBT people. For example, while the NHS Equality Delivery System (EDS2) does specifically mention sexual orientation and gender identity e.g. for better health care outcomes, it allows Trusts and other commissioned services an opt out clause by referring to sources of evidence which often do not include LGBT people (Joint Strategic Needs Assessments (JSNAs); Quality Accounts; Healthwatch and Patient Advice and Liaison Service (PALS); Friends & Family Test). This should not depend on local need as currently there is little local data to provide evidence for need.

## For the LGBT voluntary sector

Provide a range of support groups for LGBT people with cancer, including cancer specific support groups e.g. prostate cancer and in rural areas, for all cancer types.

Raise awareness of cancer among LGBT communities.

Develop resource materials (leaflets, posters, brochures) together with cancer charities for LGBT people with cancer.

Work collaboratively with cancer charities to share best practice.

#### For cancer charities

Service provision should be inclusive for all, including LGBT people; cancer charities should undertake user involvement audits to ensure that services are relevant.

Cancer charities should work with voluntary sector organisations to develop support networks or groups for LGBT people with cancer and their carers.

## **Future research**

To our knowledge, there have been no previous studies of cancer in LGB people across the differing cancer sites, and this pilot study constitutes an important first step in identifying the care needs of LGB people with cancer in the UK.

We are appreciative of the forward thinking of Hope Against Cancer in funding this new field of study, and we are hopeful that the findings of this project have identified priorities for future research.

It would seem, from our conversations with other academics, NHS professionals, voluntary sector organisations working in the field of cancer, and LGBT cancer support groups that research is now timely in the patient experience of LGBT people with cancer. The wider social and political environment is more accepting of LGBT people as a social demographic group who have distinct issues and concerns in cancer care. These issues provide an important context to develop organisational ethos and culture so that better care and patient experience will lead to improved outcomes for LGBT people with cancer.

## Appendix 1

## Research participants (anonymised)

## 01. Quentin

Quentin is in his fifties, lives in Leicestershire and five years ago had radiotherapy, chemotherapy and trial-based medication for prostate cancer. He has a partner who attended appointments and supported him throughout his treatment.

#### 02. Miranda

Miranda is in her forties, lives in Leicestershire and has had lumpectomy, chemotherapy and radiotherapy for breast cancer. She has a partner who has supported her throughout her treatment.

#### 03. Linda

Linda is in her late forties, lives in Nottinghamshire and has had lumpectomy and radiotherapy for breast cancer. She has a partner who has supported her throughout her treatment.

## 04. Tracy

Tracy is in her early fifties, lives in Leicestershire and had had surgery and chemotherapy for bowel cancer. She has a partner who has attended all appointments with her and supported her throughout her treatment.

#### 05. Nicholas

Nicholas is in his early forties, lives in Lancashire and he cared for and supported his partner who died of a brain tumour in his late twenties.

#### 06. Davina

Davina is in her early sixties, lives in Shropshire, and has had surgery and chemotherapy for ovarian cancer. She has a partner who has attended all appointments with her and supported her throughout her treatment.

### 07. Nigella

Nigella is in her early fifties, lives in Leicestershire and has supported her partner who has had treatment for bowel cancer.

#### 08. Karl

Karl is in his fifties, lives in London and has had surgery and radiotherapy for prostate cancer. He has a partner who has supported him throughout his treatment.

#### 09. Tessa

Tessa is in her late forties, lives in West Yorkshire and has had a mastectomy for breast cancer. She was supported by a friend who had been a previous partner.

#### 10. Oliver

Oliver is in his early forties, lives in Leicestershire and has had chemotherapy for lymphoma. His partner was living overseas at the time so he was supported by various family members throughout his treatment.

#### 11. Gertrude

Gertrude is in her early seventies, lives in Leicestershire and had chemotherapy for lymphoma. She was supported by her daughter and a circle of close lesbian friends throughout her treatment.

#### 12. Noel

Noel is in his fifties, lives in the West Midlands and has had radiotherapy for prostate cancer and chemotherapy for lymphoma. He started a relationship during his treatment and his partner then supported him through the remainder of his treatment.

#### 13. Timothy

Timothy is in his fifties, lives in Greater Manchester and has had chemotherapy for leukaemia and active surveillance for prostate cancer. He has a partner who has supported him throughout his treatments.

## 14. Nigel

Nigel is in his early forties and lives in Lancashire and has had surgery for prostate cancer. He has been supported by family members throughout his treatment.

#### 15. Liam

Liam is in his forties, lives in Birmingham and had had surgery for melanoma. He was supported by his partner throughout his treatment.

## 16. Craig

Craig is in his mid-sixties, lives in Greater Manchester and has had radiotherapy for prostate cancer. He has been supported by his partner throughout his treatment.

#### 17. Norman

Noman is in his early fifties, lives in Greater Manchester and has had surgery and radiotherapy for prostate cancer. He has been supported throughout his treatment by family members and friends.

All participants are White British, one participant is bisexual and living with a male partner.

## Appendix 2

## Actions to promote the study

One of the most significant aspects of the project was the work we undertook to build networks with other professionals both within the NHS and in the LGB voluntary sector where most of the work to support LGB people with cancer is provided. The intention was both to forge relationships and promote awareness of the study. A range of meetings were held including with staff at the Macmillan Centre at Leicester Royal Infirmary with Nursing staff and with the Clinical Nurse Specialist Cancer team meeting at Leicester General Hospital.

The researcher attended two of a series of six ESRC research conferences led by Dr Andrew King at Surrey University, which focused on issues relating to LGBT people and ageing. The first of these; 'Trans Ageing Issues', was held in Manchester in September 2014 and 'Older Lesbian, Gay, Bisexual & Trans People: Minding the Knowledge Gaps' was held in London in January 2015.

In September 2014 the researcher met with the Policy and Research Manager at the Lesbian and Gay Foundation in Manchester and the founder member and organiser of LGBT Cancer Support, a national social media support group, also based in Manchester. In December she attended a joint West Midlands and North West England Out With Prostate Cancer support group meeting in Manchester.

The Lead Researcher presented at the following conferences and seminars:

Fish, J. "The Watershed: Sexuality with Dying Patients and Partners. LGBT issues in palliative care" The University of Worcester, Institute of Health and Society, Thursday 4<sup>th</sup> December 2014.

Fish, J (keynote): "New Futures: exchanging research knowledge about older LGBT communities" at The future of LGBT ageing: Rethinking research directions. University of Manchester, <u>Manchester Institute for Collaborative Research on Ageing</u>, 22 October 2014. <a href="http://www.micra.manchester.ac.uk/events/lgbt-ageing/">http://www.micra.manchester.ac.uk/events/lgbt-ageing/</a>

Fish, J. *The right to health: Health and human rights for LGBT people*, Westminster Policy Forum, The Caledonian Club, London, February 4<sup>th</sup> 2015

Alongside Sian Lambert from the Lesbian and Gay Foundation Manchester, Ruth Hunt CEO and James Taylor of Stonewall, Professor Fish met with Baroness Barker in the House of Lords to discuss the wider agenda relating to lesbian, bisexual and trans women's health following a question she tabled to the Lords in November 2014.

#### References

Brown, J. and Tracy, J.K. 'Lesbians and cancer: an overlooked health disparity', *Cancer Causes and Control*, 19:10, 2008, 1237-1258.

Butler, I. (2002) A Code of ethics for social work and social care research. *British Journal of Social Work*, 32, 239-248.

Cancer Patient Experience Survey (CPES) (2013). Cancer Patient Experience Survey Programme - 2013: National survey report. London: Department of Health. Available from: <a href="http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file">http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-experience-survey-programme-national-report/file</a>

Fish, J. (2010) "It's a mixed up, muddled up, shook up world, except for Lola": transforming health and social care for trans people. *Diversity in Health Care*, 7 (2) 87-9.

Fish, J. (2010) Promoting equality and valuing diversity for lesbian, gay, bisexual and trans patients. RCGP Journal. *InnovAIT*, *3* (6) 333-8.

Fish, J. and Bewley, S. (2010) Using human rights based approaches to conceptualise lesbian and bisexual women's health inequalities. *Health & Social Care in the Community*, 18 (4) 355-362.

Fish, J. and Karban, K. (eds) (2015) *Lesbian, gay, bisexual and trans health inequalities: International perspectives in Social Work.* Bristol: The Policy Press.

Fish, J. (under submission) Evidencing the impact of human rights based approaches in the health of LGBT people with cancer.

Fish, J (under submission) Quality of life and survivorship for sexual minorities with cancer: An integrative review."

Frisch, M., Smith, E., Grulich, A., and Johansen, C. (2003). Cancer in a Population-based Cohort of Men and Women in Registered Homosexual Partnerships. American Journal of Epidemiology, 157, 966-972.

Hagger-Johnson G; Taibjee R; Semlyen J; Fitchie, I; Fish, J. Meads, C. and Varney, J. (2013) Sexual orientation identity in relation to smoking history and alcohol use at age 18/19: cross-sectional associations from the Longitudinal Study of Young People in England (LSYPE). *BMJ Open* 2013;3:e002810.

Johnson, M. And Fish, J. (forthcoming) Cancer Inequality. In D. Wyatt Dr N. Hulbert-Williams (eds.) *Cancer Care- a biopsychosocial approach*. London: Sage.