



# Coming Out About **Breast Cancer**

**Research Report February 2010**

Lesbian and bisexual women's experiences of breast cancer

**Coming out about breast cancer:  
Lesbian and bisexual women**

**Policy and practice implications for cancer services  
and social care organisations**

© Julie Fish,  
Health Policy Research Unit  
De Montfort University  
The Gateway  
Leicester  
LE1 9BH  
[jfish@dmu.ac.uk](mailto:jfish@dmu.ac.uk)

ISBN: 978-1-85721-403-1

## Acknowledgements

My deepest thanks go to the thirteen women who shared their experience of breast cancer with me and the four women whose partners had died of the disease. Their stories may help lesbian and bisexual women who subsequently develop breast cancer to know they are not alone and their ways of coping may lighten the burden of other women's cancer journeys. I am indebted to the members of the steering group who provided oversight for the project and offered helpful feedback for the final report. Their names are included in the appendices. I would also like to thank those organisations and individuals who helped to make contact with women as this was not always possible through traditional recruitment methods. There were some obstacles to bringing this project to fruition including a previous application to a funding body which was unsuccessful on the grounds that they did not believe the project would recruit 10 participants and elsewhere there was reluctance to consider that lesbian and bisexual women with breast cancer is a concern for services and policy makers.

The research would not have been possible without the support of the National Cancer Action Team, in particular, Professor Mike Richards, Paula Lloyd, Joanne Rule and Suzi Butt. I hope the report will go some way to making visible lesbian and bisexual women's experiences of breast cancer within the NHS, in cancer organisations and the voluntary sector.

JF

## Contents

Background	1
<i>Cancer inequalities</i>	1
<i>Current legal and social context</i>	1
<i>Why lesbian and bisexual women and breast cancer?</i>	2
<i>Why was this pilot study needed?</i>	2
Aims and objectives	3
Methods	3
<i>Stakeholder steering group</i>	3
<i>The sample</i>	4
<i>Ethics</i>	5
Findings	5
Health service issues	5
<i>Heterosexism in cancer services</i>	5
<i>Interactions with doctors and nurses</i>	6
<i>Coming out</i>	8
Issues for lesbian and bisexual women	
<i>Accessing support and information</i>	10
<i>Formal support</i>	10
<i>Social (or informal) support</i>	11
<i>Breast cancer information for LB women and support groups for carers</i>	13
<i>Attitudes to mastectomy and reconstructive surgery</i>	14
Conclusion	16
Raising awareness about the study	17
Recommendations	19
Appendices	21
1. Steering group members	21
2. Participant details	22
References	25

## **Background**

### ***Cancer inequalities***

The reduction of cancer inequalities has emerged as a health priority in the Cancer Reform Strategy (DH, 2007). Cancer inequalities are differences between individuals' cancer experience or outcome which result from their socio-economic status, 'race', age, gender, disability, religion or sexual orientation<sup>1</sup> (All Party Parliamentary Group on Cancer, 2009). Lesbian, gay, bisexual and trans (LGBT) people have been largely overlooked in cancer research and services. For example, a recent survey of projects designed to reduce cancer inequalities in the UK found only one initiative (out of a total of 77) which specifically targeted sexual orientation and cancer (NCEI, 2008). None of the other equality strands (e.g. 'race', class, gender) were so poorly represented in projects and this reflects the low priority often afforded to sexual orientation in health service delivery.

### ***Current legal and social context***

A number of factors combine to make this an opportune time to conduct research in breast cancer among lesbian and bisexual women: the Equality Act (Sexual Orientation) Regulations 2007 prohibit discrimination, for the first time, on the grounds of sexual orientation in health services. This, and other, legislative changes have been accompanied by shifts in social attitudes; fewer people display overtly homophobic attitudes and behaviour than in previous decades. These transformations are often reflected in the attitudes of health professionals; consequently, an increasing number of lesbian and bisexual women may disclose their sexual orientation to service providers. They should be able to expect the same standard of care from services in the statutory, voluntary and charity sectors as that afforded to everyone else.

In a recent statement, a leading UK cancer research organisation called for stakeholders to commission research in order to better understand the lesbian, gay, bisexual and trans (LGBT) cancer inequalities agenda including: unmet need for information and support relating to cancer; availability of charity and private sector cancer information, support and services; experiences of individuals when accessing health and cancer services and awareness of the needs of LGBT communities among health professionals (Cancer Research UK (CRUK), 2008). It is with these issues in mind that the National Cancer Action

Team (NCAT) commissioned this study to begin to address lesbian and bisexual women's experiences of breast cancer treatment, support and care.

### ***Why lesbian and bisexual women and breast cancer?***

Every year, around 45,500 women are diagnosed with breast cancer in the UK (CRUK, 2009). Although there is high public awareness of breast cancer among women in general, relatively little is known about breast cancer in lesbian and bisexual (LB) women. This historic neglect may be explained by beliefs that LB women form a small proportion of the total UK population. Government figures estimate that they comprise 5% of women in this country; these figures indicate that as many as 2,275 lesbian and bisexual women may be diagnosed with breast cancer each year. Population size cannot be the sole reason for the oversight because while breast cancer in men is known to be relatively small – approximately 300 cases each year - their experience of the disease has been investigated (Williams et al 2003). Moreover, previous research suggests that the disease may be more common in LB women than among their heterosexual counterparts (Valanis et al. 2000).

### ***Why was this pilot study needed?***

In their private lives, lesbian and bisexual women are increasingly likely to have come out to family and friends. A UK study of 5909 LB women revealed that 70% had come out to their families and 90% had come out to friends (Hunt and Fish, 2008). In their public lives, fewer women had come out to work colleagues (67%) or to their managers (63%); however, it was much less likely that they had come out to their GP or other health professional (44%). When faced with a potentially life threatening illness, many women may feel that the stress of coming out is an additional hurdle that they do not want to face. Because of non-disclosure, many doctors and other health professionals are not aware that they have lesbian and bisexual women patients. Indeed, other medical researchers have assumed that because lesbian identity is rarely recorded in patient notes, that there are no lesbian and bisexual women with breast cancer.

Recent innovations in health and social care policy aim to meet patient needs through personalised care. To this end, the Cancer Patient Experience Programme was established to collect information on patients' cancer journeys. Despite the increasing visibility of lesbian

and bisexual women in everyday life, it remains the case that lesbian and bisexual women do not disclose their sexual orientation in health surveys. This study provides important information that is not available through traditional data collection methods.

### ***Aims and objectives***

This pilot project was funded by the National Cancer Action Team and is the first empirical study of lesbian and bisexual women's experiences of breast cancer in the UK. It aimed to generate 10-15 in-depth interviews with lesbian and bisexual women who have a breast cancer diagnosis or carers of women with breast cancer.

#### **Objectives**

- I. To establish a steering group to provide oversight for the research;
- II. To provide new empirical data about lesbian and bisexual women's experiences of living with breast cancer and of treatment support and care;
- III. To contribute to developing understanding among health and social care providers and policy makers about the needs and experiences of lesbian and bisexual women with breast cancer;
- IV. To enable cancer charities and other providers to make services and information more accessible to lesbian and bisexual women;
- V. To provide evidence for the LGBT voluntary sector so that they can offer support to LB women with breast cancer;
- VI. To raise awareness about breast cancer among lesbian and bisexual women's communities.

### **Methods**

#### ***Stakeholder steering group***

One of the key objectives for this research was to facilitate knowledge transfer between three 'communities of interest': cancer organisations; representatives from the lesbian and bisexual women's voluntary sector; LB women with experience of breast cancer and their carers (see appendix 1 for members of the steering group). The steering group (three meetings were held in London) provided oversight and quality assurance for the research

by, for example, proposing amendments to the information pack for research participants, supporting recruitment to the study, contributing to data analysis and suggesting revisions to the final report.

The rationale for the steering group is to embed the findings of the study in organisational practice. The particular challenge in developing services and support for lesbian and bisexual women is that initiatives are often short-lived. For example, in the mid 1990s, Cancerlink established a part time, temporary post for a lesbian breast cancer development worker. In the late 1990s, Breast Cancer Care received Lottery funding to train and support groups of volunteers from hard to reach communities, including LB women. Women were enabled to deliver services and were also involved in public speaking and raising awareness. But the end of the grant coupled with a management re-organisation meant that the group could not be sustained and the expertise which had been developed was lost. These experiences are not specific to cancer provision, but rather are reflective of public services, more generally, for LB women.

### ***The sample***

From the outset, it was acknowledged that lesbian and bisexual women with breast cancer constitute a new group for study. There is something of a double jeopardy: cancer is largely an invisible disease and lesbians and bisexual women are invisible in cancer services.

Participants were recruited via a flyer that was distributed through the networks of the steering group and specifically targeted users of cancer services and LB women's groups (including older LB groups). The flyers were displayed in specialist breast care units in hospitals, Breast Cancer Haven, in generic service provision for older LB women (e.g. Age Concern) and in organisations in the LB voluntary sector, on a range of websites including those of other groups deemed hard to reach, and via email.

When participants contacted the researcher, they were sent a copy of the participant information pack which gave details about the study and informed consent procedures. Seventeen women took part in semi-structured interviews (typically lasting between 1 – 1.5 hours) which included 13 LB women with experience of breast cancer and 4 women who were carers whose partners had died of the disease (see appendix 2 for



details). Data from the interviews were audio-recorded, transcribed verbatim and analysed thematically.

### ***Ethics***

The study was conducted in accordance with the Ethical Guidelines of the British Sociological Association and the LGBT principles formulated by NHS Scotland (Inclusion Project, 2006). These include providing full information to participants, obtaining informed consent, respecting privacy, guaranteeing confidentiality and informing participants of their right to withdraw. All data were anonymised to protect confidentiality and will be securely stored in line with the Data Protection Act 1998. Ethical approval was received from De Montfort University, Faculty of Health and Life Sciences, Human Research Ethics Committee in September 2008.

### **Findings**

#### **Health service issues**

##### ***Heterosexism in cancer services***

Although public attitudes towards sexuality have become more tolerant in recent years; in this study, lesbians and bisexual women said that health professionals were not always accepting of them and this was reflected in their interactions. Naomi accompanied her partner to hospital appointments and experienced a level of discomfort and embarrassment:

If we'd had someone treating us that was maybe, was very relaxed about, you know, our sexuality, or whatever, I think it might have just made it a bit easier to ask questions...you sort of worry about it sometimes and think, oh God, they are really uncomfortable with it (Naomi, carer).

Lesbians and bisexual women become adept in detecting attitudes through body language and other subtle cues; when a doctor or nurse is not at ease, this acts as a barrier to effective communication. Nicky felt the hospital did not provide a welcoming environment:

I think they just treat you as a heterosexual woman that's it. ..I didn't want to sit in that waiting room and talk about knitting patterns and what they were going to cook for their husband's tea (Nicky, cancer services user).

By contrast, Esther felt that the hospital environment was neutral:

I didn't feel the services were set up for heterosexual couples and quite often you do, you go places and you think this is geared up for heterosexual couples (Esther, carer).

Discomfort was more commonly reported than hostility; but for Marie, her first encounter in a hospital environment undervalued her relationship with her partner:

The booking in clerk asked me about my marital status. I said I'm civil partnered, she said what's that? I said this is my partner we are in a civil partnership. She said I'll put you down as single. I said no, we are civil partnered. She said I don't have it on my form. I said let me look at the screen and there were about 10 different categories: widowed, divorced etc but not one for civil partnership. So I insisted she put me down as married (Marie, cancer services user).

The Civil Partnership Act 2004, which gave same-sex partners the equivalent status to marriage, had been implemented for four years by the time Marie attended a hospital in the South-west, with her partner, for breast surgery. Hospital booking in procedures had not been updated to take account of the new formal status and the booking in clerk demonstrated attitudes that might be described as heterosexist.

### ***Interactions with doctors and nurses***

Increasingly, doctor's relationships with their patients are seen to lie at the heart of good medical practice. The General Medical Council, states that doctors should know about the rights of patients and respect them regardless of their sexual orientation (GMC, 2009). Many of the women said that they could not fault the medical care they received in treating

their breast cancer; for example, Mercedes described her treatment as 'top'. Despite this assessment of her medical treatment, Mercedes also gave examples of routine care:

One of my visits to the oncologists...she was so business-like, no um, I didn't feel that she was taking the time to see me as a human being (Mercedes, cancer services user).

Many women said that the social skills of doctors could be improved:

But the treatment in there, the nurses were absolutely first class ... they'll be the usual stuff, which is not specific to either breast cancer or lesbians having breast cancer, she saw a different consultant every time...and they ranged from hopeless to first class. The hopeless description refers, I guess, to their bedside manner (Fiona, carer).

A common theme in the interviews was the lack of continuity of care; in an effort to meet cancer waiting targets, patients see a different doctor on each occasion:

One of the things that I've always sort of found difficult with my experience, is that you never see the same person twice. Some woman that I'd never seen before told me I had breast cancer and then that was it, I've never seen her again since (Tessa, cancer services user).

Although this is the same experience for every patient, the impact on lesbian and bisexual women may be different. Seeing a new doctor on every visit means it is difficult to build a relationship and makes it less likely lesbian and bisexual women will come out to a health professional. Some lesbian and bisexual women may prefer to be seen by female staff; for Yvette, this was very important:

Right from the first day I went I knew I couldn't cope with having males examining me and that was actually quite a problem. They always said oh yes that's fine we will write it down. ...The whole thing was very traumatic anyway obviously, and for me

the whole thing of having to keep getting undressed in front of different people was worse than the cancer... over those two weeks I must have got undressed in front of 8 or 10 different people (Yvette, cancer services user).

For Ursula, having breast cancer and coming into contact with health professionals over a protracted period meant that she was able to build relationships and contribute to changing attitudes:

I think it's really weird that cancer has made a lesbian relationship acceptable, that's what it really felt like to me. In lots of places, we maybe came across people who wouldn't have given us the time of day but they did because I'd got cancer. I suppose partly because it's their job to but I guess in some ways, we have probably changed some attitudes along the way as well (Ursula, cancer services user).

### ***Coming out***

Coming out, or disclosing one's sexuality, to professionals has a number of health benefits: lesbian and bisexual women are more likely to be comfortable and satisfied with the care they receive and experience greater ease in communicating with their doctor. Hiding one's sexuality may mean that women are subject to inappropriate questioning (e.g. what does your husband think about breast reconstruction?) and they may experience anxiety about inadvertently revealing their sexuality.

Confidentiality is important if a woman has come out and care should be taken to find out whether or not that information should be recorded, and if so, how it should be recorded. In the following extract, Esther's partner, Wynne has an appointment with a consultant:

It was written in her notes: lesbian. Because Wynne said when the doctor was trying to read this word (miming holding the notes at arm's length), and obviously it wasn't clearly written and she was trying to work it out and it was (heh heh heh). Oh right (Esther, carer).

Although Esther was amused by the doctor's struggle to read the word lesbian in the patient notes this might not be the case for every woman in this situation. Women came out in a variety of different ways; often disclosure occurred indirectly, by attending hospital appointments with their partner or during visiting hours on wards. Some women chose not to come out; in the following extract, Toni explains her reasons for deciding against disclosure:

I suppose, personally I would think that if you are going, it wouldn't be the first thing on my mind that I would say, when going in with a breast problem and say, oh by the way...I didn't say, oh by the way, you know, I'm a lesbian, um, they don't know, the hospital don't know, I was treated, I assumed, as they treated everybody (Toni, cancer services user).

Organisations often say that they treat all people equally; but equality does not always mean treating people in the same way. Sometimes treating people the same means that patients' different needs are not taken account of:

I mean these people would spot a Muslim woman and they'd know what was appropriate because that's easy, they can see that. I don't know, I'm always gobsmacked when I come across that degree of ignorance and prejudice (Irene, cancer services user).

Many people ask: why do lesbian and bisexual women come out? It might be first useful to understand why many lesbian and bisexual women have historically chosen to hide their sexuality. Homosexuality was decriminalised for private behaviour by the Sexual Offences Act 1969; until the late 1960s, many lesbians and gay men were imprisoned simply for being gay. During subsequent decades, women commonly concealed their sexuality in public spaces. One of the effects of this is that many continue to perceive their sexuality as a private matter and something that is not to be widely shared.

The reasons lesbian and bisexual women choose to come out may be influenced by the circumstances - whether their sexuality is relevant to their health concern. Examples in the interviews where sexuality was seen to be relevant included ensuring that their partner

(or friend) would be treated as next of kin, reducing the likelihood of inappropriate comments and seeing their identity as part of themselves that needs to be considered in their treatment and care.

## **Accessing support and information**

### ***Formal support***

Support groups play an important role in the survival and recovery of women with breast cancer and on their overall quality of life (Michalec, 2005). Women are often referred to formal support groups by breast care nurse specialists; these groups are usually facilitated by volunteers who are recruited, trained and supervised by a cancer charity (e.g. Fogg, 2000). Previous research has suggested that although lesbian and bisexual women were as likely as heterosexual women to have participated in a cancer support group since diagnosis, they were much less likely to report current involvement (Matthews et al. 2002). This study provided insights on lesbian and bisexual women's participation in such groups. Women talked about feeling excluded from groups because they were not able to come out:

I didn't access any support groups because I had gone along... (to a) weekend.. in the all the bits where we went off and had discussions, all really that was being talked about was their relationships with their husbands and how that had been affected... and basically all focused around men. ...And so I just felt very uncomfortable. It was staying away in (a Northern city) so even the kind of social spaces, I already felt quite excluded, so I didn't really say anything, so I never tried to access anything (Lucy, cancer services user).

One participant also felt excluded by the kind of topics discussed by breast cancer support groups. Ursula attended a group in a rural area which discussed topics often associated with Women's Institute meetings:

I went to the one in the South West ....they might have a couple of health sessions per year but then they'll do things like quilting or, do you know what I mean?

They gave us a presentation on cathedrals and I was like, oh God (Ursula, cancer services user).

For others, there was a sense that the environment was offputting: ‘There is a very girly, frilly image isn’t there?’ (Yvette, cancer services user). They felt out of place rather than excluded:

You are constantly reminded you are not mainstream, like for instance, when you go to the support groups, you are reminded of your otherness. I don’t mean my whole world is lesbian but a good bit of it is...I’m not defined by fashion or gender roles, the whole statement is slightly different (Fran, cancer services user).

By contrast, Tina talked about the benefits of attending a holistic therapies group, which was a two hour return journey from her home:

I think the first time I went there, you know, I got home and ... when I was in bed that night, I was just, felt such a sense of relief that I hadn’t felt for a long time. Because even though...they don’t particularly acknowledge sexuality or anything, it was just such a relief to be somewhere where you weren’t having to manage other people’s reactions (Tina, cancer services user).

Although Tina found the meetings emotionally supportive, the group did not acknowledge her sexuality. Her experience underlines the importance of holistic and patient centred care: being accepted as a lesbian or bisexual woman and supported emotionally.

### ***Social (or informal) support***

Previous research has suggested that social support is associated with improved outcomes in women with breast cancer (Falagas et al 2007). Social support is useful in accommodating the stress of adjusting to a new breast cancer diagnosis (Fobair et al. 2001). Informal support (often in the form of practical assistance, such as gardening or shopping) may be provided by family, friends, neighbours, work colleagues and acquaintances. Lesbians and bisexual women may not have the same social support from families of origin as

heterosexual women; however, their families of choice may include current or former partners, friends and accepting family members. Few studies have considered the range and nature of social support available to lesbian and bisexual women. Aronson (1998) described a network in Canada that numbered 30 or 40 friends and acquaintances which was organised in a semi formal way to support a lesbian with breast cancer: the network was named, meetings were held, a newsletter was designed and 'charts matched needs and responses' (Aronson, 1998: 512).

While this study is not able to provide data on whether lesbian and bisexual women have similar levels of social support to heterosexual women in the UK; a number of the women who took part in the study, even some of those in a relationship, lived alone. Some UK studies have found that high proportions of lesbian women live alone (e.g. Heaphy et al. 2003) and this may have implications for the levels of formal and informal support they may need. For one participant, a network would have provided the support needed to challenge poor healthcare:

And I didn't have the personal support network...to do something like that (make a complaint) (Lucy, cancer services user).

Or provide a listening ear for worries to be talked about:

After the dramatic bit's over, friends sort of tend to forget about it a bit but I sort of understand that really. It's sort of on my mind a lot but I can't really expect other people to have it on their mind (Tessa, cancer services user).

Some women in the study went to hospital appointments alone because of their circumstances, a sense of independence or not knowing that a friend or partner could accompany them:

At the beginning... I went with friends (to hospital) ...um, but no, I just go, no, I go on my own really, simply because I, well I don't think about it really (Toni, cancer services user).



Other women in the study felt that their support needs were met by their partner, friends, family and work colleagues:

I was quite happy that people were concerned and everything, very touched, so many people at work sort of sent flowers and cards and things, it was really lovely, people were so kind (Irene, cancer services user).

Tina who lives in an area, where a relatively high proportion of lesbian and bisexual women live, said that because she knew other women with breast cancer, she felt 'incredibly quite well prepared...in terms of information and support that I had, to go into the ward and have the operation'. The opportunity to find out about what might happen once a woman has been diagnosed with breast cancer is important and other lesbian and bisexual women could potentially provide useful insights if they are able to make contact with one another.

### ***Breast cancer information for LB women and support groups for carers***

When faced with a potentially life threatening illness, many people seek out the experiences of others with similar conditions. Sharing cancer stories is an important way of reducing the feeling of isolation, of making sense of the illness and of making visible a disease which is characteristically thought to be invisible. Many women have publicly shared their stories of breast cancer; among them are Ruth Picardie, Dina Rabinovitch, Kylie Minogue and Jenni Murray and these women have helped to change public attitudes and raise the profile of the disease. People often look for stories that reflect their own lives and experiences. In the study, Sophie describes the search for information that is relevant for lesbian and bisexual women:

I found myself having to ... deconstruct information that's there that fits with you and your life. So it's almost like going back a few steps and try and work things out for yourself and trying to sort of find the things that you're looking for that would be very difficult to explain to a straight person. ...Having to sort of deconstruct it, the information is there but it doesn't always say your name (Sophie, cancer services user).

Women were asked whether they had found information about breast cancer for lesbians and bisexual women. A number of women had read Audre Lorde's (1980) cancer journals (one woman had met her before she died) – her experiences and her refusal to wear a prosthesis may have had an influence on some of the women's attitudes towards breast reconstruction. However, most had seen no specific information; while Macmillan produce a comprehensive directory of cancer information each year, none of the resources address LB women's concerns:

It would have been quite nice if there had been a breast cancer care leaflet for gay people. And maybe this sort of study could lead towards that sort of thing. I don't know if there are enough differences and issues, but yes, even to have been told that that a support group was available for partners (Yvette, cancer services user).

Moreover, few women in the study were aware of any support groups for carers of lesbian and bisexual women. Macmillan lists the contact details for a support group for carers of LB women on their website, from which Yvette's partner had received support (this is a yahoo email group LBCKiT). Support groups are important for carers of women whose partners have died of breast cancer. There are few support groups, of any kind, for lesbian and bisexual women in the UK: those that do exist often necessitate travelling long distances to access them. Self-help groups may not always be able to undertake the outreach that lesbian and bisexual women may need in the medium to long term. There may be a role for the voluntary sector in undertaking this work.

I think there is always going to be the loneliness, but there is just a bit too much emphasis on me making the effort (Esther, carer).

### **Attitudes to mastectomy and reconstructive surgery**

Nearly half of women in the UK are offered reconstructive surgery following mastectomy and guidelines from NICE state that surgery should be an option for all women (Campbell, 2009). However, women's reasons for declining surgery are not widely understood; in this study, a number of women chose not to have reconstruction. Women were concerned

about having a silicone implant or using excess fat from another part of the body; an additional surgical procedure was seen to subject their body to an unnecessary operation. Toni felt that the breast surgeon was 'all for it' and she said 'it was just his manner that really got to me'. Cath describes an interaction with her surgeon where she felt that there was an expectation that she should have breast reconstruction:

The surgeon asked me at least twice, by saying like, it wouldn't take much as I had quite a lot of excess fat there, that he could use that, and I said no, I really didn't want a reconstruction...I was really clear all the way along you know, saying, well no, actually I wasn't clear, I said um (pause) I didn't think I wanted it but I wouldn't rule it out, and I was doing that in part because I didn't want to be seen as being (pause) completely rigid. I think I was clear in my own mind that I didn't want it ....I didn't realise the implications of saying that, because what he did was he left a flap of skin that apparently is quite common...and that is why I have had recent surgery to get rid of that (Cath, cancer services user).

For Tina, the decision not to have reconstruction meant that the consultant did not perform the operation and this led to a reduction in the quality of her surgery:

So because I was on his list and I wasn't having reconstruction, he gave it to a junior or someone to do and he really botched my surgery. And the nurse said, you know, on the ward, said it was a real pig's ear and they hadn't seen anything like that for a long time (Tina, cancer services user).

Two women chose to have an elective mastectomy. By contrast to Cath's experience, Rachel's decision against reconstruction was not contested by her surgeon:

When I saw him he said about the other breast and it was up to me and I just said take it off, for lots of reasons. One to sort of prevent it coming back, and two it was a vanity sort of thing in that I didn't want to be lopsided.

*JF: that is a brave decision.*

Well if you have got to lose one I actually think it's just easier to lose the both. He didn't argue which made me think there was probably quite a high risk of it coming back in the second one. And then you have got to go through surgery twice. So it was a preventative action. ...I could have had the left breast reconstructed free of charge, but because I chose to have the right breast removed I would have had to pay for that. And I just said I don't particularly want foreign objects in my body (Rachel, cancer services user).

It is notable that that over a quarter of the women had chosen not to have breast reconstruction. While the study cannot provide data to show whether such a decision might be more common among lesbian and bisexual women than their heterosexual counterparts, they do reveal alternative understandings and choices following mastectomy. It is important that in the drive to meet the majority of women's preference for breast reconstruction that breast and plastic surgeons do not make this choice an inevitable one for women. The decision may lend insights into lesbian and bisexual women's feelings towards their bodies post surgery.

## **Conclusion**

Lesbian and bisexual women's accounts of breast cancer included harrowing experiences of getting the diagnosis, of painful chemotherapy treatment and of a lasting impact on their lives in terms of losing their job or paying for complementary therapy. These events may happen to any woman; an established network of breast care nurse specialists, Macmillan nurses and support groups can help women to cope with some of the practical and psychological effects of breast cancer. Some of the women in this study, however, did not feel able to access existing support groups: they felt excluded by topics of conversation or by the environment of the group and this constitutes an unmet need for support relating for LB women with breast cancer. Only two of the women had found information that included representations of lesbian and bisexual women and two had found details of a yahoo based group for LB women. Women who lived in large cities were less likely to seek out specific breast cancer information especially if their existing networks included LB women with breast cancer. But finding other LB women to talk to who had experience of the disease was difficult for a number of women. The study provided evidence of LB women's experiences of

accessing breast cancer services and of their interactions with health professionals. In some areas in England, there was low awareness of the needs of LB women among health and allied health professionals.

Some women have asked 'what is the study is seeking to investigate?' This is a perfectly legitimate query because no one has previously researched LB women and breast cancer in the UK. The question: what is lesbian or bisexual about a breast cancer experience is difficult to unravel. The distinctiveness of LB women's cancer journeys are brought into sharp focus when there is sub-optimal care, for example in the discomfort of health professionals. If the person who can determine the course of your disease does not respect you and your life, then this could affect your recovery. Some women said that their partner was mistaken for a friend during visits to a ward following surgery. The lack of continuity of care may impact differently on LB women as it may make coming out to a health professional more difficult. But there are also a number of subtle ways in which being an LB woman has an impact on a woman's everyday life: from the values she may have, the nature of her social relationships, her family and partner, the clothes she wears, her feelings about her body, her breasts, her hair and even topics of conversation may serve as factors of inclusion or exclusion. As Sophie said:

...just the experience of being on the internet looking for cancer stuff but thinking, I wonder if there's any specific lesbian breast cancer stuff? Oh no, silly me for looking. And I think in a way, that lack of information reinforces a sort of negative stereotype. If you were feeling bad about yourself, you've got low self esteem or, you know, had the experience of homophobic abuse, and then you went somewhere and you couldn't find the information you wanted, it kind of reinforces the difference... But I don't know how popular it would be in the breast cancer world (Sophie, cancer services user).

### **Raising awareness about the study**

- *Coming out about breast cancer in lesbians and bisexual women.* Presentation to the 4<sup>th</sup> National LGBT health summit in Newcastle, October 6 2009. This workshop was supported by the Royal College of Nursing.

- *Cancer inequality: What have sexual minority women's experiences of breast cancer to do with it?* Presentation to the British Sociological Association, Medical Sociology Group annual conference, Manchester, Sept 4 2009.
- *Cancer inequalities and LGBT people.* Presentation to the NCEI Cancer visioning event for sexuality, Regent's College, London, July 8 2009.
- *Lesbians' risk of breast cancer,* Invited symposium, World Congress of Psychology, Berlin. July 20-22 2008.

A range of opportunities have been taken to publicise the study and it is intended to communicate the findings to a diverse audience of policy makers, health professionals, the voluntary and charity sectors, other researchers and among lesbian and bisexual women's communities.

#### **Endnote**

1. The terminology used to describe lesbian or bisexual women in the first section of the report is 'sexual orientation' as this is the term that is commonly used by the Department of Health, Equality and Human Rights Group. In the findings section, the term used is 'sexuality' because this is how women described themselves.

## Recommendations

### For the NHS

1. Create health care environments where lesbian and bisexual (LB) women feel safe to come out (if they choose to do so). This might mean changes to intake and other forms, positive images of LB women in hospital waiting rooms and the development of effective communication skills among health professionals in delivering care for LB women. Training should be provided for reception, administrative and auxiliary staff.

### For the General Medical Council

2. Provide training for health professionals so that there is broad understanding of the health needs of LB women. Medical, nursing and allied health education should include issues relevant for lesbian, gay, bisexual and trans patients in pre and post-qualifying curricula. This training is not specific to cancer services but rather for health provision more widely.

### For the National Cancer Equality Initiative

3. Ensure that LB women are included in existing research (such as the Cancer Patient Experience Survey), cancer policy and other initiatives.
4. Contribute to raising awareness of LB women and breast cancer in the Department of Health and the NHS.
5. Fund research in cancer more generally among lesbian, gay, bisexual and trans people.
6. Give grants to projects for support for LGBT people and cancer.

### For lesbian and bisexual women's voluntary organisations

7. Raise awareness of breast cancer among lesbian and bisexual women's communities.
8. Develop resource material (leaflets, posters, brochures) together with cancer charities for lesbian and bisexual women with breast cancer.
9. Improve signposting for LB women with breast cancer
10. Work collaboratively with cancer charities to share best practice.

### **For cancer charities**

11. Service provision should be inclusive for all women, including lesbian and bisexual women; cancer charities should undertake user involvement audits to ensure that services are relevant.
12. Cancer charities should work with LB women's voluntary sector organisations to develop support networks or groups for LB women with breast cancer and their carers. This would contribute to the Department of Health's work in the national cancer survivorship initiative.
13. Produce a briefing for LB women with breast cancer to influence policymakers to address the issues affecting LB women with breast cancer.
14. Offer a mentor (or buddy) for LB women, particularly in the early stages of the diagnosis for women with primary breast cancer and ongoing support for women with metastatic breast cancer. Develop support networks for carers of LB women both during recovery and when a woman dies of breast cancer. Cancer organisations and the LB women's voluntary sector may each have a role to play in supporting such networks.

### **Future research**

15. Although this pilot study represents an important first step in identifying breast cancer as a health concern in lesbian and bisexual women's communities, policy makers and service providers often want to see large scale studies before they commit resources to meet need. Large scale research is needed to provide statistical data.



## Appendix 1

### Steering group members

Emma Blows	Breast Cancer Care
Ellen Boyle	Older Lesbian Network
Natasha Burgess	Cancer Research UK
Jackie Foley	Metro Centre, Greenwich, London
Carol Gibbons	User and Involvement Projects Manager, Macmillan
Vanessa Gordon-Dseagu	University College, London
Jane Hatfield	Director of Policy, Breast Cancer Care
Steve Masters	Berkshire Older Lesbian and Gay Forum
Catherine Meads	University of Birmingham
Deidre O'Brien	Women in London/ Older Lesbian Network
Rev. Caroline Redfearn	Metropolitan Community Church
Lindsey River	Age of Diversity/ Polari
Debbie Robertson-Neil	Opening Doors Project, Camden Age Concern
Michail Sanidas	South West Strategic Health Authority
Ruth Turner	London Lesbian & Gay Switchboard

## Appendix 2

### Participant details (anonymised)

#### 1. Lucy - breast cancer services user

Lucy is 28 and had a bilateral mastectomy at the age of 22. She lives in a large city in North-west England. Her mother died of breast cancer when Lucy was 3.

#### 2. Nicky - breast cancer services user

Nicky is aged between 61-70. She lives in a large city in North-west England. She was interviewed with her partner. She had a mastectomy.

#### 3. Toni - breast cancer services user

Toni is aged between 51-60. She lives in a medium sized town in Yorkshire. She lives alone. She had a lumpectomy followed by a mastectomy. She did not have reconstruction

#### 4. Esther - carer

Esther lives in a large city in Northern England. She is aged between 51-60 years. Her partner died of breast cancer in November 2008. She lives alone

#### 5. Christine - breast cancer services user

Christine lives in a market town in Northern England. She had a mastectomy and an elective mastectomy. She is aged between 51-60. She lives with her partner and young son. She did not have reconstruction

#### 6. Mercedes - breast cancer services user

Mercedes lives in a large city in South east England. She is aged 41-50. She has a partner of more than 12 years. She had a mastectomy. English is not her first language. She is European.

#### 7. Naomi - carer

Naomi is 41-50 and lives in a medium sized town in the North west with her son. Her partner died of breast cancer in 2002.

#### 8. Rachel - breast cancer services user

Rachel lives in a small city in South East England. She had a bilateral mastectomy in 2006 and all of the lymph glands removed from her left arm pit, followed by 6 months of chemotherapy and a month of radiotherapy. She is a bisexual woman and is aged 51-60. She lives with her partner. She is a practising Christian. She did not have reconstruction

#### 9. Fiona - carer

Fiona is working class and aged between 51-60. She lives in a large city in North east England. Her partner died of breast cancer in 2004. She did not have reconstruction.

**10. Ursula - breast cancer services user**

Ursula comes from a large Irish Catholic family. Following her breast cancer diagnosis and treatment, Ursula moved from a Northern town to live in the South-west. She is 51-60. She had a lumpectomy.

**11. Tessa - breast cancer services user**

Tessa lives in a large city in North-west England. She lives alone and has an adult daughter. She is 51-60. She had a lumpectomy.

**12. Yvette - breast cancer services user**

Yvette lives in a city in the Midlands with her partner. She had a lumpectomy. She is aged 41-50.

**13. Irene - breast cancer services user**

Irene lives in a medium sized city in the Midlands. She had a lumpectomy. Lives separately from her partner. She is 61-70.

**14. Sophie - breast cancer services user**

Sophie lives in a large city in South East England. She had a mastectomy. She did not have reconstruction. Lives separately from her partner. She is 41-50.

**15. Tina - breast cancer services user**

Tina lives in a market town in North-west England. She is aged 51-60. She had a lumpectomy followed by a mastectomy. She did not have reconstruction nor did she have a second mastectomy. She does not wear a prosthesis. Lives separately from her partner

**16. Marie - breast cancer services user**

Marie had a mastectomy in October 2009. She was about to start chemotherapy. She lives in the South West with her partner. She is aged 51-60. She does not want reconstruction.

**17. Fran - breast cancer services user**

Fran is aged 51-60 and lives in a large city in the South-east. She had a mastectomy in 2005 and lives with her partner. She did not have reconstruction. She does not wear a prosthesis.

Note: Women were interviewed in the order they appear here.

## References

- All Party Parliamentary Group on Cancer (2009). Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer. Retrieved December 11 2009 from: <http://www.macmillan.org.uk/GetInvolved/APPG/ReportsAndEvents/InquiryIntoInequalityReport2009.aspx>
- Aronson, J. (1998). Lesbians giving and receiving care: Stretching conceptualisations of caring and community. *Women's Studies International Forum*, 21(5), 505–519.
- Boehmer, U., Freund, K. M., & Linde, R. (2005). Support providers of sexual minority women with breast cancer: Who they are and how they impact the breast cancer experience. *Journal of Psychosomatic Research*, 59(5), 307-314.
- British Sociological Association (2002) Statement of ethical practice. Retrieved December 9 2009 from: <http://www.britisoc.co.uk/equality/Statement+Ethical+Practice.htm>
- Campbell, D. (2009) NHS accused of failing breast cancer patients. *The Guardian*, October 2 2009; 4.
- Cancer Research UK (CRUK) (2008) Health inequalities in cancer and lesbian, gay, bisexual and transgender (LGBT) communities. Retrieved November 2 2008 from: [http://info.cancerresearchuk.org/images/pdfs/lgbt\\_policystatement2008](http://info.cancerresearchuk.org/images/pdfs/lgbt_policystatement2008)
- Department of Health. (2007). *Cancer Reform Strategy*. London: DH.
- Falagas, M. E., Zarkadoulia, E. A., Ioannidou, E. N., Peppas, G., Christodoulou, C., & Rafailidis, P. (2007). The effect of psychosocial factors on breast cancer outcome: a systematic review. *Breast Cancer Research*, 9(4), R44.
- Fish, J. (2006). *Heterosexism in Health and Social Care*. Basingstoke: Palgrave.
- Fobair, P., O'Hanlan, K., Koopman, C., Classen, C., Dimiceli, S., Drooker, N., Warner, D., et al. (2001). Comparison of Lesbian and Heterosexual Women's Response to Newly Diagnosed Breast Cancer. *Psycho-Oncology*, 10(1), 40-51.
- Fogg, C. (2000). Breast cancer care: providing practical and emotional support. *European Journal of Cancer*, 9, 136-7.
- General Medical Council (GMC) (2009) Tomorrow's Doctors. Retrieved January 3 2010 from: [http://www.gmc-uk.org/static/documents/content/TomorrowsDoctors\\_2009.pdf](http://www.gmc-uk.org/static/documents/content/TomorrowsDoctors_2009.pdf)
- Heaphy, B., Yip, A., & Thompson, D. (2003). Lesbian, Gay and Bisexual Lives over 50: A report on the project 'The Social and Policy Implications of Non-heterosexual Ageing'. Nottingham Trent University: York House Publications.
- Hunt, R. and Fish, J (2008) Prescription for Change. London: Stonewall. [http://www.stonewall.org.uk/what\\_we\\_do/research\\_and\\_policy/3101.asp](http://www.stonewall.org.uk/what_we_do/research_and_policy/3101.asp)
- Inclusion Project. (2006). Getting it Right: LGBT Research Guidelines, Glasgow: NHS Scotland & Stonewall.
- Lorde, A. (1980) *The Cancer Journals*. San Francisco, CA: Aunt Lute Books.
- Matthews, A., Peterman, A., Delaney, P., Menard, L., & Brandenburg, D. (2002). A Qualitative Exploration of the Experiences of Lesbian and Heterosexual Patients with Breast Cancer. *Oncology Nursing Forum*, 29, 1455-1462.
- Michalec, B. (2005). Exploring the Multidimensional Benefits of Breast Cancer Support Groups. *Journal of Psychosocial Oncology*, 23(2/3), 159-179.
- National Cancer Equality Initiative (NCEI) (2008b) Review of Cancer Inequalities Good Practice Matrix: Papers Presented to the NCEI meeting 16 December 2008. London: Department of Health.
- Valanis, B. G., Bowen, D. J., Bassford, T., Whitlock, E., Charney, P., & Carter, R. (2000). Sexual Orientation and Health: Comparisons in the WHI Sample. *Archives of Family Medicine*, 9 (9), 843-853.
- Williams, B. G., Iredale, R., Brain, K., France, E., Barrett-Lee, P., & Gray, J. (2003). Experiences of men with breast cancer: an exploratory focus group study. *British Journal of Cancer*, 89, 1834 – 1836.