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Well Proud Women



Don't be a mickey mouse about breast screening - do it now!



AUSTRALIAN
LESBIAN
MEDICAL
ASSOCIATION



Lesbian, bisexual and trans inclusive services at BreastScreen Victoria.

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Cover image: submission by LBT community member at Midsumma Carnival

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Introduction

This report outlines a collaboration between BreastScreen Victoria and Gay and Lesbian Health Victoria to enhance the capacity of BreastScreen Victoria to understand and meet the needs of lesbian, bisexual and transgender women. The project received funding from the Australian Lesbian Medical Association/ACON.

The context

Breast cancer is the most common cancer affecting women in Victoria, with more than 3000 women being diagnosed each year. BreastScreen Australia is a population screening program that aims to reduce deaths from breast cancer through early detection of the disease. BreastScreen Australia invites women aged 50-69 to have a free screening mammogram every two years. Whilst current evidence suggests that the benefit of routine screening mammography is greatest in the 50-69 years age group, women in their 40s and over 70 are also eligible for free screening mammograms with BreastScreen Victoria.

BreastScreen Victoria (BSV) is an accredited part of BreastScreen Australia, and is jointly funded by the Victorian and Commonwealth Governments. BSV is made up of two components: the Coordination Unit and regional Screening and Assessment Services. In 2010/2011 BSV performed a total of 207,655 mammograms. This is the highest number of screens in the history of the Program. Yet the participation rate for the state was 53.8% against a national target of 70%. The BSV Board has identified as a priority further improving women's access to and experience of breast screening, to achieve higher participation rates.

BreastScreen Australia's National Accreditation Standards identify four outcomes critical to a high quality program:

1. Maximise participation and ensure equitable access for women.
2. Maximise cancer detection while minimising harm
3. Ensure that services are acceptable and appropriate to the needs of women
4. Ensure services are well managed.

BreastScreen Victoria collects information from the women who attend screening and assessment to monitor performance against these outcomes. However, BSV does not ask women to identify their sexual orientation or gender identity. Consequently, BSV does not know the proportion of lesbian, bisexual or transgender (LBT) women who attend for screening or assessment.

In 2009, the Nurse Counsellor Quality Group at BSV requested training to better understand the needs of LBT women at assessment. The role of Nurse Counsellors is to support women recalled for further assessment after a suspicious mammogram. The assessment visit takes several hours, and may cause considerable anxiety for women. A woman recalled to assessment is encouraged to bring a partner or support person. However, standard practice is for the partner or support person to remain in the waiting room while the woman undergoes her tests.

A number of Nurse Counsellors reported requests from LBT women that their same sex partner be allowed to accompany them throughout their assessment visit. Another issue identified was that staff were unable to provide information about breast cancer risk and screening recommendations to transgender women recalled to assessment. Furthermore, transgender women reported feeling uncomfortable and anxious about disclosing information about their gender identity to staff.

To address some of these issues Gay and Lesbian Health Victoria (GLHV) was approached to deliver a professional development workshop for Nurse Counsellors on the needs of LBT women at assessment. A workshop was attended by nine Nurse Counsellors and received positive feedback from the participants (see photo below).

Figure 1: presentation by Gay and Lesbian Health Victoria



The presentation provided an opportunity for Gay and Lesbian Health Victoria and BreastScreen to explore the potential collaborations. Gay and Lesbian Health Victoria were successful in obtaining a grant from the Australian Lesbian Medical Association/ AIDS Council of New South Wales to work with BSV to become more inclusive of lesbian and bisexual women. The project was later expanded to include trans women.

Breast cancer, screening and lesbians – risk factors

In 2010 Gay and Lesbian Health Victoria commissioned a review of the evidence on lesbians and the risk of breast cancer (Banik, 2009). The review found that certain factors such as advancing age, family history of breast cancer and reproductive health-related risk factors including early onset of menstruation, nulliparity or older age at first childbirth were risk factors for developing breast cancer (AIHW, 2006; Bernhard, 2001; Brandenburg, Matthews, Johnson, & Hughes, 2007; Case et al., 2004; Cochran et al., 2001). Additional life style factors including alcohol consumption, the use of hormonal replacement therapy, decreased physical activity, obesity, were also identified as risk factors (Fish & Anthony, 2005; McTiernan et al., 2001). Although none of these risk factors are exclusive to lesbians, studies have found that the possible concentration of some of these risks among lesbians is unique (Brandenburg et al., 2007; Cochran et al., 2001; Grindel et al., 2006).

Studies have also shown that lesbians are less likely to undergo routine screening procedures, such as mammograms and self breast examinations than their heterosexual counterparts (Boehmer & Case, 2004; Case et al., 2004; DeHart, 2008; Diamant, Wold, Spritzer, & Gelberg, 2000). This has been attributed, in part, to negative experiences with health care practitioners, mistrust of the health care community (DeHart, 2008; Lauver et al., 1999).

UK based research

In the United Kingdom, Fish (2009) conducted a national survey of lesbians and health care. The survey asked 1066 lesbians about patterns of screening and sought qualitative data about explanations for their healthcare behaviour. The participants were asked about their perceptions of risk of breast cancer in relation to heterosexual women. Nearly three-quarters (73%) said: 'lesbians' risk is the same' while only 3% said: 'lesbians' risk is lower'. In addition, 19% of participants said: 'lesbians' risk is higher'. Analysis of the qualitative

survey data reveals that lesbians' believe that their risk factors for breast cancer are the same as those for heterosexual women. They appear to be less likely to be aware of factors which may increase the risk for some lesbians eg: not having children, alcohol consumption, being overweight and reduced participation in breast screening.

The study found that similar proportions of lesbians attend for mammograms (as heterosexual women) but they are less likely to re-attend. Lesbians were much less likely to say that appropriate attitudes and behaviour of health professionals contributed to a good experience of breast screening than heterosexual women (37% vs 69%). The study also conducted focus groups to identify reasons from never having had a mammogram and identified the key reasons were: homophobia, discrimination, cost, lack of social support.

The literature review and the UK study reinforced the value of working with BreastScreen Victoria to further develop LBT inclusive services and promote these services to LBT women.

Breast cancer and bisexual women

The review of the research evidence failed to locate data on the risk factors or screening practices of bisexual women. However, given the health and wellbeing of bisexual women is less than that of their lesbian counterparts (Leonard et al, 2012) the project included bisexual women.

Breast cancer and trans women

No data was identified on breast cancer risk for trans women, though a number of resources were found questioning the effects of hormone use on breast cancer risk. One study was identified that explored the experience of breast examination for trans women. The study by Weyers et al (2010) in Belgium found that that mammography and breast sonography were feasible and almost painless in 50 transsexual women. The study concluded that since breast cancer risk in transsexual women is largely unknown and breast exams are very well accepted, breast screening habits in this population should not differ from those of biological women.

While the project brief was initially limited to lesbian and bisexual women, the consumer consultation phase of the project revealed the importance of addressing the needs of transsexual women. Consequently, the project brief was expanded to focus on LBT women.

About LBT/GLBTI inclusive services

In 2010-2011 Gay and Lesbian Health Victoria (GLHV) developed a program aimed at assisting health and human services organisations develop practices and protocols that are inclusive of gay, lesbian, bisexual, transgender and intersex (GLBTI) clients. The program is called: How² create a GLBTI inclusive service (How²). The How² program was developed following the release of 2008 report: *Well Proud: A guide to GLBTI inclusive practice for health and human services* (Department of Health Victoria). These government guidelines outline the evidence relating to the needs of GLBTI people and present generic recommendations for GLBTI-inclusive practice. Following the release of *Well Proud*, GLHV experienced an increase in enquiries from service providers who were aware of the need for GLBTI-inclusive practice, but were unsure where or how to start. In response to the increasing requests about GLBTI-inclusive services, GLHV developed an audit tool to enable organisations to check their performance against standards for GLBTI-inclusive practice.

The audit was adapted from the Rainbow Tick – a set of national standards developed by GLHV in consultation with the Quality Improvement and Community Services Accreditation. The standards were adapted from the generic recommendations in *Well Proud* to include a series of practical strategies and quality based practice indicators of GLBTI inclusive practice. The six GLBTI inclusive standards are:

1. Access and intake processes
2. Consumer consultation
3. Cultural safety
4. Disclosure and documentation
5. Professional development
6. Organisational capacity

The guiding principle underlying the audit (and the Rainbow Tick Standards) is that GLBTI-inclusive practice requires organisational change; that is, it requires a systemic approach. The systemic approach recognises that professional development is an important component of change, but on its own is not sufficient to sustain change. Professional development needs to be supported by policies, procedures and structures that are endorsed by management.

The How² program involves a series of workshops over a 12 month period to coach participants through the practical steps involved in enhancing GLBTI-inclusive practice in their organisation. The workshops aim to support participants to plan, implement and evaluate changes in their service including:

1. Auditing the service against the Rainbow Tick Standards
2. Consulting consumers
3. Educating colleagues
4. Developing and implementing an action
5. Managing obstacles
6. Evaluating changes.

The project primarily involved Gay and Lesbian Health Victoria providing support to BreastScreen Victoria to participate in the How² program and develop more inclusive services.

Project aim

The aim of the project was to support the development of LBT inclusive services at BSV. To achieve this BSV sought to:

1. Increase BSV's understanding of LBT women's knowledge of breast cancer and screening and their participation and experiences in the Program.
2. Build strong relationships and partnerships with GLBTI organisations and communities
3. Provide services that better meet the cultural values and needs of LBT women.
4. Increase awareness within BSV services of the needs of LBT women.
5. Provide information and advice to LBT women on breast health, breast cancer and screening.
6. Increase awareness of and participation in breast cancer screening by LBT women.

The project was implemented between 2010 and 2012 with ongoing collaborations and service development expected. This report outlines the processes that were involved, the actions taken and the outcomes achieved, after outlining the role and function of BreastScreen Victoria.

Project process

The project coordinator was the Public Relations officer in the Communications Unit of BSV with a particular responsibility for communicating with the LBT community. The project coordinator has reported directly to the

CEO. However, in 2012 a project advisory group has been established to identify the most appropriate strategies for improvements.

Ethics approval for the project was obtained by Gay and Lesbian Health Victoria through the La Trobe University Human Research Ethics Committee.

Needs analysis

A needs analysis was undertaken through a survey of LBT women and through community consultation. The survey was developed in consultation with GLHV, community groups and experts in lesbian health. The aim of the survey was to understand what LBT women over the age of 40 years understood about their risk of breast cancer, what their screening patterns were and what they knew of BSV. The survey was distributed by BSV. Due to a delay in ethics approval for the project, the survey did not make reference to Gay and Lesbian Health Victoria. The survey included the following questions:

1. What age group are you in?
2. Would you describe where you live as being? (list provided)
3. Do you speak a language other than English at home?
4. How would you describe your sexual orientation?
5. How would you describe your gender identity?
6. What do you think the risk factors for breast cancer are? (list provided)
7. When did you last have a mammogram?
8. If you have had a mammogram, which of the following best describes the reason you had your most recent mammogram (routine screening, family history or diagnostic).
9. If you have had a mammogram, which best describes the type of service you used last time? (BSV, doctor's referral or private screening).
10. If you have had a mammogram, where did you go for your most recent mammogram? (list provided)
11. How likely is it that you will have a mammogram in the future?
12. How do you see lesbian's risk of breast cancer (relative to that of straight women)?
13. How do you see transgender women's risk of breast cancer (relative to that of other women)?
14. How do you see bisexual women's risk of breast cancer (relative to that of straight women)?
15. Where do you access information about breast cancer and breast screening? (list provided)
16. What do you think BreastScreen Victoria could do to be more inclusive of lesbian, bisexual and transgender women?
17. Would you like to make any comments?

The survey was uploaded to survey monkey and promoted through JOY FM (Gay and Lesbian radio) and through the GLBTI press. Hard copies of the survey were also distributed at Midsumma Carnival (an annual GLBTI Festival in Melbourne). The survey was completed by 105 women. Forty-eight percent of the respondents were in the BSV target age group of 50-69 years and identified as lesbian (79%) and female (93%) with a smaller number identifying as transgender females (4%) or gender queer (2%). The key aim of the survey was to identify what LBT women knew about risk factors and seek their suggestions for the development of services at BSV.

In response to the question about breast cancer risk factors, most women (94%) identified family history – which is actually only a minor risk factor. Only 51% identified increasing age as a risk factor - though this is the

most significantly risk factor. Other surprises included incorrect perceptions that the following were risk factors: smoking (51%) and knock or bump to the breast (26%). The risk factors and responses are shown in table one below – with items highlighted in yellow being factors that are not a risk.

Table 1: LBT women's knowledge about risk factors

Answer Options	Response Percent
A family history of breast cancer	94%
Hormone replacement therapy (HRT)	55%
Smoking cigarettes	51%
Increasing age	51%
Being overweight or obese	35%
Not having given birth to children	29%
Getting a knock or a bump to the breast	26%
Breast implants	20%
Excess alcohol consumption	16%
Using antiperspirants or deodorants	9%
Other	4%
Having large breasts	1%
Having an abortion	0%

Half (51%) of the women surveyed had had a mammogram in the past 2.5 years – a figure similar to the state average and 37% of women said that they had never had a mammogram. Most women (>90%) thought that lesbians and bisexual women had the same level of risk of breast cancer as heterosexual women. There were a range of views on the relative risk for transgender women, with 26% of respondents saying that transgender women are at lower risk of breast cancer than other women. The four transgender women who completed the survey rated their risk as the same as other women, but expressed some uncertainty about this.

The woman's doctor was the most common source of information on breast cancer and screening, followed by articles in newspapers or magazines. These results are similar to recent surveys of straight women. The main barriers women identified to attending BreastScreen were staff ignorance of LBT women's needs, or failing to provide a welcoming and LBT inclusive service. These barriers were seen as greater for transgender women. The most frequent suggestions for services improvement were advertising in GLBTI media, staff education, and more inclusive signage at BreastScreen clinics.

Strategies to meet the GLBTI inclusive practice standards

Over a two year period BSV worked with Gay and Lesbian Health Victoria to meet the standards for GLBTI inclusive practice described earlier in this report. The achievements are outlined in the following section.

Standard 1: access and intake processes

BSV Information Officers have provided posters welcoming LBT women in all fixed screening clinics. In 2012 BSV plan to develop a fact sheet for lesbians and bisexual women on breast cancer risk and screening, as well as information for trans people about breast screen. These resources will be available on the BSV website and

in print. BSV also hope to include testimonials on their website from LBT women who attend screening and/or were diagnosed in the program.

A training session was held in 2009 for Nurse Counsellors on the needs of LBT women at assessment. As described in standard four and six, BSV will continue working on organisational systems to ensure that access and intake processes are LBT inclusive.

BSV has undertaken a number of activities to promote its services to the LBT women. This has included a 12 week radio campaign on JOY FM that began in Breast Cancer Awareness month in 2010. The campaign included an interview with BSV's CEO and promoted the participation of BSV in the Midsumma Carnival day in 2011 (see standard 2). In 2012, BSV sponsored a film about a lesbian's experience of breast cancer at the Melbourne Queer Film Festival. BSV will continue their sponsorship of the MQFF and other relevant events to increase awareness of breast cancer risk and screening in the GLBTI community.

Standard 2: consumer consultation

The major achievement to date has been the development of an online survey of LBT women. Other strategies have included participating in a stall at Midsumma Carnival, a Lesbians and Breast Cancer Forum as well as a Forum on underscreened women.

Participation in Midsumma involved having a stall, established to provide information about BSV services, to seek feedback from women about what BSV needed to do to be more inclusive, and to encourage women to complete the survey. As shown in Figure 2 below – the stall provided paper and arts materials and invited Carnival participants to write, draw or paint a message to BSV or a message about LBT women and breast cancer.

Figure 2: BSV at Midsumma Carnival



A common response from LBT women as they walked past and saw the stall was: *Ooh!* This response was discussed with one participant who reported that the stall reminded her that she needed to have a mammogram but had been '*putting it off*' because she '*didn't want to know.*'

Feedback from women at Midsumma

In all 34 responses were recorded from LBT women at Carnival – most were written feedback and three were images. These responses were coded into eight categories that included: gratitude, age, cost, pain, equity, difference, the role of GPs, and messages to peers. Examples of these codes and the art work developed by women are presented in the following section.

Gratitude

Many participants took the opportunity to question BSV about the cost, procedure and their own risk factors. This was particularly the case with a number of trans women. In addition, a number of transmen enquired about their risk of breast cancer, post transition. Generally, people expressed gratitude that BSV had made the effort to be there and noted:

1. *I think it's good that you are here.*
2. *They [BSV] do a good job.*

3. *I am really glad you are here.*
4. *Keep up the great work*

Age, cost and pain

Several participants made comment about the cost of mammograms. One woman reported that she had an annual mammogram in a private clinic and that it cost her \$600, another reported that she didn't realise that BSV was a free service. The issue of cost was also raised by an older woman who reported: *Women have to pay for BreastScreen after 70 years. I think that is ridiculous!* The issue of age was also raised with one participant who noted that women over the age of 70 don't get reminders for breast screen, but felt they should. Another participant who asked that the efforts to be LBT inclusive would also encompass younger women: *Please promote breast health awareness to younger lesbians.*

One participant noted that pain was a barrier to regular mammograms. The participant reported: *I've had lots of those (breast screens)—not at BreastScreen Victoria. And it hurts a lot because my breasts are small.* This provided the opportunity to discuss how to reduce pain and outline strategies utilised at BSV to minimise pain and discomfort to women.

We have equality – inclusive practice is not an issue

One of the surprising themes in the responses was from four women who reported they didn't see the need for the project. Some felt that recent CentreLink changes (recognising same sex relationships) meant that services would not discriminate against LBT women. Others agreed:

1. *Now with Centrelink they have to accept same sex couples. If they don't 'girl' will they hear about it.*
2. *I think women are smart enough to use the services. It's not necessarily an issue for lesbians.*
3. *Homophobia is not an issue in health services- it just needs to be addressed when/where it occurs.*
4. *I have never felt excluded.*

While BSV has not received a report of homophobia or transphobia from a client, one of the aims of the project was to make LBT women more aware that the service was inclusive - to encourage participation.

A breast is a breast – no difference

Similarly, three participants reported that they didn't see a particular need for LBT women to have breast screen because they didn't believe that there was a difference in risk. These women also felt that LBT women would not feel that they were unwelcome because of their sexual orientation or gender identity. For example, one participant wrote: *I'd never thought about lesbians having more risk, or not feeling not as welcome.* Another asked whether it was true that lesbians had a higher risk of breast cancer, reporting that she had 'heard something about the link' on JOY FM. Finally, another participant highlighted the belief that there was no difference stating: *For me it's not different—a breast is a breast is a breast.*

The role of GPs

Three lesbians reported misconceptions that lesbians do not require pap smears or mammograms. One participant reported: *I have friends who think they don't have to have a pap smear because they are lesbian. It's the same with breast cancer.* One participant reported that this misconception had come from her GP and said: *GPs need to be proactive and informed- my GP didn't think I needed a pap smear.* Another reported similarly: *I was told that as a lesbian I don't need a pap smear. There's ignorance I guess it is the same for*

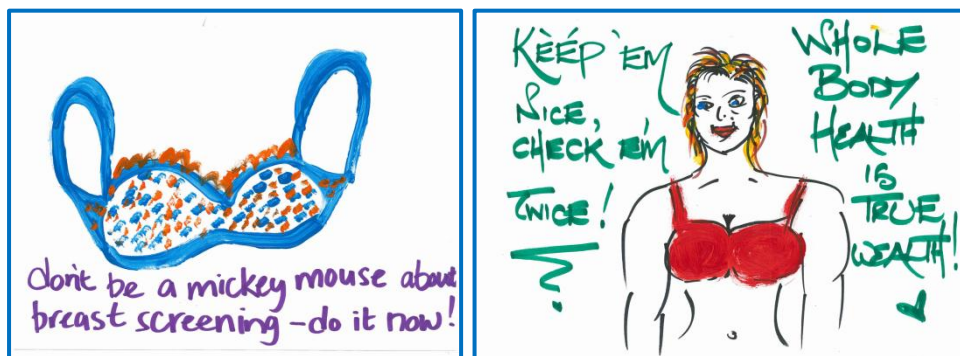
breast screen. These findings are significant given that most women reported that GPs are an important source of information about breast screen. One participant suggested that to increase awareness of the importance of mammograms for LBT women that BSV could distribute posters in: *queer friendly clinics eg Northside, VAC, Prahran Market clinic targeting lesbians*.

Messages to peers - Just do it

Ten of the women that approached the BSV stall developed messages for other LBT women about the importance of breast screen. The messages are listed below and Figure three shows two of the images developed:

1. *Just do it – get screened*
2. *Lesbians should be better at this than any other group – checking each other’s breasts*
3. *Don’t be complacent*
4. *If you like boobs–look after your own–get screened*
5. *It’s important that queer women do this definitely.*
6. *We still have the same organs–we need to be screened.*
7. *We both check our breasts.*
8. *Breast is best.*
9. *Keep em nice, check em twice – whole body health is true health*
10. *Don’t be a mickey mouse about breast screen – do it now.*

Figure 3: messages from LBT women to their peers

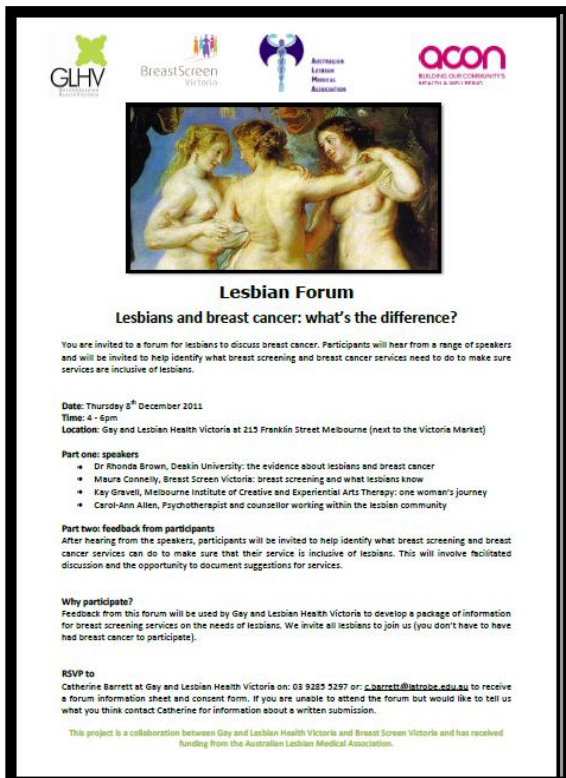


In the year after Midsumma Carnival, BSV participated in a Lesbians and Breast Cancer Forum facilitated by Gay and Lesbian Health Victoria (see figure four, following page).

Lesbians and breast cancer forum

A Forum on lesbians and breast cancer was facilitated in December 2011. The Forum included presentations by a researcher on the rates of breast cancer in lesbians, stories from two lesbians with breast cancer and a presentation on this project by BSV. The Forum, entitled: *Lesbians and Breast Cancer, What’s the Difference?* (see figure 4) was widely promoted and attended by eight women. While the numbers were small, a number of valuable suggestions were made to assist BSV develop GLBTI inclusive services. In addition, the promotion of the forum in the GLBTI community provided another opportunity for BSV to demonstrate its commitment to LBT inclusive services.

Figure 4: flyer for the lesbians and breast cancer forum



The women attending the Forum were provided with an information sheet and consent form. A small number of notes were made by the project coordinator – however, the key focus was the exchange of information. A key outcome from the Forum was a general consensus that the group appreciated the efforts of BSV to be LBT inclusive and supported the work undertaken to date. A particular strategy suggested by the group was to ensure that the project did not contribute to minority stress of LBT women by making frightening claims about the links to breast cancer. The group suggested that BSV needed to find positive ways of engaging LBT women and reaffirmed that the participation in Melbourne Queer Film Festival and at Midsumma Carnival were effective ways of doing this. The group suggested that attendance at the Forum may have been increased if more positive ways of engaging LBT women had been utilised.

Women who were unable to attend the Forum were invited to develop a written submission to share their experiences of breast cancer and make suggestions

for the development of LBT inclusive services at BSV. The written submissions were widely publicised, but again the response was small. Three women requested written submission packs and only one woman completed a written submission. One participant provided feedback that she was enthusiastic about participating but found it emotionally difficult to reflect on her experience of breast cancer. The written submission received did not relate directly to BSV services. The lesbian who wrote the submission reported wanting to share her insights to encourage all screening and cancer services to be inclusive. The written submission is provided as an attachment (see page 00) and key insights are outlined in the following section

Written submission

The story received by Katy (not her real name) outlined her experience of breast cancer and a mastectomy. While Katy's experience didn't relate directly to breast screening services it provides valuable insights into how an inclusive service can be developed. Katy describes feeling that, as a lesbian, her sexuality was dismissed in a booklet provided by a breast cancer service. She noted that the booklet's 'lesbian' heading was smaller than the remainder of headings in the booklet and the information provided was dismissive and unhelpful. As a result Katy reported feeling isolated and invisible. Katy speculated that the information had not been developed in consultation with lesbians and as a result it was not helpful.

Katy also noted that the breast cancer service was not supportive of her and her female partner. She felt that the service did not understand how to provide support to a female partner – nor what the difference might be to a woman being supported by a male partner. Katy felt that the role of the breast care nurses was pivotal and that education should target them to provide support. She also felt that there was an opportunity to provide support for lesbians to make life style changes to reduce their risks of breast cancer as well as understanding lesbian culture and developing culturally appropriate campaigns to assist lesbians to examine their breasts and identify changes.

The insights provided by Katy reiterate the value of BSV's approach to consult the LBT community about strategies to be inclusive.

BSV Stakeholder Forum at BreastScreen Victoria – for under screened women

A further opportunity to explore the needs of LBT women came through a Forum held by BSV. The Forum was conducted in 2012 to explore women's first screening experience, and what BSV can do to encourage more women to return to screening. The Forum included a range of diverse groups and an invitation was extended to Gay and Lesbian Health Victoria to attend to represent the needs of LBT women. The Forum resulted in putting these needs on the agenda.

Standard 3: cultural safety

The 2009 training session for Nurse Counsellors was provided to increase their understanding of the cultural values and norms needs of LBT women at assessment, and how these may differ from our standards assessment processes. The establishment of a working party – with a range of experts aims to further identify how BSV can ensure the cultural safety of LBT women attending breast screen.

Standard 4: disclosure and documentation

BSV does not ask women for information about their sexual orientation or gender identity. However, women recalled to assessment are invited to bring their partner or a support person with them. Women who bring a same sex partner with them are likely to be identified as lesbian or bisexual. In addition, trans women who are recalled for assessment may be asked to provide additional information relevant to their breast cancer eg: the use of hormone therapy or the presence of breast surgery or implants. In these cases women are likely to disclose that they are trans.

Consequently, while BSV does not directly ask about sexual orientation or gender identity it is likely that this information will be revealed for women who are recalled for assessment. Given being recalled is a particularly stressful time (women often think this means they have cancer) it is important that disclosures about sexual orientation or gender identity are responded to in affirmative and valuing ways at this time.

The client registration form and assessment consent forms includes information about the confidentiality of women's personal information, and how we use this information for quality improvement. In addition, future professional development planned will help to ensure staff understand how to respond to disclosure. Furthermore, information and posters in clinic waiting rooms, particularly assessment centres will assist in sending the message to LBT women that diversity is valued.

Standard 5: professional development

The training that was initially provided by Gay and Lesbian Health Victoria was very well received by the Nurse counselors. On-going training for Nurse Counsellors and other assessment centre and screening clinic staff will be needed to ensure that service provision is respectful of the values and norms of LBT women. This training will be developed and delivered in collaboration with GLHV, Transgender Victoria and other relevant GLBTI organisations and will be informed by an advisory group described in the next standard.

Standard 6: organisational capacity

The work undertaken by BSV to date has been to explore the needs of LBT women and has been coordinated by the Public Relations officer in the Communications Unit of BSV. Discussions about the progress of the project have identified the opportunity to identify a Nurse Counsellor position with responsibility for staff training on LBT inclusive practice. In addition BSV will establish an expert advisory group to guide further

develop the capacity to provide LBT inclusive services. Individuals and groups have been approached and the group will include:

1. A representative of BSV's Research Committee
2. A representative from Gay and Lesbian Health Victoria
3. A representative from Transgender Victoria
4. Representation from the Zoe Belle Gender Centre
5. The Senior Policy Advisor on GLBTI Health & Wellbeing at the Department of Health, Victoria
6. A researcher in epidemiology of lesbians and cancer
7. A GP with expertise in lesbian health
8. BSV operational and communication staff

The advisory group has been asked to consider a number of activities, including providing advice on the education of staff to ensure LBT inclusive services. The group will also assist BSV to explore the feasibility of identifying a BSV service that can be promoted as LBT inclusive. The initial focus on developing one particular service could assist BSV to understand how to further develop other services. The advisory group will also assist BSV to develop information for LBT women on breast screen. The information for lesbian and bisexual women would aim to encourage them to have regular mammograms. The information for trans people will outline cancer risk and provide screening information. The group would also assist BSV to develop a policy on transgender eligibility for breast screening.

Outcomes

The first aim of the project was to increase BSV's understanding of LBT women's knowledge of breast cancer and screening and their participation and experiences in the Program. The 2010/11 on-line survey provided some information on LBT women's knowledge of breast cancer risk and screening and their participation in screening. While the sample size of women surveyed was small (105 women), results for questions on cancer risk factors and screening history were similar to larger surveys of Victorian women conducted by BSV. In particular almost half the women did not consider age as a risk factor for breast cancer and only just over half were regularly attending screening.

There is a challenge for BSV to identify ways of proactively seeking feedback from LBT women about their screening experience and attitudes, given that we do not routinely collect any identifying information from women.

The second project aim was to build strong relationships and partnerships with GLBTI organisations and communities. There has been progress on this with a strong relationship with GLHV. The formation of an advisory committee in 2012 will expand and strengthen these relationships.

The third project aim was to provide services that better meet the cultural values and needs of LBT women. This process has begun, with the education of nurse counsellors – which also assisted us to meet our aim of raising awareness within our services of the needs of LBT women. The establishment of an advisory group and a LBT specific service will be significant steps towards meeting this aim.

The aim of providing information and advice to LBT women on breast health, breast cancer and screening was achieved, in part, through our attendance at Midsumma Carnival and will be advanced further through the

development of resources for LBT women. A key strategy for moving forward with all these aims is the establishment of the advisory group.

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Attachment 1: Written submission

I had been having mammograms since I was 40 because my sister died of breast cancer when she was 33. I lived in the country and was having them at the local country hospital. There was only one radiographer and I found him to be very insensitive. It was an incredibly painful experience, one time I nearly fainted with the pain. Now that I have had lots of people give me lots and lots of mammograms, I realise he was very unskilled in the way he did it. He was the general radiographer for the local area, so he didn't have any special expertise in reading breast mammograms. He would do the x-rays after footy, ankles, arms, everything. Being in the country there is that real disadvantage in that you don't get specialised services. He had done an x-ray for my daughter when she had a fractured cheekbone; she was 18 months old and was screaming and terrified and he yelled at her. It was a terrible experience my daughter was screaming, I was in tears and he was just saying through gritted teeth – just hold her down so she's still for God's sake! I had to go and confront him for a breast screen every year – it was horrible.

Then I had non lactating mastitis. And so I went to a major metro public hospital and saw a surgeon and had a mammogram every year. The radiographer was really good but I saw a different surgeon every year. The challenge wasn't about being a lesbian; it was about being a public patient. You would walk in and see a different surgeon every time and they would open your file for the first time. I had an operation and they found a papilloma and hyperphasic cells. This old male surgeon told me I needed another operation and he would need to remove my nipple, but that would be 'alright'. He spoke as if I was getting my big toe nail removed not my nipple! I was booked in for surgery but I was bumped and I then thought maybe I don't have to have surgery and so went back to a surgeon I had previously seen in the private system. In one of my annual breast screens and scans they picked up a lesion. I had a biopsy and that started my whole journey.

They told me I had DCIS and gave me a booklet. The booklet is about understanding ductal carcinoma insitu. The breast cancer nurse gave it to me. It felt like when I got my period and I was so terrified because when I got my period I started bleeding and I didn't know what it was about and my mother just gave me a book and said: read this. I had to read this book about periods. I realise that was what this felt like. It was like: now you have got cancer, just go away and read this book. It felt like the nurse was saying this is too big and hard to talk to you face to face. It was like for her: it's all a bit too scary and I don't know how to do it so take this away and read it in the privacy of your own home. It was like: it's your problem, in a way, it's your responsibility.

The booklet has these little graphs about how successful treatments are. The graphs include smiley faces for people that lived and sad faces for people that didn't live. How amazing that they used happy faces and sad faces to represent life and death. There is nothing subtle about it. Here I am in the medical system where there is a smiley face if you are alive and a sad face if you are dead. There it is – move on.

The booklet includes section 11 about – your feelings: *coping and support, dealing with difficult feelings you might feel you are being treated as a medical problem, rather than as a woman with a medical problem. Depression and anxiety – impact on your sexuality.* Then in really small print, a tiny heading that says: for lesbian women that says:

You might feel a lot of attention is placed on heterosexual couples and that lesbian sexuality isn't mentioned when the effect of the diagnosis on sexuality isn't mentioned when the effect of the diagnosis on sexuality is discussed. Some partners feel excluded, or even discriminated against. Whether you tell your treatment team about your sexuality is up to you. However, if you feel comfortable with your team telling them could help you feel more supported. If you don't feel comfortable with your treatment team you might decide you prefer to see a different doctor or health profession. You might find you get a lot of support from your partner, family, friends or other groups you are involved in. If you would like to find out about support services specifically for lesbian women contact your local women's health centre or the cancer help line. (National Breast Cancer Centre, Ductal Carcinoma in situ: Understanding your diagnosis and treatment, 2004, reprinted 2006 National Breast Cancer Centre, Camperdown.)

There is no responsibility on the treatment team to actually be responsive to you. You just have to keep searching around till you find someone who is going to be accepting of your lesbian sexuality. They don't even

give a lesbian help line. They give a cancer help line - but you are feeling that you have been discriminated against and you have to ring the cancer help line which I am sure is not going to be helpful.

As a lesbian woman sitting at home reading this I just thought, well this is not very supportive. If I didn't have my support networks I would have felt totally isolated. There was nowhere that provides helpful information about where you could go. There is not even information about the Gay and Lesbian Switchboard or something that might be supportive. It felt like a bit of a post script. It was like they had thought:

We need to put something in and we don't know what to put in. You are all a bit too hard, we'll put you in, but it's all a bit too hard - so it's up to you all to sort out. Obviously somewhere there are a few of lesbians so we need to raise that, but we are not going to give you anything useful.

You know you are already in a state of shock and this doesn't feel helpful. It doesn't feel like they have asked any lesbians what might be useful to have in there. Even if they had asked one lesbian I am sure they would produced something that was more useful before they printed hundreds and hundreds of the booklets.

My partner came to the MRI and the next appointment with me. They explained the surgery. I had it at a catholic hospital and someone came around asking if I wanted them to pray for me, which was a bit off putting when you were about to go into surgery. And there was this big Jesus cross on the wall. I felt that they were fairly accepting of my partner, they treated her as if she were a supportive friend, but not really like a partner who was freaked out thinking that I might die!

My partner didn't get any support at all to assist her with her experience. I feel that being a female partner of a woman with breast cancer is different to being a male partner. You have the same physiology. So the idea of getting your breast cut off is far more real. It's a different level of empathy. It's a more powerful experience. Not only is that not acknowledged but there is not really any support – most of the support is about how you can support your male partner. On the breast cancer network association website there is a page for partners written by men for men and there is not that recognition that there are female partners.

I think because I ended up having three operations each time there was more anxiety. I think in a way it was harder on my partner than it was for me. She would have to go for a walk around the block and worry about whether I was going to pull through. There was no offer of support. Apart from what I could offer her there wasn't anywhere where she felt she could get support. We didn't know how to access that support.

Maybe in the public system the breast care nurses would be the one to offer support. In the private system the breast care nurse was very 'hockey sticks', how are we today, are we good? Very old fashioned, I couldn't imagine talking to her about my sexuality. I couldn't imagine her being sensitive to the different needs a female partner might have. My surgeon was sensitive, but she was too busy, she just came and did the procedure. The breast care nurses are the ones before and after that you have the time with. They are the ones you need to educate. They could ask if your partner needs support and provide information on where to go.

A good service should be inclusive of everyone. A good service should be sensitive and responsive to the individual context. In some ways it might be easier for a woman to bring her female partner to a breast screen place than a male partner. It's more about being sensitive to the individual situation.

For me it's around, the thing I really felt was that a lesbian partner potentially feels it more strongly than a male partner and there is no support that assists female partners. There are lots of online opportunities for support but I haven't seen any that could provide support for lesbians, particularly for lesbian partners supporting other lesbian partners. I think it would be really useful to have something like that

I have dilemmas about screening. There is no evidence about whether you die with DCIS. There are some real advantages living your life without interventions, without the dangers of x-rays. There should be support for breast screen but there also needs to be support for making lifestyle changes to reduce risk that might be more useful and cheaper. In the lesbian community there are women who have a complex relationships with their breasts. Some lesbian women don't feel comfortable in their female body, they don't want to have breasts, and may feel quite disassociated from them. For these woman it is very confronting to have breast screening so they may avoid it. On the other hand there are a lots of lesbians, like me, who love breasts and love other women's breasts. There is a whole opportunity to educate women on how to examine breasts and

reduce breast cancer. There could be a really effective health promotion program designed around the humour of encouraging lesbians to examine each others breasts.

Educating breast care nurses, where most people go is really important. Also most people get information on line and if there was good information online that would be really useful. Knowing where the resources are. It would be good if Breast Screen Victoria had a booklet for lesbian women that had the right information in it. Breast care nurses don't need to have all the answers, just knowing where to refer people to.

One of the biggest things for me in terms of having breast cancer was that as a lesbian I felt invisible. There wasn't stuff that was saying: look as a lesbian this is information that you might want to know. There might be something for young women or women from CALD backgrounds but I haven't come across anything for lesbian women. I think in the last year the Breast Cancer Network of Australia have put something on their website, which is good. Before that there was nothing. It feels quite isolating. I think the issues are more about being a female than being a lesbian – but there is a part of my reality and experience that is not reflected in the information about breast cancer; that is not acknowledged or reflected anywhere else.

There are differences.

All the stuff around breast cancer is all the pink stuff. It's the very antipathy of lesbian culture. Not only is lesbian stuff not recognised but the stuff that is there is so other extreme, so Stepford wives, pretty female pink. Where is my experience reflected? Where does my experience sit? It doesn't really.