# BreastScreen Victoria

# Developing trans and gender diverse services at BreastScreen Victoria

**MARCH 2019** 

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MARCH 2019

#### For more information

For more information about BreastScreen Victoria and LGBTI inclusive service go to: https://www.breastscreen.org.au/get-involved/in-your-community/lgbti-people/

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BreastScreen Victoria would especially like to thank the community forum participants, some of whom appear in the photos in this report.

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BreastScreen Victoria acknowledges the traditional custodians of the land on which our program takes place and pays respect to Elders past and present.

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# FOREWORD



The ways in which people express identity and belonging are incredibly diverse. The Victorian Government values and celebrates diversity. It affirms the right to equality, fairness and decency and is committed to removing discrimination from Victorian laws, services and society. BreastScreen Victoria wholeheartedly supports this commitment. We are committed to undertaking this journey to make BreastScreen Victoria more LGBTI inclusive, both for the people using our services and our staff.

A recently published report '<u>Out at Work</u>' shows that acceptance alone is not enough unless actions to affirm and include LGBTI people are in place. As this report shows, partnering with trans and gender diverse (TGD) people is crucial to our understanding of how to make our service safe and accessible.

In 2019, the Breast Screen Coordination Unit is aiming to be the first BreastScreen location in Victoria and in Australia to be accredited with the Rainbow Tick.

BSV hopes this report sends a message of welcome to all TGD people and demonstrates our commitment to understanding the needs of TGD people and providing inclusive services.

While this report sheds light on some of the barriers perceived by TGD people in accessing screening, more importantly it reminds us that building an inclusive service is an ongoing commitment and requires a willingness to engage and take genuine and bold leadership on LGBTI issues.

#### Vicki Pridmore

Chief Executive Officer, BreastScreen Victoria



BreastScreen Victoria has been doing amazing work with TGD people across Victoria. They haven't done anything incredibly significant – other than consult with TGD people. That is something that any health service provider could do. I would encourage other health service providers to have a look at what BreastScreen Victoria have been doing. They are making their services inclusive for TGD people and that's what we want. We don't want special treatment – we just want inclusive services – and we know that health services need to look at their LGBTI intake processes and make sure they are inclusive and affirming of TGD people.

Congratulations to BreastScreen Victoria on the launch of this TGD community consultation report and all the hard work that you have done to ensure your services are TGD inclusive. Congratulations also to Transgender Victoria on partnering with BreastScreen Victoria on this important work – we know that this is an issue that people in our community need to address.

#### **Ro Allen**

Commissioner for Gender and Sexuality

# **INTRODUCTION**

BreastScreen Victoria is part of BreastScreen Australia, the national breast cancer screening program, inviting women aged 50–74 to have free breast screens every two years. About 4,200 Victorians are diagnosed with breast cancer each year. BreastScreen Victoria aims to reduce deaths from breast cancer through early detection of the disease.

BreastScreen Victoria is committed to providing equitable access to all eligible Victorians, including trans and gender diverse (TGD) people. Groups that participate in screening and cancer prevention programs at lower rates than the rest of the Victorian population are at higher risk of latestage cancer diagnosis and have poorer survival outcomes.

There is limited evidence on both breast cancer risk and suitable screening for TGD people. Consequently, BreastScreen Australia had no guidelines or eligibility policy for screening TGD people. However, we know that hormone treatment may increase breast cancer risk.

In 2015, BreastScreen Victoria established an LGBTI Advisory Group to guide the development of accessible and inclusive services for LGBTI people. The development of LGBTI inclusive services is also consistent with the Victorian Government's <u>Rainbow eQuality guide</u>, that requires that all Government funded services are inclusive of lesbian, gay, bisexual, trans, gender diverse and intersex clients.

In 2017, BreastScreen Victoria began working towards Rainbow Tick accreditation as an LGBTI inclusive service. That same year, members of our LGBTI Advisory Group identified the need to focus specifically on the development of TGD inclusive services. In particular, the Advisory Group critiqued progress to date and noted that the focus had primarily been on lesbian and bisexual women. The Advisory Group suggested there were gaps relating to TGD inclusive services at BreastScreen Victoria – and little guiding information at national and international levels. As BreastScreen Victoria does not ask clients about their gender identity or sexual orientation, so there is no information available about the number of TGD people accessing BreastScreen Victoria services. However, in 2017, BreastScreen Victoria's annual consumer survey included, for the first time, a question about gender identity– and three respondents identified as TGD. The 2018 survey found that 0.03% of the 11,423 respondents identified as transgender, and a further 0.01% as gender diverse/non-binary.

BreastScreen Victoria radiographers reported they were screening TGD clients and felt ill-equipped to answer queries. In particular, the radiographers wanted information for TGD people on their breast cancer risk and recommended screening regime to inform their screening decisions – and they wanted an internal policy and education. It was also noted that the Victorian Government recommended screening for TGD people in their online Rainbow eQuality guide – <u>Health of trans and gender</u> <u>diverse people</u>, however more detail is needed around eligibility.

To address these gaps, BreastScreen Victoria engaged a consultant, Dr Catherine Barrett, to work with BreastScreen Victoria and TGD Victorians to develop a policy on screening eligibility for TGD people, and information about breast cancer risk and screening options.

This community report aims to assist in communicating BreastScreen Victoria's commitment and progress towards the development of TGD inclusive services for TGD people and staff. We also hope that the report will assist in informing the development of TGD inclusive breast screening services in other states and territories.

# **PROJECT OUTLINE**

The first step involved in the process was to establish a subgroup of the LGBTI Advisory Group–the TGD Expert Advisory Group, including representatives from Transgender Victoria, to provide advice during the project.

The project comprised five key stages, implemented over a 12 month period:

- 1. Developing a TGD policy
- 2. Undertaking a survey of TGD people
- 3. Facilitating a TGD community forum
- 4. Developing an information sheet for TGD people
- 5. Presenting at the 2018 BreastScreen Australia Conference.

Each of these stages is outlined in the following sections.

# STAGE 1: DEVELOPING A TGD POLICY

A TGD policy was considered necessary to provide guidance on screening eligibility. BreastScreen Victoria's Clinical Reference Group and Research Committee reviewed the international evidence. The evidence identified was limited. A number of papers presented case studies and expert opinion. However, two key sources of evidence were referenced:

- 1. The Canadian Cancer Society's (undated) guidelines on breast, cervical and colorectal screening
- Clinical practice guidelines co-sponsored by the American Association of Clinical Endocrinologists, American Society of Andrology, European Society for Pediatric Endocrinology, European Society of Endocrinology, Pediatric Endocrine Society, and World Professional Association for Transgender Health (Hembree et at, 2017).

The evidence suggests that there is some cancer risk for trans people with breasts; particularly if they are aged over 50 years and have taken oestrogen for more than 5 years. Hembree et al (2017) identify the medical risks of hormone therapy for trans individuals and listed breast cancer as a risk for trans women on oestrogen, and for trans men on testosterone. They recommend the following for trans people on testosterone: "Conduct sub- and periareolar annual breast examinations if mastectomy performed. If mastectomy is not performed, then consider mammograms as recommended by the American Cancer Society." (p.3)

The Canadian Cancer Society also recommend breast screening, and this has also been adopted by the Quebec Health Ministry (2017), which recommends screening for trans women aged 50-69 years.

Drawing on the evidence, a policy was drafted that includes: key definitions, legislative context and a series of statements about eligibility that mirror the new information sheet for TGD people. It also notes that TGD people do not have to disclose their gender identity and what will happen if they do. It also notes that staff will be trained to meet the needs of TGD clients.

The TGD policy was considered an important document to inform the development of the information sheet for TGD people and the development of staff training. The policy was also informed by the results of the consultation with TGD community members.

The policy was endorsed by BreastScreen Victoria's Clinical Reference Group, and Radiology Quality Group, and discussed at a Continuing Education Meeting for radiographers.

## STAGE 2: UNDERTAKING A TGD SURVEY

The Expert Advisory Group identified the opportunity to conduct a short survey of TGD people in Victoria to seek feedback on barriers and enablers to TGD inclusive services, particularly from TGD people who would be unable to attend the community forum.

#### **Method**

The survey instrument included:

- demographic questions related to age, location, gender identity and sex
- screening questions that mirrored BreastScreen Victoria's survey of 105 lesbians, bisexual and transgender (LBT) women in 2010. Including the

same questions enabled comparison between responses of TGD participants and the broader LBT cohort on key issues such as: whether they had ever had a mammogram; what they thought their personal risk of breast/chest cancer was; where they find information

 additional questions relating to barriers to TGD inclusive services, and what BreastScreen Victoria could do to be more inclusive.

The survey was uploaded to an online platform and participants were informed that BreastScreen Victoria would use the information to inform policy, staff education and information for TGD people.

The survey was promoted through social media of the project partners including Transgender Victoria over a 6-week period between October and December 2017. The survey results are presented in the following section.

## **Participants**

The survey was completed by 34 trans and gender diverse people. The majority (68%) were aged 40 and over (see Figure 1), and most (76.5%) lived in a metro area.

#### Figure 1. Age



Over half of the participants (59%) identify as trans women or females and 62% reported they were assigned as male at birth (see Figure 2).

#### Figure 2. Gender identity



### Results

Twenty two (67% of the 33 participants who answered this question) had never had a breast screen. Of those 22, eight said they were not sure if they needed to have one. In contrast, the survey of a broader cohort of LBT women in 2010, reported significantly higher levels of participation, with only 35% reporting that they had never had a breast screen, and 2% said they would definitely not have a screen in the next two years.

In response to the invitation to describe their experience of a mammogram, one participant, who identified as a trans man, reported that the experience was distressing:

Once because I had a lump. Horrid experience was misgendered, stared at, felt embarrassed and invalidated. Will never have another one.

While this experience was a diagnostic test (not performed at a BreastScreen Victoria service) there are still important lessons to be learned about the impacts of misgendering and transphobia, including trauma to TGD people and reduced access to health services.

All the 11 participants who had a breast screen and identified as trans women/female or gender diverse/non-binary/gender queer found the procedure acceptable. One participant described a recent mammogram:

In Geelong. First time. Just over a week ago. Pleasant experience. The radiographer was a bit confused so happily explained what she needed to know.

Participants were also asked to estimate their personal risk of developing breast/chest cancer compared to the rest of the population. As shown in Figure 3, over half reported that their risk was either the same or lower than the broader population – and 24% were unsure.

The lack of knowledge is not surprising given there is currently little information for TGD people on breast/chest cancer risk. Other unique factors for TGD people were also acknowledged. As one participant commented:

### I have no idea. I have a poor relationship with my chest as it currently is but can't afford chest surgery.

The lack of information is likely to influence the willingness of TGD people to access BreastScreen Victoria services. TGD people have the right to access information on their personal risk – and make informed decisions about screening. This compares to the 2010 survey of LBT women, where 91% said they thought lesbians had the same level of risk as the rest of the population.

After participants were asked about their risk – they were asked the main sources of information on screening. The key sources of information were doctors (65%) and the Internet (50%) (see Figure 4).

It is not surprising that only 21% of participants accessed data through BreastScreen Victoria, given that, at the time of survey, BreastScreen Victoria had no information



#### Figure 4 Sources of information



for TGD people. Two participants commented that they received letters from BreastScreen and noted opportunities for BreastScreen Victoria to make the information more accessible. For example, one participant commented:

I imagine that if I was TGD (especially masc/ or non binary) I would find the language of most online material pretty unrelatable to my experience, and the whole bright pink, gendered, highly feminised language, look and feel of BreastScreen material fairly unappealing/ potentially even quite triggering.

It is interesting to note the role of the internet in providing information. In the 2010 survey of LBT women, the top two sources of information were doctors (80%) and friends (30%). The internet was only mentioned by 12%, however as this survey was conducted 8 years earlier, this may reflect lower rates of use of websites for health information at that time.

The final questions related to barriers to screening and suggestions for the development of TGD inclusive services. Barriers that were identified by survey participants included: staff ignorance, transphobia, fear of being mis-gendered or having to 'out' themselves, not knowing about screening, embarrassment, fear of the test causing dysphoria/anxiety. A number of participants who identified as trans men or gender diverse reported a major barrier was seeing BreastScreen Victoria as a 'woman's space'. A number of participants commented that they were unaware that BreastScreen Victoria was building TGD inclusive spaces and comments indicated that a default was for service to not be TGD inclusive. As one participant commented, a major barrier is:

The unknown – I didn't know they provided that service [not personally, but] generally that self-doubt–the internal fear of having to "out" to someone else not knowing exactly what will happen when going for the mammogram.

Suggestions to address these barriers included visual cues in clinics (trans flag/rainbow flag/stickers), staff education on inclusive language and service, tailored information and promotional resources for TGD people, education for doctors. One participant commented on the need to:

Provide information about services, how to access and when to start appointments. Also training staff on what language and questions are appropriate and inappropriate.

Other suggestions included separate sessions for trans men or gender diverse people who aren't comfortable attending LGBTI group sessions.

# STAGE 3: FACILITATING A COMMUNITY FORUM

In November 2017, BreastScreen Victoria hosted a community forum at the Rose Clinic for TGD people to discuss the results of the survey and explore further barriers and enablers to TGD inclusive services at BreastScreen Victoria. The forum was chaired by Vicki Pridmore, CEO of BreastScreen Victoria and attended by 15 people including:

- 1. Brenda Appleton, Chair, Transgender Victoria
- 2. Sally Goldner, Treasurer, Transgender Victoria
- 3. Michelle McNamara, Committee Member, Transgender Victoria
- 4. Ro Allen, Victorian Commissioner for Gender and Sexuality
- 5. Dr Ruth McNair, Associate Professor, Department of General Practice, University of Melbourne
- 6. Anne Barton, Program Manager, St Vincent's BreastScreen
- 7. Monique Warrilow, then State Radiographer, BreastScreen Victoria
- 8. Cate Houlihan, Service Delivery Coordinator, BreastScreen Victoria
- 9. Maura Conneely, then Rainbow Tick Project Officer, BreastScreen Victoria.

The 90-minute session began by inviting participants to review the survey results summarised on posters around the clinic walls. CEO Vicki Pridmore then welcomed participants and talked about the commitment of BreastScreen Victoria to be a TGD inclusive service – and the understanding of the importance of 'getting it right'.

In response Dr Ruth McNair and Commissioner Ro Allen commended BreastScreen Victoria on their work to be TGD inclusive and discussed the importance of BreastScreen Victoria recognising that it is easier to be the second service developing TGD inclusive services and policies. Ruth and Ro noted it is not uncommon for pioneering services to worry about getting it right. There is a need to be careful that the fear of 'getting it wrong' does not paralyse services from undertaking this important work. It was agreed that BreastScreen Victoria's concern about getting it right is an indication of their commitment.

Next, participants were invited to brainstorm barriers and strategies to provide more TGD inclusive services. Suggestions were documented as the session progressed and at the end of the session they were fed back and further clarified by participants.

Five key themes were identified from the 37 suggestions made:

Theme	Suggestions
1. Educate BreastScreen Victoria staff	14
2. Send a message of welcome	8
3. Provide information for TGD people	6
4. Use feedback for service improvement	4
5. Influence other states/territories	2

Each of these themes and the related suggestions are outlined in the following section.



## Theme 1: Educate BreastScreen Victoria staff

- It was noted that BreastScreen Victoria has developed an online training module for staff in consultation with the LGBTI advisory group. There is a need for ongoing staff training so that TGD people have positive experiences of BreastScreen Victoria.
- 2. There is a need to educate all staff not just the mammographers (radiographers).
- 3. The evidence base is building; BreastScreen Victoria needs to keep up to date with evidence.
- 4. The College of GPs (RACGP) has endorsed the screening of TGD people. Need to make sure that BreastScreen Victoria staff understand this.
- 5. Identify and support internal LGBTI champions to help work through issues and build TGD inclusive services.
- 6. Develop a Queer employees' network to help educate other BreastScreen Victoria services (beyond the Rose Clinic and Coordination Unit). LGBTI employees have a valuable role to play in identifying the need and opportunities for service improvements.
- Develop a community report outlining the work done by BreastScreen Victoria for 2017 and disseminate to staff in all services to educate them about the importance of being TGD inclusive.
- 8. It is important that BreastScreen Victoria understand the historical mis-gendering of TGD people and how hurtful and harmful this has been.
- 9. It is important that BreastScreen Victoria understand the context of inappropriate questions asked by 'curious' service providers. For example, give TGD people context on why you are asking about HRT and breast implants (i.e. that this question is asked of all consumers because HRT and breast implants impact on breast density/the reading of breast screens).
- 10. Staff need to be educated not to make assumptions about a consumer's gender identity or sex, based on their voice or appearance.
- 11. A good understanding of the evidence is an important basis on which to understand the individual needs of TGD consumers. Service providers should educate themselves; the onus of responsibility should not be placed on TGD people to educate staff. Some TGD consumers are willing to educate service providers but it is not reasonable to ask a TGD person to educate them about something the service provider should already know. We are breaking new ground here–the needs of TGD people in breast screening services are not well documented–however the responsibility is on staff to educate themselves.
- 12. Staff need to understand that reception and contact centre staff are key to a positive experience of screening.



#### Theme 2: Send a message of welcome

- Identify TGD champions of breast screening and chest care who could encourage other TGD people to access TGD inclusive services like BreastScreen Victoria Rose Clinic.
- Develop a community report outlining the work done by BreastScreen Victoria to develop LGBTI inclusive services and disseminate through Transgender Victoria and other TGD networks to demonstrate to TGD people the commitment to inclusive services at BreastScreen Victoria.
- Engage TGD community members to undertake an audit of BreastScreen Victoria's physical and online spaces to determine: if someone who is not a woman comes here – what messages do they get that they are welcome? What are the indicators? Is the language solely focused on 'women' – where are the messages of welcome for TGD people?
- Reception and call centre staff are key to a positive experience; it is important that they don't make assumptions about consumer's gender identity or sex – based on their voice or appearance.
- 5. Display certificates of LGBTI training and invite staff who participate in training the opportunity wear a Rainbow pin.
- 6. Display a Rainbow and Trans Flag.
- Undertake LGBTI focused sessions (Rainbow Rose) and have free space between general screening and the Rainbow Rose sessions so that TGD people don't arrive early and get unwelcome stares from people in the waiting room.
- 8. A message of welcome could be particularly important for those who experience body dysphoria after screening.

### Theme 3: Provide information to TGD people

- It was noted that BreastScreen Victoria has drafted information sheets on breast screening and chest care for TGD people – it was agreed it is important that TGD people are given the information they need so they can make informed choices about breast screening and chest care.
- 2. We need to review the evidence then get the language right then get the word out to get conversations happening about TGD inclusive screening and chest care.
- Information for TGD people needs to identify the context of questions that may be deemed inappropriate e.g. why you are asking about HRT and breast implants – i.e. that you ask this question of all consumers because both impact on breast density/the reading of mammograms.
- 4. Let TGD people know that questions about HRT will be asked by the radiologist rather than by reception or call centre staff, as this will build confidence.
- Given that mammography training is only open to women in Australia – and some TGD people may not want to be screened by a woman – it is important to offer TGD people the opportunity to be accompanied at screening by a person of their choice.
- 6. Include the support by Transgender Victoria in information for TGD people to help build trust.
- Consider having a dedicated staff member (concierge) who is a contact person for information about TGD screening (and LBTI more broadly) and also promote this service as a portal for feedback about TGD inclusivity – what works and what doesn't work.

# Theme 4: Use consumer feedback for service improvement

- 1. One participant shared the story of having to 'out' themselves as gender diverse in a diagnostic service - that was not a BreastScreen Victoria service. The participant reported that reception staff asked, "can I help you sir?" The participant corrected the receptionist who later asked, "is your wife here sir?" The impact of this on the participant, who had heightened emotions as a result of significant symptoms, was "disempowering, traumatic and horrific." It was also noted that the experience was so traumatic the participant did not feel empowered to provide the service with feedback. While this was not a BreastScreen Victoria service – there is a lesson here about the impact of misgendering on TGD people - and the importance of consumer feedback in the development of TGD inclusive services.
- BreastScreen Victoria's consumer satisfaction survey should include questions on sexual orientation, gender identity and intersex status to enable experiences of LBTI people to be identified and appropriate actions taken in response.
- How is information captured when problems arise

   particularly from a person who is disempowered?
   Feedback forms are available at reception in all screening centres – but unlikely to be completed if consumer is feeling disempowered. Consider the IKEA Model of instant feedback. Add an online feedback form inviting LBTI people to provide feedback on LBTI inclusivity.
- 4. Use information gathered from the concierge service to feedback into service improvements.



## Theme 5: Influence other states and territories

- It was noted that BreastScreen services in at least one other state are discouraging TGD people from accessing their services. There is an opportunity for BreastScreen Victoria to share the work they are undertaking, in relation to TGD inclusivity, with other states and territories to educate them about their responsibility to be TGD inclusive – and to help ensure that TGD people have access to this specialist service.
- Develop a community report outlining the work done by BreastScreen Victoria towards LGBTI inclusive services and share with Breast Screening services in other states/territories to build their capacity to become TGD inclusivity. Also share with other LGBTI organisations in other states and territories.

# STAGE 4: DEVELOPING INFORMATION FOR TGD PEOPLE

Drawing on the policy, survey results and community forum, an information sheet for TGD people was developed. The information sheet went through multiple reviews by the TGD expert advisory group, as well as the broader LGBTI Advisory Group.

Following multiple reviews the final version of the document was agreed upon and includes sections on: a message of welcome, information on breast/chest health, risk factors, eligibility, location of BreastScreen Victoria services, questions that are asked at screening, what happens at screening, how to book an appointment and where to go to for more information. See a copy of the information sheet in Attachment 3.

# STAGE 5: PRESENTING AT A NATIONAL SCREENING CONFERENCE

In discussion with BreastScreen services in other states and territories there was considerable interest in learning from the experiences of BreastScreen Victoria and developing more TGD inclusive services. It was also apparent that some services did not understand their responsibilities to provide TGD inclusive services. To address these gaps BreastScreen Victoria elected to present on the work undertaken to develop TGD inclusive services at the BreastScreen Australia's bi-annual conference in 2018.

The Conference is generally attended by hundreds of clinical staff (radiographers, radiologists, surgeons, pathologists, nurses and counsellors) as well as health promotion and education staff and program administrators from all states and territories. The following is an abstract from the paper presented by BreastScreen Victoria's (then) State Radiographer:

Trans and gender diverse (TGD) people have a unique set of factors that may affect their risk of breast cancer. They also face significant levels of discrimination and exclusion and, in general, their mental and physical health is significantly worse than the general population. There is limited evidence to guide BreastScreen services on breast cancer risk and suitable screening for TGD people. Consequently, BreastScreen Australia has no quidelines or eligibility policy for screening TGD people. BreastScreen registration forms do not ask about gender identity; so there is no information about the number of TGD people who are screening.

The sharing of information this way will help build awareness at state and National level of the need to address this gap – and the opportunity to learn from BreastScreen Victoria. In the work to undertake a Rainbow Tick this also addresses the Standard 2 on workforce development which requires that "*The organisation participates in relevant professional associations and other forums aimed at improving the quality of services provided to LGBTI consumers*" (Indicator 2.4).

# RECOMMENDATIONS

In this section, we reflect on the results of the survey and consultation and document recommendations for BreastScreen Victoria to develop more TGD inclusive services.

# ACTION 1: EDUCATION OF BREASTSCREEN VICTORIA STAFF

- Ensure that staff training includes the unique concerns of and issues for TGD people outlined in this report, including: adverse effects of misgendering, impacts of responses from other clients in waiting rooms, historical treatment – contemporary transphobia and the fear of services, the importance of staff selfeducating and not relying on clients to teach.
- 2. Implement the online training module to all staff and ensure that the unique experiences of TGD people are addressed.\*1
- 3. Provide staff education on the information sheet and policy.
- 4. Develop an education module for staff that explores TGD inclusive assessment.
- 5. Review training modules annually.
- 6. Establish a LGBTI employees network to help build and sustain momentum for change.
- 7. Disseminate this community report within BreastScreen Victoria services.

# ACTION 2: SENDING A MESSAGE OF WELCOME

- Identify TGD champions of breast screening and chest care who could encourage other TGD people to access TGD inclusive services like the Rose Clinic at BreastScreen Victoria.
- 2. Disseminate this community report through Transgender Victoria and other TGD networks.
- 3. Establish a webpage for LGBTI inclusivity and include TGD specific information.<sup>2</sup>
- 4. Engage TGD community members to undertake an audit of BreastScreen Victoria's physical and online spaces to determine TGD inclusivity.
- 5. Display certificates of LGBTI training and give staff who participate in training the opportunity to wear a Rainbow pin.
- 6. Display a Rainbow Flag.
- Undertake LGBTI focused sessions (Rainbow Rose) and have free space between general screening and the Rainbow Rose sessions so that TGD people don't arrive early and get unwelcome stares from women in the waiting room.

## ACTION 3: INFORMATION FOR TGD PEOPLE

Incorporate information from this consultation into the information sheet including: context of questions, who will ask questions and include information on choice to be accompanied at screening by a person of their choice.

## **ACTION 4: FEEDBACK FROM CLIENTS**

- Update BreastScreen Victoria consumer satisfaction survey to include questions on sexual orientation, gender identity and intersex status.<sup>3</sup>
- 2. Add online feedback form inviting LGBTI people to provide feedback on LGBTI inclusivity.
- Identify dedicated staff member who is a contact person (concierge) for information about TGD screening (and LGBTI people more broadly) and also promote this service as a portal for feedback about TGD inclusivity – what works and what doesn't work.
- Identify opportunities to work with trans men and gender diverse people to ensure strategies for LGBTI inclusivity are inclusive of these groups.
- 5. Undertake resurvey of TGD community every two years to monitor progress and any issues.

## **ACTION 5: INFLUENCING OTHERS**

- Share these strategies at the BreastScreen Australia national conference in 2018 to influence the development of TGD services in other states and territories.<sup>4</sup>
- 2. Share this report with BreastScreen services in other states/territories to build their capacity to become TGD inclusivity.
- 3. Identify opportunities to education GPs to provide information to their TGD patients.

- 1. This recommended action was implemented in 2018.
- 2. This recommended action was implemented in 2018.
- 3. This recommended action was partly implemented in the 2018 Consumer Satisfaction survey
- 4. This recommended action was implemented in 2018.

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# ATTACHMENTS

# **ATTACHMENT 1: COMMUNITY SURVEY**

### Trans and gender diverse inclusive BreastScreen

There is currently limited information available on breast screening and chest care for Trans and Gender Diverse (TGD) people. To address this, gap BreastScreen Victoria is reviewing the research to inform policy, staff education and information for TGD people. In addition, BreastScreen Victoria would like to hear from TGD people about how best to make breast screening services TGD inclusive.

This confidential survey for TGD people in Victoria includes 11 questions, and will take around 10-15 minutes to complete. The information from the survey will be presented at a community forum on TGD inclusive breast screening services presented by BreastScreen Victoria in November 2017. The survey and forum are being undertaken in consultation with representatives from Transgender Victoria.

If you would like more information on the survey, or to speak with the survey coordinator please contact Dr Catherine Barrett: 0429 582 237 or email: director@celebrateageing.com

If you would like to speak with BreastScreen Victoria about this project, please contact Maura on 96606863 or email: maurac@breastscreen.org.au

## **Demographic questions**

This section includes demographic questions to help us understand the reach of the survey.

### 1. What is your age (please circle one of the following)?

- · 18-29
- · 30-39
- · 40-49
- · 50-59
- · 60-69
- · 70-75
- · 75+

2. How would you describe your usual place of residence?

- Metro
- $\cdot$  Other
- 3. How do you describe your gender identity (please describe)?

#### 4. What sex were you assigned at birth?

- Male
- · Female
- · Other please specify:
- · Prefer not to specify

#### 5. Are there any other comments you would like to make?

# **Screening questions**

This section includes questions about your breast/chest screening knowledge and experiences and your suggestions for BreastScreen Victoria.

#### 6. Have you ever had a mammogram?

- · Yes (please describe where you had the mammogram and how you found the experience)
- No (please describe why you haven't had a mammogram)
- Not applicable
- · Would you like to make any comments?
- 7. What do you think your personal risk of developing breast/chest cancer is?
  - $\cdot~$  Higher than other people (please briefly describe why)
  - · Same as other people (please briefly describe why)
  - · Lower than other people (please briefly describe why)
  - · Not sure
  - · Would you like to make any comments?
- 8. Where do you go to find information about breast/chest cancer and breast/chest care and screening? (tick as many that apply to you)
  - $\cdot$  doctor
  - $\cdot$  friends
  - Internet
  - $\cdot$  TV/radio

- newspaper/magazine articles
- · BreastScreen Victoria
- $\cdot~$  I have never looked for this information
- · Other (describe)
- 9. What you think are the barriers to accessing BreastScreen Victoria services for TGD people?
- 10. What do you think BreastScreen Victoria could to do to be more inclusive of TGD people?
- 11. Are there any other comments you would like to make?

Thank you for taking the time to complete this survey.

## **ATTACHMENT 2: INFORMATION SHEET**

# Breast/chest<sup>\*</sup> screening for trans and gender diverse people

# BreastScreen Victoria

#### Welcome

At BreastScreen Victoria we think it is important that our services are accessible for trans and gender diverse (TGD) people. We have been working with Transgender Victoria to achieve this and towards a Rainbow Tick accreditation for safe and welcoming services.

This sheet provides information about breast/ chest health, breast cancer and screening. If you have any suggestions to improve this information, or our services more broadly please <u>contact us</u>.

# What are the risk factors for breast cancer?

- Being female at birth.
- Age is the biggest risk factor. We recommend screening for people over 50.
- Most people with breast cancer do not have a family history of the disease.
- Having breast implants or binding your chest does not increase your risk. See our fact sheet, <u>Breast screening with implants</u>, for more information.

#### Do I need screening?

Screening means checking for cancer before you have any symptoms — early detection could save your life. This table summarises whether screening for breast cancer may benefit you. TGD people have a unique set of factors that may affect their risk. Ask your doctor about your personal risk factors and the need for screening.

If you are 50 years or older:

Trans women	If you have been taking gender-affirming hormones (like oestrogen) for five years or more, screening every two years may be of benefit. If you have taken hormones for less than five years, or have not taken hormones, screening is not recommended.
Trans men	If you have <b>not</b> had chest surgery, screening every two years is recommended. There are no clear recommendations for people who have had chest surgery. We suggest talking to your doctor about your individual risk factors including previous surgical and hormone treatment. If your doctor confirms that you have no remaining breast tissue, screening is not recommended.
Gender diverse/ non-binary people	If you were assigned female at birth and have not had chest surgery, screening is recommended. There are no clear recommendations for people who have had chest surgery. We suggest talking to your doctor about your individual risk factors including previous surgical and hormone treatment. If your doctor confirms that you have no remaining breast tissue, screening is not recommended. If you were assigned male at birth and have been taking hormones (like oestrogen) for 5 years or more, screening every two years may be of benefit.

\* A note on terminology: We refer to breast/chest screening and surgery. This is because we recognise that many trans men and gender diverse people do not identify as having breasts, feel ambivalent about having breasts and prefer the term "chest" on its own.

See over

#### Where can I have a screen?

You are welcome to attend any of our clinics throughout Victoria. Our Rose Clinic in Melbourne's CBD provides LGBTI inclusive services, including 'Rainbow Rose' screening sessions for TGD people.



#### How do I book an appointment?

You can book at breastscreen.org.au or call 13 20 50. You can request the Rose Clinic or another clinic of your choice.

#### What will you ask me?

- We ask every person who books an appointment if they have breast implants. This is because we need to allow for a longer appointment time.
- We also ask everyone if they:
- have had breast/chest surgery
- are taking hormone therapy.

We ask these questions because they may affect the appearance of your screening images.

 We do **not** ask questions about gender identity.

#### What happens at screening?

- You will be welcomed by a staff member who will explain what will happen during the screen. You will be asked to remove your top clothing in private. Please ask us if you would like to wear a gown.
- A mammographer will take you into the screening room. During a screen it is normal to feel discomfort, but this should only last a few seconds. This is because your breasts/ chest will need to be pressed firmly between two plates in the screening machine so that a clear picture can be taken.
- You can ask for the screen to stop at any time.
- You are welcome to bring someone with you to your appointment.

#### **Breast/chest health**

Get to know the usual look and feel of your breasts/chest. See your doctor if you notice any unusual changes.

#### More questions?

You can talk to one of our staff members about screening. Call 13 20 50 or email info@breastscreen.org.au.

#### Tell us what you think

If you have any suggestions to improve this information, or our services, call 13 20 50 or email info@breastscreen.org.au.

## Book at breastscreen.org.au or call 13 20 50



visit breastscreen.org.au or call 13 20 50

For more information or to change your details,

For interpreter assistance call **13 14 50** 

Translated information: breastscreen.org.au/translations



**TTY 13 36 77** if you have hearing or speech difficulties



speech announces



See over



breastscreen.org.au