VICTORIAN LESBIAN, GAY, BISEXUAL, GENDER DIVERSE AND INTERSEX PEOPLE’S PARTICIPATION IN CERVICAL CANCER SCREENING 2015

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Acknowledgements

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Sue Dyson
Elizabeth Smith
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Executive Summary
1. Introduction

PapScreen Victoria engaged the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University to survey the cervical screening behaviour of people with a cervix who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI) or are same sex attracted.

LGBTI people constitute a priority population for PapScreen Victoria’s Pap Screen program. In 2014 PapScreen Victoria (PSV) conducted a literature review of cervical screening among lesbians and bisexual women. The review aimed to reduce inequalities in access to screening and treatment for cancer among this group. Based on this (unpublished) literature review and the findings of this survey, PSV plan to develop a range of targeted communication strategies via print and online media for sexually and gender diverse people. These strategies will address some of the myths and misconceptions around cervical cancer screening and aim to increase the use of screening services.

Anyone who has a cervix is at risk of being infected by the human papillomavirus and in the long term at risk of cell changes in the cervix that can lead to cancer. Lesbians and bisexual women are only part of the same sex attracted and LGBTI community who need of Pap testing to ensure they are not at risk of cervical cancer. As a result, this study aimed to be as inclusive of the diversity of people who are at risk of cervical cancer as possible. People with a cervix and who identify as gay, lesbian, bisexual, same sex attracted, transgender, gender diverse, or who have an intersex variation were therefore the target population for the study. In this report they will be referred to collectively as either GLBTI people, or as the ‘target population’.

To understand the needs of the study population it is necessary to understand some central concepts that affect the lives and health seeking behaviour of LGBTI people. Heteronormativity refers to the assumption that gender is a simple masculine/feminine binary and that ‘normal’ sexual relations only occur between a man and a woman (Warner, 1991). Social institutions and policies often reinforce heteronormative beliefs and in health care these assumptions can underpin practice and shape practitioners’ attitudes, which can lead to prejudice and discrimination against anyone who does not fit the binary and limit inclusive practice. The other associated concept is ‘cisgender’, which is the term that describes people whose assigned gender at birth matches their bodies and their gender identity (Schilt & Westbrook, 2009). Cisgender (‘cis’ meaning ‘the same’) is the antonym for transgender. Heteronormativity leads to heterosexism, the prejudiced assumption that everyone is heterosexual. It also leads to homophobia, often described as fear and loathing of homosexuality, but better understood as prejudice against sexual diversity. The assumption that everyone is cisgender leads to prejudiced assumptions known as
cisgenderism (Ansara, 2010) that excludes those who are gender diverse or identify as transgender.

1.1 Research aims and questions

The research aimed to understand the cervical screening behaviour of people in the target population, who are aged between 18 and 69 years and live in the state of Victoria, Australia. The research questions asked:

1. To what extent do people in the target population participate in the cervical screening program?
2. What do people in the target population know about the human papillomavirus (HPV) and its association with cervical cancer and how it is transmitted? Have they participated in the HPV vaccination program?
3. What experiences have people in the target population with cervical screening and what barriers do they experience in accessing sexual and reproductive health care and screening?
4. What are the best and most appropriate ways to communicate with different groups within the target population to increase participation in Pap testing and improve knowledge and awareness about HPV and safe sexual practices?

2. Methodology

To achieve the study aims a survey was developed by Associate Professor Sue Dyson and Dr Elizabeth Smith in consultation with representatives of PapScreen Victoria. It was piloted by Dr Smith in-house at ARCSHS, and with individuals from of gender diverse and intersex communities. Based on feedback from the pilot, the survey was amended, and launched online in August 2015. Ethics approval for the project was obtained from La Trobe University Human Ethics Committee. The survey was completely anonymous and participants who had questions or wanted further information about screening, testing or HPV in general were referred to PapScreen Victoria.

2.1 Recruitment and sampling

Both the researchers and PapScreen Victoria used a wide range of networks to recruit a diverse range of participants who met the recruitment criteria. This included banners on web sites, with assistance from various GLBTIQ organisations and groups and via social media such as Twitter and Facebook. The Victorian Gender and Sexuality Commissioner, Row Allen, supported the survey and was quoted in a media release from PSV, saying “cervical screening is an important public health measure and we need to ensure that all people who require it have an inclusive pathway to appropriate care”. In addition to networks and social media recruitment Facebook advertising targeted people in the target population who had ‘liked’ or ‘followed’ a page related to LGBTI issues. Nine thousand
people were reached via Facebook and 63 people clicked on the link in the advertisement that took them to the survey.

![Facebook advertisement image](image)

**Figure 1. Facebook advertisement image**

### 2.2 Data analysis

The survey was made available online using Qualtrics, a tool for building online surveys. When the survey was complete, data were downloaded and cleaned. Quantitative data were analysed by the researchers using SPSS; qualitative data was analysed thematically using N’Vivo 10. Three hundred and thirty-eight people participated in the survey. Once the data were cleaned, 303 valid responses remained.

### 3. Findings

Three hundred and thirty-eight individuals participated in the survey, after the data were cleaned, 303 of the responses were useable. In the findings section we discuss the demographics of the participants in the research, including information provided by them about their sexuality and gender identity. This is followed by a section that discusses the findings concerning participants’ engagement with the health sector for sexual and reproductive health care and screening. The following two sections discuss knowledge about HPV and Pap testing, and reported experiences with and intentions about participation in the PapScreen program. The final section discusses the findings and makes recommendations for sensitive, inclusive practice that meets the needs of sexually and gender diverse people.

#### 3.1 Demographics

The survey investigated demographic information such as age, gender identity, and postcode, as well as sexual attraction and sexual health and health seeking behaviours.

The majority of respondents (86% n=260) were born in Australia; other countries where participants were born included, New Zealand (n=9), England/UK (n=8), Ireland (n=2). Other participants were born in a variety of countries including Israel, Hong Kong, Croatia, and
Papua New Guinea. Three respondents indicated that they were of Aboriginal or Torres Strait Islander descent, which represents 1% of all survey participants. Ninety-seven per cent (n=254) of respondents indicated that they spoke English at home and five spoke a language other than English at home including Cantonese, Vietnamese, and Spanish. The average age of participants was 32 years; the youngest was 17 years and the oldest 69 years.

3.1.1 Employment Status

Participants were asked about their employment status. Over a third were employed full time (37.2% n=97), a quarter worked part time (n=64), 10% worked casually (n=27) and 14.6% were full time students (n=80) (see Figure 2 below).

![Figure 2. Employment status]

The survey also asked ‘do you have a health care card/pension card/ concession card?’ One third (32% n=84) indicated they did have a concession card of some kind.

3.1.2 Gender Identity

Participants were asked about their gender identity; five options were provided on the survey along with space to add comments. Seventy-five per cent (n=210) identified as a woman, 2.5% as a man (n=7), 5% (n=15) as a trans man/FTM, 2% (n=6) as trans, and 12.5% (n=35) as a gender identity in the gender diverse spectrum. Seven participants (2.5%) indicated another identity, including “non-binary” (n=3), “demigirl”, “queer”, “trans masculine”, and “stone butch”.

Many participants expanded on the above five options offered by the survey, and a diverse sample is represented that cannot be easily captured by a short phrase or acronym. It is clear that a binary masculine/feminine approach to gender is inadequate to capture the breadth of ways in which gender is experienced. One participant explained: “I'm okay with
being referred to as female but I don't identify completely to either of the binary sexes. I feel like a mix between the two”. Another said:

[I’m] comfortable with a more androgynous look. Have been more comfortable wearing men’s clothing ever since I was born. Tomboy all through school played football with the boys ... I’m more comfortable in the company of men and always seem to find myself surrounded by them.

A person who identified themselves as transgender explained:

[I am] transgender and non-binary. Somewhere along the Trans masculine spectrum, but I'm still quite a feminine guy who loves to wear makeup and dresses. My doctor describes me as "third gender" on my medical paperwork, and I think that fits well.

While for other trans people:

I identify strictly as male, but embrace my Trans identity. I express myself broadly and am not limited to 'traditional' male interests and pastimes.

∞

I'm assigned female at birth and I identify as gender diverse, and have a gender neutral name and prefer gender neutral pronouns 'they/them'.

Some people who were assigned female at birth with a male affirmed identity reject the term ‘trans’ outright, for example: “I identify as male, but do not identify as transgender”.

Four participants (1.4%) identified themselves as having an intersex variation, and two offered more information about their intersex variation: one wrote ‘adrenal hypoplasia’, and the other said: “I'm biologically more female than male, was raised as a woman, identify as a woman”. With regard to gender identity, another explained:

I am open about the intersex aspects of my biology, but my social identity category is Woman. While I am happy as "woman" as a pragmatic category for social functioning in the world we live in, I don't endorse the gender binary as an "essential" or fixed aspect of people. My superficial presentation is quite "fem" (it works with my curvy body), but my manner and physicality has both strong masculine and feminine aspects.

This participant’s comments about the gender binary was echoed by many participants who used the term ‘cisgender’ to describe themselves, but qualified this with terms such as gender fluid. The explanatory notes were more likely to come from people who did not feel
the gender binary was appropriate, however, one did note that she was exclusively female: “I currently identify as a cis-woman and have never questioned my gender”.

### 3.1.3 Sexual Identity

The survey did not specify sexual identities but asked an open question ‘how do you currently define or understand your sexuality (including identity, desire and behaviour)?’ Participants described their sexual identity in terms of both attraction and the gender of their current partner. Eighty-three identified as lesbian and one as ‘dyke’; 56 identified as queer. One woman who identified as lesbian explained “[I’m] lesbian..... Always have been.....always will be. Have never had any sexual or intimate relationship with a man. All my sexual experience has been with woman”. Another said: “[I’m] 100% lesbian. Attracted to female identified people”. Some lesbians identified themselves as ‘femme’ others as ‘butch’ but most simply wrote ‘lesbian’.

The second largest sexual identity category was ‘queer’ and this represented more diversity and a greater relationship to gender identity. One person in this group explained:

> I’m queer. I’m a man, but in a queer way so that I don't think I would be an acceptable partner for a straight ciswoman who had no affinity for queer identification. I am sexually interested in people across the spectrum of gender presentation and sex-assignment. I am in a committed relationship with a non-binary (fab) person and appear straight to society. This is mostly ok and sometimes really frustrating/funny.

Others who identified as queer wrote:

> [I’m] in a monogamous heterosexual relationship. I have previously only been in queer relationships (monogamous lesbian relationships and also polyamorous relationships). I consider myself queer and am same sex attracted.

∞

Specifically, I identify as a lesbian because I identify as a woman, and I date a person who also identifies as a woman. More broadly I would identify as queer because I am attracted to/have dated people who are trans men, or gender queer. So I see myself as having the capacity to date outside cis women.

Thirty-three people identified as bisexual, 22 as pansexual, 16 as gay, 14 preferred to give no definition of their sexual identity, 10 identified as same sex attracted and five identified as straight. Bisexually identified people acknowledged attraction to, or past relationships with people of the same and/or opposite gender, but were more likely to state that they were in a current monogamous relationship, for example: “[I am] Bi attracted to both men
and women but am [currently] in a committed relationship with a woman”. Another wrote “[I am] Bi attracted and have had long-term relationships with both men and women”.

Both women and men identified themselves as gay. One man explained:

[I’m] attracted to men, from the persona/feeling of being a man. So if I had to define my sexuality, it would be as a gay transgender man.

And a woman wrote:

Currently I identify as a gay woman, though I understand my sexuality as fluid and don’t believe that my sexual behaviour can be defined by how I identify today. This may change in the future and can be performed outside of sexual norms or binaries as understood by majority.

Another gay man wrote about his attraction and sexual practice:

I’m gay, as in attracted to men as a man. However, I do have sex inclusive of my vulva and vagina.

Participants who avoided aligning themselves with any identity category did so for various reasons, for example:

I am attracted primarily to other trans/GNC [gender non-conforming] people, but not exclusively. I am not exclusively attracted to any one gender. I have had sexual experiences and relationships with people with a variety of genders and birth assignments.

Another participant defined her sexual identity in terms of the gender of her partner:

[My sexual identity is] undefined. Did identify as lesbian but partner has transitioned (FtM) so would (probably) be considered bisexual.

Another participant explained that their capacity for love was not limited by gender:

... I think I will be able to fall in love with anyone and not just limit my heart to one person and not expect them to give all of themselves only to me. Sex with women has been consistent since [age] 13, sporadic with men since [age] 15. Very attracted to men, but growing up as a lesbian in a small town I would get picked on for not being a real lesbian if I slept with men.

3.2 Engagement with the health care sector

The survey explored sexual health, health seeking and prevention attitudes and behaviours among participants; they were asked if they had a regular health care provider (HCP). Over
half (56%) did have a regular HCP (n=157), 30% (n=84) only saw one when required, and 14% (n=38) saw different providers at the same clinic: (Figure 3 below).

![Figure 3. Do you have a regular health care provider?](image)

Survey respondents who had a regular health care provider were most likely to tell their health professional about the gender or sexuality identity.

Participants were then asked if they had told their health care provider about their sexuality and/or gender identity. Thirty-five per cent (n=98) answered ‘yes, always’, 40.5% (n=113), sometimes told their health care provider and a nearly one quarter (24.4%, n=68), had never told their health care provider about their sexuality and/or gender identity (Figure 4 below). Individuals who identified as gender diverse were least likely to have ever told a health care professional about their sexuality and/or gender identity: One third of those who identified as gender diverse (34%, n=12) had never come out.

<table>
<thead>
<tr>
<th>Do you have a regular health care provider (e.g. GP, nurse etc.)?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Have you told your current or regular health care provider about your sexuality and/or gender identity?

<table>
<thead>
<tr>
<th></th>
<th>Yes, always</th>
<th>Yes, sometimes</th>
<th>No, never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>51.0%</td>
<td>30.6%</td>
<td>18.5%</td>
</tr>
<tr>
<td></td>
<td>11.9%</td>
<td>51.2%</td>
<td>36.9%</td>
</tr>
<tr>
<td></td>
<td>21.1%</td>
<td>57.9%</td>
<td>21.1%</td>
</tr>
<tr>
<td></td>
<td>35.1%</td>
<td>40.5%</td>
<td>24.4%</td>
</tr>
</tbody>
</table>

Figure 4. Are you out to your current HCP? BY do you have a regular HCP?

There was a moderate relationship between age and whether or not participants had told their current or regular health care provider about their gender identity and/or sexuality (Cramer’s V .281, p<.01). All participants aged 20 years and under were the most likely to have never told a health profession this information.

Figure 5. Told health care provider BY age

In addition to the yes/no answers represented in the above graph, participants could expand on their response and many took the opportunity to clarify the things that influenced their decision about whether or not to come out to their HCP. Some indicated that they would like to come out to their doctor but the decision was mediated by their confidence that the provider would understand them. This was particularly so for transmen, as one explained:
I would like it if I could mention it without feeling like it would make the appointment go on for ages while I do a Tans 101 with them. This is obviously an assumption of what would happen but it has happened enough that I just try and avoid it.

One transman talked about the transphobic attitude demonstrated by his GP:

I'm in the market for a new GP, my current one is uneducated in and uninterested in educating himself on trans issues, refuses to use my chosen name, misgenders me, is fatphobic, slut shames me...

Not all experiences were negative, another trans participant related a positive experience:

I recently saw my GP to ask about physically transitioning and he was wonderfully helpful, I didn't even know that non-binary/middle ground transition was an option. I've been seeing him for a few years now so I felt very comfortable talking to him about it and knew that he would be understanding despite the fact that I'd never brought it up with him before.

The experience of discussing sexuality and gender with a GP can also be difficult for intersex people, one explained 'My GP still doesn't understand intersex variations. She expects me to tell her what to do'.

Some participants indicated that they had a regular GP, to whom they had not come out and for sexual health, instead they specifically attended a sexual health or speciality LGBTI clinic for sexual health matters.

For some the decision to come out was based on whether or not they thought it was relevant, for example, one participant explained “only if the appointment is about my sexual health”. Another said “if it’s relevant to my visit”, another explained “only if I feel comfortable with my health provider”. One transman explained “I tell psychs (sic) and sexual health nurses about my gender identity, I do not tell GPs seen for unrelated reasons”. Many others made comments about their GP making heterosexist assumptions or homophobic comments when they did come out. For example, one woman explained:

I went to the doctor recently and tried to enquire about a Pap smear. The doctor (female) asked me repeatedly if I had a boyfriend, made me very uncomfortable that I had never had penis in vagina sex and asked why I would want a Pap smear if I hadn't had one before. It made me feel very uncomfortable and unwilling to disclose my sexuality to healthcare professionals

One participant drew attention to assumptions that doctors make about sexuality:
My doctor assumes that I am straight but I find it too awkward to correct her. I selected this doctor because the clinic is LGBTI friendly but I actually feel really uncomfortable. I recently went to the doctor complaining of pain during sex and she immediately started asking me about my use of contraceptives, gave me a lecture when I said I didn’t use them and then proceeded to use the word 'penis' a lot when talking about my issues with painful sex. My [female] partner sees the same doctor and was immediately asked whether her partner was male or female - I think this discrepancy is probably due to the fact that our appearances differ and I am not readily identifiable as a lesbian from my appearance which is ridiculous.

3.2.1 Decisions about health care providers

Participants were asked to nominate the things that would most likely influence their decision to see a particular health provider. They were provided with four possible answers as well as the option to add their own text. Word of mouth and knowing that the provider has LGBTI expertise were the most likely factors to influence the decision to see a health care provider (33% and 33.6% respectively). Thirteen per cent nominated another reason (detailed below). Nearly ten per cent of participants nominated that being a member of an LGBTI community was most important and 10% indicated that having specific policies around LGBTI service users would most likely influence their decision.

![Figure 6. Factors influencing choice of health care provider](image-url)
Of the 28 respondents who mentioned another factor that most influenced their decision to see a particular health professional, cost and convenience were influencing factors, while friendliness and professionalism was important for other respondents. Other participants expressed that they would only see a general practitioner whom they know and trust, while others said that they would prefer to see a female doctor, or attend a sexual health clinic. Other participants indicated that respect within LGBTI communities was important, for example:

Word of mouth that the practitioner is a supporter of the LGBTI community” and another said, “My GP was recommended to me by a well-respected lesbian doctor who I trusted, even though that GP is heterosexual.

Participants were asked if they had a preference for the gender of the person carrying out the Pap test. A large majority of respondents told us that they would prefer a woman (n=152, 69%), and 26% (n=57) told us that they didn’t care. Less than one per cent (n=2) indicated that they would prefer a man, while four per cent chose the ‘other option’ and provided more information. For example, one participant said, “woman or gender diverse person”, and a couple of respondents mentioned that they would be happy with any gender as long at the person wasn’t a heterosexual cisgender man.

![Gender preference for Pap test practitioner](image)

**Figure 7. Gender preference for Pap test practitioner**
3.2.2 Information seeking

Participants were asked where they get their information about sexual health and cervical screening. They were provided with six options and an option to provide another place where they get this information. Respondents could order the options from most likely to least likely. Health care providers were the first preference for almost half of the participants, followed by the internet and family and friends. Figure 8 below details the findings about most likely sources of information.

![Figure 8. Most likely source of cervical screening and sexual health information](image)

3.3 HPV Knowledge

Participants were asked if they had heard of the human papillomavirus (HPV) and 96% (n=266) of respondents indicated that they had, 3% (n=8) had not, and 1% (n=3) responded that they did not know. Two hundred and seventy-five participants responded to a question about how HPV can be transmitted. Of these, 77% (n=212) knew that it could be transmitted through vaginal intercourse, 69.5% (n=191) through genital skin to skin contact, and 47% (n=129) through anal intercourse. A further 18% (n=50) indicated that they did not know, or couldn’t say how it was transmitted.
<table>
<thead>
<tr>
<th>HPV knowledge</th>
<th>Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transmitted through vaginal intercourse</td>
<td>77%</td>
</tr>
<tr>
<td>Skin to skin contact</td>
<td>69.5%</td>
</tr>
<tr>
<td>Anal intercourse</td>
<td>47%</td>
</tr>
<tr>
<td>Don't know/can’t say</td>
<td>18%</td>
</tr>
</tbody>
</table>

### 3.3.1 HPV Vaccine

Participants were asked if they had received the HPV vaccine, and almost half (48% n=128) had received the vaccine. A quarter of participants (n=68) had received the vaccine at school; 21% (n=55) had received it ‘for free with a health professional’; 42% had not received the vaccine; and a further 10% did not know whether they had received the vaccine or not (Figure 3 below). Of those who had received the HPV Vaccine, 65% had received three doses, 7% two doses, and 3% 1 dose. A further 25% (n=32) were unable to say how many doses they had received.

![Figure 9. Have you had the HPV Vaccine?](image)

When data concerning whether or not participants had received the vaccine were analysed by age those women aged over 30 years were less likely to have had it than younger women.
Figure 10. Have you had the HPV Vaccine? By age of respondents

Given the national roll-out of the HPV vaccine in secondary schools over recent years, it is not surprising that there was a positive correlation between younger age and having received the vaccine.

3.4 Pap test knowledge, experiences and intentions

Participants were asked if they had heard of the Pap test and almost all had (97% n=267), only 3% (n=7) had not heard about Pap tests. Of the seven participants who had not heard of a Pap test, three were aged between 18 and 20, 3 were aged between 21 and 30, and one was aged between 41 and 50 years. Some misinformation about the purpose of Pap tests was found. In response to a question that asked which conditions a Pap test checks for (they could choose as many as applicable) and 274 people responded. Figure 2 below details the proportion of people who chose each response.
Participants were then asked to select from a list of seven options concerning who should NOT participate in Pa Screening, and 265 responded. Almost 50% (n=127) of those indicated that all of the groups listed should participate in Pap screening by choosing ‘none of the above’. Around a quarter of respondents responded that people who had never had sex did not require a Pap test (26%, n=68), and one fifth (21%, n=56) indicated that ‘people who had had a hysterectomy’ did not need to participate. The remaining 12.5% (n=33) indicated that they did not know/could not say who should not participate. Figure 12 below illustrates the responses to this question.
3.4.1 Participation in Pap Screening.

Participants were asked, 'have you ever had a pap test?'; 20% (n=35) of all respondents did not answer this question. Of those who responded, 77% (n=206) had a Pap test at least once, and 23% (n=62) had never had a Pap Test.

Participants were asked to describe how often they participated in Pap testing. Thirty-eight per cent (n=76) said that they had a Pap test every two years and a further 20% (n=40) indicated that they meant to have one every two years, but usually left it longer. Eight per cent (n=15) told us that they usually had a Pap test when they received a reminder letter, and 13% (n=25) have only had one or two Pap tests. Ten per cent indicated that they had Pap test irregularly, and 7% had them once a year or more frequently. The majority of respondents who had ever had a Pap test had had one in the last one to two years (67%, n=138). Ten per cent (n=22) of respondents had not had a Pap test for more than 5 years and 1.5% (n=3) did not know or couldn’t say.

![Figure 13. Time since last Pap test.](image-url)
Participants were asked to select from a list of possible responses (figure 15 below) what prompted their last Pap test.

<table>
<thead>
<tr>
<th>Last time that you had a Pap test, what prompted you to make the appointment?</th>
<th>Frequency (n)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>A reminder letter from my health professional</td>
<td>37</td>
<td>18%</td>
</tr>
<tr>
<td>A reminder letter from my Pap test registry</td>
<td>35</td>
<td>17%</td>
</tr>
<tr>
<td>I didn’t, I went for a different reason</td>
<td>26</td>
<td>13%</td>
</tr>
<tr>
<td>I just remembered</td>
<td>25</td>
<td>12%</td>
</tr>
<tr>
<td>Routine check-up/screening</td>
<td>19</td>
<td>9%</td>
</tr>
<tr>
<td>Other, please specify</td>
<td>18</td>
<td>9%</td>
</tr>
<tr>
<td>Health professional recommendation</td>
<td>14</td>
<td>7%</td>
</tr>
<tr>
<td>Family/friend recommendation</td>
<td>11</td>
<td>5%</td>
</tr>
<tr>
<td>Worry about a symptom or problem</td>
<td>10</td>
<td>5%</td>
</tr>
<tr>
<td>Follow up of an abnormal test</td>
<td>6</td>
<td>3%</td>
</tr>
<tr>
<td>Don’t know/can’t say</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>I saw something in the media</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>205</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

*Figure 14: what prompted your last Pap test*

In addition to the forced choice questions, participants could add their own text, and 18 added their own reasons to the list. A few participants explained that they had a Pap test at the same time as a sexual health check. For example, one said: “had an overall sexual health check-up, the Pap test was part of it” and another: “I was getting an STD test and they recommended I get a Pap smear at the same time”.

For one participant, their Pap test was prompted by the general practitioner, “GP Kept hassling me for years”. For another it was a feeling of guilt, “a couple of colleagues went and I felt guilty/concerned as it had been 4 years and I am meant to go yearly”.

For a few of the participants the Pap test was related to reproductive health. One said, “I needed an up-to-date Pap test to commence IVF treatment” and another, “Recommended
before fertility treatment”. For other participants, it was their partner reminding them that prompted them to make the appointment, or their partner’s abnormal result, “My partner had an abnormal Pap test and she/her doctor suggested I have a Pap test to see if there was anything abnormal going on for me”.

There was a strong correlation between age and whether or not the participant had ever had a Pap test; older participants were more likely to have participated in screening than younger participants. All of the survey respondents who were aged 51 years and above had ever had a Pap test, as had over 90% of those aged between 31 and 50 years. Among those aged 21 to 30 years, only 70% had ever had a Pap test, while only 14% of those aged 18 – 20 years had (Cramer’s V .556, P=.000).

Figure 15. Ever had a Pap test BY age

Eight-three per cent (n=220) of respondents indicated that they planned to have a Pap test in the future, 11% didn’t know, and 6% did not plan to. There was a moderate relationship between whether or not a participant had had a Pap test and whether or not they planned to in the future (Cramer’s V .405, P=.000) (See Figure 16 below).
Have you ever had a Pap test?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>N=187</td>
<td>N=31</td>
</tr>
<tr>
<td></td>
<td>91.2%</td>
<td>55.4%</td>
</tr>
<tr>
<td>No</td>
<td>N=8</td>
<td>N=7</td>
</tr>
<tr>
<td></td>
<td>3.9%</td>
<td>12.5%</td>
</tr>
<tr>
<td>Don't know/can't say</td>
<td>N=10</td>
<td>N=18</td>
</tr>
<tr>
<td></td>
<td>4.9%</td>
<td>32.1%</td>
</tr>
<tr>
<td>Total</td>
<td>N=205</td>
<td>N=56</td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Figure 16. Intention to have a Pap test BY have ever had a Pap test

3.4.2 Barriers to testing

Participants were asked about things that make it difficult for them to have a Pap test; they were provided with a list from which to choose and could choose as many as they thought applicable to them and could also add their own text. Two hundred and forty people responded and 32% of these (n=78) indicated that none of the reasons listed applied to them; the other 162 participants identified one or more barrier. Embarrassment was the most commonly identified barrier to testing, closely followed by lack of time. For 17% of those who responded getting a Pap test was painful and participants who selected this option were offered the option to explain further if they knew why it was painful for them. Five did expand on this answer; reasons were varied including ‘unsure’, ‘post-traumatic stress disorder’, and ‘extremely uncomfortable’. One participants explained “I have cerebral palsy … I have tight muscles and lax ligaments/joints. I’m more difficult to examine than most people”. Barriers at listed in Figure 17, below.
<table>
<thead>
<tr>
<th>Barriers to Pap screening</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>The test is too embarrassing.</td>
<td>54</td>
<td>22.5%</td>
</tr>
<tr>
<td>It is hard to find the time to have a Pap test</td>
<td>51</td>
<td>21.3%</td>
</tr>
<tr>
<td>It is too painful. Please tell us if you know why it is painful for you.</td>
<td>41</td>
<td>17.1%</td>
</tr>
<tr>
<td>I don't know if or when I should have a Pap test</td>
<td>35</td>
<td>14.6%</td>
</tr>
<tr>
<td>It's hard to find a doctor or get an appointment</td>
<td>30</td>
<td>12.5%</td>
</tr>
<tr>
<td>I have had a homophobic experience in the past.</td>
<td>26</td>
<td>10.8%</td>
</tr>
<tr>
<td>Other, please specify</td>
<td>21</td>
<td>8.8%</td>
</tr>
<tr>
<td>It's too expensive to have a Pap test</td>
<td>19</td>
<td>7.9%</td>
</tr>
<tr>
<td>The services I have access to don’t know how to work with transgender or gender diverse people.</td>
<td>17</td>
<td>7.1%</td>
</tr>
<tr>
<td>It's hard to travel to an appointment</td>
<td>13</td>
<td>5.4%</td>
</tr>
<tr>
<td>I have been pressured to take inappropriate or impractical tests in the past.</td>
<td>7</td>
<td>2.9%</td>
</tr>
<tr>
<td>I have had a transphobic experience in the past.</td>
<td>6</td>
<td>2.5%</td>
</tr>
<tr>
<td>The services I have access to don’t know how to work with people with an intersex variation.</td>
<td>3</td>
<td>1.3%</td>
</tr>
</tbody>
</table>

Figure 17. Barriers to Pap Screening

3.4.3 Pap test experiences

In response to the question ‘last time you had a pap test who carried it out?’ three quarters (74%, n=142) indicated that it was with a general practitioner. Others were with a nurse (14%, n=28), or gynaecologist (10%, n=20). Others identified having a Pap test with a medical student, a sexual health clinic doctor, and a surgeon.
The majority of participants had never had an abnormal Pap test, only one in three responded that they had had an abnormal result.

Respondents who indicated that they had never had a Pap test were to choose from a list of reasons why. They could choose all the reasons that applied, or add their own text and 56 answered this question, identifying at least one reason why they had not had a Pap test. Six themes were identified, and are discussed below.
‘I don’t think I need one’

Of the 56 participants who had not had a Pap test, 16 (28%) did not think that they needed to have a one. Reasons given for not needing a Pap test included having had exclusively same sex sexual relations, never having penetrative sex with a man, never having had sex. One participant explained: “I don’t like to go into that with the GPs who wants to give me tests, but usually telling them I’m a gold star lesbian is enough”. Two indicated that they understood that HVP testing every five years was more effective cervical cancer detection than Pap tests and had made “educated decisions” not to participate n Pap screening.

‘Embarrassing or frightening’

Over half of respondents (52%, n=29), who reported they had never had a Pap test, explained that is because they are embarrassed or frightened. When asked to tell us more, participants noted a range of reasons why the thought of having a Pap test was embarrassing or frightening. For some fear of pain was a barrier, one explained: “It sounds kinda painful, and because it’s unnecessary I’m not particularly searching it out”, and another said “It’s a completely irrational fear, and the idea of pain is never glamorous…” Some people also felt uncomfortable exposing their genitals:

Apparently it hurts and is super uncomfortable. I’m also really private with my junk and am embarrassed a person that is not my partner will see it.

∞

I feel self-conscious about my body and don’t want to have the test done, and I feel anxious at the doctors so I avoid going unless it is absolutely necessary.

For some participants the discomfort of exposing their genitals was compounded by lack of understanding about what a Pap test involves. For example, one explained: “I don't really know what's involved and I don't like my genitals or the thought of people seeing them.” And another said: “I think it's a bit embarrassing, but I think it's a bit more embarrassing because I know so little about what it helps to do”.

People with addition complex needs also avoided having Pap tests, for example, some explained they had post-traumatic stress disorder (PTSD) – as one explained: “I have PTSD so the idea terrifies me even though I know it's nothing to worry about”. Another who had experienced sexual assault explained:

I attempted to have a Pap test some time ago, with my regular GP at Northside clinic who is amazing. I am a survivor of sexual abuse from an intimate partner and it was too difficult to get through the process. My GP instead did some other thing involving a swab and believes I do not need to have a Pap test again for some time.
Some GLBTI people who have not had penetrative sex fear the invasive nature of Pap tests, as one explained:

I've never had penetrative sex and find it difficult to use tampons. I'm afraid it will hurt and embarrassed to tell my doctor that I haven't had sex.

‘I am worried about homophobia or transphobia’

Nineteen per cent (n=11) of respondents who had never had a Pap test told us that they were worried about homophobia or transphobia and took the opportunity to expand. Participants described past experiences of homophobia and/or transphobia with health professionals, concerns about needing to educate the doctor about being trans or intersex, and concerns about prejudiced HCPs who invalidated their identity. One participant explained:

I experienced homophobia/confusion the last time I enquired about getting one, so this makes me reluctant to ask again.

Others explained that they “have come to expect it” and one explained that their doctor was ill informed about the range of sexual practices:

It's annoying the way GPs always assume I'm straight and I have to correct them. One GP actually assumed my having only had sex with women would mean I couldn't get a pap smear. Probably true in my career but showed she had no idea the range of what women do in bed.

One effect of the health care provider’s lack of understanding about the diversity of people’s sexual practices, is that individuals are often called on to explain – which can be embarrassing, as one participant explained:

I've never had sex with guys before and will probably have to explain that I'm not a virgin yet have never had sex with a dude before

‘I am concerned that I will be mis-gendered’

Nine people (16%) told us that they were concerned about their doctor making incorrect assumptions about their gender, or ‘mis-gendering’ them and that this contributed to their avoidance of Pap tests. For example, one explained how their university health service that promotes being Trans friendly excludes Trans people by promoting Pap testing as exclusively ‘women’s health’:

I don't want to go to the medical centre at Uni because, even though they are explicit trans inclusive in some of their intake forms, they still list Pap smears as women's health.
Other participants explained how difficult assumptions about gender can be: “I have trouble convincing people I am a woman quite a lot. Embarrassing” and “The medical profession is super heteronormative and doesn't understand gender diversity”.

I am too young or haven’t had sex yet

Sixteen per cent (n=9) indicated that they had not had a Pap test because they had not had sex yet and 11% (n=6) because they were too young to require one. One young participant, who had learned about Pap tests at school explained:

I was taught in school you only get need to get them after you turn 18 or become sexually active. Also I’ve been told that you don’t need to have them if you’ve never had penis-in-vagina sex.

Another young participant, who had never received education about Pap tests explained:

It hadn’t really occurred to me that I’d need one now that I'm 18. I don’t really know anything about Pap tests. I feel like perhaps there is a particular age where I should think of getting it done, but no one ever told me that I should start now.

Other reasons

Nearly a quarter (23%, n=13) of survey respondents who indicated that they had never had a Pap test explained it was because they had never had symptoms; 12% (n=7) indicated that did not need it because they had received the Gardasil vaccine. Other participants explained that they did not trust medical professionals and that this impacted their decisions about having Pap tests (n=4).

5. Discussion

5.1 Sexual and gender diversity

In terms of gender, three quarters of the participants in this research identified as a woman, a quarter of those people who have a cervix who completed the survey identified themselves on the gender diverse spectrum. In terms of sexuality, while most participants identified as lesbian, many also used the term queer, and some described their sexuality as bisexual or gay. Identity, attraction and sexual practices are not stable and do not always align with a particular identity. Some of the participants expressed their identity in relation to the gender of their partner, as exemplified by the person who explained having been in a lesbian relationship with a partner who transitioned gender from female to male (FtM), so currently identifying as bisexual. In terms of sexual practices, trans and intersex people have the capacity to engage pleasurably in a range of genital practices, as exemplified by the participant who identified as gay, described himself as a man attracted to other men, and having sex that included his vulva and vagina. The complexities of human sexuality and
gender identity that was communicated by participants in this research demonstrates the inadequacy of the acronym LGBTI to recognise or describe people in this population. It is also likely that assumptions about heterosexuality and gender as a M’F binary are as inappropriate for the delivery of sexual health care and screening for the wider population as they are for the target population for this research. Nonetheless, for brevity in this report LGBTIQ will be used when discussing the target population. The ‘Q’ has been added to the earlier assumptions because of the numbers in the research who identified themselves as queer.

When addressing the needs of GLBTIQ communities for sexual and reproductive health care and screening, an intersectional approach is necessary. Intersectionality is a theory that addresses this type of approach. It refers to “the relationship between multiple dimensions and modalities of social relations and subject positions” (McCall, 2005, p. 1771). This approach focuses on the complexity of lived experience and seeks to understand the impact factors such as sexuality, gender, gender identity, race, class, culture, and dis/ability impact on experience. In health care settings this approach is essential for sensitive, inclusive care.

5.2 Access to inclusive, sensitive health care

A basic principle for high quality health service provision is that everyone should be treated with respect by a knowledgeable professional who they trust and with whom they can be open about the intimate details of their lives. This is particularly important for sexual and reproductive health care and screening, however, for many GLBTIQ people doctors and health care providers do not provide this kind of care. This report finds that for the most part, doctors in mainstream general practice appear to be failing to deliver high quality, inclusive services for GLBTIQ people both in terms of non-judgemental acceptance of the individual and their sexual health and cancer screening needs.

5.2.1 Barriers to inclusive care

The survey findings paint a picture of many health care providers who are poorly informed about sexual and gender diversity which affects the quality of care they provide. For GLBTIQ people this does not engender confidence in the medical profession in general, and often leads to avoidance of screening and health care.

Homophobia and heterosexism have been identified as problematic in health care settings since at least the 1990s (Brotman, Ryan, Jalbert, & Rowe, 2002), and existed since long before it was named in academic literature. Fears about and actual experiences of heterosexism and cisgenderism were identified as barriers to cervical screening by participants in this research. Some reported that their doctor was uninformed about sexuality and/or gender diversity and non-heteronormative sexual practices.
Age was another barrier for people in the LGBTIQ communities. Until recently concepts such as heterosexism and cisgenderism were not recognised by the wider community and many older GLBTI people have experienced overt homophobia and transphobia in the health care system. Half of the participants in this research who were aged over 60 years had never told a health care provider about their sexual practices or identity, and were fearful about the consequences if they did come out. Younger participants aged under 20 years were also less likely to have told a provider about their sexuality or gender identity. GLBTI people in these age groups should be considered vulnerable and attention paid to helping them to find providers who are inclusive, knowledgeable, and sensitive to their needs.

Many GLBTIQ people who fear prejudice and discrimination avoid having a regular health care provider and only see a doctor when they have an urgent health related problem. Over half of the participants in this research did not have a regular health care provider and a little under one third only saw a doctor only when it was necessary. This results in lack of continuity of care and inadequate or non-existent screening. For those without a regular, trusted and inclusive health care provider, this can have unacceptable consequences.

Because of the lack of sensitivity and understanding on the part of so many HCPs, people who are sexually and gender diverse constantly have to assess whether or not the medical encounter is safe or supportive, which means that this group are left to navigate the system on their own. The importance of trust and comfort cannot be underestimated in the relationships between the health care provider and LGBTIQ patient seeking Pap screening or sexual health information.

5.2.2 Enablers of inclusive care

Just as not having a regular, trusted health care provider can be barrier to high quality care, having a regular trusted provider can be an enabler. Finding a provider that meets the criteria for inclusive care is important for in the LGBTIQ community, and two thirds of those in this study relied on word of mouth to find an acceptable provider. One Melbourne based general practice came in for praise from survey participants. This clinic specifically caters to the needs of GLBTIQ people although time and distance creates a significant barrier for those who do not live close to the area where they are located. The positive feedback about this service from participants in this research makes it apparent that even the most significant barriers can be overcome by knowledgeable, sensitive and inclusive care.

When GLBTIQ people have a trusted health care provider they find it easier to discuss intimate matters concerning gender and sexuality. Although it is based on a small sample from the survey, nurses and psychologists appear to be more trusted by people in the GLBTI community than mainstream doctors. Further research is indicated to better understand the role of non-medical professions in providing inclusive care.
5.1 Experiences with, and barriers to Pap screening

As discussed above, the experience of heterosexism, homophobia, and cisgenderism affects GLBTIQ peoples’ health seeking behaviour. This research finds that many experience prejudice and discrimination in health care settings, which is a barrier to cervical screening or sexual health care. This is due, in part, to mainstream health care providers’ lack of knowledge, sensitivity and understanding about sexual and gender diversity. As a result LGBTI people do not trust, and frequently avoid health care and screening that involves coming out, exposing their bodies or discussing their sexual practices.

Only a third of the participants in this study were always out with their HCP, and a quarter had never come out. Two fifths only came out to their HCP if they thought it was relevant to the consultation. Even if LGBTI individuals have not personally experienced discrimination, or received misinformation about their screening needs from a doctor, knowledge about the existence of these attitudes and behaviours is a barrier that leads to some people avoiding health care and screening.

To deliver effective sexual health screening and care practitioners need to understand the range of diverse, complex sexual practices and be able to discuss these appropriately with their patients. Many of the participants in this research avoided discussing their sexual practices (which may include possible transmission routes for HPV) because they felt constrained by embarrassment or judged by the health care practitioner. Health care providers need to be well informed and non-judgemental about the diversity of sexual practices in order to provide effective sexual health care and screening.

5.3 Screening knowledge and intentions

Some women who have sex with women reported that their doctor had informed them that they did not need Pap tests if they had never had heterosexual sex. One participant explained that their doctor did not understand the range of sexual practices between women who have sex with women or the potential for HPV to be transmitted via these practices. While a confident person might be able to educate their HCP about gender and/or sexuality and their sexual practices, it should be the responsibility of all HCPs to know and be comfortable to communicate about these matters.

In addition to the barriers constituted by prejudice and discrimination discussed above some specific barriers to cervical screening also emerged. For example, some people avoid any procedure that involves vaginal penetration. The reasons for this were not the focus of this research, but some survey participants offered explanations. For example, for people who have never had penetrative sex fear of pain can be a barrier; having past experiences of sexual assault or post-traumatic stress disorder were also barriers for some participants. For trans people on male hormone therapy the specific procedures necessary to enable vaginal
penetration to obtain a cervical smear can lead to pain and discomfort. One person noted that this barrier had been overcome by an understanding doctor replacing Pap tests with HPV testing. Intersex people may feel uncomfortable about exposing their genitals to a doctor who is not sensitive to their needs and GLBTI people with disabilities may also experience multiple forms of discrimination when seeking sexual health care and screening.

Despite the barriers and challenges involved in participation in cervical screening this research found good levels of knowledge about the Pap test and its purpose, however, some misconceptions do exist. One fifth of the participants thought that Pap tests screened for ovarian cancers in addition to cell changes that can lead to cervical cancers. Just under a third thought that it also screened for STIs. A quarter of participants thought that people who had never had sex do not need to have Pap tests. The majority of participants had also heard of HPV and three quarters knew that it could be transmitted sexually via sexual intercourse or skin to skin contact. Just under half of the participants had received the HPV vaccine and were most likely to have received it at school.

Older participants were more likely to have had a Pap test than younger participants. One third of the participants had not had a Pap test for three or more years. A concerning seventeen percent of participants did not intend to have a Pap test in future. Getting a Pap test was most likely to be promoted by a reminder letter from a doctor or Pap Screen registry.

Despite concerns from the study population about general practitioners not understanding their needs or being inclusive, those who had a Pap test in the past two years were most likely to have had it carried out by a GP. GPs and health clinics appear to be the most likely place where GLBTIQ (and other) people have their Pap tests. This, taken together with the finding from this research that many GPs lack the sensitivity needed to ensure high quality care for GLBTIQ people, is problematic. To overcome this barrier it is imperative that general practitioners’ lack of knowledge about the sexual health and cancer screening needs of GLBTIQ people is addressed. Everyone who works in general practice should contribute to the practise or clinic by providing accepting and inclusive health care for everyone regardless of their sexuality, gender identity or sexual practices.

5.6 Inclusive research and inclusive sexual health care

The participants in this survey were diverse in terms of both gender and sexuality. Simple binaries such as man/woman or gay/lesbian are inadequate to represent the diversity of human sexuality’s capacity for attraction, identity and practices. As surveys such as this, that seek out diversity and offer a variety of options beyond the usual gender/sexuality binaries are rare, it is likely that a broader population based survey that offered similar options for individuals to explain the breadth of their attraction, identity and sexual practices would reap richer data than those that limit the possible responses to within binary options.
6. Recommendations

- It is important for health care providers who provide Pap and sexual health tests to be knowledgeable about gender diversity, intersex variations and the range of sexual practices. Further, health care providers should be trained to understand the diversity of human sexuality and gender, and all services should be inclusive, non-judgemental, safe places for everyone who needs preventative screening, and any kind of health care.
- Diversity training and accreditation, and sexual health education should be part of pre-service training for all health care providers, particularly GPs and nurses. To ensure this universities providing pre-service training should include sexual and gender diversity and inclusive, sensitive care in the curriculum.
- In service diversity training and sexual health education should be provided for all health care providers, particularly GPs, nurses and their staff.
- Pap Screen Victoria should pursue the provision of accreditation for physicians and others who provide Pap testing to confirm they have participated in diversity training to identify their practises as inclusive and sensitive to the needs of GLBTIQ people.
- Pap Screen Victoria should commence discussions with Gay and Lesbian Health Victoria about the possibility of providing diversity training and accreditation in the form of the ‘rainbow tick’.
- A directory of accredited health professionals and sexual health services that are LGBTIQ inclusive would help people in these populations to find health services that will meet their needs.
- This research finds that word of mouth is an effective way of facilitating access to inclusive, GLBTIQ sensitive practitioners. Given this finding, the possibility of peer education in the various communities should be investigated.
- A range of online education resources and information for GLBTIQ people should be provided. This should include smart phone/tablet apps, YouTube and all forms of social media to educate both LGBTI people and health care providers.
- The national curriculum for sexuality education should include correct information about whom requires regular Pap tests. Including information related to people of trans and intersex experience.

7. References


