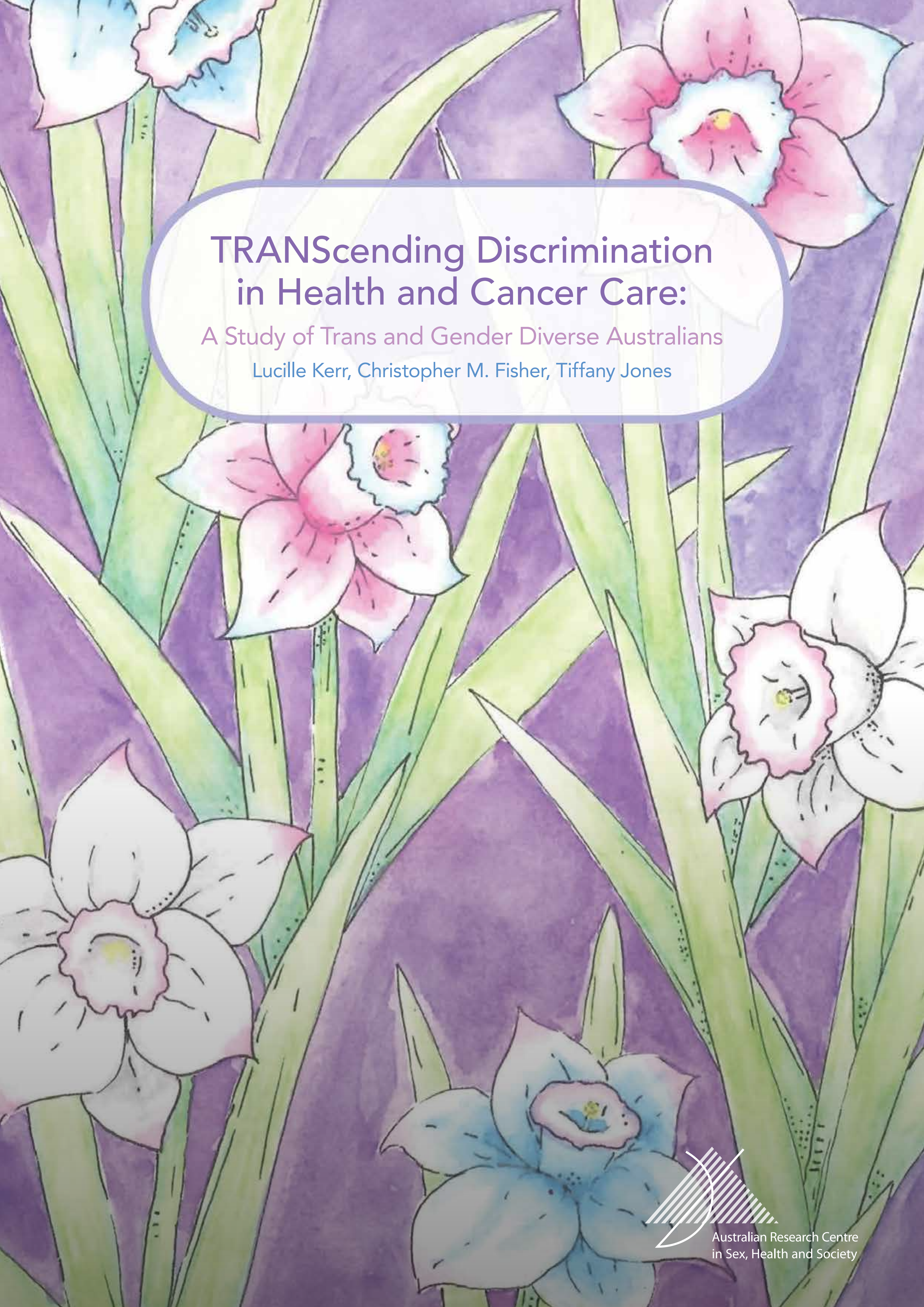

TRANSCending Discrimination in Health and Cancer Care:

A Study of Trans and Gender Diverse Australians

Lucille Kerr, Christopher M. Fisher, Tiffany Jones

Australian Research Centre
in Sex, Health and Society

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2019

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Suggestion citation:

Kerr, L., Fisher, C.M., Jones, T. 2019. *TRANSCending Discrimination in Health & Cancer Care: A Study of Trans & Gender Diverse Australians*, (ARCSHS Monograph Series No. 117), Bundoora: Australian Research Centre in Sex, Health & Society, La Trobe University.

DOI: 10.26181/5d3e1cc21a99c

ISBN: 978-0-9953969-5-1

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Acknowledgements

This study has been made possible and strengthened with the help of many in the trans and gender diverse community. Firstly, we would like to thank all of the people who took the time to either chat with us or fill out the survey, from the initial key informant interviews through to the main survey and interviews, we have been very privileged to have so many people share so many valuable insights and often intimate experiences.

We would also like to show our appreciation for every person and organisation that promoted the study and provided feedback on the design including (but not limited to): Transgender Victoria - especially Andrew Eklund, Sally Goldner and Brenda Appleton, Jeremy Wiggins, Shoshana Rosenberg, Dr Ruth McNair, Gender Diversity Australia, The Gender Agenda (JOY 94.9), Dr Damien Riggs, t150, Northside Clinic, Commissioner Ro Allen, Zoe Belle Gender Collective, Hares & Hyenas, Alice's Garage, Australian Transgender Support Association Queensland, Transgender Tasmania, Transfolk of WA, GenDA, Trans Health Australia, and Northwest Rainbow. Additionally, other people shared it in private groups or as individuals, many did it unbeknownst to us, and we are most grateful for this. It is because of such support that we surpassed the sample size we aimed for and have such rich data.

We would also like to acknowledge and pay our respects to the Wurundjeri people of the Kulin nation, who are the traditional custodians of the land on which La Trobe University (Bundoora campus) stands.

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Preface from Sally Goldner

It is my honour and pleasure to write the preface to Lucille's report *TRANScending Discrimination in Health and Cancer Care: A Study of Trans and Gender Diverse Australians*.

Many times, in the last 25 years of my life since being more my authentic self, finding a supportive and inclusive health professional (in a range of aspects of health) has been a matter of luck. This is of course far from ideal: every person has a right to inclusive and equitable health care. Rather than being down to luck, equality, equity and inclusivity needs to be the 100% rule.

When the focus of health care for trans, gender diverse and non-binary (TGDNB) people turns specifically to cancer, the binary (either/or) nature of our society overwhelmingly has an impact. I remember at a clinic in the late 1990's (which in fairness was very good) being asked by a less experienced GP "so when was your last Pap smear?" This assumes someone like myself (sex assigned male at birth (AMAB)) has had lower surgery. I'm not saying whether I had completed surgery or not at that point (or now either). I was able to deal with the situation with humour. But for another person who has faced case after case of discrimination it might have been the proverbial "death by 1000 paper cuts" and caused distress.

I also recall parking one day in a location just outside Melbourne's CBD. I saw a sign: "the prostate organisation – working together for men's health." And I thought: would I be understood and welcome there?

Certainly, cases like these can be a case of unconscious bias or "you don't know what you don't know." All the same, with more TGDNB people living as our authentic selves, health care, both at the front end in clinics and in other situations e.g. research, funding, will need to move forward to ensure inclusivity and equity. I mention funding as it is possible some government funding for breast cancer is under the branch that deals with women's health. Given all bodies and all gender identities may need breast screening, any possible barriers such as these need urgent removal.

Lucille's research will definitely help equity and inclusivity. We need inclusive healthcare everywhere e.g. all suburbs, regional and rural not just inner metropolitan, and locations with culturally diverse populations. I urge people to read and act on this report as quickly as possible.

I can only say what a pleasure it was to be involved in the preparation of the research. Lucille's careful preparation meant there was very little to change – and that is a great piece of allyship and quality work. The fact that 537 people felt comfortable to respond to the need for research in one "niche" of TGDNB health speaks to the heart that went into the preparation of the research. The collaboration of expertise and willingness to participate now provides a way forward for Australia and maybe other locations. Further, an indirect bonus is that the terms used for self-identification in the report shows more evidence that the façade of the gender binary is rapidly dissolving – and not before time.

Lucille’s work creates better health for people whose health is often damaged in other ways through no fault of our own. Lives can be saved and changed for the better because of this report. Thanks again Lucille and team. To those service providers reading this report I urge your organisation to please adopt the report’s recommendations.

Sally Goldner AM
July 2019

Sally Goldner’s twenty-year involvement in Victoria’s LGBTIQ communities includes Transgender Victoria, co-facilitating Transfamily, presenting 3 CR’s “Out of the Pan” and as Bisexual Alliance Victoria Treasurer. She was awarded an Order of Australia in 2019, is a life member of 4 organisations, the 2015 LGBTI Victorian of the year and joined the Victorian Women’s Honour Roll in 2016.

1. Executive Summary

The Trans Health and Cancer Care Study was conducted in 2018-19 and involved 537 trans and gender diverse (TGD) people from across Australia over the age of 18. Results of the study highlight ongoing challenges faced by TGD persons in Australia in their experiences of gender affirmation, accessing healthcare and their awareness and participation in cancer care. Overall, considerable work across practice, policy and research, remains for Australia to provide equitable experiences in health and cancer care for this community.

The sample was young, with a particularly strong response from those aged 18-24 (60.7%). There was a variety in pronoun usage, with 40.6% using they/them/theirs. Almost a third of the participants had experienced homelessness at some time, over a third experienced neurodiversity and a quarter disclosed a disability. Over half of participants were in the lowest income bracket ($0-$18,200), which is three times that found in the Australian population (Australian Tax Office, 2019).

1.1 Experiences of Gender Affirmation

There was much diversity in the experiences of gender affirmation. Key issues identified include limited ability to change identifying documentation, sourcing hormones from somewhere other than a healthcare provider, high rates of disliking their body, limited access to medical gender affirmation, and high levels of discrimination.

- Only one in ten participants reported that they have been able to change all of their documentation.
- Almost one in ten trans women get hormones from sources other than a healthcare provider.
- Over two thirds of the sample indicated that they had strong or moderate dislike for their bodies.
- Of the participants desiring gender affirming care, 43.2% reported that at some time in the past year they had been unable to access this.
- Only 8.8% of participants said they had not experienced any form of discrimination or abuse.
- One in five participants had been physically assaulted.
- Just over a quarter had experienced sexual assault.

1.2 Accessing Healthcare

The physical and mental health of TGD Australians continues to be poorer than the general population. Accessing healthcare for our participants was highly problematic, with high levels of unmet healthcare needs, discomfort discussing their needs, feeling misunderstood, emergency department avoidance, barriers to care, numerous instances of poor treatment in the healthcare system and hesitancy to disclose their gender.

- Only 3.4% of participants rated their health as excellent.
- Kessler 6 scores indicated that over half of participants had significant levels of distress.
- Almost half of participants reported a time in the last year they needed healthcare but did not receive it.
- Most participants were either very uncomfortable or uncomfortable (81.3%) discussing their needs as a TGD person with a healthcare provider that they did not know.

- Approximately a quarter of participants indicated that in the past year they did not have a health professional that had a good understanding of their healthcare needs and preferences.
- Of those who needed emergency care at some point, 41.3% did not attend the emergency department because they were TGD.
- The most common barriers that sometimes or often stopped participants going to the doctor were too many other things to worry about (70.7%), inability to find a doctor they are comfortable with (68.9%), being too busy (59.6%) and fear of mistreatment (58.8%).
- Almost a third had to educate their healthcare provider on TGD issues in the last year.
- Almost a quarter have been refused gender affirming care.
- One in five have been refused general healthcare.
- Within a healthcare setting, 14.2% have been verbally harassed, 5.7% have experienced unwanted sexual contact and 2.3% have been physically attacked.
- One in eight participants said that they never disclose their gender to healthcare workers.

1.3 Cancer Care and Awareness

Our findings in relation to cancer care show that many TGD Australians would delay seeking care if they had a cancer symptom, there is limited awareness likely due to awareness campaigns not reaching this community, healthcare providers are not having the relevant conversations and there is a resulting under-screening in this population. In an open-ended question about desired cancer information, participants indicated that they most wanted to know more about TGD specific issues.

- If they had a symptom they thought was a sign of cancer, one in six participants said they either would not make an appointment or would wait up to a year, and over a third said they would make an appointment within a month to a few months.
- For many of the cancer awareness questions, there was a high rate of 'I don't know' responses.
- Most participants indicated that their healthcare provider had never talked to them about cancer (60.5%).
- The reported rate of HPV vaccination for the age brackets were 47.0% in 18-24, 52.2% in 25-34, 18.2% in 35-44, and for 45+ no one had received this vaccination.
- Half of people with a cervix eligible for cervical screening never had a healthcare provider recommend this.
- Over half of eligible people with a cervix had never had cervical screening.
- Only 18.7% of eligible people with a cervix reported being regular screeners.
- Of those who had cervical screening, over a quarter had received an abnormal result.
- More than half of participants self-checked breast or chest tissue 'never' or 'rarely'.
- The highest rated responses on what would help participants access cancer care were training of healthcare workers in TGD needs, welcoming services that specifically address TGD concerns, and cancer awareness campaigns specific to TGD people.

2. Introduction

> *My feelings were all over the place when I was first diagnosed. I was like, 'fuck!' and I knew I wasn't stage 4 and things like that, but at that time I was like, 'fuck, I don't know.' I knew I'd get through it - I've been through worse I suppose. You just keep going through it, and you're all by yourself because no one goes through it with you, you just have to go through it yourself. People can be around you when you go through cancer but they don't go through it with you, it's a very personal thing to have to deal with and understand… and in all honesty, my testicles had caused so many problems for me throughout my life, I should never have had them.*
>
> \- Trans woman, testicular cancer.

> *I was eleven months old when I was diagnosed, so every moment in my life that I can remember has a connection to cancer… I would tell that experience to other children who were at school during show and tell, you have to share something about yourself, and this was just so normal to me, I'm like, 'oh yeah, I had cancer,' and everybody would gasp and suddenly, 'are you okay?' and 'yeah, no I'm fine.' So, I felt very other from them because they didn't have that experience and I knew that I was very, very different in that kind of regard - which in a sense is a little bit intersectional to being trans. So yeah, it was isolating in the sense that I didn't know how to approach, quote unquote, normal people, people who didn't have connections with cancer, because it was always treated as something sad, and it is sad, but that was their entire sum of their perception.*
>
> \- Trans man, liver cancer.

The Trans Health and Cancer Care Study was conducted to help address the gap in evidence that exists for trans and gender diverse people in health and cancer care, particularly within an Australian context. This survey builds on the findings from previous Australian research on trans and gender diverse health and wellbeing, which has highlighted issues related to marginalisation and discrimination, leading to poorer health and wellbeing in this community (Boza & Nicholson Perry, 2014; Couch et al., 2007; Hyde et al., 2014; Jones, del pozo de Bolger, Dune, Lykins, & Hawkes, 2015; Riggs & Due, 2013; Smith et al., 2014; Strauss et al., 2017).

The invisibility of trans and gender diverse people in population-based research and registries means that this community is rarely considered in health and cancer policies or allocation of resources (Ansara, 2016; Burkhalter et al., 2016). Further to this, there is a paucity of literature that health professionals can refer to when seeking guidance on the treatment and care issues for trans and gender diverse people throughout healthcare, but also specifically within cancer care and screening (Kerr & Jones, 2017). Limited research exists on the epidemiology of cancer in the trans and gender diverse community, and whilst there appears to be no increased risk from gender affirming hormones (McFarlane, Zajac, & Cheung, 2018), emerging evidence suggests specific patterns of cancer (Silverberg et al., 2017). Overall, health and cancer care workers continue to be under-informed on the health and wellbeing needs of trans and gender diverse individuals, resulting in problems with service provision, hence the necessity for more attention directed to this group in research, policy and practice.

This report details the results from an online survey for trans and gender diverse people on health and cancer care and contains a selection of quotes from qualitative interviews with trans and gender diverse people who have had cancer. Following the introduction, methodology is outlined, followed by a chapter on experiences of gender affirmation, including data on discrimination and community engagement. Sections detailing the findings in relation to accessing healthcare, and cancer care and awareness make up the central part of this report. Finally, the last chapters are on the conclusions and recommendations for practice. Trans and gender diverse community organisations were consulted regarding design, and key informant interviews were also conducted to guide the research. We hope that the result is a sensitive and accurate portrayal of trans and gender diverse individuals' experiences within the area. There are particular difficulties associated with capturing diversity in quantitative research; individual experiences may not always be recognisable from the numbers, obscuring the diversity of lived experiences. Much care has been taken to be inclusive and representative while staying true to the story told by the aggregate data.

The decision to use the umbrella term 'trans and gender diverse' was made based on community recommendation. This term is used to encompass transgender individuals and all gender non-binary, non-conforming or diverse people. Whilst we recognise that trans women are women and trans men are men, for the purposes of this research and its' aims to reach a broad audience, we will use the terms 'trans women' and 'trans men'. The phrase 'gender diverse' is intended to capture the variety of other identities of our survey participants, including genderqueer, non-binary, genderfluid, agender, butch woman, demigirl/demiboy, auti- or neuro-gender, third gender, and more.

3. Methodology, Survey Instrument & Sample

3.1 Methodology

This study used principles found in community-based participatory research (Adams et al., 2017; Gehlert & Coleman, 2010; Hacker, 2017). This meant that the community was consulted and involved in important decisions, including the survey design and writing up the report. Survey questions were included or left out based on recommendations and use of language has been carefully attended to. Additionally, prior to starting this research, a key informant interview study (HEC18034) was conducted with trans and gender diverse community members and professionals/academics that had relevant knowledge to guide development of the survey.

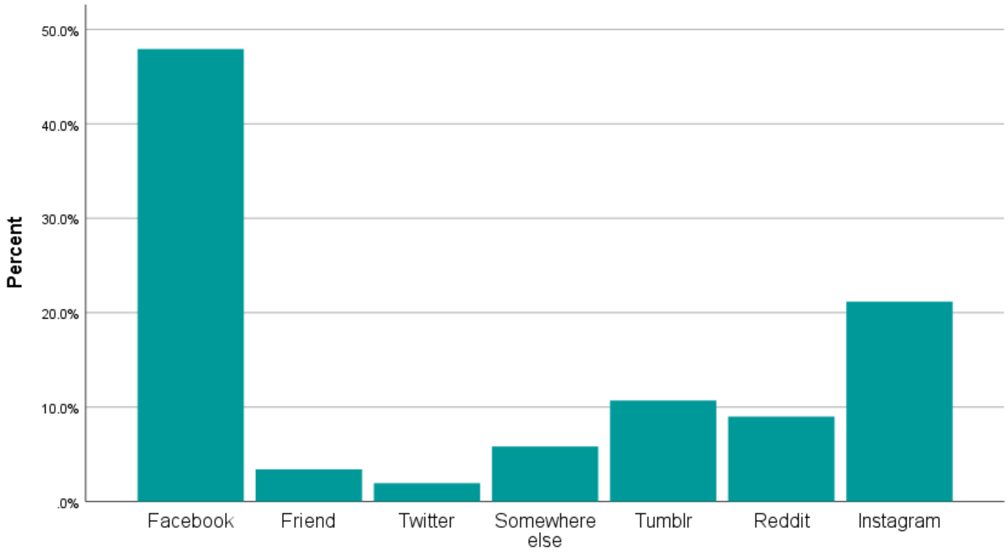
3.2 Survey Instrument

The survey was an anonymous questionnaire provided in a secure online format. Questions were informed by the community reference group, the 2016 Australian Census, the ABS Survey of Health Care, the Canadian study Trans PULSE (Bauer & Scheim, 2015), the 2015 U.S. Transgender Survey (James et al., 2016), and the Cancer Awareness Measure (Stubbings et al., 2009). The survey began with general demographic and 'about you' questions, followed by a series of questions on healthcare and experiences in this area, then sections on gender affirmation, cancer care and experiences, and finally more 'about you' questions. There were options throughout the survey at various points for participants to write text responses, and many participants chose to do this. Almost all questions contained a 'prefer not to answer' response.

3.3 Sampling Method

This sample is a convenience sample obtained through online Facebook advertising. Trans and gender diverse people and organisations also shared the post amongst the community, generating a snowball sample. Participants were asked at the end of the survey how they heard about it (Figure 1), with almost half of participants indicating it was through Facebook, one fifth through Instagram (an area of Facebook advertising), one tenth through Tumblr, and 9.0% through Reddit. Drawing on this data, snowball sampling accounts for at least 30.8% of the sample.

Figure 1 - Could you please tell us how you heard about this survey?



3.4 Ethics

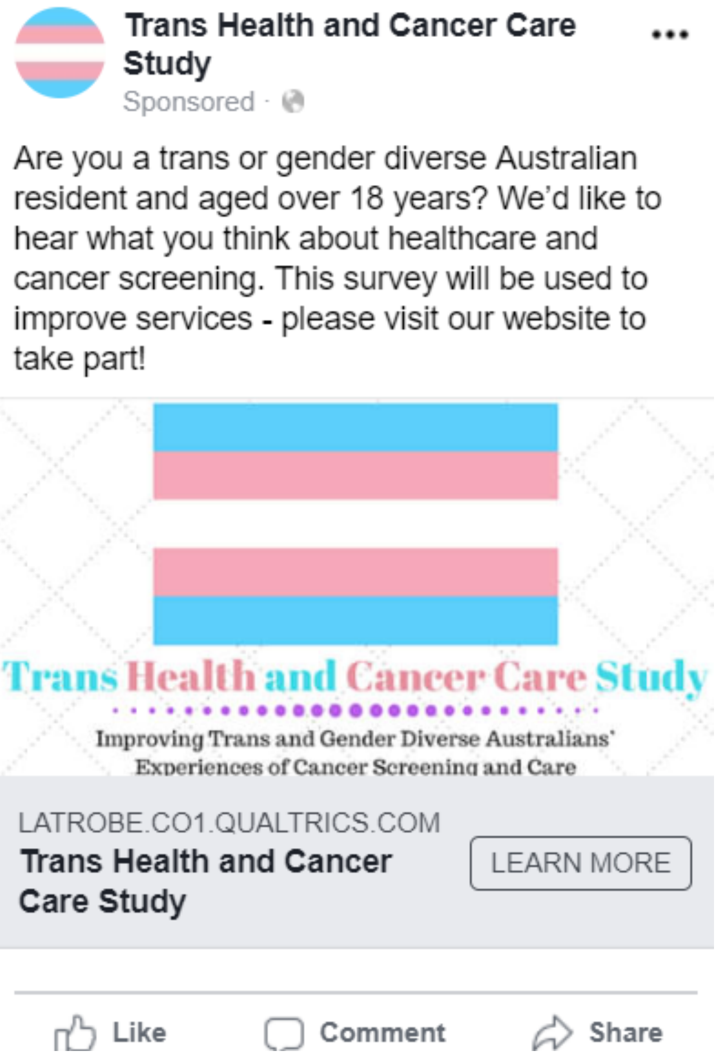
Much effort and time was devoted to designing and conducting this research in an ethical manner, placing emphasis on community consultation to ensure that the study was sensitive to TGD people's needs. The study received ethics approval from La Trobe University's Human Research Ethics Committee (HEC18341).

3.5 Survey Administration

The survey was launched with advertising on the 5th of September 2018, and the final completed response was recorded on the 21st of January 2019. Facebook advertising contained a link to the Qualtrics website where the survey was hosted (Figure 2).

The Participant Information Statement began the survey, describing the survey purpose, what participants would be asked to do, and benefits of participation. For any participants that did not agree to participate, they were re-directed to a page that thanked them for their time. For participants that did agree to participate, they went straight to the first section of the survey, 'about you'. Participants were directed to cancer screening questions (cervical, breast, and prostate) based on what body organs they said that they had. Average completion time was approximately 22 minutes.

Figure 2 – Facebook Advertising.



Trans Health and Cancer Care Study
Sponsored ·

Are you a trans or gender diverse Australian resident and aged over 18 years? We'd like to hear what you think about healthcare and cancer screening. This survey will be used to improve services - please visit our website to take part!

Trans Health and Cancer Care Study

Improving Trans and Gender Diverse Australians' Experiences of Cancer Screening and Care

LATROBE.CO1.QUALTRICS.COM
Trans Health and Cancer Care Study

An information sheet about cancer signs/symptoms and screening for trans and gender diverse people was available for download at the end of the survey. Additionally, at the end of the survey was the option for people to give their email address for an interview if they had been diagnosed with cancer.

3.6 Data Management and Analysis

Survey responses were automatically saved on completion or timing out. A total of 854 surveys were saved, roughly one third of which were incomplete surveys. Data cleaning removed 21 responses which were illegitimate (mischievous responders), leaving 537 participants. Data analysis in this report is descriptive of trans women, trans men and gender diverse participants. SPSS was used to analyse the data.

3.7 Demographics of the Sample

The total sample size of the survey was 537. There was a wide variety in participant's gender, including many of participants' own terms as entered into a provided text box (Table 3.1). Agender was the most frequent response to 'something else', used by 11 participants (2.0%). Gender responses had to be simplified for analysis, so three groups were created – trans woman, trans man, and gender diverse (Table 3.2). Gender diverse people made up the largest portion of the group (44.3%), followed by trans men (33.0%) and trans women (22.7%). People who were assigned female at birth were more likely to respond to the survey (70.9%) compared to people who were assigned male at birth (26.6%) (Table 3.3). The sample was young overall, with 60.7% being aged between 18-24, and 20.5% between 25-34. (Figure 3).

Table 3.1 What is your gender?

	n	%
Woman	31	5.8%
Man	26	4.8%
Trans Woman	90	16.8%
Trans Man	146	27.2%
Brotherboy	1	0.2%
Genderqueer	32	6.0%
Non-binary	142	26.4%
Gender-fluid	29	5.4%
Something else	40	7.4%
Total	**537**	**100.0%**

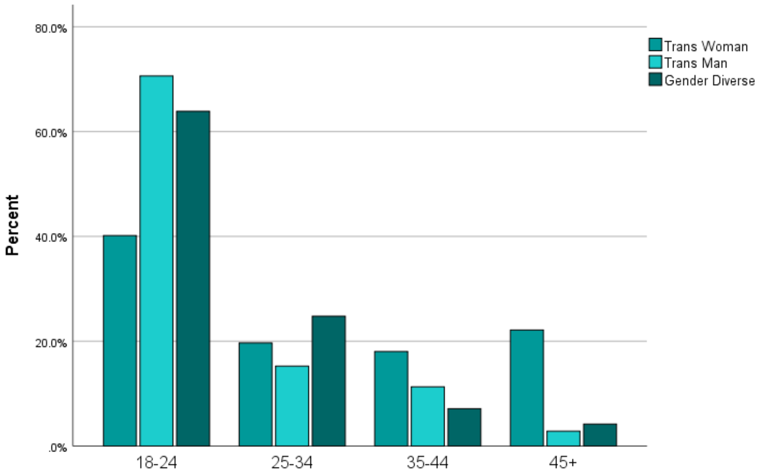
Table 3.2 Gender simplified to three groups.

	n	%
Trans Woman	122	22.7%
Trans Man	177	33.0%
Gender Diverse	238	44.3%
Total	**537**	**100.0%**

Table 3.3 Sex assigned at birth.

	n	%
Female	381	70.9%
Male	143	26.6%
Prefer not to answer	13	2.4%
Total	**537**	**100.0%**

Figure 3 – Age brackets.



> *I only realised I was non-binary about three or four years ago, but it was one of those things that when I found the word I was like, 'this is how I've been all my life and I just haven't had access to the vocabulary for it,' because when I was younger I thought I was binary trans, that I would be going towards becoming a man, and I'm like, no, that's not quite right either.*
> - Non-binary person, hereditary paraganglioma-pheochromocytoma syndrome.

All states and territories were represented, with Victoria slightly over-represented. New South Wales and Western Australia were somewhat under-represented while all other states and territories were similar when compared with 2016 Census data (Figure 4) (Australian Bureau of Statistics, 2018). Most respondents lived in major cities (76.6%), followed by inner regional areas (18.7%). Outer regional, remote, and very remote combined to make up 4.7% of the sample (Figure 5). In the general Australian population, 71% live in major cities, followed by 18% in inner regional, 8.6% outer regional and 2.1% in remote/very remote areas – the sample in this study was less likely to live in outer regional and remote/very remote areas, and more likely to live in major cities (Australian Institute of Health and Welfare, 2018a).

Figure 4 – State/Territory.

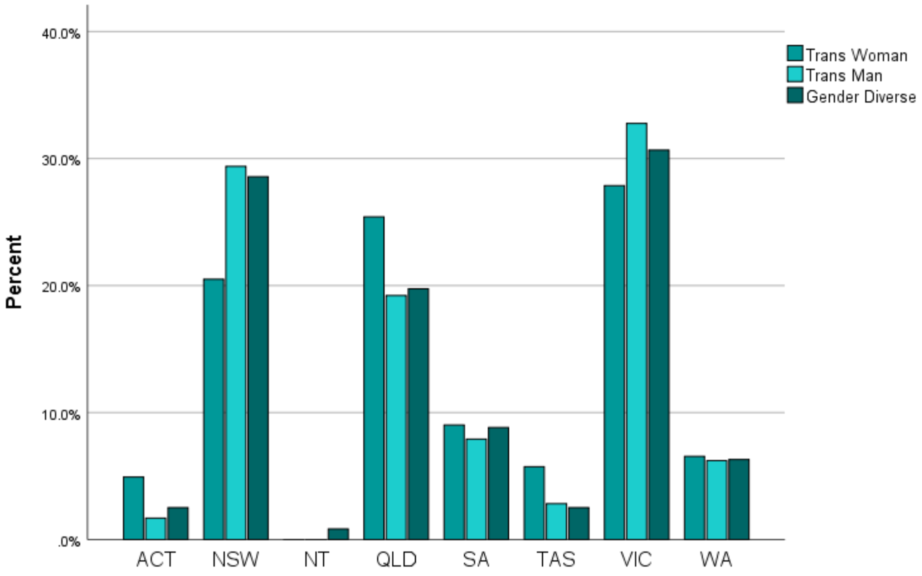
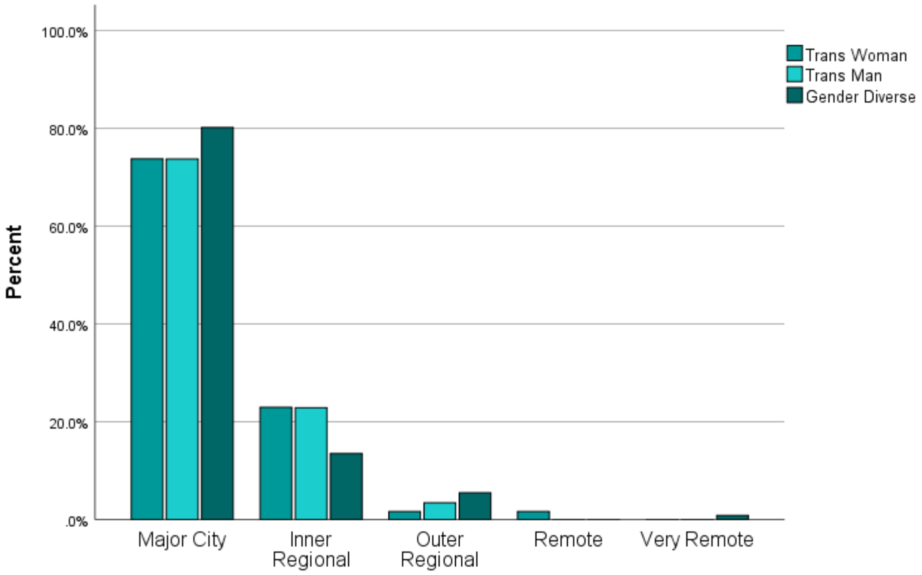


Figure 5 - ABS Remoteness Rating by postcode.



Participants were asked a series of 'about you' questions both at the start and the end of the survey (some of the following tables contain fewer participant responses as a result of not every participant fully completing the survey). Most of the questions contained a 'prefer not to answer' option, and these have not been included in the frequency tables below. Table 3.4 shows which pronouns participants indicated that they used, with a quarter opting to click multiple responses, and a large proportion making use of the pronouns 'they/them/theirs' (40.6%).

Table 3.4 What pronouns do you use, if any? (Multiple response answer).

	n	%
She/Her/Hers	180	33.5%
He/Him/His	227	42.3%
They/Them/Theirs	218	40.6%
Zie/Hir/Hirs	6	1.1%
I don't use pronouns	15	2.8%
I don't mind	72	13.4%
Multiple	140	26.1%

Participants described their current relationship and marital status (Figures 6-7); around half of the sample were single, most of whom were not dating. Being in a relationship was also common, with 24.8% living together, 20.6% living apart, and 3.4% in a polyamorous relationship. Three quarters of participants were never married, with 10.1% in a de facto relationship and 6.8% married – comparatively, the 2016 Census found 10.4% of Australians in a de facto relationship, and 48.1% married (Australian Bureau of Statistics, 2018).

Figure 6 - Relationship status.

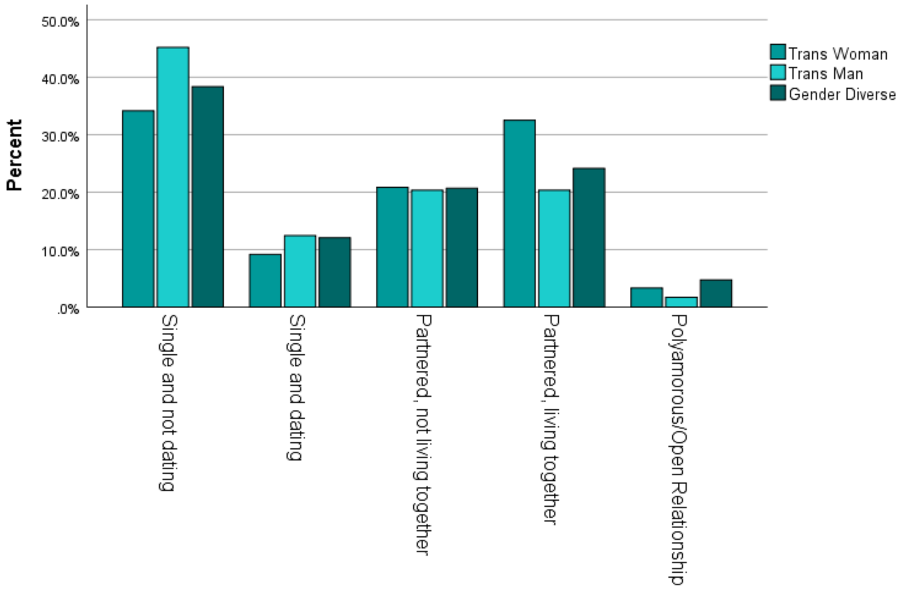
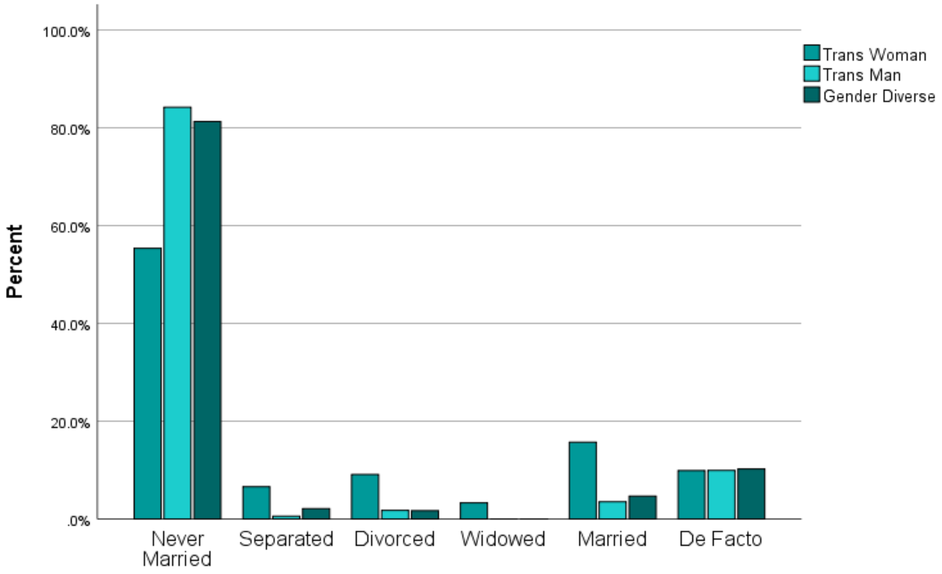
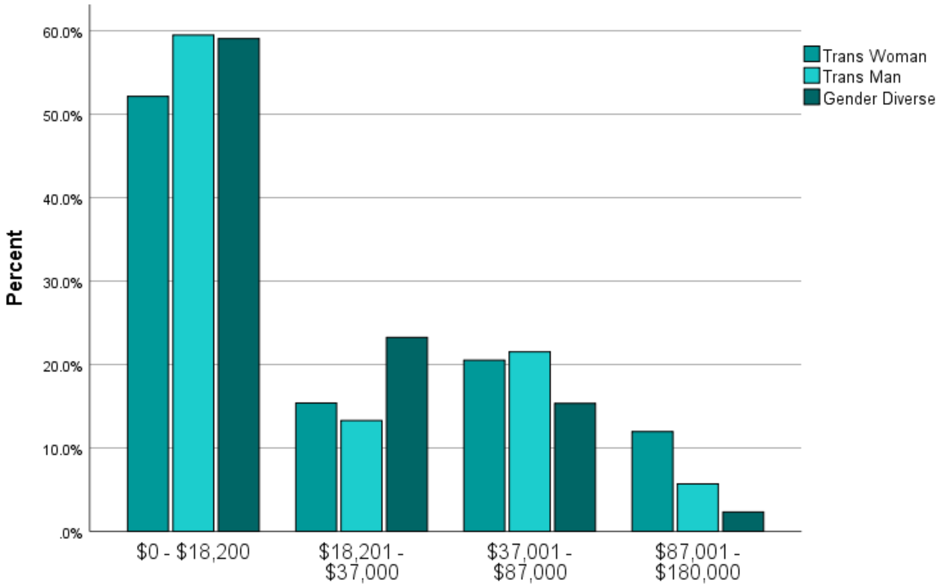


Figure 7 – Marital status.



Individual incomes were low, with 57.6% indicating that they were in the lowest bracket (Figure 8), which is higher than has been found in previous Australian research on TGD people (45.1%), however, this may be partly a result of the young sample and high proportion of students (Hyde et al., 2014). Data from the 2016-17 financial year show that 19.1% of Australians were in this bracket (Australian Tax Office, 2019).

Figure 8 - Individual income before tax.



> *I had to change my passports and everything… and basically they just weren't having it, so I got sacked. I was no more stupider or smarter about my job, but they treated it like I had brain surgery.*
>
> - Trans man, lung cancer and lymphoma.

Education levels were high compared with 2016 Census data, with 30.0% having a Bachelor's degree or above (22% in the Census) (see Table 3.5) (Australian Bureau of Statistics, 2018). Around one in ten participants did not complete high school (9.4%).

Table 3.5 What is your highest level of education completed?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Did not complete high school	9	7.4%	12	7.0%	28	12.1%	49	9.4%
Completed high school	33	27.3	65	38.0%	81	34.9%	179	34.2%
Certificate I-IV	16	13.2%	24	14.0%	27	11.6%	68	12.8%
TAFE/trade school	9	7.4%	9	5.3%	11	4.7%	29	5.5%
Diploma/Associate degree	12	9.9%	18	10.5%	13	5.6%	43	8.2%
Bachelor's degree	30	24.8%	27	15.8%	54	23.3%	111	21.2%
Graduate certificate	5	4.1%	4	2.3%	6	2.6%	15	2.9%
Master's degree	5	4.1%	12	7.0%	8	3.4%	25	4.8%
Doctoral degree	2	1.7%	0	0.0%	4	1.7%	6	1.1%
Total	**121**	**100.0%**	**171**	**100.0%**	**232**	**100.0%**	**524**	**100.0%**

The most common living arrangement was with family (44.3%), with a relatively low level of living alone (12.3% compared with 2016 Census data of 24.4%) – previous Australian research found that 22.7% of TGD people lived alone (Table 3.6) (Australian Bureau of Statistics, 2018; Hyde et al., 2014). Approximately one fifth lived with their partner/s and another one in five lived with people who are unrelated to them.

Table 3.6 What is your current living arrangement?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Alone	22	18.0%	20	11.5%	23	9.8%	65	12.3%
With my partner/s	27	22.1%	37	21.3%	51	21.8%	115	21.7%
With family not dependent on me	38	31.1%	72	41.4%	91	38.9%	201	37.9%
With family dependent on me	12	9.8%	10	5.7%	12	5.1%	34	6.4%
With people who are unrelated	23	18.9%	35	20.1%	57	24.4%	115	21.7%
Total	**122**	**100.0%**	**174**	**100.0%**	**234**	**100.0%**	**530**	**100.0%**

Table 3.7 shows participants who had been diagnosed with an intersex variation. Only 0.5% indicated that this was the case.

Table 3.7 Have you been medically diagnosed with an intersex variation?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	0	0.0%	2	1.4%	0	0.0%	2	0.5%
Total	**100**	**100.0%**	**140**	**100.0%**	**181**	**100.0%**	**421**	**100.0%**

Participants described their sexuality in a number of ways, with the option to tick more than one box. The most common responses were pansexual (35.4%), bisexual (30.4%), and asexual (21.0%). Both pansexuality and asexuality were more common in this sample than in previous Australian research with TGD people (Riggs & Due, 2013).

Table 3.8 How would you describe your sexuality? (Multiple response answer).

	n	%
Heterosexual	40	9.4%
Gay	61	14.4%
Bisexual	129	30.4%
Lesbian	61	14.4%
Pansexual	150	35.4%
Queer	44	10.4%
Asexual	89	21.0%
Total	**424**	**100.0%**

> *I was always a lesbian, I'd never had sex with men. I actually changed my orientation after the cancer because women weren't interested in me anymore… I think I'm a bit pansexual or demisexual or whatever they call it, because I'm really attracted to people's personalities more than their physical form, so I never had a type of woman or a preferred skin colour, hair colour, racial characteristics, body shape – I always just like the person and found them attractive because I liked them.*
>
> - Trans woman, prostate cancer.

Participants also indicated the terms that best described their gender expression and were able to tick more than one box (Table 3.9). There was a wide variety in gender presentation; many participants chose to tick more than one box.

Table 3.9 How would you describe your gender expression? (Multiple response answer).

	n	%
Feminine	137	32.3%
Masculine	197	46.5%
Non-binary	158	37.3%
Androgynous	142	33.5%
Genderqueer	81	19.1%
Femme	54	12.7%
Butch	43	10.1%
Total	**424**	**100.0%**

The sample included 26 Aboriginal or Torres Strait Islanders (6.3%) (Table 3.10). This is a higher percentage than is found in the general Australian population (3.3%) (Australian Institute of Health and Welfare, 2018a).

Table 3.10 Are you Aboriginal or Torres Strait Islander?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	7	7.1%	5	3.6%	14	7.9%	26	6.3%
Total	**98**	**100.0%**	**139**	**100.0%**	**178**	**100.0%**	**415**	**100.0%**

One in eight participants were not born in Australia. Approximately one in twelve speak a language other than English at home (Tables 3.11-3.12).

Table 3.11 Were you born in Australia?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	14	14.0%	18	12.9%	20	10.9%	52	12.3%
Total	**100**	**100.0%**	**140**	**100.0%**	**183**	**100.0%**	**423**	**100.0%**

Table 3.12 Do you speak a language other than English at home?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	6	6.0%	13	9.2%	15	8.3%	34	8.1%
Total	**100**	**100.0%**	**141**	**100.0%**	**180**	**100.0%**	**421**	**100.0%**

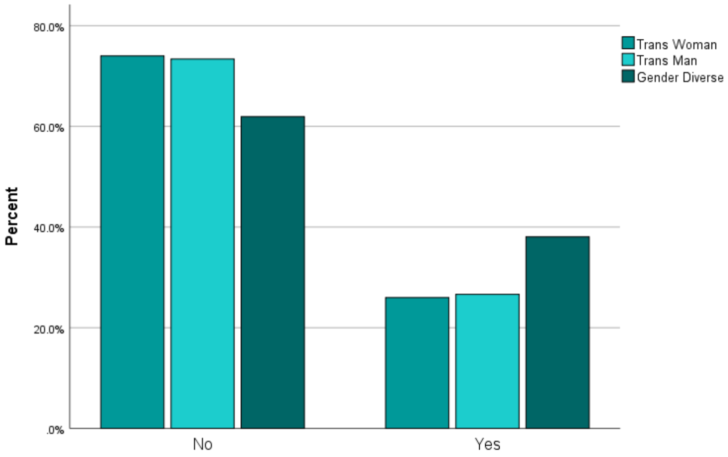
Over half the participants indicated that they were non-religious (54.7%), almost twice that found in the general Australian population (Australian Bureau of Statistics, 2018); 20.1% of the participants were agnostic and 7.6% pagan (Table 3.13). The trend to agnosticism distinguished these participants from other studies on trans Australians (of whom 86% were non-religious) (Jones et al., 2015).

Table 3.13 What are your religious/spiritual views?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Agnostic	15	15.6%	29	21.2%	38	21.7%	82	20.1%
Buddhist	1	1.0%	1	0.7%	2	1.1%	4	1.0%
Catholic	3	3.1%	2	1.5%	4	2.3%	9	2.2%
Islam	0	0.0%	0	0.0%	2	1.1%	2	0.5%
Judaism	0	0.0%	4	2.9%	5	2.9%	9	2.2%
No religion	56	58.3%	79	57.7%	88	50.3%	223	54.7%
Other Christian denominations	3	3.1%	2	1.4%	5	2.9%	10	2.4%
Pagan religion	9	9.4%	7	5.1%	15	8.6%	31	7.6%
Something else	9	9.4%	13	9.5%	16	9.1%	38	9.3%
Total	**96**	**100.0%**	**137**	**100.0%**	**175**	**100.0%**	**408**	**100.0%**

Almost a third (31.3%) of participants had experienced homelessness at some point, which is consistent with U.S. research (James et al. 2016). Homelessness was most likely to be reported by gender diverse participants (Figure 9).

Figure 9 – Homelessness.



Participants were asked if they would like to disclose any areas of neurodiversity or disability, and in both cases given a text box to provide further description. In terms of neurodiversity, 38.0% responded yes, with autism and ADHD being common responses. A quarter of people (25.8%) disclosed a disability, with mental illness occurring frequently, but also physical disabilities such as chronic pain, hearing impairment and fibromyalgia. As a comparison, an estimated 18% of Australians have a disability (Australian Institute of Health and Welfare, 2018a).

Table 3.14 Would you like to disclose any areas of neurodiversity?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	N	%	N	%
Yes	30	30.9%	46	34.6%	76	44.7%	152	38.0%
Total	**97**	**100.0%**	**133**	**100.0%**	**170**	**100.0%**	**400**	**100.0%**

Table 3.15 Would you like to disclose any areas of disability?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	N	%	N	%
Yes	15	15.5%	27	20.0%	61	36.3%	103	25.8%
Total	**97**	**100.0%**	**135**	**100.0%**	**168**	**100.0%**	**400**	**100.0%**

Many participants were students. Almost half were currently studying (44.4%) (Table 3.16).

Table 3.16 Are you currently studying?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	N	%	n	%
No	74	74.7%	63	45.3%	96	53.0%	233	55.6%
Yes – full time	16	16.2%	61	43.9%	53	29.3%	130	31.0%
Yes – part time	9	9.1%	15	10.8%	32	17.7%	56	13.4%
Total	**99**	**100.0%**	**139**	**100.0%**	**181**	**100.0%**	**419**	**100.0%**

3.8 Limitations of the Survey

There were several limitations to the survey. These included the wholly online nature of the survey, that the sample is one of convenience, participants self-selected to participate, and the advertising may have been directed at trans and gender diverse people who are more open about their identity online. This means that it is likely the sample is missing people who do not access the internet (particularly Facebook, but advertising and promotion of the study was circulated elsewhere online, on radio and in the receptions of organisations), may contain a relatively high proportion of 'out' people who engage with the TGD community regularly, and also may have a relatively high level of people who have had issues with health and/or cancer care (as they may have been more likely to see the study as relevant to them and thus to take part). Another limitation to the survey is the young sample which means that certain cancer screening may not be relevant to them.

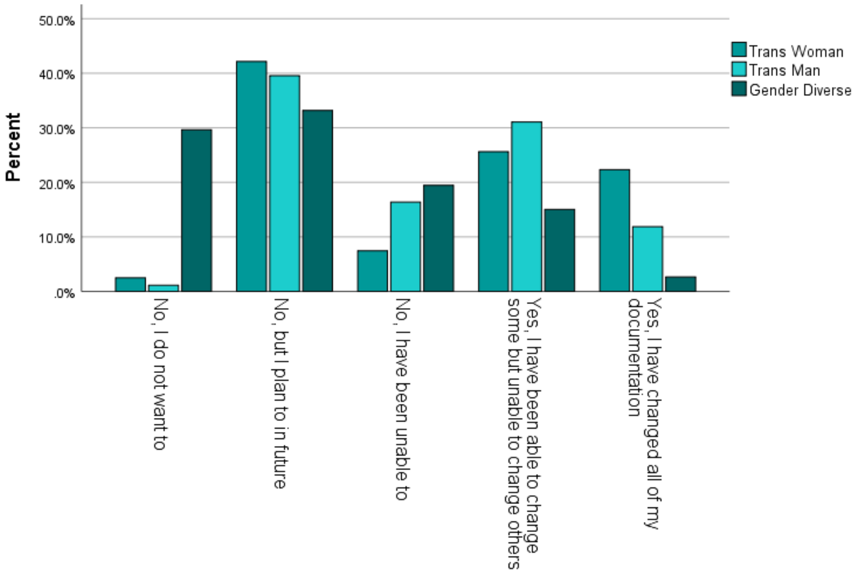
4. Experiences of Gender Affirmation

> *I had to battle the institution, I was put through therapies, I did two religious conversion therapies, state government, unofficial conversion therapy which is a lot of sitting on men's knees, and stuff like that… You had to report to psychiatrists every week, you had to do what they said… The women got social workers and all that, but we got nothing, well, I got nothing because there was no 'we' about it, there was only me and the women, and what they did was whatever they did for the women, they reversed it for me. So, I wasn't allowed to have earrings. Well, all my peers had earrings, so I was forever chucking an earring in and out. It was what the psychiatrists thought a man was, and that had to be projected onto me and I had to live it.*
>
> - Trans man, lung cancer and lymphoma.

> *I can pretty much guarantee there's no statistics on how many trans girls seek medical aid for erectile dysfunction, and if there is I've never heard of them, but I expect it wouldn't be that high because they're all told at commencement of HRT that you're going to lose your erections more than likely… Younger trans girls, some of them don't, that's not always the case, and some girls have dysphoria, but that was just an immediate assumption on [the doctor's] part that I'm a trans woman, so I must hate my penis and want to chop it off, and that's just not the case at all.*
>
> - Trans woman, prostate cancer.

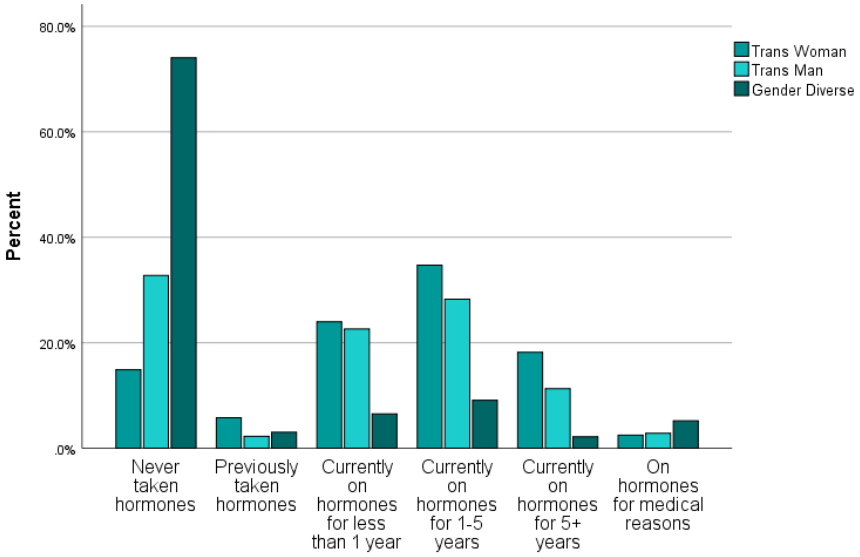
Participants were asked a series of questions on gender affirmation and care. The first question in this section was on changing documentation. The most common response was 'no, but I plan to in future' (37.4%), followed by 'yes, I have been able to change some but unable to change others' (22.9%), and 'no, I have been unable to' (15.6%). Around one in eight participants stated that they did not want to change their documentation, with this being considerably higher amongst gender diverse participants (29.6%) and very low amongst trans women (2.5%) and trans men (1.1%). Overall, one in ten have been able to change all of their documentation, with trans women being most likely to (22.3%), followed by trans men (11.9%), and gender diverse people to have done this at a low rate (2.7%). Previous Australian research has found that 21.1% have been able to change all their documentation, 30% of Canadian TGD people have been able to change all of their documents, and in the U.S. this drops to 11% (Bauer & Scheim, 2015; Hyde et al., 2014; James et al., 2016).

Figure 10 – Changing Documentation.



Just under half of the sample were currently on hormones, with 46.7% indicating that they had never taken hormones (Figure 11). Gender diverse people were most likely to report never taking hormones (74.0%). In 2007, TranZnation found that 73% of their participants had ever used hormones, and in 2014 it was reported in a trans mental health study that 59.8% of their participants were currently using hormones (Couch et al., 2007; Hyde et al., 2014). The lower hormone use in the current study is likely related to the high proportion of gender diverse and younger participants – 76.9% of trans women and 62.1% of trans men indicated that they were currently using hormones.

Figure 11 – Hormone Use.



Respondents who indicated they were currently or had previously taken hormones were then asked which hormones they had taken. The most common responses to this were testosterone (57.1%), oestrogen/estradiol (39.0%), spironolactone (21.3%), progestin/progesterone (16.0%) and cyproterone acetate (15.6%) (Table 4.1). In terms of gender differences: 65.9% of trans men had taken testosterone; and for trans women, 81.8% had taken oestrogen/estradiol, 44.6% spironolactone, 33.9% cyproterone acetate, and 26.4% progestin/progesterone. Only trans men had taken puberty blockers (5.1% of trans men), and gender diverse people reported that they had taken all of the hormones except puberty blockers, showing a diversity in the ways that hormones can help to affirm their genders. Only one person did not know what hormones they had taken (0.4%).

*Table 4.1 Please indicate which hormones you take or have taken.**

	n	%
Oestrogen/estradiol	110	39.0%
Testosterone	161	57.1%
Spironolactone	60	21.3%
Cyproterone acetate	44	15.6%
Progestin/progesterone	45	16.0%
Puberty blockers	9	3.2%
I don't know	1	0.4%

*Percentages based on participants who are taking or have taken hormones (n=282).

Respondents who take or had taken hormones were also asked what form the hormones were in. Injections (53.9%) was the most common response, followed by pills/tablets (41.5%) and cream/gel (18.1%). There were specific gender differences to the form of hormones: trans women made up 83.8% of people who take/had taken pills/tablets and 96.0% of people who used patches. Trans men made up 68.4% of people who reported injections, and 47.1% of people who used cream/gel.

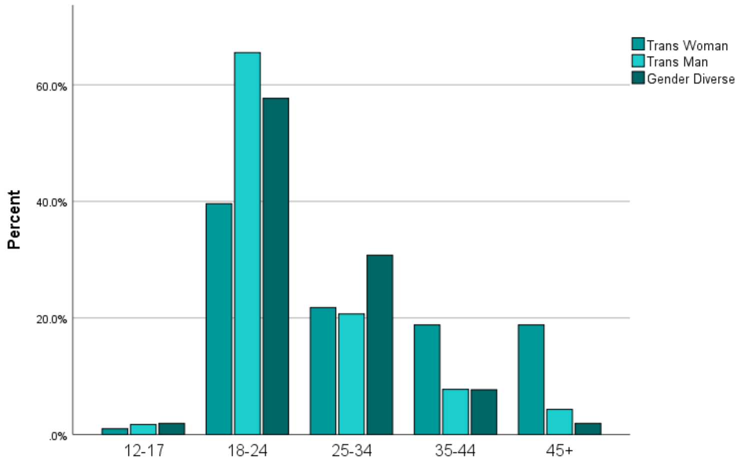
*Table 4.2 What form are or were these hormones in?**

	n	%
Pills/tablets	117	41.5%
Patches	25	8.9%
Injections	152	53.9%
Cream/gel	51	18.1%

*Percentages based on participants who are taking or have taken hormones (n=282).

Participants who indicated taking hormones were then asked at what age they first started. Young adulthood was the most common time: 54.3% started between the ages of 18-24, and 23.0% between the ages 25-34. Only a very small minority began hormones in early adolescence (ages 12-17, 1.5%).

Figure 12 – Age when started hormones.



Participants currently taking hormones were asked where they obtained their hormones from, with the vast majority responding that they only got their hormones from a healthcare provider (95.7%). Trans women were more likely to report getting hormones elsewhere (9.4%) (Table 4.3).

Table 4.3 Where do you currently get your hormones?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Only from a healthcare provider	87	90.6%	112	99.1%	48	98.0%	247	95.7%
Healthcare provider and friends, online or other sources	6	6.3%	1	0.9%	1	2.0%	8	3.1%
Only from friends, online, or other sources	3	3.1%	0	0.0%	0	0.0%	3	1.2%
Total	**96**	**100.0%**	**113**	**100.0%**	**49**	**100.0%**	**258**	**100.0%**

Rates of surgery were low; three quarters of participants reported not having had any surgery, likely due to the sample being generally young (Table 4.4). Previously, TranZnation reported that 39.1% of their participants had surgery, whereas in this survey 27.3% of trans women, 28.4% of trans men and 14.1% of gender diverse people had some form of surgery. Common surgeries for different genders included: mastectomy in trans men (23.9%) (similar to findings in TranZnation) and gender diverse people who were assigned female at birth (8.6%); orchidectomy (20.7%) and vaginoplasty for trans women (17.4%). Only 6.8% of trans men reported hysterectomies, which is lower than previously found in TranZnation (17.7%) (Couch et al., 2007). Two trans men reported they had phalloplasty (1.1% of trans men) and one trans man had had metoidioplasty (0.6% of trans men), which is unsurprising given the inaccessibility of these procedures in Australia, and is consistent with other studies (GLBTI Health and Wellbeing Ministerial Advisory Committee, 2014). Participants were given the option to enter in another surgery they had for gender affirmation, with facial feminisation reported by 8 trans women (6.6% of trans women) and tracheal shave by 3 (2.5%). Other surgeries entered into this text box include endometrial ablation, breast reduction, hair transplants and body sculpting.

Table 4.4 Never had surgery.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Never had surgery	88	72.7%	126	71.6%	195	85.9%	409	78.1%
Total	**121**	**100.0%**	**176**	**100.0%**	**227**	**100.0%**	**524**	**100.0%**

Table 4.5 Mastectomy (people assigned female at birth).

	Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%
Mastectomy	42	23.9%	18	8.6%	60	15.9%
Total	**176**	**100.0%**	**209**	**100.0%**	**385**	**100.0%**

Table 4.6 Chest reconstruction (people assigned female at birth).

	Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%
Chest reconstruction	15	8.5%	5	2.4%	20	5.2%
Total	**176**	**100.0%**	**209**	**100.0%**	**385**	**100.0%**

Table 4.7 Hysterectomy (people assigned female at birth).

	Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%
Hysterectomy	12	6.8%	3	1.4%	15	3.9%
Total	**176**	**100.0%**	**209**	**100.0%**	**385**	**100.0%**

Table 4.8 Bilateral oophorectomy (people assigned female at birth).

	Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%
Bilateral oophorectomy	14	8.0%	1	0.5%	15	3.9%
Total	**176**	**100.0%**	**209**	**100.0%**	**385**	**100.0%**

Table 4.9 Orchidectomy (people assigned male at birth).

	Trans Woman		Gender Diverse		Total	
	n	%	n	%	n	%
Orchidectomy	25	20.7%	2	11.1%	27	19.4%
Total	**121**	**100.0%**	**18**	**100.0%**	**139**	**100.0%**

*Table 4.10 Trans women surgeries.**

	n	%
Breast implants	13	10.7%
Vaginoplasty	21	17.4%

**Percentages based on total n=121.*

Participants were asked whether they had ever practiced chest binding, tucking of testicles or had silicone injections. Chest binding was very common amongst trans men (94.3%) and gender diverse people (75.8%) (Table 4.11). Chest binding was also practiced by a few trans women, who explained in their comments this was due to having unaccepting partners. Tucking of testicles was common amongst trans women (69.4%) and gender diverse people who were assigned male at birth (50.0%) (Table 4.12). Very few participants had silicone injections (n=4, 0.7%). Participants were also given the option to enter in text anything else they practiced that they thought might be relevant. Some of the answers to this included disordered eating, clitoral pumping/stretching, packing (which may cause excessive sweating and skin irritations in the area), and self-harming dysphoria.

Table 4.11 Chest binding.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Chest binding	3	2.8%	166	94.3%	172	75.8%	341	65.1%
Total	**121**	**100.0%**	**176**	**100.0%**	**227**	**100.0%**	**524**	**100.0%**

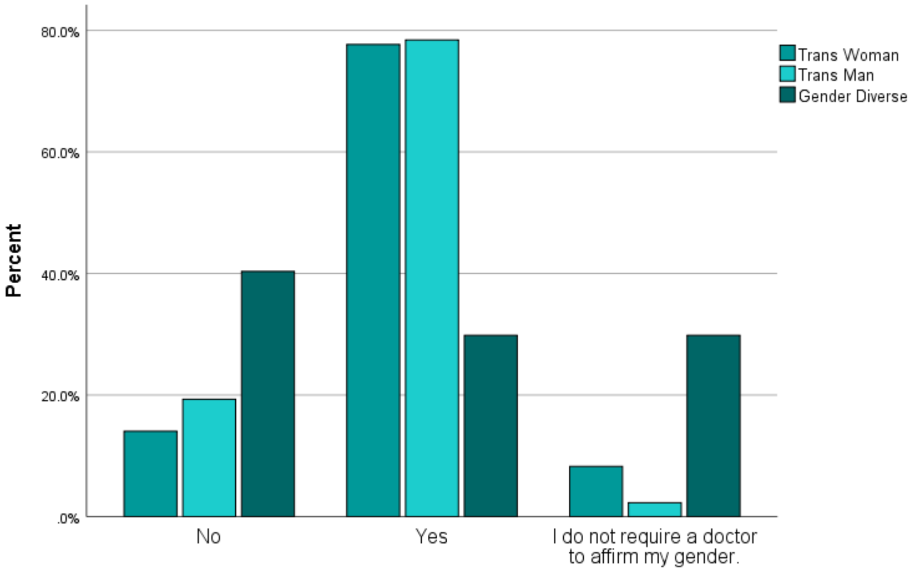
*Table 4.12 Tucking of testicles.**

	Trans Woman		Gender Diverse		Total	
	n	%	n	%	n	%
Tucking of testicles	84	69.4%	9	50.0%	93	66.9%
Total	**121**	**100.0%**	**18**	**100.0%**	**139**	**100.0%**

*Percentages based on participants who indicated that they were assigned male at birth.

Over half of participants indicated that they had seen a doctor for their gender affirmation during the last year. Around a quarter had not (27.5%) and around one sixth indicated that they do not need a doctor to affirm their gender (15.9%) (Figure 13).

Figure 13 – Seen a doctor for gender affirmation in the last year.



Of the participants who had seen a doctor for their gender affirmation in the last year, 57.8% had seen them 2-5 times. Additionally, 22.9% had seen them 6-11 times, 12.6% had seen them once, and 6.6% had seen them more than 12 times (Table 4.13).

Table 4.13 You indicated that you have seen a doctor for gender affirmation – how many times in the last 12 months have you done this?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Once	12	12.8%	16	11.7%	10	14.3%	38	12.6%
2-5 times	51	54.3%	83	60.6%	40	57.1%	174	57.8%
6-11 times	26	27.7%	26	19.0%	17	24.3%	69	22.9%
12+ times	5	5.3%	12	8.8%	3	4.3%	20	6.6%
Total	**94**	**100.0%**	**137**	**100.0%**	**70**	**100.0%**	**301**	**100.0%**

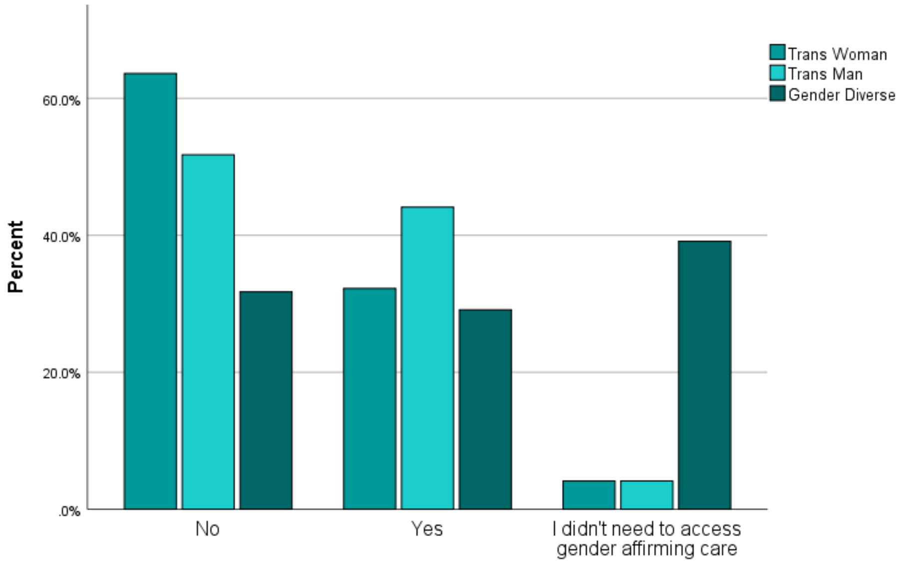
Participants who reported seeing a doctor for their gender affirmation in the last year were asked whether their usual general practitioner or healthcare provider (GP/HCP) seemed informed about their gender affirming care after their last visit. The most common responses to this was that their usual GP/HCP was the one who provided the care (37.0%), and yes (28.3%). Approximately one out of eight participants said that their usual GP/HCP was not informed, and a further one out of eight said that their usual GP/HCP did not know until they told them (Table 4.14).

Table 4.14 After the last time you saw a doctor for your gender affirmation, did your usual GP or healthcare provider seem informed about your gender affirming care?

	n	%
No	36	12.1%
Yes	84	28.3%
I don't know	26	8.8%
My usual GP or healthcare provider was the one who provided gender affirming care.	110	37.0%
They didn't know until I told them	34	11.4%
I don't have a usual GP or healthcare provider	7	2.4%
Total	**297**	**100.0%**

Participants were asked if there was a time in the last 12 months that they had needed to access a doctor specialising in gender affirming care but had been unable to do so. Overall, one third indicated that this was the case, and almost one fifth (19.6%) indicated that they did not need to access gender affirming care (Figure 14). This means that upon recalculating the percentage, leaving out those that did not need to access gender affirming care, 43.2% were unable to access a doctor that specialises in gender affirming care when they needed to.

Figure 14 – Unable to access gender affirming care.



Participants were asked the furthest distance ever, and most recently, they had travelled for their gender affirming care (Tables 4.15-4.16). The most common responses were within their city/town and driving to another city. However, one in ten reported that they had flown to another city/state. One in ten trans women had flown to another country.

Table 4.15 Whilst living in Australia, what is the furthest distance you have ever travelled for gender affirming care?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Within my city or town	52	47.7%	63	42.6%	58	62.4%	173	49.4%
Driving to another city	36	33.0%	65	43.9%	26	28.0%	127	36.3%
Flying to another city or state	9	8.3%	19	12.8%	8	8.6%	36	10.3%
Flying to another country	12	11.0%	1	0.7%	1	1.1%	14	4.0%
Total	**109**	**100.0%**	**148**	**100.0%**	**93**	**100.0%**	**350**	**100.0%**

Table 4.16 Whilst living in Australia, what is the furthest distance you have travelled most recently for gender affirming care?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Within my city or town	72	66.7%	82	55.4%	67	73.6%	221	63.7%
Driving to another city	26	24.1%	62	41.9%	20	22.0%	108	31.1%
Flying to another city or state	7	6.5%	4	2.7%	4	4.4%	15	4.3%
Flying to another country	3	2.8%	0	0.0%	0	0.0%	3	0.9%
Total	**108**	**100.0%**	**148**	**100.0%**	**91**	**100.0%**	**347**	**100.0%**

Table 4.17 shows the rates of people who have experienced various types of discrimination or assault. A large majority had experienced at least one type of discrimination or assault, with only 8.8% indicating they had not experienced any type. The most commonly experienced were silent harassment (84.7%), verbal harassment (71.1%), sexual harassment (43.2%), and physical intimidation and threats (37.1%). One in five participants had been physical assaulted, consistent with previous Australian research, and one in four have been sexually assaulted, which is considerably higher than previously reported (10% in TranZnation) (Couch et al., 2007).

*Table 4.17 Have you ever experienced the following because of your gender expression?**

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Silent harassment	98	82.4%	157	89.2%	200	85.8%	455	84.7%
Verbal harassment	76	63.9%	129	73.3%	177	76.0%	382	71.1%
Physical intimidation and threats	36	30.3%	71	40.3%	92	39.5%	199	37.1%
Physical violence	19	16.0%	36	20.5%	50	21.5%	105	19.6%
Sexual harassment	45	37.8%	63	35.8%	124	53.2%	232	43.2.%
Sexual assault	30	25.2%	47	26.7%	78	33.5%	155	28.9%
None	15	12.6%	13	7.4%	19	8.2%	47	8.8%

**Percent out of 528 participants, missing 9 who indicated 'prefer not to answer'.*

Participants who had indicated that they had experienced the above types of harassment and assault were then asked whether they had experienced this in the last year (Tables 4.18-4.23). Silent, verbal and sexual harassment were more likely to have been experienced recently.

Table 4.18 You indicated that you have experienced silent harassment - have you experienced this in the last 12 months?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	86	87.8%	128	81.5%	180	90.0%	394	86.6%
Total	**98**	**100.0%**	**157**	**100.0%**	**200**	**100.0%**	**455**	**100.0%**

Table 4.19 You indicated that you have experienced verbal harassment - have you experienced this in the last 12 months?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	55	72.4%	90	69.8%	138	78.0%	283	74.1%
Total	**76**	**100.0%**	**129**	**100.0%**	**177**	**100.0%**	**382**	**100.0%**

Table 4.20 You indicated that you have experienced physical intimidation and threats - have you experienced this in the last 12 months?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	17	47.2%	27	38.0%	54	58.7%	98	49.2%
Total	**36**	**100.0%**	**71**	**100.0%**	**92**	**100.0%**	**199**	**100.0%**

Table 4.21 You indicated that you have experienced physical violence - have you experienced this in the last 12 months?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	5	26.3%	12	33.3%	19	38.0%	36	34.3%
Total	**19**	**100.0%**	**36**	**100.0%**	**50**	**100.0%**	**105**	**100.0%**

Table 4.22 You indicated that you have experienced sexual harassment - have you experienced this in the last 12 months?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	31	68.9%	34	54.0%	69	55.6%	134	57.8%
Total	**45**	**100.0%**	**63**	**100.0%**	**124**	**100.0%**	**124**	**100.0%**

Table 4.23 You indicated that you have experienced sexual assault - have you experienced this in the last 12 months?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	11	36.7%	18	38.3%	21	26.9%	50	32.3%
Total	**30**	**100.0%**	**47**	**100.0%**	**78**	**100.0%**	**155**	**100.0%**

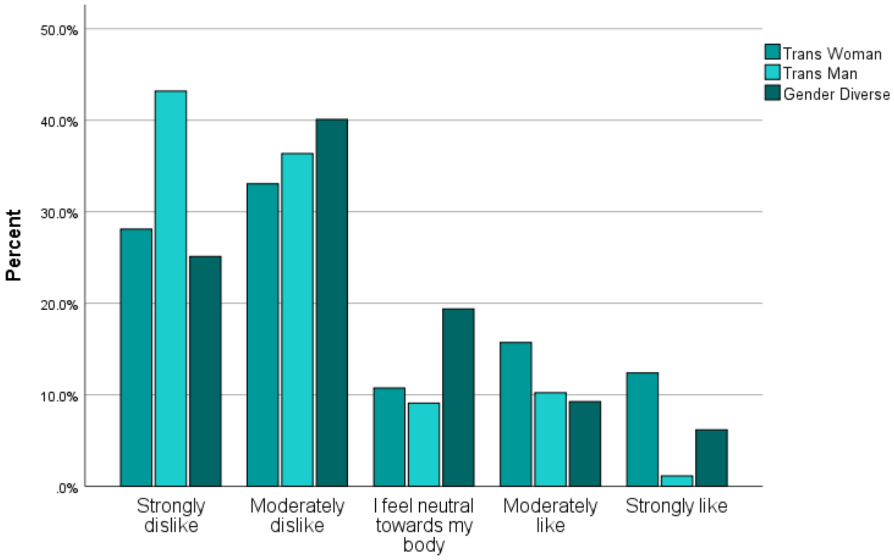
Table 4.24 shows the number of types of discrimination experienced. Participants had most commonly experienced two types (25.5%), but the majority had experienced more, and one in eight participants had experienced all forms of harassment and assault.

Table 4.24 Number of types of discrimination experienced.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
1	25	24.0%	29	17.7%	29	13.5%	83	17.2%
2	30	28.8%	41	25.0%	52	24.2%	123	25.5%
3	14	13.5%	32	19.5%	39	18.1%	85	17.6%
4	11	10.6%	31	18.9%	35	16.3%	77	15.9%
5	11	10.6%	14	8.5%	29	13.5%	54	11.2%
6	13	12.5%	17	10.4%	31	14.4%	61	12.6%
Total	**104**	**100.0%**	**164**	**100.0%**	**215**	**100.0%**	**483**	**100.0%**

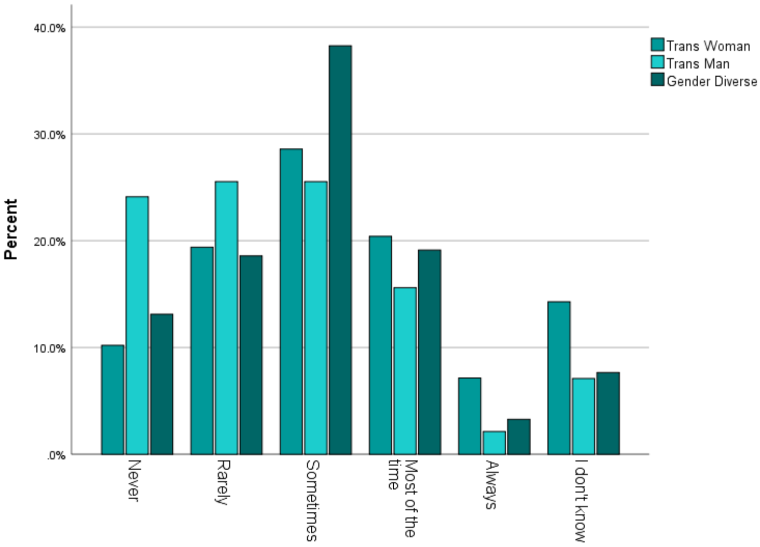
Participants were asked how strongly they liked or disliked their body. Most either moderately (37.2%) or strongly (31.9%) disliked their body (Figure 15).

Figure 15 – Like for body.



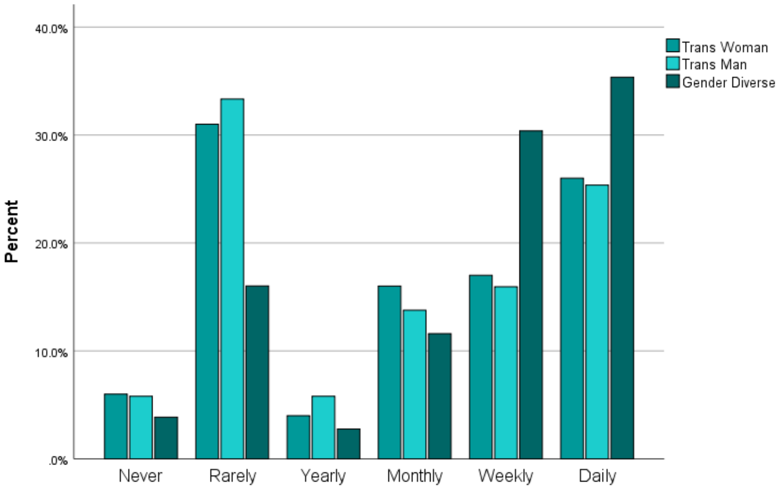
Participants were asked how often they thought that other people were able to identify them as trans or gender diverse. The most common response was sometimes (31.8%), followed by rarely (21.1%) and most of the time (18.2%). Only 3.8% of participants thought that other people could always tell that they were trans or gender diverse based on presentation. Trans men were the most likely to respond never (24.1%).

Figure 16 – How often do other people identify you as trans or gender diverse.



In terms of how often participants engaged with the TGD community, there were a variety of responses, with the most common being daily (29.8%), rarely (25.3%) and weekly (22.4%) (Figure 17). Gender diverse people were the most likely to report daily (35.4%) and weekly (30.4%) engagement.

Figure 17 – How often do you engage with the trans and gender diverse community?



Participants were also asked the ways in which they engaged with the TGD community. Online (71.6%), friends (65.4%) and Facebook (57.5%) were the most common responses to this question.

Table 4.25 Please indicate the way/s that you mostly engage with the trans and gender diverse community.

	n	%
Friends	274	65.4%
Facebook	241	57.5%
Online	300	71.6%
Phone Apps	64	15.3%
Support Groups	96	22.9%
Events	121	28.9%
Something else	44	10.5%
I do not engage with the TGD community	14	3.3%
Total	**419**	**100.0%**

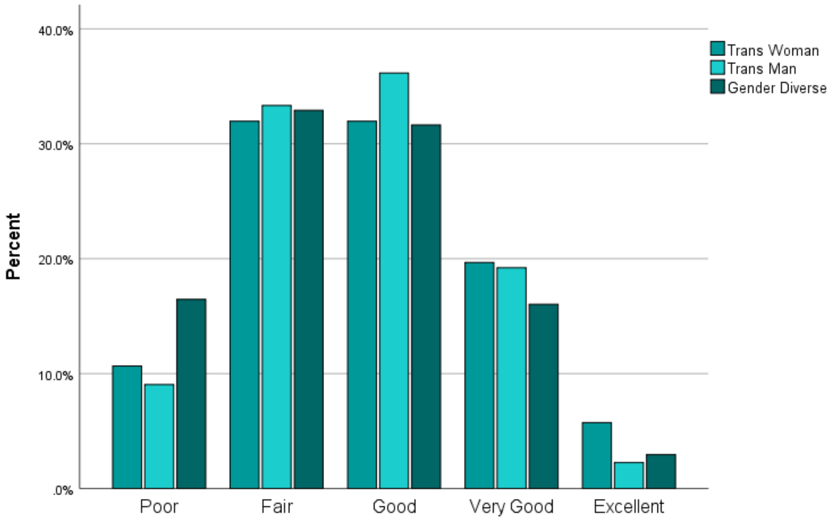
5. Accessing Healthcare

> *She stripped me naked and scrubbed me in public, and these people here were taking photos and posting them on the internet… and every time there was no one around either the father or the son would come in and threaten my life and say I was a waste of space and they were going to kill me… and I kept trying to relay to the nurses and the doctors that my life was being threatened, and they thought I was hallucinating… Eventually the dude come with an axe, and it was for the sake of a nurse who stopped him, she just said to him, 'you can't bring that in here.'*
>
> \- Trans man, lung cancer and lymphoma.

> *I felt like I was dealing with the 1920s CWA, and because I did not fit their strict gender criteria, they just simply didn't know how to relate to me… There was no recognition in the system of my preferred name or anything like that, I was continually being referred to by my female name. They get me upstairs and they want to put me in a ward with three women. I just lost it. I said, 'no bloody way am I going to be on this ward with three women. I need to be treated with a bit of dignity and respect in this matter'… [one of the nurses] looked at me and said, 'you were born a woman, you will behave like woman'… I cancelled all my post-operative appointments, never went back near them again, I just didn't want to be anywhere near it again, and for better, for worse, whatever, too bad. Even in the greater scheme of things, it's now at the point where if I developed any form of symptoms of having cancer in any of the remaining bits that are still left down there, I wouldn't go near a doctor. I wouldn't dare. It doesn't matter if it's going to kill me.*
>
> \- Trans man, BRCA gene mutation.

Participants were asked a series of questions on their access to and experiences within healthcare, including self-rated health and the Kessler 6 Psychological Distress Scale. Self-rated health was overall lower when compared with data on the general Australian population – 12.7% of our respondents rated their health as poor (4% nationally), 32.8% fair (10% nationally), 33.2% good (29% nationally), 17.9% very good (37% nationally), and 3.4% excellent (20% nationally) (Australian Institute of Health and Welfare, 2018a).

Figure 18 – Self-rated health.



The Kessler 6 uses six items to assess the presence of psychological distress (Kessler et al., 2011). Scoring ranges from 0-24, with a score over 13 being indicative of potential serious mental illness. Table 5.1 shows the scores of participants broken into those below 13 (low levels of psychological distress) and those above 13 (high levels of psychological distress). Half of the sample reported high levels of psychological distress; data for the general Australian population using the K10 has found that 11.7% of people have high or very high psychological distress (Australian Bureau of Statistics, 2015).

Table 5.1 K6 Dichotomous Scoring.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
High level of psychological distress	51	41.8%	93	52.5%	136	57.4%	280	52.2%
Low level of psychological distress	71	58.2%	84	47.5%	101	42.6%	256	47.8%
Total	**122**	**100.0%**	**177**	**100.0%**	**237**	**100.0%**	**536**	**100.0%**

Participants were asked to indicate who they turned to for emotional, practical and informational support and were given ten options plus the option of ‘no one’ or ‘someone else’. They could choose multiple responses. Participants most commonly sought emotional support from friends (74.5%), practical support from family (57.7%), and informational support from the TGD community (67.8%) (Table 5.2).

Table 5.2 Who do you mainly turn to for emotional, practical and informational support?

	n	%
Friend/s Emotional Support	400	74.5
Friend/s Practical Support	296	55.1
Friend/s Informational Support	248	46.2
Partner/s Emotional Support	297	55.3
Partner/s Practical Support	245	45.6
Partner/s Informational Support	174	32.4
Family Emotional Support	182	33.9
Family Practical Support	310	57.7
Family Informational Support	173	32.2
Family of Choice Emotional Support	283	52.7
Family of Choice Practical Support	251	46.7
Family of Choice Informational Support	206	38.4
TGD Community Emotional Support	207	38.5
TGD Community Practical Support	169	31.5
TGD Community Informational Support	364	67.8
LGBTIQ Community Emotional Support	206	38.4
LGBTIQ Community Practical Support	153	28.5
LGBTIQ Community Informational Support	324	60.3
Neighbour Emotional Support	7	1.3
Neighbour Practical Support	34	6.3
Neighbour Informational Support	22	4.1
Mental Health Professional Emotional Support	308	57.4
Mental Health Professional Practical Support	240	44.7
Mental Health Professional Informational Support	268	49.9
Healthcare Professional Emotional Support	77	14.3
Healthcare Professional Practical Support	287	53.4
Healthcare Professional Informational Support	309	57.5
Religious Provider Emotional Support	26	4.8
Religious Provider Practical Support	12	2.2
Religious Provider Informational Support	18	3.4
No One Emotional Support	38	7.1
No One Practical Support	27	5.0
No One Informational Support	30	5.6

Figures 19-21 show the scores of each participant for emotional, practical and informational support. Around half of participants had 2-4 supports for each of the domains.

Figure 19 – Number of Emotional Supports.

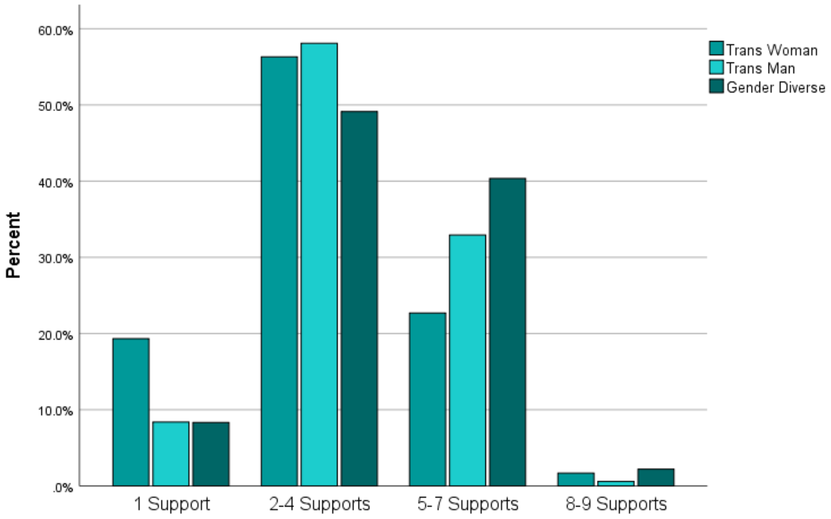


Figure 20 – Number of Practical Supports.

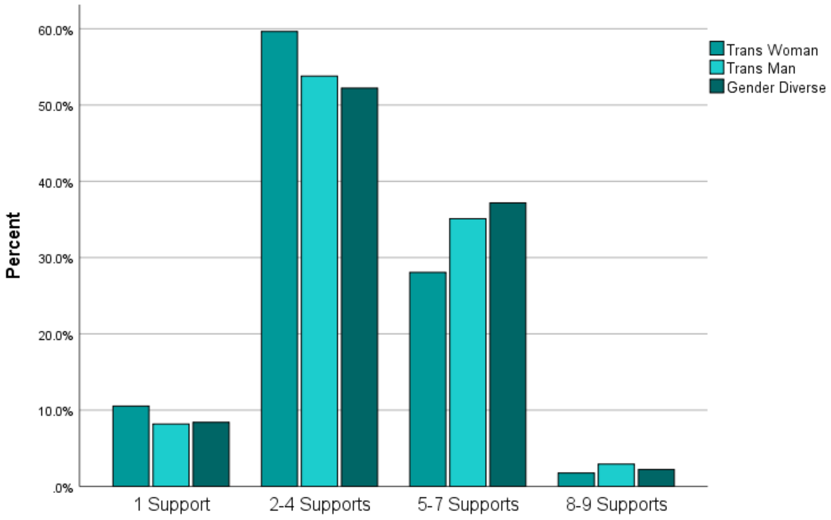
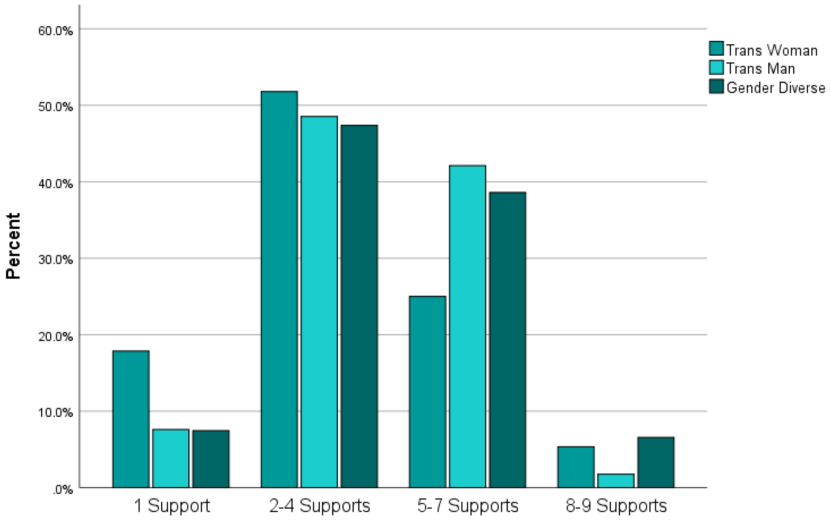


Figure 21 – Number of Informational Supports.



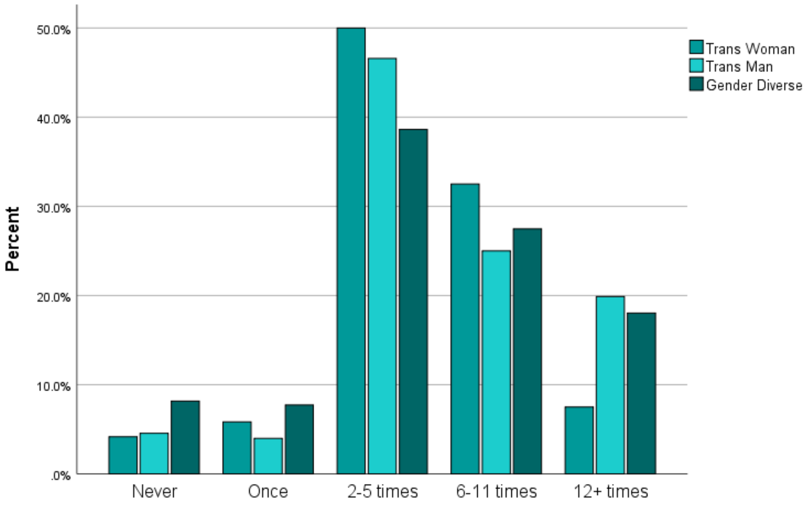
Participants were asked if they had anything that gave them discounted healthcare (e.g. Health Care Card, Pensioner’s Concession Card, private health insurance). Many participants had a Health Care Card (44.1%), and 16.4% had a Pensioner’s Concession Card (Table 5.3). Private health insurance was lower than that found in the general Australian population (40.8% compared to 57%) (Australian Institute of Health and Welfare, 2018a).

Table 5.3 Do you have any of the following...?

	n	%
Private health insurance	219	40.8%
Health Care Card	237	44.1%
Pensioner's Concession Card	88	16.4%
None of the above	93	17.3%

Frequency of GP visits over the last year was assessed, with the most common response being 2-5 times (43.9%). Over a quarter had seen a GP 6-11 times, and one in six had seen a GP 12+ times in the last year (Figure 22). Only 6% had not seen a GP in the last 12 months for their health, which is 10% lower than found in the general Australian population (Australian Bureau of Statistics, 2017).

Figure 22 – GP Visits in the last 12 Months.



Over half of the sample indicated that there was ever a time that they felt they needed healthcare but didn't receive it (Figure 23). Of these participants, eight out of ten stated that this happened within the last 12 months, which means that 47.5% of the sample had an unmet healthcare need in the last year, twice that of the general Australian population (Table 5.4) (Australian Bureau of Statistics, 2017).

Figure 23 – Unmet Healthcare Need.

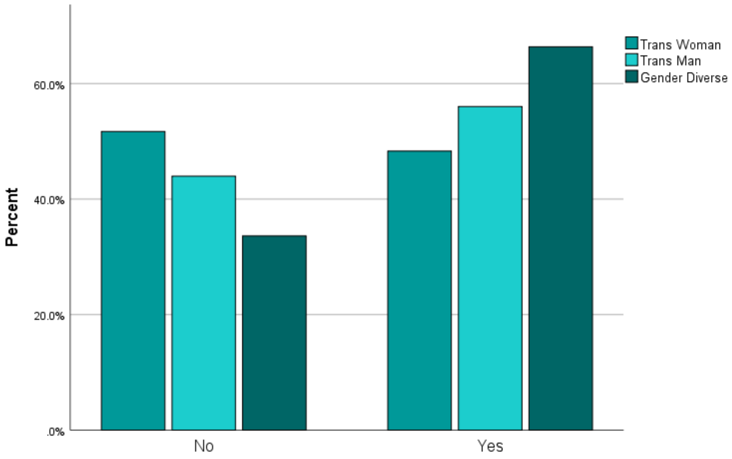


Table 5.4 You indicated that you didn't receive healthcare when you felt you needed it – has this happened in the last 12 months?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Yes	44	77.2%	73	79.3%	125	83.9%	242	81.2%
Total	**57**	**100.0%**	**92**	**100.0%**	**149**	**100.0%**	**298**	**100.0%**

*Note: this question was asked of participants who reported that they ever had an unmet healthcare need.

Of the participants who reported not receiving healthcare when they felt they needed it, 46.0% indicated that this was because of financial cost, 44.3% because they thought they would be disrespected or mistreated, 35.0% because they could not get an appointment when they needed one, 15.3% because there are not services nearby, and 8.0% because they were refused services (Table 5.5). Other reasons that participants gave in a textbox were related to personal reasons (e.g. anxiety, depression, parental consent), healthcare workers (e.g. not being taken seriously, gatekeeping), and barriers related to the system (e.g. appointment cancellations, long waiting lists)

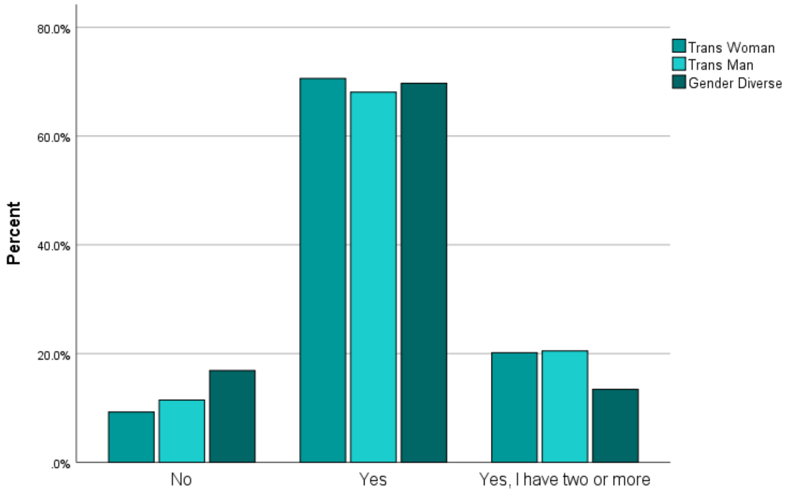
*Table 5.5 You indicated that you didn't receive healthcare when you felt you needed it – what were all the reasons for this?**

	n	%
Financial cost	138	46.0%
I thought I would be disrespected or mistreated	133	44.3%
I could not get an appointment when I needed one	105	35.0%
There are no services nearby	46	15.3%
I was refused services because I was trans or gender diverse	24	8.0%

*Percentage based on people who answered yes to not receiving healthcare when they needed it (n=300).

The majority of the sample reported having one or more usual GP/s or place/s of care (86.6%) (Figure 24). In a survey of Australian people aged over 45, the Australian Bureau of Statistics found that 98% had a usual GP or place of care (Australian Bureau of Statistics, 2017).

Figure 24 – Usual GP/s or Place/s of Care.



Participants with usual GP/s or place/s of care were asked if they were LGBTI friendly or trained, with the most common answers being yes (43.7%) and 'I don't know' (31.6%) (Figure 25). They were also asked how knowledgeable their usual GP/s or place/s of care were about TGD needs, with over half indicating they were either not knowledgeable at all or somewhat knowledgeable (53.4%) (Figure 26). Finally, these participants were asked how comfortable they are talking about their needs as a trans or gender diverse person with their usual GP/s or place/s of care, with 57.7% indicating that they were either comfortable or very comfortable (Figure 27). Comparatively, 80% of the general Australian population are either comfortable or very comfortable discussing their personal needs with their GP (Australian Bureau of Statistics, 2017).

Figure 25 – LGBTI Friendly or Trained GP/s or Place/s of Care.

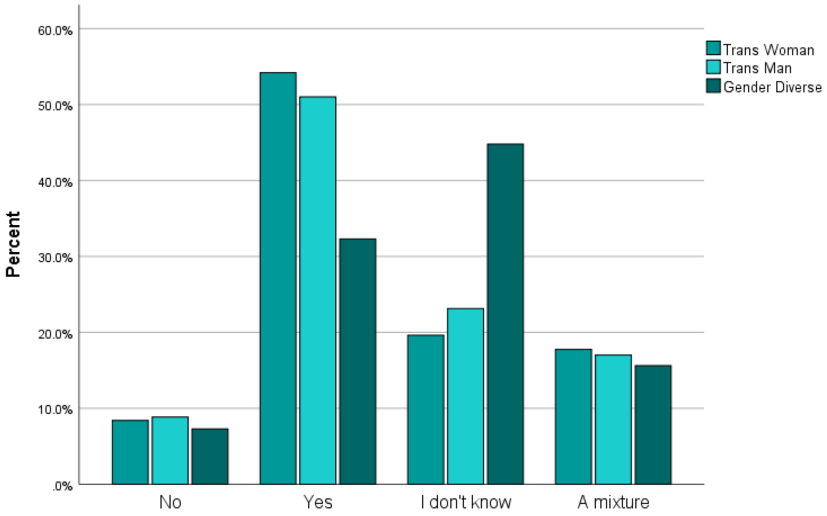


Figure 26 – Knowledge Levels of Usual GP/s or Place/s of Care.

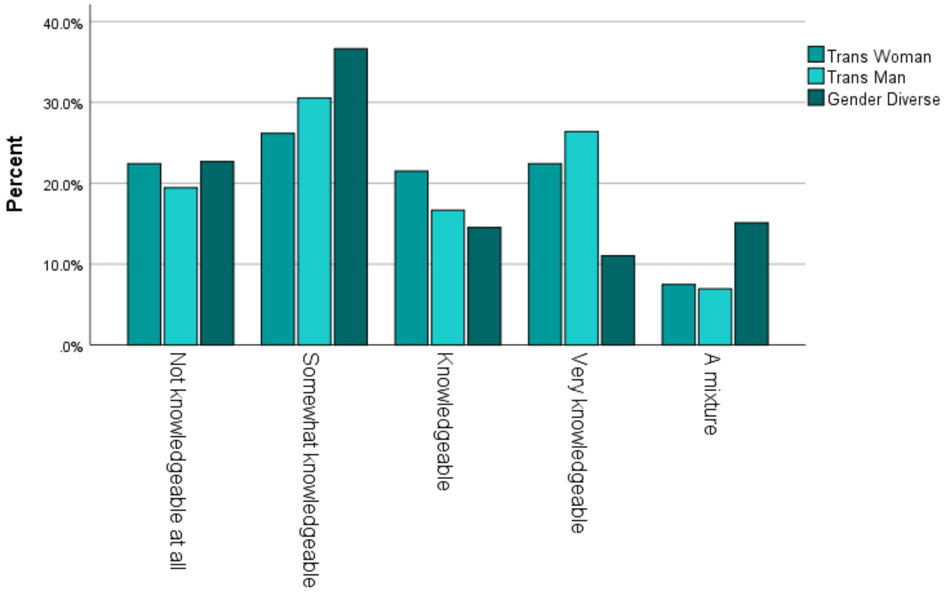
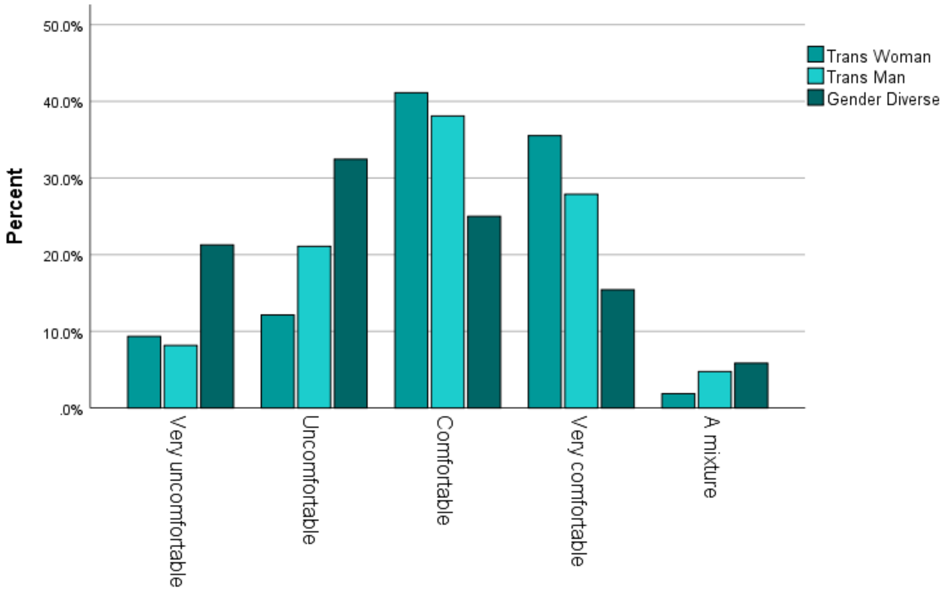
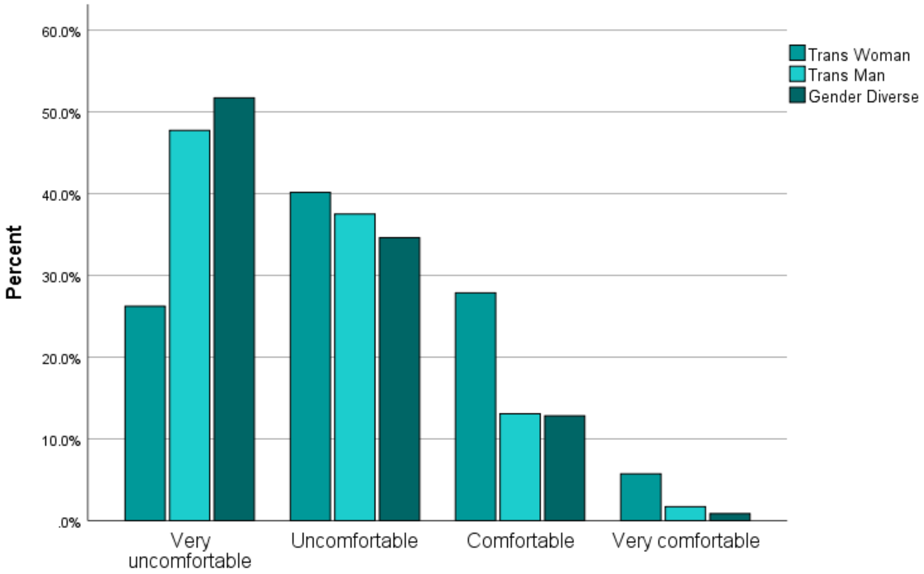


Figure 27 – Levels of Comfort Discussing Needs with Usual GP/s or Place/s of Care.



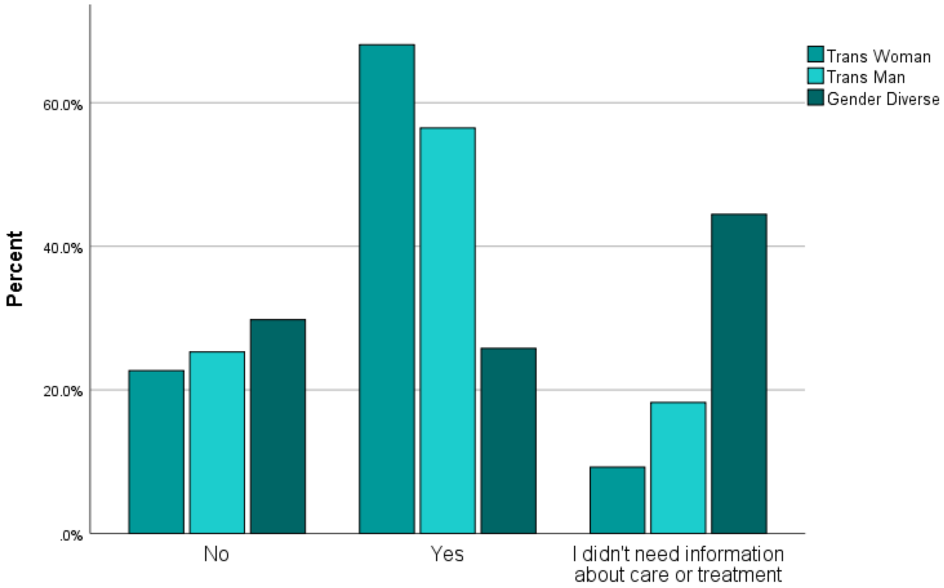
All participants were asked how comfortable they are discussing their needs as a trans or gender diverse person with a healthcare provider that they do not know, with most being very uncomfortable (44.5%) or uncomfortable (36.8%) (Figure 28).

Figure 28 – Levels of Comfort Discussing Needs with a Healthcare Provider they do not know.



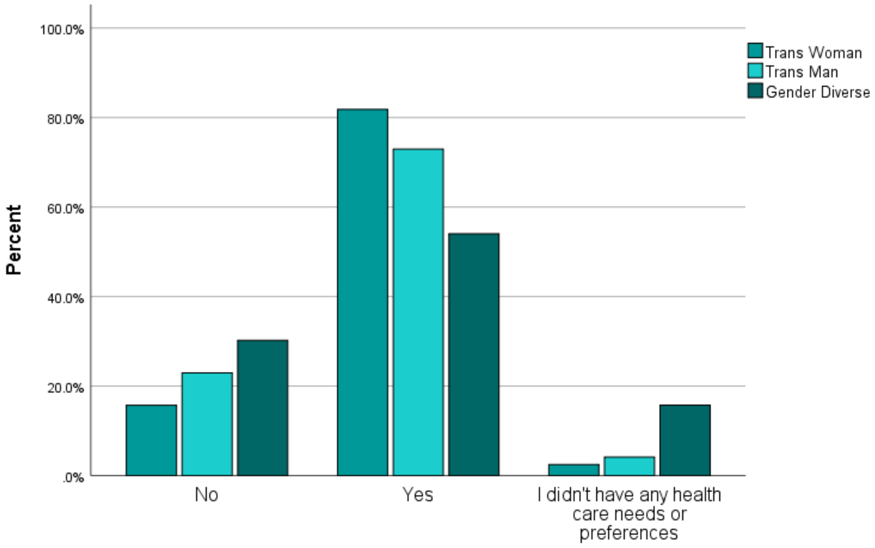
Just over a quarter of participants reported not receiving enough information about their care and treatment in the last 12 months, compared to 8% of the general Australian population (Figure 29) (Australian Bureau of Statistics, 2017).

Figure 29 – Given enough information about their care or treatment in the last 12 months.



Participants were asked about whether they had a health professional who had a good understanding of their needs and preferences in the last 12 months, with almost a quarter reporting that they had not – just 9% of the general Australian population experience this (Australian Bureau of Statistics, 2017). Trans women were the most likely to feel they had a healthcare professional with a good understanding of their needs (81.8%), with gender diverse people much less likely to feel this way (54.0%) (Figure 30).

Figure 30 – Healthcare Professional with a Good Understanding of Your Needs (last 12 months).



Over half of participants indicated that they sometimes (44.6%) or often (14.5%) had to make several attempts in the last 12 months to get the healthcare they needed (Figure 31). Further to this, many indicated that a health problem became more serious sometimes (32.7%) or often (12.2%) because it took a long time to get appropriate healthcare (Figure 32).

Figure 31 – Multiple Attempts to get Needed Healthcare (last 12 months).

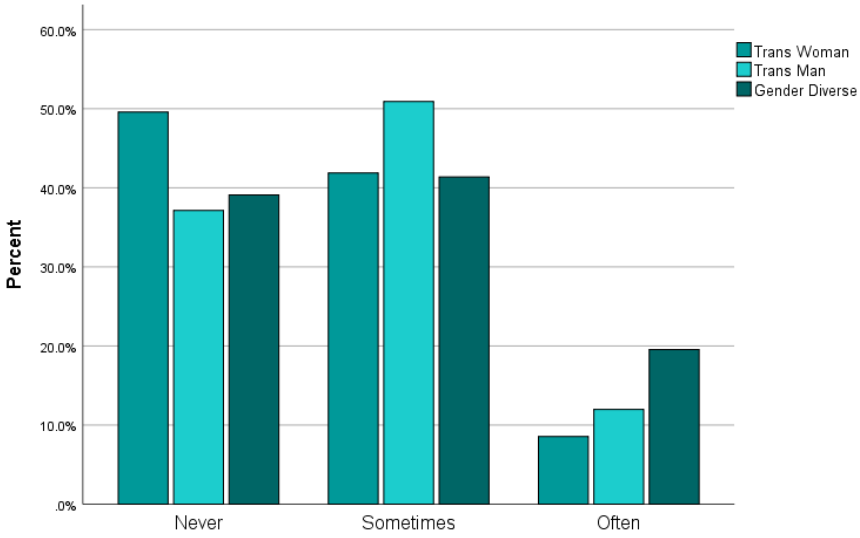
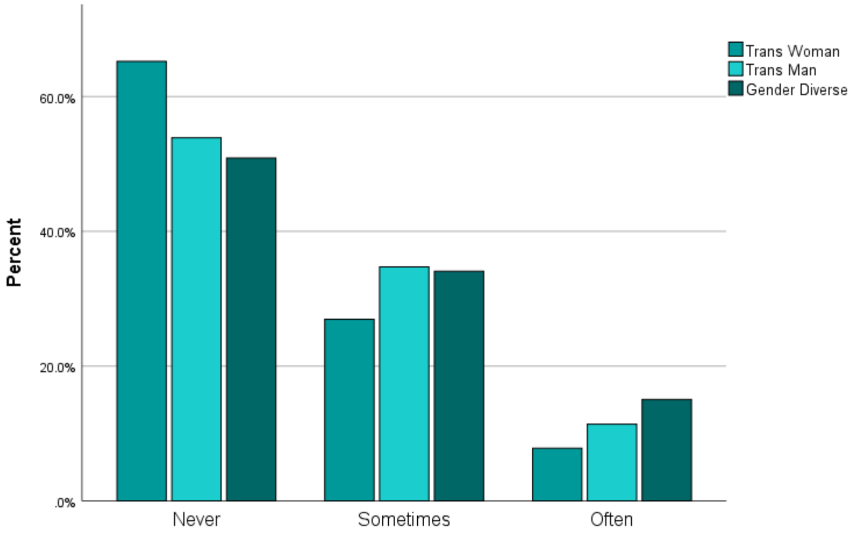
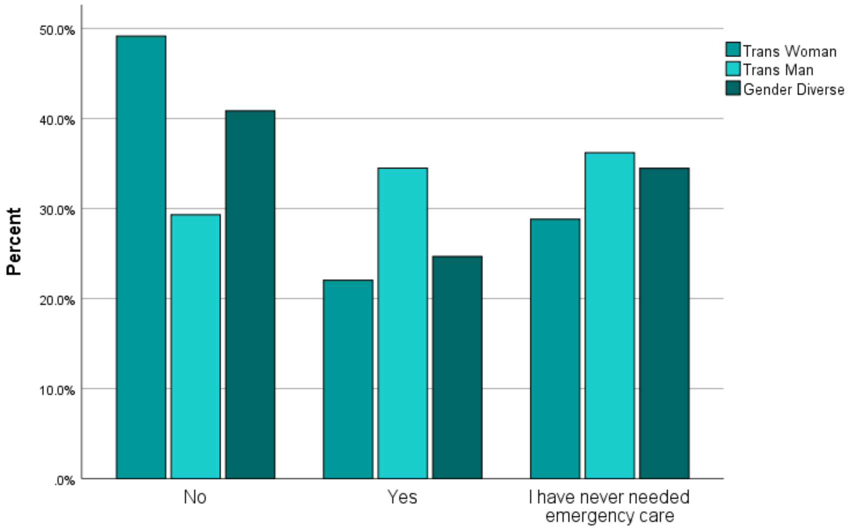


Figure 32 – Health Problem Became More Serious due to Delay in Accessing Appropriate Healthcare (last 12 months).



Emergency department avoidance was high, with over a quarter of participants stating that they had not attended because they were trans or gender diverse, which is consistent with Canadian research (Figure 33) (Bauer, Scheim, Deutsch, & Massarella, 2014). After removing the third of people who reported that they have never needed emergency care, the recalculated percentage of people avoiding the emergency department is 41.3%. Trans men were the only group that was more likely to report avoiding the emergency department than not.

Figure 33 – Emergency Department Avoidance.



Participants were asked a series of questions on things that stop them from going to the doctor. The most common barriers that sometimes or often stopped participants going to the doctor were too many other things to worry about (70.7%), inability to find a doctor they are comfortable with (68.9%), being too busy (59.6%) and fear of mistreatment (58.8%) (Tables 5.6-5.14).

Table 5.6 Fear of mistreatment.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	67	55.4%	63	36.2%	89	37.7%	219	41.2%
Yes - sometimes	47	38.8%	80	46.0%	108	45.8%	235	44.3%
Yes – often	7	5.8%	31	17.8%	39	16.5%	77	14.5%
Total	**121**	**100.0%**	**174**	**100.0%**	**236**	**100.0%**	**531**	**100.0%**

Table 5.7 Unable to find a doctor I am comfortable with.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	63	51.6%	52	30.1%	50	21.3%	165	31.1%
Yes - sometimes	41	33.6%	74	42.8%	105	44.7%	220	41.5%
Yes – often	18	14.8%	47	27.2%	80	34.0%	145	27.4%
Total	**122**	**100.0%**	**173**	**100.0%**	**235**	**100.0%**	**530**	**100.0%**

Table 5.8 I find my doctor difficult to talk to.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	76	62.8%	83	47.2%	86	36.4%	245	46.0%
Yes - sometimes	33	27.3%	65	36.9%	106	44.9%	204	38.3%
Yes – often	12	9.9%	28	15.9%	44	18.6%	84	15.8%
Total	**121**	**100.0%**	**176**	**100.0%**	**236**	**100.0%**	**533**	**100.0%**

Table 5.9 Difficult to make an appointment.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	69	57.0%	72	41.4%	98	41.9%	239	45.2%
Yes - sometimes	31	25.6%	65	37.4%	80	34.2%	176	33.3%
Yes – often	21	17.4%	37	21.3%	56	23.9%	114	21.6%
Total	**121**	**100.0%**	**174**	**100.0%**	**234**	**100.0%**	**529**	**100.0%**

Table 5.10 I am too busy.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	73	59.8%	55	31.4%	87	37.0%	215	40.4%
Yes - sometimes	37	30.3%	78	44.6%	88	37.4%	203	38.2%
Yes – often	12	9.8%	42	24.0%	60	25.5%	114	21.4%
Total	**122**	**100.0%**	**175**	**100.0%**	**235**	**100.0%**	**532**	**100.0%**

Table 5.11 I do not have money to see the doctor.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	66	54.1%	88	50.0%	109	46.4%	263	49.3%
Yes - sometimes	37	30.3%	54	30.7%	75	31.9%	166	31.1%
Yes – often	19	15.6%	34	19.3%	51	21.7%	104	19.5%
Total	**122**	**100.0%**	**176**	**100.0%**	**235**	**100.0%**	**533**	**100.0%**

Table 5.12 Too many other things to worry about.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	59	48.4%	47	26.7%	50	21.4%	156	29.3%
Yes - sometimes	42	34.4%	84	47.7%	114	48.7%	240	45.1%
Yes – often	21	17.2%	45	25.6%	70	29.9%	136	25.6%
Total	**122**	**100.0%**	**176**	**100.0%**	**234**	**100.0%**	**532**	**100.0%**

Table 5.13 Difficult to arrange transport to the doctor.

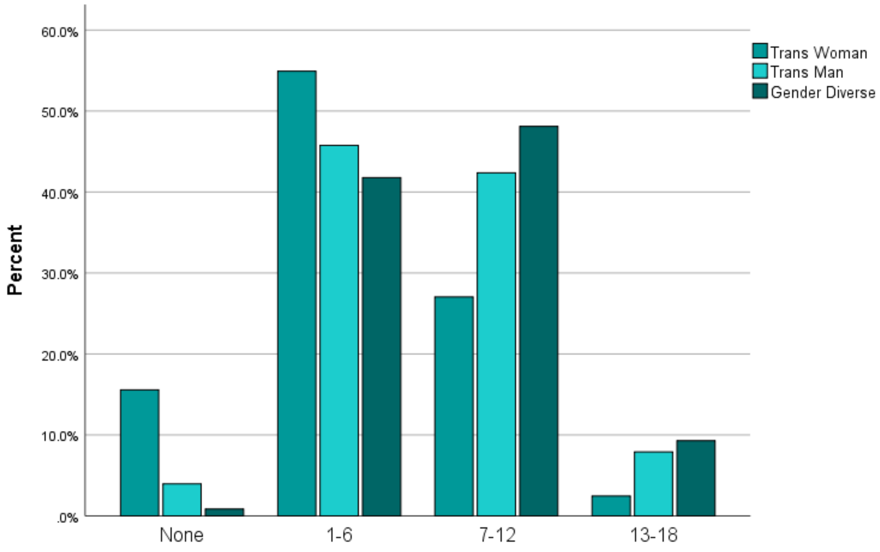
	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	88	72.1%	108	61.4%	133	56.4%	329	61.6%
Yes - sometimes	20	16.4%	46	26.1%	69	29.2%	135	25.3%
Yes – often	14	11.5%	22	12.5%	34	14.4%	70	13.1%
Total	**122**	**100.0%**	**176**	**100.0%**	**236**	**100.0%**	**534**	**100.0%**

Table 5.14 Worrying about what the doctor might find.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No	88	72.1%	95	54.0%	113	47.7%	296	55.3%
Yes - sometimes	30	24.6%	53	30.1%	78	32.9%	161	30.1%
Yes – often	4	3.3%	28	15.9%	46	19.4%	78	14.6%
Total	**122**	**100.0%**	**176**	**100.0%**	**237**	**100.0%**	**535**	**100.0%**

Figure 34 shows calculated scores for the number of things that stop participants attending the doctor (no = zero, sometimes = 1, often = 2).

Figure 34 - Number of things that stop participants going to doctor.



Participants were then asked a series of questions on their experiences within healthcare (both ever and within the past year), and responses related to the last twelve months were consistent with U.S. research (Tables 5.15-5.24) (James et al., 2016). Approximately three quarters of participants stated that they had ever had a healthcare provider know they were trans or gender diverse and treat them with respect (gender diverse people were much less likely to experience this). Over half have had to educate their healthcare provider on TGD issues. Almost a quarter have been refused gender affirming care and one in five have been refused general healthcare. Over a third were asked invasive or inappropriate questions by healthcare providers and almost one sixth have had a healthcare provider use harsh or abusive language. One in twenty have had a healthcare provider be physically rough when treating them and within a healthcare setting, 14.2% were verbally harassed, 5.7% experienced unwanted sexual contact and 2.3% were physically attacked.

Table 5.15 My doctor or healthcare provider knew I was trans and treated me with respect.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	9	7.5%	25	14.8%	99	46.5%	133	26.5%
More than 12 months ago	16	13.3%	17	10.1%	14	6.6%	47	9.4%
Within the last 12 months	95	79.2%	127	75.1%	100	46.9%	322	64.1%
Total	**120**	**100.0%**	**169**	**100.0%**	**213**	**100.0%**	**502**	**100.0%**

Table 5.16 I had to teach my doctor or healthcare provider about trans or gender diverse people so that I could get appropriate care.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	57	47.1%	62	37.3%	104	48.4%	223	44.4%
More than 12 months ago	33	27.3%	49	29.5%	44	20.5%	126	25.1%
Within the last 12 months	31	25.6%	55	33.1%	67	31.2%	153	30.5%
Total	**121**	**100.0%**	**166**	**100.0%**	**215**	**100.0%**	**153**	**100.0%**

Table 5.17 A doctor or healthcare provider refused to give me gender affirming care.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	92	76.0%	119	73.5%	174	80.2%	385	77.0%
More than 12 months ago	22	18.2%	29	17.9%	22	10.1%	73	14.6%
Within the last 12 months	7	5.8%	14	8.6%	21	9.7%	42	8.4%
Total	**121**	**100.0%**	**162**	**100.0%**	**217**	**100.0%**	**500**	**100.0%**

Table 5.18 A doctor or healthcare provider refused to give me other healthcare.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	103	85.8%	133	79.6%	171	75.7%	407	79.3%
More than 12 months ago	12	10.0%	21	12.6%	34	15.0%	67	13.1%
Within the last 12 months	5	4.2%	13	7.8%	21	9.3%	39	7.6%
Total	**120**	**100.0%**	**167**	**100.0%**	**226**	**100.0%**	**513**	**100.0%**

> *The doctors don't know how to deal with you, that's the thing. I've been refused treatment by two doctors this year, and I said to one doctor, 'you just told me to go somewhere else,' and he said, 'I don't treat your kind, I don't know anything about you,' and I wasn't asking him for any medication for being trans, he was actually supposed to be arranging a colonoscopy for cancer, but I said to him, 'what are you talking about? I've got the same organs as everyone else, my blood's red, I'm not from another planet.'*
>
> - Trans woman, prostate cancer.

Table 5.19 A doctor or healthcare provider asked me unnecessary/invasive questions about my trans status that were not related to the reason for my visit.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	82	67.8%	97	57.1%	142	63.4%	321	62.3%
More than 12 months ago	22	18.2%	36	21.2%	35	15.6%	93	18.1%
Within the last 12 months	17	14.0%	37	21.8%	47	21.0%	101	19.6%
Total	**121**	**100.0%**	**170**	**100.0%**	**224**	**100.0%**	**515**	**100.0%**

Table 5.20 A doctor or healthcare provider used harsh or abusive language when treating me.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	104	86.0%	150	88.2%	184	81.1%	438	84.6%
More than 12 months ago	15	12.4%	15	8.8%	24	10.6%	54	10.4%
Within the last 12 months	2	1.7%	5	2.9%	19	8.4%	26	5.0%
Total	**121**	**100.0%**	**170**	**100.0%**	**227**	**100.0%**	**518**	**100.0%**

Table 5.21 A doctor or other healthcare provider was physically rough or abusive when treating me.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	112	92.6%	167	96.5%	215	93.5%	494	94.3%
More than 12 months ago	9	7.4%	5	2.9%	9	3.9%	23	4.4%
Within the last 12 months	0	0.0%	1	0.6%	6	2.6%	7	1.3%
Total	**121**	**100.0%**	**173**	**100.0%**	**230**	**100.0%**	**524**	**100.0%**

Table 5.22 I was verbally harassed in a healthcare setting.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	105	86.8%	151	87.8%	192	83.8%	448	85.8%
More than 12 months ago	11	9.1%	14	8.1%	26	11.4%	51	9.8%
Within the last 12 months	5	4.1%	7	4.1%	11	4.8%	23	4.4%
Total	**121**	**100.0%**	**172**	**100.0%**	**229**	**100.0%**	**522**	**100.0%**

Table 5.23 I was physically attacked by someone during my visit in a healthcare setting.

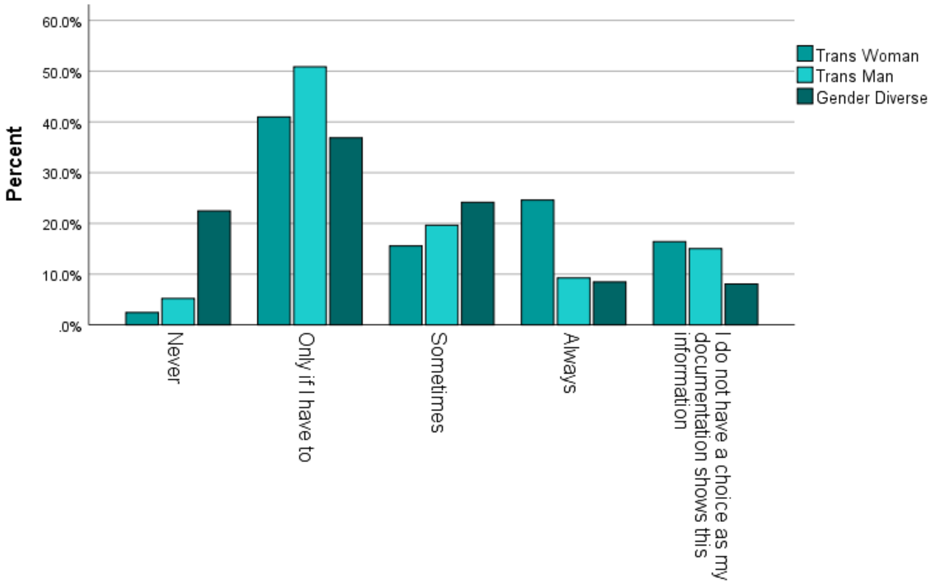
	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	118	97.5%	170	98.3%	224	97.4%	512	97.7%
More than 12 months ago	3	2.5%	2	1.2%	5	2.2%	10	1.9%
Within the last 12 months	0	0.0%	1	0.6%	1	0.4%	2	0.4%
Total	**121**	**100.0%**	**173**	**100.0%**	**230**	**100.0%**	**524**	**100.0%**

Table 5.24 I experienced unwanted sexual contact in a healthcare setting.

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
This has never happened to me	113	93.4%	170	97.7%	214	92.2%	497	94.3%
More than 12 months ago	8	6.6%	3	1.7%	11	4.7%	22	4.2%
Within the last 12 months	0	0.0%	1	0.6%	7	3.0%	8	1.5%
Total	**121**	**100.0%**	**174**	**100.0%**	**232**	**100.0%**	**527**	**100.0%**

One in eight participants said that they never disclosed their gender to healthcare workers, which is similar to previous Australian findings (Figure 35) (Hyde et al., 2014). Most commonly, participants said they did so only if they had to (42.4%). Only 12.4% said that they always disclosed, which is considerably lower than previously found (20.4%) (Hyde et al., 2014).

Figure 35 – Disclosing Gender to Healthcare Workers.



Participants were asked an open-ended question about any terms that they used for their body that healthcare workers should be aware of. In total, 177 participants opted to answer this question. There were a wide range of responses, some indicating a strong aversion to particular words/phrases, and others stating that anatomical terms are best. Many mentioned the use of the word ‘chest’, referring to genitals without taking ownership of them, not using ‘female’ or ‘male’, or using vaguer terms (e.g. ‘genitals’ or ‘crotch’). Some people stated that they called their clitoris a penis or vice versa, others called their chest tissue ‘man titties’ or their penis a ‘girl cock’. Overall, the responses to this question showed how diverse body terms can be, and how for some people they are very dysphoria-inducing and for others they do not pose an issue. This suggests a patient-centred approach, where wording preferences of each individual are collected and used, is most likely to meet TGD patients’ needs.

Participants were also asked, ‘what do you think could be done in healthcare to minimise the body discomfort (dysphoria) that may be felt during certain procedures (e.g. ones that involve genitals)?’ There were 340 responses to this open-ended question, with the main themes being: use of language and terms; the manner, approach or characteristics of healthcare workers; having patient control and preparation (patient-centred care and informed consent); education, training and research; ‘not sure’ (either because the participant did not have dysphoria or have alleviated their dysphoria with gender affirming surgery and/or hormones); ‘nothing’ (that is, it will always be uncomfortable); and access to gender affirming care (both surgery and hormones). Some individual response examples on what can be done to minimise the discomfort around these procedures follow:

- *That's going to depend a lot on the person. Speaking for myself, there's little to nothing that can be done.*

- *Taking a lot of care to demonstrate understanding of discomfort, using appropriate pronouns, asking the patient what language they have for their body parts and being open to the conversation.*
- *Give me warning of when it is to happen, what exactly happens. have them aware of the discomfort and anxiety it will bring and be given a sedative beforehand.*
- *Clinical, detached language involving body parts (e.g. "the" instead of "your"), avoiding using gendered language when referring to other people who have those parts (e.g. "most people with X would describe..." vs "most women would describe...").*
- *Complete thorough understanding of the patient's circumstance and feelings. Professionals must be able to empathize and understand the underlying issues and challenges dysphoria brings.*
- *Patient being given info and options to withdraw consent regarding procedure, to have doctors explain procedures, to ask how I want to refer to my genitals and also chest as words can result in dysphoria, as can anything to do with genitals, practitioner giving option of a support person that I can bring in, ensuring practitioner receives training from an lgbtiqa org on engaging with lgbitqa bodies.*
- *A brief concise acknowledgement from the doctor saying they understand this may be challenging, that they are sorry, but they will only do what is medically needed, i.e. keep it professional and then move on.*
- *On patient information forms have a box for biological sex and one for gender identity. Have the option for people to write down their identity, pronouns, and preferred name.*
- *Thorough explanation of what will be done, explicit communication that it can stop at any time and person can bring support people along, if needed.*
- *Having more trans and queer practitioners who understand our discomfort.*
- *I'm not sure, I am too uncomfortable to even disclose that I am nonbinary. I feel like if you're at least binary trans, doctors feel like you have an 'end game' if they're tolerant, but if you're non-binary trans, it's just not worth the trouble of even attempting to ask for different (they/them) pronouns. I just deal with the dysphoria of being constantly misgendered. It'd be nice if I wasn't called 'lady' all the time.*
- *Not assuming it's always always okay just to touch folks. Permissions. Options. Discussions.*
- *More education for doctors - use of language, respectfulness etc.... more education for patients about what to expect from visits.*
- *Sedating me. Just knock me out.*

6. Cancer Care and Awareness

> *There's so much help for breast cancer and support services, but there's nothing for any sort of other cancer... For instance, I had a full beard and hair on my head, and it fell out within a week, and to a trans man your beard is all, and I'm known for my beards, and there's nobody out there that could possibly counsel me on how I feel about that loss, and the anxiety of will it grow back, and what I look and see in the mirror now, but if I was female I would have been offered a wig straight away, if I was female with breast cancer I would've got the cool-cap.*
>
> \- Trans man, lung cancer and lymphoma.

> *Over a period of time I stopped being able to dilate, and there was nothing I could do about it. I had a check-up with the radiation oncologist, and I said to him, 'I'm having problems down below, I'm not able to dilate now. I made it clear to you that I was a post-operative trans woman, things down below were different to a genetic female'… in other words I wasn't self-lubricating or anything like that, and I said, 'you knew this, I made you aware of this and your only caution to me was that I might feel dryness. I've closed up, you've welded me shut,' and he said to me, 'I saved your life, what more do you want?' How do you respond to that? Okay, yeah, on one hand you've got a point, but you had no concern or care for me as a person, your only concern was that tiny little tumour, whatever happened from that, 'bugger it, I don't care', and I was devastated by that.*
>
> \- Trans woman, bowel cancer.

Participants were asked a series of questions on cancer care and awareness. Just over a quarter of the sample indicated that they did not have a family history of cancer, with a further 22.1% reporting that they did not know. The most common family histories for cancer were breast (29.1%), bowel (17.7%) and gynaecological (11.2%).

*Table 6.1 Do you have a family history of cancer, please indicate which type/s?**

	n	%
No	119	27.7%
Bowel	76	17.7%
Breast	125	29.1%
Gynaecological	48	11.2%
Prostate	30	7.0%
Brain	11	2.6%
Haematological	17	4.0%
Lung	26	6.0%
Skin	42	9.8%
I don't know	95	22.1%

**Percentage calculated on people who answered this question (n=430).*

Participants were also asked if they had a personal history of cancer, with some indicating that they had more than one type (Table 6.2). 'Something else' responses included testicular cancer, lymphoma, liver cancer, a rare cancer syndrome (SDHD gene fault), Burkitt's lymphoma, brain cancer, and basal cell carcinoma. Additionally, participants indicated they had inflammatory bowel syndrome, cervical pre-cancer awaiting results, and precancerous breast cysts.

*Table 6.2 Do you have a personal history of cancer, please indicate which type/s?**

	n	%
No	400	93.0%
Bowel	3	0.7%
Breast	4	0.9%
Melanoma	10	2.3%
Ovarian	4	0.9%
Something else	11	2.6%

**Percentage calculated on people who answered this question (n=430).*

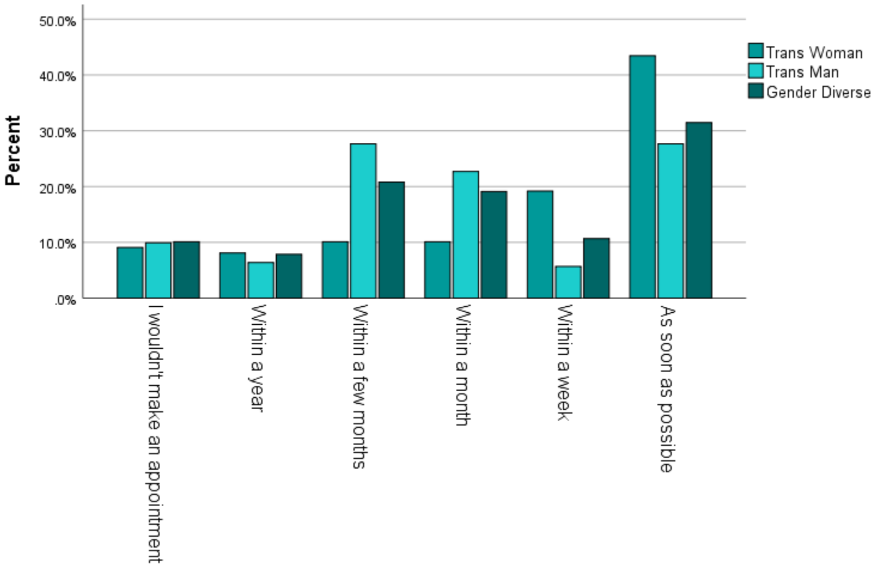
The most common screening services people had accessed/practiced were self-checking breasts/chest tissue (54.0%), cervical screening (24.9%) and a healthcare provider checking breasts/chest tissue (18.1%) (Table 6.3). One in four participants reported that they had not had any type of cancer screening.

Table 6.3 Can you please indicate which of the following screening services you have had?

	n	%
Mammogram	48	11.2%
Self-checked breasts or chest tissue	232	54.0%
HCP checked breasts or chest tissue	78	18.1%
Cervical screening	107	24.9%
Prostate check (digital rectal exam)	9	2.1%
Prostate check via vagina	1	0.2%
Prostate-Specific Antigen (PSA) test	20	4.7%
Bowel cancer test self-collected at home	20	4.7%
Colonoscopy for bowel cancer	21	4.9%
None of the above	116	27.0%
Total	**430**	**100.0%**

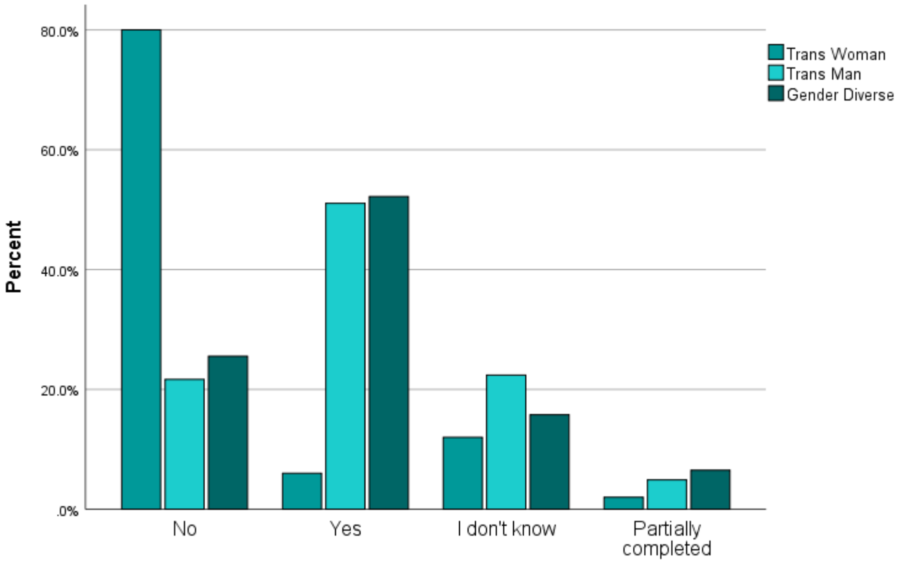
Participants were asked how soon they would make an appointment if they had a symptom they thought was a sign of cancer (Figure 36). Almost half of the participants reported that they would make an appointment as soon as possible or within a week (44.0%). Approximately one in six indicated that they either wouldn't make an appointment or would wait up to a year.

Figure 36 – If they had a cancer symptom, how long participants would wait to make an appointment.



HPV vaccination was introduced in Australia in 2007 for young females and extended to include males in 2013. The overall rate of reported HPV vaccination was 41.0%, with 17.1% indicating that they did not know. Trans men and gender diverse people were more likely to have completed a vaccination series, whilst trans women were more likely to report that they had not (80.0%) (Figure 37). For the age brackets, 47.0% of 18-24 year olds reported completing vaccination, 52.2% of 25-34 year olds, 18.2% of 35-44 year olds, and no one over the age of 45.

Figure 37 – HPV Vaccination.



Participants were provided with a series of ten factual statements on cancer-related knowledge (Tables 6.4-6.13). For many of these questions, there was a high rate of 'I don't know' responses, particularly in relation to 'hormones can affect everyone's cancer risk' (47.4%), 'the Australian cervical cancer screening program has recently changed' (65.7%), and 'Australia has a nation-wide prostate cancer screening program' (55.6%). Other cancer knowledge questions had higher rates of correct responses: 'the risk of cancer does not increase with age' (false, 75.5%), 'people assigned male at birth cannot develop breast cancer' (false, 91.8%), 'people do not have any risk of developing breast cancer if they have had a mastectomy' (false, 61.7%), 'people with breasts/chest tissue between the ages of 50 and 74 should have a mammogram once every two years' (true, 73.4%), 'Australia has a nation-wide breast cancer screening program' (true, 66.8%), and 'Australia has a nation-wide bowel cancer screening program' (true, 51.4%). Only one knowledge item had a high response of incorrect answers, which was 'it is not necessary to have screening for cervical cancer if someone with a cervix has never been sexually active in any way' (71.9% believed this to be false when it is true).

Table 6.4 Hormones can affect everyone's cancer risk (TRUE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	56	55.4%	49	34.3%	86	46.7%	191	44.6%
False	8	7.9%	17	11.9%	9	4.9%	34	7.9%
I don't know	37	36.6%	77	53.8%	89	48.4%	203	47.4%
Total	**101**	**100.0%**	**143**	**100.0%**	**184**	**100.0%**	**428**	**100.0%**

Table 6.5 The risk of getting cancer does not increase with age (FALSE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	4	4.0%	12	8.3%	9	4.9%	25	5.8%
False	82	81.2%	104	72.2%	138	75.0%	324	75.5%
I don't know	15	14.9%	28	19.4%	37	20.1%	80	18.6%
Total	**101**	**100.0%**	**144**	**100.0%**	**184**	**100.0%**	**429**	**100.0%**

Table 6.6 It is not necessary to have screening for cervical cancer if someone with a cervix has never been sexually active in any way (TRUE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	5	5.0%	16	11.1%	21	11.5%	42	9.8%
False	69	68.3%	102	70.8%	136	74.7%	307	71.9%
I don't know	27	26.7%	26	18.1%	25	13.7%	78	18.3%
Total	**101**	**100.0%**	**144**	**100.0%**	**182**	**100.0%**	**427**	**100.0%**

Table 6.7 The Australian cervical cancer screening program has recently changed (TRUE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	19	18.8%	48	33.3%	76	41.5%	143	33.4%
False	1	1.0%	2	1.4%	1	0.5%	4	0.9%
I don't know	81	80.2%	94	65.3%	106	57.9%	281	65.7%
Total	**101**	**100.0%**	**144**	**100.0%**	**183**	**100.0%**	**428**	**100.0%**

Table 6.8 People who are assigned male at birth cannot develop breast cancer (FALSE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	1	1.0%	2	1.4%	4	2.2%	7	1.6%
False	94	94.0%	130	90.3%	168	91.8%	392	91.8%
I don't know	5	5.0%	12	8.3%	11	6.0%	28	6.6%
Total	**100**	**100.0%**	**144**	**100.0%**	**183**	**100.0%**	**427**	**100.0%**

Table 6.9 People do not have any risk of developing breast cancer if they have had a mastectomy (FALSE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	7	7.0%	15	10.5%	10	5.5%	32	7.5%
False	55	55.0%	85	59.4%	123	67.2%	263	61.7%
I don't know	38	38.0%	43	30.1%	50	27.3%	131	30.8%
Total	**100**	**100.0%**	**143**	**100.0%**	**183**	**100.0%**	**426**	**100.0%**

Table 6.10 People with breasts/chest tissue between the ages of 50 and 74 should have a mammogram once every two years (TRUE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	74	73.3%	107	74.3%	133	72.7%	314	73.4%
False	1	1.0%	2	1.4%	4	2.2%	7	1.6%
I don't know	26	25.7%	35	24.3%	46	25.1%	107	25.0%
Total	**101**	**100.0%**	**144**	**100.0%**	**183**	**100.0%**	**428**	**100.0%**

Table 6.11 Australia has a nation-wide breast cancer screening program (TRUE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	68	67.3%	98	68.1%	120	65.6%	286	66.8%
False	2	2.0%	1	0.7%	1	0.5%	4	0.9%
I don't know	31	30.7%	45	31.3%	62	33.9%	138	32.2%
Total	**101**	**100.0%**	**144**	**100.0%**	**183**	**100.0%**	**428**	**100.0%**

Table 6.12 Australia has a nation-wide prostate cancer screening program (FALSE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	35	34.7%	54	37.5%	82	44.8%	171	40.0%
False	9	8.9%	6	4.2%	4	2.2%	19	4.4%
I don't know	57	56.4%	84	58.3%	97	53.0%	238	55.6%
Total	**101**	**100.0%**	**144**	**100.0%**	**183**	**100.0%**	**428**	**100.0%**

Table 6.13 Australia has a nation-wide bowel cancer screening program (TRUE).

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
True	56	55.4%	79	54.9%	85	46.4%	220	51.4%
False	5	5.0%	0	0.0%	5	2.7%	10	2.3%
I don't know	40	39.6%	65	45.1%	93	50.8%	198	46.3%
Total	**101**	**100.0%**	**144**	**100.0%**	**183**	**100.0%**	**428**	**100.0%**

Most participants had never had a healthcare provider discuss any cancer information with them (60.5%) (Table 6.14). The most commonly discussed cancers were breast cancer (20.7%), cervical cancer (17.4%), and ovarian cancer (9.3%). Considering the high rate of oestrogen and cyproterone acetate usage in trans women, it is disappointing that so few have had healthcare provider's discuss meningiomas and prolactinomas with them, given the evidence indicating monitoring and awareness for these tumours when on these hormones (Committee on Health Care for Underserved Women, 2011; Wengel, Martin, Gooren, den Heijer, & Peerdeman, 2016).

Table 6.14 Have any of your healthcare professionals ever discussed or provided information on…?

	n	%
Breast cancer	89	20.7%
Bowel cancer	29	6.7%
Cervical cancer	75	17.4%
Prostate cancer	20	4.7%
Ovarian cancer	40	9.3%
Testicular cancer	17	4.0%
Meningiomas	3	0.7%
Prolactinomas	2	0.5%
None of the above	260	60.5%
Total	**430**	**100.0%**

Participants were asked an open-ended question about what they would like to know more about in relation to cancer, and 158 participants responded to this. The most common answers were TGD specific information, risks and causes, prevention, screening and diagnosis, services (including where to access inclusive ones), and signs and symptoms. Some stated that they did not want to know anything more and others stated that they wanted to know more about everything. TGD specific information was the most common theme and related frequently to risks and causes (e.g. how do hormones or surgery affect this), appropriate screening and concern regarding whether services would be inclusive.

6.1 Cervical Cancer Screening

Participants who had previously indicated that they had a cervix were asked a series of questions on cervical screening. For people with a cervix, most had little or no concern of developing cervical cancer (69.9%) (Table 6.15).

Table 6.15 What is your level of concern for developing cervical cancer?

	Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%
No concern	25	21.0%	39	25.3%	64	23.4%
Little concern	63	52.9%	64	41.6%	127	46.5%
Moderate concern	28	23.5%	40	26.0%	68	24.9%
Extremely concerned	3	2.5%	11	7.1%	14	5.1%
Total	**119**	**100.0%**	**154**	**100.0%**	**273**	**100.0%**

The cervical screening program in Australia changed in December 2017, raising the starting age from 18 to 25 (Australian Institute of Health and Welfare, 2018b). Given that data collection for this study started less than one year after this, 18 year olds have been excluded from the following two tables

(Table 6.16 and Table 6.17). All people with a cervix aged over 19 should have experienced a recommendation and potentially been screened in line with the previous recommendation as they would have been eligible. Half of people with a cervix aged over 19 had never had a healthcare provider recommend cervical screening to them (Table 6.16).

*Table 6.16 Has a healthcare provider ever recommended to you that you have cervical screening?**

	Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%
Never	51	51.0%	64	49.6%	115	50.2%
Once	32	32.0%	33	25.6%	65	28.4%
Often	17	17.0%	32	24.8%	49	21.4%
Total	**100**	**100.0%**	**129**	**100.0%**	**229**	**100.0%**

**Excludes participants aged 18.*

Participants with a cervix were asked whether they had accessed cervical screening (those aged 18 have been excluded from analysis based on ineligibility) (Table 6.17). Of those aged over 19, 54.3% had never had cervical screening, which is considerably higher than previous Australian research has found in this population (23.3%) (Smith & Dyson, 2015). This was more likely to be the case for trans men (66.3%) compared with gender diverse people (45.0%). Gender diverse people with a cervix were more likely to be regular screeners (26.4%) than trans men (8.9%). National data estimated that in 2015-16, 55% of eligible people with a cervix were screened (Australian Institute of Health and Welfare, 2018b).

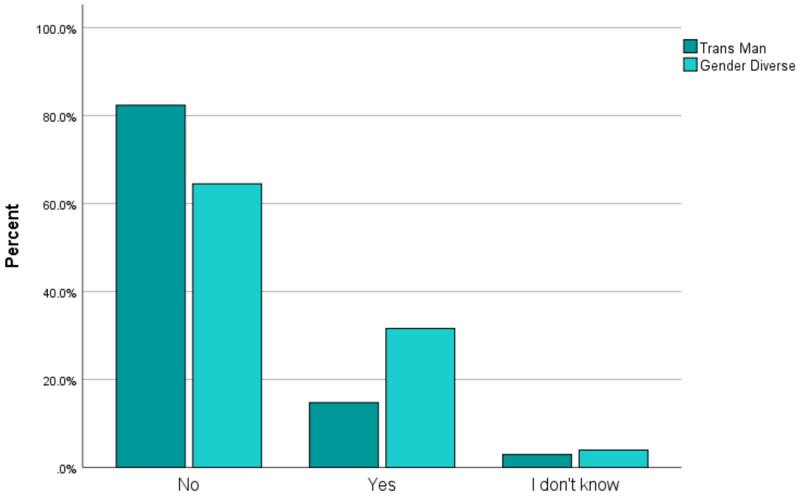
*Table 6.17 Have you ever had a Pap test or cervical screening?**

	Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%
Never	67	66.3%	58	45.0%	125	54.3%
Once/rarely	25	24.8%	37	28.7%	62	27.0%
Regularly	9	8.9%	34	26.4%	43	18.7%
Total	**101**	**100.0%**	**129**	**100.0%**	**230**	**100.0%**

**Excludes participants aged 18.*

Of the people with a cervix who had participated in cervical screening, over a quarter reported that they had received an abnormal result, a relatively high percentage given that the general Australian population has a rate of 8% (Figure 39) (Australian Institute of Health and Welfare, 2018b). Gender diverse people with a cervix were more likely than trans men to report this (31.6% compared to 14.7%). Previous Australian research focusing on LBT people with a cervix reported that 28.8% of their sample had previously had an abnormal Pap test (Smith & Dyson, 2015).

Figure 39 – Abnormal Pap test or cervical screening.



Participants who had accessed cervical screening were asked if they would like to provide any comments on their experiences. Forty-eight participants chose to do so, with the majority of comments indicating that their experience was bad, however, one in four spoke of good experiences.

Some sample responses include:

- *I turned up for a cervical based ultrasound with a service I wasn't familiar with and continued to get asked which family member the appointment was for and then got treated in a way that was significantly different before transition that made me feel uncomfortable when they finally did the screening.*
- *I usually cannot walk or sit without enhanced pain for several weeks after and it makes it quite impossible to pretend I do not have one, so it is a repeated dysphoria trigger.*
- *My gynaecologist is trans friendly and sees a lot of trans men. She uses inclusive and non-gendered language and my experience with her was positive.*
- *I am so blessed to have an LGBTIQ specialist healthcare provider, it makes life so much easier because they use appropriate language. I would find it really hard to get pap smears, etc., without a specialist provider, especially because of the downstairs growth. I don't feel like most doctors would understand that at all.*
- *It was horrible and one of the most painful experiences of my life. It felt like a wood rasp was being used to slowly scrape my insides. This happened both times I had it done and I was told it was abnormal to be so sensitive and then given no further information. I would prefer to get cancer and have my parts removed than go through that again.*
- *Since I started taking T my clit has grown heaps. There is zero chance I would go anywhere other than a specialist LGBTIQ service to get a pap test now. And there's only a few in Melbourne. Can't imagine how hard regional trans people have it.*
- *I have PTSD from rape and have had one very traumatic pap test and one less-traumatic pap test but both were highly traumatic experiences. I've never had one again since. GPs are poorly*

> *trained to deal with sexual trauma re: pap tests, especially given the high amount of sexual assault statistically.*

For those with a cervix who had never had screening, over half responded that this was because it is emotionally traumatic for them, two out of five were not comfortable with healthcare providers, and almost two out of five have never been sexually active in any way (Table 6.18). Open-ended responses for this question indicated other reasons for not having had cervical screening, an important one being younger age.

Table 6.18 Can you please tell us why you have never been for cervical screening? (Multiple response answer).

	n	%
Physical pain	14	8.9%
I have never been sexually active in any way	60	38.2%
I find it emotionally traumatic	81	51.6%
I have had previous bad experiences in healthcare	15	9.5%
I am not comfortable with healthcare professionals	66	42.0%

6.2 Breast Cancer Screening

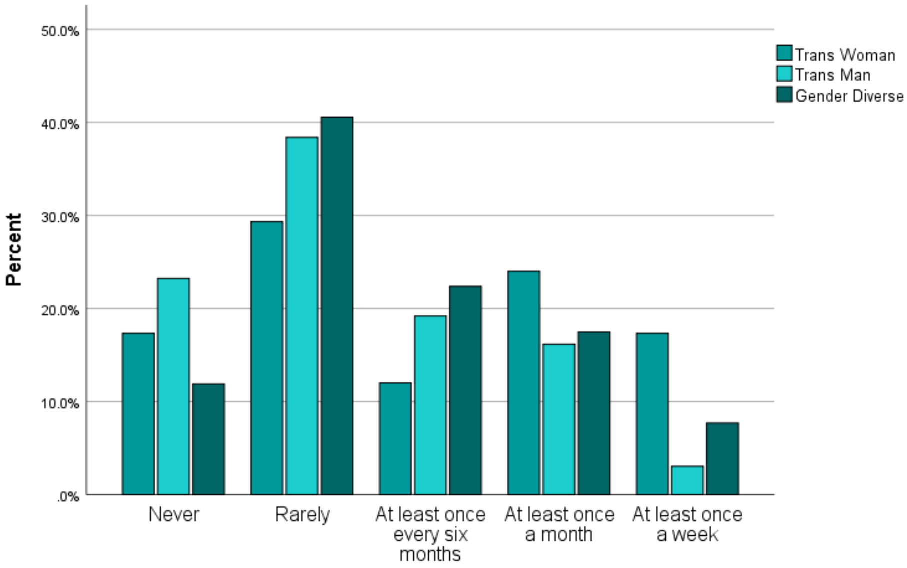
People who reported that they had significant breast or chest tissue were asked a series of questions on breast cancer screening. Most participants with breast or chest tissue have little (49.5%) or moderate (32.5%) concern of developing breast cancer (Table 6.19).

Table 6.19 What is your level of concern for developing breast cancer?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
No concern	9	12.0%	10	10.1%	20	14.0%	39	12.3%
Little concern	45	60.0%	52	52.5%	60	42.0%	157	49.5%
Moderate concern	19	25.3%	29	29.3%	55	38.5%	103	32.5%
Extremely concerned	2	2.7%	8	8.1%	8	5.6%	18	5.7%
Total	**75**	**100.0%**	**99**	**100.0%**	**143**	**100.0%**	**317**	**100.0%**

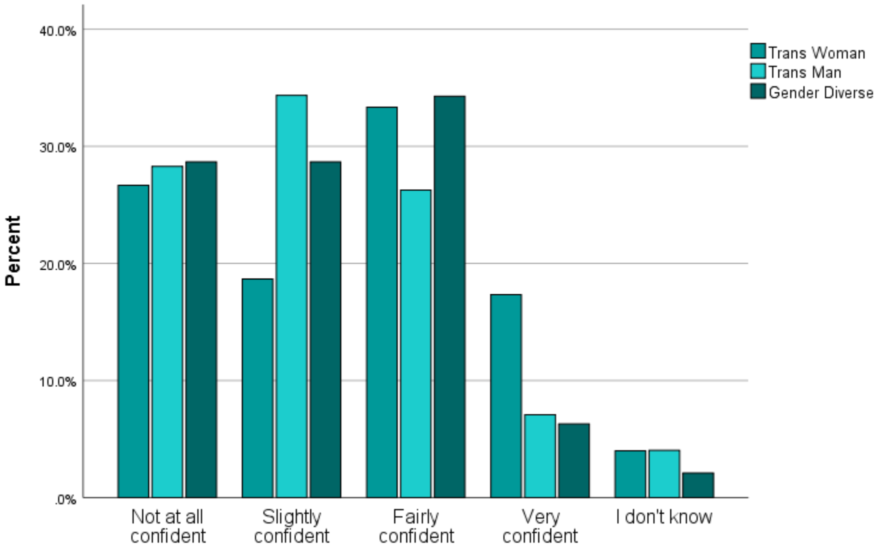
The most common response to self-checking breast or chest tissue was 'rarely' (37.2%), with trans men most likely to report never checking (23.3%), and trans women most likely to report checking once a week or monthly (41.3%) (Figure 40). Australian research has reported that around half of women perform self-examinations on a monthly basis (Leung, McKenzie, Martin, Dobson, & McLaughlin, 2014) – across all genders our participants are checking less frequently than this.

Figure 40 – Self-Checking Breast/Chest Tissue.



Most participants with breast or chest tissue were either slightly or fairly confident that they would notice a change in the tissue (59.6%) (Figure 41). Trans women were the most likely to report they were 'very confident' they would notice a change (17.3%).

Figure 41 – Confidence in Noticing a Change in Breast/Chest Tissue.



Most participants had never had a healthcare provider recommend breast cancer screening, which is to be expected as the targeted age group is 50-74 (Table 6.20). Of those aged over 50 (n=16), 56.3% had never received a recommendation (n=9), 31.3% once (n=5), and 12.5% often (n=2).

Table 6.20 Has a healthcare provider recommended to you that you have cancer screening for your breast or chest tissue?

	Trans Woman		Trans Man		Gender Diverse		Total	
	n	%	n	%	n	%	n	%
Never	65	87.8%	81	81.8%	113	80.1%	259	82.5%
Once	7	9.5%	16	16.2%	22	15.6%	45	14.3%
Often	2	2.7%	2	2.0%	6	4.3%	10	3.2%
Total	**74**	**100.0%**	**99**	**100.0%**	**141**	**100.0%**	**314**	**100.0%**

The majority had never been for a mammogram (Table 6.21). As above, this is to be expected given the samples' young age. Of those aged over 50 (n=15), 26.7% had never had a mammogram (n=4), 46.7% had once (n=7), and 26.7% regularly had mammograms (n=4). It is significant to note that there were people below the age of 50 who had been for mammograms (n=29).

Table 6.21 Have you ever been for a mammogram?

	Trans Woman		Trans Man		Gender Diverse		Total	
	N	%	n	%	n	%	n	%
Never	64	86.5%	89	89.9%	121	85.8%	274	87.3%
Once or rarely	6	8.1%	9	9.1%	18	12.8%	33	10.5%
Regularly	4	5.4%	1	1.0%	2	1.4%	7	2.2%
Total	**74**	**100.0%**	**99**	**100.0%**	**141**	**100.0%**	**314**	**100.0%**

6.3 Prostate cancer screening

People with a prostate were asked a series of questions related to prostate cancer screening. The majority of people with a prostate had little (54.9%) or moderate (30.4%) concern of developing prostate cancer (Table 6.22).

Table 6.22 What is your level of concern for developing prostate cancer?

	Trans Woman		Gender Diverse		Total	
	n	%	n	%	n	%
No concern	12	13.6%	2	14.3%	14	13.7%
Little concern	48	54.5%	8	57.1%	56	54.9%
Moderate concern	27	30.7%	4	28.6%	31	30.4%
Extremely concerned	1	1.1%	0	0.0%	1	1.0%
Total	**88**	**100.0%**	**14**	**100.0%**	**102**	**100.0%**

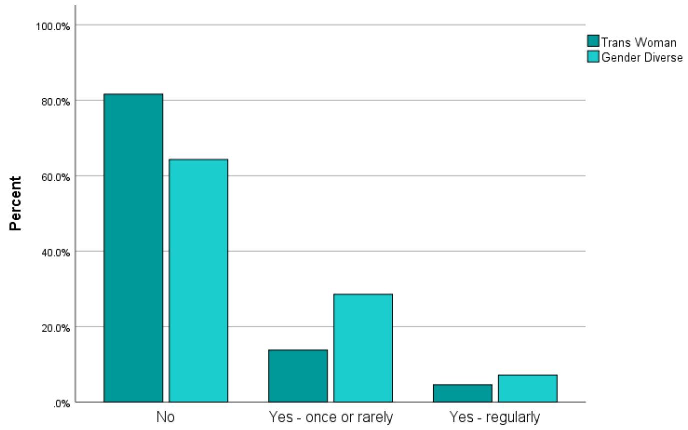
The majority of people with a prostate had not had a healthcare provider recommend prostate cancer screening (83.3%) (Table 6.23). This is unsurprising given the overall young age of the sample. Further to this, prostate screening is based on informed choice, and not universally recommended. Of those aged over 50 (n=16), 37.5% had never had a recommendation (n=6), 37.5% had once (n=6) and 25% experienced this often (n=4).

Table 6.23 Has a healthcare provider recommended to you that you have a prostate check?

	Trans Woman		Gender Diverse		Total	
	n	%	n	%	n	%
Never	74	84.1%	11	78.6%	85	83.3%
Once	11	12.5%	2	14.3%	13	12.7%
Often	3	3.4%	1	7.1%	4	3.9%
Total	**88**	**100.0%**	**14**	**100.0%**	**102**	**100.0%**

Overall, 20.8% of people with a prostate had prostate cancer screening (Figure 42). Of those aged over 50 (n=16), 37.5% had never been checked (n=6), 31.3% once (n=5) and 31.3% regularly (n=5).

Figure 42 – Ever Checked for Prostate Cancer.



6.4 Accessing Cancer Care – Areas for Improvement

Participants were asked to rank a series of items 1 through to 6 (1 being most important, 6 being least important) in relation to what would help them access, what would stop them from accessing, and what they think should change in cancer care.

Participants' highest ranked responses in terms of what would aid their cancer care access were: healthcare workers being trained in TGD needs; welcoming services that specifically address TGD concerns; and cancer awareness campaigns specific to TGD people.

Table 6.24 Frequencies of top ranked responses (sum of 1st and 2nd most important) to 'What things might help you in accessing cancer care?'

	n	%
Healthcare workers that are trained in trans and gender diverse needs	291	67.9%
Welcoming services that specifically address trans and gender diverse concerns	259	60.5%
Cancer awareness campaigns specific to trans and gender diverse people	135	31.6%
Doctor's suggestion	107	24.9%
General awareness campaigns for cancer	56	13.1%
Encouragement from family or friends	54	12.6%

Participants' most common barriers to accessing cancer care were: healthcare providers lacking knowledge of TGD needs; not being comfortable having a healthcare provider look at or touch their body; and this not being their priority.

Table 6.25 Frequencies of top ranked responses (sum of 1st and 2nd most important) to 'What things might stop you from accessing cancer care?'

	n	%
Healthcare workers that lack knowledge of trans and gender diverse needs	268	62.5%
I am not comfortable having a healthcare provider look at or touch my body	228	53.1%
This is not my priority	112	26.2%
I don't think I need to	103	24.1%
Previous bad experiences	97	22.7%
General awareness campaigns that do not address my concerns	60	14.0%

In terms of changes that participants would like to see in cancer care, the highest rated response was 'training and education'. This was followed by a directory or list of organisations that are safe and inclusive for TGD people, and inclusive policies (Table 6.26).

Table 6.26 Frequencies of top ranked responses (sum of 1st and 2nd most important) to 'What do you think should change in cancer care in order to better meet the needs of trans and gender diverse people?'

	n	%
Training and education	234	54.6%
A directory or list of organisations that are safe and inclusive for TGD people	199	46.5%
Inclusive policies	136	31.7%
Changes to the ways healthcare systems collect information	133	31.0%
Partnerships with trans and gender diverse community organisations	125	29.2%
Research	94	22.0%

7. Conclusion

> *Cancer's a teacher, that's what I've said since the start. It teaches you who your friends are, who loves you, what or who you really are, that's what I found about cancer. It's definitely a teacher.*
>
> - Trans woman

> *I think having breast cancer and the whole sequence of events to having no breasts, I think it's made me a lot stronger about what I identify as, I feel like for many years I was in denial.*
>
> - Non-binary person, breast cancer.

> *You've got your processes you've got to go through, you've got to tick your boxes, you've got to meet your KPIs, you gotta do all that, but lay aside that, you wouldn't have to worry about all that if you didn't have patients, and your patients are going to come from very diverse backgrounds.*
>
> - Trans man, BRCA gene mutation.

This report details an important snapshot of trans and gender diverse people accessing health and cancer care in an Australian context. The sample was diverse, including people from all around the country. Many of the questions had not been asked of this community until now and have shed light on the issues facing trans and gender diverse people in relation to their health. These issues are wide-ranging, including: persistent social marginalisation and discrimination; problems with gender affirmation (limited ability to change identifying documents, lack of services related to medical gender affirmation); healthcare workers and services that are unaware of the TGD community's needs and/or prejudiced toward them (with resulting avoidance on the part of TGD individuals); and limited awareness of cancer care due to general awareness campaigns not being inclusive of TGD people and healthcare providers not initiating the relevant conversations. All of the above form a complex web of interacting factors that result in poor mental and physical health and wellbeing. However, this sample is not representative, for example several sub-communities such as those born overseas appear to have been less likely to respond to the survey, and more research is needed to fully understand the needs of these people.

The participant characteristics captured show the diversity in this population. We had a considerable response from young people and individuals with diverse genders, indicating a strong and evolving community. Some of the findings that relate to social marginalisation (e.g. low income, high rates of harassment and assault) hold consistent with previous research both within Australia and internationally (Hyde et al., 2014; James et al., 2016; Riggs & Due, 2013; Strauss et al., 2017). Social acceptance may remain an issue, however, our participants show the powerful connection that many have to the trans and gender diverse community, particularly when searching for information. This is significant for any health promotional activity that aims to include this population, as partnerships with the community will have the best results.

Other characteristics of this population which are significant to consider in relation to the provision of healthcare include the relatively high rate of neurodiversity, psychological distress and trauma (e.g. physical and sexual assault). Other Australian research has noted that trans and gender diverse individuals may be more likely to be neurodiverse (Strauss et al., 2017), and numerous studies have showed high rates of poor mental health due to stigma and discrimination (Hyde et al., 2014; James et al., 2016). People who are neurodiverse may find aspects of healthcare encounters difficult, and healthcare providers are often not sensitive to this (Lehmann & Leavey, 2017). Those with a history of trauma may experience increased distress in healthcare and be re-traumatised (Reeves, 2015). Considering these factors, to improve healthcare access for trans and gender diverse individuals, healthcare providers must consider how to make their practice friendly for neurodiversity and take a trauma-informed approach. Trauma-informed care involves sensitive screening for a trauma history, developing trusting relationships, minimising distress and maximising autonomy (Reeves, 2015).

As our report shows, many trans and gender diverse people have significant body discomfort, which necessitates sensitive patient-centred care and communication on the part of clinicians. Many trans and gender diverse people are not visibly 'identifiable', and very few people *always* disclose in a healthcare environment. Healthcare providers need to be aware of this and able to know when to ask the right questions and create a way in which trans and gender diverse people can easily and safely disclose if they wish to, including on forms and in databases.

Accessing health and cancer care for trans and gender diverse people can be difficult due to the issues related to the provision of care. Our data show that too often trans and gender diverse people are unable to access appropriate healthcare when they need it, do not receive enough information about their care, do not benefit from having a healthcare provider who has a good understanding of their needs, and have numerous bad experiences. Given trans and gender diverse people's position within healthcare, bad experiences are unlikely to be reported through complaints systems, which may be difficult to navigate and result in re-traumatisation. There is a need for capacity building around complaint pathways for this population to ensure that such experiences are documented and addressed adequately and sensitively.

Trans and gender diverse people are wary of discussing their preferences with healthcare workers. Their justified fear and hesitancy to seek healthcare results in avoidance, including in emergency situations. This problem is not exclusive to Australia (Bauer et al., 2014). Problems with accessing general healthcare must be addressed with widespread training and policy changes. Of particular focus should be language use and general understanding of the issues facing this population. Information about what services have been trained needs to be put on a directory and communicated to the trans and gender diverse community, whom healthcare organisations need to make partnerships with to guide health promotion. A good example of this is BreastScreen Victoria's recent achievement of Rainbow Tick Accreditation. Additionally, trans and gender diverse people need visibility and presence within the healthcare sector, particularly in any service that specifically addresses this community.

The report shows there are also problems related to the availability of gender affirmation care. There was a high rate of people desiring access to gender affirmation care who have been unable to in the last year, and many are travelling great distances to get what they need, including going outside of

Australia. Long waiting periods and a lack of services has been documented elsewhere, and effects this community's health and wellbeing (GLBTI Health and Wellbeing Ministerial Advisory Committee, 2014; Hyde et al., 2014). To address the cumbersome barriers associated with gender affirmation care, the Informed Consent Model is recommended (Schulz, Kamens, Robbins, & Flanagan, 2018). The Informed Consent approach focuses on ensuring that trans and gender diverse people are informed and able to make their own decisions regarding their medical care (Schulz et al., 2018). By employing the Informed Consent Model widely, gender affirming services will become easier to access and less distressing for trans and gender diverse people. This model must be supported by clear guidelines for healthcare providers. Further to this, surgeries should receive increased funding and attention so that trans and gender diverse people are not burdened with the travel, cost and stress of seeking these overseas.

Following on from gender affirmation in the medical area, data show that few trans and gender diverse people have been able to change all of their documentation. The process of changing one's identifying documents is an important step for many trans and gender diverse people in the recognition of their gender, and not being able to do so may expose them to discrimination (Hyde et al., 2014; Jones et al., 2015). Depending on the identity document, legislation associated with these may be at a Commonwealth or state/territory level, and therefore there are differing requirements, some of which have an unreasonably high burden of proof such as gender affirming surgery to change one's birth certificate (GLBTI Health and Wellbeing Ministerial Advisory Committee, 2014). Where relevant, it is advised that surgery be removed as a pre-requisite for changing gender on birth certificates, as many trans and gender diverse people have not and will not undergo surgery.

In terms of cancer care and knowledge, that many would delay seeking advice if they had a symptom they thought was a sign of cancer may put these people's lives in danger. Many reported lacking knowledge about cancer, showing that general awareness campaigns are not reaching this population. Participants showed a desire for more knowledge, given to them in ways that address their needs as trans and gender diverse people. There is a need for specific tailored information for trans and gender diverse people in relation to cancer. Further, population-based health promotion, especially those related to cancer screening, should reconsider the use of language, which may be exclusionary for trans and gender diverse people. The National Cervical Screening Program provides a good example of using inclusive language such as 'people with a cervix' and explicit mention of trans individuals.

There was a high rate of people with a cervix not receiving a healthcare provider recommendation for cervical screening and not participating in this. Given that the most significant risk for developing cervical cancer in Australia now is not attending screening (Australian Institute of Health and Welfare, 2018b), combined with the recent changes to the test and addition of self-administered swabs, trans and gender diverse people with a cervix should have the choice of self-screening made open to them as a priority under-screened population.

Population-based research and registries need to reconsider and change their collection of gender, so there is data on which professionals can draw on to make evidence-based decisions. There is a need for the Australian Bureau of Statistics, in consultation with the community, to develop a standard for the consistent collection of data on gender and sex. Such a standard should then be mandated by the government for use in all health systems (including electronic medical records and intake forms), and research.

In this report there are many areas that are in need of attention, however, also offered in this report are ways forward, based on what trans and gender diverse people actually want. The response from the trans and gender diverse community and support they have given to this study show that this population is proactive about their health and has a strong desire to affect change so that they can access appropriate services. Community organisations are valuable resources that healthcare professionals can draw on in design and delivery of services, consulting and including trans and gender diverse people in any services that are directed at them. The healthcare system, broadly, needs to become more inclusive of this population, and the participants in this study have given much to inform this transformation.

8. Recommendations

1. The data strongly support a patient- or person-centred approach to health and cancer care for TGD individuals, which considers gender, language use, neurodiversity and trauma histories. Healthcare workers need to be initiating the relevant conversations in a sensitive manner and tailoring their care appropriately.

2. Health and cancer services need to make partnerships with TGD community organisations to inform any initiative aimed at improving care for this population.

3. General cancer awareness campaigns need to be inclusive of TGD people and specific awareness campaigns must be designed that address TGD concerns, for which funding is needed. Brochures produced by the Cancer Council Australia require reviewing generally for inclusivity, and development of targeted brochures is also necessary.

4. TGD people should be given visibility within health and cancer care services, and, most importantly, in any services that are targeted at them. A peer-navigator role would help this.

5. Capacity building around complaints pathways is necessary to help TGD people report their bad experiences and have them adequately and sensitively addressed.

6. There is a need for widespread training and education, including for those already working within healthcare (including auxiliary staff and in regional areas) and in pre-vocational courses. Training should be delivered by the community and professionals working together.

7. Once training has been completed, this needs to be communicated to the TGD community, preferably in a directory that is easy to access, and by using recognised signs/symbols.

8. Policies, including those within health/cancer care services and at a state level (e.g. *Victorian Cancer Plan 2016-2020)*, should specifically address TGD people as a priority population.

9. Changes need to be made to the collection of gender/sex data in population-based research and registries, in consultation with the TGD community. There is a need for an ABS standard that can be used widely and consistently throughout health systems.

10. The Informed Consent Model for gender affirmation should be adopted universally throughout Australia – enhancing the accessibility of gender affirmation care.

11. Affirmation surgeries should receive funding (governmental and private health insurance).

12. Where relevant, state and territory governments need to reconsider the requirement for gender affirming surgery in order to change one’s gender on birth certificates, as many TGD people have not, and will not, undergo surgery.

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DC35683 09/19