“You just end up feeling quite rejected by the entire healthcare system”

A mixed methods study of perceived barriers to healthcare access in New Zealand LGBTQ+ teens, and their impact on sexual risk behaviour

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Abstract

Background

In recent years, research on lesbian, gay, bisexual, trans*, queer/questioning (LGBTQ+) youth has shifted from risk-based to resilience research. Research suggests that three factors contribute to resilience: environmental support (e.g. school, family), positive interpersonal relationships (e.g. LGBTQ+ peers), and intrapersonal aspects (e.g. self-efficacy, ability to define one's own gender). Unfortunately, even in settings that could contribute to building LGBTQ+ youths' resilience, this population often encounters rejection, bullying, and even violence in the everyday spaces they inhabit. As a result, adolescent sexual and gender minorities (SGM) are at heightened risk for adverse mental and physical health events, compared with their heterosexual, cis-gendered peers. Yet little information exists on the experiences of older (15-19 years) LGBTQ+ teens in the New Zealand healthcare system. International research indicates that LGBTQ+ people encounter barriers to healthcare access that arise from stigma and discrimination. A recent New Zealand study (Veale et al., 2019) of trans* teens and adults showed they, too, encounter difficulties accessing and receiving gender-affirming care.

This study aimed to examine whether a sample of LGBTQ+ teens in New Zealand perceive interpersonal barriers to health care services. In addition, the study aimed to explore whether perceptions of health care barriers influence sexual risk behaviours, and uptake of preventive behaviours. This specific relationship has not been examined in earlier studies either.

Methods

Adopting a mixed methods, sequential explanatory study design, this research comprised an online anonymous survey with 310 respondents and in-depth, semi-structured qualitative interviews with a convenience sample of 15 LGBTQ+ teens. The survey included

multiple choice and open-ended questions. Descriptive statistics and regression analysis were used to analyse the multiple choice questions. Content analysis was done on the open-ended questions. The qualitative interviews were analysed using reflexive thematic analysis (Braun & Clarke, 2006).

Results

By combining quantitative and qualitative data, I was able to generate a more complete picture of the answers to my research questions. Building on the quantitative survey data to develop interview questions, which in turn expanded on and illustrated the quantitative findings.

This study found that participating LGBTQ+ teens perceive interpersonal barriers to healthcare services, and these barriers have potentially serious consequences not only in the sexual health arena but also in terms of the participants' emotional wellbeing. The impact of these barriers seemed most pronounced in the gender diverse population.

The participants predominantly attributed these barriers to lack of knowledge and training on the providers' side. Such perceptions caused participants to feel dismissed or misunderstood, and at times reluctant to continue seeking care. The perception of barriers also stems from the participants' own experiences of being LGBTQ+, driving their fear of coming out to providers lest they suffer discrimination and judgement, which may be a common occurrence in other areas of their lives.

Participants' experience of a widespread heteronormative attitude in healthcare allows them to continue receiving care without having to come out. However, this attitude adds a layer of complexity and additional barriers to gender diverse individuals who require, at minimum, gender-affirming care in the form of respectful language.

These above barriers, and the perceived lack of adequate sexuality education resources elsewhere, create a knowledge gap in the study population. No direct connection was found between sexual risk behaviour and participants' ability to fully utilise healthcare services as LGBTQ+ individuals. However, the barriers found in this study contributed to lack of knowledge and lower uptake of preventive measures, which increase the risk of adverse outcomes (e.g. STI exposure) in this study population.

Conclusions

In a population already affected by marginalisation, participants' healthcare needs are not being met. This was especially true with regards to gender minority participants. Gender diversity was also associated with a lower health communication self-efficacy score, itself a barrier to healthcare utilisation.

Mental health struggles were commonly reported in the interviews, and participants related those to being LGBTQ+ (the most cited factor) and New Zealand's inadequate mental health system. Long wait times for mental health appointments, as well as being told that "asking for help means you're well enough" raise the risk of exacerbating depression, anxiety, and suicidal ideation. These are conditions that already affect LGBTQ+ adolescents disproportionally.

Participants' common concerns (e.g. confidentiality, denial of care, judgement and discrimination) around disclosing their sexual or gender identity, together with other research, indicate there are serious gaps in meeting the healthcare, including sexual health needs, of LGBTQ+ teens in New Zealand. These common concerns make the necessity of repeatedly coming out to new providers a daunting task for these participants. Inability to discuss their SGM status openly also creates a knowledge gap in sexual health knowledge, resulting in possible public health implications.

Dedication

This work is dedicated to the memory of my grandmother, Rina Gelman. Her courage and determination in the face of unspeakable adversity have been an inspiration to me throughout my life. Her love sustains me to this day.

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And to my "Big Sister" Lisa Wilhelm, because some friendships can't be described, they can only be experienced.

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Lastly, and perhaps most importantly, I would like to thank and acknowledge my study participants, who spoke out about deeply personal matters and allowed me an honest glimpse into their world. Your eloquence and courage moved me deeply, and I am in your debt.

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AFAB	Assigned female at birth
AIDS	Acquired Immune Deficiency Syndrome
AMAB	Assigned male at birth
ART	Antiretroviral therapy
BYS	Boston Youth Survey
CBPR	Community based participatory research
CI	Confidence interval
CIOMS	Council for International Organizations of Medical Sciences
COVID-19	Coronavirus disease 2019
CRC	The United Nations Convention on the Rights of the Child
EC	Ethics Committee
ESR	Institute of Environmental Science and Research
GLAAD	Gay and Lesbian Alliance Against Defamation[1]
GP	General practitioner
GSA	Gay-straight alliance
HEC	University of Canterbury’s Human Ethics Committee[2]
HIV	Human immunodeficiency virus
HPV	Human papilloma virus
HRC	Human Rights Commission
HREC	University of Canterbury’s Human Research Ethics Committee[3]
HVTN	HIV Vaccine Trials Network
IAT	Implicit association test
IP	Internet protocol
IUD	Intrauterine device
LGBTQ	Lesbian, gay, bisexual, trans*, queer/questioning
LGBTQIA	Lesbian, gay, bisexual, trans*, queer/questioning, intersex, allies
MA	Massachusetts
MDS	Modified Depression Scale
MSM	Men who have sex with men
NSW	New South Wales
NY	New York

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[1] This organisation is now officially named GLAAD. The spelled out version has been dropped from its name.

[2] Former name, used at the time this study was approved

[3] Current name

NYC	New York City
NZ	New Zealand
NZAF	New Zealand AIDS Foundation[4]
OECD	Organisation for Economic Co-operation and Development
OR	Odds ratio
PATHA	Professional Association for Transgender Health Aotearoa
PE	Physical education
Pharmac	Pharmaceutical Management Agency
PrEP	Pre-exposure prophylaxis
QSA	Queer-straight alliance
RADS-SF	Reynolds Adolescent Depression Scale – short form
SCT	Social cognitive theory
SD	Standard deviation
SDG	Sustainable development goal
SGM	Sexual and gender minorities
SLT	Social learning theory
SOGIESC	Sexual Orientation, Gender Identity and Expression, and Sex Characteristics
STI	Sexually transmitted infection
TA	Thematic analysis
TaP	Treatment as Prevention
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children’s Fund
US	United States
VPN	Virtual private network
WHO	World Health Organization
WSW	Women who have sex with women
YOSS	Youth one stop shop

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[4] Renamed The Burnett Foundation Aotearoa in June, 2022.

Glossary

Cis-gendered	A person whose gender identification matches the sex they were assigned at birth.
Cisnormativity	The assumption that individuals identify with the sex they were assigned at birth. For example, a person assigned female at birth is assumed to identify as female.
Coming out	The process of disclosing one's sexual or gender identity to others. It is a process that only sexual and gender minority individuals have to go through, as people are generally assumed to be heterosexual and cis-gendered.
Gender-affirming surgery	Surgical intervention(s) that bring a person's anatomy in line with their self-identified gender. Not all trans* people choose to have these surgeries done.
Gender expression	The way a person chooses to show their gender externally – through clothes, name, hair style, and other cues society classifies as masculine or feminine. Gender expression is the external manifestation of a person's gender identity.
Gender identity	A person's innate understanding and knowledge of their own gender. This concept of who they are (male, female, or neither) does not always match their sex assigned at birth.
Gender-queer	A person who identifies as neither man nor woman. Some gender-queer people see themselves as somewhere between man and woman, some see themselves as a combination of both, and some define themselves as something completely different than either man or woman.
Heteronormativity	The prevailing assumption that individuals are heterosexual. For example, a new GP may ask a sexually active woman what form of contraception she uses, without checking first if her sexual partners are male or female. The term heteronormativity often implies cisnormativity as well.

Non-binary	See Gender-queer.
PrEP	PrEP is given to HIV-negative individuals who are at risk of being exposed to the virus. It is a combination of anti-retroviral medications that prevent HIV infection.
Sexual orientation	A person's attraction to others. Such attraction can be emotional or physical, or both. A person may be attracted to people of the same gender, different gender, or multiple genders. Sexual orientation should not be conflated with gender identity. E.g. a transman attracted to women would likely identify as a straight man.
Takatāpui	Originally the word meant "intimate companion of the same sex." Today it has been reclaimed to include both sexual and gender diversity and expression among Māori people.
TaP	TaP is given to HIV-positive individuals to eliminate the possibility they will infect others with the virus. Treating an individual with anti-retroviral drugs until their viral load is undetectable ensures they do not sexually transmit HIV.
Transgender	A person whose gender identification is the opposite of the sex they were assigned at birth. **Transfemale:** A person assigned male at birth identifying as female. **Transmale:** A person assigned female at birth, identifying as male.
Transition	The process of changing one's gender from the sex they were assigned at birth to the gender they identify as. This process may include some or all of the following: changing name and pronouns, changing one's appearance (including chest binding), dressing differently, taking puberty blockers or hormones, and having gender-affirming surgery.

Chapter 1. Introduction

> *Everybody else had a childhood, for one thing – where they were coaxed and coached and taught all the shorthand. …I'd long since accepted the fact that nothing had ever happened to me and nothing ever would. That's how the closet feels, once you've made your nest in it and learned to call it home. Self-pity becomes your oxygen. …I still shiver with a kind of astonished delight when a gay brother or sister tells of that narrow escape from the coffin world of the closet. Yes yes yes, goes a voice in my head, it was just like that for me. When we laugh together then and dance in the giddy circle of freedom, we are children for real at last, because we have finally grown up.*
>
> *(Monette, 1992, pp. 1-2)*

Paul Monette's description of growing up gay in the 1950s would still ring true with many people today. Though no longer criminalized in many parts of the world -- and actually accepted in many areas -- adolescent sexual and gender minorities (SGM) still face cultural biases and stigmatization. They are particularly vulnerable as they often find themselves rejected by family and friends and therefore socially isolated, with no means to support themselves. They may find themselves party to a relationship with older individuals, and thus in a position to be exploited or abused (Armstrong et al., 2015). Bullying at school and threats of violence are common against adolescent SGM everywhere (Armstrong et al., 2015).

The risks listed above, resulting from the imposition of social norms and ideologies on individuals who are perceived to deviate from those norms, are potential stressors that accumulate in those individuals. When these stressors overcome the individual's resilience, a decompensation response occurs (Riggs & Treharne, 2017)[5]. For the individual, this response often manifests as adverse health events, physical and/or emotional, including high rates of depression and anxiety (Herrick et al., 2011).

1.1. Rationale for Studying SGM Teens

In recent years, research on lesbian, gay, bisexual, trans*[6], queer/questioning (LGBTQ+) youth has shifted from risk-based to resilience research (Robinson & Schmitz, 2021). Resilience is defined as the ability to recover from or overcome difficulties and stressors (Robinson & Schmitz, 2021; Smith & Gray, 2009). Resilience requires the presence of protective factors, and therefore resilience is developed throughout life as a person establishes and acquires these protective factors (Robinson & Schmitz, 2021).

Smith and Gray (2009) suggest that three factors contribute to resilience: environmental support (e.g. school, family), positive interpersonal relationships (e.g. LGBTQ+ peers), and intrapersonal aspects, such as self-efficacy (Colpitts & Gahagan, 2016) and the ability to define one's own gender (Singh et al., 2014). Systematic reviews have identified strong resilience in LGBTQ+ communities, and especially youth LGBTQ+ (Colpitts & Gahagan, 2016; Robinson & Schmitz, 2021).

Herrick et al. (2011) point out that the fact the LGBTQ+ community grew stronger despite the ravages of acquired immune deficiency syndrome (AIDS) in the 1980s and 1990s is a testament to their collective resilience. Furthermore, resilience in the LGBTQ+ community is not confined to individuals. As Robinson and Schmitz (2021) point out, an

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[5] The concepts of minority stress and the Decompensation Model are discussed further in Chapter 5.

[6] The use of trans* indicates inclusion of all variations of the transgender identity (e.g. transmale, transmasculine, etc.)

important protective factor for LGBTQ+ youth is a “collective identity” of being LGBTQ+, which allows for better understanding of discriminatory events group members encounter. Such understanding allows individuals to relate these incidences to living in a hetero- and cis-normative society, and not be troubled by them.

Unfortunately, even in settings that could contribute to building LGBTQ+ youths’ resilience, this population often encounters rejection, bullying, and even violence in the everyday spaces they inhabit (Garcia et al., 2020). As a result, adolescent SGM are at heightened risk for adverse mental and physical health events, compared with their heterosexual, cis-gendered peers (Fraser et al., 2022; Hoffman et al., 2009; Lucassen et al., 2015; Lucassen et al., 2017). Those risks, which stem largely from being part of a marginalized group (Stevens, 2013), include sexually transmitted infections (STIs) including human immunodeficiency virus (HIV), sexual and physical abuse, and higher rates of mental health problems, especially anxiety, depression, and suicidal ideation (Fenaughty, Sutcliffe, Clark, et al., 2021; Fenaughty, Sutcliffe, Fleming, et al., 2021; Fraser et al., 2022; Hoffman et al., 2009; Lucassen et al., 2015; Lucassen et al., 2017). In New Zealand, for example, adolescent SGM are considerably more likely than their heterosexual peers to report clinically significant depressive symptoms (Lucassen et al., 2015). For in depth discussion of New Zealand SGM teen health, see Chapter 2.

The acknowledged health disparities between the lesbian, gay, bisexual, trans*, queer, and other SGM persons (LGBTQ+) and the dominant heterosexual, cis-gendered populations (Alpert et al., 2017; Stevens, 2013) are often created by lack of knowledge or provider discomfort (e.g. McPhail et al. (2016). They can be exacerbated by the presence of biases and discrimination in medical professionals, a certain percentage of whom, like the general population, still harbours such biases. Examples range from denial of care (“we don’t treat your kind” or “we are fully booked”) (HIV Vaccine Trials

Network, personal communication) to outright hostility that can include abusive language (Alpert et al., 2017).

There are scant data currently on healthcare perceptions and utilization of health services by SGM in New Zealand. All teens are affected by developmental changes that, in turn, affect their access to healthcare (Alderman et al., 2019). However, stories shared by LGBTQ+ persons in a Christchurch medical students' forum, conducted by the Burnett Foundation Aotearoa[7], suggest that discrimination and stigmatization of this population by healthcare providers occur here, just as they do elsewhere (A. Le Fevre, personal communication, 2018). Furthermore, the Rainbow Health report (Stevens, 2013) found that many adult LGBTQ+ people in New Zealand delay seeking or utilizing healthcare resources and providers due to fear of stigma and biases. More recently, the Counting Ourselves survey, which aimed to study the health and wellbeing of gender diverse individuals in New Zealand, found that 36% of respondents avoided visiting healthcare providers due to concerns about discrimination affecting their care (Veale et al., 2019). Such delays carry potentially adverse health consequences, in the form of missed diagnoses or exacerbations of pre-existing conditions, physical or mental.

Adolescents (defined by the World Health Organization as aged 10-19 years) (World Health Organization, n.d.) have even less flexibility than when it comes to finding an accepting healthcare provider. They often see their family's general practitioner (GP) and may be reliant on parents for transportation, appointment settings, and any fees due.

Studies outside New Zealand show that fear of discrimination leads to underutilization of healthcare resources. For example, a study of lesbian women's

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[7] In 2018 this was still the New Zealand AIDS Foundation – the name was changed in June, 2022.

compliance with Pap smear guidelines in the United States (US) showed that 29% of study participants (N = 225) delayed their screening, or never had one, due to fear of discrimination (Tracy et al., 2010).[8] These “non-routine screeners” were also significantly less likely to disclose their sexual orientation to their primary healthcare provider (Tracy et al., 2010). There were no differences between routine and non-routine screeners in the perceptions of the risk of cervical cancer, or in understanding the risks associated with skipping the screening. In a study by Simpson et al. (2013), 25% of sexual minority US military veterans (N = 356) avoided seeking health services at Veterans Administration hospitals and clinics due to concerns about stigma.

Sexual and gender minority persons have specific health needs that may appear in addition to health concerns that are common across the population at large. The HIV pandemic still centres heavily around men who have sex with men (MSM) – of the key HIV populations listed by the World Health Organization[9], MSM comprise 21%, the largest group (World Health Organization, 2022). According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), “The HIV epidemic among young MSM [men who have sex with men] is not well defined. There is a lack of global data on the number of young MSM, their levels of risk for HIV and their protective behaviours. This is due in part to a lack of research and surveillance, and also to the difficulty of reaching young MSM who may fear disclosing their same-sex behaviour” (Armstrong et al., 2015, p. 6). In 2021, gay men accounted for 63% (n = 70) of the 112 HIV notifications in New Zealand (AIDS Epidemiology Group, 2022). In other countries, young MSM (under 30 years of age) are disproportionately represented among MSM with new HIV infections or

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[8] There was no national population screening programme in the US, rather there were recommended timelines for screenings. It is up to the patient and their healthcare provider to follow the guidelines. (Current guidelines have changed to HPV testing alone, every 5 years.)

[9] IV drug users, sex workers, their clients, transwomen, MSM, and partners of these key populations.

new HIV diagnoses (de Lind van Wijngaarden et al., 2013; Dickson et al., 2015; Hamers & Phillips, 2008; Lu et al., 2008; Machado et al., 2017; Van Griensven et al., 2009). This disproportional representation was still the case in New Zealand in 2020, where 35% of new in country HIV infections among MSM were in men under 30 years, the highest percentage of all age groups that year (AIDS Epidemiology Group, 2021). In 2021 the bulk of the cases was in the oldest age groups, but that may have been due to overall decreased transmission rates due to the novel coronavirus disease 2019 (COVID-19) restrictions and limited access to testing (AIDS Epidemiology Group, 2022)

LGBTQ+ youth, facing rejection by family (and often homelessness), may turn to prostitution to afford basic needs. Thus, they are not only at increased risk of STIs and substance abuse, but also at risk of violence – sexual and physical (McCann & Brown, 2019). Additionally, LGBTQ+ youth often turn to older individuals for financial and emotional support, increasing their risk of abuse and exploitation (Armstrong et al., 2015). These factors may contribute to the very high rates of STIs, new HIV infections, and new HIV diagnoses among LGBTQ+ youth (including bisexual girls) (McCann & Brown, 2019).

A survey published in 2008 (Clark & The Adolescent Health Research Group, 2008) showed some children younger than 13 years (without regard to sexual/gender identities) were already sexually active in New Zealand. Yet there is currently very limited information on the sexual health indicators of young people in New Zealand, despite the fact that STIs in New Zealand teenagers constitute a considerable public health problem (Ellis & Aitken, 2020; New Zealand Ministry of Health, 2015a) (see Chapter 2).

Recent New Zealand studies concerning the LGBTQ+ community (e.g. Counting Ourselves) included a range of ages in each study, from teens to older adults. Therefore, a specific focus on LGBTQ+ adolescents and their needs is still missing from the New Zealand literature. The Youth2000 survey waves (see Section 2.4.2), while focusing only on the health and wellbeing of New Zealand adolescents, include both SGM and heterosexual, cis-gendered students. This study aimed to focus only on older LGBTQ+ adolescents (aged 15-19 years).

There is a tendency to pathologize SGM youth, of which framing LGBTQ+ teens in the context of sexual risk behaviours, is a prime example (Quinlivan, 2002; Talburt, 2004). That is not the viewpoint I hold, nor mean to imply with this study. While health disparities exist between LGBTQ+ youth and their heterosexual peers, my position in undertaking this research was that these disparities are not due to any intrinsic pathology on the part of SGM people. As Riggs and Treharne (2017) and Meyer (2003) assert, there is a clear difference between pointing out that social stressors on marginalised groups have well documented effects on health and wellbeing, and saying the groups themselves are inherently “disordered.” The latter is pathologising, while the former is a societal failure to protect and include all of its members (Riggs & Treharne, 2017).

As discussed below in Section 1.3, the language of sexuality and gender is ever-changing. To ensure a uniform understanding of important concepts in this study, I am using The World Health Organization’s (WHO) definitions of sexuality and sexual health in this study. These definitions were arrived at after extensive work and consultation with experts in the field. Furthermore, they form part of the United Nations’ Sustainable Development Goal (SDG) 3: “Ensure healthy lives and promote well-being for all at all ages” (World Health Organization, 2017, p. 3), and thus they are widely accepted by countries working towards achieving this and other SDGs.

The WHO defines sexual health as:

> …a state of physical, emotional, mental and social well-being in relation to sexuality…. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. (World Health Organization, 2017, p. 3).

The WHO definition ties sexual health with society and politics. This definition is appropriate and applicable to this study because the rights of LGBTQ+ people are often curtailed or expanded by governments (e.g. legalisation of same-sex marriages, the banning of conversion therapy in New Zealand this past year). LGBTQ+ individuals are also subject to societal pressures (i.e. stigma and discrimination), which can affect their state of health, including mental health (Riggs & Treharne, 2017). Because this definition ties sexual health with mental and physical health, it provides the appropriate context to this study's research questions.

Similar to sexual health, the WHO definition of sexuality recognises the importance of political influences:

> …a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. …Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal,

> historical, religious and spiritual factors. (World Health Organization, 2017, p. 3).

This definition, again, provides a thorough summary and guidance that sexuality is far more than a person's attraction to another, and that it is influenced by a variety of factors, both individual and societal/cultural. By tying both sexual health and sexuality to politics and society, these definitions place them in the context of human rights that should be protected.

This study aims to look at the connection between access to healthcare, which is influenced by societal norms and politics, and its impact on the sexual health of adolescent SGM.

1.2. Problem Statement

Adolescent SGM experience increased adverse health events compared with their heterosexual, cis-gendered peers (Fraser et al., 2022; Hoffman et al., 2009; Lucassen et al., 2015; Lucassen et al., 2017).These healthcare disparities can lead to adverse consequences that include (but are not limited to) delayed consultation (or avoiding care altogether), suicide, self-harm, and an increased risk of STIs.

In New Zealand, young people across all sexual and gender identities (especially in the 15-19 years age group) bear the heaviest burden of STIs (Ellis & Aitken, 2020; New Zealand Ministry of Health, 2009). Limited information exists on the experiences of LGBTQ+ teens in the healthcare system, but as stated above this group experiences increased rates of adverse health events compared to their non-SGM peers. The available information does not specifically look at the ties between LGBTQ+ teens' healthcare experiences and sexual health in this population. This study aims to fill the existing gap by answering the research questions below.

Research Questions

1. Do the LGBTQ+ teens in this study perceive interpersonal barriers to healthcare services?
2. Do perceptions of healthcare barriers influence sexual risk behaviours (e.g. condom use)?
3. Do these perceptions affect the uptake of preventive behaviours (e.g. sexually transmitted infections [STI] screening)?

1.3. The Language of Sexuality and Gender Identity

It is the insistence upon the nature of language as constantly changing and varied in its meanings that is the keystone of social constructionism, and language is seen as having a much more important role in life than mainstream psychology has given it (Burr, 2015, p. 52). The social constructionist idea that language is a social construct can be seen clearly in the current rapidly changing landscape of sexual and gender identity vocabulary, in the population aged under 25 years (Bragg et al., 2018; Cover, 2018). The advent of social media allowed groups of diverse sexualities and gender identities to connect as never before, and the young people's frustration with the current binary vocabulary (male/female; heterosexual/homosexual) gained strength in numbers and turned into a quiet but significant revolution (Cover, 2018).

Young people's views of gender and sexuality have widened and changed, becoming more inclusive and accepting over the past several decades (Bragg et al., 2018; Cover, 2018). The change emerged first in alternative communities on the social media site Tumblr (Cover, 2018), and stemmed from many teens' need to find a definition of their own gender or sexuality that went beyond the rigid binary norms mentioned above. Furthermore, there was a perception among many of these young people that the current LGBTQ+ groups excluded those who did not precisely fit into a predefined identity category (Cover, 2018).

Bragg et al. (2018) interviewed youth aged 12-14 years in schools and in LGBTQ youth groups. The study looked at young people's experiences of the current gender culture. The researchers found participants used 23 different words to describe their gender identities. Though many felt that "we need gender" (Bragg et al., 2018; p. 423) they also felt gender categories should not constrain people: "if you want to be a boy that wears dresses, you should be able to. If you want to be a girl who walks around in jumpsuits and a big top then you should be able to," said one 14-year-old participant (Bragg et al., 2018; p. 423). The research found that participants did not assign gender roles or behavioural expectations to gendered language ("boy" "girl"). Participants recognised there are differences between the sexes, as symbolized by these words, but such differences should not extend to setting expectation of what each gender can or should be able to do. Thus, we see that not only is the language expanding to accommodate people's needs, even the traditional language in these young people's vocabularies takes on a somewhat different meaning (Bragg et al., 2018). Many participants embraced a feminist point of view that strips the words of the traditional gender roles imbued in them (Bragg et al., 2018).

Social media played an important part in the participants' lives. In general, social media allowed them to educate themselves and others about issues of sexual and gender diversity (which includes learning/teaching the new lexicon of gender identities) (Bragg et al., 2018). And in fact social media has been at the forefront of this linguistic expansion. In 2013, Facebook already had 50 gender descriptors for users to choose from (Cover, 2018). Cover (2018), however, cautions against the view that digital media created these new sexuality and gender identifiers. Rather, Cover states that digital media provided the right conditions for young people to come together and, in response to the right cultural conditions, develop new frameworks for discussion of sexuality and gender.

The proliferation of gender terms has also created controversy within members of the SGM community, and uncertainty among allies who are no longer sure how to refer to the community at large. A well-known example is the use of the term MSM for “men who have sex with men.” The term started in the clinical realm in 1994. It was coined, in part, as a way to reduce the stigma of HIV/AIDS, which was associated in the public’s view with gay people, though of course in reality it cut across all populations, and it is the behaviour, not the population, that put people at risk (Young & Meyer, 2005). It was also coined to ensure that men who did not identify as gay, but still had sex with men, were included in studies of men having sex with men. The term soon left the clinical and epidemiological realms and began to be used widely in health research as a moniker for sexual minority men, along with the term WSW (women who have sex with women), which was used for sexual minority women. As Young and Meyer (2005), who coined the MSM term originally pointed out, among other problems, the MSM/WSW terms deflect attention from and mask social and behavioural patterns. These patterns can be important for public health research and intervention. As an example, Young and Meyer (2005) mention the higher rates of smoking and obesity in “women having sex with women,” pointing out that these differences cannot be tied to sexual acts.

The third problem Young and Meyer call attention to is that the generalised use of the MSM (or WSW) term erases people’s self-determined sexual identity, one that they have fought long and hard for. Intersectional understanding of sexual identity, from a social construction point of view, suggests that sexual identities, which comprise diverse populations and cultures, “can be meaningful, powerful forces for group affiliation and political action” (Young & Meyer, 2005, p. 1145). Applying a generalised term that erases these identities also erases or conceals important distinctions within and between these groups. These same arguments can apply to gender identities.

When interviewing study participants, the recommended action from organisations such as GLAAD[10] (GLAAD, n.d.) is to check first if they had a preferred community identity designation (after establishing their personal preferred identity terms). The need to define a suitable sexual or gender identity is precisely the reason for the proliferation of terms discussed above, and why these terms should be respected. Respecting these terms means not only checking with individuals for their preferred identity terms, but also not erasing this identity by applying a generalised term that focuses on only one aspect of this identity.

1.4. Thesis Structure

This thesis has 10 chapters. Chapter One provided a general overview of the issue my study aimed to illuminate, and the specific research questions it sought to answer. It also gave an overview of the thesis structure.

Chapter Two provides the research context, starting with an overview of adolescent health and wellbeing in New Zealand. The chapter then moves on to looking specifically at the LGBTQ+ communities in New Zealand, starting with a history of LGBTQ+ people in the country, and moving on to the health and wellbeing of LGBTQ+ teens. The chapter also examines the Māori Takatāpui culture (Māori are the indigenous people of New Zealand). Additionally, Chapter Two discusses the New Zealand healthcare system, with a separate overview of the mental health system.

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[10] Formerly the Gay and Lesbian Alliance Against Defamation, they are now officially known only as GLAAD.

Chapter Three is the literature review that identifies the knowledge and gaps underpinning the various elements this study comprises, in order to place the study in context. The focus is on the current state of affairs in various domains applicable to this study.

Chapter Four is the study's methodology chapter, beginning with a discussion of the study's epistemology – Social Constructionism. The chapter also discusses the mixed methods study design, my positionality, and the ethical considerations that came to bear on this study when seeking ethics approval.

Chapter Five summarises the theories that guided the thematic analysis and survey interpretation. It begins with a discussion of Minority Stress as the basis for the Decompensation model, explains why Decompensation was chosen over Minority Stress, and moves on to discussing Alfred Bandura's Social Cognitive Theory, particularly its central construct – Self-Efficacy.

Chapter Six provides a discussion of the methods used to collect and analyse the data. It starts with an overview of the population and the inclusion/exclusion criteria. The chapter then addresses the specific parts of the survey instrument, statistical analysis, and content analysis for the open-ended questions. The second part of the chapter describes the participants and interviewing method for the qualitative part, and details how the thematic analysis was undertaken to analyse the interviews.

Chapters Seven and Eight present the results of the quantitative (Chapter Seven) and Qualitative (Chapter Eight) analyses.

Chapter Nine presents an integrated discussion of the study's results, based on the picture presented by both quantitative and qualitative parts, supplemented by relevant literature. The chapter also presents the study's strengths, and limitations.

Chapter 10 presents the study’s conclusions.It includes a discussion of recommendations arising from this research, and potential future research directions.

1.5. Summary

Though recognised as a resilient group, many adolescent SGM encounter enacted stigma and discrimination. The result is a heightened risk for adverse health events in this group, compared with their heterosexual, cis-gendered peers. These disparities occur due to a multitude of reasons, and can lead to adverse consequences that include (but are not limited to) delayed care (or complete avoidance of care), suicide, self-harm, and an increased risk of STIs.

Little information exists on the experiences of older (15-19 years) LGBTQ+ teens in the New Zealand healthcare system. Additionally, with STIs being of particular concern in New Zealand adolescents regardless of gender and sexuality, this study aims to examine whether there are ties between LGBTQ+ teens’ healthcare experiences in New Zealand and their sexual health. This specific relationship has not been examined in earlier studies either.

Chapter 2. Research Context: LGBTQ+ Teens in New Zealand

> *"Everyone has the right to the highest attainable standard of physical and mental health, without discrimination on the basis of sexual orientation or gender identity."*
>
> *(International Commission of Jurists, 2007b)*

2.1. Introduction

In 2006, human rights violations of SGM around the world brought about a meeting of human rights experts from across the globe in Yogyakarta, Indonesia. The result of the meeting was a set of principles that concern the human rights of SGM individuals (International Commission of Jurists, 2007a)

Though not legally binding, the Yogyakarta Principles apply existing human rights legal principles to sexual and gender identity and expression (New Zealand Human Rights Commission, 2020). They have been referenced and acknowledged in New Zealand practically since their inception in 2007. The New Zealand Human Rights Commission (HRC) referenced these principles in 2007, in its report on trans* rights (Sanders, 2008). Paul Hunt, the current HRC Chief Human Rights Commissioner, is one of the original signatories on the Yogyakarta Principles (New Zealand Human Rights Commission, 2020, 2022). More recently, the principles were referenced in findings from the Counting Ourselves survey (https://countingourselves.nz/), detailing mental health inequities in transgender people in New Zealand (Tan et al., 2020). These principles have been extensively cited in a variety of New Zealand documents, including government bills and legal decisions (New Zealand Human Rights Commission, 2020).

Yet, despite the Principles' wide acceptance in New Zealand, the realisation of Principle 17, quoted above, still seems far from becoming a reality.

This chapter presents the context for this study, by reviewing what is known about the lives of LGBTQ+ teens in New Zealand. It begins by examining the history of LGBTQ+ people in New Zealand, and moves on to examine the Māori Takatāpui culture – Indigenous views of sexual and gender minorities in Aotearoa. Because LGBTQ+ teens are teens, the chapter also looks at the health and emotional wellbeing of New Zealand teens in general. Sexual activity characteristics and sexual health (e.g. common STIs) are also examined. The chapter then examines the same elements in the context of New Zealand LGBTQ+ teens, with the addition of examining stigma and discrimination against LGBTQ+ community members. Finally, the chapter examines the New Zealand healthcare system, which provides the overarching context for this study.

2.2. An Overview of LGBTQ+ Legislative History in New Zealand

In Te Ao Māori (the Māori worldview), the concept of Takatāpui (original meaning: "intimate companion of the same sex") was an accepted part of the life of the Māori people, as were expressions denoting gender diverse people (New Zealand Human Rights Commission, 2010). With colonisation, Christian values were enforced on the Indigenous population. The word Takatāpui was lost, as was the acceptance of sexual and gender diversity among Māori (Kerekere, 2015). Male homosexuality first became illegal in New Zealand in 1858 with the passage of the English Laws act, which applied all English laws in existence as of January 1840 to New Zealand (Laurie, 2003). Lesbian sexual acts were ignored in the criminal code, but lesbians were targeted in other ways throughout the years. For example, they were denied promotions in public service, could not serve in the armed forces, and were dismissed from jobs in the education sector (Laurie, 2003). Additionally, being lesbian was treated as a psychiatric malady and women were often institutionalised for it (Laurie, 2003).

In 1986, male homosexuality was decriminalised in New Zealand, and in the 1993 Human Rights Act sexual orientation was included in the list of items that were prohibited grounds for discrimination. Though gender identity was not explicitly included in the Act, sex (i.e. male/female) as a prohibited item of discrimination *was* included, and has since been interpreted to also include gender identity and expression as well (New Zealand Human Rights Commission, 2010).

In 2005, civil unions were recognised in New Zealand, which included same-sex couples. An attempt to define a marriage as a union between a man and a woman that same year was defeated in Parliament. Though civil unions gave couples many of the same rights as married people, they could not jointly adopt children. However, a single person of any sexual or gender identity was legally allowed to adopt, creating what many saw as a paradox in the legal system. While a court case in 2010, brought by a heterosexual couple, resolved the adoption issue for heterosexual civil unions, same-sex couples still could not adopt (New Zealand Human Rights Commission, 2010). Same-sex marriage was eventually legalised in New Zealand in 2013 (New Zealand Human Rights Commission, 2020).

In 2012, the Department of Internal Affairs began allowing passport applicants to select X for sex, an option that was added to the M/F sex options. A year later, the New Zealand Transport Agency began allowing an “Indeterminate” sex option on New Zealand drivers’ licenses (New Zealand Human Rights Commission, 2020).

In 2017, the New Zealand Government issued a formal apology to men convicted under the homosexuality criminal laws. However, the stigma and discrimination impacting members of New Zealand's LGBTQ+ community are still present (New Zealand Human Rights Commission, 2020; Office of the Clerk/Parliamentary Service, 2017).

2.3. The Māori Population

2.3.1. Takatāpui – the Māori LGBTQ+

The term Takatāpui had been supressed when New Zealand was colonised by the British, but starting in the late 1980s it was revitalised and reclaimed as an umbrella term akin to the English "Rainbow," which encompasses all SGM, including intersex people (Kerekere, 2017). Unlike the Western "Rainbow" term, however, the Takatāpui identity is closely connected with one's Māori ancestry and identity, emphasizing their cultural and spiritual self as at least equal to – if not more important than – their SGM identity (Kerekere, 2015, 2017).[11]

In line with other Indigenous cultures (Aspin & Hutchings, 2007; Picq & Tikuna, 2019), Māori society pre-colonisation was one of fluid gender and sexuality (Aspin & Hutchings, 2007; Kerekere, 2017). The Māori language itself is mostly genderless; for example, the third person "ia" can mean either "he" or "she" (Kerekere, 2017). This open and fluid state of affairs ended with colonisation. Over decades of subjugation Māori cultural norms shifted to absorb Christian (and Western) ideologies that stigmatised sexual and gender diversity, along with a shift to a patriarchal society in a culture that previously treated all genders as equal (Hamley et al., 2021; Kerekere, 2017). For this reason, Takatāpui today may encounter stigma and discrimination not only from Pākehā

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[11] Similarly, Farran (2010) quotes a Samoan fa'afafine (the term denotes someone who is biologically male but dresses and behaves as a woman) who equates the word not only with gender identity but also with being part of the Samoan community.

(New Zealand Europeans), but from within their community as well (Aspin & Hutchings, 2007). It is worth noting that indigenous cultures all around the Pacific, for example the Samoan fa'afafine and Fijian vakasalewalewa (both terms can be literally translated as "in the manner of a woman"), follow the same history of precolonisation gender and sexual fluidity, followed by the enforcement of Christian morals and attitude, which criminalised and pathologised said fluidity (Farran, 2010; Presterudstuen, 2019).

A key principle of Māori identity is whanaungatanga – relationship building among families and communities – rejection by one's family or community is felt deeply by today's Takatāpui whose families are not accepting of their SGM status. Takatāpui may then draw upon whanaungatanga to develop connections with other Takatāpui and create their own community and "found" families (Hamley et al., 2021).

The intersection between ethnic and sexual/gender marginalisation leaves young Takatāpui frequently experience additional challenges compared to their LGBTQ+ Pākehā peers. The Youth19 survey (see Section 2.4.2) found that Māori Takatāpui are more than twice as likely to experience housing instability and food insecurity (26% and 50%, respectively), compared with Pākehā LGBTQ+ youth (10% and 20%, respectively). These figures are also larger than those for non-Takatāpui Māori youth (17% and 39%, respectively), showing the additional toll of the Takatāpui status. Takatāpui youth were also less likely to feel safe at school (69%) compared with Pākehā LGBTQ+ youth (78%) and non-Takatāpui Māori youth (85%) (Greaves et al., 2021).

2.3.2. Māori in New Zealand's Health System

As a culture that holds a deeply spiritual connection with their land, colonisation with its attendant dislocations and separation from ancestral lands had left deep intergenerational trauma on the Māori people (Hamley et al., 2021; McIntosh et al., 2021). Combined with other impacts of colonisation, which include institutionalised racism (Wilson et al., 2021), Māori people experience substantial health inequities. The average lifespan of Māori people is seven years shorter than Pākehā; lack of access to timely and safe quality care among Māori populations results in avoidable deaths that account for as much as 53% of this seven-year gap (Wilson et al., 2021). As Wilson and colleagues point out, research has shown that Māori patients are less likely to be referred to specialists, less likely to receive effective interventions in the form of medication or surgery, and more likely to be released early from hospital (Wilson et al., 2021).

Māori health models consider spirituality and whānau (family) involvement as integral parts of a person's health and wellbeing (Graham & Masters-Awatere, 2020; New Zealand Ministry of Health, 2015b; Wilson et al., 2021). In their review, Graham and Masters-Awatere (2020) pointed out that these models are the opposite of the individualistic medical care practiced in New Zealand since colonisation. The review noted that, in addition to racism and discrimination encountered by Māori patients, feelings of alienation were reported by patients who describe a healthcare system whose philosophy they perceived as "Get them better, throw them out the door, who cares about their spiritual [health] or whatever" (Graham & Masters-Awatere, 2020, p. 197). High staff turnover, which prevented the formation of a trusting relationship with healthcare providers, and a reluctance to bother healthcare workers were other barriers to accessing care in a timely manner for Māori patients (Graham & Masters-Awatere, 2020). Conversely, whānau support, a respectful and warm care provider, and healthcare navigators that helped patients through an unfamiliar foreign system were considered enablers for timely care access (Graham & Masters-Awatere, 2020).

Recognising these inequities in care outcomes, and the patchy performance of Māori health services across New Zealand, the New Zealand Government established the Māori Health Authority as part of the health system reform that went into effect on 1 July, 2022 (Department of the Prime Minister and the Cabinet, 2021). The purpose of this new government agency is to ensure current healthcare services are sensitive to Māori healthcare needs, and to design new services targeted at the Māori population.

As discussed in the previous section, the intersectionality of ethnic and sexual/gender minority status takes an additional toll on Takatāpui youth, and this is also true for healthcare outcomes. Takatāpui youth experienced more healthcare discrimination (9.4%; 95% CI, 4.7 -14.2) compared with Pākehā LGBTQ+ youth (3.1%; 95% CI, 1.5-4.7) and non-Takatāpui Māori youth (6.5% 95% CI, 5.0-7.9) (Greaves et al., 2021). They have also decided to forego healthcare more (32.5%; 95% CI 23.6-41.4) than Pākehā LGBTQ+ youth (27.8%; 95% CI, 20.9-34.8) and non-Takatāpui Māori youth (25.9%; 95% CI, 23.0-28.8) (Greaves et al., 2021).

2.4. LGBTQ+ Teens in New Zealand

2.4.1. Introduction: New Zealand Teens' Health

As discussed in the Introduction, LGBTQ+ youth have worse health outcomes than their non-LGBTQ+ peers. Understanding the baseline status of adolescent health is therefore important for the study's context and conclusions.

According to Stats New Zealand (2018), the New Zealand youth population aged 15-19 years (the age range of this study's population) account for 6.5% of New Zealand's population, with 24% identifying as Māori. Due to the demographic profile of Māori and Pasifika populations in New Zealand, which have a higher proportion of younger people, this age group is more diverse than the total population, and includes many additional ethnicities and multiple ethnic identities.

Physical and mental wellbeing is strongly tied to education, environment, and the economy. The United Nations Children's Fund (UNICEF) report on child wellbeing in developed countries (before the COVID-19 pandemic) (UNICEF Innocenti, 2020) is a summary of children’s wellbeing and skills (e.g. maths and reading) in 41 developed countries. The countries, including New Zealand, are members of the Organisation for Economic Co-operation and Development (OECD) and the European Union. This report places each country’s children’s lives in the context of the country’s social policies, its economy and environmental conditions, and its educational system. There are 19 indicators in the report, covering various age ranges (e.g. child mortality – ages 5-14 years; overweight – ages 5-19 years). The indicators cover topics from health outcomes and family relationships to unemployment levels and water quality. Data for various indicators were not necessarily available for each country, and therefore the country rankings are often for fewer than the full 41 countries surveyed.

The report is important because it lays the baseline of children’s health and wellbeing, and the support structures available to them, for each country represented. The 2020 Innocenti report cites “deeply embedded and terrifying childhood trends around obesity, suicide, as well as declining proficiency in reading and maths” in New Zealand (UNICEF, 2020). It places New Zealand in last place (38th of 38) for children’s mental health wellbeing, and in the bottom third (33rd of 38) in children’s physical wellbeing. New Zealand has the second highest suicide rate in teens 15-19 years old among the countries in the UNICEF report (14.9/100,000 teens), and its rates of child overweight/obesity (39% of children aged 5-19 years, as of 2016) were second only to the US. It ranked in the middle of the list for child mortality (0.87 per 1,000 children, as of 2018) (UNICEF Innocenti, 2020).

Since sexual health is a focus area of this study, a closer look at barrier protection and the state of sexually transmitted infections in the general youth population is warranted. With the exception of HIV, syphilis and gonorrhoea since 2017, STIs are not notifiable in New Zealand, which means that under-reporting of STIs is likely. Data collection is through voluntary provision of information from clinics and laboratories (Smith & Wilby, 2020). Syphilis, chlamydia, and gonorrhoea cases have increased steadily between 2014 and 2019, before dipping in 2020 (Institute of Environmental Science and Research, n.d.). As the Institute of Environmental Science and Research notes, 2020 data should be interpreted with caution due to the effect of COVID-19 on behaviour and access to testing. Chlamydia and gonorrhoea cases were especially widespread among adolescents and young adults (aged 15-29 years) between 2013 and 2020 (Institute of Environmental Science and Research, 2022). Cases numbers increased in this age group between 2017 and 2019 (Smith & Wilby, 2020). Ellis and Aitken (2020) found that adolescents in New Zealand have a pattern of inconsistent use of barrier protection over a range of sexual practices, which may partially account for the higher observed rates of STIs in this age group.

2.4.2. The Youth2000 Surveys

The most detailed information about New Zealand's adolescent health and wellbeing comes from the Youth2000 surveys. To date, there have been four waves of these surveys: 2001, 2007, 2012 (known as Youth12), and 2019 (known as Youth19).

The Youth19 survey was administered to students randomly selected in school Years 9-13 (ages 12-18 years), as an online anonymous survey (Rivera-Rodriguez et al., 2021). Students completed the survey in open environments, such as gyms, in groups of up to 160 participants (Fleming, Peiris-John, et al., 2020). Unlike previous Youth2000 surveys, which sampled schools across New Zealand, the sampling for this study came from the Auckland, Waikato, and Te Tai Tokerau areas – all of which are in the central to northern areas in the North Island. These three regions account for 47% of Years 9-13 students in New Zealand, and they are more ethnically diverse than other areas in the country; they also comprise a range of living environments, from rural to urban (Fleming, Peiris-John, et al., 2020). Consent forms were sent from the school digitally and on paper to parents of students in Years 9-13. Parental consent was in the form of an opt-out, that is, consent was automatic unless parents chose not to allow their child to participate. It has been shown that asking for parental consent for studies that involve sexuality and gender questions can lead to selection bias, with students who are worried about being outed to parents choosing not to participate (Flores et al., 2018; Liu et al., 2017). Whether some students declined to participate due to fear of being outed in Youth19 cannot be verified, but of all the eligible students in the mainstream schools 60% participated, and in the four kura kaupapa Māori (Māori immersion schools) that took part in Youth19, 71% of eligible students participated (Fleming, Peiris-John, et al., 2020). Of note, students not withdrawn by their parents could still decline to participate in Youth19 (Fleming, Peiris-John, et al., 2020).

Youth19 had a large sample size (7,374 students), which represented nearly 6% of the Years 9-13 student population in eligible schools (Fleming, Peiris-John, et al., 2020). This representation might be somewhat skewed, however, as participation of the schools was voluntary. In the Youth12 survey, for example, 40% of invited rural schools declined participation. Of 86 invited schools in the Youth19 study, 49 participated and the rest declined. Two-thirds of the participating schools were large (over 350 students);

35% were low-decile; 40% of the students were of European ancestry (Fleming, Peiris-John, et al., 2020). The study design, including the calibration approach, has been described in Rivera-Rodriguez et al. (2021).

Perhaps the most problematic aspect of the sample represented in the survey is the large percentage of students (40% in the mainstream schools and 29% in the four kura kaupapa Māori) who actively declined participation. In 16 schools where participation was below 50% of selected students, factors included a teacher strike and measles outbreak. However, these factors do not account for all the students who chose not to participate across all eligible schools. As the Youth12 report points out (Adolescent Health Research Group, 2013), students who decline participation in health surveys are usually those whose health and wellbeing status is worse than those taking the surveys. Therefore, by the Adolescent Health Research Group's own admission in Youth12, "This means that the survey is likely to present a somewhat positive picture of the health and wellbeing of young people" (Adolescent Health Research Group, 2013; p. 12). This concern was echoed by the Youth19 researchers as well (Fleming, Peiris-John, et al., 2020).

Despite those limitations, and with other information sources lacking, Youth19 did provide detailed information about the health and wellbeing of adolescents, including SGM, in New Zealand.

The majority of New Zealand youth (91%) ranked their physical wellbeing as "Good" or better in Youth19 (Fleming et al., 2022). This survey also showed decreased dangerous driving (or being a passenger in a car driven dangerously) reports from 59% in the 2001 wave to 34% in Youth19. Binge drinking (at least once in the previous four weeks) declined from 42% (2001) to 22% (2019), and rates of smoking and use of marijuana also showed a decrease in the same interval (from 18% to 5% and 19% to 10% between 2001 and 2019, respectively) (Fleming et al., 2022).

The measured mental health needs of the New Zealand teen population have worsened with each successive wave of the Youth 2000 survey (Fleming et al., 2022; Fleming, Tiatia-Seath, et al., 2020; Fleming et al., 2014). The survey uses the WHO-5 measure of mental wellbeing. The WHO-5 is a self-reported instrument that consists of five statements. Participants rate each statement on a six-point scale where 5 is “All the time” and 0 is “At no time.” WHO-5 was first introduced in 1998 (Child Outcomes Research Consortium, n.d.). In the Youth19 survey, 69% of participants scored in the “Good” or above categories on the WHO-5 Wellbeing Index, a decline from 76% in 2012[12]. There was a noticeable increase in the percentage of students experiencing significant depressive symptoms in 2019 (23%), as measured by the Reynolds Adolescent Depression Scale – Short Form (RADS-SF). That percentage was 12% in 2001, and 13% in 2012 (Fleming et al., 2022).

Factors that may affect physical and emotional wellbeing include housing and food instabilities. Research cited by Fleming et al. (2022) theorises that increased usage of social media and smartphones have caused increased mental distress as well. However, studies show that the connection between these factors is not uniformly observed. It is more likely that individual factors, such as being a target of cyber-bullying, are responsible for any connection between social media, smartphones, and mental distress (Fleming et al., 2022).

In the Youth19 survey, 4% of Pākehā teens indicated they have experienced housing instability, and 16% experienced food instability. Māori and Pasifika

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[12] The measure was introduced to the survey in the 2007 wave, where 78% of students scored in the “Good” or above range.

communities carry a disproportionate hardship burden. In the Youth19 survey, 17% of Māori participants and 20% of Pasifika participants indicated they have experienced housing instability, and 39% and 49%, respectively, have experienced food instability (Clark & Fleming, 2020).

A total of 15% of the non-LGBTQ+ Pākehā participants indicated they have foregone healthcare in the past (Clark & Fleming, 2020). The number rose to 26% among non-LGBTQ+ Māori and Pasifika participants. Additionally, 3% of Pākehā, 6% of Māori, and 8% of Pasifika non-LGBTQ+ respondents indicated they have experienced healthcare discrimination in past dealings with the healthcare system.

2.4.3. The Health and Wellbeing of New Zealand's LGBTQ+ Teens

While there are no comprehensive figures tracking the numbers of SGM people in New Zealand, Youth19 found that out of 7,891 youths surveyed, approximately 1% identified as transgender or non-binary, and an additional 0.6% were unsure what gender they identified as (Fenaughty, Sutcliffe, Fleming, et al., 2021). In terms of sexual identity, 9% of respondents identified as being attracted to the same sex as theirs or to multiple sexes. An additional 7% were still unsure or not attracted to any sex (Fenaughty, Sutcliffe, Clark, et al., 2021). These sexual identity figures are an increase over the Youth12 sexual identity percentages, which saw 4% of respondents identify as attracted to same sex, multiple sexes, or not attracted to any sex (Adolescent Health Research Group, 2013).

As mentioned in the Introduction chapter, there are very few data on the health of LGBTQ+ people in New Zealand, and fewer for youth alone. The mental health of SGM individuals in New Zealand has recently been studied by Fraser (2020), with a follow-up focus on youth published in 2022 (Fraser et al., 2022). The first study to focus on the health needs (mental and physical) and healthcare experiences of the gender-diverse population in New Zealand was Counting Ourselves (Veale et al., 2019). Counting Ourselves recruited people aged 14 years and older. Additionally, results concerning the general state of health and wellbeing in LGBTQ+ teens were also published by the Youth19 group in a series of briefs and reports, e.g. Fenaughty, Sutcliffe, Clark, et al. (2021), Fenaughty, Sutcliffe, Fleming, et al. (2021), and Greaves et al. (2021), and are discussed further in section 2.4.3.2.

2.4.3.1 Mental Health

Fraser (2020) found in her mixed methods New Zealand study that LGBTQ+ participants had assorted experiences with mental health professionals; some developed a helpful relationship with their providers, while the majority described negative experiences, especially among trans* participants. Participants noted that a lack of knowledge among mental health professionals compromised these providers' ability to deliver suitable care to LGBTQ+ clients. Additionally, structural barriers such as long waiting times for publicly funded services, and the high cost of seeing a mental health professional privately were encountered by many of Fraser's participants. Hetero- and cis-normative assumptions on the part of the provider complicated matters for their LGBTQ+ clients. Gender diverse individuals felt they had to "prove" their gender identity to their mental health provider, based on a dominant trans* narrative. This narrative required them to tell a story of being binary trans* (i.e. transmale or transfemale only), knowing they were trans* since childhood, and wanting a full medical transition. Mental health professionals often acted as gatekeeper if participants wanted medical gender-affirming care. These results, which comprised participants across a range of ages, were also reflected in Fraser et al.'s 2022 study, which focused on LGBTQ+ youth (Fraser et al., 2022). Fraser's (2022) studies also noted participants' accounts of what is known in

New Zealand as the “postcode lottery,” whereby the quality of care, and ease of access to mental health services, and to procedures such as hormone treatment or gender-affirming surgeries, depend on the region one lives in. Elimination of the postcode lottery was one of the main drivers of the New Zealand healthcare reform that took effect in July 2022 (Little, 2022).

The Youth19 study found that 57% of gender diverse students had significant depressive symptoms, compared with 23% of their cis-gendered peers. Similarly, 53% of sexual minority students had significant depressive symptoms, compared with 21% of their heterosexual peers. Furthermore, 26% of gender diverse and 13% of sexual minority students have attempted suicide in the past, compared with 6% in each of the cis-gendered and heterosexual groups (Fenaughty, Sutcliffe, Clark, et al., 2021; Fenaughty, Sutcliffe, Fleming, et al., 2021). Collectively, data in this section demonstrates mental health inequities affecting sexual and, particularly, gender minority youth are continuing to increase.

2.4.3.2 General Health

Veale and colleagues (2019) studied the health needs and experiences of gender-diverse individuals (Counting Ourselves). Participants (N = 1,178) ranged in age from 14 to 83 years, with 46% being in the 14-24 years old age-group. The study was conducted through a national anonymous online survey. It found that many participants had difficulties accessing gender-affirming care. Percentages varied from 19% of those needing hormone treatments to 67% in trans men needing breast reconstruction. Fear of discrimination had caused 36% of participants to avoid healthcare in the past. Seventeen percent of the participants answered Yes to the question “Has any professional (such as a psychiatrist, psychologist or counsellor) ever tried to make you identify only with your sex assigned at birth (in other words, tried to stop you being trans or non-binary)?" (Veale et al., 2019, p. 38). A further 12% were unsure. Notably, the New Zealand Parliament passed the Conversion Practices Prohibition Legislation Act 2022 (2022/1) on 15 February, 2022 (Office of the Clerk/Parliamentary Service, 2022). This Act bans the practice of conversion therapy described in the Counting Ourselves question quoted above; it also applies to conversion therapies aimed at sexual minorities.

With regards to healthcare access, Youth19 found that 55% of gender diverse students were unable to access healthcare in the 12 months preceding the survey, as were 31% of sexual minority students. The figure across the entire survey population was 20% (Fenaughty, Sutcliffe, Clark, et al., 2021; Fenaughty, Sutcliffe, Fleming, et al., 2021; Peiris-John et al., 2020).

2.4.3.3 Sexual Health

There is very little information about sexual health in New Zealand's LGBTQ+ youth, apart from statistics regarding STIs. This is one gap my study may be able to assist with. Of the notifiable infections (syphilis and gonorrhoea), rates of syphilis increased in the general population aged 15-19 years in 2020, from 2.2% of cases in 2019 to 3.7% in 2020. Cases among MSM have decreased, with the sharpest decrease showing in the 20-24 years old age group (Institute of Environmental Science and Research, 2022). Since syphilis is a risk factor for HIV, the Institute of Environmental Science and Research (ESR) notes that the proportion of MSM with syphilis who are also HIV-positive was 13.8%, which was a decrease over past years (2016 onward). Chlamydia positivity rates are highest in the 15-19 years age group (13.9%) (Institute of Environmental Science and Research, 2022).

Of 41 new in country HIV diagnoses in 2021, 9 (22%) were in people under 30 years old (AIDS Epidemiology Group, 2022). This is a decrease not only in new diagnoses, but in the percentage of young adults (aged under 30 years) who were diagnosed. In 2020, 35% of new diagnoses (n = 22) were in the same age group (AIDS Epidemiology Group, 2021).

Of the total notifications for gonorrhoea in 2020, 25% (n = 922) were for MSM, and 2% of these MSM were in the 15-19 years age group. In an additional 22% of cases sexual behaviour was “unknown” (Institute of Environmental Science and Research, 2022). Of the 922 MSM with gonorrhoea, 7.7% were also HIV-positive. Women having sex with women and trans* individuals accounted for 2% of total gonorrhoea notifications.

The ESR notes that marked health inequities in STIs in New Zealand exist not only among ethnic minorities but also among MSM, who are the largest group in both the gonorrhoea and syphilis diagnoses, when analysed by sexual identity (Institute of Environmental Science and Research, 2022). As the report points out, these inequities are likely attributable to several factors, including differences in accessing healthcare.

2.5. The New Zealand Healthcare System

In 1938 New Zealand became one of the first countries in the world to propose free universal healthcare for its citizens, with the Social Security Act of 1938 (Goodyear-Smith & Ashton, 2019). Among the services the government proposed to fund through tax revenue was general practice. This proposal met with strong resistance from medical professionals. A compromise with the New Zealand Government left GP services privately funded while hospital and maternity services, as well as pharmaceuticals, were fully funded by the government (Goodyear-Smith & Ashton, 2019; Horn & Gorman, 2021). From 1941 GP services were subsidised via general medical services subsidies, and GPs were also allowed to charge an additional fee-for-service on top of the subsidy

(New Zealand Parliament, 2009). The country was divided into 18 District Health Offices and 29 Hospital Boards. The 8-14 members of each Hospital Board were locally elected for three-year terms (New Zealand Parliament, 2009).

In 1983, 14 Area Health Boards were created, whose members were elected by the communities they served. In 1991, a right-of-centre government introduced a neoliberal market system into the public health structure in New Zealand. The Area Health Boards were dismantled, and commissioners were appointed in place of elected representatives; four Regional Health Authorities (RHAs) were created. Public hospitals became for-profit, and renamed Crown Health Enterprises (CHEs) as the government hoped competition would drive efficiency. Both RHAs and CHEs were run by government appointees, not a local Board of Trustees. These changes proved damaging, as access to healthcare became more restricted and many providers could not survive in a market-driven environment (Goodyear-Smith & Ashton, 2019). Additionally, it became clear that the changes sought by these reforms – a leaner and more efficient system – were not likely to happen (Ashton, 2005). By 1997, hospitals reverted to their not-for-profit status, and the RHAs were replaced by the Health Funding Authority.

The year 1993 also saw the establishment of Pharmac – the Pharmaceuticals Management Agency | Te Pātaka Waihoranga. Pharmac was a response to rapidly escalating pharmaceutical costs throughout the 1980s (Pharmac, 2021). Their task was to negotiate better prices for pharmaceuticals in New Zealand, and today they maintain what amounts to a national formulary. In 2001 Pharmac became a Crown Agency, meaning they operate independently and are answerable directly to the Minister of Health (Pharmac, 2021).

Pharmac negotiates low prices through tendering (competitive bidding) and reference pricing. It has a set budget each year for funding medicines and they must work within it (Calnan, 2020). The agency's aggressive price settings and decisions on which medicines to fund (or not) brought both accolades and criticisms. Pharmaceutical companies consider New Zealand an antagonistic market (Calnan, 2020); Pharmac has been criticised in the past for preventing important or innovative drugs from reaching New Zealanders who need them (Calnan, 2020). Often, however, Pharmac 's slow and deliberate process allows additional safety data to accumulate on these newer drugs, proving that the cautious approach had been warranted (Davis, 2022). Sarkisova et al. (2022), traced the funding of newer Type 2 diabetes medications in New Zealand. The authors pointed out that Pharmac was in fact more cautious in its approach than Medsafe[13], whose duty is to ensure the quality and safety of medicines approved in New Zealand. Pharmac 's refusal to fund some of these drugs was based in part on the lack of long-term safety data, while Medsafe did not wait for such data to become available. Sarkisova and colleagues did point out, however, that the very long wait for funding might have a detrimental effect on populations where diabetes is a significant problem – namely Māori and Pasifika people. They concluded that special access guidelines for funding should be revisited and refined.

In 1999 a new left-of-centre government came to power and scrapped the existing health service structure, in favour of more democratic and decentralised District Health Boards (DHBs), which were reminiscent of the RHAs (Ashton, 2005). The new system abolished the market-driven approach in favour of a collaborative one between the 21 DHBs and service providers. While the DHBs were mostly autonomous in their control of allocated funds and priority setting, they also had to adhere to a national

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[13] Medsafe is the New Zealand Medicines and Medical Devices Safety Authority

framework of required services and priorities, which sometimes conflicted with local ones. The decentralised semi-autonomy of the DHBs also failed to resolve the problem of the postcode lottery, and the inequities in health outcomes between various ethnicities in New Zealand (Ashton, 2005).

The 2022 healthcare reforms took effect on July 1. These reforms abolished the DHBs in favour of two centralised health authorities working alongside the Ministry of Health – one of which is Māori-specific. The new system also promises to increase the involvement of and input from Māori communities in tailoring health services to fit their needs (Department of the Prime Minister and the Cabinet, 2022). As these reforms only took effect in July 2022, no conclusions regarding their effectiveness or performance can be drawn.

In assessing the reasons for the constant reforms that (so far) failed to achieve expected efficiency gains and equitable access in the New Zealand healthcare system, Horn and Gorman (2021) referred to a “political calculus” that is driven by strong representation of special interest groups (e.g. those employed in the healthcare sector). These groups, who have political influence, oppose reallocation of health funding away from their special interest. The healthcare budget, therefore, is always allocated to keeping the status quo – budget increases go to raising salaries to existing providers for existing services, and innovative services and service providers are rarely allocated funds. Thus wait lists grow longer and populations suffering from health inequities – people who do not have strong representation – continue to languish. Horn and Gorman recommend looking beyond the immediate demands of special interest groups, into future costs that will be incurred (e.g. workforce productivity loses) if under-served groups’ needs are not met. A similar call was voiced recently by Bagshaw et al. (2022). The authors called for increased investment in healthcare in New Zealand, in order to allow for balanced and equitable treatment for all, rather than the current system that favoured increased rationing of secondary (“elective”) care.

Currently the New Zealand healthcare system is funded by the taxpayers, and most primary care services are subsidised but not free for people 14 years and older, while public hospital services are fully-funded. Sexual and reproductive health services are free for those under 22 in Family Planning clinics. Services for children aged 13 years and younger are free. In 2001, in an effort to cater more to population needs, a new Primary Healthcare Strategy was implemented. This strategy called for the formation of Primary Health Organisations (PHOs). PHOs are not-for-profit networks of primary care providers. These networks are funded based on the number of people enrolled (capitation funding) rather than a fee-for-service funding (Goodyear-Smith & Ashton, 2019). PHOs also receive payments for special services such as primary mental healthcare. They charge patients aged 14 years and older co-payments for various services. For primary care, these services can cost teenagers from $15 to upwards of $50, depending on several factors that include where they live and their family income level (Goodyear-Smith & Ashton, 2019).

2.5.1. Youth One Stop Shops

While it is typical for teens to use the same healthcare provider or clinic as their parents, a unique service available in New Zealand is focused solely on young people’s health. Youth One Stop Shops (YOSS) are primary care clinics around New Zealand offering a range of services from physical healthcare to sexual and mental healthcare. Some YOSS offer additional services, such as career mentoring (Health Navigator, 2022). Services are free for youth who enrol. There are currently 11 YOSS operating in New Zealand (Health Navigator, 2022), including Christchurch’s 298 Youth Health Centre, which provided me not only with space to conduct my Christchurch-based study interviews, but also with feedback and assistance in preparing the interview questions (see Chapter 4). YOSS are important in the context of this study because they offer inclusive care to SGM, something that according to international literature is uncommon in primary care settings (see the Literature Review chapter).

2.6. Summary

While LGBTQ+ rights in New Zealand have come a long way from the days of colonisation, LGBTQ+ youth and adults are still struggling with stigma and discrimination, and those at the intersection of SGM and ethnic minority even more so. Currently, there are very little data on the experience of SGM youth in New Zealand's healthcare system, though the Government had recently acknowledged some of those struggles, and pledged to allocate more funds to improving specific shortfalls (NZ Herald, 2021; Radio New Zealand, 2022).

The next chapter will review the pertinent literature for this study, noting knowledge gaps that exist and how I hope to fill them.

Chapter 3. Literature Review

"I'm sorry, Mama. Not for what I am, but for how you must feel at this moment. I know what that feeling is, for I felt it for most of my life. Revulsion, shame, disbelief - rejection through fear of something I knew, even as a child, was as basic to my nature as the color of my eyes."

(Maupin (2000), as cited in Pharmac, 2017)

Michael Tolliver's coming out letter to his mother, in Armistead Maupin's *More Tales of the City,* conveys the stigma and struggles experienced by LGBTQ+ people living in a hetero- and cis-normative society. The reality of being LGBTQ+ impacts every aspect of a person's life, not the least of which is their journey through the healthcare system.

Sexual health and access to healthcare in the LGBTQ+ population are both multifaceted issues that in past decades were not extensively researched beyond the risk of HIV infection (Snyder et al., 2017; World Health Organization, 2015). The increasing number of recent studies looking at barriers to healthcare access in this population points to a recognition that a knowledge gap exists. LGBTQ+ teens are often afraid to participate in research that may expose their sexuality or gender identity, due to the stigma and discrimination (and criminal prosecution in some countries) that may follow such exposure (World Health Organization, 2015). This concern is also a barrier for SGM teens when seeking to engage with healthcare providers (Snyder et al., 2017).

This chapter reviews the current knowledge we have today on the intersection of sexual and gender minorities with the healthcare system. I will look at both sides of the equation – the patients' and the providers' – before turning to look at the specifics of

LGBTQ+ teens and sexual health and risk behaviours. In this way I hope to shed light on what is already known and what is missing, and thus identify where more research is needed in the context of this study's research questions.

3.1. Search Strategy

I searched academic databases through the University of Canterbury's database search engine for published, peer-reviewed journal articles. I used key words for the different headings in this literature review. For example, for "Patients Expectations vs. Experiences" I searched "LGBTQ* [AND] patient* [AND] expectation* OR experience* OR healthcare" as one search string. I then added a search with "youth OR adolescent* or teen*" to the above search string, and tried a few variations of these main ones. Searches were restricted to English, and started out limited to the most recent five years. Especially in the early days of the study, it was hard to find much research on adolescent LGBTQ+ patients that was not HIV-focused, so I expanded the time limit on the studies included.

There were several searches where it made sense to use non-specific databases to find material, particularly medical students' views on the state of LGBTQ+ medical education, and reports. I used Google Scholar for these searches, because I was unsure if these regional opinion pieces would be indexed in databases such as Medline, PsychInfo, or Embase.

3.2. Patients' Expectations vs. Experiences

SGM healthcare consumers have their own expectations of the healthcare providers they attend. While many of these expectations overlap with those of cis-gendered, heterosexual healthcare consumers, others may seem unique to the LGBTQ+

community – for instance, (Alpert et al., 2017, p. 1375) found participants wanted a provider who was comfortable with LGBTQI+ patients. These needs and expectations should be attended to just as seriously as heteronormative standards and expectations.

The *reality* of the experiences of SGM in healthcare settings is often very different than the *expectations*. Alpert et al. (2017) list several “historical traumas” inflicted by the healthcare community at large on members of the LGBTQ+ community. Those include psychiatric diagnoses (e.g. homosexuality as a mental illness diagnosis), “conversion therapies” to “change” people into cis-gendered and/or heterosexuals (those are still practiced today, though recently banned in New Zealand), and forced surgical and hormonal treatments of intersex babies and children. To these the authors add biased treatments by providers, another issue that persists to this day (see below).

Alpert et al. (2017) conducted six focus groups with LGBTQI persons aged 18 years and older in the US. The groups were held in Burlington, Vermont; New York City, New York; Oakland, California; and Washington, DC. There were 48 participants altogether in the groups, with the largest group numbering 15 participants and the smallest four. The 48 participants were evenly split between Whites and people of colour. Participants identified across the spectrum of gender and sexual identities.

These groups both related the participants’ experiences in the healthcare setting and provided information about their expectations from their healthcare providers, offering a window into the reality of some sexual and gender minority people seeking healthcare, and why they often choose not to come out to their providers.

The five themes that emerged from the focus groups in terms of suggestions to physicians were labelled by the researchers “community-identified provider competencies.” They were: “Be comfortable with LGBTQI patients”; “Share medical decision-making with patients”; “Avoid assumptions about sexual orientation, gender identity, behavior, or anatomy"; "Apply knowledge of LGBTQI identities, anatomy, and common sexual practices"; and "Acknowledge and address the social context of health disparities."

Participants expected the same level of comfort and respect their providers gave non-LGBTQI patients. They reported a negative shift in attitude and treatment following disclosure of their SGM status. Participants referred to times when physicians failed to carry out routine exams on trans* people (e.g. giving a Pap smear to a transman), or "freaked out" and "shamed" patients because they were unprepared for frank talk about sexual habits. They discussed the need for physicians to understand their status is, in fact, a social determinant of health. Participants also pointed out that the lack of understanding of a patient's social situation can also lead to harm.

The study's importance in the context of my study is in the variety of negative experiences it relates. This study was undertaken in 2013-2014, at a time when acceptance of LGBTQ+ individuals was growing around the world and in the US (e.g. New Zealand and England legalised same-sex marriage in 2013; the US legalised same-sex marriage in 2015, though many states in the US legalised same-sex marriage earlier – my state did so in 2012). Yet stigma, discrimination, and ignorance in the healthcare profession were still rife. Furthermore, if such stories circulate among the community they can make many LGBTQ+ people wary of seeking healthcare. In fact, Bandura's Social Cognitive Theory (SCT; see Chapter 5) suggests that this is exactly what happens. The stories themselves, therefore, become a barrier to accessing healthcare.

Similarly, Griffin et al. (2018) conducted interviews with young adult gay men in New York City (NYC). The purpose of the study was to understand the cohort's "current healthcare engagement, including experiences with the healthcare system, provider knowledge of healthcare needs, and desired provider characteristics" (p.368). The 40 participants came from the P18 Cohort Study, a longitudinal study that recruited MSM aged 18-19 years old at baseline (between 2009 and 2011). The study discussed here recruited from the larger cohort in 2015, and the mean age of the 40 participants was 23.34 (*SD* ± 0.75). The participants, all still actively participating in the P18, identified as gay and male, were HIV-negative, still lived in the greater NYC area, and had not lived outside the US in the five years preceding the 2015 study. The study was qualitative, and the interview guide was prepared according to Andersen's Behavioral Model of Health Services Use, which served as the theoretical basis for the study (Griffin et al., 2018).

The three topics (the term used by the authors) that emerged from the analysis were experiences with the healthcare system, provider's knowledge, and desired characteristics in healthcare providers. In addition to cost and lack of health insurance, barriers to engaging with care (which includes coming out to their providers) included previous homophobic experiences that left them wary of disclosing their sexual orientation. An additional barrier was an intersecting minority factor such as being an ethnic minority, where cultural norms came into the discussion of sexual orientation.

With regards to provider knowledge, Griffin et al. (2018) found that participants normally sought help from sources outside their regular healthcare provider, such as an LGBT centre, where the participants felt that doctors understood their needs better. For some participants, the knowledge they found outside their primary provider's office led to a change in providers (Griffin et al. 2018).

When it came to desired characteristics in a healthcare provider, similar to the participants in the Alpert study, Griffin et al., (2018) found participants prioritised skills over demographics, specifying they preferred a provider who was non-judgemental, open-minded, and able to discuss their needs and sexual health comfortably and knowledgeably. Griffin et al., (2018) reported that ethnic minority participants showed a preference for a provider from a marginalised population, though no clear trend emerged in this regard.

Though the study sample was a small, urban population limited to gay men only (Griffin et al., 2018), many of the points brought up in this study were also reflected in the Alpert study, discussed above. Notably, with the possible exception of ethnic minorities, LGBTQ+ patients prioritise a healthcare provider's knowledge and non-judgemental attitude over demographic features such as ethnicity or sexual orientation/gender identification. The inability to find such a provider, or the uncertainty of the provider's attitude towards SGM, was a barrier to accessing adequate healthcare, as these studies show (Griffin et al., 2018).

In New Zealand, Neville and Henrickson (Neville & Henrickson, 2006) carried out a national survey to investigate how sexual minorities felt about disclosing their sexual identity to their healthcare providers. The research was undertaken through a self-administered questionnaire that was available both on paper and online with recruitment through mainstream and LGB-focused media and venues (Neville and Henrickson, 2006). The questionnaire contained 133 items, and 2,269 people aged 16 years and over completed it (Neville and Henrickson, 2006).

As Neville and Henrickson (2006) point out, having to disclose sexual identities is an experience only sexual minorities have to go through, since "heterosexuality is almost inevitably assumed" (p. 409). This, in and of itself, can be a barrier to accessing healthcare. In the study, Neville and Henrickson (2006) found that 71.7% of the women and 64.7% of the men who responded to the survey were out to their provider. The difference was statistically significant (*p* = .002). That percentage differed by age group

(75.5% of those aged over 40 years vs. 61.2% of those younger than 40 years). The difference by age was also statistically significant (*p* < .001). The provider's attitude towards sexual orientation was important to both men and women. When analysed by age (<40 years, >40 years), the importance of the provider's attitude was statistically significantly higher in the younger group (*p* < 0.001) (Neville and Henrickson, 2006; p. 411). Of note, roughly three-quarters of the respondents said their providers "always" or "usually" assumed they were heterosexual.

It is interesting to note that according to the authors, their sample was above-New Zealand-average in terms of income and education. Health research shows that income and education levels affect health access (Levesque et al., 2013). There are no indications in the paper as to whether the authors considered these factors and their potential impact on the results.

This study highlights two points that are of interest to my study: 1) Men may be more reluctant than women to come out to their providers; 2) Younger people may be more reluctant to come out to their providers. Importantly, however, this study was done in 2004. In the intervening years, same-sex marriage was legalized in New Zealand and the overall recognition of SGM has advanced. Since there are no recent data on the topic, and none at all on adolescents, my study has the potential to fill a gap that is important in public policy discussions.

Overall, the studies above paint a particular picture of sexual/gender minority patients' experiences in seeking healthcare. These patients are not seeking special treatment. They expect to be treated with the same knowledge, respect, and consideration their heterosexual, cis-gender peers are given. Yet research findings suggest that many of these patients are treated with at best ignorance, and at worse hostility and derision (e.g. Griffin et al., 2018; Rossman et al., 2017).

3.3. Medical Education

To competently and sensitively cater to sexually and gender diverse patients, healthcare providers must understand their patients' needs and be comfortable talking about sexual habits and gender perceptions that may be quite different from their own. They must also be comfortable with the patients themselves.

In their 2002 study, Khan et al. (2008) studied GPs' attitudes towards patients with STI in New South Wales (NSW), Australia. Through stratified random sampling, they drew a 15% sample of GPs practicing in New South Wales and mailed them paper questionnaires. The response rate was 45% (409/900).

Khan and colleagues (2008) found that while up to 72% of participating GPs were comfortable working with young (<25 years) heterosexual patients with STIs, less than half were comfortable working with marginalized populations with STIs. These populations included sexual minorities. Those GPs who were comfortable working with sexual minorities took more initiative in taking sexual histories from their sexually diverse patients, and were more likely to provide information about treatment and prevention of STIs (Khan et al., 2008). Practitioners uncomfortable working with sexual minorities were, interestingly, more likely to conclude they cannot change their sexually diverse patients' behaviours (32% vs. 20%, $p = .019$), and reported more difficulty taking sexual histories.

As the authors concluded, "These data suggest that uncomfortable practitioners experience difficulty in meeting patients' clinical needs and their expectations for non-judgemental care" (Khan et al., 2008, p. 151). As noted above (see Patients' Expectations vs. Experiences), patients are not only sensitive to physician discomfort with them, they also rate a non-judgemental attitude as one of the most important qualities they look for in a physician. It is difficult to know, however, how representative the findings are of NSW GPs in particular, and practicing GPs in general. This is because only 45% of a 15% sample responded, so the overall percentage of respondents would be ~7% of the entire NSW eligible GP population. Furthermore, with such a high percentage of non-respondents, a limitation of this study is the possibility that selection bias played a part in the results – that the 45% of GPs who responded differed in a way that was fundamental to this research from those who chose not to respond (Khan et al., 2008). Nevertheless, though the study was limited only to GPs' attitudes regarding STIs, and less than half of the eligible participants responded, it does support the observations made by Alpert's focus group participants, and suggests the existence of an important barrier sexual and gender minorities face in their quest to obtain quality healthcare.

Khan et al. (2008, p. 151) conclude by stating, "The results of the present study have implications for improvements in both undergraduate and continuing medical education." Nevertheless, as of this writing, the following research suggests that Australasian medical schools' curricula remain deficient when it comes to educating future physicians about sexual and gender diversity.

Sanchez and colleagues (Sanchez et al., 2017) surveyed medical schools' curriculum administrators in Australia and New Zealand. Their survey gauged how many hours were dedicated to LGBTQI health in each school's curriculum. Fifteen schools responded, 1 from New Zealand and 14 from Australia. Sixty percent of the schools (n=9) responded they dedicated 0-5 hours in the preclinical years, and LGBTQI content was "interspersed throughout the curriculum." Five schools (33%) had dedicated modules for LGBTQI content. The content covered by the schools varied, but 80% of the schools included content on obtaining information about "same sex sexual activities," and 67% of the schools covered material regarding the difference between sexual identity and behaviour. Gender-related material was less defined – 47% of respondents were not sure what was taught.

Though only one respondent answered in each school, and they may not have been familiar with the entire school's curriculum, the picture that emerges is grim. This view is supported by Australian medical student Amy Coopes (Coopes, 2018), who wrote a featured article for a publication of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists. In addition to the scarcity of the content, writes Coopes, who defines herself as "same-sex attracted," "Often, this content is not taught by, or in consultation with, gay, bi, lesbian, trans or non-binary, or intersex people. It is tokenistic, overly pathologising or reductive, and can be delivered in a way that makes sex and gender diverse students feel exposed, embarrassed, ashamed and marginalised" (Coopes, 2018, p. 45). As a result, Coopes says, citing Mansh et al. (2015), 1 in 3 sexually- or gender-diverse medical students hides their identity, particularly from faculty and staff members. She adds, "I have cried in hospital bathrooms and quiet corners of labs after a thoughtless or overtly homophobic remark; some days I just can't face it again." (Coopes, 2018, p. 46). It is unclear whether the attitudes and educational deficits Coopes (2018) describes are prevalent across the entire region's medical education system or are typical of her school only.

It is noteworthy that in 2013 the Rainbow Health report (Stevens, 2013, p. 8) pointed out in its Executive Summary: "New Zealand's health system needs to develop cultural competency in working with Rainbow communities to help alleviate the effects of minority stress and provide the healthcare that all New Zealand citizens are entitled to." This note raises the possibility that Coopes' medical school is not the only school showing deficits in its LGBTQ+ curriculum and attitudes.

Taylor and colleagues (2018) conducted a mixed-methods survey looking at New Zealand's two medical schools' preclinical curricula. They contacted all staff responsible for the preclinical curriculum oversight (N=38). Fifty-four percent of respondents replied "None at all" when asked how much LGBTQI content was included in their module. In modules that did include LGBTQI content (n=11), it was presented in "discrete blocks" in 70% of the modules, and "interspersed throughout various parts of the curriculum" (Taylor et al., 2018, p. 37) in 20% of these modules. The majority of respondents (42%) said it was difficult to find the time to teach LGBTQI content.

As Taylor et al. (2018) point out, most of the respondents in the study felt the LGBTQI content was very important, but felt the preclinical modules (which largely deal with basic sciences) were the wrong place to teach issues relating to sexuality and gender, which are more relevant to patient care modules. However, as the authors also highlight, this attitude may reflect a basic lack of understanding of LGBTQI issues and their relevance to basic sciences. The authors cite as an example the possibility of teaching the biochemistry of hormone treatments in a biochemistry block. This view dovetails with patients' experiences, as detailed above, of providers not being familiar with their SGM patients' unique needs. The assumption that LGBTQI issues do not have relevance to basic science may also reflect an "uncritical acceptance of heteronormativity and cisnormativity" (Taylor et al., 2018; p. 41).

As of 2022, judging by Halliwell (2022), little has changed in Australia (there is no new information on New Zealand medical schools). Halliwell writes:

> Equally concerning is that much of the limited content taught in Australian medical schools is done so in ways which, in the experience of many LGBTQIA+SB [lesbian, gay, bisexual, transgender, queer, intersex,

> asexual, sistergirl and brotherboy[14]] identifying medical students stereotypes, pathologises and sometimes even actively discriminates against LGBTQIA+SB people, in turn teaching our future medical workforce to do the same. (Halliwell, 2022, para. 5).

Furthermore, he notes: "…not only is LGBTQIA+SB health largely excluded from the curriculum, but … most content which is included is outdated, reductionistic, inaccurate and harmful" (Halliwell, 2022, para. 9).

Halliwell goes on to note that the LGBTQ+ arm of the Australian Medical Students Association (AMSA) – AMSA Queer – is developing an online open access educational resource for medical students and healthcare professionals (https://www.wavelengthmeded.org/). As yet, he notes, there is no change in the Australian Medical Council's standards for assessment and accreditation regarding the need for specific LGBTQ+ education in Australian medical schools.

An example of an LGBTQ+-centred curriculum was developed at the University of Washington School of Medicine in Seattle, Washington (US) (Gibson et al., 2020). This curriculum pathway was a student led initiative, developed in collaboration with LGBTQ+ community members. Interested students in their preclinical years (1st and 2nd year in the 4-year US medical school curriculum) were eligible to apply. The pathway, stretching across all 4 years, utilises a variety of teaching and practical methods to expose students to LGBTQ+ patients and community advocacy work. The first cohort to go through this curriculum pathway comprised six students who entered in 2016 (the initial acceptance in the pathway's pilot year was capped at six). Surveyed at the end of their preclinical years, all six said the curriculum had a positive impact on their medical

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[14] The terms sistergirl and brotherboy [SB] are used by Aboriginal people in Australia to denote transgender and other gender diverse individuals.

education and career goals, and felt it improved their ability to care for SGM patients. At the time of the paper's publication (2020), the pathway had 43 students in various stages of completion. The original six pilot students all passed their clinical clerkships in LGBTQ+-centred clinics.

3.4. Provider Bias

The other facet of providers' relationship with their SGM patients is the existence of implicit bias. Unlike explicit bias, which is outwardly visible, implicit bias is not a bias the provider is aware of or can consciously control (Sabin et al., 2015). Sabin et al. (2015) studied implicit bias in healthcare providers across the globe. The study lasted six years (2006-2012) and involved thousands of various providers (doctors, nurses, mental health professionals, and other healthcare providers).

Participants were not recruited specifically for this study. Rather, they chose (or were assigned by an employer or professor) to participate in Project Implicit ("a non-profit organization and international collaboration between researchers who are interested in implicit social cognition"; https://implicit.harvard.edu/implicit/aboutus.html) and took the Sexuality implicit-association test (IAT) when arriving at the project web site. According to the authors, the validity of the Project Implicit datasets (the cumulative responses to the different tests available), has been proven in numerous peer-reviewed publications across a variety of topics, including sexual orientation (Sabin et al., 2015). Test takers provided extensive demographic information and had to be aged at least 22 years for their responses to be analysed in this study. Occupational categories and highest degrees were used to classify test takers into one of several categories of healthcare workers and providers. The IAT is described in detail in the paper. Explicit bias was tested through choosing one answer from a list of seven statements that went from “I strongly prefer straight people to gay people” to “I strongly prefer gay people to straight people.” (Sabin, Riskind, & Nosek, 2015; p. 1834)

The study found that “implicit preferences for heterosexual over lesbian and gay people are pervasive among the majority of healthcare providers” (Sabin et al., 2015; p. 1840). In general, providers explicitly favoured people who shared their sexual identity, with the exception of heterosexual female mental health providers, whose explicit preferences were for gays and lesbians (Cohen *d* = -0.52; 95% CI -0.54 to -0.49).

The study included a large number of respondents, although in every category at least 75% of them resided in the US. Therefore, while the study is based on a very large number of participants, it is not clear how representative it is of attitudes outside the US. Furthermore, as the participants were not randomly selected, it is hard to tell if the sample is even representative in the US. In addition, the study only gauged biases towards gays and lesbians, not gender diverse individuals. Nevertheless, the study does show that implicit and explicit sexual orientation biases do exist among healthcare workers. What the study does not tell us is whether such biases affect treatment quality (as was demonstrated by Khan et al. (2008), above). In my study, I am looking to answer this question from the patients’ perspective. Through open-ended survey questions and face-to-face interviews, the perceptions of bias and whether that bias impacted the provider-patient relationship should become clearer, at least as they pertain to providers and adolescent LGBTQ+ patients in New Zealand.

Implicit bias may very well develop as a result of the stigma that accompanies the various identities of sexually- and gender-diverse individuals. Sabin et al. (2015; p. 1831) defined stigma as “the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination in a situation in which power is exercised”. If people grow up with such socially constructed negative messages, it is hard not to accept them subconsciously. For the various healthcare providers, the best time to counter such implicit bias would be in the various school programs (e.g. medical school, nursing school, etc.) that prepare people for these professions. Currently, only a small amount of curriculum time is devoted to this, and it seems by Coopes (2018) testimony that at least one medical school in our region is failing in this task.

3.5. LGBTQ+ Teens and Health

Most available information on the experience of sexual and gender minorities in the healthcare system comes from research on adults aged 18 years and over, and it is discussed in Section 3.2. Very little research exists on the experiences of teen LGBTQ+ while accessing healthcare (Snyder et al., 2017), and even less so in New Zealand. The most recent information on LGBTQ+ youth's health and wellbeing in New Zealand comes from the Youth19 survey. It is discussed in Chapter 2. Of note, the information about the LGBTQ+ teens in the Youth19 study came from subgroup analyses. Youth19 was not an LGBTQ+-specific study.

Stern (2021) conducted a literature review to assess the needs and experiences of LGBTQ adolescents (defined as aged 11-21 years in that study) in the US paediatric primary care setting. The study also assessed primary care providers' ability to render inclusive care to this patient population. With no limit on date of publication, only four studies were eligible for inclusion, signalling the dearth of information on the topic. Two of those four publications looked at doctors' perspectives.

One of the studies Stern reviewed was by Hoffman et al. (2009). The authors used an internet survey to sample LGBTQ youth and young people (aged 13-21 years) across the US and Canada. The survey was placed on the Youth Guardian Services web site (http://www.youth-guard.org/). The site is dedicated to supporting LGBTQ youths and allies. Survey items were generated from data gathered in focus groups held in Chicago, New York City, Washington DC, and Atlanta. A total of 733 responses were included in the analysis. While the US respondents were spread almost evenly across the different US regions, only 5% of responses came from Canada, so it is hard to tell how applicable the results are to Canadian LGBTQ youth.

The purpose of the study was to discover the population's preferences concerning providers and clinic settings. The survey also asked what health issues they considered important. The authors found that among the provider qualities ranked most important in this population were being respectful and non-judgemental, and having the ability to treat LGBTQ people the same as any other person (this last item was ranked most important). Other high-ranking items included knowledge of gay/lesbian issues and experience working with youth. The provider's gender and sexual orientation were *not* ranked as important. In the "clinic settings" category, the most important items included the ability to come in without a parent or guardian, and the ability to get confidential referrals to mental health providers and youth agencies, both with LGBTQ experience. Health concerns that were ranked most important included mental and physical health and wellbeing (i.e. treatment and maintenance of good health), and family issues.

LGBTQ youth in the Hoffman study were asking for the same things we all expect from our healthcare providers – a respectful, non-judgemental attitude and familiarity with our own unique needs. Every population has unique medical needs (e.g. genetic disorders that are more common in certain ethnicities; talking about sensitive issues with families from very conservative cultures). The fact that the provider's gender or sexual orientation were not ranked as important points out that the young people in this study do not actually require special care conditions. They require a competent healthcare provider attuned to their needs, one who respects them as much as he or she respects any other patient. This study is in fact an excellent argument for more inclusive education in medical, nursing, and allied health schools (see Medical Education and Provider Bias).

The second study of LGBTQ+ youths’ relationship with their primary care provider was the smaller but more recent Snyder et al. (2017). The study enrolled 60 LGBTQ+ youths aged 14 years and up (27% of the participants were over the age of 18 years) in New Jersey, US. Participants came from five community based LGBTQ+ programs across the state. The mixed-methods study involved a paper survey and focus groups of one-hour duration.

Only 16.7% of the participants reported being asked about their sexual orientation by their doctor, and slightly over a third reported their doctor discussed safe sex with them (Snyder et al. 2017). Less than half (45.6%) felt comfortable discussing their personal life with their provider. The focus groups revealed issues of disrespectful behaviour from the doctor related to participants’ age (Snyder et al., 2017, p. 447). There were stories of insulting behaviour towards sexual minorities and trans* patients (Snyder et al., 2017, p. 447). In addition, various participants reported their doctor did not listen to them, was judgemental, and did not want to discuss matters concerning sexual orientation.

The authors point out that the qualitative information tended to point out the areas needing improvements in the way doctors treat LGBTQ+ youths. Richer data detailing negative experiences of healthcare was communicated in the focus groups, compared with the survey. This study shows the advantage of using mixed methods to study sensitive topics. Additionally, the finding of Snyder et al. (2017) – that the healthcare needs of LGBTQ+ youth are not being met, and that the healthcare environment can be hostile to LGBTQ+ youth, support the hypotheses underlying my study.

Rossman and colleagues (2017), while not focusing on adolescents, studied LGBTQ young adults aged 18-27 years (partially overlapping the study population age in this study, which is 15-19 years). They used thematic analysis on computer-based survey responses to open-ended questions to understand what encouraged or discouraged identity disclosure to a healthcare provider. Of the 206 participants, 63% (n=130) came out to their provider and 37% (n=76)[15] did not. Three themes emerged among participants who did not disclose their identity to providers: One theme was the perception that one's sexual and/or gender identity was unrelated to healthcare, with one example being a 22-year old gay, cis-gendered participant saying, "Disease effects [sic] both straight and LGBT equally without discrimination" (Rossman et al., 2017, p. 1399). A second theme was provider characteristics that contributed to not coming out: this theme had two subthemes – the provider never asked, and the nature of the relationship with the provider. In the latter subtheme, relationship factors discouraging coming out were either dislike of the provider, providers who made heteronormative assumptions about their patients, or providers who have known the participant since childhood. In this case, some participants felt uncomfortable coming out to someone who has taken care of their health since they were babies.

The third theme, resistance to disclosure, had four subthemes. One of the two most common subthemes was the desire for privacy e.g. "I feel like my sexuality is my business in what I do and who I do it with" (Rossman et al., 2017, p. 1399) The other common subtheme was labelled as Stigma by the authors, and included fear of being

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[15] The paper erroneously states "(n=67)." Since this is an obvious error I am giving the correct number.

treated differently, concerns about the provider’s reaction, and not wanting to be labelled. The other two subthemes occurred less frequently. One was ambivalence about the coming out process and the necessity for it (Rossman et al., 2017, p. 1399) — participants wanted to keep their sexuality to themselves but understood it was medically important information. The other subtheme was the “Conditional Disclosure” – participants who were willing to consider coming out if it would help them in some way. This study shows that fear of the response to coming out, as well as heteronormative assumptions on the part of providers, can be powerful barriers to utilising healthcare resources. These elements appear in most studies reviewed in this chapter.

3.5.1. Physical and Emotional Wellbeing

As discussed in Chapter 1, LGBTQ+ adolescents are at higher risk for adverse mental and physical health events, resulting from societal norms and ideologies. The Decompensation model (Riggs & Treharne, 2017), which is discussed in Chapter 5, suggests that the norms and ideologies that marginalise LGBTQ+ people cause constant stress, in the form of enacted stigma and discrimination. Such stress can result in adverse health events, and the wellbeing disparities between LGBTQ+ teens and their heterosexual, cis-gendered peers.

Gower et al. (2021) set out to understand the context and lived experiences of enacted stigma on LGBTQ youth (aged 14-19 years). The study was a secondary analysis of the Research and Education on Supportive and Protective Environments for Queer Teens (Project RESPEQT). The 66 participants came from British Columbia (Canada), Massachusetts, and Minnesota (US). They lived in diverse areas (urban, suburban, small city, and rural), and had diverse ethnic backgrounds. Data were collected through semi-structured interviews and thematic analysis was used to analyse them.

Participants described encountering enacted stigma in both school and community (e.g. malls, restaurants, on the street) settings. These incidents ranged from verbal insults to physical violence. The result of these experiences often led them to restrict where they went or what activities they participated in, which frequently resulted in limited socialising opportunities. In addition, some participants described second-hand enacted stigma experience (stories they heard from friends or acquaintances) that brought on the same responses (e.g. restricting where they went) as the people experiencing enacted stigma in person. From a social cognitive theory (SCT) perspective, the participants who restricted their own movements and activities likely had low self-efficacy when it comes to social interactions. Self-efficacy translates to how much control of an action or task a person feels they have (Schwarzer & Luszczynska, 2005). Higher self-efficacy means a person is surer of their ability to perform a task or achieve a desired outcome. Self-efficacy is influenced by past experiences such as skills mastery. Additionally, self-efficacy is also influenced by social interactions, including other people's retelling of their own experiences in similar situations. Therefore, anecdotes of enacted stigma being related to a teenager by a friend may lead to lower self-efficacy around the same activities or social interactions, resulting in an identical avoidance response to second-hand enacted stigma.

Given the fact that LGBTQ+ youth experience enacted stigma in multiple areas, and its impact can be so profound as to restrict their movement and socialisation, the higher rates of mental and physical adverse events in this population are not surprising. Research, though mostly in adults, shows that similar stressors exist for LGBTQ+ people in the healthcare environment as well.

In 2010 a Lambda Legal review found that 10% of sexual minorities and 21% of trans* patients experienced harsh or abusive language when they disclosed their identity to healthcare providers; 8% of sexual minority patients and 27% of trans* patients were refused care when they disclosed their identity (Lambda Legal, 2010). Consequently, many adult LGBTQ+ patients chose not to disclose their identity. However, as Rossman and colleagues (2017) point out, the lack of research on identity non-disclosure in LGBTQ+ youth is problematic, because their rates of non-disclosure *and* adverse health outcomes tend to be higher than rates in adult LGBTQ+ patients.

3.5.2. LGBTQ+ Adolescents and Sexual health

While there are no data on New Zealand adolescents' and young adults' access to sexual health services, the high rates of chlamydia, alongside increasing rates of gonorrhoea and syphilis in this population as a whole, point to unmet needs in this area (Rose et al., 2021, p. 395). Options available to teens in New Zealand to obtain such care include their GP, Family Planning clinics, sexual health clinics, and YOSS. Cost and availability of these services vary across New Zealand, though most of them will be free to those aged under 20 years (Rose et al., 2021).

Rose et al. (2021) surveyed youth and young adults, aged 15-24 years and living in Hawkes Bay, New Zealand regarding their experience seeking sexual healthcare. The authors specifically sought to include SGM in the study, and sought to ensure at least one-third of the participants were Māori. Advertising materials therefore contained both a rainbow and a Māori design in the background. Survey questions were piloted in two focus groups, and revised based on feedback from the groups. The survey was distributed online via the Qualtrics software.

Five-hundred responses were analysed. The majority of participants (60%; n=300) received sexual healthcare in the past, most of them in a GP clinic (74%; n=223). A total of 40.8% (n=204) indicated they needed sexual healthcare in the past but did not receive it, or chose not to seek it. Among the subgroups more likely to have this unmet need were the LGBTQ+ participants. LGBTQ+ participants who did not have sexual healthcare before the study (41%) were significantly more likely to not want to go to their regular GP for sexual healthcare compared with the heterosexual/cis-gendered group (21%; $p < .05$) (Rose et al., 2022). Overall, 133 LGBTQ+ and heterosexual, cis-gendered participants out of 500 preferred not to see their regular GP, for reasons that included ease of access, confidentiality concerns, and the perception that the staff at their alternative clinic were more knowledgeable and less judgemental (Rose et al., 2022).

Among the 300 participants who had received sexual healthcare in the past, proportionally fewer LGBTQ+ people reported that reception personnel were welcoming (42.7% compared with 51% of the heterosexual, cis-gendered participants) (Rose et al., 2022). LGBTQ+ participants were also proportionally less trusting that their privacy would be maintained – 69% compared with 75% of the heterosexual, cis-gendered participants. The most important aspects of care across all participants included confidentiality and inclusive healthcare that extended to both SGM and ethnic minorities (Rose et al., 2022).

The subgroup analyses in the above study concentrated mostly on difference in perceptions and experiences between Māori and Pākehā, and less so on differences between LGBTQ+ and heterosexual, cis-gendered participants. Furthermore, the study was limited to one area in New Zealand, though participants came from a variety of living environments, from urban to rural. Thus, the study may not be generalizable to the rest of the New Zealand population of adolescents and young adults, but certainly common threads with other research in this population of similar ages can be seen here. It would seem, therefore, that New Zealand teens and young adults experience unmet needs when it comes to sexual healthcare.

Given New Zealand has a high STI rate by international standards (Denison et al., 2018), and as discussed in Chapter 2, these rates are likely under-reported, one question that requires an answer is what motivates young people to get tested for STIs, which is a crucial part of sexual health? To date, research has been scarce in this area. Denison et al. (2018). Denison and colleagues interviewed New Zealand university students who had an STI test at the university's health clinic and completed a follow-up questionnaire. Based on their answers to specific items some of the students were contacted for the follow-up interviews. Participants ranged in age from 19-32 years (median 23 years). There were 24 interviews in total, and from these interviews five "drivers for testing" were identified.

The first four drivers were Crisis (e.g. finding out a sexual partner was diagnosed with an STI); Partners who requested the participant be tested; Clinicians, who brought up the suggestion for testing when the participant was in the clinic on an unrelated, but often sexual health matter (e.g. contraceptives). Interestingly, none of the male participants (n = 7) mentioned this driver; and Routines – participants who tested at regular intervals or at the start or end of a relationship, as part of their routine healthcare. This driver was more common in participants whose families openly discussed sexual health.

The last driver was previous knowledge about STIs, and it was often the realisation of how common STIs were that motivated people to be tested. This driver interacted with the other four drivers. For example, some participants in the Crisis category wished they had better prior knowledge about STIs. Participants expressed their understanding that knowledge was the key to safe sexual behaviour, and many participants expressed the feeling that the sex education they received in school was inadequate, and often meant to scare students rather than inform them (Denison et al., 2018).

The study focused on an important aspect of sexual health, one that Denison et al. (2018) point out is not extensively studied. Though not LGBTQ+-focused (only one interviewee was gender-queer, and sexual orientation was not collected), these drivers point out the importance of good communication – including communication between a healthcare provider and their patients. The study also highlights the importance of a comprehensive sexuality education curriculum in secondary schools, and the perception that such curricula are uncommon (Denison et al., 2018).

The importance of a comprehensive sexuality education curriculum beyond the prevention of pregnancy and STIs has been investigated in a systematic review conducted by Goldfarb and Lieberman (2021). As the authors state, most research into sexuality education curricula focuses on programs aimed at preventing pregnancy and/or STIs. These programs emphasise behaviour changes. Goldfarb and Lieberman were interested in programs that were more comprehensive, focusing on all aspects of human sexuality as defined by the Sexuality Information and Education Council of the United States: "...the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. Its various dimensions involve the anatomy, physiology, and biochemistry of the sexual response system; identity, orientation, roles, and personality; and thoughts, feelings, and relationships" (Goldfarb & Lieberman, 2021, p. 14). The review covered literature from 1990-2017 and the programs reviewed covered a range of ages starting in preschool and going through Grade 12 (Year 13 in New Zealand – the final year of secondary school).

In the context of LGBTQ students, the review found comprehensive curricula increased awareness of sexual and gender diversity and decreased incidents of bullying and homophobia. Such programs also increased awareness of gender roles, equity, and social justice. The most effective curricula took specific steps (e.g. bringing in LGBTQ speakers) to be inclusive, and to discuss topics that were of concern to LGBTQ students.

HIV is frequently mentioned in the context of LGBTQ+ research in Western countries. The toll of HIV infections in the first two decades of the AIDS pandemic was termed “the single greatest reversal in human development” (Bekker et al., 2018, p. 13). The advent of antiretroviral therapies (ART) and, more recently, pre-exposure prophylaxis (PrEP) has slowed down the rate of new infections (Bekker et al., 2018) and extended the life expectancy of infected individuals significantly. Nevertheless, new infections are occurring at a rate that will not end the pandemic (Bekker et al., 2018), and young MSM are one key population that is disproportionally represented (Kteily-Hawa et al., 2022).

The risk of acquiring an HIV infection is 27 times higher in MSM, and 12 times higher in transwomen, compared to their cis gender, heterosexual peers (UNAIDS, 2018). Yet there is a global lack of research on *young* MSM in general, and on the HIV pandemic in young MSM in particular (World Health Organization, 2015). What is known is that young MSMs often experience multiple stressors that can include any combination of violence, discrimination, homelessness, sexual abuse or exploitation, stigma, and bullying (Bekker & Hosek, 2015). These stressors also often serve as barriers to healthcare access, denying young MSM the tools and the knowledge to protect themselves against HIV and other sexually transmitted infections (Bekker & Hosek, 2015).

To date, very little research about specific HIV risk behaviours (e.g. lack of HIV testing, condom use) has been undertaken in New Zealand. Lachowsky and colleagues examined HIV testing behaviours among young MSM (aged 16-29 years) in New Zealand (Lachowsky et al., 2014). The data were obtained from New Zealand's HIV sociobehavioural surveillance program for MSM. These data were collected in 2006, 2008, and 2011, before the PrEP era and before same-sex marriage was legalized in New Zealand. Whether the wider acceptance of same sex relationships and the availability of PrEP changed the behaviours and beliefs listed below is currently unknown, and that is an unfortunate gap that should be filled, as it can serve to guide targeted public health policies. The study, however, does shed light on an important aspect for my study.

The New Zealand's HIV sociobehavioural surveillance program consisted of two surveys, for which participants were recruited differently. First, the Gay Men's Periodic Sex Survey recruited at a community fair in Auckland in February and at gay venues during the following week. Second, the Gay Men's Online Sex Survey recruited on gay dating sites online. Participants could take one of the surveys but not both, and though results were pooled over the years, only the first time they completed the surveys counted towards the analysis discussed here. Participants were eligible to take part in the study if they identified as a man and had sex with another man in the previous five years.

Lachowsky and colleagues (2015) looked at what motivated young MSM to be tested for HIV within the most recent 12-month period. Participants were asked on the survey if they have ever had an HIV test and if so, when. For the independent variables, participants were asked about their sexual behaviour, whether they had a regular sex partner (someone they had sex with four or more times) and whether that partner was a boyfriend (someone with whom they shared a full long-term relationship that extended beyond sex) or a long-term partner for sexual purposes only. People using condoms for anal sex were asked about their condom use habits and attitudes, and the results were analysed for a second study (Lachowsky et al., 2015).

Of 3,352 responses, 1,338 participants (40%) reported a recent (within 12 months) HIV test. The majority of those recently tested did so at their doctor's office (48%), sexual health clinic (39%), the New Zealand AIDS Foundation (10%), and the rest of the testing locations were unspecified (Lachowsky et al., 2015).

Having a recent HIV test was positively associated with being older (OR for each increased year of age 1.06, 95% CI, 1.03-1.08), spending time with other gay men, being more educated (having at least some tertiary education), and having more sexual partners. Additionally, people who used condoms more regularly and did *not* believe HIV was no longer a threat were also more likely to have tested within the previous 12 months. Factors negatively associated with having a recent test included having less HIV-related knowledge, not having a regular partner or, conversely, having one for over three years, being recruited online for the study, and being bisexual (Lachowsky et al., 2014).

These results are in agreement with international research showing that teen MSM are less likely to be tested for HIV or know their HIV status (Bauermeister et al., 2018), and that the majority of HIV infections in young MSM occur between primary partners (Gamarel et al., 2019). Culturally sensitive education can address many of the factors negatively associated with regular HIV testing, and a healthcare provider can start the process by honestly talking to young MSM about HIV and their risks of getting infected. This is a key assumption in my study: that not only is unhindered access to healthcare required to receive testing and PrEP, but that the lack of a trusted healthcare provider deprives young LGBTQ+ people (especially those who are not “out” to family and friends) of a key ally in the fight against HIV infection and other STIs.

The key to preventing new HIV and other sexually transmitted infections in high risk LGBTQ+ people is understanding their risk behaviour patterns and motivations. Valencia et al. (2018) conducted a systemic review and meta-analysis of US research into risk behaviours in adolescent sexual minority males (aged 14-19 years). Eligible papers had quantitative data on sexual risk behaviours in the above population. The authors identified 21 eligible papers detailing 16 unique studies, and extracted for meta-analysis sexual behaviours that had at least three statistics associated with them (i.e. appeared in at least three studies). The behaviours were: lifetime sex with another male, recent sex, condomless sex in the past six months, condomless sex at last sexual encounter, under the influence (drugs or alcohol) at last sexual encounter, aged younger than 13 years at their first sexual encounter, lifetime forced sexual encounter, mean number of lifetime sex partners, and mean age at first sex.

The meta-analysis results showed the mean age at first sexual encounter was 13.6 years (95% CI, 13.3-13.8), and the mean number of lifetime sex partners (of any gender) was 6.92 (95% CI, 4.54-9.30). Of participants who were described as sexually active, 44% had condomless sex in the six months prior to the study, 32% were under the influence of drugs or alcohol at their last sexual encounter, and 50% did not use a condom at their last sexual encounter (Valencia et al., 2018).

Compared to studies looking at the general population of adolescent males, this meta-analysis showed adolescent sexual minority males have much higher rates of sexual risks, starting with the rate of forced sex (30% in the meta-analysis, 3.7% in non-sexual-minority males in the US’s Youth Risk Behavior Surveillance System). As mentioned above, sexual minority youths are at increased risk for sexual exploitation and violence, and this meta-analysis supports previous research. Elevated risky sexual behaviour in the youth MSM population has many causes, including lack of family support when coming out, lack of LGBTQ+ education in schools, and lack of information from medical providers (Valencia et al., 2018). The latter is one of the important assumptions in my study, linking the possibility of increased sexual risk behaviour with barriers to healthcare access.

3.6. Summary

SGM experience adverse physical and mental health events at a much higher rate than their heterosexual, cis-gendered peers (Fraser et al., 2022; Hoffman et al., 2009; Lucassen et al., 2015; Lucassen et al., 2017). These disparities stem from pressures resulting from stigma, discrimination, and ignorance that SGM are subjected to in every part of their lives, including healthcare.

Studies cited in this chapter point to a healthcare environment that is often hostile to its LGBTQ+ clients, and is certainly in need of an overhaul in terms of its professional education curricula. This chapter also shows that the expectations of LGBTQ+ health consumers are for a non-judgemental, accepting, and knowledgeable provider. Yet scant research focuses on the experience of adolescent LGBTQ+ patients in such an environment, and even less research is available to look at the connection between the difficult to navigate healthcare system and LGBTQ+ teens' sexual health. This study aims to fill some of this gap in the context of New Zealand.

The next chapter will look at the study's methodology, including its theoretical framework, social constructionism, and the mixed methods design.

Chapter 4. Methodology

In the US, my car always had political bumper stickers, including pro-LGBTQ+ equality stickers, on it. My car was also vandalised. There were swastikas involved, and homophobic notes on the windshield. When I filed a police report, they assumed I was LGBTQ+, or else why have those bumper stickers on?

Though I trace the roots of this study directly to my work in the HIV arena (as discussed in Section 4.3), I believe the seeds were planted during those incidents. I was appalled at the assumption that a person will not speak up against social injustice unless they were directly impacted by it.

The term “ally” or “straight ally” identifies a heterosexual, cis-gendered person who supports LGBTQ+ people (GLAAD, n.d.). Grzanka et al. (2015) identified two types of allies: *passive allies* do not take part in organised advocacy campaigns, nor are they members of any formal organisations. They form their identity as an ally based on moral principles of support and respect for all. *Active allies*, on the other hand, are members of pro-LGBTQ+ organisations, and participate in the politics of the LGBTQ+ movement.

This study marks my transition from a (mostly) passive to active ally, one who operates, according to Grzanka et al. (2015, p. 177) “with purposeful and organized efforts to bring about social transformation.” I am hoping, with this study, to contribute to a discussion about much needed changes in healthcare provision to LGBTQ+ teens in New Zealand. My ontological journey has brought me to this point where the ability to make a contribution to social justice and health equity demand that I do so.

This chapter reviews the study’s methodology. The rationale for the study was discussed in the Introduction chapter. The chapter begins with a discussion of the study's epistemology. This is followed by a review of the study's mixed methods design and the rationale for choosing it for this study, which is then followed by a discussion of my positionality. The last part of the chapter is a discussion of the ethical considerations involved in this study.

4.1. Epistemological Framework: Social Constructionism

The study's epistemology is social constructionism. I chose to use individual semi-structured interviews in this study to provide an understanding of the realities constructed and experienced by the participants. These reality constructions are at the heart of social constructionism.

Social constructionism, as defined in Berger and Luckmann's seminal work (1966) posits that our social reality and our identities are constructed through interactions with the world around us, and this constructed reality is steeped in our history and cultural background (Berger & Luckmann, 1966; Burr, 2015). As Cunliffe (2008) points out, today there are various "streams" of social constructionism, and the critical difference among them is the notion of social reality. There are two critical choices researchers may make when deciding on their social construction orientation. One is between subjective reality (the individual creates their own social reality based on interactions with others) vs. intersubjective reality (social reality is created jointly by people interacting with each other). The other critical difference or choice in social constructionism is that of objectified social reality (social reality that has objective parts) vs. realities that are always created by people's interactions with each other (multiple realities). Objectified social reality is the basis of Berger and Luckmann's social construction theory, and the one this study follows. They posit that "the social world is... experienced as being objective in that it affects our lives on an ongoing basis, and we have to go out and learn about it (objectivation)" (Cunliffe, 2008, p. 125). Any regular and predictable interaction between society and an individual -- for example, the repeated, routine measuring one's blood pressure during a medical examination – turns into an objective reality people believe. In this case, the message that becomes objectified is: "blood pressure is a measure of health; it is important." Berger and Luckmann were *not concerned with the objective reality of the physical world around us*, but rather how this world is understood and experienced by humans, individually and as a society. As Andrews points out, much of the criticism of constructionism arises from incorrectly assigning it claims that concern areas beyond our social construction of knowledge of our world (Andrews, 2012, p.40). Lupton (2013) brings high cholesterol as an example – differing levels of cholesterol in the blood is a phenomena that exists objectively. However, the identification and labelling of levels higher than a certain number as "risky" is relatively new – in the past, high cholesterol was not associated with or considered a risk.

A social constructionist epistemology seems at odds with a study containing a quantitative element which is often associated with positivist origins, and this criticism calls to mind the "paradigm wars" that produced the "incompatibility hypothesis" (Doyle et al., 2016) discussed in the next section. My social constructionist leaning is aligned with Berger and Luckmann's concept that reality has objective parts to it, and what is socially constructed is our knowledge around these objective parts (Andrews, 2012; Lupton, 2013). To bridge the gap between the positivist and constructionist views, I brought in multiple perceptions of the same phenomena in the form of open-ended questions in the quantitative part of the study (the online survey). These questions were appended to quantitative questions specifically to understand the participants' construction of their reality around areas such as standards of care and STI risks.

Burr (2015) adds that social constructionism cautions us to look critically at knowledge we often take for granted, bringing sex and gender as one example. As Burr points out, the existence of intersex people and gender affirming surgery means even sex is not biologically set in stone. Rather, our division of the sexes is bound in our socially constructed ideas of gender, in which “men” and “women” are divisions that fit our cultural ideas of masculinity and femininity. Likewise, Burr points out that sexuality is such a deeply divisive issue because the meaning of sexuality in Western culture is tightly connected with society’s social and economic structure (e.g. how many people are available to work, how many children are born and who cares for them).

Spector and Kitsuse (1977) brought social construction into social problems research, defining social problems as distinct from social conditions. Social problems, they stated, are "the activities of individuals or groups making assertions of grievances and claims with respect to some putative conditions” (p.75). This definition, which related social problems to people’s perceptions and actions, rather than to measurable social conditions, opened an entirely new field of social research (Best, 2002).

That gender and sexuality norms are socially constructed ideas is clear when comparing the Western (colonising) society’s view of “sexual and gender minorities” to Indigenous cultures across the globe. In the latter, as Picq and Tikuna (2019) assert, there are no straight sexualities, and no gender binaries. The concepts of sexual and gender identities are a Western invention, and the language used by Indigenous people to describe them defies accurate translation. For example, the idea of *muxes* (third gender among the Zapotec in Mexico) refers to people who are biologically one sex but embody the spirit of a third gender, neither male nor female. In ancient Zapotec society, they were considered a divine blessing (Picq & Tikuna, 2019). This is a similar concept to the Two-Spirit identity in North American Indigenous tribes, who are also neither male nor female. They were also held in high regard, and had special ceremonial duties (Robinson, 2019). Chapter 2 discusses New Zealand’s Takatāpui among Māori, another Indigenous construct (and cultural norm).

Western traditions, meanwhile, not only steadfastly recognised only two sexes, which they equated with genders; they considered anything not conforming to these sexes and their roles as abnormal – a mistake made by nature (similar to how homosexuality was viewed) (Hines, 2020).

The theories I use in this study to analyse the survey and interviews– Social Cognitive Theory and Decompensation (discussed in the next chapter) – also regard social interactions and influences as central in their respective models. Therefore, they align with the epistemological framework of social construction. The decompensation model suggests that societal norms and ideologies are the stressors that lead to a decompensation response in LGBTQ+ individuals. In social constructionist terms, LGBTQ+ teens’ social reality is already constructed around society’s negative language, and the negative attitudes surrounding sexual and gender diversity. As Burr (2015) points out, we use language to label our experiences and make sense of them (Burr, 2015, p. 54), and “the meaning of words is intimately bound up with social practice” (Burr, 2015, p. 55).

Bandura’s self-efficacy construct, the pivotal element in social cognitive theory and the central element in my survey analysis, is largely influenced by social interactions. Of the four ways through which people develop their perceived self-efficacy, two are socially constructed – social modelling and social persuasion. A person’s self-efficacy is affected by the experiences of people they consider important in similar circumstances. Positive experiences related by such people will raise the person’s self-efficacy, while negative ones will lower it. Likewise, verbal feedback from people whose opinion the individual values will have a similar effect on their self-efficacy.

A social constructionist framework is suitable for this study because I wanted to show how LGBTQ+ teens perceive their ability to access healthcare in New Zealand, and how these perceptions affect them. Such perception is borne out of interactions between individuals and their healthcare providers, and these interactions are often influenced by societal norms.

4.2. Statement of Positionality and Reflexivity

> *"Positionality is a positive and integral element of qualitative work because without contextualising the researcher and research environment, often the meaning of any research output is lost."*
>
> *(Jafar, 2018, p. 323)*

The impact of the researcher's own lived experience is as important in a qualitative or mixed method study as that of the participants'. In this study, I sought to expand on the quantitative information gained from my survey, to establish a deeper understanding of the issues found in the numerical data. In doing so, I had to acknowledge that everything from the research questions I posed at the outset of this project to the way I analysed and interpreted the interview transcripts stemmed from assumptions, specific interests, and, possibly, biases I brought with me into the study. This very human "design flow" is common to all qualitative and mixed methods studies. It is the reason a statement of positionality is an essential part of such studies. My positionality impacted my study design, choice of research methods and theoretical frameworks, and the way I interacted with my participants and interpreted their experiences. This section attempts to clarify my own lived experience's effect on my work. I have both personal and professional experiences that influenced this project, and I review them below.

I grew up a child and grandchild of Holocaust survivors, a fact that had always made me acutely alert to social injustice and prejudices. Witnessing racial and ethnic discrimination in the US ceased to be a theoretical problem for me when, during my undergraduate studies, I personally experienced several anti-Semitic incidents. I learned to hide the Jewish part of my identity, and therefore developed a better understanding of the concept of intersectionality, and showing only one's "acceptable persona" to the world. I was privileged, however, in that my Jewish identity was never visible, and it was never such a big part of me that concealing it became a daily struggle. To all outwards appearances I am a white, cis-gendered, heterosexual woman and I enjoy the privileges that come with these societal constructs. Nevertheless, understanding that I can present only the more "acceptable" parts of my identity to society to reduce my risks of experiencing negative reactions set me on the path to understanding, and having an affinity to, social constructionism and later on, the minority stress and decompensation theories.

The original study proposal for this thesis was born out of a combination of two passions of mine: HIV prevention, and the mitigation of healthcare disparities among minority populations. My professional background included working in the HIV prevention clinical studies arena with gay men and transwomen who have sex with men. For many of our studies' participants, taking part in a clinical study was the only chance at regular healthcare, and that is why they enrolled. The fact that so many of them experienced such significant difficulties in accessing healthcare in their daily lives opened my eyes to the realities of healthcare access in the LGBTQ+ populations in the

US. I thought it was worthwhile to see if, despite differences in the health systems and culture, such realities existed in New Zealand as well.

I am aware my work experience led to certain assumptions and biases on my part, though the work I was doing was with an adult population in the US, not a teen population in New Zealand. I had to be careful not to assume that the hostile, homophobic, and transphobic climate of the US was the same one in New Zealand. On the positive side, my work and personal experiences have also given me insights a different researcher may not have had. I understand what it feels like to hide part of your identity for your own safety. I've seen first-hand the struggles of LGBTQ+ to obtain access to standard medical care, and the impact those struggles had on their mental health. I've also heard first-hand accounts of the stigma that burdens so many members of the LGBTQ+ community, and its social consequences. These insights helped me construct the survey and interview questions, and increased my sensitivity to the difficulties faced by members of the LGBTQ+ community. In addition, as discussed in the next paragraph, my work experience allowed me to recognise the complementary roles of quantitative and qualitative research.

My decision to design the study as a mixed methods project stems from a process of professional growth. I come from a background of clinical studies that were all quantitative in nature. Though I have worked with social scientists in the clinical studies arena, their work at that particular time and place was not usually part of the studies themselves, but was often aimed at understanding how to increase participation in our studies by groups who traditionally eschewed participation in clinical trials[16] (see for example Andrasik et al., 2014, and more recently Collins et al., 2018). Their work did

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[16] In the US, these were particularly ethnic minorities

make me realize, however, how the lived experiences of would-be participants (or those refusing to participate) are an important part of the study itself, even in a study that is, by nature, quantitative (such as testing the efficacy of an experimental treatment or vaccine). The beliefs of the participants, and their realities before and during the studies they took part in, often influenced their behaviours during the study, and even whether or not they remained in the study.

Based on these observations of others' work as it intersected with mine, when I was designing my own study I recognized that simply quantifying the presence or absence of a problem as complex as the one I was trying to tackle is not enough. Worse, it does the topic an injustice by skimming the surface but never delving into the details that can tell us what the current system is "getting right" or "doing wrong," from the point of view of the people utilizing it. My decision to design the research as a mixed-methods study stemmed from this realization

A disadvantage for me at the outset of this study was my quantitative orientation and, at the time, a residual bias against qualitative studies (something that still happens often in health sciences; Morse, 2016a). As stated above, I did recognize the necessity of the qualitative approach while designing my study, despite any biases I might still have held. My horizons expanded considerably and my knowledge grew at a very rapid pace since I took a required Qualitative Methods class. I can confidently say at this juncture that any residual bias I held has disappeared, but I recognized my limitations as a beginner qualitative researcher, particularly when it came to conducting interviews. I have tried to overcome this particular deficit by watching focus group discussions and individual interviews that were conducted by Professor Kathleen Quinlivan, my original senior supervisor on this study. I have also read volumes of material regarding the purpose and process of carrying out interviews in a qualitative or mixed-methods study. I definitely feel that my interviews improved the more I did them; they flowed better and I was able to probe participants' answers better, leading to greater nuance in their answers. However, watching examples and reading the theoretical background to interviewing in studies has given me a solid base from which to start.

I also have to acknowledge being what most people would call a "privileged outsider" to the group I was studying – I am older, and part of the "dominant culture" (i.e. the hetero- and cis-normative culture). As Parson (2019) noted, defining the researcher's own identity is the first step to understanding the challenges facing a marginalised population when the researcher comes from a position of privilege. It is followed by understanding how the researcher's identity relates to that of the marginalised group they study. Exploring relatedness instead of differences, as was traditionally the case, allows the researcher to acknowledge the differences (Parson, 2019). To me, exploring the relatedness in order to acknowledge the differences negates the "insider/outsider" view of the researcher's position, and favours the idea of multi-positionality. For example, I can relate, to some degree, to an LGBTQ+ person's need or desire to hide their SGM identity, and the feeling that comes with it. On the other hand, coming from the "dominant culture" and with a healthcare-centred background, my biases – both implicit and explicit -- tend to lie with the familiar constructs that are dominant and accepted in the domains I occupy. For example, the image of a healthcare provider as a knowledgeable expert, which as I came to discover is not always the case when it comes to topics not sufficiently covered in medical school. Being aware of these biases, and remembering my own areas of relatedness to my study population, hopefully allow me to represent their views accurately without silencing their voices (Parson, 2019).

In a study population marked by a power imbalance (by virtue of being teens and SGM), my position could have closed doors for me, rather than encourage openness and participation. These are pitfalls I needed to watch for and continuously evaluate as the study progressed. I made sure to listen to feedback from community members when it was offered, and changed the original language in my survey subtly, based on some of these conversations. The feedback helped me see the dominant conceptual identity assumptions I was still slipping into -- for example, instead of using the term “born male/female,” which implies that trans* people seek to change the way they were born, I started using the term “assigned male/female at birth.” This term acknowledges that a person’s biological characteristics leading to sex assignment at birth are not always in agreement with the gender a person identifies as. Throughout the study, as I read survey responses and talked with my interviewees, I became far more cognizant of, and sensitive to, the issues of identities and the assumptions we make around the ways a person looks and behaves.

A result of being sensitive to community needs as well as input from my supervisors was the expansion of the study population from teens who were assigned male at birth (and an HIV risk focus) to all genders and a broader, safer sex focus. The more I talked to people (academics and community members), and learned about the problem of pathologising the LGBTQ+ community in general, the more I realized that the original study design played into this problem unintentionally. While my original perception of risk was rooted in my HIV Vaccine Trials Network (HVTN) experience, where the emphasis was on individual behaviour (and thus coming from a pathologising viewpoint, and focusing on one high risk group), it has shifted as I was designing the study, reading current literature, and talking to people. As I mention in the Introduction, by the time the study started recruiting, my position was focused on external intersecting factors that caused an increased risk of healthcare disparities in the LGBTQ+ population as a whole. As aligned with a social constructionist point of view articulated by Lupton

(2013), I became increasingly interested in risk as part of my study population's lived experience, and the cultural norms and ideologies that combine to produce the perceived behaviours and consequences our society defines as risk. In other words, my position shifted considerably from a positivist and individualistic view to what Lupton calls "soft constructionism."

From a public health standpoint, limiting the population in this study also did not make sense, as the presence or absence of perceived barriers and enablers to healthcare access should be discussed in the community context, not just as it applies to one part of the community. This expansion was one example of my new-found ability to look beyond my immediate interest, which was HIV-focused. In that respect, my positionality changed. I became more broadly interested and invested in the experiences of the LGBTQ community in the healthcare system in general. This change in positionality also led to a reconstruction of my research questions, since as Jafar (2018, p. 323) points out, "positionality… defines the boundaries within which the research was produced." For example, my sexual health questions expanded beyond the original HIV focus to prevention of STIs in general; the angle from which I perceived these questions also changed, from a focus on personal behaviours and responsibility to more systemic failures that act as barriers to sexual health in the study population. I had also narrowed down my first research question, focusing on interpersonal barriers as my understanding of the topic and its nuances grew.

4.3. Study Design: Mixed Methods

> *"Questions that profit most from a mixed methods design tend to be broad and complex, with multiple facets that may each be best explored by quantitative or qualitative methods."*
>
> *(Tariq & Woodman, 2013, p. 2)*

Mixed methods studies have become more common in health research (Doyle et al., 2016; Tariq & Woodman, 2013). Creswell and Plano Clark (2007) defined mixed methods research as research that “focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or a series of studies” (as cited in Tariq and Woodman, 2013, p.2). Johnson and Onwuegbuzie (2004) referred to mixed methods as “the third research paradigm” (p. 14), sitting on a continuum between the qualitative and quantitative research paradigms. “The goal of mixed methods research is not to replace either of these approaches [qualitative or quantitative],” they declared, “but rather to draw from the strengths and minimize the weaknesses of both in single research studies and across studies” (Johnson & Onwuegbuzie, 2004, pp. 14-15).

Doyle et al. (2016, p. 624) enumerated seven reasons for using mixed methods research; namely: *triangulation* (also known as convergence), where the quantitative and qualitative findings are used to corroborate each other. As Doyle and colleagues point out, triangulation can also be an incidental finding in a mixed methods study that was designed with another reason in mind. *Expansion*, where unexpected findings require explanation by a different method. Alternatively, in a study designed in several phases, the first phase yields results that need explanation or elaboration by a different method. *Exploration*, where an initial phase is used to develop an instrument, a hypothesis, or an intervention that is subsequently tested. *Completeness*, where the topic being studied can be understood more completely by using both quantitative and qualitative methods. *To offset weaknesses*, though Doyle and colleagues caution against using this reason as primary motivation for a mixed method study. Though this reason calls for each method to compensate for weaknesses in the other, the authors point out that when embarking on a study each method should be rigorous enough on its own. *Different* *research questions*, requiring different methods (quantitative or qualitative) to answer them. *Illustration*, in which the qualitative data illuminate the quantitative findings.

I envisioned my study as mixed methods with three of those reasons foremost in my mind (though other reasons remained germane):

Completeness – I realised quantitative data alone will not supply the kind of comprehensive information the addition of the qualitative data will. For example, as more survey data was coming in, there was a seeming lack of connection between having a GP and the participants' sexual health. This was an unexpected pattern in the survey, and it led me to probe deeper in the interviews as to where and how participants received sexual health information and help, and whether they discussed these matters with their GP. The quantitative data alone may have indicated a relationship, but the complexity of this relationship was only unearthed by the qualitative data. Adding these results together supplied the study with a more complete, clearer picture of answering one of the research questions.

Exploration – I wanted the quantitative data to inform the development of interview questions.

Illustration – I wanted the qualitative data to draw a more comprehensive picture, illuminating the quantitative data.

This study is a sequential explanatory mixed methods design (Creswell et al., 2003). In this type of design, a preliminary analysis of the quantitative element informed my qualitative study by indicating areas that needed deeper exploration. This design can lead to lengthy studies if the quantitative and qualitative components are run independently and one after the other (Creswell et al., 2003). However, as Creswell points out, if both the qualitative and quantitative components have equal weight in the study, they need not run completely separately. That is, the quantitative or qualitative phase does not have to be completed before the other phase begins. If the phases overlap to some extent, the length of the study can be shortened. I considered both quantitative and qualitative data to be of equal importance in answering the research questions underlying this study. My study's research questions could have been answered qualitatively or quantitatively, though each method alone would have yielded superficial, incomplete information. Thus, the quantitative part (online survey) ran first until enough responses were collected to yield the foundation for the semi-structured interview questions. For example, the large gap seen in the survey between participants' self-rating of their overall health vs. emotional health led to the addition of interview questions probing how participants' physical vs mental healthcare needs were (or were not) being met (see Appendix E for interview questions). These questions yielded significant data regarding the state of mental healthcare in the study population. The data generated in the interviews were not available through the survey, but the survey data were instrumental in constructing these interview questions.

The complexity of the issues the study examines – interpersonal barriers to accessing and utilising healthcare resources in the LGBTQ+ community, and the sexual health of SGM teens in New Zealand – made the mixed methods approach particularly suitable. As Tariq and Woodman (2013) pointed out, it is the broad, complex, multi-faceted questions that tend to be most suitable for this study design. This is because multifaceted or complex questions rarely if ever have one correct answer. In order to answer a complex question it should be examined from multiple angles, and a mixed method study does just that.

Integration – seeing the big picture that emerges from the study -- is an important concept in a mixed methods study, where multiple types of data are generated. The majority of discussions around integration surround the integration of data (Doyle et al., 2016). However, as both Bryman (2007) and O'Cathain (2010) note, to achieve successful data integration the study must be designed, from the ground up, with data integration in mind. In this study, I wrote the research questions so they would be explored both quantitatively and qualitatively. I had intended, as discussed above, for the mixed methods approach to be used for completeness, illustration, and exploration. Thus, not only were the questions meant to be answered and expanded on in a mixed methods approach, the study was designed so that the quantitative part would lead directly into the qualitative one, by providing the basis for at least some (if not most) of the topics explored in the interviews.

Proponents of both qualitative and quantitative research engaged in a long dispute –the “paradigm wars” – mostly between the 1970s and 1990s (Doyle et al., 2016), This prolonged argument amongst purists on both sides promoted the “incompatibility thesis,” which asserted that the qualitative and quantitative research paradigms, coming from such different world views, cannot be combined. Though mixed methods research proves otherwise, some of the most common criticisms of this paradigm were concerned with the integration of data, and whether mixed methods research is truly mixed methods. Giddings (2006) asserted that much of the research in the health field is in fact underpinned by a postpositivist approach, which marginalises other approaches and reduces the strength of actually combining qualitative and quantitative methods. Furthermore, Giddings argued that the rising popularity of efficient and more generalizable mixed methods research impacted funding preferences, such that qualitative research on its own became even further marginalised. Bryman (2007) points out that data integration is still a weak area of mixed methods research. Most studies, he argues, are written as two separate sets of data – one qualitative and one quantitative. Tariq and Woodman (2013) also discuss the evident difficulties in data integration. They pointed out that conducting mixed methods research properly requires skills in both quantitative and qualitative methods, which often means it requires a team of researchers. Combined with the fact that mixed methods studies are often lengthy, the requirement of multiple researchers adds to the higher cost of a mixed methods study.

4.4. Ethical Considerations

Studies involving human participants are regulated under the broad headline of "human participants' protection." Normally, the principles guiding such protection are those set forth in the Declaration of Helsinki (World Medical Association, 2013). In this study, beyond the overarching theme of "human participants' protection," two specific ethical considerations were pertinent to the study's conduct:

1. The ethics of studies involving participants who are minors; specifically, in this study, the ethics involving waiver of parental consent in such studies.
2. The ethics of doing studies in minority populations; specifically, in this study, the ethics of studies involving LGBTQ+ populations.

4.4.1. Studies Involving Minors – Waiver of Parental Consent

Though not required by New Zealand regulations (Medical Council of New Zealand, 2019), parental consent is normally required by Ethics Committees if participants are under the age of 16 years. Because this study's target population was teens who identify as SGM (or questioning), I felt the requirement of parental consent significantly increased the risk for conflict between parents and teens who are not yet out to their family. This, in turn, increased the risk of harm to the participants, a direct violation of one of the principles in the Declaration of Helsinki. In addition, as I stated in my ethics committee application, enrolling only those who can safely receive parental consent (meaning teens who are out to their families) will seriously undermine the results of the study through an insurmountable selection bias. I therefore requested that the Human Research Ethics Committee at the University of Canterbury grant this study a waiver of the parental consent requirement.

A waiver of parental consent in cases such as this is directly supported by the Council for International Organizations of Medical Sciences (CIOMS), in its 2002 International Ethical Guidelines for Biomedical Research Involving Human Subjects (Commentary on Guideline 14: Research involving children):

> Some studies involve investigation of adolescents’ beliefs and behaviour regarding sexuality or use of recreational drugs; other research addresses domestic violence or child abuse. For studies on these topics, ethical review committees may waive parental permission if, for example, parental knowledge of the subject matter may place the adolescents at some risk of questioning or even intimidation by their parents. (Council for International Organizations of Medical Sciences, 2002)

The council further states that “It may be assumed that children over the age of 12 or 13 years are usually capable of understanding what is necessary to give adequately informed consent” (Council for International Organizations of Medical Sciences, 2002).

The issue of parental consent in adolescent research is of major ethical importance not only due to the potential harm a parental consent requirement can bring to study participants, but also because such a requirement may result in silencing the voices of populations most in need of representation in studies that influence public health policy (Macapagal et al., 2017). For example, in one meta-analysis, Liu et al.

(2017) found that in studies requiring active parental consent, the rates of self-reported substance use were lower, compared to studies with passive consent[17] ($Z = 3.05$). The same meta-analysis also found that ethnic and racial minorities were underrepresented in studies requiring active parental consent ($Z = 2.73$).

The United Nations Convention on the Rights of the Child (CRC) (UNICEF, 1989) states, in article 12(1):

> Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (UNICEF, 1989, Pg.4)

New Zealand ratified the CRC on 6 April, 1993. Some have argued (Hildebrand et al., 2016) that adult gatekeeping of children's access to research (for example, through parental consent requirements) is in contradiction of Article 12 and therefore ethically uncertain at best.

In examining the challenges involved in waiving parental consent for adolescent research, the question is often whether adolescents are competent to give fully informed consent. The Medical Council of New Zealand defines competency in this context as: "Generally, a competent child is one who is able to understand the nature, purpose and possible consequences of the proposed investigation or treatment, as well as the consequences of non-treatment" (Medical Council of New Zealand, 2019, para. 33).

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[17] In active parental consent, parents must consent to their children's trial participation. A passive consent is one where parents can "opt-out" of a study, but otherwise are assumed to have consented to their child's participation.

As noted above, it is CIOMS' determination that adolescents older than 13 years are, in fact, fully capable of giving informed consent. Several studies support this assertion, including Fisher et al. (2016, p. 3), which found that teens aged 14-17 years,

> ...demonstrated understanding of research benefits, medical side effects, confidentiality risks, and random assignment and felt comfortable asking questions and declining participation. Reasoning about participation indicated consideration of health risks and benefits, personal sexual behaviour, ability to take pills every day, logistics, and post-trial access to PrEP [pre-exposure prophylaxis].

The participants referred to in the quote above were enrolled in a study regarding sexual minority teens' attitude towards guardian permission requirements, using a hypothetical HIV prevention trial as an example.

New Zealand law regarding a child's competency to make informed consent decisions has been influenced by the landmark United Kingdom case Gillick vs West Norfolk and Wisbech AHA (van Rooyen et al., 2015), which asserted that a child under 16 years of age can be competent to make informed healthcare decisions. "This case is a clear rejection of the 'status based' approach, where a set age limit dictates the competency of a person," says van Rooyen et al. (2015, p. 91). The case signalled a shift in perception of children (including adolescents) from passive and dependent on parents or the state to active participants capable of making significant decisions affecting their own lives (Powell & Smith, 2009).

It is also noteworthy that countries (including New Zealand) where adolescents are considered competent enough to seek sexual and reproductive health services (including pregnancy termination) without parental knowledge, nonetheless require parental consent for research participation in the same age group. This seeming double standard stems in large part from confusing regulations regarding informed consent in minors, and lack of clarity as to when waiving parental consent is acceptable (Flores et al., 2018; Hildebrand et al., 2016; Powell & Smith, 2009).

One of the three basic tenets of research in humans is respect for persons (Council for International Organizations of Medical Sciences, 2002). Within this principle is the concept of respect for autonomy, which CIOMS defines as the requirement that "those who are capable of deliberation about their personal choices should be treated with respect for their capacity for self-determination" (Council for International Organizations of Medical Sciences, 2002, General Ethical Principles, para. a). As mentioned earlier in this section, CIOMS is of the opinion that children as young as 12 years are capable of such deliberations. The Gillick case, and the studies cited in this section, among others, support this assertion. Therefore, a blanket rejection of waving parental consent cannot be justified by today's Ethics Committees. Rather, cases should be judged objectively and individually, on their own merit.

4.4.2. Studies in LGBTQ+ Populations

Studies in minority populations in general may be difficult. More often than not, minority populations are overwhelmingly underrepresented in research studies (Agodoa et al., 2007; Braunack-Mayer & Gibson, 2017; Kurt et al., 2017). For this reason, community based participatory research (CBPR) is becoming more common as an approach for involving minority or marginalised community members in research. (Collins et al., 2018; Lovell & Rosenberg, 2016). CBPR negates many of the issues discussed below, though it presents several different ethical challenges, such as privacy and confidentiality protection (Collins et al., 2018); it also has the potential to place a considerable burden on the community (Lovell & Rosenberg, 2016). Alternatively, research involving minority or marginalised populations is done by an “insider” researcher – a member of the community. As Harrison and Michelson (2022) assert, such research can get dismissed as “me research” pushing “an agenda.” The consequences can be delegitimisation of research conducted by insiders, and further marginalisation of the group in question. The authors also note that one insider cannot possibly represent the perspectives of an entire group, and therefore “insider research” runs the risk of reification of the group or community the researcher studies. However, when all these potential pitfalls are taken into consideration and minimised during the study design phase, CBPR can be a powerful tool. It is increasingly used in the Māori community in recent years (Oetzel et al., 2020), for example, and its value and importance are recognised in academic circles more and more.

This study is conducted by someone occupying a multi-positionality role, as discussed in my Statement of Positionality, above (see Section 4.2). Harrison and Michelson do call on researchers who are not part of the marginalised community they study to declare their positionality clearly, which I have done in Section 4.2. The discussion below is written from my position as a researcher who is not part of the community, but shares some common ground with members of the community.

Underrepresentation of marginalised communities stems in part from reluctance and mistrust on the part of members of minority groups, due to past incidents of abuse. However, though mistrust is touted as the chief reason for low minority representation, evidence is mounting that the chief reason is that members of minority groups are simply not asked as often as their “dominant culture” peers (Agodoa et al., 2007; Braunack-Mayer & Gibson, 2017; Kurt et al., 2017). Complicating matters is the fact that a history of past abuses led to designating these groups as “vulnerable” in research settings (Rogers & Lange, 2013). This designation has led to an ironic cycle, whereby the extra protections afforded these populations often become a barrier to their participation in research that can improve their wellbeing and make them less vulnerable. This is often the case with LGBTQ+ research (Flores et al., 2018).

The Declaration of Helsinki states, with regards to vulnerable groups:

> Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research. (Vulnerable Groups and Individuals, Guideline 20).

However, there are two major problems with the concept of vulnerable groups as it stands in human research right now. One is that the concept is not well defined. The other, related, problem is that the concept of vulnerability today fails to distinguish different forms of vulnerability (Blair, 2016; Rogers & Lange, 2013). There is vulnerability that comes from diminished capacity to give consent, normally due to cognitive deficits or stage of neurocognitive development (e.g. young children). But there is also the type of vulnerability that comes from a power differential (e.g. incarcerated people who are asked to participate in a clinical study). These vulnerabilities should be approached differently when enrolling participants in research studies, and yet all populations designated as vulnerable are treated the same, and usually as people with diminished capacity (Rogers & Lange, 2013).

For the LGBTQ+ community this type of labelling is doubly bad. It perpetuates the pathologising of the community, a trend that in the past let to practices such as forced castration and involuntary commitment at mental institutions (Blair, 2016). Yet, as

Blair notes, possibly in an effort to make up for the mistakes of the past, ethics bodies across nations, including those in New Zealand, layer so much protection on this population it is nearly impossible to study issues relating to LGBTQ+ people. And this lack of research contributes to keeping the population marginalized (Blair, 2016).

Two major protective measures resulting from the vulnerability label emerge in the study described in this thesis. The refusal of Ethics Committees (or their international equivalents) to waive parental consent in LGBTQ+ adolescent research studies has been frequently cited as a major barrier to studies in these populations, and the reason many researchers will not engage in such studies (Fisher & Mustanski, 2014; Flores et al., 2018; Liu et al., 2017; Macapagal et al., 2017; Shah et al., 2018). Another hurdle ethics committees place in front of researchers is the argument that sexuality or sexual-health-related research will cause such distress in participants that it will actually do harm. Several studies to date (Fisher et al., 2016; Kuyper et al., 2012; Macapagal et al., 2017) show that, by and large, LGBTQ+ adolescents feel as or more comfortable answering these types of research questions as they do talking about sexuality with their healthcare provider. Furthermore, these youths generally did not find the studies any more discomforting than everyday activities, and in fact many of them felt they benefitted from the research by reflecting more on their own sexual risk behaviours or learning facts they had not been aware of (Macapagal et al., 2017). These studies' findings are echoed by Mayo's (2017b) experiences in queer research with youths. Her research participants, she writes, felt that, "parental permission to talk about issues that youth regularly talk about with other adults" was patronizing (pg. 533). In addition, as Mayo (2017a) opines, the protectiveness itself is misplaced. "Youth and researchers alike may also be frustrated by research guidelines that position the research scene as itself the source of risk, rather than understanding that risk is already one part of the LGBTQ experience” (pg. 26). In my study, one objection the Ethics Committee raised to waiving parental consent was the fact that adolescents under 16 years could not waive their own medical confidentiality. The disconcerting part of this objection was that it seems to harken back to the days when being LGBTQ+ was a medical issue (i.e. this population is still pathologised, as mentioned above). Nothing in my research proposal indicated that I was looking for any sort of medical information from my participants. However, my subsequent interactions with the Ethics Committee, and the fact that my request for waiving the parental consent requirement was eventually granted, show that these historical constructs and their legacies can change, given the people involved are made aware of their implicit heteronormative biases and attitudes.

While protection of confidentiality and participants’ identity is an ethical requirement in every study involving human participants, here too I encountered the view of LGBTQ+ youths as needing special protection (and perhaps being of diminished capacity). In critiquing my online advertisement text, the Ethics Committee wrote: “The young men, by clicking the [survey] link in social media will be contributing to dataset about themselves which social media companies will be using. In this case the likely conclusion of that click will be indicate [sic] sexuality. Are you comfortable with that? Participants need to be made fully aware of this possibility.” My text was very similar to an advertisement the Committee approved for roughly the same age range for a study dealing with eating disorders, where the survey link was also in that social media ad. Recent research has shown that adolescents are well-versed in the use of internet and social media (Pacheco & Melhuish, 2018). Unlike forcing participants to out themselves to families if parental consent is required, asking teens to click a link in a social media platform gives them the choice of clicking the link directly or copying it and opening in a different browser, on a different device, from outside the social media app. In the end, the ethics committee (EC) approved the recruitment advertisement as I wrote it, after being presented with the above reasoning.

Another ethical consideration for this study stemmed from my being an “outside” researcher (straight, cisgendered). Despite my best efforts to use inclusive language, a potential participant queried me early in the study about using the term “both genders” in a recruitment advertisement, thus unintentionally ignoring non-binary people. I then changed the term to “all genders” and notified the Ethics Committee. This “heterosexist bias” is something both Bettinger (2010) and Blair (2016) caution against while discussing the ethics of LGBTQ+ research. Clearly, such bias can also seep into the study’s methods or conclusions, and is something to be aware of at all stages of research.

In this study, I respected the participants’ rights, autonomy, and decision making abilities by obtaining a waiver of the parental consent requirements, allowing the participants to make a fully informed and voluntary decision about participating. In addition to obtaining a waiver of parental consent, this study protected the participants’ confidentiality and anonymity in several ways. The online survey was anonymous. Participants wishing to leave their contact information for the voucher draw or interview participation were taken to a different survey that collected this personal information, and was not connected to the main survey. Data (including audio recordings of interviews) were kept online on a secure University of Canterbury server, accessible only by me and my thesis supervisors. Printed data were kept in a locked file cabinet accessible only by me. Interviewees’ identities were concealed by fictitious initials in all publications, including this thesis.

4.5. Ethical Approval

Ethical approval for this study, including a waiver of the parental consent requirement, was received from the University of Canterbury's Human Ethics Committee (HEC) on December 17, 2018. HEC ref # 2018/109. The approval letter is enclosed as Appendix A.

Māori consultation, beyond the initial proposal filing with the Ngāi Tahu Consultation and Engagement Group, was deemed unnecessary by the Ngāi Tahu group. This was partly because I did not intend to specifically recruit Māori adolescents, I was recruiting across the entire population of New Zealand adolescents, regardless of ethnicity. In addition, my application demonstrated an awareness of bicultural requirements and an understanding of Māori traditions, such as whanaungatanga – the building of relationships that took place at the start of interviews. Though I did not have Māori interviewees, I did start each interview by describing my background in depth and what led me to where I am today. This was a way of creating familiarity with all of my interviewees, before encouraging them to introduce themselves. This in depth introduction would have been the first step in whanaungatanga in an interview with a Māori participant.

The Māori Consultation response from the Ngāi Tahu Consultation and Engagement Group is included as Appendix B.

4.6. Summary

This chapter outlined the study's social constructionist epistemology, and its sequential explanatory mixed methods design. In my positionality statement I traced the roots of the study and the changes in my perceptions and attitudes that have taken place before and throughout this study. The chapter also examined the complex ethical considerations in conducting this type of research in minors belonging to a marginalised population.

The next chapter will discuss the theories that served as a lens through which I examined the quantitative and qualitative results in this study – Decompensation and Social Cognitive Theory.

Chapter 5. Minority Stress, Decompensation, and Social Cognitive Theories

> *"The individual who must hide of necessity learns to interact on the basis of deceit governed by fear of discovery…"*
>
> *(Hetrick & Martin, 1987, p. 36)*

5.1. Introduction

The high rates of mental health problems in LGBTQ+ individuals are attributed to stress resulting from living as marginalised people in societies with varying degrees of tolerance for people who deviate from the norm.

To analyse the results in this study I needed to construct a hypothetical model that incorporated the mental processes resulting from the stress of "othering," and what may drive this study cohort to respond to stress (perceived or anticipated) the way they do. To develop this model I turned first to two well-established theories – minority stress and social cognitive theory. While delving deeper into the minority stress theory, I was acquainted with the Decompensation model, which I found more fitting, for reasons discussed below.

This chapter discusses the Minority Stress theory first, not only because the model is of major importance in LGBTQ+ research, but mainly because its foundational assumptions serve as the basis for the decompensation model. The chapter moves on to discuss decompensation, and concludes with a discussion of Bandura's SCT and the self-efficacy concept, which is essential to the model developed for this study. The Communication – Self-efficacy – Sexual Health model itself is illustrated in Figure 7.1, and discussed in depth in Section 9.2.

5.2. Minority Stress

Minority stress is defined by Meyer as “psychosocial stress derived from minority status” (Meyer, 1995, p. 38). The concept has become a cornerstone in the study of SGM population health.

Meyer goes on to explain that minority stress is not just the result of negative stressful events in the life of the person experiencing it. Rather, it is “the totality of the minority person’s experience in dominant society” (Meyer, 1995; p. 39). In 2003, Meyer elaborated on his model, noting that it is inferred from several theories in sociology and social psychology. These theories, Meyer explained, discuss “the adverse effect of social conditions, such as prejudice and stigma, on the lives of the affected individuals and groups” (Meyer, 2003, p. 675). Ironically, as Riggs and Treharne point out, Meyer’s minority stress model positions the individual at its centre, ignoring the role of social conditions (i.e. norms and ideologies) in stressing that individual (Riggs & Treharne, 2017).

In his 1995 model, Meyer suggests there are three processes that can contribute to minority stress: internalized homophobia, perceived stigma, and concrete prejudicial events (Meyer, 1995). Internalized homophobia, according to Meyer, is the application of society’s negative labels and attitudes towards sexually- and gender-diverse people to the self. Meyer points out that children grow up hearing these negative messages even before they understand their own sexuality or gender identity. When they do realize they fit into one of the minority labels (e.g. gay, lesbian, trans*) they apply the negative attitudes and labels they grew up with to themselves (Meyer, 1995).

The process of internalized homophobia is bound in the use of language and the messages words convey. Several studies, for example, Russell et al. (2018), Ryan et al.

(2010), and Poštuvan et al. (2019) support this assertion, showing that accepting and acknowledging a young person's sexual and gender identities lead to improved mental health and self-esteem. Russel, for example, showed that simply using a trans* teen's chosen name "was associated with lower depression, suicidal ideation, and suicidal behaviour" (Russell et al., 2018, p. 503).

Perceived stigma and internalized homophobia are somewhat overlapping processes. The stigmatized individual, Meyer notes, understands that they will never be treated as equal by the "dominant culture." The negative attitudes of society – the stigma that accompanies the labels "sexual minority" and "gender-diverse" (and related labels) – provoke, according to Meyer, an anxiety in the stigmatized people at every encounter with new people, and a state of constant vigilance. By vigilance, Meyer means the "expectations of rejection, discrimination, and violence" (Meyer, 1995; p. 41). Vigilance is a constant stressful state, leading to "fear and mistrust in interactions with the dominant culture" (Meyer, 1995; p. 41). The stress of the perceived need for constant vigilance leads to the development of coping mechanisms, which in adolescents is often in the form of hiding their stigmatized identity (i.e. living "in the closet") (Meyer, 1995; Meyer, 2003; Stevens, 2013). During Meyer's initial study, stigma and discrimination against gay men were heightened due to the AIDS epidemic, and anti-gay violence was on the rise for the same reason (Greer, 1986), increasing both stress and the need to be vigilant.

Meyer's concept of the minority individual's response to negative social attitudes and acts (e.g. stigma, discrimination) directly relies upon societal reaction theory (Meyer, 1995, p. 39). According to this theory, negative societal reaction to straying from the "norm" (e.g. the dominant heteronormative culture) leads to the development of responses, some of which are maladaptive and can include symptoms of poor mental health (Meyer, 1995). The societal reaction model "views deviance as a product of the social interaction between individuals and various types of audiences, such as peer groups, anonymous onlookers, and representatives of formal social control organizations (Grattet, 2011, p. 186).

Meyer studied the effects of each minority stress process on the mental health of gay men, concentrating on five indicators of psychological distress: demoralization, guilt, suicide (ideation and behaviour), sex problems, and AIDS-related traumatic stress response (Meyer, 1995). He enrolled gay men in NYC in a longitudinal study in 1985. The original purpose of the study was to investigate the impact of the AIDS epidemic on the psychology and behaviour of men who did not have an AIDS diagnosis. Recruitment was done through random sampling of members of 100 gay organizations (39% of participants), and through snowballing with men not belonging to these organizations (61% of participants).

Meyer and his colleagues found that, whether measured independently or as a group, the three stressors (internalized homophobia, perceived stigma, and prejudicial events) were associated with significantly increased psychological distress in this population. Men who reported high minority stress (as measured by the three stressors) were 2-3 times more likely to have reported “high” or “very high” distress levels, compared with their peers who experienced lower levels of minority stress (Meyer, 1995).

The study featured robust recruiting that resulted in a sample that Meyer felt was representative of the urban gay population makeup of major US cities (Meyer, 1995). It did, however, enrol people for a very specific purpose – to study the effects of AIDS on the population of those not afflicted by the disease. It was conducted when AIDS was decimating gay populations in urban centres in the US, especially NYC and San Francisco. Accounts of the early years of the AIDS pandemic can be found in the classic

And the Band Played On (Shilts, 1987), *Replacing Citizenship* by Brown (1997), and the excellent documentary *We Were Here* (Weissman & Weber, 2011). The impact on the survivors (poignantly expressed in *We Were Here*) cannot be overemphasized. It would be fair, then, to question the applicability of the study to today's sexual and gender minority populations, particularly the younger generation who grew up with HIV as a chronic but manageable infection, and can now protect themselves not only with condoms but with pre-exposure prophylaxis (PrEP) as well.

Meyer expanded and refined his minority stress model in 2003 (Meyer, 2003). He outlined the underlying assumptions regarding the concept, positing that minority stress has three characteristics:

1. It is unique. That means this stress comes in addition to, or on top of, stressors that all people experience as part of their lives. As a result, Meyer reflects, "stigmatized people are required an adaptation effort above that required of similar others who are not stigmatized" (Meyer, 2003, p. 676).
2. It is chronic.
3. It is social. Minority stress stems from social norms, unlike everyday stressors that stem, for example, from singular events or a person's health.

More significantly, Meyer suggested minority stress exists along a continuum of distal to proximal. Stress stemming from lived experiences (suffering acts of discrimination, experiencing threats of violence based on one's LGBTQ+ status, etc.) is distal. The individual's response to these events – their perception and interpretation of them – is proximal stress (Meyer, 2003). Distal stress is not tied into the person's personal identification. Someone can suffer discrimination or threats of violence simply because they are assumed to be LGBTQ+ (Meyer, 2003). Relating back to Meyer's 1995 model, concrete prejudicial events would be distal stressors, while perceived stigma and internalized homophobia proximal.

Meyer and colleagues later went on to study the effects of minority stress on the physical health of lesbian, gay, and bisexual (LGB) adults. They were interviewed as part of Meyer's 'Project Stride', a study looking at "identity, stress, and health among sexual minority individuals" in New York City (Frost et al., 2015). Participants were interviewed at baseline and at a one-year follow-up. Measures assessing experiences perceived by the participants to be minority stress related, such as everyday discrimination, were used alongside measures that used a standardised definition of minority stress events (see Frost et al. (2015) for a discussion of their methods and analysis).

The study found that those participants who experienced a prejudicial event (independently rated) were statistically significantly more likely to experience a physical health problem within a year of the event. This association remained after adjusting for normal (non-prejudicial) stressful life events (Frost et al., 2015).

The study gave further credence to the minority stress model, but there may be some questions as to the applicability of this model across a wider range of demographics, including rural residents and younger teens (under 18 years of age). Sexual minority teens are at heightened risk for adverse mental and physical health events, compared with their peers who are solely attracted to the opposite sex (Alpert et al., 2017; Hoffman et al., 2009; Lucassen et al., 2015; Stevens, 2013). While in the past such disparities were attributed to the individuals themselves (i.e. the result of their "deviant" sexual behaviour or gender diversity), research has shown that these disparities can be attributed in large part to the stress of being part of a minority group that is often victimised in its various facets.

5.3. Decompensation

Meyer's model came under criticism by Riggs and Treharne (2017). While agreeing in principle with the concept of minority stress, the authors felt Meyer's emphasis on the individual's perception and response to stress ignores the workings of modern society – specifically, the concepts of ideology, norms, and privilege – and thus misses important opportunities to address issues of intersectionality and the consequences of marginalisation. Riggs and Treharne refer to a "stressed minority," rather than minority stress, to show that their model emphasises the stress exerted by society on the individual.

> When living in a society where particular ideologies serve to marginalize certain groups of people, such groups are continually required to compensate for the wrongdoings, injuries, or harms enacted against them. When discrimination is enshrined in public institutions, thus authorizing the actions of individuals, for many people finding ways to compensate for discrimination is a daily requirement… "Just getting out of bed is a revolutionary act." (Riggs & Treharne, 2017, p. 600)

Riggs and Treharne offer a model based on a decompensation framework. From the outset, they clarify that though the term decompensation is often used in a pathologising manner, it is not the way their model treats the decompensation phenomenon (Riggs & Treharne, 2017). Rather, they use the term to signify a state of accumulated societal stress that has overwhelmed the individual's ability to compensate for it and keep functioning. This accumulated stress comes from discrimination against different identities of the same individual (e.g. sexual, ethnic, gender, class). Decompensation results in the mental and physical effects that also feature in Meyer's minority stress model. What Meyer's model neglects, according to Riggs and Treharne, is the "institutionalized nature of stress" (Riggs & Treharne, 2017, p. 596).

Riggs and Treharne speak of norms, particularly those concerning identity (e.g. race, sexuality, gender, etc.) that when institutionalised become ideologies through which society at large judges an individual's humanity, their "right" to belong in that society. Like institutionalised racism, these ideologies, then, become institutionalised sources of stress for those that do not fit within their parameters (e.g. a gay man in a heteronormative society). Riggs and Treharne also take care to point out that not one ideology stands alone in the effect it exerts on people. The concept of intersectionality[18], where minority stress falls short, is incorporated into the decompensation model. The intersectionality concept is important in this study since LGBTQ+ teens are, first and foremost, teens. As discussed in earlier chapters, adolescence is a fraught developmental stage that confers its own stresses on an individual. These stresses must be acknowledged as additional stressors affecting an LGBTQ+ teen.

The differences between the decompensation and minority stress models are illustrated in Figure 5.1. In this figure, the supportive surface is the individual. Meyer's minority stress model concentrates on stress as subjective. The individual's response to perceived stressors produces ill effects. Riggs and Treharne look at stress as part of living in modern societies that set norms (that can become ideologies) people are expected to conform to. Norms are a source of stress even for people who by and large conform to them. Conforming to these norms (or at least some of them) confers privileges that act as protective factors. This way of framing stress and privilege allows for consideration of intersectionality, as discussed above. It recognises that a Pākehā

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[18] Intersectionality refers to the way different features of a person's identity may expose them to overlapping types of discrimination.

gay man is not going to have the same stress experience as a Māori gay man (who has less privileges[19] than a Pākehā man) for example, and thus their stress levels, and their need to compensate, will be different.

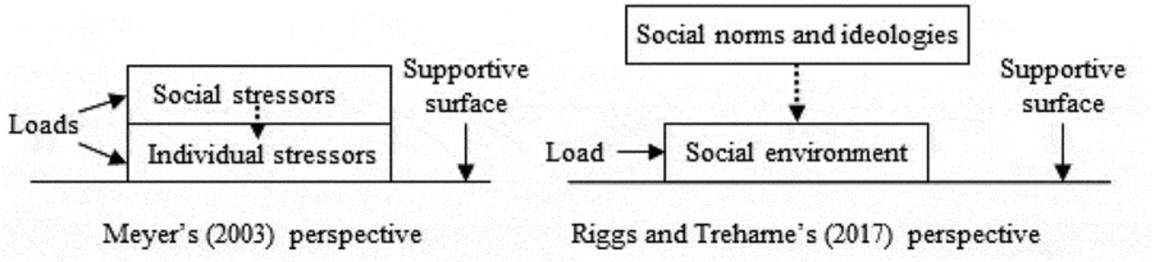

Figure 5.1 Minority stress vs decompensation. Dashed line indicates a mediation or influential effect. Reprinted with permission from Tan, K. K. H., Treharne, G. J., Ellis, S. J., Schmidt, J. M., & Veale, J. F. (2020). Gender Minority Stress: A Critical Review. Journal of Homosexuality, 67(10), 1471-1489. http://www.tandfonline.com/.

Riggs and Treharne tested their decompensation theoretical framework in a study that focused on the mental health of adult trans* people in Australia (Riggs et al., 2015). Specifically, they examined the effect of perceived cisgenderism on the individuals' mental health, through the decompensation lens. Cisgenderism was defined as "the ideology that delegitimises people's own understanding of their genders and bodies" (Riggs et al., 2015, p. 34). This is usually done through pathologising (e.g. treating people's body and gender perceptions as a pathology, if it differs from their assigned sex), and misgendering (e.g. consistently referring to a person by their given, not chosen, name; referring to their assigned sex rather than their self-identified gender) (Riggs et al., 2015). As Riggs and colleagues pointed out, based on a review of existing research in Australia, cisgenderism can affect any aspect of a person's life – from access to hormones and gender affirming surgery to interactions with strangers. Their

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[19] Riggs and Treharne (2017) define privilege as the automatic benefits bestowed on members of a dominant group at the expense of those who are not members of this group (p.598).

study applied their decompensation model to data collected in an earlier study. For this secondary analysis, participants were divided into two age groups – “young adults” and “adults.” (Riggs et al., 2015).

The authors found that, compared with the “adults” group, the “young adult” group was more concerned with other people’s perception of them, less likely to have had gender-affirming surgery, and less satisfied with services received from psychologists or psychiatrists. There was an overall negative relationship between participants’ “concern with other people’s perception” and their mental health ($r = -.37$, $p < .05$) (Riggs, et al., 2015, p. 36). The authors’ analyses showed the impact of cisgenderism varied with age, and likely resulted in lower access to gender affirming surgery in the younger group (i.e. people in the younger age group were less likely to have had gender affirming surgery, but more likely to want it). This lower access to gender affirming surgery led to misgendering of the younger participants that, in turn, rendered the them more vulnerable to decompensation, according to the model. Participants in the younger age group did report worse mental health than the older participants ($t = 4.930$, $p < .1$) (Riggs et al., 2015, p.36).

Additionally, the authors found an overall positive correlation between a sense of being connected to the community and the participants’ mental health ($r = .320$, $p < .001$), and between age and a sense of being connected to the community ($r = .259$, $p < .01$) (Riggs et al., 2015, p.36). The authors point out that these findings suggest younger participants benefited less from the protective factors that community connectedness offers trans* individuals (Riggs et al., 2015).

A study that was done to support the minority stress concept also supports the decompensation theory. Almeida and colleagues (Almeida et al., 2009), studied the effects of perceived sexuality-based discrimination on emotional distress in LGBT teens.

Participants were US high school students in grades 9-12 (age range: 13-19 years old) from Boston, Massachusetts. The sample included both heterosexual, cis-gendered students and sexually/gender-diverse students. The study sample came from a random sampling of the Boston Youth Survey (BYS) 2006, an anonymous paper survey that included the Modified Depression Scale (MDS) (Dahlberg et al., 2005) to assess depressive symptoms in participants. The MDS, a short version of the DSM Scale for Depression (which is aimed specifically at adolescents), measures depressive symptoms occurring during the 30 days prior to filling the scale (Kelder et al., 2001). The study only included data from students who answered the BYS questions about sexual orientation, depressive symptoms, and prejudice.

Their results show that when there was no perceived homophobic discrimination, the rates of depressive symptoms were similar between heterosexual, cis-gendered teens and LGBT teens. However, LGBT adolescent males scored higher on the depressive symptoms instrument than their heterosexual, cis-gendered counterparts when faced with homophobia-based discrimination. Youth who reported perceived homophobia-based discriminations also had significantly higher rates of self-harm (25.0% vs. 6.3%, *p*-value not supplied) and suicidal ideation (23.9% vs. 7.4%, *p*-value not supplied), compared to those not reporting such incidents. Sexual minority youth were also much more likely to perceive discrimination based on their sexual orientation compared with their heterosexual peers (33.7% vs. 4.3%, $p < .0001$) (Almeida et al., 2009).

The study supports the decompensation theory by showing that the added stressors (homophobic discrimination) resulting from a heterosexist ideology caused an increase in decompensation responses (depressive symptoms, self-harm). In the absence of these additional symptoms, no differences were noted in the mental wellbeing of LGBT and heterosexual youths. As with the Meyer studies, this study is representative of a specific urban community, and there is no telling how a more rural community (or urban centres elsewhere) would compare. It is a valuable study in that it demonstrates the experience of LGBTQ+ youth in an everyday environment. The Almeida study also supports an underlying assumption in my study, that health disparities between cis-gendered heterosexual youth and sexual/gender minority youth are associated with life circumstance (such as decompensation), rather than from any pathology inherent in the SGM population itself.

The minority stress model was based on sexual minorities and later applied in populations of gender minority study participants. The foundations of this model, which are common to the decompensation theory as well, show a connection between one's status as part of a marginalised community and their state of mental and/or physical health. Moreover, both models, which are two perspectives of the same construct, show there is no inherent pathology in an LGBTQ+ individual. It is this assertion, and the volume of studies showing its fit with existing evidence, that have made minority stress such a cornerstone concept in studies of LGBTQ+ populations.

I find the decompensation model more complete, as it takes into account the totality of the individual's lived experiences, not just their (separate) sexual and gender identity. Studies employing minority stress normally have to add on intersectionality frameworks to allow research on SGM combined (Williams et al., 2020) or LGBTQ+ people of colour (Schmitz et al., 2020). Decompensation allows for intersectionality to come into play as part of the model. As Mayo pointed out,

> …maintaining an intersectional focus not only opens our research to more possibilities, it also reminds us that we cannot centralize queerness without focusing on race, gender, ethnicity, age, and a whole array of other aspects

> of identity. Indeed queerness ought to resist the center. (Mayo, 2007, p. 71).

Importantly, as Rodriguez-Seijas and colleagues found, "…failure to attend to diversity *within* marginalized groups can obscure important mental health distinctions among individuals with multiple marginalized identities" (Rodriguez-Seijas et al., 2019, p. 326). Such failure can also mask difficulties beyond mental health issues. For example, in recent analyses of the Youth19 survey (Clark & Fleming, 2020), LGBTQ+ Māori youth were less likely to feel part of school (72%) than their Pākehā LGBTQ+ peers (78%) or non-LGBTQ+ Maori peers (85%). Fewer Maori LGBTQ+ youth felt safe at school (69%) than either their Pākehā LGBTQ+ peers (78%) or their non-LGBTQ+ Maori peers (85%) (Clark & Fleming, 2020).

Failure to consider intersectionality can also mask protective factors that may play a part in an individual's reaction to being marginalized or stigmatized. For instance, while fewer LGBTQ+ Pasifika[20] teens felt safe at school than their Pākehā LGBTQ+ peers (76% vs. 79%, respectively), more of them felt part of school (85%) then their Pākehā LGBTQ+ peers (78%) (Clark & Fleming, 2020). Such discrepancies, as both Meyer (2003) and Rodriguez-Seijas (2019) pointed out, merit further research and prove that "…important nuance… can be overlooked without careful consideration of multiple forms of marginalization and their joint associations with mental health" (Rodriguez-Seijas et al., 2019, p.326).

The decompensation model fits well within the social constructionism framework anchoring this research (see Section 4.1). Social constructionism, as defined in Berger and Luckmann's seminal work (Berger & Luckmann, 1966) posits that our social reality

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[20] Pasifika refers to people living in New Zealand and identifying as ethnically belonging to other Pacific islands, including Samoa, Cook Islands, Tonga, Niue, Tokelau, and Fiji.

and our identities are constructed through interactions with the world around us, and this constructed reality is steeped in our history and cultural background (Berger & Luckmann, 1966; Burr, 2015). Riggs and Treharne base their model on institutionalised cultural norms that construct the notion of what it means to be fully human in a given society. Their premise is that decompensation is a response to stress produced by living in a social environment and interacting with it.

5.4. Social Cognitive Theory

SCT is a theory of behaviour control and regulation, developed by Albert Bandura. SCT is widely used as the basis of health promotion campaigns, due to its emphasis on the social environment as a conduit of learned behaviour (LaMorte, 2019). Additionally, SCT looks at how behaviour is acquired and maintained long-term, another factor that makes it particularly popular with studies that attempt to change unhealthy behaviours into healthier ones.

The theory was first known as the Social Learning Theory (SLT), and its core principle was that learning is a social endeavour, done through interactions between the person, their social environment, and their behaviour. When SLT evolved into SCT, Bandura added the concept of self-efficacy – the sense of mastery one feels over a task or behaviour (LaMorte, 2019). SCT places a strong emphasis on the role social reinforcement plays in learning and modifying behaviours. As such, SCT aligns with Berger and Luckmann’s (1966) social constructionist perspective of a person as a product of their social environment. Bandura, however, embraces a more constructivist viewpoint. His concentration is on a person’s construction of knowledge within themselves, rather than the constructionist concentration on knowledge construction through language and conversation. As with social constructionism, however, SCT holds that people actively create their own meanings and experiences (Schwarzer & Luszczynska, 2005). In the realm of health behaviours, SCT posits that cognition, behaviour, and environmental factors interact and reinforce one another to influence health behaviour (Biello et al., 2019).

At the centre of SCT is the concept of self-efficacy, or one's sense of control over a situation. Higher self-efficacy means a person is surer of their ability to perform a task or achieve a desired outcome. Bandura considers self-efficacy central to the concept of personal agency, which contributes to a person's wellbeing and overall functioning.

Self-efficacy is constructed from four sources, according to Bandura: *experiences*, such as skills mastery. Additionally, self-efficacy is influenced by *social interactions*, including other people's recounting of experiences in similar situations, or verbal feedback from peers (Bandura, 2010). Thus, anecdotes of discrimination in healthcare settings told to a sexual minority teen by their peers may lead to lower self-efficacy around being open with a healthcare provider around the teen's sexuality.

The third source of self-efficacy is *social modelling* – seeing peers similar to oneself succeed will encourage a person to believe in their own abilities in a given task or situation. The fourth source impacting self-efficacy is one's *physical and emotional state*. A person is more likely to feel in control and believe in their abilities if their physical and emotional wellbeing are strong.

The survey instrument contained questions assessing the participants' self-efficacy around the areas of coming out to their healthcare provider and condom use.

Sexual minorities experience stigma and discrimination on a regular basis, as discussed previously. Almeida and colleagues (2009) showed in a Boston, Massachusetts (US) study that perceived discrimination in LGBTQ youth (age range: 13-

19 years) correlated with increased depressive symptoms, increased risk of self-harm, and increased suicide ideation. I investigate whether previous experiences with stigma and discrimination, as well as peers' experiences, lead LGBTQ+ teens to anticipate the same in the healthcare setting. This, in the social constructionism sense, may be a perceived barrier to accessing and utilizing healthcare resources. According to SCT, teens who do not feel empowered to handle possible negative reactions from their healthcare provider are considered to have low self-efficacy around coming out to their provider are more likely to avoid getting regular healthcare, or avoid coming out to their providers. They, therefore, may be missing opportunities to address health concerns, particularly those specific to LGBTQ+ teens.

Avoiding healthcare utilisation can lead to increased risk of STIs, including HIV, in several ways. Without regular check-ups or disclosure of unprotected anal intercourse, PrEP is not an option for these teens – taking the medication requires regular check-ups (Centers for Disease Control and Prevention, 2014; Akira LeFevre, New Zealand AIDS Foundation [NZAF], personal communication). However, there is a very real possibility that the lack of regular contact with a healthcare provider will also lead to low efficacy around the use of condoms. This might happen because teens are getting the message from peers or significant others that condoms are unnecessary or "not cool" (Brafford & Beck, 1991). It may also happen because they are not sure how and when to use one correctly (Brafford & Beck, 1991). They may be unsure how to start a conversation about condom use with a potential sex partner, or they may be having sex while under the influence and don't feel they can use a condom under these circumstances (Brafford & Beck, 1991). While the reasons are plentiful, the result is low self-efficacy and therefore, according to SCT, there will be a lack of motivation to engage in condom use. An honest, open, and supportive relationship with a healthcare provider can increase the self-efficacy of LGBTQ+ teens around condom use. Therefore, the study also asks whether perceived barriers to healthcare access will have an impact on sexual risk behaviour

5.5. Summary

The decompensation model is a newer concept in LGBTQ+ studies. Like the minority stress model, decompensation is predicated on the concept that the increased rate of adverse mental health events in the LGBTQ+ population is due to societal stressors, not an inborn pathology in LGBTQ+ individuals. Unlike minority stress, decompensation incorporates intersectionality and the concept of privilege into the model, accounting for additive stressors and the protective effects that can come from partly belonging to a “dominant” group. As such, decompensation goes a long way towards “de-pathologising” the LGBTQ+ community. This assertion also underlies this study. Because it fits Berger and Luckmann’s social construction model and incorporates important elements missing in the minority stress model, I find it more robust and useful than the minority stress model.

Chapter 6. Methods

This section discusses the data collection methods for the quantitative (survey) and qualitative (interviews) parts of the study.

6.1. Quantitative Methods

This section introduces the survey instrument used in this study. The discussion starts with a review of the sampling method and recruitment procedure, and then turns to a detailed review of the different parts of the survey. Discussion of the statistical and content analyses of the survey follow. Survey results will be discussed in the next chapter. The survey itself is enclosed as Appendix D.

The aims of the survey were to investigate the study population’s perceptions of their relationships with their healthcare provider (primarily GP), and their concerns around these relationships in the context of their gender and sexual identities. The survey also aimed to assess the respondents’ sexual risk behaviour and knowledge. The ultimate goal of the survey was to investigate whether this population’s relationships with healthcare providers impacted in any way their sexual risk behaviour or knowledge around sexual risk. This study sought to examine how the study population perceived their relationship with their healthcare provider, and whether such perceptions impacted the study population’s sexual health. The study did not consider specific interventions GPs could apply to address sexual risk behaviours.

Technology occupies a very large part of New Zealand teens’ lives (Pacheco & Melhuish, 2018). Furthermore, teens use multiple devices to go online. Pacheco and Melhuish (2018) found in their study that 59% of their respondents used three or more devices to go online, while the remaining 41% used one or two devices. And while internet access may vary along socioeconomic and ethnic lines, a report by the MOSH social media company found that as of February 29, 2020, 93% of New Zealand households had internet access (MOSH Social Media Limited, 2020).

Social research is increasingly making use of online platforms to conduct research (Chandler et al., 2019; Willis, 2012). In recent years, despite criticisms of potential pitfalls associated with online research (discussed more in depth in the *Limitations* section of the Discussion chapter), the advantages of online research when it comes to engaging marginalised populations (such as the LGBTQ+ population) have become clearer, and this platform is used more frequently in studying marginalised populations (McInroy, 2016). As Willis noted, “The use of online research methods is an ethical strategy for amplifying the voices of young LGBTQ people as a hidden population” (Willis, 2012, p. 143).

Online surveys can offer anonymity, which is an attractive feature for stigmatized youth who may choose not to participate in “traditional” surveys, especially if they are not out to family and friends (McInroy, 2016; Mustanski, 2001; Willis, 2012). Being able to take the survey at a place and time of their choosing, on a device of their choosing, affords participants an increased sense of autonomy, which may also encourage greater honesty (McInroy, 2016; Mustanski, 2001). The promise of anonymity may also reduce the possibility of “answering to please” and the natural inhibition that prevents people from divulging sensitive personal information (McInroy, 2016; Mustanski, 2001; Willis, 2012). In addition, online surveys can reach a diverse and geographically dispersed population easily and at no additional costs to the researcher (McInroy, 2016; Mustanski, 2001).

The survey was built in QualtricsXM (Provo, Utah, US), a survey management software owned by SAP (Germany). Qualtrics is required by the University of Canterbury for all research surveys deployed by the University's staff and students, if they survey other UC students or staff. As it was reasonable to expect this study would include participants from UC, and the University also supports this tool, it was the logical choice. Qualtrics has strong security features that include data encryption and continuous network monitoring. It also has an easy user interface, using drag and drop elements for building the survey, and allows a combination of different question and answer types in one survey. This is important because it allowed for open-ended fields to be incorporated into several multiple-choice questions, thus enabling participants to elaborate on their choices.

The questions in this survey were developed specifically for this study, with the exception of the Condom Self-efficacy questions discussed in Section 6.8. The questions sought to probe the perceived patient-provider relationship from the patients' (participants') point of view, and to asses specific sexual health domains (e.g. condom use, STI testing) in this population.

Scales that may have been appropriate for this study were not validated in a New Zealand population, which has unique diverse features. Even the Condom Self-Efficacy Scale used in this study was validated only in university students in the US. However, given my lack of experience probing self-efficacy, it was more appropriate to start with a source constructed specifically for that purpose.

6.2. Sampling Method

The study used convenience sampling. Though often criticised for its lack of generalizability, this sampling method is often used in developmental science (Jager et al., 2017). The target population was, at the start of this study, both very narrow and hard to reach (teens assigned male at birth identifying as sexual and/or gender minority).

Recruitment in schools was ruled out by the Ethics Committee (due to the waiver of parental consent granted to this study). Convenience sampling was the most efficient and financially feasible recruitment option.

6.3. Survey Participants' Recruitment

Recruitment began in January 2019 and ran through January 2021. While the survey closed in April 2020, recruitment for interviewees continued.

A study web site (https://www.teenhealthcareaccess.com/, hosted on the Wix blogging platform) was set up and connected to a Facebook study page. Posts on the Wix site were shared and periodically promoted through Facebook (examples of recruitment posts are in Appendix G In addition, flyers (see Appendix F) were sent to YOSSs around New Zealand. Flyers were also distributed through Qtopia in Christchurch, InsideOUT in the Wellington area, RainbowYOUTH in the Auckland area, and the local office of the New Zealand AIDS Foundation in Christchurch. Depending on the organisation's policy, the flyers were either hung on the walls in the reception area, or distributed to individuals who came to group meetings. I sent out a combination of tear-away and stand-alone flyers, to allow each organisation to determine their own distribution methods. Study information was also sent to Facebook pages of New Zealand universities' queer organizations (e.g. Q Canterbury, UniQ Auckland). A total of 310 usable surveys were obtained in this fashion.

6.4. Demographics

The inclusion criteria for the study were:

- Aged 15-19 years at the time of completing the survey;
- Identifying as LGBTQ+ (excluding asexual individuals); and

- Living in New Zealand.

The Year of Birth question was used to determine age eligibility. Participant's internet protocol (IP) address was used to determine New Zealand residency. Thus, surveys with IP addresses that were outside New Zealand were deemed invalid and excluded from the results. This may have excluded New Zealanders who completed the survey while traveling to another country. However, there was no other way to validate New Zealand residence in an anonymous survey.

Information was also collected on the participants' region, ethnicity and family income. Both ethnicity and income categories were derived from the New Zealand Census.

6.5. Sexual and Gender Identity

Participants were asked what their gender was to establish their gender identity, and what sex they were assigned at birth. This two-step method of establishing gender identity as separate from sex assigned at birth has been recommended in the literature and well received by survey respondents, especially when the target population is strictly LGBTQ+ (Lombardi & Banik, 2016; Pinto et al., 2019). Participants were then asked what their sexual orientation was. Gender and sexual identity options available to the participants can be found in the survey (Appendix D). These options are some of the common answers that appear in the literature (for a summary table of examples see (Suen et al., 2020, pp. 2304-2305).

As the study was to include questions on sexual risk behaviours, the decision was made during the study design phase to exclude those identifying as asexual from the study. People identifying as asexual experience "a lack of sexual attraction or desire for others" (Bogaert, 2015), and there was a concern that the part of the study examining sexual risk behaviour will be inaccurate if it contained information from people who are not interested in sexual relationships. In hindsight, the decision to exclude people identifying as asexual should have been explicit in the advertised inclusion criteria, rather than have the survey respondents arrive at a survey termination notice when they checked the “Asexual” option in the sexual orientation question.

When the survey was first released the “Strictly Heterosexual” choice was another survey termination point. However, a colleague who is a trans woman called my attention to the fact that trans people who have sex with or are attracted to their opposite gender (regardless of sex assigned at birth) also consider themselves heterosexual. Once the study was amended to allow those assigned both male and female at birth to participate, the danger of inadvertently excluding large numbers of trans individuals necessitated removing the termination point from this choice. Instead, surveys submitted by people identifying as “Strictly Heterosexual” were excluded from the study at the data clean-up stage if they also identified as cis-gendered (those whose sex assigned at birth matched their gender identification).

6.6. Participants’ Health and Relationship with Healthcare Providers

Participants were asked to rate their overall health and their emotional health, on 5-point Likert scales ranging from Excellent to Poor. They were also asked if they have a medical condition that required regular doctor visits. The survey then split at the question “Do you have a regular GP?”

Those answering “Yes” were taken to a series of questions regarding the frequency of their visits with their GP, and their relationships with their provider and office staff. If participants indicated they did not see their provider at least once in the 12 months preceding the survey, they were asked to indicate a reason (or multiple reasons). Included in these reasons were “I don’t feel comfortable with my GP” and “My GP doesn’t understand me.” If they checked either or both of these options, participants were given the opportunity to elaborate in subsequent open-ended questions.

Participants were then presented with six statements regarding their comfort level with their GP (see Appendix D). Each statement also included a text box where participants were prompted to elaborate on their choices.

Other questions in this section evaluated the level of trust the participant had in their GP, and asked them to rate their provider on a scale of 1-10, with 1 being the worst possible provider and 10 being the best. Additionally, participants were asked to check the option best describing how medical decisions were handled by their providers (see Appendix D).

Participants indicating they **did not have a regular GP** were asked to indicate a reason (or multiple reasons – see Appendix D). Included in these reasons were “I don’t feel comfortable with my GP” and “My GP doesn’t understand me.” If they checked either or both of these options, participants were given the opportunity to elaborate in subsequent open-ended questions.

The survey converged at a section containing open-ended questions asking participants to recount good and bad experiences (in two separate questions) they had with any healthcare provider. Identical questions were asked about experiences with office staff. These questions were aimed at collecting actual barriers and enablers information from as many participants as possible.

Participants were then asked if their sexual or gender identity ever stopped them from seeking medical care when they needed it.

6.7. Perception of Health Communication Self-Efficacy

“Perceived self-efficacy,” Bandura writes, “is concerned with people’s beliefs in their ability to influence events that affect their lives” (Bandura, 2010). As discussed in more detail in Chapter 5, Section 5.4, people’s perceived self-efficacy develops mainly from four sources that include social modelling and social persuasion, and from a person’s own wellbeing, both mental and physical (e.g. depression and anxiety lead to lower perceived self-efficacy) (Bandura, 2010). As Bandura notes, people’s perceived self-efficacy changes across activities and situations, so that a high level of perceived self-efficacy in one area (e.g. relationships with friends) does not guarantee a high level in a different area (e.g. relationships with healthcare providers) (Bandura, 2012). People’s beliefs about their self-efficacy “affect the slate of options people consider and the choices they make at important decisional points” (Bandura, 2012).

The participants’ perception of self-efficacy in their relationship with any healthcare provider was probed in a question block comprising 13 statements, to which the participants responded on a Likert scale ranging from “Strongly Agree” to “Strongly Disagree.” Participants were asked to “…answer even if you do not have a regular GP or do not see your GP regularly.” These statements were informed by (Brafford & Beck, 1991) and the Condom Use Self-Efficacy Scale in the same paper (see also Appendix B).

Questions 1-5 expressed positive emotions denoting higher perceived self-efficacy. They were scored from 5 (“Strongly Agree”) to 1 (“Strongly Disagree”). Questions 6-13, denoting low self-efficacy, were reverse coded. In this way, a higher total score on this scale meant a higher self-efficacy, signifying the respondent had more confidence in discussing their sexual/gender identity openly, and fewer concerns regarding the provider's response to such a discussion. The lowest possible score on this question (assuming all parts were answered) is 13, and the highest is 65.

The survey included five items on gender identity and five sexual identity items. Disclosure of sexual identity was considered important to prompting conversations about sexual risk behaviour between the participant and his/her GP. Questions regarding privacy concerns probed a known and significant barrier to an open and completely honest relationship with a healthcare provider -- see for example Fisher, Fried, Puri, et al. (2018).

The statements for the healthcare self-efficacy question can be seen in Appendix D.

6.8. Sexual Risk Behaviour

Sexually transmitted infections in young people are a matter of significant public health concern (Ellis & Aitken, 2020; Normansell et al., 2016). Worldwide and in New Zealand, rates of chlamydia and gonorrhoea among teens aged 15-19 years are high, especially among those who are biologically female (Ellis & Aitken, 2020; Institute of Environmental Science and Research, 2019; Normansell et al., 2016). The rates of HIV infections in youth men who have sex with men are also disproportionally high, as previously discussed. However, STI and HIV testing rates in international studies are low for this age group (Biello et al., 2019; Normansell et al., 2016).

There is not much information, however, about teens' sexual health in New Zealand, as Ellis and Aitken point out:

> To date, there is no NZ research that comprehensively explores the sexual activities, sexual health practices and knowledge of STI among teenagers

> and, therefore, little is currently known about prevalence of STIs among 15 to 19 year olds. (Ellis & Aitken, 2020, p. 65).

The questions in this survey were informed by questions commonly asked in sexual risk or sexual behaviour surveys (Valencia et al., 2018), and by the author's experience with sexual risk questionnaires administered at the HIV Vaccine Trials Network while she worked there.

The survey split at the question "Are you sexually active?" Participants who answered "Yes" were taken to a block of questions designed to evaluate their sexual risk behaviour. They were asked if they have had sex with a man in the past 12 months, and whether they use a condom when having sex. The question was not changed with the expansion of the population based on existing Stats New Zealand results showing nearly 70% of people identifying as bisexual were female (Stats New Zealand, 2019b). The data further showed that the majority of people in the 18-24 group (which overlapped my study group's upper age limit) identified as bisexual (Stats New Zealand, 2019b). They were then asked whether they have ever been tested for HIV (not whether they were referred for testing) and whether they have been tested for STIs besides HIV (two separate questions). Those who have been tested were asked whether they knew their test(s) results (they were not asked to disclose the outcome). International data, for example Biello et al. (2019), show that a high number of youth who are tested for HIV/STIs do not know their test results, and therefore continue to put themselves and others at risk. Those who were not tested were given a multiple choice question to indicate their reasons for not getting tested. Those who were tested but did not know their results were taken to an open-ended question to explain why they did not know their results. The survey then converged at the condom self-efficacy question.

Those who were not sexually active were taken directly to the condom self-efficacy question. The statements in this question were taken from Braford and Beck’s Condom Self-Efficacy Scale (1991) with permission (copy of permission email is attached as Appendix C). The question’s structure and response options are the same as the healthcare self-efficacy structure and responses, above (see Perception of Health Communication Self-Efficacy, above). These two questions are designed to test if there is an association between the participants’ perceived healthcare self-efficacy and condom self-efficacy, as condom use is a mark of safe sexual behaviour in this survey. Participants were told to “…answer these questions even if you are not currently sexually active or have never used a condom. In such cases, answer how you think you might feel in such a situation.” The question is widely applicable to most LGBTQ+ teen community members, as sexual orientation development for non-heterosexual teens tends to go through a bi-sexual phase, and in general fewer women identify as strictly lesbians compared to bisexual (Kaestle, 2019; Rosario, 2019). The statements in this question can be found in Appendix D

The participants were then taken to a set of PrEP related questions, where they were asked if they were familiar with the concept and could they define it. They were also asked how likely they were to use PrEP, and whether the requirement for regular doctor visits while on PrEP would change their decision on whether or not to use it. They were asked to explain their answers in open-ended questions.

6.9. Support Information

The last three questions in the survey were where participants get the medical information they need, whether they belong to an LGBTQ+ organization, and whether they used the services of a sexual health clinic, the New Zealand AIDS Foundation, or (in Christchurch) 298 Youth Health Centre. Dependent on observed numbers, analyses that investigated differences in healthcare self-efficacy and sexual risk knowledge between the groups were to be investigated.

6.10. Interview and Draw Options

The last question in the survey asked whether participants wanted their name entered in a draw for a $50 gift card. To preserve the anonymity of the participants, those who answered yes were taken to a separate mini-survey, not linked to the study survey. There, they entered their email for the draw. They also had an option on this mini-survey to volunteer to be interviewed. The Information Sheet for the interview was available on this mini-survey, to help people who may have been interested in the interviews learn more about what to expect.

6.11. Data Analysis

Quantitative data analysis was done in SPSS (IBM Corp, Armonk, NY, USA) using descriptive statistics and regression analysis. The Qualtrics dataset was downloaded and imported into SPSS. Open-ended questions were analysed using content analysis in NVivo 12 (QSR International, Burlington, MA, USA).

Frequencies were used to describe the participants' demographic data. Cross-tabulation was added to show the percentages of gender identities within the "Sex assigned at birth" category, and to show the breakdown of self-reported sexual orientation within each self-identified gender.

To analyse the data related to the research questions, cross-tabulation with Fisher's exact test of independence (using the Monte Carlo method) was used to compare independent groups (e.g. participants with a regular GP vs. those who did not have a regular GP).

Regression analysis. Bivariable regression analysis was done to examine the effects of sexual and gender identity on select variable: Self rating of overall health and emotional health, coming out to one's GP, trust in GP's medical decisions, and healthcare communication self-efficacy score. Of note, for all regression analyses the gender identity category of Transfemale had to be excluded, as only 2 participants identified as such. This low number caused errors in the regression calculations, when included in the analyses.

Exact tests of symmetry and marginal homogeneity were used to explore the relationships in matched bivariable investigations.

6.12. Qualitative Data Methods

As noted in Chapter 4, the mixed-methods design provides both breadth and depth to the study. To understand the motivations and reality constructs behind the perceptions and behaviours captured in the survey instrument, we need the narratives provided in the interviews. The in-depth, semi-structured interviews allowed me to understand the different ways in which participants perceive their reality in the context of their daily lives, their environment, and their social connections.

Morse (2016b) stated that qualitative inquiry has a moral imperative to humanise healthcare, and that "[t]he most compelling reason to conduct qualitative health research is a moral one – in the name of social justice" (p.51). This social justice agenda ensures everyone is heard and represented according to Morse. The truth of Morse's assertion strongly resonated with me in the context of this study, where the study population is often marginalised and stigmatised. By ‘humanising the numbers’, I hope to humanise the healthcare environment encountered by members of my study population.

This section reviews the methods used to obtain the results outlined in Chapter 8. It gives an overview of the participants and interviewing methods, details how interviews were processed, and goes on to describe the thematic analysis method and how it was used.

6.12.1. Participants and Interviewing Methods

There were 15 interviewees in the study (Table 6.1). Most of them volunteered through the survey. Three interviewees enrolled through word of mouth or the study blog (https://www.teenhealthcareaccess.com/). The process for interviewees who volunteered through the online survey is outlined in Section 6.10.

Table 6.1 Table of interviewees

Interviewee	Age (Years)	Sexual Identity	Gender Identity	Healthcare Provider
HK	18-19	Queer	Gender-queer	YOSS
RB	18-19	Bisexual/questioning	Male	Family GP, since childhood
LJ	18-19	Bisexual/pansexual	Male	University clinic
LT	18-19	Pansexual	Non-binary	YOSS
TT	18-19	Questioning	Non-binary	University clinic
SL	15-17	Gay	Male	Clinic (the whole family goes there)
DS	18-19	Lesbian	Female	Family GP, since childhood
KB	15-17	Pansexual	Female	Family GP, since childhood
CS	15-17	Bisexual	Female	YOSS
GV	18-19	Bisexual	Female	Yes, but normally just consults parent, who’s a GP
BL	15-17	Queer	Non-binary	Family GP, but BL no longer goes there as family situation became unsafe after coming out
LD	18-19	Bisexual	Non-binary	Family GP, since childhood
SW	15-17	Bisexual or gay	Male	Family GP, since childhood
EM	15-17	Lesbian	Female	Family GP
WA	15-17	Lesbian	Demigirl	Family GP, since childhood

YOSS = Youth One Stop Shop.

Interviews lasted between 35:33 minutes : seconds and 71:23 minutes : seconds (mean: 54:22). The interview format was semi-structured. In a semi-structured interview, the interviewer asks pre-prepared questions but the interviewee’s answers are allowed to guide the conversation beyond the original topic. The pre-prepared questions can be found in Appendix E.

All but four interviews were conducted in person in a public building where private rooms could be reserved (e.g. a public library). I travelled to different parts of New Zealand to meet the participants. Interviews were voice recorded, with the interviewees’ permission. During the COVID-19 national lockdown in New Zealand, an emergency authorisation was obtained from the University of Canterbury’s HEC to conduct online interviews. Of eight interviews scheduled to take place during what became the lockdown period, three interviews were carried out via Skype. Two potential interviewees indicated they could not safely carry out an interview in their lockdown location, as they were not out to the people they lived with (family or flatmates). The rest of the scheduled interviewees did not respond to the request to reschedule online.

Only the audio portion of the Skype interviews was recorded, through my laptop’s internal recording mechanism. The Skype recording capability was not used, as both the University’s ethics committee and I deemed the Skype storage insecure for the purpose of retaining confidential information. Several months after the lockdown period ended, an additional interview was conducted online, as the interviewee was in a part of New Zealand that saw several COVID-19 community outbreaks in succession, and travel was not advised to that area. This interview was done through the Zoom platform. Zoom creates both audio and video recordings automatically, and the interviewee was made aware of that fact. They were also aware that the video recording would be deleted, and only the audio retained.

Consent for all online interviews was obtained through Adobe's secure e-signature service, which I subscribe to.

6.12.2. Processing the Interviews

Interviews were uploaded from the digital voice recorder (used in face-to-face interviews) or a laptop to the Otter.ai (https://otter.ai/) transcription web site. The Otter service has no human transcriptionist (Lai, 2021), and therefore confidentiality of the material is maintained. Transcripts were downloaded from the Otter website onto a password-protected University of Canterbury laptop and immediately deleted permanently from the Otter server. This was done to ensure the continued confidentiality of participants and the interview content. The transcripts were then checked and corrected manually. The finished transcripts were imported into NVivo, which was used to code the transcripts and organise the codes into categories and subcategories, and ultimately themes and sub-themes. Each interview was coded manually – the automatic coding feature of NVivo was not used. The software was used because it provides an easy way to organise codes (and later themes) in one place, across multiple interview transcripts.

6.12.3. Qualitative Analysis

Thematic analysis was selected because it focuses on patterns across multiple texts in a dataset (Braun & Clarke, 2012). In looking for these patterns (themes) across the entire dataset (as opposed to an individual interview at a time), thematic analysis enabled me to see the commonalities in the lived experiences of the participants. It is also a flexible analytic method in that it does not require a specific theoretical framework (Trainor & Bundon, 2020). I was therefore able to use latent thematic analysis (Braun & Clarke, 2006), and apply my chosen lens of Decompensation and SCT, through which I interpreted the results. As Braun and Clarke stated, the latent approach to thematic analysis comes from a more constructionist model (Braun & Clarke, 2006), which is my study's overall epistemology.

Analysis was done according to Braun and Clarke's reflexive thematic analysis stages (Braun & Clarke, 2006). The term reflexive thematic analysis reflects the importance of the researcher (and their subjectivity) in the analytical process (Braun et al., 2019). In my analysis, I used an inductive approach, which allows the themes to develop from analysing the entire dataset – all 15 interviews.

In the first stage, I thoroughly familiarised myself with the interview transcripts once they were completed. One transcript was used for an exercise with my Senior Supervisor, Dr Sarah Lovell, to ensure I understood the process of coding and drilled down to the right amount of detail. When all transcripts were finished and I had read them all individually, I reread them as a set, including the transcript that was used as the practice one. I started noting some ideas I saw emerging in the text. This flowed into the second stage of the analysis.

The second stage involved initial coding of the data using all transcripts. I modified some codes in the practice transcript – which was now part of my set -- while leaving others as they were since they fit the rest of what was emerging in the transcript set as a whole. This became the basis of my coding. To these existing codes I added others as they were identified from my systemic reading and analysis. I found that some data fit into more than one code. These codes were still at a very detailed level of the text, and not as broad as the final themes would be. In creating the codes I was mindful of the information I was interested in. Namely, the perception of barriers or enablers to healthcare access, and any impact of healthcare access on the participants' sexual health.

In the third stage, I started collating separate codes into broader themes and creating a preliminary thematic map, showing what themes I had and what sub-themes went with each theme. I kept in mind the research questions for the study as I looked for themes that related to my questions. This was also the point at which I started formulating the results chapter, in a rudimentary form.

The fourth stage was that of refining and redefining themes. This involved looking at the data extracts for each code the theme comprised, and determining if it agrees with the theme. For example, themes that had contradicting data were split into two sub-categories of the theme. These sub-categories were then examined to see if they both fit the overarching theme, or could be combined with other sub-categories to create new themes that were more internally consistent. This stage was also the stage when my “miscellaneous” codes – the ones that did not fit any themes, were either incorporated into my refined themes or discarded.

The fifth stage involved the final refining and the naming of the themes. Themes were grouped under umbrella terms (e.g. “Coming out complexity”), and all extracted narratives that reflected the themes were re-examined. The latter step was done not only to ensure that the participant narratives aligned with the themes, but also to identify representational quotes for the theme. There were some areas of overlap between the original subthemes, and I had to re-refine the themes and subthemes to ensure each was focused (i.e. the theme was not too broad) and true to the participants’ meanings. At this stage, my writing of the results began to take on the full narrative form that related the themes to the research questions, and presented the representative quotes.

The final stage of the thematic analysis was in drafting and refining the results chapter, including the addition of supporting literature and the finalisation of the narrative relating the themes to each other, and to the research questions.

6.12.4. Data Security and Confidentiality

Interviews were recorded on a handheld digital voice recorder (DVR), except for those interviews done online, where the recording was done through my password-protected laptop. Interviews were uploaded from the DVR into the laptop and deleted from the device. The device, as well as the signed consent forms, were kept in a locked drawer at my work station at UC.

Interviewees were assigned fictitious initials as shown in Table 6.1. The spreadsheet detailing interviewees’ names and emails and their corresponding fictitious names was password protected and kept on my password protected laptop.

Chapter 7. The Survey Results

7.1. Introduction

The quantitative part of the study comprised the online survey, and its results are presented in this chapter. This study focused on aspects of communication between the participants and healthcare providers, regarding sexual and gender identity. These areas were probed to answer the research questions anchoring this study, namely:

1. Do the LGBTQ+ teens in this study perceive interpersonal barriers to healthcare services?
2. Do perceptions of healthcare barriers influence sexual risk behaviours (e.g. condom use)?
3. Do these perceptions affect the uptake of preventive behaviours (e.g. STI screening)?

Sexual health aspects examined in this study can be divided into two realms: *Primary Prevention* includes behaviours that prevent the acquisition of diseases (Kisling & Das, 2020), in this case STIs. In this study the primary prevention category was represented by condom use and condom self-efficacy, as well as PrEP knowledge. *Secondary Prevention*, which broadly concerns the early detection and treatment of diseases (Kisling & Das, 2020) is represented in this study by questions regarding STI and HIV testing. As the survey did not ask participants to disclose their confidential test results, the information elicited for secondary prevention here only concerns detection, not treatment.

The conceptual approach to the analysis in this chapter was informed by the Communication – Self-efficacy – Sexual Health model depicted in Figure 7.1 (see

Section 9.2 for information on the model's development). This model proposes that communication with one's GP is associated with the utilisation of healthcare services and preventive sexual health behaviours.

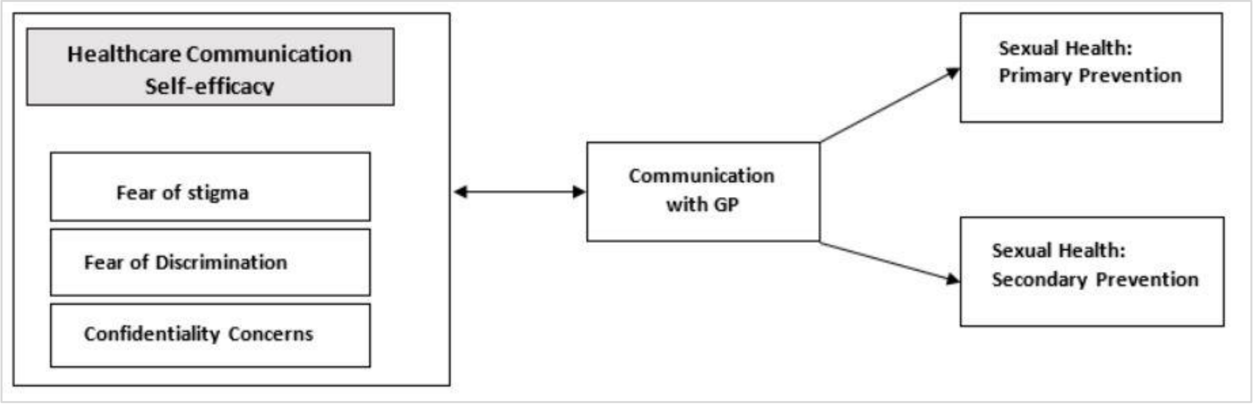

Figure 7.1 The proposed Communication – Self-efficacy – Sexual Health model

Communication with one's GP, as the model suggests, affects and depends on the patient's health communication self-efficacy; that is, the patient's feeling of control when communicating with their GP (a discussion of self-efficacy can be found in Section 5.4). Healthcare communication self-efficacy was evaluated through a series of questions asking the participants to consider situations and circumstances in the GP's office they may or may not have thought of previously. The literature indicates that health communication self-efficacy in populations like this study's population is frequently driven by fear of stigma and discrimination, and fear of being "outed" to family and friends. Therefore, these factors are included in the analyses discussed in this chapter, both as part of the communication variable (in the health communication self-efficacy scale), and as an independent variable relating to participants' trust in their GP and the quality of care they get.

The anonymous online survey went live on 21 January, 2019 and closed on 30 April, 2020. Recruitment methods were discussed in detail in Section 6.3. As mentioned previously, for most of 2019 the survey was only open to teens assigned male at birth.

During that time, 22 responses were collected. On 9 December 2019, following an amendment approval by the University of Canterbury's Human Ethics Committee[21] (Appendix A), the survey opened for an expanded population comprising those assigned either sex at birth.

With the exception of the consent form, no question on the survey was mandatory. This was done to minimise the risk of people abandoning a survey if they could not get past a question they found uncomfortable or distressing. The survey's consent form informed participants that "Some of the questions may make you feel uncomfortable or embarrassed. Some questions may cause you stress or make you feel sad. You do not have to answer any questions that make you feel uncomfortable or distressed in any way."

The results reported here are informed by the STROBE guidelines (www.strobe-statement.org) (Vandenbroucke et al., 2014). Results are reported in the order corresponding to the research questions listed at the beginning of the chapter. The study population's demographic characteristics are outlined first, followed by the respondents' sexual and gender identity characteristics. The discussion then turns to a descriptive analysis of the participants' self-rated health. Following descriptive analysis of perceptions of healthcare accessibility, the primary analysis -- assessing for unmet needs and understanding the relative importance of interpersonal barriers to healthcare - was done by examining the relationship between the participants and their healthcare provider (or reasons they do not have one). The second part of the analysis addresses the second and third research questions, by examining associations between healthcare barriers and the adoption of both preventive and sexual risk behaviours. Lastly, content

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[21] Recently renamed to "The Human Research Ethics Committee of the University of Canterbury."

analysis of open-ended questions in the survey provides additional insights into the issues raised by the quantitative results.

7.2. Participants

A total of 367 responses was received by the time the survey closed, of which 310 were valid and included within the final analysed sample (Figure 7.2). Criteria for inclusion were teens aged 15-19 years at the time of completing the survey, living in New Zealand, and identifying as LGBTQ+ or still questioning. As discussed previously, people identifying as asexual and those whose IP addresses were from outside New Zealand were excluded from the final sample. Respondents identifying as both cis-gendered and "Strictly heterosexual" were also excluded.

With regards to participants' age, the University's HEC advised that the collection of birth year alone (with no month) was sufficient for ascertaining participants' age to determine eligibility; therefore age is taken as of 31 December each year, and is calculated according to the year the participant took the survey (e.g. a participant born in 1999 would be eligible to take the survey in 2019, but not in 2020). Respondents born before 1999 or after 2005 were excluded from the study.

Intentionally erroneous responses (see Appendix H) were excluded by consensus of the author and supervision team. These surveys contained hate speech, patterns of responses that were clearly unrealistic, an impossible gender/sex combination response (Sex = Female, Gender = Transfemale), and in one case, a survey consisting of only one comment railing against the exclusion of asexual people from the study.

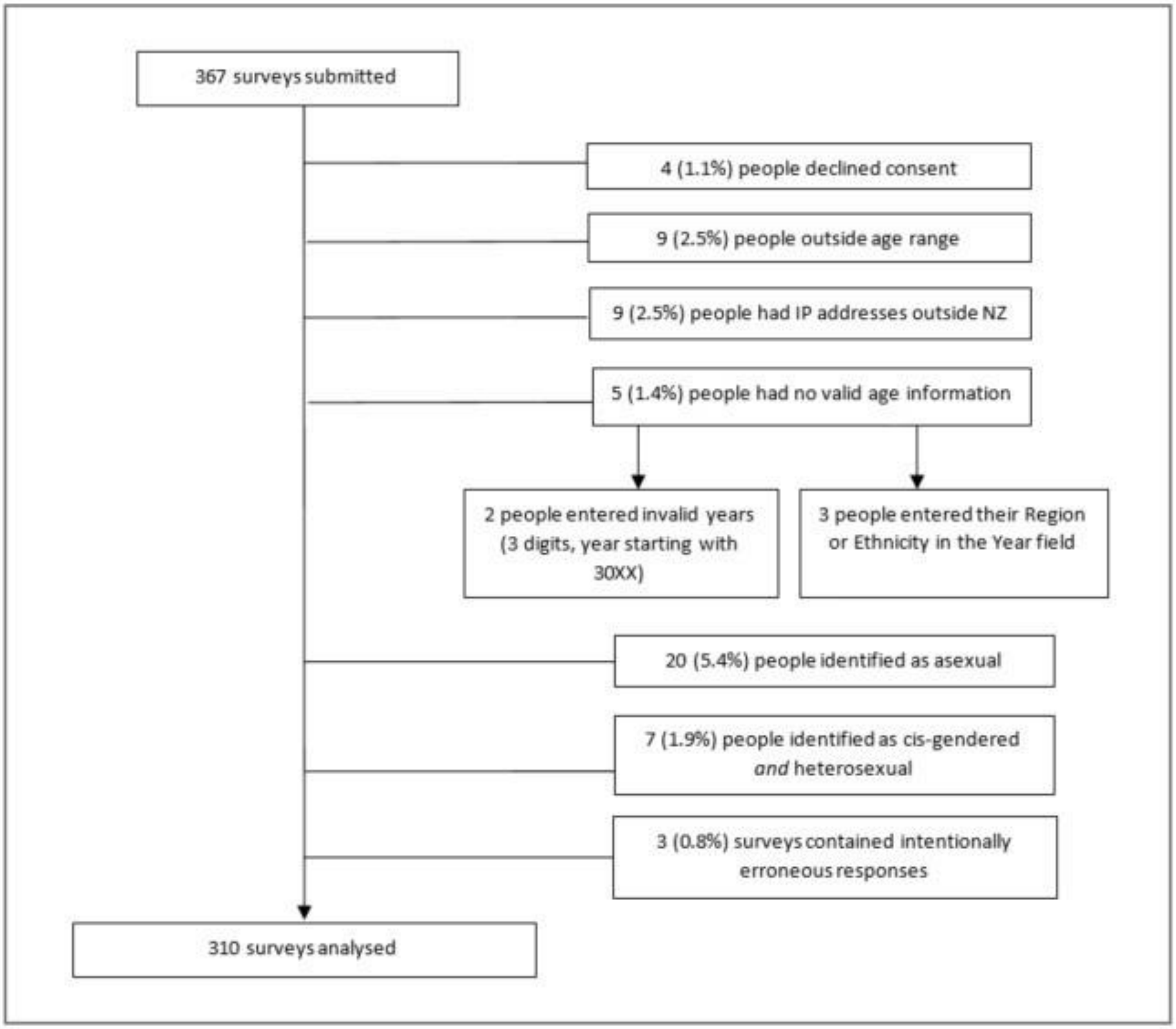

Figure 7.2 Participants flowchart.

7.3. Participants: Demographic Characteristics

Variables measured in the demographics category were year of birth, region of residence, family income, and ethnicity. Responses came from all across New Zealand (see Table 7.1). The largest numbers of responses were received from Canterbury (n=69, 22.3%), Auckland (n=47, 15.2%), and Wellington (n=35, 11.3%). To protect participants' anonymity, regions with fewer than five responses were combined into an "Other" category. The exceptions were the Nelson and Tasman regions, which were collated into a single "Nelson-Tasman" region in the table, as they are contiguous. This table also provides a comparison of the study population per region with the percentage of New Zealand population aged 15-19 years living in each region. This is done to help readers unfamiliar with New Zealand demographics, and to see how the study sample compares with the general population of the same age in each region.

The ethnic identification of the participants is shown in Table 7.2. Because some participants indicated multiple ethnicities, the final number of responses exceeds 310 (n=321, not including the five participants who checked “Prefer not to say”). This method of collecting ethnicity information is the method used by Statistics New Zealand for reporting ethnic groups in census data (see discussion in Chapter 6). This table also provides a comparison of top-level ethnicities (see Section 6.4) in the study sample to the percentage of each top-level ethnicity in the general New Zealand population of the same age. This is done to help readers unfamiliar with New Zealand demographics, and to see how the study sample compares with the general population of the same age in each ethnicity. The participants’ year of birth is also shown in Table 7.2.

Though family income information was collected in the survey, the majority of participants (57.7%) were either unsure of, or preferred not to disclose, their family’s income. This large percentage rendered the information not useful, and the data are not included here or analysed further.

Table 7.1 Demographics: Region (n=310). This table lists the participants' self-reported location by region.

Region	Study Population *n* (%)	New Zealand Population[3] (%)
North Island		
Northland	6 (1.9)	(3.6)
Auckland	47 (15.2)	(34.0)
Bay of Plenty	21 (6.8)	(6.3)
Waikato	26 (8.4)	(9.9)
Gisborne	7 (2.3)	(1.1)
Hawke's Bay	17 (5.5)	(3.5)
Manawatu-Wanganui	26 (8.4)	(5.1)
Taranaki	10 (3.2)	(2.3)
Wellington	35 (11.3)	(11.1)
South Island		
Nelson-Tasman	8 (2.6)[1]	(2.0)
Canterbury	69 (22.3)	(12.3)
Otago	21 (6.8)	(5.6)
Southland	10 (3.2)	(1.9)
Other	5 (1.6)	N/A
Unknown	2 (0.6)[2]	N/A

[1] To ensure participants' anonymity, responses from the Nelson and Tasman areas were combined into one region to ensure the participant count was >5.

[2] Missing or ambiguous region, but the IP address was from New Zealand.

[3] The percentage of New Zealand population aged 15-19 years living in each region (Stats New Zealand, 2019a).

Table 7.2 Demographics: Ethnicity (n=310*) and Year of Birth (n=310).

Category	Study Population *n* (%)	New Zealand Population, 15-19 years old** (%)
Ethnicity		
New Zealand European	242 (79.3)	(50.1)
Māori	28 (9.2)	(9.3)
Pacific	5 (1.6)	(7.5)
Asian	20 (6.6)	(12.4)
Other (Please specify)	26 (8.5)	(0.7)
Prefer not to say	5	-
Year of Birth		
1999	3 (1.0)	
2000	23 (7.4)	
2001	29 (9.4)	
2002	84 (27.1)	
2003	95 (30.6)	
2004	60 (19.4)	
2005	16 (5.2)	

*The denominator for calculating the % is based on [the number of participants who responded (n=310)] – [the participants who checked “Prefer not to say” (n=5)]. Therefore, the percentages are calculated for n=305. Those who indicated multiple ethnicities were counted in each ethnicity they indicated. Therefore, the total number of responses is >305, and the percentages add up to more than 100%.

** The percentage of New Zealand population aged 15-19 years Level 1 ethnicity (Stats New Zealand, 2019a)

7.4. Participants: Sexual and Gender Identity

Of the 310 participants, 308 provided information on sex assignment at birth, with 62 (20.1%) assigned as males and 246 (79.9%) assigned females (Table 7.3). Of those assigned male at birth, 56 (90.3%) also identified as male in the gender question (i.e. they were cis-gendered). Of those assigned female at birth, 175 (71.1%) were cis-gendered (Table 7.3). Three participants who were assigned female at birth identified as male – rather than transmale – on the survey. The decision was made to respect the participants’ self-identification and count them as male, not transmale, in all analyses.

Table 7.3 Participants' self-reported gender (n=308). Survey participants' self-reported gender within the "Assigned Sex at Birth" category.

	Gender Identity n (%)						
Sex Assigned at Birth	Male	Female	Transmale	Transfemale	Gender queer	Non-binary	Other
Male	56 (90.3)	0 (0.0)	0 (0.0)	2 (3.2)	2 (3.2)	1 (1.6)	1 (1.6)
Female	3 (1.2)	175 (71.1)	19 (7.7)	0 (0.0)	23 (9.3)	15 (4.5)	11 (6.1)

Originally, gender categories in the survey did not include "Non-binary." However, of the 28 participants who originally answered "Other (Please specify)" to the gender identity question, 16 (57.1%) indicated they were non-binary. The "non-binary" category was coded as an additional gender identity for the purpose of further analyses. The tables in this chapter all reflect this additional coding. Further responses in the "Other" category of gender identity included "Agender," "Genderfluid," and "Not sure."

The majority of participants (*n* = 186, 60.0%) identified as bisexual/pansexual, followed by 79 (25.5%) who identified as strictly homosexual. One trans* participant identified as heterosexual. Twenty-seven participants (8.7%) indicated they were still "Unsure/Questioning," and 17 participants (5.5%) selected "Other." Responses in the "Other" category included "Queer" and "Demisexual." Participants identifying as females largely identified as bisexual/pansexual (*n* = 121, 68.7%), while the largest portion of those identifying as males (*n* = 36, 60%) identified as strictly homosexual (Table 7.4).

Table 7.4 Participants' self-reported sexual identity broken down by self-reported gender (N=310).

	Sexual orientation n (%)				
Gender	Strictly homosexual	Strictly heterosexual	Bisexual / Pansexual	Unsure / Questioning	Other
Male	36 (60.0)	0 (0.0)	22 (36.7)	2 (3.3)	0 (0.0)
Female	29 (16.5)	0 (0.0)	121 (68.7)	18 (10.2)	8 (4.5)
Transmale	4 (21.0)	1 (5.3)	9 (47.4)	3 (15.8)	2 (10.5)
Transfemale	1 (50.0)	0 (0.0)	1 (50.0)	0 (0.0)	0 (0.0)
Gender queer	3 (12.0)	0 (0.0)	18 (72.0)	3 (12.0)	1 (4.0)
Non-binary	3 (18.7)	0 (0.0)	8 (50.0)	1 (6.3)	4 (25.0)
Other (Please specify)	3 (25.0)	0 (0.0)	7 (58.3)	0 (0.0)	2 (16.7)

7.5. Participants: Self-Rated Health

Participants were asked to self-rate their overall health and their emotional health in separate questions. As discussed previously, LGBTQ+ individuals tend to have worse health outcomes, and especially mental health outcomes, than their heterosexual, cis-gendered peers.

In this study there was a noticeable difference between participants' self-rating of their overall health and their emotional health. Of 308 responses, 72.4% rated their overall health as Good/Very Good/Excellent, compared with 26.6% who rated their emotional health Good or above (Table 7.5). Fisher's exact test was significant ($p < .001$), showing the difference between these two categories is not random. Correlation testing was significant and of moderate strength (Spearman's $\rho = 0.59$; 95% CI, < 0.001), showing the rankings tend to move in the same direction – as overall health increases, emotional health tends to increase as well, though not by the same magnitude.

Table 7.5 Participants' self-ranking of overall and emotional health (n=-308).

Category	n (%)
Overall Health	
Excellent	20 (6.5)
Very Good	84 (27.3)
Good	119 (38.6)
Fair	68 (22.1)
Poor	17 (5.5)
Emotional Health	
Excellent	7 (2.3)
Very Good	19 (6.2)
Good	56 (18.2)
Fair	117 (38.0)
Poor	109 (35.4)

Ordinal logistic regression analysis was carried out to examine whether participants' gender or sexual orientation were associated with ratings of overall and emotional health. The regression analysis tested the assumption that the association between self-rated health (overall and emotional) and gender is stronger than the association between self-rated health and sexual orientation. The analysis (Table 7.6 for overall health and Table 7.7 for emotional health) did show that gender diversity (specifically transmale, gender queer, and non-binary participants), but not sexual orientation, was associated with self-rated health. For example, transmales had 0.21 the odds of ranking their overall health as high as males (the reference category); they had 0.14 times the odds of ranking their emotional health as high as males. There were no statistically significant associations between sexual orientation and self-rated health.

Table 7.6 Ordinal logistic regression (bivariable comparisons): Impact of self-identified gender and sexual orientation on overall health self-ranking

		Excellent	Very Good	Good	Fair	Poor		
Category	*n*	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	OR	(95% CI)
Gender								
Male	60	5 (8.3)	27 (45.0)	15 (25.0)	11 (18.3)	2 (3.3)	1.00	(reference)
Female	174	14 (8.0)	47 (27.0)	69 (39.7)	35 (20.1)	9 (5.2)	0.57	(0.32, 1.03)
Transmale	18	1 (5.6)	1 (5.6)	8 (44.4)	6 (33.3)	2 (11.1)	0.21	(0.08, 0.58)
Gender queer	25	0 (0.0)	3 (12.0)	12 (48.0)	8 (32.0)	2 (8.0)	0.23	(0.10, 0.57)
Non-Binary	16	0 (0.0)	3 (18.8)	7 (43.8)	5 (31.3)	1 (6.3)	0.33	(0.12, 0.95)
Other	12	0 (0.0)	2 (16.7)	6 (50.0)	3 (25.0)	1 (8.3)	0.32	(0.10, 1.05)
Sexual Orientation								
Strictly homosexual	78	4 (5.1)	32 (41.0)	17 (21.8)	22 (28.2)	3 (3.8)	1.00	(reference)
Bisexual/pansexual	185	12 (6.5)	42 (22.7)	82 (44.3)	38 (20.5)	11 (5.9)	0.99	(0.59, 1.67)
Unsure/questioning	25	4 (16.0)	6 (24.0)	11 (44.0)	4 (16.0)	0 (0.0)	1.98	(0.84, 4.67)
Other	17	0 (0.0)	3 (17.6)	7 (41.2)	4 (23.5)	3 (17.6)	0.60	(0.22, 1.65)

Table 7.7 Ordinal logistic regression (bivariable comparisons): Impact of self-identified gender and sexual orientation on emotional health self-ranking

		Excellent	Very Good	Good	Fair	Poor		
Category	*n*	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	OR	(95% CI)
Gender								
Male	60	4 (6.7)	7 (11.7)	9 (15.0)	23 (38.3)	17 (28.3)	1.00	(reference)
Female	174	3 (1.7)	9 (5.2)	43 (24.7)	65 (37.4)	54 (31.0)	0.75	(0.42, 1.33)
Transmale	18	0 (0.0)	1 (5.6)	1 (5.6)	3 (16.7)	13 (72.2)	0.14	(0.04, 0.43)
Gender queer	25	0 (0.0)	1 (4.0)	1 (4.0)	12 (48.0)	11 (44.0)	0.34	(0.14, 0.84)
Non-Binary	16	0 (0.0)	1 (6.3)	0 (0.0)	7 (43.8)	8 (50.0)	0.31	(0.10, 0.93)
Other	12	0 (0.0)	0 (00.0)	2 (16.7)	4 (33.3)	6 (50.0)	0.35	(0.11, 1.17)
Sexual Orientation								
Strictly homosexual	78	1 (1.3)	7 (9.0)	14 (17.9)	28 (35.9)	28 (35.9)	1.00	(reference)
Bisexual/pansexual	185	5 (2.7)	10 (5.4)	36 (19.5)	68 (36.8)	66 (35.7)	1.13	(0.67, 1.93)
Unsure/questioning	25	1 (4.0)	2 (8.0)	4 (16.0)	11 (44.0)	7 (28.0)	1.60	(0.67, 3.80)
Other	17	0 (0.0)	0 (0.0)	2 (11.8)	7 (41.2)	8 (47.1)	0.84	(0.29, 2.41)

To understand participants' unmet need for healthcare, respondents were asked whether they have a medical condition requiring regular doctor visits. Of 308 responses, 91 (29.5%) participants indicated they did, and 12 (3.9%) responded with "Prefer not to answer." Of the 91 people who responded in the affirmative, 11 (12.1%) did not have a regular GP.

RQ1: Do the LGBTQ+ Teens in this Study Perceive Interpersonal Barriers to Healthcare Services?

7.6. Healthcare Utilisation

Healthcare utilisation is determined in part by access to healthcare. The analyses in this section thus concern the first research question, "Do the LGBTQ+ teens in this study perceive interpersonal barriers to healthcare services?"

Of 308 respondents, 61 (19.8%) indicated they did not have a regular GP at the time of survey completion. Of these 61 participants, 57 answered the question, "Please check all the reasons you do not have a regular GP." The largest portion of responses (n=25, 43.9%) cited cost as the main reason for not having a GP, followed by inability to make time (n=20; 35.1%) as the main reasons for not seeing a GP (see Table 7.8 for complete list).

Table 7.8 Reasons participants did not have a regular GP (multiple responses possible) (n=57)

Reason	*n* (%*)
Cost	25 (43.9)
Clinic too far	10 (17.5)
Lack of transportation	16 (28.1)
Unable to make time	20 (35.1)
I don't feel comfortable with my GP	17 (29.8)
My GP doesn't understand my needs	11 (19.3)
Other	20 (35.1)

There were 119 responses to this question from the 57 participants. The majority (n=40, 70.2%) checked one or two options. One person checked all six options.

Open-ended questions or space to elaborate in text form were provided for participants to probe the areas that were the main interest of this study's first research question.

Table 7.9 Open-ended questions for "Reasons you do not have a regular GP."

Response	Responses to quantitative question	Responses to open-ended question – *n* (%*)	Sample Quote
Other	20	19 (95.0)	"I feel healthy enough"
I don't feel comfortable with my GP	17	12 (70.6)	"It's always someone different, and sometimes when it's a male doctor I feel awkward about sex related stuff especially when they have beliefs that are shown on the wall in offices etc"
My GP doesn't understand my needs	11	8 (72.7)	"dismissive [sic] of all issues brought forward. Things were brushed off all the time and I feel I wasn't taken seriously."

* Percent of those answering the quantitative question

Forty-two participants responded to the open-ended questions in Table 7.9. Six participants identified that mental health issues prevented them from going to a doctor – these were either acute discomfort with doctors or people in general, or discomfort leaving their house. Nine participants cited the perception that their GP did not understand or was "dismissive" of their healthcare needs, especially as it related to sexual or gender identity (five out of nine responses). Two of these participants described the difficulty they encountered with GPs misgendering them and lacking the tools to respond to them sensitively ("Even with my best efforts, the correct pronouns aren't used and my 'lady parts' are treated with such... fragility" – transmale participant). Five participants indicated they were enrolled with a clinic that did not assign a regular GP. This was stated in response to both the statement "I don't feel comfortable with my

GP," and "Other" indicating continuity of care affected their healthcare use. Remaining responses addressed a variety of barriers including confidentiality concerns ("I haven't come out to my GP but I know she's very religious and she talks a lot to my mother, who is homophobic and religious"), parents not making appointments, respondents not registering with a new GP when they lost their former, and a shortage of GPs. Being in good health was a further reason for not seeing a GP for three participants.

To examine another aspect of unmet healthcare needs in the study population, Fisher's exact tests were carried out to characterise self-rated health (overall and emotional) in people with and without a GP. Neither overall health (p = .72) nor emotional health (p = 0.30) were associated with having a GP. Ordinal logistic regression analysis to examine whether sexual or gender identities were associated with the likelihood of having a regular GP showed no significant association (p = .83 for gender, p = .69 for sexual orientation).

7.6.1. Perception of Care Quality

Of 247 participants with a regular GP, 245 rated their GP's quality on a scale of 1 to 10 (1 being the worst provider, 10 being the best). The majority of participants (n = 169, 68.6%) ranked their GP's quality 7 or above. Results are shown in Figure 7.3. The study hypothesised that gender and sexual identities will impact communication and relationship with one's GP, and therefore might impact the perception of care quality. A simple cross tabulation analysis was done to see if gender or sexual identities impacted the participants' perception of their GP's quality of care. There were no statistically significant differences in quality ratings based on gender (Fisher's exact test p = .27) or sexual orientation (Fisher's exact test p = .63).

Self-rated health was also hypothesised to have an effect on the perception of care quality in participants. There was an association between participants' rating of their overall health and their rating of their GP's quality (Fisher's exact test *p* = .012). Participants rating their overall health as Excellent were more likely to rank their GP's quality higher, compared with participants who ranked their overall health as Poor. However, there was no statistically significant association between rating of emotional health and care quality (*p* = .65).

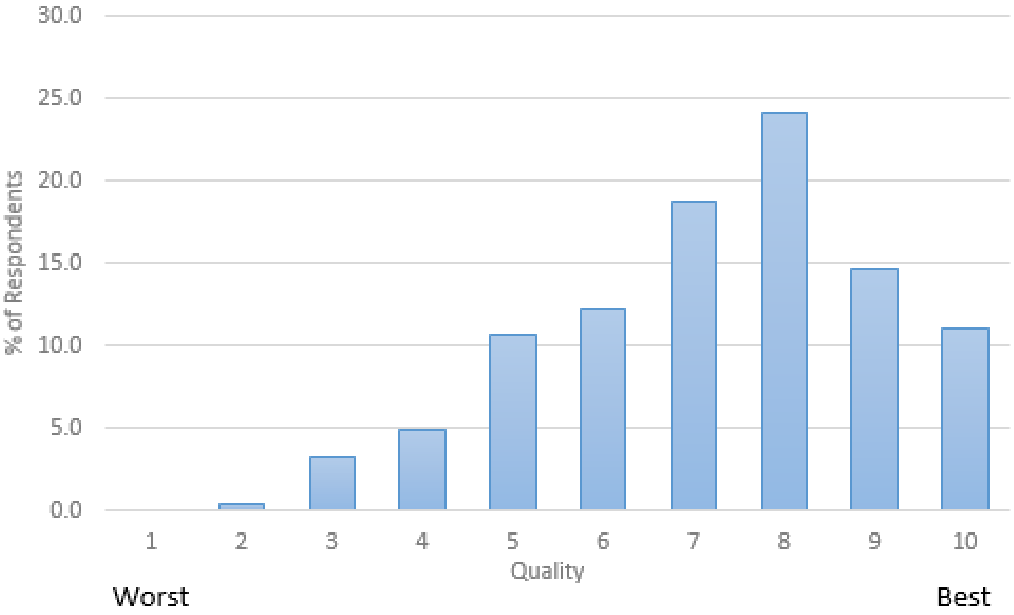

Figure 7.3 Participants' ranking of their GP's Quality (n=245).

There were significant differences (Fisher's exact test *p* = .001) in ratings of GP quality between participants who believed their GP had an anti-LGBTQ+ bias and those who did not. Fifty percent (*n* = 4) of those who believed their GP had such bias rated their GP quality below 7, double the percentage of those who did not perceive their GP to be biased (*n* = 49, 24.5%). A similar association was noted in people who ticked the option "I've experienced biased responses / discrimination from my GP." In that group, 73.4% (*n* = 11) of participants ranked their GP quality below 7, compared with 21.9% (*n* = 42) of the participants who did not experience such bias (Fisher's exact test *p* < .001).

7.6.2. Barriers to Regular GP Visits

As seen in Chapter 1, LGBTQ+ teens are at higher risk for adverse health outcomes; probing the reasons participants did not see their GP regularly was tied to the first research question assessing perceived barriers to accessing healthcare when it is needed.

Of 247 participants with a regular GP, 215 (87.0%) indicated they saw their GP at least once in the preceding 12 months. The presence of a condition requiring regular doctor's visits was significantly associated with visit frequency – the majority of participants with such conditions (n = 57, 71.3%) visit their GP more than five times per year (Fisher's exact $p < .001$).

When participants were asked "If you do not see your GP at least once a year, please check all the reasons why," 58 responded. The top three reasons were cost (n = 25, 43.1%), "Other" (n = 24, 41.4%), and inability to make time (n = 14, 24.1%) (see Table 7.10 for complete list). Interpersonal factors appear fourth and fifth in importance, ranking above transport/distance barriers. There were 87 total responses from 58 participants. The majority of participants (n = 51, 87.9%) checked one or two options. One person checked all five options. Responses to open-ended questions elaborating on the last three choices are discussed below (see Table 7.11 for sample responses).

Table 7.10 Reasons participants did not see their GP every year (multiple responses possible) (n=58)

Reason	*n* (%*)
Cost	25 (43.1)
Clinic too far	3 (5.2)
Lack of transportation	3 (5.2)
Unable to make time	14 (24.1)
I don't feel comfortable with my GP	12 (20.7)
My GP doesn't understand me	6 (10.3)
Other	24 (41.4)

* Percent refers to percent of cases.

Table 7.11 Open-ended questions for "Reasons you do not see your GP at least once a year."

Response	Responses to quantitative question	Responses to open-ended question – *n* (%*)	Sample Quote
Other	24	23 (95.8)	"It seems unnecessary"
I don't feel comfortable with my GP	12	12 (100.0)	"It feels like my GP doesn't really care about my health. …And they're always really weirdly standoffish like I've never vibed with a GP (which is weird because I've vibed with surgeons and nurses)."
My GP doesn't understand my needs	6	4 (66.6)	"I just feel like she's really judgey [sic] and doesn't listen to what I'm saying"

* Percent of those answering the quantitative question

Among the reasons for not visiting the GP at least once a year, no perceived need (e.g. "*I don't need regular check up [sic] and don't get sick often*") was the most common response (15 of 39 respondents). Other participants described feeling dismissed or not understood, particularly when discussing mental health concerns ("*She doesn't understand my… disorders and just tells me to grow up when I explain I have [condition]*"), or fearing rejection particularly with regards to one's LGBTQ+ identity ("*if I go there seeking to transition I don't want to be misunderstood or denied or disrespected. So i've [sic] been avoiding it*"). Again, difficulty getting an appointment, general discomfort with doctors and confidentiality concerns were raised by a small number of participants.

The feeling of not being taken seriously by healthcare providers is a common barrier among teens in general (not just LGBTQ+ teens) (Jacobson et al., 2001). However, in LGBTQ+ teens this barrier becomes an additional stressor on top of their LGBTQ+-related stressors, leading to a decompensation response (Riggs and Treharne, 2017) which is often avoidance of care.

7.6.3. Interpersonal Barriers to Healthcare among Participants with a Regular GP

Analysis of perceptions of patient-provider relationships was undertaken to understand communication barriers to health services used by participants with a GP.

Participants' perceptions and concerns surrounding their relationships with their provider was assessed with a multi-response question, "Thinking about your regular GP, check all that apply" (Appendix D, Q21).The components of the question, and the percentages of respondents who checked each, are shown in Table 7.12. Each statement also contained an optional text field where participants were asked to explain their answer. These open-ended answers are discussed in detail in Section 7.10.1.

Table 7.12 Participants' perceptions and concerns surrounding relationship with GP (*n* = 207)

Question component	*n* (%)*
I feel comfortable talking to my GP about any health-related issue	169 (81.6)
I feel comfortable discussing my sexual/gender identity with my GP	82 (39.6)
I came out to my GP	39 (18.8)
I'm worried my GP will tell my family/whānau things I tell them	59 (28.5)
I believe my GP has an anti-LGBTQ bias	8 (3.9)
I've experienced biased responses / discrimination from my GP	15 (7.2)

* Percent refers to percent of cases

There were 372 responses from 207 participants. The majority (*n* = 165, 79.7%) checked one or two options.

Overall, a few details stand out in this table. The majority of participants (*n* = 169, 81.6%) felt comfortable talking to their GP about health-related issues, compared with 39.6% (*n* = 82) who were comfortable discussing their sexual and gender identity with their GP, and 18.8% (*n* = 39) who actually came out to their GP.

Disclosure of sexual/gender identity. From the health communication self-efficacy scale (see Section 7.7) an analysis to examine if there is a relationship between having a regular GP (Y/N) and being comfortable disclosing one's sexual identity (Table 7.13) was done, using Fisher's exact test. There was no statistically significant association (*p* = .44) in this study population. The same analysis was carried out to test whether there was a relationship between having a regular GP and being comfortable disclosing one's gender identity (Table 7.13). There was no statistically significant association (*p* = .10).

Table 7.13 Crosstabulation of having a regular GP by sexual and gender identity discussion with GP

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Having a regular GP			Comfortable disclosing my sexual identity		
Yes	19 (7.8)	51 (20.9)	69 (28.3)	69 (28.3)	36 (14.8)
No	2 (3.4)	16 (27.1)	18 (30.5)	12 (20.3)	11 (18.6)
			Comfortable disclosing my gender identity		
Yes	17 (7.0)	20 (8.2)	24 (9.8)	51 (20.9)	132 (54.1)
No	3 (5.1)	12 (20.3)	5 (8.5)	14 (23.7)	25 (42.4)

Coming out. A total of 39 (18.8%) participants checked "I came out to my GP." To test whether gender or sexual identity was associated with coming out to one's GP, a binary logistic regression was run (Table 7.14), with both gender and sexual orientation in the same model. There was a statistically significant association for gender (*p* = .04), but as seen in Table 7.14; there was no statistically significant association for sexual orientation (*p* = .47).

Table 7.14 Bivariable binary logistic regression results for participants who came out to their GP, by gender and sexual orientation

Category	*n*	OR	95% CI (for OR)
Overall Gender	208		
Male	44	1.00	(Reference)
Female	121	1.02	(0.32, 3.29)
Transmale	12	0.15	(0.03, 0.68)
Gender queer	14	0.54	(0.10, 2.83)
Non-Binary	10	0.27	(0.05, 1.40)
Other	7	0.42	(0.06, 3.02)
Overall Sexual Orientation	208		
Strictly homosexual	59	1.00	(Reference)
Bisexual/Pansexual	116	0.65	(0.24, 1.75)
Unsure/Questioning	20	1.57	(0.27, 9.18)
Other	13	0.41	(0.09, 1.85)

Listening skills. Another question directly measuring the perception of good communication between the participants and their GPs was “During your most recent visit, did your GP listen carefully to you?” A total of 246 participants answered this question (out of 247 with a regular GP). Just over half of the respondents (54.1%, n = 133) responded “Definitely,” while 98 (39.8%) participants responded “somewhat.” Fifteen (6.1%) participants felt their GP did not listen carefully to them on their last visit.

7.6.4. Decision Making and Trust in GP

Decision-making in a clinical setting can be an indicator of mutual trust, respect, and effective communication. When it came to making medical decisions with their doctor (Figure 7.4), the majority (*n* = 159, 68.8%) of the 231 participants who responded were split between “We make decisions together” (*n* = 73, 31.6%) and “My GP explains things to me, then encourages me [to] make my own decision” (*n* = 86, 37.2%). Both response options convey a level of trust and respect between GP and client. Of the 14 (6.1%) participants who answered “Other,” two indicated in the open text field that their GP consults the respondents’ guardian or parent. Three participants indicated their GP consults them but ultimately the GP makes the decision. In contrast, one participant wrote, *“my gp [sic] tries to make decisions on their own but im [sic] pushy.”*

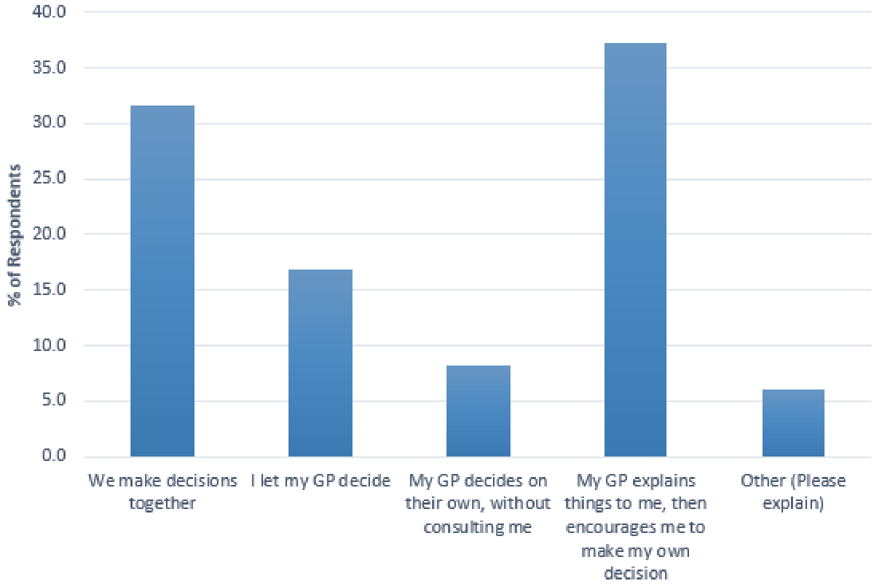

Figure 7.4 Medical decision making in participants with a regular GP (n = 231).

In line with the decision-making results, a high level of trust in a regular GP’s medical care was evident when participants were directly asked “How much do you trust your GP to make medical decisions that are in your best interest?” Of 247 participants who answered this question, 61.9% (*n* = 153) answered “A great deal” or “A lot.” Only 8.1% (*n* = 20) ticked “A little” or “None at all,” and 30% (*n* = 74) chose “A moderate amount.”

There was, however, a statistically significant difference in trust levels between those who believed their GP had an anti-LGBTQ+ bias and those who did not. While only 4.5% (*n* = 9) of those who did not think their GP held an anti-LGBTQ+ bias ticked "very little" on the trust question, 25% (*n* = 2) of those who thought their GP was biased ticked that option (Fisher's exact test *p* = .014). A similar difference was noted among those who ticked "I've experienced biased responses / discrimination from my GP" and those who did not. Among participants who have experienced bias from their GP, 20% (*n* = 3) indicated "very little" trust in their GP's medical decisions, compared with 4.1% (*n* = 8) in the group who did not experience bias from their GP (Fisher's exact test *p* = .001).

As part of the investigation around the first research question in this study, an analysis was run to test whether sexual or gender identities present a barrier to healthcare access in terms of trust. Ordinal logistic regression for the "trust in medical decisions" question above showed self-identified gender was associated with the level of trust respondents had in their GPs' care decision (Table 7.15). Transmale, gender queer, and those identifying in the "Other" category were less likely to rate their trust in the GP's care decision as high as those identifying as males (the reference category).

Table 7.15 Ordinal bivariable logistic regression: Impact of self-identified gender and sexual orientation on trust in GP's medical decisions.

		A great deal	A lot	A moderate amount	A little	None at all		
Category	*n*	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	OR	(95% CI)
Gender Identity	244							
Male	48	18 (37.5)	16 (33.3)	13 (27.1)	1 (2.1)	0 (0.0)	1.00	(reference)
Female	142	33 (23.2)	60 (42.3)	41 (28.9)	7 (4.9)	1 (0.7)	0.60	(0.31, 1.16)
Transmale	13	2 (15.4)	5 (38.5)	2 (15.4)	4 (30.8)	0 (0.0)	0.25	(0.08, 0.79)
Gender queer	20	3 (15.0)	5 (25.0)	10 (50.0)	2 (10.0)	0 (0.0)	0.26	(0.10, 0.73)
Non-Binary	11	4 (36.4)	1 (9.1)	3 (27.3)	3 (27.3)	0 (0.0)	0.32	(0.09, 1.10)
Other	10	1 (10.0)	3 (30.0)	4 (40.0)	1 (10.0)	1 (10.0)	0.20	(0.05, 0.71)
Sexual Orientation	244							
Strictly homosexual	64	18 (28.1)	23 (35.9)	18 (28.1)	5 (7.8)	0 (0.0)	1.00	(reference)
Bisexual/pansexual	144	36 (25.0)	50 (34.7)	46 (31.9)	10 (6.9)	2 (1.4)	1.04	(0.57, 1.88)
Unsure/Questioning	22	3 (13.6)	13 (59.1)	5 (22.7)	1 (4.5)	0 (0.0)	1.25	(0.50, 3.17)
Other	14	4 (28.6)	4 (28.6)	4 (28.6)	2 (14.3)	0 (0.0)	1.34	(0.44, 4.11)

7.6.5. Confidentiality Concerns

Over a quarter (n=59, 28.5%) of the participants with a regular GP were concerned about confidentiality, as seen in Table 7.12. Confidentiality concerns were hypothesised to be a barrier to healthcare utilisation in LGBTQ+ teens, since many of them would be using the family GP by default. Further analysis was undertaken of the statement “I worry that if I come out to a healthcare provider my family/whānau will find out,” and a 5-point Likert scale response was part of the health communication self-efficacy assessment (Section 7.7). The latter comprised individuals both with and without a regular GP. A total of 45.2% of the participants agreed or strongly agreed with this statement regarding whānau finding out in the health communication self-efficacy assessment. However, a larger percentage of participants with no regular GP (67.2% vs. 40.0%) strongly agreed/agreed with this statement. Conversely, a larger percentage of participants with a regular GP (45.8% vs. 24.1%) disagreed/strongly disagreed with this statement (see Figure 7.5). A Fisher’s exact test of independence was significant for these differences (p = .002), showing an association between heightened confidentiality concerns and not having a regular GP. Spearman’s correlation (ρ = -.225), showed a negative weak correlation between confidentiality concerns and having a regular GP.

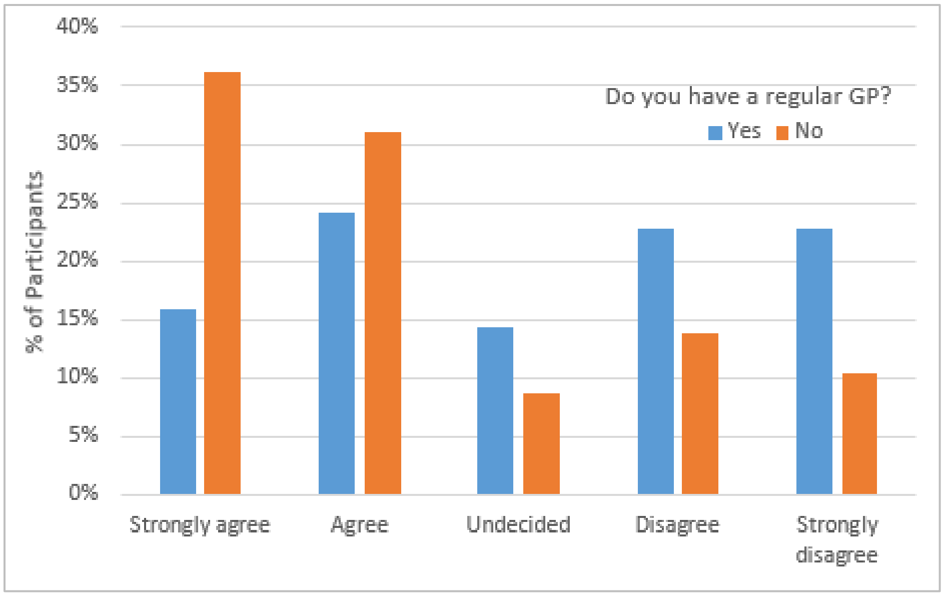

Figure 7.5 Confidentiality concerns in participants with and without a regular GP. Responses to the statement, “I worry that if I come out to a healthcare provider my family/whānau will find out.”

Confidentiality concerns were also associated with trust in the GP’s medical decisions, among participants with a regular GP. The percentage of participants who said they had “a little” trust in their GP’s medical decision was greater among those who ticked the box for “I worry that if I come out to a healthcare provider my family/whānau will find out” (13.6%, $n = 8$), compared with those who did not express confidentiality concerns (2.0%, $n = 3$); a difference that was significant (Fisher’s exact test $p < .001$). Similarly, the perception of a GP’s quality tended to be worse in participants expressing confidentiality concerns, where 44.1% ($n = 26$) of the participants with confidentiality concerns rated their GP lower than 7, compared with 18.1% ($n = 27$) of those who did not have confidentiality concerns (Fisher’s exact test $p < .001$).

7.7. Health Communication Self-Efficacy

Health communication self-efficacy forms the basis of the analytic model for the survey results (see Figure 7.1). As will be addressed in the Discussion chapter, the model proposes that health communication self-efficacy impacts communication with one's GP, therefore affecting the utilisation of healthcare resources (which speaks to the first research question). Through its influence on communication with one's GP, it is hypothesised that self-efficacy also impacts sexual-risk behaviour, thus it is also important to research questions 2 and 3. The analyses in this section, however, concern Research Question 1.

The health communication self-efficacy multipart question examined the respondents' level of confidence communicating with a healthcare provider in the context of their sexual and/or gender identities. The structure of this assessment and the individual questions can be found in Appendix D (Q31). Responses to the questions ranged from 294 to 303.

Only responses where all 13 questions that constituted the scale were completed were used in the analysis (*n* = 294). Scores on the scale ranged from 15 (1 participant) to 65 (4 participants), with a mean score of 44.2. Higher scores signify higher self-efficacy. The method of scoring is discussed in the Methods chapter, Section 6.7.

To test whether sexual or gender identities were associated with health communication self-efficacy, linear regression was done using the scale's total score as the dependent variable. Whereas sexual identity was not associated with the self-efficacy score in this study population, gender identity (with the exception of those identifying as female) was associated with significantly lower total scores, as seen in Table 7.16. This indicates gender identity, outside the cis-normative male/female, may act as a barrier to accessing healthcare.

Table 7.16 Bivariable linear regression model: Sexual or gender identity impact on total healthcare communication self-efficacy score.

Category	*B**	Std error	(95% CI)
Gender *identity*			
Male	0		(reference)
Female	-.523	1.60	(-3.67, 2.61)
Transmale	-7.97	2.72	(-13.30, -2.64)
Gender-queer	-7.07	2.44	(-11.86, -2.28)
Non-Binary	-9.42	2.89	(-15.08, -3.75)
Other	-16.29	3.18	(-22.52, -10.06)
Sexual identity			
Strictly homosexual	0		(reference)
Bisexual/Pansexual	1.05	1.44	(-1.77, 3.87)
Unsure/Questioning	-.66	2.38	(-5.33, 4.02)
Other	1.44	2.78	(-5.69, 5.20)

* Unstandardized coefficients

Considering the reported worsening mental health among teens in general throughout the Youth 2000 waves (Fleming, Tiatia-Seath, et al., 2020; Fleming et al., 2014), the interaction of health communication self-efficacy and emotional health were of interest in this study. As self-efficacy is hypothesised to play a role in communication with one's GP in this study's analytic model (see Figure 7.1), factors that affect self-efficacy may therefore form a barrier to interacting with a healthcare provider. Among people who rated their overall health Good or above, and their emotional health Fair or Poor, there was a statistically significant difference in the mean total score of this scale between people who have a regular GP (n = 110; M = 44.97; SD = 9.18) and those who do not (n = 26; M = 37.27; SD = 8.53; t (134) = 3.90; p < .001). It is possible the presence of a GP is a mediating factor – the issue is explored in the context of existing literature in the Discussion chapter. Among participants who rated both their overall and emotional health Good or above, the difference between those who did and did not have a regular GP was not statistically significant (p = .062).

As a further test of whether sexual or gender identity are perceived as barriers to healthcare access, the total self-efficacy score of people who avoided care in the past due to their LGBTQ+ status was compared with those who did not avoid care. Among the participants who avoided care in the past due to their LGBTQ+ status (*n* = 64), the mean score was on this question 36.75 (*SD* = 9.13). None of them scored above 55. Among those who did not avoid care in the past due to their LGBTQ+ status (*n* = 213), the mean score was 46.28 (*SD* = 9.80), and the scores covered the entire range up to 65. An independent samples t-test showed the difference in mean total score between the two groups was statistically significant (*t* (275) = -6.93; *p* < .001). As with previous findings in this study, it is not possible to infer causality from these findings – whether people avoided care due to low self-efficacy stemming from their minority status, whether they experience low self-efficacy due to past incidents that also made them forego care, or whether an additional (unknown) factor is influencing this association. However, this finding shows that health communication self-efficacy and avoidance of care due to one's sexual or gender identity were associated with each other in this study population.

Being out to one's GP might be expected to be associated with a person's health communication self-efficacy. However, there were no significant differences between total scores on this scale in participants who did or did not come out to their GP (independent samples t-test *p* = .172). Concern about confidentiality was associated with self-efficacy. In participants with regular GPs who worried about confidentiality (n = 57), the total mean score for this scale (40.86) was significantly lower compared with those who did not express such concern (*n* = 152; mean score: 47.47; *t* (207) = -4.165; *p* < .001).

Of 303 participants, 128 (42.2%) respondents felt comfortable disclosing their sexual identity to a healthcare provider, while 87 (28.7%) respondents were undecided. These figures include all study participants, unlike the figures in Section 7.6.3, which included only participants who had a regular GP. When it came to disclosing gender identity, 222 (73.3%) respondents felt comfortable doing so, with 29 (9.6%) respondents undecided. The overwhelming majority of responses in the Strongly Agree category identified as "Female" (*n* = 103, 65.6%) and "Male" (*n* = 41, 26.1%). There was no association between sexual identity and ease of disclosing one's sexual identity to their GP (Fisher's exact *p* = .221).

There was a noticeable difference in participants' responses to two sets of questions on this scale. While 49.7% (*n* = 145) Strongly agreed/Agreed with the statement "I worry about being discriminated against by a healthcare provider if I disclose my sexual identity," only 16.4% (*n* = 48) Strongly agreed/Agreed with the statement "I believe my medical care will suffer if I disclose my sexual identity to a healthcare provider." Similarly, 24.7% (*n* = 72) of the participants Strongly agreed/Agreed with the statement, "I worry about being discriminated against by a healthcare provider if I disclose my gender identity," while only 13.4% (*n* = 39) Strongly agreed/Agreed with the statement, "I believe my medical care will suffer if I disclose my sexual identity to a healthcare provider." In both cross-tabulations there is significant asymmetry and significant marginal heterogeneity (all *p* < .001).

7.8. Sexual Health

A total of 308 participants answered the question "Are you sexually active?" Of these, 143 (46.4%) indicated that they were. Only those participants who were sexually active were asked about preventive behaviours (Condom use, HIV and STI testing, PrEP knowledge). The distribution of sexual activity by year of birth is shown in Table 7.17.

Analyses in this section concern research questions 2 and 3 of this study.

Table 7.17 Sexual activity by year of birth (*n* = 308).

	Are you sexually active?	
	Yes	No
Year of birth	*n* (%)	*n* (%)
1999	3 (100.0)	0 (0.0)
2000	14 (60.9)	9 (39.1)
2001	19 (65.5)	10 (34.5)
2002	44 (53.0)	39 (47.0)
2003	41 (43.6)	53 (56.4)
2004	20 (33.3)	40 (66.7)
2005	2 (12.5)	14 (87.5)

RQ2: Do Perceptions of Healthcare Barriers Influence Sexual Risk Behaviours (e.g. Condom Use)?

7.8.1. Sexual Health: Primary Prevention

7.8.1.1 *Condom Use*

Of the 143 participants who stated they were sexually active, 142 answered the question about condom use (Table 7.18). Of these, 50 (35.2%) stated they use a condom consistently when having sex, while 21 (14.8%) stated they never use a condom.

Table 7.18 Condom Use frequency (n=142)

Frequency	*n*	(%)
Never	21	14.8
Every time I have sex	50	35.2
Only with new or casual partners	30	21.1
Other (Please specify)	22	15.5
N/A	19	13.4

Answers to the "Other" field included an open-text option. All 22 people responded in the open-text field, with three stating they were on oral or injectable birth control. This points to a possible gap in knowledge, if a condom is viewed only as a method of birth control, rather than also being a barrier protection against STI. Three people responded with "sometimes." Other responses pointed to knowing the partner was tested for STI regularly, having a partner who had no prior partners, and making the decision in consultation with the partner.

To ensure the "never use" results were not simply limited to those with female anatomy, an analysis was carried out to test whether there was a relationship between gender and condom use (Table 7.19). However, no significant difference was found (Fisher's exact test $p = .059$). This analysis arose out of the concern that the wording of the question was not changed when the study population was expanded. While the original wording was gender neutral – "Do you use a condom when having sex?" – the concern was that participants assigned female at birth will not think the question applies to them.[22] Because certain sexualities have a higher risk of STIs (including HIV), a test was carried out to determine whether there was an association between condom usage frequency and sexuality (Table 7.19). However, this test was not significant (Fisher's exact test p = .191).

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[22] Female condoms were not referenced because of their very low use in other surveys.

Table 7.19 Condom use frequency by self-identified gender and sexuality (*n* = 142)

	Usage frequency				
Category	Never	Every time I have sex	Only with casual partners	Other (Please specify)	N/A
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Gender					
Male	4 (12.1)	16 (48.5)	8 (24.2)	5 (15.2)	0 (0.0)
Female	13 (15.7)	24 (28.9)	16 (19.3)	13 (15.7)	17 (20.5)
Transmale/Transfemale	2 (20.0)	5 (50)	0 (0.0)	3 (30.0)	0 (0.0)
Gender queer / Non-binary	1 (9.1)	3 (27.3)	5 (45.5)	0 (0.0)	2 (18.2)
Other	1 (20.0)	2 (40.0)	1 (20.0)	1 (20.0)	0 (0.0)
Sexual identity					
Strictly homosexual	9 (21.4)	12 (28.6)	7 (16.7)	6 (14.3)	8 (19.0)
Strictly heterosexual	0 (0.0)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)
Bisexual/Pansexual	12 (13.5)	35 (39.3)	22 (24.7)	11 (12.4)	9 (10.1)
Unsure/Questioning	0 (0.0)	1 (25.0)	1 (25.0)	2 (50.0)	0 (0.0)
Other	21 (14.8)	50 (35.2)	30 (21.1)	22 (15.5)	19 (13.4)

* Percent within categories

7.8.1.2 ***Condom Self-Efficacy***

The condom self-efficacy multipart question examined the respondents' level of confidence in using a condom – or suggesting its use to a partner – when having sex. The structure of this assessment and the individual questions can be found in Appendix D. Since each question was coded as an independent question, the number of valid responses to each question varied from 302 to 304. For the descriptive statistics, only questions that were answered in full (all 14 parts of the scale) were used. The actual number of fully completed questions was n=301.

Scores on the scale ranged from 18 (1 participant) to 70 (6 participants), with mean score of 50.16. The method of scoring is discussed in the Methods chapter, Section 6.8.

In trying to answer whether having a regular GP influenced sexual health, one of the factors examined in this study was the self-efficacy score for condom use in people with and without a regular GP. An independent samples t-test was conducted to compare the mean scores of people in these two groups. Among the entire study population, there was no statistically significant difference between people with a regular GP (*n* = 242, *M* = 50.53, *SD* = 9.24) and those without (*n* = 59, *M* = 48.64, *SD* = 10.39; *p* = .171).

7.8.1.3 ***PrEP Knowledge***

PrEP is a combination drug that can greatly reduce the risk of an HIV-negative person developing an infection following unprotected sex with an HIV-positive individual. When taken correctly, PrEP is 99% effective in preventing HIV infections (The Best Practice Advocacy Centre New Zealand, 2019). It does not, however, prevent other forms of STIs. PrEP is available in New Zealand as a subsidised drug to men and trans* individuals having sex with men, if they meet certain additional high risk criteria.

A total of 65 participants (of 307; 21.2%) answered “Yes” to the question “Are you familiar with PrEP?” PrEP knowledge was not related to having a GP (Fisher’s exact test *p* = .862). Because PrEP in New Zealand is used by men and transwomen who have sex with men, an analysis was done to see if PrEP knowledge was related to gender. A Fisher’s exact test was significant (*p* < .001), showing an association between PrEP knowledge and gender. Of those who answered yes, 49.2% (*n* = 32) identified as Male. Similarly, sexual orientation was associated with PrEP (Fisher’s exact test, *p* < .001). Of those who answered yes, 52.3% (*n* = 34) identified as strictly homosexual.

Table 7.20 Familiarity with PrEP, by gender and sexual identity (n=307)

	Are you familiar with PrEP?	
	Yes	No
Category	*n* (%*)	*n* (%*)
Gender identity		
Male	32 (53.3)	28 (46.7)
Female	18 (10.3)	156 (89.7)
Transmale	4 (21.1)	15 (78.9)
Transfemale	2 (100.0)	0 (0.0)
Gender-queer	3 (22.0)	12 (88.)
Non-Binary	4 (26.7)	11 (73.3)
Other	2 (16.7)	10 (83.3)
Sexual identity		
Strictly homosexual	34 (43.0)	45 (57.0)
Strictly heterosexual	0 (0.0)	1 (100.0)
Bisexual/Pansexual	27 (14.6)	158 (85.4)
Unsure/Questioning	1 (4.0)	24 (96.0)
Other	3 (17.6)	14 (82.4)

* % within category

Of the participants who answered “Yes,” 58 (89.2%) went on to answer the question, “In your own words, please tell us what you know about PrEP.”

The NZAF definition of PrEP, which is publically available on the NZAF web site, was used as the bar against which answers were measured.[23]

The majority of respondents had at least a good general idea of what PrEP was. Many said it’s used to prevent AIDS, others replied with a variation on *“it’s used to prevent HIV [infection].” “PrEP is specific antiretroviral drugs used to treat HIV, used*

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[23] NZAF defined PrEP as “…the use of HIV medication by people who are HIV-negative in order to reduce their risk of HIV infection…. These are the same drugs used to treat and suppress the virus in people living with HIV” New Zealand AIDS Foundation. (n.d.). *Pre-exposure Prophylaxis (PrEP)*. New Zealand AIDS Foundation. Retrieved 20/07/2021 from https://www.nzaf.org.nz/awareness-and-prevention/prevention/pre-exposure-prophylaxis-prep/. Note that NZAF has since changed its name to The Burnett Foundation, and its website content and addresses changed as of June, 2022.

without having HIV when in a high-risk relationship. It kills the virus before it can take hold, and stops you from getting HIV."

Of the 58 responses, 6 (10.3%) were not in accord with the NZAF definition of PrEP. Four of the six participants thought PrEP prevented STIs. The other two likened PrEP to a contraceptive pill. Examples include: *"It's kinda like vaccines, you let your body identify and fight off small amounts of whatever so that if you were to get any std [sic] or sti's [sic] your body has a better chance to fight it off"*; *"Like the pill woman take to stop pregancy [sic] but for gays."*

Three respondents had heard of PrEP but could not describe it. Six respondents confused the concept of PrEP with Treatment as Prevention (TaP; for the treatment of HIV-positive participants).[24]

RQ3: Do These Perceptions Affect the Uptake of Preventive Behaviours (e.g. STI Screening)?

7.8.2 Sexual Health: Secondary Prevention

7.8.2.1 *HIV Testing*

Knowledge of one's HIV status is important not only to the infected person's health, but also to reduce the likelihood of transmitting the infection to their sexual partners (Biello et al., 2019). A total of 41 participants indicated they were tested for HIV, out of 143 sexually active respondents. The breakdown of participants' HIV test status by sexual and gender identities is shown in Table 7.21. Of those who did test, 53.6% (*n* = 22) identified as female, and 65.8% (*n* = 27) identified as bisexual/pansexual.

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[24] TaP aims to reduce the viral load in the blood stream to undetectable levels, which than makes the virus untransmissable. While the drugs and the concept of prevention are the same for PrEP and TaP, if an HIV-negative person thinks the only preventive available is for people already carrying the virus, they may not think to ask about a drug that can protect them.

Fisher’s exact tests for the associations between gender identity or sexual orientation and HIV testing status showed no connection between these variables (*p* = .679, *p* = .842 respectively).

Table 7.21 HIV testing status by sexual and gender identity

	Have you been tested for HIV?	
	Yes	No
Category	*n* (%)	*n* (%)
Gender identity		
Male	12 (35.3)	22 (65.7)
Female	22 (26.5)	61 (73.5)
Transmale	2 (22.2)	7 (77.8)
Transfemale	1 (100.0)	0 (0.0)
Gender-queer	2 (40.0)	3 (60.0)
Non-Binary	1 (16.7)	5 (83.3)
Other	1 (20.0)	4 (80.0)
Sexual identity		
Strictly homosexual	12 (27.9)	31 (72.9)
Strictly heterosexual	0 (0.0)	1 (100.0)
Bisexual/Pansexual	27 (30.3)	62 (69.7)
Unsure/Questioning	0 (0.0)	4 (100.0)
Other	2 (33.3)	4 (66.6)

* % within category

Of the 143 participants who were sexually active, 101 (70.6%) also answered whether they came out to their GP, and whether they felt comfortable discussing their sexual and gender identities with their GP. There were 33 (32.7%) participants out of these 101 who were tested for HIV, and 68 (67.3%) who said they were not tested.

Because the risk of HIV is higher in men and transwomen who have sex with men, the study looked at whether open communication regarding one’s sexual and gender identities translated to higher HIV test rates. An analysis to examine if there is a relationship between participants’ comfort discussing their sexual/gender identity with their GP and their HIV test status was done (Table 7.22), but no difference was found (Fisher's exact test *p* = .137). Thus, no association was found between the participants' ability to openly discuss their sexual and gender identity with their GP and being tested for HIV.

The same analysis was repeated to determine whether there was a relationship between coming out to one's GP and HIV testing behaviour. A Fisher's exact test was not statistically significant (p = .085); no association was found between the two variables either (Table 7.22).

Table 7.22 Crosstab analysis: HIV testing behaviour * sexual/gender identity discussion with GP (*n* = 101)

	Have you been tested for HIV?	
I feel comfortable discussing my sexual/gender identity with my GP	Yes *n* (%)*	No *n* (%)*
Yes	20 (40.8)	29 (59.2)
No	13 (25.0)	39 (75.0)
I came out to my GP		
Yes	12 (48.0)	13 (52.0)
No	21 (27.6)	55 (72.4)

* % within "I feel comfortable discussing my sexual/gender identity with my GP" and "I came out to my GP"

People who responded they had not been tested for HIV were asked why not (a multi-response question). The percentage for each response is shown in Table 7.23. There were 199 responses from 102 participants. The majority of respondents (n=55, 53.9%) checked one choice. Three participants checked all five choices.

Table 7.23 Reasons for not getting an HIV test (*n* = 102)

Answer choices	*n*	(%)
I don't think I'm at risk for HIV	79	77.5
I'm not sure how to get tested	36	35.3
I'm not sure where to get tested	33	32.4
I'm afraid someone will find out I got tested	25	24.5
I'm afraid I'll test positive	14	13.7
Other (Please specify)	12	11.8

* Percent refers to percent of cases (n=102)

The reasons for not testing, according to gender and sexual identities, are shown in Table 7.24. While in most gender categories participants overwhelmingly felt they were not at risk for HIV, the percentage of males ticking this option was lower than other gender categories. There may have also been more indecision or uncertainty among males with regards to testing for HIV, as several choices were ticked by at least 50% of that group. A similar picture emerged with those identifying as gender-queer, though with fewer choices being at or above the 50% mark.

There was no statistically significant association between participants' age and HIV testing behaviour (p =.149).

Twelve people who ticked "Other" wrote in the open text field. Six of the 12 felt no need to get tested. Three gave a reason – stating they or their partners were newly sexually active. One other participant cited anxiety, one cited cost for women, and another cited "Inconvenience with locations and times." Another participant said they would not even know if they needed a test, there is no education about it in "sex ed." The last two participants "Just haven't gotten around to it."

Table 7.24 Reasons for not testing for HIV, by sexual and gender identity

Category	I don't think I'm at risk	Not sure how to get tested	Not sure where to get tested	Afraid someone will find out I got tested	Afraid I'll test positive	Other
	n (%)*					
Gender *identity*						
Male	13 (59.1)	12 (54.5)	11 (50.0)	11 (50.0)	5 (22.7)	3 (13.6)
Female	49 (80.3)	15 (24.6)	14 (23.0)	11 (18.0)	7 (11.5)	6 (9.8)
Transmale	6 (85.7)	3 (42.9)	3 (42.9)	1 (14.3)	1 (14.3)	0 (0.0)
Gender-queer	3 (100.0)	3 (100.0)	2 (66.7)	1 (33.3)	0 (0.0)	0 (0.0)
Non-Binary	4 (80.0)	2 (40.0)	2 (40.0)	1 (20.0)	1 (20.0)	2 (40.)
Other	4 (100.0)	1 (25.0)	1 (25.0)	0 (0.0)	0 (0.0)	1 (25.0)
Sexual identity						
Strictly homosexual	22 (71.0)	12 (38.7)	14 (45.2)	9 (29.0)	4 (12.9)	3 (9.7)
Strictly heterosexual	1 (100.0)	1 (100.0)	1 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)
Bisexual/Pansexual	51 (82.3)	18 (29.0)	13 (21.0)	13 (21.0)	9 (14.5)	8 (12.9)
Unsure/Questioning	2 (50.0)	3 (75.0)	3 (75.0)	2 (50.0)	1 25.0)	0 (0.0)
Other	3 (75.0)	2 (50.0)	2 (50.0)	1 (25.0)	0 (0.0)	1 (25.0)

* % within category, based on number of cases per category

7.8.2.2 ***STI Testing***

As mentioned previously, LGBTQ+ youth are at higher risk of STIs than other population groups. Fifty-nine participants indicated they had been tested for STIs (not including HIV). The breakdown of participants' STI test status by sexual and gender identities is shown in Table 7.25. Of those who did test, 59.3% (n=35) identified as female, and 71.2% (*n* = 42) identified as bisexual/pansexual. Tests for the associations between gender identity or sexual orientation and STI testing status showed no association between these variables (Fisher's exact test *p* = .621, *p* = .421, respectively).

Table 7.25 STI testing status by sexual and gender identity

	Have you been tested for STI?	
Category	Yes *n* (%)	No *n* (%)
Gender identity		
Male	11 (32.4)	23 (67.6)
Female	35 (42.2)	48 (57.8)
Transmale	3 (33.3)	6 (66.6)
Transfemale	1 (100.0)	0 (0.0)
Gender-queer	3 (60.0)	2 (40.0)
Non-Binary	3 (50.0)	3 (50.0)
Other	3 (60.0)	2 (40.0)
Sexual identity		
Strictly homosexual	14 (32.6)	29 (67.4)
Strictly heterosexual	0 (0.0)	1 (100.0)
Bisexual/Pansexual	42 (47.2)	47 (52.8)
Unsure/Questioning	1 (25.0)	3 (75.0)
Other	2 (33.3)	4 (66.6)

* % within category

Among the participants who were tested for STIs other than HIV, half (*n* = 22, 50.0%) indicated they were comfortable discussing their sexual/gender identity with their GP. Of those not tested (*n* = 30) 52.6% were not comfortable discussing their sexual/gender identity with their GP (Table 7.26). There was no association between STI test status and being comfortable disclosing one's sexual or gender identity to their GP (Fisher's exact test *p* = .843). The same analysis was carried out to test for a relationship between STI test status and coming out to one's GP (Table 7.26); no association was found (Fisher's exact test *p* = .169). People who responded they were not tested for STI were asked why not (a multi-response question). The percentage for each response is shown in Table 7.27.

Table 7.26 Cross tabulation of STI testing status by sexual/gender identity discussion with GP (*n* = 101)

	Have you been tested for any STIs other than HIV?	
I feel comfortable discussing my sexual/gender identity with my GP	Yes *n* (%)*	No *n* (%)*
Yes	22 (44.9)	27 (55.1)
No	22 (42.3)	30 (57.7)
I came out to my GP		
Yes	14 (56.0)	11 (44.0)
No	30 (39.5)	46 (60.5)

* % within "I feel comfortable discussing my sexual/gender identity with my GP" and "I came out to my GP"

Table 7.27 Reasons for not getting an STI test (n=102)

Answer choices	*n*	(%)
I don't think I'm at risk for STIs	59	(71.1)
I'm not sure how to get tested	23	27.7
I'm not sure where to get tested	28	33.7
I'm afraid someone will find out I got tested	20	24.1
I'm afraid I'll test positive	16	19.3
Other (Please specify)	6	7.2

There were 152 responses from 76 participants. The majority of respondents (*n* = 49, 64.5%) checked one choice. Three participants checked all five choices. The breakdown of reasons for not testing, by gender and sexual identities, is shown in Table 7.28. There was no statistically significant association between participants' age and STI testing behaviour (*p* =.162).

Six people who ticked "Other" wrote in the open text field. One participant cited anxiety, two participants "Just haven't gotten around to it." Three felt no need because they were newly sexually active or had a partner that "tested clear."

Table 7.28 Reasons for not testing for STIs, by sexual and gender identity

Category	I don't think I'm at risk	Not sure how to get tested	Not sure where to get tested	Afraid someone will find out I got tested	Afraid I'll test positive	Other
	n (%)*					
Gender identity						
Male	12 (54.5)	8 (36.4)	9 (40.9)	8 (36.4)	4 (18.2)	1 (4.5)
Female	37 (77.1)	12 (25.0)	16 (33.3)	10 (20.8)	10 (20.8)	1 (2.1)
Transmale	5 (83.3)	1 (16.7)	1 (16.7)	1 (16.7)	2 (33.3)	1 (16.7)
Gender-queer	2 (100.0)	1 (50.0)	1 (50.0)	1 (50.0)	0 (0.0)	0 (0.0)
Non-Binary	1 (33.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (66.7)
Other	2 (100.0)	1 (50.0)	1 (50.0)	0 (0.0)	0 (0.0)	1 (50.0)
Sexual identity						
Strictly homosexual	16 (57.1)	7 (25.0)	9 (32.1)	7 (25.0)	5 (17.9)	2 (7.1)
Strictly heterosexual	1 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)
Bisexual/Pansexual	38 (80.9)	13 (27.7)	16 (34.0)	11 (23.4)	8 (17.0)	2 (4.3)
Unsure/Questioning	1 (33.3)	2 (66.7)	2 (66.7)	1 (33.3)	1 (33.3)	1 (33.3)
Other	3 (75.0)	1 (25.0)	1 (25.0)	1 (25.0)	1 (25.0)	1 (25.0)

* % within category, based on number of cases per category

7.9. Sources of Health Information

If there are perceived barriers to accessing healthcare in this study population, it is likely that the majority of participants would name other resources – not their care provider – as their main source of health information. Participants were asked "What is your main source of information about any health risks you may have?" Of 203 responses received, 119 (58.6%) mentioned the internet by itself (*n* = 62) or in combination with other sources (e.g. school nurses, family, GP). Fifty people (24.6% of respondents) mentioned healthcare providers, with 37 of those specifically mentioning their GP. Thirty-seven people (18.2%) named school as their main resource – this category included health classes and staff members, but did not include friends. Other resources included family members who are healthcare workers, friends, partners, and YOSS – youth spaces providing comprehensive physical and mental health services (see Context chapter, Section 2.5.1).

7.10. Open-Ended Questions in the Survey

This section provides content analysis of open-ended questions in the survey not discussed above. The first part of this section elaborates on questions regarding participants' perceptions of their healthcare experience. The second part looks at actual experiences – good and bad – that participants provided from their encounters navigating the healthcare system. This section further illuminates RQ1.

7.10.1. Participants' Perceptions of the Healthcare Experience

Participants could select up to six responses to a question about their relationship with their current GP (see Table 7.12); all responses provided space for a text response (see Table 7.29 for sample responses). These short answer responses are discussed in detail in the subsections that follow.

A high percentage of respondents (81.6%) checked the statement "I feel comfortable talking to my GP about any health-related issue." The most common sentiments were "it's their job" (*n* = 14), that is, listening to patients is an expected part of the GP role, and the perception of the GP as a good listener (*n* = 10). Eight respondents cited the perception of their GP being understanding as contributing to an open discussion about health issues. Other attributes that encouraged open discussions included GPs being non-judgemental, friendly, and honest. Length of association and confidentiality were other factors that increased some participants comfort with their GP.

Table 7.29 Open-ended questions for "Thinking about your current GP, please check all that apply."

Response	Responses to quantitative question	Responses to open-ended question – *n* (%*)	Sample Quote
I feel comfortable talking to my GP about any health-related issue	169	105 (62.1)	"…even if something's embarrassing to talk about you can be assured that they've likely had experience with it at some point in their careers"
I feel comfortable discussing my sexual/gender identity with my GP	82	47 (57.3)	"Initially I was worried because I didn't know how she would respond but when I came out to her she didn't change the way I'm [sic] which she treated or cared for me"
I came out to my GP	39	24 (61.5)	"My mother helped me explain that I am transgender and he fully accepted me and didn't see me any differently"
I'm worried my GP will tell my family/whānau things I tell them	59	32 (54.2)	"I want to be able to talk to someone and not have them tell the family."
I've experienced biased responses / discrimination from my GP	8	7 (87.5)	"My previous GP was unwilling to provide gender affirming care."
I believe my GP has an anti-LGBTQ bias	15	16**	"Does have religious items in his office, so it is very possible. Not something that comforts me."

* Percent of those answering the quantitative question

** One person did not tick the box but wrote "I have not ☺" in the text field

Some respondents used the open ended response to qualify their comfort discussing health-related issues. Mental health and sexuality were not considered by some participants to be a discussion they were comfortable having with their GP. Others cited barriers to an open discussion of health related issues, such as having parents in the room or the physician's gender (e.g. *"Because my doctor is also female it helps and makes me feel more comfortable talking to her"*).

The next statement on this multipart question was "I feel comfortable discussing my sexual/gender identity with my GP." A total of 82 (39.6%) participants ticked the statement. Forty-seven of these 82 also used the open text field to explain. Responses ranged widely with five participants indicating they in fact did not feel comfortable (e.g. "*I feel like I dont [sic] know my GP well enough to say those sorts of things"*) to those who experienced no concerns discussing sensitive issues. Eight participants wrote that the topic has never come up in their visits to the GP, with three adding that if it did come up they would feel comfortable. Seven participants noted their GP was non-biased or non-judgemental, which contributed to their comfort discussing these topics. Four other participants noted they have come out to other healthcare professionals in the past and encountered no negative reactions. They were therefore not concerned about discussing their gender or sexual identity with their GP.

Personal context appeared important, with those participants who were already out to everyone indicated this made them more comfortable discussing their sexuality and gender identity (*n* = 3; these are not the same participants who came out to healthcare professionals in the past). Two participants mentioned their GP being LGBTQ+ themselves as helpful in this type of discussion. The common thread running through the rest of the responses were the GPs' "accepting," "supportive," and "understanding" attitudes that made these discussions or disclosures easier.

Of the 39 participants who indicated they came out to their GP, 24 filled in the open text field. Five indicated they actually did not come out, two because they saw no reason to and one indicated they were still unsure of their sexuality. These five participants were not included in the quantitative analyses as being out to their GP.

The majority of the remaining 19 who did come out and commented, they either did not come out directly (e.g. some changed their name and pronouns on their health records as part of their gender transitioning), or they came out because they had a specific need (e.g. a referral to specialist services for the purpose of transitioning). Two participants came out in the course of a conversation regarding mental health difficulties. One female participant came out as a lesbian because she did not want to keep getting the heteronormative questions regarding the possibility of her being pregnant.

Thirty-two participants explained their confidentiality concerns in the open-ended question. Concerns regarding disclosure of mental health difficulties were expressed by seven of the participants – the largest group, two of whom experienced what they perceived as breaches of confidentiality in that area (e.g. *“I have talked about my mental health with my GP but she ended up talking to my mum about it when I would've just preferred a private conversation”*). Four participants were concerned about sexual health details being shared, and five participants worried about being outed when they did not wish to be. Five participants felt they had no expectation of confidentiality as their parents were always in the room with them or they knew their GP calls their caregiver regarding issues discussed at appointments. Four other participants expressed concern because the whole family sees the same GP.

The last two statements on this multi-response question dealt with the perception of actual LGBTQ+ bias on the part of the GP. Fifteen participants ticked “I believe my GP has an anti-LGBTQ bias.” Seven of them (46.7%) responded in the open text field. Two of those responded in the negative to the statement – indicating they did not think their GP had such bias.

Of the other five responses to this question, two mentioned religion as the basis of their assumption of bias. Two of the other responses centred on things the GP had said in the past, which were interpreted as homophobic, and one participant indicated his GP does not like discussing LGBTQ issues.

Of the 15 participants who responded to the open-ended text regarding the statement “I’ve experienced biased responses / discrimination from my GP,” five (33.3%) provided actual examples, including *“Not my current GP but my most recent two previous GPs have exhibited casual transphobia, misgendering and completely arrogant lack of understanding on the topic.”*

7.10.2. Participants’ Experiences within the Healthcare Environment

Open-ended questions invited participants to share good and bad experiences they had with a healthcare provider, and with reception/office staff in a healthcare setting. See Table 7.30 for sample responses.

There were nearly twice as many good experiences with healthcare providers as bad ones. The good experiences centred around professionalism and respect, whereas most of the bad experience centred on medical errors and lack of professional conduct.

Encountered with office staff were more evenly split between good and bad experiences, though good experiences still outnumbered bad ones. Good experiences centred on a generally polite and professional attitude, including gender-affirming behaviours. Bad experiences were the opposite, citing unprofessional conduct and instances of discrimination, not all of which were LGBTQ+ related.

More detailed results are discussed in the following sections.

Table 7.30 Participants' experiences within the healthcare environment.

Category	# of Responses	Sample Quote
Good experience with a healthcare provider	155	"I had a lot of conflict with my parents due to their strict religious views and approach to vaccines, LGBTQ+, and medication. I met with my doctor independently and they gave me a lot of support, reassured my [sic] of my rights and medical autonomy, and gave me practical and emotional assistance when I was struggling. They made sure I knew what facilities I had access to, and that everything they did would be done in complete confidentiality."
Good experience with reception/office staff	68	"correct name and pronouns, checking how i [sic] wanted to be referred to in front of my parents"
Bad experience with a healthcare provider	86	"I remember feeling sick at school and my school nurse telling me it was no big deal suck it up…there was no pill that just makes everyone feel better."
Bad experience with reception/office staff	48	"called [sic] me my deadname for no reason. As in, i [sic] had changed my name legally and informed them and they didnt [sic] respect it."

7.10.2.1 *Good experience with a healthcare provider*

Of 155 responses, helpfulness (37 responses) and professionalism (39 responses) were the biggest attributes referenced by people recounting good experiences with a healthcare professionals. Participants spoke not only of a healthcare provider taking good care of health problems but also referred to the manner in which professional services were rendered; for example, *"she went through the whole process of explaining to me without making me feel emabarrased [sic] or stupid or uncomfortable as well as what all my medication was for."*

The providers' personality or disposition was the third largest group addressed in the responses (*n* = 26). Attributes mentioned in this category were "caring," "kind," "calm," "nice," and "supportive."

An equal number of responses (n=26) was received for providers acting with respect and acceptance towards their LGBTQ+ patients. Eight respondents (30.8%) mentioned gender affirming care. Other responses spoke of being accepted when they came out to their provider (e.g. *"…the nurse I remember at the hospital was very kind and sweet to me. At this time I identified as male, she was very non-judgemental and accepting as a whole"*). Participants also highlighted being respected and supported after coming out (e.g. *"They were supportive of my sexuality, and respected me"*).

The importance of a healthcare provider's communication style, both in listening and in speaking to the patient, was highlighted by many of the participants. The listening part was highlighted in anecdotes from 17 participants. Most of them spoke of their providers listening in order to render the best care, while others felt that the listening conveys caring and a sincere willingness to help (e.g. *"…they listen carefully and work with you to get the best outcome"; "I feel like he listens to me and genuinely wants the best for me"*).

Eleven participants highlighted clear communication (e.g. *"Helpful and clear words when diagnosing me"*) and the completeness of information providers relayed (*"The school nurse gave me great information on …how to practice safe sex with both genders, rather than just with the opposite gender"*).

Five participants highlighted the providers' respect for confidentiality; for example, *"When I did tell my GP I was gay and at the time didn't wish to tell my family she understood and agreed to keep it between us…."*

7.10.2.2 Good Experience with Reception/Office Staff

The most frequently used attributes for positive office staff interactions were "friendly," "helpful," "polite," and "kind."

Six participants cited gender affirming care in this question, e.g. *“some staff have even remembered my name and greeted me politely as I’ve come in. They continued to do so with my preferred name after coming out with no slip-ups as far as I recall.”*

7.10.2.3 Bad experience with a healthcare provider

Of 86 responses, the biggest response category was of participants recounting medical errors they’ve experienced (*n* = 18, 20.9%); for example, *“Nurse once took too much blood and gave me nerve damage throughout my entire arm which still hasn’t healed after a year.”* A close second (*n* = 17, 19.8%) was perceived unprofessional behaviour. Such conduct sometimes included anti-LGBTQ+ sentiments (e.g. *“was casually transphobic, very dismissive and binary, and in addition very very derogatory about my specific complex health conditions”*), but more often were unrelated to the participants’ gender or sexual identities. For example, one participant recalled, *“Was taken to a GP for a suicide attempt to stitch a wound. Was ignored, sighed at and not shown any compassion. He called me “you people” with negative connotations, grouping all people who struggle as one. Made my distressing situation worse.”* At the heart of many of those experiences was the perception of having been denigrated or having the person’s basic needs ignored, thus increasing their distress. Examples include *“I got treated like shit when I was put into hospital because I couldnt [sic] move or stand, these two nurses on site told me I was making it up and forced me to stand and made me cry”; “When I said I didn't want vaccinations she told me I was a dumb child.”*

Fifteen people related the inability to receive gender-affirming care. For example, *“My GP treated me coming out as male as a joke”*; *“I went to a GP to get an IUD [intrauterine device] put in and throughout it they called me 'she'* [participant is gender-queer] *and their reassurances were things like 'good girl' … it would have been a lot less traumatizing if I hadn't been misgendered.”*

Fifteen responses concerned inadequate care, such as *"I was having a lot of chronic pain issues and had to push to have tests done and there was no follow up and very little initiative shown to try to find out what the cause was."*

Thirteen responses concerned a discriminatory or biased response, either anti-LGBTQ+ or age-related, or in some cases both: *"A councillor once told me when I had relationship problems with a female that I'm too young to be part of the LGBT+ community and that it doesn't matter because it doesn't really exsist [sic]."* These responses ran the gamut from dismissal and invalidation to actual suggestions of conversion therapy -- *"had a doctor tell me my homosexuality was treatable. had [sic] a therapist tell me he could fix me etc."*

7.10.2.4 Bad experience with reception/office staff

The biggest response category concerned perceived unprofessional behaviour – seven responses described receptionists who were "rude," snappy" (these words appeared in multiple responses) and, in one case *"generally pissed off with the world."*

Six responses concerned experiences of discrimination. These ranged from age to anti-LGBTQ+ discrimination, including refusal to provide gender-affirming service, for example, *"Refusing to use my preferred pronouns and name because it "wasn't accurate to me or my case.""*

7.11. Summary

In this convenience sample of 310 adolescent LGBTQ+ participants, the survey found indicators for potential barriers to healthcare access that include cost, gender identity, and confidentiality concerns. Over 43% of participants with and without a regular GP cited cost as a barrier to having a GP or seeing one regularly, making it the most cited factor, followed by inability to make time (35.1%). While cost and inability to make time may have been the most often cited barriers, interpersonal barriers in this study were associated with every aspect of the provider-patient relationship, including trust and perceived quality of care. Thus, they likely carry more impact relative to cost and timing issues.

Participants with and without a GP cited the perception of being dismissed or not understood as a barrier, and most of the people in this category cited these perceived attitudes (or actual incidents) specifically in the context of their gender identity. Gender diversity was also associated with lower health communication self-efficacy score.

The analytical model used in this chapter (Figure 7.1) places significant importance on communication self-efficacy as a possible barrier or enabler to healthcare utilisation. In examining the factors that affect communication self-efficacy in this study, gender identity, poor mental health, and a past history of avoiding care due to being LGBTQ+ all emerged as factors that are negatively associated with communication self-efficacy. Thus these may be barriers to healthcare access in this study population.

Confidentiality concerns may be a barrier in this population. A larger percentage of participants with a regular GP was observed to have confidentiality concerns than to have come out to their GP (28.5% vs. 18.8%, respectively). Confidentiality concerns were seen in people with no regular GP even more, with 67.2% of them indicating such concern on the self-efficacy scale. It is also worth noting that confidentiality concerns seemed to have been associated with overall trust in the GP's treatment decision, and the perceived quality of care participants attributed to their GP. Confidentiality was also mentioned as an enabler to communicating with the GP in the open-ended questions. In the context of young people from marginalised populations who may still be dependent on their families, confidentiality is clearly an important factor to consider.

Overall this study population seems to rate the quality of care they get as fairly high, but caution should be taken not to ignore those reporting low quality of care. The perception or actual experience of bias, just like confidentiality concerns, are associated with poorer ranking of GP quality in this study. Therefore, there may be a high index of suspicion that participants who perceive their quality of care as low may be experiencing the effects of bias from their providers. That bias and discrimination in the healthcare system exists at least in this study sample is supported by experiences related in the open-ended answers in the survey, where trans* participants repeatedly spoke of transphobia or ignorance around caring for trans* patients. In addition, though trust in the GP's medical decisions was high, trust levels were also associated with the perception or actual experience of bias. Additionally, trust was also associated with gender; gender-diverse participants were less likely to display a high level of trust in their GP's care decision. Thus, gender diversity again seems to be a barrier that negatively affects regular utilisation of healthcare resources, due to a variety of fundamental reasons.

There was no obvious direct connection between having a GP or being out to one and sexual health. There was a weak correlation between the health communication and condom self-efficacy scale, and individual prevention/protection measures were not impacted by the presence of or relationship with one's GP. Conversely, the open-ended questions reveal a lack of knowledge that, in a population already at high risk for STIs, can lead to elevated health risks and perhaps requires a dedicated approach from GPs. Most participants cited Google as their main source of health information (this was counted as part of the "Internet" source in Section 7.9). While not surprising, more guidance may be needed to ensure those who rely on the internet to learn critical health information, including sexual health, are able to critically choose suitable sites that provide up-to-date, correct information. From answers given in the healthcare questions, it would seem most teens do not consider sexual health a topic of discussion with their GP, and the GPs who do bring it up (according to the few open-text responses) do so in heteronormative terms that do not promote a conversation with an LGBTQ+ individual.

The next chapter – results of the thematic analysis – will provide a more complete picture of the participants' lived experience around some of the issues raised by the survey.

Chapter 8. The Interviews: Thematic Analysis Results

8.1. Introduction

Why would a teenager volunteer sit down with a stranger and talk about deeply personal topics? For many of the interviewees in this study, it was a sense of community responsibility.

> *I do a bunch of work with like, queer people who are even younger than I am. And I think if I can contribute to something that's going to benefit them by like, shedding light on the barriers to healthcare, then I am happy to do everything I can to help with it. (TT)*

This chapter lays out results of the thematic analysis from the 15 interviews conducted in this study. A discussion of reflexive thematic analysis, and the particular process used in this study, appear in Section 6.12.3. Chapter 6 also includes a Table of Interviewees (Table 6.1), which provides basic pertinent information on each interviewee, including the fictitious initials that identify them in this chapter.

When analysing the interviews, four themes were identified, each with its own subthemes: the complexities of coming out impact the participants' interactions with the healthcare system; gender diverse teens face profound barriers to utilising healthcare; LGBTQ+ Teens have a dearth of sexual health resources, increasing their sexual health risk; and participants expect inclusive healthcare.

These themes and their subthemes are summarised in Figure 8.1.

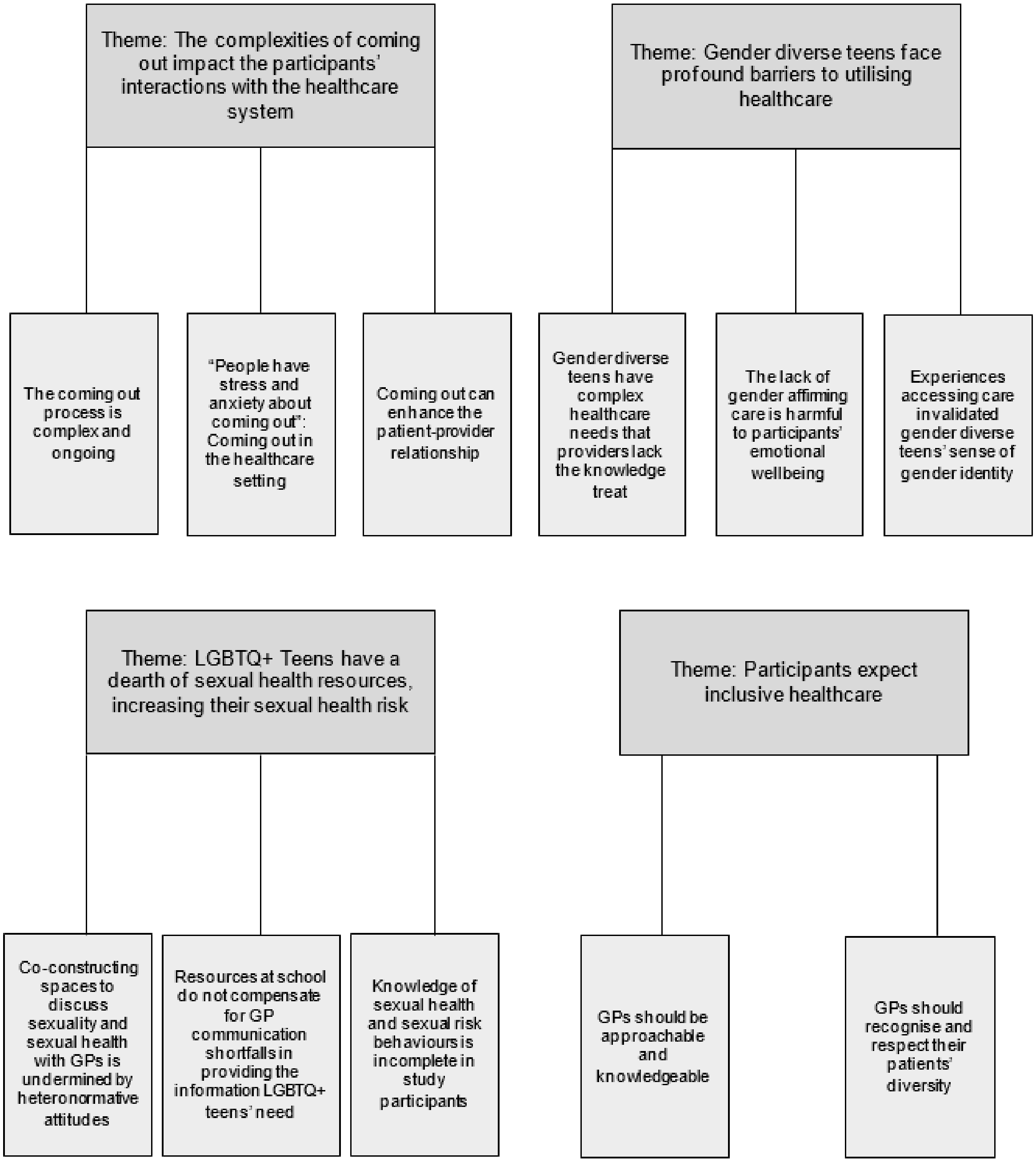

Figure 8.1 Summary of themes and subthemes arising from study interviews.

Most of the 15 interviewees were eloquent and thoughtful in their responses. Their reflections provided a rich insight into both difficulties and positive experiences encountered by LGBTQ+ teens as they navigate the healthcare system in New Zealand.

8.2. The Complexities of Coming Out Impact the Participants' Interactions with the Healthcare System

Coming out is the process of disclosing one's LGBTQ+ identity to others (Fish, 2020). In the traditional models of identity development, which have been a subject of criticism, coming out is considered a necessary stage to achieving a healthy life as an LGBTQ+ individual (Fish, 2020; Klein et al., 2015; Rasmussen, 2004). It is often presented as a political imperative to advance LGBTQ+ equality (Klein et al., 2015; Rasmussen, 2004). Coming out is a highly personal process and no two coming out stories are the same.

The topic of coming out to providers, or the providers' responses to such disclosures, recurred throughout the interviews, appearing in various narratives that discussed different healthcare-related topics. It became obvious to me that this was a central theme for many interviewees when talking about their healthcare experiences.

Three subthemes emerged in this theme: The coming out process is complex and ongoing; Coming out in the healthcare setting is a source of concern or stress; and Coming out can enhance the patient-provider relationship.

8.2.1. The Coming Out Process is Complex and Ongoing

The growing acceptance of sexual minorities (and, to a lesser extent, gender minorities as well) has seen the average age of coming out in the LGBTQ+ population drop by nearly a decade over the past 40 years (Fish, 2020), from 21 years of age in the late 1970s to approximately 14 years in 2015 (Russell & Fish, 2016). While such empowerment is a positive development, it also means that LGBTQ+ people are now coming out during adolescence, a developmental period that presents its own challenges and stressors. As one interviewee noted,

> *...as a teenager, a lot of things I'm going through are more like teenage based problems. And there is like the added stress of school, of being in high school… practically everyone at school has something going on that is making it very hard for them, whether that be school or family or friends. (KB)*

Another interviewee, LJ, was more succinct: *“Being a teenager, it sucks. And it's hard.”*

Coming out exposes the LGBTQ+ teenagers to risks of rejection and even violence from family and peers (Fish, 2020). One study participant recalled,

> *I came out as queer… quite young, and that caused a big rift, but we sort of patched over, ignored it as best we could for quite a while. And then I came out as non-binary in my first year of high school…. And that did not go over well, but I moved out [of home] actually in the middle of lockdown. So yeah. (BL)*

BL’s first experience of coming out, and having the topic ignored by their family, fits with Pauline Boss’ (2007) theory of ambiguous loss. Boss defines ambiguous loss as one that remains unclear, where information about the status of a loved one as absent or present is lacking. The absence can be psychological (as in the case of a loved one with traumatic brain injury) or physical (a deployed soldier). Dziengel (2015) explains that ambiguous loss can be applied to the lived experience of LGBTQ+ people: “[S]ome people may experience ongoing involvement with family members, yet experience a lack of psychological support or acceptance" (p.306). This is the type of ambiguous loss Boss referred to as "physical presence, psychological absence" (Dziengel, 2015). Ambiguous losses are a source of ongoing stress if not resolved. This stress accumulates on top of other stresses an LGBTQ+ individual (especially a teenager) must manage daily. Such ongoing stresses that continue to accumulate increase the risk of mental health difficulties (Riggs & Treharne, 2017).

BL's quote also highlights the often precarious position of a child coming to terms with their own identity and disclosing it. For this participant, during the COVID-19 lockdowns in New Zealand, the safest choice after coming out as gender-diverse was to leave home, despite the pandemic restrictions that were in place then. BL was not in a unique position, either. As indicated in the Methods Chapter (Section 6.12), two participants indicated they could not take part in an interview during lockdown as they did not feel safe talking due to not being out to their families.

Another interviewee was still struggling with lack of parental acceptance at the time of the interview:

> ***TT****: Well, they think non-binary doesn't exist. But they also don't like not accept it... Like, they just think, they think it's a phase. They think I'll get over it. Yeah*
>
> ***AF****: Are you worried about what will happen when you start taking hormones, because your appearance will change? Your voice will change?*
>
> ***TT****: Yeah, I mentioned to my mother that I was on the waiting list and she cried.*

TT's parents did not reject their child, but they did not yet accept TT's identity, either. By thinking TT will "get over it," these parents engaged in what Riggs and Treharne (2017) refer to as the ideology of cisgenderism, which "delegitimizes people's own accounts of their bodies and gender" (p.597). According to Riggs and Treharne's decompensation theory, gender-diverse people must constantly compensate for cisgenderism. They do so in a variety of ways that in this group of interviewees included participation in online social media groups, being active in their school's gay- or queer-straight alliances (GSA/QSA), and individual counselling. Cisgenderism is another source of stress and anxiety in their daily lives.

LT was no longer in contact with their family of origin, due to a difficult family background that included a "very homophobic" (in their words) parent. Their psychological needs were unmet long before they cut off all contact with their family of origin. LT reflected on the toll such circumstances take on a teenager: *"[E]ven if it was somebody who didn't particularly accept you, if you have a parent, you can kind of call them up and ask for help. And I don't have anybody I can just call, you know."* This quote speaks to the sense of isolation and loneliness many LGBTQ+ people experience. It also shows why many teenagers prefer to stay "in the closet" rather than come out and risk losing their families' support.

While often perceived as a one-time event (Shurts et al., 2020) in a linear journey (per traditional developmental models), Klein et al. (2015) point out that the coming out process is in fact complex, can take place in stages, and it is impacted by many factors. One such factor is the fluid and evolving nature of gender and sexuality, especially in the teenage years. As seen above, BL came out first as queer (sexuality-wise), and later on as non-binary (gender-wise). The journey to understanding their gender identity took longer and was less clear than their understanding of their sexual identity. BL related that for years, since they were a young child, they strongly disliked their name (a decidedly gendered name that fit the sex BL was assigned at birth), but never quite knew why. It wasn't until BL became aware of their own gender identity as non-binary that the realisation of why they always disliked their name became clear in their mind. *"The first thing I did [when realizing they were non-binary] was I looked into how I would legally change my name. Because I was like, I want out! I want out!"* BL recalled.

KB remembered first considering herself a strong ally (a heterosexual, cis-person who is dedicated to LGBTQ+ equality), before realizing that she was, in fact, part of the LGBTQ+ community herself. Another participant, HK, similarly reflected on the fluid nature of gender identity, elucidating a sense of discovery common in participant narratives:

> *It's kind of a bit hard for me to say, because I have sort of moved around with labels quite a bit. At the moment, my identity I kind of identify myself as non-binary. Not in the sense of being something other than a guy or a girl, but kind of just everything altogether.*

And participant CS recalled: *"So one of my friends was a good example. She was bi for three years, and then she was bi with a strong female preference. And then she just went, you know 'no men.'"*

Despite often being hailed as a political necessity for the greater good, coming out is not always possible, or advisable, for teens who rely on their family for shelter and sustenance. Factors such as socioeconomic status, ethnicity, and geographic location all influence a person's ability to come out (Klein et al., 2015; Rasmussen, 2004). For example, LT recalled that *"I had a childhood where I couldn't speak much about this [gender identity] I was from a very, very rural town."* Their perception of the less-tolerant rural mind-set is echoed by KB, who spoke of the merciless bullying of a transitioning friend by the boarders (students who boarded at the school, as opposed to day students) in her school. *“…they basically all live on farms. They're the ones who are the really homophobic ones,”* she said. Two other interviewees who came from smaller rural areas mentioned the struggle to find adequate mental health resources in their towns, specifically referencing the rural environment as a contributing factor to the scarcity of resources.

EM, who came from a conservative religious background, was particularly concerned about the interview’s confidentiality protection, and whether any quotes used would have her name attached to them as she was not out to her family, and the family’s country of origin criminalises sexual and gender minorities. She clearly loved her family and her concern was not safety-related but rather the fear of rejection and loss. EM was looking forward to moving out shortly following the interview and being able to support herself. She revealed that currently she was experiencing a sense of isolation, as she couldn’t talk to others about who she really was. As mentioned above, parental and peer support greatly impacts an LGBTQ+ teen’s mental health (Newcomb et al., 2019; Watson et al., 2019). EM’s sense of isolation, she said, especially her inability to come out to her parents, affected her mental health. Her words echoed LT’s quotes earlier in this section, conveying the same sense of isolation and lack of support, while at the same time longing for the security a family has to offer. For EM, who enjoyed a family that met her needs while she was closeted, the difficult choice of when (and whether) to come out echoes the choices faced by participants in Klein’s study, where one participant pointed out that “…to have to make that choice is terrible. It’s not even a choice sometimes, like, “Should I pretend I’m straight? Or should I lose them?” (Klein et al., 2015, p. 309).

Participants also refuted the common view of coming out as a singular event in a person's life. As Dziengel (2015) describes in his Be/coming out model, the process of coming out and *being out* – that is, living daily as an out LGBTQ+ person – is a continuous process that requires daily decisions about who the person comes out to (if they come out at all), when, and where. In essence, a person may present multiple identities to the world, depending on their environment. This is, in effect, the process that LGBTQ+ people, including this study's participants, go through when deciding whether to come out to a healthcare provider, as discussed in the following section. In addition, as Klein et al. (2015) showed in their study, teens come out multiple times as their identity shifts and changes. Many of the participants spoke of coming out to immediate family *or* to friends first, and slowly enlarging the circle of people they've told. For example, WA said, *"I'm out to my mom dad and my brother...I'm basically out at school and stuff but not my extended family."* SW came out to his friends first, and recalled a time, prior to coming out to his parents, when *"my friends came over and they accidentally said something. And my parents were here [sic], so that was like, a really big anxiety for me [potentially] being outed, I guess."*

In addition to showing the step-wise process that coming out often is, SW's words convey a major concern for many LGBTQ+ people: that of being outed. SW was unsure how his parents would react if they found out he was bisexual, and wanted to wait before telling them. The concern over the possibility of being outed played a part in many participants' considerations of whether to come out to their healthcare providers, as discussed in the following section.

The intersection of religion and sexual/gender minority status is a particular source of concern and conflict for study participants, as already seen in EM's concerns above. Participant LJ talked about the more religious members of his extended family:

"…nothing against people who are religious or religion in general. But like people use religion as an excuse to be homophobic." Religiosity did impact some participants' decision regarding who to come out to. Participant CS noted:

> *Well, I, so a few people in my family are extremely religious. So that's probably the only place I would feel unsafe. I, I don't go around telling everyone who I am or what I am. Because that shouldn't have an impact that, it's not something that I use as a personality trait. So if someone asked me, I'll be upfront about it, as long as they're not religious.*

This conflict between religion and identity, which is common in LGBTQ+ people (Shurts et al., 2020) spills into the healthcare environment, as seen in the next subtheme.

8.2.2. "[P]eople have stress and anxiety about coming out": Coming Out in the Healthcare Setting

Participants expressed more reticence toward coming out to adults with whom they do not share close personal relationships, and this included healthcare providers. They described coming out to healthcare providers as a source of stress or concern that is exacerbated in situations where they did not know the doctor well and questioned how they might respond to the information. KB's reflections demonstrate an awareness that the professional responsibilities of her doctor may be tempered by the doctor's personal beliefs when responding to a self-disclosure:

> *I don't know if she would look at me differently. Like, I know that she's a doctor. And then it's just supposed to be like, solid, like medical and everything. But like, I don't know what her like personal agenda is. I don't know how she'd feel.*

Another participant indicated they looked for cues that would indicate a healthcare provider’s religious orientation prior to coming out to a doctor. They were cautious where there were signs a provider was overtly religious: *“if I see the doctor wearing like a cross or something that's an immediate sort of no go for me, or at least tread very lightly”* (BL). Interestingly, BL felt a shared status as a marginalised part of society might temper religious bias: *“if I perhaps had a hijabi [sic]-wearing doctor, I might be more inclined to come out anyway. Because… they're a marginalized person too.”*

LT similarly gauged a person’s responsiveness based on their personal characteristics, in this instance perceptions of a doctors’ sexual identity:

> *…when you're talking to some old white straight guy at a doctor's clinic, you kind of go like, “well, I don't really want to disclose all these really personal details to you because I feel like I'm just kind of gonna be rejected again.*

A further participant described being more cautious when seeing a new healthcare provider, indicating the importance of continuity of carer within the primary care setting. TT: *“I think it definitely, like whenever I see someone new, it definitely, like makes me quite hesitant to bring it up. Because I'm never quite sure how they'll react.”*

Participants were cognizant of the fact that coming out in the healthcare arena is a lifelong process, due to the multitude of healthcare providers they will see throughout their lives. KB’s closing remarks, at the end of the interview, included this:

> *It's the dream to not have to constantly feel like I have to constantly come out to people like I'm worried that like, if something's wrong when I go to my doctor that they're not going to treat me properly because of their prejudice.*

Her quote conveys not just the frustration of having to repeatedly come out to providers – a product of the healthcare system's heteronormative/cisnormative mindset – but also a common fear among the LGBTQ+ community that their care will suffer as a result of homophobia/transphobia.

BL also felt the prospect of repeated coming out is daunting, and makes them more selective about information they choose to reveal to their provider:

> *And so the process of coming out to health professionals it's, it's a, it's a long process because it doesn't ever end. Every doctor I'll ever come across… is why I've been so hesitant to start telling health professionals that I'm non-binary, is because every health professional I see for the rest of my life, I'm gonna have to tell.*

These participants' quotes, as above, speak to the importance of continuity of care, especially for members of the LGBTQ+ community. The complexities of the coming out process, with all of its attendant risks (e.g. negative, hurtful responses) is one LGBTQ+ patients face every time they see a new provider, and it provokes repeated anxiety with every appointment. This repeated anxiety is one factor that accounts for the number of LGBTQ+ people seen in this and other studies who choose to forego care due to their sexual or gender identity.

Participants described weighing the potential consequences of coming out. Non-binary participants feared discrimination and restricted access to healthcare resources if they came out as non-binary (as opposed to simply trans). These participants' narratives indicate the choice not to come out was a strategic decision to avoid compromising their healthcare access and the emotional struggle that came with the denial of healthcare resources. For example. HK recalls:

> *And also being non-binary I tended, until recently I tended to just present as binary [trans]male. So that's Yeah, I just felt like there were some things I wouldn't, I might be denied, if I told them that I was non-binary.*

BL shared HK's concern:

> *I haven't currently come out to any doctors as non-binary. Because I am worried about how that's going to affect my access to healthcare. And with all that I'm going to new doctors and stuff, and that's really not what I want to put time and energy into…*

For LGBTQ+ teens in this study, familiarity with a healthcare provider had a potential downside. It could lead to specific concerns about confidentiality that were grounded in the participants' feelings of being neither a child nor a fully independent adult, and the fact that most of them saw their family's GP since they were very young. The same GP also sees other members of their immediate or extended family. Several participants raised confidentiality concerns connected with coming out, or the potential for "being outed" by their healthcare provider. *"I was worried that it [sexual orientation] might just come up accidently with my Nana or my granddad"* (KB); *"I experienced that sort of thing in high school a lot where I was talking to my school counsellor or my school doctor, and I was afraid they would out me to my parents"* (LT).

In some cases, participants mentioned their parents came with them to their doctor appointments, or they had to make the appointments through their parents. This became a barrier to coming out to their provider specifically, and to seeking care for sensitive issues in general. EM revealed that *"I don't think I would be as candid about, you know, my health regarding being queer, because I'm not out to my parents, if my* *parents were present in the room."* TT, who still struggled with parental acceptance of their non-binary identity, recalled:

> ***TT****: …when I was living at home and seeing a family GP. I wouldn't want to tell my parents if I needed to see a doctor unless it was for like, like an ear infection or something. And so that was a barrier.*
>
> ***AF****: So you wouldn't want to tell your parents because…*
>
> ***TT****: We've just… like never been, we've never really talked about, like sex or relationships or anything, or like mental health or anything. So…*

TT felt they had to forego care at times because they had to go through a parent to set up a GP appointment, and were not willing to ask their parents for appointments dealing with mental health or sexual health. It is worth noting that TT's perception was that unrelated topics could not be discussed in an appointment set for a specific problem. KB, who is out to her family, related a similar barrier, especially in matters concerning sexual health. In KB's case, it is more likely a general teenage discomfort at talking to parents about issues relating to sexuality and sexual health. Nonetheless, the need to involve parents in making GP appointments presents a barrier that can be multi-layered and hard to overcome in LGBTQ+ teens who are not out to their families.

Interviewees sometimes had prior experience on which to base their reluctance to come out. BL remembers the first time they came out in the healthcare setting, at the age of 12 years:

> *Prior to coming out, like I had had really good experiences, you know, as best you can get from imperfect people. I think I had big issues when I very first came out, I happened to go to [clinic name] here in town that provides*

> *counselling service through the government. And the, the first sort of adult in the healthcare systems I came out to offered me conversion therapy.*

Such an extreme reaction may be, at least in part, why BL finds the prospect of coming out repeatedly to providers, for the rest of their life, so daunting. And since, like other interviewees, they recognise that sexual diversity is better tolerated than gender diversity, this reaction to their first coming out experience may also be in part why they chose not to disclose their non-binary identity.

Asked what providers can do to encourage coming out, participants felt visual cues of a safe environment were important. *“I guess something just to make people feel like they're comfortable. So maybe like a pride flag something in the office or something just to make people feel comfortable with going there”* (SW); *“I guess somewhere that has… flyers and stuff about, like, LGBT and everything, which I would prefer to see…instead of having to ask around…just find out whether that’s something that is talked about there”* (CS).

As participants have already indicated in the discussion regarding religious cues, they observe the provider’s environment and form a strong impression based on a variety of visual cues that are present. The importance of visual cues in creating a more accessible environment for LGBTQ+ patients has been validated previously in framework recommendations for clinical spaces (e.g. Lim et al., 2018) and in studies with LGBTQ+ participants (e.g. Wilkerson et al., 2011). Grant and Nash (2019), who studied bisexual women’s access to sexual healthcare in rural Australia, found that visual cues were important to their participants as well, signalling to them that the clinic cares about their needs. These visual cues also served to normalise sexual and gender diversity to the clients. Participants in a study of adolescents and young adults’ sexuality communication with their healthcare providers (Fuzzell et al., 2016) expressed the same feelings, explaining how seeing visual cues of LGBTQ+ inclusivity made them more comfortable disclosing information and discussing their needs.

8.2.3. Coming Out Can Enhance the Patient-Provider Relationship

Despite the prevailing anxiety surrounding coming out in a healthcare setting, participants who had a positive coming out experience with their providers found the added transparency brought several advantages with it. Among the 15 interviewees, five were out to their current GP and one was out to a counsellor. Of these six participants, five came out directly and one person came out through registering for specific sexual health workshops at their clinic.

One advantage was enhanced communication:

> *Any difference would be more positive if anything, I'm more communicative about that sort of stuff [bisexuality]. [?] because we never really talked about anything like that beforehand until I brought it up. And then he's like, he was always he was like asking how it is and … things along those lines in terms of bisexuality and stuff, I suppose. I don't see any negatives, probably. (RB)*

This quote shows that not only was RB able to articulate questions about a topic that weighed heavy on his mind (he was still unsure of his sexuality at the time of the interview), but his GP was able to check in with him and clarify any concerns RB might have about his developing sexual identity.

Like RB, CS felt that being out to her providers at the clinic she attended "*made it a lot easier to talk to whoever it was that I would be talking to.*" This is likely because the anxiety of the need to hide her identity, as discussed by both Meyer (2003) and Riggs and Treharne (2017) is no longer present.

One participant, SL, related how coming out to his provider helped smooth things over when he came out to his family, an additional advantage:

> *Um, it was definitely a bit of a process for them, just because they're also like, sort of traditional [ethnic origin]. So, um… There wasn't like the best response…. And actually, the GP was kind of really helpful towards that as well. Because, um, at the time that I came out to my GP, my mom also like, while she was still concerned about it, she sort of asked him about it. And he explained to her sort of like, yeah, and I think that helped her a lot as well to get sort of like a medical professional saying that it was fine.*

SL's parents come from a culture where doctors are accorded a high level of respect and authority. It is also a traditional culture, so his coming out by itself was a shock to his parents. SL and his siblings were raised in New Zealand and his sibling's reactions were, he said, "fine." But he took advantage of his parents' traditional values with regards to their GP's status, and agreed to waive confidentiality to help gain his parents' acceptance of his sexuality. SL described feeling closer to his doctor after coming out, explaining: "*I have a lot more respect for him after [coming out]*" and also noted his perception of his GP altered as a result of a coming out experience that went "*really well.*"

Being out also allowed providers to address specific difficulties the participants were experiencing regarding their developing identity:

> *Well, I mean, most of my positive experiences have been with the nurses here. One in particular who I see the most [name], she, she was the one who I came out to as non-binary. When I was sort of struggling with that even more and she, she was really helpful. She like asked if I wanted to*

> *see a counsellor for it.… And she, yes, she asked ‘cause I had come to get my testosterone shots she asked me if I still wanted it, it was really nice it felt like she cared, and she wasn't making any judgment. (HK)*

HK, who was assigned female at birth and is “okay with any pronouns” struggled with gender identity since his early teens, and still resents the fact that the first GP he talked to about his gender and body dysphoria did nothing to help him[25]. His quote shows the importance of having a receptive, non-judgemental provider who is knowledgeable and caring. The provider’s attitude and offer to get HK to see a counsellor went a long way in relieving past anxieties and hurts. He is still unsure about coming out to providers as non-binary, however, because his past experience showed him that non-binary people, much like those who are bisexual, are considered “undecided” and “confused” by providers lacking proper knowledge. This perception resulted in more hurdles he had to get over to receive the treatments he wanted, such as gender-affirming surgery.

This theme highlights the importance of understanding the coming out process in the context of the healthcare environment. While it can be a positive experience that enhances the participants’ overall care and wellbeing, it is a source of anxiety and stress. Coming out to a healthcare provider is a uniquely LGBTQ+ experience, and when handled improperly can become a barrier to seeking care in the future. Healthcare providers can encourage conversations that lead to coming out by providing both verbal and visual cues that communicate a safe space for sexual and gender minority teens.

This theme also highlights the more difficult position trans* (including non-binary) participants find themselves in when considering coming out to their healthcare

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[25] *I refer to HK as male in this study because that was how he presented at the time of his interview.*

providers. Not only do they recognise that gender diversity is not as accepted as sexual diversity, they also *have* to come out to their providers in order to receive care that addresses their body dysphoria and physical transitioning needs, such as hormone treatments and gender-affirming surgeries. In a study by Haimson and Veinot (2020), healthcare professionals were among the very first people trans* bloggers came out to. Bloggers described these coming out experiences as “often anxiety provoking and emotionally draining,” (pg. 162) similar to words used by some of the participants in this study. Importantly, these bloggers described an emotionally demanding process of finding trans-friendly providers *before* coming out to them. The option of looking for the right provider is not available to the large majority of this study’s population. They are not financially independent, and attempts to change providers would usually entail having to explain why to parents who may then reject them. The coming out process for gender diverse teens in this study is complex and has potential implications for the participants’ physical and emotional wellbeing. As discussed in the next theme, the complexities of coming out as gender diverse in a healthcare setting are not the only difficulties these participants encounter in the healthcare arena.

8.3. Gender Diverse Teens Face Profound Barriers to Utilising Healthcare

While barriers to healthcare utilisation were perceived by both sexually and gender diverse participants, gender diverse participants observed that their overall healthcare needs tended to be complex. For starters, several participants perceived that *“sexuality as a whole is a lot more accepted than gender identity at the moment,”* as LT put it. LT was observing that while same sex relationships (for example) have become normalized, gender diversity remains at the margins of social acceptability.

Hammack et al. (2022) and Pascoe (2019) discuss in their papers the role that masculinity plays in silencing the voices of LGBTQ+ teens assigned male at birth (AMAB)[26], sometimes pushing them into desperate acts. At the heart of even homophobic slurs, Pascoe argues, is gender (not sexuality) policing. Deviations from the Westernised ideal of masculinity carry societal consequences that run the gamut from insults to homicide. The study identified that gender-diverse people faced an often-dangerous, complex path to navigate in society.

Three subthemes emerged in this theme: Gender diverse teens have complex healthcare needs that providers lack the knowledge to treat; the lack of gender-affirming care is harmful to participants' emotional wellbeing; and experiences accessing care invalidated gender diverse teens' sense of gender identity.

8.3.1. Gender Diverse Teens Have Complex Healthcare Needs That Providers Lack the Knowledge to Treat

Gender diverse teens recognise that they have medical needs that are not standard teenage care. LT compared their needs to their sexually diverse friends:

> *So for me, a lot of my friends are… they identify as gay, or bisexual, pansexual… whatever. So they're, I suppose their medical needs may be only sexual health related whereas mine I… because I also identify as non-binary and because I'm like, oh, well, I, I'm thinking about hormone treatment, there's a whole lot more medical stuff that comes into that than if it was just about my sexuality.*

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[26] Of the five gender-diverse interviewees, only one was AMAB.

When I asked BL about their healthcare needs compared to other LGBTQ+ peers he knows, he said, *"I do need more, or different healthcare than what I get even just as a [sexually] queer person. So yeah, a little more [sic] needs."*

Adolescence is a crucial time in a person's physical development, when secondary sexual characteristics appear. Specific healthcare needs for this gender diverse population might therefore include puberty blockers for young adolescents, or male/female (as appropriate) hormone injections for the older teens who choose to transition (Safer et al., 2016; Winter et al., 2016). Depending on the circumstances, gender diverse adolescents assigned female at birth (AFAB) may want to bind their chests, and need careful guidance on the correct binders and how to use them, to avoid causing damage to the skin and ribs. If a gender diverse teen elects to have gender-affirming surgeries, the appropriate referrals are needed to start the process. Because sexual activity usually begins in adolescence, gender diverse teens AFAB must also be guided regarding appropriate contraception that will work with their hormone treatments, as two interviewees pointed out.

The mental health aspects of caring for gender diverse adolescents are equally complex. In addition to their own feelings regarding their gender identity journey, family conflicts, the threat of discrimination and violence, and the difficulty in obtaining gender-affirming care will be the lived experience of many. These additional outside pressures may cause the decompensation response suggested by Riggs and Treharne (2017), accounting for the high rates of anxiety, depression, and suicidal ideation in gender diverse adolescents (Olson et al., 2016). As seen below, the difficulty in obtaining gender-affirming care is significant, and the gender diverse interviewees in this study expressed a considerable amount of frustration and hurt as a result. Most of them struggled with mental health issues, as suggested by Riggs and Treharne.

Many GPs are unprepared for the additional needs of gender diverse teens (see for example McPhail et al. (2016), Nowaskie and Sowinski (2019), as well as the medical school curriculum discussion in the Chapter 3). This lack of preparation was a source of frustration or anger for the participants. HK recalled:

> *I had really bad gender dysphoria around the age of 15. And I told the doctor about that, and she diagnosed me with gender identity disorder, but she didn't offer any help for it and at that point, puberty blockers would have been very effective and would have helped a lot. So that's sort of a big piece of resentment…*

HK was unsure why his former provider did not offer him the treatment he needed at the time. When asked, his response was a very terse “I really have no idea,” betraying the resentment and anger he still felt at being denied treatment that he believed would have improved his emotional wellbeing and his quality of life.

LT had been through several GPs before finding the YOSS they were with at the time of the interview. Their anger and anguish at the experience they had is obvious:

> *[T]hey've obviously never been trained, they've never done courses, they might have not even experienced people coming to them with those sorts of problems before. And so they're just unequipped to deal with it. And then it causes problems for the patient who's coming to them hoping… “Well you're a doctor, you trained for years, why can't you help me?” And so you just end up feeling quite rejected by the entire healthcare system.*

Because they had been rejected by family, it is easy to see why a sense of rejection by healthcare providers might feel overwhelming for LT. While they recognised there is a systemic problem of healthcare practitioners lacking the knowledge, training, and experience to care for gender diverse patients, their inability to receive the care and support they needed led to an emotional response of feeling quite overwhelmed by “the entire healthcare system.” In contrast, when LT talked about the YOSS they were currently with, and the referrals they gave LT to LGBTQ+ youth support organisations and groups in their area, their entire demeanour changed and their relief was obvious. Several studies, for example, Eisenberg et al. (2020), showed that the presence of support organisations (e.g. GSAs/QSAs, LGBTQ+ youth groups) decreased the odds of emotional distress in LGBTQ+ adolescents, compared to those living in areas where such support structures were not available. LT came from a rural area where they were the only gender-queer person they knew of. Their distress at their memories of lacking supportive and knowledgeable healthcare is therefore understandable as it was one more stressor imposed by society.

TT recalled they often had to advocate for themselves with regards to treatments they wanted, as their GP was not providing them with options. When I asked what they thought the reason for this was, they felt it was mostly lack of knowledge on the GP’s part, “*And also this idea that like I am 18 I can't know what I want yet. I only vote which is like okay.*”

I asked TT what would be a good starting point for educating providers:
“Honestly, like queer 101 would be really important. Like, I had to explain to my doctor that non-binary came under the trans umbrella. And like, quite, that's quite rudimentary.”
LD commented that many gender diverse people are frustrated at always having to be the educators with every new person they meet. She felt that for GPs, *“just generally, having a baseline understanding of how to interact with trans or non-binary people is very good.”*

Several interviewees recalled being referred to other providers, due to their original providers' lack of knowledge. These referrals were a source of resentment for some. In LT's words: *"…they were always kind of like, 'Oh, we could refer you to somebody else.' But so you end up getting that feeling of being passed around a lot."* As seen in the coming out theme, LT was already struggling with the isolation and family rejection so many LGBTQ+ teens experience. "Being passed around a lot" can only serve to increase this sense of isolation and rejection.

HK needed a new GP when his previous GP left the practice. He had a more positive take on his referral, though it happened for an identical reason:

> *When I met with a [new] GP at [former clinic], she pretty much just like when I told her that I was trans, she didn't know exactly what to do. But she did want to help so she just referred me over here [the YOSS where we met for the interview].*

HK is out to most of his extended family as trans, rather than non-binary, but there was no mention of a conflict around his gender identity when it came to his immediate family. It is possible his family's acceptance was a protective factor against the feelings of isolation and rejection LT experienced by being "passed around a lot" by health professionals. It is also possible the GP who referred him to the YOSS was more proactive and positive about her reasons for referring him, as he perceived that *"she did want to help"* and did not simply refuse to treat him. He also only had one long-term GP prior to being referred to the YOSS, whereas LT had been to multiple providers.

Even though the referral experience can be quite different for people, depending on their circumstances, gender diverse interviewees all agreed that overall the lack of providers' knowledge and training made it harder (or sometimes impossible) to receive gender affirming care.

8.3.2. The Lack of Gender Affirming Care is Harmful to Participants' Emotional Wellbeing

The Professional Association for Transgender Health Aotearoa (PATHA) defines gender affirming healthcare as "Healthcare that is respectful and affirming of a person's unique sense of gender and provides support to identify and facilitate gender healthcare goals" (Oliphant et al., 2018). Gender affirming care may include hormone treatments, surgeries, and support and advice for the patient and their family. Included in gender affirming care is the correct use of language.

HK had experience with multiple specialist healthcare providers. When I asked him about his quality of care among the different providers, he answered, *"Yeah, most places are pretty good. It's just that they don't have training in like the right language to use, I guess."*

Language is a big issue in the life of a gender-diverse individual. As Russell et al. (2018) point out, the use of a gender diverse individual's preferred name and pronouns validates that person and has 'has implications for their mental health. Russell and his colleagues found that using preferred names and pronouns even in one context (e.g. school) reduces a person's suicidal behaviour by 56%, as well as reducing depressive symptoms by 29%. BL's eagerness to change their name, as related in the coming out theme (Section 8.2), is helpful in understanding the importance that names and pronouns can play in a gender diverse teen's life. BL also spoke of their frustration being unable to legally change their name (due to age -- BL is under 18 -- and parental rejection), recalling how reception staff in a healthcare provider's office the day of our interview insisted on calling BL by their legal name. BL pointed out that the intake forms (on which they wrote their preferred name) did not have any way for them to indicate they were non-binary. Since their preferred name is one that would be considered a “nickname” to people who hear it, the office staff refused to use it, unknowingly denying BL gender-affirming care. BL remarked it would be great if the intake forms allowed people to make a note about preferred names.

HK, who is gender-queer, also wished that pamphlets discussing sex-specific tests and procedures simply referred to AFAB or AMAB. This sentiment echoes participants in a Taylor et al. (2019) study, who complained of feeling invisible in a binary culture.

Riggs and Treharne, in their decompensation model (2017), talk about institutionalised ideologies in relation to identity categories. Binary gender (with its attendant language) can be considered one such institutionalised ideology. Riggs and Treharne define such ideology as social norms that form what society considers an individual. Being outside that norm, Riggs and Treharne argue, means being outside the realm of proper human personhood. Thus, dominant ideology becomes a source of stress for those who do not conform to the associated norms. HK was constantly reminded of his existence outside the norm every time he failed to see healthcare resources that included gender-queer people in their language.

Misgendering – using the wrong pronouns – was a problem for those interviewees and their peers who were gender diverse, and the problem extended to their healthcare providers. TT said, *“Especially with like mental healthcare providers, like I'm a little hesitant to mention it because I've had people either completely ignore it, and like misgendered me or whatever.”* TT’s perception that mental health professionals are especially prone to denying their clients gender affirming care is of particular concern, considering the mental health toll already exacted on members of the LGBTQ+ community by society's norms and ideologies (Riggs & Treharne, 2017). Such perception can cause a person to avoid much needed care, exacerbating existing mental health issues.

The importance of language as a facilitator/barrier to healthcare was evident in a story BL relayed about a friend of theirs who no longer goes to the doctor.

> *…he's out at home, he's out in the community. That's all good, but he just can't go to the doctor because he's like, "Well, I know that they've got an F for female written on, you know, some [form] there and I know I'm gonna get misgendered the moment I walk in there and I'm not equipped to deal with them."*

For BLs friend, the mental toll of being misgendered by their healthcare provider demonstrates the long lasting effects of denying gender affirming care to gender diverse individuals. The fact that BL's friend now foregoes medical care is deeply concerning but consistent with findings in the Counting Ourselves study, in which 36% of the participants avoided healthcare in the past for fear of being disrespected or mistreated due to their gender diversity (Veale et al., 2019).

HK added dimensions to understanding the toll of misgendering, noting how being misgendered by people who know him conveys a lack of respect, and the sting of misgendering is made worse when it is accompanied by a sense of betrayal:

> *I'm relatively at peace with myself and my identity provided I'm the only one around. When other people [come] into the situation that becomes a bit messy…. just being misgendered all the time. By the people who supposedly care about me, things like that... the people who I care about*

> *and the people who care about me when they don't show that they respect my identity. Like I have to keep seeing them, anyway.*

Developing a relationship of trust with a healthcare provider requires being treated with respect. Being constantly misgendered sends a message of disrespect and invalidation to the patient.

The constant language difficulties gender-diverse interviewees encountered were not only examples of not receiving gender-affirming care, but were also akin to having to confront discrimination at every healthcare visit where such incidents occur. Though not always done with malice or borne out of biases, the interviewees' frustration was evident when they spoke of these incidents.

8.3.3. Experiences Accessing Care Invalidated Gender Diverse Teens' Sense of Gender Identity

Individuals who fall outside the (cis or trans) male/female gender binary identity face additional hurdles in society and in the healthcare system. Like bisexual people, non-binary people often experience rejection from both the dominant culture and the LGBTQ+ community (Matsuno & Budge, 2017). Thus, they also experience worse health outcomes, especially in the mental health arena, where rates of suicide are higher for non-binary individuals than for binary trans* people (Matsuno & Budge, 2017). Because gender non-binary in all its forms ("genderqueer," "agender," "non-binary," "two-spirit," etc.) is a concept that is not well defined in research or medical terms so far, non-binary interviewees in this study found they were treated as if they were simply undecided when it came to their gender. Consequently, they were denied gender-affirming care or made to go through additional processes to prove they knew what they wanted, and some of them decided the easiest way to get the treatment they wanted was to lie about their identity.

> *When I was seeking testosterone, I didn't feel comfortable telling the person I saw to get my referral, I didn't feel comfortable telling them that I was non-binary. Because I didn't have faith that the public health system would treat me like I knew what I was doing, I guess. (HK)*

HK had prior experiences that taught him to be wary.

> ***HK:*** *Like I did run into a little bit of trouble when I was seeking my referral for top surgery, because I knew that the top surgeon that I wanted did perform on non-binary people. So I had that opportunity to not lie about my identity. But when I was seeing the psychotherapist because I was non-binary, she sort of was a bit uncertain about referring me, because she didn't want me to like close any doors, so to speak, which [**AF**: Close any doors?] like in case I decided later on that I wasn't, basically. So what I was hearing from her she didn't believe [**AF:** She didn't believe you].*
>
> ***HK:*** *Yeah, exactly. And I was very, like, since puberty began. That was the one thing that I've never had any doubt on. I just wanted them gone. Like, bad cuz, you know we it was the first time I'd seen her like she'd only known me for about an hour compared to my several years of knowing myself and those feelings. Yeah. But I did manage to get it in the end.*

LT experienced similar dysphoria regarding their chest, and they were also met with resistance, though for a different reason. When we talked, they were still not approved for surgery.

> *I've had a lot of, I have a lot of a lot of rejections for breast reduction surgery because they're like, "Oh, that's not causing you an issue is it, it's not causing you any pain, any physical pain" and I'm like, "no, but it's a mental and emotional pain," but they will… Yeah, I've still not been put on a waiting list or anything for that because they've said that I need to think about it further or anything. (LT)*

Denial (or delays) of gender affirming surgeries is a facet of denying gender affirming care. LT's quote highlights the mental health costs of denying gender diverse patients gender affirming care. The insistence that they have to think about this surgery more, after trying to get it unsuccessfully for several years, also robs LT of their body autonomy and their ability to make their own healthcare decisions.

LT was also getting pushback on getting a Mirena (a hormonal intrauterine device) when they originally asked for it because heavy periods were exacerbating their body dysphoria. They were only able to receive it when they asked for relief from extremely heavy periods. *"And so it was only when I went to them with a very physical very medical reason that they were willing to do it…. not many providers want to help you unless there's something very physically wrong."* It is worth noting that the guidelines for gender affirming care in New Zealand (Oliphant et al., 2018) list Mirena as an option for bleeding cessation in gender diverse individuals who have not yet started testosterone therapy (like LT) but wish to stop menstruation.

TT mentioned that disclosing their non-binary gender identity to some mental health professionals caused these providers to focus solely on the topic of TT's gender identity, pathologising it by considering it the source of all of TT's problems. HK recalled a similar experience and never went back to that counsellor. This phenomenon, which Mizock and Lundquist (2016) call "gender inflation" in psychotherapy, can lead to clients leaving psychotherapy altogether (which almost happened to HK), and according to Mizock and Lundquist can also cause clients to feel they are not viewed as a complete person, but rather as their gender diversity only. In doing so, therapists who engage in gender inflation also run the risk of missing the true aetiology of a client's problem (Mizock & Lundquist, 2016), as was the case for HK.

This theme demonstrates that gender diverse study participants encountered unique complexities that became hurdles in their healthcare journey. Many of these participants described experiencing medical assessments that failed to reflect their long-held beliefs and attitudes toward their gender at birth. The additional medical requirements in this population, beyond standard adolescent care, were considered essential to supporting participant's physical and emotional wellbeing. Studies have shown that supported gender diverse children and adolescents do not differ from their cis-gendered peers in terms of emotional wellbeing (see, for example Olson et al., 2016; Alanko and Lund, 2020).It is therefore a matter of urgency to overcome the barriers preventing them from obtaining gender-affirming care.

8.4. LGBTQ+ Teens Have a Dearth of Sexual Health Resources, Increasing Their Sexual Health Risk

As sexual health comprises two of the three study questions, a good portion of the interviews was devoted to this general topic, ranging into sexuality, risk behaviour, and knowledge. From these general discussion topics, a central theme emerged that paints a picture that is a far cry from the WHO's ideal for sexual health attainment, which includes having "pleasurable and safe" sex that is free of discrimination and violence, where the sexual rights of all persons must be respected, protected and fulfilled. (World Health Organization, 2017, p. 3).

This theme has three subthemes: Co-constructing spaces to discuss sexuality and sexual health with GPs is undermined by heteronormative attitudes; Sexual health resources at school do not compensate for GP Communication shortfalls in providing the information LGBTQ+ teens need; and Knowledge of sexual health and sexual risk behaviours is incomplete in study participants.

8.4.1. Co-Constructing Spaces to Discuss Sexuality and Sexual Health with GPs is Undermined by Heteronormative Attitudes

The interviews revealed that communication with a GP regarding sexuality and sexual health commonly lacked in both quantity and quality. Several factors contributed to the problem.

The WHO definitions of sexuality and sexual health, cited in Chapter 1, both include a physical or biological component (World Health Organization, 2017), and it stands to reason that biology or physical health have a bidirectional interaction with sexuality and sexual health. Yet throughout the interviews, it appeared that participants did not connect sexual or gender identity, or even sexual health, with physical health. KB explained that her sexuality, unlike her physical health, was a part of her she could not see or change, and in her mind that is what separated sexuality from physical health:

> *I feel like my sexuality is like part of who I am. And it's sort of like…it's like inside, whereas in like my physical health, I can physically see it, I can physically do things to improve it. And I just feel like the two, I really haven't made like a connection, or anything yet, at least in my mind, at least it's sort of like the almost two different things, like my sexual health and my sexuality compared to my physical health.*

LD added a gender diverse viewpoint: *"Because it [physical health] tends to be mostly biological, like medical stuff tends to be mostly biological. Gender doesn't necessarily have an impact on that."* Their thoughts echoed those of KB, in that they saw gender as set apart from the "mostly biological" physical health, and therefore the former did not impact the latter. This perception resulted in interviewees not immediately thinking of their GP as a source of information for sexual health, as one interviewee explained rather well below.

While interviewing DS, we talked about the lack of adequate school resources for sexual health (see Section 8.4.2). She mentioned doing her own research if she needed information and I asked her, "why not ask your GP if you needed to?" DS put a lot of thought into her response:

> *I probably could have done that. But yeah, I don't know. It's an interesting question. …Obviously that's what they're there for, but I never really, the GP for me was always more like a physical health ailment type thing. …anything to do with like sex or relationships I didn't see my GP as that type of person. I saw more like my own research or going to see like one of the Citizens Advice Bureau health professionals or something like that.*

DS, like other participants, did not see sexual health as a physical component of her overall health. She then followed up with an interesting observation – her GP's office was filled with posters and pamphlets for a variety of health conditions, vaccinations, and guides to maintaining good overall health.

> *…and there was never any, like, LGBTQ+ stuff around. …there was never even just like one thing on like, a gay relationship or HIV or stuff like that….*

> *So maybe that's like, the absence of that was why I didn't see the GP as being that kind of person. I'm not sure.*

In the coming out theme (Section 8.2), interviewees discussed the importance of visual cues to create an environment that felt safe for them to open up and discuss their sexual or gender identities with their provider. DS's reflections point to an additional potential benefit of creating a visually inclusive practice environment – it may encourage discussions of sexual health. Though interviewees enrolled in a YOSS did not mention sexual health specifically in the context of clinic environment, they spoke of immediately being able to open up to clinic staff about a variety of issues that have been bothering them, issues they did not feel able to discuss with their previous GP. This is consistent with DS's experience, as YOSS clinics have plenty of LGBTQ+-friendly materials.

Participants did agree that it is important for a healthcare provider to know a person's sexual identity. GV said:

> *I think medically it's important to know for sexuality. I think it's important to know what, what, what genitalia they're involved with. And that's, that can be important to discussions that are medical related. But I think in terms of having a good relationship with your provider, it could be important to know what the actual… if you're, if you're using labels, what the label you're using is and that sort of thing.*

KB added that it was also important for a provider to know whether she was sexually active, not just what gender(s) she was attracted to. However, participants felt a conversation about sexuality should be initiated by the GP. SW summed up the topic succinctly: *"it should be a question that they ask, not something that's upon the patient to tell, I feel like."* BL outlined the reasons why:

> *I think it should be something that the providers bring up just, just in case because obviously, there's a lot of straight people and there's a lot of hetero relationships out there. But it's still, there's enough people that it needs to be brought up. Because it's important for them to be able to give the right information*

BL correctly points out that a GP's practice is likely not made up solely of heterosexual clients, and their patients' sexualities is information that is important for the GP to know. This last point was also voiced by the healthcare providers participating in the Logie study (Logie et al., 2019). BL goes on to say:

> *I think it would be the sort of thing you'd bring up in a general sort of checkup as, as an aside, just, hey, this is this is a topic that's important. This is a, this is a safe space. This is confidential. And then just, I don't know how you, how that would -- I suppose it would depend on the person. But just ask, just ask straight out because it would be, it's better to ask straight out than to just have lots of wish wash and wasting time.*

In an interesting contrast to the last part of BL's quote, the refrain "it never came up" in the context of discussing sexuality or sexual health information with one's GP was repeated by most interviewees. Participants were either not inclined or, as seen above, did not think to discuss these topics with their GP, and the GPs for the most part did not bring it up. As seen above, some participants thought it should be up to the GP to bring it up. KB's thoughts were similar, suggesting that healthcare providers open the door to discussing any topic, regardless of the actual reason for the visit:

> *And maybe like… like at the start of like when you're like [at] an appointment or something they'd be like, "I know that you're here for this,*

> *but feel free to ask about anything else that's bothering you." Because even though if you want to go like once or twice a year, you can still like right from the start make, like have them know that they can ask you anything and have a really like open communication with them as well. So maybe something like that, like saying at the start, like if you need to talk about anything else. I know you're here for this, but…*

Starker et al. (2018) conducted a small survey of LGBTQ+ young adults in the US. The survey showed that 77% of those surveyed were never asked about their sexual or gender identities by their paediatricians during their teen years. KB's point is therefore especially important in light of participants' comments that the topic of their sexuality "never came up" with their provider, and they didn't think they could bring it up in an unrelated appointment. KB's suggestion that the GP bring up the topic even in an unrelated appointment, simply to open the door for future discussion, might alleviate the stress many LGBTQ+ teens feel regarding coming out and discussing their specific sexual health concerns with their healthcare providers.

SW was one of the participants for whom "it never came up," though he hoped it was only a function of his age, as he was under 16 at the time of the interview, and *"it's not legal age,"* in his words. When I asked him what would help him discuss sexual health with his provider, in addition to the provider initiating the discussion SW wanted the assurance *"…that he's accepting… that he won't respond in a negative way."* He was not out to his GP at the time, and the two parts – his sexuality and his sexual health – were tied in his mind, with the sexual health discussion leading into identity disclosure.

EM reiterated that the safe space assurance was important:

> *So actually verbalizing that would be important to just have that conversation before anything sort of like a, you know, a disclosure before, you know, that this is like a no judgement space. We can have this conversation… if you want to, but not sort of like pushing it either.*

Participants also related that when their provider did ask about sexual health related issues (and the questions were mostly limited to the possibility of pregnancy), heteronormative assumptions were underlying the questions.

> *Like whenever I came in, she would ask if I had a boyfriend. It was like, if there's any chance I could be pregnant… she would ask, was I sexually active? And when I said yes, she would be like, Okay, are you using condoms? Are you on birth control? And so it was like, that's an assumption." (TT)*

TT's frustration was obvious when talking about their former GP's heteronormative assumptions. Their experience was not unique. BL mentioned that, *"Unless you explicitly tell them then, they're not gonna know, just thinking in this very binary, heteronormative standards [sic]."* They added:

> *I've got a bunch of friends who have gone mad. Sometimes [they] go to the GP and they're [the GP] like, "are you sexually active?" And [the friends are] like, yeah, and… "is there any chance you can be pregnant?" and they're like, "no, not in hell!" And [the GP is] like, "how's that possible?" And you're like, [sarcastically] "think about it for a quick second. Yeah. Think about it."*

KB described her sexual health conversation with her GP as, *"Usually the only thing is like, oh, like have you had a boyfriend yet? Like only ever asking, have you had a boyfriend ever? … [and] nobody's ever asked me what my pronouns are."* Despite being cis-gendered, KB felt the failure to ask for her preferred pronouns, along with always asking her about a boyfriend, were symptoms of the bigger problem, namely her GP's hetero- and cis-normative assumptions.

In the Fuzzell et al. (2016) study, the use of inclusive language (which included not making heteronormative assumptions in conversations) was also shown to be important in increasing the participants' comfort. Logie et al. (2019), who studied sexual healthcare experiences among LGBTQ+ people in in Arctic Canada, also found hetero- and cis-normativity was a factor that limited LGBTQ+ participants' access to sexual healthcare. In this study, BL's story about their friend who no longer sees their healthcare provider due to misgendering was similar to the Logie study.

As we saw in other themes, there is a reluctance among participants to discuss their sexual/gender identities and their sexuality, and sometimes lack of awareness regarding the necessity of such disclosure. Avoiding hetero- and cis-normative assumptions, along with the assurance of a safe space (especially if the office environment supports this assurance with visual cues) can help ease patients' anxieties and encourage a more open, trusting relationship with their healthcare providers.

8.4.2. Sexual Health Resources at School Do Not Compensate for GP Communication Shortfalls in Providing the Information LGBTQ+ Teens Need

In 2015, sexual and gender diversity were added to the sexuality education curriculum guideline of the New Zealand Curriculum (Ellis & Bentham, 2021). These guidelines, however, call only for affirming sexual and gender diversity as identities

(Quinlivan, 2018), they give no instructions on teaching sexual health from any diverse (i.e. non hetero- and cis-normative) perspective.

Most of this study's participants felt that school resources on sexuality and sexual health were largely inadequate and irrelevant to LGBTQ+ teens.

> *[A] lot of the time like with sex ed in schools, a lot of it doesn't really apply to gay people. So you sort of tune it out. And don't tune back in when something is actually useful. Yeah, you just don't really know what's important, they're talking about men and women. And that doesn't apply to you. [HK]*

HK's observation was repeated by quite a few of the interviewees, who all felt that "sex ed" in school did not consider the needs of LGBTQ+ students. The lessons, according to most interviewees, were very heteronormative, and as KB noted, even role-playing scenarios (e.g. how to respond if you are being pressured into having sex) were always enacted with male and female students, never same-sex students. BL added, somewhat bitterly, that the only times gay people were mentioned in their sexuality education classes were when talk turned to the subject of bullying, and how it was wrong to bully gay people. BL's observation underscores Quinlivan's (2018) argument that the requirement to affirm sexual and gender diversity in the sexual health curriculum in fact re-pathologises this group by "othering" them. She argues that efforts should instead be directed to addressing the dominant hetero- and cis-normative cultures underpinning the curriculum, and the interviews in this study support her views. Participants repeatedly complained that only matters of heterosexual sex and relationships were covered.

HK's quote above also brought up another point – that of increased risk to a student's sexual health as a result of inadequate education. In HK's narrative, it was a case of tuning out irrelevant material, and failing to tune back in when relevant information *was* presented. TT identified what they considered a gap in the curriculum while talking to lesbian friends, who asserted that they were not at risk of STIs because they do not have sex with men, which TT properly identified as a risky (and incorrect) assumption. *“And so I think it's good to be trying to fix the, I guess the gap in the sex education curriculum at schools,”* TT said, and LT voiced a similar thought. *“I think when you don't receive adequate sexual health education, you know, you're just, you're blind to [the] risks.”* EM also brought up the lack of important safety information for LGBTQ+ teens, listing topics she felt should have been covered in her classes: *“…how would you go about using contraception and having sex? Or how would you go about, having discussions about HIV. We don't really look at HIV [?] education. Yeah, that sort of thing.”* Since she was unable to be out in her family and migrant community, EM had few resources to turn to.

Ellis and Bentham (2021) explain that, though sexuality education in New Zealand is mandatory, schools are required to hold community and stakeholders consultations regarding the content taught in these classes. Consequently, the authors note, students may receive different breadths of content in different schools. SL’s school did attempt to teach about sexual and gender diversity, but as Quinlivan observed (above), the focus was on identities:

> *It's pretty much only for like, one or two lessons and it sort of just covers sort of the different type of sexualities or genders that are sort of existing currently. And just goes a little bit into that. Yeah, it's just sort of it doesn't go very deep into it. It's sort of just surface level about all of that, and maybe a bit about pronouns as well, but also just not very deep. (SL)*

The school also incorporated some talk of LGBTQ health and sex into their curriculum, but SL felt the lessons and messages were still very much centred on a heteronormative pedagogy. When asked if he knew how to stay safe as a gay man, he answered, *“obviously the biggest one, the contraception [sic] for like STIs are condoms. So that would probably be my go to but I have heard about other things such as PrEP, for like preventing AIDS and stuff like that.”* He was unable to describe PrEP correctly, however, saying it was for HIV-positive people, not realising it was an additional form of protection *he* could use against HIV.

In contrast to SL, DS’s school did not have sexual health classes per se.

> *Um yeah, well school never actually had like, health classes. I think they kind of just skipped all that they what they did is they got like outside organizations to come in. So like once a year, they'd have like a speaker come in, and they'd always do that thing at the start when they say like, we're going to be referring to like straight relationships, but we understand you guys just do your things. That's the only kind of mention that talked about it.*

The above quote shows that LGBTQ+ students are acknowledged only superficially in that particular school’s sexuality curriculum, potentially contributing to a sense of othering. Two additional interviewees related how the teachers in their school seemed uncomfortable teaching this material in their sexuality education class, and a third student felt their physical education (PE) teacher lacked appropriate qualifications to teach health classes. Health teacher training may benefit from a focus on sexuality education with a greater level of comfort and inclusivity, benefiting all students.

For LGBTQ+ students who are already struggling with isolation, and may be unable to come out to family, the lack of school resources and sexuality education increased the feeling of isolation. *“I don't think there are any spaces that give support* *and education. Even in school, we usually have a very heteronormative dialogue about… sex and all that. And so, yeah, I do. I do think more is necessary,"* EM said. She proceeded to say that her perception of the school counsellors is that they wouldn't have the resources she needed, and the school nurses *"judge you even if like, you're coming into… period like, you know, ministration [sic] sort of resources. So, I don't know, I don't think I would even be able to have that [sexual health] conversation."* Unlike several other interviewees who felt their school nurses were a good or excellent resource for sexuality education material, EM's experience was different. As mentioned earlier in the coming out theme, she was unable to come out to family because her country of origin (which the family visited regularly during non-pandemic times) imposes severe penalties on LGBTQ+ individuals. Her parents came to her GP appointments and she therefore felt unable to talk openly with her provider.

The observations from this study's interviewees match the findings by Ellis and Bentham (2021), who note that "… LGBTIQ youth in Aotearoa/New Zealand are poorly served by school-based sexuality education; with much of what is delivered falling short of what is stipulated in national guidelines" (p. 718).

8.4.3. Knowledge of Sexual Health and Sexual Risk Behaviours is Incomplete in Study Participants

"I really lack LGBT sexual health education, because it's just not readily accessible really," said LT, and proceeded to give an example of the difficulties incomplete knowledge (theirs and their provider's) presented for her:

> *I've been in a relationship with a transgender female before [LT is anatomically female, their partner was anatomically male]. And, you know, like, no one really knew what to do. We were just like, "I guess we'll use a*

> *condom," because you didn't really have any idea. You know, how does oestrogen affect sperm development? You know, what are your risks of pregnancy? …You don't know how that works with all that different biology involved.*

The lack of resources and sufficient communication with healthcare providers regarding sexual health has clearly created a knowledge gap in this group of interviewees. This gap puts the group at a heightened risk of STIs, a fact that is borne out by New Zealand and global statistics on rates of STIs in LGBTQ+ teens (see discussions in Chapter 1 and Chapter 2).

The majority of interviewees knew that barrier protection was the best way to prevent STIs, though not all of them were confident in their ability to talk to their partners about it. It is interesting to note that Rasberry et al. (2018) found a distinct difference between LGBTQ+ and non-LGBTQ+ students in condom use, even if both groups were taught in the same sexuality education class, from the same curriculum. Non-LGBTQ+ students were more likely to have used a condom at their last sexual encounter, compared with their LGBTQ+ peers. One theory the authors had was the relevance of the sexuality curriculum in general to the LGBTQ+ students. As we saw above in this study, some LGBTQ+ students tune out of irrelevant material, and miss important discussions along the way.

In contrast to their knowledge of barrier protection, most interviewees were unsure how to get tested for STIs/HIV, and what such testing involved. More worrisome, and indicative of the problem of high STI rates in teens in general, is the lack of knowledge about STIs and the symptoms of infections. CS admitted that:

> *I had a fair idea on what some of them were like common ones like chlamydia, and AIDS and stuff like that. But I didn't know too much about symptoms, or what to do if you did have it or whether they were curable, or anything like that.*

The quote from CS is concerning because it shows a knowledge gap that has public health implications beyond the individual participant (the unaware person might spread an infection unknowingly), and has health implications for the individual themselves (if they have an STI that goes unrecognised and untreated for too long).

TT, while they lived at home before going to University, did not ask their GP about getting tested for STIs, though they were sexually active, for fear their family would find out they were sexually active, and because they felt there was a stigma attached to getting tested. In the Logie study, the stigma attached to STIs (especially HIV) in the LGBTQ+ community was the greatest barrier to testing for these infections (Logie et al., 2019).

Not surprisingly, when asked what they did if they needed health information to keep safe, all interviewees said they get their relevant information from the internet, mostly due to not knowing where else to go for information, as discussed previously in this theme. However, many were not sure how to judge a site as credible for collecting the information they needed. LD said, *“General sex positivity, I suppose helps. Just the attitude of that. And that's a difficult question. Yeah, I'm not sure.*” SL commented that *“I'll probably just type it and look through different websites to see like what they would all say. And go with probably the most popular or like, I guess.”* In the era of conspiracy theories and fake scientific information, the participants’ lack of knowledge regarding what constitutes credible sites dispensing credible information is potentially damaging. A small minority of participants mentioned professional sites such as Family Planning or WebMD.

Several participants mentioned they relied on social media “mentors” for getting information – these are older LGBTQ+ group members who were more experienced and offered advice in the social media groups they participate in. This strategy is not uncommon in LGBTQ+ adolescents (McConnell et al., 2017), and is not limited to health related support.

As discussed previously, LGBTQ+ teens have an elevated risk of STIs. This theme highlights several (but not all) reasons as to why that is. The lack of LGBTQ+ specific sexual health/sexuality resources, and the inability to communicate with one’s healthcare providers about this important yet sensitive subject create a knowledge gap that puts this group at risk. Many of my interviewees acknowledged this risk exists, while expressing frustration at the lack of resources.

8.5. Participants Expect Inclusive Healthcare

The idea of inclusive healthcare refers to giving marginalized populations the same benefits of, and access to, healthcare as those of the mainstream population (Newman et al., 2021). Several avenues can lead to inclusive healthcare for the LGBTQ+ population. Some examples include hiring more LGBTQ+ employees in clinics and healthcare providers’ offices, sensitivity training reminding providers not to engage in hetero- or cis-normative assumptions, and medical education that prepares providers to treat LGBTQ+ patients (Newman et al., 2021).

Inclusive care fosters a sense of belonging among the population being served, which in turn also bolsters resilience (Mattes & Lang, 2021). In a population subjected to constant stressors stemming from stigma and discrimination, resilience is an important protective factor, as discussed in Chapter 1. Furthermore, a sense of belonging can help to counter the sense of isolation that several of the interviewees discussed in previous themes, isolation borne out of marginalisation. As seen in their comments below, the participants' expectations of inclusivity are nothing more than the expectations of the standards mainstream healthcare consumers take for granted. During the interviews, participants spoke about what would encourage trust and openness in their relationships with their providers, and what they felt would be helpful to get from their GP to assist in achieving their best physical and mental wellbeing. The responses almost uniformly spoke to the participants' need for a competent GP – one with the knowledge of caring for LGBTQ+ patients, and their need to be respected.

8.5.1. GPs Should Be Approachable and Knowledgeable

The importance of trust and openness in the interviewees' relationships with their GP is evident in participant narratives across preceding themes, for example, in the concern participants voiced about confidentiality, their hesitation to come out to their GP, and the positive relationships described by those who were out.

One aspect of developing such trust is the healthcare providers' approachability. Participants described wanting their GP to be approachable and interactive. Their narratives indicate that all aspects of the consultation – from casual conversation as they multitask through to engaging the patient in developing their care plan -- are an opportunity for GPs to make the patient feel at ease. The quotes below highlight the affective nature of the GP-patient relationship and showcase what Hanlon (2021) called the "ambivalent role" of emotion in practice – namely the difference between "caring for" someone, which is the healthcare provider's work, and "caring about" someone, in an emotional sense.

> *I just feel like the relationship between [the] two needs to be good enough that you feel like you could ask for anything… not feel afraid to ask anything, and then with them, even if they don't offer it themselves to be able to give you more options. (KB)*

> *And I need them to be approachable, because, and like making you feel comfortable with talking to them. And not be like, oh, stoked in just sitting there? Like, on the computer, I guess. (AF: Right. So be more interactive.) Yeah. Even like some casual conversation while he's like doing my prescription or something. (SW)*

As seen in the previous themes, a visit to a healthcare provider can be especially anxiety provoking for LGBTQ+ teens. The participants above spoke of the need to feel comfortable in their relationship with the doctor who in turn is approachable and responsive to their needs.

In opposition to a culture of care, fear of discrimination or judgement was expressed by multiple interviewees, based on their own or others' experiences. Fear of discrimination has been shown to impact healthcare communication self-efficacy (Cavalhieri et al., 2019), and consequently the utilization of healthcare services. SW observed:

> *I guess, like the discrimination point. If they were homophobic… Ah, I really feel like they'd be like, they wouldn't want me there. And I[’d] feel really nervous about how they like treat me and talk to me.*

SW is not out to his GP, and is not sure what his GP's attitude would be if SW came out as bisexual or gay[27]. He thought that if his GP were homophobic, he would switch GPs. When asked how easy he thought switching would be, he admitted, "…he's known me from when I was little; I guess it would be a little hard to change to someone else. Just you. There's a relationship there." For him, the prospect of having to change providers was clearly an uncomfortable one, as it entailed the loss of a trusting relationship that was not only between him and his current GP, but also between his family and the GP. Changing to someone else, "just you" without his family to support him once again conveys the isolation that interviewees have discussed in previous themes, which seems to pervade multiple aspects of their lives.

As Newman et al. (2021) pointed out, inclusive care is harder to come by for gender diverse individuals compared with those who are sexually diverse (see also Section 8.3) and fear of discrimination was also on LT's mind: *"I think I'm always worried that my medical care will suffer if I come out with my gender identity versus my sexuality."*

Heteronormative attitudes are pervasive in the health sector (Laiti et al., 2019). When a GP makes heteronormative assumptions, they fail to practice inclusive care and risk undermining trust they may have established with the patient. The importance of using more inclusive language was evident in participant narratives which suggested GPs encourage conversation by asking questions without heteronormative assumptions. The possibility for missteps is particularly pronounced when discussing sexual health. TT mentioned the need for GPs to use more inclusive language, such as "boyfriend or girlfriend" when talking about someone's partner, or simply asking "what are the genders

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[27] SW identifies as "somewhere between bisexual and homosexual."

of your sexual partners?" BL echoed these sentiments by saying it all "boils down to respect," expressed in inclusive language and correct pronouns. BL is out to their provider, who also knows they are in a (biologically) same sex relationship. Yet their GP asks them at every appointment if there is a chance they are pregnant.

> *…that's sort of a deliberate… Well I don't know if it's deliberate or not but I'm gonna say deliberate. Maybe not malice, but what really is. I mean, it's a bit dismissive. Like, you know, oh well, I don't have to remember that, because it's not important type of thing. But it's like, well, this is really important.*

BL wants to know *that they* matter to their GP just as much as every other patient does. In other words, as discussed above, they wanted to feel their GP not only cared *for* them, but also cared *about* them. A perceived dismissal such as the one they experience regularly drives home the sense of "othering" or not belonging. HK recalled his own experience with lack of inclusive language*, "I have had issues when seeking like sexual health related things with just that not being very inclusive and being misgendered because of that."* This type of experience can set the tone for future interactions between participants and their healthcare providers.

A major point brought up by nearly all interviewees was the lack of knowledge and training providers display when it comes to treating LGBTQ+ patients. BL described a typical encounter: *"…a lot of them are just surprised and like, fumbling a little bit when you come out, because they're like, 'Oh, I wasn't prepared for this scenario. I don't know what we're supposed to do now.'" LT related her anger and* frustration watching doctors check WebMD during consultations with them: *"I could have done this at home. And I often do…. just look things up myself, because I'm like, what's the point of paying like 30 bucks [in a raised voice] TO WATCH SOMEBODY DO IT!"* This frustration was a common thread when the topic of GPs’ lack of knowledge in the LGBTQ+ arena came up. When asked if their healthcare needs were being met, BL replied:

> *I mean, like, you know, the big dream, like the wildest idea, fantasy kind of thing would be, all GPs and all healthcare providers in any, you know, sort of facet, have to undergo some sort of training or… I suppose training is the best word for it, on how to fully equip themselves to be dealing with problems that they are unfamiliar with ‘cause of their, you know, sort of narrow view of the world.*

Beneath the sarcasm, BL’s words convey their frustration at being excluded from what people consider care standards. As mentioned previously, BL’s first experience of coming out to a healthcare provider elicited a suggestion of conversion therapy from that provider. Though BL’s subsequent experiences were not as extreme, they have repeatedly come across providers’ lack of knowledge and lack of inclusive care, and it was mentioned several times throughout their interview. As Newman et al. (2021) pointed out, younger LGBTQ+ health consumers now expect inclusive treatment from their healthcare providers, and are critical of those who are not supplying it. BL’s words definitely contain such criticism, in addition to his notable frustration. It is also worth noting that Newman and colleagues identified that gender diverse participants (such as BL) found it much harder to obtain inclusive healthcare, compared to their sexually diverse peers.

Some GPs take a proactive approach. TT related how their GP, who is “*really accepting but she doesn't always like, know, a huge amount*” sometimes asks TT questions unrelated to the reason for their visit, “*just like for future reference for other patients that she sees.*” Having a good relationship with their GP, TT does not mind being an educator because “… I'd rather she asked me then ask someone who's like way more vulnerable and *way less knowledgeable, and all of that.*” And like TT’s GP, GV’s mother, who is a GP herself, did her own research when it came to the sexual health of non-heterosexual patients, an area GV said her mother was not very familiar with.

8.5.2. GPs Should Recognise and Respect Their Patients’ Diversity

During some of the interviews, I had a variety of LGBTQ+ sexual health resources arranged on the desk. I encouraged participants to browse through them (with the option of me leaving the room) and take some home if they found anything useful. While interviewing LJ, I asked him what he would like to see his provider do differently now that he was out to his GP. LJ pointed at the leaflets on the desk, saying, *“More towards this sort of stuff.”*

LJ wanted his GP to provide resources appropriate to who he was, or as LT put it, *“Realize there are so many people who are so wildly varied and different that you need to accommodate for.”* According to Riggs and Treharne (2017), the implications of being “outside the norm” (in this case, not heterosexual, non-cis-gendered) is that the individual is less than a person. It is easy to see how this lack of inclusive care -- not having resources that apply to one’s community -- sends a message that they are somehow not as important, or count less than the majority of clients the GP sees.

Respect was an oft-repeated need from participants. As LT pointed out above, GPs treat a wide variety of people and respect may mean different things to each of them. For all of the gender-diverse interviewees, the use of correct pronouns was one of the most important elements of respect. Additionally, some interviewees wanted the GP to be honest about their need to consult with others, if the GP’s lack of knowledge prevented them from rendering care to an LGBTQ+ person.

As discussed previously, lack of knowledge on the provider’s part can lead to refusing to care for a patient (McPhail et al., 2016), as LT found out:

> *Yeah, if somebody was just like, ‘You know what I actually don't know. Let me, let me find that out for you.’ Because I think time and time again, you just get the, ‘I don't know, find someone else.’*

LT also felt clinics and GP offices should have at least one trained professional or LGBTQ+ representative on staff. *"… if you have all these services for cisgender people, why do you not even have one person on an entire staff that that can help you out with this* issue?”

LT’s justifiable expectation of having at least one knowledgeable staff person in a clinical setting is reflected in a recent scoping review (Hudson & Bruce-Miller, 2022). In this scoping review of nonclinical best practices for LGBTQ+ affirming healthcare environment, the authors found that having an LGBTQ+ inclusive workforce informed all other best practices domains. They noted that “LGBTQ staff can provide valuable knowledge and perspectives about serving LGBTQ patients, as well as help patients feel represented and comfortable” (Hudson & Bruce-Miller, 2022, p. 12). This observation touches on many of the recurrent topics the interviewees raised; e.g. lack of training, heteronormative assumptions, lack of gender affirming care. It is also probable that helping patients “feel represented and comfortable” (i.e. providing inclusive care) will increase their overall self-efficacy when interacting with anyone in that clinical setting, thus improving their healthcare utilization and their ability to communicate openly with their provider.

LGBTQ+ teens’ expectations from their care providers are seen in this theme as not more complex or unique than what every patient should expect from their healthcare provider. There is an expectation that the provider will be knowledgeable, easy to talk to, respectful, and willing to initiate discussions that may challenge their hetero- and cis-normative assumptions. How this culture should be implemented and when should change begin are two areas that require more research.

8.6. Summary

The interviews in this study painted a picture of a diverse teenage population whose healthcare needs are often unmet. Many of the needs discussed in the interviews centred on communication – verbal and visual. Participants needed assurances they can talk about any topic in a safe and confidential environment. They were looking for words and visual cues that indicate inclusivity. However, underneath the communication difficulties issues of biases and inadequate knowledge were also revealed.

The barriers experienced by these LGBTQ+ teens navigating the New Zealand healthcare system also impact their sexual health. Since school resources are not meeting their needs either, the inability to discuss their sexuality with their healthcare provider leaves them with the internet, which carries a mixed bag of grossly inaccurate to medically factual material. Not all of the interviewees knew how to judge the credibility of various internet sources.

Mental health was a topic that kept coming up during interviews. It is threaded through every theme discussed in this chapter. When asked about their struggles, the overwhelming response from participants tied their mental health difficulties to their experiences being LGBTQ+. Specifically, interviewees talked about the pressure from society on members of the LGBTQ+ community – the discrimination, threats of violence, bullying, and upheaval in family lives. Their words lend more credence to Riggs and Treharne’s decompensation model, which argues that the psychological harm that results from being a member of the LGBTQ+ community comes from the imposition of societal norms, not from internalised discrimination (Riggs & Treharne, 2017).

New Zealand's mental health system is inadequate, and especially so for children and adolescents (Whitcombe-Dobbs, 2022). A 2020 UNICEF Report Card found that New Zealand had the second highest youth suicide rate in the developed world, at 14.9 deaths per 100,000 adolescents (UNICEF, 2020). As discussed in previous chapters, studies have shown that mental health outcomes for LGBTQ+ youth are worse than those of their heterosexual, cis-gender peers, as a result of being a marginalised population. For interviewees who struggled with mental health issues (as most of them did), the feeling was that there are not enough resources to meet their needs. As one interviewee bluntly stated, *“mental health is just not as high as a priority as it should be… [i]n New Zealand.”*

In recent decades, there has been more discussion about inclusive healthcare for LGBTQ+ people. In fact, younger patients today have increasingly come to expect inclusive, knowledgeable care from their providers (Newman et al., 2021). Some of my interviewees felt that the younger generation of doctors is more inclusive and understanding, as they grew up in a changing societal climate. Overall, however, there is still apparently work to be done.

Chapter 9. Discussion

9.1. Overview

> *"Overt and subtle forms of discrimination are widespread against people with an actual or perceived diverse SOGIESC[28], and they are more likely to become victims of crime."*
>
> *(New Zealand Human Rights Commission, 2020, p. 5)*

The truth of the HRC's observation above came in the form of surveys containing hate speech in this study. They were excluded from the dataset (see Section 7.2), but a small example can be found in Appendix H (Figure A). These survey responses are a symptom of a problem that drove me to do this study in the first place. After all, healthcare providers come from the same population (and often the same culture) where such opinions are still, according to the New Zealand HRC, "widespread."

The Youth19 survey found that 55% of gender diverse participants were unable to access healthcare in the year prior to the survey, as were 31% of non-heterosexual students; of the heterosexual, cis-gendered participant population, 20% were unable to access care in the same timeframe (Fenaughty, Sutcliffe, Clark, et al., 2021; Fenaughty, Sutcliffe, Fleming, et al., 2021). These statistics indicate a potential serious access problem that New Zealand's LGBTQ+ teens are experiencing these days.

The aims of this study were to understand what, if any, perceived barriers do the New Zealand LGBTQ+ teens in this study experience as they try to access healthcare services, and whether these barriers affect their sexual health. The focus of the sexual health component was on primary and secondary prevention of STIs, including HIV. The

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[28] Sexual Orientation, Gender Identity and Expression, and Sex Characteristics

study itself has been a journey of personal and professional growth for me, and I hope it does not end here. This chapter raises several concerns regarding the lack of inclusive care for LGBTQ+ teens in New Zealand, and the following chapter sets up recommendations and future research opportunities. The ultimate aim of this study is to be the basis of a discussion that will lead to changes in the way the New Zealand's healthcare system approaches its LGBTQ+ community members.

This study found that LGBTQ+ teens do perceive interpersonal barriers to healthcare services, and these barriers have potentially serious consequences not only in the sexual health arena but also in terms of the participants' emotional wellbeing. The participants usually attributed these barriers to lack of knowledge and training on the providers' side. Such perceptions caused participants to feel dismissed or misunderstood, and at times reluctant to continue seeking care. The perception of barriers also stems from the participants' own experiences of being LGBTQ+, driving their fear of coming out to providers lest they suffer discrimination and judgement, which may be a common occurrence in other areas of their lives. A widespread heteronormative attitude in healthcare allows participants to continue receiving care without having to come out. However, this attitude adds a layer of complexity and additional barriers to gender diverse individuals who require, at minimum, gender-affirming care in the form of respectful language.

These above barriers, and the perceived lack of adequate sexuality education resources, combine to affect the participants' sexual health negatively. The lack of knowledge and education on sexual health as an SGM individual raises the participants' risk of STIs (Diana & Esposito, 2022).

This chapter brings together the quantitative and qualitative study results to answer the three research questions underlying this study. The conceptual approach to analysing the survey was informed by the Communication – Self-efficacy – Sexual Health model. This model will be discussed first, as it was developed for this study. A discussion of the results, as they relate to the research questions, follows. The study's strengths and limitations will be discussed last.

9.2. The Communication – Self-efficacy – Sexual Health Model

The conceptual approach to the quantitative survey analysis was informed by the Communication – Self-efficacy – Sexual Health model, depicted in Figure 7.1, which was developed for this study. Simply stated, this model proposes that good communication with one's GP (or other primary care provider) affects sexual health behaviours. The model primarily pivots on the premise that good healthcare communication with one's GP both impacts and is impacted by the patient's healthcare communication self-efficacy, which in itself is a multifactorial construct. For the purpose of this study, the drivers of self-efficacy I was concerned with are fears of stigma, discrimination, and being outed to one's family.

The above assertions are supported by literature; for example, Fisher, Fried, Macapagal, et al. (2018) found that adolescent MSM whose GPs initiated discussions regarding their sexual orientation were more likely to utilise STI and HIV preventive services ($\beta = 0.23$; $t = 3.46$, $p < 0.01$), and to be tested for these conditions ($\beta = 2.10$; $W_1 = 27.64$, $p < 0.001$). Levy et al. (2014) conducted a comprehensive literature review regarding adult Black MSM utilisation of HIV testing and prevention services, and found that a non-supportive relationship with one's healthcare provider was a barrier to accessing these services. Such non-supportive relationships specifically included instances of racism and homophobia, as well as a general lack of cultural competency in working with sexual minorities. The latter, the authors found, means that, “Many healthcare providers … fail to recognize the importance of discussing sexual health with patients as a routine component of medical care” (Levy et al., 2014, p. 990). A meta-analysis carried out by Ruben and Fullerton (2018) and limited to sexual minority patients, found that coming out to providers was associated with “more healthcare seeking and screening” (pg.1549) among other benefits that also included better psychological wellbeing.

Good communication, as the model suggests, also affects and depends on the patient’s perceived health communication self-efficacy, that is, the patient’s feeling of control when communicating with their GP (a discussion of self-efficacy can be found in Chapter 5). The literature, for example Fisher, Fried, Macapagal, et al. (2018) and Levy et al. (2014), indicates that health communication self-efficacy in this study population is driven by fear of stigma and discrimination, and fear of being “outed” to family and friends. Cavalhieri et al. (2019) showed that healthcare communication self-efficacy directly impacts healthcare utilisation. Furthermore, the authors found that instances of discrimination, even outside the healthcare setting, impacted a person’s perceived healthcare communication self-efficacy and thus decreased their healthcare utilisation. Therefore, confidentiality concerns, stigma, and discrimination are contained within the self-efficacy box.

The connection between patient-provider communication and health-related self-efficacy is also supported in the literature. For example, Chen et al. (2013) found that higher GP engagement leads to higher treatment adherence self-efficacy in people living with HIV. Rutten et al. (2016) found that positive patient-centred communication with one’s GP was associated with higher levels of health-related self-efficacy, in people with a variety of chronic conditions.

The model predicted that health communication self-efficacy in the study population would be driven by fears of stigma, discrimination, and confidentiality concerns. These would lower health communication self-efficacy, which in turn would negatively impact communication with the participants’ GPs. The interviews, as the Sexual Health theme (Chapter 8, Section 8.4) shows, revealed a lack of effective communication with a GP that was bidirectional. On the one hand, participants, driven by concerns regarding discrimination and being outed, often chose not to disclose their SGM identity to their provider. At the same time, the GPs, most likely operating on heteronormative assumptions according to the participants, rarely brought up sexuality and sexual health. When sexual health was mentioned, it was in the context of preventing pregnancy.

It is important to note a multitude of factors shape teens’ choices and sexual risk behaviours, with this model focussing on GP communication. In analysing both quantitative and qualitative results, I found that the model was a good fit for the data I collected. The quantitative data by itself showed a seeming lack of association between sexual health and communication with one’s GP (or having a regular GP). The interviews helped uncover this lack of connection was really lack of effective bi-directional communication, driven (on the participants’ side) by lower self-efficacy around communicating their SGM identity and needs.

9.3. RQ1: Do the LGBTQ+ Teens in This Study Perceive Interpersonal Barriers to Healthcare Services?

The lives of LGBTQ+ teens can be quite complex. Most teenagers experience difficulties at this age, but as the Coming Out theme (Section 8.2) shows, LGBTQ+ teens must also wrestle with the decision to come out or stay in the closet. Too often, coming out results in interpersonal conflicts with people who know them. LGBTQ+ teens are aware that coming out exposes them to the risks of violence, rejection, and loss of family and friends. These constant additional pressures – from making the decision on coming out to possibly experiencing the consequences of coming out -- can bring on the decompensation response (Section 5.3) (Riggs & Treharne, 2017), accounting for the increased rates of mental health struggles in this group. In line with the decompensation model, in this study's group of interviewees, mental health struggles that the interviewees spoke to tended to centre around LGBTQ+-related family conflicts, a sense of isolation due to being LGBTQ+, and the denial of gender-affirming care. As the Decompensation model suggests, these additional stressors that stem from being LGBTQ+ are the ones that, when added to "everyday" stressors (ones that most adolescents experience as part of adolescence), can cause the decompensation response. Importantly, the people who expressed the least struggles with mental health in the interviews were also the ones who were out to supportive family and friends. This may point to the fact that the absence of additional stressor(s) associated with coming out was beneficial to the participants' emotional wellbeing. Conversely, it is also possible that LGBTQ+ teens who already had good emotional wellbeing were more likely to come out.

The decision on whether to come out to their healthcare provider is difficult and confusing for LGBTQ+ teens for somewhat different reasons. As seen in the sexual health theme (Section 8.4, many sexually diverse teens do not consider their sexuality to be related to their health status, and therefore they do not feel their sexual orientation is their GP's business. This finding was corroborated by Rossman et al. (2017). But several of the teens who spoke about coming out in the interviews, as well as 50% of participants who answered the health communication self-efficacy questions in the survey, also expressed concern about being discriminated against by their GP if they disclosed their sexual orientation. Moreover, as the coming out theme makes clear, participants are very aware that coming out is a decision they will have to make multiple times in their lives, as they change healthcare providers or require the care of a specialist. Many found the prospect daunting. Thus, sexual identity by itself can be a barrier to accessing healthcare, but whether it actually becomes a barrier depends on the individual. As Riggs and Treharne point out, not all people are able to compensate – to keep going without physical or emotional adverse reactions (Riggs & Treharne, 2017, p. 600). Unwillingness to engage in repeated identity disclosures, resulting in healthcare avoidance, may be one decompensation response individuals engage in. This is supported by Ruben and Fullerton (2018) (discussed in Section 9.2), who found that coming out to one's provider was associated with more healthcare seeking.

It is also worth considering that individuals not only react differently to similar stressors, but may perceive a completely different experience in similar situations. Tan and colleagues (2022) point out that negative experiences can lead to future avoidance of healthcare. The interviews showed that experiences could be constructed differently by individuals, possibly depending on their background and support systems. The theme speaking to gender diverse participants' barriers to healthcare included accounts from two people who were referred to a different clinic when they came out to their (previous) provider. One person saw the referral as a rejection, while the other saw it as their provider trying to help. It is possible that the person who felt rejected will have lower self-efficacy in the future regarding coming out in healthcare settings (they are currently with a YOSS), or even seeking care, compared to the person who saw the referral as an attempt to help them. These individuals had very different experiences coming out to their families, and different journeys through the healthcare system, as discussed in

Section 8.3.1. Of note, however, Baldwin et al. (2018) found that their study participants saw any referral, even one done due to the provider's lack of knowledge (and their wish to ensure adequate care for the participant) as denial of care. The study population in the Baldwin et al. study comprised those aged 18 years and older residing in the US. It is possible their context and healthcare journey were quite different from the New Zealand youth participants in this study, and therefore the perceptions or interpretations of such events are different. However, a study by Tan et al. (2022) of a subgroup from New Zealand's Counting Ourselves study population showed many of the same concerns were raised in both the Baldwin and Tan studies. The Tan study is discussed in the following section in more detail.

Gender diverse individuals experience an added layer of complexity in their relationship with their healthcare provider, as discussed below.

9.3.1. Gender Identity Presents Additional Challenges

Gender diverse people have a complex relationship with the healthcare system. Though not all gender diverse people intend to medically transition, many gender diverse people will encounter problems receiving gender-affirming care (Tan et al., 2022). Both survey and interviews detailed such episodes from every gender diverse participant who utilised an open ended-forum (interview or open-ended survey questions). These experiences form part of the theme "gender diverse teens face profound barriers to utilising healthcare." From clinic intake forms that only recognise two binary *genders* to providers who refuse to use their patients' proper nouns, a gender diverse individual's healthcare journey is fraught.

Gender diverse participants in this study were less likely to come out to their GP compared with cis-gendered participants, despite the fact that gender diverse individuals may utilise the healthcare system more, if they intend to medically transition. Moreover, as the interviews have shown, even treatments designed to alleviate body dysphoria, which may be as simple as prescribing a common contraceptive device, are met with resistance by the healthcare provider. As the theme shows, such repeated denials of gender-affirming care are harmful to the participants' emotional wellbeing.

It is important to note that in addition to the benefits of giving a healthcare provider a complete picture of one's health status, coming out to a healthcare provider seems to confer both direct and indirect health benefits, including better screening uptake and better self-reported wellbeing (Ruben & Fullerton, 2018). However, adolescence is a time of hyperawareness and sensitivity to judgement (Russell & Fish, 2016). Even teens who have not come out yet would be influenced by peer accounts of and opinions about coming out to providers, as peer experience is one of the constructs of self-efficacy (Schwarzer & Luszczynska, 2005). Peer opinion is especially important in adolescence and young adulthood (Russell & Fish, 2016; Stout et al., 2020). These factors are likely to impact youth participants' willingness to come out to their provider, possibly leading to a conflicted state of needing to come out – for the sake of transitioning, or treating body dysphoria – and fearing the consequences of coming out. This conflict becomes another stressor in the decompensation model.

In the survey, regardless of whether participants had a regular GP or not, they cited the perception of being dismissed or not understood as a barrier to utilising healthcare fully (e.g. the ability to openly discuss sensitive topics with their GP). Most of the people in this category cited these perceived attitudes (or actual incidents) specifically in the context of their gender identity. Gender diverse interview participants also spoke of the difficulty obtaining gender-affirming care, mostly due to lack of providers' knowledge and training. Their anger and frustration at these difficulties clearly lingered even among interviewees who were happy with their current provider.

Current deficits in medical school curricula in New Zealand, as they pertain to LGBTQ+ care, are discussed in the Literature Review, Section 3.3. The study results (Chapter 8, Section 8.3) demonstrate the frustration and anger that result when gender diverse teens are confronted by healthcare providers' lack of knowledge with regards to treating gender diverse patients. This issue was showcased in the subtheme "Gender Diverse Teens Face Profound Barriers to Utilising Healthcare," and also reported in a sub-analysis of the Counting Ourselves study (Tan et al., 2022). The study by Tan and colleagues was not limited to adolescents, Tan et al., (2022) also found that lack of providers' knowledge was one factor explaining why trans* people in New Zealand had significantly less trust in their GP (Cohen's *d* = .39; 95% CI, 0.32 – 0.46) compared to the general population[29]. It is also not the place of a teenager to educate their GP about being queer, as one participant was constantly asked to do by their provider, however laudable the provider's effort might be. Here, again, we find that participants in this study were not unique in their role as educators. Tan et al. (2022) also found that their participants had to act as educators

While the majority (69%) of this study population rated the quality of care they got as 7 or above on a 1-10 scale (10 being the best), caution should be taken not to ignore those reporting low quality of care, for they are the ones most in need of help. In addition, even though trust in the GP's medical decisions was high (62% said they trusted their GP's medical decisions "A great deal" or "A lot"), it was also associated with gender; gender-diverse participants were less likely to display a high level of trust in their

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[29] The general population results came from the 2018/2019 New Zealand Health Survey.

GP’s care decision, consistent with the findings in Tan et al. (2022). Gender diversity was also associated with a low health communication self-efficacy score in this study, which also lowers healthcare utilisation (Cavalhieri et al., 2019).

Thus, gender diversity seems to be a barrier that negatively affects regular utilisation of healthcare resources, due to a variety of fundamental reasons. Indeed, gender (but not sexuality) had a negative effect on participants’ self-ranking of health, both physical and emotional, signifying an unmet need. As with the mental health situation discussed above, the New Zealand Government has recently acknowledged the problem with gender affirming care and allocated $2 million to set up eight GPs throughout the country who would be providing gender affirming care (Verrall, 2022).

9.3.2. Mental Health

In this convenience sample comprising LGBTQ+ adolescents aged 15-19 years, the first notable finding is the gap that exists between the participants’ self-ranking of overall and emotional health, signifying a likely unmet healthcare need. A total of 72% of respondents rated their overall health as Good/Very Good/Excellent, compared with 27% who rated their emotional health Good/Very Good/Excellent.

In the New Zealand Health Survey (2020-2021 update), where the closest age group to this study’s population was 15-24 years old, 92% of respondents aged 15-24 years ranked their health as Good/Very Good/Excellent, and 16% in the same age group experienced psychological distress. There was no question regarding emotional health in the New Zealand Health Survey (New Zealand Ministry of Health, 2021a). It is possible that a population comprising only adolescents, as in this study, would have a higher baseline rate of poorer emotional wellbeing, as adolescence in itself is a challenging time psychologically (Chervonsky & Hunt, 2019). The difference may also be attributable, at least in part, to the sampling differences between this study (which used convenience sampling) and the New Zealand Health Survey, which used a stratified multi- stage area design, intended to provide prevalence estimates for the New Zealand population (New Zealand Ministry of Health, 2016). However, as previously noted (see Chapter 2), adolescent SGM have worse mental health outcomes compared with their cis-gendered, heterosexual peers. The gap between the New Zealand Health Survey results and the study population, especially in the emotional health area, deserves attention as it may be due to reasons other than differences in sampling and survey design. As the survey closed in April 2020, the effects of the COVID-19 lockdown would not have played a role in these results.

Mental health was clearly a significant concern for participants. Interviewees talked about the pressure society exerts on members of the LGBTQ+ community, and this was in line with Riggs and Treharne's decompensation model (Riggs & Treharne, 2017). The model speaks of stressors stemming from society's ideologies, which can accumulate and reach a critical point where a marginalised person has a physical or emotional response (or both) to these stressors. In the case of the study population, the dominant societal ideology is hetero- and cis-normative. Society still views deviation from this norm as abnormal, and stigma and discrimination are frequent stressors Gower et al. (2021), often escalating to violence, especially against gender diverse individuals. The lack of knowledge on the providers' part in treating LGBTQ+ patients attested to the fact that this is a consistent part of the study population's healthcare journey.

Both the interviews and open-text questions in the survey showed the perception of inadequate mental healthcare in New Zealand causing distress in some participants and anger in others. Here, as well, lack of training or provider biases were evident as participants' gender identities were pathologised by the professionals meant to help them. This finding echoes a much earlier New Zealand study by Lucassen et al. (2011) showing that LGB teens (gender-diverse teens were not included in that study) were more likely than their heterosexual peers to seek help for emotional difficulties, and more likely to have more trouble obtaining such help, compared to their heterosexual peers.

9.3.3. Confidentiality Concerns and Identity Disclosure

Approximately 40% of the participants indicated they were comfortable discussing their sexual and gender identities with their GP, and less than a fifth of the participants had actually come out to their GP. This implies that GPs may be unaware of risks to many of their patients' physical and emotional wellbeing that come from being part of an often-marginalised group, as explained by the decompensation model, discussed in Chapter 5 and previous sections in this chapter.

Concern about confidentiality was a barrier for accessing GPs, reported participants in the survey. In the interviews, confidentiality concerns were mostly concentrated around being outed to family, as described in the Coming Out theme (Section 8.2). One interviewee also expressed concern about having their parents find out they were sexually active. Adolescence is a stage where sexual activity usually emerges, and parents are often uncomfortable discussing the topic with their children (Estes, 2017). In this theme participants described how concern about confidentiality added to their stress and anxiety concerning coming out to their GP. Participants who saw their regular family GP since childhood often worried that their GP would disclose confidential information – either accidently or on purpose – to their families. This concern was a deterrent to coming out. In contrast, some participants felt that, having known their provider for so long, they could trust them. For those participants, as seen in the third coming out subtheme, coming out actually enhanced the patient-provider relationship (see section 8.2.3, "Coming out can enhance the patient-provider relationship").

The percentage of participants with a regular GP who had confidentiality concerns was observed to be larger than the percentage of participants who came out to their GP (29% vs. 19%, respectively). Confidentiality concerns affected people with no regular GP even more, with 67% of them indicating such concern on the self-efficacy scale. This may mean that participants avoided regular care due to confidentiality concerns

There is very little data in the literature on the percentage of adolescents who came out to their GPs (Rossman et al., 2017). Meckler et al. (2006), studied how many youths aged 14-18 years disclosed their sexual identity to their doctors. The sample comprised high school LGB students invited to participate in a Youth Pride Empowerment conference. The percentage of people who were out to their doctors in that study was 35%. Though it is nearly double the percentage seen in this study (19%), it is reasonable to assume that a population of teens participating in a Pride-related event may be largely out to their families. Therefore, it is hard to draw conclusions from that study. Rossman et al. (2017) found that 63% (n=130) of their participants were out to providers, but their study population was aged 18-27 years. As discussed in the coming out theme (Section 8.2), most LGBTQ+ individuals come out to family and/or friends during their teen years these days. It is reasonable to assume that an older population in New Zealand will be mostly out to family and/or financially independent. Therefore, the fear of being outed is less common in the age range Rossman and colleagues studied. As discussed above, the Coming Out theme clearly showed that interviewees found the prospects of repeatedly coming out to providers daunting.

Confidentiality concerns were shown through the survey to impact the patient-provider relationship. As seen in Section 7.6.4, of the people who marked they only had “a little” trust in their GP’s medical decisions, a larger percentage was observed to be those who were worried about being outed, compared to those who were not concerned about being outed (14% vs 2%, respectively, p < .001). Similarly, a statistically significant larger percentage of people worried about being outed (44%) rated their GP's quality below 7 (on a 1-10 scale, where 1 is worst and 10 is best), compared with only 18% of those who did not worry about being outed (p < .001). It would seem, then, that confidentiality concerns not only serve as a barrier to openly communicating with one's GP, they may actually colour one's entire perception of their GP and the quality of care the GP provides.

9.3.4. Low Health Communication Self-Efficacy

The analytical model used for the survey (Figure 7.1) places significant importance on health communication self-efficacy as a possible barrier or enabler to healthcare utilisation (the subject of RQ1). In examining the factors that affect communication self-efficacy in this study, gender identity, poor mental health, and a past history of avoiding care due to being LGBTQ+ all emerged as factors that impact communication self-efficacy negatively. Thus these may be considered barriers to healthcare access in this study population.

The connection between communication self-efficacy and mental health deserves additional consideration in view of one of the more notable findings in this study, namely the gap that exists between the participants' self-ranking of overall and emotional health, signifying a likely unmet healthcare need. Among people who rated their overall health Good or above, and their emotional health Fair or Poor, there was a statistically significant difference in the mean score of the health communication self-efficacy scale between people who have a regular GP ($M = 44.97$; $SD = 9.18$) and those who do not ($M = 37.27$; $SD = 8.53$; $t(134) = 3.90$; $p < .001$). The direction of this interaction is unclear, and the studies below do not shed light on the direction of the interactions, either. Among participants who rated both their overall and emotional health Good or above, the difference between those who did and did not have a regular GP was not statistically significant ($p = .062$). This observation finds support in the literature, where health self-efficacy and mental health seem connected not only with each other, but with GP engagement (health communication) as well. Furthermore, the healthcare provider's effect on a patient's health self-efficacy was greatest in patients with the greatest disease burden, as discussed below (Chen et al., 2013; Rutten et al., 2016).

Chen and colleagues (2013) studied the effects of engagement with a healthcare provider in people living with HIV in the US, Canada, Puerto Rico, Namibia, and China. They defined engagement as shared decision making, information sharing (both ways), and access to the provider as needed. They found that more engagement with the provider raised the patient's self-efficacy regarding treatment adherence ($t = -5.22$, $p < 0.001$)[30], and resulted in patients reporting better quality of life ($t = -3.39$, $p < 0.001$) and fewer symptoms ($t = 3.25$, $p < 0.001$). Furthermore, self-efficacy and self-esteem were correlated ($r = 0.28$, $p < 0.001$).

The study by Rutten et al. (2016) is especially interesting in view of the finding in this study. Rutten and colleagues found that health self-efficacy in their study participants was significantly lower in people diagnosed with depression/anxiety, compared to those who were not. Health self-efficacy was defined as the participants' confidence in being able to take care of their health Rutten et al. (2016, p. 1440). They also found that "higher ratings of patient-centred communication were positively and significantly associated with health self-efficacy" (Rutten et al., 2016, p. 1445). More importantly, their study found that the association between patient communication and

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[30] Degrees of freedom (df) were not reported in the paper.

health self-efficacy was greater in people diagnosed with depression/anxiety than in those without those diagnoses. (Patient-centred communication was defined as the patients' perceptions that their healthcare provider involved them in decision-making, allowed them to ask questions, was attentive to their emotions, and could be trusted with their care.) Therefore, the Rutten et al. results show the healthcare provider can have a strong influence on healthcare self-efficacy through communication. This finding supports and potentially explains the differences seen in this study's healthcare communication self-efficacy score, in people who rated their emotional health as “Poor,” as discussed above.

The studies above show that in a population with high rates of anxiety and depression, such as LGBTQ+ youth (this study's population), good communication with one's GP is important for health maintenance. Since good communication with one's GP depends in part on the patients' health communication self-efficacy (as per the model discussed in Section 9.2), attention should be paid to ways of raising a patient's health communication self-efficacy.

9.3.5. Communication with GP

Communication with one's GP depends in part on the patient's health communication self-efficacy: how confident the patient feels about their ability to clearly and honestly direct a conversation with their GP, regarding topics of concern. Health communication self-efficacy is also impacted by communication with one's GP – negative experiences such as judgemental attitude or misgendering a patient will lower the patient's health communication self-efficacy.

Of the people responding to the survey question regarding their relationship with their GP (*n* = 207), 11% indicated they either experienced or believed their GP has an anti LGBTQ+ bias. Thematic analysis of the interview data identified coming out was a complex process that impacted the participants' interactions with the healthcare system. Participants described actual cases of transphobia and refusal to provide gender-affirming care in the interviews, as well as refusal to discuss other LGBTQ+ issues. Of the participants who did not yet come out to their GPs, a common concern was that their interpersonal relationships with their GP will change following identity disclosure. Though participants acknowledged their GPs' professionalism, and were therefore not concerned that their treatment would suffer, they did not trust that personal biases wouldn't alter the interactions with their GP, for the worse.

The majority of participants in the survey (82%, n=169) indicated they felt comfortable discussing health-related issues with their GPs. Enablers included the perception of the GP as a professional, a long history with a family GP, a GP's good listening skills, and a friendly, non-judgemental attitude. The open-ended survey questions did make clear, however, that "health-related issues" did not include sexual health or, to a lesser extent, emotional wellbeing. The point regarding sexual health was strongly emphasised in the interviews, in the subtheme "co-constructing spaces to discuss sexuality and sexual health with GPs is undermined by heteronormative attitudes" (see Figure 8.1 and Section 8.4.1). It became clear in this subtheme that participants do not consider sexuality or sexual health to be related to physical health, and therefore did not consider it within their GP's purview. This cognitive disconnect may explain why nearly twice as many participants with a regular GP (40%, *n* = 82) checked that they felt comfortable discussing their sexual/gender identity with their GP, compared with those who actually came out to their GP (19%, *n* = 39). It is possible the participants felt that in theory they would be comfortable having the discussion, but did not actually feel the need to do so as they saw no health-related need to come out. In both survey and interviews (the same subtheme mentioned above) participants also alluded to the fact that in many cases the topic of sexuality or, in fact, sexual health, “never came up.” Similarly, Sequeira et al. (2020), who studied only trans* youth and young adults (aged 12-26 years), found that 47% of their study participants preferred their healthcare provider initiate the discussion leading to disclosure of their gender identity, and only 25% preferred to initiate the discussion themselves.

It would seem, therefore, that absent a direct question from their GP, and with little understanding of the connection between sexual health and physical and mental health, few participants in this study were actually cognisant of the need to come out to their healthcare provider. Similar findings were reported by Rossman et al. (2017), though their study participants were actually older (aged 18-27 years) than this study’s participants.

The idea that physical health is not related to sexuality or sexual health may be a reflection of what many interviewees mentioned as a completely inadequate sexuality education curriculum in schools, as illustrated in the subtheme “Sexual health resources at school do not compensate for GP communication shortfalls in providing the information LGBTQ+ teens need” (Section 8.4.2). As the sub-theme illustrates, mention of SGM in sexuality education classes is often done in the context of “bullying is bad” or simply a brief acknowledgement that SGM exist. The interviews described a sense of disconnect in the classroom, with people “tuning out” or feeling angry at an attitude that enforced “othering” of SGM. Tuning out is likely a decompensation response to repeatedly being invalidated by a curriculum that simply ignored their needs. This issue represents a potential research avenue, and certainly deserves closer attention. On a possibly related note, choosing not to come out to their provider may be a protective act on the part of the participants. By choosing carefully who (not) to come out to, these participants may be protecting themselves against additional stressors (e.g. discrimination, judgement) that could lead to a decompensation response.

9.3.6. Participants’ Expectations of Inclusive Care

Certain personal attributes of providers and staff were central to participants’ depictions of healthcare experiences as positive or negative. Kindness, friendliness, and helpfulness were often highlighted, as well as a respectful and non-judgemental attitude, one that included gender-affirming care. None of the participants conveyed expectations of special treatment due to their age, sexual orientation, or gender identity. What these analyses do convey is the expectation of inclusive care, where the same “gold standards” of competency and compassion are extended to *all* patients, including those from marginalised groups. These expectations were discussed in the theme “Participants expect inclusive care” (Section 8.5). Participants expressed their wish that their providers be approachable, creating a sense of safety. They reiterated their current fear of discrimination (or actual experiences of it) if they come out, and looked for a sense of a provider who truly cared *about* their patients, rather than simply caring *for* them. Two major points that seem to be related, and were repeatedly stressed were the need for providers who had the knowledge to treat LGBTQ+ patients, and the need for respect from providers, which included the use of preferred names and pronouns in gender diverse participants. This theme illustrates the need for better education of providers on providing inclusive care to LGBTQ+ patients, and as part of this education, the foundations of gender-affirming care provision should be emphasised. These findings are also consistent with the PATHA Guidelines (Oliphant et al., 2018).

These responses detailed above are similar to some of the community-based core competencies documented by Alpert et al. (2017), as discussed in Chapter 3. As Alpert and colleagues pointed out, some of the core competencies that community members wanted, e.g. autonomy, shared decision-making, and an end to gatekeeping that puts obstacles in the way of patients seeking transition are not included in professional societies’ core competencies. They continue to note, “because of the multiple barriers to health and medical care that these patients face, we believe that their needs are particularly important to consider when creating medical education competencies” (Alpert et al., 2017, p. 1383). The same argument can be made for this study’s participants, whose voices are not always heard in a dedicated forum. The only other study focusing on NZ LGBTQ+ health care experiences focused on the mental health system and found professionals in the sector had knowledge gaps that impacted their ability to provide responsive care to their clients.

In interviews, participants also mentioned their annoyance with the prevailing heteronormative assumptions in the healthcare environment. By adhering to what Riggs and Treharne (2017) call societal norms and ideologies (hetero- and cis-normativity) GPs emphasize the marginalisation of their LGBTQ+ patients, and deny them inclusive care. Heteronormative assumptions can be interpreted as discrimination by LGBTQ+ patients, and can limit access to sexual healthcare (Logie et al., 2019).

9.3.7. Cost

In this study population, 43% of participants with and without a regular GP cited cost as a barrier to having a GP or seeing one regularly, making it the most cited factor. In the New Zealand Health Survey (2020-2021 update), the percentage of people who did not see a GP due to cost was 10.2%, across the entire adult population (15 years and older) (New Zealand Ministry of Health, 2021b). Because many adolescents are financially dependent on their parents, the considerably higher percentage of participants citing a cost barrier in this study may be explained by this dependence. The study did not probe whether part of the cost barrier has to do with participants’ reluctance to disclose to their parents that they need to see a doctor for anything having to do with their sexual health or SGM status. Of note, the reluctance to set appointments through parents has been brought up in the interviews as a barrier, in the context of sexual health.

9.3.8. Lack of Inclusive Office Environment

Symbols in the clinic (e.g. religious symbols, rainbow flags) were perceived as an indicator of bias or safety, and were described as impacting trust and openness on the part of the participants towards their GP. This point was illustrated by participants in the Coming Out theme. Religious symbols and religiosity were first brought up in this theme when participants talked about coming out in general, and the conflict their SGM identity created with religious members of their family. It is therefore understandable why religious symbols in the healthcare setting might make individuals wary.

Lim et al. (2018) pointed out that “LGBTQ patients may have particular sensitivity to physical cues that affirm LGBTQ sexuality and identities, due to historically contentious relationships with healthcare establishments” (p.18). LGBTQ+ themed pamphlets, rainbow flags or stickers, and rainbow lanyards all increased their comfort levels and were considered enablers of trust and open communication. In an Australian study, Grant and Nash (2019) quoted a bisexual cis-gendered woman who felt that even if her clinic had LGBTQ+ materials targeted only at gay men, she would still find it a safe and inclusive place, as it acknowledged sexual minorities. The importance of an inclusive office environment was recognised in guidelines such as those of the American Association of Critical Care Nursing (Lim et al., 2018)

Several interviewees and survey takers also noted the importance of front office staff in influencing the type of overall experience participants had with their GP. The importance and complexity of the receptionist's role in the New Zealand general practice clinic have been discussed extensively by Neuwelt and colleagues (2015, 2016). Neuwelt and colleagues (2016) note the receptionists serve as a bridge between the practice and the community, tasked with ensuring equitable access to all. As such, they must often carry out multiple tasks simultaneously, and these tasks might actually be in conflict with each other. They work in a public space and, as the authors note, "The waiting area, 'shared' by patients and GPRs [general practice receptionists], is a particularly challenging space for people with complex social and health needs, as it has the potential to be further marginalising" (Neuwelt et al., 2015, p. 294). The findings of the present study demonstrate that reception spaces were often experienced as sites of marginalisation by participants due to experiences of rude, short-tempered receptionists, and receptionists who would not honour gender-diverse participants' preferred names and pronouns. As discussed in the "Gender diverse teens face profound barriers to utilising healthcare" theme (Section 8.3), the use of a person's correct pronouns and preferred name has important mental health implications for a gender-diverse individual (Russell et al., 2018). Not using them has caused gender-diverse individuals to avoid medical care, and as the theme discussed here demonstrated, participants feel frustrated and upset by providers' and office staff's refusal to use their correct pronouns and preferred names. Therefore, inclusive care environments extend beyond the consultation room and demonstrate the need for a practice-wide response to SGM.

9.4. RQ2: Do Perceptions of Healthcare Barriers Influence Sexual Risk Behaviours (e.g. Condom Use)?

This question probed the impact a GP has on sexual risk behaviours in LGBTQ+ teens in New Zealand. Given that some of this study's participants were under the age of consent, and I requested a waiver of parental consent for the study, the Ethics

Committee expressed extreme concern regarding approaching this topic at all (see discussion in Section 4.4.2). As a result, I could not probe the study population's sexual risk behaviours in detail. The EC's view of this study's population was one reason that, when a Postgraduate Student Representative position opened on the current committee, I immediately applied (and am currently finishing my second term).

Talking about sexuality with teenagers in general should be done with understanding and sensitivity. Teenagers are still learning to navigate intimate relationships. In the case of LGBTQ+ teens, the theme "LGBTQ+ Teens have a dearth of sexual health resources, increasing their sexual health risk" raises concerns about the availability of basic resources, such as sexuality education in schools.

9.4.1. Talking About Sexual Health

The utility of a mixed methods study in a topic so sensitive is best illustrated by the results pertaining to the sexual health related research questions. The survey did not show any relationship between being out to one's GP, and sexual risk behaviour. Thematic analysis of the interviews, however, illuminated possible reasons behind this seeming lack of connection (see Section 8.4, "LGBTQ+ Teens have a dearth of sexual health resources, increasing their sexual health risk"), exposing the presence of communication and perception barriers that prevented important discussions from taking place. As discussed below, the connection between sexual and physical health was not apparent to many participants. Others acknowledged that the discussion is important but it was up to the GP to initiate it. These findings are aligned with the study's proposed Communication – Self-efficacy – Sexual Health model discussed in Section 9.2. The model suggests that positive impacts on sexual risk behaviour may occur if two-way communication exists between the patient and their provider. The qualitative interviews identified that two-way communication was rare within the study population.

Analysis of the interviews indicated that many interviewees did not see sexual health as related to physical health, and therefore never thought to bring it up during appointments with their GP. One of my gender diverse interviewees, who fully related their sexuality to their gender, was also of the opinion that gender was not related to biology, and therefore neither gender nor sexuality were really in the purview of the GP. Gender diverse individuals have been taught (this is a socially constructed knowledge) that sex assigned at birth – which is biological – has nothing to do with gender identification, which is not biological. In addition to possibly being inaccurate (Polderman et al., 2018), studies show that gender affects a person's health in many ways, subtle and not so subtle (Conger, 2017). It may be helpful to amend the message, and teach sexually diverse young people that while sex and gender are separate concepts, they both impact physical and emotional health. If nothing else, young people should be aware of how gender norms can impact their health (Weber et al., 2019).

In addition to not seeing a connection between their SGM identity and their physical health, participants noted that GPs also did not bring up sexual health. In the subtheme "co-constructing spaces to discuss sexuality and sexual health with GPs is undermined by heteronormative attitudes" (Section 8.4.1) most interviewees, and the survey respondents who answered a related open-ended question, agreed that the topic of sexual health (and by extension, sexuality) "never came up." As the theme went on to illustrate, participants also felt they needed reassurance from their GP, in the form of a safe space that didn't risk judgement. The interviews themselves were an indication of how difficult a discussion of sexual health can be with teens, as the topic did not arise spontaneously. Unlike the conversations about healthcare needs and experience with providers, the interviews did not smoothly veer into sexual health discussions; rather, I often had to bring up the topic in what felt like a rather abrupt change of direction.

In one study of sexual minority youth in the US, approximately three-quarters of the participants believed their doctors thought they were heterosexual (Fisher, Fried, Macapagal, et al., 2018). Heteronormative assumptions were related by the majority of this study's participants as well, perhaps partially accounting for the lack of sexuality and sexual health discussions in this study's population. Of the Fisher et al. (2018) study participants who were asked about their sexual orientation by their healthcare providers (approximately one-third), 40% felt comfortable discussing it with those providers, the same percentage as participants in my study.

9.4.1.1 Lack of resources

Since the survey findings indicated there was no connection between having a GP and primary (or secondary) sexual risk prevention, the topic of sexual health and risk behaviours was explored further in the interviews. As discussed above, it emerged that interviewees did not see their GP as an information source on sexual health. When probed further, many expressed frustration at being unable to find sources that could reliably answer their sexual health questions. Almost all interviewees agreed that sexuality education classes were not relevant to them, as they only dealt with heterosexual sex and relationships.

The implications of such perceptions can be serious, as Rasberry et al. (2018) showed. In their study of students from seven Florida (US) high schools, adolescent sexual minority men were less likely to report having been taught about HIV or AIDS, compared to their heterosexual male peers (from the same schools; OR = .58, $p = .04$). The sexual minority participants were also less likely to report having used a condom at last sex (OR = .39, $p < .01$). Among the heterosexual students, those who indicated they were taught to use a condom at school were more likely to have used one at last sex (OR = 4.78, $p < .01$), which was not the case for sexual minority students. It seems clear that sex education resonates differently with people who don’t perceive it as applicable to them, like my study participants.

Participants were unsure where to get information apart from the internet. When using the internet, not all of them knew how to filter credible information from the not so credible type. Some turned to older LGBTQ+ mentors on social media groups. The lack of resources yielded knowledge gaps in the participants’ understanding of sexual risk behaviours and prevention uptake. Some of those gaps were unfamiliarity with risks that exist in a female-female sexual relationships; unfamiliarity with HIV routes of transmission (e.g. “Can I get infected from kissing?”), and unfamiliarity with symptoms of STIs and what to watch for.

9.4.2. Condom Use

Like other sexual health measures in the survey, condom self-efficacy was unrelated to having a regular GP. Though the observed mean total score on the condom self-efficacy scale was slightly lower in people with no regular GP, the difference was not statistically significant. Since the study’s Communication – Self-efficacy – Sexual Health model posits that condom use is associated with open two-way communication with one’s GP, and in this study, such communication largely did not happen in the area of sexual health, the lack of association between condom use and having a regular GP is not surprising. It is important to note that while this study looked at the relationship between communication with one’s GP and condom use, condom use in adolescence is impacted by many other factors, such as substance use and parental rejection.

9.5. RQ 3: Do These Perceptions Affect the Uptake of Preventive Behaviours (e.g. STI Screening)?

The survey analysis showed no direct connection between having a GP or being out to one and uptake of preventive behaviours. The only exception was the fear of being found out (“I’m afraid someone will find out I got tested”), which was not a concern for participants who were out to their GP. In the interviews, participants’ reasons for not being tested spoke to both a lack of confidence navigating the health system and elements of the decompensation model. Participants described not knowing where to go for testing and what is involved in the testing itself. Participants’ fear of stigma, was expressed as fear of having to answer the screening questions for STI testing, fearing the judgement that will come in the wake of the answers.

9.6. Strengths and Limitations

9.6.1. Strengths

This study is the first to look specifically at barriers to healthcare access among New Zealand LGBTQ+ teens, and to probe their health communication self-efficacy and the relationships between the study population and healthcare providers, mainly GPs.

The study’s mixed methods design has some advantages over current reports utilising only quantitative surveys.

The mixed methods design helped illuminate results that, by themselves (i.e. just the quantitative or qualitative part) would give incomplete information leading to potentially wrong conclusions. For example, the survey showed no connection between having a regular GP (or being out to one) and the participants’ sexual health. Based on the Communication - Self-efficacy – Sexual Health model (Section 9.2) such a connection was expected, as communication with the GP was the mediating element between the participants and their sexual health behaviours in the model. When the communication part was probed through the interviews, qualitative analysis illuminated the nuances of the communication pathway (or lack thereof) between the participants and their GP. The participants' perception of sexual health as being outside the GP's purview often led them to not consider bringing up sexual health at GP appointments. Interviewees who did consider the topic to be relevant to their health also thought it should be up to the GP to initiate the discussion. Taken together, these observations clarify why the mediating role of the GP, as predicted by the model, failed to materialise. The integrated observations not only clarify the perceived role of the GP in the study population's view, but they also point towards potential changes that GPs can make to communicate better with their adolescent patients regarding sexuality and sexual health.

As cost was identified as a barrier to healthcare access in this study, it seems inevitable that cost also affects participants' ability to come in for sexual health appointments. Morgan and Haar (2009) studied the impact of free sexual health visits for patients aged 18-24 in 20 general practice clinics in New Zealand's Waikato region. Morgan and Haar (2009) primarily focused on the rates of testing and diagnoses of Chlamydia. In the three years these clinics ran, there was a noticeable increase in both testing and diagnosis of Chlamydia, signifying another avenue for change to improve LGBTQ+ teens' sexual health.

Lastly, it should be noted that a mixed methods study by Martel et al. (2017) found the Registered Nurses working in general practice in New Zealand were largely uncomfortable initiating sexual health discussions with adolescents, due to lack of knowledge and resources. This despite the fact that GPs perceived such discussion to be the Practice Nurse's job. Here, again, is another avenue for change and potential further investigation.

In addition, the sequential explanatory design of this mixed methods study helped generate the interview questions that filled in the gaps in the survey data, and allowed information to be gathered to shed light on survey results that were particularly interesting, or unexpected. Consequently, what emerged was a holistic picture of the study population's healthcare perceptions alongside their lived experience. As such, the results lend themselves much better to making clear recommendations for changes that may help alleviate the barriers in existence today for this study population, and others like it.

9.6.1.1 Strengths Related to the Survey

The survey contained a large number of open-ended questions. My aim was to give as many participants as possible a voice even while collecting quantitative data. I felt the topics covered were important and sensitive enough that the people experiencing them daily should get as much of a chance as possible to describe their reality. I also hoped that the guaranteed anonymity of the survey would allow more people to feel comfortable expressing their thoughts and feelings.

The answers participants gave were a rich source of information. The content analysis contributed greatly to understanding the quantitative results. It also helped triangulate the study's conclusions when all analyses were complete.

9.6.1.2 Strengths Related to the Interviews

The interviews were informed by the survey, as discussed above, allowing for a seamless integration of the results, and a more in-depth look at issues that were raised by the survey.

The interviewees were very forthcoming with answers and information, and the conversations felt natural, with no awkward pauses or backtracking. Considering the fact that I was a stranger, older than they were, and not from New Zealand I was surprised at how comfortable and willing to talk they were. This is especially true since the topics we covered – the questions I was asking – were highly personal and sensitive. The wealth of detailed information gained in the interviews is the qualitative component's greatest strength.

9.6.2. Limitations

As discussed in my positionality statement my perspective and priorities changed as the study developed. I believe the study should have been designed with all genders in mind from the beginning (instead of being limited to teens assigned male at birth originally). I also believe the study would have benefitted from a strength-based approach, e.g. "How can healthcare providers increase health self-efficacy in LGBTQ+ teens in New Zealand?" It would have demonstrated to the participants how they could bring their lived experience to bear on concrete suggestions for improving the current conditions, which are less than ideal.

The study employed convenience sampling, which means it cannot be generalised to the entire New Zealand LGBTQ+ teen population. This type of sampling was necessary and advantageous due to budget considerations, and the difficulties inherent in trying to recruit a marginalised population. These difficulties include issues of trust, as Hughes et al. (2021) point out. As an "outsider," there was a chance my recruitment efforts would be met with such mistrust. Using convenience sampling through social media recruitment was an affordable and quick method that yielded good response. Many of the findings in this study parallel findings in studies from other countries.

9.6.2.1 Limitations Related to the Survey

The survey was an anonymous online survey. It is possible that some responses were fake, or that multiple responses came from one person using different devices (the survey was set so it could not be taken twice on the same device). It is also possible, though less likely, that people from outside New Zealand filled in the survey using a virtual private network (VPN) server in New Zealand.

The survey population is unbalanced in terms of gender makeup. Eighty percent of the participants were assigned female at birth, and 57% identified as female on the survey. It is likely some survey results were skewed as a result. For example, in the Youth19 study, the percentage of females who scored Good or above on the psychological wellbeing scale (60%) was noticeably lower than the percentage of males who scored in the same range (78%), and noticeably more females had significant depressive symptom (29%) compared to males (16%) (Fleming et al., 2022). These Youth19 results are for the entire participant population, and it is hard to say if they would be similar for just the SGM portion of the study population. Interestingly, the Youth19 intersectionality analysis (Clark & Fleming, 2020) featured similar population imbalances in their LGBTQ+ Māori (70% female) and Pasifika (62% female) participants.

Participants were asked to report the region they live in, to gauge the geographical coverage of the survey. As the survey was anonymous, the only way to validate a New Zealand residence was through the IP address information collected by Qualtrics (the survey software) when a participant filled the survey. Nine potential participants were therefore excluded from analysis based on IP addresses outside of New Zealand. It is possible that the people filling out the survey were, in fact, New Zealand residents on holiday or studying abroad (these surveys predated the COVID-19 pandemic). Therefore, their exclusion may have been in error; however, there was no other way to verify their eligibility.

The scales used in the survey are not validated, as it was beyond the scope of the original (Masters level) study. However, the condom use self-efficacy scale is adapted from the validated Beck scale (Brafford & Beck, 1991) with Dr Beck's permission (see Appendix C).

The survey was slightly adapted when the study population was extended to all genders, but, in retrospect additional questions catering only to those identifying as females should have been added.

9.6.2.2 Limitations Related to the Interviews

Due to COVID-19 restrictions, some interviews were conducted online, rather than in person. I found the interactions online to be harder than and not as natural as the face-to-face interviews. The participants also seemed more formal and inhibited. Additionally, I could not observe the participant's body language online – I only saw them from the neck (or shoulders) up. This partial view and less natural interaction were akin, in my opinion, to missing data. Indeed, Johnson et al. (2021) found that compared to online interviews, qualitative face-to-face interviews produced richer, more detailed transcripts, though in both modes interview lengths were similar.

Five of the 15 interviewees were gender diverse. Although some may interpret this as too small a sample, considering the substantial importance of gender diversity in most aspects of the study results, and particularly in the identification of a large theme with complex subthemes in the qualitative analysis. Braun and Clarke (2021, p. 212) are clear in their position that "when it comes to reflexive TA [thematic analysis], data saturation is not a particularly useful, or indeed theoretically coherent, concept." They consider the concept of information power ("the more relevant information a sample holds, the fewer participants are needed," Braun & Clarke, 2021, p. 210) to be a more suitable alternative. The five participants that spoke of their gender diversity experience in the healthcare context were expressive, communicative, and were not afraid to voice their opinions. They offered a rich narrative filled with relevant information. Nevertheless, it is possible that additional gender diverse voices might have offered additional views or experiences to consider when interpreting the data, or strengthened the information already supplied by these five interviewees.

9.7. Summary

This study identified several important barriers to healthcare utilisation among older LGBTQ+ teens in New Zealand. While members of the LGBTQ+ community may encounter some of these barriers across all ages, adolescents have fewer options and fewer means, financial and otherwise, to successfully navigate these barriers. Additionally, as these barriers do impact these teenagers' sexual health, and in the absence of alternative resources, actions to remove these barriers should be considered a public health priority.

The following chapter lists the study's conclusions and recommendations. The recommendations are broken down by type: Policy recommendations, recommendations for GP offices and clinics, and recommendations for GPs.

Chapter 10. Conclusions and Recommendations

An obstacle was there that stopped me

many times when I was about to speak

…

Later, in the more perfect society,

surely some other person created like me

will appear and act freely.

C P Cavafy, "Hidden Things"

10.1. Introduction

Constantine Cavafy, the famous gay Greek poet, lived in a time when his true identity could not be acknowledged. He "came out" so to speak through his poems, which during his lifetime he only shared with a small circle of trusted friends (Sprott, 2004). Yet even today, in a more equitable and just society "Hidden Things" rings true to many SGM individuals, including many of this study's participants. Moreover, the obstacles that prevent them from speaking extend into their healthcare journey.

It has been nine years since the Rainbow Health Report (Stevens, 2013) delivered several policy recommendations for public health in New Zealand's LGBTTI[31] community, the first of which was, "Rainbow community service users will receive equitable and culturally safe access to general and mental health services across their

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[31] The report uses LGBTTI for lesbian, gay, bisexual, trans*, takatāpui, and intersex.

lifespan." Listening to the voices of teens in this study, this ideal remains an unfulfilled wish.

The following sections list the study's conclusions, and detail recommendations that perhaps can be a first step towards Cavafy's "more perfect society."

10.2. Conclusions

In a population already affected by marginalisation and minority status, physical and especially mental health needs are not being met. Many participants felt their healthcare providers lacked the basic knowledge to treat them. This was especially true with regards to gender minority participants. Participants also cited the perception of being dismissed or not understood as a barrier, and again, most of the people in this category cited these perceived attitudes (or actual incidents) specifically in the context of their gender identity. Gender diversity was also associated with lower health communication self-efficacy score, itself a barrier to healthcare utilisation.

Though participants largely rate their providers' quality of care as high, there is a reluctance to fully confide in healthcare providers. Both surveys and interviews showed that many participants felt discrimination does not necessarily affect care quality, but can be expressed in other ways (e.g. facial expressions). This belief that care quality and possible discrimination can be completely unrelated to each other may be a case of cognitive dissonance – where a person tries to resolve an internal conflict between inconsistent or contradictory beliefs (McGurgan et al., 2021).

Participants' common concerns (e.g. confidentiality, denial of care, judgement and discrimination) around disclosing their sexual or gender identity suggest there are serious gaps in meeting the healthcare, including sexual health needs, of LGBTQ+ teens in New Zealand. These common concerns make the necessity of reputedly coming out to new providers a daunting task for these participants.

It is important to note that these reported negative responses from providers may affect more than the participant who reported them, but their peers as well. Based on Bandura's model of self-efficacy, peer experience and attitudes can influence others' perception of their own self-efficacy (Schwarzer & Luszczynska, 2005). For example, Stout et al. (2020) found that among college students in the US, friends' perceived attitudes towards human papilloma virus (HPV) vaccination affected the students' HPV vaccine self-efficacy and thus their intention to get the vaccine. The student's own positive attitude towards the vaccine did not mediate the relationship between the friends' attitude and intentions to receive vaccines. Casillas et al. (2019) found that being in a peer navigator cancer survivorship group significantly increased adolescents' and young adults' survivorship care self-efficacy as well as their intention to proactively seek such care. That is not to say that LGBTQ+ teens cannot shape their own narratives, often through activism, as they do in hostile school environments (McGlashan & Fitzpatrick, 2017).

Mental health struggles were noticeable across both parts of this study, and participants related those to their experiences being LGBTQ+ (the most cited factor), providers' lack of knowledge when it comes to treating LGBTQ+ patients, and New Zealand's inadequate mental health system. As noted by Whitcombe-Dobbs (2022), the New Zealand mental health system is outdated, inadequate, and fails its younger clients more than the adults. Long wait times for appointments, as well as being told that "asking for help means you're well enough" (as one of my interviewees was told) raise the risk of exacerbating depression, anxiety, and suicidal ideation. These are conditions that already affect LGBTQ+ adolescents disproportionally, as previously discussed in this thesis.

Participants described reading items in GP offices as visual cues that shaped their perception of the provider's attitude towards LGBTQ+ people. Where items were considered to denote religiosity, this was considered a barrier to disclosing one's identity, whereas images of Rainbow flags and LGBTQ+-themed pamphlets in the office made them feel welcome and secure. As discussed in the previous chapter, and in Chapter 8, the office environment plays an important part in inclusive care, and may encourage or discourage people from coming out to their providers. Therefore, visual cues can be either a barrier or enabler to healthcare utilisation in this study population.

Current resources for sexual health education specific to this study population are severely lacking, and participants' lack of knowledge puts them at higher risk of STIs and unintended pregnancies (note that 60% of the study population identified as bisexual).

Sexual health risks in LGBTQ+ teens is a complex issue deserving special attention. While New Zealand currently enjoys very low rates of in-country HIV infections, the epidemic may not be stoppable without targeting key at-risk populations with better education and testing. Other STIs, such as chlamydia and gonorrhoea, are present in high rates in New Zealand teens in general (see Chapter 2). Unfettered access to culturally competent and compassionate, understanding physicians should be a priority in any HIV/STI public health campaign.

10.3. Recommendations

When interpreting these findings, the first recommendation is discussing how to foster trust in a population that is often under constant stress conditions. Many of the recommendations below aim to do just that, at various levels.

10.3.1. Policy Recommendations

Medical school curricula should be updated to include considerably more LGBTQ+ content. A variety of studies (Cooper et al., 2018; Desrosiers, 2019; Park & Safer, 2018; Safer & Pearce, 2013; Wahlen et al., 2020) show that increasing LGBTQ+-related knowledge and comfort in healthcare workers could improve the experiences of sexual/gender minority patients. As seen in both the open-ended survey responses and the thematic analysis of the interviews, many participants felt their healthcare providers lacked the basic knowledge to treat them. This was especially true with regards to gender minority participants. As seen in the Literature Review (Section 3.3), current medical school curricula in New Zealand devote very little time in either pre-clinical or clinical years to educating future doctors about sexual and gender minority populations. It might be helpful for medical schools in the Australasia region to engage in a dialogue with the LGBTQI community and identify, similar to Alpert’s study, “community-identified provider competencies” that can be incorporated in medical schools’ curricula starting with the preclinical years.

In addition to adding to the medical and other health professionals’ curricula, standard topics of discussions in current classes should be made more inclusive and start normalising SGM language and references, from undergraduate studies and up. For example, one area that can significantly change is human genetics instructions, as exemplified by Hales (2020).

For practicing healthcare providers, workshops such as the one trialled by Desrosiers (2019) should be created, expanded, and regularly available. LGBTQ+-related continuing education classes or workshops should be mandatory for all healthcare providers, at regular intervals, as the field changes quickly. Though several workshops are available currently and listed on the Ministry of Health website, their focus is only on trans* patients. To the best of my understanding, they are not mandatory.

Training for health teachers, likewise, should be expanded. Those tasked with teaching health classes should receive mandatory training that enables them to comfortably and competently teach appropriate materials *to* all students, *about* all students. Curriculum requirements should be amended to go beyond simply requiring an acknowledgement of sexual and gender diversity.

New Zealand's mental health care should shift from a biomedical focus to one of emotional wellbeing. Increasing the numbers of trained counsellors and psychologists will help move in that direction.

The concept of the YOSS should be supported by regular government funding. The interviews with people who were receiving their healthcare through a YOSS showed the value of a clinic dedicated to the care of teens, and knowledgeable in LGBTQ+ adolescent healthcare. It is telling that, during those interviews, participants who talked about healthcare access difficulties usually referred to a previous healthcare provider, and differentiated this from their current healthcare provider at the YOSS. With the majority of participants relating how their regular (non-YOSS) GPs lack the knowledge and training to treat them, the presence of providers trained in LGBTQ+-specific healthcare at YOSS provides the kind of inclusive, accepting care LGBTQ+ teens in this study clearly need. All of the interviewees in this study who were getting their care through a YOSS were out to their providers and there was no indication this process was daunting, or brought up the concerns listed previously.

Finally, with the widespread use of digital health records (Dobson et al., 2022), careful consideration should be given to how parental access to young teens' records should be handled (young teens in this case means under 16 years of age). This should ideally be done at a national level as a guidance or better yet, a directive. According to the s 22F Health Act 1956, "A parent or guardian has a right to access the health information of their young person under 16 years, except where contrary to the young person's wishes or interests or where another withholding ground applies" (The Royal New Zealand College of General Practitioners, 2017). The Royal New Zealand College of General Practitioners suggests three options for general practice patient portals of patients under 16 years: 1) only the patient has access, if they are judged "Gillick competent" (see Methodology, Section 4.4); or 2) patient and parents/guardians share access; or 3) only the parent has access (usually this option would apply if the children are young or cognitively impaired). Currently, general practice portals in New Zealand only allow access to patients 16 years and older, contrary to the RNZCGP's recommendation (Dobson et al., 2022). Dobson and colleagues feel that parental access to young teens' patient portals should be restricted to non-confidential material only, and that the patient themselves should be allowed to adjust the privacy setting on their portal. This will benefit all teenagers who are reluctant to talk about certain topics (e.g. alcohol consumption, sexual health) for fear their parents will see related notes in the portal (Dobson et al., 2022). However, **absent from the Dobson et al. paper** is consideration of SGM teens, many of whom are already concerned about being outed by their healthcare provider, as seen in this study. For all the benefits that digital patient portals provide, they run the risk of being another perceived barrier for SGM teens trying to access healthcare. Current existing systems, and those being designed now, should consider confidentiality protection for SGM teens, who are at risk of emotional and physical harm if such confidentiality is unprotected or breached.

10.3.2. Recommendations for GP Offices and Clinics

10.3.2.1 Appointments

The necessity of setting appointments through one's parents has been brought up as a barrier by participants. There should be a mechanism whereby patients under 16 years of age can call for special appointments they may not want their parents to know about. Quite often these appointments concern sexual health, and they may provide an excellent opportunity to bring up sexual and gender identity with these patients. If such arrangements are not feasible, or cost is a factor for the young patient, providers should be in the habit of informing patients about the consultations available through Family Planning. Most of my interviewees were not aware of this option. These consultations are free to New Zealand residents under 22 years of age, and confidentiality is guaranteed – the appointment and its contents will not even be disclosed to the GP without the patient's consent (Family Planning, 2015)

Alternatively, or in addition, patients arriving to appointments with their parents should be offered time alone at the beginning or end of appointments, and encouraged to bring up topics they do not want discussed while their parents are in the room. This is a guideline that already exists in the US (Al-Shimari et al., 2019). The PATHA guidelines (Oliphant et al., 2018) also provide this recommendation, which this study's findings support. However, this recommendation should be made across the board, as it applies to all LGBTQ+ teens (indeed, to all teens), not just trans* teens.

Intake forms should be revised to consider not only binary and binary trans* individuals, but other gender diverse patients (it can be as simple as “Other (please specify)”). Patients should be able to designate their preferred name/pronouns on the forms. More importantly, staff should respect these preferences. Several interviewees and survey participants recalled clinic staff, including receptionists, calling them by the wrong name or referring to them by the wrong pronouns. Related to this, clinic forms should display preferred names and pronouns first and most prominently. This way, patients are assured they will be addressed appropriately, according to their own stated identity.

10.3.2.2 Environment

Offices/clinics should signify visually they are a safe space and welcome LGBTQ+ persons. This can be done in a variety of ways, from having a Rainbow flag at Reception to staff wearing Rainbow lanyards.

Offices and clinics should have LGBTQ+ resources (e.g. pamphlets) available in the waiting area.

10.3.2.3 Training

Clinic or office staff, including receptionists, who are the first people a patient encounters, should undergo training in how to meet the needs of LGBTQ+ patients. Topics should include confidentiality, sensitivity, and gender-affirming care. Such training is available online, and several LGBTQ+ organisations in New Zealand offer workplace training.

The topic of sensitivity training should be emphasised for front-office staff. Several answers in the survey spoke of rude receptionists, including one who openly mocked a trans* participant when she thought they were out of earshot.

If training is not feasible, an LGBTQ+ liaison should be on staff – a representative who can advocate for the patient and answer questions other staff members cannot.

10.3.3. Recommendations for Healthcare Providers

The biggest takeaway from this study is the need for healthcare providers to be better educated in caring for LGBTQ+ patients. Lack of knowledge and training was an undercurrent in every theme in the interviews, and appeared frequently in the survey's open-ended questions. As discussed in the Literature Review (Chapter 3), discomfort with a patient population can impact not only the quality of care patients receive, but the assumptions they make about patients and the patients' chances of successful treatment (Khan et al., 2008). Studies such as that by Safer and Pearce (2013) have shown that improving a healthcare provider's knowledge of treating LGBTQ+ patients also improves the comfort of both.

Currently, there are online resources e.g. https://www.lgbtqiahealtheducation.org, https://gpsupervisorsaustralia.org.au/download/12796/) that provide educational materials on a variety of LGBTQ+ health topics. Importantly for this study, the New Zealand (PATHA) guidelines for gender-affirming care (Oliphant et al., 2018) can be downloaded at: https://patha.nz/resources/Documents/Guidelines%20for%20Gender%20Affirming%20Health%20low%20res.pdf. These guidelines use Durie's Te Whare Tapa Whā (the four cornerstones) Māori health model to address different aspects of trans* health. Oliphant and colleagues point out one of the important points of this model for their purpose was that it (re)positions mental health as equally important to all other aspects of health (in Te Whare Tapa Whā (a Māori model of health), the other three are: spiritual health, family health, and physical health). As Oliphant et al. (2018) explain, in the past, gender diversity was pathologised as a mental illness. As a result, Oliphant and colleagues point out there is a tension in healthcare between recognising the importance of mental health in the complete wellbeing of gender diverse individuals, and the need to avoid pathologising them again. Te Whare Tapa Whā resolves this tension by making mental health one of the four cornerstones – as equally essential as the other three. These guidelines provide background material as well as “Practice Points” for healthcare professionals. The guidelines are detailed and provide valuable information on topics ranging from social transition to preservation of fertility.

In addition to avoiding heteronormative assumptions, providers should avoid using heteronormative language. For example, instead of asking “Do you have a boyfriend/girlfriend” use the more neutral “Are you seeing anyone?”

Providers should initiate conversations on sexuality and sexual health with teen LGBTQ+ patients, using non-judgemental, non-heterosexist language. These discussions should take place without the presence of parents or other legal guardians in the room.

Free sexual health visits for teens and young adults, of the kind trialled by Morgan and Haar (2009), should be available across the country, especially in areas where access to Family Planning or sexual health clinics (both offer free services) is not easy due to distance and transportation costs. Alternatively, where Family Planning or free sexual health clinics are easily accessible, GPs should mention these options to LGBTQ+ patients.

10.4. Future Research Directions

As my study focused exclusively on LGBTQ+ teens, the providers’ view is missing from this discussion and is a gap in the research, which can be addressed in future research. Additionally, another gap in this study is that it does not delve into

LGBTQ+ teens' understanding of sexual health, and its place in the general spectrum of healthcare. Therefore, future research in relation to this study's topics should be two-pronged, focusing on the study population and on the healthcare providers.

Wahlen et al. (2020) found in their study that most medical students in their cohort had favourable opinions towards LGBTQ+ people, but felt they were unequipped to care for them. It would be beneficial to survey primary healthcare providers in New Zealand regarding their attitudes, perceived needs, and suggestions for improvements when it comes to treating LGBTQ+ patients in general, and LGBTQ+ teens in particular.

Future research in LGBTQ+ teens in New Zealand should concentrate on their understanding of sexual health, and how it relates to overall health. Such research should lead the way to improving their understanding of the connection between sexual health and physical and mental health. As seen in the survey and subtheme 8.4.1, many participants did not realise that sexuality and sexual health fall under the healthcare purview, and therefore never discussed it with their GP. Though changes to sexuality education curricula in schools will be beneficial, as discussed in Section 8.4, the recommended curriculum is not always taught in all schools. Printed educational materials that are LGBTQ+-specific can be easily distributed in clinics, schools, and other areas frequented by LGBTQ+ teens.

Additionally, studies should investigate improving this population's health communication self-efficacy, which would be beneficial in removing some of the barriers this study has uncovered. A somewhat related research should investigate ways to assist LGBTQ+ teens understand their rights in the healthcare arena and assert them.

Lastly, a New Zealand-specific resource[32] on caring for LGBTQ+ patients should be written and made available to primary care providers in New Zealand. This resource should be developed as a collaboration between GPs and LGBTQ+ youth representatives. As mentioned previously, while the PATHA guidelines (Oliphant et al., 2018) are an immensely valuable resource for GPs with gender diverse patients, there is a need for an inclusive LGBTQ+ educational reference guide.

10.5. Summary

To the best of my knowledge, this study is the first to look specifically at the experiences of older LGBTQ+ teens in the New Zealand healthcare system. The study's mixed methods design yielded detailed information on the difficulties experienced by this population when attempting to access inclusive care.

Many of the barriers perceived by the study participants are due to systemic problems. Some can be alleviated with commitment to changes such as revamping medical education curricula and mandating professional development topics covering LGBTQ+ care, and the specific needs of LGBTQ+ teens. Other barriers are harder to overcome, such as stigma and discrimination, or the country-wide problems facing the mental healthcare system. It is clear from the results, however, that changes are necessary as the healthcare needs of this study population are not being met.

Future research should aim to further illuminate ways to increase providers' knowledge while also increasing consumers' knowledge and understanding of their rights, and the impact their SGM identity has on their mental and physical health.

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[32] Similar to The Equal Curriculum, which is US-centric (https://link.springer.com/book/10.1007/978-3-030-24025-7)

My hope for this study is that it will bring about directed discussions on how to make the healthcare system in New Zealand more equitable and just for the study participants and their peers.

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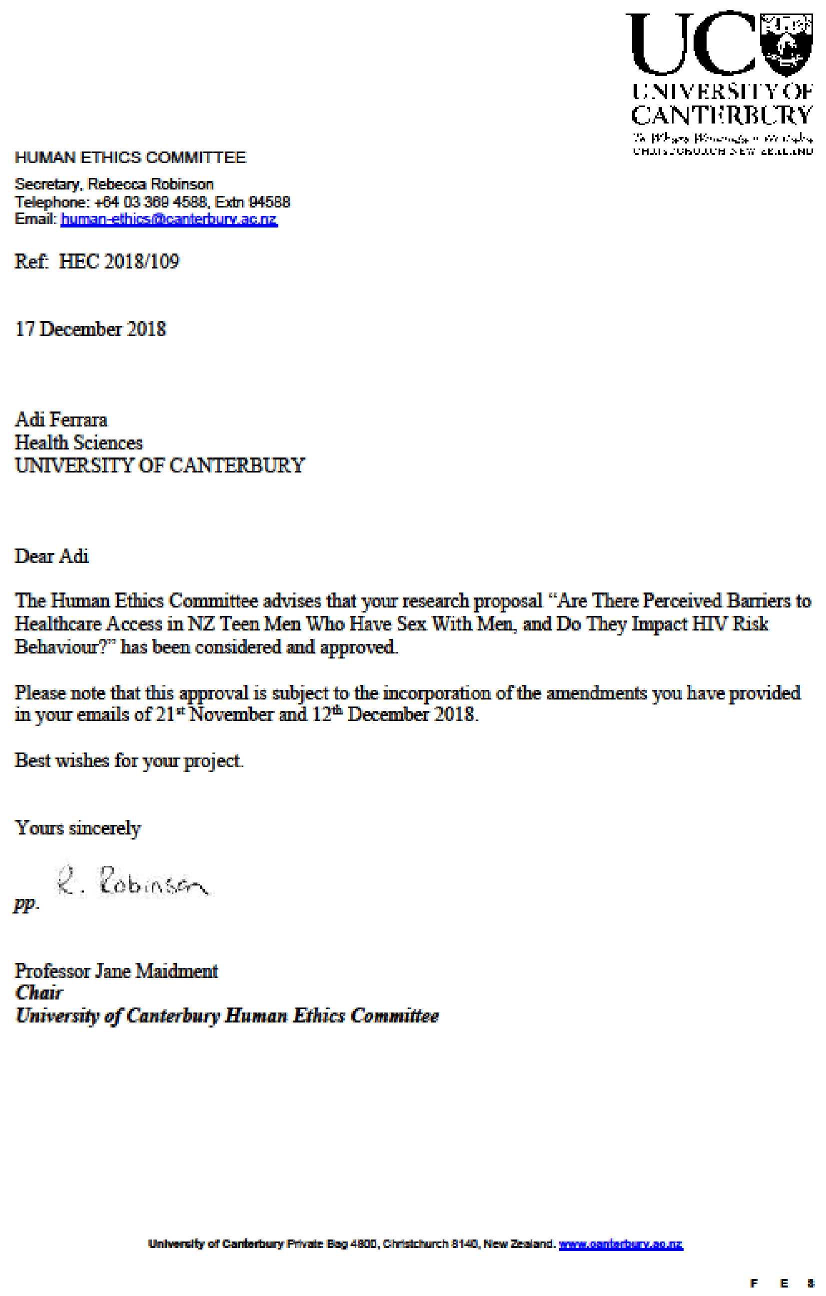
Appendix A. Ethics Approval

1. Original Approval



HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2018/109

17 December 2018

Adi Ferrara
Health Sciences
UNIVERSITY OF CANTERBURY

Dear Adi

The Human Ethics Committee advises that your research proposal "Are There Perceived Barriers to Healthcare Access in NZ Teen Men Who Have Sex With Men, and Do They Impact HIV Risk Behaviour?" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your emails of 21st November and 12th December 2018.

Best wishes for your project.

Yours sincerely

pp. R. Robinson

Professor Jane Maidment
Chair
University of Canterbury Human Ethics Committee

University of Canterbury Private Bag 4800, Christchurch 8140, New Zealand. www.canterbury.ac.nz

F E S

2. Approval of Study Expansion

UC
UNIVERSITY OF
CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE
Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2018/109 Amendment 3

29 October 2019

Adi Ferrara
Health Sciences
UNIVERSITY OF CANTERBURY

Dear Adi

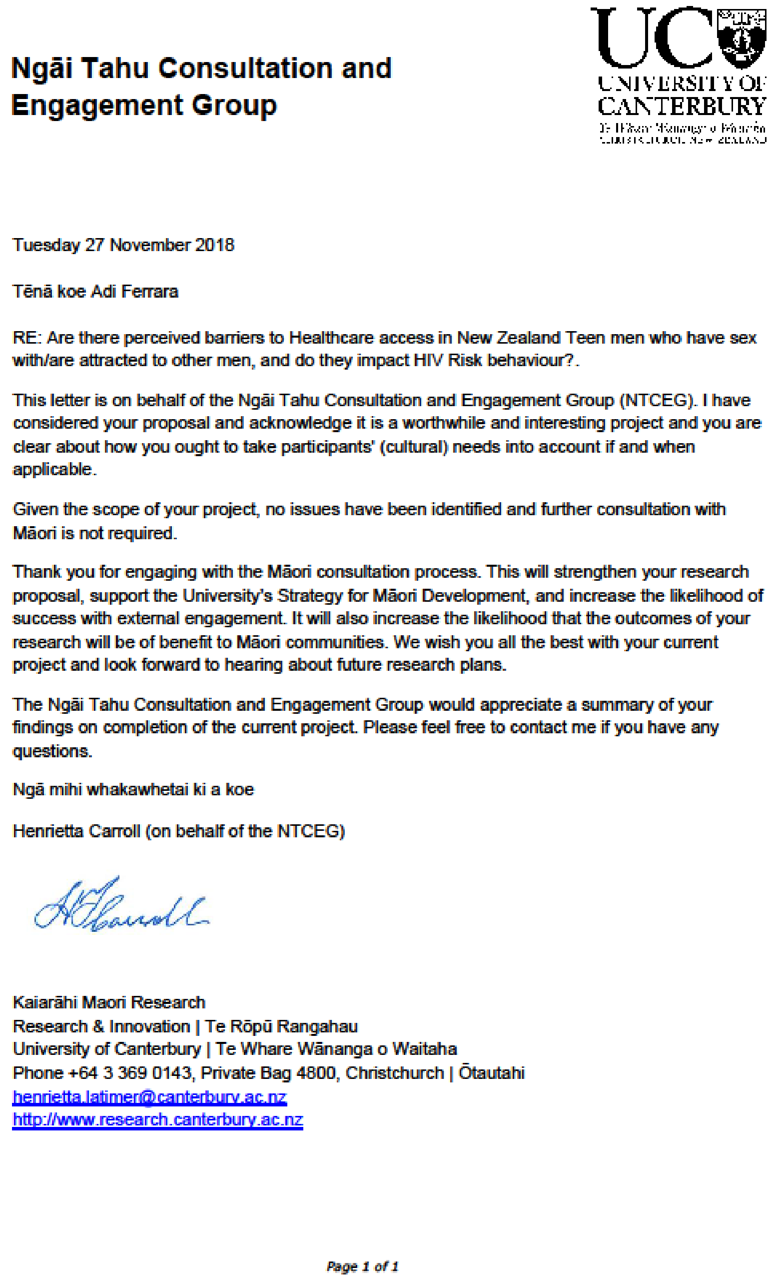
Thank you for your request for an amendment to your research proposal "Are There Perceived Barriers to Healthcare Access in NZ Teen Men Who Have Sex With Men, and Do They Impact HIV Risk Behaviour?" as outlined in your email dated 22nd October 2019.

I am pleased to advise that this request has been considered and approved by the Human Ethics Committee.

Yours sincerely

Dr Dean Sutherland
Chair, Human Ethics Committee

Appendix B: Maori Consultation Response



Ngāi Tahu Consultation and Engagement Group

Tuesday 27 November 2018

Tēnā koe Adi Ferrara

RE: Are there perceived barriers to Healthcare access in New Zealand Teen men who have sex with/are attracted to other men, and do they impact HIV Risk behaviour?.

This letter is on behalf of the Ngāi Tahu Consultation and Engagement Group (NTCEG). I have considered your proposal and acknowledge it is a worthwhile and interesting project and you are clear about how you ought to take participants' (cultural) needs into account if and when applicable.

Given the scope of your project, no issues have been identified and further consultation with Māori is not required.

Thank you for engaging with the Māori consultation process. This will strengthen your research proposal, support the University's Strategy for Māori Development, and increase the likelihood of success with external engagement. It will also increase the likelihood that the outcomes of your research will be of benefit to Māori communities. We wish you all the best with your current project and look forward to hearing about future research plans.

The Ngāi Tahu Consultation and Engagement Group would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any questions.

Ngā mihi whakawhetai ki a koe

Henrietta Carroll (on behalf of the NTCEG)

Kaiarāhi Maori Research
Research & Innovation | Te Rōpū Rangahau
University of Canterbury | Te Whare Wānanga o Waitaha
Phone +64 3 369 0143, Private Bag 4800, Christchurch | Ōtautahi
henrietta.latimer@canterbury.ac.nz
http://www.research.canterbury.ac.nz

Page 1 of 1

Appendix C: Permission Letter, Dr Beck

https://outlook.office365.com/mail/search/id/AAQkADRhN2RlMDB...

Re: Use of the Condom Use Self-Efficacy Scale in a Thesis Study

Kenneth H. Beck <kbeck1@umd.edu>
Fri 9/14/2018 1:15 AM
To: Adi Ferrara <arf54@uclive.ac.nz>

Dear Adi Ferrara,

You have my permission to use the Condom Use Self-Efficacy Scale in your research. Please cite the original source of the scale.

Good luck with your thesis.

Sincerely,

Kenneth H. Beck, Ph.D., FAAHB
Professor and Associate Chair, Academics
Department of Behavioral & Community Health
School of Public Health
University of Maryland
College Park 20742
Tel: (301) 405-2527
Fax: (301) 314-9167

On Thu, Sep 13, 2018 at 6:41 AM Adi Ferrara <arf54@uclive.ac.nz> wrote:

> Dear Dr. Beck,
>
> I am a Masters student in Health Sciences at the University of Canterbury in Christchurch, New Zealand. My thesis looks at perception of access to healthcare resources in teen men who have sex with men, and whether these perceptions affect their HIV risk behavior. My theoretical framework is Bandura's Social Cognitive Theory.
>
> As part of my study, I am conducting a survey and would like to use questions from the Condom Use Self-Efficacy Scale (Brafford and Beck, 1991). Am I allowed to use it, while of course crediting your paper in the thesis and any resulting publications? Is there any specific text I should add in the citation or anywhere else?
>
> Thank you so much for your help!
>
> Sincerely,
>
> Adi Ferrara

--
Kenneth H. Beck, Ph.D., FAAHB
Professor and Associate Chair, Academics
Department of Behavioral & Community Health
School of Public Health
University of Maryland

1 of 2

8/06/2020, 1:23 pm

Appendix D: Online Survey

Start of Block: Informed Consent

Q1

Department of Health Sciences

Telephone: +64 22 505 3236

Email: adi.ferrara@pg.canterbury.ac.nz

07/01/2019

HEC Ref: 2018/109

Healthcare access in New Zealand LGBTQ+ teens: Perceived barriers and enablers and their impact on sexual risk Behaviour

Information Sheet for Survey Volunteers

My name is Adi Ferrara. I am a PhD candidate at the school of Health Sciences at the University of Canterbury. I am doing this study as my PhD thesis project. In this study, I am trying to find out answers to the following questions:

- Do LGBTQ+ (lesbian, gay, bi, trans, queer, etc.) teenagers (including those who are still unsure) have problems or particularly good experiences using healthcare resources, such as a GP?
    - If they do have problems, what are they?
    - If they do have good experiences, what are they?

- If problems exist, do they influence sexual risk behaviour? (These risk behaviours include using condoms for sex and getting tested for HIV and other sexually transmitted infections [STIs].)

To participate in this study, you must be between the ages of 15 – 19 years, and identify as LGBTQ+ or still unsure (questioning). If you choose to take part in this study, you will be asked to fill out a survey online. The survey should take you about 20 minutes to complete. You do not have to give your name or contact information when you fill up the survey – you can stay completely unidentified.

At the end of the survey, you will have a choice to leave your email information for a voucher draw, as a thank you for participating. If you choose to participate in the draw, you will be taken to a separate mini-survey where you will enter your email. There will be no way to connect this survey's answers to your email. Your answers will remain completely anonymous.

You can also choose to give us your contact information if you want to take part in a focus group. The focus group is a face-to-face discussion group with 5-6 people in the group. There will be a separate information sheet for the focus group at the end of the survey. As with the draw, you will leave your contact information on a separate survey, and there will be no way to connect your answers with your focus-group contact information.

Taking the survey involves some risks. Some of the questions may make you feel uncomfortable or embarrassed. Some questions may cause you stress or make you feel sad. You do not have to answer any questions that make you feel uncomfortable or distressed in any way.

Participation is voluntary, and you can decide not to finish the survey – there is no penalty. Your answers will not become part of the study until you press the "Submit" button at the end of the survey.

The results of the project may be published, but your data will remain completely confidential. Any personal information you choose to share will not be made public. To ensure anonymity and confidentiality, the only people who have access to this survey data are my supervisors and me. The survey program does not collect information on your location or what device you are using to take your survey.

Please note that a thesis is a public document and will be available through the University of Canterbury Library. No identifiable information will appear in the thesis document.

A summary of the results will be available in the spring 2019 on the following web page: https://arf543.wixsite.com/website.

The project is being carried out as a requirement for a PhD degree by Adi Ferrara (adi.ferrara@pg.canterbury.ac.nz) under the supervision of Professor Ann Richardson, who can be contacted at ann.richardson@canterbury.ac.nz and Professor Sarah Lovell, who can be contacted at sarah.lovell@canterbury.ac.nz. They will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form below.

Q2 Your Consent

By clicking the button below, you acknowledge that you have read the information provided above and you agree to it. You further acknowledge that your participation in the study is voluntary, and that you are aware that you may choose to terminate your participation in the study at any time and for any reason.

○ I consent, begin the study

○ I do not consent, I do not wish to participate

Skip To: End of Survey If Your Consent = I do not consent, I do not wish to participate

Q3 This resource list is provided to you to help you if you are struggling in your daily life. It is not part of the survey.

Where to Go for Help

In any case where you feel your life or a friend's life is in danger, call 111.

The following general resources are available if you're struggling (listed in alphabetical order):

Alcohol Drug Helpline Free call 0800 787 797 https://alcoholdrughelp.org.nz/

Depression Helpline Free call 0800 111 757 or free text 4202

Healthline (For advice from trained registered nurses) Free call 0800 611 116

Lifeline (For counselling and support) Free call 0800 543 354 or free text 4357

The Lowdown Email team@thelowdown.co.nz or call the free 24/7 helpline 0800 111 757 or text 5626.

Male Survivors Aotearoa For male survivors of sexual abuse: https://malesurvivor.nz/contact/#

Need to Talk? Free call or text 1737 to talk with a trained counsellor.

New Zealand AIDS Foundation Free confidential counseling and HIV testing.

nzaf.org.nz

OUTLine Free call 0800 688 5463 10AM - 9PM weekdays, 6PM-9PM weekends

www.outline.org.nz

The only rainbow-specific phone counselling line in NZ.

Sparx sparx.org.nz Online self-help tool that teaches young people the key skills needed to help combat depression and anxiety

Suicide Crisis Helpline 0508 828 865

What's Up Free call 0800 942 8787 Webchat at whatsup.co.nz from 12pm - 10pm

Youthline Free call: 0800 376 633 or free text 234 email talk@youthline.co.nz
Webchat at www.youthline.co.nz from 7pm–11pm

Your District Health Board has a local list of healthcare resources, including mental health:

District health boards in New Zealand
Auckland District Health Board
Bay of Plenty District Health Board
Canterbury District Health Board
Capital & Coast District Health Board
Counties-Manukau District Health Board
Hawke's Bay District Health Board
Hutt Valley District Health Board
Lakes District Health BoardMid
MidCentral District Health Board
Nelson-Marlborough District Health Board
Northland District Health Board
Southern District Health Board
South Canterbury District Health Board
Tairawhiti District Health Board
Taranaki District Health Board
Waikato District Health Board
Wairarapa District Health Board
Waitemata District Health Board
West Coast District Health Board
Whanganui District Health Board

End of Block: Informed Consent

Start of Block: Block 2

Q4 In what year were you born?

____

Q5 In what region do you live?

____

Q6 What is your race/ethnicity? (Check all that apply)

○ NZ European
○ Māori
○ Samoan
○ Cook Island Māori
○ Tongan
○ Niuean
○ Chinese
○ Indian
○ Other (Please specify) ________________
○ Prefer not to say

Q7 What is your family's income level?

○ Zero
○ $1-$5,000
○ $5,001 - $10,000
○ $10,001 - $20,000
○ $20,001 - $40,000
○ $40,001 - $60,000
○ $60,001 - $80,000
○ $80,001 - $100,000
○ $100,001 or more
○ Not sure
○ Prefer not to say

End of Block: Block 2

Start of Block: Block 3

Q8 What is your gender?

○ Male	○ Transfemale
○ Female	○ Gender queer
○ Transmale	○ Other (Please specify)

Q9 What sex were you assigned at birth?

- ○ Male
- ○ Female

Q10 What is your sexual orientation?

- ○ Strictly homosexual
- ○ Strictly heterosexual
- ○ Bisexual / Pansexual
- ○ Asexual
- ○ Unsure / Questioning
- ○ Other (Please specify)

Skip To Q56 If What is your sexual orientation? = Asexual

End of Block: Block 3

Start of Block: Block 4

Q11 In general, how would you rate your overall health?

○ Excellent

○ Very Good

○ Good

○ Fair

○ Poor

Q12 In general, how would you rate your overall emotional health?

○ Excellent

○ Very Good

○ Good

○ Fair

○ Poor

Q13 Do you have a medical condition that requires regular doctor visits?

○ Yes

○ No

○ Prefer not to answer

Q14 Do you have a regular GP (Family Doctor)?

○ Yes

○ No

Skip To: Q25 If Do you have a regular GP (Family Doctor)? = No

Q15 On average, how often do you see your GP each year?

○ 1 - 2 times
○ 3 - 5 times
○ More than 5 times
○ I do not see my GP each year
○ Prefer not to answer

Q16 In the last 12 months, did you visit your GP for any reason (including regular check-ups) at least once?

○ Yes
○ No

Q17 If you do not see your GP at least once a year, please check all the reasons why:

☐ Cost
☐ Clinic too far
☐ Lack of transportation
☐ Unable to make time
☐ I don't feel comfortable with my GP
☐ My GP doesn't understand me
☐ Other (Please specify)

____

Q18 If you checked “I don’t feel comfortable with my GP” please explain here:

____

____

Q19 If you checked “My GP doesn’t understand my needs” please explain here:

____

____

Q20 During your most recent visit, did your GP listen carefully to you?

○ Definitely

○ Somewhat

○ No

Q21 Thinking about your regular GP, please check all that apply:

☐ I feel comfortable talking to my GP about any health-related issue (Please explain) ____

☐ I feel comfortable discussing my sexual/gender identity with my GP (Please explain) ____

☐ I came out to my GP

____

☐ I'm worried my GP will tell my family/whānau things I tell them (Please explain)

____

☐ I believe my GP has an anti-LGBTQ bias (Please explain)

____

☐ I’ve experienced biased responses / discrimination from my GP (Please explain) ____

Q22 Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate your GP?

	Worst	Best
	0 1 2 3 4 5 6 7 8 9 10	
GP Quality ()		

Q23 How much do you trust your GP to make medical decisions that are in your best interest?

○ A great deal

○ A lot

○ A moderate amount

○ A little

○ None at all

Q24 Does your GP work with you to make medical decisions, or do they make these decisions on their own?

○ We make decisions together

○ I let my GP decide

○ My GP decides on their own, without consulting me

○ My GP explains things to me, then encourages me to make my own decision

○ Other (Please explain)

____

Q25 Please tell us about good experiences you had with:

☐ A healthcare provider (GP, nurse or both) ________________________________

☐ Reception/office staff at a healthcare setting (hospital, clinic, or private practice) ________________________________

Q26 Please tell us about bad experiences you had with:

☐ A healthcare provider (GP, nurse or both) ________________________________

☐ Reception/office staff at a healthcare setting (hospital, clinic, or private practice) ________________________________

Q27 Did your sexual or gender identity ever stop you from seeking healthcare when you needed it?

○ Yes

○ No

End of Block: Block 4

Start of Block: Block 5

Display This Question:

If Do you have a regular GP (Family Doctor)? = No

Q28 Please check all the reasons you do not have a regular GP

☐ Cost (1)

☐ Clinic too far (2)

☐ Lack of transportation (3)

☐ Unable to make time (4)

☐ I don’t feel comfortable with my GP (5)

☐ My GP doesn’t understand my needs (6)

☐ Other (Please specify) (7)

____

Display This Question:

If Do you have a regular GP (Family Doctor)? = No

Q29 If you checked “I don’t feel comfortable with my GP” please explain here:

____

____

Display This Question:

If Do you have a regular GP (Family Doctor)? = No

Q30 If you checked “My GP doesn’t understand my needs” please explain here:

____

____

End of Block: Block 5

Start of Block: Block 6

Q31 The following 13 questions ask about your personal feelings about visiting healthcare providers. Please answer even if you do not have a regular GP or do not see your GP regularly.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
I feel comfortable disclosing my *sexual* identity to a healthcare provider	○	○	○	○	○
I feel comfortable disclosing my *gender* identity to a healthcare provider	○	○	○	○	○
I feel comfortable discussing my sexual health with a healthcare provider	○	○	○	○	○
I believe I will get the best medical care if I disclose my *sexual* identity to a healthcare provider (4)	○	○	○	○	○
I believe I will get the best medical care if I disclose my *gender* identity to a healthcare provider	○	○	○	○	○

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
I worry about being judged if I disclose my *sexual* identity to a healthcare provider	○	○	○	○	○
I worry about being judged if I disclose my *gender* identity to a healthcare provider	○	○	○	○	○
I worry that if I come out to a healthcare provider my family/whānau will find out	○	○	○	○	○
I worry that if I come out to a healthcare provider my friends will find out	○	○	○	○	○
I worry about being discriminated against by a healthcare provider if I disclose my *sexual* identity	○	○	○	○	○
I worry about being discriminated against by a healthcare provider if I disclose my *gender* identity	○	○	○	○	○
I believe my medical care will suffer if I disclose my *sexual* identity to a healthcare provider	○	○	○	○	○
I believe my medical care will suffer if I disclose my *gender* identity to a healthcare provider	○	○	○	○	○

End of Block: Block 6

Start of Block: Block 7

Q32 Are you sexually active?

○ Yes

○ No

Skip To: End of Block If Are you sexually active? = No

Q33 In the past 12 months, have you had sex with a man?

○ Yes

○ No

Q34 Do you use a condom when having sex?

○ Never

○ Every time I have sex

○ Only with new or casual partners

○ Other (Please specify)

○ N/A

End of Block: Block 7

Start of Block: Block 8Display This Question:

If Are you sexually active? = Yes

Q35 Have you been tested for HIV?

○ Yes

○ No

Display This Question:

If Have you been tested for HIV? = No

Please tell us why you have not been tested for HIV. Check all the reasons that apply.

☐ I don’t think I’m at risk for HIV

☐ I’m not sure how to get tested

☐ I’m not sure where to get tested

☐ I’m afraid someone will find out I got tested

☐ I’m afraid I’ll test positive

☐ Other (Please specify)

____

End of Block: Block 8

Start of Block: Block 9

Display This Question:

If Have you been tested for HIV? = Yes

Q37 Do you know the results of your HIV test? (YOU WILL NOT BE ASKED TO REPORT THEM)

○ Yes

○ No

Display This Question:

If Do you know the results of your HIV test? (YOU WILL NOT BE ASKED TO REPORT THEM) = No

Q38 If you answered “No” please explain why.

____

____

End of Block: Block 9

Start of Block: Block 10

Display This Question:

If Are you sexually active? = Yes

Q39 Have you been tested for any sexually transmitted infections (STIs) other than HIV?

○ Yes

○ No

Display This Question:

If Have you been tested for any sexually transmitted infections (STIs) other than HIV? = No

Q40 Please tell us why you have not been tested for STIs. Check all the reasons that apply.

☐ I don’t think I’m at risk for STIs

☐ I’m not sure how to get tested

☐ I’m not sure where to get tested

☐ I’m afraid someone will find out I got tested

☐ I’m afraid I’ll test positive

☐ Other (Please specify) ____

End of Block: Block 10

Start of Block: Block 11

Display This Question:

If Have you been tested for any sexually transmitted infections (STIs) other than HIV? = Yes

Q41 Do you know the results of your STIs test? (YOU WILL NOT BE ASKED TO REPORT THEM)

○ Yes

○ No

Display This Question:

If Do you know the results of your STIs test? (YOU WILL NOT BE ASKED TO REPORT THEM) = No

Q42 If you answered “No” please explain why.

____

____

End of Block: Block 11

Start of Block: Block 12

Q43 The following 14 questions ask about your personal feelings about using a condom in specific situations. Please answer these questions even if you are not currently sexually active or have never used a condom. In such cases, answer how you think you might feel in such a situation

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
I feel confident in my ability to put a condom on myself or my partner	○	○	○	○	○
I feel confident I could purchase condoms without feeling embarrassed	○	○	○	○	○
I feel confident in my ability to discuss condom usage with any partner I might have	○	○	○	○	○
I feel confident in my ability to suggest using condoms with a new partner	○	○	○	○	○
I feel confident I could suggest using a condom	○	○	○	○	○

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
without my partner feeling "diseased"					
I would feel embarrassed to put a condom on myself or my partner	○	○	○	○	○
If I were to suggest using a condom to a partner, I would feel afraid that they would reject me	○	○	○	○	○
If I were unsure of my partner's feelings about using condoms, I would not suggest using one	○	○	○	○	○
I feel confident in my ability to use a condom correctly	○	○	○	○	○
I would feel comfortable discussing condom use with a potential sexual partner before we ever had any sexual contact (eg, hugging, kissing, caressing, etc)	○	○	○	○	○
I would not feel confident suggesting using condoms with a new partner because I would be afraid they would think I have a sexually transmitted disease	○	○	○	○	○

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
I would not feel confident suggesting using condoms with a new partner because I would be afraid they would think I thought they had a sexually transmitted disease	○	○	○	○	○
I feel confident that I would remember to use a condom even after I have been drinking	○	○	○	○	○
I feel confident that I would remember to use a condom even if I were high	○	○	○	○	○

End of Block: Block 12

Start of Block: Block 13

Q44 Are you familiar with PrEP?

○ Yes

○ No

Display This Question:

If Are you familiar with PrEP? = Yes

Q45 In your own words, please tell us what you know about PrEP.

____

____

End of Block: Block 13

Start of Block: Block 14

Display This Question:

If Are you familiar with PrEP? = No

Q46 PrEP stands for "pre-exposure prophylaxis." It is a once-daily pill that, when taken every day consistently, can prevent HIV infection if the person has unprotected sex with an infected individual. The pill is now available freely in New Zealand to people in high risk groups, such as men who have unprotected anal sex with men. Because of possible side effects, regular check-ups with a GP are required if a person uses PrEP. The brand name of the medicine is Truvada.

End of Block: Block 14

Start of Block: Block 15

Q47 How likely would you be to use PrEP?

○ Not likely at all

○ Somewhat likely

○ Very likely

○ I will definitely use it

Q48 Please explain your answer.

____

____

Q49 Taking PrEP requires regular check-ups with a GP. Does knowing this change your interest in using PrEP?

○ Yes

○ No

Q50 Please explain your answer.

____

____

End of Block: Block 15

Start of Block: Block 16

Q51 Do you belong to an LGBTQ organization, such as Rainbow Youth or Q-topia?

○ Yes

○ No

Q52 Do you use any of the following resources: 298 (Christchurch area only), New Zealand AIDS Foundation, or a sexual health clinic?

○ Yes

○ No

Q53 What is your main source of information about any health risks you may have?

____

End of Block: Block 16

Start of Block: Block 17

Q54 Would you like to leave your email for a drawing for 1 of 2 $50 gift vouchers? Your contact information is entered on a separate survey, not connected to your answers here.

○ Yes

○ No

Q55 Please press the Submit button to record your survey answers.

End of Block: Block 17

Start of Block: Block 18

Q56 I'm sorry, based on your current answers you are not eligible to participate in this study. Thank you for volunteering!

End of Block: Block 18

Appendix E: Interview Questions

Below are the main questions guiding the interviews. The interviews were semi-structured, semi-structured with prompts and follow-up questions employed where appropriate.

Introduction:

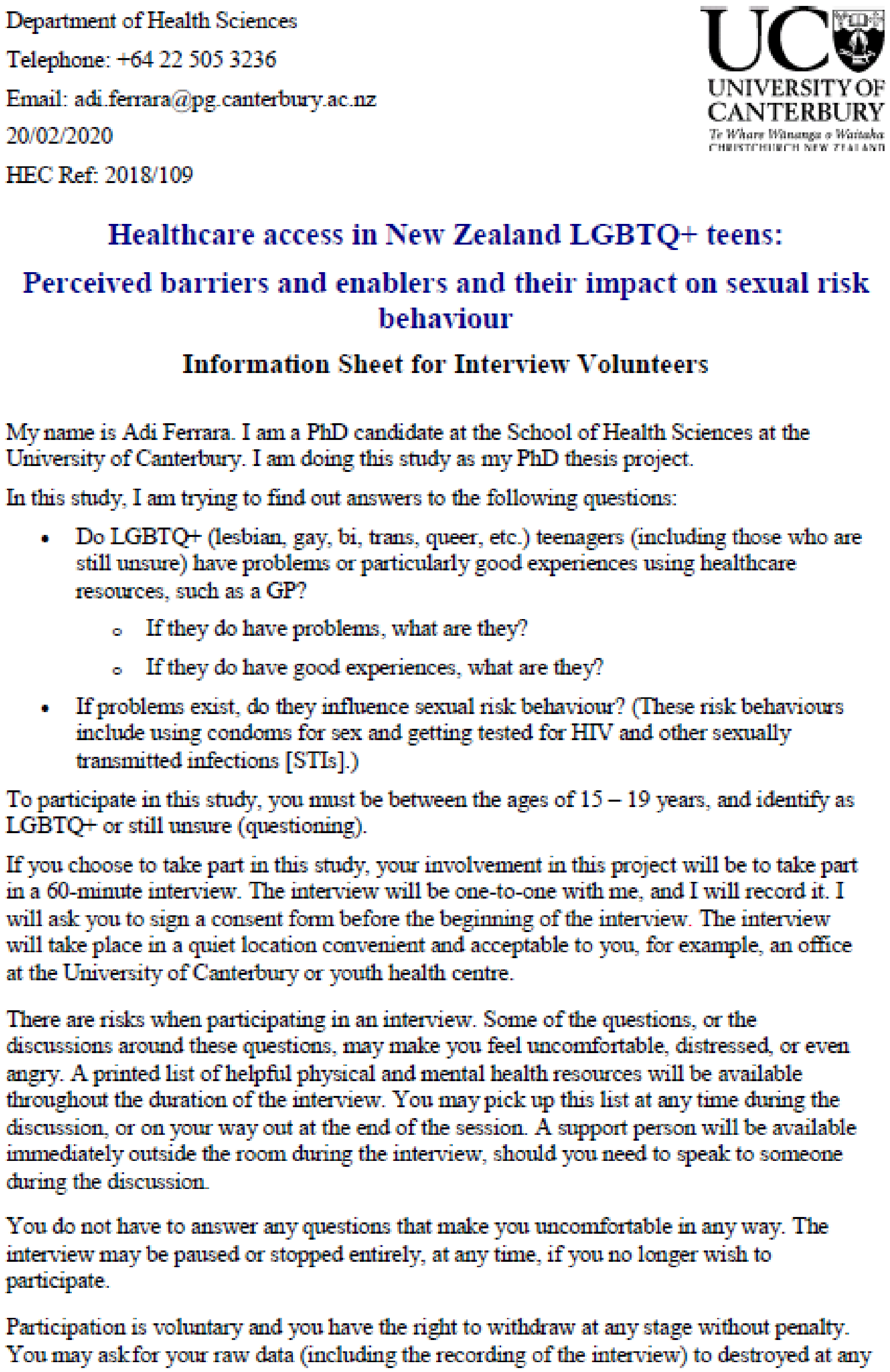
Name, pronouns, age, sexual & gender identity.

Interview:

- What made you want to participate in this interview today?
- Can you tell me the story of how you signed up with your current healthcare provider?
- Is there anything that stops you from seeing a/your doctor or nurse when you want to? (e.g. cost, transportation)
- What has been your experience with the quality of care you get from your provider?
- Thinking about the physical and mental health needs you've had in the past 6 months, do you feel those needs are being met?
- Have you ever discussed your sexuality or gender identity with your provider? Why or why not?
    - Thinking about the **care you get** from your provider, do you think knowing your sexual/gender identity actually affects (or "would affect" if participant not out to provider) the care you get?
- What do you think is important for your provider to know about you, in order to best meet your health needs?

Appendix F: Interview Information Sheet and Consent Form

1. Interview Information Sheet – Face-to-Face



Department of Health Sciences
Telephone: +64 22 505 3236
Email: adi.ferrara@pg.canterbury.ac.nz
20/02/2020
HEC Ref: 2018/109

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Healthcare access in New Zealand LGBTQ+ teens:

Perceived barriers and enablers and their impact on sexual risk behaviour

Information Sheet for Interview Volunteers

My name is Adi Ferrara. I am a PhD candidate at the School of Health Sciences at the University of Canterbury. I am doing this study as my PhD thesis project.

In this study, I am trying to find out answers to the following questions:

- Do LGBTQ+ (lesbian, gay, bi, trans, queer, etc.) teenagers (including those who are still unsure) have problems or particularly good experiences using healthcare resources, such as a GP?
  - If they do have problems, what are they?
  - If they do have good experiences, what are they?
- If problems exist, do they influence sexual risk behaviour? (These risk behaviours include using condoms for sex and getting tested for HIV and other sexually transmitted infections [STIs].)

To participate in this study, you must be between the ages of 15 – 19 years, and identify as LGBTQ+ or still unsure (questioning).

If you choose to take part in this study, your involvement in this project will be to take part in a 60-minute interview. The interview will be one-to-one with me, and I will record it. I will ask you to sign a consent form before the beginning of the interview. The interview will take place in a quiet location convenient and acceptable to you, for example, an office at the University of Canterbury or youth health centre.

There are risks when participating in an interview. Some of the questions, or the discussions around these questions, may make you feel uncomfortable, distressed, or even angry. A printed list of helpful physical and mental health resources will be available throughout the duration of the interview. You may pick up this list at any time during the discussion, or on your way out at the end of the session. A support person will be available immediately outside the room during the interview, should you need to speak to someone during the discussion.

You do not have to answer any questions that make you uncomfortable in any way. The interview may be paused or stopped entirely, at any time, if you no longer wish to participate.

Participation is voluntary and you have the right to withdraw at any stage without penalty. You may ask for your raw data (including the recording of the interview) to destroyed at any point. If you withdraw, I will remove information relating to you from the study. However, once analysis of raw data starts on 01/03/2021, it will become increasingly difficult to remove the influence of your data on the results.

The results of the project may be published, but your data will remain completely confidential. Any personal information you choose to share will not be made public without your prior consent. To ensure anonymity and confidentiality, the only people who have access to the interview's recordings and transcripts are my supervisors and me. Any published material from the study (including the thesis itself) will use fictitious (made up) initials instead of real names. Only my supervisors and I will have access to the list of real names and made up initials.

Please note that a thesis is a public document and will be available through the University of Canterbury Library. No identifiable information will appear in the thesis document.

A summary of the results will be available in the spring of 2021 on the following web page: https://arf543.wixsite.com/website.

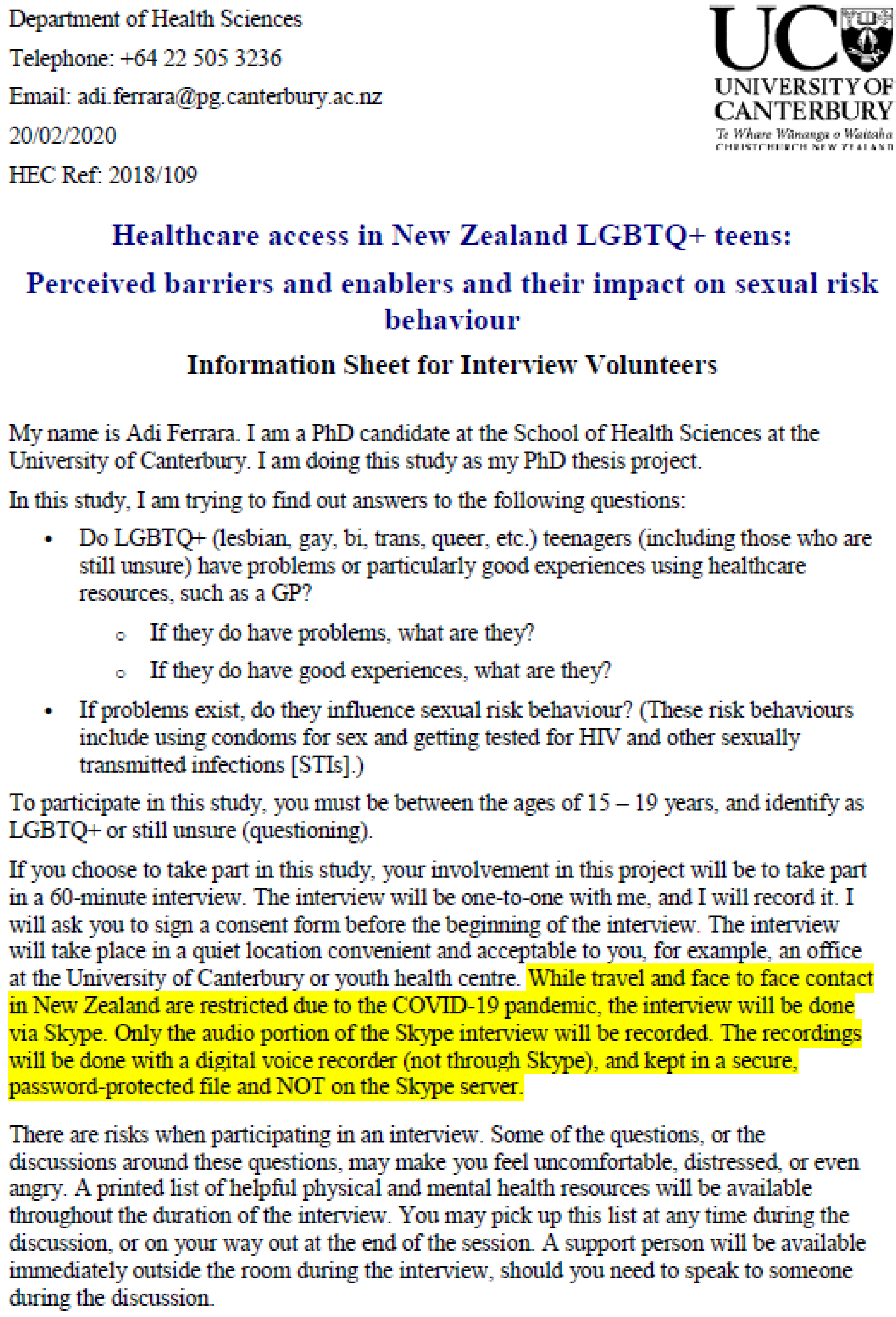
The project is being carried out as a requirement for a PhD degree by Adi Ferrara (adi.ferrara@pg.canterbury.ac.nz) under the supervision of Professor Philip Schluter, who can be contacted at philip.schluter@canterbury.ac.nz and Professor Sarah Lovell, who can be contacted at sarah.lovell@canterbury.ac.nz. They will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch 8140, (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return it to me prior to the start of the interview. There will be time allotted for reading and signing the consent form.

Please indicate to the researcher on the consent form if you would like to review a copy of your interview transcript.

2. Interview Information Sheet – Skype



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There are risks when participating in an interview. Some of the questions, or the discussions around these questions, may make you feel uncomfortable, distressed, or even angry. A printed list of helpful physical and mental health resources will be available throughout the duration of the interview. You may pick up this list at any time during the discussion, or on your way out at the end of the session. A support person will be available immediately outside the room during the interview, should you need to speak to someone during the discussion.

You do not have to answer any questions that make you uncomfortable in any way. The interview may be paused or stopped entirely, at any time, if you no longer wish to participate.

Participation is voluntary and you have the right to withdraw at any stage without penalty. You may ask for your raw data (including the recording of the interview) to destroyed at any point. If you withdraw, I will remove information relating to you from the study. However, once analysis of raw data starts on 01/07/2020, it will become increasingly difficult to remove the influence of your data on the results.

The results of the project may be published, but your data will remain completely confidential. Any personal information you choose to share will not be made public without your prior consent. To ensure anonymity and confidentiality, the only people who have access to the interview's recordings and transcripts are my supervisors and me. Any published material from the study (including the thesis itself) will use fictitious (made up) initials instead of real names. Only my supervisors and I will have access to the list of real names and made up initials.

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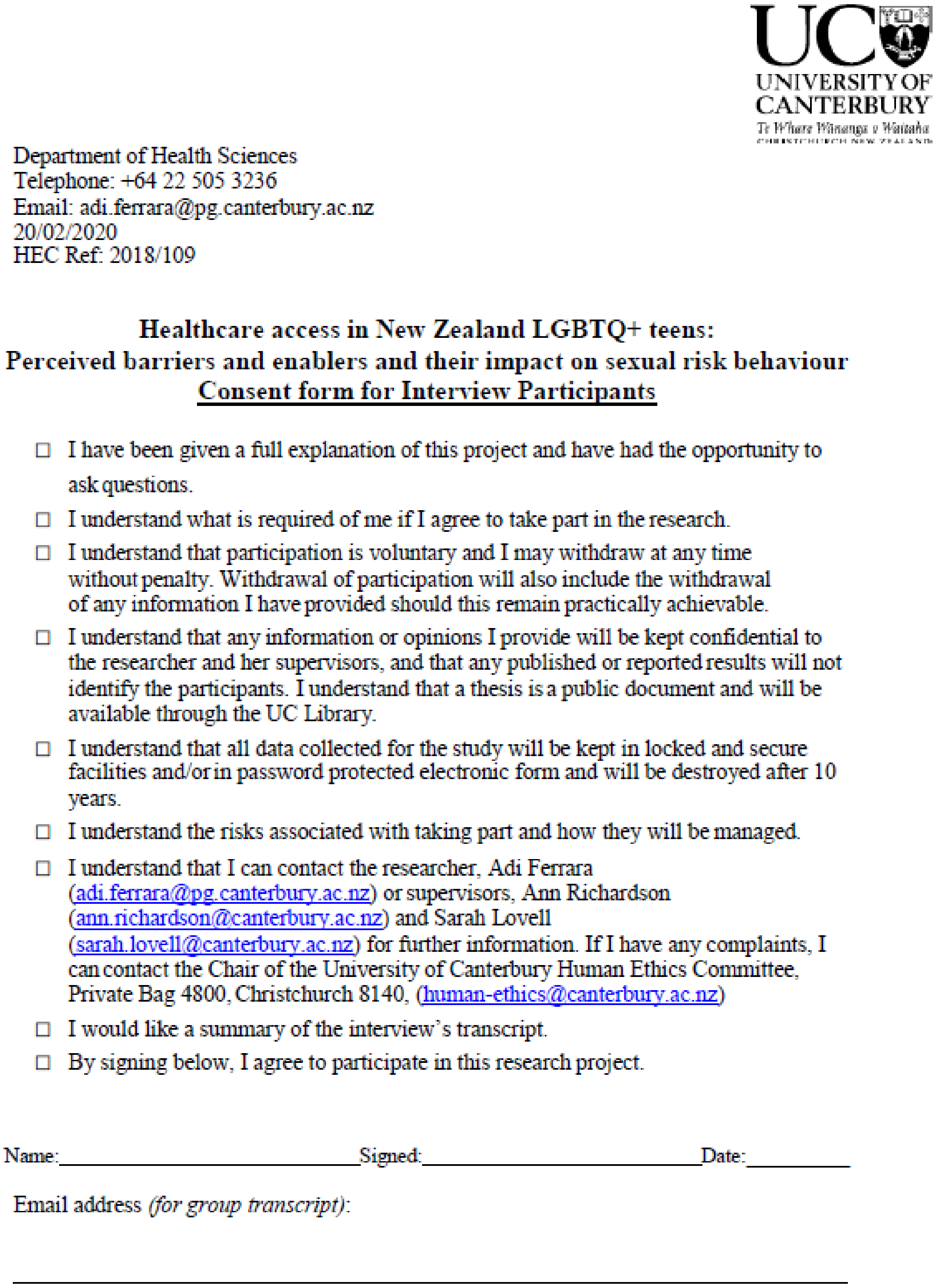
Please indicate to the researcher on the consent form if you would like to review a copy of your interview transcript.

3. Interview Consent



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Consent form for Interview Participants

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what is required of me if I agree to take part in the research.
- ☐ I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- ☐ I understand that any information or opinions I provide will be kept confidential to the researcher and her supervisors, and that any published or reported results will not identify the participants. I understand that a thesis is a public document and will be available through the UC Library.
- ☐ I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after 10 years.
- ☐ I understand the risks associated with taking part and how they will be managed.
- ☐ I understand that I can contact the researcher, Adi Ferrara (adi.ferrara@pg.canterbury.ac.nz) or supervisors, Ann Richardson (ann.richardson@canterbury.ac.nz) and Sarah Lovell (sarah.lovell@canterbury.ac.nz) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch 8140, (human-ethics@canterbury.ac.nz)
- ☐ I would like a summary of the interview's transcript.
- ☐ By signing below, I agree to participate in this research project.

Name:______________________________Signed:____________________________Date:__________

Email address *(for group transcript)*:

____

Appendix G: Recruiting Materials

1. Tear-away flyers

Volunteers Needed

Be in a draw for 1 of 2 $50 Visa vouchers for taking the survey (requires leaving email separate from survey)

Interview participants

receive $15 Visa voucher

For a PhD study of how LGBTQ+ teens perceive their access to healthcare resources, and whether this perception impacts safer sex behaviour.

The study involves taking an anonymous computer survey. There is an option for volunteering to be interviewed after the survey.

If you:

☐ Are aged 15–19 years

☐ Identify as LGBTQ+

☐ Live in New Zealand

You are eligible to be in this study. Scan the QR code or enter this link in your browser: https://bit.ly/2PORodJ

Researcher: Adi Ferrara

University of Canterbury College of Education, Health and Human Development:
School of Health Sciences

email: adi.ferrara@pg.canterbury.ac.nz

University of Canterbury Human Ethics Committee Approval: 2018/109

Rainbow Teens Healthcare Access Study https://bit.ly/2PORod

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Rainbow Teens Healthcare Access https://bit.ly/2PORod

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2. Social media ad

Volunteers Needed

For a PhD study of how LGBTQ+ teens perceive their access to healthcare resources, and whether this perception impacts safer sex behaviour.

The study involves taking an anonymous computer survey. There is an option for volunteering to be interviewed after the survey.

If you:

* **Are aged 15-19 years**
* **Identify as LGBTQ+**
* **Live in New Zealand**

You are eligible to be in this study. Scan the QR code or enter this link in your browser:

https://bit.ly/2PORodJ

Appendix H: Examples of Intentionally Erroneous Responses (Survey)

A

Q48. Please explain your answer.

faggot

Q53. What is your main source of information about any health risks you may have?

imagine your phd about mental queers

B

Q42. The following 14 questions ask about your personal feelings about using a condom in specific situations. Please answer these questions even if you are not currently sexually active or have never used a condom. In such cases, answer how you think you might feel in such a situation

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
I feel confident in my ability to put a condom on myself or my partner	●	○	○	○	○
I feel confident I could purchase condoms without feeling embarrassed	○	●	○	○	○
I feel confident in my ability to discuss condom usage with any partner I might have	○	○	●	○	○
I feel confident in my ability to suggest using condoms with a new partner	○	○	○	●	○
I feel confident I could suggest using a condom without my partner feeling "diseased"	○	○	○	○	●
I would feel embarrassed to put a condom on myself or my partner	●	○	○	○	○
If I were to suggest using a condom to a partner, I would feel afraid that they would reject me	○	●	○	○	○
If I were unsure of my partner's feelings about using condoms, I would not suggest using one	○	○	●	○	○
I feel confident in my ability to use a condom correctly	○	○	○	●	○
I would feel comfortable discussing condom use with a potential sexual partner before we ever had any sexual contact (eg, hugging, kissing, caressing, etc)	○	○	○	○	●
I would not feel confident suggesting using condoms with a new partner because I would be afraid they would think I have a sexually transmitted disease	●	○	○	○	○

Examples of intentional erroneous responses that invalidated the entire survey.

A: Hate speech

B: Unrealistic response pattern