# "Who Am I? This is Me" A Grounded Theory of Transgender Young Adults Navigating the Healthcare System

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# Attestation of Authorship

I hereby declare that this submission is my own work and that to the best of my knowledge contains no material previously published or written by any other person (except where explicitly defined), no material which to a substantive extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed: Date: 30 November 2021

## **Abstract**

Youth and young adults often report difficulties in accessing comprehensive healthcare to meet their health and wellbeing needs. An uncoordinated and under-resourced healthcare system results in young people reporting numerous barriers in seeking services when they need them. For transgender young adults, the challenges are even greater, with fewer services able to cater for their specific health and wellbeing needs. A constructivist grounded theory approach was used to guide the collection of data to understand the processes transgender and young gender-diverse adults use to navigate the healthcare system. Semi-structured interviews were undertaken with a small cohort of ten transgender young adults aged between 18 and 24 years. The processes of constant comparative analysis, theoretical sampling and saturation were used to generate a substantive grounded theory Who am I? - this is me. Three categories emerged from this study in relation to the young people's interactions with the healthcare system. These were: Seeking My Authentic Self and the process of gender affirmation and validation; Knowing I Matter But..., which is defined as having meaningful engagement with healthcare providers; and the third category, My Transition Enabled, is about being able to access trusted and accessible health care for life. This study has highlighted that, despite the recent developments in acknowledging the needs of transgender young adults, there continue to be significant gaps in consistent transgender healthcare provision across New Zealand. The study also confirms that there are barriers preventing young people accessing the right level of care for their health, and mental wellbeing needs. From the substantive theory, a framework of affirmative healthcare is proposed to provide healthcare decision-makers and planners a consumer-informed road map, which prioritises meaningful and trusting engagement between healthcare providers and service users. Mitigating barriers to accessing services and building the capability of the workforce in transgender health and mental health is crucial for better healthcare for transgender young adults.

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# **Chapter 1 – Introduction**

Sammy walked into my office in 1987. She was of slight build with long well-groomed hair. When I asked what she understood was behind the referral to see a psychologist, she said she didn't really know, but she had got into trouble hanging out with her older mates on K Rd. Sammy was 20, Māori, and her birth gender was male; and to anyone else meeting her for the first time, she presented as a quietly spoken young woman. As we began to talk about her life choices, it was clear that she felt she had limited choices and that it was only on the street with her mates (of similar ethnic and gender diversity) that she felt she belonged and could access health advice without judgement, and was accepted for just being the gender she felt most comfortable with. Accepting being marginalised and discriminated against had become her norm.

#### Research Overview

Internationally, transgender individuals' experience of difficulties navigating the health care systems and accessing comprehensive health care are well-documented (Aiken, 2016; Roller et al., 2015; Safer et al., 2016). Locally, there is recognition that young transgender people face considerable health and well-being disparities due to difficulties in accessing healthcare in safe environments (Clark, Lucassen, et al., 2014; Tan et al., 2020).

This research utilises constructivist grounded theory to explain transgender young adults' perceptions and experiences of healthcare services. Semi-structured interviews undertaken with transgender participants and a review of the literature were used to explore young people's interpretations of their experiences and interactions with the healthcare system. The question used to guide the research was: What are the processes young gender-diverse adults use to navigate the health system? The intention of this research is to make an empirical and theoretical contribution to improve decision-makers and healthcare providers' understanding of how healthcare services can better serve the needs of transgender young adults.

In undertaking this study, I had originally included the descriptor *gender-diverse* during my participant recruitment to accommodate young people who felt more aligned to all gender groupings broader than transgender. My early learning during this study is that all participants were proud to describe themselves as *transgender* or *trans*, regardless of whether they aligned with the binary or non-binary genders. The consensus from their comments is that the term *transgender* simply represents moving beyond their gender assigned at birth. In taking the participants' lead, the term *transgender* will be used when referencing the participants in this thesis. Other terms will be used if applicable when

referring to research studies or publications which refer to *trans*, *gender-diverse* or *gender non-conforming* participants.

For the purposes of this study, the use of the term transgender is that defined by the World Professional Association for Transgender Health (WPATH) the Standards of Care,

"A diverse group of individuals who cross or transcend culturally defined categories of gender. The gender identity of transgender people differs to varying degrees from the sex they were assigned at birth."

(World Professional Association for Transgender Health, 2012, p. 97).

This definition covers a broad spectrum of gender-diverse expressions and allows for the often-moving perspectives of young people exploring their identities. For those not identifying as *transgender*, the term *cisgender* will be used. Over the last 15 years, this term has become more widely used. In 2015, *cisgender* was added to the Oxford dictionary with the following meaning, "denoting or relating to a person whose sense of personal identity and gender is the same as their birth sex" (Lexico., n.d.): Throughout this thesis, references will be made to *transgender*, or the abbreviated term *trans*, which is often used in the literature. The acronym LGBTQI represents lesbian, gay, bisexual, transgender queer or questioning, and intersex individuals. The term *Rainbow* was used by participants in this study in reference to their peer groups or their community of people of similar diverse sexual orientations, gender, and sex identities. Services described as *Rainbow*-friendly were recognised as catering for the needs of the LGBTQI community.

# Background to the Research

For more than three decades, I have worked within a health system that has not served young adults entirely well. Advocating for a better healthcare response to the youth and young adults, particularly those of minority groups who have been underserved, seemed a salient starting point for this research. As the former Clinical Lead of an adolescent and young adult health service known locally as the Youth Health Hub, I discovered that almost a fifth of our registered patients, between the ages of 13 and 24 years, identified as transgender.

Funded by the District Health Board, the Youth Health Hub provided primary care to young people aged between 12 and 24 years. A key priority was engaging young people with unmet needs. A frequent concern expressed by healthcare colleagues and clients was that there seemed to be, in general, limited options to access healthcare provided by clinicians who were experienced in transgender health. With the benefit of a team of youth-friendly medical health specialists with transgender health knowledge, mental health and youth development practitioners, the Youth Health Hub welcomed increasing numbers

of transgender or gender-querying young people and their family's seeking advice and support. Some were requesting medical support for gender transition, while others were simply exploring their gender identities and options. The positive aspect of many youth-dedicated health services is, as the Youth Health Hub did, had a youth advisory group that participated in the set-up of the service, and so it was very evident that the environment had been guided by the young people, outwardly conveying that young people of diverse genders, sexual orientations, and cultures would be welcomed. The service was also able to offer several health and wellbeing options from one location. The drawback, however, was that similar publicly funded services across the country were few, which meant that not all young people could access an array of services at one location.

Easy to access healthcare for young people might seem an obvious area for significant government investment; however, the funded capacity for youth and young adult health falls short of the demand. Commissioning decisions have often been based on the prevalence of healthcare needs across the population. It could be argued that as the population of transgender individuals is relatively small, health targets are more likely focussed on cisgender needs. The local Youth 2000 studies surveyed secondary school students aged between 13 and 18 years, and found that 1.2% identified as transgender, while 2.5% were unsure of their gender (Clark, Lucassen, et al., 2014). In the USA, estimates of the transgender population among youth 13 to 17 years ranged from 1.3% to 3.2% (Wilson & Kastanis, 2015), and for the 18 to 24 year age group, it was estimated at only 0.7% (Herman et al., 2017). These statistics highlight the importance of population health targets being inclusive of gender-diverse people to avoid inadvertent prejudice. For evaluation activities to contribute to better wellbeing outcomes for gender and sexually diverse people this population should be included in evaluation activities(Adams & Neville, 2021).

In 2016, the Ministry of Health signalled reforms in transgender health care. While a government focus was certainly welcomed, there was still some way to go to build the capacity in both services and the workforce to achieve the service reach needed across New Zealand. Since commencing this study, *Guidelines for gender affirming healthcare for gender-diverse and transgender children, young people and adults* (Oliphant, Veale, Macdonald, Carroll, Bullock, et al., 2018) have now been developed. There has also been the release of, *Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand*, recommending more support for health and wellbeing initiatives led by trans and non-binary communities (Veale et al., 2019).

# The Health and Wellbeing Needs of Young Adults

Over the last two decades, there has been strong advocacy for improving health services for young people in general. The United Nations defines persons between the ages of 15 and 24 years as youth, in recognition of the developmental and transition issues that young people in the 19-to-24-year age band face (United Nations, 2013). Young adulthood is clearly a critical developmental period, as the transition to adulthood presents the young person with challenges across all the life domains. The success or failure in navigating these paths will strongly affect young adults' trajectories in later life (World Health Organization, 2014). It has also been described as a period of heightened psychological vulnerability and the potential onset of serious mental health disorders (National Research Council, 2015). From the results of the New Zealand Mental Health Survey that Te Rau Hinengaro conducted between 2003 and 2004, it was estimated that 28.6 per cent of youth between 16 and 24 years will experience a mental disorder in a 12-month period (Oakley Browne et al., 2006). Youth suicide is a key concern in New Zealand. National suicide rates are among the highest in the world, particularly for males aged 15-19 years and females between 20 and 24 years (Patton et al., 2012), with Māori significantly over-represented in this group (Snowdon, 2020). Regardless of various life stressors, most young people in New Zealand seem to thrive, but at least 20% of young people will exhibit behavioural and emotional distress unless they have access to effective interventions to meet their needs (Gluckman, 2011).

#### Access to Healthcare

While GP practices are an obvious first point of call for young adults, the *Counting Ourselves* survey found that over a third of participants had avoided seeing a doctor because they were worried about disrespect or mistreatment as a trans or non-binary person (Veale et al., 2019). Young adults are also less likely than other age groups to consult a General Practitioner for their mental health concerns (Biddle et al., 2006). This reluctance to access health care is likely an opportunity missed to improve the health and wellbeing of a group already known to be at risk of poor health (Stroud et al., 2015). If we are to reduce the disparities for young adults, the challenge for healthcare providers is how to engage young people and provide appropriate care.

The importance of youth-friendly health care has been well documented globally (World Health Organization, 2014) and locally (Bagshaw, 2012; Malatest International, 2016; McKinlay et al., 2021; Social Policy Evaluation and Research Unit, 2017). Young people themselves want better coordinated and free youth-focussed services which provide a safe environment with friendly caring staff who listen and promote youth development focus (Christiani et al., 2008; Hetrick et al., 2017). Integrated models of care that bring a

number of service elements together in a cohesive manner (World Health Organization, 2016) would seem an obvious solution.

In a local evaluation of Youth One-Stop Shops (YOSS), young people, providers, and stakeholders cited access to low cost, convenient, welcoming non-judgmental healthcare with staff who know about youth-related issues to be helpful (Communio, 2009). Young people also indicated that having access to a range of different services in one place reduced the stigma (Communio, 2009). Youth one-stop shops or community-based youth-specific health services were also more likely to increase access to health care, particularly among groups of young people not well served by mainstream health services (Fleming & Elvidge, 2010; Hetrick et al., 2017).

Local Youth One-Stop Shops (YOSS) are typically funded to provide services for the 12 to 24-year-old age group, accommodating both youth and young adults. With the exception of GP practices, specialist healthcare services tend to cater for children and youth (0-18 years), while 18 – 24-year-old young adults are referred to services for allage adults. This means that young adults are left to access services that may or may not recognise the various interrelated factors associated with their developmental stage (Farre & McDonagh, 2017). Despite YOSS services being favoured by young people, there are only eleven across New Zealand (Communio, 2009). Since 2009, this situation has remained static.

The various studies outlined above highlight why developmentally appropriate healthcare should be considered a key principle and defining characteristic of health services. In designing services for youth and young adults, the multiple domains, including gender, mental health, physical health, schooling, family functioning, and quality of life, need to be considered (Tollit et al., 2019). Each of these interrelated domains needs to be considered within a developmental context. Farre and McDonagh (2017) identify five conceptual dimensions which potentially provide a framework for health workers' provision of care for adolescents and young adults. The dimensions include:

- Biopsychosocial development and holistic care.
- Acknowledgement of adolescents and young adults as a distinct group.
- Adjustment of care as the young person develops.
- Empowerment of the young person by embedding health education and health promotion.
- Interdisciplinary and inter-organisational work or integrated models of care.

(Farre & McDonagh, 2017)

# The New Zealand Healthcare System Context

For improvements in the health system to occur, reforms will be needed across a number of domains. The overriding challenge is whether the public health system prioritises adequate funding to enable change. To provide the context for the current provision of healthcare services for transgender young adults, a brief overview of the health reforms that attempt to address disparities will be outlined.

Priorities and the level of investment targeting improvements in the healthcare system are influenced by the policies and focus of the government in place at that time (Morgan & Simmons, 2009). There have been various reforms to the New Zealand health system since the late 1930s. Throughout these reforms, the legislation has given the Ministry of Health the function of improving, promoting, and protecting public health (Ministry of Health, 2014b). Other legislative changes have since provided an impetus for the government to reset priorities and strategic direction for prioritising funding for health improvements.

In the early 2000s, new reforms identified the government's intention for healthcare to be directed at those areas that would ensure the highest benefits for the population and reduce inequalities in health (King, 2000). Reducing inequities for Māori has been a longstanding priority. The Māori health strategy *He Korowai Oranga* highlighted the interdependence of the health and wellbeing of people, recognising that a person's social context, supporting whānau, hapū, iwi and community development, was just as important as physical health (Ministry of Health, 2002a).

It was also during the early 2000s that the Government proposed a shift in the way the health sector viewed youth. The intention was to move from a problem-focussed perspective to encouraging young people to take a participatory and active role in creating a healthier world (Ministry of Health, 2002b). This resulted in the proposal *Youth, A Guide to Action,* which acknowledged the vulnerability of young people (Ministry of Health, 2002b). The changed perspective highlighted in this proposal was encouraging young people to be active participants in their own healthcare, recognising that health services should be more youth-focussed and youth-knowledgeable (Ministry of Health, 2002b).

In 2006, The Human Rights Commission (2008) undertook an inquiry to investigate trans people's experiences of discrimination, access to health services, and barriers to legal recognition of gender status. The findings demonstrated significant gaps and inconsistencies in the provision of health services and recommended that there be improved access for transgender people to public health services. The Human Rights Commission

recommended that discussions between healthcare professionals, the Ministry of Health and transgender individuals should occur to map out treatment pathways and standards of care. The report highlighted that young transgender people should have the right to be accepted for who they are but recognised their dependence on others for acceptance, such as parents and teachers. The report also acknowledged that there was a need for information and resources for transgender children and young people, their parents and families and schools (Human Rights Commission, 2008).

The Government's impetus to invest and prioritise youth and young adult mental health continued to be reflected in the report *Improving the Transition: Reducing Social and Psychological Morbidity During Adolescence* (Gluckman, 2011). This report raised concerns about mental health issues during the period when young people move from childhood to adulthood, including depression and other mental health disorders, cannabis use and harmful use of alcohol, and youth suicide. A number of initiatives were, as a result of this report, prioritised to increase the early detection and access to early intervention responses in primary care and within school settings (Office of the Prime Minister, 2012). While this has raised some awareness of youth health needs and increased access, further development is still required to build service and workforce capacity (Malatest International, 2016). These initiatives did not specifically target transgender young adults.

For some time, there has been good evidence that social, cultural and economic factors are the most important determinants of good health (National Advisory Committee on Health and Disability, 1998). Despite good intentions, as highlighted, there are still gaps and inconsistencies in how healthcare is delivered (Ministry of Health, 2014). There is an acknowledgement that New Zealand has a healthcare system that struggles to ensure equitable access to limited resources, resulting in ongoing health disparities (Ministry of Health, 2015b). This predicament has highlighted that more research is needed to better understand the model of care which is likely to be most effective with young people and particularly for ethnic or diverse gender minority groups (Clark, Johnson, et al., 2014).

A number of key government-driven reviews and reports have refreshed the health sector's strategic priorities and sought to identify continuing gaps in healthcare provision and disparities. Future directions for the health sector into 2026 are outlined in the New Zealand Health Strategy, emphasising a whole health perspective (Minister of Health, 2016). The report of the Inquiry into Mental Health and Addiction Health in New Zealand, He Ara Oranga (Paterson et al., 2018). and the Health and Disability System Review, Pūrongo Whakamutunga (Health and Disability System Review, 2020) reinforced the priorities identified in the NZ Health Strategy (Minister of Health, 2016). Both reports noted the unmet need, not only among Māori but also Pacific peoples, disabled people,

Rainbow communities, the prison population, and refugees and migrants (Paterson et al., 2018). The recommendations in each of these reports point toward a common focus which includes a more integrated healthcare approach, enabling the voice of the consumer and supporting families and whānau to be active participants in their care.

# Developments in Transgender Healthcare in New Zealand

While the current direction of the government is encouraging and acknowledges that the healthcare system needs to change, when and how this will cascade down to cater for the needs of young transgender people remains unknown. The transgender community has been one of the most underserved populations in terms of their medical and health needs (Roberts & Fantz, 2014), so there is still a need for ongoing advocacy and education in transgender healthcare.

Internationally, there has been growing awareness and longstanding pursuit by health practitioners to address the health needs of transgender people. This resulted in the formation of The World Professional Association for Transgender Health (WPATH) in 1979, whose mission was to promote evidence-based care, education, research, advocacy, public policy, and respect for transgender health (World Professional Association for Transgender Health, 2012). The Association has continued to provide strong guidance in generating standards of care for the health of transsexual, transgender, and gender-nonconforming people (Coleman et al., 2012).

In 2009, ANZPATH (Australia and New Zealand Professional Association for Transgender Health, n.d) was initially formed to provide a professional organisation with the intention of improving access to gender affirming care and broader health outcomes for transgender people in both Australia and New Zealand. In 2018, the PATHA (Professional Association for Transgender Health Aotearoa, n.d.) was established as an interdisciplinary professional organisation working to promote the health, wellbeing, and rights of transgender people with a New Zealand focus. ANZPATH has since renamed its organisation the AusPATH (Australian Professional Association for Transgender Health, n.d.) to reflect a focus on Australia.

Guidelines for gender affirming healthcare for gender-diverse and transgender children, young people and adults, as mentioned earlier in this chapter, have now been completed (Oliphant, Veale, Macdonald, Carroll, Bullock, et al., 2018). Using Mason Durie's Te Whare Tapa Whā (Durie, 1984) as a health framework, the guidelines provide recommendations and practice advice to support the development of local health services providing gender affirming healthcare. The authors do note that these guidelines provide

additional advice and are not intended to replace the WPATH standards of care (Oliphant, Veale, Macdonald, Carroll, Bullock, et al., 2018).

The recognition of Māori concepts and experiences has been further captured in the information resource "Takatāpui: Part of the Whānau" (Kerekere, 2017). The development of this resource stems from Kerekere's doctoral research on takatāpui identity and well-being. Kerekere (2017) refers to the term takatāpui as embracing all Māori with diverse gender identities and sexualities, noting that within that broad definition, takatāpui has a deeper meaning for those who have claimed it. The guiding tips outlined by Kerekere highlight that being *takatāpui* is based on whakapapa, mana, identity and inclusion and recognising the importance of whānau to the well-being and mental health of takatāpui (Kerekere, 2017). These five domains align well with what are key features of young adult life and health and wellbeing.

Quality standards and guidelines for transgender health care provide a foundation for future service development. Unfortunately, health service delivery, particularly for young transgender people, continue to be somewhat piecemeal, and there remain considerable unmet health needs. Keeping in mind that reforms advocate for better consumer participation in their own care, understanding young transgender people's perceptions and experiences of the health system appears to be an important next step.

# Cisgender versus Transgender Led Research

The decision to embark on this research was largely driven by my frustration and concern that, in terms of easy access and choice to the right health service options, young people, and particularly young transgender people, have been underserved. From my experience in health care settings working with transgender youth and young adults and advocating for services to be at a low or at no cost, I discovered that offering comprehensive support was certainly needed. I observed young people's struggles to access the range of services required but also admired their resilience navigating their transition while trying to seek appropriate support. As a clinician, it seemed obvious to offer support and advocate for better services.

It is, however, important that I address the responsibilities and potential implications of identifying as cisgender and undertaking research with transgender young adults. I also acknowledge that I belong to an older age group, so capturing the perspectives of young adults might also provoke some concern that, without a youthful lens, the meaning of the information might be lost in translation.

Concern has been expressed that there is an over-representation of cisgender researchers investigating transgender identity and experience (Veale, 2017). It is also

important to consider, as a cisgender person, whether the interpretation of the data is likely to be biased or influenced in some way by this (Veale, 2017). Galupo (2017) discusses her experience as a cisgender researcher, noting that as a researcher the intention is to be objective, but acknowledges that she will have biases which may influence her approach. She does add that this should not detract from engaging with trans perspectives but it is important to acknowledge being cisgender and that due care and consideration should be given to how the study is conducted (Galupo, 2017, p. 242). For research focusing on the transgender community, it is important that it ensures a collaborative, non-stigmatising, and consenting approach which accurately and sensitively reflects the stakeholder's perspectives (Adams et al., 2017).

Researchers and clinicians focusing on issues associated with transgender people may claim to be transgender allies, but as Patterson (2018) points out that allyship and cisgender privilege allows researchers or academic institutions to gain profit from "trans spaces, people and perspectives" (Patterson, 2018, p. 147). Cisgender researchers can have a role in supporting a better representation of transgender researchers by offering mentoring (Veale, 2017). Similar points are raised by Fischer (2017), who suggests that researchers should move beyond allyship and consider how their cisgender privilege can be used to gain leverage for the service of those at the focus of the research. Fischer adds that when capturing their voices and experiences of transgender participants, that the researcher acknowledge their intellectual efforts and lists them as co-authors (Fischer, 2018). The researcher, rather than being an ally, can take on the role of a coconspirator, so they actively leverage off any cisgender advantage (Patterson, 2018). The researcher than has the responsibility to demonstrate competence and commitment to improving their knowledge of transgender people, acknowledge and amplify their voices, and ensure any research conducted offers a real benefit back to them (Patterson, 2018).

In reflecting upon these commentaries, I have been prompted to review my motives behind undertaking this research with young trans people, and importantly consider the responsibility that comes with this study. As I reflected on my "why" for the research the initial reason was feeling I needed to do more than just be a passive clinician or healthcare provider when there were obvious gaps in services for the young people I was trying to support. As I have outlined in this chapter, there has been increasing awareness that better and more accessible services are needed, but much of the development to date has been clinician, funder or policymaker informed. The missing informants have been the young adults and even their families. When scoping the gaps currently in youth and young adult healthcare, supporting young people to have a voice and enabling their perspectives to be expressed, giving them a chance to express themselves in the

research seemed to be an important contribution this study could have. I acknowledge the responsibility that accompanies this task, and so I will endeavour to demonstrate how I have kept this in front of mind in the methodology used in this study. The overarching aim in this study is that any findings and conclusions that are drawn be used to the advantage of young transgender people in New Zealand.

"Nothing about us, without us"

Patterson (2018, p. 148)

## Structure of the Thesis

## Chapter 1

This first chapter has provided the overview and rationale for the study. It outlines the current challenges that young adults face in navigating the health system to have their health needs met and highlights how young transgender adults' health needs continue to be underserved. The key reforms which have shifted health priorities will be outlined, as will the developments to date supporting improvements in health care for transgender young adults. This chapter also discusses key issues to consider in undertaking this research and with transgender young adults.

#### Chapter 2

In this chapter, literature is reviewed to identify key issues impacting youth seeking healthcare, with specific articles selected for their relevance to the target age group of adolescence to emerging adults and those who identify as transgender or gender diverse. Gaps in the literature research will also be discussed.

#### Chapter 3

The rationale for utilising a qualitative investigation and constructivist grounded theory approach is outlined. The origins and benefits of this methodology are discussed with further explanations as to the relevance of this approach in addressing the research aims. This chapter will also outline processes used to generate theory.

### Chapter 4

The methods used will be outlined in this chapter and will include the key components of constructivist grounded theory analysis. Examples of the data analysis tools will also be provided. The research process and ethical considerations will also be discussed.

#### Chapter 5

The findings are reported in this chapter with a reflective description of the processes applied to sort, categorise, and apply meaning to the emergent data and uncover theoretical possibilities. The substantive theory will be presented, which offers an understanding of what is important for young transgender people navigating the health system.

#### Chapter 6

In this chapter, the key findings are discussed in the context of transforming knowledge into action. The implications of this research are considered and reviewed against the original intention and the emergence of the substantive theory. The rigour and limitations of this study will also be reviewed, and the relevance of constructivist grounded theory

for enabling the discovery of new information. Learnings in undertaking this research will also be shared.

## Chapter 7

This chapter will draw together the findings in relation to the original research question, summarise and offer reflections with regard to this study. Recommendations for future work will be considered, together with the hope that this research can contribute to reforms within the healthcare system for the benefit of transgender or gender-diverse young adults.

# **Chapter 2 – Literature Review**

In this chapter, I canvass key themes in the literature on transgender and gender-diverse young people. I will, firstly, discuss the role of a literature review in a grounded theory approach and then review the literature as it relates to our understanding of transgender experiences. I will conclude this chapter with a summary of the discrepancies in the research to date and how this thesis can contribute to identified gaps.

# The Grounded Theory Perspective

As this study utilises grounded theory methodology, a key dilemma to consider is when the literature review should be conducted. Typically, most research paradigms begin with a literature review that sets out the context and assumptions of the area under investigation. Grounded theorists align this approach to research as largely deductive, with a focus on testing rather than developing theory (Glaser & Strauss, 1967). Initially, the approach was that the grounded theory researcher should come to the research without preconceived ideas and hypotheses (Glaser & Strauss, 1967). However, this became somewhat of a contested notion as proponents of later iterations of grounded theory accept that researchers cannot be entirely free of bias (Charmaz, 2006; Strauss & Corbin, 1994). As Charmaz (2006) suggests, reviewing the literature can sensitise the researcher's knowledge and understanding of relevant issues and topics.

Keeping in mind that the intention of this study is to discover new information and not simply finding further evidence for existing premises, it could be argued that conducting a comprehensive literature review too early could restrict my openness to conceptualising new meanings from the data. A preliminary literature review, however, is often an expectation of institutional research proposals (EI Hussein et al., 2017), so in embarking upon this study, the literature review has been conducted in two stages. During the first stage, the literature was canvassed to identify developments in transgender healthcare for young adults while identifying potential research gaps. This stage provided the opportunity to scope out the contribution this study could give. During the second stage, the substantive theory generated by this study has guided my search focus for updated literature.

#### Search Strategy

In undertaking this literature review, the initial strategy was to identify key issues impacting youth seeking healthcare, with specific articles selected for their relevance to the target age group of adolescence to emerging adults and those who identify as transgender or gender diverse. The literature was searched using internet search

engines (such as Google) and electronic databases available through the Auckland University of Technology library (specifically EBSCOS CINAHL, Evidence Based Medicine Reviews, PsychINFO), internet-based and publication-based bibliographies and published content from a range of relevant organisations such as the World Professional Association of Transgender Health (WPATH).

Key words associated with transgender identity and health were used in the initial searches: Gender-diverse young people, transgender healthcare, models of care for trans youth and young adults, trans youth health, youth and young adult health needs, gender dysphoria, transgender stigma, gender non-conforming, intersectionality, gender identity, gender transition, transgender health care training, gender identity development, and young adult healthcare barriers, and youth transitions.

Further searches for relevant publications were made using frequently cited by or following further exploration of themes emerging from the reviewed literature. Data was collected, coded keyword searches were revised, allowing a more focussed search during the second stage of reviewing the literature.

#### **Inclusion Criteria**

The literature search included published research articles, reviews, meta-analyses, books and reports published since 2000. Older publications were also included if considered influential. Full-text journal publications were ideally sought, although relevant commentaries were also considered. All publications not in the English language were excluded.

# Understanding Being Transgender

#### **Defining Gender Identification**

Definitions of gender and associated gender descriptions have historically varied. For this study, the following definitions are provided for clarification of terminology and meaning. Health and legal system official records typically require a person's gender to be declared. In addition to binary categories of male or female has, the category of assigned sex at birth has been added to records. This can be further delineated into 'assigned male at birth' or 'assigned female at birth' (Oliphant et al., 2018). Individuals who identify as a gender different to their assigned sex at birth may abbreviate this term to birth gender, as was the case with young people in this study. Consequently, this term has also been included as a descriptor of assigned sex at birth, along with the commonly used terms that describe diverse gender identities.

There is a broad spectrum of labels used to describe diverse gender identities (Bockting, 2008). Some of the common terms used to describe young people of diversity include transgender, trans, gender non-conforming, gender-diverse, gender variant, gender neutral, gender fluid, non-binary, or Male to Female (MTF) and Female to Male (FTM) to indicate transition direction. Descriptors such as gender variant and gender non-conforming are often used interchangeably (Edwards-Leeper et al., 2016). The literature also includes references to lesbian, gay, bisexual and transgender, abbreviated to LGBT. This has been extended to LGBTQI with the addition of Q and I. The letter Q denotes either queer or questioning youth, referring to young people who are not certain of their gender orientation. The letter I refers to individuals born with, or who develop naturally in puberty, biological sex characteristics which are not typically male or female.

In New Zealand, terms used to describe gender-diverse people are also varied. The Youth 2000 series of wellbeing surveys of New Zealand secondary school students described the definition of being transgender as "a girl who feels like she should have been a boy, or a boy who feels like he should have been a girl" (Clark, Lucassen, et al., 2014, p. 94). Kerekere (2017) pointed out that pre-colonial Māori were sexually experimental people who openly accepted gender and sexual fluidity. From her research into historical records, it was discovered that *takatāpui* was a term for all LGBTQI, including non-binary, whom she noted were very much a part of their whanau, rather than outliers (Kerekere, 2017). In the recent report *Counting Ourselves*, the authors elected to use three gender groups; trans men, trans women and non-binary in describing people who are gender-diverse (Veale et al., 2019).

Despite these broad terms providing a starting point for common terminology, it should be noted that there is still variability among transgender individuals and healthcare providers regarding the most accurate definitions and preferred descriptors. It is therefore important that, as researchers and clinicians, we do not assume that one size fits all without considering each young person's unique situation. It is important to be guided by the young person so that respectful inquiries about preferred terms can enable positive and supportive interactions.

#### **Gender Expression**

In New Zealand, there has been a general view that gender expression is binary, and this has been reflected in our national collection of demographic data, including gender (Stats NZ, 2018) and in healthcare data (Ministry of Health, 2019). Stats NZ has confirmed that this will change for the 2023 Census and that gender and sexual identity data will be collected. While this is a move in the right direction, this has highlighted that system changes do not happen quickly. Suggestions for expanding the categories for

demographic information collection in medical records have, in the past, been rejected by medical associations (Cahill & Makadon, 2014). While modifying electronic or patient management systems is complex, there is concern that this resistance may well be influenced by clinicians' attitudes (Broussard et al., 2018). In exploring the influence of attitudes on openness to more inclusive demography, a study by Broussard et al. (2018) canvassed three groups of men and women about their perspectives regarding demographic categories. Two groups were cisgender men and women across sexual orientations, respectively, and the third group were transgender and gendered non-binary individuals across sexual orientations. The study found that cisgender lesbian, gay or bisexual men and women and the transgender and gender non-binary individuals across sexual orientations preferred non-binary formats for gender demographics. The cisgender group with heterosexual orientation preferred binary formats (Broussard et al., 2018). Certainly, these findings suggest conservatism, or it may reflect that cisgender people simply do not have the experience of stepping outside of their familiar binary roles and associated societal traditions.

Considering the growing awareness of gender expression and ensuring equitable recognition for those individuals identifying as transgender, the guiding standards and positions of The World Professional Association for Transgender Health (WPATH) have provided a pragmatic point of reference. WPATH in 2017 released a media statement replacing its 2015 Identity Recognition Statement, which declares "that, for optimal physical and mental health, persons must be able to freely express their gender identity, whether or not that identity conforms to the expectations of others" (World Professional Association for Transgender Health, 2017, p. 1).

The statement recognises that there is a spectrum of gender identities and endorses the right of all people to identity documentation consistent with their gender identity. The intention of the statement is to enable all gender identities to access and enjoy the rights and opportunities equal to those available to others across a spectrum of health, social, educational and vocational domains. Of particular note is WPATH's declared opposition to medical and other barriers to gender recognition that may harm physical and mental health (World Professional Association for Transgender Health, 2017). The importance of position statements and guidelines that uphold the health and wellbeing interests of transgender individuals are crucial to raising awareness and de-marginalising transgender identities.

#### **Prevalence of Transgender Young Adults**

New Zealand currently still has a health system with outdated processes and information that fails to be inclusive in the way it collects data (Cahill & Makadon, 2014; Thompson,

2016). This has hampered the intention of achieving an accurate picture of the extent of health needs of transgender or gender-diverse young people. The challenge of gathering gender identity information has been further compounded by the lack of brief, validated tools with which to identify gender-diverse populations in surveillance systems (Reisner et al., 2015). Advocating for high-quality official gender identity data has consequently become a priority for transgender health research in the United States (Institute of Medicine (US) Board on the Health of Select Populations, 2013). In New Zealand, there has been a national statistical standard set for gender identity data collection (Pega et al., 2017). In reviewing national demographic data collected on primary care (Ministry of Health, 2021), only binary categories have been used, which suggests that the standard has yet to be fully implemented across the healthcare system.

It is clear that the process of capturing gender identity information has presented researchers and healthcare providers with challenges. The one-question method of collecting gender identity information does not account for transgender people who strongly identify along the gender binary as "male" or "female" (Cahill & Makadon, 2014). The Gender Identity in U.S. Surveillance Group, a group of experts focussing on increasing population-based data, recommended the two-question method as the best practice (The GenIUSS Group, 2014). An example is the data collected using the twoquestion method shows an individual's sex assigned at birth and their current gender identity (The GenIUSS Group, 2014). Others contended that the two-step question would increase and normalise transgender visibility in the clinical setting, improving cultural competency and health outcomes (Deutsch & Buchholz, 2015). This would also reduce the risk of stigmatisation impacting transgender individuals' self-esteem negatively (McLemore, 2015). What needs to be considered is whether this position protects the privacy of transgender individuals to be the binary gender they want to be without having to explain that they are transgender. It is, therefore, important that a contextual and qualitative lens be retained when drawing conclusions from evaluative data.

Due to the general acceptance of the lack and accuracy of gender identity data from population and census surveys, there are only estimates of the number of people identifying as transgender. While there is some variation in the estimate's prevalence, it is usually equated to less than 4% of the general population. Due to challenges already noted in routinely collecting information, this figure may well be an underestimation. Reisner and Poteat et al. (2016) estimated that globally between 0.3% to 0.5% of people are transgender. While the proportion of transgender people is small, the health equities transgender individuals face is nonetheless high. Existing studies measuring transgender identity among young people, however, suggest that the percentage of youth that identify as transgender is larger than the global population, between 1.3% and

3.2% (Wilson & Kastanis, 2015). In the local Youth 12 health and wellbeing survey of 8,166 New Zealand secondary school students undertaken in 2012, 1.2% identified as transgender, and 2.5% indicated being undecided with regards to their gender (Clark, Lucassen, et al., 2014). A more recent USA study by Herman et al. (2017) estimated that the number and percentage of transgender youth aged between 13 to 17 years is 0.7% per 150,000. The estimated figure for young adults between the ages of 18 and 24 years identifying as transgender is also 0.7%, which is slightly more than the 0.6% of adults aged 25 to 64 years and the 0.5% of adults aged 65 years or older identifying as transgender (Flores et al., 2016; Herman et al., 2017). While there is a general sense in the literature that the prevalence is increasing, the way data has been collected may well be an underestimation of the actual prevalence of transgender young adults. Due to the low prevalence of transgender individuals, their needs can easily become overshadowed by a focus on population-focussed outcomes. There is no doubt that better processes and tools are needed to ensure transgender and gender-diverse people can be more accurately counted so they are not overlooked, and health issues for them can be examined.

Transgender young adults are a vulnerable group in general. Globally, young adults in the 18 to 24-year-old age range have a higher prevalence of unmet health needs (World Health Organization, 2014). Transgender young adults will also be represented in this group, so without the right services to address their general developmental transition needs, inequities may well be magnified (Lassi et al., 2017). In the Auckland district, more than a quarter of 15 to 24 year olds were found to not be enrolled with a primary health provider (Ministry of Health, 2019). While recent rates have shown slight improvement (Ministry of Health, 2021), it is still likely that a significant number of young adults have not been receiving regular healthcare, so there is a risk that they have unmet health needs (Irurzun-Lopez et al., 2021).

#### Misgendering

The main theme in the literature focusses on transgender people having their gender identity respected and validated, which is as strong a theme as being counted. Within the healthcare sector, identity misclassification, or the experience of not having one's social identity verified by others, has been described as psychologically disruptive (McLemore, 2015). As already highlighted, due to outdated patient management systems using only binary classification systems, misgendering occurs by default. This is also the case with online government databases, as mentioned earlier, which still use the two-gender binary categories for data capture and analysis (Ministry of Health, 2021; Stats NZ, 2018). While misgendering may or may not occur intentionally, it nonetheless

represents non-acceptance or disregard of the transgender individual's preferred gender and the transgender population in general. This is a form of structural stigmatisation, given the impact misgendering has on how transgender and gender-diverse people feel and how they evaluate themselves and their social identity (McLemore, 2015).

The risk of misgendering by health service providers negatively impacts treatments for transgender patients, which reiterates the need for national guidelines to implement training for health practitioners (Jones et al., 2015). It is, however, unlikely that guidelines alone are sufficient to modify practitioner behaviour. Education of Health practitioners should also include sensitivity to the diversity of gender identity and expressions (Reisner et al., 2015). While education raises awareness, it may not be able to shift personal values and beliefs to commit to inclusive practice. The notion of unconscious bias needs to be mitigated with multileveled strategies implemented concurrently to raise awareness of diversity and enable culture change (Marcelin et al., 2019). Examples of strategies targeting organisations and workers include leadership commitment to culture change, meaningful diversity training, self-reflection on personal biases, countering stereotypes, diversifying experiences, providing mentorship, encouraging cultural humility and curiosity, and mitigating implicit bias (Marcelin et al., 2019).

What is evident throughout the literature is that preferred gender acknowledgement is important, suggesting that healthcare providers do need to be guided by the transgender individual. With the growing acceptance of non-binary gender categories, it is important to note that not all non-binary youth identify as transgender and that many transgender people identify as either men or women (Currah et al., 2006). As Clarke (2019) pointed out, a contextual approach to non-binary gender rights avoids the uniform definitions or universal rules and provides more freedom for young people to define their preferred gender position. These studies highlight that until our medical and clinical systems are able to extend their gender classification options and health providers and clinicians receive robust training in transgender healthcare, the likelihood of misgendering having a negative impact is high. The commitment for healthcare providers to show genuine respect for gender diversity will also need to come with a willingness to adopt an attitude of openness and an expectancy of diversity when supporting or providing healthcare.

#### **The Identity Transition**

Traversing adolescence to young adulthood successfully is, in itself, challenging (Munford & Sanders, 2019). The formation of identity is most pronounced in adolescence as young people progress through their teenage years. There is, however, increasing acknowledgement that identity development extends into young adulthood (Wood et al.,

2018). Young people now reside in a world where there is global communication through the internet and social media platforms as a part of their daily lives (Anderson et al., 2017). The internet, social media and online mediums, therefore, provide an accessible opportunity for young people to explore their identity formation and increase their access to health messaging (Villanti et al., 2017). Both online and offline information can have an impact on a young person's identity development, providing an opportunity to access knowledge for those who have not yet disclosed their gender (McInroy & Craig, 2015). These authors highlighted their concern with the inconsistency of online media representations, particularly when they are negative, such as sensationalising or exploiting transgender people (McInroy & Craig, 2015). An example of a negative representation is depicting transgender people comically, as criminals (Shelley, 2008), associated with the sex industry or being mentally unwell (Davis, 2009).

A study assessing the use of online resources exploring gender identity by youth and caregivers found that there was a need for online content to be verified so that it was reliable and trustworthy but nonetheless, it could be a valuable tool (Evans et al., 2017). A virtual world for transgender people, without the boundaries or exposure to discrimination that the real world may impose, can be empowering (Marciano, 2014). Technology can provide online help and a virtual retreat from the complexity of everyday life. However, the digital media environment is not without challenges (Cavalcante, 2016). Online accessible information and resources related to transgender health can also be useful to the general public and health professionals (McInroy & Craig, 2015). As the literature highlights, online resources and opportunities to explore identity provide an accessible option, not only for young transgender people but also for families, the public, and healthcare providers. The caveat is that information needs to be credible, trustworthy and accessible, so safe and reliable cyber-connections are crucial. Locally, the Health Navigator website was established to be a reliable and trustworthy online source of health information and self-care resources (Health Navigator Charitable Trust, 2021). This website now has gender identity-related topics and links to other available resources. There was, however, no available research on the uptake of this local navigational tool by young adults.

For a young transgender person, the formation of identity and gender identity intersects with several life-course domains. These domains include education, vocation, relationships (family and peers), and health status (Wood et al., 2018). A study that interviewed 16 families of cisgender parents and transgender and gender-diverse youth found that their gender development is influenced by the parents' and caregivers' adjustment and support of their child's gender identity transition and the subsequent interactions in their relationship (Katz-Wise et al., 2017). This study provided a

conceptual model of understanding transgender identity development and the intersectional nature of the various aspects of the young person's life (Katz-Wise et al., 2017). Noting the importance of understanding the contextual nature of transgender identity development, these authors highlighted that there would be several factors that may include sociocultural and biological influences, the impact of family adjustment stigma or cisnormativity and the availability of support, resources, and gender affirmation (Katz-Wise et al., 2017).

While these contextual factors may shape identity, gender identity transitions take time and progress through stages to reach the point when the individual is confident in their identity (Devor, 2004). A model proposed by Devor (2004) was an early attempt to understand a likely transition journey for these individuals. I will summarise the key stages of Devor's model. In the initial stages of transition, an individual may experience anxiety, followed by confusion about their gender and sex. Devor explained that the expectation to conform to their assigned sex might result in suppression of any transgender expression until they move to the next stage of identity comparison and begin exploring ways of expressing themselves. The next stage progresses to the discovery of transsexualism or transgenderism, which may result in identity confusion, but prompts information seeking and exploration of a viable gender option. A further stage of identity comparison leads to the next stage of tolerance and acceptance of the identity. The validation of gender identity is then often gained from intimate relationships, which highlights the intersectionality between sexual orientation and gender preference. Devor also suggests that when a transgender person is exposed to others of a similar identity, this reinforces their identity validation and acceptance of their preferred gender identity. It is at this point that the transgender person may decide to move to physical transition or gender reassignment. Devor acknowledges that this may be a lengthy process, if it occurs at all. Transitioning to this stage assumes a binary gender perspective and psychological readiness to leave a way of life behind. The final stages are marked by the acceptance of post-transition and integration into everyday living as a gender (Devor, 2004).

Devor's model may well be an oversimplification of the transgender transition journey and does not account for individuals' unique experiences. Devor noted that the model may not apply to all in the same way. A strength of the model, similar to the model by Katz-Wise et al. (2017), is that it highlights the complexity and intersectionality of the broader context, challenges and stages that a young transgender person will face throughout their journey. Importantly, the framing of impact transition may provide a starting point, shaping the support that could be offered by healthcare and social services.

Klein and her colleagues (2015) point out that linear models that assume the identity transition process follows stages and is finite are restrictive. Utilising a participatory approach, Klein and her team recruited 15 LGBTQ young people aged between 16 and 25 years, providing them with cameras to capture meaningful images and those related to their lives. The findings from the study suggested that coming out was often complicated by various interrelated and contextual factors such as forms of privilege, levels of social support, financial independence, family relationships, and geographical location (Klein et al., 2015). While this study has limitations in terms of empirical validity, what is captured is the complexity of identity transition for the young person themselves. While the linear model described by Devor (2004) can provide health professionals with guidance on the various stages of identity transition, it is important to acknowledge that young transgender people may need support, and it is important for any model to be able to flex with the multifaceted influences.

## The Contextual Factors

#### Stigma, Discrimination and Victimisation

Stigma manifests in negative behaviour, often toward people of minority groups, triggered by societal prejudices and discriminatory attitudes. The stigma is a key factor in adverse mental wellbeing outcomes for transgender individuals (White Hughto et al., 2015). Transgender stigma occurs at multiple levels; individual, interpersonal, and structural (White Hughto et al., 2015). Those subjected to stigma and discrimination have increased vulnerability and are a risk for depression and suicide (De Santis, 2009). Even the anticipation of the stigma can provoke anxiety for a transgender person (Verbeek et al., 2020).

A local, national survey on the health and wellbeing of trans and non-binary people, *Counting Ourselves*, found that 67% of participants (n=1178) had experienced discrimination at some point, of which 29% were young adults (Veale et al., 2019). In another study of 350 self-identified transgender individuals across the youth and adult age range, 41% reported transgender-related discrimination in their experiences across health care, employment, and housing. (Bradford et al., 2013). A high rate of healthcare discrimination was also reported in a study of 1711 Female to Male (FTM) transgender adults (Shires & Jaffee, 2015). Shire and Jaffee concluded that healthcare providers receive little or no training in transgender healthcare and that services lack processes and policies to address transgender care needs.

Vulnerability to victimisation is also significant for young transgender people. Mustanski et al. (2016) examined the effects of cumulative victimisation experienced by LGBTQI

youth. The study gathered information from in-depth interviews with several data collection points across a four-year period of 248 participants with a mean age of 18.7 years, with 54.7% of an ethnic minority. The authors concluded that those youth exposed to moderate and increasing victimisation and those with high steady victimisation were more at risk for depression than young people who experienced low and decreasing victimisation. While the sample size may not provide sufficient confidence for generalised claims, the findings were consistent with the local New Zealand study in which 32% of the trans participants reported being victims of sexual violence (Veale et al., 2019). This study also found those who had been victims were twice as likely to have attempted suicide in the past year (Veale et al., 2019). This does suggest that victimisation can compromise young transgender people's mental wellbeing.

Stigma, discrimination, and victimisation are lifelong challenges that young transgender people endure, which, as the studies outlined above highlight, compromise their mental health (White Hughto et al., 2017; White Hughto et al., 2015). If stigma, discrimination or victimisation occurs in the context of receiving healthcare, it can seriously compromise the healthcare provider-patient relationship and trust. In reviewing the literature, it is clear that transgender people experience high levels of both deliberate and unintended persecution, confirming the vulnerability of young transgender people more so than the general population.

#### Gender Dysphoria

One of the challenges faced by transgender individuals is the poor understanding and inconsistent use of the term gender dysphoria. Gender dysphoria is described as discomfort with one's biological sex and/or the gender role assigned to it (Edwards-Leeper et al., 2016). Gender dysphoria is considered to be a diagnosable condition under the Diagnostic and Statistical Manual of Mental Disorders — DSM-V (American Psychiatric Association, 2013). The term *dysphoria* replaces the previous term, *gender identity disorder*. The aim was to move away from categorising the condition as a disorder and instead describe it as a condition related to a marked difference between the individual's expressed/experienced gender, and the gender others would assign him or her, and it must continue for at least six months. This condition causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (American Psychiatric Association, 2013, p. 1).

While there has been a deliberate move in the most recent edition of the DSM-V to reduce the stigma of dysphoria as a mental health disorder and change how the condition was categorised, it still sits within a diagnostic manual of mental health disorders. This continues to pathologise gender dysphoria as a treatable variant. For those health

professionals who are inexperienced in transgender health, a diagnosis of gender dysphoria results in the perception that the transgender person is suffering from a mental illness, which may make it difficult to reach an agreement on the care needed (dickey, 2017). A comprehensive review of 387 articles referring to gender dysphoria found that despite the stated intention of the DSM-V to encourage the diagnosis of gender dysphoria to be used in relation to identified distress and impairment, the term was inconsistently applied in the reviewed literature (Davy & Toze, 2018). Davy and Toze (2018) suggested the frequent diverse usage of the term gender dysphoria applied to populations who may not meet the criteria potentially undermines any progress to depathologise transgender identities. It is, therefore, important not to make assumptions that all transgender or gender-diverse people will experience gender dysphoria. The key point is that health providers may need to consider whether the term has been used simply to describe gender incongruence and exploration, which may not necessarily be associated with distress and impairment.

#### **Mental Health and Addictions**

Young adulthood is a period when any vulnerability to serious mental health disorders may be first identified (Oakley Browne et al., 2006). A study of young transgender people aged 12-24 years seeking care for dysphoria found that a third of the respondents reported depression symptoms in the clinical range, with more than half having experienced suicide ideation. A third of these young people had made at least one suicide attempt (Olson et al., 2015). In comparison with cisgender youth, transgender youth have a two to three times increased risk of depression, anxiety disorder, suicide ideation, self-harm, and admission to inpatient and outpatient mental health treatment (Reisner et al., 2015). These psychological difficulties can be evident at an early age, with many transgender youths experiencing high rates of verbal harassment, physical abuse, bullying and violence (Clark, Lucassen, et al., 2014; Stieglitz, 2010).

A similar prevalence of mental health concerns among young transgender people was also identified in the national survey conducted by Veale and colleagues (2019), with 71% of trans participants reporting high or very high psychological distress, significantly higher than the 8% rate for the general population, with 56% reporting serious suicide ideation in the last 12 months. Almost two in five participants (37%) had attempted suicide at some point, and 12% had made an attempt in the last 12 months (Veale et al., 2019). While the survey cohort was trans individuals 15 years and older, the incidence is likely representative of the issues facing young adults. A systematic search of the literature conducted by Surace et al. (2021) on young transgender people aged up to 25 years also found a higher prevalence of suicidal ideation and suicide attempts higher

among the transgender group compared to the general population and specifically cisgender youths.

These studies highlight that young people already grappling with adolescence and emerging adulthood face additional challenges that may be associated with their gender identity and sexual orientation. These challenges may stem from estranged family relationships, peer rejection, societal marginalisation or other external influences (McCann & Sharek, 2016). Already, highlighted exposure to prejudice through stigma and discrimination can also have an extremely negative effect on young transgender people (Kelleher, 2009; White Hughto et al., 2017). Any or all of these adverse factors can trigger significant mental health distress for a young person. These studies highlight significant needs. Therapeutic and support strategies for this vulnerable population need to be prioritised (Surace et al., 2021).

## Family Whānau and Social Connectedness

There are various studies which have found supportive family relationships and connectedness are likely to be protective factors for transgender people from poor outcomes (Andrzejewski et al., 2021; Bernal & Coolhart, 2012; McConnell et al., 2016; Tankersley et al., 2021; Westwater et al., 2019). Family support for the young transgender person, in particular, can be a buffer for a range of stressors, including psychological distress, posttraumatic stress disorder, depression, suicide, eating disorders, and a perceived burden from being transgender (Johns et al., 2018; Olson et al., 2016; Puckett et al., 2019; Veale et al., 2017; Watson et al., 2017).

In taking a closer look at these studies, not only can family relationships be a protective factor but the absence of family support or family rejection of young people's gender choices can also have a negative impact on the young person's mental wellbeing. A systematic review of 46 publications about the familial understanding of youth gender diversity was undertaken by Westwater et al. (2019). The study concluded that supportive family systems have a beneficial effect on transgender youth, while a lack of family support tended to result in poorer mental health and adverse outcomes (Westwater et al., 2019). Similar conclusions were reached by other studies taking different research approaches. One study conducted in-depth interviews with 33 young transgender people found that most experienced some form of general parental support, noting that support specific to gender identity was more limited (Andrzejewski et al., 2021). A study surveying 66 transgender youths and the relationship between parental support, quality of life and depression found that "parental support was significantly associated with higher life satisfaction, lower perceived burden, and fewer depressive symptoms" (Simons et al., 2013., p. 3). Another study involved analytic sampling of 232

LGBT youth aged 16–20, comparing developmental trajectories of psychological distress across a period of five and a half years (McConnell et al., 2016). This study found that if a young person experienced family support, this might decrease psychological distress. When there was no family support, then alternative supports could act as a buffer for the young person from distress. If the young person experienced no support at all, the likelihood of increased psychological distress was high (McConnell et al., 2016). This highlights that a lack of familial support, particularly if there are no alternative supports, is likely to increase the risk and vulnerability to external stressors and psychological distress. Rejection, in relation to gender identity, was also likely to increase the risk of distress and mental health concerns (Bradford et al., 2013; Katz-Wise et al., 2016).

There were many findings in the international literature. As indicated earlier in this chapter, in the New Zealand Youth 2012 survey of 8166 school students, 1.2% identified as transgender, with 2.5% unsure of their gender (Clark, Lucassen, et al., 2014). The results of the survey found that the majority of the transgender students reported "that they had at least one parent who cared for them, that school was okay, that they felt safe in their neighbourhood, and that they were not suicidal and did not have significant depressive symptoms" (Clark, Lucassen, et al., 2014, p.96). Despite the presence of these positive factors, Clark, Lucassen, et al. (2014) noted that transgender students and those who were not sure of their gender compared to non-transgender students were at an increased risk of being bullied, having physical fights, experiencing depressive symptoms, and suicide attempts, The results from the Counting Ourselves study also found 57% of participants reported a lot of support within their family/whānau who knew they were trans or non-binary (Veale et al., 2019). This survey found that "if participants had support for their gender from at least half of their family/ whānau, they were almost half as likely (9%) to have attempted suicide in the last 12 months, compared to those who said most of their family/whānau were unsupportive or very unsupportive (17%)" (Veale et al., 2019, p.93).

Parents and families have a key role to play in offsetting the mental health impact of societal harassment and discrimination their children may experience. Specific family support that affirms and allow young people to express their gender identify is likely to be protective against mental health risks (Olson et al., 2016). It was evident, however, that many of the studies used varied research approaches with small samples affecting confidence regarding generalisability (Westwater et al., 2019), so clearly, more research is needed. Despite these limitations, the studies reviewed suggested that family support, in general, is likely to result in better health outcomes. There was also a lack of research on how well families have been included in healthcare responses and service provision.

Promoting parental or family support and acceptance, in particular, are clear areas for consideration in healthcare service delivery (Rafferty et al., 2018). From the available literature experiences of family acceptance or rejection should be routinely canvassed with young transgender people (Katz-Wise et al., 2016).

Support from transgender peers can also moderate the psychological distress experienced (Bockting et al., 2013). Young peoples' resilience can be positively impacted by supportive communities (Puckett et al., 2019). From the local study, *Counting Ourselves*, 56% of participants surveyed felt connected to other trans or non-binary people, with 58% stating that they provided a lot of support for other trans or non-binary people.

For young transgender people, significant, gender-related stresses are an anticipated reality. Adverse impacts can be buffered by social support from family, friends and transgender community connectedness, which results in lower levels of depression and anxiety symptoms and higher levels of resilience (Mizock & Mueser, 2014; Puckett et al., 2019).

#### **The Intersectional Perspective**

The challenges and issues that transgender young adults might face are multifaceted. What is evident from the research is that there are influencing and intersecting factors that converge and create impacts that are common to many transgender young adults. The notion of intersectionality may be worthwhile to consider when attempting to understand the various factors which are impacting young transgender people. The concept of intersectionality, first proposed by Kimberlé Crenshaw (1989), was focussed on the context of violence against women of colour, recognising the interconnectedness of categories such as gender, ethnicity, and politics as overlapping and interdependent systems of discrimination or disadvantage. The nature and collective impact of these intersecting influences resulted in these women experiencing an oppressive system which reinforced inequity and marginalisation. As Atewologun (2018) points out, "intersectionality is a critical framework that provides us with the mindset and language for examining interconnections and interdependencies between social categories and systems" (Atewologun, 2018, p. 1).

Young transgender adults' needs are often related to gender dysphoria or gender transition as the presenting focus. However, there are also intersecting broader issues. A study by Kylan de Vries (2015) captured the relevance of intersectionality in understanding the experience of transgender individuals. This study sought to analyse the multifaceted nature and connectedness across 12 categories: Race, gender,

sexuality, class, nationality, ability, language, religion, culture, ethnicity, body size, and age. This approach made no assumption that individuals share a universal experience, but rather, their experiences needed to be considered according to the contextual factors impacting them. Further to this, de Vries advocated for an intersectional narrative that recognises other domains will be interacting and influencing the person's social identity and experience. Overall, de Vries reminded researchers to acknowledge their own position and allow an opportunity for the transgender individual's voice, which may reflect a continuum of experiences.

The value of applying intersectionality to research is that it allows us to make group-level comparisons while recognising the diversity within groups and other intersecting factors (Atewologun, 2018). In particular, it gives a voice to those who may be experiencing oppression or marginalisation (Byrd, 2014), recognising that these complex stigmatising factors impacting health may not be well understood (Turan et al., 2019). So, while young transgender people may be viewed as a homogenous or specific group because of their gender identity, intersectionality helps us to understand how heterogeneous members of specific groups might experience situations differently depending on various factors such as their ethnicity, sexual orientation, and/or class and other social determinants. If research is to inform and affect change, an intersectional framework can raise awareness of the multiple influences and interrelationships between domains that may be involved (Rodriguez et al., 2016). This research highlights that the current healthcare system, in responding to the needs of young transgender people, will need to recognise the intersecting factors impacting their health. This will require services to be equipped and agile enough to accommodate the complexity and multidimensional nature of transgender health and wellbeing needs.

### The Health Care Environment

Young adults, in general, tend to not seek care for their general health and wellbeing needs until they are experiencing an emotional crisis (McDermott et al., 2013). Fear of the stigma associated with mental health concerns has often been assumed to be a factor in young people's reluctance to seek help. However, there does not appear to be a significant difference between help seeking for mental health or physical health needs or between transgender and cisgender people (Howell & Maguire, 2019).

When young transgender people do decide to seek support for their health and wellbeing needs, trying to access comprehensive healthcare is a common challenge (Aiken, 2016; Roller et al., 2015). The inability to access health care by transgender students compared to non-transgender students was also noted in the nationwide Youth 2012 survey (Clark,

Lucassen, et al., 2014). There are many barriers that young transgender people encounter which contribute to health disparities (Dunbar et al., 2017; Kcomt et al., 2020; Klein et al., 2018; Levine, 2013; Torres et al., 2015). These include uncertainty over accessing services, uncertainty over eligibility, cost, embarrassment, fear of discrimination, and mistrust of health providers (Dunbar et al., 2017). Due to these various barriers, transgender people avoid seeking healthcare, resulting in poor physical health and unmet mental health needs (Kcomt et al., 2020).

The provision of appropriate services and support is crucial to reducing disparities in receiving accessible and equitable healthcare for transgender individuals who represent an underserved, highly stigmatised, and under-resourced population (Reisner, Radix, et al., 2016). To address young transgender people's reluctance to seek healthcare, it is important that healthcare providers offer safe environments. A reluctance to discuss their gender concerns or having a mistrust of the health provider maybe due to the young person anticipating discrimination (Dunbar et al., 2017; McDermott et al., 2013) is very common. Unfortunately, transgender-related discrimination is prevalent in not only healthcare but also in employment and housing (Bradford et al., 2013). Multilevel and multifaceted approaches which address the contextual influences or social determinants are particularly relevant for youth (Bradford et al., 2013; Kcomt et al., 2020).

The necessity of services to be welcoming, safe and supportive environments, combined with having improved processes, are identified in various studies (Bolderston & Ralph, 2016; McClain et al., 2016; Torres et al., 2015) and are an important step in engaging young transgender people. Services need to be flexible, take a holistic approach and enable trans people's involvement in service development (Oliphant, Veale, Macdonald, Carroll, Bullock, et al., 2018). Healthcare services typically focus on treating symptoms of illnesses. Rather than taking a deficits approach and only dealing with presenting risks, a better approach for services is to provide resources that promote resilience in young transgender people to navigate a complex health system (Torres et al., 2015). Incorporating a positive youth development approach also promotes the resilience and healthy development of gender-diverse young people (Clark, Lucassen, et al., 2014), which provides an age-appropriate response to meeting the health and wellbeing needs of transgender or gender-diverse young people.

Increasingly within the literature on transgender health are references to affirming or affirmative models of care. The affirmative model of care has emerged in relation to child and youth gender health predominantly and "is defined as a child's opportunity to live in the gender that feels most real or comfortable to that child and to express that gender

with freedom from restriction, aspersion, or rejection" (Hidalgo et al., 2013, p. 286). An example of an affirming model of care when working with children and youth illustrates how developmental needs of the young person and a family-inclusive approach have been incorporated into the care provided (Edwards-Leeper et al., 2016). The first step is to understand the motivation for a young person's desire to live in a certain gender role. This step also establishes a relationship with families and acknowledges the parent-child dynamics that drive behaviours (Edwards-Leeper et al., 2016). The second step involves how decisions that recommend gender transition should prioritise the child's psychological well-being, including the benefits and risks of not transitioning (Edwards-Leeper et al., 2016). The third step is ensuring that any transition occurs gradually to gauge the child's readiness for transition and in other settings (Edwards-Leeper et al., 2016). While this model is aimed at children and youth, it is worthwhile to consider how this approach may resonate with transgender young adults. As already highlighted, increasing family acceptance is a protective factor and can act as a buffer for the young transgender person, preventing the development of mental health or substance problems (Bernal & Coolhart, 2012; Westwater et al., 2019). Within the affirming model of care, the addition of pubertal-suppressing medication is also a recommended treatment option for transgender adolescents (Coleman et al., 2012), mainly as it provides time for the young person to explore their gender identity. As the effects of this medication are reversible for the gender-diverse adolescent, it can alleviate the added stress and pressure of the usual pubertal changes (Edwards-Leeper et al., 2016). It also can also improve psychosocial functioning and quality of life in young adulthood (deVries et al., 2014).

In New Zealand, the Guidelines for Gender Affirming Healthcare for Gender Diverse and Transgender Children, Young People and Adults in Aotearoa, New Zealand have described an affirmative model of care that "is respectful and affirming of a person's unique sense of gender and provides support to identify and facilitate gender healthcare goals. These goals may include supporting exploration of gender expression, support around social transition, hormone and/or surgical interventions" (Oliphant, Veale, Macdonald, Carroll, Johnson, et al., 2018, p. 4). The guidelines acknowledge that the World Professional Association of Transgender Health standards of care encourages culturally appropriate approaches which are contextually based (Coleman et al., 2012). Consequently, the guidelines have been framed within the Māori model of care, Te Whare Tapa Whā, which integrates four different aspects of health: Taha tinana or physical health, taha hinengaro or psychological wellbeing, taha wairua or spiritual wellbeing, and taha whānau or family wellbeing (Durie, 1994). While Te Whare Tapa Whā supports an integrated and holistic model of care, it does not necessarily account for racism, cultural dominance, oppression, and other factors that young trans people

encounter. Oliphant and colleagues (2018) have, however, made reference to Durie's model for health promotion development, Te Pae Māhutonga (the Southern Cross), and the guiding principles that represent the pointer stars of the constellation, Te Mana Whakahaere and Ngā Manukura (Durie, 1999). The main principle of Te Mana Whakahaere represents people and communities' control and self-determination of their own health, while Ngā Manukura represents community leadership and the importance of health promotion being led by communities (Durie, 1999). There is some obvious relevance to the intersecting influences discussed earlier as it raises the importance of contextual factors impacting the health and wellbeing of transgender people. The challenge is, however, how well these guidelines are translated into service delivery on the ground, considering that young people may well be exposed to discrimination, stigma or victimisation.

In reviewing the literature, there was considerable information and studies identifying transgender health and wellbeing needs and guidelines for promising models of care but there was a lack of examples of fully integrated services where all needs were being met and that specifically catered for youth and young adults. Integrated models of care that provide an affirmative response certainly align well with an intersectional perspective. While there is recognition that more research is needed, it is suggested that services should consider an evidence-based model that is holistic and flexible and is guided by transgender individuals who determine the best outcomes (Riggs et al., 2015). There is concern that services have been shaped by cisgenderism (Riggs et al., 2015) rather than being guided by those who are the service consumers. This highlights the value of intersectional reflexivity to mitigate any associated biases which might be influencing service development but also prompts a consideration that as we review the research, to what extent has it been guided by the young transgender person as the client.

### The Workforce Challenge

Improvements in the healthcare system need to be twofold, with a focus on both the environment and the provider (McClain et al., 2016). There was general acknowledgement throughout the literature that clinicians receive little or no training in transgender health and need better education in transgender care to improve the quality of care (Bolderston & Ralph, 2016; Gamble Blakey & Treharne, 2019; Shires & Jaffee, 2015). The number of professionals competent in transgender health internationally and in New Zealand is generally low (Bernal & Coolhart, 2012; Gamble Blakey & Treharne, 2019; Rafferty et al., 2018).

The interactions between patient and healthcare provider can make the healthcare journey a positive and affirming experience or, conversely, a negative and unhelpful experience. This, in turn, impedes transgender individuals' opportunities and potential access to the resources and services that are needed (White Hughto et al., 2015). A study in the United States found that transgender patients anticipate and expect that the health provider will not know how to meet their needs (Poteat et al., 2013). Without relevant training or experience, the healthcare provider may present with ambivalence and uncertainty, which may compromise the provider-patient relationship, and reinforces inequality and stigma (Poteat et al., 2013). This adds to the recurring theme that unless the healthcare system implements additional practice guidelines and processes, young transgender people will continue to feel marginalised and not valued.

As already noted, transgender individuals will avoid seeking healthcare if they assume that they will be discriminated against or that they will encounter a health professional who is not trained and competent in transgender health care (Bauer et al., 2014). Several studies have demonstrated the discomfort experienced by transgender people when accessing care (Bauer et al., 2015; Costa et al., 2018; Safer et al., 2016; Sallans, 2016; Warner & Mehta, 2021). In a study of 356 transgender patients, of which a third of the cohort were aged between 16 and 24 years, discomfort in discussing transgender health issues with a family physician was a commonly reported barrier to accessing primary care (Bauer et al., 2015). A Brazilian study addressing the health needs and vulnerabilities of transgender and gender-diverse people echoed these findings. In a survey of 626 individuals (average of age 26.4 years), the majority of respondents reported they felt uncomfortable expressing their needs to health professionals, had experienced discrimination, and most felt that they had to teach the professionals about their issues (Costa et al., 2018). Costa and colleagues also highlight how their sample had a level of education higher than the Brazilian average and so individuals with less education may face additional barriers, such as poor access to tertiary healthcare or the internet (Costa et al., 2018).

To reduce disparities, young transgender people should have the right to accessible and competent care. This has resulted in a recurring issue for young transgender people, which is having to educate their doctors or healthcare provider (dickey, 2017; Jones et al., 2015). As dickey (2017) stated, transgender and gender-diverse individuals should not have to be the healthcare providers' primary source of education. Having to educate the healthcare provider is an added stressor for transgender individuals (Shipherd & Sloan, 2019). Healthcare providers, however, who understand the healthcare journey of transgender clients are found to be more likely to provide better care and advocate for

changes in policies to reduce health disparities and improve experiences (Roller et al., 2015).

Healthcare providers need the knowledge and skills to respond to the complex health issues that transgender young adults may be seeking help for. Unfortunately, as already noted, there still is a lack of knowledge among healthcare providers in relation to transgender care (Gamble Blakey & Treharne, 2019; Roberts & Fantz, 2014). An important consideration in improving young people's access and experiences of services is the clinician's competence and confidence to respond to health needs outside of the traditional range of medical presentations. If healthcare providers want to foster engagement with young people, then they need knowledge and skills to achieve this, recognising the need to also engage with whānau or family (Patton et al., 2016). Agencies involving families, partners and schools were valued, as were the positive attitudes of staff considered to affect young people's experience of services (Darbyshire et al., 2006).

### Summary

One of the most prominent messages that was evident from the review is that, while there has been a surge of attention to understanding the needs of transgender youth, the research is still lacking in understanding what is needed to better support transgender and gender-diverse young people (Edwards-Leeper et al., 2016). There is also a lack of empirical or evidence-based research related to interventions (Holt et al., 2021; Sloan & Shipherd, 2021) and a lack of inclusion of transgender and gender-diverse people within and overseeing clinical research (Puckett & Matsuno, 2021). There is a consistent theme throughout the literature that reform is needed before the experience of health care for transgender or gender-diverse young adults improves and better health outcomes arise. While the last decade has seen a growing awareness of transgender and gender-diverse individuals within the community, further development in integrating service approaches, connecting clinical pathways, and building competency in the clinical and non-clinical workforce is still needed.

More research is needed to gauge whether new or existing service models are adequately addressing the myriad of interconnecting influences impacting the health and wellbeing of young transgender people. As highlighted in this chapter, there was a lack of research on effective integrated programmes and how other disparities, such as equitable healthcare for Māori transgender young adults, have been addressed. Further development of current service provisions is clearly needed, which incorporates the voices of transgender young adults in the design and delivery of services. There are multiple stands of influences that impact young transgender people's perceptions and

experiences of the healthcare system, which need to be considered by decision makers and the healthcare workforce.

It is these gaps that have influenced the rationale for undertaking this study. While there are various areas where more research is needed, I believe the starting point needs to be focussed on the young people themselves. The intention of this study is to understand their perceptions of the healthcare system in the context of their own personal gender identity journey. I am hoping this study will help highlight the key considerations relevant to their needs that need to be made in improving our healthcare services. In the following chapter, I will outline the rationale for the methodology and its relevance to the research query.

# **Chapter 3 – The Research Methodology**

In this chapter, I discuss the rationale behind the choice of a qualitative approach and a specifically constructivist grounded theory. I will provide an overview of the philosophical paradigms which underpin this methodology and illustrate the pragmatic nature of this approach and how it explicitly acknowledges the reality of human experience, as well as the lens that I, as the researcher, bring to the study.

### **Quantitative versus Qualitative Approaches**

The preconception that has dominated my outlook on research is that it should be able to be verified. To achieve validated findings, I have typically assumed that credible outcomes are best derived by applying quantitative research paradigms. A closer look at this approach has, however, highlighted limitations. For this study, a qualitative approach seemed to be a more relevant approach. I will briefly outline the limitations of what was once my preferred research approach and my rationale for opting for qualitative methodology in this study.

Quantitative researchers identify the variables of observed phenomena, develop conceptual and operational definitions of those variables and then collect numerical data that can be statistically analysed (Polit & Beck, 2010). While the quantitative approach examines the relationship between influencing factors or variables (Polit & Beck, 2010), the categories for sorting data have often been pre-set and assumptions already made (Tuli, 2010). Researchers usually propose a hypothesis and set out in their research to validate or disprove their assumptions. Social observations are therefore treated as entities similar to physical phenomena (Tuli, 2010). The limitation of applying this paradigm to human experiences is that it does not have the flexibility to accommodate the complexity and dynamic nature of the social world (Jerrim & de Vries, 2017).

The main strength of qualitative methodology is that it enables the researcher to interpret people's experiences in natural settings according to the context and meanings people bring to them (Yilmaz, 2013). The researcher then attempts to establish the meaning of a phenomenon from the views of the participants (Creswell, 2014). In doing so, a qualitative approach allows insight into people's attitudes, beliefs, emotions and experiences to be captured (Tong et al., 2016). Delineating the context or conditions in which the phenomenon happens minimises the risk that the meaning will be misinterpreted (Corbin & Strauss, 2008). Despite my initial view that quantitative research was a more credible and valued approach, it became evident that qualitative methodology was appropriate for the purpose of this study, as it allows participants'

feelings, opinions, and experiences; and interpretations of the meanings of their actions to be discovered (Denzin, 1989).

Having resolved the dilemma of which research approach to follow, the next decision was to identify which qualitative approach would enable my research objective. Qualitative research comprises various theoretical paradigms, methodologies, research strategies and methods, of which grounded theory is one of these paradigms (Yilmaz, 2013). My initial attraction to grounded theory, versus other qualitative methodologies, was its pragmatic approach to identify theory from patterns found in data. What I found particularly interesting about this approach is that it encourages the researcher to remain open to the ideas emerging from data and to avoid having this overshadowed by any preconceived notions (McGhee et al., 2007). Consequently, there is less reliance on a pre-requisite literature search. It had been my experience that research often begins with a review of the existing literature to scope the area of interest, determine what is known, and where the likely gaps are in our knowledge that would benefit from further research. This, in turn, provides the context for the area under investigation. This aligned well with my aim to capture new information and ensure that I was drawing meaning from the perceptions of the participants toward the health system rather than what was already known in the literature.

# An Overview of Grounded Theory

The origins of grounded theory stem back to the 1960s, when two American sociologists and researchers, Barney Glaser and Anselm Strauss, recognised that quantitative approaches were largely deductive and focussed on testing rather than developing theory (Glaser & Strauss, 1967). While collaborating on a study of patients dying in hospitals, Glaser and Strauss proposed that theory could be discovered from data (Glaser & Strauss, 1967). This work introduced a new method of comparative analysis, which involved the ongoing systematic process of collecting, coding and analysing data (Glaser & Strauss, 2015). Throughout this comparative analysis, researchers are tasked with the responsibility to, from their own understandings, give meaning to the data and to separate the pertinent from the not pertinent information (Strauss & Corbin, 1990). This process of collection and coding, with theoretical sampling, deciding which data to collect next, and comparing the emergent categories continues until saturation occurs (Hood, 2007). It is this constant comparative method which allows for the development of a well-integrated theory that is analytically grounded (Strauss & Corbin, 1990); hence, the term grounded theory.

By the 1970s, grounded theory had become an established qualitative methodology; however, Glaser and Strauss diverged in how they conceptualised grounded theory. The

differences were considered to relate largely to their ontological and epistemological perspectives (Bryant, 2017; Tie et al., 2019). Glaser tended towards a post-positivism and critical realism stance, describing grounded theory as a rigorous and systematic way of conceptualising and generating theory (Glaser, 2002, 2010). A strong feature of the this early grounded theory approach was the expectation that the researcher retains an openness to what is discovered from the data, so enters the analysis without being limited by preconceived ideas and hypotheses (Charmaz, 2006; Glaser & Strauss, 1967; Higginbottom & Lauridsen, 2014). Glaser favoured the objective independence between the researcher and the phenomena being observed. He acknowledged that the researcher's experiences could influence their analysis of the data. However, he also argued that objectivity could be maintained, provided potential biases were declared (Glaser, 2010).

Anselm Strauss, together with his research collaborator Juliet Corbin, had taken a more deductive approach, noting that the aim was to generate findings that had substance and contributed to new knowledge while recognising the multiple layers of meaning that were potentially embedded in the data (Corbin & Strauss, 2008; Strauss & Corbin, 1998). Strauss had also adopted a symbolic interactionism lens, introducing a second step in the analysis of axial coding, which enabled connections and interactions between the data to give rise to a category or phenomenon (Strauss & Corbin, 1990). Despite their philosophical differences, both Glaser and Strauss maintained a general agreement that grounded theory generates theory derived from constant comparative analysis and is a generator of conceptual methodology (Corbin & Strauss, 2012; Glaser, 2002, 2016).

# From Classic Grounded Theory to Constructivist Grounded Theory

While Glaser and Strauss followed divergent pathways, other researchers developed their interpretations of grounded theory. Kathy Charmaz described her iteration and constructivist approach as a contemporary revision of Glaser and Strauss's classic grounded theory (Charmaz, 2017b). Glaser and Strauss's original assertion was that theory emerges from data separate from the scientific observer (Glaser & Strauss, 1967). Charmaz (2006) rejects the idea that the researcher has little or no engagement in the data and instead states, "we construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices" (Charmaz, 2006, p. 10).

Although Charmaz's approach to grounded theory embraces elements of postpositivism, she still viewed Glaser's classic grounded theory as not accounting for the wider complexities often apparent in research (Charmaz, 2014). Charmaz argued that researchers make consistent and ongoing interpretations of their ideas, which are grounded in their own "perspective, privilege, positions, interactions and geographical locations" (Charmaz, 2014, p. 240). This perspective certainly aligned with the post-positivism and interpretivism stance held by Corbin and Strauss, who concluded that "to generate new knowledge requires sensitivity to the multilayers of meaning that are embedded in data" (Corbin & Strauss, 2012, p. 18). While Glaser remained wary of interpretivism, he acknowledged the world's complexity recognising that inductive generations of the theory comes from data which embodies the realities and complexities of people's main concerns and substantive areas (Glaser, 2002).

In Charmaz's version of grounded theory, she has sought to acknowledge the complexities of particular world views and actions to generate theory (Charmaz, 2006). Initially adopting a constructionist paradigm, Charmaz (2008) prompts the researcher to consider the whys, whats, and hows; in other words, to understand participants' social constructions. So rather than simply accepting that a theory emerges from data, it is the researcher who constructs categories from the data (Charmaz, 2008, 2014). In developing her version of grounded theory, Charmaz (2014) moved beyond her initial constructionist perspective, noting that peoples' constructions were influenced by their experiences and learnings, hence, introducing the term constructivism. The point she was making is that the researcher's relationship and interpretation of the data cannot be separated from the various influences which might impact their subjective understanding of the data (Charmaz, 2014). The construction of theory is based on the researchers' interpretive understanding of the participants' context and world. Constructivist grounded theory was intended to delineate these differences.

Referring to grounded theory as a cluster of methods for collecting, analysing and managing data (Bryant & Charmaz, 2007; Charmaz, 2014), two main paradigms feature in Charmaz's version of grounded theory, specifically constructivism and interpretivism (Charmaz, 2008, 2014). I will briefly outline the role these paradigms have in the distilling of data into a meaningful understanding of observed phenomena. I will also introduce symbolic interactionism, which features strongly in constructivist grounded theory and discuss how it accounts for the interplay between researcher and participant. Finally, I will also outline how researcher reflexivity provides an opportunity to scrutinise data and balance researcher biases and assumptions with open-minded interpretation during the analysis (Charmaz, 2014).

#### Constructivism

Constructivism is defined as understanding the meanings and actions of how people construct their realities and, from an epistemological perspective, emphasises the

subjective interrelationship between the researcher and participant (Charmaz, 2014). In exploring constructivist grounded theory more closely, it is important to keep in mind its relativist epistemology. As Charmaz readily declares, a revision of grounded theory was necessary as objectivist grounded theory was focussed on a single reality, with the researcher being a neutral and passive observer (Charmaz, 2008). The assumption of a single reality fails to consider the context of the person or participant's real life and the way in which they interact with their world. In leaning toward a constructionist philosophical perspective, knowledge about another person can only be attained by understanding their processes, language, meanings and actions (Charmaz, 2017a).

Charmaz (2008) presents a pragmatic rationale for constructivism, highlighting its strong relationship with social constructionism and relativism. Andrews (2012) does, however, question Charmaz's interchangeable use of constructionism and constructivism. As Andrews (2012) points out, a constructionist's view of knowledge is constructed, not discovered, but recognises connections in reality. As such, Andrews suggests that constructionism sits between the polarised perspectives of realism or single reality and relativism, which describes multiple realities with multiple interpretations (Andrews, 2012). Constructivist grounded theory firmly incorporates relativist epistemology as a point of difference from its objective grounded theory predecessors. Charmaz (2017a) acknowledges that both the participants and the researchers have their own multiple realities, perspectives, and roles. Consequently, there is a need for reflexivity and understanding of the research in the context of the conditions at that time (Charmaz, 2017a).

It has been important to understand Charmaz's general philosophical stance in developing constructivist grounded theory. Her concern that the objective grounded theory did not account for knowledge within a context, or the possibility of multiple realities, certainly makes sense in applying grounded theory to natural settings. It is useful, however, to note the tension between the epistemological stances and consider how this affects my interpretation, as the researcher, of the data. It may well highlight both strengths and limitations of the constructivist grounded theory approach.

A fundamental aim of healthcare is to enable patients to have a positive experience in which their health needs are met. The grounded theory seeks to explore and understand the processes people use to solve or navigate areas of concern or interest for them. What this means in practice is that constructivism allows us to understand how participants in a study construct their respective realities through their stories and also from what they do not say (Charmaz, 2008). In her commentary, Charmaz (2017a) reiterates the four key features of constructivist grounded theory, recommending that the

researcher apply these considerations as part of their methodological approach. These are: Assuming a relativist epistemology; acknowledging the researcher and participants, multiple standpoints, roles, and realities; adopting a reflexive stance and also recognising the interrelationship with research participants; and keeping the research study situated within the historical, social, and situational conditions at the time it is being produced (Charmaz, 2014, 2017a). In my role as the interviewer, my aim was to capture explicit content and other aspects of the participants' experiences, including their tone of voice, their silences, and any other information which provided a platform for exploring emergent understandings (Charmaz, 2008). As the information was collected, the data began to inform a formulation or theory of how the participant had constructed their reality from their experiences, worldview and behaviour. In making a formulation, I was essentially attributing meaning (coding and categorising) to the information and utilising my own insight and capability to try to "sift the wood from the trees" or determine whether the data was pertinent or not (Corbin & Strauss, 2008). This process highlights the interaction between data and theory and, as Charmaz (2008) highlights, validates experience. This approach recognises that my role as the researcher is making sense of another person's experience and, at the same time, acknowledging that my interpretation cannot be fully separated from my own perspective, context, and experiences.

### Interpretivism

The degree to which I, as a researcher, can achieve theoretical understanding is typically attributed to my interpretation of the phenomenon being studied (Charmaz, 2014). Interpretivism implies a reciprocal interaction in which the researcher interprets the participants' meanings, experiences and actions guided by their own beliefs and feelings about their world (Denzin, 1989). What this means is, from the outset, my values, experiences and areas of interest will likely influence my investigative approach and my subsequent interaction with the emergent data. This would likely be reflected in the design of the questions and my interpretation of the responses.

From a constructivist grounded theory, perspective interpretivism acknowledges the subjectivity of the participant and the subjectivity of the researcher (Charmaz, 2014). This is another example of the interplay between the researcher and participant in the construction of what might be multiple realities. From a grounded theory perspective, this interaction is described as symbolic interactionism, which I will discuss in more detail in the next section. As previously highlighted, Glaser's interpretation of theory allows the researcher to transcend from participant descriptions to abstract understandings which do not need to be causal or indicate specific patterns or connections (Glaser, 2002). Corbin and Strauss, on the other hand, believed that the subjectivity of our own

experiences, acknowledging our biases and assumptions, is likely to enhance the analytic process (Corbin & Strauss, 2012). So while interpretivism may result in theories that have been influenced by subjectivity, it can also offer an "imaginative theoretical interpretation that makes sense of the phenomenon" (Charmaz, 2014, p. 231). This means that theorising can extend beyond the individual situation and interactions (Charmaz, 2014).

In reflecting upon how my values, experiences and interests could influence my interpretation, I anticipated there would be both benefits and limitations. In embarking upon this research, it was, in part, to advocate for change, so combined with my experience in working with young adults, which meant I was already sensitised to the likely issues which might emerge from the study. The drawback is that it could potentially restrict my openness to the participants' interpretations yet to be discovered.

### Symbolic Interactionism

As already outlined, a feature of constructivist grounded theory recognises the interaction between the researcher and participant, which helps us understand how data and analysis are social constructions. In Charmaz's discussion of symbolic interactionism in constructive grounded theory, she frequently refers to sociologist and psychologist George Mead's original work during the early 1930s and Herbert Blumer's later interpretations of this perspective (Charmaz, 2014). Charmaz refers to Blumer's premise to explain that meanings are derived through social interactions with others. Charmaz does extend this premise, adding that meaning is interpreted through shared language and communication (Charmaz, 2014). Applying this theoretical perspective to research suggests that understanding and making meaning of the data and the participants' constructions will occur when the interpretation and action are reciprocal processes (Charmaz, 2014). As Charmaz points out, our interpretation of the participants' actions and the data arises from these interactions (Charmaz, 2014).

In exploring the relevance of symbolic interaction for this study, there are several important aspects of this theoretical perspective that Charmaz (2014) describes that resonate with this study. In particular is the notion that language is key in the development of self and that how we construct our sense of self and have agency over ourselves and interact with our world. Subjective meanings will be drawn by both the researcher and the participant based on their own experiences, values or interactions with others or society (Charmaz, 2014). The other aspect of the symbolic interactionism stance notes a difference between the self as a process and the self as an object (Charmaz, 2014). People are continually constructing their realities, and life is seldom static. Their ongoing sense of self is influenced by interactions with the world and so

consists of process and change, aptly captured by Charmaz, who stated that "we receive reflections from the mirrors that others provide us about how we appear" (Charmaz, 2014, p. 266).

### Reflexivity

As highlighted earlier, from a constructivist grounded theory approach, the researcher's interpretation of the participants' context and their world will inform theory development. Charmaz (2014) argues that the researchers' experience and knowledge will influence their subjective understanding of the data. Reflexivity is the action in which researchers recognise and make explicit, to themselves and the audience, their own influence on the research (Gentles et al., 2014). In declaring their interests, positions, and assumptions, the researcher allows themselves to monitor their own actions, decisions and interpretations that they may have made during the course of the data collection and analysis (Charmaz, 2014). Staying reflexive serves to minimise preconceptions and prevent the researcher's own biases from resulting in a temptation to force data into concepts (El Hussein et al., 2017).

### Summary

Qualitative approaches have often been criticised for lacking empirical evidence and rigour. Constructivist grounded theory aligns well with my leaning towards a pragmatic approach that captures and can accommodate the complexity of real-world research. As people, we all construct our social realities and act accordingly. As a researcher, a grounded theory approach provides an opportunity to understand our participants' world and attribute meaning to their constructions.

Constructivist grounded theory generates theory from data systematically obtained and analysed. With constant comparative analysis, meaning is drawn from the data. Importantly, as this approach encourages the researcher to keep an open mind, minimising preconceptions, the discovery of new information which may not have been anticipated is more likely. While my own learnings and biases can influence how, as a researcher, I conceptualise the data, it can potentially enhance the analysis as well. Maintaining a strong awareness of these influences and remaining reflexive will accompany both my data collection and analysis. In the next chapter, I will outline how I used the grounded theory methods and processes, which have enabled the capture and analysis of the data to help develop a substantive theory.

# Chapter 4 – Methods

In this chapter, I introduce my role as the researcher and the lens I bring to this study. I then provide an overview of the principles and ethical considerations guiding this study. Having set the context for this research, I reiterate the aims of the study and outline the method and processes used to recruit participants. I will then outline the method and tools that I used to enable a continuous comparative analysis of the data until I was confident that a grounded theory in response to the original research question had been generated.

## Personal and Professional Perspectives

As I indicated in the opening chapter of this thesis, I had for many years worked with young transgender people and also within the health system. My experience has been that youth and young adults, in general, experience difficulty accessing healthcare designed around their needs. Transgender young adults face not only the same challenges but encounter a healthcare system which may not have the knowledge and skills to respond to their gender identity-related needs and any impact this has had on their health and wellbeing. Having been a clinician advocating for equitable healthcare is a strong reason and motivation behind this research.

When embarking on this study, it was important that I acknowledge how my role as a researcher might impact the participants and their communities. Acknowledging that I was undertaking this study to pursue my own academic journey required continual reflection to ensure that my own personal goals did not overshadow the integrity of the research. From my past experiences in working with young people and in reviewing the literature, young people are vulnerable to being marginalised and their views being overridden. It was particularly important that my research approach was sensitive to the young people's experience of being a participant and sharing their stories in this study

The value of reflexivity throughout the research process cannot be underestimated, as it allows for my potential biases to be acknowledged, enabling my openness to both expected and unexpected themes that may emerge. Throughout the data collection and analysis, I kept a journal of reflections which described some of the challenges in undertaking this study, but also the learnings and my own potential biases or shortfalls in making sense of emergent categories. What these reflections confirmed was that it is not possible to separate the way in which I, as the researcher, was interacting with the data. My interpretation of the data was, no doubt, influenced by my own position and

assumptions and the way I related or represented the participants' perspectives (Charmaz, 2014). In acknowledging my subjective experience and the influence of my personal perspective, I did have to revisit my motive and, albeit aspirational, goals. With my previous experience as a clinician working with young transgender people directly, I had first-hand knowledge of the inadequate or piecemeal provision of services, which are completely lacking in some parts of the country. As a clinician, I have also felt a duty to provide the best healthcare, regardless of funding constraints. Advocating for improvements in the healthcare system became a clinically responsible action to adopt routinely. These previous experiences, however, do have the potential to influence the meanings I may attribute to the data. This can be both positive in that it allows early detection of categories, but it could also inhibit my openness to new or unexpected meanings. Consequently, it has been important to maintain a reflexive stance throughout the analysis.

Another consideration is the impact of being an outsider to the group, being cisgender and not being young. While there are intersectional linkages to the relevance of my research focus, it has been important that I note this and reflect on how I have balanced being an outsider but also an ally. To mitigate this potential bias, it has been important to keep front of mind the overarching aim of my new role as a researcher. Transitioning from clinician to researcher requires a different kind of accountability. As a researcher, my responsibility is to the young people in this study and to capture their information accurately, without prejudice, and translate this into a true representation of their experiences and perspectives. I hope, as I conceptualise and draw meaning from the young people's stories, that my research findings are meaningful to the participants. The advice and guidance provided by the youth advisors have been invaluable for ensuring the goal of the study, and my approach would be appropriate for young adults and those who identify as transgender. In Chapter 6, I will, again, discuss how these potential influences affected the conclusions that were drawn from this study's findings.

### **Research Principles and Ethical Considerations**

Ethics approval was received from the Auckland University of Technology Ethics Committee (AUTEC 18/211) as outlined in Appendix 1. The research was undertaken under the guidance and supervision of Professor Denise Wilson, with secondary supervision from Dr Jeffery Adams.

In keeping with Auckland University of Technology's recommended ethical protocols (National Ethics Advisory Committee, 2019), this study has maintained a commitment to the principles of beneficence, non-maleficence, respect and justice.

As my overarching aim was to support the participants' voices being heard so it could inform improvements in healthcare, I felt the research process needed to also uphold principles relevant to the Aotearoa, New Zealand context and specifically equity. As I had hoped to recruit a cohort of participants with strong Māori representation, I was keen to ensure that my approach aligned with Te Tiriti O Waitangi, recognising obligations and the relationship with Māori as tāngata whenua. Having reviewed the WAI2575 Waitangi Tribunal report on Health Services and Outcomes (Hauora) and the clarification of Te Tiriti O Waitangi's guiding principles as they relate to primary healthcare (Waitangi Tribunal, 2019), I have included them in my approach. Incorporating these recommended Hauora principles into this research, I hoped that young people who identified as Māori in this study would be afforded appropriate and equitable respect. Hudson and Russell (2009) referenced an earlier study (Hudson, 2004) which identified three themes which raise pertinent areas to consider regarding ethical relationships with indigenous communities. These are respect, control and reciprocity (Hudson & Russell, 2009). These themes, combined with principles from Te Tiriti O Waitangi, have provided guidance to my research approach.

While Te Tiriti O Waitangi principles offer guidance to my research approach for Māori, it also has helped provide a perspective on how non-Māori participants of diversity who may face inequity or marginalisation should also be treated in relation to their health needs. I have grouped the ethical considerations under the principles and themes outlined, recognising that all participants of this study would benefit from an equitable approach. This would mitigate any potential imbalance of power between researcher and participant or as a cisgender researcher collecting data from transgender participants.

### Tino rangatiratanga and control

Tino rangatiratanga recognises the importance of Māori sovereignty. This translates to self-determination and mana (personal power and influence). While the importance of self-determination and agency is an important ethical consideration for Māori, I felt it was relevant to guide my interactions with all participants, including non-Māori. In promoting this study, I was conscious of needing to instil a level of trust and openness between the researcher and participant. The integrity of this study relied on all participants reserving control over the level of participation they wanted to have in the study. Through the advertising and data collection, I was committed to full transparency of the research purpose and methodology and making clear the rights they had as participants throughout the data collection process. The participants were asked to consent to participate in the study only when there was a shared understanding of the vision,

purpose, expectations of them and how their information may be used. I also provided reassurance that their participation was voluntary and that their right to withdraw from the study for any reason would be respected. Each participant was advised that, at any point, they reserved the right of complaint and accordingly would have access to complaint processes as part of the Auckland University of Technology oversight.

Informed consent was paramount to the recruiting process, so ensuring interested participants were given time to consider the information provided to make an informed choice as to whether they would like to participate in the study or not. Considering the targeted participant population age group, a time frame of two weeks to review study information material was prioritised. While this allowed time for the information sheets and consent forms to be read, it was hoped that the timeframe was not too long that interest could be lost. Unfortunately, a number of young people who had expressed initial interest and willingness to be interviewed did not make contact again, did not respond to messages, or disengaged due to other commitments.

### **Protection and Respect**

In acknowledging that the information participants may share is a taonga (treasure) in participating in this research, the participant was assured that they retained ownership of their information, that it would be stored securely, and key findings associated with their information would be made available to them once the research study was completed. The privacy of the participants has been preserved by employing unique identifiers (codes) assigned to participants.

To ensure cultural or other diversity needs were respected, the participants were asked whether the information provided and the process outlined sufficiently catered to these needs. As highlighted, participants were recognised as being the owners of their information and had consented to be participants in this study. Consequently, participants were fully informed of the process and were provided with an opportunity to consent without coercion to participate in the study in a safe and non-judgemental setting. As the researcher, I needed to remain sensitive to potential vulnerability without being patronising or making assumptions.

To maintain the participants' privacy, any information that identified the participant, such as names, place names, or organisational names, was removed from the transcripts and quotes. A numerical code was applied to each participant and their transcripts. To preserve the young people's anonymity, actual names or initials have not been used. For the purposes of identifying quotes, random letters were linked with the code to represent fictitious initials, as shown in the findings section.

It was also important that I respected the diversity of all participants in this study and how they wanted to be represented. Misgendering is viewed as a direct dismissal of who they are and want to be. Many of the young people preferred being referenced with the pronoun "they" rather than "he" or "she", so for those young people who identified as nonbinary, the pronoun "they" has been used. It was, therefore, inherent that in my role as the research investigator, I acknowledged and upheld the rights of the participants. To preserve the young people's confidentiality when using their quotes, I also decided against using pseudonyms, opting, as I have already outlined, for fictitious initials only. New name choices associated with their preferred gender identity often had strong meanings for the young people, and I felt it was important to respect this by not ascribing a pseudonym that did not have the same symbolic meaning. The participants were reassured that their contribution and data would be kept confidential and not be used or divulged without permission for any purpose other than that for which it was originally given. Participants were also advised that their data would be transcribed, and the transcriber had signed a confidentiality agreement. The participants were advised that their data may be held securely to be used later in presentations and publications for a period of six years and then would be destroyed.

Should any participant wish to withdraw from the research study, all data collection would be suspended. The participants were advised that a check-in phone call would occur within 24 hours to ascertain whether follow-up support was required and to provide an opportunity for feedback. If required, a further call would be made a week later for a final check-in. Should the young person confirm withdrawal at this point, they were advised that all data relating to them would then be destroyed immediately, except for their consent form and notification of their withdrawal from the project. A note outlining how data was destroyed would also be stored with the other consent forms for this study. For all other remaining participants, all research data would be held for six years and then would be destroyed. During this time, the consent forms would be stored separately from the research data.

### Partnership and Reciprocity

From the outset, I recognised that as this study focussed on young transgender people, it was important that I consult and be guided by the view of young adults. I was able to enlist the time and advice of three young adults who had lived with experience with transgender identity transition and the healthcare system. Two of the young people identified as transgender and had been involved in providing youth and lived experience advice to youth health and social services. The third young person identified as cisgender and was employed as a youth consumer advisor. The recruitment material, participant

information sheet, consent form and interview questions were reviewed by each of the advisors, and amendments were made according to the feedback received.

For this principle, it was important to note the value of respecting the collective rights of the researcher-participant relationship. To achieve this, my intention was to provide a transparent description of the research process, the rationale for the study and the parameters of data collection while respecting that the participant would bring their own perspectives, culture, values or norms to the process. My aim was to promote an atmosphere of safe and open communication, providing a safe space for the participant to share their experiences.

Regarding reciprocity, it was important to also indicate from the outset that no direct benefits for the participants were being promoted. The study's participant information sheet (refer to Appendix 2) indicated that taking part in the research was an opportunity for the young person to share their perceptions, thoughts and experiences navigating the health care system, which could contribute to aiding decision-makers, service managers and clinicians. Any potential benefits, however, would not necessarily be imminent but rather become apparent across the medium to longer term. As a result of their contribution to the overall findings, however, they may benefit indirectly from improved healthcare service provision.

I acknowledged their contribution and willingness to share their stories. In keeping with the values of reciprocity, a small koha (gift voucher) was provided at the completion of the interview. The koha was offered not as an incentive but rather as a token of appreciation for the time they had made available to participate.

# Participant Recruitment

Ten young people were recruited for this study who met the following eligibility criteria:

- Aged between 18 and 24 years, and
- Identified as transgender or gender-diverse

The study was advertised via posters and flyers (see Appendix 1) displayed at services that worked with transgender and gender-diverse young adults. These recruitment activities invited those who were interested or willing to participate and met the inclusion criteria to either email, text or message their contact details (email address and phone number) to an email address dedicated solely to this study or to my mobile number. I also provided a brief presentation, either by phone or in person, about the study to services supporting young transgender people by arrangement. All expressions of interest were acknowledged promptly, with information about the study (see Appendix 2

- Participant Information Sheet). Once the potential participants were fully informed about the study and were satisfied that any queries they had were answered, then consent was sought (see Appendix 3 - Consent to Participate). The information sheet for the study made it clear that it was the potential participant's choice to take part in the study and emphasised that their participation was purely voluntary, and they could withdraw from the study at any time.

### **Exclusion Criteria**

The only criterion for exclusion from the study was set as "Currently experiencing acute or high-risk mental health concerns". While the study and interview process was not expected to place the participants in a stressful situation, it was important to acknowledge that the recall of experiences may prompt distress. All participants were advised prior to the interview commencing that at any time in sharing their story, should they become distressed, the interview would be stopped to check whether the participant was okay to continue or required a break from the interview. Participants were also reassured that if they decided to discontinue the interview, their choice would be respected. If this did occur, all participants were advised that they would be contacted the following day and again a week later to ensure they were okay and whether they had any feedback. If necessary, the research protocols indicated that the researcher would facilitate a referral to the Auckland University of Technology counselling service.

None of the participants who were interviewed opted to discontinue at any point or required follow-up support. Feedback was sought from each person at the completion of the interviews to gauge how the interview process had been for them. A summary of this feedback will be provided in the next chapter.

### **Equity Focus**

Due to the recognition of inequities in our healthcare system, particularly for Māori and Pacific young people, a priority selection criterion was initially established to ensure the representation of Māori and Pacific young people across the specified age range. Recruitment, however, proved to be far more challenging than anticipated. While expressions of interest were received from 19 young people, there was a noticeable drop in this interest following the two-week period between initial engagement and follow-up contact. It was particularly evident that those who did not engage again were predominantly Māori and Pacific people. Most of the young people who did not make contact again reasons for not engaging were unknown. Of the young people who were contacted, one young person deferred scheduling times, citing other commitments, or they were busy with moving locations; or too much study; and one young person had

ambivalence about participating in a research study. The presentations given to groups increased interest, with some young people willing to be interviewed immediately. This was particularly evident in candidates who were not students. What it did highlight is that, for young people, there was a relatively small window of readiness to participate in a study. Despite their initial enthusiasm, when given the option to make contact later, participation in a research study was not necessarily a priority, and the window of opportunity was unfortunately lost.

There are varying perspectives on what an ideal sample size should be in qualitative or ground theory research. Some suggest that there are no rules (Patton, 2015). Charmaz (2008) noted that the size of the sample is dependent on the research purpose and the number of interviews needed to develop new categories and what she described as a "credible analysis" (Charmaz, 2008, p. 107). The more heterogeneous the sample, the greater the risk of poor data quality, which may need to be mitigated with an increase in interviews, while a more homogeneous sample with common themes and experiences may be adequate (Guest et al., 2006). These authors suggested that in this case, a sample size of eight to 12 interviews may be sufficient. Charmaz (2014) appeared less supportive of smaller cohort groups, commenting that while themes may be generated, the research may not command respect.

My aim was to collect sufficient data to enable saturation, a strong feature of grounded theory (Charmaz, 2014). This allows the collection of data to be undertaken in a stepped approach, analysing and comparing, followed by more data gathering until such a time that a category reaches saturation (Corbin & Strauss, 2008). Saturation is achieved when there is no new data that generates further categories (Glaser & Strauss, 1967) or there are no new properties occurring in the data (Charmaz, 2014). Despite the position taken by grounded theory proponents', not all qualitative research relies on saturation (Braun & Clarke, 2021) but rather that data collection stops when the researcher has acquired a sufficient depth of understanding to build a theory (Dey, 1993). During the analysis, these two processes almost ran parallel. As I reached a point where there were no further categories emerging, this also coincided with my own confidence that I was reaching a level of understanding where the conceptual meanings emerging from the data were substantive.

# The Research Question and Aims

For this study, the key question used to guide the research was: "What are the processes that young gender-diverse adults use to navigate the health system?"

In taking part in the research, young people were provided with an opportunity to voice their perspectives and share their perceptions of healthcare, reflecting on their own gender transition. The aims of this study were to:

- Ascertain the perceptions and interpretations transgender young adults have of the current healthcare system and how that influences their help-seeking behaviours.
- 2. Identify the relationship between the young people discovering their gender identity and their interactions with healthcare services.
- 3. Generate a consumer-informed substantive grounded theory.

### **Data Collection**

### The Participant Sample

Due to challenges in recruitment, the participant sample was eventually drawn from the following regions: Auckland, Waikato, Wellington, and Christchurch. All young people identified as New Zealand European, with two young people also acknowledging their Māori identity. As illustrated in Table 1, the participants ranged in age between 18 and 24.

**Table 1: Participant Age and Gender Identity** 

Participant	Age	Gender Identity
1	24	Male Trans
2	18	Non-binary Trans
3	19	Non-Binary Trans
4	19	Male Trans
5	21	Male Trans
6	24	Gender fluid
7	23	Female Trans
8	19	Non-Binary Trans
9	20	Female Trans
10	19	Non-Binary Trans

#### The Interview Process

It was important that both the recruiting and interview processes provided a safe and supportive setting. The goal was to ensure that the participant felt comfortable, providing an opportunity for the participant to feel able to talk about their experiences and perspectives without judgement of their gender, culture, employment or financial status, or any other issue that might have impacted them.

The principles already outlined earlier in this chapter guided my approach in engaging with the participants prior to the interview. Ensuring the participants were fully informed about the study and what was involved and reassurances that participation remained a choice at all stages of the data collection process were well-received by the young people. To aid initial engagement, the writer, in introducing the purpose of the study, disclosed that she had previously worked in health services and recognised the challenges transgender young people face accessing healthcare. In seeking a focus for her doctoral research, the writer explained to the participants that the voice of young transgender people seemed to be missing in research and healthcare service development. The writer conveyed that this had been a motivating factor in undertaking a study aiming to understand the processes transgender young adults use to navigate the healthcare system. From the outset, the writer declared her own gender orientation as cisqender, providing an opportunity for the participants to decide whether they were comfortable with proceeding. The participants were then invited to nominate where they would prefer to be interviewed to ensure ease of access and a setting that was familiar but allowed for a confidential discussion. The offer of information and a possible choice of interview setting provided an opportunity for initial engagement and for the young people to be active participants in the research process prior to the interview. The interview process was conveyed and subsequently conducted as a facilitated conversation with check-ins prior to the interview and again at the conclusion of the interview to gauge participants' comfort with the researcher's approach. The overarching intention of the data collection process was to ensure it provided an affirming context for young people to share their stories. This appeared to contribute to the building of rapport between the researcher and participant.

Each participant was interviewed individually, with interviews lasting between one and one and half hours. As already highlighted, the interview was conversational in approach, using key open-ended questions to elicit the participants' responses. A range of probe questions was used to explore or capture more fully each participant's perspective (see Appendix 4). All interviews were audio-recorded, to be subsequently transcribed by a university-recommended transcriber. A confidentiality agreement (see Appendix 5) was signed to ensure the required privacy of participant information. The transcripts were available to participants upon request if they wanted to verify that the transcript was an accurate representation of their perspectives and views. All transcripts were read and checked with the audio for accuracy. Only one participant requested their transcript. The

transcript was emailed to the participant with a request that if they did not consider it an accurate representation of their story, they could return an amended transcript. No amendments were received.

# **Data Analysis**

In this section, I will provide an overview of the comparative analysis that was undertaken and the constructive grounded theory tools used to interrogate, sort and analyse the transcript data. The tools that were used in this analysis were coding, concept mapping, category formation, theoretical sampling, and memo-writing. I will outline how these tools were applied to understand the participants' meanings, actions and processes, providing examples of this analysis. An illustration of steps in the analysis process is outlined in Figure 1. As this figure highlights, there is an interactive process between data collection and the first step of coding. Coding allows the data to be grouped into categories that can be constantly compared and prompt conceptualisation. This step is concept mapping and category development. It is the step in the analysis in which, as the researcher, I am making sense of and attributing meaning to the data groupings while extracting and generating concepts. At the point that new properties and categories are emerging is the point that theoretic saturation has been reached, and the substantive theory can be finalised.

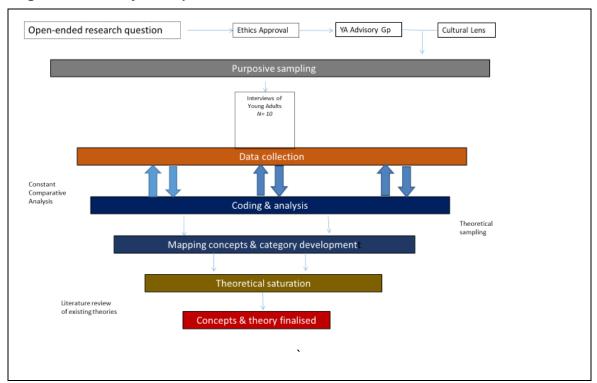


Figure 1: The Analysis Steps

### **Coding and Concept and Category Formation**

In this study, rich data was gathered from participants that required sorting, separating and evaluating. The coding of statements, actions, events and documents (Charmaz, 2006) is the first step. Coding does not just sort or summarise data; it chunks the data into components identifying actions and processes (Charmaz, 2014). Coding begins with initial codes and then by drawing on participants' own language, which can be sorted into in-vivo codes. With further analysis, this can be narrowed down into focussed codes which allows the mapping of concepts in which categories emerge. Coding is done according to a unit. Possible units can be line by line, paragraph by paragraph or story by story, or event by event. The choice of the unit depends on how it will fit the purpose of the research. Charmaz (2006) puts forward a pragmatic reason for beginning analysis with a line-by-line unit approach. The breaking-down of the data in this manner can reveal new information and allows data that may have been overshadowed by other elements to be seen. The line-by-line units also work well with interviews (Charmaz, 2014).

The stories shared by the participants in this study provided rich data. Verbatim transcripts were reviewed, with the data initially coded according to common themes. For this analysis, I used a line-by-line approach to identify initial codes. This allowed each participant's story to unfold in the transcripts, which articulated their experience and perception of their personal journey toward validating their gender and identity and, subsequently, their encounter with the healthcare system. The participants' own words and phrases were used to form "in-vivo" codes, which were further analysed with reference to guiding questions sourced from Charmaz (2014), as outlined in Table 1.

#### **Table 2: Transforming Data to Codes**

- 1. What processes are occurring, and how can they be defined?
- 2. How does the process develop?
- 3. How does the participant act while involved in this process?
- 4. What does the participant profess to think and feel while involved in this process?
- 5. What might their observed behaviour indicate?
- 6. When, why and how does this process change?
- 7. What are the consequences of the process?

Source: Charmaz (2014, p. 127)

Analysing the data utilising in-vivo codes provided a useful starting point to make sure that each participant's speech, intonation, and associated feelings and experiences were captured. The value of this was to minimise the participant's meanings being lost in translation and analysis. In effect, it anchored the participant's position, which then allowed further analysis of the processes that might be occurring. Charmaz (2014) describes this process as interrogating the data. An example of the coding process is illustrated in Table 2. The initial coding process highlighted the frustration and dissatisfaction young people were experiencing in relation to the healthcare they received.

**Table 3: Open Coding Example** 

Initial Narrative Data to be Coded	In-Vivo Coding	Focussed Coding
Ref # 18005 – Interview Excerpt Encounters with health professionals. How do you find that?  I find it very annoying sometimes because I don't think I, as the patient, should have to educate you on basic trans healthcare. I don't think I should have to explain that even if I take out like, I'm having problems with my uterus and it's like I don't think I have to educate you about if I do this option, I'm still going to have to do this option like two years from now kind of thing. I don't think I should. You should have some vague idea, you should have some if you're going to deal with trans, you need to, you need to know how their bodies basically work, and you need to know some form of how they, how their reproductive systems work on hormones. A lot of, a lot of people understand bodies, but they don't understand the reproductive systems, and I'm sitting there, in like a 15-minute appointment, which turns into a half an hour. By the time I'm done explaining to them, well yes, I can do this option, but it's not a good long-term option because this is still going to happen.  And they look at me blankly, and I have to explain it to them.	Feeling Annoyed  As the patient, I shouldn't be educating the clinician If you are going to deal with trans, you need to know the physical aspects, particularly regarding trans reproductive health  Health professionals are not informed  Feelings of frustration  Lack of knowledge of trans health care likely to be an ongoing problem  Focus of the consultation is providing information rather than receiving information	Service dissatisfaction  The patient is the clinical educator  Trans health not validated  Under-trained health workforce  Mistrust of healthcare Lack of faith in the health care system  Lack of engagement with health care services Required level of care not accessible

### **Codes to Concepts and Categories**

The discovery of theory comes about as concepts are compared and refined. In this study, it is important that conceptualisations are a meaningful interpretation of the participants' perspectives. The value of a grounded theory is that you can keep returning to the data, repeating the comparative analysis until the codes or categories that were initially applied are empirically robust enough to inform a theoretical perspective. This process also enabled the identification of other new categories that invite more analysis.

The use of constant comparative methods allows comparisons of the data to be made at each level of the analysis (Glaser & Strauss, 1967). From the emerging codes, concepts and categories, I was able to follow Charmaz's suggestion to identify similarities and differences in the data and sequentially across interviews (Charmaz, 2006, 2014). Applying the guiding queries (Table 1) to the in-vivo codes drew out patterns in the data, enabling more focussed coding to occur. Comparing the data across the interviews combined with theoretical sampling from the literature helped increase the coding focus. This required ongoing sorting, which also provided an opportunity for conceptualising the

data from a sociological construct perspective. Throughout this constant two-way processing of data through analysis, coding, then rechecking the data, and making comparisons eventually generated identifiable concepts and their associated properties. These initial concepts are outlined in Table 3.

Table 4: Example of In-vivo Codes and Sociological Constructs

In vivo Codes	Sociological Constructs	
Categories:	Categories:	
Validation sought	Engaging with health services	
Navigating the health system	Establishing trust in health providers	
Concepts:	Concepts:	
Inconsistent health care	Self-reliance	
Variability of competent clinicians	Self-management of own health needs	
Experience of dissatisfaction	Accessibility to the right health services	
Access to informed health care	Patient's health care experience matters	
Properties:	Properties:	
Influence and authenticity of trans identity and	Influence and authenticity of trans identity and	
gender validation.	gender validation.	

In constructivist grounded theory, the initial coding attributes meaning to the data, which guides further data-gathering, which through a constant comparative analysis consolidates the identification of prominent categories or theoretical codes. Outlined in Table 4 is an example of how the various initial codes drawn from the data and constantly compared provided clarity of the predominant categories and their associated properties. This then informed my construction of a theoretical concept.

**Table 5: Condensing Codes from Data into Properties and Categories** 

Level One Codes	Level Two Properties	Level 3 Concepts
20101 0110 00000	- Love Two Tropolities	
Identity exploration Naming confirms identity Name change is a passage of rite during transition Confirmation of identity important Reinforced by appropriate gendering by others Use of preferred pronouns and name Formal recognition by agencies Resentment that had to prove self Frustration, anger and doubt Feeling different Being trans becomes a mental health issue, Not well understood, having to prove self Dysphoria associated with anxiety and depression Vulnerability to victimisation Feelings of alienation Doubt self initially	PROPERTY: IDENTITY VALIDATION  Confidence in transition Acceptance of self Appropriate gender referencing  PROPERTY: GENDER AUTHENTICITY Self-efficacy Overcome self-doubt Assert gender identity Listen to own feelings	Identity Validation  Gender Authenticity
Mostly no engagement until late teens with healthcare or School based or Youth Health Service were helpful GP's unaware of Trans needs Child and Adolescent Mental Health Services don't check gender issues Not be overtly expressing gender preference – by dysphoria present GP unaware trans needs Not given health care options Health clinicians should initiate discussions	CARE ENGAGEMENT  Transgender health needs validated Clinicians need training General identity important	
Navigation of Health care and support is not	PROPERTY: ACCESSIBLE HEALTH CARE	PROPERTIES
easy Someone who knows the system (health and social support Finding services precipitated by a helpful adult e.g. teacher	Clear health care pathways needed Better coordination of services needed	Health Care Engagement
Incidental interaction with peers who are trans helps navigation Health and support providers uncoordinated and uninformed Usually started with online search of the area Not easy to navigate Unclear what the options are Pathway not straight forward Publicly funded services not available so limits	Advocacy and peer support are helpful	Accessible Health Care
access to the right service.  Multiple barriers create distress  Lengthy wait-times  Reluctant to Engage with Health Providers -	PROPERTY: SAFE, TRUSTED HEALTH CARE PROVIDERS Better coordination of services needed	
GP's lacking knowledge GP Practice could be health care home if GP's trained Trans specific counselling support hard to access – not funded Stigma associated with counselling Lack of specialists with transgender training Service user is the educator Lack of safe, informed and confidential services needed	Trained healthcare workforce Service user perspective should inform type of services Safe services important	Safe, Trusted Health Care Providers

### **Theoretical Sampling**

As I coded and categorised the transcript data, I was both attributing meaning to the information and also increasing my understanding of how each participant had constructed their reality from their experiences, worldview and behaviour. This comparative analysis allowed me to sift through the data and provided a springboard, in my role as the researcher, to progressively attribute meaning to the emerging concepts.

The intention of this study was to generate a theory from the young people's stories in relation to their gender identity transition and interactions with the healthcare system. Charmaz and Thornberg (2021), who refer to Charmaz's earlier work, describe theory as the relationship between abstract concepts that try to provide an explanation of the researcher's interactions with the participants and an understanding of the participants' voices. As I interacted with each of the young people and captured their stories, I began generating various concepts to gain an understanding of their perspectives. Utilising the strategy of theoretical sampling (Charmaz, 2014), the initial analysis resulted in several emergent categories. As I collected additional data, I was able to expand and refine the categories and uncover the main theoretical constructs. Excerpts and participant quotes are used to illustrate and ground the substantive explanatory theory which emerged from the findings.

Theoretical sampling in grounded theory, in some respects, provided the balancing mechanism between my initial coding of the data and the consolidation of the meanings emerging from the data. This tool allows the researcher to take a set of categories already identified and seek out information either to highlight or further identify the parameters of the category and its relevance. This substantiates the category by providing an endorsement for the emerging theoretical concepts (Charmaz, 2014). The constant comparative analysis, as illustrated previously in Figure 1, highlights the distillation process in which data is analysed and moves through various steps to reach theoretical saturation.

As a researcher, the cyclic and constant reviewing of the data in detail, coding, developing categories and returning to the transcripts to compare reinforced my increasing confidence in the emerging categories. Having immersed myself in the data and to avoid prematurely reaching my own saturation point, I began to experience the value of applying data generation techniques to the rich data that was coming from the participants. The techniques used included open coding, memo writing, clustering, substantive coding and theory construction.

### **Memo Writing**

One of the most helpful analytic tools in grounded theory is the use of memos as an aid in working through and chunking down data. Memo writing allows the researcher to stop and write ideas, make comparisons or reflect in relation to the coding of data and emerging categories (Charmaz, 2014). The memos accumulate during the analysis of data to allow ideas to be refined with each successive memo and insights to be gained. Memos can also be gathered in a reflective journal which provides a useful mechanism for the grounded theory researcher to engage in reflexivity so the influence of preconceived ideas, biases and assumptions can be minimised.

Memos were made throughout the analysis and were in addition to a reflective journal kept which highlighted methodological challenges, learnings and insights. I found it most useful to create a memo when I noted reoccurring references to similar concepts and associated properties apparent in the interviews. My thinking was further consolidated by some of the literature I had read, which provided some clarity on how to make sense of the data being captured. During the comparative analysis, the initial memos acted like building blocks to help me make connections between the narrative, associated ideas, and the emerging codes. Rewriting memos and visually mapping each memo recorded concepts with further confirmed linkages, as the example in Table 6 of a memo relating to Seeking Self-Acceptance illustrates.

Table 6: Example of a Memo

#### EXCERPT OF MEMO (14/9/19): Seeking Self-Acceptance

The importance of self-acceptance was a recurring theme across participants (01, 02, 03, 04, 05, 06, 07), underpinning their reach for identity and self-discovery. The self-discovery appears to have been precipitated by experiences of being caught in a gender dilemma, often becoming more pronounced in adolescence. This has often been followed by a childhood of unconscious alignment to their preferred gender, which for some (01, 02, 05, 06, 07) provoked feelings of loneliness and being lost (04, 06, 07), while for others, it caused a rejection of their birth gender (01, 03, 05, 08).

The awareness of gender dysmorphia heightened a sense of being displaced, often through their teenage years. The need for acceptance seems to have intensified their feelings of anxiety and low mood, with intermittent episodes of fear of being different and rejected. For most young people, the journey of self-discovery was hampered by a lack of informed services, either for themselves or their parents, with limited availability of transgender-specific healthcare and support. Self-acceptance for many was not realised until they were able to source affirmative healthcare (including counselling) support.

The collection of memos aids conceptualisation and helps support the identification of codes. As codes begin to emerge, the comparative analysis highlights any potential linkages between the various codes. Memo-writing helps with the interpretation of what processes are likely occurring and what the connections between the various properties are. Collating categories and codes into clusters provided a platform for illustrating the relationships between categories.

The category of *Gender Dilemma* became prominent with comparative analysis and in delving into the processes, then linked into *Discovering Identity*, which further led to *Gender Validation*. As illustrated in Figure 2, clustering allowed the identification of what Charmaz (2014) refers to as *essentials* bringing forward the more pronounced categories.

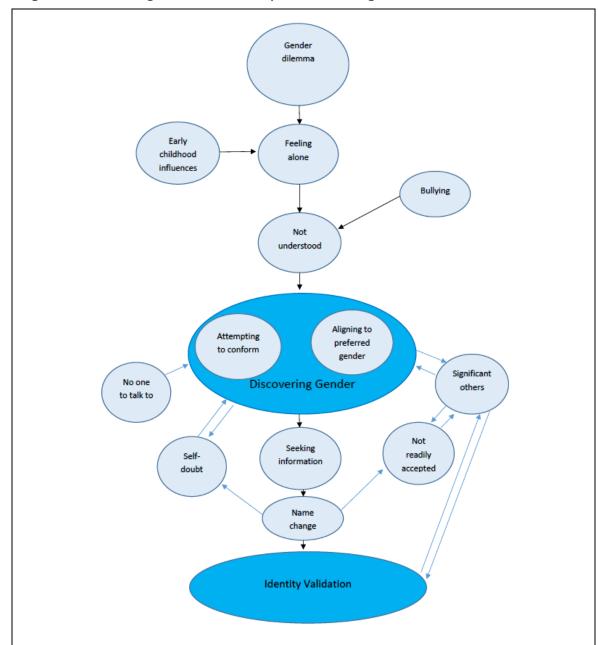


Figure 2 Discovering Gender- An Example of Clustering

### **Theory Construction**

The subsequent validation of the theory occurs with the integration of the coding and categorising, which has been achieved through the various methods already highlighted, such as memos, diagrams or through writing storylines that can then be analysed further to reach theoretical saturation (Corbin & Strauss, 2012). Charmaz (2014) refers to substantive coding as "the theoretical interpretation or explanation of a delimited problem" (Charmaz, 2014, p. 344)

The substantive area being researched in this study is the perceptions of transgender and gender-diverse young people navigating the health system. In analysing the data and applying codes then resorting into categories, it became apparent that there were various processes influencing how young people interacted with services, how they perceived services, and what they expected from the healthcare system. In identifying codes and categories, the data groupings and clusters identified connections, conceptual relationships and shared properties. Strongly underpinning young people's perceptions were social and psychological processes, specifically *seeking self-acceptance*, and *identity validation*, which were strongly linked to engagement and trust in healthcare. There were obvious gaps in healthcare service provision for transgender and gender-diverse young people. This was clearly notable to the point of saturation.

So, in establishing a theoretical perspective, as the researcher, I had to ask the following questions: Is there any more that can be added to the conceptualisations? Are there any gaps in the logic? Are any new properties emerging? Have I reached a point of saturation? As I cast my eyes across the last sheets of paper with core categories colour-coded for grouping with a myriad of properties listed on post-it notes scanning for connections, linkages, and emergent concepts, it became evident that a saturation point had been reached. Reviewing the data, I also repeatedly sought to understand whether I had gained a sufficient theoretical interpretation of why participants construct meaning and actions in specific situations. Once I had exhausted all linkages, and there were no more new data and concepts, I was confident that I had arrived at a substantive theory which will be detailed in the next chapter.

# Methodological Rigour

To instil confidence in this study, it was important that the methodological approach I used was trustworthy and demonstrated rigour. There is a belief among some researchers that qualitative research is disorganised and non-methodological (Charmaz, 2008). Grounded theory counters this criticism with its rigour and is considered to be one of the most recognised approaches in qualitative research (Birks & Mills, 2012;

Higginbottom & Lauridsen, 2014). The benefit of the grounded theory approach is that it utilises a qualitative research paradigm which is considered to have sufficient rigour to provide a robust framework for data collection (Charmaz, 2014; Glaser & Strauss, 1967). Constructive grounded theories continue to uphold this rigour with its cyclical method of data collection, coding, categorisation, and theoretical sampling to derive a theory to respond to the initial research question. Instead of being disorganised, grounded theory utilises an approach that is systematic, replicable and rigorous, amalgamating data collection and analysis into a collective task which then encourages theory development (Charmaz, 2006, 2008).

To review whether my study was demonstrating sufficient methodological rigour, I utilised the *Criteria for Grounded Theory Studies* adapted from Charmaz (2014). There are four key domains of rigour. These are credibility, originality, resonance and usability (see Appendix 7 for the matrix overview). Outlined below is an overview of how I evaluated the rigour of my research.

A key question I needed to consider was whether the data was sufficient to give confidence to my substantive theory. I had initially hoped to recruit Māori and Pacific representatives to my sample, but the response was lower than hoped, so I have not sought to make claims specific to Māori. The sample was relatively homogeneous in terms of gender identity, being transgender and within the young adult age range, which allowed for a smaller sample to be acceptable. While the observations were limited to single interviews, the depth of data gathered provided full accounts of participants' experiences. Being able to make systematic comparisons between observations and between categories is also considered to add to the credibility of the study. Due to recruitment challenges, the participant interviews were staggered over an eight-month period. This did allow the data to be constantly compared throughout the data collection process. This was followed by a repeated review of data throughout the analysis stage to check the strength of the emergent categories. Checking for strong logical links between the gathered data, my argument, and analysis also add to the credibility of the study. It was my experience that as categories became more pronounced, it strengthened my confidence in the emergent theory. Also, with repeated reviews of the data during the analysis, the linkages and interrelationships between categories became more apparent.

In terms of my research providing enough evidence to support my findings, I believe that the processes I used and the rationale described in my methodology highlight the journey of capturing the rich stories of the participants and translating them into a theoretical construct. The examples of data captured provided in this section, and in the next chapter, regarding the findings clearly highlight the emergent categories. In terms of overall credibility, while I do feel that I met most of the criteria suggested by Charmaz (2014), one of the limitations was that the data was not collected across a range of empirical observations. Data were collected from single interviews only across the sample group, and while these were in-depth, they did not provide an opportunity for collecting collateral information that may have given further weight to the emergent categories.

The second domain suggested by Charmaz (2014) is originality. I believe the categories are original in that they highlight underlying issues for the sample group which might not have been otherwise captured. The new insights are particularly reflected in the interrelationship of the categories. In terms of whether the analysis provided a new conceptual rendering of the data, the initial analysis prompted my conceptualising ideas about the data. These notions were further refined into codes, subsequently evolving into categories. The clustering memoing of the categorised data and open coding has enabled ongoing comparative analysis, which has then separated prominent categories from outlier codes. The value of this process is that the categories either lose or gain strength and become the building blocks of my substantive grounded theory. The constant comparative analysis and repeated reviews of the data provided a distillation of data, allowing categories to be refined until there was a concentrated focus on core categories. The key challenge and reminder were to remain open to this process and not be impeded by assumptions or the influences of any past reviews of literature.

In considering the social and theoretical significance of this work, the identified categories from the findings reveal key issues which impact the everyday lives of the participants. This highlighted the intersectional nature of various social influences. The findings from this study consequently provided validation of young adult experiences while also raising the visibility of what is most important for them to inform improvements in healthcare service delivery, specifically that health services should be delivered in a trusted and authentic manner. The literature had sensitised my initial approach, but it was important that, as a grounded theorist, I remained reflexive to minimise preconceptions and suspend any biases or tendency to force the data into concepts (Gentles, Jack, Nicholas, & McKibbon, 2014). The result was that, in this study, the development of concepts refined and extended my current thinking. Key information emerged, both expected and unexpected, related to the participants' sense of self in navigating the healthcare system. This has implications for improvements in healthcare provision and practice.

The third domain was resonance, which questions whether the categories that emerged reflected the fullness of the participants' experiences. I believe this was achieved given

the depth of the rich information gathered by participants, which ensured that relevant categories came to the fore during the analysis. In terms of the potential of the analysis to be influenced by liminal meanings initially in the data collection and during interviews, I was alert to my tendency to assume meanings, which was reflected in some of my earlier memos. The code of *vulnerability* was an early identified meaning. Through the comparative analysis and repeated line-by-line reviews, other meanings became more apparent. Subsequently, I made a deliberate attempt to restrain assumptions and work through the transcripts in an open manner. I drew links between the universality of the prominent categories across the participants and the impact on their day-to-day lives and relationships. With regards to whether the grounded theory makes sense to the participants or people who share their circumstances, the early findings were presented to the youth advisors for comment. Their comments suggested that the emergent categories were resonating for them. I have yet to provide a summary of my findings of the participants to gauge their reaction.

The fourth and last domain to test for rigour is usefulness. Overall, I do think my analysis provided an accurate representation of young people's experiences, and I do think useful learnings have been gained. These learnings can inform improvements in healthcare for young transgender people and can have a high use in young people's everyday worlds. I do think the analysis will offer an accurate representation of experiences that young people have not overtly articulated and which may have been previously overshadowed by assumptions and stereotyping. The value of this is that it gives weight and validation to a collective and shared understanding of being transgender. Charmaz (2014) prompts the consideration of linkages between the analytic categories and any generic processes. It was strongly evident that the categories were relevant to all participants, which, despite the small sample, may be generalisable to a wider cohort of gender-diverse young adults. In examining these generic processes across the sample, linkages with other categories highlighted clusters of interrelating categories. This suggests that certain generic categories, if targeted in the right way by healthcare service reform, might act as a 'driver' or catalyst of change throughout the cluster.

In terms of further research, the theoretical constructs identified in this study have identified other substantive areas which could be further investigated. For example, exploring the relevance of these constructs to cohorts of younger adolescents or older adults. The final consideration is the contribution of this study to knowledge and ultimately to a better world. This study has illustrated that the health and wellbeing need of service users have not been fully accommodated by the current healthcare system or the health workforce. This study confirms that transgender and gender-diverse young people's expectation of meaningful and fit-for-purpose healthcare. It is hoped that the

grounded theory from this study will be informative of how healthcare can be more responsive to this marginalised group.

## Summary

In this chapter, I have illustrated how the constructive grounded theory processes have been applied to participant data to generate concepts as a meaningful interpretation of the participants' constructions of their social realities. The validity and reliability of the information drawn from the data, however, is influenced by our philosophical perspective of our internal and external contexts. Building on post-positivist and constructionism perspectives, constructivist, and grounded theory has provided a pragmatic methodology to categorise constructs to generate a substantive theory. The systematic management of data through comparative analysis and theoretical sampling refined with memo-writing and interpretive induction has identified concepts both expected and unexpected, allowing theory to emerge and be validated. As a novice researcher and being cisgender, the value of reflexivity and guiding principles has been vital for the integrity of this study.

In the next chapter, I will present the substantive theory and the contributing constructs, which will address my initial research queries and translate these into purposeful actions to guide healthcare service improvements.

# **Chapter 5 – Findings**

In this chapter, a substantive theory is presented which offers an understanding of what is important for young transgender people navigating the health system. It is important to note that each young person interviewed was traversing a pathway of discovery unique to them. Consequently, in presenting these findings, it is important that each young person's story and their journey is respected and validated as their own. There are, however, common themes in the young people's shared experiences of their gender-affirming journey, which informs the construction of the grounded theory.

The various interactions and connections between gender identity, gender transition and identity validation emerged from a reflective analysis of the data. Weaving through these constructs are other influences such as family and peer relationships, wellbeing, vulnerability, and access to transgender-informed healthcare, resources and information. Throughout this chapter, quotes from the participants are provided to illustrate aspects of the grounded theory presented.

The grounded theory that has emerged from this study is *Who am I? This is me*, which relates to young transgender people making sense of who they are and the identity which resonates with who they want to be. The theory reflects the young people's gender identity journey, their experiences and the influences impacting their interactions with the health system.

## Who am I? This is me.

The substantive theory *Who am I? This is me* is central to young transgender people's interactions with their world and the healthcare system. It reflects the process of young people forming their sense of self and connection with their whole identity. *Who am I? This is me* comprises three main categories, as outlined in Table 6. These are *Seeking My Authentic Self, Knowing I Matter But...*, and *Transition Enabled*. The key feature of these categories is that they form an interactive system to explain the interconnecting needs the young people experience in their own gender transition journey. This, in turn, significantly influences both their perceptions and experiences of the healthcare system. The theoretical outcomes for the first category, *Seeking My Authentic Self*, is gender affirmation and validation. For the second category, *Knowing I Matter But...*, the theoretical outcome is having meaningful engagement with healthcare providers, and the

third category, *My Transition Enabled*, concerns being able to access trusted and accessible health care for life. If young transgender people's experiences of health services and healthcare providers is positive, there is a greater likelihood that they will experience the healthcare system as validating and enter into a meaningful and enduring partnership with a healthcare provider, which can support their health and wellbeing.

Table 7: Overview of Grounded Theory of Who Am I? This is Me

Core	Focus	Concepts	Properties	Outcomes
Category				
		Who am I?	Being stuck Deciding to conform or not to conform Asking where I belong? Discovering who I am	
Seeking my authentic self	Discovering gender while being an outsider	Asking where I belong?	Being an outsider Self-doubt and conflicted My secret Vulnerable	Gender alignment Validation of identity
		Seeking acceptance	Being accepted by family and friends Letting go Deciding I can be who I want to be	
Vacuuisa "I	Discovering transgender is not	Encountering barriers to transgender healthcare	Feeling devalued Feeling judged Un-informed services Mistrust of health services	Having trust when
Knowing "I matter", but	accepted and encountering barriers to being involved in health care.	Engage with me	Knowing I am unique "don't box me in" Having my perspective and knowledge count	Having trust when engaging with health providers
		This is my journey	Having agency over my health and wellbeing Seeking support from peers Overcoming barriers	
My transition enabled	Improved access to an informed and affirming health care system	Validating opportunities	Information and education Barriers to service minimised Transgender health-trained workforce	
		Accessible healthcare partners	Ally ship and advocacy Affirmative care Engaging and trusted partnership	Trusted and accessible healthcare for life
		Informed and integrated health and wellbeing services	Clear care pathway Provision of choices Culturally responsive Young adult guided Whanau/family inclusive	1

For young transgender people, being able to be fully present in their authentic identity without reservations becomes both enabling and affirming. The substantive theory, *Who Am I? This Is Me* represents the young person's declaration that they own their identity in relation to the gender spectrum. Identity formation spans multiple domains, of which gender is one. It is a dynamic process influencing the way in which young people construct their social realities. Their strengthening sense of who they are contributes to their resilience to meet various challenges, such as the healthcare system's multiple barriers. This is a healthcare system not yet fully equipped to meet young transgender people's health needs. The participants' stories all highlighted the challenges they faced in their personal lives and in their interactions with the healthcare system. The young people have navigated potential roadblocks but are able to persist with their journey to have their identity recognised and validated. The strong incentive for young people seeking their authentic self is to have their choices respected with the goal of achieving happiness, as per SJ's comments:

It's going to be hard. It's going to be long. You're going to be sad at points but you just have to do it, you know you have to go through it. It's like a gauntlet you've got to go through, the gauntlet to get the prize at the end. It's a tough journey and I'm still on this tough journey and I have to get reminded almost daily by my loved ones that's still worth going. It's going to be really hard but you've got to do it. Because there's like no other way you can ever feel that happiness you feel when someone sees you as how you want to be seen. (S.J.)

# Category – Seeking My Authentic Self

The category of Seeking My Authentic Self explains the young people's quest to discover who they really are as unique individuals. For young people, identity development typically runs parallel with the onset of adolescence. The growing independence as an individual often necessitates young people to confront their relationship with their external world, their heritage, family, and peers. Their stories illustrate how gender, sexual orientation, culture, and hope for the future intersect during this formative and developmental stage of their lives. Seeking My Authentic Self comprises three concepts which mark the young person's exploratory pathway. These are: Discovering me, Finding where I belong, and Seeking acceptance.

The desire for acceptance is a strong incentive for the young person to achieve validation of their authentic identity in the process of *Seeking My Authentic Self*. As illustrated in Figure 3, like cogs in a machine, the process of *Seeking My Authentic Self* only occurs when each cog works together, maintains momentum, and is not impeded. Initially, identity discovery ignites a process or journey, prompting further queries concerning the young person's sense of belonging. How well these cogs turn can be influenced by

various factors, such as the degree of self-doubt or conflict experienced. As the young person grows more comfortable with their sense of belonging, they are increasingly able to feel accepted and valued.

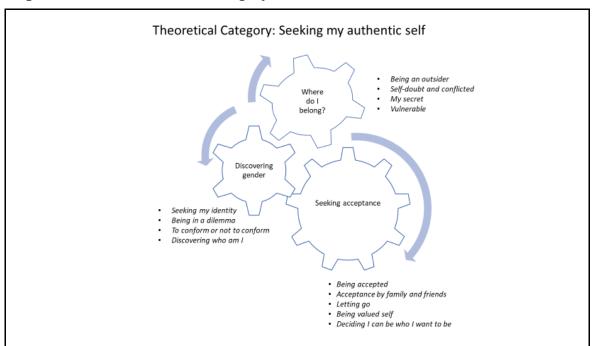


Figure 3 Process Overview: Seeking My Authentic Self

#### **Discovering Gender**

The starting point of *discovering gender* for many young people is questioning who they are. *Discovering gender* brings them to a crossroads in their journey as they face their identity. Feeling confused and uncertain about which choice is the safe option then prompts a dilemma. The uncertainty heightens a disconnect between the identity that their families and peers are familiar with and their authentic selves. M.L. describes increasing discomfort with their own body, recounting the associated confusion and wondering whether it is how other transgender people feel.

Felt awkward about my body. Felt weird about body bits so thought might be normal, that everyone feels awkward trying to fit into their bodies. (M.L.)

This discomfort contributes to anxiety, and a low mood as the young person is faced with a difficulty in understanding what is happening to them in relation to their gender and general identity. Opportunities for broadening their own knowledge combined with gradual socialisation provide time to explore how *discovering gender* resonates with their own feelings and thinking in relation to their identity. G.A found that *discovering gender* was a gradual process of increasing their awareness of gender diversity and becoming familiar with peers who identified as transgender.

Hearing other people's stories and their thoughts and feelings who were also trans and then just seeing the similarities between how I was feeling and thinking and how they were feeling and thinking. (G.A.)

For those young people who, as children, were perceived to align more with the opposite sex e.g., *tomboy* or *girly*, making choices concerning their gender identity seemed less daunting. Getting to know their authentic self and accepting descriptions from others validates the natural alignment of their overt characteristics with their gender leaning. For one participant, it came as little surprise as he had identified with more masculine characteristics as a child.

I think I've always just been quite a masculine person, so that felt kind of natural as I was always put in the category of tomboy. (D.S.)

Young people also face gender stereotyping by others. Favourable or indifferent reactions tend to affirm acceptance. Negative reactions or rejection, however, reinforced a sense of being different and heightened feelings of alienation. How well a young person can navigate these social responses and continue to seek help for their health needs also depends on the information they have available to them and the support they feel they have from others. If the young person does not receive an affirmative social response from family, peers or health professionals, this could mean that they become stuck in a gender dilemma, needing to decide whether *to conform or not conform* to their gender assigned at birth. As G.A. shares, this can result in staying in the middle ground:

To most people, I tend to just leave off any mentions towards gender so most people just assume I'm a guy still. I'm very much stuck in the middle still. Just like to be comfortable with myself in general I guess. (G.A)

The property to *conform or not conform* is evident in other life decisions young people make during their teenage years as they loosen their dependency on parents and caregivers and progress toward independent living as young adults. *Letting go* marks this increasing independence, enabling young people to make choices with fewer restrictions so they can fully explore their gender and sexuality. Many of the young people related experiences of experimentation across the gender spectrum, as K.T describes:

There's always a mixture, it's a spectrum and it's fluid, so you can kind of mix the two together and I realised that I was non-binary. I identified myself as a non-binary trans man for a while. And then, recently I dropped the trans man part of it, and I'm saying I'm a genderfluid non-binary person. (K.T.)

To conform or not to conform is evident in young people's conflicted position about dealing with others' expectations of who they think they should be. For some of the young people, this increased their awareness of their general discomfort about being categorised firmly as either female or male. Embracing a non-binary identity to some extent neutralised the dilemma and mitigated confusion and uncertainty. For many young

people, not being locked into a gender label allows the possibility of their identity not being thought of as a static and rigid gender identity, allowing more space for *discovering gender*. As K.T. highlights, discovering others experienced similar movements backwards and forwards on the gender spectrum helped normalise their gender fluidity and unique identity.

This is the thing that's been in my brain all this time that's just been throwing me off, and I've been trying to put it down as something else because I just didn't know that this was a thing. I didn't know that it wasn't normal to have these gender-swappy, gender-changy thoughts. (K.T)

## Where Do I Belong

The concept of *where do I belong* represents young people's discoveries that their birth gender no longer reflects what they feel is their authentic self. This can pose a challenge to their sense of belonging and connectedness to their family and peers. The properties contributing to this concept are *self-doubt*, *feeling conflicted*, *being alienated* and *being vulnerable*. Affirmation of young people's identity, inclusive of their gender orientation, is significantly influenced by family and peer reactions. Family reactions of acceptance and unconditional regard in response to their gender expression lessened young people's internal conflict compared to those too anxious to raise it because of their families or peers' potential reactions.

The property, *self-doubt and conflicted feelings* relates to being anxious about others' reactions or experiencing rejection, which can persist throughout teenage years. This fear of how others may react often results in young people keeping their gender preferences hidden. This anxiety contributes to the property *my secret*. The sense of being different manifests in feeling *conflicted* and young people who perceive themselves as an *outsider* in their family or societal expectations of the norm. The property of *being an outsider* was evident for some young people trying to understand themselves and what was happening. M.L. shared their conflicted experience of the increasing discomfort their female body was causing them. Attempts to be feminine and be okay with their female identity only intensified feelings of *vulnerability*, another property. Trying to conform to their birth gender while feeling disconnected from their own body triggered depression and losing sight of a future. M.L. had become *an outsider* to their own self.

It was like I was sort of looking at this body that I supposedly had and was like, I can't understand. It was like speaking a different language. I just didn't know what was going on. (M.L.)

Being an outsider to their physical body perpetuates feelings of being alone and confused as the young person struggles to understand their situation. This may result in a feeling of *vulnerability* that can compromise a young person's mental wellbeing. Not yet able to

articulate what is happening, young people find themselves and others explaining their distress in terms of a mental health problem. Labelling this *vulnerability* as a mental health concern offers a more palatable explanation for their experience that brings some comfort. However, the realisation that their distress may, in fact, be related to gender dysphoria, the feeling that one's psychological identity is misaligned with their birth sex, can be unsettling. This then intensifies the young person's query of *who am I*? As G.A. explained, being depressed is easier to understand and accept than the experience of gender dysphoria:

Before I thought and realised I was trans, it was cool; I'm just depressed. But now it's like, oh I've got all this discomfort around various parts of me because of gender-related stuff. And now it feels, at the moment, worse than when I was just depressed. (G.A.)

The onset of puberty marks a developmental milestone where the physical characteristics of gender differences become more evident. This also runs in parallel with the young person developing their emerging adult identity, their sense of belonging, and where they fit in wider society. As such, this developmental stage of adolescence is often associated with considerable anxiety for young people uncertain about their future. Intermittent episodes of anxiety and depression, promoted by the fear of being seen as different or rejected by significant others, are not unusual experiences for some young people. Feeling alienated or estranged from family only intensifies the uncertainty surrounding their sense of belonging.

Still feeling uncertain and confused with who I was, I felt vulnerable. So I began pushing away those who could help. Not understood by the counsellor at school, I was told it was just a phase I was going through. I experienced rejection by my birth mother as a daughter, and then rejection as a son. I felt kind of like an outsider to my own birth family, and it was quite horrible. (N.C.)

For some young people, despite, at times, feeling like an outsider, they remain determined to navigate the roadblocks and assert who they feel they are, regardless of negative reactions. For others, without validation by significant people in their lives of their new self, they feel compelled to retreat and conform to their birth gender. Essentially, they resort to keeping *the secret* while they look inward for validation. K.S. reflects on their self-doubt:

You may as well tackle it as early as you can anyway. I think initially I did have some doubts about whether I want to just stick with what I was born with. But then, actually I think, deep down, everyone sort of knows and you know I also had doubts like, "Do I really want this? Do I really want to change?" But actually, I think everyone knows themselves deep down pretty well so you shouldn't doubt that just because of what other people say. (K.S.)

## **Seeking Acceptance**

The concept of *seeking acceptance* relates to young people consolidating their new identity. Their being viewed positively by others means that things could click into place, with their preferred gender feeling comfortable and natural. The concept of *seeking acceptance* and its associated properties are key drivers for young people on their gender identity journey.

While the discovery of gender represents an important milestone for young people in their journey of finding themselves, an overriding influence is the young person's comfort with themselves and who they are. The dilemma of whether they should remain in a comfort zone or take risks is largely contingent upon a young person's own self-efficacy and confidence with their new gender identity and their readiness to interact with others once they feel ready to reveal their identity. Taking the risk to do what potentially renders the young person vulnerable to judgement, stigma, and ignorance is a daunting step. Without the right support, any confidence in their newfound identity may be eroded. For some, this adversely affected their mental wellbeing. N.C. described this experience:

I was confused about who I wanted to be and the gender I wanted to be and struggling a lot mentally with trying to figure out who I wanted to be. I was losing quite a lot of friends because I came out as trans at school. I cut my hair off, I got bullied for that. (N.C.)

The property of *being accepted by family and friends* highlights the impact significant others have on the way young people experience their sense of self-worth, being affirmed, and validated. Generally, most families' initial lack of knowledge about the meaning of transgender results in the young person themselves being responsible for explaining the term to families and others.

Families having access to people that could actually explain what being trans is like, what gender diversity is, how important it is for trans people to live as their authentic selves rather than it just being a fad or it just being like something that makes you slightly more comfortable would be lifesaving and affirming. I think that would be very valuable for families, as the more accepting the family is, the better it is for the trans person involved. (D.S.)

Families' adjustment to their young person's authentic gender identity takes time. Many of the young people acknowledged that their families needed the time to process and understand the situation of their child. It is evident that parents face their own journey of adjustment, and this highlights the property of *letting go*. For parents, it is not only *letting go* of their child moving to independence but also *letting go* of their child's birth gender. Adjusting to their child's authentic identity enables parents to provide unconditional regard and support for their child's transition. Reluctance or any other negative parental reactions were generally perceived by the young people as their parent's natural inclination to be protective of their child.

They [parents] are having that reaction because they love their kid and they think that something [is] wrong, and a lot of the time they think it's because their kid is going to get hurt. And the thing is, your kid is going to get hurt if you act like this, but if you act like that, you can protect your kid from so much out there. (K.T.)

Parents' adjustment to their child's rejection of their birth gender can bring challenges and sometimes a degree of grief for families. For those parents who continue to resist or reject their child's transition, relationships remain strained or, in some cases, estranged. Fractious family relationships occur when one parent is more open to their child being transgender than the other. When parents or family members have polarised perspectives, alliances may then form between the affirming parent or family member and the young transgender person and withdrawal from the non-accepting parent. These experiences can threaten the young person's sense of belonging, reinforcing that they are an *outsider*.

Families' eventual adjustment to their child's gender transition correlates with the parents' openness to gender diversity, access to transgender education and accessing their own support. N.C.'s experience provides an example of the importance of families being provided with an opportunity to openly discuss feelings related to the past, share fears, and reset family relationships without compromising their transgender identity.

My clinician physically went to my mum's house and spoke to her about being trans and stuff like that. They had a good chat about where I was at and why I was wanting to be this person, which gave my mum quite a lot of clarity around that. I was able to understand Mum's perspective. (N.C.)

Successfully navigating gender transition requires validation, which is both externally and internally driven. In the face of *self-doubt* and feeling like *an outsider*, families and peers are a key source of validation. A sense of belonging to a community or culture, as well as affirmative healthcare or community support, adds to the validating experience.

Without someone there or without just putting myself back there without anyone, I wouldn't have done anything. I would have just lived with it and then felt very dark, and honestly, I probably would have ended my life sometime because you don't know what to do in these things. (S.J.)

Another property, this is who I want to be, is the marker that the young person is moving beyond their gender dilemma and is prepared to stand up and declare the identity that resonates with them. It is important to note that for many young people, their identity is not static.

Re-naming is an important process of identity and is part of the property, *this is who I want to be.* Young people are deliberate in their choice of name, as it is a choice representing their new identity and reflects a symbolic declaration of their transition to their authentic identity. A new name is a celebratory process of affirmation of who they

want to be and *letting go* of their dead or former name, which is no longer seen as relevant. The chosen or favoured name significantly provides a metaphor for and a meaningful representation of the young person's quest for their authenticity. The acknowledgement of the new name by others (family, friends and others, including health providers) is particularly important as an acceptance of their identity, as D.S. reflects:

I had a lot of support from friends as well with my name. I was very lucky that I was given my name and people supported me in keeping that name. Definitely, at the beginning of my teens, I just didn't like my dead name, I didn't feel connected to it. I always wanted nicknames, I never wanted to use it. So, I finally got permission to get a different name. (D.S.)

For families, the adjustment to their young person's new name may be associated with a need to reset their aspirations for their child associated with their birth gender. Typically, parents bestowed their child with a name linked to significant family members, family lineage, or the name's meaning being associated with affirming character attributes. L.K. acknowledged that the choice of their birth name had a significant meaning for their mother.

They've taken a little while to get used to it. It was a little harder when I said I wanted to use a different name and eventually change my name. My mum especially took that quite hard. She's like, she's happy for me but she picked that name, and it means a lot to her. It still means a lot to me. I'm not, I don't hate that name, I don't like, refer to it as a dead name or like I know some people would. I love that name and I don't want to lose it but it doesn't fit with me, so she's having a bit of trouble dealing with that. (L.K.)

Conversely, not acknowledging a new name brings anger and disappointment. Validation by significant others is crucial for a young person exploring and gaining confidence in their new identity, as previously highlighted. Family members resorting to using the young person's birth or dead name undermines the young person's agency to make decisions and a young adult's right to be respected.

They [my family] wrote on the calendar, my dead name is moving out. And I remember feeling so angry. I was talking to my boyfriend, I'm like, you know what? I'm just going to, I'm going to go over there and scratch that out really hard and write my new name in and wait for them to ask me about it. (S.J.)

Finding where they fit as a unique individual in society also prompted cultural exploration for some. The discovery and affirmation of cultural identity is a parallel process in seeking self. Discovering their authentic selves also brought two of the young people in the study closer to their cultural origins. Neither had been strongly immersed in their culture during their childhood and had not felt their identity of being Māori had been fully validated by others as part of their upbringing. With the validation of their gender and the actualisation of their authentic self, it was clear that these two young people also found themselves growing more secure in their identity as Māori. For C.Z, identifying as takatāpui resonated strongly, but it was only as her gender identity was increasingly affirmed that they also

experienced affirmation of their sense of being Māori. This strengthened C.Z.'s confidence in using the term takatāpui.

[I] Always identified with the term takatāpui, but [I] didn't use the term as not Māori enough. (C.Z.)

While gaining the acceptance of others is important and reinforces the young person s identity and preferred gender, self-acceptance also emerges as a significant milestone in the transition journey. Self-acceptance generally occurs once the experiences of incongruence and dysphoria dissipate. *Accepting self* provides a foundational step toward the young person taking charge of their transition. As K.S. concludes, there may not be a need to rely on others for validation when that validation can be found in ourselves.

I would think, why can't I just find that in myself and not always rely on other people kind of a thing to make me feel like I have that identity? I should just, you know, find it in myself. (K.S.)

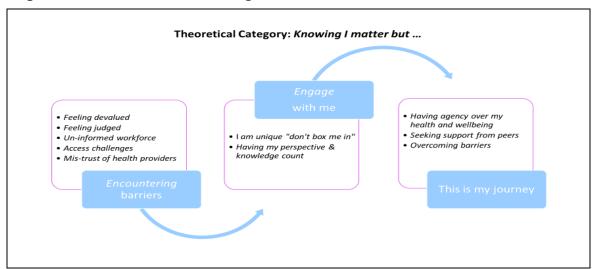
In Seeking My Authentic Self, the outcome young people seek is a point in which their identity feels authentic and they have a comfortable fit with who they want to be. As already discussed, the transition journey is not without multiple challenges for young transgender people. However, as the obstacles in the pathway clear and the turmoil of conflicted emotions reduces, they are increasingly able to interact with their external world as their authentic self.

I felt so liberated. I also remember thinking, no matter how I end up identifying, I'm still going to be me. To me that was not changing, going from something to something else. It was me just aligning everything so that I could be me. I felt like a weight had been lifted off my shoulders. (M.L.)

## Category - Knowing I matter but ...

The second category, *Knowing I matter but...*, focusses on young people knowing their intrinsic worth but discovering that the health system is not always transgender-accepting. Being acknowledged and validated is important to young people; it conveys that they are important and their choices will be respected. The importance of validation and respect transfers to the health system – how well young transgender people engage with the health system is strongly related to their experiences with health providers and services. This category comprises three concepts: *Encountering barriers*, *engage with me*, and *this is my journey*, as illustrated in Figure 5.3.

Figure 4 Process Overview: Knowing I Matter But...



## **Encountering Barriers**

The concept of *encountering barriers* highlights the challenges young people encounter and is comprised of various properties. Healthcare providers with limited information or appreciation of transgender health and wellbeing provoked anxiety, mistrust and frustration among young transgender people. When facing n untrained healthcare workforce, the young transgender person had to explain to a healthcare professional what it means to be transgender. This prompted experiences of not feeling valued and of being judged. The responsibility or burden often falls on the people to educate and inform others about being transgender. Although many young people reside in communities, homes, or attend schools or tertiary institutions where the LGBTQI community are now acknowledged, most people have little or no experience with transgender people.

So, all the explaining information comes down to me and it just requires so much emotional energy. I don t want to have to explain this thing to everyone forever. (S.J.)

The quality of the initial contact with health providers such as GPs, counsellors or even teachers at school influences young people's willingness to seek ongoing support for their physical, emotional, or practical needs. Unhelpful encounters with either primary care or specialist health providers result in the young people *feeling devalued*. Short session times, typically offered by primary healthcare providers, further compromise the quality of these encounters.

I don't know if it's just because doctors have a lot of patients, and they have a lot to deal with, but I don't think I've ever had an experience where I can sit with them and talk to them. Sometimes I feel like I've gone out faster than I would get a meal at McDonalds. (S.J.)

The property, an *uninformed workforce*, describes healthcare providers who lack knowledge and training in transgender health. Young people frequently encounter an

uninformed workforce, which impacts their experience of healthcare. Healthcare providers either lack awareness or present with insensitivity or behaviours which are experienced as stigmatising. This kind of experience inhibits young people from disclosing their gender orientation to the healthcare provider.

The counsellors that I went and talked to never acknowledged that I might be trans. They never asked "what are your pronouns" or "what's your gender identity", just asked about family and boyfriends. (D.S.)

An *uninformed workforce* means the health and wellbeing needs associated with being transgender are potentially not addressed or remain undetected. A healthcare provider's knowledge gap can result in many young people *feeling judged* or being recipients of ill-informed assumptions. Healthcare providers not making overt efforts to either increase their transgender knowledge or show sensitivity to how young transgender people might feel and how they want to be treated evokes young people's frustration and disappointment. Young people interpret these behaviours as ignorance on the part of the clinician.

It is important having the training and the knowledge how to deal with trans and gender-diverse people. Like some people just straight up don't get the idea of they/them pronouns. It's like, you live in 2020! But I mean, it's not usually from a place of transphobia. It's from a place of ignorance. It's like they straight up don't know or haven't encountered or maybe don't have the resources to counter that ignorance. So, I think those guys [Rainbow organisations] doing the workplace trainings is so good. (C.Z.).

Similarly, the lack of training and competency in transgender health potentially leads to health providers making uninformed assumptions, which was a part of the experience of most participants in this study. Consequently, young people feel health providers are trying to fit them into categories or boxes and failing to appreciate the individual circumstances and complexity of their situation.

Healthcare professionals, they want you to fit in this box. That's not how nature works; there is no box with nature. The box is ripped apart and crumpled to pieces. It's like one of the first things I learned in LGBTI community, it's like you can't get something as complex as nature or like life in such a small thing. (S.I.)

Health care services often lack systems or protocols to change birth or legal genders on their medical records. Increased knowledge of transgender health is needed across not only the clinicians but also those planning and designing policies, systems and processes within services. Misgendering is an example of systems that do not support affirmative transgender models of care. As outlined previously, frequently incorrect use of pronouns is experienced and reinforces the young people not feeling valued or respected. This becomes another barrier for young people engaging positively with a healthcare provider.

The property access challenges refers to a lack of low-cost health care and difficulty accessing services in a timely manner. This is particularly pronounced for those young people seeking support for their transgender health needs. Lengthy wait-times between the various steps in their health care journey of assessment, counselling support and medical intervention results in young people experiencing prolonged periods of uncertainty. Consequently, this compounds their vulnerability to anxiety and being in a continual state of low mood.

Well, I have been trying to manage my depression and waiting for things hasn't really been helping that too. It's just frustrating, and I'm not coping too well with having to wait for what feels like forever. And then it feels like I'm going to have to keep waiting after that for other things. (S.J.)

Dedicated comprehensive transgender healthcare services are lacking. The existing services are largely uncoordinated with barriers such as cost, location and availability, which are common challenges for young people.

I had one counselling that I did pay for myself. But it was like \$60 a session or \$80. I can't afford that personally, like right now when I only have \$50 a week for food and transport. (S.J.)

Accessing specialists in a timely manner is also a common complaint. A key milestone in seeking entry-level transgender health support is securing an appointment with an endocrinologist. This can be further hampered by a difficulty in accessing other clinicians such as psychologists, typically a pre-requisite step in accessing hormone treatment. The cost and delays in accessing assessments or general and family counselling leave young people feeling frustrated, anxious, and generally disempowered. Many young people shared that this contributed to their cyclical experiences of low mood. G.A. recounts their experience:

The two and a half months waiting to get the report back from the psych assessment was a bit of a kick in the teeth because my GP had told me it will take them like a week to write the report. (G.A.)

The prospect of undergoing psychological evaluations significantly contributes to young people worrying about whether their rationale for gender transition will be validated by health providers. Being required to provide proof of their gender orientation places considerable stress on these young people. To relieve this stress, some felt they had to resort to orchestrating additional evidence to prove their transgender orientation was genuine. This included ensuring their appearance and gestures presented as overtly feminine or masculine. This experience leaves young people feeling that their authenticity is being questioned, so they inevitably evoke another property that is the *mistrust of health providers*.

I had to go and see her [psychologist] for six months because my endocrinologist didn't believe me. They didn't think I was trans, they didn't think it was the right decision, and that I didn't understand what I was doing. (T.N.)

Encounters in which a healthcare provider is perceived as dismissive or challenging of the authenticity of their transgender identity can be traumatising. Young people feel they need to be on guard and refrain from being open about their situation. The adverse outcome of this situation is young people feeling disempowered and mistrusting of the health system.

Sometimes at the psychologist meetings, they try and put words into your mouth, and you have to be really careful because they will try and slip you up. (K.T.)

What the young people ideally seek is health providers who have the time and the right approach to listen to their struggles, offer reassurance, and provide sound advice on choices, including medical options and services.

If I'm having a bad dysphoria day, if I could sit down with someone who is trained in that area and just talk through why am I having this dysphoria. What can I do to help it? It's okay to feel this way and like, options for the future. Just being able to sit down and talk, it's just really nice. (L.K.)

## **Engage with Me**

The second concept is *Engage with me*. Young transgender people face the challenge of navigating barriers and challenges before they have the confidence to engage in meaningful interactions with a healthcare provider. It is only when the experience is affirming and informative that their help-seeking behaviour is reinforced. There marks a point in which young people have the confidence to move beyond the barriers, and trust can form with a healthcare provider. *Engage with me* is about young people having their voices heard and their perspectives acknowledged by health providers. This concept consists of two main properties, *knowing I am unique* and *having my perspective and knowledge count. Engage with me* offers reassurance to the young people that health providers will respect their decisions and reflect what they are looking for in a healthcare provider.

As highlighted earlier in this chapter, re-naming is very much a symbolic action, allowing the young transgender person to make a declaration that they have moved beyond their birth gender. For some, re-naming is a risky action because it publicly signals that they are defining themselves as transgender, which may elicit varied reactions from others. Many young people talk about the emotional toll the decision can have, as they oscillate between self-doubt and dogmatic determination to make a stand and overtly declare their

new identity to healthcare providers and those who potentially have a crucial role in supporting their transition. As T.N comments:

Naming confirms identity. Name change is that passage of rite and confirmation of identity. (T.N.)

The property *I* am unique, don't box me in signals to others, including health providers, that a young person has arrived in their new identity and the importance that others be open to how this is expressed. As K.T. adds,

It is such an individual journey. No one trans thing is the same. (K.T.)

For services to engage young people, the acknowledgement of the young person's preferred name and their uniqueness is a key signal that the healthcare provider is accepting of diversity and potentially can be trusted. Failure by others, including health services, to acknowledge their new name or attempts to restrict the use of how they want to express themselves is a direct dismissal of the young person's authentic self.

All of the young people interviewed consistently conveyed the importance of young people being viewed as individuals with unique experiences. While the experiences of transgender peers are valued, the young people's message to healthcare providers is to not assume that being transgender is a homogenous group. While all participants affiliate with the Rainbow community, it is important that others, particularly healthcare providers, respect their uniqueness and not assume that all young transgender people follow the same path.

Everybody experiences their gender differently, and I definitely say that I haven't fitted into the gender binary like my entire life. Obviously, gender is very social. There are lots of factors that go into it, but I'd say my personal gender identity and my personal journey has been about putting words to feelings that I've had my entire life and then being able to explore myself more fully because I can talk to people, explain what's going on and then actually do things about it rather than just being confused the entire time. (D.S.)

The property having my perspective and knowledge count is a key milestone for a young person in developing trust in health professionals and reinforcing the category knowing I matter. Uninformed health providers who make assumptions about transgender health needs or who did not have sufficient time during consultations to listen to the young person's perspective, respect their knowledge, and understand concerns were viewed as unhelpful. Meaningful engagement with healthcare providers will only occur when young people's perspectives and knowledge inform how services should be delivered to them.

## This Is My Journey

Experiences of being listened to, combined with genuine attempts by healthcare providers to understand their patient's unique journey, were readily welcomed. The property having agency over my health and wellbeing highlights young people's ownership over their healthcare journey and provides the impetus to navigate the health system's barriers and to assert their right to receive appropriate healthcare.

I like to be involved more in my decisions, and I just want to feel valued as a person. (S.J.)

Young people value allies or transgender-informed role models working within health services who improve engagement and provide reassurance that queries around gender can be discussed. Feeling supported, affirmed, and encouraged in their gender transition journey by their peers is important to young people. The property *seeking support from peers* endorses the value that a peer-support workforce can have for young people within healthcare provision.

The property *overcoming barriers* is reflective of the young people's resolve to pursue their journey to reach their authentic selves. Facing hurdles and disappointment arising from delays in accessing specialist healthcare is widely known and anticipated. Young people resign themselves to the idea that they may need to consider alternative pathways or simply be more persistent in finding what they need. Drawing on the support of peers and Rainbow-affiliated support services, the young people seek out clinicians, allies and services who can respond to their needs. For some, this means relocating cities. Despite feeling frustrated and, at times, disempowered by the barriers, most of the young people remain committed to their direction of travel to be who they want to be. S.J. offers some encouraging advice:

It's going to be really hard, but you got to do it. Because there's like no other way you can ever feel that happiness you feel when someone sees you as how you want to be seen. (S.J.)

# Category – Transition Enabled

The third category, *Transition Enabled*, marks the young person's interaction and aspirational engagement with the health system. For relationships with the healthcare system to be meaningful and enduring for young people, three sub-categories provide touchstones along a connected care pathway in which the young person's access to healthcare intersects with their journey of discovering gender, reaching a point in which they experience being their valued self. As illustrated in Figure 5, the young person's relationship with healthcare providers, when working well, provides validating

opportunities and support to enable the transition. This transition is not solely represented physically. Rather it is the young person's sense of *being*, of who they are and who they want to be. As already highlighted in the two previous categories, the pathway is currently not without challenges and gaps. The stories of the young people in this study highlight their varied experiences and navigational resilience to seek to interact with a healthcare system which offers varied responses to young transgender people.

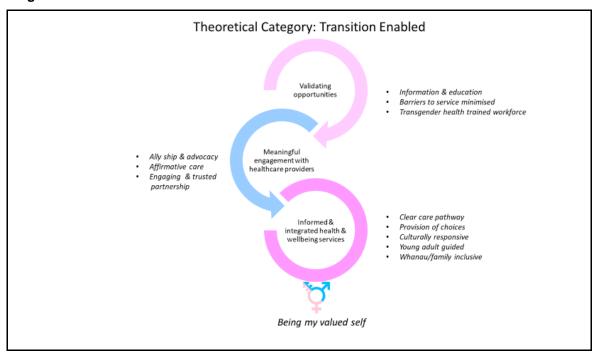


Figure 5 Process Overview: Transition Enabled

## **Validating Opportunities**

Validating opportunities is the sub-category that reflects the young person entering the gateway to formalising their transition intent. During this stage, the young person is consolidating their journey of discovering gender and their learnings so they can now navigate the healthcare system. The first property that underpins this sub-category is *Information and education*. Online searches, social media, and web-based sites and platforms such as YouTube are the most common avenues for seeking information and guidance. Social media and online searches are used as portals to web-based transgender-specific sites and provide opportunities to hear other young people seeking assurance and guidance. Young people's main challenges are being unsure of where to look for information and determining the credibility of online information.

The internet can be quite wonderful at times and not wonderful at other things, and it can be really hard to find information on things. (G.A.)

Navigating services and pathways recommended from online sites typically reference overseas systems that do not necessarily resemble the local healthcare system. This provokes frustration and disappointment, as young people are left unsure of options or

where to access support. Access to the right knowledge offers a validating opportunity for young people. Consequently, young people seek navigational aids to better access information and locate services. Recognisable national bodies or centres of excellence that collate and disseminate resources would provide the reassurance that the information they are accessing is credible. Access to quality information for parents to aid their understanding of what it means for the child in being transgender is also sought. Informed parents are more likely to validate their child. As L.K. explains:

If they [parents] can just be given that knowledge and assurance in whatever way that they need, that it's okay. Like here's the knowledge you need to know about your child's new journey. Like how you can support them, but also how we [services] can support you because we know it's hard for you to like, learn to get to know your child again. (L.K.)

## **Accessible Healthcare Partners**

Even when equipped with information from online or peer and educational sources, young people's experiences with local health services vary. Poorly defined health system processes and fragmented care pathways pose complicated challenges for a young person seeking guidance and support. M.L's experience highlights the impact this can have:

It was like fumbling my way through the dark, not really knowing the next steps or then being told I have to, you know, do x, y, z. That was the whole uncertainty. I think the thing that affected me the most, and I think affects people the most... (M.L.)

There is a degree of self-reliance needed for young people to access what they will need to advance their transition. This means young people need to be proactive and draw on their own internal resources for self-care and self-affirmation. Young people realise that it is crucial to be informed themselves, to access information and seek out the right pathway of care and service provider.

Important to love yourself really gets you through things, boosts confidence. Even though it's very hard to every day, try and find something that you kind of love about yourself. Because that will not only help you mentally but it also will help you when you come across people that aren't going to be that accepting. (S.B.)

Being unable to access consistent and transgender-informed care often results in an intermittent relationship with their health provider. A familiar GP is ideally sought by young people. The brief consultations, however, frustrate young people and do not provide sufficient time to build a meaningful and trusting relationship.

I kind of just stopped seeing doctors for a little bit, except for like, just getting a repeat prescription just because it felt like I wasn't getting anywhere. I was just exhausting myself and I was just wasting my money trying to see a doctor who would send me a referral, see somebody, and that person actually was of use and didn't just blame everything on something unrelated. (K.T.)

In the absence of a responsive or easy-to-access healthcare provider, young people resort to being their own healthcare manager, supported by transgender peers, friends, family or other advocates. In taking this pathway, young people will seek out healthcare specialists when needed, but due to the barriers such as accessibility and cost, they prefer to be self-reliant.

It's positive, being enabled to manage your own health. Doing your own injections. Cost is big, and tough for trans who are struggling with getting jobs and work on benefits. Being able to do our own injections is life-changing. Otherwise, it often means multiple visits to the GP just to get things underway. (K.T.)

The properties of *allyship and advocacy* are strong protective factors for young transgender people navigating healthcare. While transgender-informed health providers are preferable, feeling welcomed to a service, being acknowledged as a transgender person, with health staff willing to advocate for the young person as their client provides clear signals that a healthcare provider can be trusted and has the potential to be an enduring healthcare partner. Locating a youth and rainbow-friendly GP willing to broaden their knowledge and advocate for a timely response to referrals to their services was an exception, but when it did occur, it was appreciated by the young person and viewed as an act of advocacy.

Then going to see the GP, it was on my record, and which said, obviously, I was trans. I didn't have to come out to her, but she immediately used my correct name, used my correct pronouns and made sure I was very comfortable and just immediately made me feel a lot more confident about going there myself. (L.K.)

Allyship, in which the young person's authentic gender identity is supported, was welcomed by the young people, either from clinicians, community, peer support, family or friends that considered transgender important. A non-transgender (cisgender) ally is also considered valuable in providing advocacy and support, as K.T. explains:

I think when it comes to like the reformation of the healthcare system to help trans and gender non-conforming people, there needs to be trans people on board every step of the way as well. That s a huge important piece. I also think having cisgender people being the liaison is something that's important, because people are more likely to listen to a cisgender person talk about trans needs. (K.T.)

As K.T. notes, the reality is that cisgender support people are sometimes able to cut through any stigmatisation, ill-informed perceptions, or other prejudices more easily than their transgender peers.

I got along far quicker when an able-bodied cisgender person started speaking up for me in the health system. (K.T.)

The property of *affirmative care* is described as respecting each young transgender person as a unique individual with their own context of social, family and individual factors. This property certainly emerged as a sought-after feature of what a healthcare

provider should offer. The healthcare provider conveys genuine interest in understanding the young person's needs. Their transgender identity is not being questioned, support is willingly provided, and the healthcare provider is prepared to advocate for the right services and interventions. The experience of an affirmative stance from the outset, rather than an evaluative one, provides a platform for the client and health provider's enduring partnership to form. Being acknowledged as a unique individual with unique needs was important to all of the young people.

Young people are seeking an engaged and trusted partnership with a healthcare provider. Young transgender people welcome an enduring relationship with a clinician who is well-informed in transgender health. Whether young people engage with a health provider depends on how informed the health provider is in relation to transgender healthcare and their willingness to listen. In general, there continues to be a lack of clinicians who are trained in transgender health. When health providers know less than the patient about transgender health, the young person has to take on the role of the educator.

Annoying that, as the patient, I need to explain or educate the clinician. (T.N.)

Health providers who retain an expert role in transgender health without the relevant expertise or training in transgender health leads to young people feeling angry and resentful. This is made worse when they make assumptions and do not take the time to listen to young people about their needs.

It's not just telling people about trans people, it's telling people who've never heard of this concept and might have some really extreme stigmatisation about this, and you have to do it in a way that you don't lose your cool. You keep respect, this is something that trans kids essentially are expected to do. It's so hard to like, keep your cool when adults that have superiority over you keep shutting you down. (K.T.)

While clinicians with knowledge and skills in transgender health are favoured, a non-judgemental attitude, values, and warmth are qualities that signal to the young person that a trusting relationship can be formed. Important properties underpinning this category are allyship and advocacy, affirmative care, and openness to an engaging and trusted partnership that can be reciprocated.

Clinicians actually, they care, they come from a place of caring and empathy. So I think they just need the training to apply that empathy to trans and gender-diverse youth. (C.Z.)

## Informed and Integrated Health and Wellbeing Services

The third sub-category in which services come together in an informed and integrated manner is sought by all young people but has only been experienced by some of the participants. While overtly Rainbow-friendly services provide a welcoming environment

to people who identify as transgender, this needs to be more than just a sign displayed on the reception counter with a Rainbow tick, suggesting the service is friendly to LGBTQI people. Services need to demonstrate this commitment in all aspects of service provision. Young people expect these services and clinicians to be fully committed to reducing inequities that impact transgender individuals. Services fully demonstrating their commitment to the Rainbow community provide informed and appropriate processes. Examples include systems and forms which cater for all genders, the correct use of pronouns, and public toilets not restricted to binary genders.

Transgender health-informed and integrated health and wellbeing services consistently available throughout Aotearoa, New Zealand remain aspirational. Integrated services ideally reflect a comprehensive set of service options which have been drawn together to enable the young person to access the whole of health support, together with social support.

Just knowing that I'm not alone and just being able to hang out with like people and just being like, cool, these are people who understand the sort of things I'm going through. Even if it's not stuff that we talk about all the time, it's just like, no, these are people who understand. (G.A.)

The property *provision of choices* impacts strongly on young people having confidence in the healthcare service. Choices are reflected in the type of services being offered, but also in how well the service enables the young person to make their own choices. As outlined above, a comprehensive array of service options across physical health, as well as wellbeing and social support, is sought. For physical health, G.A. highlights the importance of being informed on options:

This is what female-to-male transgender people need, and this is what male-to-female transgender people need. It's like, cool, this is the process to get oestrogen if you're wanting to transition to female. This is the process to get testosterone if you want to transition to male. There are also other things that you can do, like waiting lists for vasectomies and all the rest of it. (G.A.)

Other choices include access to counselling and connecting with peers experiencing similar journeys or having opportunities to talk with others who are transgender-informed. The availability of social and practical support regarding clothing selection, job-seeking and accommodation are also important as wider social needs associated with gender transition. For example, shopping for the right type of underwear or seeking advice on how you tell your employer about your gender.

Young people value having choices but reject the idea of their choices being restricted. Healthcare providers who only accommodate binary gender choices because of outdated forms and processes in the patient management system restrict choice and

evoke frustration among young transgender people. Being transgender does not imply that gender identity is necessarily a fixed state. K.T's comment highlights that young people can be enabled to make their own choice across the gender spectrum.

People and young trans people need the ability to see that their journey doesn't necessarily have to be binary because that's what the medical system is kind of pushing, it's like you either have to be 100% a trans guy or 100% a trans girl and not having any in-between-ness. (K.T.)

Young people view youth dedicated services with a reputation for working with young transgender people favourably, particularly due to their welcoming approach and clear efforts to be Rainbow-friendly and relevant. Those who had the opportunity to see a GP or nurse practitioner within a youth one-stop shop or youth hub (which specifically caters for 12 to 24-year-olds) reported positive experiences. Being able to access free services with youth-friendly practitioners in welcoming environments reduces the young person's anxiety about being able to share their issues. Young people appreciate these services with their non-judgemental vibe, as well as access to information, mental health support, and support workers.

With the youth health service here in Wellington, I physically walked into the space, and there were visual cues that the space is trans-friendly. Colours symbolise inclusion. Rainbow-friendly, not tokenistic but genuine ... I was glad to go to this place because they were known as trans-friendly, and that was really helpful. (M.L.)

The pressure to move from a youth health service when a young person no longer meets the funded age eligibility can evoke uncertainty and anxiety. The general worry relates to a concern that non-youth-focussed services will not be welcoming and or will not be able to provide safe care. N.C. reflected on his experience of the youth health service in Auckland, which has been his main healthcare provider throughout his teenage and young adult years.

It's very good on your mental health because you don't have to go from trusting one person to the next, then when you have to move to the adult service, it's like a family member who just leaves your life. It's someone you really trust and you suddenly can't see them anymore because you're not of age to be that service anymore. (N.C.)

Options for services to be whānau or family-inclusive weaves further strength to an integrated service platform. Affirmative family support tends to align with the young people's increased confidence in their gender exploration and transition.

The experience of *being acknowledged and respected* for young people is paramount, regardless of ethnicity, age, gender or sexual orientation. Although only two participants identified as Māori, both strongly felt that services should be willing to state and demonstrate a genuine commitment to equity for all ethnicities and gender identities. Their experiences suggest that they prefer health providers to not make assumptions

and rather let young people's experiences and perspectives be the guide. It was felt that healthcare providers should be able to respond sensitively to cultural needs accordingly. As N.K. notes, the importance of both the person's cultural context and their gender as all parts are important in their identity of who they are:

Don't have to hide certain parts of me, or I don't have to keep them quiet or keep them, you know, locked away. I am the sum of the parts ... I think it's really important to make special spaces for people who are gender-diverse and have cultural identities and acknowledging how their genders are based in their culture. (N.K.)

For services to be fully informed and integrated, the intersectionality between culture, gender, age and sexual orientation and whānau must be recognised and supported. Not only does the workforce need to be competent in understanding transgender health, but an integrated service needs to include a broad range of roles such as psychologists, counsellors, peer and support workers, and cultural and whānau focussed workers.

An accessible and responsive health system that meets the needs of young transgender people can streamline and reinforce their gender discovery and transition progress. When the young person's health and wellbeing are enabled, it contributes significantly to confidence and self-efficacy of their identity, reinforcing *Who Am I? This Is Me.* L.K. highlights the reality:

It's going to be a rough ride, but if you're willing to look for or have people help you, there are people who are going to help you through that. (L.K)

# A Grounded Theory Informed Affirmative Framework of Healthcare

From the emergent grounded theory of Who *Am I? This Is Me, a* framework for affirmative health and wellbeing care enabling flourishing transgender young adults is proposed. The emergent categories from the young people's stories provide a strong indication of which key principles should underpin the delivery of health services if it is to achieve the outcome of *enduring affirmative health and wellbeing care for flourishing transgender young adults*. These principles are readily apparent from the young people's experiences, perspectives and preferences. This includes easy access, choice, promoting safe and culturally responsive care, having trust in the healthcare provider, and prioritising engagement. What has been learned from the young people in this study is that healthcare which embraces and meets their expectations subsequently reinforces and validates who they are and their identity as a young transgender person.

Based on these findings, I have proposed a framework of affirmative care, as depicted in Figure 6, which outlines the cornerstone principles which have emerged from the various properties of each of the three categories of the substantive theory. The framework highlights the relationship of these cornerstone principles with the young

transgender person's healthcare journey. It is clear from the findings in this study that services are still underdeveloped and so may not yet fulfil the cornerstone benchmarks of affirmative care that resonate for young transgender people. This means that their journey may not always be linear, as they encounter various service roadblocks. Regardless, as highlighted by the grounded theory, the central focus for the young person is their personal goal of being accepted as the person that they want to be. Healthcare services embracing these cornerstones can then become affirmative and enabling for transgender young adults.

Who Am I? This Me 6 Young Person's Seeking my Knowing I **Transition** Journey authentic matter...but enabled self Meaningful Gender affirmation Trusted and accessible **OUTCOMES** engagement with and validation health care for life health providers Information, Healthcare Informed & Accessible education & Cornerstones **Integrated Health** Healthcare validating & Wellbeing **Partners** opportunities Services A framework of Affirmative Health Care for Flourishing Transgender Health & Wellbeing Accessible, Safe, Culturally responsive, Trust worthy, with Choices, Young Person guided, Whanau/family inclusive.

Figure 6: A Framework for Affirmative Healthcare for Flourishing Transgender Young Adults

The first cornerstone is information, education and validating opportunities. Many of the young people felt that a recognisable national body or "centre of excellence" that can post resources and lists of recommended health providers would speed up retrieving the right information to inform what steps they can take.

The second cornerstone is meaningful engagement with health providers. The importance of developing meaningful engagement with a healthcare service and a health provider emerged as a strong message throughout the young people's stories. For young people who had identified a healthcare provider prepared to listen, this has marked the start of their ongoing trusted relationship within the healthcare system. While a transgender health-trained clinician is preferred, a healthcare provider willing to be an ally or advocate is welcomed.

The third cornerstone is informed and integrated health and wellbeing services. A source of considerable frustration for the young people in this study was the lack of knowledge

with regard to transgender health and specific needs among healthcare professionals in general. Challenges in accessing services were another source of frustration and disappointment. There were delays to access, or in some locations, services were lacking or not available. This was further complicated by various aspects of care being provided by different healthcare providers at varying locations. Young people welcomed their GP or local health service being able to provide all aspects of transgender-specific care, but this was seldom the case. Young people might typically begin the healthcare journey with a GP consultation. However, the pathway to endocrinology, mental health, psychological evaluations or social support were experienced as quite separate. The exception to this was the dedicated youth health services, which attempted a more integrated approach.

## Summary

In this chapter, the substantive theory of *Who Am I? This Is Me* has been presented and explained. Underpinning the main theory are three interconnecting categories: *Seeking My Authentic Self, Knowing I Matter But ...,* and *Transition Enabled,* which play a key role in the way young transgender people perceive and engage with the healthcare system. The healthcare system, in its current state, falls short of providing for the needs of young transgender people's needs and their whanau in a coordinated or comprehensive manner. There are multiple barriers impeding easy access to healthcare services and an undertrained healthcare workforce. How well the young transgender person navigates the healthcare system depends on how validated their sense of self is and their determination to be the person that they are meant to be. The findings in this chapter have provided an informed context to develop a framework of affirmative care for future transgender health services development.

In the next chapter, I provide a discussion related to these findings and consider this in the context of the literature and current developments in healthcare. The implications of the substantive theory are discussed as well, as are the limitations of the research.

# **Chapter 6 – Discussion**

In this chapter, I provide a discussion related to the grounded theory that has been generated from the findings in this study, considered in the context of the literature and national directions in healthcare. I will then discuss the implications for improvements in the provision of healthcare for transgender young adults based on the framework of affirmative healthcare proposed in the previous chapter. I will also discuss the credibility of a grounded theory approach in providing an original contribution to the understanding of the needs of young transgender people. This will highlight the methodological strengths and weaknesses of this study and identify areas for further research.

# Constructing A Grounded Theory of Young Transgender People Navigating Healthcare

For this study, I set out to understand young transgender people's perceptions of and their subsequent experience of healthcare services. This was based on an initial concern that the health and wellbeing needs of transgender young adults have been underserved by our healthcare system. Progress has been made in the development of guidelines for New Zealand, promoting affirmative models of care. However, it does not necessarily equate to better services. It is also not clear to what extent young people have been part of the conversation to understand what they want in creating meaningful partnerships between them and the healthcare provider. In taking a grounded theory approach, this study has generated a consumer-driven theoretical perspective of how healthcare can better serve transgender young adults. This study confirmed that the provision of services needs to improve across a number of domains to enable more accessible and responsive healthcare. In particular, as the findings highlighted, healthcare should ideally be delivered in a manner that is meaningful to young transgender people with systems, processes and an informed workforce that can affirm and validate their gender identity journey.

The substantive grounded theory, *Who am I? this is me,* is the conceptualised process central to young transgender people navigating the healthcare system. Underpinned by three theoretical categories: *Seeking my authentic self; knowing "I matter", but...;* and *my transition enabled,* this generated grounded theory facilitates an understanding of the young people's perspective of their interactions with healthcare providers. Emerging from young people's collective stories were three interrelated propositions contributing to the emergent substantive theory. One proposition is that the young person's quest to discover their authentic selves is a key driver in making sense of themselves and

discovering their identity on the gender spectrum. The second proposition is that each young person, regardless of barriers and setbacks, assumes ownership of their gender discovery journey. The third proposition is the affirmation and validation that being engaged with a healthcare provider can bring, but to optimise these opportunities, the healthcare system needs to be integrated. These intersecting propositions can significantly impact a young transgender person's ability to navigate a health system which is currently uncoordinated and under-resourced.

This journey plays a crucial role in determining how equipped the young person will be in navigating the challenges which lay ahead in their interaction with the healthcare system. The young people's subsequent experiences with healthcare services and healthcare professionals contribute significantly to how a young person is likely to construct their social reality of the healthcare system. These propositions are reflected in the proposed Framework for Affirmative Healthcare for flourishing Transgender Young Adults (refer to Figure 6) presented in Chapter 5. The successful progression along the framework's pathway is marked by three outcome milestones, which I will now outline in the context of the substantive theory and literature.

#### **Gender Affirmation and Validation**

Before we discuss the processes of affirmation and validation, it is important to note that the central premise of the emergent grounded theory is the young person's search for identity authenticity. "Who I am, this is me" becomes a critical driver of the young transgender person's health and wellbeing and influences their interactions with the healthcare system. The formation of identity is critical to all young people's development (Becht et al., 2016; Klimstra et al., 2010; Meeus et al., 1999), moving through from adolescence to young adulthood. The development and stability of the identity is an iterative process throughout adolescence to adulthood related to psychosocial functioning and wellbeing (Crocetti, 2017). Making sense of self is also referred to as narrative identity, which is a continual process in relation to life events (Bloshinsky & Menon, 2020). Coming to terms with a gender identity which steps outside of their birth gender for the young person brings other transitional challenges, internally and externally, as they seek validation. As highlighted in this study, the young person's search for their identity begins long before their engagement with the healthcare system. Gender or gender identity may influence the formation of the transgender narrative. which is constructed and reaffirmed by validating experiences (Bloshinsky & Menon, 2020).

Certainly, in discovering gender identity and the sense of belonging, this study found that families play a strong role in validating identity (Olson et al., 2016). Parents can play a role in mitigating risk factors, offering validating support, minimising conflicted feelings and supporting the young person's confidence and sense of belonging, regardless of their gender choice (Johns et al., 2018). Validating parental support specific to identity, including expressions of love and affirmation, can contribute to the young person's resilience in life (Andrzejewski et al., 2021). These overt validating behaviours, such as parental acceptance, contribute to the young person developing a healthy sense of self (Katz-Wise et al., 2016).

While relationships with families and peers play a significant role in providing validating life experiences which contribute to the identity narrative for youth and young adults, young people will also seek experiences beyond their immediate support system. For many young people, the increasing presence of digital and virtual options provides a navigational portal for young adults to explore their identity. A key feature of the 21<sup>st</sup> century is that, for many young people, the construction of their social reality is internet-driven and heavily influenced by social media (Villanti et al., 2017). The findings of this study highlighted that online searches and references to social media platforms and YouTube were typically the first points of reference for young people to explore their gender identity and options. While for many young people, it provided answers, it also prompted their realisation of a sense of being different, precipitating their own internal queries of where they belong. Online exploration has provided an opportunity for young people to anonymously search for information without having disclosed their gender (McInroy & Craig, 2015). As Crocetti (2017) suggests, identity formation is often an interplay between exploration and commitment.

While many of the young people in this study reported concerns about the credibility of online information, it was viewed as a helpful starting point and, as others have suggested, has the potential to be a valuable tool (Evans et al., 2017). The virtual world for transgender people can be empowering (Marciano, 2014), and certainly for young people in this study, it was an accessible source of information across a wide range of topics related to gender identity and the transgender community. While acknowledging that the digital media environment will have challenges (Cavalcante, 2016), the general perception of the young people was that it provided information that was not readily available elsewhere. Young people from this study were worried about the credibility of the information posted but, at the same time, accepted that there was little alternative. There was little doubt that access to online sites, transgender communities, and information, if navigated carefully, was a validating opportunity. For several of the young

people participating in this study, online resources contributed to discovering the gender process and subsequent commitment to their gender identity.

The staged model proposed by Devor (2004), as described in the literature review, highlighted the importance of transgender identities being validated and reinforced with experiences and exposure to other young transgender people. This was evident in the stories shared by the participants, highlighting how life experiences provided affirming and validating opportunities. These experiences, however, have been varied, with young people alternating between feeling positive about their gender identity and having experiences which feel like setbacks. Regardless, young people have constructed their realities and their sense of self, which is not necessarily static. Identity development is not necessarily a process with an endpoint and may, in fact, move forward more than in reverse (Meeus et al., 1999). Identity formation is guided by progressive changes in the way in which young people deal with identity commitments (Klimstra et al., 2010). This highlights the earlier comments on identity formation being an iterative and continuous process of seeking meaning and purpose (Bloshinsky & Menon, 2020; Crocetti, 2017).

While Devor's linear modelling of identity development (Devor, 2004) provides the healthcare provider with an understanding of transitional stages, it does not account for the varied trajectories that participants experienced in discovering their identity. There are multiple and unpredictable external variables which may impact a young person (Klein et al., 2015), so it is important to recognise the heterogeneity of the transgender population (Bradford & Catalpa, 2019; Cicero et al., 2020). As this study has illustrated, the young person's journey is unique to them.

So, in seeking their authentic selves, young people embark on a journey of exploration, enabling identity commitment which may change in relation to a range of gender-affirming or validating opportunities. There may also be varied and sometimes challenging life experiences which may prompt the young person to reconsider their identity commitment (Meeus et al., 1999). The experience of change or loss may also precipitate a reconstruction of their self and identity (Charmaz, 2014). The personal goal, however, of the participants in this study was to feel affirmed as a transgender person. This relies on the transgender person's subjective perceptions of gender-affirming processes and social interactions (Glynn et al., 2016; Sevelius, 2013). What was evident from this study is that the more the young person's identity is affirmed and validated, the greater their likely resilience to navigate the healthcare system is.

## Meaningful Engagement with Healthcare Providers

The young people in this study reported a myriad of barriers to accessible transgender-informed healthcare, which was consistent with the other reported findings (Aiken, 2016;

Clark, Lucassen, et al., 2014). The lack of transgender-informed services and the healthcare workforce resulted in the young people facing ongoing challenges and encountering barriers which contributed to a mistrust of healthcare providers and little or no engagement. As young people may not seek help until they are in crisis (McDermott et al., 2013), the lack of trust in healthcare providers increases the likelihood that health and wellbeing needs will not be met. Healthcare services can, however, play a role in supporting young people to advocate for their own health needs (Cooley & Sagerman, 2011). It is evident from the young people's stories in this study that it has only been with persistence that they have been able to find a pathway to realize their authentic selves and seek the services needed. For others, the pathway is not readily accessible, and they have not received the support needed. The availability of transgender-affirming healthcare, coupled with a transgender heath-trained healthcare workforce, has been lacking or inconsistent. During the period of young adulthood, if health needs are neglected, inequities become magnified, and the usual bio-psychosocial development is impeded (Park et al., 2014). For transgender young adults, there are even more challenges to be worked through, as their gender identity development runs parallel to the usual youth to young adult developmental transition.

While accessible pathways to services are vital, a precursor to this is young people's willingness to connect with healthcare providers. Past experiences or the fear of discrimination by healthcare services often results in young people avoiding interactions with healthcare providers (Roberts & Fantz, 2014). While youth-dedicated health services were viewed as welcoming and experienced in catering for LGBTQI clients' needs, young people's experience in other areas of the healthcare system, both in primary care and hospital-based, were less positive. Young people may be reluctant to seek help for general or emergency health issues due to system-based barriers to care, overt discrimination, lack of clinician competence in transgender care, or past experiences which had been emotionally traumatising (Samuels et al., 2018). This study also suggests that poor experiences could result in young people avoiding services.

The importance of patient engagement is well-documented in the literature (Anderson & Lowen, 2010; Stavely et al., 2018). In investigating the processes occurring, it is clear that receiving healthcare from clinicians with little knowledge of transgender health was, for the young people in this study, a continual source of frustration, contributing to a lack of trust in clinicians in general. This subsequently affected some of the young people's confidence in healthcare providers, which then became a barrier to seeking healthcare support. Underpinning the substantive theory was the construct "engage with me" in this study, which highlights the importance of healthcare providers engaging with the young person in a meaningful manner. (Asquith et al., 2021). This calls on commitment from

healthcare services and clinicians to ensure processes and interactions with the young person are respectful and validating. The findings of my study resonate strongly with a recent study in Sweden, which explored transgender persons' experiences and perceptions of encounters with healthcare staff (Carlström et al., 2021). The key theme emerging from Carlstrom and colleagues' study was that young people want to be treated with respect, be accepted, and be treated according to their needs and with competence (Carlström et al., 2021). Both my study and the study by Carlström et al. (2021) point toward the role healthcare providers need to have in engaging and respecting transgender people. Only then can a trusting relationship between the healthcare professional and patient or client be built.

As noted in the literature and evidence in this study, misgendering has a significant impact on how the young person will perceive the service and whether a meaningful relationship will result (McLemore, 2015). As already highlighted, outdated gender binary systems are not confined to healthcare and are still evident in how data is captured in online government databases (Ministry of Health, 2021; Stats NZ, 2018). There remain various structural barriers to updating processes to better accommodate the needs of young transgender people (Mikulak et al., 2021). There was a general sense, as also reported in the literature, that seeking healthcare was a challenging and frustrating process (Mikulak et al., 2021; Roller et al., 2015). Consistent with similar commentary in the literature (dickey, 2017; Jones et al., 2015), participants in this study rejected ill-informed assumptions being made about their health needs and shared their frustration in having to educate the healthcare provider themselves.

In overcoming barriers, a common experience reported by the young people in this study was the need to inevitably assert their gender identity, stand up for themselves, and be noted. The importance of young people feeling they can have agency over their decisions, particularly in relation to their gender choices, is crucial to building their autonomy and confidence to navigate the healthcare system. This is certainly recognised by those working in the field (de Vries et al., 2020; Oliphant, Veale, Macdonald, Carroll, Bullock, et al., 2018). As the emergent construct, *this is my journey,* highlights, young people seek to be active participants in their ongoing healthcare. It also signals that their resilience comes from their determination to be their preferred gender and pursue the support needed. These findings also highlighted that young transgender people want to participate and have a voice in how healthcare is delivered. Involving transgender communities in healthcare delivery would help shape gender-affirmative and responsive healthcare care (Reisner, Radix, et al., 2016).

In understanding young transgender people's perspective of their interactions with health care providers, it is crucial, as this study found, that they feel acknowledged and respected. The category *I matter but...;* asserts this position but recognises that this will not be without challenges due to the multiple barriers in our healthcare systems. Most importantly, however, is the key message emerging from this study that each young person, regardless of barriers and setbacks, will endeavour to assume ownership of their gender discovery journey.

#### **Trusted and Accessible Healthcare**

Improved models of practice are needed to assist health professionals in providing better care (Roller, Sedlak et al., 2015). The WPATH standards of care (Coleman et al., 2012) provide a strong platform with guiding principles for services to follow. The recent New Zealand guidelines outlining affirmative care (Oliphant, Veale, Macdonald, Carroll, Johnson, et al., 2018), which are framed within a holistic Māori model of care Te Whare Tapa Whā (Durie, 1984), provides guidance, taking into account wider contextual needs. The guidelines developed by Oliphant and others provide sound direction to what changes need to occur with the intention of creating equitable and accessible genderaffirming healthcare services that have a solid grounding from evidence-based literature and community feedback (Oliphant, Veale, Macdonald, Carroll, Johnson, et al., 2018). The positive aspect of the guidelines is that the recommended elements of improved healthcare align well with the literature but also provide a solution to the challenges and experiences that the young people in this study faced. Services that have flexible and responsive pathways that prioritise informed consent and self-determination resonate well with the young people in the study who want to retain agency over their healthcare. The inclusion of patient participation in the development and delivery of services also aligns well with young people wanting to be active partners in their healthcare. The challenge now for our healthcare system is investing the right level of resources for these guidelines to be actioned. Referencing the guidelines against Durie's (1984) Te Whare Tapa Whā model of care ensures a more holistic and ideally integrated approach. Whether services will authentically embrace the four elements of Taha Tinana, Taha Hinengaro, Taha Wairua, and Taha Whānau have yet to be seen. The successful translation of guidelines to practice often depends on resourcing, expertise, policy changes and mitigating barriers, which often results in a significant lag before recommendations are actioned (Morris et al., 2011; White et al., 2021).

Across Aotearoa, New Zealand, service options are uncoordinated and not readily accessible for various reasons, and there is still a shortage of healthcare professionals with working knowledge in transgender health (McKinlay et al., 2021). The young people

in this study routinely encountered a range of barriers, a lack of coordination between services and varied accessibility. As the findings in this study indicate, there were, however, positive examples of services meeting the needs of young transgender people. Unfortunately, the availability and consistency of similar service options across the country were found to be varied. This means that trusted and accessible healthcare, while the desired outcome in supporting better transgender health is still very much aspirational. Young transgender people, due to their experiences, as this study highlighted, are very willing to share their ideals for a healthcare service, recognising that improvements are needed. In canvassing the literature, there is still a lack of evidencebased examples of effective models of practice (Busa et al., 2018; Holt et al., 2021; McCann et al., 2021). This gap offers opportunities for more research and innovation. As Edwards-Leeper and colleagues (2016) pointed out, in the absence of clear empirical evidence for one model of intervention, affirmative practice allows the clinician to take into consideration the wide variability and complexity of factors impacting the young person's life (Edwards-Leeper et al., 2016). So, while the research on working models of effective services is limited, the gaps present an opportunity for creating services that are fit for purpose. Building on what is working well from the perspective of the young people and involving the transgender community are steps in the right direction to ensure gender-affirmative and responsive healthcare (Noonan et al., 2018; Reisner, Radix, et al., 2016).

Young people who had received healthcare from a youth-dedicated and integrated health and wellbeing service reported positive experiences of the care received. This endorses the view that integrated models of care which address the various domains of health and wellbeing, including social determinants and developmental transitions, are also likely to help young people to navigate the transition to adult healthcare (Farre & McDonagh, 2017). This captures the third proposition that being engaged with a healthcare provider providing integrated healthcare is a validating experience for young transgender people. When the young person feels that they have engaged and partnered with a healthcare provider or providers, then they are enabled to receive the right level of service for their evolving needs.

In terms of an enduring relationship with a healthcare provider, the national healthcare system cites a strategic goal that all New Zealanders have equitable access to healthcare to "live well, stay well, and get well" (Minister of Health, 2016, p. 3). The same strategic document also acknowledged the shortfalls in the current system, and more recent reviews are signalling further reforms (Health and Disability System Review, 2020). The young person's ability and confidence to assert and articulate their health and wellbeing needs is a crucial key step to each young person navigating the relevant services to

initiate and support their gender identity affirmation and transition. For some young people, gender affirmation does not necessarily result in a binary gender journey. It simply means that they are able to receive informed healthcare to maintain their general health and wellbeing when needed. It is also important to consider that gender transition is not finite (Klein et al., 2015). Transgender people will experience gender-related challenges across their life course (Veale et al., 2019), so trusted engagement with an informed healthcare service and a provider is a key protective factor.

#### **Vulnerability and Resilience**

The literature highlights the multitude of influences and colliding pressures that young transgender people have to deal with while trying to validate their gender identity. These include stigma, harassment, mental health issues and family issues, as well as developmental transitions to independence (Katz-Wise et al., 2017). While young transgender people might appear to be a homogenous group, it is important that their experiences, as evident in this study, are recognised as unique to them. Recognising the diversities involved across interrelated domains (Rodriguez et al., 2016) provides a more realistic recognition of the real world for young transgender people. If a situation is experienced by the young person as more challenging, it is probable that there are several influencing factors colliding, subjecting them to a cluster of external pressures. The intersection between societal expectations toward gender, sexual orientation, and the associated societal stereotyping is a significant influence. If the young person is perceived as an outlier to these societal stereotypes, it is not surprising that stigmatisation, victimisation, and marginalisation become a product of these intersecting systems. The addition of ethnic minority affiliation adds further weight to both marginalisation and inequity.

The literature identifies co-morbidities, risks and stressors that impact this potentially vulnerable population (Olson-Kennedy, 2016; Reisner et al., 2015). Mental health concerns, particularly depression and vulnerability to suicide, feature significantly in young transgender people who experience high levels of discrimination, stigmatisation and victimisation (Olson et al., 2015; Veale et al., 2019). For the young people in this study, it was evident from their stories that many had experienced various challenges in their lives that, at times, compromised their wellbeing. These experiences were consistent with the findings by Veale and colleagues, in which two-thirds of those surveyed reported experiences of discrimination (Veale et al., 2019). As already highlighted in the literature review, stigma occurs at multiple levels (White Hughto et al., 2015), manifesting in various ways being both overt and less intentional. The latter may occur in response to health professionals' lack of training in transgender health. Whether

this should be viewed as a knowledge gap or unintentional ignorance (Mikulak, 2021) does need to be explored, recognising that stigmatisation and discriminatory behaviour increases vulnerability to mental health issues, anxiety, depression or even suicide (De Santis, 2009; Verbeek et al., 2020; White Hughto et al., 2017). As expected, being a recipient of stigma and discrimination increases the general vulnerability to victimisation. It is the impact of cumulative victimisation which increases the risk of young transgender people experiencing depression (Mustanski et al., 2016). Transgender individuals are more likely to have been victims of sexual violence than the general population and then are twice as likely to have attempted suicide in the previous twelve months (Veale et al., 2019).

While gender dysphoria is often referred to in the literature, most of the young people in this study did not readily associate the distress in relation to their gender incongruence with dysphoria, labelling it as depression or anxiety. Most young people were more familiar with the meaning of depression rather than dysphoria. Whether this was a default position due to the lack of access to transgender health information or psychological or wellbeing support is not clear. Those young people pursuing a medically assisted gender transition recognised that it was necessary to meet the criteria for gender dysphoria during a pre-requisite psychological evaluation. The tension between meeting the criteria for a diagnosable condition while not resorting to pathologising gender identity preferences has resulted in the term not being consistently applied (Davy & Toze, 2018). As dickey (2017) points out, the diagnosis of gender dysphoria as a mental health condition may become an unnecessary barrier to accessing healthcare. Acknowledging the lack of research on gender dysphoria, a recent position statement released by the Royal Australian and New Zealand College of Psychiatrists noted the complexity and differing perspectives relating to gender dysphoria and that a comprehensive assessment exploring the patient's gender identity is crucial (The Royal Australian & New Zealand College of Psychiatrists, 2021).

As already highlighted, it is well documented that young transgender people have an increased risk of depression, anxiety disorder, suicidal ideation, suicide attempts, and self-harm than cisgender youth (Reisner et al., 2015; Surace et al., 2021). The potential causes of distress may well be the result of colliding or complex pressures and adverse events. This can be related to family relationships, peer rejection, societal marginalisation or other external influences (McCann & Sharek, 2016), or stigma and discrimination (White Hughto et al., 2017). The young people reported delays in accessing psychological evaluations and cited barriers to receiving help for their distress, low mood or issues associated with their gender identity. Consequently, most young people reported that they were seeking support outside of healthcare, including from peers,

friends and family. This study highlighted that young people typically resigned themselves to lengthy wait times in accessing psychologists and accepted that there were few trained counsellors or mental health providers familiar with transgender health.

There is considerable literature on the vulnerability of transgender people but little focus on their resilience in navigating challenges. Evident in this study was the young people's commitment to their gender identity and the determination to navigate the barriers and be proactive in managing their own healthcare. While setbacks, delays and costly access were a source of frustration and, at times, triggered periods of depression, all of the participants could identify support from partners, peers, or family/whānau support which provided affirmative encouragement. This is consistent with a study conducted by Puckett et al. (2019), which found that family and peer support buffered young transgender people from stressors and contributed to their resilience against anxiety and depression. While more research is needed, parental support, in particular, does appear to be a protective factor contributing to resilience and better health outcomes for young transgender people (Andrzejewski et al., 2021).

All of the young people participating in this study were active seekers of information either via the internet, from peers, supportive whānau, or healthcare services. Their motivation to access online resources and sites was so that they could navigate both the healthcare system and the wider social system. It is important to note that this cohort of young people was also prepared to participate in research to advocate for improvements in healthcare, which suggests this is a group who are more assertive in both seeking help and taking agency over their needs. Consequently, these young people may display resilience that other young transgender people may not yet have. What is clear is that access to dedicated LGBTQI social support services have played a significant role in providing advice and support to navigating societal structures and systems barriers. Access also to integrated youth and young adult dedicated health and wellbeing services such as one-stop shops and youth health hubs, which provide physical, mental health, social and whānau support, were highlighted as the preferred model of care.

#### Whānau/Family as Protective Factor

A recurring property emerging from this study was support from whānau or families. Whānau and family also included a significant supporter, partner, or extended family member identified by the young person. It was evident that supportive families are strong protective factors which can mitigate young transgender people's vulnerability to external stresses, which can compromise psychological wellbeing. This is consistent with reported findings in the literature, which highlight the positive impact of supportive family

systems (Andrzejewski et al., 2021; Westwater et al., 2019). Family support for young transgender people can act as a buffer across a broad range of mental health issues, including depression and suicide (Johns et al., 2018; Olson et al., 2016; Puckett et al., 2019; Veale et al., 2017; Watson et al., 2017). While most of the participants in this study described having support from at least one family member, they also experienced varied and changing support from other family members, with differing levels of acceptance between parents. This is consistent with the literature, which has suggested that care and support provided by just one parent is linked with reduced incidence of suicidal and significant depressive symptoms (Clark, Lucassen, et al., 2014; Veale et al., 2019).

While the value of general family support was clearly evident from the study, the family's acceptance of transgender identities was reported as their need for more time. This is similar to the findings by Andrzejewski et al. (2021), in which young people experience some form of general parental support, but gaining parental or family acceptance in relation to their gender identity tended to be less prevalent. Parental support is significantly associated with higher life satisfaction, a lower perceived burden of being transgender and fewer depressive symptoms (Simons et al., 2013). However, a lack of family support and no alternative support is likely to increase the risk and vulnerability to external stressors and psychological distress (McConnell et al., 2016). Parental rejection, in relation to gender identity, results in an increased risk of mental health concerns (Bradford et al., 2013; Katz-Wise et al., 2016). This was certainly the case with some of the participants, who reported the adverse impact of their gender identity being rejected by family members. While in all cases, the parental position changed over time, this occurred only when families had access to information or were able to meet with healthcare professionals to discuss their reservations.

There is little doubt from the findings in this study that young people who had family support tended to have more confidence in navigating the healthcare system and other support services. For those who experienced parental acceptance for their transgender identity, even if by only one parent, they were provided with affirmation and validation that played an integral role in the young people feeling that they mattered and their choices as young adults were respected. Having this respect from significant others within the family provided a safe environment to disclose and express their gender identity. This, then, is likely to provide protection against mental health risks (Olson et al., 2016). Given that parents and families can offset the mental health impact of the myriad of external stressors their children may experience (Simons et al., 2013), early engagement of families by healthcare providers seems crucial. Many of the young people shared this perspective, describing how ideally, services should be whānau or family-inclusive, enabling families to become informed and educated to have a better

understanding of their transgender child. There was a general sense that parents and whānau needed access to their own counselling, transgender education, or support groups. Promoting parental or family support and acceptance should be integrated into routine and comprehensive service delivery (Katz-Wise et al., 2016; Rafferty et al., 2018)

# Grounded Theory to Action – Toward Transgender Health and Wellbeing

Integrated models of care which provide an affirmative response can provide a platform for providing a multi-levelled response. While there is recognition that more research is needed to demonstrate the effectiveness of interventions (Holt et al., 2021; Puckett & Matsuno, 2021), services should consider an evidence-based model that is holistic and flexible and which is guided by transgender individuals who determine what the best outcomes should be (Riggs et al., 2015). Reducing inequities for ethnic minority youth and young adults, as highlighted by this study and the literature, continues to be an area where investment is needed to develop appropriate services which fully consider the needs of this group. As this study has revealed, healthcare services and healthcare providers could play a stronger role in supporting young transgender people by having access to all aspects of affirmative transgender health care. To improve service connectedness, it is important that all services along the healthcare pathway commit to a shared value base of affirmative and integrated care, which can then be translated into accessible services offered across the country. In reflecting upon the intersectionality of the need for young transgender people's healthcare services which cater for physical, psychological, social and cultural needs, an aspirational solution to connected and timely healthcare is provided. Unfortunately, this is not the experience of the young people in this study who experienced a hard-to-access, fragmented system of care, which was not responsive to the needs of young transgender people.

Healthcare providers' lack of training in transgender health was a recurring concern in this study. It is clear that usual clinical training has not included transgender care and that more education and information on understanding diversity is needed to strengthen the manner in which health care to this population is delivered (Dubin et al., 2018; Gamble Blakey & Treharne, 2019; McPhail et al., 2016; Pantalone & Abreu, 2021). As highlighted in the literature review, informed clinicians are also more likely to advocate for better policies to reduce inequities (Roller et al., 2015).

The substantive theory generated in this study has provided a clear indication of outcomes that are meaningful to young transgender people. The three main constructs are *validation*, *trust*, and *accessibility*, contributing to an enduring partnership with a

healthcare provider. The outcomes can be measured from patient satisfaction and other affirmative indicators. Outcomes, however, do not necessarily represent an end goal. Rather they are predictors or enablers of improved health and wellbeing for transgender young adults. The proposed Framework for Affirmative Healthcare for *flourishing* Transgender Young Adults presented in the previous chapter (refer to Figure 6) incorporates key principles which can guide healthcare service delivery across New Zealand. For the healthcare system to be available and reach young transgender people, it needs to be accessible, provide choice, promote safe and culturally responsive care, promote trust in the healthcare provider, and maintain engagement with the transgender community. The framework outlines cornerstones generated from the various properties within each of the three categories of the substantive theory. The central focus for the young person is their personal goal of being the person that they want to be, which should guide healthcare services to ensure the care provided is affirmative and enabling for transgender young adults.

The first cornerstone is information, education and validating opportunities. Many of the young people felt that a recognisable national body or "centre of excellence" that can post resources and lists of recommended health providers would speed up retrieving the right information to inform what steps they can take.

The second cornerstone is meaningful engagement with healthcare providers. Unfortunately, for the young people in this study, the care pathway is often unclear, confusing and not readily accessible. While the main city areas have been better resourced with a publicly available specialist or youth dedicated services, for those young people living in provincial areas of New Zealand, there is not the same ready access to transgender-trained or informed services. The positive aspect of youth and young adult dedicated services is their demonstrated commitment to ensuring the voices and perspectives of young people as the end-user are represented. Consequently, the service environments are also experienced and seen as more inviting, open-minded, and youthful. The range of publicly funded health services able to provide transgender healthcare, however, are less identifiable. Access to these services can also be difficult and hampered by eligibility criteria and location.

The third cornerstone is informed and integrated health and wellbeing services. The barriers and issues encountered by young adults provide a clear indication of some of the key considerations in designing services which engage young people. For young people aged 18 or older, sitting on the cusp between adolescence and adulthood, the expectation currently in New Zealand is largely that their health needs will be met by adult services. Unfortunately, these services tend not to provide a more developmentally

targeted approach to accommodate young people still not financially or emotionally independent from family and still in the process of developing their own autonomy. The exception to this is the Youth One-Stop Shops or the small number of youth-dedicated health services across the country.

Availability of youth and young adult-focussed services, as already highlighted, is also limited (Communio, 2009) and has remained under-resourced (Bagshaw, 2012; McKinlay et al., 2021). The young people who have received their care from a youth-dedicated clinic experience healthcare as inclusive and catering for their broader needs and family issues. The experience of young people in this study has been that dedicated youth services have felt safe and affirming.

#### **Implications for Healthcare**

As this study highlights, there continue to be barriers which make healthcare access for young people challenging. The young people in this study also experienced the search for healthcare as a challenging and frustrating process, which has also been noted in the literature (Roller et al., 2015). There are clear implications for the healthcare system and providers if progress is going to be made in reducing these barriers. The availability of services, workforce capacity and competence need to increase if the healthcare system is going to be more responsive to the needs of transgender young adults. Improvements will need to occur in systems, research, and clinical settings across the social, psychological, medical, and legal constructs of gender affirmation (Reisner, Radix, et al., 2016).

Overcoming barriers was both a challenge and a key milestone for young people in making progress in their transgender healthcare journey. As Mikulak et al. (2021) points out, barriers occur across several domains. This includes structural, technical, educational, cultural and social (Mikulak et al., 2021). A further barrier identified by the young people in this study was access to mental health and wellbeing support. The implication for healthcare providers is to consider how a holistic approach can be translated into a multidisciplinary or integrated practice.

While various national health reforms and associated strategies (Health and Disability System Review, 2020; Ministry of Health, 2002b-a, 2015b) have provided the impetus for a more responsive health system, for change to take effect, there also needs to be the necessary investment to ensure that the infrastructure and mechanisms are in place to address the structural barriers such as wait-times, limited service availability, and the workforce shortage. Adolescent and young adult development have also yet to be adequately acknowledged in the delivery of healthcare (Farre & McDonagh, 2017).

National guidelines which support improved information provision and clearer standards have been signalled for some time (Jones et al., 2015). Guidelines on affirmative care specific to Aotearoa, New Zealand's transgender population have now been developed (Oliphant, Veale, Macdonald, Carroll, Bullock, et al., 2018) and provide a promising start to improving healthcare provision.

To address structural barriers, systems improvements are required. The recent Health and Disability Review in New Zealand is planning changes in how healthcare is delivered, prioritising consumers, whānau and communities, noting that they are central to an integrated health system (Health and Disability System Review, 2020). Healthcare reforms should not only be only at a policy and medico-legal level (Aiken, 2016) but must cascade down to practice. Ideally, they should also be consumer-driven. Integrated and holistic models of care which provide easy access and connected care have already been a recurring theme in the literature (Kcomt et al., 2020; Puckett et al., 2019; Reisner, Radix, et al., 2016; Safer et al., 2016). A holistic and integrated model of care has strongly been advocated as relevant for Māori for almost four decades (Durie, 1984). Unfortunately, this has yet to be routinely incorporated into the delivery of healthcare services. With Te Whare Tapa Whā now incorporated into the New Zealand Guidelines for Affirming Care (Oliphant, Veale, Macdonald, Carroll, Johnson, et al., 2018), there is an opportunity for the model to inform structural changes in healthcare delivery.

The importance of young people having a meaningful engagement with health providers emerged as a prerequisite to developing an ongoing relationship with a healthcare provider. A lack of education and training in transgender health was a key barrier to services across the health system. While education and training can target clinicians and practitioners', staff at all levels of the healthcare system would benefit from greater awareness of transgender health and wellbeing. It is important that knowledge gaps are addressed and not simply noted with no action, which may inadvertently contribute to barriers (Mikulak, 2021). Education is needed on supporting systemic approaches, particularly when working with young people and their families or whānau, to be able to respond or engage well with transgender patients.

For healthcare providers to be able to deliver affirmative and integrated care, the technical barriers, such as inflexible electronic systems and processes, will need to be mitigated. Processes which misclassify young transgender people or fail to accommodate their gender identity can be psychologically disruptive (McLemore, 2015). As this study highlighted, most of the young people's initial search for healthcare support and information was via online and internet sites. Healthcare providers should therefore

consider how technical barriers can be transformed into technical aids and be a valuable tool for both patients and clinicians (Evans et al., 2017; McInroy & Craig, 2015).

As clearly identified by the findings in this study and the literature, young transgender people experience compromised mental health and personal safety, so they need appropriate services in safe environments (Clark, Lucassen, et al., 2014; McKinlay et al., 2021). The availability of welcoming spaces which visibly convey affirmative messaging with posters and health information contributes significantly to reducing anxiety and the avoidance of health services (McClain et al., 2016). Mental health and wellbeing options also need to be accessible (Clark, Lucassen, et al., 2014) and incorporated into routine service delivery. While young transgender people's vulnerability to external stressors is an important priority, it is also important that healthcare services focus on facilitating opportunities for promoting protective factors and building resilience (Johns et al., 2018; Watson & Veale, 2018). Healthcare providers can also act as allies to young transgender people by creating safe environments and facilitating protective factors (Eisenberg et al., 2017). Taking an ecological perspective, as outlined earlier in this chapter, family and whānau play an important role in the affirmation and validation of young transgender people. Family-inclusive healthcare can support family connectedness and promote acceptance and gender-affirming behaviours (Andrzejewski et al., 2021; Tankersley et al., 2021) or support young people's re-engagement with families (Shelton & Bond, 2017).

The health and wellbeing of young transgender people are influenced by multiple factors, including their interaction with their interpersonal, community, and sociocultural environments (McInroy & Craig, 2015). Young adults also face other developmental transitions, which combined with their gender transition, can be, at times, multifaceted and complex (McCann & Brown, 2021; Munford & Sanders, 2019). These authors suggest that young people are keen to exert agency over their transitioning experiences but can find that their autonomy is limited and influenced by the actions of others (Munford & Sanders, 2019). This was consistent with the perspectives shared by the young people in this study. The implications for healthcare providers are to include support for the various aspects of the young people's life transition (Johns et al., 2018). This includes their broader social needs for housing, employment, health and social services (McCann & Brown, 2021). Access to practical support and resources to aid their gender affirmation and transition needs would also contribute to a better quality of life (Glynn et al., 2016).

The final implication for healthcare providers is engaging and involving transgender communities in healthcare research, design and delivery (Noonan et al., 2018; Reisner,

Radix, et al., 2016). While structural and systemic improvements are needed across the healthcare system, providers will need to be led by young transgender people who are their end-users. As the grounded theory generated from this study indicates, central to engaged and enduring healthcare for young transgender people is the engagement and validation of their identity. The recognition of their agency as a young adult and that they matter was also important. Young people want to be treated with respect and to feel able to trust the healthcare being provided (Carlström et al., 2021). For the young people seeking their identity, healthcare services should be able to cater for the multiple strands of needs which can protect and promote their health and wellbeing and account for the intersectionality between culture, gender, age and sexual orientation and whānau. As this study demonstrates, the collective voice of transgender young adults provides both a resource and measure of what needs to change in our healthcare system.

#### Implications for Healthcare Workforce

As noted in the previous section, the lack of education and training in the healthcare workforce has created a barrier in the delivery of healthcare to young transgender people. From the findings in this study, young people's initial experience with healthcare providers affected their perception of the healthcare system as either being welcoming or dismissive. It was evident that their interactions with a healthcare provider were affected by the varying levels of clinician capabilities, knowledge, attitude, and interpersonal style. This, in turn, renders the experience affirming or negative (White Hughto et al., 2015).

Consistent with the literature (Poteat et al., 2013), the young people in this study tended to anticipate that the health provider would know less than them in relation to transgender health. This provoked frustration and disappointment. If the health provider, however, was prepared to seek knowledge and take an advocacy or ally role, the young people acknowledged the effort, recognising there were limited training opportunities. Evident from the findings is that the young people's experience with healthcare has been influenced by interactions with all healthcare staff, including those working in reception, physicians (general practitioners and specialist endocrinologists), nursing staff, mental health clinicians, counsellors, and peer support. Emerging from this study was the significant variation in knowledge, attitudes and approaches, which as McPhail et al. (2016) points out, could result in denial of care. Increasing healthcare providers gaining some competency in transgender health and wellbeing is vital.

As highlighted in the proposed framework based on the substantive, key cornerstones are needed to enable an integrated model of affirmative care for the transgender community. These are: Information and education, meaningful engagement, and

informed and integrated care. Each area is consistent with other studies and reviews (Bolderston & Ralph, 2016; Gamble Blakey & Treharne, 2019; McClain et al., 2016; Shires & Jaffee, 2015). While structural and systemic changes provide the infrastructure for healthcare services, the quality of care depends on the healthcare professionals and other practitioners who collaborate to facilitate an integrated approach.

Recognising that the healthcare workforce trained in transgender health, internationally and in New Zealand, is low (Bernal & Coolhart, 2012; Gamble Blakey & Treharne, 2019; Rafferty et al., 2018), a workforce development strategy will be needed. This assumes that investment into service provision for young transgender people will include more job opportunities for clinicians and practitioners. Drawn from the findings of this study and supported by the literature (Dubin et al., 2018; Gamble Blakey & Treharne, 2019; McPhail et al., 2016; Safer & Pearce, 2013), several training topics are listed under the priority areas proposed in the framework generated from this study. To ensure appropriate information and education are made available to young people seeking support and advice, all healthcare clinicians who may work across a variety of settings require foundation-level knowledge and skills in transgender health, including gender identity, use of language and pronouns, youth and young adult development and diversity awareness. To enhance meaningful engagement, all staff involved in providing general, primary and specialist care should be encouraged to engage in reflective learning and practice with attitudes, personal biases and diversity comfort being a focus. The aim is to strengthen healthcare providers' competencies in transgender affirmative care, including promoting protective influences and fostering resilience. For the third priority area, informed and integrated care, all healthcare professionals involved in providing care require access to training to develop core and advanced competencies that are discipline-specific to enhance early screening, assessment and interventions. Training and practicum experiences would ideally be applied within a Te Whare Tapa Whā context (Durie, 1984; Oliphant, Veale, Macdonald, Carroll, Johnson, et al., 2018), capturing the bio-psycho-social, spiritual and cultural context. Opportunities to experience familyfocussed and whānau ora approaches in practice should also be sought.

The challenge for public healthcare organisations is to achieve an appropriately trained workforce in young adult transgender care. There needs to be tertiary institutional support and a shift in educational curriculums toward pedagogical interventions (Dubin et al., 2018). Further research on addressing the systemic barriers impeding clinicians' access to training and developing the broader skill set needed for integrated ways of working is suggested.

#### Challenges, Strengths & Limitations of this Research

In undertaking this study, my concern was that a qualitative approach could be criticised for lacking empirical evidence. Consequently, I used a constructivist grounded theory approach for this research. The hallmark feature of grounded theory is that it generates theory from data systematically obtained and analysed (Charmaz, 2014; Corbin & Strauss, 2012). As outlined in Chapter 4, Charmaz's criteria for grounded theory studies (Charmaz, 2006, 2014) have been used as a reference to determine whether this study reflects a robust methodological design within a grounded theory context. For the most part, this study demonstrated methodological rigour, but there were limitations, which I will now discuss.

There were considerable challenges in recruiting young people for this study, despite advertising the study in healthcare services that work with young transgender people and via networks of other health professionals and researchers. Noting that the avenues to reach young people can be difficult than it also suggests that the opportunity to have their voices heard may also be impeded (Turner & Almack, 2017). Various studies across a range of health needs and concerns have faced similar challenges in recruiting young adults for research studies. (Fern & Taylor, 2018; Hays et al., 2020; Hudson et al., 2017; Kenten et al., 2017; Newington & Metcalfe, 2014; Reagan et al., 2019). Young adults reflect an age group that is moving through life transitions, so it can be a problem to locate them or for them to prioritise participation in a research study (Hays et al., 2020). This seemed to be the case with some of the young people in this study who expressed initial interest in the study but did not take up the invitation to make contact. Other studies have found that the percentage number of young people from the total eligible target cohort of a study who do opt to participate is usually lower than expected (Hays et al., 2020). Others have found that the conversion rate from eligibility to participation is well under 50% (Hudson et al., 2017; Reagan et al., 2019). This was certainly the case for this study. As the youth and young adult transgender population in New Zealand is estimated to be 1.2% (Clark, Lucassen, et al., 2014), there is already a relatively small pool to draw from.

The question arises as to whether the recruitment methods of academic research resonate with young people. It has been known for some time the importance of involving young people in the design of youth-focussed research where possible (Kirby, 2004). In this study, I sought input from a small group of young people to check whether my approach, the flyer and the information used were acceptable to young adults. The method of promoting the study relied on dissemination through healthcare service networks and community groups rather than via Facebook or other social media platforms. Studies have found that Facebook is the most low-cost and effective method

for recruiting young adults (Whitaker et al., 2017), offering recruit convenience (Parkinson & Bromfield, 2013), but the best results are achieved with paired approaches such as face-to-face with web-based methods (Young et al., 2020) and multiplex approaches (Hays et al., 2020). For this study, however, the recruitment campaign was confined to dissemination via known health and support services and did not include Facebook.

Barriers to recruitment can also exist at various levels. The recruitment of young people into health-related studies often relies on health professionals or research institutions to support engaging young people in the way that works best for the young person, so there needs to be a better interconnected system (Kenten et al., 2017; Taylor et al., 2016). The local study Counting Ourselves, which involved an online survey, reported 46% of the 1178 survey participants being youth and young adults (Veale et al., 2019). This is an encouraging result and highlights that it is possible to engage young people. These authors also highlighted their collaboration with diverse community advisory groups, professionals and organisations in preparing the survey (Veale et al., 2019), which may have helped reduce some of the hurdles that may arise with meeting academic research and institutional requirements.

While recruitment may be more successful when utilising social media platforms, the challenge that remains is the conversion from an invitation to participate in a research study. The literature tends to suggest that more public and patient awareness, as well as provider education, is needed in research studies to promote participation (Fern & Taylor, 2018; Hays et al., 2020). Is a study that utilises a survey that is offered online and requires immediate uptake more convenient and accessible for young adults than participating in a qualitative study? I would suggest from the findings of this study that there is merit in both modalities. In comparing the online survey and qualitative methodology as already discussed, online options provide convenience and immediacy. Young people between the ages of 18 and 24 can be transient in their lifestyle opportunities to provide their perspectives and experiences need to be varied. What was noted is that young adults participating in this study tended to be involved in tertiary education or were active in youth advisory forums, which suggests a greater familiarity with the role of research and participatory opportunities.

Despite the small sample, rich data was captured that offered meaningful information about how healthcare services can build trust with transgender young adults. There are varying views concerning the sample size. As already highlighted in Chapter 5, the gender identity and age focus resulted in a homogenous or specific participant group for these domains, which as Guest et al. (2006) suggests, can offset the smaller sample

size. The limitation of a small sample is that viewed alone, it may not necessarily provide full confidence that the findings can be generalised to represent other young transgender people. On the other hand, while a survey may be able to enlist more participants, which increases generalisability without capturing the depth and meaning of young people's perspectives, we may not discover vital information. The young people's stories reflected both commonalities and also unique differences. The data was constantly compared throughout the data collection process, the analysis stage giving weight to the emergent categories. As the data supporting the categories became more pronounced, it strengthened my confidence in the emergent theory *Who am I? This is me*.

To ensure the integrity of my approach, feedback was sought from each young person at the completion of the interviews. The aim was to gauge whether the principles of my research approach had been enacted. All young people reported that the process had been positive, and for some, it was the first time they had reflected on their experiences and in relation to healthcare. Their general comments also confirmed that the constructivist grounded theory methodology, and constructivist enquiry, which starts with people's experiences to understand how they construct their respective realities (Charmaz, 2014), was a useful mechanism for capturing the voices of young adults and translating it into theoretical constructs.

In reviewing the literature, I discovered that much of the research has focussed on healthcare providers' perspectives of what young transgender people need. The research is often presented in case studies, summaries, or reviews and, while taking a strong advocacy position, has not necessarily captured the experiences of young transgender people. I believe the emergent categories generated in this study are fresh and highlight underlying issues for the sample group which might not be otherwise captured. The new insights are particularly reflected in the interrelationship of the categories. The identified categories reveal key issues that impact the everyday lives of the participants. This work provides validation of these experiences. The constant comparative analysis allowed categories to emerge and contribute to the generation of the substantive theory. The value of analysing the data while still collecting data is that emergent categories could be tested with consecutive interviews. It was readily evident, with exploratory questioning, that there were resonating connections with prominent categories across the participants' experiences and the impact on their day-to-day lives. Many of the young people readily acknowledged at the end of the interview that sharing their stories had also been a reflective opportunity, as well as recognising connections between their experiences and perceptions.

The grounded theory that has been generated offers an accurate representation of experiences that the young people had not previously articulated and that may have been overshadowed by assumptions and stereotyping. The value of this theory is that it gives weight and validation to a collective and shared understanding of being transgender. The categories and clusters of interrelating categories suggest generic processes relevant to all participants, which may be generalisable to a wider cohort of transgender young adults. What this means is that these generic categories, if targeted in the right way by healthcare service reforms, might act as a driver or catalyst to effect change through the cluster. As this study has illustrated, the health and wellbeing need of transgender young adults has not been fully accommodated by the current health system or the health workforce. The analysis has generated the priorities that healthcare services should consider to be meaningful and fit for purpose for these young people.

#### Calibrating with A Reflexive Lens

In undertaking a qualitative approach and having worked in the area as a clinician, there was a risk of making premature assumptions concerning meaning. Drawing on my own reflexivity, I was able to restrain assumptions and work through the transcripts in an open manner, which, combined with comparative analysis and repeated line-by-line reviews, allowed other meanings to become visible. I needed to be mindful of whether I was applying a cisgender lens to these findings and consider to what extent the interpretation of the findings had been affected by this. Riggs et al. (2015) point out that decisions in relation to transgender care tend to be shaped by cisgenderism.

As I mentioned in the opening chapter, it was important that I recognised the responsibilities and potential implications of identifying as cisgender and undertaking research with transgender young adults. The question of whether I was the right person to be conducting the research with transgender young adults as a cisgender researcher remained at the fore throughout the study. It certainly prompted my early disclosure to participants that I was cisgender to ensure that at no point the participants would feel uncomfortable with this or my approach or my motives behind the research. It was particularly important that the process was not viewed by participants as exploitative and that they retained control over their level of participation in the study. The constant awareness of the potential imbalance that could occur between participant and researcher did, however, contribute to my reluctance to assertively promote the study in any manner which could be perceived as coercive or unduly persuasive. Upon reflection, this may have hampered recruitment. I was strongly aware of an ongoing level of discomfort, despite the unanimous feedback from participants that the interview process had been an affirmative experience. It was reassuring to hear that the participants had

welcomed the opportunity to share their experiences with the hope that this study may inform improvements in the healthcare system. The balance, however, between discomfort and accountability to the participants in this study has reinforced my continued responsibility to ensure that this research amplifies their voice and perspectives.

The value of a constructivist grounded theory approach is that it prompts the researcher to consider all intersectional domains, including how the researcher interprets the information, which includes being mindful of my own potential biases or views. It is certainly true that, just as much as we may shape our research, analysis with reflexivity also changes and shapes us as the researcher (Corbin & Strauss, 2012).

#### Further Research

Despite the increasing acknowledgement of the health and wellbeing needs of transgender young adults, there is still considerable work needed to build both services and the workforce capacity and capability in affirmative transgender healthcare. There continue to be many barriers to health care for transgender youth, which contributes to low rates of access to the recommended treatment (Breland et al., 2016). The concern is that there is an inequitable provision of health services which cater specifically for young people of diversity.

The literature highlighted that the research on the health needs of young transgender people is varied, using many methodological approaches. These include descriptive case studies of service delivery and examples of model of care frameworks to position statements and more specific discussions of the issues facing transgender and gender-diverse individuals. The quantitative studies were mostly either retrospective evaluations, surveys or observational research. Despite the varied approaches to researching issues facing both transgender and gender-diverse youth and adults, the initial search highlighted pertinent topics for this population, particularly in experiencing stigmatising, discrimination, social stresses, mental health concerns, and struggles in accessing health services with health professionals with training in transgender healthcare.

Several research gaps were identified in the literature. While there was considerable literature on transgender and gender-diverse children and youth, there was less research specifically on the needs of young adults. As highlighted above, there is a strong perception that young adults are hard to recruit; however, that perception can act as a barrier (Young et al., 2020). Young adults are most vulnerable to having unmet health needs compared to other age groups (World Health Organization, 2014), and so would clearly benefit from research that heightens the awareness of these needs, so it is important that we increase research studies on this age group (Fern & Taylor, 2018).

Notwithstanding the need for more young adult-focussed research, exploring the relevance of the theoretical constructs identified in this study to a younger or older cohort of transgender people is also suggested.

Gender dysphoria is frequently referenced in the literature as an issue that requires more common understanding. An example of this is identifying the predictors of gender dysphoria, why it persists from childhood to adolescence, and the impact and nature of appropriate interventions (Olson-Kennedy et al., 2016). What was also noticeable was the lack of empirical reviews, particularly in relation to effective models of healthcare for transgender individuals (Puckett & Matsuno, 2021). There has been a growing number of studies on transgender health and wellbeing, but as indicated in systematic reviews, only a reasonably small percentage are considered to have a strong empirical review or suggest a strong evidence base (Holt et al., 2021; Puckett & Matsuno, 2021). This study has indicated that integrated models of care may provide the affirmative healthcare required to address the needs of young transgender people. More empirical research is needed to strengthen the evidence of effective models in improving the health and wellbeing of young transgender people.

Another key area of concern was the lack of research in New Zealand relevant to transgender youth of Māori descent or other ethnic cultures. In light of the health inequities and vulnerability faced by Māori, further research will need to be prioritised. While the international research provides important information in relation to promising models of care, unless this is integrated with the local context, the value of suggested health reforms may well be undermined. Further research is needed to ascertain whether the delivery of affirmative healthcare is meeting the needs of Māori and their whānau.

Finally, as this study has found, system improvements are still needed to ensure the consistent provision of accessible, connected, and comprehensive healthcare for young transgender people. There are also gaps in the general healthcare workforce's knowledge in relation to transgender identity and health. A multi-levelled approach is necessary to address the complexity of issues experienced by young people. Further research is needed to identify the impact of national health reforms on addressing both the system's barriers and catalysts that have resulted in positive change.

### **Summary**

In this chapter, the findings of this study have been discussed in relation to the literature, current national directions and challenges. There are various systemic factors which significantly impact a young transgender person's ability to navigate a health system

which is currently uncoordinated and under-resourced. The substantive grounded theory generated in this study has made it clear that the young person, and their search for their identity, is central to how they will navigate the health system. Understanding that young transgender people require a meaningful, trusting, and enduring engagement with healthcare services highlights what is needed within the healthcare system to build capacity and capability. The challenges, strengths and limitations of this study were also discussed, highlighting key learnings when conducting research focussed on young adults and a relatively small population group. This study has also identified those areas that would benefit from further research to aid our understanding of how to best support transgender young adults.

In the next and final chapter, I will revisit the original intention of this research, reflect on the key learnings, and highlight how the contribution that the collective voices of the young people participating in this study, together with the substantive theory, have helped our understanding of how young transgender people have navigated the health system.

# **Chapter 7 – Conclusion**

The intention of this research was to understand the processes transgender and gender-diverse young adults use to navigate the healthcare system. This study has highlighted that, despite the developments in acknowledging the needs of transgender young adults, there continue to be significant gaps in consistent transgender healthcare provision across New Zealand. The study also confirms that there are barriers preventing young people from accessing the right level of care for their health and mental wellbeing needs. From the substantive theory, a framework of affirmative healthcare is proposed to provide healthcare decision-makers and planners with a consumer-informed road map, which prioritises meaningful and trusting engagement between healthcare providers and service users. As this study has highlighted, mitigating barriers to accessing services and building the capability of the workforce in transgender health and mental health is crucial for better healthcare for transgender young adults.

A grounded theory informed by transgender young adults has generated *Who am I? – this is me*, which describes the central process that drives and influences how young people interact with their world, which includes the healthcare system. A constructivist grounded theory approach with a process of systematic and comparative analyses was used to generate concepts, categories, and various properties until such a point that saturation was reached. Three categories emerged from this study. These were: *Seeking My Authentic Self* and the process of gender affirmation and validation; *Knowing I Matter But...*, which is having meaningful engagement with healthcare providers; and the third category, *My Transition Enabled*, is being able to access trusted and accessible healthcare for life.

Affirmation of the young person's authentic self was found to be central to their engagement and confidence to navigate the healthcare system. Young transgender people's quest to discover their authentic or true selves featured strongly in this study. Developing their sense of self, for young people, is an iterative and continuous process of seeking meaning and purpose in their lives. Being able to be fully present in their authentic identity without reservations becomes both affirming and validating. The substantive theory, *Who Am I? This Is Me,* represents the young person's declaration that they own their identity in relation to their orientation on the gender spectrum. Their strengthening sense of who they are contributes to their resilience to meet various challenges, such as the healthcare system's multiple barriers. If young transgender people's experiences of health services and healthcare providers are positive, there is a greater likelihood that they will experience the healthcare system as validating and enter

into a meaningful and enduring partnership with a healthcare provider to manage their health and wellbeing. This study highlighted that the healthcare system that young transgender people are navigating is not yet fully equipped to meet their health and wellbeing needs. The participants' stories all highlighted the challenges they faced in their personal lives and in their interactions with the health system. The young people have navigated potential roadblocks in pursuing their journey to have their identity recognised and validated.

The emergent categories from this study have shown that there are multiple intersecting influences impacting young people as they move through a formative stage of their life from youth to young adult. For young people, discovering who they are have, at times, challenged their sense of belonging and connectedness and heightened their vulnerability. Healthcare services can play a key role in encouraging young transgender people to seek help when needed and promote protective influences to buffer them from potential stressors, both external and internal. Having access to affirmative healthcare with validating opportunities can strengthen the young person's resilience to be the person they want to be. For the young people in this study, their experience of healthcare has been varied. While some of the young people reported positive experiences with committed and informed healthcare, most reported mixed experiences. Unfortunately, as evident from this study, young transgender people frequently experience frustration and disappointment when encountering health professionals with little or no knowledge of transgender health. Misgendering has a significant impact on how the young person will perceive the service, which highlights the importance of healthcare services and providers committing to ensuring their processes, and behaviour reflect their affirmative commitment. This includes hospital emergency departments, specialist services including mental health services, and primary care. Without this affirmative and responsive approach, young people will continue to mistrust healthcare providers and avoid seeking support for their health and wellbeing needs. The key issue here is that young people would like to receive care for all their health and wellbeing needs from clinicians who are, at least, transgender-informed. Remediating this gap will require structural and systemic changes to ensure that transgender health is included in training curriculums.

Healthcare providers also need to consider engaging with the young transgender person in a meaningful manner. For young people, being acknowledged by healthcare professionals that they matter is important, as it conveys that they will likely be valued and their choices will be respected. Meaningful engagement also includes young people feeling that they have agency over their decisions, particularly in relation to their gender choices and subsequent care. A trusting healthcare provider and patient partnership is

crucial to building the young person's autonomy and confidence to navigate the healthcare system.

As highlighted throughout this study, young transgender people are vulnerable to various stresses that compromise their wellbeing, so it is vital that, within the healthcare system, safe and trusted environments are accessible. Safe and trusted service provision, however, requires the healthcare workforce across all levels of the healthcare system to commit to increasing their awareness of gender diversity and knowledge of transgender health. Providing a welcoming environment with relevant information and resources explicitly signals the affirmation of gender diversity. Young transgender people's fear of discrimination can be mitigated with all healthcare providers demonstrating that their environments are safe and affirming.

It is well documented that young transgender people have an increased risk of depression, anxiety disorder, suicidal ideation, suicide attempts and self-harm than cisgender youth and it is recognised that this may well be the result of colliding or complex pressures and adverse events. This can be related to family relationships, peer rejection, societal marginalisation or other external influences, such as stigma and discrimination. Consistent delivery, however, of integrated models of care which cater for all the young people's bio-psycho-social, cultural, or spiritual needs are still lacking. This study highlights that young people would like access to services that enable not only their gender transition if sought but also their wellbeing and social needs. Services with integrated service options that addressed physical, mental health and social support needs were indicated as preferred. Those young people who had received healthcare from a youth-dedicated and integrated health and wellbeing service reported positive experiences of the care received. Participants living in other localities without these services felt that similar integrated health services, which are transgender and young adult-friendly should be available throughout the country.

The substantive theory generated in this study suggests that it is important that transgender young adults' perspectives inform improvements across the healthcare system. The implications of the findings from this study are that the starting point for improving healthcare is engaging and involving transgender communities from the outset in healthcare research, service design and delivery. Transgender young adults as endusers should also be involved in the co-design of measures that evaluate successful service delivery. As the literature highlights, there is a lack of empirical research on effective service provision. However, this should also include service user satisfaction. The framework, Affirmative Health Care for Flourishing Transgender Health & Wellbeing (please see Figure 6), generated from the substantive theory, provides healthcare

decision-makers and planners with a consumer-informed road map to aid young transgender people's navigation of the healthcare system. The integral core to these processes is that the young transgender person's gender identity journey is affirmed, enabled, and validated. The overarching aims are that the healthcare system can offer appropriate information and education, meaningful engagement, and informed and integrated care. It is recommended that the following service elements and structural improvements be incorporated into service planning, design and development:

#### Service elements

- Young person guided,
- Safe and welcoming environments
- Culturally responsive,
- Trustworthy,
- Services offering holistic choices
- Whanau/family inclusive.

#### Structural improvements

- To support improvements in the provision of healthcare to young transgender people, investment into extending service capacity to cater for the needs of young adults recognising the all-gender nature of New Zealanders.
- Updating of training curriculums and clinician competency frameworks to include transgender health and wellbeing.
- More research is needed to support the development and delivery of evidencebased and integrated models in transgender health care within Aotearoa, New Zealand, which prioritises consumer co-design.

Currently, in New Zealand, there are national reforms planned for the health sector (Health and Disability System Review, 2020), with a focus on creating a more responsive health system. There is an opportunity for consumer-informed perspectives to guide improvements in healthcare provision. This includes strengthening the healthcare workforce's knowledge and skills to effectively engage with transgender young adults. All of the participants in this study noted that one of the reasons for participating in this research was the hope that their perspectives could influence healthcare improvements. Involving transgender young adults and transgender communities in the development of improved healthcare delivery is key to ensuring these services are shaped in a way that increases access, engagement and choice. For better health outcomes for transgender young adults', opportunities for affirmation and validation must remain paramount.

# **Appendices**



# Tell us how you Navigate the Health System?

We know it is not always easy to find the right service to meet your health needs. We are keen to hear your story of what has worked, what hasn't, what have been the challenges and your thoughts as to what services and clinicians need to do to create "trans friendly" health services for youth and young adults?

With your views, experiences and ideas we hope this study can potentially inform health care improvements and highlight what information and support young adults would really like to have from health care providers.

#### So if you :

- Are aged between 18 and 24?
- \* And consider yourself to be Gender diverse or Transgender?
- And keen to participate in this study or hear more about it

Please send a text or email that you are interested to find out more and I will send you an information sheet and arrange a time to call you.

Please contact me now (Tania Wilson)

Txt/Ph 021 398 760 or email me at taniaw.healthresearch@gmail.com



# **Participant Information Sheet**

#### **Date Information Sheet Produced:**

5/6/18 Revised 1/8/18

Project Title - Understanding the processes young gender-diverse adults use to navigate the health system.

#### An Invitation

Kia ora koutou and greetings.

My name is Tania Wilson. I am currently a Doctor of Health Science (DHSc) candidate at AUT University and I am inviting you to take part in a research study which aims to understand how young transgender people navigate the health system to have their health needs met.

#### What is the purpose of this research?

We know from the research, and from working in the health sector, that the transgender community is one of the most marginalised and underserved populations in terms of their medical and health needs. Unfortunately there are very few health care services able to respond well to the health needs of young people who experience gender variance. It is hoped that this research will help inform the improvements required to build both service and workforce capacity across the care continuum from primary to tertiary care for gender-diverse young people.

#### How was I identified and why am I being invited to participate in this research?

You may have heard about this research from either someone you know (like a friend, health professional or whānau/family member) or you may have seen our flyer. I am keen to talk to transgender or gender-diverse young adults who are

- Aged between 18 and 24 years
- Willing to share their stories (thoughts, ideas and experiences) of the health care they have sought or received, or even had trouble finding

#### How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate is totally up to you, and at any point you can change your mind.

You will be encouraged to ask questions about the study so that if you decide to take part you feel fully informed prior to making your choice. If you decide to participate you will need to sign a Participant Consent Form.

You are able to withdraw from the study at any time, for any reason. If you choose to withdraw from the study, you will be offered the choice between having any data belonging to you removed, or, allowing it to still be used. If you allow the data to be used please note, that once the findings have been produced, removal of your data at a later data may not be possible.

#### What will happen in this research?

I will be asking participants to take part in an interview to share your stories and thoughts from your experiences accessing and receiving healthcare. The interviews will be approximately 1 % - 2 hours in duration and will be audio recorded so that they can be transcribed to a written form. You will be asked whether you would like to receive a copy of the transcript.

#### What are the discomforts and risks?

We recognise that contemplating or moving through gender transition is a vulnerable time. Sometimes sharing our personal stories can be uncomfortable and even distressing. We have found that often having an opportunity to talk about tough issues can be helpful in moving forward.

#### How will these discomforts and risks be alleviated?

If, at any time, in sharing your story you become distressed, we will stop the interview and check whether you are okay to continue or would like a break. It is important to note, that the interview can be stopped at any time. If you decide to discontinue the interview that is totally okay. We will contact you the following day, and again a week later to ensure that you are okay, and we will check in whether there is a need for us to facilitate a referral to the AUT counselling service.

#### What are the benefits?

In taking part in the research, you will be provided with an opportunity to voice your perspective on what works well for services and what doesn't. Often sharing our stories can be a helpful and affirming experience. It is also hoped that your thoughts and experiences of navigating the health care system, will help health services and clinicians understand what works well and what doesn't for Transgender and Gender-Diverse young people.

We also hope that this research will inform funders and planners where the service gaps are in community-based health care for young people.

The benefit to the researcher will be the completion of the Doctor of Health Science programme requirements.

#### How will my privacy be protected?

We will keep your contribution confidential, and will make sure that we change all details that identify you. This includes removing any information, from interview transcripts or quotes, that may identify you in some way such as names, place names, and organisational names. We intend protecting your privacy fully in all presentations and publications of the study's findings.

All information that is collected in the process of this study will be stored securely either in a locked cabinet or in password protected files at AUT University. After six

years we will destroy all the information held by either shredding copies of information sheets and consent forms, or erasing digital files.

#### What are the costs of participating in this research?

The cost will be your time (approximately 1 % - 2 hours) participating in this research. The interview will occur at a venue convenient to you.

#### What opportunity do I have to consider this?

Once you receive this Information Sheet, we will give you two weeks to consider whether you would like to participate in this study and then we will contact you by text or email, or by phone.

#### How do I agree to participate in this research?

After you have had time to think about the study, read the Participant Information Sheet, and I have clarified any questions you may have please advise by email, text or phone that you would like to proceed. I will then ask you to sign a consent form that you agree to participate in the study and we will arrange a date, time and place to meet.

#### Will I receive feedback on the results of this research?

If you would like, I will send you a summary of the findings at the end of the research, and notify you of any papers that are being written and which journals we are submitting these for publication. We also intend sharing this information at relevant conferences, seminars and interested groups.

#### What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, *Prof. Denise Wilson Email denisel.wilson@aut.ac.nz*, or 09 921 9999 ext 7392

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

#### Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

#### Researcher Contact Details:

Researcher: Tania Wilson, <u>Taniaw.HealthResearch@gmail.com</u> or phone 021 398760

#### **Project Supervisor Contact Details:**

Primary Supervisor: Prof. Denise Wilson, <a href="mailto:denisel.wilson@aut.ac.nz">denisel.wilson@aut.ac.nz</a> or phone 09 921 9999 Ext 9392

Secondary Supervisor: Dr Jeff Adams, j.b.adams@massey.ac.nz



# **Consent Form**

Projec	τ τιτιε:	navigate the health system.	e aauits use to					
Projec	t Supervisor:	Prof Denise Wilson						
Reseal	rcher:	Tania Wilson						
0		understood the information provided about this researc dated 19 July 2018	h project in the					
0	I have had an oppose.	portunity to ask questions and I feel I am fully informed ab	d the information provided about this research project in the uly 2018 of ask questions and I feel I am fully informed about the research be taken during the interviews and that the questions and my d and transcribed. Stopy of the transcript is sharing our personal stories can be uncomfortable and even I can ask for the interview to be discontinued at any time.  We from the study then I will be offered the choice between having its belonging to me removed or allowing it to continue to be used. ave been produced, removal of my data may not be possible.					
0	I understand that notes will be taken during the interviews and that the questions and my responses will be audio-taped and transcribed.							
0	I understand I can request a copy of the transcript I understand that sometimes sharing our personal stories can be uncomfortable and even distressing. I understand that I can ask for the interview to be discontinued at any time.							
0	I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.							
0	I agree to take part in this research.							
0	I wish to receive a	summary of the research findings (please tick one): YesO	NoO					
Participant signature:								
Particip	ticipant name:							
Particip	ant Contact Détails	:						

Approved by the Auckland University of Technology Ethics Committee on 30 July 2018 AUTEC Reference number 18/211

#### **Appendix 4 - Interview Guide and Questions**

### **Interview Guide and Questions**

#### **Date Questions Produced:**

28/2/2018

#### Welcome and Introduction

- Demographics (include ethnicity)
- Duration and Format of the interview
- Contingencies if the interview is distressing
- Consent

# The Question options - Probe questions may be used to explore responses further how, what, where and when

- Tell me about where you are from.
- When did you have a sense that your birth gender did not feel a good fit for you.
- Tell me about what happened.
- What influenced some of your decisions?
- How did you go about accessing help or support?
- How did you discover these services/supports?
- What struggles, if any, did you encounter in seeking help and support?
- What was most helpful?
- What do you think are the most important ways to seek help/and support?
- Tell me about how it was for your family when they found out about your gender needs.
- How well did the services cater for their needs?
- Tell me about services or people that were helpful.
- What positive changes have occurred in your life because of the help and support you received?
- What negative changes have occurred in your life?
- Has your experience receiving or not receiving help affected how you have handled your transition?
- Tell me how would you describe the person you are now, and what most contributed to this.
- After having these experiences what advice would you give another young person who has discovered that his/her birth gender doesn't fit for them?
- Is there anything that you might not have thought about before the interview that has occurred to you during the interview?

Is there anything you would like to add?

Appendix 5 - Transcriber Confidentiality

# Confidentiality Agreement for use with Transcription Services

Research Study Title: Understanding the processes young gender-diverse adults use to navigate the health system. transcriptionist, agree to maintain full confidentiality of all research data received from the research team related to this research study. 2. I will hold in strictest confidence the identity of any individual that may be revealed during the transcription of interviews or in any associated documents. 3. I will not make copies of any audio-recordings, video-recordings, or other research data, unless specifically requested to do so by the researcher. 4. I will not provide the research data to any third parties without the client's consent. 5. I will store all study-related data in a safe, secure location as long as they are in my possession. All video and audio recordings will be stored in an encrypted format. 6. All data provided or created for purposes of this agreement, including any back-up records, will be returned to the research team or permanently deleted. When I have received confirmation that the transcription work I performed has been satisfactorily completed, any of the research data that remains with me will be returned to the research team or destroyed, pursuant to the instructions of the research team. 7. I understand that AUT has the right to take legal action against any breach of confidentiality that occurs in my handling of the research data. Transcriber's name (printed) Transcriber's signature \_\_\_\_\_

#### Appendix 6 - AUTEC Ethics Approval Letter

#### **Auckland University of Technology Ethics Committee (AUTEC)**

Auckland University of Technology D-88, Private Bag 92006, Auckland 1142, NZ T: +64 9 921 9999 ext. 8316 E: ethics@aut.ac.nz www.aut.ac.nz/researchethics

30 July 2018
Denise Wilson
Faculty of Health and Environmental Sciences

Dear Denise

Re Ethics Application: 18/211 Understanding the processes young gender-diverse adults use to navigate the health system

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 30 July 2021.

#### **Standard Conditions of Approval**

- 1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/research/researchethics.
- 2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through <a href="http://www.aut.ac.nz/research/researchethics">http://www.aut.ac.nz/research/researchethics</a>.
- 3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: <a href="http://www.aut.ac.nz/research/researchethics">http://www.aut.ac.nz/research/researchethics</a>.
- 4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
- 5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor Executive Manager

**Auckland University of Technology Ethics Committee** 

Cc: <u>twilson.healthresearch@gmail.com</u>

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# Appendix 7 – Criteria for Grounded Theory Studies

Criteria for Grounded Theory Studies (adapted from Charmaz, 2014)							
Domain	No/Not achieved	Partially achieved	Yes/Achieved	Comment			
Credibility							
Has the research achieved intimate familiarity with the setting or topic?			<b>√</b>	The depth of disclosed information provided by the participants enabled rich data to be gathered reflecting commonalities and unique differences			
Are the data sufficient to merit your claims? Consider the range, number and depth of observations contained in the data			<b>✓</b>	The size, and Maori and Pacific representation of the sample was less than hoped. However, the sample was relatively homogeneous which allowed for a smaller sample to be acceptable. While he observations were limited to single interviews, however the depth of data gathered provided full accounts of participants' experiences. were			
Have you made systematic comparison between observations and between categories?			<b>√</b>	The data was constantly compared throughout the data collection process, and followed with a repeated review of data through the analysis stage to check the strength of the emergent categories,			
Do the categories cover a wide range of empirical observations?		<b>√</b>		Data was collected from single interviews only across the sample group, and while these were in-depth it did not cover a wide range of observations			
Are there strong logical links between the gathered data and your argument and analysis?			<b>✓</b>	As the categories became more pronounced it strengthened my confidence in the emergent theory but also the linkages and interrelationships between categories			
Has your research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?			<b>√</b>	I believe that the process I used, and my rationale described in my methodology highlight the journey of capturing the rich stories of the participants and translating into a theoretical construct			
Originality							
Are your categories fresh? Do they offer new insights?			<b>✓</b>	I believe the categories are fresh in that they highlight underlying issues for the sample group which might not be, otherwise captured. The new insights are particularly reflected in the interrelationship of the categories			
Does your analysis provide a new conceptual rendering of the data?			<b>~</b>	The initial analysis has prompted me to have some notions about the data, which with more refinement become codes.  These codes evolve to categories. The clustering memoing of the categorised data, and open coding has enabled on-going comparative analysis which has then separated prominent categories from outlier codes. During this process the categories either lose or gain strength to become the building blocks of grounded theory.			
What is the social and theoretical significance of this work?			<b>√</b>	The identified categories reveal key issues and impacting on the everyday lives of the participants. This work provides validation of these experiences.			

How does grounded theory challenge,		<b>✓</b>	Grounded theory encourages the researcher to remain open to the process of discovering new properties from the data.
extend, or refine current ideas, concepts and practices?			So, while the literature had sensitised my initial approach it was important to let the analysis be impeded by assumptions or the influences of any past reviews of literature and experiences. The result was that in this study the development of concepts refined my current thinking and it extended it to include key information related to the participants' sense of self. This has implications for practice.
Resonance			
Do the categories portray the fullness of the studied experience?		✓	I believe the categories do reflect the fullness and depth of the rich information gathered by participants
Have you revealed both liminal and 'taken for granted' meanings?	<b>*</b>		Initially in the data collection and during interviews I was alert to my tendency to assume 'meanings' which was reflected in some of my earlier memos. The code of "vulnerability" was an early identified meaning. Through the comparative analysis, and repeated line by line reviews other meanings became more apparent and so I subsequently made a deliberate attempt to restrain assumptions and work through the transcripts in an open manner.
Have you drawn links between collectivises or institutions and individual lives, when the data so indicate?		<b>√</b>	Yes, I did draw links between the universality of the prominent categories across the participants and the impact on the day to day lives and relationships
Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?	<b>√</b>		While the early findings were presented to the youth advisors for comment suggested the emergent categories were resonating for them, I have yet to provide a summary of my findings to participant to gauge reaction.
Usefulness			
Does your analysis offer interpretations that people can use in their everyday worlds?		<b>√</b>	I do think the analysis will offer an accurate representation of experiences that the young people have not have overtly articulated, and which may have been previously overshadowed by assumptions and stereotyping. The value of this is that it gives weight and validation to a collective and shared understanding of being transgender.
Do you analytic categories suggest any generic processes?		✓	Yes, the analytic categories do suggest generic processes relevant to all participants which may be generalizable to a wider cohort of gender-diverse young adults
If so have you examined these generic processes for tacit implications?		<b>√</b>	Yes, in examining these generic processes across the sample, linkages with other categories highlighted clusters of interrelating categories. This suggests that certain generic categories if targeted in the right way by health service reform might act as a 'driver' or catalyst of change through the cluster.
Can the analysis spark further research in other substantive areas?		✓	The theoretical constructs identified in this study have identified other substantive areas which could be further investigated e.g. the relevance of these constructs to a younger cohort.
How does your work contribute to knowledge? How does it contribute to a better world?		✓	This study has illustrated that the health and wellbeing need of service users have not been fully accommodated by the current health system or the health workforce. This study's analysis confirms what type of health service is meaningful and fit for purpose for transgender/gender-diverse young people. It is hoped that the grounded theory from this study will be informative of how health care can be more responsive to this marginalised group.

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