




Priorities for data collection through a prospective cohort study on gender-affirming hormone therapy in Aotearoa New Zealand: community and clinical perspectives

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ABSTRACT

Introduction. Gender affirming hormone therapy (GAHT) is an important aspect of health care for many transgender and non-binary (TNB) people, but little is known about the long-term outcomes for TNB people in Aotearoa New Zealand (NZ). Pathways to access GAHT are shifting from secondary care towards primary care, so this is an opportune time to commence local research on long-term health and wellbeing outcomes for people initiating GAHT. **Aim.** This paper aims to report on the key findings from four meetings held to inform the design of a prospective cohort study to follow the journey of people initiating GAHT in primary and secondary care settings in NZ. **Methods.** We worked with a community advisory group of six TNB young people and sought input from 14 health care providers involved in the care of TNB people initiating GAHT (GPs, secondary care doctors, and mental health providers). Semi-structured interview schedules were used to guide discussions. Template analysis was used to initially code data based on themes identified from the interview schedule and new themes from discussions were added. **Results.** Participants shared ideas about recruitment and data collection priorities for baseline and follow-up surveys. These included understanding the journey to starting hormone therapy (information-seeking, decision-making), access to services for GAHT initiation, appropriateness of information provision, receipt of the first prescription, goals for and experience of GAHT, and the unique needs of non-binary people. **Discussion.** Input from a TNB advisory group and health care professionals has informed the development of a survey that will be used to understand the experience of, and outcomes for, people starting GAHT in NZ. Findings from this planned prospective cohort study have the potential to improve access to GAHT for TNB people who wish to pursue this option.

Keywords: community collaboration, general practice, hormone/endocrinology, non-binary, primary care, prospective cohort study, transgender.

Introduction

Little is known about the health care pathways and long-term outcomes of transgender and non-binary (TNB) young people who are seeking gender-affirming hormone therapy (GAHT) in Aotearoa New Zealand (NZ). GAHT can play an important role in gender affirmation by helping align a person's body with their gender. It can help reduce gender dysphoria, and improve psychological wellbeing and quality of life.¹ In NZ, GAHT has traditionally been initiated in secondary care, usually requiring an assessment from a qualified mental health professional before prescribing.² This approach can be experienced as pathologising of gender identity, and often results in long wait times and potential cost barriers for patients.^{2,3} In recent years, pathways have been developed to initiate GAHT in primary care by general practitioners (GPs)⁴ and guidelines for the initiation of GAHT in primary care have been endorsed by the Royal New Zealand College of General Practitioners,⁵ although adoption of these in practice is inconsistent due to a lack of funding and education. This approach takes the ethical stance of respecting people's bodily autonomy and an adult's capacity to provide informed consent for treatment, while recognising

WHAT GAP THIS FILLS

What is already known: There is a shift towards general practitioners (GPs) prescribing gender-affirming hormone therapy (GAHT) in primary care settings using an informed consent model of care. There is a lack of long-term data on health and wellbeing outcomes for people taking GAHT in Aotearoa New Zealand.

What this study adds: The insights from this study offer a blueprint for current and future survey design, to ensure data collection is responsive to the needs of transgender and non-binary (TNB) communities and health care providers. These findings will inform future research to equip health care professionals involved in prescribing GAHT with local, evidence-based data to support their delivery of quality health care to TNB people.

the GP as a specialist in taking a holistic approach which considers all aspects of a patient's wellbeing.⁶ This model has advantages for TNB people, with clear potential to reduce stress and improve service access and acceptability.^{4,6}

GPs have expressed concerns about initiating GAHT in younger adults related to age, co-existing mental health issues, neurodivergence and fears around regret, and possible de- or retransition (when a person stops their gender affirmation or transition, or transitions back to their gender assigned at birth).^{1,7} For GPs to feel comfortable and confident in their care of TNB patients, local evidence on long-term outcomes of this approach is needed. No longitudinal data exists for people initiating GAHT in NZ, but two small cross-sectional studies suggest that GAHT initiation in primary care is more acceptable to TNB people than in secondary care.^{4,8} In the absence of local long-term health data, GP concerns may be hard to allay. However, international research in specialised gender clinics and secondary care has shown low rates of physical risk⁹ and improvements in mental health.^{10–12} Alongside increased GP involvement in GAHT initiation, Te Whatu Ora (NZ's national public health agency) are funding new community-driven models of gender affirming health care,¹³ making this an ideal time to gather long-term health and wellbeing outcomes for people on GAHT. This paper describes the findings from stakeholder engagement undertaken to inform the development of a survey-based prospective cohort study to understand the experiences of TNB people who initiate GAHT in NZ.

Methods

Participants

Community members

TNB people aged 18–25 years living in NZ were eligible to join the community advisory group (CAG). Invitations

were sent to rainbow support groups to share with members. Eleven people contacted the researchers expressing interest; nine agreed to participate, and six attended the first hui (meeting).

Healthcare professionals

Contacts known to the authors, who work with TNB people, were emailed a brief description of the project inviting participation. Participants included health care

Table 1. Characteristics of the community advisory group and health care professionals participating in hui.

Characteristic	Total participants (n = 20) n
Community advisory group (CAG) members total	6
Age range	
18–20 years	3
21–24 years	3
Ethnicity (total count) ^A	
NZ European	4
Asian	3
Gender (total count) ^A	
Non-binary	4
Transmasculine, male	2
Transfeminine	1
Region of residence	
South Island cities	3
North Island cities	3
Health care professionals (HCP) total	14
Secondary care	
Endocrinologist	2
Adolescent health physician	1
Sexual health physician	1
Mental health	
Psychologist	3
Psychotherapist	1
Counsellor/Social worker	1
Primary care	
General practitioner (GP)	5
Region of employment/work	
South Island cities	3
North Island cities	11

^ASome participants have more than one ethnicity or gender so total count sums to more than six.

professionals (HCPs) who prescribe GAHT in primary care (GPs) and secondary care (endocrinologists, adolescent health, sexual health), and mental health professionals who support TNB people. Sixteen professionals expressed interest; 14 agreed to participate and attended the hui. HCPs were divided into three group based on their profession (GPs = 5, secondary care = 4, mental health = 5).

Six CAG members and 14 HCPs shared their views about data collection priorities and design of a prospective cohort study. Characteristics of participants are presented in [Table 1](#).

Data collection and analysis

All participants signed consent forms prior to the first hui. Participants were given gift vouchers in recognition of their contribution to this work. Ethical approval was granted by University of Otago Human Ethics Committee (Ref. D22/339, 8 December 2022).

Semi-structured interview schedules were used to guide discussions about study recruitment and data collection priorities to better understand the journeys to starting GAHT for TNB people in NZ (see Supplementary Table S1

and S2). An online hui was held with the CAG in April 2023 co-facilitated by three members of the research team: AK (transmasculine, Pākehā), MP (bisexual cisgender, Māori), and RC (cisgender, Pākehā). Three online hui with the three HCP groups were facilitated by RC and SG (cisgender, Pākehā) between May and June 2023.

Audio-recordings were transcribed using AI software Sonix, with manual corrections made by authors AK and MP. All authors familiarised themselves with the transcripts. Template analysis was used where data was initially coded based on themes identified from the interview schedule.¹⁴ New themes were added, if not already appearing in the initial coding list, and then the template was applied to all the transcripts and modified as necessary to take account of new data. The final template involved the over-arching themes of accessing, starting, and continuing GAHT as well as data about participant recruitment.

Results

[Table 2](#) presents a descriptive summary of the important factors to consider when recruiting and [Table 3](#) includes

Table 2. Key considerations identified by the community advisory group and health care professionals related to participation in a prospective study of people initiating GAHT.

Factors	Community advisory group suggestions	Healthcare professional suggestions
Participant eligibility	<ul style="list-style-type: none">• Explicitly include non-binary people and use this term alongside the term transgender in study advertising.	<ul style="list-style-type: none">• Suggested age range 18–30 years. As people get older the questions would differ, so this age range captures most people and at a similar stage.• Recruit from all over the country to capture experiences in different regions, including urban and rural experiences in NZ.• Include TNB people initiating GAHT in both primary and secondary care.
Motivation to participate in this research	<ul style="list-style-type: none">• Highlight and reinforce benefits of participation and explain mechanisms for how the findings will help people who are considering initiating GAHT.• Be clear about the purpose of the survey and its intentions.	<ul style="list-style-type: none">• The TNB community will want to participate if they feel the study is going to help others.• Confidentiality and feeling safe is important, participants need to understand what data are being used for.• Involve TNB people in the project.• Incentivise participation with a prize draw.
Recruitment considerations	<ul style="list-style-type: none">• Include community-based recruitment in addition to recruitment via clinical settings to increase reach to potential participants.• Recruit through social media, queer community spaces, word of mouth (pass on to a friend), advocates, champions, or influencers, news, or traditional media.• Hold community days for people to learn more and help each other to complete a survey.	<ul style="list-style-type: none">• Involve prescribing clinicians and recruit at the time of first GAHT prescription (via email, text, link for patients).• Having a champion in each service would support recruitment.• Provide other opportunities to increase enrolment, eg include survey details on clinic letters and allow self-referral into the study.• Word of mouth and social media could also be used to recruit participants.• Uptake may be better if consent is sought for HCPs to pass details of potential participants to researchers.
Survey accessibility	<ul style="list-style-type: none">• Paper format important for people without digital access.• Consider survey accessibility for neurodivergent people.	<ul style="list-style-type: none">• Provide access to paper copies of the survey.
Follow-up	Not discussed.	<ul style="list-style-type: none">• Suggested timing of follow up surveys – at 1, 3, and 5 years and ongoing at 5 year intervals.

Table 3. Data collection deemed important by the community advisory group and health care professionals for inclusion in a prospective study of people initiating GAHT.

Data collection topic		Community advisory group suggestions	Health care professionals' suggestions
Journey to starting hormone therapy	Information and decision-making	<ul style="list-style-type: none"> • Include questions about where people find information to help their decision-making, eg where and how to access GAHT, and determine when in their decision-making process it was accessed. • Explore reliability of information sourced. • Enquire how long people have been thinking about starting GAHT (this can often be a long time before seeing a HCP). • Explore the impact of GP knowledge on accessing information about GAHT. 	<ul style="list-style-type: none"> • Explore where people are accessing information about GAHT, and their decision-making process towards initiating GAHT. • Gather information on the use of puberty blockers prior to GAHT. • Find out about the levels of family support during the transition process. • Find out about preparedness of TNB people to start GAHT once information has been provided.
	Provider accessibility (wait times, cost, regional differences, and any other barriers)	<ul style="list-style-type: none"> • Ask about the impact of long waiting times to start GAHT. • Include questions about the journey to the prescriber and whether other HCPs were seen along the way. • Capture any experience of having to move regions or cities to access gender affirming care. • Determine whether people were required to see a psychologist, what that experience was like, any challenges with finding a psychologist and costs involved. • Ask about the cost of accessing care (eg ongoing appointments, injection administration and prescriptions). 	<ul style="list-style-type: none"> • Find out about the process of finding an HCP to prescribe GAHT. • Include questions about wait times to access a GAHT prescriber and the impact of wait times on wellbeing. • Capture experiences of psychological or readiness assessments; including cost and wait times. • Explore regional differences in GAHT access in NZ. • Find out if people are accessing hormone medication online or from overseas suppliers and if so, explore the reasons for this. • Determine whether there are GAHT medications people would like to access but can't.
GAHT initiation and the first prescription	Information provision	<ul style="list-style-type: none"> • Capture perspectives on the information provided at the time of initiating GAHT and how well it was understood. • Ask if information was offered about different ways to use hormones (eg being on testosterone for a short time only). • Determine whether information was provided about genital changes, effect on sexual function and fertility. 	<ul style="list-style-type: none"> • Ascertain whether information provided by HCPs was sufficient, pitched at the right level and met the needs of GAHT users. • Explore participants understanding of the effects of GAHT on fertility.
	Informed consent model	<ul style="list-style-type: none"> • Enquire about the experiences of informed consent approaches (ie initiating GAHT without a required psychological assessment). 	<ul style="list-style-type: none"> • Gather insights of people's experience with the informed consent model of care (versus the readiness assessment model). • Seek the experiences of primary care/ GP-led GAHT initiation.
	Initiating GAHT	<ul style="list-style-type: none"> • Capture how people felt immediately after commencing GAHT, as many people describe an immediate sense of relief, once GAHT has started, or an improved 'headspace' or ability to live better. 	<ul style="list-style-type: none"> • Capture the range of specific medications that are prescribed for TNB initiating GAHT. • Consider the possibility of temporary improvements and fluctuations in mental health at the time of first prescription (eg due to initial happiness at finally having their prescription).

(Continued on next page)

Table 3. (Continued)

Data collection topic		Community advisory group suggestions	Health care professionals' suggestions
Goals and experience of GAHT	Understand goals among non-binary people	<ul style="list-style-type: none"> Find out if different medication options were discussed, including the option of lower doses. Explore how the participant felt about how the prescribing HCP listened to and accepted people's individual transition goals. Capture the health care, transition needs, and experiences of non-binary people, and determine whether they felt supported. Understand whether their non-binary identity was respected or if they felt pressure to present as binary trans. Explore experience and decision-making about any unwanted physical effects from GAHT (eg not wanting breast growth but wanting other effects of oestrogen). 	<ul style="list-style-type: none"> Gain an understanding of people's unique goals and whether they have achieved these over time. Understand non-traditional ways of taking GAHT eg using testosterone for a short time to gain some effects and stopping once these are achieved, or use of low doses. Understand more about the goals non-binary people have when taking GAHT. Answer questions about whether non-binary folk feel they need to present as binary transgender to access GAHT.
Social transition and other gender-affirming measures		Not discussed	<ul style="list-style-type: none"> Understand the timing of social transition in relation to initiating GAHT. Describe the ability or desire to access other gender affirming care (eg surgery, voice therapy). Ascertain whether people were advised that GAHT was a requirement to access further gender-affirming health care.

factors related to survey content. Both the CAG and HCPs shared ideas about eligibility, recruitment strategies, and people's willingness to participate. Understanding information needs, decision-making, and factors impacting on access to services were key considerations related to GAHT initiation across all groups, as were questions around goals and the unique gender affirmation needs of non-binary people.

Table 4 presents HCPs suggestions about data collection to capture longer-term outcomes (topics that were not discussed in the CAG hui). Understanding the psychosocial impacts of GAHT (eg on wellbeing and mental health, social participation, employment, and relationships) and any mitigating factors that were deemed important. A number of HCPs expressed a desire for local data on the long-term medical and physical impacts of GAHT, some of which would need to be measured via clinical follow-up.

Discussion

TNB community members and HCPs agreed that NZ-specific data relating to long-term outcomes for people on GAHT is needed and identified priorities for data collection. Overall, the CAG focused on the need to understand people's experiences accessing GAHT and the barriers faced (including not

being trusted or believed by HCPs). HCPs wanted the proposed research to improve information provision at initial appointments and commented on the potential for the findings to increase the confidence of GPs to initiate GAHT. Both the CAG and HCPs said they thought that TNB people would want to participate in this research for altruistic reasons.

The CAG and HCPs identified a need to ensure the information provided about GAHT is thorough and well understood, including on decision-making relating to fertility. The HCPs were also interested in the alignment of current information about the effects of GAHT with people's experience of being on GAHT over time. Through a survey that follows people's experiences of initiating and continuing GAHT, insights can be gained into TNB people's knowledge and the impact of the information on their decisions during their GAHT journey.

Understanding the unique health care needs, goals, and experiences of non-binary people was identified as a priority by both groups. There is a gap in international (and local) research on understanding non-binary people's experiences of GAHT. The CAG wanted to explore non-binary people's experiences with HCPs, around being respected, honouring their gender affirmation goals, and understanding their desire for and access to variations in the standard hormone regimes. HCPs acknowledged the need for knowledge about

Table 4. Data collection deemed important by health care professionals to understand the longer-term impacts of GAHT.

Data collection topic	Description of knowledge gaps
Psychosocial impacts of GAHT over time	<ul style="list-style-type: none">• Psychosocial wellbeing, including mental health and suicidality – possible use of scales to measure these experiences (eg PHQ9,¹⁵ GAD7,¹⁶ Gender Minority Stress and Resilience Measure,¹⁷ Gender Congruence and Life Satisfaction Scale).¹⁸• Social participation and employment (eg taking part in activities such as sport, work, employment, and community connection).• Intimate, sexual, social, or whānau (family) relationships.• Sexual function.
Understanding the role other factors potentially have on wellbeing (in a positive or negative way), such as:	<ul style="list-style-type: none">• Support from friends, family, school, and/or work.• Societal impacts such as being misgendered and minority stress.• Internalised transphobia versus feelings of pride in being trans.• Any other factors that might be mitigating the positive impact of GAHT, such as lack of access to gender affirming surgery.• Anything that might have been done differently to better support people in their GAHT journey.
Ongoing use of, and access to GAHT (beyond the initial prescription)	<ul style="list-style-type: none">• Ease of getting ongoing prescriptions from their GP (including cost), and experience of their GP's knowledge about ongoing prescribing.• Whether testosterone self-administration was taught and utilised.• Capturing non-linear journeys and understanding reasons people might stop and sometimes restart hormones or change their medications.• Range of doses and types of medication in use, reasons for changes in formulations over time, including any medications prescribed outside of clinical guidelines.• Exploring use of non-prescribed GAHT (eg sourcing online).
Understanding medical and physical impacts of long-term GAHT use	<p>Self-reported outcomes:</p> <ul style="list-style-type: none">• Effect of GAHT on gender congruence and satisfaction with GAHT (eg meeting goals).• Physical effects and timing (and how this relates to the standard information given at initiation).• Experiences with different choices of medications.• Any changes in decisions about fertility (eg their decision to store/not store sperm).• Explore how the initial information provided aligns with the reality and actual experience of being on hormones.• Explore experiences of pelvic pain or bleeding issues with testosterone use. <p>Biomedical outcomes:</p> <ul style="list-style-type: none">• Monitoring of liver function and potassium and hormone levels was of interest to some HCPs (but this is outside the scope of planned work).• Long term impact on physical health (eg CVD, VTE, bone health, breast cancer).

the unique health care needs of non-binary people including goals, outcomes, and prescribing. Both the HCP and CAG discussed their experiences of non-standard GAHT prescribing for this group – an area where evidence to guide practice is currently lacking.¹⁹

HCPs deliberated on follow-up measures of psychosocial wellbeing, and the need to understand potential mitigating factors. HCPs shared that it was important to understand experiences of stopping (and sometimes restarting) GAHT as individual experiences are varied, nuanced, and have not been well researched. Limited overseas research shows low levels of regret among people taking GAHT,^{20–22} yet fear of future regret is often cited as a concern and contributes to reluctance among GAHT prescribers. Following participants over time will enable collection of information about satisfaction, regret, and continuation or cessation of GAHT. Increasing the available information about GAHT for HCPs and TNB people could promote appropriate access to GAHT for TNB people. Exploring longer term medical and physical consequences of GAHT was of interest to some HCPs, and while complications are uncommon in international research, no local data exist.¹² Obtaining biomedical results

and data from medical records will be beyond the scope of future research.

Strengths and limitations

We drew on the expertise of TNB people and HCPs from a range of disciplines involved in transgender health care, who were knowledgeable about existing research and knowledge gaps. Our CAG was small, so ideas shared about research priorities may not reflect those of wider communities. We lacked input from Māori and Pacific TNB people, and people from rural areas where experiences might differ. Outreach and ongoing partnership with TNB community members from diverse backgrounds will be prioritised in subsequent phases of this research.

Conclusions

There is a need to collect data from people commencing GAHT in NZ, but this research should include TNB community input to ensure it is responsive to their needs as well as

those of health care providers. This stakeholder engagement informed the design of a prospective cohort study to follow TNB people starting GAHT in primary or secondary care in NZ. We intend to commence recruitment in 2024. This research will help equip HCPs with knowledge that will improve the quality of care provided to TNB people in NZ.

Supplementary material

Supplementary material is available [online](#).

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Data availability. The data presented here are not available for sharing due to the small number of participants and in order to preserve their confidentiality.

Conflicts of interest. The authors have no conflicts of interest to declare.

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