



Co-design Partners in Care case study

Gender-affirming care in Canterbury – Simplifying the complexity (Pegasus PHO)

Context

Education about gender-affirming care has been limited in the past, and gender-affirming care in Canterbury has been mostly delivered by a few under-resourced champions and experts.

Gender-affirming journeys do not come in one-size-fits-all, making it complex to develop a coordinated, responsive and equitable health service.

In Canterbury, and indeed across the country, access to gender-affirming health care is confusing for both health care staff and the population requiring access.

Gender-affirming services involve interactions between clients and a multitude of health professionals and services including, but not limited to, GPs, mental health professionals, endocrinologists, and surgeons. This large mix of individual services and organisations often leads to a poor customer experience from a client perspective. Further complicating matters is the fact that clients may utilise the services of just one, some, or all of the services listed above.

Adding to the poor customer experience is that it's often not clear what services are actually on offer in Canterbury, nor what the process is to access those services. Both health professionals and clients have previously relied on word of mouth to obtain the required information. Additionally, there was no coordination or overview of this system.

The team, made up of three members of the transgender¹ community, a member of Manawhenua Ki Waitaha, a general practitioner (GP) with an interest in transgender health, and a Pegasus health manager, saw this co-design process as an opportunity to improve this situation within Canterbury.

Acknowledgements

The group wishes to acknowledge the Health Quality & Safety Commission and Pegasus Health for their support for this co-design project and the improvements it has contributed to.

We would also like to acknowledge that our work is only a part of a large collective effort from Canterbury trans community members, Christchurch District Health Board (CDHB), and primary health care and non-governmental organisation colleagues involved in gender-affirming care, advocacy and social support for transgender people. We would like to acknowledge in particular Sue Bagshaw, Heather Youngs, Ed Coughlan, Josie Todd, Karen McKenzie, Carolyn Doughty, Q-topia, Kindred, the New Zealand Group of Parents and Guardians of Transgender Children, The Collaborative, the Pegasus Health Education team, colleagues at CDHB Planning and Funding,

¹ 'Transgender' and 'gender diverse' are umbrella terms that cover a wide variety of gender identities, including non-binary identities. We use the word transgender or trans in this report, acknowledging that people may use different terms to describe their gender identity, including gender diverse, genderqueer, non-binary and transsexual, as well as Māori and Pacific terms such as aikāne, akava'ine, fa'afafine, faafatama, fakafifine, fakaleiti, māhū, palopa, takatāpui, tangata ira tāne, vakasalewalewa and whakawahine.

the Canterbury Initiative, Streamliners and Leading Lights, Jamie Veale, Jack Byrne, Jeannie Oliphant, Rachel Johnson and many more.

Aim

The group's overall aim was to improve both the quality of, and access to, gender-affirming health care in Canterbury. Given the trans community's request of 'nothing about us without us', we aimed to improve communication, collaboration and the overall relationship between themselves and primary and secondary health-based services along with other teams nationally doing similar work. This fed into collaborative work on the development and delivery of services.

This project aimed to:

- improve quality of information provided to both community and health care professionals
- develop a clear pathway for gender-affirming care
- develop a group of 'champions' within the Canterbury health system tasked with assisting in 'continuous improvement' of the services and communication.

Our participation in this project, and the relationships the group members developed, triggered a domino effect of opportunities for contributing to kōrero about gender-affirming care at the intersection of health, mental health and education, and in the area of professional development of health professionals.

The Health Quality & Safety Commission co-design workshop and the support from Pegasus Health gave us the opportunity to formalise the group and provide a 'package' of expertise and points of view to other services in Canterbury (Canterbury HealthPathways, HealthInfo, Leading Lights, etc).

We think this improved the interest in collaborating with our group and allowed for faster progress than we would have experienced working in isolation. Pegasus Health's support was critical to enable the group to work together and, with very minimal funding, contributed to more progress in improving clarity and coordination of gender-affirming services than in the previous five years.

Start up

A key challenge in this work has been a lack of existing data on both gender-affirming services and, indeed, the trans community itself. This has made it difficult to collect quantitative data on aspects such as wait times and access to gender-affirming care. We have benefited, however, from the fact that the transgender community, both locally and nationally, are very engaged and knowledgeable on issues around accessing health care.

Our group is made up of people with lived experience and good connections to the diversity of the transgender community, people passionate in the area of health equity and access issues, and a clinician with experience of supporting transgender clients to navigate gender-affirming services. This has enabled us to fill the data gaps and interpret international and national research about access and equity of outcomes for transgender people to the local context.

We canvased planners and clinicians in Christchurch and found that in Canterbury there had been many unsuccessful attempts to improve the coordination of gender-affirming care. These attempts never gained enough momentum to address the complexity of the diversity of gender-affirming journeys. Following discussions with the trans community, we also found out that they had not been involved in developing and delivering services that were intended to address their needs.

Community and health professionals agreed there were significant inconsistencies, misconceptions, and gaps in information on gender-affirming care services in Canterbury. For example, two people wanting to access the same service could go to two different GPs and receive two completely different responses, and therefore have two completely different

experiences. It was common for trans people to be turned away and told that a service is not available when in fact it was.

It was also observed that most services available are provided in secondary care, meaning longer wait times and barriers for the community. This was also an inefficient use of CDHB resources.

Our plan was to involve the trans community in the review of gender-affirming services, improve education on gender-affirming care and gender identity among health professionals, and develop a clear pathway that includes definitive information on what services are available and has clear criteria for referral. This will contribute to a consistent, positive experience for Canterbury consumers in the future.

Engage

To engage people within this project, we developed an elevator pitch which provides a short narrative to help them understand what we are aiming to achieve.

Elevator pitch

We want to reverse the current inequity of access, the substandard health outcomes for Canterbury transgender people, and the confusion around gender-affirming health services.

This can be done through good communication and trust between the trans community and health professionals as well as improving communication and coordination between health services.

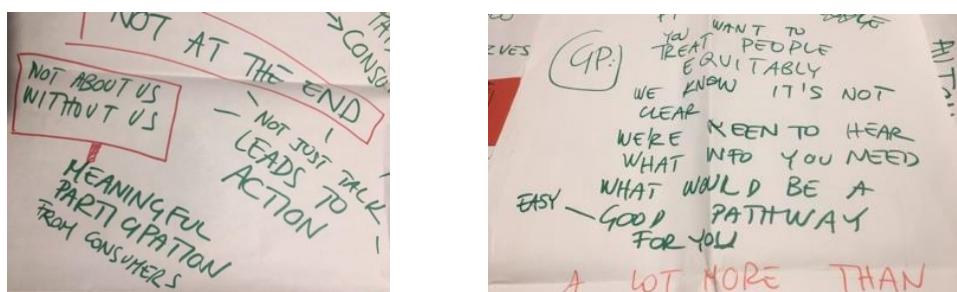
Right information, right care and clear pathways mean the best possible outcome for all.

Our community engagement

- The group's engagement started with a series of hui with the trans community and health professionals held in Christchurch in 2017 and 2018.
- Throughout the duration of the project, there was frequent engagement with the trans community via the trans members of the co-design team, who were able to provide immediate feedback at every meeting, as well as passing queries along to the wider community.
- Throughout the duration of the project, there was frequent engagement with CDHB and primary health care professionals through raising the issue of access and equity of health outcomes for transgender people and gender-affirming care at peer group sessions, clinical meetings, education meetings, planning meetings, and service improvement meetings, and through presentations to the Canterbury Clinical Network, primary health organisations (PHOs), and CDHB leadership and boards.
- A group member was involved in current research on equity of access to gender-affirming services and health outcomes for queer and transgender people and made the information available to the group.

Capture

Figure 1: Working out our elevator pitch



We benefited from the fact that the transgender community, nationally and locally, are incredibly engaged and knowledgeable about their health care. It's common to hear of trans people being 'the expert' in meetings with their health care providers.

There has been a lot of feedback over the past decade or two on issues around health care access, and we felt it was much better to draw on this existing feedback rather than go back to the community to once again ask them to tell us what was wrong.

Instead, we collated information from:

- the team's pre-existing knowledge and experiences
- pre-existing community feedback, such as documents from three hui on trans health held in 2017 and 2018
- current research being done on queer and trans experiences of accessing health care; New Zealand research
- members' conversations with Canterbury and New Zealand health professionals involved in gender-affirming care
- education meetings for GPs; specifically, areas of gender-affirming health care they found they wanted more education on

After collating this information about what wasn't working, we informally presented it to the community along the lines of 'Here's what we already know. Have we missed anything? What is working?' This approach confirmed what we already knew and provided some new understanding.

Understand

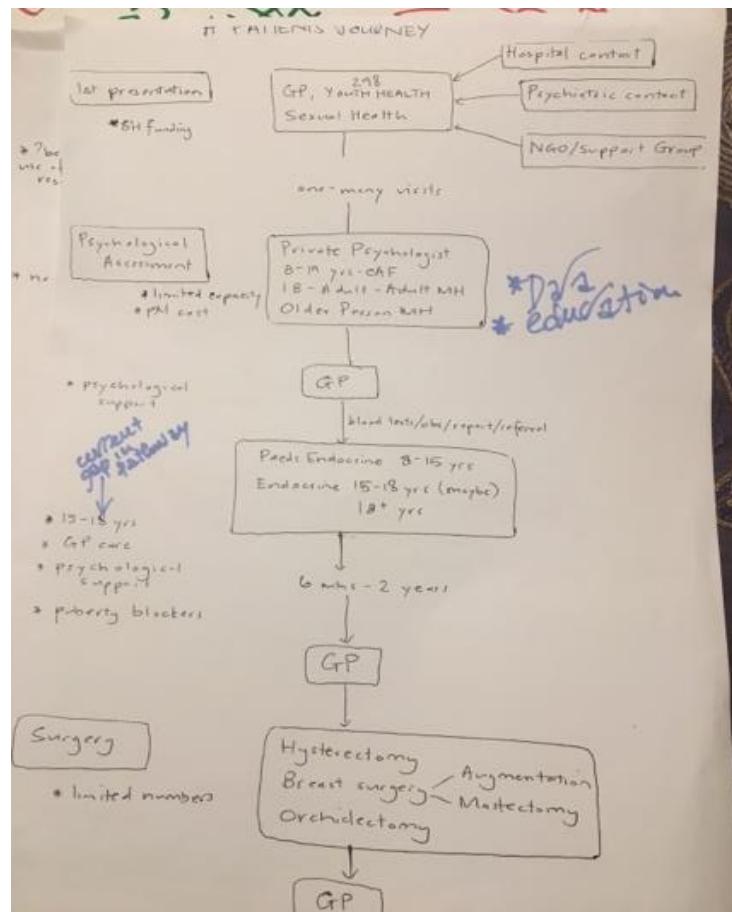
A common theme from the capture phase was overwhelming frustration from both sides.

- Trans consumers stated they would often be required to have repeat visits, often to different practices, to try to find a GP that understood or knew enough to enable access to gender-affirming services.
- Health professionals expressed frustration at the lack of clear information. This made it hard to know when and where referrals could be made.
- A common misconception amongst health professionals was that gender-affirming services were not available in Christchurch, or if they were, they were not available through the public health system. Additionally, it was assumed that a high level of specialisation was required to provide such services.

In spite of the general frustration, we all shared hope about the positive impact of increased awareness, in society and among health professionals, of transgender people and their experiences. Most of all, the momentum at local and national level was for positive change and improvements to equity of access to health and participation. We were all confident in our ability to connect people with an interest or a passion, believing that small breakthroughs would lead to a large system change.

Improve

Figure 2: Rebecca used flowcharts like this one when meeting with colleagues from secondary health care departments to describe the journey of a person accessing gender-affirming care.



Successes so far

- The three trans members of the co-design team are advising on the development of the gender-affirming health update for the Community and Hospital HealthPathways. They are helping to identify barriers to accessing services and gaps in the services needed. They also help in testing the options available, and have enabled wider community input through their contacts.
- CDHB surgical teams have agreed to provide services not previously available through the public health system: orchiectomy, breast augmentation, mastectomy/chest masculinisation. For surgical services that were previously available (eg, hysterectomy/oophorectomy), surgical teams agreed to code and capture data appropriately.
- Primary and secondary health professionals are involved in creating new Community and Hospital HealthPathways, including developing new ways of collaborating and increasing services available in both primary and secondary care.
- Most CDHB services have shown interest and willingness to improve their delivery of gender-affirming services as part of their services. Referrals and new ways of working are being discussed and agreed on to reduce wait and improve the quality of the services offered to trans people in Canterbury.
- A network of GPs supportive of transgender people has formed and is expanding and developing, with plans to run regular peer group sessions for around 15 Canterbury GPs to continue strengthening their knowledge in gender-affirming care and their collaboration with secondary care (eg, endocrinology and mental health) with the aim to move more services like hormone therapy into primary care.

- A CDHB hospital champion for transgender health has been identified.
- We made a formal connection to the Ministry of Health team working on access to gender-affirming care, which may improve communication with the Ministry about gender-affirming services.
- Comprehensive community information for HealthInfo on gender identity and gender-affirming care and for Leading Lights (a Canterbury website that provides advice to primary school teachers on how to support the well-being of students) on gender identity was developed and has been peer reviewed by members of the trans community. In May 2019, the HealthInfo Canterbury website was updated to include this information. The improvements to the website are described below.

Before improvements

Figure 3: ‘Gender dysphoria’ web page from the HealthInfo Canterbury website before it was updated (two pages)

<p>Gender dysphoria</p> <p>Page 1 of 2</p> <p>HealthInfo Canterbury</p> <p>Home > Health conditions > Hormones ></p> <p>Gender dysphoria</p> <p>When someone feels their gender identity doesn't match the sex they were born with, we call this gender dysphoria.</p> <p>It can also be called:</p> <ul style="list-style-type: none"> ▪ gender nonconformity ▪ gender variance ▪ gender incongruence ▪ gender identity disorder ▪ transgenderism. <p>The sex someone was born is called their biological sex. It depends on whether they have the body of a boy or a girl. Gender identity is the gender that a person feels they are. For example, someone may have the body of a man (with a penis and testicles), but feel they are a woman.</p> <p>A transsexual is someone who has a strong feeling of gender dysphoria that doesn't go away. Many transsexuals want to change their bodies to match their gender identity. Some transsexual people feel they are neither male nor female, but both, or somewhere in between.</p> <p>“Trans” is often used as a general term. People might prefer other words, including:</p> <ul style="list-style-type: none"> ▪ transsexuals ▪ transgender people ▪ trans people ▪ trans woman (male becoming a female) or trans man (female becoming a male). <p>Some just prefer male or female.</p> <p>HealthInfo recommends the following pages</p> <ul style="list-style-type: none"> ▪ Inside Out – Education resources A guide for educators working to support young people in accepting sexual and gender diversity. It includes videos and a free resource pack. Also see Making schools safer for trans and gender diverse students. ▪ NHS – Gender dysphoria Information about the diagnosis and treatment of gender dysphoria. <p>For queer and trans youth</p> <ul style="list-style-type: none"> ▪ I'm Local Information and links to support groups throughout New Zealand. ▪ Inside Out Inside Out is a national youth organisation that works to make Aotearoa a safer place for all young people of diverse sexualities, sexes and genders to live and be in. ▪ Rainbow Youth <p>https://www.healthinfo.org.nz/Gender-dysphoria.htm</p> <p>19/04/2019</p>	<p>Gender dysphoria</p> <p>Page 2 of 2</p> <p>Rainbow Youth is an Auckland-based organisation that provides support for queer and trans youth.</p> <p>Written by the Department of Endocrinology, Christchurch Hospital. Adapted by HealthInfo clinical advisers. Last reviewed October 2016.</p> <p>See also:</p> <p>Reading in Mind book scheme Sexual orientation & gender identity</p> <p>Canterbury</p> <p>District Health Board Te Poari Hauora o Waitaha</p> <p>https://www.healthinfo.org.nz/Gender-dysphoria.htm</p> <p>19/04/2019</p>
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What did not work well:

- There was no information about gender-affirming health care in Canterbury.
- There was no information about different ages or stages.
- No local support organisations were listed.
- The single photo was not representative of the diversity of transgender people.
- The terminology was not up to date. For example:
 - ‘*The sex someone was born is called their biological sex. It depends on whether they have the body of a boy or a girl. Gender identity is the gender that a person feels they are.*’
 - ‘*A guide for educators working to support young people in accepting sexual and gender diversity.*’

After improvements

Figure 4: 'Gender identity' web page from the HealthInfo Canterbury website after it was updated (over 10 pages of useful information)²

The screenshot shows a well-organized and informative web page. The top navigation bar includes links to 'Home', 'A-Z health topics', 'Look up your medication', and 'How to get medical help'. There are also buttons for 'Send us your feedback' and a search bar pre-filled with 'Gender dysphoria'. The main content area is titled 'Overview of gender identity' and features a large, vibrant photograph of two young women smiling and cheering at an outdoor festival. The text on the page is clear and accessible, providing definitions and explanations for various terms related to gender identity. A sidebar on the left side of the page lists numerous other health topics, such as 'Home', 'A-Z health topics', 'Emergencies & first aid', 'Health conditions' (with sub-sections like 'Allergies', 'Assault & abuse', etc.), 'Sexual health' (with sub-sections like 'Cervical screening & cervical smears', 'Contraception & sterilisation'), and 'Gender identity' (with sub-sections like 'Transgender people', 'Intersex', 'Sexuality', 'Sex assigned at birth', 'Sexual orientation', and 'Gender diversity'). This sidebar indicates that the page is part of a much larger and updated website.

What has been improved:

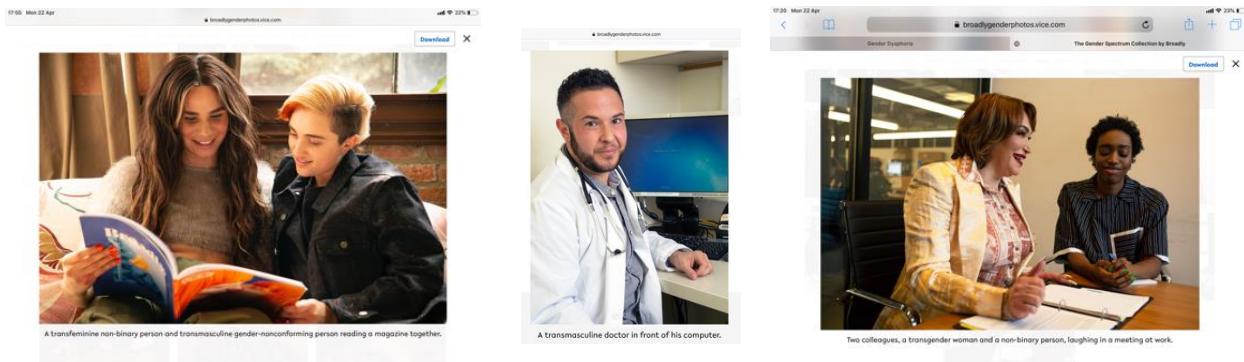
- The terminology is up to date.
- Information is based on different ages and journeys.
- There is a strength-based and empowering approach. The language and themes covered acknowledge the mana of transgender people and their whānau and their rights. For example:

'It's OK to ask if the professional you're contacting has experience working with gender identity and gender diversity issues. You may want to contact peer support groups to ask for recommendations of professionals with relevant experience. See Support networks for transgender people or Support networks for transgender children, youth & their whānau/families.'
- There are useful links to quality information and local support networks.
- The page provides information on gender-affirming services available through the public or private health system, or nationally, and how to access them. For example:

'The following services are available in Canterbury through the public health system. You can ask your GP or practice nurse how to access these services and how soon you can expect an appointment.'

² www.healthinfo.org.nz/index.htm?gender-identity.htm

- *Endocrinology (hormone) services: Puberty blockers and feminising and masculinising hormones (cross-sex hormones)*
- *Counselling and psychological support.*
- *Mental health assessment (readiness for hormones).'*
- There is positive and diverse imagery showing children with loving family members, and young people, trans men, trans women, and binary and non-binary identities engaged in positive activities. For example:



- There is practical information about current Canterbury services and support, including some realistic scenarios and solutions to common challenges. For example:

'Name and gender marker changes in your health records'

You can ask your health professionals to use your preferred name, gender and pronouns. You don't have to prove that you've transitioned or have changed your name legally to do this. It's enough to ask.

You can also get prescriptions, test results and correspondence from health professionals in your preferred name, gender and title. To do this, you need to ask for the National Health Index (NHI) to be updated. Your GP practice can do this for you. There's no cost to make this change. While many health information systems are integrated, occasionally records won't get updated correctly. This is often a genuine mistake. If you update your name and gender marker in your health records and keep getting correspondence with wrong details, speak to your practice nurse, GP or other health professional. They'll try to correct it.'

Measure

Our group's work has contributed positively to these outcomes:

- The number of health professionals in practices reaching out for support for their transgender clients and to form a network of champions has grown to around 15 GPs, up from less than five widely known to be supportive only two years ago.
- HealthInfo has been updated from a simple and outdated single page on gender dysphoria, to over 10 pages of information on gender identity, gender diversity, support networks and gender-affirming care.
- The HealthInfo information will now also feed into the Leading Lights pathway for primary health teachers supporting gender-questioning and gender-diverse students.
- The gender-affirming care pathways on the Canterbury HealthPathways are in final draft stages. The current single pathway on gender dysphoria will be replaced by five health pathways specific for different ages and services, including a surgical pathway, which previously did not exist.
- There is increased communication between the community and health professionals, particularly in primary health care.

- The co-design group has worked as a pilot for a shared community and clinical advisory board to advise on gender-affirming care services design. This advisory board would be valuable as an ongoing resource to the Canterbury health system to contribute to quality improvement, service updates, community engagement and education.

Working as a co-design team

These elements were critical for our group's work:

- All members have a very good understanding of health inequities and of the current gaps in gender-affirming services in Canterbury and nationally.
- Transgender community members on the group have been gracious about previous breakdowns in communication and relationships with the Canterbury health system and have been willing to give this process a go to improve outcomes for their community. Our group discussions have always felt safe and positive.
- All members are passionate about health equity and improving access and health outcomes for transgender people in Canterbury. We all were very proactive in raising awareness and looking for opportunities for the group to contribute to this kōrero.
- We enjoyed working together and found ways to stay in touch despite very busy work lives, with a combination of emails, phone calls, meeting face to face (with pizza!) and the odd text messaging.
- The strength of the group was to have members with different points of view who are able to relate and connect to different groups of people, both in the trans community and in the health system, and both locally and nationally.
- It has been invaluable to have three people in the group with personal lived experience of gender-affirming care and close relationships with many others with lived experience. Having a member who is the parent of a transgender child brought the whānau perspective to the group.
- It has been invaluable to have a clinician in the group with experience in supporting clients to access gender-affirming care, with excellent relationships within primary and secondary health care. Her experience developing other health pathways helped to develop a successful strategy.

Next steps

The group plans to:

- attend the first Aotearoa New Zealand Trans Health Symposium in Hamilton in May 2019, thanks to a sponsorship by the Health Quality & Safety Commission and support from Pegasus Health. The group will share our co-design experience and give an update on the Canterbury gender-affirming care pathway. The symposium will be an opportunity to connect to community members and health professionals from other regions, and share resources developed for Canterbury with other DHBs and PHOs
- feed back to the Canterbury trans community and health professionals
- propose setting up a gender-affirming care peer group for the group of primary health professionals champions
- propose setting up an advisory group based on the experience of the co-design team, to continue the partnership between the transgender community and health professionals in improving the quality of gender-affirming care and continuing to improve access and equity of outcomes for transgender people
- continue raising awareness of:
 - inequities in access and health outcomes experienced by the Canterbury trans community (differential access to social determinants of health, structural discrimination)

- the complexity of gender-affirming care services (diversity of people within the trans community, diversity of gender-affirming journeys, multiple services involved across primary secondary services and community)
- help identify opportunities for, and prioritise:
 - education of health professionals in gender-affirming care and practices
 - improvements in data collection – referrals for gender-affirming care from primary to secondary health, and within CDHB services
 - resourcing services for gender-affirming care, and creating funding streams to address barriers to access to gender-affirming care
- continue sharing with other PHOs and DHBs our co-design experience, what we have learned and any resource we've contributed to.

The project team



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