



Department of Health and Social Care

Rheynn Slaynt as Kiarail y Theay

DHSC

Gender identity services engagement exercise 2023

Results



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1. Background

In January-February 2023 we asked our Island's trans and gender diverse (TGD) community to talk to us about how we can improve gender identity services.

We wanted to find out what our TGD community sees as the biggest gaps in current services, and which improvements would have the biggest impact on their health and wellbeing. We need to know this because we are working with Manx Care to improve gender identity services, and we want to make sure that the support we design will meet the community's needs.

We asked people to tell us about their experiences of gender identity support and gender affirming care to help us find out which elements work well and where there are gaps in support.

We also asked people to talk to us about their experiences of health and social care more generally, so that we can better understand how to promote equality and inclusion for TGD people. We want to use this information to help us create policies and processes that will make sure TGD people feel safe and accepted in any health and social care setting they may encounter.

2. Responses

In total 42 TGD people, a mix of adults and young people, took part in this engagement exercise.

Colleagues from Manx Care helped us to facilitate an in-person workshop event for adults which was attended by 15 people. Another 2 adults returned replies to our questions by post and email. Ages ranged between 22 and 40 years.

Colleagues in the Department of Education Sport and Culture's Youth Service team helped us to include younger TGD people, speaking to 25 13-18 year olds in their LGBT+ youth group.

3. Experiences of gender identity support

The most prominent theme in the feedback we received was a lack of continuity and care coordination. People told us their experiences of gender identity services in the Island felt fragmented and unsupportive.

The experiences people told us about highlighted the lack of a comprehensive pathway in the Island for TGD people seeking gender affirming care. People described gaps in support at each stage of their gender affirmation journeys, and the risks and difficulties caused by those gaps.

3.1 Seeking support

3.1.1 Difficulty finding information

At the first stages of questioning their gender identity or seeking gender affirming support, people told us they found it difficult to find information about who to approach and what support would be available. The information that was available used language that people found alienating, and didn't offer clarity or reassurance about what their care would look like.

3.1.2 Difficulty approaching professionals

People also told us it had been daunting to approach professionals to seek advice or help. The absence of clear and reassuring information meant that people didn't know what to expect when they first approached a professional for advice (for most people, the first point of contact was their GP).

Concerns about approaching professionals for help or advice were particularly difficult for young people. In situations where young people have unsupportive relationships with their parents or caregivers, they can be fearful of seeking support for gender identity issues because they can't find clear assurances of confidentiality.

There was inconsistency in whether people were met with understanding and acceptance when they sought advice – some said professionals had been dismissive,

others said they had been supportive. Even when professionals were supportive, people told us there was a general lack of knowledge about what care and support was available; people were sometimes given inaccurate or misleading information and experienced delays in referral processes.

People also described a lack of professional understanding about wider gender diversity issues. The knowledge that most professionals had related only to trans care, and there was little understanding of the different support requirements for non-binary people.

3.2 Gender identity clinic referral

3.2.1 Lack of care coordination

Once people had sought help and been referred to a UK gender identity clinic (GIC), they found there was no continuing on-Island management of their gender affirming care, and no central point of contact to coordinate information sharing between different professionals. There was a particular difficulty for people moving back to the Island having been referred to a clinic whilst living in the UK – upon moving jurisdiction, people’s referrals are cancelled and need to be started again from the beginning.

People told us they had to chase for updates about their referrals, and pass information like blood test results between different professionals themselves. They told us there were no joined-up processes linking people to other services for advice about fertility and family planning or sexual health.

They also told us there was no on-Island point of contact for troubleshooting or guidance with hormone therapy. They said that check-ups were infrequent, and some people didn’t know how to access support for concerns about identifying and managing side-effects or contraindications.

The lack of coordination in updating and maintaining medical records was also a concern – people had found it frustrating to separately update their personal

information on a range of different systems (e.g. GP, Nobles, mental health services).

3.2.2 Lack of active support

Waiting lists for GICs are notoriously long, and people told us they felt left without support or communication during lengthy delays in accessing care. People said the most difficult gaps in support were in mental health and endocrinology.

Without access to specialised mental health support on Island, people told us they struggled to cope with difficulties like coming to terms with their gender identity, tolerating the distress of waiting for gender affirming care, navigating family and relationship issues, or coping with bullying and abuse. People said check-ups with mental health services were infrequent and sometimes felt like lip-service exercises.

People told us clearly about the importance of being able to access proper mental health support with a professional who understands gender identity issues. Without support, TGD people face a high risk of serious mental health concerns including depression, anxiety, and suicidal ideation. People told us they were pleased that the World Health Organisation has reclassified gender identity issues to reflect that being trans or gender diverse is not in itself a mental health problem, but they also said they were worried that the reclassification might remove what mental health support there currently is.

We were told that hormone therapy was the most important life-changing event for many people. Without an on-Island GP specialised in bridging prescriptions, people face waits of several years to start hormone therapy under the care of a GIC. Some people paid for private prescriptions online, but they struggled with the expense and had limited access to advice or help with adverse reactions. In some cases people were using home blood-testing kits to monitor their dosage.

People said that no assistance was available for gamete storage, and even private options were difficult to find. People also told us they struggled without access to supports like speech therapy or vocal training and laser hair removal or electrolysis.

3.3 Aftercare and ongoing support

Once discharged from a GIC, people told us there was no continuing management or coordination of their ongoing care needs. People said there was no on-Island follow-up for their surgical aftercare, and no organised schedule of check-ups for physical, mental or sexual health.

People also told us there was no coordination of care records to ensure appropriate health screening checks continued – a number of trans women told us they received unnecessary invitations for cervical cancer screening, but no invitations for prostate cancer screening.

4. Improving gender identity support

We heard about a range of ways that gender identity support services could be improved to reduce some of the risks and discomfort currently experienced by TGD people in the Isle of Man.

People told us they would like to see a gender identity care pathway that includes:

- Easily accessible locally relevant information about which services and supports are available
- Signposting for support with wider TGD issues (e.g. safe tucking and binding, domestic abuse or bullying)
- Tiered mental health support options, including facilitated peer-support groups, professionals trained in gender incongruence issues, and a crisis support offering
- A GP trained in bridging prescriptions
- Shared care arrangements between on-Island GPs and UK GICs
- A central point of gender affirming care coordination – a single professional able to take responsibility for joining-up the work of teams or departments providing different elements of support (including off-Island support)

- Appropriate data capture and sharing protocols to ensure information is accurate and up-to-date across different health and care record systems – including cancer screening services
- Person-centred care planning which recognises people’s differing support needs
- A multi-disciplinary team of professionals with special interest or training in gender incongruence, able to offer mental health, endocrinology, fertility and family planning, and sexual health advice – accessible as and when needed
- Post-surgical aftercare support on-Island
- Ongoing support, available on an open-door basis, for hormone management, mental health, sexual health, and fertility and family planning

5. Acceptance, equality and inclusion

When we asked people to tell us about their broader experiences of health and social care services, it was clear that a lack of understanding and acceptance created barriers to accessing help in general.

People felt distrustful of professionals if they had experienced prejudicial or negative attitudes in the past, and some told us they avoided healthcare settings entirely.

People described a systemic lack of awareness and absence of protocols for inclusivity, which lead to situations that compromised their dignity and privacy.

People told us about a range of ways we could improve inclusion and equality across health and social care settings.

5.1 Staff training

People told us they had experienced a range of positive and negative interactions with professionals across health and social care services. They told us how relieved they felt when they encountered understanding professionals, and about the anxiety and upset caused by encountering people who were less than understanding.

People said they felt it was important to introduce gender diversity awareness education for health and social care staff, with basic introductions for all public-facing roles and more specific gender incongruence training for GPs, mental health and sexual health professionals.

5.2 Information capture and sharing

People told us that incidents like being publically addressed by a dead-name, or incorrect pronouns or titles, can be embarrassing and distressing. Because these incidents are made more likely by the lack of integration between care record systems, people told us they would like to see safe protocols for sharing relevant information updates so that details match across different record systems (e.g. GP and Nobles).

People also told us they often felt overlooked in the design of information capture processes. Forms and surveys which confuse sex with gender, and offer only binary response options (e.g. male and female, or Mr, Miss, Mrs) can leave people feeling alienated and uncared for. People told us they would like to see forms and surveys which reflect greater awareness of the difference between sex and gender, and of the breadth of gender diversity. Simple changes can easily make people feel more accepted, like providing an option to self-describe for questions about gender, widening the range options available for titles (or removing the requirement for titles altogether), and giving an option to disclose pronouns.

5.3 Representation and visibility

People told us about the importance of representation and visibility in helping to increase understanding and acceptance. The introduction of optional schemes like pronoun badges and disclosing pronouns in email signatures can help to increase the visibility of TGD staff within health and social care. This in turn helps to build trust and feelings of acceptance in TGD patients and service users.

People also told us it would help to see more gender-inclusive language in medical and care related information. Small changes can help TGD people feel safe to approach care services they might otherwise be wary of. People suggested using gender-neutral defaults (like 'people invited for breast screening' rather than 'women invited for breast screening'), or adding gender-inclusive language (like 'mothers and birthing parents').

5.4 Environmental inclusivity

People told us there are some relatively minor environmental adjustments that can help to make health and care settings more inclusive. In particular, unisex toilet options and providing sanitary bins in men's toilets can help to protect people's dignity. Similarly, quiet areas for sensitive or confidential discussions can help to protect people's privacy.

People also said that in-patient care could be difficult to navigate. Some said they would prefer the option of a mixed ward, and others said they would appreciate a private room, although they recognised the resource pressures and appreciated that arrangements had to be made on a case-by-case basis.

6. Next steps

The results of this engagement exercise will help us to work with Manx Care in redesigning the Island's gender incongruence pathway. Getting this right will take some time, but we are committed to making changes that will improve the health and wellbeing of our TGD community.

We will provide an update about the progress of the pathway development by September 2023. Please contact the DHSC Engagement team at dhscengagement@gov.im for any further information.