INFORMED CONSENT IN PRIMARY HEALTHCARE

- What it is
- What it's not
- Health and disability commission
- Hormones, surgical referrals
- Checklist

GENDER MINORITIES AOTEAROA

Irawhiti Takatāpui, Transgender, & Intersex NZ

Introduction

In transgender healthcare, the “Informed Consent Model” is where a transgender person’s right to consent to gender-affirming medical treatment is presumed to exist.

This is contrasted to the “Diagnostic” or “Gatekeeping” model, where medical professionals presume that a transgender person is not able to consent without having extra assessment - often in the form of psychosocial or mental health screening.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

From The Informed Consent Model of Transgender Care: An Alternative to the Diagnosis of Gender Dysphoria, Sarah L Schulz

"An alternative to the diagnostic model for transgender health is the Informed Consent Model, which allows for clients who are transgender to access hormone treatments and surgical interventions without undergoing mental health evaluation or referral from a mental health specialist."

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

From the Australian Informed Consent Standards of Care for Gender Affirming Hormone Therapy, AusPATH:

“Gender affirming medicine is a part of general medical care within the primary health care system.”

“A ‘gender assessment’ with a psychiatrist is not required and is not a mandatory requirement prior to commencing medical gender affirmation.”

“Depression, anxiety, and suicidality are not contraindications to hormone therapy. In most cases mental health can be exacerbated by denial or delay, and improves following initiation of gender affirming hormones.”

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

So, if there is reason to believe that a patient may not be capable of giving informed consent, then mental health professionals may be involved to help establish whether this is the case.

However, unless there is a specific reason, trans patients are presumed competent to give informed consent.

There is no need for routine psychological or psychosocial assessments as prerequisite.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

When most medications are prescribed, informed consent is implied, and minimal documentation is used. The majority of prescriptions do not require abbreviated informed consent forms to be signed, let alone a psychological evaluation.

Routine ‘readiness assessments’ presume that transgender patients categorically do not have the ability to consent to healthcare. This means that once a treatment is classified as ‘gender affirming’ it becomes more difficult to access.

The existence of a higher standard of informed consent for transgender people's healthcare is discriminatory, as it imposes extra testing and barriers that do not exist for other kinds of healthcare.

Let's take a quick look at why the myth of psychological evaluations as prerequisite has become common belief within the healthcare sector in NZ.

In the early 1900's, when "transsexual" first became a diagnosis, patients had to meet specific criteria in order to be diagnosed.

This was so that they could receive gender-affirming healthcare rather than electroconvulsive treatment or lobotomy, which were common at that time.

The diagnosis was based on the work of Dr Harry Benjamin, founder of WPATH, whose theory was that trans women had a "female brain" and a "male body" . Patients had to prove that their brain was "as female as possible", through meeting stereotypes for women.

Science has moved on, but our systems are still catching up.

In modern times, best practice diagnostic criteria relies on a person's self-reported gender experience, rather than requiring professional approval of the authenticity of a person's gender.

Informed consent centres autonomy and a person's right to make informed decisions about their own body.

Let's look at the legal framework.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

The Health and Disability Commissioner is the person responsible for holding medical providers accountable to respecting the rights of healthcare consumers.

The Health and Disability Commissioner Act (1994) tasks the commissioner with creating a code of healthcare rights, which defines informed consent in New Zealand.

Every healthcare provider is legally accountable to this code of consumer rights.

Under the code, there are 2 very important rights related to informed consent, which healthcare providers need to be aware of. These are right 6 and right 7.

"Right 6: The Right to be Fully Informed, meaning that healthcare providers have a legal obligation to give consumers a full and accurate account of all of their options for treatment, and the expected timeframes for receiving these."

"Right 7: The right to make an informed choice and give informed consent includes the right to be presumed competent, unless there are reasonable grounds to presume a consumer is not competent.

Without medical grounds to presume incompetency, consumers have the right, once fully informed, to make their own decisions regarding their treatment - their medications, dosages and referrals."

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

There is one type of situation in which the right to give informed consent is taken away, and patients are required to undertake psychiatric assessment. This takes place under the Mental Health Compulsory Assessment and Treatment Act (1992).

“A person may lose the right to give informed consent and be required to undertake psychiatric assessment and treatment under the Mental Health (Compulsory Assessment and Treatment) Act 1992”

- Information, choice of treatment and informed consent, Medical Council of NZ

Now we've heard about what informed consent is and isn't, we're going to take a quick look at how it works.

Gender Minorities Aotearoa
Irawhiti Takatāpui, Transgender, & Intersex NZ

Planned Parenthood Great Northwest run gender clinics where trans people can go to start hormone treatment.

In one appointment, the clinician and patient discuss treatment options, goals and potential contraindications. They also carry out a blood test.

The patient can leave this first session with a hormone prescription.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

From Planned Parenthood, United States:

“You don't need to participate in therapy or provide information from a mental health provider to receive hormone therapy”

“In most cases your clinician will be able to prescribe hormones the same day as your first visit. No letter from a mental health provider is required.”

This is often regarded as the gold standard of informed consent.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

From the Guidelines for Gender Affirming Healthcare for Gender Diverse and Transgender Children, Young People and Adults in Aotearoa, New Zealand:

“While many trans people access psychotherapy for support with living in their affirmed gender, psychotherapy is not a requirement of accessing gender affirming care.”

“In New Zealand young people aged 16 years and older are considered to be able to consent to medical care (Care of Children Act 2004), however it is increasingly recognised that there may be compelling reasons to initiate hormones prior to the age of 16 years for some individuals”

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

The NZ guidelines provide support for an informed consent process. They give the information necessary for a primary healthcare provider to diagnose, prescribe hormones, and provide ongoing maintenance care.

Some informed consent standards, including the internationally recognised Callen-Lorde standards, don't use regular hormone maintenance testing, instead relying on patient feedback.

The NZ guidelines include forms for Informed Consent (sometimes called ‘abbreviated informed consent') in appendices C, D, E, and F. These are a simple way to manage legal liability.

Now we're going to discuss our simple 18 point checklist of what you need to be aware of when initiating gender-affirming hormone therapy.

You can also download this checklist separately, with reference citations, from our website at genderminorities.com

Checklist:

1. General medical intake (medical history, family history, etc.)
2. Discuss the patient's gender (sometimes referred to as "gender identity")
3. Discuss gender-affirming healthcare goals
4. Discuss expected outcomes of hormone therapy
5. Baseline blood work
6. Blood pressure, cardiovascular, and respiratory exams
7. Review of relevant health records

Gender Minorities Aotearoa
Irawhiti Takatāpui, Transgender, & Intersex NZ

Next:

8. Discuss contraindications (e.g. hormone sensitive cancers)
9. Discuss treatment options, and the timeframes for receiving these
10. Make recommendations for treatment, and discuss the options which the patient prefers
11. Review potential side effects of the specific treatments
12. Discuss any fertility implications of the specific treatments
13. Discuss risk mitigation (e.g. smoking cessation support)

Finally:

14. Assess patient capacity to consent for hormone treatments (have they demonstrated intellectual capacity to understand and give consent)
15. If there are reasons to believe they do not have capacity to consent, refer to mental health. Otherwise -
16. Review and sign consent form(s)
17. Prescribe hormone treatments
18. Review recommendations for ongoing monitoring and maintenance

You may wish to discuss further supports, as appropriate (not needed for commencement of hormone treatment):

- Discuss support systems, such as family, peers, work, school
- Discuss referrals, such as gender affirming surgeries, mental health, transgender advocacy and peer support services

You can find both medical and plain language guides to hormone therapy on our website at genderminorities.com

There are a few other things to consider, which are sometimes not included in guidelines. We'll touch on these next.

A central risk in HRT prescription is that a patient will be prescribed a high level of hormone blockers, without adequate levels of a replacement sex hormone (testosterone, estrogen, etc).

Low levels of sex hormones (Hypogonadism) can result in anxiety, depression, fatigue, difficulty concentrating, low sex drive, hair loss, osteoporosis and hot flashes. It is also associated with heart disease and other cardiovascular issues.

This means it's important that sex hormone levels are high enough. A simple indication of a high enough level is how the patient feels.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

Many transgender patients will prefer to take a safer course of HRT, where blockers are prescribed at lower levels or not prescribed at all, and sex hormones are prioritised.

For estrogen treatments, The Endocrine Society Clinical Practice Guideline (2017) recommends 100 to 200 pg/mL – which translates as 367.09 pmol/L to 734.19 pmol/L.

The NZ guidelines recommend up to 500 pmol/L, which is quite low compared to many international clinics. Ask your patient for feedback.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

The AusPATH Guidelines tell us:

“Recommended ranges should be used as a guide, rather than a rule. This means prescribing gender affirming hormones based on how a patient responds to treatment and alongside risk factors, rather than based solely on specifically targeted levels.”

The patient’s response should be measured in terms of their transition goals. Patients respond differently to different levels of hormones, so appropriate levels will depend on an individual’s level of bodily change and positive psychological response.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

Now we'll touch on surgical referrals.

Genital Reconstruction Surgeries are available through public healthcare in New Zealand, through a pathway managed by the Ministry of Health.

Referrals to this pathway are arranged between the Ministry of Health and DHBs, whereby DHB specialists are expected to make referrals. This can include endocrinologists, sexual health doctors, and some other specialists.

In some cases, General Practitioners are authorised to make these referrals, as approved by their DHB.

Ideally these referrals should come from primary healthcare, and primary healthcare providers should be able to find out how these referrals work.

It should not be the responsibility of transgender patients to find out how to get a surgical referral.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

The surgical criteria for Genital Reconstruction referrals are based on the WPATH criteria, and are within a primary provider's ability to assess:

a. Persistent, well-documented gender dysphoria;
b. Capacity to make a fully informed decision and to consent for treatment;
c. Age of 18 years or older;
d. If significant medical or mental health concerns are present, they must be well controlled;
e. 12 continuous months of hormone therapy as appropriate to the patient's gender goals (unless hormones are not clinically indicated for the individual*);
f. 12 continuous months of living in a gender role that is congruent with their gender identity.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

The WPATH criteria is a little outdated, and their criteria do not align well with an informed consent model.

The WPATH criteria include "living in a gender role", which is a subjective judgement of gender expression, rather than being based on a patient's presumed competency to make informed choices.

Note that while it is not explicit, "unless hormones are not clinically indicated" means that hormones are not required, if hormone treatment is not indicated by the patient's transition goals.

How to support your patient with referrals:

- Understand the current criteria.
- Talk about all of the options, ask what your patient wants.
- Make referrals promptly, ensure that referrals prioritise and support your patient's ability and right to give informed consent, and provide detailed information to your patient throughout the process.

Under the Privacy Act, referrals should contain only the necessary information required.

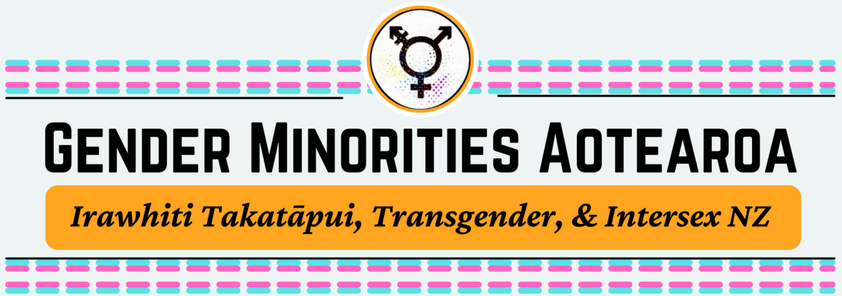
GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ

You can find out which other treatments are available in your region using the 3D Health Pathways tool online, and which specialists can receive referrals.

You can also find what each DHB offers, and a wealth of resources, on our website at genderminorities.com

If there is anything you can't find, or you need information, we are here to support not only your patient's journey but yours as well.

GENDER MINORITIES AOTEAROA
Irawhiti Takatāpui, Transgender, & Intersex NZ



genderminorities.com

Illustration by Sam Low