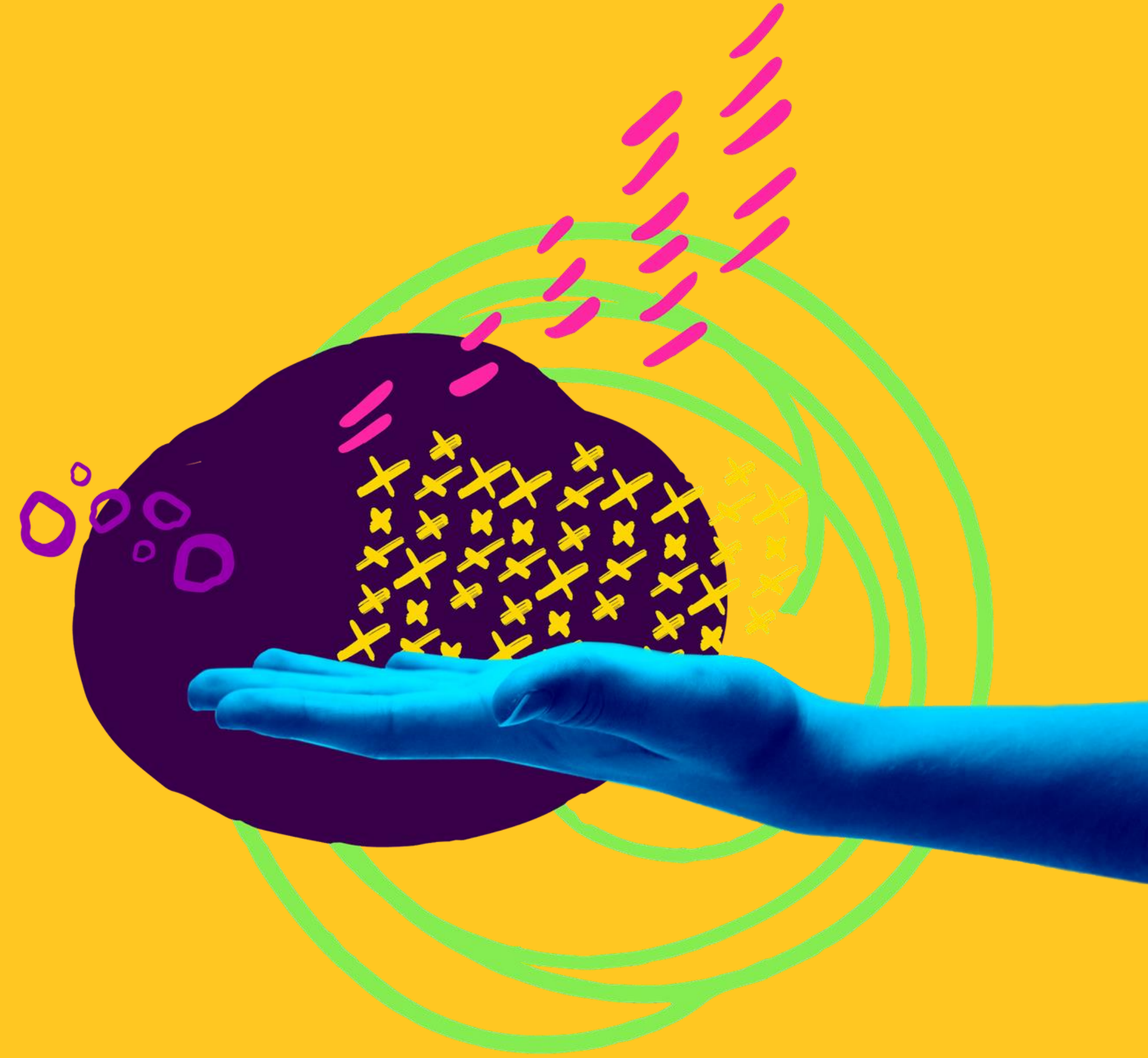


18 May 2023

Trans Health

Patient-Centred Care and Community Support



Part 1

Framing

What does “gender affirming care” mean?
What does informed consent mean?

Part 2

Putting It Into Practice

What does it mean to:

- Demonstrate Respect
- Protect My Privacy
- Support Self-Determination

Part 3

The Big Picture

Multi-disciplinary collaboration to transform the health system



Part One: Framing

What do we mean by “gender-affirming care”?

What is an informed consent approach in trans health?



Language

“Gender-affirming care” is different to being affirming about gender in healthcare more broadly

When we say ‘gender-affirming healthcare’, we’re talking about medical interventions that people access to affirm their gender. For many trans and non-binary people, this healthcare is medically necessary and can be life saving.

Depending on people’s individual needs and transition goals, gender-affirming healthcare can include counselling, hair removal, voice therapy, puberty blockers, hormones and surgeries.

This is different to being affirming about gender (or being inclusive of trans people) in general healthcare services. We are talking about both gender affirming care and broader healthcare in this presentation.



We advocate for wider access to gender-affirming healthcare that is:

- guided by the principle of **mana motuhake** - respecting trans people's autonomy over their own bodies and wellbeing.
- based on **informed consent** - that is, enabling trans people to make their own supported decisions with their doctors, consistent with their self-determined gender goals, given clear information about the known risks and benefits of any medical treatment.
- **depathologised** - based on the core understanding that transgender identities, bodies and lives are not expressions of illness or disorder.

Te Ngākau Kahukura's Principles for Provision of Gender Affirming Care



We advocate for wider access to gender-affirming healthcare that is:

- **holistic** and supportive of broader understandings of what supports a person's wellbeing, such as those described by Te Whare Tapa Whā (which encompasses the health of people's tinana (body), hinengaro (mind), whānau (family and social connections) and wairua (spirit and sense of purpose and belonging) as well as their connections with whenua (land or environment)).
- **developed and led by and with trans communities - informed by lived experience at every level of decision making.**
- **in solidarity with intersex healthcare needs and aspirations - recognising shared issues such as bodily autonomy, as well as differences.**

Te Ngākau Kahukura's Principles for Provision of Gender Affirming Care





Patient-Centred Care using an Informed Consent Approach

“In a health setting, informed consent (also known as ‘affirmation enablement’) simply means being given correct and adequate information about gender affirming hormones, risks, effects, combinations and how they might work with other medications or recreational drugs.

This is so you are able to make a decision (or consent) about your body, health and health care. Doctors need to ensure their patients are making informed decisions about their health every day.

As it relates to trans people and gender affirming care, informed consent is a model that places the experiences, expertise and needs of the trans patient first. This means we are also working with a doctor to not take undue risks or place ourselves at risk of harm.”

From: <https://www.transhub.org.au/informed-consent>



Removes barrier of diagnosis/mental health assessment

One of the key aspects of the informed consent model is that it removes the requirement of a mental health professional assessing the mental health or transness of the trans person. It does not remove the possibility of mental health support being something that clinicians can help us to access.





“It should be emphasized that informed consent is not “hormones on demand,” which would give no scope to the prescribing clinician’s expertise and judgment. Rather, it facilitates the patient’s and clinician’s collaborative determination of the best available treatment. Clinicians do, and should, have these kinds of conversations with their patients all the time, and do not generally require the input of a mental health practitioner to help them in this decision-making process.”

From: AMA J Ethics. 2016;18(11):1147-1155. Doi: 10.1001/journalofethics.2016.18.11.sect1-1611.



Resources about Informed Consent

GMA video resource:

<https://genderminorities.com/2022/03/31/informed-consent-101-a-3-minute-guide/>

Checklist for initiating hormone treatment:

<https://genderminorities.com/2022/06/20/checklist-for-gender-affirming-hormones/>

“Informed Consent in the Medical Care of Transgender and GenderNonconforming Patients,” Timothy Cavanaugh, MD, Ruben Hopwood, MDiv, PhD, and Cei Lambert, MFA:

<https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-07/sect1-1611.pdf>

Primary care guidelines for NZ and national guidelines for gender affirming care: <https://patha.nz/Guidelines>

Our website page:

<https://www.tengakaukahukura.nz/gender-affirming-healthcare>

Trans Hub page: <https://www.transhub.org.au/clinicians>



Part Two: Putting it into practice

**What does it mean to demonstrate respect,
protect my privacy, and support self-
determination?**



What does patient centred care mean in the context of individual practice and interactions between trans people and their healthcare providers?

Demonstrate Respect

Protect My Privacy

Support Self-Determination



Demonstrate Respect Language and Possibilities

Use my correct name and pronouns

- Ask about this in one-on-one contexts first

Adapt to the language we use about ourselves

- Listen to how we talk about ourselves and our lives

Reflect on your own perspective and cultural lens about what is possible in terms of gender and bodies and personhood

Recognise that I am the expert on my experience and work collaboratively with me about my healthcare

Consider tools like “organ inventories” and other ways we can shift our language from binary gender assumptions towards more neutral inclusive frameworks



Demonstrate Respect Mistakes and Transparency

Check in about assumptions you're making, apologise for mistakes and don't make a big deal about them

Don't assume we all want the same things from our healthcare providers

Be honest about the limitations of software and forms etc, tell us what the options are for gender and other relevant fields (we know it's not perfect)

Meet me where I am at in terms of how much knowledge and data I have about myself, my health, and the provision of gender affirming care

If you don't know something, be transparent about that (and follow up if needed)



Privacy is different to secrecy and shame.

To protect my privacy you need to have awareness of your own gender related shame.

This is an area where trans people have solidarity with intersex people.

Being trans is not shameful. Being intersex or having a variation of sex characteristics is not shameful.

White western medical approaches to trans and intersex bodies have been historically (and currently) steeped in shame and secrecy, with the goal of reproducing 'normal' (white) bodies.

This is changing slowly.

Protect My Privacy: Self-reflection and Medical Investment in Normalcy



Be mindful not to ask questions about names and pronouns in front of other people in a waiting room area

Be aware that some of us are stealth (we do not tell people that we are trans)

Work with us to ensure information about our bodies and healthcare needs are as confidential as possible

Do not “out” us to other people without talking to us first

Be respectful about our lives, our relationships, our bodies, in a way that prioritises our privacy

**Protect My
Privacy:
Prioritise
Confidentiality**



Be adaptable about how much information you expect us to share with you - in healthcare settings some of us share more and some of us share less.

We want information from you, and you want information from us.

Power dynamics - do not ignore them. Providing patient-centred care through an informed consent approach entails being aware of our different positions in this interaction.

It is helpful for you to know what you need to know from us (and what you don't need to know).

Be aware of your own curiosity, don't expect us to educate you automatically, and be willing to look things up together or after an appointment, as appropriate.

Protect My Privacy: Be Aware of Power Dynamics



Support Self-determination

Collaborate and Navigate

Recognise my bodily autonomy and remain open-minded about what different people might want or be aiming for in terms of gendered embodiment and how that relates to gender affirming care and healthcare more broadly.

Remember that trans and intersex people have sexualities.

Work collaboratively and transparently with me, be clear about the limits of your authority and the reasons behind your decisions and recommendations.

Find information about pathways of care and how we can navigate them together.



Support Self-determination

Widen the Scope of Possibilities

As much as possible, refrain from narrowing the scope of possibility.

Ask me about my hopes and goals. Do not assume you know what I want or need.

Check in with me about how you are taking notes or updating my records, be flexible if I offer corrections or edits.

When I share information with you, be respectful and responsive. Do not force me to share information that is not clinically relevant or necessary for my healthcare.

Find opportunities to upskill yourself about trans health, especially in settings led by trans people and trans organisations.



Resources to support you putting this into practice

Supporting Aotearoa's Rainbow People: Practical Guide for Mental Health Professionals <https://www.rainbowmentalhealth.com/>

Primary Care Webinar Series from 2022:

<https://www.tengakaukahukura.nz/webinar-series-a-conversation-about-trans-health-and-primary-care>

GMA's e-learning course Supporting Transgender People:

<https://genderminorities.com/2021/05/11/supporting-transgender-people-online-course/>

Our website has list of rainbow/trans/intersex/takatāpui/MVPFAFF+ organisations: <https://www.tengakaukahukura.nz/rainbow-organisations>

Trans Hub (Australia) has many great resources including videos about healthcare provision:

<https://www.transhub.org.au/clinicians/getting-started>



Part Three: The big picture

**Multi-disciplinary collaboration to
transform the health system**



Healthcare system relies on community sector

The healthcare system relies on community expertise as well as clinical expertise

- Distinction between community support and community expertise
- Be careful of “clinical and consumer” framework when this does not capture community expertise
- Trans people may want to access community support services - be aware that these services are often provided by under-resourced community groups
- Consider how you can support your local community rainbow/trans/intersex/takatāpui groups and organisations
- Clinicians and healthcare workers also need community support services - whether that is peer support or developing relationships with trans led groups and organisations



Community organisations are a crucial part of the healthcare system (especially when addressing context that causes ill health)

Locate the problem in the context we live in (transphobia/racism/ableism/homophobia etc) not inside the person in front of you

- Community organisations provide crucial support built on our deeper understanding of the impacts of heteronormativity, cisnormativity, white supremacy, ableism etc
- Learn what is available in your region or online nationally
- Relates to an informed consent approach - you may find mental health support options from these community organisations that you can offer to connect someone with
- Relates to depathologising your approach to gender
- Recognise minority stress and discrimination are real and have material effects on our lives



Working together from our different paradigms to improve the healthcare system

There are trans people who are community advocates and educators, who have community expertise, who work with clinicians and healthcare workers of all kinds to improve front line services and write guidelines and produce resources and improve the pathways and healthcare system on so many levels.

We are stronger when we work together and recognise our different and overlapping areas of expertise.

Trans and intersex and rainbow-led community organisations offer support to community members and also professional development opportunities for healthcare providers. We also develop policy, undertake research, translate research for community use, provide feedback and submissions on government planning, and more.





Multisector partnerships linking health with advocacy, social justice, and human rights are crucial to address the public health needs of transgender people across the world

**“Global health burden and needs of transgender populations: a review”,
Reisner et al, 2016, DOI:[https://doi.org/10.1016/S0140-6736\(16\)00684-X](https://doi.org/10.1016/S0140-6736(16)00684-X)**

Public health framework provides a collaborative paradigm

Public health is a framework that can bring together community expertise and clinical expertise alongside policy and planning expertise.

We can use existing data (e.g. Counting Ourselves, see resources slide) to advocate for improved healthcare and recognise that this relates to the material effects of marginalisation on trans populations.





Recognising community expertise and the leadership of trans/intersex/takatātpui/rainbow organisations is essential to improving the health system

A comprehensive approach is needed that includes gender affirmation as a public health framework, improved health systems and access to health care informed by high quality data, and effective partnerships with local transgender communities to ensure responsiveness of and cultural specificity in programming.

“Global health burden and needs of transgender populations: a review”, Reisner et al, 2016, DOI:[https://doi.org/10.1016/S0140-6736\(16\)00684-X](https://doi.org/10.1016/S0140-6736(16)00684-X)



The problem is transphobia

Recognising the social determinants of health and the impact of transphobia in the areas of housing, employment, education, etc is part of improving the healthcare system.

Transphobia operates in combination with racism, ableism, homophobia, etc.

Improve the healthcare system by working with trans and intersex-led organisations.

Shift your practice towards supporting self-determination.



Source: adapted from Dahlgren and Whitehead, 1991

Locate the problem in the system (not the worker); in the environment (not the person); find ways to collaborate across disciplines and sectors.



Resources

Household Economic Survey data about trans and non-binary population in NZ:

<https://www.stats.govt.nz/information-releases/lgbt-plus-population-of-aotearoa-year-ended-june-2021/>

Curated resources about gender affirming healthcare from our website: <https://www.tengakaukahukura.nz/gender-affirming-healthcare>

PATHA's vision for transgender healthcare under the current health reforms: <https://patha.nz/vision2022>

Intersex Aotearoa: <https://www.intersexaotearoa.org/>

Bodily Autonomy: Trans and Intersex Conversations Webinar: <https://www.tengakaukahukura.nz/webinar-bodily-autonomy-intersex-and-trans-conversations>

Counting Ourselves Fact-Sheets and Webinars: <https://countingourselves.nz/fact-sheets-and-webinars/>

Read more about intersex communities/organising and human rights - *Darlington Statement: Joint consensus statement from the intersex community retreat in Darlington, March 2017:* <https://darlington.org.au/statement/>



Upcoming webinars...

Next week:

Human Interactions: Dealing with Limitations of Patient Management Software

with Cassie Withey-Rila

Register: <https://www.tengakaukahukura.nz/webinars>



Human interactions

A free webinar about dealing with limitations of patient management software for people working in healthcare settings who want to respect the self-determination and autonomy of trans and non-binary people

Thursday 25 May 2023, 12-1pm
[tengakaukahukura.nz/webinars](https://www.tengakaukahukura.nz/webinars)



Keep in touch!

All of our webinars are free and recordings are available on our website with slides and other resources/links.

Please tell us what you want to learn more about for future webinars:
<https://www.tengakaukahukura.nz/suggest-a-webinar-topic>

The collage features several elements:

- Three video call thumbnails showing participants in a meeting.
- A poster for a webinar titled "Fix the whole world" with the subtitle "a free webinar about rainbow suicide prevention in Aotearoa", dated September 9 2022, 11am-12pm, with the URL [tengakaukahukura.nz/webinars](https://www.tengakaukahukura.nz/webinars).
- A graphic for a "FREE WEBINAR SERIES HOSTED BY TE NGĀKAU KAHUKURA" with the title "A CONVERSATION ABOUT TRANS HEALTH AND PRIMARY CARE".
- A hand holding a blue pen in the bottom right corner.

watch more webinars:
www.tengakaukahukura.nz/webinars

