

# Minutes of Ngā Reo Māhuri Young Voices group hui – 7 May

Chair	DJ Adams
Ngā Reo Māhuri members	Joshua McMillan, Jaden Hura-White, Ataahua Hepi, Jack Ruddenklau
Te Tāhū Hauora staff	Kelly Palmer, Dez McCormack
Apology	Natasha Astill, Naomi Vailima, Tiare Makanesi (absent), Penita Davies

The hui was held on-line via Teams

The hui began at 12.00 noon

# 1. Welcome, karakia and whakawhanaungatanga

The group had whakawhanaungatanga for Kelly Palmer, Director, Māori Health and Consumer.

#### 2. Members Environmental scans

The scans were taken as read. Members commented further on some aspects of their scans and asked questions on each other's reports. There was some further discussion around gender affirming care. In addition, discussed issues with patients getting their personal information held by medical professionals in a timely way.

# 3. Standard business - previous minutes, actions items and interests register

Minutes were accepted. Action items complete. No changes to Interests register.

## 4. Structure of Advisory groups

DJ updated this process that was previously discussed at the previous hui. Advised that following Te Kāhui Mahi Ngātahi feedback, the board paper on the proposed structure would be updated. Members also advised of the additional commitment required for whoever may be elected to the cochair role. i.e. attending Te Kāhui Mahi Ngātahi hui as well as Ngā Reo Māhuri.

Attached as Appendix 1 is a diagram of the proposed structure.

#### 5. Māori Health & Consumer report - Q3

The report is attached at Appendix 2.

DJ added that the EOI for Ngā Reo Māhuri closes on Monday 26 May and urged members to encourage young people in their networks to apply. We are looking for a wide representation from various communities.

Regarding the Code of Expectations review, DJ gave an update that the formal review has concluded, and a final report being developed. Feedback was good and we are developing a

comms plan around education and development and other meaningful engagement, and also looking at resources. An action plan will be developed to include and link into our work programme.

Jaden raised for consideration, including He Whakaputanga in the process: https://nzhistory.govt.nz/culture/declaration-of-independence-taming-the-frontier

DJ then covered off further work with the primary care context for the implementation guide, which was discussed at the last hui. Feedback sessions have been held, and the final guide will now move to proofing and design, prior to its launch.

An update was provided on  $\bar{O}$  Mātou Reo Our voices 2025 forum. Some key questions were asked of the group. i.e. What are some priorities for rangitahi/young people and thinking about the communities you represent, what are their priorities, needs and wants? Some feedback was provided. For ideas, please send to Hariata at ourvoices@hqsc.govt.nz

# 6. QSM paper March & September Submissions

DJ provided an update on the process and the paper and said there had been an improvement since the last submission. Health entities are taking on board suggestion provided via the moderation exercises.

#### 7. Other business

DJ proposed for the next hui, that we meet in person in Tāmaki Makaurau. The group agreed this was best for accessibility challenges.

DJ also proposed that we move the combined hui with Kōtuinga Kiritaki forward from 6 Nov to 31 October, the day after the Ō Mātou Reo forum. This makes sense on many levels and the group agreed to this.

DJ mentioned we are profiling our consumer advisory group members in the consumer health forum Aotearoa newsletters. We plan to create more consumer videos with focussed stories and are looking for interested members. Josh volunteered to do a profile story for the newsletter.

The group reflected on the hui and general comments were around how everyone enjoys coming together in this group and sharing their experiences.

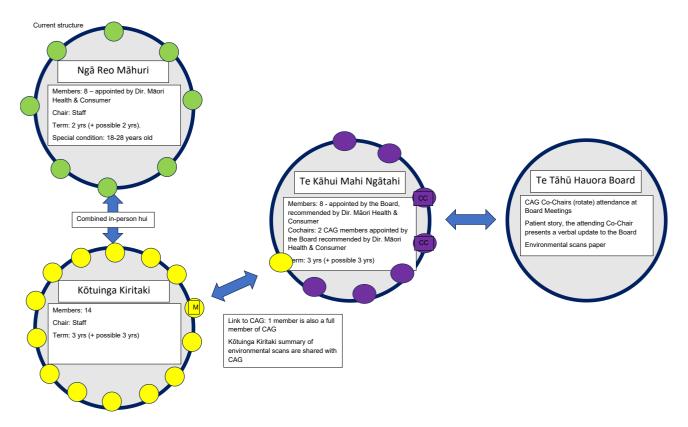
#### 8. Karakia and close

The hui closed with karakia at 3.30 pm

Next hui: 17 July 2025 – in person in Tāmaki Makaurau (MoH building)

# **Appendix 1**

# **Proposed new structure of consumer Advisory groups**



# **Appendix 2**

# Māori health and consumer team Q3 report

The following are highlights for Q3 (January – March) of the 2024-25 financial year.

On 17 March a mihi whakatau was held to welcome Jahminique Chivers to Te Tāhū Hauora and the Māori Health and Consumer team as the Māori Data Governance Lead. A new Māori Health and Consumer Advisor role was advertised with the successful candidate to start early April.

The team held a team day on 27 February for program planning.

# Consumer health forum Aotearoa



# Te Tai o Poutini West Coast Regional Consumer Workshops Wednesday 19 February 2025 & Reefton: Thursday 20 February 2025

Hokitika:

The consumer workshops were presented and although the numbers of attendees were small, the sharing and learning was great. Thank you Zechariah Reuelu, Kōtuinga Kiritaki for joining the team and providing your consumer perspective at the workshops and provider hui.

At Hokitika, mana whenua and haukainga of Arahura Marae welcomed the team with pōwhiri and shared their whakapapa and mātauranga, a beautiful start to our time in Te Tai o Poutini | West Coast. The workshop was attended by representatives from the community including:

- Community Voice West Coast
- West Rural Education Activities Programes (REAPS)
- Te Kāhui Hauora o Te Tauihu Iwi Māori Partnership Board (IMPB)

From Hokitika we headed to Reefton where members of the community attended including representatives from:

- Community Voice West Coast
- Who Cares
- Te Waipounamu Regional Consumer Council

Consumers shared their aspirations and challenges for health care in Te Tai o Poutini. Discussions about the code of expectations were positive including how the code provides levers for the community to contribute to the design, delivery and evaluation of health. They shared ideas on how to improve awareness and education through community newsletters and social media groups. Consumers are enthusiatic to be enaged by the health system and asked that we pass this message directly to the attendees of the provider hui.

## Greymouth: Thursday 20 February 2025 - Health providers hui

The hui was attended by Health NZ staff and primary and community care providers. They shared examples of their work engaging with consumers, whānau and the community and are keen to share practical guidance to support the health sector.

# **Consumer forum opportunities**

The following opportunities were shared with the consumer health forum Aotearoa (CHFA) –listed on the webpage here:

- Adult primary care patient experience survey pretesting
- Pacific Member for the Northern Regional Consumer Council Health NZ
- Northern Clinical Governance Committees Health NZ
- Psychology Board Role of Assistant/Associate Psychology role survey
- Code of expectations review survey
- Collaborative Aotearoa Telehealth Patient Voice Survey
- Putting the patient first: Modernising health workforce regulation public consultation Ministry of Health

#### **Update and News**

The February newsletter was emailed to the CHFA to the members on Friday 14 February 2025. Read the February update <a href="here">here</a>. February issue included:

- Message from the Director's desk
- Kōtuinga Kiritaki | Consumer Network welcomes three new members
- Regional workshops register to attend
- Clinical governance framework
- New Zealand Psychologists Board Assistant/Associate Psychologist role development

#### Forum membership

The total number of individuals who have signed up to the consumer health forum Aotearoa forum members is 965 (increase of 5) We continue to encourage new membership. You can keep the forum growing by sharing this sign-up link with those in your networks:

The following table shows the breakdown of members by ethnicity from end of quarter 4 2023-2024 through end quarter 2 (31 March 2025).

Ethnicity	Quarter 4 2023-24	Quarter 1 2024-25	Quarter 2 2024-25	Quarter 3 2024-25
Māori	Quarter 4 total: 190 (20.2%)	Quarter 1 total: 190 (20.2%)	Quarter 2 total: 195 (20.3%)	Quarter 3 total: 195 (20.2%)
Pacific	Quarter 4 total: 91 (9.6%)	Quarter 1 total: 91 (9.6%)	Quarter 2 total: 93 (9.7%)	Quarter 3 total: 94 (9.7%)
Asian	Quarter 4 total: 53 (5.6%)	Quarter 1 total: 53 (5.6%)	Quarter 2 total: 54 (5.6%)	Quarter 3 total: 54 (5.6%)
Pākehā/Caucasian	Quarter 4 total: 507 (53.9%)	Quarter 1 total: 509 (54%)	Quarter 2 total: 519 (54.1%)	Quarter 3 total: 522 (54.3%)
Middle Eastern/ Latin American/ African	Quarter 4 total: 19 (2.0%)	Quarter 1 total: 19 (2.0%)	Quarter 2 total: 19 (2.0%)	Quarter 3 total: 20 (2.0%)

Other ethnicity or ethnicity not specified	Quarter 4 total: 80 (8.5%)	Quarter 1 total: 80 (8.5%)	Quarter 2 total: 80 (8.3%)	Quarter 3 total: 80 (8.3%)
Total	Quarter 4 total: 940	Quarter 1 total: 942	Quarter 2 total: 960	Quarter 3 total: 965

# **Engagements**

The Māori Health and Consumer team engagements with consumers, whānau, the community and the health sector.

- New Zealand Psychologists Board
- Collaborative Aotearoa
- Regional Consumer Councils Northern and Te Waipounamu,
- Whaikaha Chief Advisor Māori & Policy and Insights
- Whānau Voice Leadership Group cross agency
- Tonic Media Network
- Community Voice West Coast
- Te Pou Hauora Tūmatanui | Public Health Agency Policy
- Te Kāhui Hauora o Te Tauihu Iwi Māori Partnership Board
- Pharmac Consumer Advisory Committee (CAC)
- Royal New Zealand College of General Practitioners (RNZCGP)
- Carterton Medical Centre
- Te Omanga Hospice
- Rare Disorders New Zealand
- Manatū Hauora | Ministry of Health Communications and engagement
- Royal New Zealand College of Urgent Care
- Tū Ora Primary Health Organisation (PHO) Health Care Home Peer Group
- Health & Disability Commissioner Māori Directorate
- New Zealand Blood & Organ Service (NZ Blood)
- Evolution Healthcare
- Ministry for Youth Development
- Hauora Māori Tūmatanui | Māori Public Health, National Public Health Service

# Code of expectations review and primary and community care implementation guidance

Stakeholder engagement activities for the code review were undertaken throughout Q3 with initial findings shared with the cross-agency Consumer Voice Reference Group (CVRG) at a Tuesday 4 March hui convened specifically for this purpose. A draft report which identifies items for an action plan will be shared with consumers and the sector in Q4. Development of the action plan and it's implementation will be intergrated into the program plan for 2025-26.

A framework for implementation guidance for the primary and community care sector was presented and accepted by the Consumer Voice Reference Group at their Wednesday 29 January meeting. The 2019 'Progressing consumer enagement in primary care' resource was reviewed and updated to align with the code of expectations and the SURE (Supporting, Understanding, Responding & Evaluating) framework. Consumers and the primary and community care sector contributed at the inital stage – understanding expectations, the feedback received was intergrated into a draft version that will be reviewed by consumers and providers in Q4.

# Quality Safety Marker for consumer engagement (QSM)

Health entities were supported to submit to the March 2025 QSM. The Māori Health and Consumer team met with the teams from the four Health NZ regional teams to provide support and guidance.

As at 31 March submissions from NZ Blood, Pharmac and Te Tāhū Hauora had been received. Submissions from Health NZ – Northern, Te Manawa Taki, Central and Te Waipounamu are expected by the middle of April (Q4).

The moderation team including two members of Kōtuinga Kiritaki – Oliver Taylor and Zechariah Reuelu will meet in April to consider the submissions, develop feedback and discuss possible improvements for the SURE framework and submission process.

A section for the March submissions will be added to the QSM 2024-25 report.

# Website analytics & Summary of consumer hub website traffic

#### **Summary**

Data for the October-December 2024 period shows engagement with the code of expectations implementation guide content has slowed significantly. Traffic and engagement is down by more than 50% across the board.

It's important to note a drop in online engagement is normal through the Christmas and New Year periods when people tend to be on holiday and/or offline. The drop in traffic and engagement with the code of expectations content mirrors the drop in traffic more generally to the Te Tāhū Hauora website.

We would expect engagement to pick up again from the second half of January.

A pattern emerging over time is the repeated views of a page by the same people – particularly the first three resources. This is a good reflection of the value of these resources to the people using them.

The Code of expectations for health entities' engagement with consumers and whānau page is the 28<sup>th</sup> most viewed page on Te Tāhū Hauora website, out of more than 3,000 pages.

The next report will cover the period of the consumer hui in Te Tai o Poutini West Coast (and its promotion) which should drive traffic to these pages and engagement with this content.

The broader focus on the promotion of the code of expectations in 2025 will similarly help to reach new audiences and strengthen engagement.

2024/25: 1 October - 31 December, 2024

Websites and video resources	October –	1 April – 30	1 October 2023-
	December 2024	September 2024	11 April 2024
	Views: 233	Views: 588	Views: 573
tahi me ngā kiritaki me ngā whānau <u>here</u>	Users: 132	Users: 360	Users: 337
Code of expectations for health entities'	Views: 868	Views: 2,338	Views: 1,526
engagement with consumers and whānau   Te tikanga mō te mahi tahi a ngā hinonga	Users: 578	Users: 1,425	Users: 1,282
hauora ki ngā kiritaki me ngā whānau <u>here</u>			

Code of expectations for health entities' engagement with consumers and whānau	Views: 585	Views: 1,334	Views: 1,596
here	Users: 415	Users: 873	Users: 1,067
(This page hosts the code translations and accessible formats)			
Code of expectations implementation guide	Views: 136	Views: 476	Views: 700
Te aratohu tikanga ( <u>new landing page</u> <u>here</u> )	Users: 95	Users: 293	Users: 391
	Views: 215	Views: 614	Views: 442
Co-designing with consumers, whānau and communities   Hoahoa tahi me ngā kiritaki, ngā whānau me ngā hapori <u>here</u>	Users: 149	Users: 422	Users: 309
Video: Co-design explained in 30 seconds	Views: 21	Views: 69	Views: 49
	Users: 18	Users: 65	Users: 36
Video: Co-design: making it business as usual	Views: 7	Views: 43	Views: 31
	Users: 6	Users: 39	Users: 25
Video animation: The co-design process	Views: 27	Views: 105	Views: 63
	Users: 20	Users: 86	Users: 50
Using lived experience to improve health services   Te whakamahi wheako mātau hei whakapai ake i ngā ratonga hauora here	Views: 163 Users: 125		Views: 364 Users: 265
Video: Co-design case study: Susanne Cummings here	Views: 12	Views: 34	Views: 26
cummings <u>nere</u>	Users: 11	Users: 33	Users: 22
Video: Consumers share how their lived	Views: 7	Views: 46	Views: 23
experience contributed to health improvements here	Users: 6	Users: 39	Users: 18
	Views: 135	Views: 449	Views: 235
Improving equity through partnership and collaboration   Te whakapai	Users: 100	Users: 322	Users: 153
ake i te mana taurite mā te mahi tahi here			) (I
Video: Te Whatu Ora Taranaki consumer council members outline the importance of	Views: 4		Views: 10
consumer engagement (no YouTube data	Users: 4	Users: 14	Users: 8

available links to external Facebook page for Bryan Vickery Media Taranaki clicks avail on request).  Note: it is not possible to see the number of Facebook views by quarter.	Facebook total views: 954	Facebook total views: 953	
Video: Consumer voice: What does equity	Views: 33	Views: 69	Views: 88
mean to you and your community?	Users: 32	Users: 64	Users: 63
	Views: 52	Views: 212	Views: 160
Accessibility and resourcing for	Users: 43	Users: 115	Users: 88
consumer, whānau and community			
engagement   Te whai wāhi me te whai			
rauemi mō te mahi tahi ki te kiritaki, te whānau me te hapori <u>here</u>			
Video: Enhancing accessibility: how to begin	Views: 4	Views: 12	Views: 14
	Users: 4	Users: 11	Users: 11
Video: Practical accessibility tips for producing	Views: 7	Views: 12	Views: 11
consumer resources	Users: 5	Users: 10	Users: 8
Video: What is the code of expectations and	Views: 3	Views: 12	Views: 11
are we achieving what's required?	Active users: 3	Users: 11	Users: 10

# **Aotearoa Patient Safety Day content**

Video: Elevate the voice of consumers and whānau (YouTube)	YouTube: Has had 705 views in
https://www.voutube.com/watch?v=AoF47Au77s4	total 27 views since last report (Sept 30)

### Appendix 3

# Summary of Ngā Reo Māhuri member reports – 7 May 2025

Joshua McMillan (Tāmaki Makaurau)

#### **Environmental Scan**

Admittedly, I have been preoccupied with more personally related matters in recent weeks.

General environment from my vantage point seems unchanged since I last provided on – strain on services, confusion and uncertainty within various health sector areas. Concerning govt/regulatory rhetoric that can/will impact health services and infrastructure.

## **Activity (since last report)**

Attended the Consumer QSM Report hui on Wednesday, 19<sup>th</sup> March. In general, a notable discussion on how effective consumer engagement is going and how to improve on measurements going forward.

#### **Services**

I've heard multiple instances of hospitals not providing patients access or copies of their records that are needed for myriad things; one example - Tauranga hospital not providing someone with copies of their radiology scans, which the patient needed to provide external carer for ongoing treatment. As far as I'm aware, patients cannot be refused access to their data(?), as they are the owners of said personal data/records.

The motion to repeal the Plain Language Act 2022 is concerning. It has already passed its first reading in parliament, being labelled 'a waste of time and money.' Concern is greatest for those populations that this bill seeks to empower, such as disabled and impaired communities who interact with public services frequently. In the context of TTH, this can/would impact health information provided to consumers across various formats, creating space for confusion, errors and situations that could otherwise be avoided with clear communication in easy to digest forms. Ensuring this bill is NOT repealed is vital for consumer groups of different cultures, abilities, English-second language, and general populations who don't understand, nor do they need to, the jargon.

https://www.stuff.co.nz/nz-news/360663004/law-aimed-removing-jargon-public-service-line-it-worth-saving

#### Considerations for Te Tāhū Hauora

I think TTH should consider acting upon the potential repeal of the Plain Language Act 2022, providing some kind of evidence and/or submission detailing the negative impacts this will have on the populations that it was designed to help. The option must remain, whether that means having a plain language/easy read version and a 'regular' version or leaving the law unchanged and as is. Repeal should not be the only option here.

# Natasha Astill (Tāmaki Makaurau)

#### **Activity and services**

I had the opportunity to attend the I Lead committee meeting in April 2025. We were discussing what's been happening in the disability community and to see if there were any opportunities to get our voices heard.

In the disability community at the moment, we as a community want to get our voices heard and would love the opportunity to but unfortunately there aren't a lot of opportunities available to do so especially in health consumer perspectives.

#### Considerations for Te Tāhū Hauora

The disability community would like the opportunity to share our experiences around the health system and what currently works best to support us.

# Jack Ruddenklau (Te Whanganui-a-Tara)

# **Activity**

Te Waipounamu Regional Consumer Council - Ongoing attendance

#### **Services**

Access to gender affirming healthcare

- Many trans and rainbow takatāpui taiohi are struggling just to find clear information on how to access services
- Different health professionals (GPs, school nurses, counsellors) are giving different information and advice. There is no consistent, trustworthy information source.
- Some providers are pre-emptively pausing puberty blockers access due to uncertainty around the national consultation (this is despite no policy change). This has caused major distress among many.
- There is a district discrepancy here, and some districts have decided to pause these at a district level and there are disparities across the system nationally and regionally.

## Access to neurodivergent support

- Getting assessments for ADHD and autism remains a significant barrier. This is especially challenging for those with intersecting identities (like rainbow people).
- Without early diagnosis and support, transitions into study, work, and independent living are harder, and this locks people into disadvantage.

#### Primary care pressures

- People are waiting four weeks to access basic GP services in Murihiku. This is even more evident for home visits - this is particularly concerning for older people.
- This is leading to unnecessary hospital admissions for conditions that could be managed earlier in the community.
- Vulnerable groups like older people, palliative care patients, and those with complex conditions are disproportionately affected.
- Home support workers are often missing scheduled visits, fail to notify changes, or simply do not turn up.
- Fear of service withdrawal means people are reluctant to complain (even when the quality of care is poor).

#### Palliative care

- Over 23% of applicants for assisted dying in Aotearoa were not receiving palliative care at the time of application.
- Timely and proactive referrals to palliative care services are still not consistently happening.

# Disordered eating among rainbow youth

- Disordered eating is a major and under-addressed issue, and this especially affects trans young people.
- Current models often do not account for the intersection of gender, body image, and trauma.

# Positive stories and exemplars

- Community-based services like Vibe are providing important spaces for rainbow youth to seek support. This is despite them being forced to fill gaps the formal health system should be covering.
- Rainbow-led research projects like Counting Ourselves provides evidence-based insights into where the system is falling short.

#### Considerations for Te Tāhū Hauora

- Push for nationally consistent and accessible information for gender affirming healthcare.
   This is becoming a safety issue. There needs to be interim guidance released on puberty blockers.
- Recognise disordered eating in rainbow communities as a serious and distinct health issue and ensure models of care are inclusive of these experiences.

## Jaden Hura-White (Pongakawa)

#### **Environmental scan**

In the Diabetes consumables space

- Final push to get insulin pumps updated to new software for app integrations (NZMS). Huge call for NZMS to be more efficient with providing relevant information.
- Diabetic's frustrated by GP's lack of knowledge with CGM/Insulin Pump funding
- Pharmacy supply of CGMs (lack of)
- Consumers confused from lack of in-depth educations around intricacies of CGMs and Insulin Pumps even though technology is prescribed.

#### **Activity (since last report)**

Attended a iwi hui, regarding our taiao/hauora. It was a journal launch, spearheaded by rangatahi Tūwharetoa. The journal for the Taupō community, focusing mainly on maramataka connecting with our Taiao, the importance on iwi having connection to the whenua and the taiao, not only for the health and betterment of the taiao but also for our iwi, for Oranga ā Tinana, ā Wairua, ā Hinengaro, ā Ngākau.

## **Positive stories and exemplars**

A positive experience I felt was seeing the peoples wairua come alive in conversations around hauora of whenua and the wellbeing of people. The journal being a tangible way to keep track of and get in tune with ourselves and the environment. This was during the taiao hui ā iwi. People came away feeling impowered and hopeful.

Stoked to see NZMS providing great educational material and training before the access to the new T-Slim X2 (insulin pump) updates, making sure consumers stay safe and can make informed judgements in interaction with this new technology integration.