



Te Tāhū Hauora
Health Quality & Safety
Commission

Minutes of the Kōtuinga Kiritaki / Consumer Network hui

Chair	DJ Adams
Kōtuinga Kiritaki members	Mary Schnackenberg, Oliver Taylor, Ricky Ngamoki, Jennie Harré-Hindmarsh, Zechariah Reuelu, Tyson Smith, Toni Pritchard, Amanda Stevens, Vishal Rishi, Joanne Neilson, Mark Rogers, Eden Li, Vivien Wei Verheijen, Tee Siataga.
Māori health & Consumer Team	Carlton Irving, Hariata Bell, Dez McCormack
Te Tāhū Hauora staff:	Doug Edwards
Guests	Collaborative Aotearoa - Ny Brunenberg; New Zealand Psychology Board - Gina Giannois, Deputy Registrar and Vanessa Simpson - CE
Apology	Arana Pearson, Peter Jansen, CE

The hui was held at Rydges Wellington Airport, on **13 February 2025**.

The hui began at 9.15 am.

1. Mihi Whakatau for new members

Doug conducted this session

2. Whakawhanaungatanga

Whanaungatanga was undertaken for the three new members.

Members shared some of their experiences and passions for the mahi they do as consumers in the health system.

3. Standard business

Previous minutes – accepted

Interests register – some updates for next hui

Action items – addressed in this hui

4. Feedback on previous Te Kāhui Mahi Ngātahi CAG hui –

Mary provided this update. Her written reports as follows:

Te Tāhū Hauora Health Quality & Safety Commission (HQSC) has four groups of consumer advisors across the organisation:

- the Consumer Network, Kōtuinga Kiritaki;
- Young Voices Advisory Group, Ngā Reo Māhuri;
- Consumer Advisory Group (CAG) Te Kāhui Mahi Ngātahi; and

- Te Kahui Piringa, the Māori advisory group to the board.

Māori Health and Consumer team will soon have a te reo Māori name. After consultation, there is now a revised process for establishing te reo Māori names for groups and projects that HQSC has responsibility for.

There are consumer advisors on other groups in HQSC. And HQSC promotes consumer advisor roles in other health-related entities through its emails, newsletters and its website.

I serve on both this Consumer Network and the Consumer Advisory group. My role at the Consumer Network meeting is to keep you up to date with the activities of the Consumer Advisory Group. Since the Network met on 7 November, CAG has met on 12 November, 26 November including time with the HQSC Board, and 7 February.

Reading your environmental scans, as well as recalling previous conversations here, I want to assure you that the environmental scans, wherever they come from among HQSC groups, are promoted to the Board. Dez and DJ are careful to lift recommendations into a joint report that goes to Board meetings. At the beginning of each Board meeting there is a Patient Story. This is followed by a 20-minute presentation from one of the two co-chairs of the Consumer Advisory Group who take it in turn to attend the Board meetings. We are told the Board absolutely values this input.

Everyone is reporting the lack of consumer engagement at the Consumer Council regional level. I have been involved in Auckland as a consumer advisor since 2017. I have to report that almost all over the country, consumer engagement with proper support to the consumer advisors has gone backwards. It is the HQSC team who is reading your scans and listening to you. Environmental scan stories inspire as well.

Please may I encourage each of you in the work you are doing. To get a health practice able to talk and work with your local Work and Income staff as well as an ACC counsellor is a success of almost heroic proportions. Now if we could all learn from that, how much better off everyone would be, especially in rural New Zealand. And that's only one example from your scans.

The suicide rate among our youth is the highest in the world. Mortality Reviews continue to say the same things they have said for years, that is, change is not happening as a result of previous reports. HQSC is actively looking at ways to improve its reports by developing action-focused recommendations.

We have previously talked about the HQSC policy now called Healing, Learning and Improving from Harm. It used to be called the National Adverse Events Policy. One Board paper CAG looked at during its 7 February meeting is about how to better present not just statistics but also stories about what has been happening and what needs to change.

The evidence of a significant decrease in health funding is driving more innovative approaches to highlight the problems. And language is changing. Demand for succinct, clearer language is growing. Oliver, you and a member of CAG have drawn attention to lengthy Terms of Reference prescriptive documents. Long, verbose, prescriptive documents don't get read by their intended implementers.

Today you are looking at the beginning of work to encourage consumer input at primary healthcare level. The 2019 document circulated to CAG and the Network is very good. However, several references are to documents that may not be fully accessible and may be out of date even after as little as five years. And the country has to find ways of injecting consumer advice into an already over-worked primary healthcare system. The current HQSC writing team, supported by current consumer advisors, will come up with the language that will cut through I am confident.

Carlton Irving reminded CAG at its 7 February meeting that the HQSC remit was changed from “providing insights” to “making recommendations”. HQSC insights come from all the statistics and stories it collects. Recommendations are prioritised actions. However, no matter how good HQSC recommendations are, it has no enforcement powers. HQSC's advocacy and networks with the Ministry of Health and the other health entities are key to the adoption of the recommendations. And no matter how good the recommendations are, they need government funding. That is where consumer-led innovation has a significant part to play. Your environmental scans share examples of local innovation of national importance.

Changes will occur this year on CAG itself. A resignation came in last week from a member in his first term on CAG. Three more of us have terms that expire this year. I think all three of us can have our terms extended. However, I have not asked to extend my time for a further year. This gives HQSC a good opportunity to explore succession planning and seek members from its other consumer groups who can move into CAG. And, yes, I will be attending our May meeting.

5. Māori Health & Consumer report and update

DJ provided this update. This Māori Health and consumer report is tabled as Appendix 1.

Carlton advised of Peter Jansen's (CE) extended leave. Carlton also noted that he will be away from mid-April for six months working as a doctor in Hawkes Bay Hospital. He will keep abreast of our mahi but at a reduced level.

6. Member reports

Member reports were taken as read.

The summary of reports is at Appendix 2. Members were given the opportunity to expand on their reports.

7. Updates on Trauma resources and Aotearoa New Zealand Rare Disorders Strategy

Mark Rogers provided an update on the Trauma resources and thanked the group for the feedback provided at a previous hui. There were noticeable changes to the final resources after consumer input.

Regarding the Rare Disorder strategy, this has not progressed due to Te Whatu Ora Health New Zealand (Health NZ) not currently in a position to advance work on the strategy. The Rare Disorders organisation was grateful for the engagement Te Tāhū Hauora had instigated, and this relationship is continuing with regular hui.

8. New Zealand Psychologists Board (NZPB) – Developing Assistant/ Associate Psychologist (AP) role/s

Gina Giannois and Vanessa Simpson from the Psychologists board presented on the development of a new scope of practice within the psychology profession.

Points from their presentation:

- There is demand for psychological services. Many people are waiting.
- An effective framework/model of delegation will allow registered psychologists employed in mental health and addiction services to effectively utilise their full scope of practice
- NZPB are the lead for developing a regulatory framework for an AP role in Aotearoa
 - This is part of a wider scope of work directed by Te Whatu Ora
 - The new scope of practice will establish and grow AP roles
 - for at least 20 students per year
 - will allow those with suitable undergraduate qualifications to enter further training

- The AP role will increase the mental health and addiction workforce from 2025

An Associate/Assistant Psychologist (AP) is:

- A psychology graduate from an NZPB accredited training programme
- Has gained applied experience in a professional setting
 - While assisting and working under the supervision of a registered psychologist or senior associate/assistant psychologist
 - They contribute to psychological care within a team environment for tāngata whai ora who are experiencing:
 - Mental distress
 - Mental health issues
 - Addiction issues
 - They may work in diverse health sector settings
 - APs must work in a team with clear clinical responsibilities and cannot practice independently
 - Supervision by a Registered Psychologist or Senior Associate/Assistant Psychologist is mandatory
 - APs engage with consumers of psychological services, including caregivers, whānau, professionals, students, or research participants, based on their role
 - APs differ from Registered Psychologists, as they have not completed the training required for NZPB registration as a Registered Psychologist
 - APs cannot make independent diagnostic or treatment decisions in clinical settings but should be supported in gaining relevant skills and experience

The group asked several questions and provided their comments, which were gratefully received.

Ethnicity detail of the membership of the Psychologist Board

Group	Total	Break down
Māori	81	
Pacific	40	Cook Islands Māori 4 Fijian 2 Niuean 8 Other Pacific Peoples 2 Pacific Peoples 1 Samoan 17 Tongan 6
Asian	260	Asian 32 Chinese 124 Japanese 12 Korean 15 South East Asian 20 Sri Lankan 18 Other Asian 39
MELAA	146	African 56 Latin American 23 Middle Eastern 15 South African 52

9. FIT for symptomatic project

DJ presented on this project via a PowerPoint supplied by Marni Adlam. The project is designed to better and more quickly identify where further investigation is needed into possible Bowel cancer in patients. The project is underway, and a consumer sits as a member on the Equity working group for the project. Consumer input is being sought at different stages of the project.

10. Collaborative Aotearoa – Telehealth

Ny Brunenberg presented. Collaborative Aotearoa works with approx. 250 primary & community care providers to improve patient outcomes. The Telehealth projects look at providing and improving access to effective and responsive healthcare services. A survey was conducted to determine the effectiveness of telehealth services and Ny provided a summary of the survey.

The group asked several questions relating to the survey results.

11. Implementation Guide – Primary Care context

DJ advised the group of the work to update the 'Progressing consumer engagement in primary care' resource. Developed and printed prior to the enactment of Pae Ora (Health Futures) Act 2022 and the Code of expectations for consumer and whānau, it is necessary to review the resource and align with Pae Ora and the Code. We are working closely with Comms and feedback will be sought from consumers when a draft is available.

12. Farewell Ricky Ngāmoki

The group acknowledged Ricky for his mahi and was appropriately farewelled by all members with speeches and presented with a gift and letter of appreciation

13. Comments and wrap on today. Other business

Dez advised the group that Te Tāhū Hauora (Wellington office) will move to Manatū Hauora |Ministry of Health (the Ministry) building in Molesworth Street in late April. Dez also confirmed the date and location for the groups next hui.

There was no other business or comments.

14. Karakia and close

DJ closed with karakia

Next hui: 15 May 2025 – Rydges Wellington Airport

Actions list

Date	Action	Responsibility
13 Feb	Share the Briefing to the Incoming Minister (BIM) when it is available	DJ
	Provide ethnicity data of the Psychologist Board membership: Māori, Pacific, Asian, MELAA	DJ
	Reshare the link to the Telehealth survey	DJ

Appendix 1

Māori health and consumer team Q2 report

The following are highlights for Q2 (Oct - Dec) of the 2024-25 financial year.

In October, Carlton Irving joined Te Tāhū Hauora as the new Director of Māori Health and Consumer. In November, Hariata Bell joined the team as the Māori Health and Consumer Advisor, she was previously the programme coordinator for the Mental health and addiction quality improvement programme. Both were welcomed with mihi whakatau. Also, in November, DJ Adams was appointed as Senior Consumer Advisor. The current number of staff is now five.

A new role for Māori Data Governance Lead is advertised and closes 27 January.

Consumer health forum Aotearoa



Te Tai o Poutini West Coast Regional Consumer Workshops

The programme for the workshops is confirmed and promoted. Registrations are slowly being received with the team taking every opportunity to promote in their meetings with stakeholders. We appreciate the support of our consumer advisory members to socialise the workshops with their whānau and connections.

Hokitika: Wednesday 19 February 2025

Reefton: Thursday 20 February 2025

Greymouth: Thursday 20 February 2025 – Health providers hui

We will share resources developed to inform consumers and whānau about the health system and opportunities for engagement to contribute and influence improvement. The ‘honouring our stories’ kaupapa will also be shared with attendees. The code of expectations, particularly the review, will feature as a specific workshop item and feedback and comments will be integrated into the outcome report.

Consumer forum opportunities

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

- Collaborative Aotearoa Telehealth Patient Voice Survey - current
- Code of expectations review survey - current
- Ambulatory Care and Community Health design guidance review
- Mental Health Intensive Care design guidance review
- Renal Dialysis Unit design guidance review
- Rheumatic Heart Disease Echo Screening Study

- Kōtuinga Kiritaki | Consumer Network
- Ngā Reo Māhuri | Young Voices Advisory Group
- FIT for symptomatic project equity group

Update and News

Two newsletters were emailed to the CHFA to the members on 30 October and 16 December.

October issue included:

- Message from the Director's desk
- Review of the code of expectations
- New Aotearoa New Zealand System Safety Strategy Rōpū
- Collaborative Aotearoa Telehealth Patient Voice Survey
- Aotearoa Patient Safety Day 2024

December issue included:

- Message from the Director
- The code of expectations review
- Regional workshops update
- Quality and safety marker (QSM) update
- Surgery and risk in Aotearoa New Zealand | Te pōkanga me te tūponotanga i Aotearoa
- Register of Chinese Medicine Practitioners: Supporting Safe and Effective Care
- Aotearoa Patient Safety Day 2024 update

Read the October update [here](#) and the December update [here](#).

Forum membership

The total number of individuals who have signed up to the consumer health forum Aotearoa forum members is 960 (increase of 18) 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 3 2023-2024 through end quarter 2 (31 Dec 2024).

Ethnicity	Quarter 3 2023-24	Quarter 4 2023-24	Quarter 1 2024-25	Quarter 2 2024-25
Māori	Quarter 3 total: 181 (19.7%)	Quarter 4 total: 190 (20.2%)	Quarter 1 total: 190 (20.2%)	Quarter 2 total: 195 (20.3%)
Pacific	Quarter 3 total: 91 (9.9%)	Quarter 4 total: 91 (9.6%)	Quarter 1 total: 91 (9.6%)	Quarter 2 total: 93 (9.7%)
Asian	Quarter 3 total: 46 (5.0%)	Quarter 4 total: 53 (5.6%)	Quarter 1 total: 53 (5.6%)	Quarter 2 total: 54 (5.6%)
Pākehā/Caucasian	Quarter 3 total: 504 (54.7%)	Quarter 4 total: 507 (53.9%)	Quarter 1 total: 509 (54%)	Quarter 2 total: 519 (54.1%)
Middle Eastern/ Latin American/ African	Quarter 3 total: 19 (2.1%)	Quarter 4 total: 19 (2.0%)	Quarter 1 total: 19 (2.0%)	Quarter 2 total: 19 (2.0%)
Other ethnicity or ethnicity not specified	Quarter 3 total: 80 (8.7%)	Quarter 4 total: 80 (8.5%)	Quarter 1 total: 80 (8.5%)	Quarter 2 total: 80 (8.3%)

Total	Quarter 3 total: 921	Quarter 4 total: 940	Quarter 1 total: 942	Quarter 2 total: 960
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Engagements

The Māori Health and Consumer team has been busy as we continue engagement with our stakeholders – consumers, whānau, the community and the health sector.

- Mental Health and Addictions programme – Te Tāhū Hauora
- Whānau Voice Leadership Group – cross agency
- Improving Together: – Improvement advisors programme
- National Clinical Network – Trauma – cross agency
- Consumer engagement and whānau voice – Health NZ
- Northern Regional Consumer Council secretariat – Health NZ
- Rare Disorders New Zealand
- Digital Health Equity Network – cross agency
- Chinese Delegation Concerning Primary Health – visit with Te Tāhū Hauora
- Code of expectations review:
 - Carterton Medical Centre Community Health Forum
 - Te Omanga Hospice Consumer Advisory Group
 - Manatū Hauora Disability Policy Team
 - Whaikaha

Code of expectations, implementation guide and the code review.

The cross-agency Consumer Voice Reference Group accepted the framework for the review that sets out the aims and plan for the review which will be completed by June 2025.

The review was an agenda item on Te Tāhū Hauora consumer advisory groups – Te Kāhui Mahi Ngātahi, Kōtuinga Kiritaki and Ngā Reo Māhuri.

Other stakeholders including consumers, whānau and the health sector were engaged through hui, presentations, focus groups and workshops.

The consumer and whānau survey was developed with consumer input. The survey was promoted with our consumer advisory networks, CHFA, and stakeholders. At the end of Q2 (31 December 2024) 38 responses were received. The survey will continue to be promoted up till the closing date 7 February 2025.

Quality Safety Marker for consumer engagement (QSM)

The September 2024 submissions were published to the public dashboard on December 5. A story in the December CHFA News and update invited consumers to check out how health entities are reporting consumer engagement and enactment of the code of expectations.

A report was drafted and will be presented to Te Tāhū Hauora executive leadership team (ELT), Te Kāhui Piringa - the Māori advisory group and Te Kāhui Mahi Ngātahi Consumer Advisory Group (CAG) and will inform a briefing paper to the Minister of Health following the March 2025 submission round.

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 28th 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 – December 2024	1 April – 30 September 2024	1 October 2023- 11 April 2024
Engaging consumers and whānau Te mahi tahi me ngā kiritaki me ngā whānau here	Views: 233 Users: 132	Views: 588 Users: 360	Views: 573 Users: 337
Code of expectations for health entities' engagement with consumers and whānau Te tikanga mō te mahi tahi a ngā hinonga hauora ki ngā kiritaki me ngā whānau here	Views: 868 Users: 578	Views: 2,338 Users: 1,425	Views: 1,526 Users: 1,282
Code of expectations for health entities' engagement with consumers and whānau here (This page hosts the code translations and accessible formats)	Views: 585 Users: 415	Views: 1,334 Users: 873	Views: 1,596 Users: 1,067
Code of expectations implementation guide Te aratohu tikanga (new landing page here)	Views: 136 Users: 95	Views: 476 Users: 293	Views: 700 Users: 391

 <p>Co-designing with consumers, whānau and communities Hoahoa tahi me ngā kiritaki, ngā whānau me ngā hapori here</p>	Views: 215 Users: 149	Views: 614 Users: 422	Views: 442 Users: 309
Video: Co-design explained in 30 seconds	Views: 21 Users: 18	Views: 69 Users: 65	Views: 49 Users: 36
Video: Co-design: making it business as usual	Views: 7 Users: 6	Views: 43 Users: 39	Views: 31 Users: 25
Video animation: The co-design process	Views: 27 Users: 20	Views: 105 Users: 86	Views: 63 Users: 50
 <p>Using lived experience to improve health services Te whakamahi wheako mātau hei whakapai ake i ngā ratonga hauora here</p>	Views: 163 Users: 125	Views: 541 Users: 369	Views: 364 Users: 265
Video: Co-design case study: Susanne Cummings here	Views: 12 Users: 11	Views: 34 Users: 33	Views: 26 Users: 22
Video: Consumers share how their lived experience contributed to health improvements here	Views: 7 Users: 6	Views: 46 Users: 39	Views: 23 Users: 18
 <p>Improving equity through partnership and collaboration Te whakapai ake i te mana taurite mā te mahi tahi here</p>	Views: 135 Users: 100	Views: 449 Users: 322	Views: 235 Users: 153
Video: Te Whatu Ora Taranaki consumer council members outline the importance of consumer engagement (no YouTube data available links to external Facebook page for Bryan Vickery Media Taranaki clicks avail on request).	Views: 4 Users: 4 Facebook total views: 954	Views: 15 Users: 14 Facebook total views: 953	Views: 10 Users: 8

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

Aotearoa Patient Safety Day content

Video: Elevate the voice of consumers and whānau (YouTube) https://www.youtube.com/watch?v=AoF47AuZZs4	YouTube: Has had 705 views in total 27 views since last report (Sept 30)
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Appendix 2 –

Summary of Kōtuinga Kiritaki Consumer Network reports – 13 February 2025

Mary Schnackenberg (Tāmaki Makaurau)

Environmental scan

Pharmac has an email newsletter of their media releases. Several invitations come through each month seeking feedback about proposals to change different medicines.

Input / involvement in Te Tāhū Hauora meetings/groups.

I was an apology for the HQSC Consumer Advisory Group meeting on 26 November.

Services

More family, friends and colleagues in my network are facing challenges about supporting parents into rest home care. Managing assessments, enduring powers of attorney and more can bring out long held tensions.

One family with a 90-year-old father needed to get him a wheelchair. Auckland City Hospital said there was a nine month wait for an assessment. The family had the resources to lease a wheelchair from an Auckland provider. An occupational therapist is visiting early in February to begin the process of rest home assessment of their father.

Considerations for Te Tāhū Hauora

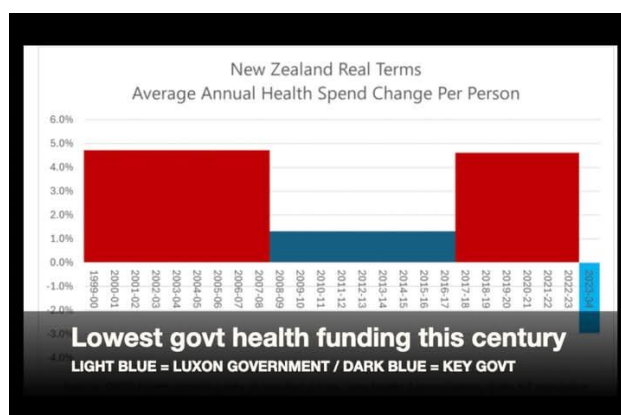
In the midst of everything that is not happening because of cost cutting, please try to remember to praise other organisations for good communications about whatever it might be. My Pharmac example may be worth a mention, especially as in the past they have had such deserved criticism.

Jennie Harré Hindmarsh (Tairāwhiti)

Environmental scan

The health system's "postcode lottery" continues to get worse. Equitable access to nationally consistent health services of all types has further deteriorated, with very serious repercussions and even more so in rural and provincial communities. Endless examples are everywhere of increased suffering, anxiety and loss of hope and trust in having a responsive needs-based 'health system', let alone one which champions proactive prevention programmes. This is so frustrating given research and experience demonstrates how timely treatment and preventative interventions support us all to live better, saves lives - and saves money.

This drastic decrease in the quality of health services is even more frustrating given (contrary to the current Coalition Government's claims) recent analyses by health economists, as depicted in the graph below, show that average government health spend per person decreased significantly in the 2024 Budget. And this funding reduction, combined with the last National-led government's large reduction in annual Health spend per person during 2008/17, goes a long way to explaining why we are experiencing such a deterioration in timely (if any) access to primary and specialist care, let alone preventative programmes. The cumulative effect is even more concerning given projections that one in four persons will be over 65 years by 2040....



From: Peter Huskinson *Opinion* in NZ Doctor Rata Aotearoa 27 June 2024

Much community time and energy is being consumed in expressing concern about health and wellbeing impacts of, and writing Select Committee submissions in opposition to, the Coalition Government's 'Treaty Principles Bill' and related legislation proposals/enactments (including the Regulations Standards Bill, repeal of section 7aa in the Oranga Tamariki Act, repeal of Smoking Cessation legislation, amongst many others).

Furthermore, the Coalition Government's recent decisions around vaping and cumulative damage being inflicted on decades of effective evidence-based, community-led progress in 'smoking cessation' interventions is gobsmacking. The damaging consequences, immediate and long-term, to the quality and safety of our health are far-reaching and require more decisively bold push-back from us all.

The Te Tāhū Hauora Board's response to the Whanaketia Commission of Inquiry into Abuse in State Care's findings is encouraging, especially the Board's underlining of the crucial "importance of consumer input, from the top down and the bottom up" to ensure such abuses are never again repeated within care systems: <https://www.hqsc.govt.nz/news/abuse-in-care-statement-from-te-tahu-hauora-health-quality-and-safety-commission-board/>

Input / involvement in Te Tāhū Hauora meetings/groups.

Advisory Group for National Mortality Review Committee (NMRC) strategic workstream on the impact of avoidable mortality on families, whānau, 'aiga and other collective groups.

Informed by this Advisory Group's online discussions (Aug-Oct), the staff provided a briefing paper to the NMRC in November 2024 which proposed the Committee progress this workstream by adopting an approach whereby the first step in any mortality review is to identify if currently relevant documentation of lived experience for the issue under consideration exists, and to ensure families and whānau with lived experience are central to formulating NMRC's recommendations for change. It noted that a 'whole of Te Tāhū Hauora' approach was needed and recommended NMRC continue to engage with the Māori Health and Consumer team, Te Kāhui Piringa and Te Kāhui Mahi Ngātahi, to guide the Committee's incorporation of lived experience into the centre of work to shift its focus from solely making recommendations, to - in partnership with kinship groups - formulating specific actionable, evidence-based and culturally responsive recommendations to influence system changes and implementing those recommendations.

Advisory Group for Te Tāhū Hauora HQSC 'Clinical Governance Framework' Project.

On 20 November 2024 the long anticipated, updated Clinical Governance framework was published on the Te Tāhū Hauora website (<https://www.hqsc.govt.nz/news/updated-clinical-governance-framework-released/>). This Framework was developed during 2022/24 to embed in clinical

governance policies and practice, the Pae Ora (Healthy Futures) Act's intention to give effect to Te Tiriti o Waitangi and principles of equity, tino rangatiratanga and engagement with Māori and other population groups.

- It is now very concerning to note confirmation that the Pae Ora Act is included in Coalition Government's proposal to change or remove Te Tiriti o Waitangi provisions in 28 Acts.
[Govt to change or remove Treaty of Waitangi provisions in 28 laws - Newsroom](#)

Activity (since last report)

13 Nov 2024, Building Community Resilience to Climate Change – Learnings from Recent Cyclone Disasters.

I was interviewed for a study (by Massey University with Environment Hubs) which is documenting our communities' lived experiences of responding to disasters like Cyclones Hale and Gabrielle. Their aim is to inform initiatives that further support and strengthen community resilience to climate change, including the resilience of community health and health-related services, by improving our understandings of:

- challenges faced by communities in responding to the disasters
- key resources, skills and support which communities define as important to enhance our capacity to respond to future climate related disasters
- ways in which government agencies and other organisations can support and collaborate with communities to enhance our resilience to climate-related disasters.

20-21 Nov 2024, Ngāti Porou Oranga Research Symposium on Pakirikiri Marae in Tokomaru Bay. Participated in a two-day gathering hosted by the Ngāti Porou Oranga (previously Ngāti Porou Hauora) Te Rangawairua o Paratene Ngata Centre of Excellence <https://www.npo.org.nz/research> to update the local community and health service providers, and to strengthen cross-disciplinary collaborations between researchers, emerging researchers, whanau/communities and health workers. For the full programme of this (now biannual) health research symposium, see https://cdn.prod.websitefiles.com/66e0eb65ab1120c986bbc9ef/673e46203ba69fa68a66744e_Tatai%20Oranga%20Symposium%20Booklet.pdf

25 Nov 2024, Genomics Aotearoa Māori Variome He Kākano Governance Roopu. <https://www.genomics-aotearoa.org.nz/our-work/health-projects/aotearoa-nz-genomic-variome>

Continue to be part of advising the research team on developing long-term governance arrangements for the Māori Variome He Kākano resource, and policies and protocols for its use as a clinical diagnosis tool which improves equitable precision of health care for Māori, and further research for this purpose. To date, 200 clinical tests had been piloted to improve the quality and safety of diagnoses for participating patients and their whānau.

Continued to participate in initiatives to improve 'Te Mana o te Wai' (freshwater quality & quantity) as an Advisory Group member to inform Gisborne District Council's development of the Waimatā-Pakare Catchment Plan, and to progress our community-led Wainui Beach Catchment Kaitiaki initiatives to restore the hauora of our awa and whenua and thus strengthen community health.

Services

In the demoralised health system, community members continue to express sincere gratitude to health providers who soldier on to provide them with high quality care – when they finally manage to access care, often with escalating pain and/or risks of complications whilst awaiting 'their turn' on longer lists where 'their turn' is based more and more on time-on-the-list rather than needs.

Positive stories and exemplars

Iwi and primary community health providers in Te Tairāwhiti have continued to host community vaccination events combined with whānau/community 'fun-days' to chip away at addressing the recent significant and worrying decrease in childhood vaccination rates (which, pre-covid was very high) and to encourage vaccinations especially for measles, 'flu, covid and now whooping cough.

Considerations for Te Tāhū Hauora

I suggest that Te Tāhū Hauora:

Collaborate with iwi and community leaders, health researchers, and national entities to ensure we retain Te Tiriti o Waitangi provisions in the Pae Ora (Healthy Futures) Act and in related Acts relevant to health and disabilities services.

Advocate urgently for both the reinstatement the evidence-based Smoke Free legislation (which was to be implemented in 2024), and for vaping products to be prescription-only.

Collaborate with consumers, health service providers and genomic health researchers to co-develop quality & safety guidelines and related education resources for more informed use of safe genetic testing services and genomic information by whānau/families, individuals, and health providers to improve prevention, decrease risk, and management of conditions.

Provides updates on the progress Te Tāhū Hauora is making to monitor, contribute to, and provide leadership with the health and disability sector to ensure changes are made - in collaboration with whānau and communities - to ensure dangerous situations are identified promptly and appropriate action is taken to eliminate abusive practices (as documented by the [Royal Commission of Inquiry into Historical Abuse in State and Faith-Based Care](#) and countless Inquiries into family/domestic violence and abuse-related injuries and deaths).

Oliver Taylor (Wellington)

Environmental scan

There are ongoing, significant leadership changes happening right now for the New Zealand health system, including a new Minister and cuts at Health New Zealand. The most recent change proposal considers removing the entire Consumer Experience and Whānau Voice unit at Health New Zealand. This will directly impact how consumers are engaged in the health system and stall ongoing work to embed consumer and whānau centred care in services. Further, consumers are unable to be recognised for their work at District-level, as there have been no budgets released since mid-last year for consumer engagement, which has reduced the amount of consumer advice work. Some projects are using individual budgets to fund this work.

As part of my recent appointment to Te Ikaroa – Central Region Consumer Council, I attended an initial meeting in December to wānanga and understand how the group will be formed. While I continue to raise several concerns (as I raise below), the group is still in initial establishment phases with plenty of potential to improve how it operates and how it will add value to regionally commissioned health services. I note that direct changes to consumer experience staff at Health New Zealand will slow any progress.

Activity (since last report)

5 December 2024 – Te Ikaroa Central Region Consumer Council, Inaugural Meeting: Central Region Integration Team, who lead the regional functions of Health New Zealand, hosted a pōwhiri in Palmerston North for members of the new group, followed by some whakawhanaungatanga, some initial establishing conversations for the group, and kai. We got to engage with Robyn Shearer (Deputy CE, HNZ Central), where I queried the consumer budgets and said she would report back to the group, and a speech from Hector Matthews, who did not provide time for questions.

On reflection, I want to first acknowledge that this is an important first step and significant milestone for Health New Zealand, who are simultaneously rolling out four regional consumer councils in the face of further restructures. Consumer engagement is a legal requirement of public health entities, and must be at all levels (governance, project, and service-levels) to ensure services meet the needs of consumers. These groups establish the basis of consumer governance in the post-reforms system.

However, I have some standing issues:

- The leadership is proposed to have an employed Health New Zealand staff member as a co-chair. As a consumer advisor with experience as a member of groups, they can only truly be effective with appropriate consumer leadership. Having a staff member lead a group aiming to improve consumer experience will not focus on the issues that matter to consumers and will continue to perpetuate injustices consumers face in services.
- There is currently a member who is a practicing clinician in New Zealand. While I recognise clinicians sometimes understand issues faced by consumers, it is inappropriate to have a clinician as a member of a group that aims to provide advice as consumers for consumers. Clinicians can provide their views and input via networks connected to their jobs (eg the Dental Association) and clinical governance groups (eg clinical councils). It is entirely unfair to allow clinical leadership in a group for consumer voice, in a health system that already listens more to clinicians.
- The initial meeting setup did not include any engagement with consumers on where and how the meeting would occur (e.g. location, time, venue).
- The draft terms of reference are incredibly prescriptive, which will lead to considerable administration burdens on consumer advisors, e.g. how they propose to manage conflicts of interest.
- There is no requirement for how Health NZ will engage with the group to provide their projects or issues to us, or how we should expect them to engage with us on receiving and actioning our advice.
- Payment of invoices (aligned with the Health NZ consumer recognition policy) has been very slow, and missed even their own self-imposed deadlines. As of writing, this still has not been processed.

While this is all to be worked through, and there are further clarifications needed on role and scope of the group, I will continue to champion the important principles and needs of all consumers in the Central Region.

15 January 2025 – AI Feasibility Project, Steering Group workshop: This follows from my report last year, where I attended a broad workshop to understand the needs of consumers when thinking about using AI to improve health services.

In further developing this, the Capital, Coast and Hutt Valley District staff supporting the project have started work on a tool which will help clinicians communicate the care needed for consumers (e.g. what will happen during a spinal operation, which decisions will need to be made, what are the

chances of things going bad). The tool would review a conversation a clinician had with a consumer, and then report back on how that conversation went and what could be improved. Feedback included that they should be having conversations with real consumers, not actors, and the specific communication needs of consumers should be factored in (e.g. tell me all the details, vs tell me only specific details. How do the chances of things going wrong compare with my chances of crashing my car?). Staff will continue to progress this project and include the feedback provided where possible.

Positive stories and exemplars

Front of Whare Emergency Department Project: This continues to be a positive project and is now in initial finalisation awaiting Cabinet Budget 2025 approval. This should happen during the coming months and will be a milestone in improving Wellington Region's emergency care.

Considerations for Te Tāhū Hauora

- Continue to work with Health New Zealand to help them understand what is meant by a consumer, who can provide consumer advice, and what is expected of engagements at different levels.
- Ensure that consumer engagement continues at all levels, despite restructures at Health NZ and across the health system.

Mark Rogers (Timaru)

Environmental Scan

Proposals for key clinical positions at our Timaru hospital being transferred to Southern have been met with several protests. The protests have been successful as the proposal has been shelved as a result of community pressure.

For many years, our DHB had MOU's (Memorandum of Understanding) with Christchurch (Canterbury) for delivery of services that couldn't be done here. Cardio/Heart being one of those. Timaru/South Canterbury aligns itself with the Canterbury district in most areas of business, education, sport etc. and not Southern (Otago/Southland).

A lot of frustration by the Rare Disorder community over Te Whatu Ora not engaging or planning over the recently released strategy. Refer Rare Disorders New Zealand website for commentary.

Many consumer engagement positions at Te Whatu Ora are proposed to be disestablished and are going through a formal consultation process now.

Public confidence in our health system is deteriorating. Regular headlines about hospitals not having doctors overnight, front line staff alerting to understaffing and long wait times, the scale back of Dunedin hospital. All of this leads to poorer than desired consumer outcomes even though our clinicians are doing their absolute best with inadequate resource.

To ensure delivery of services, Te Whatu Ora are outsourcing a lot of surgeries. There's been ample mention of this in the media and one must ask the question "is this more costly than being able to do the work inhouse?" Is this the solution of a quick fix to manage the backlog?

Activity

DEWS Expert Advisory Group (Deterioration Early Warning System) for those in Aged Residential Care.

Chest Trauma. Further progressing of material being used to give consumers at discharge time. The project has progressed to final design stage. Thanks to our Consumer Network team for their input at the November hui.

The sTBI (Traumatic Brain Injury) Consumer Team, of which I am a member, were asked to provide opinions to ICHOM (International Consortium for Health Outcomes Measurement) for Traumatic physical injuries.

Further results and outcomes from the sTBI project are pending. From what I've read, these are very pleasing.

Considerations for Te Tahu Hauora

When referring to CHFA add New Zealand at the end. Remember the 'A' in CHFA is Australia and long before us.

To share feedback, action and outcomes by the board from our consumer scans. Are the most appropriate Consumer Scans reaching the Board?

Toni Pritchard (Te Kaha)

Environmental scan

Our area continues to struggle with the issue of location being a major barrier to accessing good quality healthcare over and above our GP service – specialist appointments in particular. Complex issues that eventually just mean our people disengage and get sicker.

* A 77-year-old with suspected lung cancer had an important specialist appointment four hours away. She was sent her appointment via email to attend at 8.30am, which meant she had to have access to both her emails and internet, neither of which she had, her age being a factor in her technical understanding and the area she lived in not having any mobile reception. She also doesn't drive anymore (like most of our Pakeke) so she would have needed to arrange a ride from someone. And she would have had to leave at 4.30am to make this which is completely unrealistic. When not attending her appointment, it was put down as DNA. And had this have continued as DNA she would have been removed from her register as needing help, ultimately fallen through the cracks in this system and got sicker, had more mistrust in the medical profession that and already not taking these basic needs into consideration. Fortunately, she was referred to our service and our assigned Kaiārahi to the Complex Medical care clients was able to navigate this situation alongside her with the positive outcome of instead of going to Tauranga 4 hours away, she arranged for a phone consult with the patients and the Specialist present, at the local Ambulance Station with strong Wi-Fi. She was able to then make sure to get the patient consent (through sending docs printing and scanning back) to advocate on her behalf so this patient doesn't miss any more appointments, and she will be the one to drive her to her next appointment. She was also able to 'translate' the medical language to this Kuia (whose first language is Te Reo Māori, which also adds another layer of miscommunication) and communicate to the Scheduler the issues of our location so any further in person appointments will be in the early afternoon. This initiative alongside our GP service continues to have overwhelmingly positive results but there are hundreds of patients along the coastline just like this example and not enough people to help out. Heartbreakingly we have had three Rangatahi take their lives, and this speaks to the fact that Aotearoa New Zealand still has the highest Youth Suicide rates in the developed world with Māori

being at the top of that statistic. The strategies and initiatives that have been successful need to be taken up on a wider scale, with more resources being injected into this much needed mahi.

I have also included a snippet of the latest data from - Kahukura 2024. It is an update of earlier chartbooks published in 2006, 2010 and 2015. These chartbooks present a snapshot of the health of Māori compared with non-Māori. They present key indicators relating to the socioeconomic determinants of health, risk and protective factors for health, health status, health service use and the health system.

Key findings

Tatau Kahukura shows that Māori have higher rates than non-Māori for many health conditions and chronic diseases, including cancer, diabetes, cardiovascular disease and asthma.

Findings include:

- Māori adults were almost twice as likely as non-Māori adults to have experienced any type of racial discrimination.
- Māori boys and girls (aged 0 to 14 years) and Māori adults (aged 15 years and over) had daily vaping rates that were around three times higher than their non-Māori counterparts.
- Ischaemic heart disease rates were twice as high for Māori adults compared to non-Māori adults.
- Māori females had a lung cancer registration rate over three times that of non-Māori females.
- Māori males and females were around one and a half times more likely than non-Māori males and females to have diabetes.
- Māori aged 5–34 years were more than twice as likely as non-Māori in the same age group to have been hospitalised for asthma.

This data and the same statistics reaffirm even more that we need to integrate the Pae Ora framework into all Health and Social Services. This will be of benefit to Māori, in terms of bringing these stats down and creating better outcomes for these whānau but will also benefit non-Māori also, with principles and values that span all ethnicities.

Activity (since last report)

We recently hosted a hui in support of a new involvement with the RHIP - Rural Health Interprofessional Programme, a health training program for undergraduate students in New Zealand. The program is a collaboration between the University of Auckland and other universities in the country. This Programme provides students with clinical experience in rural New Zealand and helps students learn about the challenges people in New Zealand face when accessing healthcare. As part of a Noho Marae here in Te Whānau a Apanui - Eastern Bay of Plenty, the students did a Haerenga though the Coast including our Medical Centre, Paramedic Services and our Iwi Health & Social Services

This a very valuable hui in terms of networking, building relationships and sharing with these up-and-coming medical professionals, experiences and insights around challenges, barriers as well as positive strategies that are working within the Iwi here, from a rural and Māori perspective. We were also able to share principles and values based on Māori frameworks of working successfully with individuals and whānau and reinforced that these values can be applied across the board, to all ethnicities and socio-economic status.

I am now a part of an Eastern Bay Collective that has been independently formed to provide support, to share information and resources, and network with each other to form an awhi based group, with the goal of strengthening each other to better serve our respective Iwi, whānau/clients.

We are a group of approx. 20 Kaimahi that work for Community Mental Health Services, Māori Health and Social Services, and Nurses from various GP clinics. We have had one hui so far, which I shared the Pae Ora Framework and the value of integrating this into our mahi. We will continue to discuss this at every hui. I have made my position on this network clear and that I am happy to include issues in my reports.

* We have now had a second hui with Ministry of Social Development (MSD) managers and staff as part of an ongoing strategy to build relationships and awhi clients that we share. From just one hui, this has been a very successful approach to collaboration and support. As an organisation we have been able to understand MSD processes, how we can support our iwi in these processes to make it easier for them as well MSD. We are strengthening relationships within the local office to help our clients adhere to their obligations while helping them to receive the support they need. One of the things I envision from this mahi is that we can support our whānau in an aspirational space and use the resources MSD provides alongside ours and help whānau to get off their benefits all together. The first hui resulted in us teaching our clients how to use 'MY MSD' and how to upload timesheets so they didn't have to have face-to-face appointments a two hour round trip away. We've also been able to email the office directly to get documents in for our clients as opposed to (again) having to do a two hour round trip into town. Which they don't anyway with petrol or even having a vehicle and getting a did not attend (DNA) against their name which ultimately contributes to their benefits being cut off if they continue to get these DNAs. These are just two examples of positive outcomes coming from collaboration and relationship building between organisations.

Services

As bought up in my environmental scan, specialist services continue to raise issues, however the mahi alongside our organisation has had such success, we will continue this and possibly even look at another Kaiārahi to help with this intense mahi.

Our ACC counsellor now comes regularly to our GP clinic, weekly, which is having major success in terms of our whānau being able to talk to someone about very major issues, eg. Post Traumatic Stress Disorder (PTSD), sensitive claims including sexual abuse. The feedback I've had from whānau is that this lady is 'lovely' and 'seems like she really cares' 'it makes all the difference to connect with someone'. Again, this speaks to the importance of the Māori principle of whanaungatanga within services, to promote connection and trust to be able reach the person we are working with, to achieve the desired outcomes.

Positive stories and exemplars

Please see asterisked items above. I believe these are indirect uptakes of the code of expectations and Pae Ora framework practice that as Māori organisations we weave into our practice (to a certain degree) I believe we definitely could do better as an organisation but that's another take.

Joanne Neilson (Tairāwhiti)

Environmental scan

As we sit in a very wet Gisborne waiting for the summer to arrive the health cuts make the hospital a place of uncertainty both health and employment wise.

The most recent proposal wants to reduce our already overworked IT department from 17 to 2. These cuts will not ensure the continued service will run smoothly or safely.

The hospital is currently reshuffling office space to make more room for clinic space; this is not an open and transparent process and only leads to more division between services. It is interesting several of our services have increased by 600% but we are trying to look after these clients with

less staff and clinic space. Moreover, why is car parking always the last thing administrators think about?

As a committee member of the Out in the PSA, we worked hard to make a strong submission to the health sector submission on Gender Affirming Healthcare, in particular the use of puberty blockers. This is a dangerous road to go down and will result in more suicides and self-harm.

The international political changes are scary to say the least, and the attacks on the Trans and Diverse communities make me think what it must have been like over 100 years ago in Europe. The Nazis started just the way the US republicans and the right-wing politicians here are. Misinformation creating mistrust and lies, remember the first of the Book Burning was the LGBT institute in Germany and then most of the people working there were exterminated. Please don't let history repeat!

Personal scan

I had the privilege of starring in Priscilla, Queen of the Desert, as Bernadette. I am the first Trans woman to play the role in New Zealand and only the third in the world to play this iconic character. It was a wonderful experience, and the cast were supportive and kind. It was a bucket list item ticked off.

Cia and I continue with the renovations and are starting to see the efforts of our hard mahi. Much to my husband's frustration things are behind because of the huge amounts of rain.

Tyson Smith (Te Puke)

Environmental scan

It feels like there is a lot of movement within the Mental Health and Addictions (MHA) workforce at Te Whatu Ora Health New Zealand Bay of Plenty.

People are experiencing longer wait times to see their GP.

The shrinking funding landscape is putting increasing pressure on Non-Government Organisation (NGO) services with noticeable decline in staff morale.

I have noticed a growing tendency for other organisations to refer people elsewhere, even for services that fall within their scope.

Further community fragmentation and division possibly due to current political narratives and landscape?

Activity (since last report)

Nurse Entry to Speciality Practice Presentation (NESP)

I was invited to participate in a discussion aimed at enhancing clinicians' understanding of lived experience perspectives in mental health care. This session provided an opportunity to share insights on what is important for clinicians to know when working with tāngata whai ora.

NESP is for registered nurses entering mental health and addiction services, and new graduates.

Services

Te Whatu Ora Hauora a Toi Mental Health and Addiction Service

Te Whatu Ora Hauora a Toi Mental Health and Addiction policies remain critically outdated previously raised last year, now exceeding documented review dates by over 34 years. Despite being raised internally, policy review still does not appear to be a service priority.

Additionally, the treatment pathway remains convoluted, with seven different mental health treatment plans - only two of which actively involve the individual, causing further confusion for both the person and their whānau.

Te Whatu Ora

There seems to be no further work or updates regarding the Supporting Parents Healthy Children (SPHC) project, which was expected to be in its final stages of implementation in 2025.

The guidelines no longer seem fit for purpose (developed 2015) and feel like the “older” culture (pre inquiry). NGO providers are still expected to apply the guidelines in their existing state.

<https://www.health.govt.nz/system/files/2015-09/supporting-parents-healthy-children-sep15.pdf>

Positive stories and exemplars

The Te Manawa Taki Regional Consumer Council finally has some meeting dates (this week)

Considerations for Te Tāhū Hauora Policies

Escalate this issue - One of the key challenges facing the mental health and addiction sector is the significant lag in policy reviews, with some policies—such as those within Hauora a Toi—now over 35 years past their documented review dates. This lack of timely updates means that services may be operating under outdated frameworks that do not reflect current best practices, Te Tiriti o Waitangi obligations, equity commitments, or lived experience-informed approaches.

To address this, Te Tāhū Hauora could support the establishment of clear accountability mechanisms

1. Ask Te Whatu Ora for an update regarding the Te Whatu Ora, Hauora a Toi MHA Policy set

2. **National Policy Review Standards & Monitoring**

- Establish a sector-wide policy review framework that sets clear timeframes for updates and **monitors compliance** across health providers.
- Develop a **tiered escalation process** where policies exceeding their review date trigger intervention or additional oversight.

3. **Mandating Consumer and Lived Experience Oversight in Policy Development**

- Require that all policy review processes include lived experience representatives and whānau voices
- Create an independent policy review advisory group, including consumer leaders, to oversee updates and hold services accountable

Eden Li (Tāmaki Makaurau)

Environmental scan

In the Auckland area, we continue to see concerned consumer sentiment over wait times and delays to access a number of healthcare resources, especially GPs. Healthcare leaders are well aware of this concern as this is a long-running area of consumer concern but acknowledge the difficulty in alleviating budgetary and service complexity-related bottlenecks in the short term.

On a more positive note, I noted at the Te Toka Tumai Clinical Quality Safety Committee the pending business cases that will allow for greater access to clinical support services, as well as new medications and treatments that have recently been approved. This includes a number of new, in-demand cancer treatments. This will undoubtedly improve the quality of care for some of our most vulnerable patients.

In the youth space, I look forward to commencing data collection and outreach with members of the Youth Advisory Panel at YNorth focussing on the connections between mental health, community providers and physical recreation. The idea has been well received by the Youth Development Lead at YNorth and is also enthusiastic about expanding the report to a scope on the national level. We now are waiting for approval from the CEO and the rest of the board, and we continue to welcome input and design input from our priority populations.

Activity

National Medicines Steering Group Hui - The group has continued to improve the overall state of medicines in the country. This includes active improvements to consumers through better equity, safety and efficacy of the medicines use. Consumers in the group continue to be well-engaged with and included in these discussions.

Clinical Quality Safety Committee - Te Toka Tumai Hui

Consumer Council - Te Toka Tumai (has since been disestablished in late 2024).

UNYouth (Inaugural) SDG Summit - It was a great experience to be involved as a facilitator and a member of the design team for this Summit. The Summit was a novel departure from the typical form that UNYouth runs, with a strong focus on country-level achievements of health, education and nutrition. There was a conscious emphasis on targeting and engaging with youth from underrepresented communities. This allowed the conference to be a microphone for fresh voices and ideas surrounding health, education and nutrition policies. Through the workshops and socratic seminars, youth who participated also received invaluable skills in oral advocacy and written submissions that will allow them to feel more confident as youth leaders in their local communities.

YNorth Youth Panel - In looking forwards to continuation in 2025, the panel has continued to plan future outreach efforts. Currently the focus seems to be concentrated on improving youth involvement and youth confidence to engage with governance decisions within their communities.

Services

Restraints in usage during hospital visits has been a concern for consumers in Auckland. There are some questions over overuse of constraints on Māori and Pasifika, and also medical staff's application of informed consent and patient autonomy.

As mentioned previously, and as previously mentioned by other members of the Consumer Network, there is a significant bottleneck in consumers not being able to obtain timely GP visits. There is also the feeling that even when consumers are able to get a visit, there is often the feeling of GPs undertaking 'rushed consultations'. Especially for consumers who have language or communication divergences, this may make them less likely to state their concerns fully during their consultation.

Positive stories and exemplars

In Te Toka Tumai, there has been further strengthening of cultural competency through the Pilot Māori Health and Te Tiriti o Waitangi: Application in nursing practice programme. The programme has shown very strong results in terms of improving the cultural competency of the initial pilot group, many of which were previously unfamiliar with the New Zealand cultural context due to their overseas background. An additional benefit to the manner in how the programme has been designed has also allowed for greater team cohesion, which is associated with better overall performance (and therefore better consumer satisfaction). This demonstrates how such training undoubtedly provides a net benefit to consumers, as it has the potential to provide many unspoken benefits alongside better cultural competency.

Considerations for Te Tāhū Hauora

The National Medicines Steering Group at the Ministry of Health has commissioned a study looking at the safe use of medicines for priority groups. As a part of the project, the research team would like to hear from consumers about their lived experiences and observational understanding of what safe usage of medicines looks like. Even though the team has expressed interest in engaging with consumers through Te Tāhū Hauora, it would be fantastic if members of the Consumer Network were happy for the Network potentially being used as a point of contact for the research team.

Continued engagement with refugee, migrant and Asian communities. There still needs to be active engagement with these communities so that better understandings of patient's rights and informed consent can circulate. Additionally, translation services have been increasingly offered in several health regions, but they are still underused and unknown to a proportion of the mentioned communities. Better promotion of such services would certainly be beneficial to improve patient experience.

Arana Pearson (Advisor Consumer Engagement, Mental health & Addiction, Te Tāhū Hauora)

Input / involvement in Te Tāhū Hauora meetings/groups.

Zero Seclusion – dignity and safety for all mental health project developing Always Report and Review (ARR)
Maximizing physical health mental health project.

Activity (since last report)

Tyson with others from this group made a video recording of consumer perspectives on how to maximize physical health for clients of psychiatric services.

We made the start of the video recording whilst awaiting our flights after the last meeting. It was played to mental health services across the country in an on-line training sharing event hosted by Te Tāhū Hauora with really good feedback from the clinicians online.

Services

There is a variation of linked-up support amongst mental health services based in Hospital/secondary mandated services with community NGO and Iwi based services and GPs in the community.

With Police focussing on charging people for crimes rather than assisting with mental health transfers, we have seen increasing numbers of people being imprisoned with mental health conditions rather than accessing wrap around community support.

This is a trend that is growing in the community where I live. For example, men are left homeless, and three I know of now, all in their late forties, who have never been jailed in the justice system are now imprisoned.

Just last week a 30 year old lady who is a mother came out of a mental health inpatient ward, she remained symptomatic with psychosis and depression, and within the week she has now been charged with a verbal crime for something she was saying whilst unwell, remanded in custody, and awaits court for the first time and is facing jail time even though she is well known in her community by local police.

The KPI project reports that 16% of all inpatient discharges in NZ are re-admitted within a month. So that is business as usual, however, increasing prison incarceration of people with mental illness is an alarming fear for many people now who are diagnosed with mental ill health. Maybe our communities are becoming less accepting of difference also?

Positive stories and exemplars

We have a new service near Opotiki open its doors recently. It is a 'step up-step down' Alcohol and other drug (AOD) service. Delivered by the Iwi alliance that links three of the Iwi based services across the Eastern Bay and a number of the staff are consumers in recovery.

This service came into place through police proceeds of crime. This will be a residential service once the Opotiki council gives the 'ok' for this use of the building. Many of us have written letters of support to the council addressing the fears expressed by people in the neighbourhood who thought they did not want such a service in their community.

Considerations for Te Tāhū Hauora

Lead quality health feedback from mental health consumers of services.

Lead quality improvement in mental health but base the mahi within community-based services and not the hospital with a goal of greatly reducing the 16% readmission of people within one month of their discharge from psychiatric inpatient services.

Zechariah Reuelu (Porirua)

Environmental scan

From November 2024 to January 2025, Porirua City experienced notable shifts in both social and economic dynamics. Socially, the city saw growth in community events, with increased participation in cultural and recreational activities, fostering stronger community ties. However, concerns around housing affordability and rising living costs continued to affect many families.

On the Porirua FaceBook community page, there are endless stories of families reaching out for food assistances and affordable housing support and needs.

Economically, Porirua's retail and service sectors remained resilient, with new companies opening in Porirua. Sealord Moana opened a factory in Porirua. The seafood company, known for its significant presence in New Zealand's fishing industry, opened a new processing facility in Porirua in 2024. This new plant focuses on sustainability and creating local job opportunities, benefiting both the local economy and the broader seafood sector.

Employment rates showed steady growth, but the demand for skilled workers remained high. Cannons Creek is the hotspot focused for the number of youth unemployment.

Your input / involvement in HQSC meetings/groups.

This quarter I participated in the following:

- Code of expectations review consumer and whānau survey
- Kōtuinga Kiritaki Consumer network and Ngā Reo Māhuri Young Voices group
- Consumer Insights questionnaire #2 - General Practice

- Regional consumer workshops February 2025 - Consumer support for facilitation

Your Activity

Enhancing Gout Literacy Among Pacific Populations: Simplifying Clinical Concepts for Practical Understanding



The Pasifika Medical Association's (PMA) 28th Annual Conference took place in Christchurch, New Zealand, from November 26-27, 2024. The conference theme, "*Vunilagi ni Bula Sautu: Living our best lives*", explores a holistic approach to health and well-being across all stages of life, envisioning a horizon where individuals live lives of good health and abundance. Invited to present poster presentation at conference enhancing gout education process among Pacific populations is essential in promoting health equity and improving health outcomes for all individuals affected by this treatable condition.

By focusing on simplifying clinical concepts and providing practical information in a culturally sensitive manner, we have testimonials of Pacific gout consumers populations and their kaiga to better understand and manage gout, leading to improved quality of life and reduced healthcare equity disparities amongst our Pacific communities.

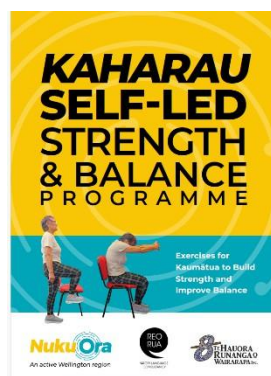
The Arthritis New Zealand Teens Camp is designed to support young people living with arthritis by providing a safe, empowering environment where they can connect with others who share similar experiences. The camp also helps to raise awareness of juvenile arthritis within the wider community, increasing understanding of the condition and its impact on young people.

These objectives combine to provide a holistic and supportive environment for teens with arthritis, helping them build confidence, improve their health management skills, and feel less isolated.



Te Rā o te Raukura is a whānau-oriented community cultural festival that promotes health (hauora), education, entertainment, culture and whānau through a range of stalls, cultural and musical groups, and activities. Arohanui ki te tangata ("Good will to all men") is interwoven into all aspects of the festival.

It is very encouraging the organiser introduced digital warranty of fitness to record appropriate health test result & literacy information. When participants entered the Hauora space, they were encouraged to register their details and ask whether they would like their recorded information (such as uric acid reading) to be forward to their GP medical clinic. This process ensure the GP clinic made aware of their reading & determine next steps of care.



During this quarter, involved with the co-design the implementation of an in-house strength and balance programme for the Atafu Tokelau Community Group and Nuku Ora.

The work programme to be implement in March 2025 targeted to the elderly community within Cannons Creek & Waitangirua.



Arthritis New Zealand collaborative with Hora Te pai Health Services to implement an innovative work programme focused on improving the lives of elderly individuals living with arthritis. This initiative, with its emphasis on a kaumatua water-based programme and alignment with Māori values and practices, offers a transformative approach to arthritis management. The programme acknowledges and nurtures the spiritual significance of wai (water) for Māori. Water-based therapy not only alleviates physical discomfort but also fosters wairua (spiritual health), creating a holistic healing experience.

The voices of the participants in this programme demonstrate its profound impact on their lives:

“This is the first time in 20 years that I am able to use the step ladder to get out of the pool, I no longer need to use the ramp at the other end” (68yrs old).

- *“The water-based exercises have not only eased my joint pain but also reconnected me to the healing properties of wai, which holds deep spiritual meaning for me.” (63yrs old).*

- *“Having my culture reflected in the programme made me feel valued and respected. It’s not just about managing arthritis; it’s about reclaiming my well-being.” (73yrs old).*

These testimonials highlight the importance of Arthritis New Zealand’s approach in providing a tailored, meaningful, and effective care model.

The programme offers not just physical relief but emotional encouragement, providing participants with a sense of purpose, optimism, and motivation to improve their quality of life despite living with arthritis. By combining Māori principles with innovative, holistic care, this programme addresses both physical and emotional well-being in a culturally affirming manner.

Amanda Stevens (Nelson) - Deafblind Association NZ Charitable Trust

Environmental scan

Since my last report:

Meeting with AUT resulting in six NZSL interpreters, graduates or Y3, now identified for Conference 2025 to train in Tactile communication. This is a first for Aotearoa NZ and will support inclusion through appropriate and effective communication methods.

Our peer-to-peer support groups continue to grow. Engagement most frequently includes wellbeing in community and how deafblind can access appropriate communication.

Research project into how many people in Aotearoa have dual sensory impairment progressing. Of five phases, phase one is due to complete at Conference.

The International Classifications for Functioning is available on request.

Positive stories and exemplars

From 1 October 2024, an additional Abbott brand of CGM is also proposed to be subsidised that will be compatible with funded insulin pumps and can be used to create an automated insulin delivery system.

This is fantastic news for deafblind and all disabled who are disproportionately underrepresented in the work force as the Blood Glucose Monitoring, Libré, has been around \$100 per fortnight. (Diabetes is one of the top four causes of sight loss in Aotearoa according to Blind Low Vision NZ.

Deafblind Association NZ, Whaikaha and iSign, Wordsworth Interpreting, and Connect Interpreting met to discuss challenges and problem solving for training of Tactile Communication methods in Aotearoa. This is the first time these organisations have been together.

The following actions have been agreed:

- Bringing together key organisations to identify actions which could be taken to improve Deafblind people's lives now set for late November.
- Identifying overseas deafblindness prevalence data and actions other jurisdictions are taking to improve outcomes (including Germany, the Netherlands, Norway and Australia). Report due this month.

In exciting news, Pharmac proposes to commence FreeStyle Libre 2 subsidy for all people living with diabetes in New Zealand, from 1 July 2024!

On 11 July 2023, Pharmac released a Request for Proposals (RFP) for the supply of insulin pumps, consumables and CGMs. As a result of the RFP, Pharmac has entered into provisional agreements with preferred suppliers (including Abbott) to fund a range of devices.