



Te Tāhū Hauora
Health Quality & Safety
Commission

Minutes of the Kōtuinga Kiritaki | Consumer Network meeting

Kōtuinga Kiritaki members	Mary Schnackenberg, Joanne Neilson, Oliver Taylor, Jennie Harré-Hindmarsh, Zechariah Reuelu, Toni Pritchard, Amanda Stevens, Vishal Rishi, Mark Rogers, Eden Li, Vivien Wei-Verheijen, Claire Turner.
Te Tāhū Hauora staff:	DJ Adams (Chair), Kelly Palmer, Penita Davies (minutes), Doug Edwards – Pou Tikanga. Don Matheson - Director National Mortality Review. Liz Pennington – He Mutunga Kore Committee Member.
Guests	Daniel Martin - Senior Policy Analyst, Emma Hindson - Policy Manager - Te Pou Hauora Tūmatanui Public Health Agency - Manatū Hauora.
Apologies	Tyson Smith, Tee Siataga, Dez McCormack, Arana Pearson

The meeting was held at Rydges Wellington Airport on **15 May 2025** from 9.15 am.

1. Mihi whakatau for Claire Turner and whakawhanaungatanga (welcome)

Kōtuinga Kiritaki and Te Tāhū Hauora welcomed Claire Turner.

Members shared insights, passions and learnings built on their experiences as health consumers.

2. Standard business

Previous minutes for 13 February were accepted. Interests register to be updated for next hui. Action items were addressed.

3. Feedback on previous Te Kāhui Mahi Ngātahi | Consumer Advisory Group meeting

Mary provided an update. Her written report as follows:

“The [Consumer Advisory Group] (CAG) advises the Board and one or other of its co-chairs attends each Board meeting. Consumer input from this group and CAG is provided to the Board in the first 20 minutes or so of each Board meeting.

Since I last met with you on 13 February, the Consumer Advisory Group met with the Board on its strategy day on 20 February. The HQSC Board Chair, Rae Lamb, in my opinion provides excellent leadership during very very challenging times. HQSC Chief Executive, Peter Jansen, resigned because of his ill health. As well as seeking a successor to Peter, HQSC has to work through yet another Minister of Health with his own spin on priorities.

The Consumer Advisory Group met over Teams on 26 March.

DJ told us about the voluntary adoption of the Code of Expectations by a broad range of health providers, including their reporting against the QSM.

The workshops held on the West Coast in February were very well received. There was a clear message from consumers to providers that they have a voice and advisors want to be engaged with.

The HQSC Statement of Performance Expectations (SPEs) is being worked on and it contains the plans for the upcoming year. This includes specifics around promoting the Code of Expectations.

DJ's team is working with the National Mortality Review Committee team to further involve the consumer and whānau voice in their work. We are seeing this on our Agenda today.

We had a presentation about the HQSC Systems Safety Strategy for stakeholder groups. Consumers and whānau are central to improving the safety strategy. Systems for ongoing learning and improvement ensure the health and disability system evolves to meet expectations for safe, effective, and culturally respectful care. CAG agreed the strategy was needed and heading in the right direction.

Turning to the review of the Code of Expectations, DJ told us the code review stakeholder engagement phase has been completed. Common themes are:

- Importance of the promotion of the code.*
- Suggestion that the code be more consumer and whānau and public focused, like the HDC Code of Rights. For example, put up posters and videos screens in waiting rooms etc.*
- More education about the code is needed for understanding of the partnerships and roles of consumers in co-design with providers.*
- More engagement was another area and this is ongoing, and a focus for the team.*
- Collaboration has to be kept in mind.*
- Accountability with more visibility needed about reporting on the code, through the consumer engagement quality and safety marker (QSM).*

The next steps are a final report, to the HQSC Executive Leadership Team and the Board and then a ministerial briefing paper for sign off.

I am very pleased that HQSC is looking at better ways to improve links between its consumer advisor groups. Succession planning is also under review. DJ introduced to the March meeting of CAG a discussion paper that provided the background of the current appointment processes and structure including previous Board decisions.

In the draft paper is a recommendation that chairs be elected by the various consumer advisor groups. There is also the possibility that chairs might serve on more than one advisory group to strengthen links and understanding. There was overall support from the group to the proposals. The final paper will come back to CAG for review before going to the Board.

Looking back over my five years with HQSC, I regret I have not seen enough improvement in accessible health literacy for everyone. Those who are online are pretty well served, despite the difficulty of the medical jargon. But if you are offline, or struggle with websites, apps, and the English language, you have an uphill battle to achieve personal health literacy.

However, I am proud of the work my consumer advisor colleagues are doing. This is despite very challenging times. Most of us understand our roles as consumer advisors. We are "inside the tent" working alongside staff, bringing our advice and experience from the field to each other, including staff and the Board. We are not advocates outside the tent. Above all, we are not the decision makers as are the collective Board.

But consumer advisors are making a difference and supporting the sector to improve the experience of patient end users.

My sincere thanks to each of you”.

5. Māori Health & Consumer report and update

The Māori Health & Consumer report was tabled and taken as read. Members engaged in discussion.

The Māori Health and consumer Q3 report is attached as [Appendix 1](#).

6. Member reports

Member reports were taken as read. The summary of reports is at [Appendix 2](#).

Toni Pritchard shared a presentation on the Māori Health Chart and Te Tiriti o Waitangi.

- Sharing an understanding of Te Tiriti o Waitangi from Toni's experience with a community health lens.

Oliver Taylor - Regional Consumer Councils item will be carried forward to the next meeting.

7. Consumer and whānau engagement quality and safety marker (QSM)

DJ and Oliver updated the group on how the QSM is progressing, key points included:

A brief update on the September 2024 and March 2025 submissions. A report is in draft to inform the improvement of consumer engagement over time.

Proposed minor changes to the SURE (Supporting, Understanding, Responding, Evaluation) framework to guide story telling through the examples. The members were supportive of the changes

8. National Mortality Review Committee - consumer involvement

Don Matheson and Liz Pennington gave a presentation providing an overview of the work of He Mutunga Kore.

Highlights from their presentation included:

- Step by step translation for Kōtuinga Kiritaki Consumer Network group, emphasising the ongoing education required for sudden infant death syndrome (SIDS).

9. Pandemic Strategy Plan

Daniel Martin and Emma Hindson presented a robust 14-minute explanation of the pandemic strategy plan. The presentation noted how consumers and whānau are being engaged in this work.

10. Consumer leadership and succession planning

Kelly led a Consumer leadership and succession planning discussion, exploring opportunities to strengthen group leadership and succession planning.

Note: A paper was planned to be taken to the Board in June, which unfortunately didn't materialise. Te Tāhū Hauora staff will provide an update at the next meeting.

11. Farewell for Mary Schnackenberg

A beautiful farewell for Mary, filled with manaakitanga and aroha. The group echoed sentiments of professional approach, timely reports and incredible insight/inspiration received from Mary at every meeting.

12. 2026 Regional Consumer Workshop (planning and ideas session)

Excellent collaboration of ideas, contact information, including Māori connections in Tairāwhiti. Penita to make connections with all suggested pathways (update to follow).

13. Other business Comments and wrap on today

N/A

14. Karakia and close

DJ closed with karakia

Next hui: 20 & 21 August, 3 hour Teams meeting each day

Actions list

Date	Action	Responsibility
15 May 2025	Send full presentation/slides	Penita
15 May 2025	Make connections regarding Regional Consumer workshops	Penita

Appendix 1

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

Hokitika: Wednesday 19 February 2025 & Reefton: Thursday 20 February 2025

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 Programmes (REAPS)
- Te Kāhui Hauora o Te Taihū 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 enthusiastic to be engaged 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 [here](#). 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 Taihū 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 its implementation will be integrated 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 engagement 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 initial stage – understanding expectations, the feedback received was integrated 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 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 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
 Co-designing with consumers, whānau and communities Hoahoa tahi me ngā kiritaki, ngā whānau me ngā hapori here	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
 Using lived experience to improve health services Te whakamahi wheako mātau hei whakapai ake i ngā ratonga hauora here	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
 Improving equity through partnership and collaboration Te whakapai ake i te mana taurite mā te mahi tahi here	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	Views: 4 Users: 4	Views: 15 Users: 14	Views: 10 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 mean to you and your community?	Views: 33 Users: 32	Views: 69 Users: 64	Views: 88 Users: 63
 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	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 – 15 May 2025

Mary Schnackenberg (Tāmaki Makaurau)

Input / involvement in Te Tāhū Hauora meetings/groups.

20 February, HQSC Board strategy session in person

26 March, HQSC Te Kāhui Mahi Ngātahi Consumer Advisory Group meeting

Services

I am concerned to discover that not everyone in the blind and low vision community knows about their entitlements to free hearing aids. If someone is registered with Blind Low Vision NZ and are assessed as needing hearing aids by an audiologist, they can receive the aids at no charge. Blindness and hearing loss are regarded as a dual sensory disability. This has been the case since at least 2010.

Positive stories and exemplars

I am pleased to report that the whole of government accessible formats service is continuing, at least in the meantime.

The latest document out for consultation is about a Draft Strategy for the New Zealand Sign Language with submissions closing on 2 June. Apart from being accessible online, it is also available in audio, Braille and large print.

Considerations for Te Tāhū Hauora

Can HQSC consider how to liaise with various health entities to make more accessible the feedback system? There is a need to strengthen support from the Health and Disability Commissioner's National Advocacy Service to enable those experiencing difficulties with the health system to get timely, skilled facilitation support.

Jennie Harré Hindmarsh (Tairāwhiti)

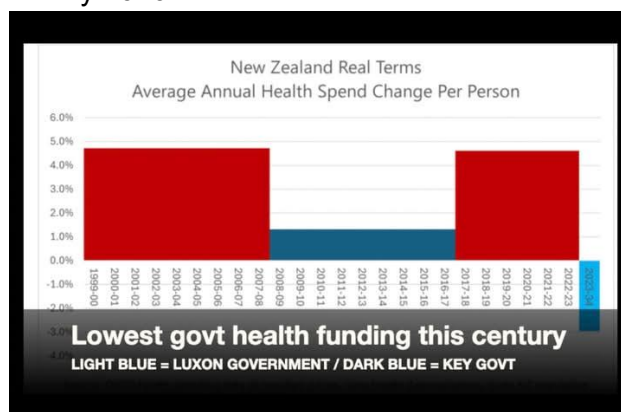
Environmental scan

Early April 2025, community members and health service workers mobilised to more publicly express concerns about escalations in the ongoing deterioration in health services in Tairāwhiti (and nationally) and plan coordinated actions in the absence of any constructive response, let alone solutions, from the National-led Coalition Government and the misinformation being promulgated by MPs: 3 April 2025 <https://newsroom.co.nz/2025/04/03/revealed-senior-doctors-told-pm-gisborne-hospital-is-on-brink-of-collapse/> and <https://newsroom.co.nz/2025/04/03/i-was-overjoyed-to-move-from-the-us-health-system-to-nzs-but-then-i-could-see-the-cracks/>)

The health system's "postcode lottery" continues to get worse. For example, Gisborne hospital continues to have the highest senior doctor vacancy rate in the country – 44%, and the Radiology department should have four full-timers, not a sole part-timer!

On top of which we have a shortage of GPs, nurse practitioners, and nurses – and until this month no primary care after hours service in the district. The consequences are far-reaching, dire, and too numerous to list here.... Equitable access to nationally consistent health services has further deteriorated, with very serious repercussions and even more so in rural and provincial communities.

This drastic decrease in access to quality health services locally and nationally continues to be even more frustrating given members of the National-led Coalition Government have continued to claim funding has increased, and to ignore health economists' analysis (27 June 2024, graph below) - which show that average government health spend-per-person decreased significantly in the 2024 Budget. 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 the serious 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

Concerns also continue about health and wellbeing impacts of the recent repeal of section 7aa in the Oranga Tamariki Act, repeal of Smoking Cessation legislation, and the current Government's inclusion of the Pae Ora Act in proposals 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](#)

Furthermore, the Coalition Government's recent decisions around vaping and refusal to make vaping prescription-only given substantial evidence now accumulated of damage being inflicted by use of vaping and tobacco products. The damaging consequences, immediate and long-term, to the quality and safety of our health are far-reaching and still require more decisively bold push-back from us all.

Input / involvement in Te Tāhū Hauora meetings/groups.

19 March, QSM Submission Zoom meeting to provide feedback on Te Tāhū Hauora HQSC's draft.

4-9 April, Informed DJ Adams about the serious deterioration in Tairāwhiti health services, now published by senior doctors in Gisborne Hospital; the actions being planned by the community and health workers, together, to publicly protest and seek constructive Ministerial-level responses and solutions; and questions being asked about the role of Te Tāhū Hauora in relation to helping to resolve these escalating threats to the quality and safety of health services. In response, DJ collated examples of the issue, locally and nationally, provided by Vishal and I, into a summary report for the Co-Chair of Te Kāhui Mahi Ngātahi CAG to speak to at the Te Tāhū Hauora Board meeting on 10 April (*Appended).

In response, the Co-Chair of Te Kāhui Mahi Ngātahi I CAG emailed: "... thank you for adding to the voice at the board table, thank you for alerting us to critical issues in your districts that you want elevated through our consumer pathway – kia mōhio ai rātou o te Poari – so our board gets the 'hot off the press' issues. It breaks our hearts to see the headlines one after the other, every day..... That is our role as consumer advisors, is to advise, to bring through

the stories; to verbalise the narratives from our communities...I will be speaking to these issues at the board....

10 April, *Insights Reports (Sept 2024, Nov 2024) and Briefing to new Minister (Feb 2025)*

On receipt of website links, forwarded these just-published HQSC Reports to local networks.

14 April, *'Progressing consumer engagement in primary care' resource: Zoom meeting* to provide feedback on the review and update this 2019 resource, the purpose of which is to align it with the Code of Expectations (and thus to add a primary care context to the implementation guide and to the Consumer Engagement QSM/quality and safety marker.

March and 15 April, *Pre-testing for the Adult Primary Care Patient Experience Survey*. Completed questionnaire in March and was interviewed online on 15 April to provide feedback on comprehension of the draft survey and ideas for improving the questions and lay-out to ensure it is easily understood by all invited to respond to the pretesting for an updated *Adult Primary Care Patient Experience Survey*. It will be informative to compare dashboard summaries of findings from the Feb 2022 surveys with those of findings from 2024/25 surveys, when published. The most recent dashboard summaries currently on the website are findings from the 2022 adult hospital & adult primary care experience surveys.

Te Tāhū Hauora conducts national patient experience surveys to regularly collect, measure and use patient experience feedback for quality improvement. The adult primary care patient experience survey has been running since 2016; it invites nearly 1 million patients per year and receives around 140,000 responses. <https://www.hqsc.govt.nz/our-data/patient-reported-measures/patient-experience/survey-results/>

6 May, *Online Interview for next Insights Report to Minister of Health, Te Whatu Ora & Ministry.*

Activity (since last report)

7 March, *Genomics Aotearoa Māori Variome He Kākano Governance Roopu* Zoom meeting to advise research team on developing long-term governance arrangements for the Māori Variome He Kākano resource; policies and protocols for its use as a clinical diagnosis tool to improve equitable precision of health care for Māori, and for further research; and plans for a national launch of the resource. To date, more than 200 clinical tests have been piloted to improve the quality and safety of diagnoses for participating patients and whānau. <https://www.genomics-aotearoa.org.nz/our-work/health-projects/aotearoa-nz-genomic-variome>

19 March, *National Webinar: The Voices of Underserved Communities in Palliative Care (Te Whatu Ora Health NZ)* Informative presentation provided about this project report which aims to begin to address troubling gaps in palliative care by foregrounding voices of people often under/not served (homeless, refugees, children & young persons, those in prisons, rural deprivation areas, gangs, rainbow communities, and with serious mental health illnesses or learning disabilities). <https://www.tewhatauora.govt.nz/assets/For-the-health-sector/Specific-life-stage/Palliative-Care/The-voices-of-underserved-communities-in-palliative-care.pdf> Common themes: underserved people neither accessing specialist palliative care to level they need nor receiving generalist palliative care from usual healthcare provider. Whānau and family often feel unsupported, and still much to do to ensure palliative care is culturally safe. Report includes two resources to guide actions by health care providers to address inequities in palliative care: *He Tapu Te Tangata The Sacred Person* (conceptual framework from the *Te Whakahekenga Dying as a health and social justice issue*), and guiding principles for much-needed equity improvements in palliative care.

1 May, *Maranga Ake Stand & Fight for Health Protest March in Gisborne* in support of health workers and public health services to highlight escalating systemic issues in the health system, chronic understaffing, underfunding, extreme staffing shortages, and recruitment and retention failures. Discussions with participants about the role of Te Tāhū Hauora HQSC and its consumer networks. <https://www.nzherald.co.nz/gisborne-herald/news/gisborne-hikoi-demands-better-health-funding-highlights-staffing-crisis/SLR4X3VAGFACZOHRUUFPP4UPJE/>

Prepared notes and references for Te Rangawairua o Paratene Ngata Centre of Excellence for a story they're preparing about the Ngāti Porou Hauora/Oranga community-led processes from 2006 (and ongoing) which I have been part of to co-design and co-lead safe, high quality genomics research and development of precision medicine. <https://www.npo.org.nz/research>

Continued to participate in community catchment and coast care initiatives to restore 'Te Mana o te Wai, te Whenua me te Hapori' (the hauora of our awa, puna & wetlands and whenua and thus strengthen the health and wellbeing of our community) as an advisory group member for the GDC Waimata-Pakarae Catchment Plan, co-leader of Wainui Beach Catchment and Coast Care, and community participant in the GDC's Climate Change Adaptation planning process with Wainui-Okitu.

Services

In the current underfunded and demoralised health system, whānau and community members continue to express sincere gratitude to health providers who soldier on to provide them with high quality care - when finally accessed, often with escalating pain and/or risks of complications whilst awaiting 'their turn' on long waiting lists.

Changes to who can refer patients for an MRI, and long delays in receiving an MRI appointment when eventually referred by a specialist (invariably to a private radiology facility due to the large % of radiologist vacancies in the public system) has compromised the quality and potentially safety of health services innumerable people, locally and nationally – including myself and one of my grandchildren so far this year. Health professionals involved (GPs, physiotherapists, and medical specialists) have shared with my family members that such delays and quality/safety issues have been escalating – they are very concerned and frustrated about increasing delays in obtaining MRIs to inform accurate diagnoses and timely treatment and management decisions.

At long last, on 3 May 2025 - after 12+ months of no community-based after-hours services in Tairāwhiti - a new primary care after-hours service for all in our communities has been launched: <https://www.npo.org.nz/our-highlight/tatai-whanau-tairawhiti-after-hours-healthcare>

Positive stories and exemplars

Te Aroha Kanarahi Trust (TAKT), a community trust based in Wharekahika that serves the Matakaoa community (aka Hicks Bay-Te Araroa area), is implementing their Strategic Vision for a "P-Free Matakaoa" by 2050: "Elimination of P(meth), Pollution, Poverty, Plastics, Pine Trees, Ports and Pandemics." The kaupapa developed from the team's involvement in leading and supporting whānau through the Covid response, then the ongoing Cyclone Recovery: <https://www.ngatiporou.com/nati-news/news-from-wharekahika-waste-warriors-workshops-and-whanau-biz-support>

Considerations for Te Tāhū Hauora

- *Regularly share* Insight Reports and succinct summaries of recent health quality and safety data, proactively and accessibly with communities and health providers.

- *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 repealed evidence-based Smoke Free legislation 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.
- *Provide updates* on progress Te Tāhū Hauora is making to monitor, contribute to, and provide leadership with the sector - in collaboration with whānau and communities - to co-design and implement changes which will ensure dangerous situations are identified promptly and actions taken to eliminate abusive practices (as documented in the [Royal Commission of Inquiry into Historical Abuse in State and Faith-Based Care](#) and many previous Inquiries into family violence/abuse and related harms/deaths).

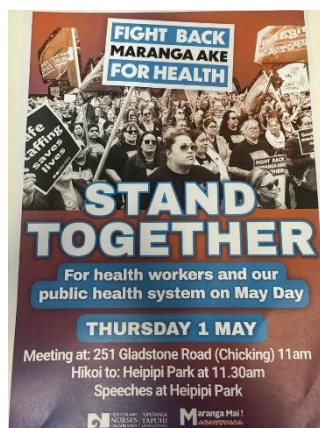
***APPENDIX – SNAPSHOT of CRUMBLING HEALTH SYSTEM, 9 April 2025**

Nelson Hospital:

- **‘Senior doctors speak out over concerns about staffing, patient safety at Nelson Hospital’ - 1 news, 30 March 2025** <https://www.1news.co.nz/2025/03/30/senior-doctors-speak-out-over-concerns-about-staffing-patient-safety-at-nelson-hospital/>
- **‘Staffing Shortages Putting Patient Safety At Risk At Nelson Hospital’ – scoop, 28 February 2025** https://www.scoop.co.nz/stories/GE2502/S00074/staffing-shortages-putting-patient-safety-at-risk-at-nelson-hospital.htm?utm_source=chatgpt.com On February 28, Nelson Hospital operated without a medical registrar between 4:00 PM and 10:00 PM, relying on a newly graduated doctor for support. This situation led to the emergency department being short-staffed, with no second senior medical officer on duty between 2:00 PM and 4:00 PM, resulting in potential delays and compromised patient care

Gisborne Hospital

- **‘Revealed: Senior doctors told PM Gisborne Hospital is on the ‘brink of collapse’ – newsroom, 3 April 2025** <https://newsroom.co.nz/2025/04/03/revealed-senior-doctors-told-pm-gisborne-hospital-is-on-brink-of-collapse/>
- **‘I was overjoyed to move from the US health system to NZ’s. But then I could see the cracks’ – newsroom, 3 April 2025** <https://newsroom.co.nz/2025/04/03/i-was-overjoyed-to-move-from-the-us-health-system-to-nzs-but-then-i-could-see-the-cracks/>



National Staffing Shortages:

- **‘Nurse staffing figures in New Zealand hospitals ‘genuinely alarming’, New Zealand Nurses Organisation warns’ – Stuff, 8 May 2024** <https://www.stuff.co.nz/nz-news/350459639/nurse-staffing-figures-in-new-zealand-hospitals-genuinely-alarming-new-zealand-nurses-organisation-warns> In 2023, over a quarter of nursing shifts across

540 public health wards were below target staffing numbers. Some wards, including those for children's care, oncology, surgical needs, women's health, and mental health, operated below safe staffing levels nearly all the time. For instance, the Neonatal Intensive Care ward at Waipapa Christchurch Hospital was understaffed for nearly 80% of shifts.

- **'Nursing shortage: Nurses 'broken' while sector faces thousands of vacancies' – New Zealand Herald, 18 June 2022** https://www.nzherald.co.nz/nz/nursing-shortage-nurses-broken-while-sector-faces-thousands-of-vacancies/L7NUXOPG4AB472OKXOH5QJSUMU/?utm_source=chatgpt.com The New Zealand Nurses Organisation (NZNO) reported that the nursing sector was more than 4,000 nurses short, leading to burnout and concerns about patient safety. Many nurses are leaving New Zealand for higher pay in countries like Australia, exacerbating the staffing crisis.

Emergency Department Pressures:

- **'Immense pressure': ED hit by chronic staff shortages' – Otago Daily Times, 24 October 2023** https://www.odt.co.nz/news/national/immense-pressure-ed-hit-chronic-staff-shortages?utm_source=chatgpt.com Front-line staff at Auckland City Hospital's Emergency Department reported "immense pressure" due to chronic staff shortages. Despite management's efforts to recruit staff, the department frequently operated at nearly 200% occupancy, leading to staff missing breaks and being unable to take leave.

Workplace Challenges:

- **Fury as New Zealand hospital bans staff from not speaking English' – news.com.au, 15 October 2024** https://www.news.com.au/lifestyle/real-life/news-life/fury-as-new-zealand-hospital-bans-staff-from-not-speaking-english/news-story/b041a1eb9477f0ddc9a1761b0f2a054c?utm_source=chatgpt.com In October 2024, Waikato Hospital issued a memo banning staff from speaking non-English languages, including Māori, in clinical settings. This directive sparked outrage among staff, particularly those from diverse backgrounds, who felt targeted and undervalued amidst existing workforce shortages.

National Trends:

- **'NZ hospital workers file 23,000 reports warning of unsafe staffing' – New Zealand Herald, 15 April 2023** https://www.nzherald.co.nz/nz/exhausted-desperate-hospital-workers-filed-23000-reports-warning-of-unsafe-staffing/3OXLDESX5NHNVOLJLT4JQBP47Y/?utm_source=chatgpt.com Between 2019 and 2022, hospital employees filed over 23,000 formal reports warning of unsafe staffing levels. Departments such as cardiology and general surgery experienced hundreds of these reports, highlighting systemic issues affecting patient safety across multiple facilities.
- **Mental Health Ward Understaffing – Otago Daily Times** https://www.odt.co.nz/news/dunedin/better-staffing-ratios-called?utm_source=chatgpt.com In 2023, more than half of the shifts at Dunedin's Wakari Hospital Ward 9A were understaffed, with 51.1% of shifts lacking adequate staffing. This shortage has led to reduced bed availability and increased strain on remaining staff, impacting the quality of care provided.

Oliver Taylor (Wellington)

Environmental scan

With the establishment of Regional Consumer Councils, consumer engagement is slowly re-starting at Te Whatu Ora. However, this is happening in an environment with an ongoing change proposal to disestablish the overall Consumer Engagement & Whānau Voice directorate, the one that maintains consumer engagement, with its status not changed since my last report.

Having recently been appointed as Co-Chair of the Central Regional Consumer Council, we have acted quickly. This includes amending our Terms of Reference to suit our needs, and writing a letter requesting an urgent return of consumer engagement funding to the Districts to Robyn Shearer, Central Regional Deputy CE – Health New Zealand. We expect to hear about this in the next month. We are also developing our work programme and communications strategy to make sure consumers know who we are, and our ways of working with Te Whatu Ora.

Young people are particularly concerned about recently announced legislation regarding gender identity. While the party is in Government, it is unlikely to progress through Parliament. However, this is creating substantial uncertainty for the rainbow community and instilling fear in Wellington, where queer people have historically been widely accepted and safe.

Input / involvement in Te Tāhū Hauora meetings/groups.

QSM Submission Moderation – Since the start of 2023, I have supported TTH moderating the submissions from health entities to the QSM. This is the second submission from the Regional level, rather than District level. In summary the submissions are getting better, while there are some ongoing areas for improvement and issues with resourcing to complete this. This included using the right evidence, putting submissions under the correct domain (Responsiveness, Engagement, or Experience), and understanding what is actually being asked or measured. Simple statements, such as “this is responding to consumers by...” or “the engagement was doing (this)...” or “the system that supports consumer engagement here is...” can greatly draw the reader to the attention of what the main focus for the example is. Ideally, through the development of the new structures, this will continue to mature to a point that better reports and acts on consumer engagement across the entities.

Te Tāhū Hauora QSM review – Prior to moderation, I also helped review the TTH submission. There were some good examples and areas for improvement, particularly the correct domain, the right evidence, or summarising things better.

Consumer Engagement in Primary Care review – I attended this hui on Zoom and provided advice that we need to create some diagrams that might provide some advice on consumer engagement structures for primary care, or where specifically consumer engagement may fit into their services. I also considered that the significance of Primary Care should be emphasised to justify why we need consumer engagement at this level – e.g. Southern Region considers 70% of care is primary.

Activity (since last report)

Regional Consumer Council hui – I have attended 3 hui since my last report, missing one due to our February Consumer Network meeting (huh!). Since then, I have pushed to allow consumers to have both Co-Chair roles and have been appointed Co-Chair, along with Angie Smith as Co-Chair (Māori). This was part of a wider Regional Terms of Reference review that we have put to Health NZ to approve. I have also led a letter to Robyn Shearer (DCE Central) to reinstate District level consumer engagement funding to ensure this engagement happens. Other members are working on our communications strategy (to consumers and Health NZ) for awareness and buy-in, new member recruitment processes, and finalising our documentation pack (induction material, report templates, response documents, ways of working).

National Regional Consumer Councils hui – We had an inaugural hui with other RCC Co-Chairs and support staff, as a platform to share what we are doing. There was much interest in our funding proposal and Terms of Reference changes, which we made clear we wanted to ensure appropriate consumer engagement across our region. We expect to have more hui with Northern / Te Manawa Taki also present.

Front of Whare Wellington Emergency Department Refurbishment Project – Since my last report, we have progressed work on the project to enable minor works for the existing ED, before the wider project gets going. We await Cabinet decisions and announcements before the project is officially launched, and there will be consumer engagement shortly to affirm the project's direction. Two consumers (myself and Dennis Te-Moana) remain actively engaged in the project steering group.

Positive stories and exemplars

The Minister of Health has made it clear he wants to return to the patient voice and local delivery and accountability. This sends a clear message (to me at least) that he wants more local consumer engagement, and this has been raised with our Regional DCE for her to consider and action.

Considerations for Te Tāhū Hauora

Continue to engage with the health system on how it can better engage consumers, including in primary care and regionally.

Mark Rogers (Timaru)

Environmental Scan

We need to build confidence back into our health system as it's been deteriorating significantly over the past 6 years. Regionally, there is too much inconsistency in delivery of services and wait lists. Also, there are many parts of the country with no Health Consumer Representation.

Health Consumer groups (Various organisations Nationwide) - I am concerned at the number of Eoi (Expression of Interest) requests still stating "we are seeking certain ethnicities".

Activity

Rare Disorders. Unfortunately, I was unable to attend the Glow up and Show up function due to Covid, however another family member did attend.

DEWS Expert Advisory Group (Deterioration Early Warning System) for those in Aged Residential Care. Our March hui focused on results of testing, report development, integration into electronic systems and various education and learning options.

Participated in the Adult Primary Care Survey.

STBI – Serious Traumatic Brain Injury. Refer HQSC 'Latest News – April 2025' where there is an update about this project. It was good to see our Board Chair acknowledging the work done in this area. This was by far the best project I was a Consumer Representative on.

<https://www.hqsc.govt.nz/resources/resource-library/serious-traumatic-brain-injury-progress-report/>

The serious traumatic brain injury national collaborative brought together nine teams of multidisciplinary clinicians and consumers with lived experience to complete quality improvement projects that would improve outcomes for those who experience brain injury in Aotearoa New Zealand.

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.

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 appts in particular. This will always be an issue for us but we are slowly getting better. This is the result of the collaboration with our PC service and the investment they have in our Iwi – connecting with our whānau and wanting to help create change.

We are in the midst of a Meth Epidemic, which I'm sure most areas, especially high in Māori, are experiencing. We have noticed a dramatic rise in family harm, drug induced psychosis & a call for awhi with kai and essential costs due to an already small income being spent on this drug. This speaks to the fact that mainstream services are not equipped to deal with this issue and the urgency of implementing Te Whare Tapa mahi with our whānau – we will see intergenerational harm from this drug if we do not do something about it now. It reinforces that EVERYTHING is intertwined (Physical Health, Mental Health, Whānau Health, a massive negative impact on all of this is a third world Housing problem we have here) it a holistic problem, that needs to be addressed from a holistic lens – Te Whare Tapa Wha being a successful Māori model of health here that does work, but doesn't fit into most mainstream funding requirements. Its exhausting trying to implement this being massively under funded and under resourced.

Input / involvement in Te Tāhū Hauora meetings/groups.

Te Tāhū Hauora insights report – Interview completed at time of Hūi.

Activity (since last report)

We held an Addiction 101 Wānanga for the community, which was very well attended by whānau from across the Iwi. The response was overwhelmingly positive — some of the basic concepts we might take for granted were eye-opening for many. It was incredibly encouraging to see the increase in awareness and the desire from whānau to continue learning and growing in this space.

Our organisation has been actively collaborating with Te Pou Oranga Whaiora, the first Indigenous methamphetamine treatment initiative of its kind. We've had several hūi with their full team, including clinicians, and are now bringing them into our Iwi to support adult Wānanga. We're also working closely with their Community Educator to co-develop a dedicated educational programme for kura in our rohe. This mahi aims to reach our tamariki and rangatahi early, supporting intergenerational change in how addiction and wellbeing are understood and addressed.

We are also pleased to share that our organisation is now collaborating with Hospice to provide a dedicated Kaimahi - similar to our Primary Care Kaimahi Collab - to coordinate end-of-life care for our whānau. This role has been warmly received. The nurse currently in the role, of Asian descent, has shown deep compassion and manaakitanga, which our Iwi have recognised, deeply appreciated, and connected with.

Additionally, we recently hosted the Sustainable Options Workshop here in Te Whānau a Apanui, with guests from 20 Degrees and the Mahi Pai Foundation. These workshops are always well received by our community. We are very fortunate to have the support of these organisations, who have provided practical solutions to help our whānau live in warmer, drier homes - from small renovations to home upgrades. Their awhi has already made a real difference for those most in need.

Services

I really want to highlight (and I always do) the positive experiences, and the PC & ACC Collab has been amazing! Having the Counsellor come to us, and breaking through that barrier of access has been amazing and this has gained so much traction. A lot of our whānau are now accessing this beautiful Tauīwi wāhine and she is making strides addressing PTSD – Sensitive Claim mahi, with our whānau here. This really speaks to the vital importance of strengthening external relationships and collaboration between Iwi Services where possible.

Positive stories and exemplars

Please see above under Services

Eden Li (Tāmaki Makaurau)

Environmental scan

Across the motu, consumers generally are facing continued challenges in their access to primary healthcare, as well as specialist care. Wait times for these services are persistent, not only for uninsured individuals but increasingly also for those with private cover, suggesting that these delays are no longer determinable even by the traditional social gradient.

From the perspective of students, these delays are also posing significant challenges, many being forced to renege on significant commitments in order to secure the closest available time.

The delays also have had deep implications for the continued health and wellbeing of less socioeconomically advanced communities, which are a big area of concern in Auckland due to the inequitable distribution of GP coverage across the region.

Individuals who are able to secure a timely GP appointment have also continued to express continued frustration at the increasingly mechanical nature of consultations. This is compounded by short wait times. It must be reiterated that this has become a significant point of dissatisfaction for a significant majority of New Zealanders, and that the health sector must be seen to be doing more to alleviate these pressures.

Consumers themselves also continue to feel frustration at the disconnect between the newly established Consumer Councils and local-hospital based consumer groups (many of which have now been disestablished). There must be greater interconnectivity between consumer voices at the regional and district level.

A growing number of consumers are also increasingly looking towards the health sector putting out renewed educational campaigns on areas such as medicine safety, healthy eating, and mental mindfulness. Although these initiatives only form part of the resource-support network for consumers, they continue to remain powerful tools of agency.

Input / involvement in Te Tāhū Hauora meetings/groups.

Involvement with Te Tāhū Hauora meetings included giving feedback and advice on the Te Tāhū Hauora submission on the QSM and Primary care consumer engagement resource draft review.

I also attended the Osteoarthritis research webinar.

Activity (since last report)

Clinical Quality Safety Committee - Te Whatu Ora Te Toka Tumai

I have continued to provide a consumer perspective into this committee, which continues as an assurance committee, guaranteeing quality across the Te Toka Tumai services. Input mostly revolved around improving the committee's role in promoting consumer interests per the Pae Ora

Bill, as well as feedback on the variance between how consumers see the system as opposed to clinicians. Though clinicians are able to see how the various organs of the system interact, a consumer only sees a fraction of these interactions. Therefore, improved clinical communication and synergy between operational subcommittees continues to remain an important factor for more efficient consumer outcomes.

National Medicines Steering Group - Ministry of Health

Continued to provide feedback on a consumer perspective of how medicines are optimally used throughout the country, as well as how consumer barriers to medicines can be lowered, to allow for more equitable outcomes.

Youth Advisory Panel for YMCA North

I have just been elected as Chairperson for the Panel, following a period of instalment as Interim Chair. Here, my focus is continuing to be leading initiatives so that we can develop the next generation of young leaders in a number of spaces, including health. There is a desire also to see how the NGO space can provide education on how individuals can take agency with their health choices.

Digital Health Research Paper

We have started to co-author a paper on the digital health sphere in New Zealand. This is an ongoing piece of work, although both myself and the primary author would like to bring the draft paper for feedback from the Consumer Network, once this has neared finalisation.

Services

The most significant community concern I have heard is about redressing the power imbalance between specialists and consumers. Often, times when a prognosis indicates potential future troubles, consumers must continue to receive a truthful indication of what the future may look like for them health wise. However, this must also be done in a manner which is not overwhelming, or makes their condition seem overly pessimistic. Although this is a cultural shift which may need to take place over time, it is important that clinicians, especially specialists, remember the importance of how such information is presented to consumers.

Positive stories and exemplars

Although consumer connections between the district and regional levels could be further strengthened, the eagerness of clinicians to engage, involve and advance consumer-centric models at the district levels continues to indicate a strong and healthy basis for consumer centred care to continue. The level of individual consultation involving consumers at the Clinical Quality Safety Committee for the reformulation of the Terms of Reference and other constitutional documents, for example, show how consumers continue to be valued beyond qualitative feedback at the reporting level.

Considerations for Te Tāhū Hauora

- Address the rising inaccessibility of timely care. Wait times for both primary and specialist care continue to disproportionately impact students and lower socioeconomic communities.
- Work with Te Whatu Ora to ensure greater connectivity between Regional Consumer Councils and local hospital-based consumer groups to ensure consumer voice continuity.

Zechariah Reuelu (Porirua)

Environmental scan

Across the Porirua Pacific community, several persistent and emerging health-related concerns were raised between January and March 2025.

Community talanoa/ conversations across Porirua and the wider Wellington region continue to surface key themes: limited culturally tailored care pathways, delayed access to GP enrolment for Pacific families (especially those recently relocating), and underutilisation of digital health tools due to digital literacy and affordability issues.

There remains significant concern around delays in general practice enrolment, particularly for newly relocated families from Tokelau and other Pacific nations. Long waitlists and closed books at practices have resulted in unmet needs for Pacific families, especially those managing chronic conditions such as gout, diabetes, and heart disease. Consumers expressed frustration at being turned away or referred to urgent care clinics for non-urgent, ongoing issues.

Although platforms like Practice Plus and Manage My Health are promoted, digital exclusion continues to hinder Pacific uptake. Community members cite issues with internet access, low digital literacy, and limited language support as key barriers.

Pacific Whānau Ora Providers affected by recent changes to Whānau Ora agencies are facing significant uncertainty and operational challenges. Many have reported disruptions to funding streams, delays in contract renewals, and a lack of clarity around future commissioning processes. This has created stress for frontline staff and limited their ability to plan and deliver culturally grounded, whānau-centred services. Concerns have also been raised about losing trust-based relationships built over years with families, particularly in Pacific and Māori communities. The instability has affected workforce morale and forced some providers to scale back critical support services at a time when demand for holistic care is growing.

Involvement in Te Tāhū Hauora / Consumer Engagement

- Health Quality & Safety Commission's Consumer Network – Te Tai Poutini workshops West Coast.
- QSM Consumer Submission Moderation Team

Activity Highlights

- **Auckland Pasifika Festival:** Collaboration with ProCare and Diabetes NZ with over 250 uric acid test and data to their GP Clinic for follow -ups.
- **Tu Ora Compass PHO at Pasifika Festival Wellington:** Facilitated community health checks for over 50 Pacific gout attendees
- The changes with **Tū Ora Compass Health and Te Awakairangi Health** Network's amalgamation. A range of broader talanoa with governance representative, structures and funding streams, with implications for practices.
- **NZ Pain Management Conference:** Formed strategic connections with researchers to advance community-based arthritis support for Pacific aigā & communities
- **Tokelau Strength and Balancing Programme:** Delivered a culturally rich six-month tino matutua elderly programme in partnership with Nuku Ora.
- Secure sustainable funding for **Wai Ora Kaumatua Water Based Programme**
- **Tu Ora Pacific Health Committee:** Quarterly reporting meeting
- **Allopurinol Reclassification Submission:** Arthritis NZ, Green Cross Health, medicines reclassification expert Dr Natalie Gauld, and rheumatologist Associate Professor Peter Gow (Counties Manukau Health NZ | Te Whatu Ora) produced a joint submission which was included as an agenda item for the February 2025 session of the Medicines Classifications Committee (MCC 73rd Meeting).

The submission calls for the reclassification of allopurinol to make it easier for consumers with gout to access this frontline medication. The model proposed would see a doctor (or other prescriber) initiate allopurinol and specially trained pharmacists to titrate (in collaboration with the general practice) allopurinol. This proposed change seeks to significantly improve current gaps relating to gout consumers' treatment and access to medication, particularly from an equity point of view.

Services – Issues & Barriers Identified

- Pacific people face barriers to Practice Plus and Manage My Health portals due to digital literacy and exclusion.
- ASH (Ambulatory Sensitive Hospitalisation) rates remain disproportionately high among Pacific people for preventable conditions—skin infections, respiratory issues, and oral health were key contributors.
- Enrolment restrictions at some GP practices are affecting patients with chronic conditions and newcomers from Tokelau.

Positive Stories & Exemplars

- The **Brain Health Seminar** model delivered with Porirua Union Community Health Services is an emerging best practice for culturally grounded dementia education.

Considerations for Te Tāhū Hauora

- Invest in culturally designed digital literacy and health navigation support for Pacific users.
- Expand support for intergenerational health models, including Pacific Cognitive Stimulation Therapy and aigā led chronic care initiatives.
- Ensure equity lens is upheld in primary care system responses, including practice enrolment flexibility and mobile outreach models.
- Promote cross-agency collaboration to address the root causes of ASH admissions (e.g., housing quality, dental funding).

Amanda Stevens (Nelson) - Deafblind Association NZ Charitable Trust

Environmental scan

Since my last report:

Convening Conference June 2025 is currently all consuming. Conference Programme now includes “Knowing your way around the Health System” – thank you DJ Adams for offering to come in for this.

Dual Sensory Impairment and experience of complexity in the Medical System – new development and shared goals.

Disability Support Services – Changes and what they mean for our community

Prevalence of deafblindness in Aotearoa NZ and international research collaboration.

This last item is being lead by Dr Sally Britnell,(Board Member Deafblind Association NZ) RN, MStJ, PhD (Computer Science) Senior Lecturer / Senior Research Fellow Nursing / School of Clinical Sciences, Auckland University of Technology

We are well positioned to be able to carry out this mahi as a first in Aotearoa NZ.

Thank you to Vishal Rishi the Asian Network Inc for financial support. We also credit the Consumer Network for bringing us together. Helen Keller "Alone we can do so little, together we can do so much"

I emphasis here the mental and social wellbeing supported by bringing our increasing peer to peer support groups together and convening conference. Mitigating social, communication, and digital isolation promotes individual's, cultures, and healthy communities-we know this. However, in the current political climate it has been harder than ever to get the funds to the people who need it most.

Vivien Verheijen (Auckland)

Environmental scan

Age population healthcare issues

The challenges elderly individuals face are complex, profoundly impacting their overall quality of life.

- **Lack of Appropriate Aged Care and Respite Facilities**
Many elderly individuals navigate inadequate options that fail to meet their diverse needs. This scarcity affects their well-being and places an overwhelming burden on families and caregivers.
- **Social Isolation and Financial Barriers**
A lot of elderly experience loneliness, which affects their mental and physical health. These financial difficulties restrict access to vital healthcare services, essential medications, and specialist treatments, leaving them trapped and unsupported.
- **Lack of Dementia Support and Care**
It highlights a significant gap in the healthcare system. Individuals with dementia often face challenges in receiving timely assessments, diagnoses and cohesive care coordination. The absence of comprehensive long-term management leads to confusion and distress for those affected and their families.
- **Digital Accessibility**
Navigating healthcare services online can be daunting, leaving them vulnerable to technological pitfalls. Furthermore, the rise in scams targeting older people poses a grave threat, as these individuals may suffer significant financial losses while losing trust in the systems designed to assist them.
- **Long Wait Time for Healthcare Assessments and Treatment**
Delays in healthcare services are ongoing with existing health issues for the elderly. Hospital waiting times have increased from 4-6 hours to 6-8 hours. GP appointments now have a waiting period of several days to weeks, while specialist appointments can take months.

Overall, these increased waiting times can lead to a decline in health and diminish the quality of life for older individuals. Many elderly patients suffer in silence due to inadequate care and oversight, resulting in preventable health declines. This situation highlights the urgent need for reform in the aging sector to improve the quality of life and ensure that older adults receive the compassionate care they deserve, particularly in areas related to Hearing, Oral, and Bone Health.

PHO's challenges

Digital budget reduction impact and concerns by GP and communities:

- Reducing digital investment poses a significant threat to the sustainability of digital health services, which jeopardizes patient care and the healthcare workforce.

- Such funding reductions are likely to exacerbate existing health inequities, particularly affecting Māori, Pacific peoples, and disabled communities that depend on digital tools for accessing essential healthcare services.
- Furthermore, the proposal to decrease telehealth positions at Health New Zealand may limit access to virtual healthcare services, potentially leading to longer wait times and delays in critical diagnosis and treatment.

Diverse cultural capacity shortage for GP workforce in Auckland

- **Asian GPs and Health Specialist Shortage**
Asians constitute over 31% of Auckland's population but only 23.1% of the GP workforce. This disparity indicates that some communities, such as Indian, Chinese, and Southeast Asian, may be underserved, highlighting the need for more specific representation. In particular, there is a significant gap in mental health and addiction services and a lack of professional experts and specialists in this area.
- **Future Projections Worsening**
Without targeted interventions, the gap between community diversity and GP workforce diversity will likely widen as Auckland becomes even more multicultural.

Critical feedback on Putting Patients First: Modernising health workforce regulation

Aiming to enhance healthcare delivery, the government's review of health workforce regulation has raised some concerns among general practitioners (GPs) and stakeholders:

- GPs and stakeholders emphasize the need for the review to go beyond merely lowering entry barriers by addressing burnout, workforce shortages, and financial pressures, particularly in rural areas.
- Recognizing the complexities of GP work can help maintain care quality, ensuring that telehealth is utilized effectively alongside in-person services.
- A comprehensive approach to patient safety that includes cultural and social factors, especially for Māori, Pacific, and diverse communities, is essential for equitable outcomes.
- Enhancing the review's effectiveness will involve prioritizing improved access for vulnerable populations and engaging frontline practitioners, guided by the principles of Te Tiriti o Waitangi.

Additionally, some noted that the documentation was poorly constructed, undermining the regulatory functions of professional organisations. A collaborative, holistic approach to health workforce reform is essential for ensuring long-term sustainability and quality in patient care.

Input / involvement in Te Tāhū Hauora meetings/groups.

This quarter I have participated in the following meetings:

- Primary care consumer engagement resource draft review
- Feedback on Te Tāhū Hauora's submission on the QSM submission
- Kōtuinga Kiritaki Consumer network in Feb 2025

Activity (since last report)

After my appointment to the HQSC consumer network, I proactively organized meetings with stakeholders from NOGs and the health sector to strengthen connections and discuss healthcare issues in our communities. These conversations have provided valuable insights and contributed to my environmental scan. I am also exploring collaboration opportunities to promote HQSC's work and the Code of Expectations.

Also, I have regularly attended the Consumer Advisory Committee Meetings, PHARMAC

- **3 March 2025- PHARMAC Consumer Advisory Committee (CAC) Special Meeting.**
The primary purpose of the meeting was to update the Consumer Engagement Report (where Dame Kerry Prendergast spoke about the two independently run workshops with consumer advocates in November last year). <https://www.pharmac.govt.nz/news-and-resources/publications/publications/pharmac-consumer-engagement-workshop-report>
The meeting highlighted the findings from those consumer engagement meetings and future implementation to improve PHARMAC consumer connection and engagement.
- **12 March 2025 PHARMAC Consumer Advisory Committee Meeting**
Discussed on how to engage with consumers to provide useful information about medicine care and accessibility.
- **9 April 2025 - PHARMAC Consumer Advisory Committee Meeting**
Providing CQSM update and also seeking inputs from the members of CAC. Besides, the meeting sought feedback from CAC on implementation plan for oestradiol patches. <https://www.pharmac.govt.nz/news-and-resources/consultations-and-decisions/2025-03-proposal-to-fund-estradiol-as-an-alternative-brand-of-oestradiol-patches>

Positive stories and exemplars

The Asian and Ethnic Health Services team from Te Whatu Ora kindly helped disseminate the Code of Expectations (Chinese, Hindi, and English flyers) at their serial community events, Group Vaccination events for Asian/ethnic communities in Auckland, Hamilton, and Wellington in April, and other community events in 2025.

I will proactively seek collaboration to promote the code of expectations and HQSC's work by tapping into suitable programmes, events, and community connections.

I have received positive feedback and constructive suggestion from one of the stakeholders; I have copied the message here:

There are still a lot of challenges in improving the health and well-being of Asian and ethnic communities. We appreciate what you have done for the communities on many fronts. We'd love to continue to work with you to voice out the health and well-being needs of our super-diverse Asian and MELAA communities. In particular:

- *There needs to be a high-level health and well-being policy for Asians and MELAA at the national level.*
- *Data disaggregation and visibility of Asian and MELAA, so that we can appreciate the nuance of the sub-groups, e.g., diabetes for Indian and South Asian, and mental health for Asian youth and senior residents – Chinese, Indian, Korean and all.*
- *Health New Zealand and HQSC are working together on community engagement and whanau voice, particularly including the voices of the Asian and MELAA communities.*

Considerations for Te Tāhū Hauora

- Enhancing its engagement and collaboration with ethnic community NGOs, health sector organisations
- Tapping into relevant events and programmes to promote HQAC's work and resources
- Translating the Code of Expectations to other ethnic languages, such as Korean and Vietnamese

Tee Siataga (Ōtautahi)

Environmental scan

This environmental scan reflects key feedback from peer and lived experience networks across Te Waipounamu and nationally. It highlights both the momentum building in lived experience leadership and critical challenges in service delivery, particularly in HSS, inpatient services, crisis care and eating disorder responses.

Several ministerially driven nationally led, regionally implemented projects including Peers in ED and Crisis Recovery Cafes continue to advance under high-pressure timeframes, limiting relational engagement with communities and mana whenua. These kaupapa need time to be built so they are grounded in the values and realities of the communities they will serve, but they are progressing rapidly.

There are concerns around the transparency of Regional Consumer Councils and increasing wariness as community members outside of the council struggle to have their concerns, requests for information or emails returned. Please note that the Regional Manager, Consumer and Whānau Voice role has been vacant for several months.

There is also a growing spotlight on **eating disorders**, where lived experience and whānau are calling attention to system gaps. Eating disorders are often treated as physical health issues only, with mental health support delayed until weight restoration is achieved. This approach disregards Māori worldviews and models that acknowledges the interconnectedness of taha wairua, taha hinengaro, taha tinana, taha whānau. An example shared highlighted how a GP visit, where a teen in early recovery and well, was weighed and told her weight aloud which led to a serious relapse.

A key development in Te Waipounamu is the development of a Regional Te Waipounamu Mental Health HSS Lived Experience Advisor rōpū, which will support the newly appointed Regional Mental Health Lead and provide system insight into local specialist mental health services. This initiative reflects a broader aspiration to amplify the Lived Experience Advisor function as a core part of hospital specialist services.

I have been seconded to Te Waipounamu Mentally Well Commissioning team to support the Consumer Peer Support Lived Experience (CSPLE) Programme of Work.

Co-leading the development of a Te Waipounamu Whānau Network that will comprise of a whānau family provider network, and an additional network for whānau voice. This network will inform Te Waipounamu Mentally Well commissioning and will occasionally come together to for shared kaupapa based collaborations and shared priorities.

Activity (since last report)

Met with Eating Disorder Carer Network NZ Chairs. Invited to join the Eating Disorder Professionals NZ SIG meeting to discuss the upcoming review of eating disorder services and eating disorder strategy which has not been updated in 16 years. I was unable to attend the first meeting but will prioritise future ones.

Met with the newly appointed Te Waipounamu Regional Mental Health Lead, to discuss the invisibility of Consumer Lived Experience Advisor voices working in specialist mental health and addiction services. I proposed establishing a Regional Te Waipounamu Mental Health & Addiction HSS Lived Experience Advisor Rōpū which received support from the Regional Mental Health Lead, including Consumer Lived Experience Advisors I had engaged with prior.

Undertook several informal hui across the motu with lived experience networks about the limited training and development for the workforce to upskill or advance, including opportunities for tāngata whaiora in recovery to enter the workforce. As a result, I have developed a Te Waipounamu MH&A lived experience mentoring programme which will be rolled out August/September when my secondment ends. I have also started a LinkedIn series Navigating the System: A guide for lived

experience roles with the aim of sharing insights and learnings as part of my broader aspiration to grow the peer and lived experience workforce.

Services

Eating Disorders

A growing area of concern among parents and whānau is the systemic response to eating disorders (ED) or disordered eating. Eating disorder services are siloed. Rangatahi are denied mental health care until they are physically stable. This continues to be a significant issue for Māori and their whānau. The absence of quality holistic eating disorder care pathways delays recovery for Māori and Pasifika who are underrepresented in eating disorder stats.

Whānau feel excluded once rangatahi turn 16 and can self-discharge, even though eating disorders thrive in secrecy. Whānau are asking for a more nuanced, relationship-based approach that recognises the chronic and high mortality nature of eating disorders; early, intensive intervention and long-term monitoring; enables family inclusive care even after aged 16 where appropriate and avoids placing full responsibility for recovery on the person too soon.

Lack of eating disorder awareness across general hospitals, GPs and primary care have been reported by whānau as extremely distressing experiences. One whānau member shared that after her 15-year-old daughter had made strong progress in recovery, a GP visit for a new script resulted in being weighed and told her weight aloud. This triggered a relapse which undid months of hard work. There is an urgent need for system-wide education and a review of hospital responses and inpatient stays, particularly for child and youth.

Whānau see promise in the refreshed Eating Disorder Strategy and review of eating disorder services as signalled by Minister Doocey, especially if it improves hospital-based responses and equips GPs and frontline staff to engage and interact safely and respectfully with those experiencing eating disorders. However, the success of this strategy will depend on the active inclusion of Māori, Pasifika, lived experience and whānau voice.

Positive stories and exemplars

A positive culture shift is being seen in the **Enhancing SPEC Project**. The Safe Practice Effective Communication (SPEC) project will intentionally elevate Lived Experience, Māori and cultural expertise across all levels from governance to SPEC trainers, to reviewing and co-designing a refreshed SPEC programme. There's increasing support for this transformation, but long-term success will depend on executive level investment and a shift in language and practice from de-escalation to relationship based, trauma informed culturally appropriate responses to working with tāngata whaiora in inpatient settings.

Considerations for Te Tāhū Hauora

Feedback has highlighted the pace and pressure of some ministerially driven initiatives such as Peers in Emergency Departments and Crisis Recovery Cafes has made it difficult to uphold relational engagement with priority populations and wider communities. The timeframes are often unmanageable, impacting the ability to design with communities. This has been named consistently by peer and lived experience leaders and Māori who seek authentic, non-transactional partnership with Te Whatu Ora.

At the same time, positive shifts are taking place. The Mentally Well team (Te Waipounamu) has shown a commitment to adapting their approach, applying lessons learned to improve future

implementation. There is growing recognition of the need to pause, reflect and reset where necessary to uphold the values of the Code of Expectations and Te Tiriti o Waitangi.

Further consideration for Te Tāhū Hauora might want to take up:

Provide national support for SPEC to ensure it remains positioned as a system wide level for change in inpatient mental health settings. SPEC is evolving beyond a training programme. Tāhū Hauora could advocate for SPEC to be embedded in national workforce development strategies across HSS. Promote ongoing co-design in the review and refresh of the SPEC programme in alignment with the Code of Expectations.

Vishal Rishi (Auckland)

Environmental scan

Kia ora and warm greetings!

Please find the quarterly Kōtuinga Kiritaki Consumer Network report as mentioned below. This report includes the latest update on Asian/ethnic health sector, system safety strategy ropu and consumer experience.

Services

Recent consumer experience: It is with an extremely heavy heart that I share the story of a consumer who has suffered greatly due to the shortcomings in our health system. The response was unacceptably slow in diagnosing the issue, and once the diagnosis was finally made, timely care and intervention were still lacking. Had the condition been identified earlier, the outcome for this whānau could have been drastically different. Tragically, this delay means that a beautiful wāhine may now face amputation. She is currently overseas for the second time in last five months, left to deal with the medical complications that our system failed to prevent the preventable harm. Details available on request!

Consumer voice concerns from Counties Manukau: The recent disestablishment of consumer councils has led to a significant gap in consumer representation in the Counties Manukau region. These councils historically played a crucial role in bringing forward the lived experiences, feedback, and concerns of patients, whānau, and communities into the planning and delivery of health and wellbeing services. Their absence has created a vacuum where consumer input is no longer formally or consistently integrated into decision-making processes. The hospital staff that was responsible to do the consumer engagement, planning and strategic work has also been drastically reduced.

In response, we have begun exploring alternative approaches to ensure the voices of consumers in this region continue to be heard. Our aim is to identify sustainable and inclusive methods to capture lived experiences and community perspectives from this important geographic area.

Activity (since last report)

Involvement at system safety strategy rōpū: It is a great learning to be part of this rōpū. I envisage elevating consumer voice at system safety strategy planning level being part of this rōpū. This rōpū will guide the co-design and development of a national system safety strategy—coordinated by Te Tāhū Hauora (Health Quality & Safety Commission) at the request of the Minister of Health. The strategy seeks to:

Establish a shared understanding of quality and safety in health care

Minimise harm and enhance quality across the health and disability sectors

Uphold commitments to Te Tiriti o Waitangi, mana Motuhake for Māori, and the Pae Ora (Healthy Futures) Act 2022

Wider engagement with Asian communities: In last three months, we have done an extensive engagement with broader Asian communities, specifically, Chinese, Korean, Cambodian and Indian communities. We have actively collaborated with a diverse range of organisations to plan and deliver health seminars, strengthening our outreach and community engagement. Key partners in these efforts included the Psychology Group, ACC, Prostate Cancer Foundation, Health NZ Waitematā, Te Whatu Ora, Well Women & Family Trust, the Active Asian Team, and the Albany, Howick, and Northcote Libraries.

In addition to these seminars, participated in several other health and wellbeing initiatives focused on Asian communities. These included health promotion activities at the Onehunga Festival, Cambodian Health Seminar, and participation in the Disability Transition Seminar.

Also delivered a range of targeted health talks, such as a Women's Health Talk for the North Auckland community at Albany Library, presentations on the New Zealand health system to ethnic women. Not only recent migrants, but even migrants who have been living here for more than ten years, do not understand the NZ health system and hence are unable to access the same.

Worked with Welcoming Communities co-ordinators and delivered educational sessions for the Long Bay Chinese Association.

Further talks addressed stress management in East Auckland at Howick Library, mental health in the North Shore community at Northcote Library, and men's and women's health at a Chinese Health Seminar in Hobsonville.

Joanne Neilson (Tairawhiti)

Environmental scan

As I am sure, you are all aware these are unsettling times in Health! I know this is an understatement. While we have seen a look in the news about Nelson Hospital, Gisborne is in a similar state. In addition, not just the state of the Hospital which needs a rebuild within the next 10 years. However, the ability to retain or even recruit staff.

While a lot can be blamed on this current government, this problem for Tairawhiti, as with Health in general, has been ongoing for many years. We have had a cardiologist vacancy for 3 years. We are desperately short of senior medical doctors and clinical staff. The pressure put on them to fit everyone in overwhelms administration teams. Now with the latest move with Pay Equity it doesn't create an environment that is harmonious, and I am sure we will see more staff move to different career options. These are indeed troubling times.

I am saddened to see the attacks on the Trans community continue. And it seems these attacks are aimed at Trans Women. I am bewildered that they haven't considered the other side. I have some very masculine, hairy, bearded and bald Trans male friends that would under the law have to use the women's bathroom. When will common sense prevail? There is no anecdotal evidence of women being harassed by a trans person in a bathroom but there is a lot of evidence of Biological women, who don't present feminine, being dragged out of bathrooms mistaken for being Trans.

Personal scan

I am still involved in the local Theatre doing makeup for an upcoming cabaret season. Theatre is a busy business in Gisborne with 4 theatre group vying for the same dollar. However, it makes it

interesting and entertaining. Renovations are moving along and we maybe on the move before the end of the year.

Arana Pearson (Ōpōtiki-Mai-Tawhiti, consumer and family engagement advisor mental health, HQSC)

Input / involvement in Te Tāhū Hauora meetings/groups.

I and the team I work in has been focused on the HQSC exiting our entire mental health team and for handing over two of our projects before we all exit our jobs here with the HQSC at the end of June 2025. I imagine this will be my last meeting with the Kōtuinga Kiritaki Consumer Network.

Outcomes with the zero seclusion project of HQSC.

1. The zero-seclusion project will become an “always report and review (ARR)” with HQSC as the quality improvement work we have done can mostly become a quality assurance process”. We have four sites testing this process at present and each of those sites has consumer engagement at all levels of the testing. There will be an ongoing need for HQSC to maintain consumer engagement internally with the review of this ARR process.
2. We as a team have also been doing some comms work. For example, we have now achieved publishing a new peer-reviewed paper, [published in the medical journal *Australasian Psychiatry*](#), which shows that since that baseline year, the rate of seclusion for all adults admitted to adult, non-forensic inpatient mental health units has been reduced by 33%. This has been maintained since March 2023. Seclusion of Māori patients has been reduced by 39%.
3. In addition to the peer reviewed article, we have been working on a story aimed at the general public to allow them to understand what we have been doing across all mental health services in NZ. This includes a key consumer story and experience of a person I have been supporting to engage with an article for publishing on Spin-Off. The editor for Spin-Off is engaged and supportive of this article. The consumer engaged for the Spin-Off article is an ex-nurse who became mentally unwell and was subsequently restrained and secluded in solitary confinement. Her finger was broken in that restraint and her finger is permanently out of line as a result. She now works as a consumer advisor, and she is part of our zero seclusion project in a local service. I am humbled to be able to engage with her and all the consumers working to eliminate the use of solitary confinement within our state-run mental health services.
4. **The background to this outcome is:**
 - The UN (United Nations) special rapporteur on use of Torture visited NZ in 2014 at the request of our government.
 - The UN report in 2014 is available here [Statement at the conclusion of its visit to New Zealand \(24 March – 7 April 2014\) by the United Nations Working Group on Arbitrary Detention | OHCHR](#)
 - The 2014 UN report stated under a heading titled “**Detention of Persons with Mental or Intellectual Disabilities**”
 - “However, it is of concern to the Working Group that the legislative framework is not effectively implemented to ensure that arbitrary deprivation of liberty does not occur. In practice, compulsory treatment orders are largely clinical decisions, and it is difficult to effectively challenge such orders. Although the Mental Health Act guarantees the right

to legal advice for all patients, persons undergoing compulsory assessments are often unrepresented in practice, as they do not have access to legal aid. The Family Court, which makes compulsory treatment orders, is not a specialist court in mental health and seems to have the tendency to heavily rely on medical reports by merely one clinician and one another medical professional, who, in most cases, is a registered nurse. The Working Group further expresses its concern relating to the widespread practice of seclusion in psychiatric units. While recognizing the Government's achievement in reducing the incidents of seclusion since 2009, the Working Group urges the authorities to eliminate this practice".

- The 2015 UN report reference above can be found here [Committee against Torture publishes findings on New Zealand, Republic of the Congo, Romania, Luxembourg, Spain, Serbia, Colombia, The Former Yugoslav Republic of Macedonia | OHCHR](#)
- This 2015 UN report is found in the human rights section of the UN and this is the report that mentions punishment is used quote "The findings, officially termed concluding observations, contain positive aspects of the respective State's implementation of the Convention against Torture, Other Cruel, Inhuman or Degrading Treatment or Punishment, and also main matters of concern and recommendations.
The concluding observations can be found here:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=961&Lang=en
The Committee against Torture is composed of 10 international independent experts.
ENDS

- Section 14 beginning page five of the above 2015 UN report says this :-

- "Excessive use of seclusion in mental health facilities

1. While welcoming the adoption of the Mental Health and Addiction Service Development Plan 2012-2017, the aim of which is to eliminate the practice of secluding persons affected by mental health and addiction issues in the State party, and the commitment of the Ministry of Social Development to finish processing all historic abuse claims submitted to it by the end of 2020, the Committee is concerned at information received on the persistent seclusion of persons in mental health facilities for the purposes of punishing, disciplining and protecting, as well as for health-related reasons. The Committee notes that a significant number of victims have been secluded for more than 48 hours, and that Māori are more likely to be secluded. The Committee is concerned at information that the State party continues to include, in new psychiatric facilities, cells specifically designed for solitary confinement. The Committee is also concerned that, according to information received from non-governmental sources, 60-70 per cent of people in detention have either a learning disability or a mental illness. The Committee notes that the State party failed to investigate or hold any individual accountable for the nearly 200 allegations of torture and ill-treatment against minors at Lake Alice Hospital. The Committee also notes the lack of relevant statistical information (arts. 11, 14 and 16).

The State party should:

- (a) Use solitary confinement and seclusion as measures of last resort, for as short a time as possible, under strict supervision and with the possibility of judicial review;
- (b) Prohibit the solitary confinement and seclusion of juveniles, persons with intellectual or psychosocial disabilities, pregnant women, women with infants and breastfeeding mothers, in prison and in all health-care institutions, both public and private;
- (c) Conduct prompt, impartial and thorough investigations into all allegations of ill-treatment in prisons and health-care institutions, both public and private; prosecute persons suspected of ill-treatment and, if they are found guilty, ensure that

they are punished according to the gravity of their acts; and provide effective remedies and redress to the victims;

(d) Compile and regularly publish comprehensive and disaggregated data on solitary confinement and seclusion.

- The above 2015 pg5 can be found directly here
tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CAT%2FC%2FNZL%2FCO%2F6&Lang=en

Our handover work in part makes sure HQSC carries on compiling, publishing, and reviewing seclusion data in all mental health services of our country.

5. Communication about consumer engagement with police service arrangements regarding mental health crisis

HQSC asked me to respond to questions from a trade union organiser about consumer engagement in the mental health process related to the withdrawal of police engagement with some mental health crisis. Initial response was made. There is now a more detailed follow up. Health NZ are responding to the need for consumer engagement with the process across the country and more work is to be done in this space. The change roll-out is timed differently across the country. Broadly speaking, a consumer view is we do want less police involvement with our times of health crisis. And we would rather a mental health crisis be responded to by the health sector just like all other expressions of health crisis. We think any dialogue which begins from a space of saying “all mental health clients carry an inherent risk of violence because of that diagnosis” is an unacceptable discrimination that is just not true.

6. Maximizing physical health

The other main project work we are handing back to the sector is maximising physical health. Mental health clients with major mental illness diagnosis and treatment die on average 30 years younger than the national average. The reasons why are complex, but one of the contributing factors is physical health markers are not followed up by the health sector. For example, people on Clozapine are not routinely given access to blood testing for diabetes (such as lipids) and other physical health tests. One health district only reported 20% of clients in this high-risk group accessed physical health tests. Our project work has been frustrated by difficulties in accessing timely data to undertake measurable quality improvement work. This is a mortality issue that for any other population in NZ would garner an outcry in the media. The discrimination and siloing of services along with the barriers between primary and secondary health services need to be worked with to create a measurable improvement on this thirty-year gap in mortality of mental health clients with major mental illness diagnosis.

Positive stories and exemplars

7. Homelessness responses for mentally ill people in NZ

A major vulnerability for some mental health clients is homelessness without effective support. A housing first approach has seemed to work well in parts of Auckland, Christchurch, Nelson, and Hamilton but is not an approach that is equally available throughout the country. A new service has in Napier has appointed a former police inspector Sam Aberahama as CEO to run a mental health service to look at solutions for homelessness amongst other presentations. This was sparked particularly by two deaths in the street-dweller community in Napier last year, including that of Boy Taylor, alleged to have been murdered in Emerson St in December.

Press statement regarding homelessness response in Napier is made here [Govt to give \\$325,000 to house Napier's homeless](#) where Sam Aberahama is reported as saying “I’d be keen to explore what we’re doing, and what’s working,” he said. “A number of people have come up to me today [at the pōwhiri] who are wanting to talk.” They would talk about whether providers, agencies and other stakeholders are “individually and collectively getting bang for buck”. Although his police career involved many encounters with the mentally unwell and homeless, he concedes: “This is all new.”

There is much homelessness of people diagnosed with mental illness across NZ and some people in smaller communities do not recognise what homelessness is, and that is part of the problem to solve. Services need to work together to solve the presentation, person by person. If communities do not attend to this, then we will see more and more mental health clients become criminalized, as prison is seen by some as one solution to homelessness.

Already we have seen our forensic mental health services receive more referrals from prisons for people already imprisoned where mental illness did not appear to play a role in precipitating the offending, and not through the court hearing process where the mental health presentation is the identified predominant factor evident in the offending, which is how forensic services were first set up to work.

Considerations for Te Tāhū Hauora

- 1) There remains a great deal of variation in services about the use of seclusion. Some are pretty much zero. But we know that one third are way above 5% goal set for last year. Some ongoing quality improvement work needs to be done with these outlier services.
- 2) There remains a need for consumer engagement with the internal reports related to ARR. How can this be assured?
- 3) The HQSC atlas of health care variation does not accurately reflect the Eastern Bay of Plenty (BOP) at all <https://www.hqsc.govt.nz/assets/resources/Health-Quality-Evaluation/Atlas/MentalHealthSF9Dec/atlas.html> The Eastern BOP is very similar population and challenges to Northland and Tairāwhiti. For example, the population of Opoitiki is 56% Māori so that here and up the coast evidences the same deprivation. For example, the persistence of heart disease owing to Rheumatic fever which you just don’t see the same rates at all in the Western BOP.

Recently the Hospital in Whakatane lost it’s Midwife unit so that women need to travel to Tauranga for service (could be a four-hour drive), in Mental health the seclusion data in Whakatane is way high compared with the work done in the Tauranga hospital. However, the HQSC Atlas uses BOP as a whole entity, and the Western BOP is predominantly pakeha, wealthy, highly populous, more elderly compared to the largely rural population in Eastern Bay, and quite a different population entirely than the Eastern BOP with larger childbirth and young people rates.

This Atlas needs to urgently look at how it skews the data away from the reality of the Eastern BOP because of the population numbers in the Western BOP. The problem is systemic in that district health areas changed a while ago in the configuration of “Bay of Plenty”.

The Eastern BOP used to be a stand-alone DHB, but it was merged with the Western BOP some time ago. This merger has resulted with increasing withdrawal of services from the Eastern BOP and gross under-reporting of the actual need of this area, which currently, the HQSC is perpetuating in its Atlas.