

Minutes of the Kōtuinga Kiritaki | Consumer Network meeting

Kōtuinga Kiritaki members	Joanne Neilson, Oliver Taylor, Jennie Harré-Hindmarsh, Toni Pritchard, Amanda Stevens, Mark Rogers, Eden Li, Vivien Wei Verheijen, Claire Turner, Tyson Smith, Stan King				
Te Tāhū Hauora staff:	Kelly Palmer (Chair), Penita Davies, Dez McCormack (minutes) Doug Edwards – Pou Tikanga (for beginning).				
Apologies	DJ Adams, Tee Siataga, Vishal Rishi, Zechariah Reuelu (absent)				
Guests	Pauline Gulliver, Impact Manager; Telesia Siale, Principal Advisor, Jo Sorasio, Senior Advisor; Tāhū Hauora (Day 2)				

The meeting was held via Teams on 20 and 21 August 2025.

1. Mihi whakatau for Stan King

Doug Edwards welcomed Stan King on behalf of Kōtuinga Kiritaki and Te Tāhū Hauora.

2. Whakawhanaungatanga

Members introduced themselves and shared brief insights.

3. Standard business

Previous minutes for 15 May were accepted. One change from Oliver Taylor for the Interests Register. Action items were completed.

4. Director's update - Māori Health & Consumer report and update

Kelly Palmer acknowledged the passing of Jo Millar and recognised her as a strong consumer voice in the health system.

Also acknowledged Mary Schnackenberg and Delphina Soti concluding their consumer roles.

Kelly spoke of our new Chief Executive – Professor Sunny Collings, and three new board members – Taima Campbell, Clare Perry and Dr Peter Watson.

Kelly provided an update from the August board hui. The board want to drive the consumer and whānau work forward with the focus on the code of expectations. The board want to be more engaged in this work and have the code more visible.

The board also wants to strengthen understanding of disability. There was a request for the disability link also put in hui chat https://www.whaikaha.govt.nz/about-us/our-work/new-zealand-disability-strategy-refresh.

The Commission has recently supported three separate disability events.

Oliver asked what socialising the code with health services looked like. Kelly asked for any ideas on how we best do this. We will have future agenda items to discuss ideas on further socialisation of the code. More tangible examples of how best to do this.

Amanda mentioned that the United Nations recognise that deaf, deaf/blind, and intellectually disabled as three most marginalised and asked the Commission to make a special effort to reach out to these groups around the code.

Kelly outlined the consumer engagement function review that will be the focus of discussions tomorrow with the Impact and Engagement team.

Kelly also covered off the rewrite to the primary care guide resource, which is now on-line. https://www.hqsc.govt.nz/resources/resource-library/progressing-consumer-engagement-in-primary-care-te-whakakoke-i-te-whai-wahi-a-te-kiritaki-ki-te-tiaki-hauora-tuatahi/

The group appreciated the direct feedback from the board Kelly provided and it's important and valuable, now that Mary has left, that the loop back to this group continues. Directors update in future to include as a standard item, the update on last board hui.

Kelly also advised his last day at the commission is this Friday 22 August.

The Māori health and consumer Q4 report is attached as Appendix 1.

5. Consumer engagement in the health sector

Oliver Taylor presented.

There are big expectations on the four regional consumer councils to represent everything, however they are not resourced for this, and they don't have the reach or connection down to local level. They are there to provide strategic advice to regional health services.

The four groups are at varying phases of establishment, – i.e., formulating Terms of Reference, working and engaging with systems; getting internal "buy-in" and external feedback, escalation pathways, and initiating projects. Also, how they can work in primary care, and the funding for consumer work.

Oliver is the co-chair of Central Regional Consumer Council which is working on a strategy to address how best consumer engagement can be done. Questions were posed to the group:

What does enacting the code of expectations look like?

What can we learn from regional consumer councils and how can we support them?

What consumer engagement principles and potential focus areas are important for consumer councils to consider?

There was general discussion around these questions and how best the consumer councils can operate and deliver by, with and for consumers – noting that these issues were again raised in several Environmental Scan reports for this meeting. Also mentioned was work needed to engage with IMPBs.

6. Member reports – matters arising from environmental scans

Member reports were taken as read. The summary of reports is at Appendix 2.

There was a general discussion about the content of the reports and the important things to highlight, that can go in the scans paper to the board.

Oliver spoke of the success as a consumer of being on the project steering group for the front of whare Wellington Hospital Emergency Department refurbishment, and that this is great example of consumer engagement at grass roots.

Amanda acknowledged the financial support Te Tāhū Hauora provided for the recent deaf/blind conference.

Vivien raised as per her report, that the code should be translated into at least three other languages – Spanish, Arabic and Korean, due to the growing populations of these groups.

Mark noted that since his report, the chest trauma report has been launched with recognition of input by HQSC. Mark was a consumer on the working group.

The group asked for feedback on their scans, to advise what has been done with the information, and if nothing done, why not? There is a frustration that suggestions are not acted on or responded to.

Stan gave some further background on himself and had several comments regarding others scans including some initial concerns he has in his communities. He outlined his hopes to be able to bring to this group at future hui.

7. Other business

Dez reminded members to register for the Ō Mātou Reo forum on 30 October.

Jennie was grateful to receive the Ngā Reo Māhuri environmental scans.

8. Karakia and close

Kelly thanks the group and closed with karakia

Next hui: 31 October joint hui with Ngā reo Māhuri | Young Voices group – (following the 30 October Ō Mātou Reo forum).

Te Tāhū Hauora will host a dinner on 30 October at the Atura Hotel.

Actions list

Date	Action	Responsibility
20 Aug 2025	Future agenda item: Discuss ideas and strategies on socialising and promoting the code to Health services etc.	DJ/Dez

Appendix 1

Māori health and consumer team Q4 report

The following are highlights for Q4 (April – June) of the 2024-25 financial year.

On 7 April a mihi whakatau was held to welcome Penita Davies to Te Tāhū Hauora and Te Pūkāea Matatika | Māori Health and Consumer team as Māori Health and Consumer Advisor.

The all-staff day on 2 April, and team planning day 3 April were held.

Te Tāhū Hauora moved Wellington offices to 133 Molesworth Street within the Ministry of Health Building 28 April.

Consumer advisor acknowledgements

Mary Schnackenberg concluded her terms on Kōtuinga Kiritaki | Consumer Network and Te Kāhui Mahi Ngātahi | Consumer Advisory Group. Mary made a significant contribution driving forward action in response to the needs of disabled people.

Delphina Soti resigned from Te Kāhui Mahi Ngātahi | Consumer Advisory Group. Delphina remains a strong advocate for the needs of youth and Pacific people.

Claire Turner was welcomed to Kōtuinga Kiritaki | Consumer Network with mihi whakatau at the 15 May hui. Claire is co-chair of Moving Forward, the Southern Consumer Council for Mental Health, Addictions and Intellectual Disability Services.

Consumer health forum Aotearoa



Ō Matou Reo: Our Voices 30 October 2025

Ko Ngā Reo. Ko Ngā Rongoā. Ko Ngā Mokopuna. Our Voices. Our Healing. Our Future. Tākina Conference and Event Centre Wellington

Development and planning for this exciting national event is well underway, integrating feedback received from previous events and working with consumers to ensure the heart of the event is consumer and whānau centric.

Save the date promotion and pre-registration have proven successful, over 200 pre-registrations received. The official registration form will go live in August with confirmation of the program.

The programme is designed to highlight and celebrate positive consumer and whānau engagement practices in the health sector with a focus on primary and community healthcare.

Visit our website events page to keep updated: https://www.hqsc.govt.nz/events/o-matou-reo-our-voices-2025-event/

Consumer forum opportunities

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

- Te Tāhū Hauora
 - o Te Kāhui Mahi Ngātahi | Consumer Advisory Group three vacancies
 - o Kōtuinga Kiritaki | Consumer Network two vacancies
 - O Ngā Reo Māhuri | Young Voices Group one vacancy
- Health New Zealand
 - o Pacific Member for the Northern Regional Consumer Council
 - Cardiac Investigation Unit design guidance review
 - Mental Health Non-Acute Inpatient Unit design guidance review
 - o Mental Health Older Peoples Acute Inpatient Unit design guidance review
 - o Transit Lounge design guidance review
- New Zealand Psychologists Board Role of Assistant/Associate Psychology role survey
- Collaborative Aotearoa Telehealth Patient Voice survey
- Ministry of Health Putting the patient first: Modernising health workforce regulation public consultation

Update and News

The April newsletter was emailed to the CHFA to the members on Friday 4 April 2025.. February issue included:

- Message from the Director's desk
- Te Pūkāea Matatika the meaning behind our name
- Ngā Reo Māhuri | Young Voices Advisory Group welcomes new member
- Ō Matou Reo: Our Voices 2025 Save the date
- Consumer advisory profile Mary Schnackenberg
- Ministry of Health Have your say on health workforce regulation
- Improving the consumer health forum Aotearoa survey
- Consumer opportunities

Read the April update here <u>tethhauorahealthqualitysafetycommission.cmail20.com/t/y-e-chhguk-ihhkuljkdl-s/</u>

The June newsletter was emailed to the CHFA to the members on Friday 13 June 2025. Read the February update here. February issue included:

- Message from the Director's desk
- Consumer and whānau engagement quality and safety marker (QSM)
- Te Tāhū Hauora support for disability events in June
- Clinical governance framework
- New Zealand Psychologists Board Assistant/Associate Psychologist public consultation
- Bachelor of HealthSciences Society connected by a drive to improve health outcomes
- Improving the consumer health forum Aotearoa survey
- Consumer opportunities

Read the June update here <u>tethhauorahealthqualitysafetycommission.cmail20.com/t/y-e-qxltld-ihhkuljkdl-it/</u>

Forum membership

The total number of individuals who have signed up to the consumer health forum Aotearoa forum members is 981 (increase of 16) 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 1 through end quarter 4 2024-2025.

Ethnicity	Quarter 1 2024-25	Quarter 2 2024-25	Quarter 3 2024-25	Quarter 4 2024-25
Māori	Quarter 1 total: 190 (20.2%)	Quarter 2 total: 195 (20.3%)	Quarter 3 total: 195 (20.2%)	Quarter 4 total: 197 (20.1%)
Pacific	Quarter 1 total: 91 (9.6%)	Quarter 2 total: 93 (9.7%)	Quarter 3 total: 94 (9.7%)	Quarter 4 total: 96 (9.8%)
Asian	Quarter 1 total: 53 (5.6%)	Quarter 2 total: 54 (5.6%)	Quarter 3 total: 54 (5.6%)	Quarter 4 total: 55 (5.6%)
Pākehā/Caucasian	Quarter 1 total: 509 (54%)	Quarter 2 total: 519 (54.1%)	Quarter 3 total: 522 (54.3%)	Quarter 4 total: 532 (54.2%)
Middle Eastern/ Latin American/ African	Quarter 1 total: 19 (2.0%)	Quarter 2 total: 19 (2.0%)	Quarter 3 total: 20 (2.0%)	Quarter 4 total: 21 (2.1%)
Other ethnicity or ethnicity not specified	Quarter 1 total: 80 (8.5%)	Quarter 2 total: 80 (8.3%)	Quarter 3 total: 80 (8.3%)	Quarter 4 total: 80 (8.2%)
Total	Quarter 1 total: 942	Quarter 2 total: 960	Quarter 3 total: 965	Quarter 4 total: 981

Engagements

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

- Mana Mokopuna Children & Young People's Commission
- Regional Consumer Councils Te Ikaroa Central, Northern, Te Manawa Taki, Te Waipounamu
- Health New Zealand
- Pharmac
- New Zealand Blood
- Health & Disability Commission
- Ministry of Health
- Whaikaha
- Evolution Helthcare
- Carterton Medical Centre
- New Zealand Psychologists Board
- Bachelor of Health Science Society Otago University
- Digital Health Equity Network
- Tonic Media
- Waitaha Youth Advisory Group
- Consumer Health Forum Australia

- DeafBlind Association
- Te Omanga Hospice
- Ministry of Youth Development
- ILead
- Pinnacle Health
- Stats NZ (Māori Data Governance)
- Internal Affairs (Māori Data Governance)
- Whānau Ora (Māori Data Governance)
- Hinz (Māori Data Governance)
- GPNZ
- Inzights (Māori Data Governance)
- Ministry of Housing and Urban Development (Māori Data Governance)
- Access Matters Aotearoa

Responding to the code of expectations review

A framework to implement the learnings from the code review is in development. Key actions include:

- Accessible plain language versions of the Code
- Promotion of the Code, the implementation guide and the consumer engagement QSM
- Partnership with the health sector to develop and embed educational resources
- Support and demonstration of meaningful consumer engagement
- Strengthened accountability, monitoring and reporting.

Te Pūkāea Matatika | Māori Health and Consumer 2025-26 programme plan intergrates appropriate activities to ensure these are delivered.

Partnership in Care: consumer, whānau and community engagement in primary and community health care

Code of expectation implementation guidance for primary and community healthcare providers was released on 27 June. Designed to provide accessible information featuring the SURE framework domains - experience, engagement and responsiveness and linking to practical examples.

You can read the guide here https://www.hqsc.govt.nz/assets/Uploads/Partnership-in-Care.pdf

Quality Safety Marker for consumer engagement (QSM)

The QSM dashboard was updated on Friday 30 May. Te Pūkāea Matatika will offer support to health entities to develop their Septemeber 2025 submissions.

There has been interest in voluntary adoption of the code of expectation and reporting to the QSM across the health sector. Te Pūkāea Matatika is committed to support health agencies and service providers to enact the code of expectations in their consumer, whānau and community engagement for the development, design, delivery and evaluation of health services.

Communications report

Te aratohu tikanga | Code of expectations implementation guide

Summary

Data for the April – June 2025 period shows traffic continues to steady to the Code of expectations pages. In some areas: co-design, equity through partnership and accessibility, it has grown slightly.

The data reflects a fairly typical "back to the work" period following the quieter summer months.

Unlike the previous quarter, this one has not involved sustained promotion of the Code or consumer pages. We shared some posts about the \bar{O} Mātou Reo: Our Voices 2025 event which will have driven some traffic, but these posts were few. There is a positive here that traffic to the Code pages remains steady even without promotion.

During this period a Code of expectations promotion plan has been drafted with the input and support of Te Pūkāea Matatika. This plan is structured around the promotion of three key areas:

- The new Primary care guide for consumer engagement
- Case studies illustrating how the Code has been used in practice
- Ō Mātou Reo: Our Voices 2025 event.

The July – October period will see a lot more promotion of the Code and our consumer resources which we anticipate will bring more people to the Code pages.

2024/25: 1 January - 31 March

Websites and video resources	April-June	January – March 2025	September 2024	1 October 2023-11 April 2024
Engaging consumers and whānau Te mahi tahi me ngā kiritaki me ngā whānau <u>here</u>	Views: 251 Users:143		 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: 847 Users: 564	Views: 884 Users: 586	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: 536 Users: 363	Views: 647 Users: 452	Views: 1,334 Users: 873	Views: 1,596 Users: 1,067
Code of expectations implementation guide Te aratohu tikanga (new landing page here)	Views: 176 Users: 109		 Views: 476 Users: 293	Views: 700 Users: 391

		Views: 261 Users: 193			Views: 442
Co-designing with consumers, whānau and communities Hoahoa tahi me ngā kiritaki, ngā whānau me ngā hapori here	Users: 346	Users: 193	Users: 149	users: 422	Users: 309
Video: Co-design explained in 30	Views: 42	Views: 23	Views: 21	Views: 69	Views: 49
<u>seconds</u>	Users: 34	Users: 22	Users: 18	Users: 65	Users: 36
Video: Co-design: making it business as	Views: 23	Views: 22	Views: 7	Views: 43	Views: 31
<u>usual</u>	Users: 22	Users: 18	Users: 6	Users: 39	Users: 25
Video animation: The co-design	Views: 66	Views: 56	Views: 27	Views: 105	Views: 63
<u>process</u>	Users: 56	Users: 39	Users: 20	Users: 86	Users: 50
	Views: 281	Views: 199	Views: 163	Views: 541	Views: 364
	Users: 191	Users: 132	Users: 125	Users: 369	Users: 265
Using lived experience to improve health services Te whakamahi wheako mātau hei whakapai ake i ngā ratonga hauora here					
,	Views: 16	Views: 14	Views: 12	Views: 34	Views: 26
Cummings <u>here</u>	Users: 16	Users: 14	Users: 11	Users: 33	Users: 22
Video: Consumers share how their	Views: 16	Views: 11	Views: 7	Views: 46	Views: 23
lived experience contributed to health improvements <u>here</u>	Users: 11	Users: 11	Users: 6	Users: 39	Users: 18
	Views: 287	Views: 165	Views: 135	Views: 449	Views: 235
	Users: 219	Users: 126	Users: 100	Users: 322	Users: 153
Improving equity through partnership and collaboration Te whakapai ake i te mana taurite mā te mahi tahi here					
Video: Te Whatu Ora Taranaki consumer council members outline the	Views: 5	Views: 7	Views: 4	Views: 15	Views: 10
importance of consumer engagement (no YouTube data available links to external <u>Facebook page for Bryan</u> <u>Vickery Media Taranaki</u> clicks avail on	Users: 5 Facebook		Facebook total	Users: 14 Facebook total views: 953	Users: 8
request). Note: it is not possible to see the	966	961			
number of Facebook views by quarter.					

2025-08-20 Consumer Network minutes

Video: Consumer voice: What does	Views: 25	Views: 19	Views: 33	Views: 69	Views: 88
equity mean to you and your community?	Users: 22	Users: 18	Users: 32	Users: 64	Users: 63
	Views: 74	Views: 18	Views: 52	Views: 212	Views: 160
	Users: 52	Users: 17	Users: 43	Users: 115	Users: 88
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 <u>here</u>					
Video: Enhancing accessibility: how to	Views: 7	Views: 9	Views: 4	Views: 12	Views: 14
<u>begin</u>	Users: 7	Users: 8	Users: 4	Users: 11	Users: 11
Video: Practical accessibility tips for	Views: 6	Views: 8	Views: 7	Views: 12	Views: 11
producing consumer resources	Users: 5	Users: 7	Users: 5	Users: 10	Users: 8
Video: What is the code of	Views: 3	Views: 3	Views: 3	Views: 12	Views: 11
expectations and are we achieving what's required?	Users: 3	Users: 3	Active users: 3	Users: 11	Users: 10

Aotearoa Patient Safety Day content

Video: Elevate the voice of consumers and whānau (YouTube)	YouTube: Has had 782 views in
https://www.youtube.com/watch?v=AoF47AuZZs4	total 36 views since Dec 31).

Appendix 2

Summary of Kötuinga Kiritaki Consumer Network reports – 20 August 2025

Jennie Harré Hindmarsh (Tairawhiti)

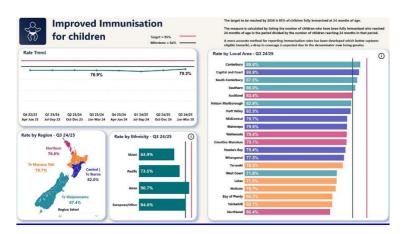
Environmental scan

Community support has continued for local Tairāwhiti health service workers' protest strikes about escalations in staffing shortages and long wait-times for health services, the ongoing "postcode lottery" for access to health services and lack of progress in creating a single integrated health-IT system, all exacerbated by the significant decrease in average government health spend-per-person since the 2024 Budget (Peter Huskinson, *Opinion* in *NZ Doctor Rata Aotearoa*, 27 June 2024) as noted in previous environmental scans.

*For example, see reports about Gisborne Hospital senior doctors' second strike in 2025, on 28 May https://www.rnz.co.nz/news/national/562347/senior-gisborne-hospital-doctors-on-24-hour-strike-say-hospital-on-the-brink-of-collapse; and about the nurses' national strike on 30 July https://www.nzherald.co.nz/gisborne-herald/news/over-100-nurses-and-supporters-rally-outside-gisborne-hospital-for-nationwide-strike/

Resourced and meaningful 'consumer engagement' also has gone backwards in Tairāwhiti, as confirmed by Te Whatu Ora Health NZ's most recent QSM report (Oct24-Mar25) for the Te Manawa Taki Region (comprising five districts of Waikato, Bay of Plenty, Lakes, Taranaki and Tairawhiti): "As highlighted in the previous report, there is disparity across the Region in terms of dedicated resource for consumer engagement... Tairawhiti has limited resource for Consumer Engagement and sits within other roles...." Consumer and whānau engagement quality and safety marker

Ongoing low immunisation rates are "another indicator of our health system not being in good health" (Dr Oz Mansoor, Medical Officer of Health blog on 3 Aug 2025). The latest data for those who turned two years during Jan-Mar 2025, shows the Te Manawa Taki region has the lowest immunisation rate in the country (70.1%), and the Tairāwhiti local area's rate of 68.1% is 2nd-lowest in the country.



This is even more concerning given that the local Tairāwhiti immunisation rate has barely improved since its rapid decline during the covid pandemic from having almost achieved the 95% immunisation target pre-pandemic, despite intensively regular whanau-focussed immunisation events being provided in communities across the region. https://www.nzherald.co.nz/gisborne-herald/news/tairawhitis-struggle-with-low-immunisation-rates-ongoing-but-situation-improving/JQIAY75IUJHHHCMTNFXGJE3K5U/

A sharp increase in vaping amongst young people has been noted in Tairāwhiti, which has the highest smoking and now vaping rates in the country. Community concern is growing in the wake of the National-led Coalition Government's recent actions, including a refusal to make vaping prescription-only despite the substantial evidence of damage inflicted by vaping and tobacco products. In response, three community organisations recently took action to attempt to address this issue. Trust Tairawhiti granted \$15,000 to Te Ha Ora (Asthma and Respiratory Foundation) for 15 school vape education workshops and a Train-the-Trainer programme to equip local educators to deliver vaping education to rangatahi https://trusttairawhiti.nz/news/may-distributions-2 And Gisborne District Council revised its 'smoke-free' policy to include electronic cigarettes and expanded smoke-and-vape-free areas in the city centre as an attempt to curb the "epidemic" of young people taking up the habit. https://www.nzherald.co.nz/gisborne-herald/news/gisborne-targets-youth-vaping-with-cbd-smoke-free-policy/DKHKVZV7SZBFLICGFGBKFDOCU4/

Input / involvement in Te Tāhū Hauora meetings/groups.

19 May, emailed information to DJ Adams & Penita Davies about contacts in three Tairāwhiti organisations who may be available to assist Te Tāhū Hauora to promote health consumer hui in the rohe, including opportunities for audio/video interviews to promote hui via Radio Ngāti Porou, Turanga FM and Rangai Studios and their Facebook pages, and these organisations' live-streaming services to increase access to hui discussions for more people throughout the large rural district.

8 August, reviewed Draft Outline of the System Safety Strategy in preparation to provide feedback via the online survey this month which Kōtuinga Kiritaki Consumer Network members recently received from Karen Gibson (Te Tāhū Hauora National Quality Forum System Safety).

Activity (since last report)

Made written submissions to another two Parliamentary Select Committee hearings, this time in response to the National-led Coalition Government's proposed Regulatory Standards Bill and the Overseas Investment Amendments Bill. Evidence-based analyses have shown that, if enacted, these Bills will have wide-ranging negative impacts - including on public health.

Genomics Aotearoa Māori Variome He Kākano Governance Roopu preparation for Zoom meeting in August 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 and further research to improve equitable precision of health care for Māori; and plans for a national launch of the resource. https://www.npo.org.nz/research-article/he-kakano---aotearoa-variome https://www.genomics-aotearoa.org.nz/our-work/health-projects/aotearoa-nz-genomic-variome

Continue 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 co-leader of Wainui Beach Catchment and Coast Care, member of Mana Taiao Tairāwhiti, GDC Waimata-Pakarae Catchment Plan advisory group member, and GDC's Climate Change Adaptation planning process with the Wainui-Okitu community.

Services

In the currently underfunded and demoralised public health system, whanau and community members continue to express gratitude to front-line health workers who soldier-on when so-thinly-stretched to provide high quality care - when finally accessed, often amidst escalating pain and risks of complications whilst waiting 'their turn'.

Considerations for Te Tāhū Hauora

I suggest Te Tāhū Hauora

- *Proactively work with* the Te Whatu Ora Health NZ's regional leaders to prioritise resources and support to re/establish nationally consistent consumer engagement systems, including in primary care and public health. A key 'improvement indicator' would be a resourced system for effective consumer engagement in Te Tairāwhiti.
- 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 reinstatement of 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 codevelop quality & safety guidelines and related education resources for more informed use of safe genetic testing services and genomic information by whanau/families, individuals, and health providers to improve prevention, decrease risk, and management of conditions.

Oliver Taylor (Wellington)

Environmental scan

With great sadness, Health New Zealand have decided to disestablish their Consumer Engagement and Whānau Voice team, with all roles expected to end in September. While this is a great disappointment to many consumers and staff, the Central Region is looking at options for replacement roles for critical staff who enable our strategic consumer engagement work and support for our Regional Consumer Council. We await what impacts this will cause the RCC and overall consumer engagement work.

I have been engaging with various consumer / community groups, including Arthritis NZ and FERNZ (a disability network). Our conversations have primarily focused on discussing how they will work with regional consumer councils, specifically understanding their priorities and high-level issues for consumer councils to promote. I will then work with them to get their issues on the agenda and hopefully improve their communities' care.

Input / involvement in Te Tāhū Hauora meetings/groups.

21 May - programme planning session Ō Mātou Reo: Zechariah and I were engaged in early conversations regarding the planning for our upcoming Consumer Network national hui. We promoted local health services to be present and discuss the way they engage with consumers and focus on upskilling the sector to engage consumers (which gives a practical element to the event). A priority I shared was ensuring the session will be focused on connecting consumers to the health system, and get consumers engaged, to maximise the day's value. I look forward to an engaging forum in October!

Activity (since last report)

Meetings with Ikaroa Central Regional Consumer Council: Each month I have been co-chairing our hui to support strategic consumer engagement with the health system. A key point of success has been getting our terms of reference approved, which will ensure that consumers are embedded in the development and leadership of our key structures. Other mechanisms, such as sharing

internal awareness and feedback with the council, are still being developed, and there is a risk with the restructure that consumer engagement staff will no longer exist, and our work will not be promoted.

Services

Members in Central Region have shared various concerns with their care and within their communities, one being eligibility for transport funding for receiving care, specifically reimbursement for renal treatment. This is a critical service that enables renal patients, some who require dialysis 3 times per week for up to 6 hours at a time, financial support for part of their transport costs. If consumers cannot access treatment, they will die. This issue is being escalated, and we await a Health NZ response.

Positive stories and exemplars

I am happy to share that, following my Private Secretary secondment ending with Hon Shane Jones, I have started a new role as Advisor, Policy – Regulatory Management System, and Regulatory Impact Analysis teams, at the Ministry for Regulation! In this role, I will be supporting the wider public service to understand and engage with New Zealand's Regulatory Impact Analysis system, ensuring that the best advice is shared with Cabinet ministers, and that agencies are meeting their requirements to do robust policy analysis for regulatory change proposals. I will also be working on the Regulatory Standards Bill, primarily the implementation of the Act and establishing the Regulatory Standards Board, who will be advising on future options for regulatory reviews.

Considerations for Te Tāhū Hauora

- Strongly advise Health New Zealand to enable an alternative consumer engagement staff structure that will maintain consumer engagement, in line with their Code of Expectations legislative requirements.
- 2. Focus on sector development for consumer engagement in all areas that are not well developed.

Mark Rogers (Timaru)

Environmental Scan

We are in an environment where there is a push for more elective surgery to be outsourced to private hospitals. I believe this will only be achievable if there is sufficient capacity, especially clinical staffing. Of concern though is the increased cost to Health NZ and ultimately the taxpayer. There is adequate media coverage of this subject.

An area that is constantly ignored is gaining employment for those with long term health issues. Being happy to pay weekly benefits opposed to helping people into work who want to work just doesn't make sense.

Activity

National Clinical Governance Framework Reference Group. Participated in Teams meetings held weekly on Tuesdays in May, June, July & August. In addition, both consumer representatives and consumer engagement staff at HNZ have met twice. Consumer engagement, contributions, respect etc. on this group has been excellent and at a high level.

Included was a session on consumers and whānau as active partners. Our consumer participation and contributions were welcomed and there is a formal mention of the Consumer Representatives inclusion within the acknowledgements.

The Framework was approved and adopted by ELT at Health NZ/Te Whatu Ora on 22 July.

Regional Clinical Governance Workshop. I attended this as an invited Consumer Representative to establish the Terms of Reference for the four regions governance groups. These groups will be realigned with the DCE's line of accountability.

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

Considerations for Te Tahu Hauora

We need to concentrate our efforts on need. There are many NZ's who also struggle to receive the health services they require.

It's time to promote the need for consumers to invest in their own selves by taking out health insurance.

Engage with Health NZ to ensure there is a better connection between Te Tahu Hauora Consumers, Regional Consumer Councils and the various local hospital-based consumer representatives. Make sure duplication of work is minimised.

Toni Pritchard (Te Kaha)

Environmental scan

Te Whānau a Apanui spans 110 kms and is an hour and half drive from one end to the other – then another hour and a half to get to the closest town. This is a big reason why we 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 with (as highlighted in previous reports) services coming to our PC provider based here.

Our Medical and Complex care Kaiārahi has continued this mahi supporting whānau to access and understand what they are going through and supporting them in planning for their own Oranga and Hauora. Even with all her mahi this is an underserviced role, with more referrals coming in than she can manage effectively.

Poverty is a huge issue for our area with the average income being \$16k a year. Poverty and poor housing diminish the mauri of whānau and undermine overall hauora. When homes are cold, damp, overcrowded or unsafe, the physical, mental, and spiritual wellbeing of individuals and whānau are all affected. These conditions disrupt whanaungatanga, limit access to kai ora and quality healthcare, and can lead to intergenerational harm. Safe, warm, and secure housing is a foundation for oranga, where whānau can thrive, feel connected, and live with mana and dignity.

We are STILL in the midst of a Meth Epidemic. I am repeating myself here, but it is still the same. We have noticed a dramatic rise in family harm; drug induced psychosis and a call for awhi with kai and essential costs due to already small income being spent on this drug.

This speaks to the fact that mainstream services are not equipped to deal with his 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 3rd world Housing problem we have here. It is a holistic problem, that needs to be adressed from a Holistic lense – Te Whare Tapa Wha being a successful Māori model of health here that does work, but doesn't fit into most mainstream funding

requirements. It's exhausting trying to implement this being massively under funded and under resourced.

I have decided to undertake a tohu to be an Addictions Counseller/Clinican. This will be delivered by Moana House and will take approx 2 years. Upon completion, I will apply for registration with DAPAANZ. I am also working very closely with a Tohunga in Te Taio, Mau Taiaha, and a keeper of Iwi Pū Rākau. I believe that a strong combined Te Ao Māori and Mainstream approach will make an positive impact on our area.

We now have a permanent Police Officer in our lwi (prior to this a Police Officer would have to travel 2 hours to get to which will help with some of the above issues. He is very community orientated, and works alongside our organisation really well. Our whānau in our lwi have responded really well to him also.

Input / involvement in Te Tāhū Hauora meetings/groups.

System Safety Strategy Survey completed

Activity (since last report)

- 1. We had our quarterly group of nursing, midwifery and doctor students come into our lwi, as a part of the Rural Health Interprofessional Programme. This has been a very successful programme with one of our permanent tangata tiriti doctors (who our people absolutely love) being one of the original students to be a part of this programme. This gives students valuable insights into rural, predominately Māori, communities what works and what doesn't and values that are important in terms of engagement and trust within our Māori Rohe.
- 2. Our organisation is still in collaboration with Te Pou Oranga Whaiora, the first indigenous methamphetamine treatment initiative of its kind. We are in the process of co-designing a Te Ao Māori approach to this important Kaupapa. It has been a huge mahi to complete but needs the time to maintain the integrity of the Kaupapa as well as the whānau we are serving. It's also extremely important to have the wrap around services in place to 'catch' our whānau in need. Not just our whānau in addiction, but their wider whānau to help them to understand and support.
- 3. Our Hospice role has been well received in our lwi with vital care and support given to our whānau at end of life, and their wider whānau to support them in this time of grief. Our tangata tiriti wāhine is so loved by our people and is perfect for this important mahi.
- 4. We hosted a successful Matariki Luncheon and Fashion Show to respond to the needs of our Pākeke (elderly) in isolation. Wintertime is lonely for our Pakeke who will stay home so they don't get sick, however this contributes to their loneliness and decline in mental health. This day was well received and enabled us to connect with our Pakeke in a meaningful and enjoyable way. Prior to this day they spent one day a week sewing kakahu with the Matariki theme to model.

Services

Our PC provider continues to do an amazing job with our lwi, with the main clinic based in Te Kaha, and taking smaller clinics to both ends of the Rohe to improve access for our whānau. They also engage with and provide space for much needed services like our counsellors, physios, and mobile ear and podiatry services.

Positive stories and exemplars

Background

The Toitū Housing Programme is a groundbreaking pilot that enables whānau to secure mortgages on Māori land — something that was previously near impossible. For the past four years, it has helped

countless whānau across the East Coast, from Ōpōtiki onwards, to achieve stability, improve health outcomes, and maintain employment.

Before joining this programme, my whānau faced significant housing and wellbeing challenges. Despite being from a hardworking family (my mātua were qualified teachers), we could never afford to build on our whenua due to the high costs of infrastructure and construction.

I was raising three children alone after leaving their father due to meth addiction and whānau violence. Covid 19 made things worse when I lost my main source of income and could no longer pay rent. We were forced to move into two small cabins on my parents' lawn, in a home my dad built himself with no insulation or adequate infrastructure.

The environment was tense due to intergenerational trauma and conflict, which deeply affected my children. One daughter developed severe mental health challenges and fell into addiction. My youngest became anxious, withdrawn, and was badly bullied at kura. The nearest mental health services were a four-hour round trip away, and after months of effort, there was little improvement. My eldest eventually became homeless, living on the streets for over a year.

The turning point

After three years of instability, I was accepted into the Toitū Housing Programme. For the first time, I could buy a home on my own whenua. We have now been here for one year.

The Impact

- **Stability & Wellbeing**: Our home is warm, dry, and safe a place where we can make our own decisions and live in peace.
- Health & Recovery: My eldest is now home, free from drugs and alcohol, engaged in counselling, and actively seeking mahi. Our whānau are healthier and no longer suffering from respiratory issues.
- **Education & Achievement**: My son is thriving as Head Boy at Wharekura, participating in regional kapa haka and speech competitions. My youngest is achieving at level in all her subjects and doing well academically.
- **Confidence & Growth**: My youngest plays netball, participates in the Mana Ake programme, and is happier than ever.
- **Whānau Healing**: Living on the same whenua just across the driveway from my parents has allowed my mum and I to heal our relationship in significant ways.

Why this matters

This programme did more than provide shelter - it restored holistic health, dignity, hope, and opportunity. It has broken cycles of instability in my whānau and empowered us to thrive. Without it, I believe we would still be trapped in hardship. There are many more stories of profound impact just like mine.

Call to Action

The Toitū Housing Programme works. It transforms lives, strengthens whānau, and creates long-term change that contributed to whānau oranga. This pilot must be expanded and funded so more whānau can access the security, stability, and future they deserve on their own whenua.

Eden Li (Tāmaki Makaurau)

Environmental scan

At the present, what communities are talking about concentrate on several areas. The biggest is pressure on primary health care access, due to difficulty in seeing GPs. What should also be highlighted is how this is now impacting on people with chronic conditions and the management of those conditions.

Individuals with diabetes, heart disease, and respiratory illnesses are noting difficulties accessing timely follow-up appointments, diagnostic testing, and health education support.

Additionally, the cost-of-living impacts in other areas, such as staples, fuel prices and living costs combined with the rising costs of seeing a healthcare provider means many community members are opting to delay care due to cost concerns.

Input / involvement in Te Tāhū Hauora meetings/groups.

Involvement with Te Tāhū Hauora meetings included attendance of the Consumer Network Hui as well as pushing through Te Tāhū Hauora opportunities given through the Consumer Health Forum.

Activity (since last report)

Clinical Quality Safety Committee - Te Whatu Ora (Te Toka Tumai)

• Continued focus on the regional service and efficiency improvements which would benefit consumers. Of note the combination of engagement with consumer groups alongside a culture and organisational framework which promotes the patient experience and patient rights.

Ministry of Health - National Medicines Steering Group

• Continued focus on refining engagement processes and procedures with focus groups for medication, with emphasis on Māori and priority groups to improve equity status.

Youth Advisory Panel - YMCA North

• Concentration on health-adjacent processes and initiatives to improve youth exercise and health.

Services

It is great that consumer services are being offered within the community in primary and secondary care, however, there needs to be greater visibility of such services. For example, Korero Mai is an extremely useful initiative for patients undergoing treatment, but often is not advertised in a manner which makes it a visible and viable option for use.

Health service providers should be encouraged to increase visibility to encourage consumer use and therefore create a better consumer experience.

Positive stories and exemplars

Community-led vaccination drives:

• Several iwi and Pacific health providers have run whānau-centred immunisation events that combine kai, entertainment, and health checks, and this has allowed for a strong uptake of flu and childhood vaccinations, especially in areas with previously low coverage.

Hospital volunteer networks:

• Feedback from families highlights the positive impact of hospital volunteers in the wider Auckland region, as they are a welcome source of comfort, guidance, and practical assistance during usually stressful stays and visits at hospital.

Considerations for Te Tāhū Hauora

Continue to push for consumer-oriented services to be more prominently visible crossorganisations and services around the country. This ensures the resources allocated for these services are (1) used and not wasted, and (2) to improve and bolster a more seamless consumer experience.

Vivien Verheijen (Auckland)

Environmental scan

Input / involvement in Te Tāhū Hauora meetings/groups.

Attended the Kōtuinga Kiritaki Consumer Network Hui on 15 May 2025

Recommendations for translation of the code of expectations

Based on my community intelligence gathering, I have made a written suggestion to HASQ to enhance its commitment to addressing equity issues within ethnic communities and to strengthen its diversity and inclusion approach. I recommend translating the code of expectations into three additional languages representative of ethnic heritage: Korean, Arabic, and Spanish. Here are the reasons for this suggestion:

Significant and Growing Populations

- Arabic, Korean, and Spanish speakers represent growing ethnic communities in Aotearoa New Zealand.
- Census and immigration data show increasing numbers of:
 - **Korean New Zealanders**: the fourth largest ethnic demographic group, especially concentrated in Auckland.
 - *Arabic-speaking communities*, including refugees from the Middle East and North Africa.
 - Latin American migrants and Spanish-speaking individuals. This group encompasses Latin American migrants and other Spanish speakers.

Language Barriers Limit Access and Equity

- Many individuals in these communities encounter significant language and literacy barriers, particularly regarding their healthcare rights and navigating the healthcare system.
- Limited English proficiency is directly linked to lower health literacy and poorer health outcomes. Translating the Code is essential for enhancing equity by enabling access to vital health information for all ethnic groups.

High Health and Social Needs

- High Health and Social Needs Refugees and migrants from Arabic-speaking countries often face complex trauma, chronic conditions, or mental health challenges.
- Korean and Spanish-speaking communities frequently deal with cultural stigma surrounding healthcare access and struggle to comprehend their healthcare entitlements.
- Providing culturally and linguistically appropriate materials is crucial for eliminating inequities in service delivery and engagement.

Supports Culturally Safe and Person-Centred Care

- Aligns with the HQSC's goals of consumer engagement, shared decision-making, and health equity and supports Te Tāhū Hauora's Consumer Voice Framework.
- Translating the Code demonstrates a commitment to respect, inclusivity, and responsiveness to cultural and linguistic diversity.
- Reflects the Pae Ora (Healthy Futures) Act 2022 and the NZ Health Charter's focus on equity and partnership with diverse communities.

Activity (since last report)

To effectively promote the work of HQSC and enhance my relationships with service providers, I have taken the initiative to engage with key stakeholders. These valuable discussions have not only increased my understanding of the quality of health services but also illuminated their impact on consumers. Furthermore, I am actively pursuing collaborative opportunities that will amplify HQSC's initiatives and reinforce the importance of the Code of Expectations. The key meetings include as follows:

• Asian and Ethnic Health Services, Health New Zealand | Te Whatu Ora

It was established to support Health New Zealand – Waitematā to deliver culturally appropriate, accessible, responsive and effective services to our growing Asian migrant and refugee communities.

Northbridge Residential Village

Northbridge is a retirement complex in Northcote, a charitable agency, one of a few in the country operating as a "not for profit" organisation. It provides various supportive accommodations for people over the age of 60, including the care facility.

• Migrant and Refugee Health Research Network

The Migrant and Refugee Research Health Centre is an interdisciplinary community of researchers dedicated to advancing knowledge and practice to enhance the health and wellbeing of migrant and refugee populations living in Aotearoa New Zealand, and globally. At a strategic level, I have promoted partnerships between Public Health Organizations (PHOs) and non-governmental organizations (NGOs) that serve ethnic communities. These partnerships aim to create integrated models of healthcare and social support. By aligning our organisational strengths, resources, and networks, we have enhanced the system's capabilities and achieved sustainable improvements in health outcomes and community well-being for New Zealand's increasing ethnic population.

PHARMAC

2022 Independent Pharmac review

Pharmac has proactively published a summary of its progress on the review's recommendations. This can be found at: Pharmac Review: progress update July 2025. Also, Natalie McMurtry has been appointed as Pharmac's Chief Executive, and she will start this role on Monday 15 September 2025

Reset Programme

Following a series of external reviews and stakeholder workshops, Pharmac is changing how it operates and improving its organisational culture to better meet public and stakeholder expectations. A five-year improvement programme is an organisational priority that will occur in two phases. The 12-month reset began on 1 July to deliver tangible change and establish foundational improvements to support future reform.

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

7 May 2025 PHARMAC Consumer Advisory Committee face to face Hui
An update on feedback (including from consumers) on comprehensive list consultation for medical devices. https://www.pharmac.govt.nz/news-and-resources/consultations-and-decisions/2025-02-devices-comprehensive-list

- June 2025 Consumer Advisory Committee Meeting
- July 2025 Consumer Advisory Committee Meeting
- 21 July 2025: Ministers LOE event

Associate Health Minister with responsibility for Pharmac David Seymour hosted a Minister Hui

PHARM resetting programme launch to transform the organisation into being better outcomes focused. The Minister's event where he spoke to the 2025/2026 **Letter of Expectations**.

Aug 2025 Consumer Advisory Committee Meeting
 Seeking feedback on a proposal to enter into a medical devices listing agreement from 1
 September 2025 with ESL Biosciences (New Zealand) Limited (ESL Biosciences") consultation link

Services Concerns

Asian mental health issue

The Asian population in New Zealand is one of the fastest-growing ethnic groups, making up over 15% of the total population according to 2023 estimates. Despite generally lower reported rates of mental health disorders, Asian communities encounter unique challenges when seeking support and are often underrepresented in mainstream mental health services. Typical issues within these communities include stress, depression, anxiety, and acculturative stress, particularly among migrants, students, and international workers.

The main issues:

• Underreporting and under detection:

Many individuals of Asian descent refrain from seeking mental health assistance due to prevailing stigma, cultural beliefs, or the apprehension of bringing dishonour to their families. It is noteworthy that mental health issues may present as physical symptoms, such as headaches and fatigue, which can lead to misdiagnosis.

High Risk in Youth and Students:

International students and second-generation youth often grapple with identity conflicts, isolation, experiences of racism, and significant academic pressures. Research indicates a concerning rise in self-harm and suicidal ideation among Asian youth, particularly among young women.

• Isolation Among the Elderly:

Older Asian migrants frequently encounter considerable social isolation, language barriers, and a reliance on family members for support. Depression is prevalent within this demographic; however, it remains a largely unspoken concern.

Serious workforce shortage

There is a significant shortage of mental health professionals who are culturally and linguistically qualified. For example, Public Health Organizations (PHOs) and General Practitioner (GP) practices, along with other relevant service providers, struggle with common challenges in recruiting suitable candidates. This recruitment difficulty leads to gaps in service delivery and results in poorer health outcomes and overall quality of care.

Recommendations

- Increase investment in culturally and linguistically appropriate services to better support diverse community needs.
- Train mental health professionals in cultural competency to enhance their ability to engage with clients from varied backgrounds.
- Support grassroots mental health initiatives to empower local organisations in providing culturally relevant services.
- Partner with Asian communities to co-design mental health services and campaigns.
- Collect disaggregated data to inform policies and service designs that accurately reflect community experiences.

PHO issues: Care Plus Services

Some GPs have charged additional fees for Care Plus consultations, even though these services are meant to be subsidized for patients with chronic conditions. The Care Plus funding is provided through Primary Health Organisations (PHOs) to subsidise care for high-needs patients. Practices receive a set amount of funding for each enrolled Care Plus patient and are expected to reduce or waive fees for these patients. Overcharging violates the terms of the funding agreement with Te Whatu Ora and the PHO. Hence, I have outlined key issues as follows:

Financial Burden on Vulnerable Patients

Care Plus patients often have chronic conditions or complex health needs and typically come from low-income backgrounds. Overcharging undermines the purpose of Care Plus, leading to unnecessary financial hardship for these individuals.

• Equity and Access Concerns

Overcharging increases health inequities by creating financial barriers to care for high-needs groups, such as Māori, Pacific peoples, and individuals with disabilities. This practice discourages patients from seeking necessary primary care.

• Legal and Compliance Risks

Practices that overcharge are also a breach of the Health and Disability Code of Rights, particularly Right 10, which grants the right to complain about services or charges. There is a risk of reputational damage and potential loss of PHO contracts.

• Inadequate Oversight or Miscommunication

The issue may arise from a poor understanding of Care Plus charging rules at the practice level, possibly due to a lack of clear communication between PHOs and practices.

• Consumer and Community Trust

Overcharging damages the trust between the community and healthcare providers and may lead to complaints being filed with the Health and Disability Commissioner (HDC) or Te Whatu Ora.

Suggestion Actions:

Audit and Monitoring:

Conduct random or targeted audits of practices' Care Plus billing. Monitor fee schedules submitted by these practices. It is vital to educate the GP practices to be accountable for their duty and care for patient rights and appropriate treatment

• Clear Communication and Guidance:

Provide clear written guidelines regarding Care Plus charges and patient entitlements. Include examples of compliant and non-compliant charging. By large, patients are not aware their eligibility and rights under Care Plus category. It's important to raise awareness among patients about the services covered by Care Plus to prevent any unnecessary charges.

• Enforce Contracts:

When breaches are confirmed, apply contract penalties, require repayments, or consider the suspension of funding. By fostering transparency and accountability could help to rebuild trust in primary care and encourage patients to seek the timely assistance they need. It would also help to rebuild trust in primary care and encourage patients to seek the timely assistance they need.

Aging care sector -Ethnic Aging Challenges

By 2043, Asians are projected to comprise 44% of Auckland's population, highlighting the need for culturally and linguistically appropriate support services for the ageing Asian community. Increasing ethnic diversity among the older population. New Zealand's aging population includes more individuals from Asian, Middle Eastern, Latin American, African, and other ethnic groups. Aged care services have not adequately adapted to this demographic shift.

- Mismatch between services and cultural needs mainstream aged care models often do
 not reflect the values, languages, food preferences, customs, and spiritual needs of
 Māori, Pacific, Asian, and other ethnic elders. Many care homes focus primarily on
 clinical care, such as dementia and disability support, while lacking holistic and culturally
 safe approaches.
- Language barriers and cultural competence limited access to bilingual staff or interpreters can lead to poor communication, misunderstandings about medical care, and isolation of elders.
- Many services lack cultural awareness and competence necessary for effectively engaging with elderly individuals from diverse backgrounds. Aged care staff often lack training in cultural awareness and responsiveness, and there is currently no consistent national standard for cultural competence in aged care services.

One of significant issue is lack of culturally responsive support services for home care:

- Elderly individuals of Asian descent face significant challenges in accessing home care services due to limited English proficiency and a lack of cultural representation in mainstream services. There is a shortage of culturally trained home care workers, and few services have been developed in collaboration with Asian communities.
- Additionally, there is insufficient investment in policies aimed at addressing these issues.
 In conclusion, tailoring services to meet cultural needs is essential for ensuring dignity and quality of care for older Asian adults.

Lack collaboration between research institutes and government health agencies:

Government agencies have acknowledged that the absence of comprehensive, reliable, and disaggregated data on migrant and refugee health significantly hinders the development of robust policies and targeted programs.

At the same time, academic institutions and research organisations have conducted practical case studies, such as chronic diseases, mental health challenges, barriers to accessing primary care, and cultural safety concerns faced by ethnic communities.

Hence, it is essential and also effective to improve and integrate these valuable research outcomes into formal health policy and decision-making processes.

The lack of standardised data collection frameworks and the fragmented nature of existing research limit the potential for evidence-based policy formulation. As a result, despite valuable insights generated at the academic level, these findings often fail to effectively influence or inform national health strategies, program design, and resource allocation.

Positive story

In July, I attended a Comprehensive Primary Care Planning Day and facilitated its Asian staff discussion table. Overall, staff highly recommends a comprehensive working model, the Asian Mental Health Hub is an excellent model showcasing collaborative work across teams and practices, particularly in establishing strong connections with local communities and delivering culturally sensitive services and supports tailored to the needs of Asian communities.

Considerations for Te Tāhū Hauora

- Strengthening engagement and fostering collaboration with ethnic community NGOs and health sector organisations requires proactive and intentional efforts.
- Showcasing HQSC's initiatives and successes with ethnic communities; such as at the Migrant and Refugee Health Research Conference or other relevant platforms, which would be valuable, especially if there is clear evidence of support for improving health outcomes in diverse populations.

Tee Siataga (Ōtautahi)

Environmental scan

There is growing concern across networks about the impact of recent changes to funding community-based services. The loss of contracts previously held by the Whānau Ora Commissioning Agency has led to the closure of several initiatives that worked closely with whānau. This has left many tāngata whaiora without continuity of care and placed emotional strain on staff who had to communicate these changes. The resulting service gap has not yet been addressed, and communities are feeling the effects.

In Te Waipounamu, the region has welcomed Dr Pete Watson into the role of Executive Regional Director.

Hauora Māori Services has now completed its transition into Te Whatu Ora. While national teams remain in place, they are operating with reduced capacity. The Oranga Hinengaro lived experience team has been restructured into regional clinical – mental health and addiction teams. They are currently developing a lived experience strategic plan and policy to support better understanding and utilisation of these roles within Hauora Māori Services.

Input / involvement in Te Tāhū Hauora meetings/groups.

Apologies for missing the last meeting—I was away attending a tangi.

Activity (since last report)

- SPEC Programme Review Hui (July 28–August 2): Led virtual workshops with HSS Lived Experience Working Group evaluating the Safe Practice Effective Communication national programme through lived experience, Māori, neurodiverse and trauma responsive lenses.
- Eating Disorder Carer Network Support: Joined as strategic lead in a voluntary capacity. Supported review of the draft Eating Disorder Draft Strategy and submission. Positive to see lived experience and whānau mentioned, though the strategy is currently more aspirational than directive.
- Te Waipounamu Lived Experience Network Establishment: Leading the creation of a network for Lived Experience Advisors employed within Te Whatu Ora specialist mental health and addiction services to support regional and local HSS specific workstreams and initiatives.
- **Internal Framework Development**: Created visual framework to map coordination and activation protocols between regional and national clinical and lived experience teams
- Te Waipounamu Suicide Prevention/Postvention Wānanga (July): Supported one of four regional wānanga, plus a virtual session, aimed at hearing directly from communities about what is needed to strengthen suicide prevention and postvention

efforts. Led lived experience discussions with bereaved whānau members in the room.

Services

- Loss of Whānau Ora services has created a significant gap in whānau-centred care.
- Loss of cultural roles has created a huge workload burden on those who remain.
- Concerns about lack of follow-up support after acute mental health interventions, especially for rangatahi Māori.
- Inconsistent application of the Code of Expectations across DHBs.
- Clinical language and processes continue to alienate whānau and tāngata whaiora.

Positive stories and exemplars

The Enhancing SPEC Project is a strong example of clinical governance enabling lived experience leadership to guide the evaluation of a significant programme, influencing both the process and its outcomes.

Considerations for Te Tāhū Hauora

Promote and support the Hauora Māori lived experience roles and functions within Te Whatu Ora, particularly as teams continue to transition and adjust. Some of the new structures may not yet be fully familiar with or equipped to support lived experience approaches, so ongoing visibility and advocacy will be important. This aligns with the Code of Expectations, which emphasises the need for inclusive, respectful, and meaningful engagement with lived experience voices across all levels of the health system.

Joanne Neilson (Tairawhiti)

Environmental scan

Te Whatu Ora is stretched almost to breaking point, this of course affects the Patients who are our first concern however, our second concern must be for the staff in the hospital system.

I see daily the work that goes into booking, rescheduling, encouraging, cajoling and at times begging patients to attend their appointments. Apathy must be the biggest killer in this country. Some patients I am aware of have DNA'd (did not attend) their appointments 11 times over 3 clinic specialities. That is 11 appointments missed out on that need to be rebooked, phone calls made, and letters posted. That is 11 other Patients that haven't been seen because someone didn't come to their appointment. And because they are actually sick, we need to keep trying to get them in. The cost to the hospital, to the community and the mental well-being is incalculable.

Personal scan

Renovating takes up most of our free time, but there is an end in sight. I am reflecting on our time in Gisborne it has been worth it for Cia's family and knowing we did all we can to ensure this next phase in their life is going as smoothly as possible.

Amanda Stevens (Nelson) - Deafblind Association NZ Charitable Trust

Environmental scan

Since my last report:

The sweep up following our biennial Conference is now drawing to a close. And the following

items are noted:

- Conference Programme included "Knowing your way around the Health System" thank you DJ for delivering this session.
- 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 was 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

In addition, we had a session on Disaster risk Reduction for deafblind. We had so many people wanting to present in the energy of dialogue and how agencies could learn that we had to turn some down.

I would like to thank the following organisations for their financial contribution in supporting this conference:

Te Tāhū Hauora, Health Quality Safety Commission, Asia Network Inc. and Whaikaha.

Here are the links to the programme and report:

https://deafblindassociation.nz/2025-conference/

https://acrobat.adobe.com/id/urn:aaid:sc:AP:73430176-c620-4d02-84ce-ba390591ea81

With the endorsement of Deafblind Association NZ, I recently completed UNCRPD-SDG's Bridge Training in Nadi, Fiji. Legal Harmonisation was one aspect that highlights the potential inequities between law and the CRPD as ratified by Aotearoa NZ in 2008.

It will be interesting to put access to medical care against the CRPD and any potential conflict pertaining to persons identifying with disability, e.g. deafblind and deaf having to pay more at Primary Health care level for longer appointments to allow for interpreting time and potentially no translators available within appropriate time frames.

Claire Turner (Murihiku | Southland district)

Environmental scan

The cost of living, insecure housing, struggle to survive is seriously impacting mental wellbeing, sense of hope, and connectedness as communities, with examples given of ostracism and some people living in almost complete isolation from human contact. One person described the transformation in the past year, of noticing that people have gone from a sense of quiet desperation to a visible, loud desperation.

There is further feedback that the use of drugs, for example methamphetamine, is across all communities and walks of life, like an 'open secret', and that addiction takes hold more quickly and is more noticeable for people who have less to lose in the first place. Feedback that for people who cannot afford to meet their basic needs, drugs are not the problem, drugs are an attempt to fix the problem, for example to make hunger go away when hungry.

GP shortages continue. There are still no GPs available to register with in Invercargill, people need to pay to go to urgent care (often telehealth doctor, in-person nurse), or present to ED. Stories of people in Invercargill, Bluff and rural surrounds registering with GP in Mataura and travelling 1.5-2hrs round trip for a GP visit.

Feedback from disabled people and communities

'The policy changes in the disability sector, especially when disabled people and carers share a household, are relentless, and they contradict each other. It's gone from exhausting to downright harmful.'

Disabled people are being harmed by funding cuts to disability supports and public services, including restrictions on the flexible use of Individualised Funding (IF), increasing wait times for equipment, and the shortage of accessible homes:

- As a receiver of Individualized Funding (IF), it's the flexibility that needs to be reintroduced and restrictions severely lessened. The flexibility allows me to ease the burden of living through allowing myself healthier and more sensory friendly foods.
- I'm only 27, I want to work, I want to socialise, I want to achieve things. Yes, I'm disabled, but it's the lack of equipment that stops me participating in life. An electric wheelchair would be life changing, but the waitlist for assessment is about three years.
- I do qualify for public housing. I'm A1 priority and have been since I left my last home over a year ago. But there's still nothing... You spend thousands modifying a rental for it to be liveable. Then thousands more to put it all back when the lease ends. It's unsustainable. I need to buy a home. Modify it once. Live my life. That's it.

People with disabilities are feeling gaslit by the amount of justification and paperwork needed to gain access to basic modifications, equipment and supports that were previously a lot more accessible and available. Overall, feedback from disabled people indicates that these changes are negatively impacting wellbeing and present increasing barriers to their 'right to full and effective participation and inclusion in society, respect for inherent dignity, (and) the freedom to make one's own choices'. (Summary of General Principles A and C from the United Nations Convention on the Rights of Persons with Disabilities.)

Input / involvement in Te Tāhū Hauora meetings/groups.

Kōtuinga Kiritaki - Consumer Network

Activity (since last report)

I-Lead

17-18 June; National I-Lead Conference

Dunedin I-Lead monthly meetings (from 9th June 2025)

16 July; Vaka Tautua Pacific Disability Expo & Health Day (stall with I-Lead Dunedin)

I-Lead is a disabled youth movement led by youth, for youth.

An outcome from I-Lead involvement has been to strengthen my networks with disabled people and as a result, four people have chosen to contribute their experiences and recommendations to this report.

Consumer Involvement

Co-Chair – Moving Forward Southern District Consumer Council monthly hui Consumer voice – Dunedin Hospital in the Home (HiTH) Operations Group weekly hui Lived Experience Knowledge Network (LEKN) monthly online hui

Outcomes from this involvement are summarised in the consumer engagement section.

Note update that the Lived Experience Knowledge Network (LEKN) run through Manatū Hauora Ministry of Health, lived.experience@health.govt.nz are creating a database of consumer networks. I informed them about Kōtuinga Kiritaki and sent a link to the webpage.

Regional Networks and Events

Ōtākou Mental Health Addictions Wellbeing Network monthly hui 22 July; Southern Consumer Peer Support Lived Experience (CPSLE) hui in Balclutha 31 August; Te Whatu Ora Health New Zealand Southern Quarterly Disability Forum

These enable me to stay connected with regional networks and in particular to maintain up to date information and connections with people in the Murihiku Southland district. As well as informing general themes to this report, four people living in the Murihiku Southland district have chosen to contribute their experiences and recommendations to this report.

Services - Issues and Barriers

Feedback indicates that the health system is not fitting to the reality of people's lives and the interconnected nature of wellbeing. 'It is very concerning, in the Murihiku district, people cannot be with both mental health services and addiction services. They go together and need to be addressed together.'

Instead of being able to work with people holistically, across the domains of their life, people are being turned away if they have unmet health needs in more than one area. 'The GP tried to get me in to respite for help with mental health, but because my main illness is physical, I couldn't get in.'

Many services have strict entry criteria, and services are not flexing to fit people, instead people must try to fit themselves to the services. 'There is a meth harm reduction service in Invercargill, but they only take under 34's, and people under 34, they don't want to stop using, and people over 34, they reach out for help and then they can't get it.'

People are being declined specialist services due to the mismatch between patient need and health system capacity. 'I got a letter from the pain clinic, it said the "number of referrals greater than the number of appointments... referral returned to the GP team who will continue to provide care", but my GP couldn't provide care, that's why I was referred.'

At the same time, people are told there is healthcare available, and so this creates a disconnect between what they are being told, and what they are experiencing. 'It's like they are daring you to do something (to harm self) and then they (mental health services) will accept you.'

Families too are experiencing a disconnect between what they are told is available for their loved one, and what they end up with. One example given is of families agreeing to have their loved one home from the inpatient mental health unit, on the understanding that community supports and services are being put in place, and then the referral is declined from community mental health services, leaving the family to try to support their loved one as best they can.

Some people who experience mental health challenges, and who may be seen as frequent users of services, are sharing their experiences of being channelled into the justice system to free up mental health resources. However, mental health services are crisis-oriented and respond mainly to acute need. As a result, people can get stuck in cycles of brief support and relief, followed by renewed need, and over time, this can create a sense of dependency on services, where people experience less control and autonomy to find other ways to cope with distress.

People with chronic health issues are also not being well supported by the health system. 'I don't think our society or systems are set up for anything that doesn't have a quick fix or goes on for a long time, so these illnesses go mostly undiagnosed or for many people it takes years and many appointments to receive any support.'

Even for those who get a diagnosis, there is a lack of treatment available. 'I fought for ten years for a diagnosis and to be taken seriously. But there is no clear pathway for patients with conditions like Ehlers-Danlos Syndrome (EDS). There is this illusion of a treatment pathway following diagnosis.' Additional example: 'I went to the GP, I said, "these are my symptoms, I think it is Long Covid", the reply was "hmm, yes, I think you've got Long Covid." And that was the appointment.'

As resources get more stretched, more people are getting stuck feeling disbelieved, unsupported and unheard. 'Always get doubted. As if my experiences aren't real';

'(I hear) "the test results are coming back normal, therefore there's nothing medically wrong with you... maybe you should push yourself harder", or other assumptions.'

Services – Positive Stories and Exemplars

People are demonstrating their resiliency in the face of systemic adversity. 'Communication, humility and empathy are crucial. Never underestimate the power of "I believe you and your symptoms are real." Being willing to say, "I don't know" and collaborate with others. Over time I've learnt how to hold information lightly, be curious and take what resonates with me, but also how to advocate for myself, know my identity and make informed decisions.'

Many people, especially those experiencing greater health inequities, are volunteering time and lived expertise to support people in their communities, including by listening, validating and demonstrating solidarity, supporting people to get informed, and advocating alongside. 'He had been told "disability is a mindset". I validated him, and he cried, told me he was so grateful... We share knowledge, empathy from our experience.'

Consumer Engagement – Positive Stories and Exemplars

I have had a very positive experience as a consumer voice to the Dunedin Public Hospital (DPH) Hospital in the Home (HiTH) Operations Group. What is working well:

- Early consumer engagement, from the initial planning stages, through to ongoing involvement, as an equal member of the weekly Operations Group meetings.
- Asking for both written and verbal consumer input. If written feedback is requested, then
 specific questions are asked, using language that I can connect with and understand. These
 questions help me to frame up and articulate my thinking.
- With verbal consumer input, I do this as part of the Operations Group, alongside all team
 members, which leads to a more collaborative discussion. This process is facilitated by the
 project staff, who demonstrate their understanding of effective consumer engagement by
 acknowledging the different perspectives in the room and asking to hear from people in their
 specific roles at relevant times.
- I can give more useful feedback thanks to having access to internal information about Hospital in the Home (HiTH), such as the referral and admission checklist. This means that I don't have to guess whether what I'm saying is relevant or not. By lessening the information imbalance between myself and clinical team members, it feels less like others hold the power, and more like I am valued as an equal member of the group.
- My role as an advisor is clear and I'm not given unrealistic workload expectations. The Project Lead is mindful and respectful of my time, and when I email, I receive a reply.
- I was told this is a paid role, and indeed, I do get paid for it. I have never had to chase up payment. So, I feel valued and appreciated for my time.
- Overall, this is a safe environment for me to try out different ways of providing a consumer perspective, so that I can learn and improve. I have learnt it is most helpful to listen and try to understand what the issues might be, and after I have given it some thought, to give feedback that is solutions-focused and actionable.

Suggested action points are followed up on, not just written down with a promise that it will
happen. This builds trust and makes me feel like it is worthwhile to share. For example, I
suggested that written information be given to support people so that they receive consistent
information. This was drafted by the Project Lead, I had the opportunity to give further feedback,
and now this is in place for all support people through Hospital in the Home (HiTH).

Considerations for Te Tāhū Hauora

Considerations suggested by people who have shared their experiences and feedback in this report:

- Advocate for a public health model for complex chronic illnesses, a smoother pathway for diagnosis and management, and more support & education for medical professionals around these conditions.
- Investigate people living in the Murihiku district that cannot access both mental health services and addictions services. They go together and need to be addressed together.

Consideration for consumer engagement:

 Build greater understanding of the Code of Expectations with roles that involve direct consumer engagement, including consumer and whānau family advisors, as well as with directorate leadership that supports advisors to engage with consumers.

Additionally, a key theme in the feedback is that the health system is saying, "we have services" whilst consumer experience is saying, "I cannot access them." Suggestions to:

- Raise the profile of the use of data and measurement for systems learning, innovation and improvement, rather than the use of data and measurement as performance targets.
- Advocate for balancing and context measures to be publicly reported alongside progress on health system targets. These could include balancing measures like staff burnout or patient experience, and context measures such as the number of referrals declined.

Tyson Smith (Te Puke)

Environmental scan

Activity (since last report)

- Te Manawa Taki Consumer Council hui
- Hauora a Toi Mental Health and Addiction Services consumer consultant group meeting
- Convergence CPSLE Workforce Forum Hui

Services

HealthNZ

Long wait times for specialist mental health and addiction services

People often face long delays getting the help they need, especially through hospital and specialist services (HSS) or their GP. This means issues aren't caught early, and people's conditions can worsen.

Repeated reports/reviews/projects that give the same recommendations ...

I heard about a narrative of people being declined services because providers cannot deliver support in a way that would meet the government target of shorter wait times for first specialist assessment. These individuals are never formally accepted into the service and are therefore excluded from official data and government performance metrics. This creates a hidden group

whose needs remain unmet and whose experiences are invisible in system reporting, masking the true scale of demand and access issues.

MHA NGO

Services are getting more people with severe or multiple issues, which makes it harder to place them in the right setting. Some services don't have the staff or skills needs to support these cases well.

Positive stories and exemplars

Peer Support in Emergency Department

Progressing at Tauranga Hospital, with the Request for Proposal process now closed and submissions currently under review.

Regional Consumer Councils

Establishing themselves and finding their place within the system

Considerations for Te Tāhū Hauora

1. Te Tāhū Hauora has a mandate to support consumer and whānau engagement, advise on improvements to quality and safety, and make sector-wide recommendations.

The establishment of a national peak body for the Consumer, Peer Support, and Lived Experience (CPSLE) workforce would directly contribute to these statutory objectives by strengthening the quality, consistency, and impact of consumer voice across the health system.

Te Pou has produced an options paper on this but is not positioned to lead implementation. Sector-led establishment is unlikely given high workloads and the contractual service delivery focus of most NGOs employing peer roles.

In the current fiscal climate, with Health New Zealand | Te Whatu Ora managing significant budget constraints, service pressures, and workforce cuts, it is highly improbable that such an initiative could be resourced or prioritised as an internal project.

Given this context, Te Tāhū Hauora should recommend that the Minister prioritise and resource the establishment of a national CPSLE peak body, ensuring independent leadership, sustainable funding, and sector-wide engagement to embed consumer voice as a driver of quality and safety improvement.

2. Te Tāhū Hauora investigate and report to the Minister on the unintended consequences of government performance priorities, such as the target for shorter wait times for first specialist assessment, on access to services and equity of care.

There is concern that these targets are influencing service delivery decisions, with some providers declining people they are unlikely to see within the target timeframe.

This practice excludes individuals from formal acceptance into services, thereby removing them from official data and government metrics.

As a result, a hidden population with unmet needs is created, and the true scale of demand and access issues is obscured. Addressing this will require adjusting measurement and accountability settings to incentivise equitable access rather than only meeting time-bound targets.

Zechariah Reuelu (Porirua)

Environmental Scan

The period from May to July 2025 reflects both emerging opportunities in Pacific-led health initiatives and persistent structural barriers affecting health and wellbeing outcomes.

Key Trends

Health and Wellbeing

- Chronic Conditions: High prevalence of long-term conditions such as diabetes, cardiovascular disease, and gout continues to place pressure on families. The Vaka Ola pilot highlights whānau-centred models as critical to managing multiple co-morbidities.
- **Diabetes Prevention:** The Ola Manuia | Live Well programme launched in July 2025 with Samoan women in Porirua, reflecting culturally designed approaches to prevention.
- Smoking Cessation: Only 13% of smokers are accessing quit support (target 20%), suggesting a need for Pacific-focused, relational engagement.
- **STI Disparities:** Rising syphilis and HIV diagnoses among Pacific populations signal a growing public health concern that intersects with stigma and inequitable access.

Social and Economic

- **Housing Stress:** Overcrowding, damp housing, and limited affordable rentals in Porirua continue to drive respiratory conditions and poor health outcomes.
- **Employment and Cost of Living:** Families face cost pressures from rising food and energy costs, contributing to financial strain and reduced ability to prioritise health.
- **Education and Youth:** Pacific youth leadership remains a strength, though disengagement and inequity in schooling outcomes remain barriers to long-term success.

Challenges and Barriers

Access to Healthcare

- Limited engagement with primary care and overdue screenings for many families.
- Workforce shortages, particularly culturally capable clinicians outside Pacific navigator services.

Trust and System Navigation

- Lingering mistrust post-COVID around vaccination and health messaging.
- Families often prefer relational, church-based engagement rather than institutional settings.

Youth and Intergenerational Barriers

- o Younger generations navigating identity, digital engagement, and systemic exclusion.
- o Intergenerational poverty contributes to cycles of poor health and limited opportunities.

Opportunities and Positive Developments

- Pacific-Led Models of Care: Pilots such as Vaka Ola and Ola Manuia show early promise in shifting care from individual treatment to family-centred, prevention-focused models.
- Community Outreach and Cultural Grounding: Increasing efforts to embed smoking cessation, diabetes prevention, and immunisation within churches and cultural events.
- **Strategic Planning:** The Tū Ora 5-Year Strategy is engaging Pacific communities directly to shape priorities, leadership, and accountability.
- **Youth Potential:** Ongoing investment in Pacific youth leadership, education, and workforce pathways can unlock resilience and innovation for future generations.

Summary

Between May and July 2025, Pacific populations in Porirua continue to face health inequities, housing stress, and systemic barriers. However, the momentum of Pacific-led health initiatives, combined with stronger system-community partnerships, positions Porirua to test and scale culturally grounded solutions.

The key to success lies in shifting power to Pacific leadership, embedding whānau-centred approaches, and tackling the social determinants of health alongside clinical care.

Whānau Ora Navigation Services – Innovative Solutions

The launch of new Whānau Ora Navigation services in Porirua, led by providers like the Atafu Tokelau Community Group, offers a culturally grounded response to long-standing barriers for Pacific families.

These services emphasise relational trust and holistic wellbeing, with navigators who walk alongside whānau to connect health, housing, education, and social services.

Often bilingual and community-rooted, navigators build trust and empower families to set and achieve their own goals. By embedding Tokelau cultural frameworks, the Atafu Tokelau Community Group highlights the value of Pacific-led solutions, strengthening access now while driving long-term systemic change through leadership and community accountability

ENDS