

Minutes of the Joint hui of Kōtuinga Kiritaki / Consumer Network and Ngā Reo Māhuri Young Voices group

Chair	DJ Adams
Kōtuinga Kiritaki members	Mary Schnackenberg, Oliver Taylor, Ricky Ngamoki, Jennie Harré- Hindmarsh, Zechariah Reuelu, Tyson Smith, Toni Pritchard, Amanda Stevens, Vishal Rishi,
Ngā Reo Māhuri members	Natasha Astill, Naomi Vailima, Joshua McMillan, Tiare Makanesi, Jaden Hura-White, Ciccone Hakaraia-Turner
Māori health & Consumer Team	Dez McCormack
Te Tāhū Hauora staff:	Arana Pearson
Guests	Peter Jansen, CE; Jess Lockett, Programme Manager, Trauma and Improvement Advisor; Mark Scott, Consumer Advisory Group Chair, Te Omanga Hospice and Mairi Lauchland, Quality Risk Manager, Te Omanga Hospice.
Apology	Joanne Neilson, Mark Rogers, Ataahua Hepi, Carlton Irving, Jim Wiki

The hui was held at Rydges Wellington Airport, on 7 November 2024.

The hui began at 9.00 am.

1. Welcome and karakia

DJ welcomed the group and opened the meeting with a karakia.

2. Whakawhanaungatanga

Whanaungatanga was undertaken as this was the first time the two groups have met.

(Standard business was done out of session for each group)

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

3. Feedback on previous Te Kāhui Mahi Ngātahi CAG hui -

Mary gave the update on the last Te Kāhui Mahi Ngātahi hui and provided a written report as follows:

HQSC has four groups of consumer advisors across the organisation:

- the Consumer Network, Kōtuinga Kiritaki;
- Young Voices Advisory Group, Ngā Reo Māhuri;
- Consumer Advisory Group (CAG) Te Kāhui Mahi Ngātahi; and
- Te Kahui Piringa, the Māori Advisory Group to the board.

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

I serve on both this Consumer Network and the Consumer Advisory group. My role today is to keep you up to date with the activities of the Consumer Advisory Group.

The Consumer Advisory Group has an additional role to today's meeting group. It reviews some HQSC Board papers which are referred to CAG by staff. In addition, the two co-chairs of CAG take turns to attend HQSC Board meetings.

Since the Consumer Network met on 22 August, the Consumer Advisory Group met on Friday, 20 September. We discussed the Aotearoa New Zealand System Safety Strategy. We gave feedback about a Board paper about Learning, Improving and Healing from harm which provided an update on adverse events. There is an international Patient Safety Action Plan 2021-2030 which New Zealand has ratified.

At the last HQSC Board meeting on 4 October, Russ Aiton, one of the CAG co-chairs, was in attendance. The CAG Co-Chair now has 15-20 minutes at the beginning of the open session of the Board and is able to effectively set the tone and scene for the consumer voice and engagement. In addition, the Board watches a video story from one of the consumers about their health experience.

Russ says that the environmental scans from our groups were well received by the Board. The headings spoken to were the high cost of living emphasising the withdrawal of school lunches and the reduction in available funds, noting the balance between either affording health care or affording food in low socio-economic areas. Workforce issues are ongoing and remain toward the top in our updates to the Board focusing on the lack of qualified staff across the clinical services. Russ spoke about the lived experience of a CAG member whose elderly family member suffering with addiction and mental health issues sadly passed away due to the inadequacies of the system.

Board member Jenny Parr raised her concerns about the Te Whatu Ora Regional Consumer Councils and the lack of progress. Russ was able, as the ex-Chair of the national group, that still meets up, to give an update and answer her questions on the challenges faced by regional consumer councils around the country to focus on the Code of Expectations and its implementation.

4. Māori Health & Consumer report and update

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

5. CE update and questions

Peter spoke of the current difficulties in the health system at a high level, and historically about system design that doesn't reflect the needs of consumers. The issues and the models of healthcare are not unique to New Zealand, they affect all western health systems.

Changing systems and can be challenging.

Te Tāhū Hauora will continue to highlight issues through consumer feedback and surveys along with evidence from data collection and advocate for change where this is possible undercurrent systems.

There was a general discussion, and questions raised about what can be done by Te Tāhū Hauora.

6. Feedback for new Medical Trauma resources

Jess Lockett introduced the mahi behind of the serious chest injury project which aimed to ensure all services have minimum guidelines in place to manage serious chest trauma.

- Reduce readmissions
- Reduce hospital-acquired complications

Reduce length of stay

The project deliverable was to produce National best practice guidelines with supported implementation across local services.

This looked at initial management (identification and ED management), pain management, Physiotherapy/Allied health, nursing management, specialty guidance and referrals (Cardiothoracic and Radiology, Special populations (Paediatrics, older adults and clinically frail, underserved populations including Māori, Pacific peoples, disabled community, rural/remote and low socioeconomic populations), Consumer resources and discharge planning and community care.

There was a review of all existing consumer handouts and education resources, the co-design of a new resource to be used nationally, and to investigate accessibility options for national use of the resource.

As part of consumer co-design, 2 consumers were engaged in this work recruited through outreach to the trauma sector. They reviewed 8 current resources in use across the country used in Clinician involvement (Physiotherapy, Occupational Therapy and Nursing)

The resulting flyer was presented to the group and feedback was provided. Follow-up after the hui allowed for further consumer input.

7. Te Omanga Hospice presentation

Mark Scott and Mairi Lauchland provided a presentation of their recently formed Consumer Advisory Group at Te Omaga Hospice. They wanted to share with the group the history behind their CAG's development, what their commitment is (TOR), what they have done to date and to ask the group for pointers/advice on what could be done better under the auspices of Hospice care.

The consumer code of expectation was raised as an important reference point. The structure developed was also covered and the representation to date on the CAG covering a range of demographics/diverse communities.

The Network provided feedback on various areas of hospice care including their own personal lived experiences of what worked well and what was important when they had family and whānau members in Hospice care.

Although a sensitive and moving session, it was very worthwhile and appreciated by all.

8. FIT for symptomatic project

This item to be moved to a future hui due to time restraints

9. Code of expectations review - update

DJ gave an overview of the framework and timeframes on how the review will be undertaken, which is to be completed by June 2025.

The cross-agency Consumer Voice reference group will be the main group tasked with managing the review. The CAG co-chairs are consumers on this group.

Te Kāhui Mahi Ngātahi Consumer Advisory Group (CAG), Kōtuinga Kiritaki Consumer network and Ngā Reo Māhuri Young Voices group will contribute to the review at their scheduled meetings. Other stakeholders including consumers, whānau and the health sector will be engaged in focus groups and workshops.

The review aims to ensure the code remains relevant, effective, and aligned with the principles of equity, partnership, and meaningful engagement with diverse communities, especially Māori,

Pacific, disabled people, older adults, rangatahi, rainbow, rural communities, migrants and refugees.

The objectives of the review are:

- Assess how well the Code of Expectations has been implemented across health entities.
- Evaluate the effectiveness of consumer and whānau engagement.
- Identify areas for improvement and alignment with evolving health system priorities.
- Ensure the code supports and reflects te ao Māori perspectives and equitable outcomes for all communities.

Members gave feedback that was recorded and will inform the review. They shared their experiences that demonstrated how the code is being applied in their communities, and organisations.

Other themes include:

- Language easy to understand, clear up mixed messages
- Cultural awareness partnering with Māori and Pacific people
- Advocacy The code is a tool to support consumers and whānau.
- Implementation There is some resistance to the code. It applies to everyone consumers, whānau, communities, the health sector and beyond. NGOs – engage with their communities and need to be included
- Governance embed the code into clinical governance frameworks
- Reporting regular planned self and peer reporting built into programmes.
- Beyond Health and Disability Kainga Ora engaging with people with disabilities in education sessions.
- Promotion Communicate better, have it everywhere.

Members were encouraged to advise of examples to the team at anytime or to the consumer email box – consumers@hqsc.govt.nz. Another avenue to share examples would be to include any examples in environmental scans.

10. Regional workshops update

DJ outlined the plan for the regional workshops in Te Tai o Poutini West Coast in February 2025. Details shared included:

- location for two consumer workshops Reefton and Hokitika
- one provider meeting Greymouth
- content and activities including the code review
- Stakeholder relationships Mana whenua, Tākiwa Poutini, Health NZ

Members were asked to support the workshops by promoting and connecting the team with their networks in the West Coast.

11. Other business (EOI's)

Dez promoted the EOIs that are currently advertised, specifically those for Kōtuinga Kiritaki and Ngā Reo Māhuri that close Nov 15th, with the request for members to promote these.

Everyone was given the opportunity to provide closing comments. The feedback was positive, and it was a worthwhile and engaging hui. Mention was made of appreciation for the CE again attending the hui to share his thoughts and challenges.

12. Karakia and close

DJ closed with karakia

Next hui: 13 February 2024 - TBC

2024-11-07 CN-YVG minutes

Actions list

Date	Action	Responsibility
7 November	Carry forward item 8 - FIT for symptomatic project	DJ Adams
7 November	further discussion at February hui re Rare Disorders strategy	

Appendix 1

Māori health and consumer team report – 7 November 2024

The following are highlights since the last report dated 22 August 2024.

Te Tāhū Hauora welcomed the new Director of Māori Health and Consumer- Carlton Irving with mihi whakatau on October 7. The current number of staff is now four. An internal EOI process is underway to fill a Māori Health and Consumer Advisor role and a Senior Consumer Advisor role.

Consumer health forum Aotearoa



Consumer forum opportunities

Following a lull in opportunities to share with the consumer health forum Aotearoa (CHFA) – we are happy to have seven currently listed on the webpage here:

- Ambulatory Care and Community Health design guidance review
- Collaborative Aotearoa Telehealth Patient Voice Survey
- Mental Health Intensive Care design guidance review
- Renal Dialysis Unit design guidance review
- Rheumatic Heart Disease Echo Screening Study
- Kōtuinga Kiritaki | Consumer Network
- Ngā Reo Māhuri | Young Voices Advisory Group

Update and News

The latest newsletter sent to the CHFA was emailed to the members on 30 October the stories included:

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

Read the update here.

Forum membership

The total number of individuals who have signed up to the consumer health forum Aotearoa forum members is 942 (increase of 2) 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 2 2023-2024 through end quarter 1 (30 June 2024).

Ethnicity	Quarter 2 2023-24	Quarter 3 2023-24	Quarter 4 2023-24	Quarter 1 2024-25
Māori	Quarter 2 total: 174 (19.4%)	Quarter 3 total: 181 (19.7%)	Quarter 4 total: 190 (20.2%)	Quarter 4 total: 190 (20.2%)
Pacific	Quarter 2 total: 91 (10.1%)	Quarter 3 total: 91 (9.9%)	Quarter 4 total: 91 (9.6%)	Quarter 4 total: 91 (9.6%)
Asian	Quarter 2 total: 43 (4.8%)	Quarter 3 total: 46 (5.0%)	Quarter 4 total: 53 (5.6%)	Quarter 4 total: 53 (5.6%)
Pākehā/Caucasian	Quarter 2 total: 494 (54.9%)	Quarter 3 total: 504 (54.7%)	Quarter 4 total: 507 (53.9%)	Quarter 4 total: 509 (54%)
Middle Eastern/ Latin American/ African	Quarter 2 total: 18 (2.0%)	Quarter 3 total: 19 (2.1%)	Quarter 4 total: 19 (2.0%)	Quarter 4 total: 19 (2.0%)
Other ethnicity or ethnicity not specified	Quarter 2 total: 79 (8.8%)	Quarter 3 total: 80 (8.7%)	Quarter 4 total: 80 (8.5%)	Quarter 4 total: 80 (8.5%)
Total	Quarter 2 total: 899	Quarter 3 total: 921	Quarter 4 total: 940	Quarter 4 total: 942

Engagements

Although a much-reduced team, we continue engagement with our stakeholders – consumers, whānau, the community and the health sector.

- Carterton Medical Centre Community Health Forum
- Te Omanga Hospice
- Tū Ora Compass Health PHO
- Tū Hauoranga Trust
- Te Whatu Ora
 - o Consumer engagement and Whānau voice
 - National clinical services
 - FIT for symptomatic Steering Group
 - o Australasian Health Infrastructure Alliance
- Manatū Hauora
- Advances in Māori Measurement Symposium
- Mortalities Review Committee
 - Avoidable Mortality
- Ao Mai Te Rā Anti racism kaupapa

Code of expectations, implementation guide and the code review.

A review framework has been created and shared for comment with the cross-agency working group that is the Consumer Voice Reference Group. The co-chairs of CAG are members of this group. This framework sets out the aims and plan for the review which will be completed by June 2025.

Te Tāhū Hauora consumer advisory groups – Te Kāhui Mahi Ngātahi, Kōtuinga Kiritaki and Ngā Reo Māhuri will contribute to the review during their scheduled meetings.

Other stakeholders including consumers, whānau and the health sector will be engaged in focus groups and workshops.

Quality Safety Marker for consumer engagement (QSM)

The September 2024 submissions have been mostly received with Te Whatu Ora (national) outstanding. Thanks to Oliver Taylor – Kōtuinga Kiritaki for his support and contribution to the moderation of the submissions. We plan to post the QSM to the public website by 21 November.

This submission round is the first time Te Whatu Ora will report at the regional level, and the third time health entities – NZ Blood, Pharmac and Te Tāhū Hauora have reported.

Te Tāhū Hauora provides feedback to Manatū Hauora on health entities progress to implement the code of expectations and improvement in consumer engagement. It is important to work smarter – efficiently and avoiding duplication in the engagement for the review.

Website analytics & Summary of consumer hub website traffic

The following reports traffic to the implementation guide. Other sections of the Consumer hub will be reported in future reports.

Overall, data for the April-September period shows engagement with the code of expectations implementation guide content has remained strong in some areas and slowed in others.

An important highlight is the page hosting the code of expectations itself receiving over twice the amount of engagement during the April-September period, as during the 6 months prior.

This strong engagement reflects the work done by the team to promote the code, including the creation of a range of resources and varied channels of distribution.

2024/25: 1 April - 30 September

	•	1 October 2023-11 April 2024
Engaging consumers and whānau Te mahi tahi me ngā	Views: 588	Views: 573
kiritaki me ngā whānau <u>here</u>	Users: 360	Users: 337
Code of expectations for health entities' engagement	Views: 2,338	Views: 1,526
with consumers and whānau Te tikanga mō te mahi tahi a ngā hinonga hauora ki ngā kiritaki me ngā whānau here	Users: 1,425	Users: 1,282
Code of expectations for health entities' engagement with consumers and whānau here	Views: 1,334	Views: 1,596

	1	
(This page hosts the code translations and accessible formats)	Users: 873	Users: 1,067
Code of expectations implementation guide	Views: 476	Views: 700
Te aratohu tikanga (<u>new landing page here</u>)	Users: 293	Users: 391
	Views: 614	Views: 442
	Users: 422	Users: 309
Co-designing with consumers, whānau and		
communities Hoahoa tahi me ngā kiritaki, ngā whānau me ngā hapori <u>here</u>		
Video: Co-design explained in 30 seconds	Views: 69	Views: 49
	Users: 65	Users: 36
Video: Co-design: making it business as usual	Views: 43	Views: 31
	Users: 39	Users: 25
Video animation: The co-design process	Views: 105	Views: 63
	Users: 86	Users: 50
	Views: 541	Views: 364
	Users: 369	Users: 265
Using lived experience to improve health		
services Te whakamahi wheako mātau hei whakapai ake i ngā ratonga hauora <u>here</u>		
<u> </u>		
Video: Co-design case study: Susanne Cummings here	Views: 34	Views: 26
	Users: 33	Users: 22
Video: Consumers share how their lived experience	Views: 46	Views: 23
contributed to health improvements <u>here</u>	Users: 39	Users: 18
	Views: 449	Views: 235
	Users: 322	Users: 153
Improving equity through partnership and collaboration Te whakapai ake i te mana taurite mā te		
mahi tahi <u>here</u>		
Video: Te Whatu Ora Taranaki consumer council	Views: 15	Views: 10
members outline the importance of consumer engagement (no YouTube data available links to external	Users: 14	Users: 8
Facebook page for Bryan Vickery Media Taranaki clicks		
avail on request).		
	•	

Video: Consumer voice: What does equity mean to you and your community?	Facebook total views: 953 (note it is not possible to see views for Q1 only) 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: 212 Users: 115	Views: 160 Users: 88
Video: Enhancing accessibility: how to begin	Views: 12 Users: 11	Views: 14 Users: 11
Video: Practical accessibility tips for producing consumer resources	Views: 12 Users: 10	Views: 11 Users: 8
Video: What is the code of expectations and are we achieving what's required?	Views: 12 Users: 11	Views: 11 Users: 10

Appendix 2 - Summary of Kōtuinga Kiritaki Consumer Network and Ngā Reo Māhuri member reports – 7 November 2024

Mary Schnackenberg (Tāmaki Makaurau)

Environmental scan

Input / involvement in Te Tāhū Hauora meetings/groups.

- 18 September: meeting to review draft QSM submission about HQSC
- 20 September Consumer Advisory Group meeting

Services

There is the ongoing challenge for those with hearing aids to be able to use them during any hospital stay. A blind friend in his 80s who uses hearing aids went into hospital recently after being knocked down by a car. He could not get home soon enough. His initial entry into hospital was an emergency and he did not have his hearing aids at the outset. His wife brought them on her first visit to him. He did use them through his stay. Even so, he had real difficulty understanding and communicating with staff who had accents. He often had to ask them to repeat something they had said. With his hearing aids intact, he is home now, gradually recovering from his injuries.

Considerations for Te Tāhū Hauora

I cannot repeat often enough the need for personal health information to be available in accessible formats. This is not just about the format (print, audio, Braille, etc.) but about the language being appropriate, meeting the needs of print disabled New Zealanders as well as those for whom English is a second language. Having access to one's own personal health information is a key component of getting well and staying well.

Jennie Harré Hindmarsh (Tairawhiti)

Environmental scan

Nationally consistent, equity of access to health services is once again becoming an unachievable pipe dream with serious repercussions – those in rural and provincial areas increasingly refer to the health system as a "postcode lottery", which is getting worse not improving.

Access to timely primary care and many specialist hospital services continues to be an issue, exacerbated by primary care no longer providing an after-hours service in Te Tairāwhiti (and other areas) given the ongoing shortage of GPs. Furthermore, issues related to the funding model for primary care are still not being addressed - despite warnings for decades; and the shortage of permanent medical specialists in Gisborne Hospital has become dangerous for the Tairawhiti community.

Morale amongst health service providers is spiralling downwards, generating a lack of confidence and hope amongst the community of having urgent health needs met. There is a widespread sense that the health system is about to implode due to funding cuts and loss of staff.

Concerns about the future, and some current, care for the elderly in many provincial and rural areas has again been highlighted in the Wairoa and Te Tairāwhiti areas. For example, there is still no

aged care residential facility in Wairoa, where the last rest home has been closed since Cyclone Gabrielle and it is estimated more than 50 whānau are caring for vulnerable elders in unsatisfactory conditions https://www.gisborneherald.co.nz/news/no-aged-care-facility-a-burden-for-families-wairoa-community-fighting-to-look-after-elders-locally. Many similar smaller towns are on the brink of having no aged care beds for frail elderly, nor adequate in-home care (as noted by the Aged Care Commissioner on RadioNZ https://www.rnz.co.nz/national/programmes/ninetonoon). An improved model for aged care is overdue – which needs to centre around elders' strong preferences to stay in their own home, supported by primary care nurse-led home support services, transport services and easy-to-arrange home modifications, with assess to local residential care when needed. On this note, a group of older persons in the Gisborne area has recently reactivated the Tairawhiti Positive Ageing Trust and is reviving its strategy for older residents.

It continues to be frustrating to watch the escalation of vaping and related addiction amongst rangatahi. Politicians urgently need to do the right thing and take bold, decisive, evidence-based action to restrict vapes to prescription-only and only to support people to quit smoking tobacco. Likewise, frustration continues to be expressed about the evidence-less decision to not implement the Smoke Free legislation.

Input / involvement in Te Tāhū Hauora meetings/groups.

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

Three online meetings - 6 Sept, 20 Sept, 4 Oct 2024 to support the National Mortality Review Committee's Engagement and Relationships Manager to draft an initial action plan for this new workstream which is to implement initiatives that reduce the inequitable impacts of avoidable mortality on families, whānau, 'aiga and other collective groups and improve the quality & safety of related services. The workstream is part of a strategic shift in the Committee's focus, from solely making recommendations, to both formulating specific, actionable, evidence-based and culturally responsive recommendations in partnership with families (kinship groups) to influence system changes *and* implementing those recommendations by partnering or collaborating with others -both internally (e.g. via the Consumer Forum or Advisory Groups) and externally with related agencies. Learnings will be incorporated across the Mortality Review Committee's other workstreams to ensure effective engagement with families/communities in learning reviews alongside agencies, supporting the family or child voice, and culturally safe & respectful healing processes.

Consumer Insights Questionnaire to inform advice to Minister of Health: Responded 4 Sept 2024.

Webinar on 29 Oct 2024 with Dr Henrietta Hughes, a GP appointed as England's Patient Safety Commissioner, organised by Health Consumer Advocacy Alliance to which members of Te Tāhū Hauora advisory groups have been invited. To discuss what this Patient Safety Commissioner role adds to England's health system, barriers experienced, what has been achieved to date and what's happening next. Interested to attend given the Patient Safety Commissioner's focus is to champion 'patient voice' and 'consumer engagement' as being at the heart of improving, monitoring, and maintaining health quality & safety, especially with reference to equity and addressing healthcare inequalities.

Advisory Group - Te Tāhū Hauora HQSC 'Clinical Governance Framework: Collaborating for Quality' Project. The status of this new Clinical Governance Framework remains unclear, final feedback on which was provided early July 2024 https://www.hqsc.govt.nz/resources/resource-library/clinical-governance-framework-collaborating-for-quality-draft-feedback/ The new Framework was developed by Te Tāhū Hauora during 2022/24 to embed the Pae Ora Act's principles of equity,

tino rangatiratanga, and engagement with Māori and other population groups into clinical governance.

(On a related note, puzzlement has been raised by Lester Levy's statement, when providing a high level overview of current issues in Te Whatu Ora to the Health Select Committee on 18 Sept 2024, that he "asked to see the framework by which clinical quality and safety is monitored and measured, and there is no framework", thus a report is now being developed by Te Whatu Ora in collaboration with the HQSC and the Australian Health Round Table to first get a "baseline of where clinical quality and clinical safety is at" - paraphrased from 5:20 to 6.10 in https://vimeo.com/showcase/10758257).

Activity (since last report)

3 Oct 2024 (5-7pm) Attended Mātai Medical Imaging Research Institute seminar about current Dementia and Mental Health Research Projects https://www.matai.org.nz/gisbornes-matai-research-institute-pioneering-brain-injury-detection/ during which eligible participants were invited to express interest to participate in several local studies, many of which are collaborations with University of Auckland and/or the Brain Institute.

Genomics Aotearoa Māori Variome He Kākano Governance Roopu zoom meeting (17 Sept) to progress plans to 'launch' the Māori variome resource in 2025 as a resource to improve equitable precision of health care for Māori and to advance further related research for this purpose. https://www.genomics-aotearoa.org.nz/our-work/health-projects/aotearoa-nz-genomic-variome

Tairāwhiti Natural Burials implementation advisory group (first meetings 4 & 9 Sept). This community-initiated group is advising the Gisborne District Council on the need to expand burial options available to whanau/families and individuals in Te Tairāwhiti to include eco-burials, natural burials and kahu whakatere (Māori traditional practices).

Continued to participate in Advisory Group meetings to inform Gisborne District Council's development of the Waimatā-Pakare Catchment Plan to *improve 'Te Mana o te Wai'* - freshwater quality and quantity - a key component for human & environmental health. And to progress community-led Wainui Beach Catchment Kaitiaki initiatives to improve the hauora of our more local awa, whenua & community.

Services

The ongoing over-reliance on GP locums, if available at all, continues to discourage community members from seeking primary care help. Diminishing or total loss of 'continuity of care' is lamented by many. For example, recently a young Māori man already experiencing gout attacks shared how he now rarely seeks help from a GP as "these days it's always someone different" (on top of being hard to get an immediate appointment). In contrast, back-in-the-day when he had built a positive relationship over time with a long-term GP in the primary care practice with which he is registered, they had co-developed an understanding of the causes and the best ways to manage his risk of 'the gout' – which not only decreased his gout attacks, but also loss of income due to the gout.

Iwi and primary community health providers continue to collaborate to host community vaccination events combined with whānau health 'fun-days' to chip away at addressing the recent significant and worrying decrease in childhood vaccination rates (which, pre-covid was very high, including in remote rural areas) and to encourage 'flu and covid vaccinations' amongst all at risk.

Community members continue to express sincere gratitude to health providers who soldier on to provide them with high quality care (when access is obtained) in an increasingly chaotic and demoralised health system.

Positive stories and exemplars

Responded to a 'Day 42 survey' received as part of the current Te Whata Ora 'consumer engagement in action' Post Vaccine Symptom Check process in which I was randomly invited to participate following my covid vaccination booster in July. (The collated results of this short survey about recent vaccination experience are being used to quantify non-serious adverse reactions, encourage participation through direct engagement with consumers, provide public confidence in vaccine safety, increase transparency and communicate expectations of a consumer's vaccination experience. https://www.tewhatuora.govt.nz/health-services-and-programmes/vaccine-information/vaccine-service-delivery/vaccine-safety-monitoring/active-monitoring-post-vaccine-symptom-check/)

Considerations for Te Tāhū Hauora

I suggest that Te Tāhū Hauora

- Respond to the final report from the <u>Royal Commission of Inquiry into Historical Abuse in State and Faith-Based Care</u> which documented many very serious failings in our systems of care by co-leading collaborative initiatives across the health system to support practitioners to stop being complicit (as much through inaction as through inappropriate actions) in dangerous situations of abuse in communities, families and in-care facilities.
- Collaborate with iwi and community leaders, health researchers, and national entities to ensure
 we retain explicit references to Te Tiriti o Waitangi 1840 and to whānau & consumer
 engagement as central to implementing the Pae Ora Act throughout the health and disabilities
 sector, including Pharmac's services.
- Advocate, urgently and effectively, for the reinstatement the evidence-based Smoke Free legislation which was to be implemented in 2024 and for vaping products to be prescriptiononly.
- Collaborate with consumers, health service providers and genomic health researchers to codevelop quality & safety guidelines and related education resources for the informed use of
 safe genetic testing services and genetic/genomic information by whanau/families, individuals,
 and health professionals to improve prevention, decrease risk, and management of health
 conditions.

Oliver Taylor (Wellington)

Environmental scan

The impact of ongoing financial stress and subsequent political responses has seen even more uncertainty. For example, our Wellington DCAG budget has not been provided yet. This has meant compensation for my work has come out of project budgets, which has significantly reduced the interest of projects generally to engage consumers.

Access to services continues to be an issue. Financial costs for access to physiotherapists, mental health professionals and other publicly inaccessible services continues to mean young people will not access them. Services that are funded are sometimes requiring consumers to utilise private / user-pays services in the first instance e.g. vaccines for PrEP, phycological assessments for access to waitlists for gender-affirming care, and physiotherapist appointments that may or may not

be covered under ACC. Mixed with general capacity issues, young people are being disincentivised to reach out.

Input / involvement in Te Tāhū Hauora meetings/groups.

Consumer Engagement Quality and Safety marker reviews:

Te Tāhū Hauora submission – I have been actively engaged with the TTH submission team to provide advice on their submission to the September reporting. While better than most submissions from health entities, there is still not a robust understanding of what the domains mean. I understand resourcing contributes to this, however, given the progression of the QSM since inception, there remains areas for improvement.

National QSM submission moderation – as a member of the review panel for the QSM framework, and a member of the moderation panel of all submissions on the QSM, I am privileged to be able to provide my consumer-level insight and experience to Te Tāhū Hauora on this important area. This is the first submission period where Health NZ / Te Whatu Ora have provided Regional-level (4 national health regions) submissions on the QSM, organised by the Regional Managers of Consumer Engagement.

I am pleased that all regions and health entities submitted in time for moderations, except the national Te Whatu Ora office. I understand the issues head-office faces when deciding whether work and projects are District, Regional, or National that may contribute to the measuring of consumer engagement, however, it would be appreciated if this could be worked out swiftly.

Feedback is yet to be released from this process, but my advice has always been to make submissions concise and to the point, without unnecessary prefaces or context: how does this directly relate to the domain? With evidence, how does this show that you responded to consumers? Where did they say this? Where is the evidence of engagement? Overall, my view is that the issues relate to entities continuing to not understand the framework.

Activity (since last report)

HPU 280 Oral Health Unit Guideline Review – I am currently engaged in meetings for the Oral Health Unit design guidelines for Australasia (NZ and Australia), which support building physical health services, and consideration of models of care (how the services work with consumers). The process has been interesting as NZ clearly has a very different oral health system than Australia, with my main feedback being that these focus on areas not relevant to an NZ context. This has been incorporated and more engagement with NZ health services has progressed. I also note that there are very vague provisions that do not contribute much, such as "most oral health services have a front door to get into the service". Many defended this, which I continued to push back on.

Front of Whare Emergency Department Refurbishment Project, Wellington Regional Hospital

- This project has progressed to final Detailed Business Case submission, which means that the Treasury and Minister of Finance will soon be considering whether the \$200+ million proposed project will be funded, and which options are preferred. There is thoughtful consideration included, such as the cultural narrative document, which implements colour pallets and themes into the physical design of the services, local artwork, and a focus on increased bed numbers and improving consumer experience with services. Meetings on the Steering Group continue to add value to the project; however, all work is now contingent on the above decisions. Happy to discuss.

Services

The current fiscal situation is being attributed to Te Whatu Ora hiring more nurses than expected, which is a good thing. It is difficult to accept that because we are hiring more nurses and clinicians, costs are too high. The impact to services on the current wave of restructures is unclear and could flow directly to services.

Primary care services are now further limiting access for young people. Cost for prescriptions have been re-introduced, Districts are now reducing eligibility criteria for funded services for young people and are also reducing the applicability age for access. All of this will contribute to poorer outcomes for young people.

Positive stories and exemplars

My work as a Private Secretary has been positive and (while it is a lot of work) is a fantastic experience. I have been engaged in so many different areas and it has been fantastic to see the inside operations and machinery of government.

In my HPU Oral Health work, the responsiveness to me on NZ related issues meant that more NZ clinical staff were included in the review process, which will hopefully mean it is more applicable to us.

Considerations for Te Tāhū Hauora

Advise that consumer advice must be made a priority for the health system, including
enabling factors such as provisions for swiftly confirming consumer engagement budgets,
specific supporting staff, and operational policies mandating consumer engagement in
services, projects, and governance.

Mark Rogers (Timaru)

Environmental Scan

I am concerned that nationally, the wait time for treatment for children with ear, nose and throat (ENT) concerns is getting longer. This poses further risks to learning and then employment in later years.

Regional Consumer Councils are yet to be 'up and running'. The August Health reset and significant structural change (as quoted by Te Whatu Ora) has been an influencing factor.

Activity

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

EAG (Expert Advisory Group) on 4 September covering progress with test sites.

DEWS is an evidenced based early warning system designed to support ARC (Aged Residential Care) staff to identify and respond to the acute deterioration of residents. EAG (Expert Advisory Group) on 4 September covering progress with test sites.

I am one of two consumers on this group and our (consumer) voice has been welcomed and considered.

Chest Trauma. Initial reviews of material being used to give consumers at discharge time. There will be an opportunity to review the proposed handout at our hui on 7 November.

22Q Deletion Syndrome - Transforming Diagnosis into Empowerment – An educational seminar from Sydney Children's Hospitals Network and the 22q Foundation Australia and New Zealand. This 3-hour interactive presentation included numerous statistics and clinical trial details.

Presenters included Dr Donna McDonald-McGinn of Childrens Hospital of Philadelphia, Dr Laura Roche of UNI, Newcastle, Dr's Emma Palmer, Madeline Delves and Honey Heussleh.

All spoke about their specialist clinical involvement with children and young adults who have 22Q11.2DS also known as Di George Syndrome.

22Q Carers Zoom. NZ and Australian 22Q members and staff discussion on how to seek improvements in several areas of need.

CEQSM Consumer Engagement Quality & Safety Marker – Te Tahu Hauora HQSC Zoom assessing our assessment.

Considerations for Te Tahu Hauora

Work on Te Whatu Ora to get regional consumer councils active and this includes details on their website.

Toni Pritchard (Te Kaha)

Environmental scan

Access to quality Health Services, other than GP services, inc Specialists, Radiologists Physios continues to improve, with more services being accessible at our Local GP clinic, including fortnightly ACC counselling (PTSD, sexual Trauma counselling etc) the feedback from this service has been overwhelmingly positive, with the main highlight of this feedback being the 'warmth' of the Counseller, and being able to 'connect' with her.

Mental Health services continue to be under pressure in our Rural District but is seeing improvement with the now regular ACC counselling as described above.

Te Rūnanga o Te Whānau initiative as described in previous Scans continues to yield positive results, with continued Quantitative and Qualitative Data reflecting this. The most recent accolade was written acknowledgment from the Head Doctor regarding one of the patients that is a part of this initiative.

Activity (since last report)

Health Promotion - Hauora Week

Our Organisation held a Hauora/Health week at our Local Kura/School, where we hosted over 20 providers during the week, ranging from Podiatrists to Dentists and everything in between. This was a huge success – more info in the positive exemplar below.

Services

Improved access to Health Services

Improved access to Mental Health Clinicians/Practitioners, and quality Mental Health Services in our Rural area, with new ACC Counselling service available.

Positive Story and Exemplar (1)

Our Organisation hosted a Hauora week, where we had Trinity Dental Services come for the whole week and do critical dental work. This service ran from 8am – 5pm for 5 days and was booked solid, with still many more people being turned away.

We also collaborated with many other services during the week including other Māori Heath Providers who were able to come and set up a mobile clinic providing ear suction, and podiatry services. This was VERY popular with their services fully booked for the 3 days they were here.

OPSM provided us with boxes of reading glasses ranging from 1.5 - 3.0 which was also very popular with boxes of glasses being given away – and exclamations of wonder at 'being able to see' for the first time.

We had St Johns services including MIS team and tent, which was very interesting for people to see.

Also, Home Based support services, Heart & Respiratory Health services, Oral Health services, Addiction services and Sports Bay of Plenty.

It was a successful week, with high engagement for the Community, with an excellent range of services over the week that the Community responded really well to. It was a great opportunity to bring much needed information and access to our isolated area, but also highlighted the high need for engagement in ALL services before things deteriorate so badly, especially in the Dental Area.

Positive Story/Exemplar (2)

Phycologists from Community Mental Health Services in Whakatāne are continuing to come into our area, to our GP Clinic, to provide their service to our Rohe. This is still a much needed and well received service.

We also have Voyagers – Child and Adolescent Mental Health Services travelling to our area and making home visits to high needs Tamariki which is also a major step towards better Hauora for our people.

Te Rūnanga o Te Whānau/Te Whatu Ora initiative as described in previous Scans continues to yield positive results, with continued Quantitative and Qualitative Data reflecting this. The most recent accolade was written acknowledgment from the Head Doctor regarding one of the patients that is a part of this initiative.

I am part of a newly formed working group aimed at improving Health, in particular Mental Health services across the Eastern BOP. We are aiming to meet every month to look at how we can help each other in this challenging yet rewarding mahi.

Amanda Stevens (Nelson) - Deafblind Association NZ Charitable Trust

Environmental scan

We increasingly get receive requests for a connect because the person or family member is experiencing stress because of social isolation – it's not that there aren't people around, it is simply that there aren't enough people teaching communication skills.

Activity (since last report)

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

The following actions have been agreed:

• Bringing together key organisations to identify actions which could be taken to improve Deafblind people's lives now set for late November.

• Identifying overseas deafblindness prevalence data and actions other jurisdictions are taking to improve outcomes (including Germany, the Netherlands, Norway and Australia). Report due this month.

Positive stories and exemplars

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

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

From 1 July 2024, FreeStyle Libre 2 is proposed to be subsidised for all people living with type 1 diabetes in New Zealand!

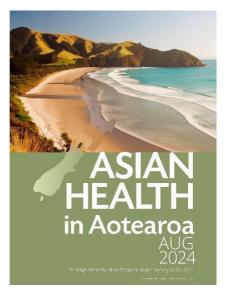
From 1 October 2024, an additional Abbott brand of CGM is also proposed to be subsidised that will be compatible with funded insulin pumps and can be used to create an automated insulin delivery system.

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

Vishal Rishi (Auckland)

Please find the quarterly Kōtuinga Kiritaki Consumer Network report as mentioned below. This report includes the latest update on Asian health, Ethnic Health Collective and general update.

Asian health in Aotearoa – Findings from the New Zealand Health Survey 2002 - 2021:



The findings, drawing on 20 years of New Zealand Health Survey data, are stark.

Obesity has doubled in over 20 years, and physical activity and nutrition indicators are poor compared to European and Other communities, setting up a pipeline of cardiovascular and non-communicable diseases to follow.

Experience of racially motivated attacks has increased markedly for South Asian and Chinese communities, setting us up for negative long-term effects on mental health outcomes.

Asian communities are less likely to access primary care and are less likely to access hospital services.

Asian communities are growing and growing fast.

In 2019-21 we made up about 15% of the adult population, and 17% of children in New Zealand, up from 6% (2002-03) and 9% (2006-07) respectively.

According to the *New Zealand Health Strategy* the Asian populations in New Zealand are projected to grow by 48% from 2018 to 2033, making us one of the largest ethnic groupings.

Highlights from the report:

Asian population: The proportion of NZ children with Asian ethnicity increased from 9% in 2006-07 to 17% in 2019-21. The proportion of NZ adults with Asian ethnicity increased from 6% in 2002-03 to 15% in 2019-21. There were increases for adults and children in all three Asian ethnic groupings (South Asian, Chinese, Other Asian).

Age: Each of the three Asian ethnic groupings, along with Māori, tended to be of younger age groups compared to European & Other.

Years living in New Zealand: Most Asian adults have been living in NZ at least 10 years or were born in NZ. This was a significant increase from 2002-03 to 2019-21 for all three Asian Ethnic groupings (South Asian 37%–52%, Chinese 27%–64%, Other Asian 26%–56%).

Ethnic discrimination: From 2011-12 to 2020-21, Chinese adults (32% to 41%) and South Asian adults (16% to 24%) were increasingly likely to have ever been the victim of an ethnically motivated verbal attack. In 2020-21, 23% of Other Asian had ever been the victim of an ethnically motivated verbal attack.

Asian adults along with Māori and Pacific, were more likely to have been treated unfairly because of their ethnicity in NZ, at work when applying for a job, or while renting or buying a house, compared with European & Other.

HEALTH BEHAVIOURS AND RISKS

Asian people living in NZ for a longer period were more likely to drink alcohol, but less likely to exercise. A major concern is low fruit and vegetable intake for children and adults and increased fast food intake for Asian children. Patterns of low physical activity and sedentary behaviour are reflected in gradually increasing obesity levels.

Nutrition and Physical activity - All three Asian ethnic groupings were less likely to report meeting fruit and vegetable consumption recommendations of 5 or more servings per day compared to European & Other. The proportion of all three Asian ethnic groupings meeting the fruit and vegetable recommendations was gradually declining for each survey year.

South Asian and Other Asian children were more likely to eat takeaway food once per week. This is more often than European & Other children. The proportion of children eating takeaway food regularly has been increasing since 2006-07.

Asian and non-Asian children had similar levels of active transport to and from school (for example, walking or cycling). However, adults from all three Asian ethnic groupings, along with Māori and Pacific adults, were less likely to be physically active than European & Other Adults. There was little change since 2002-03.

Body Size - Among children aged 2-14 years, Chinese and Other Asian had lower rates of overweight and obesity, while South Asian was similar when compared to European & Other. There was little change from 2006-07 for each Asian grouping. Obesity was higher for adults in all three Asian groupings, gradually increasing since 2002-03.

Smoking & Vaping - In all three Asian groupings, women were less likely to be current or daily smokers than European & Other, while men had similar smoking rates to European & Other. The rate of current smoking has decreased for Asian men and women since 2002-03.

All three Asian groupings were less likely to report being current or daily vapers than European & Other, though there had been increases in vaping since 2015-16 among Asians.

Drinking Alcohol - Overall, the Asian community drinks alcohol the least often and in the smallest amounts, but the proportion of people drinking and drinking hazardously has increased for all Asian groupings since 2002-03.

All Asian groupings and Māori and Pacific peoples were less likely to drink alcohol than European and Other. Asian adults who do drink alcohol were less likely to binge drink and less likely to drink at hazardous levels than Māori, Pacific, and European & Other adults.

Cannabis (Marijuana) - All Asian groupings were less likely to use cannabis than Māori, Pacific, and European & Other adults. Cannabis use increased among South Asian adults since 2011-13.

HEALTH CONDITIONS

Among Asian children, the most common conditions were:

- eczema (17%, higher for Chinese and Other Asian than South Asian)
- asthma (7%, similar among all three Asian groupings)

The most common health conditions for Asian adults aged 25 years or older were:

- Chronic pain (12%, less common in Chinese and Other Asian)
- Hypertension (10%, more common in South Asian, less common in Chinese)
- High cholesterol (8%, more common in South Asian)
- Arthritis (7%, less common among Asian ethnic groups than non-Asian)
- Diabetes (6%, more common in South Asian, Other Asian)

Depression and asthma were less common among all three Asian ethnic groupings compared to European & Other. From 2002-03 to 2019-21 the proportion of Asian adults living with chronic conditions was stable.

USE OF HEALTH SERVICES

The proportion of adults who used health services was highest among those who were born in NZ or had lived in NZ for more than 10 years. Access to services was lowest among Asian adults who lived in NZ less than 5 years.

Primary health care - Adults in all three Asian ethnic groups were less likely to have a regular health practitioner or service to visit (90%) compared to non-Asian adults (94%-97%). There has been some improvement for Chinese and Other Asian adults since 2002-03.

Secondary health care - The proportion of Asian children attending public hospitals in the last 12 months (22%-24%), was similar to European & Other children (25%). Since 2006-07 this proportion increased for South Asian and Chinese children.

Attending a public hospital in the last 12 months was less common for Chinese (16%) and Other Asian (17%) adults compared to South Asian and European & Other (28 %). Attending a private hospital was lower for all Asian groupings (3%-4%) compared to European & Other (8%).

Oral health - Among children, each Asian ethnic grouping was less likely to have seen an oral health care worker in the last 12 months (South Asian 77%, Chinese 84%, Other Asian 83%) compared to European & Other (93%).

Asian adults were less likely to have a regular dental check-up at least every two years (South Asian 19%, Chinese 28%, Other Asian 29%) than European & Other (45%).

The full report can be found here: https://www.asiannetwork.org.nz/

An update on Ethnic Health Collective:



We have launched the EHC collective website only to our membership to end of last year, as we work to resolve hiccups in the functionality and strengthen the system. We as a group decided to maintain this Kaupapa as a "think tank".

We aim to generate insights and comprehensively understand the ethnic health policy and system landscape. By doing so, we are not just shaping the discourse but also influencing policymaking and the health system in a way that is both urgent and important.

As a think tank, we will take time to conceptualise, examine, and develop innovative solutions and contribute to an informed dialogue to guide effective decision-making.

We encourage you to become a member of this 'think tank': https://ethnichealth.org.nz/

One of our recently completed works is around developing a discussion paper on the role of local government in health and wellbeing of ethnic communities in Auckland.

Knowledge product: Discussion document on role of local government in health and well-being of ethnic communities in Auckland.

As part of this Kaupapa, we gathered insights and explored the local government's role in improving the health and well-being of ethnic communities in Auckland. We recommended how the Council's system, facilities, and service delivery models could effectively support ethnic health outcomes. To do that, we examined Auckland Council's plans and strategic landscape to assess how well they considered the perspectives and needs of ethnic communities. Additionally, we looked at local initiatives focusing on innovation within local board areas.

We have structured our recommendations around eight key priorities. Four priorities focus on system changes within the Council's current planning and delivery models and the other four focus on achieving specific health and broader social determinants outcomes. In total, we have identified 25 simple yet effective actions to make progress in these areas.

This is the first discussion document we have prepared as EHC. It will be ready for release in December 2024. Based on its reception and impact, EHC might consider preparing similar discussion documents to facilitate dialogue and systemic change.

Official report ends here but please feel free to browse through the following media links in relation to the recently released Asian health in Aotearoa report.

The launch of the report attracted strong interest from media, with findings and commentary featuring on leading news and current affairs platforms:

Obesity in NZ's Asian communities doubles over 20 years – study (video) https://www.1news.co.nz/2024/08/27/obesity-in-nzs-asian-communities-doubles-over-20-years-study/

Report finds growing obesity in NZ's Asian population (audio)

https://www.rnz.co.nz/national/programmes/morningreport/audio/2018953049/report-finds-growing-obestity-in-nz-s-asian-population

Asian obesity in New Zealand doubles in almost 20 years

https://www.rnz.co.nz/news/chinese/526311/asian-obesity-in-new-zealand-doubles-in-almost-20-years

运动不足、吃外卖、肥胖率翻番,亚裔健康报告结果令人担心

https://www.rnz.co.nz/news/chinese/526310/article

Obesity among NZ's Asian communities doubles in 20 years

https://www.thepress.co.nz/nz-news/350392469/obesity-among-nzs-asian-communities-doubles- 20-years

Rising obesity and discrimination: What Asian Nzers' health looks like

https://www.renews.co.nz/rising-obesity-and-discrimination-what-asian-nzers-health-looks-like/ New report reveals the end of the 'healthy Asian immigrant effect' in Aotearoa

https://thespinoff.co.nz/society/28-08-2024/new-report-reveals-the-end-of-the-healthy-asian-immigrant-effect-in-aotearoa

Obesity Doubles In Asian Communities (joint media release)

https://www.scoop.co.nz/stories/GE2408/S00094/obesity-doubles-in-asian-communities.htm?_gl=1*17aphpx*_ga*MTc0MzI0ODI4Mi4xNzAyNDE0ODc3*_ga_GGVMM3MB8_2* MTcyNDgxMDQzOC4yNC4xLjE3MjQ4MTExNjMuNTkuMC4w

The health system is failing Asian New Zealanders https://www.thepost.co.nz/nz-news/350417529/health-system-failing-asian-new-zealanders

Ciccone Hakaraia-Turner (Tāmaki Makaurau)

Environmental scan

Although I have been away from the health industry this year more than I would have liked to, I have taken this as an opportunity to talk with my university peers (particularly Māori rangatahi) about health-related issues and services that they have had to face over the year. So far, a lot of what I have heard is either positive experiences, or concerns around lack of knowledge for resources available to them, and the health system organisations and their influence on each other.

Services

I have had conversations with individuals in my community regarding health resources. From the discussions had, the stigma around the health system remains. A lot of rangatahi are still unaware of the different organisations that make up the entire health system. Rangatahi Māori still find it challenging to use health resources or providers, purely because they simply don't look at it as a priority. This shows that some of our rangatahi Māori are still lost when it comes to the health system – they are unaware of the resources available to them, nor do they know where they are. Because of this, more rangatahi Māori are still going ahead with their everyday mahi and not seeking help.

Positive stories and exemplars

Regarding positive stories that I am hearing from individuals in my community, they have expressed their positive experiences around nurturing whānau members in times where their loved ones have remained in hospital for an extended amount of time. Some whānau members have had to sleep in the hospital alongside their unwell family members and have expressed they too were being looked after quite well. From what they were seeing during this time, the staff of the hospitals

were also taking very good care of their family member in a very respectful way. This experience alone has increased this individual's perspective of the heath-sector which I think is incredibly positive considering this individual and their whānau have not always been fond of the health system.

Considerations for Te Tāhū Hauora

To remedy the situation outlined under 'Services', Te Tāhu Hauora need to in some way increase their brand and services to rangatahi by doing more advertising or marketing work with university or high school through campaigns. From our last in-person meeting in Auckland, I remember there was a model that was shown to us about how each health sector organisation influences each other and connect. I believe this needs to be rolled out in rangatahi spaces as well with information around which organisation provides what to whom.

Joshua McMillan (Tāmaki Makaurau)

Environmental Scan

Activity (since last report)

I haven't been to any hui's lately due to time constraints. I am attending an upcoming conference hosted by SPARK NZ in November, which will talk to aspects of digital health tools and security. I will also be attending the Global Adolescent and Young Adult Cancer Congress again in December - I will be running a workshop, chairing symposia and co-presenting an original study with a friend from Teen Cancer America. I may have more to share then as the Congress especially touches on indigenous and pacific cancer care in youth.

Services

The only concerns/issues I keep hearing about is the long delays in healthcare, the rising cost of GP's and inaccessibility to them, leading to increased demand on Emergency departments and extensive wait times. From what I am hearing, many patients feel like they aren't being taken seriously or like they are just being messed about. Obviously, there's more to this; I doubt that ED staff are purposely doing this, it's just the nature of continued cuts during increasing demands.

A key issue is the extensive wait times in contrast to the expected timeframe to be seen, treated and/or discharged/admitted. If I remember correctly, the target time is 6 hours (?), but I've known people who have waited upwards of 10 hours just to be seen.

This 'lack of being taken seriously' and/or cuts have also been impacting referrals, i.e. I have been trying to see an ENT and also look into genetic investigations/testing related to my previous cancer. Both have been declined and/or ignored despite continuing symptoms. This is the case, as far as I am aware, for many people. Speaking to my GP recently, they said it's just hard to get anyone to do anything unless it's almost life or death (exaggerated, but you get the gist).

Access to mental health support, specifically in those with current or past conditions seems to also be challenging. I am aware of a few cancer patients outside of Canteens age group (13-24) who are struggling to find support, partly due to long wait times or lack of adequate support or information outside of hospital treatment. From my experience, this seems to be more present outside of major city centres.

Lastly, communication between hospital-based care and external support organisations, at least in the cancer space, seems to be dwindling. I know referral rates for support are lower than usual at Canteen and I have heard it is a similar story at Child Cancer, Cancer Society and others. I can

only assume that this may also be the case for other support organisations, which should be addressed by the health system to some degree to ensure their patients get non-clinical support that they need.

Positive stories and exemplars

The Enable funding scheme for hearing aids seems to be working relatively well from my experience. Recently, after a bit of a process, I received full funding for hearing aids which have made an unexpectedly positive impact on my ability to engage and hear things properly. Without the Enable hearing aid subsidy and funding scheme, I wouldn't have been able to afford appropriate hearing aids. Although there are some hurdles, the availability of the scheme for people who otherwise couldn't afford to address their hearing impairments is a big plus.

The only thing that could have improved this is the covering of a 'service/fitting fee', which was \$1200 out of my own pocket that I did not have, but was able to secure through some grants and a university disability fund.

Considerations for Te Tāhū Hauora

I think it is probably already happening, but increased pressure on Health NZ to properly fund and remove barriers for healthcare is critical. It is only a matter of time before dire consequences directly linked to the current situations appear (if they haven't already), such as a death due to long ED wait times or inaccessibility to primary care.

In terms of youth, relating to the youth tertiary community I've been a part of, considering something to help push for accessible health services where students increasingly cannot afford to see a doctor (money and timewise) could have benefit. There are existing schemes and funding at Auckland University and the Student Association, but they are extremely difficult to access unless someone meets strict criteria - which is great for those who do, but for the vast majority of other students there's still a huge barrier and illness spreads through the university like wildfire. I don't know what the consideration would be, but I think its relevant discussion.

Natasha Astill (Tāmaki Makaurau)

I have hosted a disability education workshop to Kainga Ora around how to best support those with disabilities. They were very interested in this workshop and the disability education will be an ongoing project with them.