

**Minutes of the Kōtuinga Kiritaki /
Consumer Network** meeting held on 16
February 2023, in Pounamu, Health Quality &
Safety Commission



Consumer Network:	Mary Schnackenberg, Tofilau Bernadette Pereira, Oliver Taylor, Edna Tu'itupou-Havea, Zechariah Reuelu, Ricky Ngamoki, Jennie Harre-Hindmarsh, Vishal Rishi, Renee Greaves (via zoom), Hyejung Kim, Amanda Stevens
He Hoa Tiaki PIC Team:	Deon York (Chair), DJ Adams, Allison Anderson, Dez McCormack (minutes), LJ Apaipo, Tanaya Shangarpawar (in afternoon)
Commission staff:	Arana Pearson (Consumer engagement advisor, Mental Health and Addiction)
Apologies:	Joanne Neilson, Marlene Whaanga-Dean, Mark Rogers, Gillian Bohm, DJ Adams

The meeting commenced at 09:50am

1. Welcome & karakia

Deon welcomed the group and LJ opened with a karakia.

2. Whakawhanaungatanga for Arana Pearson & Anne Buckley

Everyone introduced themselves and spoke of their health experience and background in being in this group.

3. Standard business

Previous minutes.

Minutes from 16 November 2022 accepted as correct. Moved by Bernadette and seconded by Zechariah.

Action items discussed. One to carry forward.

Deon asked for any updates to interests register be advised to Dez.

4/5. Feedback on Board hui and previous CAG hui

Deon spoke briefly of the board hui; there wasn't anything of note for this group. He also spoke of papers that are going to the board for their hui at the end of February, including one from PIC. Deon then handed to Mary for her report.

Mary gave a report on previous CAG hui. This is her written report:

The Consumer Advisory Group has met twice since our last Network Hui on 16 November. I will report on our meeting on 24 November and our meeting on 10 February.

On 24 November we met initially to strategise about our meeting with the Commission Board. We wanted to know what the Board did with our advice on their papers and our top issues that we raised from our environmental scans.

Then we met with the Board where we introduced ourselves. The Board clearly appreciates our advice on the papers we are shown and is also keen to see our key issues. Then we had lunch with the Board.

The Consumer Advisory Group met on 10 February.

We drew up our top priorities for reporting to the Board from our environmental scans.

a. Workforce shortages and access to care.

b. Recognition of the value of lived experience to health services planning.

- c. Need for increased awareness of code of expectations and increased consumer engagement.
- d. Accessible information for consumers.

The Health and Disability Commissioner has signalled an upcoming review of the HDC Act as well as the Code of Health and Disability Services Consumers' Rights. The HDC Code has remained largely the same since it was introduced in 1996. Since then we have matured about Te Tiriti o Waitangi and engaged with the internet and social media. Our Privacy legislation has also been updated. The health system has transformative legislation which include the Code of Expectations. The current Health and Disability Commissioner regularly attends the Commission board meetings. We have had a very initial discussion. We know the review will be publicised perhaps at the end of this year. HDC is reaching out very early to stakeholders.

We discussed in broad terms the proposed workplan for Partners in Care for 2023-2024. We received an update on the implementation guide for the Code of Expectations.

We were invited to give feedback about the Annual Report of the Commission which is leading to the next Statement of Intent which is the future three-year plan for the Commission.

Another Board paper was about supporting the sector to implement the Code of Expectations.

I am particularly interested in how we can support clinicians and health managers to embrace consumer adviser input. The Auckland Consumer Experiences Council is only one model. We have both consumer advisers and senior managers at our meetings. It's the chance for us to tease out the barriers facing today's managers and work, often through co-design, to move projects along that make improvements.

Auditors visited the Auckland DHB facilities last week. We were told at our most recent Consumer Experiences Council meeting that the auditors were very taken with their meeting with four of our consumer advisers who spoke very positively about consumer engagement.

Following Mary's report, there was a general discussion around the HDC code review being undertaken and how that relates to the consumer code of engagement. The network will have a chance to input to the HDC review via the Commission's submission, but also the general public will have an opportunity in the later part of the year.

Deon mentioned that he would ask the HDC what the consultation plan will be so we can pass that back to the group.

6. He Hoa Tiaki | Partners in Care (PIC) report:

We took that members had read the PIC report and asked for questions. There was a discussion and clarification around parts of the budget. The PIC written report follows:

Update to Kōtuinga Kiritaki / Consumer Network

Overview:

The code of expectations and the development of an implementation guide, an update of the QSM framework, and continued engagements with the sector have formed a major part of our work for quarter 2, 2022.

EOIs for consumer participation with various projects across the health sector continue.

Fielding inquiries for these and supporting the process is becoming a natural part of the work programme. Streamlining efforts for recruitment have been useful and are continually being evaluated.

Increased interest in consumer engagement is evidenced by the increasing requests for meetings and engagements between stakeholders and the team.

Programme Highlights:

1. International connections have been re-invigorated and prioritised via a joint effort via PIC and a student researcher, Penny Evans from Victoria University who is completing a literature review on consumer engagement, both within Aotearoa and internationally.
2. Consumer health forum- Te Papa and online
3. Bula Sautu group established and will meet early Q3 to develop a plan for the group.
4. Re-vamp of Quality and Safety Marker (QSM)- National QSM group re-established
5. Consumer voice framework reference group (CVFRG) group established- implementation guidance (2.1) published
6. We continue to meet with the consumer co-leads from Te Aka Whai Ora and \ Te Whatu Ora on a regular basis to share ideas and ensure no duplication of work is happening within the consumer voice framework- sharing operating models, programme plans and other collaborative discussions.

Workstream 1- Strengthen Ngā Pare Hiranga	Progress	Notes
Produce an implementation guide for the code of expectations for consumer and whānau engagement group (SPE deliverable 2022/23	In progress/on-time	Established with a cross-sector and consumer code implementation working group Q2.
Create, update, promote, refresh PIC resources (Appendix 3)	In progress	Includes amalgamation and update of DHB and Primary Care guide
Support consumers and the sector to set their own specialty satellite within ngā pae hiranga (e.g.: Māori, Pacific, rangatahi, rural communities)		
Development of an interactive innovation map linked to our consumer hub in which communities can share projects and programmes related to consumer and whānau engagement.	In progress	Contract and project scoping started.
Continued development of ngā pae hiranga, attaching analytic capability to allow further monitoring, testing, evaluating and improvement.		Website traffic tracking data is available now. Testing and improvement require further scoping.
Investigate ways to improve access to PIC resources	Ongoing	Regular capturing of access data, consumer and community feedback determines improvement
Develop and manage research literature hub	On target	Functionality is now complete. Content building- next stage.
Stakeholder mapping and engagement planning	On target	All engagements are being recorded so that we can track and follow-up. A comprehensive list of iwi, hapu and marae has been completed and similar pacific stakeholder data is also complete

Workstream 2- Consumer health forum Aotearoa	Status	Notes
Create the 'your voice, your health' media campaign to increase awareness and draw in new members to forum (goal: 1,500 by end FY)	Ongoing	Videos will be complete early Q3. CHFA Membership continues to grow. Current figures show 809 members.
Develop a bank of content and collateral that is specific in look, feel and purpose to CHFA, driven by member's input.	Complete	
Evaluating and refining the 3-year CHFA strategic plan with input from CAG, CN and CHFA	On target	Will emerge from 2-day workshop with CHFA early Q3
3x in-person forum events held throughout the country - targeting regions and/or population groups.	On Target	Nov, Feb, May
2-3x online events facilitated by He Hoa Tiaki	On target	Dec, Feb (w/Law Commission), potential for 1 more if demand is there
Analysis of each forum	Up to date	
Further development of existing digital infrastructure, continuous improvements to consumer forum 'hub' online	Ongoing	
Begin and maintain international CHFA partnerships	Ongoing	

Workstream 3- Building consumer and whānau leadership and capability	Status	Notes
Upskilling/onboarding all new CAG and CN members	Complete	

CAG, CN and CHFA offered Te Tiriti and decolonisation workshops and/or online training options as an extension of Whaingā Amorangi	In progress	CN and CAG have had training now. CHFA plans still in development
Review and refresh the Kōtuinga Kiritaki Consumer Network ToR's	In progress	Will be completed and signed-off Q4
Facilitate leadership training for CAG, CN and CHFA	Early-stage development	Q3- scope needs Q4 – plan delivery and content
Planning and developing programme, curriculum, and awareness campaign for a consumer leadership academy to launch 2023/24	Not started	Will begin once above work is near completion, late Q4
Facilitate targeted engagement training to consumer groups, as required	Not started	Will be determined by CHQ/CHFA workshop, early Q3
Summer internship/scholarship in place for summer 2022, evaluation of programme to follow	In progress	Delivery late Feb, then evaluation will follow
Partnership with consumer councils to support a transition to locality/regionally focused councils	In progress	Working with Te Whatu ora on CC transition plan. Supporting/resourcing consumers for interim period.
Development and support of a rangitahi group to inform PIC and the Commission	In progress	
Socialisation and promotion of national consumer participation policy.	In progress	Led by TWO, the Commission steering group and supporting consumers to participate
Enhancing and embedding the consumer and whānau perspective throughout the nine pilot localities	No progress	

Workstream 4- Measuring and responding to the consumer, whānau experience	Status	Notes
PIC Programme staff training for using CRM software	Delayed	CRM had been heavily delayed by an expansion of project to a wider Commission focus. Testing should begin Q4, then training to follow.

Maintenance of stakeholder relationship data (closing the loop)	Delayed	Will be able to use this relationship data once CRM is BAU for team.
QSM maintenance and improvements, promotion of new features, training, facilitating a national QSM group	In progress	National group formed. Final QSM revised framework should be complete by May.
Qualitative, Patient experience (Māori) data automation joint project w/HQI	Ongoing	
Assisting HQI to develop PREMs/PROMs	In Progress	Providing resource and contributing to advisory groups
Support teams across the Commission to identify, plan and facilitate opportunities for whānau, consumer, and community engagement	Ongoing	This work is ongoing. To date we have consulted on the development of a consumer-facing dashboard for MRC and assisted with numerous EOI's for other teams.
Formation and strategic planning of Pacific group to respond to Bula Sautu report findings	In progress	Advisory group formed in Q2. Response and planning to take place early Q3.

Ngā Pae Hiranga Insights

We have produced and published two Pacific specific stories on Co-design with Susanne Cummings from Vaka Tuatua including a case study. An additional five consumer voice stories that were produced onsite at Te Papa during the consumer health forum Aotearoa event at Te Papa, 10 November 2022. These five videos are in post-production and will debut early Q3. The most web traffic within the consumer hub has gone to [the code of expectations page](#) (1,631 hits), closely followed by our [Consumer health forum Aotearoa: Opportunities](#) page where expressions of interest are placed for consumers join p (1,035 hits).

[The consumer hub landing page](#) is the 12th most viewed page and [the consumer health forum Aotearoa](#) is the 25th most viewed page, (respectively, these ranked 13th and 25th in Q1). For reference, the Commission has around 16,000 pages or links on our website that Google Analytics tracks, so these numbers are strong.

Since August 2022, [The code of expectations for health entities' engagement with consumers and whānau](#) has been downloaded 817 times. Twenty-one translations and accessible formats have been accessed so far. This is the Commission's most downloaded pdf. Our efforts to promote the code are working!

For both Q1 and Q2 Facebook and LinkedIn were the platforms where our content received the most engagement. Conversely, Twitter and Instagram were low performing for He Hoa Tiaki digital content. Website and Social media traffic continues to be monitored and helps us to tailor our efforts to reach consumers and the community.

Consumer Health Forum Aotearoa statistics

Region	Total Q1	Percentage	Total Q2	Percentage
Auckland Tāmaki Makaurau	198	26%	221	27%
Bay of Plenty Te Moana-a-Toi	50	7%	56	7%
Canterbury Waitaha	110	14%	115	14%
Gisborne Te Tai Rāwhiti	7	1%	8	1%
Hawke's Bay Te Matau-a-Māui	18	2%	17	2%
Manawatū-Whanganui	38	5%	40	5%
Marlborough Te Taihu-o-te-waka	5	1%	5	1%
Nelson Whakatū	10	1%	10	1%
Northland Te Tai Tokerau	22	3%	23	3%
Otago Ōtākou	48	6%	53	7%
Southland Murihiku	7	1%	8	1%
Taranaki	15	2%	14	2%
Tasman Te Tai-o-Aorere	7	1%	7	1%
Waikato	43	6%	44	5%
Wellington Te Whanganui-a-tara	130	17%	142	18%
West Coast Te Tai Poutini	18	2%	20	2%
Unspecified	34	4%	26	3%
Total	760		809	
Membership breakdown by ethnicity				
	Total Q1	Percentage	Total Q2	Percentage
Māori	124	14%	136	17%
Pacific	73	8%	91	11%
Asian	51	6%	52	6%
Pākehā/Caucasian	561	65%	588	73%
Other	21	2%	19	2%
Unspecified	34	4%	33	4%

(NB: consumers may self-identify as more than one ethnic group)

He Hoa Tiaki list of stakeholder engagements

Many engagements were held this quarter (189!). Following the theme from last quarter, many involved introducing and discussing the code of expectations for consumer and whānau engagement, and several have become regularly scheduled follow-ups with stakeholders. Some key engagements include:

- 23/11 Workshop with QSM working group- incorporating code of expectations, and Te Tiriti into the framework.
- 29/11 Quality Improvement Advisor's Professional Development day
- 22/11 Health and Disability Commission
- 30/11 Rare disorders NZ
- 1/12- Consumer council chairs meeting- re: Te Whatu Ora's national engagement policy
- Pinnacle Health PHO- sharing their plans for code of expectations implementation
- Pharmac- presentation on code, recorded and used for staff training
- DPO coalition- presentation on code
- 14/12 Island Health Canada- International sharing of indigenous health frameworks and patient experience data collection/reporting
- 15/12 Youth Advisory meeting- first step in establishing a youth consumer network
- Major Trauma internal steering committee
- 16/12 Law Commission re: proposed changes to adult decision- making capacity law. CHFA to facilitate focus group to support this engagement.
- Acute flow QIP- potential PIC involvement in joint agency work.
- 19/12 QSM Advisory Group- working towards final draft and timeframe for rollout

7. Comments/questions on members reports submitted

Reports were taken as read. See Appendix A

Amanda gave a brief on her recent Deaf/blind seminar in Christchurch at which Deon presented. There were some hoops to go thru for funding interpreters etc. hand on hand tactile is required for dual sensory impairment.

Some clarification was given around the consumer QSM and how ours is different to other QSM's and framework's; and work being done on projects with a similar name.

Action item. Share the updated QSM framework with network.

8. Christchurch events in May - logistics

(Agenda items moved around)

Dez ran thru briefly what is happening over the 3 days 24-26 May. All flights made.

Transfers and dinners will be organised.

Tanaya then spoke about registration and sponsorship available.

Some network members will be contacted about assisting with the selection process for sponsorship applicants.

Amanda mentioned there is a better option than hearing "loops" and passed on details to investigate this.

We encourage everyone to help promote this event. As programmes develops we will update the website

9. Brief on leadership forum

Allison did a presentation to advise the upcoming leadership workshop with creative HQ. \ The basis of the workshop was formed from consumer feedback from previous forum.

We sought 10 people via the forum database and had applications from 137, so a difficult shortlisting process. The objectives of the form were:

Overall- taking data collected from forum events-putting into action

Agreement on terms of engagement for CHFA events/online discussions
Develop ideas about what information and topics are relevant to the forum; ex: Te Tiriti, upskilling topics, who should be 'in the room', etc.
Look at ways to facilitate further connection/dialogue amongst CHFA members

There was a spirited discussion asking if we were repeating what has already been done. Are we going down to the local level and regions? It was explained that this was a strategic workshop with a selection of people from a wide range of communities etc. It was aimed at what the forum members want to see and how the forum should develop.

10. Feedback on Bula Sautu advisory group hui

LJ gave a brief of what was covered at the last hui of this group.
Good examples from consumers of how the new localities should look in consumer engagement. Some of the suggestions not being acknowledged by localities.
Health literacy was stressed as being an important issue with more resources needed to back up work with this.
Some of the matters raised were outside the remit of influence the commission may have.
There are notes from the hui to view if anyone is interested.

11. Discuss opportunities for World Patient Safety Day 'Patient and family engagement'

Deon gave some background of this event and how this year's event on 17 Sept should involve the PIC team as the topic encompasses our work. There is further discussion to have with the patient safety programme (who normally run this) for the PIC team to be involved. There was a suggestion to do something with communities in Auckland. There will be further updates on this at the next hui.

12. Discuss ideas for programme plan for 23/24

Allison ran thru what had been proposed by the team based on our four priority areas (workstreams)

There will also be the Ministers letter of expectation to consider. There was a general discussion around areas we could focus on and general agreement on the ideas listed below. Comments were made about not duplicating any training for consumer leadership roles at both the local level and with the forum. With the new consumer lead roles in Te Whatu Ora, this local training of consumer leaders will fall with them. We are awaiting their consumer plan which is coming out for consultation soon.

Allison worked thru the ideas from the PIC team day, based on the 4 workstreams (below). The group were provided with lists and wrote down suggestions to consider as the plan progresses. There will be a zoom mid-April for an hour to further discuss the programme plan before it goes to ELT.

Workstream 1: Growing and strengthening ngā pae hiranga, the Commission's centre of excellence for whānau, consumer, and community voice. Ideas:

- Innovation map
- Code e-learning module
- More use of social media, Teams channel use for CAG (and CN?)

Workstream 2: Supporting and growing a consumer forum which embeds and enables the whānau, consumer and community voice to be heard across the health system: Ideas:

- Consumer forum events-roadshow
- Membership growth
- A feedback portal for consumers
- Evidence that CE works

Workstream 3: Building whānau and consumer leadership and capability. Ideas:

- Consumer training and education
- All TORs updated
- Driving a rangitahi group
- CAG- Code training, leadership training/governance training
- Yale university leadership academy for consumers
- Consumers lead a quality improvement project
- Locality QI work

Workstream 4: Measuring progress and responding to the whānau and consumer experience of the health system. Ideas:

- Co-design with quality improvement teams
- Disseminating our work through peer-reviewed publications and opinion pieces
- QSM moderating piece.

13. Wrap of day. Closing comments

Members provided a brief comment on their thoughts of today's meeting. Deon thanked everyone for their attendance and participation.

14. Karakia & close

No further business. LJ closed with a karakia.

Next hui: 24 May 2023 – at Distinction hotel in Christchurch

Actions List:

<i>Date</i>	<i>Action</i>	<i>Responsibility</i>
16Nov	Carried forward: Request for diagram to show the Commission's positioning in the new health system. Where consumers sit in relation to Te Whatu Ora & Te Aka Whai Ora	Allison
16 Feb	Share the updated QSM framework with network	Allison

(Member reports follow next page)

Appendix A

Summary of consumer member reports for 16 February 2023 hui

Mary Schnackenberg (Auckland)

Environmental scan/real time monitoring

Top of mind has been the flooding in Auckland particularly over the weekend beginning Friday 27 January. While I personally know of no individual whose home has been flooded sufficient for them to move out, the slow reactions and poor communications of the Auckland Emergency Management Group have left a number of disabled people worried. On the other hand, someone commented to me that she was seeing TV coverage of wheelchair users being rescued which prompted the question, "what about the rest of us?"

Auckland Council has initiated an investigation into what happened with the emergency response, with a report due back by 6 March.

Input / involvement in Commission meetings/groups.

24 November 2022: Consumer Advisory Group (CAG) meeting followed by lunch with the Commission board. CAG gives advice about Board papers referred to us for our consumer lens.

16 January 2023: hui about a proposed national reimbursement policy for consumers facilitated by Te Whatu Ora Health NZ. Still more consulting and work to complete prior to an agreed policy.

Services

In Auckland the Te Toka Tumai inpatient services are scheduled to undergo a Health and Disability Sector Standards (Ngā Paerewa) audit from 7 February to 10 February 2023. The Designated Auditing Agency carrying out the audit is the DAA Group. This is a full certification audit against the updated Ngā Paerewa standards. Progress on previous corrective actions will also be assessed.

The updated standards have a stronger focus on increasing positive life outcomes, achieving pae ora, and providing more person-centred and whānau-centred health and disability services. They also focus on how services can meet Te Tiriti obligations and improve outcomes for those underserved by the health system (e.g., Māori, Pacific, disabled, rural, and rainbow communities).

The standards strengthen clinical governance requirements to ensure that people's care and support needs are appropriately met. The audit results in a license to operate an in-patient health facility through this three-yearly Certification Audit process. Auditors collect information on how well an organisation meets the standards by reviewing the current programmes and processes and interviewing patients, whānau and staff. They also review how patient and whānau voice is heard and what outcomes there have been.

On 8 February some of us from the Consumer Experiences Council will be interviewed by the auditors for about 45 minutes.

Positive stories and exemplars

I am pleased to report our small business was able to upload audio files from the National Emergency Management Agency prepared by the Auckland Emergency Management Group about Auckland resources to get help with the aftermath of the flooding.

Jennie Harré Hindmarsh (Gisborne)

Environmental scan

Continuation of frequent very intensive rainfall events, related road closures and other damage is adding even more challenges for accessing and providing health care services, especially in the coastal rural areas of Te Tairāwhiti. Ongoing reliance on short-term locum doctors for primary care and the rural hospital also continues to be of great concern, which has been exacerbated as anticipated during summer when locums are less available, and more people are visiting the region.

Many older persons have continued to take precautions to protect ourselves from Covid during the Dec/Jan resurgence of local cases and related hospitalisations.

Turanga Health, Te Runanganui o Ngāti Porou (Ngāti Porou Oranga, including Ngāti Porou Hauora), and Te Whatu Ora Tairāwhiti continue to coordinate Covid pandemic-response support and vaccination events in the region.

Input / involvement in Commission meetings/groups.

Commission Quality and Safety Governance Framework Project Working Group member:

This project, begun in September 2022, is being led by Synergia with the Whanau Ora Commissioning Agency, and is due to be completed in April 2023. The key purpose is to embed the Pae Ora Act principles of equity, tino rangatiratanga, and engagement with Māori and other population groups into the new Quality and Safety Framework.

23 Nov 2022: Participated in Working Party's second online meeting.

6 Dec: Provided further advice and feedback to the project manager to inform Synergia's implementation of the updated engagement plan, the purpose of which is to provide a variety of perspectives and voices to be embedded into the new Framework, including from te ao Māori and non-Māori in rural and provincial communities.

7-20 Dec: Briefed senior managers in Ngāti Porou (<https://www.nph.org.nz>) and Turanganui (<http://www.turangahealth.co.nz>) health services, and the coordinator of Tairāwhiti Consumer Voice (www.tcvhub.co.nz), about this project and with their permissions have linked the Synergia project-leads to them to discuss convening a few kanohi ki te kanohi focus groups in Tairāwhiti early 2023.

➤ *Note:* Members of the Commission's Consumer Network, Forum and other groups now will be invited to contribute to the project via a Thought Exchange platform early this year.

Activity (since last report)

2 Dec: Viewed a wide-ranging panel discussion, livestreamed by Genomics Aotearoa with Otago Museum, about the impact that DNA and genomics research & technology are having (and soon will have) across many aspects of our lives - and associated opportunities and ethical challenges – including in health services, conservation, primary industries, etc. The full discussion is available on <https://www.youtube.com/watch?v=GshmpQOdCxo>

Services

Recent experiences of a terminally ill family member and a friend highlighted the urgent need to improve the design of hospital buildings and reconfigure hospital systems so that patients are provided with more peaceful environments in which to get much-needed sleep.

Positive stories and exemplars

On the other hand, the exceptional care provided to these terminally ill persons and their whānau by both the hospital cancer wards' staff and the hospices' staff was greatly appreciated. Staff members' abilities to provide high-quality and timely care and support - despite the challenging contexts in which they work - needs to be applauded.

Hyejung Kim (Auckland)

Input / involvement in Commission meetings/groups

Consumer health forum Aotearoa - Shape the future forum on 7 December

Activity (since last report)

Attended Korean society & KWWCG meetings on 2 Dec, 7 Jan and 13 Jan
Discussion on providing Health seminar, counselling service and Delivery of the Cognitive Stimulation Therapy (CST) programme to the Koreans.

Support for Koreans affected by the flooding in Auckland.

Provide information – welfare assistance, urgent accommodation, claiming insurance, find a medical centre and Tenancy' rules

Delivery food parcel with Korean consulate - more than 30 household

Services

After flooding, people found their enrolled medical centre closed, they don't know where they can go, and especially if they needed a Korean GP. I was able to help them.

Elderly couple, who needed high level of care & had to evacuate their home because of the flooding, and nowhere to go, needed support. Eventually a social worker was involved & they found a place to stay for a while.

Oliver Taylor (Wellington)

Environmental scan

Over the holiday period, health issues have been something of particular concern to people traveling, especially younger communities going home over the summer. While technologies such as telehealth have supported some to stay connected, connecting to primary care continues to be more challenging if you are physically away from your own GP, and the costs of urgent medical remain far too high, especially with the increased cost of living and low income of younger people in all communities.

The changing environment in Te Whatu Ora health systems has put pressure on staff, especially since January 1st with the 'Simplify to Unify' structural reforms. This has stoked more job insecurity for staff and led to existing consumer leaders and groups to rethink their engagement processes. Capital, Coast and Hutt Valley Consumer Advisory Groups have both been dissolved and will be re-established as a single district group over the next month through an EOI process, with all members of the two previous being invited to apply.

There also remains questions and concern regarding compensating consumers and budget issues for health entities with engaging consumers. National policy for remuneration discussions have come without an indication on budgets, and whether these will be nationalised or remain a responsibility of districts, despite being mandated nationally.

Input / involvement in Commission meetings/groups

17th November: All Day QSM Reference Hui: Discussions about altering the consumer engagement QSM has been ongoing with support from the 4 localities pilot sites and some consumers. The outcomes were that the wording would be simplified criteria that reads more easily with more ongoing input from communities and staff to come. A Te Tiriti and Code lens will also be applied through this process, with references and principles of both being added.

15th December: Youth Group Talanoa: Discussions about the work LJ has been doing regarding establishing a new youth group at the Commission. LJ has passed on much of the documentation which provides a great base and will be approved by the group once given the go ahead and established. These discussions included Māori and Pacific consumer advisors and will have a strong equity focus, while also responding to the needs of youth and youth advisors.

19th December: QSM (not) Final Draft Review: 1 hour meeting on the draft provided by Brittany. There was a response that it was difficult to provide feedback on as a framework, as well as staff members asking for more feedback prior to the next submission. A document was provided to add questions for feedback, changes around measuring including multiple (rather than one) consumers in engagement were included, and a practice-round of submissions using the new framework will be undertaken for pilot site districts. Wider feedback will be cut off at the end of March.

2nd February: QSM review meeting: 1 hour update. Changes were noted for consumer engagement structures for many so it had been difficult since the last meeting to incorporate broader feedback. Questions were asked for the wider group to add to the feedback document and if any changes to the QSM history document were needing to be added (due in 7 days from meeting). Members would ask for feedback at their first meetings of the year from wider consumer networks.

Activity (since last report)

14th November – 27th February: Summer Research Scholar in Health Information Systems and Privacy. I successfully applied for a summer research scholarship in the Victoria University of Wellington School of Information Management on a wide project called “Big Brother and Big Other” that aims to look at the history of large societal information systems and how that works for individual’s privacy. My specific project focusses on contemporary health information systems and privacy of consumer health information with a focus on Aotearoa. The project includes a literature review, interviews with eight health information staff across the public health districts and national system (Te Whatu Ora/Ministry of Health), and a report that will be used by my supervisor to publish an academic article.

6th – 8th December: Digital Health Week New Zealand Conference with Health Informatics New Zealand (HiNZ): Through my research project I was fortunate enough to be sponsored to attend this conference with a focus on digital health systems, technologies, and staff.

Thousands of delegates across the country attended the event in Rotorua from both the public and private sector. Core areas of interest included a speech by Te Whatu Ora Board Chair Rob Campbell, who discussed the system and challenges going forward with his key points being the system having both an aspirational and hard face, a discussion on Pae Ora and equity being achieved through better data provided to all decision makers in the system, a brief discussion on the ‘Unify to Simplify’ staff reforms, that there are too many monitors in the system, solutions to health issues being in the community, not in Wellington, a recognition that Te Whatu Ora needs more funding, and that they “have not and will not have enough funding/money for technology”.

There was discussion of a national data platform that will centralise our data and make sharing happen, and a new interoperability layer was being developed to connect consumer data nationally with all relevant clinicians for better health outcomes.

15th December: Consumer Engagement Meeting with HealthAlliance Auckland: One hour meeting with staff to discuss their approach to consumer engagement for their needs. This was established through networking at the HiNZ Conference as they were unsure about engagement. I provided context on how consumers can be engaged, different types of consumers, remuneration for their input, and the Code of Expectations as well as engagement

policies. They said they enjoyed the meeting and would consider what I had said, then would organise another meeting.

26th January: PEWS Meeting Wellington: Discussed with Wellington consumer manager about a project for escalating someone getting sicker above clinician leadership for faster clinical intervention in child health services. The project is looking for children/youth experience of getting sicker and being responded to for help, as well as someone who can provide a Māori lens. PLEASE CONTACT ME (OLIVER) IF YOU KNOW OF ANYONE SUITABLE IN THE WELLINGTON REGION!!

Positive stories and exemplars

Te Whatu Ora have shown interest in expanding consumer engagement in multiple ways, despite possibly being a bit ahead of themselves. The digital governance group that is being established with support from consumers is a positive step towards achieving better outcomes in a future digital health sector. This increased energy would be a positive way to advance consumer engagement and remuneration in all health districts and regions.

On the 7th February I started a new job as a Graduate Policy Advisor at the Ministry of Business, Innovation and Employment in the Market Performance team! This follows the completion of my BA degree majoring in Public Policy and Political Science in November last year and my upcoming graduation in mid-May. My role will support the team with looking into market failures and core market performance issues that impact consumers, including reforms to the supermarket duopoly. I'm excited to be able to share what I do at MBIE with my roles as a consumer advisor in health.

Mark Rogers (Timaru)

Input / involvement in Commission meetings/groups.

Commission/Major Trauma New Zealand sTBI (Traumatic Brain Injury) team, I participated in Learning session 4 and assisted the Hawkes Bay team. This ongoing project is excellent with both consumer leads being invited back for phase 2.

The Consumers (5) on this group are excellent and the TBI team have fully engaged us.

Attended the Commission Consumer Engagement Quality & Safety Marker (QSM) hui in Wellington.

Activity (since last report)

Highest Needs Review outcomes were circulated to Consumer Advisory Group & Consumer Network members. Details can be found at <https://www.beehive.govt.nz/release/new-model-better-support-kids-highest-needs>

A highlight of 2022 was representing NZ at UNESCO – IBE Global Event (United Nations Educational, Scientific and Cultural Organisation – International Bureau of Education). Refer previous Consumer Network report plus a full report has previously been circulated. The inclusive nature of this event was phenomenal, and the video put together by Nikita and myself was very well received.

Flaminia Macchia, CEO of Rare Diseases International said this was the most successful global event for RD's in her 22 years of involvement.

This project was co-ordinated through UNESCO, Agrenska and Rare Diseases International with input and nominations from Rare Disorders NZ.

Joanne Neilson (Gisborne)

Environmental scan

It has been a busy time in Tairāwhiti we have lost one of our cardiologists who has moved back to the UK and haven't been able to replace him. We are relying on Locums for our ECHO service which leaves us in a precarious position with only 2 days of ECHOES a week and not corresponding with Clinicians clinics so people are having to make two trips, difficult if you live 3 hours away in Te Araroa. This of course is just in Cardiology that is not taking into account, Oncology, Haematology and many others.

Also, the weather continues to play a part in the ability to access our services. Of course we are not alone and our thoughts are with the people of Tamaki Makarau and Northland as climate change shows us its full force.

We have been asked to prioritise Māori and Pacific people to ensure we are offering an equitable service.

Activity (since last report)

I was asked to apply for the senior Administrator role and finally after 4 months the team leader has decided she hasn't got the time to train one. This is largely the issue with the health system. People are overworked and make stupid decisions that then make the work environment a difficult place to be. I enjoy the team I work with but am frustrated by the number of people that are trying to save their own skin and are not really up to the job.

Services

This is still the same as last reports as nothing has changed. *It concerns all of us at the Hauroa the number of DNA's (did not attend) and no shows we are experiencing. We are spending a lot of money on locums only to have patients not show up, it means not only a waste of time and resources but appointments that could have been used by others, not sure how to deal with this issue. I am sure others have seen this in their districts also.*

Vishal Rishi (Auckland)

Kia ora and warm greetings!

Wishing you all a very happy new year and special greetings for the Chinese New Year as well, a year of Rabbit symbolising grace, mercy, beauty and good luck.

Environmental scan

As mentioned in the last report about invisibility of Asian, ethnic, and former refugee voices in the health reforms. Ethnic people constitute more than 20 percent of total New Zealand population. Lack of consultation, visibility and presence of Asian & ethnic people at the design & decision-making tables would certainly contribute to increasing health disparities & inequity for Asian & ethnic communities further. The recent example is the one of the locality co-lead of an identified localities did not consult with ethnic populations. If these systemic disparities are not addressed at the very beginning, a birth of another inequitable health system for other populations of Aotearoa will be unavoidable.

Activity (since last report)

In light of the above, The Ethnic Health Collective has been launched on 6 December 2022.

This is a collaborative platform which provides a space for Ethnic Health Leaders to come together in a mission to improve health equity for Aotearoa's ethnic minority communities.

The inaugural Strategy Group members shared their vision, leadership and aspirations for the collective. The collective's Strategy Group is made up of academics, researchers, medical practitioners, and community leaders who all share the common goal and vision for bridging inequities for our ethnic minority groups.

Ethnic Health Collective will be community-led, provide policy advice, and influence health outcomes of ethnic groups in New Zealand. It will also strengthen the community infrastructure and encourage local action, gather insight, and understand ethnic communities' barriers to achieving health and well-being. EHC also envisages investing in collaborative public health initiatives and developing a collective voice to influence government health policy and decision-making to ensure investment for equitable health outcomes for Ethnic communities.

Thanks a million to the Commission for the support and we envisage to collaborate more specifically in regards to consumer engagement work in Aotearoa.

Links to the media coverage are mentioned below:

<https://www.stuff.co.nz/pou-tiaki/130688841/ethnic-leaders-form-new-health-collective-to-bridge-inequities>

[Initiative to promote health equity among ethnicities - indiannewslink.co.nz](http://indiannewslink.co.nz)

Attended Te Whatu Ora CM Health Asian Health & Wellbeing Community Network

Attended to Te Whatu Ora Waitemata Consumer Council meeting

Collaborated with key stakeholders for Health seminars, Health Talk and community engagement project: *Traditional Chinese Medicine Healing Centre, Auckland Council, Northcote Library, Onehunga Library, Te Manawa.*

Services

Supporting grassroot communities in Auckland, specifically families that have impacted directly or indirectly by the recent floodings.

Some major public health concerns have been reported.

More households are accessing emergency food banks, reflecting that people are still suffering from the aftermaths of the pandemic and flooding.

Positive stories and exemplars

We have delivered five health seminars to improve Asian community's access to the health and social services in New Zealand. Four seminars were delivered in Auckland and one in Hamilton.

Consumer engagement is at the forefront for our delivery, and we continue to engage with migrant populations on regular basis.

Published quarterly newsletters in three different languages. These can be accessed by clicking on the following link and if any of our network members want to publish anything

in there, then please do not hesitate to contact us :

<https://www.asiannetwork.org.nz/news/newsletters/>

Renee Greaves (Auckland)

Environmental scan

Continuing issues for Counties District - Access to GP appointments

Social welfare support requirements, economic impacts of covid disruptions, workforce shortages across industries, continued uncertainty around the health system and its ability to respond to community issues.

Ongoing disruption in the community, resilience reserves feeling empty and the feeling of waiting for the next wave of complexities to hit our communities. This has now exacerbated by the latest floods and State of Emergency.

Consumer and volunteer capacity seems to have reduced. Involvement is challenging in the short term due to community and work pressures, because of all this uncertainty, and now additionally the flooding. Community agencies are at capacity helping flood victims. We are seeing a decline in the ability to facilitate face to face engagements due to availability of community members capacity being impacted by work commitments, whānau support. Communities are involved in the reactive support and capacity for long term involvement seems more complex.

At a local level our Consumer Council is still running consistently, influencing national work, and involved in local priority areas as capacity allows.

Te Whatu Ora CM - Three priority areas are: Workforce, Acute Patient Flow and Planned Care Recovery. Plans are underway for consumer engagement within all these large strategic system programmes of work.

Still a lack of clarity and understanding around localities and how it connects to the districts.

Input / involvement in Commission meetings/groups.

Commission Quality Safety Marker-Consumer Engagement, last meeting 2nd Feb

The Four Pilot sites (Counties, Canterbury, Waikato, Waitemata) - the same pilot sites that were involved in the inception of the QSM-Consumer Engagement, have been reconvened. We are currently restructuring the QSM framework to be more directly reflective of Te Tiriti throughout all domains, and across the maturity matrix, representative of the Code of Expectation. We are also trying to ensure that the framework is applicable to all districts and can be used as a measure for Ministry of Health in relation to progress in consumer engagement. We are undergoing local consultation around the current proposed changes to the Framework, local processes and implications. The original framework was created as a self-assessment, improvement tool and now needs to also act as a measurement tool at a national level. Underpinning questions around what needs to be routinely measured and showcased in your submission, and what is a selection of exemplars of consumer engagement in their varying degrees.

Activity (since last report)

Te Whatu Ora-Health New Zealand - National Steering group, involvement in development of new consumer recognition and remuneration policy.

Te Whatu Ora Health New Zealand - Consumer Councils Steering group, work is around the development, stakeholder engagement and implementation of the transition plans for 2023, these plans are just at concept phase, with wider consultation required in particular with the consumer councils as a whole, not just via the national consumer council chairs collective, amongst many other stakeholders, a new iteration of the transition plan is being developed for

CC feedback, and then a paper would be created and presented to Te Whatu Ora, Exec leadership teams.

Zechariah Reuelu (Porirua)

Environmental scan

The rising cost of living is putting the family household huge pressures throughout Christmas and the start of the schooling. These reality is putting families/whanau with health challenges. The COVID-19 pandemic is still intransitive hanging around. Not being able to afford the essentials, such as food, rent, heating or transport, has wide-ranging negative impacts on mental and physical health and well-being. Like the COVID-19 pandemic, the negative impacts of the cost-of-living crisis on health and well-being are being disproportionately felt by those on the lowest incomes in Porirua. In the start of the school year, we saw the impact of rises in the cost of essentials – power bills, rental housing, food, and fuel that have outstripped average increases in people's wages and welfare payments.

Input / involvement in Commission meetings/groups.

This quarter I participated in the following:

4. Bula Sautu Pacific Consumer Steering Group Response
5. Consumer Health Forum Aotearoa
6. Consumer Network
7. The Tangata o le Moana
8. Consumer health forum Aotearoa - Shape future forum events for 2023
9. Bula Sautu Advisory Group Fonu

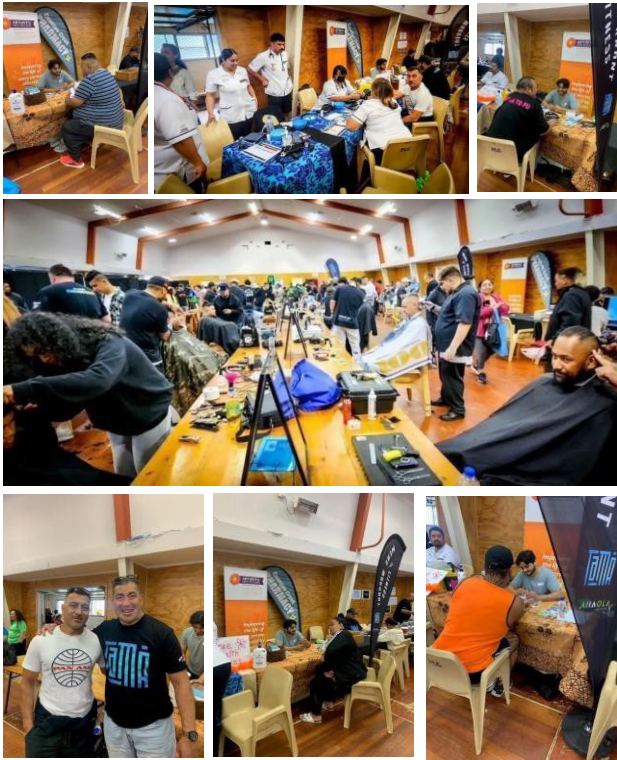
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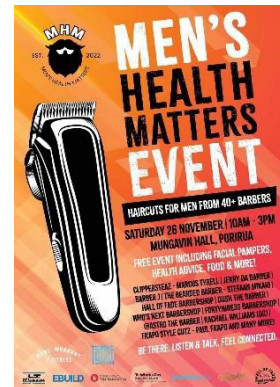
USO Bike Ride Community Celebration - Polynesian cyclists bike more than 750km from Māngere to Porirua. The USO program has increased numbers of children & youth biking. Cycling is good for your health and wellbeing, social cohesion and the environment.



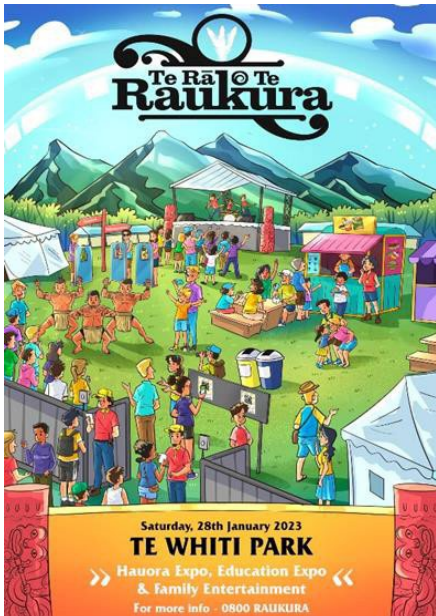
Pacific Governance Fonu Strengthening Pacific representation on the Commission's advisory groups. Tangata o le Moana to continue with their internal work programme with the Commission to help understand Pacific equity and engage with Pacific families and communities.



The event draw over 300 youth & adults for free haircuts. Our team service included gout education consults and point of care serum uric acid testing. Up to 80% of the consumer had high uric reading & instructed to contact their GP clinic. The Porirua Community Pharmacy was encouraged to engage with pharmacist to better gout management.



The establishment of a Community Leaders' collective governance body for Porirua. The purpose of this hui is to continue to develop a leadership collective between Porirua community leaders. By sharing experiences, we can strengthen bonds and direction for Porirua in a way that is meaningful, and empowering, and allows us to contribute in an enhanced way to uplifting our communities and environment. Together we can speak with a powerful unified voice.



The annual Te Rā o te Raukura (Te Rā) was held at Te Whiti Park in January 2023. 'Te Rā' is the major Māori whānau-oriented community festival in the Hutt Valley. The event draws great numbers of māori whanau and this results with high levels of testing for, gout, high blood, heart checks & diabetes.

The 'passport to health' is part of the health promotion section. This is a short activity booklet, that had a question in relation to each stall provider within the hauora marquee. Arthritis NZ provided a questionnaire for the passport. "Is gout arthritis link to your whakapapa"

This question is based on the Māori and Pacific people have a greater genetic predisposition to develop gout arthritis than other ethnicities.

Throughout the day, attendance would share their gout journey, if any, then proceed with the passport. We discussed, some Māori and Pacific people have genes that make it harder for their bodies to get rid of uric acid. Gout arthritis runs in whanau, although not all whanau members will get it, and some people develop Gout arthritis with no family history of the disease.



Community leadership and co-designs for Pacific Health Research solutions.

Services

I am hearing confusions at the community grassroots with the work of the Te Whatu Ora Health NZ & Manatu Hauora – Ministry of Health. Te Whatu Ora. Last November, Te Whatu Ora launched the “Interim Pacific Health Plan – **Ola Manuia July 2022 – June 2024**. Yet, Manatu Hauora – Ministry of Health will be hosting a fono on 16th February 2023 in Porirua to help them develop the Pacific Health Strategy. It is recognise the new health reforms is required for equitable change to happen, however, the coordination of the strategy from a consumer lens is confusing.

Arana Pearson (Commission mental health consumer engagement advisor)

Environmental scan

Clients of mental health services noticed more focussed service delivery through the first lock down. Many homeless people were domiciled somewhere at that time and services coordinated more directly across the spectrum of statutory and non-statutory services. Since then, the sector has reverted to a less focussed approach, particularly in the community service sector and non-statutory services.

Discrimination remains a barrier to services, access to services is difficult for mental health clients, physical health outcomes remain low which results in mental health clients dying on average thirty years younger than average.

Input / involvement in Commission meetings/groups.

The whole mental health team work of 5 projects, most involvement to date is with:

- Physical health needs of mental health clients
- Ending seclusion

Outside the mental health part of the Commission I have connected with:

- Partners in care
- MAPS (client expectations/ advanced directives project)

Activity (since last report)

I began working with the commission mid-January. I am employed three days per week. Usual days are Monday, Wednesday, and Thursday

Services

Hospital services are increasingly not fit for purpose. Media examples exist now of people being placed on a mattress in a seclusion room. No bed. No toilet (other than a bucket) and no water.

Some mental health clients are becoming criminalised in the absence of safe environments or discriminatory communities. For the first time NZ now has built a psychiatric hospital inside a prison. This means that our homeless people who experience mental illness are at risk of being criminalised by communities in order to achieve housing and to 'remove the nuisance' from those communities.

Positive stories and exemplars

There are some consumer run services now that provide residential care and support for people with mental illness. One in South Auckland and one in rural Nelson.

Tofilau Bernadette Pereira (Auckland)

Environmental scan

This report is brief as the events that had led to the displacement of people, infrastructure, livelihoods, animals, and general disruptions to the lives of those in Tamaki Makaurau are well known to the entire nation.

The massive floods and continued heavy rain has disrupted lives across Tamaki Makaurau. Well over 600 households have been affected, infrastructure destroyed, vehicles submerged under water, and family household belongings swept away during the flooding.

Communities and emergency management services together with Civil Defence and volunteers are trying to coordinate the massive clean-up, clear out, and moving those being displaced into evacuation centres. And the post flood clean-up continues.

Cyclone Gabrielle added its own disaster in a period of two days, and in some cases families who were affected by the flooding were hit the second time with the aftermath of CG.

Auckland is a city of ruin, with families seeking the basic needs of accommodation, food, and trying to return to some sense of normality.

In the Pacific space, the Pacific Social Providers were quick to organise its responses and the community were rallied to providing basic supports to the Emergency centres in Mangere and Manurewa that were initially set up. More EC's and services were also established to cope with both the flooding and the Cyclone.

South seas Healthcare Trust Response to the Auckland flooding and Cyclone

Southseas activated an immediate flood relief response, as one of the two key providers that were requested to provide wellbeing and food support through MSD to ensure individual families, especially those affected were supported in South Auckland, The staff worked around the clock over the long weekend to support the affected whānau and communities.

A communication plan was activated advising all communities on where to go if affected, announcing emergency centres, the 0800 numbers as well as Civil Defence numbers, the Police, and pointing people to supports that were immediately made available like warm bedding, food, transportation and supports delivered to families who were unable to move from their homes.

A much more aligned, and coordinated support from the social providers, NGOs, local Council and government agencies.

The clean-up and recovery phase for the entire City is humongous and slow.

Ricky Ngamoki (Ōtepoti)

Environmental scan

New trends

Housing is becoming a big issue in the community. This is a concern, specifically with men that have just been released from prison, and Mental Health and Addiction clients.

- Mental Health patients are unable to sustain accommodation, and a number of them appear to be over medicated, preventing them from gaining meaningful employment in the community.
- There is a known housing shortage and the Dunedin Night Shelter Trust is aware of this too and PARS struggle to locate property that will allow them to setup to have folks that have just been released from prison.

Longer wait times to access GP than previously reported. Now a week and a half if you are lucky otherwise 2 weeks.

Lack of GP's that want to live and work in Dunedin.

It has become apparent recently that it is known in the health space that Māori and Pacific organisations are exploited. They are given a promise of a carrot, they set up the process and programme, get it all ready to go, they start and get it up and get it running, then a month or so later, they are told that there is only the green top of the carrot available as the resource had to be allocated elsewhere. This is not new and has been happening for years and that is the reason that there is no change in the system. They keep robbing from Peter to give to Paul, and then Patrick, then Paula and no one ever actually has what they need. They are aware that Māori and Pacific will make things happen on the smell of an oily rag.

Lack of skilled workforce in the health sector. There is a massive shortage of qualified professionals. Once they are trained they go overseas for better money and better conditions.

Consistent concerns

Whānau are still struggling with rising costs of living, with Covid-19 still present in the rohe, it has been difficult.

Rising cost of kai and rent continue to be a stressor, along with the lack of affordable housing. (To rent or purchase)

Housing is a big issue in Otago and Southland. And the lack of healthy homes is an issue for whānau. There are several whānau still struggling with loss of income and dealing with the on-going effects of Covid-19.

Parking around the hospital is an increasing issue for Dunedin Public hospital. There is a lack of accessible parking for disabled, elderly and anyone in general, if they are driving themselves, or being dropped off at the hospital. The City Council is making alterations to the roading plans and are putting cycling lanes, and this is making it more and more difficult for whānau to access services.

Mental Health is on the increase here. There is a lack of skilled workers in the South Island, and it is difficult to get support for whānau when they need it. The services that are operating well, are over-run with waiting lists that they struggle to get through.

Men being released from Prison, have no accommodation, then they get placed into a motel, which is not sustainable. They then get put out on the street and end up in trouble and ultimately back in prison.

Activity (since last report)

We have had archaeology students being hosted at the whare wānanga, and there was a breakout of Covid-19.

There are more support services becoming available for Māori which has been positive

COVID-19 comments.

There are still people that are struggling with long Covid-19

Services

Concern is rising about the lack of services and the on-flow effect of lack of provision. (GP, Dentist, Mental Health Practitioners) – This is becoming an increasing concern, with the spike of Mental Health due to Covid-19 and the effects it has had on whānau. This is getting worse.

There is a lack of support services for those that are needing to detox from Methamphetamine – There were several services in Dunedin that were providing this, however it appears that service delivery is not the same as it was pre Covid-19

It has been positive for whānau Māori to see more support for positive Kaupapa Māori health services. Across the motu, there are new organisations that are being established, however they all face the same issues.