

Present: Mary Schnackenberg, Angie Smith, Mark Rogers, Hyejung Kim, Joanne Neilson, Bernadette Pereira, Ricky Ngamoki, Amanda Stevens, Jennie Harre-Hindmarsh, Zechariah Reuelu, Oliver Taylor, Marlene Whaanga-Dean, Edna Tu'itupou-Havea,

Apologies: Renee Greaves, Shaun McNeil, Lauagaia (Cat) Jeffries, Vishal Rishi

HQSC staff: Chris Walsh, Deon York (Chair), Dez McCormack, Allison Anderson, Tanaya Shangarpawar, DJ Adams, LJ Apaipo, Gillian Bohm

The meeting commenced at 9.45am

1. Opening and welcome

Deon welcomed everyone to the meeting, noting this is the first in person for the five new members attending. DJ opened with a karakia.

Apologies were noted.

2. Whakawhānaungatanga with new members

A Whakawhānaungatanga was completed by everyone for new members.

3. Minutes of the meeting held 24 February 2022, and Interests register.

Previous minutes accepted. (Mark moved Bernadette seconded).

One date correction from Mark.

4. Feedback on previous Board hui and CAG hui

Deon spoke about his update to the board on the consumer voice work, including progress and state of play with the consumer code and centre of excellence. This was a verbal report. One topic was the FVDRC report and ramifications of this. Rowena (now ex CAG chair) spoke to the recommendations.

Gillian also spoke of other board topics – the Board strategy session on the Commission identity, Review of National Mortality Review Function and the implementation options and the final Statement of Expectations 2022/23.

Gillian added explanation on how reports recommendations (e.g., FVDRC report) ultimately get funding, as in the recent budget announcement. Funding always links back to these report recommendations.

Mary gave an update on the Consumer Advisory group hui held prior to the board hui which had the opportunity to feed into this paper. Feedback was given by CAG on the SPE and the te Ao Māori framework. There was again mention that consumers are not consulted before policy but after its written. There's a need to have them at the table at the planning stage.

Mary provided the following written report, which she had prepared in braille to read to the group:

HQSC has three cross-organisation consumer groups:

- today's Consumer Network.
- Consumer Advisory Group (CAG) – I sit on both groups; and
- Te Rōpū Māori.

The CAG and the Te Rōpū Māori are asked for comment about some of the papers that go to the HQSC board, papers that need our consumer lens prior to the Board meeting. Sometimes the writers of the papers may amend the papers because of feedback the CAG provides. We have the opportunity to exercise influence because we come from a wide variety of backgrounds and experiences.

Some members of the CAG were available to meet in March to see a draft of a report about a review of the Mortality Review process that HQSC has used for several years. The company undertaking the review met with us at the end of their review process which was concerning for us. Consumers need to be involved at the outset of major projects, which this one was. The HQSC Board and management will have received the final report and will be working on what changes they may implement.

The CAG met last week and considered several topics. Our chair for the past five years has been Rowena Lewis. She has stepped down.

We looked at the Partners in Care work plan which we will be discussing today. We also received an update on the Te Ao Māori Framework from Dr Gunn which we will discuss today.

Thinking particularly about board papers, we provided feedback on HQSC's Statement of Performance Expectations. That's government speak for annual plan.

We also considered the HQSC Centre of Excellence. A thoughtful paper from HQSC which showed considerable research drew very positive comment and our advice on a possible renaming of the centre of excellence. Again, HQSC is seeking input from the Consumer Network today.

The Quality Safety Marker report that HQSC asks DHBs to complete is getting a refresh with a Te Tiriti lens. The QSM is a mechanism to test quality outcomes that may lead to new or amended interventions. Process is considered and outcome stories are told. The QSM has the support of the health profession.

Next month the CAG will meet again. During part of our day, we will work through the HQSC's Agenda for CAG. The other part of the day we will meet with Te Rōpū Māori. These joint meetings allow HQSC to upskill its consumers, both consciously and unconsciously. And we share perspectives with each other.

5. He Hoa Tiaki/Partners in Care (PIC) report

Deon spoke to the report. Here is the written report prepared by Allison:

Since the 29 March meeting the He Hoa Tiaki team has focused on delivering the second consumer health forum Aotearoa event and analysing feedback from the consultation on the code of expectations for health entities' engagement with consumers and whānau. Subject to sign off, the code has been completed. The consumer health forum Aotearoa and the code are therefore mostly progressed.

The focus over the last two months of this financial year will therefore be the content and organisation, and presentation of Te Kete o Hiranga | the centre of excellence for consumer and whānau engagement and completing our programme plan for 2022/23.

We welcome our newest team member, Brittany Jones. New to the Commission, Brittany has most recently worked as a research technician for the University of Otago Wellington since graduating from the University of Otago with a Master of Applied Science in quantitative genetics. She studied this and her undergraduate degree, a Bachelor of Biomedical Science, in Dunedin but she is a Wellingtonian born-and-bred. Brittany has fit right into the team and is already helping us to provide and plan more opportunities for capturing and analysing consumer data,

which helps the programme to provide more rich and targeted projects for consumers and whānau.

Key achievements

- The second consumer health forum Aotearoa event was hosted by the Commission on 7 April, Te huarahi ki pae ora | The journey to healthy futures.
- All feedback on the draft code of expectations for health entities' engagement with consumers and whānau has been reviewed and themed (169 in total).
- The draft code has been significantly updated to reflect feedback.
- The updated code has been reviewed by the group who originally worked with the team to develop it and all subsequent changes incorporated.
- The consumer health forum Aotearoa update has gone out with a summary of the key themes from the second consumer health forum Aotearoa.
- The co-design e-learning modules are progressing on-time. The project will wrap-up mid-June in time for a 'launch' of the modules early July.
- The centre of excellence has adopted a working title: Te Kete o Hiranga, however we want to know what you think it should be called. Advisors are currently consulting and compiling examples and best practice ideas.
- The Let's Plan resources have been updated and printed. They are now available in print, audio, NZSL, large print and Braille formats. Print translations are also available in the following twelve languages: Te reo Māori, Cook Islands Māori, Fijian, Hindi, Kiribati, Niue, Rotuman, Simplified Chinese, Samoan, Tokelauan, Tongan, and Tuvaluan. These are all available for ordering here: [Let's plan to leave Hospital](#) and [Let's plan for your next healthcare visit](#).
- A new guide for health care professionals [Three steps to meeting health literacy needs](#) is also available to order. This guide available in both English and Te reo Māori builds on our earlier publication *Three steps to health literacy*.

Planned activities for end of financial year

- The code of expectations for health entities' engagement with consumers and whānau has been sent to the Minister of Health with an accompanying briefing. It is hoped that a formal launch of the consumer health forum Aotearoa and the code can take place, with the time and date to be confirmed.
- The 'centre of excellence' needs a clear presence on the Commission's website and must be up-and-running by mid-June.
- The planning for three additional co-design modules is underway. We will focus these more intently on the consumer audience, and give more insight, engagement framework options, and cultural considerations for co-designing with both Māori and Pacific populations.
- We are looking at producing professional videos with the speakers of the last consumer health forum event.
- He hoa tiaki / Partners in Care are hosting the DHB consumer council chairs at an all-day hui on 16 June.

Deon then presented a PowerPoint that was shared with the commission's leadership forum earlier in the week. This posed the questions – "how do we apply the expectations of the code in our commission work?" and "how will the commission model leadership with the code"?

When the final wording of the code is signed off in the Pae ora bill an “implementation guidance” booklet will be produced for the sector.

6. He hoa tiaki / PIC Programme plan for 2022/23 to 2024/25

Allison and Deon presented a high-level PowerPoint presentation for the next three years. The plan focused on the four workstreams that have been established. These are:

Workstream one: Strengthening a centre of excellence for supporting the health sector to engage with consumers, whānau and communities (Whakamaru & Kōwhiringa)

Work stream two: Supporting and growing a consumer forum which embeds and enables the consumer and whānau voice to be heard across the health system (Pātuitanga)

Work stream three: Building consumer and whānau leadership and capability (Rangatiratanga)

Work stream four: Measuring progress and responding to the consumer, whānau, and community experience of the health system (Ōritetanga)

The programme plan is currently a work in progress and will be presented and discussed at ELT before the end of June

7. Comments/questions on members reports

Consumer network members written reports are recorded below these minutes. As usual, these will also be sent to the Executive and Senior Leadership Team and published online when ratified.

Members who submitted reports were given the opportunity to expand/discuss their report.

8. Update on Te Ao Māori Framework

Te Raina gave a presentation on the updated framework.

There were several questions asked and a lot of positive interest in the framework. The QSM to measure the use and success of the framework externally is yet to be developed. The framework is incorporated in all commission programmes.

9. Centre of Excellence (COE). What does this look like?

Chris/Deon gave an introduction to what the Centre of excellence (COE) is all about. Accessing good quality information, providing research, training aids etc.

Comments: it needs a new name. Excellence doesn't leave room for improvement.

Te Reo names were suggested that encompass the spirit of what excellence is.

Another view was that excellence meant we have high aims for achievement. Excellence is a challenging name, but we are up for the challenge.

There will be a strong education component on the website for this COE. Consumer perspectives and input are going to have an impact on the quality of information that goes in this hub.

Consumers lived experience will have to be a big part of the information and how their experience ties into the information contained on the site.

10. Summary of day. Closing comments

Comments from new members: the expertise at this table helps to inform how new people see their role in advocacy at a local level and how to use this knowledge gained to be more effective.

There is a web of pathways to navigate thru in understanding where consumer experiences fit into the health system and what effect these experiences can make for positive change in the system.

A further question was raised about the future of consumer councils and how they are coping with the current changes. There is a lot of positive proactive work being done locally and the commission is seeing this in the regular meetings they host for the consumer council chairs group.

There is still a big unknown as to how the new health system will look in the future, but the group was committed to make the consumer voice heard.

Vishal asked to be e-connected with the Waikato consumer council.

11. Karakia and close

DJ closed with a Karakia

Next Consumer network hui – 26 August 2022 (hopefully in person)

Action's list

There are no action items

Summary of consumer member reports for 25 May 2022 hui

Mary Schnackenberg

Environmental scan

Generally, there are positive feelings about the health reforms, especially the new respect for consumer engagement.

Involvement in HQSC meetings/groups:

16 March - Consumer Advisory Group. Received a presentation from Francis Health about their draft report concerning the National Mortality Review

29 March - Consumer Advisory Group meeting

7 April - Consumer Health Forum Aotearoa, attended morning session

12 May - Advance Care Plan: a fascinating conversation about their advertising programme currently aimed at Kiwis undertaking high risk activities and their understanding of the advertising. One colleague suggested an Advance Care Plan might be thought of as a medical will.

Activity (since last report)

- Auckland DHB (ADHB) Consumer Experiences Council - attended 28 February meeting which considered workplan. Our 28 March meeting was cancelled as staff were called away to support colleagues with the COVID-19 response. We expect to meet again on 23 May.
- 10 March - The Disability Advisory Panel of the Office of the Ombudsman met via Zoom. This was the second meeting I have attended, and we are learning about the panel's work and the wider work of the Ombudsman. The Ombudsman reviews places of seclusion in health facilities, among other health-related projects.
- 30 March - I commented on the draft Northern Regional submission on the Code of Expectation. My proposed wording change was agreed to and there was a significant improvement in the wording of a particular point.
- Pharmac Consumer Advisory Committee meetings on 11 March, 8 April and 13 May. The final report about the review of Pharmac is expected soon. Increasingly Pharmac is seeking early

advice from us about their several work streams. They are proactively going into the media and receiving increasing positive comment.

- Health and Wellness Group: members with various disabilities supported by the Disability Advisor at the Waitemata DHB meet to have a general catch up raising a variety of individual and systemic concerns. Their last meeting was in December 2021. For a number of reasons, the meetings planned for February and May have been deferred. We will meet again in August.

Planned work in the coming quarter

- Pharmac has monthly meetings scheduled.
- The ADHB Consumer Experiences Council should resume on 23 May.
- The Disability Advisory Panel of the Office of the Ombudsman will meet next, this time face to face in Wellington, on 17 June.

COVID-19 comments

- My business continues to produce audio and braille formats of various government documents.

Services

- Ongoing examples of personal health information for individuals not being attached to specific NHI numbers.
- For example, a deafblind person who had previously been admitted to the same hospital returned for further treatment. A visitor who came the second day they were in hospital found their cochlear implant had not been turned on. There was no print notice above the bed to explain to staff that the patient is deafblind. This same problem had occurred on the previous hospital stay.

Positive/feel good stories

- On 28 April I participated in a panel about Telehealth services to disabled patients. The takeout message was “please ask the patient what assistance they might need during the telehealth consultation”. It was altogether very encouraging for the clinicians who numbered about 100 Zoomers.
- At last, we are returning to face-to-face meetings.

Jennie Harré Hindmarsh

Te Tairāwhiti Environmental scan

The Covid-19 pandemic continues to preoccupy community networks, schools, health & social services, and aged care providers. Older persons and those who are immunocompromised, have been sharing a sense of heightened risk and associated stress around making social interaction decisions since the ‘abandonment’ of more extensive public health protection measures last month (e.g., decreased use of masks & vaccine passes) - amidst waning protection from first vaccination boosters 4-6+ months ago, and the ongoing prevalence of infections and after-effects.

On a more positive note, it appears that the pandemic-response-prompted, more effective collaborations between Iwi, iwi-led & other health providers (especially the DHB and primary care), and education & social service providers is becoming ‘business as usual’ - an important strength which builds on high levels of local community-connectedness and hopefully is helping to prepare the groundwork for implementing the now-imminent national health system reforms at our local level.

Input / involvement in HQSC meetings/groups

5 April 2022: Online facilitated workshop with Waha (Māori Creative Agency working with interim Health NZ and Māori Health Authority) to provide input for the development of “public messaging that speaks to the diversity of people in all communities about the future of our health system and the first New Zealand Health Plan”.

6 and 26 April 2022 (zooms): Consumer Network Induction sessions x 2

4 May & 18 May 2022 (zooms): DJ Adams about ideas for the PIC's centre of excellence - 'Te Kete o Hiranga' (Basket of Excellence)

Other Activity (since last report)

Negligible kanohi ki te kanohi community activity since last report given risk factors associated with Covid circulating so widely. However, I have been taking advantage of opportunities to participate in informative health sector webinars.

These have included a presentation by Don Matheson discussing the potential for learnings gained from Covid-19 pandemic responses to contribute improving the current health system reforms, 'especially the elusive pursuit of health equity'

(29 April); Jo Hikaka and Ngaire Kerse summarising their Aged Residential Care and Māori report, which includes positive examples of care provisions that have incorporated Māori leadership, Māori workforces and Māori values

(5 May); Fepulea'i Margie Apa, Chief Executive Interim Health New Zealand, about progress in setting up the new health system, its high-level organisational structures and proposed relationships between Health NZ and the Māori Health Authority

(9 May); and Reema Harrison (AIHI Macquarie University) about consumer engagement in health research & improvement.

COVID-19 comments

Disappointingly, the vaccination rollout for 5-11 year olds, direct to whānau and through schools (especially on the Coast), has not achieved the high coverage hoped for, and since March Covid infections have spread to all generations often as part of high infection rates in schools (closing some for a week or so).

The now-noticeably-scaled-back district vaccination programme continues to 'chip-away' at increasing vaccination rates, including first boosters. The Tairāwhiti district has the lowest booster rate in te motu (65.4%) thus weekend whānau vaccination events, which are supported by a wide range of community organisations, continue to be offered - but less frequently. From mid-May, the flu vaccine is also being offered at these 'Vax to the Max' events. For examples in the city, see Hauora Tairāwhiti posts on <https://www.facebook.com/Hauora.Tairawhiti>; and on the Coast, see Ngāti Porou Hauora posts on <https://www.facebook.com/ngatiporouhauora>

Since early April expressions of concern have been increasing in the community about:

- 'Delays' in offering a second booster/fourth covid vaccination dose to (at least) those over 65/70yrs given for most of us older folk it is now 5-6 months since the first booster and international evidence is our vaccination protection is now significantly reduced (for which similar countries have offered 2nd boosters to many after 4months).
- The number of people not reporting their positive Covid test results through the online system, which means they are missing out on the early pro-active support their primary care provider could have offered, and the Covid prevalence rate of those with covid symptoms is being significantly under-reported. (Some health providers estimate under-reporting is by at least 60%, based on patients' mentioning they'd had covid during later consultations.)
- Requirements (until recently) to have Covid symptoms to be eligible to collect RAT testing equipment, and the distance many need to travel, often when unwell and already infectious, to collect these tests from only two venues in the city or Coast clinics with limited open hours. (During the March/April Regional State of Emergency, it was even harder/impossible to collect RATs and report results given significant damage to rural roads and internet connections – accentuating the importance of making RATs collection

available to all, pre-infection, which is not happening (but still in few locations with limited week-day hours).

- The significant pressure on primary care and aged care personnel from the ongoing omicron outbreak, now exacerbated by more staff becoming infected and more patients presenting with covid 'after-effects'.
- On a more positive note, in the last week there has been no patients with Covid in the Gisborne Hospital, and to date very few Covid-related deaths in the district.

Hyejung Kim

Attended Consumer health forum on 7 April

Activity (since last report)

Attended Korean society & KWWCG meetings - on 24 Mar, 11 Apr, 9 May 2022 and discussed COVID 19 Vaccine, Traffic light settings & support Asian Health Service for "Boost Your Winter Immunity Event" on 30 April

Health information Seminars with Korean Society & KWWCG, zoom (100+ online each) & face to face on 26 February & 26 March

Topic: COVID 19

- Vaccine: get booster dose, children age, Novavax available
- Covid-19 test, how to report the RAT result
- How to use the COVID-19 contact tracing form
- Self-isolate and how people should prepare



These two seminars are on YouTube NZ YTV, more than 1,000 total views combined.

COVID 19 & Mental Health Seminar with Waikato Korean Society, Korean Community Wellness Society (KCWS) & KWWCG Zoom on 3 May

- Vaccine: get booster dose, children age, Novavax available
- Covid-19 test, how to report the RAT result
- How to use the COVID-19 contact tracing form
- Self-isolate and how people should prepare
- What to do when you have COVID-19 symptoms

Korean Health Day organised by Korean Society on 7 May

- Health Seminar
- Free health check – blood pressure, blood sugar level, waist-to-height ratio

Planned work in the coming quarter

Health information Seminar with Korean Society & KWWCG in June or July (not yet confirmed)

Topic can be COVID 19 info, support for seniors, diabetes, perinatal depression, and dementia care

COVID-19 comments

People didn't know they should report the RAT results whether positive or negative. When they have positive results, they just self-isolated without reporting.

One of attendees said she knew someone who had Covid-19 symptoms but didn't get the test.

Many people were confused over self-isolation as a household contact, if someone else in the household tests positive, do they need to restart isolation or not?

Renee Greaves

Environmental scan

There is a sense in the community of freedom once people have had Covid, unless affected by long Covid, but people are concerned about the implied winter season of flu and other variants coming back into the community. How much longer will they become impacted. Resilience is at a low.

Activity

I have recently returned from maternity leave

Within DHB- we are focussed on four patient experience priorities:

- Growing consumer Insights
- Increased consumer engagement
- Developing customer service ethos
- Building a health literate system

We have increased our team to include an Experience and Engagement Co-ordinator, and we are currently recruiting for a Survey system administrator and Patient information analyst.

Services

What's going to be the national and local solution to the ever-growing surgical wait lists and outpatient appointment follow ups caused by Covid disruptions?

Edna Tu'itupou

Environmental scan

Long Covid has been the talk of Victoria University since the latest lock down. Staff and students are greatly affected by long Covid and symptoms such as tiredness, brain fog and low energy levels are commonly experienced.

There has been a lot of discussion about the health reform and how that will benefit Pacific people.

COVID-19 comments.

As the secretary for the Wellington Tongan Leaders' Council (WTLC), I organised a Tongan vaccination day that took place on 13 November and 11 December 2021. Both events were well attended and supported by local community. The (WTLC) in partnership with Pacific Health Hutt Valley and CCDHB hosted these events.

The ethnic specific approach was a positive in promoting vaccination in the community and increasing the vaccination rate.

Edna added verbally: the extent of long Covid and its severity and that is a long-term thing are very real.

Services

The long waiting time to secure a GP appointment has been an issue that patients reported. At Pacific Health Plus in Porirua, staff are working overtime and afterhours to respond to the needs of Pacific communities.

Furthermore, Pacific communities are feeling the long impact of Covid especially with the decrease and or lack of income. Families are reporting higher needs post lock down for assistance with food and household bills, including rents.

Positive/feel good stories

The Whanau Ora support offered by Pacific Futures Ltd (Pacific Commissioning Agency) has been a key player in funding community assistance during 2020-present with families impacted by Covid.

Joanne Neilson

Activity (since last report)

Looking forward to Pride week in Christchurch although I am only able to attend a couple of events.

I am enjoying working at Hauroa Tairāwhiti as an Administrator. It is giving me an insight of the hospital systems. There are lots of things I would like to change but time will tell if we can make any movement there.

COVID-19 comments.

I have had Covid, and I am so grateful for the Vaccine and Booster because I would hate to think how I would have got through it without them.

Positive/feel good stories

Life is good and I am grateful to work with very passionate people both in my employment and my community work.

Mark Rogers

Environmental scan

Our region, like others is experiencing a number of Omicron cases, mainly between 100 and 300 daily. Elective surgeries/planned care is being managed based on available capacity. This should be helped by the high intake of new staff members at our DHB.

Input / involvement in HQSC meetings/groups.

'Severe Traumatic Brain Injury Steering Committee' for 2022. No activity.

I attended part of the Consumer Health Forum Aotearoa. The panel discussion by four invitees was very enlightening.

Activity (since last report)

Ministry of Education, Rare Disorders and other interested parties had a Zoom meeting to conclude submissions for the 'Highest Health Needs Education Project.

All Consumer Network and Advisory group members were sent access to the portal to enable members to make a submission. This quite robust project closed on 31 March 2022 with outcomes due from October.

In addition, I participated in the Rare Disorders collective education focus session.

I was asked to be a panellist for AICG (Australian Institute of Clinical Governance) Consumer Link Webinar. The subject was “Consumers Involved in Clinical Governance”.

Topics covered were ‘How consumers can be involved in clinical governance, reimbursements and remuneration, and training and support. I was able to elaborate further about the health changes in NZ (DHB’s to NZ Health)

Oliver Taylor

Environmental scan

Youth mental health continues to be an issue with many young rainbow people particularly bearing the highest proportion of negative health outcomes. A recent Victoria University of Wellington study shows this, and how difficult it is to find suitable mental health services. This creates further barriers for young people to access care.

Activity (since last report)

Work to establish a Children’s Consumer Advisory Group at Te Wao Nui - Wellington Children’s Hospital has begun, with draft principles being shaped into a Terms of Reference prior to recruitment of members.

The Consumer Forum met last month to discuss the future of the health system with a high-level presentation from Stephen McKernan – Director of the Health Transition Unit. While the consumer principles were accepted, more granular information was requested by the Forum.

COVID-19 comments.

COVID-19 continues to spread to young people, especially within tight social groups and living situations. Re-infection is already happening in communities living in close proximity of each other. Isolation during this time can be difficult and reduces their ability to access support.

The Hawke’s Bay DHB continues to utilise a caravan to get vaccinations into communities and suburbs that have fewer vaccinated in the population.

Services

Acute mental health services continue to be difficult to access and slow to respond. Emergency departments are not suitable for waiting emergency mental health patients and this is a major barrier for young people seeking these services. Community mental health services have supported young people; however, demand still significantly exceeds supply. Emergency department staff are not meeting the needs of people presenting, especially considering urgency and appropriately listening to consumers’ issues.

The reduction of services, closure and demolition of the Heretaunga Building at the Hutt Valley Hospital has blindsided consumers and representation networks, including staff, with many unclear about how their care will be handled moving forward. It is also curious that this is happening so close to the removal of the DHB system.

Positive/feel good stories

It is good to start work on Children’s Health in Wellington. A core issue of the reforms has been insecurity; however, consumers appear to be making gains. Likely due to the reforms having a consumer focus.

Oliver added verbally: 10–30-year-olds are the highest number of people with Covid and highest resulting hospitalisations.

Re Hutt hospital demolition – no advice/information given to consumers.

Angie Smith

Activity (since last report)

Attended the Consumer Health forum Aotearoa webinar on 7 April

Undertook 2 orientation zoom with He hoa tiaki.

Attended hui on Centre of Excellence engagement and provided input into the Waha Creative agency run on behalf of HNZ & MHA.

Attended various Adverse Events Policy & Review hui (HQSC). I regularly meet with staff to help in planning for the next AE Rōpū hui; very thankful for their expertise - Gillian Allen, Corry Joseph, Matt Coulson, Glen Mitchell, Leona Dann, Caroline Tilah.

There were many outcomes from Adverse Events Policy Review rōpū (28 April) and the breakout groups. There was one area covered that resonated with me, and that was Health Expectations – Humanising harm - this article highlights a restorative and hohou te rongopai approach to harm. It provides inspiration as to how the Commission plans to encourage the inclusion of restorative practice in the future.

As a result, I will attend two online courses on *Restorative Foundations* and *Restorative Responses for people working in the Health and Disability sector*. These will be facilitated by Jo Wailling and Graham Cameron, over the next three months.

There we will be learning about the theory, values, and principles of restorative practices within the health system context and a Tiriti o Waitangi framework. I will consider how restorative practice and hohou te rongopai (peace-making from a Māori worldview) might be applied in my own health setting.

I will also be attending a 2-day workshop on Te Tiriti o Waitangi, 29-30 September.

Other meetings attended:

HB Health Consumer Council	5-May
HB Health Consumer Council - Advocacy role	12-Apr***
HB Health Consumer Council - national group update	27-Apr****

*** HB Health Consumer Council – Advocacy role

The following is a very brief description of a long-running situation where I advocated for 12 Wairoa homecare support workers who were employed by HealthCare NZ. The workers needed help with some serious workplace issues. This journey started 21st October 2021. Seven months later there has been resolution.

Due to a HealthCare NZ restructure, a facilitator who worked 3 days a week in Wairoa was re-assigned to another role in another district. The workers were given an 0800 number to call for any assistance, most often they needed clinical support. There were wait times from ½ - ¾ hour. The telephonists in the Auckland Service Centre did not provide clinical advice, instead they referred the call on. They also had no idea of the geographical area that the workers were covering - over 4,000 sq. km – 100kms from east to west – and were sending them appointments with clients that were 1 hour away but were booked in 15 minutes.

One worker attended 22 patients in 1 day (a Saturday). She went on Sick Leave which meant the other 11 workers had to cover her 22 patients on Saturday, when they already had their own heavy caseloads. One patient needed 3 visits a day. There is no back-up for the workers and for

the services. They were experiencing a lot of stress and were exhausted. Uppermost in their minds though, was concern for their clients (200-300), some who had very complex needs.

HealthCare NZ is funded by the DHB. I met with the two HealthCare NZ Relationship Managers from Hawke's Bay and Tairāwhiti (Gisborne) and a spokesperson for the workers, on two occasions (March and April). Moving forward Healthcare NZ will be doing the following to support the workers:

- Attending a Multi-Disciplinary Meeting on Mondays at the hospital to keep abreast of complex discharges and mgmt. of clients.
- Relationship Manager (RM) committed to coming up to Wairoa, once a fortnight / open door policy to address any problems that may come up that need face to face meeting.
- Support Workers (SW) Team meeting to be organised with both RMs towards the end of May. Teams Meeting attached so Service Facilitator can also attend, opportunity to discuss any concerns/ challenges and meet and greet. These will be organised 3-4 times per year in the Wairoa Region.
- Training: The RMs to review training competencies of all Support Workers to assess where the needs are for further training.
- Communication on Discharges - SW would like to be kept abreast of clients being released from the hospital and back into homes.
- Review best way to manage this through Service Centre or RM
- Communication Books - SW request of Communication books to be placed in clients home along with Service Plan, for basic messages between SW. Service centre also needs to be informed as per normal process.
- Registered Nurses - we are still recruiting for Nurses in the Hawkes Bay region; we do have a RN coming to the region once a week and this will continue. Currently Service plans are being triaged and believe once recruitment is finished that we will get on top of the Service Plans in the coming months. Currently these are done in person and as well as through telephone consult where appropriate.
- Both RMs will be meeting the SW Team in May to assure them that their concerns are being addressed and any further concerns will be addressed in a timely manner.
- The key points that came out of the meeting was communication. They reiterated that they are committed to the region and having a presence in Wairoa.

**** HB Health Consumer Council - national group update

Met with Russ Aiton who encouraged Oliver Taylor & I to lobby for representation on the Consumer Council Chairs / Co-Chairs group, from our Consumer Council (Health Hawke's Bay). We have since done that and there was agreement from our members that Deborah Grace will be our representative.

COVID-19 comments

Precautions for mum:

Mum is 87 years old this year; she is frail and feisty at the same time. My daughter (37 years old) and I have been very cautious about visitors to our house and have advised our wider whānau of such. When we travel away from home, we are extra cautious on our return and isolate in one half of the house, until a negative RATs test three days later gives us confidence to re-enter the main rooms with Mum. There has been a huge impact on our tikanga, as we have not been attending occasions at the marae.

Impact of COVID on tikanga:

We live rurally and our marae is integral to our whānau / hapū. It is our community hub where every event is supported by everyone. But since COVID hit our shores, I have not been able to fulfil my role as kaikaranga, to 'call' manuhiri onto our marae. We have not been able to fulfil our roles as kaiwaiata – we compose waiata specific to our district, waiata that are sung to complement whaikōrero. Pre-COVID this was how we showed our support for the collective, for our whānau / hapū, for our marae.

Marae precautions:

Recently our marae hosted some of our whānau who repatriated the remains of a small baby from Christchurch to Whakakī to be interred at our whānau urupā. All precautions were taken to socially distance and everyone wore masks.

We did not attend and would not risk my mum's health and wellbeing. This has been extremely difficult to reconcile with our cultural obligation to be part of our community.

Positive/feel good stories

My cousin suffered a stroke last week. His wife posted this on Facebook:

I cannot say enough about the care from the medical staff at Hastings hospital. They have been entirely selfless and giving in their care - in the recovery of (NAME WITHHELD).

Best advice from Chris Walsh & Russ Aiton:

- ⇒ Be the one who is informed on how the localities areas are working; give feedback and how to maintain the loop.
- ⇒ By the end of the year, what you put in is what you get back.
- ⇒ Don't be afraid to say how you feel.
- ⇒ Be easy on yourself, on your expectations of how to participate.

Marlene Whaanga-Dean

Input / involvement in HQSC meetings/groups.

WDHB Consumer council – From 1 July Wairarapa are moving into a new space with the Māori HEALTH Authority and Iwi Partnership Boards representing a new way of working to shape the future health system.

Activity (since last report)

- 17/02 - Health and Safety meeting, discussed maintaining vigilance in a COVID 19 world, discussions for staff to use OCP (free counselling service)
- 06/02 Māori suicide intervention prevention training, WITH Dr Keri Lawson-Te AHO
- 10/03 Taitimu Trust Heretaunga non- Profit Māori organisation based in Flaxmere. CEO Zack Makoare has been engaging through wānanga, workshops, navigation, collaboration and Whakawhanaungatanga on nurturing inter-generational wellbeing, initiatives that are grounded in Māori cultural values, principles, and practices. Also, in the process of kainga ora for whānau-on-whānau land re homelessness.
- 12/5 (Waitemata District Health Board Ecald) Professional Development, (modules, zoom) What is Cultural Competency, working with interpreters, working with refugee patients, working with religion. The aim of the course was to increase awareness of the settlement challenges faced by refugees. To help work better with refugee patients during consultation and to guide through their traumatic experience. Identifying ethnocentric interactions with clients of different cultures.

COVID-19 comments.

Since January, Whaiora have continued to support Tekau Mā Iwa our vaccination clinic with a huge number of close contacts mainly through schools in our region. This impacted on staff, being off work (with Covid). Swabs increased; vaccination increase for Māori practically for tamariki. To help our GP practice during that time, Tekau Mā Iwa picked up flu vax to support our Medical Practice.

07/04 Whaiora is the local Māori lead to distribute RATS in our community- 136 assisted RATS were given and from that 33 were positive. 20 PCR test were given. During this time, I worked with local iwi and community to organise kai for whanau isolating, 154 requests for Mānaaki kai packs all delivered by iwi and whanau were very grateful with hygiene packs.

Services

Concerns or issues: Whanau have been frustrated with covid restrictions to get in to and see sick whanau with one person having her mum pass away.

Positive/feel good stories

The last 4 months has been busy with deployment within our organisation; however, everyone plays a role to look after their community and I believe Aotearoa have done their very best in challenging times (Covid 19) that they can do in there rohe to Mānaaki there rōpū.

Marlene added verbally: It is great to have new Māori nurses in our local PHO.

Amanda Stevens

In my last report I noted that Deafblind Association made a submission in respect of the Disability Survey Consultation 2023 to Statistics NZ. The report on this consultation has been published and it is disappointing to note that it does not look as though deaf blindness will be recognised as a unique disability. You will note from the following that, while people may register “some” difficulty with hearing and “some” difficulty with seeing, this will not trigger data on that unique combination causing disability. This has long been the issue in Aotearoa NZ that deafblind have specific challenges due to dual sensory impairment that is currently known in short as “disability”.

From the report:

The Disability Survey classifies respondents as disabled based on their answers to a series of questions about basic functioning. Respondents are asked whether they have any difficulties carrying out a range of functional activities, such as moving, hearing, or seeing.

Respondents answer the functioning questions using this scale:

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

Respondents must indicate they have at least “a lot of difficulty” on this scale to be classified as disabled in the survey. This means some respondents will report “some difficulty” with functional activities but will not meet the threshold to be classified as disabled. We refer to this area between unimpaired functioning and disability as a “mild impairment”.

Respondents who report a mild impairment will not be considered disabled within the survey but may still face difficulties in some situations. Ends

This means that the objectives set out in the report and listed below are unlikely to address unmet need for deafblind because they will still not be recognised as disabled:

- to understand the size of the disabled population usually resident in New Zealand and describe characteristics of that population. More specifically to:
- produce reliable national estimates of the disabled population by demographic characteristics, such as age group, gender, and ethnicity
- produce reliable national estimates of the disabled population by functional domain

- to understand the extent to which social, wellbeing, and economic outcomes for disabled people differ from those for non-disabled people, and how those outcomes differ between groups within the disabled population
- to understand the level and type of support disabled people need to perform activities of daily living, including identifying unmet need for support
- to understand what creates barriers or enables participation by disabled people in important aspects of life, such as work, education, civic society, and recreation.

Our consultation in 2021 aimed to inform the content of the 2023 Disability Survey and create a survey that is more aligned with the needs of disabled people, data users, and other stakeholders.

The Disability Survey is the primary source for estimating disability prevalence and disability sub-group prevalence in Aotearoa New Zealand. It collects information on the lives of disabled and non-disabled people to allow comparisons between the two groups.

Deafblind Association NZ continue to lobby for recognition of deaf blindness in Aotearoa NZ.

Bernadette Pereira

Southseas lead the locality space for pilot sites in South Auckland. This includes Papatoetoe, Mangere, Otara, Manurewa & Papakura.

Main issue seems to be work force development.

There is a food security issue in Northern Hokianga. People are returning to die. They need revitalisation and motivation to have another purpose and have a new licence in life.

In the community vaccination programme, people are experiencing vaccine fatigue. Health providers are having to increase activities enticing community families and whānau to be vaccinated – especially the flu vaccine.

Attended two meetings of the Auckland metro Clinical Governance force. They were supportive of continuing the consumer voice on the committee.

Ricky Ngamoki (Dunedin)

Environmental scan

- whānau struggling with COVID and the rising cost of kai.
- Rent increases and the rising cost of living is influencing the financial resources that whānau have. Making decisions about whether to pay their power or go to the doctor.
- Insecurity about the changes that are coming, and the impact on the services that they are receiving. There is a lot of Ngāi Tahu takeover in the health industry and the Tamariki space with Oranga Tamariki. This is concerning to those that are not Ngāi Tahu, as there is no support from those services if you are not Ngāi Tahu. People are worried locally because of what has happened in the past – A common theme that has emerged and got stronger over the past 8 months.
- Kai and the rising cost of it is continuing to be a stressor as whānau that have had COVID, have had less income as a result, particularly those that have been re-infected with COVID a second time.
- People are driving around in unwarranted and unregistered waka because they have had to pay for incidental costs related to health and COVID related costs.
- Spent a month on the Tītī Islands, this was good for the whānau that were able to come and participate in the activities and harvesting of Tītī. This is an age-old tradition that has been handed down from one generation to another.

- Bullying has increased again in Secondary schools, and this is becoming a major factor for rangatahi in the rōhe, and it is affecting whānau. This is also happening within Kura Kaupapa Māori in Te Waipounamu.

Activity (since last report)

- New Māori Minister has been appointed at the Southern District Health Board – Heike Pomare – attended her Mihi Whakatau in the hospital chapel
- Consumer Network Meeting F2F in Wellington Wednesday 25th May 2022

COVID-19 comments.

- As there has been a big drive in the hāpori, there have also been heightened concerns about the providers that are being selected and the fact that they are exclusive and focussing on Kai Tahu. This has been for health services and community space work.
- Rising cost of living is affecting whānau financially.
- Food cost increases are affecting the budgets of whare – this is becoming a major stressor for whānau as they cannot afford simple necessities at present.

Services

There have been concerns about the lack of neutral services. DHB and Ministry of Health are funding one provider that some people are incredibly insecure about, as there has been a clear stance that Ngāi Tahu is the priority and others need to seek services elsewhere (Māori and Pacific.)

Positive/feel good stories

- Being on the Tītī Islands was a great experience, there was an opportunity for younger generations to engage and be trained in the art of harvesting Tītī. Tītī harvesting is a tohu that is passed from generation to generation, it was great to see younger whānau members participate and learn the process.
- Supporting Youth Groups from Ōtautahi that have come to Ōtepoti for camping (Fishing, Ngāhere hikoi, Waka Ama, planting seedlings in the Huirapa ki Puketeraki Taiapure, Kooerero about the local Pakiwaitara)