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| **Letterhead logoMinutes of the Te Kāhui Mahi Ngātahi | Consumer Advisory Group (CAG)** meeting held on 10 February 2023, Pounamu, HQSC |

Chair**:** Russ Aiton

Members: Mary Schnackenberg, Delphina Soti, Frank Bristol, Jodie Bennett, Maine Mareko

In attendance: Deon York, Dez McCormack, Allison Anderson, Anne Buckley, LJ Apaipo (He Hoa Tiaki | Partners in Care team)

Apology: Angie Smith, Boyd Broughton, DJ Adams

Guest: Shelley Hanifan

The meeting commenced at 10:14 am

1. **Welcome & karakia**

Russ welcomed the group. LJ opened with a karakia.

1. **Whakawhanaungatanga for Anne Buckley**

Introductions from the group

1. **Standard business - Action items**

**3.1 Previous minutes**

The minutes were moved as correct and accepted. Noted the positive feedback from teams on the board papers from last hui.

**3.2 Action items**

Frank has updated. To follow-up with Angie.

**3.3 Interests register**

Maine has advised updates.

1. **He Hoa Tiaki | Partners in Care (PIC) report**

Deon spoke to the written report Allison prepared. Mentioned the SPE which we will discuss under item 9.

Also updated details about where we are at for the CHFA conference in Christchurch in May and how promotion of the event will be important for everyone to push. During meeting, advice received that registration link had just gone live. CAG members can register now.

Deon also spoke on where the QSM refresh is at and reporting from the localities. The QSM will be the basis of reporting from localities on implementation of the code.

The group also discussed stats on getting more people registered on the forum. Deon advised what we had done in the past. Suggestion made that we target those ethnicities already registered to expand membership from their networks. So action item for forum registration - to look at targeting existing ethnic groups on the database to get increases in membership thru their networks.

The PIC written report follows:

**Update to Te Kahui Mahi Ngātahi | Consumer Advisory group**

**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.

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| **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 |

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| **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 |  |

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| **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 Whainga Amorangi | In progress | CN and CAG have had training now. CHFA plans still in development |
| Review and refresh the Kōtuinga Kirtaki | 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, HQSC on steering group and supporting consumers to participate |
| Enhancing and embedding the consumer and whānau perspective throughout the nine pilot localities | No progress |  |

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| **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 assited 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](https://www.hqsc.govt.nz/consumer-hub/engaging-consumers-and-whanau/code-of-expectations-for-health-entities-engagement-with-consumers-and-whanau/) (1,631 hits), closely followed by our [Consumer health forum Aotearoa: Opportunities](https://aus01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hqsc.govt.nz%2Fconsumer-hub%2Fconsumer-health-forum-aotearoa%2Fconsumer-opportunities%2F&data=05%7C01%7CToni.Duder%40hqsc.govt.nz%7C962c7a8df0114b070cae08daf8f1c9e0%7C701cefdf35f44444863855f0e12ab1c4%7C0%7C0%7C638096014613462437%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=eyoQRPlkRmWRgz4ygZFjQjY0uXwZg7L2ddwsBl%2F2CQA%3D&reserved=0) page where expressions of interest are placed for consumers join p (1,035 hits).

[The consumer hub landing page](https://www.hqsc.govt.nz/consumer-hub/engaging-consumers-and-whanau/code-of-expectations-for-health-entities-engagement-with-consumers-and-whanau/) is the 12th most viewed page and [the consumer health forum Aotearoa](https://www.hqsc.govt.nz/consumer-hub/consumer-health-forum-aotearoa/join-the-forum/) 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](https://aus01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hqsc.govt.nz%2Fconsumer-hub%2Fengaging-consumers-and-whanau%2Fcode-of-expectations-for-health-entities-engagement-with-consumers-and-whanau%2F&data=05%7C01%7CToni.Duder%40hqsc.govt.nz%7C962c7a8df0114b070cae08daf8f1c9e0%7C701cefdf35f44444863855f0e12ab1c4%7C0%7C0%7C638096014613462437%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=WebyikZ7QmtuCLtJ9M7aGl1Dp3w99tBdNl2wiH2h8hw%3D&reserved=0) has been downloaded 817 times. Twenty-one translations and accessible formats have been accessed so far. This is the Commision’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**

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| **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 Tauihu-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** |  |

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| **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.

**5/6. Members environmental scan**

These were provided in writing and distributed prior to this hui for members to note.

These member scans appear as Appendix 1 following these minutes.

All members spoke briefly to their reports and expanded as follows.

Frank added there are complex accountability matters in the health reforms. These need to be worked thru to see how consumer engagement and priorities fit into the plans. There’s a lack of understanding/awareness on how the new consumer code fits into everyone’s work and programmes. Re the link at bottom of Franks’ report - Action to follow-up with HQI (Richard Hamblin) to see if HQSC has a model like this.

Jodie reiterated the cost of living is really affecting people. It is very tough out there especially for people with mental health issues. Some people making choices whether to eat or get medical attention when its needed. Not seeing enough lived experience input in local locality planning. Lack of awareness around the code of expectations and the practical application of it.

Mary – Te Whatu Ora struggling re reimbursement policy and its being complicated with tax issues. Auckland Te Whatu Ora undergoing a 3-year in-patient audit and the change from previous years is that consumers are being involved.

Delphina also reiterated the workforce being stretched. Huge turnover of staff. Also trying to get people to come out of the woodwork to get the help they need and letting them know what help is available. Services need to continue to do what they do well.

Maine – huge wait lists to see a doctor. Or just getting access to a GP service. Includes other services like dentists etc. The consumer code doesn’t count for much with these issues. We need to get people in the door first. In the hospital there are enough beds but not enough staff to service them. Diversity of workforce not good. Very hard to access Māori and pacific midwives and nurses.

Russreflected many of the same issues with workforce. Lack of engagement completely of code or expectations. National consumer group now armed with asking the questions of what does the transition look like, the renumeration of consumer groups and the continued involvement of consumer councils in the localities.

**7. Top 3-5 collective issues CAG identify to raise with board**

Retain the 3 items advised to board last time and add 1) the lack of code engagement and dissemination and 2) the value of including lived experience in the planning and delivery of services at a local level.

CAG would also like feedback on what engagement has been conducted as a result of CAG’s highlighted issues.

Mary emphasised accessibility to information – not just braille etc. but the language used with consumers. Also suggested linking up with the Digital transformation unit in DIA. DJ/LJ are involved with the Digital health reference equity group.

The written summary provided to the board follows:

***Summary***

*2. CAG’s discussion centred on the following themes this month:*

*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.*

*3. The CAG highlighted continued concern about pressure on mental health services and workforce shortages in general. The CAG reported difficulties for consumers in accessing services due to workforce shortages, notably in primary care. Access to general practice care was raised by representatives from both ends of the country, Ōtepoti Dunedin and Tāmaki Makaurau Auckland and was agreed to be an issue by the group as a whole.*

*4. The CAG noted the importance of the contribution of lived experience to health sector planning and delivery, especially at this time of transition and change in the sector. The view was articulated that the experience of consumers should contribute to the planning process as early as possible. Concerns about a lack of engagement to date in locality and regional planning were voiced. ‘There is emerging discussion on whether current health system planning is really transformative or merely quality improvement’.*

*5. There is as yet insufficient awareness of the code of expectations at the locality level and of its requirement for consumer engagement at all organisational and planning levels. This concern was also noted in relation to primary care planning and projects. Members of the CAG advised that they are working to socialise the code of expectations in their contacts within the sector but ‘there is a long way yet to go’ in sector-wide understanding of the code and its implications.*

*6. The CAG stated the continued need for accessible information for consumers – plain language as well as languages other than English and accessible formats, including but not limited to Braille. Information on medication was highlighted as a particular need/gap.*

*7. The He Hoa Tiaki | Partners in Care team shares this information with the relevant teams in the Commission to act upon within the Commission’s scope. The noting recommendations detail these actions.*

**8. Input into HDC’s Act and Code Review**

Deon raised the letter received from the HDC. We have early opportunity to comment on the review.

Jodie raised some issues around interaction with the Mental Health Act and considering that in the review. Changing Minds is making a submission.

Mary mentioned and that it should be bought up to date with the digital environment. Also remove/change wording for ‘complaint” to take it away from blame.

Feedback by 27 Feb to Deon.

**9. Discuss proposals for draft programme plan for 23/24**

Deon outlined our thinking – reflecting on our four priority areas. 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. Allison worked thru the ideas from the PIC team day, based on the 4 workstreams.

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.

**10. Update on consumer code implementation guide.**

This section was combined with 11.2 below.

**11. Board paper feedback.**

**11.1 Commissions performance review 2023**

Shelley Hanifan zoomed in to get feedback on this paper directly. A presentation was provided. We have a new statement of intent (SOI) being prepared. This is now underway after being postponed. The commission is doing a limited self-review (PIF) drawing on the expertise of the last reviewers who are leading this review. We are seeking the who, what & how of this review. Shelley showed our current strategic priorities.

Comment that there’s a lot of top-level people mentioned for consultation. Would they be fully cognisant of the consumer code of expectations. And would those CE’s etc. know the workings of the commission in any detail? Names of lived experience people can be passed on if appropriate for inclusion in consultation. Also, with the consumer council chairs, reps from the regional areas should be included.

Shelley ran thru the planned questions to be asked in the consultation.

**11.2 Supporting the sector to implement the code of expectations.**

Deon ran thru this paper prepared with Anne and that this paper was a follow-up to previous information supplied to the board. There was some minor feedback on reference to districts rather than localities. Deon spoke about how reporting on the code implementation should work.

**12. Discuss opportunities for World Patient Safety Day ‘Patient and family engagement’ theme for 2023**

History of World Patient Safety Day was explained by Deon and why we should be involved this time seeing the topic. This was an fyi and the group will discuss again at future hui.

**13. Brief on Consumer health forum leadership planning workshop**

Allison ran thru the objectives of this strategic day workshop run by Creative HQ next week with selected forum members. There were 137 applications with a rigorous selection to get a wide spread of experience from various groups of interest. It will also include a rep from CAG (Jodie) and the consumer network (Joanne Neilson). The workshop will develop ideas about what topics are relevant to the forum and look at ways to develop further connection and dialogue amongst CHFA members.

**14. QSM update**

This was discussed in the PIC update

**15. Wrap of day – other business**

Dez briefed on the May forum and meetings either day of the 25th, travel, accommodation etc.

There was a brief round table on members thoughts on the day.

**16. Karakia & close**

LJ closed with a Karakia.

**Next hui:** 24 November 22 – CAG hui first & then in person with Board

**Actions List:**

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| Date | Action | Responsibility |
| 15 Nov | Carry forward from last hui. Angie to provide changes to the Interests register. | Angie (Dez) |
| 10 Feb | for forum registration - look at targeting existing ethnic groups on the database to get increases in membership thru their networks. | Allison/Tanaya/PIC team |
| 10 Feb | F/up with HQI re link at bottom of Franks report and if we have anything like this.(Frank emailed Richard Hamblin) | Dez |
| 10 Feb | Further discussion for next agenda on opportunities for World Patient Safety Day ‘Patient and family engagement’ theme for 2023 | Dez |

(Member reports follow below)

**Appendix A**

# Summary of CAG members environmental scan for 10 February CAG hui

**Russ Aiton** (West Coast)

Chair - Consumer Council WCDHB

Chair - National Chairs Group (Consumer Councils)

Co-Chair – Consumer Advisory Group (HQSC)

Chair – Cornerstone Family Support Services (Greymouth)

**Environmental scan/real time monitoring**

Takiwā Poutini | West Coast Localities steering group – the newly appointed Programme Manager has asked for a hui regarding the Code of Consumer Expectations with an outcome of co-designing the ToR for Takiwā and embedding elements for engagement. I have been able to extend the invitation to wider consumer members [initially] with a view to including other consumer stakeholders.

Te Whatu Ora – West Coast continue to demonstrate a lack of energy or will in engaging the newly named Consumer Advisory Group seeking to negotiate administrative support and input to facilitate meetings, recruitment plans and remuneration enquiries, instead directing all such enquiries to “Regional”.

There is very little communication on the media streams here on the Coast for any plans to engage both consumers and communities. If such is happening, it is away from the view of the Consumer Advisory Group.

Communication and transparency continue to be non-existent (regarding consumers).

**COVID-19 comments**

There are still COVID cases, as well as seasonal flu cases, coming in via unplanned care and to health centre maintaining the pressure on health of workforce. This is still providing stress for the workforce and immediate management.

**Services**

It is difficult to give any input on how well the services are doing (or not) as little or no communication is happening or including the Consumer Advisory Group.

**National Consumer (Councils) Group**

Re-convening Feb ’23 our workload is anticipated to continue to grow as requests for Consumer engagement come via the Chair and out to the Regional Groups. Requests have been around the (National) Remuneration, CC Transition Plan, Anti-coagulant, and Code Implementation work via the HQSC.

**Angie Smith** (Wairoa)

Kaiwhakarite Māori – mahi kiritaki I Consumer representative, Māori

Co-chair, Te Kāhui Mahi Ngātahi I Consumer advisory group

Member I Consumer and whānau voice framework reference group

Ngāti Kahungunu – Ngāti Ruapani ki Waikaremoana – Ngāi Tūhoe

**Environmental scan/real time monitoring**

**Consumer Council - Te Matau a Māui Hawke’s Bay**

Penita Davies has just been taken on as Consumer Engagement Lead for Patient Safety & Quality Service, Te Matau a Māui Hawke’s Bay. I will be meeting with her to help facilitate the re-engagement of our region’s consumer council that has not been operating since last year 30 June 2022. I am particularly interested in how well consumer engagement in our region is happening, especially regarding implementing the code of expectations for health entities' engagement with consumers and whānau (the **code**) - to what extent the code has been implemented or what is planned. Furthermore, it is important that our region is represented at the consumer council chairs group.

**Services**

SEVERE staff shortage - Queen St Practice (Wairoa)

In December 2022 Wairoa’s one and only GP practice had a SEVERE staff shortage due to staff testing positive for Covid. There were delays in answering phones, in calling back and booking consultations. Of course, only urgent matters were being dealt with.

Pharmacy service concern

Wairoa Pharmacy is still not offering the best service to our community. There are delays in prescriptions – waiting for hours (days) for prescriptions, even after calling the day before to ensure the pharmacy has received the prescription order from their doctor. The main concern here is that many of our community live rurally. They travel long distances to their doctor’s appointments and to the pharmacy, so there is a cost in time and dollars that is distressing for our small, rural, low socio-economic town.

Wrong prescriptions have been given to consumers!

Another concern is that many of our community are elderly and some live by themselves. Getting their meds is challenging enough, without the added risk of taking the wrong pills.

This service has been happening for years!! Complaints have been made. I have personally submitted a complaint to the GP practice about my mum getting the wrong medication. My advice to every consumer in my community who has complained to me about the service, is to formalise a complaint for EVERY time something has happened – don't just talk about it, put it in writing (for a start) and if you are not happy with the response, then escalate your complaint, take it to the next level.

**Positive stories and exemplars**

Health clinic trailers haled as ‘amazing’

Wairoa now has a pair of extraordinary BBQ trailers which each have a generator, defibrillator, gas bottles, speaker and medical vaccination fridge, barbecue table and chairs, to enable health & social services to get out to all the rural areas and enhance community vaccination and health events.

Te Puni Kōkiri worked with Te Whare Maire o Tapuae (whānau ora provider) on their priorities to improve Wairoa's resilience and self-reliance as experienced through the lockdowns and arrival of Omicron, and with the increased occurrence of weather events and natural disasters. The working group included the Wairoa District Council, iwi, post-settlement group entities and local organisations for the initial planning which was followed by a seven months implementing the plan.

# Mary Schnackenberg (Auckland)

**Environmental scan/real time monitoring**

The holiday period has meant much less contact with consumer adviser colleagues.

However, the weekend floods in Auckland have raised the spectre of disabled people who normally live alone having difficulty getting in contact with services. I find this surprising as the Auckland Branch of Blind Citizens NZ met about 18 months ago with Auckland Emergency Management staff for a workshop. That experience was extremely positive as they talked about how some 30 different organisations around Auckland were well networked to provide the range of services in times of local disasters. There will no doubt be an investigation of what actually happened.

**Jodie Bennett,** (Auckland) Changing Minds (Mental Health and Addiction Sector)

**Environmental scan/real time monitoring**

We are hearing our communities are under increased financial distress adding to detrimental socioeconomic factors aleady impacted by the rising cost of living.   
The associated cost to access health services are impacting whai ora decisions to seek help when they need it.   
Equitable access should be addressed as a matter of priority in national, regional and locality planning.

We are still not seeing enough Lived Experience (LE) engagement in locality planning, proposals and strategies.   
It gives a sense of ‘business as usual’ that LE and consumer voices are not being sought out and heard from the beginning of a change process, as opposed to a ‘tick the box’ exercise once key decisons have already been made by those part of the existing system.   
  
Consumer voices are essential to true transformation within our health systems and services.

There is emerging discussion on whether current health system planning is really transformative or merely just quality improvement.

**Services**

Workforce shortages continue to impact the Mental Health and Addictions sector, therefore impacting access to services and wait times. This is an ongoing concern that in part needs to be addressed by continued workforce development planning and investment.

Part of this workforce development conversation includes a need for recognition that not enough Māori are in the Lived Experience workforce, including in peer support and advocacy roles.

**Positive stories and exemplars**

Changing Minds Survey

Changing Minds was honoured to be able to collate and advocate for the voices of those with Lived Experience of mental distress and/or addiction in Aotearoa. As our health system undergoes a once-in-a-lifetime change, it’s important that these changes are guided by the views and expertise of people with Lived Experience.

We asked respondents to tell us what they don’t like about the existing health system, how an ideal mental health and/or addiction service would feel and be delivered, and what an ideal service would offer.

The results can be found here: <https://www.changingminds.org.nz/storiesdb/what-does-positive-health-system-transformation-look-like-for-tngata-mtau-wheako>.

Whai Ora Mapping and Experience Project

Jodie has joined the Steering Committee for a ‘Connected Care’ project which includes the mapping of whai ora pathways through services, and alongside that, understanding the experience of whai ora who are accessing those services. This will be an influential piece of work that will make sure that the Mental Health and Addiction pathways through relevant services are trusted and safe, easy to navigate, and that they also connect whai ora to their community support networks, ensuring that whai ora and whānau voices are central to decision making.

This is led by He Hononga o te Raki Northern Regional Alliance Mental Health and Addiction Network (NRA) and covers the Tāmaki Makaurau/Northland regions.

Waitematā Co-Response Pilot

A Co-Response pilot between the NZ Police and Adult Mental Health Services has been launched in the Waitematā East/North (North Shore & Rodney District). The Co-Response team is already seeing encouraging results with less whai ora requiring Emergency Department admissions or less detention of people under Section 109 for assessment.

The Co-Response service is run Tuesday – Friday from 10am to 10pm based on demand in the ED, factoring in the time of day for the majority of emergency calls and when the response is most needed. The team responds to those aged from 15 years old and upwards.

Ola Manuia

We were pleased to see the Ola Manuia Pacific Health and Wellbeing Action Plan released, which has just been revised and released as a second version with a focus on the next two years outlining the five key priorities for the Pacific Directorate (with one key component referring to mental health).

There is a dual approach to this two-year plan which includes Pacific Health enablers and Pacific Health priorities.

These Pacific enablers prioritise oral collaboration, community and Lived Experience voices, alongside population health/good quality data and insights, commissioning, provider development and workforce development.

**Frank Bristol** (Whanganui)

**Environmental scan/real time monitoring**

**Demand and supply of clinical health services:** Many Whanganui GP practices have closed their books, even if health needs are considered urgent. Whanganui does have a 24/7 Primary Care service called Whanganui Accident & Medical (WAM). Doctors, and other registered health staff continue to be short to fill vacancies.

Mental health services continue to be under high demand but are being creative in filling vacancies with the Peer Support workforce being utilised which is great progress.

**Consumer Engagement**

Lots of pull here at Te Whatu Ora Whanganui (TWOW) and Te Pukaea (our Te Whatu Ora consumer council) for incorporating consumer engagement into operational design and planning. Leadership at TWOW Director level are now fully on board with implementing the Code of Expectations and recently trained Directors and Patient Safety and Quality Improvement. We are in the process of setting up a Consumer Network so that we have a pool of consumers with specific health service experience to draw from for projects.

The Central Region now has two consumers on the Regional Clinical Board. More work needs to be done to ensure current central region consumer issues are networked into the Regional Clinical Board.

However, there is so far no visible/noticeable consumer engagement pull from primary care for planning and projects. Re our Locality Prototype: early communication has said the Consumer voice could come through the Iwi Māori Partnership Boards. There is a need for dialogue to be led from both the national, regional and local levels so we do not end up with every locality having different ways of doing consumer engagement.

**COVID-19 comments**

Covid continues to be rampant and a threat to people’s health. People who have had access to Antivirals are reporting these are working well and it has been convenient to have pharmacies dispensing these Antivirals meds.

**Health Information accessibility**

As mentioned last year there are continuing issues with accessibility to personal digital health information being provided from health services. All health records need to be joined-up and made accessible to consumers and whānau.

**Social and Economic Factors**Food banks are busy, food inflation particularly for fresh vegetables is high, and lack of affordable housing are major barriers to health.

**A question?** Do we have something similar to the County Health Ranking Model happening in Aotearoa? I really like it.

[County Health Rankings Model | County Health Rankings & Roadmaps](https://www.countyhealthrankings.org/explore-health-rankings/county-health-rankings-model)

**Ngatamaine Mareko-Johnson** (Ōtepoti)

**Environmental scan**

Covid-19 is still prevalent in the community, which is putting stress on the workforce.

University will be starting back again for Semester 1, there is concern that this may bring flu and the next strain of Covid-19 to Ōtepoti. There is currently a virus going around that people have reported the symptoms worse than having Covid-19, and the effects after the sickness has occurred have lasted longer.

The community is still struggling with the lack of access to GP services – sadly this has not changed and continues to get worse.

People have expressed that the Christmas break was an opportunity to reset, however as 2022 was such a difficult year, it felt less like they had had a ‘break’.

There is a large back log of Surgical specialists’ appointment. Currently there is a 6–12-month waitlist for a pre-surgery appointment. Which is causing a lot of angst in the community.

This pushes out the return to work programmes and extends the wait time again sadly, no change here.

There is still an issue with a Māori health provider that is not providing the services that it receives funding for and claims to be providing. Families are struggling. We acknowledge that there needs to be for Māori by Māori, however, these partnerships should be made with organisations that have a good community standing and proven relationships within the community, through their successful programmes.

This is putting undue pressure on the workforce, that is already tired and struggling, yet are still plugging the gaps, stretching their limited resources.

The community is nervous about the new hospital build, again, as there has been announcements, that they are having to cut back on spending once more (This has been consistent), which continues to decrease the size of the new hospital, which in its initial planning stages, was already considerably smaller than the current one. This is scaring people and having them consider if they continue in the region, as there is fear that moving forward, with a smaller hospital, there will be less access and a further overloaded and stressed system, where people will die in their homes, waiting to access the healthcare that is their human right.

Due to it being the Christmas period, things have been quiet. However, as statistics have historically shown, things become dicey from February onwards in terms of requiring access to healthcare and domestic violence, as many have left the region for the holidays, though return for work and school by February.

**Activity (since last report)**

Have been completing a piece of work in collaboration with NZ Police, Otago Youth Wellness, Oranga Tamariki, Youth Forensics Team and including the Dunedin City Council about the youth offending and anti-social behaviour at the Dunedin Bus Hub – This continues to be work in progress that is adapting as required.

With this group recognising the cohort of young people,

Assess the services that are involved,

If there are not services involved, how do we navigate them to this,

We realise that this has become a problem, however the solution is not easy.

Despite the fact that it is located outside the Dunedin Central Police Station, Police, have not the resource to maintain regular policing of the area.

Working alongside the parents of the young people, to empower them with management tools for supporting their children, away from the area, and the negative behaviours. – This continues to be work in progress that is adapting as required.

The perception in public, is that the kid’s parents are not looking after them, they are on a benefit and are not parenting.

The reality is, both parents are working, after the economic impacts they have experienced because of Covid-19.

Te Mokopuna Table has been a busy piece of work and the it has been a difficult space to navigate at times, with a busy and constantly conflicting diary.

There has been a decent flow of referrals from the SAM table

Business South – Reconnected with them for the new hospital build in Dunedin.

How we can connect businesses with our young people to ensure that we get work placements and training for young people that are involved in our service.

We are having a few problems with the age of the young people, they are 15, and this makes things difficult for employment.

It has been a great opportunity to collaborate in the Community.

**Services**

Food truck – For the new Dunedin Building site (Dunedin Hospital new build)

This is a collaboration of organisations (Te Hou Ora Whānau services, Otago Youth Wellness Trust and Southern Youth Development) and will be a food truck that is utilised to train rangatahi, whilst feeding the workers that will be there.

Food Parcel – This has been discontinued, as the funding from MSD has been removed, as though it is not a priority and people are no longer struggling, which we know is not true. This has been a difficult process as the need in the community has not decreased. And we are concerned for the whānau which we support and work with.

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 has not changed and is unlikely to for some time.

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. This has not changed and is becoming a concern for the wider community as there are more people that are using in the city.

Concerned that there is a lack of diversity in services, including the youth court cultural report writers.

There are not enough Māori or Pacific practitioners in any services available to young people and this having an effect on the community as rangatahi and whānau are not engaging in the services available because they do not ‘fit’ and feel uncomfortable in sterile environments that do not acknowledge who they are or their culture.

**Positive/feel good stories.**

The weather has been great before Christmas and in this first few working weeks of the year, for those of us that only took Bank holidays off. This has allowed whānau to be able to share time together in the good weather, accessing the local parks, beaches, and rivers.

The Local Council has invested well into decent new parks and recreation area’s in the city, and it has really increased the options of activities that are free or low cost. This has improved the well-being of the whānau that are able to access them.

**Delphina Soti** (Auckland)

**Environmental scan**

Mental Health services are stretched and further impacted by Covid and recent floods.

Finding suitable Pacific Island mental health workers is difficult.

GP waiting times 1-3 days waiting times to get an appointment.

Numbers of patients attending A&E and 24 hours doctors clinics increasing due to time and working hours. The cost is high e.g. Whitecross - $100 to see a doctor.

Young people numbers to attend free wellbeing programmes are dropping due to having to work and not affording transport costs.

**Services**

Concerns or issues you have heard from your communities about health services including COVID related matters

A lot of concern on the impact of the recent floods on families.

The response to support these families was not orchestrated well. Many families were left to their own devices. All around poor communication etc

Around more than 50% of those our team are delivering food and care packs to are not isolating at home. Often they are not at home when our staff arrive there.

People are not actively testing so therefore people are unaware they are positive unless there is compulsory testing

**Positive stories and exemplars**

Collateral created by consumer engagement e.g.: the translated Code of Expectations etc received well.