



## Minutes of the Te Kāhui Mahi Ngātahi | Consumer Advisory Group (CAG) to the Te Tāhū Hauora Health Quality & Safety Commission Board

<b>Co-chairs</b>	Angie Smith & Russ Aiton
<b>Members in attendance</b>	Mary Schnackenberg, Jodie Bennett, Maine Johnson, Boyd Broughton
<b>He Hoa Tiaki in attendance</b>	Deon York, DJ Adams, Dez McCormack (minutes)
<b>Apologies</b>	Delphina Soti, Lisa Lawrence, Allison Anderson, Anne Buckley
<b>Guests</b>	Jo Sorasio, Senior Specialist Advisor, Perinatal and Maternal Mortality Review, National Mortality Review Management Group

The hui was held via zoom at 10am on 5 April 2024.

### 1. Welcome and karakia

Russ welcomed everyone to the hui and Angie opened with karakia.

### 2. General business

- 2.1. The minutes from 9 February were confirmed as true and correct.
- 2.2. Action items were completed. Nothing ongoing.
- 2.3. Interests register is up to date.

### 3. Observations/feedback from Board strategy session 22 February 2024

Angie was impressed by input from everyone. Some strong messages with main message that we sit under building relationships in the community. Good to see focus on primary care and Te Tiriti. Conversations may have been different if CAG had known about the current proposals for intimated staff reductions.

Jodie felt a good day and felt included. Was pleased we were offered the opportunity.

Maine – good experience. Interesting the different level of solutions offered.

Mary – interesting day. Feels the Board listens and wants to walk the talk of consumer advice. Good to hear from others at that level.

Boyd – Interesting day and different points of view. Didn't agree with all comments, specifically statements about treaty partners.

Russ – Found the dialogue good. Some tensions existed but were worked through. We were well included throughout the day and found our comments were consciously sought to lead conversations.

#### 4. Members environmental scans

Following is a brief outline of members comments.

**Angie** – thought all was not well with local services, although they say everything is going well.

A report in national news: Wairoa is one of the largest consumers of alcohol (measured from wastewater samples). People in smaller centres/ rural areas seem to be drinking more.

Concern at Minister of Health announcement in light of disestablishment of Te Aka Whai Ora, that Localities progress is being paused. This is disappointing after all the work done.

Angie will also follow up on Mary's last recommendation locally about GP's having access to Hospital records. Te Whatu Ora have some work underway to address this as previously advised to CAG.

**Jodie** - a lot happening in MHA sector. Lots of uncertainty. Does the mental health minister have much influence or are MHA issues all up to the Minister of Health? Would like to understand this relationship more. Submission lodged for the Pae ora Mental & wellbeing plan amendment bill with massive community response. The mental health commission should be a separate identity and not come under the MoH.

Also commented around consent from patients and who has access to patients' health data. Currently it's open to possible abuse of how & what info is accessed and used potentially used against people. Perhaps layers of access would assist here.

Trials around support services into ED have had good results in de-escalating MH responses. Proud of voice of lived experience people in contributing to everything that is going on and submissions into MH strategies.

**Mary** – access to personal health information. This needs to extend to being able to find out about medicines that are prescribed.

Healthify continues to be an important 'go to' for clear writing and to get the best info. Also, overseas info is adjusted for NZ (te reo) terms.

Also raised the funding cuts by Whaikaha and how it was handled. Disabled community not treated well in how this was announced and timeframes for submissions.

**Maine** – Social sector also feeling the Govt changes and clawing back of money. School lunches and services including health care.

Some good news happening with new GP service setting up called "Dunedin community health" with reduced costs (\$15) for lower socio-economic people. And being able to be seen in 24-48 hours. Circumcision costs privately are around \$7k and hopefully to get funding for this procedure for \$650, which would be huge for the Pacific community. Moana nui festival has been a recent huge celebration in the pacific community which was really positive.

**Boyd** – not much changed since last scan, from the IMPB point of view, still strong focus on advocating on capability and capacity and funding.

Repeal of smoking legislation will have a strong impact on whānau and their health outcomes. Te Tai Tokerau has one of the highest smoking rates.

Disestablishment of Te Aka Whai Ora means that IMPBs will have increased workload with commissioning role and we expect funding from the Minister to achieve what's expected even amongst the Localities being paused.

On-going issues: GP access and workforce, roading challenges and cost of living and housing and other social issues etc. Low immunisation rates continue to be a big issue.

Pharmacy acute care was pushed to continue and has great pick-up by whānau. Sharing patient info between GPs and other health services and secondary care, as mentioned by others, continues as an issue.

Also advocating with Roche for Clinical trials with whānau in Northland. For example, having the highest cancer rates, trial of new drugs would be beneficial.

Comment also around Te Aka Whai Ora not being given the time needed to make change and impact.

**Russ** – acknowledged all scans and much of that happening locally on Westcoast.

New clinical governance model – information not coming back up from the workforce as to how it's working. Disappointment re Localities announcement.

There was agreement to raise concerns about the recent visible attacks targeting the rainbow community and the impact this has had on the community.

## **5. Te Tāhū Hauora QSM submission & Enviro scan board paper**

Deon read the draft of the board paper which will go to CAG after this hui. The group were happy with the contents and will await the draft to be sent after the hui. Angie mentioned bringing the emotive side of the paper to the board.

Contents of the environmental scans that went to the board are attached as Appendix 1.

Deon mentioned the Patient story that Peter Jansen will present to the board. It is a video of a Whakakotahi primary care project a few years ago and ties in with the board's strategy focus on primary care. It is an example of work in diabetes in the community. See video:

[Consumers involved in Hutt Union & Community Health Services' Whakakotahi quality improvement project talk about their experience and the Toiora exercise programme they developed.](#)

Deon spoke to the QSM portion of the board paper and what scores were marked for Te Tāhū Hauora following input from Kōtuinga Kiritaki Consumer Network. The dashboard will be redesigned to better visually reflect the QSM.

## **6. Board paper – Perinatal and Maternal Mortality draft report**

Following introductions, Jo Sorasio gave an outline of where the report was at, who had input and that after 16 years, it is possibly the last report of its kind, with the five Mortality Review committees combining into one national committee. It does still need a lot of work to get certain aspects of report better shaped and the subject matter experts are working together with clinicians, researchers etc, to achieve this.

Observations – as it's hard to critique, was lack of the word 'still' in recommendations and throughout the report as inequity still persists, data & numbers etc. have not substantially changed over the years.

Ultrasound info on page 39 should also be developed into recommendations.

Lived experience could be highlighted more to assist in translating comments into actions. E.g. the ratio of clinician comments to the inclusion of lived experience is not balanced.

Acknowledgement also of living experiences being shared.

Another recommendation could be made around the near miss data as there is a lot to be learnt from these insights to inform systemic change. These near misses could be part of the solution.

There was frustration and disappointment that things haven't changed over the years.

Everyone acknowledged the sensitive subject matter and the effect this must have had on the MRC team and wider, having dealt with the information. They thanked Jo for the mahi that had been done on this report.

## 7. Partners in Care report and questions

The report was taken as read and no questions raised. The report is attached as Appendix 2.

## 8. Draft SPE (for noting)

Deon ran through PIC's two SPEs (originally four) and detailed what they included. One is sector focused on primary care, the 2<sup>nd</sup> consumer focused. Still in draft form and based on case studies.

1. Ongoing implementation of the code of expectations. Guiding responsiveness to the code in the sector.
2. Consumer health forum Aotearoa – delivering regional workshops for consumers.

Audit NZ signs off on the SPEs - i.e. how they are measured.

Angie also added feedback on attending the recent Hastings workshop and how well the team managed expectations from the group.

## 9. Wrap of day, other business

There was no other business.

## 10. Karakia and close

Angie closed with karakia.

### Actions list

Date	Action	Responsibility
	No action items	

Next hui – 31 May 2024 – Zoom.

## Appendix 1

### Contents of Board paper environmental scan

1. The following are some of the wide-ranging external factors noted in the 5 April 2024 meeting as having an impact on consumers, whānau, and communities:
  - a) pressures on the health and social sector
  - b) changes to disability payments
  - c) changes in the mental health and addictions sector
  - d) Increasing expectations on Iwi Māori Partnership Boards (IMPB) and pausing of localities
  - e) accessibility to health records
  - f) increasing expectations of the funding of pharmaceutical and medical devices
  - g) cost-of-living
  - h) visible acts targeting the rainbow community
  - i) workforce shortages in hospital and specialist services-level both generally and specifically for consumer and whānau engagement support.
2. With the dis-establishment of Te Aka Whai Ora, Iwi Māori Partnership Boards will have a larger role and be an important avenue for whānau voice and commissioning. This will require a boost in funding, particularly with the commissioning function added. Details are still to follow. IMPBs will continue to advocate for equitable funding. There are a lot of competing pressures on whānau, including the impact of changes to smokefree legislation, lack of GP access, lack of reliable roading and infrastructure, low immunisation rates, and the cost-of-living. Some IMPBs observe that Te Aka Whai Ora did not have enough time or opportunity to make the health gains for Māori. Other items on the agenda for IMPBs, particularly in the Northern regional context, include forming partnerships for clinical trials, and pharmacy consultations to improve access for whānau. In terms of the success of the pharmacy consultations initiative specifically, data provided by the IMPB for the Northern region prior to the extension to the Community Pharmacy Minor Ailments service indicated high uptake through rural pharmacies (43% of consultations), and for children ((67% of consultations). Approximately 331 consultations occurred in pharmacies per week (12 June 2023 to 29 February 2024) and 6.9% of consultations were to the unenrolled (general practice) population.
3. Localities will be paused. In terms of what replaces consumer councils and advisory groups at a former district level, this is still to be confirmed by Health New Zealand Te Whatu Ora. The Health New Zealand Te Whatu Ora team is establishing, and The Te Tāhū Hauora consumer and whānau engagement team is working alongside this team and has 'mapped' out respective areas of focus. This has been a useful exercise to ensure complementary functions and has reinforced the role of Te Tāhū Hauora as part of its function to support the health sector to engage with consumers and whānau for the purpose of ensuring that their perspectives are reflected in the design, delivery, and evaluation of health services.
4. Perspectives were shared about what is continuing to occur in local contexts and the focus on what is important for local communities. The study on alcohol consumption in New Zealand was noted, pointing to higher consumption in remote areas, but also highlighting assumptions that are made about where higher alcohol consumption occurs.

5. Clinical governance models are currently being developed locally. Engagement and access challenges need to be acknowledged alongside the disempowerment of the community.
6. The ongoing lack of integration with practice management systems and hospital records create information vacuums for both patients and the system. This is a matter of digital health equity. This will be a topic at the next consumer health forum Aotearoa on 15 May 2024. Resources such as Healthify for access were noted as useful consumer information tailored for the New Zealand context.
7. Changes to disability payments and how these were communicated was raised. The new rules were created and released on 18 March 2024. The public had until 29 March 2024 to look at these changes. Concerns were raised over how announcements were made and who was engaged with in advance. It was noted that the way the rules were introduced without discussion will now erode trust between the agency and the community. 'If we don't do things with people, this is what happens.'
8. The mental health and addictions sector have a range of concerns. There is hope with a new Minister for Mental Health, but with questions about how the authority and influence works. There was a large community response to the Pae Ora Mental Health and Wellbeing Bill. A theme coming through is that mental health and addictions infrastructure should be independent of Manatū Hauora. There are ongoing concerns about abuse of information, including layers of access to personal information. Lived experience leadership should inform any strategy. For these structural decisions, lived experience representation has tended to focus on an individual perspective of trauma rather than a collective view.
9. Low-cost primary care services are being developed in Dunedin with a target of people being seen within the first 24-48 hours. Lower cost access to medical procedures for Pacific communities are also being planned. It was noted that it is important to 'celebrate among the challenge', such as at the recently concluded Moana Nui festival.

## Appendix 2

### He Hoa Tiaki report for Te Kāhui Mahi Ngātahi | CAG 5 April 2024

The following are highlights from the past few months with a focus on the third quarter of the financial year (1 January-31 March).

#### **Consumer health forum Aotearoa**



#### **North Island consumer health forum workshops March 2024**

Three consumer workshops were hosted by He Hoa Tiaki in the North Island in March with a view to building consumer interest in and capability to engage in health service improvement. The workshops took place on Friday 15 March 2024 at Terenga Paraoa Marae in Whangārei and on Saturday 16 March 2024 at Te Ahu in Kaitaia. The following weekend, the workshop was held on Saturday 23 March 2024 at Te Taiwhenua o Heretaunga, Hastings followed by an afternoon session hosted by the Office of the Health and Disability Commissioner about the Code of Rights ([www.hdc.org.nz](http://www.hdc.org.nz)).

#### **Consumer forum opportunities**

We continue to see a growing interest in consumer opportunities being made available through the consumer health forum Aotearoa. For the period of 1 July 2023-present we have been able to assist organisations to recruit over 410 consumers to share their expertise through joining consumer councils and networks, participating in focus groups, joining advisory, steering or governance group and participating in surveys. Some examples of these include:

- Recruitment drives for Health New Zealand Te Whatu Ora programmes including work focused on palliative care, cardiovascular disease, and cancer care.
- New opportunities for consumers to work with Te Tāhū Haoura Health Quality and Safety Commission including focus and advisory groups in areas of aged residential care, a national medicines steering group and the recruiting of 2 members to our consumer network.
- Testing of IT services for the National Screening Unit
- focus groups led by HDC, University of Auckland school of Pharmacy and Health Navigator

All current opportunities are listed on our website here: <https://www.hqsc.govt.nz/consumer-hub/consumer-health-forum-aotearoa/consumer-opportunities/>. They are updated regularly and are also promoted via our newsletters and via social media. Please share widely any opportunities your networks may be interested in.

Next year's programme plan includes surveying both organisations and consumers and whānau to understand more about experience and tracking the impact that consumers are having on shaping design delivery and evaluation in the health sector.

## **Our Voices: Shaping health care together | Ō mātou reo: He tārai tahi i te tauwhiro hauora**

Our national forum event will be held on 15 May in Auckland at Waipuna Hotel and Conference Centre. We are happy to announce that our four workshop sessions are confirmed. You can read about the workshops below. Participants at the forum event may choose two of the four to attend.

- Digital health equity: What it is and how you can help: At this workshop, you can contribute to a paper on digital health equity, following an 'unconferencing' style. The important themes and messages for the paper will be developed by the group and inform the work of the Digital Health Equity Network that sits within the Telehealth Leadership Group ([www.telehealth.org.nz](http://www.telehealth.org.nz)). Presented by: Dr Ruth Large, Telehealth NZ and Dr Amio Matenga Ikihele (Niue | Te Whānau-ā-Apanui) is a registered nurse, and GM at Moana Connect.
- Honouring our stories, a workshop for consumers: This workshop is for consumers and whānau who are new to being involved in improving health services. Learn about opportunities to bring your voice to these improvements and preparing to share your lived experience safely and effectively in different settings. Presented by the He Hoa Tiaki Partners in Care consumer engagement team.
- How whānau voice can drive improvements: Introducing the new Te Whatu Ora Consumer Engagement and Whānau Voice team from Service Improvement and Innovation with kōrero from the Group Manager Communities, National Lead PREMS, PROMS and Insights, and National Lead Rainbow Communities, who will give you an overview of their priorities and how their lived experience will influence their mahi and how experience data can impact change. Presented by Presented by Akira Le Fevre, Suzanne Corcoran, Laura Ellis, Health New Zealand consumer engagement and whānau voice team.
- Reframing disability in health: Disability capability framework. Aotearoa New Zealand's health system does not always work for disabled individuals. Health New Zealand prioritises them in the Te Pae Tata plan. This workshop introduces the disability capability framework to help you assess the strengths and areas needing improvement for your organisation to be equitable for disabled people. Presented by: Rachel Noble MNZM and Leo Goldie-Anderson, Health New Zealand – Te Whatu Ora and Jonathan Tautari, Te Tāhū Hauora Health Quality & Safety Commission
- The Our Voices [event information page](#) contains more details, including programme timing and other event and venue specifics. We still have space, so please continue to spread the word with your networks.

## **Forum membership**

The total number of individuals who have signed up to the consumer health forum Aotearoa forum members is 921. We continue to encourage new membership. You can keep the forum growing by sharing [this sign-up link](#) with those in your network:

The following table shows the breakdown of members by ethnicity from end of quarter 4 2022-2023 through end quarter 2 (31 December 2023).



<b>Ethnicity</b>	<b>Quarter 4 2022-23</b>	<b>Quarter 1 2023-24</b>	<b>Quarter 2 2023-24</b>	<b>Quarter 3 2023-24</b>
Māori	Quarter 4 total: 153 (18.4%)	Quarter 1 total: 170 (19.0%)	Quarter 2 total: 174 (19.4%)	Quarter 3 total: 181 (19.7%)
Pacific	Quarter 4 total: 87 (10.1%)	Quarter 1 total: 91 (10.2%)	Quarter 2 total: 91 (10.1%)	Quarter 3 total: 91 (9.9%)
Asian	Quarter 4 total: 39 (4.5%)	Quarter 1 total: 42 (4.7%)	Quarter 2 total: 43 (4.8%)	Quarter 3 total: 46 (5.0%)
Pākehā/Caucasian	Quarter 4 total: 482 (56.0%)	Quarter 1 total: 494 (55.3%)	Quarter 2 total: 494 (54.9%)	Quarter 3 total: 504 (54.7%)
Middle Eastern/ Latin American/ African	Quarter 4 total: 17 (2.0%)	Quarter 1 total: 18 (2.0%)	Quarter 2 total: 18 (2.0%)	Quarter 3 total: 19 (2.1%)
Other ethnicity or ethnicity not specified	Quarter 4 total: 77 (9.0%)	Quarter 1 total: 78 (8.7%)	Quarter 2 total: 79 (8.8%)	Quarter 3 total: 80 (8.7%)
<b>Total</b>	Quarter 4 total: 860	Quarter 1 total: 893	Quarter 2 total: 899	Quarter 3 total: 921

## **Engagements**

External engagements for this quarter were numerous, focusing much of the activity on planning and execution of our national and regional forums and connecting with the national consumer and whānau voice team at Health New Zealand Te Whatu Ora.

The PIC team met with varied organisations in relation to the code of expectations, clinical networks, EOI development for consumer opportunities and supporting the QSM submission process across the health entities. The following workshops or presentations are of note this quarter:

- Deon presented to the Australian Medical council on the development of indigenous presence and scholarship within Te Tāhū Hauora.
- Launch of Rare disorders report at Parliament.
- Lauagaia (Cat) attended the Surgical Mesh roundtable bi-monthly workshop.
- DJ presented to the national Anticoagulation quality improvement group in Auckland re: engaging consumers.

## **Code of expectations and implementation guide update**

The implementation guide for the code of expectations was launched in July 2023 as a 'living guide' with an aim to update the guide 6-monthly. Feedback on the implementation guide can come through a number of sources including through presentations on the code and guide, the feedback option provided on each webpage, and from health entities through the

consumer voice reference group (CVRG). The code of expectations and implementation guide webpages are also monitored to review the traffic to specific webpages. In December, members of CVRG were asked to complete a survey on behalf of their entity about the current implementation guide webpages and any key changes needed. Te Whatu Ora also shared the survey with consumer engagement leads at national level. Survey responses were then used to plan immediate and later updates to the guide. For example, a few specific resources were suggested as additions, and these have now been added to the guide and further feedback is being reviewed by the team for actioning. A request for further training resources is being taken forward into planning for the coming financial year and the development of additional practical tools is ongoing in collaboration with the sector and with consumer groups.

Overall, there was appreciation of the wide range of resources included in the guide and the 'Accessibility' videos featuring Mary Schnackenberg were singled out for positive comment in the survey.

### ***Quality and Safety Marker for consumer engagement (QSM)***

The QSM submission date this period falls on 29 March, Due to the Easter holiday coupled with staff shortages, some organisations have requested more and/or assistance with this submission period. He Hoa Tiaki plan have all submissions we receive reviewed, moderated and uploaded by 21 May. We will announce the publication of these closer to the date.

### ***Website analytics (1 June 2023 to 21 March 2024)***

Our Te Tāhū Hauora website remains our main engagement tool and is used widely.

Highlights from 1 Jan to 21 Mar 2024:

- 7.2 percent of users scrolled to a depth of 90 percent on the pages they visited
- We recorded 22,367 file downloads
- There were 63,977 users that viewed 179,877 pages, and stayed for an average of 1 minute 14 seconds
- There were 2,929 users that viewed 7,897 consumer hub pages, for an average of 1 minute and 28 seconds (18 percent more that the average across the website).

### ***Summary of consumer hub website traffic***

#### **Description of Table 1.**

[Understanding co-design](#) had 667 views (426 users) in quarter 1, 518 views (375 users) in quarter 2 and 347 views (256 users) in quarter 3.

[Consumer health forum Aotearoa landing page](#) had 930 views (656 users) in quarter 1, 767 views (542 users) in quarter 2 and 663 views (332 users) in quarter 3.

[Consumer opportunities](#) had 1619 views (964 users) in quarter 1, 1840 views (1010 users) in quarter 2 and 983 views (537 users) in quarter 3.

[Code of expectations for health entities' engagement with consumers and whānau](#) had 2011 views (1117 users) in quarter 1, 1594 views (961 users) in quarter 2 and 843 views (558 users) in quarter 3.

[The code of expectations translations and accessible formats resource page](#) had 1395 views (820 users) in quarter 1, 1267 views (821 users) in quarter 2 and 522 views (385 users) in quarter 3.

[Co-designing with consumers, whānau and communities](#) had 793 views (447 users) in quarter 1, 328 views (217 users) in quarter 2 and 398 views (202 users) in quarter 3.

[Using lived experience to improve health services](#) had 389 views (243 users) in quarter 1, 245 views (165 users) in quarter 2 and 218 views (159 users) in quarter 3.

[Improving equity through partnership and collaboration](#) had 276 views (176 views) in quarter 1, 107 views (76 users) in quarter 2 and 129 views (95 users) in quarter 3.

[Accessibility and resourcing for consumer, whānau and community engagement](#) had 269 views (146 users) in quarter 1, 107 views (58 users) in quarter 2 and 86 views (56 users) in quarter 3.

## Social media

Popular content was from reflection on our voices and sharing new consumer opportunities. He Hoa Tiaki social media content have the highest engagement across all social channels.

### LinkedIn

50 percent of the top ten best-performing organic posts for Te Tāhū Hauora were from the He Hoa Tiaki team. Ranked #1 across the organisation was resharing an Our voices post 'Looking back at our favourite moments in the past 12'

- Clicks: 28
- Engagement: 63.27%
- Impressions: 49
- Reactions: 3

### Facebook

60 percent Out of the top ten best-performing organic posts for Te Tāhū Hauora, six were content from He Hoa Tiaki. The top post ranked #1 across the Te Tāhū Hauora was our post for Our voices

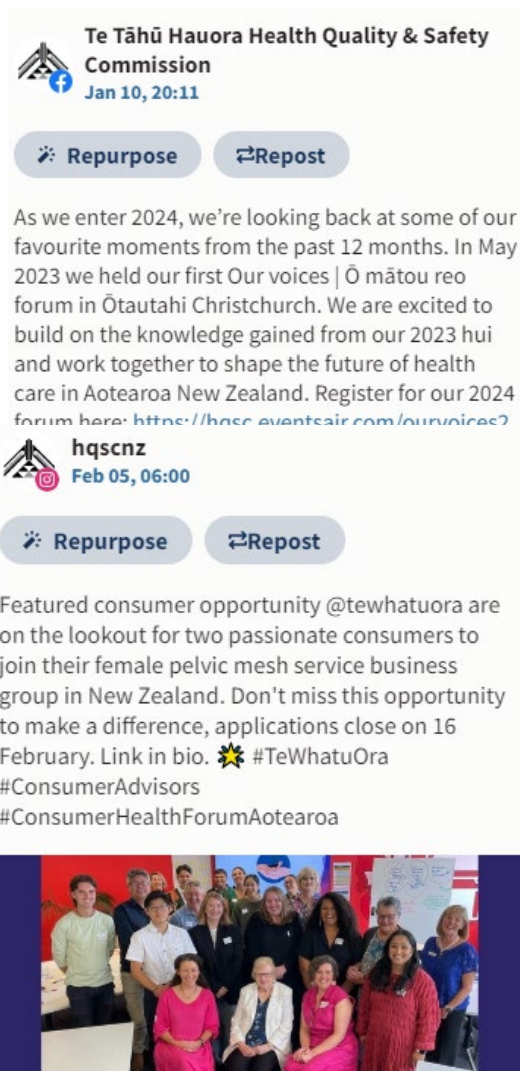
- Engagement rate: 6.32%
- Reach: 233
- Reactions: 1

Our top posts ranked: 1, 2, 4, 5, 7 and 8 across the organisation.

### Instagram

60 percent of the top ten best-performing organic posts for Te Tāhū Hauora were He Hoa Tiaki content.

Our top posts ranked: #1, 4, 5 and 8 across the organisation.



The top post ranked #1 across the Te Tāhū Hauora was A featured consumer opportunity at with Te Whatu Ora for the female pelvic mesh service business group with an engagement rate of 10.53% on 5 February 2024.

- 10.53 engagement rate.
- Reach 76
- Likes: 8