

MINUTES

WAHARUA KŌPITO (CONSUMER COUNCIL)

26 March 2024

4.00pm

Corporate Meeting Room 1, Te Whatu Ora – Taranaki and Zoom

Present: Jane Parker-Bishop (Co-Chair), Paula King (Co-Chair), Wes Milne, Graham Walker, Ngāpei Ngatai, Caroline Tyrrell, Nannette Pirikahu-Smith, Raymond Tuuta, Nicola Clarke, Ainsley Luscombe, Angela Kerehoma, Dinah King, Dinnie Moeahu, Jamie Allen

In Attendance: Lisa Varga – EA to Group Director Operations

Karakia and Welcome

- Council only time was held until 5.00pm.

Apologies

- Shelley O’Sullivan was absent.

Previous Minutes

e-Referrals

- Jane will get Jo Scott-Jones, Pinnacle Health to join a future meeting to provide an update in relation to e-referrals.

PrEP

- A list of doctors who prescribed PrEP was requested; it was noted that Chris Sorensen is currently on leave.
- In relation to equity, the Council thought the response was “under cooked” and a second-rate service.
- Ray commented that in no way would we take that position with a cancer patient when medication is available that can help them survive.
- To be further discussed under Community Insights.

Action: A letter is to go to Te Whatu Ora – Taranaki advising that the Council were not happy with the response received.

Endocrinologist

- Jane and Paula will discuss the endocrinologist service with Gillian when they next meet.

Vaccination Rates

- Graham would like the minutes amended to reflect that while he did say vaccination rates were shocking, this was in relation to inequity amongst the ethnicities.

Co-Chairs’ Update

- Second bullet point to be amended to remove “however not confident”.

With the above amendments, the minutes were accepted as a true and accurate record of the meeting held on 27 February 2024.

Co-Chairs' Update

Whare Chair Appointments

- The Co-Chairs met in separate waka to discuss their reappointment.
- Jane did hers via email and a decision made for her to stay on as Co-Chair.
- Paula set up a Teams meeting with four in attendance – herself, Ray, Angela and Ngāpei. It was nice to be able to reflect on what is happening in our rohe. The main discussion was around the role and the keenness to advocate and encourage the community to get together and hui and talk about experiences with health. Keen to encourage hapu to come together and find a collective voice. In terms of the Co-Chair role, as there were only four online it was not appropriate to make a decision. Angela was happy to nominate Paula stay in the role of Co-Chair with Dinnie seconding it. Paula accepted and will remain in the role of Co-Chair for the next two years.

Wes joined the meeting at 5.14pm

National Chairs' Position Statement

- Jane understands as a rōpū we are looking to support the national statement. As the Consumer Engagement Council, we can support day to day but can also share with local MPs. Will put together a statement from our Waharua Kōpito Consumer Council that supports the National Chairs' position and will share with members of Parliament, Councils and Te Whatu Ora – Taranaki.
- The group were happy for that to happen.
- Will have a few members that will work on the statement; Jamie and Ngāpei would like to be involved. Ainsley is happy to approach the MPs in person.

Quality Safety Markers

- Email received from Chris Sorensen who is working in the background on our submission.
- Chris is asking for members from this group to work alongside her. Previously Paula, Wes and Ngāpei assisted Jake and Mary. Is the Council happy for those people to continue, is anyone else wanting to be involved?
- Ainsley commented that she found Chris' email to be patronizing in the way it was worded, disappointing as a group. The Council need to be respected for the different knowledge each person holds. Insulting to our Council.
- Caroline commented that Chris has had a huge learning curve in the understanding of what needs to be done to carry forward.
- There is a meeting scheduled for 10am–12noon on 18 April 2024; Paula, Wes and Ngāpei will be attending.

Terms of Reference

- Discussion held at a previous meeting regarding changing the quorum.
- The current Terms of Reference are currently in draft and will remain in draft until June 2024 when we hope to have clarity around systems.
- Looking to reduce to three from each whare to meet quorum with one of the six members present being from South Taranaki.
- Would like to revise the following in relation to membership - "No more than 50% of the membership from each whare will stand for reappointment at any one time to ensure continuity". This will be removed from the Terms of Reference.

Community Discussion

PrEP and Endocrinologist Service

- The Council feel that the response received from Chris Sorensen regarding PrEP and the endocrinologist services is not acceptable.
- Ray wanted to retouch on that point mindful that Wes was not present earlier. Wanted to give some context around the discussion raised by Ainsley in relation to the information that was fed into our previous meeting around PrEP. The response was not satisfactory regarding the information provided. Regardless of the group or rōpū we would not withhold medication e.g. from a cancer patient if it could save their life. The Council were not satisfied with the response and the information provided, and the sense of how it was dealt with. Need to capture and feed this back.
- Ainsley suggested a letter be sent from the Council advising it is not satisfactory to use resourcing as the issue. One of our briefs is equity and ensuring resources are where they need to be. Not satisfactory to say it is a resourcing issue.
- Ray would like to mihi to Wes for always being an active voice for our rainbow community; you are instrumental in making change to our whānau here.
- Wes feels there is a lot of miscommunications; he would be interested to know who wrote the letter from the Sexual Health Clinic, who are working with the rainbow community as well.
- It is to be made clear that the Council are unhappy with the response, feel it was a weak response to what is always a marginalized community. When we talk about equity it is far from equitable to say it is a resource issue. It is a focus we need to have.

Action: A letter is to go to Te Whatu Ora – Taranaki advising that the Council were not happy with the response. Jane will also follow-up with Chris for some clarification in relation to where the information came from.

Patient Experience

- Caroline told the Council about a young boy she met through her playgroup a few years ago. From an early age the boy had a nasogastric tube, he managed to get along to playgroup etc however his mother felt that she had to be there to support him full-time.
- The mother told the story of trying to get her son off the tube and onto food. The weaning off of the tube and learning how to eat occurred later than most children experience.
- They came into hospital when it was time to do the changeover and all that was offered was a three-day process to go through. The mother had to watch her child suffer until he had no choice but to eat – in a small space of time.
- The mother did some research and it turned out there was a group in Auckland she could approach. She also found there was a clinic in America that had an eight-week process that was well researched. They had support groups for parents to share their experiences and to keep morale up.
- The mother said it would have been good if someone here had been able to say we do so few of these procedures and we don't have the best practice approach.
- Dinah has had experience with nasogastric tubes when her daughter was young; she would demonstrate to the nurses how to put them in and test they were in the right place. Dinah feels for the whānau. Her daughter was lucky enough to have a great speech language therapist.
- Jane asked that Caroline email Chris Sorensen in relation to what she has heard the young boy go through, copy in Jane and Paula.
- Dinah would be interested to know of other families who have had nasogastric tubes and the experience.

Adopt-a-Doc

- Ainsley talked about the “Adopt a Doc” programme running in South Taranaki.
- Ainsley showed three doctors around her personal farm and they were blown away. The purpose of this (and the programme) is to illustrate the advantages of doctors working in a rural community so that it encourages them to return to these areas once they are qualified.
- Dr Tom Dawson is very supportive of the programme, great to let them see living in a rural area is very cool.
- Doctors that come next year will be here for the whole year, need to be putting supports in for the young ones.

Position Statement

- Paula commented that there are expressions of disappointment from her community that Te Whatu Ora – Taranaki don’t have an outward position for Te Tiriti and te reo Māori. Disappointment when Te Whatu Ora went back to Health NZ. Outward facing comms has dropped Te Whatu Ora, in fact comms altogether doesn’t mention Te Whatu Ora.
- Paula thinks it would be strategic of the Council – while the hospital is an employee of the current Government and we are appointed to be a community voice – to amplify what is being felt in the community.
- Paula would like the Consumer Council to develop some sort of position statement to Te Whatu Ora – Taranaki to support upholding Te Tiriti and equity for Māori in a public facing way.
- Te reo Māori is protected under Te Tiriti Waitangi. We are part of an organization that no longer uses it in a lot of places. Do we want to accept that or advocate against it. It would be done in a way that doesn’t burn bridges and maintains relationships with the people we work with.
- Ngāpei agrees we need to be strategic.
- Dinnie moved a sub-rōpū gets together first, has a korero and drafts a statement. It will then be presented to the wider rōpū for consideration. Caroline seconded this approach.

Close of Meeting

- Jane thanked everyone for coming and for the contributions, encouraged by what has come out of the hui. Thanks to Dinnie for his contributions.
- Ray supported the closing comments. On reflection of our journey and where we are today and korero we have shared, grown as whānau in this space and acknowledge lived experience.
- Ray closed the meeting with karakia.

The meeting closed at 6.24pm.