

Present: Chris Walsh, (Chair), Ezekiel Robson, Te Rina Ruru, Tamara Waugh, Renee Greaves, Camron Muriwai, Marlene Whaanga-Dean, Bernadette Pereira, Marj Allan, Stephanie Marson (minutes)

Apologies: Deon York, Martine Abel-Williamson, Edna Tu'itupou-Havea, Courtenay Mihinui, Fonoifafo Seumanu-McFarland, Gillian Bohm, Dez McCormack, Stephanie Turner

The meeting commenced at 9:45am

1. Introductions and welcome

Chris opened and welcomed all to meeting and Camron provided us with a karakia. Apologies noted.

2. Minutes of the meeting held 12 September 2019

The minutes of 12 September 2019 were confirmed as a true record.

2.1 Actions update

The actions list was considered and updated.

2.2 Interests register

The interests register was reviewed and updated.

3. Partners in Care (PIC) report

Chris gave the Partners in Care report. Chris also spoke about John's funeral and advised Deon had been in touch with Mid Central about their new chair.

PIC written report is:

Quarterly report from Partners in Care team for the Health Quality & Safety Commission's Consumer Network

14 November 2019 meeting

Since our last meeting on 12 September 2019, our focus has been on progressing the quality and safety marker for consumer engagement and working with Dr Lynne Maher to support the co-design programme focusing on regional cancer services. With almost half of the financial year complete, we are also closely monitoring our operational budget, 2019/20 being particularly stretched. Below is a summary of activities since our last meeting:

- Deon presented on 'tools and methods for capturing patient experience' at the Mental Health and Addiction team's learning from adverse events and consumer, whānau and family experience co-design workshop in Wellington on 13 September.
- Chris and Deon supported a workshop with consumers facilitated by Canterbury DHB's quality team on 17 September. The purpose of the workshop was to look at the consumer

engagement quality and safety marker concept and gain wider consumer feedback.

- On 23 September Dez, Chris and Deon supported the first cancer co-design workshop for the programme this year in Auckland (Northern region). There are two teams participating in the Auckland region. We work closely with Dr Lynne Maher, and Te Hao Apaapa-Timu (recently appointed programme manager of co-design at CMDHB).
- On 24 September, Chris and Dez supported a further cancer co-design workshop in Hamilton (Midland region). Four teams are taking part in this region.
- Chris was involved with the restorative justice work being supported by the Ministry of Health for people impacted by surgical mesh on 3 October. Many who required surgery and had surgical mesh used in the procedure have been adversely affected over many years and have been advocating for recognition and response to these adverse events.
- Deon and Chris attended part of the Cancer Consumer Network meeting on 7 October. This part of the meeting discussed the changes to the organisation of cancer services. We provided some advice about how the group could respond to the consultation on these changes.
- On 15 October Chris and Deon attended the cancer co-design workshop in Palmerston North (Midcentral), followed by Christchurch (Southern) on 16 October. A total of eight teams are participating across these two regions.
- Chris and Deon presented the Partners in Care work, with a focus on primary care, at the Commission's primary care advisory group on 17 October.
- The consumer engagement quality and safety marker reference group met on 23 October to progress the pilot across the four DHB sites.
- Dez, Chris and Deon went to Palmerston North on 30 October to interview and film Tracey Jourdain and her multidisciplinary team. Tracey has Ehlers Danlos Syndrome, a connective tissue disorder. The video is currently being edited by the PIC team. It will focus on how the multidisciplinary team (coordinated by the patient) has led to a marked improvement in Tracey's health and wellbeing. The multidisciplinary team was filmed together and individually.
- On 30 October, Chris and Deon also provided background information about the work of Partners in Care for incoming Commission board members.
- On 5 November the Consumer Advisory Group to the Commission's board met. The group also met with the board and affirmed the importance of the consumer 'lens' being across everything that the Commission does. The new board chair is happy to receive consumer issues on the board agenda from the CAG group.
- Chris attended the Ministry of Health's consumer consortium (disability) on 13 November.

New resources

Last week was Wiki Haumarū Tūrōro – Patient Safety Week. The theme this year related to understanding institutional bias in health care. Members of your consumer network were front-and-centre:

Featuring Bernadette Pereira:

<https://youtu.be/qEZB-9iqpDo>

Featuring Courtenay Mihini:

<https://www.hqsc.govt.nz/blog/the-voice-of-whanau-communication-is-the-most-important-thing>

We have supported the recording of children and whānau stories at Camp Unity. You can read more about it here (featuring Te Rina Ruru): <https://www.hqsc.govt.nz/our-programmes/partners-in-care/news-and-events/news/3875/>

4. Feedback on Board hui last week.

Chris gave an overview of the Board meeting as it pertains to consumer. Noted also was that the new board chair (Dr Dale Bramley) was open to receiving agenda items from the Consumer Advisory Group (CAG) to the board.

5. Consumer Network reports

Bernadette Pereira

Continuing work with Southsea's Healthcare Trust on the community Consumer Network. Have held one meeting in month of October to look at work plan for the new year

On personal front - I was unsuccessful in my bid for a seat at the CMDHB local elections, however, I have applied for a place on the CMDHB Consumer Network.

Training models on "unconscious bias" launched for Patient Safety Week.

Camron Muriwai

Presented at the 71st Scientific conference of the Paediatricians Society - Our journey living with a child, young person, adult with a long-term chronic condition. Bronchiectasis.

Presented a chronic child life journey at the Northland Diabetes conference.

NDHB Consumer council. Information process improved requiring good time management with the requests for consumer input and also feedback of document changes/improvements. Great support.

Respiratory Symposium for Bronchiectasis planning well underway. Registrations now open.

Ezekiel Robson

HQSC Consumer Engagement Quality & Safety Marker group - on-going work to refine the overall framework based on feedback from various pilot sites. The process of pilot sites engaging with consumers to get input on the QSM is already having an impact on those DHBs thinking about who and how they involve consumers, both through Consumer Councils, and other means.

Health and Disability Service Standards Review - five working groups were looking at

different aspects of the standards; I was part of the 'Consumer Rights' working group. There were consumers involved on each of the working groups. There is a plan to connect all those consumers up by phone to further strengthen consumer-focused outcomes of the accreditation standards.

<https://www.health.govt.nz/our-work/regulation-health-and-disability-system/certification-health-care-services/services-standards/health-disability-services-standards-and-fertility-services-standard-review>

I was recently awarded a Kiwi bank Local Hero Medal (part of the New Zealander of the Year Awards) for voluntary service in the disability community. HQSC communications team will write up a story for the website.

<https://nzawards.org.nz/news/kiwibank-local-hero-medal-recipients-announced/>

<https://www.facebook.com/newzealanderoftheyear/photos/a.150994401650901/2500662993350685/?type=3&permPage=1>

Te Rina Ruru

Reported back on Camp Unity as part of the meeting agenda

Martine Abel-Williamson (written report provided in Martine's absence)

Met with the HQSC board which included new board directors/members,
Linked with Te Rōpū in order for our combined feedback to be collated on how equity within the Commission can be progressed,
Provided comment and feedback on various papers sent to the board such as in areas of mortality reviews.

Health Navigator, consumer advisors meeting

Date: 22 October 2019

Health Navigator is working with a number of organisations including Ministry of Health, HPA, ACC, Health Info Canterbury & HealthPathways (Canterbury DHB), KidsHealth NZ and the National Telehealth Service to form a national collaborative.

Vision

New Zealanders have a trusted and convenient source of consumer health and disability information.

A single trusted digital source of consumer health information – regardless of channel/brand/entity that can be freely shared and repurposed as required.

Current suggestion

The creation of a national health content hub/health information service that brings together the best quality consumer information and self-care resources that will lead to improved wellbeing and health outcomes for whānau and communities.

Purpose

To improve the health and wellbeing of New Zealanders by:

- Providing the right information at the right time in the right place to support people to make informed choices about their health.
- Engaging people in their own health and wellbeing.
- Supporting and promoting positive behavioural change.
- Preventing harm, illness and injury.

We also provided input to what our ideal digital health system would look like from a consumer perspective (with a focus on consumer resources). I've attached a brief outline. Gary Sutcliffe who is part of Health Navigator used to be a Consumer Network member so, he's already got connections with HQSC as well.

Meeting: ACC Scheme Customer Advisory Panel
Date: 27 September 2019

Note here that the full set of public key messages have already been circulated to the Consumer Network previously.

The meeting agenda covered a wide range of topics, including confirmation of the 2019-20 Panel Work Programme, an overview of how ACC collects and uses customer feedback, and an update on designing Health and Safety Lead Indicators. The minutes for the meeting can be found on the [Panel page](#) of the ACC website. Below we have provided key messages relating to the agenda items discussed for your information.

2019-20 AC Scheme Customer Advisory Panel Work Programme

The 2019-20 work programme for the Scheme Customer Advisory Panel has now been confirmed. The work programme includes Panel contribution to key ACC and MBIE projects, such as Enhancing the Accredited Employers Programme, building a framework that develops ACC's relationship with General Practice, and consulting on the Review Costs and Appeals Regulations. The work programme also covers broader horizon scanning items, taking a wider systems approach for upcoming changes which may impact on the AC Scheme.

ACC's Customer Feedback Channel

The ACC Customer Insights and Experience Feedback Team have introduced a new feedback management platform. The platform enables ACC to collect, analyse and act on feedback in the moment. Customers are invited to provide feedback after their interactions via multiple channels, or when they use ACC products and services e.g. [the ACC website](#) and MyACC.

The platform data and analytics engine allow ACC to identify trends, themes and systemic issues affecting the customer experience, so they can continuously improve and make more fundamental changes to the customer experience in the long term.

You can access the feedback channel through [the ACC website](#), by selecting the feedback tab on the right-hand side of the website on the home page.

Changes to ACC's Case Management Model

ACC are changing the way we work to improve the quality of service we provide. The right support from us means a better recovery for individuals. We're rolling out a new, more customer focused, way of supporting people.

Information on these changes and what it means for our customers can be found on [the ACC website](#).

ACC Sexual Violence Prevention Advisory Board

Date: various working group meetings between September and November 2019

Sapere has been contracted to do research within the disability sector and community to do a stocktake of mainstream programmes and how inclusive those are for disabled people and that

stocktake will also investigate programmes designed specifically for disabled people especially school aged children and youth.

The details of research participation will be made available to the disability and community towards the end of November and beginning of December.

Tamara Waugh

- MHA QIP CAG – Zero seclusion teleconference next week. Rest of update from Shaun McNeil.
- Rākau Roroa National Hui last week with around 80 Tall Trees attending from around the country. They were invited to do media training (including how to respond to curly questions), workshops in Social Lean Canvas, Movement for wellbeing and the Science behind a Gratitude practice (3 Good things). They were then invited to attend the following day hosted by the HPA where all the Like Minds, Like Mine providers presented what their organisations do. This included Peer zone, Otago Uni / Kites, MHF and Mind & Body. At both these days I talked to people individually about how important the work I do with HQSC is to our national program and how being on these groups really benefit both organisations.
- During this week one of our Tall Trees who also won the MHF media grant released her podcast series called 'Just Listen' accompanying the podcast were articles in print and digital and a short video interview with each participant. Three Tall Trees were participants in the podcast (including me) and the podcast reached #3 on the NZ podcast charts nationwide.
- Equally Well have formed a strategic leadership group. I have been invited to join this group as an interim group to form the terms of reference and strategic direction and establishment of the group going forward. Equally Well is working with HQSC closely.
- I have been invited to join the Atlas of Health (MH & A) group. I feel this will support the other groups I belong to and benefit a wider understanding of what is happening in the sector.
- I will be doing my final presentation for Yale transformational leadership program on 6th December and graduating in Jan 2020. My project has been transforming the ACC Sensitive Claim process, making it more accessible and humane with lived experience at the design table. I have been working with an instructional designer to ensure lived experience is at every table of the process going forward. This has been well received and successful so far.
- I have been head hunted, offered and accepted a role as Project Manager IT for Geneva Healthcare, my last day in this role is Friday 6th December. I propose that the person (potentially Bronte Jefferies) taking my role replace me on this group. She has a strong interest in youth mental health, and I feel would be an asset to this group.

Marj Allan

I was one of the Consumers involved in the final edit of the Cancer Plan 2019 -2029

This was very high level but a very rewarding Consumer Experience.

From the HQSC stand I don't feel there is anything I could have included; however, I know the Ministry of Health are finding it hard to know how to engage with Consumers. This is something I think we could help with, but this will need some work on how to get current feedback from the grass roots.

Thursday 7th November

I am a member of the Kaiwahina Workforce Working Group I attended a meeting earlier this month regarding this. I was excited to confirm that we got communication into all levels of the training. Very Satisfying. Also, the Kaiwahina Workforce Action Plan aims to recognise this as a valued

workforce. It became apparent to me that this working Group like many others are setting up training systems and standards of how to work with Maori and Pacific. Maybe the HQSC or the MOH has or could create a set of standards that health professionals could include in their workplans rather than everyone working to create their own.?

I also attended the HQSC co-design programme workshop. My group is working on Improving the use of clinical phone appointments. Was great to get the opportunity to learn more on co-design.

6. Camp Unity and Illustrations

Te Rina discussed the highlights of Camp Unity which is for children with traumatic brain injuries, and their whanau and carers. They had 33 children and 21 adults attend. There were some great outcomes and break throughs for with the children who have been struggling to talk about their situation and the impact on their lives.

Te Rina talked of an opportunity to make comics as a way of getting information out to children, especially the teenage group who are harder to connect with.

The illustrations done at Camp Unity have been put on our web site.

7. Travel – and changing airfares

A travel policy was presented to the Consumer Network and all members received a copy. Chris mentioned that one of the meetings may be replaced by a zoom if the budget does not allow for a face-to-face hui. Any costs for changes to air tickets for personal reasons to be met by the traveller unless waived by the Director, Partners in Care.

8. Partners in Care working programme 2020/21

The Consumer Network provided their views of how the 4 principles of Te Tiriti O Waitanga could be applied to the Consumer Network's work. Chris will share the notes on this from the Consumer Network with the Commission.

At the next Consumer Network meeting in March we will look at how the suggestions can be applied to the programme for 20/21.

Here is the accumulated feedback on the four Te Tiriti articles:

The HQSC consumer network was asked to provide input as to how they saw the Partners in Care team incorporating each of the four Te Tiriti O Waitangi Articles (below) in our work programme for 2020/21.

Eight of eleven members were present for this meeting. Of these members four identify as Māori, one as Pacific and the remainder as European.

1. Kawanatanga: partnering for mutual benefit

- When the treaty was signed both settlers and Maori were expected to obtain or retain resources to develop and prosper in the new shared relationship. To bring this into our work plan we need to ensure Kawanatanga agreement is considered and included in all parts of our work plan, to ensure Maori aren't disadvantaged in any way- a Partnership
- Have in mind Maori when making plans – Maori usually dictated to by Pakeha rather than a partnership – needs to be talked about right at the beginning

Connection

- More than just the language, it is the stories and the way of working. Bring the group along to understand tikanga so have Te Tiriti O Waitangi workshops for consumers.
- Try harder, in meetings address racism and acknowledge it is about colonization
- Look at your programme and see how you can incorporate tikanga component
- do we encourage DHBs to have a Maori consumer who receives healthcare at the table?
- Cultural literacy – develop tools. Pronounce people’s names properly.
- Some trauma has made some Maori move from relating as Maori but also not European
- Language pronunciation is important especially of names
- More Maori leaders and members, Wairuatanga, Camp Unity
- Talk about this world and time, history, government, church as some decisions were already made before, well in the past
- From the very beginning this will be about forming long-term relationships with hapu and iwi – not about for now but for generations to come. Create genuine partnerships. Leave space for the frame to be created more in partnerships though will be influenced by Maori
- Treaty relationship – idea of power sharing, recognize where the Commission does or does not have power, HQSC may never have had power, leave it to other people where they don’t have power
- Find a balance, can get tied in red tape. Her team got to a place where they would go to the Maori Health teams for assistance with cultural things, but it can be delayed because too busy and the team is afraid to get it wrong.

2. Tinorangatiranga: Māori retaining chieftainship over their taonga, lands, resources, matauranga (knowledge):

- This is covered in article two of the treaty. We agreed and guaranteed the chief’s te tino village and Taonga katoa all treasured things. I understand this means we need to consult with Maori to ensure we understand their wishes on how we protect and care for their people through-out the health system therefore we also need to make this very visible in the work plan
- Validating experiences and showing respect
- Know and understand the tinorangatiranga we live in that it was taken in hundreds of acres; the history and claims of the past
- Teach Te Reo in every preschool
- Join the hikoi
- Full governance over our own destiny, ownership of language and culture. It’s about increasing the confidence and competency of everyone so others apart from Maori are taking the lead even though they are not a Maori Knowledge – how do Maori want their knowledge managed (data etc).
- Taonga, how they want their kids are treated. Treatment in their own area (geographically), making things accessible
- Taonga – consumer green book, right through the book in Te Reo.
- Mental Health Foundation, Health Promotion Agency, Like Minds Like Mine, HQSC’s waiata and karakia flip book are a great resource and initiative
- Te Roopu will guide/determine how to deal with this at a structural level, in the community they have created a “two house” model where Maori will decide and determine for themselves and Pakeha meet those responsibilities
- Small team in Partners in Care, hopes that in the future the team grows and has diversity.

3. Oritetanga: all NZ citizens have the right to the same outcomes – equity

- For me this looks like an easy win for us, but inequity is entrenched right through our healthcare system. This therefore needs a lot of work. National variation is starting to be worked on in some areas and I believe when we achieve this it will help, however again there needs to be a more concerted effort in all areas to ensure we do better to give all our citizens the treatment they need
- More mentors are needed
- Not so much the same outcome, needs are different, we need different things to get there
- No such thing as equality – no one is equal. Maori are down in the pits and Pacific are down further
- Equity – addictions, Maori are only as healthy as their family. Programmes are for the individual but what is there for the children of these people.

4. Wairuatanga: spiritual diversity is assured

- This is the culture and heritage principles and values. Many Maori observe strong traditional beliefs and practices; these need to be respected and included in the way we work with Maori
- The word for this-world and time
- Acknowledge contemporary and traditional beliefs
- This was applied at the time of writing/signing the Treaty because of the Christian movement – this was around traditional spirit and beliefs
- Camp Unity was about spiritual belief, everyone is an individual and about talking about individualism
- Usually the European view becomes the dominant view. Not about cultural views
- Distinction between spirituality and religion. Resistance from funders as they don't want to push or subscribe to some sort of doctrine
- Wairuatanga - spirituality, and culture is the holistic reference to the definition of 'health wellness' in Maori, the concept of 4 pillars of wellness Te whare tapa wha.

9. Consumer Network Membership

The Consumer Network membership can be up to 14 people. Chris talked about the tenure of the current Consumer Network as Marj, Ezekiel, Te Rina's tenure will be up March 2020 and Fono Seumanu-McFarland and Courtenay Mihinui are no longer in a position to be able to attend meetings. John Hannifin passed away so there are now several spots we need to fill.

Chris discussed the need to have connections with other consumer groups including the DHB consumer councils and the MOH disability group. Also, the need for South Island representation.

The Consumer Network are considering the populations that could be on the Network such as disability, Asian, Pacific. Some names and suggestions were put forward.

Other business

The Consumer Network acknowledged Chris and her team for their work and Te Rina thanked Chris for the Commission's sponsorship of Camp Unity. Tamara acknowledged the Commission and how it considers mental health issues.

Close of meeting at 3.00pm

Next hui: 12 March 2020 at the Commission. Bernadette will open the hui and Tamara will close.

Actions list

Date	Item	Action	Responsibility	Outcome
18 October 2018	4	Load the link for the Bronchiectasis Foundation NZ to the Commission website	Dez	Dez will follow up with Comms on progress.
6 March 2019 and 21 May		Finding an Asian (Chinese) and other consumers for consumer network. Feed any further suggestions to Chris/Deon/Dez	All	Work in progress to approach suggested people to fill vacancies on our network
21 May	5	Ezekiel to provide background and proposal for a disability train the trainer that PIC will support	Ezekiel	Ezekiel is to catch up with Deon on suggestions.
12 Sept 2019		Talk to Falyn about intent for HQSC to sign up to disability charter as discussed in this hui	Chris	Falyn (from Comms) had a meeting with Chris. Paper going to the Commission's Executive Leadership Team for a contractor to scope for resources and actions.
14 Nov 2019	8	PIC programme 2020/2021 and Te Tiriti Articles.	Chris	To be discussed at the next network meeting re how they can be applied to the 20/21 programme