

Present: Chris Walsh (Chair), Ezekiel Robson, Marj Allan, Martine Abel, Te Rina Ruru, Camron Muriwai, Edna Tu'itupou-Havea, Marlene Whaanga-Dean, John Hannifin, Bernadette Pereira, Deon York, Dez McCormack (minutes) – HQSC

Guests: Laura Ellis

Apologies: Courtenay Mihinui, Renee Greaves, Fonoifafo Seumanu-McFarland, Tamara Waugh, Gillian Bohm

The meeting commenced at 9:44am

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 6 March 2019

The minutes of 6 March 2019 were confirmed as a true record. With 1 typo noted.

2.1 Actions update

The actions list was considered and updated.

3. Partners in Care report

Laura discussed her paper (content below) submitted and sought ideas/comment from the group on her proposal.

General comment was that it was a good idea. Other comments were the proposal shouldn't be a duplication of something we are doing now - especially in trying to get the DHB's to just do or try something abit different. We need it to be sustainable and true "co-design". Laura gave more detail on how co-design works in her space and how the data is interpreted and used. Suggestions provided on patient care and treatment of Māori pacific peoples. Don't put them in a box.

Talk to Te Tumu Whakarae as part of the Co-design (Camron).

We need to work in a different way to make more traction.

Happy to input care: John, Te Rina, Marlene, Camron, Edna & Bernadette, Marg

Content of Laura's paper is:

Author: Laura Ellis, Advisor consumer engagement, hospital improvement team.

Patient deterioration, Kōrero mai lead.

Background: Kōrero mai is a Commission workstream with the aim of implementing a patient, family and whanau escalation system in all District Health Boards through a series of Commission supported co-design projects. The workstream started in 2016 and is expected to complete in 2021. The aim of Kōrero mai is to improve communication between health staff,

patients, family and whanau so that concerns are heard and acted upon which will then avoid harm to patients.

Status of Korero mai

- Implemented 2018: Waitemata DHB; across two hospitals.
- In the process of implementation; Canterbury DHB and Southern Cross hospital Christchurch.
- At the testing stage; Whanganui DHB, Mid-central DHB, Capital & Coast DHB
- At the data gathering pre-testing stage; Taranaki DHB
- Due to start project 2019: South Canterbury DHB
- Due to start project 2020: Tairāwhiti DHB, Lakes DHB, Hutt Valley DHB, Auckland DHB
- Bay of Plenty Kaupapa Māori ward: Patient experience data collected and report released, next steps planned for second half of the year 2019. Article celebrating their work can be found here <http://digest.nzma.org.nz/?iid=163806#folio=16>

The work on the Kaupapa Māori ward is a major piece of equity work for Kōrero mai, seeking to understand a Te Ao Māori experience of deterioration and escalation. I am considering strengthening the Te Ao Māori perspective in this project by disbanding the national Kōrero mai working group and creating a Māori working group and a Pacific peoples working group, for Kōrero mai specifically.

Importance of Kōrero mai project for consumers. As a co-design project, all sites are reporting the value of health staff and consumers working together, this is a strong feature of the work and is highlighted in the independent evaluation reports. Also, as the projects are co-designed they rely heavily on patient experience data. This data highlights the actual experience and feeling of those using the hospital service and goes beyond a generic patient experience survey. My observation has that this data can be challenging but ultimately is well received and valued by health staff. The co-design process and experience-based data has made a major contribution in understanding why people may not call for help when they feel that they are getting sicker in hospital.

Kōrero mai has also offered an opportunity for consumers to be part of the national patient deterioration consumer group, run by the Commission, which has given opportunities such as conference attendance, networking and to be connected to the Commission in a more general way. For example, having guest speakers at the group to talk about broader issues, such as the national inpatient survey.

Consumers at the patient deterioration conference <https://www.hqsc.govt.nz/blog/consumer-reflections-from-the-patient-deterioration-nz-conference/>

A document, “ Patient, family and whānau escalation: Kōrero mai projects –what we know so far “ can be found with this link <https://www.hqsc.govt.nz/assets/Deteriorating-Patient/PR/Case-study-korero-mai-learnings-March2019.pdf>

After morning tea Deon gave the Partners in Care report.

All SPE deliverables will be achieved this year and we are tracking to budget.

Feedback was positive and that these meetings are enjoyable because PIC is always busy and doing things. It's great to see progress and action in making things happen.

Chris added the support the Commission provided to the Philipstown smoke free project. There was a wide-ranging general discussion and input re consumer representation in general and the importance of staff training. Seems like we're continually "starting all over again"

Deon's written report is:

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

21 May 2019 meeting

Since our last meeting on 6 March we are now into the final quarter of the financial year. We are on track to complete all deliverables and have had our plan signed off for the new year beginning 1 July 2019.

Below is a summary of activities since we last met:

- The team met with Counties-Manukau DHB to discuss the QSM for consumer engagement. As a result, this DHB will also be a pilot site.
- The consumer engagement QSM reference group met on 10 April to confirm the next steps for the QSM. Piloting with four DHBs will occur in early July, and the first request for data will be December 2019.
- The Commission's consumer advisory group to the board met on 17 April. Rowena Lewis attended the Commission's board meeting and put a consumer lens over the board papers.
- This quarter has been full of internal meetings (with planning underway for all Commission work programmes). Chris and Deon have been involved with the health services access atlas, advance care planning, and advised on a range of programmes in the Learning and Improvement Group.
- All three consumer 'train the trainer' workshops have been completed. These occurred in Wellington on 27 November 2018, Christchurch on 20 March 2019, and the final workshop completed recently on 14 May 2019. We had Ezekiel and Tamara in attendance from the network.
- Co-design case studies are coming in and being reviewed. The PIC programme sponsored the team (from Pegasus) who focused on clinical pathways for transgender health to attend a symposium in Hamilton and present their work.
- The all Commission consumer day will take place immediately after this meeting on 22 May.

4. Meeting with Te Rōpū

Consumer Network

A whakawhanaungatanga was conducted

Ria briefly discussed Te Rōpū's role.

- They inform the Commission board and some of it informs wider health policies.
- Ria took over as chair when the issue of health equity was coming to the fore and the issue of institutional racism was quite prevalent.
- There's been a recent change in Te Rōpū membership.
- They're working with the Commission on how to meet this challenge and the challenge of change; having discussions on the equity dashboard (where we can see DHBs performance) and the Window document. The equity dashboard is much more user-friendly and nearly at the end of development. It will be much clearer where the inequities are and show the stark differences between groups.
- Pacific health has similar inequalities to Māori work.
- There is a focus on the Treaty.
- The issues for consumers are key to Te Rōpū's work, especially co-design.
- Te Rōpū is a strategic advisory group but sometimes this is hard to focus on as the members want to get into the nuts and bolts of issues.

Chris Walsh briefly discussed the Consumer Network's role

- Consumer Network has existed for nearly 7 years and has grown from 8 to 13 members out of necessity.
- They don't focus on tokenism and just ticking representation boxes but ensure wider representation, especially Māori and Pacific representation.
- Muriel Tunoho is also on Consumer Network.
- They strongly value connections and partnerships between groups, for example, there are 60 consumer advisors at the Commission and they have a day tomorrow to connect them all together. The Commission focuses on how it can support the consumer advisors more in their role with the Commission in the advisory groups.
- The Network exists at a more operational level. They don't have a big budget, but it's spent as the network wants in themed areas. It's more directed for out into the community.
- They focus on meaningful relationships. They engage with health consumers as they are able and support their interactions in the community.
- There is a real focus on Treaty and equity also. They push for a lot of co-design and make it as meaningful as possible for patients, family and whānau.
- The language of the consumer is important.
- Chris noted that the move from the Commission into primary care sector feels like "Starting all over again". This shift comes from the Minister.
- There is now reasonable consumer engagement at the DHBs.
- CAG consists of the 4 members of the Consumer Network who have a relationship with the Board. There is no consumer representation on the Board yet as this is a ministerial appointment. In the meantime, there is an advisory group. They wanted someone with a disability, a Māori person and someone from mental health. CAG meets 4 times a year and they are supported from Partners in Care budget.
- The Network has evolved its cultural awareness to a shared platform especially for the spiritual space. E.g., the karakia doesn't have to be in Māori.

We all had a shared lunch.

5. Consumer Network reports

John Hannifin

Contributed to the Commission Consumer Engagement Quality and Safety Marker development group

This group is making a lot of constructive progress in developing quality markers to be trialled in 3 DHBs (soon)

Key Points:

- Emphasis on Consumer Councils within DHBs – markers to capture
 - Independence
 - Diversity – reflective of the local communities
 - Supported e.g. resources: remuneration, data availability, project support
 - Has influence and power. Strategic approach to DHB wide work (including primary health)
 - Has a workplan (which could be forwarded)
- That the Consumer Councils will Independently report to the Commission through the process
- It is a developmental/maturity approach with a suggested maturity index that should be the goal of consumer engagement
- Should align with the rewrite of the “Consumer Engagement” booklet

Martine Abel

Spoke about the CAG hui and the PIF review interview and how the emphasis was on Māori Equity and where disability was sitting in the commission.

Martine tabled a paper on the Disabled Persons Organisations (DPO) Coalition, highlighting the method and processes on liaising with them.

Marj Allan

Kaiawhina Work force Taskforce has an action plan working group with a consumer focus.

This group is working on a how we can get a real time for consumers and whanau to be able to give feedback on services received, including evaluation and monitoring process are embedded and wellbeing focused. Workforce hui “Living experience” is on June 5th.

Give them your feedback - Health Workforce Strategic Priorities

<https://www.health.govt.nz/our-work/health-workforce/health-workforce-strategic-priorities>

We're now at the stage of determining the final priorities and action planning around them.

You can give us your views by contributing to the Loomio page where you can discuss the different priorities: https://govt.loomio.nz/g/TSmXbE1V/developing-health-and-disability-workforce-strategic-priorities-2019-2024?group_key=TSmXbE1V

Advanced Care Planning

The 2019 Campaign has now been completed. It would be good to get feedback from you all on how worked for you and your communities.

Please give this feedback. Think about how we can all spread this work through our networks.

Patient Experience Survey.

The Health Quality & Safety Commission is moving this to a new level of importance. We have had enquiry now from other areas of the Health System to get data from this survey, which signals this survey is going to help to drive better consumer experience and system understanding of where the gaps are and where we can make change. Workforce using this as a consumer marker – so is Pharmac

Edna Tu'itupou-Havea

Attended a Pacifica meeting with CCDHB re concerns

Porirua now has Pacific Health plus service which is reshaped from an existing service.

Marlene Whaanga-Dean

1. ACP completed workshop in March 2019 (level 1a) facilitated by Helen Rigby CCDHB who is doing a good job in co-ordinating workshops in our area and other. I have received a follow up email from Helen to attend ACP SIG (special interest group) on the 19 June Masterton WDHB which myself and colleagues will attend. It will be a chance for people to feedback and get together to discuss ACP successes, challenges, practicalities and ideas.

2. Promoting Breath Easy ASTHMA Ha Nga Wari workshop in Masterton Wairarapa Developed an education morning asthma session at no cost for tamariki/whanau/consumers to attend a free workshop provided with healthy kai and hosted by staff from our Whaiora General Practice. This includes our Nurse Practitioner, Community Health workers, Family start, and with the support from WINZ in terms of information around disability entitlements also I have invited Healthy Homes Insulation Quit smoking coaches available. This will be held on 29th May at our local Marae Te Rangimarie Marae in Masterton.

These workshops that I help support putting together with health professionals is an opportunity to engage with consumers/whanau/community and evaluate what's working what's not working in terms of health literacy and resources that are available. These workshops are designed to give consumers/whanau/patients TIME for us professionals to listen, no 15-minute consults building relationships and ask the questions "what would be useful to support their health journey". So, there is whole raft of things that we cover and listen too.

Working within our Community to reduce hospitalisation for our tamariki and supporting Maori Health outcomes.

3. Confirmation - I am now a member of the Commissions Integrated Advisory Group Health Care Home (Primary and Community care).

Camron Muriwai

I. NDHB - Consumer group

I have attended two meetings. The first starting with general meet and greet introductions. The second meeting confirming our new chairperson

An issue raised: That there is an incredible number of requests for consumer input/ and several times with very short notice. How are we to give credible feedback without feeling pressured to approve.

Is our purpose changing?

I have suggested that I raise this matter at our Consumer network to ask how others deal with this process. What is the protocol? Time frames.

II. Future Planning hui - ACP, Conversations

There is opportunity for (Two) more National facilitators to be trained in June/July '19. We have confirmed one position for northland.

III. Chronic Cough working Group

I have been selected to join the Northern region CCWG. Our first video conference meeting is the 16th may '19. Look forward to sharing more.

IV. Bronchiectasis Foundation NZ

We are partnering with the College of Respiratory nurses - NZNO in planning the northland symposium in April 2020. The theme is bronchiectasis – Changing the focus.

Camron also acknowledged Te Rina's Grand round presentation and how inspiring it was.

Ezekiel Robson

- * I continue to input into the Consumer Engagement Quality Safety Marker work
- * I attended the Train the Trainer Auckland workshop for health consumer representative training
- * I gave a quote for inclusion in the updated Engaging Consumers guide

- * I have contributed to design of Health Workforce NZ's health and disability strategic workforce priorities consultation.

See background here:

<https://www.health.govt.nz/our-work/health-workforce/health-workforce-strategic-priorities>

And their Loomio discussion group here:

https://govt.loomio.nz/g/TSmXbE1V/developing-health-and-disability-workforce-strategic-priorities-2019-2024?group_key=TSmXbE1V

Bernadette Pereira

I am on the Board of Trustees of the Southsea's Health Care Trust and was able to influence the Board to include a section on "Consumer Voice" and input from the clientele of 6,000 consumers as part of the strategic direction and plan of the organisation. It is the first time considering the organisation has been in operation for some 20 years. I am also involved in the formation of the 'consumer group' for Southsea's.... watch this space!!

In transition from work in the largest men's correction's facility for settled prisoners – Auckland South Corrections Facility operated by Serco, a transnational company, and will be free to take on focussed consumer work at community level within Pacific communities in the wider South Auckland region. Also opened to undertake trainer training programme offered through the Commission with support from the Partners in Care Team

Seriously considering running for CMDHB in the October elections

Te Rina Ruru

Internal:

- Supported by Chris Walsh to present to staff at the Bay of Plenty Grand Rounds on 9 April. This was recorded and uploaded to their intranet.

External

- Attended a hui with the Royal Australasian College of Physicians.
- Planning the 2019 Safe Haven Camp for children affected by brain injuries. To be held in Rotorua at Tui Ridge on the 11th - 13th October 2019.
- Voluntarily advocating for clients and whanau affected by brain injuries.

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Both groups enjoyed a shared lunch.

7. Updates to guide

Deon gave a summary of his presentation to Te Rōpū on the guide.
His notes are:

Language of engagement and communication

When you hear experiences – whakawhanaungatanga. Talking to the back of the health professional. Why should trust you? Back to basics.

Don't do an information dump.

Organisational engagement – remove power from IPAs, wider representation was mandated. What happened was it wasn't implemented as intended and they are still controlled by doctors, Well South board – there are community reps, what are they on there for?

Practice level - flexibility to be whanau centred. Having other ears in the room.

Working with various parts of communities. 'Working with' versus 'engagement'

COMMUNICATION

The hard to have conversations

Leveraging off other relationships – the 'community' is busy.

Knowing your context and history

A number of things playing out at once

Expanding the guide

Scope

Conversations about the treaty and equity

Cultural safety/racism

How does this guide help in addressing some of these issues?

There are some basics that apply not matter what the context.

Use enable, not empower

Language about the treaty needs to change. Just an update. Te whai oranga. Latest SPE wording.

Patient and whanau centred partnership

Co-design, co-create, co-production, co-produce

Engaging communities

Chris asked the group for a singular word about what consumer means to them. These are:

Connection – So'otaga (Samoan)

Relationship

Ownership

Power sharing

Involvement

Accountability

Commitment

Shared decision making

Self management support

Informed choice

Whakaoranga - well being – the ultimate goal

Fāka'apa'apa – respect (Tongan) - shared value amongst pacific groups

Change

Impact

Improvement

Own health

Real Choices

Manatu – standing within the decsion, the knowlesdge the info.

Chris invited the group to send more

Other business

There was no other business

Close of meeting at 3.31pm

Next meeting: 12 September at the Commission

Actions list

Date	Item	Action	Responsibility	Outcome
18 October 2018	4	Load the link for the Bronchiectasis Foundation NZ to the Commission website	Di	Camron to prepare something in writing, send to Dez to pass on to Falyn for website
6 March 2019 and 21 May		Finding an Asian (Chinese) consumer for network. Feed any suggestion to Chris/Deon/Dez	All	3 received John to send another. Action in new financial year
21 May	5	Train the trainer for CN members	Dez	Dez to offer this training to members who haven't done it and organise a date
21 May	5	Ezekiel to provide background and proposal for a disability train the trainer that PIC will support	Ezekiel	Ezekiel to come up with proposal for PIC