

Minutes of the Consumer Network

meeting held on 12 March 2020, in
Pounamu at the Health Quality &
Safety Commission, Wellington



Present: Chris Walsh (Chair), Deon York, Gillian Bohm, Camron Muriwai, Te Rina Ruru, Bernadette Pereira, Ezekiel Robson, Marlene Whaanga-Dean, Martine Abel-Williamson (with Weston the guide dog), Joanne Neilson, Amanda Stevens, Mark Rogers, Russ Aiton, Hyejung Kim, LJ Apaipo, Vishal Rishi.

Apologies: Courtenay Mihinui, Fono Seumanu-McFarland, Tamara Waugh, Renee Greaves, Marj Allan, Edna Tu'itupou-Havea, Dez McCormack

Guest: Darren Douglass (Ministry of Health)

The meeting commenced at 9:50am

1. Opening and welcome

Chris welcomed everyone to the meeting and Te Rina opened with a karakia. Apologies (as above) were noted.

2. Introductions for all members

There was a round of introductions. Current, new, and outgoing members introduced themselves.

3. Minutes of the meeting held 14 November 2020

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

2.1 Actions update

The actions list was considered and updated.

2.2 Interests register

The interests register was reviewed. Any changes to the register to be submitted.

4. Partners in Care report

Deon gave the Partners in Care report.

Since our last meeting on 14 November 2019, our focus has been on progressing the quality and safety marker for consumer engagement, the cancer co-design teams, and refreshing the consumer network.

Activities since 14 November 2019

- Chris has been involved with the restorative justice work being led by the Ministry of Health (the Ministry). The basis of this work was from more than 600 stories of people affected by surgical mesh.
- The Ministry appointed panel on credentialing for surgical mesh, Chris is on this and has attended one meeting.

- The Ehlers-Danlos videos have been completed. There is a lot of material (four interviews and a panel) and Dez has put a lot of work into editing the videos. The current versions are being reviewed by communications.
- Chris and Deon have had early discussions with the Māori health outcomes team about stories of Māori experiences of the health and disability system.
- The Partners in Care team is working with the primary care team for the 2020/21 co-design programme with Dr Lynne Maher. We are also planning some 'pre-workshops' before 30 June to socialise the concepts with the teams who are successful applicants.
- Chris presented to the Ministry of Health disability group and as a result they have nominated a consumer to be on the refreshed consumer network.
- There has been a refresh of the consumer network.
- The quality and safety marker (QSM) for consumer engagement has been progressed significantly since our last meeting. The enclosed memo captures more detail.

Some meetings since 14 November 2019

- On 22 November, Deon spoke to the patient experience survey governance group about the 'nudge' intervention work completed by the team to demonstrate how patient experience data can be used.
- 10 December: Chris and Deon attended the Evidence Live Forum in Auckland and Deon spoke about *meaningful consumer engagement with evidence: can it be achieved?*
- 11 December: Deon and Chris attended a meeting with South Seas and consumer engagement quality and safety marker meeting
- 8 January: Chris discussed the rainbow tick with the Ministry
- 29 January: Chris attended the Midcentral co-design (face-to-face workshop)
- 31 January: QSM for consumer engagement reference group
- 12 February: Deon met with the Commerce Commission regarding consumer engagement
- 13 February: Deon met with the Dental Council of NZ, also regarding consumer engagement
- 18-19 February: Deon attended the Northern and Midland co-design (face-to-face workshop)
- 21 February: Deon was a workshop participant with consumers regarding the new cancer agency
- 21 February: Deon presented at the quality and risk managers leadership group to discuss the consumer engagement QSM
- 25 Feb: Deon attended the southern co-design face-to-face workshop
- 26 Feb: Deon and other Commission staff facilitated a hip fracture workshop – this was about developing a resource for people to help them once they get home
- 27 Feb: Deon met with the Health Promotion Agency about Rainbow Tick certification (what the Commission process was)

5. Feedback on last board and consumer advisory group (CAG) hui

Deon gave an overview of the board meeting.

Martine gave an update on the CAG meeting.

In summary, CAG supported the work that has been reported in this series of board papers and is particularly heartened by the projects focusing on working with consumers, family and whānau. The overall theme of feedback was CAG's interest in understanding the next steps (i.e. the 'where to from here' aspect). A summary of CAG's feedback to the board was discussed (as below).

Draft Statement of Performance Expectations

- The CAG is supportive of the direction the Statement of Performance Expectation (SPE) is taking, and the chair looks forward to the discussions at this board meeting.

Ngā Poutama

- Although the sample size is small, it is heartening that work is taking place with a focus on consumers, family and whānau.
- CAG has noted the challenges in terms of response rates and wonders whether there were other informal networks that could have been approached or be approached in the future.
- With consumer response rates being only 3.3 percent, it highlights the difficulties in people engaging with surveys. Did consumers feel the content or context of the survey was relevant to them?
- Will this survey be repeated? A lot of work was put into this survey.
- Although a small sample size, the results support existing programmes for the Commission. The lower results in the survey seem to reflect area 4 of the mental health and addiction programme, 'improving physical health'. People do not appear to be viewed holistically.

Family Violence Death Review Committee report

- CAG was supportive of the general direction of 'trauma-informed practice' (what has happened versus what is wrong with you) contained within this report.
- The linking of education with a potential stopping violence strategy raised some questions with CAG.
- How will the results be shared with consumer organisations?

Other matters arising

- CAG would like to understand the life cycle of mortality review committee recommendations and have asked for an explanation of the process for developing, implementing, and monitoring progress made against recommendations.
- The 'implications for consumers' sections of board papers are sometimes completed very thoroughly, but this is not consistent. With some staff changes, it is timely that the Partners in Care (consumer engagement) teamwork with staff to outline expectations for this section.

6. Consumer network reports

Bernadette Pereira

Bernadette is a member of the Counties Manukau consumer council as at February 2020.

A meeting between Chris, Deon, Bernadette and South Seas Health (SSH) took place in December 2019 about the possibility of the practice taking part in the 2020/21 primary care co-design programme. There were multiple projects that have resumed from 2019/20 which took precedence and the current workforce is pressed.

SSH is still keen to move at developing a framework to ensure its community are engaged and that authentic partnerships are formed to contribute towards the pilot of integration. We still believe there is value in forming this strategy for the organisation and would very much appreciate any support from the Commission.

Ezekiel Robson

Ezekiel reflected on his last meeting with the consumer network.

The QSM for consumer engagement is new, and while it has evidence, it has been a long co-design and piloting process. It has involved a lot of consumer input in terms of the philosophy of how it is developed.

The district health boards (DHBs) cannot just rely on consumer council members to provide input and gather feedback, it is something much broader.

Te Rina Ruru

Te Rina had nothing specific to report in terms of Commission activity, but it was noted that Te Rina's video about Camp Unity was played to the Commission's board and was received positively.

Martine Abel-Williamson

Activities internal to the Commission:

Meeting: Commission Patient Deterioration Leadership Group

Date: 27 November 2019

Role: Consumer representative

Comments: Most DHBs have been contact about commencing a version of Korero Mai, a system which patients and their whanau and family feel empowered to escalate it when a patient in hospital's condition is deteriorating. This might be contentious to many staff and clinicians as patients, whanau and friends could feel that they're not meant to question the formalised medical system they're in and many medical clinicians may indeed feel professionally questioned. Also, the Commission have had two Shared Goals of Care Working Group meetings, with a third one scheduled in late April.

Meeting: Commission Consumer Advisory Group

Date: 30 January 2020

Role: Attended as our Commission Consumer Network rep

Comments: we're getting up to speed with various mortality reports, its content and who's dealing or should be dealing with recommendations. We also discussed the Commission's Statement of Intent, which is a high-level, short strategic direction-setting item. CAG is also needing to get its head around how the Commission can enhance equity re Māoritanga.

External activities to the Commission:

Meeting: Auckland DHB Patient and Whanau-Centred Care Council

Date: 24 February 2020

Role, Patient and Whanau Advisor

Comments: got asked to prepare for March to discuss my journey at a Commission level, focusing on Kōrero Mai, the QSM and patient experience survey. We worked out a comms plan to promote the work of the Auckland DHB and how our networks and other groups we're on can link with that.

Meeting: Health Navigator Consumer Advisory Service

Date: 3 March 2020

Role: Consumer Advisory Service input into ProCare workshopping the meaning and re-definition of health literacy.

Comments: During that session, promoted the Commission's involvement at patient experience survey level, plus its other activities.

Items in general which have been circulated to the Commission for consumer network circulation:

Meeting: Korea Blind Union

Date: 2 to 5 December 2019

Role: World Blind Union (WBU) Asia-Pacific United Nations Advocacy Network Regional Co-ordinator

Comments: presented on social participation and the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities). This presentation is available upon request.

Meeting: World Urban Forum 10 in Abu Dhabi, United Arab Emirates

Date: 6 to 13 February 2020

Role: WBU Strategic Objective Lead, access to the environment and transport

Comments: I presented on Smart Cities and technological advances and my presentation is available upon request.

Meeting: Ministry of Health System Transformation Workforce Working Group

Date: December 2019 to 13 February 2020

Role: Disabled Persons' Organisations (DPO) Coalition rep

Comments: progressed workforce issues in the disability workforce sector alongside unions, other disabled persons, Te Pou, MOH staff, etc.

Meeting: Hui on sexual violence prevention for disabled persons

Date: 4 February 2020

Role: Accident Compensation Commission (ACC) Independent advisor with knowledge and experience in disability

Comments: participated in ACC sponsored research hui in sexual violence prevention and programmes for and with disabled persons. I am ACC's independent advisory re that topic. Research should be completed by 31 March and I'll keep all posted.

Meeting: Healthy Relationships Workshop

Date: 2 March 2020

Role: as the independent advisor on disability, participated in this workshop on behalf of the ACC SVP Advisory Board and Disabled Persons' Organisations (DPO) Coalition.

Comments: discuss inclusiveness and access to programmes for school aged children in programmes such as "Loves Me not", "Sex Wise" and "Mates and Dates". This work should be completed around end of June 2020.

Meeting: Good Start in Life

Date: December to March 2020

Role: DPO Coalition rep

Comments: this work is near its completion. We finalised Practice Guidance resource around families and others working collaborative for a good start in life for disabled children between the ages of 0 to 8 years. I've circulated this Practice Guidance resource to Commission consumers already.

7. Progressing the four Te Tiriti articles discussion

There was a wide-ranging general discussion about the new strategic priorities for the Commission as well as progressing the four articles of Te Tiriti, and the potential area of focus for the PIC programme. Some items raised included:

- Improving consumer and whanau experience, equity, Mana motuhake – but lots of discussions are going on.
- How do you understand partnership?
- Where should we focus our efforts in 2020/21?
- Partnership, participation, protection remain important. Welcome the treaty as a framework.
- How close to the coal face is the Commission? That determines what the partnership looks like.
- Who is in the room? Who is disadvantaged and more disadvantaged? Deconstruct terms. Make health accessible to everyone?
- Important to focus on rurality/rural communities, and those of retirement age.
- Leanne Te Karu's programme. Gout as an area? Meeting people at their level, where they feel supported.
- The impact of the co-design programme was noted, 'first time someone has spoken with us about ourselves rather than about us when not present'. Encouraged to continue with this work.
- Different groups make decisions differently. Ways of reaching consensus.
- Outcome focus does not fit in with other world views necessarily. What is falling from this relationship?

The current programme plan was sent around all network members, and the new plan will be discussed at the next meeting.

8. Presentation on the National Health Information Platform (nHIP)

The Ministry of Health presented on the national health platform. Matters arising from the consumer network (enclosed):

- Assurance that the Ministry's consumer reference group was part of the decision-making.
- Ensuring the process does not further (unintentionally) marginalise people.
- Planning on co-design approach for this work.

9. Other business & reflections on the day

Chris paid tribute to the work Courtenay Mihinui, Fono Seumanu-McFarland, Tamara Waugh and Ezekiel Robson.

Marj is leaving but hopefully can attend the next meeting.

Ezekiel was presented with a gift. Thank you letters and gifts were sent to the other members who were not present.

The meeting closed at 3.30pm.

Next hui: 10 June (TBC) maybe a Zoom.

Actions list

Date	Item	Action	Responsibility	Outcome
12 Sept 2019		Talk to Falyn about intent for Commission to sign up to accessibility charter as discussed in this hui	Chris	This is ongoing work for the Commission.