Minutes of the Consumer Advisory Group (CAG) meeting held on 30 January 2020, at the Health Quality & Safety Commission, Kahurangi room 17-21 Whitmore Street, Wellington



Chair:Rowena LewisMembers:Martine Abel-Williamson (with guide dog Westin), Muriel Tunoho, Frank
BristolIn attendance:Dr Chris Walsh, Deon York, Dez McCormack (Partners in Care team)

The meeting commenced at 9:35am

1. Welcome & Karakia

Rowena welcomed the group and Deon did a Karakia.

1.1 Previous minutes

Previous minutes were accepted as a true and accurate record.

1.2 Action items

Action items were discussed and updated. Some action items ongoing.

1.3 Interests register

Register noted with one amendment for Rowena. Firm name change to Lewis Mortimer Law

2. Partners in Care (PIC) update and group environmental scanning

From PIC:

Some activities since last hui on 5 November 2019

- Chris has been involved with the restorative justice work being led by the Ministry of Health (MoH). The basis of this work was from more than 600 stories of people affected by surgical mesh.
- The MoH appointed panel on credentialing for surgical mesh, Chris is on this and has attended one meeting
- The Ehlers Danlos syndrome 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 the team.
- 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 PIC 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 (and the Expression of Interest (EOI) is currently out and closes on 14 February).
- Chris presented to the MoH disability group and as a result they have nominated a consumer to be on the refreshed consumer network

1

• There has been a refresh of the consumer network. The new group has its induction on 11 March with a meeting the following day. Advised who new appointees were and the diversity of the refreshed group.

Some meetings since 5 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: Meeting with South Seas and consumer engagement Quality Safety Marker (QSM) meeting
- 8 January: discussed the rainbow tick with the MoH
- 29 January: Midcentral co-design (face-to-face workshop)
- 31 January: QSM for consumer engagement

Progress on key activities for 2019/20 (just a couple of examples, there is more)

- Measuring progress and responding to the consumer experience of the health care system – refer to QSM for consumer engagement. The QSM is included in the MoH annual plan for District Health Boards (DHB's). A breakdown of what is involved in the QSM was provided
- Promoting consumer-provider partnerships and the consumer voice in the health and disability sector refer to cancer co-design programme
- Building consumer leadership and capability revised guide, refresh of network

Rowena Lewis

Accident Compensation Commission (ACC) falls committee - Rowena was on this but it seems to have finished.

Highlighted hearing a lot about the lack of communication to aged care people and the challenges they face.

Cancer Council hui on 21 Feb. A new agency. Questions around if the Commission has a role to play here.

Muriel Tunoho

Raised the complexities of health care delivery in her Medical Practice - higher needs area. Her practice is undergoing the Health Care homes assessment in order to support better and quality delivery of health services.

Involved in a group at work to look at giving consumers a voice and understanding their difficulties.

Many clients at health centre involved with Oranga Tamariki. Pleased to see that recent funding will improve health outcomes for people in her area.

Martine Abel Williamson

Been contributing to the Ministry of Health in their reviews of various standards for auditing purposes and those include the disability residential care, aged residential care etc plus developing a new standard re homebased and community care. There will be an opportunity for public input after Standards NZ has worked on our suggested updates and will get those notifications through to CAG when they get advertised.

ACC has contracted Sapere to do research into sexual violence prevention for disabled persons and Martine is the ACC link re knowledge of disability in that process. A survey has been circulated to Commission networks already for further distribution and participation. I'll keep all posted as to progress.

Frank Bristol

19th Jan was the last date for submissions for the Mental Health Act. His organisation "Balance Aotearoa" & "Changing Minds" did a joint submission involving mental health and human rights.

Primary Care Requests for Proposals was one of many RFP's that went out as a result of recommendations.

Funding available for vulnerable Maori mothers.

New Nga Manaki network being setup by MoH consumers area.

Progress is being made with the setting up, new staff positions and other activities with the new Mental Health and Wellbeing Commission.

3. Mortality Review Committees (MRCs) - Update on progress/completion of MRC reports and the recommendations

Kere Pomare (Group Manager, MRC's) provided an update on how recommendations are progressing. The group wanted to ask what traction was being made on recommendation. Kere gave an example of what has been done in Maternity, however the committees/secretariat don't have any power (under legislation) to make things happen.

Martine raised that there is no reference in any of the reports about disability in mortality.

Discussed what improvements could be made.

CAG would like to see the process improved on how the recommendations are followed up. Perhaps at MRC Chairs level, so they can feed into the board.

Summary

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.

4. Review of board papers

In summary, CAG supports 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).

More specific comment on each paper follows:

Statement of Intent (SOI)

This was the 2nd iteration the group saw. Since this paper ELT have feedback as follows, provided by Chris:

Action words need to a line with purpose. "Quality health for all"

Achieving Maori health changes to improving Maori health changes and add words where feasible. Board to discuss at a strategy day next day.

Audit NZ wants us to include more on impact and measurement.

General commentary: CAG agreed over all with the document. Martine did suggest a change "and all other people" to "and other populations of identities"

Strategic priorities are right.

Deon will develop a paper with feed back to the board on discussions, including the MRC above.

Also discussed here that more explanation needs to be given on writing board papers re "implications for consumers" section. There are always implications. This section of board papers sometimes completed very thoroughly but this is not consistent. Chris/Deon will redefine required commentary and expectations on the consumer section of board papers.

Summary

Overall the CAG is supportive of the direction the SPE is taking, and the chair looks forward to the discussions at this board meeting.

5. Other Board papers

Family Violence Death Review Committee (FVDRC) report

A weighty document. Missed opportunities comment was discussed. A good report. A question from the CAG - what does de-colonising services mean in recommendations?

Summary

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?

The Department of Justice, and the Department of Corrections are both included as stakeholders, but the Minister responsible for corrections is not (Hon. Kelvin Davis) and the report should go to him.

Ngā Poutama consumer family and whanau survey

Executive Leadership Team (ELT) feedback from Chris: Add what the purpose of the report was up front of report. Overall accepted as a good report.

General commentary: How widely was the survey distributed? Perhaps many networks/people on the ground weren't contacted. Were DHB's given enough time to distribute? Disappointing response rate for such an in depth and important survey. Findings well received. Would like to see this done again in the near future.

Get the info out now to DHB's – while still reasonably current

Summary

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.

Review of Whanau Māori Experience of Adverse Events

General commentary:

- Mixed reaction to the contents of the report. How were Māori experiences different to the rest of the population. Many of the comments weren't specific to Māori and nor were they necessarily an adverse event. Not an equal number of each sex from sample taken. What were age demographics?
- What were the original objectives and what are the outcomes being sought?
- What were the actual adverse events? To give an explanation to what was being said.
- Info should be more in depth. It was too generalised.
- Do we need to reassess what we term as an adverse event?

• Good that it was a face-to-face interview and that this piece of work focused on the Māori consumer.

Summary

It is heartening to see work focusing on whānau Māori, and it is clear that this project was not a 'tick box' exercise.

CAG was interested to understand whether the report can give meaningful information given the sample size, recognising that this is qualitative research. There were clear recruitment challenges. It would be useful to know whether the events were SAC 1, 2 or 3, and more demographic detail from the respondents. While 'adverse events' are defined, an exploration of what this means to Māori would be useful.

It would have been useful to understand what questions and follow-up questions were asked, and how this potentially impacted the responses.

Importantly, CAG is interested in the 'where to from here'. Now the report is complete, what outcomes are now sought?

6. Discuss 10.1 on TOR – Letter to Board re conflicts

Discussed this requirement and agreed that a noting paper be sent to the next Board hui advising no-one had any conflicts of Interest with their work on the CAG. The Interests register will be attached to this noting paper.

Terms for CAG members

It was noted that the groups appointment letter was for an initial period of one year. This has never been officially extended or a definitive term set. The group were advised of the usual terms for committee and advisory group members being three years with the possibility of renewal for a further three years. The group were happy with this and requested a staggered reappointment process to assist with group continuity. They are aware that any additional terms and their length (up to a maximum of six years) is a discussion with the Chief Executive in consultation with the Director, Partners in Care who then make a recommendation to the board.

7. Other business

A brief discussion was held around the difficulties of having a meeting, combined with Te Rōpū on the same day CAG meet with the board, as Rowena and Chris are both in the Board hui and Muriel is split between CAG & Te Rōpū huis.

The best solution seems to be that members Zoom into the hour long session with the board (held twice a year) and we maintain the face-to-face huis to comment on Board papers as per timetable. One of which will be a zoom to keep the face-to-face at four meetings per year. Dez to change some Zoom huis to face-to-face and set up invites for the Zoom into the board huis.

Meetings for the remainder of the year are now as follows:

16 April – face-to-face

- 9 July face-to-face
- 30 July one-hour zoom into Board hui
- 27 August two-hour Zoom to discuss pending board papers
- 5 Nov face-to-face
- 26 Nov one-hour zoom into Board hui

All members agreed to share their email addresses as you can't reply all to a Commission group list. Dez will send an email with details.

A brief discussion also held on the tight turnaround time required to comment on board papers. Rather than dividing up papers for individuals to comment on, CAG would still prefer each member still received all papers

8. Karakia & close

Frank closed the meeting with a karakia. Rowena will open the next hui with a karakia.

Next face-to-face meeting: 16 April 2020 – Kahurangi

Actions List:

Date	Action	Responsibility
27 June 2019	PIC to look at possibility of providing Martine with an iPad.	Completed. Martine can use her phone to view papers on Diligent
27 June 2019	PIC to talk to comms about an interactive page on website that consumers can list people's stories and feed into.	Deon (on-going)
27 June 2019	Complete template Martine has sent us when we know who from the Commission will attend the DPO Coalition meeting and advise what our message will be. Keep this current on our action items.	Deon (on-going Jan- Jun 2020)
30 Jan 2020	Noting paper to board re Terms of reference 10.1. Declaring that no-one has conflicts and also attached the current interests register.	Dez actioned and paper going to Feb Board hui
30 Jan 2020	Redefine the requirements and expectations to staff writing board papers of what is required in the 'Implications for consumers' section of Board papers.	Chris/Deon
30 Jan 2020	Email addresses to all members for contact	Dez - actioned

30 Jan 2020	Two Zoom dates for huis now made face-to-	Dez has
	face. The two huis for an hour session with the	updated/sent
	board will now be Zoom.	new invites.
30 Jan 2020	Martine requested from Frank the GP related outcome of the RFP as in who got the contract and what are DHBs initiatives to do?	Frank to supply Martine with details