Minutes of the Consumer Advisory Group (CAG) meeting held on 5 November 2019, at the Health Quality & Safety Commission, Rangimarie/Kahurangi 17-21 Whitmore Street, Wellington

Health Quality & Safety Commission New Zealand

Chair: Rowena Lewis (until 11.00am) then Deon York
Members: Martine Abel-Williamson (with guide dog Westin), Muriel Tunoho (between Te Rōpū & CAG), Frank Bristol
In attendance: Dr Chris Walsh (until 11.00am), Dez McCormack (Partners in Care team)

The meeting commenced at 9:30am

1. Welcome & Karakia by Frank

Rowena welcomed the group and Frank did a Karakia.

In prep for Rowena with Board, Frank started with feedback on the Heather Simpson report. He felt there was criticism of leadership. Systems and structure in partnership needs to be visible – particularly with Māori. We need to see evidence of this happening.
Rowena & Chris feed in and expanded on the above.
Deon spoke about a recent primary care hui where Heather Simpson spoke.
Martine commented on the hard-to-reach label and that's it's overused and not acted on.
It was noted that in the board paper to the Heather Simpson review, there was no mention of consumers in feedback.
Deon prepared a briefing paper for the board induction outlining the history of the Consumer Advisory Group (CAG), Board decisions in relation to CAG, a bio on each member and the achievements. These are:

Achievements of the CAG to the board to date

Since the establishment of the CAG, most of the advice to the Commission's board has been reviewed by this group, offering a 'consumer lens' which complements that of Te Rōpū.
CAG, in collaboration with the Commission's consumer network and other consumer representatives across the Commission, have offered support and advice to the Partners in Care programme. In addition to offering new perspectives on how the system is working 'out there' for consumers, the CAG has offered a useful and welcome conduit between the day-to-day operations of the programme, and the governance level.
CAG has also fostered relationships with the board and brings a consumer voice to the board level.

For the CAG session with the Board, Rowena will mention most of this.
Rowena to also talk about how the CAG have developed and learnt to contribute and bring to the fore stronger consumer representation.
Chris mentioned the large amount of soft intelligence we are getting from the sector and requests for a national hui of consumer councils.
Chris also mentioned of approch from the Ministry of Health (MoH) last week for us to contibute to the ministers Letter of expectation (LOE) to District Health Board (DHB) chairs & what we would like included.

Muriel mentioned how the commission have moved along this year; being courageous and how this needs to be promoted and continued.
Rowena would like more of a joint discussion and getting the board feedback on thier views in the consumer arena.
Muriel mentioned the pace of change to address poverty is very slow. Demand continues to get higher in people managing every day life.

2. Presentation of Draft Strategic Priorities

Iwona presented this session jointly with CAG & Te Rōpū in Kahurangi.
(Minutes by Alexis Weaver)

Draft strategic priorities

Stephanie Turner and Iwona Stolarek updated Te Rōpū on the progress of the draft strategic priorities in the Statement of Intent (SoI).

Title – Māori world views facilitating organisation change

Details

Ria welcomed everyone and there was a whakawhanaungatanga then Stephanie began their presentation.

Staff engagement is really important so they've sought engagement for development of the strategy.

This is an opportunity for both groups to give their thoughts, about a Te Ao Māori view and change and support the sector.

Te Tiriti o Waitangi

- We have obligations to uphold Te Tiriti o Waitangi. We're all accountable for where we sit and where we uphold Te Tiriti o Waitangi.
- Stephanie comes from a place where everyone is a treaty partner.
- Talk about Te Tiriti needs to be simple so that people ask what they can do in their daily lives.

Context

- Wai 2575 claims are important to keep in mind.
- The way Te Tiriti was being used was the 3 Ps (participation, protection and partnertship) but now the way is to focus on the articles.
- Stephanie acknowledged the great work the Commission has done so far in Treaty training, the political climate which allowed Māori Health to advance, with Te Tiriti being the centre of the forward direction.
- Stephanie also acknowledged the work of the Performance Improvement Framework (PIF).
- It is important to remember that what's happening for our whānau is really bad in many ways. There needs to be more accountability.

What to focus on for Te Ao Māori

- Māori have always acknowledged their kupu, maintained their knowledge base, whakapapa for their own issues and should continue to do so.

- What are the priorities to advancing Māori health? What can the Commission do to enable that? What are the key levers that will shift things along?
- Stephanie noted the firm belief that if we uphold Te Tiriti, we will address inequity.
- What do we need from a system-, individual-, practice-level?
- The Māori Health team in the Ministry of Health is keen to partner with the Commission and Eru Pomare to review the Health Equity Assessment Tool (HEAT) tool. The Commssion needs to provide guidance and leadership to support the sector.
- There's an opportunity missed as there are many groups doing well outside the mainstream. We are a system, we work in systems. We can use a lot of the matauranga to inform what's happening in the sector. Māori world views have been slow to be taken up.

What are the priorities and what will the strategy look like?

- Te tāniko is the image/metaphor for the strategy – weaving.
- Stephanie and Iwona presented their draft thinking to the Board last time about enacting Te Tiriti and having a consumer/whānau-centred, resilient and culturally safe system.
- They've drawn in from many different materials and documents, eg, the PIF, the Health & Disability review and Wai 2575 (Waitangi tribural claim)
- The strategy needs to have equity at the centre.
- One main challenge from the PIF was to redefine the operating model. This is a challenge – not necessarily changing everything the Commission does but understanding the system better.
- Is the health system a complex system or is it just unkind, failing to adapt? The Commission should support local thinking and work which is applicable to different areas in different ways.
- It needs to be simple and applicable - people need to be able to easily elucidate what they're doing towards the strategy.
- It needs to be aligned with the Commission's government and strategic priorities.

Iwona showed the process of the SoI from information and support to where we are now: advancing Māori health, unwarranted variation, equity, supporting quality & safety.

- They are proposing Te Tiriti becomes the Commission's foundational document.
- John Whaanga and MoH have provided a Te Tiriti framework. Should the Commission use the same framework as them or create our own? It's good because it defines what it means for each of the articles. They are proposing using the Declaration of Independence as another section of the model instead of article four – promoting and protecting mana and matauranga Māori.

Discussion

Partnering with Māori – who is meant?

- Internally, Te Rōpū needs to partner with the Commission Board. The Māori Health Outcomes team needs to be built and invested in, especially how that work is integrated in.
- Externally – it will need to be determined by mana whenua in the local contexts.
- That's how it's supposed to work but it's distorted. In Mental Health and Addictions, we need to have a system in place that focuses on the consumer. Māori whānau get a bitter pill that doesn't produce the health outcomes they need. It needs to be throughout the system.

Cede power – understand local solutions

- Don’t cede power to disinvest. The way to achieve equity with a system move is to disinvest.
- The government doesn’t trust Māori providers with government funding – this is a real obstacle. Why is it that we’re not investing in Māori providers/consumers. Isn’t this a bigger risk for Māori inequity and whānau?
- Whakakotahi – weighting for equity was low but it’s been moving forward. At what point do we ask the whānau and iwi – what is quality for you?

Consumer

- The consumer programme has parallels with the discussion of the morning. At the inception of the programme, that programme was about putting a stake in the ground but change is welcome.

Consumer kupu

- Tangata whai ora, tangata whai kaha.
- Nothing about us without us. It’s about the direct participation of people at the governance level. Let us sit at the right table at the right time.

Tino rangatiratanga needs to be in the strategy as a key focus

- Tino rangatiratanga could be downplayed with this new strategy. It needs to be front and centre.
- The focus of tino rangatiratanga needs to be on power and authority.
- There hasn’t been much talk about tino rangatiratanga. We’re in a transition mode now. Kawanatanga and oritetanga are in place, but tino rangatiratanga is not defined properly and people are scared of it.
- Tino rangatiratanga needs to be there but it is very difficult. We need to build a system that survives a political environment.
- Our goal is equity and tino rangatiratanga – how do we know we’ve achieved it?
- Be careful about self-determination because that’s lends to self-responsibility, blaming and burdening people. We want people to have control over the decisions in their lives and that’s where power and authority comes in.
- It’s a good change to start talking about wairuatanga, it’s part of the knowledge and Te Ao Māori, part of the matauranga.
- Important to remember that wairuatanga is not about religion, it is spirit.

Don’t lose participation

- The one part of the principles approach that is at risk of being lost is participation. In the social services, it is participation in Māori social services that is really important.
- The intention is to articulate all of the articles against each strategic priority.
- He Korowai Oranga – Māori aspirations

Declaration of rights of indigenous peoples

- Article approach is a rights-based approach. Moving from substituted decision-making to supported decision-making.
- Declaration of rights of indigenous peoples – can take measures to ensure there’s equity.

Ria asked Wi to chair while she joins the Board.

- Kindness, humanity and love for people. Don’t lose sight of the fact that the system includes individuals/people.

Disabled Māori suffer the worst health outcomes

- Hoping that in the future there could be more language about disabled Māori, especially as this group has some of the worst health outcomes.
- Use positive language especially for more disadvantaged groups that don't focus on impairment but about where people are in their joureny. We can use these words to think about the labels that get applied to people and their baggage.

3. Mortality Review Committees (MRC's)

This session was postponed until the next CAG hui

4.1 Previous minutes from 27 June

Previous minutes were accepted as a true and accurate record.

4.2 Actions Update

Deon spoke to the actions list. MRC session noted for next hui. Some items on going.

4.3 Interests register

Noted. Frank to advise his updates.

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

Deon spoke about **Measuring progress and responding to the consumer experience of the health care system:**

- With the intelligence hub, roll out the consumer engagement quality and safety marker. Feedback to be received by pilot sites by 12 November. Update to 'form' by 15 November for pilot sites to input data.
- Community project to support Māori health advancement working with the consumer network (improving patient experience) Te Rina Ruru's Camp Unity has been completed with great success.
- Produce resources to assist with improving patient experience (Let's PLAN revisited, patient stories in disability, primary care perspectives). To date we have completed the primary care resource, the Jim Edwards video, and the Elhers Danlos Syndrome video is on the way. Looking at an update to three steps to three steps to health literacy, but this is dependent on budget
- Follow up on the interventions put in place by services to respond to the lower-scoring areas of the adult inpatient experience survey. Nudge video interventions have been complete and promoted. Nelson Marlborough District Health Board (NMDHB) says they can't go any further with intervention, but Waikato and Northland might.

Promoting consumer-provider partnerships and the consumer voice in the health and disability sector

- Continue to champion the involvement of consumers and the 'Partners in Care' approach at all levels across the sector by:

- Consumer representation at DHB-level (Aim of 100% consumer councils in place by June 2020) Looking to get around all the consumer councils? We have already visited 7/20. Perhaps to the South Island before June 2020?
- Run a co-design programme with regional cancer services focusing on cancer equity and all four first workshops complete. There are 4 teams.
- Liaise with Te Rōpū Māori through consumer advisory group Māori representative
- Strengthen relationship between Commission programmes and Partners in Care programme through Partners in Care champions. Some vacancies on the Consumer network group to fill.
- Facilitate opportunities for Commission consumer representatives to meet and learn from one another. Will consider doing this again this year
- Plan Open forum for 2020.

Building consumer leadership and capability

- Support the consumer advisory group
- Support and develop the consumer network
- Follow up on the adoption of the 'train the trainer' resources developed to build capability of consumers in the health and disability sector.
- Respond to consumer requests and sponsorship.
- Promote examples of effective consumer leadership within the Commission and in the wider health and disability environment.
- We have launched the revised guide to consumer engagement with an emphasis on primary and community settings.
- Facilitate opportunities to promote consumer engagement in primary care and following up this with Primary care staff in the commission.

Deon also talked about the Quality & Safety Marker (QSM) and S.U.R.E. (Supporting, Understanding, Responding, Evaluating)

Martine:
Trip to Denmark next week for planning meeting. Sent by Blind Foundation NZ. Also working with Google homes re smart cities and bringing access more in to the home. "Alexa" upgrades. Spoke about working with MoH re disability support with family.
Having input into the NZ Disability action plan from DPO and Citizens NZ level.

Frank:
Large amount of work and activity from MoH re transformation of Mental Health & Addiction act and the report. Primary care RFP for all the funds Government made available. Lots of change in the pipeline.

6. Dates for 2020

Dates have been advised and invites are issued. Explanation as to timeframes and how the dates were set to tie in for feedback on any Board papers.

7. Healthcare Associated Infections (HAI)

Gary Tonkin presented to both CAG and Te Rōpū in Kahurangi, updating on the HAI programme – (*notes by Alexis Weaver*)

Details

Gary talked about infections that take place in the hospital.

Context

- Adverse events are frequent during care delivery.
- People with infections are more likely to face surgery, extended therapy and are at higher risk of dying.
- There are greater impacts on family.
- Commission has had a focus on infection prevention and control since 2011.
- The scope of the programme has not included community hospital type places rather than just DHBs.

Hand hygiene part of the programme

- Five moments is just purely about clinicians washing their hands after contact with patient surroundings as well as before.
- Working with DHBs on clinical areas to train auditors on each of the DHBs.
- They've gone from 60% to 80% since 2012 of all five moments being met.
- The programme has focused on how they can support DHBs with the spread, rather than raising the targets more. This is likely why the graph has levelled out at 80-85%, not the increase but at least the spread.

Future

- Patients can be involved in hand hygiene. They should be able to notice that the practitioners are not doing so and be able to tell them. This is scary for patients but the frontline staff are being trained to ensure they listen to patients when they say this.
- There are lower rates of compliance in Māori.
- There does need to be more patient and whānau information.

Surgical site Infectiomn (SSI) part of the programme

- SSI programme – they've created a bundle to encourage improvement and reduce SSIs.
- Since 2013, the programme has monitored hip and knee surgeries. Now it monitors cardiac surgeries also.
- The Commission provides support and leadership.
- There has been success – the programme has saved 100 infections since its inception.

For Māori

- From 2013, there was a gap between Māori and non-Māori, non-Pacific. From 2016, the gap has been closed and the rate has come down a little for orthopaedic surgeries. For cardiac, it's promising but there is not enough data to say yet whether the gap has closed.
- This is an example of bringing in a programme for all that actually helped address inequities.

- Māori are having surgeries about 10 years younger than non-Māori. This is consistent with other health issues.
- People need to be informed. Māori don't want to have these operations and think they can only have a couple in their lifetime, which may not be true. In Choosing Wisely, people were informed about whether surgery was necessary, the risks and purpose of it, leading to fewer people actually getting surgery. What can the Commission do here?

Future

- There has been a constrained scope for the programme. Funding is unsure which makes planning difficult. Part of this scope and spread of success might come with the Aged Residential Care (ARC) sector. They're doing a point prevalence survey with ARC to identify where they'll focus in coming years.
- The equity graph needs to be circulated to show the success of eliminating inequities.
- At the moment, the programme is matching the data with the national collections.
- They're suggesting to the Board tomorrow to move to light surveillance – to free up data collection so they can work on improvement. The rōpū wondered whether improvement will continue after the Commission stops focusing on this programme.
- It's hard to transition to primary healthcare after this success in the Commission.
- Any new work, prioritising it, there will be a check of whether there is a difference or not. It's amazing success so far and for DHBs to follow-on then take over the funding.

8. CAG joined the Board hui for their annual session as per Terms of Reference (TOR) *(Tina Simcock notes)*

It was noted in the feedback letter prepared for the Board to send regarding the Heather Simpson report that there was no mention of the Consumer voice and its input into Board papers (this raised by CAG chair who was present at the discussion with the Health and disability review with Heather Simpson). Heather had commented on how good the Consumer Group breadth and reach was into communities across New Zealand and that she had identified this group as a good group to talk to in her consultation.

Frank spoke about a Mental health awareness - quality improvement – his take on quality and improvement used in the vegetables (nursery) he produced and funding becoming available to deliver services. Working in partnership with others. 'Placing consumers and whānau at the heart of interactions'.

Muriel spoke about how she had engaged with the Commission (community development background) as the first provider for Whakakotahi. She comes with a consumer perspective, using sensory tools such as emotions etc. She is a Te Rōpū member, likes how the Commission has reversed where health and wellbeing is up front - acknowledged functioning groups working for the same organisation.

Martine (policy background and has disability), community development / social cohesion/ community wellbeing/ Blind citizens NZ/ Disabled co-literation - disability strategy / patient deterioration leadership group / Korero Mai/ GP connect programme/ HQSC is positive about the quality and improvement of the health sector.

Rowena (CAG Chair) - Lawyer by trade/ first all lawyer firm in North Shore/ lived experience with cancer, give back, better health outcomes, consistency and care.

Discussion topics

Dale spoke about his expectation of the group being one of responsiveness – to take the lead on a few issues and front footing a couple of issues

It's a Push and pull type of relationship.

The Chair talked about the Commission's next four years – what does that framework look like and providing feedback on the Strategic Intent

It was important to tap into Consumer network and to consider the design of programmes

Did we design with Māori partnership and with consumers - what was the design process with consumers and Māori in mind?

There was a system push - funded specific positions – what would that look like? What would a consumer led quality assurance and improvement approach look like? It's a team effort because well informed consumers at any level – provides contribution that is stronger and better if you have a better-informed populace about healthcare, the ability to advocate and better their own understanding of their health.

How well does the Commission support better informed NZ community? The Consumer Group need information first like maternity high blood pressure etc.

We need to have shared values, relationships, quality tools, developing capability - design a service - balance the competing priorities - power of connectivity and collective impact.

What characteristics of good network - you're a vulnerable society - good co-design, attracted very pro-active people, who are the links in the community, the dynamic of diversity, informed consent issues. How do we get a bigger bang for our buck out there? More sustainability - Leadership from services, driving co-design at a practice, how do we lift that? What does that look like?

Process and outcomes - scaling up and down - strengths of disability and lived experience

Invitation to put things on the agenda - twice a year that this network comes together.

Nga mihi from Gwen – acknowledgements to the group for the work over the years of her board tenureship. Her parting words…. Kia ora '*you have gone too far not to go further. and you have done too much to not do more!'*

Close of meeting: No formal close. Afternoon tea with Board & Te Rōpū

Next face-to-face meeting: 30 Jan 2020 – Pounamu

Actions List:

Date	Action	Responsibility
27 June 2019	PIC to look at possibility of providing Martine with an I-Pad.	Dez Ongoing. Aaron to visit to

		demonstrate I-pad accessibility option
27 June 2019	Schedule for a representative from the Mortality Review Committees to attend the CAG hui to address some of the questions the group are asking.	Dez. Postponed in Nov. Schedule for next hui 30 Jan
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)
27 June 19	Board paper for next hui to note CAG's proposed changes to their TOR	Deon. Actioned Nov Board hui
5 Nov 19	Frank to update his interests and advise Dez	Frank