



- Present:** Chris Walsh (Chair), Ezekiel Robson, Marj Allan, Martine Abel, Te Rina Ruru, Camron Muriwai, Edna Tu'itupou- Havea, Marlene Whaanga-Dean, John Hannifin, Deon York, Gillian Bohm, Dez McCormack (Minutes)
- Guests:** Andy Simpson (Chief Medical Officer) Margareth Broodkoorn (Chief Nurse)
Item 4)
- Apologies:** Courtenay Mihinui, Renee Greaves, Bernadette Pereira
- Absent:** Fonoifafo Seumanu-McFarland

The meeting commenced at 9:47am.

1. Introductions and welcome

Dez opened the meeting with a karakia.

Chris welcomed everyone to the meeting and we had introductions from everyone.

2. Minutes of the meeting held 18 October 2018

The minutes of 18 October 2018 were confirmed as a true record. There were some amendments noted.

2.1. The actions list was considered and updated.

3. Partners in Care report

Laura presented on the Commission's patient deterioration programme, three workstreams recognition and response (national early warning score chart), shared goals of care and Kōrero mai (patient, family and whānau escalation system). Kōrero Mai is a co-design project in district health boards (DHBs). Waitemata DHB has been the first to implement Kōrero mai and is live across both hospitals receiving on average one call a month, all calls have been about communication. Another DHB and a private hospital will go live within six months. The Commission will shortly be putting out a call for more DHBs to start their co-design Kōrero mai projects. The patient deterioration programme has zoom meetings for consumers involved in co-design connected to shared goals of care and Kōrero mai, and sponsored consumers to attend the national patient deterioration conference in Auckland in 2018. A copy of the report can be found here <https://www.hqsc.govt.nz/our-programmes/patient-deterioration/news-and-events/news/3638/>.

The link was emailed 6 March to the group. A report from the consumer was tabled – 'Consumer report & reflections from the 2018 Patient deterioration NZ conference'.

(Deon continued this next section of Partners in Care report after item 4.)

All statement of performance expectation deliverables will be achieved.
 Activities planned versus expected – to discuss.
 Budget tracking to be fully utilised by 30 June 2019.
 As at January 2019, 52 percent of the operational budget remains unspent.

Activities for this quarter and other ongoing activities to be achieved by 30 June 2019 are:

Furthering understanding and responding to the consumer experience of the health care system

Plan	Progress (to March 2019)	Next steps (to June 2019)
Develop consumer engagement QSM with Intelligence hub	Concept developed (Are you SURE?)	Reference group to sign off concept and test. Roll out July 1 2019
Understand and respond to the patient experience, focusing on equity	Te Rina Ruru and Courtenay Thrupp of the consumer network are focusing on two projects to emphasis Māori experiences of health	The concept is called Mahi Ngatahi . Te Rina will complete an initial grand round at a DHB, Courtenay's project is on hold at present
Produce resources to assist with improving patient experience	Contract signed on Friday 22 February with Ogilvy to produce 'nudge' video resource	Testing, production and roll out (By June 30 2019)

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

Plan	Progress (March 2019)	Next steps
Consumer representation at DHB-level (at least 80 percent)	Meetings with PIC team and Wairarapa, Waikato, Bay of Plenty, Nelson-Marlborough consumer councils	Most DHBs have councils. QSM will explore how these groups are working, resourced and the influence they are having. Tairāwhiti and Lakes are still to form groups
Co-design with two health service providers*	Progressing with Pegasus and Capital & Coast DHB	All case studies to be published by 30 June 2019 on Commission's website
Liaise with Te Rōpū Māori through consumer network	With Muriel on the group, we have links through CAG	Ongoing – both groups review board papers
Strengthen relationship between Commission programmes and Partners	Semi-regular meetings with wider Commission teams through this group.	Discuss: how can PIC maintain both an internal and external focus?

in Care programme through Partners in Care champions.		
Facilitate opportunities for Commission consumer representatives to meet and learn from one another	Ongoing activity. Plan an 'all Commission consumer representatives' day	Discuss: Week of May 21 2019.

Building consumer leadership and capability

Plan	Progress (March 2019)	Next steps (June 2019)
Building the capability of consumers to effectively work with the health and disability sector in a partnership approach through a 'train the trainers' regional approach. *	One complete, and two to go (Auckland and Christchurch)	Three 'train the trainers' will be complete by 30 June 2019.
Respond to consumer requests and sponsorship	Ongoing.	
Resource prioritisation	Revising DHB consumer guide to be a guide for working with consumers across any health service	Ongoing – but delayed.

Additional

- Role as advisor externally (particularly among central government, and professional colleges and societies)
- Role as advisor internally
- *Ad hoc* Commission-wide projects
- Processes which PIC team leads or coordinates (e.g. Pacific liaison in the Commission, Rainbow Connection)

4. Informed consent discussion

Intro's were done by all and waiata sung. Andy asked group what they wanted out of informed consent discussion. Concerns expressed recently about consumers not receiving sufficient information or provided with choices about treatment options. Health & Disability Commissioner gets many complaints about informed consent. Asked to do something at a national level by chief medical officers – taking a step back & see what consumers want. The group then provided their thoughts/points questions to consider which were captured in bullet form on whiteboard.

- Information technology – collecting data. (How will this be managed?)
Getting consent for this: what purposes is it used for?
Confidentiality & sharing information

Pacific people – writing up data sharing requires input from Pacific people who have different ethnicities? Guide for signing for informed consent.

- Informed choices come before informed consent – how to be informed about choices.
- What makes good interaction for you as a consumer – to say yes/no//maybe.
- Individual – needs supporter/supporter/another person there.
- People with traumatic brain injury → may be confused – may involve informed family consent – how do we do this?
- Those under the Mental Health Act – impaired decision-making. Brining in family/whānau. GP's medication dispensing – coercion around mental health. Approval of reports, treatment plans – ensuring information is correct.
- Could it be a living document – added to throughout journey.
- Process & timing - when is the best time to get informed consent.
- Difference between surgical & medical – you won't ask if you don't know; general discussion needs encouragement.
- Reality is that if you are in pain/distress then discussion later; timing; context & flag around awareness & readiness to have discussion.
- What does it bring to mind -informed consent – language & terminology medically driven
- Having a record the consumer can go back to.
- Medical person has all the knowledge skills – needs to be about consumer owning their health and consent.
- Liability focus – underpins informed consent; grappling with this in the power dynamic.
- Psychology of human behaviour – people consent because they want to be well so likely to consent – confirmation bias here.
- Pacific people: we are not giving you our permission, but we are giving you our trust – is there a guideline for informed consent for pacific groups.
- English language/medical language – getting to grips with this – pacific people trust.
- Information guide for health professionals on how to get informed consent.
- Cultural context complexities of informed consent.
- Communication – important that we know how to communicate with kindness; love
- Principles of communication – repeating information back.
- Culture eats strategy for lunch; spending as long as you want – directing us as to what to do; 'minimising'.
- Guideline – planned surgery – seek 2 days before surgery.
- Family – are they the right family to be there? Determining which family is best at right time; advanced planning and documentation for this.
- What informed consent means in different settings? Eg, Mental Health Act and different contexts.
- Surgeon has to believe in own practice. So inherently bias which interferes with patient choices. Address different world views.
- My health belongs to me - getting permission for one procedure when it is a holistic view needed.
- TRUST rather than mitigation.

5. Consumer network reports

John Hannifin

On 27 November 2018 – attended the train-the-trainer workshop. The manner in which the workshop was run was great and allowed me to think how to put in place training (development programmes) for consumer council members plus the bonus of a great resource kit.

The quality standard markers for the patient experience reference group is coming along in an open way, with a sub meeting being organised by Lynne Maher in Auckland on 7 March – to test out some of the approaches.

The Committee involves consumers and health professionals including from the DHB who will trial the new system.

While the consumer experience dashboard provides some standardisation across country information on patient experience in secondary care (hospitals) and in primary health there is a need to capture some quality based and equity information on patient experiences. In primary health the comments from the public on access to general practitioner type services do not match those collected in the current dashboard and other options need to be considered.

Great headway is being made on setting measurements for the embedding and supporting of consumer councils and consumers within health services - a work in progress — next meeting 10 April.

Martine Abel-Williamson

On 27 November I participated in the train-the-trainer workshop. This was attended by consumer group reps from various DHBs. It was very interactive and inclusive.

On 29 January the Consumer Advisory Group (CAG) met and items discussed included:

- A paper on aged care where various models of aged care got raised and future initiatives in this area got flagged, including in the area of patient deterioration.
- The Commission gave us an update on its Māori equity documentation and our CAG's Māori representative plus Te Rōpū Māori provided input as requested.
- We promoted the Commission gather more knowledge about the disabled persons Organisations' Disabled Persons Organisation (DPO) Coalition to increase disability community engagement as this is still lagging behind engagement in the health sector. For my sins I and CAG member, Frank from Balance Aotearoa, one of the DPO Coalition members, got tasked to draft a paper for attention at the next CAG meeting.

Patient deterioration working group update:

This meeting will take place on 4 March so I'll be able to provide an update following that date.

Marj Allan

- Inpatient and primary care patient survey groups moved to one group from December.
- Career force Workshop; reviewed the NZ Certificate in Health and Wellbeing Levels 2,3, and 4 suggested a stronger focus on communication is put into the training.
- The first cut of data released showing up some variations in treatments across NZ in radiation treatments. Hopefully this will drive change to get treatments for patients the same no matter where you live.
- The Standards of Care for all tumour Streams is available on the Ministry of Health web site.
- Health Workforce NZ now have a Minister appointed governance group working. Hopefully this will put workforce planning onto the radar.

- The national travel policy has moved forward in the review process. Check the Ministry of Health's website for this update.
- Cancer Crossroads Conference highlights many issues for our cancer patients. Triaging came to my radar.

Edna Tu'itupou-Havea

Research paper on access on consumer engagement. Focusing on Pacific peoples and would like PIC's help.

Marlene Whaanga-Dean

- I will be attending advance care planning, held 19 March at Masterton.
- Whaiora in Masterton, we are strong supporters of relay for life with Kaimahi (workers) joining in on raising money for those that are diagnosed with cancer and those on a cancer journey. Cancer Society Wairarapa have support groups and workshops Koru-iti room therapies with (NTA) that provides financial travel assistance and accommodation (covered by Ministry of Health), also volunteer driving service at no charge. WINZ support entitlements website <http://www.workandincome.govt.nz>. 0800 559 009 for personal assistance.
- **In your shoes** – Wairarapa consumer council creating patient feedback and for whānau to share their experiences in the care of the Wairarapa DHB this work shop was held 18/19 February 2019 based on 'your voice your vision your values'.
- **07/02/09** – Project contractor Moira Crispe of Capital & Coast DHB is leading a project called systems review of health responses to suicide and suicidal behaviours on behalf of Wairarapa, Hutt Valley and Capital & Coast. This hui I attended was held at Whaiora in the board room.
- A review of the health service to respond to suicide and suicide behaviours. My suggestions for suicide prevention; dial a kaumatua (some have requested this option in the pass); mental health attached to primary care outlets to support crisis on the spot opposed to a referral process; more training for kaimahi to identify and to keep safe; create a hub – prevention and intervention to mental/suicide.

Tamara Waugh

- I did not attend the train-the-trainer workshop. I missed the invite, but I look forward to hearing more about it.
- Rakau Roroa is doing a training workshop this weekend for the recipients of the Mental Health Foundation journalism grants and will then focus on developing the online version of the programme.
- Consumers are now a regular part of the agenda for the national DHB child youth and adolescent KPI forum held annually in Wellington.
- A collaboration of non-government organisation senior management has been asked to set up a wellbeing coalition. The coalition will respond and work with the ministry around what the inquiry advises.
- Zero seclusion and connecting care programmes continue to have consumers at the table to ensure better consumer outcomes.

1. Looking at suicide prevention and how to bring the consumer voice in and asking the question from lived experience – how do you stay alive

Camron Muriwai

I have been co-opted as a consumer/community representative, completed a LI workshop. I attended my first meeting in February. A great group of people and opportunity to offer another perspective or direction. A highlight is the train-the-trainers and I am contemplating the opportunity to put myself forward in the near future. I have also joined a sub group to discuss training pathways etc. (I need to understand a little more but intend to learn as much as possible)

Ezekiel Robson

I continue to participate in the consumer quality and safety marker work alongside other members of the consumer network.

Te Rina and I attend the Consumer Advisory Group of the Royal Australasian College of Physicians. Royal Australasian College Physicians are holding their annual conference in Auckland 6–8 May 2019. The Commission could help boost the profile of health consumers and consumer engagement by supporting people to attend. Further details can be found here <https://racpcongress.com.au/>.

Te Rina Ruru

- I will be presenting my family's story at the Bay of Plenty DHB's grand rounds on 9 April 2019.
- Attended a meeting with the ACC whole of pathways collaborative regarding commissioning for outcomes. This was the third workshop.
- Attended a meeting with the consumer advisory group with the Royal Australasian College of Practitioners (RACP) where we set our workplan for 2019 – 2020. RACP Congress 2019 is taking place from 6–8 May 2019 in Auckland. You may find more information on their website.

6. Planning for 2019/2020 and beyond (group work)

The group were asked to make suggestions for consideration in the next financial year for our programme.

Ideas –

Share for better care – recent experiences that can improve the experience.

Let's plan properly – going to GP or out patients. Clip board info provided. What you want to talk about. What's on your mind. A tick box form.

“Let's plan better plus”

Putting a stake in the ground to support health providers to upskill in responsiveness to cultural needs.

Higher quality engagement by PHO's.

More collateral.

Getting a return on investment.
And disability – not just word – do something about it.

How to be more visible in the community. More engagement with ethnic communities being visible in community promoting the Commission.

Family/whānau partnership & support. Co-design. Workshop. What needs to be done for consumers. How to support family to keep the disabled well.

Focus on adolescent health and care. Apps. School programmes etc.

Designing specific workshops (with standard framework) that have ability to be framed for specific audiences. Rural/urban/ethnic etc.

Action/principles/methods.

7. Other business

Close of meeting at 3:40pm

Next meeting: 13 June at the Commission

Action list

Date	Item	Action	Responsibility	Outcome
18 October 2018	2	Rowena and Bernadette will link in relation to Pacific health.	Rowena & Bernadette	completed
18 October 2018	3	Send contact details of: Muriel, Marlene, Bernadette, John and Camron to Sue Wells to enable further discussion.	Di	completed
18 October 2018	4	Update Traci's profile with her new Board membership.	Di	Received resignation and it was acknowledged by group
18 October 2018	4	Load the link for the Bronchiectasis Foundation NZ to the Commission website	Di	To discuss with Falyn re interview with Camron for website
18 October 2018	4	Send bullet-pointed, Commission related, reports electronically to Di prior to the meeting	All	Reports now to Dez
18 October 2018	9	CAG to take the DHB stocktake to the Commission Board meeting	Rowena / Chris	Not complete. Now to go in CE report for Board papers

6 March 2019		Finding an Asian (Chinese) consumer for network. Feed any suggestion to Chris/Deon/Dez	All	Dez emailed Marg as reminder.
6 March 2019		Camron and Martine to open and close the next meeting with a karakia		