



**Present:** Chris Walsh (Chair), Traci Stanbury, Ezekiel Robson, Marj Allan, Courtenay Mihinui, Martine Abel, Renee Greaves, Camron Muriwai, Fonoifafo Seumanu-Mcfarland, Edna Tu'itupou- Havea, Marlene Whaanga-Dean, John Hannifin, Bernadette Pereira, Tamara Waugh, Deon York, Gillian Bohm, Diane de Rochester (Minutes) – HQSC

**Guests:** Rowena Lewis, Chair of Consumer Advisory Group, Muriel Tunoho; Frank Bristol – Consumer Advisory Group (*Item 3*); Sue Wells (*Item 5*), Gary Sutcliffe and the Health Consumers Advisory Service Committee (*Item 7*)

**Apologies:** Te Rina Ruru

The meeting commenced at 9:30am

## 1. Introductions and welcome

Di de Rochester opened the meeting with a karakia and the members responded with the waiata.

Chris welcomed everyone to the meeting.

## Minutes of the meeting held 27 July 2018

The minutes of 27 July 2018 were confirmed as a true record.

## 2.2 Actions update

The actions list was considered and updated.

## 2. Introductions and discussion with Consumer Advisory Group to the Board

Members introduced themselves to the full group.

In the first instance Muriel discussed the current Waitangi Tribunal discussions around equity and most importantly the inequities in Māori health.

Rowena spoke to the group and advised them of where the Consumer Advisory Group sat in their advice to the Board. She also raised the issues they had with the draft cancer equity paper and how the CAG had managed to influence this positively.

There was also discussion around the CAG being able to look at the MRC papers as it was believed that this could have a very positive outcome on these reports.

Rowena asked that the group give ideas on where the CAG can sit and if there were any ideas from the Consumer Network on how the CAG can make the most useful contribution.

Bernadette would like to be involved with discussions on the problems of Pacific women dealing with breast cancer.

Ezekiel talked about the CAG being “critical friends” being both friends and critical. Speak forcefully and honestly. Consumers need to be involved in a meaningful way.

Marj felt that having CAG was a great advantage, and the CN could possibly feedback through them to the Board. There is a link to both groups via Martine who has requested feedback from the Consumer Network.

There was further discussion around the best ways and techniques to highlight consumer concerns and ideas.

**Action:**

Rowena and Bernadette will link in relation to Pacific health.

**3. Commission Partners in Care report**

Deon went over the Partners in Care report, highlighting the key points:

Since our last meeting on 27 July we are now into the second quarter of the financial year. In terms of representation, the consumer network and advisory group are at full membership, and the planned activities for 2018/19 are well underway.

Below is a summary of activities since we last met.

- Meeting with regional cancer managers (2 August): Chris and Deon discussed the Partners in Care programme. A theme of the conversation was equity. We are looking at working with the regional cancer networks in 2019/20 and running a cancer equity focused co-design programme.
- Meeting with Auckland region DHBs (16 August): Chris and Deon were invited to a meeting to discuss the management of patient complaints at DHB level. We shared the work of the Commission, including adverse event review and the involvement of consumers in review. There are no actions arising out of this meeting at this point.
- On 21 August Chris and Deon were part of Bay of Plenty DHB’s grand round. All teams from the last co-design programme presented their projects. There were about 50 DHB staff in attendance with good audience engagement.
- On 4 and 7 September the co-design programme with Dr Lynne Maher for 2018/19 with Capital & Coast DHB and Pegasus PHO (as well as affiliated PHO organisations) commenced. The projects are very diverse this year, particularly those presented by the PHO.
- Chris and Deon presented at the British Medical Journal and Institute for Healthcare Innovation Forum in Melbourne on training for consumers.

- Between the 4 to 15 October Chris and Deon have met with Waikato, Bay of Plenty and Wairarapa DHB consumer councils.

Activities for this quarter have included:

- Planning with the intelligence team for the next meeting of the consumer engagement quality and safety marker reference group in early November. This includes drafting the concepts for the QSM and the Partners in Care team testing some of these concepts with the consumer councils noted above. We are piloting the approach with Canterbury, Waitemata and Waikato DHBs and looking at how to incorporate a wider community perspective. The marker will likely take the form of a dashboard, with qualitative data being of relevance.
- Planning for the upcoming 'train the trainer' workshops. The Partners in Care team are running three 'train the trainer' workshops (Wellington, 27 November 2018; Christchurch, 20 March 2019; Auckland, 14 May 2019) to train consumers and providers on delivering four modules: 'health and disability context', 'consumer experience base', 'evidence base', and 'partnership'. While the training is now full, the modules will be available on the Commission's website by 30 November 2018. By the end of the three workshops participants from both DHBs and the community will be trained to deliver these consumer-focused modules.

Other ongoing activities to be achieved by 30 June 2019:

- Bringing Commission consumer representatives together: we plan to hold a day for all consumer representatives connected with Commission programmes.
- Promotion of refreshed guide to working with consumers
- Developing video resources - themes about what made the difference and cultural aspects of care
- Promoting simple interventions to improve the patient experience (based on findings from 2017/18 work)

### **3. Quality improvement in primary care**

Sue Wells joined the meeting at 10:45am to discuss the involvement of consumers in primary care. She presented a PowerPoint with a Scottish model for collaboration with consumers.

There was much discussion around how the Primary Care area can work in a more positive way with consumers. The group stressed the need that there needs to be a lot more effort into relationships and communication.

Sue commented that the work needed now is to shape the comments and suggestions. She will go out and talk widely with communities and have further, more thorough, discussions with some members of the group.

**Action:**

Diane to send contact details of:

Muriel, Marlene, Bernadette, John and Camron to Sue Wells to enable further discussion.

**4. Consumer Network reports**

***Traci Stanbury***

Earlier this month Traci attended the Australian Transplant Games on the Gold Coast. She made contacts with the CEOs of the Australian Organ and Tissue Donation and Transplantation Authority as well as Transplant Australia and was able to observe their ongoing collaboration, which is something they are striving towards with the new Organ Donation Authority in New Zealand that should be established next year.

While they were at the Transplant Games Traci's 13-year-old son, Ben, won 7 gold medals and one silver. The family has been profiled in the Nor 'West Newspaper in Christchurch as well as The Press and the Stuff website with a video of his health experiences. Shorter versions of his experience have been on the Kidney Kids, Cure Kids, Kids Foundation, Immune Deficiencies Foundation New Zealand, New Zealand Transplant Games Association, Transplant New Zealand, Organ Donation New Zealand, ARPKD, and ARPKD/CHF Alliance Facebook pages. It's been great to profile what transplant recipients can do and to promote organ donation.

Traci has been liaising with the promotions advisor at Organ Donation New Zealand and is working on a collaboration with her on a video messaging project to increase the number of organ donors.

Since our last meeting Traci has been elected to the board of Kidney Health New Zealand and is currently writing a report on how they can improve their business resiliency in the changing health environment.

***John Hannifin***

John has been selected as one of the Consumer reps for the "Consumer Engagement Quality and Safety Marker Reference group ' of HQSC. They have had one online meeting with a fellow up face to face meeting coming up early in November.

John is keen to make a contribution especially from the assessing of DHB on Consumer Engagement – 'watch this space'.

***Bernadette Pereira***

Bernadette will continue to create opportunities through Pacific forums, events, and consultations to raising the awareness of Pacific People on why it is important to provide feedback and seek further information on their health and wellbeing every time they are in touch or connected with the health system. One such opportunity was at the PACIFICA Inc. mini-conference held in September 2018 at Auckland Cancer Society where Ezekial presented to the conference on the work of Health & Safety Commission, and the role of the

National Consumer Group. A total of 35 women leaders from Whangarei, Tokoroa, Tamaki, Manukau, and Central Auckland attended the conference. A robust discussion ensued following Ezekiel's presentation.

Bernadette hopes to invite Chris & Deon to support the establishment of Southseas Healthcare Trust Otara in late November early December 2018.

A meeting between Bernadette Chris & Deon is planned for mid to late November for discussions around planning project/s for Pacific under the Consumer group.

### ***Martine Abel***

Internal involvement at HQSC level:

In September the Consumer Advisory Group was asked to comment and to make suggestions on the Learning from Adverse Events annual report 2017-2018, that was going to the HQSC board on 20 September. Martine commented around the need for improved engagement with the disability sector and community and it was good to note that in 2019 a review will take place re how reporting can be improved.

External involvement to HQSC:

In August Martine joined a new panel, set up by ACC, as they established an ACC Scheme Customer Advisory Panel. The inaugural meeting went well but they are still finding their feet in terms of the vast area of possible involvement for this panel.

Martine also recently appointed to a newly established entity, set up by Auckland DHB, namely to be a member of their Patient and Whanau Centred Council. Again, the work and scope of this entity is still being shaped, but her hope is that it would be strategic by nature.

The ACC Sexual Violence Prevention Advisory Board has met in August and Martine has sent the group all their most recent update already. Their next meeting will be held on 8 November.

Martine's involvement continues as part of the government's System Transformation Workforce Working Group and now that the Mid-central pilot has commenced, they are hoping to still do some streamlining in terms of what the employment hub does, etc.

In August Martine presented at a conference in Turkey, on behalf of the World Blind Union (WBU) on access to the environment and inclusive tourism. That presentation can be shared with those who are interested. It contains a great reference list of available universal design and barrier free design checklists, regulation and legislation examples.

On 6 and 7 September, in Auckland, a Universal Design conference was held. Attendees and presenters at national and international level contributed. Martine presented on accessibility of self-driving and autonomous vehicles and again, people are welcome to request this presentation. Important contacts were made over the 2 days, including with the first keynote Speaker, Victor Calise, Commissioner, New York City Mayor's Office for People with Disabilities, Lui Greco, National Manager Advocacy at the Canadian National Institute

for the Blind (CNIB), and Dory Reeves, Professor of Planning, School of Architecture and Planning - Faculty of Creative Arts and Industries, The University of Auckland.

In September Martine also presented at the WBU Asia-Pacific Mid-term General Assembly on implementation of the Sustainable Development Goals (SDGs) and how they are linked with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), so, people can let her know if they'd wish to learn more about that, as NZ has signed up to the SDG's as those are not just of value for developing countries but for all nations;

Martine has also provided wide ranging updates to networks about community forums, review opportunities, etc in many areas of health and disability.

### ***Marj Allan***

Over half this quarter Marj was on holiday chasing sun!!

There are four new Consumers joining the South Island Cancer Consumer Group which is giving them a full group covering the whole South Island, including Māori representatives.

The main item that come out of their last meeting was regarding survivorship and the fact that there are large inequalities within tumour streams. i.e. breast patients have the option of a full reconstruction where as other tumour groups don't seem to get much, if any, support in recovering physically and mentally from their illness. As the ministry is working on these now the group will be bringing this to their attention.

The patient experience surveys are now getting some useful feedback; however, they are still struggling to get full participation from Māori and Pacific. Marj would like the group to encourage people to make sure their email address is up to date on their NHI number They can do this at their GP. Also, when they are asked to participate in a survey that they do these to help with quality improvement. The Inpatient and Primary Care Patient survey groups are moving to one group from December.

Marj attended the Career Force Workshop to Review the NZ Certificate in Health and Wellbeing Levels 2,3, and 4. This was an interesting day, learning how they had divided the credits amongst the topics they covered. These Certificates are mainly for homecare workers and older person in patient care. Marj was shocked to find that Communication wasn't included in the topics. Hopefully now they will be. One of the issues that has be identified as a lacking across the health system.

### ***Edna Tu'itupou-Havea***

Edna has been invited as a guest speaker for the Patient Safety paper for MA students at the Graduate School of Nursing, Midwifery and Health to speak about her experience as a health consumer with an adverse event. She used this opportunity to promote HQSC and its role in patients' experience.

Edna suggested that maybe they could invite people from the team to talk to the Bachelor of Nursing Pacific about 'patients' experience' and HQSC roles. This will be a great opportunity to reach Pacific communities because most of these students are health consumers themselves.

### ***Renee Greaves***

Nothing to report. Just a cute baby.

### ***Courtenay Mihinui***

On August 23 Courtenay participated in the first zoom meeting for the Consumer Engagement Quality and Safety Marker Reference Group. Their next meeting will be face to face in Wellington on November 6.

On September 5 Courtenay attended the first meeting of the Korero Mai Working Group. This is one work stream of the Commission's Patient Deterioration Programme. Korero Mai was born out of the recognition that escalation shouldn't just come from a piece of paper or form. There are numerous occasions where Patients, family/whānau recognise deterioration and clinicians don't. They are the 2<sup>nd</sup> cohort of the Korero Mai work stream. Shared Goals of Care is another work stream around conversations at the bedside about a patient's wishes if serious physical deterioration happens. We were due to have a zoom meeting on October 25 but this had to be cancelled.

Courtenay resigned from the Commission's Advanced Care Planning steering group due to not being able to contribute because of other commitments. She raised this with the Consumer Network to see if there was any interest from other members to perhaps take up this role.

Courtenay will be attending a Consumer Maori resource hui on Nov 22 at the Commission and lastly she is looking forward at attending the Patient Deterioration 2 day Conference being held in Auckland Nov 29-30.

### ***Marlene Whaanga-Dean***

Te Mauri pilot program has been running for 5/6 months at Whaiaora. Te Mauri is a support group for Maori whanau experiencing cancer. Using trained facilitators Te Mauri offers a safe and nurturing space where you and your whanau can meet, learn and share your stories and knowledge with others.

Te Mauri seeks to prioritise your cancer support needs and will walk beside you, wherever you may be on your journey.

This is held on a marae setting ' Te Rangimarie Marae' Masterton every Tuesday 10am to 12pm provided with a beautiful lunch for those who attend.

### ***Tamara Waugh***

- Developing a relationship with Mason Clinic OT's with the aim to gather more consumer voice at that end
- Speaking and attending the Healthy Futures AsPac conference
- Interviewing the top 1% of people that have been in psychiatric care for longer than 244 days consistently
- Oct media surge requests for interviewing people with lived experience
- Corporate surge to have lived experience speakers talking about mental health in the workplace

- Extension of the Mental Health Inquiry report until 30<sup>th</sup> November
- LMLM Provider Hui

***Ezekiel Robson***

Ezekiel reported on the disability stocktake in Auckland region

***Camron Muriwai***

Camron explained the respiratory website and showed video's - [www.bronchiectasisfoundation.org.nz](http://www.bronchiectasisfoundation.org.nz)

**Actions:**

- Di to update Traci's profile with her new Board membership.
- Di to load the website for the Bronchiectasis Foundation NZ
- Members to send their bullet-pointed, Consumer related, reports electronically to Di prior to the meeting

**5. Joint meeting with the Health Consumers Advisory Service Committee**

All participants at the meeting introduced themselves and Gary Sutcliffe gave a PowerPoint presentation explaining how the HCASC began and what their roles are.

Simon Morten is working with the group to help tell the stories of the consumers via video.

The HCASC is advocating for the consumer voice and invited the CN and CAG to contribute with their stories if they wished to.

Members of CN and CAG discussed various issues and ideas with the HCASC, including:

Reasons for joining and remaining with the group

How to manage the responsibilities required for supporting other consumers along with whatever health issues they are dealing with on a personal level.

Ensuring that health professionals treat consumers consideration and respect.

Changing the model of care, as it isn't working.

**6. QSM discussion**

Deon briefly discussed the draft QSM, and noted the following:

Outcome markers

Community involvement

Process Markers

Having consumer engagement in governance

Deon reiterated that this was still a draft and not the final document.



Chris discussed the draft structure for consumer engagement quality and safety marker and asked the group for comments.

- **Indicators**
- **What's important to consumers**

## **8. Training guide**

Deon discussed the upcoming Train the Trainer and outlined the contents of the modules.

Chris confirmed that the links included would be available for everyone to view and asked that the Consumer Network look at them and provide any feedback, particularly around anything which needs improvement.

Looking for feedback (better name?) for the *Engaging with consumers: a guide for health and disability service providers and consumers*. This will go onto Loomio for feedback.

## **9. Other business**

Muriel raised some questions about the stocktake which Ezekiel carried out on the consumer councils in DHBs.

### **Action:**

CAG to take the DHB Stocktake to the Board meeting

### **Close of meeting**

**Next meeting: 6 March 2019**

## Actions list

Date	Item	Action	Responsibility	Outcome
18 October 2018	2	Rowena and Bernadette will link in relation to Pacific health.	Rowena & Bernadette	
18 October 2018	3	Send contact details of: Muriel, Marlene, Bernadette, John and Camron to Sue Wells to enable further discussion.	Di	
18 October 2018	4	Update Traci's profile with her new Board membership.	Di	
18 October 2018	4	Load the link for the Bronchiectasis Foundation NZ to the Commission website	Di	
18 October 2018	4	Send bullet-pointed, Commission related, reports electronically to Di prior to the meeting	All	
18 October 2018	9	CAG to take the DHB stocktake to the Commission Board meeting	Rowena / Chris	