

## **Minutes of the Consumer Network**

Zoom meeting held on 10 June 2020,  
in Pounamu at the Health Quality and  
Safety Commission (HQSC),  
Wellington



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**Present:** Chris Walsh (Chair), Deon York, Gillian Bohm, Camron Muriwai, Bernadette Pereira, Ezekiel Robson, Marlene Whaanga-Dean, Martine Abel-Williamson, Amanda Stevens, Mark Rogers, Russ Aiton, Hyejung Kim, LJ Apaipo, Vishal Rishi, Renee Greaves, Marj Allan,

**Apologies:** Edna Tu'itupou-Havea, Joanne Neilson, Te Rina Ruru

**Guests:** Jane Thompson, Falyn Cranston

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The meeting commenced at 11.00am

### **1. Opening and welcome**

Chris welcomed everyone to the meeting which is our first zoom (zui) one as a group. Some etiquette and protocols established. Camron opened with a karakia. Apologies (as above) were noted. Some were late due to technical difficulties.

### **2. Minutes of the meeting held 12 March 2020**

The minutes of 12 March 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.

### **3. Partners in Care (PIC) report**

Deon gave the Partners in Care report.

Some activities since 12 March 2020

#### **Quarterly report from Partners in Care team for the Health Quality and Safety Commission's Consumer Network as at 28 May 2020**

Since our last meeting on 12 March 2020, our focus has been on continuing to progress the quality and safety marker for consumer engagement, the cancer co-design teams, and planning for 2020/21. We have also adjusted our activities and ways of working following the COVID-19 pandemic including keeping in regular touch with consumers about COVID-19. Our first face-to-face team catch-up was on 26 May. Up until this point we have been operating solely as a virtual team with many Zoom meetings and phone calls.

#### **Some activities since 12 March 2020:**

- The Ehlers Danlos videos have been completed. Captioning has just been complete. This took longer due to lock down.
- The PIC team was originally working with the primary care team for the 2020/21 co-design programme with Dr Lynne Maher. We were also planning some 'pre-workshops' before 30 June to socialise the concepts with the teams who were successful applicants.
- With the primary care team needing to re-prioritise, we are now predominantly going to run the co-design programme with input from the primary care team. We are currently looking at pushing out the start date to September/October 2020. There is a strong interest from primary care to participate.
- The Quality and Safety Marker (QSM) for consumer engagement continues to be progressed, and the form will 'go live' from July 1.
- We are scheduling interviews (subsequent to delivering a survey monkey) with previous co-design participants to understand the barriers and enablers to socialise the spread of co-design in the health and disability sector.
- The PIC programme plan for 2020/21 has been complete and was sent to you all.

#### **Some meetings since 12 March 2020:**

- The PIC team provides coordination and support to the Rainbow Network of the HQSC.
- The PIC team has been regularly supporting and providing advice and support to the Maori Health Outcomes Team, the trauma team, Advanced Care Planning (ACP), and primary care programmes, and working with the intelligence hub on the QSM.
- On 30 March, Chris and Deon met (via Zoom) with Kevin Harper of the Ministry of Health to discuss consumer engagement across mental health services in the COVID-19 context.
- 1 April and 20 May: the QSM for consumer engagement reference group met with the team via Zoom.
- 16 April: The Consumer Advisory Group to the Commission's board met.
- 19 May: Chris, Deon and Dez met Ruth Large (via Zoom) who is the chair of the New Zealand telehealth leadership group. Telehealth will become more of a focus for the system in the future. The group sits under the Ministry of Health's data and digital group. It promotes the use of telehealth in the provision of health care and advises the Ministry of Health on telehealth priorities. Chris and Deon were invited to join the group.

Chris added that PIC are setting up regular zoom meetings with Consumer Council Chairs/deputy chairs around the QSM – providing information, outlining the background, and supporting the implementation of the QSM etc. Russ and Renee fed into this conversation. Russ mentioned that as a result of COVID-19 the need for the QSM was highlighted and well received by WCDHB.

#### **4. Feedback on Last Board and Consumer Advisory Group (CAG) huis.**

Martine gave an update on the CAG meeting. This update is included in Martine's notes. She spoke about how the CAG was adapting to the processes at the Board level. Commented on the limited time frames for processes and decision making and this level.

Chris gave an overview of the board meeting. Chris mentioned the makeup of the new members and Gillian spoke to this. A lot of discussion was on COVID-19 and how our SOI and SPE is now being adjusted as a result of COVID-19. Our bid for additional budget did not eventuate. The Board Chair (Dale) would like more regular and shorter meetings in future.

It was noted new members are very supportive of consumer and their needs.

The preference is for zoom meetings as opposed to person to person

Both Camron, Vishal and LJ raised concerns and commented on the need for person-to-person hui. Other mediums have their place but cannot replace this personal approach to hui. This point is important and was emphasised by other general comments from the group. Chris assured the meeting that she would be including person-to-person hui for consumer network hui. Fiscal restrictions were acknowledged and noted. Bernadette talked about the constraints of interacting difficult. Don't let \$\$ be an obstacle to this. Pacific community want to engage in person. Marlene also mentioned the desire for face-to-face as much as possible.

Mention was made of using the word zui and that we first heard it from a range of Maori. Some Maori don't agree with the term, while others are fine with its use. This reminds us of the fact that not all Maori are the same, and we can't treat everyone the same.

Russ asked if a connection between Consumer Councils and the CAG can be established and how these local groups can feed in. Gillian explained the purpose of the Statement of Intent (SOI) and Statement of Performance Expectation (SPE) and who feeds into it. Not really the platform to include specifics of consumer councils. However, the proposed QSM consumer council chair/deputy chair meetings may open some dialogue to discuss how this might be organised.

## 5. Effects of COVID-19

**Marj** reflected on her experience with her new diagnosis. How will future viruses affect consumers - specifically cancer patients. Using this recent situation as a learning experience. she felt there wasn't any input sought from cancer consumers.

Chris then talked about us inviting consumers to share stories from their COVID-19 experiences and what they'd like to see for any future situations.

**Marlene** issues with people that couldn't get to their appointments and the impact of this in people identified - getting sicker. Trying to maximise the outreach services for their consumers in primary care. For consumers, using telehealth was great for advice. The helpline really helped people. A bit tricky in directing people where to go.

**Bernadette** thanked everyone for the good wishes and congratulations on receiving her MNZM in the Queen's birthday honours. She also supported the conversation around meeting face-to-face. Involved in the COVID testing centre in her area. Peoples concerns were centred around the need for food parcels, but preference for food vouchers so people could be more independent about the food they selected. . She had input into community responses into the Government select committee group on COVID 19. Her community realise they can't do everything alone and so are reaching out to other organisations, including churches, to work together. Government response was good for them to make assistance easier.

**Hyejung** was contacted by many in her community about the effects of COVID-19 and family not being able to contact each other's/detail issues.

**Mark.** Family member in pain and procedures postponed. Couldn't be done locally. Great communication in getting them to Christchurch under trying circumstances and how District Health Boards (DHB's) worked so well together.

**Vishal.** In the Asian community, extra work with DHB and Primary Health Organisations (PHO's) due to direct messages that were being received around resources and these needing to be translated. Had opportunity to do some radio advertising and also dealing with some racial issues with police to assist in bridging the information gap (translations). Many food parcels delivered. So great to see all different communities come together for the one purpose. Personally, not a good experience with a family member's illness and how the system treated her.

**Martine** thought that some disability services suffered during COVID. Larger providers not having personal protective equipment (PPE) for in house help. Providers questioned if people had been self-isolating. Was it safe to go into people's home to provide the services? There were inconsistencies in providing services. People with private assistance were better off than those relying on larger organisations. Other services were good. e.g. free taxis till end June.

**Camron.** Locally providing manikitanga like a tent with cuppa tea while family members went for hospital appts. Noted the service of bronchiectasis didn't operate during COVID and they had to work around with zoom support. Worked around providing support for services that were affected by lack of in person appointments.

## **6. Questions on Consumer reports**

There were no questions

The written reports are listed below:

### **Mark Rogers**

Our DHB as part of a Consumer Engagement project engaged with local Maori at the Arowhenua Marae. This included a Powhiri where our Board were invited.

At a separate session, small groups discussed Maori health today and into the future. The focus being the views of Whanau Maori.

Although in the early stages, we are reviewing how consumers can benefit from different delivery of their Primary and Secondary care.

Consumer Council structure. Our team reviewed reporting lines and Terms of Reference.

Promoted to our Board, Chief Executive and Consumer Council that our DHB has Consumer Network representation

HQSC has actively been promoting Korero Mai

### **Korero Mai**

This aim of project is to develop an escalation of care pathway for patients/family/whanau within our hospital when there are concerns about a deteriorating patient. Patient surveys were carried out on the medical/surgical wards about whether there were barriers to communicating concerns. Staff were also interviewed. The project team agreed on preparing a brochure and poster for waiting areas/wards/bedsides communicating the pathway in which concerns can be expressed to clinical staff. This involves: 1) speaking to your nurse/doctor, 2) speaking to Charge Nurse Manager/Duty Doctor and 3) ringing a phone number and speaking to the Duty Nurse Manager. The brochure is in draft form awaiting finalisation. Also discussed was having a sticker containing the escalation steps and tick boxes to go into the clinical record. It will be tested on a ward before being implemented throughout the hospital. The intention was to have this completed by June 2020 but due to Covid-19 this will be delayed

### **Hyejung Kim**

Attended, as a member, the Korean Society Committee meeting on 23 May 2020.

Suggested to run a health workshop for Korean.

Introduced the HQSC Consumer Network and my membership of it.

Explained HQSC and discussed running a workshop to provide information on NZ health services such as GP roles, ACC, ACP, eligibility for public health services, elderly care etc.

The workshop is scheduled on 28 July 2020.

Topic: ACP, Dementia (prevention and care), Eligibility for publicly funded health services and PHO

Meeting on 2 June with a director of Korean Catholic Radio

Explained HQSC and discuss radio session for Korean – provided Health information

### **Joanne Neilson**

Attended the Christchurch Pride meeting on 16<sup>th</sup> March

Discussed my role on the HQSC Consumer Network. The lockdown happened so quickly I have not been attending any other meeting.

### **LJ Apaipo**

23 April - Acute Theatre workstream meeting in Dunedin to discuss the different trials that have taken place and discuss the space allocated to the acute theatres in the new build.

4 May - whole building block and stack meeting to share the concept design of block and stack for the entire new build and conversations about the SoA (Schedule of Accommodation). All community advisors were present and raised questions about different areas of the proposed new build.

6 May - Mortuary Services, concept design 1. Discussion about the new mortuary services design plan. Frustration raised about this being the third lot of architects that have been involved with the plan, meaning that we have wasted millions of dollars just in planning. Queries about having ING specific spaces and lifts for tupāpaku and having the appropriate access points, that do not cover communal areas for the respect of the deceased and their whānau. Discussion about the fact that this hospital needs to be future proofed and ready for the next 100 years, to be able to cater to the Māori, Pacific, and other ethnic communities that have very specific rituals in the preparation of their dead.

13 May - endoscopy and procedures unit groups session Question and Answer. This was another space where we discussed the transferring of patients from procedure units without public thoroughfare at any point in their inpatient journey, other than when they report for surgery prep.

All of these meetings have been good feedback. Has been compiled and received well by the teams, and they are taking into consideration the requests and explanations about cultural practices and why it is not appropriate for certain things to take place.

### **Marlene Whaanga-Dean**

Worked from home through Covid-19, volunteer for packing hygiene packs (Whanau Ora) delivery with local iwi and local police completed 2,200 deliveries since lockdown in the Wairarapa.

Volunteer for EOC Wairarapa helpline call centre.

## **ZOOM meetings**

- 9/04/20 Staff hui by ZOOM **Whaiora** – working from home making sure my clients/whānau are coping under COVID lockdown. Using our community nursing support to check up on elderly clients that have no phone or whānau to check up on them.
- 15/04/20 networking - Kahugunu ki Wairarapa iwi lessons with Mariana Mutu to organise food/heating for kaumatua/whānau.
- 16/04/20 Te poumatakana, whānau direct funding (urgent support for whānau) Naomi Waka Trainer.
- 22/04/20 training for EOC Wairarapa helpline to set up Awhina excel sheet for call centre
- 22/04/20 zoom Pae Ora team hui
- 30/04/20 zoom Pae Ora team hui
- 07/05/20 zoom Consumer Council WDHB
  
- Volunteered to work for Environment of Care (EOC) call centre Wairarapa area, working four times a week with allocated hours to help navigate people/whānau to services for support/help. Food had been a focus point for whānau during covid-19, and extra blankets. Some loss of jobs.
- Contacting clients on a regular basis and making sure we are available by phone to support and help during lockdown. Whānau had my number to make contact if it was urgent.
- Te Poumatakana - Using Whānau direct funding applications for vulnerable whānau (Māori) to support with extra food and resource's for children with asthma/eczema, new-born babies for treasures/milk powder/heating etc.

## **ISSUES/CONCERNS: Feedback from working on Wairarapa Helpline**

- A struggle of transport availability for individuals to attend Wellington Hospital appointment follow ups, especially for the elderly that relied on St Johns and Red Cross transport. Nothing was put in place to accommodate these appointments.
- Support for our Pacific whānau (language) for example Samoan community (English is second language) communication not understanding Covid-19 lockdown Level 4 at the beginning. Accessing support of services and food parcels became worrisome for our Pacifica whānau as partners had been laid off work.
- Mental health – helping those through isolation became challenging.
- Single/solo mums struggling with limited money not able to buy in bulk during Level 4 COVID-19.

## **Achievements**

- Medications pharmacy free delivery for consumer
- Using our community nursing support to check up on elderly/kaumatua that had no phone or whānau to check up on them was great.
- Whaiora - Contacting my clients making sure we are available by phone to support and help during Covid-19 - L4. Whānau have my number to make contact if urgent.
- Whaiora - Whānau direct applications and training to support whānau for emergency needs
- Whaiora – Drive through flu vax completed up to 80% vaccinated during Covid-19.

## **Martine Abel-Williamson**

23 March, 27 April and 25 May 2020. Meeting with Auckland District Health Board (ADHB) Patient and Whānau Centred Care Council (PWCCC).

I was asked to provide an update to this group on the HQSC's work in the following areas: Korero Mai, Quality and Safety Marker (QSM), Patient Safety Experience survey and around its success re linking various consumers from DHBs at national level for all to learn from one another. We're now busy finalising our recruitment and induction guidelines and resources, and some of the content of the Commission's Consumer Training Guide are being included.

April 2020 - HQSC Patient Deterioration Leadership Group

Attended as consumer rep:

We provided input into some DHB's resources such as to do with Advanced Care Planning (ACP). Discussing ACP with family and friends during the period of COVID-19, plus forwarding to them the ACP article, published by HQSC in its regular publication for the medical profession as well as for consumers, proved to be very well received and timely.

16 April Meeting: HQSC Consumer Advisory Group (CAG)

Participated as rep to Consumer Network (CN):

The group reflected more on the Commission's Statement of Intent (SOI) and Statement of Performance Expectation (SPE). I've already drawn the CN's attention to these items as they've been under discussion for some time now. We do feel we're overall on the right track at high strategic level.

New board members have joined the Commission, so, it will be interesting to experience the impact of this new group dynamic.

Some mortality review reports have been discussed again and one of the CAG members raised issues around Folic acid and its inclusion into our diets and whether these reports make strong enough observations and recommendations around that.

Meeting: Family Violence and Sexual Violence Pandemic Working Group

Date: weekly on Wednesdays

Participating as the Disabled Persons Organisations (DPO) Coalition's representative:

All the government agencies and crown entities already involved in the Joint Venture (JV) to do with family and sexual violence are on this group. Pauline Gulliver is the commission's rep.

Items I've circulated to the CN on behalf of this group include: - Recommended Prerequisites for non-specific service providers re handling family and sexual violence, new initiatives such as the "Silent Solution" for persons to contact the police when they're not in a position to talk, etc.

Items in general:

Other items I've forwarded to the Consumer network (CN) over this past quarter for all to utilise in COVID-19 times:

The Total Mobility™ Scheme solution during COVID-19 for disabled persons which means that many disabled persons have access to free taxis until 30 June in the light of many not being able to use public transport, for instance if a bus driver only opens the inaccessible back door of a vehicle to adhere to physical distancing and so that blind persons do not have to struggle knowing where others are in order to maintain social distancing requirements.

In April I circulated to all the launch of the Paerangi website. The Commission, amongst other government agencies and crown entities were invited for their resources to be promoted via Paerangi in various accessible formats. This has received a very good uptake. Here is the link to their website: <https://paerangi.nz/>

**Russ Aiton**

The focus of Consumer Council West Coast has been the availability of members to support Leadership teams during the COVID-19 lockdown and transition to the current (expected) Level 1.

The opportunity to discuss the HQSC QSM for Consumer Engagement has enabled this document to be communicated to the Operational Leadership Group (OLG) and specifically in the Clinical Advisory Group (CAG) which is tasked by the Emergency Operational Team to look at the impact of “unintentional consequences”. The demonstrable of actions taken by the DHB in facilitation of the transition back to Level 1 and the new Green status have been held up against the QSM framework.

I have been able to outline the HQSC activities focusing on Consumer Engagement and advised the General Manager and OLG that HQSC will be supporting DHB’s with this QSM and that as Consumer Chair, I am involved in that process.

Overall, the QSM Consumer Engagement has been well received and the value of reflection during the COVID-19 transitions in providing health services has been embraced by the General manager (GM) and OLG.

#### Monthly Meeting with Philip Wheble General Manager

- discussed Consumer issues and how communication is managed to Communities
- Introduction (ongoing) and outline of the HQSC QSM Consumer Engagement and top view of opportunities to assess WCDHB current standing against the framework
- Re-engagement plan of Locality Managers and Consumer Council introducing the QSM to the regional consumer groups as a work (intended) plan
- Planning for HQSC Team visit and ensuring availability of OLG Clinical Advisory Group

#### Weekly meeting - Brittany Jenkins - Director Nursing representative to the group, specifically to

- provide the consumer lens in proposed transition and potential changes to health services provision
- Presented the HQSC QSM Consumer Engagement document and outlined the intention of GM and OLG
- Mental Health In Patient Unit (IPU) planning. Meeting as required.  
Involvement as Chair in the preparation of the Business Case to the WCDHB Board for the new IPU facility on campus. This has been time critical and involved a lot of off-line work by the project team to meet the deadlines. This is ongoing and no clear opportunity for HQSC in this area yet.

#### HQSC Projects - Zero Seclusion/Connecting Care Weekly meeting/updates

- Ongoing work around Plan Do Study Act (PDSAs) and focus on Consumer journey and Whanau involvement
- Opportunity to join Zoom updates with HQSC

I look forward to the challenges in presenting further the HQSC QSM Consumer Engagement document and how DHB’s will approach this requirement. I hope to be able to both learn and contribute my own experiences to the HQSC Consumer Network.

### **Bernadette Pereira**

Been an extremely busy two months pre-COVID-19 and during lockdown of 4 weeks working closely with the Southseas Healthcare Trust Board and staff to ensure that our 6,000 plus clients/consumers were taken care off during this time.

Our Board was divided into two teams, one working with the clinic, the other working to ensure that staff (essential workers) were provided with relevant gear especially frontline workers who



were also deployed in supporting the Community Based Assessment Centre (CBAC) for COVID-19.

Working on the COVID-19 welfare packages for staff, allocation of 32 staff between, the clinic, social services, and the CBAC Clinic which included the clinicians (doctors/nurses). Worked with HR Lead in providing IE contractual support, and supported workforce during lockdown period.

The organisation also set up a food bank which was a collaboration with providers within Otago that provided basic social support to the general public as they queued up for testing at the Otago CBAC. The CBAC is still operational up to the end of June.

Following post COVID-19, Southseas Healthcare now heads a community 'hub' where families, and consumers/patients continue to use it as a centre where they can access not only health care but also social and basic needs.

### **Camron Muriwai**

Northern DHB - Consumer Meetings

All face to face meetings were cancelled until further notice. Providing email/feedback to information/pamphlets being designed.

COVID-19 (Marae)

Involved with our local marae collective in providing food/kai parcels to the elderly and young families. This included organising a marae base to work from, volunteer workforce, delivery and clean up. Funding provided by our Runanga.

COVID-19 (Church)

A coordinator role keeping in touch by email, phone call/mail drop off to our community and providing spiritual counsel, resources information or other support as required.

NDHB - Chief Nurse and Midwifery Officer

Newly appointed to the position: Maree Sheard.

Maree is currently a Senior Lecturer at the School of Nursing, Massey University and has extensive operational and strategic management experience together with an in-depth knowledge, wealth of experience and passion for nursing.

### **Marj Allan**

In February I was diagnosed with Multi Myeloma and started treatment two weeks before lockdown. My husband learnt to do my injection (part of my treatment and has continued to do this). Lockdown was really hard for us. Got put in the old persons category, groceries delivered, really missed having my family visit when I was not feeling well, then an infection and cough got me to have a test which was scary. Thought it came in the cornflakes.

The Doctor did telephone consultations which worked well to a point but when I was really struggling it was hard for me to portray how I felt. Interesting times especially for a consumer who felt "I've got this".

As you may be aware Cancer diagnosis was put on hold so sadly there is a big catch up for those whose cancer was moving on while they had to wait. I just hope they get some priority.

This is my last meeting, so I want to wish you all well going forward. The group has come a long way over my time as a consumer in this great team.

I want to acknowledge Chris, Deon and Dez for their amazing commitment to this consumer group.

### **Renee Greaves**

Slow progress due to COVID 19, majority of the team were seconded into COVID 19 activities, we have been working on clarifying our internal process for collecting submissions that would help form our National upload for the QSM, comms plan for Internal socialisation. Finalising a small-scale test with two services/ dept before a full stocktake is undertaken.

Remainder of activities were around supporting our Counties Manukau Health Consumer Council members through COVID 19 both personally and as a council. We have been operating via zoom for our April/ May and June meetings.

Five new members to join our team in the next few months just finalising recruitment that had begun before the lockdown.

### **7. Programme Plan for 2020/21**

Deon present the PIC plan and how it tied in with the SOI/SPE.

Reiterated capturing narratives of people's experiences on video of the good and what can be improved from COVID-19 from the consumer perspective.

Qualitative analysis of the primary care survey will be done in house.

A small resource is set aside to promote work done by members. Reference to Te Rina's.

Telehealth is also a focus now due to this becoming prominent during COVID for video and phone appointments.

Education and training on Te Tiriti o Waitangi is scheduled.

Co-design in Primary care with a focus on health equity.

Supporting Consumer Councils

Roll out of QSM and supporting DHB and Councils on the input of data etc.

Deon and Chris expanded on the co-design history (for new members) and the upcoming programme.

For more detail see the plan.

### **8. Other business and reflections on the day**

Chris gave a breakdown on the proposed Te Tiriti o Waitangi workshop, date commitment etc.

Holding dates to be sent out via invite. 10/11 Nov.

Also, to send Consumer Council chair spreadsheet for updating

### **9. Promotional material on Patient Safety day**

Jane and Falyn gave a rundown on the history and what is proposed for Patient Safety Day. There is an emphasis on COVID-19 including mental wellbeing of consumers and health workers.

There will be social media around this day as well. DHB's will be given a heads up of what we are doing.

There was input and questions raised around the programme and material for the day. An invite will be sent to the group for 1-2 interested members to be part of the "Patient Safety Day 2020 ideas group" meetings.

## 10. Close

Before closing, Chris gave acknowledgment to Marj on her dedicated service to the network and all the consumer work she has done around Cancer.

Chris then closed with a Karakia

### **Actions list**

<b>Date</b>	<b>Item</b>	<b>Action</b>	<b>Responsibility</b>	<b>Outcome</b>
12 June	8	Send invite for 2-day Te Tiriti o Waitangi workshop 10/11 Nov	Dez	Actioned
12 June	8	Send DHB Consumer Councils list for any amendments	Dez	Actioned
12 June	9	Invite for Patient Safety Day 2020 ideas group	Falyn	Actioned