Minutes of the Consumer Network meeting held on 7 March 2018, at The Health Quality & Safety Commission, Pounamu, 17-21 Whitmore Street, Wellington 6011



Present:	Chris Walsh (Chair), Deon York, Traci Stanbury, Ezekiel Robson, Shaun
	McNeil, Marj Allan, Courtenay Mihinui, Renee Greaves, Shreya Rao, Te
	Rina Ruru, Diane de Rochester (Minutes) – HQSC

Guests: None

Apologies: Martine Abel, Gillian Bohm – HQSC

The meeting commenced at 9:30am

### 1. Introductions and welcome

Chris welcomed everyone to the meeting and outlined the agenda

### 2. Minutes of the meeting held 23 November 2017

The minutes were confirmed as a true record

### 2.2 Actions update

The actions list was considered and updated.

## Actions:

- Follow up item 4 23/11/2018 with Lizzie. Interviews have taken place and Stephen has taken notes. Needs to be completed Chris
- Health consumer councils of NZ. Contact Graeme Norton to see what the Commission can do to assist. Chris

#### 3. Commission Partners in Care report

Deon went through this report which was previously circulated to the Network.

- The CAG to the board met with the board at its last meeting of the year on December 1. It was attended by 3 of the consumers on the CAG, Rowena Mortimer, Martine Abel and Frank Bristol. The Partners in Care team put together a paper in preparation for this meeting.
- The Commission's Consumer Advisory Group to the board met on 8 February 2018 to discuss the input to the next board meeting, including the Statement of Performance Expectations.
- Chris discussed a Commission programme for training consumers as an SPE deliverable.
- The board at its meeting on 22<sup>nd</sup> February 2018 confirmed the appointment of Muriel Tunoho as the fourth member of the group, representing Maori/family whanau views.
- The co-design programme second workshop took place in Tauranga on 13<sup>th</sup> February 2018. Six teams are actively engaged in this programme.

- The 'Raising the Bar Interventions' at various DHB sites are well under way. Nelson-Marlborough DHB is doing follow up phone calls, Waikato DHB is doing the home safe checklist and Northland DHB is doing the transfer of care/discharge summary.
- The *Let's talk forum* has taken up much of our time. It takes place on 8<sup>th</sup> and 9<sup>th</sup> March, 2018 at Te Papa. Registrations are full, we have 240 attendees excluding staff and speakers.
- Presentations and meetings have continued to be part of our core activities and we have responded to a number of complaints and queries from consumers about treatment and care concerns.
- Deon raised the idea that the RACP is looking to put together a consumer advisory group. They are asking for suggestions and CVs. The group discussed this briefly and Chris asked them to send their expessions of interest and CVs.

# Actions:

- Send outcomes and notes from CAG to the Consumer Network Di
- Put together a list of potential candidates and CVs for the RACP consumer advisory group. Deon

## 4. Consumer Network Reports

## Traci Stanbury

Across the South Island Alliance Child Health they are now focusing on the first 1000 days for mental health, which includes the year before birth. This is a great step but does miss the mark on the mental health of current child and youth as their services are only funded to catch the top 3%. The Healthy Weight project for children originally consulted with stakeholders but had a low retention rate of patients completing the full course. After consulting with consumers directly they created a condensed version of the programme over a couple of weekends and achieved full participation and rave reviews. Traci thought it was a great example of how co-design can work.

Traci mentioned on the day about Positive Deviance and how it had worked in Vietnam and the group are looking at this for the Healthy Weight in children project. Link follows: <u>http://fearlessleadersgroup.com/blog/the-story-of-a-positive-deviant/</u>

## Courtenay Mihinui

On February 26 Courtenday Co-facilitated a Shared Goals of Care in Acute hospital settings forum with Laura Ellis, Jenny Hill and Alex Psirides.

This was held at the Intercontinental Hotel in Wellington and was attended by about 10 people. The discussion was riveting and everyone had very different experiences and perspectives.

Some points we discussed were What matters to you? Who should have the conversation about options should there be a deterioration in the patient? What has worked/not worked in your experiences?

Courtenay enjoyed this forum very much and looks forward to seeing what issues were identified from their discussions.

On February 27 Courtenay attended a Exploring the "why" of Clinical delays workshop held at Brentwood Hotel in Wellington. This was attended by many people including Professor Alan Merry, Chair of HQSC.

A few of the presenters were Clinicians and there was also the opportunity to present as consumers about their perspective on delayed diagnosis.

Courtenay was particularly interested in the presentation by Peter Jansen, clinical lead treatment injury at ACC, as his talk was very relevant to her and her family.

Courtenay also enjoyed the Unconferencing part of the day and her fellow colleagues on the consumer network, Te Rina Ruru and Ezekiel Robson felt very empowered to give their opinions.

### Marj Allan

The CCNZ is hoping that a teleconference with the Ministry of Health next week may stimulate some work for them, as it has been quite quiet since the change of government.

The Radiology Working Action Group is moving closer to going live with the National Data Set they have been working on for over one year. This is the first of its kind and is believed to be the template for more systems to follow. Marj's concern is that it doesn't have any data collection points for the patient experience, as it is purely clinical. Hopefully going forward they will be able to include this.

The inpatient experience survey group met and they are continually trying to make the survey more user friendly. A survey has been completed however, mainly focused on Maori and Pacifica. Since then it has been suggested that the survey needs to be translated into these languages. This is a very costly exercise and one would wonder how much more input this would generate. There is also a need to get the GPs to use the data they are receiving, to date there doesn't seem to be a lot of this.

Marj is on the National Travel Assistance Advisory Group. The have had two get togethers so far and are gradually getting to a point to agree on all the areas that need improvement. The group realise that the improvements are going to cost more for the DHBs so they are collecting Patient Stories to show how the patient is being affected. They also know that there are other areas of cost for the DHBs if the patient's do not attend appointments, so they need to try and find out the ripple effect here, which has never been measured.

#### Ezekiel Robson

Ezekiel attended the HQSC Exploring Clinical Delays workshop on 27 February. One topic mentioned was 'patient-focussed booking' which did not sound all that related to patient-centred experience.

Deon indicated this will be a topic to bring back for future discussion with the consumer network.

### Shreya Rao

Shreya has been asked to speak at the Asia-Pacific 13<sup>th</sup> Biennial International Mental Health and Addictions conference in Auckland late October/Nov. The keynote presentation will be on youth perspectives of mental health

Shreya organised for a few Asian youth from Waitemata to take part in a video showcasing the importance of cultural competency and highlighting our online cultural training. She was also interviewed on her perspective on cultural competency. The video is the first one on this page: <u>https://www.ecald.com/about-us/videos/</u>

Their leadership teams have received training from David Price on utilising co-design in their services. Shreya is currently undertaking two co-design projects in their community

Waitemata Stakeholders Network YAG – the Child and Youth work stream have recruited seven young people to help co-design a systemic plan for mental health and addictions services. We have had four youth-only sessions and one co-design session with staff. As part of the commitment to work towards a Positive Youth Development approach, Shreya has linked them in with a series of external opportunities to provide their perspective. This includes supporting the Health Promotion Agency with evaluation of their four year plan with Like Minds, Like Mind.

One project is still in the interim stage, we are looking at co-designing service improvements for people transitioning between community and psychiatric wards.

The Mental Health Foundation is developing a resource for adults to talk with young people about suicide. They are having a range of consultation workshops with interested parties across New Zealand. Shreya met up at an Auckland workshop with a range of young people and adults working with youth to provide her perspective.

#### 5. Let's Talk Forum

The Consumer Network discussed the 'Let's Talk forum and made plans and gave ideas for the next two days.

#### 6. Experience year – Improving experience every day, everywhere, for everyone The Network discussed the paper which Renee tabled at the meeting.

It was agreed that this was an excellent document, which covered a wide range of areas, and showed how much work was being done in co-design and consumer centric work.

This document would be a very valuable resource for the wider community and it was agreed that a link to the document would be loaded onto the Commission website.

#### Action:

Arrange for a PDF of the Experience year, 2017 paper to be loaded onto the HQSC website. – Di

# 7. General business

• New members – it was agreed that there was a need for two more members of the Network and the group discussed how this could be achieved. If there are any opportunities amongst attendees at the forum the Network will make contact and get names and details.

# Close of meeting 3:10pm

# Next meeting: 21 June 2018

Actions:

Date	Item	Action	Responsibility
7 March	6	Arrange for a PDF of the Experience year, 2017 paper to be loaded onto the HQSC website.	Di
7 March	4	Send a link to the article on Vietnam and the community programme to support nutrition.	Traci
7 March	3	Put together a list of potential candidates and CVs for the RACP consumer advisory group.	Deon
7 March	3	Send outcomes and notes from CAG to the Consumer Network.	Di
7 March	2	Health consumer councils of NZ. Contact Graeme Norton to see what the Commission can do to assist witht their group.	Chris
7 March	2	Follow up item 4 23/11/2018 with Lizzie. Interviews have taken place and Stephen has taken notes. Needs to be completed.	Chris
23 November 2017	4	Renee to put together information around the consumer council of the CMDHB for the Comms department to send out to stakeholders and community.	Renee
14 September 2017	5	Have Ezekiel teleconference into a CAG meeting to discuss the issue with non- consumer representation on the DHB Boards.	Di / Now prior to 3 May Board