



- Present: Kula Alapaki, James Ahipene, Te Rina Ruru, Courtenay Thrupp, Traci Stanbury, Martine Abel, Allison Franklin, Renee Greaves, Shreya Rao, Ezekiel Robson, Marj Allan, Mary Campbell, Vicki Culling, Diane Aaltonen (Minutes) – HQSC
- Guests: Gillian Robb, Sarah Upston - HQSC, Jane Bawden – Consumer Representative (*Item 4*), Liz Price (*Item 5*)
- Apologies: Shaun McNeil, Gillian Bohm. Renee Greaves

The meeting commenced at 9:00am

1. Introductions and welcome

Chris welcomed everyone to the meeting and the committee was asked to send any conflicts of interest to Di.

Chris acknowledged Allison leaving the Network and thanked her for everything she has done. Allison has been with the Network for just over two years.

1.1 Minutes of the meeting held 9 December 2015

The minutes were confirmed

1.2 Actions update

The actions list was considered and updated.

2. Brief activity reports from Consumer Network members on Commission work

Allison Franklin

Participated in a video with the DHB around patient experience and will still be doing some related consumer work in Canterbury. Ngaire Dawson is doing making the video and the Network will be able to link into it.

Courtenay Thrupp

Courtenay recently attended the Henry Marsh Forum and found it to be an amazing experience. She really felt the Consumers were are the forefront of the forum, and it made her feel like “a rock star”.

Ezekiel Robson

Ezekiel was pleased to note in January on the Health Quality & Safety Commission website; the study by KPMG around Pressure Injuries. He has wanted to see a focus on this and found it valuable to see the work which was being done.

Ezekiel was asked to join the Window on Health Quality Working Group for reporting on various strands of work i.e. atlas groups, and other data to get a view on current quality standards. He will provide ongoing updates and the next refresh of the report will be on the website in a couple of weeks.

Ezekiel further suggested that targets are set for suicide prevention in the future, with DHBs putting more focus into this.

James Ahipene

The new mental health unit open, called Nga Rau Rakau which is the name of a collection of tree.

James has been working on a seclusion project so that fewer consumers get secluded and those that do spend less hours in seclusion. Along with this he has also been working on Single Point of Entry so that consumers do not have to tell their story several times and to more than one person.

Kula Alapaki

Kula will be attending the Patient Health and Safety Week Workshop in Auckland 11 March which is being organised by Counties Manukau District Health. Chris and other members from Commission team are also attending this workshop.

Kula is also attending the workshop with Dr Jeanne Huddlestone - Deteriorating Patient at the Langham Hotel in Auckland on 22 March.

Marj Allan

Marj accompanied Chris Walsh and Deon York to the Grand Round on the West Coast of South Island prior Christmas. This was well received and highlighted the extreme effort it was to visit all the DHBs throughout New Zealand. She believes that this gives the Commission a great profile and brings the Commission's work to the ground roots of our communities. Engagement with Consumer work has certainly tied in well with the National Health Plan, highlighting the importance the consumer voice at all levels.

The National Cancer Consumer group invited Chris along to inform the group of the work the Commission is doing. The group was keen to continue to be updated on new initiatives going forward.

Marj also attended the Henry Marsh Forum on behalf of the Consumer Network for the Commission and found it to be a very enjoyable and positive experience.

Martine Abel

Martine took part in face to face meetings as a consumer rep on the "Deteriorating Patient Expert Advisory Group and expects that these meetings are going out further with the Commission. Martine felt she was able to contribute however she found it to be quite

challenging. A large amount of it was about de-escalation, and there were a lot of acronyms which were tricky. Martine believes that doctors should be more open with patients, rather than put off talking about pending death.

Mary Campbell

Mary has been asked to trial the Patient Portal Initiative by her primary health provider. This portal has been designed for people with long term health conditions. She also attended a three day fono around Pasifika Disability and Mental Health and Addictions. The overall conclusion was that Pasifika need to be treated with a more holistic approach.

Mary has been promoting the Health Literacy Paper by the Commission amongst her networks. She also attended the Henry Marsh Forum, and like others on the Consumer Network, found it to be a very informative and valuable experience.

Shreya Rao

Shreya is involved in designing and delivering (in conjunction with youth in the area), two health expos for Mahurangi College and Rodney College. These areas have youth with high health needs, particularly mental and sexual health but are geographically isolated from health services they can access. The aim of the expo is to introduce the students to health services they can access, people they may meet within these services, as well as have clinicians talk to students to see what their needs are. Shreya will email a copy of the pamphlet to Chris for circulation through the Networks.

Te Rina Ruru

Te Rina has circulated a number of notices from HQSC and other members to her various networks.

At the Health Quality & Safety Commission Board meeting Te Rina share her Patient story around the effects of her Brother's head injury on him and her whanau.

During 2015 Te Rina became an ex-officio member of the Maori Advisory Board Te Roopu Maori.

Te Rina also attended the Henry Marsh Forum as a representative of the Consumer Network. She felt it was an incredibly valuable experience.

Traci Stanbury

Traci is currently working with a new national group which is developing a paediatric patient experience survey. The group is reviewing existing and emerging tools for obtaining consumer experience information from children 4 years and above. This is with the view of having a standardised tool kit to use across New Zealand and they are seeking further membership for this group to include more consumers and consumers with Maori and Pasifika descent. Any recommendations from the Consumer Network around the country would be appreciated.

Traci attended the Henry Marsh Forum and was very impressed with Libby Burgess, Consumer Representative in breast cancer and Dawn Elder, Paediatrician, who is promoting a paediatric experience survey.

Vicki Culling

Vicki is the Co-chair of a Commission committee looking at incorporating maternal morbidity

3. Commission Partners in Care report

Chris Walsh presented the quarterly report from Partners in Care with the following key points:

Patient stories continue to be presented at Commission board meetings, the most recent being a video with Lana Bartlett around the experience her father and whanau had in hospital and focused on communication. These are aimed at making the Board aware of the challenges for Consumers. Chris asked the Network to keep any speakers in mind.

Chris presented as a Key Note speaker at a Consumer Seminar in Melbourne and found it very interesting to see where NZ stands in Consumer Engagement. She will also be presenting an abstract / poster submission at the International Forum on Quality and Safety in Healthcare, from the 12th to 15th of April in Gothenburg, Sweden.

Malatest International is continuing with the evaluation of PIC and has nearly completed all the interviews. A workshop will be held with the Consumer Network at this meeting and another with staff on 4 April.

Work continues with the appointment of Consumers to mortality review committees. Scoping work for a quality and safety marker for consumer engagement has begun. The Australian Commission is keen to be involved as well.

The Henry Marsh Forum took place on 9 March with 5 members of the Consumer Network attending. This was an incredibly successful and informative event.

Chris is currently facilitating consumer reps in DHBs and EAGs within the Commission. In the area of adverse reactions to medicines, the MOH is looking for consumer input. Vicki Culling has offered to provide feedback on this in regards to her mother's recent experience. Chris will go back to the Ministry and discuss what areas they would like to receive feedback from and how far reaching this would be.

4. Serious Adverse Events – Gillian Robb, Sarah Upston and Jane Bawden

Gillian Robb and Sarah Upston from the Health Quality and Safety Commission (HQSC), and Consumer Representative Jane Bawden presented a discussion around Serious Adverse Events (SAE) to the Consumer Network.

The presentation prompted useful and in-depth discussion around potential tools to assist with this issue, including suggestions of what Consumers would like to see happen during and after a SAE. The main concern was a lack of communication and respect and the feeling of not having been "listened to".

Actions:

- SAE team to attend the next Consumer Network meeting for further discussion and updates.
- Feedback provided by the Consumer Network will be fed back to SAE group.
- Sarah to send the SAE policy to Di for uploading onto Loomio for feedback on the involvement of Consumers.
- Consumer Network feedback is to be sent directly to Sarah.

5. *Let's PLAN for better care* – Liz Price

Liz Price from the HQSC presented a discussion around the *Let's PLAN for better care* campaign to the Consumer Network.

Liz outlined the usage of the Lets PLAN sheet in DHBs, PHOs and GPs and asked the Consumer Network for any ideas on how useful this is.

The overall agreement was that it was a very useful resource, however it is believed that there is resistance from medical professionals to actually use it.

It was agreed that there needed to be a stronger push from a Consumer perspective, so that patients can arrive at an appointment with the sheet.

Actions:

- Di to send electronic copies of *Let's Plan* and Get Them Talking posters to Martine
- Di to put a copy on Loomio for feedback and suggestions on promotion
- Liz to advise when the sheet will be available on-line

6. Malatest Evaluation Workshop

Debbie McLeod, Justine O'Reilly and Vicky White from Malatest directed a workshop around the evaluation of Partners in Care.

Action:

- Di to check whether the evaluation report needs to go the Board for sign-off.

7. Programme Planning

Chris briefly discussed the Programme Plan with the Consumer Network.

Actions:

- Chris to load on Loomio for Network feedback
- Chris Follow-up with Health and Disability Commission on the Health Passport

8. DHB Websites

Di presented a spreadsheet with a breakdown of all the DHBs and the level of usefulness to, and acknowledgment of, consumers.

The Network felt this was a very useful beginning document from a consumer point of view.

Action:

- Members to send feedback to Di to incorporate changes / additions to the document.

9. General Business

Sue Ineson of Choosing Wisely is coming to talk to the Consumer Network at the June meeting. This is around how medical practitioners can talk to consumers.

Vicki Culling was granted a scholarship for Winston Churchill Memorial Trust. This programme offers scholarships for ordinary New Zealanders and application close on 31 July.

Action:

- Anyone interested in applying for the Winston Churchill Memorial Trust Scholarship to contact Vicki, who will provide information and support around their application

10. Closure of Meeting

The meeting closed at 3.54pm.

11. Next Meeting

14 June 2016

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Action List

Date	Item	Action	Responsibility
10/3/2016	4. Serious Adverse Events	<ul style="list-style-type: none"> SAE team to attend the next Consumer Network meeting for further discussion and updates. Feedback provided by the Consumer Network will be fed back to SAE group. Send the SAE policy to Di for uploading onto Loomio for feedback on the involvement of Consumers. Consumer Network feedback is to be sent directly to Sarah. 	Gillian R / Sarah Sarah Sarah / Di All
10/3/2016	5. <i>Let's PLAN for better care</i>	<ul style="list-style-type: none"> Send electronic copies of <i>Let's Plan</i> and <i>Get Them Talking</i> posters to Martine Put a copy on Loomio for feedback and suggestions on promotion Advise when the sheet will be available on-line 	Di Di Liz
10/3/2016	6. Malatest Evaluation Workshop	<ul style="list-style-type: none"> Di to check whether the evaluation report needs to go the Board for sign-off. 	
10/3/2016	7. Programme Planning	<ul style="list-style-type: none"> Load Programme Plan on Loomio for Network feedback Follow-up with Health and Disability Commission on the Health Passport 	Chris Chris
10/3/2016	8. DHB Websites	<ul style="list-style-type: none"> Send feedback to Di to incorporate changes / additions to the document. 	All
10/3/2016	9. General Business	<ul style="list-style-type: none"> Anyone interested in applying for the Winston Churchill Memorial Trust Scholarship to contact Vicki, who will provide information and support around their application 	All / Vicki