



Present: Chris Walsh (Chair), Gillian Bohm – HQSC, Kula Alapaki, Courtenay Thrupp, Traci Stanbury, Martine Abel, Allison Franklin, Renee Greaves, Shreya Rao, Ezekiel Robson, Marj Allan, Mary Campbell, Vicki Culling, Shaun McNeil, Diane de Rochester (Minutes) – HQSC

Guests: Stephanie Fletcher – Consumer Representative with the National IT Board Consumer Council (*All day*), Richard Hamblin – HQSC (*Item 4*), Sue Ineson & Derek Sherwood – MCNZ (*Item 5*), Karen Orsborn – HQSC (*Item 6*)

Apologies: James Ahipene, Renee Greaves, Te Rina Ruru

The meeting commenced at 9:00am

1. Introductions and welcome

Chris welcomed everyone to the meeting and introduced Stephanie Fletcher who is a Consumer guest for the day and is involved in the National IT Board Consumer Council. Consumer Network members introduced themselves. The members were asked to send any conflicts of interest to Di.

1.1 Minutes of the meeting held 10 March 2016

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

Courtenay Thrupp

Courtenay advised that they have a new Quality and Risk Director at her DHB who she is hoping to meet soon in order to review her role as a Volunteer Consumer Representative and what the role will entail in the future.

Courtenay has resigned from the Infection Control committee as she felt she wasn't quite the right person for the role.

Courtenay remains on the Clinical Governance and Management team and is also the Consumer Representative on the Child Health Hub design team, which she enjoys.

Recently she was asked to sit in on the Restraint Minimization Committee within the DHB which will take place later this month and she is looking forward to learning more about that.

Last month Courtenay attended a Choosing Wisely forum in Wellington for Clinicians and was thrilled with this campaign and the positive feedback, general excitement and passion the speakers demonstrated. She believes this campaign is really empowering for the consumer/clinician conversation and is looking forward to contributing to the steering committee. Vicki presented at this forum and Courtenay said she did a brilliant job.

Ezekiel Robson

After the last Consumer Network meeting, the Auckland DHBs were having a consumer rep meeting. This set a good precedent of DHB consumer groups working together. The Northern electronic health record was discussed in a further meeting which included Northland DHB.

Ezekiel participated in a project with Richard Hamblin on Window to Health, but has no further updates at this stage.

Ezekiel is talking to Counties Manukau about the 'Let's Plan' resource and on-line patient portals.

The CMDHB elections are coming up so Ezekiel is working within the community to encourage disabled people to have a say with the elections of Board members. Ezekiel will be standing as a Board member.

Ezekiel is involved in work with disabled members of the community who are confined in solitary environments as in the case of Ashley Peacock.

Kula Alapaki

Kula participated in Patient Experience Week 2016 – Consumers Representative Regional Forum organised by ADHB, WDHB, CMDHB

The main focus is for the Consumer representatives to share experiences, gain practical advice and tips on working with the DHBs and advise what the DHBs could be doing better.

Kula participated in Interview/Research around Serious Adverse Events in Health and Disability Services, issued by Louise Thornley. This survey was seeking details and inputs on strengths and weaknesses of current reporting systems and advice on how the Policy can be improved.

Kula also took part in a 40 minute interview on the phone with Caroline Gunn around SAE

Kula provided feedback to Chris on his view as a consumer on the UK website – 'Patience Opinion – Every Voice Matters' in relation to his own experience and to the New Zealand DHB system.

He also completed research on *Qualitative analysis of in-hospital patient experience*

Marjorie Allan

Marj attended one meeting for the PES Governance Group which is overseeing the Patient Experience Surveys being carried out between the Ministry of Health and the Health Quality & Safety Commission. There have been some trial surveys done and at present they are working through the results and uptake and deciding how best to present the next phase. The next meeting is Thursday 16 June so Marj will have more information by then.

Marj is also involved in the planning of an Advance Care Planning Forum to be held in Auckland on 28 and 29 November this year. Bob Fox and Chris Walsh are also part of this team and they are trying to get as much consumer input into this as possible. It is proving challenging but she believes they will make it work.

Marj participated in the SAE interview with Caroline Gunn.

Martine Abel

SAE interview with Caroline Gunn.

Mary Campbell

Took part in the SAE interview with Caroline Gunn

Shreya Rao

Shreya has nothing Commission related, however her group is looking at creative ideas for young people (POD), looking at music therapy, art drama etc., to aid with mental health issues.

Shaun McNeil

As Shaun was unable to attend the meetings held on 9 December 2015 (due to work pressure) and 10 March 2016 (as he was on holiday in beautiful Northland), he has however, tried to keep in touch with the Loomio group and ensure he could be available for future meetings.

Shaun shared his biography and contact details in September 2015 and gave feedback on the Government's Health Strategy in October. He was also asked to participate in a group looking at the HQSC's Annual Report, by Richard Hamblin. Unfortunately due to an administration error Richard didn't receive Shaun's response and the opportunity passed.

In November 2015, in response to Martine's prompt about White Ribbon Week, Shaun participated in a motorcycle event, meeting white ribbon ambassadors in the Manawatu and riding with them into Kapiti to have a public meeting, encouraging people to pledge to stop violence against women.

In December 2015, Shaun submitted a response on the Guide to the Commissioning Framework on Mental Health and Addictions.

In February 2016, Shaun sent a message to Allison Franklin acknowledging her contribution to the group as he was unable to do so at the March meeting.

Traci Stanbury

Over the last three months Traci has continued to work on the Paediatric Survey development and has been working with the South Island Alliance as they finalise their Consumer Engagement South Island stocktake. She also attended the annual Organ Donation Memorial Service and was impressed with their inclusion of 'patient' stories.

The CDHB have nominated her for the 2016 Ministry of Health Volunteer Awards and she has received the award. The Consumer Network congratulated her on this wonderful achievement.

In the coming month Traci will be preparing a submission to the Ministry of Health as they look to develop a strategy to increase organ donations. Her submission will focus on increasing social and digital media surrounding transplant donor and recipient stories with the aim of prompting a population '*culture shift*' towards more donations.

Vicki Culling

Vicki has been working with the Council of Medical Colleges on the *Choosing Wisely* campaign. This has involved attending steering group meetings, presenting to a clinician's meeting and preparing for other consultations/meetings being held over the next couple of months.

Vicki is now a member of the Ministry of Health Maternal Foetal Medicine Governance Board. There are two consumer representatives on this Board.

Actions:

- Le Va link to be sent to the Network – Di
- Supply an update to the communications team to load an interview onto the website. Chris to give Dylan a briefing. – Traci & Chris
- Follow up on the programme for Post-natal depression – Mary?
- Send feedback to Chris around the Patient Opinion concept - Ezekiel & Shaun

3. Commission Partners in Care report

Chris presented her report to the Consumer Network.

Patient stories continue to be presented at Commission Board meetings and Chris asked that the Network please consider anyone they think would be a good presenter and to discuss this with her.

Chris presented a poster at the International Forum on Quality and Safety in Health Care 12-15 April in Gothenburg, Sweden. The poster titled: '*Using consumer engagement and partnerships to drive quality improvement*' was a good opportunity to promote New Zealand and the work the Commission is doing in the consumer area.

The final web-ex for the co-design course at Nelson Marlborough and Mid Central DHBs has been completed. Both DHBs are promoting the work they are doing on co-design with the Commission through media releases and internal communication bulletins. Short reports on the work the co-design teams have completed should be available on the Commission website in the next 2-3 weeks. Negotiations are underway to invite 2 other DHBs to undertake the 2016/17 co-design programme. The programme is also being evaluated by an external provider.

Evaluation of the last 3 years of Partners in Care has been completed by Malatest International. The Consumer Network will be discussing this on today's agenda. The senior leadership team at the Commission has discussed the report and given a preliminary response. The HQSC Board will discuss the report at its next meeting in July. Chris advised that the response of SLT to having no consumer on the Board is to discuss this with the

Board or the Minister to look at co-opting for the position. The Consumer Network members believed that a Consumer member of the Board should be a full member, not just co-opted.

Scoping work for a quality and safety marker for consumer engagement is underway and the report is due mid-June 2016. This will provide the basis for considering how and when to progress this work.

A new position for a consumer in the deteriorating patient work programme is currently being advertised. The programme manager for the PIC programme has also been advertised and will be appointed once the interview process is completed.

An internal consumer champion's staff group has been set up and will have its first meeting on 22 June. Its purpose is to strengthen the consumer perspective across all our programmes, work smarter, avoid duplication of effort and gain and maintain oversight of all consumer engagement activities planned / happening across the Commission.

Actions:

- Forward names for Patient Story to the Board - Shreya & Martine
- Email Di regarding registration for WCIC4 - All

4. Aged Care Survey

Richard Hamblin presented the paper around the Aged Care Survey to the Consumer Network. He advised that this was first designed for use in hospitals, and then moved on to Primary Care. The survey asks about different specific aspects of experience.

There are four main criteria:

- Communication
- Physical and Emotional needs
- Participation
- Coordination

Richard noted that aged residential care involves the whole of someone's life. This means questions need to be asked about 'quality of life' rather than 'quality of experience'. Therefore, the Aged Residential Care Survey works towards the following:

- There needs to be an interview process
- Moved away from the regulatory area to an improvement target.
- 6 months to a year to develop the tool.

Richard discussed the issues of staffing this process. Whether outsourced or carried out by the facilities involved, which raises the concern of issues of integrity.

Feedback from the Consumer Network

- Will there be a Pacific and Māori point of view?
- Will there be reporting people's stories?
- There is a need for interviewers who are well versed in dealing with the extended families of Māori and the difficulty of interviewing them alone.
- Increased public awareness of quality indicators for aged care facilities.
- Looking at existing government areas which can help with defining what quality is in aged care facilities.
- Skilled interviewers are at the essence of this.

- Need to address issues of families not wanting older family members going into quality care.
- Awareness that Pacific and Māori have issues with shame at putting people into residential care homes so need to look at support within the homes.

Richard is taking the feedback of the Consumer Network back to include in his re-write of the paper, and the next steps are to take this through to Ministerial review.

5. Choosing Wisely Programme

Sue Ineson, Vicki Culling and Derek Sherwood presented the Choosing Wisely Programme to the Consumer Network.



CW NZ ppt to
Consumers final pptx

Feedback on questions

Do I really need this test or procedure?

What are the risks?

Are there simpler, safer options?

What happens if I don't do anything?

What are the costs?

- remove question five
- option grids for comparison
- cost of different options
- value rather than costs
- question 1, a closed question, can this be opened up?
- simpler, safer implies the procedure, medication could be dangerous or more complicated
- include test, *medication*, or procedure
- use *operation* instead of *procedure*
- include questions on what's important to them
- questions around tapering off of medication
- instead of '*what happens if I don't do anything?*', replace with '*am I choosing the right option for me?*'

Actions:

Any further feedback to be sent to Sue Ineson at sue.ineson@karoconsulting.co.nz - All

6. HQSC Strategic Alignment update

Karen Orsborn presented the HQSC Strategic Alignment update to the Consumer Network. This Strategic Alignment of the Commission follows on from the feedback the Ministry of Health received from the Consumer Network and other stakeholders to bring about the NZ Health Strategy.

7. Loomio Feedback

Chris asked that the members of the Network persevere with their use of Loomio.

8. Evaluation of Partners in Care programme – Consumer Response

Feedback

Traci – Hard reading but interesting. Useful and interesting document with no surprises. Good terminology used ‘major culture shift’. Liked quotes within the document, what is the response to these? Liked the need for induction and training for consumers. Interested in the Future Focus in the Commission - Page 21.

Courtenay – Hard read. Found it interesting because it is very new to her. Believed that consumer induction is essential

Kula – Has had a quick look but wants to go back over it, will report back within the next 2 weeks.

Ezekiel – Good document with a good executive summary. Stand outs for him were that within the Commission not everyone felt they had an equal hand on Consumer involvement; some had better intuition than others. Malatest opinion expressed a generalisation that the consumers may not have ability and experience at a governance level, and he found this generalisation to be disappointing.

Martine – Induction very important because people come in on different levels and support mechanisms. People’s values and perceptions shined through as there seems to be a belief that consumer support is tokenism. The more people excluded at Board level, the less there will be with the experience. Very thorough and interesting read.

Vicki – Making Consumer engagement a priority. Support from key central agencies is highly important. HBDHB has listening sessions and Vicki will look up the details. Believed that Co-design is brilliant and the sort of thing the Commission needs to concentrate on. Regarding consumer engagement in governance, there is a gap with consumers and those within organisations. How does the Commission educate other organisations, or model it?

Mary – Trauma based awareness training for Primary care service providers. Adverse effects: emotional/ physical/ sexual/ Mental distress and or illness/ Domestic Violence.

Health Literacy awareness rolled out to Primary health care providers.

Family with genetic dispositions to diabetes/ strokes etc. have regular check-ups provided by outreach nurses.

Culture awareness training provided to primary health care services with an emphasis on Maori/ Pasifika.

Shaun – Challenging and a little overlong. There were some things which were no surprise, particularly the difference between those who want involvement and those who don’t. Getting consumers to the governance level, not co-opted, but a full member is essential. Indicates movement in terms of a good body of people accepting consumer representatives. How to go about supporting individuals and organisations that this is the right thing to do. What can we do to advocate for increased resources?

Shreya – Active promotion of Commission training for consumers is important: need to recognise consumer networks and disseminate this information through them.

Mismatches between consumer skills and the role itself: Roles are often not flexible enough to work with the skills of the consumer.

Finding 'health literate' consumers is a reflection of what the service is doing to promote the work to our service users. Are we letting people know about consumer advisors in the first place, encouraging people to get in contact with them to find out more about their role, or building leadership capacity with those consumers who seem they would be a good fit for the role?

For governance, consumers need to receive feedback as to what is happening within the services to individual consumers, as other managers and clinical directors do. This is regularly sent to other governance members as part of their leadership roles but quite frequently, the consumer advisor is left out unless they have a good connection with staff. This is as imperative as lived experience.

Including governance, consumer advisors need to have facilitated time to meet with other consumers to discuss what is happening to them. This is imperative for understanding the issues of consumers from different backgrounds. (i.e. ethnic, age, diagnostic type etc.)

Staff briefing needs to include a component around how their consumer experience can be useful/is different. There are constant issues of contention around this.

One way of increasing visibility of consumer engagement and the HQSC's efforts is through universities who train the next generation. As the workforce is aging, it seems paramount to get into these establishments to ensure the incoming workforce is completely aware of the role of consumers and consumer engagement.

Training as a 'consumer advisor' is often not carried out but some do not need this. They could quite easily learn on the job and prefer attending normal training with staff to understand clinical components to be able to critique them. More skills-based training where it is identified what training is important.

Marj – Very in depth and long document. Would have like to see key points at the beginning of the report. 66% of people surveyed wanting consumers is not enough, but that figure could also relate to the selection of those surveyed. Partners in Care, the Consumer Network and the Commission need to be prepared for what they need to do to keep moving forward.

Action:

Send feedback to Network - Di

9. General Business

Chris reiterated that the half day before a meeting, that reading and preparation is done for that half day.

Chris further advised the group that all travel will be booked early on flexi tickets. Any changes need to be made by the traveller.

It was suggested that there could be one day of regional training for consumers

10. Closure of Meeting

The meeting closed at 3:52pm.

11. Next Meeting – 20 September 2016

Action List

Date	Item	Action	Responsibility
14/06/2016	Reports from Consumer Network Members	<ul style="list-style-type: none"> Le Va link to be sent to the Network Supply an update to the communications team to load an interview onto the website. Chris to give Dylan a briefing. Follow up on the programme for Post-natal depression. Send feedback to Chris around the Patient Opinion concept 	Di Traci & Chris Mary? Ezekiel & Shaun
14/06/2016	Commission Partners in Care Report	<ul style="list-style-type: none"> Forward names for Patient Story to the Board. Email Di regarding registration for WCIC4. 	Shreya & Martine All
14/06/2016	Choosing wisely programme	<ul style="list-style-type: none"> Any further feedback to be sent to Sue Ineson at sue.ineson@karoconsulting.co.nz 	All
14/06/2016	PIC Evaluation	<ul style="list-style-type: none"> Send feedback to Network 	Di
10/3/2016	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 - September meeting Sarah Sarah / Di All
10/3/2016	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