

Minutes of the Consumer Network meeting held on 22 June 2017, at The Health Quality & Safety Commission, Pounamu, 17-21 Whitmore Street, Wellington 6011



HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND



Present: Chris Walsh (Chair), Deon York, Gillian Bohm – HQSC, Traci Stanbury, Martine Abel, Renee Greaves, Ezekiel Robson, Shaun McNeil, Marj Allan, Diane de Rochester (Minutes) – HQSC

Guests: Hilary Sharpe (*Item 5*)

Apologies: Shreya Rao, Te Rina Ruru, Courtenay Mihinui,

The meeting commenced at 9:30am

1. Introductions and welcome

Chris welcomed everyone to the meeting

2. Minutes of the meeting held 9 March 2017

The minutes were confirmed as a true record

2.2 Actions update

The actions list was considered and updated.

Database for consumer representatives – there was discussion around the scope and range of the database. There was an agreement with keeping the internal details of the existing representatives up-to-date.

Action:

Database for consumer representatives - Add 'Region' to the Consumer form template. Sharpen the content and put out through social media and on the Commission website.

3. Commission Partners in Care report

Deon York presented the Commission report to the meeting, highlighting the following.

- The co-design programmes at both Hutt Valley and Taranaki DHBs have concluded. These are the case studies that have been submitted for the 2016/17 programme:
 - Pacific B4SC or ASH on 0-4 olds
 - Colonoscopy - bowel screening
 - Safe Surgery
 - Repeat prescriptions in community mental health
 - ED Clinical Pharmacist Role
 - Moving child bleeding to the lab
 - After hours' primary care
 - Communications around outpatients/letters

- The case studies will be posted on our website by 30 June.
- The pilot with Waitemata and Canterbury DHBs looking at the Always Events® toolkit as a first step to developing a quality and safety marker for patient experience has been completed. The draft report is still with the team and will be available to the network once we have finalised it.
- The medication discharge project has been completed. **Raising the Bar on the National Patient Experience Survey** responds to the national adult inpatient experience survey results by investigating the lower scoring areas of the survey and recommending interventions to improve these results. Four DHBs participated and provided opportunities for staff and patients to explore the reasons behind the responses to information about medication side effects and discharge from hospital through interviews, observation and focus groups. The results suggest there are interventions that could improve the experience for patients and staff and lead to improved patient outcomes, reduced readmission rates, and reduced health care costs associated with these readmissions.
- The *Raising the Bar* report details both 'quick wins' and 'big wins' to improve the patient experience of care. For instance, information about medication side effects was found to be shared in an ad-hoc manner, and mostly verbally. It was therefore difficult for a number of patients to recall important information. Currently, discharge summaries are of less value to patients and appear to be more targeted to clinician need. Ways to respond to this are discussed. The report can be accessed here: <https://www.hqsc.govt.nz/our-programmes/partners-in-care/news-and-events/news/2942/>
- A new video has been developed that explores effective consumer representation at the governance level and how this works with clinical leadership. It explores the governance model of the Board of Directors of the World Federation of Hemophilia, a board with equal representation of clinicians and patients/family. This is an example to consider for anyone setting up or developing consumer councils and other mechanisms to include the consumer voice at all levels of decision-making. It reinforces the Commission's view that consumers should be involved at all levels of decision-making in the health and disability sector. The video can be accessed here: <https://www.youtube.com/watch?v=HOBf3nYS7OE>
- Chris met with the executive leadership team of Wairarapa DHB. As a result, they are going to be one of the co-design sites for 2017/18. The other will be Bay of Plenty DHB. We are working with the patient deterioration team on this.
- We attended a conference in April, the patient voice symposium, along with Ezekiel and Traci. Chris presented at a conference in May, Healthcare Reform, Funding and Innovation. Deon facilitated a discussion on involving consumers in decision making.
- Chris will be presenting on using data to improve the experience for consumers in Malaysia in August at the BMJ International Quality Forum. Our always events paper has been accepted for the ISQua conference in London and this year's APAC conference. Deon is presenting at IsQua and Chris is presenting at APAC.

The date for our first consumer forum will be March 8/9 2018. Our first keynote speaker has been secured, Janine Shepherd. Janine was a keynote speaker at the last APAC forum and was a very inspirational speaker. The other speaker is Jake Bailey who was the young man who was head boy of his school in Christchurch who has survived cancer and has since written a book about what cancer taught him. He will be giving a youth perspective of the system. Lynne Maher is also going to give a talk about Co-Design. There was discussion around the cost of clinicians attending and also encourage “ordinary” members of the public to attend. Marj raised the idea of DHBs being able to use the attendance of staff as part of their accreditation within their system.

An entry about Janine on Wikipedia: Janine Shepherd, AM (born 7th January 1962) is an Australian author, aerobatics pilot and former cross-country skier. Shepherd's career as an athlete ended when she suffered life-threatening injuries when hit by a truck during a training bike ride. Before the accident, she had been in contention to win Australia's first ever medal at the Winter Olympics. Though she was told she would never walk again or have children, and doctors had significant doubts as to whether she would survive at all, she defied all of these, and her story later became the focus of national attention, as well as a popular telemovie.

The Network discussed the detail of the Ogilvy report *Raising the Bar*. This included the negative and lethal side effects of medication and also the new moves to limit this. The move away from the main concern being with the medical practitioner, rather than the patient.

Martine asked whether the deaths of side effects, such as constipation were happening in hospital and in the home. She felt there was great concern if this was happening in hospitals particularly and possibly more information could be brought to the next meeting.

4. Consumer Network Reports

Martine Abel

HQSC related initiative involvement from March till June 2017:

Martine participated in another Patient Deterioration Expert Advisory Group (PTEAG) meeting in June. Laura Ellis is doing a great deal of work on Co-Design. An independent agency will be doing a survey to determine how patient and whanau escalation's currently working across DHB's and private hospitals or not. There is still a great deal of resistance for this to progress. The other 2 work streams to do with measurement of vital symptoms and development of shared goals are progressing as planned. New members have joined this PTEAG, for instance representatives from within the private hospital sector.

External initiatives involvement:

Martine has circulated many community notices, funding and engagement opportunities to the panel and other constituent groups.

Martine was also appointed to the ACC Sexual Violence Prevention Advisory Board as an independent expert in the disability field. This board is still to commence most of its work.

Work planned to commence in July:

Ministry of Health - National Ophthalmology Service Improvement Expert Advisory Group member (in her role as part of the MOH Consumer Advisory Service).

At the end of June Martine will be presenting at the Vision 2017 Congress in The Hague. She is looking forward to bringing back information to share with the group in areas that will be covered such as eye health care, inclusive education research and accessible environment and transport initiatives.

Traci Stanbury

Since the last HQSC meeting Traci has been studying for my Master of Health Sciences. Specifically, she has been

- Researching communities – their strengths and how they development and support, the determinants of their health issues, how to target them with health promotion projects, and interventions for specific communities that would positively impact their quality of life
- Family resilience – the stressors that impact on family resilience and how to build capacity in the family to cope
- Carer fatigue and developing strategies to prevent it.

Traci has also been involved with the CDHB's proposal to HQSC for a New Zealand trial of a paediatric experience survey.

In April she attended the *Many Patients One Voice Patient Symposium*. Her favourite two speakers were quite different, with one motivated to build consumer alliances e.g. 16 cancer groups working together on a white paper, and getting the right people in front of the decision makers. And the other speaker was an economist with research on the economic cost of treatment delays – the cost of lost productivity, lost wages, lost taxes, increased social welfare payments, lost payments to your super scheme so you get less in retirement, and all that is in addition to the health burden caused by your condition. He has all the numbers for Australia, and they are starting to think about the full dollar cost of delaying treatments. Traci enjoyed the symposium and it was well worth attending.

Shaun McNeil

It has been seven months since Shaun has been able to attend a meeting and the major HQSC event which he was involved in, back then, has now come to fruition:

- October 2016: Shaun participated in a Mental Health Quality Improvement Forum with other leaders in mental health and addictions to support and inform an HQSC proposal to look at an improvement programme for mental health and addiction, improving the quality of mental health and addiction services. He was also asked to be a speaker at the Asia Pacific Mental Health Conference "Recovered Futures" in Brisbane, Queensland.
- November 2016: Shaun provided Suicide Prevention Training to the NZ Police Negotiation Team Training Course.

- February 2017: Shaun participated in a National Mental Health and Addictions Adult Key Performance Indicator Benchmarking Forum, where the focus was service improvement, including work towards the elimination of seclusion.
- March 2017: Shaun participated in a learning experience, spending two days working on suicide prevention at the Black Dog Institute in Sydney, New South Wales. He then attended the International Initiative for Mental Health Leadership two-day Conference in Sydney on the subject of Contributing Lives, Thriving Communities. Shaun also delivered Applied Suicide Intervention Skills Training to a mixed group of Professionals and Community members. He attended an Interrelate Videoconference with Service User/Consumer Leader colleagues from Australia, Scotland, England, USA and Iceland.
- April 2017: Shaun was pro-active in spreading information about how widespread and serious Depression is, on the World Health Organisation's World Health Day, this year focused on Depression. He also participated in a workshop developing an online peer support toolbox, Shaun also delivered another Suicide Prevention training session and he attended another Interrelate Videoconference, connecting with peers around the World.
- May 2017: Shaun participated in two Ministry of Health Suicide Prevention Strategy community meetings in May, one in Palmerston North and one in Wellington, in his capacity as an Expert External Advisor to the Ministry. He participated in the Lower and Central North Island Mental Health and Addictions Regional Leadership Network on Forensic Mental Health, which looks to identify and resolve relevant issues and link with other Regional Groups. Shaun also participated in another Interrelate Videoconference and he met with the Head of Mental Health at the Health Promotion Agency, in his capacity as out-going chair of the National Depression Initiative, www.depression.org.nz.
- June 2017: Shaun have supported the success of Mind and Body Limited (a consumer led and run NGO) in an RFP process to provide Peer Mental Health and Addictions Advocacy, in the Wellington Region, provided by consumers, for consumers, and helped in the development of the service to commence provision in July 2017. In addition he has become the Regional Champion and will be organising the Hopewalk Wellington, a community event, standing up and speaking out about Suicide, which will take place on Saturday September 9th in Wellington Botanic Gardens. Finally, Shaun was also invited by the CEO of the HQSC to join the Leadership Group of the Mental Health and Addiction Quality Improvement Programme, an initiative which the Health Minister formally approved in May.

Marj Allan

Marj advised that It has come to her notice that the Regional Cancer Networks are having difficulty in deciding how to comply with the Health Strategy and the Cancer Plan with the regard to consumers, and how they should be utilised.

There is great variation from Region to Region as with many other areas of our health System. Funding is a big part of this and the practical topic of how do we support them. Marj

believes it is watch this space and hopes the MOH with help and become the driver of this. She believes the same could be said for the Consumer Groups within the DHBs. And asks the question, is this OK?

The Patient Experience Advisory Group has commissioned a review process to the pilot of the Primary Care Patient Experience Survey. Marj was fortunate enough to be part of the team involved in this, and she is looking forward to these results and hopes it will answer some questions.

In the South Island, her group has just lost our Southern Cancer Network Manager and one of the top Project Manager positions. Marj could be part of this interview process, and is pleased to advise they have two great people to fill these positions.

Marj's SI Cancer Consumer group reviewed their terms of reference.

The Radiation Oncology Working Group now has a new Chair from Auckland. A lot was agreed on last meeting and there is now a real feel of acceptance to all work together throughout NZ to get a much better system for patients. The concern here is also variation but Marj is much more confident they can get this sorted soon. Going forward there is a view that there will be a shortage of radiologists, and that the NZ immigration policy won't help this at all, as most of the specialist around the table are from overseas.

The SI Palliative Care Advisory Group has the Voices Survey almost underway. They have commissioned a specialist to work on this process. They are also reviewing the Lippincott procedures to ensure they are correct for the NZ system.

Marj also became involved in the brochure creation for the CCN Supportive Care Brochure. She found this an interesting process and there seems to be a move to try and get maybe too much wording and information confusing the message and seems to have a don't read response. Marj believes that after the Loomis discussion this month this is maybe something which should be looked at. Also, every DHB around the country is creating their own brochure which creates a huge cost and again variation. With the bowel screening coming up, this again has been highlighted even more as it is a slow roll out.

Inter Hospital transfer has also been brought to Marj's notice. The patient rode in a brand-new ambulance but the ride, and the bed were so hard for a patient whom had just had open heart surgery. The trip was over 4 hours and left the patient traumatised, who had to be transferred in an ambulance because of equipment. Marj wondered whether anyone else experienced these situations.

The new funding from the government in the budget is great but it seems to Marj that it isn't even turning the ink pink in places! Hopefully we can get more thoughts on how this can be fixed.

Ezekiel Robson

Ezekeil attended *Patient Voice Symposium* in April along with other consumers and NGO groups. This was run by Medicines NZ which is a drug lobbying group, this gives benefits to the public and also to industry.

Renee Greaves

Renee has been asked to be a consumer key note speaker for the HQSC Quality Improvement Scientific conference in November, which she has accepted. There are currently discussions around key messages for that presentation in the next few weeks.

In role as Patient & Whanau Care Advisor @CM Health:

- After two years of the Consumer Council being operational, they have conducted a formal evaluation to ascertain how they are positioned in the organisation, value, sustainability and improvements that could be made, and where they have been able to achieve great success. Their evaluation is currently both the Council and Organisation to review and discuss the next steps, once this has been decided their report will be available for public access.
- Renee lead the campaign around What Matters to You, this is the second year they have participated in the global event, which started in 2014, and is now led by NHS Scotland <http://www.whatmatterstoyou.scot/>. The day was held globally on or around 6 June, CMH chose to hold their main event on May 24th, they have 37 units involved and have received 222 responses.

They asked each unit to complete 4 questionnaires, 2 with staff and 2 with patients and whanau. Currently the findings are being compiled, and will hopefully be ready for circulation within the next two weeks.

- Under their premise of holding a focus on Experience for 2017, they have changed their approach from typically holding a Patient experience week in March. This has been for a number of reasons being that they are changing culture around exploring staff and patient experience and the availability of staff to attend events given the huge pressures on the health system. In the areas of communication strategy to help teams promote work they are doing in the areas of Patient / Staff experience, Consumer engagement and Co design; to date they have released approx. 50 communications including a number of case studies.
- A Nursing Grand round was held in May to tie in with International Nurses Day, with focus on projects that nurses have been leading around improving patient experience. This included three presentations:
 - *Call for Concern*-Our patient deterioration programme
 - *Patient Safety leadership walk rounds*, which look at wards using a three pronged approach, looking at environment, exploring both staff and patient experience around Safety, these are conducted fortnightly across the organisation.
 - *ED Scholarship students: Explored repeated questioning of patients in the ED.*

- Renee presented recently at The Medical Grand round on aspects of using your reason for entering health as you're the heart of your approach to resilience, linking to the efforts and exploration on what matters to our patients and staff.

5. Horizon Scan Project presentation

Hilary Sharpe provided a presentation to the Consumer Network. Hilary asked the Consumer Network for their views on the following:

Which topics or sectors should we focus on in the future?

What type of support adds most value to the sector?

Ezekeil believed there should be more patient centred systems. If there is no evidence to make improvements, it needs to be sourced

Hoping that it is acknowledged how critical the involvement of consumers is, however there is currently no way of measuring that for evidence. The involvement of consumers is critical to a good health system.

Marj believed that prevention is not done well enough in New Zealand, it has been proved that prevention means a 65% saving in health costs. The Commission's role needs to show how important this is.

Shaun spoke about NZ having the worst rates in the OCD in youth suicide. The government has decided not to support the SuMRC which would provide the much needed data. There needs to be expert assistance to get a better platform to better pool resources. Generated evidence needs to be gathered around what works. There is a need to become better organised and strategic.

Traci believed there needed to be more focus on disabilities as well. Ezekiel believed that improvement needed to be carried out in a multi-sectorial manner. Assessing what conditions affect people's lives.

Marj raised survivorship as people get older, because that is the time when there is more strain on the health system. There needs to be a focus on aging well and healthy.

What is lacking in aged care is a consumer / family focus. There needs to be a lens of intersectionality.

Martine mentioned that there are a large number of plans for disabilities, but it may be worth at CE level to check whether some fit into the disability action plan. The Commission needs to look at linking into groups such as the CEs of Ministries and the Office of Disability Issues. The Commission needs to raise the issue that nothing is being done about concerns raised within HQSC.

Renee believes that work needs to be done around access and preventing people being bounced in and out of the system. There is also a need to educate consumer representatives on what is quality improvement and what they are working towards.

How do consumers get promoted out to the public to highlight the great work which is being done within the Commission?

Chris suggested a quality improvement programme on communication. This is a key issue which is raised by consumers repeatedly.

The issue with hard data is that figures from one area are compared to another area, and appear to be less important, however there is nothing in place to assess this on a level playing field.

Health literacy can link in with communication and needs to be in formats which are applicable to the individual using it.

Is there a way to get some basis to say because consumers and families gave feedback into how serious adverse events are reported?

Could there be a workshop with consumers (possibly at forum) to bring forward the key ideas.

Who's the crew

Chris & Deon discussed the *Who's the Crew* resource which came out of focus groups and family members. With an aim of making patients and families being able to identify who they could call and when.

The Consumer Network gave feedback on the resource.

Shaun advised that if they were going to use family/whanau it should be used consistently throughout the document.

Ezekiel mentioned that the resource needed to change / remove lines like 'green sheet' and 'second space'.

Have up to two 'nominated people, instead of 'next of kin'
Better title than who's the Crew
Change family to support person or people.

Improving communication between medical people and nominated support people.

Change 'fewer complaints'

Actions:

Members to come back with a better title than "Who's the Crew"

6. Patient Safety Week 2017

Deon York spoke to the Consumer Network around the details of Patient Safety Week and sought feedback from members for a consumer perspective. This year is about medication safety.

The Consumer Network provided feedback, which will be taken back to the Communications team.

Actions:

Take the feedback on the medication safety aspect of Patient safety week to the Communications area

7. Revisiting the Consumer Network

The Consumer Network discussed the following areas of the committee.

- Membership – Waiting to see what is happening at a governance level
- Terms of Reference
 - Revise front page.
 - 14 members not 10
 - Values – Go with the Commission values
 - Support a Māori member to attend Te Roopū meetings
 - 4. Revise final sentence.
 - Reports – each meeting members will provide a written report. Make 13.2
 - Remove 6.3
 - Switch 6.1 and 6.2
 - Combine 6.2
 - 8. Remove last sentence
 - 10. All meetings will be held in Wellington
 - 11. Add. Unless by arrangement
 - 13.2 and 13.3 Remove
 - New 13.3 Put minutes on website
- Changes
- Feedback

Actions:

Updated TOR to be brought back to next meeting.

8. SPE Deliverables

Chris opened discussion with the Consumer Network around SPE deliverables.

9. Open Forum

The Consumer Network discussed ideas for the Consumer Open forum to be held in March 2018

10. General Business

The Consumer network discussed the following areas:

- Education & Training of the Board
- Video – Patients and Clinicians governing together
- <https://www.youtube.com/watch?v=HOBf3nYS7OE>
- Accelerating consumer engagement
- Mental health quality improvement programme
- Consumers with disabilities
- Loomio update
- **Close of meeting 4:15pm**

- **Next meeting: 14 September 2017**

Actions:

Date	Item	Action	Responsibility
9 March 2017	Actions Update	<ul style="list-style-type: none"> • Upload the minutes onto the Intranet and send a link to HQSC staff, plus attachment, to remind them of the work the CN does. Also send a link onto the Chairs of the Consumer Councils at DHBs. 	Di - Completed
9 March 2017	Patient Safety Week	<ul style="list-style-type: none"> • Put a summary on Loomio asking for feedback on the suggestions. - Di 	Di – On 22 June Agenda
9 March 2017	2017 / 2018 Planning	<ul style="list-style-type: none"> • Put together a database of consumer reps and compile a form with: <ul style="list-style-type: none"> <u>Name</u> <u>Contact</u> <u>Experience</u> <u>Release of information agreement</u> 	Di - Completed