Minutes of the Consumer Network meeting held on 23 November 2017, at The Health Quality & Safety Commission, Pounamu, 17-21 Whitmore Street, Wellington 6011



Present: Chris Walsh (Chair), Deon York, Gillian Bohm – HQSC (10:03am), Traci

Stanbury, Martine Abel, Westin, Ezekiel Robson, Shaun McNeil, Courtenay Mihinui, Renee Greaves, Shreya Rao, Te Rina Ruru, Diane de Rochester

(Minutes) – HQSC

Guests: Jeanette Woltman-Black, Jon Warren, Rob Egan, Ross Johnston

Physiotherapy Board (Item

Apologies: Marj Allan

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 14 September 2017

The minutes were confirmed as a true record

2.2 Actions update

The actions list was considered and updated.

3. Commission Partners in Care report

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

- With the Commission's board agreeing to the establishment of the Consumer Advisory Group, this group had its inaugural meeting in October. At this meeting:
 - the CE, Dr Janice Wilson was introduced and spoke about how consumer engagement has progressed at the Commission.
 - the group had a 'mini' induction to the Partners in Care programme and to the wider Commission programmes and governance.
 - o they discussed their objectives and what they hoped to achieve
 - a brain storming exercise was undertaken to identify what issues the group could identify might be important to focus on
- The CAG to the board will be meeting with the board at its last meeting of the year on December 1st. The Partners in Care team has put together a paper in preparation for this meeting (see attached).
- This year's co-design programme is now solely focusing on Bay of Plenty DHB, with teams forming and confirming the focus of respective projects. To date there have been 2 web ex sessions.

- The timelines for the next pilot with Waitemata and Canterbury DHBs looking at the Always Events® toolkit have been confirmed. The focus will be on reliably implementing an 'always event'. First, the team will look at some baseline measures of current patient experience on the chosen wards, conduct the intervention, and see if any changes occurred.
- A site visit is planned between Ogilvy and Nelson-Marlborough DHB for the medication discharge project. Northland and Waikato are on board and are confirming the timelines.
- Presentations and meetings:
 - Presented to the New Zealand Nursing Organisation section day meeting on 'being a consumer advocate'
 - Deon presented at the International Society for Quality in Health Care's 34th forum in London. His presentation is included in the meeting papers.
 - Attended a meeting with the newly forming Health Consumer Councils of New Zealand. There were about 30 people at this meeting, mostly from DHBs.
 Graeme Norton is the current chair. There was further discussion amongst the group regarding this committee.
 - Met with Jeanette Woltman-Black (Physiotherapy Board of NZ) to discuss how to access consumers
 - Teleconference with Gloria Johnson (acting CE, Counties Manukau DHB) and Dr Janice Wilson to discuss consumer advisor roles in the Auckland region and delays in appointments to local community and public health and disability advisory committees. Gloria has agreed to follow this up and get back to us.
 - Attended the Health and Disability Commission annual forum (Consent, Culture and the Consumer Experience) in Wellington on 13th November and heard presentations updating and analysing data from complaints-main areas of concern are around access to services and communication
 - Attended the Science Working for NZ forum in Wellington where the Crown Research Institutes highlight their work
 - Met with Te Kete Hauora (a PHO in Lower Hutt) to discuss co design and hear about the work they have done
 - Met with Technical Advisory Services (TAS) to discuss our work around medication safety
- The day workshop for cardiac consumers was attended by about 14 consumers. An 'unconferencing' session was held as part of this. The two "big ideas" that received the most votes were: a standardised discharge checklist co-designed by consumers and clinicians and a structured questionnaire at discharge and post discharge, patient stories (as feedback). All this work is part of the HQSC, Ministry of Health and the All New Zealand Acute Coronary Syndrome Quality Improvement (ANZACS-QI) group around public reporting and transparency. Gillian Bohm advised that this had been an extremely successful event and those who attended and spoke were from a broad spectrum of the population and contributed a high level of information and suggestions. Carl Shuker, who organised this will be putting together a narrative of the day.
- Registrations are coming in for our consumer forum in March, but there is capacity for many more – so continue to get the word out!
- Shaun McNeil has been appointed the role of National Consumer Engagement Advisor -Mental Health and Addiction at the Commission. He will be stepping aside from his role on this consumer network but won't be stepping back!

4. Consumer Network Reports

Traci Stanbury

The South Island Child Health Alliance have agreed to fund \$10,000 for the paediatric inpatient survey pilot. They are still \$10,000 short and are waiting to see if the Paediatric Society are able to help otherwise they will have to halve the pilot project.

Traci has been working with Kidney Health NZ regarding organ donation initiatives. An updated Ministry of Health Strategic Plan to increase the number of organ donations in NZ has been released and now includes increasing public awareness, using social media and also states that there will be an organ donation button on the new e-Health record. This is all positive but with the new government they aren't sure when/if the development of the national organ donation agency will happen.

Traci also finished her Masters of Health Sciences, majoring in health and community. The Consumer Network group all congratulated Traci on this fantastic achievement.

Courtenay Mihinui

Courtenay updated the group on what had been happening with her and her whanau. The group expressed its support for her.

Shaun McNeil

- In September Shaun attended Red Cross First-Aid Training and also Engaging Pacifica training, provided by Le Va.
- In October he attended a community suicide workshop presented by Mike King and his Key to Life charity.
- On November 6th, Shaun commenced in his new role as an employee of HQSC, National Consumer Engagement Advisor-Mental Health and Addictions. He received confirmation that he can still continue his involvement with the Like Mind, Like Mine and National Depression Initiative campaigns.
- Shaun is excited by the HQSC's 5 year Quality Improvement Programme and feels that the timing is good with the new government also committing to a Review in Mental Health and the Re-establishment of the Mental Health Commission.
- Shaun made contact with James Boyd, a Youth Consumer Advisor, the National Mental Health and Addictions Consumer organisation-Nga Hau E Wha and the National Addiction and Mental Health Service Consumer Advisor's Group (NAMHSCA). He also met Laura Ellis who works as a Consumer Advisor for HQSC in the Deteriorating Patient Programme.
- On 13th November, Shaun attended the Health and Disability Commission's 'Consent, Culture and Consumer Experience' conference.
- On 15th Shaun attended the National Mental Health and Addictions Adult KPI Forum and a Co-Design/Co-production presentation hosted by ANZEA.
- On 20th and 21st November Shaun attended the 'Service User Academia Symposium' at the University of Otago, Wellington.
- On 22nd Shaun visited Auckland to attend a presentation by the Chief Executive of Turning Point (UK), Lord Victor Adebowale, hosted by Platform and HQSC.

 On 24th, Shaun will be participating in a teleconference with two representatives from the Mental Health Commission of Canada, who he had facilitated visiting HQSC in Wellington and Auckland.

Te Rina Ruru

Te Rina advised that Camp Unity - bringing vulnerable children together in a safe and secure environment) had gone ahead and was an incredible success and they are looking at some big sponsors. There are more camps coming up in the future.

Te Rina has Te Roopū Māori and Medication Safety meetings next week.

Marj Allan

Cancer Consumer New Zealand had a face to face meeting on July 21st with the Ministry of Health. They discussed the way forward for this group and work-shopped different scenario journeys of a cancer patient from pre-diagnosis through to palliative care. This still has a lot of work to be done on it, which hopefully will be done over the next few months. The plan here is to help inform the new or updated plan for cancer going forward. It is thought this will be a living document.

With the new government things are a little in limbo until some clear direction is given by the new Health Minister. There is talk of forming a new Cancer Agency which would have much more power to drive change and policy so Marj will keep everyone posted on this.

Marj was fortunate enough to be invited to the Kakawhina Workforce Conference in Wellington in August. There were some very good speakers at this conference with some great ideas, however not once was there encouragement for everyone there to pledge to work together on the same page to strengthen the service. Marj feels that there needs to be much more of a consumer focus here to help with this. Since then she has been to a meeting where they went over the next 2/1/2 years for a 5-year work-plan. A workshop was carried out at this meeting and as consumers Mary and Marj came up with some more input to be included.

Consumer Focus

Healthy Ageing Strategy Consumer Focus

Increased consumer representation – supported for preference for co-design in policy and practice development. Marj feels that it is a start to have these things included here but more work is needed.

Marj also attended the ROWAG meeting. This group is finalising their data collection, it seems to be a first and may be a template for other groups

Key Messages

The online radiation oncology application with real data included, was presented for the first time. The application still needs to go through testing and validation, but initial results show that there is variation in fractionation and intervention rates across DHB/ centres which warrants further investigation. The application will be made available to ROWAG members

early in the new year. The private providers reiterated their willingness to participate in this project.

A paper was presented on the potential development of a Radiation Oncology integrated alliance in New Zealand. This alliance would support a 'hub and spoke' model of service provision with services being delivered closer to home where possible. This would be balanced by providing some services at specialist centres to support 'gold standard' treatment. An alliance would also support better research opportunities and specialisation for radiation oncologists. This paper will be developed further and be informally circulated to the radiation oncology sector for feedback.

The Inpatient Survey Advisory Group has been working on some small adjustment to the survey to help make it more attractive to get feedback, so this is looking positive.

The South Island Cancer Consumer group is meeting on Monday, however they did engage with all the Consumer Councils through the South Island and their plan is to work closer with them in the future.

Marj is sad not to be at the meeting, however wishes everyone all the best and looks forward to updates on the future, with our conference coming up early in the New Year.

Ezekiel Robson

Disability support 'System Transformation'

The way in which disability support services are funded and delivered is in a process of change. Since April 2017, a co-design team of disabled people, families/whānau, service providers and Government officials have been working together on the most recent system design which aims to increase choice and control over the government-funded supports disabled persons have access to. This covers Ministry of Health, Education, Social Development and other government funding.

The overarching goal of transformation is that disabled persons will be able to live a good life with less systemic control.

The current developments have their origins in the 2007 Social Services Select Committee inquiry on the Quality of Care and Services Provision for People with Disabilities, which made a raft of recommendations for changes to the system. Amongst these was a clear signal that the service options and mechanisms in operation at the time were not flexible enough to meet everyone's unique needs.

As a result, in 2010 the Ministry of Health piloted Local Area Coordination (independent facilitation), Individualised Funding, and supported self-assessment processes, allocating dollar amounts as opposed to service lines.

In 2012, the Government's Ministerial Committee on Disability Issues (which is a group of chief executives from various Government ministries/departments) agreed to demonstrate the principles of a facilitation-based support model, called 'Enabling Good Lives'.

The first trial of EGL was run in Christchurch in 2013-2016, with a focus on school leavers. Today, any school leaver in that region with ORS status goes through an EGL process. The second demonstration, in the Waikato region, began in 2015, and has been extended to June 2019. Both EGL demonstrations were developed in consultation with the local disability communities.

Co-design has been a feature of the recent 'system transformation' agenda. The co-design process is important because it means disabled people and families/whānau are actively involved and contributing to decision-making processes on issues that affect them. The co-design process has led to the creation of a 'high level' disability support system design / framework, which is currently being considered in more detail by over 20 working groups and virtual testing groups.

To begin with, a 'transformed system model' will be rolled out in and around Palmerston North, in July 2018. This region was chosen as the location to test the new system as it offers a mix of people living in urban and rural areas, has around 1500 people accessing disability support services, and has a large Māori population.

The work being done on this is led by a group made up of disabled people, family/whānau, Mana whenua, providers, and officials. The purpose of the group is to build local leadership, contribute to ongoing co-design work, and local implementation. Monitoring and evaluation of what is happening in the MidCentral will help ensure that the design is fine-tuned before it is rolled out in other areas of the country.

The new system has the potential to build a strong foundation from which a non-disabling society can be built and a good life for everyone can be achieved. It's important to remember though, funded disability support services are just one part of a much broader context for living a good life. The system on its own won't ensure disabled people have all the same ordinary life outcomes as non-disabled people.

Martine Abel

Internal:

Martine attended her first meeting of the newly established HQSC Consumer Advisory Group. The group was supported by HQSC staff and discussed its purposes and planned on meeting with the HQSC board for the first time on 1 December. They were a group of 4 members but one has since resigned.

External:

As part of the Consumer Advisory Services (CAS), facilitated by Health Navigator Charitable Trust, Martine participated in initiatives such as the Ministry of Health (MOH) National Ophthalmology Service Improvement project. This project is near its completion and most of the work streams will now be picked up at DHB level, and this has already commenced in many instances.

As a member of the CAS Martine also participated in a NMOH organised long-term conditions NGO workshop, hosted in October where NGO's working in the fields of chronic conditions and disability could raise issues to do with sustainability, funding shortages and areas of growth.

Martine also attended her first meeting of the ACC Sexual Violence Prevention Advisory Board in October. ACC is drafting a communique that we'll be able to circulate to networks, so, do watch this space.

The DPO (Disabled Persons' Organisations" Coalition met on 20 and 21 November and she formed part of that meeting this time around. They met briefly with the Minister for Disability Issues, Carmel Sepuloni and once she has their Briefing to the Incoming Minister (BIM) she will get it through to HQSC networks.

The DPO's also met with Paula Tesoriero, Disability Rights Commissioner re her priority list and recent activities.

Planning is underway for NZ to draft a shadow reports or more than one re the implementation of the CRPD (Convention on the Rights of Persons with Disabilities: towards the end of next year, and to that regard, discussions took place with Marcia Rioux – Disability Rights Promotion International (DRPI) re Methodology / Disabled People Led Monitoring

A reminder to all to participate in and be on the look-out for events around Disability Pride week – 1 to 7 December, in the light of International Disability Day being on 3 December.

Martine has been actively circulating community notices to this and other networks.

Shreya Rao

POD

This is a creative incubator project for young people to design their own stigma/discrimination campaigns. Final hui for this project has finished. They will go into evaluation of the project and provide report to the Health Promotion Agency.

Waitemata Stakeholders Network

This group has started the co-design process for a medium-term regional plan for child and youth mental health and addictions services across the DHB. At this stage they are doing a lot of team building and explaining the background of the WSN plan.

Inpatient Unit

In the process of developing a co-designed pathway for supporting young people who go into an adult inpatient unit while under youth service. It is the very early stages so right now we are looking at a survey to understand experiences of young people and their whanau. My personal interest is to have this showcased as an example of service user led participatory research.

National Youth Consumer Advisors Network - We are hoping to set up a consulting network of youth consumer advisors to input into the new government decisions around youth mental

health. This is as the national body of consumer advisors has no proper youth representation. My counterpart at the Werry Workforce Wharaurau, James Boyd, and I are in talks about how to launch this. There is potential for collaboration with the new HPA and Changing Minds project Rakau Roroa which seeks to train mental health consumer leaders.

Teaching at Unitec

I completed a presentation around Indian perspectives on mental health based mostly off my experiences. The presentation was to social work students from Unitec. Feedback was very positive.

Environmental Audit

In consultation with James Boyd at Werry Wharaurau, I have designed an environmental audit to assess 'youth friendly spaces'. The audit was written for community mental health centres but could work well for primary care facilities. James and I will be trialling this tool in Waitemata DHB youth mental health facilities

Renee Greaves

HQSC Related

- Key note presentation for the Quality Improvement Scientific Symposium (held in Auckland)
 - 14th November-Co-design the new normal
 - Co-design is a partnership approach to improving healthcare services which involves people who plan and deliver services and people who use those services. This is fast becoming the way to strategize, design and deliver quality improvements.
- 26th October- Attended the Shared Care Goals workshop https://www.hqsc.govt.nz/our-programmes/patient-deterioration/shared-goals-of-care/

CM Health Related

Carolyn Canfield visit to CMH



Lead a visit by Carolyn Canfield to CM Health Carolyn Canfield collaborates internationally as an independent citizen-patient with clinicians, patients, managers, researchers, and educators to embed the patient's voice in improvement processes. Patient expertise can drive creativity and sustain system scale reform to meet the aspirations of both clients and practitioners for care excellence. The unexpected death of her husband in 2008 after care failures after

successful surgery challenged her to understand how skilled and dedicated healthcare workers could fail a patient, and then suffer terribly themselves from the very system in which they work. She dedicates her passion to countering burnout and harm across the full spectrum of healthcare. Carolyn was recognised as Canada's inaugural individual Patient Safety Champion in 2014. She is an honorary lecturer in the Faculty of Medicine at the University of British Columbia in Vancouver.

Carolyn was able to meet with the medication safety and Pharmacy teams, attend and participate in one of their leadership walk rounds.

Renee led a session at out Frontline Friday meeting: "Relationship-based Healthcare for Safer Care and greater Quality and Value"

It's a matter of trust! Learning to listen to the patient and families/whānau about what constitutes wellbeing forms the foundation for appreciating what is safer care, where value lies and when desired outcomes are realized. Without the patient, how can we possibly see and understand safety, quality and value? Join me for a patient's eye view on care quality and safety within the ever-dynamic and complex relationships that make up healthcare and wellbeing. Join me for a practical start today on how to build greater trust and support stronger care networks for yourself and your patients.

Leadership Safety Walk rounds

Keeping leaders in touch with frontline care.

Counties Manukau Health is keeping its leaders in touch with frontline care and improving patient safety with the Leadership Walk Rounds.

The Leadership Walk Rounds were introduced in 2014 after the publication of the Francis Report in 2013 highlighted the dangers of leaders becoming distanced from the reality of frontline care.¹

"The Francis Report showed that a healthcare organisation can perform well against quantitative targets while actually delivering appalling standards of care. That can happen when leaders focus on the numbers at the expense of listening to what patients and their families, and frontline staff, say about their experience of care. Our leaders need to see and hear first-hand what's happening on our wards to get a complete picture of whether we're providing safe care," says Jacqui Wynne-Jones, Clinical Nurse Director.

Ms Wynne-Jones led a collaborative team, which included the directors of nursing, patient safety and innovation, an improvement advisor and a consumer advisor, to develop the Leadership Walk Rounds.

The Leadership Walk Rounds are held every fortnight. In each one, a team of six CM Health staff visit a ward or unit. Teams are typically made up of: members of the Executive Leadership Team; clinical leaders; heads of departments; representatives from Health & Safety, Quality Assurance and Human Resources; patient and whānau care advisors; clinical directors and senior medical officers. A wide variety of other staff, as well as visitors from other healthcare organisations, have also participated. A staff member with expertise in patient experience accompanies the team.

During the Leadership Walk Round, the team use three qualitative tools to perform an assessment of how safe the ward is and capture the experience of staff and patients on that ward: The First 15 Steps, a patient experience questionnaire, and a staff experience questionnaire. The First 15 Steps is an assessment of how safe award is based on first

impressions of the ward environment.² The patient and staff questionnaires each comprise ten questions about experiences on the ward. The team aim to speak to patients of different ages and ethnicities and staff in a variety of roles to get a representative perspective. Following the visit, team members agree on the key themes they found. The ward's charge nurse and service manager participate in the discussion to ensure transparency and are encouraged to take ownership of outcomes. A summary celebrating the positive aspects and identifying areas for improvement is supplied to the charge nurse, head of department, service manager and clinical nurse director within 24 hours. Ms Wynne-Jones's team maintain communication with wards to follow up on actions taken and provide any assistance needed.

"So far, we've visited 40 areas, and spoken to more than 250 patients and 300 staff. What's interesting is that we've been back to 20 of the areas since our first visit and we're seeing encouraging results," says Ms Wynne-Jones.

"One of the big improvements we've noticed is in communication. In the initial Leadership Walk Rounds, many patients said that they didn't feel involved in their care or didn't understand medical terminology. And staff described a different culture operating on the ward when the charge nurse wasn't around. This point was reinforced by some patients commenting that they felt uncomfortable because nurses were speaking in their own languages after-hours."

"In response, wards have started initiatives known to improve communication, such as huddles and bedside handovers. One ward has also started including nurses in the doctors' rounds, so they can explain any medical terminology that patients don't understand." Duty managers and the Patient at Risk (PAR) team have reported improved communication and behaviour after-hours.

In addition, wards have de-cluttered, and charge nurses report that the Leadership Walk Rounds are helping them to strengthen their leadership, build teamwork and highlight staff and rostering issues.

"Staff tell us that when strong leadership is visible, they feel valued and love coming to work. They enjoy celebrating the positive points about their wards through the Leadership Walk Rounds and value the feedback on areas for improvement as a platform for change."

References

- Francis R. (Chair). The Mid Staffordshire NHS Foundation Trust Public Inquiry: Report of the Mid Staffordshire Foundation Trust Public Inquiry. London: The Stationery Office; 2013.
- NHS Institute for Innovation and Improvement. The Fifteen Steps Challenge. 2006-2013.
 Accessed 22 April 2015 from http://www.institute.nhs.uk/productives/15stepschallenge/15stepschallenge.html

The Patient Safety Leadership Walk rounds at CMH have been sustained for over 4 years due to the support of staff from Board to ward. Our point of differences is that we interview staff as well as patients, and that we have continued to have a steady flow of staff who give up their time to be participants. Participants have told us that they really enjoy the collegial

experience as well as the experience of interviewing patients and staff and doing the observational environmental audit.

This was in support of Patient Safety week, a videoed interview, and her session will be available in the near future (I will send the link to the network)

Consumer Council

- Support of CM Health Consumer Council, just recently finished recruitment phase of another four members to join the team beginning December. Facilitated the beginning of quarterly meetings between CMH executive leadership team and Consumer council.
- Working on new annual plan that developed in discussion with executive leadership team
- Attended the Annual NZ Consumer council collective meeting, 20 DHB's in attendance (all at varying stages of implementing or discussing a consumer council) Chair- Graeme Norton.

Still in progress

 Leading a project around creating and providing Patient Stories to be shared at each DHB Board meeting, the purpose is to help set the scene for the board meetings.

Actions:

- Renee to put together information around the consumer council of the CMDHB for the Comms department to send out to stakeholders and community.
- Put Martine in touch with Comms to follow up on sharing information to the wider community concerning Disability Awareness Week

5. Discussion with Physiotherapy Board

The Physiotherapy Board attended the meeting and gave an overview of their work and processes, uncluding accreditation of physiotherapists. They discussed opportunities for working with the Commission through the Consumer Network.

6. Recruiting consumers to the Network

Members of the Consumer Network discussed the best process to recruit new members to the Consumer Network.

The Network currently has 8 members and there is a need to address diversity. Suggestions were Pasific male and possibly an older person, as most of the Network were reasonably young. Also, possibly more rural areas, rather than urban.

Renee suggested that we could go to DHB Consumer Councils and collectives for suggestions. Also look at the EAGs of the Commission.

A brainstorming session was held with many suggestions to be considered.

7. Let's Talk Forum

Deon ran through the latest programme for the forum and explained where the suggestions of the Consumer network had been incorporated.

He also outlined the different Keynote speakers, plus those clinicians and consumers in the PechaKucha. There will also be input to the conference by some members of staff and codesign.

The group further discussed other ideas for the forum and Deon noted these.

All members of the Consumer Network, who are available, have been asked if there was something they would like to assist with on the day of the forum. This would give the Network a good profile.

Action:

• Deon to send around a further updated programme

8. General Business

A farewell was held for Shaun and everyone wished him well in his new role at the Health Quality & Safety Commission. Shaun also responded with some very nice words of his own for everyone.

Close of meeting 3:10pm

Next meeting: TBA

Actions:

Date	Item	Action	Responsibility
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
23 November 2017	4	Martine in touch with Comms to follow up on sharing information to the wider community concerning Disability Awareness Week	Deon
23 November 2017	7	Send around a further updated programme	Deon
14 September 2017	3	Send link to KL conference to the Consumer Network	Di
14 September 2017	3	Send PowerPoint for Chris presentation to Consumer Network	Di
14 September 2017	3	Come back with ideas around involvement of the Consumer Network in the Forum in March	All
14 September 2017	4	Send link to patient stories on Patient Deterioration to Consumer Network	Di
14 September 2017	5	Have Ezekiel teleconference into a CAG meeting to discuss the issue with non-consumer representation on the DHB Boards.	Di
14 September 2017	8	Send information to Di for distribution to the Consumer Network on Loomio	RNZCGP / Di