



Present: Chris Walsh (Chair), Deon York, Traci Stanbury, Martine Abel, Shreya Rao, Ezekiel Robson, Marj Allan, Diane de Rochester (Minutes) – HQSC

Guests: Richard Turton, Ben Copsey, Andrew Scott and Christian Nejm – Ministry of Health (*Item 4*)

Apologies: Renee Greaves, Te Rina Ruru, Courtenay Mihinui, Shaun McNeil, Gillian Bohm – HQSC

The meeting commenced at 9:30am

1. Introductions and welcome

Chris welcomed everyone to the meeting

2. Minutes of the meeting held 22 November 2016

The minutes were confirmed with minor edits.

2.2 Actions update

The actions list was considered and updated.

There was discussion around the Serious Adverse Events report and the Network supported the higher level of involvement by the Commission.

It was agreed that the minutes of the Consumer Network be dispersed on the Intranet and to HQSC staff.

Action:

Di to 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.

3. Commission Partners in Care report

Chris Walsh presented the Commission report to the meeting, highlighting the following.

- The co-design programmes at both Hutt Valley and Taranaki DHBs concluded the second master classes and the most recent webinar was on 22 February. The co-design section of the Commission's website is due for an overhaul as a number of Commission programmes are now using the co-design method and one central place for all this activity would be useful. Deon added that the groups took a second look at what was really needed around service change, which was often different to their initial ideas on what the problem was.
- Waitemata and Canterbury DHBs are the confirmed sites to help us develop and test a quality and safety marker for consumer engagement. Sapere Research Group were contracted to progress this work with us.

- The medication discharge project is well underway, with four DHBs involved: Nelson-Marlborough, Waikato, Bay of Plenty, and Northland. Ogilvy has completed data collection in Nelson-Marlborough and Northland. The team have been observing discharge discussions around medication management, and conducting focus groups with both staff and consumers to understand their experience. This project will inform small interventions to improve this lower scoring area of the inpatient experience survey. Ogilvy use a programme for behaviour modification called Nudge. They have discovered some comparisons with DHBs, i.e. Patient information at the back of documentation, rather than at the front and easily accessible.
- The internal consumer Partners in Care champion's staff group has had its fourth meeting (13 Feb). As well as team updates, we discussed ensuring we have complete information about all consumers on our work programmes and that consumers working across different expert advisory groups are given opportunities to connect.
- The PIC team have been doing presentations and visits including at the NZ National NASC group (presented co-design), and optimising patient experience through digital innovation (presented on responding to patient experience). The team also attended the NZ Disability Network Leadership Forum. A summary of reflections on the optimising patient experience conference is included at the end. Deon discussed the new digital options so that patients can make their own appointments (Patient Focus Booking), rather than them being made by the DHB. Traci advised that a programme is used at her workplace which is called Timely. They find it a very effective system. There is a general trend amongst GPs to move towards patient portals.
- Chris will be presenting on using data to improve the experience for consumers in Malaysia in August at the BMJ International Quality Forum.
- Deon attended the Ministry of Health's Patient Focused Booking meeting. This concept is being promoted by the Ministry, and expect to hear more about it from the next financial year. The Ministry plans to run a workshop for DHBs on 4 April, and Barbara Broome will be providing a consumer perspective on patient focused booking. The Commission may also be presenting.
- The Commission's Board met on 16 February. The Board had requested a series of training and education modules about working with consumers. In addition, a paper will be presented in May on governance and consumers, particularly in the NZ setting.
- Last year the PIC team submitted a bid as part of the Commission's prioritisation process to seek funding to explore improving communication between clinicians and patients/families/whanau. We are still awaiting the results.

Reflections from optimising patient experience through digital innovation conference:

- Interesting stats coming out-76% of the overall NZ population have a smart phone, the over 55s form 48%.
- The clinician has the potential with all the advances in technology to be a 'data scientist'.
- Interesting free websites for analysing big data, Auckland university <https://www.stat.auckland.ac.nz/en/about/our-research/software-development/sw-the-r-project.html> and Weka <https://weka.waikato.ac.nz/explorer> at Waikato university
- The consumer panel seemed to agree that while technology had its place, they didn't believe that it should trump talking.
- Telehealth looks to be something to put resources into, the distance challenges with 'seeing' patients can be overcome by using telehealth. This website has good

information. <http://www.telehealth.co.nz/> We saw some good examples being used in Waikato.

- NZ Blood service did a great presentation on their mobile app, it cost them about \$150,000 to develop. Only 4% of the NZ 4.7 million population are blood donors and they need to ensure these numbers are kept up. <http://www.nzblood.co.nz/give-blood/smartphone-app-for-donors/>
- We saw more mobile apps, one doctor talked about his development of apps, and said it is rare for doctors to prescribe apps as a tool-for patients. There are over 165,000 health apps!
- Strong consumer/patient focus throughout, all presentations were along the philosophy of what the Commission does
- Questions from this to consider, some patients will respond well to a health app, despite the 'data' about populations having smart phones and being savvy with technology, bringing everyone along will be challenging. The infrastructure in New Zealand to support health technology is disparate and goodness knows as a small country we should be able to line up the ducks better.
- People give away a huge amount health data on apps (eg fitness, health, sleep), websites (social media, sharing forums eg patientslikeme) and devices (apple watch). These sets can be linked together to create a pretty picture of an individual which unlike IDI is not anonymised in any way. Watch the movie Terms and Conditions may Apply <http://www.imdb.com/title/tt2084953/>
- Re: apps – I couldn't think of any obvious uses for Commission work as they need to provide some useful function to the consumer, eg storing health information or apt times
- With the proliferation of apps, are we setting up a future where we end up discussing how to integrate data across all apps and ensure interoperability? Will this therefore be the IT issue to replace the current ones?
- Interesting concept of prescribing apps to consumers
- By the time you have designed a project around a particular technology, it is already out of date.

4. Electronic Health Records (eHR)

Richard Turton and Ben Copsey, Andrew Scott, Christian Nejm gave a presentation to the Consumer Network, outlining the uses and details of the electronic health records system.

The following ideas were presented by the Consumer Network to the Ministry of Health team around their expectations from electronic health systems.

- Seamless life – easy access to information and everyone using the same log and data
- The ability to check risk management
- Education on interpreting information
- Different assumptions need to be noted for long term conditions as compared to someone who goes into hospital once a year.
- Frustration with constantly reminding clinicians about your condition or health.
- Easy access to names and dosage of drugs when travelling, particularly when travelling in non-English speaking countries.
- Disaster situations and access to information on your medications.
- Discharge summaries going directly to GPs and can be accessed by the patient.
- Being able to correct / change your records.
- Immediate personal responsiveness to health needs. For example over the counter medications.

- Digital information trumps hard copy information, much more suitable for encouraging self-improvement.
- Self related opportunities with knowledgeable access to your medications
- Family / whanau / third party access – this raises issues for privacy.
- Must be up to date

What is empowerment and what does it mean to consumers?

- There will be consumers who do not take ownership of electronic information
- There is a habit of relying on health professionals to be the experts
- For families it will be very beneficial to be able access records
- Would be beneficial for ambulance services to have access to records
- Encourage integrated care.
- Timely / available information – accessible in the home
- Ability to create / direct narrative
- Create a wider story about yourself and your needs.
- More eyes on care and more people responsible to prevent people falling through gaps in the system and having their treatment overlooked.
- More refined communication that can tackle the difficult issues. For example, complicated therapies and Google health sites.
- Score things – If I had trust, confidence in these things, I would have trust / confidence in the system
- Would respond to information / data etc, if weight was put on to take responsibility to respond
- An ability to inform the doctor about what we think is important
- EHR – Cuts down on repetition.

What do you consider would be innovative

- Donor information being available, rather than on drivers licence
- Having all information about your health and any future thoughts about your health at your fingertips with an app on the phone.
- Early warning about results
- ACP Interface – Lets Plan
- Taking blood pressure prior to doctor appointment

Barriers / Risks

- Media / Marketing
- Unwell / vulnerable people who can't help themselves
- Perception of power devolving to people
- Privacy
- Firewalls
- Education and training of clinicians / consumers
- Not getting buy-in from providers / patients
- Not co-designing with consumers
- The first shot is the best shot, so need to get it right in the first instance.

5. Consumer Network Reports

Martine Abel

In November attended the Integrated Health Care Conference, hosted by HQSC in Wellington over 3 days. I provided a written report to HQSC, focussing on what I experienced as the highlights, as well as making suggestions of how such events could be more accessible.

In December, I participated in a MOH and HQSC hosted workshop on palliative care which explore the current jargon, terms, contradictions, etc.

I'm also still attending meetings of the Patient Deterioration Expert Advisory Group (PTEAG), as one of the appointed consumer reps. Varying measurement tools across all DHB's are a focus topic, for there isn't really a move for synchronicity. Only 1 DHB is currently trialing patient and whanau escalated reports of deterioration I think. There's still a great deal of angst around seeming to not wishing to annoy clinicians. Laura from HQSC recorded excellent DVD footage of interviews with terminally ill patients, where they discuss how they experience the medical profession treating and including them in their care, really gripping stuff.

Shreya Rao

Digital Conference

Shreya presented as part of a consumer panel discussing how technology can be used to enhance patient care. The conference was promising, offering a number of potential future avenues for transforming how patients/consumers can prevent illness or manage their conditions. Questions centered on youth views around technology, privacy and what particular technologies were attractive. The panel was a youthful one but had differing views around the efficacy of technology.

Shreya is working on a plan to collate feedback on the assessment and brief intervention pathway and wish to make it publishable. The feedback shall be a questionnaire based methodology with potential for semi-structured interviews to flesh out themes and provide information for service development. It is hoped that this is a piece of work which shall be published and showcase the innovations being made in mental health care for young people.

As part of the consumer team at WDHB Shreya's group spends a few days a year lecturing allied health or nursing students about mental health. The focus is on consumer and family perspectives on clinical care, stigma and discrimination, as well as how their own experiences in service were. This quarter they were at Massey University discussing these topics with Nursing students in their second year of university about to go on placement within the services.

Traci Stanbury

Traci is currently focused on inequities in primary health care, particularly with Māori and the use of Māori health care models to increase cultural competencies in clinical staff and reduce disparities in health outcomes.

The South Island Alliance Child Health team have been looking into how patient deterioration processes work within paediatrics throughout Australia.

With interest from 11 DHBs about a national paediatric inpatient survey, CDHB, Kidsfirst and Traci have been discussing how a survey might run, how it could give children a voice in their care and what could potentially be actioned from the results. With no evidence-based research currently available within New Zealand on this, the teams are looking at how they could run a six month trial in one hospital to assess and report on, and to provide evidence-based research.

Marj Allan

Marj commented that this seems the slowest of the quarter however when thought is put into it becomes the most important part of the year as we all plan the work plan for the year ahead.

The Cancer Consumers NZ team supported the Cancer Society in a paper to the Ministry regarding a review of the current Travel policy. This hasn't been looked at for some time and has variations on how it is implemented across the nation. Marj asked that people keep this one on their radar as hopefully there will be opportunities for input by consumers.

At the South Island CCG they had a Clinical Nurse specialist come and talk to them on her success with Telehealth for out-reaching patients, ensuring them they are supported and doing work-up appointments prior to surgery etc. This has saved patients a lot of travel time and in some cases been a lot easier for them. Hopefully this will evolve going forward.

Information Technology collection is certainly coming onto the radar for all consumers There is a need to ensure the correct data is collected to give us the information in order to make decisions to drive change. This will help the DHBs to become aware of where the gaps are.

Advance Care Planning with the support of HQSC is undergoing a review of the current national work around this and where to go from here. This isn't completed yet, however, with a lot of work from our colleagues at HQSC, a paper has gone to the DHBs for consideration of the going forward process and funding.

The first National Forum was held in December and the consumers who spoke had a huge impact. Well done to those consumers.

Marj was pleased to note that patient portals are also on the Consumer Network agenda. There has been a strong message from the Ministry of Health on this.

Our CCNZ group is also looking at a consumer heat tool for groups, to measure consumer involvement. This is in the very early stages.

Ezekiel Robson

The Window EAG is considering "how do we move to a system with a unanimous safety culture that generates its own set of expectations for safety and quality and its own local quality improvement activities to meet those expectations?"

Organisational safety culture can be seen as evolving over time, progressing along a continuum through five stages:

1. The 'pathological' stage sees safety as 'a problem caused by workers' with an attitude of 'who cares as long as we're not caught'.
2. In the 'reactive' stage organisations start to take safety more seriously but action is only taken after incidents occur.
3. In the 'calculative' stage, the approach is still very top down with management systems in place to manage hazards and a focus on collecting data.
4. In the 'proactive' stage, there is more workforce involvement around identifying and working on problems, whereas...
5. In the final 'generative' stage, there is active participation at all levels based on increasing trust and 'informedness': 'Safety is how we do business around here'.

Our system is presently somewhere between the calculative and proactive stages – where management systems are developing to manage hazards, there is an increasing focus on data collection and analysis, and some workforce engagement and involvement in improving quality.

In thinking about how we move New Zealand healthcare further along the continuum, it will be helpful to know how consumer input and participation can strengthen and be an integral component in all areas of quality improvement.

It was agreed that there can be a stronger consumer focus placed on the comments within Ezekiel's document.

The Consumer Network is very supportive of this work

6. Patient Safety Week

Dylan Moran from the Communications area of the Commission spoke to the meeting about Patient Safety week. This is aimed at raising health literacy amongst consumers and how health professionals interact with patients.

Health professionals introducing themselves 'Hello my name is'

Health details card, which can be carried with the patient for all appointments

Admission and Discharge sheets – 'making your stay with us safer'

This year is focussed on medication safety and the team wants to have a strong consumer focus and want to concentrate on health literacy. They will also be concentrating on the most populous illnesses.

Resources:

Medication safety brochures will be updated to the Open branding and updating the figures and statistics.

The Network came up with the following ideas:

- Top two tips for..... for consumers to lock into?

- Hello my drugs are.....?
- Look at some of the more common drugs (most prescribed)
- Plastic container with stickers – ‘remember to pop your pills today’
- Look for something gimmicky
- ‘Ask your pharmacist’ ?
- ‘Name one side effect from the medications your taking’
- Competition at each DHB for suggestions
- Lets Plan for talking to a pharmacist Upgrade the ‘When you collect your prescription’ poster
- Limericks?
- If I don’t take my drug what will happen to me?
- Each foyer have a giant replica of a capsule representing a different drug each week, with a competition to go with it.
- Get doctors to talk about their own medicine
- A picture of each different medication which can be printed over with a saying, information, limerick or anything else they would like.

Actions:

Di to put a summary on Loomio asking for feedback on the suggestions

7. 2017/2018 Planning

Deon worked through the consumer training modules with the Consumer Network and asked the group for feedback on these

- Include Mental Health
- Include DHB Consumer guide
- Include Te Whare Tapa wha
- Include Pacific Island strategy
- Reference other strategies
- Hierachy of which pieces of strategy could be laid out in relation to each other (disability)
- Pull back a slide or two to expand without more slides.
- Could be sent out in email form so that people in remote areas can work through at their own pace
- Small online training module
- Chris advised that the aim of the training and modules were originally designed to bring consumers together.

Draft programme plan

Deon went through the programme plan, explaining the various workstreams and the timeframes.

There was a suggestion that a National consumer list with expertise of each consumer be compiled.

Actions:

- Di to put together a database of consumer reps and compile a form with:

Name

Contact

Experience

Release of information agreement

- Include this database in the plan – Deon & Chris

Deon outlined the brainstorming session held by the PIC team around the International Consumer Forum for 2018. The CN gave their feedback and suggestions.

- Pechakucha speakers ☺
- Key note speakers – national or international - inspiring
- Networking session
- Drinks & canapes session
- Interest groups
- Spot speakers (stickers under chairs)

Deon ran through the budget template, which is still at the development stage.

Where can the PIC add value for consumers?

- Workstream three to be taken out and integrated with workstreams one and two.
- Have a stronger equity emphasis.

Send any feedback or thoughts to Deon around the programme plan – Deon -

8. Any other business and close.

Day forum on: Building a sustainable healthcare system. The role of the patient voice symposium – Tuesday 4 April. Will sponsor two consumers plus airfares

The meeting closed at 4:11pm

9. Next Meeting – 22 June 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
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
9 March 2017	2017 / 2018 Planning	<ul style="list-style-type: none">• Put together a database of consumer reps and compile a form with: <u>Name</u> <u>Contact</u> <u>Experience</u> <u>Release of information agreement</u>	Di