



Present: Chris Walsh (Chair), Traci Stanbury, Ezekiel Robson, Mar Allan, Courtenay Mihinui, Martine Abel, Deon York, Gillian Bohm Diane de Rochester (Minutes) – HQSC

Guests: Shaun McNeill (*Item 5*), Falyn Cranston (*Item 6*) – HQSC

Apologies: Renee Greaves, Te Rina Ruru

The meeting commenced at 9:15am

1. Introductions and welcome

Chris welcomed everyone to the meeting and outlined the agenda.

eNewsletter to give acknowledgment to Ezekiel and Te Rina on their new roles as consumer advisors with the Royal Australasian College of Physicians.

2. Minutes of the meeting held 7 March 2018

The minutes of 7 March 2018 were confirmed as a true record.

2.2 Actions update

The actions list was considered and updated.

There was discussion around

Actions:

3. Commission Partners in Care report

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

- Immediately following the consumer network meeting we had our first national forum, *Let's talk* which was a great success. The summary is included. There has been a very positive buzz following this event, and it has generated discussion about what is next. We do not plan on running a forum in 2018/19, but will likely organise an event for 2019/20.
- Chris has been involved with the bowel screening-related work. The Commission was directed by the Minister to provide support to the Ministry of Health.
- The terms of reference for the consumer network have been updated (and included in your meeting papers). Please let us know if you have any further comments.
- Our programme plan for 2018/19 as well as our budget has been approved.

- Chris and Deon were involved in short-listing candidates for the mental health and addiction programme's consumer representatives.
- We have a short-list of candidates to refresh the consumer network and will be conducting interviews next week (week beginning 25 June) with Marj.
- Chris attended a leadership forum this week.
- Deon attended an age-friendly communities' forum run by the office for seniors this week.

We have engaged with a range of individuals and organisations since March, including:

- PHARMAC - regarding consumer representation models
 - There was further discussion around this and Deon explained that there are people who are working within PHARMAC who are interested in getting consumer involvement in that area and have put in place a Consumer Advisory Group, which according to the TOR does not have any influence on the organisation. The network agreed that there was a need to have further discussions
- Social Investment Agency – data and privacy
- Children's Commission – ensuring the voices of children are included
- Auckland DHB – meeting new team
- Mortality review committees – discussion with all consumer representatives

The Consumer Advisory Group will meet with the board on 19 July.

Congratulations to Ezekiel and Te Rina for being selected to be on the RACP's consumer group!

Congratulations to Martine Abel on being awarded the Queens Services Medal.

Sample of planned activities for 2018/19:

- Piloting and rolling out a quality and safety marker for consumer engagement: the pilot will take place in three DHBs and will be rolled out in the last quarter of 2018/19.
- 'Train the trainers' for consumer representatives and staff: we will run at least two, with one occurring in the second half of this year.
- Bringing Commission consumer representatives together: we plan to hold a day for all consumer representatives connected with Commission programmes.
- Promotion of refreshed guide to working with consumers and re-promotion of PIC resources, including Let's PLAN.
- Developing video resources - themes about what made the difference and cultural aspects of care
- Promoting simple interventions to improve the patient experience (based on findings from 2017/18 work)
- Chris advised that the Commission has two other groups, the Rainbow Connection for the LGBT and supporters of the Commission staff. This group put through a

submission on behalf of the Commission to Statistics NZ to make changes to the next census. There is also the Partners in Care Champions team who are staff members from different teams and programmes in the Commission who are aiming their work to support consumers

- The two Co-design sites have been confirmed. CCDHB and also Pegasus, which is the first primary care organisation to participate.
- Work is in place to get the DHBs to respond to the Patient Experience survey, however unfortunately this is moving very slowly and is impacting on the SPEs for this financial year.

Actions:

Invite chair of PHARMAC Consumer advisory group to the next meeting of the Consumer Network. (David Lui)

4. Consumer Network Reports

Te Rina Ruru

Internal:

- Te Rina was a Keynote speaker at the Let's Talk: our communities, our health forum. She commented:
"I am humbled by the positive feedback and grateful to have all the support from our beautiful consumer network. *(Thank you Chris, Deon, Di, Maria P, Courtney and the team for your amazing support. I don't think I could have done that without you all. I appreciate you all so much).*"

External:

Te Rina presented at the Central Trauma Symposium held on 26 May 2018 at the Wellington City Hospital.

Te Rina was appointed as a member of the Royal Australasian College of Physicians along with Ezekiel:

- First meeting was held in Sydney on the 24 May 2018.
- They spent the morning getting to know everyone and sharing positive personal experiences.
- RACP provided an overview of the organisation then presented their framework for Patient Centred Care. *(Te Rina is happy to share their annual report if anyone is interested in learning about the organisation. She is also happy to share the consumer bio's if everyone would like to know who is on the consumer board).*
- They then carried out a post-it activity, where they had the opportunity to share their thoughts and experiences of their organisation and propose options for growth and engagement.
- The next meeting will be in August/September (yet to be confirmed)

Camp Unity – Teen Girls Empowerment Camp to be held on 20-22 July 2018

Marj Allan

Marj advised that the Regional Cancer Networks are doing some great work at this time and wanted to share some of this with the Consumer Network. She believed there was a need for more support for primary care.

The Southern, Midland and Northern networks are developing systems to identify and monitor how cancer patients enter the system. There is evidence that patients who enter via the emergency department have lower one-year survival rates. The Central network has focused on developing primary care cancer pathways, via Health Pathways and Map of Medicine, to support primary care to recognise and investigate signs and symptoms that may be suggestive of cancer and appropriately refer people into secondary care. This will be part of the Early Diagnosis and prevention programme the Ministry are looking at in the next Cancer Plan.

Radio Oncology Working Advisory Group

ROWAG has made some great progress in developing an online collection tool. This is the first tumour standard to have done this.

The radiation oncology collection and online tool is in the final stages of development and testing. This project enables the collection of detailed treatment data for people with cancer receiving radiation therapy across the country. The online tool makes non-identifiable and aggregated information transparent and available to cancer centres, DHBs and Regional Cancer Networks (RCNs) so they can compare treatment protocol against one another and against national guidelines.

The primary goals of the project are more equitable access to radiation oncology services across the country, alignment of treatment protocols with nationally agreed guidelines and reduce variation.

Quality performance indicators for bowel cancer

The National Bowel Cancer Working Group is developing quality performance indicators so bowel cancer standards can be measured and publicly reported. There will be a range of quality of care measures (including outcomes data) across the bowel cancer diagnosis and treatment pathway to support continuous improvement in quality and safety of cancer services. The measures will have meaning for both people with cancer and the clinicians who provide their care. Consumers, colleges, professional bodies and clinicians have all been involved in defining and selecting relevant outcomes and process measures.

The Southern Bowel Screening role out is going well; they have put out some stories of Champions whom tell their story which has been accepted well. As we know stories work well.

Multidisciplinary Meetings gap analysis

All regional cancer networks have completed reviews against the current state of MDM business processes, data capture, roles and responsibilities and the future state requirements developed by the Cancer Health Information Strategy. The Southern Cancer

Network is planning to Train the Chairs of the MDMs and work closely with the teams to streamline this process. MDMs are a positive part of Cancer Care and planning.

National Survivorship Programme

Central Cancer Network, Cancer Society NZ and the Cancer Nurses College have partnered to develop a national survivorship consensus statement. A project around survivorship is currently being scoped. It is planned that this will be part of the 2018/19 Cancer Plan.

The Patient Experience Surveys are in progress, however again it came to their attention that they do need to support Primary Care more. It is also difficult to get Māori and Pacifica to participate in these surveys.

Martine Abel

Internal to HQSC:

In April Martine attended a meeting of the Consumer Advisory Group that supports the board, where they progressed items such as, welcoming a new member to the group, Muriel Tuhono, and they started to look at some papers, discussed at HQSC Board level, either in order to provide input, or to get a feel and a sense of what kind of matters are being discussed at strategic level.

At patient deterioration level, Martine circulated a notice of the Patient Deterioration NZ Conference, planned for 29 and 30 November where the 3 major aspects of patient deterioration, which includes patient and whanau escalation, will be discussed.

External to HQSC:

At Health Navigator level Martine contributed to the National Ophthalmology Service Improvement Board which is progressing well in that they dealt with: The Service Review Checklist which lists aspects of good practice across the ophthalmology pathway and is intended to be a resource that can be used by Ophthalmology services to assess where they may have opportunities for improvement. They also finalised the Change Package which is intended to outline for ophthalmology services what needs to be done to implement the updated guidelines for AMD and Glaucoma (once confirmed). This is in draft and not yet complete but provides a summary of the approach and work that ophthalmology teams would need to undertake to identify specific actions, gather organisational support and implement new processes.

Also with Martine's Health Navigator consumer hat on, she provided advice to the MOH re its work in the area of their physiotherapy patient and whanau centred care project, in terms of web accessibility and re preparing to take a document out to the community for consultation purposes later on this year.

As Vice-President of Blind Citizens NZ, Martine had the opportunity to participate in a Work and Income work initiative to do with Front of House service improvement. A large number of issues such as inconsistency in basic customer service, inaccessibility of facilities and a demoralising and punitive social environment were raised and hopefully this piece of work will help with specific improvement strategies.

Blind Citizens NZ is in touch with Labtest NZ and the Northern Regional Alliance re the inaccessibility of the new self-serving kiosks that replaced receptionists as a human resource at all labs. Blind persons plus many others are struggling to do certain tasks independently such as knowing where to deliver specimens, knowing how to digitally scan for a number to be received so that they can get a turn to have their tests done, etc. There is a proposal on the table now that includes having a phone present on the entrance desk where people can simply pick up the receiver to be then in touch with someone who'd be able to provide verbal advice. This is still to be trialled and doesn't solve all the experienced barriers.

In Auckland they are busy planning the International Universal Design Conference, to be held on 6 and 7 September, hosted mostly by Auckland Council. Keynote speakers and concurrent presentations will be heard on connected communities, accessible tourism and transport and housing. Martine has already distributed this notice to the group.

At MOH System Transformation level, Martine is involved at the Workforce Workstream initiative which looks at co-management by disabled persons and their support staff of employment aspects, collective bargaining opportunities, education and upskilling disabled persons in how to recruit and retain support workers, etc.

Martine is also on the ACC Advisory Board re Sexual Violence Prevention.

Firstly, Martine noted down the public communication from ACC following this meeting, then, following that, she makes comment about her contribution in the disability space.

Martine Abel-Williamson – Sexual Violence Prevention ACC Advisory Board:

3 May 2018

At our 3 May meeting we welcomed a new member to the Advisory Board, Jessica Borg, who replaces Zoey Henley, our previous Department of Corrections' representative. Jan Logie, Parliamentary Under-Secretary to the Minister of Justice (Domestic and Sexual Violence Issues), attended part of the meeting, with her officials - Claire Lyons and Heather McDonald.

For the benefit of Under-Secretary Logie members gave updates on what's happening in sexual violence prevention in the agencies and groups they represent.

Under-Secretary Logie then outlined the government's direction for family violence and sexual violence, including the importance of government recognising the expertise of the sector and working with NGOs so there is a joined up / whole of system response. She explained that Cabinet agree there is an opportunity to do better, to have an integrated approach, which needs sustained cross-agency and government commitment to doing things differently.

During the meeting the Advisory Board heard four presentations:

National Council for Women

Sandra Dickson provided the Advisory Board with an overview of the Gender Equal NZ campaign for gender equality for all New Zealanders. The campaign was launched in September 2017 and includes a national gender attitudes survey to test New Zealanders' attitudes to gender equality and gender roles. The campaign also proposes a Gender

Equality Dashboard and a Gender Culture Taskforce. Sandra explained that the Gender Culture Taskforce aims to reduce everyday sexism in the media and promote a gender positive culture; she also spoke about media reporting of sexual violence.

Sexual Violence Law Reform

Megan Noyce from the Ministry of Justice provided an update on the work they are doing in sexual violence law reform. Work includes:

- Sexual Violence Court Pilots in Whangarei and Auckland (led by the judiciary)
- Providing advice to Under-Secretary Logie on options for a package of legislative reform in response to outstanding recommendations in the 2015 Law Commission report “The Justice response to victims of sexual violence”
- Operational initiatives, already underway, including:
 - developing specialist training for court staff who will interact with sexual violence victims
 - Crown Law developing Solicitor-General Guidelines for prosecuting sexual violence cases, with training for Police and Crown prosecutors to follow
 - judicial education on best practice for dealing with vulnerable witnesses in sexual violence cases, delivered by the Institute of Judicial Studies
 - developing online guidance and information for sexual violence victims and their supporters about what to expect in the criminal justice system.
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‘Are you that someone?’ Campaign

Zaffa Christian and Rick Manly outlined the proposed rebranding of the social campaign, to be aimed at young men aged 14-25 years, focused on healthy relationships and challenging social norms.

The Advisory Board discussed the proposal and was of the view that it seemed not so much a rebrand but rather a change of direction. The proposed campaign seemed to move into a space that other agencies and organisations are already working in, and within which we are trying to ensure initiatives are connected and reinforce the wider community of work. The view was that now isn't the right time for such a campaign.

The Advisory Board did not endorse the re-branding of the campaign.

Prehabilitation / Sexual Ideation Research

Dr Sarah Christofferson updated the Advisory Board on her and Dr Gwenda Willis' proposed research '*Helping them before they harm: A proposal for prevention*'. The research aims to understand the current need in New Zealand for sexual ideation support services. The research will also inform service design of support pathways for those seeking help. The research will help create an intervention framework and service guidelines for the treatment of sexual ideation.

Drs Christofferson and Willis intend to approach the research in two phases:

- *Phase 1: Intervention Development* proposes to research and create all the materials and resources needed to form the base of a sexual ideation support service. (Note: In March 2018, the Advisory Board endorsed the commissioning of Phase 1 of the research).
- *Phase 2: Intervention Pilot* would be a joint programme pilot and research project.

Update from Martine:

National Council for Women:

I've provided Sandra Dickson with the Disability Rights Aotearoa Media report, published by the Independent Monitoring Mechanism (IMM) about 3 years ago to supplement media related knowledge around disabled persons' exposure in the media.

Sexual Violence Law Reform: I draw the meeting's attention to the opportunity that ADL can provide Crown prosecutors, judges, police and others disability responsiveness training and I've passed on ADL's contact details to Megan Noyce from MOJ.

I also provided People First's and Cyndi John's details to ACC staff who're working on a resource for victims working their way through the court system, as the communicator support systems in place need promoting. Other resources I've passed on to ACC for inclusion in this resource via referencing is the work and publications by the Domestic Violence and Disability working group, ADL's details as well as other items on accessible women's refuges and research done in the field of sexual violence and disability.

Courtenay Mihinui

Courtenay attended the Patient Deterioration meeting on 31 May held in the Commission boardroom. They all watched the short documentary she had filmed earlier in the year with Jenny Hill and Laura Ellis about her experiences with her daughter, Demar's, health journey thus far. At the conclusion of the film they all engaged in a great discussion about their feelings about some of the topics discussed and they all agreed that communication is a crucial and extremely important and valuable part of improving our health care system. It was even said that Consumer/Family, Whānau engagement may need to be a project of its own because of the enormity and complexities it requires which Courtenay was very happy to hear.

Courtenay was also asked to be a keynote speaker at the Patient Deterioration Conference being held in Auckland on 29-30 November to which she accepted.

Courtenay is also part of the ACP steering group but has been unable to make 2 of the Zoom meetings unfortunately so she hasn't met anyone in that group as yet.

On a personal note, Courtenay recently turned 40 and enjoyed a surprise celebration put on by her husband which was fantastic! They have also bought 3 logging trucks so are navigating a new working routine.

Ezekiel Robson

Ezekiel provided a table covering the hours and existence of statutory advisory committees in DHBs. There are DHBs who show no indication on their websites of having these groups.

There was discussion in the group around the best way to handle this information. In the first instance it was agreed that the first step would be to work through CAG.

Traci Stanbury

As recommended by the CDHB Traci is currently studying the PostGraduate Certificate in Strategic Leadership at the University of Canterbury. Last weekend she was on a block course for Leading Change and watched 44 change proposal presentations including about 20 from CDHB staff. The vast majority mentioned co-design and collaboration and one even mentioned the Partners in Care programme. They also looked at the Collaborative vs Transactional model, and what stage to add the Co-Design in. Traci thought it was a really good tie-in to all the work the HQSC does, in particular the Partners in Care programme. I have attached the Collaborative vs Transactional model which comes from Chris Jansen & Higgins' The LinC Project (yet to be published).

In addition, Traci is meeting with the Kidney Kids CEO next week and last week met with Kidney Kids, who are trying to build regional communities of support.

Actions:

Look at the DHB data supplied by Ezekiel and prepare a more comprehensive paper to go through CAG and then take to the September Board meeting.

5. Update – Mental Health & Addictions programme

Shaun McNeill, the consumer advisor of this programme provided an update to the Consumer Network, including the following:

The Commission did a formal response to the enquiry panel and Shaun met with Ron Paterson, Josiah and ? who are also on the panel.

Shaun provided the panel with the perspectives of the Commission. This panel is looking at a wide concept of what people feel needs to change in this area.

Already had 5000 submissions and have met 4000 people around the country, so will need to go through all of this to make submissions.

Quality improve programme. Part through zero seclusion by 202 project. Meeting with half of the DHBs involved with the project which will include update presentations.

Challenges are in the forensic area due to the Corrections perspective so still a bit more resistant. The programme is using the leadership and reference group which includes psychiatrists, so have more influence. Designing a survey of staff of DHBs and NGOs in mental health to benchmark how they feel in terms of the culture and environment they are working in. Will re-survey further on to track changes.

Second project connecting care, improving service transitions. Serious events and complaints are around points of transition. Breakdowns of communication and transfer of information. This will be starting in July.

Recruiting a project manager to assist with the workload.

Consumer involvement Shaun has been invoking relationships with other consumer groups. Including developing a CAG of 6 people, which was very successful.

Marj queried whether there was going to be a co-relation between the Commission programme and one being set up for psycho-social services and support, by the cancer network. Shaun agreed that they would be looking at some of the same areas, particularly in support services in the community.

6. Draft Patient Safety Week resources

Falyn Cranston and Liz Price presented the ideas and work so far on the Patient Safety week resources and sought feedback and comments from the Consumer Network.

These resources are in development. The focus is on hand hygiene and they have identified a gap in resources, which is a poster and the Comms team will be developing a companion poster which includes cartoon bugs in graphics and animation. There will be information on each bug with the illness which can be transferred from each bug. The other poster is a clinician based one, which emphasises cleaning hands being the last thing done before touching the patient.

The CN gave different ideas in using the bugs and posters to get to as wide arrange of people possible.

Should be ready by November so would be good to push prior to the flu season next year.

Actions:

7. State of cancer inequities in NZ

Chris spoke to an email sent to the group by Maria Poynter around cancer inequities in New Zealand.

Comments were made initially about wanting a better consumer focus. Chris asked the Network for any comments or suggestions.

Ideas were taken down on the whiteboard and photographed, then sent to Maria Poynter. *(Attached)*

8. New members for Consumer Network

Chris and Deon provided an update of the EOIs received for the increased membership of the consumer Network. These have been short-listed and are now at the interview stage commencing next week.

9. QSM Consumer Engagement paper to ELT

The Consumer Network provided feedback on the QSM paper which will be going to the Board on 19 July.

Feedback included:

- Very good document
- Not sure how to get the DHBs to engage in this. Perhaps bring the Q&S people together to discuss.
- May put together a webinar as some sort of training around using the QSM.
- Chris talked to the CMOs last week, but the response was a little understated, though they were ok with the idea.
- Looking at pilot sites and have had 4 responses, and will be using 3.
- Need 2 consumers on the reference group for the pilot sites, one Māori. One or two from the DHB who are involved in the pilot, Lynne Maher.
- There seems to be a bit of push-back in the sector around QSMs. The QRMs are meeting in August to discuss the resources needed to deal with these QSMs. This is their greatest concern. Richard Hamblin will be attending this meeting.
- The pilot will help to understand what some of the barriers are with the implementation of the QSM.
- Need to make sure this is across the breadth of what DHBs do, aimed at all roles within DHBs. This would ensure there were less things falling through the gaps.
- There is a standard for payment, FTEs and structure for having consumer advisors.
- There is a need for a tick box situation where there is a firm indication that consumers have been involved.
- There is a marker which states “Level of Consumer involvement” rather than specifics like consumer councils.
- In Reviews of adverse events there is a section which notes whether the family / whanau has been contacted. This could be added to the QSM.
- There needs to be a strong equity lens through the QSM, particularly Māori and Pacific, but also covers diversity.
- Will need to have further and more in depth discussion.

10. Revised DHB Guide for Consumers

The Consumer Network reviewed the draft CE guide for 2018 and made the following comments:

Actions:

Members to send any comments of examples, corrections etc to him and he can forward to Amanda is currently holding the pen on this document.

11. Other Business

The Consumer Network discussed the Health & Disability review with the following comments:

- Where is the patient being at the centre in this review
- Looking at getting feedback for policy ideas for the next election, so will be looking at fixing some of the issues mentioned.

- There will be some debate around whether local communities should have input into health services in their areas.
- Who are they consulting with and talking to in this review. Some NGOs need to be consulted.

Actions:

Network to send any further comments to Deon around the

Deon to discuss the feedback on the review with Shelley. Deon will then ensure that the Network is advised on how this feedback is used

Close of meeting 2:56

Next meeting: Carry out a Doodle Poll for this date once the new members are instated.

Actions:

Date	Item	Action	Responsibility
7 March	6	Arrange for a PDF of the Experience year, 2017 paper to be loaded onto the HQSC website.	Di
7 March	4	Send a link to the article on Vietnam and the community programme to support nutrition.	Traci
7 March	3	Put together a list of potential candidates and CVs for the RACP consumer advisory group.	Deon
7 March	3	Send outcomes and notes from CAG to the Consumer Network.	Di

7 March	2	Health consumer councils of NZ. Contact Graeme Norton to see what the Commission can do to assist with their group.	Chris
7 March	2	Follow up item 4 23/11/2018 with Lizzie. Interviews have taken place and Stephen has taken notes. Needs to be completed.	Chris
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
14 September 2017	5	Have Ezekiel teleconference into a CAG meeting to discuss the issue with non-consumer representation on the DHB Boards.	Di / Now prior to 3 May Board