



**Present:** Chris Walsh (Chair), Deon York, Gillian Bohm – HQSC, Traci Stanbury, Martine Abel, Westin, Ezekiel Robson, Shaun McNeil, Marj Allan, Shreya Rao, Te Rina Ruru, Diane de Rochester (Minutes) – HQSC

**Guests:** Laura Ellis (*item 4*), Stephanie Fletcher (*Item 6*), Katie Mathison, Chris Jenkinson & Emma Wicks – RACGP (*Item 8*)

**Apologies:** Courtenay Mihinui, Renee Greaves

The meeting commenced at 9:00am

### **1. Introductions and welcome**

Chris welcomed everyone to the meeting

### **2. Minutes of the meeting held 22 June 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 York presented the Commission report to the meeting, highlighting the following.

- This week (12 September), we were with Dr Lynne Maher and the Commission's deteriorating patient team at Tauranga Hospital for the first co-design workshop of 2017/18. We reported last quarter that Wairarapa would be the other co-design site. They have now withdrawn citing a lack of consumer council as the primary reason.
- The pilot with Waitemata and Canterbury DHBs looking at the Always Events® toolkit will continue, with the contract soon being finalised. Both DHBs would like to work with us again. The next phase will focus less on evaluating the 'always events' approach, and more on running an improvement designed to have a positive impact on patient experience. This project will run until June 2018. The earlier report was sent to the network previously.
- Northland, Waikato and Nelson-Marlborough DHBs will take part in the next phase of the medication discharge project. We have just signed another contract with Ogilvy to continue this work. The report and their engagement with DHBs was positively rated.

- Chris recently presented at the BMJ International Quality Forum and ended up having a 75 minute slot which gave lots of time to fly the consumer engagement flag. Chris gave the Consumer Network an update on this forum.
- Deon is presenting a paper about the always events pilot at IsQua in early October.
- Our consumer forum on March 8/9 2018 – *Let's talk: our communities, our health* is progressing well and we will devote some time at today's meeting to progress the programme. All members of the consumer network will have a role to play in the running of the day of course!
- In addition to Janine Shepherd and Jake Bailey, we also have Dr Lynne Maher and Dr Lance O'Sullivan delivering keynote presentations as well as our very own Te Rina Ruru! The keynotes are a balance of clinicians and consumers to show a partnership approach.
- Deon mentioned to the group that we want involvement in the forum by all the Consumer Network. Deon requested that members think about what it is they feel they would want that involvement to be, and come back to him and Chris with these suggestions and feedback.
- Our board has agreed to the establishment of a Consumer Advisory Group at the Commission which will report to the board and work closely with all of you. The Terms of Reference (included in the meeting papers) are based on Te Roopu Maori.
- There are four members of the group. Martine will be the conduit between the network and the advisory group. Below is brief biographical information of the other three members for your information.
  - Frank Bristol (Whanganui) is the manager of Balance Aotearoa which provides peer support and consultancy services to the Whanganui DHB area. Through Balance he is contracted to provide consumer leadership, consultancy and liaison for Whanganui DHB's Mental Health and Addictions Service. He has been heavily involved in the development of community based peer run Mental Health services. He has been a speaker on self-management at various Mental Health conferences in NZ, Australia, United Kingdom, USA and Canada. He is a keen and passionate facilitator of approaches based on self-care, relationship-care and community-care philosophies embodied in Intentional Peer Support. Frank is also a member of the Whanganui DHB Community Public Health & Disability Support Board Advisory Committees, and is the consumer representative on the Central Region Clinical Mental Health and Addiction Network. He is on the National Te Pou/Ministry of Health Mental Health & Addiction Information Reference Group. He also serves on the Commission's Mental Health & Addiction Quality Improvement Programme's stakeholder group.
  - Rowena Lewis (Auckland – recommended as Chair) is a partner at North Shore-based Law firm Lewis Callanan. Rowena was diagnosed with breast cancer in 2005. At her legal practice, Rowena has an increasing number of older people as clients and has concerns that many of their health needs are not represented. These concerns and her experience of breast cancer guides her motivation to work with

health consumers. Rowena has served on many health consumer-related groups, including several at governance level such as the consumer representative on the Cross Sector Alliance Governance Group (ACC, HQSC, MOH), focusing on improving falls and fracture service outcomes for older people (2016 – present), the Cancer Governance Board for Northern Region consumer representative (2013 – 2014) and consumer member of ProCare Health Limited’s Clinical Guidance Committee (2010-2012). Rowena is former chair of the Northern Cancer Network’s Consumer Reference Group (2008-2013), and was an advisor on the implementation of the guideline into suspected cancer in primary care as part of the former New Zealand Guidelines Group.

- Lisa Paraku (Wellington) is the consumer member of the Perinatal and Maternal Mortality Review Committee and works as Head of Māori Business and Partnerships (Acting) at Spark, a role that includes developing and leading a Māori Strategy and Action Plan for Spark and developing a structure and framework to ensure meaningful engagement with Māori. She has significant governance experience through her roles on steering committees and as a Trustee of the Ahu Whenua Trust Board, and director of her Whānau Trust. Lisa has qualifications in commerce, business law, business management, Māori language and culture and has completed a Leadership New Zealand programme. She has personal experience of loss of a child and is motivated by inequitable perinatal outcomes for Māori and Pasifika babies.

#### **Actions:**

Send link to KL conference to the Consumer Network – Di

Send Powerpoint for Chris presentation to Consumer Network – Di

Come back with ideas around involvement of the Consumer Network in the Forum in March - All

#### **4. Patient Deterioration programme**

Laura Ellis, the consumer advisor working on the Patient Deterioration programme joined the meeting at 9:50am to provide an update of the programme, with the following key points:

Outlined the Kōreo mai and Co-Design initiative and provided fact sheets for the Network. These sheets explain Co-Design and the programme

The team is currently working with Co-Deisgn in the Whakatane area with emphasis on Māori and Pakifika health.

Laura went on to discuss the input of the programme in DHBs and some of the areas of difficulty, such as Pacific families feeling comfortable to speak up if they have concerns. Her belief is that one-on-one communication is much more successful than giving people a number to call. Staff need to be encouraged to listen to worries and concerns of patients.and their families.

There was a query on whether mental deterioration is also being considered. Laura advised that there has been a great deal of interest from Mental Health, so this is something the

programme will be looking at as well. Currently the emphasis is on physical deterioration, but there is definitely a move towards supporting mental health.

Martine raised the question of families being listened to when there is possibly a family member with dementia, and the issue is that the patient cannot escalate any problems themselves. Laura advised that these things are part of the project briefs and are being looked into now.

The emphasis of the project is that if someone calls, regardless of what about, they need to be listened to and their queries need to be acted on. This develops trust in the medical professionals when patients and families feel they are being listened to.

Chris suggested that the members of the Consumer Network watch the patient story videos which are up on the website.

Laura advised that the programme had evaluations on the success of the system to keep in touch with whether there has been an improvement in this area.

**Action:**

Send link to patient stories on Patient Deterioration to Consumer Network - Di

**5. Consumer Network Reports**

***Shaun McNeil***

At the end of June, and also the end of July, Shaun attended meetings of the 3DHB (Capital and Coast, Hutt Valley and Wairarapa) Acute Mental Health Pathway of Care Group, as they are co-designing a new Pathway of Care which illustrates how Adults move through the local mental health care and support system.

Shaun was on holiday in Scotland and Northern Ireland between 3<sup>rd</sup> July and 28<sup>th</sup> July.

On 7<sup>th</sup> August, Shaun attended a HQSC Mental Health and Addictions Quality Improvement Workshop in Palmerston North-as Shaun is the Consumer Member of the Sector Leadership Group for the HQSC-led Mental Health and Addictions Quality Improvement Programme. He was asked to facilitate a workshop in the afternoon of that meeting which looked at one of the Programme's Priority Areas: "Minimising Restrictive Care". The other four Priority Areas are: learning from serious adverse events and consumer experience, maximising physical health, improving service transitions and improving medication management and prescribing.

On 9<sup>th</sup> August Shaun attended Platform Central's meeting. Platform Central is a network of mental health and addiction non-governmental organisations in the lower North Island, that believe a modern mental health and addiction system requires strong community-based supports for people who experience mental illness and addictions. Platform encourages sector collaboration and provides a contact point for feedback on issues relating to mental health and addiction community organisations. Platform is currently lobbying for mental health support workers inclusion in the Equal Pay legislation and for better workforce planning in the MH and A Sector.

On 17<sup>th</sup> August Shaun participated in an Interrelate Videoconference. Interrelate is an international coalition of mental health consumer leaders, involving nine countries (Australia, New Zealand, Canada, USA, England, Ireland, Scotland, Iceland and South Africa) and celebrating its tenth anniversary this year. Interrelate aims to inspire hope and strengthen the capacity of people with mental health issues to lead national and international policy, and achieve recovery and wellbeing.

On 9<sup>th</sup> September Shaun led the Hopewalk in Wellington, as six months ago he was appointed as the Wellington Hopewalk Champion. This is the first time it has taken place in the Wellington Region and was timed to coincide with World Suicide Prevention Day on 10<sup>th</sup> September annually. Hopewalk is a suicide awareness and prevention movement, a community action group which gives individuals, families and communities, who have been effected by suicide, a place to connect with others who have also lost love ones to suicide. Hopewalk also highlights the existing organisations and agencies that provide suicide prevention, intervention and post-vention support. The walk took place in the Wellington Botanic Garden and around 250 people participated, raising awareness of the issue of suicide, commemorating those they had lost to suicide and collaborating on ideas and action to prevent further suicides in Aotearoa/New Zealand.

### ***Te Rina Rao***

#### *HQSC Internally*

- Attended the meetings with Te Roopu Maori/board meeting
- Presented at the Commission day at the Marae
- Attended the medication safety meeting as an observer

#### *External work*

- Active consumer rep on ACCs TBI whole pathways project
- Consumer rep advising in the MOH's Health Workforce Strategy
- Working with the Royal College of GP's to establish a consumer group to advise on the health equity strategy
- Planning Camp Unity – A safe haven for children affected by head injuries (to be held on the 13 October 2017).

Te Rina raised an issue of attending a meeting where they had decided to do a survey of patients and families of serious head injuries. Despite her best efforts to tell them that this was not a good idea, as it set up expectations in the families when surveys were carried out but not acting upon. Te Rina felt unsupported and became very upset and asked the group whether they had also faced this situation. Chris advised that as a group the Consumer Network were all here to support each other and talk to each other at times like this, even bring it up on Loomio for support.

### ***Marj Allan***

In July Marj attended a meeting with the Ministry of Health in Wellington for all Cancer Consumer NZ members. This meeting was called to decide how to engage in the future with Consumers throughout NZ. Deon York came along to this meeting and worked with

consumers to discuss what they really want from the health system. This was an interesting exercise, however predominately everyone came to the same conclusions.

One outcome of this meeting was the Ministry are now planning a new structure with the support of a number of leaders in the field of Consumer Work, including Chris Walsh. There has been no outcome yet but shouldn't be far away.

Marj attended the Workforce Development Conference on behalf of Kaiawhina Workforce Taskforce. This conference covered a variety of topics with some inspirational speakers. It was attended by many NGOs and people from across the workforce and health system. Unfortunately, they didn't discuss Co Design or gave a message of working together across the sector to generate a more interegrated health system. Marj feels this was an opportunity missed.

More work has been carried out on the application to the Advanced Care Plan proposal for funding to the DHBs. Hopefully a decision is getting closer.

The Primary Care Survey Advisory Group have met, and we now have Sapere doing a review on the pilot to see where to from here, and how we can better the uptake.

The South Island Cancer Consumer Group met on 11 September and invited the chairs to form the South Island Consumer Councils to attend, though most call in on teleconference. It was a very good meeting and they are all working hard and are all different, however this will be really beneficial for the inpatient experience in the future.

A reminder that it is Blue September. One man gets diagnosed with Prostate Cancer every 3 hours in New Zealand and one out of every 8 men in New Zealand get Prostate Cancer All men over the age of 40 should have a PSA Test done regularly.

### ***Ezekiel Robson***

Ezekiel detailed the on-going long delays since the October 2016 DHB elections, for community representatives to be appointed to local Community & Public Health, and Disability Advisory Committees around the country.

Problems at the Auckland & Waitemata DHBs, and Counties Manukau DHB were highlighted in this blog post.

<https://inclusiveactioneverydaylives.wordpress.com/2017/08/10/auckland-dhbs-treat-consumer-reps-with-contempt/>

which prompted this online news article

<https://www.newsroom.co.nz/2017/08/23/44327/auckland-dhbs-drop-disability-reps-from-advisory-committees>

Apart from disabled people, this cuts across all consumer / community engagement as Health of Older People, Asian and Pacific community representatives were also unexpectedly cut from the advisory committees.

Ezekiel hoped the HQSC could do whatever it could to re-enforce the principle of there being value in consumer engagement in health service planning, funding and governance decision-making, at least in the public arena, if not directly with DHBs.

*Post script: since the Consumer Network meeting another case of poor process and accountability has come to light, this time in Canterbury DHB - as per this article.*

**Action:**

Have Ezekiel teleconference into a CAG meeting to discuss the issue with non-consumer representation on the DHB Boards - Di

***Martine Abel***

*Work stemming from HQSC involvement:*

Martine liaised with staff from MOH re the development of an electronic health record, when consumer panel members were invited to do so and found the input opportunity informative, valuable and there was ample time to explore topics and issues;

*Initiatives external to HQSC but related:*

Presented on accessible and safe design of shared spaces and the work of the World Blind Union, at the Vision 2017 Congress, held at the end of June in The Hague, the Netherlands;

As part of the MOH Consumer Advisory Services Martine participated in meetings of the National Ophthalmology Service Improvement Advisory Group as a consumer rep and this is progressing well in terms of systems reviews, identifying of future work streams, enhancement services planning, etc.

Martine still participates in the Access Alliance campaign that was established to ask political parties to commit to drafting access legislation. So far both the Greens and Labour have committed. Other parties are still contemplating this such as NZ First while National is most certainly not in favour of such legislation. Work will continue post-election.

Participated in engagement opportunity by Waitemata DHB during its finalisation of its Disability Strategy;

Continued to forward to networks various items such as community notices, participation opportunities and updates of a general health and disability nature.

***Shreya Rao***

*LookUp*

Shreya helped facilitate the annual youth conference Look Up on the theme of relationships and their impact on wellbeing. This event saw close to 300 individuals taking part in workshops looking at identity, body image, safe sex and consent. Stalls from various agencies like Youthline and Netsafe were popular. Her role there was to help facilitate smaller groups and interview young people about their experience on the day. More information is available on [LookUp.org.nz](http://LookUp.org.nz)

*POD - Point of Difference*

This group has begun the last incubator for five new projects designed and run by young people to address mental health stigma in communities. To date this programme has delivered ten projects including: short films, spoken word events, youth social enterprises, and political movements. Their most high-profile young person is Lucy McSweeney who has been lobbying government for better mental health education in schools. [POD.org.nz](http://POD.org.nz)

### *ReThink*

Using funding from the health promotion agency, peer network Mind and Body has developed a free resource for educating young people about mental illnesses and addressing any stigma that may come from that. The resource is targeted at adults facilitating groups of young people and doesn't require any formal training as facilitator guides are available and easy to follow.

### *WDHB Co-Design*

The consumer team has started the process of normalizing co-design in projects. They have engaged the groups patient experience manager to begin training interested staff in co-design principles and we're all tasked with delivering a co-designed project by March 2018.

Shreya is working on a co-designed project looking at a regional mental health and addictions improvement strategy for the next five years. They are also looking at transition planning for our young people moving into adult services.

### *HQSC Mental Health Engagement*

Shreya attended this workshop to offer the team insight into improving the quality and safety of mental health services.

### *NDI - Depression.org*

Shreya was consulted on the Journal as part of the process to improve its service. She will be updated later by the project lead who she has scheduled a time with to meet..

### *Environment Audit*

Shreya is developing an audit of youth friendly services for community mental health services. This is to ensure reception and clinical spaces are welcoming. She is doing this alongside her counterpart James Boyd at Werry Workforce Wharaurau.

### **Renee Greaves**

The majority of involvement for Renee has been mostly related to Counties Manakau Health.

Renee is leading the visit to CM Health for Chris Pointon (Co-founder of #hello my name is global campaign). Chris is visiting CM Health as part of his global tour to carry on the legacy and message of Kate's work. Chris has taken twelve months out of work to pursue this dream and the promise he made to Kate.



During a hospital stay in 2013, terminally ill Kate Granger was disturbed that the staff looking after her did not introduce themselves when delivering her care. The doctor and cancer patient who has since passed away felt the absence of such a basic step was “incredibly wrong.” Her husband, Chris Pointon, encouraged her to do something about it and on 31<sup>st</sup>



August 2013 the #hellomynameis campaign was born.

The campaign, based on four simple words, reminds healthcare staff through social media about the importance of introductions. It has inspired millions of people and become a global movement, achieving over 1.6 billion Twitter impressions since 2013.

Chris Pointon now speaks on the subject worldwide, and will be coming to share the incredible journey Counties Manukau staff 25 September, 2017.

Support of CM Health Consumer Council, currently recruiting for some new positions. <http://www.countiesmanukau.health.nz/about-us/performance-and-planning/patient-and-whaanau-centred-care/latest-news-and-updates/call-out-for-new-consumer-council-members-2/>

Renee is 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.

Renee is supporting Patient Safety Week at CM Health, including a patient safety leadership walk round- focused on medication safety.

*External to CM Health:*

Renee attended a workshop by MOH- National Electronic Health Record 6<sup>th</sup> September

Renee will be judging a health care team challenge- held at AUT on 4 September

## **6. Electronic Health Record**

Stephanie Fletcher joined the meeting and distributed handouts of information around the electronic health record.

This included information based on information received from advisory groups on how best to use electronic health records.

The indicative business case goes to Parliament for approval in December. Cabinet has asked for more detailed costing.

Chris queried how much the Consumer input informed the decisions made in the proposals put forward to the Cabinet.

Stephanie advised that the information today was just an update and was aimed at finding out what else the Consumer network may want from them. They found the previous inout of the Consumer Network to be very valuable and would like to continue the relationship.

Six workshops were held with scenarios on present healthcare and asked people to consider what information they wanted and how to get it, where they would like it to go and how the information sharing would happen.

Chris advised that the Commission liked to have an indication of what feedback and information from consumers has actually been used. Stephanie advised that there would be

There was concern that despite the large budget not many consumer groups had been approached, but Steaphanie advised that this was just the beginning and there would be more consultation.

The issue was raised of future proofing and the commitment from the government to keep updating the technology.

Privacy, confidentiality, auditing will be in phase two with follow-up on any unusual activity with access.

The Consumer Network further discussed the Electronic Health Record and agreed that they would need to get further information from those who are more involved with this project.

## **7. Progress on March Forum**

Deon went through the draft agenda for the *Let's talk: Our Communities, Our Health* forum which is taking place on 8 & 9 March 2018.

The group came up with the following suggestions and ideas.

An opportunity for attendees to meet and discuss amongst themselves

Electronic interactive floor and / or wall pads

Questions which are presented electronically on screens rather than spoken.

Hats or T.Shirts which indicate who is organising the conference.

Make the Open Space a longer period of time.

Use "Let's Talk" stickers for nametags.

## **8. Consumer perspective of General Practitioners**

Katie Mathison, Chris Jenkinson and Emma Wicks from the RNZCGP joined the meeting to run through questions with the Consumer Network.

With the areas of evacuation and complaints the group felt that these areas should just be a given, rather than something at the forefront of communication with GPs and their patients.

RNZCGP advised that they were trying to establish the standards which consumers actually care about and those which are of no interest to them.

#### Cornerstone standards

- Security of information and confidentiality – rated as important
- 24 hour access to doctor etc in the case of palliative care – patients need to be aware of funding for calling out a doctor.
- Incident during procedure used for training
- Clinical correspondence governance process to ensure everything is actioned – would like to see it in plain English.
- Confidentiality, signed confidentiality agreement – rated as important but should be mandatory
- Practice teams deliver preventive care and healthy lifestyles – Should be a given, there is funding for some treatments.

Ezekiel raised the issue of upholding the human rights laws for disability consumers, which would cover these standards.

Ranked in the following order:

#### 1. Confidentiality and security of information

Timeframes with GPs. Chris raised the use of “Let’s Plan” so that patients can make the most of their 15 minutes with the GP. This is on the website, but they are unsure of how much they are used.

GPs should ask the patient firstly “What is important to them”. The standards need to be underpinned with a Consumer focus.

#### **Action:**

Send information to Di for distribution to the Consumer Network on Loomio

#### **9. General Business**

**Close of meeting 2:45pm**

**Next meeting: 23 November 2017**

Actions:

Date	Item	Action	Responsibility
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