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| Minutes of the Consumer Network meeting held on 12 September 2019, in Pounamu at the Health Quality & Safety Commission, Wellington |



**Present:**Deon York (Chair), Ezekiel Robson, Martine Abel, Te Rina Ruru, Tamara Waugh, Camron Muriwai, Edna Tu’itupou-Havea, Marlene Whaanga-Dean, Bernadette Pereira, Dez McCormack (minutes), Gillian Bohm (joined after lunch)

**Guests:**Kim Dougall (Quality Improvement Advisor, Maori), Corry Joseph

(Programme Coordinator), Lucia Bercinskas & Donna Jones (RNZCGP)

**Apologies:**Chris Walsh, Courtenay Mihinui, Renee Greaves, Fonoifafo Seumanu-McFarland, Marj Allan

**In Memory of:** John Hannifin

The meeting commenced at 9:48am

1. **Introductions and welcome**

Deon opened and welcomed all to meeting and Camron provided us with a karakia, prayer for John and waiata. The floor was opened for mention of John’s life. Apologies noted.

1. **Minutes of the meeting held 21 May 2019**

The minutes of 6 March 2019 were confirmed as a true record.

**2.1 Actions update**

The actions list was considered and updated.

1. **Interests register**

Dez spoke to this and explained the register is a governance requirement. If in doubt about what to include (whether it’s a conflict or otherwise) just list it. General rule is to list all interests. Transparency is the key.

1. **Partners in Care (PIC) report**

Deon gave the Partners in Care report.

Also spoke of Heather Simpsons report and a presentation she gave last week that Deon attended. There was some discussion around this.

Deon played the nudge videos.

PIC written report is:

**Quarterly report from Partners in Care team for the Health Quality & Safety Commission’s Consumer Network**

**12 September 2019 meeting**

Since our last meeting on 21 May all planned deliverables have been achieved in the last quarter of the financial year. We are now almost one quarter down for the 2019/20 financial year. Below is a summary of activities since we last met.

* Immediately after our last meeting we had the ‘all Commission consumer day’ on 22 May. We have included the feedback in the meeting papers. Overall, this was evaluated as a positive day. The next step will be to continue communicating with the wider group. We have done this as a team to some extent already.
* All three ‘train the trainer’ workshops were completed. The feedback on these is also included.
* On 27 May Chris and Deon met with the Canterbury Consumer Council, attending with Catherine Gerard (evaluation manager). This was to talk about the consumer engagement Quality and Safety Marker and demonstrate the data the Commission collects with a focus on how consumer councils can use it to improve services.
* On 17 June, the Commission received the Rainbow Tick. The Rainbow Tick is awarded to organisations who complete a diversity and inclusion process, which assesses whether or not a workplace understands, values, and welcomes sexual and gender diversity. It was noted by the Rainbow Tick organisation that the level of detail and evidence provided in the Commission’s self-assessment and staff focus groups, far outweighed the requirements for an organisation of its size. Although this is a Commission-wide assessment, the Partners in Care team were quite involved.
* Deon attended the Ministry of Health NGO forum on 18 June. The main purpose of this was for the new senior leadership of the Ministry of Health to be introduced to the NGO sector.
* On 27 June the Consumer Advisory Group to the board met face-to-face.
* On 28 June Dez and Deon went to New Plymouth and interviewed Jim Edwards (along with someone to film it). This is a new patient story being developed. Jim spoke at a Commission staff meeting about his late wife’s care for her terminal cancer. The video is currently being edited. We decided that a refresh of our stories is needed.
* We met with the Waikato Consumer Council on 4 July, and the Counties-Manukau Consumer Council on 11 July. Both meetings had a similar purpose to the one with the Canterbury Consumer Council. Richard Hamblin (director, Health Quality Intelligence), and Ying Li (senior analyst) attended as well. The data intelligence and partners in care teams are working together to develop the consumer engagement QSM.
* The Commission’s board met on 18 and 19 July. The consumer advisory group provided feedback on board papers, including the latest Perinatal and Maternal Mortality Review Committee’s report.
* Between 25 – 28 July Dez, Deon and Chris attended the RNZCGP’s annual conference in Dunedin. We were primarily there to promote the new resource to progress consumer engagement in primary care.
* The consumer engagement QSM reference group met on 31 July to progress the piloting of the consumer engagement QSM. The PowerPoint from this meeting is included.
* Dez, Deon and Chris met with Tracy Jourdain in Palmerston North on 8 August (Ehlers Danlos Support Organisation) to discuss a patient story being filmed in late October which will include the multidisciplinary team involved with Tracy’s care.
* Chris has responded to the Medical Council of New Zealand’s consultation on updating patient records.
* The 2018/19 co-design programme concluded in June 2019. The case studies published can be found here:
  + Case study: [Smoke-free Phillipstown – Pharmacy @ Phillipstown (June 2019)](https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Co-design-smoke-free-Phillipstown-Jun-2019.pdf)
  + Case study: [Gender-affirming care – Pegasus PHO (June 2019)](https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Co-design-gender-affirming-care-Jun-2019.pdf)
  + Case study: [Doing things better so you feel better – Travis Medical Centre/Pegasus PHO (June 2019)](https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Co-design-doing-things-so-you-feel-better.pdf)
  + Case study: [Youth self-harm – Christchurch PHO (June 2019)](https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Co-design-youth-self-harm-Jun-2019.pdf)
  + Case study: [‘We’ve got your back’ – Capital & Coast DHB (June 2019)](https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Co-design-youth-self-harm-Jun-2020.pdf)
  + Case study: [Patient scheduling – Capital & Coast DHB (June 2019)](https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Co-design-patient-scheduling-Jun-2019.pdf)
* The team has been involved in a range of Commission activities, including: the health service use atlas, progressing a kaupapa Māori approach to quality improvement, discussing the accessibility charter, cognitive testing of the primary care experience survey, development of the advance care planning consumer survey, and the Commission’s four-year strategic framework.

**New resources from the Partners in Care team**

*Progressing consumer engagement in primary care* (released 23 July)

This resource aims to support primary care providers, alliances and primary health organisations (PHOs) to progress consumer engagement in primary care. It offers context, tools and examples for primary care providers, alliances and PHOs to consider.

You can access the resource here: <https://www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/3777/>

*Nudge videos* (released 15 August)

*Video one*

What is a ‘nudge’? It’s a way of subtly influencing the choices we make, by changing the way those choices are presented to us.

Using insights from behavioural science, the Health Quality & Safety Commission worked with Ogilvy and Nelson Marlborough, Northland and Waikato district health boards (DHBs) to develop ‘nudges’ to respond to the lower-scoring areas of the national adult inpatient experience survey.

*Video two*

The results of the national inpatient experience survey consistently tell us that patients often leave hospital not knowing enough about their medications, and how to manage their condition when they leave hospital.

We worked with district health boards to co-design nudges to improve patient experience in these areas.

The ‘nudges’ included a home safe checklist to prompt discussion about medications and how to manage at home.

*Video three*

Studies tell us that patients need time to reflect when they’ve been given new information and giving it out at a time when they’re well-rested and able to absorb new information saves a person and the health system more time in the long run.

Nelson Marlborough DHB piloted calling the patient to talk about their medication side effects after they’d been discharged. At Northland DHB they changed the patient discharge sheets, cutting up, information into clearly-defined chunks, which helps health care professionals and consumers.

These small ‘nudges’ prove the biggest challenges don’t always need complex solutions.

You can access the resource here: <https://www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/3774/>

The disability charter was discussed, and Martine raised if the commission is signing up to this. Deon will follow up with Comms. Ezekiel also expanded on this.

1. **Updated Terms of Reference.**

Dez covered the changes that have been made.

1. **Consumer Network reports**

**Bernadette Pereira**

Still working heavily in the Southsea’s Health Care Trust to solidify the organisation's Council for Consumers.  In addition, the Health Provider is looking at partnerships with the other South Auckland Health Providers in the Primary Health Care for strengthening the ability of joint funding proposals in view of likely outcomes of the Heather Simpson's review of the health system.   Southsea Healthcare is also developing a model of care with consumers at the centre of its practice and delivery of services.  BP's participation at the HSQs Train the Trainer will benefit the organisation with the training carried out for the newly formed consumer council for the organisation.

Bernadette is also running for the CMDHB board for the upcoming local body elections. Good luck Bernadette.

**Camron Muriwai**

1. **NDHB – Ground Round presentation – Serious Conversations**

Guest speaker alongside the Northland/Hospice/palliative team. An opportunity to share a personal journey with a daughter on the palliative pathway.

1. **NDHB – Serious Conversations**

Invitation to discuss this journey in a small group. Opportunity to offer a cultural lens.

1. **Society of Paediatricians conference – November 2019**

Invitation to share our Journey with a child living with bronchiectasis and where we are now.

1. **The Royal Australasian College of Physicians**

EOI – Consumer representative – Awaiting confirmation

1. **Respiratory and Bronchiectasis Symposium – 2020**

Planning of hui in Northland well underway with speakers working in the respiratory field. Margareth Broodkoorn (Chief nurse, MOH) is our special guest, keynote speaker opening our symposium for 2020.

**Special celebration**

My wife and I are now great grandparents to a beautiful boy named Maletino.

**Edna Tu’itupou-Havea**

Very busy with a focus with students’ curriculum in the Mental Health area for Pacifica. Edna providing a focus on patient experience through students being at the frontline.

Still working on completing her degree.

**Ezekiel Robson**

First time dad. So very busy! Also standing for CMDHB board. Good luck Ezekiel.

Attended the Health & Disability service standards review workshop in Auckland. The standards effect many providers – aged care, mental health, home care etc. The standards are an audit tool. Invited to go on a working group for consumer rights. This is a large and ongoing process (until March 2020) and as the review determines regulations, it is very high level.

**Marlene Whaanga-Dean**

* We have a new WDHB CEO Dale Oliff who attends our Consumer Council Hui’s she is well involved with our group. The CEO would like to have the Council become more visible with the ability to voice at the Wairarapa District Health Board (WrDHB) meetings and input into strategic documents.

Informing our people that we have a Wairarapa Interpreting services that are available for the GP clinics where there are language barriers. Service is called Language Line, provided through Tu Ora (Compass HEALTH)

**Procedure for accessing translators**

* Patients have the right to communication, which in some circumstances, may require the use of an interpreter.
* Assess the appropriateness of using a family member or friend that the patient may have brought with them, to act as an interpreter.
* If an interpreter is still needed, contact an interpreter service. This may be accessed through your local DHB or other reputable interpreting agency.
* The cost of an interpreter is passed on to the patient. SIA is available to help towards the cost.

**Networking/collaboration**

**Survey**

The Central Cancer Network has secured funding to run a series of hui in the lower North Island and we are fortunate to be able to host one of these hui in Wairarapa. This hui is scheduled for 28th September at the Carterton Events Centre.  Free busses will come from Masterton to Carterton and Martinborough, Featherston, Greytown to Carterton. This Panui has been shared in our ropu/community.

This is a hugely important hui and an opportunity to hear the collective Māori voice.  Māori continue to experience cancer at a much higher rate than non-Māori and often present later when the cancer is much more advanced.

The Central Cancer Network needs to hear the voice of the people so they can lobby for change and a system of care that resonates with our whanau.

**Mental Health Initiative (launch)**

Attended Piki mental health Imitative launch held 23 Aug Carterton Events centre (piki website). A free youth 18-25 mental health pilot to support mild to moderate mental health easy access on line, easy navigation, intervention –prevention this is expected to be in full operation across the 3 greater Wellington DHBs.

Working closer with Whaiora GP Practice - (Health care home initiative) Data gap analysis, what are the barriers for individual’s non-attendance – looking at our diabetic population and identifying non-attenders.

Working together with primary care and community health workers for those that haven’t been followed up or DNA appointments prioritising for MDT hui’s that we have on a weekly basis.

Attending Train the trainer – 11 September 2019

Member – Consumer Council WDHB

Member - Integrated Advisory Group first meeting on the 11 July 2019

Invited on the Consumer reference Group – Te Ora

**Martine Abel**

No quorum for the CAG on 10 Sept. Other activity:

* Commission staff have contacted the Ministry of Health to procure a presentation slot in the upcoming meeting of their Consumer Consortium meeting, this to occur in November,
* The Commission hasn’t as yet made plans to write to the Disabled Persons Organisations (DPO) Coalition as we need to be specific about our main messages, what we can offer, etc.
* Commission staff presented on progress around the Performance Improvement Framework (PIF) review that CAG contributed to as part of the external review,
* 5 reports to the board were received for us to comment on, which covered areas such as adverse health events, Maori suicide prevalence, mortality reports, etc.

**Tamara Waugh**

MH Suicide prevention strategy for 2019 -2029 report was released this week.

Discussed the creation and positions of the new Mental Health & Wellbeing Commission that has been set up with 4 members plus a chair. This group will be responsible for putting the ACTUAL commission together over the next year and half. The new commission will be formed in 2022.

Tamara’s Yale project is to explore the potential for positive improvement of the ACC Sensitive Claims process through a lived experience lens. She is working on how this may be formed in a video story-telling piece. Tamara will be graduating from Yale in December this year.

Changing Minds is hosting a National hui for Rakau Roroa participants and stakeholders in Nov in Auckland. This will be the first time all the ‘Tall Trees’ of the program will be connected and there will be an awards evening to celebrate some of the lived experience leaders’ projects that have been delivered across NZ communities this year.

Tamara has been appointed to the Equally Well strategic leadership interim group that will build the ACTUAL group that will lead Equally Well 2020 onwards.

Tamara has also been appointed to the Income Generation committee of Help Foundation

**Te Rina Ruru**

Presented at the NZ Healthcare Forum on the 1 July 2019.

Heavily involved in the organisation of a Camp Unity event “Rise Up”; for Children impacted by brain injuries. The Commission is sponsoring this by paying for illustrators to capture the event in pictures that can be shared after the event.

**Marj Allan** (provided in her absence)

**Kaiawhina Workforce Taskforce Workforce:**

July 23rd

Gave my feedback To the Health and Disability Workforce Strategic priorities and Action Plan, was unable to attend in person. This is a really important Document which works right across the Health Sector.

**South Island Cancer Consumer Group:**

July 22nd.

Again, gave my feedback but was unable to attend. The Co Design work with Commission was discussed in Depth, resulting for the establishment of Consumers to be involved in this work. We also finalised our work plan to align with the Southern Cancer Network.

**The Patient Experience Governance Group,**

August 23rd.

I attended this meeting via Zoom. This group is setting a data access matrix for this data. Including access for research purposes.

**Patient Experience Atlas.**

This has just been finalised it is a fabulous tool. pls take time to visit this site via the Health Quality Safety Commission web site.

1. **Primary Care Road Map**

Kim presented the Road map. The notes below are from the PP pres.

**Sector feedback and themes … How do we achieve quality improvement at scale in primary care?**

**Whakakotahi -origins**

Increased focus on primary care

Build quality improvement capability

Primary care led projects, focused on: Equity

Consumer engagement

Integration

**Whakakotahi -projects**

Quality Improvement Collaborative methodology

Build capability and identify initiatives suitable for implementing at scale

2017-3 projects (diabetes, gout, care post-MI)

2018-6 projects (diabetes, skin infections, access, workplace health, asthma)

2019-9 projects (3 have medicines access equity focus –PHARMAC partnership)

**A growing focus on equity**

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| 2017 – 3 projects:  All in general practice, one integrated with the DHB.  2 VLCA practices with high need populations  2 projects centred on Māori, Pacific peoples and areas of high deprivation.  2018 – 6 projects:  4 general practices (VLCA),  1 pharmacy (Hastings),  1 NGO Kaupapa Māori Health organisation (Tauranga Health, Gisborne).  All projects centred on Māori, Pacific peoples (Tuvaluan) and areas of high deprivation.  2019 – 9 projects:  Equity weighted in selection criteria.  7 embedded in general practice (6 VLCA),  3 pharmacies, 4 Iwi and Māori Health organisations and the Tongan Health Society.  All projects centred on Māori, Pacific peoples and areas of high deprivation.  **Whakakotahi 2019**  Local Doctors Otara, Tāmaki Health, Auckland –Diabetes  South City Health, Hamilton –Eczema  Victory Square Pharmacy, Nelson –Improving physical health in opioid substitution treatment clients  Te Whānauā Apanui Community Health Centre, Te Kaha –rural medicines management  (Medicines Access Equity)  Mt Eden Pharmacy & Mt Eden Correctional Facility –Asthma management  Taumarunui Community Kokiri Trust, Taumarunui –Diabetes  Tongan Health Society Auckland –Diabetes (Medicines Access Equity (MAE))  Westbury Pharmacy and Hora Te Pai, Kāpiti –Gout (MAE)  Te Taiwhenuao HeretaungaTrust, Hastings –Eczema (0-4 years)  **So how do we go about spread and scale in NZ Primary Care?**  Engage stakeholders including Māori equity expertise  **The Roadmap Objectives**  understand barriers and enablers  perspectives on quality improvement collaborative methodology  develop a deeper understanding of the primary care context  understand the potential role of a central agency such as the Commission  **inform our approach for an action plan required to drive scale and spread.**  **Key underlying themes**  *“We firstly need a definition of quality from tangata whenua”* (Te Tumu Whakarae)  *“Focus on EQUITY or go home….”* (CEO PHO)  *“Start with patients -ask people what they want”* (Chair of a DHB Consumer Council)  *“We have chronically underinvested in QI with regards to rigorous attention to data.*  *Managing and utilizing data to achieve system-wide improvement in each practice that can*  *then scale up. We need much smarter data sharing”* (CEO PHO)  **Impact of socio-economic determinants of health**    **RECOMMENDATIONS**  <https://www.hqsc.govt.nz/our-programmes/primary-care/publications-and-resources/publication/3740/>  Seek tangata whenua definition of quality & quality improvement  Investigate the collective impact model + shared national vision + plan      **Continue to build capability**    **Consider Primary care QI collaboratives**  **image006**  **ACTIONS UNDERWAY - Driving an integrated approach**  Intelligence Hub -Improvement Hub alignment  PCEAG  Partnership -PHARMAC  Partnership / cultural advice / guidance –Te Tihi  Integrated Advisory Group (primary and community care)  Plan of action to respond to sector feedback  Advancing Māori health outcomes –a priority  **What is still to be done?**  2019/20 immediate focus –continue active support for 2019 projects & QIF participants  Seek support to develop ‘Change Packages” test our focus on a few topics –  partner to gather evidence e.g.: Gout –build knowledge repository of tools/resources.  Position programme for next 3 year phase -scale & spread regionally with partners through  a collective impact model, & alternate years ‘QIF/Challenge’ to support innovation.  Grow investment in this area and look to how we strengthen Qi activity  (with appropriate use of data and intelligence), and capability building.  **“Māterongo, ka mōhio, Mātemōhio, ka mārama, Mātemārama, ka mātau, Mātemātau, ka ora.**  *“Through listening comes awareness, through awareness comes understanding,*  *through understanding comes knowledge, through knowledge comes life and well being.”*  **Discussion**  What should the next phase of Whakakotahi look like if we want to make gains in advancing  Māori health and equity –with consumer engagement as fundamental platform to all that we do ?  <https://www.hqsc.govt.nz/our-programmes/primary-care/>   1. **New consumer resource**   Deon spoke about the new resource and copies were handed out. Hard copies are available  on request and a soft copy is also on-line.   1. **RNZCGP’s – Quality Standards review**   Lucia & Donna presented the papers previously provided and the series of questions included.  There was good engagement from network members and much feedback was given on how  Doctors and practice staff can best communicate and personalise their visit. |

**Other business**

A couple of reminders from Dez:

If not advised, please provide any updates of your bio’s for website please.

Please advise any updates to the interests register as you become aware of them.

**Close of meeting at 3.10pm**

**Next meeting: 14 November 2019 at the Commission**

**Actions list**

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| **Date** | **Item** | **Action** | **Responsibility** | **Outcome** |
| 18 October 2018 | 4 | Load the link for the Bronchiectasis Foundation NZ to the Commission website | Di | Comms to ring Camron for bullet points and to get link to their website |
| 6 March 2019 and 21 May |  | Finding an Asian (Chinese) consumer for network. Feed any suggestion to Chris/Deon/Dez | All | Work in progress to call for EOI for 3 vacancies on our network |
| 21 May | 5 | Train the trainer for CN members | Dez | Completed 11 Sept |
| 21 May | 5 | Ezekiel to provide background and proposal for a disability train the trainer that PIC will support | Ezekiel | Ezekiel & Deon have discussed. More progress can be made after elections in Nov this year. We can make a start with other council groups. |
| 12 Sept 19 |  | Send accessibility charter to the network | Dez |  |
| 12 Sept 19 |  | Talk to Falyn about intent for HQSC to sign up to disability charter as discussed in this hui | Deon |  |