



**MY MEDICATIONS:  
IMPROVING CONSUMER-CENTRED  
MEDICATION MANAGEMENT  
COMMUNITY CONVERSATION**

**PREPARED BY**

DEB LANGRIDGE

*Head, CCIP Program*

AND BRIONY ABRAHAM

**SUMMARY REPORT  
NOVEMBER 2022**

# S T I L L L E T T E R S

02.

Acknowledgements

03.

What is the Consumer and Community Involvement Program

04.

What is a Community Conversation?

05.

Background

06.

Agenda

07.

The Community Conversation Team

08.

About the Community Conversation

09.

Key Themes

10.

Community Conversation Questions and Responses

18.

Community Conversation Attendee Evaluation

# ACKNOWLEDGEMENTS

## Acknowledgement of Country

The WAHTN CCIP Program acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders both past and present and pay respect to Aboriginal communities of today.

Thank you to all of the consumers and community members who attended the online Community Conversation. We couldn't have done this without any of you.

We'd also like to acknowledge the team from the University of Western Australia and the Consumer and Community Involvement Program (CCIP Program) support team for their hard work in successfully delivering the Community Conversation. Our heartfelt thanks.

## Acknowledgement of Lived Experience

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.



# WHAT IS THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM?



The Consumer and Community Involvement Program (CCIProgram) supports consumer and community involvement across the Western Australian Health Translation Network (WAHTN) partner organisations.

CCIProgram's **Vision** is to improve lives by ensuring the community's voice is heard and understood in health research

CCIProgram's **Mission** is enabling consumer and community involvement in health research by supporting and connecting community with researchers, partners and policy makers.

In order to achieve CCIProgram's Vision we:

- Are inclusive
- Trust, respect, support and value each other and those we work with
- Work as a team
- Are relevant and sustainable so as to make a difference.

# WHAT IS A COMMUNITY CONVERSATION?

## In person

A Community Conversation is an event using an abridged version of the World Café Method, known internationally as an easy-to-use format for creating open conversations around questions of importance to a specific topic.

To effectively capture what's discussed, around 6-10 community members are grouped at tables with a facilitator who directs the conversation. Specific questions relevant to the subject matter are discussed in an open and friendly environment.

All comments are written on paper and used to develop a report from the conversation.

The benefits of using this method include:

- Everyone having an opportunity to answer all questions
- Community members are encouraged to engage in conversations in a comfortable space
- Having diverse perspectives which are valued and respected
- Community members are encouraged to hear and explore different ideas
- The opportunity to build a foundation of trust among community members and facilitators

## Online

An online Community Conversation is an event using Microsoft Teams for creating open conversations around questions of importance to a specific topic.

To effectively capture what's discussed, around 6-10 community members are sent to a break out room with a CCIProgram facilitator who directs the conversation and a scribe who takes notes on paper of all the comments made by community members. Specific questions relevant to the subject matter are discussed in an open and friendly environment.

All comments are used to develop a report from the conversation.

# BACKGROUND

The University of Western Australia Geriatric Medicine team had generated 10 recommendations to 'Integrate healthcare to provide multidisciplinary consumer-centred medication management' following the National Stakeholders' Meeting on Quality use of Medicines to Optimise Ageing in Older Australians. (Page, Cross et al. 2018)\* Although these recommendations have face validity given the detailed health professional involvement, the working group included only one consumer and detailed consumer validation of the recommendations, and priorities for implementation research, would add substantial value. This low level of involvement of a person with lived experience needed to be rectified.

Work to date in quality use of medicines has generated cross discipline interest from the University of Western Australia Medical School, Allied Health and Population Health, evidencing the broad interest in these research questions. The Community Conversation embraced this interdisciplinary team of researchers.

The Community Conversation aligned with internal and external priorities (for example the World Health Organisation's Third Global Patient Safety Challenge: Medication Without Harm), and the recognition of Quality Use of Medicine and Medicine Safety as the 10th National Health Priority by the Australian federal, state and territory health ministers).

We have a substantial track record in carefully considering the facilitators and barriers to improved medication use, however to date have used an ad hoc (i.e. project by project) approach to consumer involvement in the design of our research questions.

The community conversation allowed us to synthesise the consumer priorities that will help us achieve Integration of healthcare to provide multidisciplinary consumer-centred medication management. This will benefit our research by allowing us to systematically integrate consumer priorities into our research program, and will be a further step toward ongoing consumer leadership in our research program.



*Do you take complex or multiple medications, or care for someone that does?*

**My Medications: Improving Consumer-Centred Medication Management Community Conversation**

Too many medicines? Medicines side effects? Confused about medicines? In this community conversation we will explore consumer priorities for improved medication management, particularly among older people, or people who have complex medication management needs.

**Wednesday, 30th March - 6pm to 8pm**  
Online via Zoom

To find out more and register your attendance:  
Scan the QR Code  
Follow the link: [https://bit.ly/MED\\_Mgmt](https://bit.ly/MED_Mgmt)  
Registrations close: **March 25**

**A \$70 payment is offered to those who attend**

WAHTN THE UNIVERSITY OF WESTERN AUSTRALIA WESTERN AUSTRALIAN CENTRE FOR HEALTHXAGEING Consumer and Community Involvement Program

\*Reference

Page, A. T., A. J. Cross, R. A. Elliott, D. Pond, M. Dooley, C. Beanland, C. D. Etherton-Ber. Integrate healthcare to provide multidisciplinary consumer-centred medication management: report from a working group formed from the National Stakeholders' Meeting for the Quality Use of Medicines to Optimise Ageing in Older Australians. Journal of Pharmacy Practice and Research 48(5): 459-466.

## My medications: Improving consumer-centred medication management Community Conversation 30 March 2022 – 6pm to 8pm

### Agenda

<b>5.45-6pm</b>	<b>Connect via MS Teams</b>	<b>All</b>
<b>6.00pm</b>	<b>Welcome</b> <ul style="list-style-type: none"> <li>• Acknowledgement of Country</li> <li>• Welcome to the workshop</li> <li>• Introductions</li> </ul>	<b>Deb Langridge</b>
<b>6.15pm</b>	<b>Presentation &amp; questions</b>	<b>Prof. Chris Etherton-Beer</b>
<b>6.30pm</b>	<ul style="list-style-type: none"> <li>• Process of the evening</li> <li>• Consumers to break out rooms</li> <li>• Facilitators will do a quick introduction of all present</li> </ul>	<b>Deb Langridge</b>
<b>6.35pm</b>	<b>Question 1 (20mins)</b> What are your major concerns around your current medications or when being recommended for new medications?  <b>Question 2 (20mins)</b> What resources most help you manage your medications?  <b>Question 3 (20mins)</b> Where do you see the use of technology to manage your medications?	<b>All</b>  <b>All</b>  <b>All</b>
<b>7.35pm</b>	<b>Room facilitator feedback</b>	<b>Room facilitators</b>
<b>7.50pm</b>	<b>Next steps &amp; questions</b>	<b>Deb &amp; Chris</b>
<b>7.55pm</b>	<ul style="list-style-type: none"> <li>• Evaluation (<i>Link will be sent via email post conversation</i>)</li> <li>• Honorarium payments</li> <li>• CCIP program newsletters and membership.</li> </ul>	<b>Deb</b>
<b>8.00pm</b>	<b>Close</b>	

# THE COMMUNITY CONVERSATION TEAM



## **Deb Langridge, Head of the CCI Program:**

Deb has worked in the public health and prevention space at all levels of government – Federal, State and Local – and not for profit sectors to contribute to the health and well-being of communities. She has worked to capture the voices of all parts of community including access and inclusion, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, children and young people, mental health, health and community services. Deb has been the Chair of Advisory Groups in both NSW and WA. She has always worked connecting community, government, and community with a well-being focus, and was a representative on WA Sustainable Health Review with this in mind.

Deb's role leading the Consumer and Community Involvement Program as a platform of the Western Australia Health Translation Network is to connect researchers in WA Universities, Medical Research Institutes, Government, and Health Service Providers with people with lived experience to support and encourage best practice research. Deb is passionate about ensuring research can impact policy, practice and wellbeing of communities and enjoys bringing people together to make a difference.



**Professor Chris Etherton-Beer, Lead Researcher:** Is a Professor in Geriatric Medicine at the University of Western Australia, and a Medical Co-Director at Royal Perth Bentley Group. In addition to geriatric medicine, he has specialist clinical qualification in clinical pharmacology. Christopher serves on the Pharmaceutical Benefits Advisory Committee and chairs the Western Australian Therapeutics Advisory Group. Christopher has research interests in pharmaco-geriatrics, stroke, aged care and medical education.

Thankyou to CCI Coordinators Kat Stewart, Kerry Mace and Corinna Musgrave for their assistance in facilitating the conversation with community members.

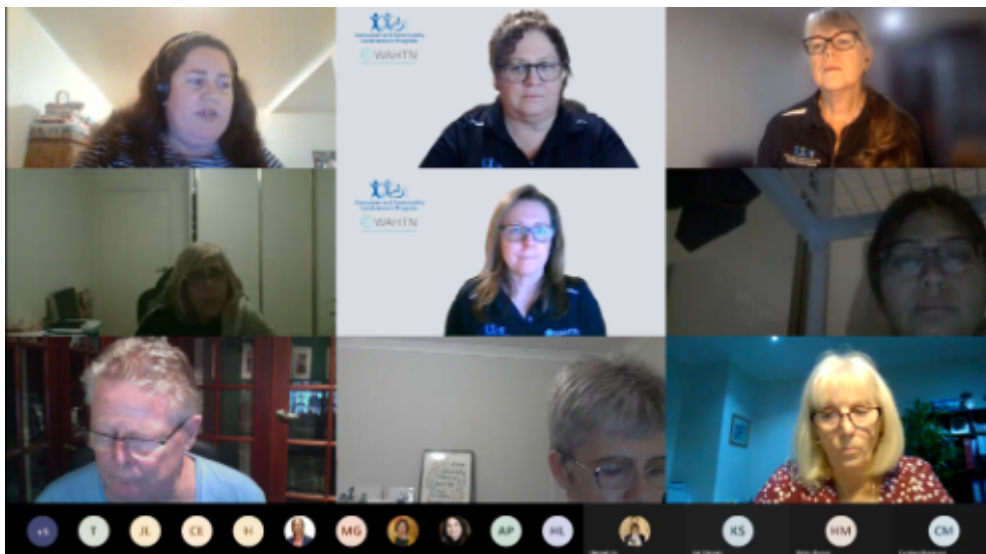


# ABOUT THE COMMUNITY CONVERSATION

On Wednesday 25th March, 2022 20 community members with a lived experience of taking complex medications or caring for someone who does, four members of the Consumer and Community Involvement Program and one researcher from the University of Western Australia joined the Community Conversation online via Microsoft Teams to participate in an online (Microsoft Teams) Community Conversation on complex medications.

In this Community Conversation the aim was to explore consumer priorities for improved medication management, particularly among older people, or people who have complex medication management needs.

***"We are the experts in our lives and the medication side-effects. Consumers need teamwork with health professionals: information, communication, negotiation about advantages, disadvantages and mutual respect."***



# KEY THEMES OF THE COMMUNITY CONVERSATION

Subject	Consumer issues/comments
Medication supply	<ul style="list-style-type: none"> <li>• Due to floods and COVID-19 border controls</li> </ul>
Long Term Effects	<ul style="list-style-type: none"> <li>• Effects on body if taking more than one medication.</li> <li>• How can a pharmacist safety advise what the cut off should be?</li> <li>• How long can I safely use this particular drug?</li> <li>• Weight gain - no warnings</li> </ul>
Medication Management	<ul style="list-style-type: none"> <li>• Labelling on medication, visual symbols, apart from one tablet in the day, stickers – day/ time – sun or moon</li> <li>• Labelling complex combinations and use of technology</li> <li>• Making rapid changes to medications throw people in to crisis</li> </ul>
Generic brands	<ul style="list-style-type: none"> <li>• Are they as effective as more expensive brands? How will you know when you are unsure?</li> <li>• Government won't subsidise name branded, only generic brands</li> </ul>
Side effects	<ul style="list-style-type: none"> <li>• Interactions of different medications taken</li> <li>• Antidepressant side effects</li> <li>• Had to Google the side-effects and adverse reactions</li> </ul>
Role of technology	<ul style="list-style-type: none"> <li>• With older/elderly people, applications can be frustrating for some, not everyone is competent or confident using the apps</li> <li>• My Health Records - a central place where all medications are listed: alternate medications could be listed</li> </ul>
Telehealth	<ul style="list-style-type: none"> <li>• Valued by consumers in rural areas</li> <li>• Very useful to have Telehealth with hospital pharmacist</li> </ul>
Plain language	<ul style="list-style-type: none"> <li>• To be able to manage medications and make it user friendly</li> <li>• Too many acronyms in pharmaceuticals</li> </ul>
Rare diseases/ conditions	<ul style="list-style-type: none"> <li>• It can be very difficult to access this type of information</li> </ul>
Psychological medications	<ul style="list-style-type: none"> <li>• Side effects of these medications</li> <li>• Dangers in this area</li> <li>• Better monitoring needed</li> </ul>

# COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

The following pages contain the responses and thoughts shared by attendees at the Community Conversation. They are categorised according to the three questions asked to inform the research team regarding people's lived experience and medication use.

## QUESTION 1

### WHAT ARE YOUR MAJOR CONCERNS AROUND YOUR CURRENT MEDICATIONS OR WHEN BEING RECOMMENDED FOR NEW MEDICATIONS?

**PROMPT:** Do you have any problems accessing these medications? Or side effects? Or interactions when you have multiple medications? These are some of the things that we really want to hear your feedback on. Plain language around the medications you are taking. Are you understanding the brochures you are getting? Anything about COVID about your medications?

- The floods in Eastern states – affecting medication supply.
- Long term effects of the build up in the kidneys of my body: if you are on regular medication, what is the safety of that? How can a pharmacist safety advise what the cut off? How long can I safely use this particular drug?
- Thoughts around generic brands: Are they as effective as the more expensive brands? Will the pharmacist say which one will you prefer? How do you know especially when you feel unsure?
- Husband takes xxx reflux medication and xxx: Generic brand does not work. The pharmacist looked confused. This particular medication finds it not effective.
- I am on so many medications, - cancer, other medical symptoms: Cholesterol: Only have the branded one, not the generic, Government won't subsidise the name branded, only the generic brand. On a pension, it costs a fortune to pay the full price for the name brand. Take another medication to take onto it, and then another one to bring it down.
- As we get older, we can overlook some side effects because we think as we are getting older it is normal to feel a certain way so we do not question it.
- Concern with psychiatric medications, overprescribed, without informed consent, side effects not being communicated.
- What is prescribed and how it is prescribed
- Have you asked for information and it hasn't been provided?
- We think that antidepressants are the easy answer – they are asked for and doctors are prescribing them without dealing with the issues, how hard they are with withdrawals. Side effects that they didn't have before.

- Anti psychotics, thinking they were anti depressants
- Weight gain as a side effect, no warning
- Some people do not get people to remove themselves from these medications after because they are deemed unfit or medically incompetent or not treated properly, and hence cannot take themselves off these medications.
- Mental health patients are often not listened to.
- Side effects, anti depressant (Three people agreed)
- Psychological medications
- Danger in this area (psychological medications)
- Making rapid changes to peoples medications which throw people into crisis.
- I have battled with psychiatric meds

### **Common points:**

- Rapid change
- Have a crisis
- Crisis is blamed on mental illness
- Medications changed again
- Destabilising people further. People are released from psych ward before medications are stabilised, doesn't need a longer stay
- More requirement of better monitoring
- No informed consent in Australia does not seem to exist
- Spoken to pharmacists - they ignore and minimise concerns about drugs.
- You don't receive prescriber, it was significant dumbed down and received consumer information instead,
- Simple information is ok, but danger is that people miss the full story – especially anti psychotics
- People when commenced drugs aren't warned, but how common these things can be
- Withdrawals are not understood competently by clinicians, withdrawn far too rapidly, sending people to crisis situations.
- Area that could deal with a meeting of its own (withdrawals)
- Only reviewed if someone has a crisis or has an adverse drugs
- Too far by the time it is discovered
- Misunderstandings between generic medicines
- Bioequivalent and ones that aren't (generic medicine)
- Maxallon and Pramen – aren't bioequivalent but people think they are (generic medicines)
- More education in this area (generic medicine)
- Management: Labelling on medication, visual symbols, apart from one tablet in the day, stickers – day/ time – sun or moon
- Colour or symbol system to help people to track how many medications they are on, people can get confused or overwhelmed, Different brands but they are taking the same thing.
- If you have been to a naturopath, Suggesting that to GP or Specialist often ignored or "in the outs" and feels dangerous and should be considered, especially if it is helping them with symptoms.

- Complex cardiac medications: Accumulation of medications, another diuretic – ended up in emergency with low BP
- Role of technology with older people going to a GP, finding the scripts on the phone: - alarms, timers. Knowing which medication and the timer and the monitoring with that, role of chemist with medications: support from them.

### **Microsoft Chat Comments - Question 1**

- Always concerned about side effects and interactions
- Had one drug threw my kidneys out
- Long term use of the same medication concerns if there are side effects later
- The health professional explained the medications, but it was all full of medical jargons and medical terminologies -finally I had to google the side-effects and adverse reactions
- Is your focus going to be on the challenges on using medications or how the meds impact us? - Great question XXX. I work with Chris, so I'll try and monitor the chat. We are actually interested in both angles. Research has focused largely around how the medicines affect people, but we are wanting to know too about the challenges for you about using medicines.
- PBS Schedule - it wasn't clear if the medication was on the revised list
- Generic brands are they are as effective as the expensive brands
- TGA has got options to report the adverse reactions, but it was not publicised or promoted by the Pharmacist
- Etimibe also called Zient ... who would know that??
- Guinea pig my elderly mother who is 88 years of age was recommended anti-depressant but with the severe side effects she had of the 1st one then moved to the next one to the point when she did not want to take any at all
- My concerns are with psychiatric medications 1) being over-prescribed for minor problems, 2) being prescribed without informed consent about side-effects and difficulties of withdrawing and 3) problems as prescribers often dismiss consumer complaints about side-effects and are not willing to discuss dose decreases, trying other medications or going medication free.
- Cost of medication sometimes varies according to IP or OP and prescribed by GP or Specialist and reason e.g., condition treated
- Written informed consent for meds that cause dependence needs to be introduced.
- I relate to the monitoring of medications particularly when the dosage is increased. Net result I felt worse than when I was admitted. It did settle down, but I was not warned!
- Thank you for being brave enough to call this out - my brother was severely impacted by these drugs & it was overlooked because he had an intellectual disability.
- While in hospital following a knee replacement, I was prescribed 2 or 3 different analgesics. All were given at different times at what appeared to be the choice of the nurse on duty with often no discussion or my choice.

## QUESTION 2

### WHAT RESOURCES MOST HELP YOU MANAGE YOUR MEDICATIONS?

**PROMPT:** Technology, who in the community helps you, what sort of access and support.

- Social media
- Trial with people with autism and the side effects of this medication
- Student assigned that I can call and text, Facebook, Instagram when I have a question, found very useful
- Elderly parents living at home: Medications in a blister/webster pack, morning and lunch compartments, the pharmacist packing and dispensing that every fortnight. Doctors and pharmacists help us check them, medication that need to be changed,
- Side effects – are they worth it in all the cases.
- CDWA: Forums, websites to learn more about the medications
- Regional Hospitals: Health advisory groups, health professionals and website. Allied health, Pharmacists, women health centres, advocates themselves, member of parliament, health professional: Lobby for prescription drug to be on PBS drugs.
- Heart transplant: fill it in myself (massive Webster pack). First time doing it took me three hours, found it difficult.
- The Alfred is well set up: they have Pharmacists who speak to you and train you on how to fill out the Webster pack. I can now do it easy, but its been three years
- Medications are a big part of my life. I tried to use some of the computer programs, from chemist warehouse, it didn't work for me.
- Main provider with The Alfred, team of people – cardiac. Pharmacy is part of that team – some best from hospital, others through the pharmacy. Some of the medications are quite dangerous, Can't let anyone else handle the drugs. Find the facility useful, available by telephone, but that is because it is so complicated and because there is funding on that support.
- Lung cancer patient: Various medications, chemists and GP cannot always keep up. Resource with the closed group of people that are under the same regiment of immune, chemotherapy. More from them than from anyone else, including professional. Closed group of patients with particular illness, rare cancers – particular mutation. Communicate with people.
- GP and Specialists - particularly focused on their own areas/specialities. Partner was recently in hospital with viral respiratory infections – ignored his cardio problems and was prescribed medications that would interfere with his kidneys. Only found out through Google. Have to be well protected by getting as much information as we can, this is a hazard that I came across.
- What makes you trust the source that you are looking at? Science based, research papers. Chronic kidney disease – surprised to find that definition of chronic kidney disease. Malfunction – how much? More or less?

- Facebook groups: peer support, one group for psych drugs, only way they can obtain information (Facebook group). Have access to accurate information. Peer support for here is on top of information. Huge difference depending on drugs
- XXX was given a medication list, that was too complicated to read and a discharge notice. He had thrown them in the bin. XXX needed: plain language, a note with dot points, what he needed to look out for, adverse effects that are needed in the emergency room
- Apps (Applications): Stigmatising – frustrating more so than useful

## Microsoft Chat Comments - Question 2

- Local Health Advisory Councils associated with Hospitals
- <https://www.nps.org.au/medicinewiseapp> I've found this resource from NPS MedicineWise helpful
- Resources: government websites
- Pharma Online
- <https://www.healthdirect.gov.au/medicines>
- I tried leaving prescriptions with the chemist but they kept losing them and mixing them up and running out without telling me to get new ones - so I changed back to keeping them myself
- Social media are NOT good sources of information they are opinion based and not evidence based.
- I fill a 7 day twice a day box which is easy to use early morning and late evening. The middle of the day single med dose I set a reminder on my phone.
- I believe that social media - used carefully, probably closed groups - can be helpful. Consumers can be valuable sources of info. Consumers can support each other with side effects of new treatments that are not recognised. Think about how long it took for opioid damage to be recognised, vaginal mesh complaints to be heard etc,. Often the "evidence" is biased research by the pharmaceutical companies. Evidence from other consumers is important evidence, though care does need to be taken. Consumers are helping each other through withdrawals more than any medical "expert" as clinicians don't understand what withdrawal is like and tend to dismiss our concerns.

***"I am so glad that the voices of consumers are being invited, heard and valued! I hope you keep up this good work!"***

## QUESTION 3

### WHERE DO YOU SEE THE USE OF TECHNOLOGY TO MANAGE YOUR MEDICATIONS?

PROMPT: Telehealth, Medicine Apps, My HR.

- Telehealth: Invaluable. I live in rural area, been a huge help to access specialist appointments when the travel time to the city is a ten hour return trip. Used to do that once a month, now I do not have this. Reduced subsidies areas.
- Medication: Not sure because they all look the same
- Painkillers: GP every thirty days, to get permission for her to give me pain killers. Needed until I can have surgery with the wait times. Waste of resources to see GP, time similar to referral.
- Pain management: Palliative care – morphine pump, quite useful, taking it away once you are better. If I could not get pain management it would not be useful. No consistency with the ailments
- Medications safety for consumers: Evidence based apps, MPS Medicine Wise, over the counter medicine – nutritional supplement, can interfere, many people do not think it is important to tell people that we are taking over the counter medications.
- Digital divide – not everyone is competent or confident in the apps. Wizard app: Find it difficult to manage, manage prescriptions, lost the scripts, muddled them up.
- Branch or app in particular did not put the support in place to address the issues.
- Med advisor
- Many medications, many scripts: all start and finish at the time, a system where you can align the scripts up, so you do not need to go in. A 6 month supply on one prescription, two weeks on another. Consistency packaging, perhaps the GP could coordinate this?
- Packaging – drug companies, work together some how
- Repeats: Number you can get, Medicare, Governments
- Prescriptions running out - one more than other
- QR Codes - on the box
- Community pharmacists: missing link, easily access, ask them questions. They do that out of the goodness of the heart, however that is not part of their role
- New prescription: only getting the consumer information in the box, after you have paid, not before-hand
- Monitoring people's medication is an integral part of the role
- Go to pharmacist before GP
- Medications review you can get within a pharmacy: helpful service for people, good to take back to GP as well
- ALFRED Health Care: Technology links in the room, pharmacists, GP
- Key Take Away
- Amount of diversity in response: mention of rare conditions, rare disease, and how it can be very difficult to access this type of information.



- Facebook group
- Getting information about medication
- Patient receiving new research that may not have been heard of: challenge for clinicians
- Some patients are going to be more educated
- Issue of care and carers is key here, not just the person managing the education
- How important pharmacists are
- Differences within technology: Who can use it, who can't, scripts
- Information: where to find it, where to search it, acronyms, too many acronyms are used in pharmacy, people do not understand and they can mean different things.
- Takes a village to manage medication
- Plain language: To be able to manage medication that is information accessible and user friendly, translation friendly – need to be spoke about, cognitive decline
- Challenges with information: consent, what side effects are about

### Microsoft Chat Comments - Question 3

- Plain English
- Easy read
- Use of tech: medication reminders but also a two-way portal for consumers to reach out to clinicians with these issues we're talking about
- Telehealth in rural and regional area
- MyHR = My Health Record
- Yes, love telehealth too even in metro areas more
- Had a telehealth appt this morning for DERMATOLOGY!!! Wasn't sure why they bothered. Although other telehealth has been great
- A problem with My Health Record is it is not complete as so many specialists and labs and Xray are not participating
- Had telehealth with hospital pharmacist about my meds, very useful
- Didn't know that there was such a thing
- I really wish TGA organises community forums or med. apps to engage--webinars will be a wonderful tool
- Hopefully My Health Record can be better used as a central place where all meds are listed - and alternative meds can also be listed.
- Tried a medication app really wanted it to work, it just didn't and was REALLY frustrating and stigmatizing
- Can you send out details of these apps?
- Perhaps they think I'm a drug dealer!
- They don't want to know Deb at times!
- Some health shop meds, (and especially St Johns Wort) have very significant effects on heart and psychiatric medications and consumers often don't realise this and forget to disclose these to other prescribers.
- My experience as well. My meds are so important I couldn't let the local pharmacy muck them up.
- They don't want to know at times!

- I just wanted to reassure XXX that it most probably the app some are not designed to be useable with all hardware we buy - android v apple etc. As in the WA Govt app!
- MyHR = My Health Record
- Great point XXX - as others have raised - and would be a good question for perhaps a pharmacist to ask this question when giving medications over the counter.
- xxx MHR is not kept up to date by health professionals - they're not paid to spend time updating it so it's a barrier. I really think it's more important & impactful to empower consumers to be their own self advocates in medication safety.
- There are baby boomers here QR codes. Only just figure a little bit about what they are
- The review are very helpful
- I have found the Consumer Medicine Information sheets on the TGA website and download the pdf. Many people don't know about the TGA and that we can complain about adverse medication events to them.
- We need to demand it!
- I agree XXX - TGA is my One stop shop for everything
- We haven't really covered those who are cognitively impaired
- CMI = Consumer Medication Information
- No doctor should be paid by Medicare until they have uploaded our information
- I wouldn't have taken anti-depressants so easily if I had read the Consumer Medication Information first. Depression is listed as a side-effect of several anti-depressants! The CMI did advise more caution and significant side-effects to watch for than the prescriber did. Too many side-effects to comprehend and remember, actually.
- Yes, to difficulties with complex conditions and medications
- Access in community languages etc should be mandatory!!
- As I had already purchased and paid for the anti-depressant before reading the CMI, I took the medication without asking any more questions.
- With apps I felt because I wasn't making the apps money that I was in the too difficult basket
- Thanks so much for this opportunity to share our experiences!
- The other vulnerable group here is those living in a group home with Intellectual Disability that are looked after 24/7 by support workers usually from overseas & English is not their first language. Resources need to be in different languages.
- The cost can be a barrier the price keeps going up & up for the pbs.
- Make sure you get your medicines from a PBS approved pharmacy
- I have nightmares about medication insecurity
- I am so glad that the voices of consumers are being invited, heard and valued! I hope you keep up this good work! We are the experts in our lives and lots of the medication side-effects (especially psychiatric meds). Consumers need teamwork with health professionals: information, communication, negotiation about advantages/disadvantages and mutual respect.
- Thanks for the opportunity-great discussion

# Attendee Evaluation

Overall attendee feedback trended towards the positive about how useful the Communication Conversation was, how informative and participative the event was. The variety of people, views, and diversity of opinions were all seen as healthy and positive overall.

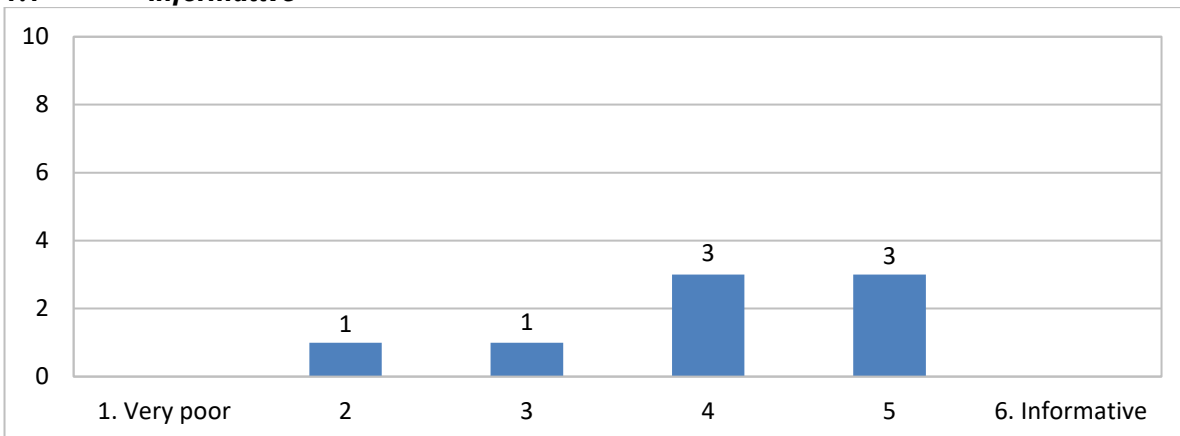
**8 forms completed / 20 attendees**

Please tick the responses which best match your view:

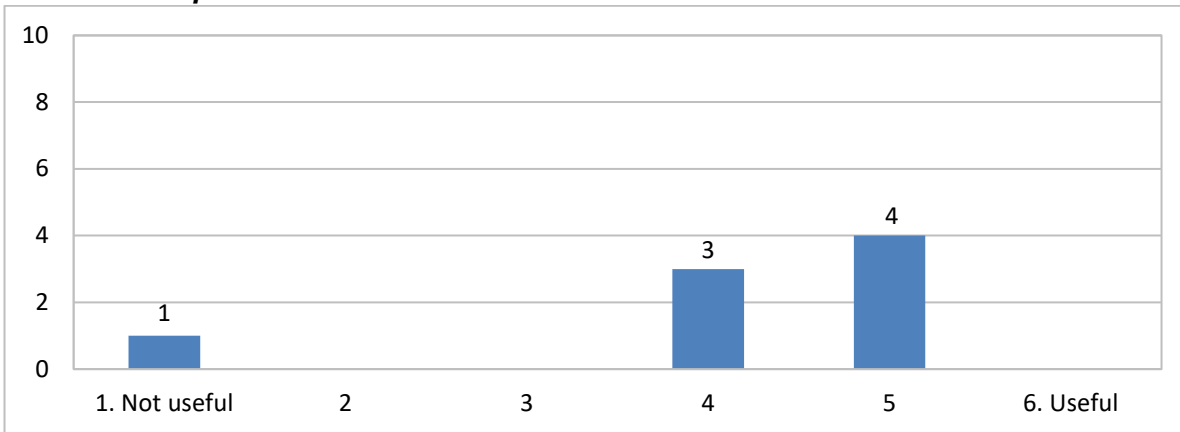
## 1. The Community Conversation was:



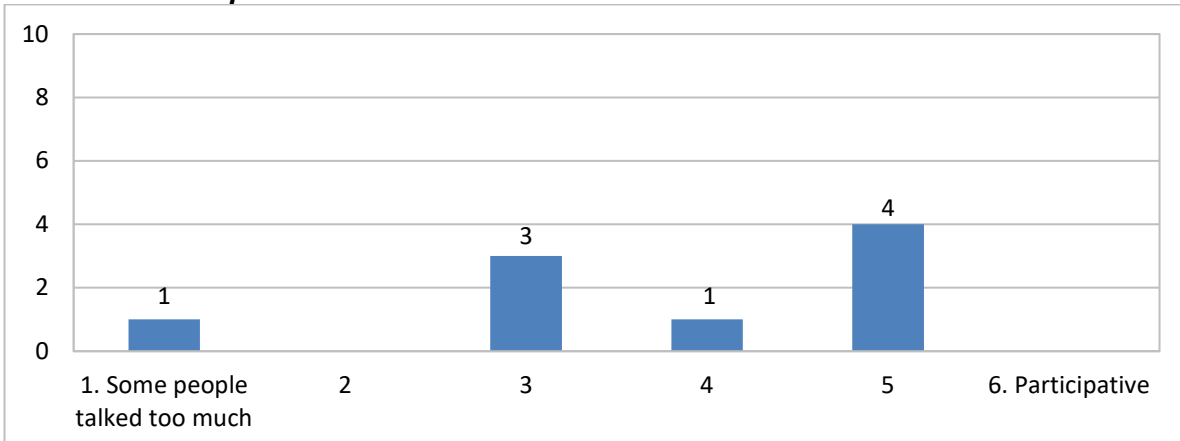
### 1.1 **Informative**



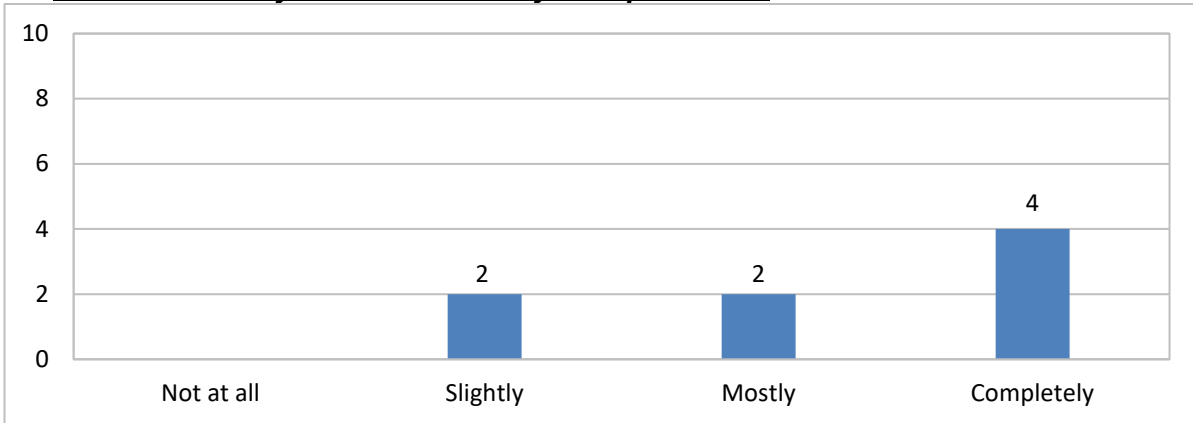
### 1.2 **Useful**



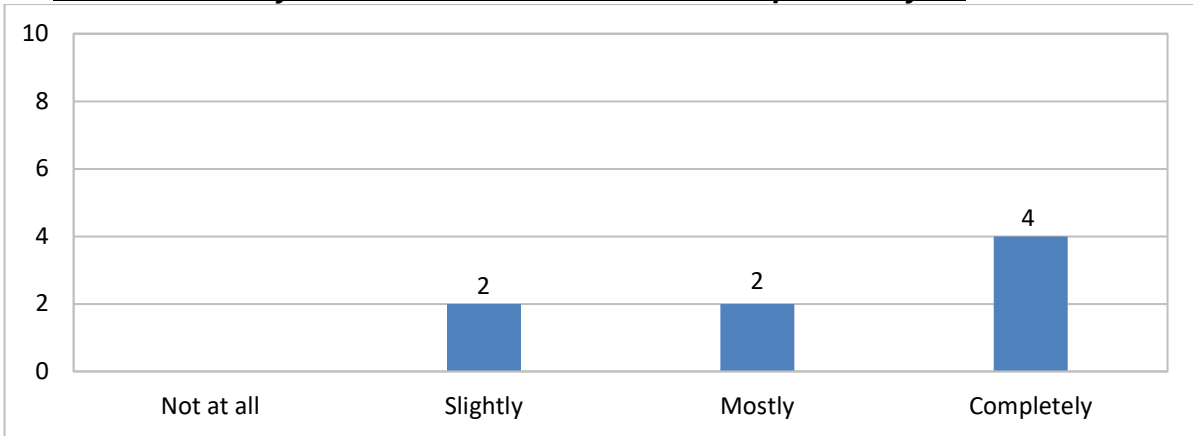
### 1.3 **Participative**



2. **Did the community conversation meet your expectations?**



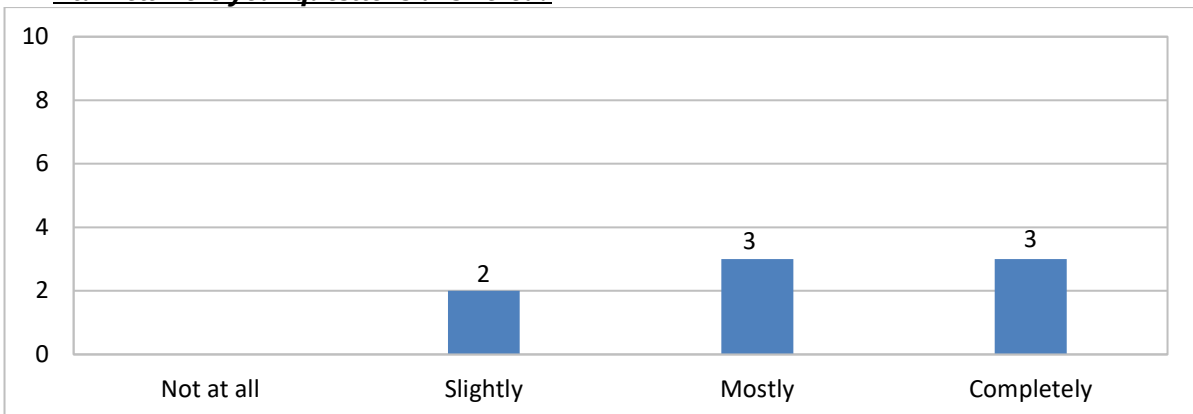
3. **Did the community conversation cover areas that were important to you?**



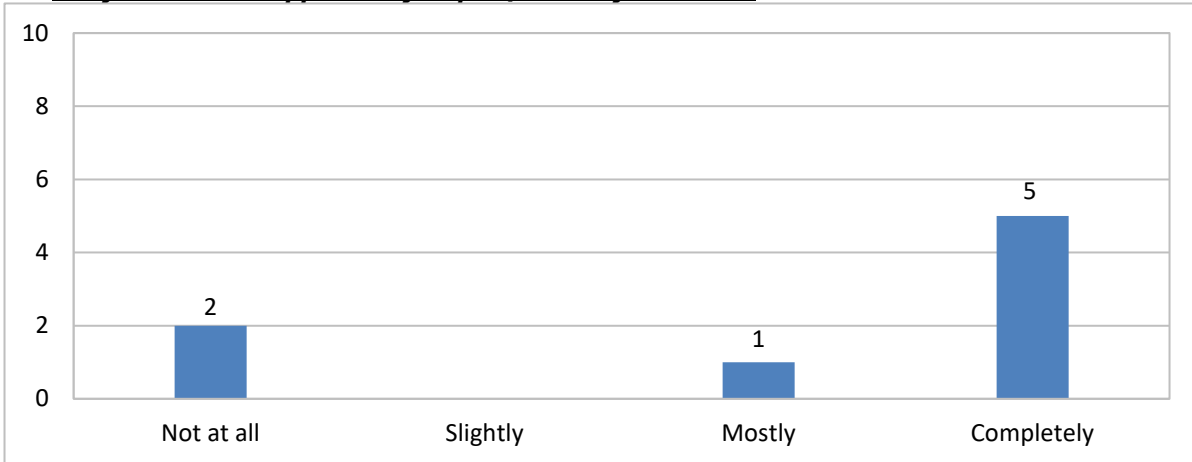
***If "not at all" please specify what additional information could have been included:***

- Think it was a very broad subject so very big space to fill in short time
- a simple easy to understand outline of how it works - same drugs - different doctors prescribing - different pharmacists - different costs

4. **Did well were your questions answered?**



5. ***Did you have the opportunity to put forward your ideas?***



6. ***Is there anything else you would like to add?***

- There is huge confusion and great difficulty understanding the rules and regulations - patients have almost no hope of comprehending any of it - we need a simple easy to understand outline of how it works
- I thoroughly enjoyed this session.
- Great to know Prof Richard was involved. His presence is always a stamp of authenticity, quality and safety
- Well done, as usual
- "I joined this discussion group mainly because I will be participating in a vaguely similar community health discussion in a few weeks' time. I have no issues at all re my medication(s) - I daily take a blood pressure pill - which has been reduced over the years. Am hugely concerned about the problems some people face. Unfortunately treating doctors don't necessarily communicate with one another about their patients' medications the mix of which can be very challenging. Currently pharmacists are able to assess medication mixes - but they do those usually out of working hours and are not paid for doing so. And talking to carers or perhaps if applicable a duty nursing sister can be time consuming.
- I spoke to three retired pharmacists, two of whom see the pharmacists' role as being one of filling the script supplied by the doctor. The third pharmacist says that pharmacy graduates in this day and age know much more about the medications that are available and are definitely qualified to take on more responsibilities as far as medications are concerned.
- I will be more than happy to participate in this research if a community health representative is required further down the line.

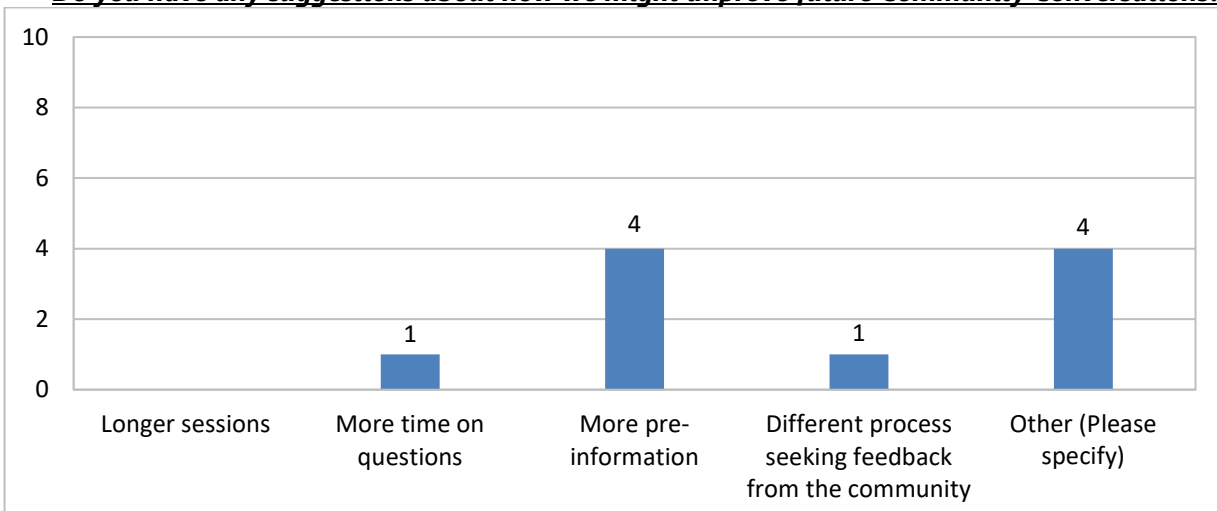
**7. The best thing about the community conversation was:**

- Help to understand problems others live with.
- But made me think of those with similar problems but not so able to have access to internet to describe their problems
- opportunity to participate and hear some of the development in this area
- Hearing from other people’s experiences.
- Compassion, good will and energy from the team as well as the diversity of participants and perspectives
- It actually took place. I learnt a lot.
- It was an eye opener - some people have to cope with the most challenging circumstances - but at the end of the day if they are lifesaving or radical pain-relieving drugs, they have a lot to be thankful for.
- Being in contact with likeminded people, with community caring ideas.

**8. The worst thing about the community conversation was:**

- Felt for staff trying to manage the problems on not being able to do what planned.
- I think that there may be some other who could not have their views heard
- Difficult to cover the complex system that exists
- Technical problems so we were unable to be split into different smaller groups.
- Nothing for me, humanity is chaotic and colourful, so any technological glitch is a reflection of humanity. It is part of what makes your model so valuable. It is not the usual show business of the fake consumer engagement industry.
- Should have happened before now.
- The dreadful message that came across - drug taking has to be undertaken with care and many people definitely need someone knowledgeable to look at the mix they are taking - preferably a pharmacist.
- I would prefer to meet in person.

**9. Do you have any suggestions about how we might improve future Community Conversations?**



**Other (Please specify):**

- Tyranny of distance and time makes conversations on important issues for older person at 10.30 at night I do not think idea.
- A strong chair is vital
- Feedback in the way of a simple easy to understand outline of how it works for the patient
- I would have liked to be put into smaller groups as was the plan.
- I have attended 2 sessions so far and I really value your model for its rawness and authenticity, capturing the voice of the population rather than the voice of advocates managed by organisations. I only have a pb with the questions asked. Why not giving us the opportunity to submit questions to you and you choose what you think would be the best questions to ask to explore the explored topics?
- So much depends on the mix of people in the discussion group. Someone will always dominate, especially if his/her personal circumstances require a 15-minute reply. To an extent perhaps the people who attend discussion groups are the minority with major problems. Targeting mainstream patients to join discussion groups I think will be difficult. Those are the people who personally sort out their problems. Members of discussion groups are more inclined to be assertive complainers. I have joined discussion groups to give back to the system that has overcome my cancer and I'm wanting to give back. But I often feel marginalized. And that's been very much the case for members of an older demographic - we tend to be less critical, we respect the doctors, and we are mindful of problems state health services experience.

---

# WANT TO KNOW MORE?

**PHONE:** (08) 6151 1071

**E-MAIL:** ADMIN@CCIPROGRAM.ORG

**WEBSITE:** WWW.CCIPROGRAM.ORG

## CONNECT WITH US



@cciprogram



@cciprogram



@CCI\_Program



Consumer and Community  
Involvement Program



Consumer and Community  
Involvement Program

