Consumers Health
Forum OF Australia

Report

Virtual Consumer Led Discussions: Health Literacy and Quality Use of Medicines

June 2020

Consumers Health Forum of Australia (2020)
Virtual Consumer Led Discussion: Health Literacy and Quality Use of Medicines.
Canberra, Australia

Leanne Wells CEO

P: 02 6273 5444
E: info@chf.org.au

twitter.com/CHFofAustralia
facebook.com/CHFofAustralia

Office Address
7B/17 Napier Close
Deakin ACT 2600

Postal Address
PO Box 73
Deakin West ACT 2600

Consumers Health Forum of Australia is funded by the Australian Government as the peak healthcare consumer organisation under the Health Peak and Advisory Bodies Programme

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Acknowledgement

NPS MedicineWise and Consumers Health Forum of Australia (CHF) gratefully acknowledge the funding and support of the Australia Government Department of Health through the Quality Use of Diagnostics, Therapeutics and Pathology Program.

CHF also gratefully acknowledges the contribution of consumer hosts who planned, coordinated and facilitated a virtual discussion and the participants for their time and insights to inform this consultation on health literacy and quality use of medicines.

Introduction

Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health care consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

Launched in December 1999, the National Medicines Policy (NMP) aims to bring about better health outcomes for all Australians, focusing especially on people's access to, and wise use of, medicines[1]. In 2020, a review of the NMP is expected to occur. A central principle of the NMP is keeping consumers at the centre.

To understand community needs, CHF was engaged and funded by NPS MedicineWise as lead agency to carry out a research project that will contribute to improving consumer health literacy as it relates to quality use of medicines (QUM).

The objectives of the research project include:

- Provide findings that reflect the knowledge, attitudes and perceptions of 'grass roots consumers' in relation to QUM.
- Identify the current understanding of consumer health literacy for Australians as it relates to QUM.
- Identify and characterise key consumer segments as they relate to QUM health literacy to assist in future resource or program development.
- Identify relevant QUM and health literacy indicators for future evaluation of collective impact
- Distribute findings to support the review of the NMP.

To achieve this, CHF are undertaking the following activities:

1. Formative Research
2. Literature review
3. Virtual Consumer Led Discussions
4. National Consumer Segmentation survey

A Rapid Literature Review on Health Literacy and Quality Use of Medicines was completed in May, and the National Consumer Segmentation Survey will follow the Virtual Consumer Led Discussions and will be informed by the findings. This report identifies and describes the methods, discussion results, key themes and messages of the virtual consumer led discussions.

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[1] Australian Government Department of Health and Ageing 2000, 'National Medicines Policy', available at: https://www1.health.gov.au/internet/main/publishing.nsf/Content/B2FFBF72029EEAC8CA257BF0001BAF3F/$File/NMP2000.pdf

Virtual Consumer Led Discussions

The purpose of these discussions were to highlight real world insights from 'grass roots' consumers (including from hardly reached communities) relating to QUM and health literacy, including what consumers want/need to know about medicines as well as what encourages consumer adherence to medicines. This section of the report outlines the process followed by CHF to undertake up to 20 virtual consumer led discussions.

Method

Recruitment

Hosts were recruited through CHF's extensive networks over a two-week period (24 April to 10 May 2020). The opportunity to apply was widely promoted across CHF and NPS MedicineWise social media, CHF's eNewsletters, CHF's Special Interest Groups, NPS MedicineWise Consumer Advisory Group and via email to CHF's consumer representatives.

A total of 82 applications were received. This included consumers and carers from each state and territory (except the NT) with a diverse range of community connections including:

- Aboriginal and Torres Strait Islander people
- Young people
- Older people
- Caring for someone with a life limiting condition
- Rural and remote people
- Culturally and linguistically diverse people, and
- From a non-English speaking background.

To ensure the virtual consumer led discussions captured a diverse range of people across Australia, the following was considered when selecting successful applicants:

- Community connections and networks to draw on to host a successful and inclusive virtual discussion
- Knowledge, involvement and/or interest in health literacy as it relates to QUM
- Location:
    - Population in each state and territory determined the number of hosts selected in each (NSW: 5, QLD: 4, VIC: 4, WA: 3, SA: 2, TAS: 1, ACT: 1).
    - Monash Modified Model, a modern geographical classification was used to determine if applicants were based in a city, urban, regional, remote or very remote area.[2]

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[2] Australian Government Department of Health 2019, 'Modified Monash Model', available at: https://www.health.gov.au/sites/default/files/documents/2019/12/modified-monash-model---fact-sheet.pdf

See Appendix A for the Application Form. Twenty people were selected to host and facilitate a virtual consumer discussion on quality use of medicines. The successful applicants were advised on 11 May 2020.

Role as the host

Successful applicants were expected to plan, coordinate and facilitate a once-only virtual consumer discussion with community members. This included:

- Inviting between 8-10 participants through their local community connections (ideally, people who do not normally have their voice heard in healthcare).
- Choosing a time and date between 18 May and 9 June 2020 that works for the host and their participants. CHF Zoom videoconferencing account details were provided to hosts to schedule their virtual discussions.
- Hosting the session.
- Completing and returning the provided feedback report to CHF by 12 June 2020.

Training, resources & support provided to hosts:

Hosts were provided with:

- A comprehensive Host Guide (see Appendix B).
- Demographic and discussion questions to ask participants during the discussion (see Appendix C), and feedback report template (see Appendix D). Hosts were encouraged to provide the discussion questions to participants prior to the discussion.
- Training (45 minutes) via Zoom video conference call on either 13 or 15 May 2020 based on their availability. The training session was an opportunity for hosts to ask questions about the resources provided to them, or any other questions about the process.
- Ongoing support from CHF to ensure hosts had a successful session. This included a group email to connect hosts for support and to ask questions.
- Debrief session (group and one-on-one) to discuss how hosts felt their session went, what worked well, and what could be improved for next time (including how CHF could better support hosts). Three group sessions were offered during the week of 15 June. Hosts were also offered one-to-one debrief sessions if they preferred.

Host Remuneration & Participant Vouchers

Participant e-Gift Vouchers: After each session, the host provided a list of participant names and CHF purchased a personalised $60 e-Gift Voucher (WISH Woolworths) for each participant as a thank you for their time. Hosts were asked to disseminate the vouchers to their participants via email. Physical Gift Vouchers were posted to participants upon request.

Host remuneration: Hosts were remunerated a full day meeting rate at $374. This was processed once hosts submitted their feedback report.

See Appendix E for activity timeline.

Results

CHF offered 20 consumers and carers from across Australia the opportunity to host and facilitate a virtual discussion with their local community on health literacy and QUM, including what consumers want/need to know about medicines as well as what encourages consumer medicine adherence. One host dropped out due to unforeseen circumstances.

A total of 19 hosts completed a virtual discussion which involved 185 consumers and carers from across Australia (except the NT). On average, nine people participated per virtual discussion.

See Tables 1-6 for participant demographics.

See Table 7 for demographics of successful hosts.

Participant Demographics

Table 1: Highlight any group you identify with:

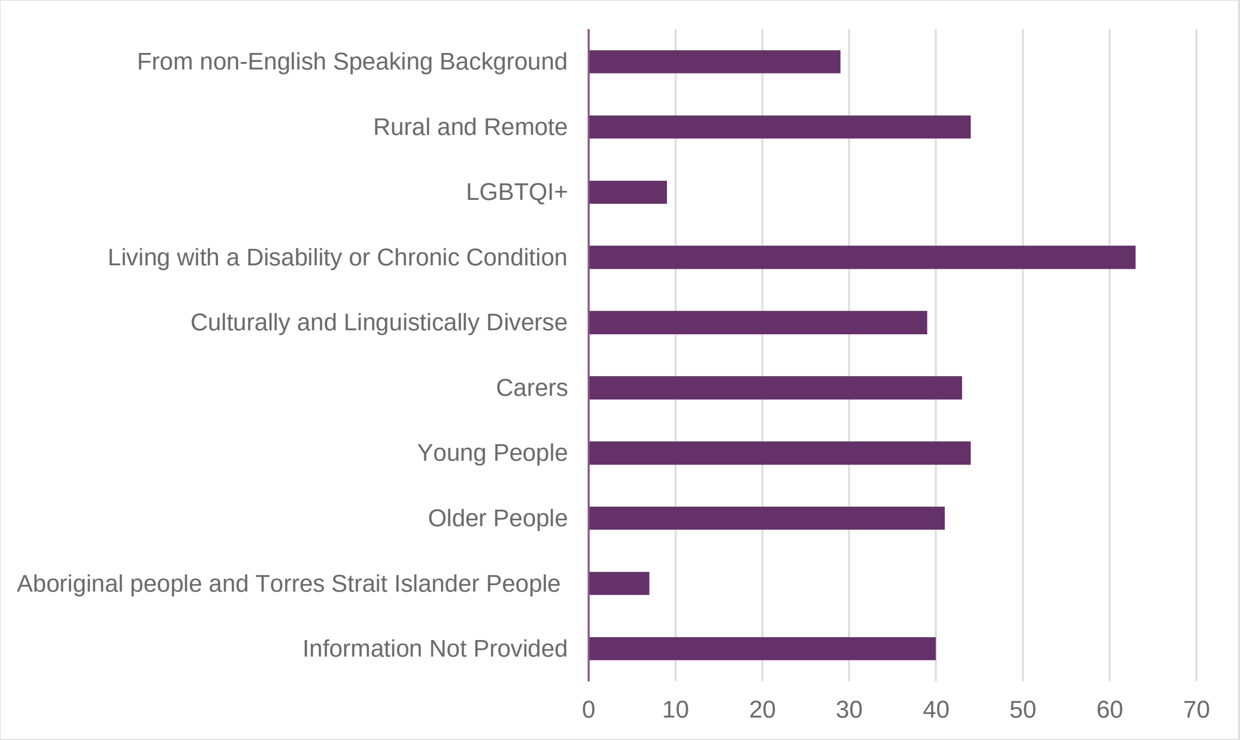

Table 2: Do you identify as Aboriginal and/or Torres Strait Islander?

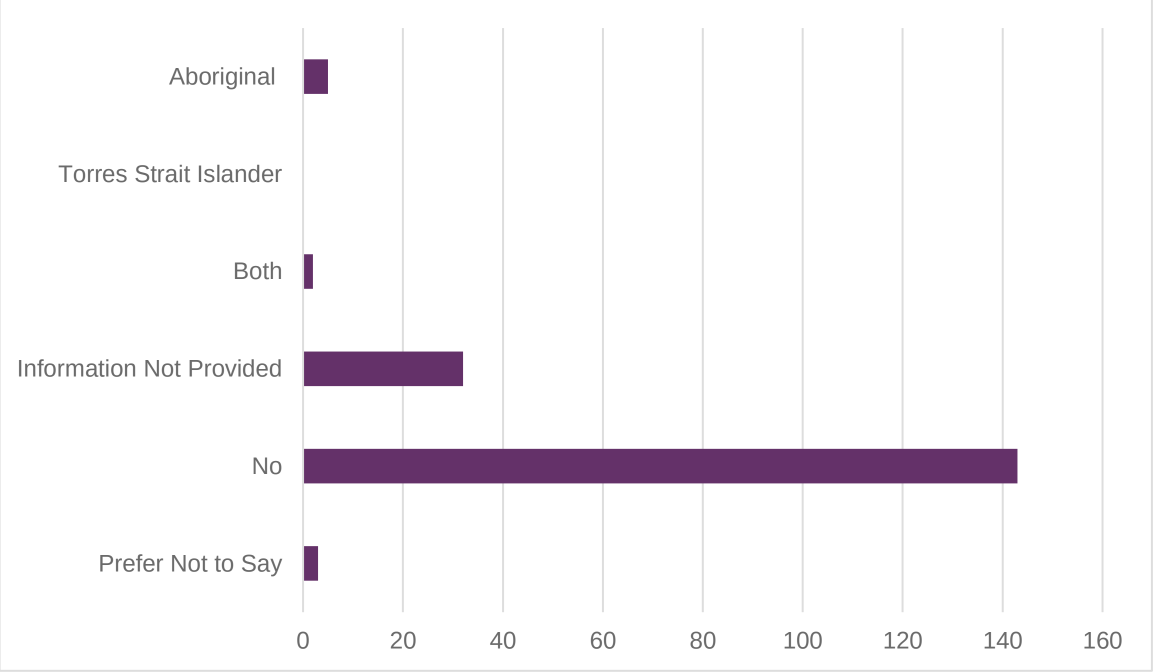

Table 3: Are you a Consumer and / or Carer?

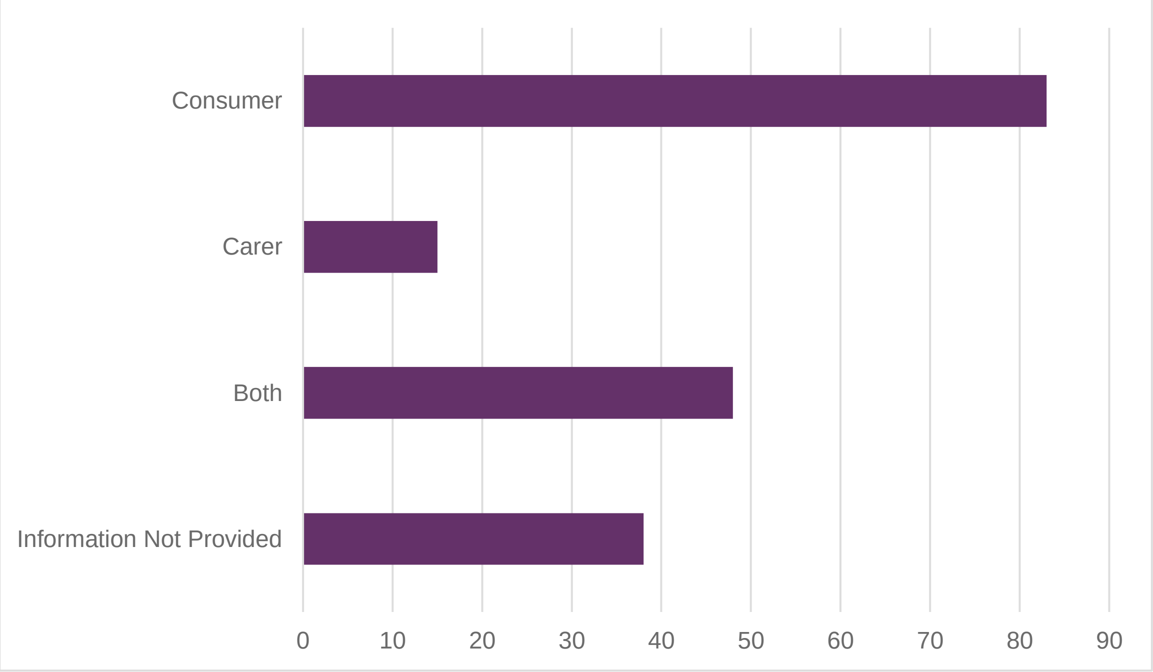

Table 4: Age Range

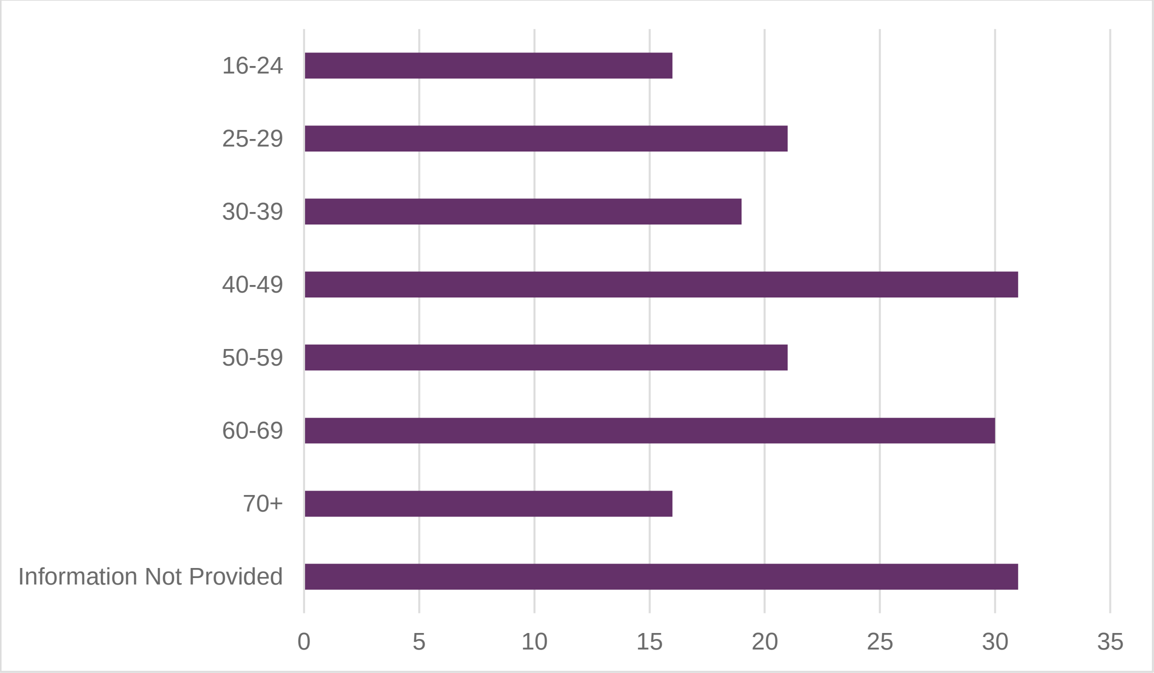

Table 5: Gender

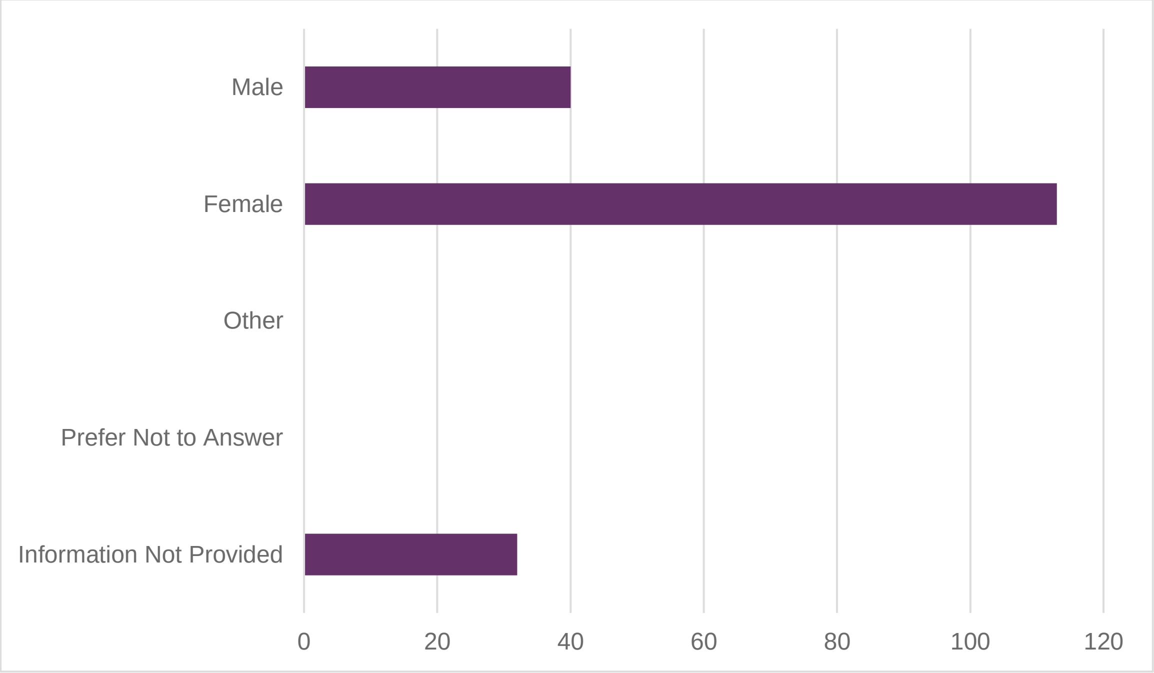

Table 6: Locality by Modified Monash Model[2]

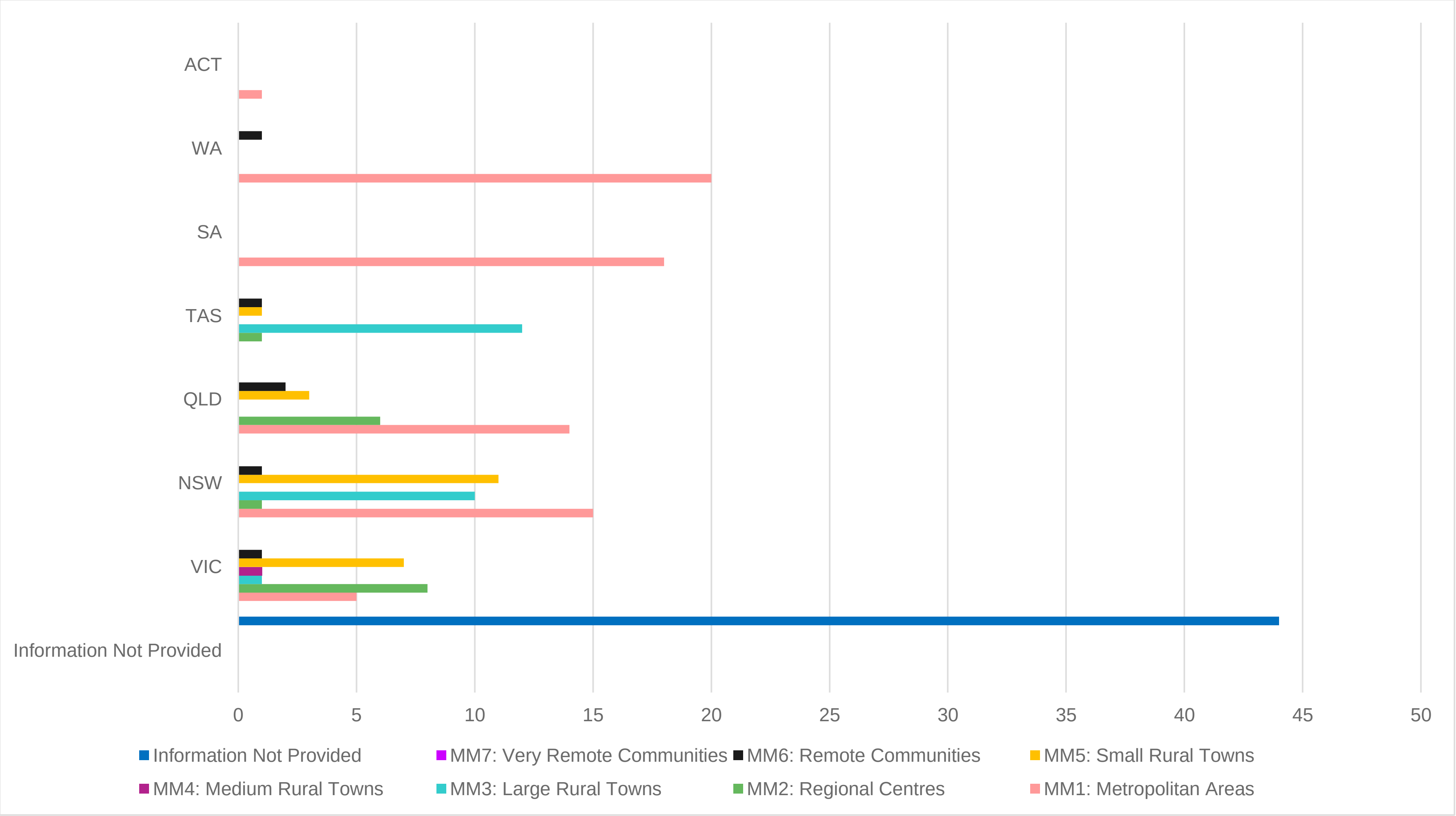

Table 7: Demographics of successful hosts

	MMM Category	Age range	Groups Hosts Identified With								
			Aboriginal and Torres Strait Islander people	Young people	Older people	Caring for someone with a life limiting condition	Rural and remote	Culturally and linguistically diverse	From non-English speaking background	Consumer	Carer
NSW	1	60 – 69				✓				✓	
	1	40 – 49								✓	✓
	1	50 – 59			✓					✓	✓
	3	30 – 39					✓	✓	✓	✓	
	5	60 – 69			✓	✓	✓			✓	✓
QLD	1	60 – 69			✓	✓				✓	✓
	1	60 – 69			✓	✓				✓	✓
	1	30 – 39	✓	✓	✓	✓	✓			✓	
	2	70+			✓					✓	
VIC	1	16 – 24						✓		✓	
	2	50 – 59								✓	✓
	5	60 – 69					✓			✓	
	5	60 – 69					✓			✓	

WA	1	50 – 59				✓				✓	
	1	40 – 49						✓		✓	
	6	40 – 49					✓			✓	
SA	1	30 – 39						✓		✓	
	1	40 – 49						✓	✓	✓	✓
TAS	3	40 – 49						✓			✓
ACT	1	25 – 29		✓						✓	

Discussion Questions

This section of the report details the participant feedback received, categorised under each discussion question and into key themes.

Question 1: What does quality use of medicines mean to you?

From the perspective of consumers and carers who participated in the virtual discussions, QUM was more than simply the act of taking a medicine to improve their health and wellbeing. Participants highlighted key elements that contribute to the QUM, all of which are underpinned by holistic, patient-centred approach. Each are outlined below.

Quality use of medicines means….

"That I take the medicines I am prescribed for reasons I know and understand; that my health professionals understand other aspects of what effects their prescription will have on me e.g. cost…and what other medications I may be taking myself…"

**

"Quality use of medicines means knowing why you are taking it, how to monitor the effect of the medication and having a plan of when to stop."

Affordable:

- Medication is affordable, particularly when medicines are required long-term.
- Cost of the medication is regulated and funded by the government.
- Additional supplements are subsidised for specific conditions.

Appropriate medicines:

- Ensuring correct, and most suitable option/s for the person and their health condition/s.
- To improve health, wellbeing and quality of life, or to slow down the degeneration of health.
- Knowing doctors and/or pharmacists communicate and work together to ensure all medication use is working harmoniously.
- Doctor and/or pharmacist should know the consumer's medication history before prescribing a new medication.
- Most effective with least negative effects and non-addictive.
- The quality of diagnosis is as important as the medicine required.

Quality use of medicines means…

"I'm confident medicines are appropriate for my condition, as appropriately identified by my trained and trusted health professionals."

Safety, Quality and Efficacy:

- Australians have a right to the best medicines.
- Quality controlled and tested.
- Regulated
- Evidence of safety and efficacy, including success rate.

Quality use of medicines means…

"reassured that the product is made to the expected standard and quality."

Patient relationship with pharmacist and/or doctor:

- Trust in the doctor to prescribe what is best.
- Feeling assured and informed by doctor and pharmacist.
- A strong relationship with both the doctor and pharmacist with two-way communication.

Quality use of medicines means…

"People want to have good self-awareness and ownership over their medicine use, but to access this via their doctors, who they want to support them to get to that point."

Benefits and Risks:

- Being assured the benefits outweigh the risks.
- Being advised and understanding the short-term and long-term benefits, risks (including potential side-effects) and impact on health, wellbeing and quality of life.

Quality use of medicines means…

"First and foremost a product that I feel comfortable taking the medicine; I want to be assured that the benefits outweigh the risks."

Alternatives:

- Minimising the need for medication is important. Taking medication should be avoided unless it is essential.
- Before prescribing any medication, doctor should consider and inform the patient of options available, including natural remedies and/or non-medication alternatives such as minimising lifestyle factors that contribute to illness.

Quality use of medicines means…

"Having all the information available about the condition and what can be done to treat it, both natural and otherwise."

Dosage and Administration:

- Understanding how many medications, when and how to take them.
- Using it appropriately in the way that it is prescribed.

Quality use of medication means…

> *"that medicines are used in the way intended and that the medicines are the optimum required for the individual."*

Packaging:

- Plain English labelling and dosing instructions, including larger font.

Consumer Rights:

- The consumer has the right to refuse medications.
- If prescribing medication, then consult with the consumer. This should be a two-way stream rather than the doctor deciding what to prescribe.

Quality use of medicines means…

> *"I, as the patient, am empowered to take responsibility and decision making of my health."*

Access to medicines:

- Access to quality medicines.
- Generic and brand name medicines are readily available so that the consumer has choice.
- Access to medicines from a reliable source (such as a pharmacy rather than a convenience store or supermarket).

Informed consent and contemplation:

- Being able to weigh potential benefits and risks before making decisions.
- Accessible, timely and effective information access, appropriate for people with a range of different needs, including varied levels of health literacy. Information including but not limited to:
    - Efficacy
    - Knowledge of potential side-effects and how to limit them
    - Dosage and length
    - Interactions with other drugs
    - Indicators of effectiveness and expected outcome
    - Support through use, i.e. is there any need of additional medication/lifestyle change if I see effect X in me?
    - Cost and available financial support
    - Possible dependency or tolerance
    - Source of the medicine (local vs imported)
    - Alternatives
    - Brand substitution vs generic brands.

- Knowing the doctor and/or pharmacist has access to up to date information and education on the most effective method of treatment for patient’s aliment.

Quality use of medicines is…

> *“When you go to the Dr you need to get given information and know that the Dr is not trigger happy and prescribing some medicine that may not be the right one for me. I want to make an informed decision.”*

Question 2: What is important to you when:

- ***A) Deciding on medicines***
- ***B) Using medicines***
- ***C) Checking outcomes and progress***

Table 8 below identifies the key messages and themes that were identified by participants for this discussion question. Some key messages and themes were evident across sub-questions A-C, while other themes were only raised under A, B or C.

Key themes	***Table 8 - Question 2: What is important to you when:***		
	a) Deciding on medicines	***b) Using medicines***	***c) Checking outcomes and progress***
Side-effects	• Being informed about any potential negative effects to be able to make informed decisions. This includes short-term (such as weight gain or mood swings) and long-term side-effects (such as damage to organs), and if the medication can be addictive. • If there is a need to take other medicines to counteract the side-effects. • Health professional/s weigh up the risks versus the benefits, is it going to be worth the potential side effects.	• That the benefits outweigh the risks. For example, the medication does not cause side effects that are worse than the condition that was being treated, especially for people on multiple medications. • That the consumer is happy to take the medication/s given any possible side-effects.	• Isolating symptoms and effects and monitoring effectiveness. • Ability to access and communicate with the doctor if the medicine is not working/side-effects are concerning.

Key themes	*Question 2: What is important to you when (continued):*		
	a) Deciding on medicines	*b) Using medicines*	*c) Checking outcomes and progress*
Adverse events		• Being aware of any adverse reactions to expect and how to manage those situations. This is particularly important for people taking multiple medicines.	
Interactions & Contraindications	• Being informed of potential interactions with other medicines including prescription, over the counter and complimentary. • This was particularly important to CALD communities that often take herbal medicines along with western medicines without knowledge of possible negative interactions and how it may impact the progress of the medicine being used.		• Monitoring to ensure medicines don’t negatively interact with other medication/s the consumer is taking.

Key themes	*Question 2: What is important to you when (continued):*		
	a) Deciding on medicines	*b) Using medicines*	*c) Checking outcomes and progress*
Consultation with health professional/s	• Two-way conversation with the treating doctor and/or pharmacist that is open and transparent where the best solution for the person is discussed. • Holistic approach important when considering treatment options. • Asking questions to feel informed and confident about health professional/s recommendation. • Understanding why the medication is required, how it will work to improve symptoms and quality of life, how to take it and expected outcome. • Trust the advice and/or recommendations provided by the health professional. • Sufficient time during consultation to ensure appropriate medications (including dosage) prescribed and/or dispensed.	• Trust and close patient-doctor/patient-pharmacist. This was important for both consumers and carers. • Consideration of the consumers level of medical literacy. Health professionals should confirm consumer and/or carer understanding. • Being comfortable about the process and having things explained in a way that is simple and easy to understand without being spoken down to If needing advice • Being able to speak to a pharmacist not just a shop assistant.	• Partnership between the GP and pharmacist key to effective management and success. • Crucial for health professionals involved in caring for the consumer to communicate effectively with one another. This is particularly important to avoid negative medication interactions and should not be up to the consumer to identify. • Ongoing relationship with health professionals to check outcomes and progress. • Reviews and/or follow up appointments. • Consumer concerns are listened to, and respected, and adapt treatment appropriately. • Take a list of medications to consultation and prepare any questions.

Key themes	*Question 2: What is important to you when (continued):*		
	a) Deciding on medicines	***b) Using medicines***	***c) Checking outcomes and progress***
Cost	• Informed of the cost of medications and consultations. This was particularly important for consumers with chronic conditions, or low income. • That ongoing treatment is affordable. • That quality of medicine is not compromised with cheaper alternatives. • If the medicine is on the PBS, or other government subsidies are available. • Weighing up costs against potential side-effects, outcomes benefits (such as improved condition or quality of life).	• Cost of medicines and consultations are affordable and sustainable. • Costs of generic versus named brand.	
Efficacy		• Confidence that the medicine will provide the intended result.	

Key themes	***Question 2: What is important to you when (continued):***		
	a) Deciding on medicines	***b) Using medicines***	***c) Checking outcomes and progress***
Approved & adherence to regulations	• Proved by the TGA as safe for use. Community trust in the TGA is important. • Approved for use by qualified health professionals. • How long the medication has been available for, and what evidence is available or expected outcomes and/or challenges (e.g. trial medicines).	• Adherence to government and independent quality-controlled regulations.	• Ability to access research, including clinical evidence, from a single source of truth if required.
Availability		• Reliable supply of medication is vital. Some pharmacies running out of medications due to COVID-19 e.g. 'heart pills'. • Restrictions and heavy regulations hinder emergency access to some medicines, for example Nurofen plus.	• Ongoing availability vital to ensure progress of the medication is not halted due to missed dosages.

Key themes	***Question 2: What is important to you when (continued):***		
	a) Deciding on medicines	***b) Using medicines***	***c) Checking outcomes and progress***
Alternatives	• Having all the information available about the condition and what can be done to treat it, both natural and otherwise (e.g. lifestyle modifications). This includes effective communication between health professionals and consumer. • The opportunity to decide, rather than be told. Ability to choose when in hospital is often limited, with insufficient information and options provided. • Understanding the consequences of not having medication. • Respecting consumers cultural beliefs and informing appropriate alternatives where possible. For example, Chinese mothers will refuse pain killers and aesthetic during childbirth, because they believe it may harm the baby. • Appropriateness for Individual (holistic approach essential). • Confidence that it is the correct medicine for treating condition/s effectively.	• Knowing that the option is the best for consumer health and lifestyle. • Assurance that if one option doesn't work that there are other options that could be explored.	• Having alternative options available, and accessible if medication is not working. Important to consider how alternative medication may interact with other medicines. • Understanding how the consumer feels about the medication they are taking, and the impact it is having on their wellbeing and lifestyle. • Second-opinion from a doctor of similar CALD background.

Key themes	*Question 2: What is important to you when (continued):*		
	a) Deciding on medicines	*b) Using medicines*	*c) Checking outcomes and progress*
Storage	• Knowing how to appropriately store medication (e.g. fridge, room temperature). • Knowing what the shelf life is.	• Make sure medicine is stored appropriately including during travel. For example, child with cystic fibrosis carries a backpack with medication to school and hospital.	
Quality of life		• It provides relief when used • Feeling and staying well • Enhance quality of life, • Positive outcome with least lifestyle changes.	• Improvement in overall health condition and quality of life. • Recovery period.
Ingredients	• Knowing what the ingredients are (including active ingredients) and the amount. For example, multivitamin – knowing how much it has of each element) • Knowing the ingredients particularly important for those with allergies. • Clear labelling is vital to alert consumers to potential allergens. Larger font is required.		

Key themes	*Question 2: What is important to you when (continued):*		
	a) Deciding on medicines	***b) Using medicines***	***c) Checking outcomes and progress***
Administration and dosage	• The dose to be taken and when they are to be taken can be a difficult for some people to remember. In these circumstances it is helpful to have access to a webster pack or some similar means of preparing daily dosages, the dose and the intervals between doses in advance. This method can save the patient of the anxiety of forgetting to use medicines. • Being aware of what reactions a patient can expect if he/she misses one or more doses. • In the event of missing a dose it is helpful to know what to do e.g. take when remember or wait until the next dose.	• Care plan/strategy at the start to check & monitor impact on consumer. E.g. starting with smaller dose first. • Ensure medicines have not expired (check expiry date). • Taking medicines exactly as prescribed including the correct dose and time, although some participants said that instructions like 'take before or after food' were really difficult to comply with, especially if you are taking multiple medications.	

Key themes	*Question 2: What is important to you when (continued):*		
	a) Deciding on medicines	*b) Using medicines*	*c) Checking outcomes and progress*
Source of medication	• Trust in the manufacturer and supplier. • Purchase from reliable sources, for example pharmacist vs Supermarket. • Choice of brand – e.g. original brand vs generic brand. Consistency in brand is also important to consumers to help recognise medicines (e.g. colour/shape can differ between brands causing confusion, particularly for older people). • Made in Australia • Dispensed by a trustworthy and competent pharmacist.		
Weaning off medication		• Guidance on how to appropriately wean off medication/s. For example, pain killers.	

Key themes	***Question 2: What is important to you when (continued):***		
	a) Deciding on medicines	***b) Using medicines***	***c) Checking outcomes and progress***
Self-monitoring and management		• Consumers of prescription medicines should keep themselves informed about the currency of their scripts, when further dispensations are required and when and how to renew script. • Blister packs are an important tool for self-management, including for both consumers and carers. • Need for sufficient information, including CMI's, when in hospital to ensure safe and effective use of medicine/s following discharge.	• Knowing the expectations of the doctor, timeframe for the expected outcome of a medicine and what can be expected between when the use of the medicine has begun and when the outcome can be expected are all useful for checking outcomes and progress of treatments. • A health diary valuable for self-monitoring how the consumer feels each day. This is also valuable for keeping general practitioners informed about progress and outcomes including keeping track of any side effects or other adverse effects from incompatible medicines for providing this information back to the practising physician.

Key themes	Question 2: What is important to you when (continued): a) Deciding on medicines	 b) Using medicines	 c) Checking outcomes and progress
Access to information	• Information needs to be appropriate for the individual circumstances. • Access to information through medical journals to get a full understanding of medication impact on condition/illness, particularly if experimental drug. • Readable, understandable labels. Larger font required and information in lay language. • Evidence to support health claims on labels for over the counter complimentary medicines. • Consistent information received from doctor, pharmacist and online (if applicable) about the medicine.	• Clear instructions that are easily followed. • Access to information leaflets to look up reliable information as required. Important that this information is simple, clear and easy to understand. For example, use of traffic light system to explain the level/severity of side effects. • Access to 24/7 helpline or a national website on all relevant medications in Australia and their side effects.	• Reliable information from authentic sources can provide appropriate criteria of progress and outcomes.
Medication Review and Medical Tests			• Retesting for measurable levels i.e. blood tests, x-ray etc. • Dosage and/or medication/s (including the need to continue medication) modify, as necessary.

Key themes	*Question 2: What is important to you when (continued):*		
	a) Deciding on medicines	*b) Using medicines*	*c) Checking outcomes and progress*
Medication Review and Medical tests (continued)			• Ensuring benchmarks are specific and relevant to the individual. • Impact on mental health, physical health and quality of life all important to monitor and review. • Know and understand personal capacity for responses and outcomes. • Health professional is proactive with reviews as appropriate (e.g. annual). • Accessibility to appropriate health professionals for follow-up/review. • Outcomes of the medical tests clearly explained to consumers. • That the medicines are appropriate for ongoing use with regards to individual circumstances.

Question 3: What do you want and/or need to know about medicines?

Consumers and carers who participated in the virtual discussions wanted to know a wide range of information about medicines. These have been listed below.

- **Why it is being prescribed?**

- **Is the prescribed medicine the best medicine available for treating the condition or are there more effective medicines available?**
  - For example, one participant wanted to know if the medicine being prescribed was part of a clinical trial, or reliable solution.

- **Are there alternative options?**
  - This appeared to be relevant to participants across all virtual discussions, with consumers and/or carers wanting to have a comprehensive understanding of alternative options. This included medication (e.g. with less side-effects), natural therapies and lifestyle changes such as exercise, diet and meditation. Participants wanted to know if these options could be as or more effective than prescription medications.
  - Consumers and/or carers wanted to feel confident and understand options available to them to help them make an informed decision.
  - Alternative options, particularly natural therapies and lifestyle changes were often not discussed with consumers and/or carers, and prescription medications were often prescribed without a holistic approach.

- **Are there long-term consequences/risks?**
  - For example, whether there are risks during pregnancy or breastfeeding.

- **How long will it take to see an improvement and/or to achieve best outcome/s?**

> *“There have been times where the antibiotics prescribed have not worked, or there has been no relief of symptoms within 72 hours, in which case I will see my GP for assurance (or seek advice from a pharmacist); perhaps more time is needed to the medicine to be effective, a stronger dose may be required, a second course of antibiotics prescribed or a different type of antibiotic.”*

- **Interactions and contraindications:**
  - Consumers and/or carers wanted to know how the medication might interact with other medication or complimentary medications they may be taking.
  - Participants raised concern that doctors often write new prescriptions without first seeking consumers’ current medication intake. Some participants highlighted the need to tell the doctor and/or pharmacist what other medicines, particularly over the counter medicines and complimentary medicines.

- **Cost:**
  - How much will it cost?
  - Is it affordable for the duration the medication is required?

  - Will the cost of the medication can be justified against the outcome?
  - Combined costs of prescription and/or complimentary medicines, particularly those not funded by the government.

- **Dosage:**
  - What is the dosage I need to take?
  - What should I do if I miss a dose?
  - How long do they need to take it for?

- **How to take the medicine:**
  - Does it need to be taken with food or on an empty stomach?
  - What time of day should it be taken?
  - How much fluid should be consumed when taking it?
  - Should I avoid alcohol whilst on the medication?

- **Side effects (short and long term):**
  - What side-effects can be expected and how to manage these when they occur?
  - Are there any rapid onset side effects that could be inconvenient or dangerous? For example, rapid onset of nausea, tremor, and disorientation with the use of Tramadol and Norspan especially if you are away from your home.

- **Adverse reactions:**
  - How and where to report adverse reactions?

- **How does the medicine work to treat the illness or symptoms?**
  - How will I know if the medication is working?
  - What will be the signs of progress?
  - Will it eliminate or just reduce my symptoms?

- **Manufacturer:**
  - Where was the medication manufactured?
  - Is the supply/availability reliable?
  - Reviews, case studies and research outcomes of the manufacturer and supplier.

- **Is the medication/s addictive?**

- **Weaning off medications:**
  - Information and therapy for weaning off medication.

- **What have other people's experience been with the medication?**
  - Testimonials and case studies

- **What is the evidence around the effectiveness of the medication?**
  - Information on medication trials, clinical evidence and evidence-based data.

- **Is it regulated in Australia?**

- **How medicine will adapt to new forms of health engagement such as Telehealth?**
    - Participants highlighted this as an opportunity but also a threat to diagnostics, continuity of support, and quality control.

- **How will using the prescribed medicine fit in with the person's lifestyle?**

- **What is the requirement of a support network/carer?**

- **What are the ingredients?**
    - Detailed information on what the medicine ingredients are and any possible allergic reaction, especially if person is anaphylactic to specific/common ingredients.

- **Brand:**
    - Generic Vs Branded Medicine

  Is the brand of medicine suitable for the patient's condition?

- **Safety, quality and efficacy of the medicine**
    - Confidence that the medicine would work how it is intended.
    - Confidence that the medicine was of high quality and safe for them to use.

- **How does the medication need to be stored?**

How do you access information on medicines?

Participants accessed information via formal and informal channels both online and in person. Regardless of how consumer and carers accessed information on medicines, it was crucial that it was clear and easy to understand, targeted to those with low health literacy, available in different languages, and when necessary, the person has access to an interpreter.

> *"But most importantly, in a simple language so that the information is easy to digest precisely for CALD adults or recent migrants."*

Health Professionals:

- Asking relevant doctor and/or pharmacist appeared to be the preference for accessing relevant, reliable, and trustworthy information.
- Participants were more likely to seek information for their pharmacist versus their doctor due to limited time during consultations and/or poor explanations provided by their doctor.
- In cases where the doctor and/or pharmacist do not have the required information, some participants then check online (particularly due to allergies).
- Chemists have good working knowledge of usage, allergies, and interactions with other medicines.
- Telehealth service provider
- Nurse

To access information on medicines, I…

> *"I use my phone to ask questions, but often the pharmacist will continue to speak AT me when I don't understand. It ends up usually me being in an argument with the person. Happens lots of times because they think deaf people can lip read magically…A lot of people are scared of deaf people and they would rather get us out quickly than try to communicate with us."*

**

> *"I ask detailed questions of our GP any time a new medication is introduced. We are also very lucky to have a fantastic GP, but in cases where Drs during a hospital stay have changed Dad's medications, I find I have to ask lots of questions to find out what I believe is enough info for us to be taking it safely and with enough education."*

Medicines leaflet and/or brochure:

- Some participants read and kept the box and enclosed Consumer Medicines Information (CMI) leaflets and/or information supplied by the doctor and/or pharmacist.
- Some participants felt the CMI leaflets and information printed on the label was too hard to read, too long and complicated to understand. More plain language required to improve understanding for those with low health literacy.
- Information posters, and brochures in clinics
- Australian Injectable Handbook

Online:

- MIMS Australia (previously known as Monthly Index of Medical Specialties).
- Medical Journals: some participants felt peer review medical journals were not always easy to understand while others searched the Cochrane Library for trusted, evidence-based information.
- NPS MedicineWise, TGA (including Australian Register of Therapeutic Goods and online CMI leaflets), Health Direct, peak organisations such as Asthma Australia, Diabetes Association, Foundations, and Mayo Clinic identified as source for trusted, up to date information.
- WebMD was mentioned by some participants however the accuracy of the information was questioned.
- Many participants referred to “Dr Google” for information to help decide about whether to take a medicine, check symptoms and/or side-effects, compare costs, and to research alternatives to a medication they have been prescribed. This was despite some participants acknowledging this was not always a reliable source.
- Internet was not always available to some participants. For example, those living in remote areas may not have access to the internet.
- My Health Record.

Social media and peer support groups and/or organisations:

- Some participants used online forums to check on symptoms and side effects
- Asking for advice on social media groups is quite common to find out other people’s experiences with medications.

Friends and/or family:

- Check with friends who have used the same medicine for lived experience including outcomes and side effects.

To access information on medicines…

“I talk to other people about their medications and then I wonder about if I should be taking what they are.”

**

I will go to social media to ask my peers what their experiences have been like. The lived experience of being on certain medications and treatment is what is missing.”

**

“I also speak to others that I know who have the same condition as me (often online) I feel it’s really good to speak to those that have experience- the leaflet will tell you but it is not the lived experience of what it is like to live on that medication is important.”

Advertisement:

- The general feeling was that advertising associated with medicines was often misleading and not reliable and just a marketing ploy to sell more.
- The false claims about over-the-counter pain medication was raised by multiple participants and distrust was a big factor in the marketing of the over-the-counter medications.
- The 'big pharma' impact on medicines was not highly regarded and participants felt money was a driving force in many aspects of the medication world without the focus on honest communication and information.

Newspaper:

- Product recalls at times in the newspaper.

Question 4: From your perspective, what encourages adherence to medicines?

From the perspective of consumers and carers who participated in the virtual discussions, they identified key motivators to encourage adherence to medicines. Each are outlined below.

What encourages adherence to medicines…

> "Important that you get the right drug at the right time, right price to improve compliance."

Improved health and/or quality of life:

- The medicine is working as expected and relieving symptoms or preventing the progression of condition/s with no or little side effects, leading to improved health (physical and/or mental) and quality of life.
- The consequences of not taking the medicines (e.g. deteriorating health and quality of life).

Duration:

- The more complex the medication regime the less likely full adherence.
- More likely adherence to short-term medicines, such as antibiotics.

Effectiveness

- The more effective the medication the more likely the adherence.

Relationship with pharmacist and/or GP:

- Strong patient-pharmacist and patient-doctor relationships encouraged adherence to medicines, with some participants describing it as "key to success".
- Trusting the advice of your doctor and able to have an informed conversation about issues and concerns.
- Sufficient time spent with doctors and pharmacists, allowing people to ask questions and receive clear explanations helps with adherence.
- Pharmacists generally more involved and accessible to people, however participants highlighted their desire for their doctor/s to be more involved and accessible as well.

What encourages adherence to medicines…

> *"Dad and I do the right thing with his medications because we respect our Drs opinion, but it's made much easier to adhere to his medication schedule because we have a blister pack made up and delivered each week from his chemist. Having a regular chemist, you use and building relationship with them is a huge help also."*

**

> *""GPs who don't take time to listen to their patients…This causes patients not to buy the prescribed medicines."*

Shared Decision-Making and Consumer Empowerment:

- Having been involved in the decision-making process helps with adherence because patients feel more confident.
- Discussion and mutual agreement that this is the best way to treat the problem.
- Taking ownership of personal health and wellness journey.
- Knowing it's being prescribed for a purpose, and that it can be prescribed with information to support it and discussion about what will happen if it doesn't work.

Medicines Reviews:

- Regular check in with GP or specialist to:
    - check progress and effectiveness
    - check consumer adherence
    - discuss options.

Individual Routine & Lifestyle:

- Integrating medicines into personal routines considering storage and usage (e.g. liquid to be kept chilled, tablets to be taken with meals only vs injections self-administered).
- Some participants spend more on medication that doesn't have to be refrigerated, to help with day-to-day adherence.
- Changes to the routine can impact on the medications.

What encourages adherence to medicines…

> *"Dr actually went through it and rather than saying you need to be better the Dr did a review where we could change some drugs to other times to fit in with changes in lifestyle and routine. She shuffled them around to fit into dad's lifestyle changes."*

Clear information on how to use medicine:

- Ease of use, clear guidelines as to how it should be used. Explanation from your practitioner of why it has been prescribed and what the expected outcomes are.
- No matter the source or delivery, clear and concise information is crucial regarding medication; the language used must be able to be easily understood to ensure correct and proper usage.
- A fact sheet of each medicine should be given when medicine is dispensed
- Information is consistent across doctor-pharmacist-CMI.
- An explanation of what the medication does and how it works that is clear and easy to understand.
- It is easier to keep taking the same medicine if its name is simple and understandable and if the instructions for dosages are short and set out in plain English. The KISS rule of keeping it short and straight forward applies here.
- Tastes good and comfortable to take.

Access to medicines:

- Ease of access to the medication (including financial access and timing of dosage/s and competing priorities)
- Reliable supply chain
- Time for medication to be dispensed.

> *"Affordability and availability are incentives for adhering to prescribed medicines. This applies to over the counter medicines that are needed for treating common and less serious ailments. These considerations are essential in the case of people of limited means and receiving little income. Affordable medicines that are readily available should be accessible by the needy, the aged, the disabled, Indigenous people and other disadvantaged groups at a reasonable cost."*

Additional motivators identified included:

- Chemist blister packs to ensure all medications taken.
  - Identified as particularly important for elderly, disabled, and non-English speaking people.
- Delivery options
- Ability to ask questions
- Provide options for natural vs chemical medicines or other therapies.

What programs and/or resources would you find helpful?

Helpful tools and resources:

- Consumer friendly Mobile Apps for reminders (including when to take, and have medication refilled) and keeping accurate details of daily progress, script reminders, journaling, & mindfulness.
- Video clips available through health professionals
- Phone reminders, including alarms.
- Belonging to support groups for particular conditions or illnesses.
- Consumer friendly medicine information leaflets written plain English and translated into other languages.
- Access to interpreting services
- Trained CALD GPs, pharmacists and other health professionals.
- One stop national information portal on all available medications.
- A medicines database for medical professional to access and quickly identify what the medication is for, the side-effects, and possible contraindications with other medicines.
- Friends and family for advice.
- Medical research journals are helpful but involve a lot of work to understand. Many participants talked about doing their own research.

> *"NPS MedicineWise produce quality educational material; unfortunately, I don't see it where it needs to be – where the consumer can benefit from it."*
>
> **
>
> *"It sucks being in a consultation and the doctor must google side effects when prescribing something to give me information."*

What could be improved?

Communication:

- Communication and the way information is presented to the consumer were the key areas for improvement. Explanations and information need to be in plain language.

What could be improved…

> *"There is no check to see if they are compatible with your current medications. Similar situation with health products from Woolworths and even from your regular chemist. Just ask for them and pay. No discussion."*

Awareness and education:

- More education and focus on prevention rather than treatment.
- Increases awareness about lifestyle modifications such as diet and exercise, to improve condition to remove or reduce the need for medicines.
- Community-Council Partnerships in achieving health goals.
- Regular roadshows by the Department of Health or local health districts advocating for programs and health benefit needs in the society.
- More visual resources such as apps or videos for people to access, made available through Telehealth or pharmacy website when medicine is delivered.
- Patients provided with trusted websites about particular conditions or medicines
- Only one source of truth in Australia, approved and endorsed by the Australian Government.
- Educational programs about identifying actual medicines to separate from brands.

What could be improved…

> *"Treatment does not always only involve drugs; alternative and allied therapies can be used in conjunction with medical advice. Consumer should feel safe and comfortable to discuss other treatment plans with medical professions without being dismissed."*

**

> *"Until I went to a 5-week intensive Pain clinic I wasn't even aware that there were other ways to live with your pain."*

Community programs:

- Community education on medicines use to new arrivals
- Programs that improve health literacy such us community programs on how to read information of medicines.
- More information needs to be provided to the Aboriginal and CALD community.

Affordability:

- More government support for alternatives to medicines. For example, pain clinics should be covered by Medicare.

Question 5: Do you have any additional comments?

Consultation with doctor and/or pharmacist

- Concerns that doctors don't have the time to ask all the questions that might better inform them of what a patient needs, nor in some instances, do they care.
- Many participants felt frustrated but very resigned to not being able to rely on doctors. They were getting good use out of their pharmacists, but many seemed to want a better option. Other participants suggested the need for better use of nurses for helping people manage their medications.
- Previously, patients often consulted their individual doctors in the general practitioners own consulting rooms. In the new arrangements of multiple practices and the frequency of using locums this is no longer likely. Patients nowadays cannot expect to see the same doctor every time they seek a consultation.

> *"It's incredibly overwhelming when you are thrust into a situation where you are caring for another person and I think the whole health literacy and medication literacy stuff is really important. You are so quickly thrust into a language that you have never heard, and Drs try to talk to you in a language that you are just learning."*

Access to consumer-friendly information

- CALD communities like information on western medication, which interact with eastern medicinal supplements. Such as herbal, natural home remedies.
- Need for a one-stop database/national website for consumer use that includes information about medication risks, benefits, side effects, interactions of medications.
- The provision of sufficient information to make a decision about a medicine and its safe use is not consistent. For example, sometimes people receive a CMI but most times don't.
- Consumer-led initiatives need to be thoroughly encouraged and supported.
- There is a need for information and communication to be provided in a way that can be understood and is reliable and honest.
- Interpreter services need to be available at all Local Health Districts, even if they have a population of 100 people.
- Hold health literacy classes for consumers and carers from non-English speaking backgrounds.
- A national medication information centre would be helpful for consumers who are afraid to ask their doctor and/or pharmacist questions about their medication.

> *"I have the fridge magnet with NPS Medicine Line number up on my fridge door, though I've never used it)."*

Feedback

- Provide clear pathways for people to provide feedback and/or complaints on medicines to pharmacies and/or GP clinics.

Medication Adherence

- Provide Webster packs as a matter of process for vulnerable groups, such as elderly, disabled and non-English speaking patients.
- Compliance is hard when condition is simpler. Easier to choose if condition is life threatening.

> *"It is a worry that I would feel so frightened to be trying to manage my dad's condition without the blister packs – they are made for people with low medical literacy. People who are taking medications are either unwell or they are trying to deal with a whole language that they don't understand so we need to make it easier for them to do it safely."*

Consumer Empowerment and Accountability

- People need to be encouraged to take more responsibility for their health and wellbeing.
- Each person is ultimately responsible for her/his own medicine regime and can be assisted only to the extent that he/she allows this.

> *"Quality is the responsibility of both doctor and patient, but not all patients are able to do everything to make sure they have quality use."*

Holistic Approach

- Medication is often perceived as being the way to treat without really knowing why or what the diagnosis is.
- Health should be view from a holistic standpoint.

Medication Review

- Patients should have their medicines reviewed at least annually by a doctor and/or a pharmacist. In cases of disabled and disadvantaged groups this responsibility will be part of the carer's role.
- Physicians when prescribing a new medicine to replace one already in use should clearly issue instructions to cease taking the earlier prescribed medicine.

> *"I found a Medicare number where someone can come to the home and go through the medicines."*

Disposing Unused Medicines

- Making sure unwanted or unused medicines are returned to pharmacy and not stored for future use or sharing with other friends/family later.
- Concern about abuse of medicines – taking them incorrectly, giving them to others, or keeping them out of date or past use by date.

> *"Disposal of medicines is critical. My mum was taking some that expired 15 years ago."*

Political & Pharmaceutical Drive

- Concern that doctors and/or pharmacists are driven by incentives, and money rather than consumer needs.

> *"What we have been talking about it the end user interface, but we also need to drive what happens at the drug development, cost, manufacture, distribution and accountability."*

Policy

- The National Medicine Policy and Quality Use of Medicines Policy should be reviewed regularly.

Evidence-based medicines:

- Stick to medicine consumers trust which carry clinically proven progress and outcomes, such as antibiotics.
- Host community forums to showcase positive research and effects of widely used medication and assure consumers that's the medication is regulated and quality controlled.

Side effects:

- Consumers prefer medications with minimum side effects.
- If side effects persist, less interventions to reduce the side effects. For example- constipation caused by medications may be managed using a high fibre diet.

Conclusion

Overall, CHF coordinated a series of virtual consumer led discussions to highlight real world insights from ‘grass roots’ consumers (including from hardly reached communities) relating to QUM and health literacy, including what consumers want/need to know about medicines as well as what encourages consumer adherence to medicines.

This report outlines key themes and messages that emerged from the virtual consumer discussions on health literacy and quality use of medicines. While the discussions questions targeted different aspects of quality use of medicines, there was an overlap of key themes and messages covering:

- Quality of life
- Affordability
- Appropriateness (including medicines and information)
- Access and availability
- Alternatives (including brands and alternative treatments)
- Safety, quality and efficacy
- Consultation and ongoing relationship with and between relevant health professionals.
- Dosage and administration
- Packaging
- Storage
- Ingredients
- Informed consent
- Benefits and risks, including side effects
- Consumer agency, health literacy and the value of shared decision making.

The importance of a holistic, patient-centred approach clearly underpins each of the themes and key messages raised. The key themes that have emerged from virtual consumer led discussion are consistent with the findings of the literature review. In particular, the Rapid Literature Review on Health Literacy and QUM identified a significant amount of high quality, valued information, resources and tools available to support medication literacy and QUM in Australia; however, there is less clarity regarding uptake, utilisation and impact of these resources. The virtual consumer led discussions also highlighted a broad range of high quality, valued information however the uptake of such resources varied and requires further investigation.

The findings from the virtual consumer led discussions, together with the findings of the Rapid Literature Review on Health Literacy and Quality Use of Medicines will be used to inform the consumer segmentation survey questions.

Appendix A: Application Form: Host Virtual Consumer Discussion

This is your opportunity to host and facilitate a Virtual Consumer Discussion with your local community members on what's important to you about medicines and health literacy.

Application closing date: 10th May 2020

About the project

The Consumers Health Forum of Australia (CHF) is offering consumers and carers from across Australia the opportunity to host and facilitate a virtual discussion with their local community on quality use of medicines and health literacy, including what consumers want/need to know about medicines as well as what encourages consumer adherence.

Launched in December 1999, the National Medicines Policy (NMP) aims to bring about better health outcomes for all Australians, focusing especially on people's access to, and wise use of, medicines. In 2020, a review of the NMP will be undertaken. A central principle of the NMP is keeping consumers at the centre.

To understand community needs, CHF has been engaged and funded by NPS MedicineWise as lead agency to carry out a research project that will contribute to improving consumer health literacy as it relates to quality use of medicines. It will help to:

- Understand the current status of health literacy amongst Australians
- Inform future NPS MedicineWise Grant activities
- Support the Review of the National Medicines Policy.

CHF and NPS MedicineWise want to ensure consumer views are central to this project and highlight real world insights from "grass-roots consumers". We are undertaking a series of (up to 20) Virtual Consumer Discussions across the country to hear from consumers about what matters to them when it comes to medicines and health literacy.

About Virtual Consumer Discussions

The Virtual Consumer Discussions (adapted from Health Consumers Queensland approach to Kitchen Table Discussions) are community engagement sessions led by local people for local people.

They will allow individuals and small groups to participate in discussions at a time of day, and in a place, that suits them. This approach aims to enable health consumers, carers and community members who do not ordinarily participate in healthcare consultation to have their say in a safe and supportive environment.

Each Virtual Consumer Discussion will be led by a Consumer Host with a strong community network and will invite up to 10 community members to a virtual discussion. The Host guides the discussion with a set of questions provided to them and reports back the outcomes to CHF. CHF will compile the responses into a set of consumer insights to help inform the Research Project.

Role of the Discussion Host

As the host, your role will be to plan, coordinate and facilitate **a once-only 90-minute virtual discussion** with community members. This includes:

- Inviting up to 10 participants who would be interested in being part of the discussion on this important subject. They will be your local community connections (ideally, people who do not normally have their voice heard in healthcare).
- Choosing a time and date between 18 May and 9 June 2020 that works for you and your participants.
- Host the session.
- Complete and return the provided feedback report to CHF by **12 June 2020**

To support you with this, you will receive:

- Training (45 minutes) via a Zoom video conference call on either **13 or 15 May 2020** based on your availability. Zoom is free to download.
- A comprehensive Host Guide.
- Questions to ask participants during the discussion, an agenda and feedback report template.
- Support from CHF to ensure you have a successful session.

Who are we looking for as consumer or carer hosts?

We are looking for:

- 20 people to host the Virtual Consumer Discussion from across all states and territories.
- We would like our hosts to have personal experience with or an interest in health literacy as it relates to quality use of medicines.
- We are also interested in representing the views of a range of consumers who may not typically have a say in healthcare. To achieve this, we are particularly looking for hosts who are consumers and/or carers and can demonstrate they have strong links with their communities.

Reimbursement and support

Hosts – you will be remunerated a full day meeting rate of $374.

Participants – CHF will provide a $60 gift voucher for each Virtual Consumer Discussion participant for their time.

How to apply

Please complete this application form below by **11:59pm AEST on Sunday 10 May 2020.**

For queries relating to this opportunity or assistance completing this application form please email Leanne Kelly, Quality Use of Medicines Lead at l.kelly@chf.org.au.

Please be aware that information in your application may be shared with NPS MedicineWise as part of the assessment of applications.

Your Details

Full Name *

Preferred phone number *

Email *

Postcode *

Consent

By completing this application, I consent for my details to be shared with the Consumers Health Forum, NPS MedicineWise and my local state/territory health consumer organisation as necessary in order to assess this application *

- Yes
- No

Please select any group you identify with:

- Aboriginal people and Torres Strait Islander people
- Young people
- Older people
- Caring for someone with a life limiting condition
- Rural and remote
- Culturally and linguistically diverse
- From a non-English speaking background

Age Range *

- 16-24
- 25-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70+

Are you a: *

- Consumer
- Carer

If applicable, do you identify as:

- Aboriginal
- Torres Strait Islander
- Both
- Prefer not to say

In 250 words or less, please describe your community connections and networks that you can draw on to host a successful and inclusive virtual consumer discussion. *

In 250 words or less, please describe your knowledge, involvement and/or interest in health literacy as it relates to quality use of medicines. *

In 250 words or less, please describe why you would like to host a virtual consumer discussion with your community on quality use of medicines and health literacy.

Appendix B: Host Guide

About CHF

Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health care consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is patient-centred care.

About NPS MedicineWise

Independent, not-for-profit and evidence-based, NPS MedicineWise is a national implementation body that enables better decisions about medicines, medical tests and other health technologies.

About the Project

The CHF has offered 20 consumers and carers from across Australia the opportunity to host and facilitate a virtual discussion with their local community on quality use of medicines and health literacy, including what consumers want/need to know about medicines as well as what encourages consumer adherence.

Launched in December 1999, the National Medicines Policy aims to bring about better health outcomes for all Australians, focusing especially on people's access to, and wise use of, medicines. In 2020, a review of the National Medicines Policy is expected to occur. A central principle of the National Medicines Policy is keeping consumers at the centre.

To understand community needs, CHF has been engaged and funded by NPS MedicineWise as lead agency to carry out a research project that will contribute to improving consumer health literacy as it relates to quality use of medicines.

The objectives of the research project include:

- Provide findings that reflect the knowledge, attitudes and perceptions of 'grass roots consumers' in relation to Quality Use of Medicines (QUM)
- Identify the current understanding of consumer health literacy for Australians as it relates to QUM
- Identify and characterise key consumer segments as they relate to QUM health literacy to assist in future resource or program development
- Provide recommendations for resources/program development to meet unmet needs
- Identify relevant QUM and health literacy indicators for future evaluation of collective impact
- Distribute findings to support the review of the National Medicines Policy

To achieve this, CHF are undertaking the following activities over the next few months.

- Literature review
- **Virtual Consumer Led Discussions**
- National Consumer Segmentation Survey

About the virtual consumer discussions

The CHF are holding these Virtual Consumer Led Discussions because we want to ensure consumer views are central to this project and highlight real world insights from people whose voices aren't normally heard through the regular consultation channels.

Health literacy and quality use of medicines is important to everyone and we want to hear from you and your communities about what consumers want/need to know about medicines as well as what encourages medication adherence.

Your role as the host

As the host, your role will be to plan, coordinate and facilitate **a once-only 90-minute virtual discussion with community members**. This includes:

- Inviting **up to 10 participants** who would be interested in being part of the discussion on this important subject. They will be your local community connections (ideally, people who do not normally have their voice heard in healthcare).

- Choosing a time and date between **Monday, 18 May and Tuesday, 9 June 2020** that works for you and your participants.

- Host the session. (**Please note** you will receive details to log into a CHF Zoom account to schedule your session).

- Complete and return the provided feedback report to CHF by **12 June 2020.** You can view and submit your report here.

Discussion Questions

To ensure consistency across these virtual discussions, please use the following questions to guide your session (key questions in bold, with additional probe questions for further guidance):

1. **What does quality use of medicines mean to you?**

2. **What is important to you when:**
    - Deciding on medicines?
    - Using medicines?
    - Checking outcomes and progress? (e.g. is the medicine doing what is intended?)
3. **What do you want and/or need to know about medicines?** How do you access information on medicines?

4. **From your perspective, what encourages adherence to medicines?** What programs and/or resources would you find helpful? What could be improved?

5. **Do you have any other comments?**

For Participants: Discussion Questions & Demographic Information

Separate to this guide, we have provided you with a version to send to your participants prior to the session. To assist you in collating the feedback from all participants, you may wish to encourage them to write down their key points (on the participant version) and request they send this to you after the session, if they feel comfortable.

To assist CHF in capturing the diversity of people involved in these consultations, we have also included some demographic questions. **All responses and information used will be deidentified.**

Host Renumeration & Participant Vouchers

Host Renumeration: you will be remunerated a full day meeting rate of $374. This will be processed once your feedback report has been submitted. You will receive the relevant form to complete when this occurs.

Participant Vouchers: CHF will provide a $60 gift voucher for each Virtual Consumer Discussion participant for their time. As the host, we ask that you disseminate the vouchers to your participants after the session has been completed. Please contact Leanne Kelly (l.kelly@chf.org.au) to arrange this process.

Any questions?

Thanks for taking on the role of hosting these virtual consumer discussions. If you have any questions, please contact Leanne Kelly, Quality Use of Medicines Lead, l.kelly@chf.org.au.

Please note:

- My normal working hours are **Monday to Friday, 7:30am to 3:30pm [AEST]**
- **Public Holidays**: Monday, 1 June and Monday, 8 June are public holidays in Canberra.

Appendix C: For Participants: Demographics and Discussion Questions

Virtual Consumer Discussion Questions

Quality Use of Medicines & Health Literacy

Thank you for your interest in participating in this Virtual Consumer Discussion about what's important to you about medicines and health literacy.

Launched in December 1999, the National Medicines Policy aims to bring about better health outcomes for all Australians, focusing especially on people's access to, and wise use of, medicines. In 2020, a review of the National Medicines Policy will be undertaken. A central principle of the National Medicines Policy is keeping consumers at the centre.

To understand community needs, CHF has been engaged and funded by NPS MedicineWise as lead agency to carry out a research project that will contribute to improving consumer health literacy as it relates to quality use of medicines.

Demographic information

To assist CHF in capturing the diversity of people involved in these consultations, please complete the demographic section below and return to your host after the discussion.

Please highlight any group you identify with:

- Aboriginal people and Torres Strait Islander people
- Young people
- Older people
- LGBTIQ +
- Carers
- Rural and Remote
- Culturally and linguistically diverse
- From non-English speaking background
- Living with a disability or chronic condition

If applicable, do you identify as: Aboriginal | Torres Strait Islander | Both | Prefer not to say

Are you a: Consumer | Carer | Both

Age range: 16-24 | 25-29 | 30-39 | 40-49 | 50-59 | 60-69 | 70+

What is your gender? Male | Female | Other | Prefer not to answer

What is your postcode?

Questions for discussion

We encourage to think about the questions for discussion prior to the meeting. Please feel free to use the space below each question to write down some key points and, if you feel comfortable, share with your host after the session. This will help your host collate the information. All responses and information used will be deidentified.

1. What does quality use of medicines mean to you?

2. What is important to you when:

   a) Deciding on medicines?

   b) Using medicines?

   c) Checking outcomes and progress? (e.g. is the medicine doing what is intended?)

3. What do you want and/or need to know about medicines? How do you access information on medicines?

4. From your perspective, what encourages adherence to medicines? What programs and/or resources would you find helpful? What could be improved?

5. Do you have any other comments?

Appendix D: Host Feedback Report Form

Thanks for taking on the role of hosting these virtual discussions. We ask that you report back the outcomes of your virtual discussions by answering the questions below. CHF will compile the responses into a set of consumer insights to help inform the Research Project.

Ideally, you should report to CHF shortly after you have hosted your virtual consumer discussions, but we understand that it is sometimes difficult to do this. We ask that you report back no later than **Friday 12 June 2020.**

We also understand that this format might not suit you, so please use another format if you prefer.

Please email Leanne Kelly, l.kelly@chf.org.au if you have any questions.

First Name *

Last Name *

Phone Number

Email *

Date of Virtual Consumer Led Discussion: DD/MM/YYYY

How many people participated? *

What does quality use of medicines mean to you? *

What is important to you when deciding on medicines? *

What is important to you when using medicines? *

What is important to you when checking outcomes and progress? (e.g. is the medicine doing what is intended?) *

What do you want and/or need to know about medicines? How do you access information on medicines? *

From your perspective, what encourages adherence to medicines? What programs and/or resources would you find helpful? What could be improved? *

Do you have any other comments?

Please attach any documentation that you wish to provide with this report.

This may include forms completed by participants (Questions for Discussion and Demographic Information). If you are unable to upload here, please send directly to Leanne Kelly via email (l.kelly@chf.org.au) no later than **Friday, 12 June 2020.**

Appendix E: Activity Timeline

Date (week starting)	April 2020			May 2020				June 2020				
	13	20	27	4	11	18	25	1	8	15	22	29
Finalise Application Form	🟩											
Confirm networks to promote opportunity	🟩											
Send and promote application form		🟩	🟩	🟩								
Assess applications					🟩							
Notify applicants of outcomes					🟩							
Zoom training for hosts					🟩							
Email Host Guide and discussion questions					🟩							
Hosts invite and organise virtual discussions						🟩	🟩					
Virtual discussions hosted						🟩	🟩	🟩	🟩			
Virtual discussion feedback report received from hosts							🟩	🟩	🟩			
Pay hosts remuneration and purchase participant vouchers							🟩	🟩	🟩			
Write up report								🟩	🟩	🟩	🟩	
Deliver report to NPS MedicineWise.												🟩