



Consumers Health  
Forum OF Australia

Final Report

**Consumer Health Literacy  
Segmentation and Activation  
Research Project**

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Activation Research Project. Final Report.*  
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## Contents

Acknowledgement and Attribution.....	4
Executive Summary.....	5
Introduction.....	8
Key Findings.....	10
<b>Identify and characterise key consumer segments as they relate to QUM health literacy.....</b>	<b>10</b>
Vulnerable Sub-Population Segments.....	10
Consumer Segmentation Survey: Identified & Characterised Segments.....	13
<b>Knowledge, attitudes and perceptions of ‘grass roots consumers’ as it relates to QUM.....</b>	<b>15</b>
<b>Identify the current understanding of consumer health literacy for Australians as it relates to QUM.....</b>	<b>24</b>
<b>Provide recommendations for resource/program development to meet unmet needs.....</b>	<b>27</b>
Initiatives to promote health literacy.....	27
Initiatives to promote medication literacy and QUM.....	28
The identified unmet needs of improving health literacy and QUM.....	29
<b>Identify relevant QUM and health literacy indicators for future evaluation of collective impact.....</b>	<b>32</b>
Next Steps.....	35
References.....	37
Appendix A: Consumer Segmentation Survey Methodology.....	41
<b>Online questionnaire.....</b>	<b>41</b>
<b>Analysis of survey data.....</b>	<b>41</b>
<b>Segmentation Analysis.....</b>	<b>41</b>
<b>Limitations.....</b>	<b>42</b>
Appendix B: Project Activity Timeline.....	43

# Acknowledgement and Attribution

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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 was engaged and funded by NPS MedicineWise as the lead agency to plan and implement a project, Consumer Health Literacy Segmentation and Activation Research. The project and resulting reports were developed collaboratively, with oversight and guidance provided by Jemma Gonzalez (Consumer Engagement Lead, NPS MedicineWise), Leanne Wells (CEO, CHF) and Jo Root (Policy Manager, CHF). The project was coordinated by Leanne Kelly (Quality Use of Medicines Lead, CHF).

The formative research, the first project activity, was conducted by Leanne Kelly, (Quality Use of Medicine Lead, CHF) with assistance from NPS MedicineWise, specifically Liz Kempton (Health Information Coordinator), Jemma Gonzalez (Consumer Engagement Lead), members of CHF's special interest groups, specially the Research and Data, and Safety and Quality in healthcare special interest group, and the Australian Commission on Safety and Quality in Health Care, specially the Medication Safety Team for their assistance in identifying relevant papers.

The Literature Review, the second project activity, was conducted by A/Prof Jane Lloyd and Ms Kathy Bell, and reviewed by CHF and NPS MedicineWise.

The virtual consumer-led discussions; the third project activity was coordinated by CHF. CHF gratefully acknowledges the contribution of the 19 consumer hosts who planned, coordinated and facilitated a virtual discussion and the 185 participants for their time and insights to inform this consultation on health literacy and quality use of medicines.

The Consumer Segmentation Survey, the final project activity was conducted by Urbis and Dynata. Urbis was contracted by CHF to develop the survey questionnaire, analyse the responses to the survey and produce a final report. Specific members of the team were: Caroline Tomiczek (Director), Christina Griffiths (Senior Consultant) and Ryan Bondfield (Research Assistant). Dynata was contracted by CHF to script and host the survey. Specific members of the team were: Mingky Sin (Senior Project Manager), Jade Park (Senior Project Manager) and Chris Jones (Account Manager).

This final report was prepared by Leanne Kelly with oversight and guidance provided by Jemma Gonzalez, Leanne Wells (CEO, CHF) and Jo Root (Policy Manager, CHF). CHF worked collaboratively with NPS MedicineWise and the Australian Commission on Safety and Quality in Health Care to identify indicators and recommend ways to support implementation. The NPS MedicineWise Consumer Advisory Group provided input into the final report and recommendations.

# Executive Summary

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CHF was engaged and funded by NPS MedicineWise as the lead agency to plan and implement a project, Consumer Health Literacy Segmentation and Activation Research (the Consumer Segmentation Research).

The objectives were to:

- Identify and characterise key consumer segments as they relate to QUM health literacy to assist in future resource or program development
- 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
- Provide recommendations for resource/program development to meet unmet needs
- Identify relevant QUM and health literacy indicators for future evaluation of collective impact.
- Distribute findings to support the principles and objectives of the National Medicines Policy and integrate into other Grant activities.

To achieve the objectives, four project activities were conducted: 1) formative research; 2) literature review; 3) virtual consumer led discussions and 4) consumer segmentation survey. This report summarises the key findings collected across the project activities, addressing each of the objectives.

While there are many population segments in Australia at higher risk of poor health literacy and sub-optimal medicines use, the literature review identified and focused on the following segments: older consumers (aged 65 years and over); Aboriginal and Torres Strait Islander people; culturally and linguistically diverse consumers; and consumers with low literacy/low health literacy. The consumer segmentation survey identified three segments:

- Segment 1 - 'Preventative Measures'
- Segment 2 – 'A Trusted Necessity'
- Segment 3 – 'The Quick Fix'

The segments are similar in size, with each comprising of around one-third of respondents. Compared to the other segments, Segment 3 – 'The Quick Fix' was found to have lower levels of health literacy, less engaged with medicines, and have higher levels of health care service usage. Furthermore, this segment had a higher proportion speak another language other than English at home and identified as Aboriginal and/or Torres Strait Islander.

From a consumer perspective, QUM was more than simply the act of taking a medicine to improve their health and wellbeing. Participants highlighted key elements (such as improved quality of life, affordability, access, appropriateness and relationship with doctor and/or GP), that contributed to QUM all of which are underpinned by a holistic, patient-centred approach. Regardless of how consumers and carers accessed information on medicines, participants emphasised the importance 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.

The consumer segmentation survey questionnaire identified a number of potential health literacy QUM indicators that NPS MedicineWise could promote as a consistent way of measuring health literacy and QUM across the sector and covered the following areas:

- Individual health literacy as it relates to QUM
- understanding of QUM
- attitude towards health professionals' role in QUM
- reading information on medicines
- information sources on medicines.

The research identified a large number of initiatives to promote consumer medication literacy and QUM in Australia. These included both population-wide initiatives, and initiatives focusing on specific population segments. An analysis of these initiatives came to the following conclusions:

- There is insufficient readily available evaluation data to adequately assess the accessibility and appropriateness of current initiatives to promote health literacy, medication literacy, and QUM in Australia.
- Most of the interventions examined in this review focus on providing information (or services) to consumers, rather than addressing health literacy in a co-ordinated way.
- There is a significant quantity 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.
- There is limited focus on consumer-centred models and consumer co-design.
- There does not appear to be a strategic, co-ordinated approach to meeting the needs of consumer segments at higher risk of low health literacy and poor QUM.

This report identifies the following next steps for NPS MedicineWise and other stakeholders to address the key findings for future collective impact.

1. Develop a strategic, co-ordinated approach to identifying and addressing the health literacy, medication literacy and QUM needs of higher-risk population segments.
2. Further research to identify the extent to which consumers, particularly those with low health literacy, are:
  - a) aware of the available resources
  - b) able to distinguish and select between high quality and poor-quality resources, and
  - c) able to utilise the resources in their health care interactions and decisions.
3. Develop a strategic, co-ordinated approach to addressing health literacy, medication literacy, and QUM, across the three action areas recommended by the Australian Commission on Safety and Quality in Health Care embedding health literacy into systems; ensuring effective communication; and integrating health literacy into education for both consumers and healthcare providers.
4. Utilise consumer co-design in the development and implementation of future initiatives making sure consumers from the various segments identified are included.

5. Ensure that initiatives include measures to promote consumer awareness of and access to the relevant programs, tools, and resources, including for consumers from higher-risk population segments.
6. Ensure that routine data collection is built into future initiatives, including data on uptake and outcomes of interventions, to support the ongoing evaluation and improvement of interventions that seek to improve consumer health literacy, medication literacy, and QUM.
7. Explore the opportunity to develop a national clearing house on health literacy and QUM initiatives, including relevant information, resources, tools, and research and evaluation findings.

# Introduction

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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. CHF was engaged and funded by NPS MedicineWise as the lead agency to plan and implement a project, Consumer Health Literacy Segmentation and Activation Research (the Consumer Segmentation Research).

The Consumer Segmentation Research contributes to improving consumer health literacy as it relates to quality use of medicines (QUM) through the implementation of research to:

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

The objectives were to:

- 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
- Provide recommendations for resource/program development to meet unmet needs
- Identify relevant QUM and health literacy indicators for future evaluation of collective impact. For example, National Consumer Segmentation Survey to measure QUM awareness and health literacy
- Distribute findings to support the principles and objectives of the National Medicines Policy and integrate into other Grant activities.

To achieve the objectives, four project activities were conducted:

- 1. Formative research:** This aimed to identify previous relevant work to inform the scope of the Consumer Segmentation Research, including literature review parameters, virtual consumer led discussions and the consumer segmentation survey questions. In addition, CHF identified the key policy documents as it relates to QUM to establish the current environment. The formative research was conducted over a 2-week period in April 2020. The full report for this activity can be viewed [here](#).
- 2. Literature review:** The literature review identified and interpreted the latest published evidence (and grey literature review) as it relates to QUM health literacy in Australia. CHF commissioned A/Prof Jane Lloyd and Ms Kathy Bell to conduct the literature review over a four-week period during May 2020. The literature review set out to answer the following questions:
  - What is known about levels of health literacy and QUM in Australia?
  - Which population segments in Australia are most at risk of poor health literacy and sub-optimal medicines use?



- What key tools and resources, including indicators, are available for measurement of health literacy and QUM in Australia?
  - What key initiatives are in place for promoting health literacy and QUM in Australia?
  - Where are the unmet needs in terms of improving health literacy and QUM?
- 3. Virtual consumer led discussions:** CHF coordinated a series of virtual consumer led discussions, over an 11-week period, to highlight real world insights from 'grass roots' consumers (including from hardly reached communities) relating to QUM and health literacy, including what consumers want and/or need to know about medicines as well as what encourages consumer adherence to medicines. The following questions guided the discussions:
- What does QUM mean to you?
  - What is important to you when:
    - Deciding on medicines?
    - Using medicines?
    - 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 adherences to medicines? What programs and/or resources would you find helpful? What could be improved?
- 4. Consumer segmentation survey:** CHF commissioned Urbis and Dynata to conduct the national survey over a six-week period from July to mid-August 2020. The consumer segmentation survey gathered quantitative data to:
- Ensure recommendations outlined in this final report are robust and represent the views of all Australians.
  - Validate the findings and further explore research gaps as indicated from previous activities.

The questionnaire was informed by formative research, the literature review and virtual consumer led discussions and designed by Urbis. CHF also worked closely with Urbis, NPS MedicineWise, and members of CHF's Research & Data Special Interest Group to finalise the survey questions. See Appendix A: Consumer Segmentation Survey Methodology for more information on the survey analysis and limitations.

See Appendix B: Project Activity Timeline for the project activity timeline.

This report summarises the key findings collected across the project activities, addressing each of the objectives. In addition, this report makes recommendations regarding:

- characteristics of key consumer groups as relates to QUM health literacy to assist in future resource or program development
- current understanding of consumer health literacy for Australians as it relates to QUM
- recommendations for resource/program development to address findings
- relevant health literacy indicators for future collective impact.

## Key Findings

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This section of the report addresses the objectives through the key findings gathered throughout the four stages of the Consumer Segmentation Research:

- Identify and characterise key consumer segments as they relate to QUM health literacy to assist in future resource or program development
- 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
- Provide recommendations for resource/program development to meet unmet needs
- Identify relevant QUM and health literacy indicators for future evaluation of collective impact.

### Identify and characterise key consumer segments as they relate to QUM health literacy

This objective was addressed through the formative research, literature review and the consumer segmentation survey. Relevant key findings from the project activities are discussed below.

#### *Vulnerable Sub-Population Segments*

The formative research and literature review identified and focused on four key vulnerable sub-population segments:

- **Older people (65 years and over):** Potential risk factors include lower health literacy, multimorbidities, polypharmacy, metabolic changes, and cognitive impairment.
- **Aboriginal and Torres Strait Islander people:** Potential risk factors include lower socioeconomic status, higher burden of disease, challenges with access to culturally safe care and appropriate communication with health professionals, and probably lower health literacy, though data on this is limited.
- **CALD consumers:** Potential risk factors include language barriers, lower health literacy, and barriers to culturally appropriate care. Refugee populations have additional risk factors including those relating to mental health.
- **Consumers with low literacy and/or low health literacy:** Low socioeconomic status, low education levels, low literacy levels, and low health literacy are interrelated, and have an independent and cumulative impact on health outcomes.

Individual consumers may of course fall within two or more of these population segments. It is important to recognise that there are many population segments in Australia at risk of poor health literacy and sub-optimal medicines use.

#### *Older people*

As life expectancy in Australia increases, the proportion of older people (defined here as people aged 65 and over) in the community is also increasing. This population cohort frequently has multimorbidities, often associated with multiple medication use, and in some

cases polypharmacy (the use of five or more medicines). Polypharmacy, unnecessary adverse drug events, confusion about therapy, and adherence issues, are common concerns in relation to QUM by older Australians.

The 2006 ABS survey, outlined earlier in this report, indicated that while 50% of Australians aged between 30-39 who completed the survey had health literacy skills that were adequate or better, only 22% of people aged 60-74 had health literacy skills that were adequate or better (Australian Bureau of Statistics, 2006).

Poor health literacy has been recognised as a limiting factor in older people's ability to comprehend written or verbal medication information and also to successfully adhere to medical regimens (Berthenet, 2016). Australia's National Statement on Health Literacy notes that in older people, low individual health literacy is associated with a poorer health status and with a higher risk of premature death (Australian Commission on Safety and Quality in Health Care, 2014).

Research by Corre et al (2018) based on interviews with older Australians living in the community, found that a significant proportion were exposed to polypharmacy and consulted multiple prescribers who manage their multimorbidity. Both inter-prescriber communication and adequate patient education were identified as vital in reducing the likelihood of adverse events. However, responses from interviews indicated sub-optimal communication between patients and their prescribers. Despite a keen interest in their medicines, patients may not be adequately educated about them, resulting in a lack of understanding, a failure to seek advice about adverse effects or limited transparency about the use of non-prescribed medicines. Similarly, Segment 2: A Trusted Necessity (representing 30% of the sample) with 61% aged 50 years and over were 'happy to take medicine recommended by their doctor'. The researchers conclude that along with an increased role for pharmacists, increased education is required in order to further develop the medicines knowledge of older people in the community, which may improve health literacy, optimise medicine use and minimise harm (Corre, 2018).

### ***Aboriginal and Torres Strait Islander people***

Aboriginal and Torres Strait Islander people experience a higher disease burden than non-Indigenous Australians, and this is particularly true for chronic disease. While the root causes of this disparity clearly relate to risk factors arising from the socioeconomic determinants of health, pharmacotherapies do have a significant role to play in closing the health gap between Aboriginal and Torres Strait Islander people, and other Australians. QUM is a critical issue in this context.

For Aboriginal and Torres Strait Islander peoples, access to medicines and QUM are closely linked. Financial access barriers can cause people to forego essential medications, making adherence to prescribed medication regimes impossible and having a negative effect on health status (Couzos S, 2011).

While there is little solid data on the health literacy levels of Indigenous Australians and Canadians, in New Zealand a higher proportion of the Maori population has low levels of health literacy, compared with the general population. The literature review reported that the situation is likely to be similar for Indigenous peoples in Australia and Canada, given similar patterns of inequity (Crengle, 2018).

The literature review notes there are reports that the levels of medication related problems among Aboriginal and Torres Strait Islander populations are of concern, “although there is scant evidence of the size or extent of the problem” (Spinks, 2019).

### ***Culturally and linguistically diverse (CALD) populations***

A person’s health literacy can be influenced by their cultural beliefs, language, disability, education, income and health status (Sorensen, 2012). Consumers from CALD backgrounds are more likely to have low health literacy (Taylor, 2017). In Australia, the 2006 ABS survey revealed that health literacy is lower among people who speak English as a second language (26%) (Australian Bureau of Statistics, 2006).

Interpreters may be used to overcome language barriers during a clinical encounter, which enables consumers to understand the language being spoken. However, if consumers have low health literacy, they will have difficulty understanding the content and the implications of the clinical encounter; therefore, the risk of poor access to health care and poor health outcomes will persist. Providing interpreters to consumers who speak a language other than English is an essential component of quality healthcare. However, interpreters do not address issues of low health literacy (Andrulis, 2007).

### ***Challenges facing refugee populations***

Resettled refugees in Australia have been shown to exhibit a high prevalence of limited health literacy. They are at greater risk of mismanaging their medication, misunderstanding issues relating to their health and not being able to access the healthcare services they need. (Ethnic Communities' Council of Victoria., 2012).

There is a small but growing amount of research exploring resettled refugees and access to primary health care including pharmacy services and the QUM (Bellamy, 2015). The most commonly cited barriers to accessing primary health care services and the QUM include communication and language concerns (Clark, 2014) (Baker, 1998), followed by differences in cultural expectations and practices, low health literacy, difficulty navigating the health care system (Bellamy, 2015) and financial barriers such as the costs of medicines (Kay, No Date). Practices that overcome some of these barriers include the use of interpreters, having a regular GP and pharmacists, community engagement, the provision of medicines information and improved health care provider training. In primary health care the supportive role of the practice nurse was especially noted (Kay, No Date).

### ***Consumers with low literacy and/or low health literacy***

There is a strong relationship between low socioeconomic status, low educational attainment, low general literacy, and low health literacy. Health literacy follows a social gradient. Consumers who have low literacy, low educational attainment and/or who are socioeconomically disadvantaged are more likely to have low health literacy. This occurs incrementally according to the level of disadvantage.

It has been demonstrated that consumers with low educational attainment are also likely to have low health literacy (Hosking, 2018) (Sorensen K, 2015). An international survey confirmed that consumers who are socioeconomically disadvantaged are more likely to have low health literacy (Sorensen K, 2015).

Research was undertaken in Canada to gather data on the major challenges’ low health literate adults face regarding their medication. The authors found the major challenges

consumers with low health literacy face with medication information from pharmacies include limited time with pharmacists, difficulty understanding medication information, forgetting to take medication, negative side effects and food–drug interactions (Wali, No Date).

### *Consumer Segmentation Survey: Identified & Characterised Segments*

Descriptive analysis was conducted on the consumer segmentation survey data to segment consumers into groups based on patterns in their responses to attitudinal and behavioural statements around the QUM, and more specifically, in terms of:

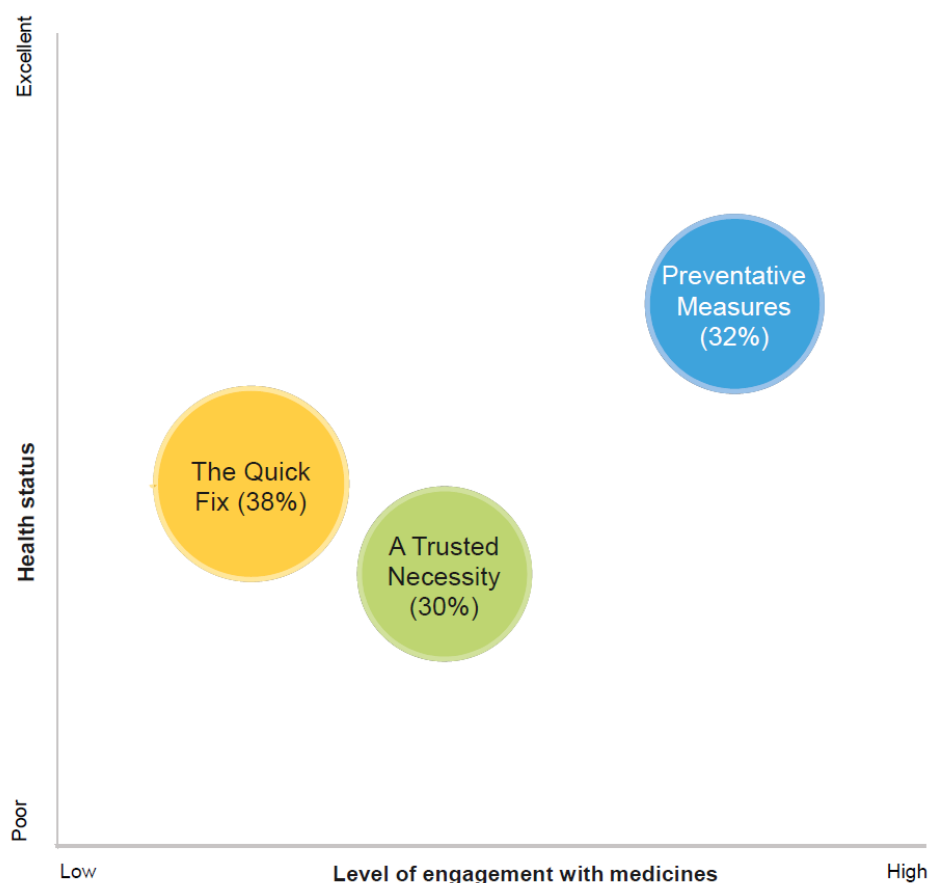
- engagement with medication
- their understanding of QUM
- attitudes towards health professional’s role in QUM
- attitudes towards complementary or alternative medicines.

The segmentation analysis identified three segments:

- Segment 1 - ‘Preventative Measures’
- Segment 2 – ‘A Trusted Necessity’
- Segment 3 – ‘The Quick Fix’.

The segments are similar in size, with each comprising of around one-third of respondents.

The graphic below identifies the three segments against their identified health status and level of engagement with medication.



Key characteristics on each of the individual segments is provided below.

#### Segment 1: Preventative measures

<p><b>Segment size</b></p> <ul style="list-style-type: none"> <li>• 32% of the sample</li> </ul> <p><b>Key demographics</b></p> <ul style="list-style-type: none"> <li>• A larger proportion are female</li> <li>• Age distribution is aligned with the population</li> <li>• A high proportion only speak English at home</li> </ul>	<p><b>People in this segment...</b></p> <ul style="list-style-type: none"> <li>• Have the highest level of health literacy</li> <li>• Rate their health as 'good' or 'excellent'</li> <li>• Want to know about the medicine before taking it</li> <li>• Are Comfortable asking doctor, nurse or pharmacist for information</li> <li>• Have a preference for alternative over prescription medicines</li> <li>• Take a preventative approach to health</li> <li>• Do not regularly take prescription medicines</li> <li>• Take vitamins or supplements regularly</li> <li>• Are highly engaged with their health</li> <li>• Generally, have lower usage of healthcare services</li> </ul>
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#### Segment 2: A Trusted Necessity

<p><b>Segment size</b></p> <ul style="list-style-type: none"> <li>• 30% of the sample</li> </ul> <p><b>Key demographics</b></p> <ul style="list-style-type: none"> <li>• A larger proportion are male</li> <li>• Slightly older, with 61% aged 50 years and over</li> <li>• A higher proportion only speak English at home</li> <li>• A higher proportion live in regional areas</li> </ul>	<p><b>People in this segment...</b></p> <ul style="list-style-type: none"> <li>• Have a good level of health literacy</li> <li>• Rate their health as 'fair' or 'good'</li> <li>• Have a higher level of arthritis, diabetes and other health conditions</li> <li>• Tend to take two or more medicines a day</li> <li>• Take medication to manage ongoing health conditions</li> <li>• Prefer prescription drugs over alternatives</li> <li>• Generally, have lower usage of health services</li> <li>• Are happy to take medicine recommended by their doctor</li> <li>• Feel that they are able to self-manage their medication</li> <li>• Have lower concerns about taking too many medicines</li> </ul>
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#### Segment 3: The Quick Fix

<p><b>Segment size</b></p> <ul style="list-style-type: none"> <li>• 38% of the sample</li> </ul> <p><b>Key demographics</b></p> <ul style="list-style-type: none"> <li>• A slightly higher proportion are female</li> </ul>	<p><b>People in this segment...</b></p> <ul style="list-style-type: none"> <li>• Have lower levels of health literacy</li> <li>• Rate their health as 'good'</li> <li>• Generally, don't have any ongoing health conditions</li> <li>• Take medication to manage health conditions as they come up and maintain a healthy lifestyle</li> </ul>
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<ul style="list-style-type: none"> <li>• Slightly younger, with 57% aged 39 years or younger</li> <li>• A higher proportion speak another language other than English at home</li> <li>• A higher proportion identified as Aboriginal and/or Torres Strait Islander</li> <li>• Slightly higher proportion live in metropolitan areas</li> <li>• A higher proportion hold a bachelors degree or higher</li> </ul>	<ul style="list-style-type: none"> <li>• Take around one or two medicines each day</li> <li>• Have higher levels of health care service usage</li> <li>• Are less engaged with medicines</li> <li>• Are happy to take what their doctor recommends</li> </ul>
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## Knowledge, attitudes and perceptions of ‘grass roots consumers’ as it relates to QUM

This objective was addressed through the literature review, virtual consumer led discussions, and the consumer segmentation survey. Relevant key findings from the project activities are discussed below.

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

From the perspective of the 185 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 contributed to QUM all of which are underpinned by a holistic, patient-centred approach. While the discussion questions targeted different aspects of QUM, 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.

### 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. costs...and what other medications I may be taking myself...”*

Being informed of potential interactions with other medicines was found to be of particular importance to consumers and carers who participated in the virtual consumer led discussions especially participants who identified as CALD who may take herbal medicines without knowledge of possible negative interactions and how it may impact the progress of the medicine being used.

The literature review highlighted NPS MedicineWise National Consumer Surveys and other polls commissioned by NPS MedicineWise provide valuable information on consumer views, knowledge and attitudes in relation to QUM. The most recent poll, undertaken in June 2019, was a nationally representative sample of 1,037. These findings suggest that consumers are accessing information about their medicines from reliable sources such as their GP's (75%) followed by pharmacists (62%) and/or a trusted website (45%), although this is less likely to be the case for disadvantaged Australians who are more likely to access social media for information compared to other Australians (NPS MedicineWise, 2019).

Similarly, the literature review outlined a review on consumer health information needs and preferences and found consumers trust their healthcare provider when seeking health information (Ramsey I P. M., 2017). This was consistent with key findings from the virtual consumer led discussions which revealed health professionals as the preferred way to access information on their medicines. However, participants indicated they were more likely to seek information from their pharmacist than their doctor due to limited time during consultations and/or poor explanations provided by their doctor.

The consumer segmentation survey found a difference between how people rated different sources of information and where they are most likely to go to find that information. The survey found that when consumers want to find out more information about a medicine, the average level of agreement showed a doctor (8.1 out of 10), followed by a pharmacist (7.6 out of 10) and medicine information leaflet (7.5 out of 10) as the highest rated information sources. Interestingly, when consumers were presented with the same list of information sources and asked to answer how likely they were to access each, doctor (46%) and pharmacist (18%) remained the most likely source, however consumers were more likely to search the internet (15%) than a medicine information leaflet (8%) for information about medicines. This finding may indicate that while consumers agree they should refer to a medicine information leaflet for information on a medicine, they are more likely to conduct an internet search (not necessarily to a trusted site).

While more research is required to understand why this is the case, participants from the virtual consumer led discussions also identified consumer medicine information (CMI) leaflets as a likely source of information but raised concerns that the information was difficult to read, too long and complicated to understand. This is further supported by a recent CHF survey that found when consumers were given CMI leaflets, less than half of the respondents thought the CMI leaflets were readable (42%) or useful (46%). More plain language is required to improve



understanding, particularly for those with low health literacy (Consumers Health Forum of Australia., 2019). It is interesting to note that whilst the literature review found the internet was identified as another source of information it is generally used as a supplement rather than an alternative to advice from a health professional. The research revealed the internet is widely used among the general population but less so among older Australian and people from specific cultural backgrounds. The internet is not necessarily seen as better-quality information, rather it is seen as convenient and accessible (Ramsey I P. M., 2017).

The literature review also identified qualitative research, undertaken by the Australian Commission on Safety and Quality in Health Care (the Commission) and the Cultural and Indigenous Research Centre Australia, using a focus group methodology to explore the consumer health information needs and preferences of Aboriginal and Torres Strait Islander people. The research found the preferred source of information is face-to-face. Some participants already access health information from brochures and posters and a few, particularly the younger people, were accessing information through the internet. Those who live in more remote communities had more intermittent access to the internet and some needed information to be provided in their traditional language. In addition, many participants reported finding current communications difficult to understand.

A consistent theme through the interviews was a preference for resources that are visually appealing and written in plain language, and that are clearly targeted towards Aboriginal and Torres Strait Islander people (Cultural and Indigenous Research Centre Australia on behalf of the Australian Commission on Safety and Quality in Health Care., 2017).

The most recent NPS MedicineWise poll found social media and blogs are accessed the least to search for information about medicines (9%) except for people aged 16-34 years (15%), those who speak English as their second language (20%) and people with Aboriginal and/or Torres Strait Islander heritage (20%). Similarly, the overall results of the consumer segmentation survey revealed social media (1%) as the least likely source consumers would seek information on medicines from. Interestingly, segmentation analysis identified the **'Error! Reference source not found.'** rated social media higher (4.6 out of 10) compared to other segments (1.7 out of 10, **'Error! Reference source not found.'** and 1.0 out of 10, **'Error! Reference source not found.'**). When compared to the most recent NPS M edicineWise poll, the demographics of the 'Quick Fix' segment share similarities. In particular, the 'Quick Fix' segment (38% of the survey sample) had a slightly younger demographic (57% aged 39 years or younger), a higher proportion who speak another language other than English at home, and a higher proportion identified as Aboriginal and/or Torres Strait Islander.

The virtual consumer led discussions also revealed social media as a source to access information on medicines, particularly asking for advice on social media groups to find out other people's experiences with medications.

#### **To access information on medicines...**

"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."

Further to this, the literature review found consumers access health information from family and friends which raises the important point that health literacy exists in networks and families (Edwards M, 2013). This suggests that interventions to improve consumers' health literacy should focus on groups and consumer segments rather than individuals.

Regardless of how consumers and carers accessed information on medicines, participants of the virtual consumer led discussions emphasised the importance 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. The importance of this is reinforced by the most recent NPS MedicineWise poll findings outlined in the literature review where around 10% of Australians have household or family members that have trouble accessing information about their medicines because English is not their first language.

The most recent NPS MedicineWise poll raises concern that only one third of consumers reported having high adherence to their prescription medications. Participants of the virtual consumer led discussions identified clear motivators to encourage adherence to medicines, including:

- improved health and/or quality of life
- effectiveness
- duration (adherence more likely for short-term medicines)
- relationship with pharmacist and/or GP
- clear information of how to use the medicine
- individual routine and lifestyle
- involved in shared decision-making (including opportunity to explore alternative treatments)
- regular medicine reviews
- access to medicines (including affordability, and home delivery options)
- Webster packs to ensure all medicines are taken (identified as particularly for elderly, disabled, and non-English speaking people)
- ability to ask questions

### 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.”*

\*\*

*“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.”*

When it comes to asking questions, the literature review identified one study that found Aboriginal and Torres Strait Islander people reported not feeling confident to ask questions about their own or their family’s health (particularly of providers who were not Aboriginal Health Workers) and being left unsure about their condition and why they were taking particular medicines. There is a clear appetite for greater understanding and involvement in healthcare decisions with Aboriginal and Torres Strait Islander participants seeking a wide range of information.

While there is growing consensus on the consumer skills necessary for the safe use of medicine, further research is needed to identify contextual challenges that may undermine consumers’ application of these skills. Factors such as limited time with pharmacists and negative side effects can influence consumers’ medication literacy and adherence. Limited time during consultations was one of the key issues raised by participants of the virtual consumer led discussions, particularly as it reduced opportunities to ask questions and feel informed about their medicines. Participants felt doctors and/or pharmacists had a responsibility to check for consumer and/or carer understanding.

### **Consumer Attitudes in relation to QUM**

The consumer segmentation survey included a series of statements to explore consumer attitudes in relation to QUM. These questions asked respondents to identify their level of agreement for each statement. The average level of agreement (with 0 being strongly disagree and 10 being strongly agree) was calculated. Interestingly, segmentation analysis shows respondents attitudes differ across identified segments (**Error! Reference source not found., Error! Reference source not found.,** Segment 1: Preventative measures

Segment size	People in this segment...
<ul style="list-style-type: none"><li>32% of the sample</li></ul>	<ul style="list-style-type: none"><li>Have the highest level of health literacy</li><li>Rate their health as ‘good’ or ‘excellent’</li><li>Want to know about the medicine before taking it</li><li>Are Comfortable asking doctor, nurse or pharmacist for information</li></ul>
<b>Key demographics</b> <ul style="list-style-type: none"><li>A larger proportion are female</li></ul>	

<ul style="list-style-type: none"> <li>• Age distribution is aligned with the population</li> <li>• A high proportion only speak English at home</li> </ul>	<ul style="list-style-type: none"> <li>• Have a preference for alternative over prescription medicines</li> <li>• Take a preventative approach to health</li> <li>• Do not regularly take prescription medicines</li> <li>• Take vitamins or supplements regularly</li> <li>• Are highly engaged with their health</li> <li>• Generally, have lower usage of healthcare services</li> </ul>
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### Segment 2: A Trusted Necessity

<p><b>Segment size</b></p> <ul style="list-style-type: none"> <li>• 30% of the sample</li> </ul> <p><b>Key demographics</b></p> <ul style="list-style-type: none"> <li>• A larger proportion are male</li> <li>• Slightly older, with 61% aged 50 years and over</li> <li>• A higher proportion only speak English at home</li> <li>• A higher proportion live in regional areas</li> </ul>	<p><b>People in this segment...</b></p> <ul style="list-style-type: none"> <li>• Have a good level of health literacy</li> <li>• Rate their health as 'fair' or 'good'</li> <li>• Have a higher level of arthritis, diabetes and other health conditions</li> <li>• Tend to take two or more medicines a day</li> <li>• Take medication to manage ongoing health conditions</li> <li>• Prefer prescription drugs over alternatives</li> <li>• Generally, have lower usage of health services</li> <li>• Are happy to take medicine recommended by their doctor</li> <li>• Feel that they are able to self-manage their medication</li> <li>• Have lower concerns about taking too many medicines</li> </ul>
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### Segment 3: The Quick Fix

<p><b>Segment size</b></p> <ul style="list-style-type: none"> <li>• 38% of the sample</li> </ul> <p><b>Key demographics</b></p> <ul style="list-style-type: none"> <li>• A slightly higher proportion are female</li> <li>• Slightly younger, with 57% aged 39 years or younger</li> <li>• A higher proportion speak another language other than English at home</li> <li>• A higher proportion identified as Aboriginal and/or Torres Strait Islander</li> <li>• Slightly higher proportion live in metropolitan areas</li> </ul>	<p><b>People in this segment...</b></p> <ul style="list-style-type: none"> <li>• Have lower levels of health literacy</li> <li>• Rate their health as 'good'</li> <li>• Generally, don't have any ongoing health conditions</li> <li>• Take medication to manage health conditions as they come up and maintain a healthy lifestyle</li> <li>• Take around one or two medicines each day</li> <li>• Have higher levels of health care service usage</li> <li>• Are less engaged with medicines</li> <li>• Are happy to take what their doctor recommends</li> </ul>
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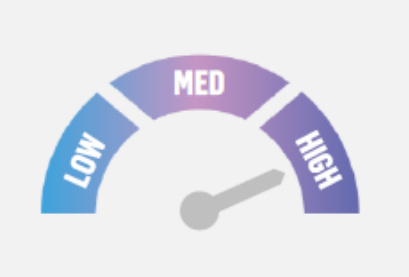
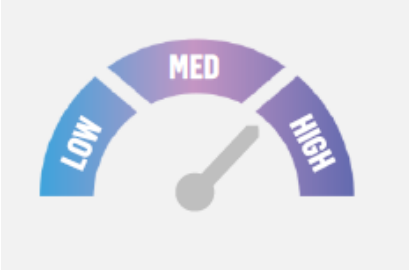

<b>Table 1: Preventative Measures Segment: Key Attitudes</b>	
<i>Scored highest</i>	<i>Difference from average score for all respondents</i>
I would prefer to explore other treatment options before I take medicines	+1.4 ↑
I like to find out lots of different information before taking a new medicine	+1.1 ↑
I only take prescription medicine when I really have to	+1.1 ↑
I understand that some medicines can be addictive	+1.0 ↑
I always ask for information about a medicine before I start taking it	+1.0 ↑
When I talk to a doctor, pharmacist or nurse, I make sure they explain anything that I don't understand about my medicines	+0.9 ↑
When I start taking a new medicine, I ensure I understand the ways it could interact with other medicines or things that I eat and drink	+0.9 ↑
I know the different ways that my medicines need to be stored	+0.6 ↑
I talk to my doctor or pharmacist before I start taking a new medicine	+0.6 ↑
I am able to monitor the positive and negative effects of the medicines I take	+0.5 ↑
I know how to dispose of leftover medicines safely	+0.3 ↑
<b>Scored lowest</b>	
I don't consider the side effects of medicines prescribed for me	-2.3 ↓
I sometimes take medicines that were prescribed for someone else	-1.8 ↓
There aren't many risks associated with taking medicines that you can buy from the supermarket	-1.3 ↓
I'm happy to take any medicine my doctor prescribes to me	-1.2 ↓
Higher/lower than total sample    ↑    ↓	
<ul style="list-style-type: none"> <li>A higher proportion hold a bachelors degree or higher</li> </ul>	

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<b>Table 2: A Trusted Necessity Segment: Key Attitudes</b>	
<i>Scored highest</i>	<i>Difference from average score for all respondents</i>
I'm happy to take any medicine my doctor prescribes to me	+1.6 ↑
I understand why some medicines can only be purchased with a doctor's script	+0.9 ↑
I feel comfortable asking my doctor or a pharmacist questions about my medicines	+0.9 ↑
I understand why I am taking each of my medicines	+0.8 ↑
I am able to manage my medicines without relying on my doctor, pharmacist or nurse	+0.7 ↑
<i>Scored lowest</i>	
I think I take too many medicines	-1.2 ↓
I have taken medicine that is outside of its expiration date	-1.3 ↓
I like to find out lots of different information before taking a new medicine	-1.3 ↓
I'm worried about becoming addicted to my medicines	-1.7 ↓
I sometimes take prescription medicines recreationally	-1.9 ↓
I would prefer to explore other treatment options before I take medicines	-2.3 ↓
I prefer to take complementary or alternative medicines rather than pharmaceuticals or prescription medicines as much as possible	-2.5 ↓
Higher/lower than total sample    ↑↓	

<b>Table 3: The Quick Fix Segment: Key Attitudes</b>	
<i>Scored highest</i>	<i>Difference from average score for all respondents</i>
I sometimes take prescription medicines recreationally	+3.1 ↑
I sometimes take medicines that were prescribed for someone else	+2.9 ↑
I'm worried about becoming addicted to my medicines	+2.1 ↑
I think I take too many medicines	+2.0 ↑
I have taken medicine that is outside of its expiration date	+2.0 ↑
I don't consider the side effects of medicines prescribed for me	+1.8 ↑
There aren't many risks associated with taking medicines you can buy from the supermarket	+1.4 ↑
I prefer to take complementary or alternative medicines rather than pharmaceuticals or prescription medicine as much as possible	+1.4 ↑
<i>Scored lowest</i>	
I am able to monitor the positive and negative effects of the medicines I take	-0.5 ↓
I always ask for information about a medicine before I start taking it	-0.5 ↓
I know how to dispose of leftover medicines safely	-0.5 ↓
I am able to manage my medicines without relying on my doctor, pharmacist or nurse	-0.7 ↓
I know the different ways that my medicines need to be stored	-0.8 ↓
I talk to my doctor or pharmacist before I start taking a new medicine	-0.9 ↓
When I start taking a new medicine, I ensure I understand the ways it could interact with other medicines or things that I eat and drink	-0.9 ↓
When I talk to a doctor, pharmacist or nurse, I make sure they explain anything that I don't understand about my medicines	-1.1 ↓
I only take prescription medicines when I really have to	-1.2 ↓
I understand why I am taking each of my medicines	-1.2 ↓
I feel comfortable asking my doctor or a pharmacist questions about my medicines	-1.3 ↓
I understand why some medicines can only be purchased with a doctor's script	-1.4 ↓
I am able to monitor the positive and negative effects of the medicines I take	-1.4 ↓
Higher/lower than total sample    ↑ ↓	

The following provides an indicative overview of how each of the segments rate against the attitudinal areas within the consumer segmentation survey.

Segment	Attitudes towards health professional roles in QUM	Attitudes towards complimentary or alternative medicines
<b>Preventative Measures</b>		
<b>A Trusted Necessity</b>		
<b>The Quick Fix</b>		

## Identify the current understanding of consumer health literacy for Australians as it relates to QUM

This objective was addressed through the literature review and the consumer segmentation survey. Relevant key findings from the project activities are discussed below.

The literature review found ABS survey data from 2006 indicated that only 40% of Australians have at least an adequate level of health literacy, while 60% have a low level. Health literacy levels for specific consumer segments were even lower, with only 22% of survey respondents aged 60-74, for example, having health literacy skills that are adequate or better (Australian Bureau of Statistics, 2006). The National Health Survey: Health Literacy, 2018, which used a different measure to examine health literacy levels, showed that one-third of Australians (33



per cent) found it always easy to discuss health concerns and actively engage with their healthcare providers; 56 per cent found this usually easy; while 12 per cent found it difficult (Australian Bureau of Statistics, 2019). There is insufficient comparable data to track changes in population health literacy levels over time.

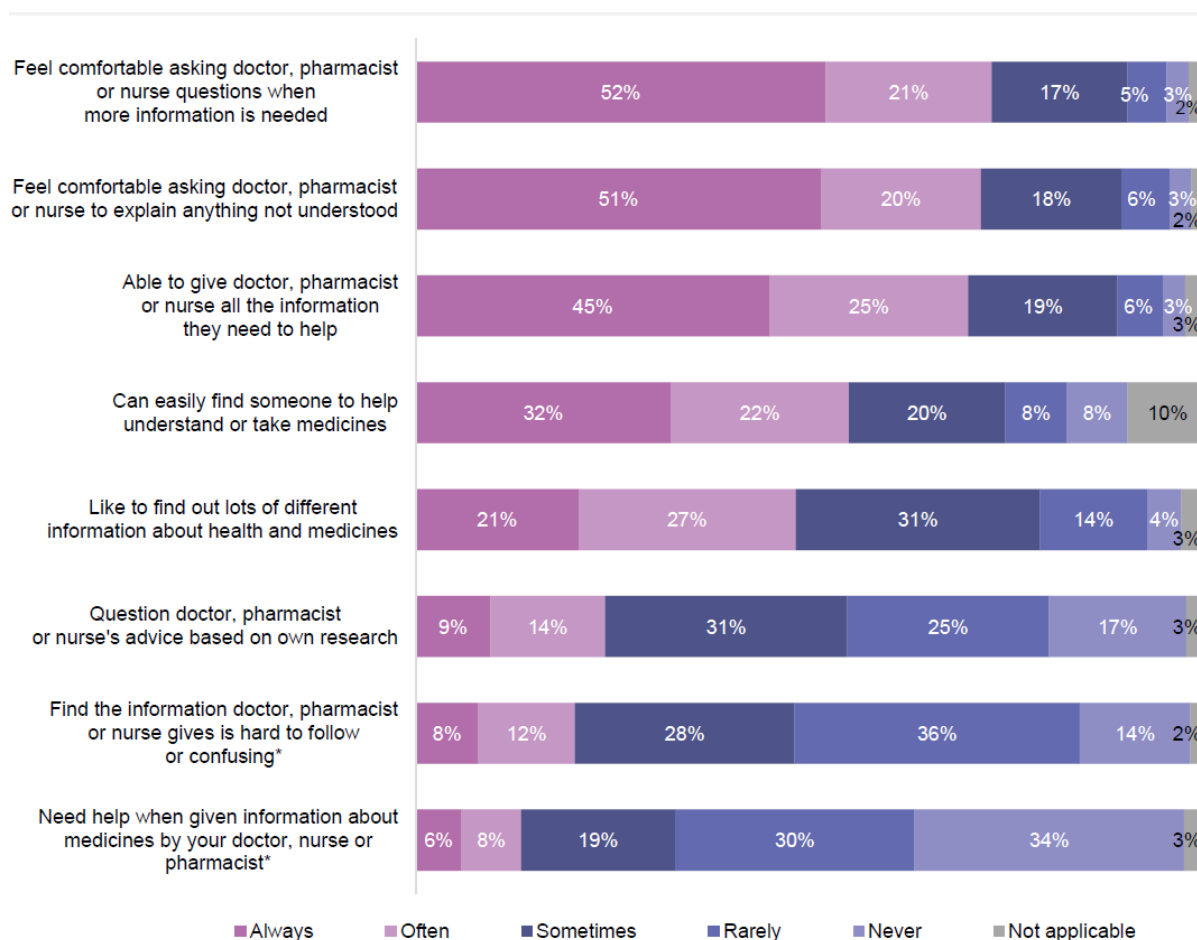
Population-level measurements of medication literacy/QUM are limited. NPS MedicineWise consumer surveys provide some information on consumer awareness, knowledge and attitudes around specific medication-related issues, but do not provide an overall picture of the medication literacy and QUM behaviours of Australians over time.

Medication-related hospital admissions may be seen as a partial proxy for medication literacy and QUM. Available data indicates cause for concern, with an estimated 250,000 hospital admissions in Australia each year, and an additional 400,000 presentations to emergency departments due to medication-related problems, 50% of which are preventable.

While data on health literacy and QUM in Australia is limited, the literature review suggests there is sufficient evidence to indicate room for improvement.

The consumer segmentation survey was completed by a total of n=1,503 respondents. Data was representative of the Australian population based on age, gender and location (but not ethnic background) in accordance with ABS 2016 census data. The consumer segmentation survey asked respondents a series of eight questions to assess their overall health literacy as it relates to QUM. A mean across all eight responses was calculated to get an indicative rating of health literacy for each respondent. The average rating across all respondents (n= 1,487) was 2.6 out of 4.

### Consumer segmentation survey: individual health literacy indicators


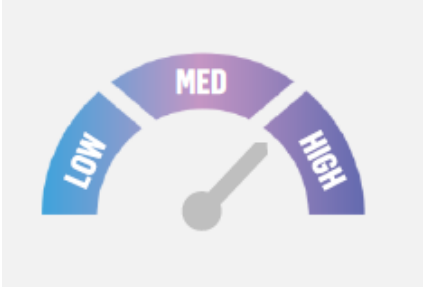

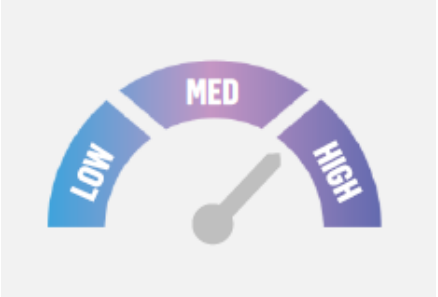

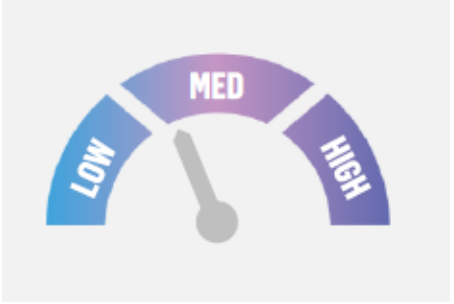


Base: 1,503

Various questions

\*These two questions have a reversed scale where the responses 'always or often' indicate low health literacy.

The following provides an indicative overview of how each of the three segments rate against understanding of QUM and Health Literacy\*.

Segment	Understanding of QUM	Health Literacy*
<b>Preventative Measures</b>		
<b>A Trusted Necessity</b>		
<b>The Quick Fix</b>		

\*Responses to questions regarding health literacy in the consumer segmentation survey were recorded and a mean rating across all questions allocated for each respondent with 0 being the lowest and 4 being the highest. The rating above indicates the mean for each segment.

## Provide recommendations for resource/program development to meet unmet needs

### *Initiatives to promote health literacy*

The Consumer Segmentation Research found there are an increasing number of initiatives to promote general health literacy in Australia. A key national resource is the Commission’s National Statement on Health Literacy, which provides a framework and call to action on health

literacy. The NSQHS Standards (Australian Commission on Safety and Quality in Health Care, 2017) provide both an incentive and guidance on ways to improve health literacy in health care settings.

Australia has also seen various initiatives that seek to address the Commission's three recommended action areas:

- Embedding health literacy into systems: for example, the OPTimising HEalth Lliteracy and Access (Ophelia) process, and the organisation-wide approach taken by Illawarra-Shoalhaven Local Health District.
- Ensuring effective communication: for example, tools and resources to support readability of written materials, to support codesign of communications with consumers, or to support improved verbal communication including through teach-back.
- Integrating health literacy into consumer and health provider education, for example through formal education, and interactive platforms such as websites and apps.

### *Initiatives to promote medication literacy and QUM*

The literature review identified a wide range of tools, resources, and other initiatives aimed at improving consumer medication literacy and QUM. At population-wide level, these include:

- **System level initiatives:** The Australian Government has invested significant funds into QUM, particularly through MBS items including Home Medicine Reviews, and through initiatives such as the Pharmacy Trial Program, funded through the Community Pharmacy Agreement. These programs appear to be situated across the dual aims of supporting the development of the pharmacy profession and supporting consumer health outcomes.
- **Initiatives targeting health professionals:** NPS MedicineWise represents another very significant Australian Government investment, targeted to both health professionals and consumers. NPS MedicineWise has delivered a large volume of educational programs, and resources and tools to health professionals, at considerable cost, and a range of other health professional guidance has been produced by others including health professionals. While these initiatives are generally highly regarded, the impact of these programs and resources on consumer medication literacy have not been evaluated. It is therefore not possible to assess their impact on consumer medication literacy.
- **Consumer-focused initiatives:** These have mostly been focused on information provision. It is clear from the literature review that there is no shortage of authoritative, high quality medication information available for Australian consumers. The resources and tools available for consumers include CMI, online information and tools, apps, a telephone service, and more. However, there appears to be scant evaluation evidence to demonstrate the effectiveness of these tools and resources, including consumer acceptability, consumer uptake, impact on consumer health literacy, and impact on health outcomes.

The literature review also identified a range of initiatives to improve medication literacy and QUM amongst the specific population segments of interest. The key findings for each population segment are:

- **Older consumers:** Older people are a key target group for population-wide initiatives, so are probably better served by these than other consumer segments. The main specific initiatives for older consumers are residential aged care medication reviews, and medicines information and resources specifically targeted for older consumers. Other initiatives, such as pictograms to improve readability of medication labels and instructions appear to be in developmental stages.
- **Aboriginal and Torres Strait Islander people:** The Australian Government has invested in improved access to medicines and QUM for these communities, through the Section 100 Remote Aboriginal Health Services Program and the Quality Use of Medicines Maximised for Aboriginal and Torres Strait Islander people program. Some specific resources have been developed for consumers and health professionals; and work is underway to develop an appropriate home medicines review model for Aboriginal and Torres Strait Islander people.
- **CALD communities:** Information and resources to support health literacy and QUM are available in several community languages; and health providers and consumers also have access to the Translating and Interpreting Service.
- **Consumers with low literacy and/or low health literacy:** Research has identified features of interventions which are effective in supporting health literacy and QUM in this population segment, but the literature review did not find evidence of specific initiatives for this group.

An overall observation can be made that, similar to the situation with population-wide initiatives, efforts targeting specific population segments have tended to focus on the provision of information rather than on promoting health literacy; and there appears to be little evaluation evidence to demonstrate uptake and appropriateness of these initiatives. In addition, for the specific population segments examined in the literature review, the approach to promoting medication literacy and QUM appears to be fragmented rather than comprehensive.

### *The identified unmet needs of improving health literacy and QUM*

1. **There is insufficient readily available evaluation data to adequately assess the accessibility and appropriateness of current initiatives to promote health literacy, medication literacy, and QUM in Australia.**

The literature review uncovered very little evaluation data that would support an assessment of the accessibility and appropriateness of current initiatives to promote health literacy and QUM in Australia. This lack of evidence means that for most of these initiatives, it is not possible to answer questions such as:

- What are the utilisation levels of the various tools and resources produced for Australian consumers?
- What is the profile of users of these tools and resources (across age groups, education levels, health literacy levels, population segments)?
- How do consumers view these tools and resources – what are the levels of acceptability and usefulness?
- How effectively can consumers identify reliable, high quality information and resources from trusted sources, as opposed to other information?
- What impacts have the implementation of these initiatives had on consumer health literacy, QUM actions, and health outcomes?

The above evaluation questions should be considered for future resource and/or program development and to monitor impact over time.

**2. Most of the interventions examined in the Literature Review focus on providing information (or services) to consumers, rather than addressing health literacy in a co-ordinated way.**

The Commission recommends that to address health literacy in a coordinated way, action needs to be taken across three areas: embedding health literacy into systems, such as funding mechanisms that encourage action on health literacy; ensuring effective communication including print, electronic and interpersonal communication; and integrating health literacy into education for both consumers and healthcare providers.

In contrast to this approach, the bulk of the interventions studied in the literature review, particularly the consumer-oriented tools and resources, simply focus on the provision of medication information to consumers. The position of consumers in this model is simply to receive information, rather than proactively seeking, reflecting and interacting with information and advice. This does not reflect key health literacy concepts which focus on consumers making informed decisions about their health care, and on shared decision-making between consumers and health professionals. While NPS MedicineWise develop and deliver resources that facilitate shared decision-making, such as Patient Decision Aid, and Patient Action Plan (NPS MedicineWise, n.d.) few resources in the environment take a broader approach to developing the consumer health literacy skills required to appraise and choose between different sources of information and make decisions about the risks and benefits of medicines. This potentially represents a major limitation on the appropriateness of many of the interventions.

As noted previously, the NSQHS Standards are very clear on the strategies Australian health care providers should adopt to create an enabling environment for QUM health literacy, as opposed to simply providing information on medications and QUM. The NSQHS Standards potentially represent a key resource for health care providers to promote consumer health literacy around QUM, as well as a conceptual framework for developing consumer-focused initiatives to promote medication literacy and QUM.

**3. There is a significant quantity of high quality, valued information, resources and tools available to support medication literacy and QUM in Australia; however, there is less clarity regarding uptake and utilisation of these resources.**

It is clear from the literature review that there is no shortage of authoritative, high quality medication information available for the general population of Australian consumers. The resources and tools available for consumers include CMI, online information and tools, apps, a telephone service, and more. However, as noted previously, there appears to be scant evaluation evidence to demonstrate the effectiveness of these tools and resources, including consumer acceptability, consumer uptake, impact on consumer health literacy, and impact on health outcomes. A key question is the extent to which consumers, particularly those with low health literacy, are aware of the available resources, able to distinguish and select between high quality and poor-quality resources, and able to utilise the resources in their health care interactions and decisions.

There does appear to be some duplication of consumer-focused tools and resources. For example, there are many websites providing the same, or similar medicines information, including CMI; and there are at least two medication apps funded by the Australian Government. This is not in itself necessarily a bad thing, as consumers may access information, tools and resources through a range of pathways. However, a proliferation of information can also potentially be confusing for consumers and may not represent the best use of limited health resources.

#### **4. There is limited focus on consumer-centred models and consumer co-design.**

While there has been consumer consultation on some of the initiatives identified in the literature review, it is not clear that consumer co-design is a routine element in the design of interventions; nor is it clear the primary goal for which these have been developed.

It is increasingly recognised that engaging consumers as partners in the development of health literacy interventions is essential to the success of these interventions. Consumers and communities are no longer the focus or the setting for interventions, rather they are the partners in the development, implementation and evaluation of such interventions. In the coming years it is expected that consumer and community interventions will be conducted in the community as well as in clinical settings.

#### **5. There does not appear to be a strategic, co-ordinated approach to meeting the needs of consumer segments at higher risk of low health literacy and poor QUM.**

The literature review identified a range of individual initiatives which may contribute to meeting the needs of consumer segments at higher risk of low health literacy and sub-optimal medicines use, but did not find a systematic approach to these initiatives, and found few attempts to address broader health and medication literacy as opposed to simple information provision.

While each of these population segments has its own unique characteristics and needs, there is also some commonality across the challenges faced by these groups, and clearly many consumers would fall into two or more of these segments. Whole-of-population health literacy, medication literacy and QUM measures need to take into account the needs of these population segments; and in addition, specific measures are required which address the needs of each segment.

In the absence of good evaluation data including data on consumer participation in existing initiatives, it is not possible to provide a comprehensive account of unmet needs in relation to health literacy, medication literacy, and QUM for Australian consumers.

## Identify relevant QUM and health literacy indicators for future evaluation of collective impact.

Medication literacy can be measured both at individual level, generally through individual consumer questionnaires, and at population level, generally through larger consumer surveys.

It would seem logical that robust measures of consumer medication literacy should include assessment of the consumer knowledge and skills that are identified as essential for safe and optimal use of medicines. Pouliot et al (2018), through an expert consensus process, have defined several areas of consumer knowledge as being essential for safe and optimal use of medicines, including:

- medication name
- dosing information (e.g. frequency, duration, and timing)
- when to take medication, with or without food
- time to take medication with patient's other pharmacotherapy
- treatment indication, goals and outcomes
- side effects and precautions, e.g. contraindications
- drug-drug interactions, including alcohol
- when to omit intake of medication
- when and how to expect therapeutic effects
- food-drug interactions
- instructions to follow if drug is missed
- medication storage instructions (Pouliot, 2018).

Interestingly, consumers and carers who participated in the virtual consumer led discussions were asked what information they want and/or need to know about their medicines to ensure quality use identified each listed area above (with the exception of medication name).

The consensus process applied by Pouliot et al (2018) also defined the skills necessary for optimal and safe use of medication, including numeracy, literacy, and communicating with the healthcare provider; as well as the format of information and pharmacy services necessary for optimal and safe use of medication; and the outcomes and goals of medication literacy (Pouliot, 2018).

The literature review found there is no lack of instruments available for measuring generic health literacy, with systematic reviews identifying more than 100 measures for health literacy in adults (Altin, 2014) (Haun, 2014). The best-known performance-based measures, which assess skills such as reading and numeracy in relation to health information, are the Rapid Estimate of Adult Literacy In Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). More recently, performance-based measures of health literacy have been extended to include a number of health-related stimuli, for example, the Health Literacy Skills Instrument (HLSI). A number of self-report measures are also in wide use internationally, including the Health Literacy Management Scale (HELMS) and the Health Literacy Questionnaire (HLQ).

By contrast, it appears that the field of defining and assessing medication literacy is in its infancy, with few tools and resources described in the international literature. The standout is



the Recognition and Addressing of Limited Pharmaceutical Literacy (RALPH) interview guide, which focuses on individual level medication literacy. It may be used by pharmacists to identify patients at risk of low medication literacy.

In addition to the RALPH guide, there are examples of general health literacy measures being refined and adapted to focus specifically on medication literacy. For example, the literature review identified Stilley and colleagues developed a health literacy measure for oral medications which focus on the use and understanding of information on prescription medication labels. The tool was multidimensional, measuring the constructs of prose, numeracy and documentation in a similar way to the Newest Vital Signs; and unlike the REALM measure of health literacy, this tool assessed ability to understand and use information to make decisions about medication taking rather than ability to read and pronounce health related words (Stilley, 2014). Clearly this instrument measures some components of medication literacy but does not cover all the essential areas of consumer knowledge and skills outlined by Pouliot et al (2018).

The consumer segmentation survey questionnaire identified a number of potential health literacy QUM indicators that NPS MedicineWise could promote as a consistent way of measuring health literacy and QUM across the sector. The indicators cover the following dimensions:

- Individual health literacy as it relates to QUM
- Understanding of QUM
- Attitude towards health professionals' role in QUM
- Reading information on medicines
- Information sources on medicines

Table 5 below describes the key health literacy QUM indicators identified through the Consumer Segmentation Research. NPS MedicineWise staff have identified indicators that they would use to track impact on health literacy and awareness of QUM annually (e.g. measured through the annual NPS MedicineWise National Consumer Survey).

**Table 5: Health Literacy QUM Indicators**

<b>Dimension</b>	<b>Indicator</b>
<i>Individual health literacy as it relates to QUM</i>	Proportion of consumers who feel confident asking doctor, pharmacist, or nurse questions when more information is needed to understand what is being explained.
	Proportion of consumers that search for information about health and medicines.
	Proportion of consumers that find the information given to them by a doctor, pharmacist or nurse hard to follow or confusing.
	Proportion of consumers that are happy to take any medicine their doctor prescribes to them.
	Proportion of consumers who discuss complimentary and over-the-counter medicines they are taking with their doctor.
<i>Understanding of QUM</i>	Proportion of consumers that understand that some medicines can be addictive
	Proportion of consumers that, when they start taking a new medicine, they ensure they understand how it could interact with other medicines or things they eat and drink.

	Proportion of consumers that know how their medicine(s) need to be stored.
	Proportion of consumers that have taken out of date medicine
	Proportion of consumers who sometimes take medicines that were prescribed for someone else.
<i>Attitude towards health professionals' role in QUM</i>	Proportion of consumers that ask their doctor or a pharmacist questions about their medicines.
	Proportion of consumers that talk to their doctor or pharmacist <b>before</b> they start taking a <b>new medicine</b> .
	Proportion of consumers who have one consistent doctor or pharmacist to talk to about their medicines.
<i>Reading information on medicine</i>	<p>Frequency with which consumers read the following information on a medicine:</p> <ul style="list-style-type: none"> <li>- the pharmacist instructions or directions for use</li> <li>- The active ingredients in the medication</li> <li>- The description of what the medication is used for</li> <li>- Warning or allergy information</li> <li>- Storage information</li> <li>- Information on possible side effects</li> <li>- Consumer medicine information leaflet</li> <li>- The dosage of the medication</li> </ul>
<i>Information sources on medicines</i>	<p>Rating of information sources about medicines:</p> <ul style="list-style-type: none"> <li>- Doctor</li> <li>- Pharmacist</li> <li>- Medicine information leaflet</li> <li>- Internet search</li> <li>- Allied health professional</li> <li>- Trusted online resources</li> <li>- Nurse</li> <li>- Friends and/or family</li> <li>- Telephone information service</li> <li>- Online forum and/or support group</li> <li>- Social media</li> </ul>

## Next Steps

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That the Commonwealth consider the key finding of this research, as well as the work done by the Commission, and CHF's Patient Activation Research to develop a new set of initiatives to improve QUM health literacy for consumers. The approach needs to be nuanced so that it meets the different needs of the different segments of the population.

A range of stakeholders, including NPS MedicineWise and the Commission have a role to play in the development and implementation of a set of targeted initiatives to improve QUM health literacy. CHF recommends these stakeholders consider the following as next steps to address the key findings of the Consumer Segmentation Research and relevant health literacy indicators for future collective impact.

- 1. Develop a strategic, co-ordinated approach to identifying and addressing the health literacy, medication literacy and QUM needs of higher-risk population segments.**

CHF believes this should be prioritised to help improve QUM health literacy for consumers identified to be most at risk of sub-optimal use of medicines. This should align with the three action areas recommended by the Commission: embedding health literacy into systems; ensuring effective communication; and integrating health literacy into education for both consumers and healthcare providers.

This should follow a collective impact framework. Key organisations that share the same priority to address QUM health literacy such as NPS MedicineWise, Australian Commission on Safety and Quality in Health Care, CHF, and PHNs must develop complementary strategies that deliver shared goals. This should include working in collaboration with peak organisations that represent consumers from the identified higher risk populations segments, such as Council of the Ageing (COTA), Federation of Ethnic Communities' Councils of Australia (FECCA) & the National Aboriginal Community Controlled Organisation (NACCHO).

As identified in the research, health professionals have an important role to play in improving QUM health literacy. A coordinated, collaborative approach should also work with relevant health professional peak bodies such as the Pharmaceutical Society of Australia (PSA), Royal Australian College of General Practitioners (RACGP), Allied Health Professions Australia (AHPA) and Australian Healthcare & Hospitals Association (AHHA).

- 2. Further research to identify the extent to which consumers, particularly those with low health literacy, are:**
  - a) aware of the available resources**
  - b) able to distinguish and select between high quality and poor-quality resources, and**
  - c) able to utilise the resources in their health care interactions and decisions.**

This should include both quantitative and qualitative research. There may be an opportunity to collect quantitative data on these key areas, particularly A & B, through the annual NPS MedicineWise National Consumer Survey. Further research to collect qualitative data from

consumers to understand barriers and challenges across the above key areas should be explored.

**3. Utilise consumer co-design in the development and implementation of future initiatives making sure consumers from the segments identified are included.**

In addition, Designing for Diversity, a framework for embedding responsiveness to diversity at the onset of any policy reform or service design process, should be considered to guide the design of future initiatives (Department of Health and Human Services, n.d.)

In addition, the following questions should be considered to inform program and resource design and monitor progress overtime:

- What are the utilisation levels of the various tools and resources produced for Australian consumers?
- What is the profile of users of these tools and resources (across age groups, education levels, health literacy levels, population segments)?
- How do consumers view these tools and resources – what are the levels of acceptability and usefulness?
- How effectively can consumers identify reliable, high quality information and resources from trusted sources, as opposed to other information?
- What impacts have the implementation of these initiatives had on consumer health literacy, QUM actions, and health outcomes?

The above questions should also support recommendation 2 & 6.

**4. Ensure that initiatives include measures to promote consumer awareness of and access to the relevant programs, tools, and resources, including for consumers from higher-risk population segments.**

**5. Ensure that routine data collection is built into future initiatives, including data on uptake and outcomes of interventions, to support the ongoing evaluation and improvement of interventions that seek to improve consumer health literacy, medication literacy, and QUM.**

This includes using the indicators identified in the report to track impact on health literacy and QUM awareness.

**6. Explore the opportunity to develop a national clearing house on health literacy and QUM initiatives, including relevant information, resources, tools, and research and evaluation findings.**

This should involve exploring existing online resources, (such as the Health Literacy Hub, Better Health Channel, Healthdirect, NPS MedicineWise), and working in collaboration to enhance existing resources, and channels.

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# Appendix A: Consumer Segmentation Survey Methodology

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## Online questionnaire

A questionnaire was developed to provide insight into the Australian population's attitudes, knowledge and perceptions on QUM.

The questionnaire covered the following key areas:

- Health status
- Usage of health services and medicines
- Level of engagement with medicine use
- Understanding of QUM
- Attitude towards health professionals' role in QUM
- Attitude towards complementary or alternative medicines
- Information sources on QUM
- Health literacy
- Demographics.

## Analysis of survey data

The survey was conducted by a third-party online consumer panel survey provider and was in field from Friday 17 July –Thursday 23 July 2020. The survey was completed by a total of n=1,503 respondents. Data was representative of the Australia population based on age, gender and location in accordance with ABS 2016 census data.

Frequency analysis was conducted on demographic questions to understand the overall profile of the sample and analysis to determine the mean ratings and the standard deviation of each attitudinal statement was also undertaken.

Responses to questions regarding health literacy were recoded and a mean rating across all questions allocated to each respondent with 0 being the lowest possible rating and 4 being the highest.

## Segmentation Analysis

The respondents were segmented based on responses to the attitudinal items included in the survey (0-10 agreement scale). Segmentation is a form of analysis that examines relationships between several variables and divides a population into segments based on shared characteristics—for example, geographic, demographic, attitudinal, or behavioural factors—that cause them to behave in similar ways or have the same needs. Urbis undertook a segmentation to gain a better understanding of the range of views regarding quality use of medicines across respondents.

For the segmentation, factor analysis was undertaken, reducing the attitudinal battery of items to four factors. A score for each factor (factor scores) was then identified for each respondent. The factor scores were then put into a clustering algorithm (Quick Cluster).

Urbis did not specify the number of clusters; instead, a series of optimal solutions were identified by the statistical software. The resulting output was the segment bases, i.e. the segment membership for each respondent. The size of the various segments for each solution was then charted for easy interpretation and mapped against attitudinal statements and key demographics to identify the best solution (three segments), which is included in this report.

## Limitations

The survey results should be considered with the following limitations in mind:

- Opinions may be biased to those who participate in online panels and may not be representative of the whole population.
- Selection of respondents is limited to those who have access to the internet.
- Panel respondents may not have responded accurately or honestly which may bias results.
- A fully validated scale for health literacy was not adopted for this questionnaire, and therefore results should be interpreted with caution.
- The proportion of respondents identifying as speaking a language other than English at home is lower than the Australia population (16% of respondents compared to 21% of the Australian population). This is largely due to a lower representation of Culturally and Linguistically Diverse (CALD) people subscribing to online panels.
- The proportion of respondents identifying as having a bachelors degree or higher is much higher than the Australian population (45% of respondents compared to 22% of the Australian population). This may be due to the topic for the survey (QUM) attracting online panel members who have higher levels of education.

## Appendix B: Project Activity Timeline

Date (week starting)	April 2020			May 2020				June 2020					July 2020				August 2020					September 2020			
	13	20	27	4	11	18	25	1	8	15	22	29	6	13	20	27	3	10	17	24	31	7	14	21	28
<i>Formative Research</i>																									
<i>Literature Review</i>																									
<i>Virtual Consumer Led Discussions</i>																									
<i>Consumer Segmentation Survey</i>																									
<i>Final Report</i>																									