

# NATIONAL CONSUMER SURVEY

## 2021 Report

December 2021 | v0.1

QUM Grant Agreement Details			
<b>Reference details:</b>	Schedule 6k: Consumer Engagement		
<b>Deliverable:</b>	Report of findings from the National Consumer Survey and interviews with three seldom heard population groups		
<b>Version:</b>	Submission	<b>Action:</b>	For acceptance
<b>Date:</b>	22 December 2021		

Independent, not-for-profit and evidence based, NPS MedicineWise enables better decisions about medicines, medical tests and other health technologies.



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## Suggested citation

NPS MedicineWise 2021, National Consumer Survey 2021 Report, NPS MedicineWise, Sydney.

## Acknowledgments

Thank you to Consumers Health Forum of Australia (CHF) for providing recommendations to inform the QUM and health literacy indicators. Thank you to NPS MedicineWise personnel for reviewing the questionnaire and report. Thank you to the Australian Commission on Safety and Quality in Healthcare and the Department of Health for reviewing the questionnaire, and to consumer representatives and organisations for providing input into the initial questionnaire; Consumer Advisory Group members, National Aboriginal Community Controlled Health Organisation (NACCHO), Federation of Ethnic Communities Councils of Australia (FECCA), Carers Australia, COTA Australia, CHF special interest groups, and other consumer representatives. Thank you to Angela Romero for conducting the consumer interviews and analysing interview data.

This work was funded by the Commonwealth Department of Health.

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# EXECUTIVE SUMMARY

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This report presents the findings from the 2021 National Consumer Survey, and interviews with consumers from three seldom heard populations. The survey was conducted with 2,032 consumers from the Australian population. The aims of the survey were to identify consumer health trends and measure levels of consumer awareness of quality use of medicines (QUM) and health literacy as it relates to QUM. The 2021 survey findings were compared where appropriate with 2020 survey findings to identify whether any changes in health-related trends had occurred over this time.

## Key findings

Most trends measured in the National Consumer Survey remained consistent between 2020 and 2021. Changes in health literacy can be difficult to measure, and the level of consumer reach required, as well as access to those outside the typical audiences for NPS MedicineWise programs poses a challenge for addressing and improving QUM awareness and health literacy.

### Differences in trends between 2020 and 2021

- ▷ Respondents commonly exhibited a medium level of awareness of QUM in 2020 and 2021. However, fewer respondents exhibited high awareness and slightly more respondents exhibited low awareness in 2021. This is likely due to marginally higher proportions of youth and culturally and linguistically diverse respondents completing the survey in 2021 compared with 2020
- ▷ Respondents commonly exhibited a medium level of health literacy as it relates to QUM. No significant difference in health literacy was observed between 2020 and 2021
- ▷ A 5% increase from 29% in 2020 to 34% in 2021 was observed in the proportion of respondents who agreed that medical tests could give misleading results
- ▷ The level of reported adherence to medicine regimes was commonly high in 2020 and 2021. However, the proportion of respondents exhibiting high adherence dropped by 5% and those exhibiting medium adherence increased by 6% in 2021 compared to 2020.

### Positive health-related trends

- ▷ Respondents mainly sourced information about health conditions and medicines from a doctor. Utilising a doctor as a source of information increased with respondent age
- ▷ Over half of respondents (58%) asked their doctor or pharmacist questions the last time they received a new medicine
- ▷ Those that were aware of Choosing Wisely Australia and NPS MedicineWise were more likely to ask a doctor or pharmacist questions than those who were not
- ▷ Most respondents agreed that some medicines could be addictive, understood why they were taking medicines and knew how to safely store medicines
- ▷ Almost half of consumer respondents 'always' feel confident asking their doctor or other healthcare practitioner questions when they need more health information and feel comfortable making shared decisions with their doctor.

### Gaps in QUM awareness and health literacy among consumers

- ▷ Most survey respondents and interviewees from the seldom heard population groups were not familiar with active ingredients. Less than half of respondents knew what an active ingredient was in relation to medicines, and only one-third knew the active ingredients in their own medicines. Youth aged 16-19 years were the least likely respondent cohort to understand active ingredients
- ▷ Respondents were mostly uncertain about the risks of medical tests in potentially causing harm or leading to unnecessary treatment
- ▷ Keeping a medicines list was not a common practice among survey respondents or interviewees from the seldom heard population groups

- ▶ The safety and efficacy aspects of taking medicines appear to be less understood by consumers, including the safe disposal of medicines, taking medicines beyond expiry, sharing prescribed medicines with others or telling a doctor about over-the-counter or complementary medicines taken alongside prescription medicines
- ▶ For consumers from seldom heard population groups, there appears to be a gap in knowing what to ask healthcare practitioners, which limits their confidence to make shared treatment decisions.

## Demographic differences in QUM awareness and health literacy

- ▶ Awareness of QUM elements and health literacy behaviours tended to increase with age. Respondents aged 16-24 years were less aware of QUM and exhibited lower health literacy than other age cohorts
- ▶ Having the confidence to ask a doctor or other healthcare practitioner questions, and being comfortable making shared treatment decisions with a doctor increased with age
- ▶ Higher proportions of respondents in fair or poor health did not feel they had access to enough information to manage their medicines or general health
- ▶ A higher proportion of respondents residing in remote locations reported taking medicines prescribed for someone else and were unsure why they were taking medicines
- ▶ Respondents in excellent health and those who identified as Aboriginal and/or Torres Strait Islander more often required help from healthcare practitioners to understand health information
- ▶ Respondents who identified as Aboriginal and/or Torres Strait Islander were more likely to source health information from pharmacists and other healthcare practitioners
- ▶ Respondents who were born overseas and spoke a language other than English were more likely to source health information from family and friends
- ▶ Respondents who spoke a language other than English at home had a lower awareness of how to store or dispose of medicines and had taken medicines prescribed for someone else
- ▶ Respondents who spoke a language other than English at home more frequently required someone they know to help them understand information about health and medicines.

## Key recommendations

Recommendations have been made in this report for consideration in possible future workplans for the consumer engagement program. These include:

- ▶ Conduct national consumer surveys (if required) every two – three years, rather than annually, to allow time for consumer health literacy and behaviour changes to occur and be measured
- ▶ Further education on active ingredients to build consumer awareness about the importance of knowing active ingredients in medicines (e.g., via a national consumer QUM campaign)
- ▶ Further education on quality use of medical tests to help consumers understand the risks of unnecessary testing (e.g., via Choosing Wisely Australia messaging)
- ▶ Increase accessibility of Choosing Wisely Australia messaging, including physical and online resources to promote greater health literacy actions
- ▶ Provide further education to consumers on the importance of keeping a list of their medicine/s
- ▶ Partner with key consumer and community organisations to conduct regular consumer education campaigns to reinforce QUM messages specific to their communities and increase awareness
- ▶ For the seldom heard population groups, reduce knowledge gaps by utilising trusted healthcare practitioners such as doctors, pharmacists and nurses to distribute resources and initiate discussions.

# INTRODUCTION

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NPS MedicineWise has developed a *Consumer Engagement Plan* to ensure that consumer needs and insights are incorporated into QUM Grant programs and activities. Within this plan, NPS MedicineWise has committed to monitoring trends and evaluating changes over time in consumer awareness, knowledge and health literacy in relation to QUM. The key evaluation measures, as specified in the consumer engagement workplan, are:

- ▶ Consumer awareness of quality use of medicines (QUM) shows consistent improvement over time (establish a baseline and monitor changes over time)
- ▶ Consumer health literacy shows consistent improvement over time (establish a baseline and monitor changes over time).

Health literacy has been defined as; how people access, understand and use health information as it relates to QUM to engender better health outcomes<sup>1</sup>.

The main challenges for NPS MedicineWise in being able to address and improve QUM awareness and health literacy include the level of consumer reach required, and access to consumer populations who are outside of the typical audiences for NPS MedicineWise programs. Broadening consumer reach will require strategic planning and partnership with key consumer and community organisations.

Consumers Health Forum of Australia (CHF), the national peak body representing the interests of Australian healthcare consumers was engaged in 2020 to conduct a consumer health literacy segmentation and activation research project. The findings and recommendations from this project informed the indicators used in the National Consumer Survey to measure awareness of the key elements of QUM and health literacy as it relates to QUM<sup>2</sup>.

NPS MedicineWise conducted a baseline National Consumer Survey in 2020 with a representative sample of Australian consumers. The 2020 questionnaire was developed in consultation with consumer representatives and reviewed by several peak consumer bodies. This questionnaire was reviewed and amended in 2021 after feedback from the Department of Health and the Australian Commission on Safety and Quality in Healthcare (ACSQHC). The 2021 National Consumer Survey was conducted in October-November 2021.

Several seldom heard populations were identified as being underrepresented in the online National Consumer Survey. In addition to the survey, it was decided to conduct qualitative interviews with a sample of consumers from three seldom heard population groups to understand their awareness of QUM and gaps in health literacy. These groups were: consumers with limited digital access or low digital literacy, consumers living with a physical disability and consumers residing in rural and remote areas.

This report outlines the findings from the 2021 National Consumer Survey and compares key findings with the 2020 survey to identify whether any changes have occurred in consumer health trends over the past year. Key insights from the consumer interviews are also outlined.

# METHOD

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## Online survey

A cross-sectional survey was implemented with a random sample of consumers aged over 16 years. The sample was recruited from a consumer research panel owned by research company Dynata. The sample was representative of the Australian population as per the 2016 Census in terms of gender, age, geographic location and Aboriginal and Torres Strait Islander origin. The 2021 survey was distributed to the same sample of consumers who received the invitation to participate in the 2020 survey.

The questionnaire was developed by NPS MedicineWise and consisted of 45 questions, estimated to take about 15 minutes to complete. The questions were informed by key performance indicators, health literacy and QUM indicators as identified in the CHF research, and advice from the Consumer Advisory Group. Feedback was also sought and received from internal managers and external stakeholders, including individual consumer representatives, CHF special interest groups, and peak consumer organisations; National Aboriginal Community Controlled Health Organisation (NACCHO), Federation of Ethnic Communities Council of Australia (FECCA), Carers Australia and COTA Australia. The questionnaire was reviewed, and a few questions amended for 2021 based on feedback from The Department of Health and ACSQHC.

A period of three months was used for several questions to provide consumer respondents with a frame of reference and because this time period has been found from experience and testing to be most appropriate for accurate recall by consumers.

## Interviews with seldom heard consumers

Semi-structured interviews were conducted with 19 consumers from three seldom heard populations:

- ▷ 7 consumers with limited digital access or low digital literacy
- ▷ 7 consumers living with a physical disability
- ▷ 5 consumers residing in rural and remote areas (as defined by the Department of Health's Rural, Remote and Metropolitan Area classification)

The interview guide was based on QUM and health literacy information collected in the National Consumer Survey. It was developed with advice from the Consumer Advisory Group. Participants were provided with a participant information sheet and consent form prior to the interview. The interviews were 30-minutes in duration and conducted by telephone. Participants were provided (with Department approval) with a \$50 gift voucher for their time.

Consumers were recruited through social media and consumer and community organisations, including: Physical Disability Australia, Queenslanders with Disability Network, Men's Shed, Read Write Now Western Australia, Brisbane City Council, and Bankstown Wellness Centre. These organisations reached out to their networks to find eligible candidates to participate in the interviews.

## Data collection and analysis

The questionnaire was built in the online survey software platform, Alchemer, and a link to the questionnaire was provided to Dynata to manage and distribute the survey to the consumer sample.

The survey was conducted online between 25 October and 8 November 2021 and was completed by 2,032 consumers. Data analysis was performed using SPSS statistics version 28.

This report presents frequencies, descriptives (i.e., mean responses) and cross-tabulations of data. For questions measuring medicine adherence, QUM awareness and health literacy, a mean score

was calculated across all indicators to identify an average for each individual respondent and across all respondents. Negative statements were recoded for a more accurate calculation of the mean.

Mean scores were categorised as high, medium and low as follows:

- ▷ Medicine adherence: inclusion of indicator statements b through e. Statement a was excluded as it was about general decision-making rather than adherence to a specified medicine regime. Respondents with a mean score of 1.0-2.99 were categorised as having 'low' adherence, a mean score of 3.0-3.99 as 'medium' adherence, and a mean score of 4.0-5.0 as 'high' adherence.
- ▷ Health literacy: inclusion of all 8 indicators. Respondents with a mean score of 3.01-5.0 were categorised as having 'low' health literacy, a mean score of 2.01-3.0 as 'medium' health literacy, and a mean score of 1.0-2.0 as having 'high' health literacy.
- ▷ Awareness of QUM: inclusion of all 15 indicator statements. Respondents with a mean score of 1.0-2.99 were categorised as having 'low' awareness of QUM, a mean score of 3.0-3.99 as 'medium' awareness, and a mean score of 4.0-5.0 as 'high' awareness of QUM.

Pearson chi square and independent samples T-Test were used to determine if there were any significant differences between responses for 2021 compared with the 2020 National Consumer Survey. Percentage increases discussed in the report are absolute increases.

## Limitations

One of the main limitations of the survey was that it was conducted in English only, limiting participation by culturally and linguistically diverse populations who speak English as a second language. It is acknowledged that conducting the survey online also precluded consumers without access to a computer or the internet or who have a low level of digital literacy from participating.

The survey methodology may be less accessible for other seldom heard populations, such as people living with disability and those in rural and remote communities. This is why consumers with low digital literacy/limited access to the internet, living in rural/remote areas and living with a physical disability were selected as the three seldom heard populations for interview.

The use of a small suite of 8 health literacy indicators may not have been as nuanced as a larger measurement tool. However, these indicators were selected based on the CHF consumer health literacy segmentation research to measure health literacy as it related to QUM, rather than health literacy in general, as measured by existing tools. For the purpose of this survey, the measurement tool needed to be practical and not a burden for respondents to complete. This measurement of health literacy also enabled a mean rating to be calculated and for categorisation of health literacy levels.

The survey collected self-reported data from consumer respondents, which may have introduced bias and may differ from statistics available through other sources using different methods.<sup>3</sup> However, efforts were made to minimise self-reported bias as much as possible through the development of appropriate questions in consultation with key consumer stakeholders and ensuring anonymity of responses.



## RESPONDENT DEMOGRAPHICS

Respondents invited to participate in the survey were selected based on their representativeness of the Australian population, as per the 2016 Australian Bureau of Statistics census demographic data<sup>4</sup>, for gender, age, geographic location and Aboriginal and Torres Strait Islander origin (Table 1).

Consumers born overseas equated to 26% of the survey sample, compared to 24% in 2020. This was fairly representative of the Australian population, where an overseas birth rate of 29% is recorded. Country of birth included: New Zealand, England, India, China, Pakistan, Philippines, Bangladesh, Hong Kong, Korea, Malaysia, Vietnam, Japan, Nepal, France, Italy, Germany, Greece, Croatia and South Africa.

About 15% of respondents spoke another language at home compared with 12% in 2020 and 22% for the Australian population. Other languages spoken at home included: Cantonese, Mandarin, Greek, Arabic, Japanese, Vietnamese, Korean, Croatian, French, Italian, German, Urdu and Bengali.

The location description specified by respondents was similar in 2021 and 2020, with fewer respondents living in metropolitan areas than identified for the Australian population. Respondents in 2021 and 2020 were more highly educated than the general population, with higher proportions of consumers having completed TAFE or university qualifications.

**Table 1. Demographic profile of survey respondents % (n)**

	2021 survey respondents		2020 survey respondents		Australian population
	%	(n)	%	(n)	%
<b>Gender</b>					
Male	45.5%	(922)	48%	(970)	49%
Female	54%	(1,097)	51.5%	(1,049)	51%
Other	0.5%	(13)	0.5%	(9)	*
<b>Age category</b>					
16-19 years	3%	(54)	1%	(20)	6%
20-24 years	6%	(125)	4%	(73)	7%
25-34 years	18%	(365)	17%	(341)	14%
35-44 years	19%	(375)	19%	(379)	14%
45-54 years	16%	(335)	18%	(376)	13%
55-64 years	17%	(344)	17%	(344)	11%
65-74 years	12%	(241)	15%	(301)	9%
75-84 years	6%	(129)	7%	(146)	5%
85+ years	3%	(64)	2%	(48)	2%
<b>Location</b>					
ACT	2%	(50)	2%	(48)	2%
NSW	29%	(597)	32%	(653)	32%
NT	1%	(16)	0.5%	(6)	1%
QLD	18%	(368)	19%	(391)	20%
SA	9%	(173)	8%	(153)	7%
TAS	3%	(70)	2%	(42)	2%
VIC	27%	(540)	27%	(553)	26%
WA	11%	(216)	9%	(178)	10%
<b>Location description</b>					
Metropolitan	67.5%	(1,371)	67%	(1,359)	76%
Regional	22%	(444)	23.5%	(471)	*
Rural	10%	(202)	9%	(185)	*
Remote	0.5%	(6)	0.5%	(2)	*

	2021 survey respondents		2020 survey respondents		Australian population
	%	(n)	%	(n)	%
<b>Aboriginal and/or Torres Strait Islander origin</b>					
No	96%	(1,953)	96%	(1,951)	97%
Yes	4%	(79)	4%	(77)	3%
<b>Country of birth</b>					
Australia	74%	(1,511)	76%	(1,545)	71%
Other country	26%	(521)	24%	(483)	29%
<b>Language other than English</b>					
No	85%	(1,724)	88%	(1,789)	78%
Yes	15%	(308)	12%	(239)	22%
<b>Highest level of education</b>					
Never attended school	0.4%	(5)	0.4%	(5)	0.8%
Some primary school	0.6%	(13)	0.6%	(12)	*
Completed primary school	2%	(35)	1%	(25)	*
Some high school	10%	(207)	10%	(203)	23%
Completed high school	19%	(377)	17%	(344)	16%
TAFE or Trade certificate/diploma	30%	(618)	32%	(640)	25%
University or other tertiary institute degree, including post-graduate	38%	(772)	39%	(792)	22%
<b>Employment status</b>					
Self-employed	7%	(138)	8%	(155)	*
Employed for wages/salary	46%	(957)	46%	(931)	
Unemployed	9%	(198)	9%	(190)	
Unpaid work	2%	(32)	2%	(35)	
Student	4%	(95)	3%	(64)	
Carer on carer pension	2%	(38)	2%	(44)	
Retired	23%	(468)	25%	(505)	
Unable to work	4%	(83)	4%	(83)	
Other	3%	(53)	-	-	

\*Data not collected or reported in a way that can be directly compared.

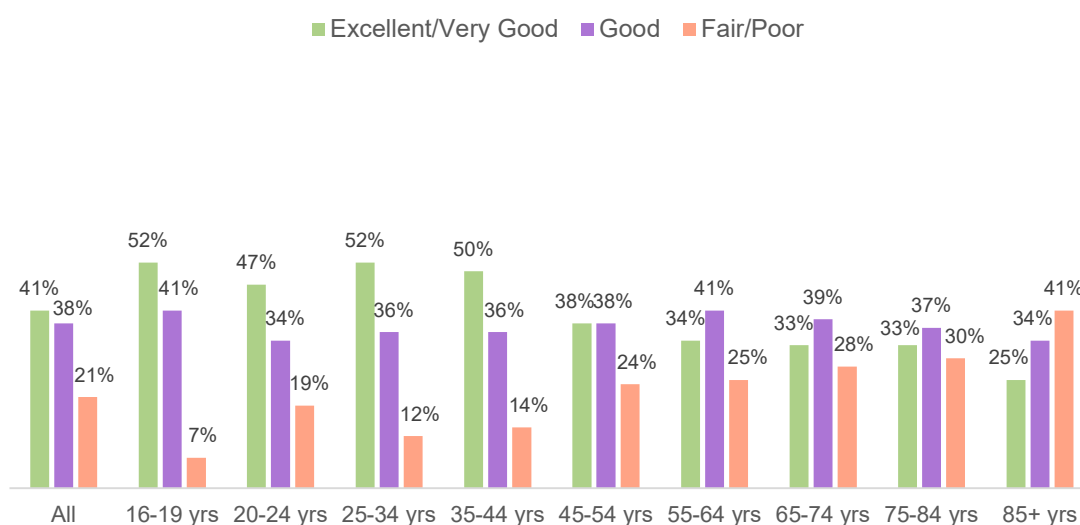
# CONSUMER HEALTH STATUS

## Current status

Most respondents indicated that they were in good health, rating their health status as 'excellent' (10%, n=209), 'very good' (31%, n=637), or 'good' (38%, n=764). Less than one-quarter (21%, n=422) of respondents rated their health as 'fair' or 'poor'. Health status was similar across genders and geographic location. Overall trends in health status for 2021 were consistent with the 2020 National Consumer Survey.

As shown in Figure 1, the proportion of respondents who rated their health as fair or poor tended to increase with age. About 41% of respondents aged 85+ years perceived themselves to be in fair or poor health compared with 21% for the general survey population.

Figure 1. Proportion of respondents by health status and age category



## Consultations with a doctor

About 28% (n=556) of respondents had not seen a doctor at all in the last three months, and a further 28% (n=561) had only seen a doctor once. Almost one-third of respondents (31%, n=613) had seen a doctor two or three times, 8% (n=152) four or five times, and 5% of respondents in poorer health had seen a doctor six or more times. The proportion of respondents who had seen a doctor two or more times in the last three months was 4% higher in 2021 than reported in the 2020 National Consumer Survey.

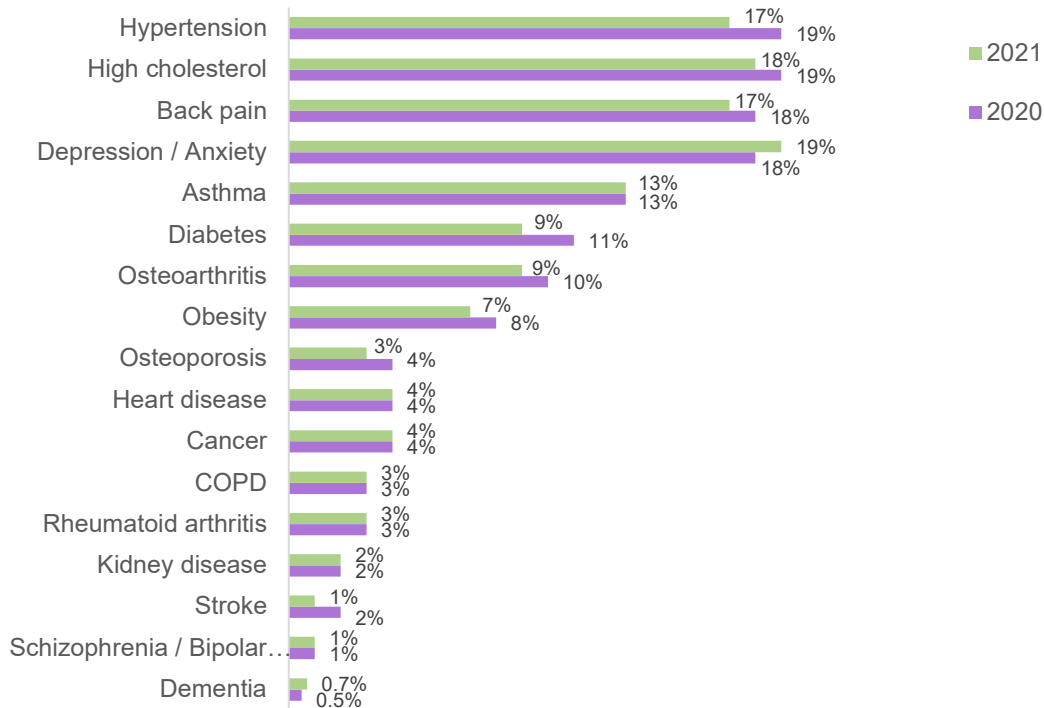
On average, consumer respondents had visited a doctor 1.9 times in the last three months, which is comparable with 2020 (i.e., 1.8 times).

## Health conditions

About 37% (n=760) of consumer respondents had not been diagnosed with a chronic health condition. However, the majority of respondents (63%, n=1,272) reported having been diagnosed with one or more chronic health conditions.

Figure 2. shows the chronic conditions experienced by respondents in 2021 and 2020. The most common health conditions were depression / anxiety, back pain, high cholesterol and hypertension. The top four conditions were the same for both years, although the order of prevalence differed slightly.

**Figure 2. Proportion of respondents by chronic health conditions**



For respondents with a chronic health condition, 20% (n=250) needed to visit the hospital in the last three months because of their condition. A small proportion of respondents (8%, n=156) were participants of the National Disability Insurance Scheme, and 20% (n=400) of respondents identified themselves as being a carer for someone else with a chronic health condition. These findings are consistent with 2020 survey findings.

## Taking or using medicines

The majority (86%, n=1,750) of respondents had taken or used a medicine in the last three months, while the remaining 14% (n=282) of respondents had not taken or used any medicines during this time. This trend is consistent with the 2020 National Consumer Survey (i.e., 85% used a medicines; 15% had not).

### Number of medicines

About 13% (n=227) of respondents indicated that they did not take medicines on a daily basis. For respondents taking or using medicines daily:

- ▷ 25% (n=424) were taking one medicine
- ▷ 33% (n=576) were taking or using two or three medicines
- ▷ 29% (n=497) were taking or using four or more medicines each day.

These findings align with the 2020 National Consumer Survey findings.

## Type of medicines

Those respondents who were taking or using medicines were asked to consider three types of medicine in their responses: prescription, over the counter (OTC) and complementary medicines. The survey provided a description of each.

Most respondents were taking prescription medicines (63%, n=1,270), followed by OTC medicines (53%, n=1,066) and complementary medicines (36%, n=728). This trend is similar to the 2020 National Consumer Survey findings.

## Having medical tests

Most respondents (61%, n=1,245) had not had a medical test in the last three months. The remaining 39% (n=787) of respondents reported having a medical test during this time period. This trend aligns with the findings of the 2020 survey.

Of those who had a medical test, 64% (n=497) discussed the benefits and risks of having the test with their doctor, which is 4% higher than reported in the 2020 survey.

In 2021, respondents identified the main reasons for having a medical test as:

- ▷ it was recommended by their doctor / GP (66%, n=517)
- ▷ it was recommended by a specialist (17%, n=133)
- ▷ the consumer asked their doctor if they could have the test (11%, n=82)
- ▷ another healthcare practitioner recommended the test (2%, n=19)
- ▷ it was recommended by family or friends (1%, n=4)

These findings align with the 2020 National Consumer Survey.

# CONSUMER AWARENESS & ATTITUDES RELATED TO HEALTH & MEDICINES

## Sources of information about health conditions and medicines

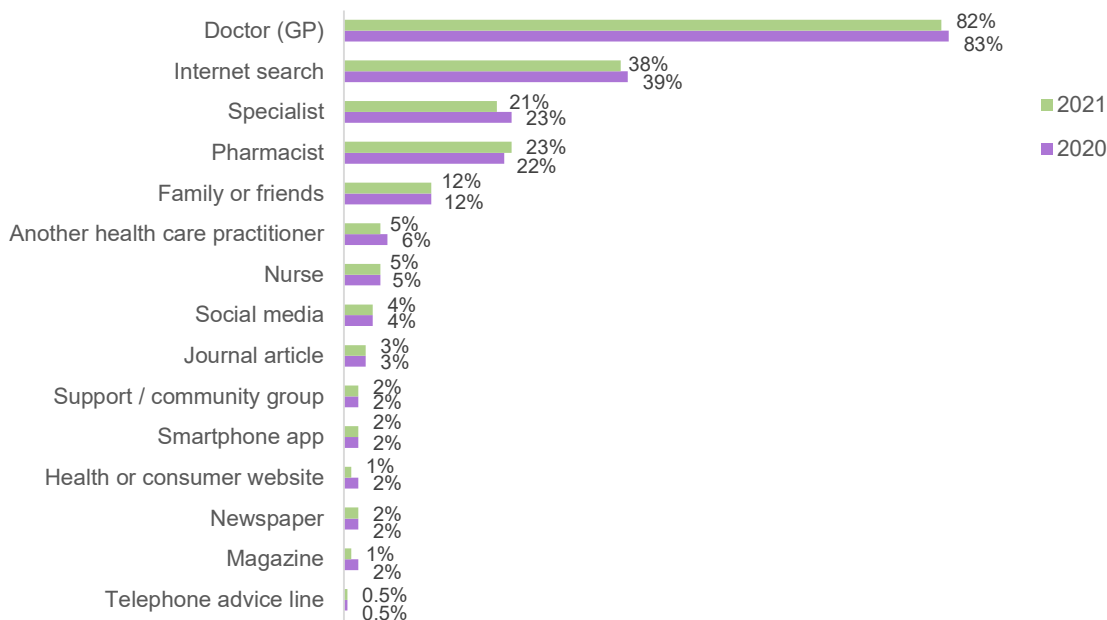
Respondents were asked how often they had tried to find information about health conditions or medicines in the last three months. About 36% (n=675) of respondents did not try to find information on health conditions or medicines. Over the last three months, 39% (n=730) tried to find information once a month or less often, which is 4% higher than reported in the 2020 National Consumer Survey.

One-quarter of respondents tried to find information more often, with 12% (n=215) looking for information several times a month and 13% (n=233) looking once a week to several times a week.

For those respondents who tried to find health information, 84% (n=989) were trying to find information for themselves, up from 79% in the 2020 National Consumer Survey. To a lesser degree, respondents also looked for information for their partner, child or parent.

Respondents indicated a doctor (GP) was their main source of information about health conditions or medicines. Over one-third of respondents also used internet search engines, such as Google, as a source of information. Sources of health information indicated by respondents were consistent in the 2020 and 2021 surveys (Figure 3).

**Figure 3. Proportion of respondents by sources of information about health conditions and medicines**



Further analysis of demographic data identified that utilising a doctor and specialist as a source of information significantly increased with respondent age ( $p < 0.001$ ). A higher proportion of respondents who identified as Aboriginal and/or Torres Strait Islander used a pharmacist, specialist or other healthcare practitioner as a source of health information compared with non-Aboriginal respondents ( $p < 0.001$ ). Higher proportions of respondents who were born overseas and spoke a language other than English at home used family and friends, internet search and social media as sources of health information ( $p < 0.001$ ).

## Sources of health information among seldom heard consumers

Most consumers from the three seldom heard population groups who participated in an interview indicated relying on a doctor or pharmacist as the most trusted and credible source of health information. For those with low digital literacy or limited digital access there are few other avenues available to access information. In general, these consumers felt more comfortable asking a nurse or pharmacist for information because they were perceived to be less intimidating and have more time to provide assistance. Brochures or factsheets available at doctor's surgeries were also perceived to have a high level of credibility.

Other sources of information for consumers living with a physical disability and residing in rural/remote areas included health shows (on SBS or ABC), Facebook support groups and online research. Searching for information through additional sources was often due to a lack of information provided by the doctor. For some of these consumers, searches on 'Dr Google' meant that information they found may have been out of context, not specific to their circumstances, prompted them to stop their medicines or take more than instructed. Those with family and or carers who had medical knowledge defaulted to them for further information.

*'I use Health Direct as a symptoms checker. I usually use it for actual medical things like looking for remedies for sleep and things like that' [Consumer residing in rural / remote area]*

*'My daughter is a nurse, so I often get her to come to the appointments with me. She's able to butt in and ask questions' [Consumer with low digital literacy]*

*'I try and have some rest weeks from my medications. I try and have 5 days a month where I don't take anything. I'm concerned I'll get addicted so it's just something I decided to do' [Consumer living with physical disability]*

*'The vitamin D drops are supposed to be just one drop a day. I have a swig out of the bottle. There's a doctor in Melbourne that I read about who says it's very good for MS' [Consumer living with physical disability]*

## Awareness of NPS MedicineWise

The survey asked consumers whether they were aware of NPS MedicineWise as an organisation that provides health advice and information. The majority of respondents in 2021 (89%, n=1,817) and 2020 (88%, n=1,788) were not aware of NPS MedicineWise.

About 11% (n=215) of respondents indicated being aware of NPS MedicineWise before completing the survey, which is consistent with the 2020 National Consumer Survey (12%, n=240). These respondents had commonly heard about NPS MedicineWise from an internet search or health professional such as a doctor or pharmacist.

Of the 215 respondents who were aware, 67% (n=140) rated the trustworthiness of the organisation as 'very good' or 'good', 26% (n=55) as 'adequate' and 7% (n=15) as 'poor' or 'very poor'. This is consistent with the 2020 survey findings.

The survey data indicates that respondents who were aware of NPS MedicineWise were more likely to ask a doctor or pharmacist questions about medicines than those who were not aware of the organisation (72% vs. 56%, p<0.001).

## Awareness of Choosing Wisely Australia

The survey asked consumers if they were aware of the Choosing Wisely Australia initiative and the [‘5 questions to ask your doctor’](#) resource. While the majority (88%, n=1,780) were not aware, about 12% (n=252) of respondents were aware of Choosing Wisely Australia before completing the survey and 10% (n=208) were aware of the ‘5 questions to ask your doctor’ resource. This is consistent with awareness of Choosing Wisely Australia (13%, n=269) and the resource (10%, n=196) reported in the 2020 National Consumer Survey.

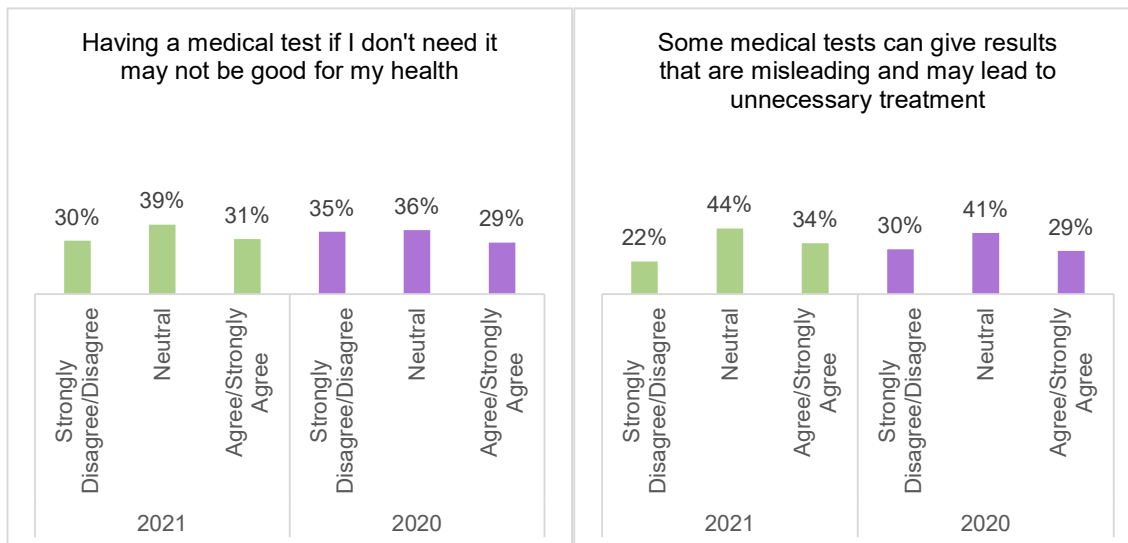
The survey data indicates that respondents who were aware of Choosing Wisely Australia were more likely to ask a doctor or pharmacist questions than those who were not aware of the initiative (68% vs. 56%, p=0.001). This suggests translation of key messaging into action.

## Attitudes towards medical tests

Respondents were asked to indicate their level of agreement with two statements about medical tests. Responses indicate that consumers are mostly unsure (neutral response) whether having medical tests can be harmful or lead to unnecessary treatment. The 2021 survey showed a 5% increase in the proportion of respondents who agreed or strongly agreed that medical tests can give misleading results that may lead to unnecessary treatment compared with the 2020 National Consumer Survey (Figure 4).

Ongoing consumer education on the quality use of medical tests and low value care is required to help consumers understand the risks of unnecessary testing, which is an area that most consumers are less familiar with than medicines.

**Figure 4. Comparison of proportion of respondents by attitudes about medicine tests**





# CONSUMER KNOWLEDGE & SKILLS RELATED TO HEALTH & MEDICINES

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## Recording medicines

About 32% (n=560) of respondents taking or using a medicine reported keeping a list of their medicines, either as a written list or an electronic list accessed through their mobile phone. This was 2% higher than reported in the 2020 National Consumer Survey (i.e., 30%). Respondents commonly keep a list to have a record of their medicines, and in-case they need to share the list of medicines with a doctor or at an emergency hospital visit.

Respondents were more likely to keep a medicines list if they were taking prescription medicines and were taking two or more medicines daily.

## Use of a medicine list among seldom heard consumers

Most consumers from the three seldom heard population groups who participated in an interview did not keep a list of medicines. This was mainly due to a lack of awareness of the benefits of keeping a medicines list, a lack of awareness of existing medicine list resources or apps that could be used or the perception that keeping a record of the medicines they were taking was the domain of their doctor.

Once the idea of a medicine list was raised, it was something consumers were happy to try, particularly as an app, although physical medicine list templates still need to be available for those with low digital literacy or limited digital access. Possible use of the MyGov website or app as a centralised site for medical documents and medicines lists was also suggested.

*'I like the idea of the list. That would be the best thing if it's on the phone. I think that's one of the key things that would help me' [Consumer living with Physical Disability]*

*'An app would be great to be able to just upload everything in there and track what I'm taking and when I've taken it' [Consumer residing in rural / remote area]*

*'A lot of places won't upload reports onto it [MyGov]. It would make it so much easier for when you need to see a new doctor there's less anxiety on me to explain everything. If it was all there in front of them, then I wouldn't have to do that' [Consumer residing in rural / remote area]*

## Asking questions

The last time they received a new medicine, 58% (n=1,063) of respondents asked their doctor or pharmacist questions about the medicine. This was 2% higher than reported in the 2020 National Consumer Survey (i.e., 56%). Respondents were more inclined to ask their doctor questions rather than a pharmacist.

About 34% of respondents in 2021 and 2020 reported that nothing would stop them from asking their doctor questions during a consultation. However, it was also recognised that for some consumers there may be barriers to asking questions when visiting the doctor. The top two barriers to asking questions for respondents in 2021 and 2020 were:

- ▷ they trust the doctor to do what is best for them
- ▷ they couldn't think of any questions to ask at the time of the visit.

## Understanding quality use of medicines (QUM)

### Active ingredients

Consumer knowledge of active ingredients within the medicines they take or use is essential for medicines safety. Respondents were asked to indicate whether they know what an ‘active ingredient’ is in relation to medicines. About 41% (n=832) of respondents indicated knowing what an active ingredient is, while 34% (n=696) did not know, and 25% (n=504) were unsure. Higher proportions of male respondents, those who spoke English only and those with higher levels of education reported knowing what an active ingredient is. A significantly lower proportion of youth aged 16-19 years reported knowing what an active ingredient is.

Almost three-quarters of respondents (71%, n=1,450) understood that the active ingredient is what makes a medicine work, which is consistent with the 2020 survey findings. However, less than half (48%, n=962) reported knowing the difference between a medicine brand name and active ingredient, and only one-third (34%, n= 702) knew the active ingredients in their own medicine (Table 2).

In another question, respondents were asked to indicate how frequently they engaged with information about active ingredients in their medicines. About 40% (n=801) in 2021 and 43% (n=869) in 2020, ‘always’ or ‘often’ read information on active ingredients in relation to their medicines. The survey findings suggest that active ingredients is an area of QUM where consumers require further education.

**Table 2. Proportion and number of respondents by knowledge of active ingredients**

Statements	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The active ingredient is what makes a medicine work	2% (32)	2% (41)	25% (509)	49% (993)	22% (457)
I know the active ingredient/s in my medicine	7% (141)	22% (443)	37% (746)	24% (493)	10% (209)
I know the difference between the active ingredients and brand name of a medicine	5% (97)	15% (318)	32% (655)	33% (664)	15% (298)

### Awareness of active ingredients among seldom heard consumers

Most consumers from the three seldom heard population groups who participated in an interview were unsure about the term ‘active ingredient’ in relation to medicines. This was not a concept they had discussed with a healthcare practitioner or that had been raised with them. These consumers were not sure where to find the active ingredient in their medicines but guessed that it would be on the box or in the consumer medicine leaflet. In general, they trusted their healthcare practitioners to not allow them to take two medicines with the same active ingredient.

A small number indicated being worried that they might overdose on the active ingredient, or that their medicines could interact. However, for most unless they experienced an adverse reaction, they would not think to ask about active ingredients. There also appeared to be a lack of awareness that over-the-counter and complementary medicines could have the same active ingredients or interact adversely with prescription medicines.

*‘It’s probably in all the fine print wrapped around the bottle. I’m not terribly interested’ [Consumer living with physical disability]*

*‘If I looked at all those ingredients it wouldn’t mean anything to me. It’s like with food labels, it’s only recently that we are educated to look at labels’ [Consumer with low digital literacy]*

*‘It’s something I’ve not really thought of. I might question my specialist or GP. Not sure what else you could do’ [Consumer living with physical disability]*

*‘I just figure if my doctor has told me to take it then they must know what they’re doing’ [Consumer residing in rural / remote area]*

## Elements of QUM

To understand consumer awareness of QUM aspects, respondents were presented with 15 statements (Table 3) and asked to indicate their level of agreement or disagreement with each. Eleven statements are positive and four are negative. Most respondents agreed that some medicines could be addictive, understood why they were taking medicines and how to safely store medicines. Almost three-quarters of respondents had a regular trusted doctor and knew that medicines had benefits and risks. Fewer respondents reported knowing how to safely dispose of unwanted medicines, had a regular trusted pharmacist or felt they had access to enough information to manage their own health.

**Table 3. Proportion and number of respondents by level of agreement with positive QUM statements**

(\* Preferred responses to these statements are reversed)

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>	<b>Mean 2021</b>	<b>Mean 2020</b>
I am aware that some medicines can be addictive	1% (19)	3% (59)	16% (317)	47% (958)	33% (679)	4.09	4.16
I understand why I am taking or using each of my medicines	1% (19)	3% (56)	17% (338)	48% (979)	31% (640)	4.07	4.13
I know how to store my medicines safely	1% (16)	3% (59)	18% (368)	51%(1044)	27% (545)	4.01	4.06
I have a regular doctor that I trust	3% (55)	8% (160)	18% (372)	39% (798)	32% (647)	3.90	3.96
The medicines I take or use can have benefits and risks	1% (20)	3% (67)	24% (477)	49% (995)	23% (473)	3.90	3.94
I take an active role in improving my own health	2% (39)	3% (68)	22% (445)	50%(1008)	23% (472)	3.89	3.90
I have access to enough information to manage my own medicines	2% (33)	5% (102)	25% (509)	48% (976)	20% (412)	3.80	3.81
When I start taking a medicine, I make sure I understand how it might interact with other medicines/things I eat or drink	2% (35)	6% (116)	24% (496)	48% (973)	20% (412)	3.79	3.83
I have access to enough information to manage my own health	2% (32)	6% (125)	26% (524)	49% (997)	17% (354)	3.75	3.80
I know how to dispose of my medicines safely when I don't need them anymore	2% (45)	10% (200)	26% (521)	40% (820)	22% (446)	3.70	3.85
I have a regular pharmacist that I trust	4% (81)	13% (261)	29% (587)	33% (668)	21% (435)	3.55	3.59
I'm not worried about side effects of medicines my doctor tells me to take*	6% (127)	20% (409)	35% (704)	30% (609)	9% (183)	3.15	3.08
I think medicines can be taken or used even when they have passed their expiry date*	24% (479)	23% (472)	28% (577)	20% (403)	5% (101)	2.59	2.56
Sometimes I don't buy medicines when I need them because of the cost*	27% (549)	26% (538)	20% (401)	20% (406)	7% (138)	2.53	2.45
I sometimes take medicines that were prescribed for someone else*	51% (1030)	15% (311)	15% (308)	14% (289)	5% (94)	2.07	1.99

A comparison of means for the QUM statements shows similar trends in responses between 2021 and 2020 (Table 3). Although, compared with the 2020 National Consumer Survey, a slightly lower proportion of respondents in 2021 agreed that they knew how to dispose of medicines safely. On a positive note, fewer respondents in 2021 disagreed with the statements that they don't buy medicines when needed because of cost and that they sometimes take medicines prescribed for someone else.

## Awareness of QUM among seldom heard consumers

Most consumers from the three seldom heard population groups who participated in an interview felt they knew how to safely store and dispose of medicines, however on probing this was often not the case. There tended to be a lack of strategy for storing medicines safely and while some consumers were aware of the importance of returning unwanted or unused medicines to the pharmacy for correct disposal, others thought it was safe to dispose of medicines in the rubbish bin or by flushing them down the toilet. Several consumers believed it was okay to take out-of-date medicines or to take medicines that had been prescribed for someone else if they believed their symptoms or condition to be the same.

Most of the consumers living with a physical disability and with low digital literacy/access had established a trusting relationship with a doctor or pharmacist and this provided them with the confidence and feeling of safety to ask questions or learn more about their condition or medicines.

*'Yes, I've got them in a cupboard. It is down low so if there were any children about, they could probably get them, but I don't have any kids living with me' [Consumer with low digital literacy]*

*'My husband had a script for antibiotics that he'd never used, and I had a cold, so I just filled it instead of needing to go to the doctors and probably get the same thing anyway' [Consumer residing in rural / remote area]*

*'You never use up a whole packet of things like cold and flu tablets. As long as it's not been years, I don't think a few months out of date makes a difference' [Consumer living with physical disability]*

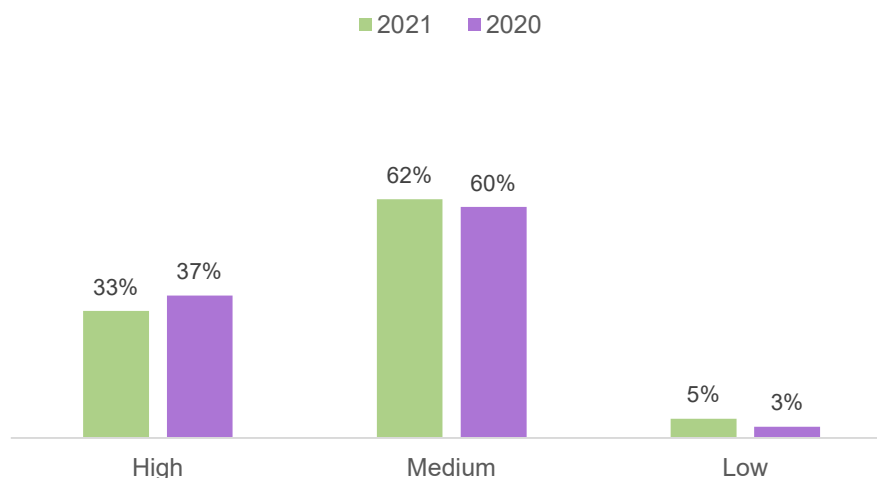
*'My pharmacist is really good. He always gives me the option for the generic so I'm not paying through the roof. And he's the one who always tells me how to take my medication' [Consumer with low digital literacy]*

## Level of QUM awareness

The mean score for overall QUM awareness among 2021 survey respondents was 3.7 out of 5, which is consistent with the overall mean of 3.8 reported in the 2020 survey. Respondent awareness, across the 15 QUM elements, was categorised as low, medium and high. The majority of respondents (62%, n=1,261) exhibited a 'medium' level of QUM awareness. One-third (33%, n=663) exhibited a 'high' level of QUM awareness and 5% (n=108) exhibited 'low' QUM awareness.

Figure 5 shows a comparison of levels of QUM awareness between the 2021 and 2020 National Consumer Survey findings. The proportion of consumers categorised as exhibiting high QUM awareness dropped by 4%. The proportions of consumers exhibiting medium or low QUM awareness increased by 2% in 2021 compared with 2020 survey findings. This difference may be explained by the marginally higher proportions of youth and those who spoke a language other than English at home who responded to the 2021 survey compared with the 2020 National Consumer Survey.

Figure 5. Comparison of proportion of respondents by levels of QUM awareness



### Key differences in QUM awareness by consumer demographics

Further analysis looking at responses to the QUM statements by respondent demographics identified the following trends:

- ▶ The 'high' QUM awareness category comprised significantly higher proportions of respondents; aged 55 years and over, with poor health status, higher educational attainment and who speak English only. The 'low' QUM awareness category comprised significantly higher proportions of respondents; aged 16-24 years, with primary school education, and of Torres Strait Islander origin.
- ▶ Awareness of QUM elements increased with age. The proportion of respondents aged 16-24 years who were aware of each of the QUM elements was significantly lower compared with awareness of QUM among those over 25 years.
- ▶ Higher proportions of respondents in fair/poor health felt they did not have access to enough information to manage their medicines or health compared with those in good/excellent health.
- ▶ A higher proportion of respondents residing in the Northern Territory were not active in improving their own health, did not have a regular trusted doctor, and did not feel they had access to enough health information compared with those in other States and Territories.
- ▶ A higher proportion of respondents residing in remote locations reported taking medicines prescribed for someone else and exhibited a lower understanding of why they were taking medicines.
- ▶ Higher proportions of respondents in excellent health believed it was okay to use medicines after expiry and reported taking medicines prescribed for someone else.
- ▶ Significantly lower proportions of respondents who spoke a language other than English at home had a regular, trusted doctor or pharmacist. This cohort also had less awareness of how to store or dispose of medicines, that medicines had risks as well as benefits and had taken medicines prescribed for someone else.
- ▶ Awareness of most QUM elements were lower among respondents who identified being of Aboriginal and/or Torres Strait Islander origin compared with non-Aboriginal respondents. However, Aboriginal and Torres Strait Islander respondents were more likely to have a regular pharmacist that they trust to help them with their medicines.
- ▶ Respondents who had attained a higher level of education (i.e., completed secondary school or higher) exhibited a greater level of awareness of QUM elements.

## Health literacy in relation to QUM

To understand the level of consumer health literacy, related to QUM, respondents were presented with 8 indicators (Table 4) and asked how frequently they performed the specified actions or felt a particular way when visiting a doctor, health clinic or pharmacy.

Positively, almost half of consumer respondents 'always' feel confident asking their doctor or other healthcare practitioner questions when they need more information about a health condition, medicine or medical test, and feel comfortable in the role of shared decision-maker with their doctor to determine the most appropriate treatment to manage their health condition.

About one-quarter of consumer respondents always or often needed help to understand information provided to them on a health condition, medicine or medical test, and found information provided by doctors or other healthcare practitioners confusing or difficult to understand.

A comparison of means for the health literacy indicators shows similar trends in responses between 2021 and 2020 (Table 4). Compared with the 2020 National Consumer Survey, a slightly higher proportion of respondents in 2021 'always or often' feel comfortable asking a trusted healthcare practitioner to help them understand information about health and medicines, while slightly fewer respondents 'always' feel confident asking a healthcare practitioner questions.

**Table 4. Proportion and number of respondents by response to health literacy indicators**

	Always	Often	Sometimes	Rarely	Never	Mean 2021	Mean 2020
Feel confident asking a doctor or other healthcare practitioner questions when you need more information	41% (821)	28% (578)	24% (493)	5% (102)	2% (38)	2.00	1.88
Feel comfortable deciding with your doctor which treatment is best for you	40% (808)	30% (606)	22% (454)	6% (116)	2% (48)	2.01	1.95
Feel comfortable asking a trusted healthcare practitioner to help you understand information about your medicines	38% (782)	31% (626)	23% (469)	6% (117)	2% (38)	2.02	2.15
Feel comfortable taking whatever medicine or other treatment your doctor prescribes for you*	31% (641)	37% (746)	25% (512)	5% (100)	2% (33)	2.08	2.00
Tell your doctor or other healthcare practitioner about OTC or complementary medicines you are taking	33% (671)	28% (567)	27% (543)	8% (171)	4% (80)	2.22	2.21
Look for information about health conditions, medicines or tests to prepare for the visit	18% (368)	25% (505)	34% (696)	17% (338)	6% (125)	2.68	2.69
Find information given by a doctor or other healthcare practitioner confusing or hard to understand*	10% (211)	17% (334)	34% (681)	30% (614)	9% (192)	3.12	3.13
Need someone you know to help you understand the information you've been given about medicines*	8% (157)	15% (306)	24% (483)	26% (525)	27% (561)	3.51	3.54

\*Preferred responses to these statements are reversed.

## Health literacy in relation to QUM among seldom heard consumers

Consumers from the three seldom heard population groups who participated in an interview felt more confident asking questions and more comfortable discussing issues or making decisions if they had been seeing particular health practitioners for a long time and had an established relationship. A common barrier to asking questions or initiating discussions was not wanting to take up precious time in a short appointment when it was understood that health practitioners were time poor. Health practitioners who actively welcome a conversation provide a cue to consumers that it is okay to ask questions or for further information.

Forming a rapport with health practitioners is a particular challenge for consumers residing in rural or remote areas. These consumers face a lack of local health services, seeing different locum or transient doctors or long-distance travel to access health practitioners. These factors can impact on health literacy and continuity of care.

There was a tendency for consumers to believe that the onus was on the pharmacist when dispensing their medicines to tell them all the important information or ask necessary questions. If the pharmacist didn't ask questions or provide any additional information, these consumers felt that everything must be fine, missing the opportunity to clarify anything they didn't understand.

*'I would like to ask him more about my osteoporosis, but I don't want to waste his time' [Consumer with low digital literacy]*

*'He [doctor] knows that I don't really like taking medicines, so he explains everything well before he prescribes something. Having that conversation makes me feel more comfortable' [Consumer with low digital access]*

*'Out here it's remote so we can't get doctors to stay. In NSW, I had the same doctor for my whole life. Now out here, you are shipped from one doctor to another, and they can only go by the notes from the previous doctor, which never seem to be very comprehensive' [Consumer residing in rural / remote areas]*

*'The closest hospital is 40KM away. I have to go there for specialist appointments. I've done some telehealth calls...but not everything can be done over the phone. For some of my bigger health ailments I have to travel to Adelaide which is 500KM away' [Consumer residing in rural / remote areas]*

*'The pharmacist always asks if I've taken the drug before and then they tell me how to take it. I feel like I'm get covered' [Consumer with low digital literacy]*

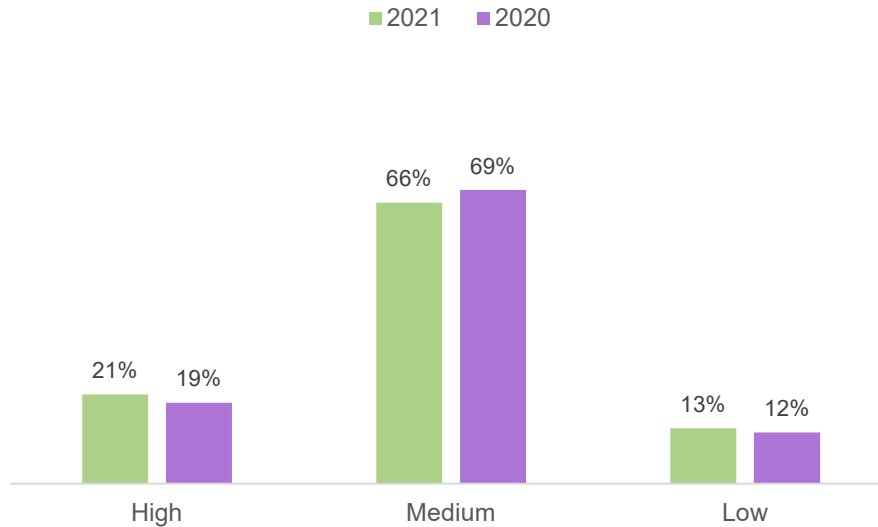
*'The chemist is very good. They go through and explain the side effects, so I feel confident' [Consumer residing in rural / remote area]*

## Level of health literacy in relation to QUM

The mean score for overall health literacy in relation to QUM among 2021 survey respondents was 2.5 out of 5, which is the same as reported for the 2020 survey. Respondent health literacy, across the 8 indicators, was categorised as low, medium and high. The majority of respondents (66%, n=1,344) exhibited a 'medium' level of health literacy. Less than one-quarter (21%, n=419) exhibited a 'high' level of health literacy and 13% (n=269) exhibited 'low' health literacy in relation to QUM.

Figure 6 shows a comparison between the 2021 and 2020 National Consumer Survey findings. There was no significant difference observed in the level of health literacy of respondents between 2020 and 2021.

Figure 6. Comparison of proportion of respondents by levels of health literacy related to QUM



### Key differences in health literacy by consumer demographics

Further analysis looking at responses to the health literacy indicators by respondent demographics identified the following trends:

- ▶ The 'high' health literacy category comprised significantly higher proportions of respondents; aged 55 years and over, with higher educational attainment and who speak English only. The 'low' health literacy category comprised significantly higher proportions of respondents; aged 16-24 years, primary school education only, of Aboriginal and/or Torres Strait Islander origin and residing in remote areas.
- ▶ Having the confidence to ask a doctor or other healthcare practitioner questions when more information is required and feeling comfortable making shared decisions with a doctor consistently increases with age.
- ▶ Respondents aged 16-19 years were less likely to tell their doctor or other healthcare practitioner about OTC or complementary medicines they may be taking.
- ▶ Respondents aged 55 years and older are more comfortable taking whatever medicine or other treatment their doctor prescribes for them without question compared with respondents under 55 years.
- ▶ Respondents in excellent health, and those who identified as being of Aboriginal and/or Torres Strait Islander origin, more often require assistance understanding health information and find information provided to them by a doctor or health practitioner confusing or hard to understand.
- ▶ Respondents who speak a language other than English at home more frequently require someone they know to help them understand information about medicines and find information provided to them confusing or hard to understand compared with respondents who speak English only.
- ▶ Female respondents more often look for information on health conditions, medicines or medical tests in preparation for visiting a doctor, health clinic or pharmacy compared with male respondents.
- ▶ Respondents who have attained a higher level of education feel more comfortable asking questions and making shared treatment decisions with their doctor.



# CONSUMER SELF-MANAGEMENT RELATED TO HEALTH & MEDICINES

## Adherence to medicine regimes

Most respondents reported 'rarely' or 'never' performing the actions listed in Table 5, indicating adherence to medicine regimes. Although almost one-quarter would 'always' avoid using medicines if possible. Higher proportions of respondents aged 55 years and over 'never' avoid taking medicines, decide to miss out a dose or take more or less than instructed compared with younger age cohorts.

Higher proportions of respondents in excellent to very good health 'always' avoid medicines, miss out a dose, forget to take their medicines or take more or less than instructed compared with those in poorer health.

**Table 5. Proportion and number of respondents by medicine adherence**

	Always	Often	Sometimes	Rarely	Never
a. I avoid using medicine if I can	21% (433)	22% (451)	29% (593)	14% (274)	14% (281)
b. I decide to miss out a dose	3% (70)	7% (141)	21% (424)	30% (611)	39% (786)
c. I take less than instructed	3% (63)	7% (136)	19% (378)	23% (476)	48% (979)
d. I forget to take my medicines	3% (65)	8% (154)	26% (538)	36% (731)	27% (544)
e. I might take more than instructed	3% (62)	4% (90)	14% (278)	17% (349)	62% (1,253)

## Medicine management and adherence among seldom heard consumers

Most consumers from the three seldom heard population groups who participated in an interview indicated having an established 'routine' for managing their medicines. Some consumers living with a physical disability had professional carers who managed their medicines for them. Consumers who were digitally savvy used apps such as Medadvisor to manage their scripts or set reminders or alarms on their phones to take their medicines.

Blister packs were a common strategy used by these consumers to help them manage and adhere to their medicine regime, although cost could be a barrier. Despite having strategies in place, many of these consumers admitted to forgetting to take medicines or missing out a dose, however this was not perceived to be an issue.

*'I've got a great team who are really supportive. We've got a whole system going. They are properly trained carers, and they stay on top of what I do. Everyone in the team knows what's going on'* [Consumer living with physical disability]

*'I just have it in the bowl next to the kettle. If I forget I think it's not too bad'* [Consumer with low digital access]

*'I've got one of those pill boxes with days of the week. If I didn't have that I would lose track. The pharmacy gives me the box with the whole months' worth of tablets, and I dispense it myself on a weekly basis'* [Consumer living with physical disability]

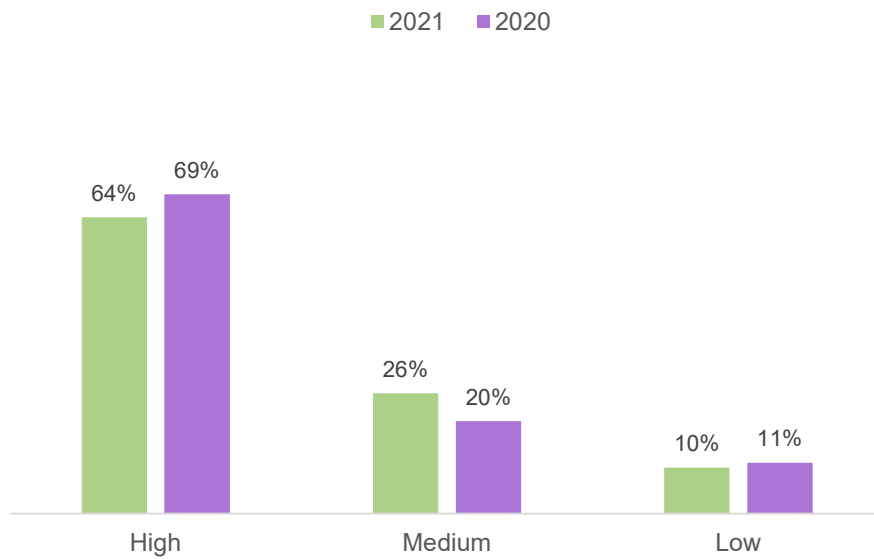
## Level of adherence

The mean score for reported adherence to medicine regimes among consumer respondents was 4 out of 5. Respondent adherence, across four adherence actions (b-e), was categorised as low, medium and high. Respondents predominantly exhibited 'high' adherence to medicine regimes (64%, n=1,293), followed by 'medium' adherence (26%, n=531). A comparatively small proportion exhibited 'low' adherence to medicine regimes (10%, n=208).

This level of consumer adherence may appear to be quite high, however other consumer studies with similar respondent characteristics have found levels of adherence to be in the realm of around 60%.<sup>5,6</sup>

Figure 7 shows a comparison between the 2021 and 2020 National Consumer Survey findings. The proportion of consumers categorised as exhibiting high adherence dropped by 5% and the proportion categorised as exhibiting medium adherence increased by 6% in 2021 compared with 2020 survey findings ( $p=0.003$ ).

**Figure 7. Comparison of proportion of respondents by levels of adherence to medicine regimes**



## CONCLUSION

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The 2021 National Consumer Survey was conducted with 2,032 consumers who were selected to be representative of the Australian population in terms of gender, location, age and Aboriginal and/or Torres Strait Islander origin. Interviews were conducted with 19 consumers from three seldom heard population groups.

Most of the health and medicine trends, including health literacy related to QUM, remained consistent between 2020 and 2021. Challenges in being able to address and improve QUM awareness and health literacy include the level of consumer reach required, and access to consumer populations who are outside the typical audiences for NPS MedicineWise programs. Broadening consumer reach will require strategic planning and partnership with key consumer and community organisations.

Consumer respondents generally perceived themselves to be in good to excellent health. Health status was similar across genders, and geographic location, and tended to decrease with age. Most respondents had been diagnosed with one or more chronic health conditions and just under one-quarter of respondents were caring for someone else with a chronic condition.

Most respondents had taken one or more medicines in the three months prior to completing the survey, predominantly prescription and over-the counter medicines. In contrast, only a small proportion of respondents reported having a medical test in the same period. A doctor was the main source of information about health and medicines for most respondents, and over half of respondents had asked their doctor or a pharmacist questions when they received a new medicine.

The survey found that less than half of respondents reported knowing what an active ingredient is in relation to medicines, and only about one-third of respondents were familiar with the active ingredients in their own medicines. Consumers from the seldom heard populations who participated in an interview were also unsure of active ingredients and the potential risks of not knowing the active ingredients in medicines they are taking.

Consumer respondents commonly exhibited a medium level of awareness of QUM. Some differences were observed in QUM awareness with fewer respondents exhibiting high awareness and slightly higher proportions of respondents exhibiting medium and low awareness in 2021 than reported in the 2020 National Consumer Survey. Most respondents understood that some medicines could be addictive, why they were taking medicines and how to safely store medicines. Almost three-quarters of respondents had a regular trusted doctor and knew that medicines had benefits and risks. Fewer respondents reported knowing how to safely dispose of unwanted medicines, had a regular trusted pharmacist or felt they had access to enough information to manage their own health.

Consumer respondents commonly exhibited a medium level of health literacy related to QUM. No significant difference in health literacy was observed from 2020. Almost half of consumer respondents always feel confident asking their doctor or other healthcare practitioner questions when they need more information and feel comfortable making shared treatment decisions with their doctor. About one-quarter of consumer respondents always or often needed help to understand information provided to them on a health condition, medicine or medical test, and found information provided by doctors or other health practitioners confusing or difficult to understand.

Respondents to the National Consumer Survey had commonly attained a higher level of education, were Australian born and spoke English only at home, which may explain why the proportion of respondents exhibiting low health literacy is comparatively small, as lower health literacy has been associated with lower levels of education and culturally and linguistically diverse backgrounds.<sup>1</sup>

The findings suggest that most respondents who are taking or using medicines are highly adherent to their medicine regimes and are managing their medicines as per the instructions provided to them by a healthcare practitioner. This is particularly the case for those in poor health and aged over 55 years. Consumers are also making informed decisions to avoid medicines wherever possible, particularly if they perceive themselves to be in good to excellent health. Some differences in adherence were

observed between 2020 and 2021, with fewer respondents exhibiting 'high' adherence and more respondents exhibiting medium adherence in 2021.

## Gaps in awareness of QUM

Findings suggest that the 'active ingredient' in a medicine is an area where consumers require further education and accurate messaging from sources they trust, such as a regular doctor, pharmacist or nurse. Most survey respondents and consumers from the seldom heard population groups who were interviewed were not familiar with the active ingredients in their own medicines and did not appear to appreciate the risks of not knowing the active ingredient in medicines they are taking.

Another gap in QUM knowledge related to medical tests, with respondents appearing to be uncertain of the risks of medical tests in potentially causing harm or leading to unnecessary treatment.

Fewer respondents seemed to understand the safety and efficacy aspects of taking medicines, believing that it is okay to take medicines beyond expiry or share prescribed medicines with others. Many survey respondents and seldom heard consumers who were interviewed were also unaware of how to safely dispose of unwanted medicines.

Younger consumers (i.e., 16-24 years) had the least awareness of QUM elements among survey respondents suggesting that they are at greater risk of medicines misuse due to their lack of QUM knowledge and self-efficacy in managing their health and medicines.

## Gaps in health literacy related to QUM

For consumers from the seldom heard population groups, there appears to be a gap in knowing what to ask their healthcare practitioners, which has reduced their level of confidence to make shared decisions about treatment. It has also resulted in a perceived lack of dialogue where these consumers often left a consultation not fully understanding aspects of the medicine prescribed, such as dose and frequency, interactions with other medicines, food or drink or whether it needs to be taken with or without food.

Consumer respondents often don't talk to their doctor or other healthcare practitioners about over-the-counter or complementary medicines they are taking alongside prescription medicines. This may be due to a lack of awareness of potential interactions between the types of medicines, or concern about telling their doctor they are taking or using other types of medicines.

Respondents who speak a language other than English at home, those in excellent health and those who identified as being of Aboriginal and/or Torres Strait Islander origin required more assistance to understand health and medicine related information. Developing a targeted strategy for disseminating consumer friendly and in-language information may assist consumers to better understand health and medicine information and increase their health literacy.

Young people aged 16-24 years commonly exhibited lower health literacy related to QUM. This could be a target audience for QUM education to assist in building health literacy in this population.

## Recommendations

In light of the survey and interview findings, the following recommendations have been made for consideration in possible future workplans for the consumer engagement program:

- ▷ Conduct national consumer surveys (if required) every two – three years, rather than annually, to allow time for consumer health literacy and behaviour changes to occur and be measured
- ▷ Further education on active ingredients to build consumer awareness about the importance of knowing active ingredients in medicines. This could be via:
  - direct messaging to consumers on a national level (i.e., national consumer campaign)
  - educating GPs to have discussions with their patients about active ingredients to address this identified gap

- ▷ Further education on quality use of medical tests to help consumers understand the risks of unnecessary testing (e.g., via Choosing Wisely Australia messaging)
- ▷ Increase accessibility of Choosing Wisely Australia messaging, including physical and online resources to promote greater health literacy behaviours, given that awareness of Choosing Wisely Australia is correlated with performing positive health literacy behaviours (e.g., asking questions)
- ▷ Provide further education to consumers on the importance of keeping a list of their medicines
  - promote the MedicineWise app more broadly and clearly articulate its purpose which may not be understood from the name alone
  - ensure the physical copy of the NPS MedicineWise Medicines List is accessible for consumers with low digital literacy, limited digital access and consumers residing in rural and remote areas
  - promote Medicine List resources developed with stakeholders (e.g., NACCHO)
- ▷ Partner with key consumer and community organisations (e.g., condition specific organisations, peak bodies, PHNs) to conduct regular consumer education campaigns to reinforce QUM messages specific to their communities and increase awareness
  - use different strategies to specifically target populations with lower QUM awareness and health literacy as it relates to QUM (e.g., consumers aged 16-24 years, consumers with primary school education, consumers in rural /remote areas)
- ▷ For the seldom heard population groups, seek to reduce gaps in knowledge and QUM / health literacy requirements by:
  - partnering with key consumer and community organisations who have the reach and credibility to disseminate information
  - utilising doctors, specialists, pharmacists and nurses to distribute resources, as they are the most trusted sources of health information
- ▷ Consider conducting further research with other seldom heard populations, who may have been underrepresented in this evaluation, to better understand their QUM and health literacy needs and inform NPS MedicineWise products and services
- ▷ Investigate other possible methods or tools for measuring health literacy among consumers that may deliver more nuanced information about gaps and education needs
- ▷ Where national consumer surveys are conducted in the future, include resourcing for an audit of health literacy activities across the sector and their targeted audiences to assess collective impact of activities on health literacy changes
- ▷ Identify opportunities to leverage future national health literacy strategies.

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