# NATIONAL CONSUMER SURVEY

**Baseline Report 2020** 

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

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# **EXECUTIVE SUMMARY**

This report presents the findings from the 2020 National Consumer Survey. The survey is crosssectional in design and was conducted online between October and November 2020, with a representative sample of consumers from the Australian population. This was a baseline survey with the primary aims of identifying the perceived health status of consumers and measuring current levels of consumer awareness and understanding of quality use of medicines (QUM) and health literacy as it relates to QUM. The survey will be repeated in 2021 to monitor and assess identified trends.

# Key findings

## Consumer health status

- Consumers generally perceived themselves to be in good health, with over three-quarters of respondents rating their current health status as good to excellent. Health status was similar across genders but tended to decrease with age
- Over one-quarter of respondents had been diagnosed with a chronic health condition and 37% were living with multiple morbidities. The most common conditions were; hypertension, high cholesterol, back pain and depression or anxiety. About 8% of respondents were also living with a disability, and 21% were caring for someone else with a chronic health condition
- Most respondents had taken one or more medicines in the last 3 months, predominantly prescription (65%) and over-the counter medicines (52%). As might be expected, the proportion of respondents taking prescription medicines increased as health status deteriorated.

## Consumer awareness

- Consumer respondents predominantly sourced information about health conditions and medicines from a doctor (GP), followed by internet search engines. Utilising a doctor as a source of information increased consistently with respondent age
- Respondents who identified as Aboriginal and/or Torres Strait Islander were more likely to source information from social media, and respondents who spoke a language other than English at home were more likely to source information from family and friends
- Most respondents were aware they needed to engage with information about their medicines and were especially vigilant in reading information about the dose of the medicine and instructions from the doctor or pharmacist on how to take the medicine correctly
- Respondents were less familiar with and less sure about medical tests than they were about medicines, with a comparatively high proportion not believing that having unnecessary medical tests can be harmful or lead to needless treatment
- About 13% of respondents were aware of Choosing Wisely Australia, which is a 7% increase since 2017. Respondents who were aware of Choosing Wisely Australia were more likely to ask their health practitioners questions than those who were not aware

## Consumer knowledge and skills

- About one-third of respondents reported keeping a list of their medicines and over half asked their doctor or pharmacist questions the last time they received a new medicine
- Over one-third of respondents were not confident that they could find the active ingredient on a medicine packet and over half did not belief that there could be repercussions from not knowing the active ingredient in medicines
- On average, consumer respondents exhibited a medium level of *awareness and understanding of QUM*, with a mean of 3.8 out of 5

- Understanding of QUM was lower among younger age cohorts (16-24 years) who were less likely to take an active role in managing their health and less aware of possible interactions, how to safely store or dispose of medicines or that medicines had risks as well as benefits
- Respondents in poor health were less active in improving their own health and did not feel they had access to enough information to manage their health or medicines
- Aboriginal or Torres Strait Islander respondents were more likely to have to forgo buying medicines they need due to the cost compared with other consumer respondents
- On average, consumer respondents exhibited a medium level of *health literacy as it relates to QUM*, with a mean of 2.5 out of 5
- Having the confidence to ask a doctor or other health practitioner questions, and being comfortable making shared treatment decisions with a doctor increased with age
- Respondents in excellent health and those who speak another language at home more often require help understanding information about medicines and find information provided to them confusing or difficult to understand
- Culturally and linguistically diverse populations appear to be less comfortable participating in shared decision-making with a doctor, and less confident asking a doctor or other health practitioner questions.

#### Consumer self-management

- On average, the level of reported adherence to medicine regimes among respondents was high, with a mean of 4.1 out of 5
- In managing their health, about one-quarter of respondents would try and avoid taking medicines at all if possible
- Respondents in good to excellent health were more likely to avoid medicines, forget to take their medicines or to take more than instructed compared with those in poorer health.

## Key recommendations

- Leverage current changes in active ingredient prescribing and build consumer awareness and health literacy about active ingredients via a two-pronged approach of directly educating consumers and GPs to have discussions with their patients about active ingredients
- Conduct a targeted QUM social media campaign to reach Aboriginal and Torres Strait Islander consumers
- Consider a QUM education program targeted at youth (16-19 years) so they are armed with the knowledge and skills required to manage their own health and medicines into adulthood
- Conduct further research with culturally and linguistically diverse populations to better understand their QUM and health literacy needs, and to inform products and services
- Take a collective approach to planning and conducting regular consumer education campaigns on QUM, in partnership with other organisations (e.g. peak bodies, PHNs), to reinforce QUM messages (e.g. possible interactions, accessing trustworthy information)
- Leverage Choosing Wisely Australia messaging and resources to promote an increase in QUM knowledge and actions (e.g. asking health professionals questions, knowing benefits and risks of medical tests) among a broader consumer audience.

# INTRODUCTION

NPS MedicineWise has developed a consumer engagement plan to ensure that consumer needs and insights are incorporated into Grant programs and activities, in order to improve quality use of medicines (QUM), build consumer health literacy and ultimately improve health outcomes for Australians.

As part of the consumer engagement 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).

In this instance, health literacy is about how people access, understand and use health information as it relates to QUM to engender better health outcomes<sup>1</sup>.

To address these measures, NPS MedicineWise conducted the 2020 National Consumer Survey with a representative sample of Australian consumers. The questionnaire was developed and reviewed in consultation with consumer representatives and reviewed by several peak consumer bodies.

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 served to inform the indicators used in the National Consumer Survey to measure awareness of the key elements of QUM and a baseline level of health literacy as it relates to QUM<sup>2</sup>.

This report outlines the baseline findings from the 2020 National Consumer Survey and identifies the perceived health status of consumer respondents, followed by current trends in awareness, knowledge and skills and self-management in relation to health and medicines. A follow-up survey is scheduled to be conducted in 2021 to identify any changes in trends.

## Survey design

A cross-sectional survey design 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, and 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 questionnaire was developed by the Evaluation team at NPS MedicineWise and consisted of 45 questions, estimated to take about 15 minutes to complete. The questions were informed by key performance indicators that needed to be measured, the CHF research, and advice from the NPS MedicineWise Consumer Advisory Group.

Feedback was also sought and received from key internal managers and external stakeholders, including members of the Consumer Advisory Group, 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.

A period of 3 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.

## Data collection and analysis

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

The survey was conducted online between 26 October and 6 November 2020 and was completed by 2,028 consumers. Data analysis were performed using SPSS statistics version 25.

Frequencies, descriptives (i.e. mean responses) and cross-tabulations of data are presented within the report. For the questions measuring medicine adherence, QUM awareness and health literacy, a mean was calculated across all indicators to identify an average for each individual respondent and a mean rating across all respondents. The few negative statements were recoded for a more accurate calculation of the mean.

The categorisation of high, medium and low has been applied to medicine adherence, health literacy and awareness of quality use of medicines. These categories were defined as:

- 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.

## 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 appropriate or accessible for other seldom heard populations, such as people living with disability, the oldest-old and those in rural and remote communities. Future qualitative research could be considered to capture the valuable insights of these consumer groups.

The use of a small suite of 8 health literacy indicators may not have been as nuanced as a larger measurement tool. However, this suite of indicators was 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 purposes of this survey, the measurement tool needed to be practical and not a burden for respondents to complete, so that consumer response was optimised. 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**

The characteristics of the survey sample were selected to be representative 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. The proportion of respondents achieved for gender, location and Aboriginal and Torres Strait Islander origin matched the Australian population, however the proportion of survey respondents aged 25-74 years was slightly higher and the proportion of 16-24 years slightly lower than the Australian population (Table 1).

Representation was also sought from culturally and linguistically diverse populations. This cohort is more difficult to capture through online surveys, so it is anticipated that follow-up qualitative evaluation will need to be conducted with this audience to fully comprehend their understanding of quality use of medicines and health literacy.

This survey captured 24% of consumers born overseas compared with 29% for the Australian population. For respondents born outside of Australia, country of birth included; New Zealand, United Kingdom, Canada, United States of America, India, Sri Lanka, China, Pakistan, Philippines, Bangladesh, Hong Kong, Korea, Malaysia, Indonesia, Vietnam, Japan, Nepal, Chile, Argentina, France, Italy, Germany, Netherlands, Macedonia, Egypt and South Africa.

This survey captured 12% of respondents who spoke another language at home compared with 22% for the Australian population. Other languages spoken at home included; Bengali, Urdu, Tagalog, Cantonese, Mandarin, Japanese, Vietnamese, Dutch, Spanish, French, Italian, German, Arabic and Afrikaans.

Fewer respondents to this survey lived in metropolitan areas than identified for the Australian population, which suggests a greater diversity in our respondents with higher proportions residing in regional and possibly rural locations. Respondents were also more highly educated than the general population, with higher proportions of consumers having completed TAFE or university qualifications.

	Number of respondents	% of respondents	% Australian population
<b>Gender</b> Male Female Other	970 1,049 9	48% 51.5% 0.5%	49% 51% *
Age category           16-19 years           20-24 years           25-34 years           35-44 years           45-54 years           55-64 years           65-74 years           75-84 years           85+ years	20 73 341 379 376 344 301 146 48	1% 4% 17% 19% 18% 17% 15% 7% 2%	6% 7% 14% 14% 13% 11% 9% 5% 2%
Location ACT NSW NT QLD SA TAS VIC WA	48 653 6 391 153 42 553 178	2% 32% 0.5% 19% 8% 2% 27% 9%	2% 32% 1% 20% 7% 2% 26% 10%

#### Table 1. Demographic profile of survey respondents (n=2,028)

	Number of respondents	% of respondents	% Australian population
Location description			
Metropolitan	1,359	67%	76%
Regional	471	23.5%	*
Rural	185	9%	*
Remote	2	0.5%	*
Aboriginal and/or Torres Strait			
Islander origin			
No	1,951	96%	97%
Yes	77	4%	3%
Country of birth			
Australia	1,545	76%	71%
Other country	483	24%	29%
Language other than English			
No	1,789	88%	78%
Yes	239	12%	22%
Highest level of education			
Never attended school	5	0.4%	0.8%
Some primary school	12	0.6%	*
Completed primary school	25	1%	*
Some high school	203	10%	23%
Completed high school	344	17%	16%
TAFE or Trade certificate/diploma	640	32%	25%
University or other tertiary institute	792	39%	22%
degree, including post-graduate			
Employment status			
Self-employed	155	8%	*
Employed for wages/salary	931	46%	
Unemployed	190	9%	
Unpaid work	35	2%	
Student	64	3%	
Carer on carer pension	44	2%	
Retired	505	25%	
Unable to work	83	4%	

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

## Current status

Most consumer respondents believed that they were in good health, commonly rating their health status as 'excellent' (11%, n=222), 'very good' (31%, n=630), or 'good' (36%, n=737). Less than onequarter (22%, n=439) of respondents rated their health as 'fair' or 'poor'. Health status was similar across genders and geographic location, except for the Northern Territory, which had a higher proportion of respondents in fair health compared to other states and territories.

As shown in Figure 1. the proportion of respondents who rated their health as fair or poor tended to increase with age, with 31% of respondents aged 85+ years perceiving themselves to be in fair or poor health compared with 22% for total respondents. Those aged 20-34 years were the healthiest cohort, with about 87% perceiving themselves to be in excellent or very good health.

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



## Consultations with a doctor

In reflection of their good health status, 30% (n=605) of respondents had not seen a doctor at all in the last 3 months and a further 30% (n=599) had only seen a doctor once. Just over one-quarter of respondents (27%, n=531) had seen a doctor 2-3 times, 6% (n=124) 4-5 times, and 7% of respondents in poorer health had seen a doctor between 6 and 50 times in the last 3 months.

On average, consumer respondents had visited a doctor 1.8 times in the last 3 months. This will be assessed again in late 2021 to see if changes in GP visiting behaviour occurs if the situation with COVID 19 eases.

## Health conditions

About one-third (35%, n=701) of consumer respondents had <u>not</u> been diagnosed with any chronic health condition.

About 28% (n=558) of respondents reported having been diagnosed with one chronic health condition, and 37% (n=769) are living with multiple morbidities of two or more concurrent chronic health conditions.

Figure 2. shows the chronic conditions experienced by respondents. The most common health conditions among respondents were; hypertension, high cholesterol, back pain and depression and/or anxiety.

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



For respondents with a chronic health condition, 19% (252) needed to visit the hospital in the last 3 months because of their condition, with about half of those having to visit the emergency department. A small proportion of respondents (8%, n=156) were also living with a disability and were participants of the National Disability Insurance Scheme.

Just under a quarter (21%, n=430) of respondents identified themselves as being a carer for someone else with a chronic health condition.

# Taking or using medicines

The majority (85%, n= 1,729) of respondents had taken or used a medicine in the last 3 months, while the remaining 15% (299) of respondents had <u>not</u> taken or used any medicines during this time period.

## Number of medicines

For respondents taking or using medicines, just under one-quarter (22%, n=369) were taking one medicine daily and over one-third (36%, n=619) were taking or using 2-3 different medicines daily. About 30% (n=499) of respondents were taking or using 4 or more medicines each day. The number of medicines taken or used daily was associated with health status and age, with respondents in fair or poor health and those aged 55 years and over more likely to be taking 4 or more medicines a day.

## Type of medicines

Respondents were asked to consider three types of medicine in their responses; prescription, over the counter (OTC) and complementary medicines and were provided with a description in the survey. Over one-third of respondents (36%, n=730) reported taking or using only one type of medicine, 30% (n=603) two types of medicines and 19% (n=396) all three types of medicines in the last 3 months.

For those who reported taking or using medicines, most were taking prescription medicines (65%, n=1,310), followed by OTC medicines (52%, n=1,046) and complementary medicines (38%, n=768).

The proportion of respondents taking prescription medicines was similar across genders, however a higher proportion of females reported taking or using OTC medicines (+11%) and complementary medicines (+12%) than males. A higher proportion of respondents who identified as Aboriginal reported taking prescription medicines (+12%) than other respondents.

As might be expected, the proportion of respondents taking prescription medicines increased as health status deteriorated, with 95% of people in poor health taking prescription medicines compared with 54% in excellent health. This same trend was observed for OTC medicines and complementary medicines. As shown in Figure 3. medicines use typically increased with age, particularly in the case of complementary medicines, and prescription medicines until reaching the oldest-old cohort of 85+ years.



#### Figure 3. Proportion of respondents by medicine type and age category

## Having medical tests

Most respondents (61%, n=1,233) had <u>not</u> had a medical test in the last 3 months, with the remaining 39% (n=795) of respondents having had a medical test during this time period.

Of those who had a medical test, 60% (n=471) discussed the benefits and risks of having the test with their doctor. Two-thirds of these consumers (67%, n=511) had the medical test because their doctor (GP) recommended that they have it. Other reasons for having the medical test were; that it was recommended by a specialist (17%, n=126), the consumer asked their doctor if they could have the test (11%, n=83), another healthcare practitioner recommended the test (4%, n=30) or it was recommended by family or friends (1%, n=11). These findings are similar to the 2017 National Consumer Survey<sup>5</sup>.

# CONSUMER AWARENESS 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 3 months. Just under half (42%, n=793) of respondents did not try to find information on health conditions or medicines and 35% (n=664) only tried to find information once a month or less often over the last 3 months.

About one-quarter of respondents tried to find information about health conditions or medicines more often, with 11% (n=204) looking for information several times a month and 12% (n=220), looking once a week to several times a week.

For those respondents who tried to find information on health conditions or medicines, over threequarters (79%, n=867) were trying to find information for themselves. To a lesser degree, respondents also looked for information for their partner (20%), child (14%), parent (9%) or other relative (7%).

Positively, the predominant source of information about health conditions or medicines for consumers appears to be a doctor (GP), although over one-third of respondents also used internet search engines, such as Google, as a source of information (Figure 4).

While 39% (n=798), referred to only one source of information, respondents commonly referred to multiple sources to find information about health conditions or medicines (57%, n=1,158).

#### Figure 4. Proportion of respondents by sources of information about health conditions and medicines



Sources of information about health conditions and medicines was similar across genders, except for internet search, where a higher proportion of females referred to this source of information than males (44% versus 34%). The use of the internet was slightly lower (-6%) for respondents in rural areas.

Utilising a doctor as a source of information increased consistently with respondent age, from 55% in 16-19 years to 94% in 85+ years.

A higher proportion of respondents who identified as Aboriginal and/or Torres Strait Islander used social media as a source of information about health and medicines than respondents who did not, 18% versus 4%. This cohort was also more likely to refer to sources such as magazines and newspapers.

A slightly higher proportion of respondents who spoke a language other than English at home used family and friends as a source of information about health and medicines than those who only spoke English, 17% versus 11%.

## Reading information about medicines

Most consumer respondents reported 'always' engaging with information about their medicines and appear to be especially vigilant in reading information about the dose of the medicine and instructions from the doctor or pharmacist on how to take the medicine correctly (Table 2).

Medicine information with lower engagement from consumers were CMI leaflets, possibly because they relate only to prescription medicines, and the active ingredients in medicines, which may be a red flag for medicines safety and point to an area where further consumer education is needed.

In general, female respondents appear to be more engaged with reading information about medicines than males, and engagement tends to increase with age.

	Always	Often	Sometimes	Rarely	Never
CMI leaflet provided with prescription medicines	29% (592)	22% (439)	26% (525)	14% (282)	9% (190)
Description on the packet of what the medicine is used for	40% (819)	26% (527)	21% (416)	7% (150)	6% (116)
The dose of the medicine	62% (1,268)	16% (333)	13% (268)	4% (80)	4% (79)
Active ingredients in the medicine	23% (460)	20% (409)	28% (564)	18% (375)	11% (220)
Doctor / pharmacist instructions on how to take the medicine correctly	59% (1,192)	19% (377)	14% (288)	4% (88)	4% (83)
How to store the medicine safely	47% (947)	20% (413)	19% (388)	8% (157)	6% (123)
Warnings, contraindications and allergy information	40% (806)	23% (460)	22% (440)	9% (192)	6% (130)
Information on possible side effects	39% (790)	24% (494)	21% (426)	10% (195)	6% (123)

#### Table 2. Proportion and number of respondents by frequency of engagement with medicine information

## 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 or disagree that having medical tests can be harmful or lead to unnecessary treatment (Figure 5).

Further targeted consumer education on the quality use of medical tests and low value care is required to help consumers understand the risks of unnecessary testing.



#### Figure 5. Proportion of respondents by attitudes about medicine tests

## Choosing Wisely Australia messaging

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 were not aware, about 13% (n=269) of respondents were aware of Choosing Wisely Australia before completing the survey and 10% (n=196) were aware of the '5 questions to ask your doctor' resource.

There has been a 7% increase in consumer awareness of Choosing Wisely Australia since the 2017 National Consumer Survey was conducted, and a 2% increase in awareness of the 5 questions resource.<sup>5</sup>

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, suggesting translation of the messaging into action.

About one-quarter of respondents reported 'sometimes' asking their doctor similar questions to the five specified in the Choosing Wisely resource. The questions asked most often by consumer respondents were about the risks of taking medicines or having medical tests or procedures, and the costs involved (Table 3).

Table 3. Proportion and number o	f respondents by how o	often they asked their o	doctor the five questions
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	Always	Often	Sometimes	Rarely	Never
Do I really need this medicine, test or procedure?	17% (342)	17% (340)	30% (608)	18% (366)	15% (300)
What are the risks?	22% (444)	24% (489)	27% (555)	14% (282)	10% (195)
Are there any simpler or safer options?	16% (332)	19% (384)	29% (586)	19% (390)	13% (268)
What happens if I don't do anything?	19% (385)	21% (417)	29% (581)	14% (291)	13% (259)
What are the costs?	22% (437)	19% (392)	22% (442)	17% (352)	15% (313)

About 3% answered 'Not applicable' to this question.

## Awareness of NPS MedicineWise

The survey asked consumers whether they were aware of NPS MedicineWise as an organisation who provides information and advice about health conditions and the quality use of medicines and medical tests. The majority (88%, n=1,788) of respondents were not aware of NPS MedicineWise before completing the survey, and 12% (n=240) of respondents were aware.

These 240 respondents had heard about NPS MedicineWise; from a health professional such as a doctor, pharmacist or nurse (77%), an internet search (43%), NPS MedicineWise website and social media (12%) or at a community event (8%).

Two-thirds (66%, n=152) of respondents who were aware of NPS MedicineWise rated the trustworthiness of the organisation as 'very good or good'.

A small proportion of respondents indicated being aware of NPS MedicineWise resources, including;

- Medicines List (12%, n=238)
- NPS MedicineWise website (11%, n=228)
- Medicines Line telephone advisory service (11%, n=228)
- Consumer factsheets and other resources (11%, n=221)
- Website for Choosing Wisely Australia (10%, n=196)
- MedicineWise app (9%, n=182).

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.

# CONSUMER KNOWLEDGE & SKILLS RELATED TO HEALTH & MEDICINES

## **Recording medicines**

Almost one-third (30%, n=515) of respondents who are 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. Respondents commonly keep a list to have a record of their medicines, particularly in-case they need to share the list of medicines with a doctor or in the event of an emergency hospital visit.

Respondents were more likely to keep a medicines list if they were taking 2 or more medicines and were taking a prescription medicine (89%) versus OTC (57%) or complementary medicines (46%).

## Asking questions

The last time they received a new medicine, over half of the respondents (56%, 1,025) asked their doctor or pharmacist questions about the medicine. Respondents were more inclined to ask their doctor questions rather than a pharmacist.

For the 44% (n=801) of respondents who did not ask any questions, in about one-third of cases, the doctor or pharmacist dispensing the new medicine discussed the medicine with the consumer and gave them information unprompted.

About one-third (34%, n=700) of respondents 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. Figure 6. below shows the main barriers to asking questions, with the top two being; they trust the doctor to do what is best for them (34%), and that they couldn't think of any questions to ask at the time of the visit (28%).

#### Figure 6. Barriers to asking a doctor questions

Trust the doctor to	Couldn't think of	Familiar with
do what is best	any questions to ask	medicines & medical
(34%)	at the time (28%)	tests (23%)
Appointment to	Don't want to take	Don't feel confident
short to ask	up the doctor's time	asking questions
questions (21%)	(15%)	(12%)
The doctor doesn't welcome questions (10%)	Completed own research (9%)	Prefer a carer / family member to ask the questions (2%)

# Understanding quality use of medicines (QUM)

## Active ingredients

Consumer knowledge of the active ingredients within the medicines they are taking or using is essential for medicines safety in order to prevent allergic reactions or interactions with other medicines or substances (e.g. food or drink), and the risk of overdosing by taking or using more than one medicine at the same time with the same active ingredient (e.g. pain medicine plus cough syrup containing paracetamol).

The survey findings suggest that active ingredient is a quality use of medicines area where consumers require further exposure to education and accurate messaging from sources they trust. Almost threequarters of respondents understood that the active ingredient is what makes a medicine work, however higher proportions of respondents were unsure (neutral) or disagreed that they could confidently find the active ingredient on a medicine packet or that they could accidently take different medicines with the same active ingredient (Figure 7).

#### Figure 7. Proportion of respondents by knowledge of active ingredients



same active ingredient

## Elements of QUM

In order to understand the baseline level of consumer awareness and understanding of varying aspects of QUM, respondents were presented with 15 statements (shown in Table 4) and asked to indicate their level of agreement or disagreement with each. Eleven of the statements are positive QUM statements, where a response of 'strongly agree or agree' would be anticipated by consumers who have a good understanding of QUM, and 4 of the statements are negative QUM statements, where a response or disagree or disagree' would be anticipated.

These statements, reflecting an understanding of QUM, were identified from the CHF literature review and segmentation research and agreed in consultation with consumer representatives.

Most respondents understood why they were taking medicines, how to safely store medicines and that some medicines could be addictive. Three-quarters of respondents had a regular trusted doctor and knew that medicines had benefits and risks. Fewer respondents were aware of possible interactions between medicines and other substances or understood that medicines shouldn't be used beyond their expiry date for reasons of safety and efficacy. Consumer respondents were also less certain about accessing enough trustworthy information to be able to manage their own health and medicines.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Mean
I am aware that some medicines can be addictive	1% (21)	2% (37)	14% (283)	46% (943)	37% (744)	4.16
I understand why I am taking or using each of my medicines	1% (14)	2% (44)	14% (292)	49% (998)	36% (680)	4.13
I know how to store my medicines safely	1% (27)	3% (51)	15% (310)	50% (1,021)	31% (619)	4.06
I have a regular doctor that I trust	3% (53)	7% (137)	16% (334)	40% (816)	34% (688)	3.96
The medicines I take or use can have benefits and risks	1% (19)	3% (58)	21% (429)	52% (1,050)	23% (472)	3.94
I take an active role in improving my own health	2% (34)	3% (68)	21% (423)	52% (1,048)	22% (455)	3.90
I know how to dispose of my medicines safely when I don't need them anymore	3% (53)	7% (144)	20% (412)	42% (856)	28% (563)	3.85
When I start taking a medicine, I make sure I understand how it might interact with other medicines, or things I eat or drink	2% (30)	6% (125)	23% (467)	46% (943)	23% (463)	3.83
I have access to enough information to manage my own medicines	2% (42)	6% (127)	22% (448)	48% (962)	22% (449)	3.81
I have access to enough information to manage my own health	2% (37)	6% (128)	22% (452)	49% (998)	21% (413)	3.80
I have a regular pharmacist that I trust	4% (92)	12% (249)	26% (523)	35% (701)	23% (463)	3.59
I'm not worried about side effects of medicines my doctor tells me to take*	8% (158)	22% (454)	33% (673)	28% (557)	9% (187)	3.08
I think medicines can be taken or used even when they have passed their expiry date*	25% (518)	23% (553)	27% (553)	19% (380)	6% (115)	2.56
Sometimes I don't buy medicines when I need them because of the cost*	31% (616)	26% (533)	19% (379)	17% (352)	7% (148)	2.45
I sometimes take medicines that were prescribed for someone else*	53% (1,075)	17% (339)	13% (265)	13% (260)	4% (89)	1.99

#### Table 4. Proportion and number of respondents by level of agreement with positive QUM statements

\*Preferred responses to these statements are reversed

## Average QUM awareness level of consumer respondents

On average, consumer respondents exhibited a medium level of awareness and understanding of QUM, with a mean of 3.8 out of 5. The mean for individual respondents across the 15 QUM variables was used to categorise respondents into low, medium and high levels of QUM awareness. Overall a small proportion of respondents exhibited low awareness of QUM, with the majority exhibiting a medium level and over one-third, high QUM awareness (Figure 8). As this is a new measure, findings will be compared with the follow-up 2021 consumer survey findings.

The 'low' awareness category comprised significantly higher proportions of respondents; aged 16-24 years, with little education, residing in the ACT and NT and of Aboriginal or Torres Strait Islander origin. The 'high' awareness category comprised significantly higher proportions of respondents; aged 55 years and over, those with a poor health status and who speak English only.



#### Figure 8. Proportion of respondents by levels of QUM awareness

## Key differences in understanding of QUM by consumer demographics

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

- Understanding of QUM elements increased with age, with a higher proportion of the 16-24 year age cohort not taking an active role in managing their health and being unaware of how to safely store or dispose of medicines, that some medicines could be addictive or have interactions, or that medicines had risks as well as benefits. This age cohort was also less certain of how to access information about health or medicines.
- Higher proportions of respondents in poor health were less active in improving their own health and did not feel they had access to enough information to manage their medicines or general health compared with respondents in good or excellent health
- Higher proportions of respondents in excellent health, perhaps due to having less experience with medicines, believed that medicines were okay to use after the expiry date had passed and reported taking medicines prescribed for someone else.
- Higher proportions of respondents who spoke another language at home (other than English) or who identified as Aboriginal or Torres Strait Islander also believed that medicines were safe to take or use after expiry and had taken or used medicines that had been prescribed for someone else.
- A higher proportion of respondents who identified as Aboriginal or Torres Strait Islander reported sometimes being unable to buy medicines that they need due to the cost compared with other consumer respondents. On a more positive note, Aboriginal and Torres Strait Islander respondents were more likely to have a regular pharmacist that they trust to help them with their medicines.

## Health literacy in relation to QUM

To understand the baseline level of consumer health literacy, related to QUM, respondents were presented with 8 indicators (Table 5) and asked how frequently they performed the specified actions or felt a particular way when visiting a doctor, health clinic or pharmacy. These 8 indicators were informed by the CHF literature review and segmentation research.

Positively, almost half of consumer respondents 'always' feel confident asking their doctor or other health practitioner questions when they need more information about a health issue, 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 frequently needed help to understand information provided to them on a health issue, medicine or medical test, and found information provided by doctors or other health practitioners confusing or difficult to understand.

	Always	Often	Sometimes	Rarely	Never	Mean
Feel confident asking a doctor or other health practitioner questions when you need more information	46% (933)	28% (566)	20% (401)	5% (97)	1% (31)	1.88
Feel comfortable deciding with your doctor which treatment is best for you	42% (850)	31% (629)	19% (396)	6% (113)	2% (40)	1.95
Feel comfortable taking whatever medicine or other treatment your doctor prescribes for you*	35% (721)	36% (737)	22% (448)	5% (92)	2% (30)	2.00
Feel comfortable asking a trusted health practitioner to help you understand information about your medicines	34% (690)	30% (604)	26% (517)	8% (172)	2% (45)	2.15
Tell your doctor or other health practitioner about OTC or complementary medicines you are taking	35% (718)	26% (529)	25% (505)	10% (197)	4% (79)	2.21
Look for information about health conditions, medicines or tests to prepare for the visit	18% (378)	25% (500)	33% (664)	17% (346)	7% (140)	2.69
Find information given by a doctor or other health practitioner confusing or hard to understand*	11% (232)	16% (324)	30% (608)	33% (674)	10% (190)	3.13
Need someone you know to help you understand the information you've been given about medicines*	9% (176)	14% (297)	21% (423)	26% (525)	30% (607)	3.54

#### Table 5. Proportion and number of respondents by response to health literacy indicators

\*Preferred responses to these statements are reversed.

## Average health literacy level of consumer respondents

On average, consumer respondents exhibited a medium level of health literacy as it relates to QUM, with a mean of 2.5 out of 5. The mean for individual respondents across the 8 health literacy indicators was used to categorise respondents into low, medium and high levels of health literacy. Overall, most respondents exhibited a medium level of health literacy, with smaller proportions exhibiting high or low health literacy as it relates to QUM (Figure 9).

The 'low' health literacy category comprised significantly higher proportions of respondents; aged 16-24 years, with a primary school education only, and of Aboriginal or Torres Strait Islander origin. The 'high' health literacy category comprised significantly higher proportions of respondents; aged 55 years and over, female, those with a higher educational attainment and who speak English only.



Figure 9. 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:

- Possessing the confidence to ask a doctor or other health practitioner questions when more information is required consistently increases with age, as does feeling comfortable making shared decisions with a doctor about treatment (i.e. from 40% in 16-19 years to 89% in 85+ years).
- Respondents in excellent health more often require help understanding information about medicines and frequently find information provided to them confusing or hard to understand compared with respondents in poorer health, likely because those in poorer health have more experience with medicines and the health system.
- Respondents who speak another language at home (other than English) 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. This culturally and linguistically diverse audience are also less comfortable participating in shared decision-making with a doctor about possible treatments for their health conditions, and less confident asking a doctor or other health practitioner questions.
- 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 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. This is particularly true for the oldest-old cohort of 85+ years.

## Adherence to medicine regimes

Consumer respondents predominantly reported adhering to medicine regimes, most often following the instructions given in terms of frequency and dose, although almost of one-quarter of respondents would try and avoid taking medicines at all if possible (Table 6).

Higher proportions of respondents aged 55 years and over 'never' avoid taking medicines, decide to miss out a dose or take more than instructed compared with younger age cohorts.

As might be expected, respondents in good to excellent health were more likely to avoid medicines where possible compared with those in poorer health. These respondents were also more inclined to forget to take their medicines or to take more than instructed compared with those in poorer health with arguably more experience in taking and using medicines, and for whom adherence to a medicine regime is of greater necessity.

		Always	Often	Sometimes	Rarely	Never
a.	I avoid using medicine if I can	23% (469)	22% (437)	25% (515)	12% (250)	18% (357)
b.	I decide to miss out a dose	3% (69)	7% (146)	18% (356)	28% (567)	44% (890)
C.	I take less than instructed	4% (74)	6% (112)	16% (331)	21% (428)	53% (1,083)
d.	I forget to take my medicines	3% (67)	7% (138)	23% (464)	35% (713)	32% (646)
e.	I might take more than instructed	3% (62)	5% (92)	10% (208)	15% (302)	67% (1,364)

#### Table 6. Proportion and number of respondents by medicine adherence

#### Average adherence level of consumer respondents

On average, the level of reported adherence to medicine regimes among consumer respondents was high, with a mean of 4.1 out of 5. The mean for individual respondents across the 4 adherence variables (statements b-e) was used to categorise respondents into the adherence categories of low, medium and high. Respondents predominantly exhibited high adherence to medicine regimes, followed by medium adherence, with only a comparatively small proportion exhibiting low adherence to medicine regimes (Figure 10).

This level of adherence appears to be quite high. However, while there may be some bias inherent in self-reporting of adherence, other consumer studies have found levels of adherence to be in the realm of around 60%.<sup>6,7</sup>

#### Figure 10. Proportion of respondents by levels of adherence to medicine regimes



# CONCLUSION

The baseline National Consumer Survey was conducted with over 2,000 consumers who were representative of the Australian population in terms of gender, location, age and Aboriginal and Torres Strait Islander origin. Survey respondents were not quite as diverse as anticipated in terms of culturally and linguistically diverse populations.

Consumers generally perceived themselves to be in good health, with over three-quarters of respondents rating their current health status as good to excellent. Health status was similar across genders but tended to decrease with age. Over one-quarter of respondents had been diagnosed with a chronic health condition and a further one-third were living with multiple morbidities. The most common conditions were; hypertension, high cholesterol, back pain and depression or anxiety. A small proportion of respondents were also participants in the National Disability Insurance Scheme, and just shy of one-quarter of respondents were caring for someone else with a chronic health condition.

Most respondents had taken one or more medicines in the last 3 months, predominantly prescription and over-the counter medicines. As might be expected, the proportion of respondents taking prescription medicines generally increased with age and as health status deteriorated. In contrast, only a small proportion of respondents reported having a medical test in the last 3 months.

On average, consumer respondents exhibited a medium level of awareness and understanding of QUM. Most respondents understood why they were taking medicines, how to safely store medicines and that some medicines could be addictive. Three-quarters of respondents had a regular trusted doctor and knew that medicines had benefits and risks. Fewer respondents were aware of active ingredients, possible interactions between medicines and other substances or understood that medicines shouldn't be used beyond their expiry date for reasons of safety and efficacy. Consumer respondents were also less certain about accessing enough trustworthy information to be able to manage their own health and medicines.

On average, consumer respondents exhibited a medium level of health literacy related to QUM. Positively, almost half of consumer respondents 'always' feel confident asking their doctor or other health practitioner questions when they need more information and feel comfortable making shared treatment decisions with their doctor. About one-quarter of consumer respondents frequently needed help to understand information provided to them and found information provided by doctors or other health practitioners confusing or difficult to understand. Respondents were commonly highly educated, Australian born and spoke English only, 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 CALD backgrounds.<sup>1</sup>

The findings suggest that consumer respondents who are taking or using medicines are highly adherent to their medicine regimes and are commonly monitoring their health and responsibly managing their medicines. Consumers are also making informed decisions to avoid medicines where possible if other effective alternatives are available.

## Gaps in understanding of QUM

Findings suggest that the 'active ingredient' in a medicine is an area where consumers require further exposure to education and accurate messaging from sources they trust, such as a regular doctor. Consumers were not overly confident about being able to recognise the active ingredient on their medicine packet and appeared to be unaware of the risks of not knowing the active ingredient in medicines they are taking or using.

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, and were often unaware of possible interactions with other medicines, including complementary medicine, foods or drink.

The findings suggest that younger consumers (i.e. 16-24 years), although they may be taking fewer medicines, are at greater risk of medicines misuse or an adverse event due to their lack of QUM knowledge and self-efficacy in managing their health and medicines.

Having the self-efficacy to know where or how to access relevant, accurate information to manage health and medicines also appears to be a QUM gap for some consumers, which may be exacerbated by the growth of telehealth and health and medicine related information moving online.

## Gaps in health literacy related to QUM

Almost three-quarters of respondents indicated that they would take or do whatever treatment was prescribed for them by a doctor. This may be indicative of a potential gap in skills that contributes to health literacy, which is feeling empowered enough to question an authority figure on the prescribing of a medicine, other treatment, or referral for a test. Helping consumers to understand that they 'have permission' to question whether a prescribed treatment is best for them is essential within consumer focussed campaigns and interventions to building health literacy skills.

Over 40% of consumer respondents aren't frequently talking to their doctor or other health practitioners about OTC or complementary medicines they are taking or using alongside their prescription medicines. It is unknown whether this is due to a lack of awareness of the potential consequences of interactions between the types of medicines, or if respondents are concerned about telling their doctor they are taking or using other types of medicines that may be deemed ineffective or lacking in evidence.

Consumers who spoke another language other than English at home required more assistance to understand health and medicine related information. Developing a targeted strategy for disseminating consumer friendly and in-language information about common medicines may assist this consumer group to better understand health and medicine related information without relying so heavily on the assistance of others, and in doing so expand their health literacy.

Young people aged 16-24 years commonly exhibited lower health literacy related to QUM. Perhaps providing education for youth on QUM, focussing information around key life events such as leaving home, making and attending medical appointments and taking medicines, could establish a foundation for building confidence, knowledge and skills early and enable young people to manage their health and medicines more effectively throughout their adult life.

#### Self-management

As self-management of health conditions and medicines is a skill built upon awareness, attitudes and knowledge, this was not covered to a great extent in the baseline National Consumer Survey, where the main aims were to measure awareness of QUM and levels of health literacy. Measurement of self-management and action-oriented behaviour is a next step that may involve use of the Patient Activation Measures (PAM) tool to gain a greater understanding of this element within a nationally representative consumer sample.

## Recommendations

The following recommendations have been made based on the survey findings:

 Further targeted consumer education is needed on the quality use of medical tests to help consumers understand the risks of unnecessary testing (e.g. via Choosing Wisely Australia messaging)

- Leverage current changes in active ingredient prescribing and build consumer awareness and health literacy about active ingredients via a two-pronged approach of directly educating consumers and educating GPs to have discussions with their patients about active ingredients to address this identified gap in knowledge and skills
- Consider a QUM education program targeted at youth (16-19 years) so that they are armed with the knowledge and skills required to manage their own health and medicines into adulthood
- Conduct further research with culturally and linguistically diverse populations to better understand their QUM and health literacy needs, and inform NPS MedicineWise products and services
- Develop a targeted education strategy for delivering consumer-friendly in-language QUM resources to culturally and linguistically diverse audiences
- Take a collective approach to planning and conducting regular consumer education campaigns on QUM, in partnership with other organisations (e.g. peak bodies, PHNs), to reinforce QUM messages (e.g. safe use of medicines, possible interactions, accessing trustworthy information) and promote translation into knowledge and skills
- Conduct a targeted QUM social media campaign to reach Aboriginal and Torres Strait Islander consumers
- Educate healthy consumers about medicines and medical tests to build their level of awareness and literacy before they may require medical intervention, as healthy consumers exhibited a lower level of understanding of QUM and were less inclined to adhere to medicine regimes than consumers in poorer health
- Leverage Choosing Wisely Australia messaging and resources to promote an increase in favourable health literacy actions (e.g. asking health professionals questions) among a broader consumer audience.

## Next steps

- Disseminate key findings from this report to relevant partners and stakeholders, including NPS MedicineWise operational staff and advisory groups
- Consideration of the findings in the design of consumer campaigns, products, interventions and engagement opportunities, including how to leverage current changes to active ingredient prescribing
- Use or adaption of the health literacy indicators to measure topic specific consumer health literacy within NPS MedicineWise educational programs
- Plan and conduct qualitative evaluation with consumer populations that were underrepresented in the national consumer survey, for example, culturally and linguistically diverse populations, to gain a more complete picture of QUM awareness, health literacy and concerns of this audience in relation to health and medicines
- Consider undertaking a Patient Activation Measures (PAM) survey, disseminated to the same representative consumer sample to identify how consumers translate awareness, knowledge and health literacy into action and self-management
- Conduct a follow-up National Consumer Survey in 2021 to monitor trends in relation to consumer awareness and knowledge of QUM and identify any changes in levels of health literacy over time.

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