

Report

Health Literacy and Quality Use of Medicines in Australia: A Rapid Review of the Literature

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## Acknowledgement

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

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CHF were engaged and funded by NPS MedicineWise as the lead agency to plan and implement a project, Consumer Segmentation and Activation Research.

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

## **Executive Summary**

This rapid literature review was commissioned by Consumers Health Forum of Australia (CHF) as one element of a larger Consumer Segmentation and Activation Research Project, which in turn was commissioned by NPS MedicineWise as part of the Department of Health's Quality Use of Medicines Grant. The review set out to answer the following questions:

- What is known about levels of health literacy and quality use of medicines (QUM) in Australia?
- Which population segments in Australia are most at risk of poor health literacy and sub-optimal medicines use?
- What key tools and resources, including indicators, are available for measurement of health literacy and QUM in Australia?
- What key initiatives are in place for promoting health literacy and QUM in Australia?
- Where are the unmet needs in terms of improving health literacy and QUM?

This report represents the findings of an investigation of both academic and "grey" literature, relevant to these questions.

This review was conducted over a four-week period during May 2020. The limited timeframe required the review to utilise a narrow focus. Generic health literacy and QUM measures and initiatives were included in this review. Disease specific measures and initiatives were excluded. The timeframe was also limited to academic articles published from 2015, although we cast a wider net for the grey literature. It is probably that many of the advances in health literacy initiatives focus on particular population segments or diseases. This is an evidence base that may be tapped into when time and resources allow such an investigation.

The review identified that in 2006 levels of general health literacy in Australia were low, with only 40% of Australians having at least an adequate level of health literacy. The National Health Survey: Health Literacy, 2018, which used a different measure to examine health literacy levels, showed that one-third of Australians (33 per cent) found it always easy to discuss health concerns and actively engage with their healthcare providers; 56 per cent found this usually easy; while 12 per cent found it difficult (Australian Bureau of Statistics 2019).

Population measures of medication literacy and QUM are limited; but if the high level of avoidable hospital admissions for medication-related issues is seen as a partial proxy measure, there is significant room for improvement.

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

Several well-utilised generic health literacy measures were identified, but the review found few tools and resources for measuring medication literacy described in the international

literature, other than the Recognition and Addressing of Limited Pharmaceutical Literacy (RALPH) interview guide.

The Australian Commission on Safety and Quality in Health Care (the Commission) has taken a national leadership role in improving health literacy; and a number of initiatives across Australia were identified that seek to embed health literacy into systems, ensure effective communication, and/or integrate health literacy into consumer and health provider education.

The review identified a large number of initiatives to promote consumer medication literacy and QUM in Australia. These included both population-wide initiatives, and initiatives focusing on specific population segments. These were categorised as system level initiatives, initiatives targeting health professionals, and consumer-focused initiatives. An analysis of these initiatives came to the following conclusions:

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

Based on these findings, the review identified the following gaps, which may be seen as opportunities for the future:

- Developing a strategic, co-ordinated approach to addressing health literacy, medication literacy, and QUM, across the three action areas recommended by ACSQHC: embedding health literacy into systems; ensuring effective communication; and integrating health literacy into education for both consumers and healthcare providers.
- Developing a strategic, co-ordinated approach to identifying and addressing the health literacy, medication literacy and QUM needs of higher-risk population segments.
- Utilising a consumer-centred approach and consumer co-design in the development and implementation of future initiatives.
- Ensuring that initiatives include measures to promote consumer awareness of and access to the relevant programs, tools, and resources, including consumers from higher-risk population segments.
- Ensuring that routine data collection is built into future initiatives, including data on uptake and outcomes of interventions, to support the ongoing evaluation and improvement of interventions that seek to improve consumer health literacy, medication literacy, and QUM in Australia.

There may also be an opportunity to develop a national clearing house on health literacy and QUM initiatives, including relevant information, resources, tools, and research and evaluation findings.

## **Background**

#### Context for this review

This rapid review was commissioned by Consumers Health Forum of Australia (CHF) as one element of a larger Consumer Segmentation and Activation Research Project, which in turn was commissioned by NPS MedicineWise as part of the Department of Health's Quality Use of Medicine grant program.

The National Medicines Policy (NMP) was launched in December 1999 as a cooperative endeavour to bring about better health outcomes for all Australians, focusing especially on people's access to, and wise use of, medicines. In 2020, a review of the NMP will be undertaken. A central principle of the NMP is keeping consumers at the centre. To support an understanding of community needs, CHF has been engaged and funded by NPS MedicineWise, as part of the Commonwealth Department of Health's Quality Use of Medicine grant program, as lead agency to plan and implement the Consumer Segmentation and Activation Research Project. This project will: review information and evidence of what is currently known; audit any currently available health literacy resources related to Quality Use of Medicines (QUM); establish the priorities and needs of grass roots consumers; identify any unmet resource/ program needs; and identify and characterise consumer segments.

To achieve this, CHF is undertaking the following activities:

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

This report represents the outcome of the first of these activities.

CHF defined the scope of the rapid literature review as: exploring existing evidence of what is currently known about health literacy of Australian consumers, specifically as it relates to QUM; exploring existing tools and resources for measuring health literacy and QUM; and auditing the current health literacy resources that relate to QUM and identifying unmet needs.

#### **Method**

#### Study questions

This rapid literature review was undertaken over a four-week period in May 2020. It set out to answer the following questions:

- What is known about levels of health literacy and QUM in Australia?
- Which population segments in Australia are most at risk of poor health literacy and sub-optimal medicines use?
- What key tools and resources, including indicators, are available for measurement of health literacy and QUM in Australia?
- What key initiatives are in place for promoting health literacy and QUM in Australia?
- Where are the unmet needs in terms of improving health literacy and QUM?

#### Study selection

There is no standard and agreed approach to conducting a rapid literature review. Our approach was to limit the number of academic databases and websites we searched, and to limit the time period of interest. We focussed mainly on literature in Australia, although many of the measures, tools and resources are from the US.

Searches were conducted in one academic database (Medline). The search was limited to articles published in English from 2015 onwards. The term QUM is not a MeSH subject heading, so we used the indexed terms pharmacy and medication adherence as proxy terms. The Medline search strategy for the search included:

- 1. Health literacy
- 2. Medication adherence
- 3. Pharmacy
- 4. Combine 2 or 3
- 5. Combine 1 AND 4
- 6. Limit to English and from 2015

The grey literature was sourced from the following websites:

- The Health Literacy Tool Shed
- Australian Commission on Safety and Quality in Health Care
- Australian Indigenous HealthInfoNet
- the Agency for Healthcare Research and Quality
- NPS MedicineWise
- Consumers Health Forum of Australia
- National Aboriginal Community Controlled Health Organisation
- Pharmacy Guild of Australia
- Australian Government Department of Health (including Therapeutic Goods Administration)
- Australian State and Territory Departments of Health.

Additional publications were identified through an iterative approach. CHF provided a list of publications that were included as part of their formative research for the larger project of which this literature review is a part. While the academic literature search was restricted to articles published from 2015, we took a more liberal approach to the grey literature and included resources and tools that were developed and used any time in the 2000s that were relevant to our review questions. This was because the majority of the websites are Australian, and we were asked to focus on resources and tools available in Australia.

Inclusion criteria were developed based on the aims and scope of the review. The review was restricted to work published from 2015 onwards, from an OECD country, which either described barriers or enablers to the QUM for population groups, or included examples of tools, resources and measures for QUM and health literacy.

Overall, the review utilises a total of 110 references including 9 peer reviewed articles from the academic literature search and 69 articles identified through other sources, including peer-reviewed journals, as well as journals of professional associations and special interest groups; as well as 32 reports and additional resources such as websites. A more detailed description of the academic literature search and results can be found in **Appendix A.** 

#### Data synthesis and analysis

These papers and resources were synthesised and analysed using a narrative approach. Emphasis was placed on providing practical information on ways to measure the QUM and health literacy and on tools and resources that may assist in improving the QUM and health literacy in Australia. The gaps in the literature were discussed and agreed by the authors and used to form the final section of this report which focuses on the unmet needs in terms of measuring, understanding and improving health literacy and QUM in Australia.

#### **Definitions**

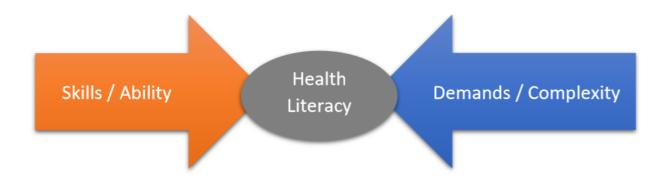
#### Health literacy

Sorensen and colleagues conducted a systematic literature review to identify definitions and conceptual frameworks of health literacy. Seventeen definitions and 12 conceptual models were discovered (Sorensen K et al. 2012). Sorensen and colleagues synthesised the elements of existing definitions to develop the following all-encompassing definition that we are using for the purposes of this review.

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.

Parker and Ratzan (2010) proposed a health literacy framework that makes explicit the extent to which health literacy is mediated by the situational demands and complexities that are placed on people (Parker R and Ratzan SC 2010).

Figure 1: Dual nature of the determinants of health literacy



Health literacy can be understood as the combination of personal skills and the environmental demands that are placed on individuals. Therefore, intervention efforts can be directed towards improving individuals' skills and capacities through educational intervention,

and also reducing the impact of situational demands and complexities by simplifying communication and reducing organisational complexities.

Personal health literacy skills have been categorised as functional, interactive and critical health literacy (Nutbeam 2009). Functional health literacy are the most basic skills that are sufficient for consumers to listen to and apply health information to a range of circumstances such as medications adherence. Interactive health literacy describes more advanced literacy skills that enable consumers to access health information from different forms of communication. Consumers with interactive health literacy skills are able respond to health communication and education that is more interactive, such as mobile apps. Critical health literacy describes the most advanced literacy skills that can be applied to critically analyse information from a wide range of sources. Consumers with these skills can obtain and use information to make decisions about life events and situations that have an impact on health (Nutbeam 2009).

At each level of health literacy, consumers respond to health information in a dynamic and subject manner. It is dangerous for health professionals to assume that once health information is provided to consumers that it was received as intended. Consumers may not have understood what was communicated, or they may interpret what was communicated in different ways.

#### Quality Use of Medicines (QUM)

This review adopts the definition outlined in Australia's National Strategy on Quality Use of Medicines (NSQUM) (Commonwealth of Australia 2002), which defines QUM as:

- Selecting management options wisely by:
  - considering the place of medicines in treating illness and maintaining health, and
  - recognising that there may be better ways than medicine to manage many disorders.
- Choosing suitable medicines if a medicine is considered necessary so that the best available option is selected by taking into account:
  - the individual
  - the clinical condition
  - risks and benefits
  - dosage and length of treatment
  - any co-existing conditions
  - other therapies
  - monitoring considerations
  - costs for the individual, the community and the health system as a whole.
- Using medicines safely and effectively to get the best possible results by:
  - monitoring outcomes,
  - · minimising misuse, over-use and under-use, and
  - improving people's ability to solve problems related to medication, such as negative effects or managing multiple medications.

This definition of QUM applies equally to decisions about medication use by individuals and decisions that affect the health of the population.

The term 'medicine' includes prescription, non-prescription and complementary medicines.

#### Medication literacy

Medication literacy is used here as an equivalent term to pharmaceutical literacy or QUM health literacy, and is defined as follows:

"Medication literacy is the degree to which individuals can obtain, comprehend, communicate, calculate and process patient-specific information about their medications to make informed medication and health decisions in order to safely and effectively use their medications, regardless of the mode by which the content is delivered (e.g. written, oral and visual)." (Pouliot et al. 2018)

#### Medication adherence

Medication adherence is defined as the extent to which patients are able to follow recommendations for prescribed medications. Low health literacy, low reading ability, financial issues, patient transport issues, and lack of social support, can lead to medication nonadherence (Yeung et al. 2017). Medication nonadherence can be unintentional, intentional, or both (Usherwood T 2017). While there is a relationship between medication literacy and medication adherence, they are not interchangeable terms.

#### Patient activation

The detailed examination of patient activation in relation to medication literacy is out of scope for this review but is relevant to the broader CHF project. Patient activation has been defined as: "the knowledge, skills and confidence a person has in managing their own health and health care". Patient activation scores have been robustly demonstrated to predict a number of health behaviours. They are closely linked to clinical outcomes, the costs of health care and patients' ratings of their experience. Highly activated patients are more likely to adopt healthy behaviour, to have better clinical outcomes and lower rates of hospitalisation, and to report higher levels of satisfaction with services. People who have low levels of activation are less likely to play an active role in staying healthy. They are less good at seeking help when they need it, at following a doctor's advice and at managing their health when they are no longer being treated. Their lack of confidence and their experience of failing to manage their health often means that they prefer not to think about it (Hibbard J and Gilburt H 2014).

## The relationships between health literacy, medication literacy, and patient activation

If we apply Nutbeam's levels of health literacy – functional, interactive and critical – to the definition of medication literacy provided by Puoliot, it suggests that the concept of medication literacy emphasises the functional aspects of literacy, following instructions and advice. The last sentence of the definition states that 'content is delivered' rather than accessed, sought, appraised, or assessed. This places individuals in the position of receiving information rather than proactively seeking, reflecting and interacting with information and advice. Further work is required to expand the concept of medication literacy to adequately consider the interactive and critical literacy skills required to appraise and

choose between different sources of information and make decisions about the risks and benefits of medicines.

We also note that while Puoliot's definition does include reference to individuals making informed decisions about their medication use, it does not refer to the concept of shared decision-making between consumers and health professionals. The literature on shared decision making is relevant here (Muscat et al. 2017; Muscat DM 2019) and would provide an important addition to expanding the concept of medication literacy.

In addition to expanding the concept of medication literacy to explicitly consider the role of interactive and critical literacy in order to make informed medication decisions, there is also the opportunity to consider how the literature on shared decision-making might enhance the definition and understanding of medication literacy. However, it is beyond the scope of this review to do so here.

In short, there is a positive association between general health literacy and medication literacy, but the literature indicates a moderate rather than a complete correlation (Koster et al. 2018).

Despite the introduction of the term medication literacy to the academic literature, there is a strong evidence base that examines the relationship between health literacy and the QUM. This evidence base includes the impact of low health literacy on understanding medication information and adherence to medication regimes.

This evidence indicates that consumers with low functional health literacy are likely to have more difficulty understanding medication information including labels, instructions, and written and verbal information. They are 10 to 18 times less likely to correctly identify their medication, in comparison to those who have adequate health literacy (Wali et al. 2016; Wali and Grindrod 2016). Low health literacy has been recognised by the World Health Organisation (WHO) as the primary patient-related factor contributing to medication nonadherence (World Health Organization 2003).

Consistently across the literature, better functional health literacy has been found to be associated with improved knowledge about medications, including correct dosage and frequency of use, medication names, medication purpose and side-effects, and reduced errors involving understanding of medication, including improved understanding of label instructions (Ostini R et al. 2019). Differences in interactive health literacy status also influence whether consumers will question pharmacists about prescriptions and medications. People with higher levels of interactive health literacy are more likely to ask questions, while people with limited health literacy are more likely to indicate that they understand pharmacists' instructions and advice, even when this is not the case.

Despite the demonstrated relationship between health literacy and medication knowledge, health literacy is not consistently found to be directly associated with medication adherence (Ostini R et al. 2019). This may be because medication labels may be correctly understood by consumers who have sufficient general literacy and numeracy skills irrespective of their health literacy status. It is also important to note that understanding medication labels and taking action to adhere to medications are related but they are not the same thing.

Patient activation is also not synonymous with health literacy; indeed, a study examining the association between health literacy and patient activation in a population of frequent users of healthcare services with chronic diseases found no such relationship (Couture et al. 2018).

However, Australian survey data indicates that patient activation and medication adherence are positively correlated. The data indicates that: the more activated a consumer is, the better their adherence to medicines; more consumers who are highly activated have 'excellent health' compared to those who have medium/low activation; the more adherent a consumer is, the less they have problems doing their usual activities; and admission to hospital is more likely for consumers that have low adherence to medicines (NPS MedicineWise 2015).

## A note on terminology

Throughout this report we refer to Indigenous Australians as Aboriginal and Torres Strait Islander People to respectfully recognise the diversity of Aboriginal and Torres Strait Islanders communities in Australia. The term Indigenous people is used when referring to Indigenous populations in other countries, or across a number of countries including Australia.

#### **Conclusion**

QUM is both a laudable and an effective policy direction. It has the potential to save lives and minimise harms resulting from adverse events. Related concepts of health literacy, shared decision making, patient activation, medication literacy and medication adherence provide several lenses through which to unpack and benefit from the concept and practice of QUM. There are complex relationships between these concepts, but all are underpinned by the concept of consumer centred care. Despite their importance and value, there is insufficient scope to address these concepts fully in this rapid review. The aim of this rapid review is to explore the existing evidence of what is currently known about health literacy of Australian consumers, specifically as it relates to QUM.

## Policy context: QUM and health literacy in Australia

## Australian policies and strategies for QUM

QUM is a critical component of achieving better health outcomes for individuals and the community. Each year an estimated 250,000 Australians are hospitalised due to problems caused by their medicines (Pharmaceutical Society of Australia 2019), and this arguably represents the tip of the iceberg in terms of negative health outcomes from sub-optimal use of medicines.

The Australian Government's initial policy on QUM dates as far back as 1992. The policy aimed to foster judicious, appropriate, safe and efficacious use of medicines through active partnerships between consumers, health professionals, the pharmaceutical industry and government (Smith A 2012). QUM was subsequently integrated as one of the four pillars of Australia's NMP 2000, developed in the late 1990s in a partnership approach between governments, healthcare professionals and providers, the medicines industry, healthcare consumers, and the media. The other three pillars of the policy are: timely access to medicines, at an affordable cost to individuals and the community; medicines meeting appropriate standards of quality, safety and efficacy; and maintenance of a responsible and viable pharmaceutical industry (Commonwealth of Australia 1999).

The NMP states that to achieve QUM, all medicines should be used:

- judiciously: medicines, whether prescribed, recommended, and/or self-selected should be used only when appropriate, with non-medicinal alternatives considered as needed;
- appropriately: choosing the most appropriate medicine, taking into account factors such as the clinical condition being treated, the potential risks and benefits of treatment, dosage, length of treatment, and cost;
- safely: misuse, including overuse and underuse, should be minimised; and
- efficaciously: the medicines must achieve the goals of therapy by delivering beneficial changes in actual health outcomes (Commonwealth of Australia 1999).

The policy identifies health practitioners as having significant responsibility for promoting QUM. However, the policy also notes that consumers must have the knowledge and skills to use medicines to their best effect. In particular, the policy notes that consumers – like health practitioners – should have timely access to accurate information and education about medicines and their use. It recommends that public health and health education programs, like other programs relating to QUM should be coordinated between the Commonwealth Government and State/Territory Governments as well as others in the partnership; that industry and health practitioners should contribute through appropriate information, education and promotion activities; and that issues relating to use of medicines should be reported accurately and responsibly by the media (Commonwealth of Australia 1999).

A NSQUM was released in 2002 (Commonwealth of Australia 2002). The goal of the NSQUM is to make the best possible use of medicines to improve health outcomes for all Australians. The five objectives of the National Strategy are to:

- improve QUM by healthcare consumers;
- improve QUM by health practitioners, healthcare providers and health educators;
- gain the commitment of the medicines industry (including manufacturers and distributors) to QUM;
- gain the commitment of governments to QUM; and
- improve the commitment of healthcare consumers; health practitioners and educators; the medicines industries; the media; healthcare facilities, funders and purchasers, and governments—commonwealth, state and territory—to working in partnership to achieve QUM.

The NSQUM also embodies five principles, the first of which is the primacy of consumers. The strategy recognises both the central role consumers play in attaining QUM and the wisdom of their experience, and states that consumers must be involved in all aspects of the National Strategy. The NSQUM holds that consumers themselves have several responsibilities in achieving QUM, including: asking for and utilising objective information, resources, and services to support informed decision-making; becoming more aware of the risks and benefits of medicines, the possibility of non-drug options, and the benefits of a healthy lifestyle; developing skills and confidence to use medicines appropriately, and to seek help if problems arise; and becoming more aware of the place of medicines in the broader context of health and society (Commonwealth of Australia 2002).

NPS MedicineWise (previously the National Prescribing Service) was established by the Australian Government in 1998, with the primary aim of promoting better use of medicines (this aim was extended to also cover medical tests). NPS MedicineWise provides evidence-based information to health professionals and consumers through interventions including academic detailing, audit and feedback, and interactive learning. The target audiences have typically been general practitioners, pharmacists and nurses in primary care. Consumer programs, including mass media campaigns have supported the work with health professionals. NPS MedicineWise receives most of its income from the Australian Government and in return it is required to show savings to the Pharmaceutical Benefits Scheme and the Medical Benefits Schedule. Changes in knowledge and attitudes, changes in prescribing and test ordering behaviours, and improvements in health outcomes have been shown through annual evaluations (Weekes LM et al. 2018).

A review of the delivery of QUM by NPS MedicineWise was undertaken in 2018-19 (Sansom L 2019). The review noted that in the twenty years since establishment, NPS MedicineWise had received over \$600 million in core Commonwealth funding, and had grown into a large company with over 200 employees and with a wholly owned subsidiary. The review's recommendations encompass improvements in NPS MedicineWise governance, embedding QUM across the health system, improved grant management, enhanced transparency, enhanced stewardship, and improved performance measurement. The report does note:

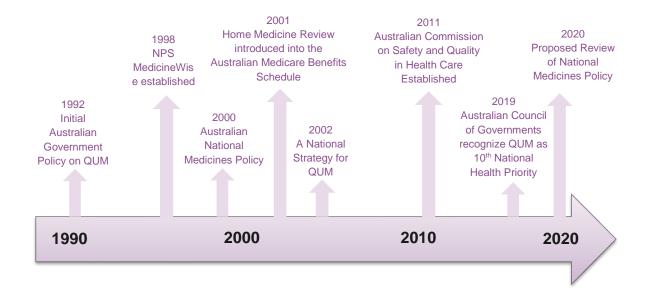
"As the QUM landscape becomes more crowded, the five principles of the NSQUM take on even more importance... Actions that uphold the primacy of the consumer, require a partnership approach based on consultation, collaboration, multidisciplinary activity, leverage existing activities and are system based." (Sansom L 2019).

The review recommended that NPS MedicineWise's processes are refocused to ensure consumer involvement in a genuine collaborative manner in the priority setting, co-design, and where applicable, the delivery of programs; and that NPS MedicineWise should use its national networks to facilitate collaborations with consumer groups so that disease-specific groups' priorities and activities are better integrated with objectives (Sansom L 2019). These recommendations, along with all others in the report, were accepted by Government.

The National Health Priority Area is an initiative which aims to focus public attention and health policy on causes which significantly contribute to the nation's burden of illness and injury. The initiative is governed through the Australian Council of Government (COAG) where Commonwealth, state and territory Governments, work collaboratively to create holistic strategies to improve the situation. In late 2019, the COAG announced Quality Use of Medicines and Medicine Safety as the 10<sup>th</sup> National Health Priority, recognising the urgent need to ensure medicines improve health of Australians, not put them at risk of harm (Pharmaceutical Society of Australia, 2019). The announcement responded to PSA's call for this following the release of the Medicines Safety: Take Care Report that was released early 2019 and was the first action in the *Pharmacists in 2023* Report released in February 2019. At the same time of the announcement, the Interim Report from the Royal Commission into Aged Care Quality and Safety recognised the magnitude of the problems we have with the safe and quality use of medicines (Royal Commission into Aged Care Quality and Safety, 2019). To support this recent announcement, the Department of Health have funded the Commission to develop a benchmarking report.

In late 2019, the Federal Health Minister announced an upcoming review of the NMP. McLachlan and Aslani (2020) argue that given the changing landscape since the introduction of the NMP two decades ago - including changes to healthcare systems, subsidies, health services remuneration, digital technologies, the pharmaceutical industry, and medicines themselves as well as consumer expectations - the time is ripe to update the NMP with a greater focus on implementing and measuring outcomes (McLachlan A and Aslani P 2020). In relation to consumers, the authors note that compared with twenty years ago, health consumers are living longer, have more chronic health conditions, and so are taking multiple concurrent medications, often including complementary and alternative products. Consumers also have greater access to information and advertising via the internet and online networking groups and expect to be more informed and involved in their own health. They note that people "expect to receive high-quality, safe and effective health care that is tailored to their needs while reducing their out-of-pocket costs". At the same time, challenges to QUM are increasing, including poor outcomes for people living with mental illness, antimicrobial resistance, and a continuing burden of medication-related harms (McLachlan A and Aslani P 2020).

Figure 2: Timeline of Australian initiatives on QUM



## Australian policies and strategies for health literacy

The overarching national policy document on health literacy in Australia is the 2014 National Statement on Health Literacy, produced by the Australian Commission on Safety and Quality in Health Care (the Commission) (Australian Commission on Safety and Quality in Health Care 2014). Companion documents to the National Statement include Health Literacy: Taking Action to Improve Quality and Safety, which provides a fuller context and practical strategies for implementing the actions outlined in the National Statement (Australian Commission on Safety and Quality in Health Care 2014); and Health Literacy: A summary for Consumers (Australian Commission on Safety and Quality in Health Care).

The role of the Commission is to ensure safe and high-quality health systems, including through the establishment of the National Safety and Quality Health Service Standards and the ongoing accreditation of healthcare services. The Commission is not a governing body, therefore the National Statement does not constitute a formal government policy; however, it was endorsed by all federal, state and territory health ministers, signalling their in principle commitment to addressing health literacy in Australia. The Commission developed the National Statement in order to increase an understanding of health literacy across relevant sectors and promote a coordinated and collaborative national approach. The document describes three strategic areas: embedding health literacy into systems; ensuring effective communication; and integrating health literacy into education. It also lists a range of actions for consumers, healthcare providers, healthcare organisations, government organisations and policymakers (including regulatory and advisory bodies). The National Statement is reinforced by the incorporation of health literacy into the National Safety and Quality Health Service Standards (Trezona, Rowlands, and Nutbeam 2018).

The summary for consumers outlines the ways that both individual health literacy, and the health literacy environment, impact on how well a person can find, understand, and use health information; and suggests actions that both consumers and health professionals can

take to support improved health literacy (Australian Commission on Safety and Quality in Health Care).

While the set of health literacy documents produced by the Commission do not explicitly refer to health literacy around use of medicines, as noted above, the National Safety and Quality Health Services Standards administered by the Commission have a strong focus on partnering with consumers, and on health literacy, including in relation to medication management, as outlined later in this review (Australian Commission on Safety and Quality in Health Care). In practice, these standards are perhaps the most explicit national statement of strategies Australian health care providers should adopt to create an enabling environment for QUM health literacy.

Some Australian jurisdictions have also developed policies and strategies on health literacy, most notably Tasmania and NSW. Tasmania's Health Literacy Action Plan covers the five year period commencing 2019, and has four focus areas: improving health literacy awareness across the community; increasing health literate organisations; developing a health literate workforce across Tasmania; and creating partnerships (Tasmanian Government Department of Health 2019). NSW has also developed a five-year health literacy framework commencing 2019, based on four priorities: patients, families, and carers are active partners in their health care; staff communicate with patients, families, and carers in ways they understand; health facilities and centres are easy to access and navigate; and health systems are built to be sustainable and reliable for every patient, every time. The framework includes specific consideration of health literacy in Aboriginal communities (Clinical Excellence Commission 2019). These jurisdictional plans are mainly focused on strategies by providers to improve the health literacy environment. There is also evidence of efforts at regional level to adopt health literacy frameworks, and embed health literacy into health systems (Vellar, Mastroianni, and Lambert 2017).

## The interface between QUM and health literacy strategies in Australia

The national policies and strategies for QUM, and the national policies and strategies for health literacy, have been developed somewhat separately, but they overlap in their intent.

Policy development on QUM predates policy development on health literacy in Australia, so it is not surprising that existing QUM policies do not fully reflect contemporary thinking on health literacy. The NSQUM includes responsibilities for consumers around improving their health literacy with respect to their medicines (for example, asking for and utilising objective information, resources, and services to support informed decision-making; becoming more aware of the risks and benefits of medicines, developing skills and confidence to use medicines appropriately, and seeking help if problems arise). The NSQUM says less about the responsibilities of health professionals and providers around supporting improved consumer health literacy, referring only to health professionals "assisting people in making informed decisions", and providers "providing facilities, systems, training opportunities and structures that support staff, health practitioners and consumers in using medicines wisely and that avoid medication errors" (Commonwealth of Australia 2002). There appears to be a greater focus on individual health literacy, than on the health literacy environment.

As QUM is a key contributor to health outcomes, QUM and medication literacy must be a consideration in policies and strategies on health literacy. However, the inclusion of QUM and medication literacy in Australian policies and strategies is generally implicit rather than explicit. As noted above, the National Safety and Quality Health Services Standards do include statements relating to provider responsibility for the QUM and medication literacy environment; similar national statements on individual medication literacy have not been identified.

Given the overlapping intent of QUM and health literacy policies and strategies, better alignment and integration of these policies and strategies could be considered. There may be an opportunity to develop a greater focus on health literacy in national QUM policies and strategies, given the forthcoming review of the NMP. There may also be opportunities for a more explicit consideration of QUM and medication literacy in health literacy policies and strategies.

## What is known about health literacy in Australia?

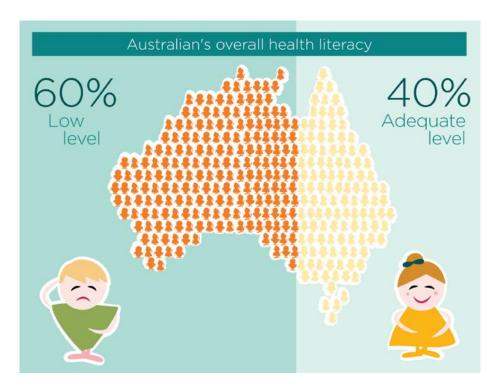
The health literacy of the Australian population was measured in 2006 (Australian Bureau of Statistics 2006) and again in 2018 (Australian Bureau of Statistics 2019) by the Australian Bureau of Statistics (ABS). In this section of the report we present the broad findings and information on the measures used.

In 2006 the ABS released Adult Literacy and Life Skills Survey (ALLS), Summary Results. The ALLS provided information about whether Australians' literacy skills were adequate for the challenges they face in work and daily life. The survey examined how well people were able to use materials and carry out basic tasks related to their health care, such as interpreting a medication label and an information leaflet.

The survey found that 50% of Australians who completed the survey aged between 30-39 had health literacy skills that were adequate or better. However, only 22% of people aged 60-74 had health literacy skills that were adequate or better. The levels of adequate health literacy were similar for males and females. More details results for the 2006 Australian survey are available here:

https://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4233.0Main%20Features22006

The Commission provided this infographic of Health Literacy in Australia based on the 2006 survey results.



In 2018 the ABS conducted the Health Literacy Survey (HLS). The sample for the HLS was respondents aged 18 years and over who had already participated in the National Health Survey (NHS 2017-18). These respondents agreed to be contacted for further ABS surveys and had provided their contact details. The HLS was conducted from January 2018 to August 2018 with 5,790 fully responding adults (Australian Bureau of Statistics 2019).

The 2018 Australian HLS used the nine subscales of the Health Literacy Questionnaire (HLQ) to measure health literacy. The nine HLQ domains are: feeling understood and supported by healthcare providers; having sufficient information to manage my health; actively managing my health; social support for health; appraisal of health information; ability to actively engage with healthcare providers; navigating the healthcare system; ability to find good health information; and understanding health information well enough to know what to do (Osborne et al. 2013).

The National Health Survey: Health Literacy, 2018, shows that one-third of Australians (33 per cent) found it always easy to discuss health concerns and actively engage with their healthcare providers; 56 per cent found this usually easy; while 12 per cent found it difficult (Australian Bureau of Statistics 2019)

Leanne Kelly's analysis of the 2018 Health Literacy Survey (Kelly 2019) presented in the Health Voices Journal, indicates that overall Australians have a positive view of their own health literacy:

- 96% of people strongly agreed (32%) or agreed (64%) that they felt understood and supported by healthcare providers. (Subscale 1)
- 97% of people strongly agreed (23%) or agreed (74%) that they had sufficient information to manage their health. (Subscale 2)
- 91% of people strongly agreed (18%) or agreed (73%) that they could actively manage their health. (Subscale 3)

- 95% of people strongly agreed (25%) or agreed (70%) that they had social support for health. (Subscale 4)
- Just over **four in five people** strongly agreed (11%) or agreed (72%) that **they could appraise health information**. (Subscale 5)
- 89% of people found it always easy (33%) or usually easy (56%) to actively engage with healthcare providers. (Subscale 6)
- 86% of people found it always easy (26%) or usually easy (60%) to navigate the healthcare system. (Subscale 7)
- 88% of people found it always easy (25%) or usually easy (63%) to find good health information. (Subscale 8)
- 93% of people found it always easy (39%) or usually easy (54%) to understand health information well enough to know what to do. (Subscale 9).

However, Kelly reported a different picture for Australians who are from marginalised groups. For example, Australians who completed the survey with multiple health conditions were more likely to find it difficult to actively engage with health care providers (subscale 6) and were less likely to agree they had sufficient social support for health (subscale 4) compared to Australians who did not have multiple chronic conditions or a disability (Australian Bureau of Statistics 2019; Kelly 2019).

#### **Conclusions**

The ABS surveys undertaken in 2006 and 2018 provide some useful information about the health literacy of Australians. Notably, the 2006 survey found that only 40% of Australians have at least an adequate level of health literacy. The 2018 survey found that overall, Australians have a positive view of their own health literacy; but that this was less likely to be so for people from marginalised groups.

The results of the two ABS surveys, conducted over a decade apart, are not comparable because they used different measures. Therefore, it is not possible based on currently available data, to track changes in health literacy in Australia over time.

## Medication literacy levels in Australia and selfreported consumer views, knowledge and attitudes to the QUM

Medication-related hospital admissions may be seen as a partial proxy for consumer medication literacy and QUM. The Pharmaceutical Society of Australia (PSA) reports that there have been 16 separate Australian studies since 1988 providing estimates of the extent of medication-related hospital admissions. Based on these studies, it is estimated that 250,000 hospital admissions in Australia each year, and an additional 400,000 presentations to emergency departments, are a result of medication-related problems. It is further estimated that 50% of this harm is preventable (Pharmaceutical Society of Australia 2019). While there are multiple contributing factors to preventable hospital admissions for medication-related reasons, consumer medication literacy is undoubtedly among them.

This review identified only the following sources of direct data on population-level medication literacy in Australia in recent years:

- NPS MedicineWise biennial National Consumer Surveys.
- Other polls commissioned by NPS MedicineWise, through Galaxy Research.

A brief overview of these surveys and key findings is provided below. A more comprehensive summary can be found at Appendix B.

## **NPS MedicineWise consumer surveys**

NPS MedicineWise undertakes a National Consumer Survey every two years, conducted online with a representative sample of around 2,500 consumers from the Australian population. The surveys aim to track changes in consumer awareness, knowledge and attitudes about NPS MedicineWise program-related topics over time, and inform NPS MedicineWise product and program refinement and development (NPS MedicineWise 2015, 2017).

The most recent available data is from the 2017 survey (NPS MedicineWise 2017), which particularly focused on consumers' use of online health information. Some key findings from this survey include:

- Consumers who need to obtain information about medicines ask a GP (75%) followed by a pharmacist (62%) and/or visit a website (45%).
- Social media and blogs are accessed the least to search for information about medicines (9%) except for people aged 16-34 years (15%), those who speak English as their second language (20%) and people with Aboriginal and/or Torres Strait Islander heritage (20%).
- Some issues consumers experience when searching for information about medicines online include trusting (26%) and understanding (21%) the information provided on a website.
- The top five most important attributes consumers look for in an online source of information about medicines are:

- Trustworthy source
- Up-to-date
- Easy to understand
- o Recommended by a health professional
- Research or 'evidence-based' information.

The previous national survey, undertaken in 2015, focused on medicine adherence, antibiotics, and medical tests (NPS MedicineWise 2015). Some key findings in relation to medication adherence include:

- One third of consumers currently prescribed medicines have high adherence to taking their medicines. Approximately half (47%) of consumers have medium adherence and nearly 2 out 10 (19%) have low adherence.
- Key drivers of adherence include: having a set routine or strategy in place to ensure
  consumers take their medicines every day; trust in the GP's decisions on which
  medical treatments and medicines are best for the consumer; being able to discuss
  concerns about medicines during a GP consultation; willingness to take medicines
  vs. vitamins or supplements; and belief that the benefits of taking medicines outweigh
  possible risks.
- Cost of medicines was a barrier to adherence to only a minority of consumers; 16% of consumers delayed buying or did not buy prescribed medicine due to cost in the past 12 months.

## **NPS MedicineWise Galaxy Polls**

NPS MedicineWise also commissions Galaxy Research to undertake polls to inform its work, particularly its annual Be Medicinewise Week (BMW) public education campaigns. The polls are usually of 1,000 Australia adults. The most recent of these polls, undertaken in June 2019, comprised of 1,037 Australians aged 18 years and older distributed throughout Australia. The data was weighted by age, gender and region to reflect the latest ABS population estimates.

Some key findings from the most recent of these polls, undertaken in 2019, are as follows:

- Only about one in three (31%) Australians who regularly take two or more medicines actually keep a list of all their prescription, over the counter and complementary medicines.
- A further 26% of people who take regular medicines only keep a list of their prescription medicines, while the remaining 3% only record some, and 40% record none, of their medicines.
- People are better at recording the brand of their medicine than the active ingredient. Of those people who record information about their medicines, only one in five (22%) said they'd record the active ingredient of the medicine, compared to half of those people (48%) saying they'd capture the brand name of the medicine, 63% saying they record information on the dose and how and when to take the medicine, and 52% saying they record the reason for taking the medicine.
- Around half of all people surveyed said they had spoken with a doctor or pharmacist about how much of a newly prescribed medicine they needed to take each time, when and how to take the medicine, how long they should take the medicine for or what side effects might happen. However, only 16% of people said they had discussed what active ingredient was in the medicine

Around 10% of Australians have household or family members that have trouble accessing information about their medicines because English is not their first language (NPS MedicineWise 2019).

#### **Conclusions**

In the absence of direct measures of medication literacy levels in Australia, medicationrelated hospitals admissions may be used as a partial proxy. An estimated 250,000 hospital admissions annually for medication-related problems, half of which are likely to be avoidable admissions, indicate cause for concern.

NPS MedicineWise National Consumer Surveys and other polls commissioned by NPS MedicineWise provide valuable information on consumers views, knowledge and attitudes in relation to QUM. Taken as a whole, these findings suggest that consumers are accessing information about their medicines from reliable sources (their GPs, pharmacists or a trusted website), although this is less likely to be the case for disadvantaged Australians who are more likely to access social media for information compared to other Australians. It is concerning that only one third of consumers reported having high adherence to their prescription medications. A similar proportion of respondents who regularly take two or more medications, reported keeping a list of the medicines. It appears that greater strides are required to improve the levels of medication literacy in Australia.

# Population segments at greater risk of poor health literacy, medication literacy, and sub-optimal QUM

While many population segments within the community may have higher risks and specific needs in relation to health literacy, medication literacy, and QUM, this review has focused on the challenges faced by older people, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people, and people with low literacy/low health literacy. Issues facing each of these groups are outlined below, followed by an overview of key findings.

## Older people

As life expectancy in Australia increases, the proportion of older people (defined here as people aged 65 and over) in the community is also increasing. This population cohort frequently has multimorbidities, often associated with multiple medication use, and in some cases polypharmacy (the use of five or more medicines). Polypharmacy, unnecessary adverse drug events, confusion about therapy, and adherence issues, are common concerns in relation to QUM by older Australians (Corre et al. 2018).

The risk of problems with medicines increases with age for two main reasons. The first reason is changes in the body: the ageing process can affect levels of water, fat and muscle in the body; some health conditions also create further changes that may make an individual become more sensitive to the effects of medicines, not be able to process medicines properly, have difficulty removing medicines from the body, or become more prone to side effects and medicine interactions; and finally, the brain and nerves also change with age, so problems like memory loss or poor eyesight might start to affect the practical aspects of taking medicines. The second reason is prescribing of multiple medicines, and particularly polypharmacy. Taking more than five medicines means a person is twice as likely to have side effects than others; is far more likely to be taking medicines that could interact with each other; and potentially has a greater risk of making mistakes, simply due to having more medicines to manage (healthdirect 2020).

Page et al (2019) have undertaken analysis aiming to establish the prevalence of polypharmacy amongst Australians aged 70 years or more, between 2006 and 2017, based on dispensing claims data for prescribed medicines. They found that in 2017, an estimated 935,240 people, or 36.1% of this age group, were affected by continuous polypharmacy (five or more unique medicines dispensed during two separate, defined three-month periods in a calendar year). Cumulative pharmacy rates (five or more unique medicines dispensed within just one of the three-month periods) reached as high as 52.7%. Further, they found that polypharmacy rates were increasing over time as the population ages and were progressively higher for older age groups within the over-70 cohort. They note that their estimates are probably low, as they do not take over the counter and complementary medicines into account. The authors cite evidence that polypharmacy places older people at risk of harm, including from adverse drug reactions, and is associated with poor clinical outcomes, including nutritional deficiencies, falls, frailty, impaired cognition, more frequent hospitalisation, and premature mortality. They point out that reducing polypharmacy is one of the areas highlighted by the WHO in its third global patient safety challenge, which aims to

halve the global burden of iatrogenic medication-related harm. The authors conclude that while polypharmacy can be appropriate, there is substantial evidence for its potential harm. and for the importance of rationalising unnecessary medicines, particularly in older people (Page A et al. 2019).

Sub-optimal prescribing and use of medicines is a significant factor in preventable hospitalisations for older people in Australia. A PSA report on medication safety in Australia notes that the use of potentially inappropriate medicines as a contributor to hospital admission has been identified in a number of Australian studies. The report cites studies showing that for people 65 years and over with medical or surgical admissions to hospital, up to 55% were on a potentially inappropriate medicine, and 6% of all admissions were due to the potentially inappropriate medicine; that 63% had potential prescribing omissions at the time of admission; and that 33% of potential inappropriate medicines were associated with a possible adverse clinical outcome (Pharmaceutical Society of Australia 2019).

There are well-documented issues with medication safety in residential aged care settings. The PSA report quotes research indicating that over 90% of residents in aged care facilities have at least one medication-related problem; and as many as 80% are prescribed potentially inappropriate medications. By comparison, 40% of older people living in the community are prescribed at least one potentially inappropriate medication (Pharmaceutical Society of Australia 2019).

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

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

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

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

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

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

There are very limited hard data either on health literacy, or on QUM, amongst Aboriginal and Torres Strait Islander people.

The Australian Commission on Safety and Quality in Health Care (the Commission) engaged the Cultural and Indigenous Research Centre Australia (CIRCA) to undertake qualitative research, using a focus group methodology, to explore the consumer health information needs and preferences of Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander people. In relation to the health literacy of Aboriginal and Torres Strait Islander people, the research found:

- There is a significant need to help Aboriginal and Torres Strait Islander patients understand more about their health challenges. Many participants reported not feeling confident to ask questions about their own or their family's health (particularly of providers who were not Aboriginal Health Workers) and being left unsure about their condition and why they are taking particular medicines. There is a clear appetite for greater understanding and involvement in healthcare decisions with Aboriginal and Torres Strait Islander participants seeking a wide range of information.
- The preferred source of information for Aboriginal and Torres Strait Islander
  participants is face-to-face. Some participants already access health information from
  brochures and posters and a few, particularly the younger people, were accessing
  information through the internet. Those who live in more remote communities had
  more intermittent access to the internet and some needed information to be provided
  in their traditional language.
- Many of the people interviewed were managing pre-existing and on-going conditions and were therefore most interested in information relating to self-management of health conditions.
- Many participants reported finding current communications difficult to understand. A
  consistent theme through the interviews was a preference for resources that are
  visually appealing and written in plain language, and that are clearly targeted towards
  Aboriginal and Torres Strait Islander people (Cultural and Indigenous Research
  Centre Australia on behalf of the Australian Commission on Safety and Quality in
  Health Care 2017).

Crengle et al (2018) note that while there is little solid data on the health literacy levels of Indigenous Australians and Canadians, in New Zealand a higher proportion of the Maori population has low levels of health literacy, compared with the general population. They

surmise that the situation is likely to be similar for Indigenous peoples in Australia and Canada, given similar patterns of inequity (Crengle et al. 2018).

Spinks et al (2019) note that there are reports that the levels of medication related problems among Aboriginal and Torres Strait Islander populations are of concern, "although there is scant evidence of the size or extent of the problem" (Spinks et al. 2019).

Deacon-Crouch et al (2016) undertook interviews with community members in a regional Victorian Aboriginal community, seeking to understand perceptions about chronic disease, medications, and lifestyle. They found that the majority of participants perceived that changes in lifestyle factors such as diet, exercise, and smoking cessation would help improve their health. Most patients reported having been counselled about their medicines. The majority reported adherence, and acknowledged the efficacy of their medicines, but there was a lack of clarity regarding long term maintenance on regimens. The majority reported taking over the counter products, but some did not see the need to inform their doctor about this or chose not to. The authors found that it is important for ongoing education and counselling to be provided, so that patients understand that continued adherence to the medication regime is required in order for longer term health benefits to be seen, particularly for conditions such diabetes and cardiovascular disorders. This was seen as particularly important in light of the comments by some participants that they would cease their medicines if they perceived that they were no longer needed or if they thought they were not helping. The authors also suggested that education is needed regarding the importance of reporting side effects from medicines, so that alternatives may be prescribed, rather than patients ceasing to take them because of adverse reactions (Deacon-Crouch et al. 2016).

## Culturally and linguistically diverse (CALD) populations

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

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

Access to interpreting and translation services and the cultural competence of staff are often cited as ways to improve access to primary health care. However, it is important that health care professionals and organisations do not inadvertently conflate low health literacy with other concepts such as speaking another language. Low health literacy cannot be 'fixed' with an interpreter, nor can low health literacy be 'fixed' by providing culturally competent care.

It has been established that limited English proficiency is associated with poor access to health care and poor health outcomes. Despite this knowledge, few health literacy interventions have been developed or validated for smaller linguistic populations (McKee and Paasche-Orlow 2012).

#### Particular challenges facing refugee populations

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

For refugees, health status has evolved in the context of organised violence marked by persecution, forced exile from their homelands, and grief and loss at many levels. On arrival in Australia refugees may have significant physical, mental and emotional health care needs. Resettlement in a new country has its own challenges. Refugees may need to learn a new language, culture and way of life. They also need to learn to use social services such as transport and access to income support and to access the health care system.

There is a small but growing amount of research exploring resettled refugees and access to primary health care including pharmacy services and the QUM (Bellamy et al. 2015). The most commonly cited barriers to accessing primary health care services and the QUM include communication and language concerns (Clark et al. 2014; Baker et al. 1998), followed by differences in cultural expectations and practices, low health literacy, difficulty navigating the health care system (Bellamy et al. 2015) and financial barriers such as the costs of medicines (Kay et al.). Practices that overcome some of these barriers include the use of interpreters, having a regular GP and pharmacists, community engagement, the provision of medicines information and improved health care provider training. In primary health care the supportive role of the practice nurse was especially noted (Kay et al.).

Trauma and mental health problems are significant issues experienced by refugees. However, some refugees come from health systems where mental illness is not recognised. Therefore, it is not surprising that resettled refugees have high levels of mental health problems but are less likely to access mental health services. One of the possible determinants of this inverse care law is that resettled refugees have low levels of mental health literacy. A study conducted with resettled Iraqi refugees in Sydney used a culturally adapted Mental Health Literacy Survey method to determine knowledge of, and beliefs about, helpfulness of treatment interventions and providers for posttraumatic stress disorder (PTSD). Less than 15% of the participants were able to identify the symptoms of PTSD. Most participants believed that effective interventions included reading a religious text such as the Bible or Koran and seeking help from a psychiatrist (Slewa-Younan et al. 2014).

Further work and resources are required to support the development of health literacy skills generally and mental health literacy skills specifically among refugees in Australia.

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

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

Low literacy is an independent determinant of health, that is closely related to educational attainment and socioeconomic status. A systematic review of the relationship between literacy and health outcomes in 2004 found consumers with low literacy were generally 1.5 to 3 times more likely to experience a poor health outcome (Dewalt, Berkman, and Sheridan 2004).

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

The maldistribution of these determinants leaves some population groups marginalised. When discussing the social determinants of health there is a tendency to assume the mechanism for determinants of health resulting in poor health outcomes is via an increased number of risk factors such as smoking and poor diet among population groups with low health literacy. While people with low literacy are less likely to respond to health messages, literacy levels are an independent determinant of health (Commission on the Social Determinants of Health 2008).

Literacy is an asset that enables consumers to develop their knowledge and opportunities. It also enables consumers to participate more fully in society and the economy. There are two main elements of literacy that can be assessed: skills and tasks. It is possible to measure consumers' skills and knowledge; it is also possible to assess consumers' ability to undertake tasks such as reading basic text.

While there is growing consensus on the consumer skills necessary for the safe use of medicine, further research is needed to identify contextual challenges that may undermine consumers' application of these skills. Factors such as limited time with pharmacists and negative side effects can influence consumers' medication literacy and adherence.

Research was undertaken in Canada to gather data on the major challenges' low health literate adults face regarding their medication. One-on-one semi-structured interviews were undertaken, each beginning with a verbal health literacy assessment, followed by openended questions focused on medication information. After each interview was complete, a written health literacy assessment was given in English, which was later used to compare self-assessed health literacy to written health literacy scores. Low health literacy levels were found in 75% of participants, which suggested many participants overestimated their selfassessed health literacy levels. The authors found the major challenges consumers with low health literacy face with medication information from pharmacies include limited time with pharmacists, difficulty understanding medication information, forgetting to take medication, negative side effects and food-drug interactions (Wali and Grindrod).

#### **Conclusions**

This review has identified that older people, Aboriginal and Torres Strait Islander people, CALD people, and people with low literacy and/or low health literacy all face particular challenges in regard to medication literacy and QUM.

While each of these population segments has its own unique characteristics and needs, there is also some commonality across the challenges faced by these groups, and clearly many consumers would fall into two or more of these segments.

All of these population segments experience higher levels of ill health, and greater challenges in accessing appropriate health information and making informed decisions about their health. It has been shown that many people within these segments are more likely to turn to their health professionals for health information than to seek information from other sources.

Whole-of-population health literacy, medication literacy and QUM measures need to take into account the needs of these population segments; and in addition, specific measures are required which address the needs of each segment.

Tools and resources which have been developed and implemented for each of these population segments are discussed later in this review.

## **Tools for measuring health literacy**

Over 100 instruments for measuring health literacy in adults have been identified through systematic reviews (Altin et al. 2014; Haun et al. 2014). These include general measures of health literacy across populations and settings, and disease-specific measures of health literacy.

Examples of population and community measures of health literacy include the HLQ, described in an earlier section (Osborne et al. 2013) and the HLS-EU-Q (Sørensen et al. 2013). The HLQ is self-administered and has good coverage of the functional, communicative and critical domains of health literacy.

There are disease specific measures for conditions such as diabetes, asthma, cancer, oral health, genetics, HIV, chronic disease and there are language or population specific measures (see Health Literacy Tool-shed https://healthliteracy.bu.edu/) (Crengle et al. 2014). These specific measures may be more sensitive to change in health literacy specific interventions but tend to less comprehensively cover the domains of health literacy.

Measures of health literacy can be performance-based. These measures conduct a direct test of skills. They offer a more objective view of health literacy; however, they are limited in their focus on basic numeracy and literacy. Other measures of health literacy are based on self-report of perceived skill. These subjective measures have a greater potential for response bias, and some are designed for screening for health literacy in clinical practice rather than measuring health literacy.

The appropriateness of different instruments depends on the purpose of measurement. For example, a single-item measure (e.g. the Chew Brief Health Literacy Screening Questionnaire) may be useful in screening adults to identify patients with limited health literacy, but is unlikely to detect a change in health literacy skills of individuals which result from health literacy interventions. Similarly, longer measures of health literacy may be more comprehensive and able to detect change over time but are time-consuming and not practical in busy clinical settings (Chew, Bradley, and Boyko 2004; Chew et al. 2008a) (Chew et al., 2004).

In this section of the report we provide an overview of performance based and self-report measures and discuss the strengths and limitations to each approach. We provide an overview of key characteristic of health literacy measures and their application in different contexts.

#### **Performance-based measures**

The most known performance-based health literacy measures were developed in the 1990s. They are the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al. 1991b) and the Test of Functional Health Literacy in Adults (TOFHLA) (Baker et al. 1997; Baker et al. 1999). The REALM is a word pronunciation test that uses medical words. TOFHLA takes a broader approach to measuring health literacy. It includes reading, numeracy, and document literacy (Nguyen, Paasche-Orlow, and McCormack 2017).

Performance based health literacy measures generate empirically grounded data which is inherently valuable. However, assessing peoples' skills in that way can feel like a test and, if people know that their skills are being evaluated, this can potentially cause stigma. In addition, a person's test score in one domain or content area may not reflect their skill in another aspect of health literacy (Nguyen, Paasche-Orlow, and McCormack 2017). For example, an individual's ability to correctly pronounce health-related words may not reflect their ability to perform other health-related tasks.

More recently, performance-based measures of health literacy have been extended to include a number of health-related stimuli. For example, Health Literacy Skills Instrument (10-item short form): The 25-item Health Literacy Skills Instrument (HLSI) was designed to measure the ability to read and understand text and locate and interpret information in documents (print literacy), to use quantitative information (numeracy), to listen effectively (oral literacy), and to seek information through the Internet (navigation). It is a publicly available measure that can be used in surveillance activities, to evaluate interventions, and in research examining the relation between health literacy and health outcomes. The authors developed a 10-item, short form (SF) version of the HLSI, the HLSI-SF, using data gathered for the development of the longer form. The HSLISF has many of the same advantages of the longer version with the additional benefit of taking only approximately 5 to 10 min to administer. The HLSI-SF offers researchers and practitioners a valid and reliable measure of health literacy skills (Bann et al. 2012).

## **Self-report measures**

The main challenge with measures that rely on self-report is that there is no way to know how a person's responses relate to their actual skill level. However, a benefit of self-report measures is the ease of testing because these measures typically involve less cognitive effort than performance-based measures (Nguyen, Paasche-Orlow, and McCormack 2017) and self-report measures have the potential for rapid application.

Examples of self-report measures include:

- The Health Literacy Management Scale (HELMS), which consists of 8 scales with 4– 5 items and aims to assess health literacy by using a comprehensive approach. It encompasses multiple domains such as patient attitudes towards health and their proactivity as well as access, understanding and use of health information and access and communication with healthcare professionals (Jordan, Buchbinder, and Osborne 2010).
- 2. Health Literacy Questionnaire (HLQ), which is a subjective measure of health literacy comprising nine independent scales related to the understanding of, engagement with, and use of health services, from both an individual and organisational perspective (Osborne et al. 2013).

Table 1 provides information about the characteristics of some of the most widely used generic measures of health literacy.

Table 1. Key characteristics of some generic health literacy measures and their coverage of domains of health literacy

Name	Characteristics	Literacy	Numeracy	Functional	Interactive	Critical	Strengths and limitations	
Brief measures								
Three item screener (Chew et al. 2008b)	Brief measure. Self-administered. 5 item Likert scale for difficulty with health literacy (3 questions)	<b>√</b>		<b>√</b>	<b>√</b>		Validated against other measures. Easy to administer but may miss low health literacy.	
Newest Vital Sign (Weiss et al. 2005)	Brief measure – administered at consultation Questions about a nutrition label. (6 questions)	<b>√</b>	<b>√</b>	<b>✓</b>			Internationally validated and a high score reliably excludes low health literacy. However reliant on moderate numeracy.	
CHAT Conversational Health Literacy Assessment Tool (O'Hara et al. 2018).	Based on six of the nine domains of the Health Literacy Questionnaire (HLQ)			<b>✓</b>	<b>✓</b>	<b>✓</b>	Conversation starter that can be used in clinical practice. Not a definitive measure of health literacy.	
More comprehensive measures								
Rapid assessment of literacy levels in adults REALM(Davis et al. 1991a)	Administered. Word recognition and pronunciation (66 items)	<b>*</b>					Reliance on word pronunciation and comprehension makes it unsuitable in many cross-cultural contexts.	
Test of functional health literacy in adults	Administered. Reading comprehension. (67 items)	<b>√</b>	<b>√</b>	<b>√</b>			Often used as "gold standard". Complex to administer and requires	

TOFHLA (Parker et al. 1995)						considerable time.
Health Literacy Questionnaire (HLQ) (Osborne et al. 2013)	Self-administered questionnaire. 44 items grouped into 9 scales		<b>√</b>	<b>√</b>	<b>√</b>	Validated and used in Australia and developing countries
European Health Literacy Questionnaire (HLS-EU-Q) (Sørensen et al. 2013)	Self-administered questionnaire. 47 items in 12 Subscales. 16 items in short form HLS-EU-Q16		✓	✓	✓	Validated and extensively used in cross country comparative studies in Europe.

## **Tools for measuring medication literacy**

Medication literacy can be measured both at individual level, generally through individual consumer questionnaires, and at population level, generally through larger consumer surveys. This section focuses on tools and resources available for the measurement of individual consumer medication literacy levels.

## **Defining the components of medication literacy**

It would seem logical that robust measures of consumer medication literacy should include assessment of the consumer knowledge and skills that are identified as essential for safe and optimal use of medicines.

Puliot et al (2018), through an expert consensus process, have defined several areas of consumer knowledge as being essential for safe and optimal use of medicines, including:

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

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

## **Recognition and Addressing of Limited Pharmaceutical Literacy (RALPH)**

Few tools and resources for measuring medication literacy are described in the international literature (Stilley et al. 2014). An exception is the RALPH interview guide, which focuses on individual level medication literacy. It was developed in the Netherlands as a practical set of questions to support pharmacy staff to recognise patients with limited pharmaceutical literacy in daily pharmacy practice. The developers note that while there are many tools available to measure general health literacy, they had found scant evidence of previous attempts to develop tools to measure pharmaceutical literacy and illiteracy in clinical practice (Vervloet et al. 2018; Koster et al. 2018).

The RALPH guide consists of ten guestions, across four domains, all directly linked to the patient's own medication, to be used during medication counselling. The four domains include the following aspects: pharmaceutical literacy; functional medication literacy (understanding medication use instructions); communicative medication literacy (finding and understanding medication information) and critical medication literacy (critically analysing information) (Vervloet et al. 2018). Data from RALPH interviews with over 500 patients were compared with data from the same patients, obtained by administering the Functional Communicative Critical Health Literacy (FCCHL) instrument. The study found that people with low pharmaceutical literacy, as measured by RALPH, also demonstrated low general health literacy, as measured by FCCHL; but overall agreement between scores on the two measures was moderate. The authors found that most patients (more than 90%) had correct understanding of frequency and timing of medication use, but 25% did not understand warnings or precautions correctly. Finding understandable information (39%), assessing information applicability (50%) and reliability (64%) were mentioned as difficult by patients. The authors found that patients experienced difficulties with more complex skills, such as interpretation of warnings or precautions when using a medicine and finding and analysing medication information. They conclude that while the FCCHL questionnaire is useful to assess general health literacy, the RALPH interview guide provides insight in the level of skills needed for good medication use and is more suitable for use in a medication specific context such as community pharmacy (Koster et al. 2018).

# Adapting general health literacy measures to focus on medication literacy

Some researchers such as Stilley et al (2014) have adapted general health literacy measures to focus on medication literacy specifically (Stilley et al. 2014). Stilley and colleagues developed a health literacy measure for oral medications based on data from two studies conducted at the University of Pittsburgh. The instrument focused on measuring the use and understanding of information on prescription medication labels. The tool was multidimensional, measuring the constructs of prose, numeracy and documentation in a similar way to the Newest Vital Signs; and unlike the REALM measure of health literacy, this tool assessed ability to understand and use information to make decisions about medication taking rather than ability to read and pronounce health related words. Analysis documented internal consistency and reliability within acceptable limits (Stilley et al. 2014).

Clearly this instrument measures some components of medication literacy, but does not cover all the essential areas of consumer knowledge and skills outlined by Pouliot et al (2018); and it is unclear whether further development and broader uptake has followed the initial results published in 2014 (Pouliot et al. 2018).

# **Conclusions**

Taken as a whole, it appears that the field of defining and assessing medication literacy is in its infancy. The RALPH guide is a stand-out measure of individual medication literacy in the academic literature. It may be used by pharmacists to identify patients at risk of low medication literacy. In addition to the RALPH guide, there are examples of general health literacy measures being refined and adapted to focus specifically on medication literacy.

The further development and refinement of individual medication literacy tools will enable pharmacists to identify patients at risk. However, the development of medication literacy measures alone will be insufficient in improving medication literacy. Further attention is required to support pharmacists and other health care providers to better support consumers with low medication literacy to make informed decisions about their medication use.

# Initiatives for improving health literacy in Australia

A range of initiatives to improve health literacy have been developed, piloted, and in some cases implemented, in Australia and/or internationally. Key initiatives are categorised and summarised here.

Note that this analysis focuses on generic health literacy initiatives that have been developed for use across the population and across disease groups. There are also a number of initiatives that have been developed for specific population segments, or for consumers with specific conditions. Due to limitations of time and scope, these resources are not included in this rapid review.

In 2014, the Australian Commission on Safety and Quality in Health Care (the Commission) prepared a National Statement on Health Literacy that provides a framework and call to action to improve safety and quality (Australian Commission on Safety and Quality in Health Care 2014). The National Statement is based on the principle that having consumers as partners in the processes of health and health care is necessary for safe and high-quality care. The Commission state that in order to address health literacy in a coordinated way, action needs to be taken across the three areas:

- embedding health literacy into systems, such as funding mechanisms that encourage action on health literacy;
- ensuring effective communication including print, electronic and interpersonal communication; and
- integrating health literacy into education for both consumers and healthcare providers.

Examples of key initiatives under each of these three areas are discussed below.

# A systems approach to health literacy

The Illawarra Shoalhaven Local Health District provides an example of a systems approach to health literacy. Their organisation-wide approach includes the following dimensions:

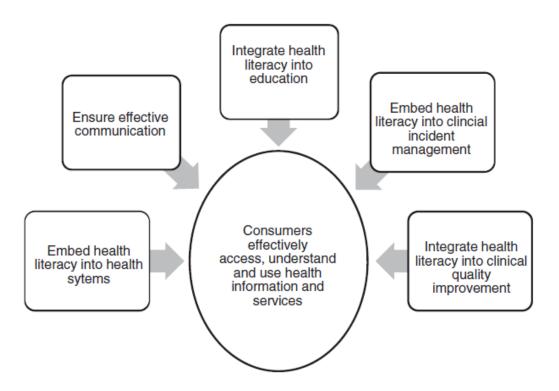
- assigning health literacy as a portfolio under the responsibility of the Clinical Governance Unit
- developing a plain-English policy for consumer information
- developing a process for reviewing consumer information using the plain-English policy and consumer feedback
- including introduction training on health literacy to all new staff at orientation, as part of cultural diversity training
- developing an interactive Patient Information Portal for staff and clinicians to search for and develop simpler consumer information
- develop a Health Literacy Ambassador Program where staff are trained to be health literacy champions.

This approach was underpinned by seeking 239 consumer experience stories. These stories provided a useful grounding for the project. They identified the key difficulties facing

consumers as including poor access to information, difficulty navigating the healthcare system and difficulty communicating with providers (Vellar, Mastroianni, and Lambert 2017).

Figure 3 below depicts the multipronged systems approach to the health literacy intervention.

Figure 3: Illawarra Shoalhaven Local Health District Health Literacy Model



The program leaders indicate that the success of the intervention lies in the multipronged approach, ongoing leadership commitment to the intervention, meaningful engagement with consumers and direction and leadership for health literacy at the national and state levels (Vellar, Mastroianni, and Lambert 2017).

The OPtimising HEalth Literacy and Access (Ophelia) process provides an example of a systematic approach to improving health literacy at multiple levels within communities and in health care settings. The phases of the process are outlined in Figure 4 below. The process draws on the principles of co-design and consumer engagement. It is a systematic process rather than a single intervention that is adopted across settings. The process is also informed by the quality improvement cycle: Plan Do Study Act (Batterham et al. 2014; Beauchamp et al. 2017).

Figure 4: Phases of the Ophelia Process

#### Phase 1

Identifying local strengths, needs and issues

#### Phase 2

Co-design of interventions

#### Phase 3

Implementation, evaluation and ongoing improvement

Health literacy data are collected from a representative sample of the target population. Data are presented to stakeholders for interpretation. Effective local practices and innovative solutions are identified

Local stakeholders make decisions about priorities for action. Interventions with potential to respond to local health literacy needs or improve information and service access are designed and planned

Health literacy interventions are applied as quality improvement cycles where organisations implement trials and actively improve the effectiveness, local uptake and sustainability of the interventions

# Steps for each phase

Step 1: Project set-up

Step 2: Data collection and extraction

Step 3: Co-design workshops

Step 4: Intervention design (program logic models)

Step 5: Intervention planning (implementation and evaluation plans developed)

Step 6: Intervention refinement (quality cycles to test processes and materials)

Step 7: Implementation and evaluation activities

Step 8: Development of an ongoing quality improvement strategy

# **Ensuring effective communication**

Ensuring effective communication including print, electronic and interpersonal communication is an essential component of improving health literacy. Effective communication is based on the principles of trust, understanding, empathy and cooperation. Effective communication uses both the spoken and written word.

Tools for effective communication include three strategies:

- 1. assessing the readability of written materials and the ease at which materials may be read:
- 2. use of teach-back and other approaches to improving verbal communication between health professionals and consumers;
- 3. encouraging consumers to ask questions through tools such as Ask Me 3 and providing education to consumers on the type of questions to ask health professionals.

#### Making resources readable and easy to understand

When developing easy to understand written materials it is possible to focus on how readable materials are by looking at factors such as word length (number of syllables used) and sentence length. Some common readability tools include:

- Flesch Kincaid Grade Level
- Gunning Fog Score
- Simplified Measure of Gobbledygook Index (SMOG)
- Coleman Liau Index
- Automated Readability Index.

There are several websites that provide information and enable services to test the readability of their material. For example:

https://www.onlineutility.org/english/readability\_test\_and\_improve.jsp or https://www.readabilityformulas.com/free-readability-formula-tests.php

It is necessary to prepare the text before conducting a readability assessment. Usually at least 300 words are required; white spaces and incomplete sentences need to be removed. When conducting a readability assessment, it is best to aim for a reading age of less than or equal to Grade 6 to address the needs of consumers with low health literacy.

The majority of the examples of readability assessments focus on improving the readability of disease specific questionnaires or consumer information (Betschart et al. 2018).

It is also possible to focus on an array of features that make materials easy to understand such as the use of white space and icons and larger fonts. Written communication can be simplified by using strategies such as Easy Read. The Council for Intellectual Disabilities have numerous resources available in Easy Read, including information on goal setting, visiting a doctor and mental health (see <a href="https://cid.org.au/resource-tag/easy-read/">https://cid.org.au/resource-tag/easy-read/</a>). Most relevant to this review is the guide on taking medications: https://cid.org.au/resource/meandmy-medication-guide/.

Asking consumers for feedback on written communication is an effective way to develop and refine easy to read written materials and is recommended in the National Quality and Safety Health Service Standards developed by the Commission. The Commission recommends that consumers be involved in codesigning written materials and that consumers give feedback on and evaluate forms and other written materials. Tips for getting feedback from consumers can be found in the Universal Precautions Toolkit (Brega AG et al. 2015).

## Verbal communication strategies

Verbal communication strategies that may be used in consumer communication include the use of teach back, diagrams and pictograms, navigation support and following up to ensure consumers are able to attend their appointments. Teach back is a simple yet effective tool used to check consumers understanding of what was communicated. Teach back allows health professionals to see how well they explained health information to consumers. The advantages of teach back are that it helps consumers to remember and understand health information. Relaying information in one's own words encourages deeper sematic processing. This is not the case when consumers simply repeat the same words back to the case managers. The effective use of teach back also increases consumer satisfaction and helps gain trust. Further details and resources on teach back can be found at the following website (http://teachback.org/).

# Consumers asking questions

There are several resources available to support consumers to ask questions of their health professionals. For example, the NPS MedicineWise Choosing Wisely strategy has three resources: 5 questions to ask your doctors, tips for talking with your doctor, and conversation starters. These resources are available at

https://www.choosingwisely.org.au/resources/consumers-and-carers/5-questions-to-askyour-doctor-or-other-healthcare-provider-before-you-get-any-test-treatment-or-procedure.

The Agency on Healthcare Research and Quality also has a resource entitled: Do you know the right questions to ask? Questions are the answer. This is available at www.ahrq.gov/questionsaretheanswer.

Encouraging consumers to ask questions is a laudable approach, but it may be insufficient to ensure that consumers are more engaged in their healthcare. Power imbalances between providers and consumers can leave consumers unsure and afraid to ask question of health professionals, even if they know the right questions to ask.

# Integrating health literacy into education for consumers

The main platforms for developing consumer and population health literacy skills include adult education, school education and interactive platforms such as apps and websites. A systematic review on the effectiveness of health literacy interventions in the European Union found the following interventions types: group, individual, web-based, component such as information leaflet, and multicomponent (Visscher BB et al. 2018).

Visscher and colleagues describe a number of multicomponent interventions. For example, a group training program on evidence-based medicine that was conducted over five days. Participants included patients, patient counsellors, consumer representatives and healthcare professionals. Another example of a group intervention focused on marginalised women and included computer courses, lectures on topics related to health, and language training (Visscher BB et al. 2018). This suggests that group interventions can focus on specific consumer segments or can be broader and include health professionals.

In 2018, Nutbeam and colleagues conducted a systematic review on community health literacy interventions (Nutbeam, McGill, and Premkumar 2018). The review found only a limited number of interventions, most of which had been located in clinical settings and have focused on improving functional health literacy. While there is a growing evidence base on interventions to improve health literacy with consumers, it is not of the scale required to make great strides in improving population level health literacy.

In addition to taking action to address health literacy as discussed in the paragraphs above, it is also possible to monitor and examine consumer preferences for accessing health information.

# Consumers' health information needs and preferences

In 2017 the Commission contracted a rapid review on consumer health information needs and preferences. Meeting consumers' health information needs is a necessary prerequisite for consumers to make decisions about their own care and the options associated with it. Consumers will seek information about their illness, symptoms, treatment and how to prevent errors and increase safety over the course of their health care journey. The review addressed the following questions:

- When do consumers look for information about healthcare safety and quality?
- Where do consumers find information?
- How do consumers use information?
- About which topics or subjects do consumers need healthcare quality and safety information?

The rapid review found that consumers seek information at different stages through their healthcare journey including during screening, diagnosis, treatment, decision-making, recovery and discharge. Consumers' health information needs change throughout the consumer's journey.

Consumers trust their healthcare provider when seeking health information. Other sources of information include printed resources and interpersonal communication with friends and family. The internet is another source of information, but it is generally used as a supplement rather than an alternative to advice from a health professional.

Preferences for where consumers find information can vary between different groups. Notable examples include consumers from CALD backgrounds and older people. Both these consumer segments prefer to turn to their health professionals for health-related information. Low health literate consumers are less likely to seek health information and place greater reliance on the health professional to provide information.

Health professionals are the preferred source of information when consumers are looking for an accurate medical diagnosis, information about prescription medication, information about alternative treatments, a recommendation for a doctor or specialist, or a recommendation for a hospital.

The rapid review indicates that consumers' decisions about when to access health information and from what source is determined by the context. This suggests that consumers will access a range of sources for different purposes. The internet is widely used among the general population but less so among older Australian and people from specific cultural backgrounds. The internet is not necessarily seen as better-quality information, rather it is seen as convenient and accessible (Ramsey I et al. 2017).

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

# **Conclusions**

There is a growing evidence base of interventions to improve health literacy among consumers and communities. However, there is a need to increase the scale and scope of the work to match the low levels of health literacy in Australia generally.

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

It is important to note that there is an evidence base of effective interventions that may reduce the complexities and demands of the health care environment, such as improving navigation support to consumers accessing health care (Lloyd et al. 2018). However, these interventions were excluded from this review which focused on consumer and clinical level interventions.

# Population-wide initiatives for improving medication literacy and QUM in Australia

A range of initiatives to improve medication literacy and QUM by consumers have been developed, piloted, and in some cases implemented, in Australia and/or internationally. These initiatives are varied and include, for example, information resources, tools, funding programs, and research studies and pilots.

The initiatives identified from the literature are grouped into:

- population-wide initiatives (initiatives which target the whole of the population rather than specific segments), which are covered in this section of the report; and
- initiatives targeting specific population segments, which are covered in the next section of this report.

Key population-wide initiatives identified in the rapid review are categorised and summarised below. Given that this list has been drawn up from a rapid review methodology, it is not claimed to be a comprehensive or complete list of initiatives. In particular, this analysis focuses on generic initiatives that have been developed for use across the population and across disease groups. There are also a number of initiatives that have been developed for consumers with specific conditions, such as diabetes, heart disease, or cancers. Due to limitations of time and scope, these resources are not included in this rapid review.

The initiatives are further broken down into three categories, being:

- System-level initiatives
- Initiatives targeting the health workforce (particularly pharmacists)
- Consumer-focused initiatives.

A summary in tabular form of all initiatives outlined in this section of the report is at Appendix C.

Key findings from the examination of population-wide initiatives for improving medication literacy and QUM are outlined at the end of this section.

# **System-level initiatives**

At system level, governments have put measures in place to either incentivise certain models of care, or to require adherence to certain standards of care, which impact on consumer medication literacy and QUM. Key initiatives of this nature are outlined below.

#### The NSQHS Standards

The National Safety and Quality Health Service (NSQHS) Standards provide a nationally consistent statement of the level of care consumers can expect from health service organisations. The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health service provision. They are the standards against which hospitals and health services across Australia are assessed for accreditation. The Standards were developed by the Commission in collaboration with the Australian

Government, states and territories, private sector providers, clinical experts, patients and carers (Australian Commission on Safety and Quality in Health Care). The 2nd edition of the NSQHS Standards, published in 2017, can be found at the following address (https://www.safetyandquality.gov.au/standards/nsghs-standards).

The NSQHS Standards have a strong focus on partnering with consumers, and on health literacy, including in relation to medication management. The NSQHS Standards state that: "The patient is the focus of the medication management pathway. Health service organisations should apply the principles of partnering with consumers, health literacy and shared decision making when developing, reviewing and implementing processes or practices within the medication management pathway." The NSQHS Standards set out actions for health providers to take, particularly in relation to providing information to patients, and supporting shared decision making (Australian Commission on Safety and Quality in Health Care).

As noted earlier in this review, in practice these standards are perhaps the most explicit national statement of strategies Australian health care providers should adopt to create an enabling environment for QUM health literacy, as opposed to simply providing information on medications and QUM, which is the focus of most of the tools and resources listed below. In this sense, they represent a key resource for health care providers to promote consumer health literacy around QUM, and a potential framework for the development of consumer-focused initiatives.

#### Home medicines review MBS Item

The Home Medicines Review (HMR), initially introduced in 2001, is an MBS item for patients living in the community setting. The goal of the HMR is to maximise an individual patient's benefit from their medication regimen and prevent medication-related problems through a team approach, involving the patient's GP and preferred community pharmacy. This may only be initiated by a patient's GP after assessing the patient's need for the service. In addition to the consumers' GP and pharmacy, the HMR may also involve other relevant members of the health care team, such as nurses in community practice or carers.

In collaboration with the GP, a pharmacist comprehensively reviews the patient's medication regimen in a home visit. After discussion of the pharmacist's report and findings, the GP and patient agree on a medication management plan. The patient is intended to be central to the development and implementation of this plan with their GP. The program is funded by the Australian Government and managed by the Pharmacy Guild of Australia, with the pharmacist component provided at no cost to the patient (Commonwealth Department of Health 2014).

The reviews have been identified as being particularly useful for people who: take more than five medicines a day; have recently spent time in hospital; are concerned about their medicines; are confused about their medicines; or do not always remember to take their medicines. Resources and tools are available to inform consumers and carers about the program (e.g. <a href="https://www.nps.org.au/consumers/managing-your-medicines#getting-ahome-medicines-review-(hmr)">https://www.nps.org.au/consumers/managing-your-medicines#getting-ahome-medicines-review-(hmr)</a>; <a href="https://www.healthdirect.gov.au/home-medicines-review">https://www.healthdirect.gov.au/home-medicines-review</a>) as well as to support pharmacists in the delivery of HMRs (e.g.

https://www.ppaonline.com.au/programs/medication-managementprograms/homemedicines-review).

There is significant information available on activity levels under the program, but less information has been identified in relation to program outcomes. A 2008-09 evaluation focusing on the economic value of HMRs was quite inconclusive (Stafford AC et al. no date). Other research has identified low consumer and carer awareness of HMRs, and the need for a marketing plan to increase consumer demand (White L and Clarke C no date). Chen (2016) notes that while the positive impact of such services has been demonstrated using a variety of validated measures, there remains a need to also evaluate actual clinical outcomes and/or patient-reported outcomes (Chen 2016).

There has been limited research into consumer perspectives of HMRs. A qualitative study by Ahn et al (2015) found that a well-performed HMR process within a patient-centred paradigm can enhance patient understanding and lead to patient benefit. The majority of participants reported positive outcomes from their HMR experience, including increased knowledge, a holistic review, medication improvement, increased health seeking behaviour, strengthened self-management and interest of participants in encouraging others to seek out an HMR. However, difficulties were encountered when patient's expectations were not met, particularly with respect to the initial GP meeting, limited information and engagement by the pharmacist, long delays in the process and limited GP follow-up and support for the program. Such difficulties led to patient frustration and disappointment, and a lost opportunity to enhance health literacy and engagement (Ahn et al. 2015).

Overall, it appears that the development and implementation of HMRs has been driven by the pharmacy sector, with limited opportunities for consumer co-design; and that evaluation of program effectiveness and consumer perspectives has been relatively limited.

# The Pharmacy Trial Program

Through the 6th Community Pharmacy Agreement, the Australian Government is investing \$50 million to support a Pharmacy Trial Program. The Pharmacy Trial Program seeks to improve clinical outcomes for patients and/or utilise the full scope of a pharmacist's role in delivering primary health care services. These services provided through this program include medication management programs and patient support services focusing on pain management, diabetes, mental health and reducing medicine induced deterioration and adverse reactions. There is a particular focus on programs which benefit Aboriginal and Torres Strait Islander peoples, and consumers from rural and remote areas (Australian Government Department of Health 2018).

CHF undertook a consumer survey in 2015, to ensure that consumers' opinions were considered and reflected in the development and implementation of the Pharmacy Trial Program. Most respondents in this survey were supportive of a larger role for pharmacists in the provision of primary care services, though some concerns were raised about GPs potentially being "out of the loop", the potential safety and quality of the services to be provided, and the level of privacy afforded in the pharmacy setting. Consumer views about expanded roles for pharmacists appear to be more complex, however, than the survey results might indicate. CHF noted a trend, while running the survey, that comments on CHF's social media pages concerning the proposed expansion of pharmacists' role in

primary care were very strongly in opposition. Additionally, the consumers who agreed to postsurvey interviews tended to be sceptical – if not outright opposed – to the notion of pharmacists' involvement in primary care (Consumers Health Forum of Australia 2015).

There does appear to be a potential tension in the Pharmacy Trial Program's conceptual framework, between extending and enhancing the role of pharmacists, and addressing the needs and preferences of consumers.

# Health workforce initiatives

Health professionals have a key role to play in supporting consumer medication literacy and QUM. The 2017 NPS MedicineWise National Consumer Survey found that when consumers look for information about medicines, the majority (86%) ask a health professional (NPS MedicineWise 2017). It is therefore important not to underestimate the role of health professionals in consumer medication literacy. The role of pharmacists is of particular interest, as surveys of consumer patterns in utilising the health system routinely find that consumers in general have more interaction with their local pharmacists than any other health professional (Consumers Health Forum of Australia 2015).

While a comprehensive review of education, tools and resources for health professionals in relation to consumer medication literacy and QUM is out of scope for this review, some key tools and resources implemented in Australia and internationally to assist pharmacists and other health professionals to support consumer medication literacy and QUM are summarised below.

# NPS MedicineWise information and programs for health professionals

As noted earlier, NPS MedicineWise was established by the Australian Government in 1998, with the primary aim of promoting better use of medicines. NPS MedicineWise provides evidence-based information to health professionals and consumers through initiatives including academic detailing, audit and feedback, and interactive learning. The target audiences have typically been general practitioners, pharmacists and nurses in primary care. Considerable health professional-focused activity has been delivered over a more than 20-year period, involving considerable funding.

# Health Literacy in Pharmacy Project (HeLP)

Australia's 5th and 6th Community Pharmacy Agreements have included significant funding to develop the role of pharmacists in QUM. The HeLP project was funded through the 5th Community Pharmacy Agreement, and undertaken by a research team from universities across Australia as well as the PSA. The aim of the HeLP research project was to increase Australian pharmacists' and pharmacy staff members' knowledge of health literacy, and ability to detect and respond to consumers' health literacy issues.

This was to be achieved through the delivery of an education package to help overcome communication barriers regardless of consumers' perceived health literacy. The study found that while there was an increase in pharmacists and staff in the initiative group asking consumers, "What questions do you have?" (a primary outcome measure, recognising the value of open-ended phrasing in communication), there were no statistically significant

differences between the pharmacy initiative and control groups in relation to use of teach back (the other primary outcomes measure) and secondary outcomes, such as provision of hard copy information.

The researchers found some beneficial effects from the initiative, but noted that "The results from this study highlight the difficulties in altering pharmacists' and pharmacy staff members' behaviours in regard to communication with consumers, and provides scope for refining the health literacy educational package to increase the likelihood of affecting change after a wider dissemination to community pharmacies in the future" (Duncan G, Emmerton L, and Hussainy S no date).

This research does identify barriers to utilising pharmacists and pharmacy staff as a channel for supporting consumer health literacy and medication literacy. It is not clear whether, or in what ways, the outcomes of this research have been utilised.

# Brown Bag Medication Review tool

The "brown bag medicine review" developed in the United States, is a practice in which patients aid in medication reviews by putting all their medications in a bag and bringing them to their clinicians for review. However, it can be difficult to get patients to bring all their medications to clinic visits, which can limit the value of the reviews. The Health Literacy Universal Precautions Toolkit, developed by the US Agency for Healthcare Research and Quality (AHRQ), was designed to help clinicians improve communication and support for patients at all literacy levels. One of the tools in the toolkit ("Brown Bag Medication Review" tool) provides guidance on effectively implementing medication reviews. The toolkit can be accessed at this address: https://www.ahrq.gov/health-

literacy/qualityresources/tools/literacy-toolkit/healthlittoolkit2-tool8.html. The guidance focuses on getting patients to bring their medications to office visits, conducting the medication review, confirming patient understanding of medication regimens, clarifying medications and medication instructions, identifying drug therapy problems (e.g. unnecessary drug therapy, incorrect dosages, duplicate medications), documenting review results, and providing an updated medication list to patients (Weiss et al. 2016).

Studies evaluating the outcomes of implementing the tool appear encouraging. In an initial study, implementation of the toolkit's Brown Bag Medication Review in two family practices in the US found that practices made the changes recommended in the toolkit to encourage patients to bring medications to office visits. Evaluation before and after implementation found a 3-fold increase in the percentage of patients who brought all their prescription medications and a 6-fold increase in the number of prescription medications brought to clinic visits. The percentage of reviews in which drug therapy problems were identified doubled, as did the percentage of medication regimens revised (Weiss et al. 2016). Another study, aiming to improve medication adherence in a low-income population without significant disruption of the current model of care using the Brown Bag Medication Review tool, has demonstrated the ability to accurately identify medication nonadherence in patients, as well as the health literacy gaps contributing to nonadherence. The brown bag medication review also allowed direct comparison of medication versus verbalised recall by the patient. The authors conclude that the brown bag review is an effective, safe, and feasible initiative (Murtha, Elder, and Faragher 2020).

Given the US studies provide good evidence of the effectiveness of the Brown Bag Medication Review tool, it may have applicability for utilisation in the Australian context. It is not clear whether the tool has been considered for uptake in Australia.

# **Consumer-focused initiatives**

Key consumer-focused tools and resources aiming to support medication literacy and QUM in Australia include:

- Written information, primarily Consumer Medicines Information
- Online information and resources (websites)
- Apps
- Telephone support
- Media and public relations (PR) campaigns
- Social media
- Enhancements to readability of medicine labels and instructions.

Initiatives across each of these areas are outlined below.

#### Written medicines information

#### **Consumer Medicines Information**

The most important form of written information for Australian consumers is Consumer Medicines Information (CMI) for prescription and pharmacist-only medicines.

The 2017 NPS MedicineWise National Consumer Survey found that CMI provided with the medicine is read by 22% of consumers (NPS MedicineWise 2017).

A CMI document is written by the pharmaceutical company (sponsor) responsible for the medicine. A CMI includes:

- Name of the medicine
- Names of the active and inactive ingredients
- Dosage of the medicine
- What the medicine is used for and how it works
- Warnings and precautions, such as when the medicine should not be taken
- Interactions the medicine might have with food or other medicines
- How to use the medicine properly
- Side effects
- What to do in the case of an overdose
- How to store the medicine properly
- Name and address of the sponsor
- Date the CMI was last updated.

CMI documents may not be available for every product. Sponsors are required to provide CMIs prior to new prescription medicines and specified over the counter (OTC) medicines being released to the market. Products that have been registered but not yet released to the market will not have accompanying CMI documents. For medicines that do have a CMI, the sponsor is required to make it available to consumers either in the pack or in another manner that will enable the information to be given to the person to whom the medicine is

administered or otherwise dispensed (Australian Government Department of Health Therapeutic Goods Administration 2019).

In July 2019, the Australian Government announced that it would be introducing an improved format for CMI documents. This was in response to concerns raised by doctors, pharmacists and consumer health advocates regarding the complexity and readability of such documents. The Government stated that the new template for the documents is shorter, better laid-out and features a one-page summary that succinctly provides people with the most critical information relating to the safe and effective use of their medicines. The format was user-tested and received excellent feedback from participants. The overwhelming majority of people preferred the new format, finding it easier to use and understand. The new template also received unanimous support from doctor, pharmacist, industry and consumer representatives, who were consulted as part of this project. Digital enhancements for CMI were also explored and may be introduced in the future. It was noted that given there are several thousand CMIs, there will be a transition period as medicine companies progressively revise their materials (Australian Government Department of Health 2019).

CMIs clearly represent an important and authoritative source of medication information for consumers, with available data suggesting use by one in five consumers. It is to be hoped that the enhancements to useability may help to increase use by consumers. Information on uptake across age groups, health literacy levels, and population segments would be helpful.

#### Written information for OTC medicines

Written information is also available for some OTC products. In a qualitative study, Tong and colleagues (2018) explored UK and Australian consumers' receipt and use of spoken and written medicine information, with particular reference to leaflets for OTC medicines. They found that Australian and UK consumers' experiences were similar. Consumers did not often seek spoken information and reported that pharmacy staff provided minimal spoken information for OTC medicines. Leaflets were not always received or wanted and were less relevant as an information source for repeat OTC purchases. Consumers tended not to read OTC labels or leaflets, mainly due to product familiarity. The authors note, however, that familiarity does not assure safe or effective use of medicines; and argue that strategies to promote the value and use of these OTC medicine information sources are important and needed, particularly given minimal spoken information provision and an increasing move to reschedule some prescription medicines to OTC status (Tong, Raynor, and Aslani 2018).

As consumers appear not to need or value OTC leaflets, this would not appear to be a priority for future efforts, unless warranted by significant down-scheduling of prescription medicines.

### Online information and resources for consumers (websites)

The 2017 NPS MedicineWise National Consumer Survey found that when consumers look for information about medicines, 45% visit a website (NPS MedicineWise 2017). In addition to the NPS MedicineWise website, even within Australia, let alone internationally there are multiple health websites for consumers which include information on medicines and QUM. The 2017 NPS MedicineWise National Consumer Survey found that consumers used several other websites as a source of medication information, and gave high ratings to the

Better Health Channel, healthdirect, and Diabetes Australia websites (NPS MedicineWise 2017). There are also multiple additional sites providing medicines information for people from particular population segments (for example, people with an intellectual disability), and for people seeking information on particular conditions, such as diabetes, heart disease or cancers; these are not reviewed here.

A few key Australian sites are outlined here. Other than the information available from NPS MedicineWise surveys, this review uncovered no evidence regarding the usage of these websites. Given the proliferation of online information, it would be helpful to have data on the number and attributes of people accessing information from authoritative websites such as those listed here, in comparison with those accessing information from less authoritative online sources.

#### NPS MedicineWise website

NPS MedicineWise maintains a dedicated section of its website with comprehensive information and resources targeted to consumers and carers (<a href="https://www.nps.org.au/consumers">https://www.nps.org.au/consumers</a>). The NPS MedicineWise website offers fact sheets and other information for consumers, as well as a range of resources and tools, such as medicine name finder, medicines lists, access to CMI's, decision support tools, and action plans, as well as a downloadable app.

The 2017 NPS MedicineWise National Consumer Survey found that 18% of consumers responding to the survey had visited the NPS MedicineWise website, an 11% increase from 2015 levels. 62% of consumers who were aware of NPS MedicineWise rated the organisation's trustworthiness as good to very good. The NPS MedicineWise website rated most highly on being a "research or evidence-based" source of health information (69% gave a 6 to 7 rating out of a 7 point scale) followed by being "trustworthy" (67% gave a 6 to 7 rating). Fewer consumers perceive that the NPS MedicineWise website is recommended by a health professional (46%) (NPS MedicineWise 2017).

In addition to the information on the NPS MedicineWise website, NPS MedicineWise also offers consumers a range of other tools and resources including an app, telephone advice, and more, as outlined below.

#### CHF/TGA web pages

CHF's Be Health Aware web page for consumers (<a href="https://chf.org.au/be-healthaware#medicine">https://chf.org.au/be-healthaware#medicine</a>) includes a section on medicines and medical devices, with links through to the Therapeutic Goods Administration (TGA) website. Topics covered include:

- General consumer information about medicines and devices
- Reporting of adverse events and side effects
- Safe and effective use of prescription and OTC medicines
- The Black Triangle scheme
- Understanding medication labels
- Buying medicines or medical devices online
- Tips for travelling with medicines and medical devices
- The Medsearch app
- Return of unwanted medicines.

#### Healthdirect

Healthdirect is a government-funded service providing quality, approved health information and advice. The healthdirect website includes a comprehensive consumer page on medicines at https://www.healthdirect.gov.au/medicines.

Healthdirect also has an online medicine information service launched in 2016, which aims to reduce confusion and misuse of medicines by making information more consumer friendly and easy to understand (https://about.healthdirect.gov.au/healthdirect-medicineinformationservice). The site uses data and images from a range of publicly available trusted medicine data sources and lists nearly 10,000 separate pages of medicines registered for sale in Australia, comprising the most comprehensive medicine catalogue available in Australia. The information, which is updated monthly, includes:

- A description of the medicine
- The conditions it is used to treat or prevent
- How to store it
- Its form (tablet, capsule, ointment, cream or injection)
- How it is administered, if there have been any recalls
- Links to the relevant Consumer Medicines Information (CMI) leaflet.

Healthdirect recently conducted user testing and a health literacy review of these pages, which resulted in improvements to the way the information is presented and simplified language wherever possible to improve consumer understanding. A recent inclusion to the medicine information service is the ability for users to report adverse events and side effects after taking their medications, with information fed into the TGA's safety monitoring system.

#### Better Health Channel

The Better Health Channel website is funded and managed by the Victorian State Government, and aims to provide health and medical information to improve the health and wellbeing of people and the communities they live in. The website includes a significant quantity of information on medication and QUM for consumers, including a range of general information about different categories of medications; guidance on safe use of medications; and links to CMIs

(https://www.betterhealth.vic.gov.au/conditionsandtreatments/medications).

Overall, there does not seem to be any lack of high-quality online information available to Australian consumers. However, there is limited data on the uptake and utilisation of this information.

### Mobile applications (apps)

Apps have become increasingly utilised in a wide range of fields and for a wide range of purposes, including QUM. A 2014 search identified a staggering 461 medication adherence apps, and found that the design, functionality, and quality of these apps, including levels of health literacy compliance, varied widely. While a majority of the adherence apps were capable of handling straightforward medication instructions, fewer than half were capable of adequately handling complex medication regimens, where reminders may be of most importance. The authors noted that people that are more likely to use and sustain use of apps for medication adherence are those that are older and are on more medications, which highlights the importance of apps handling complex medication regimens (Heldenbrand et al. 2016).

The world of apps has developed exponentially, and the number and variability of apps available can in itself present pitfalls for consumers. However, there are high quality medication apps available to Australian consumers. Two leading apps in Australia are the NPS MedicineWise app and the MedSearch app.

#### NPS Medicine Wise app

The MedicineWise app (previously known as the MedicineList+ app) is designed to assist consumers keep track of medicines and access important health information anytime and anywhere, especially in emergencies (<a href="https://www.nps.org.au/medicinewiseapp#it's-time-to-testdrive-medicinewise-app">https://www.nps.org.au/medicinewiseapp#it's-time-to-testdrive-medicinewise-app</a>). The app allows a consumer or carer to:

- Create a list of medicines by scanning their medicine barcodes or searching the comprehensive Australian medicines database;
- Record important health information such as medical conditions, allergies and health professional contact details;
- Set reminders for when to take medicines and attend doctors' appointments;
- Access Consumer Medicines Information (CMI) to learn more about their medicines;
- Generate and share their medicine lists and usage reports with healthcare professionals via email;
- Store, graph and share their test results;
- Create separate profiles for those in their care to manage medicines and health info for others;
- Store notes and questions to ask their doctor.
   (https://www.nps.org.au/consumers/medicinewise-app#what-is-the-medicinewiseapp?)

The NPS Medicine Wise 2017 National Consumer Survey found that the MedicineWise app feature that encouraged the most downloads and use among consumers overall was the health information record (44%), while the drug interaction checker attracted interest as an additional feature of the app. About half of the consumers (49%) who had low adherence and 60% of those who had difficulty managing their condition were motivated to download and use the app for its health information record feature. The reminders functionality motivated 32% of those who had difficulty in managing their condition and 49% of those with low adherence to their medicines. Over half of the carers who responded to the survey (53%) were particularly drawn to use the health information record feature of the app. Consumers were most interested in having access to a drug interaction checker feature (43%) followed by an information portal (36%) as part of the suite of features which could be added to the app (NPS MedicineWise 2017).

The survey also assessed interest to consider using a smartphone app for medicines reminder and prescription management features across certain groups, and found that:

- People who have difficulty managing their health conditions are more likely to consider using a medicines management app
- People who have low adherence to medicines are more likely to consider using a medicines management app
- There is a relatively high level of interest among carers to use a smartphone app

 People who have depression and/or anxiety as well as those who have asthma have more interest in using a smartphone app compared with those with other selected conditions (NPS MedicineWise 2017).

The findings suggested that more people who have difficulty managing their health conditions and those who are less adherent with their medicines could be encouraged to download the MedicineWise app for these two functions, compared with people who easily manage their condition and people who are adherent with their medicines (NPS MedicineWise 2017).

#### MedSearch app

The MedSearch app was developed by the Australian Government Department of Health Therapeutic Goods Administration (TGA) and launched in June 2017. The app is intended for doctors and patients to access CMI and scientific Product Information (PI) targeted to prescribers, for prescription medicines approved in Australia.

For doctors, the process of finding information is streamlined, with PI being immediately accessible through the app, including adverse effects, dosage instructions, indications and precautions. Consumers, who previously needed to consult the leaflets found within the packaging of their medicines, speak with their healthcare professional or search the TGA website, can now access information on the safe and effective use of their medicine anywhere, any time and save the results for future reference.

Each time a PI or CMI is downloaded, the app automatically accesses the most recent version, ensuring access to the most current information possible. The app also undergoes periodic updates to uphold and improve functionality.

Users can save their 'favourite' PIs and CMIs, and these can then be quickly and easily accessed through the main menu. The app also makes it easy for users to share links to documents with other people via other applications, such as email (https://www.tga.gov.au/medsearch-app).

## Telephone support

NPS MedicineWise collaborates with healthdirect Australia to deliver Medicines Line, a telephone service providing consumers with information on prescription, over the counter and complementary medicines. Consumers who call 1300 MEDICINE from all states and territories in Australia (except Queensland and Victoria), speak with a registered nurse. The consumer's question may be answered on the spot, or the consumer may be referred to a GP or pharmacist, or to another health professional. Complex enquiries may be put through to an NPS MedicineWise pharmacist. Consumers calling from Queensland or Victoria are connected directly with an NPS MedicineWise pharmacist (https://www.nps.org.au/medicines-line).

In 2017-18, Medicines Line answered 7,263 calls.

# Media and PR campaigns

#### NPS Be Medicinewise Week

NPS MedicineWise has run an annual Be Medicinewise Week since 2011, aiming to improve medication literacy and QUM among consumers. Key components of recent campaigns have included:

- An articulated theme for each campaign: for example, 2019 was "learn the language of medicines"; 2018 was "safe and wise medicines use by families"; 2017 was "avoid medicine misuse by knowing the active ingredients in your medicines".
- Consumer surveys to underpin and generate media interest in the campaigns;
- Campaign resources and toolkits for pharmacists and other providers
- Videos promoting medicinewise behaviour, particularly intended for use on social media
- Links to information and resources for consumers (<a href="https://www.nps.org.au/bemedicinewise#download-resources">https://www.nps.org.au/bemedicinewise#download-resources</a>).

#### World Antibiotic Awareness Week

World Antibiotic Awareness Week is an annual global campaign spearheaded by the WHO to promote safe and appropriate use of antibiotics and raise awareness of the growing threat of antimicrobial resistance. Both NPS MedicineWise

(https://www.nps.org.au/news/worldantibiotic-awareness-week-handle-antibiotics-with-care) and the Commission (https://www.safetyandquality.gov.au/our-work/antimicrobial-stewardship/antibioticawareness-week/resources-antibiotic-awareness-week-2019) participate in the campaign in Australia, providing information and resources for consumers and health care providers. NPS MedicineWise has also run a consumer survey to underpin the campaign.

Survey data on the impact of these campaigns is outlined at Appendix B.

#### Social media

Consumers generally access a wide range of information through social media. However, NPS MedicineWise survey data indicates that social media and blogs are not routinely accessed to search for information about medicines, with only 9% of respondents using these sources. However, there are important exceptions. People aged 16-34 years (15%), those who speak English as their second language (20%) and people with Aboriginal and/or Torres Strait Islander heritage (20%), were significantly more likely to turn to social media and blogs (NPS MedicineWise, 2017). This is a potential concern, given the potential vulnerability of these groups, and the lack of quality control in the social media sphere. However, as noted above, NPS MedicineWise develops videos on medicinewise behaviour, for use on social media during Be Medicinewise Weeks. NPS MedicineWise also maintains a YouTube library (<a href="https://www.youtube.com/channel/UCkzFd3DvdMiK7Sb6eYbnEQw">https://www.youtube.com/channel/UCkzFd3DvdMiK7Sb6eYbnEQw</a>), and operates Facebook and Twitter accounts. Such activities no doubt help to ensure the availability of authoritative information from a trusted source, on social media platforms.

# Readability of medication labels and instructions

Research evidence is being developed to inform enhancements to the readability of medication labels and instructions. The evidence to date appears to indicate that simple enhancements to labelling can be highly effective; and that while pictograms have some usefulness in supplementing text instructions, their usefulness should not be overestimated.

#### Labelling improvements

Many patients do not understand their prescription drug labels, and therefore may not take their medications as prescribed. This problem is more common in patients with limited health literacy. A systematic review of best practices for labelling of prescription drugs has identified the importance of simple measures to enhance labelling, including increased font size, use of san-serif fonts and numerals rather than text for numbers, use of clear and simple language, and an emphasis on patient-centred information (McManus et al. 2018).

A study in Ireland has assessed the impact of a Universal Medication Schedule (UMS) on the knowledge and consolidation of a prescription drug regimen compared to standard pharmacy labelling, among adult patients fluent in English, at a specialised rehabilitation hospital. The UMS offer simplified dosage instructions using standardised time intervals (morning, noon, evening, bedtime); and has been studied and adopted in parts of the US. Those in the UMS group displayed better understanding of the prescription regimen than those in the usual care group, but this was not statistically significant; and subgroup analysis did not find any additional benefit of UMS in those with limited health literacy, though paradoxically it did benefit patients who said they found instructions on tablets hard to understand. The researchers found that participants with adequate health literacy were more likely to self-report finding instructions on tablets from the chemist hard to understand, which may imply better insight by these participants. There was no significant association between having limited health literacy and reporting finding instructions on tablets hard to understand. Notably, a significant cohort of patients did not self-identify as having difficulty with medication instructions but were unable to accurately dose out the sample medication regimen (McManus et al. 2018).

Garada and colleagues (2017) investigated the perspectives of Australian consumers, pharmacists and prescribers on documenting the indication on prescriptions and dispensed medicines labels, which is not standard practice in this country. Interviews with thirty-four participants found that most agreed that documenting the indication would be beneficial, especially for patients who are forgetful or take multiple medications. Participants also believed it would improve consumers' medication understanding and adherence. Prescribers and pharmacists believed it could help reduce prescribing and dispensing errors by matching the drug/dosage to the correct indication. Prescribers refrained from documenting the indication to protect patients' privacy; however, most patients did not consider documenting the indication as a breach of privacy. Prescribers raised concerns about the extra time to include indications on prescriptions and best language to document indications, using plain language as opposed to medical terminology (Garada et al. 2017).

# **Pictograms**

Leong and colleagues (2018) tested the theory that pictograms may improve patient understanding of medication schedules, by assessing the value of pictograms versus text instructions in enabling consumers to correctly fill pill boxes. They found that the use of pictograms did not significantly improve participants' ability to correctly fill a pill box; however, 77% of participants reported that pictograms help them to understand medication instructions; 67% of participants preferred pictograms; and 93% felt pictograms should be used on all medication labels. The authors conclude that further research is needed to determine the efficacy of pictograms for specific populations (Leong et al. 2018). Similarly, a study aiming to validate pictograms for medication instructions with older consumers found only modest levels of consumer comprehension of the pictograms, as set out further below (Berthenet, Vaillancourt, and Pouliot 2016).

# **Conclusions**

This review has identified a wide range of tools, resources, and other initiatives aimed at improving consumer medication literacy and QUM for the Australian population as a whole. These include system level initiatives, initiatives targeting health professionals (particularly pharmacists), and initiatives targeting consumers themselves.

In relation to system level initiatives, the Australian Government has invested significant funds into QUM, particularly through MBS items including HMRs, and through initiatives such as the Pharmacy Trial Program, funded through the Community Pharmacy Agreement. These programs appear to be caught between the dual aims of supporting the development of the pharmacy profession and supporting consumer health outcomes.

In relation to health professional initiatives, NPS MedicineWise represents another very significant Australian Government investment, targeted to both health professionals and consumers. NPS MedicineWise has delivered a large volume of educational programs, and resources and tools to health professionals, at considerable cost, and a range of other health professional guidance has been produced by others including health professional However, the outcomes of these programs and resources have not been well evaluated, and it is not possible to assess their focus or impact on consumer medication literacy.

Consumer-focused initiatives have also been funded and implemented, most of them focused on information provision. It is clear from this review that there is no shortage of authoritative, high quality medication information available for Australian consumers. The resources and tools available for consumers include CMI, online information and tools, apps, a telephone service, and more. However, there appears to be scant evaluation evidence to demonstrate the effectiveness of these tools and resources, including consumer acceptability, consumer uptake, impact on consumer health literacy, and impact on health outcomes.

# Medication literacy and QUM initiatives targeting specific population segments

As noted earlier, a range of initiatives to improve medication literacy and QUM by consumers have been developed, piloted, and in some cases implemented, in Australia and/or internationally. The initiatives identified from the literature are grouped into:

- population-wide initiatives, which are covered in the previous section of this report;
- initiatives targeting specific population segments, which are covered in this section.

The population segments included here comprise: older consumers; Aboriginal and Torres Strait Islander people; CALD consumers; and consumers with low literacy/low health literacy.

Key initiatives identified in the rapid review which target specific population segments are categorised and summarised below. Given that this list has been drawn up from a rapid review methodology, it is not claimed to be a comprehensive or complete list of initiatives. Again, disease-specific initiatives were not examined.

The initiatives are broken down into three categories, being:

- System-level initiatives
- Initiatives targeting the health workforce
- · Consumer-focused initiatives.

A summary in tabular form of all initiatives outlined below is at **Appendix D**.

Key findings from the examination of initiatives for improving medication literacy and QUM in specific population segments are outlined at the end of this section.

# **Initiatives targeting older consumers**

Given that older people (people aged 65 and over) are high users of medication, older people are clearly a prime target group for the whole-of-population initiatives listed above. This review did, however, identify some additional initiatives specifically targeting older people.

# System level initiatives

#### Medication reviews for aged care residents

Similar to HMRs, funding is available through the MBS for pharmacists to undertake medication reviews for residents of aged care services. Koria et al (2018) have investigated the impact of medication reviews on inappropriate prescribing in aged care. They find that pharmacist-led medication reviews are effective in reducing inappropriate prescribing among aged care residents, and therefore have the potential to reduce avoidable drug related harm and adverse clinical outcomes. The study also found that inappropriate prescribing is common among residents in aged care settings, which the authors argue supports the need for pharmacist-led medication reviews in these settings (Koria et al. 2018).

Recommendations on consumer-centred medication management for older Australians
In 2015, a national multidisciplinary working group dedicated to improving the QUM for older Australians issued ten recommendations for better integrating healthcare to provide consumer-centred medication management in the older Australian population, across settings and practitioners. The recommendations were:

- 1. Every health professional should ask the consumer (or their advocate) if they are carrying a list of any medications they take.
- 2. Consumers (or their advocate) should be encouraged to bring their medications to facilitate medications review at all healthcare assessments.
- 3. All older people taking medications should be offered an opportunity to review their medications through a consumer-centred prism (i.e. focusing on their own goals) at least annually.
- 4. Facilitate consumers' control, and sharing between health professionals, of medication information by encouraging shared electronic health records.
- 5. All older people should identify a primary community pharmacist and general practitioner.
- 6. Improve access to community multidisciplinary teams (e.g. multidisciplinary medical homes) as a policy priority.
- 7. The Australian Policy framework requires urgent updating to add contemporary steps for comprehensive medication review, medication reconciliation and communication of medication information at every transition of care.
- 8. Novel solutions using available technologies (e.g. matrix 'quick response' (QR) codes on medication labels) need to be explored. A QR code could be incorporated into the manufacturer's packaging on the front of boxes (distinct from the pharmacy dispensing label). This QR code could link the consumer (or health worker) to information at the reading level they require in the language they prefer and as a voice recording for those with low functional literacy.
- 9. Alternative versions of CMI leaflets should be available for older consumers, particularly those with a low level of health literacy.
- 10. There should be renewed consideration of a single funding mechanism for medications and medication management in Australia (Chalmers J 2018).

The status of these recommendations and their implementation is unclear.

#### Health workforce initiatives

Defining the role of aged care nurses and staff

Price and Boylan (2015) argue that aged care nurses and care staff can play a vital role in improving older people's health literacy and ensuring safe and effective use of medicines. They state that aged care nurses have a responsibility to ensure that older people have the skills, knowledge, motivation and capacity to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action. To achieve this, a critical first step is that aged care staff must ensure they themselves have the required level of knowledge, necessary skills, motivation and capacity to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action. Aged care staff need to also ensure that the infrastructure, policies, processes, materials, people and relationships that make up the environment in which they work impacts in positive ways on the way that older people

access, understand, appraise and apply health related information and services (Price K and Boylan J 2015).

Again, the uptake of these practice recommendations is not clear.

#### Consumer-focused initiatives

#### Consumer education and resources

Smith et al (2019) report on a study which examined the effectiveness of an education intervention on complementary medicines (CM), aiming to improve older adults' decision making and health literacy. Participants were randomly allocated to receive a CM education intervention (delivered using a website or DVD) plus booklet, versus booklet only. The primary outcome was decision self-efficacy, with secondary outcomes including the Preparation for Decision-Making scale and health literacy. The authors found that decision self-efficacy improved for participants but did not differ between groups. There were no significant differences on any outcome between the delivery of information using a website/DVD and booklet, versus booklet only, suggesting no particular format was more effective than the other. Both groups of participants found the resources useful, and their scores suggest the resources better prepared them to communicate with their practitioner at a consultation focused on making a health decision (Smith et al. 2019).

This study is one of the few initiatives reviewed here which goes beyond measuring consumers' access to medicine information and assesses the impact of an intervention on health literacy and active decision-making. It is encouraging that the provision of educational resources appears to be effective in influencing positive outcomes in these spheres, for older people.

#### Tailored online information for older consumers

Healthdirect (https://www.healthdirect.gov.au/medication-safety-for-older-people) and other sites include tailored information on medicines and QUM for older consumers. The review did not find data on the uptake and impact of such information on medication literacy and QUM for older consumers.

#### Pictograms for medication instructions

As is the case with other community segments, pictograms appear to offer some benefits in supporting the medication literacy of older people but are not a quick fix. A Canadian study set out to validate a set of pictograms depicting medication instructions for use among older people to support health literacy. One-on-one structured interviews were held with 135 older people recruited through community pharmacy, to assess comprehension of 76 pictograms. Comprehension was assessed using transparency testing and pictogram translucency, or the degree to which the pictogram represents the intended message. A total of 50 pictograms out of the 76 achieved more than 67% comprehension. Pictograms depicting precautions and warnings against certain side effects were generally not well understood. Gender, age, and education level all had a significant impact on the interpretation scores of certain individual pictograms, with younger males having a significantly higher comprehension score than older females, and participants with a higher level of education having significantly higher translucency scores. The authors conclude that given the modest level of comprehension of most of the pictograms, validation in this subpopulation should be conducted prior to using specific pictograms; and that it is important to accompany

pictograms with education about these pictograms and important counselling points. They do also note that combining text with pictures is more effective than using text alone; and that participants with low literacy skills benefit from the use of pictures more than highly literate patients, as those with low literacy rely more on spoken explanations, and pictures can help them remember what they hear and improve comprehension (Berthenet, Vaillancourt, and Pouliot 2016).

# Initiatives targeting Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people have significantly worse health status and outcomes than other Australians. Improved health literacy and QUM has the potential to help close the gap, particularly in view of the high rates of chronic disease in Aboriginal and Torres Strait Islander communities. While Aboriginal and Torres Strait Islander people in Australia potentially have access to the whole-of-population QUM initiatives outlined in the previous section, due to multiple barriers, specific initiatives have also been needed to address the needs of these communities.

# System level initiatives

#### The Section 100 RAHSP and QUMAX programs

The Australian Government has funded significant initiatives both to reduce financial access barriers to medications, and to address QUM issues, for Aboriginal and Torres Strait Islander people.

Since the late 1990s, Aboriginal Health Services (AHSs) in remote and very remote areas (RRMA categories 6 and 7) have been able to provide access to medicines for their patients, with the co-payment waived, through the Section 100 Remote Aboriginal Health Services Program (RHASP). QUM initiatives, involving local community pharmacies, have been implemented alongside these access reforms.

The Quality Use of Medicines Maximised for Aboriginal and Torres Strait Islander people program (QUMAX), was introduced in 2008 as a collaboration between the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Pharmacy Guild of Australia (PGoA), funded by the Commonwealth Department of Health under the Community Pharmacy Agreement. QUMAX is delivered by Aboriginal Community Controlled Health Organisations (ACCHOs) and community pharmacies and aims to improve health outcomes by optimising QUM for patients. QUMAX operates in urban, regional, and rural areas (RRMA categories 1 – 5), complementing the RHASP which operates in remote and very remote (RRMA 6 and 7) areas. The QUMAX program was trialled from 2008 to 2010, then fully implemented in 2010 (Starling R et al. 2016).

Importantly, the QUM activities were complemented in the initial QUMAX trial with copayment relief arrangements, leading to a significant increase in the number of PBS medicines dispensed to patients participating in the program (Couzos S, Sheedy V, and Delaney Thiele D 2011; Urbis 2011).

Building on this experience, as part of efforts to close the gap in health between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, the Australian government in 2010 extended co-payment relief to many Aboriginal and Torres Strait Islander people in non-remote areas, through reduced medication co-payments for Aboriginal and Torres Strait Islander people living with, or at risk of, a chronic disease. Patients were registered for this incentive by their general practitioner. Trivedi et al (2016) found that declines in hospitalisations for chronic conditions among Aboriginal and Torres Strait Islander people were observed, following targeted reductions in medication copayments for this population. These declines were largely limited to areas with higher uptake of the co-payment incentive and were not observed for admissions related to acute conditions; however, the authors do not claim to have demonstrated a causal effect (Trivedi et al. 2017).

The QUMAX program has continued to operate, separately to these co-payment reforms. By 2015-16, 75 ACCHOs in every State and Territory engaged with QUMAX, comprising more than half of NACCHO members as well as two non-member service providers. A total of 508 community pharmacies had also participated (Starling R et al. 2016).

The QUMAX program is intended to benefit Aboriginal or Torres Strait Islander people of any age who present to participating ACCHOs and are assessed by a GP to be at risk of adverse health outcomes from a failure to adhere with their medicine regime without assistance. The categories eligible for support under QUMAX are:

- 1. Dose Administration Aids (DAA);
- 2. QUM Pharmacy Support, to enable additional community pharmacy involvement and support in areas such as QUM planning, policies, protocol development, medicine quality assurance and appropriate Safety Net utilisation;
- 3. Home Medicines Review (HMR);
- 4. QUM Devices, predominantly devices for managing asthma and diabetes;
- 5. QUM Education and health promotion for ACCHO employees and their clients;
- 6. Cultural Awareness resources and training for community pharmacy;
- 7. Transport (Starling R et al. 2016).

Local work plans are drawn up by ACCHOs which allocate QUMAX program budgets against any or all of these seven categories (Lawson S and Storen S 2018; Pharmacy Guild of Australia and National Aboriginal Community Controlled Health Organisation 2017). During 2010-15, expenditure across categories was concentrated largely on Dose Administration Aids (50%) transport (21%), and QUM devices (9%). The proportion of expenditure on other categories was relatively small, and generally decreased over time (Starling R et al. 2016).

In October 2017, NACCHO and PGoA signed a Memorandum of Understanding (MoU) focusing on the implementation of Aboriginal and Torres Strait Islander pharmacy programs and trials. The MoU was intended to build on initiatives announced by the Government under the 6th Community Pharmacy Agreement, including improved medication management for Aboriginal and Torres Strait Islanders through community pharmacist advice and culturally appropriate services. Initiatives supported by the MoU focused largely on improved access to medicines, but also included some QUM-related measures including streamlined access to DAAs for patients not already eligible through QUMAX (Pharmacy Guild of Australia and National Aboriginal Community Controlled Health Organisation 2017). It is notable that the initiatives undertaken through QUMAX and other government-funded programs are strongly focused on overcoming access barriers, through addressing copayments, providing transport assistance, and providing dose administration aids and devices. There has been limited focus through these programs on improving medication literacy amongst Aboriginal and Torres Strait Islander Australians, as a means of improving QUM.

HMRs for Aboriginal and Torres Strait Islander people

Initiatives that aim to address QUM and medication literacy through HMRs in Aboriginal and Torres Strait Islander communities are at a developmental stage.

Swain and Barclay (2015) have investigated the value of HMRs for Aboriginal and Torres Strait Islander people. Swain and Barclay note that there is very little uptake of HMRs for Aboriginal and Torres Strait Islander people, and that increasing uptake has the potential to increase patients' medication knowledge and medication adherence and thus improve chronic disease management. Indeed, the study participants, both health professionals and consumers, "identified that increased medicine knowledge and empowering consumers to make medicine choices were the major HMR benefits". Swain and Barclay found that while HMRs have potential for Aboriginal and Torres Strait Islander clients, in practice there are significant barriers relating to an inappropriate and complex program model, the paternalistic attitudes of some health professionals ("there's no point filling them up with a huge amount of education if they are not going to take the medicines anyway"), and suboptimal relationships between pharmacists and AHS-based health professionals. The authors suggest that revising and simplifying the HMR approach and integrating the program with the AHS model of care, including embedding pharmacists within the AHS, would overcome many of these barriers (Swain and Barclay 2015).

Griffith University, in partnership with NACCHO and PGoA, is undertaking an Indigenous Medication Review Service Project (IMeRSe) funded through the 6th Community Pharmacy Agreement. The project's starting point is that medication review services including HMRs have been successfully implemented in the general population in Australia. However, there are a number of barriers to access these services for Aboriginal and Torres Strait Islander peoples including a lack of cultural appropriateness, restrictive referral pathways and eligibility criteria, a lack of integration with existing primary health care services, as well as geographic isolation. The IMeRSe study has been developed to support community pharmacists to work with clinicians and health workers, to incorporate the essential clinical elements and objectives of existing medication review services and address barriers to access (Wheeler et al. 2018). Wheeler et al (2018) and Spinks et al (2019) note the importance of medication reviews as a means of identifying and addressing medication related problems and outline the implementation of the IMeRSe feasibility study across nine Australian sites. The authors report on the establishment of the feasibility study and the development of outcome measures for the study; findings are not yet available (Spinks et al. 2019; Wheeler et al. 2018).

#### Health workforce initiatives

PSA Guide to Providing Pharmacy Services to Aboriginal and Torres Strait Islander People In 2014 the professional association for community pharmacists, the PSA, published a guide to providing pharmacy services to Aboriginal and Torres Strait Islander people (Pharmaceutical Society of Australia 2014). The publication includes guidance on understanding culture, how to build relationships, how to communicate, and how to provide pharmacy services to Aboriginal and Torres Strait Islander people; as well as a range of background information on Aboriginal and Torres Strait Islander health, and service provision. There is guidance for pharmacy support for consumer medication literacy and QUM, including advice on patient medicine counselling, communicating about medicines, assisting medication adherence, medicine labelling and directions, medicine education, and use of tools and resources such as medicine lists, MedChecks, and medication management plans.

Information on the uptake and appropriateness of the guide was not found in the course of this review.

#### Consumer-focused initiatives

#### Good Medicines Better Health resources

This set of resources for consumers and practitioners, relating to Aboriginal and Torres Strait Islander people's medication use and cardiovascular health, was produced jointly by NPS MedicineWise, the Heart Foundation, NACCHO, and the Aboriginal Health Council of South Australia, and includes flipcharts, brochures, fliers, and a medicines list. A disclaimer on the website states that these resources were developed "several years ago" and should be used "only when considered appropriate for the respective consumer's needs and circumstances". (https://www.naccho.org.au/programmes/medicines/good-medicines-better-healthresources/)

Medication education programs for Aboriginal and Torres Strait Islander people Literature examined for this rapid review indicates that the delivery of education sessions for Aboriginal and Torres Strait Islanders peoples can be effective in increasing medication knowledge and health literacy practices. Such initiatives can, however, be difficult to scale up, often being time-consuming and costly to implement.

Crengle et al (2018) found that an initiative consisting of a series of education sessions delivered by health professionals who had received training in health literacy and principles of adult education, complemented by electronic and hard copy resources, was highly effective in increasing knowledge about medications amongst Indigenous CVD patients in NZ, Australia, and Canada, from a low baseline. The measures included knowledge of: the name of the medication (scientific or brand name), and the ability to pronounce this correctly; the name of the medication class, and the ability to pronounce this correctly; the function/s of the medication; instructions for use; serious side effects; and treatment targets (Crengle et al. 2018).

Smylie et al (2018) report on an educational initiative with Indigenous patients in Canada. This initiative also consisted of a series of education sessions, in this case provided by an Indigenous nurse, and supplemented with a tablet application, pill card and booklet.

Knowledge of specific medications and health literacy practices were assessed before and after the program. Following the program, mean medication knowledge scores were 3.3 to 6.1 times higher than baseline for the included medications; and participants were also more likely to refer to the customised pill card and booklet for information, and answer questions from others. While mean medication knowledge scores at baseline were low enough to put participants at risk of medication error, upon completion of the initiative, participants had near-perfect medication knowledge scores. Notably, almost all of the knowledge acquisition occurred after the first educational session. The authors conclude that the customised education program was highly effective in increasing medication knowledge and health literacy practice among participants (Smylie et al. 2018).

# Initiatives targeting consumers from Culturally and Linguistically Diverse (CALD) backgrounds

#### Health workforce initiatives

#### Guidance for health professionals

The Centre for Ethnicity and Health has developed numerous health literacy resources for health professionals working with CALD consumers. Notable among these is a resource that guides health professionals on the process of using teach-back via an interpreter <a href="https://www.ceh.org.au/resource-hub/health-literacy-using-teach-back-via-an-interpreter/">https://www.ceh.org.au/resource-hub/health-literacy-using-teach-back-via-an-interpreter/</a>. Other health literacy resources developed by the Centre include guidance on verbal communication, written communication, and assumptions in the communication encounter.

https://www.ceh.org.au/resource-hub/health-literacy-verbal-communication/

https://www.ceh.org.au/resource-hub/health-literacy-written-communication/

https://www.ceh.org.au/resource-hub/assumptions-in-the-communication-encounter/

NPS MedicineWise has encouraged pharmacists to address the needs of CALD communities, through their Be Medicinewise campaigns (e.g. <a href="https://www.nps.org.au/media/bemedicinewise-week-multilingual-communities">https://www.nps.org.au/media/bemedicinewise-week-multilingual-communities</a>). The review

did not find information regarding the impact of this guidance.

#### Consumer-focused initiatives

#### Information and resources in community languages

To support health literacy in the community, the Commission has developed Top tips for safe health care, a booklet designed to help consumers, their families, carers and other support people get the most out of their health care. The booklet and infographic have been translated into 15 community languages

(https://www.safetyandquality.gov.au/top-tips-safe-health-care-translations).

While the Australian Government requires CMI to be produced in English, information and resources on medications and QUM, translated into a range of community languages, can be found on the following websites, among others:

- NPS MedicineWise: Key resources and fact sheets, and medicines lists (https://www.nps.org.au/translated-info)
- Victorian Government: A range of resources and tools including fact sheets and brochures, medicines lists, medication reminder cards and videos (https://www.healthtranslations.vic.gov.au/bhcv2/bhcht.nsf/PresentEnglishResourceA II?Open&x=&s=Medications)
- NSW Government, via the Transcultural Mental Health Centre, offers a range of online brochures on medications and mental health (https://www.dhi.health.nsw.gov.au/transcultural-mental-healthcentretmhc/resources/multilingual-resources-by-title/consumer-medicationbrochures).

The Agency for Healthcare Research and Quality has developed explicit and standardised medication instructions and translated these into five commonly spoken languages in the US. These instructions include phrases such as "Take 1 pill in the morning, 1 pill at noon and 1 pill in the evening"

(https://www.ahrq.gov/healthliteracy/pharmhealthlit/prescriptionmed-instr.html).

This review did not find information on the uptake and appropriateness of such resources.

#### Translating and Interpreting Service

The Translation and Interpreting Service (TIS) National is an interpreting service provided by the Department of Immigration and Citizenship for people who do not speak English and for the English speakers who need to communicate with them. TIS National is available 24 hours a day, 7 days a week for any person or organisation in Australia requiring interpreting services. It provides immediate telephone interpreting services, as well as pre-booked telephone and on-site interpreting. Access to free telephone interpreting services is available for registered pharmacies, general practitioners providing Medicare services and their reception staff, non-profit, non-government, community-based organisations; and local government authorities (https://www.nps.org.au/translated-info).

# Initiatives targeting consumers with low literacy/low health literacy

#### Consumer-focused initiatives

#### Research into consumer-focused interventions

Wali and colleagues (2016) have undertaken a systematic review of interventions to improve medication information for low health literate populations. Relevant interventions were classified into six groups: 1) written information 2) visual information 3) verbal information 4) label/medication bottle 5) reminder systems and 6) educational programs and services. The authors found that interventions designed to support low health literate populations can improve patients' medication knowledge and adherence, with results demonstrating significant improvement of knowledge in 27 of 37 initiatives and a significant improvement of adherence in 19 of 26 interventions. The most common interventions were written interventions, but other effective strategies include visual information, verbal information, specialised labels, reminder systems and education programs. The most effective interventions include additional aids that enforce written information, information that is personalised, information that is easy to navigate, and tools that can be accessed when needed (Wali et al. 2016).

Yeung et al (2017) report on a study of a pharmacist-run intervention using low health literacy flashcards along with mobile video reinforcement (a smartphone-activated QR barcoded educational flashcard video) to increase medication adherence and disease state understanding. The intervention group demonstrated significantly improved medication adherence compared with that of a control group. Patients in the intervention group were highly satisfied with the medication and disease state education, and they believed that the intervention helped them better understand the purpose and instructions for taking their medications. The authors conclude that novel low health literacy educational interventions could be feasible strategies in improving medication adherence versus traditional standard of-care counselling at the pharmacy (Yeung et al. 2017).

# Conclusions

This rapid review has identified a range of initiatives to improve medication literacy and QUM amongst the specific population segments of interest, being older consumers; Aboriginal and Torres Strait Islander people; consumers from CALD backgrounds; and consumers with low literacy/low health literacy.

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

An overall observation can be made that similar to the situation with population-wide initiatives, initiatives targeting specific population segments have tended to focus on

provision of information rather than on promoting health literacy; and that there appears to be little evaluation evidence to demonstrate uptake and appropriateness of initiatives. In addition, for the specific population segments examined here, the approach to promoting medication literacy and QUM appears to be fragmented rather than comprehensive.

# **Discussion and conclusions**

This final section of the report discusses the findings of the rapid review and the implications of these findings and draws some broad conclusions.

# **Discussion**

What is known about levels of health literacy and QUM in Australia?

ABS survey data from 2006 indicated that only 40% of Australians have at least an adequate level of health literacy, while 60% have a low level. Health literacy levels for specific consumer segments were even lower, with only 22% of survey respondents aged 60-74, for example, having health literacy skills that are adequate or better. The National Health Survey: Health Literacy, 2018, which used a different measure to examine health literacy levels, showed that one-third of Australians (33 per cent) found it always easy to discuss health concerns and actively engage with their healthcare providers; 56 per cent found this usually easy; while 12 per cent found it difficult. There is insufficient comparable data to track changes in population health literacy levels over time.

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

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

Overall, while data on health literacy and QUM in Australia is limited, there is sufficient evidence to indicate room for improvement.

Which population segments in Australia are most at risk of poor health literacy and suboptimal medicines use?

While there are many population segments in Australia at risk of poor health literacy and sub-optimal medicines use, this rapid review identified and focused on the following segments:

- Older consumers (65 years and over): Potential risk factors include lower health literacy, multimorbidities, polypharmacy, metabolic changes, and cognitive impairment.
- Aboriginal and Torres Strait Islander people: Potential risk factors include lower socioeconomic status, higher burden of disease, challenges with access to culturally safe care and appropriate communication with health professionals, and probably lower health literacy, though data on this is limited.

- CALD consumers: Potential risk factors include language barriers, lower health literacy, and barriers to culturally appropriate care. Refugee populations have additional risk factors including those relating to mental health.
- Consumers with low literacy and/or low health literacy: Low socioeconomic status, low education levels, low literacy levels, and low health literacy are interrelated, and have an independent and cumulative impact on health outcomes.

Individual consumers may of course fall within two or more of these population segments.

What key tools and resources, including indicators, are available for measurement of health literacy and QUM in Australia?

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

By contrast, it appears that the field of defining and assessing medication literacy is in its infancy, with few tools and resources described in the international literature. The standout is the Recognition and Addressing of Limited Pharmaceutical Literacy (RALPH) interview guide, which focuses on individual level medication literacy. It may be used by pharmacists to identify patients at risk of low medication literacy. In addition to the RALPH guide, there are examples of general health literacy measures being refined and adapted to focus specifically on medication literacy.

What key initiatives are in place for promoting health literacy and QUM in Australia?

#### *Initiatives to promote health literacy*

There are an increasing number of initiatives to promote general health literacy in Australia. A key national resource is the Australian Commission on Safety and Quality in Health Care (the Commission) National Statement on Health Literacy, which provides a framework and call to action on health literacy. The NSQHS Standards (Australian Commission on Safety and Quality in Health Care, 2017) provide both an incentive and guidance on ways to improve health literacy in health care settings.

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

- Embedding health literacy into systems: for example, the OPtimising HEalth LIteracy and Access (Ophelia) process, and the organisation-wide approach taken by Illawarra-Shoalhaven Local Health District.
- Ensuring effective communication: for example, tools and resources to support readability of written materials, to support codesign of communications with

- consumers, or to support improved verbal communication including through teachback.
- Integrating health literacy into consumer and health provider education, for example through formal education, and interactive platforms such as websites and apps.

#### Initiatives to promote medication literacy and QUM

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

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

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

- Older consumers: Older people are a key target group for population-wide initiatives, so are probably better served by these than are other consumer segments. The main specific initiatives for older consumers are residential aged care medication reviews, and medicines information and resources specifically targeted for older consumers. Other initiatives appear to be in developmental stages.
- Aboriginal and Torres Strait Islander people: The Australian Government has invested in improved access to medicines and QUM for these communities, through the Section 100 RHASP and QUMAX. Some specific resources have been developed for consumers and health professionals; and work is underway to develop an appropriate home medicines review model for Aboriginal and Torres Strait Islander people.
- CALD communities: Information and resources to support health literacy and QUM
  are available in several community languages; and health providers and consumers
  also have access to the Translating and Interpreting Service.

 Consumers with low literacy and/or low health literacy: Research has identified features of interventions which are effective in supporting health literacy and QUM in this population segment, but the review did not find evidence of specific initiatives for this group.

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

Where are the unmet needs in terms of improving health literacy and QUM?

The following key themes emerged from the literature examined in the rapid review.

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

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

- What are the utilisation levels of the various tools and resources produced for Australian consumers?
- What is the profile of users of these tools and resources (across age groups, education levels, health literacy levels, population segments)?
- How do consumers view these tools and resources what are the levels of acceptability and usefulness?
- How effectively can consumers identify reliable, high quality information and resources from trusted sources, as opposed to other information?
- What impacts have the implementation of these initiatives had on consumer health literacy, QUM actions, and health outcomes?
- 2. Most of the interventions examined in this review focus on providing information (or services) to consumers, rather than addressing health literacy in a co-ordinated way.

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

In contrast to this approach, the bulk of the interventions studied here, particularly the consumer-oriented tools and resources, simply focus on the provision of medication

information to consumers. The position of consumers in this model is simply to receive information, rather than proactively seeking, reflecting and interacting with information and advice. This does not reflect key health literacy concepts which focus on consumers making informed decisions about their health care, and on shared decision-making between consumers and health professionals. While NPS MedicineWise develop and deliver resources that facilitate shared decision-making, such as Patient Decision Aid, and Patient Action Plan

(<a href="https://www.nps.org.au/resources?q=&types=228642%2C228644&audiences=228533&dates=&sort=date">https://www.nps.org.au/resources?q=&types=228642%2C228644&audiences=228533&dates=&sort=date</a>) few resources in the environment take a broader approach to developing the consumer health literacy skills required to appraise and choose between different sources of information and make decisions about the risks and benefits of medicines. This potentially represents a major limitation on the appropriateness of many of the interventions.

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

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

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

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

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

While there has been consumer consultation on some of the initiatives identified in this review, it is not clear that consumer co-design is routine element in the design of

interventions; nor is it clear that all initiatives have been designed with the primary goal of improving consumer health outcomes (as opposed to developing the role of particular health professions). In particular, it is difficult to assess the extent to which some pharmacist-led initiatives, such as the Pharmacy Trial Program and HMRs, have been developed in response to evidence of consumer need, versus the extent to which they have been developed in response to advocacy from pharmacy groups to extend and enhance the role of their profession. This is a pertinent point, given the finding of the HeLP project outlined above suggest there are barriers to pharmacists supporting consumer health literacy and medication literacy (Duncan G, Emmerton L, and Hussainy S no date).

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

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

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

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

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

However, it is apparent that some of the opportunities for the future include:

- Developing a strategic, co-ordinated approach to addressing health literacy, medication literacy, and QUM, across the three action areas recommended by the Commission: embedding health literacy into systems; ensuring effective communication; and integrating health literacy into education for both consumers and healthcare providers.
- Developing a strategic, co-ordinated approach to identifying and addressing the health literacy, medication literacy and QUM needs of higher-risk population segments.
- Utilising a consumer-centred approach and consumer co-design in the development and implementation of future initiatives.

- Ensuring that initiatives include measures to promote consumer awareness of and access to the relevant programs, tools, and resources, including for consumers from higher-risk population segments.
- Ensuring that routine data collection is built into future initiatives, including data on uptake and outcomes of interventions, to support the ongoing evaluation and improvement of interventions that seek to improve consumer health literacy, medication literacy, and QUM.

There may also be an opportunity to develop a national clearing house on health literacy and QUM initiatives, including relevant information, resources, tools, and research and evaluation findings.

#### Limitations of the review

This review was conducted over a four-week period during May 2020. The limited timeframe required the review to utilise a narrow focus. Generic health literacy and QUM measures and initiatives were included in this review. Disease specific measures and initiatives were excluded. The timeframe was also limited to academic articles published from 2015, although we cast a wider net for the grey literature. It is probably that many of the advances in health literacy initiatives focus on particular population segments or diseases. This is an evidence base that may be tapped into when time and resources allow such an investigation.

#### **Conclusions**

This rapid review has examined literature relevant to consumer health literacy, medication literacy, and QUM in Australia. The review identified a wide range of current initiatives to promote health literacy, medication literacy, and QUM in Australia, but also found some shortcomings.

The first of these shortcomings was the lack of adequate and readily available evaluation data to adequately assess the accessibility and appropriateness of these interventions. Another important finding was that most of the interventions examined in the review focus on providing information (or services) to consumers, rather than addressing the three dimensions of health literacy (functional, interactive and critical) in a responsive and coordinated way.

The review also found that while there is a significant quantity of high quality, valued information, resources and tools available to support medication literacy and QUM in Australia, there is less clarity regarding uptake and utilisation of these resources. The review identified a limited focus on consumer-centred models and consumer co-design; and a lack of a strategic, co-ordinated approach to meeting the needs of consumer segments at higher risk of low health literacy and poor QUM.

The review identified opportunities to address these gaps, through: the development of a strategic, co-ordinated approach to addressing health literacy, medication literacy, and QUM, both for the general population, and for higher-risk population segments; utilisation of a consumer-centred approach and consumer co-design in the development and implementation of future initiatives; measures to promote consumer awareness of and

access to relevant initiatives, including consumers from higher-risk population segments; and routine data collection and evaluation of interventions that seek to improve consumer health literacy, medication literacy, and QUM. There may also be an opportunity to develop a national clearing house on health literacy and QUM initiatives, including relevant information, resources, tools, and research and evaluation findings.

## APPENDIX A: A description of the academic literature search and results

Searches were conducted in one academic database (Medline). The search was limited to articles published in English from 2015 onwards. The Medline search strategy for the search included:

- 1. Health literacy
- 2. Medication adherence
- 3. Pharmacy
- 4. Combine 2 or 3
- 5. Combine 1 AND 4
- 6. Limit to English and from 2015

The term quality use of medicines is not a MeSH subject heading, so we used the indexed terms pharmacy and medication adherence as proxy terms.

Inclusion criteria were developed based on the aims and scope of the review. The review was restricted to work published from 2015 onwards, from an OECD country, which either described barriers or enablers to the quality use of medicines for population groups, or included examples of tools, resources and measures for quality use of medicines and health literacy.

The Medline search identified 148 articles. One hundred and twenty-four of the articles were excluded on review of title and abstract because they did not meet the inclusion criteria. The two main reasons for excluding articles were the focus on a specific disease rather than quality use of medicines and health literacy generally, and also the emphasis on describing the association between health literacy and the quality use of medicine as opposed to identifying measures, tools and resources. We were not able to obtain the full text version of three of the 24 articles in the timeframe required, so they were excluded on that basis. The full text review of the remaining 21 articles resulted in nine articles being included in the academic literature search.

Eight of the nine articles were from the US. Only one article was from Australia. This paper by Kay focused on the quality use of medicines in refugee communities in Australia. Of the nine articles two focused on patients experiences of the quality use of medicines and health literacy, two focused on different ways to communicate information about medicines to patients such as reminder systems, education programs, improving the written, visual or verbal information communicated to patients, two papers focused on ways to measure health literacy and the quality use of medicines and two papers focused on the brown bag method as a way to review patients understanding and practice of using medicines.

The grey literature research identified numerous policy documents, measures, indicators, tools and resources as well as priority population groups. The websites, resources and documents identified from the grey literature search were categorised into the following groups:

 a population segment such as the elderly or Aboriginal and Torres Strait Islander Australians

- a measure for health literacy
- a measure for the quality use of medicines
- a measure for health literacy and the quality use of medicines
- a tool, indicator or resource for health literacy
- a tool, indicator or resource for the quality use of medicines
- a tool, indicator or resource for the health literacy and the quality use of medicines.

### **APPENDIX B: Data from NPS MedicineWise**

## consumer surveys

NPS MedicineWise undertakes a National Consumer Survey every two years, conducted online with a representative sample of consumers from the Australian population. The surveys aim to track changes in consumer awareness, knowledge and attitudes about NPS MedicineWise program-related topics over time and inform NPS MedicineWise product and program refinement and development (NPS, 2015; NPS, 2017).

The most recent available data is from the 2017 survey (NPS, 2017), which particularly focused on consumers' use of online health information. The survey had 2509 respondents (30% response rate). Some key findings from this survey in relation to medication literacy include:

#### Health management

- Most consumers trust their GPs decisions with regards to the medicines that are
  prescribed (77%) and the medical tests that are ordered for them (82%) with 81% of
  consumers feeling that they can tell their GP about any concerns they have.
- There was a significant decrease in the proportion of consumers who believe that the benefits of taking medicines outweigh any possible risks from 62% in 2015 to 53% in 2017.
- The proportion of consumers who agreed that they had access to sufficient information to manage their own health significantly decreased from 77% in 2015 to 60% in 2017.

#### Sources of information about medicines

- Consumers who need to obtain information about medicines ask a GP (75%) followed by a pharmacist (62%) and/or visit a website (45%).
- Social media and blogs are accessed the least to search for information about medicines (9%) except for people aged 16-34 years (15%), those who speak English as their second language (20%) and people with Aboriginal and/or Torres Strait Islander heritage (20%).
- Some issues consumers experience when searching for information about medicines online include trusting (26%) and understanding (21%) the information provided on a website
- The top 5 most important attributes consumers look for in an online source of information about medicines are:
  - Trustworthy source
  - Up-to-date
  - Easy to understand
  - Recommended by a health professional
  - o Research or 'evidence-based' information

#### MedicineList+ app (renamed MedicineWise app)

- The MedicineList+ app feature that encourages the most downloads and use among consumers overall is the health information record (44%) while the drug interaction checker attracts interest as an additional feature of the app.
- About half of the consumers (49%) who had low adherence and 60% of those who have difficulty managing their condition are motivated to download and use the MedicineList+ app for its health information record feature. The reminders functionality motivated 32% of those who had difficulty in managing their condition and 49% of those with low adherence to their medicines.
- Over half of the carers (53%) are particularly drawn to use the health information record feature of the MedicineList+ app.

#### Antibiotics

- 50% of parents will not request antibiotics if their child aged 14 years or below has a cold or flu while 33% will ask for antibiotics. Parents who ask for antibiotics believe that antibiotics will help their child recover faster (44%) or that it will help keep their child healthy (10%).
- The proportion of consumers who believe that the impact of antibiotic resistance affects them now has increased from 11% in 2015 to 25% in 2017.
- The proportion of consumers who will not ask a doctor for antibiotics to treat their cold or flu decreased from 75% in 2015 to 62% in 2017.

The previous national survey, undertaken in 2015, focused on medicine adherence, antibiotics, and medical tests. The survey was undertaken online and had 2,581 respondents. Some key findings in relation to medication literacy include:

#### Patient activation

- Most consumers agree that they have the basic knowledge about the medicines they take, believe they have access to health information, and have the skills to talk to their doctor about any issues. The majority also believe that taking an active role in their own healthcare is important. These are all necessary for patient activation (defined in this document as the level of empowerment of a consumer to manage their own health, including being equipped with the necessary knowledge, skills and confidence to act toward one's well-being).
- However, only from half to less than half of consumers 'strongly agree' that they have these skills, knowledge or beliefs.

#### Medication adherence

- One third of consumers currently prescribed medicines have high adherence to taking their medicines. Approximately half (47%) of consumers have medium adherence and nearly 2 out 10 (19%) have low adherence.
- Key drivers of adherence include: having a set routine or strategy in place to ensure consumers take their medicines everyday; trust in the GP's decisions on which medical treatments and medicines are best for the consumer; being able to discuss concerns about medicines during a GP consultation; willingness to take medicines vs. vitamins or supplements; and belief that the benefits of taking medicines outweigh possible risks.
- Cost of medicines was a barrier to non-adherence to only a minority of consumers; 16% of consumers delayed buying or did not buy prescribed medicine due to cost in the past 12 months.

#### **Antibiotics**

- The majority of consumers have a general understanding of the risks involved as a
  result of inappropriate use of antibiotics. Most (75%) survey participants agreed that
  antibiotics taken for cold and flu result in antibiotics becoming less effective in the
  future. Over 2 out of 3 respondents believe that taking antibiotics as a treatment for
  colds and flu had the risk of developing antibiotic-resistant bacteria.
- A significant proportion of consumers were not sure of the verity of the following statements: antibiotics don't help patients recover from cold or flu; antibiotics don't help patients recover faster from cold or flu; using antibiotics for cold and flu would risk passing on antibiotic-resistant bacteria; the impact of antibiotic-resistance impacts people now.

### NPS MedicineWise Galaxy Polls

NPS MedicineWise also commissions Galaxy Research to undertake polls to inform its work, particularly its annual Be Medicinewise Week (BMW) public education campaigns. Some key findings from these polls, usually of 1,000 Australian adults, are as follows.

#### 2019 BMW (focus on being better informed about one's medications):

- Only about one in three (31%) Australians who regularly take two or more medicines actually keep a list of all their prescription, over-the-counter and complementary medicines.
- A further 26% of people who take regular medicines only keep a list of their prescription medicines, while the remaining 3% only record some, and 40% record none, of their medicines.
- People are better at recording the brand of their medicine than the active ingredient. Of those people who record information about their medicines, only one in five (22%) said they'd record the active ingredient of the medicine, compared to half of those people (48%) saying they'd capture the brand name of the medicine, 63% saying they record information on the dose and how and when to take the medicine, and 52% saying they record the reason for taking the medicine.
- Around half of all people surveyed said they had spoken with a doctor or pharmacist about how much of a newly prescribed medicine they needed to take each time, when and how to take the medicine, how long they should take the medicine for or what side effects might happen. However, only 16% of people said they had discussed what active ingredient was in the medicine
- Around 10% of Australians have household or family members that have trouble getting information about their medicines because English is not their first language (https://www.nps.org.au/media/be-medicinewise-week-new-survey-findings).

#### 2018 BMW (focus on safe and wise medicine use by families):

- More than 9 million people take a prescribed medicine every day, with 8 million taking two or more prescribed medicines in a week.
- More than 2 million people take over-the-counter medicine daily and more than 7 million take a complementary medicine daily
   (<a href="https://www.nps.org.au/media/withmillions-taking-multiple-medicines-australians-are-reminded-to-be-medicine-wise">https://www.nps.org.au/media/withmillions-taking-multiple-medicines-australians-are-reminded-to-be-medicine-wise</a>).

#### 2017 BMW (focus on misuse of medications):

 More than two million Australians may have exceeded the recommended daily dose of some widely used medicines.

- Up to half a million Australians may have exceeded the recommended daily dose of a popular cold and flu tablet.
- Many Australians are putting their health at risk by taking too much of medicines containing codeine. As many as 1.5 million Australians may have taken seven or more ibuprofen + codeine tablets in a day, exceeding the recommended dosage of six tablets in a 24-hour period. Millennials are twice as likely as Baby Boomers to have overused ibuprofen + codeine.
- Almost one in three Australians admit to consuming alcohol shortly after taking prescription pain relief medicines.
- More than one in four respondents have used someone else's prescription medicine or given their own medicines to another family member, with Millennials (39%) much more likely than Baby Boomers (19%) to swap prescription medicine (https://www.nps.org.au/media/do-you-know-the-active-ingredients-inyourmedicines; https://www.nps.org.au/media/do-you-know-the-dangers-ofmixingmedicines; https://www.nps.org.au/media/survey-finds-millions-ofaustraliansmisuse-their-medicines).

#### 2017 World Antibiotic Awareness Week (focus on antibiotic use, poll of 2500 people):

- Four in every 10 Australians would ask their GP for an antibiotic to treat their cold or flu, with such requests generally decreasing with age.
- Over one-third (35%) of 16- to 24-year-olds ask their health professionals for antibiotics when they have colds or flu, indicating that younger Australians may be unaware that antibiotics are ineffective for these common viral infections.
- Respondents over the age of 75 are the least likely Australians to ask for antibiotics when they're not needed, with just 13% saying they'd ask for these medicines to treat a cold or flu.
- 25% of respondents acknowledged antibiotic resistance as a current concern for themselves and their families – up from only 11% in the same survey conducted in 2015. However, more than half (53%) of respondents claimed they were either unsure or didn't think they would ever be affected by antibiotic resistance, while the remaining respondents (22%) believe antibiotic resistance will be a problem in the next 10 or 50 years' time.
- Close to one third of parents visit their GPs with the intention of getting antibiotics to treat under-14-year-old children who have sore throats, coughs or colds (survey of 1,000 respondents) (https://www.nps.org.au/media/survey-finds-australianmillennialsconfused-about-antibiotics; https://www.nps.org.au/media/too-manyaustralianparents-expect-antibiotics-for-their-kids; https://www.nps.org.au/media/surveyreveals-australians-growing-concern-aboutantibiotic-resistance).

# **APPENDIX C: Population-wide initiatives for improving medication literacy and QUM**

Category	Initiative	Sponsor	Initiative type	Target group	Description	Implementation and evaluation
System level	National Quality and Safety Health Service (NQSHS) Standards	Australian Commission on Safety and Quality in Health Care	Standards	Health service providers (hospitals and health services)	The NSQHS Standards provide a nationally consistent statement of the level of care consumers can expect from health service organisations. The Standards have a strong focus on partnering with consumers, and on health literacy, including in relation to medication management.	The second edition of the NSQHS Standards was released in November 2017. Assessment to the second edition commenced in January 2019.
System level	Home Medicines Review (HMR)	Australian Government	PBS Item	Pharmacists, GPs and consumers	In collaboration with the GP, a pharmacist comprehensively reviews the patient's medication regimen in a home visit. After discussion of the pharmacist's report and findings, the GP and patient agree on a medication management plan.	Implemented from 2001. Quantitative data on uptake available; limited data found on outcomes and consumer perspectives.
System level	Pharmacy Trial Program	Australian Government via Pharmacy Guild of Australia (PGoA), through 6 <sup>th</sup> CPA	Funding program	Pharmacists, consumers	The Pharmacy Trial Program seeks to improve clinical outcomes for patients and utilise the full scope of a pharmacist's role in delivering primary health care services, including medication management programs and patient support services, including for specific population segments.	Some components of the program, eg QUMAX (see below) have been evaluated.

Health workforce	NPS MedicineWise information and programs for health professionals	NPS MedicineWise	Professional education, Information, tools and resources	GPs, pharmacists, primary health care nurses	NPS provides evidence-based information to health professionals and consumers through initiatives including academic detailing, audit and feedback, and interactive learning.	2019 report of Review of NPS MedicineWise was unable to determine the relative impacts of each activity targeting health professionals.
Health workforce	Health Literacy in Pharmacy Program (HeLP)	Australian Government via PGoA, through 5 <sup>th</sup> CPA	Research project to trial an education package	Pharmacists and pharmacy staff	The research aimed to increase Australian pharmacists' and pharmacy staff members' knowledge of health literacy, and ability to detect and respond to consumers' health literacy issues, through the delivery of an education package.	Information on uptake of the research findings was not found in this review.
Health workforce	Brown Bag Medication Review	US Agency for Healthcare Research and Quality (AHRQ)	Tool which provides guidance for effectively undertaking medication reviews	Pharmacists	The guidance focuses on getting patients to bring their medications to consultations, conducting the medication review, confirming patient understanding of medication regimens, clarifying medications and medication instructions, identifying drug therapy problems, documenting review results, and providing an updated medication list to patients.	US studies evaluating the outcomes of the tool appear encouraging. This review did not find information on whether the tool has been considered for use in Australia.
Consumer-focused	Consumer Medicines Information (CMI)	Australian Government requirement; CMI documents prepared by pharmaceutical companies	Written information	Consumers	Standardised written information for consumers provided with prescription and pharmacist-only medicines. An improved format is being introduced to enhance useability.	NPS survey data indicates approximately one in five consumers read CMI.
Consumer-focused	Written information for over-the-counter (OTC) products	Pharmaceutical companies	Written information	Consumers	Leaflets providing written information for consumers for OTC products where CMI is not mandated.	Research indicates OTC leaflets are not always received or wanted by consumers, particularly for repeat OTC

						purchases, mainly due to product familiarity.
Consumer-focused	Online information and resources	NPS MedicineWise CHF/TGA Healthdirect Better Health Channel (+ others)	Online information, tools and resources	Consumers	Several NGO and government websites in Australia offer a significant (and overlapping) range of high quality, authoritative information, resources and tools for consumers. In addition, both in Australia and internationally there are many sites accessed by consumers, offering less reliable information.	NPS survey data indicates that when consumers look for information about medicines, 45% visit a website. Other than the NPS site, data on accessibility and usefulness of other websites was not identified.
Consumer-focused	MedicineWise and MedSearch apps	NPS MedicineWise (MedicineWise app) TGA (MedSearch app)	Mobile applications for medication information and management	Consumers, carers, and health professionals	There is a proliferation of mobile apps to promote QUM and medication adherence, of varying quality and usefulness. The NPS MedicineWise app has broad functionality and is targeted to consumers and carers. The MedSearch app has a focus on CMI and product information and is targeted to consumers and health professionals.	The NPS MedicineWise app has been rated in an independent review as among the top five medication adherence apps internationally. It is reported that consumer and health professional awareness of quality apps could be improved.
Consumer-focused	Medicines Line	NPS MedicineWise and healthdirect	Telephone line	Consumers	Medicines Line links consumers with a registered nurse or pharmacist, who provides information on prescription, over-the-counter and complementary medicines.	In 2017-18, Medicines Line answered 7,263 calls.
Consumer-focused	Be MedicineWise Week (BMW) and World Antibiotic Awareness Week (WAAW)	NPS MedicineWise (both campaigns); ACSQHC (WAAW)	PR and online campaigns, supported by campaign	Consumers and health professionals	BMW weeks have been delivered annually since 2011 by NPS, and are used to promote specific QUM messages to consumers. WAAW is a global WHO campaign to promote QUM in relation to	NPS collects survey data on the impact of these campaigns (see Appendix B).

			materials and resources		antibiotics, and NPS and ACSQHC participate in the campaign in Australia.	
Consumer-focused	NPS social media activities (Facebook, Twitter, Youtube)	NPS MedicineWise (note: many other health organisations and governments also undertake relevant social media activities)	Social media	Consumers and health professionals	NPS MedicineWise operates a range of social media activities so that consumers utilising these channels can access reliable information.	NPS survey data indicates that only 9% of respondents use social media/blogs to access medicines information, though numbers are higher for specific population segments.
Consumer-focused	Labelling enhancements and pictograms	Various	Initiatives to improve readability of medication labels and instructions	Consumers and carers	Several studies have been undertaken to assess the potential impact of enhancements to labelling, and use of pictograms to assist with medication instructions.	Research indicates that simple measures to enhance labelling can be effective; and that pictograms can be a useful addition to text instructions, but that more research is required.

## **APPENDIX D:** Initiatives for improving medication literacy and QUM in specific population segments

Category	Initiative	Sponsor	Initiative type	Target group	Description	Implementation and evaluation
System level	Medication reviews for aged care residents	Australian Government	PBS Item	Older Australians, pharmacists, GPs, residential aged care staff	Similar to HMRs, funding is available through the MBS for pharmacists to undertake medication reviews for residents of aged care services.	Research indicates these reviews are effective in identifying and reducing high levels of inappropriate prescribing in these settings.
System level	Recommendations on consumer-centred medication management for older Australians	National multidisciplinary working group	Practice recommendations	Older Australians and their health care providers	In 2015, a national multidisciplinary working group dedicated to improving the quality use of medicines for older Australians issued ten recommendations for better integrating healthcare to provide consumer-centred medication management in the older Australian population, across settings and practitioners.	This review did not find information on whether and how the recommendations have been adopted.
Health workforce	Guidance for the role of aged care nurses and staff	Nurse researchers	Practice guidance	Older Australians, aged care nurses, and aged care staff	Guidance for the role aged care nurses and care staff can play in improving older people's health literacy and ensuring safe and effective use of medicines.	This review did not find information on whether and how the guidance has been adopted.
Consumer-focused	Consumer educational resources	Researchers	Consumer education and resources	Older people	A study has examined the effectiveness of an education intervention on complementary medicines, aiming to improve older adults' decision making and health literacy.	Decision self-efficacy improved for participants, with no significant differences in outcomes for different types of educational resources utilised.
Consumer-focused	Tailored online information for older consumers	Healthdirect and others	Online information, tools, and resources	Older Australians	Healthdirect and other sites include tailored information, tools and resources for older Australians.	Data on the uptake and impact of this information was not found in this review.

Consumer-focused	Pictograms	Researchers	Initiatives to improve readability of medication labels and instructions	Older people	A study set out to validate a set of pictograms depicting medication instructions for use among older people to support health literacy.	Comprehension levels for most pictograms were modest, indicating the need for validation in this subpopulation, and provision of accompanying education.
System level	Section 100 Remote Aboriginal Health Services Program (RAHSP) and QUMAX Program	Australian Government (with Pharmacy Guild of Australia participation in CPA initiatives)	QUM support via community pharmacy, along with copayment relief	Aboriginal and Torres Strait Islander people, and their health service providers	The Section 100 RHASP and the QUMAX program fund a range of pharmacist support for QUM, as well as copayment relief to address financial barriers to access to medicines.	Evaluation indicates the programs have increased access to medicines and some aspects of QUM, but there has been limited focus on consumer health/medication literacy.
System level	Indigenous Medication Review Service (IMeRSe) Project	Griffith University, NACCHO, and PGoA, funded by Australian Government	PBS item	Pharmacists, GPs and Aboriginal Health Workers providing services to Aboriginal and Torres Strait Islander people	The IMeRSe study supports community pharmacists to work with clinicians and health workers, towards addressing barriers to access to HMRs for Aboriginal and Torres Strait Islander peoples.	Findings not yet available.
Health workforce	PSA Guide to Providing Pharmacy Services to Aboriginal and Torres Strait Islander people	Pharmaceutical Society of Australia (PSA)	Practice guidance	Pharmacists providing services to Aboriginal and Torres Strait Islander people	In 2014 the professional association for community pharmacists, the PSA, published a guide to providing pharmacy services to Aboriginal and Torres Strait Islander people.	Information on uptake and utilisation of the guide was not found in this review.
Consumer-focused	Good Medicines Better Health resources	NPS MedicineWise, the Heart Foundation, NACCHO, and the Aboriginal Health Council of South Australia	Resources (eg flipcharts, posters, flyers)	Aboriginal and Torres Strait Islander people and their health care providers	This set of resources for consumers and practitioners, relating to Aboriginal and Torres Strait Islander people's medication use and cardiovascular health, was produced several years ago and may not be current.	This review did not find information on uptake and appropriateness of the resources.
Consumer-focused	Medication education programs for Indigenous consumers	Researchers	Research	Indigenous peoples in Canada, Australia, and New Zealand	Studies have examined the effectiveness of education sessions for Indigenous consumers, delivered by health professionals.	Educational interventions can be effective in increasing medication knowledge and health literacy

						Indigenous consumers.
Health workforce	Guidance for health professionals on working with CALD consumers	Centre for Ethnicity and Health NPS MedicineWise	Practice guidance	Health professionals working with CALD consumers	Resources and campaign materials to help health professionals support CALD consumers' health literacy and QUM.	This review did not find information on the impact of this guidance.
Consumer-focused	Health literacy and QUM information and resources in community languages	ACSQHC, NPS Medicinewise, NSW and Victorian Governments, and others	Information and resources to support health literacy and QUM	Consumers from CALD communities	Several Australian and overseas websites include information and resources to support health literacy and QUM, translated into community languages.	This review did not find information on uptake and appropriateness of the resources.
Consumer-focused	Translating and Interpreting Service (TIS) National	Australian Government	Translatiing and interpreting of health communications	Consumers from CALD communities, and their health service providers	TIS National is available 24/7. Access to free telephone interpreting services is available for registered pharmacies, general practitioners providing Medicare services and their reception staff, non-profit, non-government, community-based organisations; and local government authorities.	This review did not examine data on utilisation of TIS in the health sector.
Consumer-focused	Research into consumer-focused initiatives for people with low health literacy	Researchers	Research	Consumers with low health literacy	A systematic review has been undertaken of initiatives to improve medication information for low health literate populations.	The most effective initiatives include additional aids that enforce written information, information that is personalised, information that is easy to navigate, and tools that can be accessed when needed.
Consumer-focused	Research into consumer-focused initiatives for people with low health literacy	Researchers	Research	Consumers with low health literacy; pharmacists	A study has been undertaken of a pharmacist-run initiative using low health literacy flashcards along with mobile video reinforcement to increase medication adherence and disease state understanding.	This novel intervention for consumers with low health literacy achieved significantly improved medication adherence compared and high consumer satisfaction.

practices amongst

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