Health Literacy
Implications for Australia
What is health literacy?

“Health literacy is the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course.”

With the ageing population and the rise in chronic disease, Australia is facing a period of unprecedented demand on health services. Managing this will require the efficient and effective use of resources which to some extent will be dependent on the public’s ability to appropriately access, navigate and utilise information and resources - ie their level of health literacy.

The determinants of health literacy are multiple and include personal factors such as age, education and language and system factors such as fragmentation of care and time. Health literacy is content and context specific. For example, the content of the information required by an adolescent learning about alcohol, drugs and safe sex would differ markedly to the information requirements of a pregnant woman, which would again be different to the requirements of a newly diagnosed type 2 diabetes patient. While the issue is complex, the impacts of low health literacy suggest that focussing on improving health literacy may be a valuable contribution to social inclusion and health system utilisation. Consider Mr J:

Mr J is a 76 year old man whose care has been complicated by difficulties understanding his health care and accessing treatment.2

His medical history is significant for multiple chronic conditions including obesity and diabetes. He has an eighth grade education and stopped working when his vision failed from complications of his conditions. Mr J was recently discharged after a hospitalisation for pneumonia and prescribed antibiotics which he subsequently failed to take. When questioned about this, he stated that he did not fill the prescription because he believed it would cost $98. However, upon further investigation, his nurse determined that it would cost less than $2 to fill.

Mr. J has been prescribed over 15 medications to take consecutively to deal with his conditions; however he doesn’t believe they help him. He noted that he will take the medications if his conditions flare up rather than on a regular basis. In some cases he found the medications had immediate side-effects, and these caused him to stop taking them regardless of his physician’s advice. Mr. J noted that as a child, his mother used to make him lots of medicinal teas based on herbs and roots which he feels were more useful to him than his current prescribed medication.

Mr. J’s doctor has now established that he has low health literacy. His nurse practitioner found that when they gave him pre-packaged medications in blister packs that this improved his adherence. However both clinicians noted that Mr. J has no concept of the importance of self-management for his multiple chronic conditions. The physician noted that he has no formal way to assess health literacy in his practice, and that this has only been brought to light as a key issue given the severity of Mr. J’s condition and lack of understanding. Whilst Mr. J’s case was easily identified due to its severity, the physician feels that many cases of low health literacy which should be picked up may be missed as they are not at the extreme end of severity.


Why is health literacy important?

Only 41 per cent of Australians have adequate to high levels of health literacy. Therefore nearly 60 per cent of Australians may be unable to successfully access, understand, evaluate and communicate health information as a way to promote, maintain and improve health.³

This statistic is striking when considering that low health literacy is a statistically independent risk factor for poor health.⁴ From an epidemiological perspective, the risk of increased mortality stemming from limited health literacy is nearly the same as the impact of chronic disease – even after controlling for age, race, gender, income, education, health status, health behaviours, health access and psychological status.⁵ The following diagram in Figure 1 provides a conceptual model of health literacy as an asset which was developed by Professor Don Nutbeam.

Figure 1: Nutbeam’s conceptual model of health literacy as an asset⁶

---

According to Nutbeam’s model, in addition to changed health behaviours and practices, improved health literacy can be an enabler for advocacy and broader social engagement. The following fictional case study provides an example:

**An example of health literacy as an enabler for advocacy and social engagement**

Alex is 55 years old. Recently his son Gary was involved in a car accident resulting in catastrophic injuries and severe brain damage. Gary survived the crash but requires 24 hour care. Alex went online to research all he could about service offerings that may meet some of his son’s ongoing care needs. On investigating residential options Alex was shocked to find the lack of age appropriate facilities for his son. Alex began lobbying his local MP and got involved in a charity focussing on accommodation for young people requiring high level care. Alex was able to find a funding route to assist with managing Gary’s injuries and also advocate for others in a similar position.

Low health literacy skills are associated with poorer health knowledge, poorer health status, higher mortality, increased hospitalisations and higher health care costs. It is also noted that low health literacy often coexists with other social disadvantages such as low education and poverty – thus exacerbating its effect on vulnerable populations.

The need for a functional level of health literacy among individuals is clear. Yet when considering the complexities in developing a comprehensive but succinct definition of health literacy, one can appreciate that it will therefore be equally, if not more difficult to develop an appropriate method to measure or screen for health literacy. Attempts have been made to measure health literacy at a population-wide level through detailed surveys administered by government bodies, and at an individual level through screening tools administered by nurses and physicians. However there is debate as to the usefulness of measuring health literacy at the population level – particularly if we recall that health literacy is content and context specific.

It has been argued that measuring health literacy at the population level is not necessarily the most informative way to understand the extent of the problem, nor does it inform mitigation strategies. This is because health literacy is intrinsically related to the context of the individual and the level of contact they have with the health system. Nutbeam explains through example that what can be defined as adequate health literacy will differ for a person with diabetes who is receiving treatment information, compared with an adolescent taking health education classes through school. Different screening tools are therefore required for different ages and different stages in life.

Screening tools are not designed to be comprehensive tests of an individual’s health literacy – rather they serve as screening tools to be used by clinicians to determine whether an individual possesses functional or adequate health literacy. They are generally quick to administer and consist of having the patient interpret health information of the type found on food packaging or medication labels. They are ideally used by clinicians at an early stage along the diagnosis or treatment pathway to establish the content and context specific requirements of the patient. If screening establishes that the patient is lacking in functional health literacy, then their management and evaluation can be tailored to better suit their needs.

---

7 Fictional case study developed by PwC for illustrative purposes.
11 Ibid.
12 Ibid.
Yet screening in the absence of action may not only be redundant, it has the potential to cause harm. Patients may suffer shame and alienation, and if nothing is done to rectify this, then patient outcomes could be worse than if screening was not undertaken at all.³ It may be that the most effective measurement of health literacy is as a screening tool embedded into the health / treatment pathway and used to inform the health practitioner of the level of support required by the client. For example, screening health literacy levels prior to providing a self-management program for a chronic disease and tailoring the education and approach accordingly.

Figure 2 below describes how services may best consider an individual’s level of health literacy when engaging in treatment.

**Figure 2: Indicative relationship between health literacy and self-management**

- **High risk group** – Require individually tailored, multi-dimensional approaches to improving their health literacy
- **Medium risk group** – Require support within a clinical environment to improve their health literacy
- **Low risk group** – Should be recognised as partners in managing their health

*Source: PwC*

---

What does the evidence tell us?

Above all, health literacy should be - and needs to be - an active part of a person’s citizenship and it is a key component of social inclusion. Governments and other authorities have a critical role to play in safeguarding the health of citizens into the future.14

Despite the potential of improved health literacy, the level of evidence in this space is mixed. While there is reasonable evidence to support the impact of health literacy on certain groups in some circumstances, proof of being able to meaningfully improve levels of health literacy is variable. The systematic review undertaken by the Agency for Healthcare Research and Quality15 found that low health literacy was associated with higher mortality in seniors, lack of medication adherence, lack of ability to interpret labels and health messages, and poorer overall health status in seniors. A large proportion of the studies included in the review only examined health literacy in seniors rather than a wider population; hence the associations in younger people are unclear. Many of the trials and studies into health literacy interventions suffer from sub-par study design and lack of best practice epidemiological techniques – further evidenced by the absence of control groups or failing to control (or over-controlling) for potential confounding variables.

Nevertheless, there is some evidence to support approaches to improving health literacy. Components of effective approaches have been identified in the literature and cover the manner, timing and format of essential information presentation and delivery.16 Internationally a number of countries have and continue to trial programs to improve health literacy, and these may hold valuable lessons for Australia. In Australia there is a small but growing body of work being done to improve health literacy. A national project was recently commissioned by the Pharmacy Guild to improve awareness amongst pharmacists and trial screening. In particular, they are seeking to review existing tools and resources, develop a health literacy educational package for community pharmacy staff, and undertake a subsequent evaluation.

Interventions aimed at improving health literacy can extend beyond the health care system, incorporating the educational sectors, workplace settings, or family/community settings. They can encompass a broad range of approaches such as communication, education, community development, organisational/network development, and the development and implementation of policies. They can target a broad range of groups, including but not limited to senior citizens, young people, Aboriginal and Torres Strait Islander people, ethnic-minority groups, recent immigrants, or patients following specific treatment regimens. It has been noted however that there can be issues in ensuring that the interventions reach the correct target audience, as in the case of health literacy interventions it could very well be that individuals with low health literacy (whom the initiatives are targeting) do not know how or where to access the programs.

16 Ibid.
The need for action

“Only now do I know why some refer to this as a “silent epidemic” – the lack of understanding by most professionals and policy makers of its extent and effect, and the individual shame associated with it that keeps it even more silent and hidden.”

The health literacy of individuals is a key consideration for health services that wish to ensure patient focussed care and empower individuals to engage in the management of their health. At a population level the benefits of high health literacy suggest that it is a social inclusion issue with the potential to disadvantage those with low health literacy levels. The following recommendations are provided for improving health literacy in Australia:

**Health literacy interventions should be content and context specific**

What we can call *adequate* health literacy will differ according to a patient’s stage in life. For example, the content of the information required by an adolescent learning about alcohol, drugs and safe sex would differ markedly to the information requirements of a pregnant woman, which would again be different to the requirements of a newly diagnosed type 2 diabetes patient. Equally, the context of each of these individuals is important to consider, as life stages have an impact on their requirements, and the actions they can take to improve their health literacy will be vastly different.

When tailoring programs, it needs to be noted that language and literacy are very distinct concepts. If an individual does not speak English well, this does not imply that they have low health literacy. They could in fact have very high health literacy. This is an important point to note when considering the context of the audience a health literacy intervention is targeting. Additionally, research has shown that if medical information is being translated from English into other languages, then the translation is most effective when the original text is written in plain English, with minimal use of complicated medical terminology.

**Effective health literacy screening should be considered as a step in the diagnosis and treatment pathways**

The merits of screening only exist if the results inform decisions about the patient’s treatment or diagnosis pathway. For those patients who are found to be lacking in functional health literacy through a screening tool, the clinician can choose to either tailor the treatment or diagnosis pathway from that point forward to better meet the needs of the patient, or they can work to improve the patient’s health literacy through education or another form of intervention. The choice should be made based on the condition the patient is presenting with. If the condition requires the patient to play an active role in its management (most chronic diseases for example), then the preferred option is to improve the patient’s health literacy, as research has demonstrated that health literacy skills are vital in enabling patients to self-manage their conditions. This treatment or diagnosis pathway effectively utilising the results of a health literacy screening tool is demonstrated in Figure 3.

---

The Australian Social Inclusion Board have recommended that the Australian Government undertake a program of work to improve the culture of government-delivered services to make them more people-centred and respectful – with a specific recommendation for service delivery personnel to receive greater training in mental health literacy – a subset of health literacy. However research has shown that improving broader health literacy (as opposed to only mental health literacy) can have positive impacts on social inclusion and community mobilisation. Given the priorities identified in the Australian Government’s social inclusion policy and the benefits which can be achieved through improving health literacy, it makes social and economic sense for government action on improving the health literacy of the Australian population.

Given the increasing use of the internet by the broader population, it is implicit that the use of the internet as a source of health information is also increasing. This information may not be appropriate to an audience with a broad range of health literacy. Rather than attempting to discourage this uptake of technology, publishers of online health information need to be cognisant of the health literacy levels of their audience, and potentially consider screening and appropriately tailoring the provided information. Given that most screening tools are currently paper-based, these could also be provided online and used to direct individuals towards information appropriate for their level of health literacy.

---


The internet poses some unique challenges when online health information is accessed by individuals with low health literacy. Yet the requirement of users to effectively evaluate the sources of health information and whether or not the information is appropriate for them is not unique to information accessed online. To overcome this issue, health literacy interventions should foster the ability to evaluate the quality, reliability and appropriateness of information accessed through a range of modalities – with online health information being a key component of this.

Evaluation is crucial to understanding the impact programs are having on patients and identifying areas for improvement. Both Canada and the USA have highlighted in their national plans that program evaluation is a crucial component of improving health literacy. Further research areas include:

- the measurement of health literacy and the development of a consistent threshold for low health literacy
- the associations between health literacy and chronic disease outcomes for broader populations (rather than limiting them to senior citizens as in much of the existing literature)
- the effectiveness of health literacy interventions in improving outcomes, self-management and treatment adherence within chronic disease patients
- the optimal context for screening tools to be most effective along the diagnosis or treatment pathway
- effective evaluation of health literacy interventions based on best practice study design and epidemiological analysis

In Australia, if health literacy improvement programs are to be considered, they should:

- initially target chronic disease management and medication compliance as areas of potentially greatest impact
- reflect the evidence base of components of effective programs

Health literacy levels are a proven independent predictor of patients’ knowledge of their chronic illness. Low health literacy in patients with chronic disease also represents a significant cost to the health care industry through inadequate or inappropriate use of medicines. Given these facts as well as the fact that over 7 million Australians have at least one chronic condition and nearly all of those

---


over the age of 65 reporting at least one chronic condition\textsuperscript{25} - if Australia is going to focus its health literacy efforts in a particular area, then chronic disease would be an ideal initial focal point. The AHRQ’s seminal systematic review discusses numerous studies which provide evidence to support the argument that low health literacy is associated with poorer outcomes across a number of important areas of health – including asthma, cancer, cardiovascular health and diabetes. The programs effective in improving outcomes, self-management and treatment compliance were guided by the components of effective programs discussed here, and as such any programs developed in Australia should also be guided by these principles.

Non-adherence to medication is another common health management issue – however other than pill counts and self-reports, no gold standard exists to assess medication adherence.\textsuperscript{26} In a study of HIV patients with low health literacy conducted in 1999, it was found that health literacy is a significant and independent predictor of medication adherence after controlling for a range of related factors.\textsuperscript{27} Since this study, research has demonstrated more broadly that a lack of functional health literacy hinders a patient’s ability to answer numeracy questions relating to medication use, their ability to carry out medication directions as intended, and their ability to accurately report other medications they are currently taking.\textsuperscript{28} Therefore, in the absence of specific tools to screen for non-adherence to medication, health literacy interventions could be used to improve medication compliance. These findings also reinforce the importance of screening for low health literacy early in the diagnosis or treatment pathway.\textsuperscript{29}

A cost benefit evaluation of health literacy program application to selected chronic diseases in Australia should be undertaken to help inform resource allocation.

Resources – such as people, time, facilities, equipment, and knowledge – are scarce. Choices need to be made regarding their deployment – however often ‘gut feeling’ and ‘educated guesses’ are employed about the most efficient way to do this. Without a systematic analysis of the costs and benefits of health literacy program application to key chronic diseases, it will be difficult to clearly identify the relative alternatives. Without some attempt at this measurement, the uncertainty surrounding orders of magnitude can be critical. The costs of applying health literacy interventions in Australia needs to be considered in light of the foregone benefits of other programs which could be implemented with the same resources to determine if health literacy interventions for chronic diseases truly represent ‘value for money’ in an Australian context.\textsuperscript{30}


