

Health literacy Implications for Australia

Final Report

Medibank

FINAL

September 2011



Disclaimer

This report was prepared for the Medibank Private Limited

In preparing this Report we have only considered the circumstances of Medibank Private Limited. Our Report is not appropriate for use by persons other than Medibank Private Limited, and we do not accept or assume responsibility to anyone other than Medibank Private Limited in respect of our Report.

Table of Contents

Disclaimer	2
Table of Contents	3
Glossary	4
Background	5
Executive summary	7
What is health literacy?	11
What are the impacts of having low health literacy?	24
The dichotomy of low health literacy in an online landscape.	33
What can we learn from other jurisdictions?	40
Health literacy in Australia	46
Recommendations	52
References	56

Glossary

<i>Term</i>	<i>Definition</i>
ABS	Australian Bureau of Statistics
AHRQ	Agency for Healthcare Research and Quality
ALLS	Adult Literacy and Life Skills Survey
CPHA	Canadian Public Health Association
HSE	Health Service Executive
K-12	Kindergarten to year 12
MART	Medical Achievement Reading Test
NALA	National Adult Literacy Agency
NHS	National Health Service
NLHP	National Literacy and Health Program
NVS	Newest Vital Sign
OECD	Organisation for Economic Cooperation and Development
PIAAC	Programme for the International Assessment of Adult Competencies
REALM	Rapid Estimate of Adult Literacy in Medicine
SBSQ	Set of Brief Screening Questions
TOFHLA	Test of Functional Health Literacy in Adults
WHO	World Health Organisation

Background

This report has been prepared for Medibank Private Limited by PricewaterhouseCoopers (PwC). The objective of this paper is to consider the existing body of evidence surrounding health literacy from both an Australian and international context, and to develop recommendations for improving health literacy in Australia. The research contained in this report has been sourced through a combination of academic literature, publically available reports, websites, and through consultation with two international experts in health literacy.

The report covers:

- the definition and measurement of health literacy
- the impacts of having low health literacy
- the impacts of the internet and online information on health literacy
- lessons from other jurisdictions
- recommendations for discussion on the future of health literacy in Australia, which for completeness and ease of reference are summarised at the end of the document as well as included throughout the report.

Executive summary

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.”¹

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.

¹ Rootman, I., & Gordon-El-Bihbety, D. (2008). *A Vision for a Health Literate Canada – Report of the Expert Panel on Health Literacy*. Canadian Public Health Association.

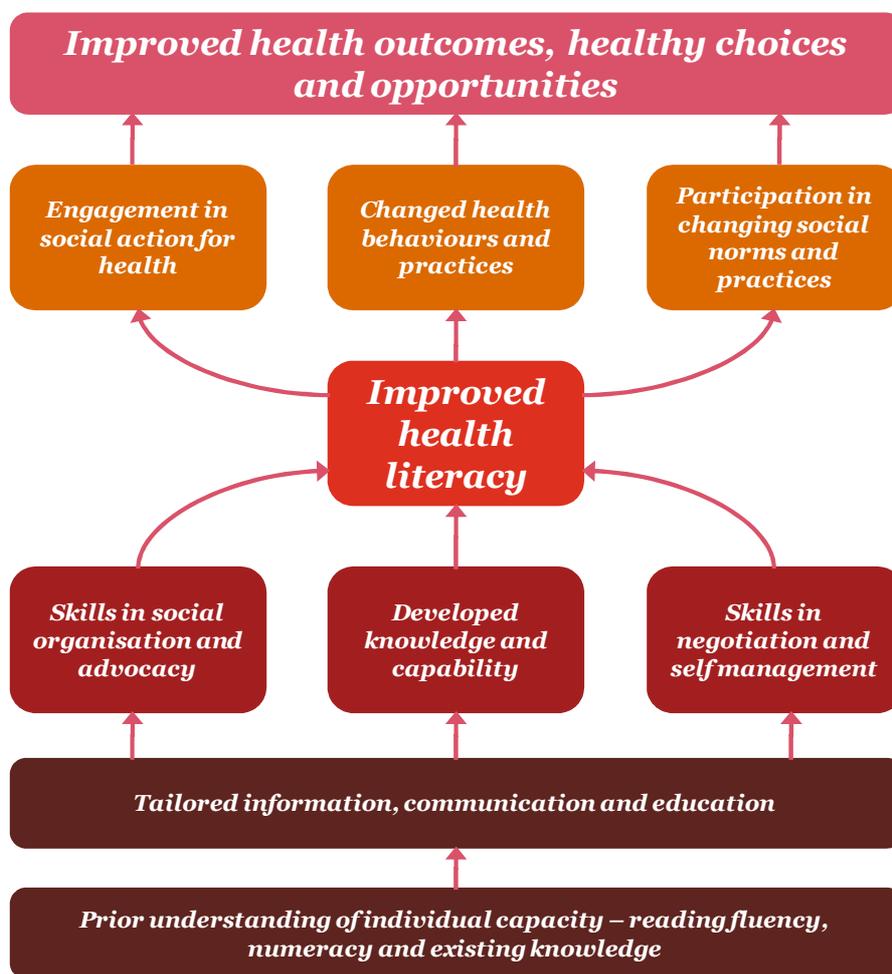
² Ship, A. (2011). A 76-Year-Old Man With Multiple Medical Problems and Limited Health Literacy. *Journal of the American Medical Association*, 306(6), pp. E1-E2.

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



³ Australia Bureau of Statistics (2006). *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS

⁴ Kanj, M., & Mitic, W. (2009). *Health Literacy and Health Promotion: Definitions, Concepts and Examples in the Eastern Mediterranean Region*. Individual Empowerment – Conference Working Document. World Health Organization.

⁵ Volandes, A. E., & Paasche-Orlow, M. K. (2007). Health Literacy, Health Inequality and a Just Healthcare System. *The American Journal of Bioethics*, 7(11), pp. 5-10.

⁶ Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine*, 67, pp. 2072-2078.

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 engagement⁷

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 but also advocate for others in a similar position.

The need for a functional level of health literacy among individuals is clear, however measuring health literacy is challenging given its content and context specific nature. In addition, 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.⁸ 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.

What does the evidence tell us?

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 Quality⁹ 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.¹⁰ 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. The Department of Health Victoria is partnering with Deakin University to apply for an Australian Research Council grant to undertake a project focussing on capacity building in the health literacy space, developing and testing interventions for individuals with low health literacy, and identifying system and practice changes which will be required to facilitate such interventions. Another research project is a national project recently commissioned by the Pharmacy Guild to improve awareness amongst pharmacists and trial screening. In particular, they are seeking to review existing

⁷ Fictional case study developed by PwC for illustrative purposes.

⁸ Paasche-Orlow, M. K., & Wolf, M. S. (2007). Evidence Does Not Support Clinical Screening of Literacy. *Journal of General Internal Medicine*, 23(1), pp. 100-102.

⁹ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

¹⁰ Ibid.

tools and resources, develop a health literacy educational package for community pharmacy staff, and undertake a subsequent evaluation.

The need for action

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:

- 1. health literacy interventions should be content and context specific.**
- 2. effective health literacy screening should be considered as a step in the diagnosis and treatment pathways.**
- 3. health literacy should be considered as a health management and social inclusion issue.**
- 4. the demand for multi-modality information suggests that mechanisms for screening health literacy need to be applicable in this context.**
- 5. health literacy interventions should seek to increase the capacity of individuals to evaluate information obtained through a variety of modalities.**
- 6. further research and evaluation is required to monitor the effectiveness of any health literacy interventions adopted in Australia.**
- 7. 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.**
- 8. a cost benefit evaluation of health literacy program application to selected chronic diseases in Australia should be undertaken to help inform resource allocation.**

What is health literacy?

“To function well in the 21st century a person must possess a wide range of abilities and competencies, in essence many ‘literacies’. These ‘literacies’ – from being able to read a newspaper to understanding information provided by a health care provider – are multiple, dynamic and malleable.”¹¹

The ageing population and increases in chronic disease are poised to make unprecedented demands on the health system in Australia. In order to manage this, health service providers and governments have increasingly looked to improve self-efficacy and management of chronic disease. At the same time there continues to be focus on the role of prevention and more recently wellness programs on influencing demand for acute services. Health literacy may have a key role to play in both these essential strategies as well as a more fundamental contribution to social inclusion and equity of access.

This report discusses key themes in the current literature surrounding health literacy, the impacts of low health literacy and mechanisms for improving the health literacy of individuals. Specifically, we consider how health literacy may be considered in the Australian context.

Defining health literacy

Whilst **literacy** refers to basic skills needed to succeed in society, **health literacy** is a more complex construct. Finding a succinct yet appropriate definition of the term is not a simple task. In both online and peer-reviewed literature, many definitions exist which differ in scope and emphasis.

Historically, the term ‘health literacy’ has been used in literature for at least the past 30 years, and was initially used to describe the relationship between a patient’s literacy levels and their ability to comply with prescribed treatment regimens.¹² In this way, health literacy merely referred to the ability of an individual to make sense of written information such as prescriptions, appointment cards and pharmaceutical directions. This narrow definition however fails to consider the role of health literacy as an enabler.

Academics have classified literacy into three key areas based on this consideration, each of which are applicable to health literacy:¹³

- **basic/functional literacy** – sufficient basic skills in reading and writing to be able to function effectively in everyday situations. This category aligns with the classical definition of health literacy described above.
- **communicative/interactive literacy** – more advanced cognitive and literacy skills, which together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. For example, individuals with chronic disease possessing communicative/interactive health literacy skills are able to identify the most appropriate sources of

¹¹ Kanj, M., & Mitic, W. (2009). *Health Literacy and Health Promotion: Definitions, Concepts and Examples in the Eastern Mediterranean Region*. Individual Empowerment – Conference Working Document. World Health Organization.

¹² Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), pp. 259-267.

¹³ Ibid.

information on their condition, can seek personally adapted information from their physicians and clinicians, and can apply this knowledge to achieve an adequate level of self-management.¹⁴

- **critical literacy** – more advanced cognitive skills which, together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations. These last two categories align more closely with modern definitions of what high health literacy represents. For example, individuals possessing critical health literacy skills are able to critically assess the quality of information and reliability of sources (particularly with regard to information sourced from the internet), and can contextualise this information to their specific situation even if the information was not personally tailored.¹⁵ They can also use health information to take on advocacy roles and effectively engage in policy discussions surrounding healthcare.

Each level of literacy increases the level of autonomy which it grants the individual. The modern usage of health literacy has connotations of being empowered to make appropriate decisions about one's own healthcare, just as the 'critical literacy' category implies.¹⁶ Basic/functional literacy can be considered in an absolute context – people either possess these basic skills or they don't. However the higher order literacies are relative measures – people can possess these skills in differing amounts.

Most definitions of health literacy currently in use include a broad range of more subtle factors than earlier published definitions.¹⁷ Given the complexities surrounding the issue however, it is easy for some definitions to become large and unwieldy.¹⁸ A definition needs to be succinct for it to be widely adopted.

The World Health Organisation's (WHO) Health Promotion Glossary defines health literacy as representing "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health".¹⁹ Whilst improving upon the classical usage of the term, it is still lacking in certain areas. One criticism of this definition is that it fails to recognise the importance of different health contexts in providing information to people in a form they can use and understand.²⁰ Others have also discussed that the social determinants of health are a critical component of health literacy, and that the WHO definition lacks reference to this.²¹

The Institute of Medicine in the USA in conjunction with the Department of Health and Human Services derived a definition of health literacy which emphasises dual responsibility for health literacy: "Health literacy emerges when the expectations, preferences and skills of the individuals seeking health information and services meet the expectations, preferences and skills of those providing information and services."²² It is important to focus on dual responsibility in the context of health literacy; however this definition still has a strong focus on fundamental literacy rather than considering broader empowerment issues.

¹⁴ Levin-Zamir, D., & Peterburg, Y. (2001). Health literacy in health systems: perspectives on patient self-management in Israel. *Health Promotion International*, 16(1), pp. 87-94.

¹⁵ Ibid.

¹⁶ Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), pp. 259-267.

¹⁷ Schnitzer, A., Rosenzweig, M., & Harris, B. (2011). Health Literacy: A Survey of the Issues and Solutions. *Journal of Consumer Health on the Internet*, 15(2), pp. 164-179.

¹⁸ U.S. National Library of Medicine, National Institutes of Health. *Health Literacy. Medline Plus*. Retrieved 14 July, 2011 from <http://www.nlm.nih.gov/medlineplus/healthliteracy.html>

¹⁹ World Health Organisation (1998). *Health Promotion Glossary*. Geneva: World Health Organisation.

²⁰ Rootman, I., & Gordon-El-Bihety, D. (2008). *A Vision for a Health Literate Canada – Report of the Expert Panel on Health Literacy*. Canadian Public Health Association.

²¹ Chinn, D. (2011). Critical health literacy: A review and critical analysis. *Social Science & Medicine*, 73, pp. 60-67.

²² Institute of Medicine of the National Academies (2004). *Health Literacy: A Prescription to End Confusion*. Washington: The National Academies Press

In more recent published articles, authors appear to be gravitating towards a definition endorsed by the Canadian Expert Panel on Health Literacy. Their definition was crafted after examining a number of existing definitions (including the WHO definition) and the criticisms levied against these, and worked to develop a comprehensive yet succinct way of defining health literacy which was accepted by all members of the panel. Their definition reads:

“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”²³

In their report titled *A Vision for a Health Literacy Canada*, the panel outline that this definition recognises the fact that health literacy is a resource in daily living, and that health status and access to ongoing education are closely linked at all stages of one’s life. They feel that it also suggests that health literacy is essential to managing one’s health, and is more than simply being able to read pamphlets and make appointments.²⁴ It appears the WHO have since adopted this definition in their reports over their original definition presented in the Health Promotion Glossary.²⁵

Given that the Canadian definition is holistic, succinct and appropriate to be applied to the Australian context, it will be adopted for this report.

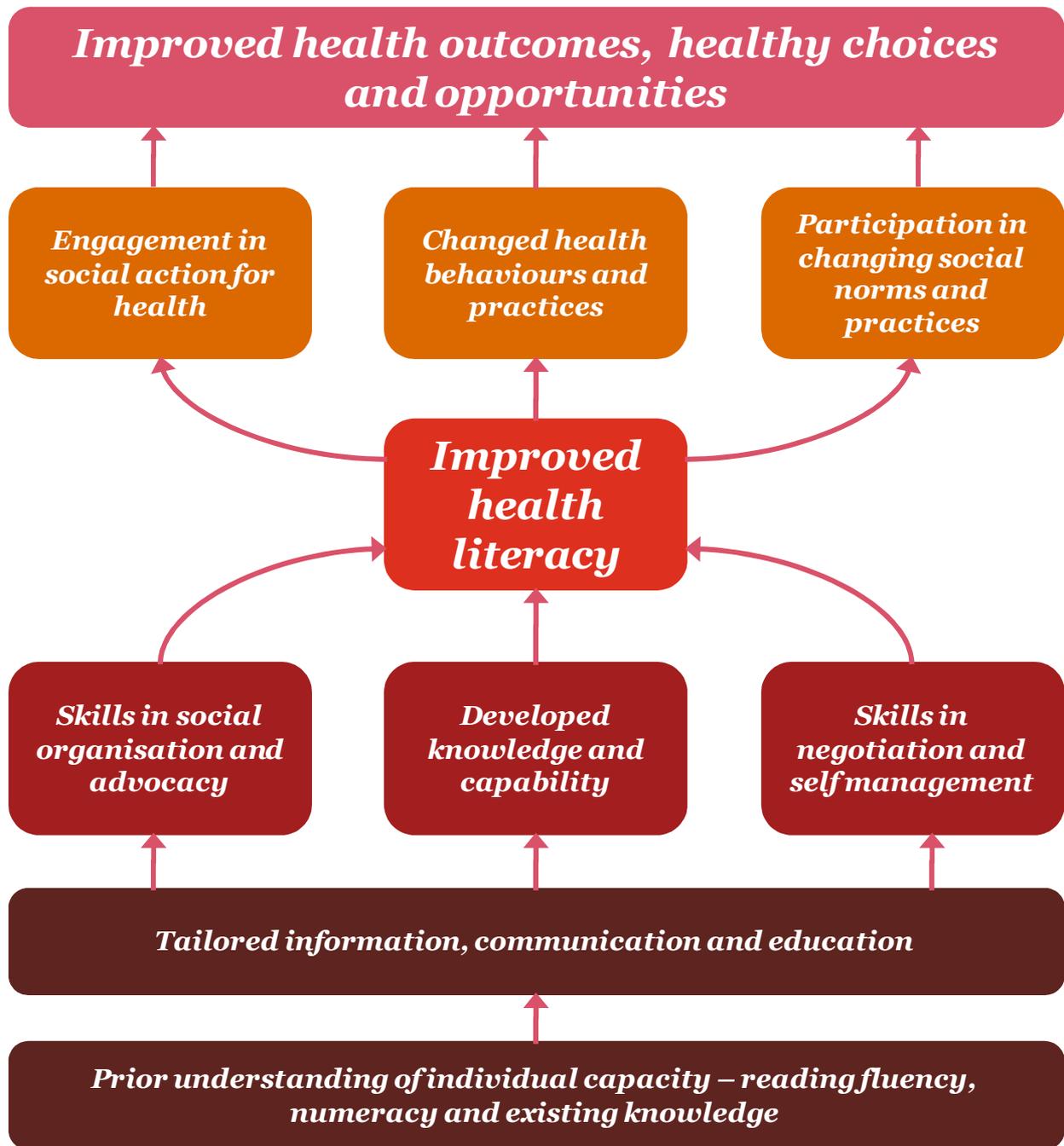
Health literacy is a distinct concept from fundamental literacy which is specific to a healthcare setting - yet the categorisations of fundamental literacy are directly applicable to health literacy. If we consider the overall outcome of health literacy to be improved health outcomes, healthy choices and opportunities, then we can visualise a pathway to this outcome through a conceptual model shown in Figure 2 developed by Professor Don Nutbeam – a leading academic in the field of health literacy.

²³ Rootman, I., & Gordon-El-Bihbety, D. (2008). *A Vision for a Health Literate Canada – Report of the Expert Panel on Health Literacy*. Canadian Public Health Association.

²⁴ Ibid.

²⁵ World Health Organisation (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva: World Health Organisation.

Figure 2: Nutbeam's conceptual model of health literacy as an asset²⁶



²⁶ Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine*, 67, pp. 2072-2078.

The following fictional case studies provide examples:

An example of differences in outcomes driven by differing levels of health literacy.²⁷

Mary and Jane are both 40 years old and have a family history of diabetes.

Mary is unaware that this history places her at risk even though her GP has asked about her family history and suggested she watch her weight and “look out for any early symptoms”. Mary does not know what she should look out for or how to find out more information. In addition Mary considers her weight to be under control. Mary has been overweight since her early 20’s but considers her weight to be “healthy and robust – not like those stick figures”. When Mary begins to suffer from frequency of urination and leg pain she considers these to be symptoms of old age and does not discuss them with her doctor. In fact, Mary doesn’t present to her doctor until she has a nasty sore on her foot that she can’t seem to get rid of.

Jane has remained very aware of her family history and called the local community health nurse to find out more information regarding risks and symptoms. This led her to discover a ‘learning about diabetes’ class held locally. As a younger woman she developed a routine of a walk each day and began to control her diet. Jane mentions her family history to her GP and requests a blood glucose test regularly. Having recently had an abnormally high result Jane is now accessing the local diabetes nurse to further examine her diet and exercise regimen and makes alterations following advice.

Mary and Jane had the same risk factor of a family history but their different levels of health literacy create discrepancies in their ability to access advice and care, their health outcomes, the type of services they access and their ultimate cost of care. In this way Mary’s low health literacy, poorer outcomes and decreased ability to access services constitute a social inclusion issue.

According to Nutbeam’s model this can be taken a step further with health literacy enabling advocacy and broader social engagement.

An example of health literacy as an enabler for advocacy and social engagement.²⁸

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.

After taking into account the complexity surrounding the definition of health literacy, Zarcadoolas et al²⁹ provide three key observations on the ways in which people notice, understand and use health information:

- ***Fundamental literacy and health literacy are different capacities*** – a person can have high fundamental literacy but low health literacy, or vice-versa. Examples given include a university graduate with a degree in physics not understanding that taking multiple over-the-counter medications could be harmful, or a single mother with a very low level of education being able to adequately manager her son’s chemotherapy regimens and being able to ask specific questions about recent blood tests.

²⁷ Fictional case study developed by PwC for illustrative purposes.

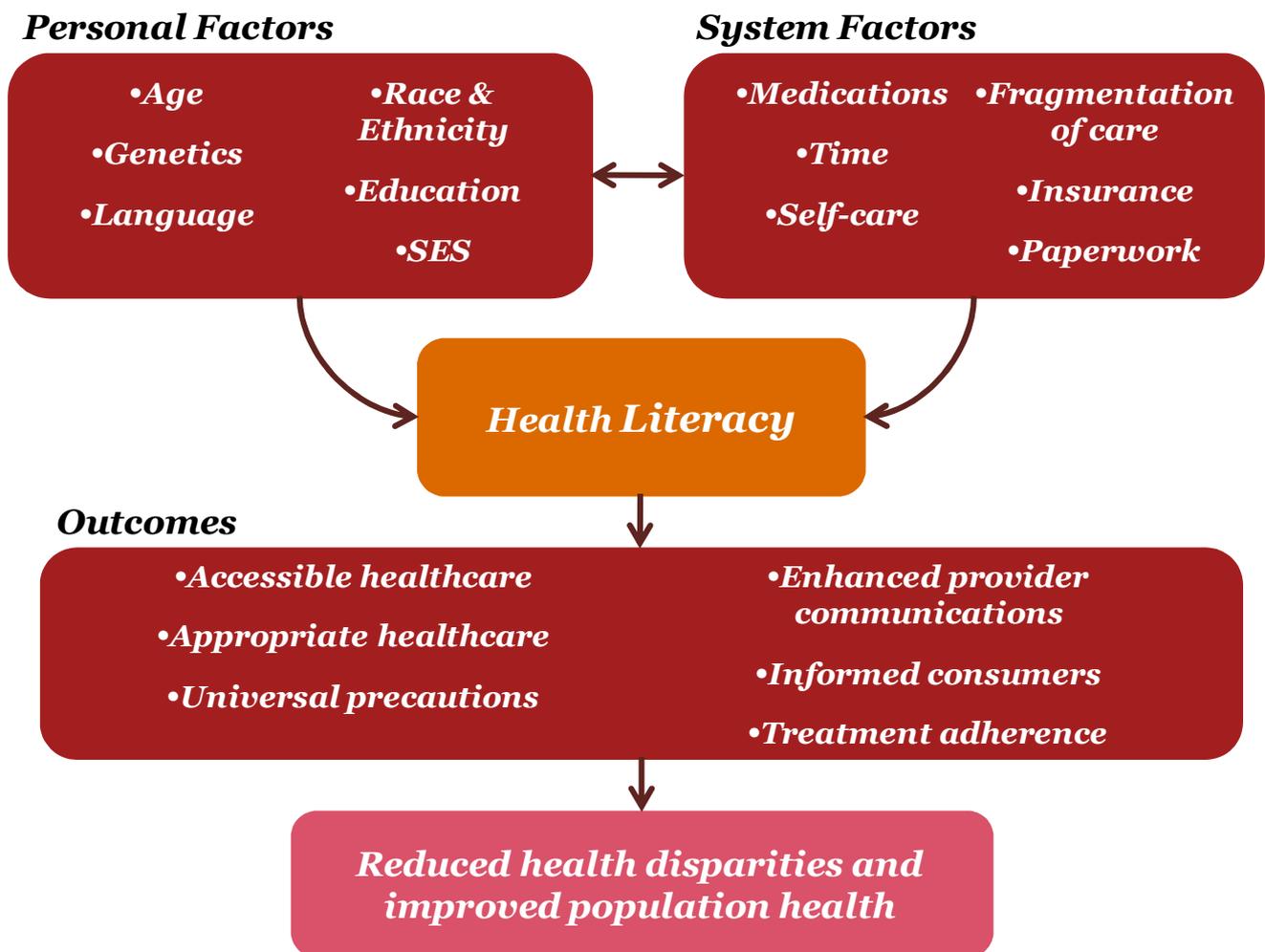
²⁸ Ibid.

²⁹ Zarcadoolas, C., Pleasant, A. F., & Greer, D. S. (2006). *Advancing Health Literacy: A Framework for Understanding and Action* (1st ed.). San Francisco: John Wiley & Sons.

- **How people understand health messages varies** – there is a great deal of variation in how people interpret and understand health messages, and this competence is influenced by many different factors.
- **Health literacy is productive and generative** – it is more than understanding a list of health facts and vocabulary. Rather health literacy consists of a dynamic group of productive skills that an individual draws on to generate positive outcomes when dealing with health situations in their life. The generative nature of these skills enables health-literate people to make informed decisions, healthier choices, and have degrees of independence from experts and knowledge intermediaries.

The health literacy of an individual is influenced by a combination of personal and system factors. Drilling into Nutbeam’s high-level conceptual model presented in Figure 2, the inputs to an individual’s level of health literacy can be broken down into **personal factors** and **system factors**. Similarly, the outcomes of improved health literacy can be further differentiated. These inputs and outcomes are represented in Figure 3.

Figure 3: Determinants and outcomes of health literacy³⁰



Social determinants such as the personal factors shown in Figure 3 are widely considered in the literature to have a strong impact on health literacy. However studies have found that despite its reliance on academic literature, mainstream media overemphasises the roles of system factors, and underemphasises the social

³⁰ Adapted from Ferguson, L. A., & Pawlak, R. (2011). Health Literacy: The Road to Improved Health Outcomes. *The Journal for Nurse Practitioners*, 7(2), pp. 123-129.

determinants of health literacy.³¹ For example, a study which interviewed health reporters in Canada found that a large proportion cited individual factors such as lifestyle and diet as being the most important indicators of health. Others in this study reported that social determinants are difficult to write about because they aren't always tangible, and are not conducive to effective storytelling or hard-news reporting.³² Brad Evenson of the *National Post* stated in this study that “social determinants are not particularly newsworthy”.³³ The importance of system factors should not be underestimated. As shown in Figure 3, system factors such as medication complexity, short office visits, increased self-care demands, care fragmentation and insurance paperwork contribute to the problem of limited health literacy. The current healthcare system requires patients to take increasingly more responsibility in managing their own care – and these challenges increase as treatment decisions become more and more complex.³⁴

Given that a key goal of improved health literacy is increased access to timely and appropriate healthcare; it is intrinsically linked to social inclusion. The Australian Government has developed social inclusion policies which aim to provide every Australian with the assistance they require to access opportunities society has to offer – regardless of setback or crises faced during their lives. Social inclusion policy operates in three ways:³⁵

- improving the quality of essential government services – particularly in the areas of education and training, employment, health and housing
- ensuring those services work more effectively in the most disadvantaged communities
- developing partnerships between governments, businesses, not-for-profit organisation and the community and engaging disadvantaged communities to help find solutions to address their particular needs.

Social inclusion also touches on economic policy as well as social policy. Ensuring that people have the resources, opportunities and capabilities to participate will reduce costs associated with low levels of social inclusion – such as the costs associated with preventable illness in the context of timely and appropriate healthcare accessibility.³⁶ Through developing individual and community strengths, tailoring services to the needs of individuals and communities, early intervention and prevention, and building future resilience – health literacy aligns with the key principles of social inclusion by enabling individuals to effectively engage with fundamental services.

³¹ Gasher, M., Hayes, M., Hackett, R., Gutstein, D., Ross, I., & Dunn, J. (2007). Spreading the News: Social Determinants of Health Reportage in Canadian Daily Newspapers. *Canadian Journal of Communication*, 32, pp. 557-574.

³² Ibid.

³³ Ibid.

³⁴ Ferguson, L. A., & Pawlak, R. (2011). Health Literacy: The Road to Improved Health Outcomes. *The Journal for Nurse Practitioners*, 7(2), pp. 123-129.

³⁵ Department of Prime Minister and Cabinet (2009). *A Stronger, Fairer Australia – Summary brochure*. Retrieved 11 August, 2011, from http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/brochure_stronger_fairer_australia.pdf

³⁶ Department of the Prime Minister and Cabinet (2011). *Australian Social Inclusion Board Annual Report 2010*. Retrieved 11 August, 2011, from <http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/asib-board-annual-repor-2010.pdf>

Measuring health literacy

“The public’s skills are not well-matched with the health information they encounter in everyday life.”³⁷

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.³⁸

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.³⁹ Different screening tools are therefore required for different ages and different stages in life.⁴⁰

As such, there are a wide variety of screening tools have been developed to assist clinicians to measure an individual’s health literacy level – each with their own psychometric properties, advantages and limitations. Examples of the most common of these tools found in the literature are:

- Rapid Estimate of Adult Literacy in Medicine (REALM)
- Test of Functional Health Literacy in Adults (TOFHLA)
- Set of Brief Screening Questions (SBSQ)
- Medical Achievement Reading Test (MART)
- Newest Vital Sign (NVS)

These 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* 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.

³⁷ Baur, C. (2011). Calling the nation to act: Implementing the national action plan to improve health literacy. *Nursing Outlook*, 59, pp. 63-69.

³⁸ Nutbeam, D. (2009). Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health*, 54, pp. 303-305.

³⁹ Ibid.

⁴⁰ Ibid.

“Much work remains to be done to develop indices that are tailored to defined health content and contexts, and that distinguish between the different levels of knowledge and skills that reflect functional, interactive and critical health literacy.”⁴¹

Some screening tools focus more on identifying personal ability, whilst others seek to identify individuals at risk. Whilst none of these screening tools fully measure a person’s ability to seek, understand and use health information, it has been noted that this could be due to the lack of consensus surrounding the definition of health literacy. It has also been noted that the screening tools should be capable of revealing a patient’s individual abilities and weaknesses in interpreting health information to enable clinicians to effectively tailor treatments and information provision.⁴² Other issues with existing screening tools include conflicting results if used on the same patient, and their content being specific to the country of origin.⁴³

Research has demonstrated that if screening programs are to be used as a key step along the treatment or diagnosis pathway that action needs to be taken to make use of the findings. This could include modifying the treatment or diagnosis pathway to ensure that the patient can comprehend it, or putting them through an intervention to improve their health literacy. The latter option is likely to be more feasible if the patient’s condition requires a high degree of active self-management. In particular, the study also noted that if patients are screened and found to have low health literacy, but no action is taken to rectify this, then patient outcomes could be worse than if screening was not undertaken at all.⁴⁴

Figure 4 describes how services may best consider an individual’s level of health literacy when engaging in treatment:

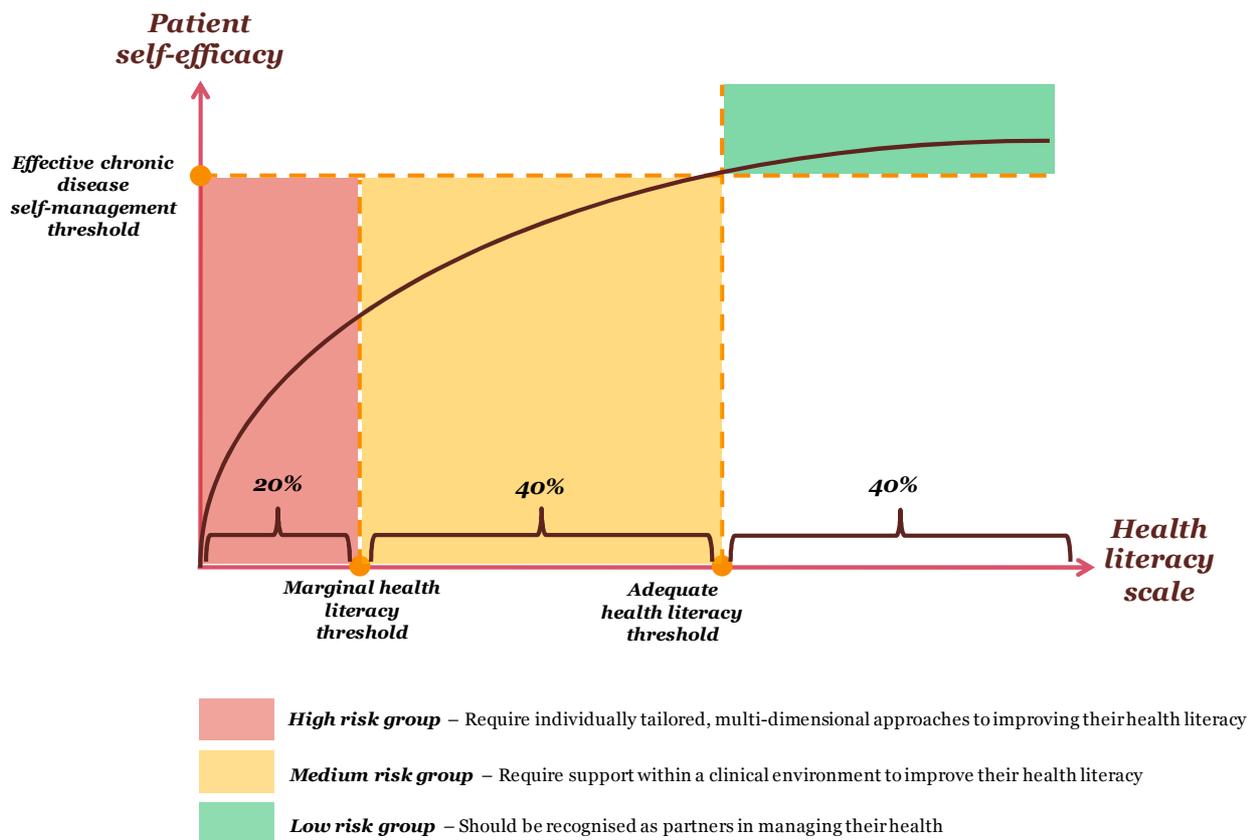
⁴¹ Nutbeam, D. (2009). Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health*, 54, pp. 303-305.

⁴² Jordan, J. E., Osborne, R. H., & Buchbinder, R. (2011). Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. *Journal of Clinical Epidemiology*, 64, pp. 366-374.

⁴³ Barber, M. N., Staples, M., Osborne, R. H., Clerehan, R., Elder, C., & Buchbinder, R. (2009). Up to a quarter of the Australian population may have suboptimal health literacy depending upon the measurement tool: results from a population-based survey. *Health Promotion International*, 24(3), pp. 252-261

⁴⁴ Paasche-Orlow, M. K., & Wolf, M. S. (2007). Evidence Does Not Support Clinical Screening of Literacy. *Journal of General Internal Medicine*, 23(1), pp. 100-102.

Figure 4: Indicative relationship between health literacy and self-management



Source: PwC

Despite the limitations of considering health literacy at a population-wide level, some countries have attempted to develop a health literacy index. This index tends to be a product of national adult literacy surveys. These surveys vary from country to country, but usually measure literacy across the following domains:⁴⁵

- **prose literacy** – the ability to understand and use information from various mediums such as newspapers, magazines, books and brochures
- **document literacy** – the knowledge and skills required to locate and use information contained in various formats, such as job applications, payroll forms, maps, tables and charts
- **numeracy** – the knowledge and skills required to effectively manage and response to the mathematical demands of diverse situations
- **problem solving** – goal-directed thinking and action in situations for which no routine solution is available.

In Australia, health literacy has been measured through the Adult Literacy and Life Skills Survey (ALLS), which is an internationally run survey coordinated internationally by the Organisation for Economic Cooperation and Development (OECD) and administered by the Australian Bureau of Statistics (ABS) at a local level. The ALLS measures literacy across the four domains listed above, and for each domain has a range of questions relating to the topics of health promotion, disease prevention, health care maintenance and systems navigation. The measure of health literacy used by the Australian government was derived from this subset of the ALLS. The

⁴⁵ Australia Bureau of Statistics (2006). *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS.

ALLS found that in 2006, nearly 60 per cent of the Australian population had less than adequate health literacy.⁴⁶

The USA was the first country to take this approach to measurement, and developed the Health Activities Literacy Scale, which is linked to their National Assessment of Adult Literacy. This approach was subsequently adopted in Canada, and then Australia. Differences in the sampling parameters and analytical processes used in the USA however imply that their measure of health literacy is not directly comparable with the Australian and Canadian scales.⁴⁷

A current drawback of this measure of health literacy is that the ALLS has only been conducted once in Australia in 2006, hence a time series of data does not currently exist to track changes in this data. However, the Programme for the International Assessment of Adult Competencies (PIAAC) coordinated by the OECD is a survey which will provide continuity with the ALLS going forward. It will be conducted internationally every 10 years, commencing in October 2011.⁴⁸ The first Australian results from the PIAAC will be available in October 2013; however consultation with the ABS revealed that there are currently no plans to derive the health literacy measure from the PIAAC going forward. This implies that there are no planned approaches to measuring the health literacy on a population basis in Australia. The reasons for this are uncertain.

“It seems that health literacy has been in large part limited by progress in developing measurement tools, more so than definitions and conceptualizations.”⁴⁹

Very broad interventions aimed at improving health literacy can actually broaden the gap in healthcare outcomes rather than narrow it. This is because a program which does not contain content which is tailored to specific contexts may not reach those lacking the functional health literacy required to access and interpret even the most basic health information. Such a program may instead improve upon the communicative/interactive and critical health literacy levels of those already possessing functional health literacy – hence widening the gap between those with and without functional health literacy. Widening this gap has negative implications for the equity and accessibility of the Australian health system for those with low health literacy.⁵⁰

“Fundamental fairness and equity are cited as quintessential in closing the gap in health.”⁵¹

As discussed throughout this report, 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

⁴⁶ Australia Bureau of Statistics (2006). *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS.

⁴⁷ Ibid.

⁴⁸ Department of Education, Employment and Workplace Relations. *Programme for the International Assessment of Adult Competencies*. Retrieved 28 July, 2011, from <http://www.deewr.gov.au/Skills/Resources/Pages/PIAAC.aspx>

⁴⁹ Berkman, N. D., Davis, T. C., & McCormack, L. (2010). Health Literacy: What Is It? *Journal of Health Communication*, 15, pp. 9-19.

⁵⁰ Kickbusch, I. S. (2001). Health literacy: addressing the health and education divide. *Health Promotion International*, 16(3), pp. 289-297.

⁵¹ Ibid.

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.⁵²

Often studies of clinical screening tools for health literacy exclude non-native English speakers from their analysis.^{53, 54} However it is extremely important to separate language from literacy. Individuals can have a high level of health literacy, but could be misclassified as having low health literacy due to their difficulty in communicating in English.⁵⁵ For these individuals, having them undertake a health literacy intervention would not improve their outcomes. They either require information to be tailored to their native language, or they need to undertake additional training in English.

Recommendation 1

Health literacy interventions should be content and context specific.

Numerous health workers have expressed concern surrounding the identification of patients with limited health literacy that may require their treatment regimens to be tailored or adapted to better suit their needs. As listed in this report, a number of current tools exist to screen for low health literacy or a lack of functional health literacy. An evaluation of NVS – a simple and quick to apply screening tool developed by Pfizer – found that whilst the time and cost constraints of using it were negligible, there was an overall lack of buy-in to its use by clinicians who failed to see its value or how to use the results to better tailor diagnosis or treatment information.⁵⁶ The evaluation report therefore recommended that screening tools be implemented along with training for the clinicians administering them to assist them with subsequently tailoring treatment or suggesting the patient take part in an intervention to improve their health literacy.

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.⁵⁷ This treatment or diagnosis pathway effectively utilising the results of a health literacy screening tool is demonstrated in Figure 5.

⁵² Burns, A., & Kim, M. (2011). Community accessibility of health information and the consequent impact for translation into community languages. *Translation & Interpreting*, 3(1), pp. 58-75.

⁵³ Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38, pp. 33-42.

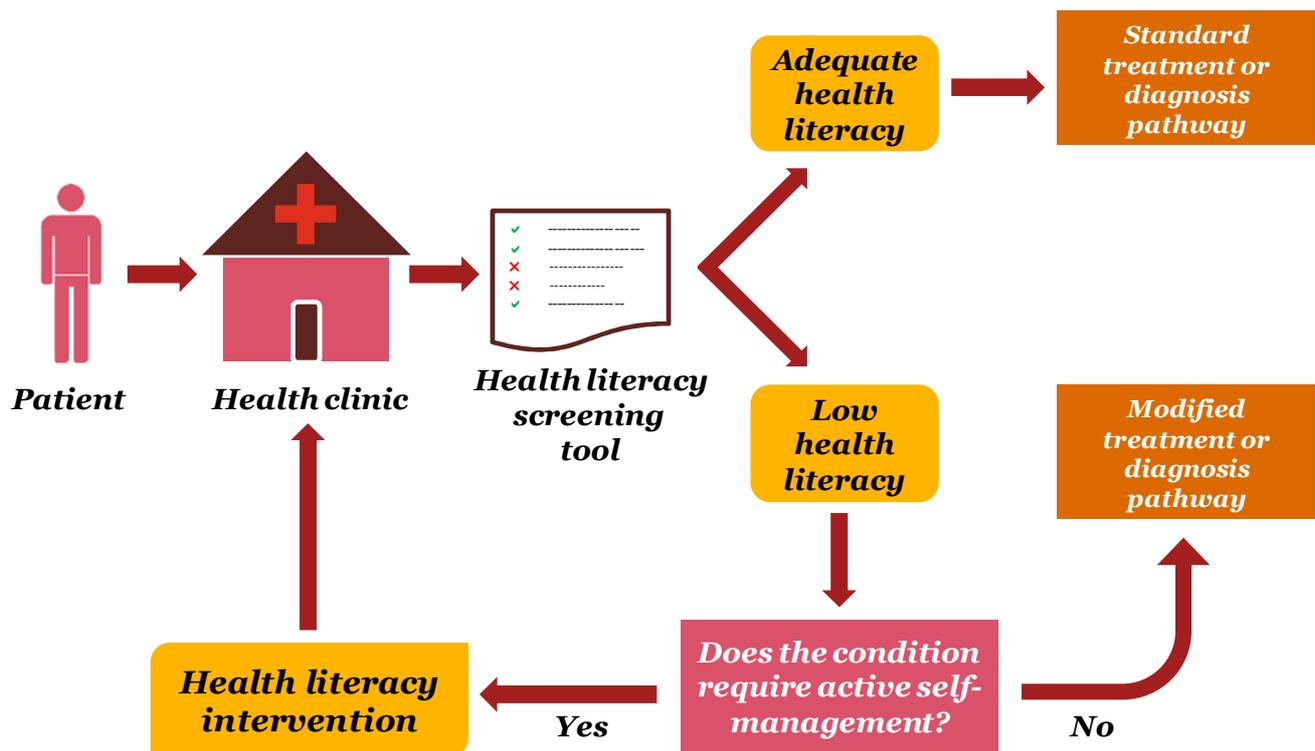
⁵⁴ Ohl, M., Harris, A., Nurudtinova, D., Cai, X., Drohobyczer, D., & Overton, E. T. (2010). Do Brief Screening Questions of Provider Perception Accurately Identify Persons with Low Health Literacy in the HIV Primary Care Setting? *AIDS Patient Care & STDs*, 24(10), pp. 623-629.

⁵⁵ Zanchetta, M. S., & Poureslami, I. M. (2006). Health Literacy Within the Reality of Immigrants' Culture and Language. *Canadian Journal of Public Health*, 97(2), pp.S26-S30.

⁵⁶ Welch, V. L., VanGeest, J. B., & Caskey, R. (2011). Time, Costs and Clinical Utilization of Screening for Health Literacy: A Case Study Using the Newest Vital Sign (NVS) Instrument. *Journal of the American Board of Family Medicine*, 24(3), pp. 281-289.

⁵⁷ Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51, pp. 267-275.

Figure 5: Screening health literacy as part of the treatment or diagnosis pathway



It is important to note however that a study undertaken by Paasche-Orlow and Wolf⁵⁸ found that clinical screening of health literacy should only be implemented if interventions emerged which could be exclusively delivered to patients with limited health literacy. They found that existing screening tools had the potential to cause harm to patients in the form of shame and alienation, and that if nothing was done to rectify this, then patient outcomes could be worse than if screening was not undertaken at all. They suggest that the modified treatment or diagnosis pathway shown in Figure 5 should be used for all patients regardless of their health literacy status if it is simpler and easier to understand. However this would not be a feasible option if the modified treatment or diagnosis pathway took significantly longer to explain or cost more to deliver. Overall, the authors of the study suggest that additional research needs to be undertaken to develop screening tests which minimise the risk of stigma and alienation.

Recommendation 2

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

⁵⁸ Paasche-Orlow, M. K., & Wolf, M. S. (2007). Evidence Does Not Support Clinical Screening of Literacy. *Journal of General Internal Medicine*, 23(1), pp. 100-102.

What are the impacts of having low health literacy?

Mr J is a 76 year old man whose care has been complicated by difficulties understanding his health care and accessing treatment.⁵⁹

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.

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

It is widely agreed that low health literacy is a public health issue. Increasingly, the public health community construct and disseminate their messages according to the theoretical constructs of *health education* (what the message says) and *health communication* (how the message is delivered), rather than considering the *health literacy* of the intended audience (whether the message is accessed and comprehended).⁶¹ This can be a significant problem for those with low health literacy – particularly given that it is this group in particular who are the target audience for many public health campaigns. Improvement in health literacy levels is an imperative to achieving the six components of high-quality health care as described by the Institute of Medicine:⁶²

⁵⁹ Ship, A. (2011). A 76-Year-Old Man With Multiple Medical Problems and Limited Health Literacy. *Journal of the American Medical Association*, 306(6), pp. E1-E2.

⁶⁰ Australia Bureau of Statistics (2006). *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS

⁶¹ Gazmararian, J. A., Curran, J. W., Parker, R. M., Bernhardt, J. M., & DeBuono, B. A. (2005). Public Health Literacy in America: An Ethical Imperative. *American Journal of Preventive Medicine*, 28(3), pp. 317-322.

⁶² Ferguson, L. A., & Pawlak, R. (2011). Health Literacy: The Road to Improved Health Outcomes. *The Journal for Nurse Practitioners*, 7(2), pp. 123-129.

-
- **safety**
 - **effectiveness**
 - **efficiency**
 - **timeliness**
 - **patient-centredness**
 - **equitable treatment.**

Studies attempting to map measures of health literacy to mortality levels have demonstrated mixed results in terms of the measures' effectiveness as an indicator for health outcomes. Whilst those who were measured to have low health literacy were found to have a greater mortality risk, the robustness of this finding has been questioned.⁶³ The results of this study also varied when the authors drilled down into more specific health indicators than broad mortality (such as physical functioning or mental health).⁶⁴

Health literacy is however a robust predictor of a wide spectrum of health related outcomes across population groups.⁶⁵ Figure 3 previously presented the outcomes of high health literacy as being accessible and appropriate healthcare, universal precautions, enhanced provider communication, treatment adherence and informed consumers. Having low health literacy therefore implies that some or all of these points may cease to exist. 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.⁶⁶ This is further evidenced for the Australian context in Figure 6. Overall, low health literacy skills are associated with poorer health knowledge, poorer health status, higher mortality, increased hospitalisations and higher health care costs.⁶⁷ 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.⁶⁸

⁶³ Wolf, M. S., Feinglass, J., Thompson, J., & Baker, D. W. (2010). In search of 'low health literacy': Threshold vs. gradient effect of literacy on health status and mortality. *Social Science & Medicine*, 70, pp. 1335-1341.

⁶⁴ Ibid.

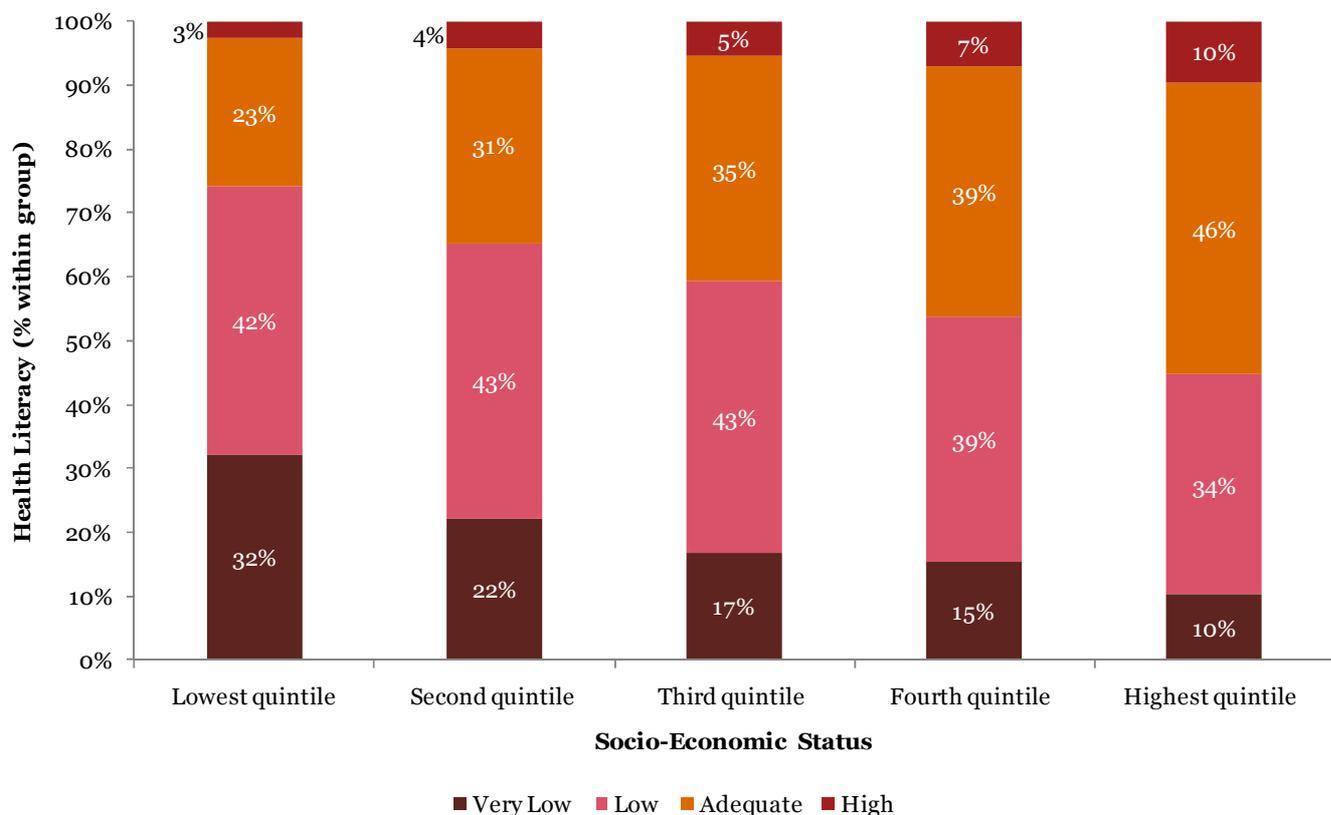
⁶⁵ Bush, R., Boyle, F., Ostini, R., Ozolins, I., Brabant, M., Soto, E. J., & Eriksson, L. (2010). *Advancing Health Literacy Through Primary Health Care Systems*. Retrieved 19 July, 2011, from <http://www.uq.edu.au/health/healthycomm/docs/APHCRI3pager.pdf>

⁶⁶ Liechty, J. M. (2011). Health Literacy: Critical Opportunities for Social Work Leadership in Health Care and Research. *Health & Social Work*, 36(2), pp. 99-107.

⁶⁷ Schnitzer, A. E., Rosenzweig, M., & Harris, B. (2011). Health Literacy: A Survey of the Issues and Solutions. *Journal of Consumer Health on the Internet*, 15(2), pp. 164-179.

⁶⁸ Volandes, A. E., & Paasche-Orlow, M. K. (2007). Health Literacy, Health Inequality and a Just Healthcare System. *The American Journal of Bioethics*, 7(11), pp. 5-10.

Figure 6: Health literacy by socio-economic status⁶⁹



Chronic diseases are characterised by complex causality, multiple risk factors, long latency periods, a prolonged course of illness and functional impairment or disability. They include conditions such as ischaemic heart disease, stroke, cancer, depression, type 2 diabetes, arthritis, osteoporosis, asthma, oral disease, chronic kidney disease and chronic obstructive pulmonary disease.⁷⁰ Despite the fact that many chronic diseases are highly preventable, their prevalence is significant in Australia – particularly in older age groups where their effects are compounded due to the presence of multiple chronic conditions, as evidenced by Figure 7.⁷¹ Chronic diseases are a particular concern to government because of the significant burden they place on individuals, communities and health services. ***An individual’s ability to self-manage their chronic condition(s) is imperative to reducing burden on communities and health services and minimising complications – and this ability is intrinsically linked to their level of health literacy.***⁷²

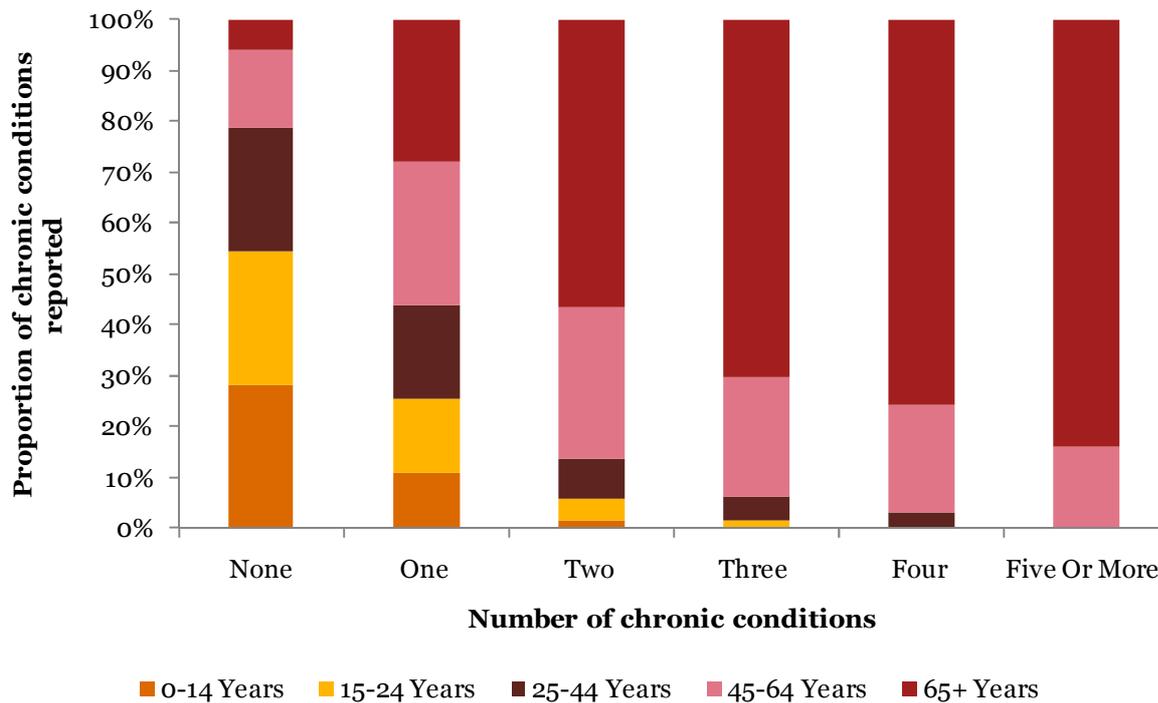
⁶⁹ Australia Bureau of Statistics (2006). *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS

⁷⁰ Australian Institute of Health and Welfare (2011). *Chronic diseases*. Retrieved 10 August, 2011, from <http://www.aihw.gov.au/chronic-diseases/>

⁷¹ National Public Health Partnership (2001). *Preventing Chronic Disease: A Strategic Framework*. Retrieved 10 August, 2011, from <http://www.nphp.gov.au/publications/strategies/chrondis-bgpaper.pdf>

⁷² Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51, pp. 267-275.

Figure 7: Proportion of chronic conditions reported by age group⁷³



Without significant intervention, Australian healthcare expenditure on chronic disease is projected to increase sharply – fuelled by expected increases in chronic disease prevalence attributable to the ageing population.⁷⁴ As well as this, there are significant losses associated with absenteeism and lack of workforce participation directly attributable to chronic disease. In particular, people with chronic disease average nearly half a day off work in the previous fortnight compared with a quarter of a day for people without chronic disease, and only 48 per cent of people with chronic disease are employed full-time, compared with 61 per cent of people without chronic disease.⁷⁵

An extensive systematic review of health literacy interventions and outcomes undertaken by the Agency for Healthcare Research and Quality (AHRQ) in the US examined a number of studies looking at the relationship between health literacy and chronic disease outcomes and prevalence. The review found that one study using nationally representative data found that lower health literacy was associated with higher odds of having a chronic illness, and higher odds of having a condition which would prevent the individual from working, after controlling for a number of relevant socio-demographic factors. Two other studies covered in the review however failed to find a significant relationship between chronic disease prevalence and health literacy status. It should be noted however that all three of these studies looked at chronic disease in terms of any illness lasting more than 6 months, rather than stratifying by specific conditions.⁷⁶

Three other studies included in the AHRQ’s systematic review examined specific chronic diseases by health literacy status; however each of these were limited to senior citizens. The first study – determined to be epidemiologically robust - found that inadequate health literacy was associated with significantly higher rates of

⁷³ Australian Institute of Health and Welfare (2011). *Chronic diseases*. Retrieved 10 August, 2011, from <http://www.aihw.gov.au/chronic-diseases/>

⁷⁴ Goss, J. (2008). *Projection of Australian health care expenditure by disease, 2003 to 2033*. Cat. no. HWE 43. Canberra: AIHW.

⁷⁵ Australian Institute of Health and Welfare (2009). *Chronic disease and participation in work*. Cat. no. PHE 109. Canberra: AIHW.

⁷⁶ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

diabetes and heart failure, but no association was found for hypertension, coronary heart disease, bronchitis, asthma, arthritis or cancer. The second study found no association for any chronic diseases – however this study design did not control for potential confounding factors, and hence the robustness of their findings is uncertain. The third study of senior citizens was undertaken in Korea, and found that low health literacy was significantly associated with higher rates of arthritis and hypertension, but not sensory disease, diabetes or pulmonary heart disease. This last study also did not control for confounding variables.⁷⁷ Given these issues, the authors of the systematic review concluded that the evidence was insufficient to form a conclusion on the effectiveness of health literacy interventions in reducing chronic disease, and that more research would need to be undertaken on this topic – specifically on wider populations than senior citizens.

Self-management has been described as the cornerstone of chronic disease care, and improving patient self-efficacy is a critical pathway to improved self management.⁷⁸ A particular study undertaken by Kanj and Mitic⁷⁹ demonstrated that low health literacy was independently associated with significantly lower health outcomes, and that efforts to improve these outcomes should focus on improving the health literacy skills which are pivotal in ensuring patients can learn, understand and implement effective self-management. A similar study undertaken by Schillinger et al⁸⁰ found that low health literacy in type 2 diabetes patients was independently associated with worse glycaemic control and higher rates of retinopathy. The authors also found that low health literacy may contribute to the disproportionate burden of diabetes-related problems among disadvantaged populations, and that efforts should be made to develop health literacy interventions specifically targeting diabetes patients.⁸¹ This point is reiterated in the AHRQ's systematic review. As mentioned above, the review found insufficient evidence that increasing health literacy decreased the prevalence of diabetes, however additional studies covered in the review found moderate evidence that self-management interventions targeted specifically at diabetes patients (as opposed to more generic health literacy programs) had a significant impact on self-management behaviours – consequently leading to improved self-monitoring and medication adherence in these patients.⁸² Consequently, more research should be undertaken to determine if self-management interventions which improve health literacy are more effective in improving outcomes for chronic disease patients than broader health literacy interventions.

The AHRQ's systematic review also found significant associations between low health literacy and other conditions prevalent in Australia. Asthmatic patients with inadequate health literacy were less likely to have mastery of their dose inhaler, and likely to have poorer asthma quality of life (based on the Asthma Quality of Life Quotient) and lower physical health status (based on the SF-36 questionnaire) when compared to asthmatic patients with adequate health literacy. Low health literacy is also associated with less screening for cervical and breast cancers. Individuals with inadequate health literacy were found to have higher cardiovascular-related mortality than those with adequate health literacy.⁸³

A lack of health literacy directly reduces a patient's ability to practice self-management, and hence it plays a crucial role in the management of chronic disease. Long-term conditions often require complex treatment

⁷⁷ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

⁷⁸ Sarkar, U., Fisher, L., & Schillinger, D. (2006). Is Self-Efficacy Associated With Diabetes Self-Management Across Race/Ethnicity and Health Literacy? *Diabetes Care*, 29(4), pp. 823-829.

⁷⁹ Kanj, M., & Mitic, W. (2009). *Health Literacy and Health Promotion: Definitions, Concepts and Examples in the Eastern Mediterranean Region*. Individual Empowerment – Conference Working Document. World Health Organization.

⁸⁰ Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., Palacios, J., Diaz-Sullivan, G., & Bindman, A. B. (2002). Association of Health Literacy With Diabetes Outcomes. *Journal of the American Medical Association*, 288(4), pp. 475-482.

⁸¹ Ibid.

⁸² Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

⁸³ Ibid.

regimens and require lifestyle adjustments to manage.⁸⁴ While Figure 6 demonstrates that low socioeconomic status is associated with lower health literacy in Australia, research has also shown that the incidence of chronic disease is higher in low socioeconomic groups.⁸⁵ Whether or not this higher incidence of chronic disease amongst individuals with low socioeconomic status is due to them also having lower health literacy however has not been established in the literature.

In the context of system complexity demonstrated in Figure 3, low health literacy can be connected to delayed diagnoses and poor adherence to treatment regimens. This is exacerbated as treatment regimens require more time and explanation – which can be difficult to provide in busy primary care practices. Discharge instructions and patient education materials are difficult to follow for those with limited health literacy, and patient follow-up is also restricted within this group.⁸⁶

In addition to the impacts listed above, limited health literacy has a number of impacts at the personal level. Low health literacy can increase stress through the shame and stigma attached to illiteracy and being unable to understand health information or navigate the health system. This leads to decreased self-efficacy and increased psychological burden.⁸⁷ Particular issues concerning ethics and justice need to also be considered for those who are unable to effectively interpret health information. A study from 2007 examining ethics and justice in the health system looked into the complexity of informed consent forms, and found that:

“The autonomy of healthcare users with limited literacy is thwarted if the forms intended to preserve their individual autonomy are inaccessible.”⁸⁸

It could be argued that because low health literacy often coexists with a range of social disadvantages that the relationship between low health literacy and poorer health outcomes is spurious. ***However numerous studies have proven that health literacy is an independent risk factor for poor health.***⁸⁹ This implies that whilst effort needs to be made to address the social determinants of health, strategies also need to be in place to specifically target improving health literacy. We can examine this from an Australian context through comparing self-assessed health status with health literacy levels as measured in the ALLS, as shown in Figure 8.

⁸⁴ Kanj, M., & Mitic, W. (2009). *Health Literacy and Health Promotion: Definitions, Concepts and Examples in the Eastern Mediterranean Region*. Individual Empowerment – Conference Working Document. World Health Organization.

⁸⁵ Hanley, O., Miner, J., Rockswold, E., & Biros, M. (2011). The relationship between chronic illness, chronic pain, and socioeconomic factors in the ED. *American Journal of Emergency Medicine*, 29, pp. 286-292.

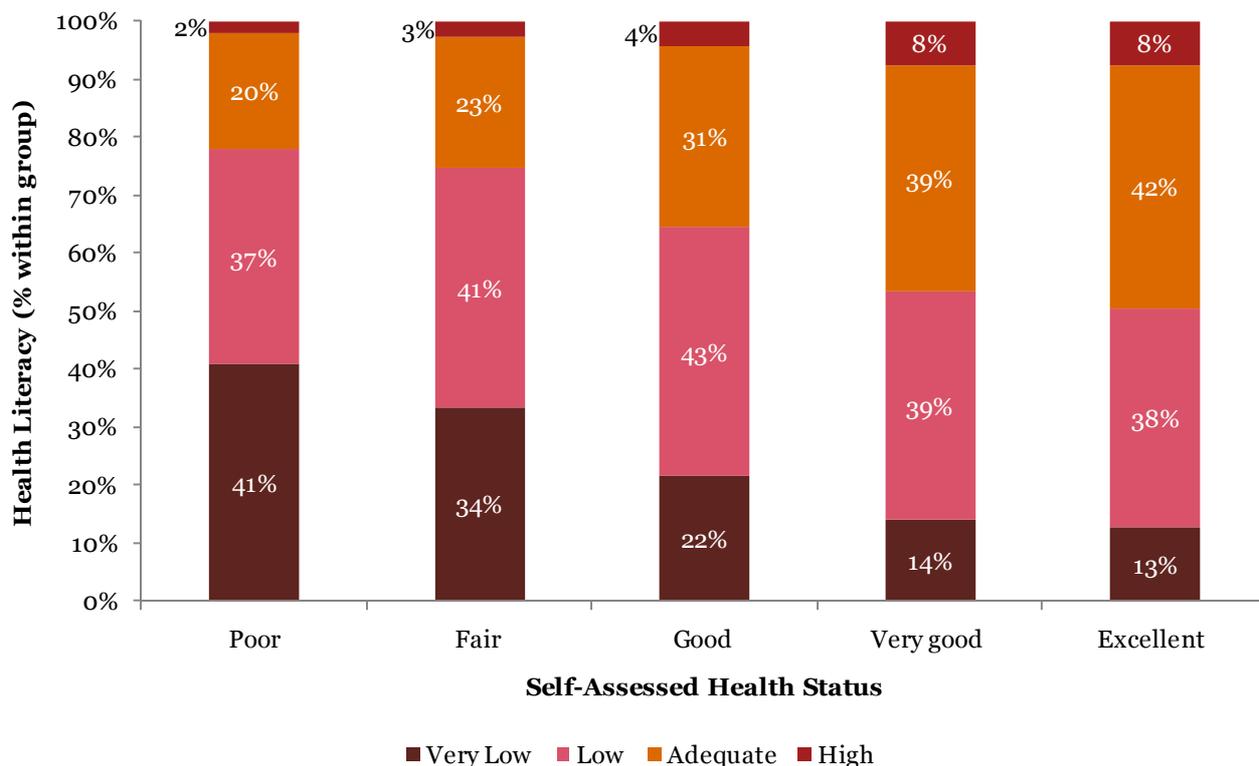
⁸⁶ Ferguson, L. A., & Pawlak, R. (2011). Health Literacy: The Road to Improved Health Outcomes. *The Journal for Nurse Practitioners*, 7(2), pp. 123-129.

⁸⁷ Ibid.

⁸⁸ Volandes, A. E., & Paasche-Orlow, M. K. (2007). Health Literacy, Health Inequality and a Just Healthcare System. *The American Journal of Bioethics*, 7(11), pp. 5-10.

⁸⁹ Kanj, M., & Mitic, W. (2009). *Health Literacy and Health Promotion: Definitions, Concepts and Examples in the Eastern Mediterranean Region*. Individual Empowerment – Conference Working Document. World Health Organization.

Figure 8: Health literacy by self-assessed health status⁹⁰



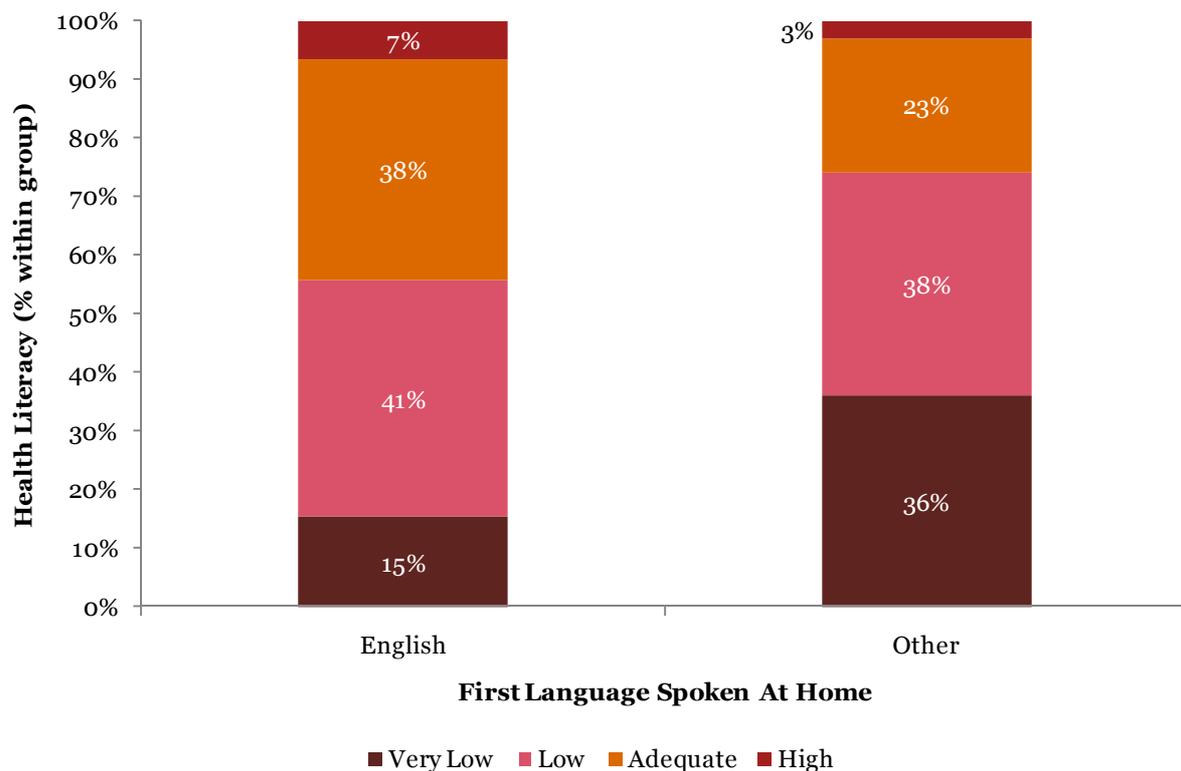
This connection between health literacy and health outcomes has significant implications for those whose first language is not English, as the ALLS found that this group have significantly lower levels of health literacy than those from English-speaking backgrounds. This is demonstrated in Figure 9. The issue of health literacy is compounded for this group in society due to the specialised vocabulary used in both spoken and written form to convey health information.⁹¹ This divide also extends to Aboriginal and Torres Strait Islanders. Research has found that their traditional and contemporary beliefs about the causes of illness can vary significantly from biomedical explanations, and it is therefore necessary to support Aboriginal and Torres Strait Islander patients in achieving health empowerment through specifically tailored approaches to improving their health literacy.⁹²

⁹⁰ Australia Bureau of Statistics (2006). *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS

⁹¹ Institute of Medicine of the National Academies (2004). *Health Literacy: A Prescription to End Confusion*. Washington: The National Academies Press.

⁹² Vass, A., Mitchell, A., & Dhurrkay, Y. (2011). Health literacy and Australian Indigenous peoples: an analysis of the role of language and worldview. *Health Promotion Journal of Australia*, 22(1), pp. 33-37.

Figure 9: Health literacy by first language spoken at home⁹³



As well as the social and medical impacts of low health literacy, the financial impacts may be substantial. The cost of health literacy has not been estimated for Australia; however the estimated cost to the US health care system is extremely high. Estimates in the literature range from between **US\$32 billion** up to **US\$238 billion** annually, based on 36 per cent of their adult population having basic or below-basic health literacy.⁹⁴ This cost blows out to trillions of dollars when discounted over a long-term period. These figures however need to be considered in the context of the American privately funded system, and therefore may not be representative of the cost in an Australian context. Other studies have also found that the costs to individuals with low health literacy can range from an additional US\$143 per year to nearly an additional US\$8,000 per year compared with someone with high health literacy.⁹⁵ The majority of research looking at the impacts of low health literacy acknowledges that it is associated with high social and economic costs; however there is a significant lack of literature devoted to understanding the dollar value of this cost under differing scenarios. In particular, given the evidence presented on the associations between health literacy, chronic disease outcomes and prevalence, and self-management, economic evaluations for Australia should initially focus on program application to key chronic diseases to inform resource allocation.

Overall, the AHRQ’s systematic review examined research which 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. The research examined did not find a lack of association for younger individuals; however a large proportion of the studies included in the review only examined health literacy in seniors rather than a wider population.

⁹³ Australia Bureau of Statistics (2006). *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS

⁹⁴ Keleher, H., & Hagger, V. (2007). Health Literacy in Primary Health Care. *Australian Journal of Primary Health*, 13(2), pp. 24-30.

⁹⁵ Kanj, M., & Mitic, W. (2009). *Health Literacy and Health Promotion: Definitions, Concepts and Examples in the Eastern Mediterranean Region*. Individual Empowerment – Conference Working Document. World Health Organization.

An example of the consequences of low health literacy⁹⁶

A 66 year-old man comes to the urgent care unit experiencing shortness of breath. He is found to be in rapid atrial fibrillation (a serious heart condition) and is admitted to the hospital. Once his heart rate is controlled, he is started on blood thinning medication. He is discharged home with verbal and written instructions to take three 1-mg tablets alternating with four 1-mg tablets daily. He does not show up for his clinical appointments, and two weeks later presents to the emergency department in a critical condition, and is admitted to the intensive care unit. His primary physician discovers that that patient had been taking both sets of tablets daily. The patient states that he did not ask questions at discharge because “everyone was so busy”. The patient did not tell anyone that he could not read the medication instructions or his clinic appointment slips.

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.⁹⁷ 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.⁹⁸

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.

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.⁹⁹

Recommendation 3

Health literacy should be considered as a health management and social inclusion issue.

⁹⁶ Youmans, S. L., & Schillinger, D. (2003). Functional Health Literacy and Medication Use: the Pharmacist’s Role. *The Annals of Pharmacotherapy*, 37, pp. 1726-1729.

⁹⁷ Department of the Prime Minister and Cabinet (2011). *Breaking Cycles of Disadvantage*. Retrieved 11 August, 2011, from <http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/breaking-cycles-of-disadvantage.pdf>

⁹⁸ Hemming, H. E., & Langille, L. (2006). Building Knowledge in Literacy and Health. *Canadian Journal of Public Health*, 97(2), pp. s31-s36.

⁹⁹ Adapted from Kickbusch, I. (2008). Health literacy: an essential skill for the twenty-first century. *Health Education*, 108(2), pp. 101-104.

The dichotomy of low health literacy in an online landscape.

“The new generation of health professionals is being raised with Health 2.0 technologies and this will increasingly make them impossible to ignore.”¹⁰⁰

The previous section of this report noted that nearly 60 per cent of Australians may have low health literacy. Yet a survey conducted by Bupa found that nearly 68 per cent of individuals use the internet to look for health-related information, with about half of this group using it to make a self-diagnosis.¹⁰¹ Given the increasing proportion of Australians accessing the internet at home, health providers and governments are increasingly providing health information and programs via the internet. This presents numerous issues if individuals lack the skills to understand and evaluate the information presented.

Whilst definitions of health literacy have evolved over time and continue to evolve, the health system itself and the mediums which individuals use to access health-related information are also evolving at a rapid pace. In particular the concept of *Health 2.0* and its rapid advancement implies that individuals without the required level of health literacy to navigate our current health system will only be left behind as the interaction between technology and consumers in shaping healthcare grows. Health 2.0 is defined as participatory healthcare which is enabled by information, software, and the community that we collect or create. The concept implies that patients can be effective partners in their own healthcare, and that they can participate in reshaping the health system itself.¹⁰² The internet is one of the main drivers of eHealth and Health 2.0 platforms. The internet has previously been regarded as more of a content platform rather than a social and interactive space within the healthcare system – however this is rapidly changing.¹⁰³ This goes hand-in-hand with a changing landscape of internet usage in Australia. The most recent figures published by the ABS (for 2008-09) indicate that 72 per cent of Australian households have internet access – and this figure has grown rapidly since 1998 as demonstrated in Figure 10.

¹⁰⁰ Spring, H. (2011). Learning and teaching in action. *Health Information and Libraries Journal*, 28, pp. 148-151.

¹⁰¹ Bupa (2011). *Aussies turning to cyberspace to self-diagnose*. Retrieved 9 September, 2011, from <http://www.bupa.com.au/portal/site/Bupa/menuitem.2aac420b606c953d7c1c9d5c297420a0/?vgnextoid=eabc275e10boe210VgnVCM100000coa400aRCRD&vgnnextfmt=7030news>

¹⁰² Spring, H. (2011). Learning and teaching in action. *Health Information and Libraries Journal*, 28, pp. 148-151.

¹⁰³ Lupiáñez-Villaneuva, F., Mayer, M. Á., & Torrent, J. (2009). Opportunities and challenges of Web 2.0 within the health care systems: An empirical exploration. *Informatics for Health & Social Care*, 34(3), pp. 117-126.

Figure 10: Proportion of Australian households with internet access¹⁰⁴

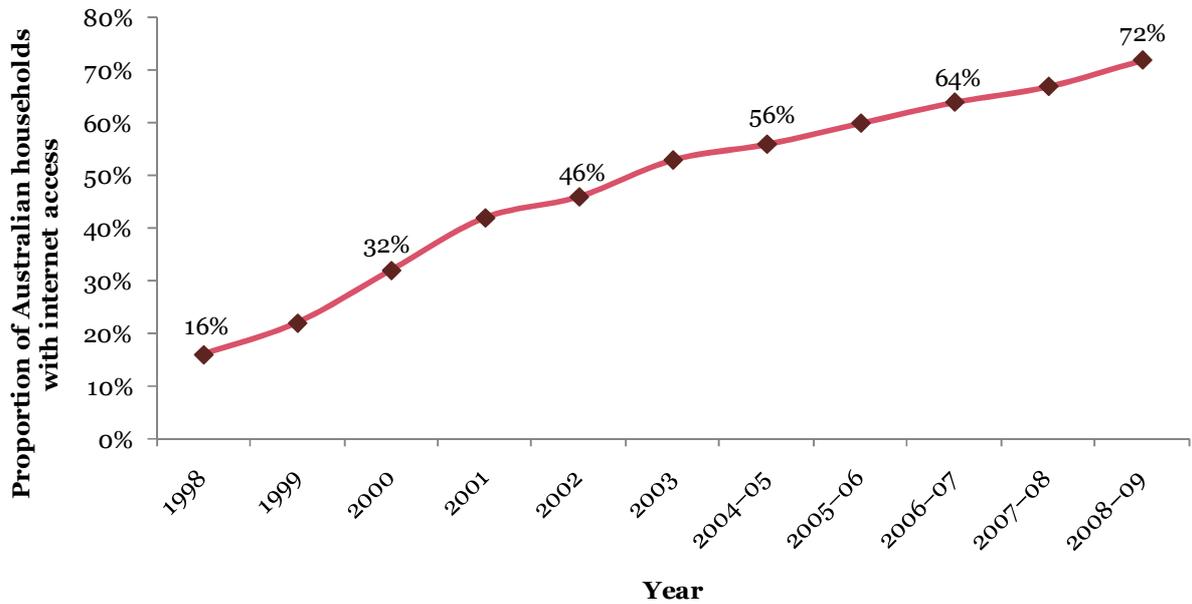
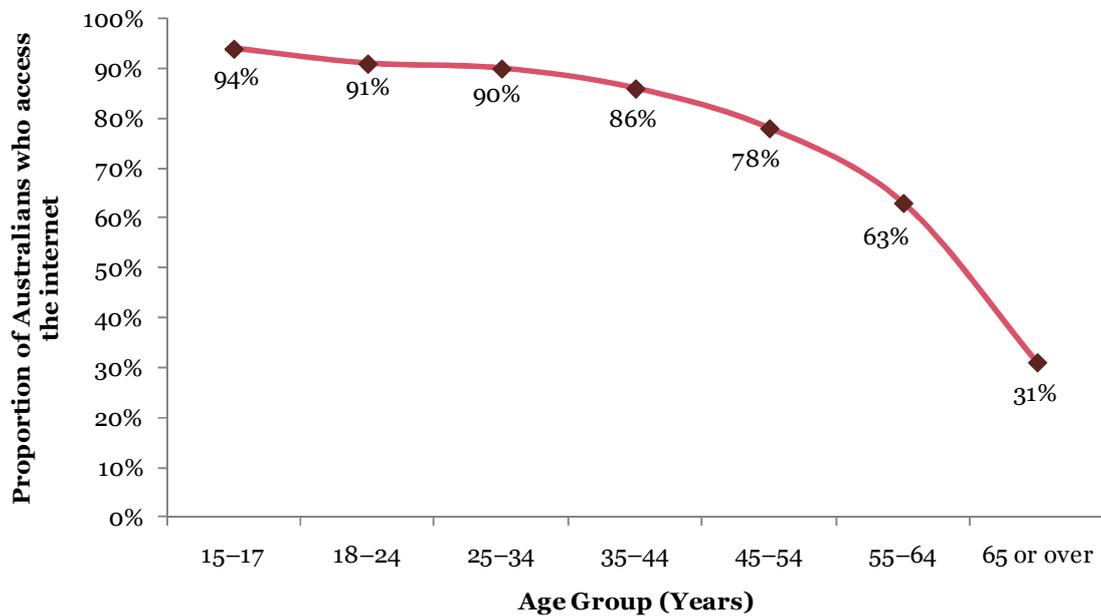


Figure 11 demonstrates that there is a sharp decline in internet usage by Australians over the age of 54 years.

Figure 11: Proportion of Australians who access the internet by age group (2008-09)¹⁰⁵



Those who use the internet for health-related information can be grouped into one of three categories:¹⁰⁶

¹⁰⁴ Australia Bureau of Statistics (2009). *Household Use of Information Technology, Australia, 2008-09*. Cat. no. 8146.0. Canberra: ABS

¹⁰⁵ Ibid.

¹⁰⁶ Cain, M. M., Sarasohn-Kahn, J., & Wayne, J. C. (2000). *Health e-People: The Online Consumer Experience*. Oakland, CA: California HealthCare Foundation.

- **the well** – making up around 60 per cent of consumers searching for health information online. These individuals are not constrained by a significant or recurring illness that affects what and how they search for information and services. The information they obtain is predominantly related to prevention and wellness type information, and would be obtained in a similar fashion to how they look for news, stock prices, and products.
- **the newly diagnosed** – representing about 5 per cent of the total. A new diagnosis of something such as a chronic illness may motivate the patient to look online for information for the first time. The searching can often be frantic and cover a significant amount of material in a short space of time. This group are transient and can move between *the well* and *the chronically ill*. Great potential exists to educate this group early on and develop their health literacy, particularly as they are the most eager for new and additional information.
- **the chronically ill and their caregivers** – representing around 35 per cent of online health consumers. This group search for health information on a frequent basis, and are more loyal to specific sites and platforms which meet their needs for disease-specific information and support. This group have a high potential to be directly affected by health information sourced online, as individuals living with chronic illness actively manage it in their day-to-day life, and seek ways to make this task easier.

A consumer's health literacy can affect every stage of finding, understanding, evaluating and using health information sourced online. Interventions to address online health literacy can target a variety of different skills and population groups, but usually focus on one or more of the following areas:¹⁰⁷

- **internet knowledge** and the ability to use the internet – directly addressing motivational and computer literacy barriers
- **search skills** – addressing barriers to information literacy skills such as knowing when and why you need information and where to find it
- **evaluation skills** – addressing barriers and strategies relating to judging the quality of information sourced from the internet
- **applying information in practice** – addressing broader health literacy outcomes relating to one's ability to understand, act on and communicate health information.

Programs developed to address online health literacy range from simple quality checklists to assist users in evaluating online information, to participatory sessions covering internet usage, effective search skills and evaluation of information. Studies have demonstrated that health information on its own has limited health benefits or behaviour-changing abilities, however enhancing a consumer's health literacy can have a positive effect on health behavioural outcomes based on information they receive online. More specifically, research has shown that online health literacy interventions which directly enhance internet skills, internet-related self-efficacy, and internet usage can lead to increased health knowledge, more active coping styles, improved information handling, and ultimately improved health behaviours.¹⁰⁸ The pathway to improved online health literacy is outlined in Figure 12.

Interventions to improve consumer or patient online health literacy can have both positive and negative effects on an individual. It has been found that online health literacy interventions can potentially avert harm caused by the use of inaccurate information or poor comprehension of accurate information. They can also help bridge the *digital divide*, and consequently have positive impacts on social inclusion.¹⁰⁹ However they could cause

¹⁰⁷ Car, J., Lang, B., Colledge, A., Ung, C., & Majeed, A. (2011). Interventions for enhancing consumers' online health literacy. *Cochrane Database of Systematic Reviews 2011*, 6.

¹⁰⁸ Ibid.

¹⁰⁹ Hemming, H. E., & Langille, L. (2006). Building Knowledge in Literacy and Health. *Canadian Journal of Public Health*, 97(2), pp. s31-s36.

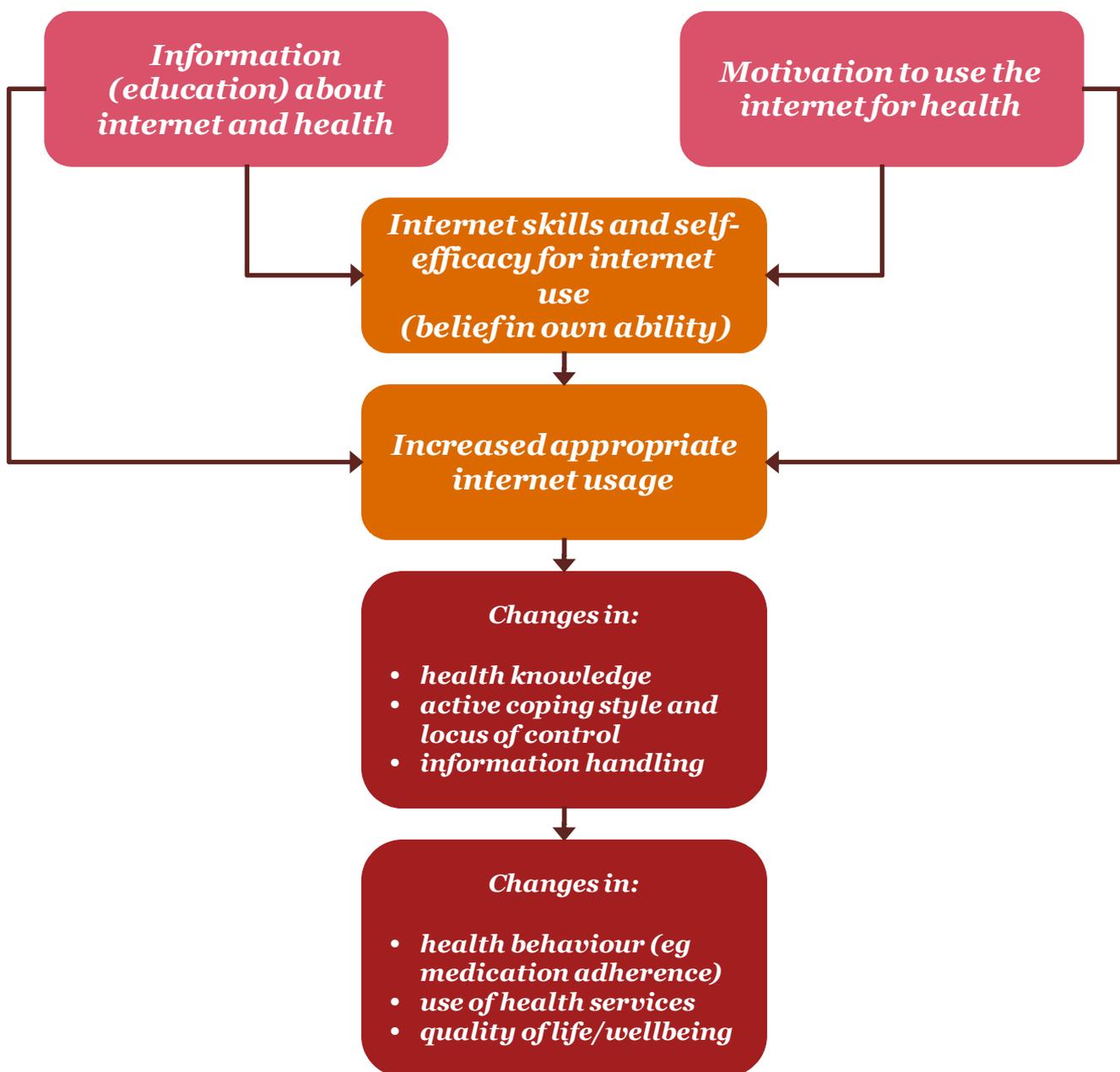
harm if consumers who would not otherwise use the internet to access health information partake in an intervention and subsequently are introduced to inaccurate or anxiety-provoking information.¹¹⁰

It is interesting to note that whilst there is widespread concern about the possible harms associated with accessing health information online, very little true evidence exists to support this, and most that does exist is anecdotal in nature. One study looking into this issue found few reported cases of harm, and noted that this could be due to an actual low risk of harm associated with online health information, under-reporting of cases, or bias.¹¹¹

¹¹⁰ Hemming, H. E., & Langille, L. (2006). Building Knowledge in Literacy and Health. *Canadian Journal of Public Health*, 97(2), pp. s31-s36.

¹¹¹ Crocco, A. G., Villasis-Keever, M., & Jadad, A. R. (2002). Analysis of Cases of Harm Associated With Use of Health Information on the Internet. *Journal of the American Medical Association*, 287(21), pp. 2869-2879.

Figure 12: Pathway of action to improved online health literacy¹¹²



In recent times, doctors have become adept at using the internet to help diagnose difficult cases – however patients are now increasingly using search engines such as Google to self-diagnose their conditions. A study looking into Google diagnoses found that on average, the correct diagnosis will be made 58 per cent of the time based on between three and five relevant search terms deemed to not return non-specific results. The diagnosis was selected from the three most prominent diagnoses provided by Google deeming to fit the symptoms and signs of the disease. The authors concluded that using Google to diagnose a medical condition is more effective for conditions with rare or unique symptoms, and less effective if the symptoms are non-specific or common to many conditions.¹¹³ Whilst the study has been criticised by some in the professional community, the fact that

¹¹² Adapted from Kalichman, S. C., Cain, D., Cherry, C., Pope, H., Eaton, L., & Kalichman, M. O. (2005). Internet Use Among People Living with HIV/AIDS: Coping and Health-Related Correlates. *AIDS Patient Care & STDs*, 7, pp. 439-448, and Car, J., Lang, B., Colledge, A., Ung, C., & Majeed, A. (2011). Interventions for enhancing consumers' online health literacy. *Cochrane Database of Systematic Reviews 2011*, 6.

¹¹³ Tang, H., Hwee, J., & Ng, K. (2006). Googling for a diagnosis – use of Google as a diagnostic aid: internet based study. *British Medical Journal*, 333, pp. 1143-1145.

more and more patients are turning to the internet for health-related information is undisputed. However, given that one can find nearly anything on the internet given the right mix of search terms, the ability to find misleading information is high – and this is amplified for those with a low level of health literacy. It has been noted in the literature that knowing the limitations of information tools and sources is a key trait of an individual with high health literacy, and that health literacy education campaigns should aim to lift the reliance on Google as a health information source through teaching (via examples) of when Google is likely to be effective and when it is less likely to be so.¹¹⁴

The internet landscape however has evolved from static pages and Google search results to applications which directly engage and connect users, such as blogs, wikis, social networking sites and podcasts. These tools give consumers a platform to voice their opinions about a healthcare service or provider's services.¹¹⁵ The uptake in these modern media platforms correlates to a decline in usage of traditional media sources such as newspapers. Part of this appeal is the interactivity and dialogues that these services promote which can lead to increased personal empowerment and clarity of thought for patients and consumers. Where traditional media feeds content to the individual, new media applications allow users to obtain or contribute to the development of personally relevant content, and foster two-way communication.¹¹⁶ Whilst these are fast becoming important channels of health communication, they require new levels of health literacy to effectively access and digest in a productive manner.

An economic study undertaken of online health users in New Zealand found that on average it took individuals 0.47 hours to find the health information they sought, and cost them NZ\$12 to find the information (the opportunity cost of their time). The average perceived value of the data found was NZ\$60, therefore implying that the net benefit to the consumer of seeking health advice online was NZ\$48 (\$60 - \$12). This high perceived value of online health information to the consumer was greater than the average one hour general practitioner consultation fee for the region under examination (NZ\$25) – implying that on average, online health users value online information over a visit to a general practitioner. Given this alongside the fact that much of this information may have been unreliable or unsafe in a practical context, the study concluded that a valuable public health policy initiative would be to provide an improved New Zealand health information website covering information on how to evaluate online health information, as well as links to useful and trustworthy sites.¹¹⁷ The authors suggest that a national official health information website should provide up to date information on treatment options and prevention for common illnesses, links to useful and reputable websites irrespective of website owner, and contact for support groups.¹¹⁸ The website should not be all-embracing, contain too much information, contain jargon and unfamiliar language, or biased towards a particular provider or funding agency.¹¹⁹

Those who use the internet to find health information tend to be younger, better educated, and have higher incomes than non-users.¹²⁰ However, the use of the internet as a health resource by adolescents is growing rapidly, and this poses unique issues compared with the rest of the population. They are more likely than any other age group to turn to the internet for health advice, and whilst they are generally healthier than adults (in terms of disease risks) overall, they are undergoing great change due to their physical, emotional and intellectual growth. This group are often comfortable utilising online social networking such as chat groups, Myspace and Facebook for social/emotional support, relationship creation and maintenance, entertainment, help seeking and information seeking. They have a very accepting attitude towards innovative and interactive resources – with minimal evaluation of the quality of their content. To date little research has focussed on the

¹¹⁴ Spring, H. (2011). Learning and teaching in action. *Health Information and Libraries Journal*, 28, pp. 148-151.

¹¹⁵ Squazzo, J. D. (2010). Best Practices for Applying Social Media in Healthcare. *Healthcare Executive*, May/June 2010, pp. 34-39.

¹¹⁶ Hanson, C., Thackeray, R., Barnes, M., Neiger, B., & McIntyre, E. (2008). Integrating Web 2.0 in Health Education: Preparation and Practice. *American Journal of Health Education*, 39(3), pp. 157-166.

¹¹⁷ Scott, W. G., Scott, H. M., & Auld, T. S. (2005). Consumer access to health information on the internet: health policy implications. *Australia and New Zealand Health Policy*, 2(13), pp. 13-21.

¹¹⁸ Ibid.

¹¹⁹ Ibid.

¹²⁰ Ibid.

specific health literacy levels of adolescents and how this affects their use of the internet as a healthcare resource. However it has been noted that kindergarten to year 12 (K-12) teachers have the greatest ability to influence the online health literacy of this group, and it has hence been suggested that interventions targeting K-12 educators could filter through to the improvement of adolescent online health literacy.¹²¹

In summary, Health 2.0 technologies have four key enabling qualities: multimodality, networkability, temporal flexibility and message-tailoring capabilities.¹²² These qualities imply that information provided online could be tailored to meet the needs of the reader based on their existing skills and knowledge in a much more informed manner than it currently is. 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 – despite health literacy showing no sign of improvement without appropriate action. 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 the screening tools listed in this report are currently paper-based, these could also be provided online and used to direct individuals towards information appropriate for their level of health literacy.

Recommendation 4

The demand for multi-modality information suggests that mechanisms for screening health literacy need to be applicable in this context.

As discussed throughout this section, 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. Hence 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.

Recommendation 5

Health literacy interventions should seek to increase the capacity of individuals to evaluate information obtained through a variety of modalities.

¹²¹ Skopelja, E. N., Whipple, E. C., & Richwine, P. (2008). Reaching and Teaching Teens: Adolescent Health Literacy and the Internet. *Journal of Consumer Health on the Internet*, 12(2), pp. 105-118.

¹²² Usher, W. (2011). Types of Social Media (Web 2.0) Used by Australian Allied Health Professionals to Deliver Early Twenty-First-Century Practice Promotion and Health Care. *Social Work in Health Care*, 50(4), pp. 305-329.

What can we learn from other jurisdictions?

“Not to focus attention on patients with limited literacy is to neglect a fundamental obligation of the healthcare system to its most vulnerable constituents.”¹²³

Other countries have taken different approaches to addressing health literacy, and these are summarised at a high level in Table 1.

Table 1: Summary of key health literacy initiatives in other jurisdictions

Country	Examples of key initiatives
England	<ul style="list-style-type: none"> • NHS patient choice initiatives • Skilled for Health program
Canada	<ul style="list-style-type: none"> • Expert Panel on Health Literacy • National Literacy and Health Program • other targeted programs (eg for educators, health professionals or specific conditions)
United States of America	<ul style="list-style-type: none"> • National Action Plan to Improve Health Literacy • AHRQ’s extensive literature review • Ask Me 3 program • integrating health literacy into education (selected states)
Ireland	<ul style="list-style-type: none"> • Literacy Audit for Healthcare Settings • MSD health literacy awards • online resources

England

The recent policy focus in England has been around improving informed patient choice. This can relate to choice of treatment, health professional, appointment time and provider. England’s focus in recent times has been particularly on the appointment time and provider aspects of choice. Patient choice in this context is designed to foster competition between hospitals and promote improvements in efficiency, equity, quality and responsiveness. However, research has found that patient choice has created a level of inequality between those with different levels of health literacy.¹²⁴ In particular, it has been found that many people find it difficult to make trade-offs between quality, safety, patient experience and location – and the difficulty of these decisions is exacerbated by low health literacy. Research undertaken by the King’s Fund on the presentation of information to inform patient choice in England found that a number of factors improved the usability of the information to allow patients to make more informed choices regarding their treatment. These included the type of

¹²³ Volandes, A. E., & Paasche-Orlow, M. K. (2007). Health Literacy, Health Inequality and a Just Healthcare System. *The American Journal of Bioethics*, 7(11), pp. 5-10.

information provided (eg simplistic and tailored information), the presentation of the information (eg clearly labelled indicators, consistent use of symbols and labels rather than traffic lights or colours, and the use of evaluative labels such as poor, good and excellent), and the ordering of the information provided.¹²⁵

The English Government have also been particularly interested in the mechanisms behind people's understanding of health. A program was developed under the Labour Government looking at health literacy, and its main activities were described as being the development of a strategic framework, supporting research, the development of health literacy networks, and a health literacy delivery program titled *Skilled for Health*.¹²⁶

Unfortunately, the UK's Department of Health website no longer contains any information on health literacy or the government's approach to improving it. The information on their program which once existed is only available from the National Archives, and was last updated in 2007. Information does exist however on the Skilled for Health program through the website of ContinYou – a community learning charity which managed the Skilled for Health program.¹²⁷ Skilled for Health aims to improve adult literacy, language, and numeracy skills through established adult education programs. The program is unique in that it uses health related subject matter to develop basic literacy and numeracy skills, while at the same time improving health literacy. Professor Nutbeam noted in consultation that there is a relatively high drop-out rate associated with adult literacy programs. However, the Skilled for Health program consistently achieved high retention and good literacy outcomes in the UK. Hence the program provided the “double benefit” of increasing both broader literacy and health literacy, as well as achieving higher than normal retention levels among those participating in adult literacy programs. An evaluation of the program found that participants demonstrated substantial increases in health literacy after attending the program, and that it opens up pathways to further learning for the participants.¹²⁸

Canada

The Canadian Public Health Association (CPHA) assembled the Expert Panel on Health Literacy in 2006 in response to recommendations made by delegates of the Second Canadian Conference on Literacy and Health in 2004. The panel comprises of 14 experts representing a broad range of expertise, experience, and knowledge related to literacy and health literacy. According to its terms of reference, the Panel's objectives include defining the scope of the problem of health literacy, identifying barriers to creating a health literate population, assess the effectiveness of health literacy interventions, and developing recommendations for improving health literacy.¹²⁹ An observation of the panel is that there has been a lack of evaluation of the effectiveness of health literacy interventions globally. They also found through their research that the most effective interventions are those which are community-based, participatory, and empowering for the participant.¹³⁰

The National Literacy and Health Program (NLHP) is one of the country-wide initiatives in place to improve health literacy. The NLHP's overall goal is to establish a framework for raising awareness about the links between literacy and health. The NLHP is run in partnership with 27 national health associations. The activities

¹²⁴ Dixon, A., Robertson, R., Appleby, J., Burge, P., Devlin, N., & Magee, H. (2010). *Patient Choice: How patients choose and how providers respond*. London: The King's Fund.

¹²⁵ Boyce, T., Dixon, A., Fasolo, B., & Reutskaja, E. (2010). *Choosing a high-quality hospital: The role of nudges, scorecard design and information*. London: The King's Fund.

¹²⁶ Department of Health (UK) (2007). *Health literacy*. Retrieved 11 August, 2011, from http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publichealth/Healthimprovement/Healthyliving/DH_080149

¹²⁷ ContinYou (2011). *What is Skilled for Health?* Retrieved 11 August, 2011, from http://www.continyou.org.uk/health_and_well_being/skilled_health/what_skilled_health

¹²⁸ The Tavistock Institute & Shared Intelligence (2009). *Evaluation of the second phase of the Skilled for Health programme*. Retrieved 04 August, 2011, from http://www.continyou.org.uk/health_and_well_being/files/Skilled_for_health_evaluation

¹²⁹ Rootman, I., & Gordon-El-Bihety, D. (2008). *A Vision for a Health Literate Canada – Report of the Expert Panel on Health Literacy*. Canadian Public Health Association.

¹³⁰ Ibid.

undertaken through this program include promotion of plain language material (including the provision of plain language editing services and workshops for a fee), planning and coordination of research projects, identify key strategies to promote health literacy, providing resources to assist health professionals in dealing with people with low health literacy, and educating students.¹³¹ Whilst evaluations have been carried out for individual programs run under the NLHP, the NLHP itself has not been evaluated to assess its effectiveness in achieving its overall goal.

Other national programs have been run which touch on more specific areas of health literacy, such as Health Canada's Community Action Program for Children and the Canada Prenatal Nutrition Program. Reviews of both of these programs found that they effectively supported the development of health literacy skills for the participants.¹³² Canada also has a range of initiatives implemented at the provincial/territorial and local levels. These include programs to support adult education practitioners in teaching health literacy, a program to assist healthcare providers overcome barriers in reaching clients with low health literacy, and a program to assist newly-diagnosed type-2 diabetes patients make sense of their treatment regimens.¹³³

United States of America

Identifying the wide spectrum of problems associated with having a society with low health literacy, the US Department of Health and Human Services developed the *National Action Plan to Improve Health Literacy* (the Plan). This Plan is based on the principles that:¹³⁴

- *everyone has the right to health information that helps them make informed decisions*
- *health services are delivered in ways that are understandable and beneficial to health, longevity, and quality of life.*

The Plan takes a society-wide approach, and calls for response from all sectors involved in health information and services. Its vision is for a society that provides everyone with access to accurate and actionable health information, delivers person-centric health information and services, and supports life-long learning and skills to promote good health. Guided by the two principles stated above, the Plan outlines seven key goals to achieve this vision:¹³⁵

1. develop and disseminate health and safety information that is accurate, accessible and actionable
2. promote changes in the health care system that improve health information, communication, informed decision making, and access to health services
3. incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in child care and education through the university level
4. support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community
5. build partnerships, develop guidance, and change policies

¹³¹ The Centre for Literacy. *Background Document on Literacy and Health: National Literacy and Health Program*. Retrieved 26 July, 2011, from <http://www.centreforliteracy.qc.ca/health/finalsum/bd/bd13.html>

¹³² Rootman, I., & Gordon-El-Bihbety, D. (2008). *A Vision for a Health Literate Canada – Report of the Expert Panel on Health Literacy*. Canadian Public Health Association.

¹³³ Ibid.

¹³⁴ US Department of Health and Human Services, Office of Disease Prevention and Health Promotion (2010). *National Action Plan to Improve Health Literacy*. Washington, DC: Author.

¹³⁵ Ibid.

6. increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy
7. increase the dissemination and use of evidence-based health literacy practices and interventions.

It has been noted that whilst the body of evidence surrounding the impacts of limited health literacy is still growing, the Plan confirms that the time has come to bring limited health literacy to the forefront of public health, and provides the starting point for healthcare professionals to initiate discussions about how to address health literacy.¹³⁶

As discussed previously in this report, the AHRQ in the US has recently (March 2011) updated a systematic review of health care service use and health outcomes related to differences in health literacy levels, and interventions designed to improve these outcomes for individuals with low health literacy.¹³⁷ The AHRQ is one of 12 agencies within the US Department of Health and Human Services, and is the lead federal agency dedicated to improving the quality, safety, efficiency and effectiveness of health care for all Americans.¹³⁸ The AHRQ commissioned the RTI International-University of North Carolina Evidence-based Practice Centre to undertake this extensive research, and the key topics it aimed to examine were whether health literacy skills are related to health outcomes and service utilisation, and which interventions have been effective at improving outcomes of individuals with low health literacy.¹³⁹

As the discussion around health literacy is relatively new, the majority of the work done to date focuses on academic research into various aspects of it. However some programs have been trialled in the US to address low health literacy. One such program is known as *Ask Me 3*, which encourages patients to understand the answers to three questions to promote communication with their providers. The questions are:¹⁴⁰

1. what is my main problem?
2. what do I need to do?
3. why is it important for me to do this?

The website also provides resources for providers covering a range of topics, such as medical jargon words which should be avoided and appropriate substitutes, health literacy statistics, and guidance for working with individuals from specific minorities prone to low health literacy. However an evaluation of the program consisting of a randomised controlled trial found that it had no significant impact on patient health literacy.¹⁴¹

¹³⁶ Baur, C. (2011). Calling the nation to act: Implementing the national action plan to improve health literacy. *Nursing Outlook*, 59, pp. 63-69.

¹³⁷ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

¹³⁸ Agency for Healthcare Research and Quality (2010) *AHRQ: Advancing Excellence in Health Care*. Retrieved 15 August, 2011, from <http://www.ahrq.gov/about/profile.pdf>

¹³⁹ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

¹⁴⁰ National Patient Safety Foundation. *Ask Me 3*. Retrieved 26 July, 2011, from <http://www.npsf.org/askme3/>

¹⁴¹ Galliher, J. M., Post, D. M., Weiss, B. D., Dickinson, L. M., Manning, B. K., Staton, E. W., Brown, J. B., Hickner, J. M., Bonham, A. J., Ryan, B. L., & Pace, W. D. (2010). Patients' Question-Asking Behavior During Primary Care Visits: A Report From the AAFP National Research Network. *Annals of Family Medicine*, 8(2), pp. 151-159.

Other initiatives undertaken in certain states have focussed on promoting health education and health literacy in schools.¹⁴² The Harvard School of Public Health have also developed tools to assist with the integration of health literacy material into adult education.¹⁴³

Nutbeam notes that the majority of academic research being undertaken in the US is focussed on ways in which the health system and health care providers can better identify, manage and respond to the needs of patients with poor health literacy. He explains that while this is valuable research, it is more appropriately described as responding to *health-related literacy* rather than health literacy itself.¹⁴⁴

Ireland

In 2002 the National Adult Literacy Agency (NALA) of Ireland undertook a research project to examine the health literacy of the country. The report found that a significant proportion of patients were having difficulty accessing and interpreting essential health information, consent forms and signage, and overall had difficulty navigating the health system. The report also found that most health practitioners were not aware of the significant problems that health literacy was causing for their patients. This prompted further work to be undertaken to address the issue in the country.¹⁴⁵ In 2009 NALA and the Health Service Executive (HSE) released a publication titled *Literacy Audit for Healthcare Settings*, which is a resource to address the issue of accessible and literacy friendly healthcare settings. It is a tool which can be used to identify possible literacy barriers in healthcare workplaces by comparing current practice to established best practice in communication. It provides background guidance material as well as a series of checklists to evaluate aspects of the healthcare setting and published documents.¹⁴⁶

In 2010 NALA received a grant from MSD (a pharmaceutical company) to conduct a literacy audit using the 2009 publication in four health settings. Key findings were that health literacy is currently not included in the formal curriculum of health professionals despite increased awareness of the issue, health literacy is not yet a feature of national policy documents, and that staff developing leaflets did not consider the health literacy levels of the intended audience.¹⁴⁷

Further recommendations from the focus groups were that the medical profession should attempt to listen to their patients and tailor advice based on their health literacy levels, that more promotion needs to be undertaken to enable patients to engage more effectively with health professionals, and that plain English should be used throughout the treatment and diagnosis pathways.¹⁴⁸

NALA and MSA have developed a website (www.healthliteracy.ie) which provides resources for the general public and health sector workers, as well as access to academic research relating to health literacy. The information provided for the general public covers topics such as defining health literacy, how to get the most out of a visit to the doctor and how to build a positive relationship with your doctor, as well as more specialised plain language booklets on asthma and arthritis. The information provided for health sector workers includes general guidance, writing and design tips, as well as the audit guidelines from the *Literacy Audit* publication.¹⁴⁹

¹⁴² Hohn, M. D. (2002). Literacy, Health, and Health Literacy: State Policy Considerations. *Focus on Basics*, 5(c), pp. 20-25, Boston: National Centre for the Study of Adult Learning and Literacy.

¹⁴³ Rudd, R., Soricone, L., Santos, M., Zobel, E., Smith, J. (2005). *Health Literacy Study Circles+*. Massachusetts: National Center for the Study of Adult Learning and Literacy & Harvard School of Public Health.

¹⁴⁴ Nutbeam, D. (2009). Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health*, 54, pp. 303-305.

¹⁴⁵ National Adult Literacy Agency (2002). *Health Literacy Policy and Strategy*. Dublin: Author.

¹⁴⁶ National Adult Literacy Agency (2009). *Literacy Audit for Healthcare Settings*. Dublin: Author.

¹⁴⁷ National Adult Literacy Agency (2010). *NALA Audit Project 2010*. Dublin: Author

¹⁴⁸ Ibid.

¹⁴⁹ National Adult Literacy Agency & MSD. *Health Literacy*. Retrieved August 1, 2011, from <http://healthliteracy.ie>

The website is also the information hub for the MSD Health Literacy Awards. These awards were launched in 2007 and are designed to recognise and reward excellence in health literacy within the healthcare sector. The awards are open to anyone working in the healthcare sector, and the award categories include best project in general practice, hospitals, and the community, and best health promotion or health communication project.¹⁵⁰

This section has highlighted that 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. This report has also identified a number of areas where the current literature is lacking or further research could be undertaken. These 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

Recommendation 6

Further research and evaluation is required to monitor the effectiveness of any health literacy interventions adopted in Australia.

¹⁵⁰ National Adult Literacy Agency (2010). *Call for Entries to Crystal Clear MSD Health Literacy Awards 2011* [press release]. Retrieved August 1, 2011, from <http://healthliteracy.ie/wp-content/uploads/2010/12/Crystal-Clear-Awards-Launch-Nov-2010-.pdf>

Health literacy in Australia

“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.”¹⁵¹

Australia does not yet have a national approach to increasing health literacy or an ongoing plan to measure population based health literacy, and this is reflected in a dearth of literature focussing specifically on the Australian context. The only ALLS survey to measure health literacy at a population-wide level was undertaken in 2006, and whilst the survey will continue going forward in the form of the PIAAC, the ABS will no longer be deriving a population-level health literacy measure from it. However, population-wide measures may not be the most appropriate measures, as what can be defined as *adequate* or *high* health literacy will differ depending on the context of the individual.¹⁵² This implies that an adequate level of health literacy for a young person without much contact with the health system would be a lot lower than what would be considered adequate in the context of someone with a chronic illness, and subsequently much higher contact with the health system on a regular basis. Given the content and context specific nature of health literacy – measurement at an individual level may be a greater priority; however this is complicated by the lack of a universally consistent threshold for low health literacy.

Health literacy is an accepted public health issue and the steps already undertaken internationally may mean Australia is well placed to learn from previous findings and adapt them to address the issue locally.

This is not to say that designing approaches to address health literacy deficiencies in Australia is without challenges. The issue is complicated by insufficient understanding of the fundamental mechanisms which underlie the relationship between health literacy and a broad range of health outcomes,¹⁵³ and the impact of more general health promotion activities.¹⁵⁴ The majority of literature covered in this report would suggest that people need an adequate-to-high level of health literacy to be able to decode the health-related information they receive on a day-to-day basis.

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. Research has also shown that there is a lack of

¹⁵¹ Witte, P. G. (2010). Health Literacy: Can We Live Without It? *Adult Basic Education and Literacy Journal*, 4(1), pp. 3-12

¹⁵² Nutbeam, D. (2009). Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health*, 54, pp. 303-305.

¹⁵³ Institute of Medicine of the National Academies (2011). *Innovations in Health Literacy: Workshop Summary*. Washington: The National Academies Press.

¹⁵⁴ Eichler, K., Wieser, S., & Brügger, U. (2009). The costs of limited health literacy: a systematic review. *International Journal of Public Health*, 54, pp. 313-324.

robust evaluation of the health literacy interventions trialled across the globe, and that many existing initiatives are short-term in nature and lack sustainable funding channels.¹⁵⁵

In Australia there is a small but growing body of work being done to improve health literacy. The Department of Health Victoria is partnering with Deakin University to apply for an Australian Research Council grant to undertake a project focussing on capacity building in the health literacy space, developing and testing interventions for individuals with low health literacy, and identifying system and practice changes which will be required to facilitate such interventions. Another research project is a national project 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.

Improving Australia's health literacy will require significant behavioural change for individuals. Research undertaken by PwC's Health Research Institute found that the most effective strategies identified to engage individuals in their own health care are health education and increasing awareness.¹⁵⁶ This is driven by two psychological states which contribute to an individual's readiness for change:

- *perceived importance*
- *confidence in ability to change (self-efficacy)*

Behavioural change can be measured on a scale from awareness to sustainability, as outlined in Figure 13. This 'stages of change' model illustrates the importance of tailoring the design and implementation of health literacy interventions to realise the program and individual success.

Figure 13: Stages of change model¹⁵⁷



An approach championed by the AHRQ (in a toolkit they publish separate to the systematic review of theirs which is discussed throughout this report) classifies health literacy interventions according to three areas of change which require improvement to see overall improved health outcomes:¹⁵⁸

1. improve *spoken and written communication* to enable patients to understand and interpret health information provided and sourced
2. improve *self-management and empowerment* – enabling patients to share responsibility for their health and healthcare
3. improve *supportive systems* – particularly outside the primary care setting, to assist individuals to make healthy choices and adhere to treatment regimens.

¹⁵⁵ Rootman, I., & Gordon-El-Bihbety, D. (2008). *A Vision for a Health Literate Canada – Report of the Expert Panel on Health Literacy*. Canadian Public Health Association.

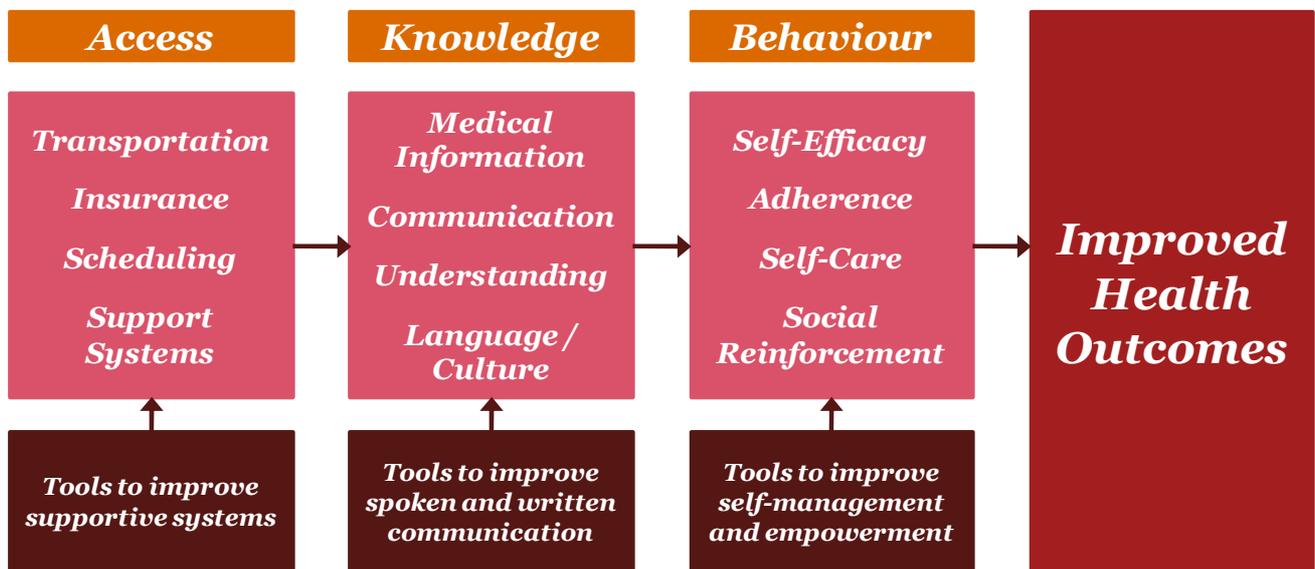
¹⁵⁶ PricewaterhouseCoopers' Health Research Institute (2010). *HealthCast: The customisation of diagnosis, care and cure*. Available from <http://www.pwc.com/us/en/healthcast>

¹⁵⁷ Adapted from Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In Search of How People Change: Applications to Addictive Behaviors. *The American Psychologist*, 47(9), pp. 1102-1114.

¹⁵⁸ Agency for Healthcare Research and Quality (2010). *Health Literacy Universal Precautions Toolkit*. Rockville, MD: Author.

This approach to improving health literacy is summarised diagrammatically in Figure 14.

Figure 14: Factors and tools to improve health outcomes through health literacy¹⁵⁹



“Australia trails behind other western countries in practical applications of health literacy.”¹⁶⁰

This approach is supported by findings from the AHRQ’s systematic review. Interventions examined in the review were classified into those which used one specific strategy to mitigate the effects of low health literacy, and those which used a mixture of strategies combined into one intervention. The evidence for interventions with single design features having an impact on low health literacy was found to be largely either insufficient or low in most cases. However the review found that some specific design features resulted in improvements in comprehension for those with low health literacy in certain studies. These features include:¹⁶¹

- presenting essential information by itself (for example, information on hospital death rates without other distracting information such as information on consumer satisfaction)
- presenting essential information first (for example, information on hospital death rates before information on consumer satisfaction)
- presenting quality information with higher numbers indicating better quality (as opposed to lower numbers indicating higher quality)
- utilising the same denominators to present the baseline risk of disease and treatment benefit
- adding icon arrays to numerical presentations of treatment benefits

¹⁵⁹ Adapted from Agency for Healthcare Research and Quality (2010). *Health Literacy Universal Precautions Toolkit*. Rockville, MD: Author.

¹⁶⁰ Adams, R. J., Stocks, N. P., Wilson, D. H., & Hill, C. L. (2009). Health literacy: A new concept for general practice? *Australian Family Physician*, 38(3), pp. 144-147.

¹⁶¹ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

-
- adding video to verbal narratives.

These design features could all be taken into consideration when tailoring the provision of information – particularly along the diagnosis or treatment pathways. One particular study covered in the review however found that some design features such as coloured traffic symbols to denote death rates in hospitals or varying quality symbols accompanying non-essential quality information can actually induce patients with low health literacy to make worse choices.¹⁶² What is particularly interesting to note is that this collection of features matches up with the findings from focus groups run by the King’s Fund in England to determine what individuals found most effective about information provided to help inform patient choice.¹⁶³

The AHRQ review found that the results for interventions combining multiple strategies were more mixed than the results for single strategy interventions. In particular, there was evidence to suggest that intensive self-management and treatment adherence interventions can be effective in reducing emergency department visits and hospitalisations, as well as increasing colorectal cancer and prostate cancer screening. The components of effective interventions in this category were found to be:¹⁶⁴

- high intensity delivery
- theoretical basis
- pilot testing before full implementation
- emphasis on skill building
- delivery of the intervention by a health professional
- immediate impacts by increasing knowledge, increasing self-efficacy or modifying behaviour – as opposed to interventions which emphasise gradual change over a longer period of time.

The authors of the review noted however that few studies looking at multiple-strategy interventions looked at the impact the interventions had on behavioural intent or disparities in participants. Hence more research would need to be undertaken in this area.

Health literacy interventions which address the issues described in Figure 14 should be developed on the evidence found in the AHRQ’s systematic review. However, it is also vital to be clear on the main goals of the program. Often it is tempting to include many messages in an intervention, and this can dilute its efficacy – particularly in audiences with low health literacy. The following questions should be answered upfront to establish goals:¹⁶⁵

- Is the intervention’s purpose to inform, to educate, or both?
- Is the purpose to produce an action or change behaviour?
- What medium will be used to deliver the intervention?

¹⁶² Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

¹⁶³ Boyce, T., Dixon, A., Fasolo, B., & Reutskaja, E. (2010). *Choosing a high-quality hospital: The role of nudges, scorecard design and information*. London: The King’s Fund.

¹⁶⁴ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

¹⁶⁵ Zarcadoolas, C., Pleasant, A. F., & Greer, D. S. (2006). *Advancing Health Literacy: A Framework for Understanding and Action* (1st ed.). San Francisco: John Wiley & Sons.

- What types of health literacy are required to effectively take part in the intervention, and which domains of health literacy dominate the message being sent?
- What health literacy skills will be developed through the intervention?
- Will the message of the intervention be reinforced or repeated in any way?
- How will you know if the intervention has been successful?
- How will you involve the target audience early and often in the design of the intervention?
- How will the audience's existing spoken and written competencies be capitalised on?
- How will the intervention advance the audience's health literacy?

Just as knowing the goals of the intervention are important, knowing the audience for the intervention is equally important. We have discussed throughout this report that health literacy is specific to the context of the individual, and as such different interventions will be more appropriate for different audiences. The following questions can be useful in tailoring the intervention to the target audience:¹⁶⁶

- What is their spoken language ability?
- What barriers do they face in reading any information intended to be provided?
- What is the level of vocabulary, sentence structure, and other important text/speech elements used in the intervention?
- What assumptions about the audience are implicitly made based on these text/speech elements, and will the target audience be able to comprehend it?
- How relevant is the intervention to this audience?
- How trustworthy will the messenger be to the audience?
- How culturally appropriate is the intervention?
- What prior knowledge does the intervention assume the audience has about science, health, civic and cultural factors?

Health literacy levels are a proven independent predictor of patients' knowledge of their chronic illness.¹⁶⁷ 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.¹⁶⁸ Given these facts as well as the fact that over 7 million Australians have at least one chronic condition¹⁶⁹ - and nearly all of those over the age of 65 reporting at least one chronic condition¹⁷⁰ - if Australia is going to focus its health literacy efforts in a particular area, then

¹⁶⁶ Zarcadoolas, C., Pleasant, A. F., & Greer, D. S. (2006). *Advancing Health Literacy: A Framework for Understanding and Action* (1st ed.). San Francisco: John Wiley & Sons.

¹⁶⁷ Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51, pp. 267-275.

¹⁶⁸ Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), pp. 259-267.

¹⁶⁹ Australian Institute of Health and Welfare (2011). *Chronic diseases*. Retrieved 10 August, 2011, from <http://www.aihw.gov.au/chronic-diseases/>

¹⁷⁰ Department of Health and Ageing (2010). *Chronic disease*. Retrieved 11 August, 2011, from <http://www.health.gov.au/internet/main/publishing.nsf/content/chronic#pre>

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.¹⁷¹ 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.¹⁷² 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.¹⁷³ 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.¹⁷⁴

Recommendation 7

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.**

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.¹⁷⁵

Recommendation 8

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

¹⁷¹ Youmans, S. L., & Schillinger, D. (2003). Functional Health Literacy and Medication Use: the Pharmacist's Role. *The Annals of Pharmacotherapy*, 37, pp. 1726-1729.

¹⁷² Kalichman, S. C., Ramachandran, B., & Catz, S. (1999). Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy. *Journal of General Internal Medicine*, 14, pp. 267-273.

¹⁷³ Youmans, S. L., & Schillinger, D. (2003). Functional Health Literacy and Medication Use: the Pharmacist's Role. *The Annals of Pharmacotherapy*, 37, pp. 1726-1729.

¹⁷⁴ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

¹⁷⁵ Drummond, M. F., Sculpher, M. J., Torrance, G. W., O'Brien, B. J., & Stoddart, G. L. (2005). *Methods for the Economic Evaluation of Health Care Programmes*. (3rd ed.). Oxford: Oxford University Press.

Recommendations

Throughout this report we have included a number of recommendations for discussion. These recommendations are briefly summarised in this section.

1. Health literacy interventions should be content and context specific.

As discussed throughout this report, 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.¹⁷⁶

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

This report has discussed the merits of screening for health literacy in a clinical setting. However, these merits only exist if the results of the screen 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.¹⁷⁷ This treatment or diagnosis pathway effectively utilising the results of a health literacy screening tool was demonstrated in Figure 5.

3. Health literacy should be considered as a health management and social inclusion issue.

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.¹⁷⁸ 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.¹⁷⁹ Given the priorities identified in the Australian Government's social inclusion

¹⁷⁶ Burns, A., & Kim, M. (2011). Community accessibility of health information and the consequent impact for translation into community languages. *Translation & Interpreting*, 3(1), pp. 58-75.

¹⁷⁷ Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51, pp. 267-275.

¹⁷⁸ Department of the Prime Minister and Cabinet (2011). *Breaking Cycles of Disadvantage*. Retrieved 11 August, 2011, from <http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/breaking-cycles-of-disadvantage.pdf>

¹⁷⁹ Hemming, H. E., & Langille, L. (2006). Building Knowledge in Literacy and Health. *Canadian Journal of Public Health*, 97(2), pp. s31-s36.

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.

4. The demand for multi-modality information suggests that mechanisms for screening health literacy need to be applicable in this context.

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 – despite health literacy showing no sign of improvement without appropriate action. 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 the screening tools listed in this report are currently paper-based, these could also be provided online and used to direct individuals towards information appropriate for their level of health literacy.

5. Health literacy interventions should seek to increase the capacity of individuals to evaluate information obtained through a variety of modalities.

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. Hence 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.

6. Further research and evaluation is required to monitor the effectiveness of any health literacy interventions adopted in Australia.

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. This report has also identified a number of areas where the current literature is lacking or further research could be undertaken. These 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

7. 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.¹⁸⁰ 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.¹⁸¹ Given these facts as well as the fact that over 7 million Australians have at least one chronic condition¹⁸² - and nearly all of those over the age of 65 reporting at least one chronic condition¹⁸³ - 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.¹⁸⁴ 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.¹⁸⁵ 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.¹⁸⁶ 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.¹⁸⁷

¹⁸⁰ Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51, pp. 267-275.

¹⁸¹ Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), pp. 259-267.

¹⁸² Australian Institute of Health and Welfare (2011). *Chronic diseases*. Retrieved 10 August, 2011, from <http://www.aihw.gov.au/chronic-diseases/>

¹⁸³ Department of Health and Ageing (2010). *Chronic disease*. Retrieved 11 August, 2011, from <http://www.health.gov.au/internet/main/publishing.nsf/content/chronic#pre>

¹⁸⁴ Youmans, S. L., & Schillinger, D. (2003). Functional Health Literacy and Medication Use: the Pharmacist's Role. *The Annals of Pharmacotherapy*, 37, pp. 1726-1729.

¹⁸⁵ Kalichman, S. C., Ramachandran, B., & Catz, S. (1999). Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy. *Journal of General Internal Medicine*, 14, pp. 267-273.

¹⁸⁶ Youmans, S. L., & Schillinger, D. (2003). Functional Health Literacy and Medication Use: the Pharmacist's Role. *The Annals of Pharmacotherapy*, 37, pp. 1726-1729.

¹⁸⁷ Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.

8. 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.¹⁸⁸

¹⁸⁸ Drummond, M. F., Sculpher, M. J., Torrance, G. W., O’Brien, B. J., & Stoddart, G. L. (2005). *Methods for the Economic Evaluation of Health Care Programmes*. (3rd ed.). Oxford: Oxford University Press.

References

- Adams, R. J., Appleton, S. L., Hill, C. L., Dodd, M., Findlay, C., & Wilson, D. H. (2009).** Risks associated with low functional health literacy in an Australian population. *Medical Journal of Australia*, 191, pp. 530-534.
- Adams, R. J., Stocks, N. P., Wilson, D. H., & Hill, C. L. (2009).** Health literacy: A new concept for general practice? *Australian Family Physician*, 38(3), pp. 144-147.
- Agency for Healthcare Research and Quality (2010)** *AHRQ: Advancing Excellence in Health Care*. Retrieved 15 August, 2011, from <http://www.ahrq.gov/about/profile.pdf>
- Agency for Healthcare Research and Quality (2010).** *Health Literacy Universal Precautions Toolkit*. Rockville, MD: Author.
- Australian Bureau of Statistics (2009).** *Household Use of Information Technology, Australia, 2008-09*. Cat. no. 8146.0. Canberra: ABS
- Australian Bureau of Statistics (2006).** *Health Literacy, Australia*. Cat. no. 4233.0. Canberra: ABS.
- Australian Institute of Health and Welfare (2011).** *Chronic diseases*. Retrieved 10 August, 2011, from <http://www.aihw.gov.au/chronic-diseases/>
- Australian Institute of Health and Welfare (2011).** *Health priority areas*. Retrieved 15 August, 2011, from <http://www.aihw.gov.au/health-priority-areas/>
- Australian Institute of Health and Welfare (2009).** *Chronic disease and participation in work*. Cat. no. PHE 109. Canberra: AIHW.
- Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999).** Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38, pp. 33-42.
- Barber, M. N., Staples, M., Osborne, R. H., Clerehan, R., Elder, C., & Buchbinder, R. (2009).** Up to a quarter of the Australian population may have suboptimal health literacy depending upon the measurement tool: results from a population-based survey. *Health Promotion International*, 24(3), pp. 252-261
- Baur, C. (2011).** Calling the nation to act: Implementing the national action plan to improve health literacy. *Nursing Outlook*, 59, pp. 63-69
- Berkman, N. D., Davis, T. C., & McCormack, L. (2010).** Health Literacy: What Is It? *Journal of Health Communication*, 15, pp. 9-19.
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohn, K. N., Harden, E., Tant, E., Wallace, I., & Viswanathan, M. (2011).** *Health Literacy Interventions and Outcomes: An Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. Rockville, MD: Agency for Healthcare Research and Quality.
- Boyce, T., Dixon, A., Fasolo, B., & Reutskaja, E. (2010).** *Choosing a high-quality hospital: The role of nudges, scorecard design and information*. London: The King's Fund.
- Bupa (2011).** *Aussies turning to cyberspace to self-diagnose*. Retrieved 9 September, 2011, from <http://www.bupa.com.au/portal/site/Bupa/menuitem.2aac420b606c953d7c1c9d5c297420a0/?vgnnextoid=eabc275e10boe210VgnVCM1000000coa400aRCRD&vgnnextfmt=7030news>

- Burns, A., & Kim, M. (2011).** Community accessibility of health information and the consequent impact for translation into community languages. *Translation & Interpreting*, 3(1), pp. 58-75.
- Bush, R., Boyle, F., Ostini, R., Ozolins, I., Brabant, M., Soto, E. J., & Eriksson, L. (2010).** *Advancing Health Literacy Through Primary Health Care Systems*. Retrieved 19 July, 2011, from <http://www.uq.edu.au/health/healthycomm/docs/APHCRI3pager.pdf>
- Cain, M. M., Sarasohn-Kahn, J., & Wayne, J. C. (2000).** *Health e-People: The Online Consumer Experience*. Oakland, CA: California HealthCare Foundation.
- Car, J., Lang, B., Colledge, A., Ung, C., & Majeed, A. (2011).** Interventions for enhancing consumers' online health literacy. *Cochrane Database of Systematic Reviews 2011*, 6.
- The Centre for Literacy.** *Background Document on Literacy and Health: National Literacy and Health Program*. Retrieved 26 July, 2011, from <http://www.centreforliteracy.qc.ca/health/finalsum/bd/bd13.html>
- Chinn, D. (2011).** Critical health literacy: A review and critical analysis. *Social Science & Medicine*, 73, pp. 60-67.
- ContinYou (2011).** *What is Skilled for Health?* Retrieved 11 August, 2011, from http://www.continyou.org.uk/health_and_well_being/skilled_health/what_skilled_health
- Crocco, A. G., Villasis-Keever, M., & Jadad, A. R. (2002).** Analysis of Cases of Harm Associated With Use of Health Information on the Internet. *Journal of the American Medical Association*, 287(21), pp. 2869-2879.
- Department of Education, Employment and Workplace Relations.** *Programme for the International Assessment of Adult Competencies*. Retrieved 28 July, 2011, from <http://www.deewr.gov.au/Skills/Resources/Pages/PIAAC.aspx>
- Department of Health and Ageing (2010).** *Chronic disease*. Retrieved 11 August, 2011, from <http://www.health.gov.au/internet/main/publishing.nsf/content/chronic#pre>
- Department of Health (UK) (2007).** *Health literacy*. Retrieved 11 August, 2011, from http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publichealth/Healthimprovement/HealthyLiving/DH_080149
- Department of the Prime Minister and Cabinet (2011).** *Australian Social Inclusion Board Annual Report 2010*. Retrieved 11 August, 2011, from <http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/asib-board-annual-repor-2010.pdf>
- Department of the Prime Minister and Cabinet (2011).** *Breaking Cycles of Disadvantage*. Retrieved 11 August, 2011, from <http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/breaking-cycles-of-disadvantage.pdf>
- Department of the Prime Minister and Cabinet (2009).** *A Stronger, Fairer Australia – Summary brochure*. Retrieved 11 August, 2011, from http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/brochure_stronger_fairer_australia.pdf
- Dixon, A., Robertson, R., Appleby, J., Burge, P., Devlin, N., & Magee, H. (2010).** *Patient Choice: How patients choose and how providers respond*. London: The King's Fund.
- Dixon, A., & Le Grand, J. (2006).** Is greater patient choice consistent with equity? The case of the English NHS. *Journal of Health Services Research & Policy*, 11(3), pp. 162-166.

- Drummond, M. F., Sculpher, M. J., Torrance, G. W., O'Brien, B. J., & Stoddart, G. L. (2005).** *Methods for the Economic Evaluation of Health Care Programmes.* (3rd ed.). Oxford: Oxford University Press.
- Eichler, K., Wieser, S., & Brügger, U. (2009).** The costs of limited health literacy: a systematic review. *International Journal of Public Health*, 54, pp. 313-324.
- Ferguson, L. A., & Pawlak, R. (2011).** Health Literacy: The Road to Improved Health Outcomes. *The Journal for Nurse Practitioners*, 7(2), pp. 123-129.
- Gallagher, J. M., Post, D. M., Weiss, B. D., Dickinson, L. M., Manning, B. K., Staton, E. W., Brown, J. B., Hickner, J. M., Bonham, A. J., Ryan, B. L., & Pace, W. D. (2010).** Patients' Question-Asking Behavior During Primary Care Visits: A Report From the AAFP National Research Network. *Annals of Family Medicine*, 8(2), pp. 151-159.
- Gasher, M., Hayes, M., Hackett, R., Gutstein, D., Ross, I., & Dunn, J. (2007).** Spreading the News: Social Determinants of Health Reportage in Canadian Daily Newspapers. *Canadian Journal of Communication*, 32, pp. 557-574.
- Gazmararian, J. A., Curran, J. W., Parker, R. M., Bernhardt, J. M., & DeBuono, B. A. (2005).** Public Health Literacy in America: An Ethical Imperative. *American Journal of Preventive Medicine*, 28(3), pp. 317-322.
- Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003).** Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51, pp. 267-275.
- Goss, J. (2008).** *Projection of Australian health care expenditure by disease, 2003 to 2033.* Cat. no. HWE 43. Canberra: AIHW.
- Hanley, O., Miner, J., Rockswold, E., & Biros, M. (2011).** The relationship between chronic illness, chronic pain, and socioeconomic factors in the ED. *American Journal of Emergency Medicine*, 29, pp. 286-292.
- Hanson, C., Thackeray, R., Barnes, M., Neiger, B., & McIntyre, E. (2008).** Integrating Web 2.0 in Health Education: Preparation and Practice. *American Journal of Health Education*, 39(3), pp. 157-166.
- Hemming, H. E., & Langille, L. (2006).** Building Knowledge in Literacy and Health. *Canadian Journal of Public Health*, 97(2), pp. s31-s36.
- Hohn, M. D. (2002).** Literacy, Health, and Health Literacy: State Policy Considerations. *Focus on Basics*, 5(c), pp. 20-25, Boston: National Centre for the Study of Adult Learning and Literacy
- Institute of Medicine of the National Academies (2011).** *Innovations in Health Literacy: Workshop Summary.* Washington: The National Academies Press.
- Institute of Medicine of the National Academies (2004).** *Health Literacy: A Prescription to End Confusion.* Washington: The National Academies Press.
- Jordan, J. E., Osborne, R. H., & Buchbinder, R. (2011).** Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. *Journal of Clinical Epidemiology*, 64, pp. 366-374.
- Kalichman, S. C., Cain, D., Cherry, C., Pope, H., Eaton, L., & Kalichman, M. O. (2005).** Internet Use Among People Living with HIV/AIDS: Coping and Health-Related Correlates. *AIDS Patient Care & STDs*, 7, pp. 439-448.
- Kalichman, S. C., Ramachandran, B., & Catz, S. (1999).** Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy. *Journal of General Internal Medicine*, 14, pp. 267-273.

Kanj, M., & Mitic, W. (2009). *Health Literacy and Health Promotion: Definitions, Concepts and Examples in the Eastern Mediterranean Region*. Individual Empowerment – Conference Working Document. World Health Organization.

Keleher, H., & Hagger, V. (2007). Health Literacy in Primary Health Care. *Australian Journal of Primary Health*, 13(2), pp. 24-30.

Kickbusch, I. (2008). Health literacy: an essential skill for the twenty-first century. *Health Education*, 108(2), pp. 101-104.

Kickbusch, I. S. (2001). Health literacy: addressing the health and education divide. *Health Promotion International*, 16(3), pp. 289-297.

Levin-Zamir, D., & Peterburg, Y. (2001). Health literacy in health systems: perspectives on patient self-management in Israel. *Health Promotion International*, 16(1), pp. 87-94.

Liechty, J. M. (2011). Health Literacy: Critical Opportunities for Social Work Leadership in Health Care and Research. *Health & Social Work*, 36(2), pp. 99-107.

Lupiáñez-Villaneuva, F., Mayer, M. Á., & Torrent, J. (2009). Opportunities and challenges of Web 2.0 within the health care systems: An empirical exploration. *Informatics for Health & Social Care*, 34(3), pp. 117-126.

Mancuso, C. A., & Rincon, M. (2006). Impact of Health Literacy on Longitudinal Asthma Outcomes. *Journal of General Internal Medicine*, 21, pp. 813-817.

Mogford, E., Gould, L., & Devoght, A. (2010). Teaching critical health literacy in the US as a means to action on the social determinants of health. *Health Promotion International*, 26(1), pp. 4-13.

MSD (2011). *Campaigns to promote suicide prevention, early detection of stroke and after school physical activity amongst winners at National Health Literacy Awards* [press release]. Retrieved August 1, 2011, from <http://healthliteracy.ie/wp-content/uploads/2011/05/MSD-Crystal-Clear-Winners-Press-Release-protrack-appFinal1.pdf>

Murphy, P. W., Davis, T. C., Long, S. W., Jackson, R. H., & Decker, B. C. (1993). Rapid Estimate of Adult Literacy in Medicine (REALM): A Quick Reading Test for Patients. *Journal of Reading*, 37(2), pp. 124-130.

National Adult Literacy Agency (2010). *Call for Entries to Crystal Clear MSD Health Literacy Awards 2011* [press release]. Retrieved August 1, 2011, from <http://healthliteracy.ie/wp-content/uploads/2010/12/Crystal-Clear-Awards-Launch-Nov-2010-.pdf>

National Adult Literacy Agency (2010). *NALA Audit Project 2010*. Dublin: Author

National Adult Literacy Agency (2009). *Literacy Audit for Healthcare Settings*. Dublin: Author.

National Adult Literacy Agency (2002). *Health Literacy Policy and Strategy*. Dublin: Author

National Adult Literacy Agency & MSD. *Health Literacy*. Retrieved August 1, 2011, from <http://healthliteracy.ie>

National Patient Safety Foundation. *Ask Me 3*. Retrieved 26 July, 2011, from <http://www.npsf.org/askme3/>

National Public Health Partnership (2001). *Preventing Chronic Disease: A Strategic Framework*. Retrieved 10 August, 2011, from <http://www.nphp.gov.au/publications/strategies/chrondis-bgpaper.pdf>

- Nutbeam, D. (2009).** Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health*, 54, pp. 303-305.
- Nutbeam, D. (2008).** The evolving concept of health literacy. *Social Science & Medicine*, 67, pp. 2072-2078.
- Nutbeam, D. (2000).** Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), pp. 259-267.
- O'Connor, A. M., Wennberg, J. E., Legare, F., Llewellyn-Thomas, H. A., Moulton, B. W., Sepucha, K. R., Sodano, A. G., & King, J. S. (2007).** Towards The 'Tipping Point': Decision Aids And Informed Patient Choice. *Health Affairs*, 26(3), pp. 716-725.
- Ohl, M., Harris, A., Nurudtinova, D., Cai, X., Drohobyczer, D., & Overton, E. T. (2010).** Do Brief Screening Questions of Provider Perception Accurately Identify Persons with Low Health Literacy in the HIV Primary Care Setting? *AIDS Patient Care & STDs*, 24(10), pp. 623-629.
- Paasche-Orlow, M. K., & Wolf, M. S. (2007).** Evidence Does Not Support Clinical Screening of Literacy. *Journal of General Internal Medicine*, 23(1), pp. 100-102.
- PricewaterhouseCoopers' Health Research Institute (2010).** *HealthCast: The customisation of diagnosis, care and cure*. Available from <http://www.pwc.com/us/en/healthcast>
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992).** In Search of How People Change: Applications to Addictive Behaviors. *The American Psychologist*, 47(9), pp. 1102-1114.
- Ratzan, S. C. (2010).** The National Health Literacy Action Plan: The Time Has Come for Action. *Journal of Health Communication*, 15, pp. 575-577.
- Rocconi, L. M. (2011).** The Impact of Learning Communities on First Year Students' Growth and Development in College. *Research in Higher Education*, 52, pp. 178-193.
- Rootman, I., & Gordon-El-Bihbety, D. (2008).** *A Vision for a Health Literate Canada – Report of the Expert Panel on Health Literacy*. Canadian Public Health Association.
- Rudd, R., Soricone, L., Santos, M., Zobel, E., Smith, J. (2005).** *Health Literacy Study Circles+*. Massachusetts: National Center for the Study of Adult Learning and Literacy & Harvard School of Public Health.
- Sarkar, U., Fisher, L., & Schillinger, D. (2006).** Is Self-Efficacy Associated With Diabetes Self-Management Across Race/Ethnicity and Health Literacy? *Diabetes Care*, 29(4), pp. 823-829.
- Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., Palacios, J., Diaz-Sullivan, G., & Bindman, A. B. (2002).** Association of Health Literacy With Diabetes Outcomes. *Journal of the American Medical Association*, 288(4), pp. 475-482.
- Schnitzer, A., Rosenzweig, M., & Harris, B. (2011).** Health Literacy: A Survey of the Issues and Solutions. *Journal of Consumer Health on the Internet*, 15(2), pp. 164-179.
- Scott, W. G., Scott, H. M., & Auld, T. S. (2005).** Consumer access to health information on the internet: health policy implications. *Australia and New Zealand Health Policy*, 2(13), pp. 13-21.
- Ship, A. (2011).** A 76-Year-Old Man With Multiple Medical Problems and Limited Health Literacy. *Journal of the American Medical Association*, 306(6), pp. E1-E2.
- Skopelja, E. N., Whipple, E. C., & Richwine, P. (2008).** Reaching and Teaching Teens: Adolescent Health Literacy and the Internet. *Journal of Consumer Health on the Internet*, 12(2), pp. 105-118.

Spring, H. (2011). Learning and teaching in action. *Health Information and Libraries Journal*, 28, pp. 148-151.

Squazzo, J. D. (2010). Best Practices for Applying Social Media in Healthcare. *Healthcare Executive*, May/June 2010, pp. 34-39.

Tang, H., Hwee, J., & Ng, K. (2006). Googling for a diagnosis – use of Google as a diagnostic aid: internet based study. *British Medical Journal*, 333, pp. 1143-1145.

The Tavistock Institute & Shared Intelligence (2009). *Evaluation of the second phase of the Skilled for Health programme*. Retrieved 04 August, 2011, from http://www.continyou.org.uk/health_and_well_being/files/Skilled_for_health_evaluation

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion (2010). *National Action Plan to Improve Health Literacy*. Washington, DC: Author.

U.S. National Library of Medicine, National Institutes of Health. *Health Literacy. Medline Plus*. Retrieved 14 July, 2011 from <http://www.nlm.nih.gov/medlineplus/healthliteracy.html>

Usher, W. (2011). Types of Social Media (Web 2.0) Used by Australian Allied Health Professionals to Deliver Early Twenty-First-Century Practice Promotion and Health Care. *Social Work in Health Care*, 50(4), pp. 305-329.

Vass, A., Mitchell, A., & Dhurrkay, Y. (2011). Health literacy and Australian Indigenous peoples: an analysis of the role of language and worldview. *Health Promotion Journal of Australia*, 22(1), pp. 33-37.

Volandes, A. E., & Paasche-Orlow, M. K. (2007). Health Literacy, Health Inequality and a Just Healthcare System. *The American Journal of Bioethics*, 7(11), pp. 5-10.

Welch, V. L., VanGeest, J. B., & Caskey, R. (2011). Time, Costs and Clinical Utilization of Screening for Health Literacy: A Case Study Using the Newest Vital Sign (NVS) Instrument. *Journal of the American Board of Family Medicine*, 24(3), pp. 281-289.

Witte, P. G. (2010). Health Literacy: Can We Live Without It? *Adult Basic Education and Literacy Journal*, 4(1), pp. 3-12

Wolf, M. S., Feinglass, J., Thompson, J., & Baker, D. W. (2010). In search of 'low health literacy': Threshold vs. gradient effect of literacy on health status and mortality. *Social Science & Medicine*, 70, pp. 1335-1341.

World Health Organisation (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva: World Health Organisation.

World Health Organisation (1998). *Health Promotion Glossary*. Geneva: Author.

Youmans, S. L., & Schillinger, D. (2003). Functional Health Literacy and Medication Use: the Pharmacist's Role. *The Annals of Pharmacotherapy*, 37, pp. 1726-1729.

Zanchetta, M. S., & Poureslami, I. M. (2006). Health Literacy Within the Reality of Immigrants' Culture and Language. *Canadian Journal of Public Health*, 97(2), pp.S26-S30.

Zarcadoolas, C., Pleasant, A. F., & Greer, D. S. (2006). *Advancing Health Literacy: A Framework for Understanding and Action* (1st ed.). San Francisco: John Wiley & Sons.

Helping you grow the discussion around health literacy in Australia