

HEALTH LITERACY:

Taking action to improve
safety and quality

© Commonwealth of Australia 2014

This work is copyright. It may be reproduced in whole or in part for study or training purposes subject to the inclusion of an acknowledgment of the source. Requests and inquiries concerning reproduction and rights for purposes other than those indicated above require the written permission of the Australian Commission on Safety and Quality in Health Care, GPO Box 5480 Sydney NSW 2001 or mail@safetyandquality.gov.au.

Suggested citation

Australian Commission on Safety and Quality in Health Care. Health literacy: Taking action to improve safety and quality. Sydney: ACSQHC, 2014.

ISBN

Print: 978-1-921983-61-0

Electronic: 978-1-921983-62-7

Acknowledgment

Many individuals and organisations have freely given their time, expertise and documentation in the development of the paper. In particular, the Commission wishes to thank the Health Literacy Advisory Group, those who provided a submission and other key health literacy experts who have freely given their time and advice. The involvement and willingness of all concerned to share their experience and expertise are greatly appreciated.

Members of the Health Literacy Advisory Committee include Ms Darlene Cox, Ms Maree Cuddihy, Dr Sophie Hill, Ms Lidia Horvat, Dr Anne Johnson, Dr Karen Luxford, Dr Imogen Mitchell, Ms Maureen Robinson, Dr Christine Walker, Ms Diane Webb and Ms Vanessa Vanderhoek.

Contents

Executive summary	2		
1 Introduction	4	Part B Addressing health literacy in a coordinated way	29
1.1 Purpose	5	6 Addressing health literacy in a coordinated way	30
1.2 Audience	5	6.1 The opportunity	30
1.3 Structure	6	6.2 Addressing health literacy in a coordinated way in Australia	32
1.4 Consultation	6	7 Embedding health literacy in systems	34
1.5 Linking with the National Safety and Quality Health Service Standards	6	7.1 Embedding health literacy in high-level systems	34
		7.2 Embedding health literacy into organisational policies and processes	39
Part A Background and context	7	8 Ensuring effective communication	42
2 What is health literacy?	8	8.1 Clear, focused and useable information about health and health care	42
2.1 Concepts that underlie health literacy	8	8.2 Effective interpersonal communication	50
2.2 How the Commission defines health literacy	10	9 Integrating health literacy into education	53
3 Why is health literacy important?	12	9.1 Why provide education to address health literacy?	53
3.1 Evidence about health literacy and health outcomes	12	9.2 Education and training for consumers about health and health literacy	54
3.2 Evidence about health literacy and safety and quality	14	9.3 Education and training for healthcare providers about health literacy	57
3.3 How is health literacy linked to outcomes?	14	9.4 Education and training to improve communication	60
3.4 What are the benefits of health literacy?	16	10 Who has a role in addressing health literacy in Australia?	62
4 How can health literacy be measured?	18	10.1 Consumers	63
4.1 How is health literacy measured?	18	10.2 Consumer organisations and other support services	65
4.2 The universal precautions approach to health literacy	21	10.3 Healthcare providers	66
5 Where does health literacy fit in?	22	10.4 Organisations that provide or support healthcare services at a local level	67
5.1 Health system context	22	10.5 Organisations that support healthcare providers	68
5.2 Education system context	22	10.6 Government organisations, regulators and bodies that advise on or set health and education policy	69
5.3 Social, personal and cultural context	23	10.7 Private organisations that provide health-based goods and services	71
5.4 Related concepts	26	10.8 Education and training organisations	72
		11 Where should we go now?	74
		11.1 A systematic approach	74
		11.2 National, coordinated and collaborative action	75
		11.3 The Commission's next steps	76
		Glossary	77
		References	80
		Index	90

Executive summary

Definition of health literacy

Health literacy is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it. Health literacy is important because it shapes people's health and the safety and quality of health care.

The Australian Commission on Safety and Quality in Health Care (the Commission) separates health literacy into two components:

- **Individual health literacy** is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.
- The **health literacy environment** is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way in which people access, understand, appraise and apply health-related information and services.

Importance of health literacy

Health literacy is a significant issue for Australia. Health information and systems have become increasingly complex and harder to understand. Like many other developed countries, almost 60 per cent of adult Australians have low individual health literacy, which means they may not be able to effectively exercise their choice or voice when making healthcare decisions.¹ Low individual health literacy is associated with higher use of health services, low levels of knowledge among consumers and poorer health outcomes.² It has been estimated that people with low individual health literacy are between one-and-a-half and three times more likely to experience an adverse outcome.³

A systematic review that examined the costs associated with low individual health literacy found that, at a system level, additional costs were equivalent to approximately three to five per cent of total healthcare spending.⁴ At an individual level, people with low health literacy spent between \$US143 and \$US7798 more per person per year than people with adequate health literacy.

Health literacy is important for consumers because it affects their capacity to make decisions and take action to manage their health and health care. It is important for healthcare providers because it affects the way that they manage their relationships with consumers and deliver health care. It is important for managers and policy makers because the complexity of their systems and services can affect the ability of consumers to use those services effectively. It is also important for broader society because health literacy contributes to people's overall health, and consequently their capacity to participate and contribute productively to society. Addressing health literacy can also contribute to reducing health disparities and increasing equity.

Partnerships with consumers are essential for both individual health and health care and for the development of better healthcare systems. Improving health literacy ensures that consumers can fully participate in these partnerships, and that the health system and healthcare organisations are oriented to support such partnerships.

Improving health literacy

There is much work happening in Australia to address health literacy, involving individuals and organisations working in research, health, education, justice, social services, local government and many other areas.⁵ However, these activities are disconnected, and opportunities for shared learning are limited. Current systems to support improvements in health literacy at a local, regional, state and territory level are variable, and are absent nationally.⁵

Addressing health literacy in a coordinated way has potential to increase the safety, quality and sustainability of the health system. Strategies are needed to build the capacity of people to understand the choices they have, make decisions and take action for their health and health care; and to build the capacity of the health system to support, encourage and allow this to occur.

To address health literacy in a coordinated way in Australia, it is necessary to:

- embed health literacy into high-level systems and organisational policies and practices
- ensure that health information is clear, focused and useable, and that interpersonal communication is effective
- integrate health literacy into education for consumers and healthcare providers.

Building on the strategies outlined in this paper, the Commission will work to raise awareness of health literacy, foster a climate of national action and collaboration on health literacy, and promote and provide resource materials for healthcare organisations to improve their local health literacy environment.

“People with low levels of individual health literacy are one and a half to three times more likely to have an adverse health outcome.”

“In the United States, people with lower health literacy spend between \$US143 and \$US7 798 per person per year more on health services.”

1 Introduction

Since 2006, the Australian Commission on Safety and Quality in Health Care (the Commission) has helped to identify, raise awareness of and support organisations to address safety and quality issues within health care.

The issue of health literacy has been raised repeatedly during the course of the Commission's work.

There are many different facets to health literacy: it is seen as a barrier and an enabler, an influencer, a by-product and a consequence of good health, education, and social policy and programs. Health literacy supports health and wellbeing across people's lives. Health literacy affects not only a person's involvement in the formal healthcare system, but also decisions they make and actions they take in the home, workplace and community.^{6,7} It influences people's lifestyle choices, the type of preventive health actions they take and the way they access, use and maintain healthcare regimens.

Almost universally, people have identified health literacy as an issue that requires national focus and attention. Improving health literacy is thought to minimise barriers to safe and high-quality care that stem from misunderstanding and miscommunication between patients and the health system, to improve health outcomes, and to reduce disparities and inequities in health.

Health literacy is also seen as fundamental to the establishment of effective partnerships between consumers and healthcare providers. There are many barriers to engaging in a true partnership, including the information, status and power imbalances that often exist in the relationship between consumers and healthcare providers. Empowering consumers to improve their knowledge and capacity for action, and reducing the demands placed on consumers by a complex health system is one way of making care more patient-centred and contributing to a safe and high-quality health system.

There have been efforts to take a national approach to health literacy in the past, with a particular focus on population-based goals and targets.⁸ These efforts have been hard to maintain, and their success is difficult to measure.⁹ There is now increasing recognition that consumers are at the centre of the health system, and that health literacy has an impact on the safety and quality of health care.^{10,11} With this recognition comes an opportunity to explore different ways to coordinate health literacy improvement efforts nationally.

Consequently, the Commission has started a program of work about health literacy.

1.1 Purpose

This paper is the first of a series of activities by the Commission on health literacy. The aims of the paper are to raise awareness of the importance of health literacy, and to start discussions about how it can be addressed systematically and who can be involved in this process.

The paper provides a broad overview of health literacy in Australia and identifies a number of areas and actions required to address health literacy in a coordinated way. Some of these areas and actions are outside the remit of the Commission; however, they are important components in ensuring a coordinated approach to health literacy across Australia.

Moving forward, the Commission will support national action to address health literacy in a systematic way, with a focus on promoting and providing useful resources to support healthcare organisations to address health literacy within their local environment. The Commission intends to build on this initial paper by developing further resources on health literacy, including tailored implementation resources for different individuals and organisations that outline strategies and actions that they can undertake to address health literacy within the healthcare system.

1.2 Audience

The primary audience for this paper is managers, policy makers and other people involved in the design and improvement of systems and services to support the health and wellbeing of Australians.

This paper can also be used by consumers, carers, healthcare providers, educators, and other health, welfare and education workers to increase their knowledge about health literacy, and inform their decision-making about what they, and their organisations, can do to address health literacy.

The information in this paper is relevant for government and nongovernment sectors, including those involved in the delivery of health and welfare services, education and training, infrastructure and planning, community and consumer advocacy and support, and professional support and development.

This paper has been designed to provide information for a range of people and organisations with different roles and responsibilities in addressing health literacy. However, the Commission acknowledges that it is important that different resources are prepared for different audiences to ensure that everyone working within the healthcare system understands their role and the actions they can take to address health literacy. The Commission will be developing more tailored resources in the future.

1 Introduction continued

1.3 Structure

Part A of this paper discusses what health literacy is, how the Commission conceptualises health literacy, why it matters, how it might be measured and where it fits in the wider context of related issues.

Part B describes how efforts to improve health literacy might be better coordinated through action taken within systems, at the interpersonal level, and through education and training programs. There are details of the types of people and organisations that have a role in addressing health literacy in Australia, and examples of the kind of actions that can be taken by these different groups. Due to the nature of the Commission's role, this section tends to focus on agents and actions within the health system, with some references to activity in other sectors. The paper concludes by identifying the next steps that will be taken by the Commission.

1.4 Consultation

From June to September 2013, the Commission sought feedback on a draft version of this paper. More than 100 submissions were received. The Commission reviewed and analysed the submissions, and undertook significant revision of the draft paper to address the key concerns identified. The submissions have contributed to the final version of this document and will also help to shape the Commission's future work in this area. A consultation report outlining key themes and issues raised during the consultation process can be found on the Commission's web page.*

1.5 Linking with the National Safety and Quality Health Service Standards

The Commission's work on health literacy links closely with the National Safety and Quality Health Service (NSQHS) Standards. The NSQHS Standards include a range of actions that require healthcare organisations to work closely with consumers in the planning, delivery and evaluation of health care to ensure that it is delivered in a way that is understandable and that meets the needs and preferences of consumers. Health literacy enables people to share in the type of active and meaningful partnerships which are required under the NSQHS Standards. Standard 1: Governance for Safety and Quality in Health Service Organisations and Standard 2: Partnering with Consumers include actions that focus on these areas, and most of the other NSQHS Standards include actions focused on making information easy to understand.

This paper provides information about the importance of health literacy and gives examples of some strategies and approaches that can be used to address health literacy. This information may be of assistance to organisations looking to both strategically address health literacy and meet the requirements of the NSQHS Standards.

* www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy

PART A

BACKGROUND AND CONTEXT

2 What is health literacy?

Consumers are at the centre of our health system. The purpose of the health system is to improve the health and wellbeing of people so they can live happier, healthier and more productive lives.

As society changes, the health system is evolving – moving from a paternalistic model where healthcare providers made care decisions for patients to a more collaborative, rights-based model where people are provided with information and choices about their health. It is now increasingly being recognised that people have the right to be partners in their health care to the extent that they want to be.¹¹

The way in which people make decisions and take action about health and health care is influenced by their own skills, capacities and knowledge; and by the environments in which these decisions and actions are taken. Together, these factors have been conceptualised as ‘health literacy’. Along with many other developed countries,¹²⁻¹⁵ Australia has low levels of health literacy (Box 1).¹

This section provides a synthesis of the definitions and concepts of health literacy, and the definition of the two health literacy terms that the Commission uses in its work.

“Sixty per cent of adult Australians have low health literacy.”

Box 1

Levels of health literacy in Australia

In 2006, the Australian Bureau of Statistics conducted the Adult Literacy and Life Skills Survey, which identified that almost 60 per cent of adult Australians have low health literacy. This means that they may not be able to effectively exercise their choice or voice when making healthcare decisions.¹

2.1 Concepts that underlie health literacy

The term ‘health literacy’ emerged in the 1970s,¹⁶ but did not gain momentum until the 1990s,¹⁷ when it began regularly appearing in academic literature. The term originated from the field of public health in the context of health education, health promotion and primary prevention.

Interest in the concept of health literacy and the way in which people apply and interpret the term has evolved to reflect a variety of perspectives on the topic. There is currently no consensus about the definition of, or conceptual framework for, health literacy, and this has been a source of confusion and debate.^{18,19} Part of the confusion comes from the application of the term ‘health literacy’ to similar, but not identical, concepts. Research that is relevant to health literacy can be found under many different banners, including health education, health communication, consumer participation and engagement, attitudes and beliefs of consumers, organisational culture and health promotion.

There has also been a tendency to broaden the scope of this term to include an increasing range of factors that may affect the way in which people interact with the health system, and the health outcomes that they achieve.

There is considerable research on health literacy, but the different use of terminology, overlapping concepts and siloed nature of health and medical research have made it challenging for people to link the concepts, draw conclusions and act to address health literacy.⁶

The concepts that are most frequently included in discussions about health literacy are as follows.

Skills and abilities of individuals

The most common use of the term 'health literacy' is associated with the skills, abilities, motivations and capacities of people to 'obtain, process and understand health information and services necessary to make appropriate health decisions'.¹⁸ These skills and abilities include the domains of cultural and conceptual knowledge, listening and speaking (oral literacy), writing and reading (print literacy), and numeracy.²⁰ Abilities that have been identified as important by consumers with regard to health literacy include knowing when and where to seek health information, verbal communication and literacy skills, assertiveness, capacity to process and retain information, and skills to apply information.²¹

Context and characteristics of individuals

A range of contextual factors and personal characteristics have been identified as affecting the skills and abilities of people to make decisions and take action about health and health care. These include age, education, health and mental health status, occupation, cultural and ethnic background, language, socio-economic status, social supports and networks, and prior knowledge and experience with illness and the healthcare system.^{18,21,22} The influence of these factors means that the needs and abilities of people may change over time, and the life course is a factor that has been included in some definitions of health literacy.^{18,19,23} Section 5.3 contains more information about many of these contextual factors.

Environmental and social factors

A different approach to health literacy has evolved from the fields of public health and health promotion. This focuses on the environmental and social factors that influence health. In this model, health literacy is an outcome of health education and communication. Improved outcomes and reduced health disparities are achieved through greater empowerment and engagement, changed health behaviours and practices, advocacy, and an understanding of the social determinants of health.²³

Demands and burdens placed on individuals

Over the last decade, there has been an increased focus on the demands and burdens placed on people who seek care in complex health systems.^{24,25} These demands and burdens relate to factors such as the way in which the health system is organised; the content and availability of printed, online and other resource materials for consumers; interactions between consumers and healthcare providers; and the physical environment of health services and settings.^{21,25,26} Some systems and processes have been designed in a way that limits access, which can impose barriers for people and lead to fragmentation of care. Many models of health literacy focus on the interaction between skills and demands, and consider that it is important to both increase skills and reduce demands to ensure that people are in the best position to make decisions and take action about their health and health care.²⁰

2 What is health literacy? continued

2.2 How the Commission defines health literacy

Because of the complexity and range of concepts that are currently included within the broad term 'health literacy', the Commission separates health literacy into two components: **individual health literacy** and the **health literacy environment**. These two components reflect the two predominant factors that influence the way that a person accesses, understands, appraises and applies information (Figure 1).²⁷

Figure 1 The two components of health literacy



Source: Parker R, *Measuring health literacy: Why? So what? Now what?* In: Hernandez L (ed), *Measures of Health Literacy: Workshop Summary; Roundtable on Health Literacy*. 2009.

The Commission defines these two health literacy components as follows:

- **Individual health literacy:** the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.
- **Health literacy environment:** the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way in which people access, understand, appraise and apply health-related information and services.

Individual health literacy and the health literacy environment influence how people undertake a range of tasks, including:

- reading, understanding and acting on preventive health messages, healthcare plans, medication instructions and other health information
- completing health and healthcare forms such as consent forms, insurance forms, Medicare claim forms and diagnostic survey tools
- finding a healthcare provider or service and making an appointment
- making informed decisions about health and health care
- navigating healthcare systems and services
- understanding signage and way-finding within and between health services.

Individual health literacy

Individual health literacy is about a person's skills and abilities and how these are applied to health and health care.¹⁸ It covers a range of skills, behaviours and activities, such as reading about what foods are required for healthy eating, the motivation to participate in a cardiac rehabilitation support group, or the capacity to make an appointment at an antenatal clinic. As well as the ability to read, comprehend and analyse information, individual health literacy includes the ability to decode symbols, charts and diagrams; weigh risks and benefits; and convert this information and decision-making into action.

A range of factors are linked to each person, their environment and upbringing that can either support or interfere with the development of individual health literacy (see Section 5.3). In some cases, the likelihood of lower individual health literacy might be increased where disadvantage and vulnerabilities connect. Individual health literacy is also dynamic: it can fluctuate depending on issues such as illness, stress and where the person is in their life course.

Different types of strategies are needed to support individual health literacy, depending on the factors that have influenced the way that a person understands and uses information. Strategies to raise awareness of health issues might need to be different for men and women; different communication requirements might be needed for those from culturally and linguistically diverse backgrounds; different cultural considerations will need to be part of strategies for Aboriginal and Torres Strait Islander peoples; and different tools and approaches may be needed for people with a disability.

Health literacy environment

The infrastructure, policies, processes, materials, people and relationships of the health system can be set up and work in a way that makes it easier or more difficult for consumers to navigate, understand and use information and services about health and health care. The way the health literacy environment works and how complex it is influences how consumers make decisions and take action about health and health care.²⁸⁻³⁰ The health literacy environment sits within the broader societal context.

The health literacy environment includes information about health and health care, and the structures and processes of how and where these are provided. The health literacy environment includes systems, policies, procedures and protocols at local, regional, jurisdictional and national levels. These cover issues such as design and layout of hospitals, health product packaging and design, referral pathways, social marketing, design of public health programs, care coordination processes, and provision of other types of education, support and infrastructure for people about health and health care. It also includes how people work within the healthcare system, including the communication processes and relationships that exist between consumers and healthcare providers, such as shared decision-making processes.

Sections 7, 8 and 9 of this paper include some examples of strategies that can be used to address individual health literacy and the health literacy environment. However, they do not go into detail about the very wide range of potential strategies that might be needed to address all aspects of these two components of health literacy.

Section 10 provides more information about the roles of the different people and organisations that should be involved in addressing both individual health literacy and the health literacy environment.

3 Why is health literacy important?

Health literacy is important because there is consistent evidence that indicates associations between individual health literacy, health behaviours and health outcomes.

Overall, it has been estimated that people with low individual health literacy are between one-and-a-half and three times more likely to experience an adverse outcome.³ Lower health literacy has also been linked to a lack of social empowerment and efficacy.³¹ In addition, a recent report by the World Health Organization suggests that low health literacy 'significantly drain[s] human and financial resources in the health system'.³²

This section discusses the evidence about health literacy, health outcomes, and safety and quality; and mechanisms that have been proposed for linking health literacy to outcomes. It also provides a summary of the benefits of health literacy to people in different roles within the health system.

3.1 Evidence about health literacy and health outcomes

The combination of low levels of health knowledge, low levels of individual health literacy in the population¹ and increasing demands from a complex health system³³ has a significant impact on health, and the safety and quality of health care in Australia. Low individual health literacy has been found to be associated with:^{2,34}

- increased rates of hospitalisation and greater use of emergency care
- lower use of mammography and lower uptake of the influenza vaccine
- poorer ability to demonstrate taking medications appropriately
- poorer ability to interpret labels and health messages
- poorer knowledge among consumers about their own disease or condition
- poorer overall health status among older people
- higher risk of death among older people.

Generally, the associations between level of individual health literacy and outcomes remain, even when contextual factors such as age, sex, education, income, ethnicity and health status are taken into account.³⁴

See Box 2 for examples of why health literacy is important throughout the health journey.

It is difficult to accurately determine the cost of lower individual health literacy to the person, healthcare organisations and the system as a whole. This is partly due to the difficulty in separating the effects of individual health literacy and other related concepts that influence behaviour. One systematic review in the United States that examined the costs associated with lower individual health literacy found that, at a system level, additional costs corresponded to approximately three to five per cent of total healthcare spending.⁴ At an individual level, people with lower health literacy spent between US\$143 and US\$7 798 more per person per year compared to people with higher individual health literacy. However, a later systematic review found that the results of cost-impact studies were mixed, and further research was needed to accurately estimate the cost of health literacy and the benefits of applying health literacy strategies.³⁵

There has been far less research about the impact of the health literacy environment on health outcomes. It has been recognised for some time that the complexity of the health system is challenging for consumers and healthcare providers,³³ and that this complexity contributes to poor-quality and unsafe care.^{36,37}

In research about the readability of written information for consumers, it has often been found that documents contain language and complex concepts that would be difficult for the average person to comprehend.³⁸⁻⁴² Other studies that have looked at the information that is provided to patients about their condition and treatment, particularly for specific conditions such as cancer, have suggested that healthcare providers may need to pay more attention to providing patient-centred information.⁴³

Consumers report that their needs regarding information are not always met. It is known that people who are provided with appropriate information (based on satisfaction with received information, fulfilled information needs, high-quality and clear information) report better health-related quality of life and lower levels of anxiety and depression.⁴³ Reports on assessments of the health literacy environment of individual health facilities identify issues such as difficulties in way-finding and written information that is too complex, particularly on consent forms.³⁰

Box 2

Health literacy across the health and wellbeing spectrum

Health literacy is important to people throughout their lives and their health journeys, whether they are in contact with a healthcare service or not. Understanding information about health and health care is important to health and wellbeing across the spectrum of primary, secondary and tertiary prevention. Examples of different ways in which health literacy affects people's lives are summarised below.

There is limited evidence of an association between health literacy levels and health risk behaviours such as smoking, alcohol use, physical activity and healthy eating habits.^{2,34} However, individual health literacy is likely to be an important factor in preventing illness.³² If a person is given complex information about the importance of these modifiable risk factors, or does not have the capacity to access, understand and act on the information, they are not being given the opportunity to make informed choices and prevent future health conditions.

Individual health literacy and the health literacy environment affect a person's engagement with the healthcare system, including their likelihood of accessing disease prevention services such as screening programs. For example, it has been shown that interventions that involve health literacy training for healthcare providers are associated with increased cancer screening rates.²⁵

Individual health literacy and the health literacy environment also influence the safety and quality of health care. A person's ability to access, understand and use information about their condition will influence the action they take and the decisions they make about treatment and management. For example, studies have shown that low individual health literacy can be a significant risk factor for improper adherence to HIV medication regimens.^{44,45}

3 Why is health literacy important? continued

3.2 Evidence about health literacy and safety and quality

Addressing health literacy is one way of protecting people from potential harm.⁴⁶ Providing unclear health information and services can lead to misunderstandings about the risks, consequences and necessity of care, or about medication instructions, healthcare plans or preventive strategies. All of these scenarios have the potential to lead to some level of harm for consumers, whether it is a faster progression of a condition, a medication error or a poorer health outcome.^{47,48}

The area that has been investigated most frequently is the contribution that individual health literacy makes to medication safety risks, particularly dosing administration risks.⁴⁹ Low individual health literacy has been found to be significantly associated with a poorer understanding of medications, medication instructions and adherence to treatment regimens.^{3,49,50} Studies have estimated that nearly half of adults misunderstand common dosing schedules (such as take two tablets by mouth twice daily) and warnings that detail important information to support safe and effective use (such as do not chew or crush, swallow whole; for external use only).^{50,51}

There is important research that indicates people with lower individual health literacy have lower adherence to anticoagulation therapy.²⁰ For example, Australian research has found that impaired cognition, depressed mood and inadequate health literacy are strong risk factors for unstable coagulation test results among people who take warfarin.⁵²

In another study based in the United States, half of patients receiving warfarin at an anticoagulant clinic thought their medication regimen was different from what their healthcare provider thought.⁵³ This suggests that communication of critical medication information between the patient and the healthcare provider (and verification of the patient's understanding of that communication) was less than optimal. In this situation, failing to think about the health literacy of the consumer and tailor information appropriately can lead to a misunderstanding of medication instructions, which can place the consumer at greater risk of a serious adverse event such as stroke or bleeding.

3.3 How is health literacy linked to outcomes?

A number of models have been proposed to explain the links between health literacy, health outcomes and factors such as age, education, socio-economic status, cultural background, social support, and the media.¹⁸ Generally, the data to support these models is limited, and the models may underestimate the complexity of the factors, relationships and interactions that exist.^{22,54} Nonetheless, understanding these models is important, as they may suggest places where action can be taken for improvement.

The key causal pathways that have been described relate to the way in which individual health literacy, the health literacy environment and contextual factors influence the following:^{22,23}

- **How people access and use healthcare services.**

For example, people with higher individual health literacy may have a greater understanding of when to seek treatment and preventive care, reducing the use of acute health services. The design of healthcare facilities may make it more difficult for people with lower individual health literacy to find the information and services that they need.

- **Interactions between consumers and healthcare providers.**

For example, healthcare providers may have limited awareness of the level of individual health literacy of their patients and may not tailor the information that they provide appropriately. People with lower individual health literacy may be less likely to ask questions of their healthcare provider, or to ask for clarification or more information if they do not understand. Both of these factors can affect the likelihood that consumers will follow the recommended treatment.

- **How people manage their own health.**

For example, people with higher individual health literacy may have more knowledge about the actions that they can take to manage their own condition (such as what medication to take in an asthma exacerbation). Programs and support services such as chronic disease self-management programs can help to increase knowledge and change behaviour.

- **How people exert control over the factors that shape health.**

For example, people with higher individual health literacy may have a greater understanding of the social determinants of health and be involved in influencing these social determinants for others. This engagement can be supported by an environment that provides health education that is focused on the development of interpersonal and social skills, as well as knowledge about specific health-related issues.

“Studies have estimated that nearly half of adults misunderstood common dosing schedules and warnings ... to support safe and effective use (of medications).”

3 Why is health literacy important? continued

3.4 What are the benefits of health literacy?

Health literacy is a complex concept, and it is not always obvious to consumers or people working in the health system what it means in practice or why it is important to address it. Table 1 summarises some of the benefits that may result from addressing health literacy for different people within the health system.

Table 1 Examples of potential benefits of addressing health literacy for individuals with different roles in the health system

Role	Addressing health literacy has the potential to:
Consumers	<ul style="list-style-type: none"> • make it easier for me to know where to go, what to do and how to find what I need to improve my health and wellbeing and that of my family • help me to make better decisions about my health, wellbeing and health care and that of my family • make it easier for me to manage my own health care and the health care of my family, including maintaining treatment and medication regimens • help me to contribute more effectively to decision-making and action about healthcare information, provision, planning or evaluation
Healthcare providers	<ul style="list-style-type: none"> • help me to deliver health care that reflects the needs and preferences of my patients and their families, in a way that is easy to understand and act on • help me to work in partnership with my patients and their families so that they can take appropriate actions and make effective decisions for their health and health care • help me to change the way I provide health care to make it easier for patients to access, understand and use the information I provide • help me to reduce the risk of harm to my patients by improving interpersonal communication and information exchange
Health service managers	<ul style="list-style-type: none"> • help me to organise the way in which health care is delivered to make it easier for consumers to take appropriate actions and make effective decisions for their health and health care • help me to make it easier for consumers to find, and find their way in, my health service • help me to make it easier for consumers to access clear, focused and useable information about health and health care • help me to increase the likelihood of consumers engaging with my healthcare organisation to improve the safety and quality of my health services • help me to reduce the risk of harm to consumers by improving communication and information exchange

Role	Addressing health literacy has the potential to:
Health service executives and board members	<ul style="list-style-type: none"> • help me to make sure that my health service understands and addresses consumer healthcare needs and preferences • help me to understand and address safety and quality issues that are of concern to consumers within the health service by actively encouraging consumers to be involved in decision-making • help me to improve the experience of consumers and healthcare outcomes by making sure the care that is delivered is what the consumer would choose • help me to make sure that the information the health service provides is effective and fit for purpose • help me to provide support and a conducive environment for partnerships within my health service • help me to be confident that consumers are providing informed consent
Policy makers	<ul style="list-style-type: none"> • help me to ensure that the health system is organised and that care is provided in a way that makes it easier for consumers to take appropriate actions and make effective decisions for their health and health care • help me to make it easier for consumers to access clear, focused and useable health information • help me to provide support and a conducive environment for partnerships between healthcare providers, healthcare organisations and consumers • increase the safety and quality, efficiency and effectiveness of health care by empowering consumers to be actively involved in decision-making

4 How can health literacy be measured?

There is a range of different approaches to measuring health literacy. These tend to reflect the purpose for which it is being measured and the different ways in which health literacy can be defined.

There is much debate about when and where it is appropriate and practical to measure individual health literacy. For example, given the time involved, it may not be practical or useful to attempt to measure the individual health literacy of every person, every time they see a healthcare provider. There are also concerns that people may feel shame or embarrassment if their healthcare provider tests their level of individual health literacy, which can affect trust and rapport. It has been suggested that the benefits of measuring individual health literacy at a clinical level are not worth the potential harms that can occur.²² Consequently, in the United States, a universal precautions approach to health literacy is recommended. This section briefly discusses the commonly used tools for measuring health literacy and explains the universal precautions approach to health literacy.

4.1 How is health literacy measured?

Given the complexity and ambiguity of the different concepts of health literacy, it is not surprising that the processes for measuring health literacy are contested.^{19,55} Definitions of health literacy are broad and include a number of concepts that are not straightforward to measure (such as the quality of interpersonal communication, or an individual's motivation, empowerment and decision-making ability).¹⁸

The majority of measurement efforts have focused on measuring the health literacy of individuals rather than the health literacy environment. There are different approaches and aims for measuring individual health literacy, and different tools have been developed to achieve these aims. The tool or method that should be used depends on why you are measuring individual health literacy and what you intend to do with the results (see Box 3 for examples of commonly used measurement tools). For example:

- Healthcare providers can use short form tools (such as the Newest Vital Sign) to measure a person's individual health literacy within a consultation to quickly identify barriers to understanding and the best way of communicating with the individual consumer.
- Healthcare organisations can use more detailed tools (such as the Rapid Estimate of Adult Literacy in Medicine) to assess the individual health literacy of the people to whom they provide services to help identify common barriers to understanding and to target appropriate education and support programs to consumers.
- Governments, policy makers and planners can use population-based measurement tools (such as the Adult Literacy and Life Skills Survey)⁵⁶ to measure individual health literacy across the population to determine trends and progress and to measure the impact of population-based strategies on health literacy.⁵⁷

Box 3**Commonly used tools for measuring individual health literacy**

The most commonly used tools for measuring individual health literacy are the Test of Functional Health Literacy in Adults (TOFHLA), the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Newest Vital Sign (NVS).^{2,19,55}

TOFHLA measures reading fluency. It consists of a reading comprehension section (a 50-item test using the modified Cloze procedure) to measure prose literacy, and a numeracy section with 17 items that assess an individual's capacity to read and understand actual hospital documents and labelled prescription vials.⁵⁸

REALM is a 66-item word recognition and pronunciation test that measures the domain of vocabulary.⁵⁹

Although these two tests measure different capacities, they are highly correlated with each other and with general vocabulary tests.¹⁹

NVS is a short practical questionnaire that requires the interpretation of health information from a nutritional label.⁶⁰

None of the commonly used tools for measuring individual health literacy provide a comprehensive assessment of an individual's capacities; they measure selected domains that are thought to be markers for an individual's overall capacity. In addition to literacy and numeracy skills, a person's baseline conceptual knowledge of health and health care will influence their individual health literacy. There is currently no commonly used tool that measures this knowledge;¹⁹ however, recent Australian research has been undertaken on the development of tools and conceptual frameworks that may better reflect the overall individual health literacy of a person, as well as their broader social and environmental contexts. These tools include the Health Literacy Management Scale⁶¹ and the Health Literacy Questionnaire (Box 4).⁶²

4 How can health literacy be measured?

continued

Box 4

The Health Literacy Questionnaire

The Health Literacy Questionnaire (HLQ) is a new measure of health literacy that has been developed by Australian researchers at Deakin and Monash universities. The HLQ comprehensively captures the broad components that contribute to individual health literacy, rather than just measuring a person's literacy or numeracy. The HLQ also provides detailed information about what needs to be done to improve systems and services.⁶²

The HLQ consists of nine domains:

- feeling understood and supported by healthcare providers
- having sufficient information to manage my health
- actively managing my health
- social support for health
- appraisal of health information
- ability to actively engage with healthcare providers
- navigating the healthcare system
- ability to find good health information
- understanding health information well enough to know what to do.

Web page: www.deakin.edu.au/health/research/phi/health-literacy-questionnaire.php

The same issues exist at the population level, with individual health literacy being measured using different tools that may be measuring different things. For example, the Australian Bureau of Statistics uses the Canadian model of the Adult Literacy and Life Skills Survey to assess knowledge and skills at a population level in the following four domains: prose literacy, document literacy, numeracy and problem solving. As a by-product of these, a fifth domain measuring health literacy was produced.¹ The most recent national survey in Australia was undertaken in 2006. In comparison, the United States uses the National Assessment of Adult Literacy, which includes a component designed specifically to measure health literacy – the 28 tasks included in the component focus on navigation, clinical and preventive health tasks. The most recent survey was undertaken in 2003.⁶³

To date, there has been much less focus on measuring the health literacy environment – that is, how easy or difficult it is for people to navigate, understand and use health services. Tools are now being developed that can be used to assess the health literacy environment of individual healthcare organisations.^{48,64,65} An Australian example of this is the Enliven Organisational Health Literacy Self-Assessment Resource,⁶⁶ which is based on the Institute of Medicine's ten attributes of a health-literate organisation (see Section 7).

Components that can be included in a review of the health literacy environment include:⁶⁴

- navigation and way-finding, such as telephone systems, signage, maps and reception areas

- print communication, such as writing style and use of appropriate illustrations
- oral communication, such as staff offering to help with filling in forms and healthcare providers checking that they have explained information in a way that consumers understand
- technology, such as the availability and functionality of televisions, telephones, computers, web pages, apps, online tools and kiosks
- policies and protocols, such as development of consumer information publications, staff orientation and ongoing training.

4.2 The universal precautions approach to health literacy

Measuring the individual health literacy of every person within the time frame of a consultation may not be practical or useful in all situations. Even the shortest health literacy measurement tool will take some time to administer, and a person's individual health literacy may fluctuate due to a range of social and personal factors, as outlined in Section 5.3. Administering a health literacy tool during a consultation may also create stress and embarrassment for the patient. Consequently, a 'universal precautions' approach to health literacy has been used in the United States, and this is also the model that the Commission supports.

The universal precautions approach works on the assumption that it is not possible to know a person's level of individual health literacy by looking at them. Therefore, it is important to assume that there will be barriers to understanding and it will be necessary to reduce the complexity of the information and services that are provided. Using a universal precautions approach can help people with a range of levels of individual health literacy, as it's based on the principle of making information and services easier for all to understand.

The Agency for Healthcare Research and Quality in the United States has developed a *Health Literacy Universal Precautions Toolkit*⁶⁵ to help healthcare organisations and providers understand the kinds of actions they can take to address health literacy

without measuring the individual health literacy of each patient (Box 5). The Universal Precautions Toolkit focuses on identifying the barriers to health literacy within the healthcare organisation by undertaking an organisational assessment and then using tools to improve the interaction between healthcare providers and consumers. Many of these tools use iterative approaches and reinforcing strategies that can be used to ensure that people who may have more complex health literacy needs are able to access, understand, appraise and apply information. As discussed in Section 5.3, people with more complex health literacy needs may also have additional barriers to their health and welfare that need to be addressed in a coordinated way.

Box 5

Health Literacy Universal Precautions Toolkit

This toolkit provides a series of tools for healthcare organisations and teams, focusing on:

- organisational preparedness and awareness
- improving spoken communication
- improving written communication
- supporting self-management and empowerment of patients
- strengthening systems.

The toolkit identifies the steps required to identify the barriers to health literacy within a healthcare organisation, improve healthcare workers' understanding of health literacy and enable action to address health literacy within the healthcare setting.

Web page: www.ahrq.gov/legacy/qual/literacy/healthliteracytoolkit.pdf

5 Where does health literacy fit in?

The Commission's work on health literacy is part of a tapestry of policies, practices, concepts and research initiatives that are relevant to health literacy in Australia.

Because of the breadth of the concept of health literacy and the range of potential strategies and approaches to address it, there can be confusion about where health literacy fits in this tapestry. This section provides an overview of the main contextual and conceptual factors that have influenced the Commission's approach to health literacy.

5.1 Health system context

Recognition that health literacy is fundamental to good health and high-quality health care is not new in Australia. Health literacy was added to Australia's first set of national health goals and targets in 1993.⁸ In 2007, the National Health and Hospitals Reform Commission identified health literacy as a key factor for encouraging stronger consumer engagement.⁶⁷

Since 2010, a program of health reform has been under way in Australia that aims to improve the effectiveness, efficiency, appropriateness and accessibility of health care. Work is occurring in eight key streams of health reform: hospitals, general practice and primary health care, aged care, mental health, national standards and performance, workforce, prevention and e-health.⁶⁸

Effective partnerships between consumers, healthcare providers and organisations at all levels of healthcare provision, planning and evaluation are fundamental to these reforms.⁶⁹⁻⁷² Such partnerships have been identified as one of the key factors needed to enhance the success of large-system transformation in health care.⁷³ A focus on health literacy is one way of ensuring that consumers can participate in these partnerships, and that the health system and healthcare organisations are oriented to support partnerships. It can also contribute to reducing disparities in health care and outcomes.

Health literacy is also part of Australia's national approach to safety and quality improvement. The Commission has identified health literacy as a priority through a number of national policies including:

- the Australian Safety and Quality Framework for Health Care, which identifies health literacy as a key action area⁷⁴
- the Australian Safety and Quality Goals for Health Care, which includes Partnering with Consumers as a goal and becoming a health-literate organisation as a core outcome (Outcome 3.0.3)¹⁰
- the Australian Charter of Healthcare Rights, which identifies the right to receive information in a way that people understand as a fundamental component of safe and high-quality care.⁷⁵

The requirement to partner with consumers is also embedded in the NSQHS Standards (see Section 1.5).

5.2 Education system context

In the late 1990s, the World Health Organization developed the Global Schools Initiative, which focused on supporting the development of health-promoting schools, and was based on the Ottawa Charter and a social model of health.⁷⁶ The health-promoting schools model was used to inform the development of the Australian National Framework for Health-Promoting Schools,⁷⁷ which takes into account the physical, social and emotional needs of all members of the school community.

Building on this framework, in recent years the Australian Government has implemented a number of initiatives aimed at improving the literacy and numeracy of Australian children, including establishing partnerships and programs to help students at risk of falling behind, and implementing the National Assessment Program – Literacy and Numeracy.⁷⁸⁻⁸⁰ Other stand-alone health-based initiatives that teach health literacy skills within the formal education context include programs such as the Stephanie Alexander Kitchen Garden National Program, MindMatters and KidsMatter.⁸¹⁻⁸³

In 2008, the Australian Curriculum and Assessment Reporting Authority (ACARA) was established to develop and administer a national school curriculum. Literacy, numeracy, critical and creative thinking, and personal and social responsibility are some of the general capabilities that underpin the curriculum developed by ACARA.⁸⁴ These capabilities are all relevant and related to building health literacy skills.

In addition, as part of its work, ACARA is in the process of developing the Revised Australian Curriculum: Health and Physical Education – Foundation to Year 10,⁸⁵ which explicitly commits to developing health literacy skills. This curriculum is expected to be implemented from 2014.

5.3 Social, personal and cultural context

As noted in Section 2, individual health literacy is influenced by a range of personal, social, environmental and cultural factors. Some of the factors that are known to influence a person's individual health literacy are described in Box 6. Although low individual health literacy can be found across the socio-economic spectrum, people from vulnerable or disadvantaged groups can be at higher risk of having a low individual health literacy.⁸⁶ Health literacy is a particular issue for Australia's disadvantaged or vulnerable groups because having low individual health literacy can exacerbate underlying access and equity issues that people from these groups may be experiencing.⁸⁷

Some of the different people who may be at higher risk of low individual health literacy include people from lower socio-economic backgrounds, people with lived mental health experience, elderly people, people living with disabilities, Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, people with drug and alcohol dependencies, people experiencing chronic or complex illness, and people who are homeless, socially isolated or geographically isolated. Because of the impact of these factors on health literacy, addressing individual health literacy is often seen as a way of reducing health disparities.

Personal factors, like a person's previous experience of health and illness and knowledge of their own health condition, will also affect individual health literacy. Individual health literacy is dynamic: being tired, in a bad mood, in an unfamiliar place, unwell, stressed or just uncomfortable will all affect a person's capacity to understand, use, apply and act on information at that time. Consequently, a person's individual health literacy can vary from day to day.

Personal factors will also influence the extent to which a person will want to partner with their healthcare provider and organisation, and the extent to which they want to understand, use, apply and act on health information. Some people may prefer to leave decisions and action to their healthcare provider, whereas others may seek a more active role in their care. A person's personal preferences should always inform the way in which interventions aimed at reducing barriers and improving health literacy are applied to that individual.

5 Where does health literacy fit in? continued

Box 6

Factors that can influence a person's individual health literacy

Age

The 2006 Adult Literacy and Life Skills Survey found that Australians aged 20–44 years had the highest level of individual health literacy, and that rates were lower for those aged 15–19 years and 45 years and older.⁸⁸ It has been suggested that differences in individual health literacy between these age groups may be associated with factors such as differing expectations of the level of participation in health care among generations, effects of cognitive decline on people's mental processing skills,⁸⁹ the length of time since leaving formal education, and the lower levels of formal education received by older generations.⁸⁸ Studies have demonstrated an independent association between low levels of individual literacy and increased mortality among elderly people.^{90,91}

Education

Education has a strong role in shaping individual health literacy.³⁵ According to the findings of the 2006 Adult Literacy and Life Skills Survey, people who had higher levels of education had higher rates of adequate or better individual health literacy. Three-quarters of people whose highest level of education was a bachelor degree or above had adequate or better health literacy, compared with 50 per cent of those who finished their education at Year 12 and 16 per cent of those who finished at Year 10 or below.⁸⁸ Similar results were found in a 2008 study that used a short health literacy measurement tool to assess the health literacy of a random sample of South Australians.⁹²

Disability

People living with disabilities may be at particular risk of low individual health literacy for functional reasons such as poor vision or intellectual impairment. The health literacy environment may also exacerbate the impact of a person's disability. For example, a person with a disability may have difficulties with physical access to health services, or have difficulty communicating with healthcare providers.⁹³

Culture and language

In 2006, almost three million Australians aged 15–74 years spoke English as a second language. The 2006 Adult Literacy and Life Skills Survey found that only 25 per cent of this group had achieved a level of individual health literacy described as adequate or better, compared with 44 per cent of people whose first spoken language was English.⁸⁸

Internationally, cultural literacy – the ability to understand and use culture and social identity to interpret and act on information – is referred to as a component of health literacy.³¹ Language and culture affect the way that people make meaning out of their experiences, and influence their moral and emotional responses to physical and psychological conditions.⁹⁴ This can lead to differing cultural expectations and understanding of health-related issues.

Box 6 - continued

Gender

The 2006 Adult Literacy and Life Skills Survey found that men and women had similar levels of individual health literacy overall, with 40 per cent and 41 per cent, respectively, achieving adequate or higher levels of individual health literacy. There were minor interactions between gender and age: slightly more younger men (15–44 years) than younger women, and slightly more older women (45 years and older) than older men had achieved an adequate or higher level of health literacy.¹ Despite these similarities, it has been suggested that gender is an important factor within this area. Men and women have different focuses, motivations and roles when it comes to health, and therefore different strategies may be needed to address health literacy.^{6,95-97}

Aboriginal and Torres Strait Islander peoples

There is no national data on the individual health literacy of Aboriginal and Torres Strait Islander peoples. However, education attainment and school-based literacy and numeracy scores for Indigenous peoples are significantly lower than for the general population.^{98,99} In addition, compared with non-Indigenous Australians, Indigenous peoples experience disadvantage across a range of socio-economic indicators, including education, employment and income.¹⁰⁰ It is therefore highly likely that Indigenous peoples may be at risk of lower individual health literacy.

Key to addressing health literacy within Aboriginal and Torres Strait Islander communities is ensuring that strategies to address literacy and health literacy build on Indigenous understandings and perspectives,¹⁰¹ including language and worldview.¹⁰² This includes looking at how information is communicated within the community. For example, in small, close-knit communities where information and experiences are shared and used to guide decisions among community members, the health literacy skills of the community can be an important influence on health behaviour. Concepts such as cultural competence, family and community-centred care, and using models of healthcare delivery that employ individuals who are trusted by the community are central to addressing health literacy within these contexts.

5 Where does health literacy fit in? continued

5.4 Related concepts

Health literacy does not stand alone; it is linked with a number of other health and healthcare concepts. Consistent themes across all of these concepts include the involvement of consumers in decision-making, healthcare providers being aware of the needs and preferences of individual consumers, and healthcare providers and the health system taking action to address these needs. These concepts tend to overlap and are often interdependent.

Key concepts are as follows.

General literacy

Health literacy is one of a range of different 'literacies' referred to in health and education. Others include cultural literacy, technology literacy, media literacy and scientific literacy.¹⁰³ A number of subject-specific literacies are also referred to in health, such as oral health literacy, nutrition literacy and mental health literacy. All of these literacies require the acquisition of different skills, abilities and knowledge, but they all build on the foundation of, and are closely related to, general literacy.

In Australia, only 56 per cent of people have the general literacy needed to cope with everyday life and work.¹⁰⁴ This means that around 44 per cent of Australians have low general literacy, compared with 59 per cent of Australians with a low level of individual health literacy.¹

General literacy is an important determinant of health;^{105,106} however, the concept of health literacy was introduced because it was recognised that people need more than general literacy skills to be able to manage some of the complex health and health system issues they face.¹⁰⁷ There is a considerable overlap between general literacy and health literacy, but there are also strong health-specific demands involved in health literacy that are different to those in general literacy.¹⁰⁸

Both low general literacy and low individual health literacy are associated with vulnerability and can lead to inequity in health care.²

Patient-centred approaches to care

Patient-centred care is 'an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients and families'.¹¹ Evidence is building that indicates that patient-centred strategies can lead to improvements in the safety and quality of care, as well as healthcare outcomes.¹¹ Other terms that are used for this concept include consumer-centred care, patient- and family-centred care, and patient-based care.

Patient-centred systems focus on collaboration and partnerships between healthcare providers and consumers to make sure that the needs and preferences of consumers are met. Individual health literacy is important to support effective communication, and an effective health literacy environment is required to make it easier for consumers to form partnerships and communicate their needs and preferences.

Patient motivation or activation

Patient activation, or the motivation to act on information about health and health care, closely interacts with health literacy. A consumer can be provided with information in a way that is understandable and that logically leads to a conclusion, but if the consumer is not motivated they may not act on the information or make the decision needed.

This lack of action may be a result of the consumer ceding their right to choose to the healthcare provider – their preference may be not to make the choice. Or it may be that the information and consequences of no action were not communicated effectively. Either way, motivation will influence the transformation of information into action.

Higher levels of activation are associated with a greater likelihood of engaging in preventive health behaviours, actively seeking information on health and health care, and fewer hospital visits.¹⁰⁹

A 2007 study found that higher levels of activation compensated for lower levels of literacy and numeracy. The researchers suggested that making good choices when trade-offs are necessary is related to activation, and that the decisions of consumers not only rely on literacy or comprehension, but also on activation or motivation.¹⁰⁹

Cultural competence

As Australian society has become more diverse, the importance of cultural competence has emerged. Culture is the pattern of a person's behaviour that is shaped by their language, thoughts, customs, beliefs, values and the groups to which a person belongs (which can be racial, social, psychological, religious or ethnic).¹¹⁰

Cultural competence is the capacity to interact with people across different cultures. To be culturally competent requires self-awareness; knowledge of, and a positive attitude towards, cultural practices and differences; and cross-cultural communication skills.^{111,112}

In a multicultural society, it is important that healthcare providers and organisations understand and address cultural barriers to health literacy. Providing culturally competent services and communicating in culturally appropriate ways supports and empowers consumers to engage in their health and health care.

“Both low general literacy and low individual health literacy are associated with vulnerability and can lead to inequity in health care.”

Human rights-based approaches to care

A number of core international statements to which Australia is a signatory include provisions about health and human rights, in particular that it is ‘the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’.¹¹³ The application of this statement is wide ranging, and has been interpreted to include, among other things, social determinants of health, access to education and information, and involvement of the population in health-related decision-making.¹¹⁴

A human rights-based approach supports the notion that people have a right to be provided with information about health and health care that is easy to understand and act on, and that healthcare systems and processes will be designed in a way that supports people to achieve the highest standards of physical and mental health.

Shared decision-making

Shared decision-making is a collaborative process that allows consumers and their healthcare provider to make decisions together, taking into account the best scientific evidence available, as well as the person's values and preferences. Generally, the healthcare provider offers options and describes their risks and benefits. The consumer and their support people discuss these options with the healthcare provider and, taking all information into account, negotiate a care pathway with which they are all comfortable. This process ensures that each person is equipped with a better understanding of the relevant factors and shares responsibility in the decision about how to proceed.¹¹⁵

Shared decision-making relies on individual health literacy, engagement and healthcare providers applying a patient-centred approach to care. Giving consumers information and options about health and health care that are easily understandable provides consumers with a tool that they can use to share decisions and partner in their own care. Consumers can choose to use that tool to the extent that they want to.

5 Where does health literacy fit in? continued

Informed consent

Informed consent is an important part of ethical healthcare delivery. Informed consent is required from a consumer regardless of the treatment – from blood test to organ donation – and reflects a person's right to decide what happens to their own body.¹¹⁶

In addition, obtaining informed consent from a consumer before starting treatment is a legal requirement in Australia, and the law imposes a duty on healthcare providers to:¹¹⁷

- warn of material risks, complications, side effects and other potential outcomes
- discuss alternative options
- discuss the consequences of not proceeding with the intervention.

The National Health and Medical Research Council's *General Guidelines for Medical Practitioners on Providing Information to Patients* provides information on informed consent.¹¹⁸

Informed consent can only be achieved if the consumer is provided with information that is easy to access, understand and act on. Communication of risk is critical to informed consent, effective communication and shared decision-making. A literature review of health literacy in oncology found that patients with low individual health literacy could struggle to comprehend the health education materials and treatment consent forms provided to them, thus impairing their health decision-making.¹¹⁹

PART B

ADDRESSING HEALTH LITERACY IN A COORDINATED WAY

6 Addressing health literacy in a coordinated way

Increasing health literacy has the potential to improve health and the safety and quality of health care.

This can be achieved by supporting and empowering consumers, providing them with greater access to useable health information and improving the capacity of individuals to use and act on this information.²⁰ Achieving these outcomes will require action from governments, healthcare providers and consumers to ensure that there is sustainable change.

In Australia, substantial activity both inside and outside the health system is aimed at addressing health literacy.⁵ This work can fall under the banner of patient-centred practice, health education, cultural competence, health information, beliefs and attitudes of consumers, health promotion and prevention, consumer behaviour and health communication. This work is being done by consumer organisations; local, state, territory and national government organisations; public and private healthcare organisations; clinical and professional groups; insurers; nongovernment organisations; the social sector; universities; industry and others.⁵

6.1 The opportunity

Action is being taken in a variety of settings using a range of different strategies, with many pockets of excellence and innovation contributing to a patchwork of health literacy activity. However, currently the work that is being done is not consistently known and applied across sectors, settings, professions, agencies, and health and healthcare environments. Health literacy work within Australia is disconnected, and consequently opportunities for researchers, healthcare providers, healthcare organisations, consumers and policy makers to learn from each other are hampered. Current systems to support improvements in health literacy at a local, regional, and state and territory level are variable, and are absent nationally.⁵

There is much that can be learned and shared from existing work in the area. Barriers to health literacy can be reduced by learning from and adapting existing systems and processes. In the United States, the development of a national action plan to improve health literacy has been a key driver for coordinated action for improvement (Box 7).

Australia does not yet have an agreed national approach to addressing health literacy. However, the increasing recognition of health literacy as a fundamental part of safety and quality provides an opportunity to agree on strategies to increase individual health literacy and improve the health literacy environment.

Box 7**The United States: A coordinated, national approach to health literacy improvement**

In the United States, federal and state governments, the Institute of Medicine, and professional and other organisations have been looking at ways to address health literacy in a more coordinated and consistent way for some time.^{13,17,120} Action has included legislating the requirement for government documents to be written in plain English,¹²¹ including requirements in accreditation standards about written and oral communication,⁴⁷ and providing toolkits with implementation strategies for addressing health literacy within healthcare organisations.⁶⁵ *The Patient Protection and*

Affordable Care Act (2010) includes a number of provisions relating to health literacy,¹²² and a national policy action plan has also been developed.

The Department of Health and Human Services in the United States developed the *National Action Plan to Improve Health Literacy* in 2010.¹³ The plan provides a framework for consistent action to address health literacy. It proposes coordinated societal action across seven different areas to improve systems, information communication and education. The seven goals in the plan are:

Goal 1:

Develop and disseminate health and safety information that is accurate, accessible and actionable.

Goal 2:

Promote changes in the health care delivery system that improve health information, communication, informed decision-making and access to health services.

Goal 3:

Incorporate accurate, standards-based and developmentally appropriate health and science information and curriculums in child care and education through to university level.

Goal 4:

Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community.

Goal 5:

Build partnerships, develop guidance and change policies.

Goal 6:

Increase basic research and the development, implementation and evaluation of practices and interventions to improve health literacy.

Goal 7:

Increase the dissemination and use of evidence-based health literacy practices and interventions.

6 Addressing health literacy in a coordinated way continued

6.2 Addressing health literacy in a coordinated way in Australia

To address health literacy in a coordinated way in Australia, it is proposed that three types of action are needed. This approach largely focuses on action within and across the health sector. These actions reflect international approaches to addressing health literacy within health care, key points where individual health literacy and the health literacy environment influence outcomes, and evidence about strategies to address health literacy and other related interventions.

A comprehensive and consistent approach to addressing health literacy in Australia requires:

- **Embedding health literacy into systems.** This involves developing and implementing systems and policies at an organisational and societal level that support action to address health literacy. These systems could include altering funding mechanisms to encourage awareness and action on health literacy, implementing policies that prioritise health literacy in program planning, and designing healthcare organisations in a way that makes it easier for people to find their way.
- **Ensuring effective communication.** This involves providing print, electronic or other communication that is appropriate for the needs of consumers. It also involves supporting effective partnerships, communication and interpersonal relationships between consumers, healthcare providers, managers, administrative staff and others.
- **Integrating health literacy into education.** This involves education of consumers and healthcare providers, and could include population health programs, health promotion and education strategies, school health education and social marketing campaigns, as well as formal education and training of healthcare providers.

Sections 7, 8 and 9 provide further information about these three areas of action and strategies that can be used to increase individual health literacy and improve the health literacy environment. A combination of actions from all three areas is needed to ensure coordinated and sustainable change (Figure 2). Actions can be undertaken by consumers, consumer organisations, healthcare providers, healthcare organisations, governments, educators, regulators, peak bodies, researchers and many others (see Section 10).

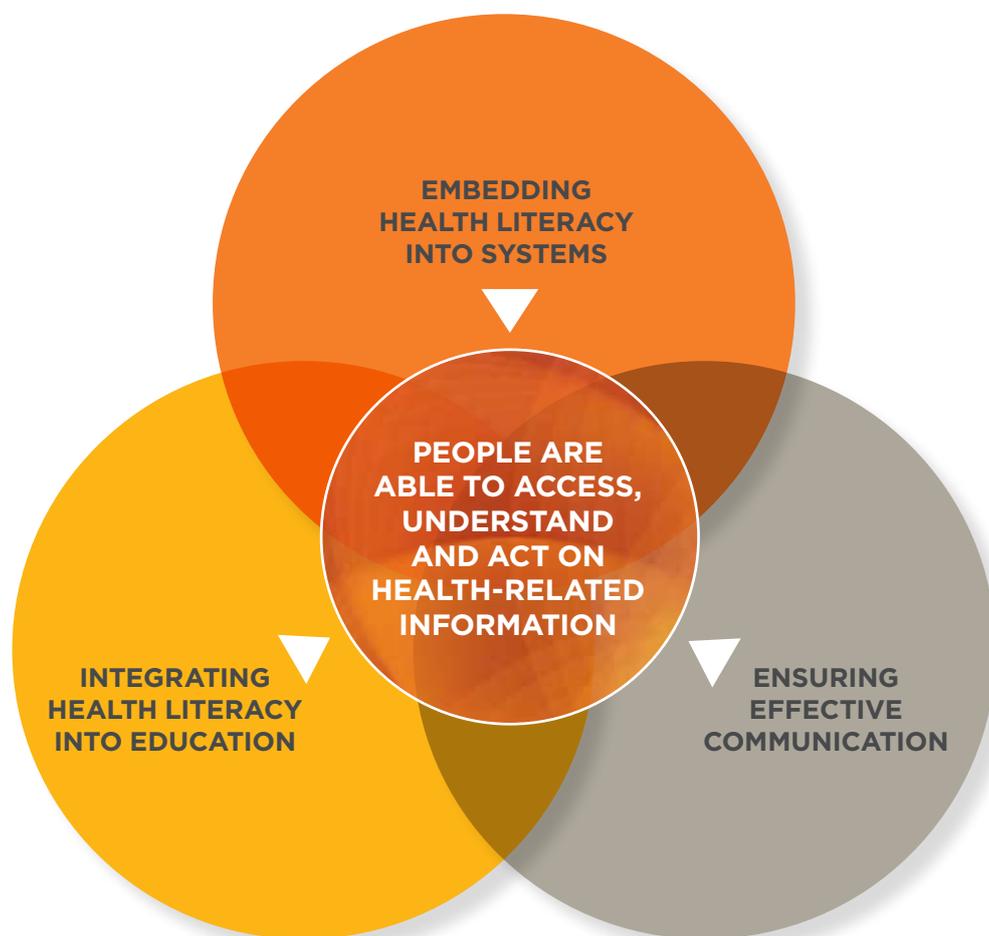


Figure 2 A coordinated approach to health literacy

7 Embedding health literacy in systems

A focus on systems is essential to ensure effective implementation of both large and small-scale change in health care.^{37,73,123-125}

To ensure that strategies to address health literacy are coordinated and sustainable, they need to be embedded in the systems and infrastructure of society, health care and other organisations.^{13,25}

In this context, 'systems' refers to all of the policies, procedures and practices within an organisation that are arranged, integrated and administered to allow the organisation to achieve its purpose. Also relevant here are wider societal systems, such as national, state and territory legislation, processes of government, regulation, policy and programs.

Organisations that have an influence on individual health literacy or the health literacy environment include a diverse mix of consumer, health, education, welfare, public, private, government and nongovernment bodies. These organisations deliver health care, welfare and other social support services; advocate for and support consumers; undertake research; educate the public, consumers and healthcare providers; provide healthcare insurance; and develop policy, legislation, processes and frameworks about the delivery of care, provision of education and other relevant issues. Individuals and organisations in the wider context of society, culture and the media also have an impact on health literacy.

There will be significant variation in how strategies to address health literacy can be embedded in systems. These strategies will be influenced by the role, context and focus of different organisations. Examples of the way in which health literacy can be embedded into high-level systems and organisational policies and practices are discussed in the following sections.

7.1 Embedding health literacy in high-level systems

At a broad societal level, ways in which health literacy could be embedded in systems include:

- legislation, such as the *Plain Writing Act 2010* in the United States, which requires federal agencies to use plain language in government communication, including health information¹²¹
- policies and plans, such as the *Communication and Health Literacy Action Plan* developed by the Tasmanian Department of Health and Human Services (Box 8) and the Illawarra Shoalhaven Local Health District's approach to health literacy (Box 9)
- standards, such as the NSQHS Standards, which include items about the need to provide information to consumers to meet their needs,⁷² and the Royal District Nursing Service's translation standard (Box 10)
- funding mechanisms, such as the funding provided by the Victorian Department of Health to community health services that are high users of language services to provide linguistically appropriate information, care and service delivery to clients from non-English speaking backgrounds⁵
- incentives, such as the component of the Indigenous Health Incentive (part of the Practice Incentive Program) that relates to cultural awareness training and requires two members of the practice (one of whom must be a general practitioner) to complete appropriate cultural awareness training¹²⁶
- curriculums, such as the inclusion of issues relevant to health literacy (including literacy, numeracy and critical thinking) in the draft Australian Curriculum for schools.¹²⁷

Box 8**A policy approach to health literacy**

The Tasmanian Department of Health and Human Services has developed a *Communication and Health Literacy Action Plan* that describes the state government's approach to improving health literacy.⁵

The key principles identified in the plan are:

- people have a right to information: it is the responsibility of government to communicate effectively
- people have a right to be involved in decision-making about their health and wellbeing
- improving health literacy is a shared responsibility, especially across the health and education sectors
- improving communication and health literacy requires small contributions from many people and organisations
- consistency of messages is important, and should be supported by evidence-informed practice.

Through the plan, the department aims to foster:

- healthcare and human services staff skills, resources and capacity to communicate effectively with people who use their services
- a reduction in literacy-related barriers for people accessing their services
- a more health-literate population in Tasmania by working in partnership with the education sector and others.

Beneath these three overarching aims, the department has identified 15 specific initiatives to achieve its objectives.

Web page: www.dhhs.tas.gov.au/about_the_department/your_care_your_say/publications/health_literacy

7 Embedding health literacy in systems

continued

Box 9

A Local Health District's systems approach to health literacy

The Illawarra Shoalhaven Local Health District addresses health literacy through a range of organisation-wide strategies, including:

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

“There has been some concern that translation of information about health and health care is not done consistently and to a high standard.”

Box 10**Developing a translation standard for health information**

Translating information for people for whom English is a second language is a part of addressing health literacy barriers for culturally and linguistically diverse populations. There has been some concern that translation of information about health and health care is not done consistently and to a high standard.

The Royal District Nursing Service has undertaken a project to develop a translation standard as a means of driving improvement in the quality of translation in health care. The standard was released in 2013 and identifies 10 components as necessary to ensure a minimum standard of translation that is of high quality and caters to the health literacy levels of the target audience. These are:¹²⁸

1. Develop the English text and/or test the translation with members of the target languages other than English-speaking (LOTE) communities.
2. Undertake a cultural and linguistic assessment of the English text in preparation for its translation.
3. Undertake a subject matter expert assessment of the English text, as appropriate.
4. Organise for the English text to be translated by an accredited translator.
5. Undertake a cultural and linguistic assessment of the translation.
6. Organise for the translation to be proofread by an accredited translator.
7. Include the title of the text in English on the translation.
8. Include the name of the target language in English, on both the English text and the translation.
9. Distribute the translation in bilingual format (English and LOTE).
10. Date, monitor, evaluate and update the English text and the translation as part of an ongoing review program.¹²⁸

7 Embedding health literacy in systems

continued

Many government policies and programs that are not specifically labelled as being about health literacy nonetheless have the potential to increase the capacity of people to make decisions and take action about health and health care.

Examples include:

- the NSW Aboriginal Health Plan 2013–23, which is founded on consumer-centred principles and supports partnership and participation at all levels of health care
- the Fourth National Mental Health Plan, which is based on principles including respect for, and recognition of, the needs of consumers as they change across their lifespan; it also focuses on recognising the value of diversity and the need for equity
- the Fifth Community Pharmacy Agreement, which has an explicit patient focus and supports consumer-centred medication safety strategies such as medication review
- the National Foundation Skills Strategy for Adults (Box 11).

Box 11

Developing foundation skills in adults

The National Foundation Skills Strategy for Adults was developed by the Council of Australian Governments Standing Council on Tertiary Education, Skills and Employment. The strategy has been informed by the findings from the Australian Bureau of Statistics which identifies that 44 per cent of Australians of working age (15–64 years old) have literacy levels below the level needed to meet the complex demands of work and life in modern economies.¹²⁹ The strategy sets an aspirational target of increasing the literacy level of two-thirds of the working population by 2022 to the level required to meet the complex demands of work and life, and all jurisdictions have committed to working towards this goal.

Web page: www.scotese.natese.gov.au/publications

7.2 Embedding health literacy into organisational policies and processes

For organisations that deliver healthcare services, the Institute of Medicine in the United States has identified 10 attributes of a 'health-literate organisation'. A health-literate organisation is one that makes it easier for people to navigate, understand and use information and services to take care of their health.²⁵ These attributes highlight some of the ways in which health literacy can be embedded into organisational systems (Table 2).^{13,25} Examples of how some organisations have demonstrated some of these organisational attributes can be found in Boxes 12 and 13.

Many of these strategies will also apply to other types of organisations that have a role in addressing health literacy. Information on the types of organisations involved in addressing health literacy can be found in Section 10.

Table 2 Ten attributes of a health-literate organisation²⁵

Attribute	Examples of actions that can be taken by organisations
1. Has leadership that makes health literacy integral to the mission, structure and operations of the healthcare organisation	<ul style="list-style-type: none"> • Assign responsibility to an individual or group for actions to improve the health literacy environment • Design the physical environment to support effective communication and navigation • Make clear and effective communication a priority across all levels of the organisation and all communication channels
2. Integrates health literacy into planning, evaluation measures, patient safety and quality improvement	<ul style="list-style-type: none"> • Audit the health literacy environment (either in the annual audit program of the healthcare organisation or by running a stand-alone audit) • Ensure that safety and quality and other improvement initiatives reflect health literacy principles and are evaluated to ensure that they improve the health literacy environment • Align a focus on health literacy with other organisational priorities such as reducing health disparities and providing patient-centred care
3. Prepares the workforce to be health literate, and monitors progress	<ul style="list-style-type: none"> • Incorporate health literacy into orientation sessions and other types of training for the workforce • Provide training that highlights the importance of health literacy and strategies to reduce barriers for administrative and front-of-house staff, such as receptionists
4. Includes populations served by the organisation in the design, implementation and evaluation of health information and services	<ul style="list-style-type: none"> • Involve consumers in governance processes • Collaborate with members of the target community in the design and testing of interventions, including design of facilities, redesign projects and evaluation

7 Embedding health literacy in systems

continued

Attribute	Examples of actions that can be taken by organisations
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatisation	<ul style="list-style-type: none"> • Adopt an approach to health literacy that does not make assumptions about levels of individual health literacy (the universal precautions approach) • Provide alternatives to written information where possible, and create an environment that does not impose high literacy demands (such as walls and bulletin boards that are not covered with a lot of print information)
6. Uses health literacy strategies in interpersonal communication, and confirms understanding at all points of contact	<ul style="list-style-type: none"> • Foster a culture that emphasises verification of understanding of every communication (both clinical and nonclinical) • Plan for and provide language assistance where needed, and treat communication failures as patient safety issues
7. Provides easy access to health information and services, and navigation assistance	<ul style="list-style-type: none"> • Design healthcare organisations with features that help people find their way • Use easily understood language and symbols on signage • Ensure that information that is available about local resources and services can be understood by consumers with low levels of literacy
8. Designs and distributes print, audiovisual and social media content that is easy to understand and act on	<ul style="list-style-type: none"> • Stock high-quality educational materials that are appropriate for consumers with low health literacy • Choose materials that reflect health literacy principles • Test consumer information publications as part of the development process with the target audience through surveys, focus groups or other engagement strategies
9. Addresses health literacy in high-risk situations, including care transitions and information about medicines	<ul style="list-style-type: none"> • Identify high-risk situations and establish plans to ensure safe communication in areas such as informed consent, referrals, end-of-life care or use of medicines
10. Communicates clearly about what is covered by health plans and what individuals will have to pay for services	<ul style="list-style-type: none"> • Provide easy-to-understand descriptions of health insurance policies, and communicate the out-of-pocket costs for healthcare services before they are delivered

Box 12**Examining the health literacy environment**

The Penola War Memorial Hospital in South Australia has developed the First Impressions Activities project to help identify some of the characteristics of the hospital that help or hinder the ability of a consumer to make their way around.⁵ Three activities are being undertaken to look at first impressions of consumers. Feedback and recommendations from the activities are then being provided to the Director of Nursing, the Leadership Group and the Health Advisory Council for action.

The three activities are:

- Telephone navigation – An observer is asked to look for the hospital phone number in the phone book and online. They are asked to call the main telephone number of the hospital and ask for advice on how to get to the hospital by car. This is repeated at different times of the day and evening to assess different situations. The observer uses the First Impressions Telephone tool to report findings and make recommendations for improvement.
- Web site navigation – An observer is asked to use a search engine to locate the hospital's web site. The observer uses the First Impressions Web Site tool to report findings and make recommendations for improvement.
- Walking interview – This involves a series of stages where an observer is asked to share their impressions about the hospital with a guide as they move through different locations and complete different tasks. The observer is asked to complete tasks such as finding an entrance to the Accident and Emergency department, and to report back on what they have noticed, how they feel and what signs or cues they used to complete the task. The guide uses the Walking Interview tool to report findings and make recommendations for improvement.

Box 13**Improving way-finding in health services**

From 2004 to 2008, Barwon Health undertook a project to develop the Barwon Health Accessible Hospitals Way-Finding Strategy. This project used a multidisciplinary approach to improving the accessibility of the site and involved senior staff from speech pathology, aged care, subacute and inpatient rehabilitation. An audit of the facility and survey of consumers were undertaken, followed by a redesign of the site, follow-up survey and development of the final way-finding strategy. The progressive surveys indicated a significant improvement in consumers' perceptions of the environment over the course of the project.

Web page: www.health.vic.gov.au/subacute/conf-211108/mccallwhite.pdf

8 Ensuring effective communication

Effective communication is a fundamental requirement for safe and high-quality health care.⁴⁷ Communication failures are one of the most commonly cited underlying causes of adverse events⁴⁷ and complaints about the healthcare system.¹³⁰⁻¹³²

The quality and accessibility of information about health and health care and the way in which it is communicated are critically important to health literacy. Health information needs vary between people, and for the same person, depending on their current situation. Providing information that is difficult to understand, overly complex, contains a lot of jargon, is in an inappropriate format or is presented in an inaccessible way creates a barrier to people's understanding of information about health and health care.

These barriers are not created intentionally. The way information about health and health care is developed and delivered is influenced by a range of factors, including organisational needs, culture, traditional practices and expectations, and availability of time, resources and skills. Addressing health literacy in a coordinated and consistent way requires tackling these barriers and improving communication and information about health and health care.

Two specific areas of communication are discussed in this section:

- The provision of clear, focused and useable information about health and health care – the content and format of written and electronic health information needs to be easy to understand for those with low levels of individual health literacy.
- Interpersonal communication – this includes how health information is communicated verbally and nonverbally between two or more people.

8.1 Clear, focused and useable information about health and health care

Information on health and health care is any information that is about health, wellbeing and health care. While primarily provided by healthcare organisations and practitioners, information on health and health care also forms the basis of health promotion campaigns that aim to inform the public about health issues and modify health-related behaviour. Health-related information can also be found in advertising and promotional material for food, exercise, medicines, insurance and other relevant products and services.

Information on health and health care is central to consumers' individual interactions with healthcare systems and processes, and is needed for them to seek out and receive services, manage their own health conditions and make everyday decisions to maintain good health.

Information about health and health care can cover a range of topics, including details of health-promoting behaviours, prevention and management of specific diseases and conditions, treatment options, potential risks and benefits associated with a particular course of action, health services, cost and treatment instructions.

Why do people need clear, focused and useable information about health and health care?

People need clear, focused, useable and evidence-based information about their health and health care to understand:

- how to maintain or improve their health and wellness
- how to access and interact with the health system
- their diagnosis and prognosis
- the processes and likely outcomes of possible tests and treatments
- how to manage their own condition
- how to prevent further illness.

They also need information to make the most of consultations, to learn about available services and sources of help, to obtain reassurance and help for them to cope, and to learn how to identify the 'best' healthcare providers for them.¹³³

Providing understandable and accessible health information to people can improve people's knowledge, understanding and recall about their health and care.^{134,135} It can also increase their feelings of empowerment, improve their ability to cope, increase satisfaction and may help to reduce anxiety in some situations.¹³⁴ These findings apply to health information provided in written materials,¹³⁶ audiotape, videotape and interactive media,¹³⁷⁻¹³⁹ and decision aids.¹⁴⁰

It is important that the information that is provided about health and health care is evidence-based, so that people are provided with options that are likely to achieve the best healthcare outcomes for their situation.

Where do people get information about health and health care?

Information about health and health care is developed and distributed by a range of public and private organisations. For example, information about medicines can be developed by pharmaceutical companies, government departments, pharmacists, healthcare organisations and researchers. It is likely that the purpose of the information provided will be different in each case, which will affect the content and format of the information.

Today, with changes in technology, people expect a large amount of information to be easily available in a format that they understand. People seek out, or are provided with, health information from a variety of sources, such as (Figure 3):

- their social community, including their parents, families, friends, neighbours and work colleagues
- the education system, including preschools, primary and secondary schools, adult education centres and universities
- the health, social and community care systems, including care providers, health organisations, and government and nongovernment care organisations
- private industry, including manufacturers and providers of food, pharmaceuticals, alcohol, exercise products and services
- mass media, including health promotion campaigns, the internet and private companies promoting their health-related products.

8 Ensuring effective communication

continued



Figure 3 Examples of sources of information for consumers about health and health care

Changes in technology and expectations about consumer involvement in health care are leading to an increase in the access and use of health information from digital sources.^{141,142} For example, a 2010 survey in the United States by PriceWaterhouseCoopers found that people use online tools and resources (54 per cent) second only to consulting a physician (75 per cent) when gathering information on treatments and conditions.¹⁴² Box 14 provides an example of health information available on social media.

Box 14**Providing information about health and health care through social media**

NPS Medicinewise provides independent, evidence-based tools and information about medicines, health conditions and medical tests for consumers and healthcare providers. One of the ways NPS Medicinewise communicates this information is through its Facebook page. The page provides access to videos, challenges and key facts in an interactive forum.

Web page: www.facebook.com/npsmedicinewise

What types of communication methods are used?

Health information can be communicated through the following methods:

- printed information – this includes information in written and visual formats such as consent forms, fact sheets, posters, brochures, written instructions and medication information
- electronic information – this includes information in written, oral and visual formats such as web sites, email, television, podcasts, blogs, twitter feeds, apps, DVDs, radio and other resources
- interpersonal communication – this involves exchange of information in a combination of written, oral and visual formats from person to person, such as verbal communication between the consumer and healthcare providers, receptionists and administrative staff within a healthcare service. Interpersonal communication is discussed in Section 8.2.

As well as including appropriate and relevant content, it is important that information about health and health care be provided in the appropriate format. The presentation of the information

should reflect the consumer's communication needs. For example, some people may require information to be interpreted, some people may prefer pictographic information, and some may need information provided in braille or through a relay service.

Providing information in the appropriate format for a person requires an understanding of any physical, psychological, social or emotional circumstances that may affect a person's capacity to access and understand the information in different formats. Box 15 provides an example of how information can be tailored for different communities and consumers.

It is also important to note that people need to be provided with multiple opportunities to access, understand and act on health information. This does not mean providing a deluge of information to the consumer, but rather providing multiple opportunities for the consumer to gain information, ask questions and confirm their understanding of information. This could be done using strategies such as providing information in different formats, scheduling follow-up appointments, providing web links or putting consumers in touch with peer-support groups.

Box 15**Providing information about health and health care that is culturally appropriate**

The Menzies School of Health Research has developed a series of talking posters focused on public health issues. These posters provide health information on coughing, hygiene and smoking in five different Indigenous languages. Information is presented on the poster, with a translation provided in audio form.

Web page: www.menzies.edu.au/page/Resources/Smoking_is_no_good_clean_air_grows_healthy_lungs

8 Ensuring effective communication

continued

What is the problem with information about health and health care?

There is a large amount of information available to consumers about health and health care, including a substantial amount of information online. Sometimes this information can be consistent, sometimes it conflicts, and other times it may appear to conflict because the authors can focus on different aspects of the same issue. A number of studies have found gaps between the health information people need and what is available or provided to them.^{133,143-145}

Health information can be unnecessarily complex.²⁰ There is evidence that the reading level of most health information materials is above the average adult's reading ability.³⁸ Many studies have shown that health information cannot be understood by most of the people for whom it is intended, suggesting that assumptions regarding the recipients' levels of individual health literacy are often incorrect.²⁰

Accessing, understanding and applying health information can be a challenge for many people. For those with low individual health literacy, this challenge is profoundly more difficult.

In addition, information about health and health care varies in quality, content and format. It can be difficult for consumers to clearly understand their options if they are provided with information that is incomplete, conflicting or not evidence-based. The complex way in which information is made available from multiple sources, each with different drivers and motivations, is a barrier for people with low individual health literacy. Having low health literacy will affect a person's capacity to determine the reliability of the information with which they are provided. Box 16 describes one tool that has been developed in the United Kingdom to help people assess the reliability of information they have been given about health and health care.

Box 16

The DISCERN instrument

There is currently a lot of information available on healthcare treatment choices available from a variety of sources, including the internet. Not all of this information is high-quality, and only a small proportion is based on good evidence. Many of the publications available provide inaccurate or confusing advice, and it may be hard to know which information to use and which to discard.

The DISCERN on the Internet Project is a project funded by the National Health Service in England to help people work out how reliable a piece of health information might be. DISCERN is a brief questionnaire which provides consumers with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem. DISCERN can also be used by authors and publishers of information on treatment choices as a guide to the standard that users are entitled to expect.

Web page: www.discern.org.uk/index.php

What approaches have been used to improve the communication of information about health and health care?

The large amount of health information available has resulted in an increase in the number of initiatives designed to improve the quality of this information, and an interest in quality assessment and accreditation schemes for reliable information. In some cases, this issue has been addressed through nationally and internationally coordinated action.

In the United Kingdom, the Information Standard has been established. This is an independent certification scheme for all organisations that provide evidence-based healthcare information for the public.¹⁴⁶ The National Institute for Health and Clinical Excellence also conducts accreditation of guidance and advice development processes.¹⁴⁷

In the United States, the *Plain Writing Act 2010* requires federal agencies to use plain language in government communication, including health information.¹²¹ This has led to an increase in guidance and resources available to aid healthcare organisations to improve the health information that they develop and distribute. Box 17 provides examples of some of these resources.

The International Patient Decision Aid Standards Collaboration has been working on a framework that could be used to support high-quality patient decision aids. Patient decision aids are tools to support the communication of information, particularly with regard to explaining risk and options. The collaboration has developed a checklist and instrument which can provide a preliminary basis for certifying patient decision aids.¹⁴⁸

There is also a range of frameworks and tools that have been developed to help organisations and healthcare providers engage with consumers for health and healthcare improvement, including improvement of communication in health care. Two Australian-developed examples of tools and resources for engaging with consumers and the community can be found in Box 18.

Box 17

Examples of international tools and resources for making health information clear, focused and useable

Over the last 10 years, there has been considerable work internationally to develop tools and resources for healthcare organisations to use in addressing health literacy. The majority of these resources focus on simplifying language and structure to make information more accessible. Examples of these resources include:

- *Health Literacy Universal Precautions Toolkit*⁶⁵ (Agency for Healthcare Research and Quality, United States)
Web page: www.ahrq.gov/legacy/qual/literacy/healthliteracytoolkit.pdf
- *Easy does it! Plain Language and Clear Verbal Communication Training Manual*¹⁴⁹ (Canadian Public Health Association)
Web page: www.cpha.ca/uploads/portals/h-l/easy_does_it_e.pdf
- *Simply put: a Guide for Creating Easy-to-Understand Materials*¹⁵⁰ (Centers for Disease Control and Prevention, United States)
Web page: www.cdc.gov/healthcommunication/ToolsTemplates/Simply_Put_082010.pdf
- *Plain Language*¹⁵¹ (United States Government)
Web page: www.plainlanguage.gov

8 Ensuring effective communication

continued

Box 18

Two examples of Australian toolkits for engaging with consumers and the community

South Australian Guide to Engaging with Consumers and the Community

In 2013, SA Health released the *Guide for Engaging with Consumers and the Community*,¹⁵² which is both a policy guide and a toolkit for healthcare organisations to assist them in engaging with consumers and minimising the barriers to health literacy. Some of the tools included in the document that are relevant for addressing health literacy include:

- **Tool 3:** Tips for communicating clearly
- **Tool 4:** The teach-back method
- **Tool 6:** Encourage questions
- **Tool 7:** Assessing readability
- **Tool 8:** Writing health information.

Web page: www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline_Engaging+with+Consumers+and+Community_Aug2013pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9

Cancer Australia Consumer Involvement Toolkit

In 2012, Cancer Australia launched the *Consumer Involvement Toolkit* web site.¹⁵³ This web site has been developed to provide a range of tools for engaging with consumers at a variety of levels across the health system.

The web site reflects the *National Framework for Consumer Involvement in Cancer Control*, which is aimed at enabling and supporting:

- committed organisations
- capable consumers
- inclusive groups
- shared focus.

The web site includes information about why engaging with consumers is useful and how it can be achieved, and provides a series of tools and supportive resources for chief executive officers and executives, service managers, healthcare providers, researchers, policy makers and consumers.

Web page: <http://consumerinvolvement.canceraustralia.gov.au/>

National Framework for Consumer Involvement in Cancer Control web page: http://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

What strategies can be used to make information about health and health care easier to understand?

Considerable research has been undertaken to identify strategies for reducing the complexity of health information and improving how information is presented. A systematic review examining interventions to mitigate the effects of low health literacy found that comprehension of health information was improved with use of a few simple strategies such as presenting essential information first and by itself, using consistent denominators for presenting risk and benefit information, and adding video to verbal narratives.² The review also noted that there were potential benefits in reducing the reading level of content and using illustrated narratives.²

Involving consumers in the development of health information materials can help to address health literacy needs by ensuring that the information is relevant, readable and understandable.^{134,154} (See Box 19 for an example.) Other strategies which can be effective include personalising written health information¹³⁴ and providing a combination of verbal and written information to reinforce key health messages.¹⁵⁵

Finally, one review found that alternative format resources, such as the internet, audiotapes, virtual health communities and support groups improved health knowledge and resulted in higher user satisfaction.¹⁵⁶ There were also beneficial effects related to self-efficacy, involvement in decision-making and confidence in consultations with healthcare providers. There was also some evidence of beneficial effects on health behaviour, particularly with web-based educational interventions.¹⁵⁶

Box 19

Working with consumers to develop information that is clear, focused and useable

The Centre for Health Communication and Participation, La Trobe University, led a multidisciplinary team in the collaborative development of the *Making Sense of MS Research* web site.

The team worked closely with healthcare providers and people with multiple sclerosis and their family members to explore the best way of presenting evidence about treatment options to people with multiple sclerosis. The material developed for the web site was the culmination of significant discussion and consultation on the issue to ensure that the information provided was accessible and understandable for a wide audience.

Web page:

www.makingsenseofmsresearch.org.au

8 Ensuring effective communication

continued

8.2 Effective interpersonal communication

Interpersonal communication is communication that occurs between two or more people. Interpersonal communication can include interactions between a consumer and a healthcare provider, between different consumers supporting each other, and between families and healthcare providers. There are many other variations to this type of communication; the overall goal is to support greater understanding of health information and empower people to share in healthcare decisions to the extent that they choose.

Interpersonal communication generally falls into three categories: socio-emotional communication, diagnostic communication and problem solving, and the provision of counselling and education.¹⁵⁷ Box 20 contains an example of a communication project based around one aspect of care.

Effective interpersonal communication is based on trust, understanding, empathy and cooperation. A patient-centred approach to interpersonal communication is frequently used for building relationships and improving the quality of care,¹⁵⁸ based on the principles of dignity and respect, sharing information, collaboration and partnerships.¹⁵⁹

Effective interpersonal communication requires healthcare providers to have an understanding of health literacy concepts, including an understanding of the potential to improve the health literacy environment, and the different capacities and capabilities individual consumers can exhibit. This understanding and awareness is needed in order to tailor health information so it is delivered in a manner that is understandable and meets the needs and preferences of each individual consumer. This may require consideration of the person's cultural needs and preferences; physical, social and psychological needs; and any barriers to interpersonal communication. It also needs to acknowledge the lived experience and expertise of the person.

The importance of interpersonal communication in the delivery of safe and high-quality health care is well recognised.¹⁶⁰ Effective communication between consumers and healthcare providers, and within the healthcare team, has been linked to improved consumer health outcomes¹⁶¹ and is closely associated with patient safety.¹⁶² Effective interpersonal communication between consumers and healthcare providers is also one of the most important contributors to consumer engagement, participation and adherence to healthcare plans.¹⁵⁷

Interpersonal communication can also be important in community and education settings. Interpersonal communication is likely to influence people's engagement with broad health messages such as those delivered through school and adult education, peer-support groups and community-based social and physical activity programs.

Box 20

Interpersonal communication about end-of-life care

The Conversation Project is a web-based project that aims to help people talk about their wishes and preferences for their care at the end of life. The project provides information, advice and tools for people to engage with their family and healthcare providers to discuss, and make decisions about, their future care preferences.

The web site includes case studies, templates and a guide for people to help them consider what care they would like, who they should talk to and how to make arrangements to ensure that their wishes are upheld. This project has been developed in the United States, but has applications within the Australian context.

Web page: <http://theconversationproject.org/starter-kit/intro>

What is the problem with interpersonal communication?

Although health information is widely available from a variety of sources, people still tend to rely on healthcare providers for information about their health and health care, and use other sources for supplemental information. People report that they seek information from doctors more than any other source.^{142,163,164} However, many people have difficulty recalling, understanding or applying what their healthcare providers tell them.¹⁶⁵

It has been found that, even immediately after leaving a consultation, people are unable to recall between 40 per cent and 80 per cent of the medical information just given to them by their healthcare provider.^{165,166} A significant amount of information that is recalled can be incorrect.¹⁶⁷ The amount of health information forgotten by people has been shown to be directly related to the amount of information presented, the person's medical knowledge, anxiety level and potentially their age.¹⁶⁸

This failure in recall can indicate ineffective communication. It reflects a potential mismatch between what the healthcare provider thinks they are communicating, what they think the consumer is capable of understanding, and what the consumer is actually understanding and recalling. Healthcare providers' understanding of health literacy and skills in interpersonal communication can contribute to improvements in recall and consumer satisfaction,¹⁵⁷ which can contribute to greater confidence, greater participation and more effective decision-making for patients.

In addition, there is evidence that people want more information than they are given and that healthcare providers tend to overestimate the information they have provided.^{169,170}

What strategies can be used to improve interpersonal communication?

Strategies to improve interpersonal communication are often based on patient-centred principles and approaches. Fostering a patient-centred approach to interpersonal communication has been shown to result in improved communication,¹⁷¹ better health care and better outcomes.^{157,172} It is also associated with increased efficiency of care.¹⁷²

Strategies that can be used by healthcare providers include using appropriate body language, confirming understanding of information provided, listening attentively and prompting for information, providing options relevant to the person's situation and following up about actions to be taken by consumers.¹⁷³

There are also specific communication interventions or tools used to foster discussion, debate, and partnerships and participation by the consumer.¹⁷⁴ These types of interventions include the use of:

- plain language to communicate health information, instructions and choices
- decision aids, which have been shown to lead to improvements in knowledge and understanding of screening, prevention and treatment options,^{134,175} and are often used to clarify the likelihood of risks and benefits of different care options (see Box 21 for an example of a tool to foster shared decision-making)
- shared decision-making processes, which have been seen as the foundation for patient-centred care, and as a means of increasing consumer participation in decision-making. Use of shared decision-making is associated with favourable health outcomes^{176,177}

8 Ensuring effective communication

continued

- educative and recall strategies, including asking people to recount the information given to them by the healthcare provider to check understanding. These kinds of approaches can include the use of the 'teach-back' method, 'ask-tell-ask' and 'teach to goal' techniques (Box 22), among a range of others. A number of these educative strategies have been shown to be effective for people with specific health conditions, demonstrating improved care management, recall and understanding of information.¹⁷⁸

It should also be noted that many of the personal contextual issues identified in Section 5.3 will have an effect on interpersonal communication, such as culture, education, gender and language. These personal contextual issues will influence decisions about effective methods of interpersonal communication. For example, a person whose first language is not English may require an appropriate accredited translator during a consultation with a healthcare provider; or a woman from an Aboriginal or Torres Strait Islander community may need to speak with a female healthcare provider if she wants to talk about women's business.

Box 21

Helping people make decisions about their care

The Ask Share Know Patient-Communication Model¹⁷⁹ is part of a University of Sydney research program designed to encourage and empower people to engage with their healthcare providers and make decisions about their health. The model encourages people to communicate with their healthcare providers by asking three questions:

- What are my options?
- What are the possible benefits and harms of those options?
- How likely are each of those benefits and harms to happen to me?

Web page: www.askshareknow.com.au

Box 22

Educative and recall strategies for working with patients

'**Teach-back**' is a method that healthcare providers can use to confirm that they have explained to patients what they need to know, in a manner that the patient understands. The healthcare provider asks the patient to state in their own words the key points of the discussion.⁴⁷ The cycle continues until the healthcare provider is certain the key messages have been delivered and understood.

'**Ask-tell-ask**' is similar to teach-back in that the healthcare provider asks the patient to describe their current issue, *tells* the patient in simple language the message they need to communicate and then asks the patient if they have understood. This is also a back-and-forth cycle of information and response.

'**Teach to goal**' is an approach based on mastery learning. This approach recognises that, with repetition, most students can achieve mastery. Teach to goal generally involves identifying overall educational objectives and then breaking down the objectives into smaller components or milestones. The learner then incrementally works towards those milestones, while achievement is progressively assessed, and instruction is tailored to help the learner work towards mastery of the overall objectives.¹⁸⁰

9 Integrating health literacy into education

Education is a critical part of promoting and maintaining health,¹⁸¹ and the links between an individual's level of education and health outcomes have long been known.²⁰

Health literacy, general literacy and education are all interrelated. A person's formal and informal education shapes their general literacy, which in turn contributes to their knowledge and skills in understanding health information and systems, and shapes their capacity for making decisions and taking action for their own health and health care.

It is also important that healthcare providers understand individual health literacy and how to develop an effective health literacy environment. This section examines how education for various groups can contribute to addressing health literacy.

9.1 Why provide education to address health literacy?

Formal and informal education are key mechanisms for increasing a person's knowledge and skills. Therefore, integrating health literacy into education and supporting education that builds health literacy skills should form a central part of a consistent and coordinated approach to addressing health literacy. In addition, education is fundamental to any change process. Education helps to provide people with the tools needed to shift to more effective methods of health care, and provides them with the support and impetus to implement new and unfamiliar processes.

There is a range of ways in which educative approaches can be used to address health literacy, including by providing education and training for:

- individual consumers to gain the skills to understand, critically analyse and apply information so that they can gain knowledge of health issues when they require it; for example, teaching general critical analysis skills within the school environment or providing an adult education course to teach consumers how to identify reliable health information on the internet
- individual consumers to improve their knowledge of specific health issues; for example, providing a sexual health course within a school in order to promote safe sex practices, or a community health course on diabetes management
- families and carers to improve their understanding of the health issues the person they are caring for is experiencing and the types of decisions that will need to be made while caring for them; for example, information sessions for families and carers on cancer treatment, end-of-life care or health promotion and prevention
- vocational, undergraduate and postgraduate health sector students to increase their awareness of health literacy and effective communication strategies; for example, providing training to healthcare providers on different communication techniques – such as teach-back – that can be used to check that they have appropriately tailored information for consumers
- other people who work across the health sector to improve their understanding of health literacy, the role it plays in healthcare outcomes and the action they can take to reduce barriers to health literacy; for example, providing information sessions to new staff (including clinical, administrative, management and reception staff) on the importance of health literacy within health care and how to avoid the negative impact associated with overcomplicated and inaccessible information
- healthcare managers to communicate the importance of health literacy to effective and efficient use of health services, and the strategies that can be used at an organisational level to create a health literate environment; for example, information sessions on the impact of co-design projects, information design or the business case for health literacy

9 Integrating health literacy into education continued

- people involved in the planning, design, development, implementation and evaluation of health, education and social services to improve their understanding of health literacy, the impact of health literacy on health and wellbeing and the role that they play in influencing health literacy; for example, continuing professional development, online training modules, workshops or discussions.

9.2 Education and training for consumers about health and health literacy

Education and training for consumers about health and health literacy focuses on building the capacity of the individual to understand, appraise, apply and act on health information.

Education for consumers can be delivered in a formal educative environment, such as through schools, vocational education providers, universities and other training providers. Education can also be delivered in a more informal environment, such as through peer-support groups, at the workplace or in a one-on-one encounter with a healthcare provider.

Education for children

The skills and knowledge needed for effective decision-making about health and health care are influenced from early childhood, when children are first taught hygiene, good eating habits, sun protection and other preventive health messages.

The education system has an important role to play in shaping a person's skills, abilities, capacities and preconceptions about health and health care. From preschool through to primary and secondary schools, children are taught about health and health care as part of the development of life and social skills. They are also taught the fundamental skills and capabilities required to find, understand, appraise, use and apply information generally through literacy and numeracy-based programs. A number of programs have been implemented at a national level to improve general literacy and numeracy, and health literacy (see Box 23 for an example of a program to teach children about health).

Box 23

Educating children about health and health care

Life Education is a nongovernment provider of health education to children through the school environment. The Life Education program was founded amidst the groundswell of health promotion and prevention activities occurring in the 1970s. The program aims to develop children's skills and capacity to become more active health and healthcare consumers by assisting them to:

- acquire age-appropriate knowledge to support informed health choices
- develop and practise skills and strategies to act upon individual decisions
- recognise the values and attitudes that may influence lifestyle choice and behaviour.

Web page: www.lifeeducation.org.au

Education for adults

There are two common ways that health education is often provided to individual consumers. The first method is by providing basic, untailed health information for the consumer. In this case, the consumer does not have to consider options or make decisions, but simply follows instructions. When a person is diagnosed with a condition, they might be provided with an information sheet that tells them how often to take their medication. These are mostly passive interactions with information, rather than communicative and discursive interactions.

The second method involves a combination of providing information while also developing the skills of the individual to independently find information, critically review it and make informed decisions about their health issue or concern. For example, a healthcare organisation may hold an interactive group education or peer-support session for people with diabetes. During the session, the organisation may provide information about different treatment options, lifestyle changes and different mechanisms that might be available to help with self-care. Box 24 provides an example of the development of a tailored communications tool for Aboriginal and Torres Strait Islander peoples.

The former method builds on basic or functional health literacy, whereas the latter looks to build skills for communicative, critical health literacy (see Box 25) and provides a foundation for consumer empowerment.¹⁸¹

This is important in a complex healthcare environment that frequently requires people to have the capacity to critically review health and healthcare information. Consumers are often provided with varied health and healthcare information from many sources, making it difficult to identify the most accurate and relevant information. Effective interactive and critical health literacy can help people to critically review and act on health information and therefore improve decision-making and health outcomes.¹⁸¹

Box 24

Health promotion tools for Aboriginal and Torres Strait Islander peoples

In 2011, the Lowitja Institute funded a study examining health promotion tools for Aboriginal and Torres Strait Islander peoples. The study involved scanning the literature to identify current health promotion tools used for Aboriginal and Torres Strait Islander peoples to identify the gaps and recommend actions and opportunities for developing new tools. The study found that there is growing evidence that health promotions designed and led by the Aboriginal and Torres Strait Islander community can result in improved health in the community.¹⁸²

An example of a tailored health promotion tool comes from St Vincent's Hospital Melbourne and the Menzies School of Health Research. In 2009, these organisations developed a package of health promotion materials on alcohol called the Grog Brain Story. The materials were developed in collaboration with Aboriginal communities and healthcare professionals, and aimed to explain, in language that was familiar to those in Aboriginal communities, how alcohol affects the brain. The package included flip charts and videos, which were translated into a number of Aboriginal languages.

Web page: www.lowitja.org.au

Web page: www.youtube.com/watch?v=2SxTAH3jq0Y and http://resources.menzies.edu.au/download/Grog_brain_story.pdf

9 Integrating health literacy into education

continued

Box 25

Functional, interactive and critical literacy

One of the most common models of literacy – which is often applied to health literacy – identifies three different types:¹⁸¹

Functional literacy: sufficient basic skills in reading and writing to be able to function effectively in everyday situations.

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.

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.

Box 26

Education about local health services

Goulburn Valley Health instituted a pilot program that aimed to provide interactive education and information to migrants and refugees about the local healthcare services and systems. The Hospital Orientation and Health Information Tours for Migrants and Refugees program involved the provision of tours for English language students from the Migrant Education Centre at Goulburn Ovens Institute of Technical and Further Education.

The tour groups were provided with information about different departments within the local hospital, as well as information about how to navigate the hospital, appropriate accredited translation services, guides and other services that were available. The touring groups were also provided with information about different safety and quality issues such as medication safety.⁵

Impact of education for consumers

There is evidence that educative strategies can make an effective contribution to the health and health care of consumers. Targeted educative interventions can help people with low health literacy to increase knowledge and understanding of their condition.² For example, there is evidence that health education and stress management programs can improve health outcomes for people with coronary heart disease.^{183,184} Telephone-based health coaching has been shown to improve health behaviour, self-efficacy and health status, with vulnerable groups showing the most benefit.¹⁸⁵ Box 26 provides an example of education for culturally diverse groups.

Training consumers in critical appraisal and evidence-based medicine has been found to increase knowledge and confidence in healthcare decision-making.¹⁸⁶

Printed and electronic consumer information materials, and educational programs can have a beneficial effect on people's knowledge and understanding of their condition.¹³⁴ Mass media campaigns can result in changes in both knowledge and health-related behaviours across large populations.¹⁸⁷

Programs that focus on improving literacy in schools and school-based health promotion programs can improve children's social and emotional wellbeing.¹³ For example, there is promising evidence that classroom-based education about alcohol may help to reduce alcohol consumption in young people.¹⁸⁸

There has also been some research that indicates that consumer-led self-management education programs may lead to small, short-term improvements in participants' self-efficacy, self-rated health and cognitive symptom management.¹⁸⁹ Box 27 provides an example of peer support for people with breast cancer.

Box 27

Peer support for people with breast cancer

The Breast Cancer Network Australia auspices a number of peer-support services, including online networks, links to local peer-support groups and personal stories from people who have experienced breast cancer. Peer support helps people to cope with illness such as cancer by providing emotional support and decreasing social isolation.^{190,191}

For those experiencing serious and/or chronic illness, linking with people who are experiencing similar health journeys and engaging with peer-support groups can help to improve quality of life.¹⁹²

Web page:

<https://www.bcna.org.au/sharing-support>

9.3 Education and training for healthcare providers about health literacy

There is a growing awareness within the health system that low individual health literacy affects outcomes, and there has been a rapid increase in journal articles, conferences, resources, training manuals and government policies on health literacy over the last few decades.¹⁷ However, a survey of perceptions of health literacy among healthcare providers found that they tended to overestimate their knowledge of health literacy.¹⁹³ The healthcare providers had a general awareness of the issue, but the researchers concluded that there was an opportunity to improve the depth of knowledge about health literacy.¹⁹³

Who should receive training about health literacy?

There are many people involved in the provision of healthcare services and the production and use of health information, and therefore many points at which failures of communication can occur. It is important that healthcare providers are aware of:

- the critical influence that health literacy has on health and health care
- how limited health literacy can influence health outcomes
- their role in contributing to an environment that makes it easier or more difficult for people to navigate, understand and use health services
- effective interpersonal and communication skills
- strategies they can use to ensure they provide information, advice and services that are easy to understand, use and act on
- how to provide, or access, support for people with specific individual health literacy challenges (such as disability, cultural or linguistic diversity, or cognitive impairment).

9 Integrating health literacy into education continued

It is not only the clinical workforce of doctors, nurses and allied health professionals who need to know about health literacy. Members of the nonclinical workforce such as receptionists, porters, ward clerks, volunteers, kitchen staff and cleaners often interact with consumers and have a very important role in creating an environment where it is easier for people to navigate, understand and use health information and services.

The health literacy environment is also influenced by executives, health service managers and other health providers who have a responsibility for education, policy, quality improvement and information technology.

People in all of these roles would benefit from some training in health literacy.

The type, intensity and content of education and training for healthcare providers will depend on the role of the person within the organisation and their level of contact with consumers. For example, simple health literacy awareness training within orientation sessions may be sufficient for administrators; basic communication and health literacy awareness training might be useful for reception staff; and more intensive training about communication and consultation styles might be appropriate for some healthcare providers. Boxes 28 and 29 provide examples of health literacy training for healthcare services.

Box 28

Health literacy toolkit for healthcare providers and organisations

The NSW Clinical Excellence Commission has developed an online Health Literacy Guide for healthcare providers and organisations to reflect on and identify ways of reducing the barriers to health literacy within their organisations.

The toolkit includes information about why health literacy is important, and tools and strategies that can be applied to address specific literacy, numeracy and way-finding issues.

Web page: www.cec.health.nsw.gov.au/hlg

“The type, intensity and content of education and training for healthcare providers will depend on the role of the person within the organisation and their level of contact with consumers.”

Box 29**Health literacy training by the Centre for Culture Ethnicity and Health**

The Centre for Culture Ethnicity and Health (CEH) developed a training course in health literacy to build the capacity of healthcare providers within the Victorian community health sector to reduce barriers to health literacy within their services. The CEH commenced a pilot training course in 2013 comprising four separate modules delivered throughout 2013. Each module focused on a different aspect of health literacy, including health literacy theory, organisation-wide aspects of health literacy, training the trainer and preparing health literacy champions.

The classroom-based training was supported by a practical project where participants had to implement a relevant health literacy-based activity within their organisation based on the principles and approaches that were taught in the program.

Web page:

www.ceh.org.au/training/topics

Box 30**The health workforce**

Around 1.3 million Australians work in health-related occupations.¹⁹⁴ In 2011, there were 70 200 doctors and 257 200 nurses working in Australia. Around 7 per cent (18 000) of the nurses were enrolled and mothercraft nurses, and 5 per cent (13 000) were midwives.¹⁹⁵

In addition, a recent survey of the aged-care workforce noted that more than 240 000 people are employed in direct care roles in the aged-care sector. The proportion of the direct care workforce that was born overseas is around 35 per cent for residential facilities and 28 per cent for community outlets. Around 80 per cent of residential facilities and 50 per cent of community outlets employed personal care assistants and community care workers who spoke a language other than English.¹⁹⁶

It is worth noting that a significant proportion of people working in the health sector are either trained through vocational education and training providers or have no post-school qualifications. In addition, there is an increasing number of people who work in the health sector who are educated overseas. Box 30 provides information about some of the different types of occupations within the health sector. Consequently, it is important that secondary school education and vocational education and training for health sector workers include information about the importance of health literacy and the link to healthcare outcomes, as well as building the skills and capacity of the future health sector workers in their own health literacy.

Impact of education for healthcare providers

Training for healthcare providers in health literacy has been associated with improved counselling and communication skills,¹⁵⁷ and increased use of evidence-based strategies by healthcare providers to address health literacy.¹⁹⁷ Interventions that involved health literacy training for healthcare providers were associated with increased cancer screening rates and increased ratings of satisfaction from consumers.²⁵

9 Integrating health literacy into education

continued

9.4 Education and training to improve communication

Effective communication between consumers and healthcare providers has been linked to increased consumer satisfaction, recall of information and compliance with treatment regimens.¹⁵⁷ It has also been suggested that improving the communication skills of healthcare providers results in better health and outcomes for consumers.¹⁵⁷

To build interpersonal relationships and provide effective communication, both consumers and healthcare providers need to know what messages should be communicated and have the skills to communicate effectively.¹⁵⁷ Many education strategies aimed at improving communication require healthcare providers to adopt new practices or adapt their current practice to more effective patient-centred communication styles. Others rely on the use of communication tools such as decision aids and shared decision-making processes with consumers.

It is important that information should be tailored to consider the needs, preferences and context of the individual consumer or consumer group that is the audience (see Section 8). This may require additional training such as cultural competence training, and training about the services and systems that are available to support people with additional needs (such as accredited translators, relay services and materials for people with a vision impairment). (See Box 31 for an example of training about cross-cultural communication skills.)

Box 31

Cross-cultural communication training for reception staff

The Centre for Culture, Ethnicity and Health provides a training course about cross-cultural communication for reception and service staff. The course provides skill development for frontline staff in effective interpersonal communication techniques and strategies, with a particular emphasis on communicating effectively with people who do not speak English or who have a low level of English proficiency.

Web page:

www.ceh.org.au/training/topics

General communication skills training and communication interventions for healthcare providers can improve their communication skills,^{171,198} increase consumer knowledge when focused on specific topics such as medications,¹⁹⁹ and increase consumers' satisfaction with the quality of their health care.²⁰⁰ Box 32 provides examples of the communication education built into medical education. However, it is also known that healthcare providers often underuse best-practice communication strategies, and that these types of interventions can be hard to sustain and may not be effective when used alone.^{25,201}

Some education and training interventions have focused on consumers and tried to improve their communication with healthcare providers, particularly doctors.²⁰² These interventions have most frequently used written booklets or checklists, as well as videos, coaching and workshops. These types of interventions have been associated with improvements in the perceptions of the consumers regarding control over their health, preferences for an active role in health care, recall of information, adherence to recommendations, attendance, and clinical outcomes.²⁰² It has been suggested that focusing on education of consumers and changing consumer behaviour may be more effective in driving more sustained change in interpersonal relationships.²⁰¹

Box 32**Examples of requirements for communication and health literacy in medical education**

Much communication training already occurs at the undergraduate and postgraduate level for a number of healthcare providers. Many professional organisations, colleges, universities, vocational education and other training providers currently develop and deliver education, standards and professional development relevant to communication, health literacy and interpersonal relationships.

For example, the Australian Medical Council's *Standards for Assessment and Accreditation of Primary Medical Programs by the Australian Medical Council 2012*,²⁰³ the Royal Australian College of General Practitioners' *Standards for General Practice* (Fourth Edition),²⁰⁴ the Royal Australian and New Zealand College of Ophthalmologists' *Social and Professional Responsibilities Curriculum Standard*²⁰⁵ and the Pharmaceutical Society of Australia's *Professional Practice Standards* (Version Four)²⁰⁶ include requirements for communicating and building relationships with consumers. However, not all health and social professions have the same level of support and infrastructure for education, standards and professional development in these areas.

10 Who has a role in addressing health literacy in Australia?

Everyone can play a part in addressing health literacy.

To address it in a coordinated way requires health literacy principles to be embedded into systems and integrated into education. Health information needs to be clear, focused and useable, and there needs to be effective communication between individuals. Many actions can be taken by a wide range of individuals, groups and organisations to achieve these aims (Table 3).

Table 3 Examples of individuals and organisations that have a role in addressing health literacy

Role	Examples of types of organisations and individuals
Consumers	Advocates, carers, consumers, families, friends, patients, support people
Consumer organisations and other support services	Consumer/volunteer/peer support/community organisations, groups or networks, family and women's resource centres, nongovernment organisations, migrant support services, welfare services, workplaces
Healthcare providers	Aboriginal and Torres Strait Islander health workers, aged-care workers, allied health professionals, ambulance officers and paramedics, complementary medicine practitioners, medical practitioners, mental health workers, nurses, people working in health administration, pharmacists, specialists
Organisations that provide or support healthcare services at a local level	Aged-care services, allied health services and practices, community healthcare services, community pharmacies, day procedure surgeries, general practices, home nursing services, local hospital networks, primary healthcare organisations, mental health services, primary healthcare services, public and private hospitals, school nursing services, specialists' rooms, residential aged-care services
Organisations that support healthcare providers and workers	Councils, professional bodies, unions, workforce associations and societies
Government organisations, regulators and bodies that advise on or set health and education policy	Australian, state and territory, and local government health, education, infrastructure and welfare organisations and agencies, colleges, professional bodies

Role	Examples of types of organisations and individuals
Private organisations which provide health-based goods and services	Accreditation agencies, exercise and fitness organisations, food and alcohol manufacturers and distributors, media outlets, pharmaceutical and medicines organisations, private health insurers, private information development companies, professional indemnity and medical protection insurers, web and online information development providers
Education and training organisations	Colleges, private training organisations, public and private schools, registered training providers, technical and further education organisations, universities and other research groups, workplace training providers

The following sections include examples of the types of actions that organisations and individuals in these categories can take to address health literacy. The examples provided are indicative of the types of actions that could be taken and are not intended to be exhaustive.

10.1 Consumers

Role	Examples of types of organisations and individuals
Consumers	Advocates, carers, consumers, families, friends, patients and support people

Different types of consumers will have different roles within the health system. The type of actions they take and the skills and information that are needed will vary depending on these roles. The main roles are:

- a person who is not currently seeking or receiving health care, but is making decisions and taking action about their own health and that of their family in their everyday life (such as through decisions about food purchases or exercise)
- a person who is seeking or receiving health care, and making decisions and taking action about their own health care (see Box 33 for a sample scenario)
- a person who is supporting a loved one to seek or receive health care, and making decisions and taking action about that person's health care
- a person who is acting in a shared role with other consumers and possibly healthcare providers (such as on a board or committee), and making decisions and taking action about issues such as healthcare provision, planning and evaluation.

Health literacy is relevant for consumers in all of these roles. Individual health literacy enables individuals to make informed decisions about their own care and empowers consumers to work within groups to engage in decision-making processes across all levels of the healthcare system. The strategies that can be used to facilitate effective decision-making and appropriate action will vary depending on the specific role of the consumer.

10 Who has a role in addressing health literacy in Australia? continued

Consumers vary considerably in terms of their expectations, preferences and needs. Some people prefer working with a more collaborative style, whereas others prefer clear, simple recommendations that are more directive.²⁰⁷ It is important to note that consumers' personal preferences will inform the extent to which they wish to partner with their healthcare provider and share decisions and responsibility in the management of their care.

Consumers can:

- discuss any difficulties they might have in understanding health and information with healthcare providers
- discuss difficulties in communicating with healthcare providers, ask family to help, or request support services such as qualified interpreters or consumer advocates²⁰⁸
- ask for further information about any aspect of their care²⁰⁸
- be open and honest with staff and provide details of medical history and medication that they are taking²⁰⁸
- improve their individual knowledge and skills by participating in education
- raise awareness in their community about the importance of health literacy
- be involved in the development and review of consumer information and resources
- be involved in the planning, design and delivery of policies, strategies and projects to reduce barriers to health literacy.

Box 33

Scenario: How a consumer can get more information

Shelly has recently been diagnosed with type 2 diabetes by her general practitioner (GP). At the first appointment after the test results have been received, the GP talks to Shelly about type 2 diabetes, providing her with information about the disease, risk factors, treatment options and potential lifestyle modifications. The GP also provides her with some pamphlets about the disease. Shelly has difficulty understanding the information that is provided to her. She feels overwhelmed and confused about the treatment options that the GP has outlined for her, but does not feel able to tell the GP that she does not understand.

Following this appointment, Shelly recognises that she has not understood what the GP has told her, what type 2 diabetes is or what she should be doing to manage it. She talks to her family and friends about her diagnosis and looks up diabetes on the internet.

Shelly is still unsure about what she needs to do, but wants to be sure she is doing the right thing. Shelly decides to ring the surgery and ask them about her diagnosis. After talking with the practice nurse, she is given a number of options to help answer her questions, including a follow-up appointment with the GP, talking to the diabetes educator and talking to someone about a local diabetes peer-support group.

Shelly opts to make an appointment, but also rings the peer-support group contact.

Before the meeting with the GP, Shelly prepares questions to ask to improve her understanding of what type 2 diabetes is, how she can manage the condition and how it will affect her in the short and long term. The focus on the specific questions helps her to understand the information provided, and Shelly and her GP agree to schedule an appointment with the diabetes educator to discuss treatment options and lifestyle modifications. The GP also provides her with other sources she can go to for more information on her condition, including books, web sites and support groups in her area. Shelly also opts to join the local peer-support group.

10.2 Consumer organisations and other support services

Role	Examples of types of organisations and individuals
Consumer organisations and other support services	Consumer/volunteer/peer support/community organisations, groups or networks, family and women's resource centres, nongovernment organisations, migrant support services, welfare services, workplaces

Consumer organisations provide support, advice and services to consumers to help them better understand their health and health care. This includes providing information and education about systems, conditions, processes and practices that consumers will encounter when improving and maintaining their health. In this way, consumer organisations have an important role to play in addressing individual health literacy.

There is also a range of other supportive services and organisations that contribute to addressing health literacy by incorporating health literacy approaches into their existing work.

Some examples include:

- nongovernment organisations that provide training programs for healthcare providers and consumers
- support services that reduce the complexity of the information they provide to consumers
- community groups and services that provide information and advice to consumers on accessing services, lifestyle behaviours and health management
- peer-support groups that provide information and advice to consumers on health, health care and self-management (see Box 34 for an example)
- workplaces that deliver health programs, messages and preventive health programs.

Box 34

Men's Health Peer Education

The Australian Government Department of Veterans' Affairs runs a Men's Health Peer Education program for veterans. Under the program, volunteers are trained to provide health information to the veteran community about lifestyle choices, health behaviour and men's health issues. Health information is provided across a range of settings – for example, giving a talk on a health issue at a local community group or ex-service organisation meeting; setting up or working with 'Men's Sheds'; running a stand at a community expo; or personally chatting to a person, such as with a mate at a barbecue.²⁰⁹

Web page: www.dva.gov.au/HEALTH_AND_WELLBEING/PHYSICAL_HEALTH/MHPE/Pages/mens.aspx

10 Who has a role in addressing health literacy in Australia? continued

10.3 Healthcare providers

Role	Examples of types of organisations and individuals
Healthcare providers	Aboriginal and Torres Strait Islander health workers, aged-care workers, allied health professionals, ambulance officers and paramedics, complementary medicine practitioners, medical practitioners, mental health workers, nurses, community or hospital people working in health administration, pharmacists, specialists

Healthcare providers are one of the main sources of information about health care for consumers. Healthcare providers can significantly influence the health literacy demand that is placed on people through the way they communicate and present information. Healthcare providers can:

- recognise the needs and preferences of individual consumers and tailor their communication style to the person's situation¹⁰
- assume that most people will have difficulty understanding and applying complex health information and concepts
- use a range of interpersonal communication strategies to confirm information has been delivered and received effectively (see Box 35 for a sample scenario)
- encourage people to speak up if they have difficulty understanding the information provided
- use ways of communicating risk information about treatment options to people that are known to be effective
- participate in improvement projects aimed at reducing barriers to health literacy within the healthcare organisation's physical environment
- participate in health literacy education and training, if available.

Box 35

Scenario: How a healthcare provider can confirm that health information is understandable

Dr Flinders, a general practitioner, has recently attended an education program provided by his Medicare Local about health literacy and effective communication. The course has motivated him to implement different methods of communicating with patients in his practice, in an effort to improve their understanding and to empower them to become more involved in decision-making about their care.

The doctor started by implementing the following two changes to communication with patients during a consultation:

Slow down:²¹⁰ speaking slowly to allow more time for people to hear and understand the information being provided.

The 'Ask-Me-3' program:²¹¹ improving communication by encouraging the person to ask the following three questions:

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

10.4 Organisations that provide or support healthcare services at a local level

Role	Examples of types of organisations and individuals
Organisations that provide or support healthcare services at a local level	Aged-care services, allied health services and practices, community healthcare services, community pharmacies, day procedure surgeries, general practices, home nursing services, local hospital networks, Medicare Locals, mental health services, primary healthcare services, public and private hospitals, school nursing services, specialists' rooms, residential aged-care services

Healthcare organisations and support services can take action to address health literacy by developing strategies to simplify the health literacy environment for consumers. Healthcare organisations can:

- develop and implement health literacy policies and processes that aim to reduce the health literacy demands of information materials, the physical environment and local care pathways (see Boxes 36 and 37 for examples)
- provide and support access to health literacy and interpersonal communication training for healthcare providers, including training in communicating risk
- provide education programs for consumers aimed at developing health knowledge and skills.

Box 36

How a healthcare organisation has developed and implemented health literacy policies and processes

ISIS Primary Care is a large primary healthcare organisation with multiple health service sites in Victoria. ISIS Primary Care established the Health Literacy Project to develop and implement a health literacy strategy across the organisation.

The key strategies identified in the project are to:

- develop a health literacy policy for the organisation
- map the health literacy environment of the organisation
- establish a health literacy working group
- develop, conduct and evaluate health literacy training for all staff, including the management team
- develop a health literacy resource kit for staff
- develop a sustainability plan to enable ongoing staff training in health literacy.

The project commenced in 2010, and by mid-2013 80 per cent of staff had attended health literacy training, an organisational health literacy policy had been adopted and consumer information materials had been improved.⁵

10 Who has a role in addressing health literacy in Australia? continued

Box 37

The Optimising Health Literacy (Ophelia) project

From 2012 to 2015, the Victorian Department of Health and Monash University are working together to develop a Health Literacy Response Framework through the Ophelia project. This framework will help healthcare organisations to efficiently recognise, understand and respond to the health literacy needs of members of their community. The aim of this project is to improve health outcomes and reduce inequalities by reducing the barriers to health literacy. The project will be developed and trialled across eight health services in Victoria to determine the usefulness and applicability of this approach in real-world settings.

Web page: www.deakin.edu.au/health/research/phi/OPHELIA.php

10.5 Organisations that support healthcare providers

Role	Examples of types of organisations and individuals
Organisations that support healthcare providers	Councils, unions, professional bodies, workforce associations and societies

Organisations that provide support to healthcare providers are often influencing organisations. Many of these types of organisations develop policies, training modules, frameworks or position statements on key issues for health and healthcare providers, and they influence the priorities for the professional development of healthcare providers. These types of organisations can:

- lead and coordinate action on health literacy within their profession (see Box 38 for an example)
- develop policies and position statements on health literacy
- encourage and support professional development opportunities and influence education programs for healthcare providers in communication, health literacy and patient-centred practice in general
- collaborate across the healthcare sector on health literacy activity, including sharing strategies and lessons learned among professions and sectors.

Box 38

Supportive organisations taking action

The Australian Dental Association (ADA) develops and implements a range of oral health education and health promotion programs including Dental Health Week, mouthguard awareness, and babies and toddlers oral health awareness campaigns. In addition, ADA develops and distributes online materials, tools, brochures, posters and fact sheets such as the *Young Person's Oral Survival Guide* and other information materials for families and schools on key oral health issues.

Web page: www.dentalhealthweek.com.au/downloads/survival_guide_web.pdf

10.6 Government organisations, regulators and bodies that advise on or set health and education policy

Role	Examples of types of organisations and individuals
Government organisations, regulators and bodies that advise on or set health and education policy	Australian, state and territory and local government health, education, infrastructure and welfare organisations and agencies, colleges, professional bodies

Government organisations in general can:

- raise awareness about the issue of health literacy
- embed health literacy principles into health and education policy (see Box 39 for an example)
- work collaboratively across all levels of government to promote coordinated action
- advocate for funding and resource allocation for health literacy initiatives
- implement, evaluate and share information about health literacy programs
- develop partnerships to facilitate the exchange of information about health literacy research and programs between research and practice communities.

Health sector – specific organisations can:

- support the design and delivery of policies, pathways and processes that reduce the complexity involved in navigating the health system, including across sectors and settings
- explore opportunities for including implementation of strategies to address health literacy as a core requirement of healthcare service design and delivery.

Education sector – specific organisations can:

- explore opportunities to incorporate the development of health literacy skills into the school curriculum and vocational training
- maintain a focus on the development of foundation literacy and numeracy skills
- provide professional development about health literacy to educators
- develop partnerships with the health sector and community to work collaboratively on health literacy initiatives.

10 Who has a role in addressing health literacy in Australia? continued

Box 39

Government organisations taking action

The Australian Curriculum, Assessment and Reporting Authority is the independent authority responsible for the development of a national curriculum, a national assessment program and a national data collection and reporting program for all kindergarten to Year 12 students in Australia.⁸⁴

There are many examples within the Australian Curriculum where health literacy and education intersect. Some of these are in the *Australian Curriculum Health and Physical Education: Foundation to Year 10 Draft*, which describes overarching aims related to developing students' knowledge, understanding and skills.²¹²

The following aims are linked to health literacy:²¹²

- Students access, synthesise and evaluate information to take positive action to protect, enhance and advocate for their own and others' health, wellbeing, safety and physical activity across the lifespan.
- Students develop and use personal, interpersonal, behavioural, social and cognitive skills and strategies to promote a sense of personal identity and wellbeing, and to build and maintain positive relationships.
- Students engage in and enjoy regular physical movement-based learning experiences, and understand and appreciate their significance to personal, social, cultural, environmental and health practices and outcomes.
- Students analyse how varied and changing personal and contextual factors shape understanding of, and opportunities for, health and physical activity locally, regionally and globally.

To achieve these aims, the *Australian Curriculum Health and Physical Education: Foundation to Year 10* has two interrelated content streams: 'personal, social and community health' and 'movement and physical activity'. Within the content, there are clear links to the development of health literacy in students; for example, the personal, social and community health stream aims to enable and empower students to 'access and understand health information, and to make health-enhancing decisions'.²¹²

Web page: <http://www.acara.edu.au/default.asp>

10.7 Private organisations that provide health-based goods and services

Role	Examples of types of organisations and individuals
Private organisations which provide health-based goods and services	Accreditation agencies, exercise and fitness organisations, food and alcohol manufacturers and distributors, media outlets, pharmaceutical and medicines organisations, private health insurers, private information development companies, professional indemnity and medical protection insurers, web and online information development providers

Private organisations and industry have a significant role in influencing the health literacy of individuals. Much of the information about health that people receive in the community is through the marketing claims and promotional materials of the health, medicine, food and alcohol industries. In addition, information about health research and treatment advances is often communicated through media outlets or web sites.

In recent years, much work has been done by private health insurers to support consumers to understand and act on health information that can keep them well. Insurers have developed a range of different tools and resources to support health literacy, shared decision-making and patient choice.²¹³⁻²¹⁵

Private organisations and industry can:

- support the dissemination of good-quality, easy-to-understand health information
- raise awareness of health information and services in the community
- develop packaging and product design that simplifies information and makes clear the action to be taken
- involve consumers in testing the usability, accessibility and ease of understanding of products and information about health and health care.

Insurers can:

- develop tools and resources to help their members make health care choices that are right for them (see Box 40 for an example)
- incorporate health literacy, communication and tailoring care to consumers as core requirements of health care that is delivered under contracts and agreements.

Box 40

Private organisations taking action

Medibank Private has established an online hosted health community called Generation Better. The Generation Better web page provides a platform for people to chat about different health activities they are doing to improve their health and wellbeing. The web page includes motivational stories and videos, photos, hints and tips about healthy food, exercise and other health activities. It is aimed at providing a place where people can exchange information and learn about healthy behaviour.

Web page: <http://generationbetter.com.au>

10 Who has a role in addressing health literacy in Australia? continued

10.8 Education and training organisations

Role	Examples of types of organisations and individuals
Education and training organisations	Colleges, private training organisations, public and private schools, registered training providers, technical and further education organisations, universities and other research groups, workplace training providers

Education and training organisations have a role in both developing the health literacy skills of individuals and in developing health literacy knowledge and capacity in healthcare providers. Education and training organisations can:

- develop consumers' health literacy skills through fundamental literacy and numeracy skills in schools and adult education courses
- teach skills in analysing and thinking critically about information in schools and adult education courses
- develop education programs for consumers that specifically address how to navigate the complexity of the healthcare system and develop self-management skills (see Box 41 for an example)
- provide education to healthcare providers at undergraduate and postgraduate level about health literacy and related issues, such as communication skills
- require the inclusion of health literacy and related issues in education and training programs (see Box 42 for an example).

Box 41

How Technical and Further Education South Australia is improving health literacy through foundation skills training

In South Australia, the Certificate I and Certificate II in Education and Skills Development were developed by Technical and Further Education South Australia and are delivered by more than 20 registered training organisations. These certificates contain units that focus on physical and psychological health, alcohol, drug use, medicines and health equipment use, and sexual health. In addition, one unit orients participants to the Australian healthcare system and another unit teaches students about critically reviewing information and making informed decisions.

Web page: www.tafesa.edu.au/tafe-sa-news/2013/03/13/tafe-sa-delivers-on-foundation-skills

Box 42**Education and training organisations taking action**

The Australian Medical Council's *Standards for Assessment and Accreditation of Primary Medical Programs by the Australian Medical Council 2012*²⁰³ includes a number of standards relating to communication, relationship building and sharing decisions with patients. For example, on entry to professional practice, Australian and New Zealand graduates should be able to:

- 2.1 Demonstrate, by listening, sharing and responding, the ability to communicate clearly, sensitively and effectively with patients, their family/carers, doctors and other health professionals.
- 2.8 Elicit patients' questions and their views, concerns and preferences, promote rapport, and ensure patients' full understanding of their problem(s). Involve patients in decision-making and planning their treatment, including communicating risk and benefits of management options.
- 2.9 Provide information to patients, and family/carers, where relevant, to enable them to make a fully informed choice among various diagnostic, therapeutic and management options.
- 3.2 Explain factors that contribute to the health, illness, disease and success of treatment of populations, including issues relating to health inequities and inequalities, diversity of cultural, spiritual and community values, and socio-economic and physical environment factors.
- 3.3 Communicate effectively in wider roles including health advocacy, teaching, assessing and appraising.
- 3.4 Understand and describe the factors that contribute to the health and wellbeing of Aboriginal and Torres Strait Islander peoples and/or Māori, including history, spirituality and relationship to land, diversity of cultures and communities, epidemiology, social and political determinants of health and health experiences. Demonstrate effective and culturally competent communication and care for Aboriginal and Torres Strait Islander peoples and/or Māori.
- 4.2 Demonstrate professional values including commitment to high-quality clinical standards, compassion, empathy and respect for all patients. Demonstrate the qualities of integrity, honesty, leadership and partnership to patients, the profession and society.
- 4.4 Explain the main principles of ethical practice and apply these to learning scenarios in clinical practice. Communicate effectively about ethical issues with patients, family and other healthcare professionals.²⁰³

Web page: www.amc.org.au/images/Accreditation/FINAL-Standards-and-Graduate-Outcome-Statements-20-December-2012.pdf

11 Where should we go now?

The Commission prepared this paper to raise awareness about health literacy and stimulate discussion about actions that can be taken to increase individual health literacy and improve the health literacy environment.

The paper is primarily aimed at policy makers and managers. But it may also be used by consumers, healthcare providers, executives, board members and others to help increase their knowledge about health literacy and inform decision-making about what they, and their organisations, could do to address health literacy.

This section briefly reviews the Commission's proposal for a systematic approach to address health literacy, including components of national action, and the next steps the Commission will be taking in this area.

11.1 A systematic approach

Having consumers who are true partners in the processes of health and health care is necessary for a sustainable and effective healthcare system that provides safe and high-quality care. A core requirement for effective partnerships is health literacy. In order for partnerships to work, everyone involved in the partnership needs to be able to give and receive, interpret and act on information in an effective way. When these conditions exist, there is the potential to not only improve the safety and quality of health care, but also to reduce health disparities and increase equity.

Many people within the healthcare sector are aware of the impact that health literacy can have on health, health care and outcomes, and many people are working in different ways to try to address health literacy within their own environment. However, this work is not always consistent, coordinated or widely disseminated.

The Commission proposes that health literacy needs to be addressed in Australia in a systematic and coordinated way. Coordination, collaboration and a systematic approach can lead to greater improvement, because everyone has an opportunity to share information, collaborate and build on the progress of all.

The Commission is in a position to advocate for and undertake the groundwork needed to foster the type of collaboration that can contribute to a coordinated approach to addressing health literacy within the healthcare sector.

To address health literacy in a coordinated way, the Commission proposes that action needs to be taken across three areas:

1. Embedding health literacy into systems.

This involves developing and implementing systems and policies at an organisational and societal level that support action to address health literacy. These systems could include altering funding mechanisms to encourage awareness and action on health literacy, implementing policies that prioritise health literacy in program planning, and designing healthcare organisations in a way that makes it easier for people to find their way.

2. Ensuring effective communication.

This involves providing print, electronic or other communication that is appropriate for the needs of consumers. It also involves supporting effective partnerships, communication and interpersonal relationships between consumers, healthcare providers, managers, administrative staff and others.

3. Integrating health literacy into education.

This involves educating consumers and healthcare providers and could include population health programs, health promotion and education strategies, school health education and social marketing campaigns, as well as formal education and training of healthcare providers.

Action needs to be taken in each of these areas at national, state and territory, regional and local levels. Action could be taken by organisations and individuals from the health, social, welfare and education sectors.

11.2 National, coordinated and collaborative action

Australia has an opportunity to improve the safety and quality of health care by focusing on health literacy and agreeing on a national approach to health literacy. This paper is a first step along this path. The Commission proposes that national action is needed to:

- raise the profile of health literacy, including raising awareness of the roles and responsibilities of different people and organisations in addressing health literacy
- reach national agreement on where and how action can be taken to address health literacy, including identifying priorities for action and opportunities for collaboration
- integrate health literacy into national, state, territory, professional and other policies, programs, planning and education, including those from health, education, social and welfare sectors
- examine how to best measure individual health literacy and the health literacy environment for the purposes of improvement at a local level
- support healthcare organisations and healthcare providers to improve the health literacy environment, including through the provision of tools, resources, materials and leadership for action
- explore opportunities and encourage cross-government and cross-sectoral approaches to addressing health literacy, including through collaborative partnerships and projects
- examine how the efforts of consumer groups, networks and other nongovernment organisations can be integrated and supported to participate in efforts to address health literacy

11 Where should we go now? continued

- promote research that addresses health literacy in the Australian context and use the results of such research to improve performance, including collaborative partnerships, evaluation of programs and other research.

These actions are long-term strategies that will require discussion, debate and planning with individuals and organisations across health, education, social, welfare and other sectors in society.

11.3 The Commission's next steps

The next phase of the Commission's work on health literacy will reflect its roles and functions. The Commission aims to work on two fronts to address health literacy by supporting and fostering action both nationally and locally. At a national level, the Commission will raise awareness and foster a climate of national action and collaboration on health literacy. At the local level, the Commission will promote and provide resource materials for healthcare organisations to improve their health literacy environment.

The Commission will develop a national statement on health literacy for consideration by Health Ministers. This statement will affirm the importance of health literacy to the healthcare system and society in general, and will act as a basis for prompting national cooperation and collaboration. The Commission will use the statement and this discussion paper as a basis for raising awareness of the issue of health literacy nationally.

To support local action on health literacy, the Commission will develop tailored resources for consumers, healthcare providers, healthcare managers, executives and boards to support understanding and action by different people within the healthcare system. This work will build on the Institute of Medicine's approach to developing health-literate organisations (see Section 7.2) and will use a universal precautions model (see Section 4.2).

The Commission will work with a wide variety of people, organisations and professions to achieve a shared understanding about key strategies for addressing barriers to health literacy within the healthcare environment. This phase of work will focus on ways in which health services can make it easier for people to navigate, access, understand and use health information and services.

Both of these streams of work – focusing on national and local action – link closely with the NSQHS Standards. The Commission will continue to support healthcare organisations in developing their understanding of the NSQHS Standards and how health literacy is integral to them.

Glossary

Carers	People who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, alcohol or other drug issue, or who are frail or aged. ²¹⁶
Commission	The Australian Commission on Safety and Quality in Health Care
Consumer engagement	A process of actively seeking out, supporting, involving and collaborating with consumers for the purposes of care and improvement in services. This improvement can be at an individual level, at the health service delivery level, or at the policy and planning level. Consumer engagement strategies range from processes to inform or disseminate information to formal partnerships with a high level of public involvement and influence.
Consumers	Patients and potential patients, carers and organisations representing consumers' interests. In this document, consumers can also refer to support persons such as family members. ²¹⁷
Critical literacy	More advanced cognitive skills which, together with social skills, can be applied to critically analyse information and use this information to have greater control over life events and situations. ¹⁸¹
Cultural competence	A set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals that enables effective work in cross-cultural situations. 'Culture' refers to integrated patterns of human behaviour that include the language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups. 'Competence' implies having the capacity to function effectively as an individual and an organisation within the context of the cultural beliefs, behaviours and needs presented by consumers and their communities. ¹¹⁰
Decision aids	Tools that help people become involved in decision-making. Decision aids are unbiased and nondirective, and aim to support an informed choice consistent with healthcare values and preferences that may be acted on. They are explicit about choices and encourage consumers to express their preference in clinical situations when there are different options. They are designed to complement, rather than replace, counselling from a health practitioner. ²¹⁸
Functional literacy	Sufficient basic skills in reading and writing to be able to function effectively in everyday situations. ¹⁸¹
Health care	The prevention, treatment and management of illness, and the preservation of mental and physical wellbeing through the services offered by the medical and allied health professions. ¹¹⁷

Glossary continued

Healthcare organisation	An organisation that delivers or supports health care at a local level. They can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, community settings, practices and healthcare providers' rooms.
Healthcare provider	An individual that provides health care. Individual healthcare providers can be doctors, nurses, allied health professionals, nurses' assistants, Aboriginal health workers and other people who provide health care.
Health information	Any information on health, wellbeing or health care. This may include brochures, fact sheets, letters, newsletters, presentations, posters, social media, web sites and videos.
Health literacy	The Commission separates health literacy into two components: individual health literacy and the health literacy environment .
Health literacy environment	The infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way in which people access, understand, appraise and apply health-related information and services. It reflects the demands and complexity of the health system and society at large.
Health-literate organisation	An organisation that makes it easier for people to navigate, understand and use information and services to take care of their health. ²⁵
Health outcomes	The health status of an individual, a group of people or a population that is wholly or partially attributable to an action, agent or circumstance. ⁷²
Health promotion	The process of enabling people to increase control over and improve their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions. ²¹⁹
Individual health literacy	The skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.
Informed consent	A process of communication between a patient and their healthcare provider that results in the patient's agreement to undergo treatment. This communication should ensure the patient understands all the available options and the expected outcomes, such as the success rates and/or side effects for each option.
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. ¹⁸¹

Interpersonal communication	Communication that occurs between two or more people. Effective interpersonal communication is based on trust, understanding, empathy and cooperation. It involves both verbal and nonverbal communication, tailoring of messages to the needs and preferences of the receiver, and the use of reinforcing educative strategies to clarify meaning and intent.
Literacy	The ability to read, write, use written information and write appropriately in a range of contexts. It also involves the integration of speaking, listening, viewing and critical thinking with reading and writing, and includes the cultural knowledge that enables a speaker, writer or reader to recognise and use language that is appropriate to different social situations. ²²⁰
National Safety and Quality Health Service (NSQHS) Standards	Standards developed by the Australian Commission on Safety and Quality in Health Care to protect the public from harm and to improve the quality of health service provision. The NSQHS Standards provide a quality assurance mechanism that tests whether relevant systems are in place to ensure that minimum standards of safety and quality are met, and that there is a quality improvement mechanism that allows health services to realise aspirational or developmental goals. ⁷²
Patient-centred care	The delivery of health care that is responsive to the needs and preferences of patients. Patient-centred care is a dimension of safety and quality. ¹¹
Plain language	Grammatically correct language that includes complete sentence structure and accurate word usage. Plain language does not mean ‘dumbing down’ or ‘talking down’ to the reader. It is clear writing that tells the reader exactly what the reader needs to know without using unnecessary words, jargon or expressions.
Policy	A set of principles that reflect an organisation’s mission and direction. All procedures and protocols are linked to a policy statement. ⁷²
Procedure	The set of instructions to make policies and protocols operational that are specific to an organisation. ⁷²
Protocol	An established set of rules used for the completion of tasks or a set of tasks. ⁷²
Universal precautions principle	A principle that assumes that everyone may be at risk and that specific actions should be taken that minimise risk for everyone when it is unclear which people may be affected. In the case of health literacy universal precautions, healthcare organisations should ensure that systems are in place to promote better understanding for everyone, not just those who are thought to need extra assistance. ⁶⁵

References

1. Australian Bureau of Statistics. *Health Literacy, Australia*. Canberra: Australian Bureau of Statistics, 2008.
2. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, et al. *Health Literacy Interventions and Outcomes: an Updated Systematic Review*. Evidence Report/Technology Assessment No. 199. (Prepared by RTI International–University of North Carolina Evidence-based Practice Center under contract No. 290-2007-10056-I) AHRQ Publication Number 11-E006. Rockville, MD: Agency for Healthcare Research and Quality, 2011.
3. DeWalt D, Berkman N, Sheridan S, Lohr K, Pignone M. Literacy and health outcomes: systematic review of the literature. *Journal of General Internal Medicine* 2004;19:1228–1239.
4. Eichler K, Wieser S, Brügger U. The costs of limited health literacy: a systematic review. *International Journal of Public Health* 2009;54:313–324.
5. Australian Commission on Safety and Quality in Health Care. *Health Literacy Stocktake: Consultation Report*. Sydney: ACSQHC, 2012.
6. Peerson A, Saunders M. Health literacy revisited: What do we mean and why does it matter? *Health Promotion International* 2009;24(3):285–296.
7. Peerson A. *Lay Healing Practices in the Household*. Deakin University, 1998.
8. Nutbeam D, Wise M, Bauman A, Harris E, Leeder S. *Goals and Targets for Australia's Health in the Year 2000 and Beyond*. Canberra: Commonwealth of Australia, 1993.
9. Nutbeam D. Achieving population health goals: perspectives on measurement and implementation from Australia. *Canadian Journal of Public Health* 1999;90(Supplement 1):S43–S46.
10. Australian Safety and Quality Goals for Health Care *Partnering with Consumers: Action Guide*. ACSQHC, 2012. (Accessed 15 March 2013, at <http://www.safetyandquality.gov.au/wp-content/uploads/2012/08/3-Partnering-with-consumers.pdf>)
11. Australian Commission on Safety and Quality in Health Care. *Patient-Centred Care: Improving Safety and Quality Through Partnerships with Patients and Consumers*. Sydney. ACSQHC, 2011.
12. Canadian Council on Learning. *Health Literacy in Canada: Initial Results from the International Adult Literacy and Skills Survey*. Ottawa: Canadian Council on Learning, 2007.
13. US Department of Health and Human Services. *National Action Plan to Improve Health Literacy*. Washington DC: Office of Disease Prevention and Health Promotion, 2010.
14. Sørensen K. *The European Health Literacy Survey*. New York: Maastricht University, 2012.
15. Williams J, Clemens S, Oleinikova K, Tarvin K. *The Skills for Life Survey: a National Needs and Impact Survey of Literacy, Numeracy and ICT Skills*. London: Department for Education and Skills, 2003.
16. Simonds S. Health education as social policy. *Health Education Monograph* 1974;2:1–25.
17. Pleasant A. Health Literacy Around the World: Part 1. *Health Literacy Efforts Outside of the United States*. Tucson: Canyon Ranch Institute [Commissioned by the Institute of Medicine Roundtable on Health Literacy], 2012.
18. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012;12(80).
19. Baker DW. The meaning and the measure of health literacy. *Journal of General Internal Medicine* 2006;21(8):878–883.
20. Institute of Medicine. *Health Literacy: a Prescription to End Confusion*. Washington, DC: The National Academies Press, 2004.
21. Jordan JE, Buchbinder R, Osborne RH. Conceptualising health literacy from the patient perspective. *Patient Education and Counseling* 2010;79(1):36–42.
22. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior* 2007;31(Suppl 1):S19–S26.
23. Nutbeam D. The evolving concept of health literacy. *Social Science & Medicine* 2008;67(12):2072–2078.
24. Rudd RE. Improving Americans' health literacy. *New England Journal of Medicine* 2010;363(24):2283–2285.
25. Brach C, Keller D, Hernandez L, Baur C, Parker R, Dreyer B, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington DC: Institute of Medicine, 2012.
26. Rudd RE, Keller DB. Health literacy: new developments and research. *Journal of Communication in Healthcare* 2009;2(3):240–256.

27. Parker R. Measuring health literacy: Why? So what? Now what? In: Hernandez L, editor. *Measures of Health Literacy: Workshop Summary; Roundtable on Health Literacy*. Washington DC: National Academies Press, 2009:91–98.
28. Brach C, Dreyer B, Schyve P, Hernandez LM, Baur C, Lemerise AJ, et al. *Attributes of a Health Literate Organization*. Washington, DC: Institute of Medicine, 2012.
29. Rudd RE. Needed action in health literacy. *Journal of Health Psychology* 2013;18(8):1004–1010.
30. Groene RO, Rudd RE. Results of a feasibility study to assess the health literacy environment: navigation, written, and oral communication in 10 hospitals in Catalonia, Spain. *Journal of Communication in Healthcare* 2011;2011(4):4.
31. Zarcadoolas C, Pleasant A, Greer D. *Advancing Health Literacy: a Framework for Understanding and Action*. San Francisco: John Wiley and Sons, 2006.
32. World Health Organization. *Health Literacy: the Solid Facts*. Copenhagen: WHO, 2013.
33. Plsek PE, Greenhalgh T. The challenge of complexity in health care. *British Medical Journal* 2001;323:625–628.
34. Bush R, Boyle F, Ostini R, Ozolins I, Brabant M, Soto E, et al. *Advancing Health Literacy through Primary Health Care Systems*. Canberra: Australian Primary Health Care Research Institute, 2010.
35. Berkman N, Sheridan S, Donahue K, Halpern D, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Annals of Internal Medicine* 2011;155(2):97–107.
36. Institute of Medicine. *Crossing the Quality Chasm: a New Health System for the Twenty-first Century*. Washington: National Academies Press, 2001.
37. Kohn L, Corrigan J, Donaldson M. *To Err is Human: Building a Safer Health System*. Washington: Institute of Medicine, 2000.
38. Rudd RE, Moeykens BA, Colton TC. Health and literacy: a review of medical and public health literature. In: Comings JP, Garner B, Smith C, editors. *The Annual Review of Adult Learning and Literacy*. San Francisco: Jossey-Bass, 2000.
39. Rudd RE, Anderson JE, Oppenheimer S, Nath C. Health literacy: an update of medical and public health literature. In: Comings JP, Garner B, Smith C, editors. *Review of Adult Literacy and Learning*. Mahwah, New Jersey: Lawrence Erlbaum Associates, 2007.
40. Paasche-Orlow MK, Taylor HA, Brancati FL. Readability standards for informed-consent forms as compared with actual readability. *New England Journal of Medicine* 2003;348(8):721–726.
41. Williamson JML, Martin AG. Analysis of patient information leaflets provided by a district general hospital by the Flesch and Flesch-Kincaid method. *International Journal of Clinical Practice* 2010;64(13):1824–1831.
42. Roskos SE, Keenum AJ, Newman LM, Wallace LS. Literacy demands and formatting characteristics of opioid contracts in chronic nonmalignant pain management. *Journal of Pain* 2007;8(10):753–758.
43. Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Annals of Oncology* 2011;22:761–772.
44. Wolf MS, Davis TC, Osborn CY, Skripkauskas S, Bennett CL, Makoul G. Literacy, self-efficacy, and HIV medication adherence. *Patient Education and Counseling* 2007;65(2):253–260.
45. Kalichman SC, Ramachandran B, Catz S. Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine* 1999;14(5):267–273.
46. Wolf M, Cooper Bailey S. The role of health literacy in patient safety. In: *Perspectives on Safety*. San Francisco: Agency for Healthcare Research and Quality, 2009.
47. The Joint Commission. *What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety*. Oakbrook Terrace. The Joint Commission, 2007.
48. American Medical Association Foundation. *Health Literacy and Patient Safety: Help Patients Understand. Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment*. AMA Continuing Medical Education Program. Chicago: AMA, 2009.
49. Hernandez L. *Standardizing Medication Labels: Confusing Patients Less*. Workshop Summary. Washington DC. Roundtable on Health Literacy, Board on Population Health and Public Health Practice, Institute of Medicine, 2008.
50. Davis TC, Wolf MS, Bass III PF, Thompson JA, Tilson HH, Neuberger M, et al. Literacy and misunderstanding prescription drug labels. *Annals of Internal Medicine* 2006;145(12):887–894.

References continued

51. Davis TC, Wolf MS, Bass PF, Middlebrooks M, Kennen E, Baker DW, et al. Low literacy impairs comprehension of prescription drug warning labels. *Journal of General Internal Medicine* 2006;21(8):847–851.
52. Diug B, Evans S, Lowthian J, Maxwell E, Dooley M, Street A, et al. The unrecognized psychosocial factors contributing to bleeding risk in warfarin therapy. *Stroke* 2011;42(10):2866–2871.
53. Schillinger D, Wang F, Rodriguez M, Bindman A, Machtinger EL. The importance of establishing regimen concordance in preventing medication errors in anticoagulant care. *Journal of Health Communication* 2006;11(6):555–567.
54. Squiers L, Peinado S, Berkman N, Boudewyns V, McCormack L. The Health Literacy Skills Framework. *Journal of Health Communication: International Perspectives* 2012;17(Suppl3):30–54.
55. Jordan JE, Osborne RH, Buchbinder R. Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. *Journal of Clinical Epidemiology* 2011;64(4):366–379.
56. Murray TS, Clermont Y, Binkley M. International Adult Literacy Survey. *Measuring Adult Literacy and Life Skills: New Frameworks for Assessment*. Ottawa: Statistics Canada, 2005.
57. Institute of Medicine. *Measures of Health Literacy: Workshop Report*. Washington, DC: The National Academies, 2009.
58. Parker R, Baker D, Williams M, Nurss J. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine* 1995;10:537–541.
59. Health Literacy Measurement Tools web page. Agency for Healthcare Research and Quality. (Accessed 16 December 2013, at <http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy/index.html>)
60. Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, et al. Quick assessment of literacy in primary care: the Newest Vital Sign. *Annals of Family Medicine* 2005;3(6):514–522.
61. Jordan JE, Buchbinder R, Briggs AM, Elsworth GR, Busija L, Batterham R, et al. The Health Literacy Management Scale (HeLMS): a measure of an individual's capacity to seek, understand and use health information within the healthcare setting. *Patient Education and Counseling* 2013;91(2):228–235.
62. Osborne R, Batterham R, Elsworth G, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health* 2013;13(1):658.
63. National Assessment of Adult Literacy web page. Institute of Education Sciences. (Accessed 5 November 2013, at <http://nces.ed.gov/naal/>)
64. Rudd R, Anderson J. The Health Literacy Environment of Hospitals and Health Centers. Partners for Action: Making Your Healthcare Facility Literacy Friendly. Boston: Harvard School of Public Health, 2006.
65. DeWalt DA, Callahan LF, Hawk VH, Broucksou KA, Hink A, Rudd R, et al. *Health Literacy Universal Precautions Toolkit*. AHRQ Publication No. 10-0046-EF. Rockville, MD: Agency for Healthcare Research and Quality, 2010.
66. Thomacos N, Zazryn T. Enliven organisational health literacy self-assessment resource. Melbourne: Enliven and School of Primary Health Care, Monash University 2013.
67. National Health and Hospitals Reform Commission. *A Healthier Future for All Australians: Final Report of the National Health and Hospitals Reform Commission*. Canberra: NHHRC, 2009.
68. Australian Government. *National Health Reform: Progress and Delivery*. Canberra: Commonwealth of Australia, 2011.
69. Australian Government Department of Health and Ageing. *Living Longer. Living Better*. Canberra: Commonwealth of Australia, 2012.
70. Australian Government Department of Health and Ageing. Primary Health Care Reform in Australia: *Report to support Australia's First National Primary Health Care Strategy*. Canberra: Commonwealth of Australia, 2009.
71. Australian Government Department of Health and Ageing. *Fourth National Mental Health Plan: an Agenda for Collaborative Government Action in Mental Health 2009–2014*. Canberra: Commonwealth of Australia, 2009.
72. Australian Commission on Safety and Quality in Health Care. *National Safety and Quality Health Service Standards*. Sydney. ACSQHC, 2011.
73. Best A, Greenhalgh T, Lewis S, Saul JE, Carroll S, Bitz J. Large-system transformation in health care: a realist review. *Millbank Quarterly* 2012;90(3):421–456.

74. Australian Safety and Quality Framework for Health Care. Australian Commission on Safety and Quality in Health Care, 2010. (Accessed 13 April 2011, at <http://www.safetyandquality.gov.au/our-work/national-perspectives/australian-safety-and-quality-framework-for-health-care/>)
75. Australian Charter of Healthcare Rights. Commonwealth of Australia, 2008. (Accessed 13 April 2011, at <http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/PriorityProgram-01>)
76. Global School Health Initiative web page. World Health Organization. (Accessed 5 November 2013, at http://www.who.int/school_youth_health/gshi/en/)
77. Australian Health Promoting Schools Association. *A National Framework for Health Promoting Schools (2000–2003)*. Canberra: Australian Government Department of Health and Family Services, 2000.
78. National Assessment Program – Literacy and Numeracy web page. Australian Government Department of Education. (Accessed 5 November 2013, at <http://education.gov.au/national-assessment-program-literacy-and-numeracy-naplan>)
79. National Indigenous English Literacy and Numeracy Strategy. Australian Government Department of Education. (Accessed 5 November 2013, at <http://education.gov.au/national-indigenous-english-literacy-and-numeracy-strategy-transitional-project-assistance>)
80. Improving Literacy and Numeracy Initiative. Australian Government Department of Education. (Accessed 5 November 2013, at <http://education.gov.au/targeted-investment-schools>)
81. KidsMatter. Australian Government Department of Health and Ageing. (Accessed 5 November 2013, at <http://www.kidsmatter.edu.au/>)
82. MindMatters. Australian Government Australian Government Department of Health and Ageing. (Accessed 5 November 2013, at <http://www.mindmatters.edu.au/default.asp>)
83. Stephanie Alexander National Kitchen Garden Program. Australian Government Department of Health and Ageing. (Accessed 5 November 2013, at <http://www.healthyactive.gov.au/internet/healthyactive/publishing.nsf/Content/kitchen-garden>)
84. Australian Curriculum, Assessment and Reporting Authority web page. ACARA. (Accessed 23 April 2013, at www.acara.edu.au)
85. Australian Curriculum, Assessment and Reporting Authority. *Revised Australian Curriculum: Health and Physical Education – Foundation to Year 10*. Canberra: ACARA, 2013.
86. Schillinger D, Keller D. *The Other Side of the Coin: Attributes of a Health Literate Healthcare Organization*. New York: Institute of Medicine Roundtable on Health Literacy, 2011.
87. PricewaterhouseCoopers. *Health Literacy: Implications for Australia*. Melbourne: Medibank Private Limited, 2011.
88. Australian Bureau of Statistics. *Australian Social Trends*. ABS Cat No. 4233.0. Canberra: ABS, 2009.
89. Baker DW, Gazmararian JA, Sudano J, Patterson M. The association between age and health literacy among elderly persons. *The Journals of Gerontology* 2000;55(6):S368–S374.
90. Sudore RL, Yaffe K, Satterfield S, Harris TB, Mehta KM, Simonsick EM, et al. Limited literacy and mortality in the elderly: the health, aging, and body composition study. *Journal of General Internal Medicine* 2006;21(8):806–812.
91. Baker DW, Wolf MS, Feinglass J, Thompson JA, Gazmararian JA, Huang J. Health literacy and mortality among elderly persons. *Archives of Internal Medicine* 2007;167(14):1503.
92. Adams R, Appleton S, Hill C, Dodd M, Findlay C, Wilson D. Risks associated with low functional health literacy in an Australian population. *Medical Journal of Australia* 2010;191(10):530–534.
93. Smith DL. Disparities in patient–physician communication for persons with a disability from the 2006 Medical Expenditure Panel Survey (MEPS). *Disability and Health Journal* 2009;2(4):206–215.
94. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competence and how to fix it. *Public Library of Science* 2006;3(10):e294.
95. Australian Government Department of Health and Ageing. *National Male Health Policy: Building on the Strengths of Australian Males*. Canberra: Commonwealth of Australia, 2010.
96. Australian Government Department of Health and Ageing. *National Women’s Health Policy 2010*. Canberra: Commonwealth of Australia, 2010.

References continued

97. Peerson A, Saunders M. Men's health literacy: advancing evidence and priorities. *Critical Public Health* 2009;19(3-4):441-456.
98. National Aboriginal and Torres Strait Islander Social Survey, 2008. Australian Bureau of Statistics, 2010. (Accessed 15 October 2013, at <http://www.abs.gov.au/AUSSTATS/abs@.nsf/>)
99. Australian Curriculum, Assessment and Reporting Authority. *NAPLAN Achievement in Reading, Persuasive Writing, Language Conventions and Numeracy: National Report for 2012*. Sydney: ACARA, 2012.
100. Australian Bureau of Statistics. *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*. Canberra: ABS, 2010.
101. Smylie J, Williams L, Cooper N. Culture-based literacy and Aboriginal health. *Canadian Journal of Public Health* 2006;97Suppl2:S21-25.
102. Vass A, Mitchell A, Dhurrkay Y. Health literacy and Australian Indigenous peoples: an analysis of the role of language and worldview. *Health Promotion Journal of Australia* 2011;22(1):33-37.
103. Keleher H, Hagger V. Health literacy in primary health care. *Australian Journal of Primary Health* 2007;13(2):24-30.
104. Australian Bureau of Statistics. *Programme for the International Assessment of Adult Competencies, Australia 2011-2012*. Canberra: ABS, 2013.
105. Baker D, Parker R, Williams M, Clark W. Health literacy and the risk of hospital admission. *Journal of General Internal Medicine* 1998;13(12):791-798.
106. Sudore RL, Yaffe K, Satterfield S, Harris TB, Mehta KM, Simonsick EM, et al. Limited literacy and mortality in the elderly: the Health, Aging, and Body Composition Study. *Journal of General Internal Medicine* 2006;21(8):806-812.
107. Kickbusch IS. Health literacy: addressing the health and education divide. *Health Promotion International* 2001;16(3):289-297.
108. Rudd R. Health literacy skills of US adults. *American Journal of Health Behavior* 2007;Sep-Oct(31 Suppl 1):s8-18.
109. Hibbard JH, Peters E, Dixon A, Tusler M. Consumer competencies and the use of comparative quality information: It isn't just about literacy. *Medical Care Research and Review* 2007;64(4):379-394.
110. Cross T, Bazron B, Dennis K, Isaacs M. *Towards a Culturally Competent System of Care: a Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*. Washington: National Institute of Mental Health, Child and Adolescent Service System Program, 1989.
111. Ethnic Communities' Council of Victoria. *Cultural Competence: Guidelines and Protocols*. Melbourne: ECCV, 2006.
112. Victoria University. Review of Current Cultural and Linguistic Diversity and Cultural Competence Reporting Requirements, Minimum Standards and Benchmarks for Victoria Health Services Project: Literature Review. Melbourne: Department of Health Victoria, 2009.
113. International Covenant on Civil and Political Rights. United Nations. (Accessed 5 April 2013, at <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx>)
114. The Right to the Highest Attainable Standard of Health. United Nations, 2000. (Accessed 11 April 2014, at <http://www.unhcr.ch/tbs/doc.nsf/%28symbol%29/E.C.12.2000.4.En?OpenDocument>)
115. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine* 1997;44(5):681-692.
116. Patient Information Forum. *Making the Case for Information: the Evidence for Investing in High Quality Health Information for Patients and the Public*. London: PIF, 2013.
117. Australian Commission on Safety and Quality in Health Care. *Australian Open Disclosure Framework*. Sydney: ACSQHC, 2013.
118. National Health and Medical Research Council. *General Guidelines for Medical Practitioners on Providing Information to Patients*. Canberra: NHMRC, 2004.
119. Koay K, Schofield P, Jefford M. Importance of health literacy in oncology. *Asia-Pacific Journal of Clinical Oncology* 2012;8(1):14-23.
120. Rootman I, Gordon-El-Bihbety D. *A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy*. Ottawa: Public Health Agency of Canada, 2008.

121. Plain Language: It's the Law. Plain Language Action and Information Network. (Accessed 5 March 2013, at <http://www.plainlanguage.gov/plLaw/index.cfm>)
122. Patient Protection and Affordable Care Act. United States, 2010.
123. Nolan TW. Execution of Strategic Improvement Initiatives to Produce System-Level Results. IHI Innovation Series White Paper. Cambridge, Massachusetts: Institute for Healthcare Improvement, 2007.
124. Nelson EC, Batalden PB, Godfrey MM, Lazar JS, editors. *Value by Design: Developing Clinical Microsystems to Achieve Organizational Excellence*. San Francisco: Jossey-Bass, 2011.
125. Grol R, Wensing M, Eccles M. *Improving Patient Care: the Implementation of Change in Clinical Practice*. Edinburgh; New York: Elsevier Butterworth Heinemann, 2005.
126. Medicare Australia. Practice Incentives Program Indigenous Health Incentive: Frequently Asked Questions. Canberra: Australian Government Department of Health and Ageing, 2010.
127. The Australian Curriculum. Australian Curriculum, Assessment and Reporting Authority. (Accessed 19 March 2013, at <http://www.australiancurriculum.edu.au/>)
128. Michael J, Ayles T, Ogrin R. Development of a Translation Standard to support the improvement of health literacy and provide consistent high-quality information. *Australian Health Review* 2013;37(4):547–551.
129. Standing Council on Tertiary Education, Skills and Employment. *National Foundation Skills Strategy for Adults*. Canberra: SCOTese, 2012.
130. NSW Health Care Complaints Commission. *Protecting the Health and Safety of the Public: Annual Report 2011–12*. Sydney: NSW HCCC, 2012.
131. Office of the Health Services Commissioner. *Annual Report 2012*. Melbourne: OHSC, 2012.
132. Health Quality and Complaints Commission. *Positive Change: Annual Report 2011–12*. Brisbane: HQCC, 2012.
133. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: Is the information good enough? *British Medical Journal* 1999;318(7179):318–322.
134. Invest in Engagement – Health Literacy. Picker Institute Europe. (Accessed 23 January 2013, at <http://www.investinengagement.info/HealthLiteracytop>)
135. Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, et al. *Assessing the Quality of Information to Support People in Making Decisions About Their Health and Healthcare*. Picker Institute Europe, 2006.
136. McPherson CJ, Higginson IJ, Hearn J. Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *Journal of Public Health* 2001;23(3):227–234.
137. Luck A, Pearson S, Maddern G, Hewett P. Effects of video information on precolonoscopy anxiety and knowledge: a randomised trial. *Lancet* 1999;354(9195):2032–2035.
138. Santo A, Laizner AM, Shohet L. Exploring the value of audiotapes for health literacy: a systematic review. *Patient Education and Counseling* 2005;58(3):235–243.
139. Scott JT, Entwistle VA, Sowden AJ, Watt I. Giving tape recordings or written summaries of consultations to people with cancer: a systematic review. *Health Expectations* 2001;4(3):162–169.
140. O'Connor A, Bennett C, Stacey D, Barry M, Col N, Eden K, et al. Decision aids for people facing health treatment or screening decisions (Review). *The Cochrane Collaboration* 2009;3.
141. National Health Call Centre Network. *Annual Report: Business Highlights 2011–2012*. Sydney: NHCCN, 2012.
142. PricewaterhouseCoopers. *Top Health Industry Issues of 2011*. New York: PwC, 2010.
143. Waldron N, Brown S, Hewlett S, Elliott B, McHugh N, McCabe C. 'It's more scary not to know': a qualitative study exploring the information needs of patients with systemic lupus erythematosus at the time of diagnosis. *Musculoskeletal Care* 2011;9(4):228–238.
144. O'Connor G, Coates V, O'Neill S. Exploring the information needs of patients with cancer of the rectum. *European Journal of Oncology Nursing* 2010;14(4):271–277.
145. Moumjid N, Charles C, Morelle M, Gafni A, Brémond A, Farsi F, et al. The statutory duty of physicians to inform patients versus unmet patients' information needs: The case of breast cancer in France. *Health Policy* 2009;91(2):162–173.

References continued

146. The Information Standard – Home. The Information Standard. (Accessed 5 March 2013, at <http://www.theinformationstandard.org/>)
147. NICE Accreditation. NHS National Institute for Health and Clinical Excellence, 2013. (Accessed 5 March 2013, at <http://www.nice.org.uk/accreditation>)
148. IPDAS – Resources page. International Patient Decision Aid Collaboration. (Accessed 31 October 2013, at <http://ipdas.ohri.ca/resources.html>)
149. Canadian Public Health Association. *Easy Does It! Plain Language and Clear Verbal Communication Training Manual*. Ottawa: Canadian Public Health Association, 1998.
150. US Department of Health and Human Services. *Simply Put: a Guide for Creating Easy-to-Understand Materials*. Washington DC: Centers for Disease Control and Prevention, 2009.
151. Plain Language. Plain Language Action and Information Network. (Accessed at <http://www.plainlanguage.gov/index.cfm>)
152. SA Health. Guide for Engaging with Consumers and the Community Policy Guideline. Adelaide: SA Health.
153. Consumer Involvement Toolkit web site. Cancer Australia. (Accessed 3 November 2013, at <http://consumerinvolvement.canceraustralia.gov.au/>)
154. Nilsen E, Myrhaug H, Johansen M, Oliver S, Oxman A. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* 2006;3.
155. Johnson A, Sandford J, Tyndall J. Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database of Systematic Reviews* 2003;4.
156. Coulter A, Ellins J. *Patient-Focused Interventions: a Review of the Evidence*. London: The Health Foundation, 2006.
157. de Negri B, DiPrete Brown L, Hernández OR, J, Roter D. Improving interpersonal communication between health care providers and clients. *Quality Assurance Methodology Refinement Series*. Bethesda: USAID, 2009.
158. American Medical Association. *Improving Communication – improving care: how health care organizations can ensure effective, patient-centred communication with people from diverse populations*. In: *An Ethical Force (TM) Program Consensus Report*. Chicago: AMA, 2006.
159. Institute for Patient- and Family-Centered Care. *Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings: How to Get Started*. Bethesda: IPFCC, 2008.
160. Hill S, editor. *The Knowledgeable Patient: Communication and Participation in Health*. Melbourne: Wiley, 2011.
161. Stewart M. Effective physician–patient communication and health outcomes: a review. *Canadian Medical Association Journal* 1995;152:1423–1433.
162. Joint Commission. *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: a Roadmap for Hospitals*. Oakbrook Terrace: Joint Commission, 2010.
163. Ellins J, Coulter A. *How Engaged Are People in Their Health Care? Findings of a National Telephone Survey*. Oxford: Picker Institute Europe and Health Foundation, 2005.
164. Gaglio B, Glasgow RE, Bull SS. Do patient preferences for health information vary by health literacy or numeracy? A qualitative assessment. *Journal of Health Communication* 2012;17(Suppl3):109–121.
165. Ong LM, De Haes JC, Hoos AM, Lammes FB. Doctor–patient communication: a review of the literature. *Social Science & Medicine* 1995;40(7):903–918.
166. Kessels R. Patients' memory for medical information. *Journal of the Royal Society of Medicine* 2003;96(5):219–222.
167. Anderson J, Dodman S, Kopelman M, Fleming A. Patient information recall in a rheumatology clinic. *Rheumatology* 1979;18(1):18–22.
168. Ley P. Memory for medical information. *British Journal of Social and Clinical Psychology* 1979;18(2):245–255.

169. Kinnersley P, Edwards A, Hood K, Cadbury N, Ryan R, Prout H, et al. Interventions before consultations for helping patients address their information needs. *Cochrane Database of Systematic Reviews* 2009; Issue 3 (Art. No.: CD004565).
170. Rosenberg E, Lussier M, Beaudoin C. Lessons for clinicians from physician-patient communication literature. *Archives of Internal Medicine* 1997;6(May/June).
171. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between physicians and patients: a systematic review of the evidence. *Medical Care* 2007;45(4):340–349.
172. Stewart M, Brown J, Donner A, McWhinney I, Oates J, Weston W, et al. The impact of patient-centered care on outcomes. *Journal of Family Practice* 2000;49(9):796–804.
173. Frampton S, Guastello S, Brady C, Hale M, Horowitz S, Bennett Smith S, et al. *The Patient-Centered Care Improvement Guide*. Derby, USA: Planetree Association and Picker Institute, 2008.
174. Coulter A. *Implementing Shared Decision Making in the UK*. London: Health Foundation, 2009.
175. Couët N, Desroches S, Robitaille H, Vaillancourt H, Leblanc A, Turcotte S, et al. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expectations* 2013; early online edition.
176. Lewin S, Skea Z, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews* 2001;4.
177. Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions. *Cochrane Database of Systematic Reviews* 2010;1.
178. Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine* 2003;163(1):83.
179. Ask Share Know. University of Sydney. (Accessed 15 March 2013, at <http://www.askshareknow.com.au/index.html>)
180. Baker DW, DeWalt DA, Schillinger D, Hawk V, Ruo B, Bibbins-Domingo K, et al. 'Teach to goal': Theory and design principles of an intervention to improve heart failure self-management skills of patients with low health literacy. *Journal of Health Communication* 2011;16(Suppl3):73–88.
181. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International* 2000;15(3):259–267.
182. Wise M, Angus S, Harris E, Parker S. *Scoping Study of Health Promotion Tools for Aboriginal and Torres Strait Islander Peoples*. Melbourne: Lowitja Institute, 2012.
183. Dusseldorp E, van Elderen T, Maes S, Meulman J, Kraaij V. A meta-analysis of psychoeducational programs for coronary heart disease patients. *Health Psychology* 1999;18(5):506.
184. Jolly K, Taylor R, Lip GY, Greenfield S, Raftery J, Mant J, et al. The Birmingham Rehabilitation Uptake Maximisation Study (BRUM): home-based compared with hospital-based cardiac rehabilitation in a multi-ethnic population – cost-effectiveness and patient adherence. *Health Technology Assessment* 2007;11(35):1–118.
185. Dennis SM, Harris M, Lloyd J, Powell Davies G, Faruqi N, Zwar N. Do people with existing chronic conditions benefit from telephone coaching? A rapid review. *Australian Health Review* 2013;37(3):381–388.
186. Odierna DH, White J, Forsyth S, Bero LA. Critical appraisal training increases understanding and confidence and enhances the use of evidence in diverse categories of learners. *Health Expectations* 2012; early online version.
187. Wakefield MA, Loken B, Hornik RC. Use of mass media campaigns to change health behaviour. *Lancet*;376(9748):1261–1271.
188. National Institute for Clinical Excellence. Promoting Children's Social and Emotional Wellbeing in Primary Education. London. NICE, 2008.
189. Foster G, Taylor S, Eldridge S, Ramsay J, Griffiths C. Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews* 2009;4 (Art. No.: CD005108).

References continued

190. Dunn J, Steginga SK, Occhipinti S, Wilson K. Evaluation of a peer support program for women with breast cancer — lessons for practitioners. *Journal of Community & Applied Social Psychology* 1999;9(1):13–22.
191. Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling* 2008;70(3):315–337.
192. Tehrani A, Farajzadegan Z, Rajabi F, Zamani A. Belonging to a peer support group enhances the quality of life and adherence rate in patients affected by breast cancer: a non-randomized controlled clinical trial. *Journal of Research in Medical Sciences* 2011;16(5):658–665.
193. Mackert M, Ball J, Lopez N. Health literacy awareness training for healthcare workers: improving knowledge and intentions to use clear communication techniques. *Patient Education and Counseling* 2011;85(3):225–228.
194. Australian Bureau of Statistics. 2013 *Labour Statistics in Brief*. Cat. No. 6104.0. Canberra: ABS, 2013.
195. Doctors and Nurses web page. Australian Bureau of Statistics. (Accessed 20 November 2013, at <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features20April+2013>)
196. King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, et al. *The Aged Care Workforce: Final Report*. Australian Government Department of Health and Ageing, 2012.
197. Schlichting J, Quinn M, Heuer L, Schaefer C, Drum M, Chin M. Provider perceptions of limited health literacy in community health centers. *Patient Education and Counseling* 2007;69(1-3):114–120.
198. Moore P, Wilkinson S, Rivera Mercado S. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database of Systematic Reviews* 2004;2.
199. Stevenson F, Cox K, Britten N, Dundar Y. A systematic review of the research on communication between patients and healthcare professionals about medicines: the consequences for concordance. *Health Expectations* 2004;7:235–245.
200. Nørgaard B, Kofoed P-E, Ohm Kyvik K, Ammentorp J. Communication skills training for health care professionals improves the adult orthopaedic patient's experience of quality of care. *Scandinavian Journal of Caring Sciences* 2012;26(4):698–704.
201. van Dam HA, van der Horst F, van den Borne B, Ryckman R, Crebolder H. Provider–patient interaction in diabetes care: effects on patient self-care and outcomes – a systematic review. *Patient Education and Counseling* 2003;51(1):17–28.
202. Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: a systematic review of intervention studies. *Patient Education and Counseling* 2004;52(1):7–16.
203. Australian Medical Council. *Standards for Assessment and Accreditation of Primary Medical Programs by the Australian Medical Council 2012*. Canberra: AMC, 2012.
204. Royal Australian College of General Practitioners. *Standards for General Practices: 4th Edition*. Melbourne: RACGP, 2013.
205. Royal Australian and New Zealand College of Ophthalmologists. *Social and Professional Responsibilities Curriculum Standard*. RANZCO, 2007.
206. Pharmaceutical Society of Australia. *Professional Practice Standards (Version 4)*. Canberra: PSA, 2010.
207. Schapira L. Communication: What do patients want and need? *Journal of Oncology Practice* 2008;4:249–253.
208. Roles in Realising the Australian Charter of Healthcare Rights. Australian Commission on Safety and Quality in Health Care, 2008. (Accessed 13 March 2013, at <http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Roles-in-Realising-the-Australian-Charter-of-Healthcare-Rights-PDF-1232-KB.pdf>)
209. Men's Health Peer Education Program web page. Department of Veterans' Affairs,. (Accessed 1 November 2013, at http://www.dva.gov.au/health_and_wellbeing/physical_health/mhpe/Pages/mens.aspx)
210. American Medical Association Foundation. *Health Literacy and Patient Safety: Helping Patients Understand – Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment*. Chicago: AMA, 2007.
211. Ask Me 3. National Patient Safety Foundation. (Accessed 14 March 2013, at <http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3/>)

212. Australian Curriculum, Assessment and Reporting Authority. *Australian Curriculum: Health and Physical Education – Foundation to Year 10 Draft for Consultation*. Sydney: ACARA, 2012.
213. Health and Wellness web page. BUPA. (Accessed 1 November 2013, at <http://www.bupa.com.au/health-and-wellness>)
214. My Health Guardian web page. HCF. (Accessed 1 November 2013, at <http://www.hcf.com.au/more-for-members/my-health-guardian/>)
215. Better Health web page. Medibank. (Accessed 1 November 2013, at <http://www.medibank.com.au/better-health/>)
216. Carers Australia web page. Carers Australia. (Accessed 5 November 2013, at <http://www.carersaustralia.com.au/>)
217. Consumer Representatives Program Policy. CHF. (Accessed 5 November 2013, at <https://www.chf.org.au/consumer-representatives-program-policy.php>)
218. Decision Aids web page. University of Sydney. (Accessed at http://sydney.edu.au/medicine/public-health/shdg/resources/decision_aids.php)
219. World Health Organization. *The Bangkok Charter for Health Promotion in a Globalized World*. Bangkok: WHO, 2005.
220. Literacy web page. ACT Government. (Accessed 20 November 2013, at http://www.det.act.gov.au/teaching_and_learning/literacy_and_numeracy/literacy)

Index

- A**
- Aboriginal and Torres Strait Islander peoples
 - culturally appropriate information, 45
 - health literacy, 25
 - health promotion tools, 55
 - NSW Aboriginal Health Plan 2013–23, 38
 - Adult Literacy and Life Skills Survey, 8, 18, 20
 - adults, educating for health literacy, 55–57
 - age as factor influencing health literacy, 24
 - alcohol, 55
 - Ask Share Know Patient-Communication Model, 52
 - ‘ask–tell–ask’ method, 52
 - attributes of health-literate organisations, 39–40
 - audience for health literacy messages, 5
 - Australian Charter of Healthcare Rights, 22
 - Australian Curriculum, Assessment and Reporting Authority, 23, 70
 - Australian Curriculum: Health and Physical Education – Foundation to Year 10*, 23, 70
 - Australian Dental Association, 68
 - Australian levels of health literacy, 8
 - Australian National Framework for Health-Promoting Schools, 22–23
 - Australian Safety and Quality Framework for Health Care, 22
 - Australian Safety and Quality Goals for Health Care, 22
- B**
- Barwon Health Accessible Hospitals Way-finding Strategy, 41
 - Breast Cancer Network Australia, 57
- C**
- Cancer Australia toolkit, 48
 - cancer screening, 13
 - cancer support, 57
 - Centre for Culture, Ethnicity and Health, 59, 60
 - children, educating for health literacy, 54
 - Commission’s role in addressing health literacy, 5
 - communication
 - clear, focused and useable information, 42–43
 - ensuring effectiveness, 32, 33f, 42, 75
 - healthcare providers role, 66
 - improving, 47–49, 51
 - information accessibility and clarity, 13
 - interpersonal communication, 50–52, 60–61, 64, 66
 - patient and healthcare provider, 14, 15
 - problems with, 46, 51
 - reducing complexity, 49
 - sources of information, 43–44
 - types, 45
 - Communication and Health Literacy Action Plan*, 35
 - consultation for this paper, 6
 - Consumer Involvement Toolkit* web site, 48
 - consumer organisations’ role in addressing health literacy, 65
 - consumers
 - benefits of health literacy, 16
 - characteristics affecting health literacy, 9, 11, 23–25
 - demands and burdens of health system, 9
 - educating to improve health literacy, 53, 54–57
 - general literacy, 26
 - importance of health literacy for, 2, 13
 - information comprehension, 46
 - information sources, 43–44
 - information types, 45
 - informed consent, 28
 - interpersonal communication, 50–52, 60–61
 - level of literacy and access to healthcare services, 14
 - and low health literacy, 12
 - measuring health literacy, 18–21
 - motivation, 26–27
 - need for effective information, 43
 - patient-centred care, 26, 51
 - role in addressing health literacy, 63–64
 - self management, 15
 - shared decision-making, 27, 51
 - skills and abilities important for health literacy, 9, 11
 - Conversation Project, 50
 - costs of low health literacy, 12
 - critical literacy, 56
 - cross-cultural communication, 60
 - cultural awareness training, 34, 59, 60
 - cultural competence, 27
 - culturally appropriate information, 45, 56
 - culture as factor influencing health literacy, 24
 - curriculums, national schools, 23, 34, 70

D

- decision aids, 47, 52
- decision-making: consumer and healthcare provider, 27
- Dental Health Week, 68
- disability as factor influencing health literacy, 24
- disadvantaged people, 23
- DISCERN instrument, 46

E

- Easy does it! Plain language and clear verbal communication training manual (Canada)*, 47
 - education
 - addressing health literacy, 53–54
 - for adults, 55–57
 - for children, 54, 57
 - as factor influencing health literacy, 24
 - health literacy benefits, 56–57, 59
 - for healthcare providers, 57–59
 - to improve communication, 60–61
 - integrating health literacy, 32, 33f, 75
 - in schools, 22–23, 34, 70
 - education and training organisations' role in addressing health literacy, 69, 72–73
 - electronic information, 45
 - end-of-life care, 50
 - English as a second language, 37
 - see also entries beginning with 'cultural'*
 - Enliven Organisational Health Literacy Self-Assessment Resource, 20
 - environmental factors influencing health literacy, 9
- ## F
- Fifth Community Pharmacy Agreement, 38
 - First Impressions Activities project, 41
 - Fourth National Mental Health Plan, 38
 - functional literacy, 56
 - funding mechanisms, 34

G

- gender as factor influencing health literacy, 25
- general literacy, 26
- Generation Better web page, 71
- Global Schools Initiative, 22
- glossary, 77–79
- government organisations' role in addressing health literacy, 69–70
- Grog Brain Story, 55
- Guide for Engaging with Consumers and the Community*, 48

H

- health insurers, 71
- health literacy
 - benefits of, 16–17
 - context in health system, 22
 - coordinating improvement to, 3, 30–33, 38, 74–76
 - costs per individual with low literacy, 2, 12
 - definition, 2, 8, 10–11
 - embedding into systems, 32, 33f, 34–41, 75
 - health outcomes, 12–13
 - importance of, 2, 12–17
 - linking to outcomes, 14–15
 - linking with National Safety and Quality Health Service (NSQHS) Standards, 6
 - measuring, 18–21
 - models of literacy, 56
 - next steps, 76
 - organisational attributes, 39–40
 - purpose of this document, 5
 - roles of individuals and organisations, 62–63
 - safety and quality, 14
 - underlying concepts, 8–9
 - see also under education*
- health literacy environment, 10–11
 - Barwon Health Accessible Hospitals Way-finding Strategy, 41
 - definition, 2
 - healthcare services role, 67–68
 - measuring, 20–21
 - Penola War Memorial Hospital, 41
- Health Literacy Guide, 58

Index continued

- Health Literacy Management Scale, 19
 - Health Literacy Project, 67
 - Health Literacy Questionnaire, 19–20
 - Health Literacy Response Framework, 68
 - Health Literacy Universal Precautions Toolkit (United States), 21, 47
 - health outcomes
 - evidence about, 12–13
 - linking literacy to, 14–15
 - health service executives: benefits of health literacy, 17
 - health service workers: educating for health literacy, 53–54, 57–59
 - health workforce, 59
 - healthcare managers: benefits of health literacy, 2, 16
 - healthcare models, 8
 - healthcare organisations
 - role in addressing health literacy, 69
 - tools for measuring health literacy, 18
 - healthcare providers
 - benefits of health literacy, 16
 - education and training, 57–59
 - importance of health literacy for, 2
 - interpersonal communication, 50–52, 60–61
 - role in addressing health literacy, 66
 - shared decision-making, 27
 - tools for measuring health literacy, 18
 - healthcare services' role in addressing health literacy, 67–68
 - HIV medication regimens, 13
 - Hospital Orientation and Health Information Tours for Migrants and Refugees program, 56
 - human rights and health, 27
- I**
- Illawarra Shoalhaven Local Health District, 36
 - Indigenous Health Incentive, 34
 - individual health literacy, 2, 10–11, 23, 63–64
 - industry role in addressing health literacy, 71
 - information see communication
 - Information Standard (United Kingdom), 47
 - informed consent, 28
 - interactive literacy, 56
 - International Patient Decision Aid Standards Collaboration, 47
 - interpersonal communication, 45, 50–52, 60–61, 64, 66
 - ISIS Primary Care, 67
- K**
- KidsMatter, 23
- L**
- legislating to improve health literacy, 34
 - Life Education program, 54
- M**
- Making Sense of MS Research* web site, 49
 - measuring health literacy, 18–21
 - Medibank Private, 71
 - medical education communication standards, 61
 - medication safety, 14, 38
 - Men's Health Peer Education program, 65
 - mental health, 38
 - MindMatters, 23
 - models of health care, 8
 - models of literacy, 56
 - motivation to act on information, 26–27
 - multiple sclerosis, 49
- N**
- National Action Plan to Improve Health Literacy (United States)*, 31
 - national approach to health literacy, 75–76
 - National Assessment of Adult Literacy (United States), 20
 - National Assessment Program – Literacy and Numeracy, 23
 - National Foundation Skills Strategy for Adults, 38
 - National Framework for Consumer Involvement in Cancer Control*, 48
 - National Institute for Health and Clinical Excellence (United Kingdom), 47
 - National Safety and Quality Health Service (NSQHS) Standards, 6, 34, 76
 - Newest Vital Sign, 18, 19
 - next steps for health literacy, 76
 - NPSMedicinewise, 45
 - NSQHS Standards see National Safety and Quality Health Service (NSQHS) Standards
 - NSW Aboriginal Health Plan 2013–23, 38

O

- Ophelia project, 68
- oral health, 68
- organisations: health-literate attributes, 39–40
- organisations supporting healthcare providers: role in addressing health literacy, 68

P

- partnerships between consumers and healthcare providers, 4, 8, 22, 74
- patient-centred care, 26, 51
- patients *see* consumers
- peer support, 57
- Penola War Memorial Hospital, 41
- plain language, 34, 51
- Plain language* (United States), 47
- Plain Writing Act 2010* (United States), 34, 47
- policies, 22, 34, 35–36, 38
- policy makers
 - benefits of health literacy, 17
 - importance of health literacy for, 2
 - tools for measuring health literacy, 18
- printed information, 45
- private organisations' role in addressing health literacy, 71

Q

- quality of information, 47

R

- Rapid Estimate of Adult Literacy in Medicine, 18, 19
- recall of medical information, 51
- references, 80–89
- Royal District Nursing Service, 37

S

- safety and quality, 14, 22
- school curriculums, 23, 34, 70
- schools model for health promotion, 22–23
- shared decision-making, 27, 51
- Simply put: A guide for creating easy-to-understand materials* (United States), 47
- social factors influencing health literacy, 9
- social media, 45

Standards for Assessment and Accreditation of Primary Medical Programs by the Australian Medical Council 2012, 73

Stephanie Alexander Kitchen Garden National Program, 23

- structure of this paper, 6
- submissions for this paper, 6
- systematic approach to health literacy, 74–75
- systems, definition of, 34

T

- 'teach-back' method, 52
- 'teach to goal' method, 52
- Technical and Further Education South Australia, 72
- Test of Functional Health Literacy in Adults, 19
- tools
 - Health Literacy Guide, 58
 - for health promotion, 55
 - for improving communication, 51–52
 - for measuring health literacy, 18–21
 - for understanding information, 46, 47–48
- training *see* education
- translating information, 37

U

- universal precautions approach to health literacy, 21

V

- veterans' health, 65
- vulnerable people, 23

W

- warfarin, 14
- workforce, 59

