

# **Health Literacy: a brief literature review**

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### **Executive summary**

Health literacy is defined as the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine, 2004). Broader definitions focus on a wider range of cognitive and social skills which enable adults to use information to promote good health. This approach sees health literacy as critical to empowerment (Nutbeam 1998). Various measures of functional health literacy and more general levels of adult literacy have been developed. National and international surveys show that around 50% of adults in most major developed countries, including Australia (Australian Adult Literacy Survey 2006) have low health literacy and general literacy, with scores indicating inadequate skills to meet the demands of everyday life. There is a large body of evidence which links low literacy with poorer health outcomes across a wide range of measures (DeWalt et al 2004). Patients with lower health literacy have poorer levels of knowledge and understanding about their condition, are less likely to attend appointments, are less adherent to medication regimens and health behaviour advice, make more medication errors, perform worse at self care activities, have high rates of hospitalisation and cost the health service more. They experience more communication difficulties and have less satisfying medical visits in terms of interpersonal and informational aspects of care. Importantly, they have higher rates of morbidity and mortality for most major diseases. The burden of health literacy is therefore substantial. There is a large body of evidence linking health literacy to poor health outcomes from the US but evidence from other countries (including Australia) is limited. Further research, with a particular emphasis on the development and evaluation of interventions to improve health literacy are now needed.



### **The concept of health literacy**

The term 'literacy' has been applied to a range of contexts including, political, financial, environmental, family, media and health. For example, the term 'computer literacy' is often used to refer to the ability to 'understand concepts, terminology and operations that relate to general computer use... (and) the essential knowledge needed to function independently with a computer. This functionality includes being able to solve and avoid problems, adapt to new situations, keep information organised and communicate effectively with other computer literate people' (Computer Literacy USA). To some extent, the wider application of the word 'literacy' reflects the many societal and technological changes demanding 'new literacy' skills. Within each context, the use of the word 'literacy' refers to the acquisition and application of specialised skills and knowledge in a particular area, and understanding of a certain topic. Thus, what it means to be 'literate' in one context will be different in another. It also means that adults who have good general literacy skills may have difficulties in environments that are unfamiliar or more challenging than everyday life, and require a different set of skills to function in them (Nutbeam 2009). On the other hand, individuals with lower general literacy skills may have developed specific skills and knowledge in order to function in a particular setting. For example, in the context of health care, patients diagnosed with chronic conditions may have developed good *health literacy skills* through regular use of the health care system and learning how to manage their conditions. The next section will focus on the term 'health literacy' (one of the discrete types of 'literacy'), and consider how it has been defined and conceptualised in the literature.

### **Definitions of health literacy**

Interest in the relationship between literacy and health has resulted in the development of the construct of *health literacy*, a term which was first applied in the 1970s (Simonds 1974). Over the last two decades, health literacy research has gained momentum as an important area of inquiry and public health priority, particularly in the United States (US). However, there are ongoing debates over the meaning and definition of the concept. In 1999, the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs of the American Medical Association (AMA) highlighted the importance of patients possessing basic literacy

skills to be able to read and understand health related materials, and defined health literacy as:

*... a constellation of skills, including the ability to perform basic reading and numerical skills required to function in the health care environment (Ad Hoc Committee on Health Literacy, 1999, p.553)*

This notion of health literacy is relatively narrow as it only considers the extent to which patients comprehend printed information provided by a health care professional. This definition has since been broadened by the National Library of Medicine (NLM) in the Institute of Medicine Report (IOM 2004) and the US Department of Health and Health Services: Healthy people 2010 Report (2000), to encompass people outside of the health care environment. The IOM report also separates health literacy into four domains: (1) cultural and conceptual knowledge, (2) speaking and listening skills, (3) reading and writing skills, and (4) numeracy; and is one of the most widely used definitions of health literacy:

*The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (IOM 2004. p.32)*

Both the AMA and NLM definitions of health literacy conceive it as a set of functional skills applied in health care contexts. Some experts however, have argued that health literacy means more than the ability to read information; it extends to a patient's ability to interact with a health professional and exercise greater control over everyday situations. This broader notion of health literacy is reflected in the following definition put forward by the World Health Organisation (WHO) (Nutbeam, 1998):

*Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy*

*means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment (Nutbeam 1998, p.10).*

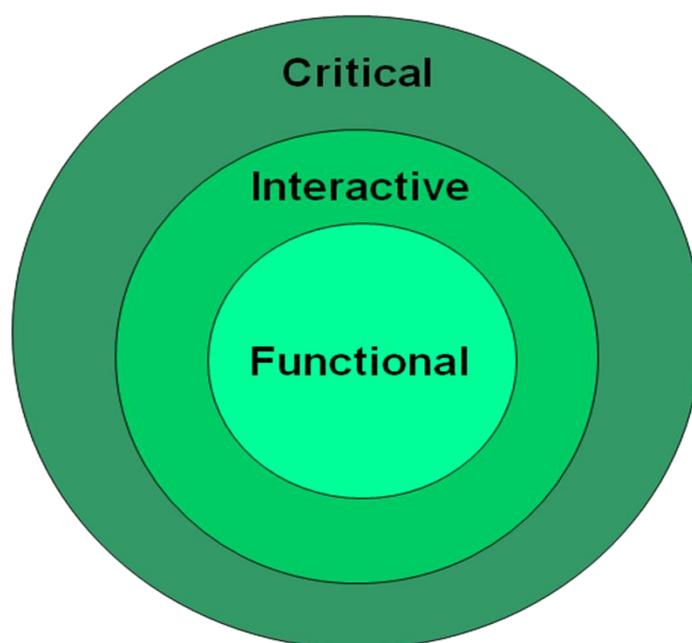
Similarly, Nutbeam (2000) has highlighted how definitions of health literacy fail to capture the broader meaning of this concept. Drawing on ideas from the adult literacy field about how literacy is conceptualised, Nutbeam proposed a model of health literacy comprising of three different types of literacy: (see 'Layers of Health Literacy' Figure 1).

1. *Functional health literacy*: the ability to apply basic literacy and numeracy skills to access and act upon health materials, traditionally aimed at increasing patient knowledge and compliance
2. *Interactive health literacy*: refers to the application of more elaborate literacy, cognitive and social skills to confidently engage in everyday health related activities such as interacting with health professionals and implementing self care plans to manage chronic disease.
3. *Critical health literacy*: considers the role that literacy plays in the process of community action and social change. From this perspective, health literacy is focused on the acquisition of skills or competencies which allow individuals and communities to engage in public discourse on health issues, with a view to modifying health care policies and practices. This in turn may lead to a better public understanding of social, economic and environmental factors which impact on health.

This broader definition of health literacy therefore encompasses core psychological and social constructs such as one's sense of personal responsibility and motivation to act on information. Nutbeam's model provides a richer understanding of health literacy that goes far beyond having the basic skills to read labels on medicine bottles. It suggests that advancement through the different 'layers' of health literacy affords a higher degree of

personal empowerment and self efficacy which in turn, influence choice and control over health and lifestyle decisions. Similarly, Zarcadoolas, Pleasant and Greer (2005) proposed that health literacy relates to an individual's awareness of public health issues, scientific processes and cultural differences, which in turn influence how they interpret, question and respond to information.

**Figure 1:** Layers of health literacy (Based on Nutbeam's 2000 concept of health literacy and Kickbusch & Magg 2008)



Nutbeam has also highlighted that the health literacy construct has emerged from two distinct perspectives – one which sees health literacy as a public health challenge and crisis (a 'clinical risk'); and the other which views it as a public health goal or outcome (a 'personal asset') (Nutbeam 2008). He notes that the former approach is widely adopted in the US, which has pioneered research documenting the negative impact of low functional health literacy on health outcomes. By contrast, the latter approach stems from concepts relating

to adult literacy education and health promotion, and is gradually being adopted in countries such as Australia, UK and Canada.

Kickbusch and Maag (2008) has made a further contribution to the health literacy construct by proposing that it should not be restricted to the boundaries of the health care environment. Rather, health literacy is just as applicable in other areas of life, including the education system, home, community, work, politics and the market. Furthermore, greater knowledge of health issues and the determinants of health, acquired through the development of more sophisticated forms of health literacy (i.e. critical health literacy) may result in greater civic responsibility. That is, citizens working collectively to address health inequalities within their communities (e.g. people actively campaigning to ban food advertising targeting children, and schools and employers readily supporting the option of 'healthy choices' on a daily basis).

### **Education, literacy and health**

Evidence has consistently shown that lower educational attainment is strongly correlated with poorer health in adult life, including life expectancy (Acheson 1998). Thus, improving education levels is regarded as a major priority in tackling health and social inequalities (CSDH 2008). Lower levels of education may shape health indirectly through its adverse effects on structural factors, such as poor housing and unemployment, which are further mediated by psychosocial variables, such as perceived social position, social isolation, and depression (Wilkinson 1999; Marmot and Wilkinson 2001). Education may also impact on health more directly through increased knowledge and awareness of the benefits of adopting healthier lifestyle choices and behaviours.

More recently, health researchers and health care professionals have focused on the role that literacy (general and health literacy) skills play in influencing health. While education level (typically measured by educational performance or years of formal schooling) acts both as a marker of a person's position within the socioeconomic structure and their skill and achievement within the education system, literacy directly measures a person's actual

skill in reading, writing and comprehending text based information. Indeed, the effects of literacy have been observed in maternal health, where equipping women with life skills (through literacy programmes) has shown to empower women to feel more confident about looking after their children's health and well being; and in turn, helping to reduce health disparities between family generations (Schell, Reilly et al. 2007; Jahan 2008). There is also a growing body of evidence (which will be described later) demonstrating that literacy contributes to a range of health-related outcomes in the community. However, before closely examining this relationship, it is important to consider how 'literacy' and 'health literacy' have been defined and conceptualised in the literature.

### **The prevalence of low literacy**

There is increasing evidence that a considerable amount of adults living in developed countries do not have the literacy and numeracy skills to function in their knowledge-based societies.

Findings from the Australian Adult Literacy and Life Skills survey (ALLS) (2006) reported that approximately 46% (7 million) adults aged between 15-74 years were described as having *very poor* (level 1) or *marginal* skills (level 2) on the prose and document scales. People tended to perform at a slightly lower level in the numeracy assessment, with about 53% (7.9 million) achieving level 2 or below for the quantitative literacy domain. These findings suggest that nearly half of Australian adults do not have the 'minimum level of literacy for coping with the increasing demands of the emerging knowledge society and information economy' (ABS 2006). Importantly, it appeared that those with lower literacy and numeracy skills generally had fewer educational qualifications, lower incomes, and were not participating in the labour force.

Large-scale literacy surveys conducted in the US and UK, present a similar picture. In 2003, the US Department of Education instigated the National Assessment of Adult Literacy (NAAL), a nationally representative survey administered to more than 19,000 adults (aged

16 or over) in households or prisons (Kutner, Greenberg et al. 2007). The results indicated that an estimated 29% (62 million adults) have *basic* literacy levels (defined as skills necessary to perform simple and everyday literacy activities), and a further 14% (30 million) have *below basic* skills (describing as no more than the most simple and concrete literacy skills for everyday life). There were variations in literacy performance across different socioeconomic, ethnic, and racial groups. For example, Black and Hispanic adults demonstrated lower literacy and quantitative skills than White and Asian/Pacific islanders.

In the UK, the Department for Education and Skills commissioned the Skills for Life survey – a survey designed to produce a national profile of adult literacy and numeracy skills using a representative sample of 8,730 adults aged 16-65 years living in England (DfES 2003). This survey found that approximately 16% (5.2 million adults) performed *at Entry level 3 or below* on the literacy assessment. A person classified at Entry level 3 ‘can understand short straightforward texts on familiar topics accurately and independently’. Similar to data from the Australian ALLS, respondents in the Skills for Life survey attained lower levels for the numeracy component of the survey, than the literacy component. Around 47% (15 million) were classified at Entry level 3 or lower, with Entry level 3 defined as the ability to ‘understand information given by numbers, symbols, diagrams and charts used for different purposes and in different ways in graphical, numerical and written material.’ Furthermore, adults living in socioeconomically deprived areas achieved lower levels of literacy and numeracy than their more affluent counterparts.

More recently, additional ‘health literacy’ components have been incorporated into some literacy surveys to assess whether individuals have sufficient literacy and numeracy skills to function effectively in the health care environment. In the Australian ALLS (2006), a fifth element was included to measure ‘health literacy proficiency’, defined as a person’s ability to ‘understand and use information relating to issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy’. Overall, 60% of adults (9 million) performed at Levels 1 and 2 (the lowest levels).

## **Understanding the relationship between literacy and health: evidence from empirical studies**

There is a large body of evidence linking literacy with health outcomes (DeWalt, Berkman et al. 2004). This section reviews some of the empirical research (mostly conducted in the United States) that has examined the relationship between literacy and a range of health-related outcomes. Within this literature, there is considerable variation in how authors use the terms *literacy* and *health literacy*, and therefore no single, universal definition is applied. Some authors seem to use the term ‘health literacy’ more explicitly and liberally, where as others simply refer to it as applying general literacy skills to printed materials with a health-related content (Paasche-Orlow, McCaffery et al. 2009). Throughout this section, care has been taken to use the precise terminology used by authors in their work depicting the relationship between literacy and health.

### ***(i) Morbidity and mortality***

*Functional health literacy* (typically described in articles as the extent to which individual’s can apply their basic literacy skills to printed materials with a health-related content, such as prescription bottles, appointment cards, and medicine labels), independently predicts morbidity and mortality. In 2006, Sudore and colleagues conducted a five-year prospective study of 2,512 men and women aged between 70 to 79 years living in the US (Sudore, Yaffe et al. 2006). Adults classified as having *limited literacy*, described by the authors as those reading below the ninth grade (completed when students are aged 14-15 years in US high school), were more likely to have poorer self-reported health, suffer from chronic conditions, including hypertension and diabetes and obesity, and be at a greater risk of death, compared to those with *adequate literacy* (reading levels above the ninth grade, a level at which they should be able to read most health care materials). In another prospective study of 3,260 American adults aged 65 years or older, Baker, Wolf et al. (2008) also found that functional health literacy skills were also independently related to an increased risk of mortality among older adults in the community (Baker, Wolf et al. 2008). In this study, the authors used the term *health literacy* to refer to how well people can read and comprehend printed materials typically encountered in a health care setting.

Participants were classified as possessing *inadequate, marginal or adequate functional health literacy*, indicating that they may correspondingly: (a) misinterpret simple health care materials, (b) have problems understanding complex medical texts such as an informed consent form, or (c) be able to read and interpret most health care materials. During the 6-year follow up period, a higher proportion of adults with *inadequate or marginal functional health literacy* had died, compared to those with *adequate functional health literacy* (38%, 28% and 19%, respectively).

In Australia, few studies have examined the impact of health literacy on health outcomes. However, a recent study conducted in South Australia found that nearly a quarter (24%) of Australian adults were classified as having limited functional health literacy as assessed using the Newest Vital Sign, and 21% were considered to have inadequate functional health literacy (Adams RJ, Appleton SL et al. 2009). In this study, limited functional health literacy was associated with self-reported poorer health status and found to be more common among people living with chronic conditions such as diabetes, heart disease and stroke. In addition, people aged 65 years and older with inadequate health literacy reported higher rates of hospital admission within the past year.

***(ii) Knowledge about disease and information seeking***

Functional health literacy has also been associated with patient knowledge and indicates with how well a person can assimilate and comprehend health information about illness and disease (e.g. Davis, Arnold et al. 1996; Williams, Baker et al. 1998; Kalichman, Benotsch et al. 2000; Gazmararian, Williams et al. 2003). This relationship has been reported across a wide range of health care settings, including asthma, cardiovascular disease, diabetes, HIV/AIDS, hypertension, and cancer screening. For example, Gazmarian, Williams et al. (2003) examined the relationship between functional health literacy and knowledge of chronic disease with 653 newly enrolled Medicaid patients with asthma, diabetes, congestive heart disease, and/or hypertension. Even after adjusting for potentially confounding variables such as disease duration, age, and previous attendance at disease education classes, they found that functional health literacy was an independent predictor of knowledge about

chronic disease. In particular, patients with *inadequate functional health literacy* demonstrated greater difficulties understanding and retaining information about their condition and how to manage it.

Research also indicates that functional health literacy affects individuals' health information seeking behaviour. Koo, Krass et al. (2006) found that functional health literacy skills (as assessed by performance on reading fluency and numeracy tests about health-related topics) were strongly related to whether patients actually read and looked for written medical information. Specifically, rheumatology patients with adequate functional health literacy were three times more interested in searching for, and engaging with written information about their condition and how to manage it than those with *limited functional health literacy* (inadequate or marginal health literacy).

### ***(iii) Use of health care and preventive services***

Research involving US samples of Medicare-managed care enrollees have shown that adults with limited functional health literacy make greater use of hospital and emergency care services, than those with adequate functional health literacy (Baker, Gazmararian et al. 2002; Baker, Gazmararian et al. 2004). On the other hand, preventive health services such as cancer screening are less likely to be used by adults with limited functional health literacy (Scott, Gazmararian et al. 2002; Garbers and Chiasson 2004; Guerra, Dominguez et al. 2005; Lindau, Basu et al. 2006). However, it should be noted that some of this data derives from studies conducted among immigrant populations whose first language is not English. It could therefore be argued that limited awareness and understanding about early disease detection may relate more to language barriers and cultural differences, than to difficulties associated with reading and understanding health care information.

### ***(iv) Chronic disease management and medication adherence***

Patients' functional health literacy skills have also shown to affect their ability to acquire new (and complex) self-care skills in order to control and manage chronic condition(s) effectively, in the context of their daily lives (Williams, Baker et al. 1998; Schillinger,

Grumbach et al. 2002; Mancuso and Rincon 2006). This is not surprising given that patients who are described as having limited functional health literacy seem to have a poorer understanding about their medical conditions. Yet, to manage chronic conditions successfully, it is important that patients have good practical knowledge to be able to engage in self-care activities, including taking medication appropriately, recognising symptoms, and knowing when to seek medical advice and assistance.

Some researchers have focused on the role of medication adherence (a specific type of self-care skill), in mediating the relationship between functional health literacy and health outcomes. However, to date, studies examining the extent to which compliance with medication mediates this association have produced mixed results (Pignone and DeWalt 2006). Some data indicates that limited functional health literacy is linked with poorer compliance with treatment regimens (Kalichman, Ramachandran et al. 1999), whereas other studies have found no connection (Fang, Machtinger et al. 2006). By contrast, some research has demonstrated that patients reading below the sixth grade (completed aged 11-12 years), report better adherence than those with reading levels above the ninth grade (Paasche-Orlow, Cheng et al. 2006; Hironaka, Paasche-Orlow et al. 2009). In the context of HIV treatment, Wolf, and colleagues have shown that a patients' perceived self-efficacy (belief in one's capabilities to achieve a goal or an outcome) mediates the effect of low literacy (reading level below the sixth grade) and poorer adherence to antiretroviral medication (Wolf, Davis et al. 2007). Clearly, the relationship between functional health literacy and adherence with medication is complex, and there may be other reasons to explain why people resist taking medicine as prescribed. For instance, patients may be concerned about the adverse reactions they could experience, or how much the regimen may change their daily routine (Pound, Britten et al. 2005).

**(v) *Patient-practitioner communication***

Patients with limited functional health literacy may not only experience difficulties with understanding written health information, they may also have problems engaging in dialogue with health care professionals (oral communication skills). In a study with type 2

diabetes patients, Schillinger et al. (2004) asked patients to rate specific features of their medical visit, including; the general clarity, elicitation of and responsiveness to patient problems, explanations of the condition, progress and prognosis, explanation of the process of care and self care, empowerment, and decision making. Importantly, patients with inadequate functional health literacy reported poorer communication in areas considered particularly important for effective disease management, namely, the doctor's overall clarity, and their explanations about the health condition and processes of care. Indeed, recorded consultations of patients with limited functional health literacy lend support to this finding. For example, Castro, Wilson et al. (2007) point out that doctors frequently use complex medical language and concepts during the consultation without adequately explaining what they mean, or checking whether patients have fully understood.

Similarly, qualitative work has shown that patients with reading levels below the US ninth grade feel that health professionals do not listen to their concerns, nor communicate information to them in a form that is easy to understand (Baker, Parker et al. 1996; Shaw, Ibrahim et al. 2009). Yet, many are reluctant to tell their doctor that they have difficulties reading and do not understand, due to feelings of shame and embarrassment. For instance, in a study by Wolf, Williams et al. (2007), patients with the poorest levels of literacy (reading levels at or below the third grade, completed aged 8-9 years) seemed highly self conscious of their reading ability. Although the vast majority of patients (over 90%) felt that it was important that a health care professional was aware of their reading level, nearly half (48%) reported feeling ashamed about their reading problems, and over one third (35%) said they would not feel comfortable if their practitioner was aware of this.

Debra Roter and colleagues (2007; 2009) have explored the oral literacy demands of the medical consultation. They report that the features of medical dialogue that may be challenging for patients include the use of technical words, abstract concepts, complex language, and structural elements of conversation such as pacing, density and interactivity. This work provides a valuable insight into the complexity and demands placed upon the patient during the medical dialogue, and demonstrates that certain features (e.g. the use of

unfamiliar terms, complex and dense language, infrequent speaking turns, and fast paced monologue) may decrease patient satisfaction and involvement in the decision making process. However, it should be noted that this work used simulated patients who had been specifically trained to act out different scenarios, and therefore does not reveal how *actual* patients would experience communication in medical consultations.

***(vi) Patient-practitioner relationship***

While a number of studies have investigated the consequences of inadequate functional health literacy on the communication process in the clinical consultation, there is relatively little empirical work exploring how functional health literacy influences the relationships that patients have with their doctors. Most of the work to date seems to focus on how the patient's social position (relative to the doctors) affects the nature and quality of the doctor-patient relationship (Lupton 1997). For example, Lupton's exploratory work of doctor-patient interactions found that people of lower socioeconomic position appeared to more readily accept the doctor's advice due to greater levels of respect; whereas those of higher socioeconomic position wanted greater autonomy and appeared more comfortable questioning the doctor.

A number of social and linguistic theories have been put forward to explain how doctors and patients interact with each other, and how the concept of power operates within this relationship. Some social scientists and health researchers (Strong 1979; Cline, Harper et al. 2006; Rapley, May et al. 2006) have drawn on interactionist social theory (Goffman 1967) in their analysis of doctor-patient interactions. This approach suggests that normative 'ceremonial or etiquette rules' are often so entrenched within the health care encounter that they are unquestioned, and subsequently serve to reinforce the status quo, hierarchy and power relations between the doctor and patient. In contrast, the work of Pierre Bourdieu (Bourdieu 1990; Bourdieu 1999), a French social theorist, highlighted that in order to understand the actions of individuals and social groups, it is important to consider how the broader structures of society including cultures, traditions, history, education and social position, shape social and communication practices. He proposes that a person's own social

position, relative to others, may shape how they view their interactions with others within social structures, institutions and organisations of authority (e.g. health care systems).

Consistent with Bourdieu's theory, studies have also demonstrated that doctors appear to act differently when interacting with patients from different socioeconomic positions. For example, they appear less likely to exhibit positive socio-emotional behaviour, such as active listening and reassurance to patients from lower social positions (Street 1991; Street 1992; Willems, De Maesschalck et al. 2005). Similarly, Waitzkin (1985) found that doctors seemed to provide relatively less information to patients with lower education, and tended to underestimate the volume of information that these patients desired. However, in our own qualitative research, patients with lower education and literacy seem to particularly value being treated 'as a person' whereby the doctor recognises their personal circumstances and conveys empathy, as reflected in a patient centred care approach (Smith, Dixon et al. 2009).

**(vii) Involvement in the decision making process**

Patients from a range of socioeconomic groups have indicated that they want to actively participate in health care decision making across a variety of decisions. A survey conducted by Davey, Barratt et al.(2002) with a community sample of 652 Australian women (of which 62% had only school qualifications) found that over 90% preferred to equally share decisions about breast cancer screening and treatment with their doctor, or wanted to adopt a more active role. A large-scale telephone survey of 8119 people across eight European countries suggests that the vast majority of people want greater autonomy in health care decision making. Overall, 74% of Europeans surveyed wanted to play a more active role in their decision making, and between 86-98% felt they should be able to choose their primary care doctor (Coulter and Jenkinson 2005).

There is evidence, however, that a patients' level of education and functional health literacy can affect their desire for involvement in decision making (Hack, Degner et al. 1994; Nease and Brooks 1995; Arora and McHorney 2000; McKinstry 2000; Adams, Smith et al. 2001). McKinstry (2000) found that patients who left full time education *before* the age of 17 were

significantly less likely to prefer consultation scenarios (presented via video vignettes) in which the patient was involved in deciding on treatment management rather than ones where the doctor directed the encounter (35% versus 46% respectively). On the other hand, patients with educational qualifications beyond school appear to desire a more 'active' and 'collaborative' role in decisions regarding their treatment and disease management. Data derived from the Medical Outcomes Study (a 4-year observational study of patients with a range of chronic conditions) revealed that patients with a college (university) qualifications were 3.5 times more likely to adopt a more active role in their decision making, than those with less than 12 years of formal education (Arora and McHorney 2000). Measures of functional health literacy have also been associated with patient preferences for involvement in decision making. A study with 268 diabetic patients found that those classified as having low literacy, defined by the authors as those with reading levels below the seventh grade (completed aged 12-13 years) were less likely to participate in medical decisions regarding their chronic disease (DeWalt, Boone et al. 2007).

However, although people with lower education and literacy seem to desire less involvement compared to those with higher education and literacy, our own work suggests that they still value receiving information, and want to be involved in decisions about their health and health care. Rather, they often lack awareness about their roles and rights as an 'active' or 'expert' patient (Smith, Dixon et al. 2009). Similarly, research indicates that people may not know whether they want to be involved until they are provided with appropriate decision support. A study conducted by van Tol-Geerdink, Leer et al(2008) found that 50% of patients (with varying educational backgrounds), who initially indicated that they preferred their doctor to make health decisions, subsequently chose to make the choice themselves once they had been provided with a patient decision aid.

### ***Limitations of empirical research***

The vast majority of research depicting the relationship between functional health literacy and health care outcomes has been conducted in the US, among patients in specialist clinical settings. Relatively little is known about the effects of limited health literacy on health outcomes in general populations, living outside of the US. However, health literacy research is gradually becoming a key research priority and public health policy agenda in Australia, the UK and other European countries (DFeS 2004; Sihota and Linda 2004; Hartley and Horne 2006; European Patients' Forum 2008; Protheroe, Wallace et al. 2009) and work has recently been undertaken in Asian countries such as Japan and Korea, where there are diverse linguistic differences and the language structure is based on characters (Lee, Kang et al. 2009; Tokuda, Doba et al. 2009). Furthermore, most of this research has focused on traditional health outcomes such as patient education and adherence. The relationship between health literacy and *informed or shared* decision making practices have received little attention. In addition, existing health literacy has focused on the relationship between functional health literacy and health outcomes. There is relatively little research investigating health literacy beyond its narrow definition of functional health literacy skills (ability to apply basic reading and numeracy skills for a health care setting). This is an issue of measurement, and will be considered in the next section.

### **Measuring health literacy**

Health literacy is a complex construct that can encompass a variety of skills and competencies, depending upon how it is defined, and whether it is viewed as a 'clinical risk', or 'personal asset' (Nutbeam 2008). These factors in turn, have significant implications for how health literacy is measured, and how to identify those at greater risk of lower health literacy (Baker 2006; Nutbeam 2008).

***(i) Tools measuring functional health literacy***

Within the literature, the two most commonly used health literacy instruments are the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA).

The REALM measures the ability to recognise and pronounce a list of common medical words typically used in patient information materials (125 items for the longer version; 66 items for the shortened version), arranged in a series of columns based on the number of syllables they contain. It takes approximately three to five minutes to administer and mark (one to two minutes for the shortened version). Raw scores are then converted into reading grade levels corresponding to four different levels of US high school achievement (Davis 1991; Davis 1993).

In contrast, the TOFHLA (which is available in English, Spanish and Hebrew, and recently has been adapted for Australian and British populations) measures a person's ability to read and understand extracts (presented using prose passages and numeric information) taken from several patient education materials (Parker, Baker et al. 1995; Barber, Staples et al. 2009). The test comprises of a reading comprehension and numeracy assessment, and takes approximately 18-22 minutes to administer and score (7-10 minutes for the abbreviated version). The numeracy component (a 17-item test) involves responding to oral questions about 10 different health care scenarios, using a series of prompt cards. Tasks for this section include following instructions for how and when to take medication, interpreting results from a blood glucose reading, and determining eligibility for financial health care assistance. The literacy component (a 50-item test) uses a Cloze method, where participants are provided with three health-related text passages (a standard informed consent form, rights and responsibilities regarding Medicaid, instructions in preparation for an X-ray procedure). Throughout each passage, there are one or two words missing from each sentence, with four possible replacements. For this task, participants are required to read the prose passages and identify the most appropriate word to fill in the blank space. The maximum score for this test is 100, with equal weighting for the literacy (50 marks) and

numeracy (50 marks) elements. Participants are classified into one of three health literacy categories, depending on their final TOFHLA score. These are as follows: (1) *Inadequate* health literacy (unable to read and interpret healthcare related texts; scores between 0-59); (2) *Marginal* health literacy (has difficulty reading and interpreting health care texts; scores between 60-74), and (3) *Adequate* health literacy (can read and interpret most health care texts; scores between 75-100).

Both the REALM and the TOFHLA measure skills at the individual level, and focus on specific areas that are thought to indicate how easy (or difficult) a person may find reading and understanding materials in future health care situations. Some authors, however, have raised concerns that neither tool fully captures an individual's 'overall capacity' to respond to other types of health care information (Baker 2006; Nutbeam 2008). The Health Activities Literacy Scale (HALS) (incorporated as part of the National Adult Literacy Survey, conducted in the US) attempts to provide a broader understanding of how well a person uses information, across a range of health care contexts, including those outside of the clinical setting (Educational Testing Service 2006). These include: health promotion, health protection, disease prevention, health care and maintenance, and systems navigation. While the HALS assessment is more comprehensive than the REALM and TOFHLA, it would be impractical to use it in most research projects as it takes up to one hour to administer. On the other hand, the REALM and TOFHLA are also limited in that they involve relatively undemanding tasks. For example, Fagerlin, Zikmund-Fisher et al. (2007) point out that the items used in the numeracy section of the TOFHLA (e.g. following medication instructions, working out the date and time of a doctor's appointment) do not give a sense of how well an individual would be able to comprehend more complex quantitative information, conveying risks and probabilities, (e.g. concept of relative and absolute risk reduction, or the outcomes of various treatment or screening options).

One potential new screening tool is the Newest Vital Sign, which places greater emphasis on the ability to apply quantitative skills to understand health information (Weiss, Mays et al. 2005). The task takes around 3 minutes to complete, and involves a form of health information that people may be more familiar with – a food nutrition label on an ice cream

container. It requires the participant to locate information (reading and comprehension skills), calculate percentages (numeracy skills), and use abstract reasoning skills to work out if a type of ice cream should be avoided because of a peanut allergy. The NVS has good correlation with the REALM and TOFHLA.

Most data linking limited health literacy with poorer health outcomes is based on research using functional health literacy measures. A systematic review of the literature, using 85 studies with data from 31 129 participants (either assessed by the REALM or TOFHLA), concluded that just over a quarter (26%) of the US population were classified as having inadequate health literacy (Paasche-Orlow, Parker et al. 2005). However, these studies are mostly conducted with clinical populations, with an overrepresentation of socially disadvantaged groups. More recently, the TOFHLA and REALM instruments have been used in general population based surveys to establish the prevalence of inadequate functional health literacy in the adult community. In random population surveys in the UK approximately 11% were considered to have either marginal or inadequate health literacy, as measured by the TOFHLA (von Wagner, Knight et al. 2007). The Australian survey also showed that around 7%, 11% and 26% of the general population demonstrated less than adequate health literacy skills according to the TOFHLA, REALM and the NVS respectively (Barber, Staples et al. 2009).

### ***(ii) Self reported measures of health literacy***

Another method of identifying people who may require assistance with understanding health information is to assess their self-reported health literacy. That is, a person's perceived ability to read and make sense of health information (both text and numeric). Three questions, in particular, have shown to be useful in detecting adults with *inadequate health literacy* (unable to read and interpret health texts; as defined by the TOFHLA). However, this measure has not been found to be good at detecting people with marginal literacy. The items are: (1) 'How often do you have problems learning about your medical condition because of difficulty understanding written information?' (2) 'How confident are you filling out medical forms by yourself?', and (3) 'How often do you read hospital

materials?’ (Chew, Bradley et al. 2004). There is also evidence that just asking one question (i.e. ‘How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?’) is an effective way of identifying individuals with *inadequate* and *marginal* functional health literacy (Morris 2006; Wallace, Rogers et al. 2006). Most of the self-report measures, however, have been evaluated with clinical populations, and there is limited understanding about the extent to which they are sensitive to identifying adults in the general population who have difficulties with literacy.

### ***Challenges of measuring health literacy***

Existing health literacy tools (e.g. the REALM, TOFHLA and NVS) have been developed and validated by researchers working in the US, from the perspective that limited health literacy skills pose a potential risk to the patient, and need to be identified. To a large extent these instruments derive from general literacy tests, and their content substituted with health-related material typically encountered in a clinical context. These tools assess related, but different constructs of health literacy and use different thresholds for indicating inadequate health literacy. As such, it is difficult to directly compare performance on one instrument with another as the proportion of participants classified as having inadequate health literacy varies between measures, and some tools appear to more demanding than others (Barber, Staples et al. 2009). In addition, most studies have examined functional health literacy levels in clinical samples which are often not representative of the general population as they tend to include a large proportion of socially disadvantaged groups.

Health literacy assessment tools used in large-scale adult literacy surveys such as the ALL and NAAL offer a more comprehensive way of examining health literacy that goes beyond how patients respond to printed materials in a clinical setting, to situations encountered in everyday life, such as understanding how to maintain good literacy skills in the functional sense (i.e. performance on health-related literacy tasks), and do not capture competencies that enable individuals to *obtain, process and understand information* to make decisions

about their health (Institute of Medicine 2004). Thus, if health literacy is defined more broadly in terms of using cognitive, personal and social interaction skills to negotiate with a health care professional (interactive literacy), or to critically evaluate the quality of information to make informed health decisions in everyday life (critical literacy), then existing instruments are clearly not appropriate (Baker 2006; Nutbeam 2008). To date, no tools have been developed to measure health literacy skills at the interactive and critical level, to fully tap into the multifaceted nature of this construct (Ishikawa and Yano 2008).

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