Health literacy and vulnerable groups: What works?

Report prepared by MONASH University
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Health literacy at the functional level, refers to an individual’s ability to read, understand, and use the information necessary to enjoy good health and to obtain adequate health care in order to maintain their health (Fineberg, 2004). It is not surprising that health literacy within such a view has often been defined as a sub-set of general literacy which is in turn measured by focusing on individuals’ prose, numeracy and documentary skills (Mantone, 2005; Root & Stableford, 1999). An alternative conceptualisation of health literacy defines health literacy more broadly though; instead considering health literacy’s role in the development of individuals’ sense of empowerment. Within such a conceptualisation health literacy represents a combination of the cognitive and social skills that enable service users to access health information and use it effectively (Nutbeam, 2000, 2008). However defined, poor health literacy is a widespread problem in both non-industrialised and industrialised nations, and has been consistently associated with poorer health and well-being (Barber et al., 2009; R. M. Parker, Wolf, & Kirsch, 2008; Sudore, 2008); which is likely to affect some migrant groups in the SEHCP catchment. Health literacy levels are thought to more accurately predict health status than education level, income, ethnic background, or any other socio-demographic variable (Allison-Ottey, 2004; Weiss et al., 2005). Individuals with limited health literacy have higher rates of illness and more hospitalisations than individuals with more well-developed health literacy skills (Baker, Parker, Williams, & Clark, 1998). That said, in the U.S.A., considerable effort has been directed at creating health education materials for service users with limited reading skills, but, to date, there is minimal evidence that these interventions have a significant direct effect on the health status of these individuals (Hester, 2009; Schaefer, 2008). Poor health literacy is a common problem with important implications for health and social status but the evidence of what works ‘best’ in terms of health outcomes together with our understanding of the causal pathways from health literacy to health outcomes remains limited (Ishikawa & Yano, 2008).

Factors that contribute to low levels of health literacy include poverty, speaking languages other than English, belonging to a culturally and linguistically diverse (CALD) community, and advanced age – all of which can contribute to low levels of personal and community empowerment. In some communities and countries, gender is a factor when girls are not given the same educational opportunities as boys (ABS, 2006; Cotton, Wright, Harris, Jorm, & McGorry, 2006; White, Chen, & Atchison, 2008). Furthermore, both low general literacy and low health literacy engender vulnerability and stress, and both are considered to underpin individuals’ abilities to participate fully in society (ABS 2006). Thus, it is no surprise that it has also been shown that in increasing the ‘critical consciousness’ of people with low reading and writing skills it is possible to empower them to become engaged in social mobilisation as well as to undertake actions to improve their own health (Nutbeam, 2000, 2008).

Regardless of the research that still needs to be undertaken to develop a clear and consistent understanding of the relationship between health literacy and health outcomes, communities and populations which are recognised as being the most vulnerable to the challenges posed by literacy and health literacy include migrants, refugees, older people, and people from low SES backgrounds. This is especially the case in the context of healthy lifestyles and chronic disease self-management (Blignault, Ponzo, Rong, & Eisenbruch, 2008; Kreps & Sparks, 2008; Zanchetta & Poureslami, 2006). The current report was prepared in 2009 for the South East Healthy Communities Partnership (SEHCP), which engaged the Department of Health Social Science at Monash University to undertake a literature review focusing on what constitutes ‘good practice’ in respect to the development of health literacy in such communities and populations.
The review was sought by the SEHCP to assist its member agencies to better understand health literacy alongside suggesting what they are able to do to enable vulnerable individuals, specifically people from culturally and linguistically diverse backgrounds, older people, and people from low socio-economic backgrounds to develop and/or enhance their health literacy skills. Based on this research, by enhancing health literacy skills and knowledge it is hoped that such service users would be able to better engage the health care organisations and agencies from which they receive care and services, whilst also enhancing their own knowledge of their personal health care needs and the organisations/services available to them.

The review has found that the literature readily and consistently recognises that low health literacy results in significant barriers to better health outcomes, as well as to accessing timely and appropriate services by older people and people from CALD backgrounds. It is also recognised that service users with low health literacy also face such barriers, with data from the U.S.A. (Lurie & Parker, 2007) and Australia (ABS, 2006; Glasgow, Jeon, Kraus, & Pearce-Brown, 2008; Nutbeam, 2000) demonstrating a consistent link between low socio-economic status and health literacy. Interventions implemented to date predominantly target individuals functioning, with wide recognition of the need for culturally sensitive and linguistically congruent communication practices to reach and influence vulnerable populations. There are also calls for community participative communication interventions to be increasingly applied, with such interventions recognised as a valuable strategy for integrating service users’ perspectives into health education efforts. There is also a need to build community commitment to health literacy issues to ensure that communication interventions reach all members of those communities.

Moreover, the literature also suggests that in order for health literacy interventions to be successful they need to be actively considered and planned from within a consistent, integrated framework. Such a framework is described in this report, and the SEHCP and its member agencies should consider the adoption, promulgation, and operationalisation of such a model to guide their future work.
As part of its strategic planning, the South East Healthy Communities Partnership (SEHCP) engaged Monash University to undertake a literature review about health literacy and health literacy strategies that will help SEHCP member agencies better understand health literacy, and in doing so suggest a range of health literacy development strategies that SEHCP member agencies might individually or collectively to develop and/or implement. The SEHCP’s interest in health literacy centres on their wish to enable vulnerable groups – specifically CALD populations, older people, and people from low socio-economic backgrounds – develop and/or enhance their health literacy skills. In identifying health literacy improvement strategies and interventions in this way, the SEHCP member agencies will consider which recommendations articulated in this literature review might be included in the strategic plan currently being developed.

**Project aims**

In order to better understand health literacy, and how it may be applicable to SEHCP member agencies’ work, three project aims were identified. Specifically, these were to:

- Undertake a review of the health literacy literature.
- Identify and make recommendations for practical strategies and interventions that can be used to enable the vulnerable groups focused on in this report improve their health literacy and enhance their sense of empowerment in respect to their health-related decision-making.
- Deliver a report containing the findings of the literature review, recommendations for health literacy-promoting strategies and initiatives that could be considered as part of the SEHCP’s strategic planning process, and, a summary table examples of ‘best-practice’ interventions in respect to the target groups of interest.

**Background**

The SEHCP catchment covers the City of Greater Dandenong, City of Casey and Shire of Cardinia. In 2007/2008, the local Care In Your Community Pilot Needs Analysis (Department of Human Services, 2007) identified:

- The City of Greater Dandenong is the most ethnically and culturally diverse Local Government Area in Victoria.
- Rapid ageing of the Greater Dandenong population; of whom more than 50% were born overseas, and the majority of whom either speak English as a second language or do not speak English at all.
- A high proportion of refugees in Greater Dandenong, face additional health issues as a result of their refugee experiences prior to their arrival in Australia;
- Pockets of very high disadvantage across the south-east region of Melbourne (i.e. the SEHCP catchment), including some of the most disadvantaged communities in Victoria.
- A significantly lower life expectancy in Greater Dandenong than elsewhere in the State, particularly amongst males.

Given these findings, alongside the current and projected demographics of the catchment, it is likely that health literacy is having (and will continue to have) a significant impact on health outcomes for vulnerable groups such as those focused on in this report.
2. Health Literacy in Australia

In Australia, the Australian Bureau of Statistics (ABS) have measured literacy and health literacy levels in the Australian population using the Adult Literacy and Life Skills Survey (ALLS), an OECD measure used in over a dozen other countries. The survey was administered most recently in Australia in 2002 and 2006.

The Adult Literacy and Life Skills Survey (ALLS) is comprised of four measures of literacy that collectively contribute to an overall measure of health literacy (ABS, 2006, p. 7). These measures include:

1. **Prose literacy**: This measure represents individuals’ ability to understand and use information from various kinds of narrative texts, including texts from newspapers, magazines and brochures.
2. **Document literacy**: This measure represents the knowledge and skills individuals require to locate and use information contained in various formats including job applications, payroll forms, transportation schedules, maps, tables and charts.
3. **Numeracy**: This measure represents the knowledge and skills individuals use to manage and deal with the mathematical demands of diverse situations.
4. **Problem solving**: This measure represents goal-directed thinking and action in situations for which no routine solution is available.

The ALLS contains 191 health-related items across these four domains. Each of the items related to one of the following five health-related activities; health promotion (60 items), health protection (64 items), disease prevention (18 items), health care maintenance (16 items), and system navigation (32 items).

The 2006 data showed that approximately 40% of all Australians have ‘adequate’ levels of general and health literacy (ABS, 2006), while 60% have less than adequate levels of literacy and health literacy. Just 6% of the Australian population have high health literacy levels (ABS 2008). While these data indicate a broad-based deficit in the health literacy of the Australian population, to meaningfully understand the issues associated with poorer health literacy requires an understanding of the underlying domains that make up the ABS’ conceptualisation of health literacy, and by reference an understanding of the health-related impact of poorer health literacy.

The ABS found that approximately 46% of Australians aged 15 to 74 years achieved less than ‘adequate’ scores for the prose domain, 47% for the document domain, 53% for the numeracy domain, and 70% for the problem solving domain. Taken together these findings are obviously troubling, as they suggest that the majority of Australians are not only able to demonstrate adequate health literacy skills generally, but only three in ten Australians are able to adequately demonstrate the goal-directed thinking and action needed to effectively manage non-routine situations such as those posed by new and or complex health needs. The net result of such relatively poor health literacy has been consistently found to be both poorer health and poorer health outcomes (ABS, 2006).

Taken further, when these data are disaggregated in respect to the populations of interest to this report – people from CALD backgrounds, older people, and people from low SES backgrounds – it is not surprising that all three of these populations demonstrate substantially lower levels of health literacy than the broader Australian population. Specifically, for people from a CALD background, the data suggests that 33% overseas born Australians enjoy adequate health literacy compared to 43% of Australian born people. When decomposed further, the percentage of overseas-born Australians with adequate levels of health literacy drops to 37% for those who have arrived in Australia within the past five years. Not surprisingly when English is not the first language spoken the percentage of people with adequate health literacy decreases further still to 26%. This compares to 44% of people whose first language is English.

In respect to older people the data again evidences low levels of health literacy, especially for people over the age of 65; with only 17% of people aged 65-74 possessing adequate health literacy. Evidencing an inverse relationship between age and level of health literacy, increased adequacy of health literacy is associated with decreasing age, such that for older adults aged 60-64 the percentage demonstrating adequate health literacy rises to 29%, and for older adults aged 55-59 the percentage demonstrating adequate health literacy is 34%.

Finally, in respect to socio-economic status, the data once more evidences a clear relationship. In this case, high socio-economic disadvantage (i.e. lower socio-economic status) is associated with lower levels of adequate health literacy. For people in the bottom 20% (i.e. the lowest quintile – that is those most socio-economically disadvantaged), only 26% enjoy adequate health literacy. This compares to 55% in the highest 20% (i.e. the highest quintile – that is those least socio-economically disadvantaged). Given the socio-demographic profile of the SEHCP it is therefore fair to conclude that a large proportion of both current and potential service users do not enjoy adequate health literacy. Such a situation, compounded by the relatively high level of need evident due to high levels of health-related chronicity and complexity (Department of Human Services, 2007), belies the need to actively consider how the SEHCP and its member agencies are able to enhance the health literacy of service users.

NOTES:

- The SEHCP is the Second Australian Health Care Partnership.
- The 2006 survey was conducted by the Australian Bureau of Statistics (ABS).
- The OECD measure is used in over a dozen other countries.
- The ALLS contains 191 health-related items across four domains.
- The survey was administered most recently in Australia in 2002 and 2006.

HEALTH LITERACY AND VULNERABLE GROUPS: WHAT WORKS
The impact and effects of inadequate health literacy

From the findings of both local and international studies, poorer health literacy has been demonstrated to result in poorer physical and mental health and to result in individuals being more likely to report their health as poor (ABS, 2006; Bartlett, Travers, Cartwright, & Smith, 2006; Institute of Medicine, 2004). Women with low health literacy are also less likely to engage in screening and prevention interventions such as pap smears and mammograms. Both men and women with low health literacy have fewer flu immunisations (Cho, Plunkett, Wolf, Simon, & Grobman, 2007; Giordano et al., 2008; Guerra, Dominguez, & Shea, 2005; Lindau, Tomori, McCarville, & Bennett, 2001), are more likely to present later with cancer (Donelle, Arocha, & Hoffman-Goetz, 2008; Westin et al., 2008), are more likely to engage in unhealthy behaviours (Carmona, 2005; Howard, Sentell, & Gazmararian, 2006; von Wagner, Knight, Steptoe, & Wardle, 2007), and less likely to be effectively engaged by health promotion activities and programs (“Don’t overlook patients with low health literacy,” 2007; Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005; Gazmararian, Williams, Peel, & Baker, 2003; Parikh, Parker, & Nurss, 1996). In a recent U.K. study (von Wagner et al., 2007), for example, poor health literacy was associated with poorer eating and diet-related behaviours, such that relatively small increase in health literacy was associated with a significant increased likelihood of eating at least five servings of fruit and vegetables a day, being a non-smoker, and exercising at least once a week (though this last finding was not significant).

In summary, the literature demonstrates that the effects of poor health literacy go well beyond poorer health and well-being outcomes, as poor health literacy has been demonstrated to predict inadequate engagement of people with necessary treatments and public health interventions. As such, these populations suffer poorer self-management of and knowledge about chronic conditions, less healthy behaviours, higher rates of hospitalisation, difficulty with verbal communications with providers and poorer health status in general particularly stress and vulnerability. Consequently, to better understand and develop the health literacy of populations and/or specific sub-populations requires more than just a behavioural understanding and approach to the pre and antecedents of different types of health outcomes. Rather the issue of health literacy needs to be couched within a social determinants framework of health that actively considers the issue from an integrated, structural perspective.
3. Theoretical frameworks for health literacy

Health literacy is a social determinant of health which has individual, organisational and structural dimensions. At the individual level, health literacy is regarded as service users’ ability to understand and to act in their own interest, such that service users have a capacity to obtain, process, and grasp the health information and services they need to make appropriate health decisions (Feinberg, 2004). Similarly, Coulter (2008) defines health literacy as:

- The ability to read, understand and act upon health information
- Reading, understanding and having the competence to make health decisions;
- Essential for service user engagement – relevant to whole population
- Critically important in tackling health inequalities that require targeted approaches.

Health literacy therefore involves more than reading and numeracy skills, and is considered to include elements such as cultural differences in understanding health and health care provision; listening, speaking and writing skills. At the organisational level, health literacy of service users can be enhanced by the development and delivery of appropriately prepared health-related information and materials, and the development and delivery of education materials for health care practitioners and planners to enable them to become more responsive to their low literate clients (Hester, 2009; Lindstrom, 2007; Schaefer, 2008).

Considerable effort has gone into the articulation of health literacy as a concept. Most of this research has been undertaken in the United States of America and Canada, where increasingly health literacy is recognised as an important underpinning of health and well-being of individuals, communities, populations, and of the country as a whole (Kaelin & Huebner, 2002; Quality, 2004; "Study reports 90 million Americans have limited health literacy,” 2004; Zahnd, Scaife, & Francis, 2009). Nonetheless, much remains to be understood as little research has managed to fully understand how health literacy strategies can make a difference to health outcomes.

Drawing on the pioneering work undertaken by the U.S. Institute of Medicine (Institute of Medicine, 2004), Zarcadoolas and her colleagues (Zarcadoolas, Pleasant, & Greer, 2005) offer a model of health literacy that attempts to integrate four different types of health literacy within a single model. The four types of health literacy that they include are:

1. Fundamental literacy, that refers to the ability to read, write, speak, and work with numbers.
2. Scientific literacy, that refers to the skills and abilities to understand and use science and technology.
3. Civil literacy, that refers to skills and abilities that enable citizens to recognise public issues and participate in civil society.
4. Cultural literacy, that refers to the ability to recognise, understand, and use the collective beliefs, customs, and worldview, and social identity of diverse individuals to interpret and act on information.

Nutbeam (2000) also proposes that health literacy is much more than a model of health education that is concerned with the transmission of health information and/or assisting service users to access the health care services they need. Improved health literacy, Nutbeam notes, is critical to empowerment. As such, he concludes that interventions focused on behavioural changes have failed to make much difference to health outcomes or to closing gaps in health status between different groups in society. The increasing literature on the role of social, economic and environmental determinants of health indicates that if we regard health literacy as a social determinant of health, then, health literacy interventions also need to be designed to actively impact on those determinants (e.g. Kamble & Boyd, 2008). Within such a public health approach to health literacy, health is an outcome of health promotion strategies and interventions that change one or more determinants of health (Nutbeam, 2000; 2008).

Operationally, health literacy is best understood as working at three levels that enable people to do the things they want to do with their lives. At a functional level, health literacy enables individuals read prescriptions or health brochures, for example. At the next level, communicative and interactive literacy are the product of cognitive and social skills combined with literacy which enable individuals to participate meaningfully in social life, to derive meaning from various forms of communication and use communication to interact socially, and to understand and effect change. At the highest level, critical literacy is the combination of advanced cognitive and social skills that are used to high levels of engagement and to exert control over life situations (Nutbeam, 2000; 2008).

While other researchers in the area have approached the concept of health literacy from a range of theoretical and practice-based approaches such as a psychologically-grounded approach (e.g. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999), a public health approach (e.g. Nutbeam, 2000), or an epidemiological approach (e.g. Paasche-Orlow, Riekert et al., 2005; Paasche-Orlow & Wolf, 2007), the model proposed by Zarcadoolas and her colleagues (Zarcadoolas et al., 2005) holds particular promise. Diagrammatically, Zarcadoolas and her colleagues’ (Zarcadoolas et al., 2005) model can be illustrated as follows, with the four types of health literacy they identify all contributing to service users’ overall health literacy.
The model to date has not been evaluated empirically as far as we are aware. In spite of this, by overlaying this model with some of the attributes of health literacy identified by other theorists (e.g. Nutbeam [empowerment], Paasche-Orlow [causality], etc), it is possible to incorporate the intrapersonal, interpersonal and structural and approaches taken by these theorists in a way that ‘maps’ the various components of health literacy identified by Zarcadoolas and her colleagues in a meaningful and actionable manner, within a social determinants framework. Such an approach is strongly advocated by Nutbeam (2000; 2008), and by Paasche-Orlow and his colleagues (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Paasche-Orlow & Wolf, 2007, 2008).

Firstly, by re-conceptualising these four domains as being interrelated, with one influencing the other, it is possible to concurrently consider how one type of health literacy impacts on, and interacts with, other domains of health literacy. For example, one type of practice-level intervention that is concerned with developing individuals and their understanding and navigation of the health care system is the delivery of health condition-focused information. To be successful though, such an intervention needs to work at a number of levels. In this example, a range of questions might be posed to understand the interdependencies among different domains. Such questions include:

- How does the intervention intend to enhance service users’ scientific literacy?
- Does the intervention have the capacity to increase individuals’ critical consciousness regarding their health?
- What does achieving health-related critical consciousness mean for health care service providers and the way that they construct and develop the scientific literacy of their service users?
- How is it possible to also enhance individuals’ civil literacy?

Thus, in order to enhance the effectiveness of proposed intervention, is it also necessary to consider and/or enhance other domains of health literacy e.g. Is there a need to also consider health care service providers’ understanding of the cultural literacy of the target population? – i.e. Is there a need for complimentary workforce capacity building interventions? By considering the nature of health literacy enhancement interventions in this way, it is possible to refashion Zarcadoolas and her colleagues’ (Zarcadoolas et al., 2005) model so these interrelationships are made manifest. Diagrammatically, this re-conceptualisation of Zarcadoolas and her colleagues’ model can be illustrated as follows.

In this re-conceptualised view of Zarcadoolas and her colleagues’ model, structural interventions represent those that involve government and its agencies. These types of interventions look to enhance and develop civil and/or scientific literacy directly, while also enhancing and developing fundamental and cultural literacy indirectly. Often representative of policy or legislatively-driven interventions, structural interventions attempt to directly address the health literacy through interventions that ‘change the way things are done or thought about’ structurally within government, government agencies, and health care providers.

Societal interventions are those that focus on enhancing and developing civil literacy and/or cultural literacy. Taken together, the focus of these types of health literacy is to enable the full and active participation of society as a whole and/or the enhancement and development of specific sub-populations/communities’ knowledge and capacities. Interpersonal interventions, as the name suggests, are concerned with interventions that either focus on the enhancement and development of cultural (i.e. community-based) and/or fundamental (i.e. individual) health literacy. Finally, practice-level interventions focus on interventions that enhance either fundamental and/or scientific literacy, which represents the way in which health care service users and health care service providers interact.
To address the challenges posed by inadequate health literacy, it is therefore important that SEHCP member agencies not only implement strategies and interventions that develop specific types of health literacy, but do so from within a framework that is informed by both theory and practice. From such a perspective best-practice represents strategies and interventions that directly address specific health literacy deficits, but do so in a way that is integrated. Given the relatively low levels of adequate health literacy evident in the three populations of interest, approaching health literacy enhancement and development in an integrated manner will help to ensure that such strategies and interventions maximise not only their reach but also their sustainability. That said, prior to considering what strategies and interventions the literature suggests, it is germane to first consider whether or not testing the health literacy of local service users is either needed or recommended.

Should service users’ health literacy be tested?
The literature reports a range of methods and tools for assessing health literacy that have been tested with specific service user groups as well as the general population. Population-based surveys conducted in Australia by the ABS and in other countries comparable to Australia (Canada, Germany, USA) have established reliable profiles of general and health literacy across the population. Indeed evidence does not support clinical screening.

Limited health literacy is a significant risk factor for adverse health outcomes. Despite controversy though, many health care professionals have called for routine clinical screening of service users’ literacy skills. Whereas brief literacy screening tools exist that with further evaluation could potentially be used to detect limited literacy in clinical settings, no screening program for limited literacy has been shown to be effective. Yet there is a noted potential for harm, in the form of shame and alienation, which might be induced through clinical screening. There is fair evidence to suggest that possible harm outweighs any current benefits; therefore, clinical screening for literacy should not be recommended at this time (Paasche-Orlow & Wolf, 2007, 2008). Thus, it is not recommended that health care professionals attempt to assess the health literacy of their service users without reviewing the literature to better understand the strengths and limitations of various test tools, and to be certain that testing will not cause more harm than good given that we already have population level data about the Australian population.
According to the literature, people’s responses to illness and subsequent behaviours are culturally determined and expressed in responses to illness including fear, pain, and anxiety (e.g. Smylie, Williams, & Cooper, 2006). Additionally, there are also cultural differences in defining ‘sick roles’, which are also related to individuals’ belief systems and health practices, as well as to when and how health care is managed and sought (C. H. Chang et al., 2007; M. Chang & Kelly, 2007). Communicating effectively with migrant populations, therefore, is a complex matter (Kreps & Sparks, 2008). As in the U.S.A. (Bibel, 2004), locating health information in Australia in languages other than English is a challenge. The significant language and health literacy difficulties faced by immigrant populations are further exacerbated by cultural barriers and economic challenges to accessing health services and once accessed, people from CALD backgrounds then need to make sense of relevant health information (Kreps & Sparks, 2008). Specific communication strategies are needed to effectively reach and influence immigrant groups not only to reduce health inequalities but to promote their health.

Communication interventions to educate vulnerable populations need to be strategic and evidence-based. It is important for health care professionals to adopt culturally sensitive communication practices to reach and influence vulnerable populations – such as people from CALD backgrounds. Alongside sensitive and appropriate practice (i.e. interventions that focus on the development and enhancement of fundamental health literacy), community participative communication interventions (i.e. interventions that focus on the development and enhancement of cultural health literacy), are a valuable strategy for integrating service users’ perspectives into health education efforts and in building community commitment to health communication interventions (Kreps, 2008; Kreps & Sparks, 2008).

As communities become more diverse, the need for material in other languages increases. A good strategy is to make available web-based resources for service user health information in foreign languages alongside basic search strategies for locating this information (Bibel, 2004). There are a number of web-based multilingual phrase books, but, as they are mostly developed in the U.S.A., the information about health services and treatments may not be appropriate for Australian service users. A search for Australian health education brochures in languages other than English reveals a patchy and somewhat idiosyncratic set of materials that is far from comprehensive.

Regardless of the country of origin, the findings of searches on materials in languages other than English suggest that there are two types of foreign language service user education sites:

• Those with online content in other languages; and,
• Those with downloadable content in other languages.

Such searches also suggest that librarians can be a good resource in assisting people to find foreign language web-based materials. Table 1 sets out some of these websites. The range of websites available suggests that librarians and health care professionals could be working together to develop specific resources for specific conditions, to assist people from CALD backgrounds.
5. Summary of health literacy strategies for people from CALD backgrounds

Table 1: Webliography of CALD-appropriate health information

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<tr>
<th>Name</th>
<th>Web address &amp; focus</th>
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<tr>
<td>Collusus</td>
<td><a href="http://www.searchenginecolossus.com">www.searchenginecolossus.com</a> This site lists search engines from many countries which is very useful for locating information in other languages.</td>
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<tr>
<td>Librarians Index to the Internet</td>
<td><a href="http://www.lii.org">www.lii.org</a> Volunteer librarians scour the Web to find good, current, accurate free sites for all kinds of information. Sites with health and medical information in other languages are included. Refer to Bibel (2004) for further detail.</td>
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<tr>
<td>EthnoMed</td>
<td><a href="http://www.ethnomed.org">www.ethnomed.org</a> This site contains information about cultural beliefs, medical issues and other related issues pertinent to the health care of recent immigrants to the US, many of whom are refugees fleeing war-torn parts of the world.</td>
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<tr>
<td>University of Utah</td>
<td><a href="http://www.library.med.utah.edu/24languages">www.library.med.utah.edu/24languages</a> This site contains health brochures in 24 languages for consumers.</td>
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<tr>
<td>NSW Multicultural Health Communication Service</td>
<td><a href="http://www.mhcs.health.nsw.gov.au">www.mhcs.health.nsw.gov.au</a> Over 450 publications on health in a wide range of languages and new publications are added regularly. Some multilingual resources produced by other services are also posted on this website and there are links to related websites.</td>
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<td>EurasiaHealth</td>
<td><a href="http://www.portal.acm.org/citation.cfm?id=1134587">www.portal.acm.org/citation.cfm?id=1134587</a> This is a knowledge network with a range of web-based multilingual resources.</td>
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<td>MedInfoRus – Patient education</td>
<td><a href="http://www.medinforus.homestead.com/Pinformation.html">www.medinforus.homestead.com/Pinformation.html</a> This site has links to Russian-language health information and a Russian interface for Medline.</td>
</tr>
<tr>
<td>u-Write</td>
<td><a href="http://www.u-write.com/foreign.shtml">www.u-write.com/foreign.shtml</a> This site provides service user education materials in a number of languages.</td>
</tr>
<tr>
<td>Family Health International</td>
<td><a href="http://www.fhi.org/en/index.htm">www.fhi.org/en/index.htm</a> This site has information about HIV/AIDS and other reproductive health issues in French, Spanish, Russian, and Arabic.</td>
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<tr>
<td>Center for AIDS Prevention Studies</td>
<td><a href="http://www.caps.ucsf.edu/pubs/FSAll">www.caps.ucsf.edu/pubs/FSAll</a> Fact Sheets are available in English and Spanish.</td>
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<tr>
<td>Immunization Action Coalition: Vaccination information for Healthcare Professionals</td>
<td><a href="http://www.immunize.org">www.immunize.org</a> This organization has produced print materials in 37 languages including Amharic, Arabic, Armenian, Cambodian, Chinese, Croatian, Farsi, French, German, Haitian, Creole, Hmong, Japanese, Korean, Laotian, Portuguese, Punjabi, Romanian, Russian, Samoan, Serbo-Croatian, Somali, Spanish, Tagalog, Thai, Turkish, Tigrinya, and Vietnamese about immunization and hepatitis B.</td>
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Health education programs, though, should be thought about in more than just terms of design so that materials used do more than present advice. Health-focused health materials need to be designed to prompt introspection, teach and encourage people to use a range of internet technologies (Birru et al., 2004; Friedman, Hoffman-Goetz, & Arocha, 2006). That said, strategies to enhance empowerment are also important for effective health education programs, and can be designed to improve service users’ health literacy with the use of pictures and diagrams as well as translations of common terms. Aside from enhancing the provision of, and access to, relevant and appropriately-written and presented information, the literature also suggests that the health literacy of people from CALD backgrounds is best enhanced when such interventions:

- Involve and empower service users.
- Are developed and implemented by inter-organisational partnerships that support integrated intervention efforts.
- Are supported by appropriate training and support for both service users and providers.
- Actively make use of appropriately-trained interpreters and translators.
- Are designed in a manner that is culturally appropriate and actively support health communication efforts.
- Focus on service users’ families and communities, so that the reach of health communication is maximised and is reinforced.
- Provide service users with choices and options for enhancing their health (Kreps & Sparks, 2008).
Generally, health care systems require or expect quite a high level of health literacy particularly for conditions that require complex care such as cancer (Sparks & Nussbaum, 2008), diabetes (Wolff et al., 2009), and heart disease (Gazmararian et al., 2006; “The Second National CDC Prevention Conference on Heart Disease and Stroke: Charting the course,” 2004). Cancer and heart disease in particular, are predominantly diseases of older age, and all make complex learning demands on service users (Baker et al., 1998). In spite of this, accessible information is consistently more limited in older and more vulnerable populations, who are less likely to use the internet, or, if they do, have limited search skills (Cutilli, 2007; Sudore et al., 2006; Tolson, 2008).

According to the literature, older adults at risk of low health literacy are known to use a range of strategies to hide their lack of understanding of health information (“Ages & stages. Health literacy & older patients,” 2004; Tooth, Clark, & McKenna, 2000; Zanchetta, Perreault, Kaszap, & Viens, 2007). This can lead to a misunderstanding of health care instructions, prescriptions, and appointments. Older adults are also less likely to ask in-depth questions and have poor medication compliance. Collectively, these issues result in poorer health outcomes, increased medical costs, and medical errors in general (Roth & Ivey, 2005; Sudore & Schillinger, 2009). In the U.S.A., for example, more than 80% of medical errors are attributed to communication breakdowns. That said, while similar research has not been done in Australia, given that our health literacy rates are similar to the U.S.A., we should expect that similar issues arise in Australia (Sparks & Nussbaum, 2008).

For older people living with chronic and complex conditions, significant skills are required for self-care. Low health literate older people have specific learning needs and likely to have less knowledge about self-care and thus be at risk for poorer outcomes (DeWalt et al., 2004; DeWalt & Pignone, 2005). Low health literacy has also been shown to result in inadequate access to health information for conditions for which older people are more at risk, particularly in respect to cancer (Donelle et al., 2008; Donelle & Hoffman-Goetz, 2009). Not surprisingly, as a consequence, older adults have been found to be substantially more challenged by poorer health literacy than younger adults (Fisher & Goldney, 2003; White et al., 2008).

The Center for Health Care Strategies (CHCS) is a U.S.-based non profit health policy resource center (sic) dedicated to improving health care quality for low-income children and adults, people with chronic illnesses and disabilities, frail elders, and ethnically diverse populations experiencing disparities in care (see www.chcs.org). Key strategies that the CHCS have identified to assist older service users achieve better health outcomes and effectively navigate the health care system include:

- Verifying that service users understand what is being said to them, or uncovering the health beliefs of such service users and tailor what is being discussed accordingly. Health care providers, for example, might ask service users to ‘teach back’ by repeating or restating the instructions as the service user might tell a friend (e.g. Can you tell me in your own words what we have discussed?).
- Create a ‘shame-free’ environment where low-literate service users can actively seek help without feeling stigmatised. In real terms this requires health care practitioners developing effective, professional, ongoing relationships with their service users.

Based on work to date, the CHCS has found that older service users with poorer health literacy tend to be more responsive to interactions and information designed to promote action, or to enhance motivation, and self-empowerment rather than to the receipt of detailed information and facts. Given that oral and visual tools appear to help service users absorb new information, which increases their learning, the CHCS recommends that health care professionals:

- Use commonly understood words. For instance, use “keeps bones strong” instead of “prevents osteoporosis”.
- Slow down and take time to listen to service users’ concerns. Create an atmosphere of respect and comfort. Build trust with the service user.
- Limit information given to service users at each visit. Remember that less than half of the information provided to service users during each visit is retained.

Refer to www.chcs.org/usr_doc/Health_Literacy_Fact_Sheets.pdf for more information.

The literature (e.g. Cutilli, 2007; Sudore et al., 2006; Tooth et al., 2000) goes further though, suggesting that most helpful written materials for all types of service users, but especially poor readers, have the following features:

- Emphasise the desired behaviour rather than the medical facts. Education is more important than information.
- Have just one or two educational objectives —what the reader needs to learn and do. In this case, less really is more.
- Use clear headings and/or bullets instead of paragraphs, and ample white space — i.e. a Q&A format works especially well.
- Use short sentences, active voice, and conversational language — “give” instead of “administer” and “birth control” instead of “contraception”.
- Use pictures and examples to illustrate important points.
- Supplement written material with conversation, video, and audio sources.

6. Summary of health literacy strategies for older service users

HEALTH LITERACY AND VULNERABLE GROUPS: WHAT WORKS
While also an issue for service users from CALD backgrounds and older service users, poor fundamental reading skills are also consistently noted in the literature as a major impediment for people from low SES backgrounds (Gazmararian, Parker, & Baker, 1999). For these service users, disempowerment is a significant consideration; with research in the area strongly advocating that empowerment development and enhancement be central to any health literacy strategy or intervention (Por, Drummond, & Richter, 2006). Taken together, best practice health literacy enhancement for this group of service users therefore represents the application of a two-pronged approach – with suggested interventions concurrently addressing both the fundamental literacy and empowerment (medical literacy) needs of such service users (Baker et al., 1998; Kickbusch, 2001; Kim et al., 1999).

Considered individually, improving health literacy through service user education consistently appears across much of the literature (e.g. Gordon & Wolf, 2007). Of this literature, much of the research focuses on the things that can be done to improve service user education for low-literate adults, including the use of simple written information combined with oral instructions (e.g. Paasche-Orlow, Riekert et al., 2005). More specifically though, many commentators conclude that it is prudent to have health information brochures available in more than one language and to provide question-and-answer pages to facilitate enhanced service user interaction. That said, while most healthcare professionals agree that the most effective form of service user education includes both oral and written materials, a range of researchers (Oates & Paasche-Orlow, 2009; R. Parker & Kreps, 2005; Root & Stableford, 1999; Schaefer, 2008) have identified the following techniques as relevant in developing service user health literacy:

- Limit teaching objectives.
- Give many examples that have meaning to service users.
- Demonstrate procedures such as measuring dosages and counting pills.
- Make learning participatory. Ask service users to restate instructions in their own words i.e. use the ‘Teach Back’ technique.
- Repeat the information several times. Find various ways to present the material/information.
- Organise the instruction with the most important messages/information presented both first and last.
- If culturally appropriate, make eye contact when addressing the service user and sit next to them, or at a comfortable eye level.
- Include family members or other caregivers in the education process.
- Incorporate materials/information that reflect cultural values and beliefs, and actively consider potential language/communication barriers.
- Be positive and encouraging.
- Work to improve health literacy through adult education.
In operationalising the above list of health literacy enhancement techniques, in 1999, a health and literacy compendium was published which provides guidance on how to scope and implement a health literacy-focused adult education program (Irvine, 1999). The compendium is a bibliography of print and web-based health materials that adult educators can use with limited-literacy service users. It covers many topics related to health, and the adult education lessons that can be used are available in a variety of formats and multiple languages. Copies of the compendium can be downloaded from http://lincs.worlded.org/docs/comp/compendium.pdf. The U.S. National Institute for Literacy has also produced a range of materials that can be used in service user education (refer to: www.nifl.gov). This website contains a wide array of information and resources for adult educators, healthcare providers, and health educators. Topics covered on this website include: what health literacy initiatives are; easy-to-read health information; health information in various languages; non-print materials; health literacy promotion activities; and, current research in health literacy.

Finally, by way of example of the types of interventions that have been previously implemented and that seek to address both these types of literacy needs, a range of educational modules for people from low SES backgrounds have been successfully implemented and evaluated. These modules include topics such as medications, medical terminology, basic anatomy and physiology, orientation to medical forms, and communication (Gardner, Jones, & Peeler, 2006; Osborne, 2004, 2006).

In respect to initiatives that enhance and develop service user empowerment, Bastian (2008) notes that such initiatives need to be grounded in a process of information development that minimise bias; use evidence as the information basis for the content, use evidence-based communication techniques; support service user autonomy; and deliver information that is service user-centred and non-directive. Operationally, Koelen and Lindstrom (2005) take empowerment development further and outline a framework that can be used to enhance and develop service users’ sense of empowerment. They suggest that empowerment-focused health literacy initiatives need to be grounded in two fundamental concepts: the general resistance resources of service users, and their sense of coherence. Thus, in order to operationalise empowerment-focused initiatives effectively, they suggest that factors that influence individuals’ sense of empowerment need to be actively considered; that is, such initiatives should focus on enhancing service users’ locus of control, mitigate their sense of helplessness, and enhance their self-efficacy and outcome expectations. In summarising their model of health literacy empowerment, Koelen and Lindstrom (2005) note that healthcare professionals can best facilitate enhanced service user empowerment by working with their service users to help them better understand the relationship between their efforts and the outcomes within a relationship that can be characterised as partnership.

7. Summary of health literacy strategies for people from low SES backgrounds
### 8. Health literacy and vulnerable groups:

**Examples of best-practice interventions and learnings**

<table>
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<tr>
<th>CALD communities</th>
<th>Source</th>
<th>Conclusions</th>
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<td>Kreps, G. L., &amp; Sparks, L. (2008). Meeting the health literacy needs of immigrant populations. Patient education &amp; counseling, 71(3), 328-332</td>
<td>Kreps and Sparks (2008) review possible health literacy interventions that meet the needs of migrant populations. This study concluded that communication interventions to educate vulnerable populations need to be strategic and evidence-based. The authors note that it is important for health educators to adopt culturally sensitive communication practices to reach and influence vulnerable populations. Community participative communication interventions are a valuable strategy for integrating consumers’ perspectives into health education efforts and building community commitment to health communication interventions. As such, this suggests that interpersonal interventions work well with migrant communities – that is, interventions that focus on the needs and attributes of specific communities.</td>
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|                  | Chang, M., & Kelly, A. E. (2007). Patient education: Addressing cultural diversity and health literacy issues. Urologic nursing, 27(5), 411-417. | Chang and Kelley (2007) note that accurate assessment of learning needs and readiness includes assessment of cultural values and health practices as well as literacy issues. Every effort should be made to ensure that teaching plans incorporate service users’ cultural values and beliefs. By addressing cultural and literacy issues, healthcare professionals can facilitate successful learning outcomes for service users and their families, enhancing their ability to cope with illness and improve overall health. This paper makes a number of clear recommendations for teaching plans and print materials, for example:  
  - Print material should be prepared at a fifth grade reading level so it will be understandable to a greater number of service users. A variety of tools and many word processing programs are available for determining reading level of print material.  
  - Graphics may be helpful, but should only be included if they add clarity to the written content. Graphics should be relevant to the reader, used to reinforce content, and be of good quality and simple design (Osborne, 2005).  
  - Older adults will need larger font (14 point or above).  
  - Blue, green, and lavender are difficult colours for older adults to differentiate and should be avoided. |

Blignault and her colleagues (Blignault et al., 2008) conducted in-depth interviews with China-born mental health patients and members of the general community, and mental health service providers. Participants identified several factors that limit access to mental health care as well as the quality of care received: mental health literacy, communication difficulties, stigma, confidentiality concerns, service constraints and discrimination. Cross-cultural communication was not just a matter of hearing individual words but also appreciating idioms and cultural and social references.

The findings from this study have implications for the prevention and treatment of mental disorders among migrants from China, and caution against assuming heterogeneity within ethnic groups. Mental health services must become more culturally competent in their attempts to engage the target group and to deliver both acute and continuing care.

Two types of interventions are suggested here – intrapersonal and interpersonal. Intrapersonal interventions need to focus on the development of the fundamental and health literacy’s of individuals from this ethnic community and the way that members of this community interact with the health care system. Interpersonal interventions on the other hand need to focus on cultural knowledge and practice regarding mental health – with such interventions focussing on how the interactions between fundamental and cultural literacy impact on individuals understanding and use of mental health services.


In this article, Lo and her colleagues (Lo, Sharif, & Ozuah, 2006) surveyed 326 English-speaking parents attending an inner-city health centre, of which many were migrants and/or refugees. The focus of the study was the correct use of medications. The authors examined whether participants 1) demonstrated how much medicine they should give, 2) stated how many times a day they should give the medicine, and 3) stated when they should give the next dose after they had read the label on a bottle of medication. Overall, 252 (77%) demonstrated incorrect medication dosing. Medication dosing was more likely to be incorrect among young parents.

The authors note that both labelling and the process of dispensing need to be enhanced in order to address the health literacy issues in such settings. Two types of interventions are suggested here. Firstly, interpersonal interventions are suggested, that is interventions that are focussed on the development of better health literacy given the fundamental literacy of this health centre’s service user population. Secondly, interpersonal interventions are also suggested, such that improving medication dosing needs to be cognisant of the communities that individuals belong to. Again, if this is issue is broader than just the communities in question, there may also be a need for the broader, societal and structural health literacy interventions.

Sarfaty and her colleagues study (Sarfaty, Turner, & Damotta, 2005) focused on a medical referral project that referred low income uninsured individuals to discounted appointments with office-based doctors, to examine the pattern of service use of low-income Latinos in the U.S.A. This project found that that some Latino patients had difficulty in taking advantage of these appointments. These individuals appeared to face barriers beyond the cultural and linguistic barriers faced by most patients in the project.

One additional bilingual staff person, a ‘patient assistant’, was hired to facilitate doctor visits by these patients. The patient assistant performed the duties of a navigator, trouble shooter, and interpreter – and assisted with communications. The project staff derived a screening question to encourage patients to identify themselves as those who would need the help of the patient assistant. These patients were subsequently questioned in a waiting room survey designed to characterize them. The characteristics of these patients were compared with a comparison group of project patients.

The target group and the comparison group differed in their levels of education. Sixty percent of the target group had less than 4 years of schooling compared to 13% of the comparison group. The target group was comprised entirely of immigrants from South and Central America. This study underscores the conclusions of the Institute of Medicine on regarding health literacy and highlights the needs of Latin American immigrants who are burdened by cultural and linguistic barriers, low health literacy, and minimal education.

The findings of this study suggest that health literacy interventions with this subpopulation need to be both practice-based and interpersonal in focus, so that the fundamental, scientific, and cultural health literacies of this community are enhanced.


Walter and her colleagues study (Walter, Salman, Krauth, & Machleidt, 2007) examined the use of health services by migrants living in Germany. Migrants are generally hard-to-reach groups in health and preventive care. Essential criteria for the sustainable effectiveness of preventive and health promotion include the careful understanding of target groups and specific engagement strategies. Understanding barriers that make the access to preventive care and health promotion more difficult (e.g. low health literacy) are essential. The difficulties of linguistic understanding or the low acceptance regarding the provider may affect adequate access by defined target groups.

Up to now, for this and particularly for the ethno-specific health behaviour of migrants in Germany information hardly exists. So far, there are only a few preventive offers which are target group focussed. The use of native speaking preventive consultants (i.e. to enhance migrants’ scientific, fundamental, and cultural health literacies) is an attempt to improve the access to preventive care for migrants by low threshold come and access-structures.
8. Health literacy and vulnerable groups:


This study examined the use of an integrated health literacy development strategy in Austria for migrant and refugee women. Due to the evident interaction between social factors and health, migrants are exposed to specific risk factors and access barriers to health services. Some examples are the lower education level, the low social position and/or the insufficient language skills. This concept is further elaborated in the multi-factorial impacts of health literacy. Female migrants often experience additional discrimination because of their gender.

Despite the lack of representative data, consistent studies show that female migrants do not regularly take advantage of health care prevention and present themselves with higher degrees of stress. For these women inadequate health care manifests itself in a lack of care in the areas of prevention and health education and in abundance in the context of medication and diagnostic procedures. To meet these demands and to further reduce barriers, in particular language barriers, specific strategies for this target group involving both politics and the health care system have to be developed. Besides the employment of interpreters with a native cultural background and the distribution of information booklets, it is an important strategy to reduce structural obstacles such as cultural diversity. To contact these women in their living environment should help to increase their self-determined health promotion.

Selected models of good practice in Austria with regard to the themes of FGM (female genital mutilation), violence, heart disease and breast cancer are presented to highlight the specific health situation and risk factors of female migrants as well as successful strategies to confront them.


In this study, Carroll (2007) sought to identify characteristics associated with favourable treatment in receipt of preventive health care services, from the perspective of resettled African refugee women. Individual, in-depth interviews with 34 Somali women in Rochester. They explored participants’ positive and negative experiences with primary health care services, beliefs about respectful versus disrespectful treatment, experiences of racism, prejudice or bias, and ideas about removing access barriers and improving health care services. Analysis was guided by grounded theory.

Qualities associated with a favourable health care experience included effective verbal and non-verbal communication, feeling valued and understood, availability of female interpreters and clinicians and sensitivity to privacy for gynaecological concerns. Participants stated that adequate transportation, access to healthcare services and investment in community-based programs to improve health literacy about women’s preventive health services were prerequisite to any respectful health care system.

Effective communication, access to healthcare services with female interpreters and clinicians, and community programs to promote health literacy are themes associated with respectful and effective healthcare experiences among Somali women. At the practice-level, adequate interpreter services are essential. Patient-provider gender concordance is important to many Somali women, especially for gynaecological concerns.
**8. Health literacy and vulnerable groups:**

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<td>Bibel (2003) notes that as communities become more diverse, the need for material in other languages increases. A good strategy is to make available web resources for consumer health information in foreign languages and basic search strategies for locating this information. This article reviews available sites (at 2003) finding there are two types of Foreign Language Patient Education Sites: a) Those with online content in other languages, and b) Those with downloadable content on other languages.</td>
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<td>In this study Rudd (2007) examined adults’ literacy proficiencies in multiple health contexts using one hundred ninety-one (191) health-related items drawn from all large-scale adult literacy surveys. The survey items used were scored in a way that resulted in a health literacy scale. Latent class analyses provided portraits of adults with different health literacy skills. Adults without a high school diploma or similar level of education, with health-related restrictions, with limited access to resources, who are members of minority population groups, and who are immigrants - had lower health literacy skills than do members of the community. Rudd concludes that the distribution of health literacy is not independent of general literacy skills at population or subpopulation levels. To address these needs therefore again requires both interpersonal and intrapersonal health literacy interventions. Given the possible wide spread nature of poor fundamental and cultural literacy, there may also be a need for societal and structural interventions to support health literacy interventions at the interpersonal and intrapersonal levels.</td>
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<td>The objective of Donelle and Hoffman-Goetz’s study (2008) was to examine and compare cancer related conversations in online forums hosted by Canadian and American associations for retired persons. A content analysis was used to evaluate archived cancer conversations of general health online forums representing two leading North American associations for retired persons. The study was built on evidence that older people find searching for cancer information to be challenging. Primary sources of cancer care information (i.e., print media and medical practitioners) can be inaccurate or confusing to the consumer. Some people find support groups to be helpful for both good medical information as well as emotional support. The availability of cancer care information, including that available online, has assisted patients in developing a sense of control, reducing anxiety, promoting self care and generating a sense of security and safety. This study examined online ‘support’ groups and chat sites for older people with cancer. They found that shared experiential cancer information formed a substantial component of the online messages and supports previous findings that found that others healthcare experiences were as important and used instead of or in addition to medical information provided by healthcare professionals. Online sites are important sources of health care information and support but a good level of health literacy is necessary for full utilisation of online resources.</td>
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### 8. Health literacy and vulnerable groups:

DeWalt, D. A., Pignone, M., Malone, R., Rawls, C., Kosnar, M. C., George, G., et al. (2004). Development and pilot testing of a disease management program for low literacy patients with heart failure in the U.S.A. The authors show in the article how they were able to demonstrate the development of heart failure self-management educational materials and tested them in a disease management program in a group of patients with poor literacy skills. The materials and program were acceptable and led to important behaviour change. Their results suggest that these patients may have improved health-related quality of life from such a program.


Pignone and his colleagues systematic review (Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005) included controlled and uncontrolled trials that measured literacy and examined the effect of interventions for people with low literacy on health outcomes, including health knowledge, health behaviours, use of health care resources, intermediate markers of disease status, and measures of morbidity or mortality.

Studies of interventions to improve the health of persons with low literacy have increased in number over the past 10 years but remain relatively uncommon. Most completed studies have examined the effect of interventions on health knowledge or behaviours; fewer studies have examined interventions designed to mitigate the effects of low literacy on intermediate markers, measures of disease incidence or prevalence, or use of health services. No research to date has examined how interventions affect the general health status of persons with low literacy or whether interventions can affect health care costs or health disparities based on race, ethnicity, culture, or age. Because too few studies examined each type of intervention (brochure, videotape, computerized tool, or oral presentation), we are also unable to comment about which types of interventions might be most effective. Completed studies to date have found mixed results: some have shown positive effects on health, others have found no effect. The diverse range of outcomes examined limited our ability to draw conclusions about effectiveness. Differences in study quality, as measured by our rating scale, did not appear to explain differences in effectiveness. Although several studies showed improved overall outcomes, most had not been designed to measure whether the intervention helped the participants with low literacy less or more than (or equally to) patients with higher literacy. We identified only 5 studies that did measure whether an intervention had different effects in persons with low versus high literacy. These studies all used controlled designs, measured literacy in all participants, and stratified their results according to literacy level, but to date such studies have examined only knowledge outcomes. Their findings were also mixed with respect to differences in their ability to improve health knowledge based on the user’s literacy level: some found that interventions worked similarly in low- and high-literacy patients, others found that low-literacy patients benefited more than high-literacy patients, and still others found the opposite.
**8. Health literacy and vulnerable groups:**

**Low socio-economic status (SES)**


The aim of Clark and his colleagues’ study (Clark et al., 2008) was to describe and contrast perceptions of self-management among socio-economically vulnerable and non-vulnerable older adults. Participants included 23 vulnerable older adults with incomes at or below 200% of the federal poverty level and no private insurance and 12 older adults with private health insurance.

The vulnerable group had lower educational attainment and lower health literacy than the privately insured group. Keeping doctor visits and taking prescription medications largely defined self-management for the vulnerable group but were just two of a number of roles noted by the privately insured group, who expressed health promotion as the key to healthy aging. The vulnerable interviewees relayed few examples of healthy aging and did not have expectations for healthful aging. In contrast, the privately insured interviewees gave examples and had expectations of living long and healthfully into old age.

Clark and his colleagues conclude that improved understanding of the role of social context in expectations regarding aging, and awareness of and priorities for self-management, could lead to improvements in self-management support and thus chronic care outcomes.


Healthy People 2010, which represents a national set of health objectives for the U.S.A. to achieve over the first decade of the 21st century, specifically mentions health literacy: drawing its conclusions from the information provided by the National Adult Literacy Survey (NAAL) conducted by the U.S. Department of Education in 1992.

Healthy People 2010 identifies health literacy as part of a larger issue of access to information and individual control and responsibility for disease management. Access to the Internet, better training for health professionals, and better evaluation of patient education programs are key objectives. Healthy People 2010 also identifies a role for libraries to target skill improvement for people with limited proficiency in English.

Burnham (2003) argues that organisations such as public and medical libraries, voluntary, professional, and community groups, and schools could offer health literacy programs that target skill improvement for low-literacy and limited English proficient individuals. If appropriate materials exist and people receive the training to use them, then measurable improvements in health literacy for the least literate can occur.


Chang (2008) argues that the literature is now showing that health literacy is an important indicator for evaluating the effectiveness of health education programs. Educational materials should be designed to prompt introspection, using a range of Internet and other technologies and designing strategies of community empowerment to conduct health education programs, in order to improve clients’ health literacy and raise the effectiveness of such programs.
Based on the current literature review, health literacy enhancement and development can be seen as representing more than just enhanced access to information and/or individual control and responsibility for health management. Factors such as access to the internet, better training for healthcare professionals, and better evaluation of service user education programs need to be actively considered when developing an integrated strategy to address inadequate service user health literacy. As such, inter-sectoral and interagency collaborations and partnerships are critical, particularly as such collaborations and partnerships avail theoretically-grounded and empirically-congruent strategies and interventions to be planned and implemented.

Turning to the strategies and interventions that the SEHCP may wish to consider in order to enhance the health literacy needs of the three vulnerable populations considered by this literature review, five different strategies along with a range of attendant interventions are suggested by the literature.

1. Health literacy can be enhanced and developed by improving service user interactions with health care professionals and agencies
   - Exploring simple interventions to assess service users’ health literacy across all member agencies. As stated earlier, one such intervention involves the use of a single item/question to assess service users’ health literacy - “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” Should member agencies wish to augment this approach, alternative strategies should be considered, such as the sixteen screening question approach suggested by Chew et al. (2004).
   - Enhancing the cultural competency of SEHCP member agencies and their staff, that is, the set of congruent behaviours, attitudes, and policies that need to come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively across and within cultures, should be explored. The National Health and Medical Research Council model of cultural competency development (National Health and Medical Research Council, 2005) is an Australian model of cultural competency that has been recently developed and is a worthwhile model for consideration by the SEHCP and its member agencies. The report containing the model and suggested development strategies can be found at: http://www.nhmrc.gov.au/publications/synopses/_files/hp19.pdf.
   - Ensuring that culturally and linguistically diverse service users are able to access appropriately translated materials and appropriately-trained and oriented interpreters.

2. Health literacy can be enhanced and developed by improving the usability of health services
   - Improving the usability of forms and instructions. This most commonly involves an audit of forms and instructions, refinement of forms and instructions, and a structured process by which all new forms and instructions are developed.
   - Improving the accessibility of the physical environment - e.g. universal symbols and clear signage, implementing an ‘easy flow’ approach to the navigation of health care facilities, and, training staff to create and maintain a respectful and shame-free environment.
   - Establishing a service user navigator program, that is a program that facilitates service user learning regarding the service system and its effective navigation.

3. Health literacy can be enhanced and developed by improving access to accurate and appropriate health information
   - Creating mechanisms for sharing and distributing plain language materials among health professionals. Such materials should also actively support service user empowerment so that service users not only enhance their understanding of their health issue(s), the services available to them, and how to best navigate the service system, they also feel more competent in managing their own health and interacting with the health care system.
   - Working with the media to increase awareness of health literacy, whilst also making scientific and medical information presented in the media easier to understand.
   - Developing and implementing new methods for health information dissemination - e.g. personal electronic devices, talking kiosks, talking books, podcasts, etc. Such a strategy does not assume that all service users respond or use traditional forms of information dissemination in the same way, and thus encourages the active exploration of alternative forms of information dissemination.
   - Collaborating with libraries and other information repositories so that they actively collect and disseminate relevant and appropriate health information. Such collaborations should also explore how health literacy development can be facilitated through targeted strategies such as adult education programs, internet searching workshops, guided and self-paced searches, etc. in facilities such as libraries, community centres and elderly citizens’ organisations, etc.
4. Health literacy can be enhanced and developed by building the knowledge needed to improve the health care workforce’s thinking, decision-making and practice

- On-going workforce training and development is needed, as it is central to the functioning of any successful health system. The healthcare workforce in the SEHCP catchment needs to understand the principles and operations of comprehensive primary health care and value prevention and promotion of health over treatment of preventable illness. As such, developing the local health care workforce’s understanding of the benefits and approaches inherent in effective primary healthcare-focused services will facilitate the acceptance and uptake of health literacy enhancement and development strategies and interventions.

- The healthcare workforce also needs to understand health literacy’s role in enabling individuals and communities achieve and maintain good health. On-going professional development of health care managers, service deliverers, and support staff regarding health literacy is particularly important, given that such training and development broadens their scope of practice and creates interest and supports innovation.

- While also mentioned elsewhere in this set of possible strategies that the SEHCP member agencies might consider, ongoing workforce development regarding the micro-skills needed to work with individuals and communities with low health literacy would enhance service interactions, planning, and evaluation. Such training and development should include health literacy assessment, strategies to support effective information giving, cultural competence, community engagement and development, advocacy, etc.

5. Health literacy can be enhanced and developed by operationalising an integrated model of health literacy

- In order to enhance the effectiveness of proposed intervention it is also necessary to consider and/or enhance other domains of health literacy. As suggested by the revised model of health literacy suggested by this literature review, it is necessary to consider how interventions that develop one type of health literacy relate and support the development of complimentary types of health literacy. For example, interventions that focus on the development of fundamental health literacy should be cognisant of how they support and are supported by the cultural literacy of the communities in question and by the scientific literacy of service users from these communities.

- To facilitate uptake of an integrated model of health literacy the SEHCP and its member agencies should consider identifying health literacy as an on-going focus of their development and work plans, both collaboratively and as individual agencies. The SEHCP might wish to convene an annual meeting for member agencies to share models of good practice and interventions that have been successfully implemented.

Concluding thoughts

The findings from the health and literacy research included in this report suggest that many SEHCP member agency service users suffer from poor literacy abilities. These service users may endanger themselves, by, for example, misunderstanding instructions on medication or misreading consent forms, and will affect health care service expenditure as well for example, misusing services. In terms of overall public health, the literature suggests that low health literacy affects service users’ health activities and lifestyles. Each of the four types of health literacy identified presents itself as a potentially modifiable area of health policy, service delivery design, and/or approach to practice. Given the composition of the SEHCP catchment population there is a pressing need to consider health literacy as an important policy issue for the SEHCP and its member agencies.
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