



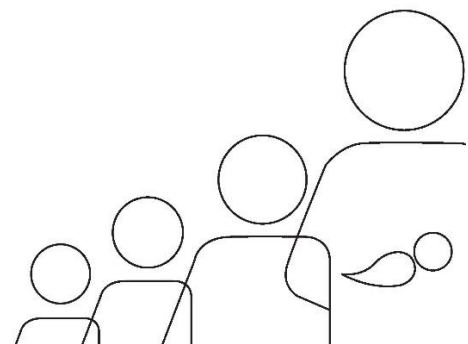
New Zealand Child and Youth  
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# Health and wellbeing of under-five year olds in the South Island 2017

Making health easier:  
Reducing inequalities in child health  
through addressing low health literacy

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# IX. MAKING HEALTH EASIER: REDUCING INEQUALITIES IN CHILD HEALTH THROUGH ADDRESSING LOW HEALTH LITERACY

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## Introduction

Keeping their children healthy and safe is one of the most important responsibilities parents and caregivers have. It requires knowledge and skills that are acquired in a number of ways: from families and friends, through cultural heritage, at school, from health professionals, through reading, and through audio-visual media, such as television, radio and the internet.

The knowledge and skills people need to meet the complex demands of health and healthcare systems in a modern society have been conceptualised as health literacy.<sup>1</sup> Being health literate means having the knowledge, skills, motivation and confidence to accurately assess the health of yourself, your family and your community, to understand the factors that influence health at each of these levels, to take responsibility for health, and to act appropriately.<sup>1</sup> It means being able to make well-informed decisions on personal health matters like nutrition, choice of healthcare providers, preventive interventions such as immunisation and screening, and treatment options for health problems.<sup>1</sup> It also means being able to form informed opinions on public health issues, such as air pollution, the safety of the water supply, workplace health and safety, the quality of food offered in school canteens, the location of liquor outlets, and the social and economic determinants of health, and being able to use political processes to affect government policy relating to such matters.<sup>1-3</sup>

When faced with a personal health problem, a health literate person can recognise symptoms that warrant medical attention, seek and obtain help from the health system, make an informed choice if they are offered treatment options, and understand and follow the advice and treatment plan they are given. They can, for example, use the information on the label to determine the correct dose of liquid medicine to give their child<sup>4</sup>, or understand informed consent documents.<sup>5</sup> They can carry out health-related tasks requiring numeracy skills, such as understanding food labels<sup>6</sup>, measuring blood sugar<sup>7</sup>, and comparing the risks of different treatment options<sup>8</sup>. They can make a phone call to make an appointment with a healthcare provider, arrange time off work to attend the appointment, get themselves to the health service, and interact confidently with health professionals by answering questions, providing a history, and asking questions about things they do not understand.<sup>9</sup>

According to the World Health Organization, health literacy is one of the three key elements of health promotion, together with healthy cities and good governance.<sup>10</sup> As will be explained further, many people have poor health literacy and this is a major contributor to poor health outcomes and to health inequities between different population groups. In their 2015 discussion paper *Health literacy: A necessary element for achieving health equity*<sup>11</sup>, Logan et al. made the following three key points about health literacy and health disparities:

- Health literacy is intrinsically linked to both an individual's and a community's socioeconomic context, and is a powerful mediator of the social determinants of health
- Health literacy interventions are viable options among other evidence-based strategies to address social adversity and environmental health determinants and should be considered when assessing meaningful actions to address health disparities
- Health literacy interventions and practices contribute to reducing health disparities, which fosters health equity and social justice.

This article discusses the research on health literacy and its relation to health outcomes, the research on interventions to improve health outcomes for people with low health literacy, and how the health system can reduce the health literacy demands it places on patients and better serve patients with low health literacy.

## Levels of health literacy in New Zealand's population

More than half of all New Zealanders have poor health literacy.<sup>12</sup> The data on New Zealanders' health literacy comes from the 2006 Adult Literacy and Life Skills Survey which tested the literacy, numeracy, and problem-solving skills of a nationally representative sample comprising 7000 people aged 16–65 years.<sup>12</sup> The survey included 191 questions that related to health matters across four domains: prose and document literacy, numeracy, and problem solving. The questions were related to five types of activities: health promotion (60 items), health protection (64 items), disease prevention (18 items), health care maintenance (16 items) and system navigation (32 items). Health literacy scores were assigned to five levels with levels 1 and 2 (scores of below 276 out of 500) indicating poor health literacy.

The report *Kōrero Marama: Health literacy and Māori* compared the health literacy scores of Māori and non-Māori.<sup>12</sup> The key finding of this report was that the average health literacy scores for both Māori and non-Māori males and females were below 276, which is the minimum threshold score for level 3 that indicates an adequate level of skills for coping with the demands of everyday life and work in an advanced society. The level 3 threshold is roughly equivalent to the skill level required to successfully complete high school and enter tertiary education. Māori males and females had significantly lower health literacy scores than non-Māori: while just over half non-Māori males and females had poor health literacy, four out of five Māori males and three out of five Māori females had poor health literacy. Mean health literacy scores increased with increasing level of education and with increasing level of income, but average scores were below 290 (in the lower range of level 3) for both Māori and non-Māori, even in the highest income and education categories.

New Zealand's results are not unusual among high-income countries: The European Health Literacy Survey (HLS-EU) conducted in 2011 in Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain found that, across all eight countries, 48% of the population lacked sufficient general health literacy.<sup>13</sup> The proportion who had insufficient health literacy varied between countries: from 29% in the Netherlands to 62% in Bulgaria. Multivariate linear regression indicated that financial deprivation was the strongest predictor of low health literacy, followed by low social status and low education.

## The healthcare experiences of patients with low literacy

Having low literacy is often source of shame. A study that interviewed patients presenting for acute care at a large public hospital in Atlanta, Georgia found that 43% had inadequate or marginal health literacy.<sup>14</sup> Of these patients, only 67% admitted to having trouble reading and understanding what they had read. Two-thirds of these patients had never told their spouses, over half had never told their children, and 19% had never told anyone about their difficulties with reading. Due to embarrassment and shame, patients with low literacy rarely ask for help with reading, and often use strategies to mask the fact that they cannot read or do not understand what they have read.<sup>15</sup> For example, they will walk out of a healthcare facility if presented with a complicated form to fill in at reception, say they have forgotten their reading glasses, sign consent forms they can't read or understand, or say "no" when asked whether they have any questions about written material they have been given.

Another study, carried out in emergency departments and clinics at two large urban public hospitals in California, used focus groups and individual interviews to explore the difficulties that patients with poor literacy experience in interacting with the health system.<sup>16</sup> This study also found that patients with low literacy harbour a deep sense of shame, which can be reinforced if hospital staff become impatient or angry when someone cannot complete a form or read instructions. Shame made patients reluctant to disclose their literacy problems to healthcare providers. Patients reported that seeking medical care was intimidating, that finding their way around the hospital was difficult, that they had made serious medication errors due to being unable to read labels, and that healthcare providers did not explain medical problems and treatments in an understandable way. They said they coped with their difficulties by relying heavily on oral explanations, visual cues and demonstration of tasks, and the help of family and friends.

## Health literacy and health outcomes

Given the difficulties that people with low literacy experience when interacting with the health system, it is predictable that they would experience worse health outcomes than other people. The early research in the area of health literacy focused on the relationship between reading ability and a variety of health outcomes. In 2003 the Agency for Healthcare Research and Quality (AHRQ) commissioned a systematic review and analysis from the RTI International-University of North Carolina Evidence-based Practice Center on the evidence for a causal

relationship between literacy and health outcomes and the effectiveness of interventions purposed to mitigate the impact of low literacy.<sup>17</sup> This review examined the following key questions:

- Are literacy skills related to the use of health care services?
- Are literacy skills related to health outcomes?
- Are literacy skills related to the costs of health care?
- Are literacy skills related to disparities in health outcomes according to race, ethnicity, culture, or age?

To be included in the review, studies had to have used a valid instrument to measure literacy skills, such as the Rapid Estimate of Adult Literacy in Medicine (REALM)<sup>18</sup> or the Test of Functional Health Literacy in Adults (TOFHLA).<sup>19</sup>

In general, there was a positive and significant relationship between reading ability and knowledge of health outcomes or health services (16 studies). Patients with lower literacy (after controlling for age, gender, race, education, and income) were more likely to have never had a cervical smear, to have not had a mammogram in the last two years, and to have not had influenza and pneumococcal immunisations (one good quality cross-sectional study).<sup>20</sup> Two good quality studies found that a lower literacy level was associated with increased risk of hospitalisation.

There were many studies that examined the relationship between reading ability and a variety of health outcomes. One of the two studies measuring adherence to antiretroviral therapy for HIV found that lower literacy was associated with increased odds of poor adherence, after adjustment for race, income, social support and education.<sup>21</sup> Some diabetes outcomes, including glycaemic control, were correlated with the reading ability of the patient or, in the case of child patients, the patient's parents (three studies). Two studies found no relation between reading ability and hypertension and single studies found no association with functional status in rheumatoid arthritis or with migraine headaches in children. Three out of the four studies that evaluated the relationship between reading ability and a global health status measure found an association between poorer reading status and poorer health. One U.S. study examined the relationship between reading ability and the costs of healthcare (Medicaid charges) and found that, among the 74 non-pregnant patients, the 18 who were reading at or below third grade level had costs that were, on average, three times higher when compared to the 56 patients who read above third grade level.<sup>22</sup>

Overall, the review found that reading ability is related to knowledge about health and healthcare, hospitalisation rates, some chronic diseases, and global measures of health status. The review authors noted that analysis of confounding factors is very important in attempting to understand how literacy affects health as many of the factors associated with poor literacy, such as lack of health insurance and poverty, are themselves determinants of health.

A subsequent review of English language studies for the AHRQ considered later health literacy related studies (reported in 98 articles from 2003 to February 2011) and studies assessing the relationship between numeracy and health (reported in 22 articles from 1996 to February 2011).<sup>23</sup> The review authors did not identify any studies dealing with oral health literacy (speaking and listening skills) and health. This review found that low health literacy was consistently associated with higher hospitalisation rates; greater use of emergency care; lower receipt of mammography screening and influenza vaccine; poorer ability to demonstrate taking medications appropriately; poorer ability to interpret labels and health messages; and, among elderly people, poorer overall health status and higher mortality rates. There was some evidence that lower health literacy contributed to racial disparities in health outcomes. The evidence regarding the relationship between low numeracy and health outcomes was very new and inconclusive.

Most of the studies in the later review used multivariate analysis to control for potential confounding variables but some did not do this in an appropriate manner. For example, many studies controlled for educational attainment (which is highly correlated with health literacy) and some controlled for variables likely to be in the casual pathway or to mediate the relationship between health literacy and health outcomes, for example they adjusted for health status when assessing the relationship between health literacy and depression. Such "overadjustment" may hide the existence of a relationship between health literacy and an outcome of interest.<sup>24</sup>

### **Health literacy and child health**

When parents have low health literacy there can be consequences for their children's health as well as their own. In their 2009 systematic review, De Walt and Hink looked at the evidence regarding the relationship between parent and child health literacy and child health outcomes.<sup>25</sup> They noted that all the research to date (2008) involved evaluations of relationships between literacy, as indicated by reading ability, and health.

All but one of the eight studies that examined parental literacy as the exposure of interest found that parents with lower literacy had less knowledge about health outcomes, health behaviours and health services.

The results of studies assessing the relationship between literacy and use of healthcare services had mixed results. One study found that asthmatic children with parents with low literacy had higher rates of emergency department visits and hospitalisation, even after controlling for potentially confounding variables.<sup>26</sup> Another study assessed the health literacy of caregivers of children who presented to an inner city emergency department in the US, and then retrospectively reviewed the children's previous use of healthcare services (four types of visits: preventive care, urgent care, emergency care, and hospital care). The study found that caregiver health literacy (in English or Spanish, as preferred) was not associated with disparities in use of child health services.<sup>27</sup> There were, however, some caregiver characteristics that were associated with greater use of child health services: being born outside the US, being a mother aged under 24 years at her child's birth, and having limited proficiency in English.

Children's literacy did not affect child health outcomes in the two studies that investigated this: one on migraine headaches<sup>28</sup> and one on glycaemic control in diabetic children.<sup>29</sup>

Four studies examined the relationship between parental literacy and child health. The previously mentioned study on diabetic children found that maternal literacy affected the child's glycaemic control. Another study found that maternal depression was associated with depressive/withdrawn symptoms in children only when there was low maternal literacy. A study of children with asthma who attended a university paediatric clinic found that children of parents with low literacy had more emergency department visits, hospitalisations, and days missed from school, and were more likely to have moderate or severe persistent asthma and greater use of rescue medications.<sup>26</sup>

A study that assessed the validity of the a newly developed Test of Functional Health Literacy in Dentistry (TOFHLiD), found that dental health literacy was not associated with parents' perceptions of either their own dental health or their children's oral health. The study authors stated that they did not know as to whether these findings meant that there was no association between dental health literacy and perceptions of oral health or that TOFHLiD was not a valid and reliable measure of dental health literacy<sup>30</sup>.

Studies published since the 2009 review by De Walt and Hink have found that lower caregiver health literacy is associated with poorer oral health behaviours, such as nighttime bottle use and lack of daily toothbrushing<sup>31</sup>, as well as with more severe oral health treatment needs<sup>32</sup> and worse oral health status<sup>33,34</sup>.

A 2017 systematic review of the evidence regarding an association between oral health literacy and oral health conditions<sup>35</sup> identified three studies that had found that low parental oral health literacy was associated with dental caries in children<sup>33,34,36</sup>. The review authors considered the evidence regarding the association between oral health literacy and dental caries in primary teeth weak and so advised that it should be interpreted with caution. They noted that the studies had used convenience samples and were relatively small (415 participants at most).

### ***Measuring the health literacy of children and young people***

There have been relatively few studies that have attempted to measure child or adolescent health literacy. A 2013 review<sup>37</sup>, which aimed to compile, analyse and describe the methodology and measurement of childhood/adolescent health literacy, identified 16 English language studies that reported on health literacy measurement in people under the age of 18, of which were published between 1980 and April 2011. Thirteen of the studies developed a new measurement tool specifically for their study and the other three used or adapted existing adult health literacy measurement tools.

The studies had a variety of reasons for wanting to measure health literacy, including: to validate a health literacy measurement tool; to measure the association of health literacy with another variable, such as behaviour, health status, social status or BMI; to measure students' perceptions of health and health literacy; and to assess the effectiveness of an intervention in improving an aspect of health literacy, for example the ability to recognise mental health problems.

The review authors concluded that the current literature did not provide a definitive description of what exactly health literacy involved for children (in or out of school settings), a definition which is required to determine what should be measured when assessing the health literacy of a child. The authors identified a lack of definition pertaining not only to health-related knowledge, but also in terms of Nutbeam's three levels of health literacy (basic/functional literacy, communicative/interactive literacy, and critical literacy).<sup>2</sup>

It follows from this that there is almost no evidence relating specifically to children and young people on associations between health literacy and health-related outcomes, the efficacy of interventions to improve health literacy, or ways to improve health outcomes for those who have low health literacy.

## **The relationship between health literacy and health disparities**

Many of the social factors associated with poor health literacy, such as low education, low income, and belonging to an ethnic minority population, are also associated with poor health status, both in New Zealand<sup>12,38,39</sup> and in other countries.<sup>13</sup> The exact nature of the relationship between social disparities and health literacy is still being investigated and so the pathways by which health literacy contributes to social disparities in health outcomes are still unclear.<sup>40</sup>

Mantwill et al.<sup>40</sup> conducted a systematic review to better understand how well the relationships between health literacy and health disparities have been systematically studied and the potential relationships and pathways identified in the literature. They included studies meeting the following three criteria: they used a valid measure of health literacy; they explicitly conceived a health disparity as being related to a social disparity, such as education or race/ethnicity; and they presented their results by comparing two or more groups affected by a social disparity and explored how health literacy affected associations between social disparity and health outcomes.

Thirty-six studies were included. Most investigated racial/ethnic disparities and a few investigated educational disparities. One study investigated the contribution of health literacy to potential gender differences in health. All but five studies had been conducted in the US, and the others in Canada, China, the Netherlands and the UK. The health-related outcomes used in the studies were: self-reported health status; cancer-related outcomes; medication adherence/management; disease control; preventive care, and end-of-life decisions. Most of the data sets that were used in the studies had been originally collected to investigate relationships other than those between health literacy and health disparities.

The reviewers found some limited evidence that health literacy mediates educational and racial/ethnic disparities in self-reported health status. For example, a study of older U.S. adults who participated in the 2003 National Assessment of Adult Literacy found that health-related print literacy significantly mediated racial/ethnic (black vs. white) disparities in self-rated health status and receiving an influenza vaccination.<sup>41</sup> There was also some evidence that health literacy mediated the relationship between racial/ethnic disparities and medication adherence/management and health knowledge. A study investigating predictors of misunderstanding instructions for paediatric liquid medications in the U.S. found that, in an adjusted analysis that excluded literacy, African Americans were more likely to misunderstand instructions when compared to Caucasians; however, when literacy was included in the analysis, the effect of race on misunderstanding became insignificant.<sup>4</sup>

The reviewers noted that only a few studies tested hypotheses concerning pathways and systematically scrutinised the relationship between health literacy and health disparities. They suggested that longitudinal studies would shed more light on the potential causal pathways that link health literacy and other mediating variables to health disparities.

It is possible that one pathway by which low health literacy leads to lower health status is in cases where a health system provides a lower quality of service to people with lower health literacy. A recent U.S. study<sup>42</sup> of caregiver health literacy done in a paediatric emergency department found that both low caregiver health literacy and minority race were associated with less radiologic testing (fewer x rays). However, it also found that, in analysis stratified by caregiver health literacy, minority race was associated with less radiologic testing only when caregivers had low health literacy and there was no difference among those with adequate health literacy. This study used bivariate and multivariate analyses adjusting for ED triage level, child insurance, and chronic illness. It measured caregiver health literacy using the Newest Vital Sign test.<sup>43</sup>

In their discussion the study authors noted that caregivers with low health literacy are less likely to provide an adequate history (describe their problem well) and tend to lack the skills to participate in shared medical decision making. They stated that their study did not support the presumption that health providers would do more testing if they had a lack of information (e.g. due to a caregiver giving a poor history) and stated that it is concerning that a disparity in healthcare resource use exists when there is no biologic basis for differential testing.

## Health literacy interventions

Policy makers, researchers and healthcare practitioners have focused on health literacy because it is something that is both amenable to intervention and a means through which health disparities can be reduced.<sup>11,44-46</sup> It may be that they feel that low health literacy is easier to address, more within the sphere of influence of the health system, and less of a political issue than other social determinants of poor health, such as poverty, lack of education, or racism. However, without action on these wider determinants of health, addressing health literacy may yield only modest population health benefits.

Interventions to address health literacy can be implemented at various levels: the individual, the population or the health system. They can aim to improve people's health literacy, or to reduce the health literacy demands of obtaining healthcare, or both. The following sections review individual-level, population-level and health system level health literacy interventions. There is a focus on interventions that can be delivered by the health system, because this article is written primarily for a health system readership. It should not be forgotten, however, that addressing health literacy requires a whole-of-society approach involving national and local government, the health sector, the education sector, workplaces and businesses, and community organisations such as libraries, the media, cultural and religious organisations, immigrant and refugee settlement services, unions, and senior citizens' groups.<sup>47,48</sup>

### ***Health literacy Interventions for individuals***

Health literacy research in this area addresses the question: How can we improve health outcomes (or health-related outcomes) for people with low health literacy? To be considered health literacy research, a piece of research examining the effectiveness of an intervention must have established that all or some study participants had low health literacy, through use of a recognised health literacy measurement tool, and measured outcomes for low literacy participants.

A number of systematic reviews,<sup>17,25,49-54</sup> and reviews of reviews,<sup>55,56</sup> have examined interventions to improve the health literacy of individuals and to mitigate the effects of low literacy on individuals' health outcomes.

The 2011 review by Berkman et al. for the U.S. Agency for Healthcare Research and Quality (AHRQ)<sup>49</sup> looked at the effectiveness of interventions to mitigate the effects of low health literacy on: use of health services; health outcomes; costs of healthcare; and health disparities.

The interventions were tested in populations with varying proportions of people with low health literacy or low numeracy. Twenty-one studies examined the effects of interventions specifically within low literacy subgroups, although many were underpowered (too small to be able to measure statistically significant differences) for these analyses and/or didn't adequately control for confounding. The other studies examined the effects of interventions in populations, including individuals with both high and low health literacy or numeracy, and so provided only supportive evidence about the effect of interventions to mitigate the effects of low literacy.

The strategies used in the single strategy interventions included alternative document design (2 studies), alternative presentation of numerical information (3 studies), additive or alternative pictorial representations (8 studies), alternative media, such as video or slideshow (4 studies), and a combination of simplification of readability and document redesign (7 studies). There was also one study examining the effects of notifying physicians of patients' literacy status on health outcomes. The mixed intervention studies included a combination of the strategies already mentioned and other strategies intended to improve patients' knowledge, disease, self-efficacy, behaviour, adherence, quality of life, and use of healthcare services.

Overall, the strength of the evidence regarding the effect of specific intervention design features for low health literacy populations was low, primarily because of differences in the interventions, and subsequent results. The review authors did note several design features that had improved understanding in low health literacy populations, in one or a few studies. These included: presenting essential information by itself; presenting essential information first; presenting information so that the higher number (rather than the lower number) indicates better quality; using the same denominator to present baseline risk and treatment benefit information; adding icon arrays to numerical presentation of treatment benefit; and adding video to verbal narratives. They also noted that their previous (2004) review for the AHRQ<sup>17</sup> had identified potential benefit from using reduced reading level and illustrated narratives. There were some design features that seemed to worsen comprehension: using coloured traffic light symbols to denote hospital quality (one study), and adding symbols to non-essential quality information such as patient satisfaction (one study).



Icon arrays (also known as pictographs) are a way of illustrating proportions, for example the proportion of patients with a disease who will benefit from a particular treatment, using a series of dots, human figures, or faces, a proportion of which are shaded to represent the proportion of individuals affected.

As well as reviewing studies in groups by intervention type, the review authors looked at studies of mixed interventions (those employing a variety of strategies) in groups according to outcomes. They found moderate evidence that the studied interventions change healthcare service use; specifically, they found that intensive self-management and adherence interventions (for chronic conditions such as asthma or congestive heart failure) appear to be effective in reducing emergency room visits and hospitalisations.

Educational interventions and/or cues for screening increase colorectal cancer and prostate cancer screening. (The review authors noted that it is questionable whether prostate cancer screening is beneficial.)

There was moderate evidence that some interventions change health outcomes: intensive self-management interventions appear to improve disease control in chronic conditions such as diabetes and asthma. They also increase self-management behaviour but, in the only study that did analysis stratified by health literacy level, a self-management intervention had a greater effect in the high health literacy subgroup than in the low health literacy subgroup. There was insufficient evidence regarding the effects of other mixed strategy interventions on other health-related outcomes, including knowledge, self-efficacy, adherence, health-related skills, quality of life, and cost. This was because the studies addressing these outcomes had mixed results. There was also insufficient evidence regarding the effects of health literacy interventions on behavioural intent or disparities, because too few studies had addressed these outcomes.

Common features of nearly all of the interventions that improved distal outcomes (such as self-management, hospitalisations or mortality) were: high intensity; a theory basis; and an emphasis on skill building, pilot testing before implementation; and delivery by a health professional, such as a diabetes educator or a pharmacist. Studies that examined multiple outcomes reported that, in addition to changing distal outcomes, interventions also changed intermediate outcomes, such as knowledge, self-efficacy and behaviour. Although none of the studies undertook formal mediation analysis (assessing how one variable affects another variable), the review authors suggested that changing knowledge and behaviour, and increasing self-efficacy, may be important aims in mitigating the effects of low health literacy.

The 2011 review by Sheridan et al.<sup>50</sup> covered 38 studies that reported results stratified by literacy level and the review, therefore, provides direct evidence about the effectiveness of interventions for people with low literacy. Of the 38 studies, 26 were included in the 2011 AHRQ review<sup>49</sup>, plus seven from the 2004 AHRQ review<sup>17</sup> and five studies identified in a February 2011 search update. As well as identifying the same effective intervention design features as the 2011 AHRQ review, this review noted one study that suggested that presenting numerical information in tables or pictographs, rather than text, improved study participants' understanding of the risks and benefits of research participation.<sup>57</sup> It also noted that several interventions had used simplified text and teach-back methodologies that have been shown to be effective in the educational and psycholinguistic literatures.<sup>58</sup>

A rapid review commissioned by the European Centre for Disease Prevention and Control (ECDPC), entitled *Interventions for Improving Population Health Literacy: Insights From a Rapid Review of the Evidence*<sup>59</sup>, summarised the findings from five reviews published from 2005 to 2009<sup>25,52,53,60,61</sup>, including a part of the 2004 AHRQ review<sup>60</sup>, and the child-specific review by De Walt and Hink<sup>25</sup> (which will be discussed in more detail later). Three of the reviews reported the quality criteria used to assess studies, and they reported that included studies were of variable quality. Almost of the studies were conducted in North America, most in the US.

Most of the interventions were directed at patients in clinical settings (or child patients' parents or caregivers, in four studies) and many were educational condition management interventions for patients with specific health conditions, such as asthma, diabetes, cancer or HIV. Most studies assessed the effects of written health information, and/or alternative formats for information presentation, such as audiotapes or videos. No studies were reported to have assessed interventions specifically for people with low literacy or for disadvantaged, minority or hard-to-reach groups. The ECDPC review authors stated that, although some studies indicated that the target group involved in their intervention had defining characteristics, such as "African-American" or "Latino-speaking", there was no indication that these groups had been chosen because they were perceived to be disadvantaged.

Like the 2011 AHRQ review<sup>49</sup>, the ECDPC review found that there was considerable variation between studies in both interventions and in outcome measures, and this made it difficult to draw firm conclusions. The ECDPC review authors stated that there seemed to be some confusion among researchers about whether health literacy should be considered as an outcome measure or as a component of the intervention process. While all five

included reviews identified some interventions that improved some outcomes, these outcomes were sometimes health knowledge or health behaviours (such as taking medication correctly), rather than health outcomes. They noted that two of the reviews' authors, Clement et al.<sup>61</sup> and Pignone et al.<sup>60</sup>, argued that, although health knowledge and health behaviours are important, improvements in these areas do not always translate into improvements in health, health services utilisation, or disease prevalence.

Not all of the reviews noted whether study results were stratified by literacy level, but, from the reviews that did, it was apparent that few studies provided this analysis. When studies do not analyse their results according to participants' literacy levels, it is impossible to measure the impacts of interventions on people with varying levels of health literacy. The ECDPC review authors stated that it is difficult to effectively target interventions to reduce health disparities and inequalities without this knowledge.

In summary, the ECDPC review, despite its title, did not identify any evidence regarding population-level interventions to improve health literacy, but did identify some interventions that may improve the health literacy skills of individual patients, for example in regard to management of their particular disease.

#### Health literacy interventions for child health

The 2009 review by De Walt and Hink<sup>25</sup> addressed the effectiveness of interventions purposed to improve health outcomes for children who have parents with low literacy, or who have low literacy themselves. It included five studies: two<sup>62,63</sup> were included in the 2004 AHRQ review<sup>17</sup>, two<sup>64,65</sup> were included in the 2011 AHRQ review<sup>49</sup>, and one<sup>66</sup> was excluded from the 2011 AHRQ review<sup>49</sup>, because it did not measure literacy or health literacy (although it was carried out in a multi-ethnic low socioeconomic area).

Four studies measured knowledge as one of their outcomes.<sup>62-64,66</sup> Two studies showed that well-designed written materials can improve comprehension for parents of all reading abilities, but had no effect on the disparity in comprehension between good and poor readers.<sup>62,63</sup> One study<sup>64</sup> evaluated four different strategies for delivering information for informed consent: (1) original consent form; (2) enhanced easy-to-read consent form; (3) computer-based presentation; and (4) video. Of the four methods, for the whole study population, enhanced written materials were as effective as video and computer-based materials. For the sub-group of parents who read below 9<sup>th</sup>-grade level, enhanced written materials were generally superior to all other methods. One study<sup>66</sup> tested a combination of a pictogram-based medication instruction sheet and brief counselling and teach-back sessions. Compared to parents in the usual-care control group, parents in the intervention group had greater knowledge about the medication dose and frequency.

This study<sup>66</sup> was the only one to measure a health behaviour outcome. It found that parents in the intervention group were more likely to use the correct medication dose and had greater self-reported adherence to the prescribed medication regimen.

One quasi-experimental study assessed an intervention for 110 minority children with moderate or severe persistent asthma in South Los Angeles.<sup>65</sup> The intervention consisted of Saturday school programme providing each child with two hours of reading instruction and 30 minutes of asthma education, plus a five day Asthma Reading Advocacy camp, held on a university campus. The minimum intervention period for each child was six months but 60% of participants enrolled for a year or more. Following the intervention there was a statistically significant decrease in both hospitalisations (from 37% to 22%,  $p < 0.001$ ) and emergency department visits (from 63% to 33%,  $p < 0.010$ ), when comparing the six months prior to the intervention with the six months during the intervention. In addition, all children showed significant improvement in their reading level and self-efficacy.

#### Information technology health literacy interventions

Information technology based interventions, often referred to as eHealth interventions, have great potential to increase health literacy through: providing information in a variety of formats (text, pictures, audio and video) and in multiple languages; supporting and enabling behaviour change; enabling communication with healthcare providers and with communities with common health interests (such as expectant parents or people with diabetes); and facilitating health and disease management.<sup>54,67</sup>

In 2015, almost three quarters of all New Zealanders had access to a smartphone (70%) and/or a laptop or notebook (72%).<sup>68</sup> Smart phones are fast becoming the most popular mobile communication device with a 48% increase in ownership/access between 2013 and 2015. Among 18–34 year olds, 91% owned or had access to a smartphone and 85% to a laptop. Forty-eight percent of all smart phone users reported using their phone more frequently than they had done in the previous year. A large majority (86%) of this group reported that they were specifically using their phone more frequently to connect to the internet with the top three reasons being looking for reference information, accessing social networking sites and online banking.

The 2015 World Internet Project New Zealand (WIPNZ) survey indicated that 91% of survey respondents were active internet users.<sup>69</sup> Older age and low income were the most important factors associated with not using the internet, although younger people aged 16 to 29 years were high users whatever their income. Pasifika respondents had notably lower internet usage scores than respondents of other ethnicities, particularly in the 40 plus age group. As more people become able to access the internet, the social disadvantage will increase for the minority who remain on the wrong side of the digital divide.

A recently published U.S. study sought to determine whether health literacy was associated with patients' uses of four kinds of health information technology (HIT) tools: nutrition and fitness apps, activity trackers, and patient portals.<sup>70</sup> Health literacy was measured using the Newest Vital Sign<sup>43</sup>. Compared to participants with low health literacy, those with adequate health literacy were significantly more likely to use all four forms of HIT. After controlling for demographic variables, greater health literacy was also associated with greater perceived ease of use and greater perceived usefulness of all the HIT tools. People with lower health literacy were more likely to perceive their information on HIT tools as private. The study authors stated that there is a pressing need to better understand how health literacy is related to HIT adoption and usage, to ensure that all users receive maximum health benefits from HIT advances, are engaged with organisations and providers they trust, and have their health and personal information kept private.

The 2016 review by Jacobs et al.<sup>54</sup> aimed to answer the question: What are the current eHealth interventions to improve health literacy? It identified 12 relevant studies. The interventions addressed a variety of issues related to health risks, lifestyles and disease management, and had a variety of theoretical foundations. The eHealth platforms included personal computers, tablets, netbooks, touchscreen computers, and personal digital assistants (PDAs) with web-based applications that included multimedia applications, such as videos and interactive self-help tools (PDAs have since been superseded by smartphones).

Due to differences between these studies in methods and rigor, quality criteria, study population, and illness or condition addressed, there were wide variations in their results and conclusions regarding computer-based applications for improving health literacy. For this reason, the review authors chose to provide only general descriptions of the major types of eHealth interventions currently being used or tested. Compared to control interventions, eHealth interventions were reportedly associated with some significantly better outcomes, or showed promise for future positive outcomes, regarding health literacy, for diverse groups of people, in a variety of settings, with a variety of diseases. The review authors concluded that: "Before eHealth interventions can be hailed as a behavior change intervention of the future, the effective components and mechanisms need to be identified, rigorously tested, and its cost effectiveness established in different contexts".

Having access to the internet does not guarantee that a person will be able to use the internet to enhance their health literacy. While there is a vast amount of health information online, the quality and accuracy of much of it is questionable.

A 2015 review by Divani et al.<sup>71</sup> aimed to review the evidence regarding the association of low health literacy and (1) people's ability to evaluate online health information, (2) perceived quality of online health information, (3) trust in online health information, and (4) the use of evaluation criteria for online information. The review included 38 articles but only four investigated the specific role of low health literacy in the evaluation of online health information. The others examined the association between educational level or other proxy measures of health literacy, such as general literacy, and one or more of the specified outcomes.

The review authors stated that, overall, the studies' results indicated a positive association between health literacy (or one of its proxies) and people's ability to evaluate online health information and trust in the internet as an information source. There was, however, inconsistent evidence regarding a relationship between health literacy and either perceived quality of online information or people's use of evaluation criteria for online health information.

Two reviews<sup>72,73</sup> have assessed the effects of interventions to enhance consumer's online health literacy (teaching people skills to search for, evaluate and use online health information). The 2011 Cochrane review<sup>73</sup> identified only two relevant studies, both of adult education classes teaching information and communication technology (ICT) skills. The review authors concluded that the evidence suggested consumer ICT skills interventions may have a positive effect on consumers' attitudes and behaviours regarding use of the internet for health information but it was too weak to permit drawing any conclusions regarding the content or the delivery of consumer internet skills interventions.

The other review, by Lee et al.<sup>72</sup>, had less restrictive inclusion criteria and reported on seven studies (one of which was a RCT included in the Cochrane review), as well as two papers from the grey literature. The reviewers provided only a descriptive critique of each study because of limitations in the design characteristics

and analysis, and perceived overall quality of the studies. Most interventions involved teaching consumers how to use the internet and/or find credible websites. Outcome measures were mostly self-assessed by study participants and included knowledge and skills pertaining to internet use and searching for reliable health information. The review authors stated that there is potential for further research to explore other ways to help consumers find reliable online health information and to assess outcomes via objective measures.

### **Interventions for populations**

According to the World Health Organization, health literacy is one of the three key elements of health promotion, along with healthy cities and good governance for health (when all government departments factor health into all their decision making and prioritise policies that prevent people becoming ill and protect them from injuries).<sup>10</sup> From a public health perspective, enhancing a population's health literacy through effective communication of health information is a key strategy for promoting health, preventing disease, and getting the best from the healthcare system. There is, however, a lack of discussion in the literature about what a health literate population looks like, or how best to assess health literacy at the population level.<sup>74</sup>

If a study is going to attempt to measure whether or not an intervention leads to improved health literacy, or an improvement in health or health-related outcomes for individuals or populations with low health literacy, then it needs to measure health literacy in some way. The existing health literacy research, most of which has been conducted with patients in clinical settings in North America, has used mostly used health literacy measurement tools such as the Rapid Estimate of Adult Literacy in Medicine (REALM)<sup>18</sup> or the Test of Functional Health Literacy in Adults (TOFHLA).<sup>19</sup> These tools have been criticised on a number of grounds: they do not actually measure health literacy; they give only a rough indication of reading skills<sup>75</sup>; and they are incapable of assessing other important aspects of health literacy, such as understanding, motivation, and ability to access and use information about health and healthcare.<sup>76</sup>

The 2015 review by Guzys et al.<sup>74</sup> looked at whether commonly used health literacy assessment tools could be appropriate for assessing critical health literacy at the population level. Critical health literacy involves having an understanding of the social determinants of health and the ability to take action to address them to promote the health of yourself, your family and your community by political and other means<sup>2,3</sup>.

The tools reviewed included, among others, the Demographic Assessment for Health Literacy (DAHL)<sup>77</sup>, the Health Literacy Questionnaire<sup>78</sup>, the All Aspects of Health Literacy Scale (AAHLS)<sup>79</sup>, and the European Health Literacy Survey Questionnaire (HLS-EU-Q)<sup>80</sup>. The review authors stated that, although developments in measuring health literacy at the population level indicate an increasing acknowledgement of the complexity of health literacy as a concept, the focus was still on the health literacy of individuals or the collation of individual data. They concluded that the current tools are unsuited for assessing critical health literacy at the societal level. They stated that collaboration with members of the general public, who have a range of literacy and health literacy levels, is required to develop an appropriate framework that could assess the critical health literacy of communities and that this framework need to integrate health promotion theories, the views of community members, a focus on the critical domain of health literacy, and a public health approach.

The lack of consensus about what population health literacy is and how to measure it is a likely reason for the lack of published quantitative studies of interventions to improve population health literacy.

Population-level interventions intended to improve a whole population's health literacy, such as health promotion or disease prevention campaigns, may be of the greatest benefit to people with higher levels of education and health literacy, and so result in increased disparity between the most and least disadvantaged groups in society.<sup>81</sup> A 2012 King's Fund study used data from the Health Survey for England to examine how four lifestyle risk factors – smoking, excessive alcohol use, poor diet, and low levels of physical activity – co-occurred in the population and how their distribution had changed over time.<sup>82</sup> This study found that, while the overall proportion of the population engaging in three or four of these unhealthy behaviours had fallen significantly, from around 33% in 2003 to around 25% in 2008, the reductions had occurred mainly among those in higher educational and socioeconomic groups. People with no qualifications were more than five times as likely as those with higher education to engage in all four unhealthy behaviours in 2008, compared to only three times as likely in 2003.

While the field of population health literacy research is in its infancy, there is a vast literature devoted to the closely related fields of health promotion and health education. It is suggested that readers view this literature with the needs of people with low health literacy in mind, and, if they are considering implementing a health education or health promotion intervention, ask themselves the question: Is this intervention likely to improve health outcomes for people with low health literacy?

## **Health literacy from a health system perspective**

Many definitions of health literacy promote the idea that health literacy is determined by the knowledge and capabilities of individuals.<sup>83</sup> Defining health literacy as an attribute of individuals suggests that improving the population's health literacy could be best achieved by improving people's literacy, numeracy, health knowledge, and communication and problem-solving skills and that this should be primarily the responsibility of the education system with the health system having a only secondary role, for example in health promotion and patient education.<sup>84</sup>

An alternative view is that poor health literacy results from a mismatch between the knowledge and capabilities of individuals and the demands of the health system.<sup>84</sup> In this view, it is the responsibility of the health system to become more user-friendly, for example by using less medical jargon in both oral and written communication, and by ensuring that written materials are not too difficult for most people to read and understand, and avoid assuming patients' familiarity with mathematical and scientific concepts. Locating health literacy in the interaction between individuals and the health system makes it possible to appreciate that a person's health literacy may vary with their situation and the barriers within their situation. For example, a person may have good health literacy in their native country but poor health literacy in a country where they do not understand how the local health system works and do not understand the local language. Anyone, no matter how good their general health literacy is, can experience low health literacy with regard to a particular decision and situation and so, for example, may find it more difficult to take in information when they are in pain, are not feeling well, or are in times of emotional stress, such as when their child is seriously ill.

New Zealand's Ministry of Health has recognised the need for healthcare organisations to reduce the health literacy demands they place on consumers and has encouraged them to carry out health literacy reviews.<sup>9</sup> The Ministry's 2015 publication *Health Literacy Review: A guide*<sup>9</sup>, offers advice on how to do this. It defines a health literate organisation as follows:

A health-literate organisation:

- Makes health literacy everyone's business – leaders, managers, and clinical and non-clinical staff
- Designs systems, processes and services that allow consumers to access services easily
- Supports operational staff to use health literacy approaches and strategies
- Eliminates confusing communication that could prevent consumers from accessing treatment easily
- Actively builds health literacy of consumers to help them to manage their health
- Makes sure operational staff understand that, no matter how high a consumer's level of health literacy is, stress and anxiety affect their ability to understand and remember new information.

There is a wealth of available information that can help healthcare organisations address health literacy barriers within their services and support their staff to build patients' health literacy. Links to some resources that may be useful are provided in the reading list at the end of this chapter. This information draws on the evidence that is discussed in the section on interventions for individuals, and on the evidence relating to healthcare consumer empowerment and communication strategies, but there is little direct evidence for the effectiveness or cost effectiveness of many of the recommended actions. This is largely because the field of health literacy is still evolving, and health literacy interventions tend to be complex and may not produce measureable changes in health outcomes for many years, and are therefore unsuited to evaluation through randomised controlled trials.<sup>48</sup>

The following sections discuss a few of the strategies that healthcare organisations and healthcare professionals can use to reduce health literacy barriers.

### Screening for low health literacy: Is it a good idea?

It can be difficult for health professionals to identify patients or caregivers with low health literacy, especially if they have good oral communication skills, and health professionals generally overestimate the health literacy of their patients.<sup>85,86</sup> Over the last twenty years, many different tools to measure health literacy in various contexts have been developed.<sup>87,88</sup> Some are sufficiently quick to administer that they are suitable as screening tools to identify patients with low health literacy.

Some people have advocated that all patients should receive health literacy screening when they enter a healthcare facility so that patients with low health literacy can be given extra help.<sup>89,90</sup> Such an approach, however, may be embarrassing and stigmatising for patients<sup>91</sup> and it has been argued that there is no evidence that additional training or support for patients with low health literacy is beneficial.<sup>92</sup> Using screening to alert healthcare professionals to patients with limited health literacy may not improve outcomes for those patients. A trial in a U.S. public hospital examined the effect of notifying physicians in cases where their diabetes patient

had limited health literacy and found that, although the notified intervention physicians were more likely (when compared to control physicians) to use management strategies recommended for patients with low health literacy, both intervention and control patients had similar post-visit self-efficacy scores and similar changes in follow-up glycosylated hemoglobin values (HbA1c, a measure of diabetes control).<sup>93</sup>

A UK study interviewed people who sought help from an Adult Learning Centre about their experiences with health and health services and asked participants to suggest ways that health services could better support people with low literacy.<sup>94</sup> Most participants strongly preferred to avoid disclosing their literacy difficulties and they reported experiencing fear of their difficulties becoming apparent, which had led them to have guarded relationships with healthcare staff and avoid querying words they did not understand. Some suggested that healthcare staff needed education about dyslexia and literacy problems. Many advocated the simplification of written information, including signage, appointment information, instructions for taking medicine, and healthcare leaflets. They also suggested that their understanding of clinical information would be much better if health professionals explained things using lay terminology rather than medical terminology and jargon.

#### The alternative: Universal precautions

To work around cases in which patients with low health literacy avoid self-disclosure and are difficult to identify, healthcare professionals can take a universal precautions approach. This means that the professional assumes that all patients, regardless of their health literacy level, may have difficulty understanding and using health information<sup>95</sup>, just as health practitioners who are exposed to patients' blood or other body fluids assume that any patient may have a blood-borne disease and wear gloves with all patients. Health literacy universal precautions aim to:

- Simplify communication with all patients, and confirm that they have understood what has been communicated to them to minimise the risk of miscommunication
- Make the healthcare system and the office environment easier to navigate
- Support patients' efforts to improve their health.

The universal precautions approach is recommended by the U.S. Agency for Healthcare Research and Quality (AHRQ)<sup>95</sup>, the U.S. Department of Health and Human Services<sup>45</sup>, the New Zealand Medical Association<sup>96</sup>, Health Quality & Safety Commission New Zealand<sup>97</sup>, and the Australian Commission on Safety and Quality in Health Care<sup>98</sup>.

#### Addressing health literacy in healthcare services by reviewing the patient experience

An approach that may be helpful for healthcare organisations that conduct health literacy reviews involves focusing on the key tasks undertaken by patients and visitors who enter a healthcare facility and identifying the health literacy demands associated with these tasks.

The U.S. publication *The Health Literacy Environment of Hospitals and Health Centers*<sup>99</sup> contains the *Health Literacy Environment Review*, a series of detailed checklists that can be used to rate a hospital or health centre in the areas of Navigation, Print Communication, Oral Exchange, Technology, and Policies and Protocols. Checklist items include items relating to the phone system, signage (including graphics and maps), the information desk, whether staff offer assistance with paperwork, whether print materials have features that improve comprehension for people with limited literacy (such as a summary of main points, simple everyday words and short sentences, an uncluttered layout, and visuals to reinforce key messages), whether staff use good oral communication practices (such as checking for understanding and avoiding unnecessary medical jargon), and whether there is health literacy training for staff.

A hospital walkthrough, in which observers take a patient's appointment letter and use it to get themselves to the appointment, is one way of finding out how easy it is for patients to navigate a hospital.<sup>99,100</sup> In Dundee, Scotland, a group of people, including adult learners, students and health workers, walked through Ninewells Hospital and found that the information in the appointment letter was different to the signs at the hospital. The letter used different terms to refer to the same place, for example the letter read "Children's Outpatient Department" while the sign read "Tayside Children's Hospital".<sup>101</sup> The group also found that, although volunteers at the hospital were helpful, the directions they offered were too complex.

Further insight into the patient experience can be obtained by shadowing a patient for a day, observing their experiences, listening to what they have to say, and mapping the flow of care.<sup>98,102</sup> It is usually preferable to choose a shadower who is not familiar with the care experience being shadowed because they are likely to be more open-minded and have fewer preconceptions.<sup>102</sup>

The use of mystery shoppers is another way to gain a better understanding of the consumer experience of health and social care services and identify areas for improvement.<sup>98,103</sup> A study conducted for the Department of

Health in England<sup>104</sup> used mystery shoppers to explore how patients, service users and carers found out about locally available services and about how to access them.

The mystery shoppers carried out enquiries into a region other than the one they lived in by phone and by acting out scenarios, for example: “I am considering moving to [area], and I am trying to find out about local services in advance”. The scenarios were developed in discussions with three distinct focus groups consisting of ethnic minority older people, people affected by long term physical conditions (multiple sclerosis and diabetes), and parents of children or young people with autism. The specific types of services sought depended on the condition the shopper was affected by. This study highlighted a number of problems: when messages were left on service provider’s answerphones, it was common to not receive a call back; it was common to be passed around within the organisation or between different organisations and general enquiry lines without being referred to individuals and information sources more relevant and potentially helpful to the enquiry; and there were cases where organisations refused to provide information to people who had not been formally referred to the service.

Other key findings included the following.

- Organisations contacted were usually friendly but sometimes unhelpful. Health professionals, who are often responsible for the first diagnosis or are the first port of call for patients seeking help in managing their condition, did not systematically or proactively provide their patients with information about accessing local services.
- There was a lack of coordination between information providers across boundaries: geographical, sectorial and organisational
- There was a lack of effective signposting. While there is plenty of information available, service users often have to dig it out for themselves, and they may not know what it is they need to know.

The authors of this study pointed out that their research participants all had experience of living with long-term health conditions, and were mostly highly motivated, articulate and assertive, and therefore represented the more capable end of the ability range for information-seekers. They stated that people who were new to needing to get service information, or who did not have the same personal skills and qualities, were likely to struggle even more.

The mystery shopper strategy was used in New Zealand in 2001 in the evaluation of the clinical safety of a pilot 24 hour telephone triage service.<sup>103</sup> Academic GPs developed four scripted clinical scenarios, designed to necessitate a referral to a GP for further investigation, that were used by simulated patients to make telephone calls to the triage service.

#### Patient navigators

Patient navigators are people trained to help patients overcome individual-level barriers to obtaining healthcare and navigating the healthcare system, especially patients disadvantaged by low health literacy, poverty, belonging to an ethnic or cultural minority, poor English language skills, or lack of social support.<sup>105</sup> The concept originated in the early 1990s in Harlem, New York where patient navigators were introduced as advocates for poor black women with abnormal cancer screening findings.<sup>106,107</sup> The navigators dealt with barriers to timely care commonly experienced by women, including: financial barriers, such as not having health insurance; communication and information barriers; medical system barriers, such as lost or missed appointments; and fear, distrust and emotional barriers. Navigation increased the proportion of women who had a recommended breast biopsy, and the women who got a biopsy did so more quickly when they had a navigator.

Patient navigators may be community health workers, lay health educators, peer health promoters, cancer survivors, social workers or nurses. The literature on patient navigators is largely related to navigators for cancer patients in the US<sup>108,109</sup> but there are some studies reporting on patient navigators for other kinds of patients, for example postpartum women<sup>110</sup>, smokers hoping to quit<sup>111</sup>, patients with chronic kidney disease<sup>112</sup>, and homeless people with serious mental illness.<sup>113</sup>

In their 2008 review, Wells et al.<sup>108</sup> provide a qualitative synthesis of the literature on cancer patient navigation published prior to October 2007. They identified 45 articles, 16 of which provided data on the efficacy of patient navigators in increasing participation in cancer screening and adherence to diagnostic follow-up care after detection of an abnormality. In comparison with control patients, the reported increases in screening ranged from 11% to 17%, and the reported increases in adherence to diagnostic follow-up care from 21% to 29%. There was less evidence that patient navigation was efficacious in reducing either late-stage cancer diagnosis or delays in starting cancer treatment, or improving outcomes during cancer survivorship. Most studies had methodological limitations, such as lack of control groups, small sample sizes, and combining navigation with

other intervention components, such as counselling. This review found no evidence regarding the cost-effectiveness of patient navigation.

The 2011 review by Paskett et al.<sup>109</sup> updated the 2008 review by Wells et al.<sup>108</sup>. It identified 33 studies published from November 2009 through July 2010, almost all conducted in either the U.S. or Canada. Consistent with the earlier review, this review found some evidence for the efficacy of patient navigation in increasing cancer screening rates. However, there was less recent evidence regarding the benefits of patient navigation in relation to diagnostic follow-up or in the treatment setting. There was still little research focussing on patient navigation during cancer survivorship. Many studies had methodological limitations including small sample sizes and lack of control groups.

One of the key strengths of patient navigators is that they understand the culture and beliefs of the patients they serve.<sup>114</sup> In many ways, the Native Patient Navigators for American Indians<sup>114</sup> perform similar roles to New Zealand services such as Dunedin Hospital's Māori Health Liaison Service<sup>115</sup> or Whānau Ora navigators.<sup>116</sup>

#### Patient navigators in New Zealand

The use of patient navigators for cancer patients has been explored in New Zealand. The Ministry of Health funded three pilot projects, which ran from the end of 2008 to June 2010, that were contracted to deliver both patient navigation for cancer patients and community health promotion.<sup>117,118</sup> The projects aimed to reduce barriers to cancer service access and care for Māori (in Rotorua and Tāmaki, Auckland) and for people living in rural areas (on the West Coast).

The projects' evaluation, based on consultation with more than 2300 stakeholders, reported that the activities of the cancer support services included smoothing patients' transitions through primary/community and secondary health and social services, and facilitating patient and whānau links with healthcare specialists, social service providers, NGOs, PHO based programmes, and community based support services.

Many service users were deeply grateful for the help they received. Service users showed their satisfaction in a number of ways, and some of these contributed to service sustainability, for example volunteering to work with the cancer support team and promoting the service to friends and whānau.

The evaluation compared the project clients who were Māori and/or had high NZDep scores with the proportion who were Māori and/or had high NZDep scores among patients first admitted to hospital with cancer during the pilot project. It was found that relatively more of the project clients were Māori or had high NZDep scores, indicating that the project was fulfilling its aim of reaching the groups most affected by disparities in cancer outcomes. For example, although only 6% of patients first admitted to hospital in the Auckland region in 2008–2010 were Māori, over 62% of the Tāmaki's project's 133 service users were Māori.

Although existing service providers initially exhibited some patch protection behaviours in response to the new service, over time these issues abated and health and social service providers noted benefits including streamlining engagement between services and service users, and time savings because patients' social and emotional needs were being addressed by the cancer support team and because patients were better prepared for appointments.

The evaluation reported that the pilot project did not have a sufficiently rigorous design to permit a direct assessment of whether it contributed to improving overall cancer outcomes for service users or the wider community.

After the end of the three-year pilot, the West Coast Primary Health Organisation decided to continue the patient navigator service and expand it cover other patient groups including patients living with social complexity and other long term conditions such as cardiovascular disease, diabetes and chronic obstructive pulmonary disease.<sup>119</sup> This service used lay navigators whose functions were to:

- Provide additional support for patients with long term conditions and family/whānau with complex social needs
- Improve access to healthcare
- Support primary healthcare
- Improve access to social support services
- Enhance health literacy and ability to self-care
- Improve health outcomes and reduce health disparities
- Decrease unplanned emergency department visits and hospital admissions.



The service chose as navigators people with experience working in primary healthcare or the community, or as caregivers, with knowledge of the local community and established networks.

After two years, an evaluation was undertaken with a focus on two key questions: was the target audience being reached; and were general practices and rural clinics feeling supported by the service? The results indicated that most of those referred to the service, 59%, lived in areas of high socioeconomic deprivation. Eleven percent were Māori, 53% were male, and 59% were aged 65 years or more. They generally had three or more chronic conditions, most commonly heart disease, cancer, respiratory disease and diabetes. The leading reasons for referral were transport, access to support services, complex social situations and financial assistance. The survey results indicated that the two main reasons health and social care professionals referred clients to the service were to improve access to services, and for support. Overall, the professionals were highly satisfied with the service, but four of the 13 who responded to the statement “the health navigator keeps me informed of the progress my patient is making” did not agree with the statement. To deal with this issue, a direct emailing system was established to provide referrers with standardised feedback on the allocated navigator and their patient’s progress.

#### Patient navigators for children

Patient navigation could be of benefit for children, especially those with long-term health conditions. The 2013 review by Raphael et al.<sup>120</sup> aimed to systematically assess the effectiveness of lay health worker interventions in improving healthcare utilisation, symptom management, and family psychosocial outcomes for children with chronic conditions. The review authors included the term “patient navigator” among their search terms.

The review authors identified 17 studies meeting their criteria. All addressed one of the following four specific conditions: asthma (11 studies), type 1 diabetes (4 studies), obesity (1 study), or failure to thrive (1 study). Most studies targeted minority populations of low socio-economic status. Due to the heterogeneity of the interventions and outcome measures, meta-analysis was not feasible. Several of the interventions were multi-faceted, including both on-on-one and group interactions. The nature of the services provided by the lay health workers varied but all included educational components. Two of the diabetes interventions involved clinic-based ambassadors who tried to improve clinic attendance and follow-up visits to the clinic through phone calls and letters. The most commonly reported positive effects of the interventions were reduced use of urgent care, decreases in symptoms, fewer missed school and work days, and improved parental quality of life. One study showed that lay health worker interventions were cost effective.

The review authors concluded that lay health worker interventions for children with chronic conditions may lead to modest improvements in urgent care use, symptoms, and parental wellbeing, and may also be cost-effective. In their discussion, the authors stated that, overall, the evidence suggested that the use of lay health workers may be an important strategy for improving care, and warrants further study. They noted that although patient navigation, as provided to adults with cancer, includes components grounded in self-efficacy and social support theories similar to lay health worker interventions, it also incorporates practical assistance to improve desired outcomes. A patient navigator might, for example, organise child care for a parent’s other children and transport to the clinic. They suggested that patient navigation may represent a new model for lay health worker intervention for children in the future.

A 2010 Cochrane review assessed the evidence on the effects of lay health worker (LHW) interventions in primary and community care on maternal and child health and the management of infectious diseases. In many of the studies, LHWs worked among low-income or minority populations in high-income countries, or in low-income countries. Meta-analyses were undertaken for four groups of broadly similar studies. In regard to maternal and child health outcomes, these indicated that there was moderate quality evidence for the effectiveness of LHWs in promoting childhood immunisation uptake and breastfeeding (initiation of, any and exclusive), in comparison to usual care. There was also low quality evidence that, compared to usual care, LHWs may reduce child morbidity, and child and neonatal mortality, and increase the likelihood of seeking care for childhood illness. For other maternal and child health issues, the evidence was insufficient to draw conclusions about the effectiveness of LHWs, or to make it possible to identify specific LHW training or intervention strategies likely to be most effective.

#### The Ophelia approach: Addressing health literacy and health inequity through partnering with consumers

Working in partnership with communities and healthcare consumers to develop services and information resources can help to both build people’s health literacy and reduce the health literacy demands of obtaining healthcare.<sup>121</sup>

The Ophelia (OPTimising HEalth LIterAcy) Victoria project is a collaboration between higher education researchers at Deakin and Monash Universities, the Victorian Department of Health, and nine health service sites across Victoria.<sup>121,122</sup> The overall aim of the project was to develop and test a structured approach that

organisations can use to enhance equitable engagement of consumers in health and healthcare. The guiding principles were: Outcomes focused, Equity driven, Needs diagnosis, Co-design, Driven by local wisdom, Sustainable, Responsive and Systematically applied.

The Ophelia approach includes three key phases. Phase 1 involves conducting a health literacy assessment on a representative cross section of people associated with a service or sector. The results of this assessment are then presented to stakeholders to stimulate discussion and idea generation for strengthening services and practises. In Phase 2, local stakeholders decide on priorities for action and plan and develop interventions that have potential to respond to local health literacy needs or improve information or service access. In Phase 3, continuous Plan-Do-Study-Act quality improvement cycles are used to implement, refine and evaluate the interventions.

A new health literacy measurement tool, the Health Literacy Questionnaire (HLQ), was developed for the project.<sup>78</sup> The HLQ is designed to capture and measure all aspects of the concept of health literacy. It comprises nine separate scales, each describing a different aspect of health literacy. People's scores on each scale reflect both their personal level of health literacy and their experiences attempting to engage with health information and health services. The nine scales are: 1) Feeling understood and supported by healthcare providers; 2) Having sufficient information to manage my health; 3) Actively managing my health; 4) Social support for health; 5) Appraisal of health information; 6) Ability to actively engage with healthcare providers; 7) Navigating the healthcare system; 8) Ability to find good health information; and 9) Understanding health information well enough to know what to do.

Eight organisations (one of which operated on two sites) were recruited into the project after expressions of interest were sought from service organisations providing Home and Community Care (HACC) services, Hospital Admission Risk Programs (HARP) or community nursing and other chronic disease services.<sup>122</sup> Each site was required to establish their own project team to lead activities and liaise with the academic research team. Most organisations developed interventions that targeted older clients with chronic conditions. They focussed on improving clients' health through mechanisms such as enhancing the ability of clients or community members to self-manage their health, understand health information, or engage more effectively with healthcare providers.

The researchers identified four distinct intervention pathways across the study sites:

- Providing clinicians with skills training and resources to support them to respond to a range of health literacy strengths and limitations when working to build clients' capacity to self-manage their long term conditions (3 sites)
- Using community volunteers to act as mentors thus building community members' capacity to achieve better health outcomes (2 sites)
- Providing clients with resources or targeted training to improve their health literacy (3 sites)
- Redesigning existing service procedures to improve access to services for people with different health literacy strengths and limitations.

Organisations undertook a variety of evaluation activities including pre-post HLQ scales, interviews and focus groups. All used a quasi-experimental (pre-post) design with five of the nine sites using a mixed methods approach. Across the nine sites, 228 clients (range 5–70 at each site) and 22 volunteers (range 8–14) participated in evaluation activities (813 clients completed an initial HLQ). Forty-two staff (range 4–10) involved in intervention delivery were also interviewed. Qualitative data indicated small, but positive, impacts for clients, volunteers and clinicians. Seven sites also undertook quantitative analysis. Effect sizes for individual HLQ scales were nil/minimal in two sites, moderate in two sites, and moderate to large in one site, although none were statistically significant due to small numbers of participants. The study authors noted that their study is one of very few studies that have shown improvement in any standardised health literacy measure.

The Ophelia project demonstrates a process that can be applied by a wide range of stakeholders and organisations to develop fit-for-purpose health literacy interventions that improve outcomes at a number of levels: organisational processes, staff knowledge and skills, community engagement and client outcomes and equity.

## Conclusions

In a modern society, the level of health literacy required to take optimal care of their own and their children's health is beyond the capabilities of many people. People with low health literacy tend to be people who are disadvantaged in other ways: by lack of education, poverty, and membership of ethnic minority groups.

Nevertheless, anyone can experience low health literacy, especially under the stress resulting from illness in themselves or a family member.

Everyone working in the health system needs to be aware of this and strive to make it easier for people to manage their own health and to navigate the health system. Making it easier requires action at multiple levels: at the health system level, at the health services level, and at the health professional level. It requires improvements in health information, communication, informed decision making, and access to health services. Partnering with healthcare consumers is essential for understanding the patient perspective and making health services more user friendly.

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