

# A Vision for a Health Literate Canada

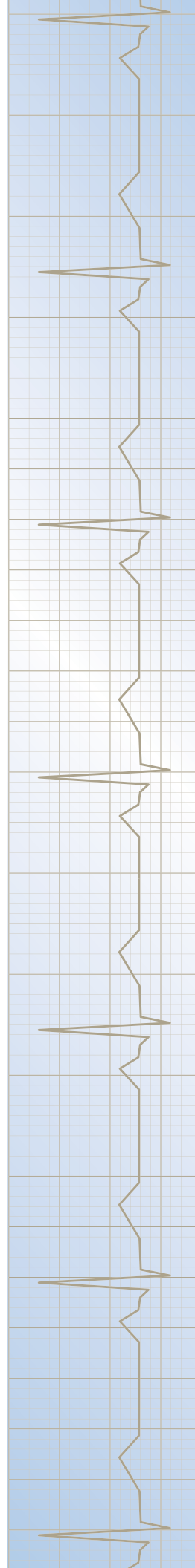
Report of the Expert Panel on Health Literacy

*Irving Rootman and Deborah Gordon-El-Bihbety*



**CPHA**  **ACSP**

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Canadian Public Health Association  
400-1565 Carling Avenue  
Ottawa, Ontario K1Z 8R1  
Tel: 613.725.3769  
Fax: 613.725.9826  
Email: [info@cpha.ca](mailto:info@cpha.ca)

The Canadian Public Health Association is a national, independent, not-for-profit, voluntary association representing public health in Canada with links to the international public health community. CPHA's members believe in universal and equitable access to the basic conditions which are necessary to achieve health for all Canadians.

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## Acknowledgements

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### Expert Panel Members

Irving Rootman, Co-chair  
Health and Learning Knowledge Centre, Canadian Council on Learning

Elinor Wilson, Co-chair (April 2006–April 2007)  
Canadian Public Health Association

Deborah Gordon-El-Bihbety, Co-chair (May 2007–March 2008)  
Research Canada

Heather Armson  
College of Family Physicians of Canada

Patricia Ashie  
Movement for Canadian Literacy, Learners Advisory Network

Bruce Beairsto  
School District No. 38 (Richmond, BC)

Monique Bégin  
University of Ottawa

Cindy Blackstock  
First Nations Child and Family Caring Society of Canada

Doris Gillis  
St. Francis Xavier University

T. Scott Murray  
DataAngel Policy Research, Inc.

Iraj Poureslami  
University of British Columbia/Simon Fraser University

Lise Renaud  
Université du Québec à Montréal, Groupe de recherche médias et santé

Linda Shohet  
The Centre for Literacy of Quebec

Ellen Szita  
Movement for Canadian Literacy, Learners Advisory Network

Lewis Williams  
University of Saskatchewan

### **Steering Committee**

Wendy Desbrisay  
Movement for Canadian Literacy

Fernando Cartwright  
Canadian Council on Learning

Penny Milton  
Canadian Education Association

### **CPHA Staff**

Helen Simson, Project Director  
Allison Imrie, Project Officer

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### **External Reviewers**

Donald Nutbeam  
University of Sydney

Rima Rudd  
Harvard University

David Kindig  
University of Wisconsin

### **Other Contributors**

Focus group participants in Edmonton, Saskatoon, Truro, Victoria,  
and rural Prince Edward Island

Key informants in Corner Brook, Saint John, Montreal, Calgary

## Foreword

When the Expert Panel on Health Literacy began its work in spring 2006, we suspected that health literacy was an important issue. However, none of the Panel members had any real idea of the dimensions of the problem because at that time, Canada-wide data on health literacy were not available. During the course of our investigation, such data became available, based on the development of a health literacy scale for the International Adult Literacy and Skills Survey (IALSS). This survey tested more than 23,000 Canadians using rigorous methods developed by Statistics Canada in collaboration with international survey organizations.

When we finally saw the numbers, we were surprised to learn that more than half of working age adults in Canada (55% or 11.7 million) are estimated to have less than adequate health literacy skills. We were shocked to learn that 88% of adults over the age of 65 (3.1 million) appear to be in this situation. Consequently, our suspicion that Canada has a serious health literacy problem has been validated.


Of even greater concern is the relationship between health literacy and self-reported health status. The IALSS found much higher average health literacy scores among adults who reported excellent health, compared to those who reported poor or fair health status. Differences in average adult literacy levels have been shown to exert a significant influence on the economic success of people and of nations. Other research shows a strong link between low health literacy and a number of negative health outcomes and suggests that low health literacy may contribute to higher health service costs. These findings imply that addressing the issue of health literacy could lead to significant improvements in the health of Canadians.

The Expert Panel also learned that health literacy involves the integrated use of a wide range of skills, so improving capacity will not be a simple task. Nevertheless, we are optimistic that a concerted pan-Canadian effort building on existing initiatives could improve health literacy levels or at least mitigate the worst effects. Policies and programs to enhance health literacy must be included in Canadian strategies to maintain a sustainable and effective health care system. These efforts must also provide supports for those who are unable to reach the levels required to cope with sophisticated health information and an increasingly complex health care system. They also must address the challenges of producing culturally coherent information that reflects Canada's diversity.

Our future as a healthy and prosperous society is intimately linked to the public policy choices we make today. This report by the Expert Panel on Health Literacy consolidates the research on health literacy and points to changes in communication strategies, practices, procedures and policies that will ultimately improve health literacy and the well-being of all Canadians.



*Irving Rootman*  
Co-Chair



*Deborah Gordon El-Bibety*  
Co-Chair

## Preface

The Expert Panel on Health Literacy is the latest in a series of health literacy initiatives led by the Canadian Public Health Association (CPHA). The Expert Panel was convened in April 2006 in response to recommendations by delegates at the Second Canadian Conference on Literacy and Health in October 2004. The delegates called for policies, programs and research to improve health literacy and reduce health disparities in Canada.

Fourteen Expert Panel members were selected according to their knowledge of and experience with issues related to health and literacy. Five focus groups were held, during which Panel members listened carefully as adult literacy learners described their experiences and the barriers they have encountered while navigating health information and services. This information was supplemented by interviews with policy makers, service providers and advocates, and by the results of an electronic questionnaire completed by more than 650 individuals across Canada.

The Expert Panel's vision for health literacy in Canada includes an integrated, nationwide strategy to tackle the challenge of low health literacy, particularly among priority groups. CPHA joins the Panel in looking forward to the day when everyone in Canada has the capacity, opportunities and support they need to access and use health information effectively.

CPHA appreciates the contribution of the Expert Panel, the project funders, the adult literacy learners and other key informants who helped shape this vision for better health outcomes in Canada. We are grateful to the Health and Learning Knowledge Centre of the Canadian Council on Learning for funding the Expert Panel's review, as well as to the National Collaborating Centre for Determinants of Health for funding additional research to inform the review.



*Debra Lynkowski*  
Chief Executive Officer  
Canadian Public Health Association

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# Chapter 1: Introduction

## 1.1 Background

Interest in the relationship between literacy and health developed in Canada in the late 1980s, partly as a reaction to growing concern about lower than expected levels of literacy among the Canadian population. This concern was stimulated by two surveys and media attention to the matter and led to a project on literacy and health by the Ontario Public Health Association and Frontier College from 1989–1993 and the establishment in 1994 of the National Literacy and Health Program, housed by CPHA.

During the 1990s, interest in the concept of health literacy continued to develop. At the international level, the World Health Organization (WHO) introduced the concept in its glossary of health promotion terms in 1998. In the United States, studies examined the relationship between health literacy and health outcomes. The American Medical Association created an ad hoc committee on health literacy in 1999. In 2000, the U.S. Department of Health and Human Services included health literacy as a national health promotion objective (U.S. Department of Health and Human Services, 2000). Subsequently, the Institute of Medicine released a groundbreaking report, entitled *Health Literacy: A Prescription to End Confusion* (Nielsen-Bohlman, Panzer & Kindig, 2004).

The concept of health literacy was discussed at the First Canadian Conference on Literacy and Health in 2000 and at the Second Canadian Conference in 2004, where delegates recommended the establishment of a Canadian expert committee on health literacy (CPHA, 2006a). In 2006, the Health and Learning Knowledge Centre of the Canadian Council on Learning funded CPHA to establish the Expert Panel on Health Literacy.

## 1.2 Expert Panel Terms of Reference

CPHA established a steering committee, which defined the following terms of reference for the Expert Panel.

1. Define the scope of the problem of health literacy in the context of literacy and health by assessing the quality of existing evidence on:
  - The extent of literacy and health literacy in the adult population in Canada and
  - The relationship between literacy, health literacy and health outcomes, including the financial burden produced by low levels of population health literacy.
2. Identify barriers to creating a health literate public reflective of Canada's unique cultural makeup, with specific reference to:
  - Francophones

- Aboriginal people
  - Ethnocultural populations
  - Other populations as identified during the project.
3. Assess the effectiveness of existing interventions to improve health literacy.
  4. Assess the implications of the evidence for policies and programs to improve health literacy through the development of recommendations for health literacy efforts in Canada.

### 1.3 Expert Panel Process

Panel members were selected by CPHA to represent a broad range of expertise, experience, and knowledge related to literacy and health literacy. CPHA staff provided project management and support services. The Panel met several times during 2006 and 2007 and information was collected using the following approaches:

- A literature review, building on several previous comprehensive reviews (Hauser & Edwards, 2006)
- An examination of data from the Canadian Council on Learning (CCL), which applied a newly developed scale of health literacy to the 2003 International Adult Literacy and Skills Survey (CCL, 2007a; CCL, 2007b; CCL, 2008)
- Focus groups with adult literacy learners in Saskatoon, Edmonton, Victoria, Truro, and rural Prince Edward Island (CPHA, 2006b)
- An environmental scan of interventions to improve health literacy (commissioned by the National Collaborating Centre for Determinants of Health, at the Panel's request) (King, 2007)
- Interviews with experts in the fields of health, literacy, medical, education and social services (CPHA 2006c)
- An e-mail questionnaire completed by over 700 policymakers, advocates and professionals working in health, literacy, education, social and community services (CPHA, 2007a)
- Consultations with a broad range of stakeholders in Corner Brook, Saint John, Montreal, and Calgary (CPHA, 2007b).

Initially, the Panel was co-chaired by Dr. Irving Rootman, Professor and Distinguished Scholar, Michael Smith Foundation for Health Research, University of Victoria and Dr. Elinor Wilson, Chief Executive Officer of CPHA. After Dr. Wilson left CPHA, Ms. Deborah Gordon-El-Bihbey, President and CEO of Research Canada and an Expert Panel member, agreed to act as co-chair with Dr. Rootman until the completion of the Panel's work.

## **1.4 Outline of Report**

Concepts and the measurement of literacy and health literacy are discussed in Chapter 2. The subsequent chapters present the Panel's findings in relation to the scope of the problem (Chapter 3), the vision of and barriers to a health literate society (Chapter 4), and effective interventions and promising approaches (Chapter 5). The final chapter looks at the implications of the Panel's findings and recommendations for policy and practice.

## Chapter 2: Concepts

There are diverse understandings of the issue of literacy and health literacy. In order to reach a common understanding of these closely-related but different concepts, the Expert Panel reviewed existing definitions, conceptual frameworks and ways of measuring literacy and health literacy.

### 2.1 Definitions of Literacy

There are many definitions of literacy in the literature. The following are some commonly used ones:

An individual's ability to read, write and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and develop one's knowledge and potential (National Literacy Act, 1991).

A complex set of abilities to understand and use the dominant symbol systems of a culture for personal and community development (The Centre for Literacy of Quebec, n.d.).

Using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential (Statistics Canada, 2005).

These definitions differ in terms of scope and focus, with the broadest definition being the one from The Centre for Literacy of Quebec. After considering these, the Panel formulated and agreed on its own definition, namely:

Literacy is the ability to understand and use reading, writing, speaking and other forms of communication as ways to participate in society and achieve one's goals and potential.

### 2.2 Definitions of Health Literacy

There are also many definitions of health literacy in the literature. Two of the most commonly cited ones are:

The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health (WHO, 1998).

The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (Ratzan & Parker, 2000, as cited in Nielsen-Bohlman et al., 2004, p. 20).

The Panel did not adopt one of these definitions because they do not explicitly recognize the importance of different health contexts in providing information to people in a form that they can understand and use. The U.S. Institute of Medicine’s Committee on Health Literacy notes that “health literacy is a shared function of social and individual factors” (Nielsen-Bohlman et al., 2004, p. 4) and “the impact of health literacy arises from the interaction of the individual and the health context” (p. 32).

In addition, health literacy changes over the course of people’s lives as a result of different information processing demands and changing skill levels. For these reasons, the Panel adapted the working definition developed by the British Columbia Health Literacy Research Team:

The degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course (Kwan, Frankish & Rootman, 2006).

In an effort to make this definition easier to understand, the Expert Panel changed it to:

The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course.

In this definition, *access* is more than the availability of information and services. It is mediated by education, culture and language, by the communication skills of professionals, by the nature of materials and messages, and by the settings in which health-related supports are provided.

This definition suggests that health literacy is a resource for daily living in the settings where people live, learn, work, worship and play. It recognizes that health status and learning are closely linked at all ages and stages of life. Effective health literacy begins in early childhood and continually builds on knowledge and experience gained throughout the life span.

The definition also speaks to the idea that health literacy is essential to taking control of and managing one’s health. It means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment (WHO, 1998).

The Panel found a lack of awareness and little agreement on the meaning of health literacy among practitioners, policy makers, adult literacy learners and the public (CPHA, 2006b; CPHA 2006c; CPHA 2007b). Nevertheless, some elements of the definition used by the Panel were acceptable to many, as well as overall interest in the concept of health literacy and eagerness to see the issue addressed by the Panel.

### 2.3 Relationship between Literacy and Health Literacy

As noted, literacy and health literacy are related, but different concepts and the exact nature of this relationship is an area of discussion among researchers. Some argue that health literacy is nothing more than literacy in a health context, while others take the view that they are completely separate and different concepts. The Expert Panel agreed that the reality is probably somewhere in the middle and until we have a completely satisfactory way of measuring health literacy, this debate will likely continue. Nevertheless, the Panel concluded that enough is currently known to warrant action and further study.

### 2.4 Measurement of Literacy and Health Literacy

Having adopted these definitions of literacy and health literacy, it became apparent to the Panel that no existing measure of either concept completely captures all aspects of the definitions. In Canada, two international surveys are the most commonly-used measures of literacy.

The International Adult Literacy Survey (IALS), developed measures of prose, document and quantitative skills for a survey conducted in Canada in 1994. The 2003 International Adult Literacy and Skills Survey (IALSS), which is also referred to as the Adult Literacy and Life Skills (ALLS) survey, was similar but changed the quantitative scale to a numeracy measure and added a problem-solving domain. Neither of these surveys measure oral skills.

The most commonly used measures of health literacy in clinical settings are the Rapid Assessment of Literacy in Medicine (REALM) test, which measures the ability to read health terms, and the Test of Functional Health Literacy in Adults (TOFHLA), which measures the ability to understand health information. These tests have mostly been used in American studies and “offer approximations of reading skills and do not test health literacy” (Rudd, Epstein Anderson, Oppenheimer & Nath, 2007, p. 188).

In contrast, the population-based measures derived from the international adult literacy surveys come closer to measuring the definition of health literacy adopted by the Expert Panel. The methodology used is described in detail by Rudd, Kirsch, and Yamamoto (2004) and by the Canadian Council on Learning (CCL, 2007a). In brief, the scale was constructed from responses to 191 test items in the U.S. adult literacy survey and 231 test items in the Canadian survey, which are related to the use of information in different health contexts. The types of activities covered were: health promotion; health protection; disease prevention; health care; and navigation—all of which are commonly encountered purposes for which people are provided with or seek health information.

The health literacy scale, which ranges from 0 to 500, allows for comparison of differences in average health literacy among different groups of adults. Proficiency on this scale has been grouped into five levels. As is the case with literacy, overall levels of health literacy are relatively low (CCL, 2007a).

While this measure of health literacy has limitations (e.g., not a measure of oral skills and not applied to certain population groups), it has the advantage of being a relatively robust measure of some key aspects of the Expert Panel’s definition of health literacy. It has also been administered to a large, well-selected sample of the population of Canada and comprehensively analyzed in recent and forthcoming reports (CCL, 2007a; CCL, 2007b; CCL, 2008). The Expert Panel therefore drew on this emerging information to help define the extent of the problem of health literacy in Canada.

The Panel also noted some efforts underway in Canada to develop new measures of health literacy consistent with the definition it used. These include projects by the B.C. Health Literacy Research Team to measure health literacy within different population groups, including seniors, young people in school and out of school, and ethnocultural communities (Kwan et al., 2006) and work by Norman and Skinner (2006) to measure “e-health literacy” for young people.

## **2.5 Conclusion**

The Expert Panel noted some recent progress in defining and measuring health literacy, but no consensus on these issues. Data from the 2003 IALSS provide the best available information on the extent and distribution of health literacy in Canada. There is also a lack of awareness and understanding of the concept of health literacy in Canada.

## Chapter 3: Scope of the Problem

The first element of the Panel's mandate was to define the scope of the problem within the context of literacy and health. This required assessing the evidence about the levels of both literacy and health literacy within Canada's adult population. The second element was to explore the relationships between and among literacy, health literacy and health outcomes, including the financial burden of low health literacy. This chapter summarizes the Panel's findings and conclusions about the extent and distribution of low literacy and low health literacy, the links among literacy, health and health literacy, and other possible consequences of low health literacy.

### 3.1 Extent and Distribution of Low Literacy in Canada

The Panel relied primarily on Canadian data from the 1994 and 2003 international adult literacy surveys to determine the extent and distribution of low literacy. These surveys involved a large number of education scholars from different industrialized nations developing a common approach to measure how well adults are able to use print materials for everyday tasks. This was an important first step in determining the extent to which population groups can manage the literacy demands of their everyday lives. Some criticize these surveys for a western bias that minimizes the influence of culture, language, gender and other social categories, such as disability, on literacy levels.

The 2003 IALSS found that substantial numbers of adults in Canada have low levels of literacy. Statistics Canada (2005) considers Level 3 to be the minimum level of proficiency required to meet the demands of modern life, independently and reliably in an industrialized nation. The IALSS estimates that among Canadians aged 16 to 65:

- 42% (about 9 million) score below Level 3 on the prose scale
- 43% score below Level 3 on the document scale
- 50% score below Level 3 on the numeracy scale.

Prose literacy is the knowledge and skills needed to understand and use information from texts; document literacy relates to locating and using information contained in materials; numeracy is the knowledge and skills required to apply arithmetic operations embedded in printed materials.

If people over the age of 65 are included in these estimates:

- 48% (about 12 million) score below Level 3 on the prose and document scales
- 55% score below Level 3 on the numeracy scale (Statistics Canada, 2005).

Levels of adult literacy are a concern in many countries. While Canada ranks well in terms of population literacy levels compared to some other countries, including the United States, there is considerable variation in literacy proficiency across the provinces and territories.



Alberta, Saskatchewan, British Columbia and the Yukon show higher literacy levels than the Canadian average, while New Brunswick, Newfoundland and Labrador, and Nunavut are below the national average. Unchanged from the 1994 survey, young working people and those with advanced levels of education have higher literacy levels while seniors tend to have lower levels of literacy.

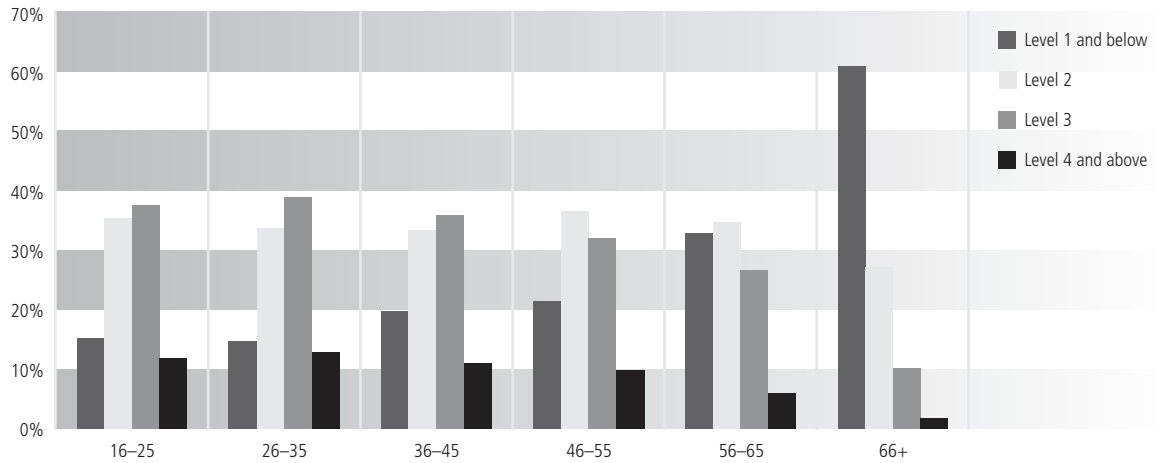
The 2003 survey also found lower levels of literacy among some populations, including people whose mother tongue is neither English nor French, and people who are not in the labour force.

This summary of literacy levels in Canada is included in this report because literacy is fundamental to health literacy and because the only national statistics on health literacy in Canada available to the Expert Panel were extracted from IALSS data (CCL, 2007a; CCL, 2008). This measure of health literacy focuses on people's ability to use health-related materials to accomplish health tasks. (For details about the development of the IALSS-based health literacy scale, see CCL, 2007a.)

### **3.2 Extent and Distribution of Low Health Literacy in Canada**

An estimated 55% of Canadians aged 16 to 65 scored below Level 3 on the IALSS health literacy scale (CCL, 2007b). Only one in eight adults (12%) over age 65 appears to have adequate health literacy skills (Figure 1). This is particularly significant since seniors are more likely to have chronic health problems and to use medication than younger age groups, facing a higher level of health information demands. The estimated 60% of people aged 16 and over below Level 3 on the health literacy scale is higher than the percentage of adults below Level 3 on the prose and numeracy scales. This suggests that health literacy requires people to use a range of skills simultaneously and that weak literacy skills impair an individual's ability to cope with health literacy tasks without calling on others to help them (CCL, 2008).

**Figure 1: Health Literacy by Age Group, Canada (2003 IALSS)**

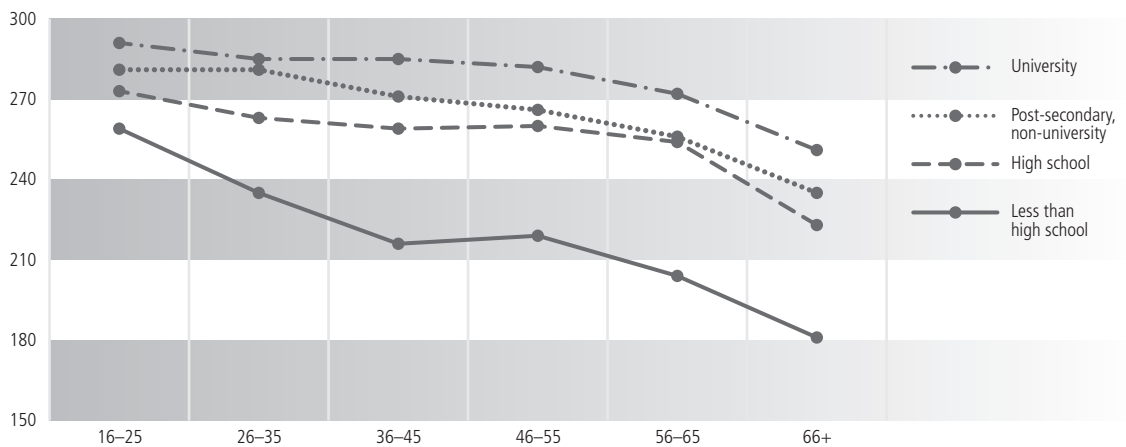


Source: Canadian Council on Learning, 2007b.

### Health Literacy and Education

Health literacy scores appear to rise with the level of formal education attained (Figure 2). This education-related difference holds true for all ages. As with general literacy, health literacy scores tend to decline with age. As a consequence, the gap between more and less educated people tends to become more pronounced as they age.

**Figure 2: Health Literacy by Age and Education, Canada (2003 IALSS)**

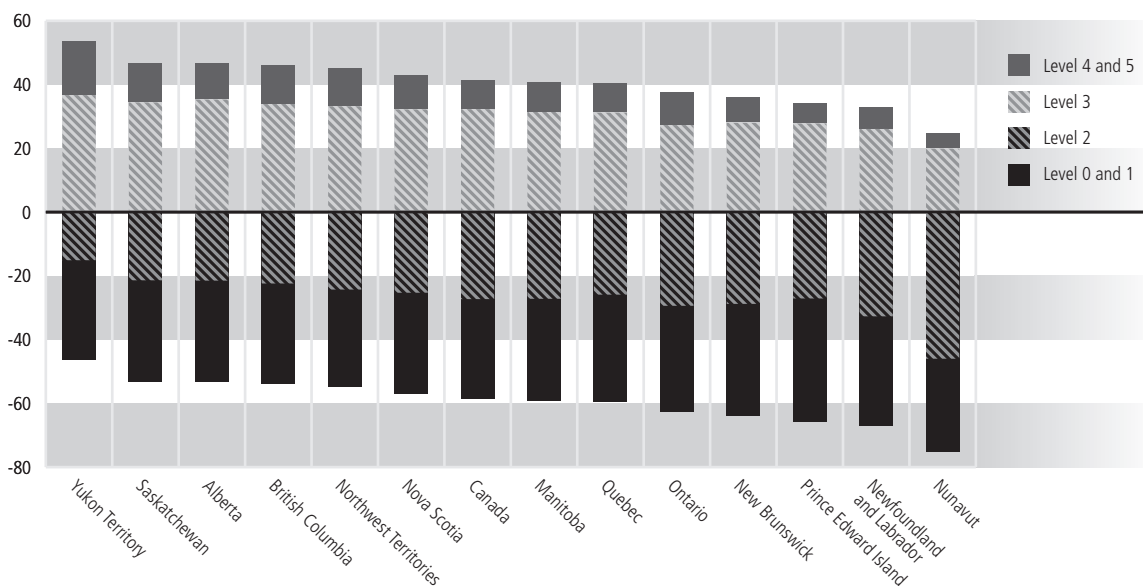


Source: Canadian Council on Learning, 2007b.

## Health Literacy by Province and Territory

Figure 3 shows that average health literacy scores vary significantly across jurisdictions. Yukon, Saskatchewan and Alberta have the highest average levels but it should be noted that average scores are so low that every province and territory has large proportions of adults with health literacy scores below Level 3 (CCL, 2007a).

**Figure 3: Distribution of Health Literacy Scores, Adults Aged 16 and Over, by Province and Territory (2003 IALSS)**



Source: Canadian Council on Learning.

## Health Literacy, Gender and Language

Overall, there is no significant difference between the average health literacy scores of men and women between the ages of 16 and 65 (CCL, 2007a).

Among immigrants, it is assumed that women have lower health literacy than men because of their lower literacy scores. The 2003 IALSS estimates that 32% of foreign-born women have extreme difficulty with and only limited use of printed materials, compared to 24% of foreign-born men and approximately one-tenth of Canadian-born women and men (McMullen, 2006). These findings point to the need for more research into potential contributors to health literacy, including educational practices and patterns of access to health information in countries of origin, as well as the implications of gender.

As with literacy, average scores on the health literacy scale tend to be lower for immigrants, especially recent immigrants and those who do not speak English or French well. The large gap in average health literacy scores between immigrants and non-immigrants is not surprising because the tests were administered English or French (CCL, 2007a).

## Health Literacy and Persons with Disabilities

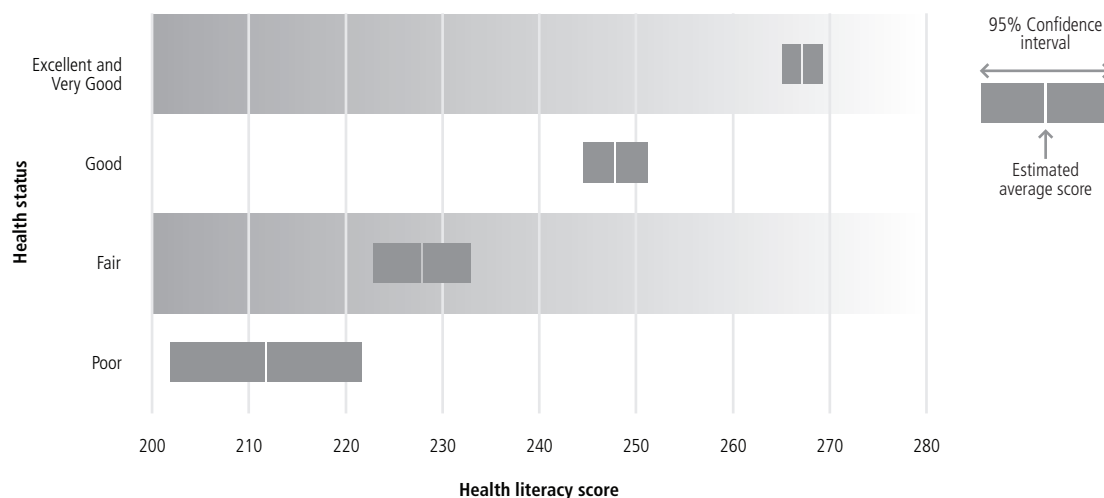
Participants in the international literacy surveys were not asked to report disabilities, so those studies do not provide information about the literacy or health literacy skills of persons with disabilities. However, data from other sources indicate the following:

- At least one in 10 Canadians has a learning disability and more than 80% of these people have difficulty learning to read (Literacy Alberta, 2005)
- People with disabilities make up a disproportionate number of Canadian adults with the lowest levels of literacy (Kapsalis, 1999 as cited in Literacy Alberta, 2004)
- One in five Aboriginal people aged 15 and over has a disability (Statistics Canada, 2003)
- Approximately 50% of Canadian adults with disabilities experience literacy barriers (Rioux, Zubrow, Stutt Bunch & Miller, 2003)
- 20% of adults with disabilities have less than a Grade 9 education, compared to 8.1% of adults without a disability (Rioux et al.).

### 3.3 Literacy, Health Literacy and Health Outcomes

The 2003 IALSS asked respondents a series of questions about their physical and mental health. Self-reported health status appears to be a relatively good predictor of health outcomes (Mossey & Shapiro, 1982; Benjamins, Hummer, Eberstein & Nam., 2004) and the IALSS data indicates a link between literacy, health literacy and self-reported health. Average prose, document and numeracy scores decline with self-reported health status in a stepwise manner and the same is true for health literacy as can be seen in Figure 4. Canadians with the lowest health literacy scores are 2.5 times as likely to see themselves as being in fair or poor health as those with skills at level 4 or 5. This relationship holds even after removing the impact of age, gender, education, mother tongue, immigration and Aboriginal status (CCL, 2008).

**Figure 4: Average Health Literacy Scores by Self-Perceived General Health Status, Canada, 2003**



Source: Canadian Council on Learning, 2007a.

Thus, on the surface at least, it appears as if there is a relationship between both general literacy and health literacy and self-perceived health status, especially among older adults.

Research based on the REALM and TOFHLA measures suggest that poorer outcomes in the following areas are associated with lower levels of reading skill:

- Physical and mental health outcomes (Gazmararian, Williams, Peel & Baker, 2003; Kalichman, Benotsch, Suarez, Cata, Miller & Rompa, 2000; Kalichman & Rompa, 2000)
- Engagement in health-promoting behaviours (Kauffman, Skipper, Small, Terry & McGrew, 2001)
- Participation in screening programs (Davis, Dolan, Ferreira, Tomori, Green, Sipler et al., 2001; Dolan, Ferreira, Davis, Fitzgibbon, Rademaker, Liu et al., 2004; Fortenberry, McFarlane, Hennessy, Bull, Grimley, St. Lawrence et al., 2001; Lindau, Tomori, Lyons, Langseth, Bennett & Garcia, 2002)
- Anticoagulation control (Estrada, Martin-Hryniewica, Peek, Collins & Byrd, 2004)
- Diabetes control (Endres, Sharp, Haney & Dooley, 2004; Kim, Love, Quistberg & Shea, 2004; Schillinger, Piette, Grumbach, Wang, Wilson, Daher et al., 2003)
- Rates of cervical cancer (Lindau et al., 2002; Sharp, Zurawski, Roland, O'Toole & Hines, 2002)
- Hospitalization (Baker, Gazmararian, Williams, Scott, Parker, Green et al., 2002)
- Compliance with breast cancer protocols (Li, Brown, Ampil, Burton, Yu & McDonald, 2000).

The Panel noted two recently published prospective studies in the United States that strongly suggest a relationship between reading ability and mortality. Baker, Wolf, Feinglass, Thompson, Gazmararian & Huang (2007) looked at mortality rates of 3,260 Americans over age 56 in four metropolitan areas and found that those with inadequate and marginal health literacy levels (as measured by the TOFHLA) had a 50% higher mortality rate over a five-year period than those with adequate skills. Low reading proficiency was the top predictor of mortality after smoking, and was a more powerful variable than either income or years of education. The other study (Sudore, Yaffe, Satterfield, Harris, Mehta, Simonsick et al. (2006), found that limited literacy, as measured by the REALM, was independently associated with a nearly two-fold increase in mortality in the elderly.

Although we cannot conclude that low health literacy causes premature death, these two studies suggest that not having adequate reading skills may predict premature mortality among older adults.

The Canadian Council on Learning (2008) also looked at the relationship between health literacy and various health outcomes by 52 health districts in Canada and found that diabetes was highly correlated with health literacy. These findings point to the need for further research into the relationship between health literacy and chronic diseases requiring lifestyle changes, as well as links with other health outcomes.

### **3.4 Literacy, Health Literacy and Other Outcomes**

Growing evidence suggests that both literacy and health literacy are related to other outcomes that have an impact on health. Health literacy data from the 2003 IALSS found that individuals at Level 1 were 2.5 times more likely to be receiving income support than those at levels 4 and 5, after removing the impact of age, gender, education, mother tongue, immigration and Aboriginal status (CCL, 2008). This implies that, as is true for literacy, low health literacy may limit people's ability to generate income and secure employment.

Those with the lowest level of health literacy skills were also 2.5 times more likely not to have participated in community groups or have volunteered in the previous year, after removing the variables mentioned above (CCL, 2008). This implies that low health literacy may limit people's ability to engage socially in their communities, which is another determinant of health (Galabuzi, 2004).

Although the Panel did not find Canadian research related to health literacy and health care costs, some studies in the United States led the Institute of Medicine's Expert Committee on Health Literacy to note that "the limited amount of data available suggests that there is an association between health literacy, health-care utilization, and health care costs (Nielson-Bohlman et al., 2004, p. 8)." A study carried out for the IOM Committee found that predicted in-patient spending for a patient with inadequate reading skills was \$993 higher than for a patient with adequate reading skills and that a difference of \$450 remained after

controlling for health status. However, Rudd, Epstein Anderson et al. (2007) report that “no studies to date have differentiated costs linked to patient literacy and costs associated with medical errors” (p. 189). Thus, more research is required to determine the costs associated with low health literacy, especially within the Canadian context.

In 1998, the total cost of illness, disability and death due to chronic disease in Canada was estimated at more than \$80 billion annually (Health Canada, 2002). More recently, more than 50% of Canadians aged 12 or older reported at least one chronic condition and by age 65, 77% of men and 85% of women have at least one chronic condition (Schultz & Kopec, 2003; Gilmour & Park, 2006). Chronic diseases often occur in combination with other medical conditions, further increasing demands for health care (Broemeling, Watson & Black, 2005). For example, individuals with diabetes and associated renal vascular disease are expected to use 10 times more health care resources than the population average. The number of people with diabetes in Canada is projected to increase from approximately 1.4 million in 2000 (with a health care cost of \$4.66 billion) to 2.4 million in 2016 (with a cost of \$8.14 billion, in 1996 dollars) (Ohinmaa, Jacobs, Simpson & Johnson, 2004).

Effective patient self-management includes gaining confidence to deal with medical management, role management and emotional management (McGowan, 2005). While low levels of health literacy present a formidable challenge to the widespread and effective use of patient self-management, there is good evidence that this challenge can be met with tailored interventions (see Chapter 5). One study estimated that providing chronic patients with education on self-management as well as ongoing supervision by a case manager could yield a savings of over \$2,000 per patient per year (Bourbeau, Collet, Schwartzman, Ducruet, Nault & Bradley, 2006).

### **3.5 Conclusions and Recommendations**

A large proportion of people in Canada appear to have lower levels of literacy than are required to function well in relation to the information demands of modern life. Even more appear to lack the skills required to respond to the health information demands in different contexts.

There is a lack of systematic information in Canada on levels of literacy and health literacy in certain populations including Aboriginal peoples, newcomers, people with disabilities and people living in rural areas, as well as on the role of gender, outcomes of low health literacy and on costs associated with low literacy and health literacy.

Research suggests that levels of literacy and health literacy vary significantly from jurisdiction to jurisdiction in Canada and among different population groups. Seniors, recent immigrants, those with lower levels of education and with low French or English proficiency, and people receiving social assistance tend to have lower levels of literacy and health literacy. Both are related to health outcomes and those with lower skill levels are more likely to

experience negative health outcomes. Other outcomes of low literacy and health literacy include lower incomes and less community engagement, which are associated with poorer health and quality of life.

Although the evidence of the financial costs associated with low health literacy in Canada is sparse, there is enough Canadian and American research to suggest that policies designed to raise average health literacy levels might lead to improvements in population health and concomitant reductions in health costs.



## Chapter 4: Barriers to Health Literacy in Canada

Before the Expert Panel could identify barriers to raising health literacy in Canada, it needed to develop a vision of a “health literate” Canada. This vision is presented below, and followed by a discussion of individual and systemic barriers.

### 4.1. Vision of a Health Literate Canada

Panel members agreed on the following vision statement:

All people in Canada have the capacity, opportunities and support they need to obtain and use health information effectively, to act as informed partners in caring for themselves, their families and communities, and to manage interactions in a variety of settings that affect health and well-being.

A health literate Canada would provide:

- National, provincial, territorial, Aboriginal and local governments with opportunities to develop and improve health literacy throughout the life course (early childhood, childhood, adolescence, adulthood and older age)
- Comprehensive policies and programs to reduce inequities in health literacy and health care access among Canadians
- Collaborative efforts by the health, social service and education systems and by the governmental, not-for-profit and private sectors to promote and facilitate health literacy
- A culturally-relevant and respectful approach to delivering health services and information
- Clear information about health and the operation of services and systems that affect health in a variety of languages
- Policies and incentives to encourage service providers and educators to facilitate health literacy in their interactions with clients, students, other community members and patients
- Individuals with the confidence, support and skills they need to promote and advocate for the health of themselves, their families and communities.

In line with the definition of health literacy adopted by the Panel, this vision implies that both individuals and society have a role to play in promoting health literacy. Consequently, both individual and systemic barriers must be recognized and addressed. The barriers discussed in this chapter came to the attention of the Panel through a literature review and findings from focus groups, key informant interviews, a survey, consultations and through the knowledge and experience of the Panel members, especially those who are learners

in adult literacy programs. Ideas for addressing these barriers were identified through the process and are also included here.

## 4.2. Individual Barriers

Individual barriers are those personal features that can make it difficult for individuals to develop or use the wide array of skills required to be health literate in today's world. These could include:

- Declines associated with aging
- Not practising skills by reading and writing
- Having low levels of formal education or a lack of knowledge and skills about health
- Having a mother tongue other than English or French
- Cultural beliefs
- Living with disabilities.

In addition to these personal barriers, social stigma and experiences in early childhood may also make it more difficult for people to attain proficiency in health literacy skills. Adult literacy learners in the focus groups described numerous ways that feeling stigmatized interferes with health literacy. These include:

- Difficulty asking doctors to explain language you don't understand
- Difficulty asking a pharmacist to read directions on a label to you
- Difficulty asking for help filling out forms
- Misunderstanding medical advice
- Feeling that you don't deserve more time with a doctor
- Feeling that you are a burden on the system
- Feeling overwhelmed by how hard it is to stand up and insist that your needs be met (CPHA, 2006b).

The Panel heard that closely related to feelings of stigma was a sense of exclusion from many of the benefits available to people with high levels of literacy and education. Adult literacy learners often regarded themselves as “have nots,” because of limitations in income, education, employment and literacy skills. Their individual experiences were tempered by circumstances, such as where they lived, who their neighbours were, the extent to which they could access health-related services and advice, or act upon advice that required material resources beyond their means, the ways educators, health professionals and others service providers treated them, and whether there was violence in their lives.

The issues are varied and complex. For example, women in literacy programs have identified men's violence (or its threat) as one of the greatest barriers to their learning (Davies, 1995, as cited in Rootman & Ronson, 2005). Violence and abuse undoubtedly affect children's capacity for learning as well, and are key reasons why young people do not complete high school and/or run away from home. According to the National Longitudinal Survey of Children and Youth, students who reported being bullied sometimes or often scored significantly lower in math and reading scores than those who did not (Totten & Quigley, 2003). Experience in the early years affects the capacity to learn and to maintain future health. Infants and young children who are not exposed to appropriate stimulation, development and learning experiences as well as a secure attachment to a loving adult may face barriers in their learning, emotional patterns, lifelong attitudes and problem-solving approaches (Mustard & McCain, 1999; Begley, 1996).

Panel members were struck by evidence from many sources about the extent to which the complex web of socio-economic conditions affecting the lives of Canadians are linked to literacy and the individual capacity to be health literate.

### 4.3 Systemic Barriers

Many barriers to literacy and health literacy in Canada relate to education, health and other services that affect health and well-being. A lack of coordination and connections among these systems can exacerbate the effects on individuals. Some of the systemic barriers are examined below.

#### Schools

School-age children and youth may face an array of health challenges, such as violence, poverty, food insecurity, sexually-transmitted infections, smoking, substance misuse and physical inactivity. The foundation for health literacy should be laid during the school years. However, schools face major challenges in implementing quality programs to address these issues, including:

- Provincial, territorial and regional differences in education and philosophies about health
- Shrinking budgets and relegating health and physical education to add-on subjects with little or no structured curriculum time
- Inadequate, inaccessible or non-existent teacher preparation courses and professional development opportunities
- A lack of teacher specialists in health and physical education
- Insufficient support for public health engagement with schools (Canadian Association for Health, Physical Education, Recreation and Dance, n.d.).

## Community

ABC Canada Literacy Foundation reports that less than 10% of Canadian adults who could benefit from literacy upgrading programs actually enrol. A national survey found that barriers to participation include the cost, conflict with paid employment, a lack of child or elder care and/or transportation. Sustainability of community-based literacy programs is another issue, as are concerns about program length, level of difficulty, the ability to work at one's own pace and the relevance of the content (ABC Literacy Foundation, 2001).

A lack of availability and accessibility of affordable programs for adults in English or French as a second language is barrier for newcomers to Canada who wish to improve their literacy and health literacy skills. This is also a concern for children. For example, in Ontario between 2000 and 2007, there was a 29% increase in the percentage of elementary schools with English as a Second Language (ESL) students, while the percentage of schools with ESL teachers declined by 23% (People for Education, 2007). Without basic literacy skills, new immigrants have difficulty becoming health literate enough to manage health-relevant information and within the context of the Canadian health system.

## Workplaces

Numerous studies have found that the workplace has a powerful effect on the health of workers (Bachman, 2000 as cited in Health Communication Unit, 2004). Health and safety and healthy lifestyle programs are important contributors to the overall health of employees and have some impact on reducing absenteeism. However, such programs are often not available in workplaces and if available, are limited in scope. Current evidence suggests that workplace health promotion programs are more effective when a comprehensive approach is used (Shain & Survali, 2001 as cited in Health Communication Unit, 2004).

This approach recognizes and incorporates efforts to provide clear information and to promote health literacy skills. But it also places health literacy within the context of the organizational change factors underlying well-being and performance on the job. In particular, management practices and the way work is organized can be important barriers or enablers for people who are challenged with low literacy skills.

## Health Information and Communications

Health literacy is compromised when health information and messages are confusing or conflicting, as they often are (CCL, 2007c). Health information on the Internet has proliferated over the past decade. People with low literary or limited computer skills may have difficulty finding answers to their health questions on the Internet. One study found that adults with low literacy preferred commercially-sponsored sites, which were colourful and written at lower reading levels, than more reputable sites, which were written at a Grade 12 reading level (Birru, Monaco, Charles, Drew, Njie, Bierria et al., 2007).

Judging the relevance and validity of information retrieved by Internet search engines can challenge even sophisticated users of online information. Aboriginal people and ethno-cultural minorities may also encounter a lack of cultural sensitivity and relevance on many Web sites (Birru et al., 2007).

The *digital divide* refers to the gap between those with regular, effective access to electronic information and technology, and those without. It encompasses both physical access to hardware as well as the skills and resources that allow for its use. Research suggests that the literacy and numeracy skills that underpin health literacy play an important role in the acquisition and application of digital literacy skill (International ICT Literacy Panel, 2002). This disparity has a serious effect on health literacy since the Internet has become one of the most popular and common sources of health information.

### Health Care System

Increasingly complex health care, scientific advancements, and new technologies have intensified the reading, writing, numeracy and problem-solving skill demands on health service consumers (Nielson-Bohlman et al., 2004). Even health professionals are sometimes baffled by the many choices they have to make to obtain the treatment they need (Hauser & Edwards, 2006). If navigating the system during the stress of an illness is difficult for those who are most familiar with it, people with lower health literacy skills can understandably feel overwhelmed when dealing with hospitals and medical services (Singleton, 2004). In addition to the general complexity of Canada's health care systems, the emerging trends of self-management and patient-centred medicine present specific challenges, as detailed below.

As the population ages, a large and increasing proportion of health care resources are devoted to treating chronic conditions. In order to manage chronic or long-term conditions, individuals have to be able to understand and assess health information, understand the concept of risk, follow complex medical regimens, plan and make lifestyle changes, make informed decisions and understand how to access care when they need it (Singleton, 2004; Institute for Health Improvement, 2007). Low literacy skills prevent many patients from engaging in effective self-management. A review of randomized controlled trial studies revealed that 62% of patients with lower reading skills were unable or unwilling to engage in self-management (Johnston, Ammary, Epstein, Johnson & Rhee, 2006). People with low literacy skills are also less likely to attend peer-led self-management programs (Heneghan, Alonso-Coello, Garcia-Alamino, Perera, Meats & Glasziou, 2006). Shared decision-making is a key component of patient-centred medicine, which is an approach designed to make patients and their families part of a team with their health care professionals in making clinical decisions. Patient-centred care puts responsibility for important aspects of self-care and monitoring in patients' hands. Shared decision-making requires that patients fully understand their health problems and treatment options. This can be challenging for people who have difficulties with reading, writing, numeracy, problem-solving and complicated oral information. It also places high demands on providers to adequately explain complex information in clear and understandable terms (Institute for Health Improvement, 2007).

## Health Professionals

The Panel commissioned an e-mail survey of professionals and policy makers in sectors pertinent to health literacy. The survey found relatively low levels of awareness and understanding of:

- How widespread low literacy and low health literacy are in Canada
- How low health literacy may affect patient health and service delivery
- Strategies to lower literacy demands and promote health literacy skills (CPHA, 2007a).

## 4.4 Addressing the Barriers

Some of the many ideas for removing barriers to health literacy that were put forward during the consultations and other information conducted for the Expert Panel's review are described below.

### Individual barriers

Declines in health literacy associated with aging might be addressed by:

- More emphasis on lifelong learning
- Practicing reading and writing skills daily
- Increasing opportunities to learn about health and developing literacy skills in the community
- More workplace health and skill development programs.
- Providing outreach to seniors who are isolated and/or have disabilities.

## Health Literacy of Professionals and Policymakers

A survey of nearly 700 professionals and policymakers found:

- Almost 30% were unaware of the term *health literacy*
- 34% said that the term is used in their organizations (23% were not sure)
- 68% said that their organizations provide direct services but more than 30% were unsure of their clients' literacy levels
- Almost 60% indicated that staff in their organizations did not know where to find resources to support health literacy efforts
- The majority of organizations addressed health literacy through informal practices, while 32% had practice standards in place
- Only 7% indicated that their organizations had policies on health literacy in place (CPHA, 2007b).

Low levels of formal education/lack of knowledge and skills about health might be addressed by:

- Increasing financial support for pursuing higher levels of education at all ages
- Establishing policies and programs to prevent school drop-out
- Introducing comprehensive school health programs that include health literacy.

Having a mother tongue other than English or French might be addressed by:

- Second-language programs that incorporate health information and skill building
- Culturally-appropriate health and social services
- Cultural competence training for practitioners
- Greater use of interpretation and social support services in health care settings
- Culturally relevant health information and translations
- Greater use of health professionals from ethnocultural communities in health care settings.

Disabilities that affect proficiency in health literacy might be addressed by:

- Increasing support for persons with disabilities to stay in school and to attend literacy and education programs in the community
- Providing affordable vision and hearing aids and tailored health materials.

Stigma might be addressed by:

- Improving the awareness and sensitivity of health professionals regarding the impact of stigma on the behaviours of people with low literacy and health literacy
- Increasing the skills of health professionals in recognizing low literacy and health literacy skills levels
- Raising public awareness about stigma associated with low literacy and health literacy and that most people experience some difficulties in understanding health materials.

Lack of stimulation and learning opportunities in early childhood might be addressed by:

- Increased support for initiatives in early childhood development, education and care
- Broader access to parenting programs and adult literacy
- More family literacy programs
- Improving parents' health literacy and their understanding of early development, in particular, for newcomers and minority groups.

## Systematic barriers

Barriers to health literacy in schools might be addressed by:

- A comprehensive school health approach including a range of activities and services, in schools and surrounding communities.

Barriers in the community might be addressed by:

- Providing affordable programs in English or French as a Second Language or literacy upgrading
- Increasing the number and quality of these programs
- Including health-related information and skills in these programs.

Barriers in the workplace might be addressed by:

- Introducing more comprehensive workplace programs with literacy and health literacy components.

Confusing, hard-to-understand health messages and information overload in the media and on the Internet might be addressed by:

- Developing plain language materials with input from target audiences
- Evaluating the effectiveness of Web sites and communication material.

Barriers in the health care system might be addressed by:

- Increasing skill building and sensitive, culturally-appropriate communications
- Providing paid or volunteer interpreters or “client advocates” (health brokers)
- Encouraging patients to ask questions and to express their feelings, preferences and values about health-related concerns
- Listening to patients carefully and taking time to clearly explain risks, research and treatment options
- Talking to patients slowly, using simple words, showing respect
- Telephone follow-ups within one week.

Lack of awareness of health and literacy professionals regarding health literacy might be addressed by:

- Wide dissemination of expert panel and other reports on health literacy
- Public campaigns to raise awareness
- Articles in journals read by health and education professionals
- Continuing education programs.



Lack of knowledge about health literacy among health professionals might be addressed by:

- Including health literacy in college and university curricula, continuing education and professional development activities for health care providers.

## 4.5 Conclusions

Many individual barriers affect people's proficiency in health literacy, including:

- Declines associated with aging
- Having low levels of formal education and/or a lack of knowledge and skills about health
- Having a mother tongue other than English or French
- Living with disabilities
- Social stigma
- Experiences in early childhood.

Many systemic barriers also affect health literacy, including:

- Health issues faced by students in schools and challenges in implementing quality school health and physical education programs to address these issues
- Lack of availability of affordable programs in English or French as a second language or literacy upgrading in the community
- Inadequate levels of training and education offered to employees in workplaces
- Confusing or conflicting health information or messages in the media or on the Internet
- Complexity of the health care system and increasing demand on patients to manage their chronic diseases and share in decisions
- Lack of awareness and knowledge about health literacy among health and literacy professionals.

Many plausible ideas for addressing the individual and systemic barriers to health literacy are suggested in the literature and by key stakeholders, but very few of them have been rigorously evaluated.

# Chapter 5: Effectiveness of Interventions to Improve Health Literacy

This chapter presents the Panel’s findings and conclusions regarding the effectiveness of existing interventions to improve health literacy in Canada. It draws mainly on a review of published literature (Hauser and Edwards, 2006), an environmental scan commissioned by the National Collaborating Centre for Determinants of Health (King, 2007), and a comprehensive analysis of the health literacy data from the 2003 International Adult Literacy and Skills Survey (CCL, 2008). The chapter is divided into four sections:

1. Evaluations of health literacy interventions
2. Findings on the determinants of health literacy
3. Some relevant initiatives in Canada
4. The Panel’s conclusions.

## 5.1 Evaluations of the Health Literacy Interventions

The Panel noted that very few health literacy-related interventions in Canada have been evaluated and the evaluations that have been done are not definitive. International research indicates that few rigorous evaluations of health literacy-related interventions have been carried out in other countries, and most available research has been conducted in the United States.

Simplifying reading material using clear language, pictures and symbols is the most widespread initiative, yet there is little evidence that this improves health outcomes. Multimedia presentations may improve knowledge of people with both low and high literacy skills, but these do not appear to change health-related behaviours (Hauser & Edwards, 2006).

Both the literature review and environmental scan conducted for the Expert Panel concluded that community-based and participatory approaches seem to show some promise. The literature review referred to the Health Literacy in Rural Nova Scotia Research Project, which explored how individuals and communities are adversely affected by limited health literacy (Gillis, 2004). Described as a participatory action research project, it included some aspects of community development and helped mobilize communities to take action.

The environmental scan found some evidence that programs built on participatory education principles and theories of empowerment appear to help parents access, understand and use health information for the benefit of their own and their children’s health. One such program is the Literacy and Parenting Skills program, an innovative family literacy program designed to provide literacy and parenting skills training to at-risk parents, developed at Bow Valley College, Alberta in 1996. Another example is Naître égaux – Grandir en santé, an empowerment project for perinatal and postnatal women living in underprivileged

conditions funded by the Quebec government, which was evaluated in 2000 (Ouellet, Dufour, Durand, René & Garon, 2000).

In addition, initiatives that empower single parents by enhancing their parenting skills, combined with public health, skills development, and recreation interventions, have been shown to improve health literacy, health status and community participation, and to reduce reliance on social assistance (Browne, Byrne, Roberts, Gafni & Whittaker, 2001).

Although evaluations of health literacy interventions to date do not provide clear answers on how best to create a health literate Canada, there are some hints regarding potentially promising directions. Some recent research findings on the determinants of health literacy also point to possible directions.

## **5.2 Determinants of Health Literacy**

The Canadian Council on Learning (2008) found that reading practices in daily life (e.g., reading books, newspapers, magazines, letters, notes or e-mails) are strongly related to health literacy. The second strongest factor explaining health literacy proficiency (independent of reading practices) was educational attainment. Having a mother tongue different than the language of assessment (in the case of the IALSS, English or French) had a strong negative impact on health literacy scores (CCL, 2008).

## **5.3 Canadian Health Literacy Initiatives**

The following summarizes promising initiatives, which came to the Panel's attention during the course of its data gathering. There are a number of initiatives, using different approaches and directed at specific groups with low levels of literacy and health literacy.

### **Canada-Wide Initiatives**

Among the notable Canada-wide initiatives is the National Literacy and Health Program (NLHP), established in 1994. The CPHA serves as secretariat for the NLHP, which currently has more than 25 non-governmental organization partners. The NLHP aims to promote awareness among health professionals of the links between literacy and health and develop resources to help health professionals serve clients with low literacy skills more effectively. NLHP operates a plain language service and has developed a guide to creating plain language materials for seniors, a health communication training package, a literacy and health resource for youth. These materials and services are promoted and disseminated through the CPHA Web site. A recent retrospective evaluation of the NLHP concluded that the program has been successful in establishing partnerships to produce resources and services and to increase the awareness among health professionals of the links between literacy and health (Wilson, 2004). The program was identified as a promising approach in the U.S. Institute of Medicine report on Health Literacy (Neilson-Bohlman et al., 2004).

Health Canada's Community Action Program for Children (CAPC) and the Canada Prenatal Nutrition Program (CPNP) are two other notable programs. A 2004 review, *Literacy Matters*, found that both programs have supported literacy-related projects or connect parents to local literacy programs in order to "build on families' strengths to support infant/child development" (Nuttall Nason & Ainsley Whitty, 2004, p. 2). One of the initiatives supported was the Literacy and Parenting Skills program, described above. It targets parents who have difficulties with reading and writing and uses learning materials relevant to parenting, such as discipline, communication and nutrition.

The Movement for Canadian Literacy and the Fédération canadienne pour l'alphabétisation en français (FCAF) have also been involved in health literacy projects across the country. Both organizations have learner advisory committees, whose members serve as speakers, reviewers and participants in research projects. These two organizations, working with five other Canadian literacy organizations, developed a results-based National Literacy Action Plan to address Canada's literacy challenges over the next 10 years (Movement for Canadian Literacy, 2005).

Another Canada-wide initiative of note is the Canadian Alliance on Mental Illness and Mental Health (CAMIMH). The Alliance's recent report (2007) defines mental health literacy as the "knowledge, beliefs and abilities that enable the recognition, management and prevention of mental health problems" (p. 8) but adds that "mental health literacy involves the same set of skills and abilities that constitute health literacy" (p. 36). The Panel agrees with CAMIMH that there are "opportunities for collaborative efforts to enhance health literacy and mental health literacy" (p. 6).

The Healthy Aboriginal Network, based in Vancouver, has a national and international focus. The Network uses comic books especially geared towards Aboriginal youth, to promote health, literacy and wellness. There are plans to use other media, such as animation, to make the comics into a type of video with an audio component, using some First Nations languages. Aboriginal youth are involved in all aspects of the production of the comic books. An evaluation of one comic book said it was "effective in improving health literacy among Aboriginal youth and young adults by communicating health issues effectively, by generating reflection or a change in thinking about health issues that are important in their communities, and in some cases, by encouraging action or information-seeking" (Broughton, Anderson, Hamilton & Day, 2007, p. 1).

### Provincial/Territorial Initiatives

British Columbia's Health Literacy Network was formed in 2000 to establish and maintain a province-wide network linking disability, health, literacy, other community groups, and individuals and health care professionals. It also provides health information through plain language pamphlets, audiotapes, as well as in Braille.

Literacy Alberta, a provincial literacy organization, developed a Literacy Audit manual and video to help adult education practitioners find out how their clients and staff rate their organization's success in meeting the literacy needs of clients. The manual contains background information on literacy and suggestions for using the literacy audit to make an organization more accessible. Although not specially developed for use within health settings, health literacy experts have recognized the usefulness of these resources (Rudd & Anderson, 2006). In addition, the Centre for Family Literacy in Edmonton developed a module on health literacy to be used in training health and family literacy practitioners to work together to address common issues (Dionne-Coster, Sauve & Shively, 2007).

Literacy Partners of Manitoba, funded by Health Canada, launched a project in 2003 “to help health care providers and administrators overcome barriers to reaching low literacy clients, and conversely, to make it easier for people with low literacy to benefit from health services” (Moody & Rose, 2004, p. 5). The project has delivered literacy and health training sessions in Regional Health Authorities across Manitoba and educated health providers in recognizing the signs of low literacy in their clients. Literacy and health workers have also been taught how to use plain language and clear design in their documents and to incorporate health topics into curricula.

In 1998, the Centretown Community Health Centre (CCHC) in Ottawa took the lead in developing a community-based education program for patients newly diagnosed with type-2 diabetes. By linking community health centres, community resource centres and local hospitals, CCHC created a network of sites and partners in the Ottawa region. A recent study of program graduates indicates the program is cost-effective so it is being expanded across Ontario.

Quebec has developed intra-governmental policies on adult education and public health, and has embedded literacy into all governmental public health projects in order to empower people to optimize their own and their families' health status. An example of this is the *Naître égaux – Grandir en santé* program described in Chapter 4. In addition, the provincial public health association, in collaboration with a number of other organizations including the Quebec Institute of Public Health, sponsored a full-day workshop on health literacy at its 2007 annual meeting.

The Centre for Literacy of Quebec has also been a leader in health literacy awareness and offers plain language resources. The Centre has offered summer institutes on health literacy, to bring together literacy and health colleagues to share their experiences and build partnerships within Canada and around the world. A series of customized training workshops for health care providers, including a curriculum module used at the McGill Graduate School of Nursing, has been developed, along with an ongoing program with the McGill University Health Centre (MUHC)—the longest running hospital-based health literacy project in Canada. In collaboration with the MUHC Nursing Research Office, the Centre has published research briefs on plain language and audiotapes for communication. Its current action-research literacy promotion project at the Montreal Children's Hospital gives books to children under age 6, and advice and support to parents regarding reading for pleasure and cognitive development. Health care providers are being trained in literacy and health and evaluation is integrated into this program.

The Health Literacy in Rural Nova Scotia project mentioned in Chapter 4, was successful in establishing a province-wide initiative in promoting health literacy and developing resources to supports initiatives related to health literacy (Gillis & Quigley, 2004).

The Literacy Alliance of Prince Edward Island aims to: develop collaborative partnerships with relevant community organizations, adult learners and government policymakers; identify health policy issues related to literacy; and increase awareness and understanding of the links between health and literacy of all project participants. As a first step, this provincial literacy association hosted a summit to introduce the project and build partnerships.

Health Check is a health and literacy program produced by the Northwest Territories Literacy Council. Major health issues were identified by learners, who contributed their stories and pilot tested program books. A plain language audit tool workbook to help people review their information in terms of plain language principles was also developed.

In Nunavut, the Ajunnginiq Centre of the National Aboriginal Health Organization published a discussion paper entitled, *Literacy and Health: The Importance of Higher-Level Literacy Skills*, to raise awareness of the issue of literacy and health within the Inuit community (Korhonen, 2006). This paper is also available in Inuktitut.

## Local Initiatives

A group of individuals in Prince Albert, Saskatchewan formed a Health and Literacy Committee made up of health providers, librarians, communications and marketing specialists, adult educators, and literacy practitioners. The committee uses a broad scope for health literacy interventions, basing initiatives literacy and health research by Gillis & Quigley (2004). Programs have included: plain language workshops for health care providers; information on health literacy on pay stubs of regional health employees; discussions of health literacy issues with health care provider students; ensuring that health literacy and the determinants of health are integral to all accreditation processes for the health service; and binders given to all schools to help the education system link with the health system in the region.

Alphabet Soup is a six-week family learning program based on family literacy and healthy eating designed by the Bookmates' Family Learning Centre and the Winnipeg Regional Health Authority. It emphasizes literacy, healthy lifestyle habits, and socialization through a play-based approach to learning. Parents and children are engaged in weekly two-hour sessions with crafts, story-time and physical activities for the children and literacy and nutrition instruction for the parents. These activities help the parents access and understand health information in a fun and enjoyable way so they can relate the learning to their shopping, cooking and eating habits. The program has reached families throughout Manitoba, Saskatchewan and Northwestern Ontario.

For a number of years, Hamilton Health Sciences Centre has worked in the area of health literacy. The staff recognizes that communication is critical for effective patient-

provider interaction. The patient educators provide workshops to students, ask patients for formative evaluation on written material, and incorporate “universal precautions” of good communication into staff development. They have also produced a guide for creating patient education materials (Wizowski et al. 2006).

## Summary

This section illustrates that there are many important initiatives related to health literacy in Canada. It should also be clear that these initiatives use a broad range of approaches, including communication, education, community development, organizational and network development as well as the development and implementation of policies. They target a broad range of groups, including older adults, people with disabilities, Aboriginal peoples, literacy learners, and people with mental illness. It is interesting to note that none of the examples presented focus specifically on recent immigrants. The British Columbia Health Literacy Research Team has carried out projects focusing on Farsi-speakers (Poureslami, Murphy, Nicol, Balka & Rootman, 2007) and is currently looking at ways to help Spanish-speaking immigrants develop health literacy skills. There are likely other initiatives as well with specific immigrant communities that are going on in Canada, but it appears more attention needs to be focused on recent immigrants.

One of the limitations of current initiatives is that people who may be interested are not aware of what is happening across the country, suggesting the need for better mechanisms for sharing best practices. In addition to the lack of evaluation that has been noted, many existing initiatives are short-term and do not have sustained funding.

## 5.4 Conclusions

Based on the findings presented in this chapter, the Panel concluded the following.

1. There are very few rigorous evaluations of the effectiveness of health literacy interventions in Canada or in other countries.
2. There is some evidence that community-based and participatory approaches have some promise in addressing health literacy issues.
3. Reading practices in daily life appear to be one of the most important determinants of health literacy.
4. Other key determinants of health literacy appear to be the educational attainment of individuals and their parents.
5. There are many potentially valuable initiatives throughout Canada to address the issues related to health literacy but no mechanisms for sharing best practices on an ongoing basis across the country and many are short-term and without sustained funding.

## Chapter 6: Implications and Recommendations

The final element in the mandate of the Panel was to assess the implications of the evidence for policies and programs to improve health literacy and to develop recommendations for health literacy efforts in Canada. This chapter discusses the implications for policies and programs and offers the Panel's recommendations.

### 6.1 Implications for Policies and Programs

There are many implications for policies and programs that could be drawn from the Panel's findings. As we have noted, there have been very few systematic health literacy evaluations to date, especially in Canada. Few, if any, of those focus on the evaluation of policies. However, the Expert Panel accepts a broader definition of evidence, beyond the results of randomized controlled studies. Based on this view, the evidence reviewed in this report has significant implications for policies and programs to achieve the vision of a health literate Canada. The following are the Panel's key conclusions in relation to policies and programs:

1. There is a need for policies and programs to respond to the extent and impact of low literacy in Canada and the increasing health information demands that are being put on Canadians as a result of an increasingly complex health system and increased calls for patient self-management to respond to increasing numbers with chronic diseases.
2. Attention should be directed to particular population groups that appear most likely to have low levels of health literacy. These include seniors, recent immigrants, those with lower levels of education and low French or English proficiency, people with lower incomes and Aboriginal peoples. With regard to Aboriginal peoples, given their unique circumstances and cultures, it is likely that a parallel process is needed to develop policies and programs appropriate to their unique needs.
3. All levels of government need to be involved in developing and supporting policies and programs related to health literacy. These must be specific to each jurisdiction given the different patterns of health literacy proficiency across the country as well as the different concentrations of groups with low health literacy in each jurisdiction. Tools, such as geographic maps of health literacy which will soon be available from CCL, will be valuable in designing population-appropriate strategies.
4. Policies and programs are required to reduce the individual and systemic barriers to health literacy. Individual and system-wide barriers to health literacy are numerous and interconnected. Many policies and programs are already in place and many promising and plausible ideas for addressing these barriers have been suggested.
5. A combination of policies, programs, resources, capacity and structures to rigorously evaluate initiatives related to health literacy are needed. There is a striking absence of such



evaluations in Canada even though many health literacy initiatives have been undertaken. It is also important to put in place mechanisms for sharing the results of these evaluations in a timely manner with those who are responsible for the programs and policies.

6. Coordination of health literacy policies and programs with those in other-related areas is needed. In particular, linking health literacy efforts to initiatives addressing general literacy, e-literacy, and literacies specific to various diseases and to mental health is timely given the growing interest in health literacy within these different domains.
7. Encouraging daily reading practices through innovative and targeted policies and programs is likely to be productive. This appears to be one of the strongest determinants of health literacy and one that requires concerted effort as it is highly amenable to improvement.
8. Research is needed that supports policy and practice development, and better understanding of the impact of health literacy on health and well-being of the population and in particular, the role of health literacy in health disparities within Canada.

## 6.2 Recommendations

The Panel agreed on one major recommendation.

A comprehensive, coordinated, cooperative and integrated Pan-Canadian Strategy on Health Literacy be developed, funded and implemented to improve the level of health literacy in Canada and the extent to which people receive the support they need to cope with the health literacy demands they encounter.

Since literacy and health literacy are inextricably linked, the Panel suggests that such a strategy needs to address both by pursuing three fundamental goals:

- To improve literacy and health literacy skills in Canada
- To reduce inequities in opportunities for developing literacy and health literacy skills in Canada
- To enhance the capacities of systems that provide health information and services to do so effectively for people with all levels of literacy and health literacy.

Achieving these goals will require cooperation and collaboration from a wide range of stakeholders including governments at all levels, the health and education systems, professional organizations, non-governmental organizations, individual health and education professionals, the media, the private sector, employers, unions, communities, families, friends, and last, but not least, all residents of Canada.

The Pan-Canadian Strategy on Health Literacy will require multiple approaches, including communication, education, community development, organizational development, research and funding. It needs to have a mechanism for monitoring, coordinating and sharing knowledge.

The Panel believes that this strategy will be best developed and implemented in collaboration with existing initiatives, such as the National Literacy Action Plan developed by the Movement for Canadian Literacy and partners, and the strategy proposed by the Canadian Alliance on Mental Illness and Mental Health. Since health literacy is related to health information, decision-making, and the management of chronic disease, the Pan-Canadian Strategy on Health Literacy should also work in collaboration with the Canadian Population Health Initiative's Action Plan 2007–10, developed by the Canadian Institute for Health Information (CIHI), the Integrated Pan-Canadian Healthy Living and Disease Prevention Strategy developed by the Public Health Agency of Canada (PHAC) and provincial/territorial partners, and other emerging national, provincial and territorial initiatives.

To initiate the establishment of the Pan-Canadian Strategy on Health Literacy, the Panel recommends that CPHA, CCL, PHAC and Health Canada (HC) undertake the following actions immediately following the release of Expert Panel's report:

- Disseminate the Panel's findings and recommendations to policymakers, practitioners, researchers and the general public to raise awareness of the scope and nature of the issue of health literacy in Canada
- Initiate consultations with governments, professional associations, voluntary organizations, educational institutions, research funding organizations, community groups and others to develop a plan for establishing the Pan-Canadian Strategy for Health Literacy
- Seek the resources required for the implementation of the plan.

A number of ideas for action that emerged from the Panel's research and consultations should be assessed for their feasibility, practicality, and cost. Some promising approaches include:

- Develop and undertake a coordinated multimedia campaign to increase awareness of the issue of health literacy in Canada among the public and specific audiences
- Integrate health literacy into curricula from primary and secondary education through to adult education and seek resources for doing so from governments, the private sector and foundations
- Set population-specific targets for health literacy, and monitor and report progress
- Make health literacy a mandatory component of service provider curricula, professional continuing education, and professional registration and certification
- Develop policies on the use of plain/clear language and visual symbols in health communications, guidelines and prototypes, including accreditation standards for health communications and interactions

- Undertake assessments/audits of accessibility of service provision systems and institutions as well as health services accreditation
- Develop pertinent funding streams to address health literacy research and programming
- Develop mechanisms to coordinate federal, provincial, territorial and Aboriginal governments' policy and program delivery to promote health literacy across the life span
- Develop mechanisms to evaluate health literacy interventions, allocate adequate funding and disseminate the findings
- Establish a multi-stakeholder Pan-Canadian Council on Health Literacy at arm's length from government to monitor and assess progress, facilitate partnerships between organizations and provide strategic direction
- Develop a parallel process to the one undertaken in producing this report by Aboriginal organizations and people.

None of this will happen without the recognition that health literacy is a serious concern in Canada, which needs to be addressed with adequate resources. The Expert Panel's report shows that low health literacy is a serious and costly problem that will likely grow as the population ages and the incidence of chronic disease increases. There are many promising initiatives in Canada that could be strengthened to address the issue and there is some momentum for action. The case for timely action is strong but very little will happen without political will, organizational leadership, and concerted efforts of practitioners and the public. The question is: are we willing as a country to make the investment that is required to create a health literate Canada?

## References

- ABC Canada Literacy Foundation (2001). *Who wants to learn? Summary of results from the national study "Patterns of Participation in Canadian Literacy and Upgrading Programs."* Available at <http://www.abc-canada.org>.
- Baker, D.W., Gazmararian, J.A., Williams, M.V., Scott, T., Parker, R, M., Green, D. et al. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*, 92, 1278–1283.
- Baker, D.W., Wolf, M.S., Feinglass, J., Thompson, J.A., Guzmararian, J.S. & Huang, P. (2007). Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, 167(14), 1503–1509.
- Begley S. (1996, February 19). Your child's brain. *Newsweek*, 54–62.
- Benjamins, M.R., Hummer, R.A., Eberstein, I.W. & Nam, C.B. (2004). Self-reported health and adult mortality risk: An analysis of cause-specific mortality, *Social Science and Medicine*, 59(6), 1297–1306.
- Birru, M., Monaco V., Charles, L., Drew, H., Njie, V., Bierria, T. et al. (2004). Internet usage by low-literacy adults seeking health information: an observational analysis. *Journal of Medical Internet Research*, 6(3), e25.
- Bourbeau J., Collet, J.-P., Schwartzman, K., Ducruet, T., Nault, D. & Bradley, C. (2006). Economic benefits of self-management education in COPD. *Chest*, 130, 1704–1711.
- Broemeling A.-M., Watson, D. & Black, C. (2005). *Chronic Conditions and Co-morbidity Among Residents of British Columbia*. Vancouver, BC: Centre for Health Services and Policy Research.
- Broughton, M., Anderson, R., Hamilton, L. & Day, D. (2007, June). *Evaluation of "Standing Together: An Aboriginal Youth Comic" as a tool for increasing Health Literacy*. Poster session presented at 19<sup>th</sup> IUHPE World Conference on Health Promotion and Health Education, Vancouver, BC.
- Browne, G., Byrne, C., Roberts, J., Gafni, A., Whittaker, S. (2001). When the bough breaks: Provider-initiated comprehensive care is more effective and less expensive for sole support parents on social assistance. *Social Science and Medicine*, 53(12), 1697–1710.
- Canadian Alliance on Mental Illness and Mental Health (2007). *Mental Health Literacy in Canada*. Retrieved June 2007, from [http://www.camimh.ca/MHL\\_Canada\\_Dec15-02-06\\_Report.pdf](http://www.camimh.ca/MHL_Canada_Dec15-02-06_Report.pdf)
- Canadian Association for Health, Physical Education, Recreation and Dance (n.d.). *Promoting quality school health*. Retrieved May 2007, from [http://www.cahperd.ca/eng/health/promoting\\_qsh.cfm](http://www.cahperd.ca/eng/health/promoting_qsh.cfm)

- Canadian Council on Learning (2007a). *Health Literacy in Canada: Initial Results From the International Adult Literacy and Skills Survey*. Ottawa, ON: Author.
- Canadian Council on Learning. (2007b). *State of Learning In Canada: No Time for Complacency*. Ottawa, ON: Author.
- Canadian Council on Learning. (2007c). *Survey of Canadian Attitudes Toward Learning: 2006 Health-Related Learning*. Ottawa: Author. Available from <http://search.ccl-cca.ca/CCL/Reports/SCAL2006/SCALHealthLearning2006.htm>
- Canadian Council on Learning (2008). *Health Literacy in Canada: A Healthy Understanding*. Ottawa: Author.
- Canadian Public Health Association (2006a). Literacy and health in Canada: Perspectives from the Second Canadian Conference on Literacy and Health. *Canadian Journal of Public Health*, 97(S2).
- Canadian Public Health Association (2006b). Report on focus groups with literacy learners. Unpublished data prepared for the Expert Panel on Health Literacy.
- Canadian Public Health Association (2006c). Report on key informant interviews. Unpublished data prepared for the Expert Panel on Health Literacy.
- Canadian Public Health Association (2007a). Report on the preliminary findings of an electronic scan on health literacy. Unpublished data prepared for the Expert Panel on Health Literacy.
- Canadian Public Health Association (2007b). Summary of key findings of national consultations on health literacy. Unpublished data prepared for the Expert Panel on Health Literacy.
- Davis, T.C., Dolan, N.C., Ferreira, M.R., Tomori, C., Green, K.W., Sipler, A.M. et al. (2001). The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Investigation*, 19, 193–200.
- Dionne-Coster, S., Sauve, L. & Shively, J. (2007). *Family Literacy and Health*, Edmonton: Centre for Family Literacy.
- Dolan, N.C., Ferreira, M.R., Davis, T.C., Fitzgibbon, M.L., Rademaker, A., Liu, D. et al. (2004). Colorectal cancer screening knowledge, attitudes, and beliefs among veterans: Does literacy make a difference? *Journal of Clinical Oncology*, 22, 2617–2622.
- Endres, L.K., Sharp, L.K., Haney, E. & Dooley, S.L. (2004). Health literacy and pregnancy preparedness in pregestational diabetes. *Diabetes Care*, 27, 331–334.
- Estrada, C.A., Martin-Hryniewica, M., Peek, B.T., Collins, C. & Byrd, J.C. (2004). Literacy and numeracy skills and anticoagulation control. *American Journal of Medical Science*, 328, 88–93.

- Fortenberry, J.D., McFarlane, M.M., Hennessy, M., Bull, S.S., Grimley, D.M., St Lawrence, J. et al. (2001). Relation of health literacy to gonorrhoea related care. *Sexually Transmitted Infections*, 77, 206–211.
- Galabuzi, G-E. (2004). Social exclusion. In D. Raphael (ed.) *Social Determinants of Health: Canadian Perspectives*. pp. 235–252. Toronto: Canadian Scholars' Press Inc.
- Gazmararian, J.A., Williams, M.V., Peel, J. & Baker, D.W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counselling*, 51, 267–275.
- Gillis, D. (2004). A community-based approach to health literacy using participatory research. *Adult Learning*, 15 (1–2), 14–17.
- Gillis, D. & Quigley, A. (2004). *Taking Off the Blindfold: Seeing How Literacy Affects Health*. Report of the Health Literacy in Rural Nova Scotia Research Project. Antigonish, NS: St. Francis Xavier University. Available at: <http://www.nald.ca/healthliteracystfx/pubs/takngoff/takngoff.pdf>
- Gilmour, H. & Park, J. (2006). Dependency, chronic conditions and pain in seniors. *Health Reports: How Healthy are Canadians?* 16 (S), 21–32, cat. no. 82-003-SIE. Ottawa, ON: Statistics Canada.
- Hauser, J. & Edwards, P. (2006). Literacy, Health Literacy and Health: A Literature Review. Unpublished report prepared for the Expert Panel on Health Literacy. Ottawa, ON.
- Health Canada (2002). *Economic Burden of Illness in Canada*. Ottawa: Minister of Public Works and Government Services Canada. Available from <http://www.phac-aspc.gc.ca/publicat/ebic-femc98/pdf/ebic1998.pdf>
- Health Communication Unit, Centre for Health Promotion, University of Toronto (2004). *An Introduction to Comprehensive Workplace Health Promotion*. Available from [http://www.thcu.ca/workplace/documents/intro\\_to\\_workplace\\_health\\_promotion\\_v1.1.FINAL.pdf](http://www.thcu.ca/workplace/documents/intro_to_workplace_health_promotion_v1.1.FINAL.pdf)
- Heneghan C., Alonso-Coello, P., Garcia-Alamino, J., Perera, R., Meats, E. & Glasziou, P. (2006). Self-monitoring of oral anticoagulation: A systematic review and meta-analysis. *Lancet*, 367, 404–411.
- Institute for Healthcare Improvement (n.d.). *IHI at Forefront of National Program to Advance Patient Self-Management of Care*. Retrieved September 2007, from <http://www.ihl.org/IHI/Topics/PatientCenteredCare/SelfManagementSupport/ImprovementStories/IHIatForefrontofNationalProgramtoAdvancePatientSelfManagementofCare.htm>
- International ICT Literacy Panel (2002). *Digital Transformation: A Framework for ICT Learning*. Princeton, NJ: Educational Testing Service. Available from <http://www.ets.org/Media/Research/pdf/ICTREPORT.pdf>

- Johnston, L., Ammary, N., Epstein, L., Johnson, R. & Rhee, K. (2006). A transdisciplinary approach to improve health literacy and reduce disparities. *Health Promotion Practice*, 3.
- Kalichman, S.C., Benotsch, E., Suarez, T., Cata, S., Miller, J. & Rompa, D. (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine*, 18, 325–331.
- Kalichman, S.C. & Rompa, D. (2000). Functional health literacy is associated with health status and health-related knowledge among persons living with HIV/AIDS. *Journal of Acquired Immune Deficiency Syndrome Human Retrovirology*, 25, 337–344.
- Kauffman, H., Skipper, B., Small, L., Terry, T., McGrew, M. (2001). Effect of literacy on breast feeding outcomes. *Southern Medical Journal*, 94(3), 293–296.
- King, J. (2007). *Environmental Scan of Interventions to Improve Health Literacy: Final Report*. Antigonish, N.S.: National Collaborating Centre for Determinants of Health.
- Kim, S., Love, F., Quistberg, D.A. & Shea, J.A. (2004). Association of health literacy with self-management behavior in patients with diabetes. *Diabetes Care*, 27, 2980–2982.
- Korhonen, M. (2006). *Literacy and Health: The Importance of Higher-Level Literacy skills*. Ottawa, ON: National Aboriginal Health Organization.
- Kwan, B., Frankish, J. & Rootman, I. (2006). The Development and Validation of Measures of Health Literacy in Different Populations. Unpublished report. Vancouver and Victoria: Institute of Health Promotion Research and Centre for Community Health Promotion Research.
- Li, B.D., Brown, W.A., Ampil, F.L., Burton, G.V., Yu, H. & McDonald, J.C. (2000). Patient compliance is critical for equivalent clinical outcomes for breast cancer treated by breast conservation therapy. *Annals of Surgery*, 231, 883–889.
- Lindau, S.T., Tomori, C., Lyons, T., Langseth, L., Bennett, C.L. & Garcia, P. (2002). The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multi-ethnic cohort of women. *American Journal of Obstetrics and Gynecology*, 186(1), 938–943.
- Literacy Alberta (2004). *Literacy and Disabilities*. Fact sheet. Available from <http://www.literacyalberta.ca/facts/LiteracyandDisabilities.pdf>
- Literacy Alberta (2005). *Literacy and Learning Disabilities*. Fact sheet. Available from [www.literacyalberta.ca/facts/LiteracyandLDs.pdf](http://www.literacyalberta.ca/facts/LiteracyandLDs.pdf)
- McGowan, P. (2005). *Self-Management: A Background Paper*. Paper presented at New Perspectives: International Conference on Patient Self-Management, Victoria, BC.

- McMullen, K. (2006). Literacy skills among Canada's immigrant population. In *Education Matters: Insights on Education, Learning and Training in Canada*(2), 5. Ottawa, ON: Statistics Canada. Available at <http://www.statcan.ca/bsolc/english/bsolc?catno=81-004-X20050059112>.
- Moody, C. & Rose, M. (2004). *Literacy and Health: Defining Links and Developing Partnerships*. Winnipeg, MB: Literacy Partners of Manitoba.
- Mossey, J.M. & Shapiro, E. (1982). Self-rated health: A predictor of mortality among the elderly. *American Journal of Public Health*, 72(8), 800–808.
- Movement for Canadian Literacy (2005). *A 10-year, Results-Based National Literacy Action Plan: 2006–2016*. Ottawa: Movement for Canadian Literacy. Available from [www.nald.ca/fulltext/10year/tenyear.pdf](http://www.nald.ca/fulltext/10year/tenyear.pdf)
- Mustard F. & McCain M. (1999). *Early Years Study*. Toronto, ON: Queen's Printer for Ontario.
- National Literacy Act, Public Law 102-73, 102<sup>nd</sup> Congress—1<sup>st</sup> Session (1991). Available at <http://www.nifl.gov/public-law.html>
- Nielsen-Bohlman, L., Panzer, A.M. & Kindig, D.A. (Eds.) (2004). *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academies Press.
- Norman, C.D. & Skinner, H.A. (2006). eHEALS: The eHealth Literacy Scale, *Journal of Medical Internet Research*, 8(4): e27.
- Nuttall Nason, P. & Ainsley Whitty, P. (2004). *Language, Literacy and Healthy Development: The Work of CAPC and CPNP Projects*, Saint John, NB: Early Childhood Centre, University of New Brunswick.
- Ohinmaa, A., Jacobs, P., Simpson, S. & Johnson, J. (2004). The projection of prevalence and cost of diabetes in Canada: 2000 to 2016. *Canadian Journal of Diabetes*, 28(2).
- Ouellet, F., Dufour, R., Durand, D., René, J.-F. & Garon, S. (2000). *L'empowerment dans Naître égaux – Grandir en santé*. Montreal, QC: Direction de la santé publique de Montréal-Centre.
- People for Education (2007). *The 2007 Annual Report on Ontario's Public Schools*. Toronto: Author.
- Poureslami, I., Murphy, D., Nicol, A., Balka, E. & Rootman, I. (2007). Assessing the effectiveness of informational video clips on Iranian immigrants' attitudes toward and intention to use the BC HealthGuide program in the Greater Vancouver Area, *MEDSCAPE General Medicine*, 9(1): 12.
- Rioux, M., Zubrow, E., Stutt Bunch, M. & Miller, W. (2003). *Atlas of Literacy and Disability*. Toronto, ON: Canadian Abilities Foundation.



- Rootman, I. & Ronson, B. (2005). Literacy and health research in Canada: Where have we been and where should we go? *Canadian Journal of Public Health*, 96, S62–77.
- Rudd, R.E., Epstein Anderson, J., Oppenheimer, S. & Nath, C. (2007). Health literacy: An update of medical and public health literature. In J.P. Comings, B. Garner & C. Smith (Eds.) *Review of Adult Learning and Literacy, Volume 7*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Rudd, R.E. & Anderson, J.E. (2006). *The Health Literacy Environment of Hospitals and Health Centers*. Boston: Health Literacy Studies, Harvard School of Public Health, National Center for the Study of Adult Learning and Literacy.
- Rudd, R.E., Kirsch, I. & Yamamoto, K. (2004). *Literacy and Health in America*. Princeton, NJ: Educational Testing Service.
- Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Daher, C. et al. (2003). Closing the loop: Physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*, 163, 83–90.
- Sharp, L.K., Zurawski, J.M., Roland, P.Y., O’Toole, C. & Hines, J. (2002). Health literacy, cervical cancer risk factors, and distress in low-income African-American women seeking coloscopy. *Ethnicity and Disease*, 12, 541–546.
- Schultz S & Kopec, J. (2003) Impact of chronic conditions. *Health Reports*, 14(4), 41–56. Statistics Canada catalogue no. 82-003-XIE.
- Singleton K. (2004). Developing health literacy curriculum for ESOL learners. *Literacy Harvest*, 11, 30–4.
- Statistics Canada (2005). *Building on Our Competencies: Canadian Results of the International Adult Literacy and Skills Survey*. Ottawa: Statistics Canada. Cat. No. 89-617-XIE. Available at: [www.statcan.ca/english/freepub/89-617-XIE/89-617-XIE2005001.pdf](http://www.statcan.ca/english/freepub/89-617-XIE/89-617-XIE2005001.pdf)
- Statistics Canada (2003). Participant and Activity Limitation Survey: A profile of disability in Canada, 2001. *The Daily*. December 3, 2003. Ottawa. Available at [www.statcan.ca/Daily/English/021203/d021203a.htm](http://www.statcan.ca/Daily/English/021203/d021203a.htm)
- Sudore, R.L., Yaffe, K., Satterfield, S., Harris, T.B., Mehta, K.M., Simonsick et al., (2006). Limited literacy and mortality in the elderly, *Journal of General Internal Medicine*, 21, 806–812.
- The Centre for Literacy of Quebec (n.d.). *Definition of Literacy*. Retrieved from <http://www.centreforliteracy.qc.ca/def.htm>
- Totten M. & Quigley P. (2003). *Bullying, School Exclusion and Literacy*. Unpublished discussion paper. Ottawa, ON: Canadian Public Health Association.

- U.S. Department of Health and Human Services (2000). *Healthy People 2010: Understanding and Improving Health*, (2<sup>nd</sup> ed.). Washington, DC: U.S. Government Printing Office. Available at <http://www.healthypeople.gov/Document/pdf/uih/2010uih.pdf>
- Wilson, R. (2004). Retrospective Evaluation of the National Literacy and Health Program. Unpublished report. Ottawa: Canadian Public Health Association.
- World Health Organization (1998). *Health Promotion Glossary*. Geneva: Author.