

# **Executive Summary**

## **A VISION FOR A HEALTH LITERATE CANADA**

### **Report of the Expert Panel on Health Literacy**

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The Expert Panel on Health Literacy was established by the Canadian Public Health Association (CPHA) in 2006. The Panel's terms of reference were to define the scope of the problem of health literacy in the context of literacy and health, identify barriers to creating a health literate public, assess the effectiveness of existing interventions to improve health literacy and assess the implications of the evidence for policies and programs to improve health literacy through the development of recommendations. The Panel used the following approaches:

- a literature review building on several comprehensive previous reviews
- an examination of analyses of data from the 2003 International Adult Literacy and Skills Survey (IALSS), using a newly developed scale of health literacy
- focus groups with adult literacy learners
- an environmental scan of interventions to improve health literacy
- interviews with experts in the fields of health, literacy, medicine, education and social services
- an e-mail questionnaire completed by policy-makers, advocates and professionals working in health, literacy, education, social, and community services,

- consultations with a broad range of stakeholders across the country.

The Panel defined *literacy* as 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. *Health literacy* was defined as 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. After reviewing the research literature, the Panel concluded that despite some recent progress in defining and measuring health literacy, there is currently no consensus on these questions. However, data from Canada's 2003 IALSS provide the best available information on the extent and distribution of health literacy in Canada. The Panel also concluded that there is a lack of awareness and understanding of the concept of health literacy in Canada.

The Panel's vision of a health literate Canada is:

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 the care of themselves, their families and communities, and to manage interactions in a variety of settings that affect health and well-being.

The Panel's conclusions about the scope of the problem, barriers, existing interventions and recommendations for policies and programs to improve health literacy are outlined below. For the detailed findings, please refer to the Panel's full report.

### **Scope of the Problem**

1. Many people in Canada apparently lack the level of literacy required to function well in relation to the information demands of modern life. An even greater number apparently lack the skills required to respond to the health information demands of different health contexts.
2. Levels of literacy and health literacy vary significantly from jurisdiction to jurisdiction in Canada and among sub-groups of the population. 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.

3. Both literacy and health literacy are related to health outcomes, and those with lower levels are more likely to experience negative health outcomes. Other outcomes of low literacy and health literacy include lower incomes and less community engagement, both of which are associated with poorer health and quality of life.
4. There is a lack of systematic information in Canada on levels of literacy and health literacy in certain populations, including Aboriginal people, newcomers, people with disabilities and rural residents. The role of gender, outcomes of low health literacy and costs associated with low literacy and health literacy also require further research.
5. Although evidence of the financial burden and costs of low health literacy in Canada is sparse, it appears that policies designed to raise average health literacy levels might lead to improvements in population health and concomitant reductions in health costs.

### **Individual and System Barriers**

1. Many individual barriers affect proficiency in health literacy. These include: declines associated with aging; low levels of formal education; lack of health knowledge and skills; having a mother tongue other than English or French; living with disabilities; social stigma; and experiences in early childhood.
2. Many system barriers also affect health literacy. These include: challenges in implementing quality school health and physical education programs to address students' health issues; lack of affordable English/French as a Second Language programs and community-based literacy upgrading programs; inadequate workplace training and education; confusing or conflicting health information from the media and the Internet; complex health systems; demanding self-care regimes for chronic diseases; and lack of awareness and knowledge about health literacy among health and literacy professionals.

3. Researchers, practitioners and key stakeholders have many plausible ideas for addressing the individual and system barriers to health literacy, but very few have been rigorously evaluated.

### **Health Literacy Interventions**

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 hold some promise in addressing health literacy issues.
3. Daily reading appears 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 health literacy issues but many are short-term and without sustained funding and there are no on-going mechanisms for sharing best practices across the country.

### **Recommendations for Policies and Programs**

1. Policies and programs are needed to respond to the extent and impact of low literacy in Canada and the increasing demands of a complex health system and the expectations for patient self-management of chronic disease.
2. Attention should be directed to the 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 people. Given their unique circumstances and cultures, it is likely that a parallel process needs to happen to support First Nations, Métis and Inuit peoples to develop policies and programs appropriate to their needs.

3. All levels of government need to be involved in developing and supporting health literacy policies and programs that are specific to each jurisdiction, given the different patterns of health literacy proficiency across the country. Tools, such as geographic maps of health literacy that are being developed by the Canadian Council on Learning (CCL), will be valuable in designing population-appropriate strategies.

4. Policies and programs are required to reduce the numerous and interconnected individual and system barriers to health literacy. 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. Health literacy policies and programs need to be coordinated with policies and programs in other related areas and take into account existing health literacy initiatives while linking with efforts to address general literacy, e-literacy, etc.

7. Encouraging reading practices in daily life through innovative and targeted policies and programs will likely be productive given that daily reading appears to be a strong determinant of health literacy.

8. Canadian research is needed to support policy and practice development and increase understanding of the impact of health literacy on population health and well-being and of the role of health disparities.

Based on these conclusions and the advice provided from consultations across the country, the Panel made the following 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:

1. To improve literacy and health literacy skills in Canada
2. To reduce inequities in opportunities for developing literacy and health literacy skills in Canada
3. 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:

1. Disseminate the Panel's findings and recommendations to policy-makers, practitioners, researchers and the general public to raise awareness of the scope and nature of the issue of health literacy in Canada
2. 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
3. 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 multi-media 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?