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Literacy and its Implications for Health Care

Presentation to 2009 CHA Intramural Learning session by Irving Rootman, Executive Director, CCL Health and Learning Knowledge Centre, University of Victoria

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Outline

- **Definition and Measurement of Literacy and Health Literacy**
- **Why you should be concerned about literacy and health literacy**
- **What Health Care Settings Can Do**
- **Some Resources and Models**
- **Implications for Health Care**

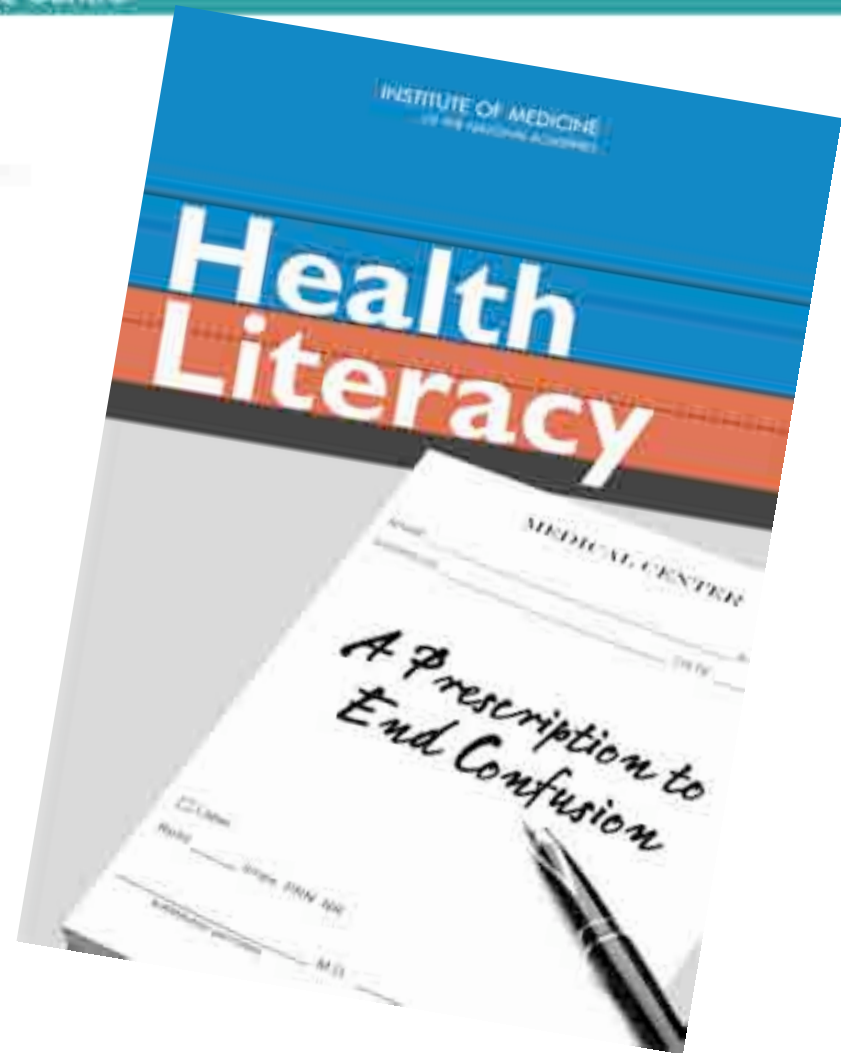
Literacy is:

“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” (CPHA Expert Panel on Health Literacy)

(Rootman and Gordon-El-Bihbety, 2008)

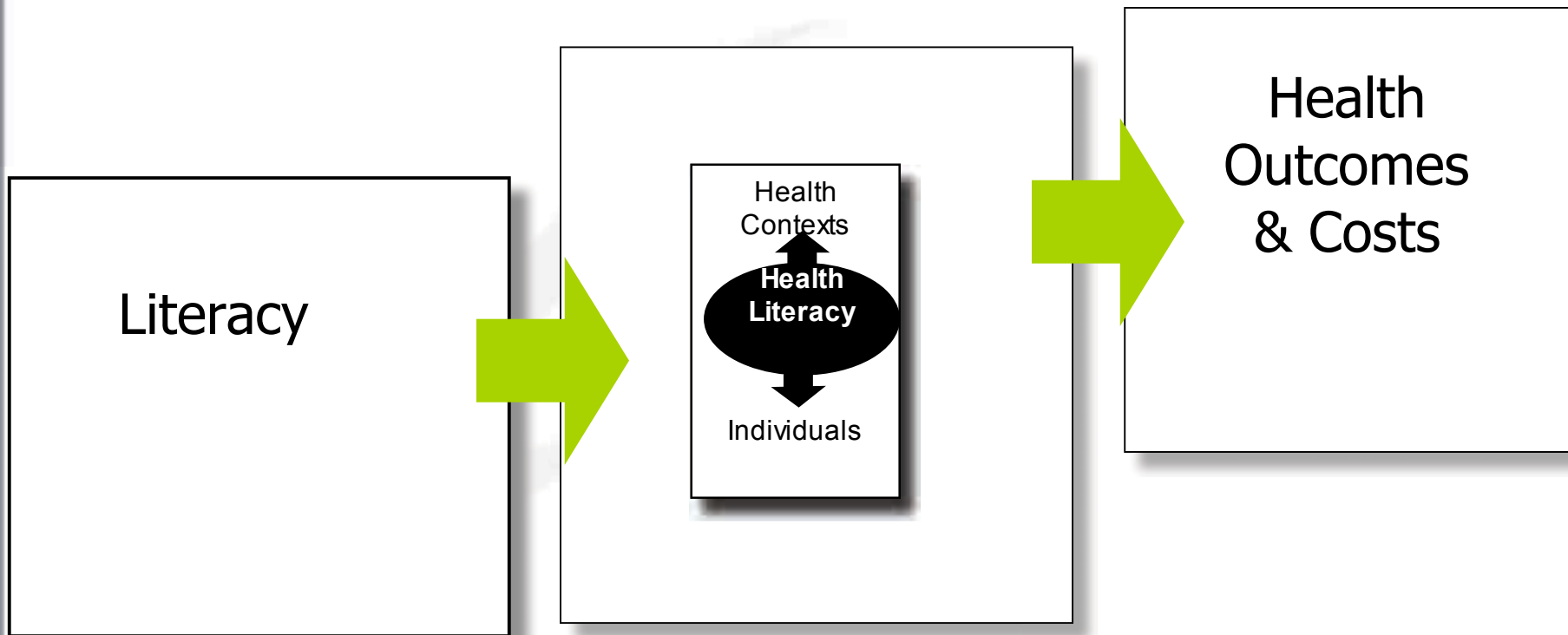
Health Literacy is:

“The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”
(I.O.M, 2004)



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Health Literacy Framework (I.O.M., 2004)

Health Literacy is:

“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” (CPHA Expert Panel on Health Literacy).



Health Literacy:

“what people need to find or help find, understand, communicate and use health information”

(B.C. Health Literacy Collaborative Advisory Meeting March 2, 2009)

How do Literacy and Health Literacy Differ?:

- **Literacy refers to basic skills required to succeed in society**
- **Health Literacy requires literacy skills but also:**
 - **Skills required to find health information**
 - **Skills required to evaluate health information**
 - **Skills required to integrate information from a variety of sources**
 - **Some knowledge of the vocabulary of health and culture of the health system**

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Commonly Used Tools to Measure Literacy:

- **WRAT: Wide Range Achievement Test** (Wilkinson, 1993)
- **IALSS: International Adult Literacy and Skills Survey** (Statistics Canada, 2005)

Commonly Used Tools to Measure Health Literacy:

- **REALM: Rapid Estimate of Adult Literacy in Medicine** (Davis et al., 1993)
- **TOFHLA: Test of Functional Health Literacy in Adults** (Parker et al., 1995)
- **NVS: Newest Vital Sign** (Weiss, 2007)
- **HALS: Health Activity Literacy Scale**



Health Activity Literacy Scale:

- Using 350 unique items in International Literacy Surveys
- 191 items judged to measure health-related activities
- Health-related items assigned to health literacy sub-domains

Health Activities	Number of Items (n=191)
Health Promotion	60
Health Protection	65
Disease Prevention	18
Health Care and Disease Management	16
Navigation	32

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Importance of Literacy and Health Literacy for Health Care Settings:

- **Large numbers of people using the health care system appear to have low levels of literacy and health literacy**
- **Lower levels of literacy and health literacy appear to be related to poorer health outcomes**
- **Increasing rates of chronic disease will likely increase need for health literacy skills**
- **Lower health literacy appears to be related to higher health care costs**
- **Increasing complexity of the healthcare system and the deluge of health information now available put high demands on people for health literacy skills**

Literacy scores among working age Canadians in 2003 (Rootman and Gordon-El-Bihbety, 2008):

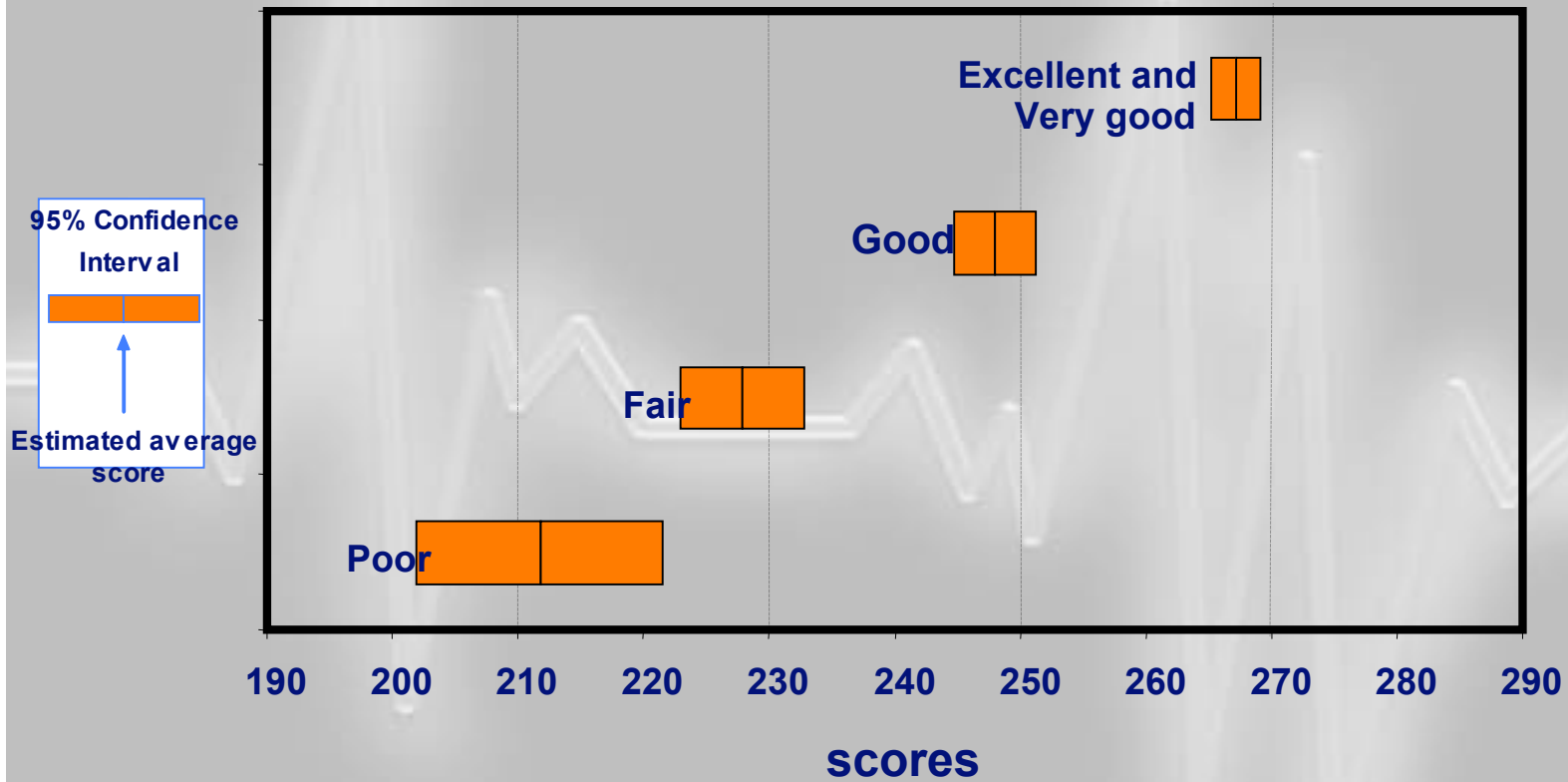
- **42% fell below Level 3 on the Prose Scale**
- **43% fell below Level 3 level on the Document Scale**
- **50% fell below Level 3 the Numeracy Scale**
- **55 % fell below Level 3 on the Health Literacy Scale**
- **88% of Canadians over the age of 65 fell below Level 3 on the Health Literacy Scale**

Level 3 is considered the minimum level of proficiency required to meet the demands of modern day life including those posed by health issues.

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Health Literacy Scores by Self-perceived General Health Status, Canada, 2003



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Health outcomes related to low health literacy (reading proficiency) include:

- **Longer hospitalizations** (Baker et al., 1997, 2002)
- **Higher rates of cervical cancer** (Lindau et al., 2002)
- **Higher rates of diabetes** (CCL, 2008)
- **Higher mortality** (Baker et al., 2007; Sudore, 2006)

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Health Literacy (Reading proficiency) and mortality:

- **A recent U.S. study examined the all-cause and cause-specific (cardiovascular, cancer, and other) mortality of 3260 Medicare enrollees over age 56 in 4 US metropolitan areas (Baker et al., 2007)**
- **Older adults with inadequate and marginal health literacy levels as measured by the TOHFLA had a 50 per cent higher mortality rate over a five-year period than those with adequate skills.**
- **Low health literacy was the top predictor of mortality after smoking, and was a more powerful variable than both income and years of education.**
- **Another recent study found that limited literacy, as measured by the REALM, was independently associated with a nearly two-fold increase in mortality in the elderly (Sudore, et al., 2006).**

Low reading proficiency is also associated with:

- **Inappropriate medication use and compliance with physician orders** (Williams, et al., 1995; Kalichman, et al., 1999)
- **Less use of preventive services and less care seeking** (Scott, et al., 2002)
- **Less expression of health concerns** (Rudd et al., 1999)
- **Difficulties using health care system** (Davis et al. 1996; Brez and Taylor, 1997)

Increasing chronic disease and health literacy:

- **The number of people with diabetes in Canada is projected to increase from approximately 1.4 million patients in 2000 2.4 million in 2016 (Ohinmaa, et al., 2004).**
- **One of the ways to address chronic disease which is being increasingly used is patient self-management (McGowan, 2005)**
- **Low health literacy is a barrier to effective self-management. A review of randomized control trial studies found that 62% of patients with lower reading skill levels were unable or unwilling to engage in self-management (Johnston et al., 2006)**
- **Improving literacy and health literacy could lead to improved self-management of chronic diseases**

Health Literacy (Reading Proficiency) and Cost:

- An analysis of expenditure data from a study of public hospital patients found that predicted in-patient spending for a patient with inadequate HL (Reading Proficiency) was \$993 higher than a patient with adequate reading skills. A difference of \$450 remained after controlling for health status (IOM, 2004).**
- Another study which looked at Medicare users found that the Medicare costs of those with less than a 3rd-grade reading level were \$10,688/year, while the costs for those with greater than 4th-grade reading level were \$2,891 (Weiss and Palmer, 2004)**

Estimated Economic Drain of Low Health Literacy on U.S. Economy:

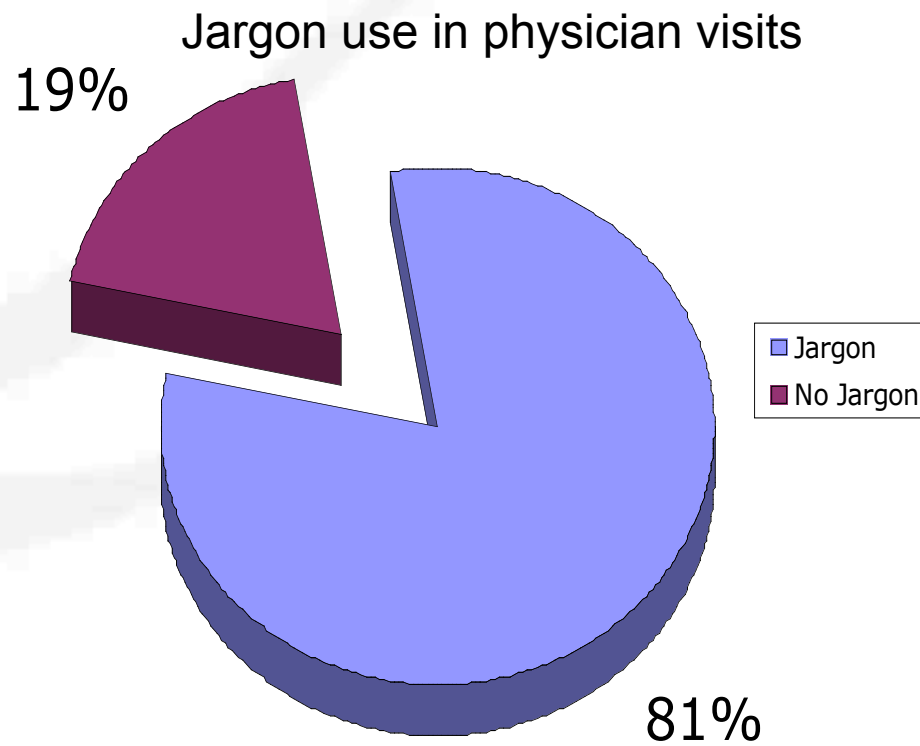
- **“initial approximation places an order of magnitude of the cost of low health literacy to the U.S. Economy in the range of \$106 billion to \$238 billion annually” (Vernon et al., 2007)**
- **“When one accounts for the future costs of low health literacy that result from current actions (or lack of action), the real present day cost of low health literacy is closer in range to \$1.6 trillion to \$3.6 trillion” (Vernon et al., 2007)**

Demands of health information materials:

- **Over 800 studies have found that health- related material for patient education far exceeds the reading levels of the average adult (Rudd, 2007)**
- **A recent study of health information websites in Canada, the U.K. and Australia found that the content of all sites was written at a higher level than recommended by literacy organizations. The lowest level was grade 11 (Petch, 2004)**

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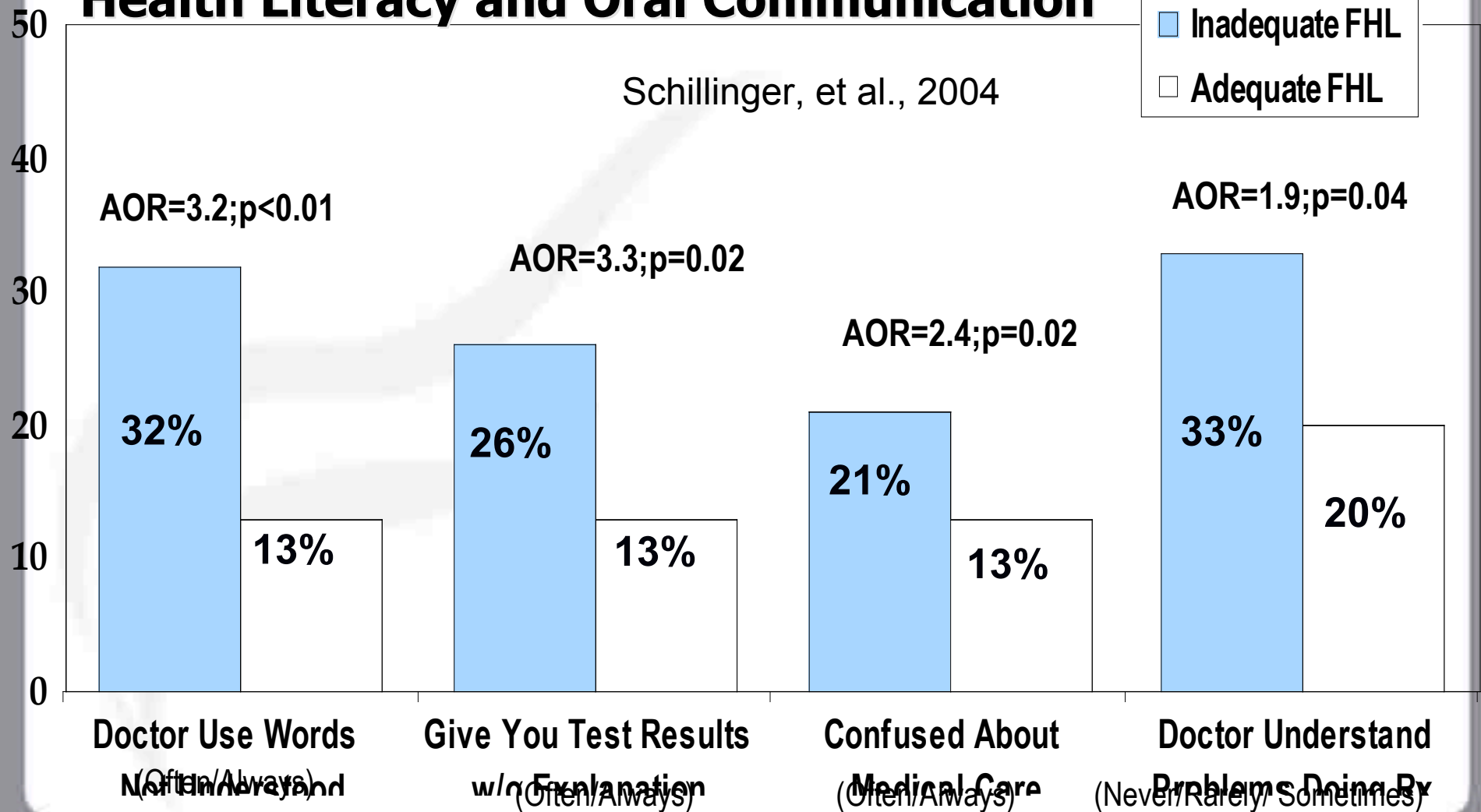
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Castro. et al., 2007

Health Literacy and Oral Communication

Schillinger, et al., 2004



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Areas in which health care facilities can make improvements

- **Navigation**
- **Print Communication**
- **Oral exchange**
- **Technology**
- **Policies and protocols**

(Rudd and Anderson, 2006)

Some recommendations for *navigation improvement* (Rudd and Anderson, 2006):

- **Adjust automated phone system and/or train people who answer phone to provide clear directions to facility using multiple forms of transportation**
- **Provide entry signs visible from street and use everyday words for signs**
- **Provide patients with customized and highlighted hand- held maps**
- **Use words consistently**

Some recommendations for *print communication*
(Rudd and Anderson, 2006) :

- **Use plain language**
- **Apply layout and design elements that make reading easy**
- **Use rigorous methods to develop materials**
- **Conduct reading grade-level assessments**

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Some recommendations for improving *oral exchange* (Rudd and Anderson, 2006) :

- **Ask patients how they learn best**
- **Match teaching approaches to learning styles**
- **Avoid using organizational jargon or specialized words**
- **Encourage questions**
- **Say “am I clear?” rather than “do you understand?”**
- **When appropriate, ask patients to repeat key points as though they were telling what they learned to someone else**

Some recommendations for improving *technology* (Rudd and Anderson, 2006) :

- **Use T.V.'s to orient and educate patients throughout facility**
- **Provide house phones to connect patients with staff or volunteers for help**
- **Phone to remind patients about appointments and preparations required**
- **Provide kiosks in various areas of facility geared to patients with average or more limited literacy**

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Some recommendations to improve *policies and protocols* (Rudd and Anderson, 2006) :

- **Use plain, everyday words in all print materials**
- **Provide patients with opportunities to ask questions about protocols and policies**
- **Develop and hold orientation programs for staff and volunteer orientation**
- **Tailor orientation programs for different groups of staff**
- **Offer on-site training on health literacy for relevant staff and volunteers**
- **Offer CME credit course related to health literacy and communication for all represented professional staff**

Some Helpful Resources

Canadian:

- National Literacy and Health Program
- Writing Health Information for Patients and Families
- Literacy Audit Tool Kit
- Health Literacy Maps

American:

- The Health Literacy Environment of Hospitals and Health Centers
- Pharmacy Health Literacy Assessment Tool
- Health Literacy Manuals for Clinicians
- Health and Literacy Discussion List

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National Literacy and Health Program:

- **Established in 1994**
- **Involves 24 National Organizations coordinated by C.P.H.A.**
- **Promotes awareness among health professionals of the links between literacy and health and provides resources to help health professionals serve clients with low literacy skills more effectively (e.g. Guidelines for medication packaging and labeling for older adults; Plain Language Service)**
- **Go to: www.cpha.ca/en/programs/literacy.aspx**

Writing Health Information for Patients and Families:

- **Developed by Patient Education, Hamilton Health Sciences Centre**
- **128-page resource book for health care providers and educators interested in developing patient education materials in plain language to promote health literacy**
- **To order, e-mail PatientEducation@hhsc.ca**

Literacy Audit Tool Kit:

- **Developed by Literacy Alberta to help organizations provide more literacy-friendly customer service**
- **A Health Literacy tool is currently under development**
- **Go to: www.literacyalberta.ca**

Health Literacy Maps:

- **Developed by Doug Willms at the University of New Brunswick for Canadian Council on Learning**
- **Interactive maps are now available on the CCL website**
- **Go to: www.ccl-cca.ca/cclflash/healthliteracy/**

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Health Literacy by Health Districts

Canada

Percent Levels 1 and 2 Health Literacy

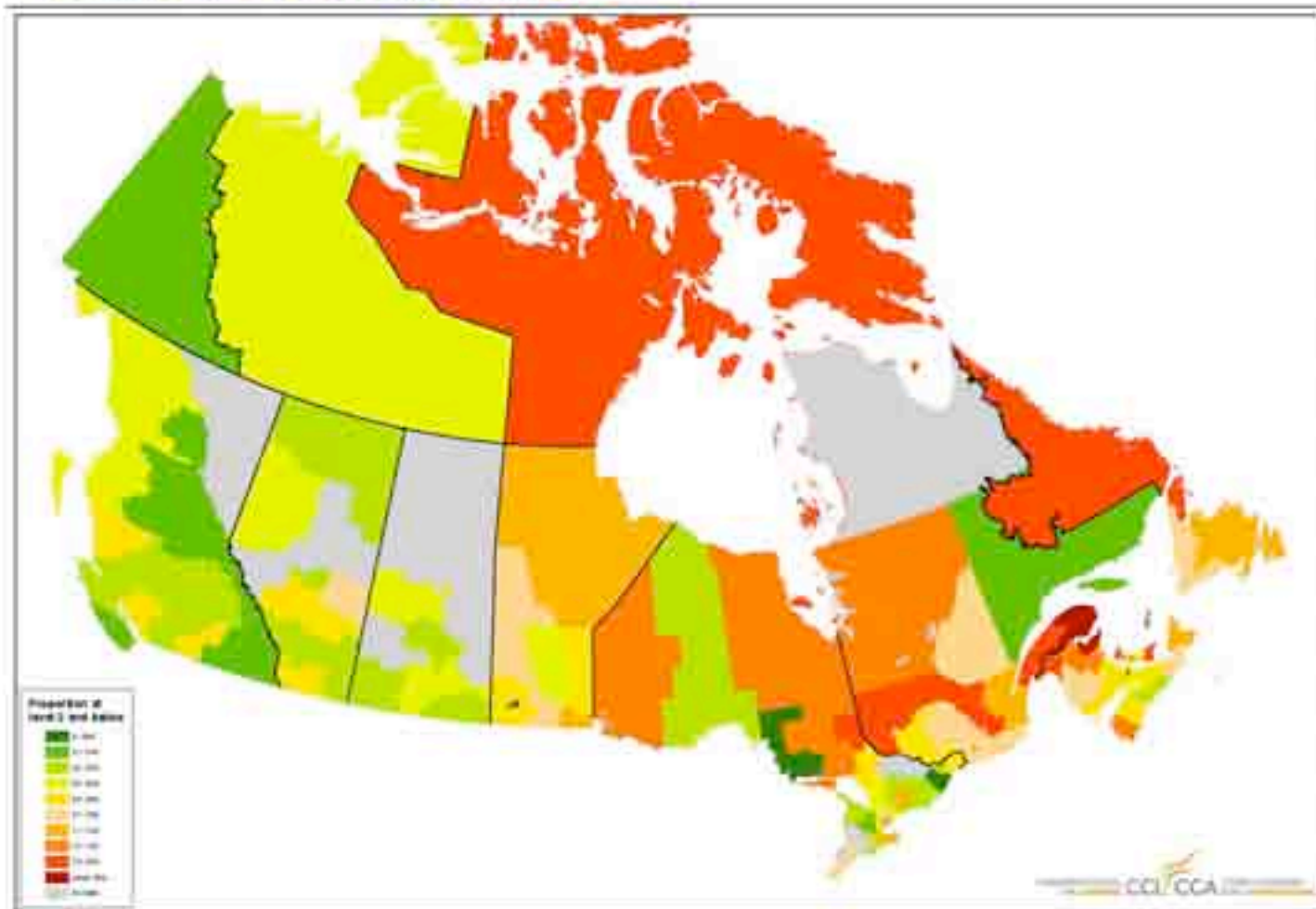
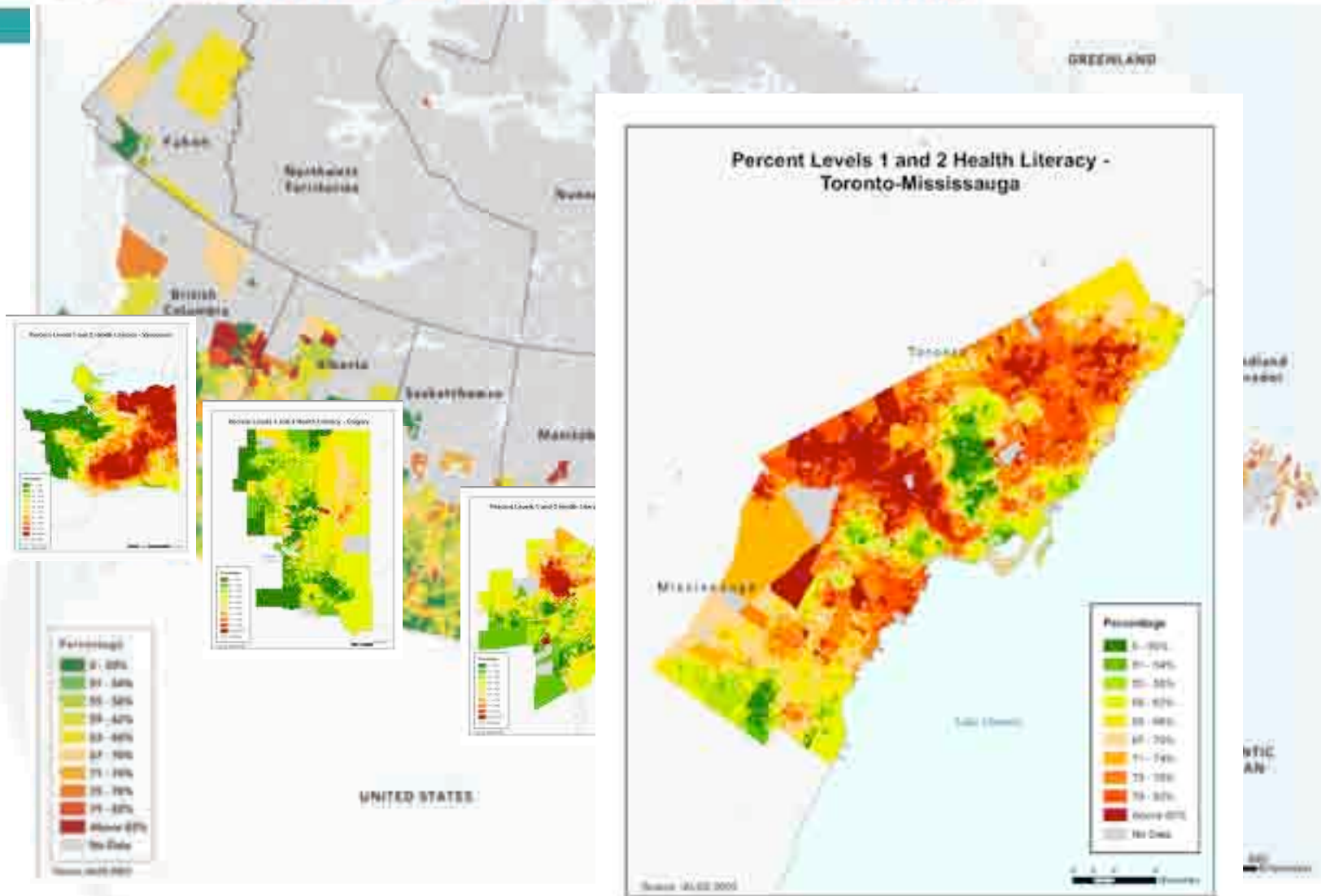


Figure 6: Proportion of adult health literacy at level 2 and below, ages 16 and older, TALSS 2003 and Census 2001



The analysis and mapping of the health-literacy results were conducted by J (UNB), with the assistance of Teresa Tang, GIS Programmer at the Canadian Research Institute for Social Policy at UNB

New Brunswick

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Health Literacy Environment of Hospitals and Health Centers:

- **Developed by Rima Rudd (Harvard School of Public Health) and Jennie Anderson (National Center for Study of Adult Learning and Literacy) and released in 2006.**
- **Covers Navigation, Print Communication, Oral exchange Technology and Policies and Protocols. Also includes suggestions specific to health care settings and background and resources on health and literacy (mostly U.S.), as well as examples of strategies for action, and tools for conducting needs assessments including a “Walking Interview Guide”**
- **Available at [www.bcsall.net]**

Pharmacy Health Literacy Assessment Tool:

- **Developed U.S. Agency for Healthcare Research and Quality for outpatient pharmacies of large public hospitals and released in October, 2007.**
- **Includes assessment tour of pharmacy, survey of pharmacy staff, patient focus groups and advice on how to use results as well as associated tools**
- **Available from [www.ahrq.gov]**

Health Literacy Manuals for Clinicians:

- A.M.A. has developed two manuals for clinicians
- The first, written by Barry Weiss, was published in 2003 as part of educational program about HL which also included a video. The second, which is a revised version by the same author was released in 2007. Both used in CME and are eligible for credit.
- Current version covers extent and implications of limited HL, assessment and measurement, strategies for enhancing patients' HL, improving communication with patients, and creating and using patient-friendly written materials. It also include case discussion, resources, a CME questionnaire and references.
- Available from [www.ama-assn.org]

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Health and Literacy Discussion List:

- **Hosted by National Institute for Literacy**
- **Purpose is to provide an on-going professional development forum to discuss health literacy needs, goals and strategies**
- **Go to:**
www.nifl.gov/lincs/discussions/subscribe_all.html

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Some Canadian Models:

- **McGill University Centre Project**
- **Quebec Centre for Literacy and Montreal Children's Hospital Project**
- **Centretown Community Health Centre Project**
- **Literacy Partners of Manitoba Project**
- **B.C. Health Literacy in Mental Health and Addiction Network**

Health Literacy Project at the McGill University Health Centre (MUHC)

- Longest running hospital-based health literacy project in Canada
- 5 hospitals in downtown Montreal serve a multi-cultural, multi-lingual population
- Current projects: Patient Education MUHC (research briefs, audiotapes); McGill Nursing project (curriculum module); MCH Literacy Promotion project. See: <http://www.centreforliteracy.qc.ca/health/healthlt.htm>

Quebec Centre for Literacy and Montreal Children's Hospital:

- **The goal of the Lire/Imagine/Read project is to integrate literacy promotion into health care practice, and to provide books to families of all children under 6 years who visit or stay at the MCH**
- **Project objectives include creating a hospital orientation to literacy and health, and building community resources to support such a program.**

www.centreforliteracy.qc.ca

Centretown Community Health Centre Project:

- Community-based education program for patients newly diagnosed with type-2 diabetes**
- Linking community health centres, community resource centres and local hospitals, CCHC created a network of sites and partners in the Ottawa region**
- Program is cost-effective and is being expanded across Ontario.**

Literacy Partners of Manitoba:

- Project to help health care providers and administrators overcome barriers to reaching low literacy clients, and to make it easier for people with low literacy to benefit from health services**
- 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**

(Moody & Rose, 2004)

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BC Mental Health and Substance Use Provincial Health Literacy Network:

- **Established by BC Provincial Health Services Authority in 2008**
- **Includes all health authorities, Ministries of Health and Education, N.G.O.'s professional associations, community organizations and academic groups in addiction and mental health**
- **Scope limited to information for the public including children, youth and adults with mental health and substance use issues and their families as well as intermediaries such as health professionals and policy makers**

Recommendation of Expert Panel on Health Literacy

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

(Rootman and Gordon-El-Bihbety, 2008)

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Implications for Health Care:

- **Inadequate literacy and health literacy is very prevalent and effects the process and outcome of treatment negatively and is costly**
- **There are relatively inexpensive actions that the health care system can take to address the issue**
- **There are resources and models available to assist**
- **There is a growing interest in addressing the issue both within and outside of the health care system**

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What are you prepared to do about it?

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