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Health Literacy: What is it and what do we know about how to address it?

Presentation to Education Working Group of Pain BC and the BC Provincial Pain Initiative

Irving Rootman, Ph.D., Executive Director, HLKC

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Outline

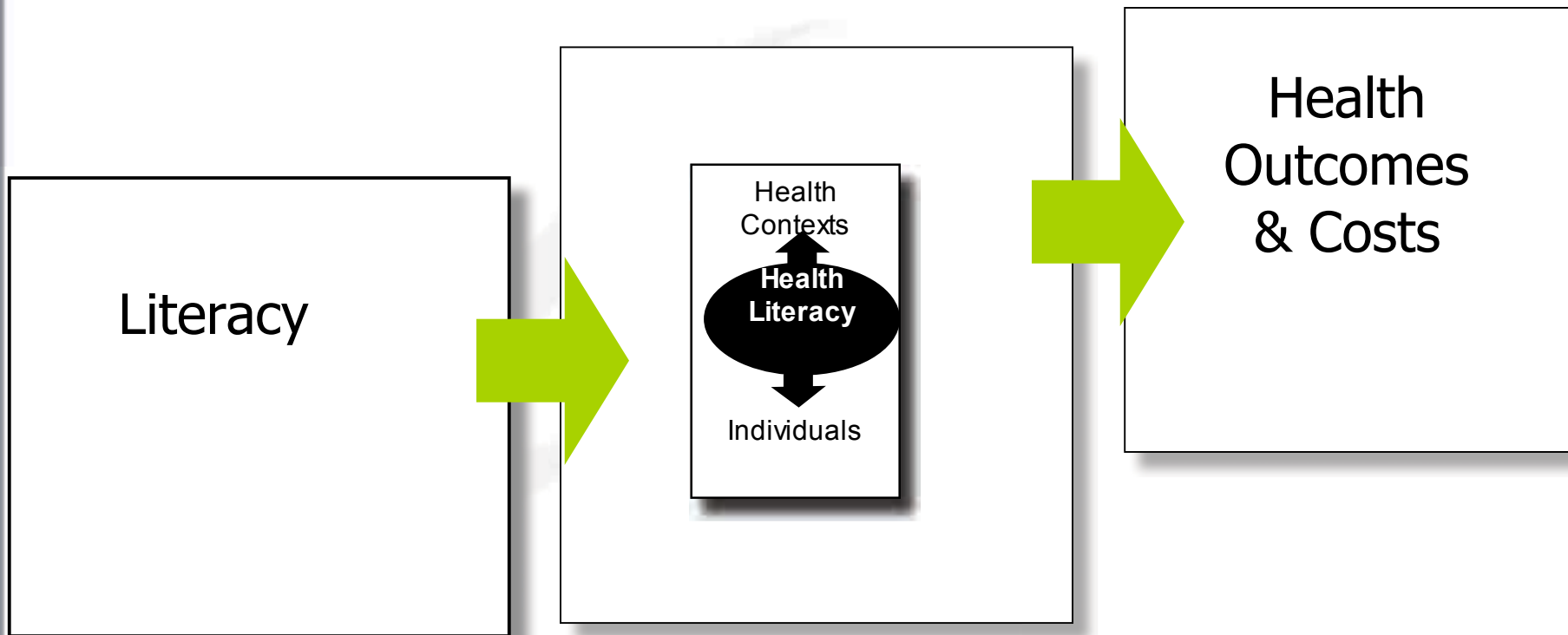
- **What is health literacy?**
- **Why should you be concerned about it?**
- **What do we know about ways to address it?**
- **What resources are available to help?**

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” (Rootman and Gordon-El-Bihbety, 2008)

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**

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** (CCL, 2007, 4)



Health Activity Literacy Scale (CCL, 2007a):

- 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 |

Why should you be concerned about health literacy?

- **Large numbers of people are affected**
- **Related to poorer health outcomes**
- **Increasing rates of chronic disease**
- **Health care costs**
- **Health information demands**
- **Equity**

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Many people in Canada have low levels of HL:

- **11.7 million** working age residents of Canada (55%) are estimated to lack the minimum level of health literacy needed to effectively manage their health information needs (CCL, 2007b).
- When seniors are added, an estimated **14.8 million** may be without adequate health literacy skills. An estimated 88% of respondents 65+ fell below Level 3 on the Health Literacy Scale in the 2003 IALSS survey (CCL, 2007b).

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

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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)**

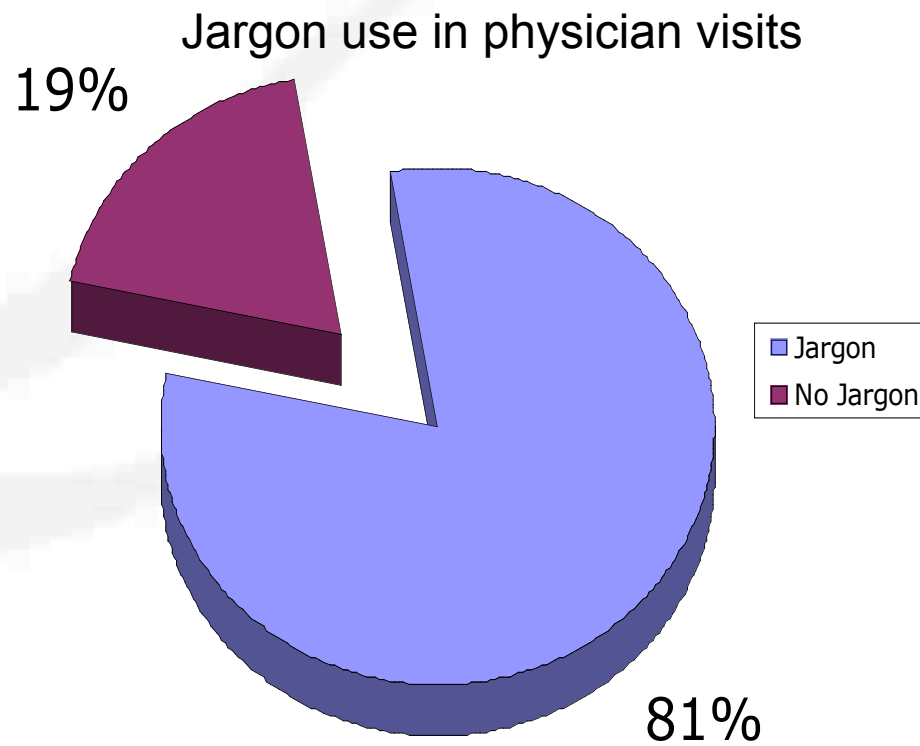
Estimated Economic Drain of Low Health Literacy on U.S. Economy:

- **“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 300 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)**

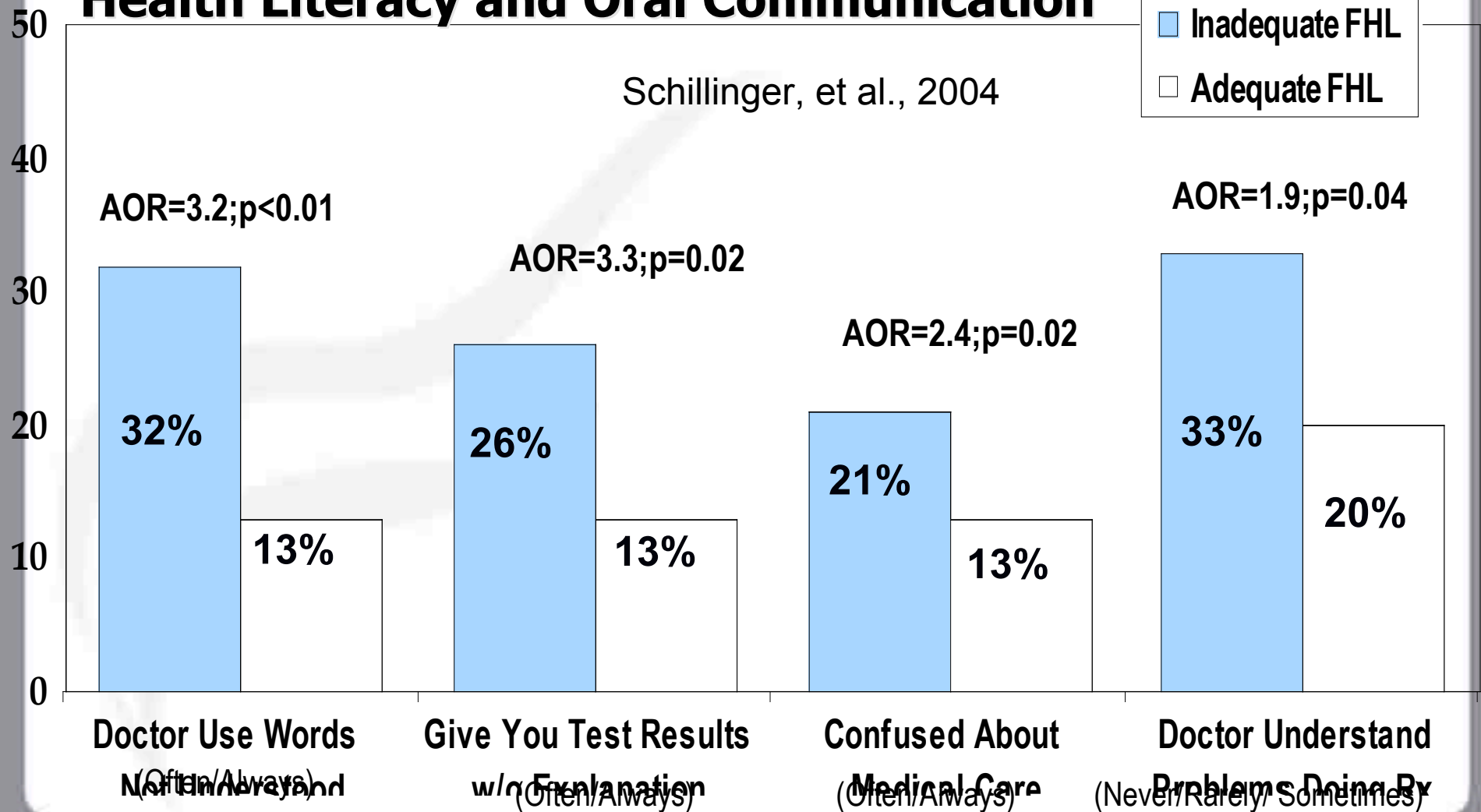
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Castro. et al., 2007

Health Literacy and Oral Communication

Schillinger, et al., 2004



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Certain population groups appear to be more likely to experience lower levels of health literacy. They include:

- Older adults
- Immigrants
- Adults with low levels of educational attainment
- People whose mother tongue is neither English nor French
- Recipients of social assistance
- Residents of particular provinces or territories

(Rootman and Gordon-El-Bihbety, 2008)

Health Literacy as an Ethical Imperative for Health Care (Volandes and Paache-Orlow 2007)

- **“Health Literacy may be a critical and under-examined mechanism of health inequalities” (p.5)**
- **“The problem of limited health literacy should primarily be understood as an issue of health inequality and justice” (p. 6)**
- **“Considering the least well-off in terms of health literacy, the most just arrangement would be one that ensured that the healthcare system was designed to benefit users with limited health literacy” (p.6)**
- **“We suggest a change in the standard of care...in which the universal assumption is limited literacy” (p.7)**

Knowledge from Research

- **Approaches that have been found to be promising based on research include:**
 - **Simplified written materials**
 - **Technology**
 - **Personal communication and education**
 - **Tailored approaches**

(IOM,2004)

Simplified Written Materials:

- **Most commonly used approach**
- **Includes simplified language, improved format, pictograms**
- **Found that:**
 - **Matching reading levels works in some circumstances**
 - **People with limited health literacy sometimes have difficulties interpreting pictograms**

(IOM, 2004)

Technology-based Communication:

- Includes videos, CD-ROMs, interactive multimedia and telephone interventions
- Found that:
 - Some show positive outcomes, but not necessarily for people with low health literacy
 - Many have not been evaluated for people with low health literacy

(I.O.M., 2004)

Personal Communication and Education:

- Includes, classes, health education sessions, and patient navigator programs
- Found that:
 - Some worked for people with low health literacy, others didn't
 - Patient navigator programs showed promise for people with low health literacy

(IOM, 2004)

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- **Tailored Approaches:**
- **Include using viewpoints and experiences of intended population to design materials**
- **Found that:**
 - **Tailored print materials can improve health outcomes**
 - **However, may not meet needs of those with low health literacy**

(IOM, 2004)

Knowledge from Experience

- Practitioners
- Patients



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Health Literacy Practices in Primary Care Settings:

- **2005 study that included an on-line survey of facilities in U.S., and interviews in five selected sites. Found that staff considered the following five health literacy practices to be especially valuable:**
 - **A team effort**
 - **Use of standardized communication tools**
 - **Use of plain language, face-to-face communication, pictorials, and educational materials**
 - **Clinicians partner with patients to achieve goals**
 - **Organizational commitment to create environment where HL is not assumed**

(Barrett et al., 2008)

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A survey of health and literacy professionals conducted for the Canadian Expert Panel on Health Literacy led to the following conclusions about how barriers in the health system might be addressed:

- Increasing skill-building and sensitive, culturally-appropriate communications
- Providing interpreters or client advocates
- Listening to patients carefully and taking time to explain
- Talking to patients slowly, using simple words, with respect
- Telephone follow-ups
- Encouraging patients to ask questions and express views

(CPHA, 2007)

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Suggested areas in which health care facilities can make improvements:

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

(Rudd and Anderson, 2006)

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- **Some recommendations for navigation improvement:**
 - **Adjust automated phone system and/or train people who answer phone to provide clear directions to facility**
 - **Provide entry signs visible from street and use everyday words for signs**
 - **Provide patients with customized and highlighted hand-held maps**
 - **Use words consistently**

(Rudd and Anderson, 2006)

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- **Some recommendations for print communication:**
 - **Use plain language**
 - **Apply layout and design elements that make reading easy**
 - **Use rigorous methods to develop materials**
 - **Conduct reading grade-level assessments**

(Rudd and Anderson, 2006)

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- **Some recommendations for improving oral exchange:**
 - **Ask patients how they learn best**
 - **Match teaching approaches to learning styles**
 - **Avoid using organizational jargon or specialized words**
 - **Say “am I clear?” rather than “do you understand?”**
 - **Ask patients to repeat key points**
 - **Encourage questions**

(Rudd and Anderson, 2006)

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- **Some recommendations for improving technology:**
 - **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**

(Rudd and Anderson, 2006)

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- **Some recommendations to improve policies and protocols:**
 - **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 volunteers**
 - **Tailor orientation programs for different groups of staff**
 - **Offer on-site training on health literacy for staff and volunteers**
 - **Offer CME credit course related to health literacy and communication for all represented professional staff**

(Rudd and Anderson, 2006)

In the Expert Panel survey of nearly 700 professionals :

- Only 32% said they had practice standards regarding health literacy in place**
- More than 30% were unsure of their clients' literacy levels**
- Almost 30% were unaware of the term health literacy**
- Only 7% reported that their organizations had policies on health literacy**

(CPHA, 2008)

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Experiences of Adults with Literacy Barriers in the Health System:

- **Interacting with Providers**
- **Interacting with the Health Care System**



Interacting with Individual Providers:

- Feelings of powerlessness, shame, stigma and fear**
- Written information that was not useful**
- Unfamiliarity with the medical jargon**
- Language and culture were not taken into consideration**
- Differences in expectations**
- Information given not precise enough**

(CPHA, 2006a)

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Interacting with the System:

- **Not enough time in patient-provider encounters**
- **Information often given only once**
- **Not enough translators available**
- **Reliance on family members resulted in role reversal**
- **Computers are a barrier**
- **Fragmentation in the health care system**
- **Often not told of other services and available health information**
(CPHA, 2006a)

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

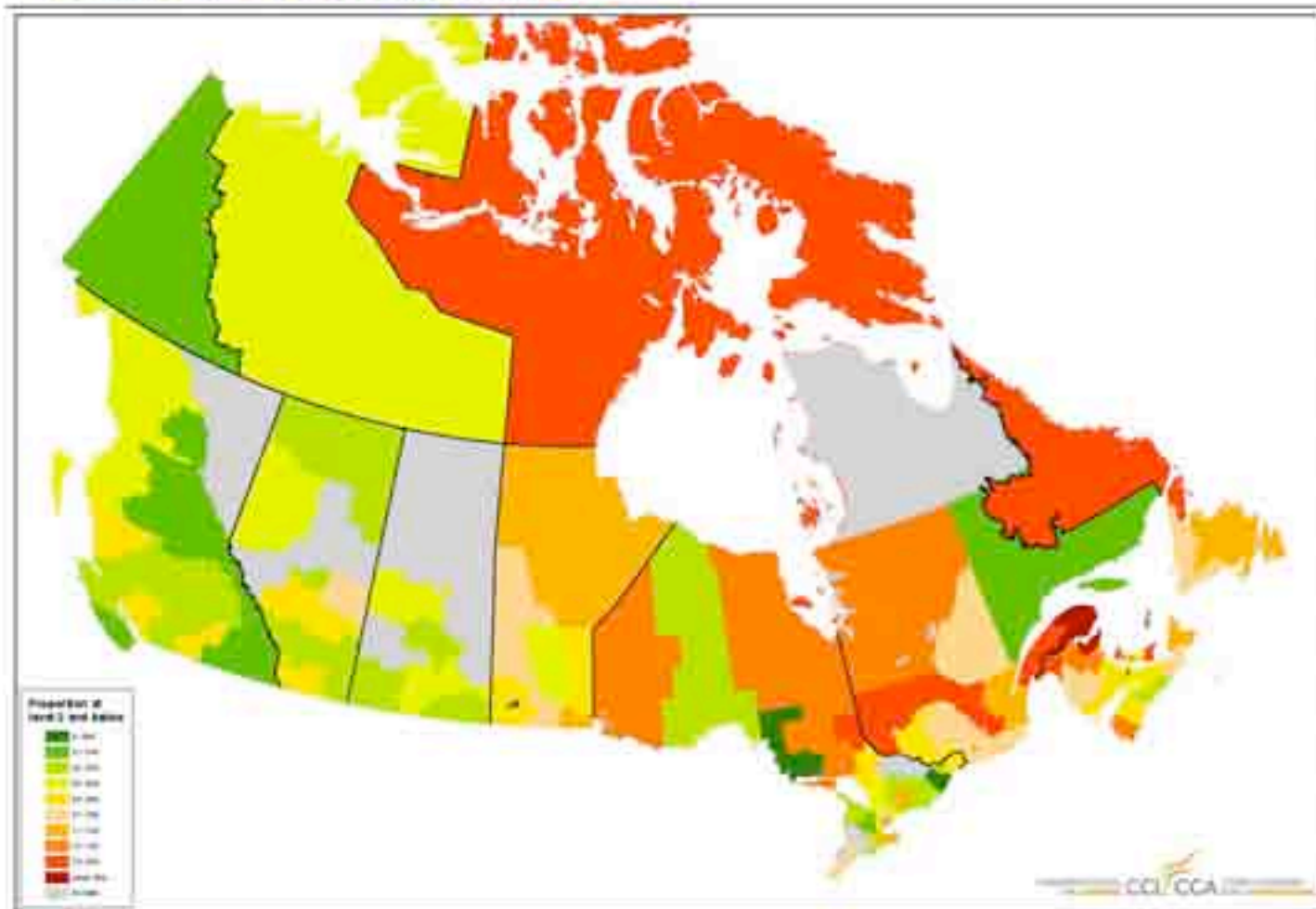
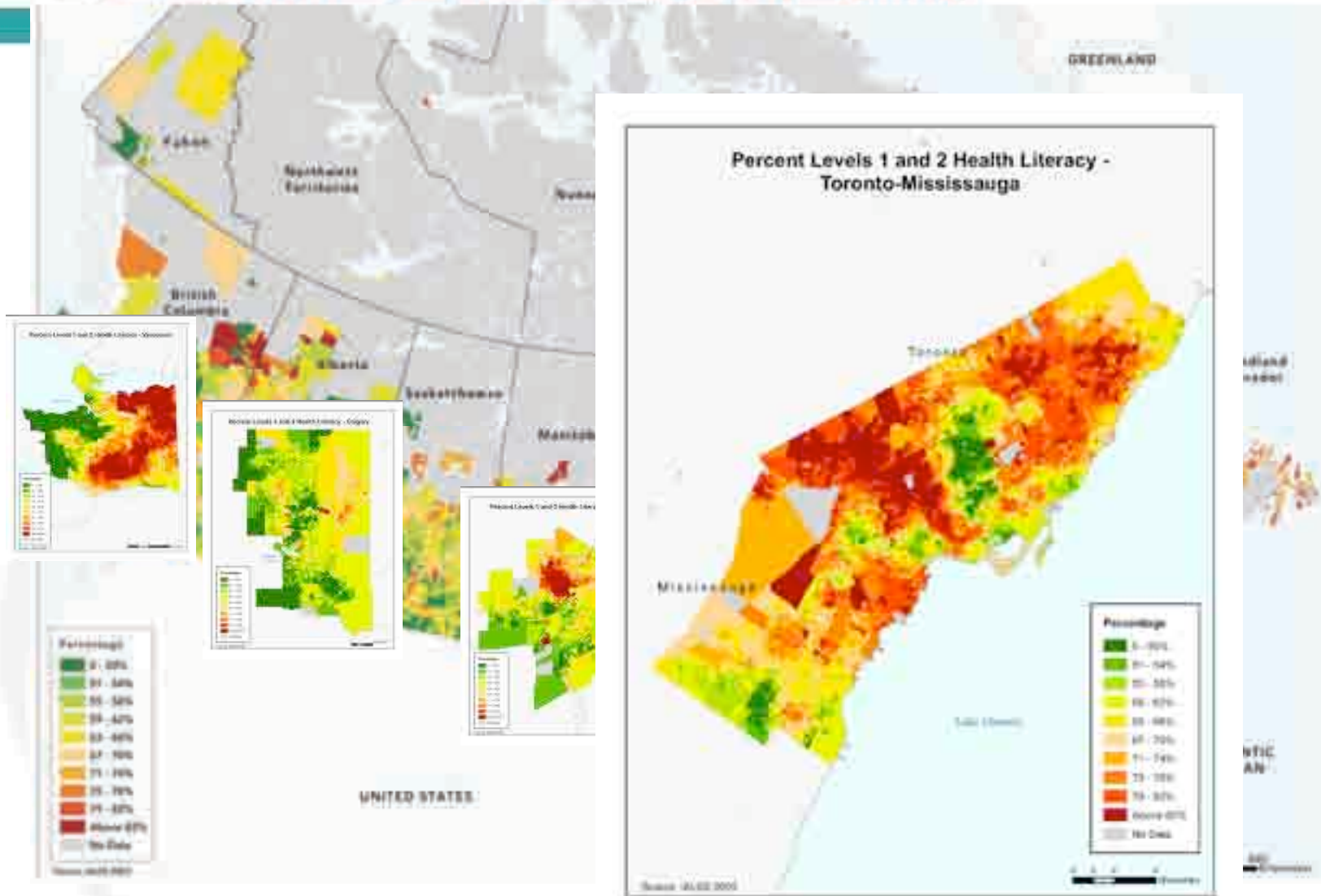


Figure 6: Proportion of adult health literacy at level 2 and below, ages 16 and older, TALSS 2003 and Census 2001



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**
- **Centretown Community Health Centre Project**
- **Literacy Partners of Manitoba Project**
- **B.C. Health Literacy in Mental Health and Addiction Network**

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.**

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>

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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Conclusions

- **Inadequate 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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To contact me:

- irootman@uvic.ca

