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Health Literacy: What do we know about it and what are the implications for Health Librarians?

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Outline

- **History of the Concept of Health Literacy**
- **Definition and Measurement**
- **Recent findings**
- **Implications for Health/Librarians**

How did I get involved in the field of health literacy?

- **Experience in health promotion (1978-)**
- **Introduction to the concept (1998)**
- **Opportunity to do research related to the concept (2002)**
- **Member of I.O.M Expert Committee on Health Literacy (2002-2004)**
- **Co-Chair of CPHA Expert Panel on Health Literacy (2006-2008)**
- **Scientific Officer and Executive Director CCL-HLKC (2006-2008)**

History of the Concept of Health Literacy (International)

- Introduced in health education in 1974 (Simonds)
- Used by CCSSO in 1993 (CCSSO, 1998)
- Introduced in clinical practice research in early 1990's (e.g. Williams et al., 1995)
- Resulted in A.M.A. Report (1999), Health Objective (US DHHS, 2000) and Expert Panel Report (I.O.M., 2004)
- Introduced internationally in health promotion (Kickbusch, 1997; Nutbeam, 1998)

History of the Concept of Health Literacy (Canada)

- Growing interest in literacy in the late 1980's
- OPHA/Frontier College Literacy and Health project (1989-1993)
- National Literacy and Health Program (1994-present); CPHA Clear Language Service (1997-present)
- National Conferences on Literacy and Health (2000, 2004)
- National Literacy and Health Research Project (2002-2006)
- CPHA Expert Panel on Health Literacy (Rootman and Gordon-el-Bihbety, 2008)
- In-depth Analysis of National Health Literacy data (CCL, 2007b, 2008)

Definitions according to Alice

**'When I use a word,' Humpty Dumpty said, in a rather scornful tone,
'it means just what I choose it to mean – neither more nor less.'
'The question is,' said Alice, 'whether you can make words mean so many different things.'
'The question is,' said Humpty Dumpty, 'which is to be master – that's all.'
Alice was much too puzzled to say anything...**



From Through the Looking Glass

Definitions of Health Literacy

- **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 (Nutbeam, 1998)**
- **Ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials” (AMA,1999).**

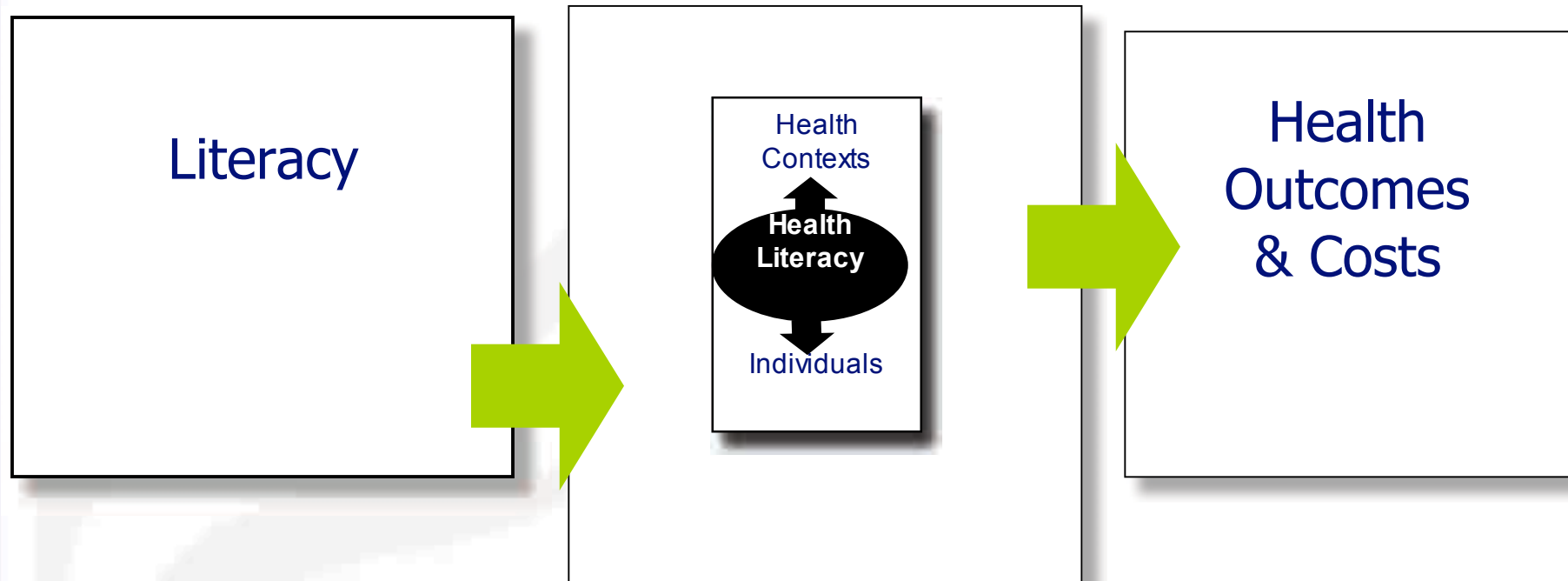
U.S. Institute of Medicine Definition of Health Literacy

- 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)



Canadian Expert Panel on Health Literacy Definition

- 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).



European Definition

- **“the capacity to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the health care system, the marketplace and the political arena”**
(Kickbusch, 2007)

- **Health information literacy is the ability to:**
 - **Recognize a health information need**
 - **Identify likely sources and use them to find health information**
 - **Assess the quality of the information and its usefulness**
 - **Understand and use the information to make informed health care decisions**

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, 2005)**
- **HALS: Health Activity Literacy Scale (CCL, 2007b)**

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 Promotion; Health Protection; Disease Prevention; Health Care and Disease Management; and Navigation)**
- **Individuals scored on a scale from 1-500 and placed into 5 levels**

Extent of low health literacy in Canada and BC

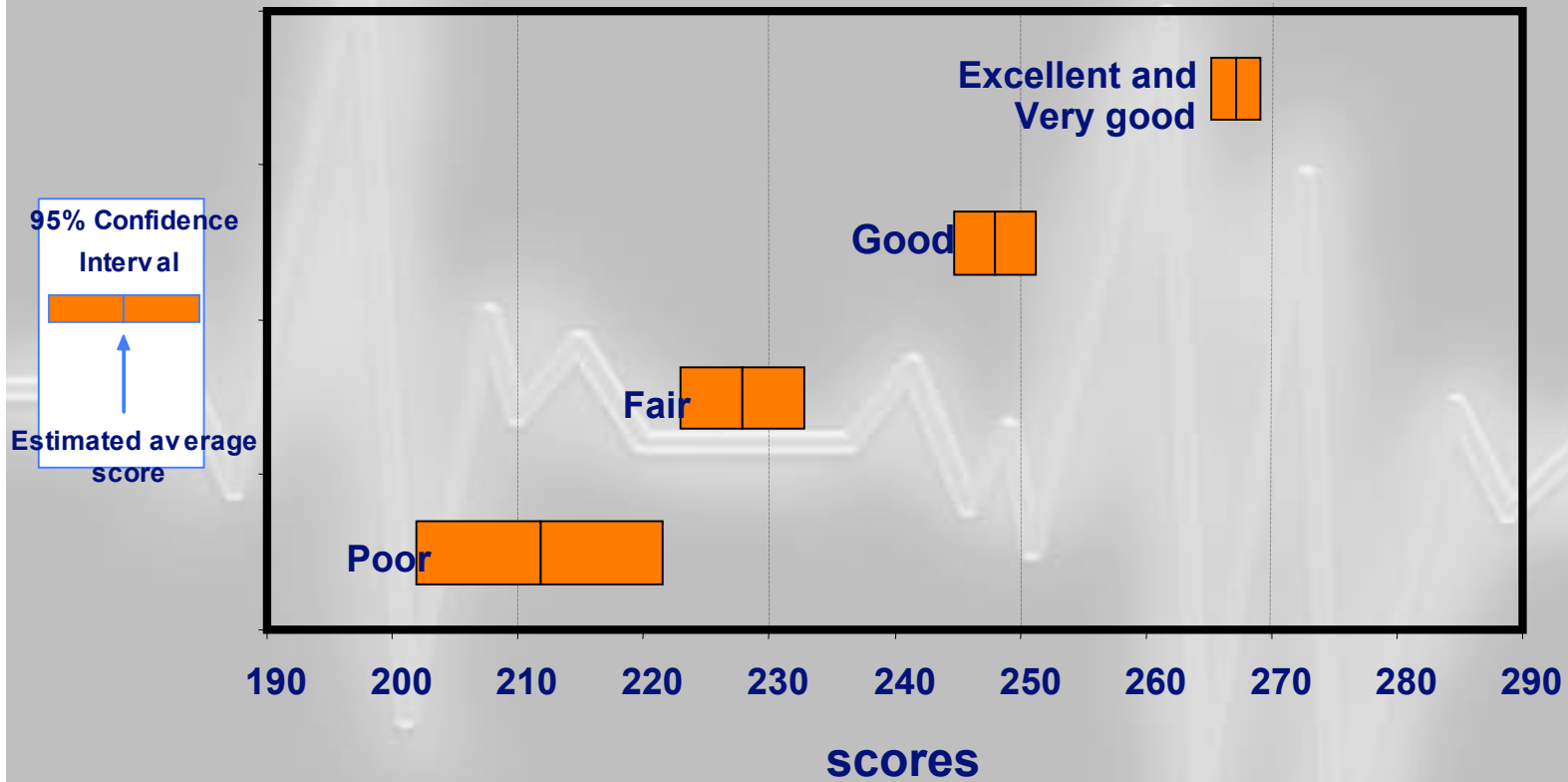
- Based on the 2003 IALSS, **11.7 million** working age residents of Canada (**55%**) are estimated to lack the minimum level of health literacy needed to effectively manage their health information needs (CCL, 2007a). **1.4 million** B.C. working age residents (**50%**) are at this level.
- When seniors are added, an estimated **14.8 million (60%)** may be without adequate health literacy skills. (CCL, 2007a). **1.8 million (54%)** in B.C.

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

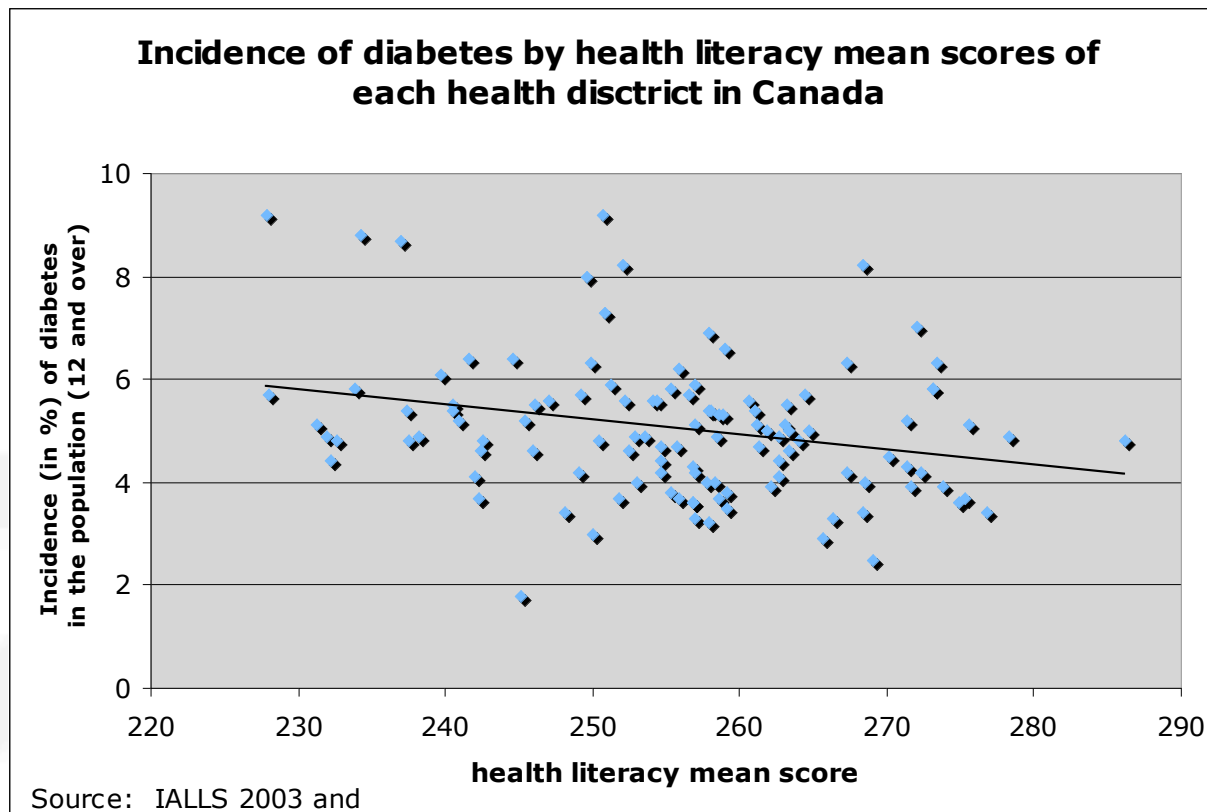


Health outcomes related to low reading proficiency include:

- **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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Source: Health Literacy in Canada: A Healthy Understanding, CCL, 2008, based on IALSS, 2003

Health Literacy (Reading proficiency) and mortality

- A recent U.S. study (Baker et al, 2007) examined the all-cause and cause-specific (cardiovascular, cancer, and other) mortality of 3260 Medicare enrollees over age 56 in 4 US metropolitan areas.
- Older adults with inadequate and marginal health literacy levels 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).

Increasing chronic disease and health literacy

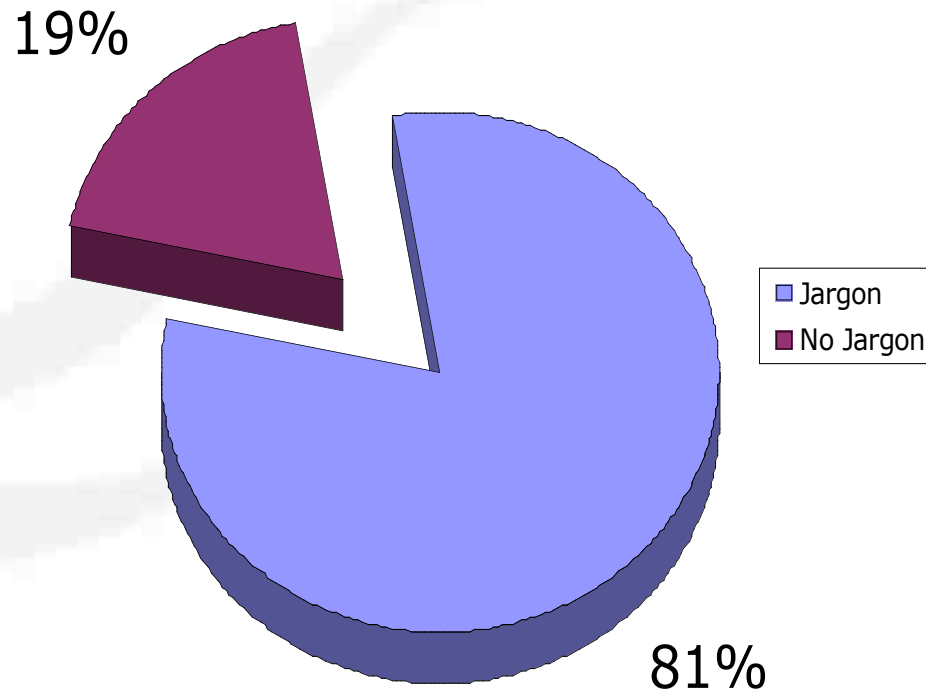
- **The number of people with diabetes in Canada is projected to increase from approximately 1.4 million patients in 2000 2.4 million in 2016 (Ohinmaa, et al., 2004).**
- **One of the ways to address chronic disease which is being increasingly used is patient self-management (McGowan, 2005)**
- **Low 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 should lead to improved self-management of chronic diseases (Rootman and Gordon-El-Bihbety, 2008)**

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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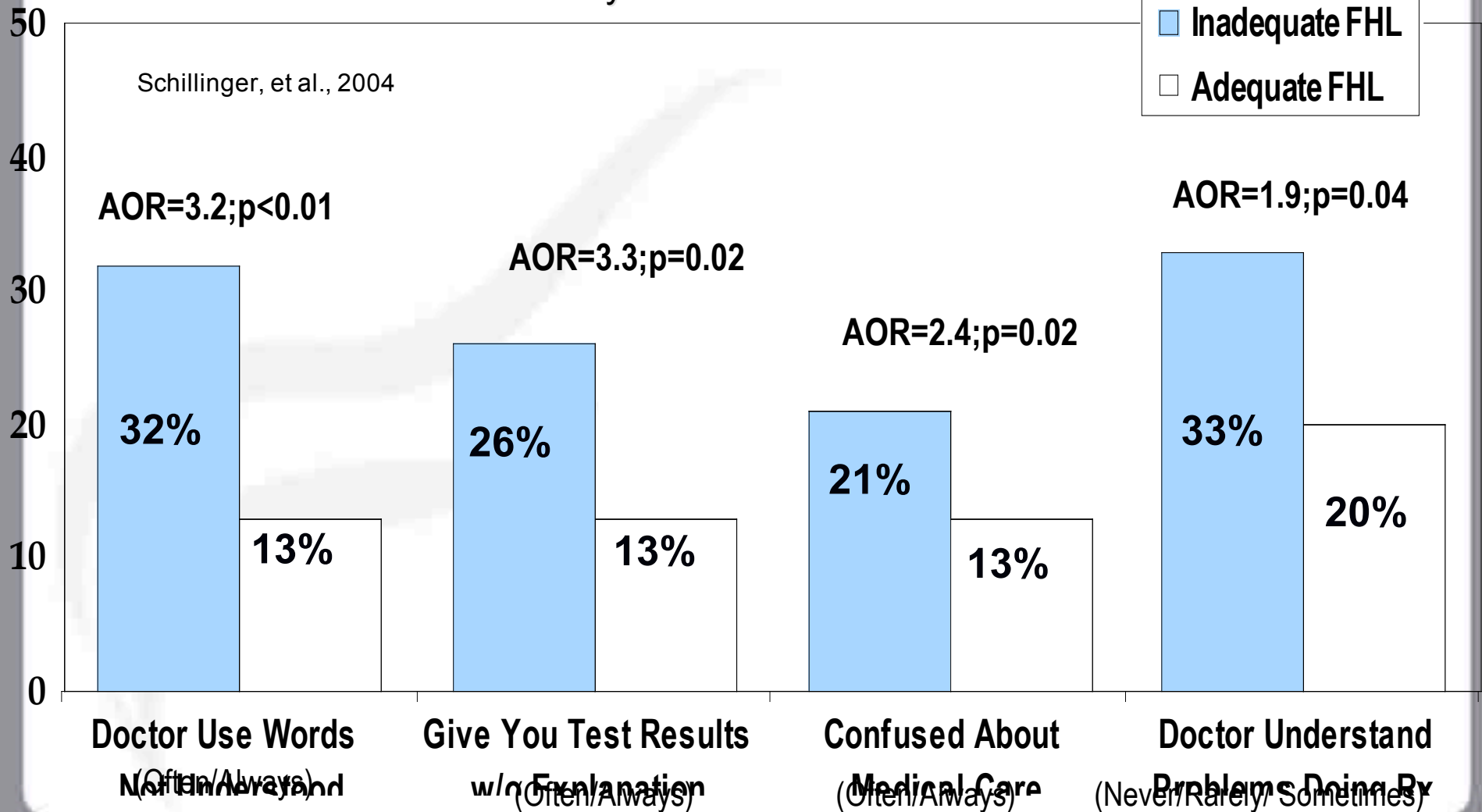
Jargon use in physician visits



Castro. et al., 2007

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Health Literacy and Oral Communication



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A survey of nearly 700 professionals and policy-makers found:

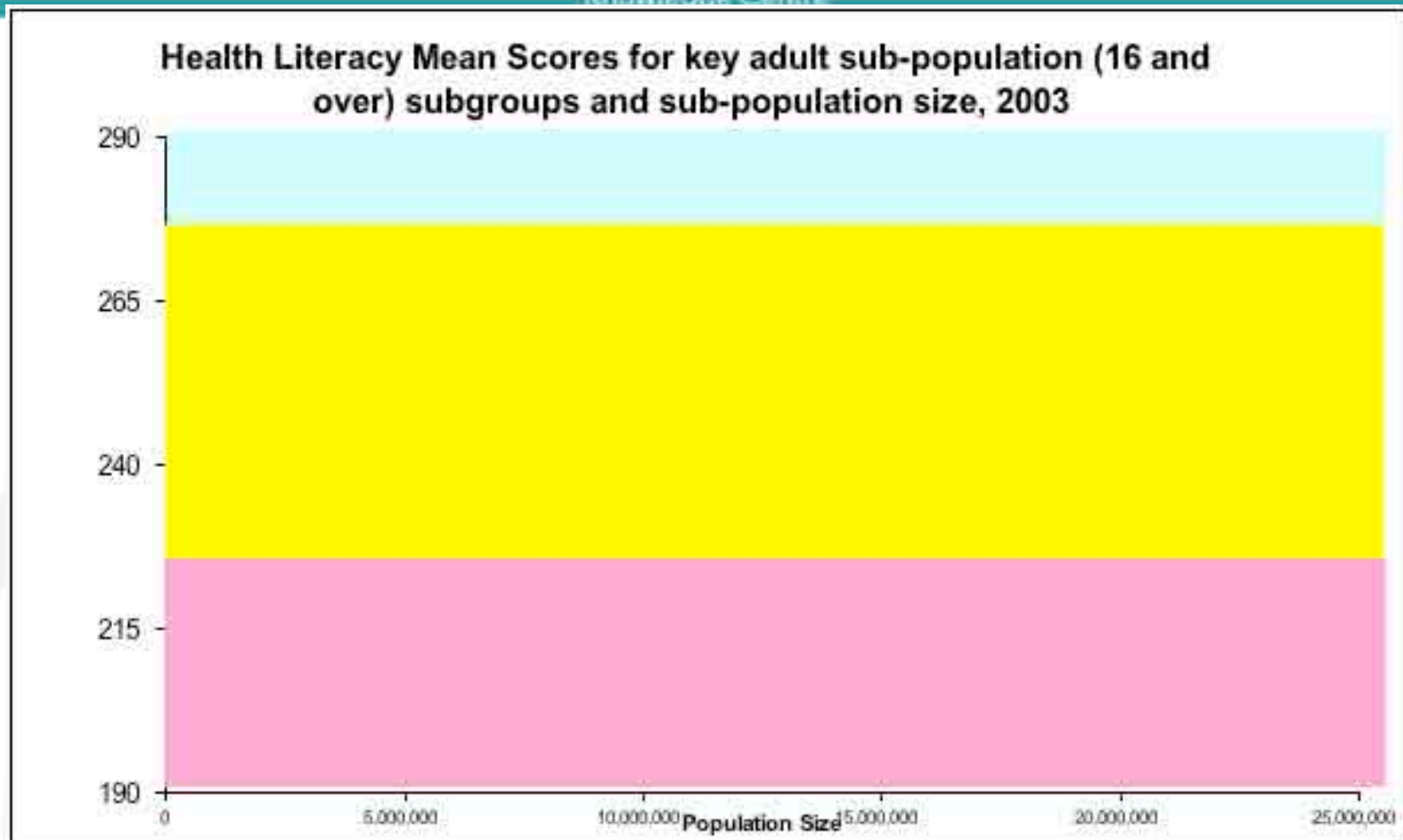
- **Almost 30% were unaware of the term *health literacy***
- **34% said that the term is used in their organizations (23% were not sure).**
- **68% said that their organizations provide direct services but more than 30% were unsure of their clients' literacy levels**
- **Almost 60% indicated that staff 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**

(Rootman and Gordon-el-Bihbety, 2008)



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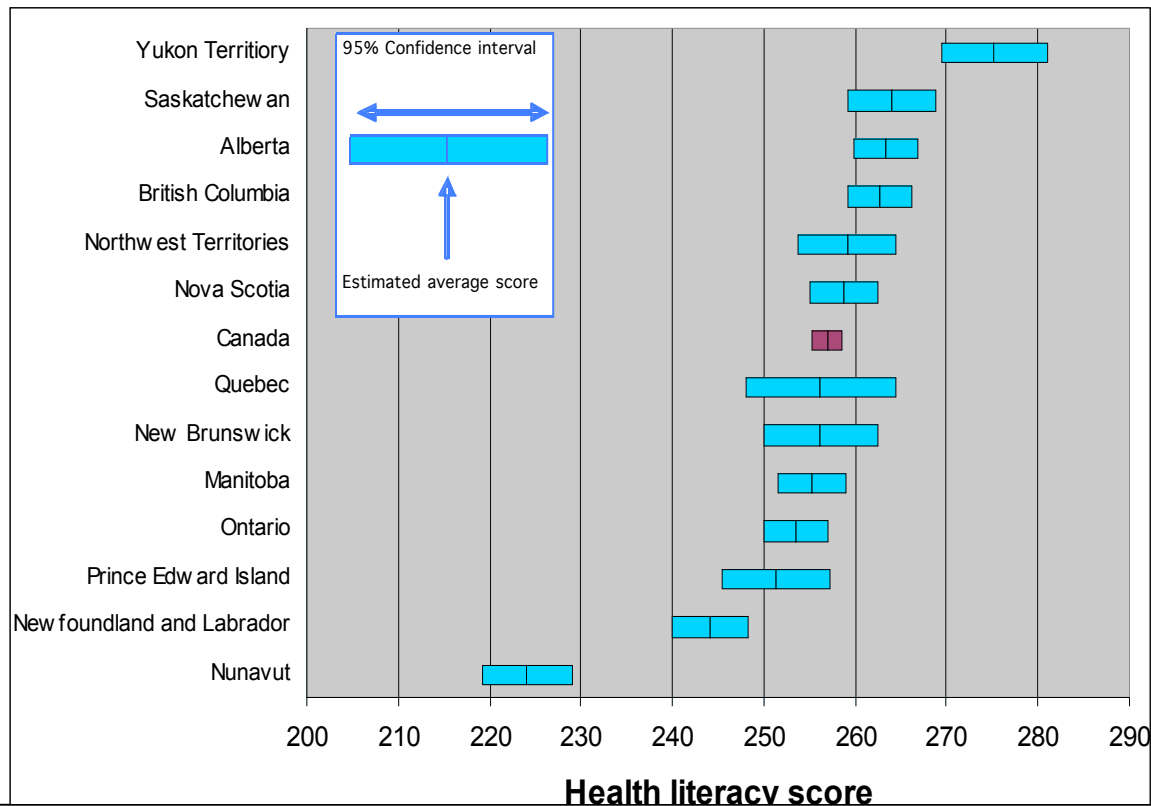
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Source: Health Literacy in Canada: A Healthy Understanding, CCL, 2008, Based on IALSS, 2003

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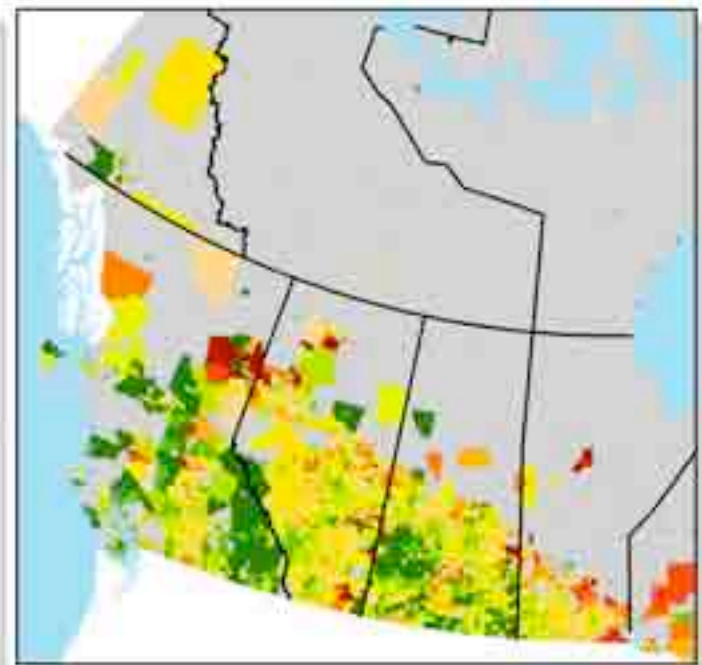
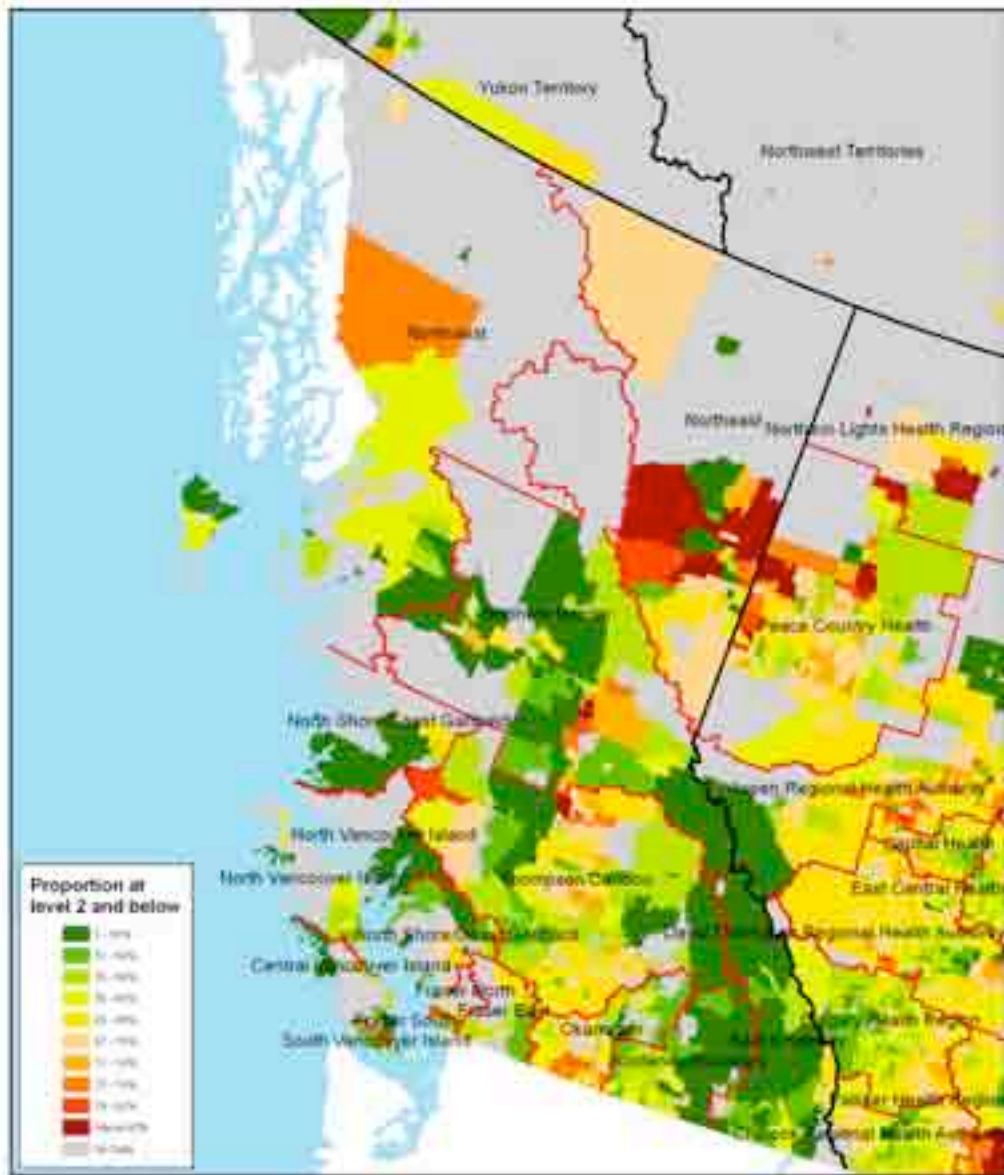
**Distribution of low health literacy in adult population in Canada
(by Province/Territory)**



Source: Health Literacy in Canada: Initial Results, 2007b, CCL,
based on IALSS 2003

The Distribution of Health Literacy in British Columbia

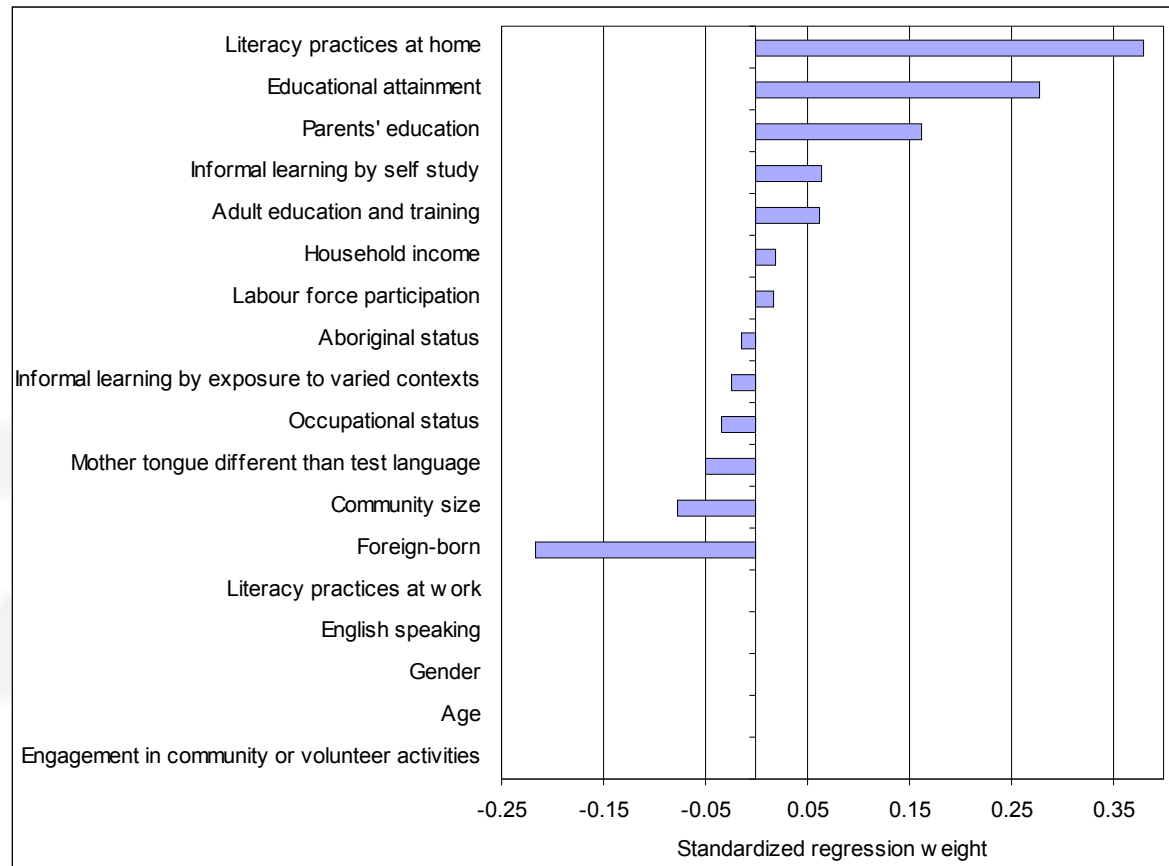
Proportion of adult health literacy at level 2 and below, ages 16 and older



Health Region	Proportion at level 2 and below
British Columbia	54%
East Kootenay	43%
Kootenay/Boundary	48%
Okanagan	50%
Thompson/Cariboo	58%
Fraser East	55%
Fraser North	54%
Fraser South	56%
Richmond	61%
Vancouver	59%
North Shore/Coast Garibaldi	50%
South Vancouver Island	49%
Central Vancouver Island	50%
North Vancouver Island	53%
Northwest	61%
Northern Interior	49%

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Factors Predicting Health Literacy for Adults aged 16-65



Source: Health Literacy in Canada: A Healthy Understanding 2008, CCL, based on IALSS 2003

Effectiveness of Health Literacy Interventions

The Expert Panel on Health Literacy found that:

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.

(Rootman and Gordon-el-Bihbety, 2008)



Examples of Promising Health Literacy Initiatives

- Health Literacy in Rural Nova Scotia Project
- Montreal Hospital project
- Patient Education project, Hamilton
- Literacy and Parenting Skills program, Bow Valley College, Calgary
- The Literacy Audit Kit (Alberta)
- Healthy Aboriginal Network (B.C.)
- COSCO Health Literacy Project (B.C.)
- Hispanic Health Literacy Video Project, Vancouver



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Health Literacy Initiatives Involving Librarians

- **Health Literacy Network** [www.bcccpd.bc.ca]
- **Canadian Health Libraries Association: Plain Talk About Health Literacy Workshop** [chla-absc.ca]
- **Colonias Project** (Olney et al., 2007)
- **Wellness Information Zone Project** [www.wellnesszone.org]
- **New York Public Library-Choices Program**
[www.nypl.org/branches/choices/]
- **MLA Health Information Literacy Research Project**
[www.mlanel.org/resources/healthlit/]

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Conclusions Relevant for Health/Librarians

1. Large numbers of Canadians don't have the health literacy skills that they need to make informed decisions about their health
2. Low health literacy appears to have a negative effect on health and health care costs
3. Certain populations and geographic areas are at risk
4. Demands for processing health information are high
5. Many health professionals are not aware of the issue or have the skills to address it
6. Daily reading outside of work appears to be strongly related to health literacy
7. There are promising health literacy initiatives including some involving health librarians

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Implications for Health/Librarians

- **Be aware of health literacy as an issue and inform yourself**
- **Be sensitive to people with low literacy/health literacy skills**
- **Practice clear health information communication**
- **Create supportive health information environments for the public and health professionals**
- **Advocate for improvements**

How can you inform yourself?

- **Attend sessions like this one**
- **Read key literature**
- **Observe your clients and environment**
- **Join a discussion group**
- **Undertake research**

Strategies to identify people with low HL:

- **Observation**
- **Questioning**
- **Testing**

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Signs to look for:

- **Never refer to written information**
- **Rely on others to read material**
- **Ignore or misunderstand advice**
- **Read slowly with obvious effort**
- **Have problems understanding how to access appropriate services**

(Gillis, 2004)

Informal Questions to ask:

- **“How do you learn best?”**
- **“What would help you most as you learn about your illness and how to take care of yourself?”**

(IOM, 2004, p.54)

General Principles of Clear Communication:

- **Use plain language**
- **Link information to previous knowledge**
- **Tailor information**
- **Personalize the message**
- **Be respectful, sensitive and caring**
- **Reinforce and repeat information**
- **Communicate in whatever ways work**

(Andrus and Roth, 2002; Osborne,2005)

Plain Language:

- Plain language is a way of organizing and presenting information so that it makes sense and is clear and easy to understand for the intended audience. (www.cpha.ca/en/pls.aspx)

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How to make verbal Communication clearer:

- Limit advice to key information
- Partition information into easy to understand parts
- Provide visual or verbal images
- Present context first
- Make instruction interactive
- Offer examples
- Tailor message
- Verify comprehension

(Doak, et al., 1998)

The teach-back/show me techniques:

- **Do not simply ask, “do you understand”?**
- **Instead, ask to explain or demonstrate how they will undertake a recommended treatment or action**
- **If person does not explain correctly, assume that you have not provided adequate teaching. Re-teach the information using alternative approaches**

(Weiss, 2003)

Planning Steps for Developing Written Materials:

- **Assess educational needs of audience**
- **Limit educational objectives**
- **Focus content on behaviour**
- **Present context first**
- **Build to complexity**
- **Include reader interaction**
- **Select visuals and layouts that match culture and gender**

(Doak, et al., 1996)

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How to provide a supportive environment:

- **Increase use of non-written information**
- **Assess suitability of materials**
- **Invite relatives and friends to participate**
- **Include community workers in team**
- **Offer ways to learn more**
- **Provide training to colleagues**
- **Collaborate with others**
- **Participate in research**

Assessment of Readability:

- **Flesch-Kincaid score (Microsoft Word)**
- **S.M.O.G. Readability Formula (NLHP/CPHA, 1998)**
- **Plain Language G.R.I.D. (NLHP/CPHA, 1998)**

Advancing Research:

- **“the literature provides very few evidence-based strategies for improving health literacy or meeting the needs of those with limited literacy” (Andrus and Roth, 2002)**
- **“Collaborative efforts between the health professions, education, public health, social work, and individual patients are needed” (Andrus and Roth, 2002)**

Health Information Literacy (HIL) Research Project

A project of the Medical Library Association with funding from the
National Library of Medicine

**Regina General Hospital Health
Sciences Library - Pilot Site**

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HIL Pilot Site Librarians:

**Jeff Mason & Mary Chipanshi
Regina General Hospital Health
Sciences**



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Goals:

- **Increase awareness of health literacy and the use of online health information resources by health care providers and their patients**
- **Promote the role of librarians as key providers of health information literacy resources and services**

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Curriculum Objectives:

- Recognize the impact low health literacy has on quality patient care**
- Name five strategies and resources to improve health literacy**
- Describe the health literacy services offered by librarians**

Curriculum Context:

- ❑ One-hour session
- ❑ Offered by librarians
- ❑ Received by hospital-based health care providers (nurse, pharmacists, physicians, social workers, etc)
- ❑ Online health information, Information Rx, and library consumer services offered as key health literacy interventions

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MedlinePlus.gov

THE WEB SITE YOUR DOCTOR PRESCRIBES

A free, comprehensive, authoritative up-to-date health information web site from the world's largest medical library, the National Library of Medicine at the National Institutes of Health, with the support of the American College of Physicians Foundation.

Information Rx

Information Rx

Hypertension =
High Blood Pressure

Dr. Kad-Rosi

4/15/08



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Health information in over 40 languages

Current Health News

- ▶ [FDA Wants More Time to Study Cold Meds for Kids](#)
- ▶ [Minorities with Disabilities Report Poorer Health](#)
- ▶ [Kids Who Wheeze with Rhinovirus at Higher Asthma Risk](#)
- ▶ [More news](#)

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New on [NIH SeniorHealth](#)
[Parkinson's Disease](#)

In the Spotlight



New on [Go Local](#): Find health services in your hometown in

- ▶ [North Dakota](#)

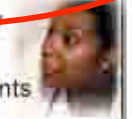
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Over 165
slideshows with
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ClinicalTrials.gov

Studies for new
drugs and treatments



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procedures



[What's New](#)



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www.MedlinePlus.gov

Pilot Phase:

- **Selected nine hospital-based, pilot site libraries from the U.S. and Canada**
- **Prepared pilot site librarians via listserv, conference calls, project blog, and working meeting**
- **Implemented and evaluated curriculum April – September 2008**

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Pilot Sites:

- **Berkshire Medical Center Health Sciences Library**
- **Billings Clinic Medical Library**
- **Good Samaritan Hospital Health Sciences Library**
- **Lake Hospital System Medical Library**
- **Regina General Hospital Health Sciences Library**
- **St. Joseph Hospital Burlew Library**
- **St. Vincent Hospital Library**
- **Stauffer Health Sciences Library and Topeka & Shawnee County Public Library**
- **University of South Alabama Biomedical Library**

Evaluation Methods:

- Pre- and post-session evaluations**
- Story-based Info Rx tracking reports**
- Semi-structured feedback collected directly from pilot site librarians**
- 2-month follow-up email survey (data not yet available)**

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Project Outcomes:

- Based on pre-/post-evaluations**
 - Increases in health literacy knowledge**
 - Increases in awareness of consumer health information resources**
 - Increases in intention to act...**
 - to use MedlinePlus**
 - to use Info Rx**
 - to refer patients to the library**

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Lessons Learned:

- ❑ **“Encourage the sharing of personal experience. The more discussion the better.”**
- ❑ **“Be ready for technical difficulties or not having the necessary equipment to show the videos.”**
- ❑ **“Add plain language exercise to make the task less abstract for participants.”**

Acknowledgements:

- Jeff Mason, Librarian, Region General Hospital Health Sciences Library
- Mary Chipanshi, Librarian, Regina General Hospital Health Sciences Library
- Sabrina Kurtz-Rossi, Project Coordinator, Health Information Literacy Research Project

Health Information Literacy Curriculum

www.mlanet.org/resources/healthlit/hil_project.html

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Advocating for change:

- **Advocate for attention to literacy and health literacy in your workplace**
- **Lobby your politicians to pay more attention to literacy and health literacy issues**

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Helpful Resources for Health Literacy

- **National Literacy and Health Program Materials and Services** [www.cpha.ca/en/programs/literacy.aspx]
- **Writing Health Information for Patients and Families** [PatientEducation@hhsc.ca]
- **Family Literacy and Health Module** [www.nald.ca/library/research/famlithea/first.htm]
- **Health Literacy Maps** [www.ccl-cca.ca/cclflash/healthliteracy/]
- **Literacy Audit Tool Kit** [www.literacyalberta.ca]
- **The Health Literacy Environment of Hospitals and Health Centers** [www.bcsall.net]
- **Pharmacy Health Literacy Assessment Tool** [www.ahrq.gov]
- **Health Literacy Manuals for Clinicians** [www.ama-assn.org]
- **Health and Literacy Discussion List** [www.nifl.gov/lincs/discussions/subscribe_all.html]

Key readings

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