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Health Literacy: What do you want to know?

Presentation to Healthy Heart Society and Impact
B.C.

Irving Rootman, Ph.D., Executive Director, HLKC
May 8, 2009, Vancouver

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Options

- **What is the history of concept**
- **What is health literacy?**
- **How is it measured?**
- **Why should you be concerned?**
- **What are the predictors?**
- **What can the public do about it?**
- **What can health practitioners do?**
- **What can organizations do?**
- **What resources are available to help?**

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)

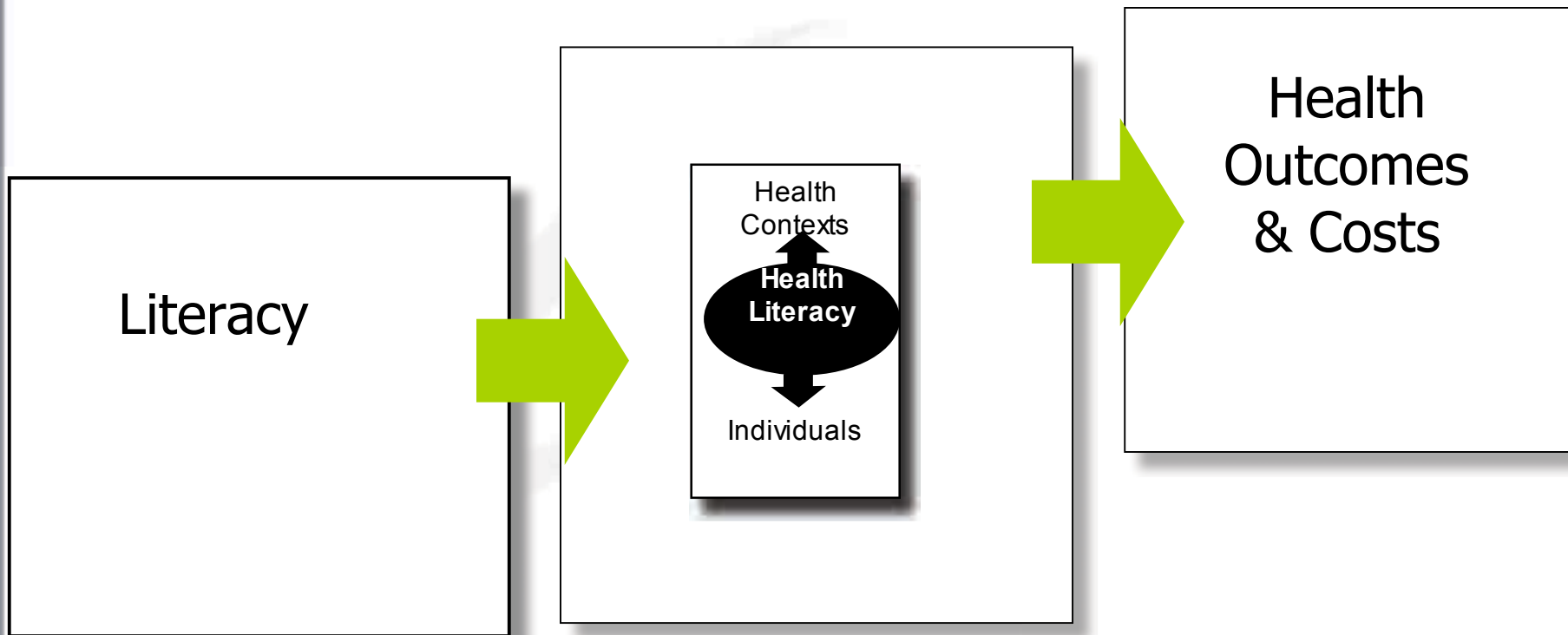
- Growing interest in literacy in the late 1980's
- OPHA/Frontier College Literacy and Health project (1989-1993)
- National Literacy and Health Program (1994-present); CPHA Clear Language Service (1997-present)
- National Conferences on Literacy and Health (2000, 2004)
- National Literacy and Health 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)

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)

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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:

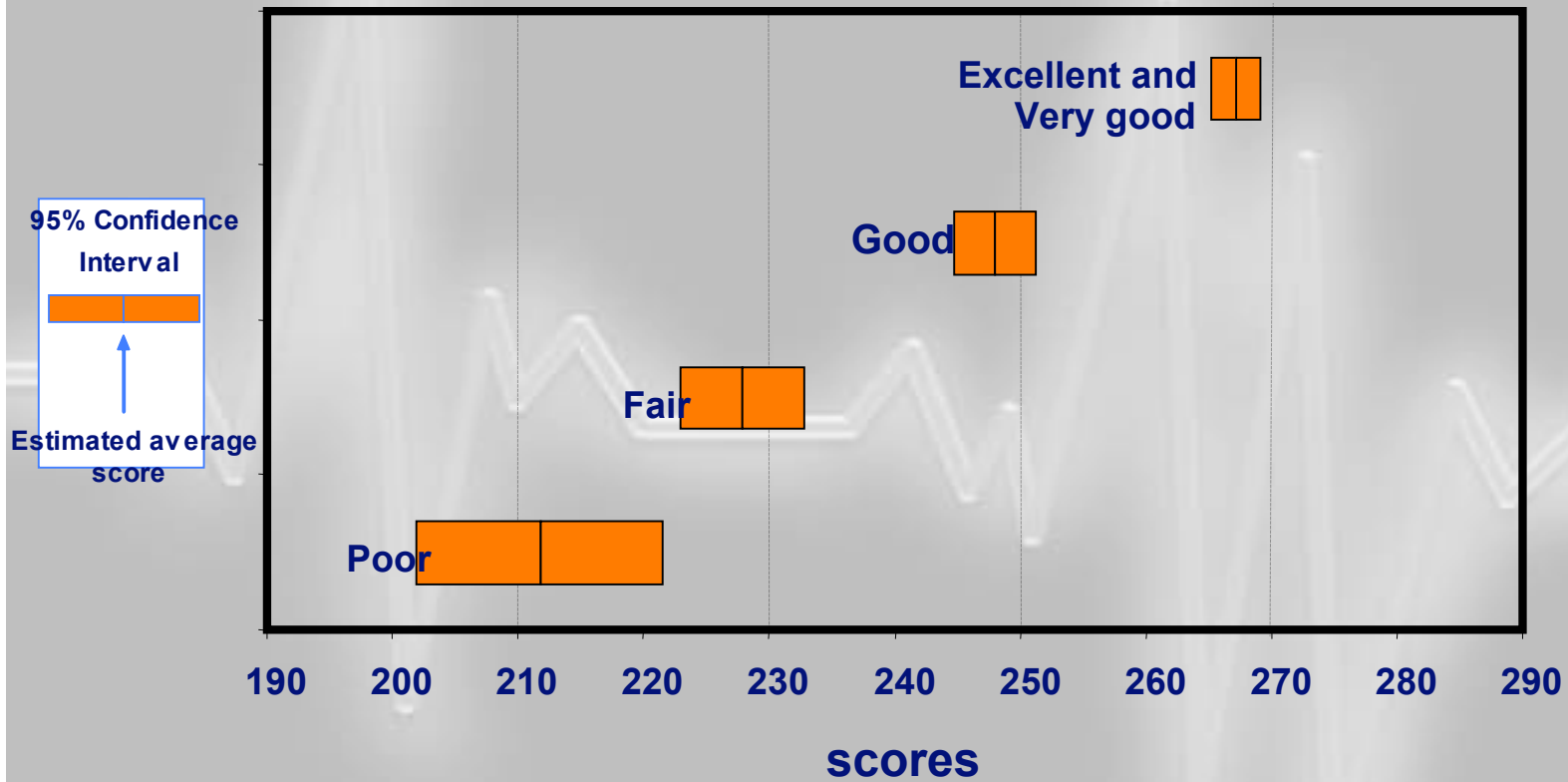
- **11.7 million** working age residents of Canada (55%) are estimated to lack the minimum level of health literacy needed to effectively manage their health information needs (CCL, 2007b).
- When seniors are added, an estimated **14.8 million** may be without adequate health literacy skills. An estimated 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)

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)**

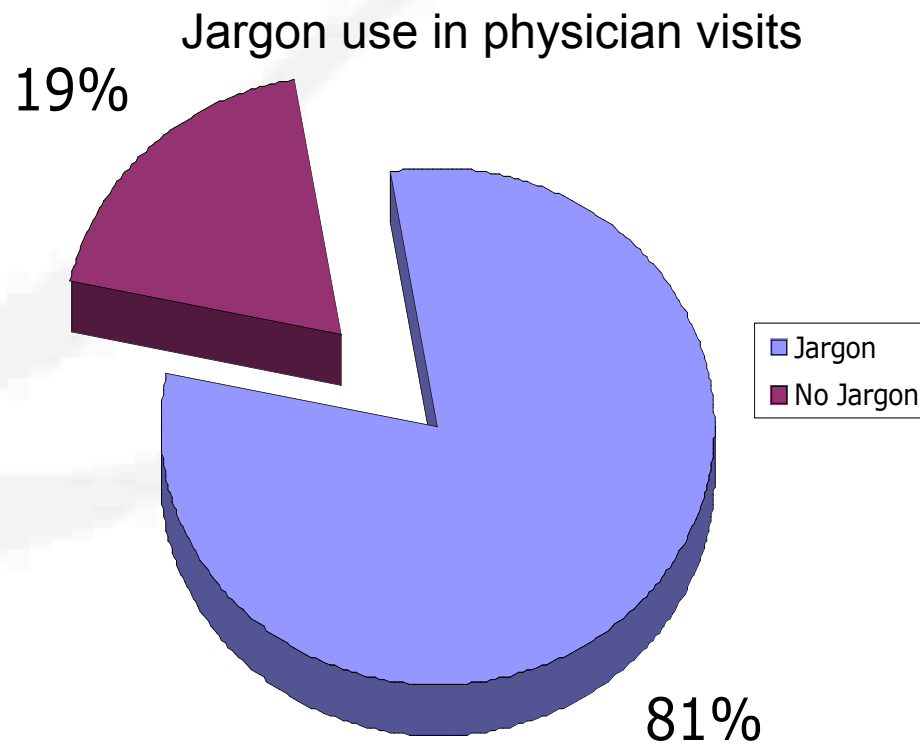
Estimated Economic Drain of Low Health Literacy on U.S. Economy:

- **“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)**

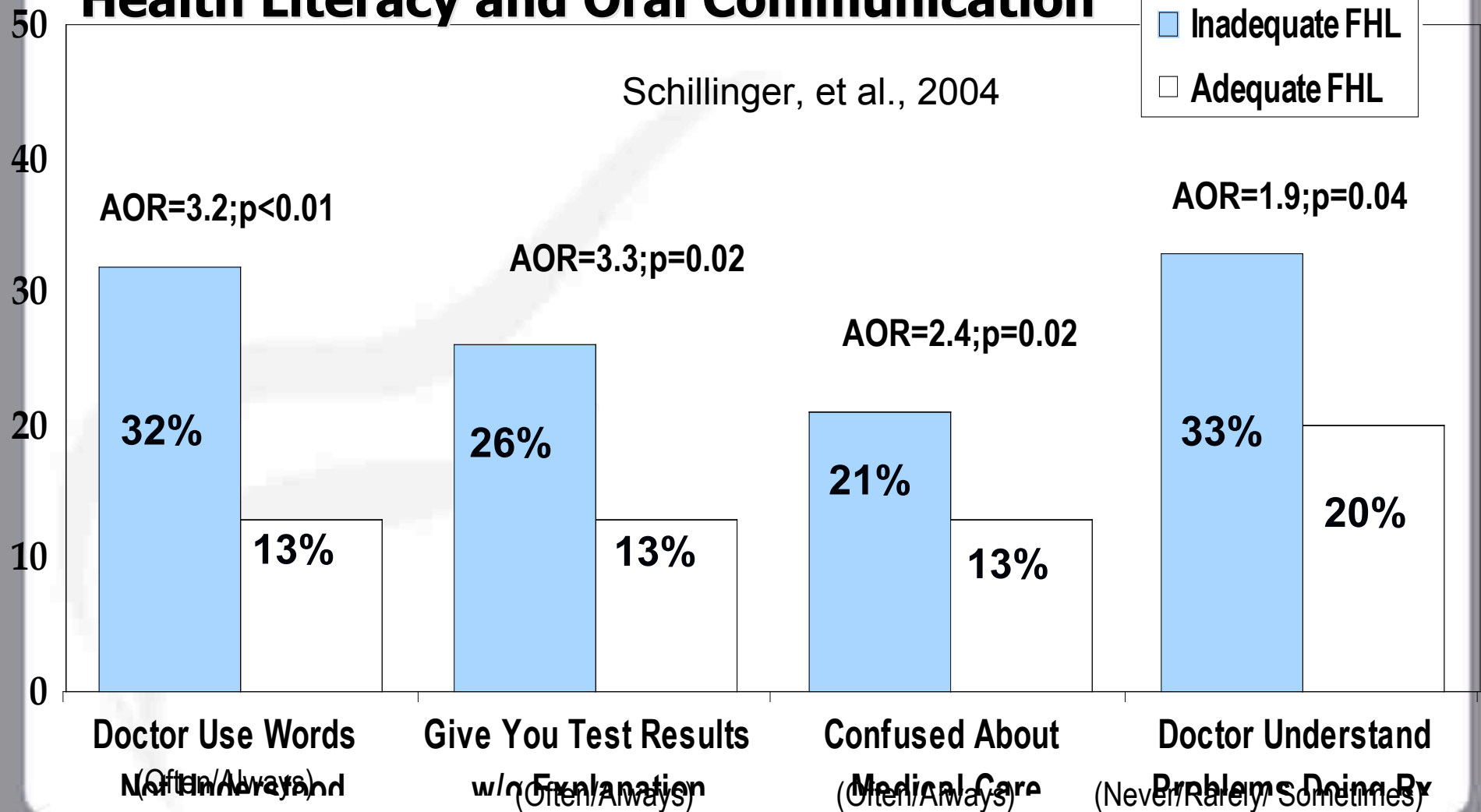
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Castro. et al., 2007

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

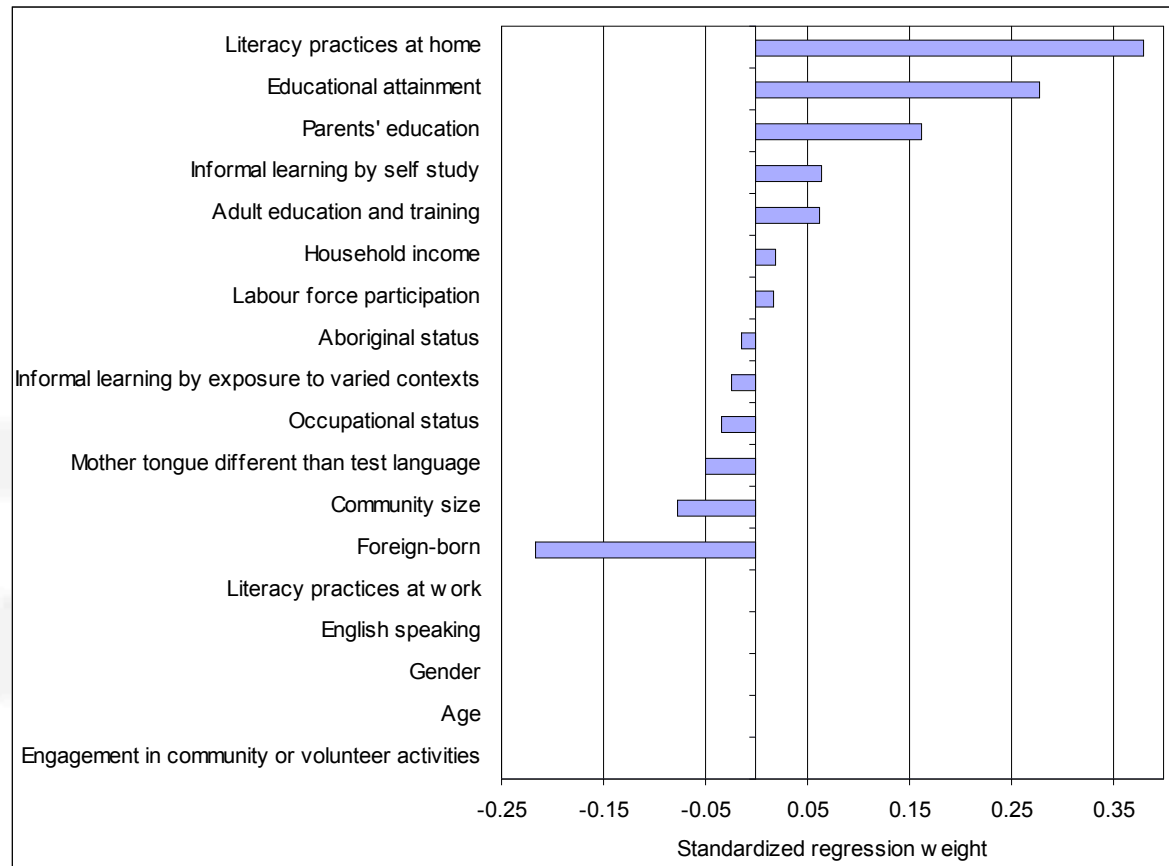
(Rootman and Gordon-El-Bihbety, 2008)

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)**

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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

What can the Public do ?

- Read on a daily basis
- Learn new skills
- Ask questions
- Advocate

What can health practitioners do about health literacy?

- Inform themselves about the issue
- Identify people who are likely to have difficulty understanding health information
- Practice clear communication
- Create supportive environments
- Advocate for improvements

How can you inform yourself?

- **Attend sessions like this one**
- **Read key literature**
- **Observe your patients 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:

- **Routinely miss appointments**
- **Arrive without completed forms**
- **Never refer to written information**
- **Avoid filling out forms**
- **Rely on others to read material**
- **Claim to have vision problems when asked to read**

(Gillis, 2004)

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Signs to look for (Cont.):

- Ignore or misunderstand advice
- Read slowly with obvious effort
- Read something faster with no comprehension
- Never jot down instructions
- Show facial signs of frustration or anxiety when reading
- 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?”**
- **“What help do you need for taking this medicine properly?”**

(IOM, 2004, p.54)

Promising Screening Questions:

- **How often do you have someone help you read hospital materials?**
- **How confident are you in filling out medical forms by yourself?**
- **How often do you have problems learning about your medical condition because of difficulty understanding written information?**

(Chew, et al., 2004)

Possible Tests:

- **Wide-Range Achievement Test (WRAT-3; Justak and Wilkinson, 1993)**
- **Rapid Estimate of Adult Literacy in Medicine (REALM; Parker, et al., 1995)**
- **Newest Vital Sign (Weiss, 2005)**

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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The CPHA Plain Language Service uses the L.I.D. Approach:

Language

The language of the text uses:

- plain words
- point form
- short sentences

• **Information**

The information in the text is organized to make it easy to understand. Less important or redundant information is removed

• **Design**

The material is designed to guide readers through the text easily

(www.cpha.ca/en/faq.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)

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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)

Clear Design Tips:

- **Use left flush justification**
- **Choose type that is clear and easy to read**
- **Use mixture of uppercase and lowercase letters**
- **Use bullets for lists**
- **Use ample “white space”**
- **Pay attention to how the text looks on the page**
- **Use appropriate illustrations and graphics**

(CPHA, 2005)

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What can health organizations do?

- 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

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Non-written information:

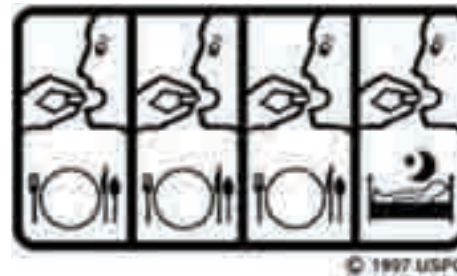
- **Videos**
- **Audiotapes and CD's**
- **Photographs and illustrations**
- **Pictograms**

(Andrus and Roth, 2002)

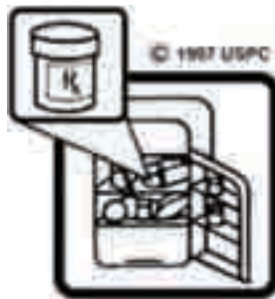
Examples of Pictograms (from <http://www.usp.org/>):



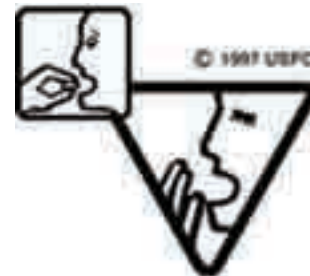
Take by mouth



Take 4 times a day, with meals and at bedtime



Store in refrigerator



This medicine may make you drowsy

Using Visuals in Text:

- **Place visual adjacent to the text to which it refers**
- **Explain the visual within the text**
- **Use captions**

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Other Possibilities:

- **Picture books**
- **Storytelling**
- **Drama**
- **Puppets**
- **Computer-based programs (www.2aida.org)**
- **Small discussion groups**

(Andrus and Roth, 2002)

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)**

What could and should be done by a Health Authority?

- Commit to addressing literacy, particularly as it relates to health
- Establish Literacy and Health Committee
- Conduct audit of facilities, services and programs in terms of literacy and health literacy demands on public
- Examine health literacy maps and consider implications for action
- Implement and evaluate health literacy interventions
- Provide training opportunities for staff related to health literacy
- Form stronger links with the literacy community
- Support the development of research on literacy and health and health literacy

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What can other kinds of organizations do?

- **Schools can provide students with more opportunities to develop health literacy skills**
- **ESL programs can integrate health information into teaching**
- **Workplaces can provide more opportunities to develop life skills including literacy**
- **Libraries can provide support to people to help them find and evaluate health information**

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)**

Some Helpful Resources

Canadian:

- National Literacy and Health Program
- Writing Health Information for Patients and Families
- Family Literacy and Health Module
- Literacy Audit Tool Kit
- Health Literacy Maps
- McGill University Health Centre Project

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**

Family Literacy and Health Module:

- **Developed by Centre for Family Literacy, Edmonton**
- **One module in a training resource for practitioners in health and in family literacy**
- **Objectives: Explore relationship between health literacy and family literacy; Explore ways that health and family literacy practitioners can work together; Establish a shared framework for bringing about positive changes in practice that will promote health literacy among Canadian families**
- **Go to: www.nald.ca/library/research/famlithea/first.htm**

Literacy Audit Tool Kit:

- Developed by Literacy Alberta to help organizations provide more literacy-friendly customer service
- 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 available on CCL website**
- **Go to: www.ccl-cca.ca/cclflash/healthliteracy/**

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 at: 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 at: 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

Key readings

- Canadian Council on Learning, *Understanding Health Literacy*, Ottawa: CCL, 2008.
- Chiarelli L. *Increasing Understanding of the Impact of Low Health Literacy on Chronic Disease Prevention and Control*. CPHA 2006. Report for the Public Health Agency of Canada.
- Institute of Medicine, *Health Literacy: A Prescription to End Confusion*, Washington: National Academies of Science, 2004.
- Osborne, H., *Health Literacy from A to Z*, Toronto: Jones and Bartlett Publishers, 2005.
- Romilly, L., *Patient self-management: Health literacy skills required*, Ottawa: Canadian Council on Learning, June 19, 2007. [www.ccl-cca.ca]
- Rootman, I. & El-Bihbety, D., *A Vision for a Health Literate Canada*, Ottawa: CPHA, 2008.

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