

# The ABC's of Health Literacy in B.C.: Connecting Research and Practice

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# Purposes

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- To inform staff of B.C. Ministry of Health and others about health literacy research and practice in B.C.
- To discuss ways in which the BC MOH could strengthen HL research and practice in BC and benefit from this work



# Outline

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- What is health literacy and why is it important?
- Where did the concept come from?
- Canadian milestones, recent and current research and practice
- BC milestones, recent and current research and practice
- Assessment of current status of health literacy work in B.C.
- Where do we go from here to strengthen health literacy research and practice in BC?



# What is Health Literacy?

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“The degree to which people are able to:

- ✓ access
- ✓ understand,
- ✓ appraise
- ✓ communicate

information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course”



(BC HL Research Team, 2006)

# European Definition of Health Literacy

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“the knowledge, motivation and competencies of accessing, understanding, appraising and applying health-related information within the healthcare, disease prevention and health promotion setting, respectively”

(Sorenson, et al., 2012)

<https://www.youtube.com/watch?v=fzMA9TIPJUK>

# Why is Health Literacy Important?

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





# Large Numbers

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- An estimated 54% or **1.8 million** BC residents in 2003 lacked minimum level of health literacy needed to effectively manage their health information needs (CCL, 2007)





# Poorer Health Outcomes

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- 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)





# Inadequate Health Behaviours

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- 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)



# Impact on People

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- It affects peoples' ability to....
  - **Navigate** the health care system
  - **Share** personal and health information with providers
  - **Engage** in self-care and chronic disease management
  - **Adopt** health promoting behaviours
  - **Act** on health related news and announcements



# Chronic Diseases

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- 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 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)



# Cost

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- “Cost of low health literacy to the U.S. Economy in the range of \$106 billion to \$238 billion annually” (Vernon et al., 2007)
- Additional costs of limited health literacy ranged from 3 to 5% of the total health care cost per year (Eichler, et al., 2009).





# Health Information

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- Over 300 studies have found that health- related material for patient education far exceeds the reading levels of the average adult (Rudd, 2007)



# Equity

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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

(CCL, 2007)



# Ethical Imperative

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## Health Literacy as an Ethical Imperative for Health Care (Vollandes 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”

# Where did the concept of Health Literacy come from?

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- Health Education (1974)
- Health Care (U.S., early 1990' s)
- Health Promotion (W.H.O, late 1990' s)
- Health Communication (U.S., 1995)





# Canadian Milestones (1989-2008)

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- 1989: OPHA-Frontier College Literacy and Health Project
- 1994: CPHA Literacy and Health Program
- 2000: First Canadian Conference on Literacy and Health
- 2002: National Literacy and Health Research project
- 2004: Second Canadian Conference on Literacy and Health
- 2006: Canadian Expert Panel on HL
- 2008: Canadian Institute on HL Curricula



# Types of HL Initiatives in Canada



## **Capacity Building / Awareness Raising**

- Training / educating the public / patients
- Educating health professionals
- Working with vulnerable groups
- Producing tailored, targeted programs, reports, and other materials
- Utilizing social media sites for communication

## **Knowledge Development**

- Health literacy definition and concept development
- Measurement of health literacy levels
- Identification of best practices by research / demonstration projects

## **Infrastructure Building & Partnerships**

- Organizing cross-agency and cross-sectoral collaboration
- Developing supports to inform policies, regulations, and standards for HL work
- Requests for additional resources & positions for health literacy work

(Frankish et al., 2011)

# Some examples of Recent Canadian Initiatives

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- PHAC supported projects (e.g. CMA Curriculum, Embedded HL, Examples from the Field; Assessment tool)
- Intersectoral Discussion Paper on Health Literacy
- Health Canada Nutrition Labeling project
- CDPAC Conference HL stream
- Book on HL in Canada





# B.C. Milestones

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- 2003: Formation of B.C. HL Research team; MOH Plan on Mental Health Literacy; Establishment of BC Partners for Mental Health & Addictions Information
- 2005: Provincial Workshop on Literacy and Health
- 2006: Establishment of CCL Health and Learning Centre
- 2007: Creation of the *Integrated Provincial Strategy to Promote HL in Mental Health and Addiction in BC*
- 2008: Establishment of HL position at BC Mental Health & Addiction Services, PHSA
- 2009: First BC HL Roundtable; BC HL Collaborative; Establishment of the BC Mental Health & Substance Use Provincial Health Literacy Network
- 2010: Second BC HL Roundtable; Strategic Plan for HL in BC
- 2011: Establishment of BC Health Literacy Network



# BC Health Literacy Collaborative

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- Prototype collaborative of MOH “Patients as Partners” Program
- 4 sites involving PHC practices and literacy practitioners
- Each site tried different interventions to build relationships, improve understanding and partner
- Improvements in outcomes found, tools produced, awareness raised
- Research was conducted in each site
- Tools and experience integrated into Practice Support Program
- Increasing interest by health practitioners to increase skills in relation to health literacy

<https://www.patientsaspartners.ca/resources>



# BC Mental Health and Substance Use Health Literacy Network

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- Established by BC Mental Health & Substance Use Services (BCMHSUS) in 2009
- The Network provides a vehicle for province-wide collaboration, partnership, and knowledge exchange across levels of government, non-profit, and community organizations, and works to identify and prioritize mental health and substance use literacy needs within the province.
- Membership includes MOH and MCFD, all H.A.'s, non-profit organizations, professional and community groups

# Mental Health and Substance Use Literacy Initiatives

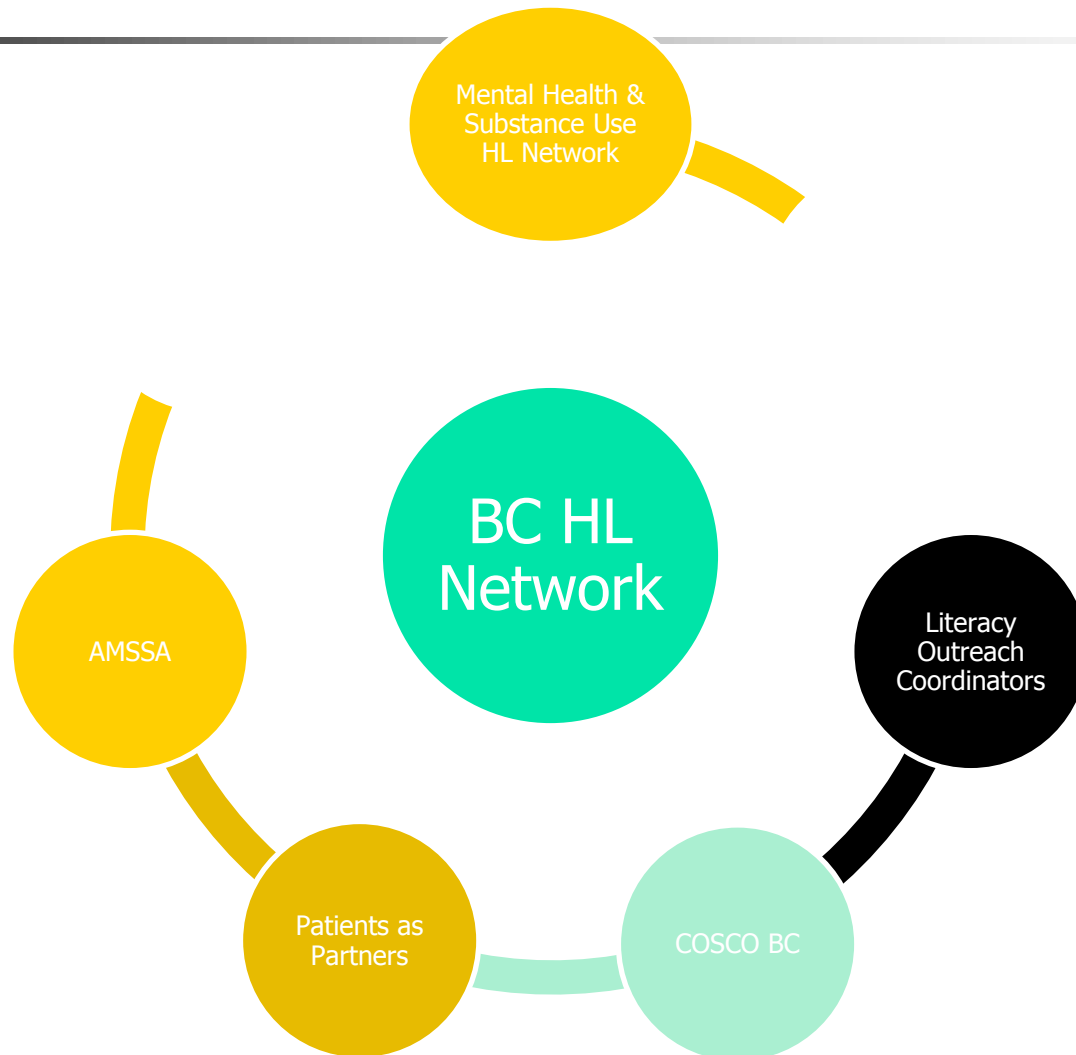
Projects, Initiatives & Resource by BCMHSUS:

- Kelty Mental Health Resource Centre
- Interactive websites and social media
- Educational series
- Resources for youth and young adults
- Cross-cultural initiatives
- School-based mental health initiatives
- Healthy living initiatives
- Eating disorders prevention
- Reproductive Mental Health Literacy initiatives



BCMHSUS manages the *BC Partners for Mental Health & Addictions Information* (through funding by MOH & MCFD)

# BC Health Literacy Network





# BC Health Literacy Proposed Initiatives (BCHLN Plan)

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- *Increase health literacy skills of B.C. Population* (organize Deliberative Dialogue Event)
- *Develop structures and expertise to support members of the public* (include HL in ongoing activities; survey health professionals; organize conference)
- *Increase the ability of stakeholders from different fields and sectors to work collaboratively* (Seek funding; develop partnerships ; Survey knowledge and awareness of health literacy in stakeholder organizations; organize workshop or roundtable to identify health literacy research agenda for BC)



# Recently Published BC HL Research

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1. Access to HIV/AIDS information in Rural Areas (Harris, et al., 2008)
2. Evaluation of BC Health Curriculum (Begoray, et al., 2009)
3. School HL Measurement Instrument (Wu, et al., 2010)
4. Predictors of HL in Older Adults (Wister, et al., 2010)
5. Prostate Cancer Support Groups (Oliffe, et al., 2011)
6. Effectiveness of Education Interventions on Asthma Self-Management (Poureslami, et al., 2012)
7. In One Voice Mental Health Literacy Campaign Evaluation (Livingston, et al., 2012 & 2014)



# Some Implications of Recent BC HL Research for Practice (1)

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1. Lay and professional info(r)mediators can challenge ignorance and the spread of misinformation (Harris, et al., 2008)
2. Need for more intensive and comprehensive approach to developing health literacy among students (Begoray, et al., 2009)
3. Introducing health literacy initiatives in schools should be given priority (Wu, et al., 2010)
4. Short social media campaigns contribute to mental health attitude changes among young people but are less effective in providing tools to help others (Livingston, et al., 2014)



# Some Implications of Recent BC HL Research for Practice (2)

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5. Programs and policies that encourage life-long and life-wide educational resources and practices by older persons are needed (Wister, et al., 2010)
6. Health support groups are an effective means for developing health literacy (Olfiffe, et al., 2011)
7. Short, culturally and linguistically appropriate education interventions can effectively improve patients' understanding and recall of information about chronic health conditions as well as their ability to effectively manage their chronic condition (Poureslami, et al., 2012)



# Involvement of practitioners in Published BC HL Research

- A variety of practitioners from health and education were involved in some way in each of the reported research projects (e.g. as investigators, advisors, developers of instruments, data collectors, data analysis, discussion leaders)
- There was more involvement in some projects than in others
- None were fully participatory





# Current B.C. Research on HL

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- Health Literacy, HIV Risk, and Men Who Have Sex with Men (Gilbert)
- Social aspects of health literacy in a low SES rural community (Nimmon)
- Nutrition labeling focus groups (Niks)
- Critical Media Health Literacy (Begoray and Wharf Higgins)





# Recent and Ongoing HL Practice Initiatives (Examples from the Field)

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1. Eating Disorders Initiative
2. Healthy Living Toolkits
3. Kelty Mental Health Resource Centre
4. Nutrition for You Course
5. Hazelton C.D. Course
6. South Okanagan-Silkameen Communication
7. Prototype Collaborative
8. Health Literacy Toolkit
9. Health Literacy Library Partnership



# Other Recent and Ongoing BC HL Practice Initiatives

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- Richmond HL Library project (Richmond Public Health)
- Undergraduate HL On-line Course (UVic)
- Health Literacy Workshop Program for Seniors (COSCO)
- Health Literacy Comic Books (Healthy Aboriginal Network)
- Health Literacy Workshop at Provincial Literacy Conference (Decoda Literacy Services)
- Community session at International HL and CDM Workshop (Centre for Clinical Epidemiology and Evaluation)





# Connections between Practice in HL in BC and Research

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- Some have implications for research (e.g. Eating Disorders project)
- Some have research built in (e.g. prototype collaborative)
- Some provide opportunities for research students (e.g. Comic book project)
- Some were developed and managed by researchers (e.g. Nutrition for You)
- Some have researchers as advisors or members of the team (e.g. COSCO Program)



# Current Strengths

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- Interest and involvement of multiple networks and organizations
- Ongoing collaboration across networks
- Some mechanisms for collaboration and capacity-building in place
- Committed researchers and practitioners
- Exemplary initiatives
- BC-developed tools and models
- Some infrastructure and resources
- Some patient and public involvement



# Current Weaknesses

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- Absence of policies by MOH and most Health Authorities
- Lack of monitoring
- Inadequate funding
- Lack of media and public interest



# Current Threats

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- Misunderstanding of the nature and scope of health literacy and its potential to address health issues
- Other priorities
- Fiscal restraint



# Current Opportunities

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- MOH Rounds
- Ongoing events (e.g. Public Health Summer Schools, Conferences)
- Funding through MSFHR, CIHR and PHAC

# **No health literacy means no self-care**



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**Dr Trevor Hancock  
Professor and Senior Scholar  
School of Public Health and Social Policy  
University of Victoria**



University  
of Victoria

Human and Social  
Development

School of Public Health & Social Policy



# Self-care defined

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**“Self-care is the action individuals take for themselves and their families to stay healthy and manage minor and chronic conditions, based on their knowledge and the information available and working in collaboration with healthcare professionals where necessary.”**

**Joining up Self-care in the NHS’ - Steering Group,**  
**UK, National Health Service**



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# The spectrum of health care

Keeping  
healthy

Getting  
better

Managing disease  
and disability

Coping with  
end of life

**Public health**

Community-based services

**Self care**

**Primary care**

**Specialty care**

Institutional care



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# A spectrum of self-care



- 1. Working with others to make your community more healthy**
- 2. Personal and family health, wellness and safety, including use of preventive services**
- 3. Treating personal and family minor ailments and injuries**
  - **And knowing when to seek help**





# Self-care spectrum/2

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**4. Emergency care and first-aid**

**5. Chronic disease self-management**

**6. Preparing for end of life**

**7. Being able to communicate effectively  
with your own or your family's care team**



# Health literacy and self-care

- **Self-care requires a reasonably good level of health literacy.**
- **Yet “Six in 10 Canadian adults do not have the skills needed to adequately manage their health and health-care needs.”**
- **Seniors – 78.9% have only level 1 or 2 health literacy in BC**
- **Immigrants – 71.9%**
- **Not employed – 67.9%**
- **Aboriginal people – 66.3%**

**NB: This is 2003 data**



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# Internet use in seniors



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**In 2010,**

- **29% of people age 75 and over and**
  - **60% of those 65 to 74**
- had used the Internet in the previous month,**
- **Internet use among those age 15 to 24 was almost universal.**



# Internet use in seniors/2

**The number of seniors using the web grew by 20 per cent from 2010 – 2012**

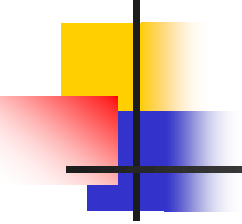
- **48 per cent of Canadians 65 or older saying they went online last year.**

- **83 per cent of Canadians aged 16 or older were Internet users in 2012**

**(Statistics Canada, January, 2013)**



# The digital divide

- 
- **62% of individuals in households in the lowest income quartile used the internet in 2012**
    - compared with 95% of individuals living in households in the highest income quartile.

**Most of this lag can be accounted for by the lack of Internet use by older, low-income Canadians.**

- **28% of Canadians aged 65 or over in the lowest income quartile used the Internet**
  - 95% of individuals aged 16 to 24 in households in the lowest income quartile.





# Kiss goodbye to self-care!

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- **The people who probably need self-care most are seniors and those with low levels of low-income and education**
- **With these low levels of health literacy and internet use, you can kiss goodbye to self-care**



# BC as a self-care and health literacy leader?

- **BC could lead the country, and be an international leader, by developing a comprehensive self-care strategy.**
- **Benefits include**
  - **improved population health**
  - **enhanced patient and provider experience**
  - **cost per capita savings and system sustainability**



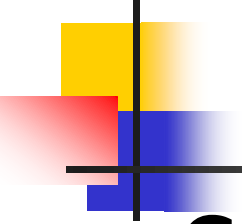


# Key elements include

- **Improving health literacy and e-health literacy in the public**
  - **From childhood to old age**
- **Developing common and linked education and training across the spectrum of self-care**
- **Improving communications and self-care skills in the practitioners**
  - **From undergrad preparation to continuing professional development**
- **Basing all this on a good evidence base**
- **Evaluating and adjusting**



# Possible first steps

- 
- **Create a Task Team to**
    - **Review the evidence on effective self-care**
    - **Identify the key features of a comprehensive self-care strategy**
    - **Identify the current elements in place and how to build on and link them to enhance reach**
    - **Identify new steps**
  - **Support a Provincial Health Literacy Initiative**
    - **Develop a provincial plain language policy**





# An Inter-sectoral Approach for Improving HEALTH LITERACY for Canadians

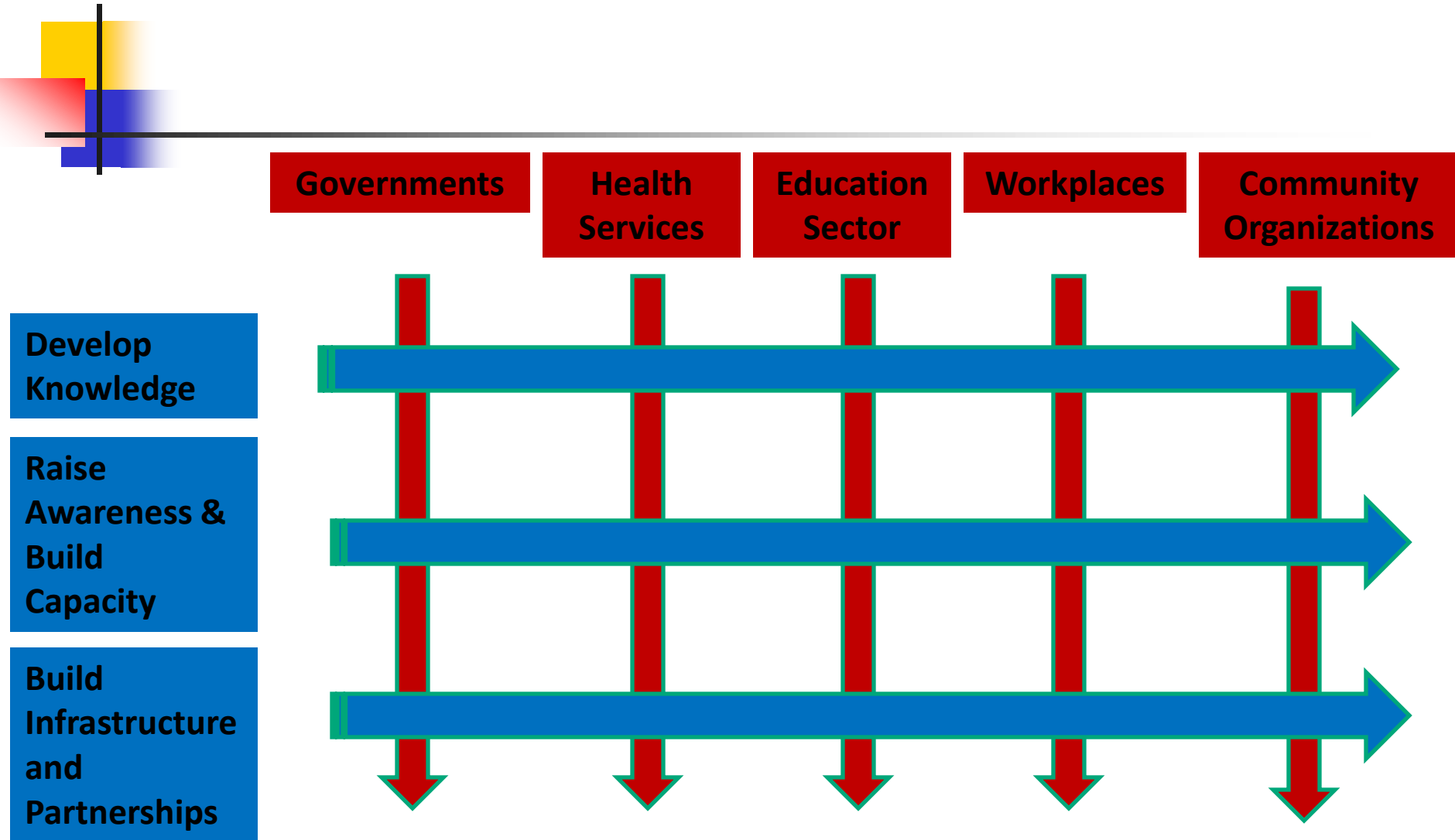
2012

A Discussion Paper

# Key Settings

- 
- **Governments** – Federal, Provincial, Territorial and municipal governments
  - **Health Services** – health care providers including medical personnel, health care institutions and clinics
  - **Education Sector** – public and private schools, post-secondary institutions, and centres for continuing education
  - **Workplaces and Businesses** – small, medium and large businesses and places of employment
  - **Community Organizations** – libraries, community recreation and community-sponsored continued learning, religious institutions and the media.

# Sample Activities



**Vision:** A Health Literate Canada in which all people can access, understand, evaluate and use health information and services that can guide them and others in making informed decisions to enhance their health and well-being.

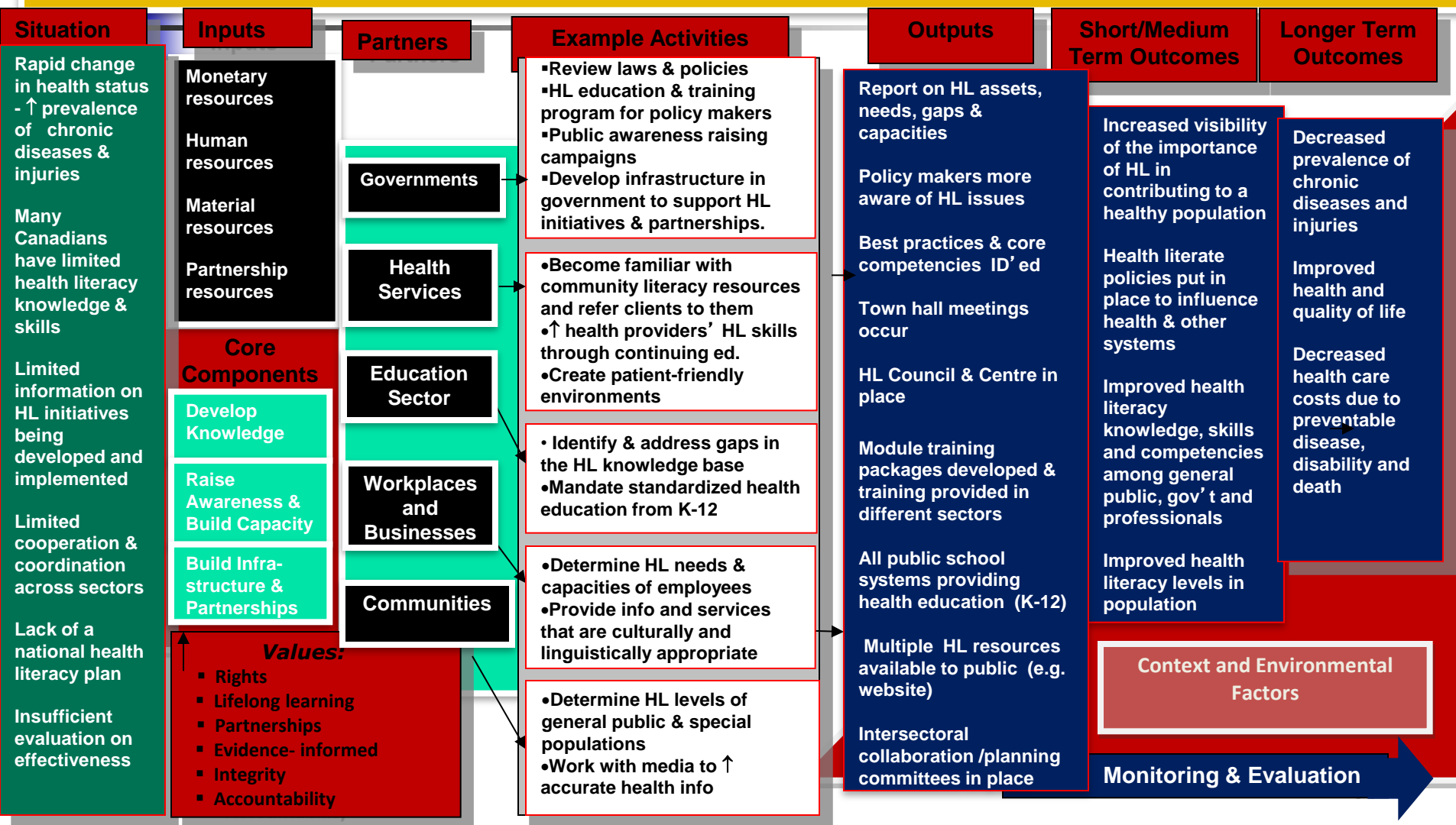
**Mission:** to develop, implement and evaluate an approach that will support, coordinate and build health literacy capacity of the general public, and people and systems that deliver health information and services in Canada.

**Goals:** To improve health literacy abilities of all Canadians by:

- developing a sound knowledge base that provides access to the existing and most recent information as well as evidence on effective ways to improve health literacy

- raising the awareness and increasing the capacity of all Canadians to improve health literacy levels

- building the infrastructure and identifying the partnerships necessary to develop a coordinated approach to advancing health literacy initiatives





# Setting Priorities for the BC Health System (Feb. 2014) BC Ministry of Health

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Setting priorities for a higher performing health system in B.C. requires analysis and decisions in three areas:

- What **outcomes do we want to achieve** in terms of the health of populations and patients? Which populations and patients require prioritized attention?
- What kind of **sustainable health service delivery system do we need** to have in place to meet those outcomes, and at what level of quality?
- What **strategy will we pursue to get results**? What enabling factors do we need to leverage and what constraints do we need to mitigate?

# Setting Priorities for the BC Health System

(Feb. 2014) BC Ministry of Health



***“Underpinning these dimensions of quality, we propose to add a priority to consistently strive to provide patient-centred care.”*** (page 18)

***“The achievement of quality is inextricably linked to the commitment and skill sets of the health workforce and the ability to optimally use all available resources to support this quality.”*** (page 18)





# Priorities to achieve meaningful improvements in population and patient outcomes

## **Quality and a Sustainable Service Delivery System**

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- **Priority 1: Provide patient-centred care**
- 
- **Priority 2: Implement targeted and effective primary prevention and health promotion through a co-ordinated delivery system**
- 
- **Priority 3: Implement a provincial system of primary and community care built around inter-professional teams and functions**
- 
- **Priority 4: Strengthen the interface between primary and specialist care and treatment**
- 
- **Priority 5: Provide timely access to quality diagnostics**
- 
- **Priority 6: Drive evidence-informed access to clinically effective and cost-effective pharmaceuticals**
- 
- **Priority 7: Examine the role and functioning of the acute care system, focused on driving inter-professional teams and functions with better linkages to community health care**
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- **Priority 8: Increase access to an appropriate continuum of residential care services**



# In Summary

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*“Health literacy pervades health issues at all levels—prevention, diagnosis, intervention, and cure for both chronic and acute diseases. Health literacy also pervades social issues—disparities, cultural differences, language differences, and access issues. There is also economic strain, both on the individual and on the system, in terms of lost human capital, lost time, and money.”*

*Marin P. Allen, Ph.D.  
Office of the Director, National Institutes of  
Health*

# What can we do in BC to Strengthen Connections Between Research and Practice in HL?

- Focus on priority issues (e.g. Chronic disease, Self-care, Patient-Centred Care, Workforce Development, Equity, Lifelong/Lifewide Learning)
- Increase involvement of researchers in practice and practice in research (e.g. participatory research, joint events)
- Build relationships with other sectors (e.g. education, private sector, community, media)
- Support and develop infra-structure (e.g. Networks, Courses, Summer Schools, Professional Training Programs)



# What can the MOH do to help HL Literacy Work in BC?

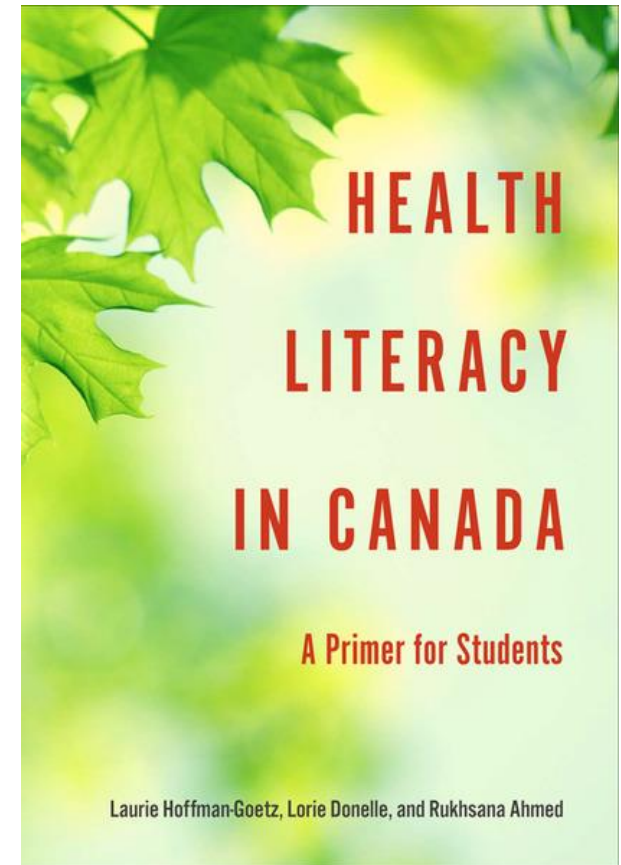
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- Appoint a point person
- Rejoin the Steering Committee of the BCHLN
- Develop policies in HL with HA' s
- Implement means of monitoring HL in population
- Encourage researchers to work with practitioners and policymakers and support capacity-building
- Do a scan of HL activities in Ministry and HA' s
- Support promising research and programs in HL
- Build on current interest in health care professional training in Brief Action Planning
- Make connections with other sectors



# Recommended New Resource

- “We believe that improving health literacy for all Canadians will require multidisciplinary, multicultural, and inter-sectoral strategies” (Hoffman-Goetz, Donelle & Ahmed, 2014)





# Discussion

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# Videos

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1. Learning is the Best Medicine (Ministry of Health)  
<http://decoda.ca/uncategorized/health-literacy-learning-is-the-best-medicine/>
2. Health Literacy and Chronic Disease Management (UBC)  
[https://www.youtube.com/watch?v=tvXEKynScKU&index=3&list=PL7QwUGl4DCMjjbXJ\\_F5n24Df04QFSCBT1](https://www.youtube.com/watch?v=tvXEKynScKU&index=3&list=PL7QwUGl4DCMjjbXJ_F5n24Df04QFSCBT1)
3. New Zealand Presentation on Health Literacy  
<https://www.youtube.com/watch?v=fF84814Ozo0>