

National Literacy and Health Research Program Needs assessment and Environmental scan

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1. Executive Summary:

This study is a component of a Literacy and Health Research Program funded in April, 2002 by the Social Sciences and Humanities Research Council through the National Literacy Secretariat. Its objectives are to identify: gaps in knowledge in literacy and health research in Canada; current and proposed initiatives in literacy and health in Canada; and resources and opportunities for research in literacy and health in Canada. Forty-eight practitioners, researchers and policymakers involved in literacy and health issues were interviewed by a team of researchers across the country. Four follow-up focus groups were also held involving a total of 33 people. Guiding questions were developed on current knowledge of literacy and health research and practice, and on gaps, barriers and opportunities for research. This report is a synthesis of the investigations of four research teams in different regions of the country.

In general it was found that Canada has an abundance of literacy and health projects, but relatively little research. Projects included plain writing services and initiatives, translation and interpretation of health information, awareness-raising publications, staff sensitivity training programs, new literacy curricula, and resource collections. Respondents reported very little knowledge of literacy and health research, however, especially current Canadian research. Yet, a great need for research was identified. Respondents explained that many practitioners still don't realize how many people are affected in how many ways by low literacy; that simplistic solutions to health problems such as relying on pamphlets at clinics and "putting everything on the internet" are adopted too often; and, that there continues to be a great need to dispel myths and reduce the stigma of illiteracy, and empower disadvantaged groups. With an aging population, proliferating use of computers, and a changing ethnic and linguistic national make-up, research in this field is especially urgent, they said. Many suggestions of topics that need study were reported, and much advice on methodology was received. There was general

consensus that collaborative efforts between diverse stakeholders and sectors were needed; and that both quantitative and qualitative information should be collected. This study also produced an inventory of researchers across Canada interested in literacy and health; an inventory of Canadian publications on the topic; and a revised conceptual framework.

2. Background:

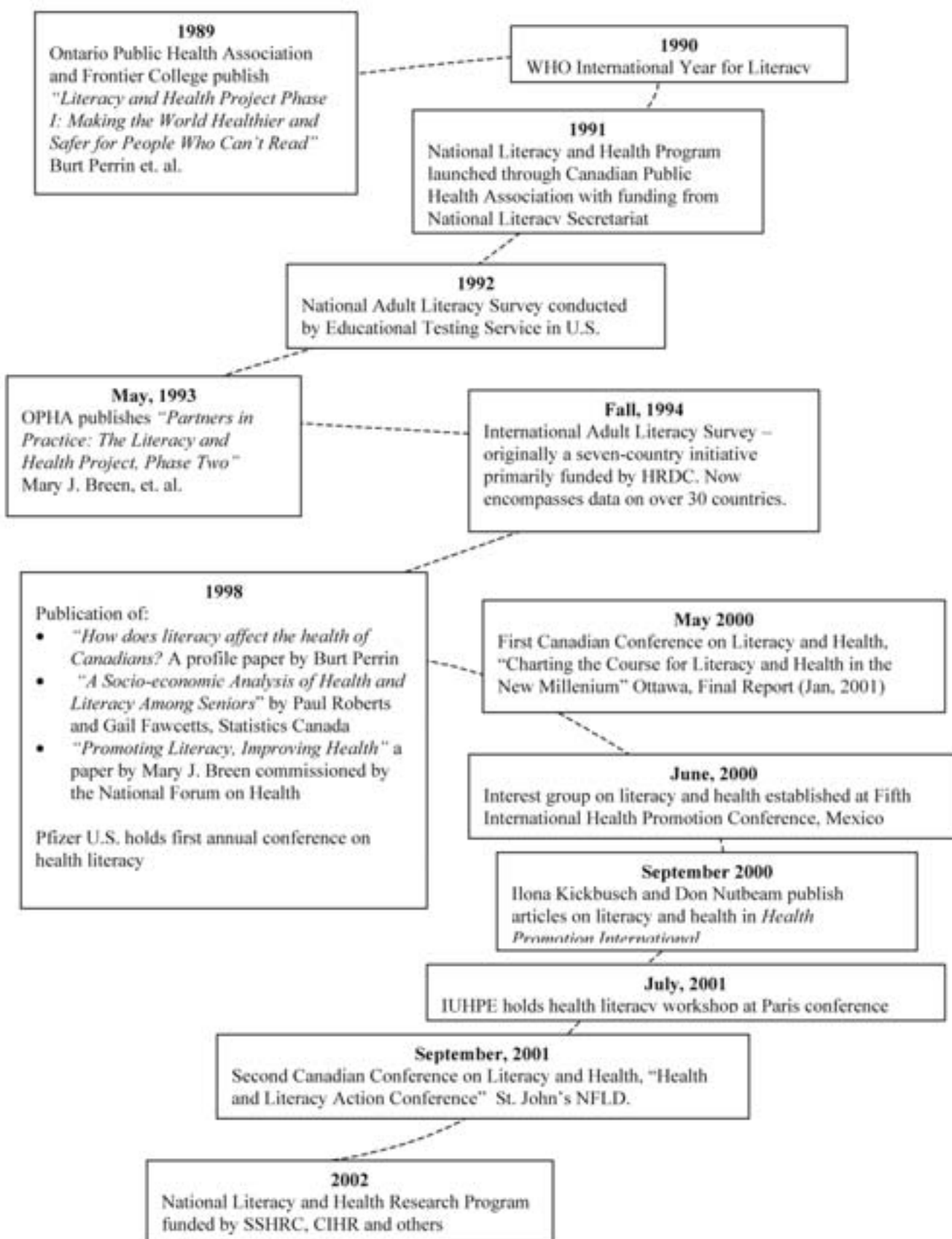
The links between literacy and health have been of growing interest in Canada and internationally for more than a decade. Canadian interest in this area can be traced back to the mid 1980's with the beginning of a series of large scale surveys of literacy levels of Canadians by Southam News (1987), Statistics Canada (1992) and HRDC/ Statistics Canada (1994, 1997). Many Canadians had not previously realized that so many people, approximately half of the population, did not read or did not read well. A speech from the throne then highlighted literacy as a key problem to address, and the National Literacy Secretariat was established in 1987. Also in the late 1980s the Ontario Public Health Association and Frontier College jointly undertook pioneering research in literacy and health in order to better understand the links between the two. WHO designated 1990 as the International Year for Literacy spurring further interest. In 1992 the National Literacy and Health Program was established by the Canadian Public Health Association, and is now supported by 27 national partner organizations. The first national conference on literacy and health was held in May, 2000 (Ottawa), and a "Health and Literacy Action Conference" was held in September, 2001 (St. John's, NFLD). Recently the *Health Promotion International* journal has taken an interest in "health literacy" as an outcome that the field of health promotion could conceivably be held accountable for.¹ This has also spurred Canadian and international interest in the area of literacy and health.

¹ Nutbeam, D (2000) *Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promotion International. 15(3): 259-267.*

In April 2002, a group of researchers led by Dr. Irving Rootman² was funded for three years by the Social Sciences and Humanities Research Council to develop a national program of research in literacy and health for Canada in partnership with the Canadian Public Health Association. Among other things, they proposed to: establish an advisory committee; conduct an environmental scan and needs assessment; organize a think tank and workshop; submit research proposals; develop a web-site and electronic newsletter; develop training opportunities for graduate and postdoctoral students; evaluate the National Literacy and Health Program and their own efforts to establish a research agenda; and develop a plan for sustaining the research program over the long-term. The current study is the final report of the Environmental Scan and Needs Assessment undertaken in the summer and Fall of 2002 in preparation for a national workshop/think-tank held in Ottawa on October 27th and 28th, 2002. The following is a chart of key milestones in literacy and health research in Canada.

² Former Director of the Centre for Health Promotion, University of Toronto and currently a Professor and Michael Smith Foundation for Health Research Distinguished Scholar at the University of Victoria.

Milestones in Literacy and Health Research and Practice in Canada



3. Objectives:

The objectives of the needs assessment and environmental scan were:

1. To identify gaps in knowledge in literacy and health research in Canada
2. To identify current and proposed initiatives in literacy and health in Canada
3. To identify resources and opportunities for research in literacy and health in Canada

4. Methodology:

Forty practitioners, researchers and policy-makers involved or interested in literacy and health issues were surveyed by telephone or face-to-face; and eight were surveyed by e-mail questionnaire. Four follow-up focus groups were held in Vancouver, Toronto, Ottawa and Wolfville, Nova Scotia (Acadia University) involving a total of 33 people. Focus groups were taped. Notes were taken during key informant interviews and some were also taped. During key informant surveys, questions were posed on current knowledge and involvement in the area of literacy and health, and on gaps, barriers and opportunities for research. In the focus groups similar questions were posed after presenting a summary of findings on each topic from the key informant surveys. In addition, participants were asked to think about and comment on a preliminary conceptual framework for literacy and health research. Preliminary regional reports were written by investigators who conducted key informant surveys (Barbara Ronson, Heather Hemming/Lisa Langille, Darryl Quantz, and Margot Kaszap) and investigators who organized focus groups (Barbara Ronson, Heather Hemming/Lisa Langille, and Darryl Quantz). These reports were synthesized to create this national report. A summary of this report was presented in a powerpoint slide show at the National workshop on literacy and health in October, 2002 and the final version was adapted based on feedback at the workshop.

5. Findings:

Findings are grouped in the following six areas:

- 5.1 Current and proposed Canadian projects in literacy and health
- 5.2 Canadian research in literacy and health
- 5.3 Canadian researchers interested in literacy and health
- 5.4 Gaps in literacy and health research
- 5.5 Barriers to literacy and health research
- 5.6 Solutions and opportunities for literacy and health research

5.1 Promising Canadian Projects related to Literacy and Health

Promising Canadian projects in literacy and health included the development of high quality health communications and education (plain writing, translation and interpretation); awareness raising regarding the links between literacy and health (publications, literacy audits, conferences, resource collections etc.); and, adaptation of literacy classes to focus on health (incorporation of health content into literacy classes, and participatory development of health information). Examples of such projects are found below:

Plain writing services and projects

The most widespread work related to literacy and health has probably resulted from a new emphasis on "plain" or "clear" writing considerations in the development of health education materials. CPHA's encouragement of this work through various publications (e.g Easy Does It!; Working with Low Literacy Seniors; Creating Plain Language forms for Seniors) and through their work in establishing and maintaining 27 National partner organizations, can be credited for much of the "flurry of activity" in this area over the past decade. Others have produced similar guides for promoting and

³Black, M (2002) *The 5 C's: Areas to consider for making your health messages accessible to a wider population* OHPE # 258.1
www.ohpe.ca/ebulletin/ViewFeatures.cfm?ISSUE?ID=258&startrow=11

producing Plain Language e.g. North Halton Literacy Guild, Michelle Black in OHPE bulletin.³ Key informants mention the following Organizations offering plain language writing services across Canada:

- "Clear Language and Design" (Sally McBeth, Executive Director);
- "Simply read writing service" (Michelle Black, owner);
- CHIP (Centre for Health Information and Promotion - formerly at Toronto Hospital for Sick Children, Toronto);
- CPHA (past and current manager of Plain Language Service);
- The Movement for Canadian Literacy's and Health Canada's medication and nutrition labeling projects and guidelines development.
- The Vocational and Rehabilitation Research Institute in Calgary;
- Ottawa Regional Cancer Centre (supported by the province and Cancer Care Ontario);
- The Halton Region Health Department; and,
- The Canadian Congress for Learning Opportunities for Women (CLOW) where health related information for disadvantaged and battered women has been produced.

Knowledge of the need for plain language usage was relatively widespread among respondents. For example, key informants in Alberta and Saskatchewan were familiar with plain language health information booklets produced by the Women's Network in PEI such as "Beyond Prescriptions: Meeting Your Health Needs" and "Is it hot in here: A Handbook for Menopausal Women and Their Families."⁴ Nova Scotia key informants knew of interest and work in plain language initiatives on the part of Population Health and Dietitians of Canada. CPHA has produced a Directory of Plain Language Health Information (1999) that lists over 375 plain language health resources produced by 49 different organizations in North America. This directory is also available in French. Some respondents said that so much of this kind of activity was generated, that it has become in some health care workers' eyes "yesterday's issue". Several prominent researchers have emphasized that plain language should not be a

sole focus of literacy and health initiatives (Perrin, 1998). Still it is a very important aspect that continues to gain momentum. New groups are continuing to advance the cause of plain language writing, and more and more groups are adopting "clear language policies" (e.g. The Ontario Literacy Coalition). The recent international plain language conference in Toronto had unprecedented attendance, further testament to the importance of increased use of plain and clear language around the world.

Translation/Interpretation of Health Information

A few respondents mentioned the work being done in translating health information. Going beyond translation to interpretation was noted to be important so that cultural differences and beliefs would be better taken into consideration in the material produced. Also, literacy levels and definitions within the language of origin need to be considered. Organizations mentioned as doing work in this regard included the Canadian Ethnocultural Council, Regional Health Departments (e.g. Halton and Toronto Public Health), and the National Aboriginal Design Committee. An independent consultant in Alberta was involved in a project collecting health education material produced in languages other than English and found that there had been very little quality control. Translations had been done by people with no training and little thought had been given to presentation, design and appeal. Moreover, there are currently no known readability assessment tools or Plain Language guidelines for languages that do not use the alphabet, nor are there for many that do. A centralized service was set up to address such problems and quality did improve.

⁴A full listing of these resources can be found in the Centre for Literacy Quebec's Health Health Literacy Project, Phase I: Needs Assessment of the Health Education and Information Needs of Hard to Reach Patients, Part 1, p. 29.

Publications:

Several respondents mentioned and/or forwarded copies of public education material that address literacy and health issues. These included:

- A fact sheet called "Warning! Poor Literacy Skills are Dangerous to your Health!" produced by the Ontario Literacy Coalition (also found on the Literacy Network of Durham Region Website);
- A publication of the Canadian Pharmacists Association called "Just Checking";
- A publication of Rx&D called "Knowledge is the Best Medicine";
- A "Need to Succeed" campaign that grew out of the Second Canadian Conference on Literacy and Health in Newfoundland;
- A thesis in production by Priscilla George on health and literacy in the broadest holistic sense, centred on the Aboriginal medicine wheel, and involving a balance of spirit, heart, mind and body. (This resource has been the source of over 25 presentations including one at the First Canadian Conference on Literacy and Health, at least two at National Aboriginal literacy conferences, and others for international audiences, firstly in Australia in 2000 and the most recent in Brazil this year.);
- Perrin, B et. al. (1989)¹ *Literacy and Health Project Phase One: Making the World Healthier and Safer for People Who Can't Read*. Ontario Public Health Association and Frontier College.
www.opho.on.ca/resources/i-n.html#literacy
- Perrin, B (1998) *How Does Literacy Affect the Health of Canadians?: A Profile Paper*. Ottawa: Health Canada; and,
- Breen, MJ et.al. (1993) *Partners in Practice: The Literacy and Health Project Phase Two*, OPHA
www.opho.on.ca/resources/i-n.html#literacy

The environmental scan found the following additional materials in this category:

- Lockert, R.C. "Health and Literacy (kit): How do they relate?" Saskatoon. Saskatchewan Literacy Network.
- Norton, M. (1998). "The Wholeness of the Individual; Linking literacy and health through participatory education". Edmonton, AB: *The Alberta Journal of Educational Research*, 44(2), 245-47.
- Norton, M. (1992) "Linking Literacy and Health: A Popular Education Approach." In *Voices from the Literacy Field*, Eds. J.A. Draper and M.C. Taylor. Toronto: Culture Concepts, 319-332.
- Breen MJ (1998) Promoting Literacy, Improving Health in *Canada Health Action: Building on the Legacy*. Papers commissioned by the National Forum on Health. Vol. 2 Adults and Seniors. Sainte-Foy Québec: Éditions Multimondes. 47-88.
- Paul, C. The Easier to Read: Easier to be Healthy Report. Toronto: Lawrence Heights Community Health Centre Press.
- Roberts. P and Fawcett, G. (1998) *At Risk: A Socio-Economic Analysis of Health and Literacy Among Seniors*. Ottawa, ON: Statistics Canada
- Woodhouse, W. (1995) Rural Literacy and Health Concerns, Rural Reflections. Dundas, ON: Literacy Field Research Group.
- Sarginson, R.J. (1997). *Literacy and Health: A Manitoba Perspective*. Winnipeg, MB: Literacy Partners of Manitoba.
- Rootman, I (2002). "Health Literacy and Health Promotion" *OHPE Bulletin* # 270.1 August 2, 2002. www.ohpe.ca

Literacy audits and hospital/ agency staff sensitivity training:

Several respondents mentioned their own or others' services in assessing and addressing issues with service providers' reception areas and their communication skills with low-literacy adults. Three key informants who offered these services were two Regional Literacy Centres in Ontario and a Literacy and Adult Learning Centre in Alberta. For one of these centres, it is a new strategic direction as of May, 2002. Serving for a long time as a hub for literacy services throughout the area, they are only now taking an interest in helping people with literacy issues who are not in and probably will never attend literacy classes. They have a new partnership with five groups that do not offer literacy classes but have overlapping or similar clients including the Association for Community Living, a Career Centre, and an Interfaith Counselling Centre. They are hoping to soon have similar partnerships with health service providers. One independent consultant in Alberta collaborated with 6-8 agencies in developing a video and handbook so that organizations could conduct their own literacy audits. In Alberta, improved work of pharmacists in ensuring that clients understand medication instructions was noted, for example, some pharmacists routinely ask seniors to repeat back what they're supposed to do.

Health Department respondents in Ontario and Alberta mentioned their own in-house staff sensitivity training programs and literacy assessments of their publications. Three hospitals that were mentioned to have (at least at one time or in the future) their own services in this regard were the Hospital for Sick Children (Centre for Health Information and Promotion - CHIP), Montreal General Hospital, and McMaster Medical Centre. McGill University Hospital (MUHC) has a health literacy page on their intranet of six hospitals that the Centre for Literacy Québec prepared for them.

Conferences/ Networks

A number of Canadian conferences relevant to the area of literacy and health that have been or will be held were mentioned by respondents. The Canadian ones mentioned were the First National Conference on Literacy and Health (Ottawa, 2000); the Health and Literacy Action Conference, (Memorial University Nfld, 2001), and the International Plain Language Conference held in September, 2002 in Toronto, co-chaired by Michelle Black and Sally McBeth, plain language consultants. The latter conference attracted over 400 participants and speakers, 8 times as many as the previous year's conference in Houston, Texas. An upcoming Canadian event in the field of literacy and health is a Literacy and Health Institute to be held in June, 2003 in Montreal. In British Columbia a Health Literacy network has been organized by the BC Coalition of People with Disabilities (<http://www.bccpd.bc.ca/wdi/hln.html>).

Resource Collections

Respondents mentioned the following useful collections of resources on literacy and health: Centre AlphaPlus Centre in Toronto; a small health section at the Ontario Literacy Coalition; and, the National Adult Literacy Database that includes 130+ references on literacy and health. Those produced in Canada and relevant to the present study are found in our bibliography of Canadian documents ([Appendix A](#))

Incorporation of health content into literacy classes

New literacy courses that incorporate health concepts were noted by some respondents. For example, some literacy volunteers and teachers were making use of Mary J. Breen's text "Taking Care" for teaching literacy. Another innovative literacy and health program called "Out and About" was developed by Pat Campbell in Alberta. In this course, participants collect health education brochures, analyze them and interview

people to help understand the politics of information: Who produces it? Who benefits? etc. An effort is made to help learners understand "not just the word but the world" .

Another literacy project related to health in its broader sense is an online course for literacy education and violence prevention called "*Taking Action*" by Jenny Horsman. Deborah Gordon El-Bihbety of CPHA also developed a course and resource for youth programming in Literacy and Health called "*What the Health!*" A program that sprang from youth involvement in that course is called "*M.O.V.E – Mind Over Violence Everywhere, A Youth Literacy Project*". Both are available on CPHA's National Literacy and Health Program website.

Participatory development of health information

A number of respondents mentioned projects in which health education material was developed collaboratively with low literacy and/or ethnic groups, usually within literacy classes. Among the projects mentioned were:

- An Alberta project involving Aboriginal women's health issues;
- Participatory research conducted by East End Literacy in Toronto;
- Focus group research during the health education material development process (Centre for Health Information and Promotion, Hospital for Sick Children, and Regional Municipality of Halton Health Department);
- Books produced by Mary J. Breen called *Taking Care and So Many Changes* (with Lindsay Hall);
- Work of the Literacy Association in Edmonton;
- Dartmouth videotape on nutrition;
- A Calgary sexuality education and literacy project;
- Health Education materials produced in collaboration with adults with low literacy

and developmental disabilities through the Vocational and Rehabilitation Research Institute in Calgary;

- Work of the National Indian and Inuit Community Health Representative Organization (NIIHRO);
- "*Learning for our health: A resource for participatory literacy and health*", by Pat Campbell and Mary Norton, The Learning Centre Literacy Association, Edmonton AB;
- Work of the Canadian Ethnocultural Council with ethnic communities; and,
- A project coordinated by Dr. Janet Smylie, Faculty of Medicine, University of Ottawa called "*Standing on Ground, Seeking Understanding*" that trains Aboriginal community health representatives to choose a health topic and develop a project.

Other participatory projects found through the environmental scan include:

- "Read to me, Read Together" a joint project of the NWT Literacy Council and Health promotion office of Yellowknife Health and Social Services (nald.ca/resource/rsc2793.htm);
- "I call it the Curse!" East End Literacy;
- "Canadian Woman Studies: Women of the North" by and about women living in northern, rural and isolated communities, York University;
- "Telling Our Stories Our Way" a review by students and volunteers of literacy materials and health education materials available for women, Canadian Congress for Learning Opportunities for Women, 1994; and,
- "A Better You: The Benefits of a Healthy Lifestyle" Video produced by students of the Dartmouth Literacy Network.

⁵ Paulo Friere, cited in Hohn, MD (1998) *Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders* <http://www.nifl.gov/nifl/fellowship/reports/hohn/HOHN.htm>

Family Literacy Initiatives:

A new trend in literacy programs is the recent proliferation of family literacy classes. These classes readily span the literacy and health arenas since health concerns and interventions during the early years are particularly frequent.

According to one respondent, such programs in Alberta sprang from the United Way "Success by Six" campaign that generated interdisciplinary work in the interest of preschoolers. The "Success by Six" campaign is one outcome of renewed interest in better support for children aged 0-6 generated in the 80's and early 90s by pioneering researchers and advocates Dr. Paul Steinhauer, Dr. Fraser Mustard and others. Family literacy programs in the U.S. were given a boost by the endorsement of Barbara Bush in the late 80's, and in the early 90's a National Center for Family Literacy was established. In Canada, interest in family literacy grew in 1993 leading up to a national conference in November 1994. Paul Martin's 1997 budget highlighted literacy as a priority with emphasis on family literacy among other areas. Preliminary research indicates that retention is higher in family literacy than in traditional literacy programs; that the goal of supporting their children's learning is a powerful motivator for adults; and that embedding literacy in activities connected to daily life leads to greater sustainability.⁶ Programs such as "Rhymes that Bind", "Books for Babies" and "Health for Two" have been developed in Canada, in part to apply new knowledge on healthy development of children from the attachment literature within the medical/psychiatric field. The Centre for Family Literacy in Edmonton (formerly called the Centre for Literacy) is one group that offers such programs that merge health and education best practices. This Centre was designated by the National Literacy Secretariat as a leading national centre for family literacy programs.

Miscellaneous:

The Literacy Network of Durham Region mentioned a "Health Hygiene Box" initiative at their centre that offers learners free health and hygiene items such and feminine hygiene products, bandaids, shampoo etc. Since most of their clients are low income, the service is appreciated.

One literacy centre offered a "Scribe" service to help fill out forms and help low literacy people with other reading and writing tasks . One Aboriginal centre offered a health team that helped clients understand prescriptions and other health information.

Also mentioned was the Optometrists' Associations "Seeing and literacy" project that offered free eye care and glasses for learners. This project sprang from the Optometrists' Association's involvement as a partner in the National Literacy and Health Program.

5.2 Canadian Research in Literacy and Health

In general little was known by the respondents about literacy and health research in Canada. However the following projects were mentioned:

- Extensive work of the Canadian Public Health Association on literacy and health, primarily as it relates to seniors, but more recently as it relates to youth and other populations;
- Current work of the Canadian Ethnocultural Council and Health Canada on "Culturally appropriate best practices for healthy aging" and on "Diabetes in older adults from Asian, Black and Hispanic populations – a community-based prevention model";
- In Nova Scotia, a research project on health and literacy in rural contexts is being conducted by a research team consisting of community organizations, health and literacy

⁶ Linda Shohet, "Canadian budget shines spotlight on family literacy", Centre for Literacy, Quebec, 1997; Retrieved from the World Wide Web on Oct. 17, 2002 at www.nald.ca/naldnews/97spring/budget.htm.

- practitioners, and researchers from Saint Francis Xavier University;
- A CPHA and Canadian Ethnocultural Council study on drugs and ethnic seniors;
 - The Health Promotion Centre and Population Health Research Unity (PHRU) at Dalhousie University was cited as investigating issues surrounding health and literacy;
 - A study of a "personal coach" project for cancer – a joint initiative of the Cancer Care Ontario program, eHealth innovation, and University Health Network;
 - A McMaster literature review on literacy and health;
 - Work in primary and secondary schools in developing better ways of improving and assessing literacy;
 - A trans-national study on health promoting activities in schools in which all participants mentioned literacy as a health matter;
 - A needs assessment report released last year in anticipation of building a health information and literacy centre at Montreal General Hospital;
 - Work of the Centre for Literacy, Québec (needs assessment with MGH, annotated bibliography etc.);
 - Participatory research of East End literacy, Centre for Health Information and Promotion, and others mentioned in the previous . . . section;
 - Work of the Centre for Health Economics and Policy Analysis (CHEPA), McMaster University; and the Canadian Health Services Research Foundation (CHSRF), Ottawa, on knowledge transfer;
 - IALS, Statistics Canada and OECD studies; and
 - National Aboriginal Health Organization work.

For a complete listing of Canadian Research on Literacy and Health found through the environmental scan and needs assessment, see [Appendix A](#).

5.3 Canadian Researchers interested in Literacy and Health

The following individuals were identified by key informants and focus group participants as involved in research in literacy and health. An effort was made to contact each of them to confirm their willingness and appropriateness for inclusion in an inventory of Canadian researchers interested in literacy and health, and to ask them to mention others who should be included. Some of these additional names have been included as well. For details on their contact information see Appendix C. Those reached and agreeable are marked with an asterisk.

Andrew Aitkens
Canadian Association for Community Care

Dr. Dyanne D. Affonso*
Faculty of Nursing
University of Toronto

Dr. Andy Anderson*
Associate Professor, OISE/UT

Dr. Eileen Antone (Oneida)*
Dept. of Adult Education, OISE/UT

Dr. Zubin Austin*
Faculty of Pharmacy, University of Toronto

Ellen Balka
Simon Fraser University

Jessica Ball
University of Victoria

Peri Ballantyne*
Faculty of Pharmacy, U of T

Dr. Deborah L. Begoray* University of Victoria

Dr. Barbara Bernhardt*
UBC School of Audiology and Speech Sciences

Dr. Heather Boon*
Faculty of Pharmacy, University of Toronto

Mary J. Breen*
Consultant (formerly at OPHA)

Sharon Brez
The Ottawa Hospital

Pat Campbell
University of Alberta

Gary Catlin
Statistics Canada

Dr. Jillian Clare-Cohen*
Faculty of Pharmacy, U of T

Dr. Annette Connors
University of Ottawa

Heather Debus*
Masters student, OISE/UT

Sucy Eapen
Canadian Ethnocultural Council

Margot Fauchon
Société Franco-Albertaine, Alberta

Gail Fawcett
Canadian Council on Social Development

Jeanette Fortin
Laval University

Dr. C. James Frankish*
University of British Columbia

Audrey Friedman
Princess Margaret Hospital

Priscilla George*
Aboriginal Literacy Consultant

Doris Gillis*
St. Francis Xavier University

Deborah Gordon-El-Bihbety*
Canadian Public Health Association

Dr. Jan Hare
Social Work & Family Studies, UBC

Ruth Hayden
University of Alberta

Dr. Michael Hayes
Simon Fraser University

Dr. Heather Hemming*
Acadia University

Dr. Clyde Hertzman*
University of British Columbia

Dr. Jenny Horsman*
Spiral Community Resource Group

Shelley Hourston, B.A., M.L.S.,
BC Coalition of People with Disabilities/Health
Literacy Network

Dr. Alejandro (Alex) R. Jadad, MD DPhil, FRCPC*
eHealth Innovation

Dr. Suzanne Jackson
Centre for Health Promotion
University of Toronto

Susan James
University of British Columbia

Alfred Jean-Baptiste*
East End Literacy

Stan Jones
Nova Scotia

Dr. Margot Kaszap*
Laval University

Judy King*
University of Ottawa

Dr. John N. Lavis, MD PhD*
McMaster University

Josée Levert
Fondation pour l'alphabétisation
Québec

Roz Levy
Youth Tobacco Coalition

Dr. Jonathon Lomas
CHSRF

Ellen Long*
Researcher and Consultant

Lisa Lucas
Action ABC

Dr. Geraldine (Jody) MacDonald*
Faculty of Nursing, University of Toronto

Dr. Lilian Magalhaes*
Institute for Work and Health

Dr. Joan Marshman
Faculty of Pharmacy, U of T

Sally McBeth*
Clear Language and Design

Doug McCall*
Canadian Association for School Health

Charles Moody*
Literacy Partners of Manitoba

Dr. Jennifer Mullett
University of Victoria

Mary Norton
The Learning Centre, Edmonton, AB

Dr. Michael Pennock
University of Dalhousie

Burt Perrin*
La Masque, France

Elsie J. Petch*
Consultant

Dr. Linda Phillips*
Centre for Research on Literacy
Faculty of Education, U of Alberta

Janet Pringle*
The Vocational and Rehabilitation Research
Institute, Calgary, AB

Lois Provost Turchetti, B.A., M.Ed.*
OISE/UT

Darryl Quantz*
University of British Columbia

Dr. Allan Quigley*
St. Francis Xavier University

Paul Roberts*
Canadian Council on Social Development

Dr. Barbara Ronson*
Centre for Health Promotion, U of T

Dr. Irv Rootman*
Community Health Promotion Coalition
University of Victoria

Ian Ross*
MA Candidate, Communication
Faculty of Education, University of Regina

Jim Sands*
Social Planning and Research Council of BC

Kathy Sanford
University of Victoria

Maureen Saunders
Centre for Family Literacy, Edmonton, AB

Rob Sarginson
Winnipeg

Ivan Seunarine
Salvation Army, Winnipeg

Dr. Linda Shohet*
Centre for Literacy Quebec

Dr. Harvey A. Skinner PhD, CPsych
Department of Public Health Sciences,
U of T

Dr. Janet Smylie
University of Ottawa, Faculty of Medicine,

June Smith
Jewish General Hospital, Montreal

Dr. Maurice Taylor*
Faculty of Education
University of Ottawa

Dr. Elizabeth Thorsen
Faculty of Pharmacy
University of Toronto

Dr. Richard Vedan
First Nations House of Learning/Aboriginal Health
Institute, Vancouver, BC

Dr. Wendy Young, Ph.D. *
University of Toronto

Dr. Margareth Zanchetta
Queen's University, Kingston

Others researchers and practitioners who were mentioned as having some role, particularly with ethno-cultural research and practice, included:

Carol Banez, Toronto Public Health (diets)

Betty Harvey, Latino community

Jacqueline James, Chair of Banting and Best
Diabetes Centre in Toronto

Burt Taylor, Western (Kenesiology)

Lillian To, Executive Director of United Chinese
Community Enrichment Services Society
(SUCCESS)

Duberlis Ramos, Hispanic Development Council

5.4 Gaps in Literacy and Health Research in Canada

As mentioned in the previous section on promising research projects in literacy and health in Canada, respondents generally reported very little knowledge of such research. Some knew of earlier research by the Ontario Public Health Association and Frontier College, the Canadian Public Health Association, the Centre for Literacy Québec, and Statistics Canada. Others knew of

related research by the Canadian Ethnocultural Council, the Dalhousie Population Health Research Unit, the Centre for Health Economics and Policy Analysis (CHEPA), the Canadian Health Services Research Foundation (CHSRF) and the National Aboriginal Health Organization. A few mentioned small pockets of participatory health and literacy research going on in various literacy centres and hospitals. However, no current studies other than one on rural literacy and health issues at St. Francis Xavier University and the present joint study by University of Toronto Centre for Health Promotion and the Canadian Public Health Association was identified, and most respondents hadn't heard of either of these. The general conclusion is that, though we may be program rich, there is a dearth of research in Canada on literacy and health.⁷

Respondents did, however, mention several potential benefits for research in this area and reasons why it was needed. They said we first need to improve knowledge about what has already been done. We should also continue to raise awareness about the need for adequately accessible and appropriate health and literacy services for low literacy or "hard-to-reach" adults. We need more people to understand that this group comprises from 1/4 to 1/2 of the population depending on how low literacy is defined. We need to eliminate myths, reduce the stigma of illiteracy, and empower disadvantaged groups. We need to disseminate effective practices, and improve the attitudes and approach of service providers. We need to forewarn against simplistic solutions that may be adopted by decision-makers such as relying on pamphlets at clinics and hospitals and "putting everything on the internet." Research, in short, is critically needed if we are to maintain and improve the health of all Canadians in our age of a "knowledge economy" when literacy demands on consumers are higher than ever before.

Participants in the key informant surveys and focus groups identified a wide range of needed research in the area of literacy and health. Their

⁷ This view was corroborated by Dr. Rima Rudd of Harvard University, keynote speaker at the October, 2002 National workshop.

responses will be discussed within three broad areas: #1. Clarifying the issue: Theoretical and conceptual research on the relationship between literacy and health; #2. Building the Case: Research related to influencing policy-makers and others about the need for research and practice in this area; and #3. Making a Difference: Participatory action research related to improving health and improving literacy for bettering the quality of life of Canadians. An effort was also made to categorize research needs within four broad forms of interventions: A. Policy B. Education/Training; C. Community Development and D. Communications The general conclusion was that most of the proposed research areas involve communications (#3D) and education/training (#3B). The areas of policy and community development are less apparent, though perhaps equally important.

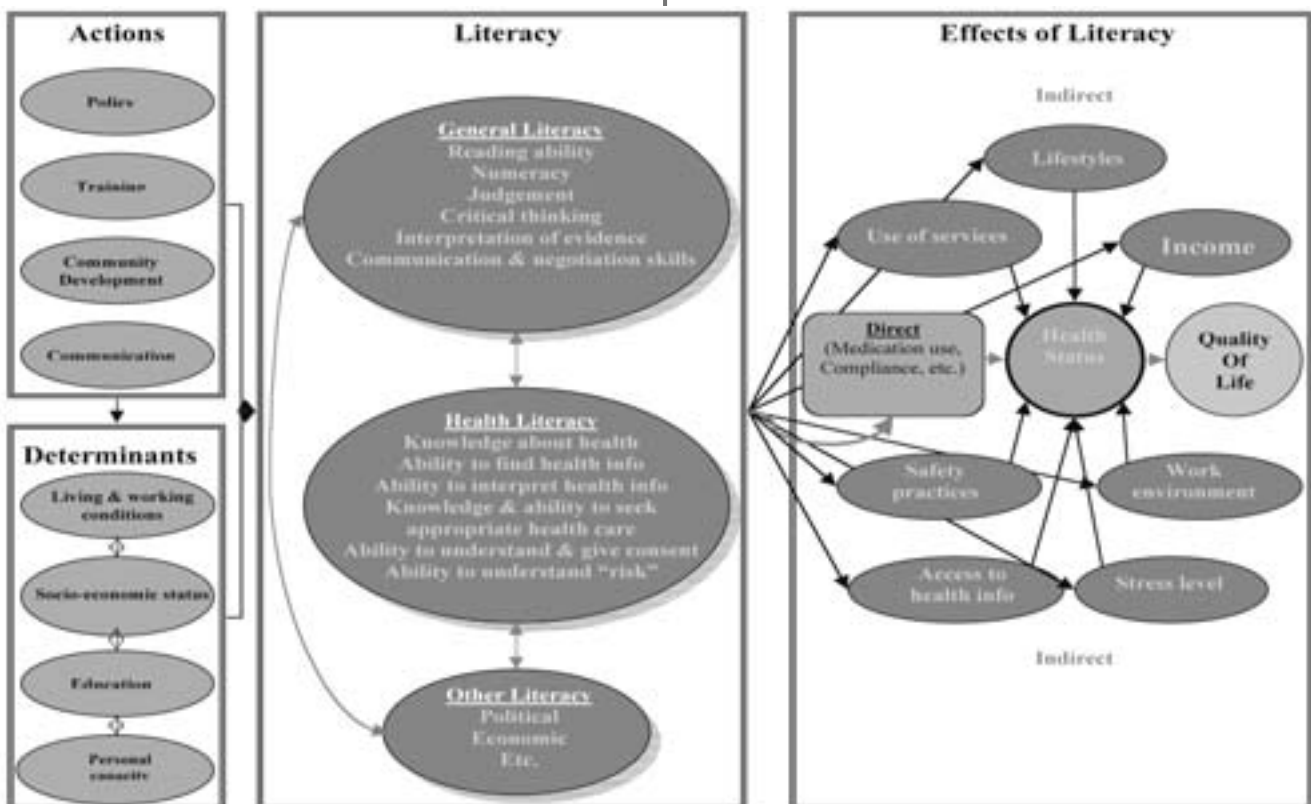
Clarifying the Issue:

An examination of definitions of literacy through history shows that this term is a "moving target" and many informants recommended giving preliminary attention to defining what we mean by "literacy" and "health literacy".

Many called for better understanding of this issue for diverse populations: urban/rural, Aboriginal, diverse ethnic and language groups, different age groups, disease and risk specific groups, the disabled, mentally ill, etc. Another recommendation was to do research within established conceptual models (such as the health belief model, precede-proceed model etc.) and using the common language of the maturing fields of population health and health promotion. For example, several called for linking literacy and health to the determinants of health. Some also said there was a need for better understanding of the impact of health on literacy and learning as well as the impact of literacy on health. Literacy program providers and learners in particular could benefit from a better understanding of how medications and chronic illness affect concentration for learning.

Participants in the focus groups were asked to consider and comment on the following conceptual framework:

Conceptual Framework



Among the comments people made about the framework were the following:

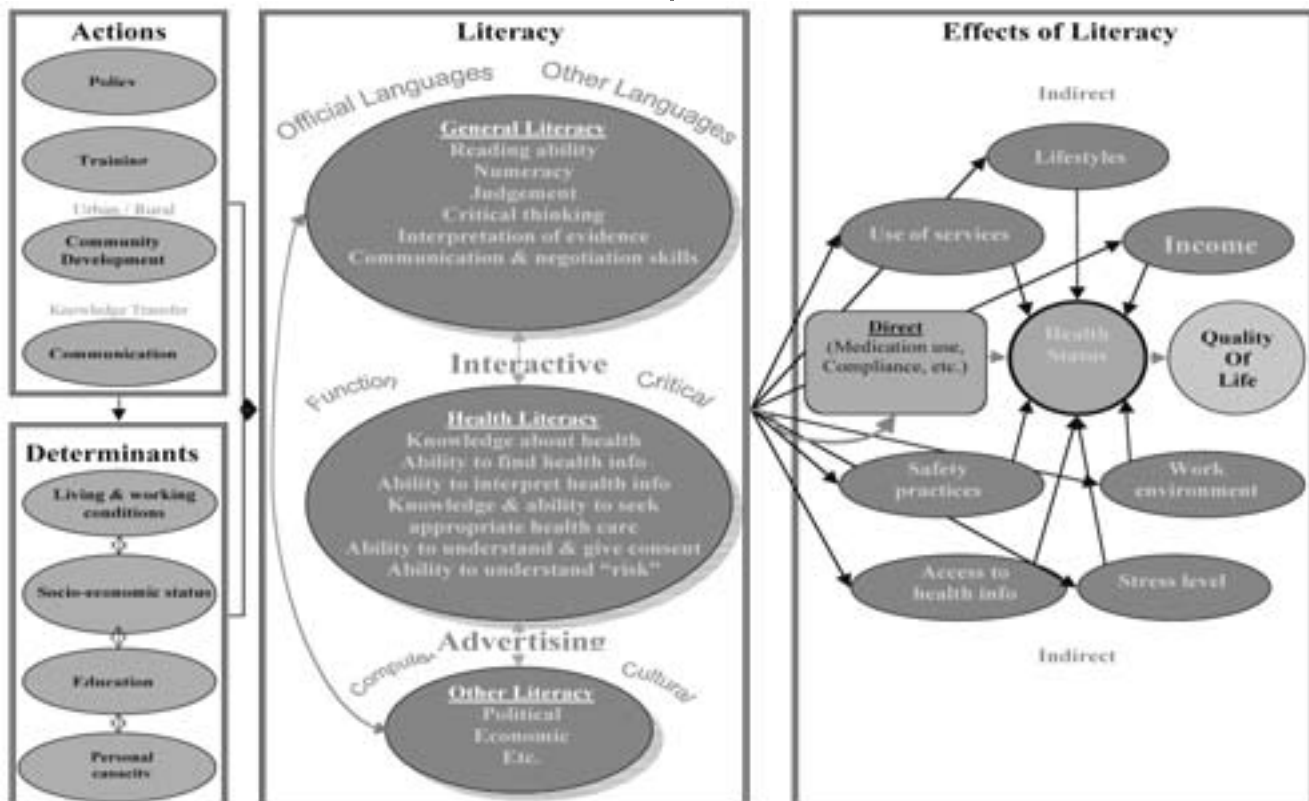
- Nova Scotia participants said that the determinants of health would be better represented within a circle with double-headed arrows connecting all determinants as they were viewed as being non-linear, complex, and all interconnected. Ottawa participants also suggested double arrows for determinants and effects since they are very similar. An alternative, they suggested, would be a circular arrow that loops back.
- Several groups suggested that values and motivation be represented. A Toronto participant explained: "Even if people understand messages, do they care?" In British Columbia, participants felt that the effect of literacy on social relationships and self-esteem was a missing element from the framework – stigma and low self-esteem were noted as contributing to difficulties in establishing and maintaining social relationships at several levels (e.g. family, personal, work). A Nova Scotia participant

also noted that "self-esteem" should be added to the indirect effects of literacy.

- Improved wording and clarification was suggested in a number of cases: e.g. the use of the word "education" instead of "training"; "knowledge transfer" along with "communication"; "advertising, cultural, media and computer" literacy along with economic and political literacy; a different word than "compliance" under direct effects – "Patterns of medication use" or "understanding of direction." Some suggested adding urban and rural categories, official language and other language categories, "advocacy" along with the other "actions". Another suggestion was to specify functional, interactive and critical levels of literacy as suggested by Don Nutbeam in his recent publication on health literacy.⁸

Several alternative models were produced by regional researchers based on these comments and this led to the following revised conceptual framework that was introduced at the National workshop for consideration:

Revised Conceptual Framework



⁸ Nutbeam, D. (2000) "Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century". *Health Promotion International*. 15(3), 183-184..

Building the Case:

Several informants noted a primary need for cost-benefit and economic impact analyses that would help build the case for work in the area of literacy and health. Respondents called for a better understanding of the impact of literacy on health, economics, poverty etc. It was important, several said, to tease out the relationship between such constructs and literacy in clearly defined terms – literacy level does not always correspond to years of education, the primary indicator traditionally used. Other kinds of research that can help build the case for literacy and health research and practice are to be found within much of the research that can also be categorized as "making a difference" – research on interventions that help improve health and literacy outcomes for "hard-to-reach" populations. Respondents suggested research that generated testimonials, case studies, and fact sheets that would be influential for policy-makers, practitioners and potential volunteers.

Making a Difference:

Most interventions have been undertaken by professionals within the health care sector, where the primary goal is to improve health; or by professionals in the education sector where the primary goal is to improve literacy and learning skills.⁹ A few literacy professionals have adopted combined goals, but health care providers, by and large, have remained focused on health outcomes. An exception may be public health nurses involved in family literacy programs related to healthy babies, healthy futures or best start programs.

Research on Improving Health Communications (and Literacy)

The following are some of the research areas recommended for improving health care providers' capacity to improve health, particularly among low literacy consumers:

1. Study the awareness of health care providers of the literacy issue and literacy services available in the community
2. Study physician and pharmacist communications
3. Study patterns of health care use and means of information gathering by people with low literacy
4. Study the degree of literacy sensitivity health care providers have in diverse settings
5. Study current print communications and the impact of PLAIN language and readability formula usage.
6. Study the impact of using alternatives to print media for health communications- video, tapes, phone recordings, oral communications, pictograms etc.
7. Study the relationship between computer "illiteracy", lack of access to computers and health.
8. Study the impact of health communications and drug advertizing on consumers – "media literacy".
9. Evaluate interventions designed to better reach low literacy health care consumers e.g. office literacy assessments, provision of two levels of information; teachback method; staff sensitivity training programs etc.
10. Study the efficiency of self-care in the current climate of expanding home care
11. Study the need for a national strategy on translation/interpretation services in the health sector and more broadly.

Research on Improving Literacy and Learning Skills (and Health)

Participants in the key informant studies and focus groups also told us that more research was needed on ways that literacy program providers and learners could help minimize the negative health impacts of low literacy and negative learning impacts of health problems.

⁹ Linda Shohet (2002) *Health and Literacy: Perspectives in 2002*. Retrieved on the World Wide Web, October 2002 at www.staff.vu.edu.au/alnarc/onlineforum/AL_Pap_shohet.htm.

For example there was a need to:

1. Study effective approaches to literacy instruction and efforts to incorporate health content and health literacy goals.
2. Evaluate literacy programs, adult basic education programs, family literacy programs etc.
3. Study the impact of the recent emphasis on literacy testing in Ontario schools and elsewhere.
4. Study early development, reading theory, family literacy and health impacts.
5. Study how people go beyond knowing to acting – "not just whether people read but how people learn."
6. Study gaps in supports for low literacy people for reproductive health, smoking cessation etc.
7. Study how medication, chronic disease etc. affect concentration for learning.
8. Study the use of computers for literacy (learning to read and write)
9. Study the use of computers for health literacy (use of the internet for seeking health information etc.)
10. Study participatory development of health information in literacy classes.
11. Study the impact of literacy on civic engagement, democracy and community health.

Need for a National Research Agenda on Literacy and Health?

Participants were asked whether there should be a national research agenda on literacy and health. Broadly, the answer was "yes", with the following advice and caveats:

- Develop guidelines for appropriate research
- Collaborate with researchers working in knowledge transfer, primary care reform, the national tobacco strategy and school reform
- Integrate learners in action research
- Collaborate with library associations, ethnocultural organizations and risk condition groups
- Do applied research

- Make findings accessible and applicable.
- Partner with Canadian Institute for Health Research (CIHR) and Canadian Health Services Research Foundation (CHSRF)
- Present the concept to the federal government in a way that it can help them build a national system for lifelong learning (as discussed in the Movement of Canadian Literacy's (MCL) National Literacy Action Agenda document¹⁰)
- Emphasize doing research in French as well as English and consider other groups as researchers as well
- Ground the research in making people's lives better, respecting people and involving them in agenda development

5.5 Barriers:

A number of barriers to research in literacy and health were identified by respondents. The most commonly mentioned was the funding and resource issue. People also noted the lack of clarity in terminology; the fragmentation of stakeholders and uncertainty regarding where this kind of research fits in traditional jurisdictions and departments; the lack of a common language and infrastructure across sectors; the lack of recognition for the need for this kind of research; the stigma issue and difficulty of population engagement; the difficulty of the research ethics review requirement; the unstable and inconsistent program availability; the emphasis on treatment over prevention; various countervailing political and corporate influences and agendas; the lack of experts and mentors in the field; the lack of grants administrators familiar with the field; the vast size and diversity of the country; and the overwhelming workload of many service providers in the field. A theme that came up repeatedly was the concern that funds for research would take precedent when inadequate funding was available for actual programming.

¹⁰ See www.literacy.ca "Creating a National Literacy Action Agenda" Fall, 2002, volume 5, No. 1.

5.6 Solutions and Opportunities:

In the focus groups held across the country, investigators presented a summary of barriers and opportunities identified in the key informant surveys. Participants were asked to comment on and add to our knowledge of barriers and opportunities for research in the area of literacy and health and suggest solutions to the barriers in our way. This is a summary of what we heard:

- Get partners and stakeholders in the same room
- Study the impact of institutional, organizational as well as individual change
- Influence policy makers
- Use research, case studies, stories, testimonials, fact sheets
- Ensure a cohesive effort
- Involve learners
- Advocate for a provincial as well as a national agenda in literacy and health research
- Tap into the good will of seniors and the enthusiasm of teenagers
- Adopt an agenda for the "3 L's": literacy and life long learning¹¹

They told us further to involve the following types of groups:

- Medical schools
- Licensing bodies
- Literacy guilds and associations
- Business
- Pharmaceutical companies and associations
- Media
- Seniors' groups
- Ethnocultural organizations
- Aboriginal groups
- Family literacy programs
- Departments of Education and Public Health
- Community and Independent Clinics and hospitals

They told us to involve the following specific groups:

- Queen Elizabeth Hospital II (currently no

- service provided)
- Population Health Research Unit, Dalhousie University
- ABC CANADA
- Canadian Public Health Association (CPHA)
- Canadian Institute for Health Research (CIHR) population health, aboriginal and gender institutes
- Social Sciences and Humanities Research Council (SSHRC) and National Literacy Secretariat (NLS)
- Canadian Health Services Research Foundation (CHSRF)
- Faculty of Pharmacy, University of Toronto¹²
- E-Health Innovation (University Health Network and University of Toronto)
- Plain Language Association International
- Ontario Institute for Studies in Education, University of Toronto (OISE/UT)
- National Aboriginal Design Committee
- Fédération canadienne pour l'alphabétisation en français¹³
- Frontier College
- Heart Health Organizations
- Heart and Stroke Foundation
- Improving Cardiovascular Outcomes in Nova Scotia (ICONS)
- Consumers Association of Canada
- Present the concept to the federal Knowledge Transfer Centre (Toronto)
- Atlantic Centre of Excellence for Women's health
- Atlantic Health Promotion Centre
- Home Care Evaluation and Research Centre, University of Toronto

More details about some of these opportunities are found in the regional reports by contributing investigators

¹¹ This term was coined by Peter Calamai at an address to Westnet 2000 conference, Calgary, Nov.2, 2000 (<http://www.nald.ca/fulltext/3ls/cover.htm>). Calamai previously wrote *Broken Words: Why Five million Canadians are Illiterate*, the influential 1987 Southam study of literacy in Canada. He also recently wrote a *Literacy Matters Report* based on a Round Table Discussion of leaders across the country sponsored by ABC Canada and others. The term has also been used by the Movement for Canadian Literacy in their Fall 2002 issue of *literacy.ca* where they discuss "Creating a National Literacy Action Agenda".

¹² A follow-up meeting in the Faculty of Pharmacy, University of Toronto to the Toronto focus group on literacy and health research was held in September, 2002.

¹³ According to the Quebec report, health and literacy is a strategic new initiative of this organization.

6. Conclusion:

Current sociological, technological and political trends have made literacy and health research a wise investment for Canadians. Some of the trends we are facing that make this kind of work so timely are that our ethnic and linguistic make-up is changing rapidly; the use of computers and new technologies is proliferating; there are greater "literacy" requirements today for functioning in our "knowledge economy"; there are unprecedented stresses on our health care and education systems; we have an aging population at the same time as there is a growing reliance on home and community care in place of institutional care; and Canadians are finding increasing opportunities and responsibility to provide healthcare information, support and education internationally as well as locally. Finally, we urgently need multi-sectoral collaboration to solve many kinds of problems including this one. The field of health promotion has a history of experience in partnership building, and literacy and health research can be a guiding light for the kind of work and methods that are needed.

It is clear from this study that research in literacy and health can help us spend our scarce health care dollars more efficiently. There are pockets of very promising work being done across the country, but huge gaps in between with very little knowledge of what is being done elsewhere and what works best. Research of this nature can help span the divides between traditional jurisdictions of work for improving the lives of Canadians and impact upon effective use of government spending in education as well as healthcare. We cannot afford to miss this opportunity for forging ahead in promising new directions for the health and well-being of Canadians.

Appendix A

Canadian Documents on Literacy and Health

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The Centre for Literacy of Quebec. *Health Literacy Project, Part 2*. Montreal: Centre for Literacy of Quebec.

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- National Literacy and Health Program; CPHA. *Easy Does It!*. Ottawa: CPHA.
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- National Literacy and Health Program; CPHA. *Plain Facts*. Ottawa: CPHA.
- National Literacy and Health Program; CPHA (1998) *Creating Plain Language Forms for Seniors*. Ottawa: CPHA.
- National Literacy and Health Program; CPHA (1999) *What the Health!*. Ottawa: CPHA.
- National Literacy and Health Program; CPHA (2001) *Mind Over Violence Everywhere M.O.V.E.* Ottawa: CPHA.
- National Literacy and Health Program; CPHA *Working with Low Literacy Seniors: Practical Strategies for Health Providers*. Ottawa: CPHA.
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A Better You: The Benefits of a Healthy Lifestyle (video written, filmed and edited by a group of adult literacy students in a 5 month video production course) Dartmouth Literacy Network.

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Canadian Congress of Learning Opportunities for Women CLOW (1994) *Telling Our Stories Our Way*. (Review by students and volunteers of literacy materials available for women.) 47 Main St. Toronto ON, M4E 2V9. 416-699-1909.

Centretown Community Health Centre & Sandy Hill Community Health Centre. *Plain Facts on Health* (22 plainly written pamphlets in English and French).

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National Council on Aging (NCOA) *Organizing a Literacy Program for Older Adults*.

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Appendix B

Literacy and Health Website Resources

Canadian

National Adult Literacy Database (131 abstracts match query "health and literacy")
<http://www.nald.ca>

National Literacy and Health Program
<http://www.nlhp.cpha.ca>

First Canadian Conference on Literacy and Health, "Charting the Course for Literacy and Health in the New Millennium" Ottawa.
http://www.nlhp.cpha.ca/conference/c_log_e.pdf

Second Canadian Conference on Literacy and Health, "Health and Literacy Action Conference" St. John's NFLD.
http://www.med.mun.ca/halatconf/Conf_report/home.htm

U.S./International

American Medical Association, Health Literacy.
<http://www.ama-assn.org/ama/pub/category/8115.html>

Center for Applied Linguistics (over 600 items found on health literacy query)
<http://www.cal.org>

Center for Health Care Strategies, Inc.
<http://www.chcs.org/resource/hl.html>

The Eastern LINCS Health and Literacy Special Collection
<http://www.worlded.org/us/health/lincs>

Harvard School of Public Health, Health Literacy Studies.
<http://www.hsph.harvard.edu/healthliteracy>

Health and Literacy Compendium: An annotated Bibliography of print and Web-based health materials for use with limited-literacy adults
http://www.worlded.org/us/health/docs/culture/materials/biblio_002.html

Health and Literacy Discussion List (facilitated by S.A.B.E.S.)
http://www.nifl.gov/lincs/discussions/nifl-health/health_literacy.html

Health and Literacy Links, UK
<http://www.tower.ac.uk/LiteracyLinks/HealthandLiteracyLinks.htm>

Health Literacy Consulting
<http://www.healthliteracy.com>

Healthy People 2010.
<http://www.health.gov/healthypeople/>

Health Promotion for Adult Literacy Students: An empowering approach (Instructional package on nine health topics)
http://www.nyadulced.org/insmat_e.htm

Institute for Healthcare Advancement (Held first annual health literacy conference last May)
<http://www.iha4health.org/>

Maine AHEC Health Literacy Center.
www.une.edu/com/orthrdep/hlit/index.htm

National Center for the Study of Adult Learning and Literacy (NCSALL)
<http://www.gse.harvard.edu/~ncsall/> (Its periodical publication *Focus on Basics* devoted its February 2002 issue to "Literacy and Health" found at
<http://www.gse.harvard.edu/fob/index.htm>)

National Health Council, Health Literacy Initiatives. http://www.nhcouncil.org/initiatives/health_literacy.htm

Pfizer Health Literacy
www.pfizer.com/hml/literacy/literacyfrm.html
(Has held an annual health literacy conference for past 5 yr.)

Pfizer Journal, Responding to the Challenge of Health Literacy.

www.thepfizerjournal.com/pdfs/TPJ04.pdf

SABES Health Page (System for Adult Basic Education Support, Massachusetts)

<http://www.sabes.org/health/index.htm>

U.S. Department of Education – Health Education for Adults "Health Literacy" information

<http://www.ed.gov/offices/OVAE/AdultEd/health1.html>

Appendix C

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