

2005 NATIONAL SUMMER INSTITUTE

Working Together on Literacy and Health Research

FINAL REPORT

July 25 – 28, 2005

Plaza 500 Hotel
500 West 12th Avenue
Vancouver BC
Canada

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**2005 National Summer Institute
Working Together on Literacy and Health Research
Vancouver, July 25-28, 2005**

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1. Background

The idea to bring together people working in literacy and health research across Canada arose in a meeting of investigators working on a project sponsored by the Social Sciences and Humanities Research Council and the National Literacy Secretariat. The objectives of this project were to: (1) stimulate research on adult literacy and health in Canada; (2) contribute to the development of research capacity in Canada on this topic; (3) encourage and assist cooperation between researchers and literacy and health practitioners; (4) improve the dissemination and application of research findings in this field; (5) encourage the training of future researchers in literacy and health; (6) stimulate collaboration among researchers from different disciplines; and (7) stimulate research that will influence policy development in literacy and health. It was agreed that a National Summer Institute on “Working Together on Literacy and Health Research” would contribute to the achievement of all of these objectives.

To this end, an Institute planning committee was convened, chaired by Dr. Irving Rootman, and consisted of two graduate students (Gail Hammond, Rose Vukovic), a post-doctoral fellow (Marina Niks), two academic faculty (Dr. Irving Rootman, Dr. Jim Frankish), and a practitioner (Sandy Middleton). Invitations were extended to various constituents across Canada and in total 17 graduate students, 10 academic faculty, 15 practitioners, and 5 representatives from funding agencies participated in the Institute. Funds were made available to cover travel and accommodation costs for all graduate students, practitioners and faculty. Both monetary and in-kind funding for the Institute was obtained from the Social Sciences and Humanities Research Council, National Literacy Secretariat, the Michael Smith Foundation for Health Research, the Canadian Council on Learning, the Canadian Institutes for Health Research – Institute of Gender and Health – Partners for Community Health Research, and Literacy BC. Local hosts for the Institute were the: CIHR/Michael Smith Foundation for Health Research Partnering in Community Health Research Strategic Training Program at the University of British Columbia; the Institute of Health Promotion Research at the University of British Columbia; the Centre for Community Health Promotion Research at the University of Victoria; the Public Health Association of British Columbia; and Literacy BC.

2. Purpose

The purpose of the Summer Institute was “to build research partnerships and create an environment for increasing capacity for conducting community-based participatory research projects focused on literacy and health issues in distinct communities and regions across Canada.” The Institute was intended to set the groundwork for a series of regional workshops to take place across Canada in the next two to three years.

3. Objectives

The objectives were:

1. To provide an opportunity for Canadian graduate students and practitioners to increase their knowledge and skills in working together on literacy and health research
2. To develop ideas for proposals for research on literacy and health
3. To develop linkages between faculty, students and practitioners interested in literacy and health research in Canada
4. To develop a network of researchers, graduate students and practitioners interested in literacy and health research in Canada

4. Agenda

The Summer Institute was held over four days including one full day for the British Columbia Workshop on Literacy and Health Research and Practice. The agenda was designed using both large and small group formats to accommodate a sharing of theories that support partnership research, success stories and challenges encountered in conducting partnership research, insights into writing proposals to achieve funding success for partnership research, and ideas for moving forward with an action plan for literacy and health research partnership initiatives across Canada. The themes for each day are provided here. The full program is found in Appendix 1.

Day 1 *Integrating Theory and Practice: Growing from Experiences*

Day 2 *Accessing Resources: Negotiating Expectations*

Day 3 *Provincial (B.C.) Workshop on Literacy and Health Research and Practice*

Day 4 *Looking Forward: Shaping the Future of Partnering in Literacy and Health Research in Canada*

5. Program Presentations

Dr. Irving Rootman, Professor and Michael Smith Foundation for Health Research Distinguished Scholar of the University of Victoria, and Chair of the Institute, welcomed participants, presented the objectives of the Institute, reviewed the program, and provided an overview of literacy and health research in Canada.

Three theoretical perspectives relevant to partnership research were presented following Dr. Rootman's overview:

Dr. Lawrence Green of the University of California presented the topic of Participatory Action Research,

Dr. Marcia Hills of the University of Victoria presented the topic of Cooperative Inquiry and,

Dr. Jim Frankish of the University of British Columbia presented the topic of Empowerment Evaluation.

Unique to this Institute was the panel of representatives from a variety of funding agencies ranging from community-centred and regionally-focused to national agencies. On Day 2 of the Institute, the invited funders presented a brief of funding opportunities within their respective agencies.

6. The Case Studies

Case studies were an integral component of the Institute activities. All participants were invited to submit a case study of community-partnered, literacy and health-focused research that they were presently engaged in, would be engaged in, or recently had been engaged in. Guidelines for presenting the case study were provided (see Appendix 2). Diversity was a strength among the 12 case studies submitted. Case studies ranged from projects that were conceptual in nature to those in which communities were taking action on an initiative.

Due to the number of case studies submitted, the Planning Committee organized the case studies into 2 groups – one group for presentation and discussion on Day 1 and the other group for presentation and discussion on Day 2.

7. Organization of the Small Group Discussions

Each person who provided a case study presented a 5-10 minute overview of their work to the large group on their respective days. Participants self-selected small group sessions to participate in each day. Each small group had a

maximum of 10 participants to facilitate opportunities for each group member to fully participate in the discussions.

On Day 1, five small group sessions were formed based on the issues presented in five case studies. Within each small group there was the case study author, and a pre-assigned facilitator (a member of the planning committee) and a recorder. The group selected a reporter whose role was to share key points from the discussion with the large group when it reconvened. This structure encouraged all participants to engage in and learn from the key discussion points. Using a framework of looking at the issues and the lessons/strategies/solutions before, during and after the research project, the objective of the small group was to use the case study as a catalyst for a broader discussion and sharing of the lessons learned with each project.

	Before	During	After
Issues			
Lessons/Strategies/Solutions			

The goal was to gain insight into potential or real challenges and solutions in conducting partnership research in literacy and health.

On the afternoon of Day 2, the large group broke out into five issue-based groups that included discussion of 7 case studies. Somewhat similar to the Day 1 small group structure, within each small group there was the case study author and a pre-assigned facilitator (a graduate student). The group selected a recorder and a reporter whose role was to share key points from the discussion with the large group when it reconvened. Using the same framework as was used for Day 1 discussions, issues and lessons/strategies/solutions before, during and after the research project were discussed. All participants were able to engage in and learn from the key discussion points. As with Day 1 small groups, the objective of the small group discussion was to use the case study as a catalyst for a broader discussion and sharing of the lessons learned from each project, and the goal was to gain insight into potential or real challenges and solutions in conducting partnership research in literacy and health.

Later in the afternoon of Day 2, following the small group discussions of the seven case studies, participants organized themselves into small groups representing their home geographic region. Five regional groups were formed:

1. Atlantic
2. Quebec
3. Ontario and Nunavut
4. Manitoba, Saskatchewan and Northwest Territories
5. British Columbia, Alberta and the Yukon Territory

Similar to the Day 1 small group structure, within each small group there was a pre-assigned facilitator (an academic faculty member). The group selected a recorder and reporter. A SWOT (Strengths, Weaknesses, Opportunities, Threats) framework of analysis was used to guide the regional discussions. The objective was to identify where regional strengths and opportunities existed for conducting literacy and health research in each region, and to discuss and/or draft potential alliances or projects for each region. Due to time constraints at the end of Day 2, reporting back to the large group was rolled over into the Day 4 activities.

On Day 4, the large group broke out into the following four regional groups: (1) Atlantic, (2) Quebec, (3) Ontario and Nunavut, (4) the Prairies, British Columbia and the Northwest and Yukon Territories. Group 4 was a combination of Groups 3 and 4 from Day 2 regional small group discussions. There was a pre-assigned facilitator within each small group and the remaining roles of recorder and reporter were decided among the members of each group. Building on use of the SWOT (Strengths, Weaknesses, Opportunities, Threats) framework of analysis that guided the regional discussions on Day 2, there were multiple goals for Day 4 discussions, including: (1) taking a scan of past, current and planned initiatives in each region, (2) identifying gaps and opportunities for literacy and health research in each region, (3) developing alliances and a stronger network of people interested in literacy and health research in each region, (4) generating ideas for potential proposals for submission to funding competitions, and (5) initiating discussion for setting an agenda for conducting partnership research in literacy and health in each region of the country.

Following the regional small group discussions, each region shared highlights from their SWOT analysis and ideas from setting a regional agenda for partnership research in literacy and health.

Highlights from the small group discussions that occurred throughout the Institute have been summarized starting on pages 12, 15 and 17. The highlights from the Provincial Workshop held on Day 3 of the Institute are available at <http://hp.uvic.ca>.

8. Program Content

DAY 1

INTEGRATING THEORY AND PRACTICE: GROWING FROM EXPERIENCES

OVERVIEW OF LITERACY AND HEALTH RESEARCH

Irving Rootman

Dr. Rootman of the University of Victoria and Chair of the Institute provided an overview of literacy and health research in Canada (available at http://www.nlhp.cpha.ca/clhrp/index_e.htm).

Literacy and health research involves systematic attempts to answer questions related to literacy and health using appropriate methods. Dr. Rootman reviewed definitions of literacy pointing out that the definitions acknowledge that literacy is not simply a technical matter, but has to do with the interaction of people with the society in which they live. Similarly, there are a variety of definitions of health but Dr. Rootman offered a widely used one: *“a state of complete, physical and social well-being and not merely the absence of disease and infirmity”* (WHO, 1947). He defined health literacy as *“the ability to access, understand, appraise and communicate information to engage with the demands of health contexts to promote health across the life-course”* (see Key Reference #1).

Dr. Rootman also described various literacy and health research projects in Canada and key topics of research these projects cover:

- Size and distribution of problem
- Contribution of early childhood development to language and literacy
- Role of technology in health literacy
- Public perceptions and experiences related to literacy and health
- Literacy in health care
- Youth health literacy
- Literacy among people with chronic diseases
- Literacy and health in Aboriginal communities
- Measurement of health literacy in different population groups
- Media and e-health literacy
- Evaluation of initiatives
- Building capacity

Dr. Rootman concluded his presentation by reminding participants of the four priorities that had been suggested by the National Workshop on Literacy and Health Research in October 2002.

- ⊙ Evaluating interventions
- ⊙ Conducting cost-benefit analyses
- ⊙ Studying the impact of literacy and life-long learning on health
- ⊙ Studying literacy and health within Aboriginal and Francophone communities and culturally diverse and challenged groups

He pointed out some overlaps but also highlighted that there are not many evaluated initiatives or studies with aboriginal and francophone groups, and no cost-benefit studies or projects that look at the impact of literacy on health over

the life cycle. He also acknowledged that very few of the projects are participatory, an aspect which was called for at the Second National Conference on Literacy and Health (see <http://www.cpha.ca/literacyandhealth/about.html>). He proposed to come back to the four priorities at the end of the Summer Institute and see how they can be useful in setting up an agenda for the future.

THEORY IN PARTNERSHIP RESEARCH

The Institute then focused on the implications for theory and practice of working together in non-traditional ways. Presentations by Lawrence Green, Marcia Hills, and Jim Frankish described three different types of partnership research and its rewards and challenges. The presentations precipitated discussion among participants about the disconnects between policy and practice, if and how external validity is achieved in this type of research, negotiating research questions and processes with communities, the impact of culture on participatory processes, and the role of the researcher as an advocate for political change.

PARTICIPATORY RESEARCH: TOWARD A SCIENCE OF TRANSLATING SCIENCE FOR HEALTH LITERACY

Lawrence Green

Dr. Green started his presentation (available at http://www.nlhp.cpha.ca/clhrp/index_e.htm) by reviewing the work that has been done since the publication of the report on Participatory Research in Health Promotion in Canada (see Key References #2 and #3). Regrettably, he acknowledged, the report seems to have been lost in the bureaucracy of Health Canada but several agencies in the United States were interested and used it.

Although translational research typically refers to getting the information from the research to practice through evidence-based practice, Dr. Green proposed that what we need is more practice-based evidence. That is, research based in the principles of practice, clients, patients, populations, etc. Traditionally research has been controlled by academia. There is now a need to move the control from the academy to practice in support of local goals, engaging the ultimate beneficiaries in identifying and providing solutions to the problems, and conducting the research in the context of their realities.

Participatory research includes three components: (1) systematic investigation, (2) active involvement of people in the co-learning process, and, (3) the purpose of the research is action that is conducive to health. Dr. Green emphasized that this notion is very different from using practitioners and community members as cheap labour. It requires that researchers include different ways of knowing.

Dr. Green enumerated the benefits of using a participatory approach in literacy and health research:

- Results are relevant to interests, circumstances, and the needs of those who would apply them
- Results are more immediately actionable in local situations for people and/or practitioners
- Generalizable findings that are more credible to people, practitioners and policy makers elsewhere because they were generated in partnership with people like themselves
- Helps to reframe issues from literacy of individuals to encompass system and structural issues.

What is needed, argued Dr. Green, is closing the gaps between the public and scientists' perception of needs, and planners' assessments and providing appropriate funding for these projects.

COOPERATIVE INQUIRY

Marcia Hills

Dr. Hills began her presentation (available at http://www.nlhp.cpha.ca/clhrp/index_e.htm) by asking the participants to think critically about what 'collaboration' means and how it can be an integral component of research practices. She then addressed three common assumptions that underlie Cooperative Inquiry (CI) (see Key Reference #4): (1) persons are self-determining, (2) there are four types of knowledge (experiential, presentational, propositional, and practical), and (3) there is a need for critical subjectivity. She compared three types of research: orthodox, social science and community-based research across the following parameters: paradigm, views of participants and researchers, values, focus, purpose and view of the research. Dr. Hills emphasized that a key to utilizing CI successfully is to be a great facilitator.

In community-based CI research, co-researchers become co-subjects and cycle through a planning phase, an action phase, and a reflective and making meaning phase. Emancipatory, transformative and power negotiation processes occur as part of practicing CI. For knowledge to develop, there is a need for critical dialogue using critical listening, critical thinking and critical questioning skills. She described knowledge as a transformation of consciousness. The importance of reflection on practice, in practice and as a dialectical perspective was presented. Dr. Hills then raised the topic of praxis and described it as not unlike a dance between theory and practice wherein each inform the other. Practicing reflexivity helps to facilitate the cycling of action moving into reflection and reflection into action. She then provided a few examples of CI and concluded her presentation with the following quote (see Key Reference #5):

It is possible to inquire systematically and rigorously into a complex field of human action, and to do justice to its wholeness without distorting or fragmenting it; it is possible to co-opt busy practitioners

into committed inquiry into their own professional and personal processes; it is possible for co-researchers to descend into the confusion that is real life without the protective clothing of questionnaires, experimental designs, and other forms of defensive armour and to emerge with worthwhile understandings.

EMPOWERMENT EVALUATION

Jim Frankish

Dr. Frankish initially provided an historical perspective to the emergence of Empowerment Evaluation (EE) and a discussion of reasons for engaging the stakeholders in research. His presentation is available at http://www.nlhp.cpha.ca/clhrp/index_e.htm. Dr. David Fetterman, an expert in evaluation research, has defined EE as the use of evaluation concepts, techniques, and findings to foster improvement and self-determination, and has further described EE in this quote (see Key Reference #6):

“EE has a deep respect for people’s capacity to create knowledge about, and solutions to, their own experiences. EE builds program capacity and fosters program improvement. It teaches people to help themselves by learning how to evaluate their own programs. The basic steps of empowerment evaluation include: (1) establishing a mission or unifying purpose for a group or program; (2) taking stock - creating a baseline to measure future growth and improvement; and (3) planning for the future - establishing goals and strategies to achieve goals, as well as credible evidence to monitor change. The role of the evaluator is that of coach or facilitator in an empowerment evaluation, since the group is in charge of the evaluation itself.”

Dr. Frankish highlighted the multiple facets of EE that include appropriate training, effective facilitation, advocacy, illumination and liberation of the participants, and provided a more detailed set of steps for conducting EE than those presented in the above quote. Although many large and small scale projects have used EE, there are several cautionary points that must be addressed when using EE: EE doesn’t abolish traditional evaluation, there may be challenges regarding ‘objectivity’, the participants may be biased, and EE may be ‘contaminated’ by positions of power and privilege. Dr. Frankish followed these cautionary notes with commonly purported advantages and limitations to using EE. He ended his presentation with a look at the possible implications of using EE and ideas that will support a broader success of EE.

PRACTICE IN PARTNERSHIP RESEARCH

THE CASE STUDIES – ISSUE-BASED SMALL GROUP SESSIONS

Five small group sessions were formed on Day 1 based on the following issues in five of the 12 submitted case studies:

1. Working with a community health board in a participatory action project titled, The Health Literacy in Rural Nova Scotia Research Project, to explore links between literacy and health in rural Nova Scotia
Presenters: Doris Gillis and Sheila Sears
2. Working within a health care delivery system to determine the health information needs of patients
Presenter: Linda Shoheit
3. Working within the school system to evaluate a new model for electronic health promotion to adolescents
Presenter: Cameron Norman
4. Working to prevent illiteracy during early childhood among low socioeconomic populations
Presenter: Pascal LeFebvre
5. Working together within a participatory action framework to provide community development opportunities for diverse First Nations bands located in a geographic region to work together to enhance aboriginal literacy and health through a smoking cessation program
Presenter: Marlene Atleo

The “before, during and after” table structure provided for recording the challenges and lessons learned while participating in partnership research was in itself challenging for some small groups to complete. Different projects were at different stages of development thus the challenges of projects and the lessons learned could not be neatly assigned to one cell or another in the table. Often times, issues arise at the beginning of a project and continue throughout, and, consequently, the ways of dealing with these issues change throughout the life of a project.

Key issues identified by the groups included:

Long-term commitment

Partnering with community is a long-term commitment. Some projects may take years to develop. Funding and academic requirements may not accommodate the long timelines.

Benefits, buy in, and rewards

Partnerships should consider what each group is getting out of their participation. The groups need to clarify who is working and how, and why so that all expectations are considered.

Non-traditional research skills

Partnership research requires that researchers play different roles. In addition to the traditional research skills, researchers have to be facilitators, coordinators, and advocates. These roles have to be acknowledged and training needs to be built into the projects.

Relationships

Small groups emphasized the importance of building relationships with partners. These relationships should be ones of trust and mutual respect.

Communication

Communication research in this context is not restricted to writing articles. Researchers have to keep the lines of communication open and make sure they are communicating with different groups about the progress of the project. Phone, email, face-to-face meetings are some of the suggested ways of communicating. Plain language and reader friendly materials have to be used.

DAY 2

ACCESSING RESOURCES: NEGOTIATING EXPECTATIONS

Day 2 of the Institute focused on funding opportunities, how to access them and what can be expected from a variety of funding agencies. Unique to this Institute was a panel of representatives from a variety of funding agencies that ranged from community-centred and regional to national agencies. The day also provided detailed information on how to develop a proposal for funding.

Discussion among participants pointed to the disparities and inequities that exist in the funding process. For example, some parts of the country have greater access to resources than others. In addition, some funding streams remain “community unfriendly”, and new investigators still face barriers to getting funded.

FUNDERS PANEL

On Day 2 of the Institute, funders presented a brief of the opportunities for funding within each represented agency.

- ☉ **Canadian Institutes of Health Research**, Miriam Stewart (presentation available at http://www.nlhp.cpha.ca/clhrp/index_e.htm)
- ☉ **Canadian Council on Learning**, Charles Ungerleider (presentation available at http://www.nlhp.cpha.ca/clhrp/index_e.htm)
- ☉ **Vancouver Foundation**, Eva Cheung Robinson
- ☉ **Literacy Now**, Brenda LeClair

PRESENTATION

WRITING SUCCESSFUL LITERACY AND HEALTH GRANTS

Jim Frankish

Dr. Frankish (presentation available at http://www.nlhp.cpha.ca/clhrp/index_e.htm) used comic strips and metaphors to describe how to write successful research grants. He recommended keeping in mind that reviewers will typically read a large number of highly competitive applications. He noted that the amount of money available for research has increased but so too have the number of applications, resulting in a very competitive process. The proposal should be articulately written so that reviewers understand what the research is about, how it is going to be done and why it is important to do this research.

Specific suggestions put forward by Dr. Frankish included:

- Familiarize yourself with the requirements of the funders
- Pay attention to the presentation of the proposal, specifically the layout of the text. For example, refrain from using font sizes that are too small or from cramming too much text into a small space.
- Set out a clear road map for the reviewers. There should be a flow of ideas from the opening line of your proposal.
- Place the most important and compelling material at the beginning of your proposal
- Tell the reviewers what you are going to say, say it clearly and then tell them what you said
- Integrate the different sections so that the proposal is a coherent whole – ensure each section fits and all the sections fit together.
- Tell a story that includes a “hook” and “deliverables”
- Be realistic about your objectives and don’t over-promise
- Keep your budget reasonable – don’t skimp or inflate the budget
- Demonstrate enthusiasm, interest, and commitment – be relevant but not ambivalent
- Once you have written a draft of your proposal, ask a colleague to read through it to see if it clearly makes sense. If you are affiliated with a university, the office of research services at some universities offer an internal review process.

- If your proposal is not funded, don't get discouraged, take all the feedback provided, hone your proposal and resubmit it

Dr. Frankish also had suggestions about the process of applying and addressed that rejection is inevitable and to keep applying. Finally, Dr. Frankish called for proposal writers to become involved in the process and to advocate for the kinds and methods and world views you value and believe in.

The second part of Dr. Frankish's presentation was a review of specific funding agencies' funding programs and selection criteria with an emphasis on CIHR and SSHRC.

PRACTICE IN PARTNERSHIP RESEARCH

THE CASE STUDIES – ISSUE-BASED SMALL GROUP SESSIONS

In the afternoon of Day 2, the large group broke out into five issue-based small groups that included discussions of 7 case studies. Two groups had two case studies to discuss (vs. one case study for the other groups). The issues presented and discussed were:

1. Working with a local community service provider to understand the nature, distribution and causes of occupational injury and the delicate relationship between the service provider, employers and injured fish harvest workers in Newfoundland
Presenter: Sophia Shaikh
2. Working together to form a health and literacy sub-committee as part of a larger regional wellness centre and to set goals for the group
Presenter: Jennifer Thornhill
3. Working with a web-based national health network to provide strategic advice to leaders at the network who were interested in making their work more accessible to Canadians of various literacy abilities
Presenter: Barbara Ronson
4. Working together in developing an equal, respectful partnering arrangement among researchers and a Dene community to develop a strategy aimed at decreasing the existing literacy and language challenges and improving the well being of the community to prevent illiteracy in early childhood among low socioeconomic populations
Presenters: Lewis Williams and Georgina Jolibois
5. Working with community groups, the RCMP, the Nunavut education system and others to disseminate media aimed at youth on making healthy choices in their relationships, especially intimate ones
Presenter: Gabrielle Stanton
6. Working with health care professionals in the health care setting to provide appropriate training on dissemination of health information to patients with specific health conditions

Presenter: Margot Kaszap

7. Working together to form a partnership with a provincial literacy advocacy organization, a professional association, two community-based organizations, and various higher education institutions to develop research capacity in the adult literacy field in British Columbia
Presenters: Marina Niks and Sandy Middleton

Due to time constraints, the challenges some groups had with completing the “before, during and after” table on Day 1, and because different projects were at different stages of development and action, the groups today focused on discussing their experiences with partnership research, and not recording their discussions. However, it is likely that issues similar to those highlighted on Day 1 (see page 12) would be consistent with the issues identified with the case studies discussed on Day 2.

Taking Stock of Regional Projects and Identifying Opportunities for Future Literacy and Health Research Projects

Later in the afternoon of Day 2, the participants convened in one of five small groups that represented their home geographic region:

- ☉ Atlantic
- ☉ Quebec
- ☉ Ontario and Nunavut
- ☉ Manitoba, Saskatchewan and Northwest Territories
- ☉ British Columbia, Alberta and the Yukon Territory

The groups used a SWOT (Strengths, Weaknesses, Opportunities, Threats) framework of analysis to guide the regional discussions. Representatives from each sub-region were present with the exception of people from the Yukon and Northwest Territories. The objective was for each group to identify where its regional strengths, opportunities, weaknesses and threats existed for moving forward with conducting literacy and health research.

DAY 3

PROVINCIAL (B.C.) WORKSHOP ON LITERACY AND HEALTH RESEARCH AND PRACTICE

The objectives of the Provincial Workshop (see Program in Appendix 1) were met through:

- Presentations on research and policy initiatives in BC by members of two panels,
- Roundtable discussions of issues identified by the participants, and
- Oral reports from each roundtable

The roundtable groups were broken out into issues in literacy and health research that had been identified by the participants on their registration forms for the workshop. The focus of the morning roundtable discussions was to identify gaps in current knowledge regarding the issues, to prioritize addressing these gaps and explain why these gaps are priorities, and to report highlights of the discussion back to the large group. The afternoon roundtable discussions focused on developing a work plan on how to address the previously identified and prioritized gaps, who needs to be involved, and what resources are required, followed by a report back to the large group of the most important point the group had discussed with regards to making progress with literacy and health research in Canada. A full report of the Provincial Workshop is posted at <http://hp.uvic.ca>.

DAY 4

LOOKING FORWARD: SHAPING THE FUTURE OF PARTNERING IN LITERACY AND HEALTH RESEARCH IN CANADA

Day 4 started with open floor reflections on the previous three days of the Institute followed by formation of four regional groups to continue the discussions held in the afternoon of Day 2. Today, the West and Prairies groups from Day 2 combined to form one regional “West” group to discuss research priorities for this region. The aim of these regional groups was to initiate discussion of potential alliances, strategic directions, research priorities, and if time allowed, a potential research plan for literacy and health initiatives in each region. Following the discussions, there were reports of the highlights from each regional group to the large group. Due to time limitations on Day 2, the SWOT reports were combined with the research priority reports from the regional groups when reported back to the large group.

SUMMARIES OF THE REGIONAL SWOT AND RESEARCH PRIORITIES REPORTS

ATLANTIC

Research Priorities in Atlantic Canada

- building alliances between adult literacy, health and literacy educators; connect with Atlantic Health Promotion Research Centre. How do we work with this group?
- building capacity for research in the area – need to connect people, identify researchers, mentoring researchers – research dialogues between health and literacy. Face-to-face, \$ bring people together – need to tap Nova Scotia Health Research Foundation and other concrete funding sources

- building on existing projects among the provinces that focuses on Health Care providers. Example: Atlantic Primary Health Care – Building a Better Tomorrow
- critical health literacy approach to public health
- chronic illness management

Strengths

- there is a history of different sectors closely working together in a collegial manner (e.g. literacy groups working at a grassroots level, health authorities and cross-provincial Ministers of Health working collaboratively (esp. around regional funding issues), and local media who like to cover health and literacy issues)
- there are low expectations which allows for risk taking
- successful model used by Doris Gillis and Sheila Sears

Weaknesses

- many ongoing small projects
- trouble with finding time and resources for people working in the field
- an out-migration of expertise from the Atlantic region
- a hierarchy of needs – food on the table is more of a priority
- Aboriginal and bilingual populations are often neglected
- a conservative culture that is not too welcoming to outsiders
- a large split between rural and urban universities
- practitioners are stressed in rural communities
- poor health outcomes and not a culture of health promotion

Opportunities

- there is a sense of community; a passion; a geographic commitment; a history of and continued desire for collaboration
- there are discussions going on at this table at this Institute
- there are funding opportunities
 - Nova Scotia Health Research Foundation provides an excellent opportunity for funding research
 - NIH Health Literacy has 5 years of funding for L&H research
 - Atlantic Health Promotion Research Centre brings in dollars
- to build capacity in the Atlantic region to explore a research agenda
- to do a needs assessment and an environmental scan
- to do collaborative research with community learning groups

Threats

- literacy and health is often thought of as a rural issue, but it is also an urban issue in Atlantic Canada
- older populations are challenged with accessing/using information technologies
- changes to senior political/healthcare leadership
- rural universities challenged by funding

QUEBEC

Research Priorities in Quebec

- establish a French network of partners for conducting Literacy and Health (L&H) research in Quebec and other francophone communities outside Québec; start by widening out each of our own existing networks and connecting with key people in associated organizations (e.g. Frontier College, CPHA, Centre for Family Literacy, research group Espace, health professionals, etc.)
- raise awareness of L&H research needs in the francophone community (e.g. letters, website (could use Literacy Centre of Québec website), conferences, use Québec broadcasting Code d'accès)
- clarify terminology
- centre research on the family and community (too much emphasis is placed on the individual) and on L&H needs across the lifespan
- health communication is a problem
- evaluation of initiatives is needed
- need for research into immigrant understanding of health, illness, prevention, treatment
- need to determine the cultural competence of healthcare providers to communicate effectively with different cultural groups

Strengths

- there are family literacy projects ongoing
- there is literacy and health research in promotion of health care and prevention of disease
- a Centre for Linguistic Minorities at Moncton University
- there is a researcher in Montreal who works with immigrants

Weaknesses

- there is lack of a common vocabulary, make research language more simple
- few researchers in adult and elderly health literacy
- French research is not widely read especially in the Anglophone community

Opportunities

- to raise awareness of French-based research to the Anglophone community
- create a French Canadian network of researchers in L&H
- develop a French repertoire of L&H research in Canada

Threats

- none reported

ONTARIO & NUNAVUT

Research Priorities in Ontario and Nunavut

1. Health literacy and men's health
 - need to determine how men understand health
2. Health as a determinant of literacy
 - access to services, use network to start a "curriculum" in PLAIN language, for example on diabetes
 - use literacy workers as health educators
 - determine what are the health issues among adult learners – or just ask instructors what issues come up
 - health and learning knowledge centres are interested in learning outcomes
 - work already exists on the impact of learning on health but we also need to study the impact of health on learning
 - quick fixes are readily available but adults often lack really good mental health services
 - York and Western conceived of a website to post medical information and research
 - we could try to replicate Marcia Howe's health action teams in Canada
3. Translate health information into PLAIN language – identify points of misunderstanding
 - does this information fit with my beliefs?
 - Cochrane collaboration has consumer focused information – is trying to publish for consumers its systematic reviews of subject areas
4. Professional education
 - doctors coming into Nunavut need to be educated – a lot of new ones are coming all the time, some for 1 month stints
 - many patients may be unilingual and need translators
 - health care providers can't assume patients don't know - nurse not willing to share information
 - train health care providers through exercises, simulations – demystify ideas, reduce speaking in complex way of social position
5. Youth health literacy
 - focus of urban health group at the University of Toronto's Centre for Health Promotion
 - link with Literacy BC
6. Remote communities
 - Grand Chief Nishawbe Aske in NW Ontario has requested help for a fly-in community with an epidemic of low literacy, ill health and suicide

- Janet Smilie had a research project on Golden Lake with youth – youth conducted research themselves and said they wanted a centre
- patients often don't know what kind of questions to ask doctors, have to learn to ask questions
- need more cross-cultural research rather than focusing on a specific population
- must not ghettoize Aboriginal issues

7. Young children –

- age from “sex to six”
- a lot already exists for this age range, not as much for adults and seniors

Specific Resources:

- RiPAL (Research in Practice in Adult Literacy)
- Janet Smilies – University of Saskatchewan (Metes)
- Roma Harris – Western
- McMaster – literacy and seniors
- Alpha Plus in Toronto
- Centre for eHealth – Alex Jadad, Harvey Skinner
- Nancy Jackson, OISE
- Nunavut arctic college of nursing, community learning centre
- Maureen Doherty
- Bernice Downey – NAHO
- Territorial literacy coalition
- Ontario Literacy Coalition (English, French, Native, Deaf)
- Quillit – Nunavut Status of Women Council
- Eileen Antone – OISE/UT
- University of Toronto health literacy work in French (Margot Kaszap and Margareth Zanchetta on advisory committee)

Strengths

- presence of CPHA – proximity to Ontario – national perspective (not as many local projects yet)
- good academic centres – could be source of momentum, provide conduit, pipeline and bridge to other parts of the country; numerous universities involved with Literacy and Health research
- research group already established at Centre for Health Promotion (CHP) in Toronto – urban health research group has identified research in the area of literacy, health and youth as a priority
- Harvey Skinner's group, Centre for eHealth, can be a resource
- CLEARNet group – a national group, mostly on East side of central Canada – said they were interested in literacy and health but hasn't done much yet, focus on childhood development work
- OHPE bulletin is a strong resource
- Roma Harris is a psychologist interested in how people get health information

- University of Waterloo has an Ontario Cancer Prevention network with a research program based on literacy tied to cancer
- Rick Glazier, a physician at U of T, is looking at health literacy
- Yves Talbot at U of T with the International Society of Social Inequities
- some libraries are interested in health literacy (e.g. Kitchener Public Library)
- Eileen Antone at OISE/UT is working in the area of Aboriginal literacy and health
- work in the area of literacy and seniors in Waterloo
- Peri Ballantyne at U of T Faculty of Pharmacy is working in the area of literacy and seniors and ethnic groups

Weaknesses

- we need to put Nunavut in perspective of what we are trying to do – create a better relation between research and practice
- often information gets translated but not culturally translated – there is a lack of understanding of cultural dimensions of literacy
- health care professionals are trained in WASP system, Western tradition – believe in empirical approach, physicians have “esoteric” belief system
- very little information is available in syllabics
- many grade 8 students are still reading at the K-3 level in Nunavut – they come to kindergarten with a deficit, some hardly speaking and can hardly lift a pen, many with low skills speak Inuktituk at home
- of 100 who start in grade 8 only about 30 graduate from grade 12; kids drop out because they can’t read and are bored because they can’t participate
- most immigrants have never heard about prevention – many have experienced “dodging bullets”
- Canada does not discuss quality of care and safety as much as the US, partly through the work of the Institute of Medicine

Opportunities in Nunavut

- broadband has been brought to Nunavut
- Kim Crocket is a strong presence on the Nunavut Literacy Council
- a broadening of knowledge needs to occur – university people need to go to learn, not just do research
- children get grounding in mother tongue up to grade seven, they often have a TV at home and have opportunities to use English when shopping

Opportunities in Ontario

- to establish a network to move to the next level
- Lieutenant Governor James Bartleman established 5 literacy summer camps in remote Aboriginal communities this summer
- Judy King is going into literacy classrooms in Ottawa schools
- Health Matters, Health Fairs

Barriers/Threats

- lack of advocacy, public awareness through TV ads, media

- a lot of time is taken up debating definitions of health promotion rather than doing it
- more funding is available through drug companies for empirical research – less for participatory action research, empowerment evaluation etc.
- high turnover of doctors and shortage of nurses in Nunavut

PRAIRIES (SK, MB)

Research Priorities in the Prairies

See notes under Research Priorities in the West. On Day 4, the Prairies and West regional groups combined to form one “West” regional group

Strengths/Opportunities

- intersectoral partnerships (i.e. “Kids First”, Lifelong learning; CBOs such as Child Hunger Education Program)
- regionally there are some cross cultural literacy programs such as Adult Learning Centres that have the potential to promote literacy and health
- regional organizations are strong (i.e. SK Literacy Network; Aboriginal Literacy Network)
- Regional Intersectoral Coordination in Saskatchewan – promote the development of partnerships amongst the sectors of health, learning, education
- the political party that is in power can serve to be an opportunity for literacy and health promotion
- tap into federal monies through avenues such as: 1) the Agricultural programs i.e. mental health literacy is connected to rural health; 2) provision of health programming/services in French
- influx of immigrant populations creates an opportunity for health literacy services, particularly through non profits such as Open Door Society
- existing resources that can be galvanized for research and practice are: Manitoba Educational research networks; religious sects; various educators such as nutritionists, home ec. teachers
- utilize “piggybacking” i.e. link health in the workplace, specifically focus on ensuring that HRDC (Human Resources Development Canada) is aware of health and literacy linkages

Challenges/Weaknesses

- demographics
 - small populations that are very spread out
 - regional disparities
 - burgeoning First Nations population
- fiscal restraints
 - lack of resources for programming/practice

- lack of financial support to NGOs in literacy (i.e. the SK Aboriginal Literacy Network)
- educational sector
 - ~there is a lack of Aboriginal educators who possess an understanding and knowledge about colonization and its detrimental affects on literacy/language of Aboriginal people
 - lack of cross cultural education
 - jurisdictional issues (federal/provincial/municipal) surface about literacy in the Aboriginal sector (i.e. whose problem is literacy on or off reserve, etc.)
- need for improved information sharing, particularly in primary health care
- discontinuity (in discourse) between community perspectives and government structures

WEST (BC, AB)

Research Priorities in the West

The Research Priorities notes summarize the discussion from a combined group of both the Prairies and the West regional groups.

- strategically link literacy and health research to community economic development (e.g. link with the business sector in a mutually meaningful way), and to quality of life, healthy communities, and a civil society – people need to be able to participate in meaningful ways in their communities
- build on strengths, current work including using the Learning Community model (as in Hazelton, La Loche), existing networks, asset mapping, etc.
- sub-population research: this research needs to be done separately with diverse communities using common indicators and methodology across communities, First Nations, etc. keeping human ecology and diversity in mind

The following SWOT report summarizes the discussion of the “West “only regional group (i.e. not combined with the Prairies regional group).

Strengths

- well-established initiatives exist (e.g. English Express Reader newsletter published by the Learning Centre Literacy Association in Edmonton, and the Centre for Family Literacy in Edmonton)
- provincial and regional literacy networks already exist (Literacy BC, Columbia Basin Literacy Network)
- Literacy Now undertaking initiatives that are linked with the 2010 Olympics

Weaknesses

- there is lack of evaluation of ongoing literacy and health interventions – what level of evaluation is required (i.e. how in depth does it need to be?)
- lack of process evaluation

-street newspapers could be an opportunity to meet cultural literacy and health (L&H) needs

Opportunities

- Canadian Council on Learning – Health and Learning Knowledge Centre is a potential opportunity
- working with the Health Authorities where there is an interest in L&H
- connecting people: get a rep from Vancouver Foundation together with a rep from the Alberta Heritage Foundation to fund a community project
- making links with the business sector between literacy and economic development (example: ICBC, Insurance Corporation of British Columbia)
- address linking literacy with the social economy (e.g. Communities First)
- there are opportunities connected with the Learning Communities
- research into L&H issues in the immigrant and refugee communities (example: highly trained professionals who arrive in Canada and don't speak the dominant language very well)
- advocating for revitalization of the Premier's Panel
- connecting with the business sector/corporations (acknowledged caution needs to be addressed) to sponsor L&H events (e.g. Peter Gzowski Golf Tournament and the Vancouver Sun Raise a Reader campaigns for family literacy)
- churches may be a place to partner with community people

Threats

- evaluation could be perceived as an opportunity or a threat

9. Wrapping Up the Summer Institute

During the latter part of the morning on Day 4, Jim Frankish led a discussion on pulling together cross-cutting themes that arose during the Institute with a particular emphasis on overcoming barriers to working together in literacy and health research in Canada. Irv Rootman opened the floor to a discussion on the next steps for literacy and health research in Canada and closed the Institute by thanking everyone for their participation and commitment to literacy and health research in Canada and thanked the funders for their support in conducting literacy and health research in Canada.

HOW TO OVERCOME BARRIERS TO WORKING TOGETHER

Jim Frankish

Dr. Frankish facilitated a session on cross-cutting themes arising from the Institute. The focus on working together across geographic boundaries was appreciated. Thinking generously was also identified as a prominent theme throughout the Institute. And, finally, in contrast to what one participant identified

as a focus on health literacy and patient compliance in Europe, the positioning of literacy and health from different social and cultural perspectives was identified as a cross-cutting theme of this Institute.

WHERE TO GO FROM HERE

Irving Rootman

Dr. Rootman presented an overview of the proposal that was submitted to the National Literacy Secretariat by a team of researchers and practitioners from across Canada. The objectives of the proposed project are to:

- ◆ build capacity for literacy and health research among practitioners, students and researchers in Canada
- ◆ stimulate research on literacy and health in Canada, and
- ◆ synthesize and disseminate knowledge and tools regarding literacy and health in Canada in both official languages.

These objectives will be achieved by:

1. Establishing a national and regional research teams
2. Establishing a national and regional advisory committees
3. Hiring national and regional coordinators
4. Conducting regional environmental scans and needs assessments
5. Organizing national and regional workshops and summer institutes
6. Developing national projects
7. Submitting research, project and infrastructure proposals to various funding agencies
8. Developing research clusters within regions
9. Developing national and regional web-sites
10. Organizing the research component of a national conference

If funded, this project will provide a concrete way to build on the accomplishments of the Summer Institute by following up on the discussions of the regional groups that was started at the Institute. He noted that immediately following the Institute there will be a discussion with a representative of the National Literacy Secretariat regarding revisions to the proposal that were suggested by the review committee.

Dr. Rootman also noted that following the Institute the planning committee will debrief and will discuss the implications of the report for further action. When completed, the report will be submitted to the organizations that supported the Institute and to all attendees. It will also be made available on the National Literacy and Health Research Program website (http://www.nlhp.cpha.ca/clhrp/index_e.htm) along with presentations from the Institute.

In the discussion that followed, numerous ideas were suggested. It was noted that it is possible that there will be a Third National Conference on Literacy and Health in 2008. Judy King suggested that it would be a good idea to develop a List-serve for graduate students interested in literacy and health to receive and give help with developing proposals. Barbara Ronson also offered to help in editing proposals in English and Margot Kaszap in French. Margareth Zanchetta suggested that we don't need a 'how to' discussion on proposals, rather we need to form small groups of researchers to work on new projects and proposals to combine ideas. She also suggested that we need to develop conceptual knowledge as to how to address new issues. Jim Frankish expressed the view that we need to build capacity in the universities. There is no definition of 'enough.' Many universities have internal review processes that will help you with your proposals. We have to consider our career and the needs of the community. Nancy Cooper suggested that we need to look at things both ways. She also indicated that she appreciated the opportunity to come to the Institute and acknowledged the work that Irv and others are doing on mentoring. She also expressed her concern for aboriginal issues becoming ghettoized. Finally, Linda Shohet expressed the view that, "We need to pay attention to the "with," to respect. We also need to understand that health and literacy need to be distinguished. Hang on to the human piece."

Other thoughts that were suggested on the next steps and future research emerging from the Institute, included:

- the potential for researchers to work together to create proposals and possibly regional groups could assist in this
- a need to work more collaboratively and for national information sharing in order to inform researchers of work that has been completed and the findings. This would help individual researchers to decide on projects that are best for their community.
- an ongoing concern about Aboriginal issues and research conducted with Aboriginal communities. "Aboriginal still gets lost even when on the agenda". It had been mentioned earlier that 'Aboriginal peoples have been researched to death' but it was noted by one person that "that was only one way [of research] and that there is still space for research in Aboriginal communities but that it needs to come from within", and that it is hard to collaborate when there is currently only one Aboriginal Centre for Learning.
- acknowledgment that conducting community research is under pressure, for example, researching homelessness with a community that states it needs housing and better education, not research. One researcher responded that there is money designated for such research. It should be used and the research should be done respectfully. In response, other participants stated the hope that "the research goes into outcomes" and that "this group of researchers [at the Institute] has the greatest focus on respect and 'with' in their research and hope everyone holds onto this".

- the need to increase equity in health, recognizing that the present costs are disproportionate
- a need for an analysis of the costs of research to the state [and that the costs at the personal level are high]
- the usefulness of conducting a cost-benefit analysis on the social side of social capital
- that moving forward after the institute includes a need to address language barriers, for example, that French speakers are usually expected to read research in English but that the opposite does not appear true
- it would be very useful “to survey the National and BC workshop participants about their language skills, [to create a list of other non-official languages that researchers across the country speak] because it would be an important resource to work with ethno-cultural groups
- there are “benefits of the [Institute] group starting from the ground up”

In concluding the Institute, Dr. Rootman thanked the planning committee, the sponsors and the participants and wished everyone who was traveling a safe trip home.

10. Key References

1. Literacy and Health Overview. Available at: http://www.nlhp.cpha.ca/clhrp/index_e.htm
2. Participatory Research Projects in Health. Available at: www.lgreen.net/guidelines.html
3. Green L, George M, Daniel M, Frankish J, Herbert C, Bowie W, O’Neill M. *The study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada*. Ottawa: The Royal Society of Canada, 1995.
4. Reason, P and Heron J. A Short Guide to Cooperative Inquiry, 2001. Available at: http://www.cpct.co.uk/cpct/CiP_anniversary/Co-operative.htm
5. Reason P. The Co-operative Inquiry Group, *Human Inquiry in Action: Developments in New Paradigm Research*. London: Sage Publications, 1988.
6. Empowerment Evaluation. Available at: <http://www.stanford.edu/~davidf/empowermentevaluation.html>

11. Summer Institute Evaluation Summary

This evaluation summary presents the findings of the evaluation questionnaire, comments from the large group discussions and some emails and forms sent after the event¹. The questionnaire was structured to collect quantitative and

¹ The majority of Institute participants also attended the Provincial Workshop on Literacy and Health Research and Practice which was evaluated separately and is not included in this summary.

qualitative feedback. The 24 questionnaire respondents who completed the form identified a range of affiliations:

- six Researcher/Academics
- six Graduate Students
- four Practitioners
- three Graduate Student/Practitioners
- three did not state their affiliation
- one Researcher/Practitioner
- one Graduate Student/Researcher/Academic

Participants were asked to rate the ‘usefulness’ of each of the presentations, the case studies and regional group discussions based on a scale of 1-4 (1: not useful; 4: very useful)². Averages are listed below³:

Participatory Action Research:	3.5
Cooperative Inquiry:	3.11
Empowerment Evaluation:	3.17
Case Studies:	3.5
Funders Panel:	3.31
Developing Proposals for Funding:	3.63
Regional Small Groups:	3.57
Synthesis Discussion:	3.5
<u>Where to Go from Here:</u>	<u>3.53</u>
Overall Average:	3.42

It should be noted that the overall average rating was 3.42 out of a maximum of 4.0 and that none of the average ratings for any presentation or session was less than 3.11. This suggests a very high level of satisfaction with the “usefulness” of the workshop as a whole and its components parts among those who responded to the questionnaire. In addition, comments on the presentations and small groups were mostly positive and included suggestions:

1. *Participatory Action Research*: “a bit abstract”, “outstanding conceptual”.
2. *Cooperative Inquiry*: “lacked groundedness”, “had more enthusiasm than information”, “was dismissive of the Aboriginal communities stories”, “need to be aware of us/them division in language” used, and “not critical enough”.
3. *Empowerment Evaluation*: ‘new’, “the challenges of EE made this difficult to present”, “appreciate the common threads among approaches rather than focus on one method or approach” and “a good critique [but] did not like the reading”.
4. *Funders Panel*: “excellent”, “a good mix”, “addressed how to apply”, “gave an understanding of CIHR and CCL structures”, “they needed to stay so

² There was no difference in the ‘usefulness’ rates overall based on affiliation.

³ The Welcome and Overview of Literacy and Health Research in Canada presentations were not included in the evaluation.

- we could talk to them” because the majority of funders left after their presentation.
5. *Developing Proposals for Funding*: “very practical” “funny”.
 6. *Synthesis*: “this was hard given the diversity of feedback”; “possibly too tired”; and “not much synthesis—but there seemed to be continuous synthesis”.
 7. *Where to go from here*: “nice and concrete”
 8. *Case Studies*: “a bit repetitive”, “too similar in presentation and discussion”, “the discussion and feedback were invaluable” and “offered some new ways of thinking about some central questions”.
 9. *Regional Groups*: “great idea”, “very useful”, “disorganized”, a “good start”, and “extremely important opportunity to establish new relations”.

Most Useful Aspect(s) of the Institute

All twenty-four people who completed the evaluation survey wrote comments in this section; most wrote more than one aspect was useful at the Summer Institute.

- networking and meeting people (14 respondents)
- sharing ideas, especially nationally and learning from others and the work they are doing across the country (13)
- small groups (4)
- the broad definition of literacy and health; diversity of perspectives and contexts in the breadth of literacy and health research across the country (3)
- the trend toward inclusive, participatory action research; the critical thinking about the role of research in creating change (3)
- the national representation and learning about challenges and opportunities across the country (2)
- regional groups (2)
- appreciating information about funding
- the people in attendance: “quality, diversity and generosity of the participants” and the “thoughtful people who come from different milieus but share a common interest and passion” (2)
- “the Institute was well conceptualized on the whole with parts fitting in”

Knowledge/Skills/ Tools Gained from the Institute that People are Most Likely to Apply

Twenty-two of the twenty-four respondents answered this question. Four areas came through quite strongly followed by other aspects:

- the importance of the meeting of the regional groups and how that will impact participants’ future work
- the benefit of the information gained about funding sources and requirements, proposals and Jim Frankish’s session specifically on tips for successful proposals

- the importance of gaining information about ideas, issues, current projects, networking and understanding current capacity in literacy and health research
- benefits of thinking critically, PAR and social justice research work, and acknowledgement of Larry Green in particular for spurring on new ways of thinking about issues
- “work to include literacy and health into day-to-day projects and make links to allied concepts such as inclusion, crime prevention and population health”
- “understanding current research priorities”
- looking to create partnerships and the importance of collaborating
- “thinking generously—allows us to find a place to plug into the agenda”
- “just watching how you made this a successful Institute”
- feeling “better equipped to analyse the role [they] desire as a researcher”.

Other Comments

- mention of the great work of the planning committee, and ‘thank you’ (10)
- the institute was excellent as it was (3) and one wrote that it “exceeded expectations”
- “it was a pleasure to attend” and “overall an enriching exciting experience”, “excellent opportunity to connect with other researchers, develop shared projects and collaborative links”, “a wonderful event which has inspired and energized me” and “the most generous, collaborative event I have ever participated in”.
- four people acknowledged and thanked Irving Rootman and others for their role in mentoring those just entering the field, and for the opportunity to attend.

Recommendations for a Future Summer Institute

1. Small Group Work

There were a lot of comments on the small groups; some wanted more, some less, some desired better structure but as the rating and comments above also demonstrated, these groups were very useful to most people. Two people felt the case studies were too long and it was difficult to stay engaged, two wanted more case studies and small group work, one mentioned the need to keep a broader perspective during the case study discussions (beyond the case), and one thought more description of the steps each researcher took should be included. One person felt that more participants should have had an opportunity to share the kinds of work they are involved in. Two comments mentioned the need to have better time and task management of small groups. The regional groups, not necessarily separated from case study groups, were also seen as invaluable.

2. Additions to Future Institutes

- to include more discussion on potential research directions for graduate students
- add discussion around transitions and overlap between students and practitioners
- to have more of a literacy and ECE (early childhood education) focus
- to have more breaks (including time to get to know participants better)
- add a spiritual component
- include more discussion about the rationale for using PAR
- add arts-based research to the mix
- to have presenters remove all acronyms
- to send readings out ahead of time (perhaps to all inform people that attachments would be coming because they were sent out ahead of time but someone may have missed them)
- to show more links between research and practice, and, practice and research
- to establish ground rules around respect for the discussion groups: one person commented that they noticed sexist, homophobic, classist and racist behaviour from some participants; another person wrote that the Institute as a whole should be 'ism' free and that academic researcher dominance in small groups be addressed by the Institute
- to provide training for facilitators and recorders in future workshops and to establish a mechanism to ensure that small groups kept on task, that facilitators and group members are respectful and inclusive of everyone and that graduate student recorders are supported in their role and in their learning.

Key Strategic Directions for Literacy and Health Research

Two participants provided the following written suggestions for future research:

- conducting "Aboriginal health literacy promotion in Aboriginal communities by the community"
- Aboriginal health and literacy
- examining "health literacy as part of cultural competency by health and education professionals (non-Aboriginals)"
- a need for "public education in health literacy" in order to make it a household word
- "linking literacy and health to CED [community economic development]" which was also discussed in the western regional group
- "quality of life and healthy communities" research, "asset mapping" and "sub-population diversity research"
- "school health promotion and literacy" because "this international model will offer highly strategic learning"
- "literacy and lifelong learning" because "our country is really ready and poised to look at schools and learning this way"
- "evaluating interventions", "opportunities for participatory action research, crossing divides, etc."

The majority of Institute participants also attended the Provincial Workshop on Literacy and Health Research and Practice which was held on a separate day in the same week as the Institute. An evaluation of the Provincial Workshop was conducted separately and is not included in this summary. A full report of the Provincial Workshop, including the evaluation, is posted at <http://hp.uvic.ca>.

12. Appendices

APPENDIX 1 SUMMER INSTITUTE PROGRAM

2005 NATIONAL SUMMER INSTITUTE

**Working Together on Literacy and
Health Research**

&

**Provincial (B.C.) Workshop on Literacy
and Health Research and Practice**

Program

July 25 – 28, 2005

Plaza 500 Hotel
500 West 12th Avenue
Vancouver BC

Local Hosts

Partnering in Community Health Research Strategic Training Program, University
of British Columbia

Institute of Health Promotion Research, University of British Columbia
Centre for Community Health Promotion Research, University of Victoria
Public Health Association of British Columbia
Literacy BC

2005 NATIONAL SUMMER INSTITUTE

“WORKING TOGETHER ON LITERACY AND HEALTH RESEARCH”

PLANNING COMMITTEE

Irv Rootman (chair)	Professor and Michael Smith Foundation for Health Research Distinguished Scholar, University of Victoria
Jim Frankish	Director – Partnering in Community Health Research Strategic Training Program; Associate Director – Institute of Health Promotion Research; Associate Professor, University of British Columbia
Gail Hammond	PhD Candidate, Human Nutrition; Academic Learner, Partnering in Community Health Research, University of British Columbia
Sandy Middleton	Projects Manager, Literacy BC; Research Friend in Research in Practice in Adult Literacy–BC
Marina Niks	Post Doctoral Research Fellow, Partnering in Community Health Research; Research Friend in Research in Practice in Adult Literacy–BC
Rose Vukovic	PhD Candidate, Educational Psychology; Academic Learner, Partnering in Community Health Research, University of British Columbia

The Planning Committee would like to gratefully acknowledge Melody Monro for her administrative support.

SPONSORS

- ☉ Social Sciences and Humanities Research Council – National Literacy Secretariat
- ☉ Michael Smith Foundation for Health Research
- ☉ Canadian Council on Learning
- ☉ Canadian Institutes for Health Research – Institute of Gender and Health, Partners for Community Health Research
- ☉ Literacy BC

2005 National Summer Institute

Objectives

1. To provide an opportunity for Canadian graduate students and practitioners to increase their knowledge and skills in working together on literacy and health research
2. To develop ideas for proposals for research on literacy and health
3. To develop linkages between faculty, students and practitioners interested in literacy and health research In Canada
4. To develop a network of researchers, graduate students and practitioners interested in literacy and health research in Canada

**.....
INTEGRATING THEORY AND PRACTICE: GROWING FROM EXPERIENCES
.....**

- 8:00 – 8:30 REGISTRATION and CONTINENTAL BREAKFAST
- 8:30 – 9:45 **WELCOME**
 📍 Irv Rootman, Professor and Michael Smith Foundation for
 Health Research Distinguished Scholar, University of Victoria
- OVERVIEW OF LITERACY & HEALTH RESEARCH IN CANADA**
 📍 Irv Rootman
- APPROACHES TO PARTNERSHIP RESEARCH**
 📍 Lawrence Green, Participatory Action Research
- 9:45 – 10:00 BREAK
- 10:00 – 11:00 **APPROACHES TO PARTNERSHIP RESEARCH (cont'd)**
 📍 Marcia Hills, Cooperative Inquiry
 📍 Jim Frankish, Empowerment Evaluation
- 11:00 – 12:00 **OVERVIEW OF CASE STUDIES**
 📍 Doris Gillis
 📍 Linda Shohet
 📍 Pascale Lefebvre
 📍 Cameron Norman
 📍 Marlene Atleo
- 12:00 – 1:00 LUNCH
- 1:00 – 2:30 **CASE STUDIES – ISSUE-BASED SMALL GROUP SESSIONS**
- 2:30 – 3:00 BREAK
- 3:00 – 4:30 **REPORT BACK FROM SMALL GROUPS**
LOOKING BACK, LOOKING FORWARD – DAY 1
 📍 Rose Vukovic, facilitator
- Evening **INFORMAL EVENT**

.....
ACCESSING RESOURCES: NEGOTIATING EXPECTATIONS

- 8:00 – 8:30 CONTINENTAL BREAKFAST
- 8:30 – 8:45 **REFLECTIONS ON DAY 1**
 @ Marina Niks, facilitator
- 8:45 – 10:30 **FUNDERS PANEL**
 @ Miriam Stewart, Canadian Institutes of Health Research
 @ Brenda LeClair, Literacy Now
 @ Eva Chung Robinson, Vancouver Foundation
 @ Charles Ungerleider, Canadian Council on Learning
 (moderator: Irv Rootman)
- 10:30 – 10:45 BREAK
- 10:45 – 11:30 **DEVELOPING PROPOSALS FOR FUNDING**
 @ Jim Frankish, Institute of Health Promotion Research, University of British Columbia
- 11:30 – 12:00 **OVERVIEW OF CASE STUDIES**
 @ Lewis Williams and Georgina Jolibois
 @ Sophia Shaihk
 @ Jennifer Thornhill
- 12:00 – 1:00 LUNCH
- 1:00 – 1:45 **OVERVIEW OF CASE STUDIES (cont'd)**
 @ Gabrielle Stanton
 @ Barbara Ronson
 @ Margot Kaszap
 @ Marina Niks and Sandy Middleton
- 1:45 – 2:45 **CASE STUDIES – ISSUE-BASED SMALL GROUP SESSIONS**
- 2:45 – 3:00 BREAK
- 3:00 – 4:30 **REGIONAL SMALL GROUP SESSIONS**
 @ Atlantic
 @ Quebec
 @ Ontario and Nunavut
 @ Prairies
 @ BC
 -use a SWOT approach to scan regional initiatives in partnership research in L&H across Canada
- 4:30 – 5:30 **FACILITATOR BRIEFING**

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**PROVINCIAL (B.C.) WORKSHOP ON LITERACY AND HEALTH RESEARCH
 AND PRACTICE**

Workshop Objectives:

- To share information on current research and practice in the field of literacy and health in British Columbia
- To discuss the findings of a provincial environmental scan and needs assessment regarding research on literacy and health
- To determine gaps and needs for research on literacy and health in British Columbia
- To develop an action plan to address these
- To provide an opportunity for networking and learning among key interests

Program:

- 8:00 – 9:00 REGISTRATION, CONTINENTAL BREAKFAST and TALK
- 9:00 – 9:15 **WELCOME**
- ☉ Irv Rootman, Professor and Michael Smith Foundation for Health Research Distinguished Scholar, University of Victoria
 - ☉ Lillian Bayne, facilitator Workshop Objectives and Plan
 - ☉ Irv Rootman, Conceptual Issues: Literacy vs. Health Literacy
- 9:15 – 9:30 **OPENING REMARKS (TBD)**
- 9:30 – 10:00 **ENVIRONMENTAL SCAN AND NEEDS ASSESSMENT**
- ☉ Irv Rootman and Gord Miller, Ph.D. Candidate, University of Victoria
- 10:00 – 10:15 BREAK
- 10:15 – 11:30 **PANEL 1 – RESEARCH AND POLICY INITIATIVES IN B.C.**
- Early Childhood Development and Literacy (Hillel Goelman, Associate Director, *Human Early Learning Partnership (HELP)*)
 - Family Literacy Programs and Health (Margaret MacDonald, Assistant Professor Faculty of Education, Simon Fraser University)
 - Health Literacy in Schools (Marjorie MacDonald, Acting Director, Nursing, University of Victoria)
 - Improving Public Access to Health Information: Evaluation of the B.C. HealthGuide Program (Jeanne Legare, Project Coordinator, B.C. Health Guide Program Evaluation)
 - Technology and Health Literacy (Ellen Balka, Professor, School of Communication, Simon Fraser University)
 - The Role of the Provincial Library Initiative in Promoting Literacy and Health (Michael Shoop)

- 11:30 – 12:30 **SMALL GROUP DISCUSSION #1**
- 12:30 – 1:15 LUNCH BREAK
- 1:15 – 2:45 **PANEL 2 – RESEARCH AND POLICY INITIATIVES IN B.C.**
- Literacy and Health in Different Ethno-cultural Communities (Iraj Poureslami, President, Canadian Multi-cultural Health Promotion Association)
 - Health Literacy and the Disabled (Shelley Hourston, Director, Wellness & Disability Program/AIDS & Disability Action Program/ B.C. Health Literacy Network)
 - Seniors and Health Literacy (Jim Frankish, Associate Professor, UBC)
 - Literacy and Health in the Aboriginal Community (Madeline Dion Stout. Former member of the National Forum on Health and FPT Advisory Committee on Population Health and Health Security-To be confirmed)
 - Mental Health Literacy (Peter Coleridge, Senior Advisor, Mental Health and Addiction, Provincial Health Services Authority)
- 2:45 – 3:00 BREAK
- 3:00 – 4:00 **SMALL GROUP DISCUSSION #2**
- 4:00 – 4:30 **REPORT OUT**
- 4:30 – 5:00 **SUMMARY AND NEXT STEPS**
@ Irv Rootman

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**LOOKING FORWARD: SHAPING THE FUTURE OF PARTNERING IN
LITERACY AND HEALTH RESEARCH IN CANADA**
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- 8:00 – 8:30 FULL BREAKFAST
- 8:30 – 8:45 **REFLECTIONS ON DAYS 2 and 3**
 @ Gail Hammond, facilitator
- 8:45 – 9:45 **REGIONAL SMALL GROUP SESSIONS**
 -working toward setting regional agendas for partnership research in
 L&H across Canada
- 9:45 – 10:30 **REPORT BACK FROM REGIONAL SMALL GROUPS**
- 10:30 – 10:45 BREAK
- 10:45 – 11:30 **SYNTHESIS DISCUSSION: HOW TO OVERCOME BARRIERS TO
WORKING TOGETHER**
 @ Jim Frankish, facilitator
DISCUSSION: WHERE TO GO FROM HERE
 @ Irv Rootman, facilitator
- 11:30 – 11:55 **EVALUATION OF 2005 NATIONAL SUMMER INSTITUTE**
- 11:55 – 12:00 **CLOSING REMARKS**
 @ Irv Rootman
- 12:00 **END OF INSTITUTE**
- 1:00 – 2:30 **MEETING OF THE NATIONAL TEAM**

APPENDIX 2 GUIDELINES FOR SUBMISSION OF CASE STUDIES

“Working with Communities on Literacy & Health Research” Case Study Framework

To facilitate discussion of literacy and health-focused case studies at the 2005 Summer Institute, we are forwarding some guidance for the structure and content of the case studies. We suggest a 2-3 page limit for describing your case study.

It will be useful to all participants to use subheadings when describing your case study. The following are suggested:

Context of the Case Study

- provide a “big picture” view as well as specifics about the case such as describing characteristics of the clientele and location of the research
- provide background reasons for the community partnership with academia
- provide a brief description of key negotiations that led to the research partnership

Purpose of the Partnership

- briefly describe why the research partnership is warranted

Goals(s) of the Research

- what is intended to be achieved by conducting research in partnership with the community organization

Approach of the Research

- if known, describe the approach you want to take or have taken to conduct this research project

Challenges of the Research

- identify potential or existing challenges to conducting the research

Case Study

- describe a specific situation that arose during the partnership that illustrates a challenge in working with communities to conduct literacy and health research
- this situation will be discussed in detail by the working groups in order to become familiar with issues involved in working with communities on literacy and health research

Lessons Learned

- identify some lessons learned on working with communities on literacy and health research