

A Productive Conversation

Summary of Invitational Workshop

April 26-27, 2006 Ottawa, Ontario

Hosted by Institute of Health Services and Policy Research

in collaboration with

Canadian Health Services Research Foundation
Health Charities Coalition of Canada
Heart and Stroke Foundation of Canada
Nova Scotia Health Research Foundation
Safe Kids Canada

A Productive Conversation April 26-27, 2006 Ottawa

Purpose

As part of its efforts to explore and build stronger links with voluntary health organizations (VHOs),¹ the CIHR Institute of Health Services and Policy Research (IHSPR) hosted this event, in collaboration with the Canadian Health Services Research Foundation, the Health Charities Coalition of Canada, the Heart and Stroke Foundation of Canada, the Nova Scotia Health Research Foundation and Safe Kids Canada. Its purpose was to bring together leaders of voluntary health organizations, researchers in health services and policy research, and representatives of health research funding organizations to:

- To explore the current engagement and concerns of voluntary health organizations in the *Listening for Direction II* priority areas.
- To build researcher and research organizations' understanding of the work of the voluntary health organizations in health services, policy development and health system decision-making, and the contribution they can make to the research process (e.g. pointing to topics that require research, engaging in research processes, exchanging knowledge in both directions, implementing research results and sharing funding).
- To build voluntary health organization understanding of health services and policy research and the contribution it can make to their organizational programming and priority-setting.
- To explore successes for the best practices they demonstrate and work at describing and reducing barriers to future collaboration.

The workshop was facilitated by Suzanne Lawson, former National Executive Director of the ALS Society of Canada and a member of the IHSPR Institute Advisory Board.

Summary of Discussions

Day 1 - April 26, 2006: Reception and Dinner

The workshop began with a reception and dinner on the evening of April 26th. Morris Barer, Scientific Director, IHSPR, reviewed the workshop objectives and hoped-for-outcomes (see Appendix A), welcomed the participants (see Appendix B) and thanked the partners for their contributions to the event. Following the dinner, Suzanne Lawson, the workshop facilitator, engaged Morris Barer and Jonathan Lomas in a conversation that aimed to provide the attendees with information about the roles of their respective organizations, the importance of evidence-informed decision making and the *Listening for Direction (LfD)* process and outcomes (see: http://www.cihr-irsc.gc.ca/e/20461.html). A brief interactive session followed, at which time several attendees requested clarification pertaining to the definition of health services and policy research (HSPR)² and how it might align with the mandates of their VHOs.

¹ Voluntary health organizations are organizations registered as charities or non-profits, run by a volunteer board of directors, often supported by individual, corporate or public donations, whose mission is to focus on some aspect of health (definition provided by Suzanne Lawson).

² IHSPR's mandate encompasses its definition of health services and policy research (HSPR): IHSPR is dedicated to supporting outstanding research, capacity-building and knowledge translation initiatives designed

Day 2 - April 27, 2006

Special announcement

Immediately following lunch on April 27th, Morris Barer announced and introduced IHSPR's incoming Scientific Director (SD), Dr Colleen Flood³ (as part of the regular cycle of CIHR Institute transitions, Dr Barer's term as IHSPR's inaugural SD will end 31 August 2006 and Dr Flood's term as new SD will begin). Dr Flood then addressed the participants and expressed her strong interest in and commitment to building on current, and forging new, collaborative relationships with VHOs and other health research organizations (e.g. provincial health research foundations). The press release announcing her appointment can be found at http://www.cihr-irsc.gc.ca/e/31051.html.

Panel of voluntary sector leaders

A panel comprised of representatives from three VHOs, Judi Farrell (Lupus Canada), Gavin Turley (The Kidney Foundation of Canada) and Sally Brown (Heart and Stroke Foundation of Canada) provided highlights of their respective organizations and interest/investment in HSPR. All three organizations have had significant interaction and partnerships with CIHR, but none to date in the area of HSPR. Highlights of their presentations and the subsequent discussion included the importance of developing and implementing a health research strategy for their organizations, the important benefits that collaboration brings to their organizations and constituents, and issues related to governance and decision-making within their organizations.

Example of a linkage between VHOs and health services and policy researchers: A case study from a VHO

Allyson Hewitt, Executive Director, Safe Kids Canada, and health researchers Colin Macarthur, Bloorview MacMillan Children's Centre, and Parminder Raina, McMaster University Evidence Based Practice Centre, presented a case study focused on their successful collaboration, *Injury Prevention Across the Lifespan (IPALS*). Their presentation highlighted how a VHO and health researchers can effectively collaborate to use research evidence to catalyze program, policy and practice change to prevent injury in children.

Panel of researchers

Sean Rourke, Scientific and Executive Director, Ontario HIV Treatment Network; Patricia Martens, Director, Manitoba Centre for Health Policy and Associate Professor, Department of Community Health Sciences, University of Manitoba; and Nicole Bernier, Chercheuse adjointe au Département de médecine sociale et préventive Chercheuse au GRIS, Universite de Montreal, provided their approaches to and perspectives on working as health researchers with voluntary health organizations. These presentations highlighted that collaboration early on in the research process with a focus on research user needs facilitates the success of applied health research efforts. In addition to applied HSPR, the session also provided an opportunity to learn more about basic research in this area.

to improve the way health care services are organized, regulated, managed, financed, paid for, used and delivered, in the interest of improving the health and quality of life of all Canadians

³ Dr Flood is currently an Associate Professor in the Faculty of Law at the University of Toronto and a Canada Research Chair in Health Law and Policy. She completed her Master of Laws (LL.M.) in 1994 and her Doctor of Juridical Science (S.J.D.) in 1998 at the University of Toronto. Her areas of research interest include comparative health care policy, public/private financing of health care systems, health care reform, and accountability and governance issues. She was the 1999 Labelle Lecturer in Health Services Research and was appointed a Senior Fellow of Massey College in 2004 and in 2006 on to the Corporation of Massey College.

Example of a linkage between research and voluntary health organizations: A case study from a health services and policy researcher

Paula Goering presented a case study pertaining to the project, *Community Mental Health Evaluation Initiative*, a partnership between researchers from the Health Systems Research and Consulting Unit (University of Toronto) and decision maker partners from the Mental Health Policy Branch of Ontario Ministry of Health, the Ontario Mental Health Foundation and the Community Mental Health Association - Ontario Branch. This long-term multi-site evaluation project (which began in 1993) provides key lessons relevant to effective collaboration and knowledge translation, such as the importance of investing sufficient resources (time and funds) towards such efforts, the need for the partners to identify common interests and complementary strengths and the realization that complex, multi-faceted relationships take time to nurture and develop. Key benefits of these investments include shared learning, impact on policy and a foundation for future work.

Overview of similar dialogue in the US: Ideas to share?

David Helms, President and CEO, Academy Health, gave a presentation about the role of Academy Health and its relationship with the National Health Council, a private, nonprofit umbrella organization of 110 US health-related organizations working to bring quality health care to all people. These two organizations are working together to engage and support voluntary health agency (VHAs) efforts to constructively employ (and support) HSPR. They regard VHAs as natural partners who can advocate for HSPR funding and help translate research into practice, policy and program improvements. VHAs are also well positioned to communicate the value of HSPR to Congress and their communities. At a recent HSPR Roundtable convened by Academy Health, VHA leaders built a common framework for understanding and communicating the value of HSPR and requested a toolkit to recreate the roundtable for other audiences. This toolkit has subsequently been developed and will be piloted this month by the Asthma and Allergy Foundation of America. Workshop participants expressed an interest in receiving more information about the toolkit when available (a CD-ROM will be available in the coming months).

Following the workshop presentations, the more interactive part of the workshop began, with a brainstorming session to identify current barriers to collaboration and suggestions for improved linkage and exchange between the communities represented by workshop participants. The following barriers were identified:

Barriers

- Lack of awareness about mutual priorities
- Lack of opportunities for interaction
- Conflicting VHO board priorities
- Lack of clear language and understanding
- Lack of incentives for researchers to engage with VHOs (i.e. promotion and tenure related issues)
- Timely access to evidence
- Time spent on diversity of health delivery systems
- Researchers do not regard themselves as providing a service to VHOs
- Lack of mutual respect
- Need win/win opportunities
- At CIHR, HSPR is not a priority and does not receive sufficient funding
- Lack of rules of engagement for working together
- Knowledge translation is under-funded

Need tools for collaboration

Ways to improve linkage and exchange and develop future partnerships between voluntary health organizations, researchers and health research organizations

Meeting participants separated into small groups and brainstormed ideas for future partnerships between VHOs, HSPR researchers and health research organizations in five general areas: priority setting, knowledge production, capacity building, knowledge translation and exchange, and developing more evidence-informed policy. The full list of brainstormed ideas that emerged from this session can be found in Appendix C. In summary, ideas from this session included the following:

- The mutual work of these partners could be greatly facilitated through partnerships to
 develop and implement a resource centre/platform focused on HSPRand its translation into
 improved practice, policy and programs. A model of such a platform, suggested by one of
 the groups that appeared to receive widespread support from workshop participants, is
 included in Appendix D.
- To the extent possible, it would be beneficial to capitalize on the efforts of existing organizations and build better bridges with Research Canada, for example.
- In all areas, but particularly in the area of building research capacity, provincial level VHOs and health research organizations need to be fully engaged.
- It would be beneficial to further explore how existing priority setting processes (e.g. the *Listening for Direction* process) could be both more inclusive and more responsive to local priorities and needs.
- To help build VHO awareness and support for HSPR, the case for support based on a clear definition of HSPR and a compelling set of success stories is needed.
- Follow-up from the meeting is necessary to maintain momentum. Follow-up ideas include
 establishing a task-force to further flesh out and develop an action-oriented implementation
 plan for the workshop's recommendations, adopting the Academy Health model (i.e.
 coalition with VHO), and/or implementing a series of similar meetings to continue the
 learning process.
- Barriers to and the advantages of health researcher involvement in community-based, partnered research need to be better understood and addressed in a systematic way.

Synthesis: Key messages for health research organizations, universities and voluntary health organizations

The interactive part of the workshop ended with the creation of a list of key messages for health research organizations (universities and health research organizations) and VHOs (see Appendix E).

Responses/reflections from Jonathan Lomas and Morris Barer

The meeting ended with reflections and responses from Morris Barer and Jonathan Lomas. The following is a summary of the highlights of their concluding remarks:

- Collectively, there is a substantial amount of funding available for health research through VHOs that appears to be currently invested primarily in biomedical and clinical research; at the same time, it appears that there is universal VHO interest in supporting and more importantly, harnessing, HSPR and CIHR needs to work harder at demonstrating and communicating the importance of HSPR through its actions and through compelling case studies and stories to VHOs.
- A wide range and blend of program funding tools are available through CIHR to facilitate collaborative HSPR investments based on identified needs and priorities, such as pilot project tools, research synthesis tools, team grants programs, etc.

- Partnerships take time to develop and success rests on long-term commitments; barriers include governance issues and conflicting priorities.
- The most effective partnerships are derived from KTE processes (e.g. linkage and exchange) and focus on KTE (using research to inform policy, practice and program improvements and system change).
- Researcher and VHO relationships are mutually beneficial researchers provide expertise and VHOs provide tentacles into the community.
- CHSRF has key expertise to share where there is interest (e.g. merit review processes, approaches to diffusion of best practices, etc).
- Partnerships are not necessarily about money; they are also about awareness raising and advocacy.
- It may facilitate partnership if organizations such as IHSPR and CHSRF could work with a
 collective VHO body rather than primarily with individual VHOs. For instance, CHSRF has
 profited on its nursing research agenda by having a consortium with a single voice for
 nursing research in Canada. This is particularly important to VHO engagement in *Listening*for *Direction* processes.
- Many HSPR issues, such as continuity of care and health human resources, may resonate
 across VHOs regardless of the communities they serve; HSPR can be a way to think about
 these common issues and messages and, ultimately, funding ways to strengthen the health
 care system for the benefit of patient groups represented by all the VHOs.

Adjournment

Morris Barer and Suzanne Lawson thanked the participants for their time and contributions to the workshop. The workshop was adjourned at 4:15pm.

APPENDIX A: OBJECTIVES



INSTITUTE OF HEALTH SERVICES AND POLICY RESEARCH in collaboration with CANADIAN HEALTH SERVICES RESEARCH FOUNDATION HEALTH CHARITIES COALITION OF CANADA HEART AND STROKE FOUNDATION OF CANADA NOVA SCOTIA HEALTH RESEARCH FOUNDATION SAFE KIDS CANADA

A Productive Conversation

April 26-27, 2006 Ottawa Marriott Hotel

...a focused discussion among researchers in health services and policy research, research funders, and leaders of voluntary health organizations enhancing the work of each group

Voluntary Health Organizations: refers to organizations registered as charities or non-profits, run by a volunteer board of directors, often supported by individual, corporate or public donations, whose mission is a focus on some aspect of health.

Objectives

- To explore the current engagement and concerns of voluntary health organizations in the Listening for Direction II priority areas.
- To build researcher and research organizations' understanding of the work of the voluntary health organizations in health services, policy development and health system decision-making, and the contribution they can make to the research process (e.g. pointing to topics that require research, engaging in research processes, exchanging knowledge in both directions, implementing research results and sharing funding)
- To build voluntary health organization understanding of health services and policy research and the contribution it can make to their organizational programming and priority-setting.
- To explore successes for the best practices they demonstrate and work at describing and reducing barriers to future collaboration.

Hoped-for Outcomes

- Voluntary health organizations will become more aware of the availability of existing research evidence when they are planning programs, developing policy and choosing priorities.
- Researchers and research organizations will know more about what issues are vital for future research to the people the voluntary health organizations serve and how they might work in collaboration in the future.
- Researchers and research organizations will see voluntary health organizations as makers of policy and promoters of public policy in health.
- Relationships will be begun which will prove beneficial to research enhancement through potential increased funding, clarification of need for research, and knowledge exchange throughout the research process through to implementation of results.

APPENDIX B: PARTICIPANTS



INSTITUTE OF HEALTH SERVICES AND POLICY RESEARCH in collaboration with

CANADIAN HEALTH SERVICES RESEARCH FOUNDATION
HEALTH CHARITIES COALITION OF CANADA
HEART AND STROKE FOUNDATION OF CANADA
NOVA SCOTIA HEALTH RESEARCH FOUNDATION
SAFE KIDS CANADA

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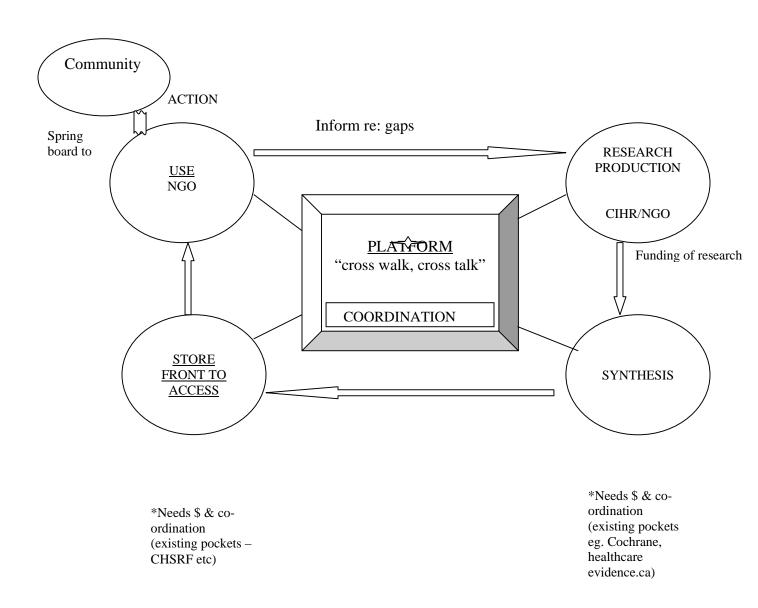
APPENDIX C: Future partnerships between VHOs, HSPR researchers and health research organizations – Summary of brainstorming session

Potential area for	Ideas
collaboration	Iucas
Priority Setting	 What do organizations do now? What has worked best so far? LfDIII is an opportunity for VHO involvement from the beginning Need to understand the reasons for engagement; need resonance Need to be more involved in Research Canada to influence its priorities Need joint involvement and inclusive priority-setting processes that include all relevant stakeholders (e.g. provincial organizations, the public and VHOs who bring different and important perspectives on priorities) Develop consensus-building strategies Demonstrate evidence of positive aspects of the process/strategy Provide incentives to support the need to work together Differentiate individual roles within the system and common areas of interest
Knowledge Production	 Involve end users as partners throughout the process Recognize differences (one size will not fit all) All knowledge production should be properly peer/merit reviewed Applied health research should be reviewed for relevance and scientific merit through a merit review process Funders develop funding mechanisms for HSPR and KT Programs need to build in evaluation Engage policy makers early on Need for advocacy to understand the importance of long-term sustainability of funding for research and the importance of HSPR Research accountability (audits) are important Need grants for research project development (e.g. relationship building)
Capacity Development	 Create mentorship programs Look for creative collaborations Need bursaries for students to work in the community Develop shared capacity-building priorities and a sustainable stream of funding for the entire career cycle Better capture, understand and address barriers to health researcher involvement with VHOs
Knowledge translation and exchange (KTE)	 Include KTE requirements in grants Identify resources to measure/evaluate the effects of KTE on the system/end-user Develop networks of like-minded organizations Need access to experts in HSPR IHSPR should look at what other CIHR Institutes have been undertaking with VHOs and learn from these experiences We need to clarify language – what do we mean by health services versus the health system? Where does public health fit in? We need a virtual resource centre that will help us access information/expertise/best practices and how to connect with

Puilding bottor	partners VHOs are key KTE partners for HSPR Expertise needs to be respected Working together will likely lead to better problem solving Need to different skills sets – knowledge brokers, partnership and KTE positions in organizations Effective KTE relationships take time! CAHSPR needs to do outreach
Building better policy	 We need a marketing strategy and tools to communicate the need for and importance of evidence informed policy-making with the
	 vHO could consider tapping into HSPR expertise to build better policy within their organizations (e.g. management and governance expertise)
	VHOs can help build awareness and advocacy for health research and health research system change

APPENDIX D: Suggested research/knowledge translation and exchange platform

A SYSTEMS APPROACH (i.e. ITSS: It's The System Sweetie)



^{* =} places that need funding/co-ord "home" or body

APPENDIX E: Key Messages

Audience	Key messages
Universities	Public service, community connection matters for researchers
	Change promotion criteria to include applied health services
	research and knowledge translation (KT)
	We're ready to work with you
VHO boards and	Our programs and services need to be evidence-informed
scientific	Applied health services research and KT are valuable and
advisory groups	can change practices, programs and policy to better help
	people, communities and populations we care about
	Sometimes the system needs a cure
	4. We might need to look at the different skills we have at the
	table so that VHOs are part of a systems change towards
	better synergy between evidence and
- CIUD broadly	practice/programs/policy – we need to be part of this dynamic
CIHR broadlyCHSRF	Develop mechanisms to share best practices amongst each other and with VHOs
■ IHSPR	2. We need a clean, clear, concise "case" for why health
■ CAHSPR	services and policy research and KT are important and why
Provincial	we should support it
health research organizations ⁴	We need more information about the mechanisms for working with more than one CIHR institute
	4. Adapt the Academy Health tool kit for Canada
	5. We need to work together to continue to develop and share
	models for review processes that value lay reviewer and
	decision maker input for both open and strategic competitions
	6. We need to work together to train and mentor all who are on
	review panels (researchers, decision makers, community
	and lay representatives) to the new models, new ways of
	conducting reviews (e.g. merit review)

⁴ 1) CIHR: Canadian Institutes of Health Research (see: www.cihr-irsc.gc.ca)

²⁾ CHSRF: Canadian Health Services Research Foundation (see: http://chsrf.ca/home_e.php)

³⁾ IHSPR: CIHR's Institute of Health Services and Policy Research (see: http://www.cihr-irsc.gc.ca/e/13733.html)

⁴⁾ CAHSPR: Canadian Association for Health Services and Policy Research (see: http://www.cahspr.ca)

⁵⁾ Examples of provincial health research organizations include the Nova Scotia Health Research Foundation (see: http://www.nshrf.ca/AbsPage.aspx?siteid=1&lang=1&id=1), the Alberta Heritage Foundation for Medical Research (see: http://www.ahfmr.ab.ca/) and the Saskatchewan Health Research Foundation (see: http://www.shrf.ca/). Please note, the provincial health research organizations/foundations have formed a collective group called the National Alliance of Provincial Health Research Organizations (NAPHRO).