

Institute of Neurosciences, Mental Health and Addiction

Canadian Institutes of Health Research

***Second Round Table on
Research Collaboration***

Calgary, Alberta

Report of Proceedings

January 19-20, 2002

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Institute of Neurosciences, Mental Health and Addiction
Round Table on Research Collaboration

Part A
Summary

Welcome and Introduction

The Institute of Neurosciences, Mental Health and Addiction (INMHA) of Canadian Institutes of Health Research (CIHR) sponsored the ***Second Round Table on Research Collaboration*** in Calgary on January 19-20, 2002. In all, nineteen volunteer or Non-Government Organizations (NGOs) as well as Health Canada sent representatives. In addition, three members of INMHA's Advisory Board, five INMHA staff members and a representative from CIHR attended.

Phil Upshall, a member of the Institute Advisory Board, welcomed the participants and outlined the purpose and background of the *Second Round Table*. CIHR is in its infancy: as such, it is breaking new ground. Its broad mandate and limited funding means that that partnerships are a *must*, and not an option. The proceedings of this meeting will provide the Board of INMHA with valuable input.

The purpose of the *Second Round Table* was to provide the opportunity for INMHA and volunteer organizations to develop a collaborative relationship with regard to research programs, funding and dissemination. The objectives of the round table were:

1. To increase awareness among volunteer organizations of the mission and goals of the Institute of Neurosciences, Mental Health and Addiction (INMHA).
2. To increase awareness among the Institute and volunteer organizations of the related activities of other volunteer organizations.
3. To investigate the means by which volunteer organizations can effectively collaborate with each other and the Institute on research-related issues.

This *Second Round Table* built on the work of the first round table held in Ottawa on June 23-24, 2001. The June round table reviewed INMHA's mission and objectives and suggested changes, several of which INMHA's Advisor Board subsequently accepted. It also identified benefits of collaboration, possible areas for involvement in INMHA activities, and made suggestions for communication and dissemination of research information. The *Second Round Table* reviewed this work, suggested changes and additions, and then moved into new territory. Participants discussed models and principles of research organization partnerships, and training priorities, strategies and actions for INMHA. As the meeting ended, participants indicated the nature and extent of their interest in ongoing collaboration with INMHA.

Overview of CIHR and INMHA

Address by Remi Quirion "CIHR and INMHA, Their Programs and Activities"

Dr. Quirion reviewed the four research pillars of Canadian Institutes of Health Research:

- Biomedical
- Clinical
- Health services and health systems
- Health of populations, societal and cultural dimensions of health, and environmental influences on health

Seventy percent of CIHR's budget is set aside for open competition. Institutes development and strategic initiatives account for the remainder (three percent and twenty-seven percent, respectively).

INMHA is one of CIHR's thirteen institutes. Its Advisory Board includes members from across the country and one international representative. Among its members are two Consumer Representatives.

The **vision** of INMHA is:

- Innovative, ethically responsible research will provide new knowledge of the biological and socio-cultural processes underlying neurological, mental and addictive disorders.
- Such a comprehensive approach to research will enhance the quality of life of Canadians suffering from illnesses covered under the broad mandate of the Institute through improved prevention, diagnosis and treatments.

Dr. Quirion described the **mission** of INMHA:

- To foster excellence in innovative, ethically responsible research in Canada that aims to increase our knowledge of the functioning and disorders of the brain, the mind, the spinal cord, the sensory and motor systems, as well as mental health, mental illnesses and all forms of addictions.
- To translate this new knowledge into a better quality of life for all Canadians through improved health outcomes, health promotion and health care services.

INMHA's **objectives** are sevenfold:

- To promote and support excellence in peer-reviewed, internationally recognized and ethically responsible research in the domains of the Institute, including co-occurrence with other health problems.
- To encourage trans-disciplinary research in order to facilitate knowledge transfer aimed at developing and improving health care treatments and services.
- To ensure the training and support of the next generation of Canadian scientists in all aspects of neurosciences, mental health and addiction by promoting and sustaining the development of trans-disciplinary programs of research and training.
- To work with non-governmental and volunteer health organizations, municipal governments and other interested stakeholders in reducing the discrimination and

prejudices associated with neurological disorders and sensory disorders, mental illnesses and addictions.

- To promote the mandate of INMHA and its contribution through effective communication with all sectors of civil society.
- To work with the Government of Canada, provincial and territorial governments, members of the scientific community, non-governmental and volunteer health organizations, foundations, and all Canadians to ensure that sufficient human and financial resources, consistent with the burden of disease of the disorders covered by INMHA, are made available to the Institute in order to enable it to achieve its goals.
- To interact with all stakeholders to identify research priorities, establish partnerships and undertake collaborative activities.

To date, INMHA has introduced several **initiatives**, such as:

- *Brain Star Award* - \$1,000 designed to recognize the excellence of the research done by trainees in all fields covered by INMHA. Dr. Quirion stressed his interest in NGO involvement in this program.
- *Training Grant Program* - supported by both CIHR central and the individual institutes
- *NET (New Emerging Team) Program* - institute-specific strategic initiatives to encourage collaboration between teams of from 3 to 6 independent investigators in multidisciplinary research.

Dr. Quirion outlined the themes of the 2001-2002 program: discrimination and stigma; understanding of the placebo effect; neurodevelopment and early life events; computational neurosciences and artificial intelligence; and two themes in partnership with other institutes: *Cognitive Impairment in Aging*; and *Violence, Gender and Health across the Lifespan*. Theme for 2002-2003 will be post-traumatic stress disorder.

- *Strategic Initiatives* - encouraging cross-pillars and trans-disciplinary research.
- *Inter-Institute Partnerships* - combining efforts among institutes on common fronts, such as gene therapy, alcoholism and gender, and training programs in Aboriginal Mental Health.
- *International Collaborations* - including the Japan-Canada Post-doctoral Fellow Exchange Program and Canada Israel Joint Meeting.
- *Workshops and Scientific Meetings* - supporting and encouraging the hosting of workshops on various research topics. Several successful INMHA-supported workshops were outlined.

INMHA's Advisory Board will undertake a review of its current focus groups. Each group is headed by a board member and will explore several areas identified at the first Round Table. Groups may be seeking NGO participation.

Current Focus Group	INMHA Advisory Board Member
Training	Marlene Reimer
Communications	Eric Single
Partnership with NGOs	Phil Upshall
Partnership with industry	
Ethics and the Law	Gordon DuVal
Budget and Accountability	Remi Quirion
Prizes & Awards (new) - to highlight excellence, promote INMHA areas of research.	

Dr. Quirion highlighted upcoming projects, including Brain Awareness Week (March 3-8, 2002) and the First Annual Meeting of INMHA in partnership with NGOs, proposed for October, 2002. In closing, Dr. Quirion emphasized the need - indeed, the desire - for clear NGO involvement in INMHA initiatives. He also encouraged direct linkages with professional societies.

Astrid Eberhart, Institute Liaison at CIHR for INMHA and the Institute of Aging, also addressed the group. The large number of stakeholder groups in each of the 3 areas in INMHA: neurosciences, mental health and addictions provide a special challenge, given the small INMHA staff.

Rather than holding one big meeting of NGOs, the decision was made to host several smaller NGO meetings (round tables). The process seems to be working well. As a result of the first round table, INMHA has made changes to its vision and objectives, hired a Communications Officer, and begun planning an Annual meeting. Several NGOs have invited Astrid or other INMHA representatives to be part of their planning process and these invitations are welcome. The relationships with the NGOs are still being developed and will be in some ways unique for each organization.

Candace Gibson, the new Communications Officer for INMHA, informed the participants that she is in the process of developing the communication strategy. Her position is part-time. Her background includes experience in both scientific research and journalism. One of her initial projects is the INMHA Website, in collaboration with CIHR, and she asked that organizations offer her their opinions on how the Website could best meet their needs. She hopes to raise the general public's awareness of INMHA and its mandate, and to inform the public about the disorders and their economic impact and social effects on Canadian society.



Introduction of Participants

In all, nineteen volunteer organizations and Health Canada sent representatives to the *Second Round Table*. In addition, six members of INMHA's Advisory Board, five INMHA staff members, and a representative from CIHR attended.

ALS Society of Canada	Health Canada
Canadian Brain and Nerve Health Coalition	Homewood Research Institute and Homewood Health Centre
Canadian Association of the Deaf	
Canadian Congress of Neurological Sciences	Huntington Society of Canada
(The) Canadian Hearing Society	Mood Disorders Society of Canada
Canadian Mental Health Association	NeuroScience Canada Partnership
Canadian National Institute for the Blind (CNIB)	Responsible Gambling Council (Ontario)
Canadian Psychiatric Research Foundation	(The) Rick Hansen Institute
Canadian Sleep Society	Schizophrenia Society of Canada
E.A. Baker Foundation for the Prevention of Blindness	Tourette Syndrome Foundation of Canada
	(The) Women's Addiction Foundation

NGOs are involved in many diseases or disorders affecting millions of Canadians. They undertake a wide variety of activities and enjoy varied levels of resources. The discussions of the day indicated a great level of enthusiasm and commitment toward working with INMHA.

From the presentations, these NGOs outlined the range of their activities:

- Advocacy regarding awareness, stigma, services and access, and research/funding
- Research Funding
- Fundraising
- Research Dissemination
- Training
- Surveillance/Population Statistics
- Best Practice Identification
- Information Dissemination and Resource Development
- Partnerships
- Community Support

For more detail on the organization's activities, see the section entitled "Self-Description of Non-Government Organizations (NGOs)" in Part B.

Each organization estimated the number of Canadians affected by their health problem/issue:

Issue	Impact on the Lives of Canadians
Addiction	100% - 30 million, if one includes those close to someone with an addiction
ALS	2,000-3,000 (?), 1/3 dying each year
Deafness	300,000 use signing, plus others with mild hearing loss
Hearing Loss	10% of population, approximately 3 million
Neurological Illnesses	10% of population, approximately 3 million
Tourette's Syndrome	3% of population, approximately 900,000
Mental Illnesses	20 – 25% of population, approximately 6 million
Mental Health	100% - 30 million
Blindness	600,000 people
Cataract	all
Glaucoma	5% (150,000)
Macular degeneration	20% (6 million)
Unsatisfactory Sleep	20% (6 million)
Huntington's	3,000 (1 per 10,000 at risk 15,000 to 20,000 individuals)
Mood Disorder	900,000 families
Gambling	1% - 3% 340,000 + 5% affected by someone else's gambling
Spinal Cord Injury	1,000 new injuries per year; 36,000 people coping with injury
Schizophrenia	1% population (3,000)



Strategic Partnerships and CIHR

Helene Plante, of CIHR's office of Strategic Partnerships and Alliances, spoke to the *Second Round Table* regarding partnerships.

The **mission** of partnerships in CIHR is:

- To create and translate new knowledge, by bringing together health research communities;
- To create innovative approaches to research questions and research agendas that respond to the health needs, concerns and priorities of Canadians; and
- To accelerate the application of knowledge for the benefit of Canadians.

Helene stressed that effective partnerships address more than simply financial concerns; they require a focussed team approach based on a set of **principles**. These principles include a strong sense of ethics, commitment to academic freedom, benefit to the public and Canada, and the right to disseminate research results. In addition, the underlying **values** of freedom of inquiry, dissemination of research results, the public good, integrity in research, accountability and transparency, and the absence of conflict of interest form the foundation of successful strategic partnerships.

It is essential that all partnerships follow some established **guidelines**, including the following:

- All research involves partnerships;
- The form of each partnership can be unique - no single ideal model exists;
- Partnership agreements should be in accordance with core values and health research strategy, and should add value; and
- Continuing relationships, collaborative or co-funded research partnerships must meet scientific and ethical standards.

Ms. Plante recommended that partnerships pay close attention to governance issues, that they include national consultation, and that CIHR be an active participant. She also stressed the need to learn from partnerships by the dissemination of their results.

Stakeholders in health research include voluntary organizations and foundations, the private sector, communities and NGOs, federal agencies, provincial/territorial governments as well as international organizations and alliances, and educational institutions. In 1998, the total investment by national health research enterprise in Canada was \$2.3 billion.

She concluded by reminding the participants that CIHR is still in its infancy, and stressed the need for organizations to work in a spirit of collaboration, encouraging the sharing of ideas and supporting joint research goals.

Summary of Round Table Discussions

Participants worked in four groups to provide input to INMHA's Board on several topics.

Review of INMHA Mission and Objectives

Participants were asked to review the mission and objectives of INMHA. INMHA's mission and objective received unanimous support. Participants felt, however, that the training objective in the mission statement needed more emphasis. They also suggested adding two objectives, one dealing with advocacy for mental illnesses, mental health, addictions and neurological disorders and the other dealing with increasing public awareness of these disorders and the manner in which research dollars are spent. Another objective could focus on INMHA's role as a bridge between researchers & clinicians.

Benefits of Collaboration

As at the first round table, the participants agreed that there were great benefits in working both with one another and with INMHA.

- Broadening of the issues addressed by researchers
- Increased focus on issues which have not traditionally been well researched, such as prevention, access to services, advocacy, knowledge transfer, public policies, and the holistic approach to health care
- Identification of cross-cutting issues affecting many health disorders
- Increased conduct of research relevant to the individuals with the disorder
- Increased collaboration among researchers from different fields
- Increased NGO awareness of the "realities" of researchers and research challenges
- Promotion of collaborative "research environment" with NGOs
- Increased transparency about research priorities, research funding allocations
- Learning from one another's failures and experiences
- Fewer grant reviews
- Development of collaborative strategic research initiatives
- Increased visibility of organizations and health issues
- Reduce duplication and increased efficiency
- More attractive for researchers to attract and retain new researchers
- Assistance from CIHR in translating/disseminating knowledge and promoting policy uptake
- INMHA can facilitate linkages with other CIHR institutes

NGO Involvement in INMHA Activities

In addition to the suggestions for involvement made at the first round table, participants recommended that NGOs be involved in

- Review panels
- Evaluation of INMHA
- Research dissemination to service providers and the public
- Assisting INMHA in setting up its NGO partnerships
- Identify speakers for a "speakers' bureau"
- Identify necessary areas of research that are overlooked
- Help define funding programs/new initiatives to foster knowledge translation

Communication

Communication among NGOs and INMHA is an essential element for successful collaboration. The *Second Round Table* participants identified the following priorities:

- Establish an infrastructure to help NGOs communicate with INMHA
- Develop a Website with weekly updates and links to NGO home pages
- Profile existing and future joint projects between INMHA and NGOs

On some occasions, INMHA will be able to consult all the organizations; at other times it will only have time and resources to consult coalitions of NGOs.

Dissemination of Research Findings

All participants acknowledged the value of timely, effective dissemination of research findings. The group identified the following priority areas for action:

- Develop a communication plan with the "stakeholders" and develop customized plans for each group (general public, industry, policy makers, influencers, planners, clients/consumers/general public/academics/policy makers/politicians)
- Database of INMHA and NGO research activities (projects funded) to be provided on Website (NGO's responsible for updating their part)
- Clearinghouse with new, important research findings
- Plain language research results fact sheets for public

All the NGOs and INMHA identified that lack of staff often makes effective communication difficult to achieve. Many were interested in sharing resources to facilitate this work. The communications officers of the NGOs and INMHA could meet to discuss the ways and means of achieving better communication.

Participants strongly supported an annual INMHA meeting for clinical practitioners and researchers to discuss best practices, ethics and structure of systems. Politicians could also be invited to discuss the structure and delivery of services. The general public as well as clients and families could add to discussions of the relevance and impact of the research, and they could be helpful in identifying research gaps.

Research Organization Partnerships

Participants reviewed their previous experiences in research organization partnerships. They identified the following characteristics as instrumental to the success of partnerships within INMHA.

- Leadership must be clear and strong. INMHA can provide this leadership and ensure a broadening of views among research partners.
- NGOs must be acknowledged as partners with joint ownership of the solution.
- The partnership must have a common vision and goals.
- The partnership will thrive in a spirit of mutual respect for the goals, aspirations, areas of interest, and expertise of all partners.
- The partnership needs to have a clear mandate with clearly defined roles for each member.
- A strategic plan, supported by a business plan, with ongoing evaluation is a vital element to a successful partnership.
- Resources and operations must be stabilized through a consistent structure and secure financial resources.
- Partners must provide feedback to one another and be willing to share information.

Training

Participants expressed strong agreement with the four strategic directions of INMHA:

- Supporting trans-disciplinary training grants
- Development of a national clinical training program
- Creation of a training centre on mental health in Aboriginals
- The BrainStar award program

Discussion on the means of improving trans-disciplinary training in INMHA-relevant areas distilled into four main areas:

Principles of trans-disciplinary training

- Trans-disciplinary training should take into account the full context of the biopsychosocial and spiritual aspects of health, with openness and receptivity to new ideas, and to the cross-disciplinary nature of research goals and issues.
- Special funding for trainees would enable them to attend conferences and train with experts in other disciplines.

Recruitment

- Encourage the development of broad interests early in school years, and educate student, parents and high school counsellors about career opportunities and career paths.
- Establish a 1- or 2-year program that provides a broad base of training early in a career; also establish short term training opportunities.

Improvement of the research environment for trainee

- Co-operation between the "service disciplines", or NGOs, and the "Service research disciplines", or academics, would create the ideal training environment.
- Early career opportunities for broad-based training in relevant research areas would encourage the development of a broad, cross-disciplinary view among trainees.

Potential NGO involvement in trans-disciplinary training in INMHA-relevant areas.

- NGOs can assist with recruitment at the high school level and facilitate access to training environments.
- NGOs can identify and express the needs and topics that are of concern to their consumers.
- NGOs can assist and support the connection of researchers with subjects for their investigations; they can also facilitate the connection between researchers and people with a disease and their families.
- NGOs can promote funding from the private sector for training opportunities based on strategic priorities.

More detailed discussion notes on all of these topics can be found in "Group Discussions" in Part B.

Conclusion

This, the second of several *Round Tables* to be held across Canada, was by all accounts, a very successful meeting. (For detailed comments, see the section entitled, "Evaluations of INMHA *Second Round Table*".) Participants revealed their organizations' great enthusiasm and interest in working in partnership and ongoing collaboration with one another and INMHA.

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