

MICYRN Network News

Newsletter 8

Spring 2010

maternal infant
child & youth
research network



réseau de recherche
en santé des
enfants et des mères

HEALTH SERVICES RESEARCH AGENDA: Building the Maternal-Child Capacity

In an effort to rise to the challenge of building stronger capacity in maternal, child and youth health services research, MICYRN contributed to an invitational workshop entitled "A Health Services

Research Agenda: Building Capacity within the Maternal, Child & Youth Sector", February 18th-19th, 2010, hosted by the Canadian Child & Youth Health Coalition in partnership with the CIHR-IDHCHYH. Building capacity for health services research has been an ongoing challenge in Canada.

Though some infrastructure and training opportunities are already available, the gaps in health services and policy research in the areas of maternal and youth health have a direct impact on levels of care. Many presenters indicated a need to sustain data collection tools throughout and after the research project. Workshop presentations and the report are posted at: http://www.ccyhc.org/work_indicators_rfa.html

CIHR FUNDING OPPORTUNITIES

In order to foster and strengthen research on **maternal health** and properly address perceived gaps in knowledge, CIHR has identified four priority research areas relevant to maternal health :

1. Determinants and consequences of maternal health disparities across the life course
2. The relationship of pregnancy and its complications to subsequent maternal physical and/or mental health
3. Health systems, health care models, and health human resources
4. Pathways to positive maternal health: interventions, actions and policies

Three different funding tools have been launched on "*Maternal Health – from pre-conception to the Empty Nest*"
<http://www.cihr-irsc.gc.ca>

MICYRN's Vision: A cohesive national network that facilitates maternal-child clinical research in Canada and beyond

ETHICS

New sectors of research pose increasingly complex ethical challenges, especially when involving children, not legally competent to understand or consent on their own behalf. The recently produced document "*Best Practices for Research Involving Children and Adolescents*" provides the means to address key issues on the ethical engagement of children in research. "*Best Practices*" is the result of a recent project orchestrated through the National Council for Ethics in Human Research (NCEHR) Emerging Issues Analysis Committee, and run in collaboration with the Canadian Institutes of Health Research's Institute of Human Development, Child and Youth Health, the CIHR Ethics Office, Health Canada, and other organizations including MICYRN. Investigators Julie Samuel, Lee Black, Denise Avard and Bartha Knoppers at the Centre de recherche en droit public (CRDP) at the University of Montreal conducted the research, reviewing ten principal guidelines to be considered by researchers and REBs in specific areas like genetic, pharmaceutical, and palliative care research, and longitudinal studies **including birth cohorts**. Consultation on content is currently underway, to ensure the "*Best Practices*" review has captured and appropriately addressed all important points.

The document is posted and inviting comment at <http://www.pediagen.org>

Focus group meetings are scheduled in 2010 to incorporate input to content, including a session organized by CIHR in conjunction with the Canadian Paediatric Society meetings: **Wednesday June 23rd, 2010 4-530pm in the Chan Auditorium at the Child & Family Research Institute @ BC Children's & Women's Health Centre**

In a second phase of consultation, MICYRN is planning a *Principles to Practice* Workshop that will bring together REB Chairs and others from the maternal-child research community. MICYRN's overarching goal is to harmonize maternal-child research review at a national level. Our principal strategy towards that goal is to promote "bottom up", ground-level harmonization, with the objectives to facilitate dialogue between REBs; and, develop consensus for REB review of specific types of research activities. This Workshop will involve the 6 self-standing REBs in Canada and begin with a focus on review of Registries, Biobanks, and Longitudinal Studies.

Opportunities with NeuroDevNet

NeuroDevNet is a newly established Canadian Network of Centres of Excellence with the vision to accelerate the pace of understanding the causes of developmental neurological deficits, with an initial focus on autism spectrum disorder, fetal alcohol spectrum disorder, and cerebral palsy. As part of this process, NeuroDevNet is requesting proposals for Opportunities Initiative Projects in the areas of developmental neurobiology and developmental brain disorders from investigators eligible to receive CIHR, NSERC or SSHRC funding. In a related initiative, NeuroDevNet has partnered with organizations across Canada to provide a number of training opportunities. See: <http://www.neurodevnet.ca>

Good Clinical Practices (GCP) & Standard Operating Procedures (SOPs)

MICYRN is a member of the Network of Network (N2). Members have access to the N2 SOPs which have been approved by CanReg; 29 tools to accompany the N2 SOPs; 16 online GCP modules (available July 2010); and an on-demand regulatory reference library. Contact us for the access codes.

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DATA MANAGEMENT

MICYRN's Data Core in Edmonton at the Stollery Women and Children's Health Research Institute (WCHRI) and the Clinical Research Support Unit at the Child & Family Research Institute in Vancouver, continue to collaborate on testing new software options for clinical research data management and surveys, including Dacima™, OpenClinica™ and RedCap™. A spreadsheet comparing features and an algorithm to help investigators determine which system will meet their needs is under development and will be posted on the new MICYRN website. You can arrange to see web-based demonstrations and discuss features to suit your needs. Whether you want advice on acquiring software and hardware for your own purposes, or you want data management and hosting services, contact:

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StaR Child Health

International Forum of Standards for Research in Children

StaR Child Health is an international quality improvement initiative which started in 2009, and seeks to enhance the quality, ethics and reliability of paediatric clinical research by promoting the use of uniform standards for clinical studies with children. A first international StaR Child Health Summit was held in Amsterdam in October 2009. The second StaR Child Health Summit is being co-organized with MICYRN, and will be held in Vancouver, BC, September 10th - 11th, 2010. For more information about StaR Child Health, please visit

<http://www.starchildhealth.org>

Registration is open for the Vancouver Summit at:

<http://starsummit2010.proreg.ca/index.html>

The StaR Child Health initiative prompts the question as to the position of the Canadian maternal-child health research community and institutes in clinical trials. Canada does not yet have legislation like Europe and the USA which promotes clinical trials to be conducted in children. Increasingly, clinical trials are being conducted on a global scale, so if Canada is to remain competitive, we should consider our role. MICYRN's "snapshot" of global trials activity showed that Canada is second only to the USA in the number of registered paediatric trials actively recruiting, and third after Australia and the Netherlands for the number of trials per population of children. You can view information about registered paediatric trials being conducted world-wide at:

<http://www.who.int/ictrp/child/search/en/>

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☆ Please join us in welcoming Maureen Lowe as the new ☆
☆ Executive Assistant to MICYRN!! ☆
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