



**Ethics Office
Annual Update
Fall 2012**

Ethics @ CIHR

**Innovation in Health,
Health Services &
Health Ethics**

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CIHR encourages interdisciplinary, innovative and integrative research on ethical issues pertaining to health, and also fosters the discussion of ethical issues to strengthen the culture of research ethics and integrity in Canada.

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Message from the Ethics Office

In 1994, David Roy, John Williams and Bernard Dickens declared in *Bioethics in Canada* that “a bioethics revolution is well and truly underway”, spurred by galloping scientific progress and social change. More than a decade into the 21st century, the pace of change has not abated.

“A bioethics revolution is well and truly underway” – *Bioethics in Canada*

“Innovation” is a rallying cry across sectors, resonating in the Science, Technology and Innovation Council of Canada’s 2010 State of the Nation report, in CIHR’s 2012-13 priority to promote “Health and Health Services Advances” ... and in the ethics arena.

A quick spin around a few of the world’s bioethics centres captures emerging ethical issues linked to advances in health-related areas. For example, the US Presidential Commission for the Study of Bioethical Issues is tackling the implications of information technology for genomic data access and privacy. The UK Nuffield Council on Bioethics is investigating

the ethics of donor conception and of novel neuro-technologies. The World Health Organization is publishing on ethics in pandemic influenza planning and in long-term care.

Closer to home, “innovation” was the theme of the Canadian Bioethics Society Annual Conference in May 2012, where the Ethics Office teamed up with two CIHR-funded ethics researchers— Fern Brunger and Éric Racine—to promote CIHR ethics research funding opportunities.

The theme of innovation also runs through the research funded by the Ethics Office in the past year: ethical aspects of e-health, health policy decision-making, global health, euthanasia, assisted reproduction, commercialization, disaster research, organ transplantation, and more.

In closing, the Ethics Office sincerely thanks Dr. Harvey Chochinov for his years of service as the Chair of the CIHR Standing Committee on Ethics, and warmly welcomes the new Chair, Dr. Nicole Letourneau.

Meet 2012 Douglas Kinsella Award for Research in Bioethics Recipient:

Maxwell Smith



Doctoral Student, University of Toronto. CIHR Fellow in Public Health Policy. CIHR Frederick Banting and Charles Best Canada Graduate Scholar.

On “Innovation”:

How would you describe the innovative nature of your work in health ethics?

First, *my work is innovative because it seeks to contribute to the relatively nascent yet growing field of public health ethics.* Second, it is innovative because it doesn’t just strive to investigate situation-based ethical issues, but rather strives to critically reflect on the very foundations upon which public health and public health emergency response are based. It asks the questions: “What are the moral foundations of public health and public health emergency response?”,

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Meet Canada Research Chair in Health, Ethics & Diversity

Barbara Pesut



Canada Research Chair in Health, Ethics and Diversity, Associate Professor of Nursing, University of British Columbia. Recipient of CIHR operating and dissemination grants. Co-recipient of SSHRC grants.

On "Innovation":

How would you describe the innovative nature of your work in health ethics?

Studies of healthcare ethics in rural palliative care have traditionally been problem based, focusing on issues such as the limited healthcare resources in rural areas, the reduced health status of rural citizens, and the challenges of dual relationships and caregiver stresses for healthcare providers.

My work in health ethics focuses on the community capacity inherent in rural areas as the foundation for high quality palliative care. Two particularly relevant areas are the value systems and the nature of the social relationships that undergird community capacity development. My research uses ethnographic methods to better understand these value systems and social relationships that form the moral fabric of rural palliative care. By better understanding this moral fabric we can strengthen the healthcare delivery system through community engagement and ensure that healthcare policies and programs enhance rural capacity.

How does your work in ethics intersect with advances or changing circumstances in other health-related areas?

Healthcare has made major advances in the area of evidence-based practice. Within this model, best practices are applied across populations. However, evidence-based practices are now being complemented by a more particularized focus that takes into account the important context of care.

An example of this would be personalized medicine. My approach to rural palliative care ethics intersects with these developments in healthcare. By complementing a principle-based approach to ethics with a more particularized emphasis on the moral geography of the rural context I am providing a more nuanced understanding of how to provide high quality care in rural areas at end of life.

Do you have any thoughts on where there may be major changes in

Ethics Office Grant & Award Funding Recipients in 2011 - 2012: Congratulations!

The Ethics Office offers regular funding opportunities and funds or co-funds applications relevant to ethics in other CIHR competitions. Check "[Find Funding](#)".

Catalyst Grants-Ethics

BACKMAN, Catherine L
GAGNON, Marc-André
GUPTA, Mona
SHOVELLER, Jean A
VOIGT, Kristin V

Planning Grants- Ethics

BAYLIS, Françoise
COLLEY, Rachel C
DHANANI, Sonny
FORMAN, Lisa
MAH, Catherine
MITCHINSON, Wendy L
RAZ, Amir
SHOVELLER, Jean A

Dissemination Events-Ethics

BATTEN, Lisa
BAYLIS, Françoise
BOIVIN, Antoine
CHAN, An-Wen
FARMER, Yanick
FILLION, Lise
FOREMAN, Thomas
HATCHER ROBERTS, Janet Louise L
RICHARDSON, Harriet
ROIGT, Delphine

Catalyst Grant: Post-Market Drug Safety and Effectiveness in Populations Underrepresented in Clinical Trials
THOMPSON, Alison K

Doctoral Douglas Kinsella Award-Bioethics

SMITH, Maxwell

Emerging Team Grants: Rare Diseases
MENON, Devidas

Expedited Knowledge Synthesis
WILSON, Michael

Operating Grants-Ethics

FELDMAN, Debbie
HERDER, Matthew
HO, Anita T
HUNT, Matthew
ILLES, Judy
STAHNISCH, Frank W
TAIT, Caroline L

Team Grants: HIV/AIDS Vaccine Discovery and Social Research
BROCKMAN, Mark A
NEWMAN, Peter A

the future at the intersection of ethics and health?

If I have one future aspiration for the intersection of ethics and health, it would be that there would be a higher level of integration between the two. Healthcare services have suffered from a silo effect and there is now a push toward integration. I would hope that this same integration would occur

across healthcare delivery and ethics. I believe that we can no longer afford to have a model of care whereby certain individuals are paid to 'do ethics' and we call upon these individuals under particularly difficult circumstances to help us resolve our dilemmas. Rather, ethics should be at the foundation of all our decisions in healthcare./



Meet Canada Research Chair in Neuroethics: Judy Illes



Canada Research Chair in Neuroethics, Professor of Neurology, Faculty of Medicine and Faculty, Brain Research Centre, National Core for Neuroethics, University of British Columbia. Recipient of a CIHR Chair-Neuroethics Establishment Grant, and operating and meeting grants.

On "Innovation":

How would you describe the innovative nature of your work in health ethics?

Neuroethics brings together biomedical ethics and the neurosciences. As scholars with interests at the intersection of these two major professional fields that have long and distinguished histories, we focus on practical ethical challenges in innovations in neuroscience that pertain to brain health and disease. These include, for example, the development of stem cells therapies for spinal cord injuries, biomarkers of disease along the life continuum from children to the elderly, the application of functional neuroimaging to improve the understanding of disorders of mental health and other conditions, and advances in gene therapy.

Our approach builds on the strengths of past thinking and research, applies qualitative and quantitative analytic methods to new problems, and delivers solutions from a multi-disciplinary perspective.

How does your work in ethics intersect with advances or changing circumstances in other health-related areas?

Our goal is to be aligned right alongside the science. We want to anticipate changes in the ethical, legal and social domain that might result from innovation and progress and to help bring the most efficient translation and application of these advances to all sectors of the health system.

Historically, bioethics has been reactive—often visible in response to an adverse event in science or medicine. Neuroethics anticipates potential outcomes and seeks to provide guidance along the entire spectrum from basic research through to clinical research and policy implementation. Avoiding adversity, misunderstandings, or negative public reaction is always a good thing.

Do you have any thoughts on where there may be major changes in the future at the intersection of ethics and health?

Fall 2012 Ethics Funding Opportunities

For details, go to: ["Find Funding"](#)

Dissemination Events: Priority Announcement- Ethics:

Application Deadline: Oct. 15, 2012

Doctoral Research Award: Priority Announcement – Ethics:

Application deadline: Oct. 15, 2012

Planning Grants: Priority Announcement- Ethics:

Application Deadline: Oct. 15, 2012

Chair: Gender, Work and Health:

Research Plan to include ethical considerations.

Application deadline: Oct. 1, 2012

Healthcare Renewal Policy Analysis:

May apply an ethics framework for analysis.

Application deadline: Sept. 19, 2012

Operating Grant: Population Health Intervention Research:

May apply an ethics framework for analysis.

Application deadline: Sept. 14, 2012

Other: ICRH Emerging Network Grants:

Must address relevant ethical issues.

Application deadline: Nov. 11, 2012

Team Grant: Health Challenges in Chronic Inflammation Initiative:

Ethics is a relevant research area.

Application deadline: Nov. 11, 2012

Yes, I think there will be major changes in at least a few areas, and ethics intersects intensively with each of these: in the ability to use biomarkers to predict diseases (e.g., Alzheimer's disease) for which there is still no treatment available; in the use of gene-based therapies for disorders of the CNS – an especially complex area when research shows that people have great difficulty understanding what this involves and what the real promises and risks are; in the use of neuroimaging for

detecting consciousness in patients with traumatic brain injuries; and in deep brain stimulation, which raises questions of when to apply or withdraw it, and what the implications are over time, among others.

The ethical questions arise at the very earliest conceptual stages of research. The relationship between ethics and advances in neuroscience is tightly woven – the more tightly woven, in fact, the better./

Meet Catalyst Grant-Ethics Recipient Mona Gupta



Assistant Professor,
University of Montreal
Psychiatric Medicine,
University of Montreal
Hospital Centre - St-Luc
Hospital. Recipient of
CIHR Fellowship
Award, and Catalyst
Grant-Ethics. Co-
recipient of SSHRC
Research Development
Initiative grant.

On "Innovation":

How would you describe the innovative nature of your work in health ethics?

A great deal of ethics research focuses, appropriately, on clinical decision-making or policy formulation in specific, complex circumstances. In my work, I problematize the circumstances themselves and ask whether the assumptions, principles, or concepts that lie behind these circumstances are well-founded.

On the one hand, examining the basic concepts of a discipline or practice is what philosophers have been doing for centuries. On the other hand, in an action-oriented field like medicine, taking time to unpack core concepts and categories in our field is innovative given that things have to get done, often quite quickly. The kind of work that I do can help us to consider the basics of why we do what we do, questions which can sometimes go unnoticed but when one

stops to reflect on them, can reveal surprising answers.

How does your work in ethics intersect with advances or changing circumstances in other health-related areas?

My work in ethics tends to highlight the areas where ethical values operate but may not be apparent. In other areas of health research such as primary care and chronic care, I see increasing emphasis being placed on the fact that patients and families may have very different perspectives than providers or institutions. These differences often expose the fact that divergent ethical values are at play.

Practice and research show that careful balance and negotiation is needed at times of clashes of values to ensure that

Ethics Resources in Canada: On the WEB

(Selected)

Canadian Council on Animal Care *in science*

[Webinars](#)

Electronic Health Information Laboratory

[Webinars](#)

Joint Centre for Bioethics, University of Toronto

[Bioethics Seminar Series](#)

Inter-agency Advisory Panel on Research Ethics

- [Course on Research Ethics](#)
- [Education- Webinars](#)
- [TCPS 2 Interpretations](#) : responses to written requests for interpretation of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, 2nd edition

Public Health Ontario

"Ethics Now" [Monthly Webinars](#)

Quebec Ministry of Health and Social Services

[Tutorial in Research Ethics](#)

people receive the care they deserve, and that providers are able to give what is needed. Psychiatry happens to be a field where great importance is placed on successfully negotiating diverse values so I believe I am in the right field to help expose some of these areas of divergent values, and contribute to the debate about how to approach such situations.

Do you have any thoughts on where there may be major changes in the future at the intersection of ethics and health?

Given the growing importance that is being placed on recognizing and understanding a variety of moral viewpoints from different stakeholders

whether in clinical practice or policy, I believe that an important future direction in ethics research will be the question of who sets the clinical and research agenda for health. We tend to rely on health experts to define what counts as good health and how we should achieve it, but increasingly I think we will be depending on patients and families to define health. How exactly to include and incorporate the full range of viewpoints on this topic may end up being an important focus in health ethics./

Continued from Page 1- Interview with Maxwell Smith

“Do our values in preparing for and responding to public health emergencies differ from our values in addressing non-emergency public health issues, and if so, how?”, and finally, “Should we draw upon central values or principles of public health (or public health ethics), in our preparation and response to public health emergencies?” By exploring the moral underpinnings of our policies and practices, I believe that greater insight can be gained to guide our actions in these areas.

How does your work in ethics intersect with advances or changing circumstances in other health-related areas?

I think that my work in ethics has a distinct orientation that can be contrasted with traditional perspectives and approaches in the field of bioethics.

Because my work is concerned with ethics and public health, it is generally concerned with ethical questions related to populations rather than the individual; the latter, many have argued, being the traditional focus of bioethics. Because bioethics has largely focused on ethical issues in the context of clinical biomedicine and, as such, has focused largely on the

individual, the field has been dominated by a paradigm with key principles, concepts, ethical theories, and methodological approaches. So, I think that my work in ethics is indicative of changes and reorientations that are beginning to be, and perhaps should be, considered not only in public health but also in other areas of health.

Do you have any thoughts on where there may be major changes in the future at the intersection of ethics and health?

I can't claim to be a great prognosticator but I think there will be two major changes: one substantive and one methodological. In the past decade much interest has emerged in the area of ethics and public health emergency preparedness and response, largely as a result of SARS, acts of bioterrorism, and the presence and persistent threat of pandemic strains of influenza.

While a great deal of scholarship and policy guidance has been produced that seeks to guide the preparation and response to each of these public health emergencies, I think that a combined, all-hazards approach to preparing for and responding to public health emergencies will be the way of the future. It is my hope that my

Upcoming Ethics Events in Canada

(Selected)

[Canadian Conference on Global Health](#)

October 21-23, 2012
Ottawa, Ontario

[Canadian Bioethics Society- National Health Ethics Week](#)

February 25 – March 1, 2013

The CBS, in collaboration with an organizing committee made up of volunteers from around the country and with the Nova Scotia Health Ethics Network (NSHEN), is currently developing materials to support a national ethics week in Canada in order to raise awareness and promote discussion about ethics issues that arise in health care practice. Materials will be available in September 2012. If you would like further information or are interested in joining the organizing committee, please contact [Marika Warren](#).

[Canadian Association of Research Ethics Boards - National Conference](#)

April 25-27, 2013
Calgary, Alberta

[Canadian Bioethics Society- Annual Conference](#)

New Heights and Broader Plains: Expanding Vistas for Bioethics
May 29-June 1, 2013
Banff, Alberta

work can contribute to a better understanding of the moral foundations that exist or ought to exist for such an approach. Second, I believe that there is a trend of combining normative-philosophical analysis and empirical research to inform how we reason about ethics and health. This trend, if you can call it that, can be very useful but

comes with significant epistemological questions about how this can be done in a meaningful and ethical manner. Scholarship will no doubt continue to investigate the intersection between epistemology and ethics, particularly in relation to health research./