



PRESENTERS AND SESSION CHAIRS PROFILES AND ABSTRACTS

Ali-Khan, Sarah E.	11	Landry, Réjean	40
Atkinson-Grosjean, Janet	12	MacDonald, Chris	41
Badulescu, Dan	13	Melon, Christina C.	42
Bhan, Anant	14	Meslin, Eric	43
Bridger, William	15	Morin, Karine	44
Brunk, Conrad	16	Murphy, Linda	45
Burgess, Michael M.	17	O'Doherty, Kieran	46
Cambon-Thomsen, Anne	18	Otlowski, Margaret	47
Caulfield, Sean	19	Phillips, Peter W.B.	48
Caulfield, Timothy	20	Phipps, Maude E.	49
Chadwick, Ruth	21	Pullman, Daryl	50
Crozier, Gillian K.D.	22	Ravitsky, Vardit	51
Culley, John	23	Ries, Nola	52
Culver, Keith	24	Ryan, Camille D.	53
Einsiedel, Edna	25	Saner, Marc	54
Fairley, Cory	26	Singer, Peter A.	55
Farris, Lily	27	Singh, Jerome A.	56
Fishman, Jennifer	28	Smyth, Stuart	57
Gagnon, Michelle	29	Tansey, James	58
Goulding, Rebecca	30	Tsang, Adrian	59
Green, Shane	31	Unterschultz, Jim	60
Griffin, Gilly	32	Veeman, Michele	61
Hannah, William	33	von Tigerstrom, Barbara	62
Hudson, Kathy	34	Wolbring, Gregor	63
Joly, Yann	35	Yasmeen, Gisèle	64
Kato, Kazuto	36	Young, Judith	65
Knoppers, Bartha Maria	37	Zhai, Xiaomei	66
Komirenko, Zoya	38	Zwart, Hub	67
Lai, Poh-San	39		



Sarah E. Ali-Khan

McLaughlin-Rotman Centre for Global Health

Sarah did undergraduate studies in biochemistry at the University of Canterbury in New Zealand, and a PhD in Pharmacology at McGill University, Montreal. Her PhD focused on molecular mechanisms of pharmaceutically-induced birth defects and pathways of abnormal gene expression in the developing embryo. She joined the McLaughlin-Rotman Centre for Global Health, University of Toronto as a post-doctoral fellow in 2007. With a keen interest in how genomics effects our perceptions of ourselves, and how emerging technologies can be leveraged to improve global health, her current research centres on the intersection of human genomic variation studies, geographical ancestry, personalized genomics, ethics and our concepts of 'race'.

Examining Differential Disease Prevalence in Sub-Population Groups, an African American Multiple Sclerosis Genetics Case Study

Admixture Mapping is a powerful genomic tool for the detection of risk factors associated with complex disease, but because it takes advantage of genetic differences between sub-population groups, a topic controversial in some quarters, there is heightened potential for GE³LS implications. This qualitative study examines an Admixture project run by the International Multiple Sclerosis (MS) Genetics Consortium (IMSGC) mapping genes predisposing African Americans to developing MS, a disease practically non-existent in Sub-Saharan Africa but that increases with genetic admixture with people of European ancestry. We endeavoured to interview scientists, genetic counselors and clinicians involved to uncover GE³LS issues emerging in this early example of Admixture Mapping; however the majority were unwilling to speak with us. Therefore we turned to experts in population genetics and 'race', African American interest groups and other stakeholders. Interviews were analyzed by qualitative methodologies. Among the emerging themes are the importance of pursuing genetic strategies to uncover the bases of health disparity, the crucial need for the responsible framing of genetic results to avoid harms, and the key role of the media in public perception of study results. We are also looking to uncover the utility of such studies in 'looking beyond' race to a more biologically-relevant appreciation of differences between populations of different ancestry, and to distil best practices and ethical guidelines.



Janet Atkinson-Grosjean

University of British Columbia

Janet holds an interdisciplinary PhD in science and technology studies (STS) and science policy (UBC 2002), and an MA in Liberal Studies with an STS focus (SFU, 1996). She received postdoctoral training in GE³LS and applied ethics. Her work focuses on large-scale science and the ways in which novel institutional and organizational arrangements affect the production and translation of scientific knowledge. She is interested in how research cultures shift in response to new incentives and how the public interest is understood and represented in such arrangements. Her current work focuses on the factors that affect scientists participation (or lack thereof) in the translational mandates attached to funding. The goal is to contribute to a more nuanced understanding within policy guidelines of what constitutes 'translational science.'

Shouting Across the Divide: Integrating Social and Natural Scientists in a Post-Disciplinary World

When natural and social scientists work together in integrated research teams, potential benefits can be significant. This is especially the case in large-scale projects, where answers provided by the natural sciences can only be fully understood in relation to the broader social, political, economic, and cultural contexts. Since Competition 3, Genome Canada has sought to capture the benefits of integrating natural and social scientists by mandating the 'embedding' of GE³LS researchers in funded large-scale projects.

In essence, this policy change creates a number of natural experiments. What are the varieties and mechanics of integration in Competition 3 projects? How are sticking-points overcome? Who holds the power in such relationships? What value is added by integration? As projects mature, how do the dynamics of integrated projects change? What is their trajectory over time? And, how are research relationships and processes (re)negotiated?

Our presentation is grounded in our experience as 'embedded' social researchers on Genome Canada's Pathogenomics of Innate Immunity project. From that embedded location, we will outline the challenges and benefits of participation on an integrated research team. Our analysis provides insight into how social researchers can retain their traditional critical perspectives as 'strangers' and 'outsiders' while functioning as 'insiders' and 'participants.' The emergence of future post-disciplinary spaces, we argue, will be influenced by what we learn about practices that contribute to success and failure in integrated teams.



Dan Badulescu

University of British Columbia

Born in Mexico, recipient of academic awards from Europe and Latin America, Dan Badulescu holds degrees from British and Mexican institutions. He has had a multifaceted career; from being a member of the Diplomatic Corps and UNICEF, active in international negotiations; to top management positions at biotechnology/chemical firms.

His involvement as industry strategy and government policy consultant in the Americas on environment, resources, food and indigenous governance has taken him to a myriad of fora and projects. He is an avid advocate of education and citizen's rights. He currently manages H&A Columbus, a specialized consulting firm with offices in Mexico and Canada and spends his time as a grad student, guest instructor and volunteer at the University of British Columbia and the Universidad Autonoma Metropolitana. E-mail: badulesc@interchange.ubc.ca

Benefits and Policy Making: Genomics and Futures Design in the Global South

Potential benefits to improve quality of life for millions have been wielded as the main drivers by industry, scientist and politicians around the globe to bring genomic technologies into practice, against perceived public mistrust.

In the South, as in the developed North, where the majority of the technologies and patents arise, a heated and polarized debate has been taking place around food and health genomics, outlining plural societies, caught in the middle of an ever increasing globalization process and with a sense of eroding legitimate governance structures.

Absent from global discussions on genomics and policy, Latin America has relied so far on imported, multilateral governance models with weak links to local realities, setting up a high degree of public and stakeholder dissatisfaction.

We argue that the benefits of genomics are localized and difficult to define unless these are brought into regional context and that policy futures can be designed by exploring local experiences around past cases. DDT, RU 486, and nuclear energy shed light on benefit allocation, networks, linkages and tensions in policy design and the ever important implementation phases. In this research, attention is given to the need of stimulating exchanges between North and South, as deep social imbalances become more ubiquitous in affluent societies, thus avoiding neo-colonial behavior at home and abroad.



Anant Bhan

Global Health Initiative, India

Anant Bhan is a physician with a masters' degree in bioethics from the University of Toronto. He works as an independent researcher in the field of global health, public health & bioethics, and is based in Pune, India. He is also a member of the Ethical, Social and Cultural Program for the Grand Challenges in Global Health Initiative based at the McLaughlin-Rotman Centre for Global Health, Toronto. In the past, he has worked for NGOs, and a public health training institution in India. Anant has published in various national and international medical journals, and is an Associate Editor for 'Public Health Ethics', a quarterly journal of Oxford University Press.

Genomics in India: Opportunities and Challenges in an 'Emerging' Economy

The field of genomics and biotechnology is growing in India, with increasing support from the government. This includes the involvement of the private sector, and also collaborations with other countries. With a large diverse population and gene pool, as well as a high prevalence of both infectious and non-communicable diseases, the field of genomics offers opportunities to identify solutions for pressing problems in various areas like health, food supply etc.

Important ethical, economic, social, environmental and regulatory concerns however have been repeatedly brought out in the field of biotechnology in India. The implications for privacy, and also ownership of the research in the field of genomics research have been getting attention. The large and strong civil society sector in India is playing a crucial role in framing some of the discussions and debates in the field. There is also caution raised because of the continuing use of technologies for uses like pre-conception and pre-natal sex selection, past experiences in conserving biodiversity and introducing genetically modified agricultural biotechnology.

The presentation will highlight some of the significant scientific work being carried out in the region. Also the issues being debated in the GE³LS sphere and possible implications for policy would be presented. The role of the civil society sector as an important actor will be examined. Drawing on discussions with experts in the field in India, a framing of some important issues will be identified. This would delve into themes like equity, justice, access, ownership, innovative partnership and economic progress as relevant to policy in India, and also global implications.



William Bridger

Board of Directors, Genome Canada

Dr. Bill Bridger has been a member of the Board of Director of Genome Canada since 2002.

Dr. Bridger was the founding President of the Alberta Ingenuity Fund (2001-2004). Prior to that, he was Vice-President (Research) at the University of Western Ontario. He is a biochemist and molecular biologist, with twenty-seven years as a faculty member at the University of Alberta. Currently, Dr. Bridger is Vice-President of RM Spencer and Associates, Inc., a consulting company with interests in research administration, evaluation, and bioethics.

He is a Fellow of the Royal Society of Canada.



Conrad Brunk
University of Victoria

Conrad Brunk is Professor of Philosophy and Director of the Centre for Studies in Religion and Society at the University of Victoria. His areas of research and teaching include ethical aspects of environmental and health risk management, risk perception and communication, and value aspects of science in public policy. Dr. Brunk is a regular consultant to the Canadian government and international organizations on environmental and health risk management and biotechnology. He served as Co-Chair of the Royal Society of Canada Expert Panel on the Future of Food Biotechnology, and from 2002 to 2004 as a member of the Canadian Biotechnology Advisory Committee. He is a member of the International Forum for TSE and Food Safety and the Council of Canadian Academies Expert Panel on Nanotechnology. He is co-author of *Value Assumptions in Risk Assessment*, a book exploring how moral and political values influence scientific judgments about technological risks, and author of numerous articles in journals and books on ethical issues in technology, the environment, law, and professional practice. Professor Brunk holds a PhD in Philosophy from Northwestern University.



Michael Burgess

University of British Columbia

Michael M. Burgess is a Professor and Chair in Biomedical Ethics at the W. Maurice Young Centre for Applied Ethics and in the Department of Medical Genetics at the University of British Columbia. His research combines qualitative and public engagement methods and social scientific literature review with ethical analysis. He is PI with Peter Danielson of the Genome Canada and Genome BC funded, "Building a GE³LS Architecture." Burgess has recently completed a deliberative engagement on biobanks in BC, and is collaborating on similar events at the Mayo Clinic and in Western Australia.

Publics, Policy and Property: Building a GE³LS Architecture

Animal use, biobanks, intellectual property, and salmon genomics provide case studies for the development of approaches to engaging publics, policy makers and experts in the governance of genomics. The design and evaluation of on-line, face-to-face and workshop-based innovations have been designed in real world contexts, and their success has been extended into international collaborations and applications. These advancements are directly relevant to providing policy advice in genomics in Canada and internationally. Extension to other jurisdictions and emerging technologies must be carefully implemented and evaluated, which require collaboration across scientific and GE³LS partners. The rigor of these methods and their assessment for policy relevance require sustained assessment capacity that is independent of their ability to promote predetermined economic and technological goals. The social-economic benefits of this research are in the development of novel teams, approaches and international collaborations. The economic challenge is to support GE³LS research that can develop integrated approaches to issues related to science and technology while supporting independent and innovative ability to assess the quality and policy relevance of the approaches.



Anne Cambon-Thomsen

Centre national de la recherche scientifique (CNRS), France

Anne Cambon-Thomsen, is MD, with a masters in Human biology and a degree in Health Ethics and is a specialist in human immunogenetics. Director of Research in CNRS (French national centre for scientific research) she presently leads a multidisciplinary team on “Genomics and public health”, involving also human and social sciences in the context of research in epidemiology and public health at Inserm (National Institute for Health and Medical Research) at the Faculty of Medicine of Toulouse, France. She also leads the “Genetics and Society” platform of the Toulouse-Midi-Pyrénées Genopole. She is involved in several EU funded projects in transplantation, genomics sciences, public health or biobanks and has been rapporteur of an EU expert group on ethical, legal and social aspects of genetic testing. Member of the steering committee of GRAPH Int (Genome based research and population health International network), she sits in several scientific advisory boards of international projects and is member of the scientific council of Inserm. She has been member of the CCNE (French national advisory bioethics committee), is a member of the European Group of ethics for science and new technologies (EGE) and Chair the Life sciences operational ethics committee in CNRS.

Social Sciences and Humanities and Genomics: Looking to Each Other or Advancing Together in the European Union and in France?

The European Union (EU) has formally included four kinds of approaches of societal dimensions of genomics in its R&D framework programmes: a first and mandatory modality is to consider ethical aspects in the management of projects; specific panels review those aspects; a 2nd one is to include them as part of the research work, as an identified research task in genomics projects; a 3rd one is a specific line of research or coordination actions in “science and society”, (now “science in society”) with specific funding, where genomics is one among other topics; the 4th one is within the EU R&D in social sciences and humanities where part of the calls make a place for genomics related issues. The advantages, pitfalls and complementarity of these various approaches will be discussed.

In France there is no GE³LS project as such and the societal dimension of genomics are addressed in independent actions: 1) debates and actions toward the public, numerous but without national coordination; participation of researchers is voluntary and often “in addition” not really as part of the research activity; 2) research in social sciences and or humanities, especially a national programme was set up some years ago on “SBSS” (Biomedical sciences, health, society) where a place was done to the development of genomics; 3) the national network of genopole, from 1999 set up some coordinated activities in the domain of ethics of genomics and communication with the general public, but this was abandoned as a nationally coordinated activity and was left since 2003 to local initiatives; this network was considered to have a technological orientation and did not include societal dimensions as a research or methodological dimension at national level. In this context, the initiative of setting up in 2004 a “Genetics and society platform” in one of the French genopoles (Toulouse) was an original initiative that will be described.



Sean Caulfield

University of Alberta

Sean Caulfield, Canada Research Chair in Printmaking and Professor in the Department of Art and Design at the University of Alberta, has exhibited his prints, drawings and book works extensively throughout Canada, the United States, Europe, and Japan. Recent exhibitions include: *Inferno*, Open Studio, Toronto, Ontario; *Recent Prints*, Yanagisawa Gallery, Saitama; and *The 14th International Print Biennial*, Seoul Museum of Art, Korea.

Caulfield has received numerous grants and awards for his work including: SSHRC Fine Arts Creation Grant; Canada Council Travel Grant; and a Visual Arts Fellowship, Illinois Arts Council, Illinois, USA. Caulfield's work is in various public and private collections including: Wright State University, Dayton, Ohio, USA; LiuHaisu Art Museum of Shanghai, Shanghai, China; and Purdue University Galleries.

***Imagining Science: An Artistic Exploration of Science,
Society and Social Change***

In conjunction with the Art Galley of Alberta and Genome Alberta, I am organizing a highly interdisciplinary project entitled, *Imagining Science: An Artistic Exploration of Science, Society and Social Change*. This initiative consists of three components: a workshop, which was held August 23-25, 2007 at the Banff Centre, Banff AB, an exhibition, which will be held at the Art Gallery of Alberta from November 14, 2008 to February 1st, 2009, and the production of a high quality book.

The primary objective of the project is to bring together a group of internationally recognized artists, scientists and "social commentators" (e.g. philosophers, sociologists, legal scholars) to explore the highly charged and complex GE³LS issues that characterize the emerging field of biotechnology. Outputs from this collaboration are twofold: the production of a body of original art work and accompanying essays for the exhibition; and the production of a novel publication that documents and profiles the cutting edge creative and scholarly research of the group.

For this presentation, I will explore the role creative research plays in shaping the discourse surrounding emerging technologies. To accomplish this, I will draw on the work of our current project, and provide a historical overview profiling how art has functioned as a mode of social commentary. The talk will feature images of participating artists, updates on their work, and insights into the ideas, motivations and subject matter driving their work. Topics covered will include: genetics and medicine, genetics and the environment, and the history of science and art.



Timothy Caulfield

University of Alberta

Timothy Caulfield is the Research Director of the Health Law Institute and a Professor in the Faculty of Law and the School of Public Health, University of Alberta. In 2001 he received a Canada Research Chair in Health Law and Policy. He has been involved in a variety of interdisciplinary research endeavours that have allowed him to publish over one hundred and fifty articles and book chapters. He is a Fellow of the Royal Society of Canada, a Senior Health Scholar with the Alberta Heritage Foundation for Medical Research and the Principal Investigator on projects funded by Genome Canada, the Stem Cell Network, the Canadian Institutes of Health Research and the Advanced Foods and Materials Network.

Translating Genomics: Current Research and Future Challenges

Over the past seven years, the Genome Alberta GE³LS research team has been exploring the issues associated with the translation of emerging genomic technologies into health systems. This has included an exploration of: public perceptions and preferences; intellectual property and commercialization challenges; how governing bodies regulate and fund relevant technologies; resource allocation and technology assessment approaches and; the role of popular representations. In some respect, our past work has been in the identification and assessment of social challenges. It is our hope that this work has helped to focus and inform policy debates. As genomic research moves forward, it seems essential to consider, in concrete terms, the ways in which genomic research will impact health care systems. Pharmacogenomics, nutrigenomics, whole genome sequencing, and increasing availability of direct to consumer genetic testing services are but a few of the emerging developments warrant consideration. By drawing on a variety of methodologies, we hope that our research team can provide both empirical data on relevant GE³LS issues and help to craft recommendations that will inform the effective translation of genomic technologies.

“Genetic Determinism in the Media: An Exploration of the Obesity Story”

The popular press plays a significant role in the translation of scientific information to the general public. While it is vital to recognize that the media does not inform or shape public perceptions in a crude linear fashion (that it, the media does not simply transmit opinions that are blindly adopted by the public), the media clearly plays a critical role. It is not surprising, then, that there has long been concern that the popular media has inappropriately represented genetics. Specifically, many scholars, most notably Nelkin and Lindee (1996), have speculated that the media simplifies the science and the relationship between genes and human traits thus facilitating an inappropriately deterministic ethos.

In this presentation, we will: 1) review the available evidence on the genetic determinism issue (e.g., are media portrayals deterministic and what impact do they have on public perceptions?); and 2) present data from our own study on the how the popular press has covered the role of genetics in the obesity epidemic. This topic has received significant media attention and, as such, provides an ideal opportunity to do a systematic analysis of the degree to which genetic stories are presented in a deterministic manner. Moreover, given the complex nature and sources of the obesity epidemic, and the public health importance of the topic, understanding media portrayals in the context seem especially valuable.



Ruth Chadwick

Cardiff University, United Kingdom

Ruth Chadwick is Distinguished Research Professor, Cardiff University, UK. She has co-ordinated a number of projects funded by the European Commission, including the EUROSCREEN projects (1994-6; 1996-9) and co-edits the journal *Bioethics* and the online journal *Genomics, Society and Policy*. She is Chair of the Human Genome Organisation Ethics Committee and has served as a member of the Panel of Eminent Ethical Experts of the Food and Agriculture Organisation of the United Nations, and the UK Advisory Committee on Novel Foods and Processes (ACNFP). She was editor-in-chief of the award winning *Encyclopedia of Applied Ethics* (1998). She is a Fellow of the Hastings Center, New York and of the Royal Society of Medicine. In 2005 she was the winner of the World Technology Network Award for Ethics.

The Impact of Social Science Research: the UK Experience

Discussion about the impact of social science research and how it is measured is the subject of ongoing discussion in the United Kingdom. For example, a recent report from a Symposium of the Economic and Social Research Council (ESRC) said that “research may directly influence changes in policy, practices and behaviour or it may, in more subtle ways, changes people’s knowledge, understanding and attitudes towards social issues”. This quotation addresses the topic of the ways in which impact occurs. There are other dimensions to the discussion, however, including where impact is to be sought; the likely timescale of impact; who the users of research are considered to be and are in fact; whether it is possible to put in place some forms of measurement. As regards the latter there is considerable skepticism, especially in the light of the recognition that subtle longer term impact may be more important than clear and short term changes of direction brought about by social science research. This presentation will take three case studies illustrative of different ways in which social science is considered to have made an impact: relating to the worlds of policy, industry and public engagement. An attempt will then be made to assess the ways in which these experiences might themselves affect future trends, in terms of how social science research is managed and directed.



Gillian K.D. Crozier

Dalhousie University

Gillian Crozier is a Post-Doctoral Fellow in the CIHR Ethics of Health Research and Policy Training Program. She is a member of the Novel Tech Ethics research team at Dalhousie University where, under the mentorship of Professor Françoise Baylis, she studies the ethical, legal, and social implications of genomics on population health. Dr. Crozier's research interests include the effects of various market conditions on the just distribution of scarce biomedical resources, such as health personnel or technologies for genomic interventions. She holds a Ph.D. in Philosophy from the University of Western Ontario, where she specialized in the philosophy of life sciences. Her doctoral dissertation was a conceptual analysis of cultural evolutionary adaptation to environmental conditions.

Market Stimulus and Genomic Distributive Justice

In the debates surrounding the potential impact of human genomic interventions on distributive justice, much attention is paid to determining whether (and if so, how) to restrict access to these technologies in order to avoid exacerbating socio-economic inequalities. In this context, I critically examine the significance of Market Stimulus – the idea that free markets can play a role in widening access to genomic technologies. Typically, novel technologies are priced too high for most consumers; yet, by initially attracting wealthy consumers, prices are expected to gradually decline as production processes become standardized (and more efficient) and as these technologies are replaced by improved versions. For example, fifty years ago computer hard drive storage cost \$10,000 per megabyte, but consumers can now purchase a thousand times this much storage for under a dollar. Analogously, one might anticipate that a germ-line intervention to enhance cognitive capacities could initially have a five or six figure price, but become affordable to middle and low-income parents within just a few generations. I argue that Market Stimulus, even if it applies to human genomic interventions, does not provide sufficient reason for deregulating germ-line enhancements. Specifically, the following three objections must be addressed when determining whether, and in what cases, a laissez-faire approach to human germ-line enhancements meets the requirements of justice: (1) this approach is unlikely to produce enough benefits for the worst off to justify this strategy, (2) this approach may have dire consequences for future generations, and (3) socio-economic status is itself a determinant of health.



John Culley

Agriculture and Agri-Food Canada

John Culley has worked with Agriculture and Agri-food Canada (AAFC) for about 15 years as a soil physicist. In 1991 he became Research Team Head, then Assistant Director at Saskatoon Research Centre where he led the establishment of the oilseed biotechnology group. Since 1997 he has worked at AAFC's HQ. Much of his time has been devoted to developing commercial technology transfer capacity in the department, and doing research and technology transfer agreements. Since 2003 he has been the Director of AAFC's Office of Intellectual Property and Commercialization.

Executing Multi-Institutional IP Development Agreements in Canada

Agriculture and Agri-food Canada has for many years engaged in important research partnerships with Canadian universities. The department maintains six research facilities on, or near, Canadian university campuses. Government-academic partnerships in agricultural research have a proud history, the development of canola being a shining example. The pervasive development of the knowledge-based global economy, and with it, the growing importance of intellectual property rights, have served to complicate both the negotiation, and the execution, of many of our multiparty IP agreements.

Agriculture and Agri-Food Canada commissioned a study of barriers to the execution of multiparty research agreements. Our purpose was to survey the prevalence of, and outcomes from, multi-institutional research agreements. Using international comparisons, we wished to assess Canadian performance in executing these agreements, identify better practices available elsewhere, and provide options for improving Canadian outcomes from multiparty agreements.

We conclude from our study that Canadian governments should contemplate options, either by way of implementation of policy or legislation, to regulate conditions including the ownership, and accountability for the transfer, of IP arising from their funding. Canada lacks performance frameworks to measure social and economic benefits arising from the public's investment in R and D. The establishment of a common measurement framework together with required monitoring and reporting of outcomes and socio-economic impacts would serve both the public and our research communities. Canadian technology transfer competencies and capacities would also benefit from a competitive market-based approach to service provision. Accredited training programs for technology transfer would also help Canada's competitive position.



Keith Culver

University of New Brunswick

Keith Culver is Associate Professor, Department of Philosophy and Director, Centre for Social Innovation Research, University of New Brunswick. A veteran of no less than five Genome Canada-supported GE³LS research projects, he led the GE³LS efforts of the first 'integrated' science-GE³LS research in the Canadian Potato Genome Project. Trained in jurisprudence, he has published in law, philosophy, and interdisciplinary efforts including (co-edited with David Castle) *Aquaculture, Innovation and Social Transformation* to be published by Springer in 2008. In 2008 Culver is Fisheries and Oceans Canada Visiting Professor in Science-Policy Integration, and will be a Visiting Fellow at the University of Edinburgh, School of Law.



Edna Einsiedel

University of Calgary

Edna Einsiedel is University Professor and Professor of Communication Studies at the University of Calgary. Her research focuses on the social issues around controversial technologies. She has also done studies on public and stakeholder participation in technology assessment and decision-making around biotechnology and genomics applications. She served as team leader for a GE³LS project supported by Genome Canada on Genomics, commercialization and society from 2001-2005. She is a co-leader on a second GE³LS project on Genomics and knowledge translation in health systems (2006-2009). Her studies have been published in a range of journals including Nature Biotechnology, Science, Public Understanding of Science, Science Communications, and Science and Engineering Ethics. She is currently editor of the international journal Public understanding of science. She also serves as member of the Board of Governors for the Council of Canadian Academies of Science and of the Science and Industry Advisory Committee of Genome Canada.



Cory Fairley

University of British Columbia



Cory is a PhD student in the Department of History at UBC and a Research Assistant on the Translational Genomics Study (embedded GE³LS component of the PI2 Project). Prior to joining UBC's History Department, he completed an MA in UBC's Department of Philosophy. His current research interests centre on the social, political, and ethical impact of 20th century biotechnology research and, in turn, the influence social and political institutions have on such research, particularly via the market economy. At the W. Maurice Young Centre for Applied Ethics he is currently engaged in a study of knowledge production and translation in large scale science, the moral and political economies in which scientists work, and the factors influencing their participation.

Industry-Academy Partnerships, Philanthropy, and Global Access: Strategies for Negotiating Conflicting Goals

As industry and the academy draw closer together, academic life sciences research has increasingly adopted expressly translational goals. Translational goals are not a new facet of life sciences research, but alterations in the funding landscape designed to increase interaction between industry and the academy have brought to the fore complex issues concerning accessibility of publicly funded research. As partnerships and industry sponsored research have become integral, even mandated parts of many large-scale research projects in Canada and elsewhere, industry has argued for the necessity of proprietary protection in order to encourage and protect investment. Recently, such measures have come into conflict with those arguing that publicly funded research ought to be accessible to the developing world where, despite the lack of a viable market for new therapeutics, such products are likely to be immensely beneficial. This paper examines strategies for negotiating conflicts between industrial investments in publicly funded research programs and demands that the fruits of such research ought to benefit those in need. Among these strategies are multi-party licensing agreements aimed at protecting proprietary rights where markets exist, while also securing access to publicly funded research for the developing world. Increasingly, philanthropic agencies play a key bridging role through targeted funding on the translational model which facilitates both proprietary protection where markets exist and accessibility for the developing world. This paper examines the benefits, challenges, and potential pitfalls of such strategies, particularly in the context of developing world access to (partially) publicly funded research performed primarily in academic environments.



Lily Farris

The W. Maurice Young Centre for Applied Ethics

Lily Farris, GE³LS Researcher: *C. elegans* Gene Knockout Consortium. Lily's past research interests include the sociology of health and illness, migration studies, ethnic relations and peace and conflict studies. As a member of the *C. elegans* knock-out consortium GE³LS team, Lily is developing methods for assessing and tracking the use of open source Canadian genomics research in order to understand the global impact of freely-available data. As a member of the Translational Genomics GE³LS Project, Lily analyzed survey data to explore the factors that impacted willingness to engage in translational research and conducted a case study on open-source bioinformatics database development. Lily's MA (UBC, Sociology) and BA (UBC, Honours Sociology) research focused on analyzing the factors that impacted public opinion toward immigration policy in Canada, the United States and the United Kingdom.

Genomics Gate-keepers: Technology Transfer Offices, IP Policy Development and the Uptake of Alternative Licensing Practices

Intellectual Property (IP) practices evolve in response to issues raised by "traditional" patenting and changes in the processes of innovation. In the case of genomics research funded by Genome Canada, Technology Transfer Offices (TTOs) are effectively the gatekeepers for commercial research translation, and as mediators for many of the issues raised by health-related genomics research they have the ability to address the following concerns: (1) patenting upstream research has anti-commons effects; (2) universities and Science are losing their historical commitment to the free flow of knowledge; and (3) claims that traditional IP diminishes potential for citizens, particularly in the developing world, to benefit from this research. Many have debated whether alternative IP practices, including patent pools, open source, and public domain, mitigate these concerns. TTOs are in the process of developing new policies and practices that may be the most direct means to lessen these concerns. We report here on our studies of several TTOs in British Columbia that are developing measures including: (1) 'graduated' licensing practices like those recommended by OECD and the "Nine Points To Consider" document; (2) principles of access that consider the needs of the developing world; and (3) performance metrics that account for factors beyond the purely economic ones traditionally employed by AUTM. In addition, we explore the relationship between the competing pressures on TTOs to respond to concerns about IP practices and those expressed by the upstream genomics research scientists themselves.



Jennifer Fishman

McGill University

Jennifer Fishman is Assistant Professor in the Biomedical Ethics Unit at McGill University. She received her PhD in Sociology from the University of California, San Francisco. Prior to joining McGill, Dr. Fishman held a faculty position in the Bioethics Department at Case Western Reserve University.

Her research focuses on the commercialization and commodification of scientific research and health care delivery. Her previous work examined academic-industry relationships for pharmaceutical drug development. Ongoing projects include examining the ethical and social implications of anti-aging science and medicine, the commercialization of direct-to-consumer genetic tests, and the bioethics of modern food production and consumption. Her work has been published in such venues as *Social Studies of Science*, *American Journal of Bioethics*, *American Sociological Review*, and *Rejuvenation Research*.

***ELSI Research in the United States:
Report from the Translating ELSI Conference***

In this brief presentation, I will attempt to characterize ongoing research in the social science and humanities on genomics and biotechnology in the United States. Analysis of the type of research in these areas in the United States will be based on the conference program from the upcoming *Translating ELSI: Ethical, Legal and Social Implications of Genomics* conference to be held in Cleveland, Ohio in May 2008. Sponsored by the Ethical, Legal and Social Implications Program (ELSI) of the National Human Genome Research Institute, National Institutes of Health, the conference is designed as a way for ELSI grantees, in particular, to present their work to the larger ELSI community. While this is not a representative sample of the work being conducted in the United States by any stretch, it is a way for us to take a broad look at the types of issues and approaches used in the United States to study ethical and social issues in genomics and biotechnology.



Michelle Gagnon

Canadian Institutes of Health Research

Michelle Gagnon is currently Acting Director of Knowledge Synthesis and Exchange (KSE) Branch at the Canadian Institutes of Health Research (CIHR). The branch is responsible for strategic programs and policies to advance knowledge translation, including commercialization. Since joining CIHR in 2001, Michelle has also spent a number of years working with the CIHR Institutes of Health Services and Policy Research and Population and Public Health as the Assistant Director of Partnerships and Knowledge Translation. Michelle holds undergraduate degrees in General Arts and Nursing and a Masters of Business Administration. She is currently completing a PhD in the University of Ottawa's Population Health PhD Program.

Bridging the Knowledge to Action Gap

Knowledge translation is a fundamental part of CIHR's mandate; "The objective of the CIHR is to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its **translation** into improved health for Canadians, more effective health services and products and by strengthening Canadian health care system, by..." ([Canadian Institutes of Health Research Act](#), 2000, p.7)

CIHR defines knowledge translation as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user.

This presentation will discuss knowledge translation at CIHR with a focus on the two types of KT that CIHR supports – integrated knowledge translation and end-of-grant knowledge translation, as well as KT policy innovations, such as open access and trials registration and results disclosure. Through our innovative and evolving suite of programs and policies grounded in collaboration with key stakeholders, CIHR aims to minimize and address the knowledge to action gap, or the gap between what we know from research evidence and how we act on this knowledge to improve health and the health system.



Rebecca Goulding

The W. Maurice Young Centre for Applied Ethics

Rebecca Goulding has recently joined the Intellectual Property Policy Research Group (IPPRG) at the W. Maurice Young Centre of Applied Ethics, UBC, as a researcher, soon to be post doctoral fellow. She received her undergraduate degree in genetics and MSc in haematology/oncology research at Trinity College Dublin. Her PhD work in genetics (UBC) at the BC Cancer Research Centre was focused on Ras protein signalling pathways in lymphocytes and the molecular genetics of leukemia development.

Genomics Gate-keepers: Technology Transfer Offices, IP Policy Development and the Uptake of Alternative Licensing Practices

Intellectual Property (IP) practices evolve in response to issues raised by “traditional” patenting and changes in the processes of innovation. In the case of genomics research funded by Genome Canada, Technology Transfer Offices (TTOs) are effectively the gatekeepers for commercial research translation, and as mediators for many of the issues raised by health-related genomics research they have the ability to address the following concerns: (1) patenting upstream research has anti-commons effects; (2) universities and Science are losing their historical commitment to the free flow of knowledge; and (3) claims that traditional IP diminishes potential for citizens, particularly in the developing world, to benefit from this research. Many have debated whether alternative IP practices, including patent pools, open source, and public domain, mitigate these concerns. TTOs are in the process of developing new policies and practices that may be the most direct means to lessen these concerns. We report here on our studies of several TTOs in British Columbia that are developing measures including: (1) ‘graduated’ licensing practices like those recommended by OECD and the “Nine Points To Consider” document; (2) principles of access that consider the needs of the developing world; and (3) performance metrics that account for factors beyond the purely economic ones traditionally employed by AUTM. In addition, we explore the relationship between the competing pressures on TTOs to respond to concerns about IP practices and those expressed by the upstream genomics research scientists themselves.



Shane Green

Ontario Genomics Institute

Dr. Shane Green is the Director of Outreach at the Ontario Genomics Institute (OGI). He is responsible for OGI's public outreach and education initiatives, which aim to increase awareness and understanding of genomics and related sciences and their social impacts, and leads OGI's GE³LS Support Program. Dr. Green holds an honours B.Sc. in Molecular Biology and Genetics from the University of Guelph and a Ph.D. in Medical Biophysics (Cell and Molecular Biology Division) from the University of Toronto. He has studied and taught bioethics and research ethics through the University of Toronto Joint Centre for Bioethics and the American Medical Association (Chicago, IL), and served on the Research Ethics Boards of two major health research centres in Toronto.



Gilly Griffin

Canadian Council on Animal Care

Dr. Griffin trained as a physiologist in the UK and has a background in both biomedical and agricultural research, the common link being the study of insulin and related hormones. Dr. Griffin has also spent many years working to further principles of humane experimental technique: as a research scientist; as managing editor of ATLA (Alternatives to Laboratory Animals), the peer-review journal published by the UK-based Fund for the Replacement of Animals in Medical Experiments; and as Executive Director of the Canadian Centre for Alternatives to Animals in Research. Since 1994, Dr. Griffin has worked for the Canadian Council on Animal Care, the national organization responsible for overseeing the ethical use of animals in science. She is currently the CCAC Guidelines Program Director.

Impact of Emerging Science and Technology on Canada's Governance System for the Ethical Use of Animals in Science

To accept the use of animals in science, the public expects good oversight, reduction of animal numbers and minimization of pain and distress. The fundamental principles of humane science on which the Canadian Council on Animal Care (CCAC) system of governance of animal use in science is based -- replacement, reduction and refinement, are being challenged by new technology. Development of genetically-engineered animals to investigate human disease is leading to an increase in the numbers of animals used, and to the potential for unanticipated pain and distress. The CCAC system is effective in focusing animal welfare issues, and the new CCAC *guidelines on: genetically-engineered animals* will introduce measures to improve the implementation of the Three Rs in this area.

The CCAC governance system involves community representation at all levels. This ensures the inclusion of societal values in the development of guidelines and during the ethical review of protocols. There are ethical issues (such as the intrinsic nature or dignity of an animal) that are broader than animal welfare and that are important to the Canadian public. These are less well handled by the current CCAC system. This presentation will examine the current points at which ethical discussions are engaged – during guidelines development and during the review of protocols by animal care committees, and consider where additional elements may be necessary in the system to ensure public confidence in the oversight of new technologies involving animal use.



William Hannah

University of Ottawa

Bill is pursuing his PhD in philosophy at Michigan State University. His research focuses on ethical and philosophical questions associated with technology and risk in society. He currently works as a Research Assistant on the Institute for Food and Agricultural Standards Agrifood Nanotechnology project. As well, he works as a Science Policy Analyst at the University of Ottawa researching policy implications for emerging technologies.

Uncertainty and Risk Assessment of Nanotechnologies

Diverse techniques and technologies described as “nanotechnologies” are in use already. However, for funding agencies, risk assessors, regulators, and the public, nanotechnology remains an emerging field. As with biotechnology, risk assessment will be used to inform the regulation of nanotechnology. This paper will argue that traditional risk assessment will not provide what regulators demand. Risk assessment will not provide evidence-based or science-based conclusions about the risks of nanotechnology. The uncertain aspects of nanotechnology combined with the inability of risk assessment to adequately deal with uncertainty will leave regulators wanting for guidance on how to regulate this emerging technology. Both intentionally introduced trait variability of nanomaterials from their natural counterparts and the inherent variability of nanomaterials from similar materials at larger sizes will make risk characterization of nanomaterials nearly impossible. Given this pervasive uncertainty, expectations must change. Regulators must be able to make use of the recommendations of risk assessment through the application of decision-rules that are democratic and adaptable. These will not come from the risk evidence.



Kathy Hudson

The Johns Hopkins Institute, USA

Kathy Hudson, Ph.D., is the founder and director of the Genetics and Public Policy Center at Johns Hopkins University. Dr. Hudson founded the Center to fill an important niche in the science policy landscape addressing public policy issues raised by advances in human genetics. Her special interests include policy issues related to human reproductive genetic technologies, genetic testing, biobank governance, and public engagement in genetic and biomedical research.



Yann Joly

Université de Montréal

Yann Joly, L.L.B., L.L.M., is a lawyer, research associate and project manager for the Humgen research group of the Centre de recherche en droit public at Université de Montréal. His research focuses on intellectual property, international law and bioethics. Yann is currently completing a doctorate in civil law (D.C.L) at the McGill University Faculty of Law. His thesis addresses the use of open models of collaboration in of biotechnology. Yann has sat as a legal representative on many research ethics committees at the McGill University Health Centre. He is currently a member of the ethics advisory committee at Genizon BioSciences and the North American coordinator of the Association for Research and Formation in Medical Law.

(Dis)interested Science? Suggestions to Protect Freedom and Integrity in Genomic Research while Promoting Technology Transfer

Research Questions: Do the benefits of commercialization justify the increasing commodification of academic science? Are there alternative ways to achieve similar or greater societal benefits while maintaining an open academic environment?

Background: University institutions in the twenty-first century have three main goals: to teach, to research and more recently, to commercialize. This third goal raises interesting ethical and legal concerns, as it has been observed that focusing on profit affects scientific performance by diverting research interests towards more financially rewarding endeavors and by creating a more secretive scientific environment. This project confronts the latter of these consequences.

Research secrecy interferes with the ability of researchers to access and build upon scientific discoveries. It raises the transaction costs of collaboration and can frustrate the dissemination of new ideas through imposed publication prohibitions and delays. In turn, this decreases the moral of the scientific community.

Method: Through both a survey of the scholarly literature and normative guidelines as well as first-hand interviews with genomic researchers, we assessed the practicality and efficiency of a range of solutions to ameliorate the adverse effect of research commercialization including intellectual property reform, good licensing practices, publication guidelines, increased guidance and oversight and open source alternatives.

Results: Based on the results of our research, a “Points to Consider” will be presented. This “Points to Consider” aims to reduce the tension between the need to protect open science and the need to ensure a smooth technology transfer process towards clinical application of the fruits of genomic research.



Kazuto Kato

Kyoto University, Japan

Kazuto Kato is Associate Professor of Science Communication and Bioethics at the Institute for Research in Humanities and Graduate School of Biostudies, Kyoto University. He has a PhD degree in developmental biology from Kyoto University. After finishing his postdoctoral research at the Wellcome Trust/Cancer Research UK Gurdon Institute at the University of Cambridge, he changed his research to the interface between bioscience and society 15 years ago. He has been working on science communication as well as ethical and social issues of bioscience. He is a member of HUGO ethics committee and was a member of the ELSI group in the International HapMap project.

Research on social and ethical issues of genomics and bioscience in Japan

Japan has been an important player in the major genome research projects such as The Human Genome Project and the International HapMap Project. It has also been spending substantial amount of money for various kinds of genomics research. However, research activities on social and ethical issues of genetics and genomics in Japan have not been as high as those in Europe and North America. While there have been relatively large numbers of research in medical ethics dealing with, for example, patient care and euthanasia, fewer research groups have been working on issues of new biomedical research such as genomics and stem cell research.

This situation has been rapidly changing in recent years. One of the notable changes is that large research projects such as Biobank Japan and the Genome Research Project supported by Grant-in-Aid for Scientific Research on Priority Areas from the government have research activities on social and ethical issues within the Projects. The newly created Center for iPS cell research and application at Kyoto University will also have a department for medical ethics.

In the past, lack of effective communication and collaboration between scientists and researchers in humanities and social sciences has been a problem in Japan, but researchers in younger generation have more flexible way of thinking. The issue of public involvement and participation is also considered as an important area and several new research projects in this area have started last year.

I will discuss the new directions of research on social and ethical issues of genomics and bioscience in Japan.



Bartha Maria Knoppers

Université de Montréal

Bartha Maria Knoppers, PhD, holds the Canada Research Chair in Law and Medicine and the Chaire d'excellence Pierre de Fermat (France). She is Professor at the Faculté de droit, Université de Montréal and Senior Researcher at the Centre de recherche en droit public (CRDP). Professor Knoppers is former Chair of the International Ethics committee of the Human Genome Organization (HUGO), (1996-2004). She was a member of the International Bioethics Committee of the United Nations, Educational, Scientific and Cultural Organization (UNESCO) which drafted the Universal Declaration on the Human Genome and Human Rights (1993-1997). She is also Co-Founder of the International Institute of Research in Ethics and Biomedicine (IIREB). From 2000-2006 she served on the Board of Genome Canada, and in 2003, became Chair of the Ethics Working Party of the International Stem Cell Forum as well as founding the international Public Population Project in Genomics (P3G). Professor Knoppers has received three Doctorates Honoris Causa from the University of Waterloo, Université de Paris V and McMaster University, Ontario. In 2002, she was elected Fellow of the American Association for the Advancement of Science, was selected as one of the 50 nation builders in Canada by the Globe and Mail, and named Officer of the Order of Canada. In that same year, she was elected Fellow of The Hastings Center (Bioethics), New York, member of the International Ethics Committee of the World Anti-Doping Agency and, in April 2005, Fellow of the Canadian Academy of Health Sciences (CAHS). She was elected Governor of the Quebec Bar in 2006 and in 2007 was elected Advocatus Emeritus.

Québec: Canadian Regional Roundup & New Directions

Québec GE³LS research is characterized by the very features that make up the acronym. Projects range from trees, to developmental brain diseases, commercialization, pharmacogenomics, population genomics and public health. Added to these research sectors is the support of the Genome Québec GE³LS Advisory Committee. The latter has recently adopted a 2008-2011 action plan with a concentration on knowledge transfer and on the study of the possible applications of GE³LS research. Several innovative public initiatives were undertaken in the last years. This presentation will highlight the above as well as offer some indicators of future directions.

"Genomics, Public Health and Privacy"

The combination of genomics with public health research and its potential applications raises fears due to associated socio-historical perceptions. Genomics together with public health may conjure up eugenics. Public health itself is associated with vaccines, quarantines and state powers. Little attention is paid however, to the issue of the research needs of public health genomics and the privacy of citizens in this context. Since public health is of interest to all, what is or will be the role and place of genomic knowledge? This presentation aims to address three questions:

- I) What are the mechanisms for access by researchers to population research databases for public health purposes?
- II) What are the mechanisms for access to public health databases for population research purposes?
- III) Is the protection of privacy and personal data the appropriate tool for the determination of such access issues?

Our research on comparative, international approaches will be used for the analysis of these issues. The quality of science, the success of public health strategies and trust, and participation in both research and societal health initiatives depend on the proper framing of these issues.



Zoya Komirenko

University of Alberta

Zoya Komirenko is a full time PhD student of University of Alberta working with Prof. Jim Unterschultz in the Department of Rural Economy. She has M.Sc. in Horticultural Economics obtained in Leibniz University of Hanover (Germany), with a thesis centered on importance of urban agriculture practices for the livelihoods of urban households in Ukraine. Her research interests include aspects of new technology adoption on the farm level and returns to agricultural research in Canada. She was born in Fastiv (Ukraine).

Cold Tolerance in Wheat: Technology Adoption Aspects

Cold tolerant cereal grain technology has a high potential impact on crop variety choice in Western Canada due to the high variability in growing season length and conditions. The Prairie Genome supported Crop Adaptation Genomics research program is researching improved cold tolerance in cereal crops. Knowledge of the factors influencing the decision of producers to adopt a new technology is useful to those developing these traits and trying to predict future demand levels. The goal of this study is to aid in focusing cold tolerance technology research on the attributes that producers want and need and to understand key determinants in the adoption process.

Data derived from an in-person survey conducted in Alberta were used to determine the characteristics desired by crop producers in developing cold tolerance wheat varieties through plant breeding. Analysis included a logit model estimation to determine producer's willingness to pay for the increased cold tolerance and decreased days to maturity in wheat. Alberta farmers are willing to pay six to eight percent more for cold tolerant varieties. It was also found that some of the traditional thoughts such as the higher the frequency of frost damage the greater the chance that the new technology will be adopted or the region has a significant influence on adoption behavior do not hold true in specific reference to adoption of cold tolerance technology in wheat.



Poh-San Lai

National University of Singapore

Poh-San Lai is Associate Professor at Department of Pediatrics, National University of Singapore and heads the Human Molecular Genetics Lab. She has been involved in the development of genetic tests for molecular diagnosis of pediatric genetic diseases in Singapore and set up the laboratory for molecular testing, prenatal diagnosis and genetic counseling in 1992. Her other major research interest is in molecular therapeutics for gene repair. She is currently the President of the Biomedical Research and Experimental Therapeutics Society of Singapore, Board Member of the Asia-Pacific Society of Human Genetics and member of the Singapore National Medical Research Council Scientific Review Committee. She is also a Senior Editor of *Annals of Human Genetics* and co-Chair, Policy Review Board of the Pan-Asian SNP Initiative. She co-ordinates the ELSI issues and policies arising from this multi-national Initiative involving more than 10 Asian countries. Through collaborative networks and training of scientists from less developed countries, this Initiative aims to study genetic diversity among Asian people and ethnicities and create an Asian SNP population database for future applications in disease association and population studies.

An Introduction to the Pan-Asian SNP Initiative and Genomics in Singapore

In response to global developments in science and technology, the Singapore Biomedical Sciences (BMS) Initiative was launched in 2000 to develop Biomedical Sciences as a key pillar of the nation's economy. This Initiative sought to develop core research capabilities, nurture human and intellectual capital, support world class research activities, drive translational research and foster international as well as regional collaborations. These strategies have significantly changed the local research landscape. Existing research activities and scientific expertise were consolidated. Public awareness of ethical, social and legal issues related to science and technology was heightened. Research priorities were defined in response to Singapore's needs, for example in addressing the SARS crisis in 2003 and the changing trends in disease burden arising from an ageing population. To promote regional cooperation in genomics, the Pan Asian SNP Initiative (PASNPI) was formed by scientists from 11 Asian countries in 2005 with a secretariat based in Singapore. Its main aim was to map the genetic diversity in the region. Completed within two years, PASNPI succeeded in characterizing more than 54,000 genomic single nucleotide polymorphisms (SNPs) in 1,928 individuals from 73 diverse ethnic populations in Asia. It established a framework for the exchange and sharing of resources and expertise between the developed and the emerging countries in Asia. It also created a publicly available genomic database as a resource for future studies in population genetics, disease mapping and pharmacogenomics. A Policy and Ethics Review Board was formed within the Initiative, and hosted in Singapore to address the complex social and ethical issues associated with this work.



Réjean Landry
Université Laval

Dr. Réjean Landry is Fellow of the Royal Society of Canada since 1999. He is the holder of a Chair on Knowledge Transfer and Innovation funded by the Canadian Health Services Research Foundation and the Canadian Institute of Health Research. Dr Landry is professor at the Department of Management of the Faculty of Business at Laval University in Quebec City where he teaches on knowledge transfer and knowledge management. He has published extensively on public policies, innovation and knowledge transfer. His most recent works on knowledge transfer and innovation have been published in *Journal of Technology Transfer*, *Research Policy*, *Public Administration Review*, *Technological Forecasting and Social Change*, *Technovation*, and *Science Communication*. His research team edits a weekly electronic newsletter: *E. Watch on Innovation in Health Services*, which is disseminated to 5000 people, including about 400 researchers and 4600 managers and professionals in health services in Canada and abroad.

***How to Create or Increase Value from the Use of Knowledge?
A Roadmap and a Short Assessment of Canadian Knowledge Transfer Practices***

The central question of this presentation will be: "How to create or increase value from the use of knowledge?" We will contend that knowledge transfer is an incomplete concept and we will advocate the more comprehensive concept of knowledge transfer as a value creation process which includes knowledge transfer and additional concepts into an integrated conceptual framework that leads to the derivation of business models. We will suggest that organizations transforming knowledge in order to create value achieve four functions performed as a sequential four-stage process that involves: identification of knowledge-based opportunities, conversion of knowledge-based opportunities into new or improved products, services and practices, communication of the developed knowledge to other units in your organization or to other organizations, and appropriation of the value of the communicated knowledge through implementation or commercialization. Knowledge and technology transfer organizations could benefit from the use of a road map that would help them to identify some overall direction regarding how they might improve their practices regarding the identification, transformation, communication and appropriation of knowledge based opportunities, and therefore to improve their knowledge business transfer models. We will conclude by comparing strengths and weaknesses of different knowledge business transfer models that currently operate in Canada.



Chris MacDonald
Saint Mary's University

Chris MacDonald is a Tenured Associate Professor in the Department of Philosophy at Saint Mary's University. His work is focused on corporate decision-making about biotechnology and nanotechnology. His research has been supported by grants from the Canadian Institutes of Health Research (CIHR), the Social Sciences and Humanities Research Council of Canada (SSHRC), and the Nova Scotia Health Research Foundation (NSHRF). He was recently a Visiting Scholar at Alberta's Provincial Health Ethics Network during Bioethics Week, and keynote speaker at CIHR's "Ethics Office Day." He has published widely on topics ranging across business ethics, professional ethics, bioethics, and moral theory, and is currently completing a book on business ethics issues in the biotechnology industry.

Regulatory Capacity & the Ethical Responsibilities of Biotech Corporations

In liberal democracies, we generally expect a 'division of labour' between industry and government. That division of labour may not be tenable regarding biotechnology. Respectful of divergent visions of "the good life" and of the goods and services the good life requires, governments *generally* leave the choice of what to produce to the discretion of the private-sector. In liberal democracies, government intervention (regarding production) is mostly limited to restricting the production and/or sale of a few goods that are seen as inherently dangerous (e.g., munitions) or that are the subject of nearly universal moral condemnation (e.g., child pornography), and setting safety and quality standards for other goods (e.g., automobiles and pharmaceuticals) that are hard for consumers to evaluate. Private-sector decision-makers, for their part, are left to focus on making profits through producing goods and services that consumers want, within the 'rules of the game' set by government. Whether those rules are adequate is generally not the concern of business: it is up to government to set appropriate limits, and up to business to work within those limits. But this idealization may weaken in regards to the biotechnology sector. Government is often accused of lacking the resources to adequately assess new biotechnologies (e.g., GMO's). This suggests that, even in well-regulated liberal democracies, biotech companies (perhaps unlike other companies) cannot simply point to having met all relevant government regulations as evidence of their good corporate citizenship. In this context, new understandings are needed of the proper interaction between government and industry.



Christina C. Melon

The McLaughlin-Rotman Centre for Global Health

Christina C. Melon is researching international research and entrepreneurial collaborations in health biotechnology under Dr. Halla Thorsteinsdóttir, at the McLaughlin-Rotman Centre for Global Health. Before joining the Centre's Programme on Life Sciences, Ethics & Policy, she was involved in several projects related to child-maternal health in India, and held varying positions within the realm of health. Christina holds a Master's degree in Public Health, Health Services Management from the London School of Hygiene and Tropical Medicine, as well as an Honours Bachelor of Arts degree from McMaster University where she studied Medical Anthropology and Health Studies.

Connecting the Dots: A Survey of South-South Entrepreneurial Collaboration in Health Biotechnology

While international collaboration is not new to developing countries, the emphasis on south-south collaboration by the governments of these nations has been growing. With policies and programmes aimed at encouraging such collaboration within the science and technology sector, and even within biotechnology specifically, the promotion of collaborative efforts between these countries is seen as a means of fostering innovation towards shared health goals, and essentially global health outcomes.

Through the collection and analysis of survey data, we have effectively mapped existing entrepreneurial collaborations in health biotechnology between Brazil, China, Cuba, Egypt, India, South Africa, and their partnering organisations in other developing countries. The responses of 288 firms in these countries have provided insight into the reasons for collaboration, activities and technologies involved, outputs, and the initiating party behind each collaboration. Of equal importance, the survey data has also permitted us to visually map the linkages that exist in health biotechnology between developing countries. All of this data, including its subsequent analysis, has begun filling a deficiency in the availability of empirical information on which developing nations have taken to south-south collaboration for their own benefit, how they have done so, to what extent, and to what effect.



Eric Meslin

Board of Directors, Genome Canada

Eric M. Meslin, Ph.D. was appointed to the Board of Directors of Genome Canada in 2008. He is Director of the Indiana University Center for Bioethics, Associate Dean for Bioethics. Born in Canada, Dr. Meslin has spent much of his professional career in the U.S. in various academic and government positions. He was Executive Director of President Clinton's National Bioethics Commission (NBAC) from 1998-2001, and Program Director in the ELSI Research Program at NHGRI from 1996-98. A productive researcher with more than 90 publications, his interests include international health, predictive health science, and the ethics of human subjects research. Among his more interesting honors is his recent appointment by the President of France as a Chevalier de l'Ordre Nationale du Merite.



Karine Morin

University of Ottawa

Karine Morin recently joined the research team of David Castle, PhD, Canada Research Chair in Science and Society where she focuses on GE³LS issues related to nutritional genomics.

Previously, she was the Director of Ethics Policy at the American Medical Association. Before leaving Canada, she worked for the Commission of Inquiry on the Blood System in Canada.

She has taught medical ethics and law at the Medical College of Wisconsin, Northwestern University School of Law, and Allegheny University of the Health Sciences.

Ms. Morin is a graduate of McGill University where she obtained a joint degree in civil and common law. She also received a Masters in Law (LLM) from the University of Pennsylvania.

Susceptibility Testing: The All Too Predictable Rise of a Technology and Interminable Policy Debate

For over ten years, scientists have anticipated a new wave of predictive genetic tests which might transform healthcare by allowing us to assess our risk of the most common diseases. This past year has seen major progress towards this goal. Scientific publications have described a series of robust, well-replicated gene-disease associations in areas such as cancer, diabetes and heart disease. Biotechnology companies have launched predictive tests to capitalise on the scientific progress.

The rapid clinical translation has not been without its critics who worry that commercialisation is premature and the field inadequately controlled. Yet, the concerns that some genetic tests enter clinical practice prematurely and without appropriate oversight to ensure safety and effectiveness have been an integral part of the prolonged policy debate that has taken place parallel to the scientific and technological advances. Committees and task forces that have reviewed the oversight of genetic testing have come to similar conclusions: genetic tests should not enter routine clinical care without thorough independent evaluation. These issues were raised in the United States by the National Academies of Science as early as 1975 and as recently as 2007 in the Secretary's Advisory Committee on Genomics, Health and Society draft report. Yet there has been little regulatory progress towards achieving well-accepted policy goals.

Using the United States as a case study, this paper explores why at the cusp of a revolution in genetic testing we find ourselves ill-prepared for developments that have received considerable attention.



Linda Murphy

Global Health Research Initiative

Linda Murphy joined the Global Health Research Initiative (GHRI) in February 2007. GHRI is a unique partnership that combines the strengths and capabilities of four federal agencies — to support the health priorities of low- and middle-income countries through innovative research and capacity building, and to inform and influence global agendas for health policy and research. The GHRI secretariat and program staff manages a suite of global health research programs with funded teams operating in over 30 countries.

Linda has extensive experience in evaluation, developing and managing innovative research granting, training, and knowledge exchange programs at Health Canada, the National Health Research and Development Program (NHRDP), and the Canadian Health Services Research Foundation (CHSRF) and she has built a rich portfolio of applied research programs featuring: research excellence; partnerships with decision makers involved in health policy and management; training and mentoring models; and inter-institutional collaborations across Canada and, increasingly globally.

Adapting the Canadian Health Services Research Foundation Linkage and Exchange Concept to the Development Context

The work done to develop the *Linkage and Exchange* (L&E) model over the last decade by Jonathan Lomas and colleagues at the Canadian Health Services Research Foundation launched a global movement, ongoing debate and a whole new vocabulary (knowledge transfer, translation, mobilization and exchange) to describe strategies intended to increase the interaction between research/researchers and its application/researcher users. To date, these strategies have been conceptually anchored in a high-income (North American) context.

This presentation provides some observations on the experience of the Global Health Research Initiative - a partnership composed of the Canadian International Development Agency (CIDA), Canadian Institutes of Health Research (CIHR), Health Canada (HC) and IDRC that is housed at the IDRC - as it integrates L&E concepts into international development health research. Our challenge is to adapt existing L&E concepts to the health system context of lower and middle income countries. The GHRI experience has the potential to influence Canada's approach and contribution to international development, as it is already influencing the discussions and approaches of colleagues within IDRC, CIDA, and the other partner organizations.



Kieran O'Doherty

The W. Maurice Young Centre for Applied Ethics

Kieran O'Doherty is a post-doctoral research fellow at the W. Maurice Young Centre for Applied Ethics, University of British Columbia, Canada. He joined the Centre to work with Mike Burgess in the Face-to-Face research group of the *Building a GE³LS Architecture* project. Kieran undertook his undergraduate training at the University of the Witwatersrand, South Africa, with majors in physics and chemistry. He subsequently completed his Honours and PhD degrees in psychology at the University of Adelaide, Australia. Kieran has published on the topics of risk communication, probability, genetic counseling, consumer behaviour, media representations of asylum seekers, and nationalism. As a result of his numerous relocations, Kieran is geographically challenged and suffers from severe and recurring national identity crises.

The BC Biobanks Deliberation: Rationale, Results, and Implications

In this paper we report on the rationale, organisation, and results of a deliberative public engagement on the topic of biobanking. The event was held in Vancouver, British Columbia, over two non-contiguous weekends and involved 21 demographically stratified, random digit dialled participants. The event was motivated by the observation that current policy approaches to biobanking manifest a “democratic deficit”. After being informed about the scientific rationale for the existence of biobanks as well as different stakeholder perspectives on biobanks (both negative and positive), participants were divided into groups to deliberate on the topic and, if possible, achieve consensus on recommendations for the design of a biobank in British Columbia. We present some of the most salient results of these deliberations focussed on the issues of governance, consent, privacy, and benefit sharing. We conclude with some thoughts regarding the translation of the results of this deliberation into concrete policy outcomes.



Margaret Otlowski

University of Tasmania, Australia

Margaret Otlowski is Professor at University of Tasmania and Deputy Director of the Centre for Law and Genetics. She has been admitted to practice and works part-time in quasi-judicial roles, currently with the Tasmanian Anti-Discrimination Tribunal. She has worked as consultant for key national bodies including the National Bioethics Consultative Committee, the Australian Law Reform Commission (inquiry with the Australian Health Ethics Committee into the protection of human genetic information as well as its privacy inquiry), and is currently on a working group for the Human Genetics Advisory Committee and the Federal Privacy Commissioner. She has been involved in a number of nationally funded collaborative projects in the area of genetics focusing on issues of regulation, privacy and discrimination, including a current project on biobanking.

Australian update on ELSI

This paper provides an update on key legal, ethical and social developments in Australia in the area of genetics research and development, and the contributions these have made to Australian law and policy. It notes some recent empirical research initiatives at the national and state level, and evaluates the areas of knowledge that these have contributed to, through *inter alia*, public opinion research, research into the phenomenon of genetic discrimination, and research into practices and attitudes of key stakeholders in the public and private sectors as well as industry.

The most significant single development over recent years, however, has been the process of inquiry undertaken jointly by the Australian Law Reform Commission and the Australian Health Ethics Committee of the National Health and Medical Research Council. The paper outlines this development, including the consultation processes undertaken, the ensuing internationally acclaimed report, *Essentially Yours*, and the subsequent process of implementation. The paper evaluates and reflects on the wider social impact of this reform process, including the benefits arising from the inquiry's high profile engagement with public participation, and the wide-ranging and multi-faceted nature of the report recommendations. It also outlines the forthcoming program of work before the newly established Human Genetics Advisory Committee, set up in furtherance of the Report recommendations, which is now spearheading these developments. Finally, whilst acknowledging the significant progress that has been made, the paper also recognises the limitations in this area, in particular, the lack of dedicated funding in Australia for ELSI related research.



Peter W. B. Phillips
University of Saskatchewan

Dr. Peter W.B. Phillips, an international political economist, is Professor and Head of Political Studies, Acting Director of the new School of Public Policy and an associate member of the departments of Bioresource Business, Policy and Economics and Management at the University of Saskatchewan.

He holds a concurrent appointment as Professor at Large at the Institute for Advanced Studies, University of Western Australia, Perth. His research concentrates on issues related to governing transformative innovation. He is the co-PI of the Genome Alberta project on Translating Knowledge in Health Systems (2006-2010) and a collaborator on six other internationally peer reviewed research programs. His latest book— *Governing Transformative Technological Innovation: Who's in charge?* was published by Edward Elgar in June 2007.

GE³LS and Genome Prairie

Genome Prairie, established by Genome Canada in 2000 to serve Alberta, Manitoba and Saskatchewan, was restructured in 2005 to serve the provinces of Saskatchewan and Manitoba. This separation of the effort in the prairies has led to a bit of a disjointed GE³LS effort. While the pre-2005 centre had a fully functioning GE³LS stand-alone program, had an ethics board and had GE³LS investigators from Alberta and Saskatchewan embedded in individual scientific projects, and the GP SAB and Board, all of that had to be rebuilt by GP since then. Since 2005, GP has reconstituted the Board and SAB, but without any acknowledged GE³LS expertise. A nascent Ethics Committee was established in 2007 but has yet to function. While there are a wide range of individual researchers in Manitoba and Saskatchewan doing GE³LS type research, few of them are connected to the four GP funded projects. Currently Alberta-based GE³LS scholars are engaged in the frost-tolerant wheat and NorCOMM mouse projects and BC scholars in the pathogenomics program. Saskatchewan scholars are directly engaged in the canola project (DOTM), are key participants in the Genome Alberta stand-alone GE³LS project and are part of the effort to create a national thematic network on GE³LS but no Manitoba-based scholars are part of any GE³LS programming. Apart from building broader GE³LS capacity across the GP area (i.e. at URegina and in Manitoba) and the general challenge of linking Ge3ls research with actual scientific and commercial opportunities and issues, GP has a major challenge/opportunity in linking to and engaging with the large volume of GE³LS-type research that is largely disconnected from the Genome Canada effort. This work is funded by a range of national agencies or programs, including SSHRC (ISRN, USask KIS), AAFC (five policy networks and ABIP) and Industry Canada (AFM, SFM and Aquanet NCEs).



Maude Phipps

University of Malaya, Malaysia

Maude E. Phipps obtained a B.Sc. Honours in Genetics from the University of Malaya, Malaysia. She completed a Ph.D. in human molecular genetics linked to the human genome project at the University of Cambridge, UK. She is Associate Professor at the Department of Molecular Medicine and Head of Molecular Immunogenetics Laboratory, University of Malaya and consultant to hospitals in Malaysia and Brunei. She is active in the Human Genome Organization (HUGO), Australian South East Asian Tissue Typing Association (ASEATTA), the UNESCO Bioethics program, Vice President of the Genetics Society of Malaysia and a member of the PASNP consortium. She is passionate about human genetics, bioethics, public education and her son. Her idea of a great time is good food, an inspiring book, travel, and interesting conversations.

The Pan-Asian SNP Initiative – Benefits and Implications

The PASNP Initiative a landmark project in Asia has been a memorable learning experience that brought together individuals with various expertise from key institutions across Asia and the Pacific. It is unprecedented in terms of the breadth of ethnicities represented and in the genomic resolution that was achieved. We have made an impact in on the educational and scientific landscape in Asia and in particular towards working out the genetic history of its' peoples. There were several tangible benefits that were evident. Firstly, the initiative addressed the paucity of human genomic databases in Asia and allows determination with high resolution, the genetic relatedness of Asian populations and the patterns of human migration across Asia. Secondly, we developed collaborative networks through the spirit of open communication and cooperation, acknowledging strengths and resources within consortium members from eleven nations including China, Japan, India, Indonesia, Japan, Malaysia, Philippines, Singapore, South Korea, Thailand and USA. This saw the consolidation of existing strengths in different institutions rather than duplication. In some countries, scientists worked closely with local authorities, anthropologists and translators to conduct fieldwork among the indigenous communities, at all times respecting for their culture and customs. Several core laboratories that were equipped with the latest sophisticated high technology platforms provided technological expertise and training. Vigorous bioinformatics analyses were undertaken by several institutions to ensure quality. Finally, in recognition of ELSI, the initiative formed a Policy Review Board with the vision statement that "What we're doing must be scientifically sound, in line with technological advances, involve international collaborative effort and ethically acceptable in our quest for greater knowledge and wisdom of the human genome, evolution and health". This experience will no doubt impact significantly on genomics in Asia.



Daryl Pullman
Memorial University

Daryl Pullman is Professor of Medical Ethics in the Faculty of Medicine at Memorial University. He is a member of the CIHR Stem Cell Oversight Committee and has served previously on the Advisory Board for the CIHR Institute of Genetics and as a member of the CIHR Standing Committee on Ethics. Daryl is the GE³LS lead for the Atlantic Medical Genetics and Genomics Initiative (AMGGI), a large Genome Canada funded project designed to cover the full spectrum of genetic work from gene discovery, to clinical application, to health policy development. Daryl has published widely on a variety of issues in research and clinical ethics.

Steering the Good Ship Biotech: Integrated GE³LS Research in Atlantic Canada

There are no free-standing GE³LS projects in Atlantic Canada. Instead ongoing GE³LS activities are fully integrated in the two major science projects funded in the last GC competition: (1) Atlantic Medical Genetics and Genomics Initiative (AMGGI), and (2) Atlantic Cod Genomics and Broodstock Development (CGP). This session will consist of a brief overview of some recent GE³LS activities associated with these projects, and identify some emerging issues germane to both including the potential impact of genetics and genomics research on social institutions, and social justice issues pertaining to the fair distribution of the benefits and burdens of large scale genomics and genetics research to the broader population. Some reflections will be offered as to how a well integrated GE³LS program can act as something of a moral compass for a broader scientific/biotech endeavor.



Vardit Ravitsky

University of Pennsylvania, USA

Vardit Ravitsky, PhD, is faculty at the Department of Medical Ethics and a fellow at the Center for Bioethics, in the University of Pennsylvania. Previously, she was a fellow at the Department of Clinical Bioethics at the NIH and at the Social and Behavioral Research Branch of the National Human Genome Research Institute (NHGRI).

Born and raised in Jerusalem, Ravitsky received her B.A. in philosophy from the Sorbonne University in Paris and her M.A. in philosophy from the University of New Mexico in Albuquerque. She received a PhD in philosophy with a focus in bioethics from Bar Ilan University in Israel. Her main research interests are ethical aspects of human genetics and reproduction.



Nola Ries

University of Victoria

Nola M. Ries, is an adjunct assistant professor, University of Victoria, where she teaches health law, and is also affiliated as a research associate with the Health Law Institute, University of Alberta. Her research work addresses public health law, legal issues in health system reform, privacy law, and regulation of genetics and biotechnology. She is co-editor of the textbook, *Public Health Law and Policy in Canada*, and the forthcoming book, *Nutrition and Genomics: Issues of Ethics, Law, Regulation & Communication*. She serves on research ethics and editorial boards, and consults to governmental and non-governmental organizations. Ms. Ries is a member of the Bar of British Columbia and has practiced constitutional, administrative and human rights law.

Policy Options for Regulating Direct-to-Consumer Genetic Tests: Balancing Consumer Protection and Consumer Autonomy

A growing range of genetic tests are advertised and sold directly to consumers via the Internet, including tests for health purposes (e.g. disease susceptibility tests), tests that aim to inform lifestyle decisions (e.g. nutrigenetic tests) and tests largely unrelated to health (e.g. genealogical tests). The burgeoning availability of whole-genome sequencing means that interested consumers have increasing access to genetic information about themselves, but less certainty about implications of test results for the individual's health, life choices and relationships with biological relatives. Early policy responses to direct-to-consumer (DTC) genetic testing often involved calls for bans and some jurisdictions prohibited DTC genetic tests. Recent policy responses suggest that a "one-size-fits-all" regulatory approach is not appropriate for DTC genetic tests. Bodies such as the American Society for Human Genetics and the UK Human Genetic Commission now advocate that regulation of DTC genetic tests should be commensurate with risk.

This presentation begins with an overview of types of DTC genetic testing services currently available through online commerce. It considers potential personal and public health harms and benefits associated with DTC genetic tests and explores emerging categorizations of genetic tests as "medical", "lifestyle" or "recreational." It discusses policy options for regulating DTC genetic tests, including full or partial prohibitions, enforcement of existing truth-in-advertising laws, "buyer beware" educational campaigns and an unregulated marketplace. The presentation concludes with recommendations for regulating DTC genetic tests to achieve consumer protection goals while not hindering access to potentially beneficial or largely harmless services.



Camille D. Ryan

University of Calgary

As a Post Doctoral Fellow with Faculty of Communication and Culture (Science, Technology and Society Program) with the University of Calgary, Camille is currently working with a team of researchers on the GE³LS NorComm Project. Cami benefits from several years of experience in administration and marketing in the biotechnology industry which has greatly influenced her academic research interests in social capital, knowledge management and performance evaluation in R&D networks in biotechnology, genomics and synchrotron science. In addition to her academic research pursuits, Camille continues to network with the broader science community working on projects with organisations such as the National Research Council's Industrial Research Assistance Program (IRAP), the International Institute for Sustainable Development, Alberta Advanced Education and Technology and Agri-Food Canada (AAFC).

***Evaluating Performance in Genomics Research:
A Network Analysis of Genome Canada Funded Projects***

Globalisation and the quest for competitiveness in a global market represents a new era of connectedness within networks of experts in an effort to pursue research objectives in genomics. Balancing the competing interests of public good and private gain, reducing the barriers in terms of access to knowledge and intellectual property and ensuring that efforts result in socially valuable outcomes in the form of new innovations can be difficult, to say the least.

Although widely advocated and implemented, research collaborations have not, as yet, been fully examined nor have appropriate performance evaluation models been developed to evaluate them. This dissertation hypothesizes that a history of social relationships or collaborative activity amongst network actors is positively correlated with high performance (technical output) in networks. Incorporating descriptive statistics with the social network analysis tool, this presentation proposes and tests a novel framework that compares two distinct Genome Canada funded research networks and their respective evolution and level of productivity over time. Other factors explored are the roles of proximity, institution and research focus in characterizing network structure and in affecting overall project performance.



Marc Saner

Carleton University

Dr. Marc Saner holds a Ph.D. in applied ecology from the University of Basel, Switzerland (1991) as well as an M.A. in philosophy with a specialization in the environmental ethics of biotechnology from Carleton University (1999). He is currently an Adjunct Research Professor at the Departments of Philosophy and Biology at Carleton University and is the Principal of a Consulting Firm in Ottawa (www.saner.ca). He has more than 15 years of experience carrying out assessments and analytical work in the natural sciences and humanities. For the last decade, his primary interest has been the intersection of governance, ethics and science. Prior to his current consulting work he was the Executive Vice President and Director of Assessments at the Council of Canadian Academies and a Director at the Institute On Governance (an Ottawa-based think tank).

A Science Policy Ethic

In my paper, I will apply a lesson learned from environmental ethics to the context of science policy. The protection of an entity – be that the natural environment or the scientific enterprise – will only take place once it is considered by decision-makers to represent a value. A practical issue arises, however. If an entire system is judged to represent value, then how does one arrive at day-to-day decisions, which often will only affect part of the system or, worse, will benefit one part while harming another?

Half a century ago, Aldo Leopold proposed The Land Ethic, which provides criteria to distinguish those actions that are right from those that are wrong when dealing with the natural environment. His deceptively simple prescriptions have stood the test of time, both in academic philosophy and in applied environmental conservation.

In close analogy to Leopold's system, I will argue that it is possible to adjudicate right from wrong actions by focusing on a small number of necessary and sufficient criteria. The emerging overarching ethical system not only provides an ethic for the broad field of science policy, it is also applicable to the parts within. In practice, it provides a foundation to justify the continued support of the scientific enterprise as an end-in-itself and a moral framework for decisions on public science.



Peter A. Singer

University Health Network and University of Toronto

Peter A. Singer is Senior Scientist and Professor of Medicine at the McLaughlin-Rotman Centre for Global Health, University Health Network and University of Toronto. His research aims to move health biotechnologies from the lab to the village. In 2007, Singer was named Canada's Health Researcher of the Year by CIHR. He has published over 240 research articles, received over \$50 million in research grants, trained over 70 graduate students and fellows, and written more than 30 op-eds in national newspapers. Singer is a member of the Scientific Advisory Board of the Bill & Melinda Gates Foundation Grand Challenges for Global Health Initiative, and has advised the UN Secretary General's Office on biosecurity.

Strengthening the Role of Genomics and Global Health

Strengthening the Role of Genomics and Global Health (SRGGH) aims to ensure that developing countries share the social and economic benefits (SEBs) of the genomics revolution, prevent the emergence of a "genomics divide" and address existing global health disparities. SRGGH is comprised of four projects:

Private Sector Development in Genomics aims to provide key international decision-makers with the knowledge they need to support private sector development in developing countries for the purpose of recruiting domestic firms to the challenge of global health inequity. One output of this project is to develop a model of good practices in national innovation policies for consideration by governments in emerging economies: India, China, Brazil and South Africa, and less developed countries: Ghana and Tanzania.

South-South Collaboration in Genomics Innovation aims to examine collaborations in genomics and health-biotechnology among developing countries to understand what factors and conditions contribute to successful south-to-south collaboration.

Human Genomic Variation and Global Health aims to apply knowledge of human genomic variation among population groups to understand disease susceptibility and drug response, and to examine the implications for global health.

Genomics, Knowledge Management and Global Food Security aims to document effective knowledge management strategies, with specific reference to genomics, for the promotion of enduring food security in developing countries.

These projects have begun to translate knowledge into SEBs for Canada and the world by developing assets that would be disseminated to influence decision makers within for key impact areas: government departments; private companies and organizations; public organizations; and foreign policy sectors.



Jerome Amir Singh

Center for the AIDS Programme of Research, South Africa

Jerome Amir Singh, BA, LLB, LLM, PhD, MHSc, is Head of the Bioethics and Health Law Programme at the Center for the AIDS Programme of Research in South Africa (CAPRISA), Durban, South Africa; Adjunct Professor in the Department of Public Health Sciences and Joint Center for Bioethics at the University of Toronto, Canada; and Course Director for Bioethics and the Law at Howard College School of Law, University of KwaZulu-Natal, Durban, South Africa. He serves on the International Research Ethics Board of Médecins Sans Frontières, the International Therapeutic Data & Safety Monitoring Board for the US NIH, the Research Ethics Committee of the South African Human Sciences Research Council, and the Scientific Advisory Board of Aurum Health Research.

Developments in the Social Sciences and Humanities Regarding Genomics and Biotechnology in South Africa

South Africa has a relatively long history of genomics and biotechnology, both in the context of research and development. In the last half decade, in particular, researchers from the humanities and social sciences have begun to consider the ethical, social, and cultural implications of these emerging disciplines. Most works in this respect have emerged from the South African Human Sciences Research Council, a statutory body, and from related initiatives such as the Africa Genome Education Institute. This presentation will provide a brief overview of some of the key works in this respect. It will also highlight their role in raising awareness of the complex ethical, social, and cultural implications implicit in genomics and biotechnology research and development.



Stuart Smyth

University of Saskatchewan

Dr. Stuart Smyth completed his Ph.D. in Biotechnology in 2005. The topic of his dissertation was on how societies deal with innovation and in particular the innovation of agricultural biotechnology. Much of his recent research has focused on the relationship between innovation and liability. He has been a researcher for the Genome Canada funded Developing Oilseeds for Tomorrow's Market Project of for the past two years. Dr. Smyth's next book is titled, *Innovation and Liability in Biotechnology: Transnational and Comparative Perspectives*, will be published by Edward Elgar in 2009.

Intellectual Property Sharing Agreements in Gene Technology: Implications for Research and commercialization

The 1990s witnessed a consolidation within the agricultural biotechnology industry through a series of mergers and acquisitions as agrochemical/pharmaceutical firms pursue life science strategies. At that time, there were concerns that the increased concentration within the industry would have negative impacts on research and development as well as commercialization of new technology. Despite these concerns, the industry has continued to make significant research investments and commercialization of new technology has continued.

Recently, there has been a new movement in the agricultural biotechnology industry, one that has seen an increase in gene trait cross-licensing agreements. While these agreements facilitate the much needed sharing of IP across research platforms, they raise additional concerns with respect to market concentration. One aspect of this is cross-licenses between small biotechnology firms and large multi-national biotechnology firms, the other is cross-licenses between the large multi-national firms.

In this paper we will examine publicly accessible information about the nature of these IP sharing agreements and examine the incentives they may create. Specifically we will examine these agreements within an industrial organizational context and analyze how these agreements may impact barriers to entry, incentives for investment, commercialization and pricing.



James Tansey

University of British Columbia

James Tansey joined UBC in 2006 and is jointly appointed between the Sauder School of Business and the W. Maurice Young Centre for Applied Ethics. James' research activities cover a number of areas including the social impacts and acceptability of new technologies including stem cells and biobanks. He has written extensively on the role of public consultation in the governance of industrial societies, industrial ecology, scenario methods and climate change. His current research focuses on emerging international markets for carbon exchange, social determinants of health in developed countries and the governance of biotechnology and genomics in Canada.

James Tansey received his PhD from the University of East Anglia in 1999. After a number of years in the Faculty of Graduate Studies at UBC in Canada, he spent two years in the UK as a lecturer in Science and Technology Studies with the Said Business School in Oxford, where he was also deputy director of the James Martin Institute for Science and Civilization.

James is Managing Editor of the journal *Integrated Assessment* and co-founder of a Canadian carbon offset entity called offsetters.com. He has taught on MBA, EMBA, Executive Education, MSc and Undergraduate programmes in the UK and Canada. He currently contributes to the MBA core and to graduate teaching in the Faculty of Graduate Studies. James has recently worked as an advisor and contributor to the World Economic Forum, the UK National Audit Office, Oxford Analytica, Cisco, Isis Innovation (Oxford), Environment Canada, Canadian Environmental Assessment Agency and the Asymmetric Threats Contingency Alliance.



Adrian Tsang

Concordia University

Adrian Tsang received his bachelor degree with first class honours in genetics from the University of Alberta. With a post-graduate scholarship from the Natural Sciences and Engineering Research Council of Canada (NSERC), he pursued doctoral studies in biochemistry and cell biology at York University. He undertook post-doctoral studies on a NATO Science Fellowship at the Imperial Cancer Research Fund in London, working on the molecular mechanisms of development. From 1981 to 1991, Adrian received a University Research fellowship from NSERC and joined the faculty of York University and McGill University. In 1991, he moved to Concordia University as an associate professor. Around this time, he switched his research focus from developmental biology to protein production in fungi, and more recently to fungal genomics. In 1999, he became the founding director of the Centre for Structural and Functional Genomics of Concordia University. Adrian is involved in several large- and medium-scale projects to identify enzymes can be used to replace chemicals in industrial processes and to develop environmentally benign products. These projects bring together researchers from multiple disciplines from Concordia University and other universities in Canada, Agriculture and Agri-Food Canada, the Institut national de la recherche scientifique, the the Pulp and Paper Research Institute of Canada, Iogen Corporation and DSM B/V of the Netherlands.



Jim Unterschultz

University of Alberta

Jim Unterschultz is an Associate Professor in Agribusiness Finance and Marketing in the Department of Rural Economy, University of Alberta. He teaches and undertakes research in agribusiness finance, commodities, farm level policy and risk models. Current research includes the applicability of risk models to evaluate investment decisions in agricultural/agribusiness, on-farm economics of adoption of environment programs and economics of improved cold tolerance in crops. Dr. Unterschultz holds four degrees from the University of Alberta including a Ph.D. in finance and a M.Sc. in agricultural economics. Prior to starting his graduate studies in 1990, he spent ten years in agricultural extension.

*Agricultural Biotechnology:
An Application of Real Options to Canadian Research Policy*

Valuing biotechnology research and commercialization projects is challenging. Yet it is important that a value is estimated for purposes such as investment decisions, public policy, and R&D programmes. Biotechnology projects are characterized by high risk as well as irreversibility of their staged investment expenditures. The CRC's Plant Biotechnology Institute (PBI) was used as a case study to evaluate the public policy aspect of the government's R&D policies. The Canadian government's R&D policy with PBI requires external agency funding (e.g. commercial firms) to move PBI's basic R&D to a commercialization stage. This R&D investment model may be problematic if the public benefits are expected to be high but it is difficult for private firms to capture a part of these benefits. Real Options (RO) models may be an improved approach to R&D valuation.

The underlying technology evaluated involves a reduction of sinapine and phytate, anti-nutritional compounds, in canola meal. Canola meal is the product remaining after extracting oil from the canola seed and the meal is used as a livestock protein supplement.

The valuation results from the Net Present Value (NPV) analysis are negative. However, the RO models estimate a significantly higher value when the sequential stages of the project are valued. However, despite the high public benefits identified by the RO analysis, the research project was having difficulty finding commercial investors. The RO approach provides a methodology to value these projects and identify projects where greater use of public funds may be justified.



Michele Veeman

University of Alberta

Michele Veeman is Professor Emerita of Agricultural and Resource Economics, Department of Rural Economy, University of Alberta. Her Ph.D. (Agricultural Economics) is from the University of California, Berkeley, Masters Degree (Economics) from the University of Adelaide, South Australia, and Bachelors (Agricultural Science) from Massey University, New Zealand. Her research focuses on the economics of food, agriculture and rural resources and includes studies of consumers' responses and trade-offs relative to food biotechnology; how individuals' risk perceptions and decisions are modified by different types of information; and public assessments of research on different applications of "plant molecular farming."



Barbara von Tigerstrom

University of Saskatchewan

Dr. Barbara von Tigerstrom is an Assistant Professor at the University of Saskatchewan, College of Law. She holds an LL.B. from the University of Toronto and a Ph.D. in law from the University of Cambridge, and has worked at the Supreme Court of Canada, the University of Alberta Health Law Institute, and the University of Canterbury. Barbara teaches health law and international law, and has published widely on topics in health law, public health, international trade, and public international law. Her current research focuses on public health law, international law issues relating to health, and the regulation of therapeutic products. She has recently published articles on the regulation of stem cell-based products and the harmonization of therapeutic product regulation.

*The Challenges of Genomics and Genetic Technologies for
Therapeutic Product Regulation*

Genetic research may result in, or be used in, technologies that will be regulated as therapeutic products, and our rapidly increasing knowledge of genomics promises to significantly alter our use of pharmaceutical products in the future. Therapeutic products, including drugs, biologics, and medical devices, are regulated in their pre- and post-market phases to ensure their safety, efficacy, and quality. Recent advances in biotechnology have yielded novel products which do not fit neatly into traditional regulatory categories and raise distinctive safety, efficacy, and quality issues. Even for traditional pharmaceuticals, the development of pharmacogenomics has significant implications for how these products are tested, marketed, and used. Concerns have been raised that existing legal frameworks may not be adequate to address these issues. While other issues relating to these products, such as patenting and research ethics, have been examined, the distinct though related question of how they will be dealt with under regulatory frameworks for therapeutic products has received surprisingly little attention. This paper reviews legislation and policies in Canada, the United States, Europe, and Australia to compare the various proactive and reactive efforts to adapt existing regulatory approaches to these new challenges. The analysis will assess the adequacy of current regulatory responses to novel technologies, and in doing so consider some of the challenges for regulatory agencies and policy makers attempting to keep up with – or anticipate – rapid and significant technological change in the medical field.



Gregor Wolbring

University of Calgary

Dr. Gregor Wolbring is an Adjunct Assistant Professor and researcher at University of Calgary, Faculty of Medicine. He is a member of the International editorial advisory board, *Journal: Studies in Ethics, Law, and Technology*; a Founding Member and Affiliated Scholar, Center for Nanotechnology and Society at Arizona State University, USA; Part Time Professor, Faculty of Law, University of Ottawa, Canada. webpage: <http://www.bioethicsanddisability.org>.

Synthetic Biology: Nothing New or Game Changing?

Synthetic biology is an emerging discipline which is seen by some as nothing new but by others as a field with potentially major strategic, economic social, legal and ethical implications for Canada and the world. Synthetic biology started to gain public visibility within the last two years. Synthetic biology is described on the webpage of the synthetic biology community <http://syntheticbiology.org/> as (a) the design and construction of new biological parts, devices, and systems; and (b) the re-design of existing, natural biological systems for useful purposes.

However as this field is still developing it is not surprising that many definitions exist which vary in their understanding of meaning, scope, processes, raw material used and products of synthetic biology. This heterogeneity of employed definitions allows for different characterisations of synthetic biology and its relationship to- and impact on- other science and technology fields such as nanotechnology, chemistry and engineering and their discourses and for different characterisations of the ethical, social, legal, economic, political, cultural, and security issues attached to synthetic biology.

The objective of this paper is to

- identify possible positive impacts of synthetic biology products and processes for Canada and globally,
- highlight the ethical, social, legal, economic, political, cultural, and security issues attached to the different existing synthetic biology definitions, processes, products and discourses,
- highlight the existing public discourse around synthetic biology



Gisèle Yasmeen

Social Sciences and Humanities Research Council

Gisèle Yasmeen, Vice-President, Partnerships, Social Sciences and Humanities Research Council of Canada, obtained her PhD from the University of British Columbia (1996). Dr. Yasmeen was previously Senior Director, Elections Canada, Outreach, Communications and Research Directorate. She was also Regional Director (British Columbia/Yukon) of the Centre for Research and Information on Canada, and its host organization, the Canadian Unity Council. She was also a French and English-language radio columnist with the CBC in Vancouver from 2000 to 2003. Dr. Yasmeen is a former Consultant to the United Nations Food and Agriculture Organization, the Canadian International Development Agency and the International Development Research Centre, and worked with other clients in the area of international development. Dr. Yasmeen has held teaching and research appointments at the University of British Columbia and Dawson College in Westmount, Québec.

SSHRC & Knowledge Mobilization: GE³LS as a Living Laboratory

The concept of Knowledge Mobilization (KMb) emerged in the late 1990s in the field of education in parallel with the Knowledge Translation approach of the health sciences as well as the Knowledge and Technology Transfer concept which tends to be favoured by natural scientists and engineers. SSHRC has adopted Knowledge Mobilization as a strategic objective. There are debates in the literature as to the nuances of meaning associated with KMb as well as the differences between KMb and Knowledge Translation / Knowledge Transfer. SSHRC prefers a wide, inclusive conceptualization of KMb which leaves room for a variety of ways to facilitate and enable maximum value and impact of research and training investments in the social sciences and humanities, not the least of which is intellectual value and impacts. Options for KMb include traditional dissemination, open-access, knowledge brokering, knowledge translation, knowledge synthesis and the co-creation of knowledge. This presentation will provide a retrospective and prospective view of SSHRC's approach to KMb by using GE³LS research as a living laboratory of multi-disciplinary collaboration between the social sciences and humanities community and the natural and health sciences and engineering. GE³LS research is an important step toward elaborating a social and policy discourse around emerging science and technology. Finally, the presentation will touch on how enhanced KMb, facilitated and enabled by the granting agencies and others in the "knowledge system", might enable GE³LS research to maximize its societal effectiveness.



Judith Young

National Research Council

Ms. Young has been with the National Research Council for 26 years, during which she has held many positions, including research officer and business development manager. None of her previous positions can be considered more exciting than her current role, however. In May 2007, she was appointed Executive Director of NRC's Central Business Support group charged with improving the Council's business practices and processes, and enabling the transfer of sought after technology. This position came after Ms. Young led the NRC 'Business Review' team tasked with ensuring NRC was well-positioned to carry out the ambitious business activities envisaged in NRC's current strategy: *Science at Work for Canada*.

Prior to leading CBS, Ms. Young spent almost ten years as Executive Advisor to a number of NRC VPs. She has also been Director of NRC's corporate Business Group, has coordinated NRC's Entrepreneurship Program, and has participated in NRC's market research and policy development activities. Ms. Young also began the business office at NRC's Institute for Marine Biosciences in Halifax. She holds a BSc in Chemistry from Carleton University and joined the Council in 1982 as a research officer.

NRC's Top Ten Factors for Successful Knowledge Translation

Canadian government, academics and industry are recognizing the importance of technology transfer and knowledge translation processes in order to realize true benefit and impact to Canadians from R&D. The Federal Government is addressing this with its new S&T Strategy – *Mobilizing Science and Technology*. This strategy calls for, among other things, "***enhanced collaboration within the federal S&T community and the development of improved approaches for fostering research, talent, knowledge transfer and commercialization among science based departments and agencies, universities and colleges, and the private sector***"

NRC is reinforcing this direction with the implementation of its own strategy. We are focusing on key national priorities to maximize the potential impact of our research activities, contributing to the competitiveness of Canadian industry in key sectors and to the economic viability of communities.

This talk will provide insight into some of the challenges we all face in commercialization and technology transfer, and how NRC is aiming to have a profound impact on Canadian industry. We are implementing innovative approaches to speed the path of our technology reaching industry, including IP management practices, market and technology assessments, and activities to bring about a more industry-focused culture. Ms. Young will share NRC's top ten factors that influence whether our technologies – especially our genomics based ones – end up in the marketplace.



Xiaomei Zhai

Chinese Academy of Medical Sciences and
Peking Union Medical College, China

Xiaomei Zhai is Executive Director, Center for Bioethics at Chinese Academy of Medical sciences and Peking Union Medical College, Director and Professor of Department of Social Sciences and Humanities at PUMC. She graduated from Changzhi Medical College and obtained Ph.D in Philosophy at Chinese Academy of Social Sciences. She was fellow /visiting scholar at Harvard School of Public health; Lancaster University (U.K); Radboud University of the Netherlands. She is a faculty member of International Collaborative Genetics Research Training Program (FIC) in China of Jones Hopkins University. She is a member of HUGO Ethics Committee; Vice Chair of Ethics committee of Chinese Society for Genetics; member of Ethics committee of Ministry of Health of China.

Abstract

Unavailable at time of printing.



Hub Zwart

Radboud University of Nijmegen, Netherlands

Hub Zwart (1960) studied philosophy (cum laude) and psychology (cum laude) at Radboud University Nijmegen. He worked as research associate at the Centre for Bioethics (Maastricht, 1988-1992) and defended his thesis on consensus formation in a pluralistic society in 1993 (cum laude). He was appointed as research director of the Centre for Ethics (Nijmegen, 1992-2000) and acted as editor-in-chief of the Dutch Journal for Medicine and Ethics. In 2000 he became full professor of philosophy at the Faculty of Science. He was European lead of the EU Canada exchange program Coastal Values (1999- 2003). In 2004 he became director of the Centre for Society & Genomics, funded by the Netherlands Genomics Initiative and established at his department. The focus of his research is on epistemological and ethical issues in the life sciences: biomedicine (1988-1996), research with animals (1996-2003), environmental research (1998-2003) and genomics (2003-present). His current research concerns: the epistemological profile of genomics; philosophical implications of the Human Genome Project; epistemological profile of ecogenomics; challenges of macro-ethics (the ethics of bio-information); scientific authorship and comparative epistemology (literary imagination as a research tool).

Genomics and Self-Understanding

Genomics is more than a set of tools or a particular branch of life science research. Rather, it is transforming the ways in which the life sciences are evolving. While the so-called genomics revolution began in the molecular life sciences, it gradually moved from there to other fields, initiating novel “converging” research areas such as ecogenomics, behavioral genomics, toxicogenomics etc. Social Science and Humanities research often tends to focus on the governance of concrete genomics applications on the basis of a case-study approach. In my presentation, however, I want to refocus attention to what I would like to call the “broader” issues. How is Social Science and Humanities research concerning genomics (or ELSA genomics) affecting our comprehensive view on human life and society, our understanding of ourselves in relationship to our environment and the world around us, our view on our past, present and future? These issues will be addresses on the basis of an assessment of our research outcomes so far (in the Netherlands and, more broadly, in the EU context) and will form the basis of an outline of future directions.