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GE³LS Alberta

NEWSLETTER SPRING 2010

The 5th International DNA Sampling Conference: The Age of Personalized Genomics

From September 16-18, 2009, the University of Alberta's Health Law Institute, in conjunction with McGill University's Center of Genomics and Policy, – institutions led by GE³LS PI's and Conference Co-Chairs Timothy Caulfield and Bartha Knoppers respectively -- co-hosted the *5th International DNA Sampling Conference: The Age of Personalized Genomics*, in Banff, Alberta.

Attended by close to 160 delegates from a broad range of organizations, institutions, agencies and businesses worldwide, this enormously successful conference investigated the complex legal, ethical and social challenges that characterize the rapidly emerging field of personalized genomics, the potential impact of these challenges on health care delivery, and their representations within both the media and policy communities.

the age of personalized genomics

Exceptional presentations made by world renowned experts in the fields of law and policy, genetics and genomics research, ethics, medicine, and communication studies (among other fields) led to hearty, lively and informed discussions that explored the current state of the science, relevant research ethics challenges, integration of personalized genomics into health care, germane regulatory and governance issues, media and popular representations of genomic testing, and the commercialization of the direct-to-consumer market.

To date, commentaries from the event have been featured in *Personalized Medicine* (2009, 6 (6): 617-619) and the *Journal of International Biotechnology Law* (2009), 6: 262-263), with an upcoming special journal series to be published in Public Health Genomics, featuring articles from conference participants Timothy Caulfield/Bartha Knoppers, Barbara Koenig, Stuart Hogarth, Eric Meslin/ Mildred Cho, Amy McGuire/Wylie Burke, Matthew Nisbet, and Angela Brand/ Jeantine Lunshof. The first commentary will be featured in the June 2010 issue.

This event was made possible by the thoughtful input of the conference's extraordinary organizing committee – Timothy Caulfield, Mildred Cho, George Church, Laurence Kedes, Bartha Knoppers, Amy McGuire and Eric Meslin – in addition to the very generous funding support provided by Genome Alberta, Genome Canada, the Alberta Law Foundation, the Alberta Heritage Foundation for Medical Research, CIHR's Institute of Genetics, CIHR's Ethics Office, the University of Alberta's Health Law Institute, Faculty of Law and Killam Research Fund, and McGill University's Centre of Genomics and Policy.

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iPS Cells: Mapping the Policy Landscape

In July of 2009, alongside Canada's Stem Cell Network, the HLI co-hosted an international policy workshop entitled iPS Cells: Mapping the Policy Landscape. This workshop was held in association with the International Society for Stem Cell Research's annual meeting in Barcelona, Spain. The purpose of this workshop was to consider ethical, legal, social and policy issues engaged by the fast-moving field of induced pluripotent stem cell research. Its distinguished participants included stem cell scientists, bioethics, philosophers, lawyers and social science researchers, among others, from five different countries. The resulting paper outlining the issues raised was recently published in ***Cell***.

Amy Zarzeczny, Christopher Scott, Insoo Hyun, Jami Bennett, Jennifer Chandler, Sophie Chargé, Heather Heine, Rosario Isasi, Kazuto Kato, Robin Lovell-Badge, Kelly McNagny, Duanqing Pei, Janet Rossant, Azim Surani, Patrick L. Taylor, Ubaka Ogbogu, Timothy Caulfield, "iPS Cells: Mapping the Policy Issues" (2009) Cell 139(6): 1032-1037.

World Leader in Health Law and Policy: Professor Timothy Caulfield Advances to Tier I Canada Research Chair

Congratulations to GE3LS Project Leader, Professor Timothy Caulfield, who recently had his Canada Research Chair (CRC) in Health Law and Policy advanced from Tier 2 to Tier 1. This remarkable achievement acknowledges the significant and enduring contributions he has made to academia throughout his career, and his recognition by his peers as an established world leader in his field. In addition, Caulfield will also be awarded annual research support for the next seven years, which will be used to continue his and his research team's investigation of the profound ethical, legal and social challenges that characterize emerging technologies and their associated research techniques. Specifically his future research plan will build on his previous work investigating, for example, patent and commercialization strategies, popular representations of science, research ethics issues, and health policy.

The CRC program is considered an integral part of a Government of Canada plan to drive Canadian research and development excellence, to create world-class centres of research and to enhance Canada's competitiveness in the global knowledge-based economy. Through the CRC program, $300 million is spent annually to attract and retain outstanding scholars and scientists. The nearly 200 chairholders included in the recent announcement from the CRC will conduct research across a range of important fields.

Publics and Emerging Technologies Conference A Success!

In October 2009, Edna Einsiedel and members from the BC GE³LS team (Mike Burgess and Kieran O'Doherty) hosted a symposium discussing the challenges around public participation and emerging technologies. This two-day event was held in Banff, Alberta and hosted twenty-three presenters from all over the world. Many engaging discussion sessions took place and extended beyond the conference setting. The product of this symposium will be a published book examining the cultures, contexts and challenges of publics and emerging technologies. The expected release date of the book will be in Summer 2010. This event was made possible by the generous funding from the Genome Alberta and Genome BC GE3LS teams.

Mavis Jones joins the Xenotransplantation Project

In August 2009, Mavis Jones, a Post-doctoral Fellow joined the "Impact of Citizen Participation on Decision Making in a Knowledge Intensive Policy Field" (CIT-PART) project funded by the European Commission.

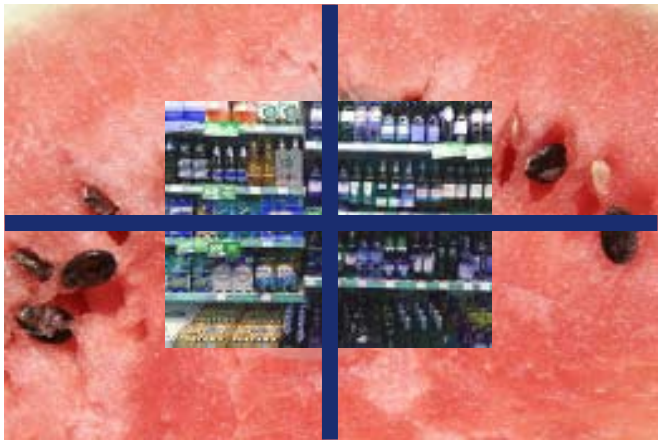
Her research involves examining how xenotransplantation policy has evolved in Canadian and US contexts. Mavis has currently drafted the country template for the U.S. context, based on interviews and documentary research. She has been conducting interviews with prominent figures in xenotransplantation science and policy debates, in both Canada and the U.S.; the interview phase is almost complete and the team will begin analysis in January 2010. With Dr. Edna Einsiedel and Meaghan Brierley, she will be producing manuscripts and conference papers over the next several months, including a paper for a proposed special issue of Science and Public Policy. The next CIT-PART meeting is in Riga, Latvia in April 2010.

Report of GE³LS Research in Progress:

Michele Veeman

The Roles of Generalized Trust and Trust in the Food System on Food Choices

In spite of growing interest in the role of trust on peoples' attitudes to risk, there are disagreements on interpreting the concept of trust. Some authors conceive trust as a generalized expectancy developed through personal experience that is stable over time. Others argue that trust is situation-specific. In economic literature there is focus on generalized trust (a world view that 'most people can be trusted') and institutional trust (reflecting confidence in institutions like the regulatory



system), but little of this work has focused on food risks. This study is one component of the PhD thesis research by Yulian Ding (advisors: Michele Veeman and Wiktor Adamowicz; University of Alberta). This work assesses both generalized trust and trust in institutions in a study of consumers' behaviour towards food risks, in the context of food with health-related attributes (omega-3 content) that may be associated with genetically modified (GM) ingredients. Analysis is based on responses drawn from a representative Canada-wide panel to a 2009 survey, conducted in the form of a marketing assessment of canola oils with different attributes.

It is found that people's responses to different measures of generalized trust are correlated. Measures of institutional trust, assessed for four food system agents (government, farmers, manufacturers and retailers) in terms of respondents' assessments of the competency, honesty and public interest exhibited by these agents, are also correlated. Further, comparison of responses of people who believe that "most people can be trusted" relative to those who chose the response "can't be too careful in dealing with people" suggests that people who are less trusting in others also exhibit lower levels of trust in institutions in the food system. However, assessing roles of various trust measures in peoples' willingness to choose foods with different health, GM and price attributes indicates that generalized trust based on respondents' answers to the standard trust question of "Generally speaking, would you say that most people can be trusted or that you can't be too careful in dealing with people?" has no predictive power on consumers' membership of different choice attitude segments, while having trust in strangers and past trusting behaviour predict this well, which also suggests that there is a component of trust which is stable over time and across situations. Males are less likely to be in the anti-GM group than are females. Older people exhibit more dislike for the GM product. Respondents who are more likely to favour purchase of the omega-3 product exhibit higher levels of education, higher income and are residents of regions other than Quebec. Overall, it is found that those who exhibit trust in food institutions are less likely to be anti-GM than those who do not trust the food system. Trust in farmers is an interesting case and implies that respondents tend to view farmers differently from other institutions: an individual's segment membership is not affected by trust in farmers.

Ongoing Research on Access Benefit Sharing and Traditional Knowledge

Peter W.B. Phillips, Sidi Zhang

The U of S research team (Peter Phillips, PI, and Sidi Zhang, Research Associate) is working to complete work on a variety of investigations of access and benefits sharing (ABS) policies related to traditional knowledge (TK). Earlier work—e.g. J. Orb, 2008, The Political Economy of Public-Private Partnerships:ForestryCo-managementinNorthwest Saskatchewan, Unpublished MA Thesis, University of Saskatchewan)—examined one specific regime of ABS related to TK in Saskatchewan.

Now the team is analyzing the results of a survey on "applying models to manage traditional knowledge". Surveys were delivered to 662 Aboriginal communities, including First Nations (FN) Bands and Reserves and Inuit community governments.

After two flights of surveys and some follow-up, by the end of August 2007 we received 53 completed surveys (2 responses were rejected as incomplete). The effective response rate was 8.3%. Because of small sample size, the survey was not statistically significant at the 95% confidence level and we cannot draw inferences from the sample about the larger population, but we are still able to derive some valuable and informative results from the responses about the practices of these 53 nations. We are in the process of undertaking correlation and cluster analysis of the data and developing pathways of common practice among the survey respondents. From the correlation tests of the respondents, we have documented that FNs which place a high value on the importance of identifying and documenting traditional knowledge tend to gather and keep their traditional knowledge especially plant for food through archives and/or knowledge maps, which they then pass along through their educational curricula.

We also have learned that FN's practices are strongly related to their experiences. Nations which encourage sharing knowledge tend to report proactive management practices and also indicated that their experiences are generally positive. Those who seek to discourage knowledge sharing and/or have no formal policies with respect to TK report more negative experiences, mostly involving unlicensed/unauthorized exploitation of their knowledge. Interestingly, we found that proactive strategies did not always lead to happy endings. Both government and university researchers, who arguably have more reflexive and thoughtful policies with respect to research involving FNs—currently codified for academics in section 6 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*—may not be as successful as some might think. The survey showed that First Nations who were contacted by university and government researchers reported relatively negative experiences; in contrast, relationships with industrial research teams tended to have more positive outcomes. A complete report on this research will be forthcoming early in 2010.

Global Governance Quandries Regarding Transformative Technologies for Bioproducts, Crops and Foods

Stuart Smyth, Peter W.B. Phillips and William A. Kerr

Smyth, Stuart, Peter W.B. Phillips & William A. Kerr. 'Global Governance Quandaries Regarding Transformative Technologies for Bioproducts, Crops, and Foods'. ***Journal of World Trade*** 43, no. 6 (2009): 1299–1323.

Abstract: The evolution of multilateral regulatory regimes is a slow process that is based on consensus-building among a large number of participants. International organizations function best in relatively stable international environments where the inherently slow pace of decision-making does not create disconnects. They are least effective during periods of rapid change. By defi nition, a transformative technological change such as biotechnology precipitates disequilibrium. Technological change leads to the need for institutional adaptation and/or the establishment of new institutions. This article provides a review of international regulatory initiatives implemented or under negotiation to develop the architecture for regulating the production, trade, and marketing of biologically derived crops, bioproducts, and foods. The results of these global governance efforts are compared and contrasted to assess how transformative technology barriers have been identified and addressed within these institutions. Options for further effort are examined.

Floating the Knowledge Management Boat in a Sea of Intellectual Property Rights

David Castle, Peter W.B. Phillips, Abbe Brown, Keith Culver, Daniela Castrataro, Tania Bubela, Shawn Harmon, Graham Dutfield , Patricia Barclay

Castle, David, Peter W.B. Phillips, Abbe Brown, Keith Culver, Daniela Castrataro, Tania Bubela, Shawn Harmon, Graham Dutfield , Patricia Barclay. 'Floating the Knowledge Management Boat in a Sean of Intellectual Property Rights.' Accepted by SCRIPTed, A Journal of Law, Technology & Society

Abstract: Intellectual property rights play a central role in biotechnology innovation. Patents, in particular, preoccupy research funding agencies, venture capitalists and governments, despite the fact that the value of patents is disputed and their impact continues to foster controversy. Perhaps more crucially to a fuller understanding of innovation, focus on instruments of intellectual property protection over-illuminates one stage of the flow of knowledge in innovation, leaving up- and down-stream phases in relative obscurity. Knowledge is an intangible asset, and is produced, tracked, managed, and accounted for in innovation systems. Yet what remains unclear, and this is problematic, are the respective roles of knowledge and intellectual property management, their relation, and the potential of a broadened perspective on knowledge flows in innovation. Participants at a recent Canada-U.K. workshop in Edinburgh examined the relationship between intellectual property rights and knowledge management by framing innovation in terms of knowledge management while attempting to bracket off the effects of patenting – the "Un-IP" approach. Eight critical issues arising at the heart of knowledge management and intellectual property rights were articulated, and general consensus emerged that, conceptually speaking, intellectual property rights needed to be subsumed under knowledge management as a particular class of intangible asset. At the same time, however, practical issues associated with patents continued to dominate the discussion, causing deviation away from the primary theme of the workshop, and highlighting the need to more fully explore eight emerging themes and contextualize the role of intellectual property rights.

GE³LS Research Projects Kick-Off in Saskatchewan

Peter W.B. Phillips, Dr. Stuart Smyth

The University of Saskatchewan co-leads three GE³LS research projects funded during the Genome Canada Competition in Applied Genomics Research in Bioproducts and Crops (ABC). Each of the four year projects started on October 1, 2009 and are managed by Genome Prairie.

Dr. Stuart Smyth, Professional Research Associate with the Department of Bioresource Policy, Business and Economics in the College of Agriculture and Bioresources, leads two new integrated GE³LS projects. The first of which is a project entitled "Assessing the Impact of Canadian Regulation Regarding Plants with Novel Trait (PNTs)". Integrated with the ABC project "Total Utilization of Flax Genomics" (TUFGEN), the project will assess Canada's unique requirement for regulatory scrutiny when a plant acquires a new trait, even if it is not a product of recombinant-DNA techniques.

The second project led by Dr. Smyth is the integrated GE³LS project "The Social and Economic Costs of Large-Scale Biofuel production". The project is integrated with "Microbial Genomics for Biofuels and Co-products from Biorefining Processes" and aims to identify issues regarding environmental sustainability as well as identify, and ultimately avoid, impediments to research due to the existence of patents.

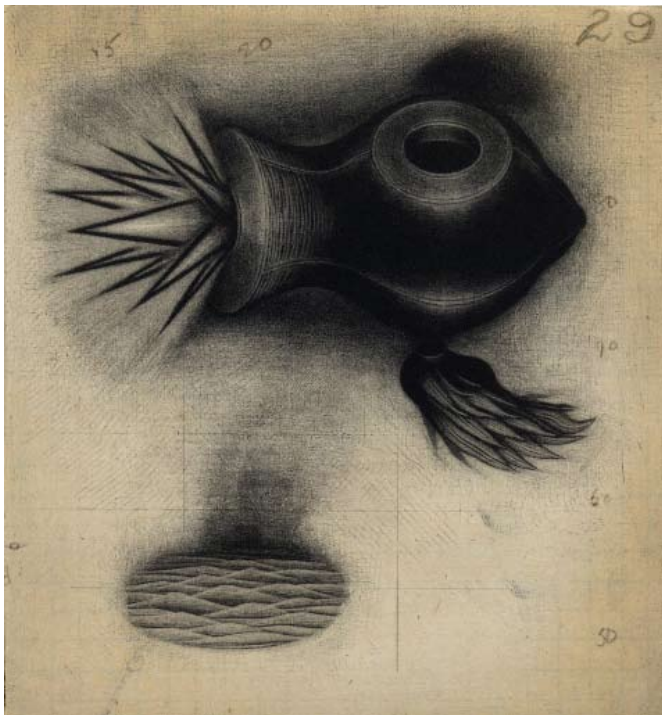
Value Addition through Genomics and GE³LS or VALGEN is co-led by GE3LS PI Dr. Peter W.B. Phillips and Dr. David Castle, Department of Philosophy at the University of Ottawa. The project answers three critical questions about the future of genomics. When any innovation emerges, those questions are: Who owns it? Who controls it? Who wants it?

The VALGEN team will investigate how new discoveries leave the laboratory as intellectual property, and the legal and business tools surrounding that property. It will also identify models for governing these new products, and finally, determine how Canadians feel about new crops and bioproducts. This leading-edge research will inform future public policy that regulates how innovative products move from the laboratory to the marketplace.

The VALGEN research team includes researchers from across the country from the University of British Columbia, University of Calgary, University of Regina, University of Western Ontario (London), University of Ottawa, McGill University (Montreal), Laval University (Quebec City), and the University of New Brunswick. Over 100 students and employees, as well as 60 industrial and government partners contributing to research design and development, are working on the VALGEN project.

Science, Social Controversy and Art: An Interdisciplinary Exchange

Building on the success of the ***Imagining Science*** initiative, GE3LS PI Timothy Caulfield in conjunction with his brother Sean Caulfield and Elizabeth Ingram, both Professors in the Department of Art and Design, University of Alberta, are leading a second highly interdisciplinary project exploring the interface between art and science. Entitled ***Science, Social Controversy and Art: An Interdisciplinary Exchange,*** this project will explore the impact of popular culture and art on public perceptions of biotechnology.



Funded in large part by the Stem Cell Network (SCN), preliminary work from this initiative will first be featured at the SCN 2010 Annual General Meeting, Calgary, November, 22-24, 2010. This will then be followed by two large group exhibitions, the first of which will take place at the Glenbow Museum, Western Canada's largest museum, next spring. The second will take place in Toronto in association with the International Society for Stem Cell Research's (ISSCR) Annual General Meeting in June 2011, and both exhibitions will be opened by public panel presentations featuring a mix of project participants.

An exhibition catalogue, featuring reproductions of artworks and essays by contributions scholars will also be produced, its launch scheduled to coincide with the opening of the Glenbow exhibition.

Other Noteworthy Publications and Awards

Timothy Caulfield, Christopher Scott, Insoo Hyun, Robin Lovell-Badge, Kazuto Kato, Amy Zarzeczny, "Stem cell research policy and iPS cells" (2010) Nature Methods; 7(1): 28-33.

Timothy Caulfield and Jane Kaye, "Broad Consent in Biobanking: Reflections on Seemingly Insurmountable Dilemmas" (2009) Medical Law International; 10: 85-100.

Timothy Caulfield, Victor Alfonso and Jacob Shelley, "Deterministic?: Newspaper Representations of Obesity and Genetics" (2009) The Open Obesity Journal; 1: 38-40.

Nola Ries, Robyn Hyde-Lay, and Timothy Caulfield, "Willingness to Pay for Genetic Testing: A Study of Attitudes in a Canadian Population" (2009) Public Health Genomics; DOI: 10.1159/000253120).

Timothy Caulfield, "Direct-to-Consumer Genetics and Health Policy: A Worst-Case Scenario?" (2009) American Journal of Bioethics; 9: 48-50.

Timothy Caulfield, Amy Zarzeczny, Jennifer McCormick, et al., "The Stem Cell Research Environment: A Patchwork of Patchworks" (2009) Stem Cell Reviews and Reports; 5(2) 96-101.

EF Einsiedel, S. Premji, RM Geransar, NC.Orton, T. Thavaratnam and L K. Bennett, "Diversity in Public Views Toward Stem Cell Sources and Policies," (2009) Stem cell Reviews and Reports; 5:2-7

E.F. Einsiedel and R.M. Geransar. "Framing genetic risk: Trust and credibility markers in online direct-to-consumer advertising for genetic testing" (2009) New Genetics and Society; Dec; 28(4):339–362.

E.F. Einsiedel (2009) Stakeholders and genomics representations. In P. Atkinson, P. Glasner, and M. Lock (eds.) ***Handbook of genetics and society: mapping the new genomic era***. London: Routledge.

P Phillips and D. Castle. Forthcoming in 2010. Science and technology spending: still no viable federal innovation agenda. Chapter 9 in B. Doern et al., ***How Ottawa Spends 2009***, McGill Queen's University Press

Rose Geransar, a Ph.D. candidate working with Dr. Edna Einsiedel received an award for the poster she presented at the Electronic Health Information and Privacy conference held November 19, 2009 in Ottawa. Her poster entitled "***Rethinking Consent in Stem Cell Research: A Case Study of Cord Blood Donation for Research & Therapy"*** outlined Rose's research into the mechanisms governing consent to the use of cord blood in clinical therapy and health research. Congratulations Rose!

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Newsletter compiled by Robyn Hyde-Lay

This project is supported by Genome Alberta and Genome Canada, a private, non-profit corporation whose mandate is to develop and implement a national strategy in genomics and proteomics research for the benefit of all Canadians. For this purpose, it has received $840 million in funding from the Canadian government.