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Intra-familial Disclosure of Genetic Information: Policy Considerations

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ABSTRACT

Genetic information can have health implications for individuals who undergo genetic testing but it can also have implications for the health of their blood relatives. Most individuals disclose genetic information to family members when they have been informed of the importance of doing so. However, some do not; and those who do often feel uncertain about when, how, and to whom to disclose. Some individuals faced with the task of disclosure attempt to balance the potential negative impact of the information against the potential health benefit that the knowledge could result in. This balancing represents conflicting approaches to the *protection* of family members, and is a moral dilemma for informers. The net effect is that blood relatives for whom genetic information may be relevant are sometimes not informed.

Methods:

This paper involves a thorough review of qualitative studies recounting individual and familial experiences with communication of genetic information so as to identify challenges, complexities, benefits, and facilitators of intra-familial communication. Reviewed literature will be synthesized and recurring issues will be identified and discussed.

Results:

Policy considerations in this context include: the need for practical guidance and counselling around disclosure; the need for education around implications of genetic information for family members; the importance of gender, family roles, and family context; the relevance of the type of genetic information and prior experience in a family with the condition; the role of cultural context; and psychosocial barriers to communication.

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Creating Second Class Citizens: A Literary Example of Cloning's Threat to Human Integrity and Autonomy

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ABSTRACT

The cloning of human organs for therapeutic uses presents liberal democracies with conflicting principles: as medical therapy, it promises to relieve human suffering, while at the same time threatening human identity and integrity. Literature offers a means for exploring the social implications of policy positions as Canadians continue to grapple with the issue of cloning, whether for reproductive or organ and tissue transplantation purposes.

The interaction between public policy, science, public opinion, and literature is a complex one in which each arena influences others. There was much less legislation governing genomic-enabled technologies when Margaret Atwood's *Oryx and Crake* (2003), was published than today. But the Raelian announcement of a successful human clone in 2002 contributed to an increasing number of countries' bans on human cloning.

This poster will not discuss the technical problems of therapeutic cloning but instead will contemplate the social implications of cloning human body parts by examining a fictional case of human cloning. *Never Let Me Go* (2005) is narrated by a clone who has been created in order to harvest her organs. In her society, they have decided the best source of organs for transplantation comes from cloning the entire body. The second class citizens this produces gives us a glimpse into how human identity and autonomy could be eroded by the construction of the human body as nothing more than a collection of interchangeable parts available for medical therapies, and acts as stimulus to discussions about the implications of allowing the cloning of human organs.



Toward a Canadian Policy Framework on Nanomedicine

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ABSTRACT

Nanomedicine is changing the way we understand healthcare and health services by bringing new drug delivery systems, real time diagnostic testing and *in vivo* medical imaging. Some predict that emerging nano systems will also enhance existing genetic applications to increase their rate of accuracy, but may inadvertently increase their vulnerability to misuse at the same time. Meanwhile, the nanomedicine industry is expanding without any restrictions forcing many to wonder if governments will address these socio-ethical and legal issues. In Canada, initiatives toward a broader policy framework for nanomedicine are still in their infancy. One area that has received little attention in these initiatives is the analysis of models. This presentation addresses this gap by identifying and examining three health services models that could guide the development of nanomedicine policy in Canada. The models are: 1) the medical model; 2) the public health model; and 3) the fundamental rights model. Each model is analyzed using information from a burgeoning area known as point-of-care testing. Point-of-care testing uses nano systems for the development of portable test kits that can provide results on site. What becomes clear in this analysis is that current concerns for how nano enabled medical tools and those who use them impact our rights as citizens and as individuals are not farfetched. We will argue that the model that best attempts to ensure quality in health services using nanomedicine is the fundamental rights model.

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Gene Discovery to Policy: A Template for Future Health Policy in Newfoundland & Labrador

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ABSTRACT

Basic science, clinical and GE³LS researchers in Newfoundland and Labrador involved with the Atlantic Medical Genetics and Genomics Initiative (AMGGI), have worked together to make important new scientific discoveries and to sort through associated ethical issues involved in translating those findings to the clinic and in the development of appropriate health policy.

One illustration of effective interdisciplinary collaboration is this team's discovery of the putative mutated gene for a particularly lethal cardiomyopathy, autosomal dominant arrhythmogenic right ventricular cardiomyopathy 5 (ARVD5). This condition is a cause of sudden cardiac death generally due to a lethal abnormal heart rhythm. It is particularly malignant in young affected males. Prior to the gene discovery the clinical diagnosis of this condition was difficult and required clinicians and GE³LS researchers to sort through a variety of ethical issues associated with the blurred demarcation between research and clinical practice.

With the recent discovery of the putative gene for ARVD5, GE³LS researchers have been tasked with developing and implementing an appropriate health policy strategy to ensure timely access to genetic testing and treatment for all those affected with this condition. This process has worked extremely well and is the hallmark for our future work to ensure effective translation of research results into clinical practice in this province. In this talk we report specifically on the steps taken to develop and implement a policy that will result in timely and appropriate intervention (i.e. Implantable Cardioverter Defibrillators) for individuals affected by ARVD5.

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Technological Governance: Social Movements, Progress and Uncertainty

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ABSTRACT

Organized movements are playing a role in decision-making related to genomics. Technological governance has become a more complex arena, partly as a result of these engaged social actors. Their use of strategies, including, promotion of specific understandings and meanings of technologies, collaboration and networking, training members in social and political action, and broadening knowledge development through funding incentives and alternative research, play a strong role in shaping developments in both technical and political domains. Some groups engage in the promotion of technologies, most notably patient groups. They have become important for scientific and political allies, particularly regarding controversial technologies, such as stem cell research. Other oppositional groups emphasize the dark side of emerging research, through building alternative frames, which have, at times, been very effective. 'Terminator technology', for example, than the original name, 'gene use restriction technology', and is a label that emphasizes the uncertainty and fear associated with possible post human futures through drawing on a popular representation. This poster will draw on examples of social movement activity around agricultural biotechnology, gene patenting and regenerative medicine to demonstrate the influence of these organizations in shaping policy, research and technical outcomes. They form fluid movements, which respond to controversy based on controversy, uncertainty and the promise of progress. Canadian and international examples will be used in this analysis.

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Tracking the academic and commercial outcomes of open source biology: *C. elegans* knock-outs as a case study

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ABSTRACT

Researchers, funding bodies (e.g., Genome Canada), and society recognize the benefits of moving scientific knowledge into the public domain in a timely manner to maximize accessibility and potential utilization. It is generally believed that access to publically funded basic research is relevant to increasing our knowledge of human development and alleviating the burden of disease. By keeping data openly accessible the potential value of this work can be optimized. Here we develop a system for tracking the use of open source Canadian genomics research in order to test this assumption and to understand the global impact of freely-available data. Using the *C. elegans* knock-out consortium and the *C. elegans* research community as a case study we track the utilization of open source resources, specifically gene knockout strains. The UBC *C. elegans* Gene Knockout Laboratory is part of an international consortium of laboratories working to produce null mutations in identified and predicted genes in the *C. elegans* genome for the research community. These strains and reagents can be tracked and can therefore act as markers to probe how these reagents are utilized. By reviewing academic peer-reviewed articles and patents we are able to report on the extent and type of asset use. We explore the downstream outputs of genetic knowledge in the form of publications and patents in order to highlight how open source resources are distributed and used. This type of analysis will also reveal the benefits these resources provide, both nationally and internationally, to Canadian researchers and the public.

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Preferential Attachment or How Genomics Databases Networks are Forming

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ABSTRACT

There are currently two poles emerging in the field of large-scale genomic projects, based on two different approaches for the integration of resources. First, there is the American method, based on the National Institutes of Health's *Policy for Sharing of Data Obtained in NIH Supported or Conducted Genome-Wide Association Studies*. It proposes the centralization of data and the standardization of procedures required for research. Second, there is the European method, based on an initiative developed by EU Member States, proposing a "federated network" of existing and *de novo* databases, within a framework called the *Biobanking and BioMolecular Resources Infrastructure*. These may be viewed as emergent from two different philosophical positions. The American approach can be associated with *contractualism*, which implies a set of common rules which permits centralization accompanied by the loss of autonomy and power over resources. The European approach is based on the necessity of attaining statistical power with larger samples without the burden of harmonizing national, legal and ethical disparities. This second approach may be associated with *utilitarianism*, characterized by the search for common interests. These initiatives contribute to the creation of a public resource for future generations of scientists, with an incredible potential for health and environmental outcomes. I propose to observe this emerging network, as inspired by the "preferential argument" developed by Barabasi on complex networks, which describes the process of attraction of new genomic research projects.

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Economics impact of white spruce's natural genetic improvement in Québec

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ABSTRACT

White spruce is a multi-purpose species of important commercial value for saw log and pulpwood sectors. Research programs on white spruce genetics have been carried out in Quebec for almost 50 years, aiming to maximize plantation yield and shorten harvest cycles. Those plantations will then contribute to reduce pressure on natural forests, while assuring sustainable yield of this resource. Analysis of economic impacts from genetic improvement programs, which selects the best natural trees by doing natural tree breeding to increase or improve the overall genetic background of a species, becomes essential to support those programs for further investments and assess future needs of industry. This analysis focuses on the potential economical value of these plantations in terms of breeding cycle, optimal rotation and forest products. The objective of this research is to integrate an economic value in calculation of allowable cut, the amount of a natural resource that may be harvested on a sustainable yield. To do so; we include the net present value criteria in the process. This approach therefore takes into account the production gains resulting from the genetic improvement. It is important to monitor and estimate the increase on wood supply and make a balance between this increase and forest conservation. The results show an increase of the allowable cut in regard to volume produced and economic benefits, while considering the breakeven point between wood supply and biodiversity in a forest zoning management approach.

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**“Evidence-based ethics” in the policy context:
An examination of the role of evidence in using case studies in stem cell research**

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ABSTRACT

The notion of evidence-based ethics (EBE) has become pervasive in multidisciplinary policy arenas for new and emerging technologies. However, the meaning of EBE has received little examination despite the phrase being commonly employed within policy contexts. The phrase ‘EBE’ is often used in ways that indicate misunderstandings regarding the nature of the normative decision making process and the structure of ethical arguments. The problem is especially evident within multi-disciplinary contexts in which the applications of EBE are often proposed. Without a commonly understood definition, EBE has become a ‘phantom concept’, a mere empty catch phrase that is proposed as a pragmatic fix to the problems of science policy-making where there is a possibility for empirical input, such as public opinion studies. In the scientific literature, it is not clear whether the term ‘EBE’ is understood to indicate: 1) the judicious use of the best available evidence in the normative decision-making process, or 2) that evidence can act as the basis of, or as a confirmation of, our normative assumptions, or another meaning. The first definition is often based on a blurred distinction between normative, applied and descriptive ethics. The second definition commits the naturalistic fallacy, if we assume a hard fact-value distinction. In both cases the terminology threatens to obscure the normative premises that are necessarily parts of the policy making process, and in that respect fails to meet the goals of transparency and public accountability in the policy context. This poster intends to re-examine the role of evidence in policy-making using Canadian stem cell research public opinion studies as an illustrative example.

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BiDil: Recontextualizing the Race Debate

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ABSTRACT

BiDil is the first drug to be approved by the US FDA for a specific ethnic population, namely self-identified blacks. Yet, BiDil remains mired in a controversy surrounding race-based medicine. Over the past 2 years we've conducted a case study of the BiDil controversy. We interviewed those involved with the development, approval and subsequent commercialization of BiDil as well as vocal supporters and detractors of the drug. In this poster, we will be presenting our findings; a substantial part of the debate focused on the risks of race-based medicine, and that this concern can be narrowly conceived, overshadowing the broader context in which the BiDil case exists. BiDil is a necessary stepping stone in the trajectory of personalized medicine and can offer valuable insight as to the pro-active measures we should be implementing as we move towards the adoption of population specific/individual specific therapeutics. We also plan to include additional themes which we are currently exploring surrounding the use of geographical ancestry/race in genomics and its medical applications.

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Human Genomic Variation Studies and South Africa

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ABSTRACT

Human genomic variation (HGV) studies are emerging globally and may result in a greater understanding of human ancestry and health, disease susceptibility, and drug response. Some suggest that developing countries (DCs) will not benefit from these initiatives because cost, accessibility and delivery challenges. However, DCs have compelling reasons to pursue HGV studies to improve the health of their populations; they can create cost-savings in drug development; reduce healthcare costs and uncover genetic diversity relevant to drug response or disease predisposition. We are conducting a qualitative case study on South Africa, as part of a larger project investigating HGV and its implications for global health, consisting of several developing and emerging countries. South Africa is home significant genetic diversity making it ideal for HGV studies. To gain an understanding of these studies and their implications for global health, we will interview scientists, ethicists, private sector, government officials and other key stakeholders. The themes we will explore include: the drivers for HGV studies, how the research may be translated into tangible benefits, regulatory requirements and the ethical, social and cultural issues (ELSI) that may arise. Given that South Africa is so genetically diverse, issues that have been discussed mainly in the West such as genomic sovereignty may need to be revisited, as it has implications for the application of knowledge derived from HGV studies for Africa. We plan to draw from this case study to provide future recommendations regarding the adoption of genotyping technologies to improve health and stimulate development in DCs.

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**Struggling for global benefits:
Colombian plant genetic engineering within global biotechnology**

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ABSTRACT

Colombian scientists operate in a world in which global connections and disconnections are crucial to the access to and application of biotechnology. Global benefit from new genetic biotechnologies in this context cannot be assumed, but rather must be engaged with and negotiated for by scientists both individually and institutionally. Drawing from a multi-sited ethnographic study of plant genetic engineering in Colombia, an international research centre set in Colombia, and in Canada, I suggest that international sources of funding, international collaborations and out of country training (for graduate students and skill development) are important connections between developing and developed biotechnological research. Furthermore, these connections are more crucial to the use of biotechnology for those in Colombia than those in Canada. Colombian and Colombian-based international scientists draw on such connections in order to advance their research projects. Using such connections, scientists situated in Colombia must transverse barriers in this field which disconnect them from participation in international research, such as scarce available research funding for tropical crops, difficulty retaining trained scientific staff within the country, complications importing basic scientific reagents, and language barriers. All of these factors place scientists working within Colombia in a position requiring them to grapple with the connections and disconnections across space and time that make up the complex patterns of international biotechnological research. These patterns in Colombian plant genetic engineering suggest that the application of biotechnology globally is affected by widespread inequalities in socio-economic and political power.

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New Models and Novel Strategies for Improved Genomic Communication

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ABSTRACT

Genomics research and gene therapy are among the most controversial areas of science, raising ethical, legal, social and other issues. This GE³LS project investigates issues related to the public communication of controversial science, with a focus on genomics. This research is thus motivated by three basic questions:

- What is the science communication process that produces journalism about genomics?
- What roles do the news media play?
- How does the public comprehend and use the information they receive?

The ultimate aim of the research is to develop new and better ways to communicate controversial science using new models and new forms of journalism that allow a democratic public to engage with and understand genomics issues.

To gain insight into how newsrooms handle science news, we performed interviews with newsroom editors and journalists who cover science at major print outlets in Canada. Collaborating with international researchers, we also performed a content analysis of genomic stories in major newspapers in Canada, France, and Belgium. Articles were analyzed using different techniques to obtain an overview of the material disseminated to the public about science and related issues.

We analyzed the stories for both factual (topic, position in news slot, headline–article tension, origin of story, types of sources, etc.) and normative (accuracy, balance, context, positive and negative implications, metaphors, frames, etc.) variables.

The next stage of the project will include an analysis of science journalism on the Internet and a theoretical critique of science journalism's role in the public understanding of science.

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Informed Consent in Pharmacogenomics: Is there enough guidance?

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ABSTRACT

Research Question:

This study provides an overview of emerging issues in relation to informed consent for pharmacogenomic research. Its purpose was to see how policy-makers are responding to novel issues that arise in relation to this research.

Background:

Pharmacogenomics holds great promise for improving the way that diseases are treated. However, it will require large-scale clinical trials in order to achieve its promised results. The difficulty and impracticability of collecting the volume of samples required, coupled with the fact that the character of information revealed can be characterized as different from standard genetic testing, raises a question of whether a more prospective consent, taking into account communal rather than individualistic values, is warranted.

Methods:

We analyzed international, regional and national guidelines and policy statements focusing on pharmacogenomics to identify whether any trends were emerging in relation to the consent process. Our analysis focused on 5 issues: (i) scope of consent, (ii) duration of the consent, (iii) confidentiality and coding of research samples, (iv) return of research results, and (v) consent to 'add-on' studies in the context of clinical trials.

Results:

Our findings show how policy-makers have tried to balance the rights of the individual with the efficient progression of research. A key observation is that while pharmacogenomics is rapidly evolving, policy is far behind. Few policies deal specifically with pharmacogenomics and most that do are outdated, particularly in their discussions of confidentiality and returning research results. As such, more direction is needed to guide researchers in this rapidly evolving discipline.

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Power/Knowledge and the Implantable Defibrillator

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ABSTRACT

The implantable cardioverter defibrillator (ICD) has become routinized in clinical genetics as an essential (life-saving) treatment for the “presymptomatic ill” ARVC patient. ARVC (Arrhythmogenic Right Ventricular Cardiomyopathy) is a lethal autosomal dominant genetic linked disease with high mortality due to sudden cardiac death. This paper traces the historical evolution of the ICD and juxtaposes that history against the illness experiences of ARVC patients living with the implanted device. Questions are raised about the shifting conceptions of genetic risk and normality that result from the experience of having the device implanted. Drawing on the Foucaultian notion of power/knowledge, the argument is made that the ICD as metaphor conveys powerful meanings about how ARVC patients “ought” to be ill. While these findings have obvious implications for genetic counselling pre- and post-implantation, more importantly they serve as an important reminder that our production of genetic knowledge and technology is neither neutral nor value-free.

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The Search for a Precautionary Principle Adapted to Public Health Policies

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ABSTRACT

As a standard for public risk policy, the precautionary principle, being at the same time both ethical and legal in nature, has made its appearance and been formalized within the context of international environmental law. Its range has not only widened to encompass local and national legislation into which it has been integrated, but equally so to be incorporated into the public health field, where its application is increasingly needed, notably in the pandemic context.

Nevertheless, a difficulty remains in that a strict definition of the precautionary principle does not exist. Indeed, it is an adaptable concept, « of variable geometry » (Arbour, 2001), its significance and subsequent impact on the decision-making process varying according to the context where it is applied. The poster will present the diverse constituent elements of the precautionary principle and will illustrate how the variables associated with them have permitted the development of different versions of this principle.

Thus, we will identify four specific versions: that is to say the design of the institutional doctrine; that of the precautionary approach; the tactical approach; and the strategic approach (Godard, 2003). We will state the principal characteristics of these various versions, present situational examples drawn from the public health field where applicable, and state the main implications associated with these concepts. It is not a question of proposing a normative framework adapted to diverse public health situations, but rather to engage in a discussion on the different potential applications of the precautionary principle.

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Are we ready for a policy making process for public health genomics? Stakeholders' point of view

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ABSTRACT

Background: Genomic research has generated a growing corpus of knowledge about genetic susceptibilities to common diseases and infections, which could be used in public health research, for example for the evaluation of disease risk. However, the relevance of genomics for public health is the object of debates while it raises ethical questions.

Objective and method: To learn about the perceptions the stakeholders have towards the relevance of genomics for the public health research and the related issues, we interviewed policy makers (7), epidemiologists and virologists (7), genomics researchers (9), and ethics and law specialists (10) concerned by the public health genomics issues. Results: Undoubtedly, genomics holds great scientific potential. Nevertheless, biobanking has to be in the public interest and issues related to framing research such as consent allowing secondary uses and mechanisms for protecting access to data need to be considered. Actions to be taken in regard to mechanisms for research participants' protection, proof of transparency and accountability need also to be considered to a lesser extent. Discussion: Although other issues have been addressed by a minority of stakeholders, these issues need to be considered for an effective integration of genomics research into public health genomics. Among these issues, we can mention those related to certain dimensions of biobanking as public goods, to public health powers and their limits on surveillance, to follow-up and audit as well as to the regulation of the use of genetic data.

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Expert and Stakeholder Involvement in a Deliberative Event on Biobanks

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ABSTRACT

Over two weekends in April and May of 2007, The Face-to-Face research team of the Genome Canada sponsored "Building a GE³LS Architecture" project brought together a group of demographically stratified citizens to deliberate about the values that should be used to govern biobanks.

As well as providing written information materials, we invited five speakers to present to participants a range of perspectives regarding genetic testing, genetic research and biobanking. This poster presentation will focus on the involvement of expert and stakeholder presenters as informational tools provided for participants. Among our speakers were a lawyer and privacy expert from the University of Victoria, the Director of the Tumour and Tissue Repository of BC, a CIHR project manager on Aboriginal ethics, a mother of a child born with a genetic illness, and a member of the CIHR Institute of Genetics advisory board.

This poster will outline the approach taken to involving expert and stakeholder speakers to present additional perspectives on biobanks to the participants without participating in participant deliberations or observing participant discussions. Analysis of the audio-recorded deliberations illustrates how expert and stakeholder knowledge was cited, criticized and incorporated into deliberations. The justification for this design was to balance concerns about informed and representative deliberation while avoiding stakeholder capture.

We can conclude our analysis by arguing that it may be a good prima facie principle to separate experts and stakeholders from deliberations when the goal is to enhance representation of citizens on technical issues and related policy.

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Regenerative Medicine Innovation in Emerging Economies: A case study of China

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ABSTRACT

China is increasingly recognized as a powerhouse in regenerative medicine (RM). China has the only two gene therapies currently licensed in the world, but it is the growth of their stem cells sector that has been drawing international attention. As a pioneer in regenerative medicine, China serves as an example that will help define RM strategies for other developing countries. In this study, we have examined the process by which China has developed capacity in this sector, with particular attention paid to the strategies and role of policy in RM development. Using qualitative case study methodology, we interviewed 34 experts in China on stem cells, tissue engineering and gene therapy from different sectors including research institutes, hospitals, firms, educational institutes, government, policy makers, and bioethicists. Preliminary results show that the return of diaspora from the West is driving innovative research in China. Government support and flexible regulations are also advantages to doing RM in China. A lack of basic research skills and a hesitant venture capital sector decrease the ability of China to deliver on the RM applications it so urgently seeks. China's desire to break into international markets reflects that their products and therapies may not only benefit China's population of 1.3 billion, but could also have a global impact on health.

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The Role of Individuals in a Knowledge Based Economy: Analysis of Attitudes towards Innovative Products with Health Benefits

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ABSTRACT

In practice, while some consumers attempt to obtain information about purchasing decisions regarding the food products with health benefits scientists and innovators incur costs while attempting to develop products with health benefits. In spite of the potential benefits from such research, scientists and investors have to deal with the challenge of demand uncertainty associated with the rapid changes in technology. Although some products with health benefits have been accepted readily by consumers some products have not. It is therefore evident that scientific research showing the benefits of a product is not sufficient to guarantee its acceptability. When framing the question of individual perceptions, extensive research has been conducted on the role of consumers as end users making purchasing decisions for innovative products. In addition, individuals function within associations that set industry standards as regulators that define the positioning rules for innovative products in the market and as scientists, retailers and processors thus setting the accessibility rules that determine the products that are available for end users to purchase. Given the fact that understandings are shaped by the social representations of the groups to which individuals belong and may result in differences in the cognitive view structures this research will use a survey instrument to investigate the factors that influence individuals when making decisions regarding innovative products with health benefits within the purchasing and accessibility domains. In addition the survey will investigate if any of the health attitudes of scientists influence the products that are developed.

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Changing Patterns in the Use of Research Animals versus Public Attitudes: Potential Conflict

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ABSTRACT

Advances in genome science have introduced new challenges to the governance of animal use in research. Genetically modified animals are responsible for a worldwide increase in research animal use from 13% in 1996 to 46% (91% mice, 7% rats and 2% pigs, frogs and zebrafish) in 2006. This increase conflicts with efforts to reduce research animal numbers, and highlights the need for research on public attitudes towards the use of GM animals in research. We compared attitudes towards different uses of research animals, with and without genetic modification and the role of information in decision-making. Using a survey, we probed participant views on the use of pigs for research to: 1) reduce agricultural pollution and 2) improve organ transplant success in humans. 65% of respondents supported research on pigs to reduce pollution but this support declined to 20% ($P=0.0$) when the research involved the use of GM pigs. A similar pattern was found for the use of pigs in biomedical research; 49% of respondents supported the use of pigs to improve organ transplants, but this support declined to just 29% ($P=0.0$) when the research involved the use of GM pigs. Thus, in both scenarios the level of support declined when genetic modification was proposed. These results indicate that the public is much less willing to accept the use of animals in research when this involves GM procedures, setting the stage for conflict between the research community and the public over the increased use of GM animals.

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**Access to Data and Materials in the Life Sciences –
A Study of *Caenorhabditis elegans* Knockout Projects as Comparative Models
for Large-Scale Knockout Projects**

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ABSTRACT

Purpose: Several whole-genome knockout projects are currently underway with the aim of creating open-access repositories. We are interested in 1) The impact of these projects on the progress of research and 2) whether these projects effectively address concerns over access to materials. We chose to study the Canadian *C.elegans* community as it has access to the *C.elegans* Gene Knockout Consortium and the National Bioresource Project (NBRP), knockout projects with contrasting resource access policies.

Methods: We did face-to-face interviews and an online survey of the community exploring participants' practices around the sharing of materials and data; use of MTAs, patents; experience with the two knockout projects and opinion of the projects' different access policies.

Results: 96% of our participants used *C.elegans* as their sole model. 96% reported that they regularly share data/materials with colleagues, yet 31% said that they had experienced withholding of data/materials from peers. We found that MTAs and patents were in widespread use. Researchers believed the knockout projects had the biggest impact in time and money saved (92%) and increased use of *C.elegans* as a model (69%). Respondents also commented that the projects allowed them access to unpublished alleles they were not able to obtain elsewhere.

Conclusions: Researchers were highly supportive of the two knockout projects. We found that the two projects' differing policies towards access to the mutants were surpassed by the benefits provided to the researchers. These researches demonstrate how a research community has clearly benefited from the establishment of a public resource.

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**Lubricating the policy wheel:
Deliberative Public Engagement in Salmon Genomics**

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ABSTRACT

Policy related to salmon genomics is likely to be contentious due to the complex social, political and economic context. This presentation emphasises how public engagement can be designed to enhance representation and legitimacy of policy related to genomics and biotechnology. We will describe the steps taken to identify particular policy issues and related democratic deficits. Issue characterization draws on literature reviews, focus groups, web crawling research related to the “meaning of salmon” on the internet, interviews with researchers using a salmon microarray developed in BC (cGRASP: PIs Davidson and Koop), experience with designing deliberative engagement on biobanks, and an online survey experiment. We will consult with collaborators in deliberative democracy and salmon related fields to assess where public deliberation is useful for policy related to salmon genomics, and to characterize the deliberation.

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McLaughlin-Rotman Centre for Global Health – From the Lab to the Village

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ABSTRACT

The McLaughlin-Rotman Centre for Global Health (www.mrcglobal.org) works at the nexus of life sciences, developing countries and entrepreneurship using scholarly research to help move health technologies from the “lab to the village”.

To date we have assisted the:

- Bill and Melinda Gates Foundation to launch the Grand Challenges in Global Health Initiative.
- Canadian Government’s commitment in a throne speech and economic update to devote 5% of R&D funding to technologies relevant to developing countries.
- United Nations Secretary General’s Office in understanding the linkage between development and security in biosciences, leading to a speech by Kofi Annan at the University of St. Gallen.
- African Union High-Level African Panel on Modern Biotechnology’s report, “Freedom to Innovate: Biotechnology in Africa’s Development”.
- United Nations Millennium Development Project Science, Technology and Innovation Task Force report, “Innovation: Applying Knowledge in Development”.

Current projects include:

- Strengthening the Role of Genomics and Global Health, funded by Genome Canada through the Ontario Genomics Institute, which seeks to understand the role of genomics research, development and commercialization activities, in order to address global health challenges in the developing world.
- The Ethical, Social and Cultural Program for the Grand Challenges in Global Health (GCGH) initiative, identifies and devises ways to address long and short term ethical, social and cultural issues raised in the GCGH projects
- The Regenerative Medicine Ethics Network, funded by the Canadian Institutes of Health Research, which strives to ensure that as regenerative medicine develops, global societal values are protected.

COLLABORATOR(S)

Faculty, Staff and Students of the McLaughlin-Rotman Centre for Global Health



Governance of International Networks: A Social Network Analysis of International Institutions related to Plant Genetic Resources

PRESENTERS: Peter W.B. Phillips, Professor, Department of Political Studies, University of Saskatchewan

ABSTRACT

Governing in the modern times has become more multifaceted with evolving governing structures over the globe. Institutions are intertwined and embedded in governing networks at state, regional and international levels. With this perspective, the paper examines the international governing system of plant genetics/genomic resources. Over the last century, issues have surfaced with technology progress and innovations that add complexity in the governing challenge, such as access and benefit-sharing and capacity-building. A network of 111 international institutions and programs was studied. Using multiple layers of social network analysis, the structures and underlying meanings of the relations in the governing network are studied.

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Genomics of Winter Wheat and Land Use Change in Western Canada

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ABSTRACT

Researchers at the University of Saskatchewan are breeding cold tolerant traits into winter wheat as part of a major research program funded by Genome Prairie. Cold tolerance is an important characteristic in winter wheat, as the seeds are planted in the fall and the seedlings must survive the winter. Improving the proportion of seedlings that survive improves the profitability of winter wheat in regions further north in the Canadian prairies. Currently, winter wheat's viable growing range is restricted to the southern portions of the Canadian Prairie Provinces. It is anticipated that development and adoption of new cold tolerant varieties of winter wheat will expand the regions in which winter wheat may be grown. However, winter wheat competes with other crops, including barley, spring wheat, and canola, for acreage land use. As well, farmers are faced with the decision to turn marginal land into pasture. The research question we focus on is to what degree can improving the cold tolerance of winter wheat influence land uses decisions. We present an overview of the methods used to examine questions of land use change. These methods include computable general equilibrium (CGE) modeling, geographic information systems (GIS) analysis and agent-based modeling. Each of these types of analysis is assessed for its potential to provide meaningful estimates of land use change induced by the adoption of new varieties of cold tolerant winter wheat. Preliminary land use responses to changes in wheat yields are reported, and conclusions are drawn regarding appropriate future research.



A Map of the Interface Between Science and Policy

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ABSTRACT

There is broad agreement that evidence and values, science and judgment are key components of policy-making and policy implementation. As a result, it is not surprising that the Government of Canada employs staff from all faculties represented in the universities. A difficult governance and management issue has arisen, however. While different university faculties may tolerate or even foster diverging cultures among students, government managers require all staff to communicate and cooperate effectively in decision-making and implementation.

My paper provides an analytic description of the issues arising at the interface between science and policy, as well as some humble suggestions for the way forward. I argue that clear language and an appreciation of the big picture are key for a productive dialogue which, in turn, is essential to overcome old and pervasive problems in the development of policies for modern technology. Addressing the issue now seems acutely important because governments world-wide are calling for "evidence-based policies."



One Size Does Not Fit All: Canada's Paradigm of Equality, a Made-in-Canada Biobank, and the Advent of Personalized Medicine

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ABSTRACT

Canada's legal system, with its expanding body of equality jurisprudence, has made an invaluable contribution to the modern liberal discourse concerning the good life. The legal definition of equality in Canada is beyond that of formal equality (sameness of treatment) and represents a nuanced approach that accounts for personal characteristics such as skin colour or gender. Canadians have come to expect equality in terms of access to health care, including therapies. However, as pharmacogenomic research is showing, sameness of treatment does not equate to sameness of results. Differences in how drugs are absorbed, and differences in metabolic rates among people, have their origins at least in part on genetic variation among population sub-groups. Canada's rights-based legal culture, coupled with expanding knowledge in the area of genomics, can provide fertile intellectual ground for a project that would profoundly affect how health care is delivered in Canada. This poster proposes a legal framework for the creation of a national, publicly-funded Canadian biobank. Population genetic research involving a representative cross-section of Canada's diverse ethnic landscape would yield data of great significance by: 1) adding to our knowledge of the complex relationship between genes and non-genetic factors such as diet and environment; and 2) contributing to the goal of personalized medicine that accounts for genetic variation to deliver more efficient therapies.

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Consensus Formation in Deliberation: The Case of Informed Consent in Biobanking

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ABSTRACT

Public engagements are becoming increasingly popular as a means for informing policy on public health issues. A recent example is The BC Biobank Deliberation, where 21 British Columbians deliberated together on what values and interests ought to be considered in the regulation and use of biobanks for health research (see: <http://biobanktalk.ca/>). This event formed part of a Genome Canada and Genome BC sponsored research project, "Building a GE³LS Architecture" (PIs M. Burgess and P. Danielson), and was an experiment in using deliberative democracy theory and practice to enhance policy approaches to ethical and social issues related to health science.

When informed about the debates around consent in the biobanking context, the 21 deliberating members of the public expressed a wide range of opinions, with some discussions leading to consensus (e.g. donors should receive a copy of the consent form for their records) and others to persistent disagreement (e.g. should sample donors be allowed to give consent for their samples to be used for any research purpose). In this poster, we focus on the process whereby deliberants achieved this consensus or persistent disagreement. We begin by outlining the group's deliberative conclusions and statements pertaining to informed consent drawn from transcripts of the actual deliberations, then attempt to make explicit the discursive process whereby individuals moved from initially disparate positions to one in which they agreed on a common course of action (in cases where consensus was achieved) or disagreement. Some practical implications of our analysis are explored.

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Accelerating Health Innovation in Sub Saharan Africa

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ABSTRACT

There remains a great inequality in development of and access to health technologies around the world, leading to big differences in the health and wealth of nations. Vaccines, diagnostics and therapeutics are in general developed in the West for Western populations and are either too expensive for developing countries to afford or not relevant to their needs. In response, a number of developing nations – such as India, China, Brazil and South Africa – have begun to invest in their own biotechnology industries to supply relevant, affordable health products. India, for example, has developed vaccines such as Hepatitis B at a fraction of the usual cost, driving prices down globally. But what about countries that are less developed still? How might they best forge a path for locally-relevant health innovation? In this study we worked with the governments of three sub-Saharan African nations – Ghana, Tanzania and Rwanda – to assess how to strengthen their health innovation systems for the future. Over 100 stakeholders from across the innovation system – including academia, the private sector and government – were interviewed according to qualitative research methodology. Preliminary findings suggest a strong unexploited potential to commercialize local innovative research especially in areas such as traditional medicine and diagnostics. However a number of barriers exist such as limited access to finance and specifically a lack of linkages between stakeholders to enable knowledge flow leading to innovation. A model for overcoming this, named 'Convergence Innovation' was developed with stakeholders in all three countries and is the subject of ongoing research and action steps.

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Economic and environmental benefits of increasing cold tolerant winter wheat acreage winter wheat in Western Canada: A bio-economic approach

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ABSTRACT

Genomic research on winter wheat cold tolerance is currently being carried out in Western Canada. The objective is to develop new varieties resistant to cold temperatures that could increase the regions in which winter wheat may be grown. The prairie region of Western Canada is an extremely important habitat area for migratory waterfowl and agriculture production is decreasing the habitat available. There is evidence that fields seeded to winter wheat provide valuable upland spring nesting habitat to migratory waterfowl. Increased cold tolerance in winter wheat due to Genomic research has the possibility to increase winter wheat acreage and the associated upland duck habitat. Our research objective is to determine the optimal seeded area of winter, spring and durum wheat in Western Canada using three different models that incorporate farm profits and a duck production function to capture the environmental benefits associated with this genomic research program.

The empirical approach is to build three different math programming optimization models. Firstly from a social planner point of view, secondly from the farmer's perspective dealing with only his/her own production and finally from the farmer's standpoint when he/she has to deal with multiple objectives that involve interaction with other producers. The first model maximizes social welfare, and incorporates producer profits and duck populations as a proxy for environmental benefits. The second model is a farm-level model that maximizes farmer profit, which include benefits to the farmer from increased bird populations. The third model incorporates multiple objectives associated with increased winter wheat acreage.

COLLABORATOR(S)

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Competition between Forestry and Agriculture Land Use in the Canadian Boreal Transition Zone: Assessing Emerging Biotechnological Factors

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ABSTRACT

Forestry and agriculture compete for land in many locations; including the forestry-agriculture interface zone of Western Canada. The potential substitution of forestry for agriculture, or agriculture for forestry, has implications for future patterns of land use as well as environmental issues (such as carbon sequestration for greenhouse gas reduction). The production economics of this forestry-agriculture interface, however, are not well defined.

Competing research programs, including genomic advances in agricultural crops and more conventional technology improvements (i.e. hybridization) in plantation forestry, may impact upon patterns of land-use in forestry-agriculture interface zones. Key considerations include: respective rates of technical change in each sector; constraints to technology adoption in forestry versus agricultural land uses (due to the relative length of forest rotations); the respective susceptibility of agricultural versus forestry crops to environmental stressors; and the potential for each sector to contribute to climate change mitigation.

Our research focuses on developing a detailed, spatially explicit bio-economic model to estimate the quantities of private and public lands that would be converted from agriculture to industrial forest plantations, and vice versa, under alternative policy scenarios for Alberta. A key advancement in this research is the incorporation of a real options model within the bio-economic framework. Our model is used to examine the potential land use impact of biotechnology induced improvements in agricultural crop stress tolerance (i.e. the Crop Adaptation Genomics Research Program) and more conventional technology improvements in plantation forest productivity. Key assumptions of climate change are also incorporated into the analysis.

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Are Country of Origin and non-GM Premia Invariant to Experimental Market Structure?

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ABSTRACT

A revealed preference choice experiment which simulates a market by using actual transactions is used to elicit values for two attributes of canola oil — GM/GE process and country of origin. The choice context is varied by changing the number of alternatives each participant faces in each trading choice situation, enabling assessment of whether revealed preference choice experiments are affected by format effects. Although some 30 percent of participants were not prepared to pay any extra for non-GM oils, premiums found for non-GM canola oil approximated \$0.40–0.60 per litre. Average willingness to pay for canola oil for which GM process is not indicated was 70 percent of the non-GM premium. Country of origin effects applied: participants were willing to pay \$0.30–0.50 per litre for Canadian canola oil relative to canola oil imported from the US. The ranges cited reflect choice format effects. Hypotheses as to why these format effects occur are suggested.

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Canadians' Views of Agricultural Biotechnology: Risk Rating Assessments

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ABSTRACT

Canadians' perceptions of different applications of modern agricultural biotechnology, expressed in the context of risk rankings for various food and environmental issues, are analyzed. Relative to other food and environmental risk situations, agricultural biotechnology is not rated as a major risk issue by the majority of those queried. However, comparison with earlier survey information suggests that GM/GE food is perceived as a food risk issue by an increasing number of Canadians. The order of risk rankings for different agricultural biotechnology applications provided by a representative sample of some 1500 Canadian adults is not consistent with the order of quantitative risk assessments implied by regulations and policy. In particular, respondents' risk ratings indicates that applications of genetic modification/engineering (GM/GE) that involve production of pharmaceuticals are seen as lower risks for food and the environment than GM/GE applications that are directed at increasing crop production. Similarly GM/GE applications to produce industrial products or more nutritious food are also viewed to be less risky than GM/GE applications to increase crop production. These assessments are, however, consistent with the hypothesis that innovations and situations which seem to provide little personal or socially accepted benefit are viewed as more risky, and thus less socially acceptable, than innovations and activities that do involve socially accepted benefits. Ordered probit models, employed to analyze respondents' risk rankings for different GM/GE applications, suggest that these are consistently associated with gender, income and location of residence as well as being influenced by respondents' trust in regulators and industry.

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**Allocation of Public Funds to R&D:
A Portfolio Choice-Styled Decision Model and a Biotechnology Case Study**

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ABSTRACT

The Canadian Government channels about one billion dollars yearly to agricultural and food research; about ten million dollars is spent on research related to plant molecular farming (PMF) involving applications of modern agricultural biotechnology to produce pharmaceuticals (drugs), industrial products (e.g. bio-fuels, bio-plastics), or modified foods with enhanced nutritional characteristics. To gain understanding of public views of risks and benefits of PMF, we use data from a 2005 nation-wide survey of a representative sample of Canadians which queried citizens' preferences for different research funding allocations relative to five different fields of PMF research (research funding allocations to health products; industrial products; nutrition-enhanced foods; environmental applications; socio-economic policy and legal aspects). Preferred PMF research funding allocations are modeled as a portfolio choice problem faced by a Bayesian decision-maker. We focus on two elements in the planner's inferential system: a conditional distribution of "returns" on a research fund allocation, given stated preferences of citizens for different research areas, and a minimum risk criterion for re-allocating research funds, given status quo levels of funding. Two allocation strategies for PMF research funding are generated as a practical result of preferred research fund allocations. The first involves increasing PMF research funding by up to 10%, while keeping current allocations between the five fields much as now. The alternative would keep the current total research funding levels as they are, while increasing the funding share of health applications and social policy areas. The approach we develop can be extended to many public decision / investment problems.

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Delving into Choice Internals: A Joint Discrete Choice/Attribute Rating Model

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ABSTRACT

Choice-based conjoint analysis and other types of discrete choice methods are often used to assess consumer acceptance of new GM products. Subjects in modern preference elicitation instruments may also be asked to rate the products' attributes, using a psychometric scale. When both choice and ratings data are available, a model that makes joint use of both offers informative inference opportunities. We develop and implement a joint model which utilizes both choice and ratings data, allows for scale usage heterogeneity, and is robust, at least to some degree, to violations of the classical utility assumptions. The model was estimated on GM canola stated choice and importance ratings data from 65 individuals from Edmonton, Alberta, using a Bayesian hierarchical approach. The median survey respondent was found to be willing to pay (WTP) an additional \$0.92/liter for a non-GM canola oil. The median WTP for non-specification of GM content was found to be approximately 80% of the WTP for the explicitly non-GM-labelled product. The median WTP to purchase Canadian canola oil versus a US product was estimated to be \$0.86/litre. These estimates of WTP values are generally consistent with the outcome of a revealed choice experiment conducted earlier and with figures reported for GM content/its absence from food in other studies.

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Understanding the Ethical Decision Making Process in the Resuscitation of Extremely Premature Infants

PRESENTERS

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ABSTRACT

Advancements in neonatal intensive care have resulted in the capacity to intervene in the survival of infants at the extremes of prematurity. However, ethical dilemmas and moral distress associated with determining for which of these high risk infants resuscitation is a viable option is evident in clinical practice. Parents and health providers may have different perceptions of various ethical issues which can complicate the decision-making process surrounding resuscitation. These differences may contribute to tension and conflict, thus, increasing moral distress regarding the initiation or withholding of resuscitation.

Focusing on Inter-disciplinary Methods, this study explores ethical issues involved with the decision-making process of key informants concerned with infant resuscitation. As much of the existing literature on ethical decision-making in the resuscitation of extremely premature infants focuses on how health-care providers rationalize decisions, we aim to examine parents' perspective of this experience.

The aim of the research is: to explore various ethical issues as identified by key informants (parents, physicians, allied health providers) and, through the use of grounded theory, develop an ethical decision-making framework for infant resuscitation that can be utilized in other situations involving ethical dilemmas surrounding public understanding of science and medicine. Focus groups and individual in-depth interviews allow participants to describe their experience with this decision-making process. Data analysis involves identifying key themes which depict an ethical decision-making framework that can be used to increase our understanding of the decision-making process and ultimately decrease moral distress for both families and health providers. Preliminary results will be presented.

COLLABORATORS

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**Does misinformation matter?
Exploring the roles of (mis)information in a deliberative
public engagement on biobanks**

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ABSTRACT

In April and May of 2007, the Face-to-Face research team from the W. Maurice Young Centre for Applied Ethics at the University of British Columbia (UBC), Canada, engaged twenty-one participants in deliberation on the topic of 'Biobanking in British Columbia (BC)'. The goals of the two weekends were to explore the values and interests important for governing biobanks (stored collections of biological materials), and to test a model for public involvement in policy-making.

"Misinformation" refers to knowledge claims made during a discussion that are incongruent with current research or practices. My research objective is to understand the effects of (mis)information on deliberation. This will determine whether there is evidence to suggest or refute criticisms of deliberative public engagement that are based on participants' lack of technical understanding, and to determine whether and when to intervene to clarify or correct deliberations. Technical information may be used to make an important point independent of its accuracy, or it may undermine the usefulness or legitimacy of deliberation. Using data from the 'BC Biobank Deliberation', I explore if and how (mis)information 'develops' or 'distracts' deliberation, contributing to an understanding of the effects of (mis)information in public engagements. Here, I focus on the results of my research, understanding the effects of the "correctness" of information on deliberation and policy recommendations from a deliberative public engagement on biobanks.

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