



OTTAWA GE³LS SERIES...

where **G**enomics, **P**ublic policy, and **S**ociety meet

June 29, 2010



G = **G**enomics *and its*

E³ = **E**thical, **E**conomic, **E**nvironmental

L = **L**egal

S = **S**ocial *aspects*



Objectives

Broker two-way knowledge transfer between researchers & federal policy-makers in order to:

- 1) facilitate dialogue needed to inform evidence-based public policy, and,
- 2) identify research priorities based on timely & socially relevant questions.



Theme for Year 1 Series

Genetic Information

Sub-Themes

- **Consent, Privacy & Research Biobanks**
- **Genetic Information & Discrimination**
- **On-line Direct-to-Consumer Genetic Testing**



Core Partners for Year 1 Series



GenomeCanada



CIHR Ethics Office
IRSC Bureau de l'éthique

 **Carleton** | School of
UNIVERSITY | Public Policy and
Administration

 **RGI**
Regulatory Governance Initiative

Office of the
Privacy Commissioner
of Canada



Commissariat
à la protection de
la vie privée du Canada



CIHR IRSC
Canadian Institutes of
Health Research | Instituts de recherche
en santé du Canada

Institute of Genetics | **Institut de génétique**



Council of Canadian Academies
Conseil des académies canadiennes



Public Policy Forum | **Forum des politiques publiques**



Government of Canada

Policy Research Initiative

Gouvernement du Canada

Projet de recherche sur les politiques

Event Format

- Small, invitation-only events in Ottawa
- Provide a neutral meeting place for open and frank discussion
- Participants are researchers, senior federal policy-makers, and interested stakeholders relevant to the theme and/or sub-theme
- Early start, half-day only, no media, focussed discussion
- Stand-alone luncheon intended for broader audience, big picture, international perspective

“Policy Directions” Briefs

- 5-6 pages, common template
- balanced synthesis of research knowledge and neutral discussion of plausible policy options
- no recommendations
- main audience = senior federal policy-makers
- peer-reviewed

The image shows the cover of a policy brief. At the top right, the title "Consent, Privacy & Research Biobanks" is written in a serif font, with "Policy Brief No. 1" in a yellow box below it. On the left, there is a logo for "GPS" (Genetics and Society) inside a rounded square. Below the logo, the text "Editor's Preface" is followed by a paragraph of text. To the right of the preface, the authors' names and affiliations are listed, along with the date "26 January 2010". Below that, the "Executive Summary" section begins with a paragraph of text. At the bottom of the page, there is a small "Acknowledgements" section and a "Genome Canada" logo.

Consent, Privacy & Research Biobanks
Policy Brief No. 1

GPS

Editor's Preface
GPS: Where Genetics, Public Policy and Society Meet is an Ottawa GPS Series led by Genome Canada bringing together leading researchers and senior federal policy-makers to explore options for addressing public policy issues at the intersection of genetics and society. The resulting "Policy Directions Briefs" present the evidence-based research to support informed debate on a range of policy options, while deliberately steering clear of making any recommendations. Topics are selected on the basis of their broad societal importance, national interest, relevance to federal policy-makers, and "openness" for policy debate.

Co-authors of this Policy Brief are renowned leaders in the field, commissioned by Genome Canada to apply their current state-of-the-art academic knowledge on a given topic and translate this into a clear and language-friendly format for senior federal policy-makers. Co-authors are asked to present a well-balanced range of feasible policy options, as much as is possible, and avoid favouring any particular position over another. The Policy Brief is not intended to reflect the authors' own views or opinions, nor those of Genome Canada.

The co-authors have benefited from valuable commentary of national and international experts and stakeholders to help them converge on a final policy report. Ottawa organizers by Genome Canada and its Core Advisory Partners, in order to ensure accessibility, practical relevance and suitability for its intended purposes, the draft briefs were then submitted to a small review committee in a confidential written appeal process review process. This led to the final Policy Brief in its present form. It is a neutral, credible and legitimate source of information for policy-makers on important bioethical questions of the research of emerging genetic technologies and their applications.

— Patricia Kossler

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Timothy Caulfield, University of Alberta and
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26 January 2010

Executive Summary

In March 2009, *Time Magazine* picked biobanking as one of the TOP 10 ideas changing the world right now. Indeed, large biobanks, linked with health demographic and administrative data, are proliferating in countries around the world, not least of which is Canada. Scientists are pleased. Internationally, with an unprecedented ability to tease out complex interactions between genes and environment, enhancing our understanding of health and disease and paving the way towards a future of personalized medicine and public health. Meanwhile, establishing legal and policy frameworks for personal data protection are founded on the concept of informed consent, the application of which has proven to be challenging for advancing biobank research and related scientific programs in Canada. This Policy Brief explores three possible policy options for implementing the concept of consent in the context of research biobanks: 1) specific and fully informed consent for each project; 2) broad initial consent accompanied by appropriate governance; and 3) opt-out model. The types of research biobanks being contemplated include: large population-based biobanks, disease-specific biobanks and biobanks created from left-over archival tissue originally collected in the context of clinical care.

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Genome Canada has funded the Core Advisory Partners of the GPS 2009-2010 Series: Office of the Privacy Commissioner of Canada, Canadian Institutes of Health Research (CIHR) Institute of Genetics, CIRRI in Montreal, Centre for Canadian Architecture, Public Policy Forum, Policy Research Initiative of Canada, and Carleton University School of Public Policy and Administration.

Indicators of Success

1. Events are considered credible, and of high interest priority for policy-makers and researchers
2. Policy-makers are informed of the evidence base underlying various policy options and researchers are informed of practical considerations and potential research questions
3. The policy directions briefs are a key resource for policy-makers to turn to when information or advice is solicited
4. Ongoing dialogue is fostered between researchers and policymakers



2009-2010 Series on Genetic Information
*Online Direct-to-Consumer Genetic Testing:
Implications of this New Business Model*
June 29, 2010, 8:00 am. - 2:00 pm.
Lord Elgin Hotel, 100 Elgin Street, Ottawa, ON

Expectations for the Day

- Please stay on time
- Please participate actively
- Please be brief and concise
- Please focus on the draft policy brief
- Please give us your feedback!

Thank you to our Co-Sponsors



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