

Genomics and Public Health: Building Public "Goods"?

News in Brief

February 2008

Project Update

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This News in Brief highlights research progress between July and December 2007

Overall Progress

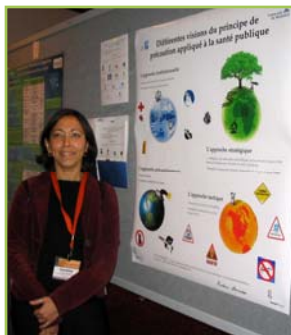
In September 2007, the International Science Review Committee (ISRC) chaired by Dr. William Gelbart assessed our progress as excellent and recommended that the research activities proceed as planned. The Review committee indicated our team was well engaged, and focused and that the *Points to Consider (PTC)* will have clear benefits for Canada and the rest of the world.

Research on Privacy

The research, review, and analysis of the policy document *Privacy and Secondary Uses of Personal Data for Public Health Research Purposes* is completed. The policy paper has been submitted for publication to the *Canadian Bar Review* in early January 2008. In this paper, the authors initially analyze the normative framework for the privacy of personal data of Québec and Canada, then compare it to countries with "federated governance characteristics" or multiple levels of government, such as Germany, Australia, United States of America and the United Kingdom.

Some key recommendations include:

- That the obligation of medical secrecy to be extended to researchers;
- That the proportionality principle to be applied to the evaluation of secondary research uses without explicit consent;
- That there be ongoing monitoring by ethics and privacy review boards of such secondary uses;
- That the definitions and concepts related to privacy to be clarified as concerns genomics and public health research involving populations.



Carolina Monardes received an award for her poster "*En quête d'un concept de précaution en santé publique*" at the "First Canadian Roundtable of Public Health Ethics: Exploring the Foundations", at the Montreal Delta Hotel.

Welcome to our Fall/Winter Newsletter.

This project addresses the socio-ethical and legal issues regarding three interlinking themes in relation to public health genomics:

- a) State powers and privacy;
- b) Public engagement; and
- c) Stakeholder perceptions.

The project team will produce and publish a series of policy papers. The culmination of the project will be a multi-sectored consensus conference, "Policy Framework: Points to Consider," based on a document of the same name that will be developed through national and international collaboration.

Research on State Powers

Nathalie Girard prepared a comparative analysis of the pandemic plans notably those from Canada, Quebec, Switzerland, New Zealand and the UK. Julie Cousineau; finalized the review of the Quebec legislation; and further defined public health and population health. Another study, prepared by Carolina Monardes, focused on the precautionary principle as it applies to public health.

Research with Stakeholders

The Stakeholder interviews revealed several themes including:

- expectations regarding the integration of genomics in public health;
- restrictions regarding the integration of genomics into public health
- actions to be taken relating to the integration of genomics into public health
- questions regarding biobanking as public goods
- powers of the public health authorities and their limits of surveillance and the
- framing of research.

Generally, all stakeholders address the importance of *protecting* and *respecting* research participants, as well as subject groups or populations in public health initiatives. They also indicated the public as well as concerned stakeholders must be sensitized to issues related to genomics.

None of the respondents raised the possibility of access to genomic databases for surveillance purposes. It was felt the integration of genomics into public health is an "*audacious amalgam*" that simultaneously raises hopes and concerns.

A New Journal Public Health Genomics



The team will house the secretariat for the new journal "**Public Health Genomics**" owned by Karger, a company well known for publishing authoritative peer-reviewed journals in biomedical sciences. This journal builds on the mandate of the former *Community Genetics* by expanding the scope and perspective beyond the field of medical genetics so as to include all topics that address the translation of genome-based science and technology into improvements in population health. Bartha Maria Knoppers and Angela Brand are co-editors, while Susan Wallace is associate editor.

This peer-reviewed journal will be published in print and online. It will report on all aspects of genomics and public health including basic science issues, public health programmes, as well as ethical, legal and social issues addressing public health genomics. The first issue of this journal will appear in September 2008.

Upcoming Events

March 16-19th, 2008

International Conference on Emerging Infectious Diseases, Atlanta, Georgia

April 28-30th, 2008

The Fourth International GE3LS Symposium, Calgary, Alberta

May 5-9th, 2008

76e Congrès de L'ACFAS, Quebec City

May 14-16th, 2008

Journées génétiques, RMGA, Quebec City

April 28-30th, 2009

Graph-Int Population Health Genomics: Translating research into public benefit, Perth, Western Australia

Research on Public Participation

Pandemic Plan Review

A comparative analysis of 20 international pandemic plans is underway to:

- Examine the place given to public participation
- Describe the goals and measures included in the plan
- Determine whether the plan includes genomics (e.g. gene variation studies, genetic data banks)
- Determine how genomics impacts on the ethical challenges or public understanding
- Determine whether the plan discusses ethical principles, values and resource allocation

The findings reveal that public participation is not considered an ethical issue by policy makers. This reinforces the importance and the relevance of hosting a Citizens Workshop on this topic.

Citizens Workshop

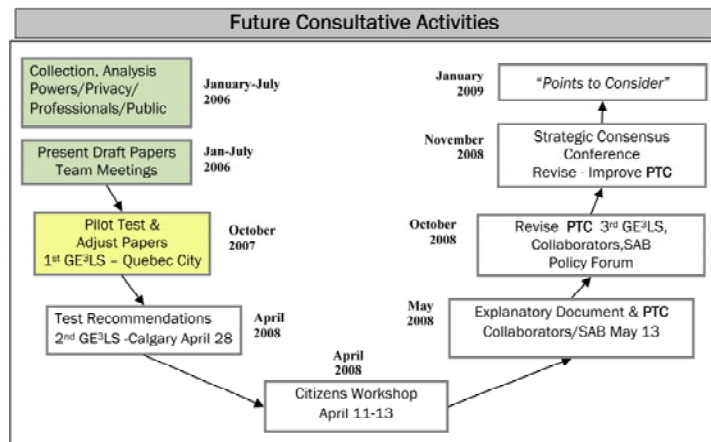
A Citizens Workshop as a response plan in case of a pandemic is in preparation. The Citizens Workshop will last three days, involve approximately 15 citizens and will be hosted on the weekend of April 11th to 13th 2008.

An Advisory committee provides direction for the Citizen Workshop and consists of representatives with experience in: pandemic planning (Sylvie Poirier, MSSS), public participation (François-Pierre Gauvin, INSPQ), genomics (Bastien Llamas, IRCM), and pandemic plan elaboration (C. Alfieri, Ste Justine).

The moderator for the workshop will be Mme Françoise Guénette, a journalist with extensive experience in hosting public events.

Points to Consider (PTC) – A Resource for Policymakers

The development of the **PTC** will involve several consultative activities including the 2nd GELS satellite meeting to test and revise the PTC and the papers; various consultations of the first draft of the **PTC** with our collaborators and members of the SAB; and a 3rd GELS satellite meeting followed by policy forum with policy makers. Consultations will be carried out with the GRaPH-Int members, and finally, a Consensus meeting on the final **PTC** as demonstrated in the outline. The **PTC** is meant as a checklist of relevant issues to take into account in preparing research or policies in public health genomics.

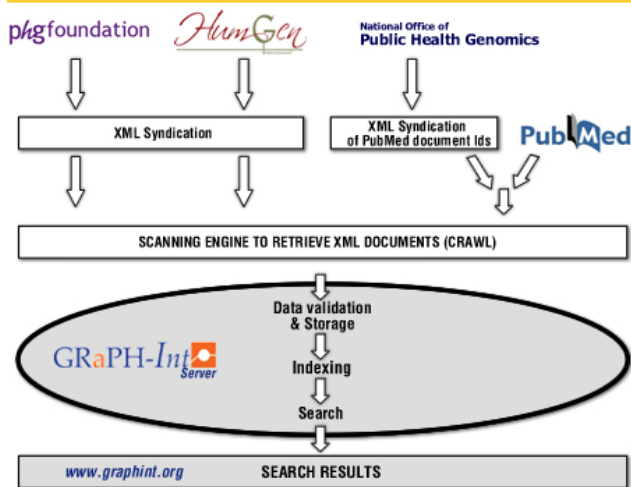


PubHealthGen Search Engine

The PubHealthGen search engine will provide practical help and guidance to policy makers for creating innovative and informed approaches to public health genomics. The graph describes the process. Our computer programmer Francois Brouillet is collaborating with programmers in the partner sites: Calvin Cheah and Simon Leese of the Public Health Genetics Foundation in Cambridge, Dan Truong of HUMGEN International in Montreal, and Wei Yu of the National Office of Public Health Genomics at CDC in Atlanta to:

- Establish a controlled vocabulary and indexing system
- Minimize the technical interventions from our partner agencies
- Design the search engine and
- Facilitate the integration of potential new partners.

A prototype of the PubHealthGen will be "Beta" tested during a GRaPH-Int infectious diseases satellite meeting at the International Conference on Emerging Infectious Diseases in Atlanta, March 16-19th 2008.



Collaborations

A new collaborator has been added to the team:

Dr. Anne M Laberge joined our team as a collaborator in January 2008. She is from the Institute for Public Health Genetics, School of Public Health and Community Medicine, University of Washington, Seattle. Dr. Laberge is a geneticist working in pediatrics and with an expertise in public health genomics.

We have extended links with:

Dr. Vural Ozdemir, a senior researcher with a CIHR career transition award, has joined the Godard team. Dr. Ozdemir is training in clinical pharmacology and bioethics and his research activities are to linking socio-ethical studies with "-Omics".

Dr. Julia Abelson, from the Centre for Health Economics and Policy Analysis, McMaster University, presented to the team on November 23rd 2007. Her talk was titled "Public Participation: Critical Reflections on a Contested Concept" was well received particularly for the members of the team who is setting up the citizen workshop.

Articles

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Farmer Y, Bouthillier ME, Dion-Labrie M, Durant C, Doucet H, "*La participation du public dans les plans nationaux de lutte à une pandémie d'influenza*" October 17-19, 2007, **2020 Vision: Adaptation to Environmental Change, Genome Canada International Conference**, Quebec, (Poster)

Fortin S, "*Human Genomic Databases as Global Public Goods*" October 17-19, 2007, **2020 Vision : Adaptation to Environmental Change, Genome Canada International Conference**, Quebec, (Poster)

Bucci L, Avard D, "*Public Health Genomics (PHG) and Public Participation*" November 8-9, 2007, **Canadian Roundtable on Public Health Ethics: Exploring the Foundations**, Montreal (Poster)

Farmer Y, Bouthillier ME, Dion-Labrie M, Durand C, Doucet H, "*La participation citoyenne en tant que facteur de valorisation éthique des politiques de santé publique : le cas de la pandémie d'influenza*", November 8-9, 2007, **Canadian Roundtable of Public Health Ethics: Exploring the Foundations**, Montreal, (Poster)

Monardes C, "*Quête d'un Concept de précaution adapté a la santé publique*" November 8-9, 2007, **Canadian Roundtable of Public Health Ethics : Exploring the Foundations**, Montreal, (Poster)

Nycum G, "*Tuberculose, voyages internationaux et intervention de santé publique*" November 8-9, 2007, **Canadian Roundtable of Public Health Ethics : Exploring the Foundations**, Montreal, (Poster)