

GenInfo

Last Issues

-  [November-December 2009](#)
-  [September-October 2009](#)
-  [July-August 2009](#)
-  [May-June 2009](#)
-  [March-April 2009](#)
-  [January-February 2009](#)

Previous Issues

2008
2007
2006
2005
2004

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GENINFO

Newsletter on the Ethical, Legal and Social
Issues in Human Genetics

EDITORIAL | LAWS AND POLICIES | EVENTS | TEAM PUBLICATIONS

March-April 2009



Dear readers,

In this month's edition of GenInfo, we would like to take the opportunity to inform you about one of the many public activities that our team has been involved with. In January, in collaboration with Genome Canada and Genome Quebec, our team organized a special public education event in Montreal entitled, "My Genes Are Unique." The goal of this event was to foster discussion between researchers and the public in order to gain better understanding of the various concerns regarding pharmacogenomic research. Issues also discussed between experts and the public included defining pharmacogenomics, the genetic diversity of the Quebec population and how genetic differences affect individual responses to certain medications. The event proved to be a great success.

With regards to newly adopted guidelines or policies for this month, we would like to draw your attention to a recent Quebec report concerning ethical challenges in prenatal screening of trisomy 21 (Down's Syndrome). This report was the result of a public consultation conducted by the *Commissaire à la santé et au bien-être* (Quebec's Health and Welfare Commission). The Commission's work was completed in 3 phases: 1) a review of targeted reports, followed by public hearings involving various interest groups; 2) an online public consultation; and 3) a final deliberation session by the Commission. The document is entitled: "*Consultation sur les enjeux éthiques du dépistage prénatal de la trisomie 21, ou syndrome de Down, au Québec – Des choix individuels qui nous interpellent collectivement.*"

Furthermore, we would like to mention that the *National Human Genome Research Institute* of the United States has published "*The Future of Genome Sequencing.*" This is the fourth in a series of documents already published and open for comment. The other three pertain to: 1) Applying Genomics to Clinical Problems - Diagnostics, Preventive Medicine, Pharmacogenomics; 2) Applying Genomics to Clinical Problems - Therapeutics; and 3) A Vision for the Future of Genomics: Education and Community Engagement). For more information on these three documents, please refer to our January/February edition of GenInfo. You may consult the fourth document online at: <http://www.genome.gov/About/Planning>.

Happy reading !

 EDITORIAL


Biobanks and Longitudinal Studies: Where Are the Children?

Julie Samuël, Nola M. Ries, David Malkin and Bartha Maria Knoppers

Abstract: The inclusion of children in longitudinal research using biobanks raises specific ethical and legal issues. This article analyzes ethical frameworks concerning participation in biobanks and suggests that such frameworks, developed in the context of competent adults as research subjects, are not adapted for research involving children. It concludes that there is a need to elaborate guidelines specific to biobanks and longitudinal studies involving children and provides recommendations regarding parental authorization, the child's assent and consent, and on the return of results in this context.

(2008) 6:3 *GenEdit*, 1-8

[Full Text](#)

 LAWS AND POLICIES NEW DOCUMENTS

INTERNATIONAL / REGIONAL

UNESCO - International Bioethics Committee (IBC): *Report of the International Bioethics Committee of UNESCO (IBC) on Consent*

Paris - December 5, 2008

Link: [URL](#)

Key Words: Access Info/Material - Assent/Dissent - Autonomy - Community/Population - Confidentiality - Consent - Data - Developing Country - Discrimination - Education - Family - Incompetent Adult - Liability - Minor/Child - Newborn - Patient/Participant/Individual - Professional - Psychosocial Aspects - Public Health - Research - Right of Withdrawal - Socio-Economic Aspects - Tissue

NATIONAL

Canadian College of Medical Geneticists (CCMG), Society of Obstetricians and Gynaecologists of Canada (SOGC): *Carrier Screening for Thalassemia and Hemoglobinopathies in Canada*

Vancouver - October 1, 2008

(2008) 30:10 *J Obstet Gynaecol Can*, 960

Link: [URL](#)

Key Words: Carrier Status - Community/Population - Consent - Counseling (general) - Foetus - Genetic Screening - Genetic Testing - Man/Paternity - Minor/Child - Newborn - Preconception - Prenatal - Woman/Maternity

France/Government: *Proposition de loi relative aux recherches sur la personne*

Paris - January 22, 2009

Link: [URL](#)

Key Words: Commercialization - Consent - Ethical Review - Ethics Review Board - Governance - Patient/Participant/Individual - Public Health - Recruitment - Research - Researcher - Storage

French Institute of Health and Medical Research (INSERM): *Tests génétiques - Questions scientifiques, médicales et sociétales (Groupe d'experts réunis par l'INSERM)*

Paris - November 1, 2008

Tests génétiques - Questions scientifiques, médicales et sociétales (Paris: Éditions Inserm, 2008)

Link: [URL](#)

Key Words: Competence - Counseling (general) - Disability - Discrimination - Employer/Employment - Family - Genetic Services - Genetic Testing - Insurer/Insurance - Patient/Participant/Individual - Predictive Testing - Psychosocial Aspects - Researcher - Socio-Economic Aspects

Human Genetics Society of Australasia (HGSA): *Australasian Society of Genetic Counsellors Code of Ethics*

Sydney - August 1, 2008

Link: [URL](#)

Key Words: Autonomy - Beneficence - Community/Population - Confidentiality - Consent - Counseling (general) - Family - Genetic Services - Justice - Professional - Socio-Economic Aspects

Parliamentary Office for Evaluation of Scientific and Technological Options (OPECST): *L'évaluation de l'application de la loi du 6 août 2004 relative à la bioéthique*

Paris - November 20, 2008

Link: [URL](#)

Key Words: Confidentiality - Consent - Counseling (general) - Discrimination - Embryo - Foetus - Gene Therapy - Genetic Services - Genetic Testing - Man/Paternity - Minor/Child - Patient/Participant/Individual - Pharmacogenomics - Research - Therapeutic Cloning - Tissue - Umbilical Cord Blood - Woman/Maternity

Fonds de la Recherche en Santé du Québec (FRSQ): *Policy regarding open access to published research outputs*

Montréal - October 24, 2008

Link: [URL](#)

Key Words: Access Info/Material - Data - Intellectual Property - Researcher

Government Quebec - Health and Welfare Commission: *Consultation sur les enjeux éthiques du dépistage prénatal de la trisomie 21, ou syndrome de Down, au Québec*

Québec - January 27, 2009

Link: [URL](#)

Key Words: Autonomy - Consent - Disability - Discrimination - Equity - Eugenics - Foetus - Genetic Testing - Integrity - Prenatal - Socio-Economic Aspects

UPCOMING EVENTS

Retos legislativos de la medicina genómica en México

Organized by: INMEGEN - Senado de la República de México

Date: March 9, 2009

Location: Ciudad de Mexico, Mexico

Information: http://www.inmegen.gob.mx/medios/2009/senado/senado-inmegen_programa.html

L'éthique de la recherche est-elle dans une impasse?

Organized by: Centre de recherche en droit public

Date: March 12, 2009

Location: Montreal, (Québec), Canada

Information: <http://www.ethique-recherche.org/>

Harmonising Biobank Research: Maximising Value - Maximising Use

Organized by: BBMRI, P3G and PHOEBE

Date: March 25-27, 2009

Location: Brussels, Belgium

Information: <http://www.bbmri.eu>

Governance of New Technologies

Organized by: University of Edinburgh

Date: March 30-31, 2009

Location: Edinburgh, United Kingdom

Information: <http://www.law.ed.ac.uk/ahrc/conference09/index.asp>

Clinical Trials in Canada 6th Edition

Organized by: Insight Media

Date: April 27-29, 2009

Location: Montreal, (Québec), Canada

Information:

Avard D., Silverstein T., Sillon G., Joly Y., "Researchers' Perceptions of the Ethical Implications of Pharmacogenomics Research with Children", (2009) 12:3 *Public Health Genomics*, 191

Abstract: This paper presents the results of an exploratory qualitative study that assesses Canadian pediatric researchers' perceptions of a pre-selected group of ethical issues raised by pharmacogenomics research with children. Methods: As a pilot study, we conducted semi-structured telephone interviews with Canadian pediatric pharmacogenomic researchers. The interviews were guided by the following themes: (1) benefits and risks of inclusion, (2) the consent/assent process, and (3) the return of research results. Results: Issues about assent, consent, risks and benefits, as well as the communication of results were addressed by the respondents. Some issues, such as the unique vulnerability of children, the long term privacy concerns associated with biobanking, additional core elements that need to be discussed and included in the consent/assent forms, as well as the challenges of communicating research results in a pediatric research were not explicitly identified by the respondents. Conclusion: Further consideration should be given to address the ethical challenges of including children in pharmacogenomics research. This exploratory study indicates that further guidance is needed if children are to be protected and yet benefit from such research.

Borry P., Howard H.C., Sénécal K., Avard D., "Ethics Watch: Direct-to-Consumer Genome Scanning Services. Also for Children?", (2009) 10:1 *Nature Reviews Genetics*, 8

Abstract: [Not available]

Frank C., [...] Joly Y. et al., "Making an Impact: A Preferred Framework and Indicators to Measure Returns on Investment in Health Research", (2008) *Canadian Academy of Health Science*, Assessment Report, Report of the Panel on the Return on Investments in Health Research, 80

Abstract: [Not available]

Frank C., [...] Joly Y. et al., "Créer un impact: Les indicateurs et approches à privilégier pour mesurer le rendement des investissements consentis en recherche en santé", (2008) *Académie canadienne des sciences de la santé*, Résumé du panel sur le rendement des investissements consentis en recherche en santé

Abstract: [Non disponible]

Henk A.M., Stanton-Jean M., "The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application", UNESCO Publishing, 2009, 370 p.

Abstract: In October 2005, UNESCO Member States adopted by acclamation the Universal Declaration on Bioethics and Human Rights. For the first time in the history of bioethics, some 190 countries committed themselves and the international community to respect and apply fundamental ethical principles related to medicine, the life sciences and associated technologies. This publication provides a new impetus to the dissemination of the Declaration, and is part of the Organization's continuous effort to contribute to the understanding of its principles worldwide. The authors, who were almost all involved in the elaboration of the text of the Declaration, were asked to respond on each article: Why was it included? What does it mean? How can it be applied? Their responses shed light on the historical background of the text and its evolution throughout the drafting process. They also provide a reflection on its relevance to previous declarations and bioethical literature, and its potential interpretation and application in challenging and complex bioethical debates.

Sillon G., Joly Y., Feldman S., Avard D., "An Ethical and Legal Overview of Pharmacogenomics: Perspectives and Issues", (2008) 27(4) *Med Law*, 843-857

Abstract: Pharmacogenomics, a field of study at the interface of the disciplines of genomics and pharmacology, strives to understand the interaction between genes and the response to therapeutics. Its introduction into clinical research trials and medical practice promises to optimize the effectiveness of medications, reduce the adverse effects experienced by patients, and improve the research and development of new therapeutics. However, while pharmacogenomics promises tremendous health benefits it is still crucial to critically analyze the ethical, social and legal issues surrounding these developments. First, we present the numerous potential benefits of pharmacogenomics. Then, using a thorough review of relevant jurisprudence, policies and literature, the main ethical, social and legal issues associated with pharmacogenomics will be identified. The likely new responsibilities for health care professionals and pharmaceutical companies as a result of pharmacogenomic development will also be discussed.

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