

# Computing Genomic and Health Data in the “Clouds”?: ELSI Challenges

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**Room A824, 8/F, Cheng Yu Tung Tower, Centennial Campus, HKU**

## **Abstract:**

Big Data computation will increasingly use commercial cloud providers such as Google, Microsoft or Amazon as the locus of analysis due to the sheer size of datasets. Modern biomedical research is international and collaborative and combines many sources of data (e.g. medical; demographic; genetic; environmental etc). Recent scandals (e.g. Snowden) surrounding governmental surveillance have raised concern among national governments, to say nothing of research participants-patients, regarding the security and privacy of their data in the "clouds". What precisely are the issues specific to global biomedical research and is there cause for concern? Are there solutions?

**Bartha Maria Knoppers**, PhD (Comparative Medical Law), holds the Canada Research Chair in Law and Medicine (Tier 1: 2001 - ). She is Director of the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics, McGill University. In 2007, she founded the international Population Project in Genomics and Society (P3G) and CARTaGENE Quebec's population biobank (20,000 indiv.). Former holder of the Chair d'excellence Pierre Fermat (France: 2006 - 2008), she was named Distinguished Visiting Scientist (Netherlands Genomics Initiative) (2009 - 2012) and received the ACFAS prize for multidisciplinary (2011). She is Chair of the Ethics Working Party of the International Stem Cell Forum (2005 - ); Co-Chair of the Sampling/ELSI Committee of the 1000 Genomes Project (2007 - 2013); Member of the Scientific Steering Committee of the International Cancer Genome Consortium (ICGC) (2009- ); Chair, Regulatory and Ethics Working Group - Co-Founder and Member, Transitional Steering Committee (TSC) of the Global Alliance for Genomics and Health. She holds four Doctorates *Honoris Causa*, is *Fellow* of the American Association for the Advancement of Science, of The Hastings Center (Bioethics) and of the Canadian Academy of Health Sciences (CAHS) and *Officer* of the Order of Canada and of Quebec. She also received an award "Prix Montreal In Vivo: Secteur des sciences de la vie et des technologies de la santé" in 2012 and in 2013 was named "Champion of Genetics" by the Canadian Gene Cure Foundation.

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