

## **Genetic Information: Consent, Privacy and Research Biobanks**

**November 27, 2009**

### **Remarks to the Genome Canada/Office of the Privacy Commissioner Workshop**

Privacy is an important value for many reasons. It protects us from intrusions on our person; it allows intimacy; it facilitates freedom of expression and thought. Privacy also provides us with the ability to control how our own personal information is used.

Although this ability to control access to our personal information is not absolute, we can, to a large extent, decide how much information to share with others about the amount of money we make, about our family life, about our health and many other matters. We exercise control over this type of information because we understand it, we see it as, well, private and we have some sense of how it might be used or misused by others.

But exercising control over genetic information is far more complex.

It's difficult to exercise control over what we don't understand and, outside the medical and scientific communities represented at this meeting, the significance of genetic information is widely misunderstood. Control is also complicated by the difficulty of defining genetic information, the rapidly increasing, and in some cases unforeseen, potential uses, the longevity of samples, and the relative ease with which samples can be collected without knowledge or consent.

Genetic information is sensitive, it's intimate; it's predictive; it's powerful and it's shared.

As Article 1 of UNESCO's Universal Declaration on the Human Genome and Human Rights states, "The human genome underlies the fundamental unity of all members of the human family".

While we share much of our genetic makeup with our family, our ancestors and our broader communities, there's also that small percentage of our DNA that makes each one of us unique. Genetic information is the ultimate identifier.

Genetic information can be used for many wonderful and amazing purposes. It can also be used in ways that intrude on our dignity and sense of self.

The protection of genetic information is an urgent and complex issue. It raises questions of law and policy, questions of ethics and social norms and questions about competing social needs. These needs range from medical research to law enforcement to commercial uses, an issue that we will explore in future workshops.

In recognition of the pressing and growing importance of protecting genetic information, our Office has identified genetic privacy as one of four strategic priorities that will help guide our policy, research, public education and investigative work over the next few years.

I strongly suspect that it will become increasingly important to all federal policy makers in the very near future.

We all know about the potential harms that can result from the misuse of genetic information. But we shouldn't protect this information or any personal information only because of the possible harm that can result from its misuse. We need to protect privacy because of its inherent social value. This point is particularly important when we're talking about genetic privacy. It's not an exaggeration to suggest that our society as a whole has a stake in the preservation of genetic privacy.

Protecting genetic information is a critically important end in itself but it also facilitates other important social objectives such as medical and scientific research.

We are here today to discuss how to give individuals some control over their personal information stored in biobanks for research purposes.

One of the ways that individuals can control information about themselves is through consent. As the discussion paper prepared by Bartha Knoppers and Timothy Caulfield clearly suggests, the long-term nature of biobanks and the uncertainty of future research projects raises questions about our existing concepts of consent. Given the amount and potential sensitivity of the information that can be obtained from a biological sample, the possibility of reusing samples and the challenge of explaining potential future uses, how can we ensure that the autonomous wishes and the interests of the participants are respected? This is the challenge before you today – and it's a significant one.

These are fundamentally important issues that you are going to be discussing today. I am very pleased that our Office was able to co-sponsor this event and contribute to this dialogue. I am looking forward to a fruitful and productive workshop.

Thank you

Jennifer Stoddart  
Privacy Commissioner of Canada