

# Learning to Live With the Human Genome: Well-Reasoned Prudence or Future Shock?

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## **Background**

The recent announcement of the nearly complete mapping of the Human Genome has led to an avalanche of assertions and proven fact about the links between genetics, human health and human characteristics. The explosion of facts has opened doors to advanced diagnostic tools, advanced medical and public health treatments, a world of profitable new medical products and services, revolutionary improvements in the quality of evidence in legal proceedings and the potential for ever more precise and widespread discrimination. This new information has left us all potential prey to "information overload." Many unanswered questions have led some to call for comprehensive application of long standing medical privacy principles to every circumstance where genetics information is collected, analyzed, stored or used.

What has genetics actually enabled us to do in diagnosing, preventing and treating illness, in estimating environmental risks, and in changing the genetic futures of our children and grandchildren? What realistic hopes and fears should we have about its potential? And how should all of this figure into public policy, private enterprise and our personal lives?

This conference reviewed the most recent developments in the genetics revolution. Our goal was to broaden participants'—including policy analysts, genetic educators, attorneys, graduate students, clinicians, and state representatives—appreciation of both the values *and* the challenges that the results of the Human Genome Project pose.

The keynote address was given by Paul Billings, MD, PhD, and Lee Hartwell, PhD: What are the Best and Worst Destinations for Society on our Map of the Human Genome? How can Privacy Help Lead the Way? In addition to the six sessions described below, there was also a lunchtime panel discussion that examined the public dialogue on genetics.

## **A Conference Sponsored by The Washington State:**

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## **Genetic Discrimination**

Like all information, genetic information has the potential to be misused or misinterpreted in many settings, particularly in employment and insurance. The most frequent and popular policy response to this threat has been the widespread support of strong privacy protections for genetics information. What are the existing rules that seek to protect against discrimination? Are they adequate? Does genetics information privacy provide the protection it is widely believed to? Are there circumstances where genetic based susceptibility to certain environmental threats warrant limiting exposures to them?

## **Research, Public Health and Privacy**

Storing human samples for future research is increasingly common. One issue that arises is whether an individual can give truly informed consent for future research on a sample. Some, but not all, genetic research can use samples whose unique identifiers have been either partially or completely removed from the sample. Is there any public interest justification for compromising absolute patient privacy of their genetic information? How can we strike a balance between respecting the privacy of the individual in a way that permits genetics research and the advancement of legitimate public health interests? How do strong privacy policies governing the exchange of genetics information affect both clinical and public health research?

## **Computers/Technology**

The huge advances that computer technology has made in the last fifteen years have allowed us to obtain and use genetic information in many ways. Gene Chip technology may make the idea of 'genotyping' populations of people a reality. The advent of personal computers, the internet and ever more powerful computing technologies have combined with these advances, not only to quicken the pace of research and the rate of new genetics discoveries, but also potentially to place genetic information in the hands of nearly anyone. What has the synergy between computer technology and genetics produced, what may be coming, and how can the beneficial potential of these advances be secured without risking the detrimental effects that can come if privacy is not adequately protected?

## **Genetics and Medicine: Privacy and the Duty to Disclose**

Genetic information is an important part of the medical record. It can be critical in the diagnosis and management of complex diseases. Because of the potential for discrimination, individuals may opt for completely anonymous genetic testing. However, difficulty in obtaining genetic information may compromise care by limiting the amount of information the health care provider can use in planning the course of treatment. In addition, a patient's genetic information can be valuable to the family of the individual. What duty does the health care provider have to disclose genetic information to promote coordinated health care and disease management and to provide important information to the patient's family about the patient's or the family's health risks? What duty does the patient have to contact his or her family?

## **Human Tissue or Intellectual Property?**

Whose genes are they, anyway? What are the implications of allowing genes to be patented? How does privacy play a role in this context?

## **Primary Prevention or Eugenics?**

Mankind has long sought to improve the quality of its next generation. As of today, scientists have developed many genetic tests that, with varying levels of certainty, can predict human health and developmental futures for children that have yet to be conceived or borne. Should these tests and related technologies be used to improve the genetic make up of future generations? If so, how will we decide what constitutes improvement? Should we use any sort of genetic information for the purposes of reproductive decision-making? If so, what limits should be observed on the use of the information? Who should determine these limits and how should they be communicated and enforced? What role does privacy play in promoting the best use of genetics information in this context?