Personal genomics and genetic information nondiscrimination legislation: Are we ready?

by

This commentary in the Genomics Law Report's ongoing series *What ELSI is New?* is contributed by David Gurwitz, Tel-Aviv University Department of Human Molecular Genetics and Biochemistry.

The age of personal genomics has arrived faster than most have expected. While the purchase of full genome sequencing services may today be too costly for most to consider, full genome sequencing costs are projected to fall under US$1000 within less than a decade. But are we ready for the personal genomics age and its far-reaching societal implications? There are countless ELSI matters that need to be considered in the context of readily available personal genomes. One key aspect is the need for more comprehensive genetic information non-discrimination legislation.

Legislation is a notoriously slow process; when it comes to handling new technologies, legislators may take many years to catch up. Israel was among the first States to pass – already in 2000 – a comprehensive genetic information non-discrimination law; some European States soon followed. In the US, however, a similar legislation process suffered a lengthy birth: The Genetic Information Nondiscrimination Act (GINA) of 2008 has been in the making for over a decade (1), in spite of strong support from research associations and groups such as the NIH Pharmacogenomics Research Network (2). GINA, finally signed into law on May 21, 2008, protects Americans against discrimination in health coverage and employment based on individual genetic information (3). However it does not protect individuals against misuse of genetic information by life or disability insurance providers, banks, schools, or immigration authorities (4-6). Amending GINA for assuring wider protections seems urgent: personal genome sequences coming from proliferating electronic health records and government forensics databases, and other sources of personal sequences, including Facebook-like websites, are being contained in innumerable internet-based resources. Safeguards are typically in place to ensure that only qualified persons may access personal genetic profile records, but no safeguards are failsafe (7).

We are the citizens of an ever more closely connected global village. Individuals may migrate to new countries in pursuit of better jobs, security, or love. The accessibility of personal genomic data on the internet, however, knows no boundaries. Individuals may find themselves living in countries where privacy protections are below the level they have been accustomed to in their homeland country, while their personal genetic data acquired at home will accompany them to their new base. There is thus a far more urgent need: a global agreement prohibiting discrimination based on personal genetic information.

This remarkable task is doable: the global ban on human cloning is a fine example. A Declaration or International Bill – ideally issued by the United Nations – may be the most efficient way forward. Article 2 of the *Universal Declaration of Human Rights*, the basis for the *International Bill of Human Rights*, states that

“Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”

Ideally, this list should also include, ‘personal genetic information’. Let us hope this will not take too long – so we can be less concerned about the age of personal genomics.

References:

1. Genetic Information Nondiscrimination Act (GINA) of 2008


