How will we handle the rapidly approaching flood of genomic information on individual patients and consumers?

by

This commentary in the Genomics Law Report's ongoing series What ELSI is New? is contributed by Hank Greely, *Stanford Law School.*

The cost of advanced genome analysis is falling rapidly. The fabled “thousand dollar genome” is less than five years away. It will be as cheap to order a whole genome as to order any one genetic test. As the price falls, many people will buy “their genomes,” or, at least, information on billions of base pairs, millions of SNPs, and unknown numbers of copy number variations and translocations. What will we do with that information?

Some may think we already are facing this problem with the “consumer genomics” companies like Navigenics and 23andMe, but those SNP-chip-based companies have the “advantage” that they produce weak information, linked to only small variations in disease risk. Fully detailed genomic information will unearth *something* frightening in all humans’ genomes, for themselves or for their (existing or possible) children and other family members.

Patients need to understand the true implications of this genomic information, but how will we accomplish that? Some primary care physicians may be able to make sense of information about a few famous disease-related genomic variations – perhaps well-known mutations in BRCA 1 or 2, the expanded CAG repeats of Huntington’s disease, or the most common cystic fibrosis-associated mutations of CTFR1. Most won’t know even that; none have a clue about the thousands of rarer genetic disease associations, let alone the hundreds of published pharmacogenomic associations. Even clinical geneticists and genetic counselors will not know all the important variations, and in any event, those professionals are far too rare to handle any significant part of the demand. Even if we had the capacity to provide counseling, our current regulatory scheme does not require that genome consumer get *any* professional explanation – good, bad, or indifferent – to genome consumers. The age of cheap full genomes is almost upon us – and we are not close to ready for it.