

POPULATION HEALTH FORUMS

The Road Ahead – Genomic Advances Raise Challenging Questions

Jennifer Dreyfus, MBA, MBE

*Principal, Dreyfus Consulting, LLC
May 14, 2014*

Jennifer Dreyfus, MBA, MBE provides consulting focused on the intersection of new technology, health care, and managing risk. As a Fellow at the Presidential Commission for the Study of Bioethical Issues, she worked on the PRIVACY and PROGRESS in Whole Genome Sequencing Report. She is very interested in examining how society will incorporate the growing field of genetics. Her academic background in business administration and bioethics offers a unique perspective on this issue.

Ms. Dreyfus opened her presentation by emphasizing the idea that next-generation genome sequencing is a disruptive technology. Although next-generation sequencing plays a significant role in cancer care, genomic testing is also used in preconception, prenatal, childhood and adult diagnostics, and treatment monitoring. Dreyfus cites one study that predicts over \$15-25 billion in national expenditures will be spent on genomics by 2021.

Dreyfus explained that this is a time of transition; genomics is a moving target that changes the way we think about genetics. For example, we are no longer looking at one gene and one disorder; we are looking at a spectrum of mutations that can be identified. There are numerous pathogenic descriptions that require sorting out and interpretation. Gene panels are used to identify a variety of conditions and will have many ramifications in the future.

The benefits of identifying disease and appropriate, personalized treatment through genomic medicine raise a number of public policy concerns. Dreyfus identifies actionability, coding, payment, provider education, and re-interpretations as significant policy challenges that warrant discussion and analysis. For example, Dreyfus states that coding is very important, but code development cannot keep pace with scientific advances. Related to this, payers want to pay for something that is known and evidence-based. What are the appropriate evidentiary requirements? What is a fair method for rate setting? These are some of the questions that Dreyfus poses.

Dreyfus summarized her presentation with an overview of ethical concerns. She raised the issue of whether or not there is truly such a thing as anonymous DNA anymore and whether or not privacy is guaranteed. She stressed that genetics is about more than an individual, and that it is also about a family and a community. Are we treating the individual or family and how does this relate to privacy? She also discussed ACMG's latest guidance on incidental findings and implications for reporting and paying.

Prenatal and newborn concerns related to genetic testing often bring ethical concerns to the forefront. In prenatal care there is often tension between a technology that gives health care information and a restrictive environment that does not view reproductive options as part of health care. Though screening for adult-onset disorders is not typical, there can be value for screening newborns when an early intervention is possible.

*To listen to Forum podcasts and access presentations visit:
JDC.Jefferson.edu/hpforum*