

EMBARGOED FOR RELEASE

2:10 p.m. Eastern Time

Friday, April 25, 2014

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To share or not to share? Decisions following personal genetic testing

Philadelphia, PA – As genetic risk information plays an increasingly important role in the treatment and prevention of many diseases, private companies have made personal genomic testing for these risk factors widely available to the public. However, few data have been gathered to understand the motivations, expectations and subsequent behavior of consumers of personal genomic services, or the associated ethical, legal and social issues. With funding from the National Human Genome Research Institute, the Impact of Personal Genomics (PGen) Study surveyed over 1,700 consumers of two U.S. companies that provided personal genetic testing to determine their responses to genetic risk information.

As a PGen Study collaborator, presenter Catharine Wang, PhD, associate professor of community health sciences at the Boston University School of Public Health, was particularly interested in whether consumers were sharing information about their testing with health care providers, and what went into that decision-making process. The study found that while consumers overwhelmingly shared results with family and friends, less than a third shared the information with primary care providers. Slightly more than half sought further information related to their results.

The study results will be presented at a symposium session entitled “Genomic Advances and Patient Decision Making: Recent Findings and Emerging Issues” at 2:10 pm EST Friday, April 25 during the 2014 Society of Behavioral Medicine’s Annual Meeting & Scientific Sessions in Philadelphia.

Consumers were surveyed prior to receiving their genetic results, at 2-3 weeks follow-up to gauge immediate reactions, and at 6 month follow-up to examine subsequent behaviors, including sharing of test results.

“We really wanted to know whether there were any privacy concerns that precluded people from sharing with their doctor,” Wang said. “Surprisingly, that wasn’t the case at all.” The study found that privacy concerns were rare, but that other factors, such as relevance of the results to a person’s for current health status or the perceived interest level of providers, played a role in consumers’ decisions on whether to share information.

“While many consumers chose not to share results with their primary care providers, over half still sought additional information, primarily from the Internet,” adds Wang. “This suggests that consumers need further clarification to understand the implications of their test results and

may not necessarily go to health professionals for this purpose.”

The study is titled, “Decisions to share results and seek further information following online personal genetic testing.” Other contributors are: Amanda Dalia, Clara Chen (Boston University), J. Scott Roberts, Mack Ruffin (University of Michigan), Robert C. Green, Sarah Kalia, Lisa Lehmann (Brigham and Women’s Hospital/Harvard Medical School), Joanna Mountain (23andMe), and Tanya Moreno (Pathway Genomics).

The data and conclusions in the paper being presented should be regarded as preliminary, until they are published in a peer-reviewed journal. The authors declare no financial or other conflicts of interest.

The Impact of Personal Genomics (PGen) study is supported by an R01 grant (HG005092) from the National Human Genome Research Institute and is led by Robert C. Green, MD, MPH of Brigham and Women’s Hospital and Harvard Medical School and Scott Roberts, PhD of University of Michigan School of Public Health. In collaboration with two U.S. companies that provide personal genetic testing – 23andMe and Pathway Genomics – the PGen Study surveyed consumers to determine their reactions to genetic risk information for common diseases of interest, including heart disease, diabetes, Alzheimer’s disease, arthritis, and breast, colon, lung, and prostate cancers. The aims of the PGen Study are to describe who seeks personal genomic testing and why; describe the impact of personal genomic testing; and assess what consumers do with their genetic information.

The Society of Behavioral Medicine (www.sbm.org) is a multidisciplinary organization of clinicians, educators, and scientists dedicated to promoting the study of the interactions of behavior with biology and the environment and the application of that knowledge to improve the health and well being of individuals, families, communities and populations.

This study was presented during the 2014 Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine (SBM) from April 23-26 in Philadelphia, PA. However, it does not reflect the policies or the opinion of the SBM.

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