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New study launched investigating the impacts of personal genomic testing

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As genetic risk information plays an increasingly important role in the diagnosis and treatment of many diseases, private companies have made personal genomic testing for these risk factors widely available to the public. However, very little data has been gathered to understand the motivations and expectations of consumers of personal genomic services, the psychological and behavioral impact of these services, and the associated ethical, legal and social issues—until now. The Impact of Personal Genomics (PGen) Study, one of the first major studies to prospectively examine the impact of consumer genomics, is prepared to launch its data collection phase.

With funding from the National Human Genome Research Institute, joint Principal Investigators Robert C. Green, MD, MPH of Brigham and Women's Hospital and Harvard Medical School and J. Scott Roberts, PhD of the University of Michigan School of Public Health teamed up with leading personal genome testing companies 23andMe and Pathway Genomics Corporation to launch PGen.

"The goal is to produce results that can be translated into recommendations to guide policy and practice in this rapidly emerging area," said Green.

The group leading PGen will survey consumers of personal genome testing to identify their motivations, expectations, and attitudes, as well as their responses to learning their genetic disease risk, carrier status, and drug response results.

PGen is set to launch with the distribution of surveys to new consumers of personal genomic services. PGen will enroll 1,000 participants in all: 500 customers of Pathway Genomics and 500 customers of 23andMe. Researchers will then be able to compare survey responses to the genetic results, providing unique insight into the risks and benefits of personal genomic services.

"There has been considerable speculation, but not a lot of data, to inform the debate about the possible benefits and harms of personal genomics services," says Roberts. "We hope that our study will help to bridge this evidence gap."

To carry out the research, Green and Roberts assembled an interdisciplinary team of experts with backgrounds in medicine, genetics, genetic testing policy and practice, health communication, genetic counseling, health psychology, health law, bioethics and web survey design, many of whom have worked together on related prior research.

At the end of the project, the PGen team expects to understand: (1) who seeks personal genomic testing and why; (2) the impact of test results on psychological response, risk perception and comprehension, and personal utility; and (3) what consumers do with their genetic information (i.e. make health behavior or insurance changes, seek further information or communicate with family and health care providers).

Provided by Brigham and Women's Hospital