Robert C. Green, MD, MPH, Contributor
Director, Genomes2People Research Program

Genetic Privacy Concerns Are On The Rise For Families And Researchers

06/06/2017 03:18 pm ET

Learn more about BabySeq and the Genomes2People Research Project

“One family asked me: ‘Will they be able to clone my baby?’”

That’s not a typical question, says genetic counselor Shawn Fayer, just an anecdote. Still, it fits a theme. For parents considering whether to have their newborn’s genome sequenced as part of the BabySeq Project, genetic privacy and discrimination are often the top

concerns.

“About fifty percent of the time they bring the question to us even before we bring it up,” says Fayer, who manages recruitment for the BabySeq Project. “It’s definitely on the minds of the families we talk to.”

The BabySeq Project is the first-of-its-kind clinical trial focused on how best to integrate genome sequencing into the care of newborns. Today, most newborns in the U.S. receive a simple heel stick test that screens newborns for some very specific biochemical conditions. With genome sequencing, parents could receive a much more extensive screening for genetic risk factors. The BabySeq Project is studying the potential benefits, risks and costs by offering genomic sequencing reports for newborns and following up with their parents afterward.

Most parents of newborns aren’t interested in joining the study, or can’t for logistical reasons —they have a lot on their plate, after all. Those who do express an interest in enrolling their newborn in the study first sit down with a genetic counselor to talk through considerations and questions. Although most families who make it this far go on to participate in the study, many have reservations about genetic privacy and insurance discrimination—and for parents who decide to opt out of the study, those concerns are the two top reasons given.

What is there to worry about? Say your newborn’s genome sequencing report finds that she will have a heightened risk of breast cancer as an adult. That information might be very useful to her later on, and could drive some big personal healthcare decisions — but if it’s going to be in her medical records, who else might have access to it? Could health insurance providers use that information someday to raise her premiums or refuse coverage? Could employers use it in hiring decisions?

Congress has addressed some of these particular concerns. In 2008, the Genetic Information Discrimination Act (GINA) made it illegal for employers and health insurers to discriminate based on genetic risk information. It also made it illegal for them to request, require, or buy that information. It was a landmark law, proactively setting up protections before genetic discrimination was a high-profile issue, helping to pave the way for an era of genomic medicine and research. And as we summarized in an earlier essay, it seemed partly to work, reassuring some patients and research participants.

GINA, however, has some gaps. It covers health insurance, but does not cover life insurance, long-term care insurance, or disability insurance. It covers discrimination by employers, but not by lenders or schools. And we seem to be heading in the wrong direction! Just in the last few months, five U.S. Representatives cosponsored HR 1313, which would weaken GINA protections by allowing employers to penalize employees who don't submit their genetic information to wellness programs, with the ostensible goal of lowering health insurance costs.

The power of politicians over genetic privacy protections isn't lost on parents in the BabySeq Project. Since the most recent presidential election, some families participating in the study have come back with new worries.

"There has been a bit more concern about privacy with the administration change and the current political climate," Fayer says. "We've actually had parents come in for disclosure and say, 'Before you give us the results, let's talk again about privacy issues—we're a little extra nervous now.'"

It remains to be seen whether there will be a significant difference in decline rates in the coming year. Parents aren't the only ones keeping a wary eye on these issues, Fayer says.

"At the end of the day, it's something we're all concerned about."

Robert C. Green, *M.D., M.P.H., is a medical geneticist and physician-scientist who directs the* G2P Research Program *in translational genomics and health outcomes in the Division of Genetics at Brigham and Women's Hospital, the Broad Institute and Harvard Medical School.*