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What About Personal Genomic Testing if You Are Adopted?



By Robert C. Green, MD, MPH

If you were adopted, you might have a hard time answering questions about medical history at the doctor's office. Family history of diabetes? *I don't know.* Cancer? *Not sure.* Heart disease? Alzheimer's? Anything else that we should know about? *Wish I knew.*

Many adoptees are acutely aware that the absence of a family medical history can put them at a disadvantage. It may interfere with risk assessment and disease prevention, and adoptees may even feel a stigma as they move through the health care system.

As [highlighted this week in the *New York Times*](#), personal genomic testing (PGT) may offer valuable information to fill in the gaps. Without that family history, however, adopted individuals will have little context to interpret the results of these genomic tests. This lack of context raises concerns: will reports of low genetic risk encourage reckless behavior? Will reports of elevated risk create unnecessary anxiety?

Wondering about these same questions, we examined responses of new PGT customers before and six months after

they received their results. We recently [published our results in the journal *Genetics in Medicine*](#).

Our study found that while personal genomic testing cannot replace a comprehensive family history, adoptees who received this information found it valuable — but that adoptees were no more or less likely than non-adoptees to seek additional medical advice or make behavioral changes based on their PGT findings.

Our study looked at a sample of 1,607 individuals, of whom 80 (5%) were adopted. The adoptees were more likely than the rest of the sample to cite their limited knowledge of family history and the chance to learn more about genetic risks as reasons they signed up for testing. Adoptees also wanted this information for family planning purposes, and to share with their own children.

“I am adopted and plan on having biological children with my wife,” said one 29-year-old man. “We wanted to get some indication of my family medical history and genetic risk factors before we started the process.” In a few cases, adoptees hoped to find relatives through the features of one of the services that connect individuals with others who are genetically related.

Six months after they received their results, we found that adoptees were glad to have this information, relieved about relatively low risk of certain genetic diseases, and in some cases frustrated about the lack of detail provided in their results. Some adoptees had expected to see more definitive genetic results, and some were disappointed that the service had not led them to any close biological relatives.

Our evidence, however, did not show that adoptees were any more likely than the rest of our sample to base important health decisions on personal genomic testing. PGT did motivate some individuals to use health-care services such as consultations or medical tests. And it did motivate some to change their health behaviors. But those actions were distributed equally among the

adoptees and the non-adoptees, and in line with the findings of our [previous studies of PGT customers](#).

It seems, therefore, that there's little reason to be concerned about adoptees overreacting to personal genomic information. Participants were glad to have this information, and some took positive steps in response to it. For many adoptees, personal genomic testing provides unexpected insights into the family history they have no other way to explore.

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