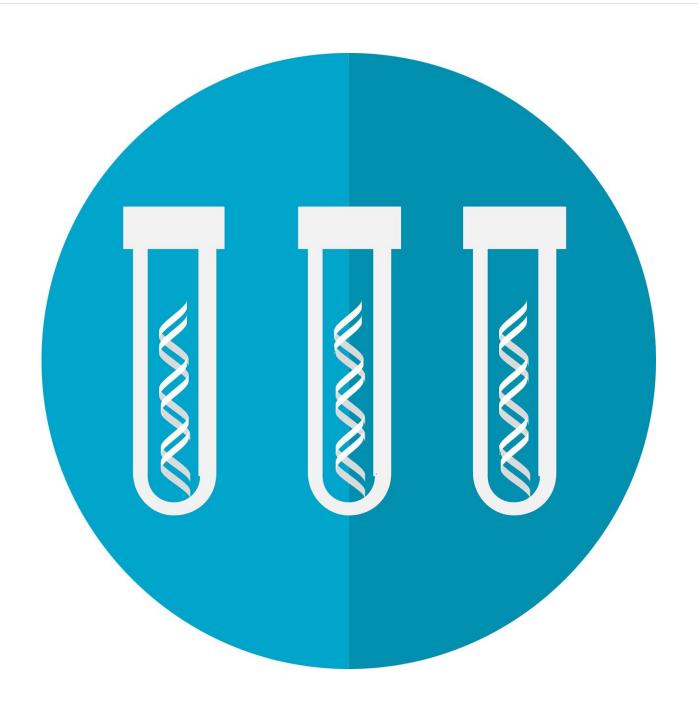


## The impacts from using genetic testing to track down relatives

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Genetic genealogy has become a popular hobby over the past several years, thanks to direct-to-consumer (DTC) genetic testing and relative-finder services offered by some DTC genetic testing companies. In a paper published February 24 in the *American Journal of Human Genetics*, researchers report results from a survey that asked people who had participated in these services what effect the discovery of previously unknown relatives had on their lives.

Among the most important findings were that identifying a genetic relative appeared to be somewhat common. Additionally, those discoveries were generally experienced as neutral or positive and didn't appear to have a big impact on participants' lives. However, some participants learned things that could be considered significant and destabilizing—such as that their biological parent wasn't who they thought. These participants were especially vulnerable to negative outcomes.

"Everyone on our team is involved in studying the ethical, legal, and social implications of DTC genetic testing, and we've been paying attention to stories in the media about individuals who've made surprising family discoveries from these tests and relative-matching services," says lead author Christi Guerrini of the Center for Medical Ethics and Health Policy at Baylor College of Medicine. "We wanted to understand if these and other kinds of discoveries are common, how they're experienced by those making the discoveries, and what people are doing as a result."

The investigators sent the survey to about one million DTC genetic testing customers and genetic genealogy database participants; more than



26,000 responded. The final sample for analysis consisted of 23,196 completed or substantially completed surveys. Among the reasons that respondents said they chose to participate in this type of testing were to learn more about their family or build their family trees; to search for a biological parent, child, or other relative; or to investigate a suspicion that they might not be genetically related to <u>family members</u>.

"It seems that many—perhaps most—are just curious about their families and interested in building out their family trees, but it's clear that quite a lot of participants are looking for someone or hoping to confirm something in particular," Guerrini says. "It might be that they're adopted and looking for a biological parent, or that they've always felt out of place in their family and want to see if there's something to that feeling. Or they might be looking for information about a branch of their family tree that's unknown to them, or to confirm a <u>family</u> story that's been passed down over the years."

Most respondents (82%) reported that they learned the identity of at least one genetic relative. Among this subpopulation, 10% identified a biological grandparent, 10% identified a full or half- sibling, and 7% identified a biological father. The survey asked whether the participant had chosen to contact any of their newly identified relatives and, if so, the reasons for doing so. It also asked whether their discoveries resulted in any life changes, including changes in health-related behaviors.

Guerrini says that the high number of people overall who identified an unknown genetic relative was not unexpected, because many of those relatives could be very distant ones. But she acknowledges that the high number of participants who found close relatives could be skewed by the type of people who choose to undergo relative matching in the first place. "Unfortunately, we can't answer that question with our data, but I'm very interested in trying to do so in future research," she says.



She adds that although these experiences appear to be interesting and enjoyable to a large number of people, it's clear that some who are participating in these services have experienced negative outcomes. "In future research, we'd like to better understand those outcomes and what resources could be helpful in managing them," she says.

**More information:** Christi J. Guerrini, Family secrets: experiences and outcomes of participating in direct-to-consumer genetic relative-finder services, *The American Journal of Human Genetics* (2022). <u>DOI:</u> 10.1016/j.ajhg.2022.01.013.

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