

Study: People want personal results from genetic research

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(PhysOrg.com) -- The majority of people from a genetic study opted to be told whether they carried a cancer-causing gene mutation, and the knowledge did not cause emotional distress or change their health behaviors, a new study shows.

The University of Michigan School of Public Health's re-contact study was one of the first of its kind specifically designed to give participants of epidemiological research follow-up information on their [genetic makeup](#), said Kurt Christensen, lead study author and doctoral candidate in the U-M SPH.

U-M researchers designed the study this way to learn the practical challenges of sharing such information and the impact on subjects. Scott Roberts, assistant professor in the U-M SPH Department of [Health Behavior](#) and Health Education, is the principal investigator.

The medical and science community is divided over whether epidemiological researchers have an obligation to disclose individual genetic results significant to the health of a research participant. Few, if any, currently do so.

"One argument against this is that participants won't understand their results and they'll get depressed or sent into a tailspin," Christensen said. "We found people wanted the information, they understood the results, and it didn't affect their mood. They very much appreciated that we gave them this information and they said it would make them more likely to

participate in research in the future."

In the study, researchers gave results to 19 U-M melanoma survivors who had donated DNA years earlier in a different study to help confirm whether a gene was associated with melanoma, Christensen said.

A genetic counselor provided the results to patients as well as educational materials specific to that gene and the study participants. Christensen said the feedback was costly and time consuming, but most likely worth it in the long run.

"A lot of ethicists talk about whether we have an obligation, but there have been few attempts to actually follow-up with study participants with individual results," Christensen said. "It's clear that people are getting tired of it. They do these things and they get nothing in return. I think providing research participants something for their time is something that will benefit research in the long run."

The re-contact study spent more than \$1,300 per participant, and 59 percent of the people said getting their results made them more likely to participate in another research study.

Three of the 19 participants had the mutation, Christensen said. The most common reason people wanted to know was for their children, which surprised researchers.

"You have to be a little bit savvy to understand that the results may be more important for your children than for you," Christensen said.

The paper, "Disclosing individual CDKN2A research results to melanoma survivors: Interest, impact and demands on researchers," is available in the February online edition of *Cancer, Epidemiology, Biomarkers and Prevention*.

More information: [cebp.aacrjournals.org/content/...
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