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Public Largely Supportive of Big Genetic Studies

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By Anthony J. Brown, MD

NEW YORK (Reuters Health) Nov 12 - A survey of over 4500 Americans reveals that most are in favor of large cohort studies examining how genes, the environment, and lifestyle interact to affect the risk of a given disease.

The survey results, which were presented Wednesday at the American Society of Human Genetics annual meeting in Philadelphia, also indicate that most subjects were willing to participate in such studies. Moreover, this willingness remained high regardless of ethnicity or other demographic features.

"We had two big findings," lead author Dr. David Kaufman told Reuters Health. "First, we saw that support for the cohort study and willingness to participate were consistent across all demographic groups including race and ethnic groups. This was a surprise, particularly since several studies have shown lower interest and participation in genetic research among African Americans and other minorities."

The other big finding related to incentives for study participation. "We found that giving study participants their individual research results related to health had a stronger influence on willingness to participate than compensation they would receive or how burdensome study participation would be," Dr. Kaufman, a researcher with Johns Hopkins University, Baltimore, said.

According to the report, 84% of respondents said that large cohort genetic studies should definitely or probably be done. Sixty percent said that they would probably or definitely be willing to participate in such studies if offered the chance.

Providing the research results to participants and providing financial compensation increased the likelihood of participation by 60% and 50%, respectively ($p < 0.0001$ for both). Reducing the study burden, by contrast, only increased the odds by 20% ($p = 0.014$).

Consistent with the other findings, 75% of subjects said that their willingness to participate would fall if not given the research results. Moreover, 91% of respondents wanted their results even if there were of no immediate clinical value.

"The larger point is that people are hungry for information about themselves and their health," Dr. Kaufman said. "If something is learned about them during a research study, they want to have the option to find out about it."

Regarding future research, he said that his team is "interested in finding out whether passage of the Genetic Information Nondiscrimination Act (GINA) changed people's attitudes about (large cohort genetic studies), since this work was conducted before the legislation was signed."

GINA, which was passed in May this year, is designed to protect Americans from discrimination based on their genetic information as it relates to health insurance and employment.