

Survey finds wide public support for nationwide study of genes, environment and lifestyle

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Four in five Americans support the idea of a nationwide study to investigate the interactions of genes, environment and lifestyle, and three in five say they would be willing to take part in such a study, according to a survey released today. The research was conducted by the Genetics and Public Policy Center at Johns Hopkins University with funding from the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH).

In a plenary session at the American Society of Human Genetics' annual meeting in Philadelphia, and in a paper published in the advance online edition of *Genetics in Medicine*, researchers presented results of their survey that sought public opinions about the prospect of a national study that would bank DNA and other biological samples from thousands of volunteers and track the volunteers' health over time. Researchers often refer to this type of study as a cohort study, with one of the best-known examples being the Framingham Heart Study in Massachusetts.

"Our survey found that widespread support exists in the general public for a large, genetic cohort study. What's more, we found little variation in that support among different demographic groups," said David Kaufman, Ph.D., lead author of the paper and project director at the Genetics and Public Policy Center, which is located in Washington.

Various experts have suggested initiating a nationwide cohort study to

address the many unanswered questions about how genetic and non-genetic factors interact to influence risk of common diseases. As currently envisioned, such a study might collect DNA and other samples from at least 500,000 people who are representative of the U.S. population and then follow them over many years to see how their genetic make-ups interact with lifestyle and environmental factors to affect their health.

The online survey of 4,659 U.S. adults was conducted between December 2007 and January 2008. When asked about their support for and willingness to participate in a large genetic cohort study, 84 percent of respondents supported the study and 60 percent indicated they would definitely or probably participate in such a study if asked.

Survey respondents were carefully selected to reflect the demographic makeup of the United States. No significant differences in support or willingness to participate were observed between whites, Hispanics, African Americans and Asians. American Indian and Alaska Native respondents expressed less support for the study (65 percent), but were just as likely to be willing to participate (63 percent) as other respondents.

Genetics and Public Policy Center researchers also looked at what factors might increase people's willingness to take part in a large genetic cohort study. According to the survey's results, the factors with the greatest impact on willingness to participate were a commitment to returning research results to individual volunteers, and an offer of compensation. On the flip side, three in four respondents said they would be less likely to participate if they could not receive their individual research results.

When asked to rank the possible benefits of participating in a national genetic cohort study, more than two-thirds of those surveyed considered

"receiving information about my health" to be a very important benefit. In contrast, only about one-third said monetary compensation would be very important.

"The public's eagerness to receive individual research results suggests that the research community may need to reassess its stance of 'protecting' research participants from their data and look for practical ways to return such results," said Kathy Hudson, Ph.D., the paper's senior author and director of the Genetics and Public Policy Center. However, Dr. Hudson noted that even if individual results were not returned, more than half of people surveyed said they probably would still go ahead and participate in a nationwide genetic cohort study.

Sample selection and online administration of the survey was managed by the consumer information company Knowledge Networks under the guidance of the Genetics and Public Policy Center. The margin of error for the public opinion portion of the survey was plus or minus 1.6 percent.

Source: Johns Hopkins University

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