

Genetic risk: Should researchers let people know?

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Should researchers inform research participants, if they discover genetic disease risks in the participants? Yes, many would say, if the information is helpful to the participants. However, the value of complex genetic risk information for individuals is uncertain. In a Ph.D. thesis from Uppsala

University, Jennifer Viberg Johansson suggests that this uncertainty needs to be acknowledged by both geneticists and ethicists.

One of the reasons people participate in large genetic studies is the comprehensive health check that researchers often include to collect data. These studies inform participants about their blood pressure, lung function and the results of different blood tests. In the future, people could also be offered information about genetic risks. Jennifer Viberg Johansson's Ph.D. thesis explores factors that researchers should consider before offering these kinds of results.

According to Jennifer Viberg Johansson, providing [genetic risk](#) information may not be as helpful to individuals as one may think. Knowing your genetic make-up is not the same as knowing your own probability for disease. In addition, the kind of genetic [risk](#) information you would get when participating in research is less "personalised" than results from a genetic test you would do in a hospital to confirm suspicions that you might be at risk, or have a genetic disorder. Instead, you are given results that are not connected to any symptoms.

Genetic risk information is complex and can be difficult to understand. Jennifer Viberg Johansson has studied how participants in the Swedish population study, SCAPIS, understand genetic risk information, and what kind of information they would like to receive. It turns out that participants think of genetic risk as something that could explain who they are, or where they are from, but also as affecting their future life. To them, learning about genetic risk represents an opportunity to plan their lives and take appropriate precautions to prevent disease.

Answering whether research participants want genetic risk information or not is more complex. Jennifer Viberg Johansson found that people's willingness to receive genetic risk [information](#) could be influenced by the way the question is asked. Risk research has shown that people

interpret probabilities in different ways, depending on the outcome and consequences. Her work points in the same direction: probability is not an essential component in peoples' decision-making in cases where there are ways to prevent disease.

Jennifer Viberg Johansson found that people have difficulties making sense of genetic risk when it is presented in the traditional numeric sense. Having a 10% or 50% risk of developing a condition is hard to interpret. Instead, people tend to understand genetic risk as a binary concept: you either have risk, or not. She suggests that we need to keep this in mind when conducting genetic counselling. According to her, genetic counselling needs to be tailored to people's often binary perceptions of risk.

"Communicating risk is difficult, and requires that genetic counsellors understand how different people understand the same figures in different ways," says Jennifer Viberg Johansson.

Facts about SCAPIS: The SCAPIS (Swedish CARDioPulmonary bioImage Study) research programme is a population study involving extensive measurements of 30,000 Swedes aged 50–64. The aim of the project is to find risk markers that allow prediction of who is at risk of cardiopulmonary disease, and prevention of this disease before it occurs. The study is a collaboration among six university hospitals in Sweden, funded primarily by the Swedish Heart-Lung Foundation.

More information: Individual Genetic Research Results: Uncertainties, Conceptions, and Preferences. uu.diva-portal.org/smash/record.jsf?pid=diva2%3A1236203&dswid=8386

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