

Does genetic testing pose psychosocial risks?

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For the last quarter century, researchers have been asking whether genetic information might have negative psychosocial effects. Anxiety, depression, disrupted relationships, and heightened stigmatization have all been posited as possible outcomes—but not consistently found. What accounts for the discrepancy?

A new special report published by The Hastings Center explores this question. It considers the ways in which the prediction of adverse consequences has not been borne out by [empirical research](#)—and also the limits of those data. Given that today's [genomic information](#) is more voluminous and complex than the results that were at issue in the older studies, it is not likely that simple answers will be forthcoming to the question of the psychosocial impacts of receiving genetic or genomic [information](#). Rather, the answers will depend on factors that include the condition being tested for, the reason for the testing, the social context of the testing, and the psychology of the individual being tested.

"Just coming to better understanding why one-size-fits-all answers will not be forthcoming is itself progress," states the introduction to the report, written by its editors, Erik Parens, a senior research scholar at The Hastings Center, and Paul Appelbaum, the Elizabeth K. Dollard Professor of Psychiatry, Medicine and Law, and director of the Center for Law, Ethics and Psychiatry at Columbia University, who is a Hastings Center Fellow.

The special report, "[Looking for the Psychosocial Impacts of Genetic Information](#)," is the product of a conference of the same name held at Columbia University in February 2018 and cosponsored by Columbia's Center for Research on Ethical, Legal & Social Implications of Psychiatric, Neurologic & Behavioral Genetics and The Hastings Center.

The report is divided into three parts, each with three essays. The first part examines the historical

and social context for current debates about research on the impacts of communication genetic information to patients.

The second part focuses on studies that are skeptical about the existence of large psychosocial harms. In one of the essays, "Assessing the Psychological Impact of Genetic Susceptibility Testing," Scott Roberts discusses the findings of a major study that found that people who learned that they had a variant of the ApoE4 gene that increases the risk for Alzheimer's disease did not show elevated signs of depression or anxiety. However, Roberts also recognizes that there's much that is not known about the psychosocial effects of ApoE4 testing, and cites evidence that people who learn of a positive result show worse performance on memory tests.

The third part is devoted to studies that support reasons for continued concern about harms from genetic testing. One of the essays, "Actions and Uncertainty: How Prenatally Diagnosed Variants of Uncertain Significance Become Actionable," recounts how women talk about their experiences learning genetic information about their fetus that is of unknown significance. For some women, this information caused anxiety both during pregnancy and after their children were born. In addition, many of the women perceived their children as vulnerable, even if they showed no signs of the condition being tested for. "Raised levels of uncertainty as a result of [variations of unknown significance] carry major implications for parenting behaviors, children's outcomes, and medical and school system overuse, outcomes seldom assessed in research about genetic technologies," write Allison Werner-Lin, Judith L. M. McCoyd, and Barbara A. Bernhardt.

"It is reassuring that, on average, the receipt of genomic information about single genes does not have large, negative psychosocial effects on those who choose to receive that information," write

Parens and Appelbaum. "But it is surely not the case that, because we see few negative psychosocial impacts in people who chose testing for informational purposes, we should expect to see equally few negative impacts among all people." They conclude that "we have an extraordinary amount more to learn about the psychosocial implications of sharing [genetic information](#)."

More information: Erik Parens et al, On What We Have Learned and Still Need to Learn about the Psychosocial Impacts of Genetic Testing, *Hastings Center Report* (2019). [DOI: 10.1002/hast.1011](#)

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