

Teens' views vary on pediatric genetic testing for adult-onset conditions

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Alanna Kulchak Rahm, PhD, Geisinger Health System. Credit: Geisinger Health System

Adolescents display a complex and nuanced understanding of the issues around pediatric genetic testing for conditions that do not appear until adulthood, according to findings presented at the American Society of Human Genetics (ASHG) 2017 Annual Meeting in Orlando, Fla.

Alanna Kulchak Rahm, PhD, MS, LGC, Assistant Professor at the

Geisinger Health System, along with colleagues at Geisinger, Sarah Lawrence College, and ASHG, qualitatively and quantitatively analyzed essays submitted to ASHG's 2016 DNA Day Essay Contest. The contest focused on whether adolescents should be encouraged to defer such testing for such [conditions](#) until adulthood, as recommended by a recent ASHG position statement. The researchers analyzed the views and reasoning expressed in 1,241 essays written by 9th-12th grade students from 44 U.S. states and 23 other countries. Approximately half of the essays agreed with the ASHG statement that testing should be deferred, and the other half refuted that argument.

Despite differences in their opinions, Dr. Rahm observed, "These kids have the ability to reason about the potential implications of genetic information for these conditions and to make thoughtful choices. Their arguments were in line with the discussions we've had with adults, including parents and genetics experts."

Essay authors were asked to choose and describe an example of an adult-onset condition with an available genetic [test](#), and to defend or refute the ASHG recommendation to defer testing until adulthood. The researchers found that students' opinions on testing deferral was associated with their choice of condition - specifically, whether that condition was preventable among those with a genetic predisposition. Among students who focused on early-onset Alzheimer's disease or Huntington disease, which are generally not preventable, a significant majority felt that testing should be deferred (64% and 62% respectively). Conversely, among those who chose BRCA-related breast or ovarian cancer, which can be prevented through medical intervention, lifestyle, and health decisions, only 46% felt that testing should be deferred.

The researchers did not find any associations between adolescents' opinions on testing deferral and demographic factors, such as gender, grade level, school type (public or private), personal experience with the

condition described, or geographic variables related to socioeconomic status. Planned questions for future research include the extent to which essays reflect understanding of test validity, reliability, and limitations; and ways to use these findings in the real world, such as developing modules to help teens facing genetic testing decisions or to help teachers address gaps in understanding.

"These findings will help us consider a variety of issues, such as how to include adolescents as we move forward in precision medicine, how to improve genetics education in schools and in the community, and how to change our discussion around genetics as the field changes and evolves," said Dr. Rahm.

More information: Dr. Rahm will present this research on Thursday, October 19, 2017, from 11:00-11:15 a.m., in Room 310A, Level 3, South Building, Orange County Convention Center.

www.ashg.org/2017meeting/

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