

Exploring Parental Perspectives on the Return of Genomic Results for Children Enrolled in a Pediatric Genetic Biorepository

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The genetics community is in the midst of delineating proper procedures and protocols for analyzing and returning genomic results in both the clinical and research realms. While professionals have yet to reach consensus on this complicated and challenging subject, it is unclear where patients and their families stand on the issues that certainly impact them most directly. To address this paucity of data, a survey study investigating parents' desire for various types of genomic information and anticipated reactions and preferences was performed. This survey was distributed to a group of stakeholders – parents of children enrolled in a pediatric genomic biorepository with anticipated return of research-derived results. Seven hypothetical result return scenarios were presented so that respondents' opinions and anticipated reactions could be compared across various disease categories. Implications about placing results in the medical record and points of view regarding child's future autonomy were also explored. Results indicated that an overwhelming majority of parents wish to learn about results related to conditions across a spectrum of perceived disease severity, preventability, and age of onset. The percentage of respondents expressing desire to know about any of these conditions range from a minimum for Alzheimer's disease (84.3% responded 'yes') to a maximum for familial adenomatous polyposis (99.4% responded 'yes'). Participants also report strong likelihood of seeking genetic testing for themselves and their other children for many of these conditions, as well as seeking care from their pediatricians, primary care providers, specialists, geneticists, and genetic counselors related to these research-derived findings. Furthermore, a majority of participants express support for placing these potential results in their child's medical records across most scenarios, though the degree of support varies by condition. All in all, this study demonstrates a strong desire for a wide variety of genetic information, and sheds light on the potential impact these research endeavors might have on the medical community at large.