**Title:** The Use of Electronic Health Records in Intellectual and Developmental Disabilities Research: Parents’ Perceptions of Risks and Benefits

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**Introduction** The advent of electronic health records (EHRs) has enabled researchers to mine vast amounts of clinical data. Advances in genomic science have led to growing numbers of research studies recruiting individuals with intellectual and developmental disabilities. These individuals may have the most to gain from participation in research, but also face increased risks. Therefore, it is important to understand their preferences for the use of their EHRs in research. The goal of this project was to examine perceptions of parents of two groups of individuals with intellectual and developmental disabilities – those with fragile X syndrome (FXS), a known genetic condition, and those with an autism spectrum disorder (ASD), a suspected genetic disorder – compared with parents of typically developing (TD) children.

**Method:** Using a semi-structured guide, we conducted focus groups in North Carolina and Maryland with parents of TD children (n=15), parents of individuals with ASD (n=11), and parents of individuals with FXS (n=12). The majority were mothers (71%). Participants were 66% White, 26% Black or African American, and 8% Asian; 5% identified as Hispanic. Focus groups were recorded, transcribed, and analyzed using directed content analysis.

**Results:** Most participants were in favor of sharing their child’s EMR for research purposes, although there was a continuum of perspectives. Parents of TD children were the most conservative in their preferences. Parents of children with ASD and FXS were very open to sharing even sensitive information about their children, and also valued receiving research results more so than did parents of TD children. All groups had reservations about insurance companies, certain government agencies, and pharmaceutical companies using their child’s EMR for research. However, the two genetic groups were more willing to share with pharmaceutical companies because of possible benefits of the research for individuals with ASD and FXS. Across all groups, the primary risk of sharing EMR data was security breach leading to misuse of data for non-research purposes (e.g., identity theft, discrimination). Perceived benefits of sharing EMR data were altruistic, with the two genetic groups also seeking benefit for their children.

**Discussion:** Overall the genetic groups believed EMR research would offer more benefits than risks. Ensuring that parents have sufficient information to make an informed decision about their children’s participation was critical to all groups’ preferences.