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Title: Qualitative Exploration of Diverse Participant Recruitment in NBSeq Research: Lessons from the BabySeq Project

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Abstract:

Newborn genomic sequencing (NBSeq) has the potential to identify predispositions to disease before symptoms develop. To ensure future applications of NBSeq are equitably implemented, it is critical that studies of NBSeq include individuals from under-represented racial and ethnic groups (URG). Rates of participation in research are lower among URG communities compared to other groups, in part attributable to a history of institutionalized racism and abuse. We conducted semi-structured interviews with 49 parents from URG communities to better understand their perspectives toward NBSeq research, develop strategies to reduce barriers to enrollment, and facilitate participation among those who may be interested.

The majority of parents (n=44) said they would be interested in participating in an NBSeq study and most (n=35) would want to receive all types of genetic results. The most frequently cited motivations for enrolling were the potential for study results to provide clinical utility, personal utility, or family health benefits. Major deterrents that parents mentioned (for themselves or for others) were challenges with enrollment procedures and parents' bandwidth to participate, potential for unfavorable perceptions of the study (e.g., distrust, misconceptions), and concerns about results they could receive. Parents also suggested specific strategies, including having a known clinician introduce the study and providing resources for follow-up after results are disclosed. Our findings demonstrate that parents from URG communities are interested in

participating in NBSeq research and provide insights that can be used to design studies that are responsive to concerns among URG communities.