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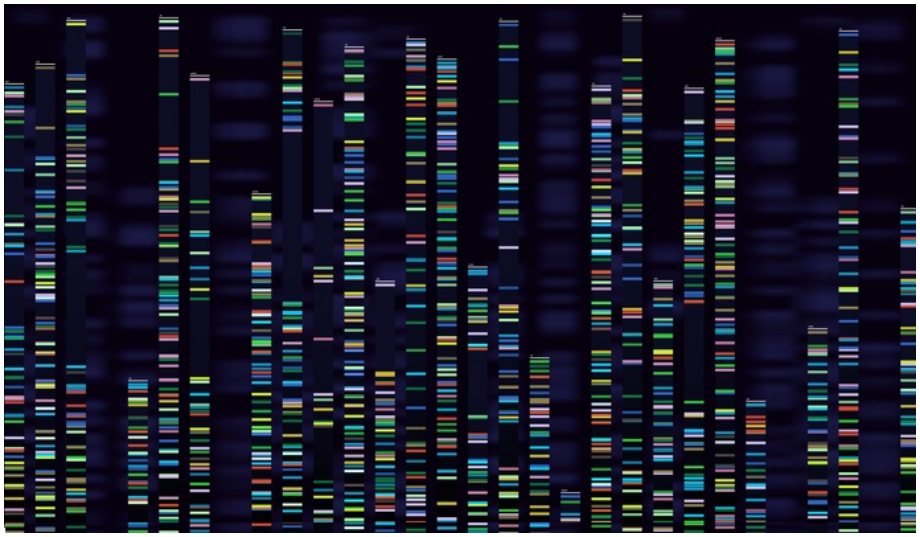
Determining Family Impact of Genome Sequencing on Newborns

Researchers examined how conducting genome sequencing on newborns can impact family dynamics.



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By Erin McNemar, MPA (mailto:emcnemar@xtelligentmedia.com)

August 26, 2021 - Genome sequencing can reveal an individual's risk for specific health conditions throughout their life. While some advocate for testing on all newborns to address disease risks early in life, others have concerns regarding the distress information can put on families.

As part of the BabySeq Project, researchers from Baylor College of Medicine, Harvard Medical School, Brigham and Women's Hospital, and Boston Children's Hospital studied the potential psychosocial impacts of integrating **genome sequencing (https://healthitanalytics.com/news/genomic-sequencing-creates-precision-medicine-for-cancer-patients)** into clinical care for newborns. The results indicated no negative impact on families during the infant's first year of life due to genome sequencing.

"This study is unique in that it looks, in part, at genetic risk for seemingly healthy babies," Corresponding author Dr. Amy McGuire said in a **press release (https://www.eurekalert.org/news-releases/926192)**.

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"Some are concerned that parents who know that their seemingly healthy child is at risk for disease later in childhood or adulthood will experience more anxiety or alter how they relate to their child. The lack of distress on the family unit is an encouraging sign as we continue to explore the potential risks and benefits, as well as ethical and equity questions related to preventive sequencing of apparently healthy people."

The BabySeq Project is a randomized clinical trial designed to examine best practices for genomics in clinical newborn medicine. The study enrolled 325 infants and families from well-baby nurseries and newborn intensive care units at academic hospitals in Boston.

Half of the newborns were assigned to a control arm and received the standard newborn screening and family history report. The other half received the same screening and report as well as whole-exome sequencing with comprehensive interpretation and return of almost 1,000 genes.

The sequencing scanned for variants related to genetic risk for childhood-onset conditions and some highly actionable adult-onset conditions. Additionally, parental **DNA (https://healthitanalytics.com/news/how-dna-testing-will-accelerate-precision-medicine-preventive-care)** was sequenced to determine if the variants were inherited.

The study examined the psychosocial effects of the testing by observing the impact on the parent-child relationship, parent psychological distress, and the parents' relationship with each other. The parents then completed surveys measuring those domains for around a year and a half after the birth.

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While there were minor differences between the study and control arm, the results did not indicate any impact on the family over time. Researchers also indicated lower self- and partner-blame in the study arm compared to the control, potentially due to sequencing information providing some peace of mind.

"Prior studies suggest that adults don't usually experience negative psychological impact when given genomic information about themselves; but how this impacts parents and the family unit when the information is about their newborns hadn't been previously explored," co-first author of the study Dr. Stacey Pereira said.

"We are proud that our work helps provide a more complete understanding of the impact of newborn genome sequencing."

The researchers noted that the study consisted of volunteers mostly of European descent and from affluent, educated families. The BabySeq Project team is looking to expand their study to include a larger and more **diverse population (https://healthitanalytics.com/news/studying-diverse-populations-will-strengthen-precision-medicine)**. The researchers also want to continue following the families over a longer period to capture long-term impacts.

"We are collecting the first robust data on incorporating genome sequencing into routine newborn care," study author Dr. Robert C. Green said.

"We have now shown that this information can be medically beneficial through early intervention and is not disruptive to the parent-infant relationship, and our ongoing analysis is measuring economic effects of genome sequencing. This type of research is critical to determine best practices for preventive genomic healthcare throughout the lifespan."

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