

Genome sequencing for newborns: What do new parents think?

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A study published this week in *Genetics in Medicine* is the first to explore new parents' attitudes toward newborn genomic testing. The findings suggest that if newborn genomic testing becomes available, there would be robust interest among new parents, regardless of their demographic background.

The study, led by researchers at Brigham and Women's Hospital (BWH) and Boston Children's Hospital, found that the majority of parents surveyed were interested in newborn [genomic testing](#).

As next-generation whole-exome and genome sequencing is integrated into [clinical practice](#), researchers and clinicians are increasingly interested in genomic testing as a way to provide valuable personalized health information for newborns beyond what existing standard newborn genetic screening produces. But such testing, done shortly after birth, will require the interest and consent of new parents.

"Several other studies have measured parents' interest in newborn genomic screening, but none focused on new parents in the first 48 hours," said Robert C. Green, MD, MPH, a geneticist and researcher at BWH and Harvard Medical School and senior author of the study.

"Since this is when genomic testing would be of the greatest value, it is especially important to study parents' attitudes immediately post-partum."

The researchers surveyed 514 parents at the well baby nursery at BWH

within 48 hours of their child's birth. After receiving a brief orientation to the genome and its impacts on human health, 82.7 percent of parents reported being somewhat (36 percent), very, (28 percent) or extremely (18 percent) interested in newborn genomic testing. Results were similar regardless of parents' age, gender, race, ethnicity, level of education, family history of genetic disease, or whether or not the infant was a first-born child. Parents who had experienced concerns about the health of their newborn, however, were less likely to be interested in genomic testing.

The study was also the first to investigate whether asking parents about their interest in newborn genomic testing would cause them to reject existing, state-mandated newborn genetic screening (NBS), one of the most established and successful public health programs in the world.

"If even one parent had rejected it, that would have been a problem," said Susan Waisbren, PhD, lead author of the study and a psychologist and researcher in the Division of Genetics and Genomics at Boston Children's and Harvard Medical School. "But out of over 500 parents surveyed, not one of them questioned or rejected NBS."

The study was also the first to survey parents separately. Most couples were in agreement about their level of interest in newborn genomic testing.

"About 75 percent of couples were in concordance," Waisbren said. "This suggests that both [parents](#) should be involved when we are addressing concerns they may have about newborn genomic testing."

"Parents' strong interest in genomic screening for their newborns, as demonstrated by this study, underscores the importance of further research exploring the public health impacts of actually providing this testing," said Green, "particularly as it continues to become less

expensive and more widely available."

Provided by Brigham and Women's Hospital

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