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# beta Boston

#### HEALTH

## Would you sequence the genome of your newborn? A majority of Mass. parents say yes

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#### TOPICS

Health, Health IT, Boston Childrens Hospital, Genetics, Brigham and Women's Hospital, Harvard Medical School, genome sequencing

Would you be willing to sequence the genome of your newborn baby, Gattaca-style, mere hours after bringing it into the world?

A little over 500 new parents were asked this question in the maternity ward at Brigham and Women's Hospital last year, and a majority said yes.

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"I would say that there's substantial interest. I think the numbers speak for themselves," said Robert Green, a physician and researcher at Brigham and Women's Hospital and Harvard Medical School, a principal investigator on this survey.

Nearly 83 percent of parents expressed some level of interest in this analysis, Green and his co-authors report in a study in Genetics and Medicine published Thursday. About a fifth of the group said they would be "extremely interested" in getting this information about their baby.

The new study is part of a larger investigation into the viability of offering whole genome sequencing to new parents. Green is co-leading the \$6 million five-year project, which has been dubbed BabySeq.

Hours after a baby is born in the United States today, a hospital staffer will prick its heel and collect a small sample of blood on a card. That is then sent away for biochemical analysis to check for certain rare diseases.

A whole genome analysis could plumb a vastly richer dataset — more than 10,000 human diseases are expected to be caused by single gene defects — and offer doctors and new parents a chance to prepare for diseases before they emerge.

But there's also a potential downside: That same information could be disadvantageous to the child, serving as a point of discrimination, for example. "There are a lot of questions

about how much information would you give to a parent under what circumstances: Would it be used? Would it be understood?" Green said.

BabySeq is a collaboration between Brigham and Women's and Boston Children's Hospital, and will examine the outcomes of offering whole genome sequencing to sick and healthy babies. It's the first of its kind assessment of potential benefits and downsides.

The survey of new parents was one of their first steps toward determining the viability of the concept. Getting into the hospital right after the babies were born was key, Green said. "You can do this at a cocktail party," he said, but "it has a bit more validity if you did it in a newborn unit."

Image via Carly Lesser & Art Drauglis on Flickr

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