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# Most new parents might welcome having baby's genome sequenced

By MELISSA HEALY DEC 05, 2014 | 5:30 AM

Just how much do you want to know about the health prospects of your new bundle of joy -- and how soon? A new study looks at parents' interest in having genome analysis of a newborn child performed and found enthusiasm to be broad. (Javier Aguilar)

Parents welcoming a new baby into their family are no longer content to count fingers and toes to assess their infant's state of health: In a survey released Thursday, nearly half said they would be "very" or "extremely" interested in having their newborn's genome sequenced, and fully a third more pronounced themselves "somewhat" interested.

Within 48 hours of a child's birth at Boston's Brigham and Women's Hospital, researchers gave 514 parents a brief orientation on the genome and its relevance for human health. They then asked how interested a parent would be in having his or her newborn's genome scanned and analyzed.

Interest was spread roughly evenly among parents

regardless of their age, gender, race, ethnicity, level of education or family history of genetic disease. Whether a child was the firstborn in a family did not seem to influence a parent's propensity toward genetic sequencing.

But married parents and parents who had experienced health concerns about their baby were slightly less inclined to express interest in genomic sequencing for the child.

Where there were two parents available, they were surveyed separately about their interest. In 3 out of 4 such unions, parents were in agreement on their interest in genomic sequencing.

The study, published Thursday in the journal Genetics in Medicine, is the first to explore the attitudes of newborns' parents toward comprehensive genome testing. If it were a market-research tool, however, the study's findings would be good news for an initiative expected to be launched soon in Boston.

Lead author Dr. Robert C. Green, a geneticist at Brigham and Women's Hospital, and Alan Beggs of Boston Children's Hospital co-direct the BabySeq Project, which in 2015 is expected to offer several hundred parents of both sick and healthy newborns the opportunity to have their child's genome sequenced.

As genomic analysis has become cheaper, faster

and increasingly revealing in terms of disease risk, the question of how routinely such scans should be conducted -- and who should have access to the results -- has been widely debated.

In March 2013, the American College of Medical Genetics and Genomics issued guidelines recommending that labs performing genome analysis for a specific health purpose search for a welter of readily-discernible genetic variations related to serious health problems, and report any such findings to the physician who ordered the test. Whether or not the patient wants or has asked for the unsought genomic findings, the group argued that physicians should pass any significant findings on to patients.

For children, however, genomic sequencing and all of its potential findings pose a dilemma. Younger minors are rarely thought capable of giving informed consent to receiving health information that may or may not turn out to be important.

Notwithstanding such ethical qualms, the American College of Medical Genetics and Genomics said that worrisome genetic findings should also be reported when they are found in children. However, in conducting routine genetic testing on newborns (who in most states are routinely screened for about 30 genetic disorders), the group did not call on genetics labs to look beyond those tests for other genetic clues to health.

Green said genomic sequencing could be of greatest value in the care and treatment of a baby

if performed in the child's earliest infancy.

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Melissa Healy CONTACT

Melissa Healy is a health and science reporter with the Los Angeles Times writing from the Washington, D.C., area. She covers prescription drugs, obesity, nutrition and exercise, and neuroscience, mental health and human behavior. She's been at The Times for more than 30 years, and has covered national security, environment, domestic social policy, Congress and the White House. As a baby boomer, she keenly follows trends in midlife weight gain, memory loss and the health benefits of red wine.