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Prenatal whole genome sequencing: Just because we can, should we?

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With whole genome sequencing quickly becoming more affordable and accessible, we need to pay more attention to the massive amount of information it will deliver to parents – and the fact that we don't yet understand what most of it means, concludes an article in the Hastings Center Report. The authors are current or former scholars at the National Institutes of Health's Department of Bioethics.

Most analyses of the ethical issues raised by whole genome sequencing have been "futuristic forecasting," but the authors conclude that "this is problematic given the speed with which whole genome sequencing is likely to be incorporated into clinical care," as its price falls to under $1,000.

Prenatal whole genome sequencing differs from current prenatal genetic testing practice in ethically relevant ways. Most notably, whole genome sequencing would radically increase the volume and scope of available prenatal genetic data. In contrast with current tests, which identify serious genetic conditions in fetuses at high risk of them, the new tests would likely be used by many more expectant parents and reveal a wide spectrum of genetic traits, including disease susceptibility.

Some of the ethical challenges posed by prenatal whole genome sequencing arise from the uncertainty of what the information means. The function of more than 90 percent of genes in the human genome is unknown and as a result, the article says, "much of the data generated from whole genome sequencing over the next few years (or even

decades) will be of questionable utility."

After analyzing the kind of information that whole genome prenatal testing will yield, the authors conclude that most of it would probably not be as helpful as information uncovered by the current categories of prenatal tests. They cited specific areas of concern.

First of all, the quality and quantity of information may augment parents' anxiety. "To the extent that parents now think of their child as a 'clean slate' during pregnancy, the prenatal image of a normal, healthy baby will be dramatically altered by this technology," the authors write. The anxiety over the results and changing views of what is "normal" could lead to an increase in pregnancy terminations.

Apart from reproductive decisions, the authors also foresee whole genome prenatal testing having a negative impact on child rearing. For example, if parents were able to get genetic information suggesting that their child's predicted IQ may be low, they might not strongly encourage and support the child's efforts in school.

Finally, the new technology could increase the tension between the interests of parents and children. Although parents have a strong interest in getting information that informs their reproductive choices, children have a competing interest in not knowing certain kinds of information about themselves – information that could limit their autonomy as they grow into adulthood.

Given the potential harms from prenatal whole genome sequencing, the authors make four preliminary recommendations.

- Since only some of the information will be relevant to most parents' reproductive decision-making, the medical community

should make clear recommendations about which categories of information should be routinely offered to parents.

- A child's right "not to know" his or her genetic information should not be breached unless the information is clearly useful for the parents or can improve health outcomes in the child. "We recommend that the relevant societies revise their prenatal testing guidelines to ensure that their recommendations are sufficient and appropriate for the next generation of sequencing technologies."
- More data are needed to guide the deliberation of professional societies and the public.
- Professional societies should play an active role in educating clinicians on how whole genome sequencing differs from traditional prenatal genetic tests, and on how to educate parents about the tradeoffs involved in choosing to engage in it.

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