

Study reveals mixed public opinion on polygenic embryo screening for IVF

May 14 2024



Credit: Pixabay/CC0 Public Domain

Three out of four U.S. adults support the use of emerging technologies that estimate a future child's likelihood of developing health conditions influenced by multiple genes—such as diabetes, heart disease, and depression—before an embryo is implanted during in vitro fertilization (IVF), according to a new public opinion survey led by researchers at Harvard Medical School.



Results of the survey, published May 14 in *JAMA Network Open*, underscore the need for public education and conversation about the positive and negative implications of these ethically fraught technologies, the researchers said.

Although the approach, known as polygenic embryo screening, is not yet available in most IVF clinics, a few companies have begun offering such estimates—or risk scores—to gauge disease risk, the researchers noted.

"Polygenic embryo screening is largely unregulated in the United States, and without proper context and focused patient education, risk scores can create false expectations," said first author Rémy Furrer, research fellow in bioethics in the Department of Global Health and Social Medicine in the Blavatnik Institute at HMS.

"This survey rings the alarm that geneticists, behavioral scientists, bioethicists, clinicians, and genetic counselors need to work together to figure out ways to communicate the limitations to people, so they understand what polygenic risk scores do and don't provide," he said.

Nearly three-quarters of respondents said they support using such screening to assess the risk of a future child developing a physical or <u>psychiatric condition</u>, such as <u>heart disease</u>, diabetes, or depression—but that number dropped when people were first presented with various concerns for individuals and society.

Far fewer respondents approved the use of the technology to predict traits unrelated to disease, such as intelligence, height, and skin color.

The results suggest that educating people better about the current shortfalls and implications—including regulating the promises that companies can make—will temper optimism and help ensure that as these technologies develop, they will be implemented in scientifically



sound, ethical, and equitable ways, the authors said.

How accurate are polygenic risk scores?

Up until now, patients undergoing IVF could choose which embryos to implant based on DNA tests that detect chromosomal abnormalities, such as Down syndrome, and diseases caused by mutations in a single gene, such as cystic fibrosis. Such screening, known as preimplantation genetic testing, is well-established and widely used.

By contrast, polygenic embryo screening estimates probabilities for conditions and traits influenced by many gene variants that each raise or lower risk by a small amount.

Experts disagree on how useful this technology might become in the future, but at present there are clear limitations to accuracy, Furrer said. Polygenic conditions arise from different combinations of genes, environment, and behaviors in ways that aren't yet fully understood. The American College of Medical Genetics and Genomics has said that polygenic embryo screening is not yet suitable for clinical use.

This gap between the state of the science and the growing availability of such tests compelled Furrer and colleagues to conduct the survey. They hope the results inspire professionals to advocate for more informed dialogue and guidance around these technologies.

"The complexities and limitations of polygenic risk scores are challenging to convey," Furrer said. "But we need to do so to ensure that people understand the high level of uncertainty that comes with estimating these risks."

By the numbers



The survey drew from the team's <u>interviews with IVF patients and</u> <u>reproductive health specialists</u>. Questions included lists of conditions, traits, and potential repercussions that participants were asked to weigh in on. The survey also made clear that polygenic risk scores could be used simply for information, to prepare for a future child, or to select an embryo for implantation.

The first part of the study surveyed more than 1,400 participants representing the wider U.S. population in age, gender, and race/ethnicity. It was conducted between March and July 2023.

Findings showed that:

- 72 percent of respondents approved of using polygenic embryo screening in general.
- 17 percent were ambivalent and 11 percent disapproved.
- 77 percent approved of selecting embryos based on risk of certain physical health conditions.
- 72 percent approved of selecting embryos based on risk of certain psychiatric health conditions.
- 36 percent approved of selecting embryos based on likelihood of certain behavioral traits.
- 30 percent approved of selecting embryos based on likelihood of certain physical traits.
- 92 percent expressed at least slight concern about polygenic embryo screening leading to false expectations about the future child.
- About half were "very" or "extremely" concerned about negative outcomes for individuals or society.
- 82 percent said they would be at least slightly interested in using polygenic embryo screening if they were already undergoing IVF.
- 30 percent said they would consider undergoing IVF to gain



access to polygenic embryo screening.

Approval was higher for using risk scores to prepare for a child than to select an embryo.

Positives and negatives

The second part of the study, conducted from March 2023 to February 2024 with about 200 respondents, placed the list of potential concerns at either the beginning or the end of the survey.

The concerns were:

- Parents having false expectations about the future child.
- Promoting eugenic thinking or practices—unethical efforts to select on a wide scale for traits considered desirable.
- Stigmatizing certain traits and conditions viewed as less desirable.
- Treating embryos like a product by selecting them based on preferred genetic chances for conditions or traits.
- Risk scores not being equally relevant for all ethnicities because of the Euro-centric nature of many genetic databases.
- Unequal access to the technology due to high cost.
- Low accuracy of genetic estimates for conditions or traits.
- Reduced diversity of human population.
- Possibility of nurtured genetics—parents consciously or unconsciously shaping their children's environments based on the genetic estimates.
- Confusion over how to interpret and use test results.
- Guilt over decisions if the child develops a particular condition or trait.
- Discarding of embryos.
- Feeling pressured to use the technology.



In the second survey, respondents given the list at the start reported lower overall approval (28 percentage points less) and more uncertainty (24 percentage points higher) about polygenic embryo screening than those who saw the list at the end—a finding that speaks to the importance of education and framing the public conversation.

How to find the right balance

Some of the <u>survey results</u> are nuanced, the authors note, and should not be taken as unqualified public support or rejection of polygenic embryo screening.

"These findings offer an initial glimpse into public opinion, predicated on a limited presentation of the technology," said Furrer. "Future research must explore how opinions evolve."

For instance, the team recommends further research into what it means that a majority of respondents approved of polygenic screening for selecting embryos but also expressed strong concerns about sliding into eugenics.

It will also be important to examine the role that personal and group values, such as reproductive freedom and autonomy, play in shaping public attitudes, the authors said.

The authors conclude that the work underscores the need to inform not only the public and IVF patients but also clinicians and genetic counselors, who need to be prepared to answer the rising tide of questions about the potential benefits, present limitations, and concerns surrounding polygenic embryo screening.



More information: Public Attitudes, Interests, and Concerns Regarding Polygenic Embryo Screening, *JAMA Network Open* (2024). DOI: 10.1001/jamanetworkopen.2024.10832

Provided by Harvard Medical School

Citation: Study reveals mixed public opinion on polygenic embryo screening for IVF (2024, May 14) retrieved 4 June 2024 from https://medicalxpress.com/news/2024-05-reveals-opinion-polygenic-embryo-screening.html

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.