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US science advisers outline path to genetically modified babies

Modified human embryos should be allowed if researchers meet strict criteria, says long-awaited National Academies report.

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Scientists should be permitted to modify human embryos destined for implantation in the womb to eliminate devastating genetic diseases such as sickle-cell anaemia or cystic fibrosis — once gene-editing techniques advance sufficiently for use in people and proper restrictions are in place. That's the conclusion of a 14 February report from the US National Academies of Science, Engineering, and Medicine.

The 261-page document follows a 2015 National Academies summit that brought together scientists, ethicists, legal experts and patient groups from around the world. Meeting organizers wanted to survey concerns about human germline editing: genetic modifications to embryos, sperm or egg cells that can be passed on to offspring.

Given the raft of scientific, ethical and legal questions surrounding the issue, the organizers concluded at the time that scientists shouldn't yet perform germline editing on embryos intended for establishing a pregnancy. But they decided that altering human embryos in the lab for the sake of basic research was acceptable.

The latest report builds on the earlier consensus and outlines strict limits under which scientists could proceed in the future. It recommends restricting the technique to severe medical conditions for which no other treatment exists. It also calls for international cooperation, strict regulatory and oversight framework, public input into decisions and long-term follow-ups of children who have edited genomes. The report adds that for now, genome editing should not be used for human enhancement, such as improving a person's intelligence or giving them super-strength.

Managing the inevitable

Scientific advances are making genetically modified babies more of a possibility, says Alta Charo, a bioethicist at the University of Wisconsin–Madison and co-chair of the report. Over the past year, she says, researchers have made progress in understanding and preventing the ways in which genome-editing techniques such as CRISPR cause unintended mutations — a necessary step before using such methods in human embryos.

"Up until now, we've been talking only hypothetically and most people assumed we simply wouldn't ever do this," Charo says. "We are not saying that you have to or you should, but we are saying that if you can meet these criteria it is permissible."

In part, the National Academies' recommendations are trying to pre-empt the inevitable. "We are very much aware that medical tourism is a fact of global life now," Charo says. Once human genome editing has proved to be effective, clinicians working in countries with few regulations and potentially unsafe conditions may begin modifying embryos and implanting them in patients. "We certainly don't want to see the same thing" in the United States, Charo says, "and a prohibition might exacerbate the problem."

The green light

For those who oppose any human germline editing, the NASEM report is a step back. "It's disappointing that the National Academies would take such a duplicitous position," says David Prentice, vice-president and research director of the anti-abortion, non-profit Charlotte Lozier Institute in Washington DC. "If there are ethical reasons not to allow most germline editing, those same reasons apply to any germline editing."

George Church, a geneticist at Harvard University in Cambridge, Massachusetts, agrees that it may be difficult to draw the line between medical use and enhancement. For instance, researchers have shown that a gene called *GRIN2B* is one of many linked to autism spectrum disorder[1]. But mutations that increase the amount of GRIN2B protein produced in the body have also been connected to higher cognitive abilities[2]. Modifying the gene to prevent autism could end up enhancing recipients compared to the general population, Church says.

But the geneticist thinks the recommendations are sensible. And he says that they follow the normal path for drug approval, in which a therapy is tested and perfected in compelling medical cases before being used for non-medical reasons.

Church is glad that the academies and numerous other organizations are tackling the issue now. “The time to get everybody worked up about it is right now, before safety and efficacy are even proven,” he says. “As soon as they’re proven, it’s very hard to deny it to people.”

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Updates

Updated: This story has been updated with comments from David Prentice of the Charlotte Lozier Institute in Washington DC.

References

1. Pan, Y. *et al*. *Sci. Rep.* **5**, 8296 (2015).
2. Mascheretti, S. *et al*. *Psychiat. Genet.* **25**, 9–20 (2015).

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Science fiction has in many ways preempted science fact in terms of the implications of a genetic engineering. In that regard I would recommend that Nature readers take a look at T. Coraghessan Boyle's fictional account of genetic alteration's CRISPR driven future which appeared in The New Yorker last year. What I particularly liked about it, is that it wasn't about an intrinsic good or an intrinsic evil, but rather about the reality that all genetic choices will have consequences. See http://www.newyorker.com/magazine/2016/11/07/are-we-not-men