

Brave new world? Why the public might be ready for gene-edited babies

Should we be able to genetically design our children before they are born — giving them the eye and hair color we prefer, deciding their sex and height, and even genetically manipulating their intelligence? Most, including top [scientists and genetic counselors](#), say *no*. But what if the genetic manipulation was done in order to cure a debilitating or potentially fatal illness before the individual was even born? And what if this *one* genetic treatment could save the individual's descendants from inheriting the disorder, too? A 2018 meeting of non-scientists in Germany indicated that public opinion may be moving in the yes direction.

Though gene editing technology isn't yet at the point where we can genetically alter unborn individuals at the clinical level — by applying gene editing tools like [CRISPR/Cas9](#) to embryos, sperm or egg cells — the technology is rapidly advancing.

Debate over the subject was rekindled last year, when a Chinese researcher [announced](#) that he used [CRISPR](#) to create the world's first gene-edited babies. According to the Associated Press, He Jiankui said he altered embryos for seven couples during fertility treatments. The treatment was designed to protect the children of an HIV-positive parent by disabling a gene that would have allowed the virus to enter their cells. The trial resulted in one pregnancy – twins who were born in November. According to the Associated Press, the researcher said:

I feel a strong responsibility that it's not just to make a first, but also make it an example. Society will decide what to do next.

The gene-editing community has grappled with the unexpected announcement in the following months. It was not well received by other researchers, with many of them condemning the action. Feng Zhang, one of the inventors of [CRISPR](#), [called for](#) an moratorium on gene-edited babies. Zhang wrote:

Not only do I see this as risky, but I am also deeply concerned about the lack of transparency surrounding this trial. All medical advances, gene editing or otherwise and particularly those that impact vulnerable populations, should be cautiously and thoughtfully tested, discussed openly with patients, physicians, scientists, and other community members, and implemented in an equitable way.

It's not unusual to see articles and reports in the media focusing on the worst possible scenarios when it comes to genome editing, as is often the case with new or particularly disruptive technologies. The mere mention of the topic tends to incite fears of a "[New Eugenics](#)" master race or exacerbation of medical inequalities along class lines — where the poor are barred from genetic interventions and the rich have easy access. Still others, such as some Catholic and [Muslim groups](#), worry that [genetic manipulation](#) of any sort is interfering with divine plans.



Image credit: Karlsruhe Institute of Technology

These kinds of fears have been gradually loosening their hold on our imaginations, while the coolly-measured possibilities of gene editing — nothing more than a new and innovative medical tool — are winning over. And as with any new technology, it comes with a particular set of risks and benefits that must be taken into consideration. The slow change in public attitude toward gene editing is evident in groups such as Germany's Citizens' [Delphi Germline Therapy](#) project at Karlsruhe Institute of Technology (KIT).

After debating detailed information on the risks and benefits over the course of a few months, and undergoing a rigorous participation process that combined aspects of Citizens' Jury with the Delphi survey method, the group has called for the loosening of bans on germline gene editing research in Germany. Their final report was presented at [Berlin Science Week](#) in late 2018. And though their verdict only applies to the current ban in Germany, which includes a ban on basic research in germline cells, the group's decision could have an impact on regulations around the world. Indeed, the participants were keen on having Germany play a more active role in the development of international gene editing guidelines.

Regarding the [Citizens' Jury](#) and [Delphi survey](#) methods used, Ralf Grötter, who developed and carried out the project in collaboration with the Department of Science Communication at the Institute for German Studies at KIT, stated, "The process is geared towards working on a complex topic with a group of laypeople, empower them to make an informed judgment, and eventually reach [recommendations for politicians](#)." Though the group only consisted of 26 German citizens, the group was representative of the population, and the topic of gene editing was thoroughly investigated from a variety of angles.

The group acknowledged the risks of genome editing, such as unknown and off-target effects, but ultimately agreed that the way forward was to open the doors to germline gene editing research at the national and global levels. Their conclusions also echoed those made by genetics experts in a position

statement published in the August 2017 issue of the [American Journal of Human Genetics](#), which stated, “At this time, given the nature and number of unanswered scientific, ethical, and policy questions, it is inappropriate to perform germline gene editing that culminates in human pregnancy.”

But to answer those scientific, ethical, and policy questions, basic research is crucial. And lines of communication need to be open between countries, and between scientists and non-scientists. Without these measures, misunderstandings and missed clinical opportunities will proliferate, along with the dangers of [underground gene editing](#) and [gene editing tourism](#). Several governments around the world are grappling with heated and unresolved debates regarding germline gene editing, which in several cases appear to be [impeding research](#).

Follow the latest news and policy debates on sustainable agriculture, biomedicine, and other ‘disruptive’ innovations. Subscribe to our newsletter.

[SIGN UP](#)

Though a great deal of cooperation and knowledge exchange is taking place between countries, other nations have yet to move away from all-out bans on germline gene editing. Canada, for example, has criminalized germline gene editing under the 2004 Assisted Human Reproduction Act. Penalties for the “crime” of germline gene tampering include a \$500,000 CAD fine and up to [10 years of jail time](#).

Following a presentation at the annual Till & McCulloch Meetings of stem-cell and regenerative-medicine researchers, Bartha Knoppers, a health policy expert at McGill University in Montreal, said, Canada’s “policy has simply shut down discussion (about [gene editing](#)). We need to start to talk.” Some Canadian scientists worry that Canada is lagging behind in gene editing research, unable to fully participate in the global conversation taking place on this important subject.

At the other end of the spectrum are countries like Japan, where a proposal allowing for the use of [gene editing tools](#) in human embryos has been drafted. The new guidelines would restrict manipulation of human embryos for reproduction, though this restriction would likely not be legally binding.

Though several countries have formal bans in place restricting germline gene editing, many of these same countries allow for somatic (or non-reproductive) gene editing applications, which is when gene editing tools are applied to adult cells. Somatic gene edits are not passed on to future generations, so there is less concern about the possible repercussions.

A version of this article previously ran on the GLP on Nov 27, 2018.

Kristen Hovet covers genetics, medical innovations, and the intersection of sociology and culture. Follow her on her [website](#) or Twitter [@kristenhovet](#)