

# Genome-edited baby claim provokes international outcry

*The startling announcement by a Chinese scientist represents a controversial leap in the use of genome-editing.*

David Cyranoski



A Chinese scientist claims that twin girls have been born whose genomes' were edited as embryos. Credit: Pascal Goetgheluck/ Science Photo Library

A Chinese scientist claims that he has helped make the world's first genome-edited babies — twin girls who were born this month. The announcement has provoked shock, and some outrage, among scientists around the world.

He Jiankui, a genome-editing researcher from the Southern University of Science and Technology of China in Shenzhen, says that he implanted into a woman an embryo that had been edited to disable the genetic pathway that allows a cell to be infected with HIV.

In a [video posted to YouTube](https://www.youtube.com/watch?v=th0vnOmFltc), <https://www.youtube.com/watch?v=th0vnOmFltc> He says the girls are healthy and now at home with their parents. Genome sequencing of their DNA has shown that the editing worked, and only altered the gene they targeted, he says.



### **Should you edit your children's genes?**

The scientist's claims have not been verified through independent genome testing or published in a peer-reviewed journal. But, if true, the birth would represent a significant — and controversial — leap in the use of genome-editing. So far these tools have only been used in embryos for research, often to investigate the benefit of using them to eliminate disease-causing mutations from the human germline. But reports of off-target effects in some studies have raised significant safety concerns.

### **HIV's entry point**

[Documents posted](#) on China's clinical trial registry show that He used the ubiquitous CRISPR-Cas9 genome-editing tool to disable a gene called CCR5, which forms a protein that allows HIV to enter a cell.

Genome-editing scientist Fyodor Urnov was asked to review documents that described DNA sequence analysis of human embryos and fetuses gene-edited at the CCR5 locus for an article in [MIT Technology Review](#). "The data I reviewed are consistent with the fact that the editing has, in fact, taken place," says Urnov, from the Altius Institute for Biomedical Sciences in Seattle. But he says the only way to tell if the children's genomes have been edited is to independently test their DNA.

Urnov takes issue with the decision to edit embryos in order to prevent HIV infection. He is also using genome-editing tools to target the CCR5 gene, but his studies are in adult cells, not embryos. He says there are "safe and effective ways" to use genetics to protect people from HIV that do not involve embryo editing. "There is, at present, no unmet medical need that embryo editing addresses," he says.



### **Don't edit the human germ line**

"Today's report of genome editing human embryos for resistance to HIV is premature, dangerous and irresponsible," says Joyce Harper, who studies women's and reproductive health at the University College London. Years of research is needed to show that meddling with the genome of an embryo is not going to cause harm, she says. Legislation and public discussion are also needed before genome editing should be used in embryos destined for implantation.

"This experiment exposes healthy normal children to risks of gene editing for no real necessary benefit," says Julian Savulescu, the director the Oxford Uehiro Centre for Practical Ethics at the University of Oxford.

### **University 'unaware'**

Southern University of Science and Technology said in a [statement on 26 November](#) that it was unaware of He's experiments, that they were not performed at the university and that He has been on leave since February.

"The Southern University of Science and Technology requires scientific research to abide by national laws and regulations and to respect and comply with international academic ethics and academic standards," the statement. The university says it will establish an independent committee to investigate the matter.

More than 100 Chinese biomedical researchers have [posted a strongly-worded statement online](#) condemning He's claims. "Directly jumping into human experiments can only be described as crazy," the statement reads. The scientists call on Chinese authorities to investigate the case and introduce strict regulations on this procedure.

"This is a huge blow to the international reputation and the development of Chinese science, especially in the field of biomedical research," the statement says. "It is extremely unfair to the large majority of diligent and conscientious scientists in China who are pursuing research and innovation while strictly adhering to ethical limits."

*Nature* is in the process of contacting He for a response to the concerns about his experiments. Making gene-edited babies goes against guidelines released by China's health ministry in 2003 but does not break any laws.

In the YouTube video, He says that the couple underwent in vitro fertilization (IVF), a procedure where a woman's egg is fertilized by a man's sperm outside the body to form an embryo. When the embryo was just a single cell, He says his team inserted an editing protein that disabled CCR5 before the embryo was implanted into the mother.

## Inevitable advance?

The news of the first genome-edited babies comes as researchers in the field gather for a major international meeting on genome editing in Hong Kong from 27-29 November. A key goal of the summit is to reach an international consensus on how genome editing to modify eggs, sperm or embryos, known as germline editing, should proceed. Many scientists in the field believed that it was inevitable that someone would use genome-editing tools to make changes to human embryos that would be implanted into a woman, and had been pushing for the creation of ethical guidelines before the first report emerged.

He only supports the use of genome-editing in embryos in cases that related to disease, and says that genetic tweaks to enhance intelligence or to select for traits such as hair and eye colour should be banned. "I understand my work will be controversial, but I believe families need this technology and I am willing to take the criticism for them," he says.

Bioethicist Tetsuya Ishii from Hokkaido University also does not think the application of genome editing in embryos to reduce HIV infection is justified. He says babies of HIV positive mother's can be delivered by caesarean section to avoid transmitting the infection during childbirth.

In the case of the twins, the father is HIV-positive but the mother was not, says He in the YouTube video, meaning there was a very small risk of transmission through the parents. But, [in an interview with the Associated Press](#), He said the goal of the work was not to prevent transmission from the parents, but to offer couples affected by HIV a chance to have a child that might be protected from a similar fate.

Recent surveys suggest that the public supports genome editing in embryos if it fixes disease-causing mutations. In July, the Nuffield Council on Bioethics, a London-based independent advisory committee, published a survey of 319 people. Nearly 70% of those supported gene-editing if it allows infertile couples to have children, or if it allows a couple to alter a disease-causing mutation in an embryo. A larger survey of 4,196 Chinese citizens released last month reported a similar level of support for modifying genes if the goal is to avoid a disease. But respondents opposed using it to enhance IQ, athletic ability or change skin colour.

## Chinese scientist's claim of gene-edited babies creates uproar

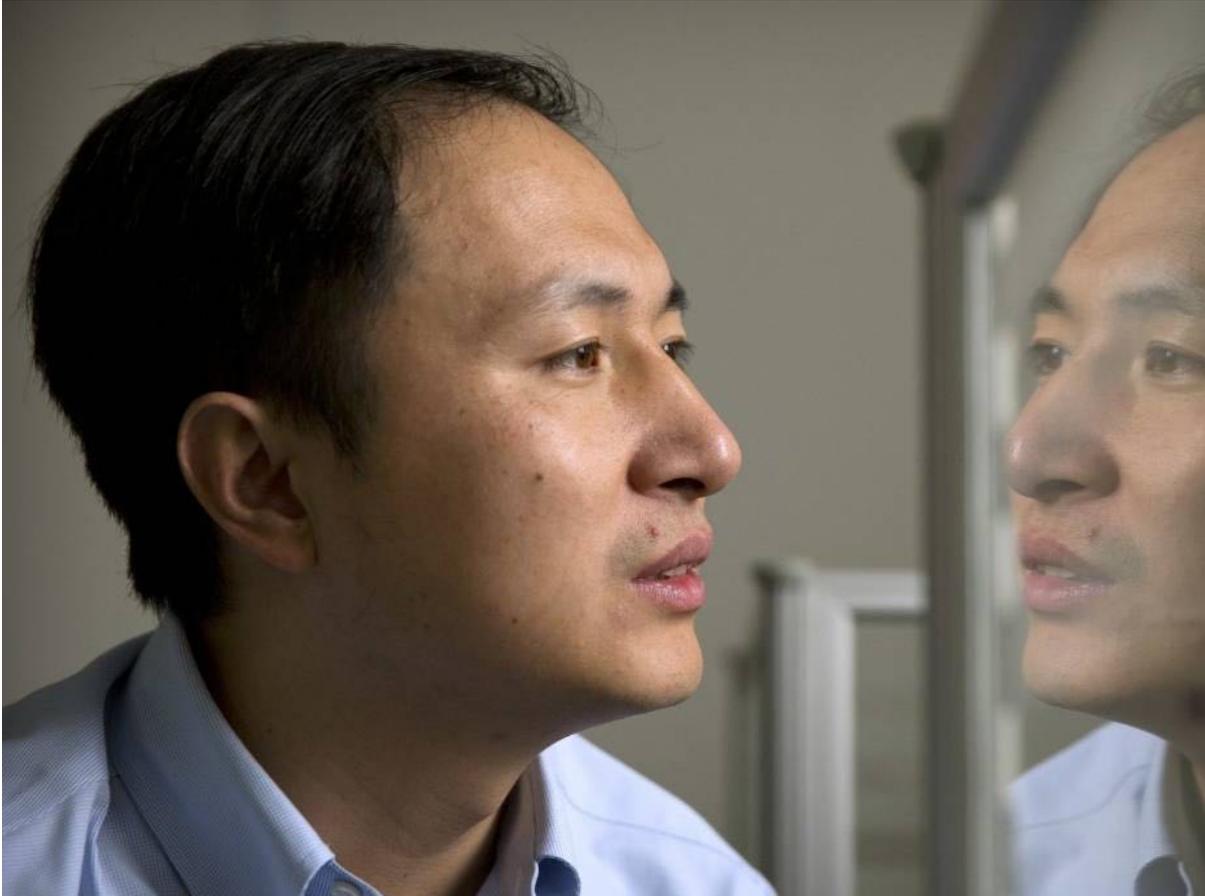
Carolyn Y Johnson  
07:02, Nov 27 2018

A Chinese scientist triggered confusion, alarm and shock across the scientific community on Monday with the claim that he had edited the DNA of two twin baby girls, Lulu and Nana, who he said had been born "crying into the world as healthy as any other babies" a few weeks ago.

The explosive announcement, made through a press interview and videos posted online by He Jiankui of Southern

University of Science and Technology of China, came on the eve of an international summit dedicated to discussing the emerging science and ethics around powerful tools that give scientists unprecedented potential to tweak traits and eliminate genetic diseases - but that have raised fears of "designer babies."

He, a physicist by training, told the Associated Press that embryos from seven couples who underwent in vitro fertilisation had been edited. He used a tool called CRISPR to disable a gene that allows HIV to infect cells, with one pregnancy resulting thus far.



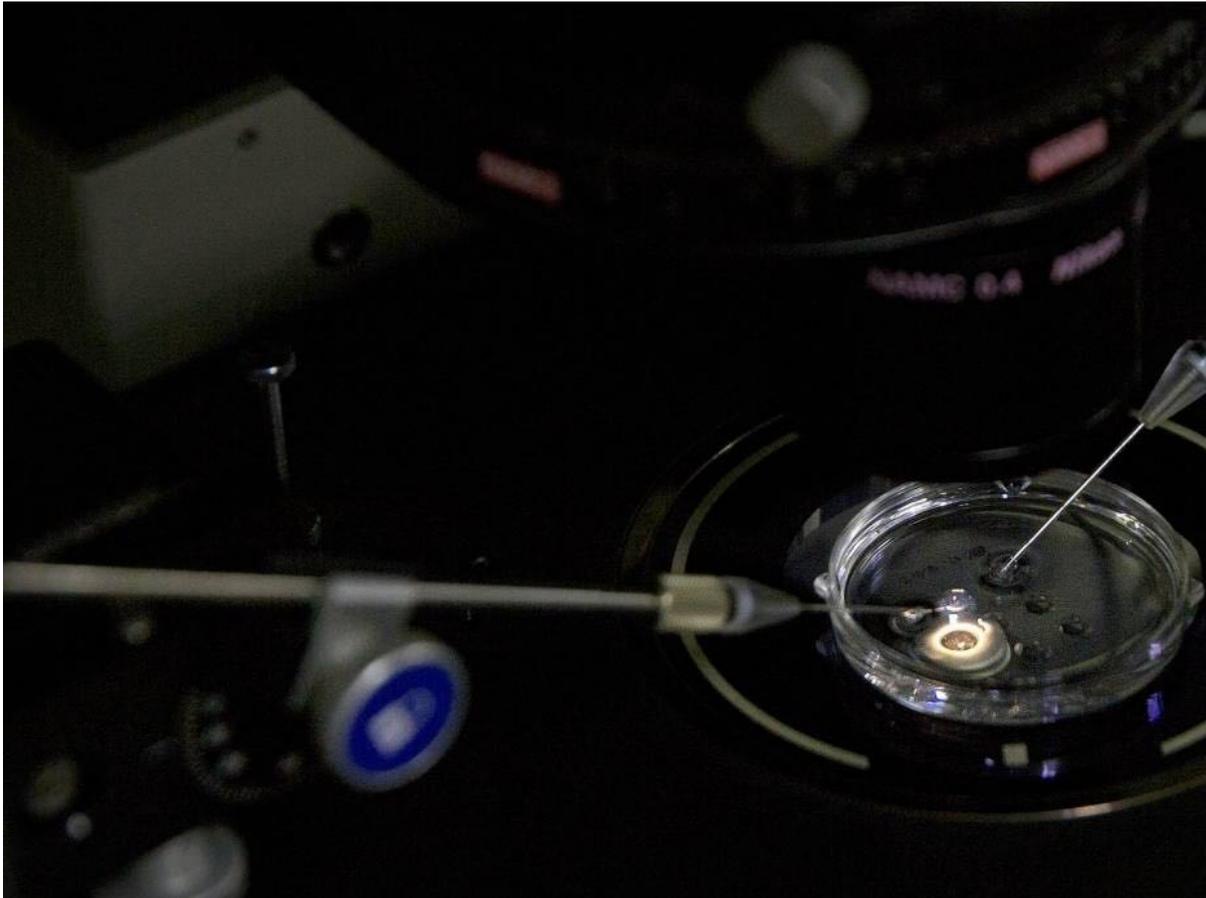
AP

Chinese scientist He Jiankui has claimed to have gene-edited twin baby girls. He did not respond to attempts to reach him by email and phone.

"I think this just shows the time is now that you have to talk about the ethics of genome-editing, because the world may not wait," said Insoo Hyun, a bioethicist at Case Western Reserve University. "We don't know how much of this is true or verified. These are all kinds of ... rumours at this point ... but in terms of scientific and medical rationale, I don't think there is one."

According to a description of the experiment posted online, He created embryos from couples with an HIV-infected father. The use of the technology immediately raised questions from ethicists since there are other ways to prevent HIV transmission to a fetus, and many think that the first applications of gene-editing should be reserved for diseases that are truly incurable.

In the video, He said that only a single gene had been changed by the editing procedure, but gene-editing is known to introduce unintended genetic effects that could raise concerns, either for the children themselves or the human gene pool if the children grow up to pass on their genes.



Chinese scientist He Jiankui claimed to have only changed one gene to prevent cells being affected by HIV in the embryos of the twin baby girls. AP

"Gene surgery is and should remain a technology for healing. Enhancing IQ or selecting hair or eye colour is not what a loving parent does. That should be banned," He said in a YouTube video. "I understand my work will be controversial, but I believe families need this technology, and I'm willing take the criticism for them."

The public announcement was highly unconventional, with no supporting data provided to verify the claims and no submission to the traditional process of peer review. It raised deep questions for scientists about whether traditional oversight channels were followed, as well as what to believe about the experiment and the results, although He posted an ethical approval form for the process on his website.

Scientists who had just landed in Hong Kong for the international summit on gene editing said the news took them by surprise.

"If it's true as reported then it's an extremely premature and questionable experiment in creating genetically modified children," said Jeffrey Kahn, director of the Johns Hopkins Berman Institute of Bioethics. "There's much to understand and discuss about oversight or lack thereof."

Matthew Porteus, a professor of pediatrics at Stanford University, said that the announcement highlights the weaknesses of the current regulatory system. "This is not the way I would like to see science advance. I have serious concerns," Porteus said.

Southern University of Science and Technology, the institution where He works, released a statement condemning the experiment, saying the university was "deeply shocked" by the news and had called an emergency meeting. The research was conducted off-campus, and the university was unaware of the project, according to the statement.

The university's biology academic committee "believes that Dr Jiankui He's conduct ... to edit human embryos has seriously violated academic ethics and codes of conduct."

In 2002, claims that a cult had created a cloned human baby caused a media firestorm. The claims were unverified, but they amplified ethical discussions about the possibility and triggered calls for banning human cloning.

"Coming on the eve of the second international summit on genome editing, this announcement looks like a cynical attempt to seize headlines," Pete Mills, assistant director of the Nuffield Council on Bioethics. "If the claims are true, it is a premature, inexplicable and possibly reckless intervention that may threaten the responsible development of future

applications of genome editing."

The Washington Post

## China baby gene editing claim "dubious"

*Prof He Jiankui's claims that he has engineered CRISPR babies are unverified and have sparked outrage from scientists*

EXCERPT: Prof Julian Savulescu, an expert in ethics at the University of Oxford, said: "If true, this experiment is monstrous. The embryos were healthy - no known diseases."

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**China baby gene editing claim 'dubious'**

By Michelle Roberts

BBC News online, 26 Nov 2018

<https://www.bbc.co.uk/news/health-46342195>

Significant doubts have emerged about claims from a Chinese scientist that he has helped make the world's first genetically edited babies.

Prof He Jiankui says the twin girls, born a few weeks ago, had their DNA altered as embryos to prevent them from contracting HIV.

His claims, filmed by Associated Press, are unverified and have sparked outrage from the scientists, who have called the idea monstrous.

Such work is banned in most countries.

### **Future generations**

Gene editing could potentially help avoid heritable diseases by deleting or changing troublesome coding in embryos.

But experts worry meddling with the genome of an embryo could cause harm not only to the individual but also future generations that inherit these same changes.

And many countries, including the UK, have laws that prevent the use of genome editing in embryos for assisted reproduction in humans.

Scientists can do gene editing research on discarded IVF embryos, as long as they are destroyed immediately afterwards and not used to make a baby.

### **'Designer babies'**

But Prof He, who was educated at Stanford in the US and works from a lab in the southern Chinese city of Shenzhen, says he used gene-editing tools to make two twin baby girls, known as "Lulu" and "Nana".

In a video, he claims to have eliminated a gene called CCR5 to make the girls resistant to HIV should they ever come into contact with the virus.

**For the information on this G-protein linked receptor see: <https://en.wikipedia.org/wiki/CCR5>**

He says his work is about creating children who would not suffer from diseases, rather than making designer babies with bespoke eye colour or a high IQ.

"I understand my work will be controversial - but I believe families need this technology and I'm willing to take the criticism for them," he says in the video.

### **'Highly treatable'**

However, several organisations, including a hospital, linked to the claim have denied any involvement.

And other scientists say if the reports are true, Prof He has gone too far, experimenting on healthy embryos without justification.

Dr Duscko Ilic, an expert in stem cell science at King's College London, said: "If this can be called ethical, then their perception of ethics is very different to the rest of the world's."

He argues that HIV is highly treatable and that if the infection is kept under control with drugs, then there is almost no risk of the parents passing it on to the baby anyway.

### **'Protected sex'**

Prof Julian Savulescu, an expert in ethics at the University of Oxford, said: "If true, this experiment is monstrous. The embryos were healthy - no known diseases.

"Gene editing itself is experimental and is still associated with off-target mutations, capable of causing genetic problems early and later in life, including the development of cancer.

"There are many effective ways to prevent HIV in healthy individuals - for example, protected sex. And there are effective treatments if one does contract it.

"This experiment exposes healthy normal children to risks of gene editing for no real necessary benefit."

Scientists say baby gene editing may one day be justifiable, but that more checks and measures are needed before allowing it.