

## Opinion

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# Gene editing like Crispr is too important to be left to scientists alone

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**T**wo little girls called Lulu and Nana celebrate their first birthday this month. The Chinese twins are the first humans to have every cell in their body [genetically modified](#) using Crispr-Cas9, a revolutionary [gene-editing](#) process that allows the DNA in embryos to be edited to carry certain characteristics that can be passed down to their children and grandchildren.

When the [twins' birth was announced](#) to the world by the [US-trained](#) biochemist He Jiankui, he described how he and his Chinese and American colleagues had used Crispr to introduce genetic mutations into otherwise healthy embryos in an attempt to minimise the girls' susceptibility to HIV infection. Such an intervention was both unnecessary and possibly ineffective, and in direct defiance of scientific consensus and

established [ethical norms](#). As a molecular biologist who has spent over a decade in laboratories, I was horrified by the experiment.

The stories of these girls' own experiences remain to be told. I sincerely hope theirs is a life filled with joy, playfulness and love, but it is likely to also feature [health consequences](#).

In the months following, He was labelled a “rogue” scientist, and elements of the mainstream scientific community scrambled to distance themselves. Government bodies rushed to assemble expert groups to develop regulatory guidelines that could prevent similar actions from other “outliers”.

But there is a big difference between trying to insulate the scientific establishment from criticism and making science fit to be a meaningful participant in society. The culture of science must fundamentally transform itself - becoming more diverse and more open - or it will be unfit for the task ahead.

The global market for Crispr gene-editing products as medicine, to develop new crops (such as spicy tomatoes or long-life mushrooms) and other uses is predicted to be [\\$5.3bn by 2025](#). Continued advances in Crispr precision and ease of use, like the just reported [prime editing](#) approach, are likely to make that number even higher. Crispr gene editing has the potential to treat a myriad of monogenic diseases from sickle cell anaemia to muscular dystrophy and cancer. Parents may one day be able to genetically customise their children's health, physical features and abilities. Crispr will be the genetic scissors that tailor the human gene pool.

With such power in hand, we must ask: whose vision of the future are we trying to create?

Most of us support a future where Crispr is used to treat over [10,000 monogenic diseases](#) that impact 75 million people every year. But should Crispr also be used to “correct” deafness, for example, and by extension, eradicate a rich and vibrant deaf community? Should it be used to increase intelligence or muscle strength? What about changing children's eye colour? Or their sexuality? The future becomes blurry when Crispr applications move beyond treating disease to instead perpetuate subjective perceptions of normalcy or supremacy.

And gene-edited children will be expensive, creating the potential to make the world more inequitable, to make those who are already vulnerable more vulnerable, and to further entrench the dominant view of the privileged. That is a future we must fight tooth and nail to avoid.

Experts in science, ethics and governance are making some efforts to ensure Crispr researchers heed these societal concerns. The World Health Organization (WHO) has enlisted an [expert advisory committee](#) chaired by the South African constitutional judge Edwin Cameron and Margaret Hamburg, head of the American Association for the Advancement of Science, to develop global governance recommendations for human genome editing. An [International Commission on the Clinical Use of Germline Genome Editing](#) has also been established by the US National Academy of Medicine and National Academy of Sciences, and the UK's Royal Society. For far too long, regulatory officials and technology developers (either academic scientists or for-profit companies) have steered the direction of technology. In addition to clear research guidelines that support safe, therapeutic gene editing, I hope to see new recommendations that can help redistribute decision-making power. An open-access online registry of Crispr clinical trials, recently [proposed by the WHO](#), will hopefully promote a more open and transparent process. Venues are also needed where early and sustained public deliberation can take place to help integrate the concerns of society in deciding how Crispr should be used.



▲ 'When the twins' birth was announced to the world by the US-trained biochemist He Jiankui, he described how he and his Chinese and American colleagues had used Crispr to introduce genetic mutations into otherwise healthy embryos in an attempt to minimise the girls' susceptibility to HIV infection.' Photograph: Kin Cheung/AP

However, guidelines for human gene editing were already in place prior to Lulu and Nana's birth. Publicly available research guidelines clearly stated that it was still too early to safely or ethically implant Crispr-edited human embryos. Yet He has defended his experiments by arguing that he had "complied with all the criteria" laid out by those guidelines. And it has since been revealed that multiple American and Chinese scientists knew of He's experimental intentions and yet allowed them to proceed. Guidelines for research and regulation can only go so far to safeguard ethical use of Crispr. Some argue that a moratorium on gene editing is needed until more effective guidelines are in place. But I worry that introducing more guidelines will only treat the symptoms of a diseased scientific system - one that lacks diversity in its scientists and is fuelled by competition.

Most of modern science, and by extension the technologies it creates, has been shaped by a very narrow and privileged worldview. The scientific enterprise has been dominated by men - even today women make up only 28.8% of researchers worldwide as of last June. It has been exclusionary to people of colour - a Nobel prize has yet to be awarded to a black scientist. And it rarely includes people with disabilities or the very people scientists are attempting to "treat".

If our ultimate goal is for Crispr to equitably serve society, then we need to make sure those who steer its development realistically represent society. Scientists who come from historically marginalised backgrounds can introduce much-needed critical perspectives.

We need to bring more diversity into the lab, but we also need to get scientists out of the lab and into society. Scientists have often been isolated from the very issues and communities their research seeks to impact. We need to support channels that allow diverse members of society to inform scientific research: channels such as the proposed global observatory for gene editing and the Association for Responsible Research in Genome Editing, which gather scientists with patient advocacy groups and disability activists to inform Crispr research. More opportunities for scientists to learn from the public are also needed, such as Involve, a nonprofit organisation dedicated to public participation, and Editing Nature, an initiative I founded to empower impacted communities in deciding how Crispr is used. As a vital first step, we must create a scientific community that values diversity and openness.

Incentive structures - in large part created by scientific funding bodies, research institutions and publishers - are fuelling unhealthy competition and opacity among scientists. In a battle to be the first to discover, scientists are

forced to shield their ideas and their research. This opacity hinders open collaborations within the scientific community and with the public.

As we saw with He’s experiments, this competition and opacity creates a dangerous scenario when Crispr is involved. To safeguard the scientific enterprise, cooperativity and humility need to instead become central virtues of science. Scientific incentive structures should reward scientists who engage with the public and participate in cross-disciplinary collaborations. Meanwhile scientists should be trained to appreciate the limits of their own knowledge, and to know when to incorporate outside expertise and worldviews.

This work doesn’t stop at the research bench, or even in the classroom. Crispr holds the potential to forever change the arc of humanity, making its ethical use everyone’s responsibility. As citizens, we must push for medical school deans, professors, grant officers, journal editors, regulatory officials and those who design global research guidelines to come from a wide variety of backgrounds.

We must also pressure our governments to uphold inclusive and open regulatory processes, as well as participating in public discourse to amplify historically marginalised voices. Only in working together can we make science more open and inclusive, and only then can its products benefit us all.

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