Rice University’s Baker Institute for Public Policy-Baylor College of Medicine
Joint Program in Health Policy Research

Are we ready for gene-edited embryos?

“No, there should be more fundamental work to make sure the tool, CRISPR-Cas9, works as intended, accurately editing the target gene and no others,” says Kirstin Matthews, Ph.D., fellow in science and technology policy at the Baker Institute. “Furthermore, we should discuss what we, as a society, are and are not comfortable with regarding gene-editing.”

In November 2018, a scientist in China — He Jiankui — announced the birth of two babies whose genes had been altered by CRISPR-Cas9. He targeted the gene for CCR5 because there is a known mutation in the gene that has been shown to protect against HIV infections. His goals seemed to be to protect the infants against HIV/AIDS as well as to be the first to genetically edit a human embryo. However, the procedure raised a number of serious ethical and scientific issues.

Ethicists questioned if HIV/AIDS was an appropriate target for human embryo gene-editing, as it is preventable and treatable. There were also questions related to the informed consent documents used, which suggested the intervention was a “vaccine.” In addition, the Chinese government claims that required documents approving the research as ethical were forged.

Scientists were also concerned. He did not replicate the known mutation but rather, targeted the area of the gene where the mutation is located. Even if the introduced mutation has the intended effect, it is believed that only one infant had both copies of the gene altered, and the other had just one copy altered. This means that only one child might be resistant to HIV/AIDS. In addition, it is unclear whether the gene was edited in all of the infants’ cells or in some. The latter would lead to “mosaicism” — in which a person’s cells have a different genetic makeup — and would not completely protect the child from HIV/AIDS. Furthermore, it is not known whether the CCR5 mutation impacts other areas of the immune system. Some studies suggest it might protect from HIV infections but make carriers more susceptible to other viruses, including the flu and West Nile.

Beyond these concerns about the experimental procedure, it is worrisome that the research lacked public consultation and discussion. In fact, very few people in China or elsewhere were aware of the experiments. The deliberate introduction of genetic mutations that impact living beings is a major advancement in biomedical research, with impacts and risks that are unknown or unknowable until the research is conducted. These considerations are magnified when altered genes can be inherited and passed to future generations that cannot give consent.

This research raises strong ethical and moral concerns. Gene-editing research should include open and public dialogues, with scientists presenting as well as listening to concerns about their work. Society has decided that scientists should not have free rein to pursue any research they please; this is why there is oversight of human subjects research. Accordingly, scientists alone should not determine the rules and guidelines for the removal, addition or alteration of heritable genetic material. The pursuit of knowledge, and how we harness it to aid humanity, is as much a social enterprise as a technical one, and it requires open and transparent engagement with the public.
HEALTH POLICY research presents a summary of findings on current health policy issues. It is provided by Vivian Ho, Ph.D., James A. Baker III Institute Chair in Health Economics and director of the Center for Health and Biosciences at Rice University’s Baker Institute for Public Policy, in collaboration with Laura Petersen, M.D., MPH, chief of the Section of Health Services Research in the Department of Medicine at Baylor College of Medicine.

This publication aims to make research results accessible to regional and national health policymakers. The views expressed herein are those of the study authors and do not necessarily represent those of the Baker Institute or of Baylor College of Medicine.

The Baker Institute and Baylor College of Medicine’s Section of Health Services Research work with scholars from across Rice University and Baylor College of Medicine to address issues of health care — access, financing, organization, delivery and outcomes. Special emphasis is given to issues of health care quality and cost.

Rice University MS-40
Center for Health and Biosciences
P.O. Box 1892
Houston, Texas 77251-1892

For further information about the program, please contact:
Rice University MS-40
Center for Health and Biosciences
P.O. Box 1892
Houston, Texas 77251-1892
phone: 713.348.2735
e-mail: bakerchb@rice.edu

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