# Human Rights Council (HRC)

Research Report

CACMUN

**Forum:** Human Rights Council

**Issue:** Implementing Measures to Regulate the Humanitarian Effects of Genome Editing.

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## Introduction

Genome editing is the genetic modification of embryos before their full development and birth. There are two types of gene editing, somatic editing, meaning editing done to non-reproductive cells (in an already fertilised egg), and these edits only affect the individual embryo.[1] The second is germline editing, which is edits made to the reproductive cells themselves in the parents, also meaning that these changes can be inherited.[2] There are some situations where fetuses are predisposed to having a genetic disease as a result of heredity, and diseases that are chromosome-related can often be located prenatally, and in early stages of fetal development,[3] and this is where gene editing is usually introduced. Gene editing is a recent technological advancement, with the first steps towards successful gene editing being in the 1960s when the first synthesis of DNA in a lab was achieved. Later, in the 1970s, it was discovered how to isolate and connect DNA, creating Recombinant DNA (or rDNA), which is DNA that is cut and connected from multiple different organisms.[4] As the technology surrounding genome editing advanced, concerns also arose from multiple fronts.

Ethical concerns regarding gene editing started proving more prominent. Changes in respect to removing hereditary diseases or chromosome-related diseases could lead the child to be born to lead a more stereotypically “normal” life. The first argument on this topic is whether this is an ableist viewpoint, stating that a child's life is not worth living, or is worth risking just to change something that isn't generally socially normalized. Gene editing

[1] “Somatic Mutation vs. Germline Mutation.” *Cleveland Clinic*, 24 May 2022, https://my.clevelandclinic.org/health/body/23067-somatic--germline-mutations. Accessed 31 July 2025.
[2] Ibid.
[3] Stavljenić-Rukavina, Ana. “Prenatal Diagnosis of Chromosomal Disorders - Molecular Aspects.” *National Library of Medicine*, International Federation of Clinical Chemistry and Laboratory Medicine, April 2008, https://pmc.ncbi.nlm.nih.gov/articles/PMC4975335/. Accessed 31 July 2025.
[4] “History of Genetic Engineering and the Rise of Genome Editing Tools.” *Synthego*, https://www.synthego.com/learn/genome-engineering-history. Accessed 31 July 2025.

can also be used by creating many eggs, then genetically modifying them all until reaching the optimum result, and after finding the optimal egg, disposing of the rest. Again, an ethical question. Genome editing is still a very new concept, and experimentation and calculations are still being developed. This experimental phase of genome editing poses further risks for both the bearing guardian and the fetus itself. These trials do have the possibility of inadvertently harming the embryo being modified and creating further deformities within the fetus. Apart from somatic editing, germline editing raises further ethical issues, with the possibility of ruining a full line of reproductive cells, as well as possibly removing the fertility of a parent completely.

International organizations like the World Health Organization have addressed multiple times their recommendations for the way in which the global community should approach gene editing, and has created the "Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing" and has established frameworks of ethical and legal applications for gene editing methods, suggesting strong regulation of gene editing research, trials, experiments, and publications.[5] Apart from the obviously affected population of children and bearing guardians, the disabled community is one of the most engaged in the topic; however, the community still has conflicting views. Some say that removing genetic diseases is a necessary advancement to help people lead better, healthier lives, while some say that these advancements are decreasing the value and respect of disabled people. Overall, this topic is a multilateral issue, with policies changing depending on multiple factors and differing from country to country.

## Definition of Key Terms

### Somatic editing

Gene editing done to DNA after conception. Is not inherited from parents.

### Germline editing

Gene editing done to a parent's reproductive cells (eggs or sperm). Can be inherited by the child.

[5] "Human genome editing: position paper." *World Health Organization*, 12 July 2021, https://www.who.int/publications/i/item/9789240030404. Accessed 31 July 2025.

### Embryo

The phase in the development of multicellular organisms after conception, but before the development of major organs.

### Ethical concern

Concerns regarding morals and principles, and socially acceptable or unacceptable actions.

### CRISPR technology

Stands for "Clustered Regularly Interspaced Short Palindromic Repeats", a recent revolutionary technology in gene editing which is able to very precisely alter specific DNA sequences.

## Background Information:

In 1974, the National Academy of Sciences had collected enough evidence to claim that genome editing posed great ethical risks, and with that, they called for a temporary moratorium (legal temporary suspension of an activity) on gene editing until the ethical concerns could be addressed. Paul Berg, who was one of the pioneers of recombinant DNA discoveries, organized a conference in 1975 to discuss the ethical concerns surrounding gene editing. He was joined by over a hundred scientists, and this conference set the ground principles of approaching genome editing in a safe way.[6] Since then, there hasn't been any fully binding law that regulates genome editing, however, there have been multiple efforts for recommendations on regulation, such as the Universal Declaration on the Human Genome and Human Rights which prohibits germline editing, and the Universal Declaration on Bioethics and Human Rights which sets broader frameworks on ethics in the bioengineering field.

### Causes of the Issue:

This contention on this issue stems from ideological and ethical issues. Ethical questions of the worth of mutated embryos, possible escalations of gene editing for unethical or dangerous purposes, the question of diversity and awareness being constantly brought up, as well as the possible risks of putting edited embryos in even larger risk of health issues due to the practice still being undergoing research. One final cause of the issue is religious ideologies which sparks the conflict more, as religions such as Catholic

[6] "History of Genetic Engineering and the Rise of Genome Editing Tools." *Synthego*, https://www.synthego.com/learn/genome-engineering-history. Accessed 31 July 2025.

Christianity, Islam, Judaism, and Buddhism have multiple views on genome editing, believing that gene editing changes the natural order and God's creation.

### Effects of the Issue:

This issue has raised multiple concerns throughout multiple communities. The first being the disabled community, with some advocating for gene editing to help solve diseases that have been lethal, or making the quality of life decrease greatly, and some advocating against gene editing, calling for diversity and claiming that gene editing further normalizes restricting the capabilities of disabled persons. Scientists in the field are also affected, for one, their jobs are depending on this field of study, and some people tend to look down upon gene scientists.

## Major Countries and Organizations Involved

### China

China has come a long way with gene-editing technologies, particularly CRISPR. It was the country where Dr. He Jiankui illegally tweaked the genes of twin embryos in 2018, which caused global outrage. Even though the Chinese government later condemned him and put in place tighter regulations, the act revealed a lack of initial regulation. Genome editing remains very much of concern to China, particularly for disease prevention and agriculture.

### United States

The United States of America has also heavily invested in genome editing research, especially through the NIH institutions. Somatic gene editing is permitted within the United States. Germline editing within clinical settings is still forbidden under stern FDA laws. The United States of America remains, generally, at the forefront of gene editing science but continues to enter the ethical debate and calls for clearer federal laws.

### United Kingdom

The UK was the first to legalize research on human embryos using genome editing instruments under regulation by the Human Fertilisation and Embryology Authority (HFEA). The government in the UK prefers regulated gene editing for the treatment and research of genetic diseases but not for reproduction or enhancement purposes.

### World Health Organization (WHO)

The WHO has also established an Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. The committee provides non-binding recommendations to member states to encourage the development of regulatory frameworks and ethical guidelines. WHO also facilitates international cooperation and transparency in the guise of a global

### UNESCO

UNESCO published the Universal Declaration on the Human Genome and Human Rights in 1997, which emphasizes human dignity and protecting generations to come. It is against germline editing and has been a strong proponent of ethical standards and international collaboration on the regulation of genome editing.

## Timeline of Events

| Date | Description of Event |
|---|---|
| July 1974 | The U.S. National Academy of Sciences calls for a temporary moratorium on recombinant DNA research due to growing ethical concerns. |
| February 1975 | ASIMOLAR CONFERENCE ON RECOMBINANT DNA: held in California, led by Paul Berg and over 100 scientists, setting voluntary guidelines for safe genome editing research. |
| November 11, 1997 | ADOPTION OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS: UNESCO adopts the declaration prohibiting germline editing and affirming the protection of human dignity in genetic research. |
| DECEMBER 1–3, 2015 | FIRST INTERNATIONAL SUMMIT ON HUMAN GENE EDITING: Held in Washington, D.C., the summit brings together global experts to discuss ethical, legal, and scientific implications of genome editing. |
| NOVEMBER 26, 2018 | BIRTH OF FIRST GENE-EDITED BABIES: Dr. He Jiankui announces the birth of Lulu and Nana, the world's first genetically edited babies, sparking international criticism and ethical outrage. |
| NOVEMBER 27–29, 2018 | SECOND INTERNATIONAL SUMMIT ON HUMAN GENOME EDITING: Held in Hong Kong, this summit responds to Dr. He's actions and reinforces the call for global regulatory frameworks. |

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| AUGUST 2019 | ESTABLISHMENT OF WHO EXPERT ADVISORY COMMITTEE: The World Health Organization forms a committee to develop global governance standards and proposes a registry for human genome editing research. |
| JULY 12, 2021 | PUBLICATION OF WHO POSITION PAPER ON HUMAN GENOME EDITING: WHO releases its official stance, advocating for international oversight, ethical governance, and the establishment of a transparent global registry. |

## Relevant UN Treaties and Events

- UNESCO Universal Declaration on the Human Genome and Human Rights (1997)
- Prohibits practices contrary to human dignity such as germline genome editing and emphasizes the rights of future generations. (UNESCO/SHS/97/CONF.202/CLD.4)
- UNESCO Universal Declaration on Bioethics and Human Rights (2005)
- Establishes broad ethical principles relating to medicine, life sciences, and associated technologies, with a focus on human dignity, autonomy, and justice. (UNESCO/SHS/2005/CONF.204/CLD.1)
- WHO Position Paper on Human Genome Editing (2021)
- Recommends establishing a global registry and ethical governance for genome editing and calls on countries to strengthen oversight mechanisms and transparency. (WHO/9789240030404)

## Previous Attempts to Solve the Issue

### UNESCO Universal Declaration on the Human Genome and Human Rights (1997)

First attempt to address ethical concerns regarding Human genome editing. The Universal Declaration on the Human Genome and Human Rights (DHG) emphasized human dignity, safety concerns and ill purposes for human enhancement. The declaration is non binding and is not enforced thus rendering it obsolete.

### International Summit on Human Genome Editing (2015 & 2018)

The summits increased global awareness regarding genome editing and the ethical problems it poses helping the world reach further consensus. In 2018, Dr. Jiankui was condemned for his work editing a human embryo. Although the summit increased global awareness, accountability remains the issue with no clear form of punishment without a direct governing body on the matter.

### WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing (2019-2021)

A committee established by WHO which suggested the establishment of a global registry for human genome editing, increasing transparency, and ethical oversight. Unfortunately, implementation is inconsistent, many countries have yet to address concerns toward human genome editing as well as implement these standards

## Possible Solutions

### Create a Binding International Convention on Human Genome Editing

Under the oversight of the UN, states should clearly outline what genome editing should be used for considering its concerns. Prohibiting genome editing for reproductive purposes, enhancement, and establishment of enforcement protocols. The UN must audit state compliance and those who do not follow new regulations.

### Establish a Global Public Genome Editing Registry

Create a global registry monitored by WHO or the UN which must register editing trials which must be accepted by the registry. States or labs require approval and registration for approval to work on human genome editing under the supervision of the registry. The registry may not be extremely transparent regarding projects but will help to establish accountability and deal with the ethics regarding the issue.

### Strengthen National Oversight Mechanisms with International Support

WHO and UNESCO could provide technical assistance to help low income countries build frameworks for genome editing to ensure accountability. Ensuring global cooperation and

regulation but may not be effective since countries could remain discreet regarding their research and work regarding the issue.

## Useful Links

WHO – Genome Editing and Human Rights:
https://iris.who.int/bitstream/handle/10665/342484/9789240030060-eng.pdf
UNESCO – Universal Declaration on the Human Genome and Human Rights:
https://unesdoc.unesco.org/ark:/48223/pf0000110220
National Academy of Sciences – Human Genome Editing Reports:
https://www.nationalacademies.org/our-work/human-gene-editing-scientific-medical-and-ethical-considerations
The Nuffield Council on Bioethics – Genome Editing:
https://www.nuffieldbioethics.org/publication/genome-editing-an-ethical-review/
National Human Genome Research Institute – What are the ethical concerns of human genome editing?:
https://www.genome.gov/about-genomics/policy-issues/Genome-Editing/ethical-concerns

## Bibliography

Finally, your Bibliography must include at least five sources you used to write your report. It must be written in Times New Roman font size 12. All citations must follow MLA 8 format. You may use mybib.com to help generate your bibliography. Cite online sources when possible, paraphrase properly, and avoid plagiarism.

All reports must follow these structural and formatting instructions. If you have any questions, consult the Secretariat before initial submission.

"History of Genetic Engineering and the Rise of Genome Editing Tools." *Synthego*, https://www.synthego.com/learn/genome-engineering-history. Accessed 31 July 2025.

"Human genome editing: position paper." *World Health Organization*, 12 July 2021, https://www.who.int/publications/i/item/9789240030404. Accessed 31 July 2025.

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