

**Committee:** World Health Organization

**Topic:** The question of ethics of human genome editing for navigating moral and scientific frontiers

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## Introduction

Due to the development of science, new technologies have also appeared in genetics. However, there are some technologies that have been discovered but not applied to our lives. Human genome editing is one of the previous cases. Genome editing is now decades old but still remains unsolved with ethical issues.

Genome editing is making alterations to the DNA of a cell or organism. It can be utilized to add, remove, or alter DNA in a genome. It can alter an organism's characteristics in a particular way. It has the capacity to alter the genes for the human embryo, potentially to remove harmful disease genes and introduce new characteristics. Furthermore, genome editing can successfully correct the mutation responsible for sickle cell disease. Technologies for altering human genomes can be used for non-heritable somatic cells and both germline cells and for reproduction. While this technology has been known to scientists for a long time, through the CRISPR-Cas9 technique, for example, the field is developing day by day. Gene editing holds tremendous potential for our health, but there are still several barriers that the world has to overcome.

According to 'The CRISPR Journal' in 2020, it was reported that the genome editing policy of 106 countries and 75 nations prohibits heritable gene editing in the early stage of the embryo. The performance of edited embryos in reproduction raises concerns about unexpected consequences for subsequent generations. Despite the huge advances in the past years, the side effects of editing are not fully known.

‘Human genome editing has the potential to advance our ability to treat and cure disease, but the full impact will only be realized if we deploy it for the benefit of all people, instead of fueling more health inequities between and within countries,’ stated Tedros Adhanom Ghebreyesus, World Health Organization Director General. Implications of human genome editing raise concerns and ethical considerations. Even if we solve all the safety, equity, and ethical problems, we can still think about whether this practice should be permitted under any circumstances and how it will impact society at large if individuals possess the ability to edit their genes. Guidelines about human genome editing are now essentially needed to perform it ethically and to meet scientific frontiers.

## Definition of Key Terms

### **Genome Editing**

One aspect of genome therapy is adding, deleting, and modifying genes in living organisms. The creation of methods for creating molecular tools that can precisely cut genomes' DNA to enable targeted changes in the DNA sequence. A number of these techniques have been introduced and successfully applied in clinical settings in recent years.

### **DNA**

Deoxyribonucleic acid is a molecule that carries hereditary material in human and other organisms. The DNA in our genes has a code that defines our physical characteristics such as height, skin, or hair color and may also influence certain behavioral traits. Genes are made up of DNA, which is the basic unit of heredity.

### **CRISPR-Cas9**

Technology that allows scientists to cut and paste a desired code in the gene. The specific location of the genetic code that is required to be altered is identified on the DNA strand. Using the Cas 9 protein, acting like scissors, its location is cut off from the strand. A DNA strand has a natural tendency to repair itself when broken. Scientists intervene during the auto-repair process, supplying the desired sequence of genetic codes that binds itself with the broken DNA strand. This technique for germline editing has made editing cheaper and more accessible for scientists and laboratories.

### **Mutation**

Changes in the DNA sequence of an organism. It creates a permanent change in the gene's DNA sequence. If they occur in cells that make eggs and sperm, they can be inherited. Mutations can be harmful, beneficial or have no effect on our body. Mutations might lead to other diseases such as sickle cell disease, and cancer.

### **Germ Cells**

A cell that develops into a reproductive cell, which is an egg in a female and sperm in males. Their precursors are capable of passing genetic changes to future generations. Germ cells are in contrast to other cells of the body, which are called somatic cells that are not hereditary. Eggs and sperm cells make up the germlines of an organism, the link between the generations.

### **Therapeutic**

Gene editing of adult human cells, including gene therapy and stem cell therapy, is used to cure disease. There is CAR T-cell therapy as an example, which uses patients' own immune cells to cure cancer.

### **Clinical Research**

Research conducted with human participants aimed at evaluating the safety and efficacy of genome editing technologies in treating or preventing genetic diseases.

## Background Information

### Medical and Technological advances using human genome editing

In November 2018, it was reported that a scientist in China had been carrying out genetic tests on fetuses as late as 24 weeks. The world's first genetically edited babies using the CRISPR-Cas9 technique, a set of twin girls, have already been born. As a result, the unofficial international moratorium on editing human embryos intended for pregnancy had been violated. The scientist in question has defended his decision to edit the genes of the baby girls, stating that the objective of his experiment was to disable a gene called CCR5 so the girls might be resistant to potential infection with HIV/AIDS. This was important because the father of the girls had HIV and wanted to ensure his children would never suffer like he had.

In the USA, a team of researchers in Portland, Oregon, attempted to create genetically modified human embryos by changing the DNA of a large number of one-cell embryos with the use of gene-editing technique CRISPR. None of the embryos were allowed to develop for more than a few days, but CRISPR was injected into the eggs at the same time they were fertilized with sperm. Besides the advances mentioned above, there have been a lot of advances about human genome editing made around the world. There have been attempts to make designer babies, edit the human genome for therapeutic purposes.

Somatic gene editing involves targeting genes in specific types of cells. The edited gene is only contained in the specific cell type. Other cells are not affected by the edited gene. Any changes, including off-target effects, are limited to the individual and are not passed down to future generations. Somatic gene editing is used to treat or cure a disease caused by gene mutation. Somatic focuses on curing diseases such as muscular dystrophy, neurological disorders, HIV. There are two types of gene therapy: ex-vivo and in-vivo. There is also germline gene editing which is quite different. Germline modifications are made at the earliest stages such as the human embryo and sperm and egg cells. The edited gene is copied in every cell including sperm and egg cells, affecting every cell. Editing one gene might fix one problem but cause another. The possible consequences of that are difficult to predict. The edited gene is heritable to the next generation. Germline gene editing focuses on curing genetic diseases.

There are two main ways gene editing can be delivered. Ex vivo gene therapy, takes cells from your body, modifies them in a lab, and puts them back into the body. In vivo uses other methods to deliver genes directly into the cells. Ex vivo gene therapy is most often used in blood related

disorders. An advantage for it is to control the entire process of creating new genetic material. However it is complex, time-consuming to prepare the cells outside the body. In vivo methods are preferred for genetic orders that affect one specific gene in the body and internal organs. Since the cell doesn't have to be removed from the body it is less complicated than the ex vivo method. The disadvantage is that they require very precise delivery of the material to the damaged area of the body and it can cause problems if the delivery isn't perfect.

CRISPR-Cas9, TALENs, ZFNs are several technologies of genome editing. ZFNs were the first custom DNA endonucleases that bind and cleave the DNA molecule to any random site. By using a series of linked ZFNs, scientists can recognize longer DNA sequences and achieve the target DNA. TALENs are composed of 33 to 35 amino molecules, each targeting a single nucleotide. TALENs are cheaper and produce faster results. CRISPR-Cas9 is the most simple, cheap, and efficient among these. While TALENs and ZFNs are man-made, CRISPR-Cas9 is derived from bacteria.

### **Ethical Issues of human genome editing and designer babies**

More than legal restrictions, it is the ethical and social issues surrounding human genome editing that act as a major block for scientific frontiers. Besides making use of human genome editing for therapeutic purposes, there is fear that permitting germ line gene editing would lead to the creation of offspring having some preferred traits. Parents who want specific traits in their children such as a specific hair or eye color, height, memory, intelligence, would opt for such genetic modification in order to get the desired baby. This may lead to a division in society where genetically modified humans are healthier and conform better to societal standards of beauty than non-genetically modified humans. When certain characteristics and traits are more desirable, this could reinforce existing racial stereotypes, resulting in racism.

Germ line gene editing can also make upward social and economic mobility for persons from disadvantaged communities more difficult as such people will not have been genetically modified to be more intelligent and attractive as compared to their richer peers. Another issue with germ line gene editing is a possible widening of the health gap between rich and poor, both within a society and between nations.

Scientists show concern that genome editing in human embryos, heritable human genome editing, can have unpredictable causes on the future generations. Unexpected gene mutations are often introduced in the genome using CRISPR-Cas 9 is applied and these changes can be passed from one

generation to the next permanently. Concerns about hostile irreversible changes in the human gene pool are valid. Random mutations can cause and create unexpected diseases. However, such concerns may also obstruct any efforts made towards developing therapies, using gene editing technologies that can not be inherited, such as developing a cure for cancer.

## Possible solutions

### **Sharing Information about Human Genome Editing Beyond Borders**

Currently, many human genome editing therapies are costly. This concerns a new type of health inequality among nations and borders. A review published in 'Nature' indicates that the gene editing revolution will fail if we do not address pricing issues. To address the question, the World Health Organization released new guidelines about the future of human genome editing in 2021. The guidelines mention a variety of issues, including concerns about global inequality in the field. To reduce the gap between nations, it seems essential to share information about human genome editing.

### **Pose global guidelines for human genome editing**

Standards and position on human genome editing varies between countries. China allows somatic cell genome editing, prohibiting clinical germline editing. While in Japan germline editing is restricted but not punishable by law. By posing global standards for human genome editing, nations would be able to set rules for experiments and scientific frontiers to perform ethically. Nations have to devise regulations on unethical practices to prevent them from happening.

In December 2018, WHO established a global, multi-disciplinary Expert Advisory Committee to examine the scientific, ethical, social, and legal challenges associated with human genome editing. The committee worked to advise and make recommendations on appropriate global governance mechanisms for human genome editing. Nations should establish guidelines of studying genome editing ethically while navigating for scientific frontiers.

Accessibility of genome editing gets higher as technology advances and cost guidelines need to be established for fair pricing. Establishing cost guidelines for genome editing is crucial for price transparency between nations and companies for the future. Ensuring that advancements benefit all nations, not just in wealthy countries, finding adjustable prices.

Unpredicted and irreversible events can happen for genome editing. Genome editing that can give influence in reproduction can cause unexpected changes and consequences. Therefore editing and treatment that impact reproduction is prohibited in most countries. However, the guidelines differ in each country slightly. Posing guidelines prohibiting reproduction genome editing is essential before unexpected consequences happen such as the advent of new diseases.

Human gene editing can be applied for military and warfare. Gene editing can enhance soldiers' physical and cognitive abilities. For example, by gene editing it can enable soldiers to endure challenging environments such as extreme temperatures, high altitudes. Due to the advances of technology, it is now possible to make bioweapons. By accessibility of CRISPR there is the potential of weaponizing viruses or bacteria. However not all countries are prepared to use gene editing or use them to enhance soldiers or use them as weapons. A clash of opinions can intensify conflicts happening and extend the gap between countries.

## Major parties involved

### **People's Republic of China**

Chinese Dr. He Jiankui's experiment of creating the world's first genome-edited babies, where he used CRISPR-Cas9 to increase the twins' resistance to HIV, showed the need for regulations to prevent unethical practices. His work was widely condemned by the scientific community, which decried the experiment as medically unnecessary and ethically irresponsible. He received a three-year jail sentence in 2019. Reflecting the outcry of Dr. He Jiankui's experiment, China strengthened its regulations. In July 2024, China presented a new set of ethical guidelines for human genome editing. In the strict new guidelines, China is prohibiting clinical germline genome editing due to the significant risks of permanent changes and ethical concerns. Somatic cell genome editing allows for focusing on treating diseases based on preclinical diseases. The regulations also address ethical concerns and ensure responsible research practices in biotechnology.

### **United States of America**

Germline gene editing is banned by acts of Congress, although there is no federal legislation that dictates restrictions or protocols about genome editing. Federal controls exist for allocating government funding for research projects, manipulating human embryos and running clinical trials. Gene editing for the embryo for non-reproduction purposes is allowed. However, genes for embryos intended for pregnancy are banned due to the unknown of whether it is safe or whether it can have unintended consequences for the babies and to future generations.

### **Japan**

Japan's germline gene editing regulations are looser than in most other countries but still restricted. Germline gene editing is permitted for research, not for reproductive purposes. Japan restricts for reproductive purposes but is not punishable by law. The guidelines presented in 2018 allow gene editing of human embryos for research about treatments to regulate only researchers and not doctors at private hospitals who might use gene editing for treatment. In 2018, for the first time in the world, Kyoto University announced that it would provide embryonic stem cells to universities and companies

for clinical trials. Most countries were hesitating to produce embryonic stem cells because it has been a controversial topic.

### **The Russian Federation**

Russia has no specific regulations directly addressing the germline gene editing of embryos for research or clinical purposes but supports the World Health Organization, which is against making changes in the human germline. Denis Rebikov created embryos with edited genes to avoid deafness, which became controversial. He also announced implanting gene-edited embryos into women to create embryos resistant to HIV. An uproar greeted him internationally, and his research has been put on hold. In 2019, the Russian health ministry stated that any clinical use of genome-editing technologies on human embryos is 'premature.' Some prominent bioethics in Russia endorsed the Russian health ministry's regulations on Rebinov's delayed plan.

### **Republic of India**

Germline gene editing is prohibited in India, although there are no enforceable and specific laws. Research for therapeutic uses is highly regulated. However, genome modifications to embryos that will not be carried into a term are allowed. Because of law ambiguities, there is malpractice, misuse, and manipulation of human genome editing. The Indian Journal of Medical Ethics mentions that India's guidelines are not legally binding and are not enforceable because of the large population and lack of specific laws to prevent them. There is yet no stunning research or products of human germline editing conducted in India.

### **United Kingdom**

Gene editing for therapeutic purposes and germline gene editing is highly regulated in the UK. Gene editing research about human embryos is permitted but requires a license from the Human Fertilisation and Embryology Authority. In 2015, HFEA allowed mitochondrial replacement therapy, correcting faulty mitochondrial DNA if it does not add some kind of inequality that can divide society. The United Kingdom is the only country that has officially approved the procedure. In 2016, the HFEA approved CRISPR gene editing research for the first time but banned the transfer of embryos for pregnancy and birth.

## **United Mexican States**

Gene editing for therapeutic purposes is lightly regulated, while germline gene editing is prohibited. In 1997, the General Law on Health prohibiting the fertilization of human eggs for any other purposes than reproduction, including gene editing research, was passed. In 2016, the first three-parent baby was born produced by mitochondrial-replacement therapy, which can help avoid certain mitochondrial diseases. Researchers from the US performed this procedure in Mexico since the therapy is not specifically regulated or banned. The Office of Scientific and Technological Information for the Congress of the Union recommends changes in the General Law on Health of Mexico, including specific regulations and supervision about CRISPR.

## Timeline Of Events

Date	Description of event
1988	<b>Human Genome Project get funded</b> The United Congress funded The Human Genome Project, which aimed to map out the human genome completely.
1993	<b>Discovery of CRISPR</b> The discovery of the principle of CRISPR was discovered by Francisco Mojica during his work with the bacteria. He noticed that the parts in the DNA repeated many times.
1999	<b>Complete of mapping chromosomes</b> Scientists working on the project mentioned in 1988 demonstrated that they had completely mapped out the sequence for 22 chromosomes.
2010	<b>World's first synthetic life form</b> Craig Venter and his team showed the world's first synthetic life form. This technically means life form that is entirely built rather than evolved or born.
2012	<b>Discovery of CRISPR genome engineering tool</b> In 2012, Jennifer Doudna and Emmanuelle Charpentier discovered the CRISPR genome engineering tool. By making precise cuts in DNA, CRISPR is now used in various fields.
2013	<b>Feng Zhang's applications of CRISPR</b> Feng Zhang's work demonstrated the utility of CRISPR in genetic manipulation of eukaryotic cells. His lab also aims to use CRISPR to control genetically modified neurons to develop therapies that will cure brain disorders.
2014	<b>Acknowledging the potential of CRISPR gene drives</b> Kevin Esvelt realized the potential of CRISPR gene drives. Esvelt also realized implications within a small ecosystem could be catastrophic.
2015	<b>Gene editing in human embryos</b> Junjiu Huang at the university in Guangzhou used CRISPR to edit human embryos. His experiment to fix gene errors to cure diseases was not considered ethical and became controversial.

2018	<b>Approval of part of CRISPR from USA</b> First human trials for CRISPR were approved from the USA. Vertex Pharmaceuticals & CRISPR Therapeutics, two companies, were approved to start clinical trials for disorders.
2020	<b>Nobel prize of CRISPR</b> Jennifer Doudna and Emmanuelle Charpentier won the Nobel Prize in chemistry for the development of CRISPR and genetic scissors.

## UN Involvement, Resolutions, Treaties and Events

- WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing, March 18-19, 2019

17 members of the committee including Africa, Asia, Europe, the Middle East, Oceania, North and South America, and observers from other organizations discussed human genome editing. The committee advised and made recommendations on appropriate institutional and global governance of human genome editing. It reviewed present applications, existing proposals and initiatives, and diverse social attitudes toward this technology.

- UNESCO (United Nations Educational, Scientific and Cultural Organization), Universal Declaration on the Human Genome and Human Rights, November 1997

The declaration contains contents about human dignity and human genome, research on the human genome, conditions for the exercise of scientific activity, solidarity and international cooperation. It includes that benefits from advances in biology, concerning the human genome, shall be made available to all, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole.

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