

Forum: World Health Organization

Topic: Ethics of Human Engineering and Emerging Biotechnologies

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Abstract

This Background Paper examines the ethics of human engineering and emerging biotechnologies, an increasingly important global issue as scientific advancements create new possibilities for treating diseases and modifying human genetic material. Delegates are encouraged to consider realistic solutions, such as strengthening international regulations, ensuring equal access to medical treatments, and establishing ethical guidelines to protect human rights and prevent the misuse of biotechnology, while promoting responsible scientific progress and safeguarding future generations.

Introduction

Biotechnology has become an important part of modern medicine, with scientists now able to study and change human genetic material in ways that were not possible before. These developments have opened up new ways of treating diseases and preventing certain inherited conditions. However, they have also raised concerns about how these technologies are being used and whether there should be

limits on what scientists are allowed to do. Issues such as genetic modification, unequal access to treatment and the possibility of misuse have made this an increasingly debated subject within the medical field.

One of the main concerns is that certain genetic changes could be passed down to future generations, who would have no say in the decisions made about their DNA. There are additional reservations regarding these technologies, and them becoming available mainly to wealthy individuals, creating further differences in access to healthcare. Although organizations such as the World Health Organization have introduced guidelines to address these concerns, many ethical questions remain unanswered. Countries must consider how to keep up with scientific developments while making sure that human rights, safety and fairness are not overlooked.

Definition of Key Terms

Human Engineering: The use of scientific technologies to influence human biological characteristics, including genetic material.

Biotechnology: The use of living organisms, cells or biological systems to develop products and technologies, particularly in medicine or healthcare.

Genetic Engineering: The deliberate alteration of an organisms genetic material to achieve specific characteristics or outcomes.

Gene editing: A technique used to make specific changes to DNA, allowing scientists to modify certain genes.

CRISPR-Cas9: A gene editing technology that allows scientists to make precise changes to DNA sequences.

Human Genome: The complete set with genetic information contained within a person's DNA.

Germline Editing: The modification of genes in non-reproductive cells, meaning the changes generally affect only the individual receiving the treatment.

Genetic Discrimination: The unfair treatment of individuals based on their genetic information or the possibility of developing certain inherited conditions.

Bioethics: The study of moral principles and ethical questions surrounding medicine, biological research and scientific developments.

Informed Consent: The process of ensuring that an individual fully understands a medical procedure, its potential risks and benefits before agreeing to it.

Embryo Selection: The process of selecting embryos based on specific genetic characteristics during assisted reproductive procedures.

Heritable: Traits that can be passed downfrom a parent to offspring; however, they are not fully genetically determined, as their expression can vary depending on environmental circumstances as well.

Synthetic Biology: The design or redesign and construction of biological parts, devices, or systems for useful purposes.

Background information

The development of biotechnology has significantly changed the medical field over the past few decades, particularly in the areas of genetic research and disease prevention. One of the most important developments was the discovery of CRISPR-Cas9, a gene-editing technology that allows scientists to make changes to specific sections of DNA. Since its development, this technology has introduced new possibilities for treating inherited diseases and understanding genetic conditions. In 2018, the issue of human genome editing gained international attention following the announcement that a Chinese scientist had created genetically edited babies. The experiment received widespread criticism from the scientific community due to concerns surrounding the safety, ethics and lack of proper approval involved. This incident highlighted the need for international guidelines to regulate human genetic research and prevent the misuse of emerging technologies.

Human engineering and emerging biotechnologies have created opportunities to improve healthcare and develop treatments for previously difficult-to-treat conditions. Genetic engineering allows scientists to study and potentially correct certain genetic disorders, while stem cell research has introduced possibilities for repairing damaged tissues and treating various medical conditions. One major example is the development of gene-editing treatments for sickle cell disease, which received approval in several countries beginning in 2023. These treatments demonstrate how genetic technologies can move beyond laboratory research and become part of modern medical care. However, access to these treatments remains limited due to their high costs, the specialized facilities required and differences in healthcare resources between countries. This raises concerns about whether the benefits of biotechnology will be available to everyone or mainly to wealthier populations.

As concerns surrounding human genetic modification increased, international organizations began taking steps towards establishing ethical standards and regulations. In 2018, the World Health Organization established an expert advisory committee to examine the scientific, ethical and legal challenges associated with human genome editing. In July 2021, WHO published its Human Genome Editing: Recommendations and Human Genome Editing: A Framework for Governance, which addressed issues such as international cooperation, research oversight and the prevention of unethical practices. These publications aimed to guide countries in developing responsible approaches to genetic research while ensuring that public health and human rights remain protected. UNESCO has also contributed to this discussion through its Universal Declaration on the Human Genome and Human Rights, adopted in 1997, which emphasizes the importance of human dignity and the protection of individuals against discrimination based on genetic characteristics.

Despite the progress made in regulating biotechnology, several concerns remain unresolved. One of the biggest debates involves the difference between using genetic engineering to prevent serious medical conditions and using it to enhance certain human characteristics. While treating inherited diseases may provide significant medical benefits, modifying embryos to select preferred physical or biological traits raises concerns about discrimination and the possibility of creating greater social inequalities. Another major concern involves germline editing, as

genetic changes made to embryos could be passed down to future generations. These individuals would have no opportunity to consent to the modifications made before their birth. Furthermore, differences in national legislation mean that certain procedures may be restricted in some countries while remaining less regulated in others. This creates difficulties in establishing consistent international standards and ensuring that scientific developments are carried out responsibly.

The growing use of biotechnology has raised concerns about whether all countries have equal opportunities to benefit from medical advancements. Wealthier countries often have better funding, research facilities and access to specialists, allowing them to develop and provide advanced genetic treatments. However, many developing countries lack the resources needed to access these technologies or properly regulate their use. This could widen the gap between countries in healthcare, leaving some populations with greater access to treatments than others. Another concern is genetic discrimination, as individuals could face unfair treatment because of their genetic information or inherited conditions. These issues show the need for countries to work together to make sure that new biotechnologies are used safely and that their benefits are not limited to those who can afford them.

Topics of Discussion

1. The limits of human genetic modification

How far should scientists be allowed to go when changing human DNA?

2. Ethics of embryo editing

Should genetic modification be allowed to prevent inherited diseases, or should it be restricted?

3. Equal access to biotechnology

How can developing countries benefit from advanced medical technologies?

4. Human rights and genetic discrimination

How can individuals be protected from discrimination based on their genetic information?

5. Human enhancement and genetic selection

Should biotechnology be used to select preferred human characteristics beyond medical purposes?

Human Rights potentially violated

1. Right to Health (Article 12 – ICESCR)

Unequal access to advanced genetic treatments can prevent individuals in developing countries or lower-income communities from benefiting from medical advancements.

2. Right to Equality and Non-Discrimination (Article 2 – UDHR)

Individuals may face discrimination because of their genetic characteristics, inherited conditions or disabilities.

3. Right to Privacy (Article 12 – UDHR)

The collection or sharing of someone's genetic information without proper permission can violate their privacy and confidentiality.

4. Right to Human Dignity (Article 1 – UDHR)

Using genetic engineering to select preferred human characteristics can raise concerns about treating individuals differently based on their biological traits rather than respecting their individuality.

5. Right to Informed Consent (Article 5 – UNESCO Universal Declaration on the Human Genome and Human Rights)

Individuals must be properly informed about genetic procedures, including their possible risks, before agreeing to participate.

6. Right to Life and Personal Security (Article 3 – UDHR)

Unsafe or poorly regulated genetic procedures may expose individuals to serious health risks and potentially harmful consequences.

7. Right to Benefit from Scientific Progress (Article 15 – ICESCR)

All individuals should have the opportunity to benefit from scientific advancements. Unequal access to biotechnology can prevent certain populations from enjoying these benefits.

Timeline of key events

- **1987 – Discovery of CRISPR sequences**

Japanese researchers first identified DNA sequences in bacteria that would later become known as CRISPR. This discovery eventually contributed to the development of modern gene-editing technology.

- **1990 – Launch of the Human Genome Project**

An international scientific project was launched to map and identify human genes. It marked a major step forward in understanding human DNA and inherited diseases.

- **1997 – UNESCO Declaration on the Human Genome and Human Rights**

UNESCO adopted the Universal Declaration on the Human Genome and Human Rights, recognizing the importance of protecting human dignity and preventing discrimination based on genetic characteristics.

- **2003 – Completion of the Human Genome Project**

The Human Genome Project was officially completed, providing scientists with a much clearer understanding of the human genetic sequence and creating new opportunities for medical research.

- **2005 – UNESCO Declaration on Bioethics and Human Rights**

UNESCO adopted the Universal Declaration on Bioethics and Human Rights, establishing international principles concerning medical research, human dignity, informed consent and the protection of human rights.

- **2012 – Development of CRISPR-Cas9 gene editing**

Scientists demonstrated that CRISPR-Cas9 could be used to make targeted changes to DNA, creating new possibilities for genetic research and potential medical treatments.

- **2015 – First International Summit on Human Gene Editing**

Scientists and experts gathered in Washington, D.C., to discuss the scientific, ethical and legal concerns surrounding human genome editing. The summit called for continued international discussion and responsible oversight.

- **November 2018 – Controversy surrounding genetically edited babies**

A Chinese researcher announced the birth of twin girls whose embryos had been genetically edited using CRISPR. The announcement received widespread international criticism and raised serious concerns about scientific responsibility, informed consent and the safety of genetic modification.

- **December 2018 – WHO establishes an expert advisory committee**

WHO established an international expert committee to examine the scientific, ethical, social and legal challenges associated with human genome editing and develop recommendations for its regulation.

- **July 2019 – WHO calls for restrictions on heritable genome editing**

WHO stated that proceeding with clinical applications of human germline genome editing would be irresponsible at that time, calling on regulatory authorities to prevent such applications until their implications had been properly considered.

- **August 2019 – WHO launches a global genome-editing registry**

WHO announced the first phase of a global registry intended to track human genome-editing research and improve transparency and international oversight.

- **July 2021 – WHO publishes its genome-editing recommendations**

WHO released its recommendations and governance framework for human genome editing, addressing research oversight, international cooperation, transparency and ethical concerns.

- **November 2023 – First CRISPR-based treatment receives approval**

The United Kingdom became the first country to authorize Casgevy, a CRISPR-based treatment for sickle-cell disease and beta-thalassemia. This marked a major development in the use of gene editing in medical treatment.

- **December 2023 – FDA approves CRISPR-based treatment**

The United States Food and Drug Administration approved Casgevy for eligible patients with sickle-cell disease, making it the first FDA-approved treatment to use CRISPR gene-editing technology.

Countries and organizations involved and how they are affected

Countries involved:

United States

The US is a major contributor to genetic research and biotechnology development. Its Food and Drug Administration (FDA) regulates gene-editing treatments, while the National Institutes of Health (NIH) supports medical research. The country faces challenges involving the high cost of genetic treatments, patient privacy and unequal access to advanced healthcare.

China

China has made major investments in biotechnology and genetic research. However, it received international criticism in 2018 after a researcher announced the birth of genetically edited babies. This raised concerns about research oversight, informed consent and the ethical limits of human genetic modification. China subsequently strengthened its regulations surrounding human genetic research.

United Kingdom

The UK has an established regulatory system for genetic research through organizations such as the Human Fertilization and Embryology Authority (HFEA). It became the first country to approve the CRISPR-based treatment Casgevy in

November 2023. Its main challenge is maintaining strict ethical standards while allowing medical research to advance.

International and Regional Organizations involved

OHCHR: Works to protect fundamental human rights, including equality, privacy and human dignity. Its involvement is important when genetic technologies create risks of discrimination or violations of individual rights.

UNESCO: UNESCO addresses the ethical and human rights aspects of biotechnology. Its 1997 Universal Declaration on the Human Genome and Human Rights emphasizes human dignity and protection against genetic discrimination.

ISSCR: Develops scientific guidelines for stem cell research and related technologies. It promotes responsible research practices and addresses ethical concerns surrounding human embryos and stem cell use.

OECD: Supports international cooperation on biotechnology policies, scientific innovation and responsible research. It also addresses the economic challenges associated with access to new technologies.

European Commission: Helps establish policies and regulations concerning biotechnology and medical research across the European Union. It addresses research safety, ethical standards and the responsible development of emerging technologies.

NGOs and Local Organizations

- Center for Genetics and Society (CGS)

  A US-based nonprofit organization that examines the social and ethical effects of human genetic technologies. It raises concerns about genetic discrimination, human enhancement and the possibility of increasing social inequalities through genetic engineering.

- Nuffield Council on Bioethics

  An independent UK bioethics organization that examines ethical questions arising from developments in biology and medicine. It has published influential

reports on genome editing and the ethical concerns surrounding modifying human embryos.

- Genetic Alliance

  A nonprofit organization that supports individuals and families affected by genetic conditions. It promotes patient involvement in medical research, access to genetic services and the responsible use of genetic information.

- Public Citizen

A US-based nonprofit consumer advocacy organization that works on healthcare safety, patient protection and government accountability. Its work is relevant to debates surrounding the safety and regulation of emerging medical technologies.

- Third World Network (TWN)

An international nonprofit research and advocacy network that focuses on development, science, technology and inequalities between developed and developing countries. Its work is relevant to discussions about access to biotechnology and the effects of scientific advancements on developing nations.

- GeneWatch UK

Monitors developments in genetic technologies and campaigns for responsible regulation of genetic engineering. Particularly relevant to concerns about genetic modification and public safety.

- ETC Group

An international NGO that examines the social and environmental impacts of emerging technologies, including biotechnology and genetic engineering.

Possible Solutions

1. Establish international guidelines for responsible human genetic modification.
2. Strengthen government regulations to prevent unethical scientific practices.
3. Ensure equal access to genetic treatments, regardless of wealth or location.

4. Protect genetic privacy and prevent discrimination based on DNA.
5. Require informed consent before any genetic procedure.
6. Increase international cooperation to monitor biotechnology research.
7. Fund further research into the long-term effects of genetic modification.

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