Committee: World Health Organization
Issue: Monitoring the ethics and development of human enhancement through genetic engineering
Student Officer: Ilektra Bampicha-Ninou
Position: Deputy President

PERSONAL INTRODUCTION

Dear delegates,

My name is Ilektra Bampicha-Ninou, I am an IB1 student of Doukas School, and I will be serving as your Deputy President at the World Health Organization of the 4th ACGMUN.

Firstly, I would like to praise you for taking part in this conference and also reassure you that the entirety of your experience will be rewarding not only in terms of elocution and problem-solving aptitude, but also regarding social skills and expertized knowledge.

As you know, one of the topics the World Health Organization will discuss is "Monitoring the ethics and development of human enhancement through genetic engineering." What I particularly like about this subject is the fact that it intertwines theoretical and empirical aspects of biology -in other words, it belongs to the domain of bioethics. Needless to say, I genuinely anticipate hearing your views and further discussions upon the matter.

Nevertheless, in order to achieve a prosperous debate, it is indispensable to be aware of the fundamental scientific facts concerning human amplification via genetic engineering; for instance, each country's policy treats the matter divergently. Hopefully, this Study Guide will enrich your knowledge upon the subject to a certain extent; however I firmly encourage you to also conduct a personal supplementary research.

I really look forward to meeting all of you -and I honestly hope you are just as excited as I am- but in case you any have occurring problems or find yourself in need of help, feel free to contact me via email at ebanibani@gmail.com.

Enjoy your preparation!

TOPIC INTRODUCTION

Have you ever watched the movie *Ghost in the Shell* or read Mary Shelly's original book *Frankenstein*?[1] Well, although they belong to different eras and art forms, they both refer to a significant topic that has always troubled humanity: human enhancement.

Remarkably, human enhancement is at least as old as human civilization. People have been trying to improve their physical and mental capabilities for thousands of years, sometimes successfully -and sometimes with inconclusive, comic and even tragic results. In our everyday life, activities like physical fitness routines, wearing eyeglasses, taking music lessons and prayer are routinely succeeded for the goal of enhancing human capacities. So, human enhancement doesn't always interfere only with people's embodied lives.

Let's move to the second term -genetic engineering- which involves the direct manipulation of one or more genes. Traditionally, humans have manipulated genomes indirectly by controlling breeding and selecting offspring with desired traits.[2] Gene editing offers new possibilities for biomedical enhancement requiring ethical, societal and practical considerations to evaluate its implications for human biology, human evolution and our natural environment, however, there are several ethical and practical considerations that must be scrutinized.

DEFINITION OF KEY TERMS

Genes

A gene is the basic physical and functional unit of heredity. Genes are made up of DNA and some of them act as instructions to make molecules called proteins. In humans, genes vary in size from a few hundred DNA bases to more than 2 million bases.

Human enhancement

According to the Stanford Encyclopedia of Philosophy, human enhancement includes the "biomedical interventions that are used to improve human form or functioning beyond what is necessary to restore or sustain health."

Genetic engineering

Genetic engineering is the process of using recombinant DNA (rDNA) technology to alter the genetic makeup of an organism.

Gene editing

The manipulation of the genetic material of a living organism by deleting, replacing, or inserting a DNA sequence, typically with the aim of improving a crop or farmed animal or correcting a genetic disorder.

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[1] Another source you can watch in order to become better acquainted with the topic is the four-part series *Unnatural Selection* on Netflix, which mentions the implications of gene therapy and CRISPR / cas9 on health care, nature and human improvement.

[2] Slowing down the aging process via biohacking or gene-editing is considered as genome manipulation. A useful video you can watch about can be found at https://www.bbc.co.uk/reel/video/p093919p/can-science-reverse-the-ageing-process-

CRISPR-CAS9

The most widely used approach to genome editing nowadays is based on Clustered Regularly Interspaced Short Palindromic Repeats and associated protein 9 (CRISPR-Cas9). In prokaryotes, CRISPR-Cas9 is an adaptive immune system that naturally protects cells from DNA virus infections. CRISPR-Cas9 has been modified to create a versatile genome editing technology that has a wide diversity of applications in medicine, agriculture, and basic studies of gene functions.

TALEN

Transcription activator-like effector nucleases (TALEN) are restriction enzymes that can be engineered to cut specific sequences of DNA. TALENs can be engineered to bind to practically any desired DNA sequence and therefore DNA can be cut at specific locations.

Human germline modification

Human germline genome editing means to make intentional changes to DNA of the germline cells of the genome of someone who is, or is hoped to become, a human person.

Biohacking

Biohacking is the biological experimentation (as by gene editing or the use of drugs or implants) done to improve the qualities or capabilities of living organisms especially by individuals and groups working outside a traditional medical or scientific research environment.

Transhumanism

The belief or theory that the human race can evolve beyond its current physical and mental limitations, especially by means of science and technology.

Bioethics

Bioethics is the application of ethics to the field of medicine and healthcare. Ethicists and bioethicists ask relevant questions, more than provide definite and certain answers (but we sincerely hope you do.)

"We are no longer living in a time when we can say we either want to enhance or we don't. We are already living in an age of enhancement."

- NICHOLAS AGAR, VICTORIA UNIVERSITY

BACKGROUND INFORMATION

Introduction to human enhancement

In 1973, Biochemists Herbert Boyer and Stanley Cohen primarily develop genetic engineering by inserting DNA from one bacterium into another. In 1982, the Food and Drug Administration approves the first consumer Genetically Modified Organism (GMO) product formulated through genetic engineering: human insulin to treat diabetes. Since then, practices of human enhancement could be visualized as upgrading a "system," where

biomedical interventions take place for a better performance of the original system. This scenario might seem as nothing more than a science fiction series, but it is far from being a hypothetical situation.

The rapid progress within the fields of nanotechnology, biotechnology, information technology and cognitive science has brought back discussions about the evolutionary trajectory of the human species by the promise of new applications which could provide abilities beyond current ones. If such a possibility was consciously embraced and actively pursued, technology could be expected to have a revolutionary interference with human life, not just helping humans in achieving general health and capabilities commensurate with our current ones, but helping to overcome human limitations far beyond of what is currently possible for human beings. The emergence of new technologies has provided a broader variety of potential human interventions and the possibility of transitioning from external changes to our bodies (e.g. external prosthesis) to internal ones, especially when considering genetic manipulation, whose changes can be permanent and transmissible.

The advocates of a far-reaching human enhancement have been referred to as "transhumanists". In their vision, so far, humans have largely worked to control and shape their exterior environments but with new technologies they will soon be able to control and fundamentally change their own bodies. Supporters of these technologies agree with the possibility of a more radical impedance in human life by using technology to overcome human limitations, that could allow us to live longer, healthier and even happier lives. On the other side, and against this position, are the so-called "bioconservatives", arguing for the conservation and protection of human essence, with the argument that something intrinsically valuable exists in human life that should be preserved.

History of genetic engineering

There are countless examples where technology has contributed to ameliorate the lives of people by improving their inherent or acquired capabilities. For example, over time, there have been biomedical interventions attempting to restore functions that are deficient, such as vision, hearing or mobility. If we consider human vision, substantial advances started from the time spectacles were developed (possibly in the 13th century), continuing in the last few years, with researchers implanting artificial retinas to give blind patients partial sight. Recently, scientists have also successfully linked the brain of a paralysed man to a computer chip, which helped restore partial movement of limbs previously non-responsive. In addition, synthetic blood substitutes have been created, which could be used in human patients in the future.

However, the reactions by each national community, accompanied with the ambiguity of the biomedical legislation and circumstances, have not always been in favor of further scientific research. Take for example Dr. He Jiankui, a Chinese researcher who stunned the world by announcing that he had helped produce genetically edited babies, which were born to be two genetically identical twins. Approximately a year following his

research, he was found guilty of conducting "illegal medical practices" and sentenced to 3 years in prison. A court in Shenzhen found that He and two collaborators forged ethical review documents and misled doctors into unknowingly implanting gene-edited embryos into two women, according to Xinhua -China's state-run press agency. The court ruled that the three defendants had deliberately violated national regulations on biomedical research and medical ethics, and rashly applied gene-editing technology to human reproductive medicine. The brains of two genetically edited girls born in China may have been changed in ways that enhance cognition and memory, scientists say. The twins, called Lulu and Nana, reportedly had their genes modified before birth by the Chinese scientific team using the editing tool CRISPR.

Criticism and controversy of views

In favor

Those who support human enhancement in general, claim that human enhancement technologies will promise a brighter future for human beings due to advanced bodies. In order to strengthen their argument, they highlight that humans have been genetically engineering organisms for thousands of years via selective breeding (i.e., plants, animals, GMO nutrition), which is opposed to natural selection. Nowadays, half a million babies are born annually thanks to in vitro fertilization (IVF), which includes the sequencing of embryos to screen them for diseases and thus bringing the most viable embryo to term. Furthermore, similar criticisms to those proposed regarding human enhancement had been addressed about the concept of surgery, nonetheless, over time, this procedure became much safer, and humans started utilizing it in less life-threatening situations -for example, consider purely elective or cosmetic surgery. As a result, disabled people will get artificial implants and people suffering from incurable diseases will be cured. This would eventually promote overall happiness and lead to prosperous communities.

Against

On the other hand, those against human modification -also known as "bio-conservatives"- state that, as promising as the aforementioned technology may sound, it could bring about some ethical problems. Firstly, they support that bio-enhancements are unnatural, whereas they compromise or offend human nature and may alienate us from our authentic selves. Many are also afraid of experimenting with genetic enhancement on themselves. Moreover, they view it as lack of gratitude of human beauty and attitude of mastery on behalf of humanity itself, while a new socioeconomic division might occur due to the technologies' expensive price, making them available to a limited group of people. Lastly, since people could become astringed from what it truly means to be human, perhaps one day biomedically durable androids -which might be used during wars- could replace human beings. Hence, the possibility of a dismal future for human beings is also prominent.

Stance of religion

When asked specifically about their own religious or moral views with regard to biotechnology, a poll concluded that most Christians and a plurality of Muslims say they are opposed to moving genes from one species or organism to another. Jews were the only religious group polled that had a majority that supported this technology.

Main ethical questions

Safety

Due to the possibility of off-target effects (when edits occur in the wrong place) and mosaicism (when some cells carry the edit but others do not), safety constitutes a primary concern. Researchers and ethicists generally agree that until germline genome editing is deemed safe through research, it should not be used for clinical purposes. Some researchers argue that there may never be a time when genome editing in embryos will offer a benefit greater than that of existing technologies, such as preimplantation genetic diagnosis (PGD) and in-vitro fertilization (IVF).

Some researchers and bioethicists are furthermore concerned that any genome editing, even for therapeutic uses, will position humanity on a slippery slope to using it for non-therapeutic and enhancement purposes, which many view as controversial. Others argue that genome editing, once proved safe and effective, should be allowed to cure genetic disease. They believe that concerns about enhancement should be managed through policy and regulation.

Informed Consent

Some people worry that it is impossible to obtain informed consent for germline therapy because the patients affected by the edits are the embryo and future generations. The counterargument is that parents already make many decisions that affect their future children, including similarly complicated decisions such as PGD with IVF. Researchers and bioethicists also worry about the possibility of obtaining representative informed consent from prospective parents, since for now the risks of germline therapy are unknown.

Justice and Equity

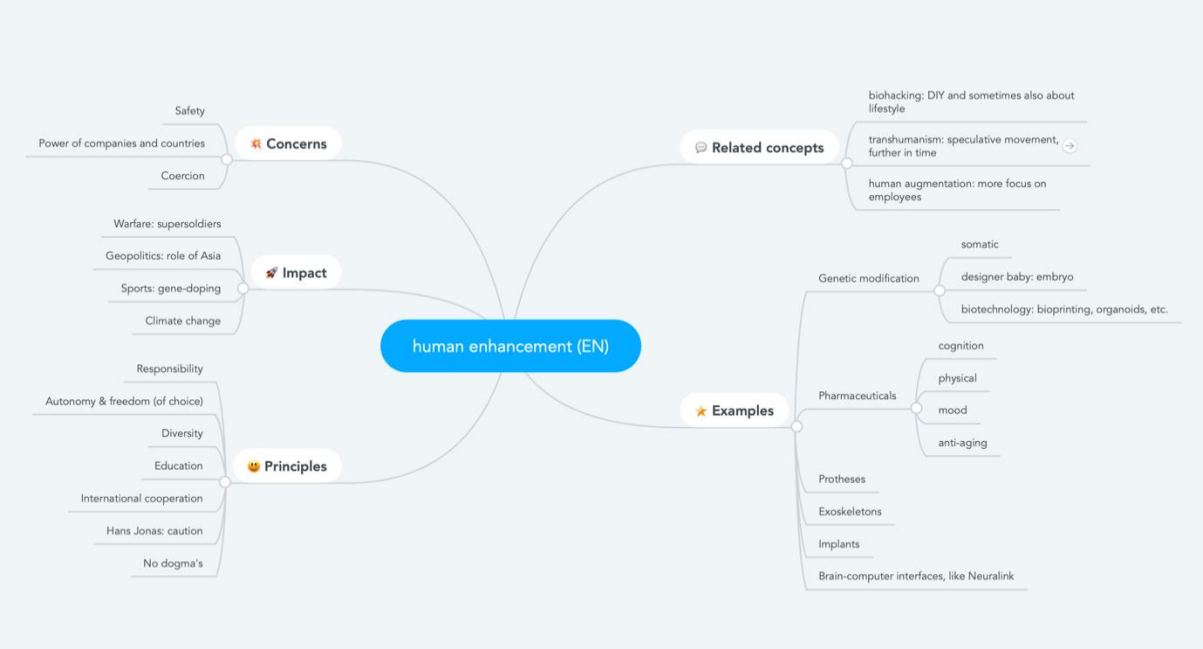
As with many new technologies, there is concern that genome editing will only be accessible to the wealthy and will increase existing disparities in terms of access to health care and other interventions. Some worry that taken to its extreme, germline editing could create classes of individuals defined by the quality of their engineered genome.

Genome-Editing Research Involving Embryos

Many people have moral and religious objections to the use of human embryos for research. Federal funds cannot be used for any research that creates or destroys embryos. Many bioethical and research groups believe that research using gene editing in embryos is important for myriad reasons, including addressing scientific questions about human biology, as long as it is not used for reproductive purposes at this time. Some countries have already allowed genome-editing research on nonviable embryos (those that could not result

in a live birth), and others have approved genome-editing research studies with viable embryos. In general, research that is conducted in embryos could use viable or nonviable embryos leftover from IVF, or embryos created expressly for research. Each case has its own moral considerations.

Doctor groups argue that a fetus cannot feel pain at 20 weeks gestational age. Indeed, the American College of Obstetricians and Gynecologists (ACOG) said it considers the case to be closed as to whether a fetus can feel pain at that stage in development. "The science shows that based on gestational age, the fetus is not capable of feeling pain until the third trimester," said Kate Connors, a spokesperson for ACOG. The third trimester begins at about 27 weeks of pregnancy.



Human enhancement by Peter Joosten (mindmeister)

MAJOR COUNTRIES AND ORGANIZATIONS INVOLVED

Brazil

Brazil provides an example of regulation and governance by accretion. It has approved laws related specifically to stem cell research and cell therapy, but they are layered on top of prior, more general rules, including constitutional prohibitions on the sale of any kind of human tissue and 1996 laws on the patenting of human biological materials, creating a situation of confusion.

Canada

There are well defined Canadian and international laws governing the use of germ line genetic engineering. Canada's Assisted Human Reproduction Act (2004) prohibits the alteration of "the genome of a cell of a human being or in vitro embryo such that the alteration is capable of being transmitted to descendants."

China

Article 29 of the Law of the People's Republic of China on Progress of Science and Technology prohibits research and development activities that endanger national security and human health, harm social and public interests, or violate ethics. This legislation provides clear guidance on the types of research and applications of science and technology that violate ethics, which would include certain gene-editing applications. However, the legislation does not mention any specific consequences for violating the regulations.

France

In France, civil law provisions on research involving human subjects, donation and use of human body parts and medically assisted reproduction -originally developed between 1988 and 1994 and generally referred to as loi de bioéthique (law on bioethics)- specify whether and under which statutory conditions activities potentially leading to human germline genome modification can be undertaken.

Germany

The creation, use, and harvesting of embryos for medical research are banned. Germany has been very reluctant to regulate or legalize genome editing because of the Nazis' plan to create a superior race consisting of people with very specific genetic traits. This could lead to the modification of human genes in order to fit the discriminatory criteria that were set by the Nazis in case human germline editing was legalized. However, in 2019, the independent German Ethics Council stated that human genome editing could fulfill "a legitimate ethical goal when aimed at avoiding or reducing genetically determined disease risks."

India

In 2017, the Takshashila Institute drafted the "Blue Paper," a document that proposes a specific framework for governing gene editing in crops and in humans for clinical trials.

United States of America (USA)

There is no current legislation in the United States that explicitly prohibits germline engineering, nevertheless, the Consolidated Appropriation Act of 2016 banned the use of U.S. Food and Drug Administration (FDA) funds to engage in research regarding human germline modifications.

United Kingdom (UK)

In the UK, it is illegal to perform this therapy on humans. Embryology is governed by the Human Fertilisation and Embryology Act 1990, while human embryos produced for research purposes cannot be implanted into any woman's womb and must be discarded after 14 days.

World Health Organization (WHO) & International Clinical Trials Registry Platform (ICTRP)

In 2018, W.H.O funded a new advisory committee on developing global standards for governance and oversight of human genome editing, which examines the ethical, social, scientific and legal challenges associated with human genome editing. Since then, the

committee has launched a registry to monitor human gene-editing-related research on a global scale, using the International Clinical Trials Registry Platform (ICTRP).

United Nations Educational, Scientific and Cultural Organization (UNESCO)

In 1977, the United Nations Educational, Scientific and Cultural Organization (UNESCO) released the Universal Declaration on the Human Genome and Human Rights, which addresses the rights of each individual over his/her genes.

Table 1
Countries establishing themselves as leaders in genomics: select projects and their objectives

Country	Initiative	Objective
Australia	Australian Genomics Health Futures Mission	Develop national standards and protocols to enhance data gathering and analysis; promote the value of genomics to the broader community; and encourage government partnerships with philanthropists and businesses
China	100,000 Genome Project	Study how Chinese population transform from health to disease, environmental impacts, and the interactions between environmental factors and genes, and its influence on people's health
Estonia	Personalized Medicine Programme	Develop genotypes that will enable personalized reports for use in everyday medical practice through the national e-health portal
France	France Génomique 2025	Integrate genomic medicine into routine patient care and establish a genomic medicine industry to fuel economic growth. By 2020, France aims to have increased its annual sequencing capacity to 235,000 genomes, of which 175,000 are to come from cancer patients, and the remaining 60,000 from rare disease patients
Japan	Initiative on Rare and Undiagnosed Diseases	Develop innovative drug candidates by targeting novel, single pathological mutations, apply new NGS-based genome analyses to cases that remain unsolved, and facilitate international data sharing
Saudi Arabia	Saudi Human Genome Program	Study more than 5,000 inherited diseases using more than 10,000 samples from Saudi patients with inherited diseases that resulted in identification of more than 2,000 variants underlying the diseases
Turkey	Turkish Genome Project	Sequence the genomes of 100,000 Turkish nationals and increase that number to 1 million genomes by 2023
United Arab Emirates	United Arab Emirates—Dubai Genomics	Sequence all of its 3 million residents. Dubai Genomics is one of numerous projects within the Dubai Future Foundation's "Dubai 10X Initiative," launched to catapult the UAE 10 years ahead of the rest of the world
United Kingdom	100,000 Genome Project	Incorporate genome sequencing in routine healthcare through the Genomic Medicine Service (GMS). Sequenced 71,095 whole genomes
United States	All of Us Research Program	Glean health and wellness data from 1 million or more Americans

Table displaying projects regarding gene-editing mechanisms in the national healthcare system and the conduction of thorough research, retrieved from "Playing with Genes: The Good, the Bad and the Ugly", United Nations, May 2019.

BLOCS EXPECTED

The delegations should be divided into two main blocs according to their financial capabilities as well as religious influence over decision-making processes regarding health care and bioethics.

Bloc 1

The first bloc should consist of more economically developed countries which possess the respective legislation in order to perform human gene-editing research. States in this bloc should be able to fund further development while supporting the use of genetic engineering in medicine. It is important for these countries not to be firmly affected by religion.

Bloc 2

The second bloc could be formed by less economically developed members with a mostly conservative legal framework and strong cooperation with religion. These states may need funding by other states or NGOs in order to conduct research and study about genome modifications on humans.

TIMELINE OF EVENTS

Date	Description of event
1967	DNA ligation links DNA fragments together: a pivotal point in molecular biology which aided to the repair and replication of DNA in all organisms
1970	Purification of type II restriction enzymes: better understanding of how restriction enzymes "cut" DNA and how host DNA works to protect itself became the foundation of the contemporary genetic engineering therapies (i.e., CRISPR)
1971	Gene splicing experiment paves the way for recombinant DNA (rDNA): commencement of the "cut-and-slice" method
1975	Hybridoma technology revolutionizes diagnostics with formulating ever-lasting monoclonal antibodies
1981	The first transgenic animal (has a gene from a foreign organism inserted in its genome) is made
1990	Gradual evolution of cloning and GMOs
1996	The cloning of Dolly the sheep: a milestone for the very first mammal to be cloned from an adult cell
2001	The first gene-targeted drug therapy in order to treat chronic myelogenous leukemia is used
2011	Discovery of TALENs which are designed for efficient cutting at the DNA site of interest
2012	Discovery of CRISPR genome engineering tool which can be developed for a wide variety of fields: cancer treatments, tackling obesity or creating hornless cows!
2015	Human embryo is edited with CRISPR (three years prior to its approval by any governing body)
2017	First CAR T therapy (artificial T-cell receptors used for immunotherapy) for cancer is approved, with their success possible to even replace chemotherapy
2018	Vertex Pharmaceuticals and CRISPR Therapeutics approve the first human clinical trials for the blood disorder beta-thalassemia
2019	A novel gene editing technique which is able to perform targeted small insertions and deletions is created
2020	The results of the CRISPR clinical trials began to show success, with Victoria Gray being the first patient to undergo the sickle cell disease treatment with promising results

RELEVANT RESOLUTIONS, TREATIES AND EVENTS

Universal Declaration on Bioethics and Human Rights of UNESCO in 1997

With the evolution of genetics rapidly accelerating during the 1970s, UNESCO has contributed to the formulation of basic principles in bioethics through in particular the Universal Declaration on the Human Genome and Human Rights, adopted unanimously and by acclamation by the General Conference in 1997 and endorsed by the United Nations General Assembly in 1998, and the International Declaration on Human Genetic Data, adopted unanimously and by acclamation by the General Conference on 16 October 2003.

International Declaration on Human Genetic Data of UNESCO in 2003

Genetic data can be used for medical diagnosis, disease prevention and population genetics studies. To address these concerns, the International Declaration on Human Genetic Data was adopted unanimously and by acclamation at UNESCO's 32nd General Conference on 16 October 2003.

Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights in 2015

In response to the rapid advancements in genetics and genomics, and within the framework of its work program for 2014-2015, the International Bioethics Committee (IBC) decided to update its reflection on the issue of the human genome and human rights, building upon the considerable work done on this topic by the IBC in the past, and in particular, taking into account the Universal Declaration on the Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003), and the Universal Declaration on Bioethics and Human Rights (2005).

PREVIOUS ATTEMPTS TO SOLVE THE ISSUE

At an international level, UNESCO Universal Declaration on the Human Genome and Human Rights provides that germ-line interventions "could be contrary to human dignity" (Article 24). Similarly, the European Convention on Human Rights and Biomedicine states that "an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants" (Article 13).

The Science and Technology Options Assessment (STOA) by the European Parliament considers human enhancement as “a phenomenon linking a range of technologies that at first sight appear very different.” That being said, the debate of human improvement can be expanded to the domains of politics, sociology and ethics. Another similar document is the “Enhancement of international cooperation in the field of human rights” adopted by the General Assembly in 2010.

A very interesting framework is the one proposed by the "Discussion Document: A Framework for Governing Gene Editing of 2017" by The Takshashila Institution. Guided by a few core principles, this discussion document develops a framework to analyse gene editing technologies. The paper explores three broad categories, corresponding to the stage of development of the technology: Fundamental R&D, Commercial R&D and Commercialisation. Each of these groups requires a different governance principle. This idea is used to develop a three-level framework (laboratory stage-trial stage-public release).

At a national level, some legal provisions and guidelines that ban germ-line interventions have already been adopted by more economically developed countries. This latter circumstance is not surprising, because human genetic engineering is possible only where the financial, human and technological means are available. In contrast, less economically developed countries have more urgent problems to solve such as improving access to basic health care services before worrying about human genetic engineering. Nevertheless, some developing nations, such as Brazil and India, have also adopted ethical and legal standards on this issue.

POSSIBLE SOLUTIONS

The delegates should propose solutions addressing the dilemma of which methods human genetic engineering shall be allowed to use, the cases -or circumstances- in which it can be performed, the funding of advanced scientific research and moreover the morality in regard to altering the genome of a human being or using human embryos. Delegates are encouraged to distinguish and address divergently the different types of use of genetic editing (therapeutic or not), as this differentiation can cause further analysis and comparison of ethical considerations and specified cases. Finally, the future of humanity marching towards a genetically enhanced civilization could be considered as debatable, as long as the delegates are aware of their countries' policies and international frameworks.

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