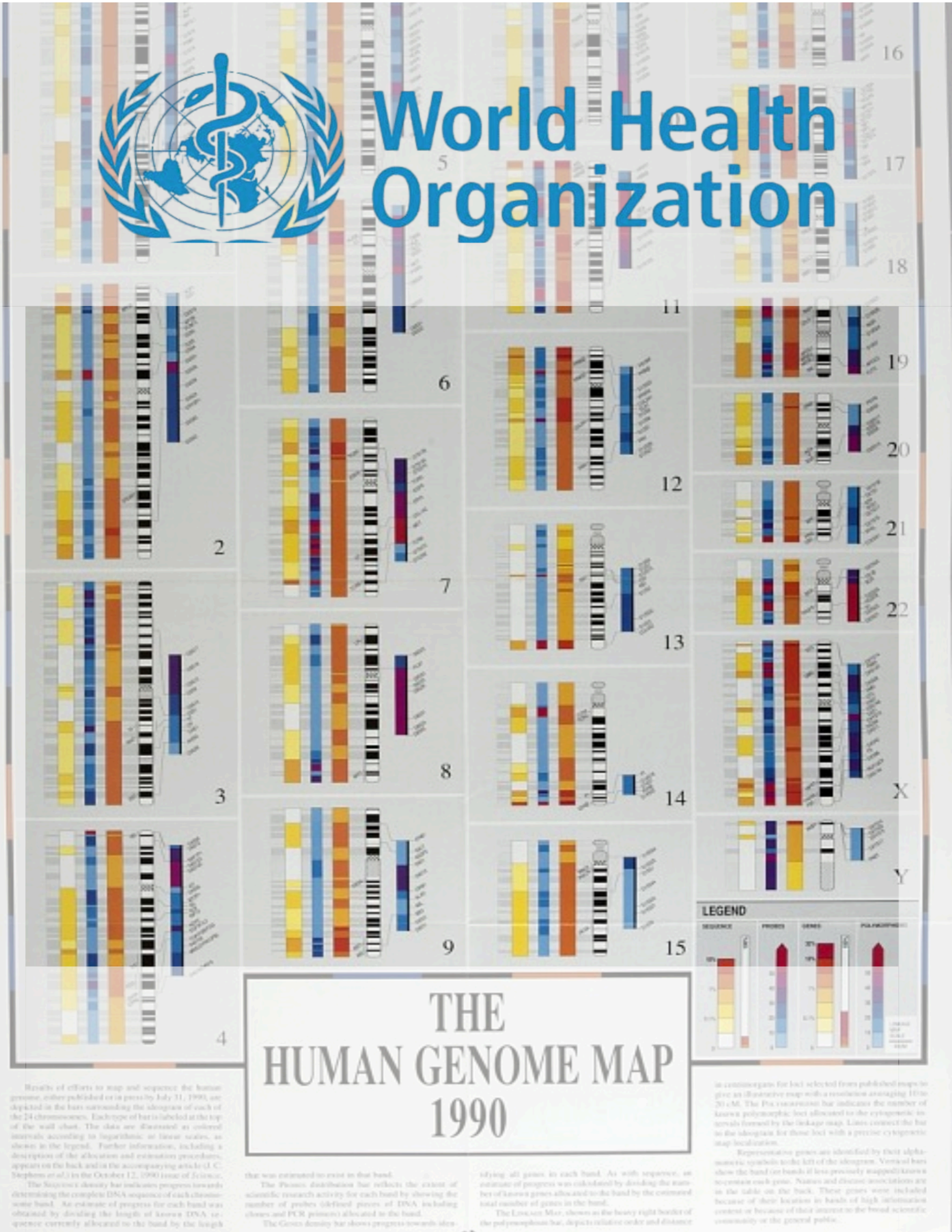
World Health Organization



THE HUMAN GENOME MAP 1990

Ethical Regulation of Gene Editing Technologies

About Chairs

Milo De Giere

Hello! My name is Milo De Giere, and I am absolutely honored to be serving as your chair for this year's GMUNC. I am currently a junior at Gunn High School, and I have been in MUN since my freshman year. Throughout that time, I have had the privilege of attending conferences ranging from just under 30 miles away to a couple of thousand miles away, representing nations as big as Germany and as small as the Cook Islands. I've been given assassination threats and issued a few. Through all of this, the most important thing I've come to appreciate and keep in mind is that MUN is ultimately about personal development. You, as delegates, will all have varying levels of experience, but I hope everyone can walk away from GMUNC XII feeling like they have grown in some way. This is my second year staffing GMUNC, and I am eternally grateful to be able to play a part in providing an environment where delegates can hone and test their diplomatic skills. Hopefully, the committee will run smoothly, and I look forward to seeing the creative, thoughtful, and diplomatic solutions you all bring this year. Happy writing, and good luck.

Sanjana Thangavelu

My name is Sanjana, I am a junior at Gunn High School. I joined MUN my Sophomore year. I have done my best to go to every conference since. Being a part of MUN has taught me how much impact a student's voice can have in solving global problems. This will be my first time co-chairing, and I'm very excited and grateful for this opportunity to help facilitate debate, encourage thoughtful discussions, and offer support as you gain more experience in MUN. I am looking forward to learning from all of you and helping make this committee an engaging and educational experience. Whether this is your first conference or the tenth I hope you have a great time and showcase your voice in world politics. Best of luck to you with your research and writing!

About Committee

In Model UN, the World Health Organization acts with the primary purpose of promoting public health and well-being for all people. Delegates will engage in meaningful discussions concerning gene editing regarding public health. This style of committee aims to craft frameworks that foster international cooperation to ensure conduct that balances scientific innovation with ethical responsibility and is equitable across a diverse set of nations and populations.

Foreword

Whether you are a first-time or returning delegate, I am honored to welcome you all to the World Health Organization of Gunn Model United Nations Conference XII. Having previously staffed GMUNC, I am exhilarated to be a part of this conference once again and excited for another memorable year of debate. This committee examines the complex ethical debate surrounding genetic engineering and its applications in therapeutic and agricultural practices, while addressing public health concerns, ethical arguments, inclusivity, safety concerns, accessibility, and rogue practices. This committee will act with the goal of producing resolutions that prioritize ethical guidelines or international standards that account for disparities, widening global health inequalities, and accountability. Since this is a GA, all writing will be done in the form of resolutions.

Position papers are due on October 3 to be considered for a research award, with the final deadline on October 10. If you do not submit a position paper by this date, you will not be eligible for any committee awards. Please send position papers and committee-specific inquiries to the committee email address: WHOGMUNC2025@gmail.com. Additionally, all delegates are required to complete contact and medical forms to participate in the conference. Please confirm with your delegation that the required documents have been submitted.

I wish you the best with writing your position papers and look forward to seeing everyone on October 11, 2025, for GMUNC XII.

Milo De Giere
Head Chair

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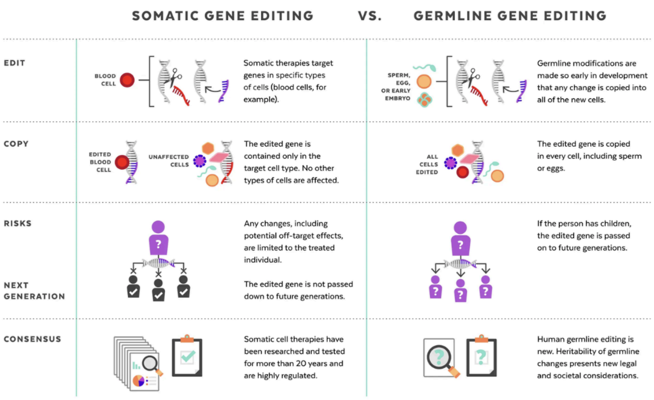
Introduction

The science fiction and Hollywood worlds are among the most prominent representations of genetic engineering, having long shaped public perception of such technologies. Dystopian films such as *Gattaca* and *The Fifth Element*, as well as blockbusters like *Spider-Man* and *Jurassic Park,* and classical novels like Mary Shelley's *Frankenstein*, offer an exaggerated and dramatized portrayal of what current technological innovations, combined with legal and ethical constraints, can enable. [1] However, as scientific innovations continue to emerge, concepts previously confined to the world of fiction have materialized as a reality, raising valid ethical concerns. With recombinant DNA-based cloning experiments on the rise and a plethora of potential coming from genome editing, to what extent can and should these technologies be used in practice? Human gene editing technologies promise great advancement for the future of humanity and the medical field. These technologies hold the potential to decrease heritable diseases, improve cancer treatments, open space for targeted treatment options, increase reproductive options for infertile individuals, and alleviate global health inequalities. However, it also raises ethical concerns related to eugenics, limited access, and heritable changes. How can ethical boundaries be used to govern their usage in a way that promotes public health while ensuring responsible and safe use?

Genetic engineering in modern terms generally refers to the technology surrounding recombinant DNA and can be defined as the artificial manipulation, modification, or recombination of DNA or other nucleic acid molecules with the goal of altering an organism or its hereditary line. [2] In general, genetic engineering follows the procedure of using a restriction enzyme to cut both the vector and the foreign DNA to create compatible “sticky ends. These ends are then joined by DNA ligase, acting as the molecular glue, forming a recombinant plasmid. This recombinant can be introduced into a host cell (like bacteria) for replication and expression. [3] More recent developments have popularized the use of CRISPR-Cas (Clustered Regularly Interspaced Short Palindromic Repeats) as a less labor-intensive, cheaper, and more precise method compared to other recombinant techniques, such as ZFN and TALENs. CRISPR is unique in its utilization of RNA strands, which promise numerous therapeutic applications. [4]



	SOMATIC GENE EDITING	GERMLINE GENE EDITING
EDIT	Somatic therapies target genes in specific types of cells (blood cells, for example).	Germline modifications are made so early in development that any change is copied into all of the new cells.
COPY	The edited gene is contained only in the target cell type. No other types of cells are affected.	The edited gene is copied in every cell, including sperm or eggs.
RISKS	Any changes, including potential off-target effects, are limited to the treated individual.	If the person has children, the edited gene is passed on to future generations.
NEXT GENERATION	The edited gene is not passed down to future generations.	
CONSENSUS	Somatic cell therapies have been researched and tested for more than 20 years and are highly regulated.	Human germline editing is new. Heritability of germline changes presents new legal and societal considerations.

Graphic by Judy Blomquist/Harvard Staff comparing Somatic and Heritable gene editing

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[1] Genetic Literacy Project. “Genetic Engineering Goes to Hollywood: 10 Movies You’ll Love and More That You’ll Hate.” Genetic Literacy Project, 21 June 2019, https://geneticliteracyproject.org/2019/06/21/genetic-engineering-goes-to-hollywood-10-movies-youll-love-and-more-that-youll-hate/. Accessed 4 July 2025

[2] World Health Organization. “Human Genome Editing.” WHO, https://www.who.int/health-topics/human-genome-editing/#tab=tab_1. Accessed 4 July 2025.

[3] BBC. “Ethical Issues - Genetic Engineering.” BBC Bitesize, https://www.bbc.co.uk/bitesize/guides/ztwg7p3/revision/7. Accessed 4 July 2025.

[4] “CRISPR vs. Other Gene Editing Methods.” Biocompare, https://www.biocompare.com/Editorial-Articles/576583-How-Does-CRISPR-Compare-with-Other-Gene-Editing-Methods/#:~:text=The%20most%20important%20advantage%20CRISPR,than%20Cas9%20when%20targeting%20heterochromatin. Accessed 4 July 2025.

Therapeutic genome editing can be categorized as somatic or heritable, differing in the type of cells that are altered. Alterations made to somatic cells (non-reproductive cells) can not be passed down to offspring. In contrast, heritable human genome editing (HHGE) utilizes germline cells (sperm, egg, or embryos) that pass traits to subsequent generations. Somatic editing is widely accepted in many parts of the world and contributes to numerous life-saving treatments, such as HIV and sickle cell anemia. [5] [6] Heritable human genome editing raises the most ethical controversy. While these innovations offer a revolutionary ability to cure diseases, prevent genetic disorders, and even improve agriculture, they raise critical ethical, social, and global governance concerns. [7] With the prospect of altering generations of individuals through heritable alteration, numerous ethical arguments arise regarding eugenics, inherited health concerns, and the lack of inclusivity in both access and genomic research. [8] Minority populations who bear the greatest health burdens historically suffer unequal benefits from emerging innovations such as CRISPR. Additional concerns arise from the safety and experimental nature of much of this field, as well as the dangers that come with relaxed regulation. [9]

The World Health Organization provides a platform for international collaboration, setting global standards that guide the ethical and equitable usage of health technologies. However, it is ultimately the responsibility of each member state to interpret and implement these standards. As such, delegates are encouraged to consider how gene editing technologies intersect with specific public health needs, scientific capabilities, legal frameworks, and ethical stances of their respective countries. The World Health Organization prioritizes promoting public health, reducing global health inequities, ensuring scientific transparency, and, above all, upholding human dignity. Given the ethical lens of this committee, particular attention should be directed toward the social and moral implications of the use and regulation of genome editing, as well as the disparities in access across regions. [10]

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[5] Innovative Genomics Institute. “CRISPR Ethics.” CRISPRpedia, http://innovativegenomics.org/crisprpedia/crispr-ethics/. Accessed 4 July 2025.

[6] Walsh, Colleen. “Perspectives on Gene Editing.” Harvard Gazette, 21 Jan. 2019, https://news.harvard.edu/gazette/story/2019/01/perspectives-on-gene-editing/. Accessed 4 July 2025.

[7] National Academies of Sciences, Engineering, and Medicine, et al. Human Genome Editing: Science, Ethics, and Governance. National Academies Press, 14 Feb. 2017. Chapter 4, “Somatic Genome Editing,” NCBI Bookshelf, https://www.ncbi.nlm.nih.gov/books/NBK447271/.

[8] National Human Genome Research Institute. “Ethical Concerns.” Genome.gov, https://www.genome.gov/about-genomics/policy-issues/Genome-Editing/ethical-concerns. Accessed 4 July 2025.

[9] “Will the ‘Rogue Science’ That Created Genetically Edited Babies Lead to Backlash against Research?” CBC Radio: Quirks & Quarks, 1 Dec. 2018, https://www.cbc.ca/radio/quirks/dec-1-2018-genetically-edited-babies-fast-radio-bursts-spinal-injury-patients-walk-again-and-more-1.4925916/will-the-rogue-science-that-created-genetically-edited-babies-lead-to-backlash-against-research-1.4925929. Accessed 4 July 2025.

[10] World Health Organization. “WHO Releases New Principles for Ethical Human Genomic Data Collection and Sharing.” WHO, 20 Nov. 2024, https://www.who.int/news/item/20-11-2024-who-releases-new-principles-for-ethical-human-genomic-data-collection-and-sharing#:~:text=The%20World%20Health%20Organization%20(WHO)%20has%20issued,use%20and%20sharing%20of%20human%20genomic%20data. Accessed 4 July 2025

Historical Context

Foundations of Genetic Engineering and Modification

On February 28th, 1953, Francis Crick and James Watson famously discovered the DNA double helix, the stable polymer of repeating nucleotides used in the modern scientific world. While this molecule was first identified in the 1860s by a Swiss chemist, this duo is often credited for defining the helix structure that would revolutionize the field of biotechnology and set the stage for understanding replicating and manipulating genetic material.[11] The process of forming recombinant DNA involved three major enzymes developed and discovered between the 1960s and early 70s. The implementation of these enzymes defines what's modernly known as genetic engineering. Engineering the human genome is done in hopes of altering the sequence of nucleic base pairs responsible for protein synthesis, which ultimately changes a desired trait. This process relied on several key enzymes, one of them being polymerase. First discovered by Arthur Kornberg in 1956, this enzyme assembles nucleotides into DNA or RNA, playing a central role in replication, repair, and degradation. Kornberg, a prolific researcher, often described his career as a "love affair with enzymes." His passion was one that led to the successful synthesis of all five nucleotides and the in vitro replication of DNA using DNA polymerase. [12] In vitro refers to an experiment conducted outside a living organism, a method often used in modern biotechnologies for medicinal treatments.

Genome editing begins with the isolation of a desired gene, performed by a restriction enzyme. Following the discovery of ligase in 1967, Werner Arber discovered the first restriction enzyme in 1968. Although the specific restriction enzyme hypothesized in 1968 is no longer used in modern procedures, the discovery of this enzyme was crucial to the development of genetic engineering. Werner Arber theorized that bacterial cells produce two enzymes, one of which can identify and cut foreign DNA, and one that recognizes host DNA and protects it from cleavage.[13] These two enzymes work symbiotically to form the basis of early genetic engineering. The restriction enzyme discovered binds at a recognition site and uses facilitated diffusion to search for target DNA to cut. Because of its mechanism, cuts are unpredictable and less favorable in modern genome modification techniques.[14] To utilize such an enzyme at a microcellular level, much higher precision and accuracy were needed.

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[11] Synthego. "A Brief History of Genome Engineering." Synthego, https://www.synthego.com/learn/genome-engineering-history. Accessed 10 July 2025.

[12] Lenzer, Jeanne. "Arthur Kornberg." *BMJ : British Medical Journal*, vol. 336, no. 7634, 5 Jan. 2008, p. 50, https://doi.org/10.1136/bmj.39429.714086.BE.

[13] See note 11

[14] Pingoud, Alfred et al. "Type II restriction endonucleases--a historical perspective and more." Nucleic acids research vol. 42,12 (2014): 7489-527. doi:10.1093/nar/gku447

Development of Modern Genetic Engineering

The 1970s marked the beginning of what modern biotechnologists refer to as genetic engineering, with the discovery of the restriction enzyme. Modern practice uses Type II restriction enzymes (REases) that operate on the basis of Linear and facilitated diffusion. These enzymes perform with higher precision, allowing for exploration of more complex therapeutic procedures and uses.[15] With the refinement of restriction enzymes enabling precise manipulation of DNA, the field of genomics and biotech gained the tools to move past observation and into active construction of genetic material, a critical point in the birth of modern gene therapies and genetic engineering.

What was previously a theoretical possibility in gene manipulation became tangible and a replicable process due to the formation of Recombinant DNA. rDNA was invented largely through the work of Herbert W. Boyer, Stanley N. Cohen, and Paul Berg, although many other scientists made important contributions to the new technology as well. rDNA is the way in which genetic material from one organism can be artificially introduced into the genome of another organism, where the material can be replicated and expressed. This is the foundation on which modern genetic engineering operates. In 1971, Boyer and Cohen came to realize that the enzyme EcoR1 made staggered cuts, allowing for the combination of DNA from other sources as long as the piece possessed complementary cuts. Numerous individuals began recognizing the feasibility of using human genetic information in plasmids as a means of combating disease and treating birth disorders. Commercial businesses quickly started up with the objective of capitalizing on their new rDNA technology. Despite the potential this emerging technology showed, as the forefront companies developed, so did controversy.

As companies began to commercialize the use of rDNA, public fear of cloning grew. These early ethical considerations were met with growing calls for caution and responsibility within the scientific community. The scientific community pushed for self-regulation and transparency. Scientists with a sense of public responsibility initiated conferences such as the Asilomar Conference in 1975. Specifically, this conference would be an attempt at self-regulation within the scientific community in order to address the probable biohazards of gene-editing technology.[16]

The Era of Gene Therapy and the CRISPR Revolution

RDNA, its realization and regulation brought genetic engineering onto the scientific stage; however, this early gene editing period remained constricted to this point. Gene modification at this point was purely concerned with what was possible in labs and didn't often extend beyond this point. The era of gene therapies transitions what was once possible in a test tube to being an applicable field of in real-world medical issues. This transition period was slow, marked by frequent failures and high risks.
It wouldn't be until it was proven that viruses could successfully insert genes into cells

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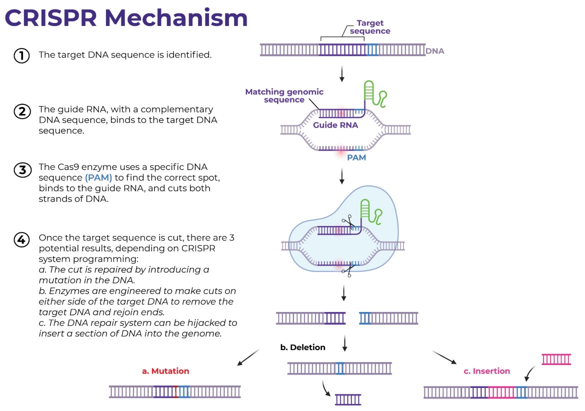
[15] Lenzer, Jeanne. "Arthur Kornberg." *BMJ : British Medical Journal*, vol. 336, no. 7634, 5 Jan. 2008, p. 50, https://doi.org/10.1136/bmj.39429.714086.BE.

[16] Cave, Abigail. "Asilomar Conference (1975) | Embryo Project Encyclopedia." *Asu.edu*, 9 July 2024, embryo.asu.edu/pages/asilomar-conference-1975.

that biopharmaceutical industries exploded with genomics. [17] Technically, this integration wasn't actually genetic engineering as defined by modern terms, but much like many early experimentations in the 1980s-90s, it was a pioneering example of gene therapies and demonstrated the feasibility for future somatic modifications.

Gene therapy operates on the basis of Ex vivo and in vivo processes. Ex vivo involves the removal of cells from a host patient in order to introduce the new genetic material. This targets cells that are easily removable and replaceable, such as blood and skin.[18] The first clinically approved CRISPR-based genome editing therapy was an ex vivo treatment of skin cancer.[19] In vivo, on the other hand, involves a direct IV infusion of the carrying vector into the bloodstream in order to reach a target organ. This vector acts as a vehicle for delivery to less accessible regions such as the eye, brain, or liver. This is important to keep in mind moving forward through a period of renaissance for gene therapy, in which applications become much more accessible and popularized. Moving forward in history, the refined era of gene therapies came with the introduction of a revolutionary process known as CRISPR.

In 1987, Yoshizumi Ishino and his team at Osaka University, during their study of the E. coli genome, developed what would later be popularized as CRISPR.[20] The actual functional usage of CRISPRs as a bacterial immune system had not been inferred until much later, with key discoveries made in the early 2000s by Francisco. In 2012, the genome editing technology was officially co-discovered by pioneering scientists Jennifer Doudna and Emmanuelle Charpentier. CRISPR-Cas9 is a revolutionary gene-editing technology that employs a protein called Cas9 and a guide RNA molecule to target and modify DNA sequences within a genome. The Cas9 protein acts as molecular scissors guided by the RNA to cut DNA at a desired location, allowing genes to be added, deleted, or altered, providing precision and efficiency in manipulation. This technology has opened numerous unexplored opportunities for gene therapy, disease treatment, and crop expansion, revolutionizing genome editing. [22]



① The target DNA sequence is identified.

② The guide RNA, with a complementary DNA sequence, binds to the target DNA sequence.

③ The Cas9 enzyme uses a specific DNA sequence (PAM) to find the correct spot, binds to the guide RNA, and cuts both strands of DNA.

④ Once the target sequence is cut, there are 3 potential results, depending on CRISPR system programming:
a. The cut is repaired by introducing a mutation in the DNA.
b. Enzymes are engineered to make cuts on either side of the target DNA to remove the target DNA and rejoin ends.
c. The DNA repair system can be hijacked to insert a section of DNA into the genome.

Visual Depiction of CRISPR Mechanism [21]

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[17] Fliesler, Nancy. "A Short History of Gene Therapy." Boston Children's Answers, 22 Dec. 2020, https://answers.childrenshospital.org/gene-therapy-history/ Accessed 10 July 2025.
[18] Williams, Elliott. "In Vivo and Ex Vivo Gene Therapies Explained." Genomics Education Programme, 26 July 2024, https://www.genomicseducation.hee.nhs.uk/blog/in-vivo-and-ex-vivo-gene-therapies-explained/ Accessed 10 July 2025.
[19] FDA Approves First Gene Therapies to Treat Patients with Sickle Cell Disease." *U.S. Food and Drug Administration*, 8 Dec. 2023, https://www.fda.gov/news-events/press-announcements/fda-approves-first-gene-therapies-treat-patients-sickle-cell-disease. Accessed 10 July 2025.
[20] Ishino, Yoshizumi, Mart Krupovic, and Patrick Forterre. "History of CRISPR-Cas from Encounter with a Mysterious Repeated Sequence to Genome Editing Technology." *Journal of Bacteriology*, vol. 200, no. 7, 2018, e00580-17. https://doi.org/10.1128/JB.00580-17
[21] "What Is CRISPR?" *RNA Therapeutics Institute*, University of Massachusetts Medical School, https://www.umassmed.edu/rti/biology/crispr-cas9/
[22] "What Is CRISPR? Your Ultimate Guide." *Synthego*, https://www.synthego.com/learn/crispr. Accessed 4 July 2025.

It is in these applications where the most pressing ethical debate arises. Jiankui's 2018 CRISPR baby scandal significantly intensified public criticism. Scientist He Jiankui proclaimed to have edited the genes of twin embryos using CRISPR-Cas9 to disable the CCR5 gene in the embryos to make the twins resistant to HIV. It sparked a global outburst due to its ethical violations, lack of informed consent, and the potential long-term consequences of altering heritable traits, where “off-target” mutations could be potentially passed down to future generations. [23] The twins Lulu and Nana were born, and it was announced that the experiment was successful and that they were safe. Due to public pressure and ethical violations, He Jiankui was suspended from his research activities and sentenced to three years in prison for illegal medical practices. As a result, the case of the 2018 CRISPR baby scandal emphasized the need for ethical caution and liable governance in the field of human gene editing. This event reignited global concern over heritable human genome editing risks of heritable health issues, the encouragement of eugenic-based ideologies, and the reinforcement of social inequality took the forefront in ethical conversation. Moreover, ethicist Michael J. Sandel has noted that unregulated applications, such as utilizing gene editing technology to edit for beauty and intelligence, have sparked debate among many, posing serious moral concerns and questions that may lead to the commodification of children as “projects of our will,” rather than individuals with autonomy. [24]

In response, the World Health Organization and other global entities have called for international guidelines to enforce informed consent, ensure the ethical conduct of clinical trials, and prevent clinics from conducting unsafe procedures under the guise of therapeutic interventions. However, despite this, voids remain in global governance structures regarding equitable access to these innovations for developing countries, where underrepresentation in genomic research threatens to broaden existing health disparities. Despite the extensive potential of gene-editing technologies to treat diseases such as sickle cell anemia and monitor viruses, their uneven distribution and inconsistent likelihood of misuse underscore the urgent need for a globally coordinated regulatory framework.

Delegates are encouraged to explore historical events beyond those mentioned that are relevant to arguments made in their position papers. Research regarding how nations have responded to past developments is essential to understanding the full scope of a country's stance on an issue.

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[23] Raposo, Vera Lucia. “The First Chinese Edited Babies: A Leap of Faith in Science.” JBRA assisted reproduction vol. 23,3 197-199. 22 Aug. 2019, doi:10.5935/1518-0557.20190042

[24] Sandel, Michael J. Ethical Implications of Human Cloning. Harvard University, https://scholar.harvard.edu/files/sandel/files/ethical_implications_of_human_cloning.pdf

Past UN Action

Early Action

Following the decades of rapid development in the golden age of genomics. The potential that early genome sequencing brought the urgent need to address the ethical and human rights implications of such technology. As a response to emerging criticism, UNESCO developed the first international agreement on genomics, the 1997 Universal Declaration on the Human Genome and Human Rights. It regards the human genome as the "heritage of humanity". And argues that the human genome underlies the fundamental unity of all members of the human family and their inherent dignity and diversity.[25] It is for this reason that the benefits of genetic research must extend to everyone. This declaration takes a stance that aligns with principles within human rights and medical ethics, outlining recommendations for conduct regarding human dignity, the rights of involved persons, research on the human genome, the Exercise of scientific activity, and international cooperation. [26]

While the declaration laid critical ethical groundwork for genomics, it was developed in 1997 before the emergence of many key technologies that define human genetic engineering. Innovations such as CRISPR and the ethical concerns that come with them are not directly addressed.[27] This declaration suffers numerous limitations, notably its non-binding status as a declaration, a form of "soft law" that expresses principles and aspirations but is not legally obligated for states.[28] However, the ethical and human rights-based approach to genetics and genome editing laid out offers a substantial starting point for future mechanisms and frameworks for ethical conduct. Early legislation such as this is important to consider when writing resolutions and developing solutions.

UN Commitments and Ethical Responsibility

Recognizing that biotechnology in a rapidly developing age can reshape public health worldwide, the WHO sets itself as the foremost international authority for setting standards for emerging sciences. The World Health Organization strives to be proactive in identifying and involving itself in the often complex science and innovation areas that pose direct impacts on public health. In accordance with The Global Program of Work1 (2019-2023), WHO is committed to maintaining an engaged role in science and innovation and is committed to identifying opportunities that may improve global health and support countries in the implementation of the norms, standards, and agreements that surround emerging opportunities.[29]

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[25] "Universal Declaration on the Human Genome and Human Rights." UNESCO, 11 Nov. 1997, https://www.unesco.org/en/legal-affairs/universal-declaration-human-genome-and-human-rights?hub=387

[26] "Universal Declaration on the Human Genome and Human Rights." UNESCO, 11 Nov. 1997, https://www.unesco.org/en/legal-affairs/universal-declaration-human-genome-and-human-rights?hub=387

[27] Harmon, Shawn. The Significance of UNESCO's Universal Declaration on the Human Genome and Human Rights. University of Edinburgh, 2005. PURE University of Edinburgh, https://www.pure.ed.ac.uk/ws/portalfiles/portal/18457597/Harmon_Significance_of_UNESCOs_Universal_Declaration_on_the_Human_Genome_and_Human_Rights.pdf

[28] "Hard Law/Soft Law." Glossary, European Center for Constitutional and Human Rights (ECCHR), https://www.ecchr.eu/en/glossary/hard-law-soft-law/

[29] World Health Organization. Terms of Reference for the Technical Advisory Group on Genomics. 1 June 2023, https://cdn.who.int/media/docs/default-source/research-for-health/tors-for-ag-on-genomics-1_06_2023_qns_cleared.pdf?sfvrsn=ad016e29_3

The United Nations, as a larger body, sets much of the global agenda for sustainable development in accordance with the 17 SDGs adopted in 2015. These goals represent the UN's most comprehensive and widely accepted frameworks for conduct in global challenges. When considering regulations and actions related to genetic engineering, the SDGs provide a framework for evaluating potential benefits and risks, as well as how these align with global priorities. UN action surrounding genetic engineering often considers this, ensuring that development is not only scientifically beneficial but also ethically guided, inclusive, and aligned with social and environmental goals. Standards such as these are crucial in coordinating international efforts between differing national capacities.

Genomics poses significant promise in advancing numerous SDGs. A major application of human genome editing centers around genetic diseases affecting approximately 10 out of every 1000 people, as estimated by the WHO. [30] There are no approved treatments for approximately 95% of rare diseases. Of the 5% of approved therapy options, only a few are limited to symptom control and comfort care. About 30% of patients with rare diseases die before their fifth birthday.[31] Genome therapies and research have the potential to expand treatment options and reduce mortality, further advancing the achievement of SDG 3. An illustration of this potential lies in disease control. A pressing disease labeled by the UN as a priority under SDG3, malaria, had an estimated 241 million cases in 2020, an increase from 227 million in 2019. Malaria has high morbidity and mortality in tropical and subtropical regions. CRISPR/Cas-9 mediated gene drives show potential to suppress the mosquito population responsible for the increased rate of infection.[32]

Beyond health, genomic technologies have shown potential to advance SDGs such as reducing poverty and approaching zero hunger through the usage of GM crops.

Ongoing Action

In 2021, the WHO's Director-General established the Science Council to advise on the WHO's scientific agenda. At its first meeting, it became clear that genomics would have substantial and extensive benefits for personal and public health. The science council made numerous recommendations, falling into four categories of goals: the promotion of genomics through advocacy, the implementation of genomic methodologies, collaboration among entities engaged in genomics, and attention to the ethical, legal, and social issues (ELSI) raised by genomics. A key recommendation that emerged from this report was the formation of an advisory group known as TAG-G [33]

The 15-member advisory body operates under these four goals with the function of providing technical guidance and recommendations on matters of accessibility and

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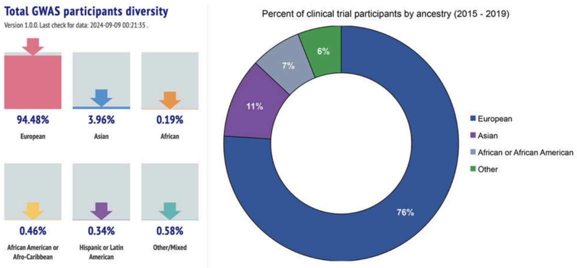
[30] "Disease Examples." The Gene Home, https://www.thegenehome.com/basics-of-genetics/disease-examples

[31] Braga, Luiza Amara Maciel et al. "Future of genetic therapies for rare genetic diseases: what to expect for the next 15 years?." Therapeutic advances in rare disease vol. 3 26330040221100840. 10 Jun. 2022, doi:10.1177/26330040221100840

[32] Snuzik, A. Assessing CRISPR/Cas9 potential in SDG3 attainment: malaria elimination—regulatory and community engagement landscape. Malar J 23, 192 (2024). https://doi.org/10.1186/s12936-024-04996-x

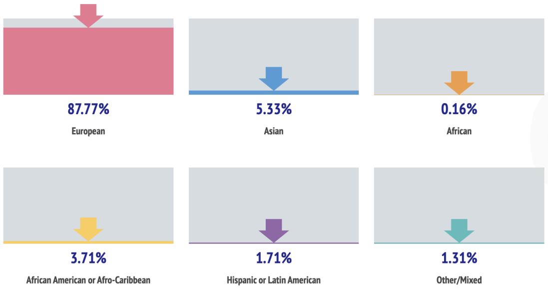
[33] "Technical Advisory Group on Genomics (TAG-G)." World Health Organization, https://www.who.int/groups/technical-advisory-group-on-genomics-%28tag-g%29

inclusivity, as well as contributing to progress assessments.[34] Discussion and action taken in this body are reported annually to the World Health Organization. In November of 2024, the WHO issued a set of principles for the ethical collection, access, use, and sharing of human genomic data as a product of TAG-G guidance. [35] These principles are centered around the concern that as genomic data expands, so do the ethical challenges surrounding privacy, equitable access, and responsible data management. This is achieved through outlining globally applicable principles that guide the ethical, legal, and equitable use of human genome data, thereby fostering public trust and protecting the rights of individuals and communities.



Genetic diversity Graphic 2024, Manuel Corpas, Mkpouto Pius, Marie Poburennaya, Heinner Guio, Miriam Dwek, Shivashankar Nagaraj, Catalina Lopez-Correa, Alice Popejoy, Segun Fatumo, Bridging genomics' greatest challenge: The diversity gap, Cell Genomics, Volume 5, Issue 1, 2025, 100724, ISSN 2666-979X, https://doi.org/10.1016/j.xgen.2024.100724.

TAG-G operates with the main goal of improving genetic diversity in data sets. Historically, Genome Wide Association Studies are conducted on primarily European populations. Across the globe, the issue of underrepresentation has prompted significant efforts to enhance diversity. Projects such as The All of Us project have been successful in bridging the genetic gap. Data sets with diversity do exist, but issues arise in the data that studies choose to use.. The majority of genetic studies currently rely on the same European-based datasets from the UK Biobank. This has led to a periodic decrease and stagnation in the percentage of underrepresented populations included in studies. The most recent survey in 2025 shows an increase in marginalized genetic data; however, it still doesn't reflect the composition of the human species across the entire globe. Data sets are advancing towards achieving diversity after the formation of TAG-G, but the application of this information is still quite limited. Delegates should consider how to build upon existing frameworks to better address issues of underrepresentation, inequity, and ethical governance globally.



Genetic data diversity statistics 2025 [36]

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Current Situation

Genetic Diseases: Their Causes and Treatments

A genetic disorder is a disease caused by a mutation affecting genes or chromosomes. These abnormalities can be either chromosomal, multifactorial, or monogenic. These inheritance patterns often shape how diseases manifest and what kinds of therapies are designed to treat them. Although considered rare disorders individually, collectively, they affect 10 out of every 1000 people, meaning between 70 million and 80 million people are living with genetic diseases worldwide. [37] Such genetic conditions can severely impair quality of life and often lead to premature death. Although relatively prevalent in society, treatment options are limited to symptom management. Developments in gene therapy hold potential to extend treatment options beyond this; however, as of 2022, approved treatments accounted for only about 5% of disorders.[38]

WHO urges member states to commit to integrating rare diseases into national health planning, elevating the issue of rare diseases to a global health priority.[39] Personalized applications of CRISPR, although still in a major developmental stage, make great strides towards achieving the WHO goals. The first instance of a successful personalized application of CRISPR gene editing occurred earlier in 2025 at the Children's Hospital of Philadelphia. The patient, KJ, was born with a rare metabolic disease: severe carbamoyl phosphate synthetase I deficiency, which interferes with the liver's ability to break down byproducts from protein metabolism. Oftentimes, in young patients, the baby would have to develop enough to receive a liver transplant. This waiting period can be fatal, with the risk of ammonia build-up having the potential to cause permanent brain damage. This personalized CRISPR technique was aimed at correcting a specific gene mutation in the baby's liver cells. "We were very concerned when the baby got sick, but the baby just shrugged the illness off," says Penn geneticist Kiran Musunuru.[40] [closing sentence] This case study demonstrates immense potential for future applications to rare diseases and should inform delegates final verdict on ethical responsibility and innovation.

With the success of individualized gene therapies arising attention is now turned toward more common or complex conditions to work toward public health betterment. A prediction projects 25.2 million people to be living with parkinsons worldwide in 2050, representing a 112% increase from 2021. The World Health Organization has estimated that neurodegenerative diseases, including parkinsons disease and alzheimers will become the second leading cause of death worldwide by 2040.[41] This puts parkinsons disease as an area of interest for public health developments. Parkinson's disease is a syndrome linked to the deterioration of neurons, mainly associated with age progression.

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Symptoms worsen from a progressive loss of dopamine affecting key motor skills. In 1969, Levodopa was hailed as a miracle drug that would supposedly cure parkinsons; however, its effects were inconsistent and possessed uncontrollable side effects.[42] Since then, the field of Parkinson's treatment has turned toward gene therapies to increase dopamine production, support the survival of dopamine neurons, reset abnormal brain circuitry, and counteract genetic mutations that contribute to Parkinson's risk. Understanding the potential of gene therapies in rare diseases are crucial for crafting resolutions and writing position papers such that WHO values in innovation are properly upheld.

Global Inequality and Underrepresentation

In recent years WHO has made commitments to addressing public health inequality emphasizing that measures to address income inequality, structural discrimination, conflict and climate disruptions are key to overcoming deep-seated health ineequities. Gene therapy much like any immerging health technology is heavily effected by such imbalances. This committee aims to alleviate and combat inequities. One key example of this phenomenon is disproportionate disease burden. The Middle East and North Africa (MENA) Region is disproportionately affected by genetic disease. This is partly due to the practice of consanguinity, a culturally prevalent tradition of close relative marriage, which represents 20-50% of marriages in the region. Children of such unions have an increased risk of genetic disease due to the increased probability of autosomal recessive gene mutations. [43] While rare diseases individually are, as the name suggests, relatively rare, their cumulative prevalence is very high. Rare diseases lack public awareness and expertise, and significantly impact the marginalized. [44] Especially in the MENA region, diseases such as these are insufficiently managed or poorly treated, causing substantial social and economic burdens on families and healthcare systems. The genomic gap is exacerbated by the limited access to genomic services.

Rooted in the same genetic and cultural factors, β Thalassemia, an inherited recessive blood disorder affecting mainly Mediterranean nations, is an example of a genetic disorder intensified by consanguinity. [45] Where these two regions differ is in the approach taken in order to curb genetic disease. The implementation of carrier screenings performed across countries such as Cyprus and Iran reduced the burden these disorders pose on individuals. After the inclusion of this practice, the frequency of the β Thalassemia mutation present at childbirth drastically dropped.

A long-standing ethical concern with gene therapies is that such technologies will further advantage the already advantaged. From an ethical standpoint, the field of gene therapy is at risk of becoming a prime example of health care inequity. Social standings and already existing societal hierarchies have long influenced health care.[46] In the United

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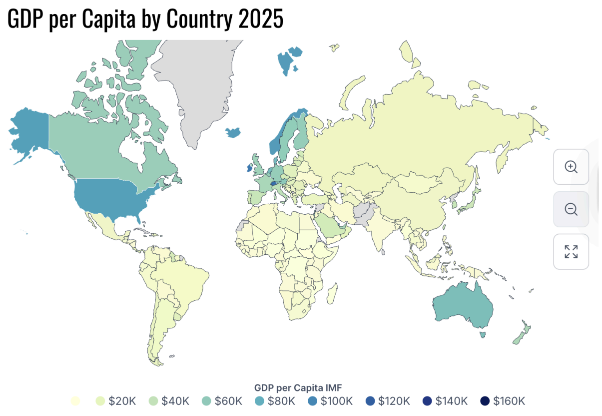
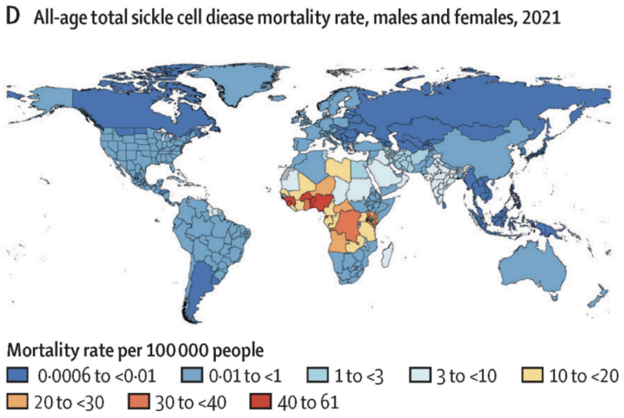
States, for example, disparities arise as a result of pervasive racial and ethnic discrimination. Health inequity is one of the WHO's top priorities, and despite global commitment to reducing inequalities, progress made has been uneven.[47] Health disparities are a huge issue spanning across economic and social demographics. In the context of gene therapies, the first approved therapy in Europe, Chimeric Antigen Receptor cell therapy, was priced at €1 million. High price tags on novel pharmaceuticals are an issue that plagues many seeking medical treatments. Cancer therapies, for example, pose a significant financial burden on individuals and families. In high-income countries, accessing gene therapies is especially challenging. Considering the bleak reality of seeking gene treatments in HICs, accessing the same technologies in low and middle-income countries can only be described as hopeless, grim, dreadful, and harrowing. This inequity becomes even more apparent when comparing the most prominent genetic disease, sickle cell, and GDP per capita.



GDP per Capita by Country 2025 graphic [48]



Sickle Cell prevalence 2021 graphic [49]

Legislation and Regulation

National approaches to genome editing vary drastically, in a committee it is imperative that delegates understand how to navigate differing legislation and conditions to properly ensure global cooperation. In May 2024, new language in South Africa's National Health Research Ethics Guidelines on heritable human genome editing (HHGE) sparked controversy. In a report, the rationale was that the new guidelines have opened the door to genetically modified children. Consequently, the National Health Research Ethics Council (NHREC) also clarified that heritable human genome editing remains illegal under the National Health Act of South Africa and that the guidelines were not to permit or legalize such activity but to show South Africa's ethical practices and legal boundaries. The NHREC has reasserted that heritable human genome editing research is still under the ambit of stringent regulation by South Africa's 2014 biomedical legislations and

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guided by constitutional values such as dignity, equality, and freedom.[50] Moreover, in November 2024, South Africa took it a step further with the revision of its guidelines to include a provision declaring conditions under which heritable human genome editing may be entertained,for example, being scientifically founded and ethically screened for long-term monitoring. [51] This middle ground that exists in the majority of nations does not legalize HHGE, but neither does it prohibit it entirely; it signifies the nation's attempt to remain scientifically up-to-date and uphold ethical responsibilities simultaneously.

In stark contrast, the European Union specifically bans germline gene editing. Germline editing is regulated by the EU Commission, the European Medicines Agency, and the Federation of European Academies of Medicine. 15 of 22 Western European nations have additional regulations banning human germline engineering. [] Ethical regulations include the prohibition of ‘eugenic practice, in particular those aiming at the selection of persons’, this declaration from the EU charter of Fundamental Rights is ratified by 29 of the 47 European states. [52]

Varying countries have contrasting approaches to governance much like in anyglobal issue. Resolutions should take this into account and optomize innovation ethical responsibility and global cooperation.

Recent Cases, Controversies, and Concerns

Genetic enhancement in particular, or the ethically related topic of reproductive cloning, has entirely altered the way philosophers and ethicists consider humanity in the context of our world.[53] Our new powers of biotechnology make questions concerning the moral status of nature and the appropriate limits of human intervention unavoidable. Is nature something with inherent values and integrity that humanity ought not violate, or is it raw material for human manipulation? [54] Modern society prioritizes the pursuit of perfection, especially in kids. [55] Concerns emerge when genetic engineering becomes a medium through which children are treated not as gifts but as possessions, projects of our will, or vehicles for our happiness. Human cloning and genetic engineering pose a potential to exacerbate troubling tendencies already present in our culture that promote unachievable perfection.

Globally, academic pressures show a strong correlation with high depression, anxiety, and suicide rates. [56] Cases such as competitive parenting in the face of US perfectionist culture, South Korea's intense academic culture, which is responsible for the

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[50] “South Africa Amended Its Research Guidelines to Allow for Heritable Human Genome Editing.” *The Conversation*, theconversation.com/south-africa-amended-its-research-guidelines-to-allow-for-heritable-human-genome-editing-241136.

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[54] Sandel, Michael J. “The Ethical Implications of Human Cloning.” Perspectives in Biology and Medicine, vol. 48, no. 2, Spring 2005, pp. 241-247, doi:10.1353/pbm.2005.0063. Harvard University, https://scholar.harvard.edu/files/sandel/files/ethical_implications_of_human_cloning.pdf

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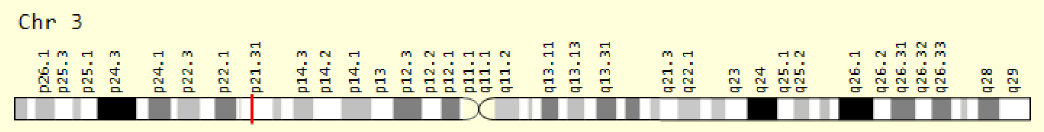
[56] “Rising School Pressure and Declining Family Support Especially among Girls, Finds New WHO/Europe Report.” World Health Organization – Europe, 13 Nov. 2024, https://www.who.int/europe/news/item/13-11-2024-rising-school-pressure-and-declining-family-support-especially-among-girls--finds-new-who-europe-report

highest teen suicide rate in the OECD, all have an underlying cause of the pursuit of the ideal. Similar statistics are reported in nations across all WHO regions.[57] [58] Reports from the OECD show children as young as three or four are aware of body stereotypes. In the same report, it was stated that six-year-olds express body dissatisfaction, and 22% of children and adolescents show signs of disordered eating.[59] Perfectionism is a factor that acts independently or in combination, which has demonstrated predisposition to disordered eating symptoms, with many patients reporting that perfectionism developed during their childhood. [60] From a public health perspective, these statistics are concerning. Perfectionism is based on the pursuit of an often unrealistic ideal; perfection itself is unattainable. This major cause for mental health disorders and a critically high adolescent suicide rate is a concept that is a heavy motivator for nontherapeutic genetic engineering. Given the World Health Organization's commitment to improving child and adolescent health, the usage of genetic engineering for enhancement and cloning for non-medical purposes starkly contrasts UN values of equity, well-being, and ethical responsibility.

The most popular controversial case in gene editing is the 2018 designer baby scandal under Chinese scientist He Jiankui. Jiankui's experimentation is considered controversial due to the unregulated heritable alterations made to two twins, Lulu and Nana. He Jiankui claims the experiment was purely motivated by modifying the twins such that they would have HIV immunity. Jiankui states that such practice could help reduce HIV/AIDs prevalence in countries throughout Africa. Issues arise in his actual conduct. Critics argued the scientist acted illegally, defying government bans and acting without significant regulatory oversight. Many claim the scientists acted in the interest of personal fame, especially considering the specific gene targeted. CCR5 is a gene that plays a role in immunity and in HIV infection, but has also been widely linked to neuronal plasticity, learning, and memory. [61] In the five videos uploaded to his YouTube channel titled "The He lab," He makes the argument that parents need access to technologies like gene surgery to improve the lives of their future children. [62] Given the ethical appraoch of this committee instances such as these are important to keep in mind. Delegates should weigh the potential harms against this technologies scientific possibilities and use ethical dillemmas to influence and strengthen arguments.



CCR5 gene in genomic location [63]

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Goals for Committee

- Establishing a global ethical framework: international structure for regulation of somatic and germline gene editing in the interest of human rights
- Preventing the misuse of technologies and rogue practices: Addressing ethical concerns related to topics such as designer babies, eugenic practices, exploitative enhancements, and other emerging risks.
- Promote equitable access to revolutionary technologies: ensuring minority groups and developing nations benefit from gene therapies and combating growing disparities that emerge from funding disparities.
- Enhancing transparency and accountability mechanisms: Facilitate ethical innovation and cooperation that enhances compliance with internationally set standards.

Questions to Consider

- Should countries be allowed to edit human embryos, and if so, under what conditions?

- How can we account for equal representation for countries in terms of research, especially for smaller countries?

- How can global advisory frameworks ensure ethical clinical trials, safety, and informed consent for genome-editing technologies?

- How can we balance innovation with equity when historically marginalized groups have remained underrepresented in gene editing research?

- How can poor or developing countries actively participate in gene editing research and benefit from these innovations?

- Is it moral for gene editing to be used to edit for enhancements such as beauty or intelligence? Should there be international laws preventing gene editing for such factors?

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