Houston Area Model United Nations
Standard Committee

UNESCO



Chair | Aashna Gurajala
Topic A: Regulating the Ethical Use of Human Genetic Technologies
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Atilgan Ozdil/Anadolu Ag

Chair Letter

Dear Delegates,

My name is Aashna Gurajala and I am a sophomore Biochemistry major at UT Austin!

My journey in Model UN began in my sophomore year of high school when I joined the club because my favorite teacher was the sponsor (and let's be honest, also because we could skip school for conferences). I had always been interested in geopolitics and public speaking separately, but it wasn't until joining MUN that I discovered how awesome it could be to combine both.

Having chaired CSW last year, I am so excited to be chairing UNESCO this year. As an organization dedicated to building peace through education, science, culture, and communication, I found that UNESCO offers a unique lens through which to address issues I care deeply about as someone in a STEM field. I hope our discussions will give you the chance to dive into some of the most pressing challenges faced worldwide, from addressing education systems to ethically representing scientific technology, and I can't wait to see the creative solutions you bring forward!

If I can give you any advice before conference, it would be to really develop an interest in the topics at hand. Be creative. Explore solutions that test the nature of global infrastructure and immerse yourself in the process of research and problem-solving. On a more practical note: bring band-aids in case your feet hurt, and please don't feel like you need to kill a forest trying to print every article you find. A few key statistics, the background guide, your position paper, and any absolutely essential research are all you need to debate effectively. And above all, don't forget to have fun! HAMUN is an incredible opportunity to step outside your comfort zone, meet new people, and make memories that last forever!



Best of luck!

Aashna Gurajala
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Topic Relevance

A unique feature of UNESCO's mandate among UN bodies, is its development of normative architecture for bioethics. Its 1997 Universal Declaration on the Human Genome and Human Rights was the first international instrument to declare the human genome "the heritage of humanity" and to state that practices contrary to human dignity, such as reproductive cloning, must not be permitted.

That declaration, along with its 2003 and 2005 successors, remains the closest thing the world has to a somewhat global consensus on the limits of genetic intervention.

But that was before CRISPR-Cas9 existed.

Since 2012, gene editing tools like CRISPR have collapsed the cost and difficulty of altering DNA by orders of magnitude. What once required years of specialized lab work can now be attempted by a graduate student with a few thousand dollars of reagents.

This democratization of genetic technology is precisely what makes governance urgent. The 1997 Declaration assumed that only a small number of well-resourced and supervised laboratories could meaningfully edit the human genome. Evidently, not true. That assumption no longer holds, and the gap between the pace of scientific capability and the pace of international consensus has only widened. It's like throwing an anarchist into a lab to boil water and being shocked they've created a nuclear explosive. Too much freedom built on the premise of a consensus on regulations.

Delegates must hold two things at once: scientific promise and cultural plurality. Member states differ for reasons rooted in religion, history, disability rights advocacy, and views on reproductive autonomy. A resolution that ignores this plurality in favor of a single cultural framework is unlikely to reach consensus. You can't all have your cake and eat it too. You'll get diabetes and have allowed someone to clone you all because you only developed governance that benefited your culture. Also, a resolution that ignores governance entirely leaves the door open to chaos and unproductive debate.

Background Information

What is genetic technology?

Human genetic technologies are tools that read, interpret, or alter the DNA that carries hereditary information within human cells. The three main categories of genetic technology to focus on are: g**enetic screening** (testing embryos, fetuses, or individuals for disease/diagnosis), **gene therapy** (adding, removing, or correcting genetic material in existing cells to treat disease), and **gene editing** (using molecular tools like CRISPR to make targeted changes to a DNA sequence)..

CRISPR-Cas9

CRISPR-Cas9 is adapted from a bacterial immune system. Without getting into too many molecular details like RNA guiding and gene-editing techniques, the greatest takeaways from this process should be the ease which it provides scientists. Compared to earlier gene editing techniques (zinc-finger nucleases, TALENs), CRISPR-Cas9 is notably cheaper, faster, and easier to redesign for a new genetic target, which the primary reason why it has spread so quickly since its adaptation.

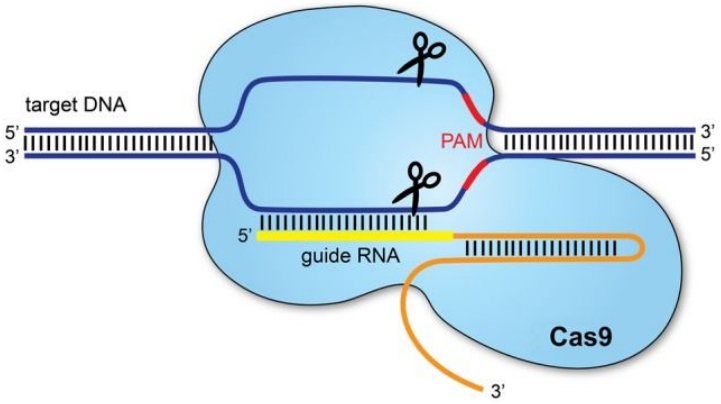


Fig. 1: Simplified View of CRISPR-Cas9

Somatic vs. Germline Editing

When debating genetic technology and editing processes, many techniques have varying levels of ethical scrutiny. Of these techniques, it is important to distinguish between somatic and germline editing. Somatic gene editing alters the DNA of an existing persons non-reproductive cells (blood, muscle, etc.). These edits only affect that individual and is not passed on to their children. For example, gene therapy to change one's eye color will not impact future generations. This is the category where real clinical progress has occurred and is far less ethically contested, though not without scrutiny. Cost, consent, and long term safety remain issues related to the technique.

Germline (heritable) editing alters the DNA of eggs, sperm, or early stage embryos, which means that the edit (plus any errors) would be passed on to every subsequent generation. Using the earlier example, if someone were to alter the gene controlling their eye color to a different one, their future generations would be impacted whether they like it or not. This is the category that produces significant controversy and has the broadest international consensus. Virtually every major scientific and governance body, including the WHO Director-General, has stated it would be premature and irresponsible to proceed with reproductive clinical applications of heritable germline human genome editing.

Gene therapy vs. Enhancement

Another common area for misconception within genetic technology is distinguishing between gene therapy versus enhancement. Gene therapy efforts aim to prevent, treat, or cure a recognized disease or disease. Gene enhancement on the other hand, aims to add a trait beyond what is necessary for health. Some examples of gene enhancement applications include, trying to increase muscle mass, altering cognitive traits, or physical characteristics that aren't linked to disease. Thankfully, almost no state or scientific body currently endorses genetic enhancement. But if that were truly the case, we wouldn't be here to debate anything at all. The line between therapy and enhancement is blurrier than you'd think. Consider a scenario where gene editing ensues to build resistance to a future, hypothetical pandemic. Is that therapy or enhancement? Is selecting an embryo's height therapeutic if the alternative involves preventative measures for a growth-hormone condition? Many of these situations are ambiguous, making developing proper language to manage definitions for therapy and enhancement, one of the central obstacles to a clean, enforceable international rule.

Genetic Privacy as Consumers

Amongst the vast amount of cases revolving genetic technology, they typically involve researchers, hospitals, or countries. Yet, more than any of these, the fastest growing source of human genetic data today is the direct-to-consumer genetic testing industry. Companies such as 23andMe have built a business model on individuals voluntarily submitting DNA samples to learn about their ancestry and health risk, leading it to become one of the largest privately held genetic databases in the world. This development meaningfully broadens what "ethical use of genetic technology" covers. Instead of the question asking who may edit embryos, it is now also about what happens to the extremely sensitive genetic data of millions of people.

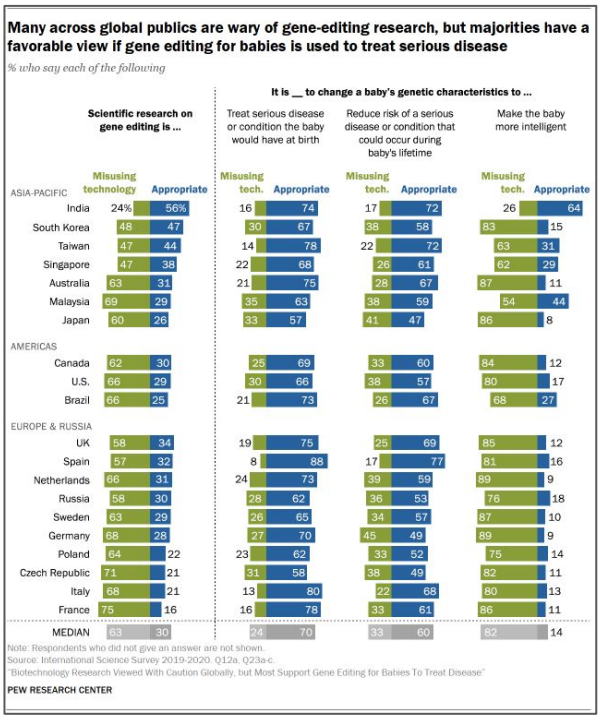


Fig. 2: Global Views on Gene Editing to Treat Disease for Babies (2019-2020)

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Existing Governance Frameworks

UNESCO

The 1997 Universal Declaration on the Human Genome and Human Rights affirms that the human genome underlies the fundamental unity of the human family, prohibits discrimination based on genetic characteristics, and states that practices contrary to human dignity, explicitly including reproductive cloning, shall not be permitted. Well what is dignity? Why, if reproductive cloning is contrary to human dignity, are screening and therapy methods studied to improve the unity of human family? This was unanimously adopted and endorsed by the UN General Assembly in 1998, but it is a declaration, not a treaty. Why wouldn't countries endorse something they aren't legally obligated to follow? This declaration creates moral and political weight, yet has no enforcement or complaint mechanism. The 2003 International Declaration on Human Genetic Data addresses the collecting, processing, and storage of genetic data. The 2005 Universal Declaration on Bioethics and Human Rights broadened the frame beyond genetics to bioethics in general. However, despite these efforts, without actionable review and oversight, little change can be expected from the world.



Fig. 3: 43rd UNESCO General Conference (2025)

WHO

In December of 2018, WHO (World Health Organization) convened an expert advisory committee to develop global standards for human genome editing. After two years of consulting, the committee released 2 companion reports in July of 2021. One was a governance framework and set of recommendations that included a proposed global registry of human genome editing research, guidance on international research, a whistleblowing mechanism for unethical research, and reference for intellectual property. One of the important things to glean from WHO's involvement on this topic is their statement that it would be irresponsible for any actor to proceed with clinical applications of heritable human genome editing at this time. WHO's framework is definitely more technical and detailed than UNESCO's declarations, yet they share the same limitation that their impact is solely advisory. All suggested strategies are voluntary and sanction power would just be a childish fantasy out of their scope of power.

Historical Ethical Breaches

Eugenics in the 20th century

Before Nazi Germany's forced sterilization and murder program, the United States had built a legal framework for restricting reproduction on genetic and hereditary grounds. The 1927 Supreme Court case Buck v. Bell ruled the enabling of sterilization laws in more than 30 states after upholding a Virginia law permitting the practice to those deemed "genetically unfit".

Hwang Woo-suk Fraud

In 2004 and 2005, a South Korean scientist Hwang Woo-suk published papers in the journal, "Science" claiming to have created the first cloned human embryos and extracted patient-specific stem cell lines. This result would have represented a major medical breakthrough, yet despite the celebration Hwang received, independent investigation raised serious concerns. In 2006, a university investigating panel concluded that these cell lines had never existed, in fact they were fabricated. Hwang has soon dismissed, stripped of his research license, and indicted on charges including embezzlement, violation of bioethics law, and more concerningly, circumstances under which a junior female researcher in his lab had donated eggs for the research.

Henrietta Lacks and the HeLa Cell Line

In 1951, physicians at Johns Hopkins Hospital collected cervical cancer cells from a Black patient, Henrietta Lacks, without her knowledge or consent. This procedure ultimately led to her death. Her cells proved capable of dividing indefinitely outside the body, which no other human cells had previously demonstrated. This "HeLa" cell line became a monumental tool in modern biomedical research, contributing to the development of the polio vaccine, COVID-19 vaccine research, and the mapping of the human genome, generating around 11,000 related patents. Lacks's family had no idea of the existence of the cell line until the 1970s and no compensation until Thermo Fisher reached a confidential settlement with them 72 years since the collection of the cells, in 2023.



Fig. 4: Henrietta Lacks Visual Along with the HeLa Cell Line

The 23andMe Settlement

Between April and September of 2023, hackers obtained data from around 6.9 million 23andMe accounts, initially by exploiting reused passwords on a small number of individual accounts then using a "DNA relatives" feature to access information on a larger number of connected users. In October, a hacker using an alias, "Golem" published a database on a cybercrime forum titled, "Ashkenazi DNA Data of Celebrities," containing information on nearly 1 million people of Ashkenazi Jewish descent and 100,000 of Chinese descent, compiled and separated by ancestry. The ethnic targeting was deliberate and prompted concern from lawmakers, including an FBI investigation over the potential for the data to be used against specific ethnic and religious communities.

23andMe's initial public response attributed the breach primarily to affected users reusing passwords on various sites, which evidently drew criticism once the full scope and ethnic targeting of the breach became clear. In 2024, the company agreed to a 30 million dollar settlement and filed for Chapter 11 bankruptcy. This raised a pretty interesting governance question: when a company holding the genetic data of millions of people becomes insolvent, who determines what happens to that data afterward?

The Havasupai Tribe

Starting in 1990 until 1994, Havasupai Tribe members in Arizona donated blood samples to researchers at Arizona State University for a study on Type 2 diabetes given that the disease had a historic impact on the community. Tribal members later discovered that the same samples had been used without their knowledge or separate consent for research on schizophrenia, inbreeding, and population migration. These subjects directly conflicted with Havasupai cultural and religious beliefs regarding the body. The lawsuit that followed was settled in 2010 after the university paid 700,000 dollars in compensation and returning the blood samples to the tribe. Although this case dd not create any binding legal precedents, subsequent standards for genetic research consent with indigenous and vulnerable communities were established.



Fig. 5: Global Gene Editing Legal Restrictions on Human Embryos

Case Studies

He Jiankui and the "CRISPR babies"

In 2018, at the Second International Summit on Human Genome Editing in Hong Kong, a Chinese biophysicist named He Jiankui announced that through CRISPR-Cas9, he had edited the CCR5 gene in human embryos with the aim to confer resistance to HIV and that twin girls (Lulu and Nana) had already been born with this change. The scientific community reacted with overwhelming condemnation. Critics pointed to inadequate, falsified informed consent documentation and a lack of peer review prior to implantation.

He was soon dismissed by his university and in 2019, was sentenced to 3 years in prison for illegal medical malpractice in reflection of the absence of a specific criminal statute covering embryo gene editing at the time. Soon China subsequently amended its criminal laws and issued new ethics-review regulations to criminalize this conduct.



Fig. 6: He Jiankui at the Second International Summit on Human Genome Editing (2018)

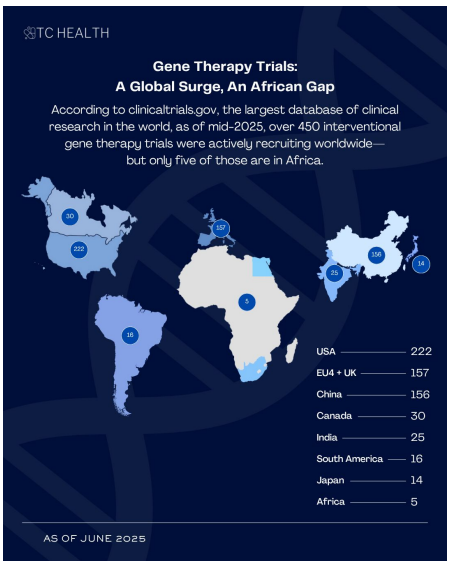


Fig. 7: Global Gene Therapy Trials and the African Gap in Access

Casgevy and the Equitable-Access Gap

In 2023, regulators from the UK and US approved of Casgevy, the first therapy built on CRISPR-Cas9 to reach the market, for sickle cell disease and transfusion-dependent beta-thalassemia. Clinical trial results revealed that the large majority of treated sickle-cell patients were free of severe pain crises for a year after treatments, and most beta thalassemia patients no longer required regular blood transfusions.

This therapy is also a case study on the limits of scientific progress without economic and infrastructural access. Vertex Pharmaceuticals priced the Casgevy therapy at around 2.2 million dollars. This treatment further required extracting patient stem cells, editing, and reinfusion through chemotherapy, making treatment only viable in high-income countries. Despite sickle-cell disease being most common in Sub-Saharan Africa, these regions had the least capacity to access this treatment.

QUESTIONS TO CONSIDER

- What binding or quasi-binding mechanisms such as obligatory real reporting registries or defined licensing/accreditation regime, could command consensus across states with differing domestic laws on embryo research and reproductive genetics?
- Should distinguishing between therapeutic and enhancement applications be defined centrally by an international body, left to national authority, or governed case-by-case? What happens when ambiguity arises?
- What obligations, if any, should high-income countries, research institutions, and pharmaceutical companies bear to ensure low and middle income countries can access approved genetic therapies?
- How should the international community respond when a nation's domestic legal system proves unable/unwilling to adequately address a violation of broadly shared ethical regulations? Should UNESCO seek any role beyond moral condemnation?
- How can the framework proposed in this committee remain enforceable and relevant given that underlying technologies in the industry continue to change faster than diplomatic consensus can be built?

CONCLUSION

The governance of human genetic technology is not a hypothetical issue to leave for the future. As in any bioethics debate, there is no single solution that will satisfy every delegations priorities, and honestly, do not expect this to occur. The path forward is one that you should foresee debating topics like unequal access, therapy vs. enhancement, scientific freedom vs. precautionary regulation, and disability-rights perspectives. The framework you devise should be precise, yet flexible enough to respect variation and technological advancement, as well as be ambitious enough to close the gap between what the world has already agreed is unacceptable and what is has built the capacity to prevent.

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