

## **WHO - World Health Organization**

### **Gene Editing and Eugenics**

#### **Overview**

Gene editing is one of the most significant scientific breakthroughs of the 21st century, enabling researchers to make precise changes to DNA using tools such as CRISPR-Cas9<sup>1</sup>, a gene-editing technology that uses a guide RNA and the Cas9 protein to locate and precisely cut and modify specific DNA sequences. This technology presents remarkable opportunities for curing genetic diseases and improving human health, but it also raises serious ethical and safety concerns. Historically, efforts to manipulate human heredity have been linked to eugenics,<sup>2</sup> a discredited practice that promoted selective breeding and discriminatory policies under the guise of scientific progress. The overlap between modern gene editing and the legacy of eugenics has sparked global debate, as misuse of these technologies could deepen inequality, reinforce discrimination and undermine human rights. Without effective international oversight, gene editing risks being exploited in ways that echo past abuses while simultaneously holding the potential to transform medicine and public health for the better.

#### **The World Health Organization**

The World Health Organization (WHO), founded in 1948, is the United Nations' primary international body for public health. Its mission is to promote global well-being by coordinating international responses to emerging health challenges, providing guidance to member states, and ensuring that new practices are developed and applied responsibly. As scientific innovation advances rapidly, WHO plays a central role in establishing ethical standards that balance the

promise of progress with the protection of human rights. In the context of gene editing, WHO is responsible for guiding the global community in maximizing the medical benefits of these technologies while preventing their misuse in ways that could replicate the harms of eugenics. By addressing both the scientific and ethical dimensions of genome modification, WHO seeks to ensure that developments in this field are applied fairly, safely, and in alignment with its commitment to health as a fundamental human right.

### **Historical Background: From Eugenics to Gene Editing**

The legacy of eugenics continues to shape global concerns about modern genetic technologies, as past abuses highlight the dangers of misusing science to control human heredity. In the late nineteenth and early twentieth centuries, eugenics emerged as a movement that claimed scientific legitimacy while promoting social and political control over human reproduction. Advocates argued that society could be improved by encouraging the reproduction of individuals with supposedly “desirable” traits and preventing those considered “unfit” from having children. This ideology was embraced by governments in Europe and North America, where policies were enacted that codified discrimination into law. In the United States, for instance, dozens of states introduced sterilization programs that targeted people with disabilities, minority groups, the poor, and those judged to be socially deviant. By the mid-twentieth century, over 60,000 Americans had been sterilized under these laws, often without consent, leaving a legacy of trauma that underscored the dangers of misusing science for social engineering. Experts today have rightly described eugenics as an “erroneous and immoral theory” that inflicted widespread suffering, dismantled human rights, and eroded public trust in medicine and genetics.<sup>3</sup>

The consequences of eugenics extended beyond the borders of the United States, as many governments in Europe adopted similar policies and reinforced systems of exclusion through sterilization, segregation, and institutionalization. Nowhere were these practices more brutally enforced than in Nazi Germany, where the regime advanced its “racial hygiene”<sup>4</sup> program as part of its larger genocidal project. Beginning with forced sterilizations and extending to the systematic killing of people with disabilities under the Aktion T4 program, Nazi eugenics escalated into one of the most horrifying examples of state violence in modern history. The policies combined pseudoscientific ideas with authoritarian power, ultimately providing justification for mass atrocities, including the Holocaust. The Nazi case demonstrated the catastrophic consequences that can arise when genetics is manipulated to serve ideological ends. Modern gene editing technologies, while fundamentally different in method and purpose, raise concerns that echoes of eugenics could resurface if such innovations are misapplied. The ability to alter DNA with precision introduces the possibility of both tremendous medical progress and serious ethical dilemmas. This history continues to shape how scientists and policymakers approach modern genetic research.

### **Scientific Foundations of Gene Editing**

CRISPR-Cas9 revolutionized modern biology by making gene editing faster, cheaper, and more precise than previous methods. Introduced in 2012, CRISPR offered researchers the ability to locate and modify specific DNA sequences with unprecedented accuracy, dramatically transforming the way scientists study and manipulate genetic material. Before its discovery, genome editing relied on older technologies such as zinc finger nucleases and TALENs, which required complex customization and were often prohibitively expensive. These earlier methods

limited the scope of genetic research, confining advanced editing to a small number of specialized laboratories. CRISPR, by contrast, has made genetic manipulation significantly more accessible. Studies have shown that it has reduced the cost of genome editing by nearly ninety percent compared to older techniques<sup>5</sup>, and the time required to carry out modifications has likewise been shortened from months or years to mere weeks. This accessibility has accelerated the pace of research worldwide, allowing not only well-funded institutions but also smaller laboratories to participate in groundbreaking experiments.

The transformative effect of CRISPR is not limited to cost and speed. Its precision has opened the door to correcting genetic mutations responsible for inherited disorders, exploring agricultural innovations, and even investigating ecological applications such as controlling invasive species or reducing the spread of diseases through engineered insects. The ability to cut DNA at targeted sites and insert, delete, or modify genes with relatively high success rates has given scientists a tool with both broad and powerful implications. Geneticist George Church captured this optimism when he predicted a future “where genetics can solve many world problems,”<sup>6</sup> including those in medicine, food security, and environmental sustainability. His statement reflects the growing recognition that the technology is not confined to theoretical research but has practical, real-world potential to reshape multiple dimensions of human life. This technical foundation provides the basis for both the promise and careful regulation of modern gene editing.

Due to the fact that the system is relatively simple to use, researches across the globe can employ it for a wide range of projects, but this accessibility also raises the possibility of misuse or poorly regulated experimentation. The same qualities that make CRISPR transformative, its efficiency, low cost and adaptability, also make it a technology that requires careful oversight.

While CRISPR's scientific innovation transformed research, its true potential lies in how it reshapes approaches to human health and disease.

### **Medical Applications and Public Health Benefits**

Gene editing carries enormous potential for public health by addressing inherited diseases and transforming the way medicine treats genetic conditions. One of the most striking areas of progress has been in the treatment of sickle cell anemia, a painful and life-threatening disorder that affects millions worldwide. Clinical trials using CRISPR-based therapies have shown dramatic improvements, with patients who received experimental treatments experiencing a reduction or even elimination of the painful crises that characterize the disease. In some cases, individuals who once required frequent hospitalizations have been able to return to daily life without recurring symptoms, suggesting that gene editing could offer lasting solutions where conventional treatments have failed. These outcomes highlight the technology's ability to correct harmful mutations directly at their genetic source rather than simply alleviating symptoms, a shift that represents a fundamental advance in medical science.

The significance of these breakthroughs becomes even clearer when placed in the context of global health statistics. According to the World Health Organization, roughly five percent of the world's population carries genes for serious inherited disorders<sup>7</sup>, meaning hundreds of millions of people live at risk of developing or passing on conditions that might one day be treated through genome editing. This includes not only blood disorders like sickle cell anemia and thalassemia but also a wide range of rare diseases that collectively impact millions of families. The promise of gene editing lies in its ability to target these disorders at their molecular roots, offering the possibility of cures rather than lifelong management. For patients, this could

mean freedom from chronic illness, reduced dependence on costly medications, and vastly improved quality of life. For healthcare systems, the shift from managing symptoms to offering cures could also reduce long-term medical costs, particularly in countries where inherited disorders place a heavy financial burden on already strained infrastructures.

Recent case studies have further underscored the life-changing possibilities of CRISPR. In 2020, U.S.-based clinical trials for sickle cell disease showed that patients who underwent experimental treatments were able to avoid the painful episodes that had previously dominated their lives<sup>89</sup>. In 2024, researchers in the United States successfully used gene editing to restore partial vision in individuals with inherited blindness<sup>10</sup>, an achievement that demonstrated the technology's versatility across different medical conditions. These results illustrate the breadth of gene editing's potential applications: what works to repair blood disorders may also be adapted to address neurological diseases, muscular conditions, and other genetic disorders that currently have no cure.

However, these benefits are not guaranteed; they depend on addressing questions of accessibility, regulation, and global equity. Without careful planning, there is a risk that such treatments could remain confined to wealthy countries or elite populations. Thus, while gene editing holds extraordinary promise for advancing public health, it also compels the international community to ensure that progress is shared fairly. Beyond issues of access, gene editing also forces society to reckon with the ethical boundaries of altering human heredity.

### **Ethical Concerns and Human Rights Risks**

Despite its promise, gene editing poses profound ethical challenges that echo the moral failings of past eugenics regimes. One of the most frequently discussed risks is the fear of

creating so-called “designer babies,” where genetic traits such as intelligence, appearance, or athletic ability might be selected or altered by those with access to advanced technologies. Such possibilities raise troubling questions about social inequality, as only wealthy families or nations might be able to afford enhancements, thereby deepening divides between privileged and marginalized groups. Public attitudes reflect these concerns: surveys show that 55 percent of Americans worry that gene editing could contribute to greater social divide<sup>11</sup>, indicating widespread apprehension about its potential misuse. The notion that powerful technologies could be leveraged to reinforce existing hierarchies has, once again, drawn comparisons to eugenics, where pseudoscience was employed to justify discrimination and exclusion.

Bioethics organizations and human rights groups have repeatedly cautioned against unregulated applications of heritable genome editing, warning that its use “could increase social divisions and discrimination.”<sup>12</sup> This danger is compounded by real-world examples that demonstrate how quickly the line between scientific innovation and ethical violation can be crossed. In 2018, Chinese scientist He Jiankui announced the birth of the first CRISPR-edited babies, whose embryos were altered in an attempt to make them resistant to HIV<sup>13</sup>. The revelation provoked global condemnation, as many scientists denounced the experiment as reckless, premature, and unethical. Jiankui’s actions led to criminal prosecution in China, but the case serves as a warning to the world about the risks of unchecked scientific ambition. It revealed how the absence of clear international regulations could result in unpredictable and potentially harmful experiments on human embryos.

The ethical debate also extends beyond cases of misuse to questions of equity and justice. Some advocates argue that if gene editing is properly regulated and equitably distributed, it could actually help reduce inequality by giving people in lower-income countries access to

advanced medical treatments that are currently available only in wealthier regions. This perspective suggests that the technology's impact will depend not only on scientific progress but also on global governance and the distribution of resources. The United Nations has emphasized this concern through formal action. In 2021, the UN General Assembly adopted Resolution 76/189<sup>14</sup>, which underscored the importance of science and technology policies that respect human rights, explicitly including fields such as biotechnology and genetics. The resolution reflects the growing consensus that technological innovation must be guided by principles of human dignity and fairness rather than left solely to market forces or individual states. Building on this framework, international conventions and organizations have taken steps to establish governance structures that ensure gene editing develops within ethical and legal boundaries.

### **International Conventions and Governance**

International frameworks have emerged to guide the safe and ethical use of gene editing, reflecting a global recognition that oversight is necessary to prevent misuse. One of the earliest and most influential milestones was the 1997 Universal Declaration on the Human Genome and Human Rights<sup>15</sup>, adopted by UNESCO, which affirms that the genome “underlies the fundamental unity of all members of the human family.” This declaration emphasized that genetic technologies must never be used in ways that undermine human dignity or equality. UNESCO built on this framework in 2003 with the International Declaration on Human Genetic Data<sup>16</sup>, which reinforced the principle that genetic research must respect ethical norms and protect individuals from exploitation or harm. Together, these declarations demonstrated an early global commitment to linking genetic innovation with universal human rights, and they continue to serve as reference points for policymakers navigating the challenges of emerging

biotechnologies.

Regional initiatives have also shaped governance in meaningful ways. The Council of Europe's Oviedo Convention<sup>17</sup>, which remains one of the only legally binding international instruments on bioethics, explicitly prohibits heritable genetic modifications. By banning germline interventions, the convention reflected widespread concerns that altering the human germline could introduce unpredictable risks and ethical dilemmas that extend across generations. While not all countries are signatories, its existence highlights a strong current of international caution toward genome editing in humans. At the same time, governments and scientific communities have sought to address the rapid pace of technological change by adopting new resolutions that keep bioethical standards current. For example, the World Health Assembly passed Resolution WHA72.35<sup>18</sup> in 2019, which established a WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. This resolution marked a significant step in positioning the World Health Organization at the center of global coordination efforts, ensuring that advances are assessed not only for their medical potential but also their social and ethical consequences.

International human rights bodies have also played a role in highlighting the broader ethical dimensions of gene editing. The UN Human Rights Council adopted Resolution 46/4<sup>19</sup> in 2021 on "Science, technology and human rights," reaffirming that developments in fields such as biotechnology must be consistent with the protection of fundamental rights. As of 2022, more than seventy-five countries had introduced policies or guidelines on human genome editing<sup>20</sup>, demonstrating that governance is not limited to a handful of states but is instead a growing global priority. However, the diversity of national approaches reveals gaps and inconsistencies that complicate enforcement and regulation. While some countries have outright bans on germline

modification, others allow research under strict guidelines, creating an uneven regulatory landscape that risks loopholes and jurisdictional conflicts.

Taken together, these international conventions and governance mechanisms illustrate both the progress and the challenges of controlling gene editing. Their effectiveness, however, becomes most apparent when examined through specific case studies that reveal how different nations interpret and apply these global standards.

### **Case Studies of Gene Editing Practices**

High-profile cases highlight both the promise and perils of genome editing. The most well-known example remains the 2018 CRISPR baby controversy in China<sup>21</sup>, where scientist He Jiankui announced the birth of twin girls whose embryos had been altered to resist HIV infection. The experiment drew immediate global outrage for violating ethical norms and scientific protocol, ultimately resulting in Jiankui's three-year prison sentence and a renewed international call for stronger regulation. Scientists described the CRISPR baby case as "a scandal that shocked the scientific world and highlighted the need for global oversight."<sup>22</sup>In the years that followed, Chinese research institutions imposed tighter controls, yet studies continued under limited, non-clinical conditions. In 2022, Chinese researchers conducted new embryo editing experiments using base-editing tools to attempt correction of Marfan syndrome mutations<sup>23</sup>. Although these embryos were not implanted, the research reignited debate about the fine line between permissible study and potential clinical misuse. Together, these two Chinese cases illustrate both the speed of scientific progress and the difficulty of enforcing consistent ethical boundaries.

Elsewhere, several other nations have engaged with gene editing through varying legal

and ethical frameworks. In 2015, the United Kingdom became the first country to formally approve mitochondrial replacement therapy (MRT)<sup>24</sup>, allowing the creation of “three-parent babies” to prevent the transmission of mitochondrial diseases. This procedure, regulated under the Human Fertilisation and Embryology Authority (HFEA), marked a significant step toward balancing medical innovation with state oversight. The United States has taken a more restrictive approach: federal law currently prohibits the Food and Drug Administration from reviewing applications for germline editing<sup>25</sup>, effectively banning heritable genome modification in public research. Nevertheless, private and academic laboratories continue to advance somatic gene therapy, including CRISPR-based trials for sickle-cell disease that have produced encouraging early results. Japan has also adopted a cautious but research-friendly stance. Since 2019, its Ministry of Education, Culture, Sports, Science and Technology has permitted genome editing of human embryos strictly for basic research, not for reproduction, under government supervision, though the implantation of edited embryos remains illegal.<sup>26</sup>

In Russia, biologist Denis Rebrikov captured headlines in 2019 by proposing to edit embryos to make babies resistant to HIB and later to correct a deafness-related gene (GJB2)<sup>27</sup>. His plans sparked international criticism for ethical recklessness, and no verified births or sanctioned experiments occurred, yet the controversy demonstrated the global community’s vigilance toward unsupervised work. India has taken a cooperative, research-oriented approach. In 2023, Indian scientists participated in international embryo gene-editing studies aimed at diseases correction without implantation<sup>28</sup>. While domestic law prohibits clinical germline editing, national research guidelines under the Indian Council of Medical Research allow limited embryo work under strict oversight. Germany, between 2019 and 2024, engaged in extensive ethical debate when the German Ethics Council suggested openness to eventual embryo editing

under potential “future medical justification.”<sup>29</sup> Despite this shift in tone, the nation’s Embryo Protection Act still forbids germline modification for reproductive purposes, and no human trials have been conducted.

Other countries have navigated the issue through cross-border tightly constrained experimentation. In 2016, a U.S. medical team performed mitochondrial replacement therapy in Mexico for a Jordanian couple to bypass legal barriers elsewhere<sup>30</sup>. The birth of the child, though successful, highlighted global disparities in regulation and raised questions about “ethics tourism,” where scientists might move projects to jurisdictions with looser laws. France reaffirmed its prohibition on reproductive germline editing in 2022<sup>31</sup>, though it allows research using non-viable embryos under bioethical review, a position consistent with many European Union guidelines. Meanwhile, in Australia, researchers have pursued in-vitro CRISPR embryo studies<sup>32</sup> to better understand early developmental genes. The National Health and Medical Research Council (NHMRC) bans implantation of edited embryos, but the country continues to support advanced gene therapy for somatic cells such as those used in blood-disorder treatments.

Across these national examples, patterns emerge that capture the dual nature of gene editing: scientific optimism tempered by ethical restraint. Some nations, such as the United Kingdom and Japan, have created tightly monitored legal channels for research, while others, like the United States and Germany, emphasize prohibition and caution. Meanwhile, the cases of China, Mexico, and Russia reveal what can occur when regulation fails to keep pace with innovation. Together, these examples demonstrate the urgent need for coherent international standards to prevent exploitation and ensure safety. To address these issues, countries and global institutions are beginning to coordinate their efforts on gene editing oversight.

## **Global Responses and Proposed Solutions**

The international community is responding to the ethical and social challenges of gene editing through regulation, collaboration, and renewed efforts to promote equity. In 2019, the World Health Organization established an expert advisory committee to create global standards for genome editing governance under Resolution WHA72.35<sup>33</sup>. This group continues to guide nations in developing ethical frameworks and ensuring that new genetic technologies are used responsibly. By 2021, over one hundred organizations worldwide had endorsed WHO's call for responsible oversight<sup>34</sup>, signaling broad recognition that gene editing requires shared global principles. WHO leadership has emphasized that genome editing must "advance health for all," not deepen inequality.

At the same time, scientists caution that excessive restriction could hinder the progress of life-saving therapies, prompting debate about how to regulate research without stifling discovery. UNESCO, the United Nations Human Rights Council, and national governments have all advocated for transparency, equitable access, and the inclusion of developing nations in these discussions. The growing number of guidelines and resolutions demonstrates that countries are beginning to align around a common goal: to ensure that gene editing strengthens global health rather than reproduces inequality. Moving forward, the WHO and its partners will remain central to coordinating ethical policy and protecting human rights as genetic technology continues to evolve.

## Questions to Consider

1. Does your country conduct or fund gene-editing research, and if so, what is it focused around?
2. What legal or ethical regulations exist in your country regarding germline modification or embryo experimentation?
3. How has your country addressed public opinion or ethical debate surrounding gene editing and its connection to eugenics?
4. Is your country collaborating with international organizations, such as the WHO or UNESCO, to develop global standards on genome editing?
5. How might an advance in gene editing affect your country's healthcare system, economy, or position in global biotechnology markets?

## Useful Delegate Resources

[Global Gene Editing Regulation Tracker and Index](#)

[Global Status of Regulatory Approvals for Gene-Edited Crops - ISAAA Infographics |](#)

[ISAAA.org](#)

[Global Gene Editing Regulation Tracker - MESA](#)

[Gene editing | Definition, History, & CRISPR-Cas9 | Britannica](#)

[What are the Ethical Concerns of Genome Editing?](#)

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