



VMUN 2026

World Health Organization

BACKGROUND GUIDE



Vancouver Model United Nations

The Twenty-Fifth Annual Session | January 23rd-25th, 2026

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Dear Delegates,

My name is Carl Hu, and I have the pleasure of serving as the Director of the World Health Organization (WHO) at Vancouver Model United Nations 2026. I have been in the world of Model UN for three years now and I am currently completing my Grade 11 year at St. George's School. Alongside your Chair Ivy Lin, and your Assistant Directors Fiona Chen and Parnav Kundi, we warmly welcome you to this iteration of VMUN 2026.

Like many others, I unexpectedly joined my school's Model UN club out of peer pressure. However, I never would have imagined the impact Model UN would have on my growth not only as a delegate, but as a person as well. From writing dozens of morally questionable notes to making dozens of new friends, every conference I have attended has allowed me to walk away with a renewed urge to engage further in the intricate world of Model UN.

For this iteration of Vancouver Model United Nations, delegates of WHO will be dealing with the complex topics of *Human Genome Editing* and *Neglected Tropical Diseases*. As you plunge head-first into the realm of diplomacy and debate, I highly encourage all of you to read over the background guide and develop a thorough understanding of your nation and its stance on the topics at hand.

On behalf of the entire dais team, we look forward to meeting everyone and seeing your work come to life. If you have any questions or concerns, please do not hesitate to contact me at who@vmun.com. I truly hope that VMUN 2026 will create lifelong memories and connections for all of you and I am looking forward to a weekend packed with invigorating debate and discussion.

Best Regards,

Carl Hu

WHO Director

Position Paper Policy

What is a Position Paper?

A position paper is a brief overview of a country's stance on the topics being discussed by a particular committee. Though there is no specific format the position paper must follow, it should include a description of your positions your country holds on the issues on the agenda, relevant actions that your country has taken, and potential solutions that your country would support.

At Vancouver Model United Nations, delegates should write a position paper for each of the committee's topics. Each position paper should not exceed one page and should all be combined into a single document per delegate.

For WHO, position papers, although strongly recommended, are not required. However, delegates who wish to be considered for an award must submit position papers.

Formatting

Position papers should:

- Include the name of the delegate, his/her country, and the committee
- Be in a standard font (e.g. Times New Roman) with a 12-point font size and 1-inch document margins
- Not include illustrations, diagrams, decorations, national symbols, watermarks, or page borders
- Include citations and a bibliography, in any format, giving due credit to the sources used in research (not included in the 1-page limit)

Due Dates and Submission Procedure

Position papers for this committee must be submitted by **January 12, 2026, at 23:59 PT**. Once your position paper is complete, please save the file as your last name, your first name and send it as an attachment in an email to your committee's email address, with the subject heading as "[last name] [first name] — Position Paper". Please do not add any other attachments to the email. Both your position papers should be combined into a single PDF or Word document file; position papers submitted in another format will not be accepted.

Each position paper will be manually reviewed and considered for the Best Position Paper award. The email address for this committee is who@vmun.com.

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Human Genome Editing

Overview

New developments in modern medicine have shifted how the world perceives illness and its subsequent treatment, especially in the realm of genome editing technologies. Human genome editing is the process of modifying DNA in an attempt to alter genetic traits.¹ In the medical field, gene editing has the potential to prevent or cure genetic disorders like sickle cell disease or cystic fibrosis.² In various other fields, such as agriculture, gene editing has continued to develop and is a tool that has been used for decades. The creation of editing technology like TALEN and CRISPR-Cas9 has made these edits faster, cheaper, and more precise than ever before.

Genome editing, especially in humans, raises several ethical concerns and requires discussion. Specifically, understanding the distinction between somatic and germline editing is imperative in discussions regarding the ethics and safety of human genome editing.³ Somatic editing refers to altering the DNA of all somatic cells—all cells in the body except for reproductive ones.⁴ In contrast, germline editing refers to altering the DNA of reproductive cells.⁵ For decades, the use of germline editing for clinical purposes has been regarded as ethically impermissible, as these germline procedures affect future generations, often without their consent, and have many unpredictable, long-term consequences, such as modified genes turning out to be pathogenic over time.⁶ The unpredictable nature of human genome editing as a whole has incentivized various governments and private companies to invest large amounts of time and money to increase their understanding.⁷

Today, attempts to research and develop human genome editing have only expanded and have now become a topic of global concern. Events such as the birth of genetically modified babies in 2018 and the proliferation of private sector gene therapy trials exemplify this fact.⁸ In the past, the World Health Organization (WHO) has responded with various advisory committees and frameworks to help guide future developments.⁹ Through various international collaborative efforts, states of the WHO have the responsibility to combat the ethical and practical dangers associated with human genome editing while balancing the therapeutic benefits that come with editing technology.

¹ “Human Genome Editing,” World Health Organization, <https://www.who.int/health-topics/human-genome-editing>.

² Staff Writer, “Using Gene Editing to Fight Deadly Genetic Diseases,” Harvard T.H. Chan School of Public Health, November 30, 2022, <https://hsph.harvard.edu/news/using-gene-editing-to-fight-deadly-genetic-diseases/>.

³ Bryan Cwik, “Revising, Correcting, and Transferring Genes,” *The American journal of bioethics* : AJOB, August 20, 2020, <https://pmc.ncbi.nlm.nih.gov/articles/PMC7473466/>.

⁴ Ibid.

⁵ Ibid.

⁶ Giovanni Rubeis and Florian Steger, “Risks and Benefits of Human Germline Genome Editing: An Ethical Analysis,” *Asian bioethics review*, July 16, 2018, <https://pmc.ncbi.nlm.nih.gov/articles/PMC7747319/>.

⁷ Rami M Major, et al, “The Public-Private Research Ecosystem in the Genome Editing Era,” *iScience*, May 3, 2024, <https://pmc.ncbi.nlm.nih.gov/articles/PMC1112366/>.

⁸ Benjamin Capps, et al, “Falling Giants and the Rise of Gene Editing: Ethics, Private Interests and the Public Good,” *Human genomics*, August 29, 2017, <https://pmc.ncbi.nlm.nih.gov/articles/PMC5575847/>.

⁹ “Human Genome Editing: A Framework for Governance,” World Health Organization, <https://www.who.int/publications/i/item/9789240030060>.

Timeline

1968 — Stanfield Rogers, a researcher at the Oak Ridge National Laboratory, conducts the first proof-of-concept for gene transfer and attempts the earliest human gene therapy.¹⁰

1972 — Theodore Friedman proposes ethical standards for the application of gene therapy to prevent unethical and unregulated application on humans, establishing the ethical backbone and framework of gene editing.¹¹

November 11, 1997 — The United Nations Educational, Scientific and Cultural Organization (UNESCO) adopts the Universal Declaration on the Human Genome and Human Rights.¹² As the first global document addressing the ethics of genetic editing, it is widely used as a foundation for national bioethics laws and foundations.¹³

April 14, 2003 — Launched in 1990, the Human Genome Project, aiming to map and sequence the entire human genome, announces its completion. The fully sequenced human genome revolutionizes understanding for advanced gene editing research.¹⁴

August 17, 2012 — Jennifer A. Doudna and Emmanuelle Charpentier release a paper in Science Magazine that details CRISPR-Cas9 as a gene editing tool.¹⁵ This paper transforms the world's comprehension of gene editing technology by shifting CRISPR-Cas9 from being mainly understood as a bacterial immune system to a programmable tool that can rewrite DNA.¹⁶

December 1–3, 2015 — The First International Summit on Human Gene Editing occurs in Washington D.C. Scientists agree that clinical usage of gene editing tools is premature and unethical without future research and guidelines, advancing the science to an issue in the political sphere.¹⁷

November 15, 2016 — Chinese scientists at Sichuan University begin the world's first clinical trial by injecting a patient suffering from aggressive lung cancer with CRISPR-modified cells. While this treatment did not cure the patient, its realized therapeutic potential sets the stage for various clinical trials to come.¹⁸

¹⁰ Ryota Tamura and Masahiro Toda, "Historic Overview of Genetic Engineering Technologies for Human Gene Therapy," *Neurologia medico-chirurgica*, October 15, 2020, <https://pmc.ncbi.nlm.nih.gov/articles/PMC7555159/#B6>.

¹¹ Ibid.

¹² "Universal Declaration on the Human Genome and Human Rights," UNESCO.org, October 2, 2015, <https://www.unesco.org/en/ethics-science-technology/human-genome-and-human-rights>.

¹³ "Bioethics and Laws," Brocher Foundation, March 16, 2023, <https://fondation-brocher.ch/bioethics-and-laws/>.

¹⁴ "International Consortium Completes Human Genome Project," Genome.gov, May 8, 2012, <https://www.genome.gov/11006929/2003-release-international-consortium-completes-hgp>.

¹⁵ Jennifer A Doudna and Emmanulle Charpentier, "The New Frontier of Genome Engineering with CRISPR-Cas9 | Science," *The new frontier of genome engineering with CRISPR-Cas9*, November 28, 2014, <https://www.science.org/doi/10.1126/science.1258096>.

¹⁶ Hossain MA, "CRISPR-Cas9: A Fascinating Journey from Bacterial Immune System to Human Gene Editing," *Progress in molecular biology and translational science*, February 17, 2021, <https://pubmed.ncbi.nlm.nih.gov/33685600/>.

¹⁷ Ibid.

¹⁸ Young Joon Kim, "World's First CRISPR Clinical Trial," *Journal of Young Investigators*, September 10, 2017, <https://www.jyi.org/2017-february/worlds-first-crispr-clinical-trial>.

November 26, 2018 — He Jiankui announces the birth of the world’s first CRISPR-edited babies, Lulu and Nana, sparking global condemnation over the ethical and legal nature of both the project and germline editing as a whole.¹⁹

March 18–19, 2019 — WHO convenes its first Expert Advisory Committee meeting on developing global standards and oversight of human genome editing.²⁰

July 12, 2021 — WHO publishes a document, Human Genome Editing: A Framework for Governance, offering international guidance on responsible research and remaining within ethical and legal bounds.²¹

November 16, 2023 — The UK Medicines and Healthcare Products Regulatory Agency (MHRA) is the first to approve the usage of CRISPR-Cas9 for therapeutic gene editing, spurring conversation on future uses and development of gene editing technology.²²

Historical Analysis

The foundations of modern genetic research were laid in the mid-20th century, marked by groundbreaking discoveries that transformed scientific focus from the basics of DNA to the complex field of genetic editing.

While the discovery of DNA’s double helix structure by James Watson and Francis Crick in 1953 laid the foundation for more science,²³ initially, gene editing technologies were used on microorganisms and crops. In the 1980s, genetically modified organisms (GMOs) were created to enhance crop yields, reduce pests, or improve nutritional value.²⁴ Specifically, countries like the United States, China, and members of the European Union began investing heavily in biotechnology in regard to agriculture, with the US commercializing the first

¹⁹ Vera Lucia Raposo, “The First Chinese Edited Babies: A Leap of Faith in Science,” JBRA assisted reproduction, August 22, 2019, <https://pmc.ncbi.nlm.nih.gov/articles/PMC6724388/>.

²⁰ “Who Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing: Report of the First Meeting,” World Health Organization, March 19, 2019, <https://www.who.int/publications/i/item/WHO-SCI-RFH-2019-01>.

²¹ “Human Genome Editing: A Framework for Governance,” World Health Organization, July 12, 2021, <https://www.who.int/publications/i/item/9789240030060>.

²² Parums DV, “Editorial: First Regulatory Approvals for CRISPR-Cas9 Therapeutic Gene Editing for Sickle Cell Disease and Transfusion-Dependent β -Thalassemia,” Medical science monitor : international medical journal of experimental and clinical research, March 2024, <https://pubmed.ncbi.nlm.nih.gov/38425279/>.

²³ Leslie A Pray, “Discovery of DNA Structure and Function: Watson and Crick,” Nature news, 2008, <https://www.nature.com/scitable/topicpage/discovery-of-dna-structure-and-function-watson-397/>.

²⁴ Melissa Petruzzello, “When Were the First Gmos Developed?” Encyclopædia Britannica, June 13, 2025, <https://www.britannica.com/story/when-were-the-first-gmos-developed>.

genetically engineered crops like the Flavr Savr tomato in 1994.²⁵ These experiments also extended to animals, particularly mice, which were often genetically modified to study the structure of human diseases.²⁶

The idea of transferring these technologies to humans soon followed after successful animal experiments. For example, one of the earliest attempts at human gene therapy occurred in 1968, when Stanfield Rogers tried to use a virus to deliver genetic material into patients with enzyme deficiency—lack of a specialized protein that helps carry out essential chemical functions within the body.²⁷ In 1972, Paul Berg’s pioneering gene splicing—the process of cutting and recombining DNA from different sources to create new genetic combinations—showed that DNA could be deliberately altered, opening the door to future research regarding genetic manipulation.²⁸ Throughout the 1980s and 1990s, scientists continued to experiment with somatic cell gene therapy—gene therapy that involves somatic cells, or any cell in the body other than reproductive cells.²⁹ For example, in 1990, American scientists successfully genetically modified white blood cells in a young girl, which drastically improved the function of her immune system.³⁰ However, these therapies were often experimental and unpredictable, spurring heated debates regarding the ethics, safety, and legality of these experiments. Scientists and critics warned that unintended consequences, such as mutations, could do more harm than good. Technical issues like off-target effects (edits at incorrect locations), genetic mosaicism (some cells being edited, while some cells are not), and challenges in accurately analyzing edits are major examples of these potential consequences.³¹

A significant development in the world of genetics came in 1990 with the launch of the Human Genome Project.³² This project was a large international scientific collaboration involving countries like the United States, the United Kingdom, and China. It aimed to sequence the entire human genome, determining the exact order of roughly 3 billion bases or “letters” of human DNA.³³ Completed in 2003, the Human Genome Project was a success. The mapped genome offered scientists a full genetic blueprint of the human species, creating opportunities for more precise development of treatment and disease identification.³⁴ Such developments set the stage for the development of increasingly sophisticated tools that moved gene editing from an idea to being practically applied.

In 1996, Professor Srinivasan Chandrasegaran and fellow scientists from Johns Hopkins University developed zinc-finger nucleases (ZFNs).³⁵ Specifically, ZFNs relied on engineered proteins that could recognize specific DNA sequences and bind to them, which then subsequently cut the DNA.³⁶ This discovery enabled targeted

²⁵ “The FLAVR SAVR TOMATO: Pioneering Long-Lasting Flavor • Food Safety Institute,” Food Safety and Quality Institute, April 7, 2025, <https://foodsafety.institute/food-biotechnology/flavrsavr-tomato-long-lasting-flavor/>.

²⁶ “Genetically Altered Mice: A Revolutionary Research Resource,” Sharing Laboratory Resources: Genetically Altered Mice: Summary of a Workshop Held at the National Academy of Sciences, March 23-24, 1993, January 1, 1994, <https://www.ncbi.nlm.nih.gov/books/NBK231336/>.

²⁷ Tamura, “Historic Overview of Genetic Engineering Technologies”

²⁸ Doogab Yi, Paul Berg and the origins of recombinant DNA, February 29, 2024, <https://www.sciencedirect.com/science/article/pii/S0092867424000096>.

²⁹ Ibid.

³⁰ “Somatic Gene Therapy,” Somatic Gene Therapy - an overview | ScienceDirect Topics, <https://www.sciencedirect.com/topics/medicine-and-dentistry/somatic-gene-therapy>.

³¹ Mohammad Reza Sadeghi, “Technical Problems and Ethical Concerns Regarding Gene Editing in Human Germlines and Embryos,” Journal of reproduction & infertility, September 24, 2023, <https://pmc.ncbi.nlm.nih.gov/articles/PMC10471948/>.

³² “Launch of the Human Genome Project.”

³³ Ibid.

³⁴ “Human Genome Project Completed.”

³⁵ Srinivasan Chandrasegaran and Dana Carroll, “Origins of Programmable Nucleases for Genome Engineering,” Journal of molecular biology, February 27, 2016, <https://pmc.ncbi.nlm.nih.gov/articles/PMC4798875/>.

³⁶ Ibid.

modification of a gene rather than random modifications, which is a dramatic step forward from earlier techniques. However, ZFNs were highly technical, expensive to design, and difficult to adapt to widespread use, which limited their practical usage outside of specialized laboratories.³⁷ Thus, in the late 2000s, Transcription Activator-Like Effector Nucleases (TALENs) emerged as an improved alternative to ZFNs. Designed in a similar style, TALENs were derived from plant proteins that could be engineered to bind to longer and more precise DNA sequences, making them comparatively more reliable and versatile with fewer unintended mutations.³⁸ However, even with this large improvement, TALENs still require complex and time-intensive design work, meaning they remain out of reach and inaccessible for the majority of laboratories.³⁹

A turning point came with the discovery and development of CRISPR-Cas9 in 2012 by Jennifer Doudna and Emmanuelle Charpentier.⁴⁰ CRISPR-Cas9 was adapted from a bacterial immune defense system that naturally cuts viral DNA.⁴¹ Unlike ZFNs and TALENs, CRISPR relies on a short RNA sequence to help guide the Cas9 protein to the right spot in the genome, making it much easier to use, more accessible, and far cheaper.⁴² The simplicity and efficiency of CRISPR meant that labs worldwide could suddenly perform targeted edits with unprecedented precision. CRISPR-Cas9 continues to be tested across a wide variety of organisms and experiments.⁴³

Past UN/International Involvement

UNESCO 1997 Universal Declaration on the Human Genome and Human Rights

In 1997, UNESCO adopted the Universal Declaration on the Human Genome and Human Rights.⁴⁴ This declaration marked the first significant multilateral effort to set guidelines regarding the ethical implications of various developments in genetic science. It declared the human genome to be the “heritage of humanity” and outlines various ethical principles, including the consideration for rights of the individual regarding testing scenarios.⁴⁵ Specifically, this document emphasized that scientific and medical developments must be guided by a commitment to maintaining fundamental human rights and ethical standards.

This declaration has shaped global bioethics and has influenced national legislation across Europe, Asia, and Latin America, encouraging governments to abide by the declaration and establish basic protections against misuse of editing technology.⁴⁶ The international legitimacy brought by the UNGA endorsement in 1998 enforced large moral and political pressure for governments to align their policies with its principles. For example, in November

³⁷ Ibid.

³⁸ J Keith Joung and Jeffry D Sander, “Talens: A Widely Applicable Technology for Targeted Genome Editing,” *Nature reviews. Molecular cell biology*, January 2013, <https://pmc.ncbi.nlm.nih.gov/articles/PMC3547402/>.

³⁹ Ibid.

⁴⁰ Irina Gostimskaya, “CRISPR-Cas9: A History of Its Discovery and Ethical Considerations of Its Use in Genome Editing,” *Biochemistry. Biokhimiia*, August 15, 2022, <https://pmc.ncbi.nlm.nih.gov/articles/PMC9377665/>.

⁴¹ Ibid.

⁴² Ibid.

⁴³ Hope Henderson, “CRISPR Clinical Trials: A 2025 Update - Innovative Genomics Institute (IGI),” *Innovative Genomics Institute*, July 9, 2025, <https://innovativegenomics.org/news/crispr-clinical-trials-2025/>.

⁴⁴ UNESCO, “Universal Declaration on the Human Genome and Human Rights.”

⁴⁵ Ibid.

⁴⁶ Ibid.

2000, Japan enacted the Human Cloning Regulation, which was created and influenced with the compatibility with the UNESCO declaration in mind.⁴⁷

However, the declaration's shortcomings extend to the document's age and irrelevance in modern-day genetic medicine. For example, it was created prior to the invention of tools such as CRISPR-Cas9 and does not reflect the complexities of current genetic editing technologies. Furthermore, concerns regarding whether or not UNESCO overstepped in the domain of the WHO and the Eurocentric nature of the declaration have led to limited adherence to the declaration.⁴⁸

Europe's Oviedo Convention / Convention on Human Rights and Biomedicine

The Oviedo Convention, formally known as the Convention on Human Rights and Biomedicine, was ratified by the Council of Europe in 1999 and remains the only legally binding international treaty specifically dedicated to bioethics.⁴⁹ The Convention's legally binding nature distinguishes it from most other international guidelines on genome editing, and it has been cited in various judicial and legislative processes throughout Europe.⁵⁰ In fact, over 30 countries have signed and ratified this agreement, with countries like France adopting laws restricting genetic interventions.⁵¹ However, despite its successes throughout Europe, the Convention has not achieved universal adoption, even within Europe. Major countries such as Germany and the United Kingdom have chosen not to ratify the Convention, fearing that its restrictions may stifle legitimate scientific advancement.⁵² Furthermore, the Convention is seen by many as simply too rigid to accommodate evolving editing technologies such as CRISPR-Cas9 and TALEN.⁵³

WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing

In 2019, in response to the global controversy surrounding the creation of genetically modified babies in China, the WHO created an Expert Advisory Committee tasked with developing international governing standards for human genome editing.⁵⁴ After two years of discussion and meetings, the committee released a report in July 2021: Human Genome Editing: A Framework for Governance and Recommendations.⁵⁵ This document outlined

⁴⁷ Tade Matthias Spranger, "The Japanese Approach to the Regulation of Human Cloning," *Zeitschrift Für Japanisches Recht*, 2002, <https://www.zjapanr.de/index.php/zjapanr/article/view/655/679>.

⁴⁸ R Andorno, "Global Bioethics at UNESCO: In Defence of the Universal Declaration on Bioethics and Human Rights," *Journal of medical ethics*, March 2007, <https://pmc.ncbi.nlm.nih.gov/articles/PMC2598251/>.

⁴⁹ "Oviedo Convention and Its Protocols - Human Rights and Biomedicine - WwW.Coe.Int," Council of Europe, <https://www.coe.int/en/web/human-rights-and-biomedicine/oviedo-convention>.

⁵⁰ "The Oviedo Convention and Human Rights Principles Regarding Health - Human Rights and Biomedicine - WwW.Coe.Int," Council of Europe, <https://www.coe.int/en/web/human-rights-and-biomedicine/the-oviedo-convention-and-human-rights-principles-regarding-health>.

⁵¹ Françoise Baylis and Lisa Ikemoto, "The Council of Europe and the Prohibition on Human Germline Genome Editing," *EMBO reports*, December 2017, <https://pmc.ncbi.nlm.nih.gov/articles/PMC5709742/>.

⁵² Tom Goffin, "Why Eight EU Member States Signed, but Not yet Ratified the Convention for Human Rights and Biomedicine," *U.S. National Library of Medicine*, May 2008, <https://pubmed.ncbi.nlm.nih.gov/18063437/>.

⁵³ Britta C van Beers, "Rewriting the Human Genome, Rewriting Human Rights Law? Human Rights, Human Dignity, and Human Germline Modification in the CRISPR Era," *Journal of law and the biosciences*, June 9, 2020, <https://pmc.ncbi.nlm.nih.gov/articles/PMC8248990/>.

⁵⁴ World Health Organization, "Who Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing."

⁵⁵ World Health Organization, "Human Genome Editing: A Framework for Governance."

a comprehensive guideline for the ethical and legal nature of genetic science. Specifically, they emphasized transparency through their emphasis on the creation of global registries and open communication. Accompanying the publishing of this document, the WHO launched the Global Human Genome Editing Registry, intended to monitor ongoing genetic research worldwide.⁵⁶

This document, released by the WHO, was widely praised for being the most detailed, modern, and globally oriented of its kind.⁵⁷ The establishment of the registry also provided a mechanism to track clinical trials and gene editing studies in real time, enhancing transparency and accountability. Regardless of the successes of these guidelines, these measures still remain voluntary. The WHO's guidance, while influential, is not legally binding. The implementation of these recommendations also relies on large amounts of political will and political power. Furthermore, some nations simply lack the infrastructure to enforce such ethical standards, creating large gaps in unilateral global oversight.

International Summit Series on Human Genome Editing

Beginning in 2015, the International Summit on Human Genome Editing has served as a recurring forum for global scientific oversight.⁵⁸ The first summit concluded that germline editing should not be allowed until various safety, societal, ethical, and legal issues were fully resolved.⁵⁹ The 2018 summit, held shortly after He Jiankui's announcement, highlighted the need for stronger international governance and discussed how far the regulation of genetic science has lagged behind its development.⁶⁰ The 2023 summit reaffirmed the commitment to cautious advancement and emphasized public engagement.⁶¹ These summits had a generally large influence on national regulations. For example, as a result of the first summit declaring that clinical germline editing would be "irresponsible" until various questions were addressed, several countries, like the United States, increased national oversight regarding germline editing.⁶²

Current Situation

Human genome editing has advanced from a theoretical concept to a field with real-world applications. Technologies such as CRISPR-Cas9, base editing, and prime editing have enabled precise, efficient, and increasingly affordable procedures at the genetic level. As of February 2025, over 250 clinical trials involving gene editing have been launched globally, with more than 150 of these trials currently active.⁶³ Currently, various challenges exist in balancing the transformative potential of human genome editing with urgent ethical, legal, and social concerns.

⁵⁶ Fadela Chaib, "Who Launches Global Registry on Human Genome Editing," World Health Organization, August 29, 2019, <https://www.who.int/news/item/29-08-2019-who-launches-global-registry-on-human-genome-editing>.

⁵⁷ "Expert Reaction to the Who's Newly Published Recommendations and Governance Framework for Human Genome Editing," Science Media Centre, July 12, 2021, <https://www.sciencemediacentre.org/expert-reaction-to-the-whos-newly-published-recommendations-and-governance-framework-for-human-genome-editing/>.

⁵⁸ Olson, "International Summit on Human Gene Editing."

⁵⁹ Ibid.

⁶⁰ Steve Olson, "Second International Summit on Human Genome Editing: Continuing the Global Discussion," National Center for Biotechnology Information, January 10, 2019, <https://www.ncbi.nlm.nih.gov/books/NBK535994/>.

⁶¹ Steve Olson, "Third International Summit on Human Genome Editing," National Center for Biotechnology Information, July 10, 2023, <https://www.ncbi.nlm.nih.gov/books/NBK593530/>.

⁶² Steve Olson, ed., "Oversight of Human Genome Editing and Overarching Principles for Governance," Human Genome Editing: Science, Ethics, and Governance., January 1, 2016, <https://www.ncbi.nlm.nih.gov/books/NBK447266/>.

⁶³ "Overview CRISPR Clinical Trials 2025," CRISPR Medicine, February 28, 2025, <https://crisprmedicineneeds.com/clinical-trials/>.

Medical Applications

Medical usage of genome editing spans a spectrum, with most research falling somewhere between therapeutic applications—such as treating or preventing disease—and non-therapeutic applications, including enhancement or modification of certain traits. While these categories are useful for understanding the basics of genome editing, in practice, the lines between them can be blurry, with some interventions having elements of both.

Therapeutic applications of genome editing are currently the most common, most unrestricted, and least controversial. Specifically, these include treatments for diseases such as sickle cell anemia, Huntington's disease, and cystic fibrosis.⁶⁴ Diseases like sickle cell anemia, an inherited disease that affects hemoglobin—the major protein that carries oxygen in red blood cells—are mostly caused by inherited harmful genetic mutations.⁶⁵ Clinical trials in China, Germany, and the United States are testing somatic gene editing and are attempting to cure infectious diseases.⁶⁶ For example, in 2023, the U.S. The Food and Drug Administration approved the first gene therapy, Casgevy, to treat sickle cell anemia after the landmark CRISPR trial began in 2019.⁶⁷

However, non-therapeutic uses raise deeper ethical and legal concerns. Non-therapeutic editing refers to applications that go beyond simply treating illness, such as altering or “enhancing” certain physical traits, intelligence, or other biological aspects.⁶⁸ A controversial usage of gene editing lies in the creation of “designer babies,” blurring the line between medicine and simple ideology. While it is currently quite infeasible, the growing capabilities of gene editing technologies make this a realistic concern.⁶⁹ The most profound example of a “designer baby” is Lulu and Nana, Chinese twins genetically modified to be resistant to HIV. However, the global debate regarding the ethics and legality of clinical trials intensified in 2018 when Chinese scientist He Jiankui claimed to have created the world's first genetically modified babies.⁷⁰ His announcement shocked the international community, and his experiment was widely condemned as unethical, unsafe, illegal, and premature. As a result, the Chinese government imprisoned He for “illegal medical practices” for three years and announced new regulations.⁷¹ Furthermore, the case of He Jiankui sparked global condemnation not only because of its reckless and unsanctioned experiment, but also for the broader implications that parents and scientists could possibly edit their children to fit societal norms or ideals.⁷² For example, without strong regulation, targeted genetic editing could reinforce ableism or other forms of discrimination by devaluing people with disabilities or those who do not meet society's ideal genetic standards.⁷³ From an ethical standpoint, various individuals and groups advocate

⁶⁴ Wenyi Liu, “Applications and Challenges of CRISPR-Cas Gene-Editing to Disease Treatment in Clinics,” *Precision clinical medicine*, July 10, 2021, <https://pmc.ncbi.nlm.nih.gov/articles/PMC8444435/>.

⁶⁵ “What Is Sickle Cell Disease?,” National Heart Lung and Blood Institute, September 30, 2024, <https://www.nhlbi.nih.gov/health/sickle-cell-disease>.

⁶⁶ *Ibid.*

⁶⁷ Ajeet Singh et al., “Revolutionary Breakthrough: FDA Approves CASGEVY, the First CRISPR/Cas9 Gene Therapy for Sickle Cell Disease,” *Annals of medicine and surgery* (2012), May 15, 2024, <https://pmc.ncbi.nlm.nih.gov/articles/PMC11305803/>.

⁶⁸ “Ethical Editing: Therapeutics and ‘Enhancement,’” Genomics Education Programme, February 20, 2017, <https://www.genomicseducation.hee.nhs.uk/blog/ethical-editing-therapeutics-and-enhancement/>.

⁶⁹ Bartha Maria Knoppers and Erika Kleiderman, “‘Crispr Babies’: What Does This Mean for Science and Canada?,” *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, January 28, 2019, <https://pmc.ncbi.nlm.nih.gov/articles/PMC6342697/>.

⁷⁰ Raposo, “Chinese's First Genetically-Edited Babies.”

⁷¹ Normile, Dennis. “Chinese Scientist Who Produced Genetically Altered Babies Sentenced to 3 Years in Jail | Science | AAAS.” *Science*, December 30, 2019. <https://www.science.org/content/article/chinese-scientist-who-produced-genetically-altered-babies-sentenced-3-years-jail>.

⁷² Sandy Sufian, and Rosemarie Garland-Thomson, “The Dark Side of CRISPR,” *Scientific American*, February 20, 2024, <https://www.scientificamerican.com/article/the-dark-side-of-crispr/>.

⁷³ *Ibid.*

for a more precautionary approach to genome editing. This increasingly precautionary approach could include involving affected communities, being transparent during research, and creating international accountability mechanisms.

Furthermore, some military research programs, particularly in China, North Korea, and the United States, have also explored the use of gene editing to enhance particular physical traits that are beneficial to the military, such as increasing muscle strength and endurance or disease resistance, inherently raising concerns about the militarization of biotechnology and genetic editing.⁷⁴

Unintended Consequences

One of the greatest concerns surrounding the editing of the human genome is the risk of unintended consequences. Even with more precise and advanced tools like CRISPR-Cas9, errors known as “off-target effects” or unintended mutations can occur, leading to unpredictable, adverse changes to the human genome.⁷⁵ Specifically, these unintended alterations to the human genome include unintentional mutations that create genomic instability or simply interfere with regular genetic function.⁷⁶ An example of this was a failed 2015 CRISPR-based trial by Chinese scientists attempting to edit the genome of human embryos. Out of 85 embryos, none were edited without error, where even in the few embryos where the target gene was changed, researchers found off-target mutations, unintended DNA mutations scattered throughout the genome.⁷⁷ Therefore, the profound ethical and technical challenge of mitigating these unpredictable genetic errors must be resolved before replicable and heritable human genome editing can be considered safe for clinical use.

Eugenic Misuse

In the modern realm of human genome editing, another concern is the potential for the revival of eugenics, where individuals or societies make choices about embryos or future generations based on subjective preferences. Eugenics has long been prevalent in countries across the world, with examples including Germany and the United States. Unethical medical practices like forced sterilization embody the premise of eugenics. A deeper dive into the United States emphasizes this fact, with federally-funded sterilization programs taking place in 32 states throughout the 20th century, and in California alone, more than 20,000 men and women were sterilized as a result of this program.⁷⁸ Even clinical usages of gene editing technologies have some connection to eugenics. For example, sickle-cell anemia has an intricate relationship with malaria. The mutation that causes sickle-cell anemia also provides resistance to malaria. A purely eugenic approach may attempt to eliminate the sickle-cell gene entirely without consideration of the protective advantage against malaria, especially in regions where the disease is rampant.⁷⁹

⁷⁴ Paridhi Billore, “Gene Editing in Soldiers: CRISPR and Human Chimeras,” TDHJ.org, March 18, 2024, <https://tdhj.org/blog/post/gene-editing-soldiers-crispr/>.

⁷⁵ Congting Guo, Xiaoteng Ma, Fei Gao, and Yuxuan Guo, “Off-Target Effects in CRISPR/Cas9 Gene Editing,” *Frontiers in bioengineering and biotechnology*, March 9, 2023, <https://pmc.ncbi.nlm.nih.gov/articles/PMC10034092/>.

⁷⁶ Ibid.

⁷⁷ Gina Kolata, “Chinese Scientists Edit Genes of Human Embryos, Raising Concerns,” *The New York Times*, April 23, 2015, <https://www.nytimes.com/2015/04/24/health/chinese-scientists-edit-genes-of-human-embryos-raising-concerns.html>.

⁷⁸ Lisa Ko, “Unwanted Sterilization and Eugenics Programs in the United States,” PBS, January 29, 2016, <https://www.pbs.org/independentlens/blog/unwanted-sterilization-and-eugenics-programs-in-the-united-states>.

⁷⁹ Adya Reddy Yala, “Sickle Cell Trait and Resistance to Malaria: A Review,” *Research Archive of Rising Scholars*, January 8, 2025, <https://research-archive.org/index.php/rars/preprint/view/2129/2984>.

The governance of human genome editing has remained a contested issue. While clinical trials based on CRISPR are gaining approval in countries like China and the United States, germline editing still remains largely banned or heavily restricted. The potential for eugenic misuse as a result of unregulated or even improper trials through germline editing remains a large concern. Governance continues to be a contested issue, and while the WHO expert advisory panel created international guidelines, it is simply not enough to guide the world into the era of human genome editing.

Social Inequity and Ethical Responsibility

Genome editing technologies are being developed in a world already characterized by large global inequities in access to adequate healthcare and scientific infrastructure. As of 2016, of 603 international laboratories offering genetic testing, none are found in low-income countries, and only 20 are found in middle-income countries.⁸⁰ This statistic demonstrates the inequities that exist between high-income countries and lower-income countries in terms of genetic science. This gap in research risks creating a “genetic divide” in which some populations would benefit from edited immunity or disease resistance, while others are left behind. Furthermore, the cost of genetic treatments remains unreasonably high. For example, the world’s first approved CRISPR-based cell therapy, Casgevy, has been priced at USD 2.2 million per patient.⁸¹ This unreasonably high cost makes genetic therapies inaccessible without large amounts of wealth or state subsidies, creating a policy dilemma: whether governments should prioritize investment in more expensive, inaccessible, and cutting-edge cures or prioritize more global and accessible public health interventions.

However, there are a few instances in which gene editing can and has been accessed by low and middle-income countries. For example, clinical trials offer access to gene therapies in countries without approved products.⁸² As well, organizations like the Bill & Melinda Gates Foundation and the National Institute of Health (NIH) are funding projects to make CRISPR-based therapies for diseases like HIV and sickle cell disease more affordable and scalable for use in various low and middle-income countries.⁸³ However, proactive strategies from both national agencies and global organizations are needed to help combat this inequitable access on a global scale.

Possible Solutions and Controversies

As human genome editing technologies continue to develop, the international community must learn to regulate their future development and application in a way that ensures global ethics and prevents misuse.

Establishing International Ethical Standards

One of the most basic and fundamental solutions is the establishment of binding or semi-binding international ethical standards that define the acceptable boundaries of the development and application of human genome

⁸⁰ Fasil Tekola-Ayele and Charles N Rotimi, “Translational Genomics in Low- and Middle-Income Countries: Opportunities and Challenges,” *Public health genomics*, June 26, 2016, <https://pmc.ncbi.nlm.nih.gov/articles/PMC4514540/>.

⁸¹ Jon Rueda, “Affordable Pricing of CRISPR Treatments Is a Pressing Ethical Imperative,” *The CRISPR journal*, October 10, 2024, <https://pubmed.ncbi.nlm.nih.gov/39392045/>.

⁸² Kevin W. Doxzen et al., “The Translational Gap for Gene Therapies in Low- and Middle-Income Countries,” *Science Translational Medicine*, May 8, 2024, <https://www.science.org/doi/10.1126/scitranslmed.adn1902>.

⁸³ Ibid.

editing. This could look like a UN-endorsed framework or treaty that builds upon existing documents such as the UNESCO Universal Declaration on the Human Genome or the Oviedo Convention, but with updated language and a more modern perspective.⁸⁴

These guidelines would help prevent unethical or dangerous clinical applications of genetic technology, particularly preventing eugenic editing or enhancement-based discrimination by simply establishing universal norms. However, the success of ethical guidelines, especially those not legally binding, relies on widespread buy-in from countries around the world. For example, the Oviedo Convention was limited simply to countries in Europe, which means that countries like China and the United States, nations both heavily involved in the world of genetics, were unable to ratify this legally binding treaty. Furthermore, even countries like the United Kingdom and Germany chose not to ratify this treaty, even with the opportunity to do so. This decision indicates that even non-legally-binding treaties require global buy-in and collaboration in order to create long-lasting positive effects.⁸⁵ Thus, it is imperative that enforcement remains effective and countries continue to adhere to the contents of the guidelines, as without set universal standards, any guidelines will become meritless.⁸⁶

Promoting Education and Transparency

Beyond the regulation and the establishment of ethical standards, fostering public understanding and ethical awareness of genome editing is crucial as a long-term solution. Many of the misconceptions surrounding genome editing, particularly the idealization of “designer babies” or unintended eugenics, stem from limited public knowledge or very oversensationalized media coverage.⁸⁷ Governments and international organizations can respond by funding widespread educational campaigns, integrating larger parts of genetic science into the high school curriculum, and implementing various other processes. On a global scale, educational campaigns can be designed with agreed-upon definitions and targets in order to maintain a coordinated and effective global response.

Generally, by promoting educational campaigns and increasing transparency, both social equity and informed consent are being addressed. This solution enables more communities, especially those historically marginalized, to engage in meaningful decisions that could impact their genetic futures, and also fosters public trust in genome editing.⁸⁸ This trust is critical for the acceptance of applications of genetic therapies. However, education cannot resolve legal issues or prevent misuse, and another challenge is ensuring global access to the aforementioned educational material across various regions to try to combat misinformation. By pairing large education campaigns with transparency measures, such as a mandatory disclosure of clinical trials to the WHO registry, the solution would be more effective.

⁸⁴ Phebe Hong, “Establishing Standards for Gene Editing: Initial Steps from Private and Public Actors - Petrie-Flom Center,” The Petrie-Flom Center, September 5, 2019, <https://petrieflom.law.harvard.edu/2019/09/05/establishing-standards-for-gene-editing-initial-steps-from-private-and-public-actors/>.

⁸⁵ Tom Goffin et al., “Why Eight EU Member States Signed, but Not yet Ratified the Convention for Human Rights and Biomedicine,” Health policy (Amsterdam, Netherlands), May 2008, <https://pubmed.ncbi.nlm.nih.gov/18063437/>.

⁸⁶ “Can There Be International Agreement on How to Navigate the Future of Genome Editing?,” Oligonucleotide Therapeutics Society, April 5, 2023, <https://www.oligotherapeutics.org/can-there-be-international-agreement-on-how-to-navigate-the-future-of-genome-editing/>.

⁸⁷ Cary Funk, “Public Views of Gene Editing for Babies Depend on How It Would Be Used,” Pew Research Center, July 26, 2018, <https://www.pewresearch.org/science/2018/07/26/public-views-of-gene-editing-for-babies-depend-on-how-it-would-be-used/>.

⁸⁸ Susanne B Haga et al., “Promoting Public Awareness and Engagement in Genome Sciences,” Journal of genetic counseling, August 1, 2014, <https://pmc.ncbi.nlm.nih.gov/articles/PMC3688701/>.

Encouraging National Regulation with International Oversight

Given the difficulty of enforcing one-size-fits-all global laws or guidelines, a more flexible and more accommodating solution may involve encouraging national regulation of genome editing backed by international oversight and guidance. This solution could look like ethical review boards, involvement with the WHO registry, or coordination with WHO expert committees. Countries would maintain their sovereignty over genetic policies while still committing to shared scientific development.

This potential solution allows for region-specific policy that accommodates a region's specific needs while promoting global cooperation and responsible use of genetic technology. It also avoids jurisdictional overreach and growing tensions by relying on recommendation-based influence rather than simple legal enforcement. However, a significant challenge is that countries with weaker regulatory systems or political will may not be able to push the scientific bounds without legal enforcement. Thus, creating a global oversight system that could manage, guide, and regulate the genomic policies of a government could mitigate this challenge to an extent.⁸⁹

Implementing Accountability Measures

A central challenge in the governance and regulation of genome editing is the lack of enforceable accountability mechanisms, especially in cases of unethical or unauthorized experimentation. These accountability measures could be coordinated through the WHO or an UN-affiliated body and could combine various reporting systems for clinical trials with independent review panels that monitor compliance and publish findings, serving as a supplementary global check where national oversight is simply no longer needed. This structured form of review and transparency creates a global standard for which future genetic ethics will be based. Accountability can be achieved and has been displayed at a national level. For example, in the case of He Jiankui in China, the national government kept him and his team accountable for breaking national law and regulations regarding human genome editing by arresting him.⁹⁰ Past international regulatory organizations have also been created to keep certain actors accountable. The most prevalent example of this is the International Criminal Court (ICC), which is given jurisdiction to charge individuals with four main crimes.⁹¹

However, similar to the creation of ethical guidelines, this solution raises several concerns. Specifically, it requires unilateral buy-in, especially from more developed states, to remain effective and legitimate. There is also a risk of politicization, especially if investigations or the review board seem to disproportionately target specific countries with different ethical norms or practices. Referring back to the International Criminal Court, concerns have arisen due to this idea of politicization and targeted investigations.⁹² To succeed, transparency and impartiality are required. Delegates must handle this delicate balance in order to effectively implement the aforementioned solution.

⁸⁹ John M Conley et al., "A New Governance Approach to Regulating Human Genome Editing," *North Carolina journal of law & technology*, December 22, 2020, <https://pmc.ncbi.nlm.nih.gov/articles/PMC8565716/>.

⁹⁰ Dennis Normile, "Chinese Scientist Who Produced Genetically Altered Babies Sentenced to 3 Years in Jail | Science | AAAS."

⁹¹ "How the Court Works," International Criminal Court, <https://www.icc-cpi.int/about/how-the-court-works>.

⁹² Benjamin Duerr, "Twenty Years on: The ICC and the Politicization of Its Mechanisms," IPI Global Observatory, September 12, 2018, <https://theglobalobservatory.org/2018/08/twenty-years-icc-politicization-mechanisms/>.

Technologically Advanced Liberal Democracies

Liberal democracies that tend to be more technologically advanced in terms of research infrastructure and current scientific capabilities, including the United States, Canada, Germany, France, Japan, and the United Kingdom, generally approach human genome editing from a position focusing more on ethics and fair regulation.⁹³ These countries mainly support therapeutic applications within frameworks and guidelines that are grounded in maintaining human rights and transparency. While most have banned germline editing, some support controlled germline research under strict ethical guidelines. For example, the United Kingdom permits germline gene editing for certain research purposes but restricts germline gene editing for any reproductive purposes.⁹⁴ This bloc tends to support more voluntary and non-binding international frameworks with incentive-based enforcement. The support for this framework is because these technologically advanced states may be hesitant to accept measures that are overly restrictive and could hamper innovation. For example, the Oviedo Convention was not ratified by various technologically advanced liberal democracies such as Germany and the United Kingdom. Taking a deeper look into Germany, government officials note that the convention is simply too rigid and restrictive to keep up with the developments in biotechnology and human genome editing.⁹⁵ Thus, these nations champion a regulatory philosophy that seeks to balance ethical precaution with the freedom to innovate, often favouring adaptable guidelines over rigid international treaties.

Emerging Scientific Powers

Countries in this bloc have invested heavily in biotechnology and often see the development of gene editing technology as a tool for economic growth, global recognition, and scientific prestige. An example of this can be found in India, where the nation approved its first genome-edited rice varieties. Not only was this to grow the agriculture sector in India and improve the lives of citizens, but it also put the world on notice in regards to the scientific capabilities of India.⁹⁶ In this bloc, countries like China, India, Brazil, and South Korea would rather promote domestic innovation in order to compete with more Western scientific powerhouses. The reason for this desired dominance can be explained by a variety of factors, from desiring scientific prestige to achieving self-sustaining independent biotech industries. This bloc may be supportive of more flexible international guidelines as an attempt to not only maintain their scientific sovereignty but also remain able to compete with these scientific superpowers.

Low and Middle Income Countries (LMIC)

LMICs, such as Kenya, Bangladesh, and Nepal, face limited access to genome editing technologies as well as the infrastructure to research genetics. However, even with limited access to biotech, they are still heavily concerned with the ethical, social, and legal implications of global governance; nations' main priority would include ensuring

⁹³ "Oversight of Human Genome Editing and Overarching Principles for Governance," Human Genome Editing: Science, Ethics, and Governance., February 14, 2017, <https://www.ncbi.nlm.nih.gov/books/NBK447266/>.

⁹⁴ Kayleen Schreiber, "United Kingdom: Germline / Embryonic," Global Gene Editing Regulation Tracker, December 22, 2019, <https://crispr-gene-editing-regs-tracker.geneticliteracyproject.org/united-kingdom-germline-embryonic/>.

⁹⁵ Eva Schewior, Speech by Ms. Eva Schewior on the Impact of the Biomedicine Convention on the national level at the Conference to celebrate ten years of the Convention on Human Rights and Biomedicine of the Council of Europe, November 3, 2009, https://www.coe.int/t/dg3/healthbioethic/Activities/10th_Anniversary/Eva%20Schewior.pdf.

⁹⁶ Subhra Priyadarshini, "India Approves First Genome-Edited Rice Varieties," Nature News, May 4, 2025, <https://www.nature.com/articles/d44151-025-00078-2>.

that genetic therapies are affordable, equitably distributed, and culturally appropriate. Global oversight, transparency, accountability, and education programs to empower local communities are also at the core of their stance. Furthermore, LMICs would prioritize the usage of genomic biotechnology for the purpose of general economic growth through prioritizing agriculture. This trend can be seen in Kenya, where they recently created guidelines to facilitate the development of gene technology and genetically modified products. While it is still heavily regulated, the guidelines enable researchers to have a more agricultural focus.⁹⁷ Overall, this bloc's stance on global governance emphasizes equitable access, local empowerment, and the application of biotechnology to address pressing developmental needs.

Conservative and Religious States

This bloc often approaches genome editing from a more theological, moral, and traditionalist standpoint. Specifically, countries in these blocs include more theocratic and religious states like Iran, Saudi Arabia, and Vatican City, among others. For example, Vatican City, and in turn the Catholic Church, is generally against human genome editing in both a clinical and research setting. Human genome editing relies on research that alters and then destroys thousands of human embryos, an inhumane practice deemed by the Catholic Church. Furthermore, members of the church also believe that the innate goal of human gene editing will promote a eugenic mindset through a drive for perfection.⁹⁸ While some therapeutic uses may be accessible, there is a deep concern over the manipulation of the human genome for non-therapeutic purposes. Many of these states would advocate for strict ethical boundaries, with some calling for a global ban on germline genome editing as a whole. For example, Iran places an emphasis on the national genome guidelines to be customized and developed according to the Code of Religious Laws in Shia.⁹⁹ In summary, nations in this bloc are likely to support binding international regulations, and they may emphasize the need for cultural pluralism and inclusion in the discussion of bioethics.

Discussion Questions

1. To what extent should international bodies be able to regulate or influence national policies on human genome editing without violating a state's sovereignty?
2. How should the international community distinguish between therapeutic and non-therapeutic genome editing? What does this distinction mean in terms of creating guidelines?
3. What accountability mechanisms could be implemented to prevent unethical or dangerous editing practices?
4. In what ways might genome editing worsen existing global health inequalities? What can be done to deal with the possibility of eugenics?
5. Should there be a universal ban on germline editing for enhancement purposes? Can it be allowed under certain circumstances and conditions? What would these conditions look like?

⁹⁷ Joan Conrow, "Kenya Publishes Guidelines Specific to Gene Editing," Alliance for Science, March 16, 2022, <https://allianceforscience.org/blog/2022/03/kenya-publishes-guidelines-specific-to-gene-editing>.

⁹⁸ Christopher M Reilly, "A Virtuous Appraisal of Heritable Genome Editing," The Linacre quarterly, March 2, 2020, <https://pmc.ncbi.nlm.nih.gov/articles/PMC7273635/#bibr12-0024363920906672>.

⁹⁹ Mohammad Reza Zali and Saeed Shahraz, "Current Situation of Bioethics in Genetic Research in Iran," The Experiences and Challenges of Science and Ethics: Proceedings of an American-Iranian Workshop., 2003, <https://www.ncbi.nlm.nih.gov/books/NBK208737/>.

6. How should the scientific community respond when a nation violates previously agreed-upon ethical norms or guidelines?

Additional Resources

National Academies of Sciences: Human Genome Editing: Science, Ethics, and Governance.

<https://nap.nationalacademies.org/catalog/24623/human-genome-editing-science-ethics-and-governance>

National Library of Medicine: The Ethics of Germline Gene Editing.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC5573992/>

International Bioethics Committee (IBC): Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights.

<https://unesdoc.unesco.org/ark:/48223/pf0000233258>

Council of Europe: Oviedo Convention and its Protocols. <https://www.coe.int/en/web/human-rights-and-biomedicine/oviedo-convention>

Nuffield Council on Bioethics: Genome editing and human reproduction: social and ethical issues.

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Neglected Tropical Diseases

Overview

Neglected tropical diseases are a group of infectious diseases that disproportionately affect communities of low-income, particularly in the tropical and subtropical regions of the world. The World Health Organization (WHO) currently recognizes 21 neglected tropical diseases (NTDs), which affect over one billion people worldwide.¹⁰⁰ Despite their significant impact, NTDs remain underresearched and underfunded in the medical field, largely due to their focus in low-income communities that lack political and adequate health infrastructure. This disproportionate characterization is the basis for these diseases to be considered “neglected.”¹⁰¹

Overall, it is estimated that 1.5 billion people require some form of NTD intervention, whether it be curative or preventative.¹⁰² NTDs can include a range of viral, bacterial, fungal, and parasitic infections such as rabies, trachoma, mycetoma, and Chagas disease.¹⁰³ Historically, NTDs had been recognized for centuries, but it was not until the early 21st century that they received formal recognition as a distinct group of diseases requiring specialized action.¹⁰⁴

NTDs flourish in regions lacking access to clean water, sanitation, and healthcare, disproportionately harming marginalized communities.¹⁰⁵ Although these diseases are generally treatable and in some cases preventable, affected populations often face systematic barriers to accessing proper health care, such as insufficient infrastructure, political instability, and the lack of incentive for large pharmaceutical companies to invest in these neglected diseases, making some treatable diseases global disasters.¹⁰⁶ As such, the consequences of NTDs can be severe. In children, they can cause malnutrition and developmental delays, while in adults, they induce disabilities, debilitating pain, or social stigma—all of which reduce their quality of life.¹⁰⁷ Addressing these issues requires international cooperation and comprehensive legal frameworks to ensure that NTDs are adequately dealt with. WHO has the unique responsibility and obligation to create these frameworks and better the lives of all suffering from NTDs.

Timeline

1960 — WHO launches the Programme for the Evaluation and Testing of New Insecticides to assess and evaluate the safety of pesticides on public health, marking one of the earliest coordinated efforts to reduce the effects of

¹⁰⁰ “Neglected Tropical Diseases,” World Health Organization, January 8, 2025, <https://www.who.int/news-room/questions-and-answers/item/neglected-tropical-diseases>.

¹⁰¹ Ibid.

¹⁰² Ibid.

¹⁰³ Ibid.

¹⁰⁴ Molyneux, David H, et al, “The History of the Neglected Tropical Disease Movement,” *Transactions of the Royal Society of Tropical Medicine and Hygiene*, January 28, 2021, <https://pmc.ncbi.nlm.nih.gov/articles/PMC7842098/>.

¹⁰⁵ Crompton, David W.T., ed, *Working to overcome the global impact of neglected tropical diseases*, 2010, https://iris.who.int/bitstream/handle/10665/44440/9789241564090_eng.pdf.

¹⁰⁶ Kuper, Hannah, “Neglected Tropical Diseases and Disability-What Is the Link?,” *Transactions of the Royal Society of Tropical Medicine and Hygiene*, December 1, 2019, <https://pmc.ncbi.nlm.nih.gov/articles/PMC6903791/>.

¹⁰⁷ Ibid.

NTDs. This programme continues to extend its responsibilities to include other public health aspects such as the control of nuisance insects and rodents, vectors of a variety of NTDs.¹⁰⁸

1967 — WHO implements the Intensified Smallpox Eradication Programme. While smallpox is not an NTD, the method to eradicate the disease serves as a model for future attempts at other disease-specific elimination.¹⁰⁹

1974 — WHO, in collaboration with other UN bodies, establishes the Special Programme for Research and Training in Tropical Diseases (TDR). This programme aims to build the capacity of low- and middle-income countries in addressing NTDs, becoming a key driver of scientific and technological advances.¹¹⁰

1978 — American physician Ken Warren and the Rockefeller Foundation creates a global network of laboratories dedicated to studying the Great Neglected Diseases of Mankind (GND)—instrumental in shaping the way independent scientists and institutions collaborate on diseases largely overlooked by mainstream medical research.¹¹¹

1986 — In a campaign to eliminate Guinea Worm disease, the Carter Center, through education and access to clean water, reduces the number of cases from 3.5 million at the time of its inception to 15 in 2024.¹¹²

1987 — With the goal of eliminating river blindness, pharmaceutical company Merck funds the donation of Mectizan, marking the first long-term drug donation with the objective of addressing a NTD.¹¹³

2006 — The U.S. Agency for International Development establishes the NTD Control Program, integrating initiatives and treatments with the target of controlling and even eliminating five NTDs: lymphatic filariasis, onchocerciasis, schistosomiasis, trachoma, and soil-transmitted helminths.¹¹⁴

¹⁰⁸ “WHO PESTICIDE EVALUATION SCHEME 50 YEARS OF GLOBAL LEADERSHIP,” World Health Organization, 2010, http://apps.who.int/iris/bitstream/handle/10665/44305/9789241599276_eng.pdf;jsessionid=9729F4FF8EFC1BF8870EEBC5DF48817A?sequence=1.

¹⁰⁹ “History of Smallpox Vaccination,” World Health Organization, <https://www.who.int/news-room/spotlight/history-of-vaccination/history-of-smallpox-vaccination>.

¹¹⁰ “Our History,” TDR For research on diseases of poverty, 2024, <https://tdr.who.int/our-history>.

¹¹¹ Keating, Conrad, “Ken Warren and the Rockefeller Foundation’s Great Neglected Diseases Network, 1978-1988: The Transformation of Tropical and Global Medicine,” *Molecular medicine* (Cambridge, Mass.), December 16, 2014, <https://pmc.ncbi.nlm.nih.gov/articles/PMC4374516/>.

¹¹² “Guinea Worm Eradication Program,” The Carter Center, https://www.cartercenter.org/health/guinea_worm/index.html.

¹¹³ “35 Years: The Mectizan Donation Program,” Merck, May 25, 2022, <https://www.merck.com/stories/mectizan/>.

¹¹⁴ Linehan, Mary, et al, “Integrated Implementation of Programs Targeting Neglected Tropical Diseases through Preventive Chemotherapy: Proving the Feasibility at National-Scale,” *The Causes and Impacts of Neglected Tropical and Zoonotic Diseases: Opportunities for Integrated Intervention Strategies*, 2011, <https://www.ncbi.nlm.nih.gov/books/NBK62525/>.

April 19–20, 2007 — The First Global Partners’ Meeting on Neglected Tropical Diseases is held with more than 200 representatives—from UN agencies and research foundations to pharmaceutical companies—to discuss coordinated strategies for combating NTDs.¹¹⁵

January 30, 2012 — The London Declaration on NTDs is signed by WHO, various governments, pharmaceutical companies, and other organizations. This demonstration of global cooperation ultimately hopes to control or eliminate ten NTDs by 2020.¹¹⁶

2015 — NTDs are appended in the UN Sustainable Development Goals (SDGs). Target 3.3 of the SDGs explicitly calls for the end of NTDs by 2030, formally integrating its eradication into the global development agenda.¹¹⁷

January 30, 2020 — World NTD Day is observed for the first time following a global advocacy campaign to raise awareness. The day was first championed by the United Arab Emirates (UAE) and now serves as an annual platform for advocacy, awareness, and global collaboration.¹¹⁸

November 9–14, 2020 — WHO launches the 2021–2030 NTD Roadmap that was endorsed at the 73rd World Health Assembly, setting targets and milestones to reduce NTD-related disability and to control 20 by the end of the timeframe.¹¹⁹

June 23, 2022 — The Kigali Declaration on NTDs officially launches at the Commonwealth Heads of Government Meeting (CHOGM). Building on the goals of the 2012 London Declaration, it renews the global commitment to end NTDs by 2030.¹²⁰

Historical Analysis

The persistence of NTDs in the 21st century did not stem from uncertainty in the scientific community; rather, it grew from the larger systemic issues that created environments that facilitated large amounts of bacterial and parasitic growth. These diseases disproportionately impact low-income communities where limited political influence and weak health infrastructure have historically led to their exclusion from the larger global health agenda.

¹¹⁵ “Report of the Global Partners’ Meeting on Neglected Tropical Diseases. 2007 — a Turning Point,” World Health Organization, May 1, 2007, <https://www.who.int/publications/i/item/WHO-CDS-NTD-2007.4>.

¹¹⁶ “The London Declaration on NTDs,” Global Health Progress, 2012, <https://globalhealthprogress.org/collaboration/the-london-declaration-on-ntds/>.

¹¹⁷ Engels, Dirk, “Neglected tropical diseases in the Sustainable Development Goals,” *The Lancet*, January 16, 2016, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)00043-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)00043-X/fulltext).

¹¹⁸ World NTD Day, Accessed July 24, 2025, <https://worldntdday.org/>.

¹¹⁹ Ntuli, Malecela Mwelecele, ed, “Ending the Neglect to Attain the Sustainable Development Goals: A Road Map for Neglected Tropical Diseases 2021–2030,” World Health Organization, January 28, 2021, <https://www.who.int/publications/i/item/9789240010352>.

¹²⁰ Elphick-Pooley, Thoko, and Dirk Engels, “World NTD Day 2022 and a New Kigali Declaration to Galvanise Commitment to End Neglected Tropical Diseases,” *Infectious diseases of poverty*, January 22, 2022, <https://pubmed.ncbi.nlm.nih.gov/35086566/>.

The early 20th century brought various scientific breakthroughs that allowed scientists and institutions to better understand and eventually begin to combat NTDs. This trend was exemplified by most vectors—a living organism, often an insect like a mosquito or tick, that transmits an infectious pathogen from an infected host to another—of NTDs being identified. For example, in the early 1900s, Australian Naturalist Thomas Lane Bancroft identified *Aedes aegypti* as a carrier of dengue fever and deduced that it was caused by an organism other than a bacterium or parasite.¹²¹ This discovery allowed scientists in the early 20th century to understand that vectors of disease are not specific to parasites. While these discoveries improved the knowledge of disease mechanisms for the scientific community, there was a very limited immediate impact on prevention or treatment in the affected regions.¹²² As a result, NTDs continued to grow as a global health risk, with the suffering in marginalized communities perpetuated disproportionately.

Global health efforts during the mid-late 20th century were largely focused on high-profile, globally threatening diseases such as malaria or smallpox.¹²³ At the time, these diseases were prioritized due to their potential to become epidemics and their large-scale economic consequences, but, in turn, resulted in systemic underinvestment in research, infrastructure, and an effective response targeting NTDs.¹²⁴

Though a critical turning point came in the 1970s, with the launch of the TDR. This initiative was created in an attempt to address the lack of research funding that is largely present in underdeveloped countries. It also helped legitimize NTDs as a priority within the global health community, and serves as the basis for various NTD eradication programs, making it unique in its commitment to a global effort.¹²⁵

By the late 20th century, the attention had begun to shift significantly as pharmaceutical companies took a larger role in the global commitment to eradicate NTDs. Most pertinent was the Mectizan donation program by Merck for the treatment of river blindness, setting a precedent for large-scale pharmaceutical donation programs.¹²⁶ Other companies, such as GlaxoSmithKline and Johnson & Johnson, soon followed, offering drugs to fight diseases like lymphatic filariasis, intestinal worms, and trachoma.¹²⁷ In 2012, 13 of the world's largest pharmaceutical companies, brought together by Bill Gates, agreed to form a large-scale drug donation program aiming to find new potential treatments for 10 more NTDs.¹²⁸

However, these efforts soon decelerated, with the recent COVID-19 pandemic showing the fragility of the current global response towards NTDs and the vulnerabilities that exist during global health disruptions. As pharmaceutical companies and the government began to redirect resources toward pandemic response, routine interventions—such as mass drug treatment, surveillance, and overall efforts to control—were delayed or

¹²¹ The Editors of Encyclopaedia Britannica, "Dengue," Encyclopaedia Britannica, July 28, 2025, <https://www.britannica.com/science/dengue>.

¹²² Molyneux, David H, "History of the Neglected Tropical Disease Movement | Transactions of the Royal Society of Tropical Medicine and Hygiene | Oxford Academic," Transcriptions of the Royal Society of Tropical Medicine & Hygiene, January 28, 2021, <https://academic.oup.com/trstmh/article/115/2/169/6121891>.

¹²³ Frank M Snowden, "Emerging and Reemerging Diseases: A Historical Perspective," Immunological reviews, October 2008, <https://pmc.ncbi.nlm.nih.gov/articles/PMC7165909/>.

¹²⁴ Ibid.

¹²⁵ "Our History," TDR For research on diseases of poverty, 2024, <https://tdr.who.int/our-history>.

¹²⁶ "35 Years: The Mectizan® Donation Program," Merck, May 25, 2022, <https://www.merck.com/stories/mectizan/>.

¹²⁷ Boseley, Sarah, "Drug Companies Join Forces to Combat Deadliest Tropical Diseases," The Guardian, January 30, 2012, <https://www.theguardian.com/global-development/2012/jan/30/drug-companies-join-tropical-diseases>.

¹²⁸ Ibid.

suspended.¹²⁹ In fairness, WHO is responsible for recommending the suspension of community-based programs during the pandemic, but this interruption caused millions to miss preventative treatment and threatened to reverse years of progress.¹³⁰ Moreover, the pandemic exposed the vulnerability of the current NTD programs to external shocks and interruptions and underscored the need to integrate these programs and treatments more deeply into local health systems, ensuring effective responses during crises.¹³¹

Past UN/International Involvement

London Declaration on NTDs and WHO NTD Roadmap

The UN and WHO have continued to play a central role in shaping international policy regarding the treatment of NTDs. Particularly, the 2012 London Declaration on NTDs marked an unprecedented moment of global unity. Led by the Bill & Melinda Gates Foundation, WHO, Pharmaceutical Companies, and various other governments, the declaration committed to controlling or eradicating 10 NTDs by 2030.¹³² This commitment was the basis for a decade of scaled-up interventions, including mass drug programs. However, there were various setbacks that prevented the declaration in meeting its ambitious goals. From being unable to reach preset targets to interruptions caused by COVID-19 and various conflicts, the vulnerability and limitations of the donation-based model and voluntary coordination without large, structured accountability systems.¹³³ Even with these setbacks, the declaration was instrumental in fabricating the idea that NTDs were, in fact, solvable challenges.

Released in conjunction with the London Declaration was the WHO NTD Roadmap 2012-2020, representing the first coordinated global framework outlining disease-specific elimination and control targets for 17 NTDs.¹³⁴ This roadmap significantly raised political visibility and facilitated the scale-up of various drug donation and treatment programs. While many countries were able to make substantial progress, the roadmap's disease-by-disease approach could be considered ineffective with an insufficient emphasis on integrating solutions into local health systems and communities.¹³⁵ The NTD Roadmap 2021-2030, released in 2020, built on its predecessor and focused more towards integrated, country-led initiatives. Specifically, this looked like the updated roadmap introducing broader goals: reducing the number of people requiring interventions against NTDs by 90 percent and eliminating at least one NTD in 100 countries.¹³⁶

¹²⁹ Itaye, Tikhala, et al, "our Interventions Are Still Here to Support Communities during the Pandemic': Resuming Mass Drug Administration for Neglected Tropical Diseases after COVID-19 Implementation Delays," *PLoS neglected tropical diseases*, June 26, 2023, <https://pmc.ncbi.nlm.nih.gov/articles/PMC10328222/>.

¹³⁰ Ibid.

¹³¹ Ibid.

¹³² "The London Declaration on NTDs," *Global Health Progress*, 2012, <https://globalhealthprogress.org/collaboration/the-london-declaration-on-ntds/>.

¹³³ Du, Rebecca Y., Jeffrey D. Stanaway, and Peter J. Hotez, "Could Violent Conflict Derail the London Declaration on NTDs?," *PLOS Neglected Tropical Diseases*, April 19, 2018, <https://journals.plos.org/plosntds/article?id=10.1371%2Fjournal.pntd.0006136>.

¹³⁴ "Who Roadmap on Neglected Tropical Diseases (2012-2020)," *Uniting to Combat NTDs*, January 1, 2012, <https://unitingtocombatntds.org/en/neglected-tropical-diseases/resources/who-roadmap-on-neglected-tropical-diseases-2012-2020/>.

¹³⁵ Ibid.

¹³⁶ "Ending the Neglect to Attain the Sustainable Development Goals: A Road Map for Neglected Tropical Diseases 2021-2030," *World Health Organization*, January 28, 2021, <https://www.who.int/publications/i/item/9789240010352>.

Multilateral Initiatives: Global Network for NTDs and Ending Neglected Tropical Diseases Fund

The Global Network for NTDs, launched by the Sabin Vaccine Institute in 2006, has played an important role in building political awareness. The importance of this awareness is immense: developing countries are able to achieve increased support by global powers in dealing with diseases that disproportionately impact their populations. By creating advocacy materials, organizing donor events, lobbying policymakers, and leveraging resources, the Network has shifted the discussion from a purely medical to a developmental perspective. This unique focus creates a distinction that often, to deal with various medical issues, especially in struggling and impacted countries, infrastructural issues must be addressed as well.¹³⁷

Furthermore, founded in 2012, the Ending Neglected Tropical Diseases Fund (END) is a philanthropic investment platform exclusively dedicated to fighting NTDs. By pooling funds from private donors and foundations, it has created and supported various NTD mass drug distribution programs across affected communities. The Fund's model attempts to emphasize transparency and country-led planning; however, the nature of the Fund may lead to the creation of parallel structures rather than strengthening local health systems for the long term, which would be critical for the sustainable control of NTDs.

Pharmaceutical Companies

Pharmaceutical companies have continued to play a pivotal role in addressing NTDs through large-scale drug donation programs and development partnerships. One of the earliest and most impactful contributions came from Merck, which committed to donating Mectizan for the treatment of river blindness.¹³⁸ This groundbreaking initiative set a model for long-term pharmaceutical donations that would be further replicated by other companies. Similarly, corporations like GlaxoSmithKline and Johnson & Johnson have all contributed medicines for a range of NTDs such as trachoma and leprosy.¹³⁹

Beyond these donations, several companies have begun collaborative research and development efforts. For example, the Drugs for Neglected Diseases Initiative (DNDi), founded in 2003, works with various private partners to try to develop new treatments specific to NTDs.¹⁴⁰ While most existing drugs are decades old, these cross-sector partnerships aim to bring innovative solutions to existing problems. Specifically, the DNDi focuses on ensuring that systemic issues that inherently discriminate against the marginalized are addressed; for example, DNDi “works to ensure the people most affected by neglected diseases are part of medical research and development, helping to set priorities, strengthen capacity, and deliver new treatments where they are needed most.”¹⁴¹

¹³⁷ “Global Network for Neglected Tropical Diseases,” LSTM, November 3, 2016

<https://www.lstmed.ac.uk/research/collaborations/global-network-for-neglected-tropical-diseases>.

¹³⁸ “35 Years: The Mectizan® Donation Program,” Merck, May 25, 2022, <https://www.merck.com/stories/mectizan/>.

¹³⁹ Boseley, Sarah, “Drug Companies Join Forces to Combat Deadliest Tropical Diseases,” The Guardian, January 30, 2012, <https://www.theguardian.com/global-development/2012/jan/30/drug-companies-join-tropical-diseases>.

¹⁴⁰ “Who We Are: Dndi,” Drugs for Neglected Diseases initiative (DNDi), May 1, 2025, <https://dndi.org/about/who-we-are/>.

¹⁴¹ Ibid.

Current Situation

NTDs continue to affect more than 1.5 billion people globally, with a disproportionate burden falling on low and middle-income households in Africa, Asia, and Latin America.¹⁴² Although considerable progress has been made through initiatives such as the London Declaration and the WHO NTD Roadmaps, there are still significant structural challenges that continue to hinder global collective efforts.

Public Health Systems

One of the primary barriers to effective long-term NTD treatment is its weak integration into national public health systems.¹⁴³ In many affected countries, NTD programs operate in isolation from broader local healthcare systems, relying instead on vertically organized interventions. The independent nature of these NTD programs in the status quo makes it difficult for collaboration with national governments of various developing countries. Government reform through actions similar to structural adjustment programs (SAPs) may be necessary to emphasize the importance of national healthcare systems and, in turn, collaborate with NTD programs. While effective for short-term mass drug administration, this approach does not address the need for surveillance, year-round care, and a true long-term solution. Furthermore, governments often lack dedicated budgetary allocations for their health departments, leaving NTD programs vulnerable to interruptions when the amount of external funding declines. A prime example of this was when NTD programs were suspended during the COVID-19 pandemic, and millions were left vulnerable.¹⁴⁴ The result is a fragmented system where NTDs are simply treated as a temporary issue rather than a long-term, ongoing public health priority.

Particularly, current health systems in low and middle-income countries are heavily reliant on pharmaceutical donations. Drug donation programs by companies like Merck, GlaxoSmithKline, and Johnson & Johnson have continued to provide billions of free treatments, significantly reducing the prevalence of several NTDs.¹⁴⁵ However, this success has created a system that is highly dependent on continued support from corporations, compounding the issues at hand. Countries frequently lack the capacity and financial capability to sustain drug access independently. This not only raises concerns about long-term program sustainability but also hinders governments from being able to develop comprehensive strategies.

Public health systems in many affected regions are further weakened by political interference and corruption.¹⁴⁶ In certain countries, health budgets may be diverted away from frontline services, while key NTD programs suffer from fraud, corruption, or simply mismanagement of donor funds; political will also remains uneven across affected countries. Since many NTDs do not cause immediate death or high-profile outbreaks, they tend to receive significantly less attention than more immediate diseases such as HIV/AIDS or malaria. Public awareness is also

¹⁴² “Neglected Tropical Diseases,” World Health Organization, January 8, 2025, <https://www.who.int/news-room/questions-and-answers/item/neglected-tropical-diseases>.

¹⁴³ Hudu, Shuaibu Abdullahi, “An Insight into the Success, Challenges, and Future Perspectives of Eliminating Neglected Tropical Disease,” *Scientific African*, March 13, 2024, <https://www.sciencedirect.com/science/article/pii/S2468227624001108>.

¹⁴⁴ Itaye, Tikhala, et al, “our Interventions Are Still Here to Support Communities during the Pandemic”: Resuming Mass Drug Administration for Neglected Tropical Diseases after COVID-19 Implementation Delays,” *PLoS neglected tropical diseases*, June 26, 2023, <https://pmc.ncbi.nlm.nih.gov/articles/PMC10328222/>.

¹⁴⁵ Bradley, Mark, et al, “Medicine Donation Programmes Supporting the Global Drive to End the Burden of Neglected Tropical Diseases,” *Transactions of the Royal Society of Tropical Medicine and Hygiene*, January 28, 2021, <https://pubmed.ncbi.nlm.nih.gov/33452881/>.

¹⁴⁶ “The Critical Health Impacts of Corruption,” *Crossing the Global Quality Chasm: Improving Health Care Worldwide.*, August 28, 2018, <https://www.ncbi.nlm.nih.gov/books/NBK535646/>.

severely limited, particularly in urban and wealthier regions, leading to a lack of domestic advocacy or pressure for reform. The resulting lack of domestic advocacy results in an agenda where NTDs remain perpetually underfunded and underprioritized.¹⁴⁷

Inadequate Infrastructure

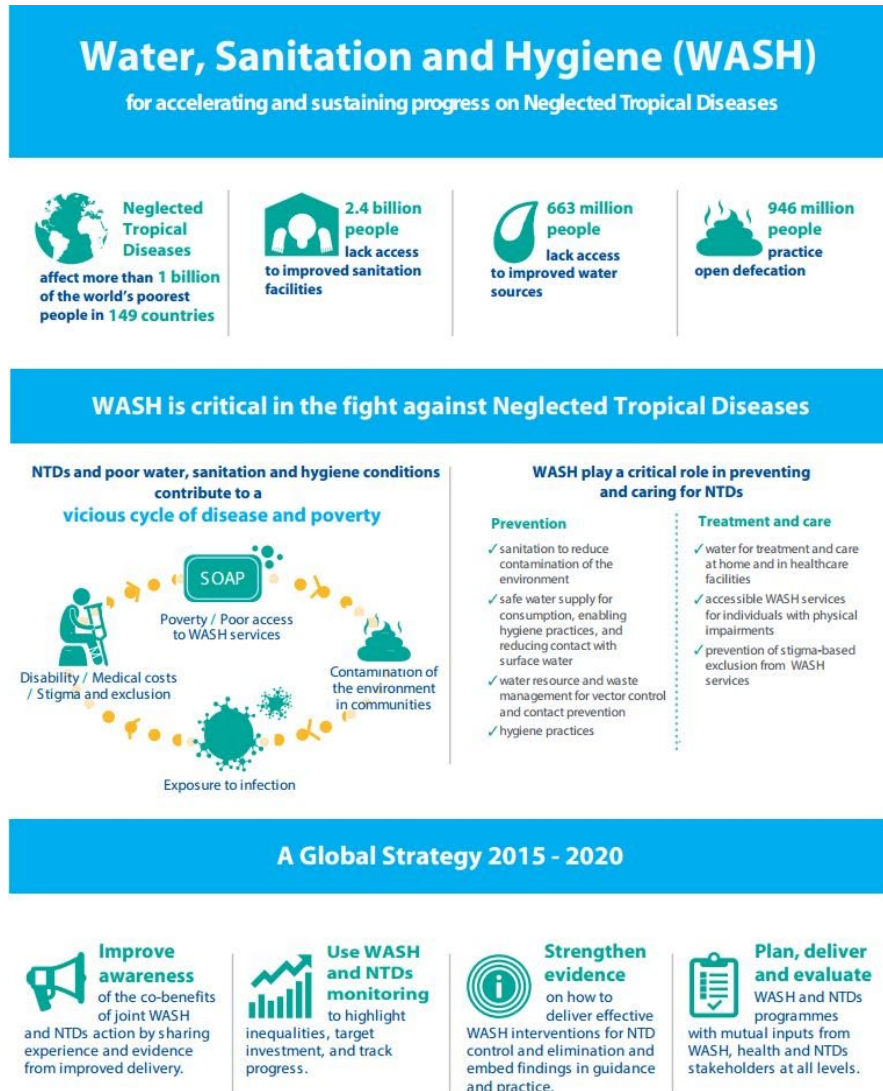


Figure 1: Infographic on Accelerating the Process of WASH Infrastructure on NTDs.¹⁴⁸

¹⁴⁷ Ibid.

¹⁴⁸ "Wash and Neglected Tropical Diseases," World Health Organization, <https://www.who.int/teams/environment-climate-change-and-health/water-sanitation-and-health/burden-of-disease/wash-and-neglected-tropical-diseases>.

The spread of NTDs is closely linked to environmental and developmental conditions, especially regarding access to adequate water, sanitation, and hygiene (WASH) infrastructure. Particularly, diseases such as trachoma, schistosomiasis, and soil-transmitted helminths are perpetuated by a lack of these basic amenities.¹⁴⁹ Despite growing recognition of this connection, investments in WASH remain insufficient and poorly coordinated with NTD programs.¹⁵⁰ As evidenced by *Figure 1*, WASH plays a crucial role in preventing and caring for NTDs—from raising awareness and improving education to treatment implementation and control strategies. Beyond WASH, broader developmental and economic barriers exacerbate the problem. NTDs disproportionately impact individuals who are already economically disadvantaged and entrenched in cycles of poverty, making it difficult to receive proper long-term treatment within their communities.¹⁵¹

Case Study: Nigeria

Nigeria, home to the largest population in Africa, has one of the greatest NTD burdens in the world, with five of the most common NTDs being endemic in the country.¹⁵² Despite substantial support from the WHO, DNDi, the END Fund, and other organizations, systemic issues have continued to limit the effectiveness of interventions.¹⁵³ The country's NTD programs have also largely relied on donated medicine and NGO-led programs, while national ownership and integration programs still have massive room for improvement.

¹⁴⁹ Phillips, Anna E, "Association between Water, Sanitation, and Hygiene Access and the Prevalence of Soil-Transmitted Helminth and Schistosome Infections in Wolayita, Ethiopia," *Parasites & vectors*, November 4, 2022, <https://pmc.ncbi.nlm.nih.gov/articles/PMC9636783/>.

¹⁵⁰ Ibid.

¹⁵¹ Alderton, Dasha L, "The Psychosocial Impacts of Skin-Neglected Tropical Diseases (Sntds) as Perceived by the Affected Persons: A Systematic Review - PMC," *PLOS Neglected Tropical Diseases*, August 2, 2024, <https://pmc.ncbi.nlm.nih.gov/articles/PMC11324132/>.

¹⁵² Hotez, Peter J, "Ten Global 'Hotspots' for The Neglected Tropical Diseases," *PLoS Neglected Tropical Diseases*, May 29, 2014, <http://pmc.ncbi.nlm.nih.gov/articles/PMC4038631/>.

¹⁵³ Fakomogbon, Gideon, "NTDs: Why Does Nigeria Have Such a Problem with Neglected Tropical Diseases?," *Global Citizen*, February 2, 2022, <https://www.globalcitizen.org/en/content/nigeria-neglected-tropical-diseases-explainer/>.

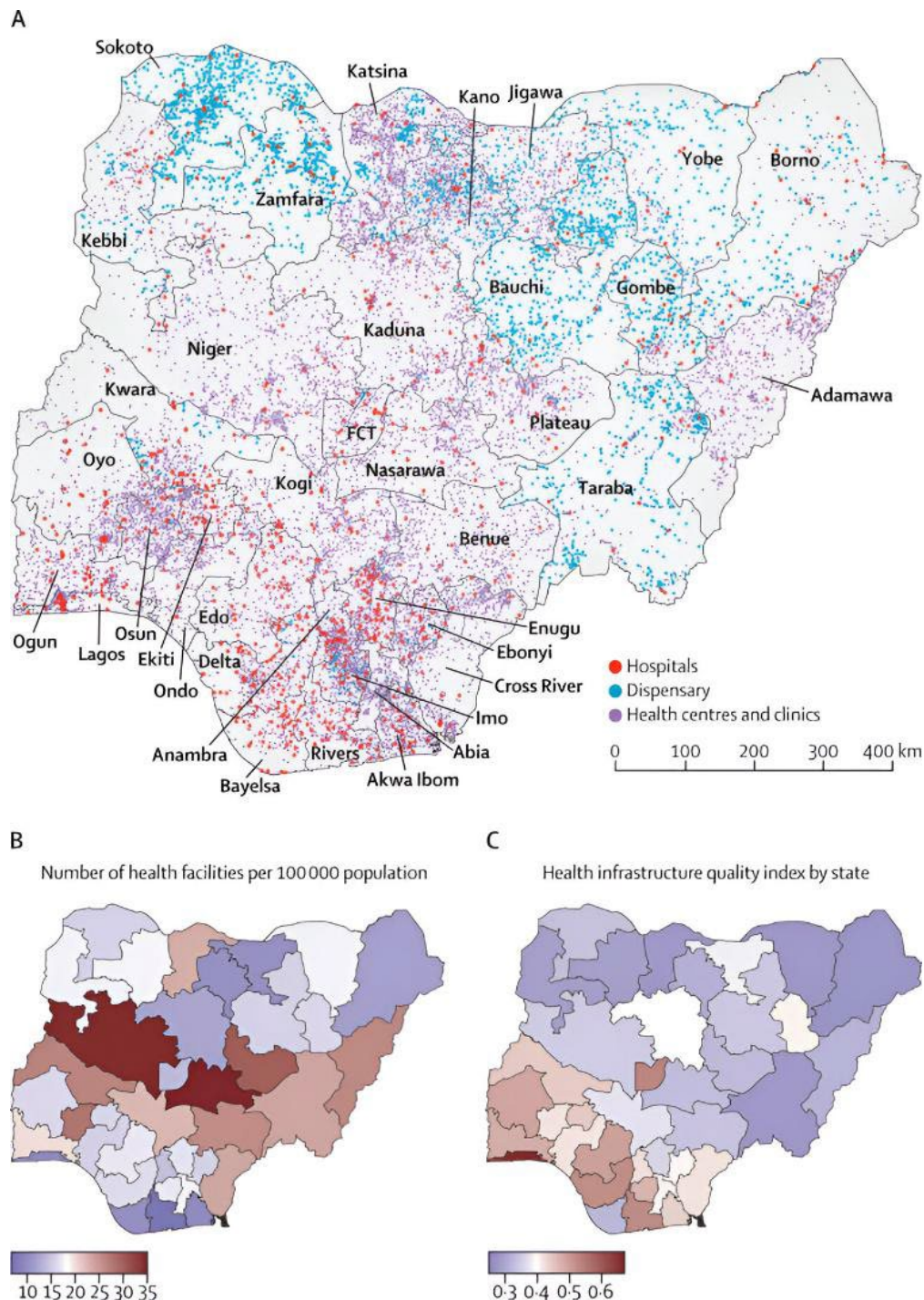


Figure 2: (A) Distribution of public hospitals, health centres/clinics and dispensaries in Nigeria (2019), (B) Number of health facilities per 100 000 population and (C) Health infrastructure quality index by state, 2012.¹⁵⁴

Nigeria's public health infrastructure is uneven across states, with northern regions, in particular, experiencing chronic underinvestment and healthcare shortages, as exemplified by *Figure 2*; in the majority of areas, the health

¹⁵⁴ Abubakar, Ibrahim, "The Lancet Nigeria Commission: Investing in Health and the Future of the Nation - the Lancet," *The Lancet*, March 19, 2022, [https://www.thelancet.com/article/S0140-6736\(21\)02488-0/fulltext](https://www.thelancet.com/article/S0140-6736(21)02488-0/fulltext).

infrastructure quality index is low and facilities do not meet the demands of the size of the population.¹⁵⁵ Moreover, coordination between federal and state health authorities is often fragmented and inefficient, and political instability in certain states has hindered the implementation of a consistent treatment program.¹⁵⁶ While progress has been made, Nigeria continues to face significant structural and systemic barriers in integrating externally-funded NTD programs into the national and state public health system. While COVID-19 led to an interruption in various NTD treatment programs in Nigeria, scientists have discussed the possibility of using COVID-19 vaccination systems to distribute treatment to rural and hard-to-reach areas.¹⁵⁷

Possible Solutions and Controversies

The elimination of NTDs will require more than simply increasing medical donations and creating treatment campaigns—in order to create a global, lasting solution, structural, systemic, and multi-sectoral reform must occur.

Integrating NTD Programs into National Public Health Systems

One of the most widely proposed solutions is embedding NTD programs into domestic health systems rather than relying on temporary, donor-driven programs.¹⁵⁸ Integrating NTD diagnostics, individual case management, and preventive education into routine care would create a lasting culture of prioritized treatment while promoting national and local ownership of disease control efforts.¹⁵⁹ In theory, this model would encourage long-term, sustainable coverage, reduce dependency on external and corporate aid, and help connect the control of NTDs to broader goals like universal access to healthcare.

However, in practice, this strategy may face struggles due to current structural and political challenges. Many health ministries and communities in endemic countries remain underfunded, understaffed, and generally politically unstable.¹⁶⁰ Integrating NTD programs into national public health systems may stretch limited resources even further, particularly in remote or conflict-affected regions. In endemic countries where corruption exists, funds intended for public health and NTD programs may be diverted, and weak accountability measures can make it difficult to track whether efforts are genuinely successful. Generally, in areas where government health services are mistreated and disregarded, integrating NTD services may not achieve the desired effect without broader health reforms. Thus, while integration is a promising solution, its success is dependent on the parallel success and stability in the government, health financing, and building local capacity.

¹⁵⁵ Ibid.

¹⁵⁶ Atobatele, Sunday, “Integrating Health Intervention into Existing Program Structure of the Neglected Tropical Diseases: Lessons Learned from Yobe and Ebonyi States,” *Frontiers in Public Health*, January 17, 2024, <https://pmc.ncbi.nlm.nih.gov/articles/PMC10827911/>.

¹⁵⁷ Ibid.

¹⁵⁸ Mwingira, Upendo John, “Integrating Neglected Tropical Disease and Immunization Programs: The Experiences of the Tanzanian Ministry of Health,” *The American Journal of Tropical Medicine and Hygiene*, September 7, 2016, <https://pmc.ncbi.nlm.nih.gov/articles/PMC5014249/>.

¹⁵⁹ Ibid.

¹⁶⁰ Manyazewal, Tsegahun, “Innovative Technologies to Address Neglected Tropical Diseases in African Settings with Persistent Sociopolitical Instability,” *Nature Communications*, November 27, 2024, <https://pmc.ncbi.nlm.nih.gov/articles/PMC11603293/>.

Reducing Pharmaceutical Dependence through Local Production and Development

Mass drug administration campaigns remain the backbone of NTD elimination efforts, but most endemic countries continue to rely heavily on large pharmaceutical donations from multinational corporations. A shift toward regional pharmaceutical manufacturing to build drug security and reduce dependency on foreign donors may reduce the impact of this dependence.¹⁶¹ Expanding local or regional production of essential medicines could improve supply chain reliability, promote self-sufficiency, and overall lower costs. In many countries disproportionately affected by NTDs, the creation of local production requires a shift in government focus towards investment in healthcare and medicinal development. With the support of international multilateral organizations like the World Bank and the International Monetary Fund, developing countries may be able to achieve the funding to complete such impactful developments.

However, building pharmaceutical manufacturing factories of such a capacity requires years of investment, robust frameworks, and technical expertise that many endemic countries currently lack. In regions without stable electricity, transport infrastructure, or cold chain systems, producing and distributing quality-assured medications over a long period of time remains difficult.¹⁶² Furthermore, there is also a risk of counterfeit or substandard drugs entering the market without strong oversight and accountability mechanisms. While donor-based models have limitations, they currently offer proven results, making a transition toward domestic or regional production a long-term rather than an immediate solution.

Improving Data Collection and Disease Surveillance

Effective surveillance systems are crucial for tracking NTD outbreaks, identifying at-risk populations, and measuring the impact of interventions. Many endemic countries, however, suffer from a weak disease reporting system. Enhancing national data systems, expanding laboratory networks, and promoting individualized mobile case tracking tools can improve the effectiveness of interventions and increase program accountability.¹⁶³ Through international accountability systems and multilateral funding mechanisms, developing countries can begin to develop such comprehensive programs.

However, establishing a reliable surveillance system is often underprioritized due to the costs of training health workers, constructing a reliable structure, and maintaining data systems. In endemic countries burdened with high levels of corruption, political interference can also skew reporting, especially if governments fear international scrutiny over the presence of disease or poor program performance.¹⁶⁴ Even more, inconsistencies in how specific regions track and report cases can also create fragmented data that hinders a coordinated, international response. While there are various prerequisites for the success of a data collection and surveillance system, the benefits of an effective system have the potential to help treat NTDs in the long term.

¹⁶¹ Weng, Hong-Bo, “Innovation in Neglected Tropical Disease Drug Discovery and Development,” *Infectious Diseases of Poverty*, June 18, 2018, <https://pmc.ncbi.nlm.nih.gov/articles/PMC6022351/>.

¹⁶² Kumraj, Ganesh, “Capacity Building for Vaccine Manufacturing across Developing Countries: The Way Forward,” *Human Vaccines & Immunotherapeutics*, January 27, 2022, <https://pmc.ncbi.nlm.nih.gov/articles/PMC8986212/>.

¹⁶³ Zhou, Xiao-Nong, “Elimination of Tropical Disease through Surveillance and Response - *Infectious Diseases of Poverty*,” *BioMed Central*, January 3, 2013, <https://idpjournal.biomedcentral.com/articles/10.1186/2049-9957-2-1>.

¹⁶⁴ Maddah, Noha, “Effectiveness of Public Health Digital Surveillance Systems for Infectious Disease Prevention and Control at Mass Gatherings: Systematic Review,” *Journal of Medical Internet Research*, May 19, 2023, <https://pmc.ncbi.nlm.nih.gov/articles/PMC10238952/>.

Meeting the Basic Amenities Required to Resolve NTDs

NTDs persist not only because of medical gaps, but also due to structural inequalities between developed and third-world nations. These factors, such as poor sanitation, lack of education, inadequate infrastructure, and socioeconomic disparities, create an environment where NTDs thrive. One of the most pressing concerns that needs to be addressed is improving WASH infrastructure. Many NTDs fester and are transmitted through contaminated water and poor hygiene practices, so in areas where clean water is scarce and poor hygiene practices are common, disease transmission becomes nearly impossible to break through medication alone.¹⁶⁵ Investing in sustainable access to safe drinking water, toilets, handwashing stations, and more, helps build long-term disease resistance beyond relying on medicines.

Education and public awareness regarding NTDs also play a vital role in implementing a long-term solution. Communities that understand how NTDs spread are more likely to practice preventative behaviours, seek treatment early, and demand better access to adequate healthcare from their governments.¹⁶⁶ Thus, integrating NTD education into school curricula and local media campaigns can help normalize good hygiene habits and reduce stigma around certain diseases, decreasing the immediate risk of epidemics. However, implementing these structural reforms is neither simple nor immediate. Large infrastructure projects require long-term planning, financing, and the political will to see these projects through, and often, these resources are scarce in NTD-endemic countries. Furthermore, it is important to consider rural and informal urban areas when implementing these policies, as historically, these regions have been underprioritized due to their marginal political power.¹⁶⁷

Bloc Positions

Sub-Saharan Africa

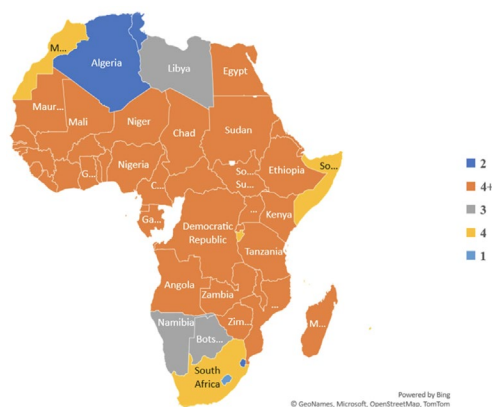


Figure 3: NTD distribution among African countries by number of NTDs per country.¹⁶⁸

¹⁶⁵ Wash: The silent weapon against NTDs,

<https://washmatters.wateraid.org/sites/g/files/jkxoof256/files/WASH%20the%20silent%20weapon%20against%20NTDs.pdf>.

¹⁶⁶ Branda, Francesco, et al, "Assessing the Burden of Neglected Tropical Diseases in Low-Income Communities: Challenges and Solutions," MDPI, December 28, 2024, <https://www.mdpi.com/1999-4915/17/1/29>.

¹⁶⁷ Ibid.

¹⁶⁸ George, Nsikakabasi Samuel, et al, "Addressing Neglected Tropical Diseases in Africa: A Health Equity Perspective - Global Health Research and Policy," BioMed Central, July 25, 2023, <https://ghrp.biomedcentral.com/articles/10.1186/s41256-023-00314-1>.

Sub-Saharan Africa remains the most heavily affected region by neglected tropical diseases, accounting for over one-third of the global burden of NTDs, as seen from *Figure 3*. Many countries in this bloc struggle with limited access to health infrastructure, trained personnel, clean water, and sanitation, which are all critical barriers to the control and eradication of NTDs.¹⁶⁹ Governments across this region, such as Togo, Benin, and Ghana, often advocate for expanded international support, increased funding, and technology sharing to attempt to resolve this disease. Furthermore, political instability, weak governing structures, and corruption in some nations—particularly notable in Sudan, South Sudan, and Rwanda—can hinder implementation and long-term sustainability. Countries in this region must also implement various transparency and accountability mechanisms parallel to NTD intervention programs to ensure long-term success. These countries typically favour solutions focused on local empowerment, capacity building, and equitable access to healthcare.

South and Southeast Asia

South and Southeast Asia continue to face a high NTD burden, particularly in rural and marginalized communities.¹⁷⁰ Many nations face over nine different types of NTDs on average, again reinforcing the disproportionate impact of diseases and the urgent priority and necessity to improve the current condition.¹⁷¹ Countries such as India, Indonesia, and Bangladesh have led large-scale mass drug administration campaigns and continued to invest in domestic pharmaceutical production and various health surveillance systems.¹⁷² While some nations are transitioning towards more self-reliant solutions, disparities in infrastructure, healthcare coverage, and education persist. Countries in this region may focus on promoting regional cooperation, cost-effective public health campaigns, and integrating domestic programs of NTD control, while still requesting external funding to strengthen current systems.

Latin America and the Caribbean

Similar to the South and Southeast Asian Bloc, countries in Latin America face a heavy burden of NTDs. Diseases like chagas, dengue, leishmaniasis, and soil-transmitted helminths are concentrated in this region, particularly in rural areas.¹⁷³ However, countries such as Brazil and Colombia stand out with their stronger research capabilities and vector control programs, while having initiated various long-term treatment programs.¹⁷⁴ Various other countries in this region have also initiated similar programs; however, they continue to rely on international support due to the political instability and economic inequality present.¹⁷⁵ Countries in this region often call for

¹⁶⁹ Ibid.

¹⁷⁰ Narain, Jai P, “Elimination of Neglected Tropical Diseases in the South-East Asia Region of the World Health Organization,” *Bulletin of the World Health Organization*, March 2010, <https://pmc.ncbi.nlm.nih.gov/articles/PMC2828791/>.

¹⁷¹ Revankar, Chandrakant, et al, “Mapping of NTDs.” *ResearchGate*, March, 2011, https://www.researchgate.net/publication/277892940_Mapping_of_NTDs.

¹⁷² Chandra, Ajay, “Healthcare Policies to Eliminate Neglected Tropical Diseases (Ntds) in India: A Roadmap,” *International journal of environmental research and public health*, September 27, 2023, <https://pmc.ncbi.nlm.nih.gov/articles/PMC10572727/>.

¹⁷³ Hotez, Peter J, “The Neglected Tropical Diseases of Latin America and the Caribbean: A Review of Disease Burden and Distribution and a Roadmap for Control and Elimination,” *PLoS neglected tropical diseases*, September 24, 2008, <https://pmc.ncbi.nlm.nih.gov/articles/PMC2553488/>.

¹⁷⁴ Dani Bancroft et al., “Vector Control Strategies in Brazil: A Qualitative Investigation into Community Knowledge, Attitudes and Perceptions Following the 2015-2016 Zika Virus Epidemic,” *BMJ open*, January 31, 2022, <https://pmc.ncbi.nlm.nih.gov/articles/PMC8808399/>.

¹⁷⁵ Ibid.

more flexible and locally-adapted programs, including a greater attention to sociocultural factors, climate-driven disease, and regional cooperation.¹⁷⁶

Middle East and North Africa (MENA)

The MENA region exhibits wide variation in the burden of NTDs, and like the majority of countries, NTDs disproportionately affect an estimated 65 million people living on less than USD 2 dollars per day.¹⁷⁷ Conflict-ridden countries such as Yemen, Syria, and Sudan also face large surges in diseases like leishmaniasis due to their collapsing health systems, mass displacement, and a lack of basic necessities.¹⁷⁸ In contrast, wealthier Gulf States, such as the United Arab Emirates, have stronger health systems and could potentially act as donors or partners in global health efforts.¹⁷⁹ Countries in MENA may push for solutions that integrate NTD response with emergency humanitarian programs and post-conflict reconstruction while advocating for increased involvement in various multilateral regional bodies.

High-Income States

High-income countries, including the United States, Canada, Japan, South Korea, and much of Europe, bear minimal direct impact from NTDs but still play a large role in funding, research, and development, and global coordination. These states often support WHO-led initiatives, public-private partnerships, and multilateral campaigns such as the London Declaration.¹⁸⁰ However, issues may arise from a perceived lack of accountability and general prioritization of short-term solutions over long-term sustainable impact. This is often the case due to the amount of resources high-income states have in the status quo that can be distributed to affected states to create more immediate change. This situation often creates a perception that change is being furthered by high-income states on a global scale, a perception that is often desired by these states. Therefore, currently, countries in this block favour financing pharmaceutical donation programs while being hesitant to fund long-term systemic reform or infrastructure without assurances of transparency and accountability from recipient countries.

Discussion Questions

1. How can countries balance the need for long-term health system development with the urgency of immediate disease control in NTD-endemic countries?
2. To what extent should pharmaceutical companies remain responsible for providing treatment for NTDs, and how can current dependency on their donations be reduced?
3. How can multilateral efforts be restructured to better address regional disparities in NTD burden, especially between urban and rural communities within the same country?
4. What lessons from past global health campaigns (e.g., malaria, smallpox, COVID-19) can be meaningfully applied to the elimination of NTDs?

¹⁷⁶ Ibid.

¹⁷⁷ Hotez, Peter J, "Neglected Tropical Diseases of the Middle East and North Africa: Review of Their Prevalence, Distribution, and Opportunities for Control," PLoS neglected tropical diseases, February 28, 2012, <https://pmc.ncbi.nlm.nih.gov/articles/PMC3289601/>.

¹⁷⁸ Ibid.

¹⁷⁹ Ibid.

¹⁸⁰ "INVESTING TO OVERCOME THE GLOBAL IMPACT OF NEGLECTED TROPICAL DISEASES," World Health Organization, 2015, https://iris.who.int/bitstream/handle/10665/152781/9789241564861_eng.pdf.

5. How should countries navigate competing health priorities, such as pandemic response or noncommunicable diseases, while also committing to NTD elimination targets?
6. What initiatives can best strengthen regional/multilateral cooperation in regions of hostility?

Additional Resources

Report: Ending the Neglect to Attain the Sustainable Development Goals: A Road Map for Neglected Tropical Diseases 2021–2030

<https://www.who.int/publications/i/item/9789240010352>.

Article: The Neglected Tropical Diseases and the Neglected Infections of Poverty

<https://www.ncbi.nlm.nih.gov/books/NBK62521/>.

Report: Investing to Overcome the Global Impact of Neglected Tropical Diseases: Third WHO Report on Neglected Tropical Diseases

<https://www.who.int/publications/i/item/9789241564861>.

Resolution: WHA66.12 Neglected Tropical Diseases

<https://www.who.int/publications/i/item/WHA66.12>.

Article: Neglected Tropical Diseases: A Comprehensive Review

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