

Genome editing and the right to equality: Charting the Ethical Horizon

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International Journal of Science and Research Archive, 2025, 16(01), 2001-2006

Publication history: Received on 17 June 2025; revised on 26 July 2025; accepted on 28 July 2025

Article DOI: <https://doi.org/10.30574/ijjsra.2025.16.1.2246>

Abstract

The CRISPR or the genomic revolution has become a breakthrough technology with immense possibilities in the fields of genetics. CRISPR is also called as the genetic scissors by the use of which DNA fragments which carry hereditary diseases or any disabilities can be removed from genome that is why it is called as genome editing. This editing can prove to be transformative for the medicine and treatment of humans but because of its apprehensive consequences it is also viewed by ethicists as casting a long shadow upon human rights in present and future. Experts also speculate that permitting of genome editing would broaden social and economic inequalities. The present article shall examine the inter play between genome editing in humans and right to equality and the challenges of ethics and law in relation to it.

Keywords: Genome Editing; Equality; Human Rights; Somatic Editing; Crispr; Enhancement.

1. Introduction

The CRISPR or the genomic revolution has become a breakthrough technology with immense possibilities in the fields of genetics. CRISPR is also called as the genetic scissors by the use of which DNA fragments which carry hereditary diseases or any disabilities can be removed from genome that is why it is called as genome editing. This editing can prove to be transformative for the medicine and treatment of humans but because of its apprehensive consequences it is also viewed by ethicists as casting a long shadow upon human rights in present and future. Experts also speculate that permitting of genome editing would broaden social and economic inequalities. The present article shall examine the inter play between genome editing in humans and right to equality and the challenges of ethics and law in relation to it.

2. Material and Methods

The present research involves analysis of different international laws relating to bioethics, human rights, and human genome. Additionally, it also examines reports and recommendation given by international organizations in regard to the use of genome editing. the methodology adopted is doctrinal and its is based on the use of primary and secondary reaasearch sources.

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3. Discussion and Results

3.1. The Potential and Danger of Genome Editing

Genome editing technologies can make it possible to edit or alter genomes in humans with precision and efficiency. Scientists can cut the DNA by tools like TANLENS, ZFNs and currently CRISPR. Genetic editing is of two types Somatic cell editing and Germline Cell editing.

Applications of genome editing are classified into broad categories:

- "Somatic Genome Editing": Somatic cells are cells in entire body except the reproductive cells. Genetic editing in the somatic cells cannot be inherited or transferred. The changes in somatic cells affect only the person treated and not to any successors. No future individuals of the treated persons are affected by the editing in them. In the present time somatic editing have been successful in cases around the globe and several countries have given way for its trials on humans. The most recent case is that of the treatment of Sickle Cell Anemia successfully in the United States. Trials for somatic editing are underway for diseases like cancers and muscular dystrophy but it also has ethical challenges in application widely like safety, and accessibility.
- Germline Genome Editing: Germline cells are reproductive cells and the alteration in them involves the altering of DNA in reproductive cells. This is a heritable editing which not only effect the treated person but also successors of the person. The editing in germline cells is carried out in the embryonic stage. The irreversibility of the germline editing raises concerns about the existence of individuals and the transformation that it can bring to future societies. Right to equality is also one concern regarding it which have been deliberated by experts in the field's human rights, law, and science. Informed consent and autonomy of future generations are also debated areas regarding the germline editing.

Apart from therapy or treatment germline editing may also be applied for enhancement of humans physical and mental capabilities just like customizing humans. This may include the editing of genes connected to intelligence or a stronger built, height, or attractiveness and more to it. Creation of such designer humans by enhancements may evoke societal inequalities by way of enhanced and not enhanced humans.

3.2. The Right to Equality: A Pillar of Human Rights

Equality right is a basic principle under the international and domestic law regimes incorporated in the form of fundamental rights or human rights. This right existing in republic or democratic jurisdictions is either based on rule of law or on the perception that all human beings are born equal and no discrimination should be applied to humans based on sex, caste, religion, or economic status. The judiciary and jurists of all civilized nations press for equality among humans. Some of the international instruments that incorporate right to equality are briefly discussed here under:

• **Universal Declaration of Human Rights (UDHR):** Article 1 says, "All human beings are born free and equal in dignity and rights." Article 2 is a negative provision that forbades discriminations among humans based on several factors including place of birth and or political opinion or economic and social status.

- **International Covenant on Civil and Political Rights (ICCPR):** ICCPR incorporates the principle of equality majorly under three articles for different spheres. Article 14, 23, and 26 Article 26 ensures equality in respect of trial or charges of criminal offences, equality of rights and duties between spouses in marriage and equality in public service in one's country.
- **International Covenant on Economic, Social and Cultural Rights (ICESCR):** Article 2 underlines that the state parties shall guarantee rights under the covenant without any discrimination among its subjects.
- **UNESCO Universal Declaration on the Human Genome and Human Rights (1997):** The Preamble of the declaration upholds the principles of equality of men and races. It further prohibits discrimination among individuals based on their genetic origin or characteristics. It declares as, "Article 6 No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity." (OHCHR, 2004, Source 6.2; UNESCO, 1997, Source 8.1).
- **Council of Europe's Convention on Human Rights and Biomedicine (Oviedo Convention, 1997):** Although the Oviedo Convention asserts provisions mainly for the regulation of biomedical research but it does incorporate basic tenets for human rights protection. Article 1 imposes duty on its member that they shall ensure dignity and integrity of all human beings without any discrimination in any research or treatment involving biology and medicine. Further Article 11 prohibits discrimination against a person based on genetic heritage. This is the only

binding convention that is applicable to the nations of European Union and thus the provisions are obligatory and not optional for the nations who have ratified it.

The concept of equality doesn't only imply that people should be treated alike, but it also means that when disparities exist despite of prohibitions on discrimination, positive actions are necessary to remove them and give equal opportunity to all for rights protection. The innovation of new technologies like genome editing gives rise to the notion of substantive equality which ensures to protect the equality of outcome for under privileged groups or sections in society and in the case of genome editing these groups and people may comprise of the ones devoid of genetic enhancements.

3.3. Genome Editing and the Threat to Equality

Genome editing is per se is not disadvantageous but the way in which it is used may be in future. However, if it is regulated by binding laws or policy from all dimensions then it can prove to be quite beneficial. The time till it is unregulated and if permitted may elevate social stratification and discriminations.

3.3.1. Access and Affordability: The Genetic Divide

One major reason for the ethical challenge of genetic editing relating to inequality is its accessibility and being highly priced. As the present societies are also divided by economic disparities genome editing can be one more dimension of such disparity as the one who are able to afford it will be lesser than the one not able to. In present also gene therapies have been stated to be quite a costly affair for middle income groups in the globe. Price for genomic medicines have been running over \$2 million for one patient

- **Widening Health Disparities:** The accessibility of such treatments if could be afforded only by a section of society then it would certainly widen health disparities and create a divide of who can pay and who cannot for it. The same would also undermine the principles of fair access of health care and right to health.

3.3.2. The "Designer Baby" Phenomenon and Social Stratification

The prospective use of genome editing for enhancement of genetic traits in humans like intelligence, hair or eye color or physical built raises serious ethical concerns in the international ethics, scientific, legal and rights communities. As there is a very blurring line between therapeutic and non- therapeutic use of genome editing techniques its application needs to be considered with utmost seriousness and morality.

- **New Discriminations:** If genetic editing is permitted globally for improvement of human personality traits it is a possibility that individuals or communities are discriminated on their genetic status. The enhanced humans will be different from the not enhanced in terms of their appearances, capabilities, and efficiency in particular fields. While the normal or unenhanced humans may not possess so and thus it can lead to social taboo or stigma of not being an enhanced human because of lack of capabilities.
- **Enforcing Prejudices in Society:** The possessing of enhanced characteristics attached to a preconceived notion of a successful and happy life. This may indeed give rise to judgmental notions about normal or natural humans being less valuable of efficient leading to a wide gap in sections of society.
- **Erosion of Intrinsic Worth:** In a race of customizing humans' social values of integrity and dignity may be diminishing, as individuals would only be seen as objects of achievement or success rather than humans.

3.3.3. Eugenics Issues and Disability Discrimination

The eugenics revolution in Germany is viewed as the most devastating incidents that demonstrated the extent of degradation of human values and rights. Enhancement may become a modern but a mild version of it however it would be voluntarily done unlike eugenics. Eugenics meant the ethnic cleansing of human race by not allowing different races to breed and considering one subordinate to the other.

- **Downgrading Human Diversity:** The optimization of humans may also bring genetic variations in any the society to a downfall. Our genes are effected by our ancestry, environment and geographical needs, which is a very natural selection and the diversity is also naturally occurring. Processing of humans for specific traits driven by demand of market and social pressure may ouster this genetic diversity from some communities completely like the ones who can afford it.
- **Genetic Discrimination in Other Contexts:** Since some humans will tend to be enhanced or improved versions than others they will be preferred over the non-enhanced in politics, sports, insurance, social engagements or specific employments because of the traits they would possess.

3.4. Ethical and Legal Frameworks for Equality in Genome Editing

For the countering of the ethical and legal challenges the international community has initiated discussion and suggestions for using genome editing for the benefit with minimal risks to humans.

- **WHO Recommendations (2021):** The World Health Organization (WHO) asserts in its recommendations that human genome editing must be looked for its positive effects and not be abused thereby increasing health and social inequalities. (WHO, 2021, Source 7.2). The recommendations call for a prohibition on genome editing till it is safe and accurate to use
- **UNESCO Declarations:** The UNESCO Universal Declaration on the Human Genome and Human Rights (1997) and the Universal Declaration on Bioethics and Human Rights (2005) prescribe ethical directions for human genome and its use in science. The fundamentals are human dignity and equality in both the Declarations when scientific freedom is to be exercised. (OHCHR, 2004, Source 6.2; UNESCO, 1997, Source 8.1). The Declaration on Human Genome and Human Rights declares the human genome as the "Heritage of Humanity." The Declaration on Bioethics calls for mutual benefits of scientific progress, with a focus that "States should consider the importance of promoting equitable access to medical and scientific advances, as well as the greatest possible flow and rapid sharing of knowledge concerning such advances and the sharing of benefits, with particular attention to the needs of developing countries" (UNESCO, 2005).
- **National Laws:** Several nations have adopted a prohibitory approach towards genome editing because of ethics and law concerns including equality. China criminalizes germline genome editing India prohibits and Germany to declares it as an offence in its substantive laws. But this is not denied that there is no binding law for all nations that is uniform in regard to regulation of genome editing.

3.5. Protecting Equality in the Genome Editing Era

To secure the benefits of genome editing equally to all a prudent, multidimensional approach is necessary before its application in reality. This can be done by applying the precautionary principle like adopted for environment issues.

- **1. Therapy Over Enhancement:** A clear and sharp line must be drawn between regulation of therapy and enhancement involving genome editing. Strict guidelines must be there for restricting its use only for sure and not for any improvement.
- **2. Equitable Access and Affordability:** States and international institutions must devise ways in which the therapies are available to all without discrimination. It also should be ensured that knowledge on genome editing must be shared between developing and non developed countries also. This must incorporate financing, price regulation, universal healthcare coverage, and global cooperative efforts to exchange information and resources
- **Inclusive Public Discussion and Education:** An inclusive public engagement is necessary for social alignment of scientific innovations i.e.; the use of science must be in coordination of ethics of society. This engagement for genome editing must include stake holders from all sections of the society like experts of subject, policy makers, public and marginalized groups including children and disabled, and religious groups as well. Public education is essential for making rational decisions about the application of genome editing and make people aware about its long term positive and negative effects.
- **Long term Monitoring** on the results of genome edited humans for assessing its consequences.

4. Conclusion

Right to equality may be posed with a treat if the reality of genetic editing comes true. It is a Genome editing is at an intersection with the potential it has for medicine but with the possible risks of affecting rights like equality and dignity of humans. The threat of diving the socio-economically by genetics, necessitates a deep and robust monitoring and regulatory responses.

The use of genome editing for therapy or treatment holds immense promise for curing hereditary diseases but heritable or germline editing calls for paramount prudence upon its ethical concerns as it may have unintended consequences upon future individuals. The argument is not so much about what science can do, but what it ought to do, informed by principles of justice, equity, and the inherent worth of all people. To realize the potential of genome editing and put it to benefit for the public its equal accessibility for all, affordability, non- must be ensured in coordination with the protection of fundamental and human rights.

Compliance with ethical standards

Disclosure of conflict of interest

The author wishes to confirm that there are no known conflicts of interest associated with this publication.

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