

Social Justice and Human Rights Principles for Global Deliberations on Heritable Human Genome Editing: Summary

DEVELOPED BY

The <u>Gender Justice and Disability Rights Coalition</u> of the Center for Genetics and Society's <u>Missing Voices Initiative</u>

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View full Principles document for background, rationale, and calls to action

Heritable human genome editing—using genetic modification tools such as CRISPR on embryos or gametes—would alter the genes and traits of future generations. It could change the shape of societies in ways that further entrench inequities and discrimination and undermine human rights. To ensure an equitable future for all, global deliberations and policy making must be grounded in principles of social justice and human rights.

The <u>Gender Justice and Disability Rights Coalition</u> developed the 11 principles below to guide policy making and public engagement with heritable human genome editing. Motivated by fundamental justice and human rights commitments, these principles center women and pregnant people's health, rights, and freedom from exploitation, and affirm the worth and full inclusion of all people with disabilities.

A feminist, anti-eugenic lens illuminates how the potential harms of heritable genome editing would fall most heavily on those groups with the least amount of power and resources. For this reason, the principles address a range of essential social justice concerns that intersect with gender, reproductive, and disability rights and justice—including racial, LGBTQ+, economic, intergenerational, and environmental justice and Indigenous sovereignty.

In light of the principles enumerated here, it is clear that there is no persuasive justification for pursuing heritable human genome editing.

Social Justice and Human Rights Principles on Heritable Human Genome Editing

- **O1.** Principle 1: Ensure the reproductive health and safety of women and pregnant people and avoid the potential harms of human experimentation
- **O2.** Principle 2: Safeguard gender justice and reproductive justice for all people
- **O3.** Principle 3: Value all lives and diversity in bodies, intellect, and ability
- **Q4.** Principle 4: Dismantle eugenic legacies and confront eugenic temptations
- **O5.** Principle 5: Promote a comprehensive understanding of health; guarantee access to health and related resources and ensure non-discrimination toward people with disabilities
- **Principle 6:** Prioritize societal and policy changes to eliminate health inequities, end discrimination, and foster thriving for all
- **O7.** Principle 7: Safeguard the rights, interests, and welfare of future generations and any people born through heritable genome editing in policy decisions concerning this technology
- **O8.** Principle 8: Ensure the right to self-govern genetic material and biological data
- **O9.** <u>Principle 9</u>: Apply a precautionary approach in policy making
- **10. Principle 10**: Prioritize people over profit
- **Principle 11**: Implement public empowerment programs to ensure inclusive decision making for the common good

Implications for Policy

Like climate change and artificial intelligence, heritable human genome editing is a global challenge that could exacerbate inequality and change humanity as we know it. The prospect of its use has prompted worldwide recognition of the need for societal action before it's too late.

A widespread consensus already exists among countries that have considered heritable human genome editing: at least 70 countries categorically prohibit it. No country in the world explicitly permits it.

Policies grounded in the Social Justice and Human Rights Principles for Global Deliberations on Heritable Genome Editing are vital to ensure a future of gender, reproductive, and disability rights and justice—and social justice and human rights for all.

We call on governments to prioritize the social justice and human rights principles detailed in this document in policy making related to heritable human genome editing. We urge scientific and international bodies to incorporate these 11 principles as they develop policy recommendations. It is essential to apply the frameworks of gender, disability, racial, reproductive, economic, environmental, and LGBTQ rights and justice, human rights, Indigenous sovereignty, and the rights of children and future generations in all policy concerning heritable human genome editing. Our future depends on it.

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<u>View endorsements</u> by 70+ advocates, scholars, and organizations from around the world