ARRIGE
Association for Responsible Research and Innovation in Genome Editing

Recent Developments in Heritable Human Genome Editing

Including human embryo base editing and conditions for responsible governance | October 2026

Recent advances in genome editing, including base editing and prime editing, have improved the efficiency and precision with which genetic variants can be modified. Studies in human embryos can deepen understanding of early development, but they do not establish reproductive safety, clinical benefits, or an ethical obligation to initiate pregnancy with edited embryos.

The 2026 studies by Jerabek and colleagues on PCSK9 and Bower and colleagues on NANOG illustrate both the scientific value and current limitations of embryo base editing [1,2]. Although editing at the intended site may be efficient, mosaic editing, bystander or off-target changes, developmental arrest and uncertainty about unsampled cells remain important concerns. Avoiding programmed double-strand DNA breaks changes the risk profile but does not eliminate unintended consequences. Development to the blastocyst stage cannot establish safety through pregnancy, childhood or adulthood, and long-term follow-up cannot retrospectively protect the individuals initially exposed.

Preventing serious genetic disease is a legitimate objective, and families affected by inherited conditions deserve serious consideration. Preimplantation genetic testing for monogenic disorders can identify unaffected embryos in many cases, although repeated IVF and the absence of suitable embryos can create real burdens. Rare circumstances warrant research and careful ethical analysis, but do not establish a general need for heritable human genome editing (HHGE). Any proposed indication would need to specify the disorder, expected benefit, available alternatives and additional risks. The argument that withholding a future safe intervention could itself cause harm remains hypothetical until safety and benefit are demonstrated [3].

In that sense, ARRIGE welcomes rigorous research within applicable legal and ethical frameworks while maintaining a clear distinction between experimental achievement and justified clinical use. We consider that present technological maturity and clinical safety are insufficient to justify clinical HHGE. This is a

position of precaution, not a claim that ethical perspectives can never evolve. Reproductive autonomy matters, but parental willingness to accept risk cannot alone authorise an intervention whose consequences may extend to a future child and descendants. The inability of a future child to consent is not, by itself, decisive; it does, however, strengthen the need for independent scrutiny of anticipated benefit, avoidable harm and proportionality. Public support for preventing severe disease does not necessarily imply agreement on a specific intervention or on acceptable uncertainty.

ARRIGE recalls that Article 13 of the Convention on Human Rights and Biomedicine prohibits interventions intended to modify the human genome in a heritable manner. Some authors have argued for reconsidering this prohibition in narrowly defined clinical contexts, while others stress that scientific uncertainty and social risks justify continued restraint [4,5]. International calls for a moratorium and recent regulatory developments also underline the need for coordinated oversight [6,7]. WHO and earlier joint statements have warned against premature clinical use and called for international cooperation [8,9].

Governance must address the wider reproductive market, including the interaction between embryo editing and embryo selection. INSERM Ethics Committee has also argued that these require joint governance [10]. Commercial services and regulatory disparities may encourage cross-border reproductive arrangements that evade safeguards, undermine public trust and expose people to unproven interventions. Regulators should coordinate oversight of testing, selection and editing across the reproductive pathway; researchers and institutions should communicate limitations accurately, disclose commercial relationships, and subject transfers of expertise, materials and data to prospective review. Fertility providers and companies should substantiate clinical claims before offering services.

Polygenic risk scoring raises related, though technically distinct, questions about reproductive decision-making, risk tolerance and social impact. Polygenic predictions are probabilistic and population-dependent; they may be misinterpreted or contribute to discrimination and indirect pressure toward genetic selection. ARRIGE's earlier statement on heritable polygenic editing cautioned against if improved editing performance resolves uncertainty about causal variants, biological interactions, environmental influences

or the prediction of an individual child's future health [11]. Precision in genome manipulation should not be confused with precision in predicting complex traits. As cultural narratives such as Gattaca suggest, genetic information can influence opportunity, autonomy and social stratification when governance is inadequate.

Equity must be central. The high costs and limitations of somatic therapies do not show that embryo editing would be affordable or accessible. Decisions about investment in prospective reproductive technologies should be considered alongside commitments to people already living with genetic disease and the capacity of health systems. Patients, disability communities and people in resource-limited settings must have meaningful roles in shaping priorities, without being portrayed as holding uniform views. ARRIGE's work on access to gene therapies emphasises the importance of public priorities and the responsibilities of public and private actors [12].

ARRIGE therefore calls for maintaining the current prohibitions on initiating pregnancies with intentionally genome-edited embryos under present conditions, while supporting appropriately governed non-reproductive research. Any future reassessment must be based on robust evidence, demonstrated safety, independent oversight, human-rights protections and inclusive societal deliberation. Scientific progress can inform these decisions but cannot substitute for evidence of clinical benefit or legitimate collective decision-making. **Responsible governance must begin before commercial expectations make reproductive use appear inevitable.**

References

1. Jerabek S, et al. Highly efficient base editing at PCSK9 and normal human embryo development. Nature. 2026. https://doi.org/10.1038/s41586-026-11118-x
2. Bower OJ, et al. Base editing reveals an essential role for NANOG in human embryogenesis. Nature. 2026. https://doi.org/10.1038/s41586-026-10792-1
3. Tie C. No bird soars in a calm: therapeutic germline gene editing. Trends in Genetics. 2026. https://doi.org/10.1016/j.tig.2026.08.011
4. Sýkora P, Caplan A. The Council of Europe should not reaffirm the ban on germline genome editing in humans. EMBO Rep. 2017 Nov;18(11):1871-1872. doi: 10.15252/embr.201745246. Epub 2017 Oct 6. PMID: 28986351; PMCID: PMC5666594.
5. Baylis F, Ikemoto L. The Council of Europe and the prohibition on human germline genome editing. EMBO Rep. 2017 Dec;18(12):2084-2085. doi: 10.15252/embr.201745343. Epub 2017 Nov 15. PMID: 29141984; PMCID: PMC5709742.
6. Barrett D, Cannon P, Forte M, Hunt T, Jang Q, Smith D et al. International Call for a 10-Year Moratorium on Heritable Human Genome Editing. A multi-stakeholder initiative to ensure safe and responsible use of genetic technologies. Cytotherapy. 2025;27(8):885–887.
7. Di Caelers. South Africa withdraws genome editing guideline over fears about ‘designer babies’. Nature Africa, News. August 2025.
8. ARRIGE, Genome Writers Guild, Japanese Society for Genome Editing. Common statement on the use of genome editing techniques in human embryos leading to live births. 2019. https://www.arrige.org/wp-content/uploads/2024/06/Common_statement_Arrige_GWG_JSGE.pdf
9. World Health Organization. Human genome editing: position paper. 2021. https://www.who.int/publications/i/item/9789240030404
10. Chneiweiss H, Hirsch F, Bourgain C, on behalf of the INSERM Ethics Committee. Embryo editing and embryo selection need joint governance. Nature Medicine. 2026. https://doi.org/10.1038/s41591-026-04669-z
11. ARRIGE. Statement on heritable polygenic editing. 9 January 2025. https://www.arrige.org/wp-content/uploads/2025/01/ARRIGE_statement_HPE.pdf
12. ARRIGE. 2025 annual meeting summary and statement. December 2025. https://www.arrige.org/wp-content/uploads/2025/12/ARRIGE_annual_2025_meeting_statement.pdf