

Genome editing *as an emerging biotechnology*



genome editing : human issues

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Why is genome editing of interest from the point of view of bioethics?

- Flexible (can be used for DNA/ RNA molecules)
- Effective (at making targeted alterations without off-target effects)
- Relatively rapid (research time reduced from years to months)
- Relatively accessible (can be used by adept microbiologists)
- Relatively cheap (compared to alternatives)
- ...and continually developing

So: increasing rate and diffusion of use

But: limitations in delivery, multiplexing, HDR, genomic knowledge, phenotype data

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Liminal spaces of genome editing

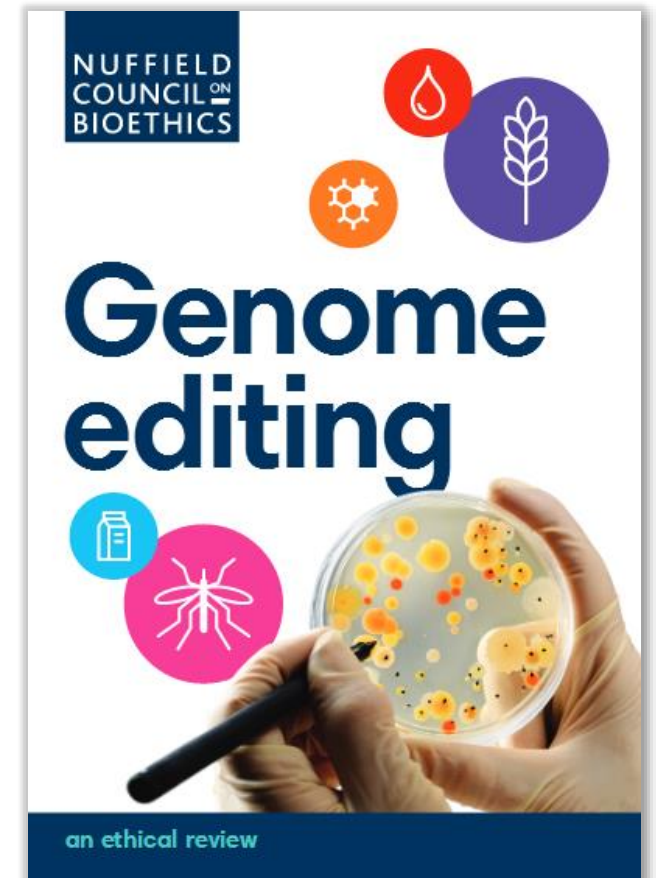
- Basic and applied research
- Scientists and Others
- States and communities
- Innovation and transformation

The initial response of the scientific elite to public concern about genome editing in 2015 was to segregate basic research from treatment and to propose a linearity (questions of safety first, then application). This failed as both a prudential and normative strategy: genome editing neither belongs to nor is within the control of the 'Republic of Science'. Henceforth, the most important questions at stake are not about how to secure safe and effective genome editing but about what to do with safe and effective genome editing when we have it.

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What kinds of ethical concern are raised by human genome editing?

- Medical ethics
 - respect for persons and individual rights
 - consent, beneficence, non-maleficence
- Public ethics
 - respect for moral and social norms
 - social justice, solidarity, rule of law
- Global ethics
 - respect for human dignity
 - categorical limits



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International consensus?



“The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity”
(Universal Declaration on the Human Genome and Human Rights, Art.1)

IBC to advise on “practices that could be contrary to human dignity, such as germ-line interventions.” (Art.24)



“An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.” (Oviedo Convention, Art. 13)



“In the fields of medicine and biology...the prohibition of eugenic practices, in particular those aiming at the selection of persons” must be respected (EU Charter of Fundamental Rights, Art.3(2))

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Governing genome editing responsibly

- Scientific self-regulation (e.g. George Church, "Gene editing: Bring it on," *New Scientist*, 26 September 2015)
- The invisible hand (e.g. Steven Pinker, "The moral imperative for bioethics", *Boston Globe*, 1 August 2015)
- Human rights (e.g. UNESCO report on updating reflection, October 2015; Council of Europe Bioethics Committee statement, December 2015)
- Democratic governance (e.g. Sheila Jasanoff, Ben Hurlbut and Kris Saha. "CRISPR Democracy: Gene Editing and the Need for Inclusive Deliberation." *Issues in Science and Technology* 32, no. 1 (Fall 2015).)

→ Responsible research and innovation (e.g. Sciencewise-NCOB (2016) *Public Dialogue on Genome Editing*)

RRI broadly encourages researchers and innovators to consider fully the implications of their research and consider how to engage with others in reflecting on the wider societal interest in science as a source of society's response to its material conditions. It emphasises democratic determination of how science is orientated towards the achievement of desirable futures, the recognition of uncertainties in the way in which scientific knowledge plays out in the wider world, and the need for built-in responsiveness to these uncertainties on the part of infrastructures and institutions.

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A cosmopolitan ethic

broad: ‘encourage intellectual hospitality and friendship toward divergent views.’

societal: ‘questions regarding CRISPR’s future cannot be segregated into distinct technical and ethical domains, the former...a matter for scientific experts, and the latter as expressions of divergent local values’

consensus: ‘about what is (or is not) at stake, what risks do (or do not) warrant immediate concern, and what common ground is needed to achieve shared and mutually acceptable endpoints for scientific and technological intervention’

A cosmopolitan ethic: ‘the parties involved in deliberation acknowledge the possibility of *more than one valid way to analyze what is at stake in the application of such technologies*’

A global observatory: ‘A new infrastructure... to facilitate exchange on key issues concerning human genome editing... to serve as a center for international, interdisciplinary, and cosmopolitan reflection on the progress of thinking about these issues around the world’



— Hurlbut JB, Jasanoff S, Saha K et al. (in press) Building Capacity for a Global Genome Editing Observatory



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Thank you.

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