

Joint Statement on the Ethics of Heritable Human Genome Editing

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**NUFFIELD
COUNCIL ON
BIOETHICS**

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Recent attempts and plans to alter the genomes of future children reflect a growing interest in making genetically modified humans a reality. The moral and societal issues raised by these developments demand a level of public ethical reflection that is not yet met by current initiatives.

The Comité Consultatif National d'Éthique pour les sciences de la vie et de la santé (French National Advisory Committee on Ethics in life sciences and health), the Deutscher Ethikrat (German Ethics Council) and the United Kingdom's Nuffield Council on Bioethics jointly call on governments and stakeholders around the world to put ethical considerations at the core of any future discussion and of the development of global governance of heritable genome editing.

Genome editing techniques that permit the deliberate alteration of targeted DNA sequences in living cells could theoretically be used in assisted reproduction to alter the DNA of human sperm or eggs, or their precursors, or of an early human embryo before it is transferred to the womb in order to influence the characteristics of a future person ("heritable genome editing"). Whilst the available methods are not yet considered safe enough for clinical use, and their premature use by Chinese scientist He Jiankui to change the genomes of twins born in 2018 was widely condemned – both within and beyond China – as ethically unacceptable, these safety concerns may diminish if future development of the techniques manages sufficiently to reduce current limitations and risks. Already, other scientists have announced plans to launch other clinical attempts at heritable human genome editing should ethical and regulatory review permit.

Although it is currently impossible to predict when or, indeed, whether an appropriate safety threshold will ever be met, the potential applications of heritable human genome editing appear so far-reaching that many committees, think tanks and individuals around the world have been contemplating their societal relevance and moral permissibility. Both a WHO committee and an international commission put together by scientific academies have begun to develop governance standards for potential future applications of heritable human genome editing. Many current initiatives do however involve a fairly narrow selection of stakeholders and a focus on practical issues such as risk-opportunity assessments or on questions of *how* and *when* applications of heritable genome editing might become appropriate.

The United Kingdom's *Nuffield Council on Bioethics*, the *French Comité Consultatif National d'Éthique pour les sciences de la vie et de la santé (CCNE)* and the *Deutscher Ethikrat*, which all provide advice on the ethical aspects of developments in medicine and the life sciences, have a long-standing and close working relationship. For several years they have been exchanging information and discussing their findings on heritable genome editing. In all three countries heritable genome editing is prohibited by law, albeit through different mechanisms. Confidence in these prohibitions frames the advice to respective national authorities. The situation is different in other jurisdictions, where the rules may be unclear, unenforced, or non-existent.

With our individual reports on the subject now published, we would like to draw attention to some fundamental points of consensus among our individual findings¹. We jointly affirm that future deliberations concerning heritable human genome editing require a stronger focus on fundamental ethical questions and principles, to ensure that global discourse and regulation proceed on sound ethical grounds. We call for consideration of the following points:

- 1. Recognising that heritable genome editing raises profound ethical issues of international scope, that many jurisdictions do not have effective legal controls in force, and that there is no international authority capable of enacting universal measures, we call on all jurisdictions to bring heritable genome editing unambiguously within the control of relevant public authorities and to make its abuse subject to appropriate sanction.**
- 2. There should be no clinical attempt to use heritable genome editing until there has been broad societal debate about the acceptability of the interventions in question. This debate must go beyond a mere risk and opportunity analysis and take into account appropriate ethical principles. Such debate should happen from the local to the international level and must involve all relevant societal groups to determine appropriate ethical standards for the assessment of possible future applications.**
- 3. No further attempts at clinical use of heritable genome editing should be made before research has reduced the considerable uncertainty about the risks of clinical use to an acceptable level.**
- 4. Before clinical trials or applications of heritable genome editing are permitted, the risks of adverse effects for individuals, groups and society as a whole must have been appropriately assessed and measures must be in place to monitor and review these.**

The three councils make different but complementary recommendations as to what appropriate ethical principles should be taken into account and the role they should play. With cultural nuances all three councils consider it essential that any ethically permissible application should not increase disadvantage, discrimination or division in society (the principle of solidarity and social justice). This principle is one of the two guiding principles proposed by the *Nuffield Council*, alongside the principle that any intervention should be consistent with the welfare of the future person. The French and German councils also emphasise the ethical concepts of non-maleficence and beneficence. In addition, the *Deutscher Ethikrat* recommends consideration of the ethical concepts of human dignity, protection of life and integrity, freedom, naturalness and responsibility.

All three councils can conceive of cases where the clinical application of heritable genome editing could be morally permissible. We do not, therefore, consider the human germline categorically inviolable. The councils differ, however, in the scope they are willing to consider for such potential permissibility. Whilst all three reports offer reasons to conclude that the use of heritable genome editing could be acceptable to prevent the intergenerational transmission of serious hereditary disorders, the *CCNE* expresses a complete ethical opposition to 'enhancement' applications. The *Deutscher Ethikrat* recommends that the assessment of such applications should be made on a case-by-case basis. The *Nuffield Council* does not advocate distinguishing acceptable and unacceptable uses on a categorical basis but recognises that judgements must take into account the interests and responsibilities of those affected in a given sociotechnical context.

We jointly encourage all participants in debates around heritable genome editing and the respective decision makers to reflect on the examples of ethical deliberation provided in our individual reports. The large range of conceivable applications and their related opportunities, risks and ethical and societal challenges calls for evaluative procedures that deal appropriately with this complexity and proceed with adequate caution, responsibility and transparency.

¹ Nuffield Council on Bioethics (2016) *Genome editing: an ethical review*; Deutscher Ethikrat (2017) *Germline intervention in the human embryo: German Ethics Council calls for global political debate and international regulation* (ad hoc recommendation); Nuffield Council on Bioethics (2018) *Genome Editing and Human Reproduction: social and ethical issues*; Deutscher Ethikrat (2019) *Intervening in the Human Germline*; CCNE (2019) *Opinion 133 on Ethical Challenges of Gene Editing: Between Hope and Caution* (its ethical reflections also cover the impact of germline modifications in other living species, including on human health and through the disruption of evolutionary systems).