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Review of Ethics positions, reports,
documents published on gene editing by
other groups and institutions

Biotechnology. A prudent path forward for
genomic engineering and germline gene
modification

Baltimore D, Berg P, Botchan M, Carroll D, Charo RA, Church G, Corn JE, Daley GQ, Doudna JA, Fenner M, Greely HT, Jinek M, Martin GS, Penhoet E, Puck J, Sternberg SH, Weissman JS, Yamamoto KR.

**Biotechnology. A prudent path forward
for genomic engineering and germline
gene modification**

- Science. 2015 Apr 3;348(6230):36-8

IBC

- Moratorium on germline editing

Oviedo

- Article 13 – Interventions on the human genome
- 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

- Article 18 – Research on embryos in vitro
- 1 Where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo.
- 2 The creation of human embryos for research purposes is prohibited.
- Sykora and Caplan “The Council of Europe should not reaffirm the ban on germline genome editing in humans”
EMBO Reports

European Parliamentary Assembly – 5 steps

Petra de Sutter – Oct. 12/ Recommendation 2015

- Member states should be urged to ratify the Oviedo Convention or at least implement ban on pregnancy with a modified embryo
- A broad and informed public debate should be fostered
- Council of Europe Committee on Bioethics should assess the ethical and legal challenges

European Parliamentary Assembly – 5 steps

- A common regulatory and legal framework should be developed
- Member states should develop a clear national position on use of new genetic technologies “setting the limits and promoting good practices”

European Group on Ethics in Science and New Technologies (former)

- Inclusive debate on “acceptability and desirability” extending to civil society not limited to safety issues, potential health risks and health benefits
- Dignity, justice, equity, proportionality and autonomy
- 3 different opinions in group: prohibit; continued research justified;

Chneiweiss et al.

Fostering responsible research with genome editing technologies: a European perspective

Foster research to assess feasibility, efficacy & safety

Reassess ban on all germline modifications of the nuclear genome

Prevent hijacking by extremists, avoid misleading the public

Raise awareness on distinction between treatment and enhancement

INSERM

- Response to request by INSERM director to present, discuss and advise on issues...
- French/English
- A technical barrier is no more a response to an ethical question than technological success is an ethical blank check.

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

REPORT

Human Genome Editing

**SCIENCE,
ETHICS,
AND
GOVERNANCE**

NATIONAL ACADEMY OF SCIENCES
NATIONAL ACADEMY OF MEDICINE

PDF] [Genome editing: an ethical review - Nuffield Bioethics](https://www.nuffieldbioethics.org/wp-content/uploads/Genome-editing-an-ethical-review.pdf)
[nuffieldbioethics.org/wp-content/uploads/Genome-editing-an-ethical-review.pdf](https://www.nuffieldbioethics.org/wp-content/uploads/Genome-editing-an-ethical-review.pdf)

Human Genome editing Science, ethics, and Governance

- absence of reasonable alternatives;
- restriction to editing genes that have been convincingly demonstrated to cause or strongly predispose to a serious disease or condition;
- credible pre-clinical and/or clinical data on risks and potential health benefits;

Human Genome editing Science, ethics, and Governance

- ongoing, rigorous oversight during clinical trials;
- comprehensive plans for long-term multigenerational follow-up; and
- continued reassessment of both health and societal benefits and risks, with wide-ranging, ongoing input from the public.

American Society of Human Genetics position statement

- Inappropriate to perform editing if culminates in pregnancy
- No reason to prohibit editing on human embryos and gametes
- Clinical application in future should not proceed unless a) compelling medical rationale b) evidence base supporting use c) ethical justification d) transparent public process

European Academies Science Advisory Council

- **Genome editing: scientific opportunities, public interests and policy options in the European Union**
- Basic and clinical research should proceed
- **Germline interventions “It would be irresponsible to proceed unless and until the relevant scientific, ethical, safety and efficacy issues have been resolved and there is broad societal consensus”**

Deutscher Ethikrat

- Keimbahneingriffe an menschlichen Embryo: Deutscher Ethikrat fordert globalen politischen Diskurs und internationale Regulierung
- Discussion in United Nations suggested
- Comment on NAS/NAM – from do not allow until risks are better understood to allow when they can be evaluated better

Human Genome Surgery

- Berlin-Brandenburg Academy of Sciences and Humanities – English and German
- Call for debate which is to lead to broader social discussion

Federation of European Academies of Medicine

- Human Genome Editing in the EU

HUGO Committee of Ethics, Law and Society

Ethical issues of CRISPR Technology and
gene editing through the lens of solidarity

Restraint on experimentation on human
germ cells

Leopoldina

- The opportunities and limits of genome editing German/English
- “It must be clear under what circumstances intervention in the germline is acceptable”
- Moratorium on all forms of human genome engineering that could have an impact on the genome of the offspring

Schweizer Ethiekrat

- Short document in German
- Divided – maintain ban on germline editing, reflect on need for continuing a moratorium, and allow work on germline editing

Italian

- Public debate including not only technical problems but also ethical consequences of introducing germline modifications;
- Divided on whether research on embryos/gametes should take place

Hinxton group

- Value of basic scientific research
- Prospect of human genome editing for reproductive purposes
- 3 categories of embryos (non-viable, supernumerary, created for the experiment)
- International and regional debate required
- Justice, equity
- Governance, meaningful engagement

Lehrer

- These are all the elements that are known in Harvard
- And there may be also others but they haven't been discovered