Genome Editing: the Nuffield Council review

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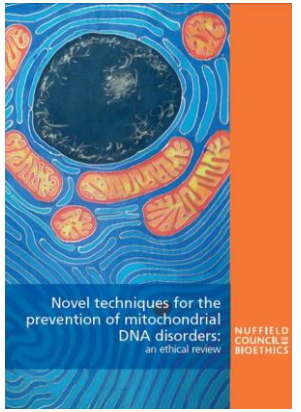
Precursors

When we refer to 'a biotechnology' we mean a productive conjunction of knowledges, practices, products and applications. 'Emerging' is the *assembling* of this conjunction. — *Emerging Biotechnologies* (2012)

The wider policy debate could benefit from a fuller discussion of the ethics of the different kinds of prospective and theoretical germline therapies than was possible within the remit of this report. This would include potential therapies that would act on the cell nucleus with heritable effects.

— *Novel Techniques for the prevention of mitochondrial DNA disorders* (2012)



A two-stage programme of work

- Stage 1 – review of conceptual and descriptive issues, leading to identification and prioritisation of key ethical questions (beginning with the technology and examining its potential applications)

Genome Editing: an ethical review published online September 2016

- Stage 2 – examination of normative questions leading to practical recommendations in a defined area of activity (beginning with challenges and looking at the impact of technology in meeting – and transforming – those challenges)

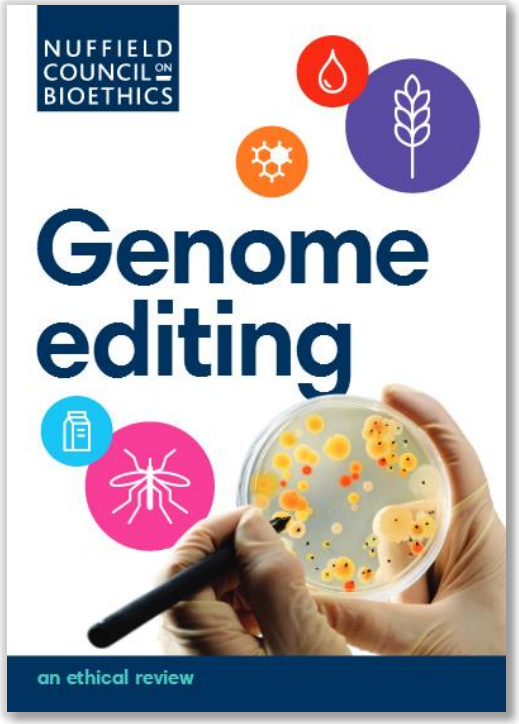
Two print publications in 2017

Method of working (stage one)

- Commissioned background paper (December 2014)
- Workshop (April 2015)
- Interdisciplinary working group (September 2015 – September 2016; 8 members)
- Open call for evidence (November 2015 – February 2016; 54 responses)
- Literature review
- 4 'Fact-finding' meetings (21 participants)
  - Perspectives on genome technologies
  - Genome editing in plant science
  - Genome editing and animal research
  - Biomedical research and applications
- 10 research interviews
- External review (6 reviewers)
- 'Applications' working parties

Structure of the ‘stage one’ review report

1. Genome editing (the emergence of techniques within biological research)
2. Science in context (the co-evolution of social, cultural, economic conditions)
3. Moral perspectives (survey of the grounds of ethical appraisal)
4. Human health (research, cell-based treatments, inherited genetic disease, genetic enhancement)
5. Food (plant science and livestock breeding)
6. The natural environment (genome editing of wild species, especially combined with gene drive)
7. Other applications (synthetic biology: industry, military, leisure, art)
8. Conclusions



Genome editing: a transformative technology?

- 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, genetic knowledge, phenotype

International governance of research

- Asilomar, 1975
- Asilomar *redux*?
  - UK Research Funders' *Initial Joint Statement* (Sept.2015)
  - Hinxton group: "concerns about human genome editing for clinical reproductive purposes should not halt or hamper application to scientifically defensible basic research."
  - National Academies of Sciences and Medicine / Chinese Academy of Sciences /Royal Society *International Summit on Human Gene Editing: A Global Discussion* (clearly distinguishes research (more needed) and clinical (therapeutic and reproductive) use.
  - INSERM meeting (March 2016)

Artefacts have politics

"In all of its guises, actual or aspirational, technology functions as an instrument of governance... As yet, however, there is no systematic body of thought, comparable to centuries of legal and political theory, to articulate the principles by which technologies are empowered to rule us."

— Jasanoff S (2016) *The Ethics of Invention* (New York: WW Norton & Co,)

Concerns about genome technologies

Three kinds of concerns can be distinguished;

- Technological momentum
- Slippery slopes
- Function creep

Moral perspectives

- Science as a moral enterprise
- Intervening in the genome – exceptional?
- Responses to challenges to established norms
  - Bioconservatism
  - Moral norms and human rights
  - Welfare and harm
  - Social justice
- Governance of genome editing?

Public interest

- Global?
- Regional?
- National?
- Communities of interest?

Specifying 'genome editing'

Practice

- ZFN/TALENs/CRISPR…
- NHEJ /HDR
- 'Editing' / GM

Organism

- Microorganisms
- Plants
- Animals
- Humans

Purpose

- Basic biology
- Biomedicine
- Public health
- Reproduction
- Agriculture
- Industry
- Military
- Art, leisure

Context

- Knowledge
- Jurisdiction
- Culture
- Faith
- Technology
- Social and economic conditions

Confusions and ambiguities

- Confusing terms ('natural', 'traditional', 'editing')
- Contested concepts ('genetic modification', 'germ line', 'human genome')
- Inconsistent framings ('risk', 'precision', 'effectiveness')
- Contending imaginaries (intensive production, healthy population)

Questions to address in stage two

The second stage of work should involve at least three elements:

- an account of the value commitments that are at stake in the distinctions that are made in existing governance arrangements that are effective in the area under consideration (and in any proposals to revise these);
- an identification of where public and private interests are mutually engaged, and the legitimate force of these (i.e. who is entitled to determine what may or should be done?);
- a comparison of the different visions of desirable future states of affairs and narratives about technological and social developments, which continually re-imagine possible outcomes, feeding back into a public discourse informing governance.

Triage and next steps

- Human reproductive applications (expected print publication mid 2017)
- Livestock applications (expected print publication late 2017)
- Disease vector control
- Xenotransplantation
- Cell-based therapies
- Plant science
- Changing patterns of technology use

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Thank you.

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