The Position of the Nuffield Council on Bioethics

Pete Mills, Assistant Director
Terms of reference

1. To identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern

2. To make arrangements for examining and reporting on such questions with a view to promoting public understanding and discussion;

3. To publish reports; and to make representations, as the Council may judge appropriate.
The Nuffield Council

“We are a bioethics council, not a council of bioethicists.”

— Professor Albert Weale, former Chair
Genome editing: opening gambits

• **Don’t rock the boat** (don’t carry out research on human embryos, e.g. Lanphier, E. *et al*. *Nature* 519, 410–411 (12 March 2015))

• **Self-denying ordinance** (voluntary moratorium on clinical use of human embryos, e.g. Baltimore D. *et al*. *Science* 19 March 2015; ISSCR 27 April 2015)

• **Control via funding** (of research on human embryos, e.g. NIH, 29 April 2015)

• **Formal moratorium with oversight** (UNESCO IBC)


• **Proceed with caution** (UK research organisations, 2 September 2015; NAS/RS/CAS Global summit, 3 December 2015)

• **A ‘starting point’ for democratic debate** (Council of Europe Bioethics Committee, 3 December 2015)
Germ line modification: an area of global consensus?

- **Structural integrity of the ‘human genome’**
  
  “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)

  “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))

- **Integrity of lines of descent/inheritance**
  
  “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)
Human germ line modification lawful in UK

“We feel that it is appropriate to call PNT and MST ‘germline therapies’ because they would have germline effects.” (NCoB, June 2012)

Although...

“...genetic modification involves the germ-line modification of nuclear DNA (in the chromosomes) that can be passed on to future generations.” (Earl Howe, Hansard, 5 February 2015)
Three kinds of question

1. What is the basis of public interest in different uses of genome editing (and to what extent does this apply to research)?
   – momentum; mission creep; slippery slope

2. How can we delineate what is unacceptable (should be prohibited) / acceptable (should be permitted) / desirable (should be promoted)
   – somatic/germline; prevention/preference; therapy/enhancement

3. What is the appropriate jurisdiction?
   – global consensus? nation state? republic of science?
Emerging approaches

• **Trust the scientists?**  (e.g. George Church, “Gene editing: Bring it on,” *New Scientist*, 26 September 2015)

• **Trust the market?**  (e.g. Steven Pinker, “The moral imperative for bioethics”, *Boston Globe*, 1 August 2015)

• **Trust the law?**  (e.g. Council of Europe, statement of 3 December 2015)

• **Trust the public?**  (e.g. Jasanoff, Sheila, J. Benjamin Hurlbut, and Krishanu Saha. "CRISPR Democracy: Gene Editing and the Need for Inclusive Deliberation." *Issues in Science and Technology* 32, no. 1 (Fall 2015). )
Nuffield genome editing project

Two part project:

• Core working group – ‘platform’ report (➔ mid 2016)
  Part 1 will address conceptual and descriptive issues relating to the impact of genome editing technology, and the prioritisation of issues for consideration

• One or more ‘applications’ working parties (➔ end 2016/early 2017)
  Part 2 will address practical and normative issues for a particular domain of problems (e.g. control of insect disease vectors, organ (xeno)transplantation, avoidance of inherited disease)

Chair
Dr Andy Greenfield

Members
Prof. Richard Ashcroft
Prof. John Dupré
David K Lawrence
Dr Tony Perry
Prof. Charis Thompson
Prof. Christine Watson
Prof. Karen Yeung
Process and progress

Workshop

Call for evidence

Interviews

Platform report

Literature review

Fact-finding meetings

Deliberation

Plant research

Animal research

Pharma

Tropical Diseases

Cell therapies

GM Insects

XenoTx

Germ line

NUFFIELD COUNCIL ON BIOETHICS
Watch this space...

The Nuffield Council on Bioethics has achieved an international reputation as an independent body advising policy makers and stimulating debate in bioethics. More about us

www.nuffieldbioethics.org
Thank you