The garden of forking paths: current regulation and implications of the Nuffield approach in the UK

Pete Mills
Nuffield Council on Bioethics (UK)
OCTOBER 17-18, 2002
MEETING AGENDA

Hotel Monaco
700 F Street, NW
Washington, D.C. 20002

FRIDAY, OCTOBER 18

8:30 am  Session 5: Regulation 8: International Models (United Kingdom).
Baroness Helena Kennedy QC, Chair, Human Genetics Commission (HGC).

10:00 am  Break

10:20 am  Session 6: Regulation 9: International Models (United Kingdom).
Suzi Leather, Chair, Human Fertilisation and Embryology Authority (HFEA).

11:50 am  Break

Noon  Session 7: Regulation 10: General Discussion.

1:00 pm  Adjournment

The President's Council on Bioethics
Why do we keep asking the wrong questions?
‘Why do we need germ line genome editing?’
'What might we do with germ line genome editing?'
“...it would be idle to pretend that there is not a wide diversity in moral feelings, whether these arise from religious, philosophical, or humanist beliefs. What is common (and this too we have discovered from the evidence) is that people generally want some principles or other to govern the development and use of the new techniques. There must be some barriers that are not to be crossed, some limits fixed, beyond which people must not be allowed to go. Nor is such a wish for containment a mere whim or fancy. The very existence of morality depends on it.”

Human Fertilisation and Embryology Act 1990

Chapter 37

Arrangement of Sections

1. Principal terms and definitions.
   1.1 Meaning of "embryo", "sperm" and associated expressions.
   1.2 Other terms.
   1.3 Activities prohibited by the Act.
   1.4 Prohibitions in connection with embryos.
   1.5 Prohibitions in connection with gametes.
   1.6 The Human Fertilisation and Embryology Authority. In functions and proceedings.
   1.7 The Human Fertilisation and Embryology Authority. Appointment and duties.
   1.8 Advisory Committee on Safety.
   1.9 Advisory Committee on the Embryo.
   1.10 Advisory Committee on Gamete.
   1.11 Licensing procedures and other regulations.

2. Scope of licences.
   2.1 Licensure for treatment, storage and research.
   2.2 License conditions.
   2.3 Conditions of licence for treatment.
   2.4 Conditions of store licences.
   2.5 Conditions of research licences.
   2.6 Grant, renewal and suspension of licences.
   2.7 General powers.
   2.8 The person responsible.
   2.9 Determinations and orders of Licensees.
   2.10 Procedures for referral, review or revocation of licence.

Human Fertilisation and Embryology Authority

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23.07.90

Code of practice

8th Edition

www.hfea.gov.uk
The HFEA’s belief that, presented with all the available material, accompanied by thorough explanations and with ample opportunity for dialogue, consensus could be reached one way or the other was rewarded. — Lisa Jardine, ‘Ultimately a decision has to be made’
“Over the period of the consultation, both the expert groups and the general public moved from risk-averse anxiety to a clearly-expressed view that the benefits of mitochondrial replacement treatment, in allowing couples to avoid bearing children with devastating diseases, outweighed the possible risks and ethical misgivings. The views of special interest groups with fixed positions about any treatment involving human embryos came increasingly to look like outliers. They were not, of course, ignored, but were put in perspective by the increasingly steady assent of widely differing sectors of the community.”

— Lisa Jardine, ‘Ultimately a decision has to be made’

Principle 1: The welfare of the future person

Gametes or embryos that have been subject to genome editing procedures (or that are derived from cells that have been subject to such procedures) should be used only where the procedure is carried out in a manner and for a purpose that is intended to secure the welfare of and is consistent with the welfare of a person who may be born as a consequence of treatment using those cells.

Principle 2: Social justice and solidarity

The use of gametes or embryos that have been subject to genome editing procedures (or that are derived from cells that have been subject to such procedures) should be permitted only in circumstances in which it cannot reasonably be expected to produce or exacerbate social division or the unmitigated marginalisation or disadvantage of groups within society.

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| Recommendation 6 | We recommend that heritable genome editing interventions should only be permitted provided that arrangements are in place to monitor the effects on those whose interests may be collaterally affected and on society more generally, and provided that legitimate and effective mechanisms are in place to redress those effects and to revise relevant policy; this should include a clear regulatory measure to trigger a moratorium and a sunset provision, requiring review and an affirmative resolution to permit the practice to continue. |
| Recommendation 7 | We recommend that consideration should be given to the establishment of a separate body or commission in the UK, independent of Government and independent of existing regulatory agencies, which would have the function of helping to identify and produce an understanding of public interest(s) through promotion of public debate, engagement with publics and monitoring the effects of relevant technological developments on the interests of potentially marginalised subjects and on social norms. |
Governance as ecology:

three venues of ‘geo-ethics’
Thank you.

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