



# Research Ethics and the Nuffield Council on Bioethics: Emerging themes

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# Nuffield Council on Bioethics

- ▶ Created in 1991
- ▶ Independent body funded currently by Nuffield Foundation, Wellcome, and Medical Research Council
- ▶ ‘We identify, analyse, and advise on ethical issues in science and health so that decisions in these areas benefit people and society’
- ▶ Comprises a Council of 16 appointed Members drawn from academic disciplines (philosophy, law, social sciences), genetics, psychiatry, pharmacy, public health, public engagement, law, medicine, that is the main deliberative body
- ▶ Executive advising Council and implementing strategy and programme of work ; and a Governing Body having oversight of the whole organization

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# Strategy over the next 5 years

- We will **shift our focus** to issues at the intersection of scientific innovation and societal challenge.
- We will expand our **horizon scanning** so we are even better placed to identify and anticipate ethical challenges and dilemmas before they arise.
- We will enhance our reputation as a trustworthy source of ethical analysis by increasing our range of **high quality outputs**, with evidence, expertise and engagement at their centre.
- We will increase our focus on **embedding ethics** in policy making.
- We will cultivate **bioethics networks** to strengthen the voice of ethics in science and health policy in the UK and internationally.
- We will identify **focus priority areas** to guide our work so that we concentrate on the most urgent challenges facing society.



# Priority areas



**Reproduction, parenthood and families:** *Innovations in human reproduction will challenge our traditional understanding of reproductive options and choice. These include developments that seek to enhance or work alongside existing assisted reproductive technologies and those that offer new opportunities for people unable to conceive or carry biologically-related children. We will explore the regulatory framework surrounding them, as well as cultural and social questions about the nature of gender, family and parenthood.*

**The mind and brain:** *Innovations which alter our minds and brains range from new approaches to research, care and treatment for neurological and psychological conditions, to those which could fundamentally alter and augment our moral and cognitive abilities. They both bring a suite of profound ethical challenges.*

**The environment:** *There is enormous public interest in, and a growing recognition of how environmental issues both impact, and are impacted by, human health and wellbeing – but there is very little in the way of rigorous ethical deliberation. We will lay the groundwork for an ethical framework for policy and practice, identifying and analysing the ethical issues provoked both by the crisis and the political, scientific and technological responses to it.*

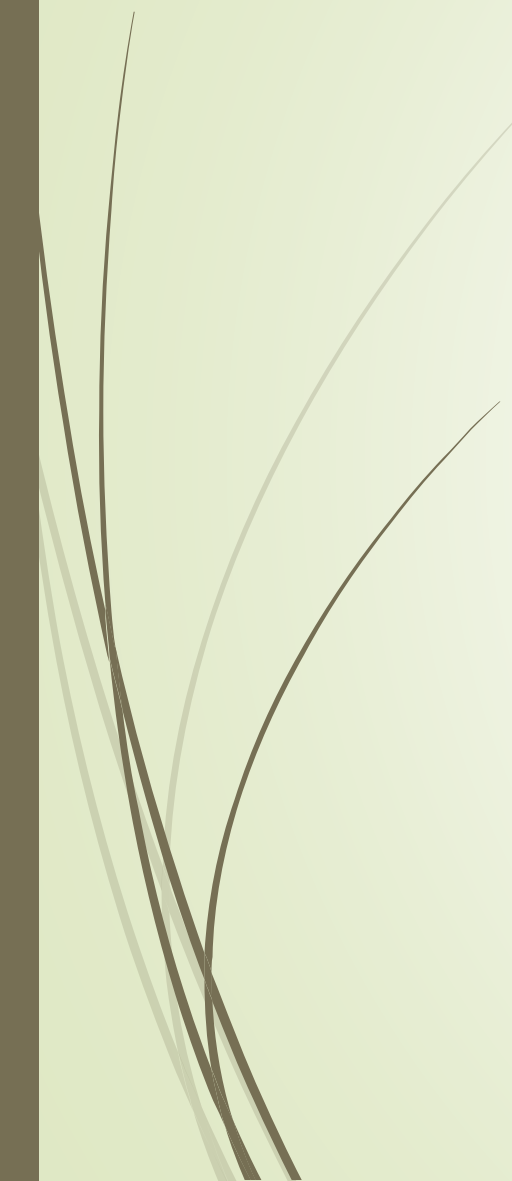



# And more....

- ▶ Commissioned work on 'disagreements' (between clinicians and parents) for Department of Health
- ▶ Probable major public engagement exercise (Citizens' Jury) in England on 'assisted dying'
- ▶ Collaborative work with Ada Lovelace Institute on 'Genomics and AI'
- ▶ Commissioned Wellcome background document on 'Climate change and health'
- ▶ Publication of major report on 'Ageing'
- ▶ Lessons of COVID



# Emergent cross cutting themes

- Embedding ethics in policy
  - Clinical versus research ethics
  - Top-down v crowded field: mapping the bioethics landscape
  - Proper regulation in the context of rapid scientific change
  - Ethical preparedness
  - Research in and on emergencies
  - Capacity building and inclusivity
  - Scientific knowledge and bioethical literacy
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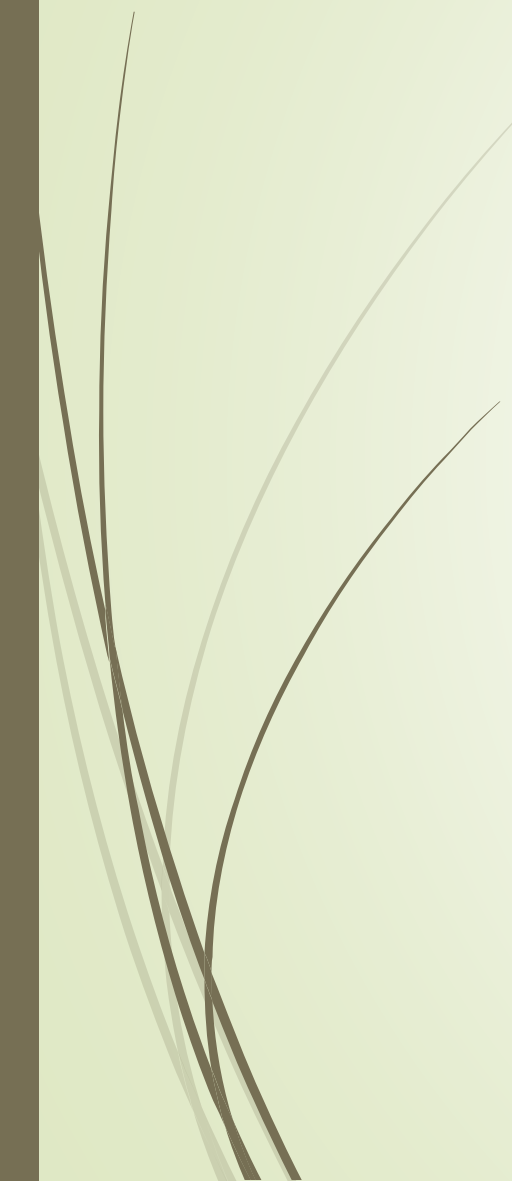


# Embedding ethics: the example of the NGB

- ▶ National Genomics Board responsible for overseeing genomics strategy and its implementation across UK
- ▶ Research is one of its three pillars (others being 'Diagnosis and personalized medicine' and 'Prevention');
- ▶ Ethical regulation is one of five cross cutting themes:
- ▶ The Vision: **All our genomic data systems will continue to apply consistent high standards around data security and the UK model will be recognised as being the gold standard for how to apply strong and consistent ethical and regulatory standards that support rapid healthcare innovation, adhere to legal frameworks, and maintain public and professional trust.**
- ▶ Insistence that ethical regulation is not restricted to data management; nor is it simply about securing public trust
- ▶ Other issues including most importantly issues of fairness in access to research and treatment



# Clinical versus research ethics

- ▶ Research ethics committees (over 80 NHS ones in the UK) subject to oversight of Health Research Authority
  - ▶ Yet clinical ethics committees not similarly regulated – only UK Clinical Ethics Network which provides support and information for what it notes is a ‘growing number’ of CECs in the health sector (accelerated during COVID)
  - ▶ Yet distinction between clinical and research ethics is not a clear bright line
  - ▶ For example, Great Ormond Street Hospital CEC will consider ‘experimental’ or ‘unproven’ pediatric treatments and insist upon evidence base and publication of outcomes
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# Top down in a crowded field: mapping the bioethics landscape

- ▶ UK notorious for – what became evident during COVID – a crowded bioethical landscape – CECs, RECs, professional bodies (BMA, Royal Colleges), official agencies (e.g. NICE), and academic organizations as well as individuals
- ▶ Nuffield Council and MEAG (Moral and Ethical Advisory Group)
- ▶ Plurality of advice – not always consistent
- ▶ Not as in – e.g. – France and Germany, single Government appointed national ethics committees
- ▶ So what system is best? How to ensure consistency of advice and optimize use of diverse resources
- ▶ NCoB currently engaged in a ‘mapping’ exercise of bioethics

# Proper regulation in the context of rapid scientific progress

- ▶ HFEA's Legislative Reform Advisory Group
- ▶ Warnock Committee and resultant legislation now over 30 years old
- ▶ Extraordinary pace of relevant new research: 'artificial' gametes; synthetic embryos; ectogenesis
- ▶ Critical question of how law and regulatory systems can anticipate and appropriately regulate emerging science
- ▶ 14-day rule as one example?



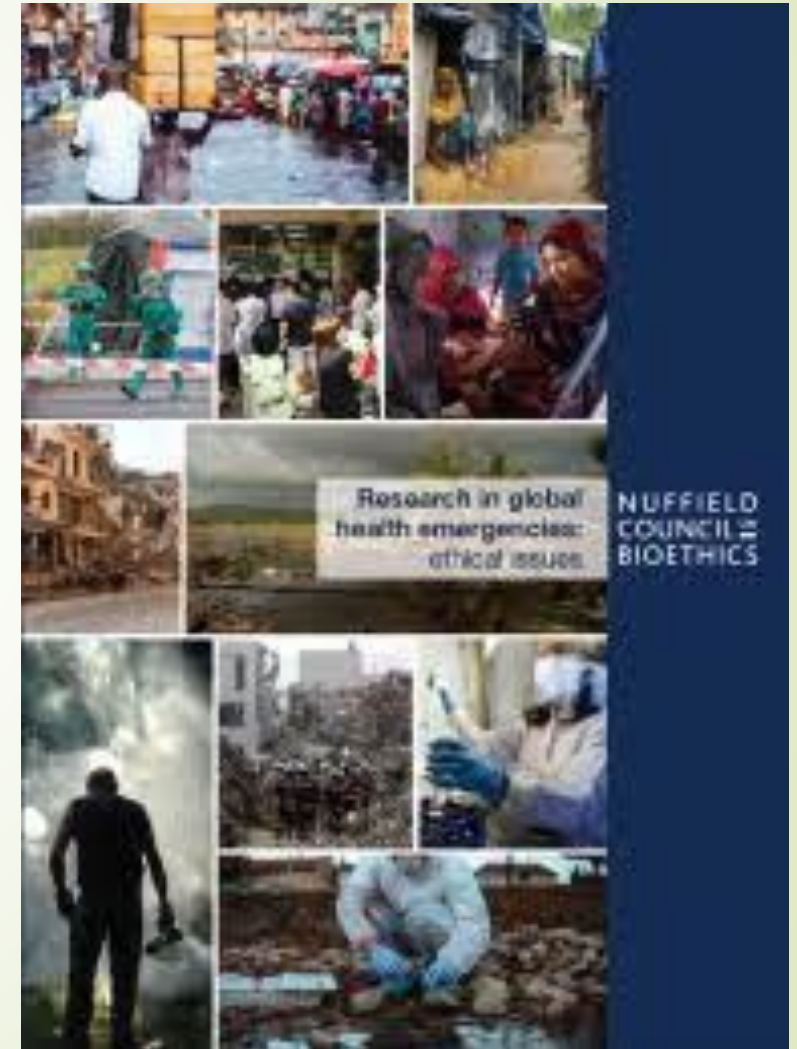
# 'Ethical preparedness'

- ▶ A concept prompted by the way in which different countries responded to the ethical challenges of COVID
- ▶ And acknowledging the importance of being ethically ready to respond to an emergency in parallel with logistical readiness
- ▶ Authoritative, clear and broadly accepted ethical guidance
- ▶ "We must be ready as a society not just to deal practically and efficiently with a pandemic, but to do so in a way that is ethically appropriate and fully justified."



# Research on and in emergencies

- ▶ Our *Research in Global Health Emergencies: ethical issues* Report (2022)
- ▶ Better evidence about what helps or doesn't help during an emergency is needed in order to improve the response to global health emergencies.
- ▶ Research conducted during an emergency itself plays a crucial role in obtaining this evidence, and helps support the immediate response, as well as learning for the future.





# Capacity building and inclusivity

- ▶ Two imperatives:
- ▶ First, ensuring that relevant research communities are empowered and that this is reflected in research funding and research outcomes (content and use)
- ▶ *Global Health Emergencies* Report and the researchers of the Global South
- ▶ Second, proper involvement of those on or with whom research is done in the design and use of such research
- ▶ *Ageing* Report and the ageing community:
- ▶ One of its recommendations says that ethics committees should all routinely expect to see meaningful collaboration with older adults in any research seeking to influence our experience of ageing



# Scientific knowledge and bioethical literacy

- ▶ The full and informed engagement of the public in research ethics requires both
- ▶ Knowledge and understanding of rapidly developing and often incredibly complex science and technology
- ▶ Horizon scanning and public education
- ▶ And an understanding of what ethics is, how it is relevant, and how it can be used to understand and evaluate those developments
- ▶ Whilst acknowledging that we live in pluralistic societies and are governed by democratic rules that protect the tolerance of fundamentally different and often irreconcilable values.
- ▶ How do we link our ethical recommendations to shared public values?



# Last personal note

- ▶ I live on the island of Ireland and have Irish citizenship
  - ▶ I very much welcome this research ethics initiative and look forward to its further development
  - ▶ Across the whole island
  - ▶ I am more than happy to contribute in any way that is appropriate
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