

Ethical challenges in bioscience and health policy for the new UK Parliament

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The Nuffield Council on Bioethics is an independent body that has been advising policy makers on ethical issues in bioscience and medicine for the past 24 years.

We aim to:

- inform policy through timely and thorough consideration of ethical implications arising out of biological and medical research
- engage a wide range of people in discussion about such issues in order to inform our deliberation process and promote public debate
- ensure that the benefits for society of developments in bioscience and medicine are realised in a way that is consistent with public values

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We have identified five key ethical challenges in bioscience and health policy for the new UK Parliament and suggest how these challenges can be addressed

Find out more about our work on topics highlighted in bold at www.nuffieldbioethics.org

Build and maintain public trust in science and medicine

Public trust in the people and institutions that drive, govern and critically examine developments in research and medicine can help the potential benefits of these developments to be realised. The Care.data initiative aimed to support research by uploading GP-held data to a central repository, but inadequacies in the way it took people's rights and expectations into account led to a damaging loss of public trust. Our work on **biological and health data** suggests ways in which trust can be rebuilt.

Transparency, openness and honesty can help build trust. The promotion across the civil service of 'open policy making' – openness to new thinking and evidence from external experts and the wider public – is commendable as long as policy makers are genuinely open to what they hear.

MITOCHONDRIAL DNA DONATION

In February 2015, Parliament approved regulations to allow **mitochondrial donation** – a new type of IVF that could prevent the transmission of mitochondrial disorders from mother to child. This was the result of an extended and transparent process that involved wide consultation with experts, including the Nuffield Council on Bioethics, and the public.

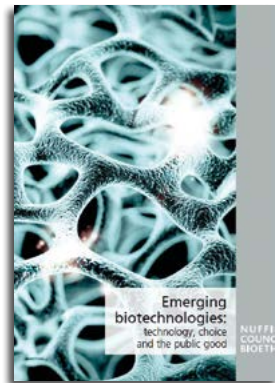


Scientists also have a vital part to play. Journalists and politicians often want definitive answers, but scientists should feel able to be honest when talking about the uncertainties surrounding new developments. And they should not feel under pressure, from those who assess research for example, to over-promise the likely benefits of research or even manipulate their findings to get a better result. The **culture of research** should support good research practice and the production of high quality science.

Embed public participation in policy and research

Taking account of the values and preferences of a wide range of people will help ensure that research, innovation and healthcare meet the needs of society and retain the confidence of the public.

The Government should invest in biotechnologies that increase our wellbeing and respond to societal challenges, not only those that are good for our economy. Public involvement is an important way of ensuring that social values help to shape and select **emerging biotechnologies**.



Open and frank public deliberation can also help determine what is ethically acceptable when it comes to new technologies, such as cutting edge genome editing techniques (see Box). Understanding the language that people use when expressing their views on new technologies is crucial for constructive debate. For example, people use the words **natural and unnatural** to express a variety of different meanings.

GENOME EDITING

New **genome editing** techniques, such as the CRISPR-Cas9 system, may allow scientists to make precise, targeted changes to human genes that can be carried on to future generations – something that is currently illegal in the UK. The ethical issues raised will require careful consideration and wide discussion.

To ensure clinical research is ethically designed and carried out, it is important that research, particularly that which involves potentially vulnerable people such as those with **dementia** or **children**, is carried out *with* people, not *on* them. Participants and others affected by research should be listened to and actively involved in shaping how research is carried out.

Take an international lead in bioethics

Taking the lead in international debates about ethics goes hand in hand with international leadership in science. The Government should take an approach to research and medicine that is both ethically appropriate for the UK and sets a benchmark for those further afield. UK and European policies on renewable fuels, for example, should be guided by ethical principles to ensure that **biofuel** development does not damage human rights and the environment in other countries.



The UK both affects and is affected by developments in research and medicine that occur beyond its borders. National support for the development of vaccines and treatments for infectious diseases, for example, and the ability of countries to share information about the spread of disease in **solidarity** with one another, are both crucial to reducing the risk of ill health at home and abroad.

Many of the areas that the Nuffield Council on Bioethics examines – such as **new health technologies**, standards in **animal research** and regulations governing **organ, tissue and gamete donation** – raise ethical questions that are being asked by policy makers across the globe. The Nuffield Council has an important role as the UK partner in networks of national and international bioethics advisory bodies. Our work is used around the world, acting as a benchmark for high quality bioethical analysis, and our international counterparts look to us and the UK for guidance. Our framework for carrying out **healthcare research in developing countries**, for example, is widely used and referred to.



Use data responsibly to advance science and wellbeing

We are generating more **biological and health** data than ever before, including GP records, hospital notes, laboratory tests, clinical trials, monitoring devices and health apps. Advances in information technology and data science mean that it is becoming easier and cheaper to gather, transfer, link, store and analyse data. This offers opportunities to generate new knowledge, improve medical practice, increase service efficiency and drive innovation in the public interest. It has led to a new attitude towards data as a valuable national resource.



Developments in data science and the drive to link and re-use data have, however, put pressure on conventional governance approaches, making it hard to meet in practice standards of informed consent and anonymisation.

Respect for people's privacy should be at the centre of any data initiative. Ethically appropriate use of data should respect individuals' dignity and human rights and reflect the expectations of patients and participants. Involving people in the design and governance of a data initiative is an important way of securing the greatest public benefit from data use and earning public trust. This should be backed up by accountability arrangements and robust penalties for the deliberate misuse of data.

In some circumstances, such as crime prevention and detection, the Government may need to use data in such a way that it restricts people's rights to autonomy and privacy. Any interference with human rights in the **forensic use of bioinformation** must be proportionate to the need to detect and prosecute offenders, and there must be evidence that the interference will be effective.

Be a steward of health

People are increasingly expected to take more responsibility for their own health – to lead a healthy lifestyle and play an active role in managing their healthcare. People are more knowledgeable about their health and are demanding healthcare services that are **personalised** and user-focused.

In this new era, the Government still has important obligations to generate the conditions that empower people to be healthy and to take measures to reduce health inequalities. We advocate taking a 'stewardship' approach, where policy makers carefully balance the need to meet these obligations while avoiding coercing people into leading healthy lives. In the case of **organ and tissue donation**, for example, the Government should make donation as easy as possible whilst also working to improve the health of the population in order to reduce the high demand for donated organs.



The Council's *Intervention Ladder* is a tool for thinking about the acceptability of different **public health** policies. Whether a public health intervention is proportionate depends on whether the public health objectives are sufficiently important, how likely the intervention is to achieve certain ends, and whether the means chosen are the least intrusive and costly whilst still achieving their aims. Restrictive measures, such as banning smoking in public places, are only likely to be successful if there is public support, based on high quality scientific evidence on both the cause of ill health and the effectiveness of the measure.



Health professionals also have responsibilities to promote health and wellbeing, but in some areas of medicine these responsibilities are not clearly set out. **Cosmetic procedures**, for example, are becoming increasingly popular and accessible in the UK, but questions have been raised about potential risks to users and the lack of regulation and professional standards in this area.