



Ethical challenges in bioscience and health policy for the UK Parliament

October 2017

The Nuffield Council on Bioethics is an independent body that has been advising policy makers on ethical issues in bioscience and medicine for more than 25 years. We are funded by the Nuffield Foundation, the Medical Research Council and Wellcome.

We aim to:

- inform policy through timely and thorough consideration of the ethical implications of biological and medical research
- engage a wide range of people in discussions about such issues to support our deliberations, and to inform 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

The Council has no party political agenda and it regards its independence as critical to help maintain public trust in its work.

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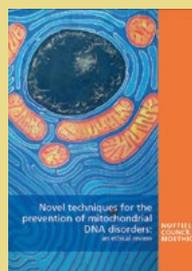
We have identified four key ethical challenges in bioscience and health policy for the UK Parliament, and suggest how each can be addressed.

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

Contact:
bioethics@nuffieldbioethics.org

1. Build and maintain trust in medical research and the life sciences

- The potential benefits of medical research are more likely to be realised when there is public trust in the people and institutions involved in it. But trust in business, government, NGOs, and media has broadly declined in recent times, suggesting that new thinking is needed about the relationship between individuals, the state, and those institutions that have an interest in research.
- The care.data initiative led to a damaging loss of public trust, and Google DeepMind's collaboration with the Royal Free hospital also revealed concerns about the way people's rights and expectations were treated. Questions have also been raised about who should gain from the commercial exploitation of NHS data. Our report on the use of **biological and health data** in research suggests that transparency, openness, and honesty are essential in securing public trust.
- We are likely to see significant developments in the field of health technology in the future. Next generation robots may be able to perform surgical procedures independently; or even provide care for people with dementia. Machine learning and artificial intelligence have the potential to make diagnostic and treatment predictions. Confidence in these technologies and trust in those who use them will be key to their success.

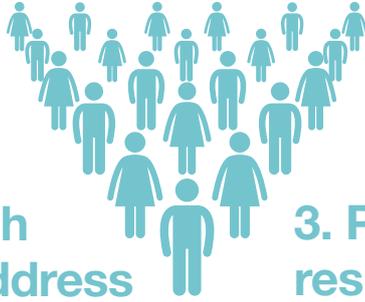


MITOCHONDRIAL DNA DONATION

Mitochondrial donation refers to techniques that can prevent mother-to-child transmission of mitochondrial disorders. Although there have been births after treatment in other jurisdictions (Mexico and Ukraine), the UK is the first country to provide a well-regulated, permissive

environment for this technology. This was the result of transparent and effective consultation with experts and the public – and informed debate in Parliament – which our 2012 report helped to inform.

- We believe that the possibilities created by life sciences research, and by big data, require an approach that considers both public and private interests and that focuses on public values and the public good. Research should be seen as a social investment, seeking to secure the benefits of science and technology in ways that are fair and equitable.



2. Ensure research and innovation address the needs of society

- Thinking about ethics in research and innovation involves looking at societal challenges, and not simply at technological development. We believe that taking into account the values and preferences of a wide range of people will help to ensure that research and innovation address the needs of society, and retain public confidence.
- Some of society's biggest challenges relate to our ageing population, the rise of mental illness and neurological disorders, growing antimicrobial resistance, and ensuring the delivery of a sustainable energy supply – as referenced in a recent [House of Commons Library paper](#).

GENOME EDITING

Genome editing techniques (the deliberate alteration of DNA in living cells), have the potential to offer significant benefits to those living with or at risk of serious disability or disease. The impact of the technology on wider society will, however, require careful consideration – including the acceptability of making changes that can be passed on to future generations. Our forthcoming report on **genome editing** for reproductive purposes will help to guide the ethical discussions that need to form the basis of effective public engagement.

- We welcome the Government's industrial and life sciences strategies, which focus on priorities for economic growth. However, it is essential that such strategies also aim to increase well-being and are responsive to societal challenges. Public involvement is an important means by which societal values can help shape and select **emerging biotechnologies**. Open, frank, and inclusive public discussion can help to determine what is ethically acceptable.
- Individuals affected by research should have the opportunity to be heard, and to be actively involved in shaping research and research policy. This includes those whose situations can potentially make them vulnerable, such as **children**, and people with **dementia** and disabilities.



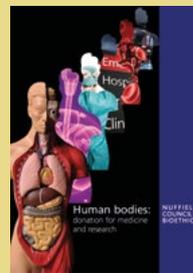
NON-INVASIVE PRENATAL TESTING

NIPT is a major breakthrough in prenatal screening and testing for a range of genetic conditions. We believe women and couples should have access to NIPT and be supported to make informed choices about testing. However, efforts should be made to minimise

any harms that might be posed by the growing use of the technology, including the stigmatisation of people with the conditions being tested for.

3. Promote responsible health policy and research

- People are increasingly expected to take more responsibility to lead healthy lifestyles (see [House of Commons obesity briefing paper](#)). In its focus on prevention, the Government still has important obligations to create conditions that enable people to do this, and to take measures to reduce health inequalities. Several of our reports advocate for a 'stewardship' approach, in which policy-makers carefully balance the need to meet these obligations when devising public health interventions, without coercing people into adopting particular lifestyles.



ORGAN AND TISSUE DONATION

The Government's stewardship role in **organ and tissue donation** should make donation as easy as possible whilst also working to improve public health to reduce demand for organs. Before any legal change is considered to introduce a presumed consent (or 'soft opt-out') system for donation, we believe more evidence of its impact is needed.

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- We have developed an 'intervention ladder' tool for considering potential **public health** interventions. The least intrusive step on the ladder is generally 'to do nothing' or to monitor the situation. The most intrusive is to legislate in a way that restricts the liberties of individuals, the population, or specific industries. Whether an intervention is proportionate depends on whether its objectives are sufficiently important; how likely it is to achieve its aims; and its cost and level of intrusiveness. Restrictive measures, such as banning smoking in public places, are only likely to be successful when supported by the public, and based on high-quality evidence. Similar considerations will be important in other policy interventions, such as 'sugar tax' proposals or the introduction of the **Soft Drink Industry Levy**.



COSMETIC PROCEDURES

There is a need for stewardship from Government with respect to the implications of increasingly popular and accessible invasive **cosmetic procedures**. Regulatory action is needed to ensure users are protected from unethical practice, both with respect to influences that encourage people to consider these procedures

(e.g. social media), and to the development and promotion of procedures. Better data on their use, and more research to improve the evidence base, are needed to improve practice and protect users.



4. Promote international leadership in bioethics

- The UK has long taken an international lead in research and policy. At a time of significant international political change, including Brexit, the UK's leadership should also extend to the ethics of life science and medical research. Because the UK both affects, and is affected by, developments that extend beyond its borders, the Government should continue to take an approach that is not only ethically appropriate for the UK, but also informs and considers those further afield.
- International cooperation to support 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 each other, are crucial in addressing important health needs in the UK and overseas. The conduct of research in a **global health** context is another area in which the UK can show leadership, and one in which we have a continuing interest.

WE ARE A KEY UK PARTNER IN INTERNATIONAL NETWORKS

Our work is considered a benchmark for high-quality bioethical analysis; and our counterparts in other countries often look to us for guidance. For example, our project on **children and clinical research** has led to an increasing focus on the active involvement of young people in the wider research agenda; and our framework for **healthcare research in developing countries** continues to inform research practice worldwide.

- Many of the issues that we examine – such as **emerging health technologies**, standards in **animal research**, and regulations governing **organ and tissue donation** – raise ethical issues that are being considered by policy-makers around the world. The UK should continue to engage internationally, providing leadership in Europe and beyond. In relation to renewable fuels, for example, we believe that UK and European policies should be guided by ethical principles to ensure that biofuel development does not damage human rights and the environment elsewhere.

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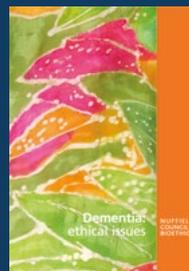


Some key reports



BIODATA

This report looks at the issues raised by data use in biomedical research and healthcare. It sets out key ethical principles for the design and governance of data initiatives, and identifies good practice examples.



DEMENTIA

This report presents an ethical framework to help address problems that arise in connection with dementia care, together with recommendations for policy-makers.



CHILDREN AND CLINICAL RESEARCH

This report looks at how children and young people can ethically be involved in research, and makes recommendations about their roles and responsibilities, as well as those of parents or guardians, researchers, and other stakeholders.