NUFFIELD COUNCIL º™ BIOETHICS

Making ethics matter Strategic direction 2024-2028

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Foreword



By Danielle Hamm, Director, and Professor Sarah Cunningham-Burley, Chair

Developments in biomedicine are key to tackling some of the pressing health issues in the world today. Yet they can raise profound ethical challenges. The Nuffield Foundation established the Nuffield Council on Bioethics (NCOB) in 1991 to help identify, meet and tackle those challenges. In 1994, the Medical Research Council and Wellcome became co-funders who shared the same ambition for us.

For over 30 years, NCOB has identified and tackled some of the most complex and controversial issues facing societies across the globe. We have brought clarity to complexity and mapped practical ways through seemingly intractable dilemmas. This has shifted public understanding and led to lasting policy change in the UK and internationally in areas ranging from public health to assisted reproduction and genome editing. However, there is more to be done if we are to succeed in putting ethics at the centre of decisions about biomedicine and health so we all benefit.

As we embark on this new strategy, we have taken stock of the landscape we are working across and the lessons we have learnt. The ethical challenges brought about by the COVID-19 pandemic forced us to think differently about what NCOB does. Previously, we focused on scientific advances, but COVID-19 demanded we respond to largescale societal challenges relating to biomedicine, health and social wellbeing; these challenges show no sign of reducing. The climate crisis, an increase in mental illness and the pace of developments exceeding that of current regulation are just a few of the issues we face, and all of these are both local and global in their nature and potential impact. As such, we have recognised that the shift to embrace the wider health relevant social challenges we experienced during COVID-19 will need to remain as we seek to tackle today's challenges.

The field of bioethics is multifaceted, covering academic centres, policymakers, practitioners, industry, and professional and civil society groups – it is relevant to us all. As the only body in the UK with an overarching bioethics remit, we occupy a distinct and unique position within this diverse landscape. Our independence means we are ideally placed to tackle the issues, map the ethical terrain, and chart clear routes to tangible policy solutions and actionable, positive change.

Delivering on this new strategy will require us to adapt our ways of working – maintaining our ability to provide robust and in-depth analysis of a topic, but diversifying our outputs and increasing our wider engagement to ensure we are providing timely insights and advice to key decision makers. We believe NCOB is well equipped to make this change and that we will see real power from having that dual focus: we will combine in-depth, multidisciplinary research and deliberation with tailored outputs that have real-world impact on debate, policy and practice.

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Our purpose

The Nuffield Council on Bioethics is a leading independent policy and research centre, and the foremost bioethics body in the UK. We identify, analyse and advise on ethical issues in biomedicine and health so that decisions in these areas benefit people and society.

Our vision

Ethics is at the centre of decisions about biomedicine and health **so we all benefit**.

Our approach to ethics

Our starting point is **evidence about what matters to people** concerning the issues at stake. Through research, engagement, consultation and deliberation, we develop ethical frameworks and principles that deliver real-world solutions.



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Rigour

Our approach to ethical analysis is multidisciplinary and deliberative. We draw on a wide range of expertise and experience and use the best available evidence.

Independence

We set our own agenda and select our own topics, methodologies and outputs. We do not represent any particular group or view.



Relevance

We explore things that matter to society so we can support real-time policy developments and debates as well as anticipate those coming down the line.



Transparency

We are open about how we conduct our work, and our outputs are accessible and relevant to our audiences.



Inclusiveness

We engage with a wide range of voices and views and are committed to increasing the diversity of the people we work with. We create safe and welcoming spaces for deliberation.

Sustainability

We manage our organisation with a focus on contributing to environmental sustainability and reducing our carbon footprint.



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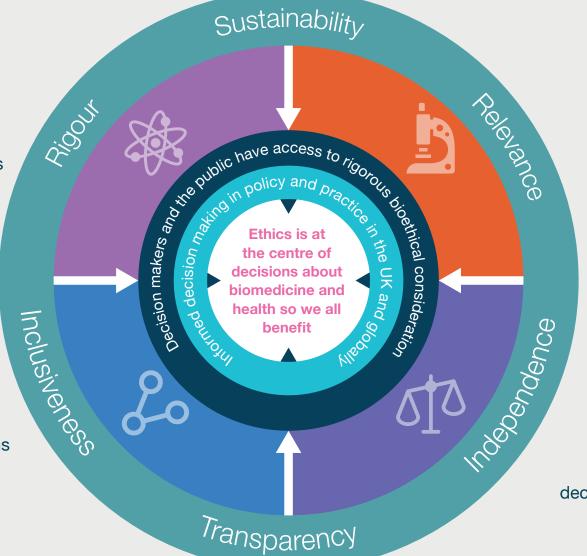
Our impact model



Anticipate developments and trends that pose fundamental ethical questions to society



Build greater connections across bioethics networks to strengthen the voice of bioethics



Undertake and

communicate rigorous ethical analysis in a way that is clear and relevant



Demonstrate the value of ethics to society and decision makers and embed ethics in policymaking

The things we will do to achieve our vision

04

We will increase our focus on embedding ethics in policymaking.

01

We will shift our focus to issues at the intersection of scientific innovation and societal challenge.

02

We will evolve our horizon scanning so we are even better placed to identify and anticipate ethical challenges and dilemmas before they arise.

05

We will cultivate bioethics networks to strengthen the voice of ethics in biomedicine and health policy in the UK and internationally.

06

We will identify priority areas for our work so that we focus on the most important challenges facing society.

03

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.

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Our goals

Goal 1

Enhancing our capability to anticipate scientific developments and health trends that pose fundamental ethical questions to society.



Goal 2

Undertaking and communicating rigorous ethical analysis in a way that is clear and relevant to decision makers and to the public.



Goal 3

Demonstrating the value of ethics to society and decision makers in order to embed ethics in policymaking.



Goal 4

Building greater connections across bioethics networks to strengthen the voice of bioethics in policy and public debate.



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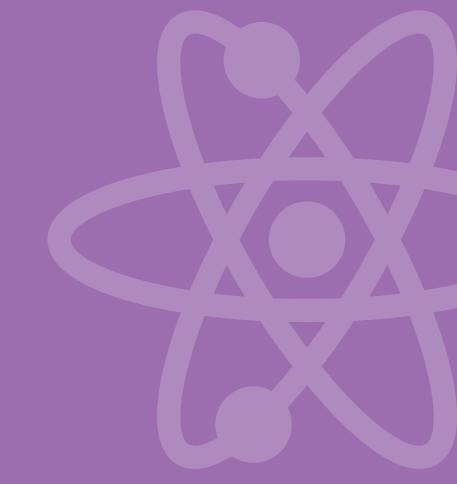
Our goals

Work with us

Goal 1: We will enhance our capability to anticipate scientific developments and health trends that pose fundamental ethical questions to society

We are the only UK organisation with a broad bioethics horizon scanning programme and we have used this approach to consistently monitor, engage with or convene a wide range of disciplines, sectors and expertise. This has helped us to identify and anticipate where future developments in biomedicine and health have the potential to impact society. These insights are then used to define our programme of work, enabling us to successfully influence the policy agenda.

We will build on what we have achieved, developing a deeper and more systematic approach to horizon scanning, which will be increasingly global in scope. This will inform our topic selection and ensure all our projects are forward-looking. In time, we will position our horizon scanning outputs as a guide for other organisations across the science health and policy sectors.



Goal 1: We will enhance our capability to anticipate scientific developments and health trends that pose fundamental ethical questions to society

We will know we have succeeded in our goal when:

- our work anticipates and shapes thinking on how new biomedicine and technologies are developed and used, or how health systems respond to societal challenges
- our foresight is incorporated into the agendas of major research funders, policymakers and other influential organisations.



Goal 2: We will undertake and communicate rigorous ethical analysis in a way that is clear and relevant to decision makers and the public

Up until now we have focused our energies on either building expertise and extensive engagement over several years so that we can produce detailed, in-depth reports with policy recommendations, or synthesising evidence and views so we can compile rapid responses to inform urgent and emergent issues. Both approaches have proved valuable.

Now we plan to diversify our outputs, tailoring them to the requirements of the topic, the change we want to make and the audience we are seeking to inform or influence. Our work will remain rigorous and multidisciplinary. We will be informed by our past work and horizon scanning insight, and take opportunities to co-create new work both nationally and internationally, leading and listening to achieve change.



Goal 2: We will undertake and communicate rigorous ethical analysis in a way that is clear and relevant to decision makers and the public

Our outputs will fall into the following broad categories:

• Rapid responses

Agile, timely and targeted outputs that are short and focused, seeking to inform thinking on current policy problems. These will include rapid policy briefings, consultation responses, commissioned essays and opinion pieces.

• Shaping agendas

Outputs that map the ethical terrain for emerging issues, identifying changing attitudes, highlighting under-researched areas for future thought, and contributing our expertise in policy settings. These will include briefing notes, public dialogue findings, reports, research syntheses, commentary, partnerships and convening.

• Setting agendas

Outputs that seek to set the policy agenda and initiate wider thinking by drawing upon extensive public and professional engagement, deliberation and synthesis. These will include outlines of research, literature reviews, public dialogue findings, think pieces, reports and policy recommendations.

This new approach will mean we can combine robust, high-quality research with clear, accessible outputs that have a real-world impact on debate, policy and practice.



Goal 2: We will undertake and communicate rigorous ethical analysis in a way that is clear and relevant to decision makers and the public

We will know we have succeeded in our goal when:

- our work informs policy, law or practice, and our recommendations are implemented
- our work shapes thinking and drives debate and is cited in academic articles, parliamentary debates and media coverage
- we are invited to share our thinking and contribute to policy-focused initiatives.



Goal 3: We will demonstrate the value of ethics to society and decision makers in order to embed ethics in policymaking

We have a strong track-record of influencing and supporting decision makers. Most recently we helped change the UK government's approach around genome editing in farmed animals, enabling the **issues to be seen as ethical as well as scientific**. We want to see this change extended and for ethical dimensions to be considered throughout the government's science and health policy agendas.

Our work will show how ethics can be built in to drive policy that successfully balances competing interests, advances health and wellbeing and is resilient to future threats.

Goal 3: We will demonstrate the value of ethics to society and decision makers in order to embed ethics in policymaking

To achieve this we will be working to deliver two types of impact:

- **instrumental** influencing the development of policy, practice or service, including shaping legislation and changing institutional behaviour
- **conceptual** enhancing understanding of the issues and reframing debates.

We operate in complex environments and know from experience that the change we seek takes time and demands sustained commitment. Our impact and engagement strategies will see us build on our influential relationships and developing the practical tools decision makers need. We will respond flexibly to the opportunities we have and use our corporate channels and journalist contacts to inform and influence public debate. **Goal 3:** We will demonstrate the value of ethics to society and decision makers in order to embed ethics in policymaking

We will know we have succeeded in our goal when:

- ethics is embedded in the delivery of science and health policy in the UK
- ethical concepts, language and expertise are used positively by decision makers and researchers when talking about biomedicine and health
- we see increased focus on ethics in the media.

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Our goals

Goal 4: We will build greater connections across bioethics networks to strengthen the voice of bioethics in policy and public debate

The COVID-19 pandemic showcased the need for a wider understanding of the relevance of ethics to public life and a more coordinated method for delivering ethics advice to policymakers.

We believe we can establish a recognisable point of entry to UK bioethics expertise for decision makers, journalists, commentators and others. Our unique position in bridging bioethics research and policy means we are well placed to play a convening role for those working in bioethics in the UK and to bring people together in new ways. But we cannot stop there; ethical implications are not limited by national borders. As such, we will use our position as a well respected and active member of the international bioethics community to develop new partnerships and connect bioethicists globally to share learning and approaches.

By establishing these deeper connections between people and organisations, we will strengthen the voice of bioethics in policy and public debate. We will also facilitate the flow of knowledge and skills, and enable collaboration on shared tasks, such as horizon scanning. **Goal 4:** We will build greater connections across bioethics networks to strengthen the voice of bioethics in policy and public debate

We will know we have succeeded in our goal when:

- bioethics networks in the UK and internationally are more connected and inclusive
- there is a shared understanding of the value of ethics in science and health policymaking
- we are at the forefront of international bioethics debate and take opportunities to share knowledge, to learn with and from others, and to have influence.

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Our priority areas

Through horizon scanning and engagement with experts, we have identified three priority areas for the first two or three years:

Priority 1:

Reproduction, parenthood and families



Priority 2: The mind and brain



Priority 3: The environment and health



These three areas represent some of today's most urgent and important developments in biomedicine and health. They each raise critical ethical, social and policy issues on which we can offer a distinctive contribution.

Of course, we recognise that we cannot anticipate everything. It will remain important for our horizon scanning to constantly feed into our work planning processes so that we can regularly review our priorities to ensure we are focused correctly.

Issues that cut across our work – such as health inequalities, use of health data, and commercial drivers in research – will be considered in the context of each of the priority areas. And we will retain the flexibility and capacity to respond to other developments, outside of our priority areas, as they emerge. We will take up opportunities to apply our past work to current policy debates, acknowledging that real change often requires long-term engagement.

Our selection criteria

Achieving change

Work in this area will put ethics at the centre of decisions about biomedicine and health

Timeliness

There are good reasons to do this work now



Distinctiveness

We have the knowledge, skills and resources to deliver work in this area, where others do not



Priority 1: Reproduction, parenthood and families



We will continue to build on our significant profile and reputation in this area by examining emerging developments and ethical issues such as:

- the creation, screening, selection, modification and implantation of reproductive tissue, gametes and embryos for the purpose of human reproduction
- gestation, including assisted and artificial gestation technologies, and labour
- parenthood and the concept of family, including questions around access to reproductive technologies and health care, as well as wider societal developments around family forms.

We will explore how current legal and policy frameworks might respond to future trends and developments, and how ethics should be embedded in this process.

There are several upcoming opportunities for us to shape policy, such as during the **review of the Human Fertilisation and Embryology Act**. This is likely to ignite discussions that will re-open some of the deep ethical questions around reproductive rights and responsibilities that have been less prominent in policy discourse in recent years.

Priority 2: The mind and brain



We will consider developments in mind and brain research and how they intersect with social and policy contexts. We will explore ethical issues raised, such as:

- new approaches to brain research including the development of neural organoids and computational models of the brain
- emerging evidence bases for the care and treatment of people with neurological and mental health conditions
- interventions that could fundamentally alter and augment our moral and cognitive capabilities.

We will provide targeted and timely advice in response to live policy questions in the UK context, which may include those around the regulation of brain tissue and data, as well as medical devices used in neuro- and mental health care.

We have identified a need for ethical guidance surrounding ethical research, patient safety and security of brain data. The pace of research in this area is generating new ethical questions around privacy, agency, autonomy and identity, which require exploration and deliberation.

Priority 3: The environment and health



The interaction between the environment and health raises ethical questions relevant to both environmental and health policy decisions. These questions are likely to intensify with the emergence of new technologies, which can and will impact the environment.

With the environmental crisis at the forefront of political and public consciousness, we will use our independence and convening powers to bring multidisciplinary and multisector expertise together to build our knowledge base, anticipate future trends, and develop ethics tools for decision makers.

Developments and issues that could be examined in this priority area include:

- the impact of climate change on health
- the environmental impact of research and healthcare practice

- our responsibility to consider global and non-human health interests
- emerging technologies that both pose risks to the environment and present potential solutions, such as genetic modification techniques e.g. the use of gene drives for insect control, geoengineering and de-extinction.

We will use a variety of approaches to apply ethical thinking to these issues, drawing on concepts such as global justice, solidarity, responsibility, intergenerational equity and the 'One Health' approach.

Our international profile and networks, and our reputation for producing high quality work in related areas such as genome editing in farmed animals, mean we are well placed to facilitate conversations on a global level and partner with key stakeholders.

Work with us

NUFFIELD COUNCIL ON BIOETHICS

Work with us

Our expertise

We are a small, uniquely positioned organisation made up of skilled, creative and committed people. Our council members bring rich and diverse expertise. They make up a deliberative body that brings intellectual credibility. Our executive team members are skilled professionals spanning the fields of bioethics, policy, public affairs, science and communication. Together, we are partners in the development of our projects and outputs.

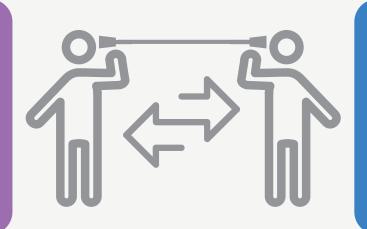
We rely on multidisciplinary excellence to deliver our work. We regularly draw on our council and executive team's expertise, and we use our convening power to bring together the skills, expertise and knowledge of others, ensuring that the insights of those most affected by developments in science and health are embedded in our work.



Our engagement is two-way

Informing our work

Consultation and engagement help us understand what matters to people.



Influencing externally

We use our networks to maximise our influence, encourage the uptake of recommendations and embed ethics in policymaking.

Our engagement is bespoke and meaningful: we listen and respond to what we hear. Deliberation will always be vital to our work and outputs. As such, we remain committed to increasing the diversity of the people we work with so we can continue to create safe and welcoming spaces for deliberation. Sometimes the best way to achieve our goals is to work in partnership, and this is something we will continue to explore and develop over the next five years. We have an open-door policy so, if you have an idea of how we could work with you, please get in touch as we would love to hear more.

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