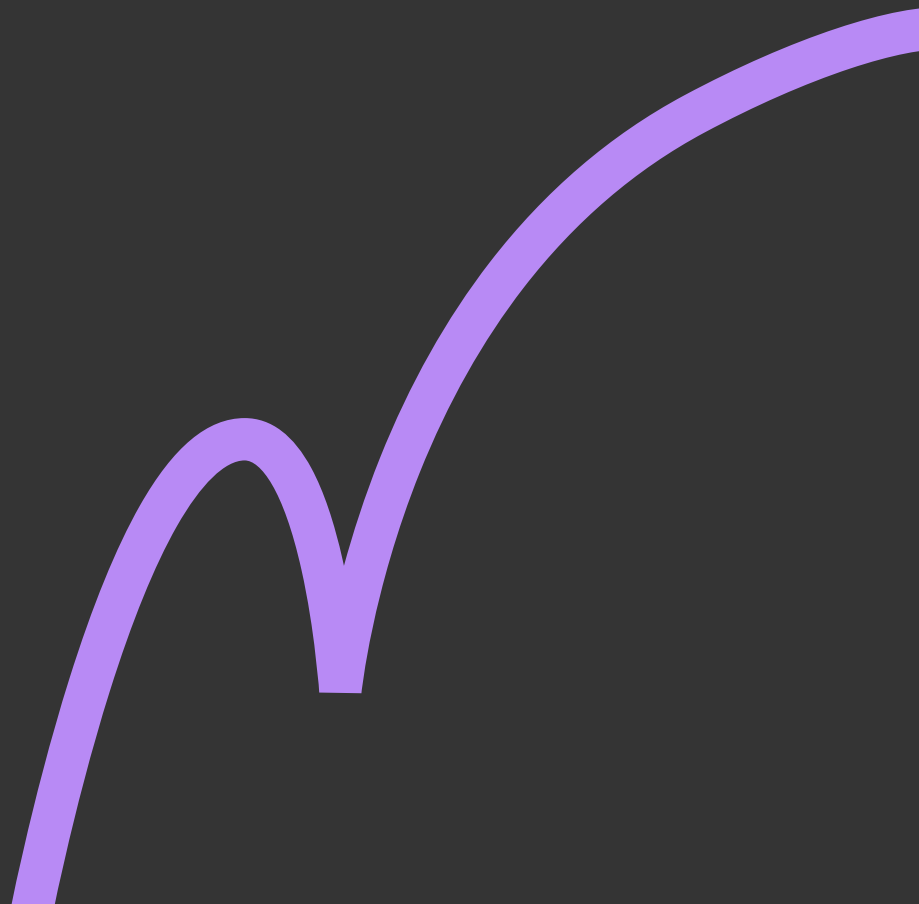




# Impact Report

2024



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# Foreword

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Danielle Hamm, Director



Professor Sarah Cunningham-Burley, Chair

At the Nuffield Council on Bioethics (NCOB) we are working to put ethics at the centre of decisions regarding biomedicine and health. By bringing ethical considerations more overtly into policy development we can create solutions that are resilient to future trends, reflect public values, and result in a better, more equitable experience for all.

Our 2024-28 strategy, **Making ethics matter**, strengthens our commitment to undertake rigorous ethical analysis and to build the networks needed to amplify bioethics' influence in policy and public discourse.

We believe the greatest impact is achieved when we work dilligently and inclusively to explore the topics that matter to society. That is why, within our strategy, we announced a shift in our focus towards the intersection of scientific innovation and societal challenge – developments which have the potential to change the way we live, how we treat illness, or indeed how we think about being human. We have also tailored our outputs to cater more towards policymaker needs. And we have adopted a greater degree of flexibility to enable us to respond to current and emerging issues.

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**“ It can take time for our work to have its biggest impact. Many of our achievements in 2024 have their roots in projects that we have delivered in previous years. It has been great to see our past work driving real world change, alongside our new workstreams taking shape.**

In 2024 we socialised our ambition and introduced new priority areas: reproduction, parenthood and families; the mind and brain; and the environment and health. One of our most substantive pieces of work has been an assessment of the ethical and regulatory implications of human stem cell-based embryo models. Our recommendations pave the way for a legal framework that would enable the science to develop in ethically robust ways for social benefit. We look forward to building on this in the year ahead.

We have taken strides to evolve our horizon scanning and foresight capabilities, ensuring that we are well placed to anticipate and advise on emerging trends. By publishing our [2024 Horizon Scan](#) in a new time-framed presentation, we are now able to indicate when identified topics are likely to need attention regarding the ethical issues they raise.

Thanks to the flexibility built into the ways we work, we have been able to engage with topics outside of our priority areas. We commissioned England's first Citizens' Jury on assisted dying, to gather the evidence needed for a well-informed national conversation on this important and timely issue. Our focus in 2025 is to ensure those involved in shaping the Terminally Ill Adults (End of Life) Bill are aware of this evidence and draw on it to ensure the Bill reflects public priorities.

We have also progressed our involvement in developing a 'gold standard' for genomics healthcare and research as set out in the Governments' Genome UK strategy, working with stakeholders to map the next steps.

We know that for some, ethics can be considered a hindrance to progression. Through our work we will continue to demonstrate how ethics can support and enable trustworthy innovation that benefits us all. We are proud of what we have achieved this year and would like to thank everyone who has worked with us to make it possible.

# Year in numbers



Launched **8** publications and a new website



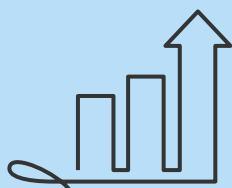
Participated in more than **50** UK events



Delivered **15** international presentations



Reached an estimated **4 billion** people through media coverage



Increased our LinkedIn community by 33% to **2,640** followers



Recorded **175,000** visits to our website



Secured **£1 million** funding for work on research using human embryos

# Priority area work

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## Our priority areas

Through horizon scanning and engagement with experts, we selected reproduction, parenthood and families; the mind and brain; and the environment and health as our three priority areas of work for the initial 2-3 years of this funding period.

Each represents urgent and important developments in biomedicine and health, and raises critical ethical, social and policy issues on which we can offer a distinctive contribution.





## Priority 1: Reproduction, parenthood and families

Research capabilities to better understand human reproduction and development are advancing at pace, raising a range of ethical issues.

This year we established an interdisciplinary expert working group to assess the ethical and regulatory questions raised by research using human stem cell-based embryo models (SCBEMs).

SCBEM is an umbrella term for a range of structures created from human stem cells which resemble or replicate aspects of embryonic development. These stem cells are derived either from embryos or through the reprogramming of cells from other human tissue such as skin or blood cells.

As a research tool, SCBEMs have the potential to bring public benefit through new insights around early human development. However, debate about their status – for example in relation to human embryos – and how they should be used, has given rise to questions about whether and how they should be regulated.

Our **resulting report**, published in November 2024, recommends a phased approach to the governance of SCBEM research to provide reassurance that ethical ‘red lines’ such as transferring a SCBEM into a human or other animal, or developing models that can feel pain, are not crossed.

As we enter 2025 we will be convening funders, regulators and Ministers to raise further awareness of our report and to map out next steps for how our insights can be best used in the Government’s efforts to culture an ecosystem of responsible innovation that is responsive to public views. In particular, we will be raising awareness of the need to review the Human Fertilisation and Embryology Act 1990 which governs fertility research and treatments in the UK, to ensure that regulators can be more agile and responsive to rapid scientific advances in this area.

We have also secured a substantial grant from Wellcome to undertake a programme of work which aims to provide decision makers with robust, independent evidence on embryo culture limits for research using embryos. This project will commence in early 2025 and will involve exploration of scientific developments and ethical debates in the UK and internationally, as well as deliberative dialogue to understand public views and values surrounding human embryo research and its limits, to help inform legislative reform.



## Priority 2: The mind and brain

Developments in this area are diverse and far reaching. We are initially focussing on three areas: neural organoids; neurotechnologies; and genomics, neuroscience and education.

Human neural organoids are used to model aspects of the developing brain. They are promising research tools that could help improve understanding of brain conditions and treatments. Research is in its early stages, but moving at pace. Key ethical questions include whether the moral and legal status of neural organoids warrant special ethical consideration, and how to design informed consent processes for research.

In March 2024, we published a [briefing note](#) providing an evidence-based, accessible summary on developments and ethical issues that may arise as this research progresses. Following this, we opened a call for evidence so that we could assess and advise on the identified ethical and regulatory concerns. A final report will be published in Spring 2025.

The use of neurotechnologies in healthcare raises ethical questions around informed consent, voluntariness, risk, environmental impacts, privacy and (in)equity. More than a decade on from our [previous report](#) looking at possible benefits and unintended consequences of technologies that intervene in the brain, the range of neurotechnological interventions has expanded hugely, both in terms of capabilities and applications. These include medical treatments such as neuromodulation which can involve implanting devices in the body, to non-invasive brain stimulation devices. Direct-to-consumer devices are also more prevalent now.

In October 2024, we [opened a call for evidence](#) to help assess significant developments in the last decade and explore current perspectives on the pressing ethical issues in relation to neurotechnology use in healthcare. Specific areas of focus within the broad field of neurotechnology will be confirmed in early 2025, using insights from our call for evidence.

In 2024 we partnered with the Nuffield Foundation on a project exploring genomics and neuroscience in education. Genome-wide association studies have identified thousands of genetic variants associated with social and behavioural traits, used to develop predictive tools such as polygenic indices (PGIs). In a research context, PGIs offer potential to help untangle the multifactorial roots of educational disparities across generations and explore genetic influences in more depth. However, significant ethical questions arise in this research and possible translation into classroom applications; there are potential risks that PGIs could be used to draw harmful conclusions, and further reinforce inequities experienced by marginalised groups.

An upcoming scoping paper will be published in February. This will outline key scientific developments in this area, and touch on ethical issues that arise. We have further work planned in 2025 to take a deeper dive into the ethics of using PGIs in education.





### Priority 3: The environment and health

Environment and human health interact in ways that are being amplified through the climate crisis. Extreme weather events and air pollution have direct and indirect physical health impacts, and there is growing evidence that climate change has a negative effect on mental health. As new technologies are developed that impact the environment, or that aim to mitigate the effects of climate change, ethical issues can arise or intensify.

Our newly published [report](#) highlights the need to recognise, consider and address the intersection between climate change and health and describes how embedding ethics from the outset can support policy and decision makers in the UK to develop urgently needed fair and effective climate measures. Ethics can ensure that competing interests and potential trade-offs are identified and addressed within their work to tackle the health impacts of climate change. For example, trade-offs may exist between:

- short-term health outcomes and negative long-term climate outcomes
- human and non-human interests
- benefits to current generations and to future generations and
- intranational, national and international priorities.

While making the case for these conclusions, the report outlines what challenges need to be overcome when developing and implementing climate measures. This includes addressing global injustices and making decisions on how best to allocate resources and expenditure.

Climate change is a global challenge, with the impacts often disproportionately falling on low and middle income countries. This is why we've joined an international collaboration which will explore developing guidelines for national and research ethics committees for research addressing the health impacts of climate change. In particular, we are investigating the right to an open future. We are working with a range of partners from Belgium, Mexico, Bangladesh, Barbados and the Ivory Coast and West Africa.



# Spotlight projects

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## Assisted dying

In October 2023 we announced we were commissioning England's first Citizens' Jury to explore public views on assisted dying. This provided policymakers with their first opportunity to understand what people in England think about assisted dying and how their reflections may be shaped by hearing evidence and engaging in deliberation.

In 2024, we published [two reports](#) summarising the jury's conclusions, their recommendations, and some of the influencing factors behind their opinions. We also shared findings from [two nationally representative surveys](#), which provided further assessment of the views of a broader public. Taken together, our work indicates that people in England support legalisation for assisted dying when it is limited to adults with a terminal illness and with capacity to choose. We found that a person's view on assisted dying is shaped by the level of confidence they have in effective safeguarding, and the imminence to which they have been confronted with their own or a loved one's death. We also found that the public were united in wanting palliative care and social care services to be improved, whether assisted dying is legalised or not.

At the end of 2024, MPs voted in favour of MP Kim Leadbeater's Terminally Ill Adults (End of Life) Bill for England and Wales passing onto committee stage. In 2025, we will work to ensure those sitting on the Bill committee are aware of our evidence so that they can use it appropriately. In Scotland, the Assisted Dying for Terminally Ill Adults (Scotland) Bill was introduced in by Liam McArthur MSP in March 2024.

Responding to our NCOB work, Liam McArthur said:

**“ I believe this has been an important piece of work on a fundamental issue that deserves detailed and nuanced scrutiny.**

**Hopefully this will help further raise public awareness and debate, and give more confidence to fellow parliamentarians that the public believe that a change in the law is the right choice for dying people.**

**I would urge parliamentarians in both Westminster and Holyrood to keep these results at the forefront of their thoughts while considering the proposals before them from myself and Kim Leadbeater.**

## Genomics

We believe the UK Government's ambition of a 'gold standard UK model' for genomics can only be achieved if ethics is truly embedded across policy and the practices of everyone involved in genomic research and healthcare. Our work in 2024 focussed on mapping existing ethics guidance in the sector in order to identify areas where further work is needed.

In January we published our **second report** in this programme of work, which made the case for coordinated action to address some gaps in ethics guidance that we identified. We concluded that having a UK-wide coordinating role to oversee the development of further resources would help to ensure that these actions can be taken forward effectively.

Our proposals were endorsed by the sector and presented to the National Genomics Board. Following this engagement, we are now working with key stakeholders on the next steps and hope to announce more in the first quarter of 2025.

## Disagreements in the care of critically ill children

Back in September 2023, we published an **independent review** into the causes of disagreements in the care of critically ill children in England, commissioned by the then Secretary of State for Health and Social Care. In January 2024, the Government commissioned a Taskforce to implement all our recommendations. We act as advisor to that Taskforce, which began its work in mid-2024.

In May 2024, the Ministry of Justice held a roundtable to discuss our recommendations on how court processes could be made easier for those involved in disagreements cases. The event was attended by senior stakeholders, including Mrs Justice Theis who has presided over high-profile cases. The Ministry of Justice has subsequently committed to exploring how less adversarial court models could be used in these distressing situations.

Lastly, we're pleased to note that NHS England has introduced regional conflict champions, resources and training for healthcare professionals on conflict management. These steps should mean that, those who are involved in disagreements between families and healthcare teams are better supported to navigate them more constructively.

## Genome editing and farmed animal breeding

Our 2021 report on genome editing technologies in **farmed animal breeding** continues to have impact on policy almost four years on. We concluded that any introduction of genome editing technologies – which are used to alter DNA sequences to attempt to secure certain traits in animals – into livestock must be aligned with public and animal interests and aimed at supporting a sustainable, high-welfare farming system.

We initiated **public dialogue** to help provide insight on public views to inform the Genetic Technology (Precision Breeding) Bill (now Act) 23, which sets out a framework for the governance of precision bred organisms including crops and animals. We felt there was an important distinction to make between the use of genome editing in crops and its use in animals.

Looking back to the **initial Government consultation** in 2021 on the regulation of genetically modified organisms – which included both plants and animals within its scope – our work has proved influential in guiding how the Government has approached changes to legislation in relation to the genetic modification of farmed animals. We have ensured that ethics was prominent in the debate and that the Act has provisions relating specifically to animals, in line with recommendations made in our report. Furthermore, in September 2024 the **Government announced** new laws to support precision breeding technology in crops, but farmed animals were not included within the scope of this legislation, a clear indication that legislation relating to genome editing in farmed animals will be treated separately.



# Evolving our horizon scanning and foresight methods

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As part of our 2024-28 **Making ethics matter** strategy, we committed to evolving our horizon scanning (HS) methods – strengthening the insights we use for topic selection and boosting our offer to the bioethics and policy community who value our annual HS infographic.

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In 2023, while scoping new methods we could bring into our HS work, we identified an unmet need in foresight methodology. While there is an array of approaches you can apply to explore the future, none have ethical considerations embedded overtly into them.

To address this, in 2024, we embarked upon an ambitious project to develop an **ethical lens** for HS and foresight – working with UK policymakers and international foresight experts to create or adapt four foresight tools to become more ethically grounded.

These approaches we are developing include:

- 1 A **rapid ethical assessment tool**, which will enable the rapid surfacing and consideration of ethical implications within an acute policy development process.
- 2 An ethically sensitive sandbox, which will assist regulators in their design of pro-innovation frameworks that can help science thrive while maintaining public trust.
- 3 A series of ethical tipping points, which will identify where in the innovation pipeline ethical considerations would be of most benefit.
- 4 A moral deliberative tool, which will create a new way to deliver and facilitate a future scenario workshop, enabling participants to grapple with ethical implications.

The ambition is to socialise these among key decision-makers, enabling them to weave ethical consideration into research and policy development much earlier than it currently is. We will also utilise them in our own HS work, strengthening the insights we gather and use.

Our [report assessing the ethical landscape of SCBEM research](#) highlighted the potential for a regulatory sandbox to support this space. The idea of a sandbox is to give space for an innovative technology or advancing research capability to be explored and guided by a regulator (or regulators) who would likely govern it, were it to come to market. In its essence, a sandbox can either be designed to assist in testing out different policy proposals, or it can be applied as a type of foresight exercise, exposing where existing regulatory frameworks will be outpaced and could prevent new technologies from reaching their desirable applications. In 2025, we will be working with UK regulators to develop our ethically sensitive sandbox.

We [tested a pilot of our 'moral deliberative tool'](#) at the 2024 Dubai Futures Conference, which gave us useful insight in how to develop this scenario-based approach. In 2025, we will be testing a beta-version of this tool with our own Council and two policy teams.



In 2024, we have invested considerable effort to evolve how we analyse and present our HS insights.

We know our annual HS output is valued by the bioethics and policymaker communities, but a frequent piece of feedback was that the graphic would be more useful if it could provide a way to prioritise or compare the topics identified. This, combined with insights gathered through our 'ethical lens' project, led us to produce a 'time-framed' evolution of our scan.

Each of the 51 topics identified in the 2024 Horizon Scan was assessed for its political context, regulatory concern, amount of funding and level of public awareness and interest. We used this insight to assign a timeframe, for example, a topic that scores high across all parameters was placed into the 'short' timeframe, as we believe there are signs to suggest it could raise ethical implications that will need addressing within the next five years.

We published [this new iteration](#) in November, asking our stakeholders to tell us what they think. So far, feedback has been extremely positive with many saying this new presentation style will provide a useful resource.

In 2025, we will be building upon this work by exploring how we can bring international insights into our work to meet an ambition of creating a global horizon scan.

# Future vision

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We are extremely proud of all that the NCOB has achieved in this first year of our 2024-28 strategy, and we want to thank everyone who has helped to make this possible.

As we look forward to 2025 and beyond, we will build on this strong start, further raising our profile with key policy audiences and sharing our ambition for ethics to be at the centre of decisions so we all benefit.

Our research programme – including our published work on stem-cell based embryo models and our planned work on embryo culture limits – is designed to support decision makers to make evidence-based policy. We are calling on the Government to commit to opening the Human Fertilisation and Embryology Act to enable regulation in this ethically sensitive area to keep pace with scientific development. Doing so will likely ignite important questions around the status of the embryo and broader reproductive rights that have been less prominent in policy discourse in recent years.

Developments in neurotechnology continue to progress, attracting considerable public interest and offering potential to bring benefits to individuals and wider society. Our work to date has shed light on the challenges facing the research community in navigating the fragmented regulatory landscape and on the ethical challenges arising as both neural stem cell-based models and neurotechnological interventions in the brain become more complex.

Our work in 2025 will prioritise bringing ethical clarity to these fast-moving areas, exploring options for future regulation and providing timely guidance to those involved in the research, adoption and governance of neuroscientific innovations.

We have started to bring bioethics into the complex world of dilemmas and decisions surrounding climate change, but as COP29 demonstrated, issues of fairness and equity are intensifying. So, our priority now will be to demonstrate how ethical analysis can support policy making at the intersection of climate change and health. For example, we will build on our new report, which explores many issues including NHS net zero and geoengineering, to ensure that ethics is embedded from the outset of climate-related measures. We will also get our teeth into an international collaboration to explore what guidelines should support ethics committees when considering climate change and health.

The expansion of our horizon scanning and foresight capabilities has attracted a high level of engagement from policymakers in 2024, who see it as a mechanism both to embed ethics in decision-making and create policy that is resilient to future trends. We believe this will be further nurtured by our development of a suite of practical tools that are grounded in ethical consideration and capable of assisting policymakers in their efforts to be more ethically informed.

Just as science and innovation is international in scope and impact, so are the bioethical questions resulting from it. Whilst we have always been active on the international stage, in 2025 we plan to think harder about what international bioethics means, how we can support it and how best to partner with our international stakeholders to enable effective knowledge exchange. We look forward to developing our international work in 2025 and engaging with the international bioethics community to support partnership working.

2024 has marked a turning point for NCOB, as we embrace our five-year strategy and become more agile in our ways of working. None of this would be possible without our excellent team – both on Council and in the Executive – and our outstanding partners. We are grateful to them and every single person who has engaged with us and our work in some way. We anticipate even greater success as we work together to embed ethics in some of the most complex and controversial issues facing societies across the globe.

**Danielle Hamm and Professor Sarah Cunningham-Burley**







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