



Foreword

By Professor Dave Archard, Chair of the Nuffield Council on Bioethics

This report summarises the work undertaken by the Nuffield Council on Bioethics (NCOB) from 2018 to 2023.

It has been an exciting six years to be chair. Our work has delivered real, tangible impact with the COVID-19 pandemic in particular presenting us with an acute moment in time to demonstrate why ethics cannot be an afterthought and why it must be embedded in policy decisions, particularly when they concern bioscience and health.

Beyond the pandemic, I am pleased to witness the growing success that the NCOB has had in number of policy areas. These have included: initiating a parliamentary inquiry on commercial genomics, which led the Government to commit to tightening regulation of direct-to-consumer genomic testing; being commissioned by the Secretary of State for Health and Social Care to undertake an independent review into disagreements in the care of critically ill children; and placing ethics firmly within the parliamentary debate around genome editing and farmed animals.

It would be remiss of me not to acknowledge that these successes have occurred at a time of increased pressure and substantial shifts in the landscape we are working across. In some respects, it could feel as though our world has more borders and boundaries than ever; views are polarised, economies are fragile, and emotions can run high. One positive to emerge from the COVID-19 pandemic was that we saw how scientific challenges bring us closer together as a species inhabiting a single world. The biomedical problems facing humanity necessitate a borderless solution, and we must work better together to take the global perspective.

In the seemingly ceaseless effort to chase scientific progress, we may face the real prospect of not just significant changes to what it means to be human, but existential threats to humanity. Rapid advances in science and technology can never mean that ethics is left behind, for in the absence of an ethical backbone we risk causing great harms, further marginalising those groups already overlooked and exacerbating the inequalities that disfigure our modern world.

I would like to thank everyone who has worked with us over these past six years. Together, I believe we have helped bioethics to become better recognised for its importance. The challenge now is to ensure that it is firmly embedded in policy and recognised as crucial by our future policymakers. The NCOB is well placed to further its ambition of placing ethics at the heart of decisions. I look forward to handing over my chair to Professor Sarah Cunningham-Burley in January, and seeing what can be achieved in the next five years.



Rapid advances in science and technology can never mean that ethics is left behind, for in the absence of an ethical backbone we risk causing great harms, further marginalising those groups already overlooked and exacerbating the inequalities that disfigure our modern world.

Our purpose and values

The Nuffield Council on Bioethics is an independent body that examines and advises on ethical issues arising from developments in biomedicine and health. We work to inform policy and public debate through our timely considerations, believing that solutions have the biggest benefit for people and society when ethics is embedded in policymaking.

Four value categories underpin our work:

Quality, rationality and rigour

Our work is based on the best evidence available, draws on a wide range of expertise, is supported by careful and comprehensive analysis and delivers to the highest possible standards.

Transparency and inclusiveness

We strive for our work to be clear and accessible to diverse audiences, favouring no single approach to bioethics and welcoming the expression of all views.

02 Independence

We consult widely but remain free to select the topics, and the content, of our outputs. The members of our council and working groups are selected for their individual qualities and expertise, not to represent a particular group or view.

Relevance and timeliness

We aim to work on issues that are of the greatest significance to society so that our outputs can support policy developments and debates where it matters most.

Six years in numbers

During 2018–2023 we:

Published

7 in-depth reports

16 policy briefings

181 news stories

105 blogs

Submitted

83 responses to policy consultations

Recorded

40 parliamentary mentions of our work

Presented our work at

62 international conferences

Recorded

5,750 mentions of our work in print media (a **34**% increase on the previous six years)

Recorded more than

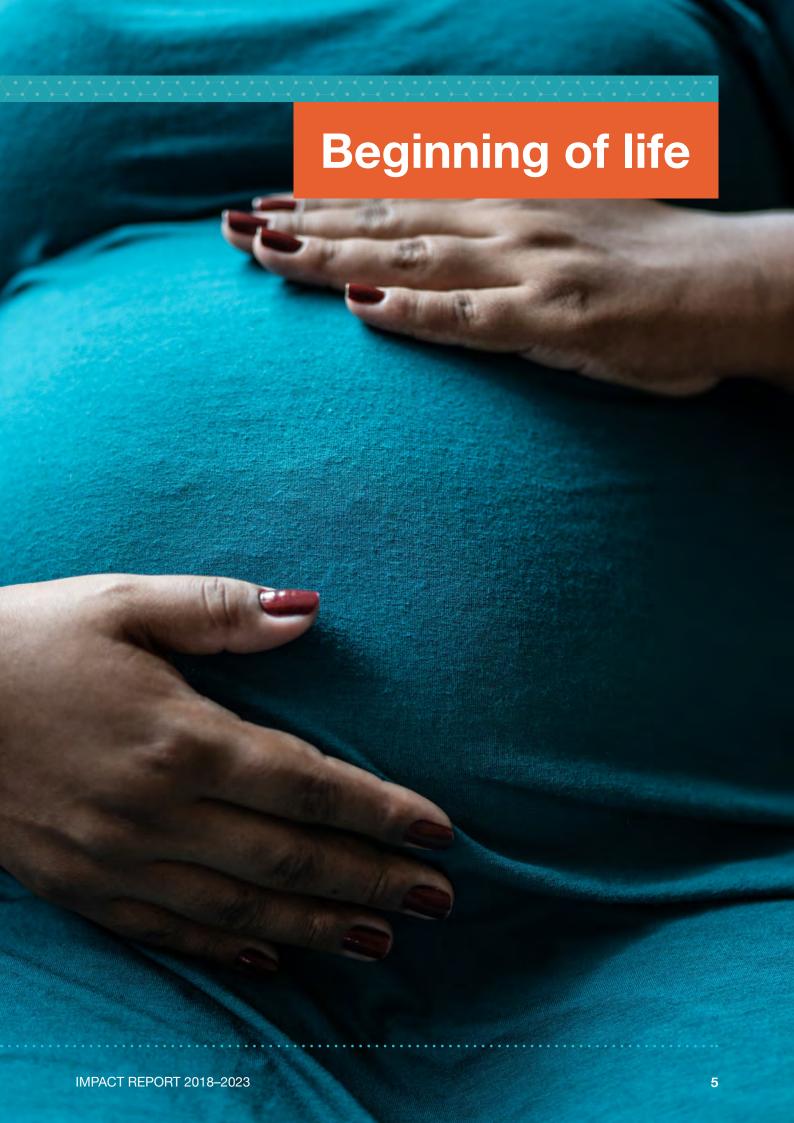
1 million visits to our website

Close to doubled our Twitter followers, to more than

11,000

Reached

5,000 blog subscribers (a **700**% increase on the previous six years)



NON-INVASIVE PRENATAL TESTING

Over the past six years we have seen recommendations from our major report into non-invasive prenatal testing (NIPT) help bring about change in industry practice. This has resulted in real improvements that are supporting women and couples to make informed choices during pregnancy.

The Advertising Standards Authority has taken action to ensure <u>accurate advertising</u> of private NIPT, and the Care Quality Commission committed to <u>inspecting private</u> NIPT clinics in England. Also, the Royal College of Obstetricians and Gynaecologists now provides <u>professional guidance</u> on the offer of NIPT as a screening test. And the NHS website has been updated to give more balanced, up-to-date and accurate information about Down's syndrome.

We are proud to have positively influenced not only policy drivers but industry too, meaning patients are now experiencing better care and have improved access to information.

Read a blog about our NIPT concerns, authored by Catherine Joynson, Associate Director at the Nuffield Council on Bioethics in 2019.

WHOLE GENOME SEQUENCING OF BABIES

In March 2018, we published a policy briefing that explored the ethical issues raised by whole genome sequencing of babies.

Interpreting the results of whole genome sequencing remains difficult, time-consuming and expensive. However, the technology is becoming cheaper, and the NHS is starting to use it to help obtain a diagnosis for some seriously ill babies. As such, it is important for us to consider what genetic information

should be shared with parents, and how genetic data should be stored, accessed and used. This all requires further public consideration.



Genome sequencing technology has moved at an incredible pace, and we are starting to see the benefits that it can offer to patients with genetic disease. But we need to think carefully about how we handle the sensitive information that can be revealed. Babies do not get a say in this, making it especially important that they, and others, are not disadvantaged in their future lives by a decision taken at birth.

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Professor Dave Archard, Chair of the Nuffield Council on Bioethics

Read a recent blog by Professor Frances
Flinter, member of the Nuffield Council
on Bioethics and Emeritus Professor of
Clinical Genetics at Guy's & St Thomas'
NHS Foundation Trust. In it she talks us
through some important issues to consider in
relation to the introduction of whole genome
sequencing of newborn babies.

GENOME EDITING AND HUMAN REPRODUCTION

In July 2018, we published <u>a report</u> that identified a range of ethical and social issues arising at the prospect of genome editing being used to influence inherited characteristics in humans.

We recommended two overarching principles be used to guide whether the use of 'heritable genome editing interventions' is ethically acceptable:

- they must be intended to secure, and be consistent with, the welfare of the future person
- they should not increase disadvantage, discrimination or division in society.

We also added that, if these techniques were to be permitted, they should be strictly regulated, licensed on a case-by-case basis, and introduced only in the context of a clinical study, with monitoring of the long-term effects on individuals and groups.

Achieved blanket tabloid coverage in the UK as well as being reported by more than 600 local newspapers and over 20 global newswires.

Our launch event (#genomeeditconf) topped the Twitter trending list for London for two days, reaching an estimated **153,902** accounts.

4 months after we published our recommendations, the world's media reported the **first ever** clinical use of heritable human genome editing in China.



There is potential for heritable genome editing interventions to be used at some point in the future in assisted human reproduction, as a means for people to secure certain characteristics in their children. Initially, this might involve preventing the inheritance of a specific genetic disorder. However, if the technology develops it has potential to become an alternative strategy available to parents for achieving a wider range of goals.



Professor Karen Yeung, Chair of the project working party and Interdisciplinary Professorial Fellow in Law, Ethics and Informatics at the University of Birmingham

EGG FREEZING

In September 2020, we published a policy briefing note that explored the ethical implications of egg freezing.

In it we highlighted how there is a pressing need for data on egg freezing success rates to be presented more clearly, accessibly and transparently. And we noted the potential for women to feel a pressure to delay motherhood if their employer were to offer egg freezing as part of a benefits package.

Read our reaction to the Government's announcement that it intends to increase storage time limits for frozen eggs, sperm and embryos.



It's vital for women thinking about freezing their eggs to be able to make informed choices. To do this, they need easy access to data on their chances of success across various stages of the process – from freezing and thawing eggs, to having a live birth. But they also need clinics to be frank about the process, and about what is known and unknown about egg freezing. This is especially important given egg freezing's increasing popularity.

Frances Flinter, member of the Nuffield Council on Bioethics and Emeritus Professor of Clinical Genetics at Guy's and St Thomas' NHS Foundation Trust

SURROGACY

In March 2023, partly in response to the Law Commission of England and Wales, and the Scottish Law Commission announcing that they were to put forward their proposals for new surrogacy laws in the UK, we published a policy briefing exploring the ethical considerations of the topic.

The evidence we reviewed suggested that there is a need for law reform to help address some of the ethical, as well as practical and legal, issues of surrogacy. In particular, in the briefing we addressed how surrogacy should be regulated, surrogates should be compensated and how legal parentage

of children born via surrogacy should be decided. We also explored the issues arising in international surrogacy.

Read our response to the Law Commissions' proposed reforms to surrogacy law in the UK.

DISAGREEMENTS IN THE CARE OF CRITICALLY ILL CHILDREN

In September 2023, we published our independent review into the disagreements that can arise in the care of critically ill children. This was commissioned by the Secretary of State for Health and Social Care in December 2022.

In the review, we focused on the relationship between parents/carers and health care teams in the care of a critically ill child and why, in some cases, the relationship breaks down. We also looked at how disagreements, once they have come to light, can be resolved as collaboratively and sensitively as possible with all involved able to have their voices heard.

We are currently working to persuade the Government to convene a new taskforce with responsibility for overseeing the implementation of our recommendations. We believe this action will help improve the sometimes harrowing experience of families and health care professionals in navigating disagreements.



Parenting a critically ill child is an unparalleled journey through uncharted territory, where every decision feels like an impossible choice. When my newborn daughter was diagnosed with a rare and life-limiting disease, I found myself thrust into this world, learning to be her advocate, faced with unimaginable decisions.

As [this Nuffield Council] report clearly demonstrates, good communication practices and practical and emotional support – for everyone involved – is at the heart of making lasting change. I sincerely hope that all of the recommendations outlined are put into action to ensure that the parents and professionals caring for the most medically complex children in this country are both supported and heard.

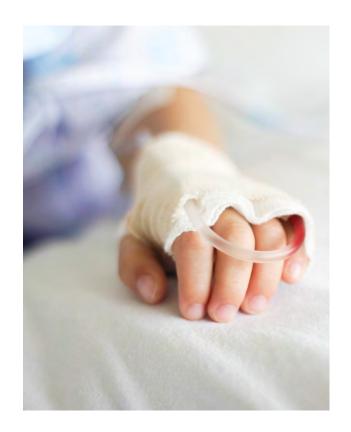
Steph Nimmo, expert by experience as a parent of a critically ill child, and contributor to the Nuffield Council on Bioethics review



Our tweet announcing the report had been published was viewed more than **14,300** times, making it one of our most viewed tweets of 2023.

Our recommendations were widely reported by national tabloids, broadsheets, specialist medical press and over **200** regional UK newspapers.

Lord Bellamy KC, Parliamentary Under Secretary of State in the Ministry of Justice, **welcomed our report** and invited a meeting to discuss our recommendations with Cafcass and the Ministry of Justice.





MEDICAL IMPLANTS

In June 2019, we published a policy briefing exploring the ethical issues raised by using medical implants, such as hip implants, pacemakers and glucose monitors. In this briefing we assessed the challenges faced by regulatory bodies, manufacturers, and health care professionals working in this area.

Read our reaction to the Government's announcement that it intended to introduce new safety measures for the use of medical devices, through its Medicines and Medical Devices Bill 2019–2021.

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The medical implants market is thriving and it's likely to continue to do so. Medical implants can greatly improve a person's quality of life, even save their life, but their invasive nature leads to challenges in testing for safety and efficacy, and raises a number of ethical considerations. In light of recent cases of patients coming to significant harm through the use of medical implants, and the emergence of 'smart' implants, our briefing note aims to help guide policymakers in promoting innovation in the sector to address patient need, while ensuring equitable and timely access to safe and effective implants.

Hugh Whittall, Director of the Nuffield Council on Bioethics at the time of publication

Read our reaction to an independent review into the safety of medicines and medical devices, which was triggered by concerns about the effects of three medical interventions: Primidos, sodium valproate and vaginal mesh.

COSMETIC PROCEDURES

Our work, stemming from a major report we published in 2017, has contributed to positive changes in the beauty industry, ensuring a more ethical provision of cosmetic procedures for people in the UK.

One of our recommendations was that people aged under 18 years should not be able to access cosmetic procedures other than in the context of multidisciplinary health care. We followed this up with government ministers and officials, which resulted in them writing to us to confirm their plans to ban Botox for under 18s through a Private Member's Bill. We also advised members of parliament on the establishment of an All Party Parliamentary Group (APPG) on Beauty, Aesthetics and Wellbeing, which went on to publish a report into Botox, fillers and similar non-surgical cosmetic treatments.

In February 2022, a licensing scheme for non-surgical cosmetic procedures, including Botox and fillers was introduced. This reflects the influencing work we have done over several years calling for more regulation of non-surgical cosmetic procedures.



A national licensing scheme is a great step towards improving the safety of the procedures and reducing the risks to the people who choose to have them, and we look forward to seeing this plan being implemented. However, we urge the Government to consider whether they could go even further to ensure safety by strengthening regulation of the products themselves – for example, by making all dermal fillers 'prescription-only'.

Danielle Hamm, Director of the Nuffield Council on Bioethics

COVID-19 RESPONSE

Between 2020 and 2022 we worked to bring ethics expertise into the public debate on COVID-19 policymaking.

We adopted a rapid response publication model, publishing 9 reports and policy briefings in 2020 alone (compared to an average of 2–5 publications in previous years). This enabled us to provide timely support, information and advice to help embed ethics within government and societal responses to the COVID-19 pandemic, especially in the UK.

This was furthered during 2021 and 2022, when we partnered on the <u>UK Pandemic</u> <u>Ethics Accelerator</u>, funded by UK Research and Innovation, co-leading the public values, transparency and governance workstream.

And in the spring of 2022, we met with director generals responsible for the Cabinet Office COVID-19 Taskforce to discuss how we could support consideration of ethics in moving to an endemic COVID-19 situation. As a result of this discussion, we produced and published an ethics toolkit for decision makers responding to public health threats, which we presented at a policy workshop, held jointly with the UK Pandemic Ethics Accelerator, in the House of Commons.



Public health threats such as COVID-19 are ethically challenging because they cannot be managed effectively by individuals alone, and any action taken will have broad and relatively indiscriminate impact. We believe looking at the problem through an ethics lens can help us reach good decisions about how to respond.

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Katharine Wright, lead author and Assistant Director of the Nuffield Council on Bioethics at the time of publication

AGEING

In April 2023, we published a report looking into the role that biomedical research and technological innovation has to play in responding to the needs of an ageing population. We gathered insights through a deliberative public dialogue, to ensure that the policy changes we are calling for are informed and inclusive of public views and values.

In the report, we focused on three broad areas of research and innovation that are seen to have the potential to support people to flourish in older age, but could also raise significant ethical questions about how ageing is perceived, and how older adults are valued in our society:

- research into biological ageing
- assistive, monitoring and communications technologies (for example, health apps)
- data-driven detection and diagnosis of age-related conditions.

Reviewing evidence in these areas enabled us to propose an 'ethical framework' to help everyone involved in conducting research relating to ageing to think through the ethical implications of their work. We set out 15 recommendations for policymakers, research funders, researchers, regulators and professional bodies, health care professionals and others involved in shaping research.

Our efforts to influence policy are under way with Sir Chris Whitty, Chief Medical Officer (CMO) for England, welcoming our report, and featuring our work in his **annual CMO report**, published in November 2023.

Our future of ageing report has been viewed more than **2,500** times on our website since publication.

The Chief Medical Officer's Annual Report 2023, Health in an Ageing Society, cited our work as "hugely important".



Advances in research and innovation are showing how we might enable older people to spend more of their later years in good health and with a good quality of life. Today's report from the Nuffield Council on Bioethics is a valuable contribution to making this happen, ensuring that an ethical approach is embedded across the research sector. We can all work together collectively to achieve this.

Professor Chris Whitty, Chief Medical Officer for England





It is vital to involve older people as technology advances. Everyone benefits from inclusivity; exclusion benefits no one.

Rachel Oliver, public participant in the Future of Ageing engagement work

ASSISTED DYING

In October 2023, we <u>launched our project</u> to assess public views on assisted dying. Over the next 12 months, we will be working with Hopkins Van Mil who will be partnering with M.E.L Research and the Sortition Foundation to design, facilitate and organise a series of surveys and a Citizens' Jury. Together, these activities will enable us to explore and best reflect how people living in England think and feel about assisted dying including the underlying ethical, social and practical complexities.



As an independent body that is dedicated to examining ethical issues in bioscience and health, we are used to navigating emerging and evolving debates. We believe public views must inform the ethical analysis of questions that have the potential to impact us all. This is why we have a responsibility to explore topics like assisted dying, which we believe currently lack the much-needed detailed fresh insights into the public's views.

Rebecca Mussell, Associate Director of Policy and Research at the Nuffield Council on Bioethics





GENOME EDITING AND FARMED ANIMALS

In December 2021, we published a report examining the social and ethical issues raised by the potential use of genome editing technologies in the breeding of farmed animals.

The Government had recently stated its intention to relax regulation for animals to be bred using genome editing techniques. We felt any introduction of these technologies into food and farming must be aligned with public and animal interests – and part of an overall vision for a food and farming system that supports, promotes and rewards sustainable farming with high standards of animal welfare.

As such, we focused our influencing work on the Genetic Technology (Precision Breeding) Bill 2022–23, which sets out a framework for the governance of 'precision bred organisms' (including crops and animals). We proposed five principles to guide the development of food and farming systems and the introduction of new breeding technologies for farmed animals. Pete Mills, our Associate Director in 2021 gave evidence to the Bill Committee and physical copies of our report were waved on both sides of the Commons during one debate. Our work proved influential in guiding how the Government approached changes to legislation of genetic modification in farmed animals, ensuring that ethics was prominent in the debate. We also secured cross-party support for the protection of animal welfare as part of the regulatory framework.

Read Pete's blog on how this Act has passed, with provisions relating to animals mirroring many of the recommendations made in our 2021 report.

ENVIRONMENT AND HEALTH

In October 2023, we published a background paper exploring the key ethical issues relevant to health and climate change.

The paper is the outcome of a scoping exercise, carried out to assess any ethical implications of actions taken to mitigate and/ or adapt to climate change. It examines these ethical issues under three linked headings:

- the ethics of the climate crisis
- ethical issues arising in responses to the climate crisis
- ethical issues relating to research into those responses.

Danielle Hamm, Director of the Nuffield Council on Bioethics, presented the paper's findings at the American Society for Bioethics and Humanities 2023 Conference. Our insights were well received and there is enthusiasm within our networks to come together and delve into these issues further.

Animals, food and the environment



It is clear that whilst there is an appreciation for the environmental and health impacts of climate change, there is a lack of awareness for the ethical considerations that must underpin our efforts to tackle these problems. We will be exploring this topic further with our networks and key decision makers. Ethics cannot be an afterthought; it is vital to us navigating these problems effectively and meaningfully for those people and communities likely to feel the negative impacts the most.

Danielle Hamm, Director of the Nuffield Council on Bioethics







RESEARCH IN GLOBAL HEALTH EMERGENCIES

In January 2020, we published the findings of a two-year in-depth inquiry into the ethical issues relating to research in global health emergencies. The inquiry was run by an international working group which gathered evidence and experience from many contributors across the globe.

Better evidence about what does and does not 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. However, further insights were needed to understand how research can be undertaken ethically during emergencies, and this was the aim of our work.

We made 24 recommendations, which were summarised in our <u>call to action</u> for research funders, governments, and others involved in health research systems for a more ethical and collaborative approach to conducting research during emergencies. Our <u>2021 report</u> looks at the uptake and impact of our work.

In March 2020, we produced and <u>published</u> a rapid policy briefing outlining the ethical principles that must be considered when developing public health measures specifically in response to the COVID-19 pandemic.

Read our Chair, Dave Archard's 2022 blog discussing the importance of exhibiting ethical preparedness in the face of a pandemic response.

GENOMICS HEALTH CARE AND RESEARCH

We are working in partnership with the Office for Life Sciences (OLS) and genomics health care leads in Scotland, Wales and Northern Ireland to establish a UK best practice approach for applying strong and consistent ethical standards in genomics research.

In July 2023, we published a report summarising insights gathered through our workshops and some case studies – it has become clear that clinicians, researchers, patients and policymakers are encountering a variety of ethical issues in genomics health care and research, and that ethical advice and guidance is spread out over many different institutions and locations which can make it hard to navigate.

The next stage in this work will be to publish a map of existing ethics resources in order to understand what is already available and identify areas where further work is needed.



TECHNOLOGY IN MENTAL HEALTH CARE

In April 2022, we published a policy briefing that raised concerns over the effectiveness, safety and quality of technologies such as smartphone apps for people who need mental health support.

By working with the charity Rethink Mental Illness we were able to ensure that insights and views of people with lived experience were captured in our briefing. As such, we have called for potential users, their families and care professionals to be involved in the development of appropriate regulation and a strengthening of the evidence base underpinning these technologies.

ARTIFICIAL INTELLIGENCE

briefing examining the then current and potential applications of AI in health care. Back in 2018, the use of AI in health care was developing rapidly and there was much hope and excitement for the impact it could have. We sought to inform the then newlyestablished bodies, such as the Centre for Data Ethics and Innovation and the Ada Lovelace Institute, that the challenge will be to ensure that AI is developed and used in ways that are transparent, address societal needs, and that are consistent with public values.

Now, in 2023, together with the Ada Lovelace Institute, we have published a report highlighting the pressing ethical, legal and social questions surrounding the convergence of Al and genomics.

The application of AI to genomics, dubbed 'AI-powered genomics', could have several uses in health care. For example, analysis of a person's genetic makeup could be used to

inform the 'personalisation' of their treatment plan or assist in predicting the probability of them developing a certain health condition. The next stage of our work will involve public deliberation to better understand the implications of these uses and test whether the UK is prepared to navigate the new waters ahead.



The combination of AI and genomics offers a great deal of opportunity, such as AI-powered genomic health prediction. With the technologies moving at pace, discussion of the ethical, legal and social implications of introducing them into our society must keep up. In the next phase of this work we will be exploring how the development of AI-powered genomic health prediction can be effectively steered and governed in line with public values and priorities, to make the most of its potential.

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Professor Dave Archard, Chair of the Nuffield Council on Bioethics

This report has been viewed on our website more than **1,000** times by readers from **64** countries.

Our commitment to diversity, equity and inclusion

The Nuffield Council on Bioethics exists to examine and advise on ethical issues arising from developments in bioscience and health. We believe that solutions have the biggest benefit for people and society when ethics is embedded in policymaking.

We want to ensure our work is as inclusive as possible and that our outputs can be accessed by anyone who is interested. As such, we strive to ensure that diversity and inclusion are embedded in every aspect of our work. This includes those we employ, the projects we embark upon and the groups, organisations and individuals we convene and engage with.

We recognise that our commitment to being inclusive must be reviewed regularly. It is only by dedicating time to this self-reflection that we can be confident in our ability to identify any changes we could make to improve further and raise awareness across our organisation.







Future vision

By Danielle Hamm, Director of the Nuffield Council on Bioethics, and Professor Sarah Cunningham-Burley, incoming Chair of the Nuffield Council on Bioethics

Next year, the Nuffield Council on Bioethics will embark on a new strategic direction that will seek to build upon our strengths, working to meet today's challenges and place ethics at the heart of decision making for the biggest benefit to society.

Influencing policy is a strength of ours – but we know we can go further and gain greater traction with our work. In this new chapter we will be increasing our efforts to embed ethics in policymaking, identifying those areas where we can encourage decision makers to ensure ethics becomes integral to the Governments' bioscience and innovation agenda.

We will be developing the way we work, evolving our horizon-scanning function so we can better anticipate the scientific developments and health trends that pose fundamental ethical questions to society – strengthening and expanding our networks to enhance our ability to prioritise where we should focus our efforts and highlighting where we think others should focus theirs. We will produce more regular outputs in our chosen priority areas that remain capable of providing our high-quality ethical analysis, but in a more timely manner.

We will continue to use our unique position as the UK's only body with an overarching bioethics remit to convene and cultivate networks across the diverse groups of people and organisations working in this field. By working well together, we will communicate a strong and compelling case for the value of ethics in biomedicine and health policymaking.

We are approaching the next five years with a great deal of optimism. Building on the strong foundations of over 30 years of robust ethical analysis, we believe our new ways of working will not only serve to further raise the awareness of and debate about ethics, but they will also make the practice a fundamental consideration in any policymaking decision, both across the UK and internationally.



We will be developing the way we work, evolving our horizon-scanning function so we can better anticipate the scientific developments and health trends that pose fundamental ethical questions to society.



NUFFIELD COUNCIL^{©N} BIOETHICS

Nuffield Council on Bioethics 100 St John St, London EC1M 4EH Telephone: +44 (0) 20 7681 9619 Email: bioethics@nuffieldbioethics.org

www.nuffieldbioethics.org



X @Nuffbioethics in Nuffield Council on Bioethics