



**NUFFIELD  
COUNCIL ON  
BIOETHICS**

---

**Annual Report  
2019**

# CONTENTS

## INTRODUCTION

Chair's foreword	3
Director's foreword	4
Our mission	5

## ACHIEVEMENTS IN 2019

Programmes and activities overview	6
Impact highlights	7
Progress with strategic objectives	8

## ABOUT

People	13
Financial information	14
Contact	15

# CHAIR'S FOREWORD

As Chair I oversaw in 2019 the appointment of a new cohort of members and I am immensely grateful to them, as well as the longstanding members, for all the excellent work they did – in helping to determine our future programme of work, in contributing blogs, representing the Nuffield Council on Bioethics publicly, and in assisting the completion of a wide range of work. I would also like to acknowledge the work of those beyond Council who contributed to exploratory workshops on various topics and who reviewed our ongoing work.

Our international collaborative efforts continue, and it is important to make special reference to our ongoing partnership with the Deutscher Ethikrat and the Comité Consultatif National d’Ethique. We meet annually in a productive ‘trilateral’ and in 2019 we worked together on an important joint statement on heritable human genome editing. I sincerely trust that this European cooperation endures.

I remain extremely proud of the Council's international work and of the global reputation, and reach, it has. In difficult times this is of extraordinary significance and value. There has never been a time when it was more important to provide a space for the considered, scrupulous, intelligent, and informed ethical discussion of contemporary developments in medicine and biotechnology. The Council remains vigilant and far sighted in its role as an independent bioethics committee, with both national and international impact.

As I write this, 2020 promises to emphasise the vital worth of our work and of our position within the space of public bioethical discourse.

David Archard



# DIRECTOR'S FOREWORD

2019 was an unusual year, in that we did not publish any in-depth reports, though we did publish one in 2018 (genome editing in human reproduction) and one in early 2020 (research in global health emergencies). But the fact that we were nevertheless extremely busy and active reveals two important aspects of our work.

First, that our reports very often have a long 'tail'. Their timeliness in policy terms means that their impact can occur some time after publication, and we see it as a major part of our job to follow up, keep in touch, and ensure that relevant policymakers and parliamentarians remain aware of their continued importance. Hence the 'impact' sections in relation to earlier reports such as those on non-invasive prenatal testing, and cosmetic procedures.

The second important aspect has been the reception and reach of our active response programme. Whilst in-depth reports remain a core element of our work, the shorter briefing notes and other responsive activities have proved to be of great value in informing and guiding policymakers and the wider public on a range of issues.

Together with a further acceleration of our work in the international space; our wider public engagement; and our regular contributions to policy consultations, parliamentary inquiries, academic networks, and media activity,

this amounts to a year of success and real achievement. I am immensely grateful to all colleagues who have worked consistently and collectively to deliver this.

2020 is already underway and looks like being a challenge of a different kind and order altogether!

Hugh Whittall



# OUR MISSION

## We aim to...

Inform policy and public debate through timely consideration of the ethical questions raised by biological and medical research, so that the benefits to society are realised in a way that is consistent with public values.

## We do this by...

- Engaging a range of public, professional, political, and policy stakeholders to ensure that the Council is aware of, and responsive to, the major issues of interest and concern to them.
- Involving a broad range of expertise and opinion to develop a range of high-quality outputs and activities.
- Contributing to contemporary discussions of bioethics in professional and policy arenas, including making recommendations to Government or other bodies in a timely, practical, and relevant way.
- Leading public debate on bioethics issues by playing an active role in media, policy, and professional fora both nationally and internationally.

## In keeping with our values of...

- Quality, rationality, and rigour.
- Independence.
- Transparency and inclusiveness.
- Relevance and timeliness.

### Our four strategic objectives for 2018 – 2022 are:

- To engage and involve relevant stakeholders in our work.
- To contribute effectively to public and policy debates through a diverse portfolio of work.
- To build on our experience, reputation, and body of work.
- To situate our work within a context of social change, international collaboration, and biomedical advances.

# PROGRAMMES AND ACTIVITIES OVERVIEW



## Horizon scanning

We consult organisations and people from a range of areas of interest (e.g., science, engineering, ethics, policy, regulation), sectors (e.g., health care, academic, commercial research), and countries to identify developments of interest in health and bioscience.

2019 highlights included:

- A 'Bioethics futures' workshop which brought together leading experts to explore the future of science in the crime and security sector.
- An update of our ['What's on the Horizon for Bioethics'](#) infographic.



## Active response programme

*This was the second full year of our active response programme, designed to give us more flexibility in our contributions to policy, media, and public affairs.*

Activities in 2019 included:

- Publication of two bioethics briefing notes, with a third in progress:
  - Disagreements in the care of critically ill children
  - Medical implants
  - Meat alternatives (published in January 2020)
- A series of exploratory stakeholder meetings on gender identity in young people.
- 'Bioethics in focus' workshop exploring epigenetics and ethics.
- A successful pitch to the House of Commons Science and Technology Committee, resulting in a new Parliamentary inquiry on commercial genomics.
- Responses to 19 policy and government consultations, with the aim of translating our work into practical policy outcomes.
- 19 posts on our blog from a range of contributors.
- More than 100 meetings and presentations in 11 countries, informing national and international policy discussions.



## In-depth inquiries

*Inquiries into developments in biological and medical research, working with expert working groups, have been our core activity since we were established in 1991.*

Throughout 2019 we were running two in-depth inquiries:

- Research in global health emergencies (findings published Jan 2020)
- Genome editing and farmed animals (due to publish Spring 2021)

We were also working to further the impact of a number of our previous in-depth inquiries such as cosmetic procedures, non-invasive prenatal testing (NIPT), and genome editing and human reproduction.



## Website

We were delighted to launch our new website in November 2019, with new and improved ways to showcase our entire range of work.

# IMPACT HIGHLIGHTS

## Non-invasive prenatal testing (NIPT)

*Our work on [non-invasive prenatal testing](#) has led to real change in industry practice and improvements in patient care.*

Throughout 2018 and 2019, we actively engaged with policymakers, providers of NIPT, the media, and other stakeholders to implement the recommendations from our report on the ethics of NIPT. These activities led directly to significant changes that support the ethical approach set out in our 2017 report, including:

- the Care Quality Commission beginning inspections of private NIPT clinics in England;
- the Advertising Standards Authority banning online advertisements by three private NIPT providers and publishing an Enforcement Notice on Advertising NIPT for the entire sector;
- the Royal College of Obstetricians and Gynaecologists commissioning professional guidance on the offer of NIPT as a screening test;
- the largest private provider of NIPT in the UK, Ultrasound Direct, withdrawing their service of offering NIPT for sex chromosome conditions; and
- a review of information about Down's syndrome on the NHS website, which now provides balanced, up-to-date and accurate information about the condition.

## Cosmetic procedures

*Our report on [cosmetic procedures](#), has contributed to changes in the beauty industry to ensure a more ethical provision of cosmetic procedures for people in the UK.*

In pursuing our recommendation that invasive cosmetic procedures should be prohibited for under 18s unless a team of health professionals are involved, in 2019 we met with Department of Health and Social Care officials and the Minister of State, Jackie Doyle-Price MP. The *Botulinum Toxin and Cosmetic Fillers (Children) Bill* was introduced in January 2020. The Bill makes provision to restrict the administration of Botox and other substances for cosmetic purposes to under 18s. It will have its second reading in October 2020 and is likely to reach the statute book.

We briefed MPs on a number of parliamentary debates on cosmetic procedures and body image, and advised on the establishment of a new All Party Parliamentary Group (APPG) on Beauty, Aesthetics and Wellbeing. The APPG has recently launched an inquiry into non-surgical cosmetic procedures to investigate how standards for undertaking and advertising treatments such as Botox and dermal fillers should be improved to support the beauty and aesthetics industry and protect public safety.



# PROGRESS WITH STRATEGIC OBJECTIVES

## 1. Engaging and involving relevant stakeholders in our work

*We seek to engage and involve a range of people in our work so that we can inform public debate in reflective and balanced ways, and increase our policy influence.*

International perspectives are central to much of our work and were a significant feature of our inquiry on [research in global health emergencies](#), which was published in January 2020.

Throughout this inquiry we actively engaged with people and organisations in other countries, for example by holding meetings outside of the UK, ensuring our findings were disseminated at international meetings, sharing our work through international media outlets, translating our materials into other languages, and collaborating with international partners.

We benefited from the evidence and experience shared by many contributors across the globe. The map below shows the locations of all of those who contributed to our work on this topic.

Contributions were made through responses to an open call for evidence, participation in roundtable and one-to-one meetings, critique of early drafts of the report, and involvement in international workshops and events. For example, in March 2019, we partnered with the African coalItion for Epidemic Research, Response and Training (ALERRT); the Institute for Health Research, Epidemiological Surveillance and Training (IRESSEF) in Senegal; and the Wellcome Centre for Ethics and Humanities (WEH) to hold a joint workshop on community engagement for ethical research in outbreaks of infectious diseases and other humanitarian crises. Following the workshop we published the findings on our [website](#) and through the [media](#).





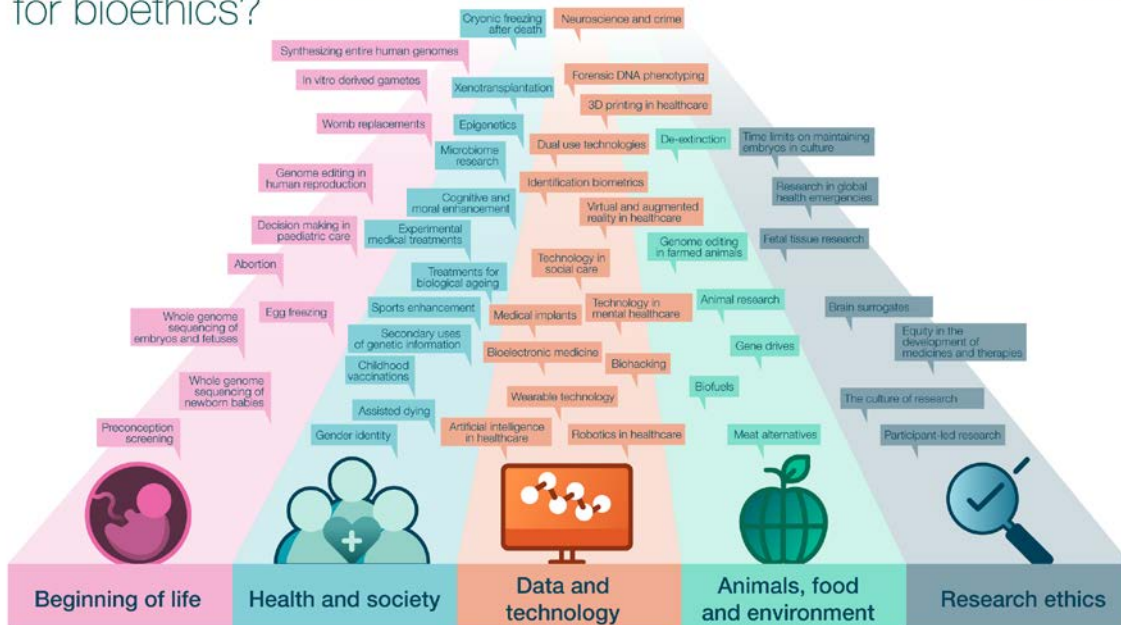
We gathered evidence in a variety of ways to ensure diverse input into our inquiry on genome editing and farmed animals. We held an open call for evidence aimed at those working in farming, food science, veterinary science, animal genetics, agricultural economics, public engagement, ethics, and law. We met with a range of stakeholders including technical

experts on food and farming systems, disease resistance, the ethical treatment of animals, and regulation of genomic technologies. In 2020 we intend to run a citizen engagement activity in collaboration with UKRI and BBSRC to enable public reflections on the use of genome editing in animals to be included in our findings.

We refreshed and updated our horizon scanning infographic (originally published in 2018) based on feedback from our followers on social media as well as continued meetings with key stakeholders throughout the year.

### What's on the horizon for bioethics?

NUFFIELD COUNCIL ON BIOETHICS



## 2. Contributing effectively to public and policy debates through a diverse portfolio of work

*To complement our in-depth inquiries, the addition of bioethics briefing notes and a strengthened public affairs capacity have created more opportunities for contributing to important developments in medical and bioscience research. In 2019 we were able to secure significantly more meetings with Ministers, MPs, Peers, and senior Government officials to build relationships and discuss relevant work. Some examples are below.*

In April 2019 we published a bioethics briefing note on [disagreements in the care of critically ill children](#) following which we engaged with interested parties and key stakeholders. We met with a range of Department of Health officials and policy staff at NHS England to explore what more can be done to support good healthcare environments that foster collaborative relationships between parents and healthcare professionals. We later heard NHS England are in the early stages of a programme to improve care for children and young people and are looking at ways to improve collaboration and support clinicians.

As part of our work on [medical implants](#) (bioethics briefing note published in June 2019), we met with Baroness Cumberledge who Chaired the [Independent Medicines and Medical Devices Safety Review](#). The review was published in 2020 and made a range of recommendations which aim to reduce the risk of avoidable harm to patients in the future, to improve the patient experience, and to help restore trust in the system. The review highlighted a number of areas we flagged in our briefing note, e.g.:

- the responsibilities of healthcare professionals to report adverse events
- conflicts of interests
- uncertainty about the long-term effects of implants
- challenges around informed consent
- liability when something goes wrong

Throughout the year we were regularly in touch with key UK and international policymakers. We responded to 17 UK Government and policy consultations, based on our current and previous work. We discussed our work regularly with the UK Department of Health and Senior NHS officials and also met with the Government's Chief Scientific Advisor, Chief Medical Officer and Deputy Chief Medical Officer to discuss ethical considerations in healthcare.

Throughout 2019 our work received frequent and widespread coverage in the news media. Across all projects our work was featured in 67 broadcast pieces. We gained coverage in over 650 press articles including high-readership UK and international outlets such as the BBC, The Times, The Guardian, Financial Times, The Telegraph, The Daily Mail, The Sun, The Independent, The Mirror, The Express, Metro, Wired, The Washington Post, Le Monde, Business Insider, India Today, Al Jazeera, Bloomberg, RT, New York Post, and more.

Increased activity on our blog has led to a steady increase in user numbers: we gained just under 200 followers in 2019, compared to 100 gained in 2018. Our top blog post for 2019 was written in February and focused on non-invasive prenatal testing. This blog has been viewed over 46,000 times and received over 60 comments, demonstrating how a timely blog helps us reach new audiences far and wide.

### 3. Building on our experience, reputation, and body of work

*Whilst our work often generates significant interest at the time of publication, the impacts and outcomes of the work can happen over an extended period.*

Our website is our most important tool to connect us to those with an interest in our work. The launch of our new website in November 2019 was a huge achievement for the Council. An important part of the upgrade was to better showcase our entire body of work – the breadth of our topics, the news, blogs and responsive types of content that we produce, and the connections between our different outputs and projects. We have now organised our work into themed topics which allow visitors to our website to browse by their interest. It creates a more effective display of the breadth of our work.

The collective experience, knowledge, and skills of our executive team, Council members, and working group members are a valuable resource that we exploit in various ways. Increasingly, the executive team and members are invited to share their expertise by giving presentations, acting as advisors, and sitting on influential policy committees. Often these invitations are from governmental or high-profile international bodies. In 2019, we gave over 40 presentations in 11 different countries and members of the Executive took up the following advisory roles:

- **Council of Europe Committee on Bioethics** – Pete Mills (Assistant Director) has worked with the Council of Europe Committee on Bioethics including leading the drafting of its [Guide to public debate on human rights and biomedicine](#).
- **Genomics England** – Catherine Joynson (Assistant Director) was a member of the Genomic Analysis in Children Task and Finish Group, which provides advice to the National Genomics Board. Catherine advised the group based on the findings of our 2018 bioethics briefing note on [whole genome sequencing of babies](#), which is just one example of how the impact of our work can happen over months and years after publication.
- **Organisation for Economic Co-operation and Development (OECD)** – Director Hugh Whittall attended meetings of an OECD Working Party on Biotechnology, Nanotechnology & Converging Technologies. Our report on novel neurotechnologies (2013) was influential in informing the [OECD Recommendation on Responsible Innovation in Neurotechnology](#), the first international standard in this domain.
- **National Ethics Committees** – our Chair, David Archard, has given presentations at meetings hosted by National Ethics Committees in Germany and Portugal, and at the EU Forum of National Ethics Committees.
- **COVID-19 Clinical Research Coalition** – following our work on global health emergencies research, in early 2020 Katharine Wright (Assistant Director) and Michael Parker (Chair of our working group on research in global health emergencies) were invited to set up an ethics working group to support the important work of this Coalition in responding to the COVID-19 crisis.

## 4. Situating our work within a context of social change, international collaboration, and biomedical advances

*We have initiated projects that respond to social change, for example on meat alternatives, and gender identity in young people, and we have developed our international partnerships and profile.*

The care and treatment of young people in relation to their gender identity has been the subject of intense media, academic, and public debate. In 2019, we held a series of meetings with a range of people and organisations to explore the ethical challenges. There were some clear areas of agreement among the meeting participants, as well as some areas of disagreement. We published a summary of the meetings in 2020, which was [welcomed](#) by a range of stakeholders including the Tavistock and Portman NHS Foundation Trust, Gendered Intelligence, and the British Association for Counselling and Psychotherapy. The meetings have given us a basis on which to plan further work in this area.

Our in-depth inquiries on research in global health emergencies and on genome editing in farmed animals both have an inherently international dimension and have built our international relations and profile substantially through our evidence gathering processes, consultations, contributions to international events, and high levels of media coverage in international media outlets. Our report on genome editing and human reproduction has

given us a prominent voice in international debates about the regulation and oversight of this technology throughout 2019. We ensured our report fed directly into a large number of international initiatives, through representation by our executive team and members, including those undertaken by the US National Academy of Medicine, the Council of Europe, and the OECD.

We led an international collaboration with the French and German national bioethics councils to publish a [joint statement](#) and secure publication of a letter to [Nature](#) on the ethics of heritable human genome editing.

In addition, we participated fully and actively in networks of national bioethics advisory bodies so that we are well-placed to recognise relevant new developments. For example the Council – through its Chair, Director and senior executive team – have been active participants in annual meetings of the EU Forum of National Ethics Committees; the biennial Global Forum of National Ethics Committees; and the Global Forum on Bioethics in Research. The Council also meets annually with the French and German National Ethics Councils.

# PEOPLE

## Council Members 2019

Council Member affiliations and register of interests are [available here](#).

*\*New Council members, joined April 2019*

David Archard (Chair)  
 Shaun Pattinson (Deputy Chair)  
 Simon Burall\*  
 Simon Caney  
 Melanie Challenger\*  
 Tara Clancy  
 Frances Flinter\*  
 Elaine Gadd\*  
 Ann Gallagher  
 Andy Greenfield  
 Anne Kerr\*  
 David Lawrence  
 Michael Reiss  
 Mehrunisha Suleman\*  
 Christine Watson  
 Robin A Weiss  
 Heather Widdows  
 Adam Wishart  
 Paquita de Zulueta

## The Executive

Biographies for all staff, and a register of interests for senior staff, are [available here](#).

Arzoo Ahmed, Research Officer  
 Sophia Griffiths, Communications Officer  
 Kate Harvey, Senior Research Officer  
 Catherine Joynson, Assistant Director  
 Richella Logan, Public Affairs Manager  
 Pete Mills, Assistant Director  
 Carol Perkins, Executive Administrator  
 Jade Rawling, Office Administrator  
 Ranveig Svenning Berg, Research Officer  
 Sarah Walker-Robson, Communications Manager  
 Hugh Whittall, Director  
 Anna Wilkinson, Research Officer  
 Katharine Wright, Assistant Director

## Governing Board

*Our Governing Board is responsible for reviewing and challenging the work of the Council, providing assurance that the Council is operating within its remit and is committing expenditure in line with the terms of the funding grant and the goals of our [Strategic Plan](#).*

*The Chair of the Governing Board and its other members are independent and appointed and remunerated by the funders.*

Sally Macintyre (Chair)  
 Stephen Holgate  
 Vivienne Parry  
 Brian Scott

# FINANCIAL INFORMATION

## Financial Report for the year to 31 December 2019

	2019 Actual £	2018 Actual £
<b>Expenditure</b>		
Salaries and staffing costs	709,859	647,139
Reviewers' and consultants' fees	20,745	24,299
Office and premises costs	2,851	6,503
Journals & subscriptions	10,774	16,432
Travel and meeting costs	98,093	114,654
Web, printing, and publicity	30,481	25,379
<b>Total expenditure</b>	<b>872,774</b>	<b>834,408</b>
<b>Funded by:</b>		
Nuffield Foundation	288,690	275,714
Medical Research Council	288,690	275,714
Wellcome	288,690	275,714
Other	6,705	7,265
	<b>872,774</b>	<b>834,408</b>
<b>Total funding</b>		
Medical Research Council	387,977	
Wellcome	387,977	
The Nuffield Foundation	387,977	
Other	6,705	
Less contribution to overheads shared equally among funders	- 261,000	
	<b>909,636</b>	
Amount drawn	872,774	
Outstanding funding 2019	<b>36,861</b>	



# CONTACT

Nuffield Council on Bioethics  
28 Bedford Square  
London  
WC1B 3JS

Email: [bioethics@nuffieldbioethics.org](mailto:bioethics@nuffieldbioethics.org)  
Press enquiries: [press@nuffieldbioethics.org](mailto:press@nuffieldbioethics.org)  
Telephone: +44 (0)20 7681 9619

Website: [www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)  
Blog: [nuffieldbioethics.org/blog](http://nuffieldbioethics.org/blog)  
Twitter: [twitter.com/nuffbioethics](https://twitter.com/nuffbioethics)  
Facebook: [facebook.com/nuffieldbioethics](https://facebook.com/nuffieldbioethics)  
Newsletter: [sign up](#)