



**NUFFIELD
COUNCIL ^{ON}
BIOETHICS**

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Annual Report 2020



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INTRODUCTION

Chair's foreword

David Archard

I am extremely proud of the way that the Nuffield Council on Bioethics adapted its work during 2020, as the COVID-19 pandemic unfolded across the world. In a time that was disruptive to all aspects of our everyday lives, the Council played a leading role in identifying and responding to pressing ethical issues, and was able to quickly produce high-quality work to support national and international responses to the pandemic.

Our work on research in global health emergencies (published January 2020) was extremely timely and played a large part in this, and we were also able to draw on our previously published work such as our influential report *Public health: ethical issues*.

To pick out one example, amongst a host of work in our responsive programme, the emerging potential for immunity certification or 'vaccine passports' was quickly identified as an issue that required urgent ethical attention. As an independent and authoritative body working at the intersection of bioethics policy and academia, one of our key strengths is our convening power. We used this to quickly bring together experts for a policy workshop on COVID-19 testing, immunity, and civil liberties. From this, we developed a briefing note on the topic and were able to offer several important contributions as the Government shaped its policy. We participated in workshops and discussions with Government and other policymakers about the ethical issues arising from use of vaccine certification, including giving evidence to the Government's inquiry into COVID-status certification. We were frequently contacted by the UK and international press to speak on the topic.

We pride ourselves on our considered approach, but this year has demonstrated the Council's ability to adapt and react to social changes and biomedical advances. I thank the Executive and our Council Members for all the excellent work they did in challenging circumstances.

2020 was also a significant year in that it was Hugh Whittall's last as Director of the Council. I am immensely grateful to Hugh for all that he's done for the Council in his 14 years as Director. Amongst his many achievements in his tenure, he can be particularly proud of establishing our reputation as an internationally respected thought leader and policy influencer; developing our work to engage the public on key bioethical issues; and shaping our new programmes of work in rapid policy response and horizon scanning to complement our renowned in-depth inquiries.



INTRODUCTION

Director's foreword

Hugh Whittall

2020 was year without precedent. The pandemic would demonstrate the power of scientific research and innovation, but would also lay bare global and national inequalities, raise tensions between nationalism and global solidarity, and change daily life and personal freedoms for many of us.

Two days after we published the findings of our [inquiry into ethical research in global health emergencies](#), the World Health Organization declared the COVID-19 pandemic a Public Health Emergency of International Concern. I have always said that amongst the Council's many strengths are farsightedness and timeliness, and this report might be the pinnacle of that. Much of our focus in the early part of 2020 was on developing international partnerships to raise awareness of, and implement, the findings of this report. Our work was influential in the global response to COVID-19, including being featured in the WHO's own guidance, and many of our working group being invited to join international collaborations to aid global responses to COVID-19.

In the following months we strategically diverted our attention from our planned work programme towards contributions aimed at embedding ethics within the rapidly developing governmental and societal responses to the pandemic, particularly in the UK. We produced important briefings that got to the heart of the ethical challenges faced by Governments, health services, research communities, and others both in the UK and internationally. These included: *Ethical considerations in the COVID-19 pandemic*; *Fair and equitable access to COVID-19 treatments and vaccines*; *COVID-19 antibody testing and 'immunity certification'*; and *Ten questions on the next phase of the COVID-19 pandemic and a Guide on the ethics of surveillance and quarantine for novel coronavirus*. As ever, this work has proved to be both timely and durable.

On a personal note, 2020 would also be my last full year as Director of the Nuffield Council on Bioethics.

When I arrived in February 2007, I knew that 'the Nuffield' had an outstanding reputation that I think we have maintained and enhanced. I knew that it carried out important and influential work, but I didn't really know how it was achieved. I knew that it drew on a wide range of contributors, though I didn't realise how extensive this was, across the UK and way beyond. And I knew that its work was really interesting, though it didn't realise how much fun it could be.

So I have learned a lot, and for all of this learning and enjoyment I am immensely grateful to colleagues – staff and Council members – who have helped make my time at the Council so positive and rewarding. I would like to note in particular the excellent Chair/Director relationships that I have been privileged to enjoy - with the late Bob Hepple, and with Albert Weale, Jonathan Montgomery and Dave Archard. But my final note of thanks must go to the colleagues in the Executive team who have brought the values, commitment, intelligence, and humour that together keep the thing moving. I have no doubt that it will continue to move forward with my successor, Danielle Hamm, to whom I offer a warm welcome and my sincere good wishes.



INTRODUCTION

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.

ACHIEVEMENTS
IN 2020

Programmes and activities overview

Throughout 2020, we were working to provide support, information, and advice to ensure that ethics was a key consideration in rapidly developing government and societal responses to the COVID-19 pandemic, especially in the UK.



Horizon scanning

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

2020 highlights included:

- A new edition of our '[What's on the horizon for bioethics](#)' infographic.
- A series of workshops which aim to bring a range of stakeholders together to shine a light on the role of bioethics in governance. The first of these workshops looked at the role of bioethics in COVID-19 policy-making and pandemic preparedness.



In-depth inquiries

Inquiries into developments in biological and medical research have been our core activity since we were established in 1991. Our inquiries are overseen by a multidisciplinary working group chosen for that topic, and are informed by extensive consultation and research.

In January 2020, we published the findings and conclusions of our two-year inquiry in a report, [Research in global health emergencies: ethical issues](#). When we began this work we couldn't have anticipated that shortly after the publication of our findings, much of our focus would be shifted to responding to ethical issues arising from a global pandemic, and that our report would be influential in the global response to COVID-19, including the WHO's guidance on ethical conduct of COVID-19 research.

We continued our in-depth inquiry into the implications of the use of [genome editing in farmed animals](#), which is due to be published in 2021.

What does it mean to 'live well' in older age? This question will be at the heart of our in-depth inquiry into the [future of ageing](#). The inquiry, chaired by Professor Bella Starling, launched in July 2020.

We worked to further the impact of a number of our previous in-depth inquiries including cosmetic procedures, non-invasive prenatal testing (NIPT), and genome editing and human reproduction. See the impact highlights section for further information.



Active response programme

Throughout 2020, much of our active response programme turned to providing support, information, and advice to ensure that ethics is a key consideration in rapidly developing government and societal responses to the COVID-19 pandemic, especially in the UK.

[COVID-19](#) activities included:

- Four policy briefings:
 - [Ethical considerations in the COVID-19 pandemic](#)
 - [Fair and equitable access to COVID-19 treatments and vaccines](#)
 - [COVID-19 antibody testing and 'immunity certification'](#)
 - [Ten questions on the next phase of the COVID-19 pandemic](#)
- A [guide](#) on the ethics of surveillance and quarantine for novel coronavirus.
- Over 20 [opinion pieces](#) on our blog providing different ethical perspectives around issues raised by the pandemic.
- A widely shared [statement](#) on COVID-19 and the basics of democratic governance, followed by a [joint letter](#) with Involve to the Prime Minister calling for greater transparency and public involvement in the response to COVID-19.
- A [statement](#) on the need for national guidance on resource allocation decisions in the pandemic.
- Six [webinars](#) and two workshops that brought together experts to share their perspectives and discuss ethical issues raised by the pandemic.
- Collating a repository of resources which focus on the ethical aspects of the COVID-19 pandemic.

- We were part of a successful funding bid to establish the '[UK Pandemic Ethics Accelerator](#)' in partnership with the University of Oxford, University of Bristol, University of Edinburgh, University College London. This initiative harnesses expertise from across the UK to provide research, guidance, and analysis on ethical issues raised by the pandemics. The 18-month project officially started in 2021.

In January, we published a bioethics briefing note on emerging [meat alternatives](#). This briefing examines the ethical, social, and policy challenges of meat production and how current research and scientific developments into meat alternatives may meet rising consumer demands.

In September we published a briefing note on [egg freezing](#), concluding that there is a pressing need for available data on likely success rates of egg freezing to be presented clearly, accessibly, and transparently.

In the same month, we published the [findings of a series of meetings](#) that we held in 2019 to explore experiences, expertise, and ethical challenges in the care and treatment of young people in the UK in relation to their gender identity. Based on these meetings, we decided to pursue an [in-depth inquiry](#) on the topic, which was launched in early 2021.

ACHIEVEMENTS
IN 2020

Impact highlights

COVID-19

Throughout 2020, the Council reacted to the coronavirus outbreak by turning its attention to providing support, information, and advice to ensure that ethics is a key consideration in rapidly developing government and societal responses to the COVID-19 pandemic, especially in the UK.

We were featured in over 200 original media articles or interviews which discussed ethical aspects of the pandemic response. Our work was cited in over 200 academic publications and guidance documents.

Cosmetic procedures (2017)

One of the recommendations we made in our [report](#) was that under 18s should not be able to access cosmetic procedures other than in the context of multidisciplinary healthcare. We have been following up this issue with Ministers and with the Department of Health and Social Care, and were influential in the creation of new Bill, [Botulinum Toxin and Cosmetic Fillers \(Children\)](#), which was introduced in 2020. This Bill has now been enacted.

Research in global health emergencies (2020)

Many of the issues we raised in our research in [global health emergencies report](#) have emerged as central in the global response for research relating to COVID-19. For example, our advice on the importance of locally appropriate study designs and the benefits of early community engagement are embedded in the WHO toolbox on good participatory practice for COVID-19 clinical trials.

Following the completion of our inquiry, our working group members were invited to join or co-chair national and international expert groups that have guided and influenced the research response throughout the pandemic. These include the WHO's COVID-19 working groups on Ethics, Vaccine prioritization, and Social science research, and the UK Government's Scientific Advisory Group for Emergencies (SAGE).

Non-invasive prenatal testing (NIPT) (2017)

An important recommendation of our [report](#) was that information and support provided to pregnant women undergoing NIPT and their partners could be improved. We engaged with the Royal College of Obstetricians and Gynaecologists on this issue and in December 2020 they [published a consensus statement](#) with the Royal College of Midwives, and Society and College of Radiographers on supporting women and their partners through prenatal screening. The statement emphasises the need to provide information, support, and NIPT results to pregnant women and their partners in an unbiased and non-directive way. Women and their partners should be informed about all of their options following screening and be given time and appropriate support to decide upon their next steps.

ACHIEVEMENTS
IN 2020

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 influence in policy circles. Whilst we do this on a day-to-day basis across all of our workstreams, the following are some stand out examples of our success:

In the lead up to publishing our report on research in global health emergencies, we secured support from a number of leading international research funders and research organisations and developed a joint [Call for Action](#) to ensure that research is undertaken ethically during global health emergencies. The call for action gave us an excellent grounding for carrying forward our recommendations with the close attention and support of the people in the right positions to enact change. The Call for Action was supported by:

- International Rescue Committee
- The African Academy of Sciences
- Wellcome
- Médecins Sans Frontières UK
- London School of Hygiene & Tropical Medicine
- Elrha - a global humanitarian research charity
- Fundação Oswaldo Cruz (Fiocruz)
- Geneva Centre for Education and Research in Humanitarian Action
- University of Oxford, Medical Sciences Division

As part of our responsive work on [COVID-19](#) we made the most of our convening power to bring together experts for two important workshops that would inform our briefings to policy makers. The first was on global equity in the development of COVID-19 treatments and vaccines, and the second on COVID-19 testing, immunity, and civil liberties. Our ability to quickly convene expert groups to help define and advise on key ethical questions helped us to provide authoritative and balanced advice.

We built on our work to explore the ethical challenges involved in providing care and treatment for young people in relation to their gender identity, which began with a series of [stakeholder meetings](#) held in 2019. We listened to a range of people, including those who have experiences of using gender identity services in the UK, medical practitioners and others involved in the provision of these services, and researchers with expertise in this area. After further engagement with stakeholders and careful consideration, towards the end of 2020 we decided that to carry out more work in this area and initiated our [current in-depth project](#).



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

Alongside our in-depth inquiries, our series of bioethics briefing notes and a dedicated public affairs capacity have created more opportunities for contributing to important developments in medical and bioscience research. In addition to our contributions on the response to COVID-19 which are discussed above, our portfolio of work included the following outputs.

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In January, we published a bioethics briefing note on the ethical and social issues around emerging [meat alternatives](#). This topic emerged from our 2018 horizon scanning workshop on food sustainability.

We published this to coincide with the 'Veganuary' campaign, and the briefing note received a high amount of media coverage, including interviews with our spokespeople on BBC Radio 5 Live, BBC Scotland, and Channel 5 News. Across print media we gained coverage in The Times, Press Association, Daily Mail, The Telegraph, and Food Navigator, a well-read trade publication for the food industry.

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In September, we published our eighth bioethics briefing note, [Egg freezing in the UK](#). The briefing note highlighted the need for data on egg freezing success rate to be presented more clearly, accessibly, and transparently. The briefing note was well received, and was very timely in its presentation of issues such as the current time limits on egg storage, and the increasing use of egg freezing as an employment benefit.

The briefing note was featured in the BBC, The Telegraph, The Times, Press Association, and the Daily Mail, amongst other publications and broadcast sources. We secured an interview on BBC Radio 4's Today programme and participated in a panel discussion for Tortoise Media's Sensemaker.

We have since been asked by the Department of Health and Social Care to contribute to the development of the Government response following their consultation on the possibility of changing the legislation around statutory storage limits for frozen eggs, sperm, and embryos.

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Throughout 2020 we responded to seven [policy](#) consultations, drawing on our diverse portfolio of work – from genome editing to cosmetic procedures. We were invited to give oral evidence to Parliamentary Committees on two occasions. Our Director, Hugh Whittall, [gave evidence](#) to the House of Lords Science and Technology Committee for their inquiry on the science of COVID-19. Clare Chambers, Council member, [gave evidence](#) to the All-Party Parliamentary Group on Beauty, Aesthetics and Wellbeing as part of their inquiry into non-surgical cosmetic procedures. Our evidence was widely cited in the concluding report of the inquiry.



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 often develop over an extended period.

The collective experience, knowledge, and skills of our Executive team, Council members, and working group members are valuable assets in building the Council's reputation for authoritative and balanced advice. Increasingly, the Executive team and Council members are being invited to share their expertise and have impact in various ways, for example acting as advisors, sitting on influential policy committees, and giving presentations. Often these invitations are from governmental or high-profile international bodies. In 2020, Council representatives were involved in the following organisations and Committees:

- **Council of Europe Committee on Bioethics** – Pete Mills (Assistant Director) is the UK delegate to the Council of Europe Committee on Bioethics. He is a member of a new Article 13 working group. Article 13 is the prohibition on heritable genetic modification.
- **Global Observatory on Genome Editing** – Pete Mills was appointed to the advisory board for the Global Observatory for Genome Editing. He is also working with an international collaboration to develop a resource on genomic ethics.
- **UK National Screening Committee** – from April 2020 to June 2021, Catherine Joynson (Assistant Director) was seconded to the UK National Screening Committee. There she helped develop an ethical framework for screening and contributed to a public dialogue on whole genome sequencing in newborns, a topic of one of our previous bioethics briefing notes.
- **Promoting Global Clinical Research in Children** – Katharine Wright (Assistant Director) is a member of the decision-making subgroup of the Multi-Regional Clinical Trials Center's project on promoting global clinical research in children.
- **National Ethics Committees** – our Chair, Dave Archard, gave two presentations to the Forum of National Ethics Councils of the European Union on *Ethical lessons from the COVID-19 pandemic: the UK experience* and *Vaccines for COVID-19*. Director Hugh Whittall presented on human genome editing, focusing on our joint statement with the French and German ethics committees.
- **COVID-19 Clinical Research Coalition** – Katharine Wright 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.
- **World Health Organization (WHO) COVID-19 working groups** – following our report on research and global health emergencies, members of the working group were invited to join a number WHO working groups. Beatriz da Costa Thomé is Co-Chair and Michael Parker is a member of the Ethics and COVID-19 working group, and Emily Chan is Co-Chair of the COVID-19 Social Science Committee.
- **Scientific Advisory Group for Emergencies (SAGE)** – Michael Parker, Chair of our working group on research in global health emergencies, was invited to sit on the UK Government's Scientific Advisory Group for Emergencies (SAGE). He was asked to contribute input from the Nuffield Council on Bioethics, so we held fortnightly meetings to brief him on relevant issues.



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

Throughout 2020, the Council reacted to the coronavirus pandemic by turning its attention to providing support, information, and advice to ensure that ethics is a key consideration in rapidly developing government and societal responses to the COVID-19 pandemic.

The COVID-19 pandemic led us, like many others, to new ways of working. Remote working and a new focus on online collaboration brought new opportunities for us to engage with our international colleagues. We participated in over 20 international events throughout the year, including our own series of webinars that attracted a global audience.

In the first wave of the pandemic we worked to convene a [series of webinars](#) on different ethical issues arising in relation to COVID-19. Online activities meant that we were able to include people from across the world with ease.

International collaboration would be especially important in the development of our briefing note on fair and equitable access to COVID-19 vaccines and treatments. We were able to convene an international group for a meeting to discuss equity in the development of COVID-19 vaccines and treatments, which would feed into our [briefing note](#) on the topic. This briefing led to an invitation from HM Treasury to present the findings at a meeting with 48 UK Government officials from different departments concerned with global health policy (Treasury; Cabinet Office; DHSC; and Foreign, Commonwealth and Development Office). This meeting would help inform policy on the UK's obligations to support global access to effective COVID-19 interventions. We later became a signatory of the [WHO's 'COVID-19 vaccine equity declaration'](#).

From early on in the pandemic, it was clear that immunity certification would play a significant role in developing public health policy. We convened a group of multi-disciplinary experts to discuss the ethical issues around COVID-19 testing, immunity, and civil liberties. This discussion would feed into our briefing note on [COVID-19 antibody testing and 'immunity certification'](#).

We worked with colleagues, partners, and collaborators to publish the [short guide and overview](#) of our research in global health emergencies report in Chinese, Farsi, French, Portuguese, and Spanish, and the overview in Arabic.

We worked together with The Global Health Network to launch a [free online course](#) based on our report. The course is available in English, French, Portuguese, and Spanish.

We led the production of a [joint statement](#) on human genome editing with the French and German National Ethics Councils and secured placement of the statement in *Nature*.

ABOUT

People

Council Members 2020

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

David Archard (Chair)
Shaun Pattinson (Deputy Chair)
Carol Brayne
Simon Burall
Victoria Butler-Cole
Simon Caney
Melanie Challenger
Clare Chambers
Tara Clancy
John Coggon
Frances Flinter
Elaine Gadd
Andy Greenfield
Anne Kerr
Michael Reiss
Mehrunisha Suleman
Susan Tansey
Christine Watson
Robin A Weiss
Heather Widdows

The Executive

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

Arzoo Ahmed, Research Officer
Ruth Campbell, Programmes Manager
Claudia Corradi, Research Officer
Molly Gray, 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

ABOUT

Financial information

Financial Report for the year to 31 December 2020

	2020 Actual £	2019 Actual £
Expenditure		
Salaries and staffing costs	808,251	709,859
Reviewers' and consultants' fees	31,246	20,745
Office and premises costs	2,269	2,851
Journals & subscriptions	19,033	10,774
Travel and meeting costs	20,508	98,093
Web, printing, and publicity	18,156	30,481
Total expenditure	899,463	872,774
Funded by:		
Nuffield Foundation	283,212	288,690
Medical Research Council	283,212	288,690
Wellcome	283,212	288,690
Other	49,826	6,705
	899,463	872,774
Total funding 2020		
Medical Research Council	394,523	
Wellcome	394,523	
The Nuffield Foundation	394,523	
Other	49,826	
Less contribution to overheads shared equally among funders	- 261,000	
	972,395	
Amount drawn	899,463	
Outstanding funding 2019	72,932	

ABOUT

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Facebook: facebook.com/nuffieldbioethics
Newsletter: [sign up](#)