

NUFFIELD
COUNCIL^{ON}
BIOETHICS

Annual Report 2017

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Chair's foreword

Taking up the Chair of the Nuffield Council on Bioethics in 2017 was a great honour. The first year in the post has proved incredibly challenging but at the same time immensely rewarding. The meetings I have already attended across the world have provided ample evidence of the reach and enormous reputation of the Council's work.



The Council has repeatedly been described to me as setting the gold standard in ethical review of the major topics in biological and medical science and practice. Getting to know both the Council Members and the Executive team has made me all too aware of the range of talent, skills, and commitments within the Council as a whole and the reason it has been able to produce such consistently excellent work.

The Council is a fantastic body of individuals. Nevertheless, I trust, following a review of our approach to recruitment, that we can welcome future expressions of interest to serve from a wider diversity of backgrounds and interests. That review of membership has been one part of a more general implementation of strategic change. Our new horizon scanning process is an excellent innovation that allows Council to be ahead of the curve when identifying appropriate topics to consider amongst a bewildering array of new scientific and medical developments. Moreover, broadening our portfolio of outputs now allows us to respond in different ways and I particularly welcome the initiative of producing short briefing notes, which will help us to contribute to a wider range of current debates.

In-depth inquiries are nevertheless still central to our ongoing work, and my first year in post has seen the near completion of the highly important and eagerly anticipated report on *genome editing and human reproduction*, as well as the beginnings of the process of producing a major report on *research in global health emergencies*.

It is important to me that the Council consolidates and expands its international links, and I have been especially pleased to be involved in establishing new relations in China and Hong Kong.

The Council now has a new governance structure and I have been delighted to share my first year with the new Chair of the Governing Board, Sally Macintyre. The introduction of the Governing Board has been a positive step and it promises to be a highly constructive relationship for the Council.

Finally, it has been a pleasure working with the Executive and I am extremely grateful to the Director, Hugh Whittall, for the exemplary help and advice he has offered me during my first year. I look forward to more exciting years helping to shape the unique and important work of the Nuffield Council on Bioethics.

David Archard

Director's foreword

2017 was a year of positive change for the Council, driven by our desire to evolve as a trusted organisation that helps shape and inform policy and public debate of bioethical issues. Whilst maintaining our in-depth inquiries, on which our reputation for quality and thoroughness is founded, we created the space for a new flexible work programme that will enable us to respond more rapidly and effectively to issues as they arise.



We have worked to develop a more strategic and dedicated approach to horizon scanning, to strengthen our ability to anticipate questions that are, or are likely to be, of public concern. This included setting up a new Horizon Scanning Advisory Group and working to develop an extended range of external contacts.

We have developed a new active responsive programme to maximise our contributions to policy and public affairs, including policy-focused briefing papers, media activity, opinion pieces, workshops, and briefings for parliamentarians and Ministers. An important aspect of this is creating the capacity to make more effective use of our intellectual capital and extensive range of previous work, which we know has lasting relevance for new questions that arise with advances in biological and medical research, as well as for older questions that persist. As I write, the fruits of this work have already become very evident, not least through well-received briefing notes on *the search for a treatment for ageing* and on *whole genome sequencing of babies*.

We have devised a new communications and engagement strategy, with increased focus on engagement with parliamentarians and policymakers, and on increasing our international profile and influence.

We have implemented a new governance framework, including setting up a Governing Board, conducting a review of Council membership, and improving our business planning.

Alongside all this, we have published two major reports this year, on *non-invasive prenatal testing* and *cosmetic procedures*. Both of these reports have already had significant influence in informing policy, practice, and public debate in their respective areas, as you can read about in the following pages. We also look forward to the publication of our report on *genome editing and human reproduction* in 2018, which will benefit tremendously from the thorough research, consultation, and engagement carried out throughout this year.

I am extremely grateful to my colleagues in the Executive who have continued to show great skill and commitment in delivering a significant programme of work whilst embracing and supporting some important changes in our priorities and practices.

We were delighted in early 2017 to welcome Dave Archard as our new Chair, following his appointment by our funders. We have already benefitted greatly from his thoughtful leadership over the course of this year. I am pleased to report that our funding bid for 2018-2022, incorporating our new approaches and systems, was successfully completed and our core funding has been agreed until 2022. We have a new strategic plan for 2018-2022 and I look forward to working with colleagues on delivering our goals as we build on the groundwork that we have laid this year.

Hugh Whittall

Non-invasive prenatal testing: ethical issues

Our [report](#) on non-invasive prenatal testing (NIPT) was published on 1 March 2017, following extensive consultation and engagement activities to gather the views of a wide range of people affected by prenatal testing.

The report explores the ethical issues arising from current and possible future uses of NIPT, and considers how this could change the way we view pregnancy, disability, and difference. We make a number of recommendations regarding the use of NIPT for significant medical conditions and impairments, for other genetic conditions and variations, and for whole genome sequencing of fetuses.

Policy and impact highlights



The report was launched at an event held in Speaker's House at the Palace of Westminster. Following the launch, we were invited to present our findings to two Department of Health Ministers. We emphasised the need for better information and support for women and couples undergoing screening for Down's, Edwards', and Patau's syndromes, and set out the reasoning behind the Council's recommendations

that NIPT should not be used to determine the sex of a fetus very early in pregnancy, nor for whole genome sequencing outside research environments.

Our report has informed the work of Public Health England in developing patient materials and training for healthcare professionals involved in prenatal screening ahead of the roll out of NIPT in the NHS in 2018. As recommended in our report, people with first-hand knowledge of the conditions being screened have been involved with this work.

To help improve the information women receive through commercial providers of NIPT, we produced a [guidance leaflet](#) for manufacturers and private clinics on the kind of information they should include on their websites and patient leaflets about NIPT and the conditions being screened for.

In line with our recommendations, the UK National Screening Committee has set up an Ethics Task Group to develop methods for considering ethical issues relating to screening programmes.

From the blog

- [NHS Wales offers non-invasive prenatal testing one year on from our ethics report](#)
- [Reflections on reactions to the Council's report on NIPT](#)
- [NIPT – exploring the views of patients, families and advocacy groups](#)

Media

Our media campaign for the launch resulted in coverage in the [Daily Mail](#), [The Sun](#), [The Telegraph](#) and on [BBC Online](#), a broadcast debate on BBC2's Victoria Derbyshire show, and specialist articles including the [BMJ](#) and [Nursing Times](#). A longer interview with Chair of the Working Group, Professor Tom Shakespeare, was later published in [The Telegraph](#). Comment articles responding to the proposal for a new 'reflex' model for prenatal screening were published in [BioNews](#) and [Genetics in Medicine](#).

Cosmetic procedures: ethical issues

This [report](#) was published on 22 June 2017 following a two-year inquiry. As part of our evidence gathering work, we ran an online survey for members of the public to contribute their views on the increasing use of cosmetic procedures (including surgical procedures, and non-surgical interventions such as the use of Botox and dermal fillers). We consulted with a range of professional organisations, providers of cosmetic procedures, researchers, and stakeholders.

A policy-focused discussion event was held launching the report to key audiences. The report makes a number of recommendations to policy-makers and others for action to promote ethical practices with respect both to influences that encourage people to consider cosmetic procedures - such as social media and advertising - and to the supply of those procedures.

Policy and impact highlights



The report has attracted interest from a number of Parliamentarians, and we have been invited to discuss our recommendations for the regulation of cosmetic procedures with the Health Minister.

We provided support on parliamentary questions on the regulation of cosmetic procedures including the effectiveness of voluntary schemes

for the registration and certification of practitioners offering cosmetic procedures to individuals.

We briefed Lord Lansley regarding his Private Members' Bill on standards in cosmetic surgery provision, and organised a roundtable that brought together major commercial providers of cosmetic surgery with the GMC, Royal College of Surgeons, and others to discuss practical ways forward regarding training and accreditation of surgeons.

Members of the Working Group and Executive took part in a panel discussion at the Bush Theatre, following a showing of [The B*east](#)s, a play by Monica Dolan.

From the blog

- ["You don't put a bad picture on Instagram"](#)
- [Regulation and cosmetic procedures: counselling caution](#)
- [Beauty and the business](#)

Media

Our findings generated wide news coverage for example: articles in [The Telegraph](#), [The Daily Mail](#), [The Guardian](#), [The Sun](#); discussion on ITV's Good Morning Britain and on several BBC radio stations including Radio 1, Radio 5 Live, Radio 4 Today Programme and local stations.

In-depth feature articles followed in the [British Medical Journal](#) and [Aesthetics](#). Members of the Working Group took part in discussions on BBC World Service [Health Check](#) and BBC Radio 4's [You and Yours](#), and we had a letter published in the [Guardian](#).

Genome editing: human reproduction

Throughout 2017, extensive research was undertaken to inform this [inquiry](#), which focuses on the potential use of genome editing to influence inherited genetic characteristics in humans. This included an online survey, which received 320 responses. We also ran a call for evidence, held a series of factfinding meetings, organised panel and individual interviews, and commissioned two reviews to inform the Working Group's deliberations.

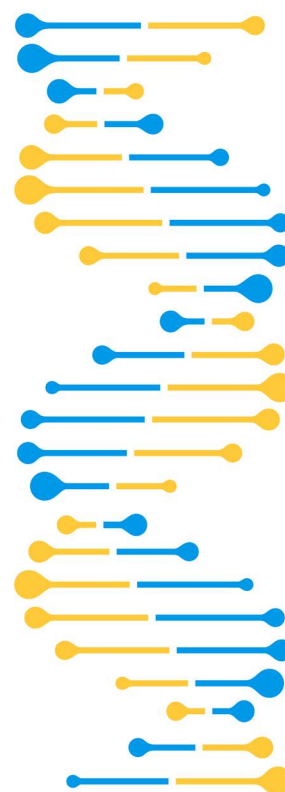
As this work was progressing, we were taking part in a number of national and international discussions and initiatives on genome editing. Highlights include presentations at the 20th Anniversary of the Oviedo Convention at the Council of Europe, and major congresses in Germany, Hong Kong, Jerusalem, Spain, and India. We were invited to give [evidence](#) to the House of Commons Science and Technology Committee inquiry on genomics and genome editing.

This project builds on our previous report [Genome editing: an ethical review](#) published in September 2016, which set out preliminary findings on the impact of genome editing across different areas of biological research and applications, and identified key ethical questions to address.

The report on genome editing and human reproduction will be published in 2018, after which we will begin work on a further project on the use of genome editing in livestock.

From the blog

- [Assessing the security implications of genome editing technology](#)
- [Genome editing, human rights and the 'posthuman'](#)
- [CRISPR in North America: the National Academies' report](#)



Research in global health emergencies

A new [inquiry](#) was established in November 2017 to examine the ethical issues raised by conducting health-related research in global health emergencies.

Recent global health emergencies such as the Ebola epidemic have highlighted the important role of health research in outbreak responses. The Working Group will be addressing the current lack of consensus on what is ethically acceptable during emergencies and will launch a consultation in the early part of 2018 as part of its evidence gathering activities. We expected to publish this report by the end of 2019.

As with all of our in-depth inquiries, we had been tracking this issue for some time prior to setting up a working group. We commissioned a background paper and held an exploratory workshop in 2016 to inform our thinking and the scope of the inquiry. We used these to develop a [briefing note](#) setting out key ethical challenges, which we published in July 2017.

From the blog

- [Research in the context of global health emergencies: writing a background paper for the Nuffield Council on Bioethics](#)



Time limits on maintaining human embryos in research



In August, we published a series of [discussion papers](#) on the statutory limit for maintaining human embryos in culture. The publication includes a report of a workshop that we convened, prompted by research that raised the possibility that embryos could successfully be grown in the laboratory beyond the current UK legal limit of 14 days. It includes a

commissioned background paper, 12 individual reflections from workshop participants from different perspectives and backgrounds, and an introductory essay from Professor Jonathan Montgomery, former Chair of the Council.

The publication aims to provide greater clarity for anyone involved in reviewing existing policies and arrangements for embryo research. Whilst it acknowledges the significant potential benefit that could flow from extended embryo culture in the future, it notes that the UK Parliament is unlikely to consider a change in the law without having a much more clearly articulated scientific case to consider.

From the blog

- [Loomings: extended embryo culture and the Pillars of Hercules](#)

UK Parliament briefing: Ethical challenges in bioscience and health policy

In October, we published a [briefing note](#) for Parliamentarians on four key ethical challenges in bioscience and health policy:

- Building and maintaining trust in medical research and the life sciences
- Ensuring research and innovation address the needs of society
- Promoting responsible health policy and research
- Promoting international leadership in bioethics

We set out suggestions on how to address these challenges, bringing together conclusions and recommendations from our portfolio of current and previous projects.



We received a response from the Secretary of State for Health, Jeremy Hunt, who said,



The ethical challenges you describe [in genome editing and opt-out organ donation] form an important part of the debate, and the insights offered within as to how these can be addressed will no doubt prove to be an invaluable resource to Parliament.”

Influencing Parliamentary discussions on research integrity

In October 2017, Professor Dame Ottoline Leyser, who chaired the Council's steering group on the [culture of scientific research](#), gave oral [evidence](#) to the House of Commons Science and Technology Select Committee as part of its inquiry on research integrity. Highlighting our [key finding](#) from 2014 that the hypercompetitive culture of academic science, and the way in which science and scientists are assessed, can have a negative impact on the production of high-quality, ethical, and valuable science, she called for more diversity in assessment criteria to bring about change in the culture of research.

The inquiry was initiated following the publication of a POSTnote on research integrity in January (see below).

Parliamentary Office for Science and Technology (POST) Fellowships

Back in 2014, we began a partnership with POST to support three Fellowships to produce topical briefing notes on areas of public policy that raise bioethical issues. Two of these POSTnotes were published in 2017:

A POSTnote on [research integrity](#), examining approaches to promoting high-quality, ethical, and valuable research. This note drew on our 2014 report on the culture of scientific research. It was researched and written by POST Fellow Cressida Auckland.

A POSTnote on [global health inequalities](#), reviewing trends in global health inequalities and the different ways in which these have been measured. It examines different approaches to reducing health inequalities and challenges in implementing targets such as the Millennium Development Goals, the Sustainable Development Goals, and Universal Health Coverage. It was researched by POST Fellow Stephen Barrie.

Consultation responses

During the year, we responded to eight consultations of the following organisations, building on recommendations we have made in our published work:

- Cosmetic Practice Standards Authority consultation on its standards
- House of Commons Select Committee on Health inquiry on Brexit: medicines, medical devices and substances of human origin
- Independent Advisory Group on the use of biometric data in Scotland
- National Institute for Health Research 'Future of Health' project
- British Youth Council Youth Select Committee consultation on body image
- House of Commons Select Committee on Science and Technology inquiry on research integrity
- European Commission Directorate for Health and Food Safety consultation on the Paediatric Regulation
- House of Commons Select Committee on Science and Technology inquiry on genomics and gene editing

Consultation responses are published in full in the [policy section](#) of our website.

Blogs

In 2017 we published 18 blog posts written by the Executive, Chair, Members, and guest bloggers. These blogs covered a range of topical news and policy issues in health and biosciences that our current work and past projects have touched on.

The top three (most read) blogs from 2017 were:

1. [Making unbearable decisions about the care and treatment of a seriously ill child – ethical reflections](#)
2. [Public health ten years on](#)
3. [A new social contract for Generation Genome?](#)

Presentations and events

To ensure our continued engagement in a range of science, policy, and research networks, we organise and participate in numerous events each year, reaching key audiences in the UK and on influential international stages.

In 2017, our Executive and Council took up invitations to present our work at 41 meetings and conferences, half of which were in the UK, with the remaining events in countries including India, China, USA, Peru, Israel, Thailand, Italy, Germany, Spain, Switzerland, and France.

We held or attended a further 35 meetings with national and international policy-makers and stakeholders to discuss how our work could inform policy and practice.

International highlights

Director Hugh Whittall continued his leading role with the Steering Committee of the Global Summit of National Ethics Committees, which is supported by WHO and UNESCO, in preparation for the 2018 Summit in Senegal. Hugh led the drafting of the statement that was published following the Summit, agreed by delegates from 65 countries.

Assistant Director Pete Mills was the UK national delegate on the Council of Europe Committee on Bioethics (DH-BIO) which met twice in 2017.

Director Hugh Whittall and Chair Dave Archard attended the 20th Anniversary of the Oviedo Convention at the Council of Europe in Strasbourg in October and the Global Forum of National Ethics Committees in Estonia in November.

The annual trilateral meeting with the French and German national bioethics commissions was held in Paris on 30 June, where the discussions focussed on human reproductive medicine, and ageing.

Web audiences

Demonstrating our international reach, 61% of visits to our website in 2017 were from outside of the UK. Of the total 142,000 visits to our website:

- 45%** were from Europe (including UK)
- 25%** were from North America
- 17%** were from Asia
- 6%** were from Australasia
- 4%** were from Africa
- 3%** were from Central and South America

Council Members

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

Chair

David Archard

Deputy Chair

Julian Hughes

Members

Simon Caney
Tara Clancy
Ann Gallagher
Andy Greenfield
Erica Haines
Roland Jackson
David Lawrence
Shaun Pattinson
Tom Shakespeare
Mona Siddiqui
Christine Watson
Robin A Weiss
Heather Widdows
Adam Wishart
Paquita de Zulueta

Executive

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

Hugh Whittall
Katharine Wright
Peter Mills
Catherine Joynson
Shaun Griffin (maternity cover)
Carol Perkins
Kate Harvey
Ranveig Svenning Berg
Anna Wilkinson
Sophia Griffiths (maternity cover)
Jade Rawlings (maternity cover)
Bettina Schmietow (maternity leave)
Sarah Walker-Robson (maternity leave)
Busayo Oladapo (maternity leave)

Governing Board

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

Chair

Sally Macintyre (Chair)

Members

Stephen Holgate
Vivienne Parry
Brian Scott

Financial information

	2017 £	2016 £
Actual expenditure		
Salaries and staffing costs	657,355	615,345
Reviewers' and consultants fees	25,878	42,342
Office and premises costs	5,411	7,146
Journals & Subscriptions	15,512	12,857
Travel and meeting costs	53,935	105,487
Web, Printing and Publicity	35,836	30,756
Total	793,927	813,933
Actual expenditure funded by:		
Nuffield Foundation	264,257	271,131
Medical Research Council	264,257	271,131
Wellcome Trust	264,257	271,131
Other	1,155	540
	793,927	813,933
Total funding 2017	£	
Medical Research Council	169,000	
Wellcome Trust	169,000	
The Nuffield Foundation	169,000	
2012-2016 funding's underspend	319,198	
Other	1,155	
	827,353	
Amount Drawn	£	
Year ending 31 December 2017	793,927	
Outstanding Funding 2017	33,426	

About us

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