



NUFFIELD
COUNCIL^{ON}
BIOETHICS

ANNUAL
REPORT
2016

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Foreword from the Chair and Director

Chair

I am delighted to be assuming the position of Chair of the Council. Since I was involved in the report on *Critical care decisions in fetal and neonatal medicine* more than ten years ago, I have actively followed the Council's work and have seen its reputation and influence grow nationally and internationally. The vital role it plays in providing independent advice to policy-makers and in stimulating debate will, I believe, become even more important in the future.

Over the next five years, I look forward to leading the Council in the development and delivery of a new Strategic Plan, in what is an increasingly complex and fast-moving context of biomedical scientific progress. The Plan will see us enhance our horizon-scanning capability, increase our range of outputs within the terms of reference, develop new partnerships, and extend our international reach and status. I also look forward to working closely with Sally McIntyre who chairs our new Governing Board, an initiative that will help us remain focused and relevant.

Whilst I cannot take credit for the work of the last year, I have been nothing but impressed by the quality and breadth of the Council's outputs. I would like to thank all those who have served on the Council and the Executive over the year, especially Geoff Watts whose term came to an end. I reserve particular thanks for Jonathan Montgomery, whose five-year term as Chair left us with a fantastic legacy for which we are extremely grateful.

Professor Dave Archard

Director

This year saw the 25th Anniversary of the Council and my 10th Anniversary as Director. Back in 2007, I said I had the privilege of joining an organisation that had developed a strong national and international profile and reputation, based on the quality of its work. That still stands and I hope has been enhanced. During my tenure, we have produced reports on subjects as diverse as mitochondrial DNA disorders, children's involvement in clinical research, the use of biodata in research and healthcare, dementia, and biofuels. These have been hugely influential in informing policy, practice, and public opinion.

In September 2016, we published *Genome editing: an ethical review*, which identified key issues and ethical questions raised by the range of possible applications of genome editing. We identified priorities for future work by the Council, the first of which, on the potential use of genome editing in human reproduction, is now underway.

Work on our cosmetic procedures report got well progressed throughout 2016, looking not only at the scientific and technological developments in this area, but also at the pressures that help to drive demand. And our inquiry into non-invasive prenatal testing, established in April, started to consider how this new technology could change how we view pregnancy, disability,

and difference; and what the wider consequences of its use might be.

The range of outputs in terms of subject matter, as well as format, was reflected in the diversity of inputs from experts, including the Council, Working Party members, and the many different groups and individuals that attended factfinding meetings and responded to our consultations.

We held workshops on the ethics of research on ageing, research in global health emergencies, and the '14-day rule' in embryo research; and published briefing papers on a diverse range of subjects on our website, which serve as a resource in themselves. The Council is currently prioritising its future work activities and will, alongside its major reports, develop even more diverse outputs that are more agile and responsive to emerging developments.

Our reports have currency for many years after their publication. Highlights over the last year included the international symposium on children in clinical research, attended by representatives from the World Health Organisation and researchers from low- and middle-income countries. Our biodata report was influential in informing the House of Commons Science and Technology Committee inquiry on the subject. In addition, our report on the culture of scientific research and our rapidly produced briefing on ethical considerations relating to the Zika virus epidemic informed two other inquiries by the same Committee.

During our 25th Anniversary year, we sponsored the 13th World Congress of the International Association of Bioethics, presented at the US



Presidential Commission for the Study of Bioethical Issues, and took part in discussions with the Council of Europe, the European Commission, the Global Summit of Global National Ethics Councils, and many others.

The year was an opportunity for us to reflect on where we had come from and where we are going and, as we said goodbye to Jonathan, with whom it has been a great pleasure to work, we welcomed David Archard. I look forward to embarking on a new episode in the Council's journey with him.

I cannot close without saying a huge thanks to the Executive team who have worked so hard, sometimes too hard, in producing outputs of high quality and impact and in maintaining the Council's role and profile in an increasingly complex world.

Hugh Whittall

Publications and activities

In 2016, the Council published *Genome editing: an ethical review*, which itself will inform two further inquiries. The Council also produced background papers and held workshops on the ethics of research on ageing, on research in global health emergencies, and on time limits on maintaining human embryos in culture.

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Genome editing: an ethical review

The idea of making controlled alterations to the genome is not new, and some may see the techniques now available as new tools, much better in many respects than those that have been previously available, but serving a similar range of ambitions. Others, however, may see them as transformative, opening up new horizons of possibility in science and technology.

On 30 September 2016, the Council published *Genome editing: an ethical review*. In the review we explained that the possible uses of genome editing techniques, such as the CRISPR-Cas9 system, raise important ethical questions across many areas, including human health, food production, wildlife and ecosystems; and industrial, military and amateur uses.

Genome editing: an ethical review will inform two further inquiries by the Council which will take as a starting point the challenges where genome editing is having, or is expected to have, an impact. The first of these will focus on the potential use of genome editing in human reproduction and the second on its use in livestock to potentially improve systems of animal husbandry and food production.

The Working Group

The Working Group of eight members was chaired by Dr Andy Greenfield, Council member, Programme Leader in Developmental Genetics at the Medical Research Council's research unit in Harwell, and member of the Human Fertilisation and Embryology Authority. [Find out more....](#)

From the blog

- [CRISPR in South America: a case for 'liberation genomics'?](#)
- [Public dialogue on genome editing: Why? When? Who?](#)

What's next

The next stages of this work programme are already underway. A new Working Party looking at genome editing in human reproduction is well-established (see section on Projects in progress for more detail). A Working Party looking at genome editing in livestock is due to begin its work in 2018.

Other activities

The Working Group's call for evidence, which closed in February, elicited 54 responses. The Group also conducted a number of fact-finding exercises, which, in 2016, included meetings on genome editing and animal research; and on biomedical research and applications.

Alongside the inquiry, in March, The Council and [Sciencewise](#) co-hosted a workshop to discuss the possibilities and limitations of public dialogue for genome editing policy and regulation. Participants included researchers, funders, policy makers, and experts in dialogue design and evaluation. More information is available in a [report](#) from the day and on our [blog](#).

Launch

Genome editing: an ethical review was published on 30 September. [Media coverage](#) included BBC Radio 4's Today programme, a front-page story in *The Guardian*, as well as articles in *The Times*, *Financial Times*, *Telegraph*, *Nature* and the *British Medical Journal*. We held a launch event for the review in London on 6 October.

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Workshops and background papers

The Council held three scoping workshops with stakeholders in November and December to explore subjects that were prioritised for further exploration following the Council's Forward Look meeting in February:

The ethics of research on ageing

The aim of this workshop was to identify the key ethical and social issues raised by research that is seeking to slow or prevent ageing. The discussion was informed by a background paper on longevity.

Ethical challenges of pursuing research and scientific innovation in global health emergencies

This workshop explored the ethical challenges of pursuing research and scientific innovation in the face of global health emergencies, including public health emergencies, such as those recently arising out of Ebola and Zika epidemics. The discussion was informed by a background paper commissioned for the workshop. A note of the meeting has been published, and a short briefing note drawing on the discussion will be published later in 2017.

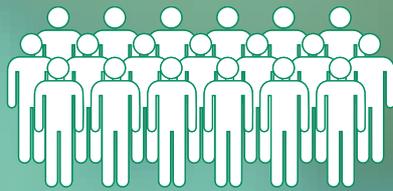
Time limits for maintaining human embryos in research

This workshop considered whether or not there may be persuasive reasons to review the legal time limit for maintaining human embryos in culture. It was informed by the 2016 Forward Look discussion on artificial gametes. A report of the meeting and other materials including a new background paper commissioned for the meeting will be published later in 2017.

Two other background papers were prepared for exploratory workshops in 2016 and informed further work over the year. A paper on Dual use in biology and biomedicine, commissioned for the Forward Look meeting, helped in part to inform Genome editing: an ethical review which was published in September; and the background paper for an expert meeting on non-invasive prenatal testing (NIPT) would go on to inform the 2017 report on NIPT.

The Council is currently considering whether to carry out any further work on these topics.

Projects in progress



Genome editing:
human reproduction



Cosmetic procedures



Non-invasive
prenatal testing



Foreword from the Chair
and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Genome editing: human reproduction

In September, following on from the publication of *Genome editing: an ethical review* (see previous section), a new Working Party was established to develop practical ethical guidance for the application of genome editing in human reproduction. Its terms of reference are:

- to examine ethical questions relating to the attempted influence of inherited characteristics in humans, in the light of the likely impact of genome editing technologies;
- to review relevant institutional, national and international policies and provisions; and to assess their suitability in the light of the ethical questions examined; and
- to report on these matters, and to make recommendations relating to policy and practice.

A Council report on the subject is due for publication in early 2018.

The Working Party

The Working Party, which has eight members, is chaired by Professor Karen Yeung, Professor of Law and Director of the Centre for Technology, Ethics & Law in Society, King's College London. [Find out more....](#)



Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Cosmetic procedures

There has been increasing demand for invasive cosmetic procedures in the UK in recent years, prompting questions about what might be the drivers of this demand, potential risks to users and the role of regulation and professional standards in this area. Over the course of 2016, this project has been exploring ethical issues in cosmetic procedures, with a particular focus on the roles and responsibilities of health professionals and others in responding to, or indeed stimulating, demand for invasive, non-reconstructive, procedures that aim to enhance or 'normalise' appearance.

The Working Party's online survey, which sought to gather views on issues around cosmetic procedures from interested members of the public between March and June, had 448 responses. Over the same period, its call for evidence – aimed at professional bodies, practitioners and academics working in the field and policy bodies – generated a substantial number of comments on a range of questions. Analyses of both will be available on the Council's website when the Working Party's final report is published in June 2017.

The Working Party also held a number of deliberative workshops with young people to explore the ethical issues arising from the use of cosmetic procedures, including with members of the NIHR's Young Persons' Advisory Groups, who previously worked with the Council as part of its project on *Children and clinical research: ethical issues*. In December 2016, the Working Party also hosted a focus group with stakeholders from the charity [Changing Faces](#) to discuss a range of issues, including how society responds to people with a disfigurement.

In addition, over the course of the past year, the Working Party met various organisations and individuals to explore issues raised by the project's [terms of reference](#) in greater detail. These included professional bodies and regulators; commercial providers of cosmetic procedures; and practitioners. The Working Party also engaged academics with expertise in visual culture, medical history, law and gender issues; journalists; as well as representatives from Facebook and Instagram.

The Working Party

The Working Party has 12 members and is chaired by Jeanette Edwards, Professor of Social Anthropology at the University of Manchester. [Find out more....](#)

From the blog

- [Routine vs exceptional cosmetic procedures: a helpful distinction?](#)

Update

The report *Cosmetic procedures: ethical issues* was published in June 2017: www.nuffieldbioethics.org/cosmeticprocedures



Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Non-invasive prenatal testing

Non-invasive prenatal testing (NIPT) is a technique that can be used to test a fetus for genetic conditions and variations. It involves taking a blood sample from the pregnant woman at around 9 or 10 weeks of pregnancy. NIPT is already used in the NHS to test for conditions such as cystic fibrosis, and from 2018 it will be available as a second-stage screening test for Down's, Edwards' and Patau's syndromes, as part of the NHS fetal anomaly screening programme. NIPT is more accurate than other screening tests; it carries no risk of miscarriage (although a diagnostic test is still required in the case of a positive test to get a definite diagnosis); and, in some circumstances, it can provide earlier results than current screening and diagnostic tests.

The Council established a Working Group in April 2016 to consider, at an early stage of its use, how NIPT could change the way we view pregnancy, disability and difference, and what the wider consequences of its increasing use might be.

Between April and December, the Working Group consulted widely and listened carefully to those with an interest in NIPT. In August, it commissioned the learning disability charity Mencap to carry out interviews with people with Down's syndrome. Other consultation activities included an online survey that elicited over 700 responses, an open call for evidence, and meetings with people with experience of and views about NIPT. The latter included women who had recently had prenatal screening, families of people with genetic conditions, companies developing and offering NIPT, healthcare professionals, and regulators and professional bodies.

Update

The report *Non-invasive prenatal testing: ethical issues* was published in March 2017: www.nuffieldbioethics.org/NIPT

The Working Group

The Working Group had seven members and was chaired by Tom Shakespeare, Professor of Disability Research, University of East Anglia. [Find out more....](#)



Informing policy

The Council contributes to policy discussions and informs decision-making in a number of ways. These include follow up of our reports and other publications, Parliamentary engagement, responses to policy consultations, meetings with policy-makers and influencers, and participation in roundtables and workshops. In this section, we present some highlights from our policy activities and impact in 2016.

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Follow up of publications

Children and clinical research: ethical issues (published May 2015)

International

In March, the Council hosted an [international symposium](#) with the [Global Health Bioethics Network at the Ethox Centre](#), and the [Wellcome Trust Brighton and Sussex Centre for Global Health Research](#). Participants included representatives from the World Health Organization (WHO), CIOMS and PAHO, alongside researchers from low- and middle-income countries. Following the event, the Council published a [detailed report](#) of the discussion and a [compilation](#) of delegates' accounts of children's participation in clinical research in different countries.

Working with industry

In April, the Council [hosted a meeting](#) with the NIHR to explore collaboration between life-sciences industry and young people to improve research. The meeting resulted in a number of plans for future action including a '[statement of aspiration](#)', published in June, to which all of the life sciences companies present at the meeting signed up.

Joint statement on protection of time for Research Ethics Committees

The Council worked with the Royal College of Paediatrics and Child Health (RCPCH) and NHS Employers to produce a [joint statement](#) on the protection of time for paediatricians to take part in Research Ethics Committees. The statement, which was issued to NHS workforce-planning bodies, called on them to acknowledge the importance of capacity-building.

Animation

Following the translation of the Council's successful animation *Health research: making the right decision for me* into Spanish, 2016 saw its translation into [Arabic](#) and [Mandarin](#).

Young Person's Advisory Groups

The Council has played a role in promoting the UK's model of Young Person's Advisory Groups, which support children and young people's involvement in the design and delivery of health research. For example, in June the Council took part in the International Children's Advisory Network (iCAN) workshop in Barcelona, and it has supported current and new advisory groups with materials. One such advisory group has now been set up in the [Angkor Hospital For Children](#) in Siem Reap, Cambodia, and plans to set up further groups are under consideration in Kenya and Malawi.

Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review (published 2012)

The UK is the first country to approve regulations on mitochondrial donation and as a result there has been significant international interest in the Council's 2012 report. The US National Academies of Sciences, Engineering, and Medicine report on the ethical, social and policy considerations for mitochondrial replacement techniques published in February 2016 reflected many of the conclusions of the Council's report, and referenced it extensively.

The Council continues to present this report to international meetings; for example in February it was invited to discussions with a delegation of Norwegian Members of Parliament from the Committee on Health and Care Services, and was part of a fact-finding tour for officials from the Norwegian Department of Health in November.

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Novel neurotechnologies: intervening in the brain (published 2013)

This report recommended that brain stimulation devices intended for non-medical purposes should be included in the new EU Medical Devices Regulation. This was taken up by the Medicines and Healthcare products Regulatory Agency, and wording proposed by the Council is reflected in the current draft EU Regulation which was agreed in May 2016, adopted in April 2017 and will come into force in 2020.

The collection, linking and use of data in biomedical research and health care: ethical issues (published 2015)

The Council responded to the consultation on the National Data Guardian Review of Data Security, Consent and Opt-Outs. Jonathan Montgomery was subsequently invited to present the report at the NHS Expo in Manchester.

After giving written and oral evidence to the **House of Commons Science and Technology Select Committee** inquiry 'The big data dilemma', the Council was cited extensively in its final report published in February. The report echoed the Council's recommendation to criminalise serious misuse of data. The report suggested the Government should establish an independent 'Council of Data Science Ethics' and the Council has since been involved with discussions about the establishment of such a body.

The findings of a series of engagement activities exploring the culture of scientific research in the UK (published 2014)

The Parliamentary Office of Science and Technology (POST) published a briefing note on Research Integrity in January 2017, which drew on the Council's findings on the [culture of scientific research](#).

The note was researched and drafted by Cressida Auckland, who took up a Fellowship at POST in 2016 as part of the Council's [ongoing partnership](#) with POST to support and promote informed debate of bioethics among Parliamentarians.

The publication of the POSTnote led the **House of Commons Science and Technology Select Committee** to announce an inquiry into Research Integrity in January 2017, which the Council later submitted a [response](#) to.

Zika: ethical considerations (published 2016)

In an example of responding to an issue of international concern in an agile way, the Council's Executive published a [briefing note](#) on ethical considerations relevant to the Zika epidemic. The note, published in February as a rapid response to the emerging Zika epidemic, drew on previous Council reports on [public health ethics](#), [research in developing countries](#), [solidarity](#), [biological and health data](#) and the regulation of [emerging biotechnologies](#).

The briefing was cited in evidence given to the **House of Commons Science and Technology Select Committee** during its [Zika inquiry](#).

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Responses to policy consultations

Response to consultation *Fulfilling our potential: teaching excellence, social mobility and student choice*

Department for Business, Energy & Industrial Strategy

Submitted in January – informed by [The culture of scientific research](#) project.

Response to *European Commission report on the Paediatric Regulation: consultation document*

European Commission

Submitted in February – informed by the [Children and clinical research](#) report.

Response to *inquiry on genomics and genome-editing*

House of Commons Science and Technology Select Committee

Submitted in February – informed by the [Genome editing review](#), and [Emerging biotechnologies](#) and [Biological and health data](#) reports.

Response to *Lord Stern's review of the Research Excellence Framework*

Department for Business, Energy & Industrial Strategy

Submitted in March – informed by [The culture of scientific research](#) project.

Response to *consultation on UK Policy Framework for Health and Social Care Research*

Health Research Authority

Submitted in March – informed by the [Children and clinical research](#) report.

Response to *Revision of CIOMS 2002 International Ethical Guidelines for Biomedical Research Involving Human Subjects*

The Council for International Organizations of Medical Sciences (CIOMS)

Submitted in March – informed by the reports on [Research in developing countries](#), [Public health](#), [Dementia](#), [Human bodies](#), [Children and clinical research](#), [Biological and health data](#).

Response to *inquiry on science communication*

Science and Technology Select Committee (Commons)

Submitted in April – informed by the reports on [Naturalness](#), [Emerging biotechnologies](#), [Neurotechnology](#), [Biological and health data](#).

Comments on *WHO Ethical Guidance for Managing Epidemic Outbreaks*

World Health Organisation

Submitted in April – informed by the report on [Public health](#), the [Zika briefing note](#), and the [Children and clinical research](#) report.

Foreword from the Chair
and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Response to the consultation on *Ethical dimensions of next generation sequencing*

National DNA Database Ethics Group

Submitted in August – informed by the reports on [Forensic use of bioinformation](#), [Biological and health data](#) and [Emerging biotechnologies](#)

[Response to Review of Data Security, Consent and Opt-Outs Consultation](#)

National Data Guardian for Health and Care

Submitted in September – informed by the [Biological and health data](#) report

[Response to consultation on Ethical considerations for clinical trials on medicinal products conducted with minors](#)

Directorate General for Health and Food Safety, European Commission

Submitted in September – informed by the [Children and clinical research](#) report

Response to *Proposed World Medical Association (WMA) Declaration on Ethical Considerations regarding Health Databases and Biobanks*

Submitted in September – informed by the [Biological and health data](#) report.

Response to *WHO public consultation on the draft proposal on Principles for global consensus on the donation and management of blood, blood components and medical products of human origin*

World Health Organisation

Submitted in October – informed by the [Human bodies](#) report.

[Response to call for evidence on data governance](#)

Royal Society and British Academy

Submitted in November – informed by the [Biological and health data](#) report.

Wider engagement



**More than
250,000 visits**
to the Council's website
(up from **140,000**
in 2015)



Passed 6000
followers on Twitter
(up from **5000** in 2015
and **3000** in 2012)



**Nearly 2,800
subscribers**
to our UPDATE
newsletter



90 people
at our annual
public lecture



**65 talks and
presentations**
given at conferences,
workshops, festivals



15 blog posts
by Council staff,
Members and
guest bloggers

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

National and international activities and events

Events during its 25th anniversary year served to emphasise the important role the Council continues to play in the global bioethics community. Highlights from 2016 included:

13th World Congress of the International Association of Bioethics

The Council was a sponsor of the 13th World Congress of the International Association of Bioethics, which took place in Edinburgh on 14–17 June. In celebration of its 25th anniversary, the Council organised a symposium – chaired by Jonathan Montgomery – that brought together an international panel to discuss progress made in and through bioethics over that time. The speakers were Professor Ruth Macklin, Albert Einstein College of Medicine, New York, USA; Professor Christian Munthe, University of Gothenburg, Sweden; Dr Calvin Ho, National University of Singapore; and Council member Professor Erica Haimes, Director of the Policy, Ethics and Life Sciences (PEALS) Research Centre, Newcastle University. Erica Haimes wrote a blog post summarising the discussion: <http://nuffieldbioethics.org/are-we-making-progress-in-bioethics/>

Assistant Director Katharine Wright spoke at a symposium on **Children’s participation in clinical studies**, which explored approaches and challenges to the greater participation of children in clinical research.

Hugh Whittall Chaired the Symposium: **Ethics and regulation of global beauty practises and procedures**, which brought together academics, practitioners and artists to consider the ‘Changing Requirements of Beauty’. The session also featured contributions from Council member Heather Widdows, and from Katharine Wright.

Hugh Whittall was also a panellist in a session on **Funding, Policy and Careers** in bioethics, and chaired a symposium about **Bioethics at the World Health Organization**.

The Council also showcased its work exploring the **concept of naturalness in debates about the biosciences**. As well as featuring a performance by poet [Kayo Chingonyi](#), a panel discussion involved Catherine Joynson, Programme Manager at the Council; Anna Smajdor, Lecturer and Researcher in Biomedical Ethics, Norwich Medical School; and Darian Meacham, Senior Lecturer in Philosophy, University of the West of England.

US Presidential Commission for the Study of Bioethical Issues

On 31 August Jonathan Montgomery attended the 27th public meeting of the Presidential Commission for the Study of Bioethical Issues (the Bioethics Commission) in Philadelphia. The Bioethics Commission (2009–2017) advised the US President on bioethical issues arising from advances in biomedicine and related areas of science and technology. Jonathan presented on the subject of Public Bioethics and the Virtues of National Ethics Committee.

Annual meeting with French and German national bioethics commissions

The annual trilateral meeting with the French and German national bioethics commissions took place in Berlin on 21 October, and focussed on genome editing. A [joint statement](#) from the three Chairs of the committees was published subsequently, and stated that: “*urgent attention needs to be given in respect of a number of key areas, including potential uses in human reproduction, plant and animal farming, and in insects for ‘gene drives’*” and “*it will be important to encourage wide public debate on these questions*”.

Foreword from the Chair and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

25th anniversary event

On 14 November, the Council held an event to celebrate its 25th anniversary at the Institute of Contemporary Arts in London. The event brought together diverse perspectives to reflect on how issues in bioethics are an important part of debates and decision-making in policy and public environments; how these issues are discussed and debated; and how they can influence society in different ways. The speakers were:

- Roger Highfield, Director of External Affairs, Science Museum Group
- Sharmila Nebhrajani OBE, Chair of the Human Tissue Authority
- Mark Robertson, Director, Science Policy Compass Ltd
- The Earl of Selborne, Chair of the House of Lords Science and Technology Select Committee (Lords)
- Chris Whitty, Chief Scientific Adviser for the Department of Health
- Professor Peter Dabrock, Chair, Deutscher Ethikrat

Professor Whitty noted that the informal [non statutory] status of the Council was essential to the independence it has maintained, on which its reputation and impact has depended.

Other events, memberships and committees

- Hugh Whittall has been a regular member of the Steering Committee for the World Health Organisation Global Summit of National Ethics Committees, which was held in Germany in 2016.
- The Council currently provides the UK national delegate on the Council of Europe Committee on Bioethics (DH-BIO) and is currently an adopted member of the Council of Europe Bioethics Unit Working Group developing guidance on the “prohibition of financial gain” with respect to donated bodily material.
- Assistant Director Peter Mills participated in a panel session on precision medicine and bioethics organised by the UK Science and Innovation Network at the AAAS Annual Meeting in Washington DC in February 2016.
- During the year, Council representatives were invited to present the findings of many of its reports to a number of National Ethics Councils.
- The Council also acted in an advisory capacity in a number of areas including on activities in ‘Einstein’s Garden’ at the UK’s Green Man festival.



Future work

Future work programme

The Council has a thorough, ongoing process for selecting new topics, which is overseen by its Future Work Subgroup. As part of this horizon-scanning process, the Council maintains an ongoing list of possible future work topics to inform our rolling programme of activities which could include the production of background briefings and papers, workshops and events, or more substantial projects.

Foreword from the Chair
and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Future work

As well as holding a two-day expanded Forward Look meeting, the Council increased its ‘horizon-scanning’ activities exploring what the future might look like, and made the outputs of these activities more accessible.

‘Forward Look’ meeting

On 25 February the Council held its annual 2016 ‘Forward Look’ meeting, which focused on discussion of three specific areas with experts in the field:

- **Artificial gametes** – with presentations by Dr Amel Alghrani, Senior Lecturer in Law, University of Liverpool; Professor Azim Surani, Director of Germline and Epigenomics Research at the Gurdon Institute; and Professor Stephen Wilkinson, Professor of Bioethics, Lancaster University
- **‘Dual use’ in biology and biomedicine** – with presentations by Dr Caitriona Mcleish, Senior Research Fellow at the Science Policy Research Unit, University of Sussex; Professor Malcolm Dando, Professor of International Security, University of Bradford; and Dr Brett Edwards, Lecturer in Security and Public Policy, University of Bath.
- **Longevity** – with presentations by Professor David Gems, Professor of the Biology of Ageing and Deputy Director of the Institute of Healthy Ageing, University College London; Professor Geoffrey Scarre, Professor of Philosophy, University of Durham; and Professor Anthea Tinker, Professor of Social Gerontology, King’s College London.

Notes of the discussion in each area have been published alongside background papers on each topic, which were written by external experts commissioned by the Council. A background paper on non-invasive prenatal testing (NIPT) went on to inform the project.

Future challenges – 2016 roundtable discussion

On the second day for the Forward Look meeting, the Council held a new roundtable event that brought together bioethicists, clinicians, academics, policymakers and others to discuss future challenges and issues arising in bioethics. Its aim was to help inform the Council’s deliberations on its future work programme. Issues that were discussed included: genome editing; data science, covering issues around care robots, health apps, storage and use of personal data; and access and social justice, exploring issues around disability, personalised medicine, impact of the private sector, care of older people and representation in research. A report of the meeting was published on the Council’s website. Given its success, we plan to hold similar events of this type in future.

Foreword from the Chair
and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Possible future work: topic summaries

In addition to its background papers, the Council published a new set of [topic summaries](#) in a new accessible format on the Council's website. They covered a range of topics suggested to Council by stakeholders and members of the public or identified as part of the Council's horizon-scanning processes for further investigation by the Council. These summaries, produced by the Council Executive, are available alongside an open invitation to suggest topics for Council consideration. Possible future work topics are selected and/or revised regularly, following discussions among members of the Council's [Future Work Subgroup](#).

New or updated topic summaries for 2016 were:

- [Animals and research](#)
- [Artificial wombs \(ectogenesis\)](#)
- [Autism](#)
- [Biotechnology and globalisation](#)
- [Building genomes from scratch](#)
- [Chimeras](#)
- [Citizen science](#)
- [The human/technology frontier in health and social care](#)
- [The human/technology frontier in the wider context](#)
- [In-vitro derived gametes and embryos](#)
- [Innovative therapies](#)
- [Nagoya protocol](#)
- [Predicting phenotype from genotype](#)
- [Social egg freezing](#)
- [Sports science](#)
- [Suppressing the extra chromosome in Down's syndrome](#)
- [Whole genome sequencing of newborns](#)

Foreword from the Chair
and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

People

Council Members

Jonathan Montgomery (Chair)

Professor of Health Care Law, University
College London and Chair,
Health Research Authority

The Revd Dr Michael Banner

Dean and Fellow of Trinity College,
Cambridge

Simon Caney

Professor in Political Theory at the
Department of Politics and International
Relations, University of Oxford, Fellow and
Tutor at Magdalen College

Tara Clancy

Consultant Genetic Counsellor, Honorary
Senior Lecturer, Manchester Centre for
Genomic Medicine

Jeanette Edwards

Professor of Social Anthropology, University
of Manchester. Co-opted as chair of the
Working Party on cosmetic procedures

Ann Gallagher

Professor of Ethics and Care at the
International Care Ethics Observatory,
University of Surrey

Andy Greenfield

Programme Leader, Mammalian Genetics
Unit at MRC Harwell, and member of
the Human Fertilisation and Embryology
Authority.

Professor Erica Haimes

Professor of Sociology at Newcastle
University and Founding Executive Director
of PEALS (Policy, Ethics and Life Sciences)
Research Centre

Professor Julian Hughes (Deputy Chair)

Consultant in Psychiatry of Old Age in
Northumbria Healthcare NHS Foundation
Trust, Honorary Professor of philosophy
of ageing at the Institute for Ageing and
Health, Newcastle University

Sir Roland Jackson

Executive Chair of Sciencewise (until April
2016) and previously Chief Executive of the
British Science Association

David K Lawrence

Non-Executive Director at Syngenta
AG, Chair of the Syngenta Science &
Technology Advisory Board, and a member
of the Biotechnology & Biological Science
Research Council

Shaun Pattinson

Professor of Medical Law and Ethics,
Durham University

Tom Shakespeare

Professor of Disability Research at Norwich
Medical School, University of East Anglia

Mona Siddiqui

Professor of Islamic and Interreligious
Studies, Assistant Principal for Religion
and Society, University of Edinburgh

Christine Watson

Professor of Cell and Cancer Biology,
Department of Pathology, University of
Cambridge

Robin A Weiss

Emeritus Professor of Viral Oncology,
University College London

Heather Widdows

John Ferguson Professor of Global Ethics,
Department of Philosophy,
University of Birmingham

Adam Wishart

Writer and documentary maker, focussing
on the ethics and policy of science and
medicine

Paquita de Zulueta

General Practitioner, cognitive behavioural
therapist, Honorary Senior Clinical Lecturer
at Imperial College London

Foreword from the Chair
and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Members of Council who completed terms in 2016

Geoff Watts

Science and medical writer and
broadcaster

Executive

Hugh Whittall,

Director

Katharine Wright,

Assistant Director

Dr Peter Mills,

Assistant Director

Catherine Joynson,

Assistant Director

Carol Perkins,

PA to the Director and
Secretariat Administrator

Sarah Walker-Robson,

Communications Manager

Kate Harvey,

Senior Research Officer

Ranveig Svenning Berg,

Communications Officer

Dr Bettina Schmietow,

Research Officer

Dr Anna Wilkinson,

Programme Officer

Busayo Oladapo,

Office Administrator

Alison Toop,

Temporary Researcher

Sophie Bertaud,

Temporary Researcher

Contact

Nuffield Council on Bioethics

28 Bedford Square, London WC1B 3JS

Telephone: +44 (0)20 7681 9619

Email: bioethics@nuffieldbioethics.org

Online

Website: www.nuffieldbioethics.org

Blog: www.nuffieldbioethics.org/blog

Twitter: www.twitter.com/nuffbioethics

Facebook: www.facebook.com/nuffieldbioethics

Subscribe: www.nuffieldbioethics.org/subscribe

Foreword from the Chair
and Director

Publications and activities

Projects in progress

Informing policy

Wider engagement

Future work

People

Financial information

Financial information

Financial Report for the year to 31 December 2016

| | 2016 | 2015 |
|---------------------------------------|------------------|----------------|
| | Actual | Actual |
| | £ | £ |
| Expenditure | | |
| Salaries and staffing costs | 615,345 | 631,322 |
| Reviewers' and consultants fees | 42,342 | 79,491 |
| Office and premises costs | 7,146 | 6,122 |
| Journals & Subscriptions | 12,857 | 16,237 |
| Travel and meeting costs | 105,487 | 79,803 |
| Web, Printing and Publicity | 30,756 | 78,886 |
| Total Expenditure | 813,933 | 891,861 |
| Funded by: | | |
| Nuffield Foundation | 271,131 | 297,064 |
| Medical Research Council | 271,131 | 297,064 |
| Wellcome Trust | 271,131 | 297,064 |
| Other | 540 | 669 |
| | 813,933 | 891,861 |
| Five year Funding 2012-2016 | £ | |
| Medical Research Council | 1,435,896 | |
| Wellcome Trust | 1,435,896 | |
| The Nuffield Foundation | 1,435,896 | |
| Other | 10,930 | |
| | 4,318,618 | |
| Amount Drawn | | |
| Year ending 31 December 2012 | 768,734 | |
| Year ending 31 December 2013 | 758,317 | |
| Year ending 31 December 2014 | 766,575 | |
| Year ending 31 December 2015 | 891,861 | |
| Year ending 31 December 2016 | 813,933 | |
| | 3,999,420 | |
| Surplus as at 31 December 2016 | 319,198 | |