

# Annual Report 2015

**NUFFIELD  
COUNCIL ON  
BIOETHICS**

# Foreword from the Chair



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It was once said that ‘The Nuffield Council on Bioethics *never shrinks from the unthinkable*’. Amidst myriad developments in the rapidly advancing fields of biomedicine and biotechnology the Council is uniquely placed to anticipate and respond to some of the most pressing and difficult questions that arise, consulting widely and offering robust, comprehensive and independent analysis and advice.

Having been at the forefront of discussions and debates on some of the most controversial developments in science and technology for almost 25 years, one thing the Council never loses sight of is that there are many ways in which bioethical issues can be discussed and many audiences who have a stake in that discussion. One of the most important roles of the Council is to bring people together, to give people opportunities to share their views, to consider all perspectives – we do what we can to make ‘*unthinkable*’ questions ‘*thinkable*’, and we are immensely grateful for the contributions of the many people we involve in our work. In 2015 we stepped up our efforts to engage with broader audiences and amongst notable firsts for the Council we found ourselves collaborating with poets to further explore the concept of naturalness and commissioning an animation to explore the questions young people might ask about medical research.

Meanwhile, we remain committed to informing and influencing policy in the areas we work, present and past. Following publication of the report on biological and health data we have hosted roundtable discussions with the National Data Guardian and given evidence to MPs on the ‘*big data dilemma*’. In February we saw the Council’s report on mitochondrial DNA disorders referred to in many preparatory briefings and debates in the chambers as the UK Parliament voted on new regulations to allow mitochondrial donation techniques to be used in treatment.

I would like to thank sincerely all of the Members of Council, especially those who finished their terms in 2015: Professors Bobbie Farsides, Peter Furness, Robin Gill, Graeme Laurie, Tim Lewens, Anneke Lucassen and Martin Richards. Their contributions and insights have been greatly valued and we will miss working closely with them. I would also like to offer special thanks to our outgoing Vice-Chair of Council Professor Ottoline Leyser who has given so much to the Council over the past six years, and to welcome Professor Julian Hughes to that role.

**Professor Jonathan Montgomery**

# Foreword from the Director



The Council published the findings of three major projects in 2015: *The collection, linking and use of data in biomedical research and health care: ethical issues* in February, *Children and clinical research: ethical issues* in May, and (un)natural: *Ideas about naturalness in debates about science, technology and medicine* in November. Illustrating our breadth and diversity of work, and showing our strategic commitment to a balanced portfolio and a flexible approach to activities and outputs, these projects not only covered a lot of different ground but each project involved its own distinct set of contributors, carefully devised different methods of deliberation and different forms of output.

Alongside this we started work on two new projects - genome editing and cosmetic procedures. The programme on genome editing is being carried out in stages, considering first the impact of genome editing in research and the range of questions to which this gives rise, to be followed a more focused ethical analysis in a number of specific fields of application. The cosmetic procedures work will explore ethical issues with a focus on the role and responsibilities of health and scientific professionals and others in responding to (and perhaps helping to stimulate) the increasing demand for invasive non-reconstructive procedures that aim to enhance or normalise appearance.

It is a testament to the Council's timeliness in selecting topics and the enduring relevance of its past reports that 2015 was a busy year for follow up work on earlier Council work. This included, most notably, our report mitochondrial DNA disorders (2012), but other reports that are frequently called back into action include those on donation (2011) public health (2007) and even healthcare research in developing countries (2002).

We continued our rigorous process for identifying possible future work topics, with a commitment to being more responsive to external developments and debates. Four background papers were commissioned, exploring a range of topics: non-invasive prenatal testing (NIPT), dual-use technologies, artificial gametes and longevity. We convened a workshop on NIPT and will be taking this work forward in 2016.

Throughout the year the Council has continued to build its international presence and influence and to foster relationships with bioethics organisations globally, sending speakers to numerous international symposia, conferences and workshops on current and previous work topics. A highlight of the year was our annual public lecture given by Dr Amy Gutmann, Chair of the United States Presidential Commission for the Study of Bioethical Issues.

As we look ahead to the 25th Anniversary of the Nuffield Council in 2016, I look forward to sharing the findings of our latest projects and to another year of hard but rewarding work.

**Hugh Whittall**

# Publications in 2015

## **Reports and project findings**

- Biological and health data
- Children and clinical research
- Naturalness

## **Background papers**

- Artificial gametes
- Dual use in biology and biomedicine
- Longevity
- Non-invasive prenatal testing (NIPT)

## **Parliamentary briefings**

- Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review
- Ethical challenges in bioscience and health policy for the new UK Parliament

## **Topic overviews**

- Autism
- Biotechnology and globalisation
- Citizen science
- Dignity
- Global health inequalities
- Innovative therapies
- Nagoya protocol
- Non-human technologies in health and social care
- Relational autonomy
- Suppressing the extra chromosome in Down's syndrome

**Publications:** Reports and project findings

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## [The collection, linking and use of data in biomedical research and health care: ethical issues](#)



From GP records to health apps to clinical trials, data about our health and biology has become increasingly available. At the same time, computing and data science techniques have become more sophisticated, meaning that data has become a valuable resource to be re-used, linked, combined and analysed indefinitely, for a variety of purposes. Whilst this offers opportunities to generate knowledge and improve medical practice, it brings with it significant concerns about people's privacy.

This report concludes that more must be done to ensure that respect for participants and their data is at the centre of any data initiative. The report sets out key ethical principles for the design and governance of data initiatives: *respect for persons, respect for human rights, participation and accountability for decisions*. It examines a number of data initiatives in relation to the ethical principles, identifies examples of good practice, and makes recommendations including the introduction of criminal penalties for the deliberate misuse of data.

### **Launch: 3 February 2015**

The report was launched at a public event in Westminster and was discussed on *BBC Radio 4 Today Programme* and in articles including in the [BMJ](#), [Guardian](#) and [Independent](#).

### **Follow up highlights**

Many themes of the report have been taken up in meetings with policy makers, responses to national and international consultations, and in a range of presentations and events. For example, the Council hosted two roundtable meetings with the Department of Health, on public trust and on data security, and responded to the Department of Health consultation on the role of the National Data Guardian for health and social care. The Council gave evidence to the House of Commons Science and Technology Committee inquiry *'The Big Data Dilemma'* and submitted written comments to the World Medical Association declaration on health databases and biobanks.

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Find out [more about developments](#) since this report was launched.

### **The Working Party**

The Working Party had 11 members and was chaired by Martin Richards, Emeritus Professor of Family Research at the University of Cambridge. [Find out more...](#)

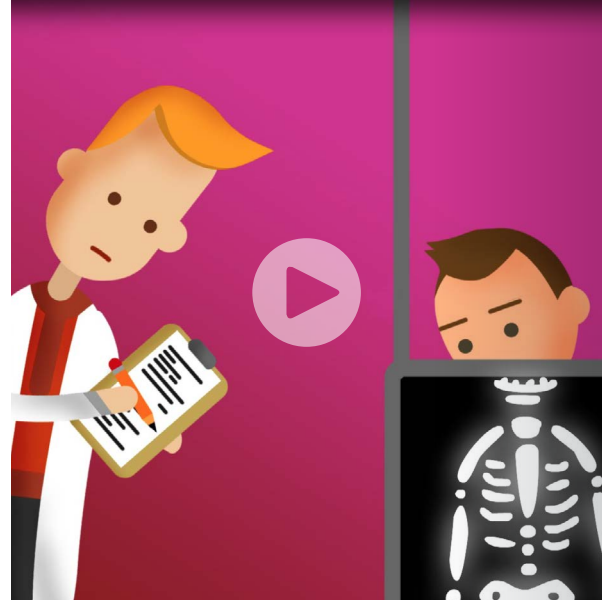
### **From the blog**

- [Biological and health data: 8 months on](#)
- ["If you know it, I'd like to know it too" – involving participants in genome research](#)
- [Trust and transparency must underpin technological change](#)

**Publications:** Reports and project findings

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## Children and clinical research: ethical issues



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Clinical research involving children is essential to increasing our understanding of childhood illnesses and improving healthcare for children, so that children can benefit from the best possible treatment when they are ill. However, concerns about risks associated with research, or burdens such as hospital visits, blood tests and possible discomfort or pain may lead to a reluctance from parents and health professionals to ask children to take part in research.

This report considers how children and young people can ethically be involved in clinical research, and makes recommendations about the roles and responsibilities of children, their parents or guardians, researchers and others.

### **Launch: 14 May 2015**

The report was launched at a public event which included lively debate and contributions from young people, parents and members of the Working Party. It was discussed on BBC One Breakfast and in articles including a front page editorial in *The Lancet*, the *Daily Mail* and *BBC News*. The findings were published in several formats aimed at different audiences – a [report](#), [magazine](#), [one-page summary](#), and [animation](#).

### **Follow up highlights**

The Council has developed links with a number of UK and international organisations to broaden the reach of this work. For example, in the UK the Council has been working with the Royal College of Paediatrics and Child Health (RCPCH), in several areas including input to

their UK Child Health Research Collaborative which aims to strengthen all areas of child health research. The Council is a member of an advisory group developing the UK network of Young Persons' Advisory Groups for children's research (Generation R). The Council is also facilitating discussions on developing good industry practice for young people's engagement in research through hosting a meeting between young people, key individuals working in industry and the National Institute for Health Research.

The Council is organising an international symposium to explore how the recommendations made in the report apply in a wide range of contexts, in particular in low and middle income countries, and to develop practical recommendations concerning research with children and its governance worldwide. It is also working with the Global Health Network to produce an online training course for researchers and members of ethics committees globally, available in English and Spanish. Through international sponsors the magazine, report summary and animation were translated into Spanish, and further translations into Mandarin and Arabic are expected in 2016.

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Find out [more about developments](#) since this report was launched.

### **The Working Party**

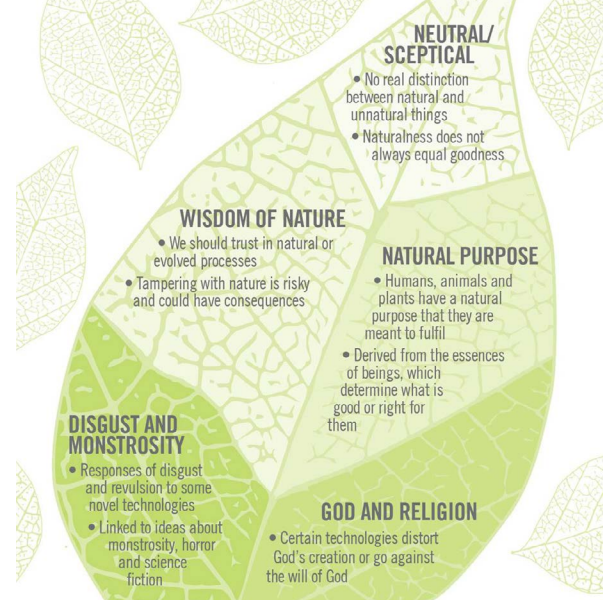
The Working Party had 14 members and was chaired by Bobbie Farsides, Professor of Clinical and Biomedical Ethics at Brighton and Sussex Medical School. [Find out more...](#)

### **From the blog**

- [The Paediatric Regulation – a work in progress?](#)
- [Involving children in clinical research: GenerationR grows up](#)
- [Building on what we heard from children in Kilifi, Kenya](#)

**Publications:** Reports and project findings

## (un)natural: Ideas about naturalness in public and political debates about science, technology and medicine



Ideas about naturalness have arisen in many of the Council's inquiries. This project examined how ideas about naturalness feature in and affect policy and public discussions about the ethics of science, technology and medicine. The findings provide clarification on the different things that people mean when they refer to naturalness, and a number of recommendations are made to policy makers, journalists, scientists and advertisers on steps that can be taken to help avoid people speaking at cross purposes about naturalness.

### The findings

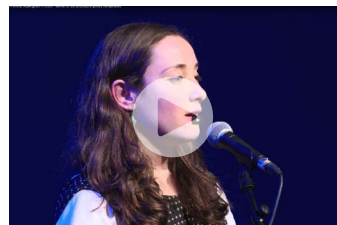
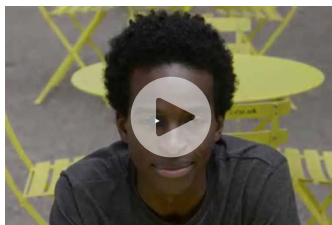
Many different ideas, associations, anxieties, hopes and fears underlie different people's uses of the terms natural, unnatural and nature. The Council sets out five broad understandings of naturalness.

### Poetry collaboration

As part of this project the Council wanted to explore ideas about naturalness in creative ways and to engage contributions from a wider audience. We collaborated with Apples and Snakes, England's leading organisation for performance poetry, to commission a poet and run a poetry competition exploring ideas about naturalness in bioethics debates. A series of poems by Kayo Chingonyi, and the competition winners and runners up are available on the Council's website. [Find out more...](#)

### Launch: 30 November 2015

The findings were announced at a launch event which combined presentations from the Steering Group with live poetry performances and audience discussion. Held in the evening, at an arts venue, this event attracted a wide public audience and offered the opportunity for reflective and stimulating conversation in an informal, social setting. A suite of materials was published on the Council's website including a booklet summarising the findings, a detailed analysis paper and the reports of a range of evidence gathering activities.



### The Steering Group

The Steering Group was made up of six members of Council and was chaired by Roland Jackson, Executive Chair of Sciencewise\*.

\*Affiliation correct at the time of publication

### From the blog

- [Are poets the unacknowledged bioethicists of the world?](#)
- [Naming something that is at the limits of naming](#)
- [What do you mean 'it's unnatural'?](#)

# Projects in progress

Genome editing

Cosmetic procedures

Exploratory work on-invasive pre-natal testing (NIPT)



## Projects in progress

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# Genome editing



**Genome editing techniques such as the CRISPR-Cas9 system are transforming many areas of biological research owing to their relative efficiency, low cost and ease of use. Whilst these technologies have been embraced with enthusiasm by many researchers, their use has also provoked debate about the possibilities to which they might lead, for example in human germ line modification, ecological engineering, and novel plant breeding.**

The Council announced a new project on genome editing in April 2015, and set up a Working Group, which met for the first time in September 2015. The project will be carried out and published in stages: the first will consider the impact of genome editing in research and the range of questions to which this gives rise, and subsequent stages will focus on ethical and practical questions arising from the application of the technologies in a series of different contexts.

The Council is conducting evidence gathering through an open call for evidence (started in December 2015), a literature review, stakeholder engagement, fact-finding meetings and expert interviews.

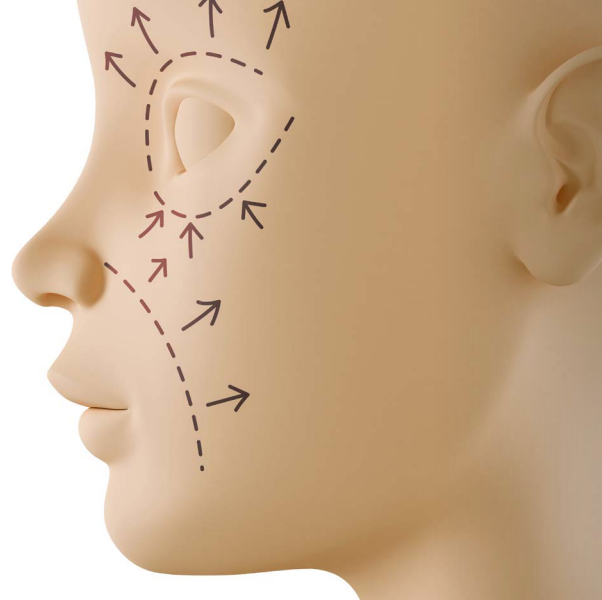
Following a number of developments in the UK and internationally, including the approval of an application by UK researchers for a licence from the Human Fertilisation and Embryology Authority (HFEA), genome editing received considerable media attention throughout 2015. References to the Council's work were included in articles in the *Financial Times*, *The Guardian*, *BBC News Online*, and Assistant Director Dr Pete Mills was interviewed on *BBC Radio Scotland*.

### The Working Group

The Working Group has eight members and is chaired by Dr Andy Greenfield, Council Member and Programme Leader in Developmental Genetics at the Medical Research Council research unit in Harwell [Find out more....](#)

### From the blog

- [Human gene editing: keep calm and carry on conversing](#)
- [Gene gibbering](#)
- [The moral implications of genome editing in 300 words?](#)



# Cosmetic procedures

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Demand for cosmetic procedures is growing, both in the UK and internationally. The substantial increase in the number of cosmetic procedures performed has led to concerns that these procedures may be becoming ‘normalised’: that is, that both cosmetic surgery, and invasive non-surgical procedures such as the use of injectable fillers and Botox, are increasingly perceived as routine, rather than exceptional, ways of changing one’s appearance. This project will explore ethical issues in cosmetic procedures with a particular focus on the role and responsibilities of health and scientific professionals and others in both creating and responding to this demand.

The Council set up a Working Party in September 2015, building on existing work in this area including a scoping workshop on the ethical issues raised by cosmetic procedures held in 2014, and the Council’s involvement as a partner on the AHRC-funded [Beauty Demands](#) project.

From the outset of this project, engagement with and input from a diverse range of people was felt to be a priority and the Working Party has developed consultative and engagement activities for a range of different audiences.

In addition to a detailed ‘expert’ call for evidence, and a wider public questionnaire, the Working Party is seeking to obtain more deliberative public input through focus group discussions, working with existing networks such as the Café Scientifique network. It is holding fact finding meetings considering issues such as law, regulation and governance, advertising and marketing, and professional responsibilities.

### **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**

- [A global perspective on beauty](#)
- [Smaller nose? Bigger boobs? Flatter stomach? There’s an app for that.](#)
- [From botox to facelifts – should professionals say yes?](#)

## Projects in progress

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# Exploratory work on non-invasive prenatal testing (NIPT)



Testing for genetic conditions such as Down's syndrome now can be carried out by means of a simple blood test from 10 weeks of pregnancy. This kind of testing is more accurate than previously available early screening tests and does not carry the risk of miscarriage of invasive diagnostic tests. However, concerns have been raised about routinisation and the potential for non-invasive prenatal testing to provide wider genetic information about the unborn child.

The Council identified this topic as a priority area for scoping work in 2015, noting that the UK National Screening Committee had recommended that the NHS should consider widening the availability of NIPT as part of the NHS prenatal screening programme.

During 2015 the Council commissioned a [background paper](#) to identify key clinical, ethical, social, legal and policy issues, and subsequently convened a [roundtable meeting](#) to discuss the ethical and social issues with an invited group of stakeholders.

### **Next steps**

Following on from this exploratory work the Council set up a project on NIPT, and has now established a Working Group, which will be taking forward this work in 2016.

[Find out more....](#)

# Informing policy

The Council contributes to policy discussions and aims to inform decision making in its areas of work in a number of ways. In this section, we present some highlights from our policy activities and impact in 2015.

- Follow up of published reports and recommendations
- Parliamentary engagement
- Meetings with policy makers and influencers
- Roundtables and workshops
- [Responses to policy consultations](#)



### [The findings of a series of engagement activities exploring the culture of scientific research in the UK \(2014\)](#)

The Council held two follow up workshops to discuss how the report's suggestions for action might continue to be addressed.

In July the Council co-hosted a workshop where research leaders and support staff from universities discussed how the suggestions for action were or should be taken forward by higher education institutions and the research community as a whole.

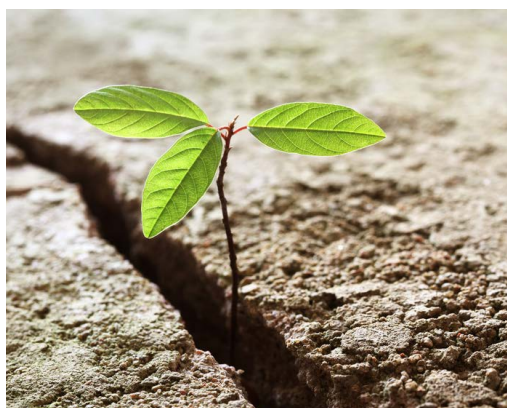
A second workshop, including an opening address from Sir Mark Walport, Government Chief Scientific Advisor, aimed to facilitate a discussion between all stakeholders in the research community about how to respond to the report's proposals for improving the quality and ethical conduct of scientific research. Following the workshop, the Council initiated discussions with key organisations in the research community about how the Council's work in this area can be continued.

Find out more about [follow up developments](#) relating to this work.

### [Novel neurotechnologies: intervening in the brain \(2013\)](#)

Following up the Council's recommendation in this report for guidance on the use of placebo surgery in clinical trials of neural stem cell therapies, the Council and the Health Research Authority organised a roundtable to discuss the use of placebo surgery. An article was subsequently published in the *Bulletin of The Royal College of Surgeons of England (RCS)* and the RCS published a position statement on the use of placebo surgery, noting the Council's role in pushing for guidance in this area.

Find out more about [developments since this report was published](#).



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### [Emerging biotechnologies: technology, choice and the public good \(2012\)](#)

The Council's call for a reorganisation of scientific advice within government was echoed in the House of Commons Science and Technology Select Committee [report on GM crops and the precautionary principle](#), published on 26 February 2015. The Committee asked the Government to "set out how the Nuffield Council's work on emerging biotechnologies has informed its research policy. We are particularly interested in how it has responded, or intends to respond, to the Council's call for structural reorganisation." The Committee also highlighted the important role of public dialogue and referenced the Council's recommendation that policy concerning emerging biotechnologies should be informed by a "public ethics", based on securing the public good.

Find out more about these and other [follow up developments](#).

### [Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review \(2012\)](#)

An [updated briefing note](#) for MPs and Peers was prepared ahead of a Parliamentary vote on this issue in February 2015 (when the UK became the first country to approve regulation on mitochondrial donation). The briefing was distributed at events organised by the All Party Parliamentary Groups on Medical Research and on Muscular Dystrophy, and the Wellcome Trust. The Council's report was referenced several times during both the Commons and Lords debate.

The US National Academy of Science extended an invitation to the Council to present its findings on mitochondrial donation at a workshop at the Institute of Medicine (IoM) in Washington DC. A [resulting report from the US National Academies](#) reflected many of the conclusions and recommendations made by the Council in 2012.

Read more about [key developments](#) following this report.



### [Ethical challenges in bioscience and health policy for the new UK Parliament](#)

Following the general election in May 2015, the Council identified five key ethical challenges in bioscience and health policy in a new document for the new UK Parliament, with suggestions as to how these challenges can be addressed. This was sent to all MPs and Peers, relevant government bodies, parliamentary staff and science policy organisations. The document draws on many of the Council's current and previous projects, including its work on cosmetic procedures, genome editing, naturalness, biological and health data, the culture of scientific research, children and clinical research, donor conception, emerging biotechnologies, mitochondrial DNA disorders, solidarity, organ donation, biofuels, personalised healthcare, dementia, public health and forensic use of bioinformation.

### [Bioethics Fellowship at POST](#)

The Council continued its partnership with the Parliamentary Office of Science and Technology (POST), to offer a PhD student from a UK university the opportunity to spend three months working in Parliament. The aim of the scheme is to promote informed debate of bioethics among Parliamentarians. The 2015 Fellow, Stephen Barrie, researched and drafted a POSTnote on the topic of global inequalities in health, which will be published in 2016 following peer review.

# Wider engagement



**141,650 visits**  
to the Council's website



**170 people**  
at our annual public lecture



**Passed 5,000**  
followers on Twitter



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



**4,200 subscribers**  
to our newsletter



**33 blog posts**  
by Council staff, Members  
and guest bloggers



## Wider engagement: events and education

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### Annual lecture

The annual public lecture had an international flavour with guest speaker Dr Amy Gutmann, Chair of the United States Presidential Commission for the Study of Bioethical Issues. The event was held at the British Library and was hosted by Council Member and broadcaster Dr Geoff Watts.



### Festivals

Links were developed with three new festivals – SICK! Festivals in Manchester and Brighton, an event on naturalness in debates about genetic modification at the Bristol Festival of Ideas and Einstein's Garden at the Green Man festival, where the Council was an advisory partner on a science and arts collaboration on the theme of human enhancement.

The Council also continued its long standing partnership with the Cheltenham Science Festival, delivering an event called 'Who owns your medical data' with two members of the biodata Working Party on the panel.



### Education

2015 saw a move towards more targeted education activities, working with organisations with expertise in running initiatives aimed at a broader public where the Council acts as an advisory or content partner rather than being responsible for development and distribution. Accordingly, the Council decided to stand down the Education Advisory subgroup, which had run for 12 years, since 2003.

In line with these developments, the Council was involved in a number of partnerships, including a Theatre of Debate workshop to develop a play for young people on the topic of involvement in patient and public involvement in medical research. 'People are Messy' has since toured schools all across the UK.

The Council's partnership with Fun Kids Radio continued with a second series 'Bene and Mal's Bioethics' airing in 2015, which explored ethical issues around science and the body.



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### International activities

Representatives of the Council presented at a number of high-level policy and bioethics conferences and symposia in 2015, in countries including Germany, USA, France, Korea, Sweden, Netherlands, Spain, Singapore, Belgium and Brazil.

Highlights include Council and Working Party Members giving plenary presentations at the 4th World Conference on Research Integrity in Brazil on the research culture report, a keynote address at the Information Security for Public Sector Annual Conference in Stockholm based on the messages in the biodata report, and hosting the trilateral meeting with the French and German National Bioethics Commissions in December 2015 to discuss topics including genome editing, cosmetic procedures and biodata.

The Council continued its prominent role in the international bioethics community, through advisory roles and committee memberships including, for example:

- Membership of the Steering Committee for the 2016 Global Summit of National Ethics Committees
- Providing the UK national delegate on the Council of Europe Committee on Bioethics (DH-BIO).
- Membership of the UK Hub advisory group developing tools for Responsible research and innovation (RRI)
- Membership of the Council of Europe Bioethics Unit Working Group on “Prohibition of financial gain”

# Future work

## Forward Look topics

In 2015 four topics were prioritised from the Council's long list of possible future work topics for further investigation: artificial gametes, dual use, longevity and non-invasive prenatal testing. Background papers on each topic were commissioned and published to inform discussions at the 2016 Forward Look meeting.

**Artificial gametes** - this paper considers possible applications in research and treatment, potential harms and benefits and regulatory challenges relating to the use of artificial gametes in reproduction.

**Dual use in biology and biomedicine** - this paper outlines current and emerging fields of research with potential for misuse, the ethical issues they raise and possible responses to the risks they pose.

**Longevity** - this paper examines a possible increase in people's lifespan and the practical challenges and ethical implications this may give rise to.

See also: [Exploratory work on non-invasive prenatal testing \(NIPT\)](#)

## Possible future work topics

The latest version of the Council's ongoing list of possible future work topics was published in October 2015, having been reviewed and updated in light of new developments. These are topics that have been suggested as possible project areas for further investigation by the Council:

- Autism
- Biotechnology and globalisation
- Citizen science
- Dignity
- Global health inequalities
- Nagoya protocol
- Non-human technologies in health and social care
- Relational autonomy
- Suppressing the extra chromosome in Down's syndrome

Find out more: download the [summary of future work topics](#).

# People

## Council Members

### **Jonathan Montgomery (Chair)**

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

### **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 HFEA.

### **Erica Haines**

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

### **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

### **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

### **Geoff Watts**

Science and medical writer and broadcaster

### **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

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## Members of Council who completed terms in 2015

### **Bobbie Farsides**

Professor of Clinical and Biomedical Ethics, Brighton and Sussex Medical School. Co-opted as chair of the Working Party on children and clinical research

### **Peter Furness**

Consultant pathologist, Leicester General Hospital and Honorary Professor of renal pathology, University of Leicester

### **Robin Gill**

Professor of Applied Theology, University of Kent

### **Graeme Laurie**

Professor of Medical Jurisprudence, University of Edinburgh, and Director of the Arts and Humanities Research Council Research Centre for Studies in Intellectual Property and Technology Law

### **Tim Lewens**

Professor of Philosophy of the Sciences, Department of History and Philosophy of Science, and Fellow of Clare College, University of Cambridge

### **Ottoline Leyser (Deputy Chair)**

Professor of Plant Development and Associate Director, Sainsbury Laboratory, University of Cambridge

### **Anneke Lucassen**

Professor of Clinical Genetics and Honorary Consultant Clinical Geneticist, University of Southampton Cancer Sciences Division and the Wessex Clinical Genetics Service

### **Martin Richards**

Emeritus Professor of Family Research, University of Cambridge. Co-opted as chair the Working Party on biological and health data

# People

## Secretariat

**Hugh Whittall, Director**

**Katharine Wright, Assistant Director**

**Dr Peter Mills, Assistant Director**

**Catherine Joynson, Programme Manager**

**Carol Perkins, PA to the Director and Secretariat Administrator**

**Seil Collins, Communications Manager (maternity cover)**

**Sarah Walker-Robson, Communications Manager (maternity leave)**

**Kate Harvey, Senior Research Officer**

**Ranveig Svenning Berg, Communications Officer**

**Dr Bettina Schmietow, Research Officer**

**Dr Anna Wilkinson, Programme Officer**

**Laura Medhurst, Office Administrator**

**Tom Burton, Temporary Researcher**

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Website: [www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)

Blog: <http://nuffieldbioethics.org/blog>

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# Financial information

## Financial report for the year to 31 December 2015

	<b>2015</b>	<b>2014</b>
	<b>Actual</b>	<b>Actual</b>
<b>Expenditure</b>	<b>£</b>	<b>£</b>
Salaries and staffing costs	631,322	577,285
Reviewers' and consultants fees	79,491	43,192
Office and premises costs	6,122	23,643
Journals & Subscriptions	16,237	12,656
Travel and meeting costs	79,803	67,626
Web, Printing and Publicity	78,886	42,173
<b>Total Expenditure</b>	<b>891,861</b>	<b>766,575</b>
<b>Funded by:</b>		
Nuffield Foundation	297,065	253,090
Medical Research Council	297,065	253,090
Wellcome Trust	297,065	253,090
Other	666	7,305
	<b>891,861</b>	<b>766,575</b>
<b>Five year Funding 2012-2016</b>	<b>£</b>	
Medical Research Council	1,435,896	
Wellcome Trust	1,435,896	
The Nuffield Foundation	1,435,896	
	<b>4,307,688</b>	
<b>Amount Drawn</b>		
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	
	<b>3,185,487</b>	
Outstanding Funding 2016	<b>1,122,201</b>	