

NUFFIELD COUNCIL ON BIOETHICS **20** YEARS

Annual report 2011 Celebrating 20 years

The Council is exploring the ethical issues raised by new technologies that intervene in the brain.

See page 8

Contents

- 1 **Note from the Chair**
- 2 **Note from the Director**
- Reports in 2011**
- 3 Biofuels
- 4 Human bodies in medicine and research
- 5 Solidarity
- New projects in 2011**
- 6 Emerging biotechnologies
- 7 Mitochondrial donation
- 8 Novel neurotechnologies
- 9 **Future projects**
- Activities**
- 10 20th anniversary
- 11 Education
- 12 Media communications
- 12 Informing policy
- 13 Events
- 13 International engagement
- Impact and funding**
- 14 Funding bid and strategy review
- 14 Financial report
- 15 Impact report
- People**
- 16 Council members
- 17 Secretariat
- 17 Contact us



Note from the Chair

In a rapidly changing world in which the biomedical sciences both promise much and prompt ethical disquiet, there are three challenges that a body like the Nuffield Council on Bioethics faces.

The first is the challenge of straight thinking. Take the case of human bodily material used in medicine and research. Everyone knows that commercialisation of such transactions leads to difficulties. But what exactly does this mean? As the Working Party on this topic showed in its report, the use of such material is both varied and subject to various principles of remuneration from straight altruism in the case of blood donation to payment in the case of first-in-human trials. Comparing and contrasting these different principles of payments is the first step in learning to think straight about the limits, and the potential, of market transactions. A similar point can be made in respect of personal responsibility, where clear thinking was shown in the report on solidarity supported by the Arts and Humanities Research Council and the Nuffield Foundation. It is easy to assume that self-inflicted injury through leading a poor lifestyle should carry a penalty, but as the report showed, the issues are not so straightforward.

The second challenge is thinking practically. In some ways this second challenge conflicts with the first, since the need to step back and place a problem in perspective takes one away from the urgency that is often needed to have practical effect. However, the Working Party on biofuels showed that it was possible to make practical recommendations, in particular about certification, and conduct a thoughtful appraisal of a complex set of technologies and policies.

The third challenge is to think ambitiously. The most demanding bioethical issue facing the world at present is that of global health inequalities, great as they are in scale and complex in operation. To celebrate its twentieth anniversary the Council held a symposium to look at issues of responsibility in global health. The two days were an exciting occasion, with Lord Crisp giving a keynote lecture and a number of colleagues from around the world providing evidence and insight. Was the ambition of the topic matched by a breakthrough to a feasible work programme? I think not. This was not because of the short-comings of the participants, but because of the magnitude of the issues and the difficulty of defining a way of thinking that would lead to a practical and straight-thinking report. This is a topic with which the Council will still have to wrestle.

This is my final report as Chair of the Nuffield Council. Each year I have recorded my thanks to the members of the Council, the staff of the secretariat and all who have supported the work of the Council, financially, practically and intellectually. I repeat that thanks warmly this year. I should also record my thanks to other bioethics councils in Europe, from whom we have benefited greatly through increasing contact and discussion. It has been the highest privileged to have chaired the Nuffield Council. I wish all associated with its work in the future well in their task of undertaking clear, practical and ambitious thinking.

Albert Weale

Albert Weale
Chair 2008–2012



Note from the Director

Well, what a busy year that was! We published significant new reports on biofuels and the donation of human bodily material, both of which had widespread media coverage and look as though they will have some lasting effect in the policy arena. And we started two other projects, looking at emerging biotechnologies and novel neurotechnologies.

But we also took a couple of new directions, exemplifying the way in which we are continuing to look for new and effective ways of stimulating debate and informing policy. One of these was a report on solidarity that was published in November. This was the result of a fellowship that was jointly sponsored by the Nuffield Foundation and the Arts and Humanities Research Council, developing a theme – solidarity as a principle in bioethics – that has been emerging in a number of our reports in recent years.

Another new departure was the launch of a project on novel treatments for mitochondrial disease, which is intended to be a much more rapid project than our usual ones and aims to support an ongoing policy discussion with a timely look at the ethical aspects. The report of this project – more a discussion paper – will be published early in 2012.

The other major piece of work initiated in 2011 was a strategic review that will culminate in the publication shortly of our strategic plan for 2012-2016. In carrying out this review we met with a wide range and large number of stakeholders, and looked afresh at the changing environment in which we will be working. One of the challenges will be to keep the conversations going so that we can identify the most important bioethical questions; hear from as many people as we can; and disseminate our work more effectively to both the public and to policymakers.

I would like to thank everyone who contributed not only to that review, but also to all of our work throughout the year. We are fortunate in being able to call on the expertise, opinion, support and goodwill of many people and their input is invaluable. Not least I would like to thank Albert Weale, the departing Chair of Council, who has led and supported us in equal measure, and who has given seemingly endless time, energy and commitment.

We look forward to 2012, which we believe and hope will be no less busy and fascinating than 2011.



Hugh Whittall
Director



Biofuels

Driven by the global challenges of climate change, energy security and economic development, there has been a rapid expansion in biofuel production around the world over the past decade.

Current methods of biofuel production have been associated with harms to the environment, threats to food security, and human rights violations in countries where they are grown. New types of biofuels, such as lignocellulosic and algal biofuels, could help to reduce greenhouse gas emissions whilst avoiding these problems, but commercial-scale production is some years away.

In April 2011, the Council published the report *Biofuels: ethical issues*. While we believe that there is a significant role for biofuels to contribute to energy security and climate change mitigation, the report suggests that all biofuels should have to meet the following ethical principles before they can be imported and used in Europe, and ideally worldwide:

- 1 Biofuels development should not be at the expense of human rights
- 2 Biofuels should be environmentally sustainable
- 3 Biofuels should contribute to a reduction of greenhouse gas emissions
- 4 Biofuels should adhere to fair trade principles
- 5 Costs and benefits of biofuels should be distributed in an equitable way

A sixth principle states that if the first five principles are respected, then there is a duty to develop such biofuels. The report urges policy makers to support further research and development into new, more ethical biofuels technologies.

Policy changes

In December 2011, the Government adopted new legislation for implementing the transport elements of the Renewable Energy Directive up to 2014, which states that 10 percent of transport fuel must come from renewable sources by 2020. The target provides stability for biofuels producers, and introduces new environmental sustainability criteria for biofuels used in Europe. However, the Council is concerned about the lack of mandatory social sustainability criteria in the new legislation, and the few incentives for the development of new, more ethical types of biofuels.

The Council hosted a briefing event in the Houses of Parliament on the implications of the changes, and gave oral evidence to the Commons Energy and Climate Change Select Committee at a one-off session on bioenergy. The issues will be debated further over the coming months as the Government prepares to set out longer-term proposals.

“There is a clear need to replace liquid fossil fuels to limit climate change and if a new biofuel technology meets ethical conditions, there is a duty to develop it”

Ottoline Leyser,
The Guardian, 13 April 2011

“A new international approach to policymaking is required, guided by a transparent standard that reflects all areas of ethical concern”

Joyce Tait and Alena Buyx
Science, 29 April 2011



Chair of the Working Party

Joyce Tait

Scientific Adviser to the Innogen Centre (ESRC Centre for Social and Economic Research on Innovation in Genomics), Edinburgh University

List of Working Party members >



Find out more: www.nuffieldbioethics.org/biofuels

Find out more: www.nuffieldbioethics.org/donation



“Three people will die every day while waiting for a transplant. We would like to test paying funeral expenses for donors.”

Keith Rigg
BBC News, 11 October 2011

Human bodies in medicine and research

Many different types of human bodily material can be donated for the treatment of others, or for research, such as organs, blood, eggs and sperm, but supply often falls short of demand. More than 10,000 people in the UK need an organ transplant, people are travelling abroad to access donor eggs and sperm, and research is often held back by difficulties in accessing tissue.

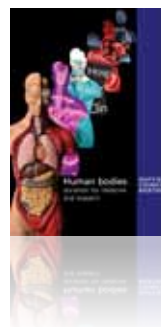
The Council published the report *Human bodies: donation for medicine and research* in October 2011, which considers how far society should go in encouraging people to donate bodily material.

The report concludes:

- The state has a role both in trying to improve public health to reduce the need for donated material, and in helping to make donation as easy as possible.
- The welfare of the donor should be the most important consideration.
- Altruism should continue to be at the heart of donation, but this does not exclude the possibility of some form of reward in some circumstances.
- Body parts should not be bought or sold directly.

The report goes on to make specific recommendations for policy. Our suggestion that the NHS could meet the funeral expenses of people who sign the Organ Donor Register and subsequently become organ donors captured the imagination of the public, and led to widespread debate in the broadcast and online media. A YouGov poll of 2400 people found 52 percent supported the idea, while 32 percent were opposed.

The report also recommends that the cap of £250 on recovery of lost earnings for egg and sperm donors should be removed. Shortly afterwards, the Human Fertilisation and Embryology Authority decided that women who donate their eggs will be compensated £750 per cycle of donation, and that sperm donors be compensated £35 per clinic visit.



Solidarity

Solidarity has arisen as an important concept in several areas of the Council's work, such as biofuels and caring for people with dementia. In 2011 the Council commissioned an analysis of the different uses and meanings of solidarity, and how it can be used to support policy discussions.

Funded by the Nuffield Foundation and the Arts and Humanities Research Council, Professor Barbara Prainsack was the Council's Solidarity Fellow between February and August 2011. She worked closely with fellow author Dr Alena Buyx, Assistant Director of the Council.

The resulting report, *Solidarity: reflections on an emerging concept in bioethics*, defines solidarity as people's willingness to help others even if this incurs 'costs' for them, such as time, emotional investment and, in some cases, money. Solidarity can take place between just two individuals, but it can also be a more widely shared societal practice. The report uses this new understanding of solidarity to help find solutions in three areas of policy-making: biobanks, pandemics and lifestyle diseases. For example:

Biobanking – traditional consenting procedures should be replaced with 'participation agreements', where participants, after being informed about aims, benefits and risks of the research, agree to their sample being used in any future research that is within the broad aims of the biobank and has been approved by a research ethics committee.

Pandemics – social media could be used more systematically during pandemics to track the spread of disease, raise awareness of public health measures, collect information, and organise assistance.

Lifestyle diseases – a solidarity-based approach supports access to healthcare granted on the basis of need, as is currently the case in the UK's NHS.

The report will be discussed by the authors in journals such as *Bioethics and Clinical Ethics*, and at international conferences, in the coming months.

"Our suggestions rest on the assumption that people are regularly willing to accept costs...to assist others based on the perception of sameness."

Barbara Prainsack and Alena Buyx
BioNews, 5 December 2011



Find out more: www.nuffieldbioethics.org/solidarity



Find out more: www.nuffieldbioethics.org/emerging-biotechnologies



Emerging biotechnologies

Over the years the Council has examined the ethical issues raised by a range of bioscience developments, such as stem cell research, xenotransplantation and GM crops. As similarly controversial technologies continue to emerge, the Council has decided to examine the cross-cutting ethical and social issues they present to society.

New biotechnologies, such as nanotechnology, synthetic biology and regenerative medicine, raise a number of common issues, including potential benefits and harms to health and the environment, uncertainty and risk, precaution and innovation, public perception, and intellectual property. The objective of this project is to develop principles and recommendations to assist decision makers to reach ethically informed judgements relating to emerging biotechnologies.

A public consultation was held from April to June 2011, which elicited 85 helpful responses from a range of organisations and individuals. Between May and July, four evidence-gathering sessions were held with experts in the field, focusing on research and development, public engagement, intellectual property and innovation, and regulation. A report with recommendations will be published in autumn 2012.

"In any new technology there are uncertainties and a decision needs to be taken about whether, and if so at what stage, to move from research to application."

British Medical Association
Consultation response, June 2011

"Ultimately, emerging technologies will only flourish if they have sufficient public support and public trust in the way they are developed, implemented and regulated."

British Science Association
Consultation response, May 2011

New projects in 2011

Chair of the Working Party

Geoff Watts

Science writer and broadcaster

List of Working Party members >

Mitochondrial donation

The treatment of inherited mitochondrial abnormalities in human embryos using donor mitochondria is an advancing area of research. The new techniques involve making changes to the embryo that would be inherited by future generations, and it is currently unlawful to offer them for treatment in the UK.

The Council is conducting a short inquiry to consider the ethical issues raised by the new techniques in order to inform forthcoming policy debates about their legality.

At present, there are no known cures for inherited mitochondrial disorders, which can cause severe symptoms such as blindness, heart and liver failure, and even death. Approximately one in 250 live births is affected by mitochondrial disorders.

The new techniques use healthy mitochondria from a donor egg to replace the mother's unhealthy mitochondria at the point of reproduction. The resulting child would have a genetic connection to three people.

The Council issued a call for evidence in early 2012 to inform its deliberations. Simultaneously, a new Wellcome Trust centre for mitochondrial research at Newcastle University was launched, and the Human Fertilisation and Embryology Authority announced that it will lead a public dialogue exercise on the acceptability of the new techniques later in 2012. The Council will publish its findings in a short report in summer 2012.

"Some people may be concerned about the ethical acceptability of these techniques, which involve making genetic changes that will be passed on to all subsequent generations if the treatment is successful."

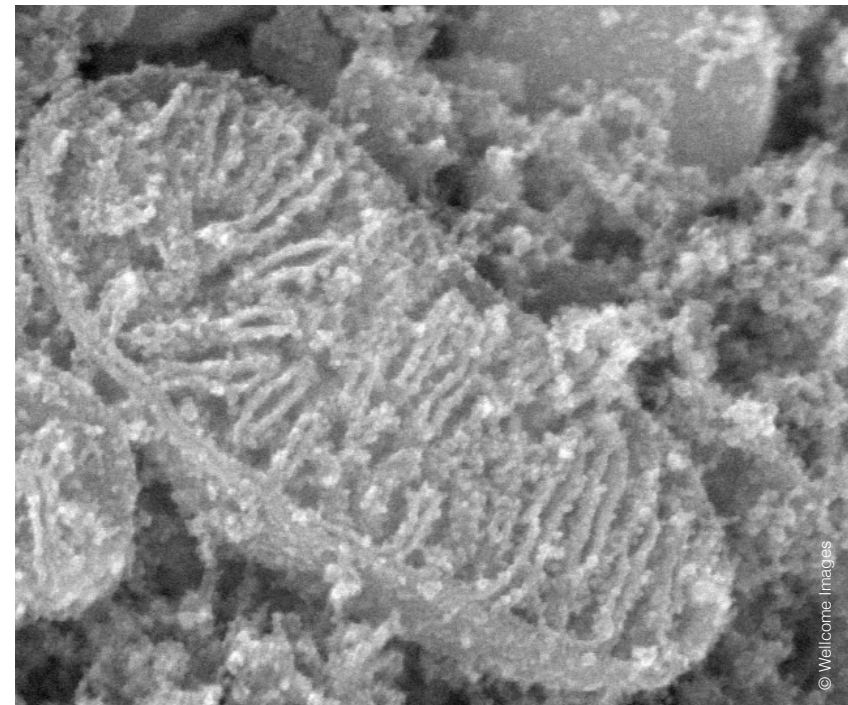
Geoff Watts

Launch of the consultation,
January 2012

"Not only are scientists, lawmakers and ethicists speaking the same language, they are also synchronizing their efforts to make Britain the first country to test the techniques in humans, taking it light years ahead of other nations."

Nature Editorial, 25 January 2012

Find out more: www.nuffieldbioethics.org/mitochondrial-donation



Novel neurotechnologies

In history, treatments that involved direct intervention in the brain were often controversial, and usually swiftly discredited. However, new techniques are emerging that are raising hopes for the treatment of crippling neurological conditions.

In this project, the Council is focusing on the ethical issues raised by three types of novel neurotechnologies in the early stages of development: brain-computer interfaces, neurostimulation, and neural stem cell therapy.

Brain-computer interfaces analyse a person's brain signals and convert them into an output. They might, for example, be used to help people who have 'locked-in syndrome' to communicate. Military applications, such as remote control of vehicles, and their potential use in computer games, are also being researched.

Neurostimulation involves the application of an electric or magnetic stimulus to nerves to alter brain activity in a specific area. It is currently used to treat depression, and research is underway on possible applications for other conditions, such as epilepsy and migraine. It is also being used to explore enhancement applications, such as improving learning and memory in healthy people.

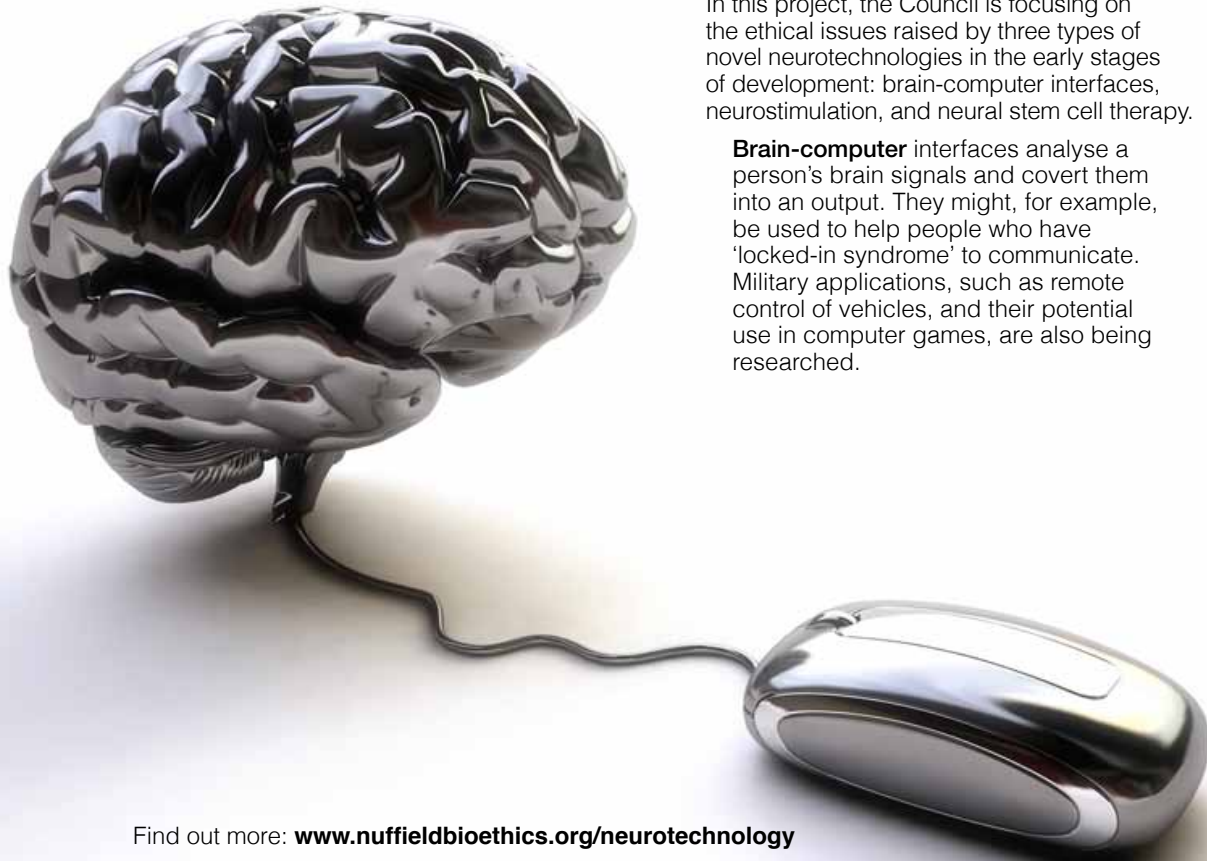
Neural stem cell therapy involves injecting stem cells into damaged areas of the brain. There is hope that this could be used for treating conditions such as Alzheimer's disease and stroke.

These technologies could have enormous benefits, but they also raise concerns for some in relation to their safety and efficacy, their impact on the individual and its mind, and the societal consequences of their widespread use.

An open call for views and evidence was issued in early 2012, and a report setting out the Council's findings will be published in 2013.

"Intervening in the brain has always raised both hopes and fears in equal measure. Hopes of curing terrible diseases, and fears about the consequences of trying to enhance human capability beyond what is normally possible."

Thomas Baldwin
Council press release,
March 2012



Future projects

Each spring, Council members and invited experts discuss potential future work topics at a two-day 'Forward Look' seminar. The topics for discussion are chosen by the Council from an ongoing long list of topics that have been suggested by members, staff and other organisations and individuals throughout the year.

The four topics chosen for consideration at the 2011 Forward Look seminar were:

- the treatment of inherited mitochondrial abnormalities
- hyper-expensive new therapies and the prioritisation of R&D
- genomics, health records, database linkage and privacy
- pandemics

Briefing papers were commissioned on each to inform the discussions.

Following the seminar, the Council decided to conduct a short inquiry on the ethical issues raised by techniques to prevent the transmission of inherited mitochondrial disorders (see p8). It also agreed to explore further the topic of genomics, health records, database linkage and privacy at a one-day workshop, which was held in February 2012.

Two topics discussed at previous Forward Look meetings were also given the go-ahead: donor conception, and children and clinical trials.

Donor conception

This project, which began work in early 2012, will consider the ethical issues raised by the disclosure of information about genetic origin in the context of families created through assisted reproduction using donor gametes. The inquiry will focus on how the sometimes conflicting interests of the various parties involved in donor conception should be balanced; and what role the state should play in what is often seen as the private domain of the family. See: www.nuffieldbioethics.org/donor-conception

Children and clinical trials

Concerns about putting children at risk by involving them in trials of new medicines conflict with concerns about giving sick children medicines that have not been tested in children. Consequently, there is little data on dosage-requirements, efficacy and safety in the use of medicines in children. A workshop was held in December 2011 to scope out the issues, and a Working Party will be set up in 2013. See: www.nuffieldbioethics.org/future-work/future-work-workshop-children-and-clinical-trials

Find out more: www.nuffieldbioethics.org/future-work





20th anniversary

2011 was the 20th anniversary of the Council, making it one of the longest running bioethics committees of its kind. In that time it has published 20 reports and discussion papers on a wide range of bioethics issues.

Throughout the year we celebrated our achievements but, more importantly, looked ahead to the next 20 years and how the Council can build on its core values of independence and quality.

Activities included:

- **Global health symposium** – an international line-up of speakers and 130 guests discussed current initiatives and future challenges in global health inequalities at the Council's 20th anniversary symposium on 22 June in London. The following day, the speakers and Council members met to reflect on the outcomes of the symposium and consider what contribution the Council might be able to make in this area. Watch a video and download a report of the symposium.
- **Anniversary review** – this report celebrates and reviews the events that have taken place over the past 20 years. The report includes comments and contributions from a wide range of people who have worked with the Council over the years, as well as a look to future bioethics topics on the horizon.
- **Public lecture** – Baroness Onora O'Neill, one of the founding members of the Council, gave a public lecture to mark the 20th anniversary on 19 May in London.

"I would like to commend the Council on the reputation it has established over the past two decades for undertaking rigorous examination of topical, and sometimes controversial, subjects using the best expertise available. The quality of the Council's reports is widely recognised and it has provided an important focus for ethical debate, both in the UK and internationally."

David Cameron, Prime Minister
December 2011



Find out more: www.nuffieldbioethics.org/celebrating-20-years

Education

By supporting teachers to facilitate debate on bioethics in the classroom, the Council aims to equip future generations with the tools they need to consider ethical issues that arise in everyday life.

In 2011, the Council published teaching resources on the ethics of biofuels, personalised healthcare, and dementia.

The Council also launched a new film-making competition for students, Box Office Bioethics, that aims to get young people making short films about contemporary bioethics issues. The winners, to be announced in 2012, will receive £200 in gift vouchers and their film will be shown at the Council's annual public lecture in May.

"The practical scenarios are particularly useful in allowing for discussion of how ethical principles can support decision making."

Teacher feedback on dementia teaching resources



- Phyllis is 79 years old and has had dementia for 3 years
- She lives with her daughter Sandra and her family
- Phyllis is becoming more confused, and is less able to do things for herself
- Phyllis recently had a fall in the bathroom of the family home and fractured her wrist
- Sandra is worried about letting Phyllis go to the toilet by herself and thinks she should be accompanied
- However, when Sandra has gone into the bathroom with her, Phyllis has become very upset

Meet Phyllis & Sandra



Find out more: www.nuffieldbioethics.org/education

Informing policy

The Council engages with government officials, parliamentarians and others to inform policy and promote debate about bioethics.

Policy activities in 2011:

- 'Bioethics in Parliament' event – this year's event, hosted by Lord Harries of Pentregarth in the House of Lords, discussed the implications of biofuels policy to coincide with Government proposals for implementing the transport elements of the European Renewable Energy Directive.
- The Council gave oral evidence to the Commons Energy and Climate Change Select Committee at a one-off session on bioenergy. Our report on biofuels was discussed as part of the agenda.
- The Council and the Arts and Humanities Research Council jointly hosted a series of policy seminars focusing on the Council's 2009 report *Dementia: ethical issues*. The seminars, which took place in Westminster in March 2011, highlighted areas of crossover between bioethics, the humanities, and policy-making in the context of dementia.
- Policy briefing papers were circulated to MPs and others on biofuels policy, the donation of organs and tissue for medicine and research, and public health measures to tackle non-communicable diseases.
- The Council submitted written evidence to a range of policy consultations, including a Home Office consultation on the protection of animals in research, a Health Select Committee inquiry on social care, and a Department of Health consultation on public health policy.

Find out more: www.nuffieldbioethics.org/informing-policy

Media communications

The nature of the media is changing. Newspaper circulations are declining, while online news and social media offer almost unlimited opportunities for interactive communication with a global audience.

The Council has been keen to grasp these opportunities and uses Twitter to engage in debate about relevant issues in the news as they are unfolding. The Council's website is steadily gaining followers with around 10,000 visits per month, and 2500 people have signed up to receive a quarterly e-newsletter.

More traditional media, such as radio, television, newspapers, magazines and journals, remain important means of communication, however, and we work closely with journalists to try to gain balanced coverage of our work.

Of particular note in 2011, the Council was pleased to advise the documentary-maker Adam Wishart on his programme "23 week babies: The price of life", broadcast on BBC2 on 9 March. The programme drew on the Council's 2006 report *Critical care decisions in fetal and neonatal medicine: ethical issues*, and discussed the very difficult decisions that parents and doctors have to make about the care of extremely premature babies.

Find out more: www.nuffieldbioethics.org/news

"People who donate organs on their death beds should have their funeral expenses paid for by the NHS, a leading medical ethics think-tank has suggested."

The Telegraph, October 2011

"Biofuels targets are 'unethical', says Nuffield report"

BBC News, April 2011

"The Nuffield Council on Bioethics recently warned that DNA profiling tests...can show up 'abnormalities' which are actually harmless"

Red magazine, March 2011



Events

Nothing replaces face-to-face interaction for really engaging people in debate about complex bioethical issues.

The Council organises its own events, and takes part in the events of other organisations in order to meet as wide a range of people as possible and gain direct feedback on its work.

In 2011, the Council organised public seminars to launch its reports on biofuels, the donation of bodily material, and solidarity; hosted a session on synthetic biology at the Cheltenham Science Festival and on biofuels at the Science Museum; and gave presentations at a wide range of conferences such as Crop World 2011, the London Genetics Pharmacogenetic Conference, and Primary Care 2011.

Find out more: www.nuffieldbioethics.org/events

International engagement

It is vital for the Council to keep abreast of international developments in order to bring context to its work, and we increasingly take a leading role in the international bioethics community.

The Council frequently meets with the bioethics commissions of other countries. In 2011, it visited the Portuguese, Danish and Austrian Commissions, hosted a meeting in London with the French and German Commissions, and attended the European Commission's annual Forum of National Ethics Councils in Brussels.

Looking to engage further afield, in June the Council hosted an international symposium on global health inequalities as part of its 20th anniversary activities. Speakers and participants travelled from India, Australia, South America, Africa, China and the US to offer their perspectives on this important issue. Watch a video and download a report of the symposium

Find out more: www.nuffieldbioethics.org/international



Funding bid and strategy review

In 2011, the Council applied to renew its core funding for the period 2012-2016. This initiated a valuable process of reflection on both past performance and future strategy.

Since the early 1990s, the Council has been funded by the Nuffield Foundation, Wellcome Trust and Medical Research Council on a five-year rolling system. At the end of each funding period, the Council reviews and demonstrates how it has fulfilled its terms of reference, which are:

- 1 to identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern;
- 2 to make arrangements for examining and reporting on such questions with a view to promoting public understanding and discussion; this may lead, where needed, to the formulation of new guidelines by the appropriate regulatory or other body;
- 3 in the light of the outcome of its work, to publish reports; and to make representations, as the Council may judge appropriate.

Following submission of a detailed application to the Council's three funders, funding has been secured to the end of 2012. Beyond this, funding has been agreed in principle to 2016 subject to the completion of a strategic review. The review process, which got underway in autumn 2011, has been a valuable opportunity for the Council to consider how it works, how it communicates, and how it is governed. To inform the review, a series of consultative meetings was held with stakeholders from a variety of backgrounds, including science, medicine, public policy, social sciences, industry, religious groups, parliamentarians and journalists. An external review of the Council's governance arrangements was also commissioned.

The outcomes of the review will be published in summer 2012 in the form of a strategic plan for the Council for the period 2012-2016.

Financial report

Financial Report for the year to 31 December 2011 (unaudited)

	2011 Actual £	2010 Actual £
Expenditure		
Salaries and staffing costs	560,111	520,571
Reviewers' and consultants fees	26,359	34,688
Office and premises costs	6,106	6,776
Journals & Subscriptions	23,366	16,885
Travel and meeting costs	110,273	94,940
Web, Printing and Publicity	71,960	41,967
Total Expenditure	<u>798,175</u>	<u>715,826</u>
Funding Due		
Nuffield Foundation	186,905	235,884
Medical Research Council	186,905	235,884
Wellcome Trust	186,905	235,884
Other	1,334	31,405
	<u>562,049</u>	<u>739,057</u>
Overheads met by Nuffield	<u>443,995</u>	<u>492,260</u>

Impact report

The Council aims to inform policy making and promote public discussion of bioethics. This section provides some indicators of how well the Council achieved these aims in 2011.

Policy impact

Measuring the Council's influence on policy can be a challenge. Policy change can take a long time to come about, and we are often one voice among many. Nevertheless, examples of policy change in 2011 where we have had an impact can be identified:

- The Government's Protection of Freedoms Bill 2010-12 proposes changes to the way people's DNA is stored on the National DNA Database, following a ruling of the European Court of Human Rights in 2008. The ruling cited the Council's 2007 report **The forensic use of bioinformation: ethical issues** heavily in its judgment. Under the new legislation, DNA profiles and fingerprints taken from people who have been arrested but never charged or convicted of a crime will be destroyed.
- In its report on Behaviour Change, the Lords Science and Technology Committee drew on the Council's 'ladder of interventions', as set out in our 2007 report **Public health: ethical issues**. The ladder was used to illustrate the Committee's conclusion that a whole range of measures will be needed to change behaviour in a way that will make a real difference to society's biggest problems.
- The Northern Ireland Executive published a new strategy for improving dementia services in the region, echoing many of the conclusions made in the Council's report **Dementia: ethical issues**. In addition, the WHO report *Dementia: a public health priority* referenced several conclusions in the Council's report on dementia, for example on supported decision-making, and its approach to ethical issues in dementia closely matches that presented by the Council.

Reports and Working Parties	
Reports published to date	23
Reports published in 2011	3
Reports published 2008-2010	2
Active Working Parties at end of 2011	3

Media coverage		
	2011	Average per year 2008-2010
No. of broadcast interviews	57	18
No. of online & print articles:		
UK national press	16	33
Other (incl national and international online media)	688	132
Articles written by Council representatives	24	17

Website & social media statistics		
	2011	2010 ¹
Visits to the website	121,476	81,325
Page views	666,072	355,209
Average visit duration	3 min 13 sec	2 min 54 sec
No. countries with more than 100 visits	60	49
Subscribers to e-newsletter	2280	1797
Twitter followers	1571	1000

Presentations at conferences and events		
	2011	Average per year 2008-2010
No. events where presentations were given by Council representatives	46	48

Consultations		
	2011	Average per year 2008-2010
Number of consultations held by the Council	1	1.3
Responses received to the Council's consultations	85	177
Responses submitted by the Council to the consultations of other organisations	8	12

Academic citations		
	2011	Average per year 2008-2010
Papers or books citing Nuffield Council on Bioethics ²	454	388

¹ Comparable data not available prior to 2010

² Data generated using Harzing's Publish or Perish software

Council members

Professor Jonathan Montgomery (Chair from March 2012)

Professor of Health Care Law,
University of Southampton and Chair,
Hampshire Primary Care Trust

Professor Albert Weale FBA (Chair until March 2012)

ESRC Professorial Fellow & Professor
of Political Theory and Public Policy,
University College London

Professor Hugh Perry FMedSci

(Deputy Chair until March 2012)
Professor of Experimental
Neuropathology, University
of Southampton

Professor Thomas Baldwin

Professor of Philosophy, University of
York. Co-opted member of Council while
chairing the Council's Working Party on
novel neurotechnologies

Professor Steve Brown FMedSci

Director, Medical Research Council
Mammalian Genetics Unit, Harwell,
Oxfordshire

Dr Amanda Burls

Director, Postgraduate Programmes
in Evidence-Based Health Care, and
Senior Fellow, Centre for Evidence-Based
Medicine, University of Oxford

Professor Robin Gill

Professor of Applied Theology,
University of Kent

Professor Sian Harding FAHA FESC

Professor of Cardiac Pharmacology,
National Heart and Lung Institute,
Imperial College London

Professor Ray Hill FMedSci

Retired 2008. Previously Head of
Licensing and External Research for
Europe, Merck, Sharp and Dohme

Professor Søren Holm

Professor of Bioethics, University
of Manchester and part-time
Professor of Medical Ethics,
University of Oslo, Norway

Dr Rhona Knight FRCGP

General Practitioner and Senior Clinical
Educator, University of Leicester. Chair of
the Council's Education Advisory Group
and Working Party on donor conception

Professor Graeme Laurie FRSE

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

Dr Tim Lewens

Reader in Philosophy of the Sciences
and Fellow of Clare College, University
of Cambridge

Professor Ottoline Leyser CBE FRS

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

Professor Anneke Lucassen

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

Professor Michael Moran FBA

WJM Mackenzie Professor of
Government, University of Manchester.
Co-opted member of Council while
chairing the Council's Working Party
on emerging biotechnologies

Professor Alison Murdoch FRCOG

Professor of Reproductive Medicine,
Consultant Gynaecologist and Head of
the NHS Newcastle Fertility Centre at Life

Dr Bronwyn Parry

Reader in Geography, Queen Mary,
University of London

Professor Nikolas Rose

Professor of Sociology and Head of
Department of Social Science, Health
and Medicine, King's College London

Professor Dame Marilyn Strathern FBA

Former Mistress, Girton College
Cambridge and William Wyse Professor
of Social Anthropology, Cambridge
University. Co-opted member of Council
while chairing the Working Party on
human bodies in medicine and research

Professor Joyce Tait CBE FRSE FSRA

Scientific Adviser to the Innogen Centre
(ESRC Centre for Social and Economic
Research on Innovation in Genomics),
Edinburgh University. Co-opted member
of Council while chairing the Working
Party on biofuels

Dr Geoff Watts FMedSci

Science and medical writer and
broadcaster. Chair of the Working
Group on mitochondrial donation

Professor Jonathan Wolff

Professor of Philosophy,
University College London

People

Secretariat

Hugh Whittall

Director

Dr Alena Buyx

Assistant Director

Dr Peter Mills

Assistant Director

Katharine Wright

Assistant Director

Laura Riley

Project Leader,
Mitochondrial donation: ethical issues

Carol Perkins

PA to the Director and Secretariat Administrator

Catherine Joynson

Communications Manager

Sarah Bougourd

Communications Officer

Kate Harvey

Research Officer

Tom Finnegan

Research Officer

Varsha Jagadesham

Research Officer

Audrey Kelly-Gardner (until April 2011)

Secretary

Johanna White (from October 2011)

Office and Communications Administrator

Contact us

Nuffield Council on Bioethics
28 Bedford Square, London WC1B 3JS
Telephone: +44 (0)20 7681 9619
Fax: +44 (0)20 7323 6203
Email: bioethics@nuffieldbioethics.org
Website: www.nuffieldbioethics.org

© Nuffield Council on Bioethics 2012

All rights reserved. Apart from fair dealing for the purpose of private study, research, criticism or review, no part of the publication may be produced, stored in a retrieval system or transmitted in any form, or by any means, without prior permission of the copyright owners.