

NUFFIELD COUNCIL ON BIOETHICS **20** YEARS

Exploring ethical issues in biology and medicine



The Council is exploring the ethical issues raised by biofuels, see page 4

Annual report 2010

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Note from the Chair

The biomedical sciences are playing an increasing role in society and public policy. That much is obvious. But what is the role of an independent council in examining the social and ethical implications of those developments? Do we not live in a world in which science proposes and politics disposes? In many cases it is so, whether we are thinking of the government's £200m fund for anti-cancer drugs or the 'cull of the quangos'. However, there is still a role for independent and well-informed deliberation on public policy, for at least three reasons.

Firstly, there is a need to challenge prevailing assumptions, well illustrated in the Council's report *Medical profiling and online medicine*, published in October 2010, which examined the bold claims often made for 'personalised healthcare'. As the Working Party pointed out, even defining the meaning of personalised healthcare is hazardous, not least because those practising medicine have always thought good practice was directed at the needs of particular individuals. Just as important was the need to realise the limits of regulation in an internet age and to tailor public action so that it was proportionate and not unduly paternalist. A similar concern with the limits of medical paternalism was shown by Professor Inez de Beaufort's splendidly entertaining annual lecture 'Whose potbelly is it anyway?' which she gave in April 2010.

Secondly, an independent Council exists to explain the practical implications of its ethical principles and approaches. We were therefore pleased when the Department of Health approached us to hold a workshop on the implications of the 'ladder of intervention', set out in the Council's 2007 report *Public health: ethical issues*, to inform the drafting of the Government's white paper on public health. Influence carries its own risks. Indeed, we have been asked if there are dangers in being too influential, and there is clearly always a danger of our words being used without their original force. Yet, the Council's mission is fundamentally practical and we cannot escape the obligations of the influence agenda with the risks that it brings.

Thirdly, an independent Council exists to highlight and define topics that come and go in the attention cycle of public opinion but that raise deep and serious matters of ethical concern. The work undertaken in 2010 in regard to social justice and biofuels, and the nature and limits of commercialisation in the use of the human body in medical research both illustrate this aspect of the Council's work.

In discharging these functions, the Council is aided by an exceptionally talented, energetic and committed staff. It has been made clear to me time after time that members of Council and of Working Parties hold the staff in the

highest possible regard and it is a pleasure to be able to acknowledge their contribution in this annual report.

Two long-standing members of Council – Roger Brownsword and Peter Harper – concluded their term of office in 2010. Each had the invaluable knack of identifying where the Council might be going wrong and firmly, but courteously, setting us back on track, exemplifying the virtues needed for true deliberation. For me it remains a privilege to be associated with an organisation that performs such vital functions.

Albert Weale

Professor Albert Weale FBA
Chair of the Nuffield Council on Bioethics



Note from the Director

If I could identify a theme for 2010, it has been, for me, complexity. Complexity both in the management of our work, and in the subjects that we address. As I reported last year, we have extended our capacity so that we now have three projects on the go at any one time, and so we publish consultation documents and reports with ever greater frequency. This increases the volume of work not only in the research and drafting of the material, but also in the communications, administration and logistics within what is still a very small office. It also means that the amount of traffic that Council members have to handle is proportionately greater. Everyone concerned has risen to these challenges with energy and enthusiasm and there is a real excitement about the way that we have been able to step up the pace, yet maintain the quality and reach of our work.

The report published towards the end of 2010, on 'personalised healthcare', was illustrative of the increased complexity of the topics that we examine. It looked at a range of technologies and applications converging around new approaches to healthcare within a social and political environment that is itself complex and changing. Meanwhile, we were working

up our ideas on the seemingly unconnected topic of biofuels, and following through on our earlier work on dementia. Whilst one would not wish to make too much of this small sample, I think it nevertheless worth noting that bioethics has increased its reach way beyond its roots in medical ethics, and into more global and wide-ranging issues. The task becomes correspondingly more complex, and we benefit from the contributions of a great number of experts through our Working Parties, consultations, fact-finding meetings and workshops, and peer review. Our job is to bring this all together in prescient, policy-relevant reports, and to promote discussion and understanding.

The work may become more complex, but the pleasure that we take in managing and executing it remains, happily, very simple.

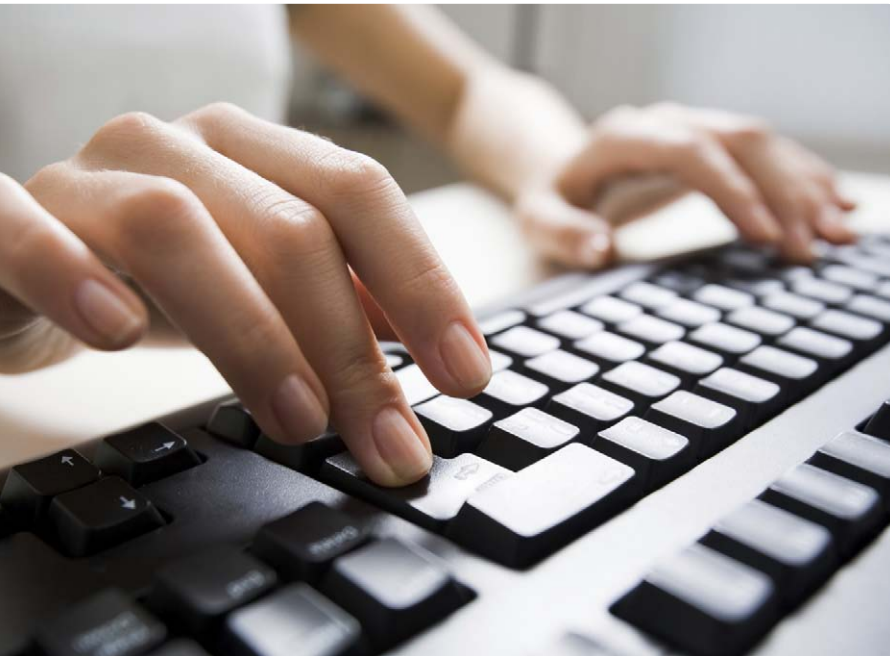


Hugh Whittall

Director of the Nuffield Council on Bioethics



Medical profiling and online medicine



New developments in medical profiling and online medicine are promised by their providers as leading to a new era of 'personalised healthcare'.

The Council published a report in October 2010, *Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age*, which weighs up the benefits and harms of some of these developments, along with the ethical values that come into play. The report considers in detail:

- Direct-to-consumer personal genetic profiling and body imaging
- Online health information
- Online personal health records
- Buying medicines online
- Telemedicine

The Council concluded that all these developments offer increased personalisation to some extent. But many of the claims for more individualised diagnosis and treatment are overstated and should be treated with caution. Key recommendations include:

- Regulators should request evidence for any claims being made by companies offering direct-to-consumer personal genetic profiling about the clinical value of their tests.
- Direct-to-consumer whole body CT imaging should be banned.
- The UK Departments of Health should ensure that high-quality health information is available on their websites.
- The Government should set up accreditation schemes for online health record providers.

The Council will disseminate and discuss its findings with policy makers and others throughout 2011.

"We don't think people should be banned from getting this kind of information. But we believe very firmly that results can be very difficult to interpret unless you have specialist knowledge."

Professor Nikolas Rose,
member of Council, on personal genetic profiling tests

"All websites offering health information and advice should state where the information originates and what it is based upon, who wrote it, and how the author or organisation is funded."

Professor Christopher Hood,
chair of the Working Party
The Scotsman

Chair of the Working Party Professor Christopher Hood FBA

Gladstone Professor of Government and Fellow, All Souls College, University of Oxford and Director, ESRC Public Services Research Programme

[List of Working Party members](#)

Biofuels

Fuel for transport makes up almost a third of the current world energy consumption. With increasing concern about climate change, energy security and economic development, the drive to develop alternative liquid biofuels for transport has grown rapidly in recent years.

Current biofuel production, which mainly uses food crops, has led to deforestation and disputes over rising food prices, human rights and land use. New approaches to biofuels, such as those using non-food crops and algae, are being developed with the aim of meeting our energy demands whilst avoiding the problems of the past.

The Council set up a Working Party in 2009 to examine the ethical issues raised by the development of liquid biofuels for transport. Over 90 organisations and individuals responded to a public consultation in early 2010, providing the Working Party with a wide range of opinions and evidence. Face-to-face meetings were also held with scientists, policy makers and non-governmental organisations.

The Council published a report in April 2011 with recommendations for biofuels policy in areas including greenhouse gas emissions, sustainability, food security and human rights.



“We want to see that the production of new types of biofuels, especially in developing countries, has a positive effect on local communities and supports economic development by creating jobs and new sources of income.”

Professor Joyce Tait, Chair of the Working Party
Guardian Environment Blog

Chair of the Working Party
Professor 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](#)



Human bodies in medicine and research

There is demand for a range of human bodily material in medicine and research, including organs, blood, eggs and sperm. Is it always right to try to meet this demand, and how far can we go in encouraging people to donate?

The Council set up a Working Party in January 2010 to explore these difficult questions. A public consultation in the spring of that year drew considerable media attention, with most coverage focusing on the issue of financial incentives for donation. The publicity led to over 170 wide ranging responses.

A one-day deliberative workshop was held in Bristol in July 2010, funded by a Wellcome Trust People Award, to find out the views of a group of non-experts. Facilitated by Opinion Leader, 43 people drawn from a cross-section of the UK community discussed scenarios that illustrated the ethical dilemmas involved.

A report of the deliberative workshop will be published at the same time as the Working Party's report, in autumn 2011.

“The Nuffield Council on Bioethics never shrinks from the unthinkable. Yesterday it asked whether it might be ethical to pay people for their body parts.”

The Guardian, 21 April 2010

Chair of the Working Party
Professor Dame Marilyn Strathern

Former Mistress, Girton College Cambridge and
William Wyse Professor of Social Anthropology,
Cambridge University

[List of Working Party members](#)

Emerging biotechnologies

Emerging biotechnologies, such as synthetic biology and nanotechnology, have the potential to provide benefits for health, the environment and the economy, but they also raise ethical issues related to risk, uncertainty, social justice and intellectual property.

The Council has set up a Working Party to consider the common ethical issues raised by emerging biotechnologies, both past and present, and the implications for policy, governance and public engagement.

Due to the non-uniform way in which new biotechnologies develop, there has been a tendency for regulatory and governance issues to be addressed separately for each technology. The Working Party will explore whether there are core issues common to all emerging biotechnologies and whether a more general ethical and policy framework could be developed. A report will be published in 2012.

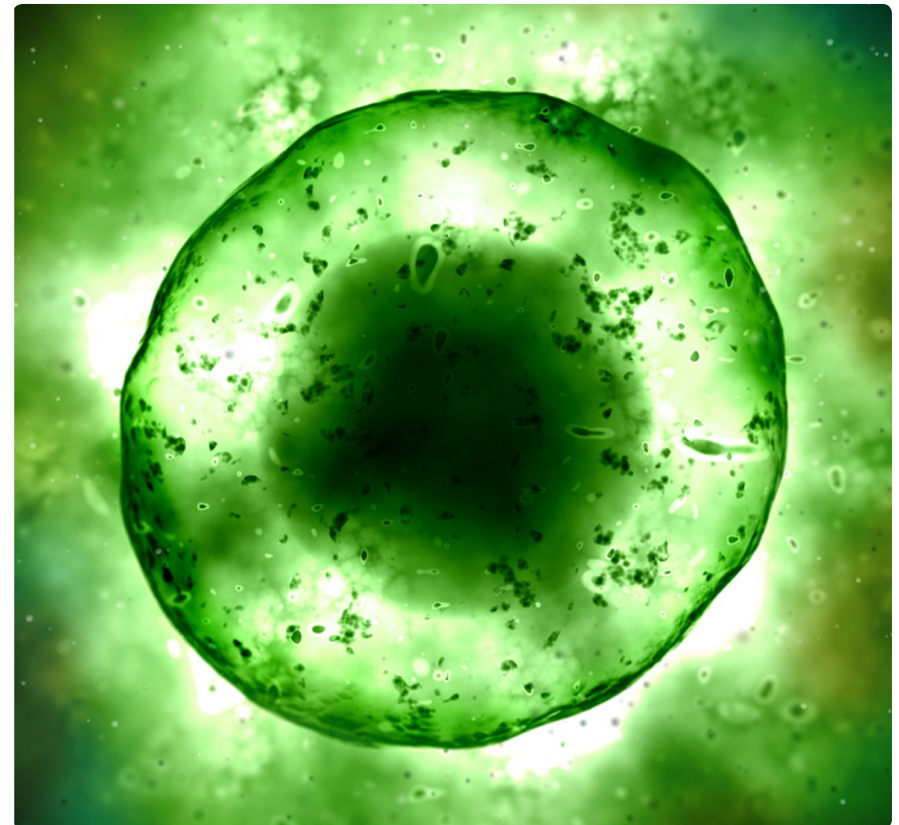
Chair of the Working Party
Professor Michael Moran

WJM Mackenzie Professor of Government,
University of Manchester

[List of Working Party members](#)

“We are concerned with ‘genie out of the bottle’ technologies, which might be impossible to withdraw once introduced.”

Professor Michael Moran, chair of the Working Party



Public health

The Council's 2007 report on public health concluded that the state has a duty to help everyone lead a healthy life and reduce inequalities in health. Our 'stewardship model' sets out guiding principles for making decisions about public health policies, and the 'intervention ladder' provides a way of thinking about the acceptability of different public health measures.



Find out more: www.nuffieldbioethics.org/public-health

Significant developments in 2010:

- In November, the Government published the White Paper, *Healthy lives, healthy people*, which outlines its strategy for public health in England. The White Paper uses the Council's intervention ladder to provide a visual demonstration of the range of interventions.
- There were several calls on the Government to implement tougher measures to tackle excessive drinking, as recommended by the Council. In new guidance published in June 2010, the National Institute for Health and Clinical Excellence (NICE) concluded that making alcohol less affordable is the most effective way of reducing alcohol-related harm. The Government, meanwhile, has pledged to ban the sale of alcohol below cost price.
- The Department of Health launched a new tobacco control strategy, which follows the Council's recommendation to recognise the special vulnerability of children and to seek to protect them from harmful tobacco use.

Dementia

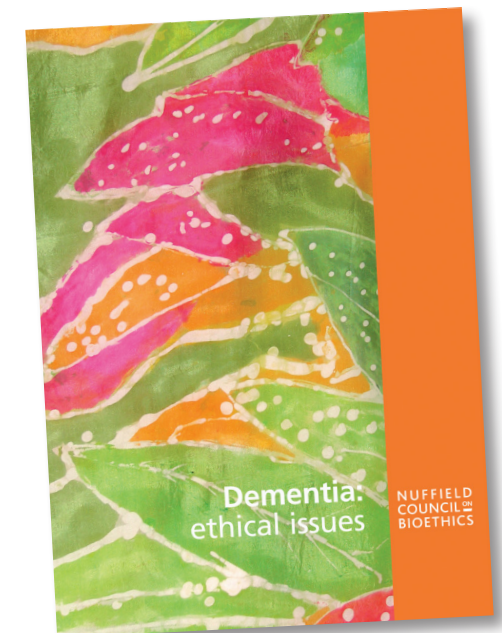
In its 2009 report, the Council concluded that people with dementia and their carers are not getting the respect and support they need. The report's ethical framework aims to help those who face dilemmas in the day-to-day care of someone with dementia and to provide a basis for policymaking. Recommendations are made in relation to diagnosis, tackling stigma and making decisions about care and treatment.

Significant developments in 2010:

- Scotland's *National Dementia Strategy*, published in June, draws on the Council's ethical framework for dementia and its recommendations on promoting the autonomy of people with dementia.
- The *Dementia Action Alliance* was set up in November, bringing together 45 organisations including the Department of Health, the Alzheimer's Society and the Royal College of Nursing. In its National Dementia Declaration, the Alliance describes seven outcomes that people with dementia and their carers would like to see in their lives. This call to action takes forward the Council's conclusions that an ethical approach to care is one that recognises the value of the person with

dementia, as well as the interests of carers who provide day-to-day support.

- New Department of Health guidance on risk-taking in the care of people with dementia recognises the Council's conclusion that an approach that focuses only on risk can be disempowering for people with dementia. The guidance sets out ways in which a person with dementia can maximise their quality of life without being placed in undue danger.



Find out more: www.nuffieldbioethics.org/dementia

Forward Look workshop 2010

Three potential new work topics were discussed by Council members and invited experts at the 2010 Forward Look workshop on 26-27 April. Following the meeting, the Council decided to explore further all three topics with a view to setting up future Working Parties.

Intervening in the brain

Scientists are exploring the use of neurotechnologies that intervene in the brain for treating conditions such as stroke, obesity and depression. There is also growing interest in using such technologies in non-medical settings, for example for enhancement of cognitive functions, in military settings, and for consumer entertainment. There are significant ethical issues to consider relating to, for example, concerns over safety, consent and access. Questions have also been raised about the way in which these technologies are represented in the media. The Council decided that a Working Party on novel neurotechnologies should be established in autumn 2011.

Genes and parenting

In 2007, around two per cent of babies born in the UK were the result of IVF and donor insemination. The increase in families that do not fit the traditional nuclear family have been reflected in recent changes in the law. Ethical issues to consider include the rights of the donor-conceived child; the role the donor should play; and the effect of tracing the donor on the donor-conceived child and their legal parents. A scoping meeting to explore this topic further will take place in 2011.

Children, medicines and clinical trials

Involving children in clinical trials raises difficult issues relating to capacity to consent, the role of payment, and weighing risks and benefits. Consequently, there is little data on dosage-requirements, efficacy and safety in the use of medicines in children. Data from clinical trials involving adults are commonly adjusted according to the child's weight. It is envisaged that a Working Party will be set up in 2012 to explore the issues further.



Informing policy

The Council engages with government officials, parliamentarians and others to inform policy and promote debate about bioethics issues. Here are the highlights of policy-related activities in 2010.

Bioethics in Parliament event

The Council's third 'Bioethics in Parliament' event was held in the Houses of Parliament in November, hosted and chaired by Professor Lord Harries of Pentregarth. Around 60 peers, MPs and others took part in a debate on how far we should go to meet the demand for human bodily material in medicine and research.

Public Health White Paper

The Council and the Department of Health co-hosted a roundtable meeting with 25 leading thinkers and practitioners as part of a series of events intended to inform the Government's Public Health White Paper. The Council's 2007 report *Public health: ethical issues* formed the starting point for the discussion and went on to be cited significantly in the [White Paper](#) published in November.

Science and Trust Action Plan

A Government action plan on science and society recognised the Council's contribution in supporting people to develop informed opinion around science. The report, [Science and Trust](#), welcomed the Council's efforts in enabling public critical reasoning and discussion of science issues, in particular the work of the [Reaching Out to Young People Advisory Group](#).

Responses to policy consultations

The Council regularly responds to policy consultations. In 2010, this included:

- House of Lords Science and Technology Committee inquiry on behaviour change
- Nursing & Midwifery Council consultation on raising and escalating concerns
- Department of Health [consultation on age equality in health and social care](#)
- National Institute for Health and Clinical Excellence consultation on [Draft Quality Standard for Dementia](#)

Find out more: www.nuffieldbioethics.org/policy

Education



The Council encourages discussion of bioethics among young people by supporting teachers to facilitate classroom debates. Our [Reaching Out to Young People Group](#), chaired by Dr Rhona Knight, draws on the advice of teachers, curriculum developers and others working with young people.

In 2010, a resource was published that explores the ethical issues raised by dementia to aid teachers and others conducting training on this topic. Scenarios illustrate some of the common ethical dilemmas experienced by people with dementia and their carers. Other teaching resources are available on the use of animals in research and the forensic use of bioinformation.

Find out more: www.nuffieldbioethics.org/education

Media coverage

Bioethics often touches on controversial, news-worthy issues. The Council's work was featured in over 280 print and online news articles, broadcast interviews and feature articles in specialist publications in 2010.

Media briefings were held at the Science Media Centre in London to launch a consultation on the donation of [human bodily material in medicine and research](#), and the report *Medical profiling and online medicine*.

"Some "health MoT" scans sold to the worried well should be banned, as their dangers far outweigh any potential benefits, Britain's most influential medical ethics think-tank will recommend today."
The Times

"We could try to increase the number of organ donors by providing stronger incentives, such as cash, paying funeral costs or giving priority for an organ in future, but would this be ethical?"
Professor Dame Marilyn Strathern quoted in The Independent

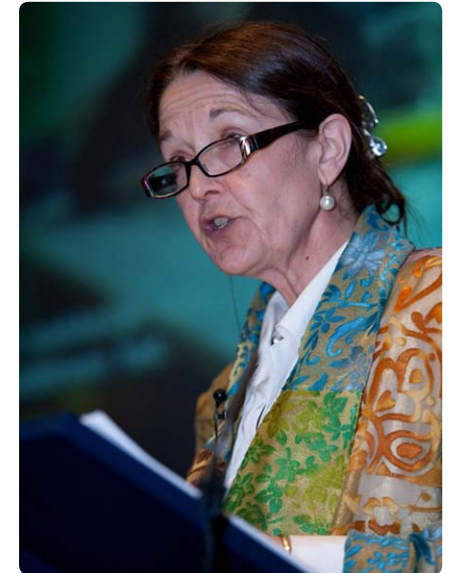
"The Nuffield Council on Bioethics is launching a consultation to see what the public think of various proposals to counter the "crisis" shortage of organ, sperm and eggs."
The Mirror

Find out more: www.nuffieldbioethics.org/news

Events and presentations

Taking part in events is an important way for the Council to engage directly with a wide range of people who have an interest in our work, and to reach those who have not had contact with us before. Highlights of presentations in 2010 include:

- Sixth-form conference on medical ethics run by Camden Council: 'Because we can create life, should we?', London
- Gatsby Plant Science Annual Lecture, Oxford
- Westminster Food & Nutrition Forum on Alcohol, London
- Scottish Caring and Dementia Congress, Edinburgh
- Annual Conference of the European Association of Centres for Medical Ethics, Oslo
- Individualized Prevention and Epidemiology, European Union of Medicine in Assurance and Social Security, Berlin
- Lecture tour of Australia to discuss the ethics of dementia



Annual Public Lecture 2010

Inez de Beaufort of the Erasmus Medical Center in Rotterdam gave the Council's 2010 public lecture to around 100 guests in London in April. Her lecture 'Whose potbelly is it anyway? Ethics, obesity and public health' discussed the ethical issues raised by policies designed to combat the so-called 'globesity' epidemic.

Find out more: www.nuffieldbioethics.org/events

Web communications

In 2010 the Council launched a new website that is more accessible, attractive and easy to navigate.



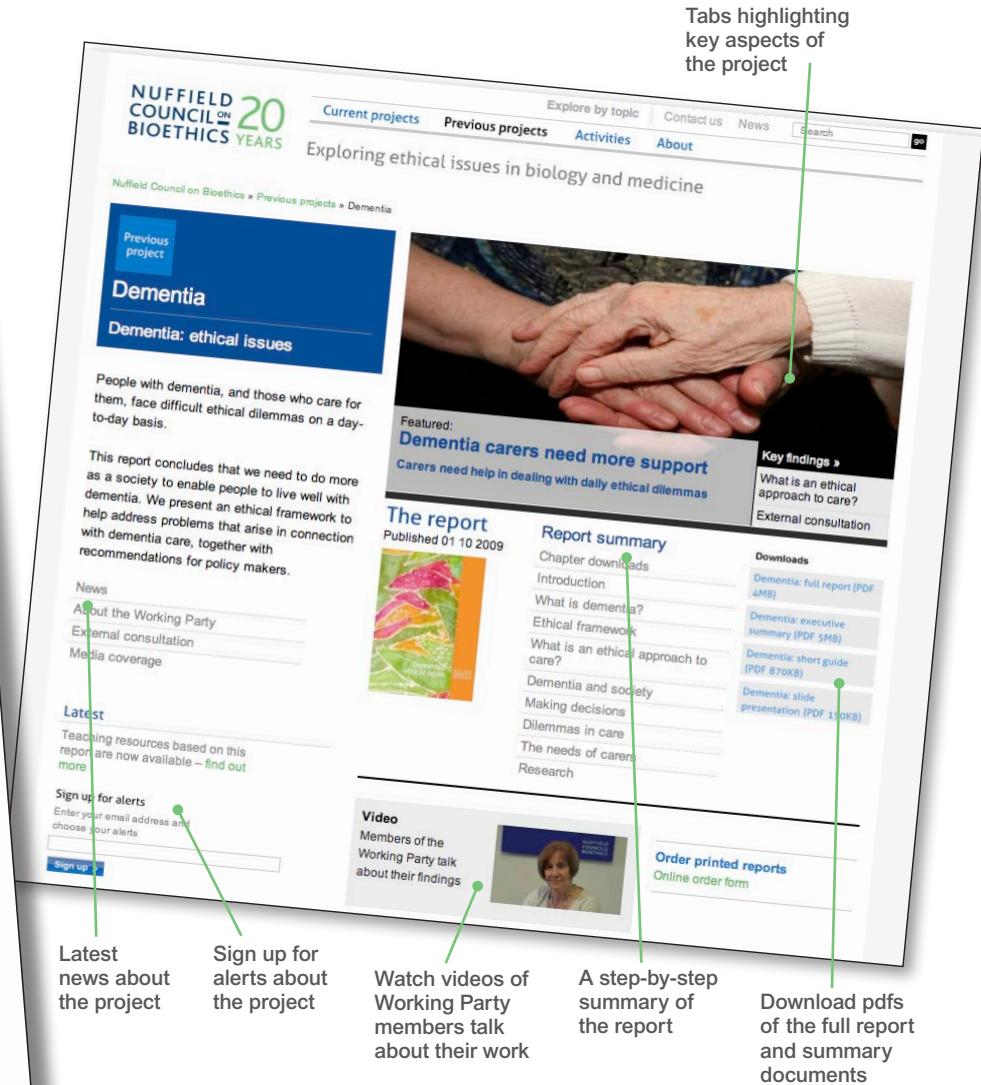
News on activities such as events, policy and education

Explore the Council's work by topic

Information about Council members, Secretariat and how the Council works

Tabs featuring the Council's latest projects

Tabs featuring activities such as events and teaching resources



Tabs highlighting key aspects of the project

Latest news about the project

Sign up for alerts about the project

Watch videos of Working Party members talk about their work

A step-by-step summary of the report

Download pdfs of the full report and summary documents

Find out more: www.nuffieldbioethics.org

International

Bioethical issues do not respect borders and many of the Councils projects have a strong international dimension. The Council engages with individuals and organisations around the world in order to share our work and gain insights from abroad. Highlights of international activities in 2010 include:

- Trilateral meeting with the French and German National Bioethics Commissions, Paris
- Presentations and discussion at the 8th Global Summit of National Bioethics Advisory Bodies and World Congress of Bioethics, Singapore
- Meeting with the US Presidential Commission for the Study of Bioethical Issues, Atlanta
- Involvement in Conference of Experts to advise European Union Council of Ministers on dementia policy



Find out more: www.nuffieldbioethics.org/international

Solidarity fellowship



In 2010, Dr Barbara Prainsack of King's College London was appointed to a six-month fellowship with the Council on the theme of solidarity as a core value in contemporary bioethics. The fellowship is funded by the Arts and Humanities Research Council and the Nuffield Foundation, and is administered by the Economic and Social Research Council. A report on the findings will be published in autumn 2011.

“Focusing on the meaning of solidarity is important in bioethics and also in light of the economic crisis. We are currently in a political climate where many feel that solidarity has lost currency and people are left to their own devices”.

Dr Barbara Prainsack

Council members

Professor Albert Weale FBA (Chair)

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

Professor Hugh Perry FMedSci (Deputy Chair)

Professor of Experimental Neuropathology, University of Southampton

Professor Steve Brown FMedSci

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

Professor Roger Brownsword (until October 2010)

Director, Centre for Technology, Ethics and Law in Society (TELOS), King's College London, and Honorary Professor in Law, University of Sheffield

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 Peter Harper (until March 2010)

University Research Professor in Human Genetics, Cardiff University

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

Professor Christopher Hood FBA (until October 2010)

Gladstone Professor of Government and Fellow of All Souls College, University of Oxford. Co-opted member of Council while chairing the Council's Working Party on personalised healthcare

Dr Rhona Knight FRCGP

General Practitioner and Senior Clinical Educator, University of Leicester. Chair of the Council's Reaching Out to Young People Advisory Group

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

Senior Lecturer, Department of History and Philosophy of Science 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 (from January 2011)

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, NHS Newcastle Fertility Centre at Life

Dr Bronwyn Parry

Reader in Geography, Queen Mary, University of London

Professor Nikolas Rose

James Martin White Professor of Sociology, London School of Economics and Political Science, and Director, BIOS Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society

Professor Dame Marilyn Strathern FBA

Mistress of Girton College Cambridge until 2009 and William Wyse Professor of Social Anthropology, Cambridge University, until 2008. 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

Professor Jonathan Wolff

Professor of Philosophy, University College London

Secretariat

Hugh Whittall

Director

Katharine Wright

Assistant Director

Dr Alena Buyx

Assistant Director

Harald Schmidt (on secondment in 2010)

Assistant Director

Caroline Rogers

Programme Manager (until October 2009)

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 Jagadeshm

Research Officer

Audrey Kelly-Gardner

Secretary

Financial Report

for the year to 31 December 2010 (unaudited)

	2010	2009
	Actual	Actual
	£	£
Expenditure		
Salaries and staffing costs	520,571	491,258
Reviewers' and consultants fees	34,688	12,961
Office and premises costs	6,776	11,033
Journals and subscriptions	16,885	9,895
Travel and meeting costs	94,940	74,562
Web, printing and publicity	41,967	82,321
Total expenditure	715,826	682,029
Funding due		
Nuffield Foundation	235,884	232,504
Medical Research Council	235,884	232,504
Wellcome Trust	235,884	232,504
Other	31,405	2,985
	739,057	700,497
Overheads met by Nuffield Foundation	492,260	419,408

Contact us

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