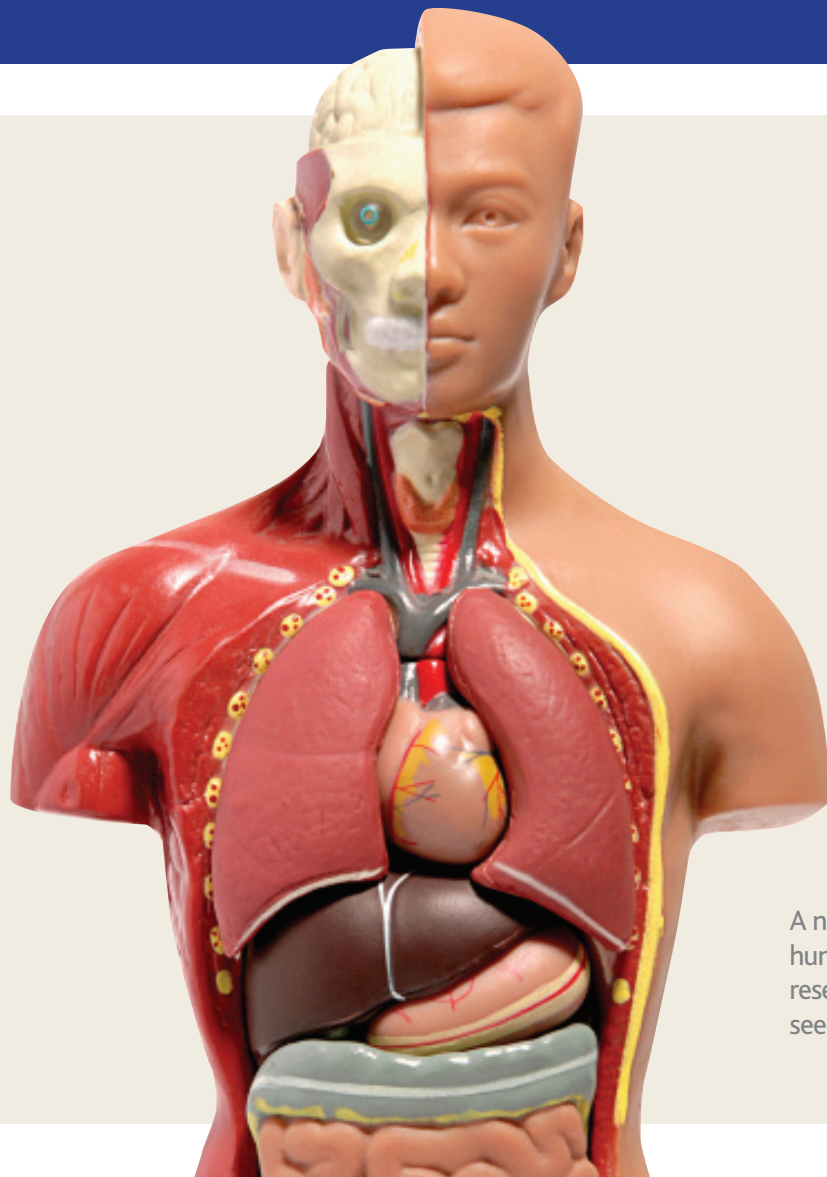


Exploring ethical issues in biology and medicine



A new Working Party on human bodies in medicine and research was set up in 2009, see page 9

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About the Council

The Nuffield Council on Bioethics examines ethical issues raised by new developments in biology and medicine, with a view to providing independent advice to policy makers and stimulating debate in bioethics.

The Council is an independent body, set up in 1991 and funded jointly by the Nuffield Foundation, the Medical Research Council and the Wellcome Trust.

The Council has produced 19 publications on a range of topics, including animal research, GM crops, genetic screening, the care of premature babies, and research in developing countries.

Note from the Chair

The bioethics agenda does not grow smaller. The remit of the Nuffield Council is to report on the social and ethical implications of developments in the biosciences. As those sciences develop, so we come to learn more about the issues of ethical value that they raise. This can mean looking at new technologies and appraising them for their ethical significance; but it can also mean looking at what developing science tells us about existing problems.

This latter element of our work was exhibited in the Council's report on the ethical dilemmas raised by the care of people with dementia. A central theme of that report was that ethical issues touch people profoundly in their everyday lives, and deal with such basic, but significant, issues as when it is right to lie to someone with dementia or how to balance risk and freedom in care homes. The Working Party went out of its way to ensure that it listened to those with care responsibilities as well as people with dementia.

At our second parliamentary event in November we drew attention to the report's findings, and we were impressed by the interest shown by policy makers and parliamentarians. Following that event, Lord Harries of Pentregarth asked a question in the House of Lords as to how the government was planning to respond to the report. The Minister welcomed the 'excellent' report and responded to a range

of supplementary questions on trust in carers and the provision of support in ethical decision making.

With the careful management of resources, the Council is now able to run three Working Parties at any one time, whereas in the past there were two. The third Working Party will consider more focussed topics and will work to a shorter time frame. The first subject chosen for this work stream is biofuels, and the Council has been fortunate to secure the services of Professor Joyce Tait to undertake the task of devising a framework of ethical appraisal against which to test future developments. It is a measure of the extent and scope of developments in the biosciences that such a topic now falls within our remit, just as was true of genetically modified crops a decade ago.

Professor Peter Smith reached the end of his term on Council in 2009. He had been the Deputy Chair, serving on the Membership Sub-Committee as well as contributing to the Council's work more generally. He was always a reliable source of insight and advice and the Council owes him a special note of thanks. I am pleased to say the Professor Hugh Perry agreed to take over the role of Deputy Chair. Elsewhere we note the arrival of seven new Council members in 2009, and our ability to attract membership of high calibre is testimony to the reputation of the Council. I should like to offer my personal thanks to Council members and to the staff for all the hard work that they have devoted to our business during 2009. For me it continues to be a privilege to be associated with such an important and well-respected organisation.



Professor Albert Weale FBA



Council members



Professor Albert Weale FBA (Chair)

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

Professor Hugh Perry FMedSci (Deputy Chair)

Professor of Experimental Neuropathology, University of Southampton and Director of Southampton Neuroscience Group

Professor Steve Brown FmedSci (from January 2009)

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

Professor Roger Brownsword

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 of the Centre for Evidence-Based Medicine, University of Oxford

Professor Robin Gill (from January 2009)

Michael Ramsey Chair of Modern Theology and Founding Chair of the Research Ethics and Governance Committee, University of Kent

Professor Sian Harding FAHA FESC

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

Professor Peter Harper

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

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](#)

Professor Tony Hope (until October 2009)

Professor of Medical Ethics, University of Oxford, and an Honorary Consultant Psychiatrist. Co-opted member of Council while chairing the Council's [Working Party on dementia](#)

Mr Anatole Kaletsky (until January 2009)

Editor at Large of *The Times of London* and founding partner of an economic, political and financial consultancy firm

[Continued >](#)

Find out more: www.nuffieldbioethics.org/members

COUNCIL MEMBERS

Dr Rhona Knight FRCGP

General Practitioner and medical educator in Leicester. Chair of the Council's [Reaching Out to Young People Advisory Group](#).

Professor Graeme Laurie FRSE (from January 2009)

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 (from January 2009)

Senior Lecturer, Department of History and Philosophy of Science and Fellow of Clare College, University of Cambridge

Professor Ottoline Leyser CBE FRS (from January 2009)

Professor of Plant Developmental Genetics and Chair of the Biology Department Research Committee, University of York

Professor Anneke Lucassen (from January 2009)

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

Professor Alison Murdoch FRCOG

Professor of Reproductive Medicine, a 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 Peter Smith CBE FMedSci
(Deputy Chair and member until March 2009)**

Professor of Tropical Epidemiology, London School of Hygiene and Tropical Medicine

**Professor Joyce Tait CBE FRSE
(from October 2009)**

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 new approaches to biofuels](#)

**Professor Dame Marilyn Strathern FBA
(from January 2010)**

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](#).

Dr Geoff Watts FMedSci (from January 2010)

Science and medical writer and broadcaster

Professor Jonathan Wolff

Head, Department of Philosophy, University College London

Membership changes

Professor Peter Smith came to the end of his term on Council in 2009. He was an active and valued member, having sat on the Working Party on healthcare research in developing countries and taking the role of deputy chair of the Council from 2006.

We were delighted to welcome seven new members in 2009: Professor Steve Brown, Professor Robin Gill, Professor Graeme Laurie, Dr Tim Lewens, Professor Ottoline Leyser, Professor Anneke Lucassen and Professor Joyce Tait. Two further new members will begin their terms in January 2010: Professor Dame Marilyn Strathern and Dr Geoff Watts.

The Secretariat



Hugh Whittall
Director

Katharine Wright
Assistant Director

Harald Schmidt
Assistant Director
(on secondment
from September 2009)

Dr Alena Buyx
Assistant Director
(from August 2009)

Caroline Rogers
Programme Manager (from
June 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 Jagadesham
Research Officer

Audrey Kelly-Gardner
Secretary

Note from the Director



The Council, throughout 2009, has continued to maintain a strong presence in the national and international bioethics community. It has also maintained a strong presence in the policy environment, where the recommendations of its reports on the forensic use of bioinformation and on dementia, in particular, have had a major influence.

The value of the Council's work is rightly measured by the quality and impact of its reports. But this sometimes disguises the immense amount of work that goes into preparing and following up the reports. I would therefore like to take this opportunity to thank the people behind the scenes. Council members and members of Working Parties offer time and expertise for no reward other than the occasional sandwich and a warm feeling. Their contribution is invaluable, and I thank them for it. But mostly I would like to thank the staff of the Council, whose work is also invaluable, but whose role is often unseen. Our reports would not get off the ground, let alone be so widely read and embraced, were it not for the planning and organising, research and drafting, communications and administrative support that the staff of the Council provide. I feel fortunate to work with this talented group of people, and I am grateful for their continuing dedication.

During the year we lost Harald Schmidt, albeit temporarily, as he took up a Harkness Fellowship for which he is spending a year at Harvard. We miss Harald greatly, but congratulate him on his success and wish him well. Caroline Rogers is back with us for the year whilst Harald is away. We have also, in expanding our workload, appointed a third Assistant Director, Alena Buyx, who comes to us from Münster, via Harvard. Welcome to you both.

There is no doubt that 2010 will be as interesting, as engaging, and as busy as 2009. Probably more so, which is why we are so looking forward to it.

Hugh Whittall

CURRENT WORK

Dementia

All those involved in dementia care face difficult ethical dilemmas. For example: how should the needs of the person with dementia be balanced with those of the carers? How should decisions about the care and treatment of someone with dementia be made?

Following a two-year inquiry, the Council published the report *Dementia: ethical issues* on 1st October 2009. The report presents an ethical framework to help those who face dilemmas in connection with the day-to-day care of a person with dementia. Key recommendations include:

- People should have access to good quality assessment and support from the time they or their families become concerned about dementia.
- Families should be treated as 'partners in care' by professionals.
- Dementia needs to become an accepted, visible part of our society. The Equality and Human Rights Commission should highlight the legal duties of service providers, such as shops and restaurants, to ensure people with dementia can use their services.
- All those involved in the care of people with dementia should have access education and support to help them deal with ethical dilemmas.
- More guidance is needed on how to apply mental capacity legislation in practice, for example, how past and present wishes should be taken into account.
- There should be more funding for dementia research, including research into how people with dementia can be supported to live the best possible lives.

Impact

Already the report has been debated in the media, in Parliament, among policy makers, and by those working at the frontline of dementia care. For example, staff and Working Party members have met officials from the Department of Health, the Scottish Executive, the Equalities and Human Rights Commission, and others, to help examine how the report's findings can be incorporated into their respective policies.

The Council will continue to disseminate and discuss its findings in 2010.

Chair of the Working Party

Professor Tony Hope
Professor of Medical Ethics, University of Oxford

Working Party members

"We want carers to have better access to support and advice to help them work out what is best in their particular situation. Giving carers opportunities to talk to others in the same situation is vital."

Professor Tony Hope, Chair of the Working Party

"Carers, health workers, and wider society will increasingly need to have access to educational resources on how to respond to ethical dilemmas that can arise when caring for someone with dementia. The Nuffield Council report is a thoughtful, valuable contribution to this learning process."

The Lancet, 3 October



Find out more: www.nuffieldbioethics.org/dementia

CURRENT WORK

Medical profiling and online medicine

The ethics of 'personalised' healthcare in a consumer age

New technologies and services are promising us increasingly personalised healthcare. We can now pay to have our DNA analysed for a wide range of health risks, and imaging services, such as CT and MRI scans, look for abnormalities that indicate disease. The number of websites offering health advice, personal health records and medicines for sale has also increased. And telemedicine, the provision of healthcare over a distance, is now easier with new information and communication technologies.

These developments can give us increased choice and control over our healthcare. Some may provide reassurance that we are healthy, or detect disease at an earlier stage. However, they may also create needless confusion or anxiety, or lead to unnecessary invasive procedures that themselves carry risks.

The Council set up a Working Party in October 2008 to consider the ethical issues raised by developments that promise increasingly personalised healthcare. It held a consultation from April to July 2009, to which it received helpful responses from a range of organisations and individuals.

A report with recommendations for policy will be published in autumn 2010.

Chair of the Working Party

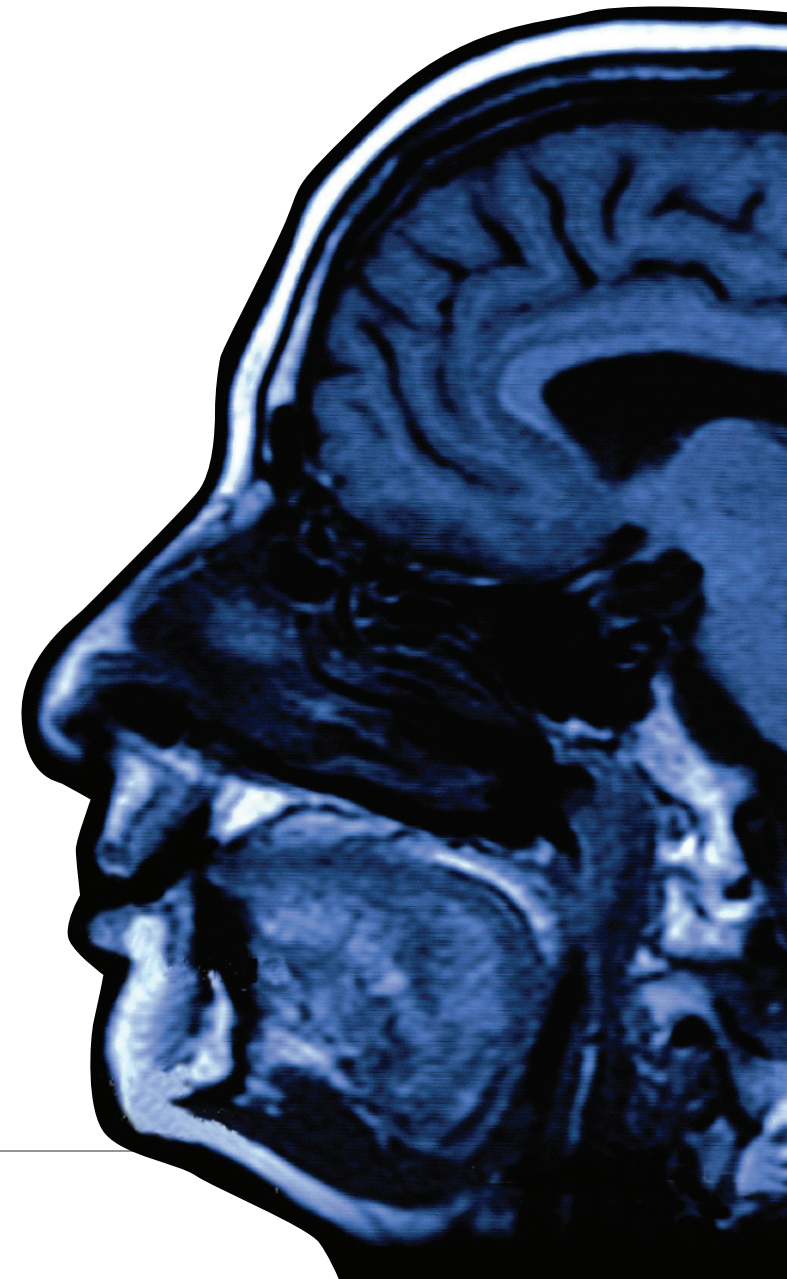
Professor Christopher Hood FBA
Gladstone Professor of Government and Fellow, All Souls
College, University of Oxford and Director, ESRC Public
Services Research Programme

Working Party members

"The risks and social challenges posed by genetic tests and other health services sold directly to consumers have prompted Britain's most influential ethical think-tank to begin an inquiry into personalised medicine."

The Times, 21 April 2009

Find out more: www.nuffieldbioethics.org/personalised



CURRENT WORK

New approaches to biofuels

'First generation' biofuels, which are mainly produced from food crops, were initially regarded as a potentially sustainable source of energy. But in many cases they were found to offer small or even negative greenhouse gas emission savings across their life cycle compared to fossil fuels. There also have been concerns about their impact on the environment, food security, and farmers and communities in developing countries.

New approaches to biofuels hope to avoid such problems. For example, in the future we may be able to use algae, fast-growing trees and grasses, and agricultural waste to produce biofuels. In addition, genetic modification is being used to increase the yield of biofuel crops and improve the production process, in order to maximise the energy output of land and reduce net greenhouse gas emissions. The emerging field of synthetic biology is aiming to develop entirely new means of generating biofuels.

The Council set up a Working Party in October 2009 to examine the ethical issues that arise in the drive to find new types of biofuels. A consultation was held from December 2009 to March 2010, and a report with recommendations for policy will be published in winter 2010/11.

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

Working Party members



"Before these new types of biofuels are brought into wider use, we are considering their potential to meet our energy needs, support economic development and, along with changes in lifestyle, help address climate change in an ethical and sustainable way."

Professor Joyce Tait, Chair of the Working Party

CURRENT WORK

Human bodies in medicine and research

We provide our bodies or parts of our bodies for medical research or for the treatment of others in a number of ways and for a variety of reasons. While we are alive, we can give blood for nothing, donate eggs in return for fertility treatment, or volunteer for clinical trials for money. After we have died, we might want to donate our organs, skin, bone and other tissue to help others.

The Council has set up a Working Party to explore the ethical issues raised by the provision of bodily material for medical treatment and research.

Questions to be considered include:

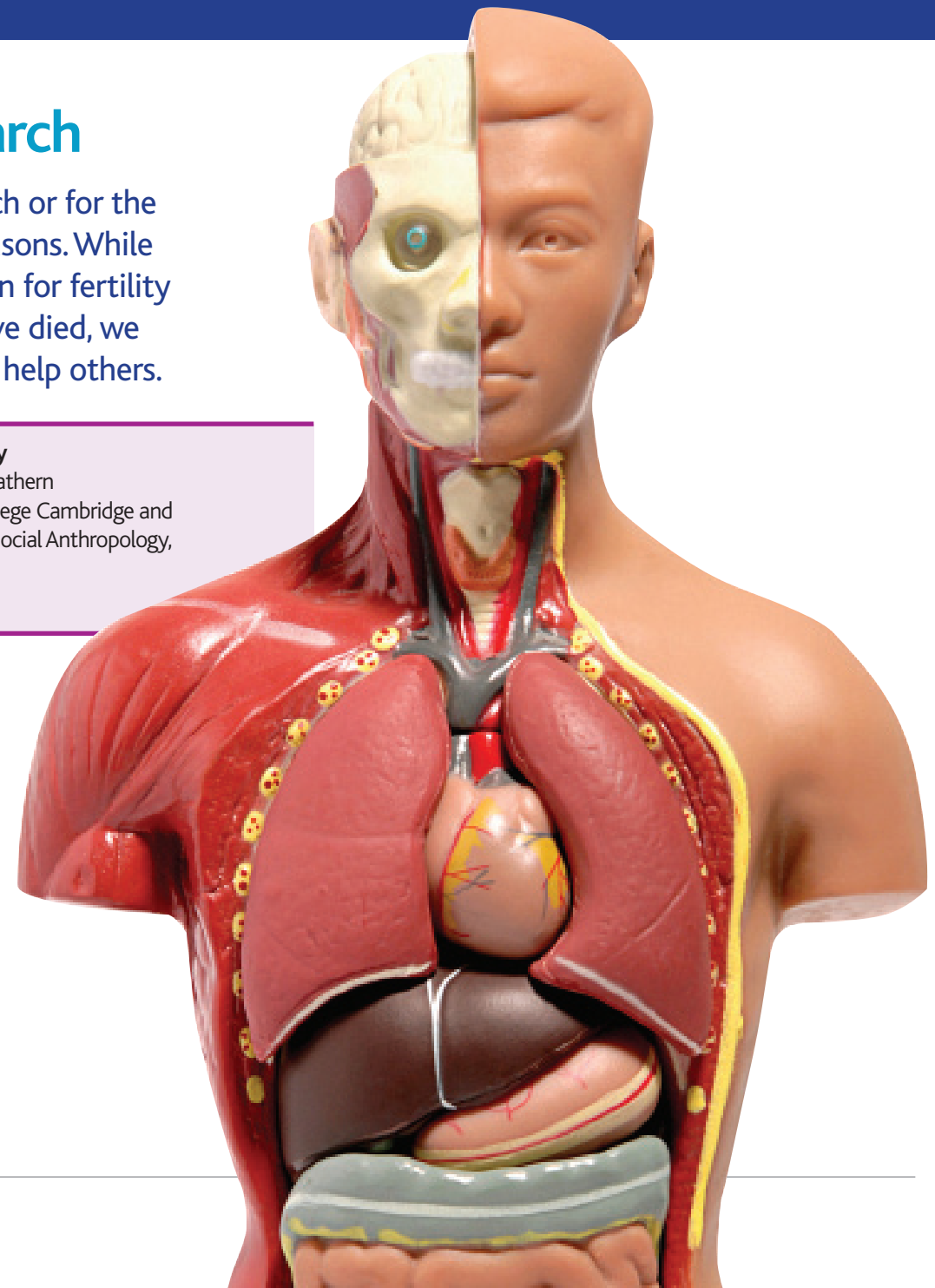
- what motivates people to provide bodily material and what inducements or incentives are appropriate?
- what constitutes valid consent?
- what future ownership or control should people have over donated materials?
- are there ethical limits on how we try to meet demand?

The group met for the first time in January 2010 and a report outlining the group's findings, including recommendations for policy, will be published in autumn 2011.

Chair of the Working Party

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

Working Party members



PREVIOUS WORK

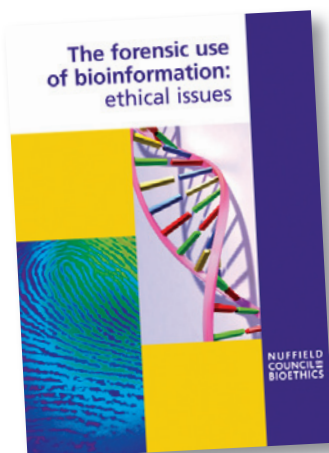
The forensic use of bioinformation

In 2007, the Council published a report on the forensic use of bioinformation. It concluded that there was insufficient evidence to justify the Government's policy of retaining indefinitely the DNA samples and profiles of anyone arrested for a recordable offence.

Significant developments:

- In the case of *S & Marper v UK* at the European Court of Human Rights in December 2008, judges ruled that keeping the DNA and fingerprints of two UK men, who had been arrested but never convicted of any crime, constituted a breach of their human rights. The Council's report was cited in the judgment.
- Following a public consultation, the Government announced a series of revised policy proposals in November 2009, including: all DNA samples taken on arrest will be destroyed as soon as they are turned into a profile; and DNA profiles of all arrested adults will be retained for 6 years.
- The proposals were introduced as primary legislation in the form of the Crime and Security Bill 2009-10 in April 2010.

Find out more:
www.nuffieldbioethics.org/forensic



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.

Significant developments:

- The National Institute for Health & Clinical Excellence (NICE) has adopted the stewardship model "as a reference point for guiding decisions about what types of intervention may be justified".
- Several organisations have concurred with the report's recommendation that the Government should implement tougher measures to tackle excessive alcohol consumption, such as the House of Commons Health Select Committee and British Medical Association. The Government recently brought in measures to ban 'irresponsible promotions' in pubs and require premises to offer free tap water and small measures.

Find out more:
www.nuffieldbioethics.org/publichealth



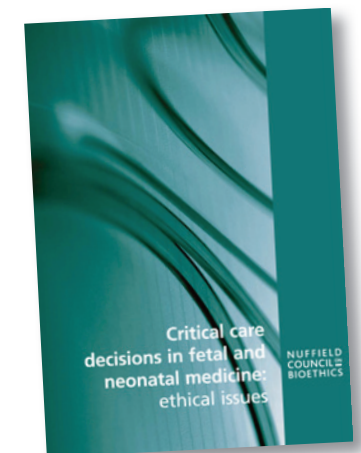
Critical care decisions in fetal and neonatal medicine

In its 2006 report, the Council proposed guidelines on when to give intensive care to extremely premature babies. Advice for parents and doctors was provided for babies born before 22 weeks up to those born after 25 weeks, intending this as a basis for discussion by professional organisations.

Significant developments:

- The British Association of Perinatal Medicine (BAPM) and other organisations used the report as a basis for developing new medical guidance for the management of extremely premature babies. This was published in 2008 and closely resembles the Council's proposals.
- As recommended in the report, Bliss, the special care baby charity, published a factsheet for parents on the survival prospects of extremely premature babies. Bliss also plans to produce guidance for parents to support them in making decisions about the care and treatment of extremely premature babies.

Find out more:
www.nuffieldbioethics.org/neonatal



FUTURE WORK

Selecting new topics

The Council has developed a thorough process for selecting new topics.

The Future Work group identifies and considers potential future work topics by consulting with a wide range of external sources. Three or four 'top topics' are considered at the Council's annual Forward Look meeting, held each spring, with the help of invited speakers and guests.

At the 2009 Forward Look meeting, four topics were considered:

- Pharmaceutical trials and prescription in children
- Ethical and effective health interventions in a global context
- New approaches to biofuel production
- Synthetic biology

New approaches to biofuels

New approaches to biofuels raise a number of ethical and social issues, such as environmental impact, food availability, land use, and the rights of farmers and communities in developing countries. Council members agreed that it could make a valuable contribution to the debate surrounding new types of biofuels and, as described on page 8, a [Working Party](#) was set up in October 2009.

Synthetic biology

Synthetic biology raises ethical issues related to public perception, risk, precaution, uncertainty and intellectual property. However, these are not necessarily unique to synthetic biology. A one day workshop with invited experts was held in November 2009 to explore the broader issue of **emerging technologies in biology and medicine**. Members agreed that a Working Party would be set up in 2010 to examine the social and ethical implications of emerging technologies, in particular for policy, governance and public engagement.



Activities

Informing policy

Bioethics in Parliament event

The Council's 2nd 'Bioethics in Parliament' event was held in the Houses of Parliament in November 2009. Evan Harris MP, Brian Iddon MP, Earl Howe and Lord Harries of Pentregarth supported the event, and around 45 people attended and took part in a debate about the care of people with dementia.

Parliamentary briefing papers

The Council provides [briefing papers](#) for Parliamentarians to help prepare them for debates relating to bioethics issues. For example, we circulated papers on public health ethics and alcohol, and the forensic use of bioinformation, to brief Parliamentarians ahead of various stages of the Policing and Crime Bill 2008-09.

Mentions in Parliament

The Council's work was referred to in Parliament on a number of occasions in 2009. For example, Lord Harries tabled an Oral Question on 2nd December:

"To ask Her Majesty's Government what is their response to the Nuffield Council on Bioethics' report on the ethical issues raised by dementia, and whether its recommendations will be incorporated into the National Dementia Strategy."

[Read the full debate](#)

Policy consultations

The Council regularly responds to policy consultations. In 2009, this included:

- Department of Health 'Shaping the Future of Care Together'
- Home Office 'Keeping the right people on the DNA Database'
- House of Commons Health Select Committee – alcohol inquiry
- Care Quality Commission 'Strategy for 2010-15'



Education

The Reaching Out to Young People Advisory Group aims to provide resources and activities to help a wide range of young people engage in debate about bioethics.

In 2009, the group developed a set of teaching resources on the forensic use of bioinformation for Key Stage 4 and above. The activities aim to help students to think about how bioinformation – fingerprints and DNA profiles – are used to investigate crime and the ethical issues that arise from the storage of bioinformation on national databases.

These add to the resources the Council produced on the ethics of animal research in 2007. These are regularly downloaded from the Council's website and are available through a range of other online resource banks. The Council plans to produce more resources for teachers in future.

Find out more:

www.nuffieldbioethics.org/education

Find out more: www.nuffieldbioethics.org/policy

ACTIVITIES

Media coverage

In 2009 the Council was featured in over 160 print and online news articles, broadcast interviews and feature articles in specialist publications.

Three media briefings were held at the Science Media Centre in London:

- Launch of report 'Dementia: ethical issues'
- Launch of consultation: the ethics of commercial DNA profiling, body imaging and online health care
- Launch of consultation on the ethics of new biofuels

We would like to thank Fiona Fox and her staff at the Science Media Centre for their ongoing support and advice on working with the media.

"Real change will come only when we start to see people with dementia for what they really are – just people."

*Hugh Whittall, Director –
Guardian Comment Is Free Blog*

"Expensive private health 'MOTs', including the use of DNA profiles to predict the risk of developing deadly diseases, could be doing "more harm than good" experts have warned."

The Telegraph

Web communications

The web is the Council's primary means of reaching wider audiences. All of the Council's publications are available to download from its [website](#), which receives thousands of visitors from around the world each year.

In 2009, the Council became a member of the Twitter and Facebook communities and the number of people receiving UPDATE, the Council's e-newsletter, continues to grow. The Council is in the process of redesigning its website to make it a more engaging, user-friendly resource (due for launch in spring 2010).

FOLLOW US ON 

 Find us on
Facebook

Sign up to the Council's e-newsletter UPDATE: [subscribe](#)

ACTIVITIES

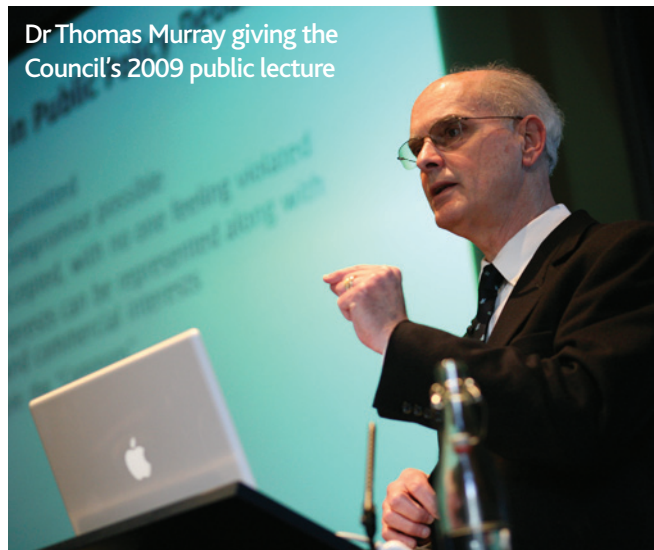
Events and presentations

The Council's members, Working Party members and staff gave over 40 presentations in 2009. These provide us with important opportunities to directly engage with policy makers, students, clinicians, academics and others. For example, in 2009 presentations were given at:

- World Congress of Science Journalists, London
- Café Scientifique meetings in Brampton, Glasgow, Leeds & Cockermouth
- UK Dementia Congress, Harrogate
- 17th Annual Public Health Forum, Brighton
- World Public Health Conference, Istanbul, Turkey
- Westminster Food & Nutrition Seminars on obesity and alcohol
- Rothamsted Research Conference on agriculture in Africa, Harpenden

Find out more:

www.nuffieldbioethics.org/presentations



Dr Thomas Murray giving the Council's 2009 public lecture

Public lecture 2009

Dr Thomas Murray, President of The Hastings Center in the US, delivered the Council's 2009 public lecture to around 80 guests in London in April. His lecture, 'New genetic recipes: are we cooking up trouble with synthetic biology?' considered the concept of non-physical harms such as affronts to nature, and the role such harms should play in public policy.

Find out more:

www.nuffieldbioethics.org/publiclecture

International

In 2009 the Council met with a range of international organisations and individuals to share its work and gain insights from abroad. For example:

- President's Council on Bioethics, Washington
- Bibliotheca Alexandrina, Egypt
- Mauritius Research Council, Mauritius
- Pontifical Academy of Sciences, The Vatican, Rome
- Caribbean Research Ethics Initiative, Jamaica
- Forum of National Ethics Councils, Prague
- Science and Innovation Network, a cross-department UK Government initiative which has staff in 25 countries around the world

Find out more:

www.nuffieldbioethics.org/international

FINANCIAL REPORT

Financial report for the year to 31 December 2009 (unaudited)

	2009 Actual £	2008 Actual £
Expenditure		
Salaries and staffing costs	491,258	404,958
Reviewers' and consultants fees	12,961	1,591
Office and premises costs	11,033	19,846
Journals & subscriptions	9,895	5,834
Travel and meeting costs	74,562	69,435
Web, printing and publicity	82,321	76,461
Total expenditure	682,029	578,125

Funding due		
Nuffield Foundation	232,504	222,224
Medical Research Council	232,504	222,224
Wellcome Trust	232,504	222,224
Other	2,985	6,315
	700,497	660,357

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