

Annual Report 2008

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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 funded jointly by the Nuffield Foundation, the Medical Research Council and the Wellcome Trust.

The Council's terms of reference require it:

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.

Find out more: www.nuffieldbioethics.org

Council members

Professor Albert Weale FBA (Chair)

Albert Weale became Chair of the Council in January 2008. He is Professor of Government at the University of Essex where his academic interests focus on political theory and public policy. He is co-editor of the British Journal of Political Science.



Professor Peter Smith CBE FMedSci (Deputy Chair)

Peter Smith is Professor of Tropical Epidemiology at the London School of Hygiene and Tropical Medicine and a Governor of the Wellcome Trust. His research interests include large-scale trials of vaccines and other interventions against tropical diseases.



Professor Roger Brownsword

Roger Brownsword is Director of the Centre for Technology, Ethics and Law in Society (TELOS) at the School of Law, King's College London, and Honorary Professor in Law at the University of Sheffield. Research interests include legal theory, bioethics and the regulation of technology.



Dr Amanda Burls

Amanda Burls is Director of Postgraduate Programmes in Evidence-Based Health Care, and a Senior Fellow of the Centre for Evidence-Based Medicine, at the University of Oxford. She works on the International Network for Knowledge about Wellbeing (ThinkWell).



Professor Sir Kenneth Calman KCB FRSE

(until January 2008)
Kenneth Calman is Chancellor of the University of Glasgow. He was Vice-Chancellor of Durham University until 2007. He trained in surgery and was formerly Chief Medical Officer for Scotland and England, and Chairman of the WHO Executive Board.



Professor Sian Harding FAHA FESC

Sian Harding is Professor of Cardiac Pharmacology at the National Heart and Lung Institute, a Division of the Faculty of Medicine, Imperial College London. She is a member of the Central Ethical Review Committee for Animal Studies and a Designated Person for administration of the Human Tissue Act.



Professor Peter Harper

Peter Harper is University Research Professor in Human Genetics, Cardiff University. His research interests include inherited neurological disorders, especially Huntington's disease and myotonic dystrophy. He has been extensively involved in the practice and development of genetic counselling.



The Rt Rev Lord Harries of Pentregarth DD FKC FRSL

HonFMedSci (until January 2008)
Lord Harries was Bishop of Oxford from 1987 to 2006. He is Chair of the Ethics and Law Advisory Group at the HFEA, and was formerly Dean of King's College, London where he is Honorary Professor of Theology.



Professor Ray Hill FMedSci

Ray Hill was Head of Licensing and External Research for Europe at Merck, Sharp and Dohme until his retirement in May 2008. He is a pharmacologist with a special interest in pain and headache research and is a Visiting Professor at ICL, Bristol, Surrey and Strathclyde Universities. He is a non-executive Director of several biotech companies and Honorary Biomedical Business Development Advisor at ICL. He is President-Elect of the British Pharmacological Society.



Professor Søren Holm

Søren Holm is Professorial Fellow in Bioethics at Cardiff Law School, and part-time Professor of Medical Ethics at the University of Oslo, Norway. He is a medical doctor and philosopher and was a member of the Danish Council of Ethics from 1994–1999. He is the President-Elect of the European Society for the Philosophy of Medicine and Health Care.



Council members

Professor Christopher Hood FBA

Christopher Hood is Gladstone Professor of Government and Fellow of All Souls College, University of Oxford. He is Director of the Economic and Social Research Council's Public Services Research Programme. Christopher Hood specialises in the study of executive government, regulation and public-sector reform and he is a co-opted member of Council while he chairs the Working Party on personalising healthcare.



Professor Tony Hope

Tony Hope is Professor of Medical Ethics, University of Oxford, and an Honorary Consultant Psychiatrist. In 1997 he co-founded the Oxford Centre of Ethics and Communication Skills in Health Care Practice (Ethox). His research areas include mental health and neuroscience and clinical ethics. Professor Hope is a co-opted member of the Council while he chairs the Council's Working Party on dementia.



Mr Anatole Kaletsky

Anatole Kaletsky is Editor at Large of *The Times of London* and a founding partner of an economic, political and financial consultancy firm. He has 30 years of experience as a journalist on publications such as *The Financial Times* and *The Economist*.



Dr Rhona Knight FRCGP

Rhona Knight has a portfolio career in medicine. She works as a General Practitioner and is involved in medical education in Leicester. She has a particular interest in making bioethical issues accessible and understandable to non-specialist audiences. Dr Knight is Chair of the Council's Reaching Out to Young People Advisory Group.



Professor Alison Murdoch FRCOG

Alison Murdoch is Professor of Reproductive Medicine, a consultant gynaecologist and Head of the NHS Newcastle Fertility Centre at Life. She is involved in setting clinical standards, embryo research, stem cell derivation and the associated practical, political and ethical issues.



Dr Bronwyn Parry

Bronwyn Parry is Reader in Geography at Queen Mary, University of London. She is an economic and cultural geographer interested in the way human-environment relations are being recast by technological, economic and regulatory changes. She has acted as consultant to the UK Government and the United Nations.



Professor Hugh Perry FMedSci

Hugh Perry is Professor of Experimental Neuropathology at the University of Southampton and Director of Southampton Neuroscience Group. He is currently Chair of the Wellcome Trust Molecular and Cellular Neuroscience Committee.



Professor Nikolas Rose

Nikolas Rose is the James Martin White Professor of Sociology at the London School of Economics and Political Science, and Director of the LSE's BIOS Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society. His current research is on the social and political implications of the new sciences of the brain.



Professor Jonathan Wolff

Jonathan Wolff is Head of the Department of Philosophy at University College London. His research interests include political philosophy, Marx and ethics.



Membership changes

The Council would like to thank Professor Sir Kenneth Calman and Lord Harries, who both reached the end of their terms in 2008, for their outstanding contributions to the Council's work over the past six years. Professor Albert Weale began his term as Chair of the Council in January 2008, and in the same month Dr Amanda Burls and Professor Jonathan Wolff were welcomed as new members.

Towards the end of 2008, the Council was delighted to appoint six new members who will begin their terms in January 2009: Professor Steve Brown FMedSci, Professor Robin Gill, Professor Graeme Laurie FRSE, Dr Tim Lewens, Professor Ottoline Leyser CBE FRS and Professor Anneke Lucassen.

Note from the Chair

2008 was the first year in which I chaired the Nuffield Council, and I should like to take this opportunity to thank my predecessor, Professor Sir Bob Hepple QC, who led the Council so successfully in the previous five years. Bob Hepple not only chaired the Council but also chaired its Working Group on the forensic use of bioinformation, which completed its work in September 2007, a measure of his commitment to the work of the Council.



That report influenced a landmark ruling of the European Court of Human Rights in the case of *S. and Marper versus the United Kingdom*. Reasoning that the UK was in breach of the European Convention on Human Rights, the Court noted the Council's view that the statistical argument for the retention of samples of those who were innocent linking to crime scenes was weak, and shared our concerns about permanently retaining the bioinformation of minors.

Earlier in 2007, the Council published its report on the ethical issues arising in public health. Arguing for a stewardship model of the state, it developed the notion of a 'ladder of intervention' that brought together the concerns of health promotion and respect for individual liberty. Drawing on evidence commissioned by the World Health Organisation, the Council supported using pricing as a means of reducing alcohol consumption. In his 2008 annual report, the Chief Medical Officer echoed some of the concerns articulated in the Council's report, proposing that a minimum charge of 50p per unit of alcohol be imposed in order to reduce over-consumption.

In my first year in the chair, I have been privileged to represent the Council at various international events, most notably the twice yearly meeting of National Ethics Committees convened by the European Commission. At those meetings I have been struck by the

high esteem in which the Council's work is held, and a great debt is owed to the staff in the Secretariat, who are so central to the quality of its work.

In 2008 two Council members, Lord Harries of Pentregarth and Professor Sir Kenneth Calman, reached the end of their terms. Both had served for six years on the Council, and a special debt is owed to them for the wisdom and experience they brought to our deliberations. The Council continues not only to renew its membership but also to grow, recruiting six new members to start their terms of office in 2009. They bring their distinctive and complementary strengths to those of already existing Council members.

Last year in his annual report, Bob Hepple was writing against the background of debates in parliament as to whether there should be a national bioethics council, quoting those in the House of Lords who valued the Council for its independence. Inevitably, however, that same House of Lords debate raised the question of whether this independence was bought at the price of influence. During 2008 the answer has been clear that independence and influence go together, along with an international reach.



Professor Albert Weale FBA

The Secretariat

Hugh Whittall
Director

Katharine Wright
Assistant Director

Harald Schmidt
Assistant Director

Carol Perkins
PA to the Director and Secretariat Administrator

Catherine Joynson
Communications Manager

Sarah Bougourd
Communications Officer (from November 2008)

Caroline Rogers
Senior Research Officer (until May 2008)

Julia Trusler
Research Officer (until August 2008)

Kate Harvey
Research Officer

Tom Finnegan
Research Officer (from September 2008)

Varsha Jagadesham
Research Officer (from November 2008)

Audrey Kelly-Gardner
Secretary



Note from the Director

2008 has been a really interesting year, and one in which the timeliness and relevance of the Council's work has never been more evident.

Our most recent reports, on ethical issues in forensic bioinformation and in public health, have given the Council the reason and opportunity to feed into a wide range of consultations and policy discussions over the year. We have also presented the work at numerous meetings and conferences throughout the UK and overseas to academics, policymakers and much wider audiences. In November we hosted our first parliamentary event in Westminster, on the subject of the DNA database, which was well attended by parliamentarians, researchers, civil servants and key interest groups. But attention has not been limited to these two issues. Other past Council reports, such as those on GM crops, the use of animals in research and on healthcare research in developing countries, also continue to be frequently downloaded, quoted and referenced. All of this goes to show that the Council's selection of topics, and the quality of its analyses, continue to provide a sound and durable platform for discussion of some of the most important ethical issues of our times. Our reports are never destined simply for the library shelf.

Our international links get stronger all the time, and we were delighted to welcome Professor Göran Hermerén as our guest speaker at what is now to be an annual lecture hosted by the Council. Göran is Professor of Medical Ethics at the University of Lund and Chair of the European

Group on Ethics, which is appointed by the President of the European Commission to advise on ethical issues arising in science and technology. The meeting was extremely popular, which augurs well for future events. The 2009 lecture will be given by Dr Thomas Murray, Director of the Hastings Center in New York.

Finally, I would like to say a word of thanks to the staff of the Council who have, as always, provided it with tremendous support, maintaining the pillars of quality, independence and timeliness. We have said farewell to two excellent colleagues during the year – Caroline Rogers and Julia Trusler – but we have also welcomed several new colleagues who have already settled in nicely. These are Tom Finnegan and Varsha Jagadeshram, arriving as Research Officers, and Sarah Bougourd, our new Communications Officer.

Together we look forward to 2009 with excitement, anticipation, and the usual curiosity as to what next will appear on the horizon.

Hugh Whittall



Hugh Whittall, Director

CURRENT WORK

Dementia: ethical issues

Carers and people with dementia face difficult ethical dilemmas on a daily basis. How are people with dementia treated and included within our society? How should carers, families and healthcare professionals weigh up what treatment and care a person would have wanted before they developed dementia, and what they appear to want now? It is ever right to deceive a person with dementia, for example, by disguising medication in food? What is an ethical approach to research into dementia?

In November 2007 the Council established a Working Party to examine these and other ethical issues surrounding dementia. The Working Party met six times in 2008 and had a good response to its consultation in the summer, with 200 people and organisations sending in evidence and views. In addition, fifty-four members of the public were recruited to deliberate the issues at a workshop hosted by the Council in Birmingham in August. The workshop was organised by Opinion Leader, a research and consultancy company.

The outcomes of all these activities will be invaluable to the Working Party as they begin to formulate recommendations for policy and practice. A report setting out the group's findings will be published in autumn 2009.

"Although the law offers guidance on how decisions for people with dementia should be made, it is often more complicated in real life. For example, taking account of someone's 'past and present wishes and values', as stated in the Mental Capacity Act, can be difficult if these appear to be vastly different."

Professor Tony Hope
Chair of the Working Party on dementia

Find out more:
www.nuffieldbioethics.org/dementia

Working Party members

Professor Tony Hope (Chair)
Professor of Medical Ethics, University of Oxford

Mary Baker MBE
President, European Federation of Neurological Associations

Harry Cayton
Chief Executive of the Council for Healthcare Regulatory Excellence, former National Director for Patients and the Public at the Department of Health and former Chief Executive of the Alzheimer's Society

Chris Chaloner
Previously Ethics Advisor, Royal College of Nursing

Dr Jim Eccles
Consultant Physician, The Leeds Teaching Hospitals NHS Trust

Dr Julian Hughes
Consultant in Old Age Psychiatry, Northumbria Healthcare NHS Foundation Trust

Dr Rhona Knight
Council member and General Practitioner

Dr Gemma Jones
Neuropsychologist and nurse working with people with Alzheimer's and their carers

Dr John McMillan
Senior Lecturer in medical ethics, The Hull York Medical School

Professor Jill Peay
Professor of Law, London School of Economics

Professor Hugh Perry
Council member and Professor of Experimental Neuropathology, University of Southampton

Professor Ruud Ter Meulen
Professor of Ethics in Medicine, University of Bristol

Dr David Wilkinson
Consultant in Old Age Psychiatry, Moorgreen and Western Community Hospitals, Southampton



CURRENT WORK

Medical profiling and online medicine: the ethics of 'personalised' health care in a consumer age

In October 2008, the Council set up a new Working Party to consider the ethical issues raised by new technologies that are making healthcare increasingly personalised. Such technologies include whole body CT or MRI scans and 'personal genomics' where the genome of individual patients is sequenced.

The Working Party met twice in 2008 and will hold evidence gathering sessions and a public consultation in spring 2009 to draw together wider views on the issues raised. A report with recommendations for policy and practice will be published in 2010.

"Imagine a future situation where a young woman has her entire genome sequenced and this tells her that she has an increased risk of developing Alzheimer's disease later in life. This does not tell her whether she will develop the disease at all and, even if she does, there are no proven ways of preventing the disease from developing. Would she have been better off not knowing? How might it affect her insurance policies, and might it increase the burden on the NHS?"

Professor Christopher Hood

Chair of the Working Party on medical profiling and online medicine

Find out more:

www.nuffieldbioethics.org/personalised

Working Party members

Professor Christopher Hood FBA (Chair)
Gladstone Professor of Government, Fellow and Director of the ESRC's Public Services Research Programme, All Souls College, University of Oxford

Professor Kay-Tee Khaw CBE FRCP
Professor of Clinical Gerontology, University of Cambridge School of Clinical Medicine, Addenbrooke's Hospital

Dr Kathy Liddell
Lecturer, Faculty of Law, University of Cambridge

Professor Susan Mendus FBA
Professor of Political Philosophy, University of York

Professor Nikolas Rose
Council member and Martin White Professor of Sociology, BIOS Centre for the Study of Bioscience, London School of Economics and Political Science

Professor Peter C Smith
Professor of Health Economics, Centre for Health Economics, University of York

Professor Sir John Sulston FRS
Chair, Institute of Science, Ethics and Innovation, University of Manchester

Professor Jonathan Wolff
Council member and Head of the Department of Philosophy, University College London

Professor Richard Wootton
Director, The Scottish Centre for Telehealth



PREVIOUS WORK

The forensic use of bioinformation: ethical issues

Published September 2007

Council representatives continued to discuss the findings of the Council's report on the forensic use of bioinformation at events and conferences in the UK and abroad, and the National DNA Database received extensive media coverage throughout the year.

In December 2008, the European Court of Human Rights unanimously ruled that the UK's policy of keeping the samples and fingerprints of two men, who had been arrested but never convicted of any crime, constituted a breach of their human rights. The ruling was in line with the Council's recommendations against storing DNA profiles and samples of innocent people, and the Council's report was referred to extensively in the judgment. The ruling has significant consequences for the Government which now has an obligation to bring its own policies into line.

"The DNA of innocent people should not be kept by police. People feel it is an invasion of their privacy, and there is no evidence that removing from the DNA database people who have not been charged or convicted will lead to serious crimes going undetected."

Hugh Whittall
Director

Find out more:

www.nuffieldbioethics.org/forensic



PREVIOUS WORK

Public health: ethical issues

Published November 2007

Obesity, binge drinking, the smoking ban, flu pandemics – these and other public health issues were debated in the news and in Parliament almost daily in 2008. The Nuffield Council on Bioethics began discussing the ethics of public health measures as far back as 2003, resulting in the publication of a report in November 2007.

Council representatives met with a range of policy makers and other stakeholders to discuss the report's findings in 2008, and engaged in debate at events in the UK, Europe, the US and Africa.

There were significant developments in public health policy in 2008, many of them along the lines of the Council's recommendations. For example, the government's recent proposals to restrict access to cigarette vending machines and ban displays in shops were seen as justified in the report in terms of protecting the vulnerable and reducing inequalities. The more coercive approach on pricing and promotion of alcoholic drinks proposed by the Policing and Crime Bill 2008-09 would also be justified within the Council's framework.

"When you don't cycle to work because the roads are too dangerous, or when your daughter comes home drunk from a party fuelled by beer costing 22p a can, then there is an argument that the Government has an ethical duty to step in to enable us to make healthier choices."

Lord Krebs

Chair of the Working Party on public health

Find out more:

www.nuffieldbioethics.org/publichealth



FUTURE WORK

Forward Look seminar 2008

Twenty invited guests joined Council members at this year's horizon-scanning 'Forward Look' seminar in May 2008. Presentations and discussion focussed on three topics: nanotechnology; volunteering, donation and payment in clinical practice and research; and the use of cord blood and other cell banks. Following the meeting, the Council decided to convene a one-day workshop to explore further the issues raised by volunteering, donation and payment in clinical practice and this took place in December 2008. The Council has subsequently decided to establish a full Working Party on this topic, which will begin work in 2009.

Find out more:

www.nuffieldbioethics.org/futurework



Workshop on volunteering, donation and payment, December 2009



Forward Look seminar, May 2008

EXTERNAL RELATIONS

Engagement with policy makers

The Council makes considerable effort to ensure that it engages with relevant government ministers, civil servants, parliamentarians and other policy makers.

The Council hosted its first 'Bioethics in Parliament' event in the Houses of Parliament in November, where participants discussed issues raised by the National DNA Database. The Council is grateful to the four sponsors of the event: Dr Ian Gibson MP, Dr Evan Harris MP, Lord Harries of Pentregarth and Earl Howe.

Council representatives gave evidence at two Parliamentary Select Committee inquiries in 2008, and fourteen responses were submitted to policy consultations, including:

- The Department of Health's consultation on the future of tobacco control
- The World Medical Association's consultation on the Declaration of Helsinki
- The Scottish Government's consultation on DNA and fingerprint retention.

All the Council's responses are available to download at: www.nuffieldbioethics.org/consultations

International

The Council has a strong international profile and 2008 saw Council representatives visiting countries in Europe, North America, Africa and Asia to discuss the Council's work and learn about developments abroad.

The Council took part in the 9th World Congress of Bioethics in Croatia, the 7th Global Summit of National Bioethics Commissions in Paris, and the 11th and 12th Forum of National Ethics Councils in Slovenia and Paris.

Find out more:

www.nuffieldbioethics.org/international
www.nuffieldbioethics.org/presentations



Bioethics in Parliament 2008 event

Media relations

In 2008 the Council was featured in almost 100 print and online news articles, broadcast interviews and feature articles in specialist publications.

The Council also distributes its e-newsletter UPDATE three times a year to around 1600 subscribers.

The Council in the media

"Hugh Whittall, the director of the Nuffield Council on Bioethics, said there was no data to suggest a significant increase in the number of solved crimes because of the inclusion of people who had not been convicted of serious offences on the database."

THE GUARDIAN, 22 FEBRUARY

"Experts from the Nuffield Council on Bioethics are calling for a debate over the ethical dilemmas those caring for dementia patients face"

BBC NEWS, 14 MAY 2008

"Debates around the potential benefits of GM crops for developing countries must be reasoned and evidence-based"

ARTICLE BY PROFESSOR ALBERT WEALE
SCIDEV.NET, 16 OCTOBER 2008

Find out more:
www.nuffieldbioethics.org/media

The website

The Council's website is regularly updated with news and activities, and all the Council's publications are available to download. The website received on average 10,000 unique visitors each month in 2008, with its pages viewed over two million times during the year.

Top five reports in 2008 (number of downloads)

The ethics of research involving animals	224,000
Public health: ethical issues	111,000
Critical care decisions in fetal and neonatal medicine	33,400
Genetics and human behaviour: the ethical context	31,200
The ethics of research related to healthcare in developing countries	29,900



Education

With ethical debate now a compulsory part of the curriculum, the Council expanded its Reaching Out to Young People Advisory (ROYP) Group in 2008 by appointing some new members. The new group met twice over the autumn and is developing plans to reach young people both inside and outside of the school setting. The Council has been working to promote debate of bioethics issues among young people for some years, for example by producing a set of teaching resources on animal research. The Group is chaired by Council member Dr Rhona Knight.

Find out more:

www.nuffieldbioethics.org/education



Dr Rhona Knight, chair of the ROYP Group

Events and presentations

Council representatives gave almost 50 presentations at events around the world in 2008, providing them with the opportunity to engage with academics, policy makers, clinicians, young people and many others. The Council's work was also showcased through exhibitions at a number of conferences in the UK.

Find out more:

www.nuffieldbioethics.org/presentations

Public lecture 2008

Professor Göran Hermerén, Chair of the European Group on Ethics and Professor of Medical Ethics, University of Lund, delivered the Council's 2008 public lecture to around 80 guests at the Royal Society in London in May. His talk focussed on 'The ranking of values as a basis for ethical decision making'.

Find out more:

www.nuffieldbioethics.org/publiclecture



Professor Göran Hermerén, May 2008

Financial Report

FINANCIAL REPORT FOR THE YEAR TO 31 DECEMBER 2008 (UNAUDITED)

	2008 Actual £	2007 Actual £
Expenditure		
Salaries and staffing costs	428,701	383,442
Reviewers' and consultants fees	1,488	5,202
Other costs including premises	19,102	12,169
Stationery, subscription and press cuttings	7,626	9,396
Photocopy, post, phone	3,865	10,359
Committee and meeting costs	45,697	47,416
Printing, design and publicity of reports	68,688	72,163
Web and other technology costs	2,959	3,315
Net Direct Expenditure	578,126	543,462
Funding Due		
Nuffield Foundation	222,224	213,792
Medical Research Council	222,224	213,792
Wellcome Trust	222,224	213,792
Reports Sold	-1,189	-1,396
Other	-5,126	310
	660,357	640,290
Overheads met by Nuffield	365,127	323,114

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