The task of the Council is to identify and analyse ethical questions raised by recent advances in biological and medical research. The members of our Council and working groups are experts in the life and environmental sciences, medicine, philosophy and theology, law and the social sciences. They find time in their busy schedules to give their services voluntarily. Their motivation for doing so is their belief in the importance of promoting public dialogue on the issues.

These issues are often highly controversial, such as the two topics being considered by our Working Parties in 2004 – research involving animals, and prolonging life in fetuses and the newborn. Our distinctive contribution is to go beyond the short-term and immediate questions and to examine the fundamentals of the subject. This involves explaining the hard science in terms that are accessible to the lay public, developing an ethical framework for considering particular issues, and laying out the policy choices that face society.

We should be judged by whether or not our reports, discussion papers and workshops have raised the quality and clarity of public debate. We are wholly independent of government, but we were glad to be told in September 2004 by Lord Warner, Parliamentary Under Secretary of State for Health, that the Nuffield Council is regarded as a key player in current arrangements for bioethical advice, and to be congratulated by him on the wise and comprehensive reports [the Council] has produced on some very difficult issues.

None of this would have been possible without the contributions of a large number of people, including members of the Council and working groups, participants in our meetings and consultations, and colleagues in other countries with whom we have discussed questions which we face in common. I express gratitude to all of them. I also pay tribute to the dedication of the Secretariat, a small but highly productive team, joined in 2004 by Dr Catherine Moody as Deputy Director. It is a particular pleasure to congratulate our Director, Dr Sandy Thomas, who is on secondment to the Council from the University of Sussex, on the award of a Professorship in recognition of her outstanding international work in the field of bioethics.
Introduction

The Nuffield Council on Bioethics examines ethical issues raised by new developments in biology and medicine. Established by the Nuffield Foundation in 1991, the Council is an independent body, funded jointly by the Foundation, the Medical Research Council and the Wellcome Trust.

The Council has achieved an international reputation for addressing public concerns, providing independent advice to assist policy makers and to stimulate debate in bioethics.

Terms of Reference

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.

Further information about the Council’s method of working and publications can be found on the Council’s website: www.nuffieldbioethics.org

Membership of Council*

a. Professor Sir Bob Hepple QC, FBA (Chairman)
Emeritus Master, Clare College, and Emeritus Professor of Law, University of Cambridge; Barrister at Blackstone Chambers

b. Professor Catherine Pechham CBE (Deputy Chairman)
Professor of Paediatric Epidemiology, Institute of Child Health, University College London

c. Professor Tom Baldwin
Department of Philosophy, University of York

d. Professor Margaret Brazier OBE
School of Law, University of Manchester (co-opted member of Council for the period of chairing the Working Party on the ethics of prolonging life in fetuses and the newborn)

e. Professor Roger Brownsword
Centre for Medical Law & Ethics, King’s College, London

f. Professor Sir Kenneth Calman KCB FRSE
Vice-Chancellor and Warden, University of Durham

g. The Rt Reverend Richard Harries DD, FKC FRSL
Bishop of Oxford

h. Professor Peter Harper
University Research Professor in Human Genetics, Cardiff University

i. Professor Peter Lipton
Head of the Department of History and Philosophy of Science, University of Cambridge

j. Lord Plant of Highfield
Centre for Medical Law & Ethics, King’s College, London

k. Baroness Perry of Southwark
Member of the House of Lords and Pro-Chancellor of the University of Surrey (co-opted member of Council for the period of chairing the Working Party on the ethics of research involving animals)

l. Professor Martin Raff FRS
Professor of Biology (Emeritus), University College London

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

n. Professor Albert Weale FBA
(until June 2004) Professor of Government, University of Essex

o. Professor Peter Smith CBE
Professor, Infectious Disease Epidemiology Unit, Department of Infectious Tropical Diseases, London School of Hygiene and Tropical Medicine

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

q. Professor Albert Weale FBA (until June 2004) Professor of Government, University of Essex

r. Dr Alan Williamson FRSE
Consultant on Biotechnology

Secretariat

Dr Sandy Thomas
Director

Dr Catherine Moody
Deputy Director (from February 2004)

Mr Harald Schmidt
Assistant Director

Ms Julia Fox
PA to the Director and Secretariat Administrator

Ms Nicola Perrin
Public Liaison Manager (until September 2004)

Ms Caroline Rogers
Research Officer

Ms Elaine Talaat-Abdalla
Secretary

Mr Mun-Keat Looi
Information Assistant

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*positions correct as of 1 January 2005
2004 Calendar

January
1st Council meeting
6th meeting of Working Party on the ethics of research involving animals

February
Workshop on the ethics of research related to healthcare in developing countries, Cape Town, South Africa

March
2nd Council meeting
7th meeting of Working Party on the ethics of research involving animals

May
Seminar: The way we reason deliberation, consultation and policy in bioethics
8th meeting of Working Party on the ethics of research involving animals

June
3rd Council meeting
9th meeting of Working Party on the ethics of research involving animals

July
Workshop on the ethics of public health
Bi-lateral meeting with Der Nationaler Ethikrat, Germany

September
1st meeting of Working Party on the ethics of prolonging life in fetuses and the newborn
10th meeting of Working Party on the ethics of research involving animals

October
4th Council meeting

November
2nd meeting of Working Party on the ethics of prolonging life in fetuses and the newborn
11th meeting of Working Party on the ethics of research involving animals
5th International Meeting of National Bioethics Advisory Bodies, Canberra, Australia

December
12th meeting of Working Party on the ethics of research involving animals

Report by the Director

Much of the Council’s efforts over the past year has been focused on two highly controversial topics: animal experimentation and prolonging life in the very young. They both raise difficult ethical issues which have attracted a good deal of wider discussion and debate in the UK. The Working Party examining animal experimentation, at eighteen members, is our largest to date; it met twelve times and will report in May 2005. The new Working Party on prolonging life in newborns, chaired by Professor Margot Brazier, started work in September 2004 and will meet throughout 2005.

Two other themes have been prominent in 2004: follow-up and international work. The Council has been devoting increased resources to follow-up its publications. In February this year we convened an international Workshop in Cape Town to consider recently revised guidance for clinical research in developing countries. Sponsored by the Wellcome Trust, the Medical Research Council, DFID and the Rockefeller Foundation, it brought together researchers, regulators, clinicians and others from 28 countries to identify and debate the issues. A discussion paper based on the Workshop will be published in March 2005.

The Council continued to strengthen its international role by hosting a bilateral meeting with the Nationaler Ethikrat, Germany and by presenting its work in Europe, the USA, Australia, New Zealand and South Africa. As ever, none of this could have been achieved without the support of the many individuals who have contributed to the Council’s work members of the Council, Working Parties, peer reviewers, and experts and organisations who have provided advice. We thank them all.

On a final note, I should like to thank Nicola Perrin (Public Liaison Manager) for her outstanding service to the Council (2001-2004).
The role of Working Parties

A feature of the way the Council works is the formation of expert Working Parties to examine and report on a particular issue.

Once the Council has identified a topic, it appoints a Working Party, consisting of seven to fourteen members, and an independent Chair. Members are chosen to represent a range of specialist experience and skills and Council tries to ensure that they cover a wide range of views. Each Working Party includes two or more members of the Council. The Chair is co-opted as a member of the Council during the course of the Working Party to facilitate communication between the Working Party and the Council. Working Parties are supported by the Secretariat, with a senior member serving as Secretary to the group.

Two new members of staff joined the Secretariat during 2004. Mun-Keat Looi was appointed Information Assistant (now a full-time position) in January, and Tom McBride and Kevin Smith helped to prepare additional information for the website.

The nature of the Council’s approach to bioethics

Council members were appointed for their breadth of knowledge and range of expertise and this had proved a successful format for discourse in bioethics. Attendees agreed that the Council should also continue to seek an appropriate representation of relevant disciplines on its Working Parties. The Council took a flexible approach rather than following a set formula. Similarly, for its Reports, the Council did not adopt a single ethical framework as the basis of its general approach.

The role of consultation in decision-making

Consultation is increasingly used to inform policy-making, with greater emphasis being given to deliberation and debate through citizens’ juries, focus groups and consensus conferences rather than views being elicited through surveys.

Several questions were considered, including:

- What is the current status of consultation with the public in policy-making?
- How can consultation best inform policy deliberation?
- Which forms of public participation are most beneficial?
- What sort of weighting should be given to public opinion?
- How should the Council consult with the public?

The Council has conducted consultation exercises, in various forms, for all of its publications and has found the responses to be very helpful in illustrating a range of opinions on a particular topic. Views are also sought through fact-finding meetings. A number of other methods of canvassing professional and public opinion were discussed.

In the light of the debate at the Forward Look meeting, the Council agreed to make responses to consultations received for past and future Reports available (with the necessary consent) through the website. The Secretariat has initiated this process, which will continue during 2005.

The Council is, first and foremost, a forum for bioethical deliberation and the meeting provided a valuable opportunity for members to reflect upon the nature of the Council’s approach.

The Council discusses strategy and broader themes at its annual ‘Forward Look’ meeting. In May 2004, this took the form of a one day seminar on ‘The way we reason: deliberation, consultation and policy in bioethics.’ Discussion covered the changing features of the policy process in the UK, the role of the Council and the nature of its approach to bioethical debate, and the contribution made by consultation to decision-making. A number of guests with expertise in public policy, law, social science and ethics attended. The Council is grateful to them for their contribution.

The policy process in the UK:

There have been a number of important changes to the way that public policy is conducted in the UK since the Council started its work. The number of ‘think tanks’, advising the government has grown significantly and more emphasis is now given to the role of the ‘expert’. There is increased interest in public engagement in policy-making and, particularly in the regulation of biotechnology, more attention is now paid to openness, participation and consensus. These trends have been accompanied by a perceived decline of public trust in the government and the rising power of the media in shaping public perception.

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work in progress

The ethics of research involving animals
Fact-finding:
As part of its research, the Working Party has held fact-finding meetings with a number of experts during 2004, including:
- Dr Jon Richmond, Head, Animals (Scientific Procedures) Division, Home Office
- Professor Michael Banner, Chair, Animals Procedure Committee (APC)
- Richard West, Secretary, Animals Procedure Committee (APC)
- Dr Ray Greek, President, Americans For Medical Advancement (AFMA)
- Professor Jonathan Wolff, Department of Philosophy, University College London

Many people are concerned about the use of animals in research. There is also widespread recognition of the need to improve our understanding of disease pathology and to develop new treatments. Since much of this currently involves the use of animals, these two views are not easily reconciled. The Nuffield Council on Bioethics, acknowledging that people feel very deeply about this topic, established a Working Party in 2003 to encourage a rigorous ethical debate. The Working Party, chaired by Baroness Perry, has 18 members who bring a wide range of views to the discussion.
The ethics of prolonging life in fetuses and the newborn

Membership of the Working Party

Professor Margaret Brazier OBE (Chair)
Professor of Law, University of Manchester
Professor David Archard
Professor of Philosophy & Public Policy, Institute of Environment, Philosophy & Public Policy, Fawcett College, University of Lancaster
Professor Alastair Campbell
Emeritus Professor of Ethics in Medicine, Centre for Ethics in Medicine, University of Bristol
Professor Linda Franck
Professor & Chair, Children’s Nursing Research Centre for Nursing and Allied Health Professions Research, Great Ormond Street Hospital and Institute of Child Health
Ms Bonnie Green
Head of Professional and Public Affairs, BLISS the premature baby charity
Professor Erica Haimes
Executive Director, Policy, Ethics & Life Sciences Research Institute, Bioscience Centre, Newcastle upon Tyne
Dr Monica Konrad
Department of Social Anthropology, University of Cambridge
Professor Neil Marlow
Professor of Neonatal Medicine, School of Human Development, Queen’s Medical Centre, Nottingham
Professor Catherine Pechham CBE
[Deputy Chair of the Council]
Professor of Paediatric Epidemiology, Institute of Child Health, University College London
Dr Stavros Petrou
Health Economist, National Perinatal Epidemiology Unit (NPEU), University of Oxford
Professor Charles Rodeck
Head of Department, Department of Obstetrics and Gynaecology, University College London
Dr Philippa Russell CBE
Policy Adviser for Disability, National Children’s Bureau, London
Ms Anne Winyard
Partner, Leigh, Day & Company., Solicitors, London
Professor Andrew Whitelaw
Professor of Neonatal Medicine, University of Bristol Medical School, Bristol

Terms of Reference

1. To identify and consider ethical, social, economic and legal issues arising from recent developments in fetal and neonatal medicine relating to prolonging life.

2. To examine scientific and medical research in these fields, considering in particular:
   a. diagnostics;
   b. fetal surgery;
   c. neonatal care (including resuscitation);
   d. recent evidence on the capacity of fetuses and the newborn to experience pain and suffering.

3. To examine current medical practices in these fields and their outcomes in the UK and more widely. In particular to review:
   a. implications arising from the possibility of survival of premature babies of increasing frailty and at lower ages;
   b. the relationship between changing survival rates and longer term outcomes

4. To consider issues raised by advances in research and practice, particularly:
   a. arguments about the moral and legal status of fetuses beyond the first trimester and the newborn;
   b. the ethical and legal basis for providing, withdrawing or withholding life-prolonging treatment;
   c. the process of decision-making, including the relative roles of families and healthcare professionals;
   d. the availability of support for families in the short and the long term;
   e. resource implications for providers of healthcare, education and social care;

5. In light of the above, to make recommendations.
In developed countries, modern medicine has reached the stage where we can sustain the life of babies who, until relatively recently, might not have survived birth. While improvements in technology and care have been successful in lowering the threshold for survival to as little as 23 weeks, parents may still be faced with complex questions about what the future holds, in terms of the quality of life for their child and their family.

This includes parents who may know before the birth that their baby has health problems, parents who may have an extremely premature baby or parents with a baby born at the normal time of between 37 and 42 weeks who is nevertheless very ill or has abnormalities.

In these situations, the baby may recover entirely or survive with disabilities. Many parents do not regard disability as a medical condition and there is no consensus on how we should place value on the quality of life for the developing child, the family and society. This is an area where there has been little systematic research to help parents and doctors make decisions. However, there are new findings that the increasing number of babies born extremely prematurely who survive are at particularly high risk of neurodevelopmental disabilities.

After discussion at a Workshop held in 2003, the Council decided that it would be timely to hold a discussion of the complex and controversial ethical, social, legal and economic issues that arise when deciding whether or not to prolong life in fetuses and the newborn. These issues concern whether or not life prolonging treatment should be offered to fetuses in poor health, very premature babies and the newborn who have experienced problems at birth, and how such decisions should be made.

A Working Party was established in 2004 for this purpose. The group will examine scientific advances and potential developments in this area of medicine, professional and legal guidance and current practice. It will formulate advice that is primarily relevant to UK policy and practice, but will draw on examples from other countries.

The Working Party is chaired by Professor Margaret Brazier of the Manchester University School of Law, and 13 other members with a range of expertise have been appointed to ensure that the roles of the family, medical professionals and the wider population will be considered.

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The Working Party is chaired by Professor Margaret Brazier of the Manchester University School of Law, and 13 other members with a range of expertise have been appointed to ensure that the roles of the family, medical professionals and the wider population will be considered.

The Working Party held two meetings in 2004, and will continue to discuss the issues over the next year. A series of fact-finding visits and meetings will be conducted as part of the research, and a consultation exercise with members of the public, professionals and organisations will be held during the spring of 2005. The Council expects to publish a Report on this topic during 2006.
Workshop on the Ethics of Public Health

The Council held a Workshop in July 2004 to discuss ethical and social issues relating to public health. The main focus of the meeting was how to find the right balance between individual choice and community benefit. Seventeen experts were invited to explore the possibility of establishing a new Working Party to examine the issues raised. The Council wishes to thank them for their contribution.

During the meeting, case studies on vaccination and the use of databanks were discussed. In common with some other public health measures, vaccination raises interesting questions because it requires interventions to be given to healthy people. A major issue in any decision whether or not to introduce a vaccination programme is the conflict between the autonomy of the individual and their duty to society. It is difficult to formulate general rules because of variations in the safety of vaccines, the risks of the disease to be prevented, the risks for those who remain unvaccinated at the uptake of a vaccine increases, potential adverse effects in vulnerable groups and questions about vaccine availability.

Great care had been taken in developing the ethics and governance for the UK Biobank, particularly over the issue of consent. The Biobank is the largest prospective cohort study in the UK to date and will enrol 500,000 participants, whose medical records will be tracked for many years. However, in many areas of public health research, near complete coverage of the population would be required. For such studies, it was unlikely to be feasible or affordable to obtain advance consent. Issues debated included how to gain public trust, the distinction between research on public health and health monitoring, issues of data protection and anonymity, and the provision of individual feedback.

Discussion focused on identifying the broad themes for ethical debate. The concept of an individual’s ‘right to choose’ would need exploration and a distinction made between choices that affected only the individual, as opposed to choices that affected the whole community. ‘Choice’ meant different things to different people and societies varied in their perceptions of individual and collective rights and responsibilities, on risk and on safety. In spheres where individual and community responsibilities overlapped, there was an overarching question of how currently accepted social standards and behaviours might best be changed.

The concept of seeking public ‘goods’ in the context of public health was considered. ‘Goods’ in relation to improving health might include information from large scale research studies in public health, promotion of equality, access to good health, public education, provision of public and transparent information; consent and public trust. The role of the state, and whether there can be a legitimate form of ‘paternalistic’ intervention, and rationing of healthcare were discussed.

It was clear from the meeting that the topic was timely and that there was substantial scope for further discussion. The Council subsequently agreed to establish a Working Party during 2005 to consider the ethics of public health in more detail.

Public health: the science and art of preventing disease, prolonging life and promoting health through the organised efforts of society.
The Acheson report (1998)
Genetic Screening: ethical issues was the Council’s first Report and remains one of its most cited and influential publications. To mark the tenth anniversary of its first Report, the Council initiated a small follow-up project in 2003.

In 1993, most genetic screening programmes were at the pilot stage. Since then, there have been major advances in scientific understanding and developments in technologies leading to new diagnostic tests and treatments. There have also been substantial changes in the regulatory and advisory framework, with the formation of the Human Genetics Commission (HGC) and the National Screening Committee (NSC). In June 2003, the Government White Paper, Our inheritance, our future emphasised the central role that genetics will play within the NHS.

This follow-up project is intended to assess the impact of the original Report and to review whether the consideration of ethical issues needs to be updated in the light of progress in research and clinical practice. A Steering Group, including members of the former Working Party, has been convened to identify developments in the area, and to give advice to Council as to whether any further work in the area might be required. This advice will be considered by the Council in 2005 with a view to publishing a discussion paper.

Members of Steering Group

Professor Elisabeth Anionwu
Professor of Nursing, Head of Mary Seacole Centre for Nursing Practice, Thames Valley University, and member of the Human Genetics Commission and the Genetic Therapy Advisory Committee
Member of the Working Party on Genetic Screening

Professor Martin Bobrow
Head of Department of Medical Genetics, Cambridge Institute for Medical Research, and Deputy Chairman of the Nuffield Council until January 2003

Professor Neva Haites
Professor in Medical Genetics and Associate Dean (Clinical), University of Aberdeen; Member of the UK National Screening Committee and the HFEA; Vice-Chairman of British Society of Human Genetics

Professor Peter Harper
University Research Professor in Human Genetics, Cardiff University; Member of Nuffield Council on Bioethics and member of the Working Party on Genetic Screening; Member of the Human Genetics Commission until August 2004

David Shapiro
Executive Secretary of Nuffield Council on Bioethics at the time of the Working Party on Genetic Screening
Workshop on the ethics of research related to healthcare in developing countries

A Workshop on the ethics of research related to healthcare in developing countries was held in Cape Town from 12 - 14 February 2004, co-hosted by the Nuffield Council on Bioethics and the South Africa Medical Research Council.

The Workshop was designed to follow up the Council’s 2002 Report on The ethics of research related to healthcare in developing countries and to explore developments in the area since publication. The aim of the meeting was to discuss the practical implications of new and recently revised guidelines for externally-sponsored research relating to healthcare in developing countries. The Workshop provided an opportunity to exchange experiences, to consider how guidance is implemented in practice, and to discuss the difficulties that may be encountered when different guidelines provide conflicting advice.

Fifty-eight delegates from 28 countries attended the meeting, bringing together researchers, sponsors, and members of ethics committees from developed and developing countries. The mix of delegates, with diverse backgrounds and a wide range of experiences, facilitated very valuable discussion. A competition for funded places attracted a high level of interest, and more than 120 applications were received from 47 countries. The Steering Committee selected 20 participants from the competition and their full costs, including travel and accommodation, were covered.

A number of common themes emerged during the discussions. These included the need to develop innovative methods of community participation, the importance of encouraging the development of expertise, and the need to ensure long-term sustainability when planning any research. Delegates emphasised throughout the meeting that the complexity of issues meant that it is important to begin discussions in advance. There was also support for the development of partnerships between researchers, sponsors, local health authorities and communities.

The Workshop also provided the opportunity for a more wide-reaching discussion about the nature of the guidance relating to externally-sponsored research in developing countries. Most of the existing guidance (with the exception of the Council of Europe’s Additional Protocol to the Convention on Human Rights and Biomedicine concerning Biomedical Research) does not have the force of law. However it does have very real implications for policy and practice of healthcare research. The Declaration of Helsinki, for example, is widely regarded as the pre-eminent ethical guidance on healthcare research. Even though it is not a regulatory device, it is far more weight than a document which merely formulates aspirational ideals. Delegates concluded that those who develop guidance must be clearer both about how it is to be understood and how it is interpreted in practice.

These issues will be explored in more detail in a follow-up Paper which will be published in March 2005. The Paper, based on discussions during the Workshop, will provide a summary of the dialogue that took place and highlight a number of areas that deserve further consideration. An international panel of experts peer reviewed a draft in August.

The Workshop was funded by the UK Department for International Development (DFID), the Medical Research Council (MRC), the Wellcome Trust and the Rockefeller Foundation. The Steering Committee has provided advice on the aims and structure of the Workshop and resulting Discussion Paper.

Nuffield Council on Bioethics 2004

Members of the Steering Committee

Professor Zulfiqar Bhutta
Professor of Paediatrics, Aga Khan University, Pakistan

Professor Sir Kenneth Calman KCB FRSE
Vice-Chancellor and Warden, University of Durham, member of the Nuffield Council on Bioethics, and former Chairman of the Working Party on the ethics of research related to healthcare in developing countries

Dr Soledad Diaz
Consultorio De Plantification Familiar, Institute Chileno de Medicina Reproductiva, Santiago, Chile

Dr Imogen Evans
Research Strategy Manager, Medical Research Council, London

Dr Richard Lane
Former Head of International Programmes, The Wellcome Trust, London. Director of Science, the Natural History Museum

Dr Alwyn Mwinga
Medical epidemiologist with the CDC Global AIDS Program (GAP), Lusaka, Zambia

Professor Catherine Peckham CBE
Professor of Paediatric Epidemiology, Institute of Child Health, University College London, Deputy Chairman of the Nuffield Council on Bioethics, and former member of the Working Party on the ethics of research related to healthcare in developing countries

Professor Priscilla Reddy
Director of Health Promotion Research and Development, South African MRC

Professor Peter Smith CBE
Professor, Infectious Disease Epidemiology Unit, Department of Infectious Tropical Diseases, London School of Hygiene and Tropical Medicine, member of the Nuffield Council on Bioethics, and former member of the Working Party on the ethics of research related to healthcare in developing countries

Dr Bella Starling
Programme Officer, History of Medicine and Biomedical Ethics, The Wellcome Trust
The use of genetically modified crops in developing countries

The Council published a Discussion Paper on The use of GM crops in developing countries at the end of 2003, which concluded that the use of GM crops, in appropriate circumstances, can have considerable potential for improving agriculture and the livelihoods of poor farmers in developing countries. The Council took the view that there is an ethical obligation to explore the potential of GM crops responsibly, and recommended that research into GM crops should be directed towards the needs of small-scale farmers in developing countries.

The Paper received significant attention during 2004 and members of the Working Group and Secretariat undertook a number of initiatives to raise awareness of the recommendations. Several presentations were given about the Paper, and the Council also responded to articles about the topic in national newspapers during the year. More than 21,000 copies were downloaded from the website.

Reaction to the Discussion Paper

House of Lords, 4 February 2004 *
Baroness Amos: The Government welcome the report from the Nuffield Council on Bioethics on The use of GM crops in Developing Countries. The report offers a constructive contribution to the on-going debate on genetic modification technologies. The Government share the report’s conclusions that achieving food security and reducing poverty in developing countries are complex issues, that GM crops are unlikely to feed the world but that in some circumstances they could make a useful contribution to improving the livelihoods of poor people in developing countries.

* from Hansard

Presentations:

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<td>October</td>
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<tr>
<td>June</td>
<td>CropLife Annual conference, Brussels: Plant</td>
<td>The use of GM crops in developing countries</td>
<td>Harald Schmidt</td>
</tr>
<tr>
<td></td>
<td>Science and the World Food Agenda</td>
<td></td>
<td></td>
</tr>
<tr>
<td>April</td>
<td>BioVision Alexandria 2004</td>
<td>Poster presentation: The use of genetically</td>
<td>Harald Schmidt</td>
</tr>
<tr>
<td></td>
<td></td>
<td>modified crops in developing countries</td>
<td></td>
</tr>
<tr>
<td>February</td>
<td>XIIth Agirgrena Seminar, Paris</td>
<td>Bioethics of GMOs</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td></td>
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</tr>
</tbody>
</table>

In addition, the Council submitted responses to a number of consultations on the topic, including:

- Agriculture and Environment Biotechnology Commission (AEBIC), Consultation on Research Agendas in Agricultural Biotechnology
- DFID consultation on agricultural policy: Response sent both to DFID and the International Development Select Committee of the House of Commons (IDC), Professor Michael Lipton, a member of the Working Group, gave evidence to the IDC in May, and presented the Council’s position.
- The Science and Technology Committee of the House of Commons, Consultation on the use of science in UK international development policy, January 2004
- BBSRC, Consultation on future directions in crop science research, November 2003
- The Prime Minister’s Strategy Unit’s report, Field Work: weighing up the costs and benefits of GM crops, November 2003
The Council has continued to receive invitations to discuss the recommendationsof the Discussion Paper, The ethics ofpatenting DNA, both with industry groups and with patent offices. The Director, andmembers of the Round Table Group, visitedthe European Patent Office in the Springand the US Patent and Trademark Office inthe Autumn, for valuable discussions aboutissues raised in the Paper.

### Other follow-up activities

The Report, Pharmacogenetics: ethicalissues, was published in September 2003and the topic received continued attentionduring 2004. A reunion dinner was held inSeptember for members of the WorkingParty to discuss the impact of the Reportand consider whether there was a need forfollow-up. Members agreed that theSecretariat should monitor developmentsin the area, with particular focus onissues relating to the stratification ofpatient groups.

**Presentations:**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Title</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>November</td>
<td>Meeting co-sponsored by the Royal Society and the Bioethics Council, Auckland, New Zealand</td>
<td>Personalised medicine: the ethics of pharmacogenetics</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>November</td>
<td>Bioissues Forum, Ministry of Research Science and Technology, Wellington, New Zealand</td>
<td>Personalised medicine: the ethics of pharmacogenetics</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>October</td>
<td>OECD Steering Group Meeting on Pharmacogenetics, Paris, France</td>
<td>Ethical issues</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>October</td>
<td>Role of pharmacogenetics in rational development and personalization of drug treatments, Pisa, Italy</td>
<td>Ethical challenges of clinical pharmacogenetics</td>
<td>Professor Peter Lipton</td>
</tr>
<tr>
<td>September</td>
<td>University College London</td>
<td>The ethics of pharmacogenetics</td>
<td>Professor Peter Lipton</td>
</tr>
<tr>
<td>June</td>
<td>European Meeting on psychosocial aspects of genetics (EMFAG) held in conjunction with European Society of Human Genetics (ESHG), Munich</td>
<td>Pharmacogenetics: ethical issues</td>
<td>Dr Catherine Moody</td>
</tr>
<tr>
<td>May</td>
<td>Affymetrix Partners’ conference, Washington DC</td>
<td>Pharmacogenetics policy issues (key note speech)</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>February</td>
<td>IIR Biosciences, London pharmacogenomics and clinical R&amp;D</td>
<td>Regulatory and scientific perspectives in Pharmacogenomics</td>
<td>Professor Peter Lipton</td>
</tr>
</tbody>
</table>

The Council adopted a new approach forfollow-up activities during 2004. Following the launch of a publication, there will be three components tofollow-up. These will be:

- immediate dissemination - to ensure effective distribution and publicity over the initial year after publication;
- continuing follow-up - to monitor and facilitate uptake of recommendations, and to identify target audiences for strategic follow-up; and
- developed follow-up - when required, to advance the debate to the next stage, or to provide focus on a specific area where there has been major developments.

Expert advice on developments in the area of each publication will be provided by a sub-group from each Working Party.

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**Human Tissue legislation**

In 1995, the Council examined ethical and legal issues raised by the increasing medical and scientific uses of human tissue. The Report, Human Tissue: ethical and legal issues, discussed the removal, use, ownership, and protection of tissue. The Council concluded that there was an urgent need to clarify and strengthen the legal and ethical framework guiding clinical and research uses.

There has been wide debate about the uses of human tissue in the ten years since the report was published. In particular, the public has become increasingly concerned by two recent inquiries, at Bristol and Alder Hey, which have investigated the improper retention of organs. The practice of storing organs and tissue without the knowledge or consent of families, particularly from the deceased, has been widespread, and this has caused grief and distress to many.

In 2004 the Government published the Human Tissue Bill, providing new legislation to govern the storage and use of human organs and tissue. While the Council supported the principle of introducing new legislation there were concerns about ambiguities in the draft text, and the limitations to be placed on the use of surplus tissue. The Council wrote to MPs in February, calling for the new legislation to be clear and coherent. The Bill established consent as the fundamental principle guiding the lawful use of human tissue. While welcoming this emphasis, members were concerned that if the requirements for consent became too onerous or too bureaucratic, potentially valuable research might be inhibited.

The importance of respect for the human body and its parts is widely acknowledged: the Council fully endorses the view that human tissue should not be used at will or abused. However, human tissue serves many beneficial purposes: for use in diagnosis and therapy, medical research, and education and training and it is also important to realise the potential benefits for diagnosis and treatment while safeguarding those from whom tissue is removed.

For these reasons, the Council was among many organisations calling for clarification and revision of the draft Bill. The Government responded to these concerns and many of the issues were addressed in the final Human Tissue Act, published in November 2004.
The Council works to promote debate of the issues considered in its Reports and also liaises with other organisations, both in the UK and abroad, to increase awareness of the Council’s activities. A particular focus during 2004 was to expand the international profile of the Council. Visits were made to the US, Australia and New Zealand, and South Africa.

The website

The Council’s website is a core element of its dissemination strategy. More than 220,000 people visited the site during 2004, with an average of more than 600 visitors per day.

A new site was launched in 2004, upgraded to meet the requirements of disability legislation and with an improved design to facilitate easier navigation. An additional section with general information about bioethics and links to other sites has also been included to help respond to enquiries that the Council often receives.

Number of downloads of reports for 2004:

<table>
<thead>
<tr>
<th>Publication</th>
<th>Number of downloads</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic Screening: ethical issues</td>
<td>19,027</td>
</tr>
<tr>
<td>Human tissue: ethical and legal issues</td>
<td>17,248</td>
</tr>
<tr>
<td>Animal-to-human transplants: the ethics of xenotransplantation</td>
<td>12,595</td>
</tr>
<tr>
<td>Mental disorders and genetics: the ethical context</td>
<td>4,134</td>
</tr>
<tr>
<td>Genetically modified crops: the ethical and social issues</td>
<td>19,175</td>
</tr>
<tr>
<td>Stem cell therapy: the ethical issues</td>
<td>2,097</td>
</tr>
<tr>
<td>The ethics of research related to healthcare in developing countries</td>
<td>12,616</td>
</tr>
<tr>
<td>The ethics of patenting DNA</td>
<td>10,880</td>
</tr>
<tr>
<td>Genetics and human behaviour: the ethical context</td>
<td>15,655</td>
</tr>
<tr>
<td>Pharmacogenetics: ethical issues</td>
<td>5,313</td>
</tr>
<tr>
<td>The use of genetically modified crops in developing countries</td>
<td>2,1696</td>
</tr>
</tbody>
</table>
Promoting discussion

The Council continues to emphasise the importance of engaging with the public and is keen to ensure that its work reaches a wide audience. Shorter, more accessible ‘Guides’ are now produced to accompany all publications, while an Advisory Group on Reaching out to Young People provides guidance on targeting educational groups. Members of the Council and Secretariat gave more than thirty national and international presentations during 2004, and also gave several interviews to the media.

Highlights of presentations

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting and title</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>Wellcome Trust Workshop on Human Genome Tools for Clinical Malaria Research, Ghana.</td>
<td>Dr Sandy Thomas</td>
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<tr>
<td></td>
<td>Presentation: ‘Intellectual property and development’</td>
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<tr>
<td>February</td>
<td>CSIR, Pretoria. Presentation: ‘Intellectual property rights and global health’</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>March</td>
<td>Research Ethics Workshop. Mauritius Research Council, Mauritius. Presentations:</td>
<td>Dr Sandy Thomas</td>
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<tr>
<td></td>
<td>‘The ethics of research in developing countries’, ‘Stem Cells’, ‘Research involving animals’</td>
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<tr>
<td>April</td>
<td>Fifth Global Forum for Bioethics in Research. Sharing the benefits from research in developing countries: equity and intellectual property Paris, France Chair: Round Table on case studies</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>April</td>
<td>The Ethics of Intellectual Property Rights &amp; Patents Warsaw, Poland. Presentation: ‘The ethics of patenting DNA’</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>April</td>
<td>UNESCO Meeting Paris, France Towards an International Declaration on Bioethics</td>
<td>Harald Schmidt</td>
</tr>
<tr>
<td>May</td>
<td>National Institutes of Health, Maryland, US. Presentation: ‘The ethics of research related to healthcare in developing countries’</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>May</td>
<td>UCL Biology and Society course for undergraduates, London. Presentation: ‘Human genetics: ethical issues’</td>
<td>Nicola Perrin</td>
</tr>
<tr>
<td>June</td>
<td>Seminar by CSIRO, NARS, and the Academy of Medical Sciences. The ethical conduct of industry-sponsored clinical trials and the regulatory burden for UK academic researchers. Panel Discussion</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td>September</td>
<td>The Danish Council on Ethics Conference and workshop</td>
<td>Dr Sandy Thomas</td>
</tr>
<tr>
<td></td>
<td>Presentation: ‘The ethics of patenting human genes and stem cells Copenhagen, Denmark’</td>
<td>Professor Tom Baldwin</td>
</tr>
<tr>
<td>October</td>
<td>Centre du Recherche Public Santé Conference on ‘What makes Bioethics evolving?’</td>
<td>Dr Catherine Moody</td>
</tr>
<tr>
<td></td>
<td>Reflection on the future role of Bioethical Advisory Bodies’, Luxembourg Presentation: ‘The Nuffield Council on Bioethics role and function within the UK framework’</td>
<td></td>
</tr>
<tr>
<td>November</td>
<td>Fifth International Meeting of National Bioethics Advisory Bodies, Canberra, Australia. Presentation: ‘The ethics of patenting DNA’</td>
<td>Dr Sandy Thomas</td>
</tr>
</tbody>
</table>

These talks are in addition to presentations relating to recent publications which are listed elsewhere in the Annual Report.
external relations

National activities
In the UK, the Council maintains close contact with the Department of Health and the Human Genetics Commission, meeting annually to exchange information about current and future work. The Council also liaises with policy-makers, professional organisations, industry, research councils and consumer groups to discuss issues raised in its publications.

Consultations and evidence submitted:
The Council is regularly asked to respond to consultative documents produced by other organisations. In general, the Council responds to consultations which have particular relevance to its work. In 2004, responses were submitted to the following:

- World Medical Association: Comment on revision of paragraph 30 of Declaration of Helsinki
- Science and Technology Committee, House of Commons: The use of science in UK international development policy
- HM Treasury: Science and innovation working towards a ten-year investment framework
- International Bioethics Committee (IBC), UNESCO: Proposal for a Declaration on Universal Norms in Bioethics
- Medical Research Council (MRC): Draft Code of Practice for the Use of Human Stem Cell Lines
- Science and Technology Committee, House of Commons: Inquiry into Human Reproductive Technologies and the Law
- The Wellcome Trust: Consultation on Position statement on Wellcome Trust-funded research involving human participants in developing countries
- Royal Society Study on Pharmacogenetics.

International activities
The Director travelled to the US on several occasions, and met representatives of the Institute of Medicine in Washington, the National Institutes of Health, the Rockefeller Foundation, and the US Patent and Trademark Office. The Director and Assistant Director also gave presentations about the use of GM crops in developing countries at Georgetown University and the National Academies Workshop on ‘Global challenges for guiding and managing biotechnologies.’

The Fifth International Meeting of National Bioethics Advisory Bodies was held in Canberra, in November, 2004. This provided the opportunity for the Director to undertake a short lecture tour in Australia and New Zealand to raise the profile of the Council. In New Zealand, she visited Christchurch, Auckland and Wellington, attending a range of meetings:

- Meeting co-sponsored by the Royal Society and the Bioethics Council, Auckland
  Presentation: ‘Personalised medicine: the ethics of pharmacogenetics’
- Bioissues Forum, Ministry of Research Science and Technology, Wellington
  Presentation: ‘Personalised medicine: the ethics of pharmacogenetics’

In Australia, meetings took place in Canberra, Brisbane and Sydney:
- Fifth International Meeting of National Bioethics Advisory Bodies, Canberra
  Presentation: The ethics of patenting DNA
- Meeting with Dr Sue Meek, Gene Technology Regulator, Canberra
- Seminar at Commonwealth Scientific and Industrial Research Organisation (CSIRO), Canberra
  Presentation: The use of GM crops in developing countries
- Meeting with industry and government participants, CSIRO, Canberra
- AusBiotech 2004, Brisbane
  Presentation: GM crops in the developing world: regulation and trade
- 7th World Congress of Bioethics, Sydney

Members of the Council participated in a wide range of international meetings during 2004 and received a number of international visitors in London. Several of the Council’s recent publications are particularly relevant to global issues and therefore emphasis was placed on increasing awareness of the Council’s work overseas.

Other international meetings attended by the Director:
- Informal Roundtable, DFID: Accelerating Research and Development for diseases of poverty: Strategies to enhance knowledge sharing and information access
- MIHR: Using Intellectual Property Management for Improved Health in Developing Countries: An Evidence-based Approach to Good Practice, Bellagio, Italy
- NAS Workshop on ‘Intellectual Property Rights in Genomic and Protein-related Inventions’, Bellagio
The Council has also participated in a range of activities with other ethics bodies abroad during 2004, including:

International Bioethics Committee / UNESCO
The International Bioethics Committee (IBC) of UNESCO initiated work to draft a Declaration on Universal Norms in Bioethics in 2004. The Council was invited to comment on the first outline of this Declaration and Harald Schmidt (Assistant Director) presented its views at a meeting held in Paris in April 2004. The Council also worked closely with the Department of Health and other relevant UK bodies to contribute to the ensuing discussion, and further comments were submitted to three subsequent meetings during the year. The Council’s submissions highlighted the importance of clarifying the relationship of the Declaration to other guidelines such as the Declaration of Helsinki, in order to be clear about the characterisation of ethical principles such as consent. Other points were made about the relationship between the proposed different Fundamental Principles, the proposed norms of the Declaration and the relationship between the Declaration and the law in individual states.

The EC Forum of National Ethics Committees
A Forum of National Ethics Committees was established in 2002, intended as an independent platform for discussion of ethical issues of common European interest and for the exchange of experiences on methodological issues and best practice in relation to the operation of national ethics committees. The Forum has a complementary role to play in supporting the activities of the European Group on Ethics in Science and New Technologies (EGE), which provides advice to the European Commission. Members of the EGE, as well as of the European Conference of National Ethics Committees (COMETH) take part in the Forum’s meetings.

The Fourth European Forum was held in Amsterdam in December 2004 and was attended by more than 60 delegates. Harald Schmidt [Assistant Director] represented the Council.

International Meeting of National Advisory Bodies
Delegates from National Bioethics Commissions and Advisory Bodies meet together every two years to facilitate international dialogue in bioethics. These meetings provide an opportunity to share information and plans, and to compare perspectives on issues of common interest. The Fifth meeting was held in Canberra in November 2004, organised by the Australian Health Ethics Committee. The Council, having previously hosted the Meeting in London in 2000, served on the Steering Committee, together with the National Bioethics Commission of Brazil.

Bilateral meetings with the Nationaler Ethikrat and CCNE
The Council welcomed members of the German National Bioethics Council, the Nationaler Ethikrat, to London in July for the first of a series of annual bi-lateral meetings. Discussion during the day covered reproductive and therapeutic cloning, the ethics of public health and the use of genetic testing in employment. A second bi-lateral meeting with the French Comité Consultatif National d’Ethique will be hosted in London in February 2005. These meetings provide an excellent opportunity for members of the different bodies to discuss ethical issues of common interest and compare different perspectives.
Financial Report for year to 31 December 2004

Expenditure

<table>
<thead>
<tr>
<th></th>
<th>2004 Actual</th>
<th>2003 Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salaries and staffing costs</td>
<td>318,101</td>
<td>273,226</td>
</tr>
<tr>
<td>Office costs including premises</td>
<td>8,923</td>
<td>7,595</td>
</tr>
<tr>
<td>Stationery and press cuttings</td>
<td>12,220</td>
<td>10,798</td>
</tr>
<tr>
<td>Photocopy, post, phone, fax</td>
<td>20,375</td>
<td>28,565</td>
</tr>
<tr>
<td>Committee and meeting costs</td>
<td>117,374</td>
<td>42,023</td>
</tr>
<tr>
<td>Printing of reports</td>
<td>19,577</td>
<td>23,091</td>
</tr>
<tr>
<td>(Loss) reports sold</td>
<td>(1,894)</td>
<td>(2,396)</td>
</tr>
<tr>
<td>Publicity of reports</td>
<td>500</td>
<td>5,464</td>
</tr>
<tr>
<td>Equipment (IT developments)</td>
<td>10,003</td>
<td>3,635</td>
</tr>
<tr>
<td><strong>Net direct expenditure</strong></td>
<td><strong>505,179</strong></td>
<td><strong>392,000</strong></td>
</tr>
</tbody>
</table>

Funding Due

- Nuffield Foundation: 160,364
- Medical Research Council: 160,364
- Wellcome Trust: 160,364
- Other income: 92,876

**Total Funding Due**: 573,968

Surplus/ (Deficit)

- 2004: 68,789
- 2003: 89,092

Balance Brought Forward

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>89,643</td>
<td>551</td>
</tr>
<tr>
<td>2003</td>
<td>158,432</td>
<td>89,643</td>
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</tbody>
</table>

Overheads met by Nuffield Foundation

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2003</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>207,056</td>
<td>176,441</td>
</tr>
</tbody>
</table>

Annex B: Publications

- Genetic screening: ethical issues
  - Published December 1993
- Human tissue: ethical and legal issues
  - Published April 1995
- Animal-to-human transplants: the ethics of xenotransplantation
  - Published March 1996
- Mental disorders and genetics: the ethical context
  - Published September 1998
- Genetically modified crops: the ethical and social issues
  - Published May 1999
- The ethics of clinical research in developing countries: a discussion paper
  - Published October 1999
- Stem cell therapy: the ethical issues – a discussion paper
  - Published April 2000
- The ethics of research related to healthcare in developing countries
  - Published April 2002
- The ethics of patenting DNA: a discussion paper
  - Published July 2002
- Genetics and human behaviour: the ethical context
  - Published October 2002
- Pharmacogenetics: ethical issues
  - Published September 2003
- The use of genetically modified crops in developing countries: a follow-up Discussion Paper
  - Published December 2003

A CD-ROM containing the reports published before 2003 is also available.

All of these publications are available to download from the Council’s website at: www.nuffieldbioethics.org

Printed copies may be ordered by contacting:
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28 Bedford Square
London WC1B 3J
Telephone: 020 7681 9619
Fax: 020 7637 1712
e-mail: bioethics@nuffieldbioethics.org

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