



Nuffield Council on Bioethics  
Annual Report 2004

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COUNCIL ON  
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## Foreword

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.

A handwritten signature in blue ink that reads "Bob Hepple". The signature is written in a cursive, slightly slanted style.

Professor Sir Bob Hepple QC, FBA

## 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](http://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 Peckham 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 Mr Nick Ross**  
Broadcaster

**n Professor Herbert Sewell**  
Pro-Vice Chancellor and Professor of Immunology, University of Nottingham

**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

\*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 focussed 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 freely contribute 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).





## Forward Look meeting

### The Way We Reason: deliberation, consultation and policy in bioethics.

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.

The Forward Look meeting provided the opportunity for members to consider the nature of policy-making and different ways to engage the political process. As several speakers indicated during the day, policy is rarely formulated according to a simple sequential model of decision-making. The Government's Chief Scientific Adviser, Professor Sir David King, discussed the challenges posed for government, the scientific community and society by the need for continued scientific input into policy, and Lord Wilson of Dinton considered the most effective ways to interact with the Government.

#### 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 are the differences between consulting with the public and researching lay beliefs?
- 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.



## Personnel

Professor Albert Weale, a member of the Council since October 1998, retired in March 2004. Professor Weale chaired the Working Party on Xenotransplantation, and also served as a member of the Working Parties on pharmacogenetics and the use of genetically modified crops in developing countries.

Professor Roger Brownsword and Lord Plant of Highfield joined the Council as members during the year, and Professor Margaret Brazier became a co-opted member for the period of chairing the Working Party on the ethics of prolonging life in fetuses and the newborn. A new process for appointing Council members is in preparation.

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 Dr Catherine Moody took up the new post of Deputy Director in February. Nicola Perrin, Public Liaison Manager, left the Secretariat in September and the position will be filled in 2005. The Secretariat was assisted in the preparation of the paper on Genetic Screening by an intern, Tom McBride and Kevin Smith helped to prepare additional information for the website.

## 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.

Producing a Report typically takes around two years, during which time the Working Party will hold approximately ten meetings

to examine issues, consider and develop arguments, and draft the Report. A number of fact-finding meetings are arranged on specialist topics, and the Working Party may also choose to commission research in specialist areas to assist discussion. Each Working Party will also consult a range of organisations and individuals with interests and expertise in the area. Typically more than 100 responses are received to a consultation exercise, and the results have proved to be very helpful in representing a wide range of views.

Working Parties draft Reports in consultation with the Council. The Council reviews drafts of each Report before it is submitted for peer review and then approves the final Report prior to publication. Independent external experts, chosen by the Working Party and members of Council, carry out the peer review. These experts are selected to represent a spectrum of expertise and they are asked to provide detailed, constructive criticism which is considered by the Working Party and by the Council. After final approval, the Report formally becomes a Report of the Council.

# work in progress



The ethics of research involving animals





## Membership of the Working Party

**Baroness Perry of Southwark (Chairman)**  
Member of the House of Lords and Pro-Chancellor of the University of Surrey

**Professor Kenneth Boyd**  
Professor of Medical Ethics, University of Edinburgh

**Professor Allan Bradley FRS**  
Director, The Wellcome Trust Sanger Centre, Cambridge

**Professor Steve Brown**  
Director, MRC Mammalian Genetics Unit, MRC Mouse Genome Centre, Medical Research Council, Harwell

**Professor Grahame Bulfield CBE**  
former Director of the Roslin Institute, currently Vice-Principal and Head of College of Science and Engineering, University of Edinburgh

**Professor Robert Combes**  
Scientific Director, Fund for the Replacement of Animals in Medical Experiments

**Dr Maggy Jennings**  
Head of Research Animals Department, Royal Society for the Prevention of Cruelty to Animals

**Professor Barry Keverne FRS**  
Director of sub-department of Animal Behaviour, Department of Zoology, University of Cambridge

**Dr Mark Matfield**  
Executive Director, The Research Defence Society

**Dr Judy MacArthur Clark CBE**  
Chair, Farm Animal Welfare Council

**Professor Ian McConnell**  
Professor of Veterinary Science, Centre for Veterinary Science, Department of Clinical Veterinary Medicine, University of Cambridge

**Dr Timothy Morris**  
Head of Comparative Medicine and Investigator Support, Laboratory Animal Science (LAS) UK, GlaxoSmithKline

**Professor Martin Raff FRS**  
MRC Laboratory for Molecular Cell Biology, University College London and member of the Nuffield Council

**Mr Nick Ross**  
Broadcaster and member of the Nuffield Council

**Dr Lewis Smith**  
Syngenta CTL

**Professor John Spencer**  
Professor of Law, Selwyn College, University of Cambridge

**Ms Michelle Thew**  
Chief Executive Officer, Animal Protection Institute, Sacramento, USA

**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 Working Party met six times during 2004 and the minutes of all meetings are available on the Council's website. The group has also held three fact-finding meetings, and considered three evidence reviews which were commissioned on issues relating to the assessment of pain and suffering in animals. A consultation exercise was conducted at the end of 2003. More than 160 responses from individuals and organisations with a wide range of expertise were discussed by the Working Party. In August, the draft Report was sent to ten peer reviewers, and a number of revisions were made in light of the valuable contributions which were received. The Working Party would like to

thank all the individuals who contributed in various ways to its work in 2004.

The Report will consider from first principles the arguments in support of, and against, research involving animals, defining the principal ethical questions and identifying and understanding areas of agreement and disagreement. It is intended to help readers to reach an informed opinion about whether or not different types of research in animals can be justified. The Council hopes that the Report will serve as a basis upon which individuals or organisations could engage in further debate. The Report is expected to be published in May 2005.

## 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, ASPD, 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), Medical Director, Europeans For Medical Advancement (EFMA)
- Kathy Archibald, Director, EFMA
- Institute of Neurology, London

## Terms of Reference

- 1 To review recent, current and prospective developments in the scientific use of non-human animals, including genetic modification or cloning;
- 2 To assess the ethical implications of these developments, and, in doing so, to consider arguments about the differing status of various non-human animals and the implications of such arguments on their use in research;
- 3 To examine ways of assessing the costs and benefits of the scientific use of non-human animals;
- 4 To assess ways of regulating and enhancing good practice;
- 5 To assess the ethical implications of using alternatives to animals in different fields of research;
- 6 To identify and review developments and differences internationally in the use of animals in research and its regulation;
- 7 To explore ways of stimulating public debate and providing information and education about the issues involved.



# 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, Furness 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 Haines**  
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 Peckham 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;
  - b. 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.

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.



Media coverage:

If parents and doctors disagree about how to treat (or withhold treatment from) a newborn child who was born extremely prematurely or has a serious illness or abnormalities, the courts can be asked to give a ruling about what treatment can or cannot be given. These applications are mostly dealt with in private by the family courts. However, the announcement of the Working Party in September coincided with open court hearings of two high profile cases, those of the infants Charlotte Wyatt and Luke Winston-Jones, which received significant publicity. The Chair, Professor Brazier and other members of the Working Party contributed to media interviews and articles.

Date	Media	Headline
3 October	The Times	Trial to trigger new law on early babies
6 October	Evening Standard	Is it cruel to keep this baby alive?
6 October	BBC Radio 4	The Moral Maze (Participation by Professor Margaret Brazier)
8 October	Evening Standard	Experts divided over Charlotte ruling
8 October	The Daily Telegraph	Doctors' dilemma: should they prolong a life just because they can?
9 October	The Independent	Ethics review set up after ruling on Wyatt baby
13 October	BBC News 24	Interview with Working Party member, Professor Neil Marlow
23 October	The Lancet	Editorial on the Wyatt and Winston-Jones cases
11 November	Hospital Doctor	Right-to-die disputes (Article by Professor Margaret Brazier)
December	Journal of Medical Ethics	Letting Charlotte die (Article by Professor Margaret Brazier)





## 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.

**Public health:** the science and art of preventing disease, prolonging life and promoting health through the organised efforts of society.  
*The Acheson report (1998)*

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 as 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.

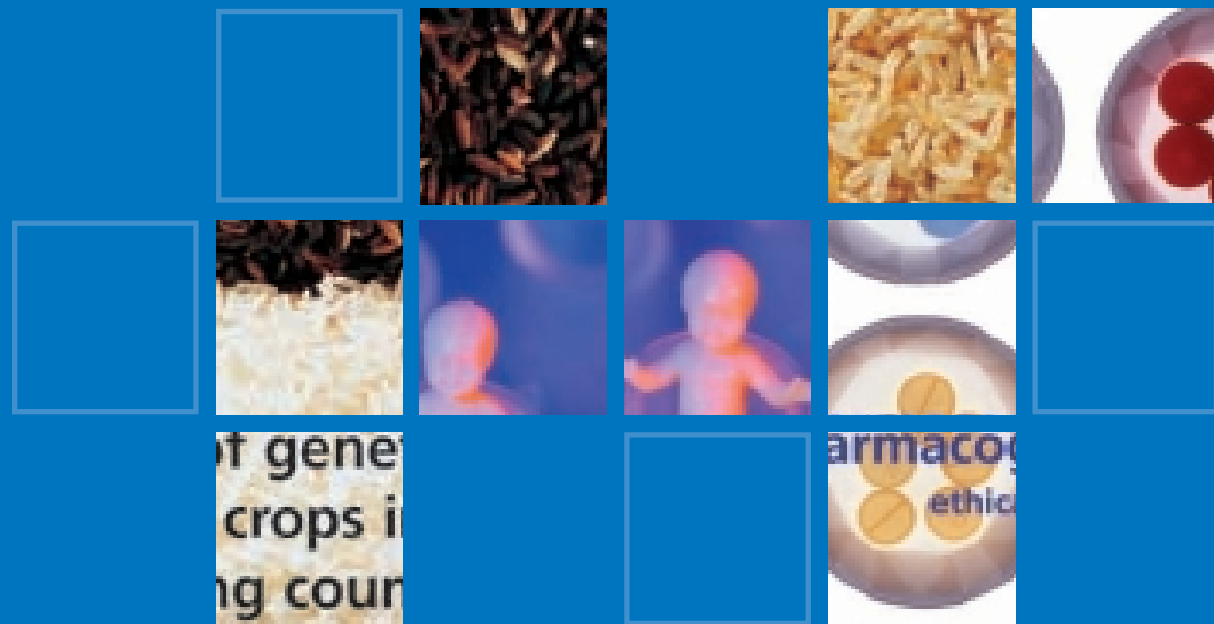
Discussion focused on identifying the broad themes for ethical debate. The concept of an individual's 'right to choose' would need exploration and a distinction made between choices that affected only the individual, as opposed to choices that affected the whole community. 'Choice' meant different things 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.

# follow-up work



Assessing the impact of a Report and its recommendations is essential, if the Council is to monitor its effectiveness. Steps may be taken to draw attention to important areas or to advance the debate if new issues have emerged. Follow-up activities represented an important part of the Council's work during the past year.

## Genetic Screening

**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

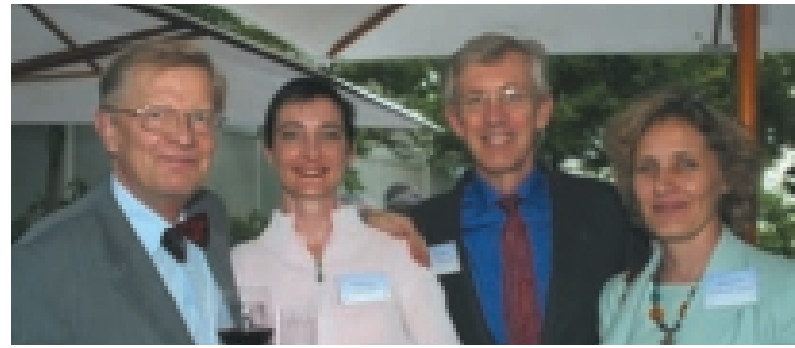
**Professor Elizabeth Anionwu**  
Professor of Nursing, Head of Mary Seacole Centre for Nursing Practice, Thames Valley University, and member of the Human Genetics Commission and the Genetic Therapy Advisory Committee  
Member of the Working Party on Genetic Screening

**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

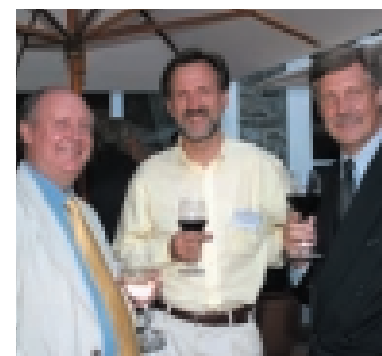
to discuss the difficulties that may be encountered when different guidelines provide conflicting advice.

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 has 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 and the Council is grateful to them for their generous support. An international Steering Committee has provided advice on the aims and structure of the Workshop and resulting Discussion Paper.

## 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 Plantificacion 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

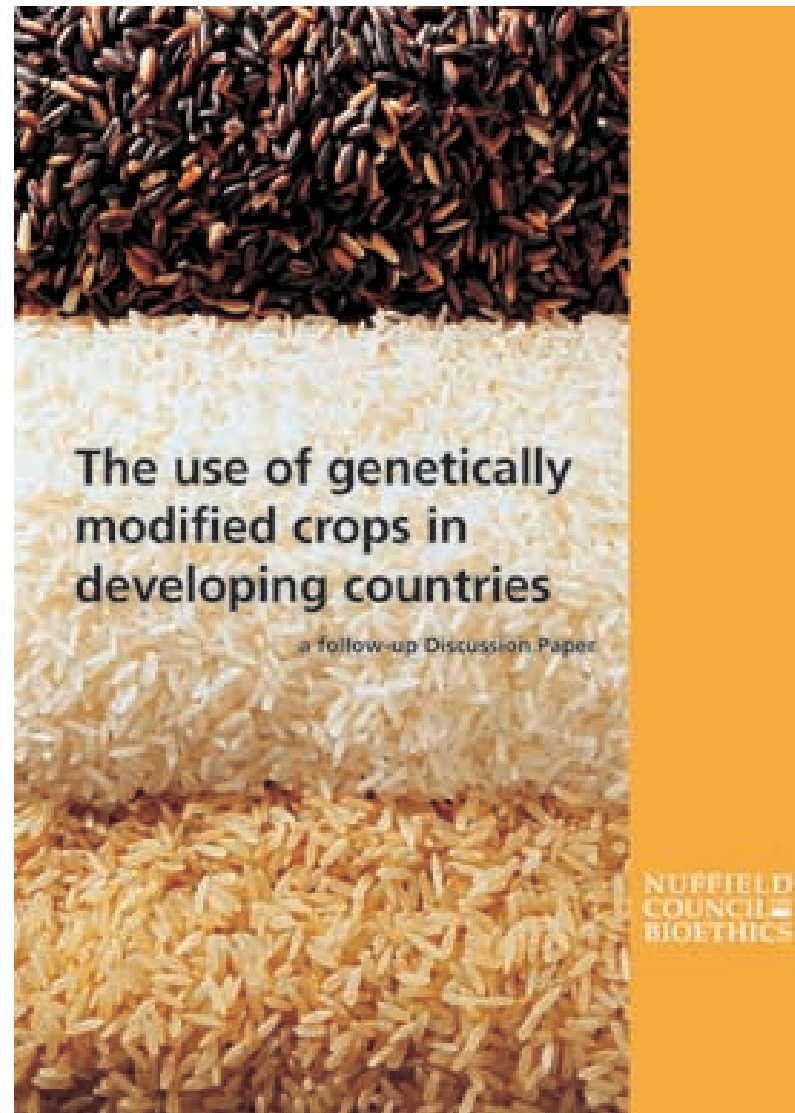
**Dr Bella Starling**  
Programme Officer, History of Medicine and Biomedical Ethics, The Wellcome Trust



## 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 livelihood 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:

Date	Meeting	Title	Speaker
December	Student Conference, Friends House, London	The ethics of genetically modified crops	Dr Sandy Thomas
November	AusBiotech 2004, Brisbane, Australia	GM crops in the developing world: regulation and traderegulation and trade	Dr Sandy Thomas
October	Georgetown University, Washington DC, USA	The use of genetically modified crops in developing countries	Dr Sandy Thomas
October	US National Academies Workshop on Global Challenges for Guiding and Managing Biotechnologies	GM technologies in Developing Countries: ways of improving participation and democratization	Harald Schmidt
October	Syngenta, Basle, Switzerland	GM crops in developing countries –Where next?	Harald Schmidt
September	St Edward's School, Oxford	What are GM crops and are they of use to people indeveloping countries?	Harald Schmidt
June	Croplife Annual conference, Brussels: Plant Science and the World Food Agenda	The use of GM crops in developing countries	Harald Schmidt
April	BioVision Alexandria 2004 New Life Sciences: Ethics, Patenting and the Poor Alexandria, Egypt	Poster presentation: The use of genetically modified crops in developing countries	Harald Schmidt
February	XIIth Agrogene Seminar, Paris: GMOs after the moratorium	Bioethics of GMOs	Dr Sandy Thomas

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

- Agriculture and Environment Biotechnology Commission (AEB), 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

## 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.

## Other follow-up activities

The Report, **Pharmacogenetics: ethical issues**, was published in September 2003 and the topic received continued attention during 2004. A reunion dinner was held in September for members of the Working Party to discuss the impact of the Report and consider whether there was a need for follow-up. Members agreed that the Secretariat should monitor developments in the area, with particular focus on issues relating to the stratification of patient groups.



## Presentations:

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

The Council has continued to receive invitations to discuss the recommendations of the Discussion Paper, **The ethics of patenting DNA**, both with industry groups and with patent offices. The Director, and members of the Round Table Group, visited the European Patent Office in the Spring and the US Patent and Trademark Office in the Autumn, for valuable discussions about issues raised in the Paper.



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

- 9 immediate dissemination - to ensure effective distribution and publicity over the initial year after publication;
- 9 continuing follow-up - to monitor and facilitate uptake of recommendations, and to identify target audiences for strategic follow-up; and,
- 9 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.

# external activities

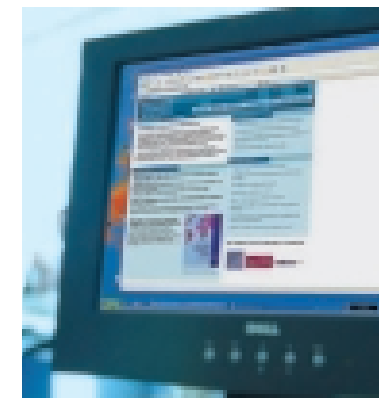


The Council works to promote debate of the issues considered in its Reports and also liaises with other organisations, both in the UK and abroad, to increase awareness of the Council's activities. A particular focus during 2004 was to expand the international profile of the Council. Visits were made 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:

Publication	Number of downloads
Genetic Screening: ethical issues	19,027
Human tissue: ethical and legal issues	17,248
Animal-to-human transplants: the ethics of xenotransplantation	12,595
Mental disorders and genetics: the ethical context	4,134
Genetically modified crops: the ethical and social issues	19,175
Stem cell therapy: the ethical issues	2,097
The ethics of research related to healthcare in developing countries	12,616
The ethics of patenting DNA	10,880
Genetics and human behaviour: the ethical context	15,655
Pharmacogenetics: ethical issues	5,313
The use of genetically modified crops in developing countries	21,696

### 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 media activities

Date	Interview by	Subject	Interviewee
January	Journal of Commercial Biotechnology	GM crops Discussion Paper	Dr Sandy Thomas
February	Nano (German Science television programme)	GM crops Discussion Paper	Professor Derek Burke and Harald Schmidt
February	KFM Radio Cape Town, South Africa	Cape Town workshop	Professor Sir Ken Calman
February	Cape Times, South Africa	Cape Town workshop	Harald Schmidt
March	The Scotsman	Government announcement about GM crops	Dr Sandy Thomas
March	Today, BBC Radio 4	Should we be able to patent plants?	Dr Sandy Thomas
May	BBC Radio Ulster	Stem Cell bank	Dr Sandy Thomas
May	BBC World Service World News	Stem Cell bank	Harald Schmidt
June	You and Yours, BBC Radio 4	GM Crops - biopharmaceuticals	Dr Sandy Thomas
October	Nano (German Science television programme)	Stem Cells	Professor Tom Baldwin
November	The Christchurch Press	Bioethics	Dr Sandy Thomas
November	The New Zealand Herald	Bioethics	Dr Sandy Thomas
November	New Zealand Press Association	Bioethics	Dr Sandy Thomas
November	The Dominion Post	Bioethics	Dr Sandy Thomas

### Highlights of presentations

Date	Meeting and title	Speaker
January	Wellcome Trust Workshop on Human Genome Tools for Clinical Malaria Research, Ghana. Presentation: 'Intellectual property and development'	Dr Sandy Thomas
February	CSIR, Pretoria. Presentation: 'Intellectual property rights and global health'	Dr Sandy Thomas
March	Research Ethics Workshop. Mauritius Research Council, Mauritius. Presentations: 'The ethics of research in developing countries', 'Stem Cells', 'Research involving animals'	Dr Sandy Thomas
April	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	Dr Sandy Thomas
April	The Ethics of Intellectual Property Rights & Patents Warsaw, Poland Presentation: The ethics of patenting DNA	Dr Sandy Thomas
April	Institute of Biology, London Science Policy Review 2001-2004, Presentation: The post-genome challenge	Dr Sandy Thomas
April	UNESCO Meeting Paris, France Towards an International Declaration on Bioethics	Harald Schmidt
May	National Institutes of Health Maryland, US Presentation: The ethics of research related to healthcare in developing countries	Dr Sandy Thomas
May	UCL Biology and Society course for undergraduates, London Presentation: Human genetics: ethical issues	Nicola Perrin
June	Seminar by GSK R&D, NHS R&D and the Academy of Medical Sciences: The ethical conduct of industry-sponsored clinical trials and the regulatory burden for UK academic researchers. Panel Discussion	Dr Sandy Thomas
September	The Danish Council on Ethics Conference and workshop Presentation: The ethics of patenting human genes and stem cells Copenhagen, Denmark	Dr Sandy Thomas Professor Tom Baldwin
October	Centre du Recherche Public Santé Conference on 'What makes Bioethics evolving? Reflection on the future role of Bioethical Advisory Bodies', Luxembourg Presentation: The Nuffield Council on Bioethics: role and function within the UK framework	Dr Catherine Moody
November	Fifth International Meeting of National Bioethics Advisory Bodies, Canberra, Australia Presentation: The ethics of patenting DNA	Dr Sandy Thomas

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.



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.

## 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

The Director also held a number of interviews with the press during her visit.

### 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
- Workshop on 'Health Biotechnology and Intellectual Property: a new framework', European University Institute, Florence.
- 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 that 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.



## Annex A: Finances

## Financial Report for year to 31 December 2004

	2004 Actual £	2003 Actual £
<b>Expenditure</b>		
Salaries and staffing costs	318,101	273,226
Office costs including premises	8,923	7,595
Stationery and press cuttings	12,220	10,798
Photocopy, post, phone, fax	20,375	28,565
Committee and meeting costs	117,374	42,023
Printing of reports	19,577	23,091
(Less) reports sold	(1,894)	(2,396)
Publicity of reports	500	5,464
Equipment (IT developments)	10,003	3,635
<b>Net direct expenditure</b>	<b>505,179</b>	<b>392,000</b>
<b>Funding Due</b>		
Nuffield Foundation	160,364	160,364
Medical Research Council	160,364	160,364
Wellcome Trust	160,364	160,364
Other income	92,876	-
	<b>573,968</b>	<b>481,092</b>
Surplus/ (Deficit)	68,789	89,092
Balance Brought Forward	89,643	551
Balance Carried Forward	158,432	89,643
Overheads met by Nuffield Foundation	201,056	176,441

## 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](http://www.nuffieldbioethics.org)

Printed copies may be ordered by contacting:  
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