

# Nuffield Council on Bioethics Annual Report 2003



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# Foreword

I entered the world of bioethics only in 2000, when I became a member of the Council as Chair of the Working Group on *Genetics and human behaviour: the ethical context* whose Report was published in October 2002. I was deeply impressed by the commitment of Council members and members of Working Parties, who give their time voluntarily, and by the professionalism and dedication of the secretariat. I therefore felt honoured to be asked to succeed Sir Ian Kennedy from 1 January 2003. He has made an enormous contribution to the seriousness with which bioethics is now taken nationally and internationally.



The two defining characteristics of the Council which I inherited are *independence* and *quality*. Unlike national bioethics commissions in other countries we are neither appointed nor funded by government. National commissions tend to be heavily politicised, particularly where they include a variety of interest groups. They are clearly useful to governments when there is a need to advise on short-term issues of relatively narrow scope. Our role is to undertake longer term, in-depth work on complex topics which are still on the horizon. We do so free from external pressures. We attach the highest importance to the quality of our reports. This is ensured by a range of procedures, such as peer review and consultation with external experts. I believe that the 12 Reports and Discussion Papers produced since 1991 are robust and have withstood close scrutiny, influencing developments not only in the UK but also internationally.

The work produced in 2003 is no exception to this. The Council published an important Report, produced by a group under the chairmanship of Professor Peter Lipton, on *Pharmacogenetics: ethical issues*, laying solid foundations for future discussion of the ethical implications of medicines which take account

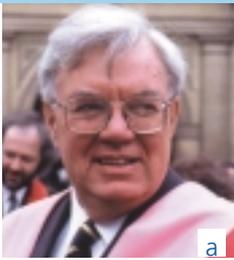
of the patient's genetic make-up. We have not avoided controversial subjects. Our follow-up in 2003 to the 1999 Report on *Genetically modified crops: ethical and social issues*, on the specific topic of *The use of genetically modified crops in developing countries*, provided a balanced and carefully researched discussion of the potential of these crops for improving agriculture and alleviating poverty in those countries. We established a Working Party, under the steady hands of Baroness Perry of Southwark, on The ethics of research involving animals, and its Report is expected to be published in early 2005. Following a successful Workshop in 2003 on the ethical issues raised by prolonging human life, the Council has, in 2004, established a Working Party on prolonging life in fetuses and the newborn.

I express my thanks to all those who contributed to our work in the year under review.

A handwritten signature in blue ink that reads "Bob Hepple". The signature is written in a cursive style with a horizontal line at the end.

**Professor Sir Bob Hepple QC, FBA**

# Members of Council\*



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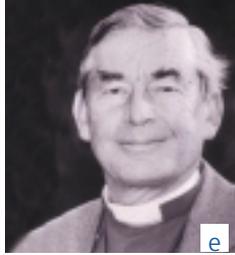
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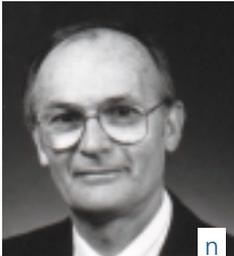
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o

- (a) **Professor Sir Bob Hepple QC, FBA (Chairman)**  
Emeritus Master, Clare College, and Emeritus Professor of Law,  
University of Cambridge
- (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 Sir Kenneth Calman KCB FRSE**  
Vice-Chancellor and Warden, University of Durham
- (e) **The Rt Rev Richard Harries DD FKC FRSL**  
Bishop of Oxford
- (f) **Professor Peter Lipton**  
Head of the Department of History and Philosophy of Science,  
University of Cambridge
- (g) **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)
- (h) **Professor Martin Raff FRS**  
Professor of Biology (Emeritus), University College London
- (i) **Mr Nick Ross**  
Broadcaster
- (j) **Professor Herbert Sewell**  
Professor of Immunology, University of Nottingham
- (k) **Professor Peter Smith CBE**  
Professor of Tropical Epidemiology, Department of Infectious and  
Tropical Diseases, London School of Hygiene and Tropical Medicine
- (l) **Professor Dame Marilyn Strathern DBE, FBA**  
Mistress of Girton College, Cambridge and William Wyse Professor  
of Social Anthropology, University of Cambridge
- (m) **Professor Albert Weale FBA**  
Professor of Government, University of Essex
- (n) **Dr Alan Williamson FRSE**  
Consultant on Biotechnology
- (o) **Professor Andrew Wilkie (May - September 2003)**  
Professor of Genetics, Weatherall Institute of Molecular Medicine,  
John Radcliffe Hospital, University of Oxford and Senior Research  
Fellow in Clinical Science, The Wellcome Trust

\* Positions correct as of 1 April 2004

# Introduction

The Nuffield Council on Bioethics examines ethical issues raised by new developments in biology and medicine. Now in its twelfth year, the Council has achieved an international reputation for addressing public concerns, and providing independent advice to assist policy makers and stimulate debate in bioethics.

The Council was established by the Trustees of the Nuffield Foundation in 1991. Since 1994, the Council has been funded jointly by the Nuffield Foundation, the Medical Research Council and the Wellcome Trust.

## 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.

## Secretariat

<b>Dr Sandy Thomas</b>	Director
<b>Ms Tor Lezemore</b>	Assistant Director (until August 2003)
<b>Mr Harald Schmidt</b>	Assistant Director
<b>Mrs Julia Fox</b>	PA to the Secretariat
<b>Ms Nicola Perrin</b>	Public Liaison Officer
<b>Ms Natalie Bartle</b>	Research Officer (until July 2003)
<b>Ms Caroline Rogers</b>	Research Officer (from August 2003)
<b>Ms Elaine Talaat-Abdalla</b>	Secretary
<b>Ms Maria Gonzalez-Nogal</b>	Information Assistant (until September 2003)

*Details of the Council's method of working, including more information about Working Parties and publications can be found on the Council's website: [www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)*

# 2003 Calendar



January	1st Council meeting 2nd meeting of the Steering Committee for Developing countries follow-up
February	1st meeting of Working Party on Research involving animals 2nd meeting of Working Group on The use of GM crops in developing countries including fact-finding meeting 3rd meeting of Working Party on Pharmacogenetics
March	2nd Council Meeting 3rd meeting of Working Group on The use of GM crops in developing countries including fact-finding meeting 3rd meeting of the Steering Committee for Developing countries follow-up
April	4th meeting of Working Party on Pharmacogenetics 4th and 5th meetings of Working Group on The use of GM crops in developing countries including fact-finding meeting
May	5th meeting of Working Party on Pharmacogenetics 2nd meeting of Working Party on Research involving animals 6th meeting of Working Group on The use of GM crops in developing countries including fact-finding meeting Council Forward Look Meeting
June	Publication of draft Discussion Paper, The use of genetically modified crops in developing countries, for comment 6th meeting of Working Party on Pharmacogenetics 3rd Council Meeting
July	3rd Meeting of Working Party on Research involving animals 1st meeting of Advisory Group on Reaching out to Young People
August	7th meeting of Working Group on The use of GM crops in developing countries Call for participation for Workshop on The ethics of research related to healthcare in developing countries
September	Launch: Pharmacogenetics: ethical issues 4th meeting of Working Party on Research involving animals 4th and 5th meetings of the Steering Committee for Developing countries follow-up
October	Launch of consultation on Research involving animals 4th Council Meeting 5th meeting of the Steering Committee for Developing countries follow-up
November	Bi-lateral meeting with CCNE, Paris
December	Launch: The use of genetically modified crops in developing countries

## Report by the Director

2003 was a very challenging year for the Council. Already committed to a full work programme with the ethics of research involving animals, and pharmacogenetics, another topic was added late in 2002. ***The use of genetically modified crops in developing countries*** was undertaken as a follow up to the Council's 1999 Report to contribute to the national debate on the introduction of GM crops. Originally envisaged as a short Paper, the complexity of the issues necessitated its expansion to the length of a Report. Thus 2003 demanded exceptional effort from the Council, its staff and the many individuals who formed its working groups.



Research involving animals is one of the most controversial aspects of scientific work. The UK in particular has experienced marked opposition to this activity. Although much attention has already been given to the subject, the Council felt that further critical analysis of the ethical issues would be valuable. A new Working Party met five times in 2003, undertook consultation with the public and held fact finding meetings with a wide range of persons.

The issues addressed by the Working Party on ***Pharmacogenetics: ethical issues*** were much more straightforward. Experience of genetic testing for serious diseases over the past decade has laid the foundations for thinking about the ethical issues posed by the introduction of medicines which take account of a patient's genetic make up. The Report, published in September 2003, concludes that pharmacogenetics could promise safe and more effective treatments in the future. There must be the right combination of constraints and incentives to protect and promote the interests of patients and society as pharmacogenetic testing is more widely introduced.

During the past year, the Council placed increasing emphasis on following up its previous publications. The topic of genetically modified (GM) crops, first examined in 1997-99, was revisited. The Report, ***Genetically modified crops: ethical and social issues***,

had concluded that there was an ethical obligation to explore the benefits that GM crops could offer people in developing countries. Much debate ensued and in 2003, a Working Group re-examined this conclusion, in the light of recent developments in science, policy, regulation and trade. The Discussion Paper, published in December 2003, concluded that, while GM crops will not 'feed the world', their use can have considerable potential, in appropriate circumstances, for improving agriculture in developing countries.

Since the Council published its Report on ***The ethics of research related to healthcare in developing countries*** in 2002, other guidance has been revised. The differing provisions in these guidelines is posing very considerable challenges for researchers undertaking externally funded research. Over the past year we have been planning an international Workshop, to be co-hosted with the South African MRC, in Cape Town in February 2004 to explore these issues further.

As ever, our work has depended on the very substantial contributions of colleagues drawn from many different national and international constituencies. Their knowledge, insights and open-mindedness have served the Council, and its audience invaluablely.

## Personnel

Professor Sir Bob Hepple QC, FBA succeeded Professor Sir Ian Kennedy as Chairman of the Council on 1 January 2003.

Ms Rebecca Burke and Professor John Ledingham retired from Council in January 2003, having served for three years. Professor Martin Bobrow, a member of the Council since 1997 and Deputy Chairman since 1999, also retired in January. Professor Peter Lipton and Professor Peter Smith joined the Council as members during the year. Baroness Perry of Southwark also became a co-opted member for the period of chairing the Working Party on the ethics of research involving animals.

There were a number of staff changes in the Secretariat during 2003. Caroline Rogers replaced Natalie Bartle as Research Officer in August. Tor Lezmore, Assistant Director, and Maria Nogal-Gonzalez, Information Assistant, left the Secretariat in the Autumn of 2003. Their positions will be filled in 2004. The Secretariat also had the benefit of assistance from two interns, Kate Miller and Shawneequa Callier.



## Forward Look meeting

The Council considers broader themes at its annual 'Forward Look' meeting. At the one day meeting in May 2003, members focused on possible topics for future work.

Two speakers gave invited presentations: Lord May of Oxford spoke about 'Incentives and obstacles to biomedical research' while Baroness O'Neill of Bengarve discussed 'Public health ethics'. The Council is grateful to them both for their contribution. Various issues raised in the presentations were taken up in the discussion about future work. One issue concerned vaccination. How should the balance be struck between the interests of parents in protecting their children and societal interests in ensuring that a sufficient

number of children were vaccinated? The ethics of individual benefit and community choice in public health was suggested as a possible topic for the Council to develop. Other problems which were debated included the use of large genetic databases and the most effective way to obtain informed consent without burdening patients with too much information. It has since been decided that the Council will hold a Workshop on the ethics of public health in July 2004.

## Obituary

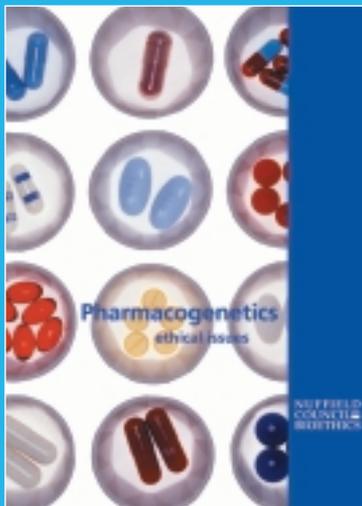
The Council regrets to report the death of Reverend Professor Gordon Dunstan, at the beginning of 2004. Professor Dunstan was one of the founding members of the Nuffield Council and served until 1995. He had a genuine understanding of the complexity of the issues and his advice, always quietly given, was invaluable.

# Publications during 2003

## Pharmacogenetics: ethical issues

*The Report, **Pharmacogenetics: ethical issues**, was published on 23 September 2003.*

### Membership of Working Party



**Professor Peter Lipton (Chairman)**  
Head of Department of History and Philosophy of Science, University of Cambridge

**Professor Haleh Afshar**  
Department of Politics, University of York

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

**Professor John Caldwell**  
Dean, Faculty of Medicine, University of Liverpool

**Professor Klaus Lindpaintner**  
Vice President, Research Director, Roche Genetics,  
Switzerland

**Professor Sir Michael Rawlins**  
Professor of Clinical Pharmacology at the University of Newcastle  
Chairman, National Institute for Clinical Excellence

**Professor Nikolas Rose**  
Professor of Sociology, Goldsmiths College,  
University of London

**Dr Nigel Starey**  
Director, Centre for Primary Care, University of Derby

**Professor Albert Weale**  
Professor of Government, University of Essex  
Member of the Nuffield Council on Bioethics

### Terms of Reference

**1.** To explore what pharmacogenetics offers now and is likely to offer in the near future;

In particular to examine the effect of pharmacogenetics on:

- a) the design of medicines, the promotion of efficacy and safety in the administration of medicines to individuals;
- b) the conduct of trials in the context of pharmaceutical research & development;
- c) clinical practice.

**2.** To consider ethical issues specifically raised by pharmacogenetics;

In particular to examine the areas of:

- a) consent, privacy and confidentiality;
- b) the management of information about response likelihood;
- c) the implications of differentiating individuals into groups based on response likelihood.

**3.** To consider the implications for the provision of healthcare.

## Introduction

People vary in their response to the same medicine. Few medicines are effective for everyone; all may cause adverse reactions or occasionally death. Some of the variation between individuals in response to medicines is due to differences in their genetic make-up.

There are many different reasons why medicines may be dangerous or ineffective, such as inaccurate prescribing, poor compliance by the patient and interaction between a particular medicine and other substances, including other medication. However, advances in genetic knowledge may enable us to take better account of differences between individuals. Pharmacogenetics is the study of genetic variation that affects response to medicines. It has the potential to play an important role in improving safety and efficacy.

In 2001, the Council held a Workshop to consider the ethical issues raised by developments in pharmacogenetics. A Working Party was subsequently established in 2002 to consider the issues in more detail.

The Working Party met six times during 2002 and 2003, and also held a number of fact-finding meetings and a consultation with the public. The draft Report was peer reviewed by an international panel of experts in early 2003. The Report was subsequently submitted to the Council for approval in June 2003 and published in September.

### Fact-finding

As part of its research, the Working Party held fact-finding meetings with the following experts during 2003:

- Professor Alastair Bellingham CBE *Chief Executive, NHS Information Authority*
- Mr Cliff Prior *Chief Executive, Rethink (formerly the National Schizophrenia Fellowship)*
- Dr Virginia Warren *Assistant Medical Director, BUPA*
- Dr Kevin Cheeseman *Director of Development Pharmacogenetics, AstraZeneca*
- Mr Andrew Freeman *RADEX Operations and Policy, GlaxoSmithKline*
- Dr Duncan McHale *Clinical Pharmacogenetics, Pfizer*
- Dr Philip Wright *Director, Association of the British Pharmaceutical Industry*
- Professor Jonathan Montgomery *Professor of Health Care Law, University of Southampton*
- Mr John Wilkinson *Partner and Joint Head of the Life Sciences Group, Bird and Bird*
- Mr Ian Dodds-Smith *Partner, Co-Head of Food, Drug and Medical Devices Practice Group and Head of European Product Liability Practice Group, Arnold and Porter*
- Dr Kathleen Fadden *Senior Associate, Arnold and Porter*

The Working Party is grateful to them for their assistance.

## The Report

Pharmacogenetics has the potential to improve both the safety and efficacy of medicines. However, both the research and its applications raise important ethical, legal, social and regulatory issues. The Report considers the implications for the research and development of medicines, clinical practice and treatment, and the use and storage of genetic information. It also addresses issues of regulation and public policy.

It is difficult to predict the extent to which ‘personalised medicines’ will become a reality. Claims of designer drugs, or ‘the right medicine, for the right patient, at the right dose’ are misleading, but it is important to discuss ethical, legal, regulatory and social issues that may be raised by improvements in predicting response to medicines.

To obtain maximum benefits from pharmacogenetics we need to address legitimate concerns and safeguard against inappropriate use. There must be the right combination of constraints and incentives to protect and promote the interests of patients and society as pharmacogenetic testing is more widely introduced. The Report aims to encourage discussion of the issues and makes recommendations for future policy and practice.

## Report Launch



The Report was launched on Tuesday 23 September and a seminar was held in the afternoon at the British Medical Association, London. More than 80 people registered to attend, including physicians, members of LRECS (Local Research Ethics Committees), policy advisers, representatives from the pharmaceutical industry, the Government and journalists. Members of the Working Party presented the main recommendations and

conclusions of the Report, and then took questions from the audience.

Approximately 600 copies of the Report were distributed on the day before the launch to interested organisations and individuals. More than 50 letters highlighting particular recommendations were also sent to relevant organisations. A short guide to the Report was produced and published simultaneously.

## Highlights of press coverage

Date	Journal	Headline
23 Sept 03	BBC News Online	Ethics backing for tailored drugs
26 Sept 03	BioNews	Ethics body reports on personalised medicines
27 Sept 03	BMJ	Ethical issues of pharmacogenetics must be addressed, says Nuffield Council
27 Sept 03	Pharmaceutical Journal	Pharmacogenetics is improving care but creating new dilemmas for practice
1 Oct 03	Research Fortnight	Pharmacogenetics could improve clinical trials

## Post-publication

By the end of 2003, nearly 1,000 printed copies had been distributed. More than 4,000 copies of the Report and 3,500 copies of the summary chapter had been downloaded from the Council's website within the first three months of publication, and the short 'Guide' to the Report was downloaded 1,500 times.

### Presentations:

- Cordia EuropaBio Convention 2003, Vienna  
Dr Sandy Thomas Dec 2003
- American Society of Human Genetics, San Francisco  
Dr Sandy Thomas, Poster presentation Nov 2003
- Sanger Centre / Cold Spring Harbor conference on Pharmacogenomics  
Professor Peter Lipton Sept 2003

It is still too early to assess the impact of the Report. However, members of the Working Party will meet towards the end of 2004 to assess its influence and to consider follow-up.

# The use of genetically modified crops in developing countries

The follow-up Discussion Paper *The use of genetically modified crops in developing countries*, was published on 29 December 2003.

## Membership of Working Group

### Dr Sandy Thomas (Chair)

Director, Nuffield Council on Bioethics

### Professor Derek Burke CBE

Former Vice Chancellor of the University of East Anglia and Former Chairman of the Advisory Committee for Novel Foods and Processes

### Professor Mike Gale FRS

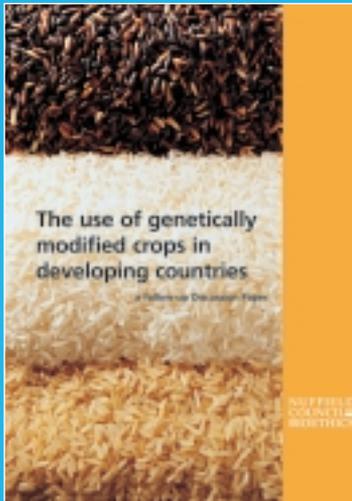
Emeritus Professor, The John Innes Centre, Norwich

### Professor Michael Lipton CMG

Poverty Research Unit, University of Sussex

### Professor Albert Weale FBA

Professor of Government, University of Essex  
Member of the Nuffield Council on Bioethics



## Terms of Reference

1. To examine recent, current and prospective developments in the use of genetically modified crops in developing countries, in particular:
  - i) to review recent progress of research in the use of genetically modified crops in developing countries
  - ii) to identify current and possible applications of genetically modified crops that would be of particular benefit to developing countries;
2. to re-examine and assess arguments set forth for and against the use of GM genetically modified crops in developing countries;
3. to assess the consequences of a moratorium on the use of genetically modified crops in developing countries;
4. to produce a short publication.

## Introduction

The Council provoked considerable debate with the publication of its Report, ***Genetically modified crops: ethical and social issues*** in May 1999. The Council concluded, on the basis of the evidence available, that there was a moral imperative for making genetically modified (GM) crops readily and economically available to people in developing countries who wanted them. The Council felt it was important to examine whether the arguments for this conclusion are still valid today.

The introduction of GM crops remains highly controversial. However, the debate has focused mainly on the needs of European countries, with little attention having been paid to the potential of GM crops for agriculture in the developing world. The Council therefore decided to produce a follow-up Discussion Paper, focusing specifically on the use of GM crops in developing countries. It was hoped that the Paper would contribute an important perspective to the national

debate on GM crops, organised by the Government during 2003 (see box).

A small Working Group comprising three former members of the Working Party for the 1999 Report, and one member of the Council was established. The Group met eight times between December 2002 and August 2003 and held several fact-finding meetings. The Discussion Paper was also peer reviewed by nine international experts.

### Fact-finding

The Working Group is grateful to those individuals who provided valuable insights into issues relating to the use of genetically modified crops in developing countries:

Mr Alex Wijeratna  
*Food Rights Campaign Coordinator, ActionAid, UK*

Dr Richard Tapper  
*Advisor, UK Food Group, ITDG (Intermediate Technology Development Group)*

Professor Ingo Potrykus  
*Professor Emeritus, Institute of Plant Science, ETH Zurich*

Professor Julian Kinderlerer  
*Professor of Law, University of Sheffield, UK*

Dr Andrew Bennett  
*Executive Director, Syngenta Foundation for Sustainable Agriculture, Basel*

Professor Gordon Conway  
*President, The Rockefeller Foundation, USA*

## Draft version

On 10 June 2003, a draft version of the Paper was released for comment at a press conference held at 28, Bedford Square. The Paper was featured in the Times, the Financial Times, the Guardian, BBC news, the Times Higher Education Supplement and the Lancet, amongst others. The Director also gave a number of radio interviews.

During the two month period of consultation, the document was downloaded 5,833 times

from the Council's website. The Council received 83 responses, from more than 20 countries, with more than a quarter from the developing world. The responses highlighted the complexity of the debate. While many respondents described the benefits they had experienced from using GM crops, others argued that economic, political or social change was more important than the introduction of new technologies. The Council is grateful to all respondents for their valuable comments.

## The Discussion Paper

Agriculture has a crucial role to play in developing countries, as a source of food, income and employment. The Discussion Paper reviews recent scientific and regulatory evidence to assess whether genetically modified (GM) crops could make a useful contribution to farming in the developing world.

The Paper concludes that the possible costs, benefits and risks associated with particular GM crops must be assessed on a case by case basis. In appropriate circumstances, GM crops can have considerable potential for tackling specific agricultural problems, such as drought and salty soils. There is therefore an ethical obligation to explore the benefits that GM crops could offer people in developing countries.

The Paper discusses the impact of European regulation on developing countries, and makes recommendations about policy, regulation and trade. Issues raised by food aid, micronutrient-enriched GM crops and the impact of GM crops on biodiversity are also considered.

## Launch of the Discussion Paper

The Paper was published on 29 December 2003, with advance articles in the Sunday papers and radio coverage on the day. The Paper was distributed to 850 relevant individuals and organisations in developed and developing countries. In addition, over 100 letters highlighting specific recommendations were sent to a range of organisations, including government departments in developing countries dealing with scientific, agricultural or environmental policy; UK and EU development agencies; agrochemical companies and Food Aid Programmes. The Discussion Paper was downloaded more than 1,880 times from the Council's website in the first week after its publication.



### GM nation?

The Government held a public debate about the impact of GM crops during 2003. This comprised three strands:

- a series of public meetings and discussions
- an economic analysis of the costs and benefits of using GM crops by the Strategy Unit
- GM Science Review: a review of the science underlying the genetic modification of crops.

The Council decided to complement these various initiatives by producing a Discussion Paper to follow up its 1999 Report. The draft Discussion Paper, and a shorter Guide, were circulated widely to the public meetings throughout the UK.

## Highlights of press coverage

Date	Journal	Headline
<b>June coverage</b>		
10 June	BBC online	GM crops 'good for developing countries'
	The Times online	Top ethics body says GM is 'moral imperative'
	Glasgow Herald	National debate on GM crops comes to Glasgow
11 June	The Times	Europe's stand on GM crops 'hitting the poor'
	The Financial Times	Scientists find modified foods are safe to eat
	The Guardian	GM crops 'can aid poor farmers'
	Washington Times, United Press International	GM crops 'good for developing countries'
	SciDev.net	GM crops 'could reduce poverty'
12 June	Crop Biotech Update	Nuffield Council: GM benefits small farmers
13 June	Times Higher Education Supplement	GM seeds of hope (Dr Sandy Thomas)
14 June	The Lancet	UK ethicists say GM foods could help poor
<b>December coverage</b>		
28 Dec	The Observer	Britain 'has moral duty to fund GM research'
	Radio 5 Live	
	BBC Breakfast News (TV and radio bulletins)	
	BBC News 24	
29 Dec	Radio 4 Today programme	
	SciDev.Net	GM decisions 'must examine all options' says report
31 Dec	British Satellite News	
	Meridian Institute Food Security and Ag-Biotech News	The use of genetically modified crops in developing countries

### Presentations:

- Hove City Council 'GM nation?' debate  
Dr Sandy Thomas  
July 03
- Institute of Technology Development Group (ITDG) Conference  
'Is small beautiful: feeding the hungry – biotechnology's role'  
Professor Michael Lipton  
September 03
- The right measures for food? Biotechnology, agriculture and food in ethical perspective; Centre for ethics in sciences and humanities, University of Tübingen, Germany  
Harald Schmidt  
October 03

# New work

## The ethics of research involving animals

*A Working Party on **the ethics of research involving animals** was established in February 2003.*

### Membership of 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, Mammalian Genetics Unit, Mouse Genome Centre, Medical Research Council, Harwell

**Professor Grahame Bulfield**

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**

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**

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 H 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**

Head of Global Development, Syngenta

**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

### 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.

## Introduction

Many people are concerned about the use of animals in research. There is also widespread acknowledgement of the need for new treatments to improve human health. Since medical research often involves animals, these two views are not easily reconciled. Recognising that people feel very deeply about animal experimentation, the Council held a Workshop in November 2001 to decide whether the topic merited further examination. A Working Party to consider ethical issues raised by research involving animals was established and held its first meeting in February 2003.



Members of the Working Party bring a wide range of perspectives to the discussion of this controversial topic, with backgrounds in animal welfare, philosophy, science, law and veterinary practice. The Council hopes that the range of expertise will allow an open and informed debate of the issues.

A major focus of the Working Party is on the increasing use of genetically modified (GM) animals. The number of GM animals used in research has risen tenfold over the last decade and the welfare implications for animals which have been designed for particular research purposes will be considered.



### Fact-finding

As part of its work, the Working Party held fact-finding meetings with the following experts and organisations:

- MORI Social Research Institute
- Pfizer, Sandwich
- Representatives of the Muscular Dystrophy Campaign, the Parkinson's Disease Society and the Cystic Fibrosis Trust
- Department of Biology, University of York
- Dr Christopher Springall, Contract Research Organisation Covance
- Professor Michael Balls, Chairman of the Trustees of FRAME, former Head of ECVAM (European Centre for the Validation of Alternatives)
- Dr Gill Langley, Scientific Advisor, Dr Hadwen Trust

The Working Party is most grateful to them for their assistance. Further fact-finding meetings are planned for 2004 in the following areas: regulation; the transferability of research results obtained from animals to humans; and research involving primates.

A total of six meetings were held during the year. A Report on the topic will be published early in 2005.

## Consultation

A consultation with the public was held during the Autumn of 2003. Hard copies of the consultation document were distributed to more than 500 relevant individuals and organisations, and the document was downloaded more than 2,503 times from the Council's website. There was also an online facility to respond to the consultation.

The consultation paper posed six main questions:

- What is your view about the use of animals in research?
- What are your views about the use of genetically modified animals in research?
- What is your view about the use of alternatives?
- What is your view about ethical issues relating to the use of animals in research?
- What is your view about the UK regulations on research involving animals in the UK?
- What do you think about the information that is available to the public about research involving animals?

More than 160 responses were received from a wide range of interested individuals and organisations, and all have been carefully considered. The Working Party would like to thank all those who contributed to the consultation.

# Workshop on prolonging life

A Workshop was held on 12 June 2003 to discuss issues raised by prolonging human life. The scope of the Workshop was broad, covering not only the issues associated with prolonging life in older people, but also similar issues raised by the medical treatment of neonates and fetuses. The aim was to provide guidance on whether the topic should be taken forward as a Working Party. It was hoped that a discussion of issues raised by treatment of the very young and older people might provide an illuminating perspective on otherwise familiar debates.

The age at which fetuses are considered viable has been reduced from about 28 weeks to as little as 23 weeks, because of recent scientific advances. Although improvements in treatment and healthcare have led to a significant reduction in neonatal mortality, assisted reproduction has increased the number of babies born prematurely. Despite these advances, very premature babies are at risk of lung disease, brain injury, infection, blindness and severe disability. The development of fetal surgery, and an increase in knowledge about the fetus, also raise ethical and legal issues. Discussion focused on:

- the role of the family and health professionals in decision making;
- wider social consequences of prolonging the lives of fetuses and neonates, including issues of resource allocation;
- the lack of empirical evidence on which to base decisions;
- the differing legal and moral status of fetuses and neonates; and
- questions about suffering in fetuses and neonates.

Issues at the end of life, particularly those relating to older people were also discussed including trends in ageing and disability, reflections on 'protracted dying' and an ethical perspective. Discussion included:

- consideration of where priorities should lie in terms of effort and funding, including the value of using resources for interventions to improve public health;

- the importance of team-based decision making and the role of the family;
- advanced directives;
- concerns about 'inappropriate' treatment (either under- or over-treatment) of older people; and
- the impact of increases in life expectancy.

A number of themes common to prolonging life in neonates and older people were identified. These included concerns about 'inappropriate' treatment and a lack of information about the reality of clinical practice. Discussion about decision-making highlighted the inconsistency between the role of parents in making decisions on behalf of their children and, later in life, the role of children in making decisions on behalf of their parents.

Participants in the Workshop recommended that the Council should focus on one of the areas, either prolonging life in older people or the newborn, or narrow the scope of the study to address specific issues raised in both areas. The Council will establish a Working Party in 2004 to examine questions raised by decision making on prolonging life in the treatment of fetuses and the newborn.



# The ethics of research related to healthcare in developing countries: Follow-up Workshop

The Council's Report, *The ethics of research related to healthcare in developing countries*, published in April 2002, concluded that externally funded medical research in developing countries is crucial but must be subject to rigorous ethical safeguards. The Report provided an ethical framework for anyone who is designing or conducting externally-sponsored research in the developing world. The Council will hold a Workshop in 2004 to follow-up developments in this area since publication.



An international Steering Committee met several times during the year to discuss the aims and structure of the meeting. The focus of the Workshop will be to discuss and debate ethical and regulatory issues raised by new and recently revised guidelines and to identify obstacles to effective implementation. The Workshop took place in Cape Town from 12 – 14 February 2004, and brought together researchers who are actively involved in externally-sponsored research related to healthcare in developing countries. In order to ensure attendance of a wide range of experts, a competition for funded places was held during the summer of 2003. This attracted a high level of interest, with more than 120 applications received from 47 countries. The Steering Committee selected 20 participants from the competition. The Workshop will be

limited to 60 participants to encourage active and focused discussion.

The Workshop was co-hosted with the South African MRC. The Department for International Development (DFID), the Medical Research Council, the Wellcome Trust and the Rockefeller Foundation agreed to fund the meeting.

Important developments in recently revised or newly established guidelines on research relating to healthcare in developing countries, were highlighted in a background paper circulated at the Workshop. An intern, Shawneequa Callier, worked with the Secretariat in August 2003 to assist in the preparation of this paper and the Council is most grateful to her for her help.

## 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. Now within the Science Directorate at the Natural History Museum

### **Dr Alwyn Mwinga**

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

### **Professor Catherine Peckham CBE**

Head, Centre for Paediatric Epidemiology and Biostatistics, Institute of Child Health, and Great Ormond Street Hospital, 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 Precilla Reddy**

Director of Health Promotion Research and Development, South African MRC

### **Professor Peter Smith CBE**

Head of Department of Infectious and Tropical Diseases, London School of Hygiene and Tropical Medicine, and former member of the Working Party on the ethics of research related to healthcare in developing countries

### **Ms Bella Starling**

Programme Officer, History of Medicine and Biomedical Ethics, The Wellcome Trust



# External activities

The Council's terms of reference require it to examine and report on questions in bioethics 'with a view to promoting public understanding and discussion'. During the past decade, a range of activities have been undertaken to fulfil this requirement, including the dissemination of Reports, presentations at public events, consultations with the public, and interviews with the media. In 2003, the Council explored new ways of reaching a wider audience and promoting debate of issues considered in its Reports. The Council regularly liaises with other organisations, both in the UK and abroad, to increase awareness of its activities.

## Highlights of media activities

Date	Interviewer	Subject	Interviewee
January	CNN	GM crops	Director
February	Norwegian press	Patenting	Director
March	Science	Body Worlds	Director
May	Encounter, National Radio, Australia	Genetics and human behaviour	Assistant Director
June	BBC World Service, World Update	GM crops	Director
	Radio France International	GM crops	Director
	BBC Radio Four	Pharmacogenetics (One Man's medicine, 20 August)	Director
July	Radio Netherlands	EU guidelines on stem cell research	Professor Tom Baldwin
	The Scientist	EC Directive on patenting	Director
August	BIOSAM, Denmark	Pharmacogenetics	Professor Peter Lipton
Sept	Ashahi (London Bureau)	Bioethics in UK	Director
	World at One	GM crops	Director
October	Sunday Express	Pharmacogenetics	Professor Peter Lipton
	The New America Foundation	Ethics of research in developing countries	Director
	The Times	European Constitution – proposed clause mentioning eugenics	Professor Tom Baldwin
November	The Guardian	Interest in brain scan data by insurance companies	Director

# Promoting public discussion

## Presentations

Members of Council and the Secretariat gave more than 40 national and international presentations during 2003, more than in any previous year. They also participated in a wide range of other events throughout the year, both in the UK and abroad.

January	BioBusiness 2003 Conference, Geneva. The changing face of drug development. Presentation: 'How will patent issues determine the future of the biotechnology industry?'	Dr Sandy Thomas
February	Norwegian Patenting Office, Presentation: 'The ethics of patenting DNA'	Dr Sandy Thomas
	Cabinet Office Strategy Unit: Biosciences: Challenges and Opportunities for Government Presentation: 'Biosciences and society: an ethical perspective'	Dr Sandy Thomas
	Cold Spring Harbor Laboratory: Celebrating 50 years of the double helix Poster presentation: Genetics and human behaviour	Dr Sandy Thomas
	Paediatric European Network for the Treatment of AIDS Presentation: The ethics of research related to clinical trials in developing countries	Professor Catherine Peckham
March	Center for Genome Ethics, Law and Policy, Duke University Presentation: The ethics of patenting DNA	Dr Sandy Thomas
	Bioethical Issues of Intellectual Property Rights, Round Table Discussion, University of Cambridge Presentation: Patenting DNA - research tools	Tor Lezemoire
April	HGM 2003, Cancun, Mexico Poster Presentation: Genetics and human behaviour	Dr Sandy Thomas
May	European Human Genetics Conference, Birmingham Presentation: Genetics and human behaviour	Professor Martin Richards
	IP Seminar series, Oxford IP Research Centre Presentation: The ethics of patenting DNA	Dr Sandy Thomas
	A Trans-Atlantic Dialogue on Genetics and Health, joint CSIS and Norwegian Embassy Symposium, Washington Presentation: Pharmacogenetics - ethical issues	Dr Sandy Thomas
	GlaxoSmithKline Presentation: The ethics of patenting DNA	Dr Sandy Thomas
	BA Science Communication Conference Presentation: Who should the Nuffield Council on Bioethics consult with and why?	Tor Lezemoire
	Genetics of complex diseases and isolated populations, Sardinia Presentation: Genetics of complex disease: the ethical context	Dr Sandy Thomas
	68th Cold Spring Harbor Symposium on Quantitative Biology, 'The genome of Homo sapiens' Member of ELSI panel	Dr Sandy Thomas

## Presentations continued

June	EU-Innovation TrendChart workshop, New Trends in IPR Policy, Luxembourg Presentation: The ethics of patenting DNA	Professor Tom Baldwin
	The Royal Institute of International Affairs: Intellectual property rights: driver of competition and growth or unnecessary constraint? Presentation: A scientific perspective – patents on research tools	Dr Sandy Thomas
	Danish Council of Ethics: Presentation: The ethics of patenting DNA	Tor Lezemoire
	Portuguese Genetics Conference: Presentation on stem cells	Professor Tom Baldwin
August	OECD Conference, IPR Innovation and Economic performance, Paris	Dr Sandy Thomas
September	British Council conference, Estonia Presentations on Stem Cells and the ethics of patenting DNA	Professor Tom Baldwin
	Randall Centre, King's College Presentation: Genetics and human behaviour	Dr Sandy Thomas
October	Lecture tour in South America Presentations: The ethics of research related to healthcare in developing countries	Professor Keith McAdam
	Basic Course on Research Ethics Conference, Lima, Peru	
	Seminar on International Ethical Guidelines for Research Involving Human Subjects, Santiago, Chile	
	Faculty of Medicine, University of Buenos Aires, Argentina	
	Why move genes around?, Symposium organised by Institute of Biology. Presentation: Ethical dilemmas	Dr Sandy Thomas
November	2nd EPIP Conference, Maastricht. Presentation: Intellectual Property Rights and Research Tools	Dr Sandy Thomas
December	7th European Conference of National Ethics Committees (COMETH), Strasbourg. Presentation: Initiatives for reaching out to young people	Professor Sir Ken Calman

Presentations relating to the Reports published in 2003 are listed elsewhere in the Annual Report.

## Accessible 'Guides'

The Council is keen to ensure that its work reaches a wide audience. However, its Reports are generally lengthy and may deter the general reader. Shorter 'Guides' will be produced to provide brief background information and include a selection of paraphrased recommendations and conclusions. During 2003, Guides to accompany the Discussion Paper on *The use of genetically modified crops in developing countries*, and the Report on *Pharmacogenetics: ethical issues* were published. Further Guides will be developed for previous publications during 2004.

## Reaching out to young people: Advisory Group

Discussion about the impact of science on society is increasingly accepted as an essential part of the education of young people. The Council is aware of the need to engage young people in debate about bioethical issues. A small Advisory Group including members of Council and also external experts with experience in the field met in July 2003 to discuss ways of reaching a wider audience.

The Group discussed two main questions: first, how might Reports be made more accessible to a wider audience? The new short 'Guides' were seen as one way of achieving this aim. Secondly, should more specialised educational materials be developed? The Group

recommended that the Council should consider producing dedicated educational resources, specifically designed for school groups or teachers and relevant to the curriculum. Educational materials which provide guidance on 'how' to think about ethical issues would be particularly useful. Further research will be undertaken to establish the demand for such resources.

The Group also advocated greater participation of young people in consultations. The Advisory Group will continue to meet as required over the next two or three years, to advise on policy and to monitor developments in the area and suggest further initiatives.

### Members of Advisory Group

**Professor Sir Kenneth Calman KCB FRSE (Chair)**

Member of the Council  
Vice-Chancellor and Warden, University of Durham

**Professor Catherine Peckham CBE**

Deputy Chair of the Council  
Professor of Paediatric Epidemiology, Institute of Child Health, University College London.

**Mr Nick Ross**

Member of the Council  
Broadcaster

**Miss Elizabeth Diggory**

High Mistress of St Paul's Girls' School

**Dr Peter Doyle CBE FRSE**

Trustee of the Nuffield Foundation  
Chair of BBSRC until May 2003 and formerly Executive Director of Zeneca Group plc

**Mr Andrew Hunt**

Director, Nuffield Curriculum Centre

**Professor Michael Reiss**

Professor of Science Education, Institute of Education

## The website

The website has become an increasingly important component of the Council's dissemination strategy. The number of visitors almost doubled during 2003, from 400 per day in 2002, to approximately 750 visitors per day in 2003. Visitors also spent longer

browsing the site, with the average visit lasting more than 14 minutes. More than 266,000 people visited the site during 2003, and nearly 169,000 copies of the Council's publications were downloaded.

Publication	No. of Downloads
Genetic Screening: ethical issues	23,975
Human tissue: ethical and legal issues	27,854
Animal-to-human transplants: the ethics of xenotransplantation	14,783
Mental disorders and genetics: the ethical context	4,166
Genetically modified crops: the ethical and social issues	10,163
Stem cell therapy: the ethical issues	2,305
The ethics of research related to healthcare in developing countries	
Report	15,380
Discussion Paper	9,911
The ethics of patenting DNA	14,117
Genetics and human behaviour: the ethical context	30,057
The use of genetically modified crops in developing countries (draft version)	9,638
Pharmacogenetics: ethical issues	6,619

The consultation for the Working Party on the ethics of research involving animals was available on-line and, for the first time, there was also a facility to send responses via the website. The Council will use this facility again for future consultations.

The website will continue to be developed and expanded during 2004. The Home Page will be revised to ensure that visitors to the site are able to navigate the site as easily as possible. The site will also be upgraded to meet new regulations for accessibility.

## External relations

In the UK, the Council continues to maintain close contact with the Department of Health and the Human Genetics Commission, meeting during the year to exchange information about current and future work. The Council also liaises with policy-makers, research councils, scientists, industry, medical charities, health professionals and consumer groups to discuss developments and raise awareness of its publications.

### Consultations

The Council is regularly invited to respond to consultative documents produced by other organisations. In general, the Council responds only to consultations which specifically address issues discussed in its publications. In 2003 responses were submitted to the:

- Human Genetics Commission: Consultation on future work on genetics and reproduction
- MRC: Consultation on the Draft Code of Practice for the UK Stem Cell Bank
- AMRC: draft position statement on patenting and commercial partners
- International Association for the Protection of Intellectual Property (AIPPI): Consultation about the scope of patent protection
- HFEA: draft sixth Code of Practice
- UK Biobank: Consultation on draft Ethics and Governance Framework
- Royal Society: Call for evidence on best practice in communicating the results of new scientific research to the public
- BBSRC: Consultation on future directions in crop science research
- Strategy Unit: Report on Field Work: weighing up the costs and benefits of GM crops.

### European Directive on tissues and cells

The Council wrote to MEPs in December 2003 to express its concern about proposed amendments to the European Directive on tissues and cells, advising that the amendments posed a real threat to research on stem cells which offer the possibility of significant advances in healthcare.

## International activities

The Council has close links with other ethics bodies abroad, especially those in the European Union. The first EC Forum of National Ethics Committees took place in Athens in June 2003, and was attended by Assistant Director, Harald Schmidt. The purpose of this forum is to allow informal discussion of current and future work of national ethics councils in the EU. It is complementary to already existing meetings such as the COMETH. The Director attended the second meeting of the Forum, held in Rome in December 2003. Representatives of Council also attended the 7th European Conference of National Ethics Committees at the Council of Europe, Strasbourg in December 2003, held to allow members of National Ethics Committees to meet and discuss issues of common interest. The main themes of this Conference were bioethics education and research on stored human tissue. Professor Sir Ken Calman gave a presentation on the Council's initiatives for reaching out to young people.

Members of the Council participated in a wide range of international meetings throughout 2002 and received a number of international visitors, including:

January	Professor Ahmed Yacoub, President of Medical Ethics Council, Sudan Dr Tikki Pang, Director, Research Policy & Cooperation, WHO
February	Dr Kreiner and Mr Wells, Affymetrix Professor Gordon Conway, President of the Rockefeller Foundation
March	Barbara Nicholas, Senior Analyst, New Zealand Bioethics Council Janet Maughan, Rockefeller Foundation
April	Members of Ministry of Health and Welfare, Korea Mrs Helen Hughes-McKay and Ms Ursula Roos, Research & Technology Office, British Embassy, Berlin Yuuki Takayama, AsahiShimbun, Osaka Department of Science
May	Dr Leon Kass and Dean Clancy, US President's Council on Bioethics
June	Dr Cathy Garner, MIHR Dr Neen Hunt and Mr Michael Brown, Mary Woodard Lasker Charitable Trust
July	Kerry Doyle, Director of BioUnit, Cabinet Office, New South Wales Dr Francesc Abel, President and Ms Nuria Terribas, Director, Borja Institute of Bioethics, Catalonia
Sept	Dr Marie Freire, CEO, Global Alliance for TB Drug Development Tamara Traubman, Haaretz Newspaper
November	Dr Egil Olsen, Norwegian Biotechnology Advisory Board
December	Meeting with Emile Frison, Director-General, Institute of Plant Genetic Resources, CGIAR, Rome



## Bilateral meeting with CCNE

The Council held the first of an annual bi-lateral meeting with the French Comité Consultatif National d'Ethique in Paris in November, on the ethics of public health. Case studies on vaccination and the storage of tissue samples in databanks allowed a comparison between different perspectives in France and the UK. A similar meeting with the German Commission, Der Nationale Ethikrat, is planned for 2004.

# Annex A

## Financial and funding Report on the calendar year 2003

<b>Expenditure</b>	<b>2003 Actual £</b>	<b>2002 Actual £</b>
Salaries and staffing costs	273,226	281,084
Office costs including premises	7,595	25,934
Stationery and press cuttings	10,798	11,807
Photocopy, post, phone, fax	28,565	28,497
Committee and meeting costs	42,023	55,800
Printing of reports	23,091	82,797
(Less) reports sold	(2,396)	(2,458)
Publicity of reports	5,464	21,193
Equipment (IT developments)	3,635	3,796
<b>Net expenditure</b>	<b>392,000</b>	<b>508,449</b>
<b>Funding Due</b>		
Nuffield Foundation	160,364	160,666
Medical Research Council	160,364	160,667
Wellcome Trust	160,364	160,667
Other income	-	27,000
	<b>481,092</b>	<b>509,000</b>
Surplus/ (Deficit)	89,092	551
Balance Brought Forward	551	-
Balance Carried Forward	89,643	551
Overheads met by Nuffield Foundation	176,441	267,729

### Notes

Reconciles to expenditure published by the Nuffield Foundation, adding overheads and recording sales against income, not expenditure. Income reconciles after deferring £51,451 of grants receivable but not claimed.

# 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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e-mail: [bioethics@nuffieldbioethics.org](mailto:bioethics@nuffieldbioethics.org)

Price for Reports:

- £10 per copy to all European countries (EU and non EU) including postage
- £15 per copy to countries outside Europe including postage
- There is no charge for orders from developing countries



