



Annual Report 2006

**NUFFIELD
COUNCIL ON
BIOETHICS**

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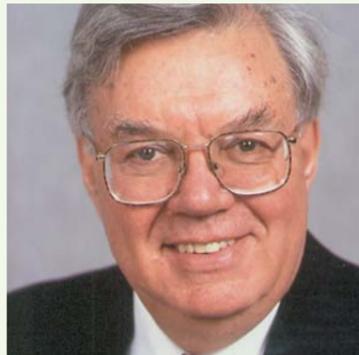
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Foreword by the Chairman



Bioethical issues attract much public attention. A large and growing number of official and unofficial committees are engaged in ethical reviews of one kind or another. What makes the Nuffield Council on Bioethics distinctive?

First, the Council is totally independent of government and commercial interests. In 2006, we were delighted to get confirmation of a renewal of funding, which ensures this independence, for a further five years from the Nuffield Foundation, the Medical Research Council and the Wellcome Trust.

Secondly, we are an interdisciplinary group of experts, including (in 2006) two lawyers, three philosophers, a bioethicist, a social scientist, a journalist, a general medical practitioner, two epidemiologists, two public health experts, a geneticist, a neuropathologist, an immunologist, and a biotechnologist. We draw on a wide range of relevant disciplines and interests in our working parties which consider particular issues. All Council and working party members give their time voluntarily because of the importance they attach to the Council's work.

Thirdly, we conduct in-depth studies of issues that are not only of immediate interest but also of longer-term significance. Although in some respects we fulfill a role similar to that of national bioethics committees in other countries, we are different from them

because we do not respond to direct requests from government or private bodies for specific advice on ethical issues. Instead, following an annual horizon-scanning exercise, we select just a few, generally cross-cutting issues, which are of special significance to science and to the way in which future generations will live. We choose topics that have not been adequately studied in the past; indeed many of our studies have been path-breaking and have provided an essential starting point for policy makers and researchers. Above all, we seek to raise public awareness of the implications of recent developments in biology and medicine. This year we added to our list of reports a major ethical, legal and social review of critical care decisions in fetal and neonatal medicine, started work on two new projects, and held a number of workshops.

None of these activities would be possible without the dedication of our Secretariat. I would like to pay special tribute to Professor Sandy Thomas who, after over nine years as Director, moved on in November 2006 to take the post of Director of the Foresight Programme at the Office of Science and Innovation. She led by example, making a key contribution herself to several reports (notably those on DNA patenting and GM crops in developing countries). She ensured the high quality of all our reports by careful monitoring and attention to detail at all stages of the process. She has been the most important public face of the Council presenting our work in many parts of the world. We wish her well in her new appointment. We are pleased to welcome Hugh Whittall, formerly of the Department of Health, as our new Director from 1 February 2007.

We adopted a new process of selection for appointment of members of Council in 2005 (as noted in the last Annual Report). We welcomed four new members in 2006 appointed under this process, and are grateful to Baroness Butler-Sloss who acted as independent Chair of the Membership

Panel. We also welcomed Professor Sir John Krebs (now Lord Krebs) as Chair of the Working Party on *Public health: ethical issues*. We express our appreciation to the members who retired after serving their (maximum) six-year terms. I would like to single out Professor Catherine Peckham, who was a wonderfully reliable and effective Deputy Chair, and Professor Margaret Brazier who served ex officio while chairing the Working Group on *Critical care decisions in fetal and neonatal medicine*, a difficult and demanding role in which she displayed her excellent skills. Professor Dame Marilyn Strathern, Professor Tom Baldwin and Professor Herbert Sewell will also all be missed for the outstanding contributions they have made to our work and our direction.

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 and providing independent advice to assist policy makers and stimulate debate on 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, including its publications and methods of working, can be found on the Council's website: www.nuffieldbioethics.org

2006 Calendar

January

1st Council meeting
1st meeting of Working Party on *Public health: ethical issues*

February

8th meeting of Working Party on *Critical care decisions in fetal and neonatal medicine: ethical issues*

Workshop on the ethical issues raised by the use of person-specific biological information for legal, forensic and police purposes

March

2nd Council meeting
2nd meeting of Working Party on *Public health: ethical issues*

April

9th meeting of Working Party on *Critical care decisions in fetal and neonatal medicine: ethical issues*

May

Forward Look Workshop on the ethical issues raised by advances in neurosciences
3rd meeting of Working Party on *Public health: ethical issues*

June

3rd Council meeting

July

4th meeting of Working Party on *Public health: ethical issues*
10th meeting of Working Party on *Critical care decisions in fetal and neonatal medicine: ethical issues*

August

September

5th meeting of Working Party on *Public health: ethical issues*
1st meeting of Working Group on *The forensic use of bioinformation: ethical issues*

October

4th Council meeting
Launch of consultation on *The forensic use of bioinformation: ethical issues*

November

6th meeting of the Working Party on *Public health: ethical issues*
Launch of Report on *Critical care decisions in fetal and neonatal medicine: ethical issues*

December

Membership of the Council



Professor Sir Bob Hepple QC, FBA (Chairman)
Emeritus Master of Clare College and Emeritus Professor of Law, University of Cambridge; Judge of the UN Administrative Tribunal; and Barrister, Blackstone Chambers, London



Professor Catherine Peckham CBE (Deputy Chairman) (until March 2006) Professor of Paediatric Epidemiology, Institute of Child Health, University College London



Professor Peter Smith CBE (Deputy Chairman) (position held from June 2006) Professor, Infectious Disease Epidemiology Unit, Department of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine



Professor Tom Baldwin (until January 2006) Department of Philosophy, University of York



Professor Margaret Brazier OBE (until November 2006) School of Law, University of Manchester (co-opted member of the Council for the period of chairing the Working Party on *Critical care decisions in fetal and neonatal medicine: ethical issues*)



Professor Roger Brownsword
Professor of Law, Centre for Medical Law & Ethics, King's College, London



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



The Rt Rev Lord Harries of Pentregarth DD FKC FRSL
Bishop of Oxford until June 2006; Chair of the Ethics and Law Committee of the HFEA and Interim Chair of the HFEA



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



Professor Søren Holm (from June 2006) Professorial Fellow in Bioethics, Cardiff Law School; Professor of Medical Ethics, University of Oslo, Norway



Mr Anatole Kaletsky (from January 2006) Editor at Large of *The Times of London*



Dr Rhona Knight (from January 2006) General Practitioner and lecturer



Lord Krebs MA DPHIL Kt FRS FMedSci (from March 2006) Principal of Jesus College Oxford (co-opted member of the Council for the period of chairing the Working Party on *Public health: ethical issues*)



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



Lord Plant of Highfield
Professor of Legal and Political Philosophy, Centre for Medical Law & Ethics, King's College, London



Professor Hugh Perry (from January 2006) Professor of Experimental Neuropathology, University of Southampton



Professor Herbert Sewell (until January 2006) Pro-Vice Chancellor and Professor of Immunology, University of Nottingham



Professor Dame Marilyn Strathern FBA (until June 2006) Mistress of Girton College, Cambridge; William Wyse Professor of Social Anthropology, University of Cambridge



Dr Alan Williamson FRSE
Consultant on Biotechnology

Secretariat

Professor Sandy Thomas
Director (until November 2006)

Hugh Whittall
Director (From February 2007)

Dr Catherine Moody
Deputy Director (Acting Director from November 2006 to February 2007)

Harald Schmidt
Assistant Director

Carol Perkins
PA to the Director and Secretariat Administrator

Catherine Joynson
Communications & External Affairs Manager

Caroline Rogers
Research Officer

Julia Trusler
Research Officer

Clare Stephens (until March 2006)
Secretary

Audrey Kelly-Gardener (from May 2006)
Secretary

Dr Carole McCartney
Project Manager, Working Group on *The forensic use of bioinformation: ethical issues*

Personnel

Professor Catherine Peckham, Professor Tom Baldwin, Professor Herbert Sewell and Professor Marilyn Strathern all retired from Council in 2006 after six years of service. Professor Peckham was a member of two Working Parties and a Steering Group and was Deputy Chairman of the Council from 2003 until 2006. Professor Baldwin contributed to a Working Party and two Round Tables. He continues to work with the Council as a member of the Working Party on *Public health: ethical issues*. Professor Margot Brazier was co-opted onto Council for the period of chairing the Working Party on *Critical care decisions in fetal and neonatal medicine: ethical issues*, which completed its work in November 2006.

The Council welcomed four new members in 2006: Dr Rhona Knight, Anatole Kaletsky, Professor Hugh Perry and Professor Søren Holm. Lord Krebs was co-opted onto Council in 2006 for the period of chairing the Working Party on *Public health: ethical issues*.

Towards the end of the year, the Council appointed five further members: Professor Sian Harding, Professor Ray Hill, Professor Alison Murdoch, Dr Bronwyn Parry, and Professor Nikolas Rose. The new members began their terms on Council in January 2007.

Audrey Kelly-Gardener joined the Secretariat as Secretary in May after Clare Stephens left this position in March. Dr Carole McCartney was employed on a part-time basis to manage the Working Group on *The forensic use of bioinformation: ethical issues*. Dr Eva Asscher assisted the Council as an intern for four weeks to help prepare briefing notes on the ethical issues surrounding advances in neuroscience. In November, Professor Sandy Thomas left the Secretariat after more than nine years as Director.

Report by the Director



2006 has been a very productive and significant year for the Council.

The publication of *Critical care decisions in fetal and neonatal medicine: ethical issues* in November, after two years of unstinting effort by the Working Party, was an important achievement. The members undertook several fact-finding meetings to ensure their discussions were well informed. These included visits to neonatal units in the UK, France and the Netherlands, and meetings with parents who had personal experiences of making critical care decisions about their own children. The Report provides conclusions and recommendations on controversial and sensitive issues such as withdrawing and withholding treatment, active ending of life, and the resolution of disputes between parents and doctors. It provoked a high level of debate and my colleagues at the Council will be discussing the recommendations further with other organisations over the coming months. I am greatly indebted to the Chair of the Working Party, Professor Margot Brazier OBE, whose dedication and leadership was pivotal in the success of the project. I would also like to thank Dr Catherine Moody, Secretary to the Working Party, and Deputy Director, for her dedication and commitment. Catherine returns to the Medical Research Council, from which she was seconded, at the end of March 2007. We wish her every success in her future career.

A Supplement to the Council's 1993 Report on *Genetic screening: ethical issues* was also published this year. The original Report remains one of the Council's most widely read publications, despite having been published 13 years ago. The Council decided that it would be useful to bring it up to date. The Supplement outlines developments in science and policy relevant to genetic screening.

The Working Party on *Public health: ethical issues* continued its work throughout the year, ably led by the Chair Lord Krebs. In 2006, the group met with representatives from a range of organisations with an interest in the five chosen case studies: infectious diseases, obesity, smoking, alcohol, and the supplementation of food and water. The public consultation, which took place from May to September, produced further evidence and views on the topic, and these will be considered carefully by the Working Party. The final Report will be published in autumn 2007.

A new study which will examine the ethical issues surrounding the use of bioinformation for forensic purposes, began work in the autumn. A Working Group led by the Chairman of the Council, Professor Sir Bob Hepple QC, will focus on the powers of the police in England and Wales to take, store and analyse the DNA of suspects, witnesses and victims. We were delighted to welcome Dr Carole McCartney from the University of Leeds, whose academic interests lie in forensic identification and criminal justice, as the project manager of the Working Group.

The Council was pleased to receive confirmation of funding for the next five years (2007-2011) from the Council's three sponsors: the Nuffield Foundation, the Medical Research Council and the Wellcome Trust. The bid that was submitted in 2005 included an analysis of the impact of the Council's work over the past five years. I am

grateful for the recognition this analysis received from our sponsors and from the external reviewers.

During my tenure as Director from 1997-2006, the Council underwent several significant changes. Steered by the wise chairmanship of Professor Sir Ian Kennedy, and later Professor Sir Bob Hepple QC, the Council significantly strengthened its reputation as an independent body which produces rigorous, coherent analysis of ethical issues in biology and medicine. It has adopted an increasingly international approach in its reports and developed new ways of working. In doing so, the Council now has achieved a significant body of analysis across a wide range of topics.

These achievements have only been possible because of sustained funding from our three sponsors which has enabled the Council to maintain its independence and thereby determine its own work programme and standards. The collective efforts of the Council staff and the many individuals drawn from academia, medicine, non-governmental organisations, industry and other sectors have also been fundamental to the Council's success.

In November 2006, I will be taking up a new role as Director of the Foresight Programme in the Government's Office of Science and Innovation. It has been an enormous privilege to serve the Council as its Director for the past nine years. I leave many good friends and colleagues at a time when the Council is well placed to take its work forward into a renewed five year funding period with the new Director, Hugh Whittall.

Professor Sandy Thomas

Forward Look seminar



Participants at the Forward Look seminar

The annual Forward Look seminar is when the Council considers topics for future work

The ethical issues raised by advances in neurosciences

What do we mean by consciousness? Neuroimaging offers new insights into the physical processes underlying mental states and challenges how we understand them. Will it become possible to predict intention, deception and intelligence, and if so, what are the potential uses of this information for employment and in solving crime?

Will we begin to attribute achievements to the use of cognitive enhancers rather than accomplishment by individuals? How will scientific and medical advances affect perceptions of human dignity and self worth?

These are some of the questions that members of the Council and invited guests considered at the Forward Look seminar in May, which focussed on ethical issues raised by advances in neuroscience. The discussions highlighted that this is a very wide-reaching topic and that the Council would need to select a particular area of neuroscience in any future work. The Council will explore further where that focus might best be directed in 2007.

Membership

Membership of Working Party

Professor Margaret Brazier OBE (Chair)

Professor of Law, The University of Manchester

Professor David Archard

Professor of Philosophy & Public Policy, Institute of 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 (until October 2006); Director, Centre for Ethics in Medicine, National University of Singapore (from October 2006)

Professor Linda Franck

Professor and Chair of Children's Nursing Research, Centre for Nursing and Allied Health Professions Research, Institute of Child Health, University College London and Great Ormond Street Hospital for Children NHS Trust

Ms Bonnie Green

Head of External Relations, BLISS – the premature baby charity, until January 2006

Professor Erica Haimes

Executive Director, Policy, Ethics & Life Sciences Research Institute Bioscience Centre, Newcastle upon Tyne

Dr Monica Konrad

Raising Fellow, 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

Professor of Paediatric Epidemiology, Institute of Child Health, University College London; member of the Nuffield Council (until March 2006)

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.
 - 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.
- 2 To examine scientific and medical research in these fields, considering in particular:
 - a. the relationship between changing survival rates and longer term outcomes.
 - b. the ethical and legal basis for providing, withdrawing or withholding life-prolonging treatment;
 - c. the process of decision-making, including the relative roles of families and healthcare professionals;
 - d. the availability of support for families in the short and the long term;
 - e. resource implications for providers of healthcare, education and social care.
- 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.
 - c. the process of decision-making, including the relative roles of families and healthcare professionals;
 - d. the availability of support for families in the short and the long term;
 - e. resource implications for providers of healthcare, education and social care.
- 4 To consider issues raised by advances in research and practice, particularly:
 - a. arguments about the moral and legal status of fetuses beyond the first trimester and the newborn;
 - b. the ethical and legal basis for providing, withdrawing or withholding life-prolonging treatment;
 - c. the process of decision-making, including the relative roles of families and healthcare professionals;
 - d. the availability of support for families in the short and the long term;
 - e. resource implications for providers of healthcare, education and social care.
- 5 In light of the above, to make recommendations.

publications during 2006

Critical care decisions in fetal and neonatal medicine: ethical issues

In November 2006, the Council published the Report *Critical care decisions in fetal and neonatal medicine: ethical issues*, which examines the ethical, social and legal issues which may be raised. Amongst other recommendations, the Report proposes guidelines to help parents and professionals make decisions about instituting intensive care for extremely premature and seriously ill babies. The Report was well received and gained extensive coverage in the local, national and international media around the time of the launch. Debate on this controversial topic continues, both in academic journals and the national media.



Neil Marlow and Stravros Petrou



Margot Brazier and Catherine Moody

The Council established a Working Party in October 2004 to consider the issues surrounding the treatment of extremely premature and seriously ill babies. The group, which met ten times between September 2004 and July 2006, included neonatologists, an obstetrician, a professor of child nursing, philosophers, lawyers, a health economist, and individuals who have worked with families of extremely premature babies and disabled children. Discussions were informed by a number of fact-finding meetings, including visits to neonatal units and a school for children with learning difficulties, meetings with parents and healthcare managers in the UK, and discussions with experts in France and The Netherlands. A wider consultation in spring 2005 yielded 100 responses, many of which are available to read on the Council's website. The Report was peer-reviewed by a panel of ten experts in April 2006, approved by the Council in August and published in November.

The Report

The Report: findings

The following is a brief summary of the Council's conclusions and recommendations, which are set out in detail in the Report.

Guidelines on giving intensive care to extremely premature babies

The Council took the view that it is not always right to put a baby through the stress and pain of invasive treatment if he or she is unlikely to improve and death is inevitable. However, the outcome for babies born between 22 and 26 weeks is often uncertain, which makes decisions about treatment very difficult. To help parents and doctors make decisions, the Council has proposed the first week-by-week guidelines on when to give intensive care to extremely premature babies.

Proposed guidelines

<22 weeks
Any treatment experimental

22-23 weeks
No resuscitation unless parents insist and doctors agree it is in baby's best interests

23-24 weeks
Precedence to wishes of the parents, although doctors not obliged to proceed if they judge that treatment would be futile

24-25 weeks
Intensive care given, unless parents and doctors agree not in baby's best interests

>25 weeks
Intensive care normally given

Active ending of life

The Council has concluded that the active ending of life of newborn babies should not be allowed, no matter how serious their condition. The professional obligation of doctors is to preserve life where they can. If doctors were to be permitted actively to end the lives of seriously ill newborn babies, there is a risk that the relationship between parents and doctors would be negatively affected. It would also be very difficult to identify an upper age limit beyond which actively ending life would not be allowed.

Withdrawing treatment and palliative care

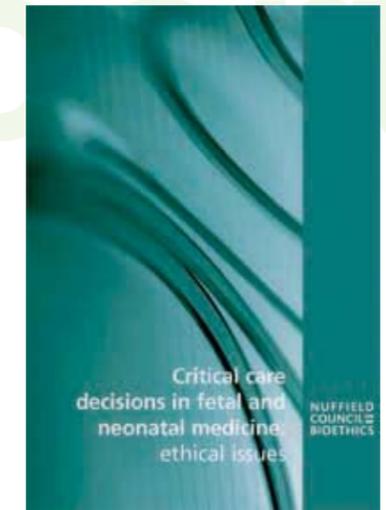
Once a decision has been made not to give or to cease giving life-saving treatment to a newborn baby, palliative care should be given. This involves relieving pain and making the baby as comfortable as possible until he or she dies, and providing support for the family. Knowledge and use of these techniques varies across the UK. The NHS should train all professionals working in neonatal medicine in palliative care.

Support for children who survive and their families

About two thirds of surviving babies born at 23-24 weeks have moderate or severe disabilities, although these children represent a very small proportion of the total number of children with disabilities. The Council urges the Government to accept further responsibility for ensuring that disabled children and their families receive equal access to high quality services.

Data collection and information

When making a decision about the care of their baby, parents must be provided with accessible information about the nature of any future disability. For this, it is crucial that more data are collected about the health of premature and seriously ill babies as they grow up, and that this information is linked to subsequent medical and educational records.



Avoiding the courts

The number of court cases where parents and doctors cannot agree on the treatment of a premature or seriously ill baby seems to be increasing. Getting a second medical opinion, or involving a clinical ethics committee or professional mediation may help to avoid the personal and financial costs of a court case.

Resource considerations

No healthcare system provides unlimited resources. At the local level, the Council recommends that doctors should continue to do the best possible for the baby in front of them. At the national level, there is a need for a much broader independent analysis of the use of NHS resources.

Fetal medicine

The Abortion Act 1967 permits termination of pregnancy after 24 weeks if the fetus is at "substantial risk of serious handicap". For terminations at 22 weeks or later, feticide is usually carried out to ensure that a baby is not born alive. When a woman does not want feticide, doctors may be concerned because they believe they are legally obliged to try to save a baby if he or she shows signs of life when born. The Council recommends that a code of practice should be developed to clarify what the law does and does not require doctors to do.

Report launch

The Report was launched at a public seminar held at the Institute of Physics on 16th November 2006. Working Party members presented the findings of the Report and took part in a lively discussion session chaired by Anjana Ahuja, a journalist at The Times newspaper. Around 100 people attended the launch, including children and parents, nurses, doctors, MPs and other policy makers, and spokespersons for disability and parent groups.

Copies of the Report and personal letters highlighting particular recommendations were sent to relevant organisations.

Over 500 copies were sent to other individuals and organisations. By the end of November, two weeks after the launch, almost 6000 electronic copies of the Report had been downloaded from the Council's website.

To coincide with the launch, Kevin Barron MP tabled an Early Day Motion (EDM) outlining the findings of the Report. EDMs are a way of raising awareness of current issues among MPs, who can sign the EDMs that they support. By the end of 2006, Mr Barron's EDM on the Report had received 46 signatures of support.



The launch seminar

Highlights of media coverage

The Report received comprehensive coverage both in the UK and around the world, a selection of which appears in the table below. A media briefing was held at the Science Media Centre, London, on 15th November to present the findings of the Report to journalists. Members of the Working Party were in high demand for interviews from the broadcast and print media in the week following the launch.

Date	Media	Item heading or description
15 Nov	The Daily Telegraph	"Babies born at 22 weeks 'should not be kept alive'"
	BBC Radio 4 Today Programme	Feature on the findings of the Report
	Radio 5 Live	Interview with Bonnie Green
	Sky News	Feature on the findings of the Report
	BBC News (News 24, One O'Clock News, 6 O'Clock News)	Feature on the findings of the Report
	Channel 4 News	Premature babies guideline (TV News report)
	ITN News	Feature on the findings of the Report
	Australian Broadcast Corporation	Interview with Professor Andrew Whitelaw
	16 Nov	The Guardian
The Independent		"Should doctors try to save extremely premature babies?"
The Times		"Very premature babies 'should not be treated'"
The Sun		"My little Luke was born at 23 weeks and he's perfect"
The Daily Mail		"Extremely premature babies 'should not be resuscitated' say doctors"
The Scientist		An article by Professor Margot Brazier: "How to treat premature infants"
New York Times		"Britain: Report Suggests No Care for Early Babies"
Canadian Broadcast Corporation News		"Earliest babies should not be revived: British medical ethics body"
Scotsman		"Should babies be allowed to die like this?"
Irish Times		"Doctors told let babies born at 23 weeks die"
British Medical Journal	"Ethics group rules on treating premature babies"	
25 Nov	The Lancet	"Editorial: The ethics of premature delivery"

Comments

Comments in response to the Report

"These guidelines will help maternity and neonatal staff to make difficult decisions in consultation with parents, and to provide the best care available to those that need it."

Professor Allan Templeton, President of the Royal College of Obstetricians and Gynaecologists

"For neonatal paediatricians there are occasionally tragic circumstances in which, jointly with the child's family, we are forced to wrestle with dreadful choices. We therefore welcome any support and guidance that can be given to staff and parents involved in these difficult cases."

Statement released by Royal College of Paediatrics and Child Health

"BLISS welcomes the clear guidelines set out by the Nuffield Council of Bioethics on resuscitation of very premature babies."

Andy Cole, Chief Executive of BLISS, the premature baby charity

"The DRC is against such a blanket rule [to offer no intensive care to babies born at or before 22 weeks]. The decision to treat or not treat should be based on individual assessment."

Bert Massie, Chairman of the Disability Rights Commission

"We warmly welcome the clear recommendation from the Nuffield Council today that "the active ending of life of newborn babies should not be allowed, no matter how serious their condition."

Joint comment by Rt Rev Tom Butler, Bishop of Southwark, and Most Rev Peter Smith, Archbishop of Cardiff, on behalf of the Church of England House of Bishops and the Catholic Bishops' Conference of England and Wales

"We support the recommendation that there should be full discussion between healthcare professionals and parents, with all the options and their consequences being explained fully."

Andrew Ross, Chief Executive of The Children's Trust



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Post-publication activities

Several presentations on the findings were given at meetings (detailed below) in the weeks after the Report was launched. The Council also distributed copies of the Report at exhibition stands at the Neonatal Update conference organised by Imperial College London in November and at the NICE Annual Conference in December. By the end of the year, the Report had been downloaded from the Council's website 9500 times. Further initiatives to raise awareness of the Report will be undertaken in 2007.

Highlights of presentations

Date	Conference/meeting	Title	Speaker
8 Nov	Shaping science: a conference for students of AS Science for Public Understanding, Bristol, organised by the Royal Institution	Treating extremely premature or seriously ill babies: decisions at the edge of life	Dr Catherine Moody
22 Nov	Shaping science: a conference for students of AS Science for Public Understanding, London, organised by the Royal Institution	Treating extremely premature or seriously ill babies: decisions at the edge of life	Professor Linda Franck
12 Dec	Literacy and Philosophy Society of Manchester, Manchester	Critical care decisions in fetal and neonatal medicine: ethical issues	Professor Margot Brazier

Membership

Membership of the Working Party

Lord Krebs MA DPHIL Kt FRS FMedSci
Principal, Jesus College, Oxford

Dr Raghb Ali
Clinical Lecturer, Department of Clinical Pharmacology, Green College, University of Oxford

Professor Tom Baldwin
Department of Philosophy, University of York; member of the Council until January 2006

Professor Roger Brownsword
Professor of Law, King's College London; member of the Council

Professor Sir Kenneth Calman KCB FRCS DL FRSE
Vice-Chancellor and Warden, University of Durham; member of the Council

Professor Christine Godfrey
Professor of Health Economics, Centre for Health Economics & Department of Health Sciences and Clinical Evaluation, University of York

Professor Trisha Greenhalgh OBE
Professor of Primary Health Care, Department of Primary Care and Population Sciences (PCPS), University College London

Professor Anne Johnson FMedSci
Professor of Infectious Disease Epidemiology and Head of Department, Department of Primary Care and Population Sciences (PCPS), University College London

Professor Sally Macintyre OBE FRSE CBE
Director, MRC Social and Public Health Sciences Unit, University of Glasgow

Professor Jonathan Montgomery
Professor of Health Care Law at the University of Southampton School of Law

Julia Unwin OBE CBE
Director, Joseph Rowntree Foundation (from January 2007); Deputy Chair, Food Standards Agency (until December 2006) and Senior Associate, King's Fund

Terms of reference

- 1 To identify and consider ethical, legal and social issues arising when designing measures to improve public health.
- 2 To consider, by means of case studies:
 - a. the variety of aims for such measures, such as informing individual choices and protecting the wider community, and their relative priorities;
 - b. the role of autonomy, consent and solidarity;
 - c. issues raised by decisions about, and perceptions of, risk;
 - d. criteria for the allocation of resources in specific areas of public health;
 - e. the special situation of children and those who are poor or socially excluded.
- 3 To examine the implications of the above for the development of frameworks for policy making in public health.

work in progress

**Public health:
ethical issues**

Public health is on the political and public agenda, with bans on smoking in public places introduced in several European countries, a dramatic rise in the level of obesity and recent controversy surrounding the MMR vaccine. The Council established a Working Party in January 2006 to consider the ethical issues raised in the context of public health. Major themes include challenges posed by balancing individual choice and community benefit, and the role of third parties, such as the role of the food and drink industry with respect to obesity.



Julia Unwin, Anne Johnson and Kenneth Calman

The Working Party on *Public health: ethical issues* met six times in 2006 and the minutes of these meetings are available on the Council's website. There are 11 members of the Working Party, with expertise in health economics, law, philosophy, public health policy, health promotion and social science. A Report is expected to be published in autumn 2007.

Public health has been described as 'the science and art of preventing disease, prolonging life and promoting health through organised efforts of society', but what are the responsibilities of governments, individuals and third parties, such as industry, in achieving this? A range of factors can affect public health, including the environment, available health services and the choices people make in relation to health risks. Equally, there are different ways in which governments can influence public health, from education programmes to legislation.

The Working Party is considering these issues in five contexts, chosen because each raises different ethical issues:

- infectious diseases;
- obesity;
- smoking;
- alcohol; and
- the supplementation of food and water.

Wider consultation

A consultation was held between May and September 2006 in order to find out more about the views of individuals and organisations with an interest in this area. Background information on the issues was provided in a Consultation Paper which asked questions in the context of the five cases above. For example:

- Are there cases where the vaccination of children against the wishes of their parents could be justified?
- Would measures such as forced quarantine, which helped to control the outbreak of SARS in Asia, be acceptable in countries such as the UK?
- What are the roles and obligations of parents, schools, school-food providers and the government in tackling childhood obesity?
- Should people who smoke or drink excessively be entitled to fewer resources from the public healthcare system, or should they be asked for increased contributions?
- Fortification of foodstuffs such as flour and margarine have been accepted for some time. Why does the fluoridation of water meet with such resistance?

The Working Party considered a wide range of responses which were received from individuals and organisations.



A response to the consultation from a school

Meetings

Fact finding meetings

Contribution from young people

With contributions from the Working Party, Ecsite-UK, the UK Network of Science Centres and Museums, organised a series of workshops for young people between April and September 2006 on the ethical issues surrounding vaccination policy during the period of the wider consultation. A total of 503 people aged 14-19 took part in debates in schools and science centres around the country. Along with the other responses to the consultation, these findings were submitted to the Working Party.

The Council and the Working Party would like to thank everyone who contributed to the consultation. Where permission has been granted, the responses will be available to download from the Council's website after the Working Party has published its Report.

Experts from the following organisations met the Working Party as part of its research during 2006:

- Food and Drink Federation
- Foresight Obesity Project, Office of Science and Technology
- MRC Human Nutrition Research, Cambridge
- London Sport Institute, Middlesex University
- British Fluoridation Society
- National Pure Water Association
- All Party Parliamentary Group Against Water Fluoridation

- British Nutrition Foundation
- Institute of Alcohol Studies, London
- British Beer and Pub Association
- South London and Maudsley NHS Trust
- Action on Smoking and Health
- Centre for Social Marketing, University of Sterling
- Tobacco Manufacturing Association
- Vaccination Awareness Network UK
- Health Protection Agency
- Department of Health
- London School of Hygiene & Tropical Medicine, London

Highlights of media coverage

The Working Party received media coverage around the launch of the consultation in spring and summer 2006, mainly in specialist publications, as shown below.

Date	Media	Item heading or description
19 May	BBC Radio 4, Today Programme	Interview with Lord Krebs
	BBC News Online	"Call for debate on public health"
	Medical News Today	"Nuffield Council seeks views on the ethics of public health"
20 May	British Medical Journal Online	"Body consults to balance public health against private rights"
23 May	Public Health Genetics Unit	"Nuffield Council on Bioethics launches consultation on the ethics of public health"
24 May	Science in School (a European journal for science teachers)	"Have your say: bioethics public consultation"
2 June	PublicHealthNews.com	"Should smokers and drinkers be denied health care?"
June	Royal Society for Promotion of Health News Brief	"Nuffield Council launches consultation on the ethics of public health"
12 July	Afiya Trust website	"Public health: ethical issues"
7 Aug	Philosophy Now magazine	"Public health and ethical issues"

Membership

Membership of Working Group

Professor Sir Bob Hepple QC FBA (Chair)

Emeritus Master of Clare College and Emeritus Professor of Law, University of Cambridge; Judge of the UN Administrative Tribunal; Barrister, Blackstone Chambers, London; and Chairman of the Nuffield Council on Bioethics

Mr Graham Cooke

Barrister

Professor Søren Holm

Professorial Fellow in Bioethics, Cardiff Law School and part-time Professor of Medical Ethics, University of Oslo, Norway; member of the Council

Professor Graeme Laurie

Co-Director, AHRB Centre for Research into Intellectual Property and Technology, School of Law, University of Edinburgh

Dr Bronwyn Parry

Reader in Social and Cultural Geography, Queen Mary University of London

Professor Andrew Read

Professor of Human Genetics, University of Manchester

Mr Robin Williams

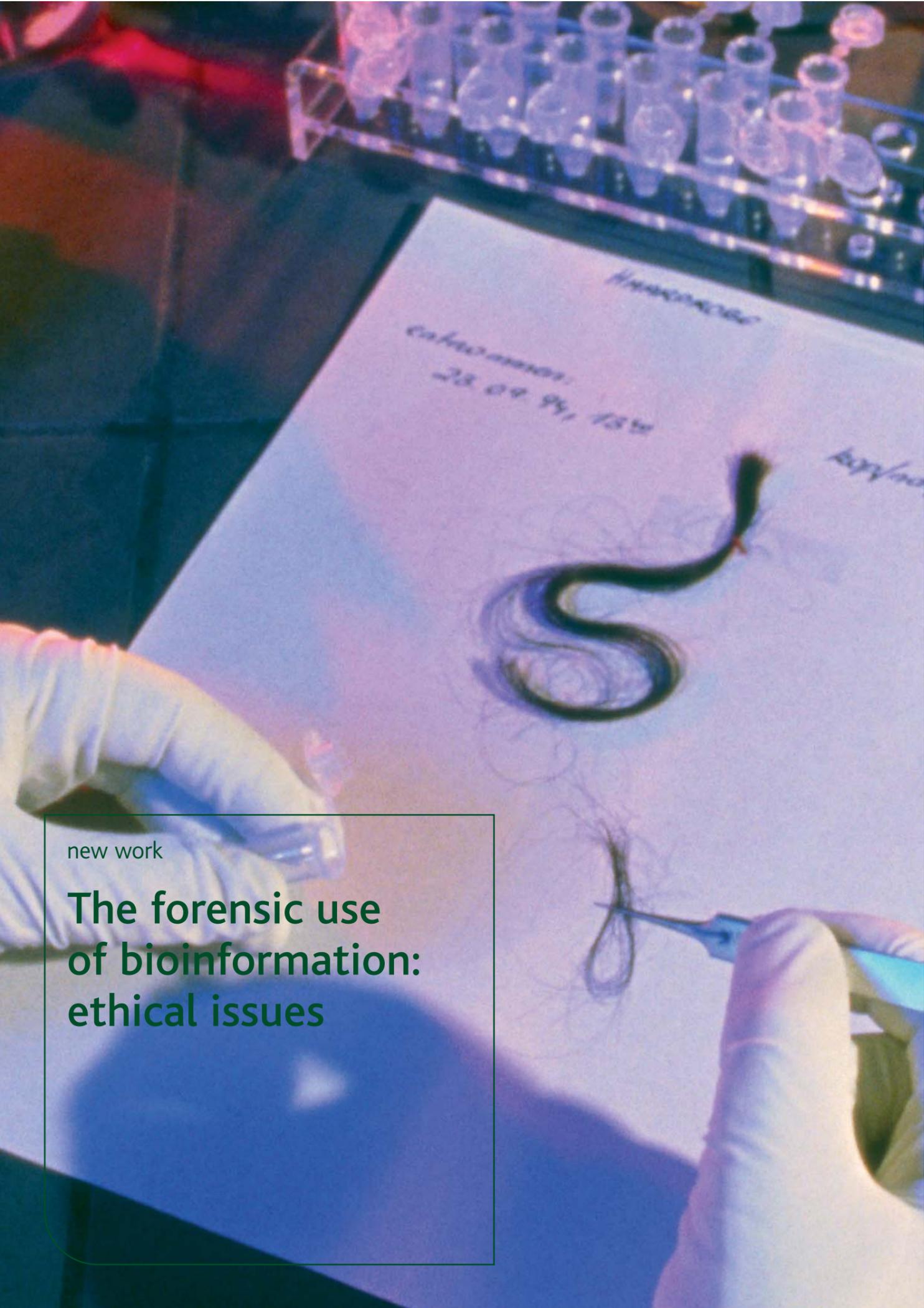
Reader in Sociology, School of Applied Social Sciences, University of Durham

Terms of reference

- 1 To identify and consider the ethical, social and legal issues raised by current and potential future uses of bioinformation for forensic purposes.
 - a. the interpretation of the information;
 - b. the collection, storage and retention of profiles and samples;
 - c. use of forensic databases for the identification of blood-related, deceased and missing persons;
 - d. issues of informed consent, privacy and confidentiality in the light of data protection and human rights legislation;
 - e. arguments for and against population-wide forensic databases;
 - f. access to and use of forensic databases for purposes of research;
 - g. admissibility and use of bioinformation in criminal proceedings;
 - h. sharing of bioinformation for forensic purposes across international boundaries;
 - i. use for forensic purposes of bioinformation collected for non-forensic purposes; and
 - j. governance of research conducted by or for forensic laboratories.
- 2 To consider, in particular:
 - a. the interpretation of the information;
 - b. the collection, storage and retention of profiles and samples;
 - c. use of forensic databases for the identification of blood-related, deceased and missing persons;
 - d. issues of informed consent, privacy and confidentiality in the light of data protection and human rights legislation;
 - e. arguments for and against population-wide forensic databases;
 - f. access to and use of forensic databases for purposes of research;
 - g. admissibility and use of bioinformation in criminal proceedings;
 - h. sharing of bioinformation for forensic purposes across international boundaries;
 - i. use for forensic purposes of bioinformation collected for non-forensic purposes; and
 - j. governance of research conducted by or for forensic laboratories.
- 3 To identify the ethical and legal principles and procedures which should govern the forensic use of bioinformation, and to make recommendations.
- 4 To draft a Discussion Paper on these issues.

new work

The forensic use of bioinformation: ethical issues



Forensic analysis of bioinformation such as DNA sampling and fingerprinting is now routinely used in crime-solving. A workshop held by the Council in February revealed a lack of ethical consistency in the way that bioinformation is used and, amid much media interest, the Council formed a Working Group in September 2006 to examine the topic further. The Group is focusing on the issues raised by the use and storage of DNA collected by the police.

The police in England and Wales have powers, unrivalled internationally, to take a DNA sample from any arrested individual, without their consent. The DNA profile (relevant information that has been extracted from the DNA sample) is stored on the National DNA Database (NDNAD) indefinitely, whether or not the person is charged. The police use the database to search for matches to DNA found at crime scenes. Under present laws, it is predicted that 25% of the male population and 7% of the female population will soon be included on the database.

The forensic use of bioinformation raises a number of ethical, social and legal issues concerning:

- the interpretation of the bioinformation;
- the collection, storage and retention of profiles and samples;
- informed consent, privacy and confidentiality in the light of data protection and human rights legislation;
- access to and use of forensic databases for purposes of research;
- sharing of bioinformation for forensic purposes across international boundaries; and
- governance of research conducted by or for forensic laboratories.

The Working Group, which includes members with expertise in law, genetics, philosophy and social science, met for the first time in September 2006. A Discussion Paper setting out the Group's findings will be published in autumn 2007.



Workshop on the forensic use of bioinformation

Consultatio

Wider consultation

To inform discussions, the Group launched a consultation in October 2006. The Consultation Paper provided background information and posed a number of questions, such as:

- Do you consider the current criteria for the collection of bioinformation to be proportionate to the aims of preventing, investigating, detecting and prosecuting criminal offences?
- Is it acceptable for bioinformation to be taken from minors and for their DNA profiles to be put on the NDNAD?
- What, if any, research on NDNAD profiles or samples should be permitted?

- Certain groups, such as ethnic minorities and young males, are disproportionately represented on forensic databases. Is this potential for bias within these databases acceptable?
- Is it acceptable that volunteers (such as victims, witnesses, mass screen volunteers) also have their profiles retained on the NDNAD?
- Would the collection of DNA from everyone at birth be more equitable than collecting samples from only those who come into contact with the criminal justice system?

The deadline for responses was 30 January 2007.

"We want to hear the public's views on whether storing the DNA profiles of victims and suspects who are later not charged or acquitted is justified by the need to fight crime."

Professor Sir Bob Hepple QC, Chairman of the Nuffield Council on Bioethics

Highlights of media coverage

The Council worked with the Science Media Centre to host a media briefing at the start of the consultation in October. The launch coincided with the Prime Minister, Tony Blair, advocating that no restrictions should be placed on the number of DNA profiles held on the National DNA Database. This may have contributed to the significant coverage that the consultation received in the printed and broadcast media.

Date	Media	Item heading or description
1 Nov	BBC Radio 4 Today Programme	Interview with Professor Sir Bob Hepple
	Channel 4 News	Interview with Professor Sir Bob Hepple
	BBC TV News	Interview with Professor Sir Bob Hepple
	BBC Radio 5 Live	Interview with Dr Bronwyn Parry
	Radio Jersey	Interview with Dr Carole McCartney
	The Independent	"Growing DNA database 'turning Britain into a nation of suspects'"
	The Mirror	"Public views sought on DNA database"
	The Daily Mail	"Alarm as innocent people fill DNA database"
	The Daily Express	"Public questioned over DNA database"
3 Nov	The Times	"We are all suspects now"
	Science	"Investigating the investigators"
	The Guardian	Comment: "We are already at the gates of the surveillance society"
16 Nov	Police Professional Magazine	"Public opinion sought on DNA Database"
22 Nov	BBC Radio Northampton	Interview with Dr Bronwyn Parry
6 Dec	Belfast Telegraph	"What is the DNA database, and why do we have so many people on it? "
11 Jan	The Barrister Magazine	Article by Professor Sir Bob Hepple: "The National DNA Database: crime solving tool or violation of civil liberties?"

Membership

Membership of Working Group

Professor Elizabeth Anionwu

Professor of Nursing, Head of Mary Seacole Centre for Nursing Practice, Thames Valley University; member of the Working Party on Genetic Screening (1993)

Professor Martin Bobrow

Head of Department of Medical Genetics, Cambridge Institute for Medical Research, University of Cambridge

Professor Neva Haites

Professor in Medical Genetics and Associate Dean (Clinical), University of Aberdeen

Professor Peter Harper

University Research Professor in Human Genetics, Cardiff University; member of the Council and member of the Working Party on Genetic Screening (1993)

David Shapiro

Former Executive Secretary of Nuffield Council on Bioethics

Terms of reference

1 To identify developments in the area of genetic screening since the publication of the Council's Report (1993), with particular reference to the Genetics White Paper published in June 2003.

2 To consider whether any further action is required and to produce a short paper.

The Council's first Report *Genetic Screening: ethical issues (1993)* remains one of its most frequently requested publications. In August 2006, the Council published a Supplement to the Report, which summarises the scientific, technological and policy-related developments that have taken place over the past 13 years.

The Supplement: findings

Only a small number of additional genetic screening programmes have been introduced since 1993. Most developments have concerned the expansion of existing projects or pilot schemes into national programmes. Although many more gene variants for rare single-gene disorders have been identified, they are rare in the population and screening has not been recommended. The difficulties in developing accurate tests for common diseases, such as coronary heart disease and diabetes, have also been a factor.

There are important issues surrounding how consent to take part in a screening programme is obtained, how professionals convey any unexpected information, and whether genetic counselling is offered prior to or after the test has been carried out. If genetic screening became more widespread, there are concerns that the demands of consent and counselling should not become so burdensome as to slow the introduction of new programmes or to restrict existing programmes. For this reason, the Council proposes that counselling should be concentrated on those conditions that threaten life or have a serious impact on the ability to live life fully.

Currently, there is no evidence that UK employers are carrying out genetic testing as a condition of employment, and the HGC has concluded that employers should not demand this in future. The Council endorses the continuation of the current Moratorium that restricts the use of genetic test results by insurance companies, which we consider places insurance companies at little disadvantage.

The ethical analysis of the original Report was judged to be still relevant and has not been expanded further in the new publication.

follow-up work

**Genetic screening:
a supplement
to the 1993 report
by the Council**



External relations

The website

The website

The Council's website continues to be an important method of communicating with its stakeholders. The site received over 114,000 different visitors in 2006. All Reports, minutes of Council and Working Party meetings, and responses to the Council's consultations (where permission is given) can be downloaded from the website.

Number of downloads of Council publications in 2006

Publication	Number of downloads
Genetic Screening: ethical issues	23,542
Human tissue: ethical and legal issues	8,050
Animal-to-human transplants: the ethics of xenotransplantation	10,076
Mental disorders and genetics: the ethical context	9,947
Genetically modified crops: the ethical and social issues	31,424
Stem cell therapy: the ethical issues	4,143
The ethics of research related to healthcare in developing countries	34,865
The ethics of patenting DNA	5,980
Genetics and human behaviour: the ethical context	14,959
Pharmacogenetics: ethical issues	4,043
The use of genetically modified crops in developing countries	2,046
The ethics of research related to healthcare in developing countries: a follow-up Discussion Paper	4,896
The ethics of research involving animals	96,201
Genetic Screening: a supplement to the 1993 Report by the Council (since 21 August 2006)	1732
Critical care decisions in fetal and neonatal medicine (since 16 November 2006)	8,467

Short Guides to Reports

Although the Council's Reports are designed to be as accessible as possible, they also aim to provide information on context, which means that they can be more than a hundred pages in length. The Council's series of Short Guides provides eight-page summaries of the main conclusions and recommendations in Reports published since 2004. In 2006, the Council published Guides to two older Reports: *Genes and human behaviour: the ethical context* (2002) and *The ethics of research related to healthcare in developing countries* (2002).



Media activities

The work of the Council has always attracted the attention of the media, but 2006 saw an unprecedented level of coverage of its publications and consultations.

Interest by journalists in the launch of the Council's consultation on the forensic use of bioinformation in October, highlighted the strong views that many members of the public have on the police use of DNA. Comments on the topic by the Prime Minister just before the launch, and by Sir Alec Jeffries (who developed the technique of DNA fingerprinting) in response to the consultation, gave the story even more 'news value'. Working Group members were kept busy conducting interviews for the national broadcast and printed press for several days after the launch, and the coverage generated raised awareness of the consultation.

Stories about premature babies arouse strong emotions and are a regular feature in the media. It was not surprising therefore that the Council's Working Party on *Critical care decisions in fetal and neonatal medicine: ethical issues* attracted regular attention from journalists after establishment in 2004. The publicity grew as the launch date of the Report approached. Articles and interviews with Working Party members

appeared in most of the national media and many international outlets around that time. Debate on the Council's findings was still appearing regularly in email discussion lists and newsletters at the end of the year. One of the key audiences the Working Party had hoped to reach was parents, which made the level of news coverage received by this Report particularly welcome.

The Council would like to thank the Science Media Centre for providing regular advice and support to the Council on its work with the national news media throughout 2006.

“SHOULD DOCTORS TRY TO SAVE EXTREMELY PREMATURE BABIES?”

THE INDEPENDENT

“PUBLIC QUESTIONED OVER DNA DATABASE”

DAILY EXPRESS

Presentations

Presentations

Members of the Council and Secretariat regularly give presentations at meetings and conferences in order to discuss the findings of the Council's Reports with a range of audiences.

Highlights of presentations relating to previous reports and general bioethics

Date	Conference/meeting	Title	Speaker
7 Jan	Association of Science Education Annual Meeting, University of Reading	The Nuffield Lecture: The ethics of animal experimentation and human embryonic stem cells	Professor Martin Raff
25 Jan	World Economic Forum, Davos, Switzerland	Human enhancements, the meaning of race and ethnicity, and science, religion and the search for truth	Professor Sandy Thomas
8 March	Lecture at the Science and Technology Policy Research Unit, University of Sussex	The ethics of research involving animals	Harald Schmidt
8 March	The Centre for International Governance Innovation (CIGI) Leaders' Summit (L)20 Project Conference, Maastricht, The Netherlands	Intellectual property rights in developing countries	Harald Schmidt
10 March	Seventh European Forum of National Ethics Councils, Vienna	Ethics and developing countries	Harald Schmidt
6 April	UK Institute of Animal Technology Congress, Jersey	The ethics of research involving animals	Harald Schmidt
27 April	BioVision Alexandria 2006, Egypt	Ethics in the life sciences: clinical research in developing countries and GM crops	Professor Sandy Thomas
20 June	Seminar held by the Animal Research Ethics Committee, University College Dublin	The ethics of research involving animals	Harald Schmidt
15 Sept	Association of Clinical Research Professionals (ACRP) 2006 European Conference on Risk and Risk Management, Brussels	The ethics of research related to healthcare in developing countries	Harald Schmidt
22 Nov	Meeting of the European Federation of Pharmaceutical Industries and Associations, Brussels	The role of alternatives in ethical animal experimentation	Harald Schmidt



Engagement with policy makers

Many of the recommendations in Reports of the Council are aimed at policy makers, such as government departments, research councils, professional and regulatory bodies and parliamentarians. In order to raise awareness of our work and discuss the implementation of recommendations, members of the Council and Secretariat regularly attend meetings and conferences to engage with policy makers. For example, the Council meets annually with the Human Genetics Commission and the Department of Health. Meetings with individuals or organisations to discuss specific recommendations are also arranged after the publication of a Report.

The Council has recently begun to send one-page summaries of Reports to all Members of the English and Scottish Parliaments after publication, providing a brief overview of the main conclusions and recommendations. Early Day Motions are also used to raise awareness of the Council's work (see p 12).

Responding to the consultations of other organisations is another way in which the Council can raise awareness of its recommendations. In 2006, responses were submitted to the following consultations:

- **Expert Group on Clinical Trials**
Evidence to the Expert Group on Clinical Trials
July 2006
- **European Commission**
Revision of Directive (86/609/EEC) for the protection of animals used in experiments
July 2006
- **Department of Health**
Draft regulations under the Mental Capacity Act 2005
September 2006
- **Human Fertilisation and Embryology Authority**
Donating eggs for research: Safeguarding donors
December 2006

International activities



Members of Council and the French CCNE in Paris

Bilateral meetings with European bioethics committees

The Council holds annual bilateral meetings with the Comité Consultatif National d'Ethique (CCNE), France, and the Nationaler Ethikrat, Germany, to discuss issues of common interest and to compare and contrast perspectives.

Members of Council visited the CCNE in Paris in January 2006 to discuss two topics of common interest: the ethics of neuroscience and the use of bioinformation for forensic purposes. The German Nationaler Ethikrat hosted this year's bilateral meeting with the Council in Berlin in April 2006. The topics discussed were ethical issues surrounding neuroscience and those relating to the possible availability of complete personal genome sequencing.

Forum of National Ethics Committees

The European Commission's Directorate General for Research established a Forum of National Ethics Committees (NEC) in 2002. The NEC aims to facilitate networking and discussion of topics of mutual concern between the national bioethics committees of EU countries. The seventh Forum took place in Vienna, Austria, in March 2006, where Assistant Director Harald Schmidt gave a presentation on the work of the Council on the ethics of clinical research in developing countries.

Educational activities

Bioethics issues are reported in the news almost every day and it is important that young people are given the opportunity to debate and discuss these topics more thoroughly. The Council has therefore increased its emphasis on engagement with this important audience.

Established in 2003, the Council's Reaching Out to Young People Advisory Group meets regularly to develop initiatives to help the Council's Reports to reach a young audience.

Members of the Reaching Out to Young People Advisory Group

Professor Sir Kenneth Calman KCB FRSE (Chair)

Vice-Chancellor and Warden,
University of Durham; member of
the Council

Angela Hall

Director, Science Learning Centre
London

Mr Andrew Hunt

Director, Nuffield Curriculum Centre

Dr Rhona Knight

General Practitioner and lecturer;
Member of Council

Dr Sarah Lindfield

Deputy Head, Haberdashers' Aske's
School for Girls

Revd Professor Michael Reiss

Professor of Science Education,
Institute of Education

Mr Ian Richardson

HMI Specialist Adviser for Science

Jenny Wales

Director of Education for Citizenship,
Nuffield Foundation



Teachers discussing educational resources on animal research

The Council works with a number of organisations in an advisory role in order to reach young people through a variety of channels.

Nuffield Curriculum Centre

The Nuffield Curriculum Centre advises the Council on the relevance of its Reports to the national curriculum and how best to make issues in bioethics accessible to teachers and students. The new science GCSE curriculum, which schools began teaching in September 2006, recognises the importance of ethical debate and encourages students to discuss the impact of contemporary science on society.

In 2006, the Council worked with the Centre to produce resources for teachers on the topic of research involving animals. At present, there is little guidance on which subject this topic should fit into or how to structure the lesson. A workshop involving a number of science and citizenship teachers took place in June 2006 to discuss the kind of resources that would be most useful. As a result, materials were developed which, it is envisaged, will be piloted in early 2007.



Students at an Ecsite-UK workshop on vaccinations

Ecsite-UK

The Council works with Ecsite-UK, the UK Network of Science Centres and Museums, to encourage young people to participate in the Council's work. In 2006, the Council's Working Party on *Public health: ethical issues* advised Ecsite-UK on the development of a workshop on the ethical issues surrounding vaccination. A total of 503 people aged 14-19 took part in debates about vaccination in schools and four science centres around the country between April and September 2006. The views expressed were reported to the Council during its consultation on the ethics of public health. In 2005, the Council worked with Ecsite-UK to develop workshops on the issues surrounding decision making about the care of premature babies. Several science centres ran this workshop for a second time in 2006 as part of their programmes of events for schools.



A scene from the play *Every Breath*

Y Touring Theatre Company

Y Touring, the Central YMCA's national touring theatre company, produces plays for young people that explore the issues of health, sex education and ethical issues in science. In 2005, the Council advised on the content of a play about the use of animals in medical research, entitled *Every Breath*. In 2006, the play toured schools, science festivals and science centres around the country, engaging thousands of young people in debate about this controversial issue. The play won an award for artistic merit and effort at the Edinburgh Festival in August 2006. A further tour of the play is planned for 2007.

Annex A: Financial report

Financial Report for the year to 31 December 2006

	2006 Actual £	2005 Actual £
Expenditure		
Salaries and staffing costs	406,894	342,932
Office costs including premises	8,478	7,642
Stationery and press cuttings	11,705	13,861
Photocopy, post, phone, fax	35,933	33,987
Committee and meeting costs	71,970	62,413
Printing and publicity of Reports	33,108	29,413
Web and other technology costs	6,955	1,075
Net direct expenditure	575,043	491,323
Funding Due		
Nuffield Foundation	137,154	160,636
Medical Research Council	137,154	160,636
Wellcome Trust	137,154	160,637
Reports sold	1,938	2,939
Other income	468	9,219
	413,867	494,067
Surplus/ (Deficit)	-161,176	2,744
Balance Brought Forward	-161,176	158,432
Balance Carried Forward	0	161,176
Overheads met by Nuffield Foundation	301,259	266,283

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

**The ethics of research related to
healthcare in developing countries:
a follow-up Discussion Paper**
Published March 2005

The ethics of research involving animals
Published May 2005

**Genetic screening: a Supplement to
the 1993 Report by Nuffield Council
on Bioethics**
Published July 2006

**Critical care decisions in fetal and
neonatal medicine: ethical issues**
Published November 2006

All of these publications are available to download from the Council's website at: www.nuffieldbioethics.org. Short Guides are also available for the more recent publications.

Printed copies or CDs may be ordered by contacting:

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