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About the Council

The Nuffield Council on Bioethics examines ethical issues raised by new developments in biology and medicine, with a view to providing independent advice to policy makers and stimulating debate in bioethics. It does this by setting up expert Working Parties on specific topics, which consider the issues over a period of one to two years. After listening to the views of stakeholders, a thorough analysis of the evidence and a public consultation, the Council publishes its conclusions and recommendations.

In the past, we have considered topics as diverse as genetic screening, genetically modified crops, the treatment of premature babies and the use of animals in research. The Council is an independent body, funded jointly by the Nuffield Foundation, the Medical Research Council and the Wellcome Trust. In 2007, it published two major reports, on the forensic use of bioinformation and public health.

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.

Detailed information about the Council and its work can be found at: www.nuffieldbioethics.org

Changes in membership

After leading the Council for the past five years, Professor Sir Bob Hepple’s chairmanship of the Council came to an end in December 2007. Professor Hepple chaired the Council’s Working Party on Genetics and human behaviour in 2002, before being appointed Chair of the Council at the beginning of 2003. More recently he headed the Working Party on The forensic use of bioinformation. He is succeeded by Professor Albert Waale, Professor of Government at the University of Essex.

Professor Albert Waale
(Chairman from January 2008)
Albert Waale is Professor of Government at the University of Essex where his academic interests focus on political theory and public policy. He is co-editor of the British Journal of Political Science.

The Council welcomed Professor Tony Hope, who is co-opted to the Council for the period of the Working Party on Dementia: ethical issues, which he is chairing. Dr Alan Williamson and Lord Plant reached the end of their term on Council in 2007.

Lord Krebs was a co-opted member for the duration of the Working Party on Public Health ethical issues and was a co-opted member of the Council for the duration of the committee’s work.

Professor Peter Harper
(Chairman from January 2008)
Professor Peter Harper is University Research Professor in Human Genetics, Cardiff University. His research interests include inherited neurological disorders, especially Huntington’s disease and myotonic dystrophy. He has been extensively involved in the practice and development of genetic counseling.

Howard Guest

Dementia: ethical issues

The Council welcomed Professor Tony Hope, who (Chairman from January 2008)

Professor Tony Hope
(Chairman, until December 2007)

Bob Hepple is Emeritus Master of Clare College, Emeritus Professor of Law at the University of Cambridge, and a barrister at Blackstone Chambers, London. In 2007, he was appointed judge of the United Nations Administrative Tribunal. In 2006–7, Professor Hepple chaired the Council’s Working Party on The forensic use of bioinformation.

Professor Peter Smith CBE FMedSci
(Deputy Chairman)

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

Professor Kwok Yung Lo

Professor Kwok Yung Lo is an Emeritus Professor at the Chinese University of Hong Kong and a co-opted member of the Council for the duration of the committee’s work.

Professor Peter Harper

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

The Rt Rev Lord Harries of Pentregarth D D FKC FRSL

Lord Harries was Bishop of Oxford from 1987 to 2006. He is Chair of the Ethics and Law Advisory Group at the HFEA, and was formerly Dean of King’s College, London where he is Honorary Professor of Theology. He chaired the House of Lords Select Committee on Stem Cell Research.

Professor Ray Hil FMedSci

Ray Hil is Head of Licensing and External Research for Europe at Merck, Sharp & Dohme. He is a pharmacologist with a special interest in pain and headache research and is a Visiting Professor at Birkbeck, Somny and Strathclyde Universities. He is an Honorary Professor at the Istanbul Institute, Cambridge.

Professor Søren Holm

Søren Holm is Professorial Fellow in Bioethics at Cardiff Law School, and part-time Professor of Medical Ethics at the University of Oslo, Norway. He is a medical doctor and philosopher and was a Visiting Professor at the Danish Council of Ethics from 1994–99. He is the President-Elect of the European Society for the Philosophy of Medicine and Health Care.

Professor Tony Hope

From November 2007

Tony Hope is a Professor of Medical Ethics, University of Oxford, and an Honorary Consultant Psychiatrist. In 1997 he co-founded the Oxford Centre of Ethics and Communication Skills in Health Care Practice (Ethos). His research areas include mental health and neuroscience and clinical ethics. Professor Hope is Chair of the Council’s Working Party on Dementia: ethical issues, and a co-opted member of the Council for the duration of the group’s work.

Mr Anatoly Kalatsky

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

Dr Rhona Knight FRCPG

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

Lord Krebs Kt FRS FMedSci

Until November 2007

Lord Krebs is Principal of Jesus College, Oxford. He is the former Chairman of the Foods Standards Agency and former Chief Executive of the Natural Environment Research Council. His areas of interest include ecology and behaviour, and the relationship between science and policy. Lord Krebs chaired the Council’s Working Party on Public Health ethical issues and was a co-opted member of the Council for the duration of the committee’s work.

Professor Peter Lipton FMedSci

Peter Lipton was Head of the Department of History and Philosophy of Science and Fellow of King’s College at the University of Cambridge (see page 4).

Professor Sir Kenneth Calman KCB FRSE

(Deceased, November 2007)

Kenneth Calman is Chancellor of the University of Glasgow. He was Vice-Chancellor of Durham University until 2007. He trained in surgery and was formerly Chief Medical Officer for Scotland and England, and Chairman of the WHO Executive Board. From 2001 until January 2006 Professor Calman chaired the Council’s sub-group on Reaching Out to Young People.

Lord Plant of Highfield

Until October 2007

Lord Plant was Master of St Catherine’s College, Oxford from 1994 to 2000 before returning to Southampton University as Professor of European Politics until 2007. He is now Professor of Legal and Political Philosophy at King’s College London.

Professor Sir Bob Hepple QC FBA

Bob Hepple is Emeritus Master of Clare College, Emeritus Professor of Law at the University of Cambridge, and a barrister at Blackstone Chambers, London. In 2007, he was appointed judge of the United Nations Administrative Tribunal. In 2006–7, Professor Hepple chaired the Council’s Working Party on The forensic use of bioinformation.

Professor Sir Kenneth Calman

KCB FRSE

Kenneth Calman is Chancellor of the University of Glasgow. He was Vice-Chancellor of Durham University until 2007. He trained in surgery and was formerly Chief Medical Officer for Scotland and England, and Chairman of the WHO Executive Board. From 2001 until January 2006 Professor Calman chaired the Council’s sub-group on Reaching Out to Young People.

Professor Peter Harper

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

Howard Guest
A tribute by Professor Albert Weale

‘An email message is perhaps not qualitatively different from a hand-written letter; but it does not follow from this that the introduction of email technology cannot substantially change people’s lives.’ I remember Peter Lipton uttering these words one day in the Working Party on Pharmacogenetics, words that eventually found their way into the report itself.

A simple, easily graspable analogy like this is just one small example of the sparkling intelligence that Peter brought to the Working Party, as he brought to the work of the Council generally. Anyone can complicate issues; it takes insight and intelligence to put difficult matters in a straightforward way without losing the essential point. Peter had just these qualities.

Council working parties need many things. They need a good issue to think about, good briefings from Council staff and good working relationships among their members. Above all, however, they need someone in the chair who can keep the party on track and direct it in the right direction. Peter was just such a chair.

Council working parties need to have someone in the chair who can be the first to notice the first indication that the Working Party was wrestling with mean that the production of the report proceeded smoothly and with dispatch.

Understanding the implications of pharmacogenetics requires an ability to follow the technicalities, but it also requires an ethical sensibility in matters of justice and potential discrimination as well as the responsibility of individuals, companies and the professions. Of Peter Lipton it could truly be said that ‘on the lips of him who has understanding wisdom is found’ (Proverbs, 10:13). The Working Party was only one of his many achievements, but his contribution embodied the virtues of understanding and wisdom.

An obituary by Peter’s colleagues at the University of Cambridge can be found at: www.hps.cam.ac.uk/news/peterlipton.html
A note from the Director

When I arrived at the Nuffield Council at the beginning of 2007 I had the privilege of joining an organisation that had developed a strong national and international profile and reputation, based on the quality of its work over many years. I arrived in time to witness two Working Parties preparing reports for publication before the end of the year, and the Council had just secured a further five year grant from its three funding bodies - the Nuffield Foundation, the Wellcome Trust, and the Medical Research Council. All of this I could have anticipated, as I had been viewing the Council from a distance, with considerable admiration, for a number of years. What I had not quite anticipated until I stepped through the door was the extent of the abilities, commitment and energy of the members and staff of the Council, and of the generous contribution of its Working party members. The first thing I must do, therefore, as we reach the end of my first year, is to acknowledge all of these people for their individual and collective efforts in maintaining the excellence and relevance of the Nuffield Council on Bioethics. I must also pay tribute to Sandy Thomas who, as Director, built the Council over the course of nine years into its current position of strength. Thanks are due also to Dr Catherine Moody who returned to the Medical Research Council in March 2007 after three years as Deputy Director of the Council - I am most grateful for her generous support during my earliest days.

The events and achievements of the last year have been notable. The publication of two reports – The forensic use of bioinformation: ethical issues and Public health: ethical issues – both of which had a strong and immediate impact, was a remarkable achievement for a small team of staff. There is little time to rest, however, and already a new Working Party on the ethical issues arising from dementia, is underway, for which we are delighted to have Professor Tony Hope as our Chair. The published reports make headlines, but there are other achievements of which we can be proud such as our collaboration with the Nuffield Curriculum Centre in preparing educational materials on the use of animals in research for 14-19 year-olds and their teachers. To give support to the teaching and learning of ethics in the context of science and citizenship curricula is possibly one of the more valuable things we can do, and we plan to build on this work over the coming years.

We have also, throughout 2007, continued to build our links and our influence in the international arena through talks, presentations and collaborative work with colleagues in the EU, the Council of Europe, WHO and UNESCO. These are ones in which we can not only promote the work of the Council, but also assist in the development of bioethics on a worldwide basis. We look forward to helping take this agenda forward once more in 2008.

Finally, I would like to reiterate my personal thanks to the staff of the Council, all of whom have helped measurably in making 2007 a rewarding first year for me and, more importantly, in making it yet another great year for the Council. We welcomed two new staff to the Council during the year – Katharine Wright and Kate Harvey – both of whom have already become highly valued colleagues. I would like to thank the members of the Council itself for their continued support, guidance, wisdom and commitment. And, most particularly, while welcoming Professor Albert Weale as the new Chair, I would like to thank Professor Sir Bob Hepple for his calm and authoritative leadership, for his good natured but firm guidance; and for his lasting contribution to the work of the Nuffield Council on Bioethics, including the important and timely report on The forensic use of bioinformation: ethical issues.

Even as we follow up with the dissemination of the recently published reports, 2008 is already giving rise to a growing agenda of issues that demand attention from scientists, policy-makers and the public. We look forward to working on these, with a wide range of colleagues and collaborators, over the coming year.
Publications during 2007

The forensic use of bioinformation: ethical issues

Introduction

The UK now has by far the largest forensic DNA database in the world, per head of population, with its four million samples representing six per cent of the population. Many criminals have been, and will continue to be, caught and convicted through the forensic use of DNA. However, the establishment of the National DNA Database and subsequent extensions to police powers were effected without thorough consideration of the ethical issues nor any meaningful public debate. Therefore, the Council decided that a critical examination of the subject was needed.

A Working Group was appointed in 2006, which included members with expertise in law, genetics, philosophy and social science. As part of its work, the committee held a public consultation, eliciting 1,358 responses. These revealed a wide range of views, from those who wholeheartedly welcomed the expansion of forensic databases, to those who viewed the increase in police powers with deep suspicion. The Council published its report The forensic use of bioinformation: ethical issues in September 2007, along with a newly-designed accompanying short guide to the report.

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.
2. To consider, in particular:
   a) the interpretation of the information;
   b) the collection, storage and retention of profiles and samples;
   c) issues of informed consent, privacy and confidentiality in the light of data protection and human rights legislation;
   d) arguments for and against population-wide forensic databases;
   e) access to and use of forensic databases for purposes of research;
   f) admissibility and use of bioinformation in criminal proceedings;
   g) sharing of bioinformation for forensic purposes across international boundaries;
   h) use for forensic purposes of bioinformation collected for non-forensic purposes; and
   i) 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 Report on these issues.
The report findings

The Council broadly endorses a rights-based approach, which both recognises the importance to human beings of respect for their individual liberty, autonomy and privacy, and the need, in appropriate circumstances, to restrict these rights either in the public interest or to protect the rights of others. The principle of ‘proportionality’ is at the heart of the recommendations in the report. This means that any interference with legally enforceable human rights, such as the right to respect for private and family life, must be proportionate to the need to fight crime.

DNA can currently be taken, without consent, from any person arrested for a ‘recordable’ offence (mostly offences that can lead to a prison sentence). Since 2003, the police in England and Wales have been able to store this DNA permanently on the National DNA Database even if the individual is never charged, or is later found to be innocent. We found little evidence that keeping the DNA of people not charged or convicted increases crime detection rates. At the same time, many people are concerned about the implications and stigma associated with their DNA being on the Database. Given this and pending further research, the Council recommends that the police should only be allowed to keep the DNA of people who are convicted of a crime. The exception would be the DNA of people charged with serious violent or sexual offences, which should be kept for up to five years even if they are not convicted. This would bring the law in England, Wales and Northern Ireland into line with that in Scotland. Instead of focusing on longer or indefinite retention, we would like to see the police put more resources into the collection of DNA from crime scenes. At present, fewer than 20 per cent of crime scenes are forensically examined.

The report included a number of other recommendations relating to storing the DNA of witnesses, victims, volunteers and children, and the expanding uses of the DNA Database, for example, for research and inferring the ethnicity of potential suspects.
The report launch

The Council launched the report at a public seminar held in London on 18th September 2007. Working Group members presented the findings during the first session, which was followed by a general discussion facilitated by the writer and broadcaster Vivienne Parry. Around 80 people attended the launch, including policy makers, academics, representatives of pressure groups and other interested individuals. Audio recordings of the presentations are available to download from the Council’s website.

Approximately 700 copies of the report were sent to relevant organisations and interested individuals. In addition, a one-page summary of the report’s conclusions and recommendations was sent to all Members of Parliament, Members of the Scottish Parliament and Members of the European Parliament.

By the end of the year the report had been downloaded from the Council’s website nearly 24,000 times.

Highlights of media coverage

The report received extensive and very favourable coverage in the national and local print and broadcast media. Coverage on the day of the launch included the following:

<table>
<thead>
<tr>
<th>Date</th>
<th>Media</th>
<th>Details</th>
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<tbody>
<tr>
<td>18 Sept</td>
<td>BBC Breakfast News, Sky News, GMTV News</td>
<td>Interviews with members of the Working Group</td>
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<tr>
<td></td>
<td>BBC Radio 4, 5, World Service, and regional stations, Independent Radio News</td>
<td>Interviews with members of the Working Group</td>
</tr>
<tr>
<td></td>
<td>The Times</td>
<td>“DNA database ‘puts innocent under suspicion’”</td>
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<td></td>
<td>The Guardian</td>
<td>“Police must not store DNA details of the innocent - report”</td>
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<tr>
<td></td>
<td>The Telegraph</td>
<td>“Storing DNA of innocent people ‘unethical’”</td>
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<td></td>
<td>The Financial Times</td>
<td>“Call for rethink on DNA of innocent”</td>
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<td></td>
<td>The Daily Mail</td>
<td>“The great DNA divide”</td>
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<tr>
<td></td>
<td>The Mirror</td>
<td>“DNA database slammed by ethics expert”</td>
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“... compulsory reading for anyone involved in the criminal process”

Counsel (The Journal of the Bar in England and Wales), December 2007

Post-launch activities

Members of the Working Group have been involved in a number of meetings and events since the launch in order to disseminate the findings to policy makers and promote public debate of the issues. Additionally, the Secretariat and members of the Working Party have submitted articles based on the findings of the report to relevant journals and responded to calls for evidence and consultations where appropriate.

Presentations

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Speakers and details</th>
</tr>
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<tbody>
<tr>
<td>25 Sept</td>
<td>Fringe event at the Labour Party Conference 2007, Bournemouth</td>
<td>Members of the Working Group were joined by Under-Secretary of State for the Home Office, Meg Hillier MP and Dr Ian Gibson MP to discuss the report’s recommendations with delegates</td>
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<tr>
<td>27 Sept</td>
<td>‘DNA in the Dock’, The Dana Centre at the Science Museum, London</td>
<td>A public discussion event about the report was facilitated by Dr Carole McCartney. The speakers were Graham Cooke, Dr Tim Clayton (Forensic Science Servce), Anna Fairclough (Liberty) and Professor Steve Bain (DNA Database Strategy Board)</td>
</tr>
<tr>
<td>19 Nov</td>
<td>Royal Institution/Nuffield Foundation 6th Form Conference, ThinkTank, Birmingham</td>
<td>Dr Carole McCartney gave a talk and led a discussion about the DNA Database</td>
</tr>
<tr>
<td>5 Dec</td>
<td>Meeting with the British Academy of Forensic Sciences, London</td>
<td>Members of the Working Group met representatives of the BAfS to discuss the recommendations in the report</td>
</tr>
</tbody>
</table>

Members of the Working Group: Professor Graeme Laurie, Dr Bronwyn Parry, Dr Carole McCartney and Professor Andrew Read

http://www.nuffieldbioethics.org/go/ourwork/bioinformationuse/introduction
Public health: ethical issues

Introduction

Public health measures are designed to improve health across the population. In the past, they have included the provision of clean housing and water, and vaccination schemes. Some measures restrict personal freedom more than others and deciding what kind of measure is appropriate and justifiable is an age-old problem for government and for policy makers.

In February 2006, the Council set up a Working Party to consider the issues, which included members with expertise in health economics, law, philosophy, public health policy, health promotion and social science. To inform discussions, the group held a public consultation and met with representatives from a range of relevant organisations. The report Public health: ethical issues was published in November 2007, accompanied by a short guide to the report.

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) 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.
The Stewardship Model

We propose a ‘stewardship model’ that outlines the appropriate goals and constraints of public health measures. Acceptable public health goals include:

- reducing the risks of ill health that people are exposed to as a result of other people’s actions or behaviours, for example reducing drink-driving and passive smoking;
- reducing causes of ill health relating to environmental conditions, such as drinking water safety and housing standards;
- protecting and promoting the health of children and other vulnerable people;
- helping people to overcome addictions and other unhealthy behaviours;
- ensuring that it easy for people to lead a healthy life, for example by providing convenient and safe opportunities for exercise;
- reducing unfair health inequalities.

At the same time, public health programmes should:

- not attempt to coerce adults to lead healthy lives;
- minimise interventions that are introduced without individual consent of those affected, or without procedural justice arrangements (such as democratic decision-making procedures) which provide adequate mandate;
- seek to minimise interventions that are perceived as unduly intrusive and in conflict with important personal values.

The Intervention Ladder

We propose the ‘intervention ladder’ as a useful way of thinking about the acceptability and justification of different public health policies. The ladder of possible government action is as follows:

1. **Eliminate choice**. Regulate in such a way as to entirely eliminate choice, for example through compulsory isolation of patients with infectious diseases.

2. **Restrict choice**. Regulate in such a way as to restrict the options available to people with the aim of protecting them, for example removing unhealthy ingredients from foods, or unhealthy foods from shops or restaurants.

3. **Guide choices through disincentives**. Fiscal and other disincentives can be put in place to influence people not to pursue certain activities, for example through taxes on cigarettes, or by discouraging the use of cars in inner cities through charging schemes or limitations of parking spaces.

4. **Guide choices through incentives**. Regulations can be offered that guide choices by fiscal and other incentives, for example offering tax-breaks for the purchase of bicycles that are used as a means of traveling to work.

5. **Guide choices through the default policy**. For example, in a restaurant, instead of providing chips as a standard side dish (with healthier options available), menus could be changed to provide a more healthy option as a standard (with chips as an option available).

6. **Regulate in such a way as to restrict the options available to people**. For example by providing participation in an NHS stop smoking programme, building cycle lanes, or providing free fruit in schools.

7. **Regulate in such a way as to entirely eliminate choice**. For example through compulsory isolation of patients with infectious diseases.

8. **Inform and educate the public**. For example as part of campaigns to encourage people to walk more or eat five portions of fruit and vegetables per day.

9. **Enable individuals to change their behaviours**. Options available to people with the aim of protecting them, for example removing unhealthy ingredients from foods, or unhealthy foods from shops or restaurants.

10. **Enable choice**. Enable individuals to change their behaviours, for example by offering participation in an NHS stop smoking programme, building cycle lanes, or providing free fruit in schools.

11. **Provide information**. Inform and educate the public, for example as part of campaigns to encourage people to walk more or eat five portions of fruit and vegetables per day.

12. **Do nothing or simply monitor the current situation.**

Alcohol and tobacco

While restrictions on smoking have been a recent government priority, the Council recommends that more coercive strategies should be implemented to reduce the harm caused by excessive alcohol consumption. For example, increasing taxes on alcoholic drinks and restricting hours of sale have been shown to be effective in reducing consumption. Producers, advertisers and sellers of alcohol should also take more responsibility for preventing harm to health.

Obesity

The Food Standards Agency is currently assessing the effectiveness of different types of front-of-pack labels on food packaging in influencing healthier choices. When the results are published, we recommend that the food industry should adopt the labelling scheme found to be the most effective. If it does not, there would be ethical justification for the UK Government to enforce it through legislation. We also recommend that town planners and architects should be trained to include measures that encourage people to be physically active in the design of buildings and public spaces.

Infectious disease

After weighing up the evidence and ethical considerations, we conclude that introducing more stringent policies for childhood vaccination (for example, penalties for those who do not comply) would not be justified at present in the UK.

Global surveillance of new and existing infectious diseases can be compromised when countries do not have the capacity for effective monitoring or where they decide not to cooperate fully with international surveillance efforts. We recommend that the UK Government should help to improve the capacities of developing countries to monitor infectious diseases effectively.

Fluoridation of water supplies

Fluoride has been added to the water supply for over 50 years in some parts of the UK, with the aim of improving dental health. There has long been debate over whether this should continue, and whether it should be rolled out in other areas of the UK. We conclude that the most appropriate way of deciding whether fluoride should be added to water supplies is through regional democratic decision-making procedure. This should be supported by better and more balanced information for the public and policy makers.
The report launch

The Council launched the report at a public seminar held in Westminster, London on 13th November 2007. Around 200 people attended, including policy makers, academics, students and others interested in the topic. Working Party members presented the findings of the report and took questions from the audience. Audio recordings of the presentations are available to download from the Council’s website.

Around 1,500 copies of the report were sent to relevant organisations and others with an interest in the area. A one-page summary of the report was also sent to Members of Parliament, Members of the Scottish Parliament, UK Members of the European Parliament, and peers.

Highlights of media coverage

The report featured widely in the media during the week of the launch. The Council’s recommendations on alcohol received particularly high coverage, possibly due to the launch on the same day of the Alcohol Health Alliance, a consortium of organisations campaigning to reduce harm caused by alcohol. Media coverage included:

<table>
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<tr>
<th>Date</th>
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<tbody>
<tr>
<td>13 Nov</td>
<td>BBC Television News, Channel 4 News, ITV News</td>
<td>Interviews with members of the Working Party</td>
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<td></td>
<td>BBC Radio 1, 4, World Service, local stations</td>
<td>Interviews with members of the Working Party</td>
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<td></td>
<td>The Telegraph</td>
<td>&quot;Experts condemn 24-hour drinking&quot;</td>
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<td>The Guardian</td>
<td>&quot;Group calls for higher tax on booze&quot;</td>
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<tr>
<td></td>
<td>The Daily Express</td>
<td>&quot;Group calls for higher tax on booze&quot;</td>
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<tr>
<td>14 Nov</td>
<td>The Mirror</td>
<td>&quot;Wasted youth: Binge drinking violence on rise&quot;</td>
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<tr>
<td></td>
<td>The Daily Mail</td>
<td>&quot;Booze is a middle-class problem, claims Health Minister&quot;</td>
</tr>
<tr>
<td></td>
<td>The Sun</td>
<td>&quot;Get boozers are wrecking lives&quot;</td>
</tr>
<tr>
<td>19 Nov</td>
<td>The Guardian</td>
<td>Leader article: &quot;Ethical inequalities&quot;</td>
</tr>
<tr>
<td>1 Dec</td>
<td>The Lancet</td>
<td>Editorial: &quot;The ethics of public health&quot;</td>
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Lord Krebs

"…the Nuffield Council on Bioethics dropped a gift in the government’s lap: a cogently argued case for large-scale public involvement in the protection and promotion of the nation’s health – and a potent argument for doing it.”

The Guardian, Leader 19th November

Post-launch activities

Lord Krebs and members of the Secretariat were invited to meet the Rt Hon James Purnell MP, Secretary of State for Culture, Media and Sport, to discuss the report’s recommendations on reducing alcohol consumption. The report was also mentioned on numerous occasions in the House of Lords and the House of Commons in the days and weeks after the launch, for example by MPs Dr Evan Harris, Theresa May and Dr Howard Stooba, and by Lord Avebury, Lord Darzi and Lord Maginnis. The Rt Hon Dawn Primarolo MP, Minister of State for Public Health, referred to the report several times in the Faculty of Public Health Annual Public Health Lecture (London, December).

Working Party members and the Secretariat have also taken part in a number of events and meetings since the launch in order to disseminate the findings to a wider audience. The Secretariat has responded to relevant consultations, and articles based on the findings of the report have been submitted to relevant journals.

Presentations

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<tr>
<th>Date</th>
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<tbody>
<tr>
<td>15 Nov</td>
<td>Public health and individual choices,Dialog Centre at the Science Museum, London</td>
<td>A public discussion event about the report was facilitated by Hugh Whitall. The speakers were Professor Andrew Hall (London School of Hygiene and Tropical Medicine), Dr Rachel Seabrook (Institute of Alcohol Studies) and Dr Andrew Jones (University of East Anglia)</td>
</tr>
<tr>
<td>3 Dec</td>
<td>A meeting with staff and students at Essex University, Colchester</td>
<td>Presentation by Harald Schmidt</td>
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<tr>
<td>5-6 Dec</td>
<td>National Institute for Health and Clinical Excellence (NICE) Annual Conference 2007, Manchester</td>
<td>Lord Krebs gave a presentation about the report and met delegates at the Council’s exhibition stand</td>
</tr>
<tr>
<td>10 Dec</td>
<td>The King’s Fund, London</td>
<td>Presentation by Harald Schmidt</td>
</tr>
<tr>
<td>14 Dec</td>
<td>National Institute for Health and Clinical Excellence Public Health Interventions Advisory Committee</td>
<td>Presentation by Professor Tom Baldwin</td>
</tr>
</tbody>
</table>

The report had been downloaded over 43,000 times by the end of the year.

“With the global rise of obesity, alcohol, and smoking-related illnesses, the report from the Nuffield Council demands careful consideration by other governments, WHO, industry, and all those interested in protecting and promoting public health.”

The Lancet, Editorial 1st December
Dementia: ethical issues

Dementia is the term for diminished brain function caused by diseases such as Alzheimer’s and vascular dementia. Due to the UK’s ageing population, increasing numbers of people, their families, healthcare staff and carers are having to deal with the difficulties that these conditions can cause. At the same time, developments in neuroscience and technologies are improving our understanding of these conditions and could have the potential to help us to provide better treatment and care.

Following an exploratory workshop held in March 2007, the Council has established a Working Party to examine the ethical, legal and social issues raised by dementia, chaired by Tony Hope, Professor of Medical Ethics at the University of Oxford.

The group is considering:
- how decisions are made by or for people with dementia and how dementia care is provided;
- the role of advance decisions or ‘living wills’ which set out what treatment a person would like to have, or not have, at a point in the future when they are unable to make decisions for themselves;
- whether it is acceptable to restrict a person’s freedom for their own safety, for example by locking doors, or deceive them for their own good, for example by disguising medication in food;
- whether and how people with dementia should be involved in research;
- how conflicts between the interests of the individual and their carers can be resolved, for example where a husband benefits from his wife’s care, but she can no longer cope;
- the implications of changes in behaviour for the individual and for their relationships with other people.

The Working Party will be seeking the views of people with dementia, carers, health and social care professionals, policymakers and members of the public on these issues during spring and summer 2008. A report with conclusions and recommendations will be published in mid-2009.

http://www.nuffieldbioethics.org/go/ourwork/dementia/introduction

New projects

Dementia exploratory workshop

Membership of the Working Party

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

Professor Janet Askham
Director of Research, Picker Institute

Mary Baker MBE
President, European Federation of Neurological Associations

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

Chris Chaloner
Ethics Advisor, Royal College of Nursing

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

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

Dr Rhona Knight
General Practitioner; member of the Council

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

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

Professor Jill Peay
Professor of Law, London School of Economics

Professor Hugh Perry
Professor of Experimental Neuropathology, University of Southampton; member of the Council

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

Dr David Wilkinson
Consultant in Old Age Psychiatry, Moseley and Western Community Hospitals, Southampton
The Council considers new topics at its annual 'Forward Look' seminar in May. This year, discussion centred around two areas: the impact and implications of the Human Genome Project, and the allocation of healthcare resources.

The increasing understanding about the structure and function of genes as a result of the Human Genome Project and other sources of genetic research is already beginning to change biomedical research and clinical practice. For example, cancer drugs that are effective in people with particular genetic characteristics have been developed. Technology is advancing at such a rate that full personal genome sequencing may be available for US$1,000 within five years. However, will this technology actually offer any health benefits to the individual? Council members and invited experts considered the implications of new genetic knowledge at the Forward Look seminar. A number of the Council’s previous reports had already covered some of these issues, however, and members decided not to pursue the topic further for the time being.

The allocation of public healthcare resources often has three competing objectives: to provide comprehensive care, to provide high quality care, and to provide care freely available on the basis of need. These raise a number of difficult questions for people making prioritisation decisions. For example, should the wealthy and the poor, and the old and the young always be treated the same? Should small, but certain benefits to many people be more or less important than large, but uncertain benefits for a few people, if both can be achieved with the same available resources? What about people who choose to lead unhealthy lifestyles? Who should make rationing decisions, and by reference to which criteria? To complicate things further, evidence about the effectiveness of treatments is often incomplete, and people with the financial means can buy treatments privately, regardless of whether the NHS chooses to provide it.

The Council decided that issues raised by the allocation of healthcare resources should be explored in more depth, and a one-day workshop with guest experts was held in December for this purpose.

The Council carries out dissemination activities for a year or so after the publication of a report. For example, Working Party members often give presentations to stakeholders to encourage uptake of recommendations, or simply to promote debate. A selection of presentations in 2007 on previous reports is listed below.

<table>
<thead>
<tr>
<th>Data</th>
<th>Event</th>
<th>Speakers and details</th>
</tr>
</thead>
<tbody>
<tr>
<td>February</td>
<td>Cafe Scientifique, Croydon</td>
<td>Dr Catherine Moody gave a presentation and led a discussion on life and death decisions about newborn babies</td>
</tr>
<tr>
<td>June</td>
<td>5th World Congress on Perinatal Critical Care, Geneva</td>
<td>Professor Linda French gave a presentation on critical care decisions in neonatal and fetal medicine</td>
</tr>
<tr>
<td>July</td>
<td>Annual Meeting of the Nuffield Foundation Oliver Bird Rheumatism Programme, Aberdeen</td>
<td>Professor Kenneth Boyd gave a presentation on research ethics in humans, animals and embryos</td>
</tr>
<tr>
<td>July 31st</td>
<td>31st British International Congress of Obstetrics and Gynaecology, London</td>
<td>Professor Charles Robich gave a presentation on critical care decisions in fetal medicine</td>
</tr>
<tr>
<td>August</td>
<td>6th World Congress on Alternatives and Animal Use in the Life Sciences, Tokyo, Japan</td>
<td>Baroness Perry of Southwick gave a talk on the ethics of animal research</td>
</tr>
<tr>
<td>September</td>
<td>Symbiosis - 13th European Congress on Biotechnology, Barcelona</td>
<td>Harald Schmidt gave a presentation on the use of GM crops in developing countries</td>
</tr>
</tbody>
</table>

The Critical care decisions in fetal and neonatal medicine: seminar to discuss the report one year on

The Critical care decisions in fetal and neonatal medicine: ethical issues report was published in November 2006. Feedback since then has been very positive, but has also suggested that implementation of some of the recommendations would require joint efforts by professional bodies, the government and organisations representing parents. To facilitate discussion between such organisations, the Council held a seminar in December 2007 to consider the recommendations one year on. Representatives attended from the relevant Royal Colleges, BLSI, the General Medical Council, the Neonatal Nurses Association, the Department of Health and others. The discussion focused on developing guidance and training for healthcare professionals and providing information to parents. The Council will publish the outcomes on its website in 2008.
The website

The Council’s website is one of the most important ways in which it communicates with other people and organisations. The site is regularly updated with news and activities, and the number of visitors to its pages reached nearly two million last year. All our publications are available on the website, and there were nearly 390,000 downloads of our reports in 2007. The website also makes available responses received to the Council’s consultations (with the permission of respondents), and, more recently, audio recordings of presentations given at launch events.

<table>
<thead>
<tr>
<th>Report</th>
<th>Downloads for 2007</th>
</tr>
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<tbody>
<tr>
<td>Public health: ethical issues</td>
<td>43,374</td>
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<tr>
<td>The forensic use of bioinformation: ethical issues</td>
<td>23,642</td>
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<tr>
<td>Critical care decisions in fetal and neonatal medicine: ethical issues</td>
<td>17,326</td>
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<tr>
<td>The ethics of research involving animals</td>
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<tr>
<td>The ethics of research related to healthcare in developing countries:</td>
<td>3,552</td>
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<tr>
<td>a follow-up Discussion paper</td>
<td></td>
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<tr>
<td>The use of genetically modified crops in developing countries: a</td>
<td>2,021</td>
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<tr>
<td>follow-up Discussion paper</td>
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<td>Pharmacogenetics: ethical issues</td>
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<td>Genetics and human behaviour: the ethical context</td>
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<td>The ethics of patenting DNA</td>
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<td>The ethics of research related to healthcare in developing countries:</td>
<td>27,227</td>
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<td>Stem cell therapy: ethical issues</td>
<td>3,038</td>
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<td>Genetically modified crops</td>
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<td>Mental disorders and genetics: the ethical context</td>
<td>6,406</td>
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<td>Animal-to-human transplants: the ethics of xenotransplantation</td>
<td>11,100</td>
</tr>
<tr>
<td>Human tissue: ethical and legal issues</td>
<td>13,341</td>
</tr>
<tr>
<td>Genetic screening: ethical issues</td>
<td>31,408</td>
</tr>
</tbody>
</table>

UPDATE newsletter

This year the Council launched an e-newsletter, UPDATE, which is sent out three times a year to those who have expressed an interest and is also posted on the website. So far, the Council communicates its news in this way to over 1,200 people. To sign up, contact: update@nuffieldbioethics.org.

Presentations and conferences
The Council very much values face-to-face interaction with its stakeholders and the wider public. Members of the Council and the Secretariat enjoyed giving presentations, taking part in debates, holding seminars, and taking part in exhibitions at a wide range of conferences and meetings last year. This year the Council held a fringe event at the Labour Party Conference in Bournemouth to discuss with delegates its report on the forensic use of bioinformation: ethical issues.

Engagement with policy makers
To encourage uptake of the Council’s recommendations, an important activity after a report has been published is communicating with policy makers. We often arrange one-to-one meetings with relevant Ministers or Government officials, and we ensure Parliamentarians are aware of our findings. The Council hosted the first ‘trilateral’ meeting with the Comité Consultatif National d’Éthique (CCNE - the national ethics committee for France) and the Nationaler Ethikrat (NER - the national ethics committee for Germany) on 4th June 2007. The three organisations discussed ethical issues in biometrics, the role and contribution of ethics advisory bodies, and the rationing of healthcare resources. Presentations on behalf of the Council were given by Dr Carole McCartney, Hugh Whittall and Harald Schmidt.

Consultations
The Council responds to the consultations of other organisations when appropriate. In the past year it has submitted responses to the following bodies:
- House of Commons Home Affairs Select Committee
- Department for Communities and Local Government
- Home Office
- National Institute for Health and Clinical Excellence (NICE)
- NICE
- Parliamentary and Scientific Committee
- Parliamentary Office of Science and Technology

International activities

UNESCO
The Council continued its cooperation with UNESCO’s Division of the Ethics of Science and Technology through involvement in the Assistive Bioethics Committees (ABC) initiative. The programme developed out of UNESCO’s adoption of the Universal Declaration on Bioethics and Human Rights and seeks to assist developing countries to establish national ethics committees (or similar bodies). In 2007, Harald Schmidt was a member of the Task Force for Anglophone countries and participated in missions to Jamaica and Malawi in June and July 2007.

Other international activities
- Global Perspectives on BioPolicy; Biocentre’s 2007 Symposium Series at the Royal Society of Medicine, March 2007
  Harald Schmidt attended and discussed the idea of human dignity in the UNESCO Declaration
- EU National Ethics Council Forum, including joint meetings with the European Group on Ethics (EGE) and with the European National Conference on National Ethics Committees (COMETH) of the Council of Europe, May 2007 and EU National Ethics Council Forum, October 2007
  First meeting attended by Professor Hugh Perry, Hugh Whittall and Harald Schmidt
  Second meeting attended by Hugh Whittall, who presented on the forensic use of bioinformation, and Caroline Rogers
- Eighth Global Forum on Bioethics Research, June 2007
  Attended by Hugh Whittall, who gave a presentation on the UK’s ethics advisory structure

World Medical Association
In August 2007, the Council contributed to the World Medical Association’s consultation on revising the Declaration of Helsinki. It proposed amendments and offered observations about how the status of the Declaration of Helsinki could be clarified.

Media
The way in which many people hear about the Council or the issues we consider is by reading an article in a newspaper, seeing an item on the news or watching a programme on the television. To encourage uptake of the Council’s recommendations, an important activity after a report has been published is communicating with policy makers. We often arrange one-to-one meetings with relevant Ministers or Government officials, and we ensure Parliamentarians are aware of our findings. The Council hosted the first ‘trilateral’ meeting with the Comité Consultatif National d’Éthique (CCNE - the national ethics committee for France) and the Nationaler Ethikrat (NER - the national ethics committee for Germany) on 4th June 2007. The three organisations discussed ethical issues in biometrics, the role and contribution of ethics advisory bodies, and the rationing of healthcare resources. Presentations on behalf of the Council were given by Dr Carole McCartney, Hugh Whittall and Harald Schmidt.

The Council’s stand at the 2007 NICE Annual Conference

“Call for rethink on DNA of innocent”
The Financial Times headline on the Council’s report: The forensic use of bioinformation: ethical issues in September

“Experts condemn 24-hour drinking”
The Telegraph headline on the Council’s report: Public health: ethical issues in November

All of the Council’s press releases can be found here: www.nuffieldbioethics.org/go/news/latest_28.html

All the Council’s responses to formal consultations are available on its website: http://www.nuffieldbioethics.org/go/aboutus/externalactivitiespage_192.html

Tri lateral meeting with CCNE and NER

World Medical Association
In August 2007, the Council contributed to the World Medical Association’s consultation on revising the Declaration of Helsinki. It proposed amendments and offered observations about how the status of the Declaration of Helsinki could be clarified.

The Council’s stand at the 2007 NICE Annual Conference

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Tri lateral meeting with CCNE and NER

World Medical Association
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Discussion of ethics has become an integral part of the national curriculum, and many of the Council’s reports provide an ideal basis for debate in the classroom. The Council’s Reaching Out to Young People Group advises the Council on how it can promote discussion on bioethics among young people. Professor Sir Kenneth Calman chaired this group from its inception in 2003 until January 2008, when his term on Council ended. Dr Rhona Knight has now taken up the post of Chair, and Professor Calman will remain on the group as a member.

Consultation with schools
As a pilot scheme, the Group plans to involve 20 specialist science schools in the Council’s consultation on dementia during the spring and summer of 2008. Teachers from the schools will receive training on how ethical issues can be brought into the curriculum, particularly around the topic of dementia, and they will then put this into practice in the classroom. These schools will be encouraged to liaise with other local schools over the teaching of this material. The views of the students involved will be recorded and used to inform the Council’s Working Party on dementia. The initiative aims to encourage cross-curricular teaching of ethics, and give students the chance to take part in policy making in the UK. We hope that these and other schools will be involved with future consultations of the Council.

Teaching resources
In 2007, the Group worked with the Nuffield Curriculum Centre to produce a set of teaching resources on the ethics of animal research. The resources, which are available to download from the Centre’s citizenship website and the Council’s website, are designed to be used in science and citizenship lessons and are aimed at helping students to develop informed opinions about the use of animals in research.

http://www.nuffieldbioethics.org/go/aboutus/externalactivitiespage_908.html

### Educational activities – Reaching Out to Young People

### Financial report

#### Financial Report for the year to 31 December 2007 (unaudited)

<table>
<thead>
<tr>
<th></th>
<th>2007 Actual</th>
<th>2006 Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Expenditure</strong></td>
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<td></td>
</tr>
<tr>
<td>Salaries and staffing costs</td>
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<td>406,894</td>
</tr>
<tr>
<td>Reviewers’ and consultants fees</td>
<td>5,202</td>
<td>–</td>
</tr>
<tr>
<td>Other costs including premises</td>
<td>12,169</td>
<td>8,478</td>
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<tr>
<td>Stationery and press cuttings</td>
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<td>11,705</td>
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<tr>
<td>Photocopy, post, phone, fax</td>
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<td>35,933</td>
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<tr>
<td>Committee and meeting costs</td>
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<td>71,970</td>
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<td>Printing and publicity of Reports</td>
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<td>33,108</td>
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<tr>
<td>Web and other technology costs</td>
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<td>6,955</td>
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<td><strong>Net direct expenditure</strong></td>
<td>543,462</td>
<td>575,043</td>
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#### Funding due

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nuffield Foundation</td>
<td>213,792</td>
<td>137,154</td>
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<tr>
<td>Medical Research Council</td>
<td>213,792</td>
<td>137,154</td>
</tr>
<tr>
<td>Wellcome Trust</td>
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<td>137,154</td>
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<tr>
<td>Reports sold</td>
<td>-1,396</td>
<td>-1,938</td>
</tr>
<tr>
<td>Other</td>
<td>310</td>
<td>468</td>
</tr>
<tr>
<td><strong>Total Funding Due</strong></td>
<td>426,498</td>
<td>409,992</td>
</tr>
</tbody>
</table>

Overheads met by Nuffield Foundation | 323,114 | 301,259 |
List of publications to date

- 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 March 1996

- Genetically modified crops: the ethical and social issues
  Published September 1998

- 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 the Nuffield Council on Bioethics
  Published July 2006

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

- The forensic use of bioinformation: ethical issues
  Published September 2007

- Public health: ethical issues
  Published November 2007

The Council’s reports and other publications can be downloaded and hard copies can be ordered from its website: www.nuffieldbioethics.org/go/publications/latest_30.html