



NUFFIELD
COUNCIL ON **20**
BIOETHICS YEARS

1991-2011

20 years of investigating and illuminating
ethical issues in biology and medicine

Enter >



The Prime Minister, David Cameron

I would like to commend the Council on the reputation it has established over the past two decades for undertaking rigorous examination of topical, and sometimes controversial, subjects using the best expertise available. The quality of the Council's reports is widely recognised and it has provided an important focus for ethical debate, both in the UK and internationally. Whilst independent from Government, the Council's work has had relevance for a wide range of policymakers.

I welcome the fact that the Council continues to identify important topics of relevance to today's

society. For example, *Dementia: ethical issues* (2009) and very recently *Human bodies: donation for medicine and research* (2011) provide a valuable stimulus for independent debate around relevant, highly sensitive and challenging ethical issues. The Council's current project on emerging biotechnologies demonstrates that it continues to explore difficult social, ethical and legal issues, alongside risks and benefits, presented by modern advances in science.

Undoubtedly, the Council will continue to contribute to, and stimulate debate around, bioethics in the future, rising to the challenge of the ever increasing complexity of issues as it does so.

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Foreword

Professor Albert Weale, Chair of the Nuffield Council on Bioethics

Scientific and medical research, together with our understanding of the conditions for public health, have contributed to a world in which people lead longer lives of better quality than at any time before.

As recently as 1950, global life-expectancy was 46 years of age; now it is 70, and in wealthier countries over 80. Yet, with these increases in well-being come questions that trouble the consciences of thoughtful people. How fairly distributed are the benefits produced by medicine and science? How can we best respond to increasingly prevalent diseases – dementia and obesity, for example – that such improvements and economic affluence have brought in their train? How can we ensure that the power that comes with knowledge – whether of the origins of life, the human genome or our ability to harness the resources of nature – is used for beneficial rather than exploitative ends? In short, how can we lead lives, collectively as well as individually, that embody respect and justice given our growing understanding of health and life processes?

The Nuffield Council on Bioethics was established by the Nuffield Foundation on a premiss that is as straightforward as it is seldom acted on, namely that evidence, analysis and careful deliberation could help provide practical answers to the dilemmas associated

with advances in the biomedical and biological sciences. Amid the clamour of conflicting claims, the still small voice of reason might play a part in identifying ethical issues, and framing opinions and recommendations that provide a reliable basis for action.

Over the last 20 years, as this brief history illustrates, the Council has sought to anticipate and not merely respond to public concerns, accepting that it will never have the last word but hoping sometimes to have the first. Its success has relied upon all those who have been on working parties, provided evidence and opinion in public consultations, worked for the Council secretariat or sat on the Council itself. A special note of gratitude is reserved for its successive directors (David Shapiro, Professor Sandy Thomas and Hugh Whittall) as well as for those who have chaired its deliberations: Sir Patrick Nairne, Baroness Onora O'Neill, Sir Ian Kennedy and Sir Bob Hepple.

We may all hope that the benefits of scientific and medical research will continue to grow. We should also hope that the distinctive work of the Council will continue to illuminate and help resolve ethical dilemmas that will inevitably follow.



Exploring developments
in science

A brief history

As the quest to map the entire human genome was gaining momentum in the late 1980s, so were concerns about the ethical issues this newfound knowledge would raise. The philosopher Baroness Warnock publicly called for “discussion, explanation and dialogue” on applying and regulating genetic knowledge.¹ Around the same time, Parliamentary debates on abortion and embryo research took place without, according to the *British Medical Journal*, “a clear and authoritative source of professional advice or a collective lead on the wider ethical and policy issues”.² Yet the government of the day were not minded to set up a national bioethics committee, instead preferring to carry out ad hoc reviews on specific issues such as human embryology.

Concerned that ethical reflection seemed to follow, rather than anticipate, research developments, the Nuffield Foundation consulted widely and found there to be far-reaching support for the establishment of an

independent ethics advisory body. The experiences of ethics councils from other countries suggested that such a body should be free from political pressure, and that its membership should be small and chosen on the basis of individual skills and knowledge.

In 1991, the Nuffield Foundation established the Nuffield Council on Bioethics under the chair of senior civil servant Sir Patrick Nairne. Prime Minister John Major welcomed the move and urged the Council to consider ethical issues raised by advances in agriculture and food as well as those within the medical field – advice that it has followed.

From the beginning, the Council focused its energies on carrying out in-depth inquiries that aimed both to clarify the ethical arguments and offer a way forward by way of specific, targeted policy recommendations. The core strengths of quality, independence and timeliness remain at the heart of the Council’s work today.



Sir Patrick Nairne, first Chair of the Council 1991-1996

I had been given an exciting role, but not an easy one. The Council had 15 members and this occasionally led to some 15 different viewpoints. What is important today is that the Council should continue to consider the many important ethical issues that are now being identified – including some that we would never have thought of in those early days.

In the Nuffield Foundation’s initial consultations a senior official remarked: ‘You say you are against *ad hoc* committees of enquiry, but your proposed Council will set up specialist Working Parties. What is the added value of a Council?’ A good question, I thought. The answer has been threefold: in the Council’s ability to survey research so that its choice of subjects is rational, its ability to build on its accumulating reports and, third, on its cooperation with other bodies national and international.



David Shapiro, first Director of the Council 1991-1997

The Nuffield Council on Bioethics has lived up to all the hopes of its early days. It has kept a tight focus on questions raised by advances in biomedical research, high independence from government, professional and corporate interests, and a knack of picking the right topics at the right time with the right expertise.

Baroness Onora O’Neill, founding member and Chair of the Council 1996-1998



¹ The Times (1990) *Warnock calls for enquiry to confront genetic research fears*. 23 August.

² Lock S (1990) Editorial: Towards a national bioethics committee *BMJ* 300: 1149-1150.



It was a great privilege to be a member of the Nuffield Council. The interaction of philosophers and ethicists with scientists and practitioners of various kinds, as part of a body with no vested interests, led to work which was and is very widely respected as the most objective and thorough analysis of these issues.

Professor Lord Harries of Pentregarth, Member of Council 2002-2008

Directing the Nuffield Council was a huge privilege and a unique experience. Unique because we were able to attract some of the country's best minds to tackle important and difficult issues that mattered to people. The quality of thinking in the reports enabled us to build a global reputation and achieve real influence.



Professor Sandy Thomas, Director of the Council 1997-2006

I was invited to speak and be questioned at one of the Council's lunches. The conversation was less digestible than the food – 'tough lunch', I thought. But with the Nuffield Council if you care about the ethical challenges facing health, science and society you must always come back for more. Whenever I get the chance I do.



Harry Cayton, Chief Executive of the Council for Healthcare Regulatory Excellence

People

The first Council membership brought together expertise from the worlds of philosophy, ethics, medicine, science, law, theology, social science and the media. Over the years, some 70 members have donated substantial amounts of time and effort to the Council, with no reward other than the satisfaction of contributing to an important cause and the opportunity to take part in stimulating debate.

But the Council is much more than its members – it brings together large networks of people through its working parties, staff, consultations and external relations work.

Working parties

Once the Council has identified a topic that requires consideration, it establishes a working party of experts in the field, which, over a period of around 18 months, explores and deliberates the issues at hand. Over the years, 200 people from very diverse backgrounds have been members of these working parties, all providing their services to the Council for free. Many have made contributions that went far beyond anything the Council could have expected, and have been integral to the high-quality reports of which the Council is so proud.

Many continue to discuss and debate the Council's findings among their own networks long after reports are published, providing the Council with valuable feedback and suggestions for future work.

Secretariat

The secretariat has also been a vital part of the network of the Council. David Shapiro, the first director of the Council, had little in the way of staff support. Now, eleven permanent members of staff work tirelessly to support the Council and its working parties in creating new reports, promoting public debate of bioethics, and drawing in advice and information from around the world.

Funding

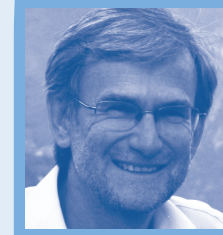
Consultations

The Council has always understood the important role of consultation in its inquiries. Increasing effort has gone into ensuring that the Council engages with a diverse range of people to create a comprehensive picture of the views and evidence that exist in society. Since 1991, almost 1,700 written submissions have been received in response to 16 Council consultations, and dozens more people have been invited to meet with the Council face-to-face to share their experiences and concerns.

For some inquiries, it was felt important to reach out to an even wider audience, and the Council ran workshops with recruited members of the public to discuss the dilemmas surrounding dementia in 2008, and organ and tissue donation in 2010.³

In 1994, the Wellcome Trust and the Medical Research Council joined the Nuffield Foundation as co-funders of the Council. Ever since, these three organisations have financially supported the Council, requiring regular evaluation of impact. Their approach of neither dictating the topics considered by the Council, nor seeking to influence Council or working party membership, has allowed the Council to produce truly independent reports on topics where independence is crucial, such as GM crops and animal research. The Council would like to thank them for their trust and foresight.

³ Detailed reports of the workshops are available at:
www.nuffieldbioethics.org/dementia/dementia-external-consultation
and www.nuffieldbioethics.org/donation/donation-external-consultation



When the Council was established I don't think anyone involved imagined that it would go on to become the influential, respected and above all necessary organisation it now is. Over the course of 20 years the message that has consistently come back to us is that two things have been fundamental to its success; the quality of the people involved, and its independence.

Anthony Tomei, Director of the Nuffield Foundation

The public consultation. That was new to me. As an academic I had had my doubts about methodology. But the 1,500 pages of responses; the face-to-face discussions; and the day in Birmingham talking to 50 members of the public were rich in ideas, arguments and, above all, anecdotes. These consultations provided both the grounding and the detail to the final report.



Professor Tony Hope, Chair of the Working Party on dementia 2007-2009

Being involved in the Council gave me an amazing array of experiences – in a small organisation you learn something across a huge range of areas including research, events management, press and PR, public affairs, and policy-making. I became immersed in the topics covered – all matter so much to people's lives around the world.



Caroline Rogers, Research Officer (2003-2008) and Programme Manager (2009-2010) at the Council



The range of the Council's work and the rigour of its analysis have allowed it to make a valuable and valued contribution to shaping policy in biomedicine and biotechnology. I was honoured to be there at the birth and salute the 20th birthday.

Sir Ian Kennedy, founding member and Chair of the Council 1996-2002

As a former Disability Rights Commissioner and the parent of a disabled son, I felt very challenged but hugely rewarded by the depth and sensitivity of the discussions and the careful collection and analysis of the evidence base for very early intervention.



Dame Philippa Russell, Chair, Standing Commission on Carers and member of the Working Party on critical care decisions in fetal and neonatal medicine 2004-2006

I learned immensely from Council and working party members' dedication to public service; from their substantive contributions; and from their focus on considering an argument based on its merit alone, irrespective of the source. I was equally inspired by my secretariat colleagues' commitment to maximising the Council's relevance, impact, and accountability - it was a great privilege to have been part of the team.



Harald Schmidt, Assistant Director of the Council 2002-2010

Changing times

In 1999, following a review and consultation exercise, the Government decided again not to set up a national bioethics advisory body. This decision was taken on the basis that the Council, together with other bodies such as the British Medical Association and several Parliamentary committees, already fulfilled this role. Instead, two Government advisory bodies were set up: the Human Genetics Commission and the now defunct Agriculture and Environment Biotechnology Commission. The Council maintains close contact with bodies such as these, so as to be aware of developments and activities going on throughout the field.

Further debate on the merits of creating a national bioethics committee took place among policy makers in 2004 and 2008. The proposal was not adopted on either occasion.

In 2010, the Government announced a review of arms length advisory bodies and, as a consequence, the Human Genetics Commission, the Human Tissue Authority, and the Human Fertilisation and Embryology Authority and their functions are soon expected to be subsumed into other advisory bodies such as the Care Quality Commission. The Council felt fortunate to be in a position where political change and public finances do not affect its work. It will, however, need to be ready to adapt to the changing environment ahead.

The Council's approach to ethics

Working parties of the Council are not given strict or specific guidance on how to approach the ethical dilemmas put before them, and different reports have adopted different ethical principles and frameworks. In 2007, an external review of the Council's publications confirmed such variation, but found a shift towards the explicit use of ethical frameworks in more recent reports. The Council had moved from making primarily policy-based recommendations to giving more consideration to the underlying ethical principles. This in turn, in the opinion of the reviewers, led to more coherent policy guidance.

The picture of the Nuffield Council on Bioethics that emerges from an external perspective is of a liberal, democratic, secular body that attempts to span both theoretical ethics and practical policy.⁴

Sarah Chan and John Harris

⁴ Chan S and Harris J (2007) *The Nuffield Council on Bioethics: an ethical review of publications*, available at: www.nuffieldbioethics.org/ethical-review



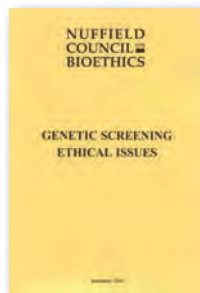
Exploring developments
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Timeline



The Nuffield Council on Bioethics is established by the Nuffield Foundation, with the appointment of **Sir Patrick Nairne** as chair and **David Shapiro** as director

1991



The first report is published, **Genetic screening: ethical issues**

1993



Professor Sandy Thomas becomes director

1997

Following a review, the Government decides not to establish a national bioethics committee. **The Human Genetics Commission** and **Agriculture and Environment Biotechnology Commission** are established

1999

Eight members of staff now make up the secretariat, including two assistant directors who each support a working party, and a public liaison officer

2001

1994

The **Wellcome Trust** and the **Medical Research Council** join the Nuffield Foundation as co-funders of the Council



1996

Baroness Onora O'Neill is appointed chair



1998

Professor Sir Ian Kennedy is appointed chair



The Council launches its first **website**, which includes details about the Council's method of working and downloadable versions of all its reports



2000

The funders provide core funding on a five-year rolling scheme to allow the Council to **work more flexibly and plan for the future**



The Council begins to produce short **'guides' to its reports**, which later become colourful **A5 booklets**

The Council begins **formal annual meetings** with the bioethics committees of France and Germany

The Council sets up the **Reaching Out to Young People Advisory Group** to bring its work to a younger audience



Professor Sir Bob Hepple is appointed chair of the Council

2003

The Council adopts a more **open and accountable process for recruiting members**, and appoints an **independent chair** to its membership sub-panel

2005



Hugh Whittall becomes director

2007



Eleven members of staff now make up the secretariat, with three Working Parties taking place simultaneously and an active communications programme

2009



The Council **celebrates its 20th anniversary** by organising an **international symposium** on global health inequalities

2011

Two reports are published (on biofuels and donation of human bodily material), bringing the **total to 22**

2002

A **CD-ROM** of the Council's work is circulated in *Nature* magazine to **celebrate its 10th anniversary**

The Council **publishes three reports in one year** (on genetics and human behaviour, patenting DNA, and research in developing countries) to bring the **total number published to ten**



2008

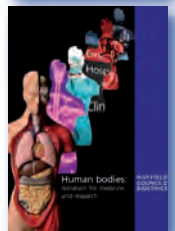
Parliament debates whether to set up a national or Parliamentary bioethics commission, but the motion does not stand

Professor Albert Weale is appointed chair of the Council



2010

A **new website** is launched which aims to be more accessible and navigable. The Council uses **Twitter** and **Facebook**





The Nuffield Council is a small miracle of levitation. It has no statutory or regulatory status, but enormous influence. This is entirely dependent on quality – the quality of Council, in choosing subjects to investigate; and the consistent excellence of the reports themselves. My time on the Nuffield Council was

amongst the most stimulating and challenging experiences of my career.

Professor Martin Bobrow, Chair of the Working Party on stem cells and member of Council 1997-2003



Writing a report for the Council was a bit like writing a PhD thesis for about 50 examiners – very demanding but also ultimately rewarding. The amount of free time the Council commands from busy people is impressive. So is the care it takes to get its facts and arguments right.

Professor Christopher Hood, Chair of the Working Party on personalised healthcare, 2008-2010



Report highlights

Genetic screening: ethical issues (1993)

The Council's first report, published in December 1993, recommended that the Government should formulate criteria for the introduction of genetic screening programmes and set up a central body to co-ordinate work in this area.

The Council therefore welcomed the establishment in 1996 of the National Screening Committee, which has since advised the Government on whether population screening programmes should be started, continued or withdrawn. Recommendations from the Committee led to all babies in the UK being offered screening for diseases such as cystic fibrosis and phenylketonuria.

The report also outlined concerns relating to consent, counselling and confidentiality in the context of genetic screening. In 1996 the Government set up the Advisory Committee on Genetic Testing and the Human Genetics Advisory Commission (both subsumed into the Human Genetics Commission in 1999). These bodies provided independent advice to the Government on the ethical, social and scientific aspects of testing, and went on to carry out detailed inquiries on several of the issues raised in the Council's report.

Media interest in the report focused on its recommendations that genetic tests should not be

used by insurance companies. From 1998-2009, the Genetics and Insurance Committee scrutinised the use of genetic tests by insurers, and only ever approved one genetic test for use by insurers, for Huntington's disease. The Council endorses the continuation of an insurance industry moratorium that restricts the use of genetic test results by insurance companies.

In 2006, the Council published an update on the scientific and policy developments that had taken place in relation to genetic screening since 1993. There have been major scientific advances, and many more single-gene disorders have been identified. However, these are often very rare and so only a small number of new genetic screening programmes have been introduced. The Council found the ethical analysis in the 1993 report to be still relevant, a view confirmed by the continuing interest in this report, now 18 years old.

The Council also maintained its original conclusion that screening for common diseases involving many genes remains some way off when it revisited this area in its 2010 report on *Medical profiling and online medicine*. It concluded that direct-to-consumer personal genetic profiling services that claim to predict people's health risks are often inconclusive, and the companies that sell them should provide better information about the evidence on which the results are based.

Human tissue: ethical and legal issues (1995)

The Council's second inquiry dealt with the lack of clarity that existed around the ethics and legalities of the use of human tissue in medicine and research. The resulting report recommended that patient consent should be sought for the disposal, storage or use of any tissue removed during treatment, and that the consent should be based on a genuine understanding of the intended uses of the tissue. The Council also recommended that removal of tissue from children or adults with incapacity should be exceptional and limited to procedures that pose negligible risk.

The Government did not take action until 1999 when it was revealed that hospitals were routinely retaining tissue and organs for research without the consent of patients and families, causing public outcry. In particular, the discovery that organs were taken from the bodies of children caused grief and distress to many.

New legislation to govern the storage and use of human organs and tissue in England, Wales and Northern Ireland was introduced in 2004, in the form of the Human Tissue Act. The Act established consent as the fundamental principle guiding the lawful use of human tissue. As the Bill travelled through Parliament, the Council and other organisations called for the

Government to ensure that an appropriate balance was maintained between respecting the human body and ensuring that the potential benefits of research involving human tissue can be realised.

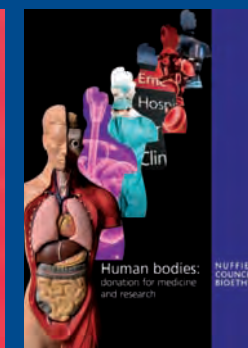
Further legislation and regulations covering the use of human tissue in the UK that have been introduced since the Council's report was published, such as the Human Fertilisation and Embryology Act 2008, include requirements for consent and safety, provisions for future control of material, and restrictions on commercial dealings in bodily material.

Fifteen years later, the demand for human bodily material was as pressing as ever, and the Council decided to revisit the area. In 2011, the Council published the report *Human bodies: donation for medicine and research*, which considered how far society should go in encouraging people to donate their bodily material. The report concluded that altruism should continue to be at the heart of donation, but that this does not exclude the possibility of some form of reward in some circumstances. The report sets out an 'Intervention Ladder' to help policy makers consider the ethical acceptability of various ways of encouraging people to donate.



The Council's independence, combined with an ability to choose topical issues to report on that are of relevance to both policy makers and the public has been beneficial in important areas relevant to the Department. For example, the debate stimulated by the Council's report on *Human tissue* (1995) was of particular relevance to the Department in its work leading to the Human Tissue Act 2004. I am sure that the Council will continue to be an important player in the bioethical arena as it looks to the future.

Earl Howe, Parliamentary Under Secretary of State for Quality, Department of Health





I have very happy memories of being part of the Nuffield Council on Bioethics. The most interesting aspect was meeting and learning from such a fascinating group of members: people with significant experience in ethical debate, from basic philosophical principles, to the practical experience of dealing with ethical issues in clinical practice. It opened up a new world to me.

Professor Sir Kenneth Calman, Chair of the Working Party on research in developing countries and member of Council 2000-2008



The work of the Nuffield Council over the past 20 years has been an invaluable resource for Chinese scientists, bioethicists and regulators in their debate on perplexing bioethical issues and developing ethical norms, guidelines or regulations on emerging biomedical technologies. I hope that in the next 20 years, the Council will extend its vision to the whole world.

Renzong Qiu, Professor of Bioethics, Chinese Academy of Social Sciences



The ethics of research related to healthcare in developing countries (1999, 2002 and 2005)

Renewed debate surrounding the ethical conduct of clinical trials was sparked following African AIDS trials in the 1990s which used placebos in the control group, even though effective treatments were available.

In 1999, the Council invited experts from 18 countries to a workshop to explore the issues at hand, and published the outcomes in a discussion paper. This led the Council to carry out a two-year inquiry, which resulted in the 2002 report *The ethics of research related to healthcare in developing countries*. The report concluded that research must be subject to rigorous ethical safeguards, particularly with regard to the standards of care offered to control groups, obtaining consent from participants, continuing treatment after the research is over, and ethical review of research proposals.

In the following years, guidance on research ethics was issued or revised by several international bodies, including the World Medical Association, the Council for International Organisations of Medical Sciences, and the European Group on Ethics. All considered the Council's ethical framework during their deliberations. Two of the UK's major funders of medical research,

the Wellcome Trust and the Medical Research Council, also drew on and referred to the Council's conclusions in their guidance on research involving people in developing countries. The Parliamentary Office of Science and Technology noted in 2008 that the Council's report was "frequently referred to by researchers and RECs [research ethics committees] in the UK and in many other countries".⁵

In 2004, the Council organised a follow-up workshop in South Africa which brought together researchers and policy makers from 28 countries to discuss the implications of the new international guidelines. Delegates reported that the guidelines were inconsistent and that faithful adherence was often unachievable, such as when attempting to obtain informed consent in emergency situations. The Council published the outcomes of the workshop in a discussion paper in 2005.

Several countries, such as Uganda and India, have since attempted to resolve the problems identified at the Council's workshop by producing national guidance that takes account of local needs and cultural context, while drawing on the general ethical principles laid out in the Council's report.

⁵ Parliamentary Office of Science and Technology (2008) *Research ethics in developing countries: POST note no.304*, available at: www.parliament.uk/documents/post/postpn304.pdf



Exploring global issues



The high level of professionalism and skill amongst the staff and the expertise of members form my strongest memory of the Council. It should continue to maintain its high reputation for inquiring into even the most controversial and difficult ethical questions, bringing in the leading experts in their field.

Baroness Perry of Southwark, Chair of the Working Party on animal research 2003-2005



The ethics of research involving animals (2005)

When it established a Working Party to explore the ethics of animal research in 2003, the Council entered into a highly controversial public debate, with ongoing disputes between scientists and animal rights activists.

Despite the widely differing views that existed on the Working Party, members were able to produce as part of their report a 'consensus statement', agreeing, for example, that a world in which the benefits of research could be achieved without causing suffering or death to animals was the ultimate goal. Building on this sentiment, a central recommendation of the report was urgent improvement and promotion of the '3Rs' (refinement, reduction, and replacement of animal research).

Since 2005, there have been a number of developments that align with the Council's findings. The National Centre for the 3Rs was set up in 2005 and has made significant progress in promoting the 3Rs in UK research by, for example, working with funders to review the way the 3Rs are implemented, monitoring the welfare of genetically altered mice, and funding research on 3Rs techniques. A European Directive on the protection of animals in research came into force on 9 November 2010. It places strong emphasis on the promotion of the 3Rs and requires retrospective assessment of the amount of suffering experienced by animals.

The report also aimed to improve public debate on animal research. It described the range of views that exist in society, not just the extreme ends of the spectrum that were often portrayed in the media. The importance of increasing transparency about animal research was also stressed.

Following a police clampdown on the criminal behaviour of animal rights extremists, and with the support of organisations such as the UK's Science Media Centre, scientists have gradually become more willing to speak publicly about animal research. Most universities now publish on their websites a policy statement about animal research, and footage of animal experiments has been shown on television, all helping to generate a climate of openness. There is still progress to be made, however. For example, there has been no increase in the number of scientific journals with ethical policies or guidelines for authors on the use of animals in research.

To encourage balanced debate among young people, the Council produced a set of freely-available teaching resources on animal research in 2006. The Council also advised the Y Touring – a theatre company which tours schools in the UK – on the script of a play which explores the dilemmas posed by animal research.

The forensic use of bioinformation: ethical issues (2007)

Police powers to take and store DNA samples in the UK has been steadily increasing since the mid-1980s, with little meaningful public debate of the conflicts raised between public safety and the protection of individual liberties.

Following an examination of the area in 2006-2007, the Council found little evidence that keeping the DNA of people not charged or convicted of a crime increased crime detection rates, and that many people were concerned about the implications and stigma associated with the storage of their DNA. In its report on *The forensic use of bioinformation*, the Council recommended that the police should only be allowed to store permanently DNA from people who are convicted of a crime, with the exception of people charged with serious violent or sexual offences, thus bringing the law in England and Wales in line with Scotland.

In 2008, the European Court of Human Rights forced a change of policy in its decision in the case of *S and Marper v UK*. Referring to the Council's report throughout its judgment document, the Court held that the blanket policy in England, Wales and Northern Ireland of holding DNA, regardless of the outcome

of arrest, was disproportionate. The Government responded by agreeing to destroy all biological samples, but retaining profiles and fingerprints of non-convicted individuals for six years. However, the coalition Government that came to power in 2010 intends to adopt the protections of the Scottish model in its *Protection of Freedoms Bill 2010-11*, thus implementing the Council's recommendation in full.

The Bill sets out a number of other proposals that are in line with the Council's recommendations:

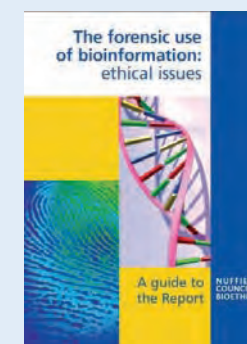
- DNA samples, such as saliva or blood, must be destroyed as soon as a DNA profile has been derived from the sample or within six months.
- DNA given by people voluntarily, for example to eliminate them from an investigation, should be destroyed as soon as it has fulfilled the purpose for which it was taken.
- For people convicted of an offence committed when they under 18, DNA can be retained indefinitely only if the custodial sentence is five years or more.

The Bill, which is currently making its way through Parliament, also puts the DNA Database and the National DNA Database Strategy Board on a statutory footing for the first time.



The secret of the Council's enormous influence is not only the dedication of the volunteers and the secretariat, but, above all, its independence from government. For example, had the issue of the forensic use of bioinformation been left to government, it is highly unlikely that we would have seen the crucial decision of the European Court of Human Rights in the Marper case or the current government Bill which follows the Council's recommendations.

Professor Sir Bob Hepple, Chair of the Council 2002





Reflection and deliberation

Future work topics

The Council has developed a thorough process for selecting new topics. It consults with a wide range of people and organisations, both within the UK and abroad, to keep abreast of new developments in biology and medicine and the ethical questions that they raise. A shortlist of topics is discussed at the Council's annual 'Forward Look' meeting with the help of invited speakers and guests. The Council then sets up expert working parties, which sit for around 18 months, to consider and report on the topics which have been chosen for further exploration.



Professor Hugh Perry, Chair of the Council's Future Work Advisory Group, provides his thoughts on what the important bioethics issues of the future will be.

The work of the Council will continue to cover a diverse range of topics that impact on ethical issues on many different scales.

Rapid advances in reproductive technology and human genetics raise important ethical issues for families and future generations. The potential for preventing mitochondrial disorders from being inherited via in vitro techniques, where healthy mitochondria from a donor's egg are used instead of faulty mitochondria from the mother's egg, exemplifies this. Artificial alterations to nuclear DNA are generally viewed as unethical – should the substitution of mitochondria, which contain tiny amounts of DNA, be viewed differently? And what is a donor's relationship to a resulting child?

Established methods of assisted reproduction involving egg and sperm donation bring forward new ethical questions, as the generations of children born through these methods grow up. For example, how much information should people created through assisted reproduction with donor gametes be offered about their genetic origins?

Our understanding of how the brain works continues to progress at a formidable rate and techniques to physically monitor brain activity, alter or interfere with brain function in non-pharmacological ways are

becoming more common place. These interventions raise numerous ethical questions of personhood, privacy and the complex issue of consciousness, to name but a few. It is apparent that these intrusions on the brain open pathways to medical benefit but also less benign outcomes. The claims and hyperbole that sometimes surround advances in neuroscience and indeed other areas of the biosciences, which make extraordinary promises to cure all manner of disease, raise major concerns for the integrity and responsibility of scientists at the forefront of these activities.

The ethical landscape in which the Council is involved is neither local nor static. None of us can fail to be aware of the global health inequalities that exist and appear to persist despite the efforts of many dedicated individuals. The recognition of these inequalities as an ethically unacceptable state of affairs will contribute as a driving force for the Council to contribute further to this arena.

All these topics are likely to feature in the Council's future work programme, along with the involvement of children in clinical trials, genomic data management, and the common ethical issues raised by all emerging biotechnologies. There is no doubt that, even after 20 years spent exploring issues such as these, the list of issues requiring our attention is not getting any smaller.

Communication and dialogue



Promoting debate on bioethics

Media communication

As the media world has changed over the past 20 years, so has coverage of the Council's work. From the beginning, the scientific and broadsheet press has taken a keen interest in our reports and, later, radio and television interviews with Council spokespeople have become commonplace.

Since 2005, the Council has held its media briefings with the Science Media Centre, a London-based independent organisation which has had much success in improving the quality of science reporting in the national media. The Council's work has been

predominantly reported in a balanced and accessible way by all areas of the media, and this has been an invaluable way for it to promote awareness and discussion of bioethics to a wide audience.

The age of the internet brought new and exciting possibilities for communication. The Council's first website, launched in 1998, enabled the Council to provide all its reports to anyone with internet access. Following major redesigns in 2002 and 2010, today's website provides summaries of reports, videos, educational resources and opportunities for visitors to the site to get involved with consultations and events.

Five website tips

The Council's Communications Officer, **Sarah Bougourd**, provides her top tips for navigating the website.



1. Report summaries: if you would like a quick overview of a report, go to the 'Report summary' menu in each project page. Links to the full report are provided if you would like to find out more.

2. News: latest news about our activities, press releases, and our quarterly newsletter can all be found in the News section. You can sign up for news alerts via email on specific projects as well.

3. Explore by topic: if you are interested in a cross-cutting issue, such as consent or privacy, you can find links to all the work the Council has done in relation to these in the 'Explore by topic' section.

4. Education: this section is for teachers and those interested in bioethics education. You can download classroom resources and you'll also find news of our education activities, such as our new film-making competition for students 'Box Office Bioethics'.

5. Video interviews: you'll find a range of videos on the website, for example you can watch working party members give their thoughts on reports they were involved in producing.



For me, the great value of the Council is not so much to answer complex ethical questions as to frame them – to highlight what the challenges posed by new technologies might be, and which ones really matter. As a journalist, I'd also be interested in the Council revisiting past reports in light of later discoveries and

ethical decisions: it would be interesting to see what changes.

Mark Henderson, Science Editor, The Times

The Council provides thoroughly researched and influential work on the ethics dilemmas and challenges facing all of us in modern society. A recent public debate on Alzheimer's care was revolutionary in its exploration of the illness. There is, it seems to me, a real hunger amongst TV viewers for well thought out discussion on the challenges facing health care, particularly, in the future.



Clare Catford, Journalist and TV and Radio Presenter

Being one of the longest running bioethics committees, the Nuffield Council is a key actor in the international bioethics community. The Council stimulates debate on bioethics with its well-founded reports and supports the establishment and work of national bioethics committees in other countries. I am sure the Council will be the first to develop new ways of interacting more directly with people through the internet and, while working on opinions or reports, have a direct exchange with interested citizens.



Professor Edzard Schmidt-Jortzig, Chair, German Ethics Council



Chairing the Nuffield Council's Working Party on public health was an immensely rewarding and stimulating experience. It took a great deal of thought and iteration, with excellent support from the secretariat, to reach our conclusions. Since its publication, the framework of our report has become very influential in public health policy. It was incorporated into the government's public health White Paper.

Lord Krebs, Chair of the Working Party on public health 2006-2007

The Nuffield Council has been a model and a source of inspiration to many ethics councils around the world through its methods of operation, the recommendations proposed, and the way its reports are presented to the general public.



Professor Göran Hermerén, Former President of the European Group on Ethics in Science and New Technologies

The CCNE and the Nuffield Council have a long history of fruitful exchanges, and of exploring together often quite different concepts. We have had many an occasion to appreciate the Council's major contribution to the creation of ever closer relations between the world's bioethics institutions. The Council's contemporary approach to issues and to their communication, in particular to the general public and the young, is a source of inspiration.



Marie-Hélène Mouneyrat, Secretary General, French National Consultative Ethics Committee for Health and Life Sciences (CCNE)

In addition, our e-newsletter delivers a regular digest of news to 2,000 subscribers in 57 countries, and Twitter, Facebook and YouTube have become valuable tools for engaging directly, and instantly, with people all around the globe.⁶

There is a huge appetite for bioethics on the internet, with blogs, discussion groups and special-interest sites joining the established news websites such as the BBC and The Guardian in covering the Council's work. The internet has helped the Council to reach a truly international audience.

Informing policy makers

The Council has no political agenda and its independence is critical to its ability to provide policy advice that is authoritative and trusted. We meet regularly with policy makers from the UK and further afield, respond to policy consultations, and hold briefing events for Parliamentarians.

Many of the Council's reports have been influential, as illustrated by the highlights on pages 10-15. Around 50 per cent of the recommendations in selected reports of the Council published between 1993 and 2005 had been taken up by policy makers in one way or another.⁷

International relations

The Council has built extensive networks in the international environment, including strong links with equivalent bodies throughout Europe, in the US, and international institutions such as WHO and UNESCO. One of its future aims will be to ensure that critical ethical reflection continues to respond to developments that have far-reaching implications in the global environment. In 2011, the Council held a symposium on global health inequalities to mark its 20th anniversary, and the Council's future work programme is likely to include a strong focus on global issues.

Events

The Council has organised or taken part in numerous events to discuss with people directly the bioethics issues of the day. From academic conferences and policy seminars, to science festivals and public debates, the Council puts a great deal of effort into reaching a wide audience through its events programme.

⁶ See: **Twitter:** www.twitter.com/nuffbioethics **Facebook:** www.facebook.com/nuffieldbioethics
E-newsletter: www.nuffieldbioethics.org/content/update-newsletter **YouTube:** www.youtube.com/user/nuffieldbioethics
⁷ Nuffield Council on Bioethics (2006) *Annual report 2005* (London: Nuffield Council on Bioethics).

Reaching young people

Promoting informed debate of bioethics among young people has been a priority since the early days of the Council. Over the years, the Council has advised Y Touring, the YMCA's theatre company, on scripts of plays about xenotransplantation, genetically modified crops and animal research. The plays went on to be performed to thousands of school students around the UK.

In 2003, the Council set up its own advisory group on reaching young people, which taps into the expertise of teachers and other people working in education. The group has helped the Council to produce teaching resources on animal research, the forensic use of bioinformation, dementia, personalised healthcare and biofuels, and it will continue to add to this bank of resources in future.

Dr Rhona Knight, Chair of the Council's Reaching Out to Young People Advisory Group, outlines the group's plans for the future.



Why is promoting discussion of bioethics among young people an important activity for the Council?

With the increasing number of bioethical issues facing the world today, we need to ensure that young people are given the opportunities to reflect on, to contribute to, and to engage in debate and policy development, honing their bioethical skills for their future roles in society. As a Council, we aim to involve young people in our consultations and in the dissemination of our reports. By developing bespoke resources based on the Council's publications, we endeavour to link in explicitly with the learning outcomes of a variety of subjects within the school curriculum, including citizenship, science, information technology, geography and philosophy. In achieving these aims the Reaching Out to Young People group benefits from the skills and expertise of a multidisciplinary advisory group of experts, including teachers and university lecturers.

How will you be engaging with young people in future?

While classroom teaching continues to be a focus, we are broadening out our reach and using social media, including Twitter and Facebook. This year sees the pilot of Box Office Bioethics, a competition which aims to encourage young people to make a three to five minute film that explores a contemporary bioethical issue in an engaging and creative way. We also hope to build on some of the work we have done outside the school curriculum, for example in extended study tasks where students have the opportunity research bioethical areas of interest.

What bioethics issues strike a chord with young people?

It is hard to avoid bioethics today. Young people reading newspapers, using the internet, watching films or reading novels will struggle to avoid ethical issues relating to medicine and to biology, be that genetically modified crops, organ donation, or dementia. Members of Council are often invited into schools to give talks on these topical issues, and while some of the areas covered in Council reports may seem, on the surface, to be more appealing to young people – for example the report on personalised health – it appears that young people have something to contribute and valuable to say on all of the issues which the Council has addressed.

Informing policy





Future directions

Hugh Whittall, Director of the Council, looks from the past to the future

For 20 years now the Council has been publishing reports that have tackled some of the most difficult issues in the biosciences, from genetic screening and xenotransplantation through to dementia and biofuels. As I meet people from the UK and indeed from all around the world I hear of how widely the Council's reports are read, respected and used. It has clearly built a sound reputation on the basis of its independence, and of the quality and impact of its reports.

Our report on health-related research in developing countries is regularly quoted, not least in international practice guidelines; the 'intervention ladder' from our public health report has been used in two recent Government White Papers; and I have lost count of the number of times I have been told of how our reports are used as undergraduate teaching material.

Whilst the reports are the most tangible product of our work, it would nevertheless be wrong to think of the Council simply in these terms. For in practice the

Council's work reaches far beyond this. Our working parties, for example, engage with many people through consultative processes, meetings and workshops. Council members and staff regularly give talks at schools, conferences, meetings, and other public events. Our work with schools, in particular, has grown over recent years, so that we now have made available, through partners working in education, curriculum-related materials based on each of our last five reports. But herein lies the future challenge – as our work will undoubtedly become more complex, the task of engaging a wider audience will become ever more demanding.

It is often said that the pace of change in science and medicine is becoming faster, and that we have to work hard to keep up with the consideration of the ethical and social aspects of these developments. This is undoubtedly so, as developments in areas such as genomics and neuroscience, when combined with rapid changes in digital technologies, produce possibilities that are potentially extremely far-reaching in their breadth and complexity. But it is also the case that the environment within which we work is changing. The global nature of research and innovation, and their effects, has implications of a scale and nature that we have not previously had to contemplate. And over the next few years we expect to see the demise (in their

current form at least) of several UK advisory bodies such as the Human Genetics Commission and the Human Fertilisation and Embryology Authority.

So the Nuffield Council on Bioethics, if it is to remain relevant both to policy makers and to a wider public, needs to recognise the importance of these changes and must be ready to work in ways that enable it to adapt to an uncertain future. We will continue to address contemporary issues in ways that both support public discussion and understanding and inform policy through rigorously argued reports, but we will keep looking for more effective ways of doing so.

One of the main tasks of the Council is to anticipate, rather than merely respond to, the social and ethical implications of developments in the biosciences. We have done that rather well, and many people are to be thanked and congratulated for that. But one of the things that makes the future so interesting is that we must now also try to anticipate the ways in which we can support a wider engagement in discussing these issues - in a world where science, technology, policy and communications media are constantly changing and interacting. The challenges are difficult, many and varied, but that is the nature of the business we are in, and we will apply ourselves to them in the future as enthusiastically as we have in the past.

List of reports

Human bodies: donation for medicine and research

October 2011

Biofuels: ethical issues April 2011

Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age

October 2010

Dementia: ethical issues October 2009

Public health: ethical issues November 2007

The forensic use of bioinformation: ethical issues

September 2007

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

Genetic screening: a supplement to the 1993 report by the Nuffield Council on Bioethics July 2006

The ethics of research involving animals May 2005

The ethics of research related to healthcare in developing countries: a follow-up discussion paper

March 2005

The use of genetically modified crops in developing countries: a follow-up discussion paper December 2003

Pharmacogenetics: ethical issues September 2003

Genetics and human behaviour: the ethical context

October 2002

The ethics of patenting DNA: a discussion paper

July 2002

The ethics of research related to healthcare in developing countries April 2002

Stem cell therapy: the ethical issues – a discussion paper April 2000

The ethics of clinical research in developing countries: a discussion paper October 1999

Genetically modified crops: the ethical and social issues May 1999

Mental disorders and genetics: the ethical context September 1998

Animal-to-human transplants: the ethics of xenotransplantation March 1996

Human tissue: ethical and legal issues April 1995

Genetic screening: ethical issues December 1993

Current secretariat

Hugh Whittall, Director

Katharine Wright, Assistant Director

Dr Alena Buyx, Assistant Director

Dr Peter Mills, Assistant Director

Laura Riley, Project Leader

Carol Perkins, PA to the Director and Secretariat Administrator

Catherine Joynson, Communications Manager

Sarah Bougourd, Communications Officer

Kate Harvey, Research Officer

Tom Finnegan, Research Officer

Varsha Jagadeshram, Research Officer

Johanna White, Office and Communications Administrator

Current Council membership

Professor Albert Weale (Chair)

ESRC Professorial Fellow & Professor of Political Theory and Public Policy, University College London

Professor Hugh Perry (Deputy Chair)

Professor of Experimental Neuropathology, University of Southampton

Professor Steve Brown

Director, Medical Research Council Mammalian Genetics Unit, Harwell, Oxfordshire

Dr Amanda Burls

Director, Postgraduate Programmes in Evidence-Based Health Care, and Senior Fellow, Centre for Evidence-Based Medicine, University of Oxford

Professor Robin Gill

Professor of Applied Theology, University of Kent

Professor Sian Harding

Professor of Cardiac Pharmacology, National Heart and Lung Institute, Imperial College London

Professor Ray Hill

Retired 2008. Previously Head of Licensing and External Research for Europe, Merck, Sharp and Dohme

Professor Søren Holm

Professor of Bioethics, University of Manchester and part-time Professor of Medical Ethics, University of Oslo, Norway

Dr Rhona Knight

General Practitioner and Senior Clinical Educator, University of Leicester. Chair of the Council's Reaching Out to Young People Advisory Group

Professor Graeme Laurie

Professor of Medical Jurisprudence, University of Edinburgh, and Director of the Arts and Humanities Research Council Research Centre for Studies in Intellectual Property and Technology Law

Dr Tim Lewens

Senior Lecturer, Department of History and Philosophy of Science and Fellow of Clare College, University of Cambridge

Professor Ottoline Leyser

Professor of Plant Development and Associate Director, Sainsbury Laboratory, University of Cambridge

Professor Anneke Lucassen

Professor of Clinical Genetics and Honorary Consultant Clinical Geneticist, University of Southampton Cancer Sciences Division and The Wessex Clinical Genetics Service

Professor Michael Moran

WJM Mackenzie Professor of Government, University of Manchester. Co-opted member of Council while chairing the Council's Working Party on emerging biotechnologies

Professor Alison Murdoch

Professor of Reproductive Medicine, Consultant Gynaecologist and Head, NHS Newcastle Fertility Centre at Life

Dr Bronwyn Parry

Reader in Geography, Queen Mary, University of London

Professor Nikolas Rose

James Martin White Professor of Sociology, London School of Economics and Political Science, and Director, BIOS Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society

Dr Geoff Watts

Science and medical writer and broadcaster

Professor Jonathan Wolff

Professor of Philosophy, University College London

1991-2011

The Council in numbers

5

Chairs of the Council

20

months on average to produce a report

22

reports

38

members of staff

57

countries that receive the Council's e-newsletter

70

Council members

71

'fact-finding' meetings

80

Council meetings

163

working party meetings

200

working party members

1,683

responses to the Council's consultations

2,040

cakes consumed by the secretariat

100,000

visits to the website in 2011

1,544,801

words in the Council's reports