

UKDEC

UK Donation Ethics Committee

UK DONATION ETHICS COMMITTEE

ANNUAL REPORT 2011—2012

**ACADEMY OF
MEDICAL ROYAL
COLLEGES**

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INTRODUCTION

The UK Donation Ethics Committee was established in January 2010, with the aim of providing an independent, UK-wide source of advice on the difficult ethical dilemmas that can arise in relation to organ donation. Its establishment is one part of a much wider programme of work initiated following the Organ Donation Taskforce's report 'Organs for Transplants', published in 2008.

This second annual report from UKDEC summarises all our work in the period January 2011 – March 2012, with a financial report covering the period October 2010 – March 2012. The Academy of Medical Royal Colleges has changed its financial year to begin in April, and future annual reports will follow Academy financial years.

HIGHLIGHTS

Ethical Framework for DCD: the first major publication for UKDEC, *An Ethical Framework for Donation after Circulatory Death* was published for consultation in January 2011. Nearly 60 responses were received, from both individuals and those representing organisations. In response to the consultation the framework was restructured into two parts, the first discussing in some detail the key ethical issues associated with DCD; and the second putting these into the context of the patient pathway. A third section sets out issues for further consideration, either by UKDEC or others. A separate Executive Summary provides a quick reference guide to the recommendations through the patient pathway. The consultation and final document, published in December 2011, are both available to download from the UKDEC pages on the Academy of Medical Royal Colleges' website.

Research in Transplantation: A paper setting out UKDEC recommendations for tackling problems in transplantation research in the UK has recently been accepted for publication in the journal *Transplantation*. Full details of the recommendations, and a report of the workshop in autumn 2010 that led to their development, are available on the UKDEC webpages. Recommendations for seeking consent for research from both donors and recipients are now being considered by NHSBT. A workshop in autumn 2010 highlighted a number of unnecessary complications arising from the regulatory framework for transplantation research. After discussion with UKDEC, the National Research Ethics Service made amendments to the IRAS application system to avoid misallocation of proposals. The Human Tissue Authority has worked hard to address issues arising from the Human Tissue Act, which prohibits removal of tissue for research unless the premises are licensed for research. A new licensing scheme will shortly come into place to enable premises to be licensed for removal of tissue, which will ease the situation although there is a financial cost to the institution. UKDEC will be continuing to lobby for changes to primary legislation should the opportunity arise.

Faith and organ donation: The aim of this workstream is to promote debate about diagnosis and definition of death in relation to organ donation among faith communities, and it builds on work carried out by the Organ Donation Taskforce in 2008 and 2009. Engagement with the Faith communities has been led by Professor Randhawa supported by UKDEC colleagues. The method of engagement has been largely defined by the faith communities themselves as they are all at different stages of debate concerning death and organ donation.

Islam:

The Islam Channel, which has the largest worldwide Muslim TV audience, hosted a live debate on organ donation in January 2011, including a phone-in for viewers to ask questions. The panel included an Islamic scholar, Professor Randhawa Komal Adris (Organ Donor Campaign).

Professor Randhawa worked in partnership with the Muslim Health Student Network to organise a symposium on Organ Donation and Islam. The panel for this event included Sir Peter Simpson and Mufti al-Kawthari (Director, Institute of Islamic Jurisprudence). Over 100 delegates attended the event. A booklet Organ Donation and Islam was launched at the event (Nov 24, 2011)

Christianity:

The Church of England appointed a new Bishop to lead on healthcare issues, the Bishop of Carlisle. He kindly agreed to write a piece about Christianity and Organ Donation for the Church of England website and an article for the Church Times. As a follow-up to this, the Church of England organised a fringe meeting to discuss organ donation at their Annual Synod Meeting. Unfortunately, this event was postponed and will be re-scheduled for 2012.

The Seventh Day Adventists have organised 2 televised debates - the first discussing organ donation (Professor Randhawa took part in this), the second discussing death (Sir Peter Simpson and Professor Randhawa took part in this).

Judaism:

Sir Peter Simpson and Professor Randhawa met with Professor Steinberg in November 2011. Prof Steinberg is one of Israel's leading authorities on Jewish medical ethics. He advises both the Chief Rabbinate and the Ministry of Health. He has become best known to the wider public in recent years for his contributions in the field of organ donation, and for the Israeli "end – of – life" law, widely known as the "Steinberg Law". Although there is acceptance of both brain death and cardio-respiratory death within the Jewish faith, there are two distinct interpretations of the requirements of halakhic medicine. The first, which is the basis of the UK's Chief Rabbi, Lord Sachs' views, is that brain death is unacceptable; while the second, to which Professor Steinberg subscribes, is that it is valid. Hence the need for any Jew to be able to know what his Rabbi's interpretation is. This pattern of different interpretations is one seen in a number of faiths, and an area of great interest to UKDEC.

Hinduism:

The National Council of Hindu Temples have produced a DVD and a leaflet – Hinduism and Organ Donation – and hosted a national launch event at Neasden Temple on July 9th 2011. A series of follow-up events is being planned.

Sikhism:

The British Sikh Consultative Forum organised a Sikhism and Organ Donation event in April 2011. The guest of honour was Fauja Singh. (Fauja Singh (born April 1, 1911) is an internationally recognised Sikh celebrity who is world record holding marathon runner in his age bracket). A debate event is being planned with the Sikh Channel TV station.

Donation after circulatory death for cardiac transplantation

As work to develop the ethical framework for DCD progressed during 2011, UKDEC was approached by two paediatric teams to advise on the development of a clinical protocol for removal of hearts for transplantation from DCD donors. Given the sensitivities in this novel area, UKDEC decided to host a workshop, bringing together not only the two paediatric teams, but an adult cardiac team with similar interests, together with legal, ethical, lay, and broader clinical and professional interests to debate the issues more fully.

The workshop provided an opportunity to consider each stage of the patient pathway, in terms of both the technical requirements of heart retrieval, and the ethical issues arising. The group were in agreement with the UKDEC view that there is no specific ethical objection to the removal of the heart from a DCD donor. The conclusions were captured in the final draft of the Ethical Framework.

Two specific recommendations for further work will be taken forward in 2012:

- Consent for donation from children; and
- Review of the legal guidance for donation after circulatory death.

COMMITTEE RENEWAL

Committee members were appointed following open competition for two years in the first instance, coming to an end in January 2012. Reviewing the expertise available at the first meetings, it was decided that most members should have their terms extended for a further three years, in line with their terms of office. An open competition was held to strengthen expertise in some areas, and 103 applications were received. A total of seven appointments were made (three of whom were previously co-opted members), bringing expertise in clinical transplantation, renal medicine, intensive care nursing and medicine, lay skills, ethics and legal skills. Observers continue to be invited from key organisations, including NHS Blood and Transplant, the Human Tissue Authority, and the UK Health Departments. Five meetings and one workshop, (attended by 60 people) were held over the 15-month period covered by this report, and members attended meetings and seminars on behalf of UKDEC.

FINANCIAL REPORT

For the period April 2010 – March 2012 the Academy has managed UKDEC under the terms of a contract with the Department of Health. The Devolved Administrations are not signatories to the contract, but have agreed to provide funding in support of the UKDEC, with the funding split between the Administrations in accordance with Barnett principles.

The Academy financial year used to run from October to September, but this has now been adjusted to run from April to March. This report covers the period October 2010 – March 2012, to match the Academy's most recent accounts, and future financial reports will be presented from April to March.

Table 1 shows financial data from October 2010 to March 2012. The Department of Health provided funding for the year 2009-10, as it was originally anticipated the committee would begin work in autumn 2009. In the event the committee could not begin work until January 2010, so most of these funds were carried over. These funds were used in part to pay for the England contribution to UKDEC running costs in the period April 2011 to March 2012, bringing the surplus down to £69,239 at the end of the reporting period. (Devolved administrations did not provide any funds in 2009-10, and have continued to pay their agreed contributions throughout the time covered by this report).

The Secretariat staff are seconded from the Department of Health, and to minimise bureaucracy the DH retains these costs and pays the staff directly.

Table 1: UKDEC Financial Data October 2010 – March 2012

Income	Total
Funds brought forward	£103,392.00
Donation Ethics Committee ¹	£61,647.00
	£165,039.00
Operating Expenses	Total
Project Costs	£43,045.62
Catering	£2,569.69
Travel & Subsistence	£9,434.49
Professional Fee	£18,250.10
	£73,299.90
Operating	£91,739.10
Other Expenses	Total
Contribution to AoMRC overheads as per contract	£22,500.00
	£69,239.10

1. Includes £20K additional funding for faith and organ donation project from England; funds from England for October 2010 – March 2011, and contributions from Scotland, Wales and Northern Ireland from October 2010 – March 2012.

FORWARD LOOK

April 2012 sees UKDEC with an expanded membership, bringing in further ethical, clinical and lay expertise. Major projects for the year will be:

- Development of an Ethical Framework for Donation after Brainstem Death, as a companion to the Ethical Framework for Donation after Circulatory Death published last year;
- A review of the legal guidance on donation after circulatory death, with particular reference to interventions carried out before death to facilitate donation; UKDEC recommended in the Ethical Framework for DCD that this legal guidance should be reviewed, and an alternative approach sought which balances risks and benefits. The Chairman wrote to the Secretary of State expressing this view on behalf of the committee, and UKDEC has now been invited to develop the evidence base supporting the case for change.
- Consideration of consent in paediatric organ donation; and
- Continuation of the work to engage faith communities in discussion about organ donation;
- A stakeholder workshop is planned for autumn 2012, with the topic yet to be finalised.

CONCLUSION

UKDEC has continued to build on the foundations from the first year. The work programme is expanding, with the first major guidance document finalised and published, and new projects beginning. When UKDEC sought new members in December 2011, it was testament to the impact that UKDEC has had in the transplant community in the short time since its establishment that we received 103 applications.

The chairman and members remain fully committed to providing the ethical frameworks and guidance that the donation and transplant communities require to deliver the care that both donors and recipients deserve.

UKDEC MEMBERSHIP

JAN 2010 – JAN 2012

Sir Peter Simpson (Chair)

Past President, Royal College of Anaesthetists

Paula Aubrey

Regional Manager, NHS Blood and Transplant

Joe Brierley

Consultant Paediatrician,
Paediatric and Neonatal Intensive Care Unit,
Great Ormond St Hospital, London

Graham Brushett

Lay member, heart and kidney transplant recipient

Stephen Cole

Consultant in Anaesthesia and Intensive Care
Medicine, Ninewells Hospital, Dundee

Heather Draper

Professor of Biomedical Ethics and Director of the
Centre for Biomedical Ethics, Department of Primary
Care Clinical Sciences, University of Birmingham

Bobbie Farsides

Professor of Clinical and Biomedical Ethics,
Brighton and Sussex Medical School

Leslie Hamilton

Consultant Cardiac Surgeon, Freeman Hospital,
Newcastle Upon Tyne

Penney Lewis

Professor of Law, School of Law and Centre of
Medical Law and Ethics, King's College London

Gurch Randhawa

Professor of Diversity in Public Health and Director,
Institute for Health Research,
University of Bedfordshire

Anthony Warrens

Honorary Consultant Physician and Dean for
Education, Barts and The London School of
Medicine & Dentistry

Eleanor Update

Writer

Helen Lovell

Secretary to UKDEC

Observers from the Department of Health and Devolved Administrations,
the Academy of Medical Royal Colleges, NHS Blood and Transplant and the
Human Tissue Authority may also be in attendance.

UKDEC MEMBERSHIP JANUARY 2012 – PRESENT

Sir Peter Simpson (Chair)

Past President, Royal College of Anaesthetists

Paula Aubrey

Regional Manager, NHS Blood and Transplant

Joe Brierley

Consultant Paediatrician,
Paediatric and Neonatal Intensive Care Unit,
Great Ormond St Hospital, London

Graham Brushett

Lay member, heart and kidney transplant recipient

Stephen Cole

Consultant in Anaesthesia and Intensive Care
Medicine, Ninewells Hospital, Dundee

Antonia Cronin

Clinical Research Consultant Nephrologist,
Biomedical Research Centre,
Guys and St Thomas' NHS Foundation Trust

Heather Draper

Professor of Biomedical Ethics and Director of the
Centre for Biomedical Ethics, Department of Primary
Care Clinical Sciences, University of Birmingham

Bobbie Farsides

Professor of Clinical and Biomedical Ethics,
Brighton and Sussex Medical School

Dale Gardiner

Consultant in Adult Critical Care, Nottingham
University Hospitals NHS Trust

Amanda Gibbon

Lay member; Kidney donor

Leslie Hamilton

Consultant Cardiac Surgeon, Freeman Hospital,
Newcastle Upon Tyne

Penney Lewis

Professor of Law, School of Law and Centre of
Medical Law and Ethics, King's College London

Muireann Quigley

Centre for Social Ethics and Policy,
University of Manchester.

Gurch Randhawa

Professor of Diversity in Public Health and Director,
Institute for Health Research,
University of Bedfordshire

Anthony Warrens

Honorary Consultant Physician and Dean for
Education, Barts and The London School of
Medicine & Dentistry

Eleanor Updale

Writer

Helen Lovell

Secretary to UKDEC

Observers from the Department of Health and Devolved Administrations,
the Academy of Medical Royal Colleges, NHS Blood and Transplant and the
Human Tissue Authority may also be in attendance.

TERMS OF REFERENCE

The UKDEC will:

- Consider ethical issues, both general and specific, relating to the field of organ donation and transplantation and provide independent advice to clinicians, policy leads and others as appropriate and/ or relevant issues referred to the group by local donation committees.
- Develop and maintain links with relevant professional and ethical associations/ societies.
- Ensure that advice given is independent and not unduly influenced by the views of any other organisation or individual.
- Produce, maintain and promulgate guidelines relating to ethical issues on organ donation and transplantation.
- Support Local Clinical and Research Ethics Committees, and Donation Committees in their provision of out of hours advice at a local level, based on DEC frameworks.
- Assist in the development of training content for those involved in organ donation and transplantation.
- Receive and collate any advice given locally, based on DEC frameworks, to harmonise advice where appropriate, determine whether any issues have any regional/ national implications and take action as appropriate.
- Be accountable to the Academy of Medical Royal Colleges:
 - a. Setting out an annual work programme
 - b. Providing an annual report summarising work undertaken and accounting for the use of funds
 - c. Liaising with the Academy before publications are put in the public domain.

