

UKDEC BUSINESS PLAN 2013-14

Introduction

1. The UK Donation Ethics Committee (UKDEC) was established in early 2010. It is hosted by the Academy of Medical Royal Colleges, and funded by the UK Departments of Health.
2. This business plan reports on activity in 2012-13, and sets out proposals for the programme of work for 2013-14, with indicative requirements for the following two years to March 2016.

Achievements in 2012-13.

Strategic projects

Faith project

3. This project, which builds on work instigated by the Organ Donation Taskforce (ODTF), is managed as a discreet workstream with ring-fenced funding. An interim report is at Annex A.

Ethical framework for donation after brain-stem death (DBD)

4. A near-final draft is due to be discussed at the UKDEC meeting on 17 May 2013. The intention is to launch a consultation in June 2013 with a view to final publication in the autumn.

Consultation document on paediatric consent

5. UKDEC has responded to a demand from the field for specific guidance on consent to donation from deceased children. In particular we were asked about the ethical implications of proceeding with donation on the basis of parental consent, when the child would not have had the time/knowledge/maturity to formulate a view on the subject.
6. UKDEC has debated paediatric consent in Committee and has drawn up a consultation document, which should be ready to issue in the summer of 2013.

Review of legal advice on interventions to optimise successful donation

7. In response to concerns raised by practitioners, UKDEC has identified a review of the current legal advice from DH on interventions as a strategic objective. Ministers asked us to examine the evidence and submit a case for review to DH.
8. A document setting out a generic decision-making framework has been developed, focussing on balancing benefits and burdens.
9. A workshop was held on 1 March 2013 to test and refine the approach in relation to a range of interventions with interested parties (including intensivists, transplant teams, specialist nurses for organ donation (SN-ODs), clinical leads for organ donation (CL-ODs), ethicists, lawyers, donor families). A submission to DH will follow in spring 2013.

Issues addressed in response to demand in-year

10. UKDEC continues to receive comments and questions from the transplant community, and we are striving to provide a flexible and appropriate response, that does not cut across the responsibilities of local ethical and other approval systems. Issues addressed during 2012-13 are summarised below.

Donation from an Anencephalic infant

11. UKDEC were asked by a clinical team to consider the ethical issues relating to a request from the parents of a deceased anencephalic infant (a child born without a forebrain, the largest part of the brain consisting mainly of the cerebral hemispheres, including the neocortex), for the child to be an organ donor. Whilst UKDEC is not constituted to provide ethical opinions on individual cases, this raised ethical issues that would be relevant not only to other anencephalic donations, but to donations from children in general.
12. UKDEC provided the team with advice on the ethical issues to be considered and the factors that needed to be taken into account in deciding the best course of action. This was well received and UKDEC agreed to a request from the team to share it with another clinical team involved in a similar case.
13. UKDEC members will collaborate with the team to produce an anonymised joint case report for publication, which will provide a valuable source of advice for future clinical teams faced with these difficult decisions.

Human Transplantation (Wales) Bill

14. UKDEC has participated throughout the consultation process on this Bill. Written evidence was submitted to the Welsh Assembly committee scrutinising the Bill, and the chairman gave oral evidence on 30 January 2013.

NHS Blood and Transplant Strategy

15. UKDEC invited NHSBT to attend a Committee meeting and present their proposals for their strategy document [“taking organ donation to 2020”]. UKDEC provided detailed comment on the Strategy and stands ready to provide ethical input as the strategy develops.

Edinburgh pilot protocol for donation from Maastricht Category II donors

16. UKDEC was asked to review the protocol, which is for a pilot scheme to enable donations from Category II donors (in whom resuscitation has failed after cardiac arrest), in January 2013. Such donations have not occurred in the UK to date, and are a potential contribution to increasing the number of organs available for transplantation.
17. Whilst UKDEC is not constituted to endorse or approve specific projects, the project raises a number of ethical issues which will be of interest to similar schemes going forward. As the team were keen to get UKDEC input in advance of their scheduled start-time of end January, UKDEC provided a rapid detailed commentary on the aspects that raise ethical questions, and debated the protocol at its meeting on 22 February 2013.
18. UKDEC is committed to continuing to work in this flexible way, balancing pieces of work that have strategic importance with more individualised responses to issues that cannot be dealt with appropriately at a local level.

Membership: Recruitment and renewals

19. Members were appointed for two years in the first instance, with the possibility to renew for up to a further three years. The first terms expired in January 2012. Replacements were successfully recruited, from a wide field of high calibre applicants.
20. The Chair's initial term came to a close in December 2012. He has agreed to stay on at least until the end of 2013 in order to maintain the momentum built up during his chairmanship and minimise disruption due to the necessary change in secretarial arrangements.

Secretarial support

21. Reorganisations within DH meant that secretarial support could no longer be provided by DH staff. The Academy therefore undertook a recruitment exercise for a part-time secretary, and the post was filled on 1 November 2012. The secretary is an employee of the Academy, and works two days per week. Full employment costs are met by the Academy out of the funding provided for UKDEC by the UK Health Departments.

Work Plan for 2013-2014

Ways of working

22. As noted above UKDEC remains committed to working flexibly, using a variety of mechanisms to take forward each issue prioritised for discussion. Workshops have been a particularly successful format where a broader debate is necessary, with very favourable feedback from participants. For more specialised matters, sub-groups have been used initially, reporting back to the main Committee; or individual committee members may take forward items on behalf of the group. Individuals may also occasionally act as representatives of UKDEC at other meetings or events. Discussion within the Committee itself remains the key mechanism for decision making.

Topics for 2013-14

Existing commitments

23. Further work is expected in 2013-14 on:
 - **Interventions before death in a potential DCD donor.** Following the workshop on 1 March 2013, further work will be needed to refine the framework for decision making. We expect to submit the case for a review of the current legal advice to DH in the early summer of 2013.
 - **Consent for paediatric donation.** Following on from the paediatric cardiac donation workshop, an outstanding question was to what extent

is it appropriate for the parents of a child, and particularly a very young child, to give consent for donation. UKDEC plans to issue a consultation document in spring 2013.

- **Cardiac DCD donation:** dialogue with the clinical teams developing protocols in this area will continue.
- **Faith workstream:** dialogue with faith groups will continue. A further programme of specific workstreams is planned. £10k is provisionally earmarked for this. See also under “new topics” for a specific issue raised by the National BME Transplant Alliance (NBTA).
- **Opt-out scheme for Wales:** UKDEC has offered to consider any specific ethical issues the Assembly may wish.
- **DBD ethical framework:** UKDEC aims to issue a draft ethical framework for DBD donation for consultation, to complement its framework for DCD donation, in the summer, with a view to final publication in the autumn.

Possible new topics

24. Potential new major topics for 2013-14 are:

- **Donation from the Emergency Department:** Donation from the ED is becoming more common across the UK. As systems for controlled donation after circulatory death become established and accepted, interest is growing in uncontrolled donation, which brings significant ethical questions.
- **Living donation:** There is growing interest in increasing living donation, with the recent launch of a new charity promoting this. This raises ethical questions about how families and others may feel pressured to donate. The first altruistic live liver donation in the UK has raised many ethical issues of interest to UKDEC.
- **Allocation of organs:** At present there is no ethical guidance relating to the allocation of organs, and allocation systems vary according to the organ concerned. NHSBT have updated the allocation protocols, and an ethical review may be timely.
- **Possible alternative allocation system – reciprocity.** NBTA are considering launching a debate on how a system linking willingness to donate, or a history of donation, with prioritisation for transplant procedures, might impact on public engagement with organ donation (especially BMS groups), and how acceptable this might be in the UK. Such systems exist elsewhere, notably Israel. UKDEC is undertaking some preliminary research on available data on the impact of such systems, and will support NBTA in considering the ethical aspects of any proposals. This work sits alongside a wider review of the ethical aspects of allocation.
- **Hand transplant:** reports of the first hand transplant to take place in the UK led UKDEC members to consider the ethical issues that arise out of such novel procedures.

Funding requirement

Financial report for 2012-13

25. Table 1 below sets out the actual expenditure to January 31 2013, and projected expenditure to the end of the financial year.

26. This shows that UKDEC expects to carry over about £115k. The majority of this is due to DH funding the secretariat costs directly. Given the future uncertainties over funding, the Academy proposes that this should be kept as a contingency to fund the completion of UKDEC work should funding not be available from UK Health Departments in the future.

Table 1: Report from 2012-13

INCOME 2012-13

Brought Forward Funds	68,658
Contribution from Wales	5,552
Contribution Scotland	9,517
Contribution N Ireland	3,286
DH funding	94,000
TOTAL INCOME	181,013

Expenditure	Actual to Jan-13	Feb-13	Mar-13	TOTAL
Secretary salary (inclERNIC)	6569.67	2189.89	2189.89	10949.45
Contribution to AOMRC overheads	12500		2500	15000
Project costs - Faith workstream	10000			10000
Project costs - publication reports/consultation	200			200
Professional fees	7321.4		2400	9721.4
Chair's fees	3700	370	370	4440
Travel and subsistence	4058.17	500	500	5058.17
Food & hospitality for meetings	381.29	100		481.29
Workshop			10000	10000
Other	34.52			34.52
TOTAL	44765.05	3159.89	17959.89	65884.83
Projected surplus				115,128

Bid for 2013-14

27. UKDEC has achieved much in its first three years, and members are keen to maintain this momentum. On this basis, the committee is seeking sufficient funding for:
- 4 full meetings per year
 - one workshop per year,
 - sub-group work on up to 2 topics per year
 - representational work
 - communications (publications)
 - Miscellaneous costs, including recruitment.
28. The terms and conditions of appointment for members are that the expected time commitment is up to 8 days per year, and fees of £160 per day are payable. The chairman is paid for a commitment of 2 days per month (£185 per day), although his time commitment substantially exceeds this.
29. Meetings are normally held at the Academy offices, or at meeting rooms at the Royal College of Anaesthetists, which are made available free of charge.
30. Secretariat costs are now met by the AOMRC, as the secretary is now an employee of AOMRC and salary and on-costs have to be met from the UKDEC budget (until the end of October 2012 the secretary was paid direct by DH).
31. In order to mitigate against any potential future loss of funding, it is proposed that the carry forward from 2012/13 (estimated as approximately £115,000) is used as a contingency fund to cover a year of continuing UKDEC operation plus any necessary activity to find alternative funding or, if necessary, wind-down UKDEC.
- 32. UKDEC is therefore seeking funding from the UK Health Departments totalling £84,390 to cover the work programme proposed for 2013/14.** Table 2 sets out how this relates to various activities. Table 3 sets out the share from each of the UK Departments.

Future years

33. Given that the committee has now reached 'steady state', costs in future years are expected to remain stable. These will be reviewed each year.

Table 2: Projected costs for 2013-2014

UK DONATION ETHICS - FORECAST EXPENDITURE
2013-14

Expenditure (£)

Secretary salary (inclERNIC)	26400
Contribution to AOMRC overheads	15000
Project costs - Faith workstream	10000
Project costs - publication reports/consultation	2000
Professional fees	10000
Chair's fees	4440
Travel and subsistence	6000
Food & hospitality for meetings	500
Workshop (room hire, T&S, catering)	10000
Other	50
TOTAL UK	84390

34. The total cost is shared between the health departments, following the Barnett principle. Table 3 below sets out the allocation for 2013-14.

Table 3 : Allocation of costs between UK countries

England (83.3%)	70718.82
Scotland (8.4%)	7088.76
Wales (4.9%)	4135.11
N Ireland (2.9%)	2447.31

Risks and mitigation

35. The main risk to the work of the UKDEC in 2013-14 is that the Department of Health will be unable to secure additional funding as the transition to the new DH structures takes place, risking an associated loss of strategic support.
36. If financial support is not available, then the existing surplus will be used to fund the year's work, with the time being used to secure other sources of funding for future years.
37. Relationships will be maintained with the DH policy team, with a flexible approach taken to managing any changes in resourcing as the year progresses.

Conclusion

38. UKDEC has established itself as an authoritative source of ethical information and advice for the transplantation community. UKDEC is ideally placed to act as a catalyst for discussion and resolution of issues relevant to transplantation, providing direct comment and recommendations on ethical issues, and facilitating debate on clinical issues.

Terms of Reference

UKDEC 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.

UKDEC Membership

The Chair and members were appointed following an open competition. A register of interests will be kept and made available on the UKDEC website.

Sir Peter Simpson (Chair), (Past President of the Royal College of Anaesthetists)

Paula Aubrey (Regional Manager for organ donation and transplantation, NHS Blood and Transplant)

Graham Brushett (Lay member; transplant recipient)

Joe Brierley (Consultant Paediatrician and Intensivist, Great Ormond Street Hospital, London)

Stephen Cole (Consultant in Anaesthesia and Intensive Care Medicine, Ninewells Hospital, Dundee)

Heather Draper (Professor in Biomedical Ethics and Director of the Centre for Biomedical Ethics, Department of Primary Care Clinical Services, 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 for Medical Law and Ethics, King's College London)

Gurch Randhawa (Professor of Diversity in Public Health and Director of the Institute for Health Research, University of Bedfordshire)

Eleanor Updale (Author)

Anthony Warrens (Professor of Renal and Transplantation Medicine at Imperial College, London).

Tim Collins (nursing representative, ICU Clinical Educator at Maidstone & Tunbridge Wells NHS Trust)

Muireann Quigley (Lecturer in bioethics, University of Manchester)

Antonia Cronin (Clinical Research Consultant Nephrologist at the NIHR Biomedical Research Centre, Guy's and St Thomas' NHS Foundation Trust, and MRC Centre for Transplantation, King's College, London.)

Dale Gardiner (Clinical lead for organ donation, Midlands)

Hilary Cass (President, Royal College of Paediatrics and Child Health)

Peter Jones (Secretary; Academy of Medical Royal Colleges)

Observers from the UK Health Departments, NHS Blood and Transplant and the Human Tissue Authority may also attend meetings.

Annex A

UK Donation Ethics Committee - Faith Workstream

Aim: To promote debate about diagnosis and definition of death in relation to organ donation among faith communities

Background: The Organ Donation Taskforce undertook a series of engagement meetings with Faith Leaders to initiate a dialogue about organ donation during 2008 and 2009. Encouragingly, faith communities were keen to discuss issues related to organ donation and recognised that the subject may not have benefitted from well-informed debate. It was found that many faith communities have a formal or informal standpoint regarding the definition and diagnosis of death. This can potentially impact upon the decision to donate organs. Faith communities were keen to discuss these issues with relevant Government and Transplant authorities to inform future debates.

Approach: 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. During 2011, UKDEC embarked on a series of engagement meetings and events with faith communities which have developed a relationship and mutual understanding between UKDEC and faith communities. This led to a range of successful faith events and faith resources being held.

Islam:

Liaise with the Islamic Medical Association, Muslim Health Student Network and Muslim Council of Britain to organise a Islamic Faith debate for Islamic scholars with an invited audience from the Muslim community.

Christianity:

The Church of England appointed a new Bishop to lead on healthcare issues, the Bishop of Carlisle. He kindly wrote a piece about Christianity and Organ Donation for the Church of England website and an article for the Church Times in April 2011. Sir Peter Simpson and Professor Randhawa will meet with the Bishop's staff to plan and organise follow-up events at national and local level to promote debate. A meeting is being planned with Dr David Jones to develop a plan of engagement with the Catholic Church.

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 has advised that following changes to the British Board of Deputy Jews, engagement in the latter half of 2012 will be more fruitful. Professor Randhawa was invited to meet with Professor Steinberg in

January 2013 and discussed how best to reassure the public concerning brain-stem death; and the Israeli organ donor register priority system.

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 local events are being planned alongside a TV debate on Hindu Channel - MATV.

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 – Sangat TV.

The Sikh leaders have also discussed the possibility of a DVD and leaflet, similar to the approach with Hindus. This will hopefully be an outcome from the Sangat TV programme.

Humanism:

A leaflet has been produced in partnership with British Humanist Association and a launch event is being planned.

Healthcare Chaplaincy:

We have stimulated significant interest from Healthcare Chaplains in our Faith Engagement work. A training event was delivered for London Healthcare Chaplains in October 2012.

Miscellaneous:

Bristol study day – 6th September 2012, Faith, death and organ donation (Sir Peter Simpson and Prof Randhawa, spoke at the event and were featured on BBC TV regional news).

Gift of Life – BBC Radio documentary featured Prof Randhawa speaking about faith and organ donation and UKDEC role in promoting debate (aired on Jan 1st 2013, BBC Radio Wiltshire, to be repeated in other UK regions).