

UKDEC BUSINESS PLAN 2014-17

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 2013-14, and sets out proposals for the programme of work for 2014-15, with indicative requirements for the following two years to March 2017.

Achievements in 2013-14.

Strategic projects

Faith project

3. This project, which builds on work instigated by the Organ Donation Taskforce (ODTF), has been managed as a discreet workstream with ring-fenced funding. As NHSBT has instigated a funded programme of work in this area, UKDEC will not commit expenditure on this work in future.

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

4. A draft framework was published for consultation in January 2014, with a deadline for comment of mid-April. Following analysis of comments and follow-up work with stakeholders, UKDEC aims to publish a final version in summer 2014.

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 was published for consultation. The consultation closed on 14 February 2014. Following analysis of

comments and follow-up with stakeholders, UKDEC aims to publish final guidance in early summer 2014.

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 was 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 was made to DH, following which UKDEC were asked to rework their advice on the basis of clinical advice on best interests decisions for particular interventions within the overall legal guidance from the UK Health Departments. This has been completed – a response is awaited at the time of writing.

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 from 2013 to date are summarised below.

Human Transplantation (Wales) Bill

11. 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

12. 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. UKDEC is represented on NHSBT’s Strategy Oversight Group.

Edinburgh pilot protocol for donation from Maastricht Category II DCD donors

13. 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). Such donations have not occurred in the UK to date, and are a potential contribution to increasing the number of organs available for transplantation.
14. 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.
15. 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

16. Members were appointed for two years in the first instance, with the possibility to renew for up to a further three years. Six members' terms expired in January 2014, and a recruitment exercise was held to replace them. There was a strong field and seven new members were appointed.
17. Sir Peter Simpson retired as Chair in December 2013. He has been replaced by Professor Chris Rudge, for a term of three years (renewable), subject to funding.

Secretarial support

18. 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 2014-2015

Ways of working

19. 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. The Committee is looking to widen the range of its outputs (for example publication in journals, shorter targeted pieces of advice) to improve the impact on key audiences (see under future topics below).

Topics for 2014-15

Existing commitments

20. Further work is expected in 2014-15 on:

- **Interventions before death in a potential DCD donor.** Following the submission to DH, UKDEC agreed to rework the framework in the form of clinical advice on particular interventions within the overall legal advice from the UK Health Departments.
- **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. A consultation document was published in 2013, and UKDEC aims to publish final guidance in early summer 2014.
- **Cardiac DCD donation:** dialogue with the clinical teams developing protocols in this area will continue.
- **Opt-out scheme for Wales:** UKDEC has offered to consider any specific ethical issues the Assembly may wish. In particular UKDEC has invited a representative from the Welsh Assembly Government to discuss issues they have identified in relation to deemed consent and pre-mortem interventions.
- **DBD ethical framework:** UKDEC aims to publish a final version of the framework in summer 2014.

New topics

21. A workshop was held on 7 March 2014 with key stakeholders to identify emerging ethical issues and prioritise where UKDEC can most effectively focus its resources. This resulted in the following key areas for UKDEC over the next three years.

- Work to address the ethical questions posed to UKDEC by the NHSBT strategy, including
 - Reciprocity
 - The role of the family in decisions about donationThe ethical principles that underlie
- Allocation of organs
- Consent

- Elective ventilation (a key issue was to define what this means as practitioners have varying understandings of what is meant by elective ventilation)
- Potential harms to donors, including the harm that might arise from not fulfilling a wish to be a donor. Flowing from this is work on the implications for hospital governance procedures when a person's wish to donate is not fulfilled.

Prioritisation

22 The Committee has prioritised work as follows over the next year:

- 1) NHSBT strategy
- 2) Completion of DBD framework document and guidance on consent to donation from children

The other issues listed above will commence during 2014/15 but are likely to carry over into subsequent years..

Funding requirement

Financial report for 2013-14

22. Table 1 below sets out the actual expenditure to January 31 2014, and projected expenditure to the end of the financial year.

Table 1: Report from 2013-14

Opening Balance	119,045.00
Expenditure	
Secretary salary (incl ERNIC)	26,251.31
Contribution to AOMRC overheads	15,000.00
Professional fees	10,690.00
Travel and subsistence	4,581.49
Food & hospitality for meetings	205.04
Other (costs workshop, telecommunications)	445.51
TOTAL	41,251.31
Surplus	61,871.65

Funding for 2014-15

23. The committee requires sufficient funding for:
- 4 full meetings per year
 - one workshop per year,
 - sub-group work
 - representational work
 - communications (publications)
 - Miscellaneous costs, including recruitment.
 - Secretarial costs including telecommunications (Blackberry).
24. 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.
25. Meetings are normally held at the Academy offices, which are made available free of charge.
26. 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). Following a pay award of 1% the secretary's salary for 2014/15 will be £24,240.
27. The level of activity for 2014/15 is likely to be higher than previous years given the range of work resulting from the NHSBT strategy and the workshop with stakeholders. Therefore running costs for 2014/15 are estimated as **£50k**.
28. Although the surplus carried over would cover these costs, the Committee needs to retain some contingency funding to protect against the risk of future difficulties in funding, and allow for commitments to be

fulfilled in the event that funding from the Health Departments dose not materialise.

29. UKDEC is therefore seeking funding from the UK Health Departments totalling £25k to cover the work programme proposed for 2014/15 and allow for contingency in the event of future funding difficulties.

Future years (2015/16 and 2016/17)

30. Given that the committee has now reached a fairly steady state, costs in future years are expected to remain stable at about **£50k**. These will be reviewed each year, but the Committee is seeking agreement in principle to funding at this level for these years.

31. The total cost is shared between the health departments, following the Barnett principle. Table 2 below sets out the allocation for 2014-15.

Table 2 : Allocation of costs between UK countries

Total Bid 2014/15	£25,000	
England (80.73%)	£20,182.50	
Scotland (10.03%)	£2,507.50	
Wales (5.79%)	£1,447.50	
N Ireland (3.45%)	£862.50	
Total annual bid 2015/16 – 2016/17	£50,000	
England (80.73%)		£40,365
Scotland (10.03%)		£5,015
Wales (5.79%)		£2,895
N Ireland (3.45%)		£1,725

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.

Current membership

Professor Chris Rudge, CBE FRRCS Chair

John Idris Baker Consultant in Palliative Medicine, Abertawe Bro Morgannwg (ABM) University Local Health Board, Wales

Joe Brierley Consultant Paediatrician, Paediatric & Neonatal Intensive Care Unit, Great Ormond St Hospital, London

Sir David Clarke Retired High Court Judge. Father of a deceased organ donor (road traffic accident 1993)

Tim Collins ICU Clinical Educator at Maidstone & Tunbridge Wells NHS Trust

Antonia Cronin Clinical Research Consultant Nephrologist, Guys and St Thomas' NHS Foundation Trust

Heather Draper Professor in Biomedical Ethics University of Birmingham

Bobbie Farsides Professor of Clinical and Biomedical Ethics, Brighton & Sussex Medical School

Dale Gardiner Consultant in Adult Critical Care, Nottingham University Hospitals

Amanda Gibbon Lay member, Kidney donor

Jeremy Henning Consultant in intensive Care Medicine (British Army), Defence Senior Lecturer in Critical Care, Military Critical Care Specialist Interest Clinical Lead

**Theofilos El Sayed Omar Visiting Lecturer and Scholar, Interdisciplinary Center for Bioethics, Yale University
Master of Arts candidate in Medical Ethics and Law, Keele University**

Penney Lewis Professor of Law, School of Law and Centre of Medical Law and Ethics, King College London

Muireann Quigley Senior lecturer in Biomedical Ethics and Law, University of Bristol

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

Will Scott

Retired – formerly Policy Lead, Organ Donation, Transplantation and Blood Issues, Scottish Government Health Directorates.

David Shaw

Senior Research Fellow at the Institute for Biomedical Ethics, University of Basel, and the Dept of Health, Ethics & Society, University of Maastricht; Honorary Lecturer, School of Medicine, University of Aberdeen.

Eleanor Updale Lay member, Author

Peter Jones Secretary