Response of the Mission and Public Affairs Council of the Church of England to the National Health Service Blood and Transplant Consultation on Organ Donation Post 2013 Strategy

The Mission & Public Affairs Council of the Church of England is the body responsible for overseeing research and comment on social and political issues on behalf of the Church. The Council comprises a representative group of bishops, clergy and lay people with interest and expertise in the relevant areas, and reports to the General Synod through the Archbishops’ Council.

The Mission and public Affairs Council presents a Christian ethos, drawing on the witness of the Christian Scriptures and reflecting on Christian tradition and contemporary thought. Belief in God as Creator and Redeemer, in human beings’ intrinsic value as creatures made in the Image of God and in the imperatives of love and justice, underpins the Council’s approach. The Council believes that the ethical and social principles that are developed from this foundation may be embraced by people of other faiths or of none.

Background

1.1 The Church of England affirms that ‘giving one’s self and one’s possessions voluntarily for the well being of others and without compulsion is a Christian duty of which organ donation is a striking example. Christians have a mandate to heal, motivated by compassion, mercy, knowledge and ability. The Christian tradition both affirms the God-given value of human bodily life, and the principle of putting the needs of others before one’s own needs.’ This forms the context for our response to the current NHSBT consultation.

1.2 A number of important messages emerge from the NHSBT consultation background paper, ‘Organ Donation and Transplantation Strategic Objectives to 2016/17: Portfolio of Evidence’ (2012). These include:

1.21 While the numbers of both living donors (LD) and deceased donors (DD), as well as the number of transplants, have increased markedly since the publication of the Organ Donation Taskforce’s report in 2008 and are expected to increase further (DD, 50% by 2012/13, 60% by 2016/17), current practices are unable to meet present and projected demand for organs, with 1,000 individuals dying each year while on the transplant list.

1.22 There are 18.9m people on the Organ Donor Register in the UK (29% of the total population, approximately, 40% of the population over 16). In 2011/12, DD figures were 1088, resulting in 2919 transplants. This represents 37% of eligible Donors after Brain Death (DBD) and 12% of non-contraindicated Donors after Cardiac Death (DCD).

1.23 There is a marked disparity between donor rates and transplant needs among minority ethnic communities, with, for example, members of these communities (11%

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of the overall population) representing 4% of kidney donors, 22% of recipients and 28% of people on the transplant list. The consent rate among relatives classified in the Evidence Portfolio as ‘non-Caucasian’ is also low: 27% for DBD compared with 71% for Caucasian relatives; 30% for DCD compared with 54%.

1.24 There has been a sharp decline (15%) in the numbers of deaths of people under 75yrs of age in the past decade while there has been a notable increase in donors with a Body Mass Index greater than 30, resulting in fewer average transplants per donor: currently 20% of donors have a BMI greater than 30, compared with 12% a decade ago. 10% of donors are currently over 70 yrs of age, with an average transplant rate of 2 organs per donor for DBD (compared with 4 per donor for under 50s) and 1.5 organs per donor for DCD (compared with 3 per donor for under 35s).

1.25 Clear difficulties have been identified in the Transplant Pathway. In 2011/12, of those identified as eligible for DBD, 93% were referred to a Specialist Nurse for Organ Donation (SNOD) of which 77% were neurologically tested for DBD. In those tested, 7% failed to lead to an approach being made to relatives, while consent was not given in 36% of cases where it was sought: overall, 37% of eligible donors resulted in transplants. For DCD the referral rate was 54%, the approach rate of those referred was 57% and the consent rate 52%: overall, 12% of non-contraindicated eligible donors resulted in transplants. SNOD involvement in approaching relatives in DBD cases resulted in a 68% consent rate compared with a 53% consent rate where there was no SNOD involvement. For DCD, the rates were 66% and 32% respectively.

Issues Raised by the Consultation

2.1 In addressing a wide range of possible changes to current practices the Consultation raises five issues that have major ethical, social or legal implications:

‘Change the consent system for organ donation- either to presumed consent for organ donation unless a person has ‘opted-out’ of the Register, or mandate that people make a choice about whether or not they want to be organ donors (‘mandated choice’);

Targeted engagement programme with Black, Asian and Minority-Ethnic communities and the councils where they live;

Review end of life protocols that conflict with the possibility of organ donation, particularly with regards the early withdrawal of life sustaining treatments in critical care units and emergency departments;

Review the ethical, legal and professional acceptability of so-called elective ventilation’ (i.e., intubation and ventilation of a gravely ill patient whose death is inevitable in order to promote donation after brainstem death’);

Making a person who has signed up to the Organ Donor Register a priority recipient for an organ if they subsequently require a transplant’
The Consent System

3.1 The present ‘opt-in’ system is based on an understanding that while, in law, bodies are not possessions, individuals enjoy a ‘right to use’ their bodies while alive and have a right to decide, within limits, what ought to happen to them after they die. Where individuals have not given any instructions with regard to the use or disposal of their bodies after death, next of kin are assumed to take precedence in decision-making unless there are over-riding factors present, such as a coroner’s investigation. This reflects a careful balance in the relationship between individuals, relatives and the state, with a presumption that the state does not have a right to dictate to either individuals or to their families how their bodies ought to be used. It does, however, accept that there are some exceptional circumstances in which it is appropriate for the state to intervene, specifically where public health might be at risk, where a death might not be from natural causes or where foul play is suspected. The issue raised by the consultation is whether or not the need for more transplants to take place ought to be seen as another ‘over-riding factor’, necessitating state intervention.

3.2 The suggestion that an ‘opt-out’ system ought to be introduced does not give the state absolute rights over the use of an individual’s body. People would still be able to choose not to be donors. It does, however, represent a major, intrusive shift in the state’s relationship with its citizens. An overwhelming case would have to be made in its favour before such a shift ought to be introduced and such a case does not, as yet, exist.

3.3 The Transplant Pathway, described in the Portfolio of Evidence, suggests that the most pressing problem in organ transplantation does not lie in getting more names on the Organ Donor Register, but in making more effective use of the nineteen million potential donors already registered. It is clear that much more could be done to narrow the gap between the number of eligible and the number of actual donors, as well as maximising the number of transplants per donor. More consistent DBD testing, greater DCD referrals and increased SNOD intervention in approaching families for consent ought to have a marked effect in increasing the number of transplants taking place. Similarly, better use of donated organs, utilising techniques such as liver-splitting and further increases in the use of Living Donors will have a positive effect.

3.4 Greater public awareness and education with regard to the nature of the consent given by individuals signing the Organ Donation Register would also affect the number of transplants taking place. At present, the UK system might best be described as ‘soft opt-in’, with the wishes of relatives often over-riding individual consent. A shift to an effective ‘hard opt-in’ policy where consent given on the Organ Donor Register is treated in the same way as an Advanced Decision or clause in a Will, would further increase transplant rates. Greater opportunities to consider organ donation by including Organ Donor Registration forms with other forms such as applications for driving or marriage licences is likely to increase the number of people on the Organ Donor Register. At the very least, these and similar interventions aimed at maximising the number of potential donors ought to be fully implemented before any major change in consent policy is envisaged.
3.5 ‘Mandated Choice’ is a preferable alternative to ‘opt-out’ in that it recognises that the state may make requirements of its citizens to provide certain information that is in the public interest, (similar to Census or tax returns), while stopping short of implying a prior right to the use of an individual’s body. If it were introduced, however, it would be crucial to learn from experience elsewhere which has been problematic. ‘Hard Mandated Choice’, where individuals must state, ‘yes’ or ‘no’ to organ donation has not been successful in jurisdictions, such as Texas, where it has been trialled; it has created resentment, resulting in a high number of people choosing to say ‘no’. ‘Soft Mandated Choice’, where individuals are given the choice of saying, ‘yes’, ‘no’ or ‘consult my relatives’ gives greater choice but still leaves issues to resolve over non-compliance. What penalties ought to be put in place for non-compliance and how would the system be policed? An ineffective law, in this instance, would be highly undesirable, while a new offence and penalties for non-compliance would create a new class of criminal. It has to be asked: is this really a good and necessary way to tackle the undoubted need to save lives through a greater numbers of transplants? Have all other possible approaches been exhausted first?

Minority Ethnic Issues

4.1 It is widely recognised that there are issues specific to minority ethnic communities, although attempts to resolve these issues have not, as yet, been very successful. While ethnicity plays a role in finding a matching tissue type in some cases, successful transplants routinely take place between people from differing ethnic groups. Nonetheless the disparity between the number of donors and the number of people on the transplant list from minority ethnic communities ought to be addressed. In doing so, care must be taken not to dilute or to compromise a foundation principle of the NHS: that treatment is based on clinical need, not on social or economic factors or on a concept of ‘merit’, a principle affirmed by the Church of England General Synod in February 2012.  

4.2 Rather than speak of a ‘targeted engagement programme with Black, Asian and Minority-Ethnic communities and the councils where they live’ it is better to consider developing better ways of partnership working with representatives of minority ethnic communities and those organisations in which members from minority ethnic communities form a significant part and in which they play a full role. In this context, faith communities have much to offer. The Organ Donation Taskforce and the Organ Donor Campaign have both piloted innovative partnership programmes in recent years that ought to be developed in the future.

End of Life Care

5.1 The General Medical Council’s guidelines on End of Life Care place a duty on doctors to act in a patient’s best interests, while giving weight to patient or family requests for treatment and adhering to valid patient decisions for treatment to be

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5.2 In the first instance, it ought to be noted that unless a patient has made a valid decision for life sustaining treatment to be withheld or withdrawn, it is incorrect to speak of ‘early withdrawal of life sustaining treatments’. A decision to withdraw treatment is to be made only in the patient’s best interests and is to be effected at the optimum time in that patient’s care; there ought never to be ‘early withdrawal of treatment.’

5.3 That doctors and other healthcare professionals are to act only in what they consider to be a patient’s best interests is based on the long-standing principles of beneficence and non-maleficence and is central to End of Life Care. It is essential that these principles are not breached, even in the pursuit of a good cause such as enabling organ donation.

5.4 Where patient consent is given for treatment to be prolonged beyond a point where it is medically beneficial to him or her, it could be argued that it is in that patient’s overall best interests to comply with this request because of the beneficial psychological effects it will have. While there are limits to how far this argument can be reasonably sustained, it forms part of the ethical basis for Living Donation. Such operations, which are not without risk, will not benefit donors medically, but may be judged to be of overall benefit to them because of the psychological and relational benefits gained in addition to the more obvious benefits offered to the recipient.

5.5 Given the acute nature of serious injuries treated in emergency departments, it is unlikely that it will be possible to gain consent from many patients receiving life sustaining treatments, unless their wishes are already known. Where patient consent cannot be given to prolong life sustaining treatment after it has ceased to have a beneficial effect it is important that doctors act only in what they perceive to be the patient’s best interests.

**Elective Ventilation**

6.1 The issues discussed in a review of End of Life Care are relevant to the practice of elective ventilation. They are made more acute, however, by the fact that elective ventilation represents actively intrusive treatment that is not, medically, in the patient’s best interests. By its nature, it is unlikely that medical staff will have opportunities to seek patient consent. Elective ventilation was practised in the UK between 1988 and 1994, but was halted by the Department of Health precisely because it breached the ‘best interests’ principle. In order for elective ventilation to become an acceptable practice, an effective Advanced Decision system would have to be devised. Consideration would also have to be given to its resource implications: as an unintended consequence, other patients requiring ventilation might be denied access to care.

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3 GMC End of life Care and Advanced Decisions (‘Treatment and care towards the end of life: good practice in decision making’ 1st July 2010
Priority Care for those on the Organ Donor Register

7.1 While this proposal might result in an increase in numbers on the Organ Donor Register, it represents a clear breach of the principle that treatment is given solely on the basis of clinical need and not because of social or economic factors or on the basis of perceived merit. If the merit principle were to be given formal approval for transplant protocols it would be difficult not to employ it in a wide range of other circumstances where lifestyle factors are relevant. Rightly, the merit principle has been formally resisted even if, on occasion, examples exist of it being informally applied.

20th September 2012