



Government Response to the
House of Lords European Union Committee
Report on 'Increasing the supply of donor
organs within the European Union,
17th Report of Session 2007–08'

Presented to Parliament by
the Secretary of State for Health
by Command of Her Majesty
September 2008



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Introduction

On 31 May 2007 the European Commission adopted a Communication on organ donation and transplantation. This Communication proposed two mechanisms for action across the European Union in the field of organ transplantation.

First, an action plan to encourage closer cooperation between Member States, sharing expertise to maximise organ donation and optimising equity of access to transplantation. The European Commission proposed also to monitor any developments in organ trafficking and if necessary consider additional action.

Second, it would put in place a legal framework to improve the safety and quality of organs for transplantation. The EU already has directives to improve the quality and safety of blood and tissues and cells. A similar European organ directive would set standards of quality and safety for organs for transplantation.

The House of Lords European Union Committee published its Report on the European Commission proposals 'Increasing the supply of donor organs within the European Union' on 2 July 2008. The Committee's view was that the proposals set out in the European Commission's Communication would help to raise the number of organs available for transplantation as well as the overall safety and quality of those organs.

The Government welcomes the Committee's report which supports action being taken nationally and internationally to increase the number of high-quality and safe organs donated for transplantation.

This Command Paper sets out the Government's response to the conclusions and recommendations within that report.

Chapter 1: Shortage of Donor Organs across the EU

Recommendations

- **We recommend that the Government should support the work of the European Commission in seeking to raise the profile of organ donation issues across the EU and in seeking ways to reduce the shortage of organs for transplantation. [paragraph 87]**
 - **We recommend also that the Government should act urgently to address the shortage of organs for transplantation in the UK by taking measures which will significantly increase organ donation rates over the next five years. [paragraph 88]**
- 1.1 The Government is keen to work with the European Commission and other Member States to support work to raise the profile of organ donation across Europe and to increase transplantation rates. As the report acknowledges, the severe shortage of organs donated for transplant remains the main challenge that all EU Member States face. Across the European Union, the number of people requiring a transplant is far greater than the number of organs available for transplant and in no Member State is there a surplus of donations.
 - 1.2 Over the years, the UK has actively contributed to ongoing work to increase donation rates across Europe, all of which have proved helpful in developing donation programmes in Member States. For example, Alliance-O is an ongoing project and the first ever coordination of donation and transplant national and regional research activities across seven different EU countries. This research aims to identify the best possible framework for efficient organ donation and transplant strategies across Europe. Further information about Alliance-O can be found at www.alliance-o.org/Alliance-O.
 - 1.3 The Government agrees that urgent action must be taken in the UK to address the severe shortage of donor organs for transplant. In the UK, some 8,000 people are currently on the national waiting list and the number is rising by about 8% each year. But only around 3,000 transplants were performed last year and each year around 1,000 people (adults and children) die either waiting for an organ to be donated or after they become too ill and are taken off the national list. Nor does the transplant list reflect the true extent of need. Many clinicians are reluctant to list more patients than are realistically likely to receive organs.

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- 1.4 There is also an urgent need to address health inequalities. People of Asian and African-Caribbean descent are three to four times more likely than white people to develop established renal failure and need a kidney transplant. NHS Blood and Transplant (NHSBT) data show that people from these backgrounds make up 23% of the kidney waiting list while representing only 8% of the population. Yet only 3% of deceased donors are of Asian and African-Caribbean descent.
- 1.5 This shortfall in the number of organs available for transplant is why the Department of Health established the Organ Donation Taskforce in 2006. The Taskforce, chaired by Elisabeth Buggins, Chairman of NHS West Midlands, was asked to consider the barriers to organ donation and to make recommendations as to how they could be overcome. The Taskforce report was published in 2008. The Taskforce believe that improvement is dependent on the resolution of three key issues – better donor identification and referral; strengthened donor coordination and improved organ retrieval arrangements. Implementation of the recommendations should bring about a 50% increase in organ donor rates within five years. All UK Health Departments accepted the 14 Taskforce recommendations. The Taskforce report is available on the Department of Health's website at www.dh.gov.uk.
- **We recommend that the Government should address the ethical and legal issues which currently limit the extent to which donation after cardiac death is accepted across the medical profession. [paragraph 89]**
 - **We welcome the completion of the work by the Academy of Medical Royal Colleges (AMRC) to produce an up-dated Code of Practice for the diagnosis of death. We urge the Government to expedite the publication of this badly needed new guidance and to draw it to the attention of the European Commission. [paragraph 91]**
- 1.6 The Organ Donation Taskforce report recommends that urgent attention is required to resolve legal, ethical and professional issues in order to ensure that all clinicians are supported and feel able to work within a clear, unambiguous framework of good practice. Only then can organ donation start to become a usual part of healthcare and donation rates rise.
- 1.7 To achieve this, the Health Departments are working with the clinical community and legal advisers as part of the wider implementation of the Taskforce recommendations, to agree how to provide the necessary clarity for clinical staff in the diagnosis of death and the process of donation.
- 1.8 The Government supports the publication of the AMRC's updated code of practice as it represents an authoritative source of guidance on the clinical aspects of the diagnosis of death in order to provide clarity for a range of clinical staff. The guidance, once published, will help clinical staff to make decisions in relation to a patient's care, treatment and diagnosis of death.

Chapter 2: Proposed EU Directive Relating to Organ Quality and Safety

Recommendations

- **We recommend that the Government should support the introduction of an EU directive on the quality and safety of organ donation and transplantation in a form which provides minimum standards across the EU, but is not overly bureaucratic and which does not impose requirements beyond those which are clinically justified. [paragraph 124]**
 - **We recommend further that the Government should seek to ensure that the directive allows sufficient flexibility for decisions, about the quality of organs to be used for transplantation, to be informed by soundly based clinical judgement of the medical urgency of need of the patient and informed patient choice. [paragraph 125]**
 - **We recommend that the Government should support the Commission in its development of an Action Plan relating to organ donation and transplantation. The action plan should provide financial and infrastructure support for information exchange and research collaboration between Member States, both reinforcing and expanding existing successful collaborations, and enabling the development of new initiatives which will address the shortage of organs for donation across the EU. [paragraph 175]**
 - **We recommend that the Government should give active consideration to investigating the merits of cooperation with local organisations, businesses and others to establish the scope for the introduction of community-based donor card schemes. [paragraph 178]**
- 2.1 The Government is fully committed to supporting action to increase the number of organs available for transplant. Clearly, there are potential benefits of a pan-Europe approach to increasing donor rates and optimising safe, high-quality organs for transplantation that need to be considered.

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- 2.2 The European Commission has not yet published proposals for an organ directive. However, if proposals are adopted, it is likely that, in light of the extensive therapeutic use of human organs for transplantation, common minimum quality and safety standards will be identified in order to minimise the risk of transmission of disease. For example, a European Community framework could set quality and safety criteria with respect to the procurement and traceability of human organs across the EU. These standards would help ensure that donated organs are of comparable quality and safety and could help facilitate exchanges of organs across borders. Like the Blood¹ and Tissues and Cells² Directives, the establishment of standards would help reassure the public that human organs procured in another Member State were subject to the same standards as those obtained in their own country.
- 2.3 With waiting lists for transplants increasing faster than organ donor rates, the severe shortage of organs donated for transplant remains the main challenge. Member States recognise that there is a need for quality and safety standards, particularly to support those countries developing their transplant programmes. However, the Government agrees strongly that these requirements must be kept to the minimum necessary to ensure safety and quality, must not be overly bureaucratic nor impose requirements beyond those which are clinically justified. In the UK, legislative and professional requirements already ensure high standards in organ donation and transplantation and there are equivalent levels of quality and safety in place in other Members States with developed programmes.
- 2.4 Therefore, the Government agrees that any directive should allow sufficient flexibility for decisions about the quality of organs to be used for transplantation to be informed by soundly based clinical judgement. A careful balance must be struck. While aiming to achieve common standards across the EU, any directive must recognise that the risk–benefit ratio with donated organs for transplantation is different than that for tissues and cells procured for human application. The overall benefits of an organ transplant are high and the clinician and potential recipient have an important role in deciding in a particular case where the balance of risk to benefit lies and whether an organ should be accepted for transplantation.
- 2.5 National competent authorities have played a key role in ensuring the quality and safety of blood, tissues and cells across the EU. In the UK, the Human Tissue Authority and the Human Fertilisation and Embryology Authority have been instrumental in establishing systems for the licensing of tissue procurement, testing, storage and distribution, based on common quality and safety criteria. Any introduction of a similar system for organs would need to be discussed with stakeholders to ensure an appropriate level of regulation and subsidiarity.

1 Blood Quality and Safety Directive 2002/98/EC, 2005/61/EC, 2005/62/EC

2 Tissues and Cells Directive 2004/23/EC, 2006/17/EC, 2006/86/EC

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- 2.6 The UK Health Departments are therefore working with the European Commission and other Member States to help ensure that any proposed requirements contained within a legislative framework do not impose a disincentive to donating hospitals or transplant centres and are sufficiently flexible to enable clinicians to decide whether a donated organ is suitable for their patient or not. Experience obtained through the negotiation, transposition and implementation of the Tissues and Cells Directive indicates that there are a number of measures that could be considered by Member States to develop helpful but proportionate legislation.
- 2.7 In respect of an action plan, the Government welcomes the opportunity to work with the European Commission to develop a framework for the sharing of expertise among EU Member States and for cooperation between countries designed to help maximise organ donation and to promote greater access to transplantation. This approach is likely to consider the identification and development of common objectives; agreed quantitative and qualitative indicators and benchmarks; regular reporting; and identification and sharing of best practices.
- 2.8 Although not recommended by the Committee, one measure suggested by the European Commission is the introduction of a European donor card. In the UK, people can carry a donor card, register on the UK national organ donor register or both. Both are recognised as consent to organ donation in the event of death though donors' families would of course still be involved. The target in the UK is to register 16 million people on the organ donor register by 2010. Currently, over 15.5 million people have registered.
- 2.9 The carrying of such a card might make initial discussions with the family about donation easier. However, different countries in the EU have different laws of consent and therefore the Government agrees with the Committee's conclusion that an EU donor card would not necessarily command public support.
- 2.10 However, as the the Committee recommends, as part of the implementation of the Taskforce report, the Government is actively considering the introduction of community-based initiatives in the UK to help promote organ donation and encourage a higher level of consent. In particular, there is a need to identify and implement the most effective methods through which organ donation can be promoted to the general public and specifically to the black and minority ethnic populations. This may include working with a range of stakeholders such as local voluntary and faith groups, organisations and businesses to raise the profile of organ donation.
- 2.11 In summary, the Government agrees with the Committee that there is much that Member States can learn from each other. For example, in the UK the Organ Donation Taskforce, in agreeing their recommendations, looked closely at action taken in Europe and elsewhere to increase donor rates. However, the UK will need to consider the text of a draft directive or action plan carefully to ensure that they do not impose an unacceptable burden of bureaucracy, but rather build on work ongoing in the EU to increase organ donation and improve the efficiency of transplant services.

Chapter 3: Organisation of Organ Donation and Transplantation Services

Recommendations

- **We commend the success of the system, introduced by Dr Rafael Matesanz and his colleagues, for the organisation of organ donation and transplantation services in Spain. We welcome the fact that, in the UK, the Organ Donation Taskforce drew considerably on the Spanish experience in formulating their recommendations for changing the UK system; and we recommend that the European Commission advises Member States also to draw appropriate lessons from the Spanish success in introducing changes to the systems in place in their own countries. [paragraph 214]**
- **We recommend, in particular, that the Commission should draw attention to the key role that has been played in improving Spanish organ donation rates by the priority given to the selection and training of the staff involved in organ donation services. [paragraph 215]**
- **We acknowledge the merits of the approach (as adopted by the UK Government) of setting up a Taskforce of qualified experts to study the issues relating to organ donation services, learning from experience elsewhere in the EU, in order to produce proposals suited to a specific country's health care system and to its social, economic, cultural and ethical environment. We recommend that the Commission should encourage Member States where there is a need to improve organ donation rates, as in the UK, to assess whether this type of approach would be helpful. [paragraph 216]**
- **We recommend that the Government gives a clear and strong commitment to funding the full implementation of the recommendations of the Organ Donation Taskforce for the re-organisation of organ donation and transplantation services in the UK, both during the crucially important first five years and beyond. [paragraph 217]**

- **We recommend also that the Government puts in place mechanisms to monitor the effectiveness of changes being made as a result of the implementation of the Taskforce proposals. This would have the aim both of ensuring progress within the UK, and of facilitating the exchange of relevant information with other EU Member States which face similar challenges and are considering or implementing similar responses. [paragraph 218]**
- 3.1 As the Committee identifies within its report, Spain has the highest donation rate in Europe at around 35 donors per million population (pmp). The UK has one of the lowest rates in Europe at around 13 pmp. However, some 15 years ago, before Spain systematically began to address its barriers to organ donation, its rates were very similar to UK rates. More recently, Spain has successfully exported its methodology to Italy and South America.
 - 3.2 Rafael Matesanz, the Director of the Organización Nacional de Trasplantes, was invited at an early stage to give evidence to the Organ Donation Taskforce to help them understand how Spain had achieved its high rate of donation and maintained it over many years. The Taskforce recommendations drew heavily on the successful Spanish system and the UK Government firmly supports the Committee's view that other countries in the EU could benefit by undertaking a similar review of their donation infrastructure and considering changes to their systems drawing appropriate lessons from Spain's success.
 - 3.3 The Government is committed to implementing and funding the Organ Donation Taskforce recommendations published in January 2008. £11 million has been made available for 2008–09 and significantly more identified within the Comprehensive Spending Review for the years 2009–11. In addition, a further £4.5 million has been agreed over the two years 2008–10 to support work to raise the public profile of and support for organ donation. Plans are being developed by NHSBT to agree how this funding could best be used. Longer-term funding requirements will be considered as part of normal business planning.
 - 3.4 The Health Departments support the recommendation that mechanisms should be put in place to monitor the effectiveness of changes being made as a result of the implementation of the Taskforce proposals. A number of measures have been identified.
 - 3.5 For example, the Taskforce were impressed with the various oversight systems in use in a number of other countries and were keen not only to monitor the number of organ donors but the number of potential organ donors that become actual donors. Accordingly, Recommendation 5 of the Taskforce report proposes that minimum notification criteria should be introduced on a UK-wide basis and reviewed after 12 months. The Taskforce also recommended that more detailed referral criteria should be considered if they were shown to be effective in increasing donor rates. Recommendation 6 of the Taskforce report recommends that donation activity should be monitored. This would include the rate of potential donor identification, referral, approach to the family and agreement to donation.

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- 3.6 Much of this data is already collected through NHSBT's Potential Donor Audit (PDA), available at www.uktransplant.org.uk. The PDA began in January 2003, as part of a series of measures designed to improve rates of organ donation. The principal aim of the audit is to determine the potential number of solid organ donors in the UK. Data are collected on every patient death in an intensive care unit. All patients for whom death is diagnosed following brain stem tests can be identified. The reasons why potential donors did not become actual solid organ donors can then be investigated. In light of the Taskforce recommendations, NHSBT is considering what changes will need to be made to the data set to improve the validity of the data, and to establish a secure and effective web-based updated version of the PDA.
- 3.7 International experience, particularly in Spain, has shown the benefits of establishing donation champions – usually consultant level clinicians – in every acute Trust. The Taskforce recommended that champions should be appointed in each hospital, and should be responsible for developing and overseeing local policies to help maximise donation. In addition, the Taskforce recommended that Trusts should establish donation committees, to whom the donation champion would report donation activity. The Taskforce recommended that the donation committee, chaired by a non-clinical donation champion, possibly a patient, should be accountable to the Trust Board through the normal governance arrangements. The Trust's chief executive and medical director would be responsible for the Trust's donation performance, and each Trust's donation information could be placed in the public domain through Trusts' annual clinical governance reports. The Health Departments will work with the health regulators to discuss whether donation performance activity could be incorporated into health regulators' standards and be part of each Trust's assessment.
- 3.8 NHSBT has written to Trust chief executives setting out the action needed to establish Trust donation committees and clinical donation champions. They have also provided a model job description and person specification for Trust donation champions and a model terms of reference for the donation committees. Hospitals with the highest potential for donation have been identified in NHSBT's 2008–09 work plan. These hospitals will be supported to appoint Trust donation champions and to establish donation committees as part of the first tranche of implementation, and also to work to incorporate organ donation into end-of-life strategies.
- 3.9 Additionally, as part of the oversight arrangements, the Taskforce further recommends that each Strategic Health Authority or equivalent authority should hold a formal preliminary meeting with those involved in donation. This could include critical care staff, senior managers, transplant teams, coordinators and commissioners. Such meetings could be used to develop local action plans to increase donor rates and review local progress. The Government will be working particularly with NHS West Midlands to develop and pilot projects directly related to the implementation of the Taskforce recommendations, including projects on workforce, training, commissioning and capacity planning. The outcomes of this work will be shared across the NHS.

- 3.10 Mr Chris Rudge has been appointed National Clinical Director for Transplantation to drive delivery of the Taskforce recommendations and to help achieve an increase in organ donation by 50% within five years. The Government has also established a Programme Delivery Board chaired by Professor Sir Bruce Keogh, the NHS Medical Director, to oversee progress. Members of the Board include those responsible for implementing the recommendations, such as NHSBT, the Royal Colleges, professional organisations and representatives from all four UK Health Departments. This is to ensure a UK-wide approach to implementation – with all parties working together within an integrated project plan, supported by appropriate metrics to measure progress and resolve difficulties.

Chapter 4: Patient Care Issues – Organ Donors and Organ Recipients

Recommendations

- **We recommend that the Government should explore the merit of making provision for the reimbursement to living donors of the costs they incur which are attributable to the transplant donation process. [paragraph 260]**
- 4.1 With the rising number of people needing kidney transplants and the shortage of organs from deceased donors, more people are considering the possibility of becoming a live donor. Over the last few years the Department of Health has funded, through NHSBT, the employment of 25 living donor coordinators in transplant centres. The coordinators discuss the possibility of live donation with people who have established renal failure and their families and friends, and help coordinate the transplant arrangements. In 2007–08, 40% of kidney-only transplants were from live donors. A much smaller number of live liver and live lung transplants are also undertaken.
 - 4.2 When the Human Tissue Act 2004 and the Human Tissue (Scotland) Act 2006 became law, they enabled two new forms of living donation. 'Altruistic non-directed donation' allows an individual to donate a kidney to a stranger, via the national matching and allocation system for kidneys from deceased donors. 'Paired/pooled donation' pairs an incompatible donor/recipient couple anonymously with another couple in the same situation, in order to exchange suitably matched organs between couples. UK-wide registration and matching arrangements are now in place for both potential altruistic donors and for incompatible donor-recipient pairs wishing to be considered for paired donation.
 - 4.3 Although it is legal under the Human Tissue Act 2004 for the live donor to receive reimbursement of expenses, such as travel costs and loss of earnings that are reasonably attributable to and directly as a result of an organ donation, donors must not be reimbursed directly by the recipient or by their family or friends. The Human Tissue Authority also requires that checks are made to ensure that no other payment of any kind is made and that the donor does not make a profit from the donation.

- 4.4 For a person with established renal failure, transplantation is both clinically effective and cost effective. Therefore, the UK Health Departments actively encourage the reimbursement of live donors' out-of-pocket expenses. However, all reimbursements must be made by a proper authority, for example by a primary care trust or hospital trust – and it is their decision about whether and how much reimbursement should be made.
- **We recommend that the Government should seek to ensure that brain stem testing becomes standard practice for all patients in whom brain stem death is suspected. [paragraph 261]**
- 4.5 The Taskforce recognised within its report that in many acute hospitals from which organ donors may be referred, donation was an infrequent event. A key plank of the implementation of the Taskforce report will be to make organ donation a usual rather than an unusual part of healthcare. Data from the Potential Donor Audit show that a significant number of patients for whom a diagnosis of death by brain stem testing was possible did not undergo such a test.
- 4.6 As part of the implementation of the Taskforce recommendations, the number of potential donors that become actual donors will be monitored. The Programme Delivery Board is working with the critical care community to introduce an overall strategy to optimise donation.
- 4.7 A key step is the performance of brain stem tests in all appropriate patients – not just because they may become organ donors – but because professional guidelines identify it as the most appropriate course of action for both the patient and their family.
- 4.8 The standards for certifying brain stem death are strict. The tests will a) only be carried out after doctors have established that the patient has suffered irreversible brain damage and b) are carried out twice, by different doctors at separate times, neither of whom must be a member of the transplant team. If the second set of tests confirms no evidence of brain stem activity, the patient is declared dead.
- 4.9 The Programme Delivery Board is working with the Royal College of Anaesthetists and the Intensive Care Society to encourage critical care teams to notify the donor transplant coordinator of all patients whose condition may lead to testing for brain stem death. This is to enable the wishes of the patient in respect of organ donation to be identified, and to undertake those tests where clinically appropriate. Following a diagnosis of death, organ donation can then proceed if consent to donation has been established.
- **We recommend that the Government should take steps to ensure that, for a person who has clearly stated their desire to donate organs, it is recognised legally that it is in their best interests to facilitate donation through the appropriate maintenance of their organs prior to or immediately after death. When the patient's wishes are unknown, but the family have agreed to donation, the same approach should be taken. [paragraph 262]**

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- 4.10 Recommendation 3 of the Taskforce report states that urgent attention is required to resolve outstanding legal, ethical and professional issues, in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice.
- 4.11 The Programme Delivery Board is working with professional organisations and legal advisors to understand these concerns and to agree what action or guidance is needed to optimise organ donation. A first step will be the publication of the revised guidance on the diagnosis and confirmation of death by the Academy of Medical Royal Colleges. This will provide authoritative guidance on the diagnosis of neurological and cardiac death. This will help the Trust donation champion and donation committees to develop and implement local protocols with their intensive care units to guide donation practice.
- **We recommend that the Government should ensure that in all cases of organ donation, sufficient staff resources are made available for caring and informed support to be given to the relatives of the donor. [paragraph 263]**
- 4.12 Currently there are approximately 100 donor transplant coordinators in the UK working in 18 teams employed within Trusts. The Taskforce recognised within their report that current practice is unsustainable and certainly could not cope with the projected 50% increase in donor rates over the next five years. Under current arrangements, a single donor transplant coordinator attends the donor hospital from the time of the initial referral until after organ removal, and will:
- assess the suitability of the potential donor;
 - talk with the potential donor's family;
 - gather medical, social and behavioural information about the potential donor that informs the offering and allocation process;
 - call in the retrieval team;
 - attend the organ removal procedure; and
 - arrange the last offices and remain on hand to support the family.
- 4.13 The Government has made sufficient funding available to expand and strengthen the current network of donor transplant coordinators. Over the next two years, 2008–2010, the coordinator network will be significantly strengthened by the employment of additional donor transplant coordinators, to bring the total number to approximately 250. The aim is that two, and possibly three, coordinators will attend each donation – one coordinator to discuss donation with the family and to obtain the necessary consent and medical and social history of the donor. A second coordinator will obtain the clinical information, register the donor on the national database and make arrangements for the retrieval team to attend. A third coordinator may join the retrieval team and will take responsibility for ongoing liaison with NHSBT around allocation and all associated documentation.

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- 4.14 Donor coordinators will be embedded within designated critical care and bereavement groups. They will work closely and collaboratively with trust donation champions to ensure local policies and protocols are in place that will help ensure comprehensive recognition and referral of all potential donors.
- 4.15 In addition, the Department of Health *End of Life Care Strategy* (www.dh.gov.uk/publications, published in July 2008), which covers care at the end of life for adults in England, recognises that, in some cases, there may be potential for organ donation to take place. The strategy addresses the needs of carers and families both during a patient's illness and into bereavement, and gives the example of the Bolton Hospitals Trust's bereavement and donor support team, which offers support to relatives and staff in the immediate aftermath of a patient's death. The team ensures that all families are offered religious and spiritual support and as appropriate, the opportunity to discuss organ donation. The Chair of the Organ Donation Taskforce has written to the End of Life Care Pathway Chairs in Strategic Health Authorities to seek their support in making organ donation a usual part of hospital care.

Chapter 5: Alternative Forms for Donor Consent

Recommendations

- **We recommend that the Government's top priority, in seeking to raise UK organ donation rates, should be to implement the re-organisation of organ donation and transplantation services. [paragraph 314]**
 - **We recommend that the Government should enhance the operation of the existing system of donor registration in the UK (which currently operates through a register and donor cards) by raising public awareness and understanding of organ donation issues generally and by targeted campaigns to encourage donor registration. We recommend also that the Government should explore the feasibility of using innovative means to expand the extent of donor registration. [paragraph 315]**
 - **We recommend further that, before a decision is taken about presumed consent, the Government should implement national and local education programmes to improve public understanding of the issue. If, at a later stage, a decision is taken to switch to presumed consent, this should not be implemented until considerable progress has been made in strengthening organ donation services. [paragraph 316]**
- 5.1 The Organ Donation Taskforce was established in 2006 to take stock of progress within the context of the transplant framework³ (published in 2003), to identify barriers to organ donation and to recommend what action needed to be taken to increase organ donation and procurement within the current legal framework. The Taskforce looked extensively at evidence of success in the UK and abroad – particularly Spain and the USA. They concluded that a 50% increase in organ donation was achievable within five years – although a major difference in terms of transplants enabled and lives saved could be seen in as little as 18 months to two years.

3 *Saving lives, valuing donors: A transplant framework for England*, Department of Health, 2003

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- 5.2 In July 2007, the Chief Medical Officer for England published his *Annual Report* for 2006 that, among other recommendations, called for legislation to be amended to create an opt-out system for organ donation, in order to address a shortage in the supply of organs for transplantation. In recognition of the complexities surrounding the subject, the Secretary of State for Health asked the Organ Donation Taskforce to continue its work by examining the potential impact that a system of presumed consent would have on donation rates across the UK.
- 5.3 As the Taskforce has yet to submit its report on consent systems, the Government must reserve its position on whether the existing system of donor registration should change. It is clear, however, that whatever system is in place, the Government will need to find new and effective ways to engage with the general public on organ donation, so that levels of awareness and understanding are raised. It is also important to understand the reasons why fewer members of some groups in society have registered as potential donors or consented to donation than other groups.
- 5.4 Also, whether or not the Government decides to move towards a different consent system, implementation of the measures necessary to deliver the infrastructure changes to organ donation and transplantation services already planned (as part of the delivery programme established in response to the Taskforce's first report), will need to continue.
- 5.5 The Government also recognises the important role that family members play in the donation process. In particular, the need for people to discuss their wishes about donation with family and friends. Therefore, the draft NHS Constitution, currently in a process of consultation, includes this as something that we can all do to help optimise donation.

Chapter 6: Ethnic and Cultural Aspects

Recommendations

- **We recommend that the European Commission should encourage Member States to collaborate on the conduct of research, and on the sharing of results from this with a view to developing appropriate actions, into the impact of cultural, educational or socio-economic factors on the identification of suitable donors, family refusal rates and access to organs among diverse communities across the EU. [paragraph 344]**
 - **We recommend that the Government should play a full part in sponsoring the conduct of such research in the UK and in sharing the findings with other Member States. [paragraph 345]**
- 6.1 The Government is keen to work with the European Commission and other Member States to collaborate on research, and on the sharing of results, with the aim of developing appropriate actions to identify and refer potential organ donors, minimise refusal rates and increase transplantation across the EU. One current EU-funded project, DOPKI, focuses on improving knowledge and developing applicable methodology that could be used to increase the potential of organ donation. The project aims to promote cooperation and sharing of good practice across Member States. Further information about DOPKI can be found at http://ec.europa.eu/research/fp6/ssp/dopki_en.htm.
- **We recommend that the Government should establish programmes to implement and audit the success of disease prevention schemes which are suited to the attitudes and beliefs of the different communities which are particularly affected by diseases associated with organ failure. The Government should also investigate the extent to which organ donation decisions within black and ethnic minority groups are influenced by experiences of, and attitudes to, the health service system more generally. [paragraph 346]**

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- 6.2 A number of programmes are in place to prevent, or detect at an early stage, diseases that could lead to organ failure. The Government has published National Service Frameworks for diabetes (in 2001) and renal services (2004, 2005) that for the first time set out national standards for the care and prevention of diabetes and kidney disease respectively. Both National Service Frameworks recognise that ethnicity can be a risk factor for disease and can affect rates of disease progression.
- 6.3 Both National Service Frameworks also recognise the importance of early identification to delay or prevent the complications of diabetes, including diabetic kidney disease, and the better management of a person with renal disease that could otherwise lead to established renal failure.
- 6.4 The Government recognises that understanding the ethnicity of the local community is vital in providing good quality services, and the Quality and Outcomes Framework rewards GP practices for recording the ethnicity of 100% of new patient registrations. The early identification of diabetes or renal disease is key to delaying or preventing later complications, or to planning care. This is particularly the case in areas with a high black and minority ethnic population. The Department of Health continues to support the NHS in implementing the National Service Framework standards, and together with the National Diabetes and Kidney Care Support Teams have produced a range of tools and guidance for local use. In Wales, the Welsh Assembly Government has published National Service Frameworks for diabetes, renal and cardiac disease that highlight the requirements for disease prevention.
- 6.5 In April 2008, the Secretary of State for Health announced *Putting Prevention First*, a national programme of vascular risk assessment and management for all those aged 40 to 74. These checks will assess a person's risk of coronary heart disease, stroke, diabetes and kidney disease and will be based on straightforward questions and measurements. These will record basic information such as height, weight, current medication, age, family history, smoking and blood pressure, and include a simple blood test for cholesterol and (in some cases) glucose levels. This will be followed up with an individually tailored assessment setting out the person's level of vascular risk and what steps they could take to reduce it.
- 6.6 When fully implemented, this programme has the potential to prevent: at least 9,500 heart attacks and strokes a year (2,000 of which would be fatal); 4,000 people a year from developing diabetes; and detect at least 25,000 cases of diabetes or kidney disease at an earlier stage, allowing people to be better managed and for outcomes to improve.
- 6.7 The Department of Health is working closely with stakeholders, including those in the third sector, to find the best ways of reaching those who will benefit most from risk assessment and management. The Department of Health is looking at making the programme available in a range of community settings. This will allow the programme to realise its full potential to narrow health inequalities. In Wales, the Welsh Assembly Government is looking at ways of strengthening the approach for identifying and monitoring those at risk of cardiac disease, stroke, renal disease and diabetes by introducing a more coordinated approach.

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- 6.8 As part of *Health Inequalities: Progress and Next Steps*, the Department of Health has also committed to testing a 'full service' model of local programmes and services to prevent and tackle child and adult overweight and obesity. This will seek to ensure that all individuals and families have the information, support and services they need to make healthy decisions on food and activity, from pregnancy through to old age. The Government will test this model in areas with the highest levels of child and adult obesity, with the aim of halting, and potentially reducing, the prevalence of obesity in these areas.
- 6.9 Lord Darzi's NHS Next Stage Review, *High Quality Care For All*, sets out the importance of commissioning prevention services. Every Primary Care Trust will commission comprehensive wellbeing and prevention services, in partnership with local authorities, with personalised services to meet the specific needs of their local populations. Efforts will be focused on six key goals, including obesity.
- 6.10 In addition, the Government is seeking to reduce alcohol-related health and social harm. In its alcohol strategy, *Safe. Sensible. Social.*, the Government laid out its key aspirations for achieving this, including a reduction in chronic and acute ill health caused by alcohol, resulting in fewer alcohol-related accidents and hospital admissions.
- 6.11 The Government sponsors various community projects that focus on disease prevention and attitudes to healthcare in communities particularly affected by diseases associated with organ failure. For example, it has part-funded a project run by Kidney Research UK to reduce the high incidence of established renal failure in certain high-risk communities.
- 6.12 In Northern Ireland, a Service Framework for Cardiovascular Health and Wellbeing is currently in the process of consultation, and is available at www.dhsspsni.gov.uk/showconsultations. Specific health promotion initiatives include work in the area of obesity, particularly aimed at the avoidance of Type 2 diabetes and the resulting risk of kidney disease.
- 6.13 In another area of healthcare, as part of the Department of Health's *Hepatitis C Action Plan for England*, there has been a national campaign to raise awareness of hepatitis C in order to increase testing and diagnosis of those already infected, and to prevent new infections. Serious liver disease caused by chronic hepatitis C infection is a significant reason for liver transplantation – 12% of first liver transplants (59 out of 478) in 2006 were for hepatitis C-related disease. One strand of the campaign is being targeted at South Asian communities, as there is evidence from epidemiological surveillance and screening of blood donations that they are at an increased risk of hepatitis C infection compared to the general population, perhaps from exposure to infection in their countries of origin. In Wales, a draft *Blood Borne Viral Hepatitis Action Plan* has been developed.
- 6.14 An equivalent range of initiatives relating to the detection and prevention of cardiovascular disease and diabetes has been introduced in Scotland, where there is a strong drive to tackle obesity. Scotland also has a hepatitis C action plan.

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- **We recommend that, as a part of a wider public awareness campaign, the Government should support locally led programmes which have the aim of encouraging black and ethnic minority communities to engage actively with the goal of increasing organ donation within their communities. [paragraph 347]**
- 6.15 The Government recognises the importance of gaining greater understanding of the impact of cultural, educational and socio-economic factors on organ donation both within the UK and across the EU.
- 6.16 There is clearly a long way to go before the impact of those factors is fully understood. The Government is, however, determined to make progress in this area and will share its findings with other Member States of the EU.
- 6.17 The Department of Health has also funded a number of organ donation-related third-sector organisations. Such funding, amounting to more than £600,000 over the past five years, has helped a number of local and national projects to raise awareness about organ donation. In addition, NHSBT is funding a two-year study to examine the reasons and circumstances in which individuals make gifts and donations generally, and how those findings might be used to increase organ donation among the UK's multi-ethnic and multi-faith population.
- 6.18 In Wales, the Welsh Assembly Government has sponsored an organ donation awareness-raising campaign that has been delivered and led by charities with an interest in organ donation, such as the Kidney Wales Foundation, and in collaboration with NHSBT. The campaign is called 'Donate Wales: Tell a Loved One'. The main thrust of the campaign is to first discuss organ donation intentions with loved ones, and second to register as an organ donor. The campaign has been well received by the public and will run until the end of September 2008.
- 6.19 In summary, the Government will continue to identify and implement the most effective ways to promote organ donation to the public, and progress will be monitored by the Programme Delivery Board as part of the implementation of the Taskforce recommendations.

Chapter 7: The Views of Faith Groups

Recommendations

- **We recommend that the European Commission should encourage Member States to collaborate on the conduct of further research, and on the sharing of results from this with a view to developing appropriate actions, into the extent to which views based on affiliation to a faith group may affect the decisions of potential donors and donor families, and the attitudes and behaviour of relevant health care staff across the EU. [paragraph 395]**
- **We recommend that the Government should play a full part in sponsoring the conduct of such research in the UK and in sharing the results obtained with other Member States. [paragraph 396]**
- **We recommend that the Government encourage the development of programmes which work at a local level with faith and community groups to clarify and communicate issues relating to organ donation. [paragraph 397]**
- **We further recommend that faith groups, and other ethically concerned groups, should be invited to advise on the development of national and local policies relating to organ donation and transplant in order to help ensure that these are sensitive to the needs and concerns of members of such groups. [paragraph 398]**

7.1 The Government recognises that while there is widespread support for organ donation from faith groups within the UK, a number of groups have concerns about some aspects. There have been low levels of engagement with organ donation from members of some groups and the reasons need to be understood. Although there are issues specific to each, there is of course extensive overlap between work aimed at engaging with faith groups and work aimed at community groups.

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- 7.2 At the request of the Organ Donation Taskforce, the Department of Health has funded a programme of interviews, led by Professor Gurch Randhawa, a member of the Taskforce, with senior members of leading faith and belief groups to seek their advice on how to achieve the engagement of grass roots members of those groups. The Government sees this as the beginning of a dialogue that will need to be sustained – possibly over many years – to build the understanding and trust necessary to enable these communities to engage fully with organ donation.



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