



**ALL-PARTY PARLIAMENTARY HEPATOLOGY GROUP**

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# **More Transplants, Saving More Lives: The Future for Organ Donation in the UK**

*Report of a meeting of the All Party Parliamentary Groups on Kidneys,  
Hepatology, Diabetes and Heart Disease*

*Tuesday 11 March 2008, House of Commons*

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## **1. Background to the meeting**

Over 1,000 people die each year waiting for an organ transplant in the UK because there is a national shortage of organ donations.

Sir Liam Donaldson, the Chief Medical Officer, highlighted the shortage of organs for transplant in his annual report in 2007 and the Government's Organ Donation Taskforce recently reported that a 50% increase in organ donation could be made possible within five years.

The Taskforce Report has already made important recommendations about the health service changes needed to improve transplant services. They are now looking into the issue of presumed consent, and are due to report to ministers on this controversial topic in the summer. The All Party Parliamentary Hepatology Group (APPHG) decided to organise a joint meeting with other All Party Parliamentary Groups (APPGs) with an interest in transplant issues, in order to have a valuable debate on the ethical and practical issues around organ donation and transplant. It is vital that both the public and Parliament are involved so that a consensus can be reached on how best to save more lives from organ failure.

Sir Liam Donaldson and the chair of the Organ Donation Taskforce, Elisabeth Buggins, agreed to come to Parliament and address the joint meeting of APPGs with an interest in transplant issues to discuss the work of the taskforce and the calls for a move to presumed consent, and to give parliamentarians and stakeholders an opportunity to put their questions to them.

## **2. Chairman's welcome**

Dr Evan Harris MP, Co-Chair of the All Party Parliamentary Kidney Group, welcomed everyone to the meeting.

Dr Harris explained the rationale for the joint meeting of APPGs. Transplant and organ donation issues are relevant for all solid organ groups in the body, and consequently this cuts across the remit of a number of APPGs. Dr Harris set out that all individuals hold different views on presumed consent, but that there is broad consensus to support the Human Tissue Act and other initiatives to increase the amount of organs made available from transplants under the current system. This has led to the APPGs' particular interest in the work of the Organ Donation Taskforce.

## **3. Presentation by Elisabeth Buggins CBE - Chair, Organ Donation Taskforce**

### **Introduction**

Ms Buggins began by thanking parliamentarians for their interest in transplant issues, as this directly led to the establishment of the Organ Donation Taskforce. She outlined some of the challenges in transplant issues and how the Taskforce's recommendations are designed to address these. Ms Buggins then went on to discuss the work of the presumed consent group.

### **There is a growing need for organ donors in the UK**

Although living donor rates and the number of non-heart beating donors are increasing, the demand for transplants is also growing every year. This is not expected to change for the foreseeable future given the increasing levels of diabetes, kidney disease and liver disease in society. It is particularly concerning that the level of heart-beating donation is down, and that the reasons for this are not clear.

Successful kidney and liver transplants have similar long term survival rates after transplantation. This is up to 43 years after renal transplantation and 36 years following a liver transplant. Transplants using kidneys from living donors are generally more successful than those which use cadaver kidneys.

The UK has not had a good supply of donated organs, as organs are being buried or cremated which could save lives. People are dying every day who could be saved by a transplant.

There is a strong case for the cost-effectiveness of transplantation. It is the most economic form of therapy; the cost of a renal transplant, for example, can be recovered in 2-4 years compared with dialysis. The Department of Health estimates that £500 million could be saved by the NHS alone over the next ten years if the rates of transplant increased to recommended levels.

### **The UK has much lower rates of organ donation than other European countries**

The Organ Donation Taskforce looked closely at trends in transplantation across the world. Given that the USA and most countries in Europe (excluding Italy) started from generally the same levels of organ donation 15 years ago, it is clear that many

other countries have improved dramatically in subsequent years. Whereas the UK had 12.9 donors per million population (PMP) in 2006, the equivalent figures for the USA and our European counterparts are:

- Germany – 15.3 PMP
- Portugal – 20.1 PMP
- France – 23.2 PMP
- USA – 26.5 PMP
- Spain – 33.8 PMP

### **The UK could learn from Spain's model for organ donation**

The Taskforce examined the situation for organ donation in Spain, and found that the family refusal rate for donation is very low compared to the UK and is continuing to decline. In the UK, approximately 40% of families refused to give their loved one's organs for donation, yet in Spain the rate was 15.1% in 2006. The Taskforce found that the context and service offered at the time of death had a significant impact on rates of organ donation.

The Spanish model is based on the following principles, and has been replicated successfully in northern Italy and South America:

- A transplant coordination network
  - Growth in the number of transplant coordinators has led to the dramatic lowering of the family refusal rate
- A medical coordinator in each hospital to champion organ donation
  - This member of staff changes after three years in order to avoid burn-out and maintain effectiveness
- Continuous brain stem death audit
  - A central office coordinates this nationally in order to track the number of patients who have had brain stem death whose organs may be available for donation
- Medical training
  - Great effort is made in training on how to request relatives to consider organ donation
- Hospital reimbursement based on the number of organs retrieved
  - The costs of organ retrieval are reimbursed for Spanish hospitals so that there is no financial disincentive to encouraging organ donation. In the UK, the Organ Donation Taskforce proposes a similar reimbursement system. This would cover costs incurred, rather than act as incentive payments. Offering incentives for achieving higher rates of donation would be a difficult message to sell to the public, who may feel anxious that they will be pushed into donating their loved one's organs
- Attention to the mass media
  - A sustained campaign continues to get messages on organ donation to the population

### **Implementation of guidance is needed to identify potential donors**

At present, approximately 25% of the UK population is registered on the NHS Organ Donation Register. This does not necessarily mean that these patients on the register go on to donate organs when they die, as so much depends on the attitude of the family.

However, the main issue to be addressed to increase the number of heart-beating organ donors is the implementation of guidance for Brain Stem Death tests (BSD). These tests should be performed on everyone – unless there are obvious contraindications to donation - in order to identify whether the individual is a possible donor. However, the latest figures show that more than 1500 potential organs for donation each year are not identified. This is because:

- BSD tests do not always take place for potential donors. Data shows that 592 potential donors each year do not have a BSD test, even where BSD is the likely diagnosis
- Where BSD tests do take place, referral for heart beating donation does not necessarily happen. The latest 3-year figures show that there were 3990 BSDs, but heart beating donation was only considered for 3607 cases
- Family members may not be approached to ask permission for organ donation, even where a potential organ donor has been identified. This accounts for 70 patients each year

### **There are number of challenges for increasing organ donation**

Fundamental issues remain to be tackled in order to increase rates of organ donation in the UK. At present, organ donation is not a normal and expected part of end of life care. Consequently, family members have not generally considered whether their loved one would want their organs donated, or have had this discussion with the individual involved. Relatives often refuse consent for organ donation, particularly in Black Minority Ethnic communities (BME), even where their loved one may have expressed their consent.

Critical care doctors need better training and support in approaching families to deal with the difficult issues surrounding organ donation, and greater numbers of donor transplant coordinators would help here. There are too few transplant coordinators at present, and very variable employment arrangements exist. In some cases, coordinators can be diverted to other areas of clinical activity. This means that there is insufficient focus on increasing organ donation rates at local level.

Under the current Payment by Results tariff, there is no reimbursement or incentive for activity to increase rates of organ donation. This activity can be expensive as operations to retrieve and transplant organs require the use of intensive care beds and theatre time for an extra 12-36 hours. The Taskforce has called for trusts to be reimbursed for all the donors identified, whether or not organs are retrieved. This should be combined with a programme for healthcare management teams to highlight the importance of organ donation and to ensure that this they consider this when determining Trusts' priorities.

### **The Organ Donation Taskforce's recommendations aim to increase the number of organ donors**

A number of recommendations, based on successful models for transplant used internationally, were made by the Taskforce to increase donation rates in the UK. The Taskforce recommended:

- **Establishing a UK wide organ donation organisation** to employ donor transplant coordinators and double their numbers across the country, and to strengthen donor transplant coordination

- **Establishing an organ donation ethics committee** across the UK to address ethical questions quickly
- **Commissioning dedicated organ retrieval teams**, rather than the current system of clinical specialists from different centres around the country
- **Reviewing public recognition and promoting the value of organ donation** by, for example, sending a letter from the Chief Medical Officer to the loved ones of organ donors to thank them for their role in the decision to donate
- **Working with the Ministry of Justice to develop formal guidelines for coroners**, as in most cases donation can continue after the cause of death has been determined

### **Making changes in the NHS at local level would increase the number of organ donors**

Organ donation should be made the norm, rather than the exception. The overall recommendations from the Taskforce on UK wide changes would be bolstered by steps taken in local health organisations. The Taskforce recommended:

- A clinical donation champion and Donation Committee in every NHS Trust
- There should be minimum notification criteria for potential donors, with success rates monitored. The patient should be referred to the Trust's donor coordinator before the BSD test is performed. This would hopefully capture every potential donor. At present, the system depends on individual clinicians' decisions about whether referral should be made and so an accurate picture is not possible. A pilot is underway in Birmingham on notification criteria and will report on the impact on organ donation rates
- BSD testing should take place, in accordance with current guidance
- Financial disincentives for organ donation to Trusts should be removed
- There should be mandatory training for staff on issues surrounding organ donation and the conversations needed with patients' loved ones

### **The issue of presumed consent is now being addressed separately**

Presumed consent was not within the original terms of reference of the Organ Donation Taskforce. Separate terms of reference have been drawn up "*to examine the potential impact on organ donation of introducing a different consent system across the UK, having regards to the views of the public and stakeholders on the clinical, legal and societal issues, and to publish its findings*".

The Taskforce is exploring the issues through six working groups, UK wide stakeholder events and an online public consultation. The Taskforce will be reporting to ministers in the summer of 2008, based on currently available evidence.

#### **4. Presentation by Sir Liam Donaldson, Chief Medical Officer**

Sir Liam thanked the APPGs for the opportunity to speak at the event, and introduced the role of the Chief Medical Officer in working with government on public health issues. In particular, the Chief Medical Officer gives independent advice, particularly in the annual report, which can have a significant impact on policy. The most powerful recent example is the ban on smoking in public places, which was recommended in the Chief Medical Officer's report in 2003, and effected by legislation in July 2007.

Sir Liam put forward that the gap is widening between the number of patients receiving organ transplants, and those who are on the waiting list. At least one person dies every day for want of an organ. There are also significant health inequalities in transplantation rates between white and BME communities. At present, 'transplant tourism', where patients travel abroad for an organ transplant, is becoming increasingly prevalent. Whilst only limited data exists on the extent of 'transplant tourism', the evidence suggests that there is a significantly higher level of medical complications associated with these procedures.

#### **There should be presumed consent with an opt-out alternative**

While there has not been a proper audit of public opinion on the issue of presumed consent, some statistics suggest that about 60% of the public are in favour. In practice, more people declare that they are willing to donate organs than actually do.

The Chief Medical Officer called for the introduction of an opt-out from organ donation based on a system of presumed consent, in addition to the recommendations of the Organ Donation Taskforce. The media does not sufficiently publicise the 'more usual' patients whose lives are disrupted by ongoing renal dialysis and who need transplants.

Some people claim that a system of presumed consent would be nationalising people's bodies. However, not only would an opt-out system contain a lot of safeguards, but the majority of people agree to a system which assumes that they would be happy to donate their organs.

There is an argument that instead of implementing an opt-out system of presumed consent, there should simply be better infrastructure for encouraging higher rates of organ donation. This is the case in Spain, for example. However, the Chief Medical Officer believes that both systems – opt-outs and infrastructure – are needed to increase transplant rates sufficiently. Evidence suggests that those countries which have an opt-out system also have higher levels of transplantation.

#### **5. Audience discussion**

##### **Question – Should there should be greater media engagement in transplant issues?**

A number of members of the audience questioned the lack of TV advertising to encourage members of the public to donate organs. Both Elisabeth Buggins and Sir Liam Donaldson agreed that there should be more engagement with the media to persuade the public of the importance of donating organs. There is evidence that the number of registered donations directly increases after media coverage. For



example, there was a significant increase in January 2008 after the media launch of the Organ Donation Taskforce report.

**Question – How can the public be made aware of an opt-out under a system of presumed consent?**

The Liberal Democrat Shadow Secretary of State for Health, Norman Lamb MP, asked how the public could be made aware of an opt-out under a system of presumed consent. The Chief Medical Officer put forward that if a system of presumed consent with an opt-out existed, there would be a range of measures to make members of the public aware of this over the course of their lifetime. This would include very regular public communications and engagement with the media, as well as a focus on those groups which are harder to reach. Children would be excluded from the presumed consent system and the opt-out alternative would be a 'soft' version, so that families would be consulted in the event of a loved one's death, have the opportunity to specify that there had been an unregistered objection and would have the an ultimate right of veto.

Sir Liam set out that the current system for organ donation does not work well in informing families of their loved one's wishes. Although the situation does of course depend on the circumstances of the death, considering whether to donate organs is just one more harrowing decision to make at a very difficult time. A clear opt-out system would allow individuals to signal to their families about his/her intentions for his/her organs after death. This may be comforting for family members at such a traumatic time because knowing their loved one's intentions may help ease the decision-making process.

**Question – What mechanisms exist to provide the funding for implementing the Taskforce's recommendations?**

Baroness Masham asked how the Taskforce's recommendations could be implemented given the capacity problems the health service already faces managing deaths. Elizabeth Buggins said that the Department of Health has committed to funding all of the recommendations in the Taskforce's report for at least the first year of the programme. She explained that ideally there should be a rate in the Payment by Results (PbR) tariff for activity on organ donation, as the PbR is the main lever available at the moment for necessary funding. She also called for a central fund for transplant coordinators, which could be allocated to NHS Blood and Transplant to oversee the network.

**Question – How can existing health service levers be used to implement the recommendations?**

The Renal Association welcomed the Taskforce's proposals, and questioned how these would be implemented through existing levers in the health service. Elisabeth Buggins explained that some kind of metric is needed to show the success of organisation at turning potential organ donors into actual donors. This would allow a conversation with healthcare managers and the clinical community about commissioning the necessary services to support this. The Chief Medical Officer emphasised the importance of introducing a system of presumed consent, as this would underpin changes in the long term. Step-by-step changes will take place through developing effective transplant coordination and financial reimbursement for encouraging donation.

## **Contribution from the National Kidney Federation**

Tim Statham OBE, Chief Executive of the National Kidney Federation, highlighted that kidney transplants represent the highest proportion of organs transplanted in the UK each year. Currently five kidneys are transplanted each day, but if this number was doubled to 10 per day there would no longer be a waiting list for kidney transplant operations. Mr Statham said he believed that implementing the Taskforce report recommendations would increase this figure to 7.5 per day, and that presumed consent would increase that number even higher to the 10 per day level that is required to wipe out the waiting list.

Now that the Organ Donation Taskforce report is being implemented by the Government, Mr Statham said that the National Kidney Federation had changed its position to support the introduction of presumed consent.

## **Contribution from the British Transplant Society**

Dr Anthony Warrens, a Reader in Medicine and Immunology at Imperial College London and representing the British Transplant Society, said that there were differing attitudes to organ donation particularly amongst BME groups. He said it was important to emphasise that there is a great deal of complexity underlying these attitudinal issues and that more understanding is needed about how different ethnic communities engage with the issue of organ donation.

In reply Elizabeth Buggins said that we do not really understand the reasons why organ donation rates from BME communities are lower. Sir Liam Donaldson agreed, and said that cultural beliefs and attitudes, and wider issues of social engagement, are the key challenges in communicating effectively with BME communities.

## **Question – Should direct consent of the individual override the rights of the next-of-kin to refuse organ donation?**

Charles Gore, Chief Executive of The Hepatitis C Trust, said that a system of presumed consent would presumably replace a system of direct consent from individuals. Given that we have very high rates of family refusal, should we not be ensuring that the wishes of individuals who give direct consent before death are respected?

Sir Liam Donaldson said that under the current system the wishes of many people who have signed-up to the organ donation register are not carried out due to the refusal of relatives. He added that if the UK adopted an opt-out system of presumed consent it might be possible to apply a 'belt and braces' approach to reinforce the wishes of those people who wanted to actively 'opt-in'.

Elizabeth Buggins said the Taskforce is now assessing all the legal and ethical frameworks in different countries and the impact these have on donations rates. The Taskforce will consider the issue of 'actual consent' but also what the most effective 'default' should be about who can and cannot override this position. For example, one issue the Taskforce is considering is should there be an option to opt-out of donation for specific organs. These are the detailed questions which the Taskforce will now consider.

### **Question – Would an ‘advanced directive’ reduce rates of family refusal?**

Bill Etherington MP supported the idea of an ‘advanced directive’ or ‘living will’ which could prevent anyone from interfering with an individual’s wishes regarding donation of their organs. ‘Advanced directives’ anticipate a time when a person may be unwell and no longer have the capacity to make his/her own treatment decisions. The directive allows a person to record their wishes in advance. Mr Etherington said a system of presumed consent with the addition of an advanced directive should have the force of law. Sir Liam Donaldson said that under ‘soft’ systems of opt-out where consent is presumed but relatives are consulted, rates of family refusal are low. In these cases, Sir Liam said that there is a strong argument that integrity of the donation and transplant system required consultation with and ultimate agreement of relatives. He also said that there would likely be a problem in getting people to sign up to an advanced directive on a mass basis, and that it may require a complex legal process.

Dr Harris added that the idea of insisting that under the current system the deceased’s express wish to donate could not be vetoed by relatives has been promoted previously by politicians such as Kenneth Clarke MP in a Private Member’s Bill, but that it was opposed because it was felt that it would be counterproductive to force doctors to override the wishes of family members. Dr Harris said that only a few countries – such as Austria has implemented a system involving an opt-out system with no relatives veto and that it is felt they achieve the same results as countries with an opt-out system of presumed consent.

Ms Buggins replied that there are two main clinical reasons why such a system of advanced directives would be counter productive. Firstly, in order to remove organs effectively, clinicians require lifestyle information from the family which requires their cooperation and a consultation. Secondly, Ms Buggins expressed concern that overriding the refusal of family members with deeply-held convictions or objections would be likely to severely compromise their grieving process.

### **Question – Can it be made easier for foreign nationals to enter the country to donate organs to family members who reside in the UK?**

Lisa Burnapp, a Consultant Nurse at Guy’s and St Thomas’ Hospital said that it was becoming increasingly difficult for foreign nationals to get visa approval to visit the UK to donate organs to British family members. Sir Liam Donaldson said he would raise this issue with the Home Office.

## **6. Summary – lessons learned for the future**

The recommendations by the Organ Donation Taskforce, published in January 2008, offer a vital opportunity to dramatically increase rates of organ donation in the UK. The number of organ donors in this country is historically low compared to other countries, notably Spain and the USA. By implementing aspects of the Spanish model for organ donation, we can have a significant impact on rates of organ donation which will save lives.

There needs to be significant changes to the mechanisms for organ retrieval and transplant in this country. This includes commissioning the necessary services within the NHS, such as dedicated organ retrieval teams to combat the problems currently caused by diverting clinical staff working in organ donation to other duties.

A UK wide transplant coordinators network, and national organisation to oversee the system of organ donation, would be a fundamental step towards changing current practice. The organisation and network would facilitate greater BSD testing to determine whether potential donors are suitable. It would also provide effective monitoring across the country to ensure that referrals for donation are taking place where possible, and that clinicians are equipped to discuss these difficult issues with families.

These structural changes need to be coupled with a programme of media engagement to raise the profile of organ donation with the public and promote understanding of the value of donating organs. The ongoing debate around a system of presumed consent is an added opportunity to raise the profile of organ donation issues with the public. The opt-out system proposed by the Chief Medical Officer would allow families the final say over the use of their loved one's organs, but would also provide guidance for them about their relative's intentions for their organs, which may help ease the decision-making process at a difficult time.

While the recommendations of the Taskforce are welcome, the key test will be the implementation of the report over the coming years. The Department of Health has committed funding for the first year to implement these changes, and it is important that Government remains focused on the significant challenge facing the UK to improve rates of organ donation.

## **7. Membership of the All-Party Parliamentary Groups involved**

### **All Party Parliamentary Group on Kidneys**

Dr Evan Harris – Co-Chair	Anne Begg
Lee Scott – Co-Chair	Hilary Benn
Janet Dean – Co-Chair	Joe Benton
Lord Davies of Coity – Vice-Chair	John Randall
Lindsay Hoyle – Treasurer	Graham Brady
Tim Boswell - Treasurer	Cheryl Gillan
Edward Vaizey – Secretary	Philip Hammond
Linda Gilroy	Michael Jack
Austin Mitchell	Mark Pritchard
Graham Stringer	Norman Baker
Russell Brown	Annette Brooke
David S. Borrow	Paul Burstow
Patrick Hall	

### **All Party Parliamentary Hepatology Group**

David Amess MP – Co-Chair	Kelvin Hopkins MP
Bob Laxton MP – Co-Chair	Lindsay Hoyle MP
Dr Brian Iddon MP – Vice Chair	Stewart Jackson MP
Tim Boswell MP	Andrew Love MP
James Brokenshire MP	Lord Mancroft MP
Dr Vincent Cable MP	Lord de Mauley MP
Jim Cousins MP	Shona Mclsaac MP
Jim Dobbin MP	Lord Morris of Manchester MP
David Drew MP	Dr Bob Spink MP
Neil Gerrard MP	Anthony Steen MP
Oliver Heald MP	

### **All Party Parliamentary Group on Diabetes**

Adrian Sanders – Chair	Des Browne
Cheryl Gillan – Vice-Chair	Betty Williams
Anne McIntosh – Vice-Chair	Janet Dean
Philip Dunne – Vice-Chair	Bob Laxton
Helen Southworth – Secretary	Tim Loughton
Lord Harrison	Desmond Swayne
Dr Desmond Turner	Lady Hermon
Dr Howard Stoate	Baroness Masham of Ilton
Dr Brian Iddon	Dr Evan Harris
Jim Dobbin	Angela Watkinson

### **All Party Parliamentary Group on Heart Disease**

Chris Ruane – Chair	Dr Ian Gibson
Lynda Waltho – Vice-Chair	Dr Howard Stoate
Andrew Lansley – Vice-Chair	Anne Begg
Malcolm Moss – Vice-Chair	Frank Cook
Dr Evan Harris – Vice-Chair	David Amess
Paul Keetch – Vice-Chair	Peter Bottomley
Lord Elder – Secretary	Lord Hayhoe
Baroness Gardner of Parkes – Treasurer	Baroness Maddock
Lord Sheldon	Dr Richard Taylor
Julie Morgan	Ann Clwyd