

# Scottish Parliament Briefing: Where next for organ donation? December 2012

## Key facts:

- In Scotland there are currently over 650 people waiting for a donor organ.
- Up to 90% of people support organ donation but less than half of Scotland's population is registered on the NHS Organ Donor Register
- Surveys have suggested that more than 70% of the public supports a shift to a soft opt-out system.
- Countries that operate an opt-out model have roughly 25-30% higher donation rates than informed consent countries.
- We believe that a move to a soft opt-out system of organ donation would increase the number of organs available for transplant in Scotland.

## Introduction

Every day, throughout the UK, three people die waiting for a donated organ. At the same time organs, that could have saved lives, are buried or cremated even though the deceased did not object to donation. We know that around 70-90% of the population are willing to donate their organs after death and we need to ensure we have a system in place that allows those wishes to be followed wherever possible.

Organ transplantation is an area that has seen amazing medical achievements but has not yet reached its full life-saving and life-transforming potential. It is difficult to know that people are dying and suffering when their lives could be saved or dramatically improved by a transplant. It is even more difficult when we know that lives are being lost unnecessarily because people who are willing to donate organs after their death simply never get around to making their views known, resulting in relatives making a decision without knowing the individual was willing to donate. For this reason we believe it is essential to look at ways in which the organ donation system can be improved further to reduce the number of avoidable deaths, increase the number of lives that could be transformed by a transplant and make maximum use of the high level of altruism in UK society.

The previous Westminster Government established an Organ Donation Taskforce in 2007 which made clear, in its two reports, that the current system was unable to meet the increasing demands placed upon it and that steps needed to be taken, as a matter of urgency, to increase donation rates. Following publication of these reports a determined effort was made to improve the situation for those who were waiting for an organ.<sup>1</sup>

Four years after the publication of the Taskforce Report, we have seen significant improvements in the infrastructure and increased donor rates. As the implementation programme reaches fruition and the new systems and arrangements are becoming settled, we need to decide, as a society, what the next steps should be. Now that we have a well-organised, well-funded, comprehensive infrastructure in place, is that enough? Can we say we have done all we can? Or, should we now look to go further and build on this progress by shifting our attention to new ways of increasing the number of donors and the number of lives saved?

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<sup>1</sup> The Taskforce's recommendations and the action that has been taken to address them, are summarised in: British Medical Association (2012) *Building on Progress. Where next for organ donation policy in the UK?* BMA, London.

### **A 'soft' opt-out system**

Repeated surveys show that the majority of the public say that they support organ donation. Up to 90% of people support organ donation but, for various reasons, less than half of Scotland's population is registered on the NHS Organ Donor Register (ODR).

We believe that genuine choice over organ donation can be facilitated through a soft opt-out system whereby adults – who have been well informed of the options – can choose to opt-out of organ donation during their lifetime, rather than having to opt into donation, as is the status quo. A culture in which donation is discussed more openly and perceived as the norm would fit better with what most people say they would like to happen. Rigorous safeguards are imperative to such a system, in order to ensure genuine choice is protected. We would emphasise the need for a wide-ranging publicity campaign to inform the public prior to any legislative change and we believe relatives should retain a role in the organ donation process.

This is how a soft opt-out system could work:

- Before the new system is introduced there would be extensive and high profile publicity to ensure all members of society were aware of the forthcoming change and to encourage them to consider their own wishes about donation after their death.
- A database would be established with mechanisms for people to easily and quickly opt out if that is their wish.
- Once implemented, when someone over the age of 16 dies and donation is a possibility, the opt-out register must, by law, be checked and if the individual had opted out, donation could not proceed.
- As an extra safeguard, if the individual had not opted out, family members would be asked if they were aware of any unregistered objection.
- If the relatives were not aware of any objection, they would be informed that donation would proceed. There would, however, be scope not to proceed if it became evident that to do so would cause severe distress to the relatives.

Those under the age of 16 and those who have not had capacity since the system was introduced, and therefore would not have had the opportunity to opt out, would be excluded from the system and specific authorisation from the young person, person with parental responsibility or the nearest relative would to be required.

Opponents of opt-out often argue that such a system is an affront to patient autonomy because it removes choice from donors but under an opt-out system individuals have exactly the same choice as under an opt-in system; to donate or not to donate. We support the principle behind an opt-out system which is that the default position should be to save lives and that, unless an individual objects to donation their organs should be used after death to benefit others. Everyone has, and would retain, the right to refuse to donate their organs after death and to have that wish respected. Under the current system, however, there is no formal mechanism for people who feel strongly against organ donation to register their objection. In the absence of such a mechanism under the current system it is impossible to be sure whether patient autonomy is being respected after death. One of the reasons relatives refuse donation is because of uncertainty about the deceased's wishes<sup>2</sup> whereas family support for organ donation more than doubles when people know about their loved one's wishes.<sup>3</sup> Under a system of opt-out, individuals are far more likely to have discussed their views with their families.

Contrary to the view that under an opt-out system individuals lose rights over their own bodies and power is devolved to the state, individuals are more likely to make decisions during their lifetime under

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<sup>2</sup> National Institute for Health and Clinical Excellence (2011) *Organ Donation for Transplantation: improving donor identification and consent rates for deceased organ donors. Clinical guideline 135: Appendices*. NICE, London, pp.81-2.

<sup>3</sup> NHSBT news releases *Family Support For Organ Donation Doubles When Wishes Are Known – Pass It On*. 9 July 2012 [http://www.organdonation.nhs.uk/ukt/newsroom/news\\_releases/article.asp?releaseld=311](http://www.organdonation.nhs.uk/ukt/newsroom/news_releases/article.asp?releaseld=311)

such a system. They will also have their decision respected after death. Moreover, it makes it easier for families because they are more likely to be aware of the individual's wishes.

We support the type of 'soft' opt-out system in which relatives are always involved as they are in the current system. Retaining a role for relatives serves a dual purpose. Firstly it acts as a safeguard – families may be aware of an unregistered objection to donation. Secondly, it recognises doctors' duty of care towards relatives to relieve, and not add to, their distress in bereavement.

The crucial difference would be in the approach to relatives. Instead of being asked to consent to donation, they would be informed that their relative had not opted out of donation. Unless they object – either because they are aware of an unregistered objection by the individual or because it would cause them major distress – the donation would proceed. Statutory guidance surrounding new legislation must provide clear guidance to professionals on how to deal with relatives' refusals. Assessment of what would cause 'distress' would have to be carried out on an individual basis by trained professionals who are experienced in dealing with bereaved relatives. The introduction of a 'soft' opt-out system would represent a shift of emphasis in favour of donation without major changes to practice. It would respect both the wishes of the potential donors and the sensitivities of their families.

Some fears have been expressed that under such a system there may be an erosion of trust as patients worry that their best interests may be jeopardised if they are seen by doctors as potential organ donors. These fears can be addressed with greater awareness of the very clear separation of responsibility that already exists between the treating and transplant teams.

### **Children and young people**

We believe that the opt-out system should apply only to those over the age of 16. Those under that age will continue to have the option of opting in to donation and, where they have not done so, the decision will be made by someone with parental responsibility.

### **Vulnerable adults**

Careful consideration needs to be given to safeguards to protect the most vulnerable adults in society, including those with impaired mental capacity, the socially isolated and those seeking asylum in the UK. Ultimately it is for legislators to decide on specific safeguards appropriate to the various different groups in society, in consultation with stakeholders. Individuals who have not had capacity since the legislation was passed, and have not, therefore, been able to opt-out must clearly be excluded. With that exception, we do not believe that automatic exclusion of certain groups would be appropriate but rather that steps should be taken to facilitate individual decision making to the greatest extent possible. Making it a priority for specially tailored information to be available in ways vulnerable people can comprehend will help. Many people with impaired capacity, for example, will be able to make a choice and are entitled to have their wishes respected. In line with our general view that relatives should also be consulted for all deceased potential donors, the views of families, advocates and legally appointed proxy decision makers would also be very important.

### **Support for opt-out**

The British Medical Association, Scotland Patients Association, the British Heart Foundation, the Royal College of Surgeons, the Cystic Fibrosis Trust, the Scottish Kidney Federation and the National Kidney Federation, have all declared their support for an opt-out system.

The Evening Times has been running an opt-out campaign since 2011. It has gathered much support from the public, various organisations and many MSPs.

A number of public opinion surveys carried out indicate that there has been a marked shift in public support for opt-out over recent years. The most recent deliberative events for the public, undertaken by the Organ Donation Taskforce in 2008 found that 72% of those questioned supported a shift to an opt-out system.<sup>4</sup> We believe that with further debate and information about the way such a system would operate, there will be widespread public and professional support for such a change, and that people will be encouraged to think about making their wishes known about what happens to them after they die. .

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<sup>4</sup> Organ donation Taskforce (2008) The potential impact of an opt out system for organ donation in the UK – A report from the Organ Donation Taskforce. Supporting Information. Department of Health, London, Annex J,p. 43.

## Assessing the success of opt-out systems

Meaningful data on the success of opt-out in other countries are difficult to achieve because such legislation is only one of a number of factors influencing donation rates. There is, however, increasing evidence that countries that adopt an opt-out system have higher donation rates than those that do not. We believe that key factors for increasing donation rates in Scotland include those already identified by the Taskforce, such as better resources, higher staffing levels including numbers of transplant surgeons and co-ordinators, more training and availability of ITU beds and specialist units. We also believe that a culture in which donation is the normal thing to do could be hugely influential.

The Organ Donation Taskforce commissioned the University of York to undertake a systematic review of all relevant published data on opt out<sup>5</sup>. This identified:

- Eight studies comparing countries with an opt-out system and those without, four of which were methodologically sound. All four studies found that opt-out law or practice was associated with increased rates of donation and, in all except one of these, the results were statistically significant.
- Five studies of countries before and after the introduction of opt-out legislation which were methodologically sound. All of these studies reported an increase in donation rates following the introduction of an opt-out system.

The authors of the review concluded that:

*“The available evidence suggests that presumed consent legislation is associated with an increase in organ donation rates, though the size of the association varied between studies. A number of other factors also appear to be associated with organ donation rates, such as transplant capacity, GDP and health expenditure per capita.”*<sup>6</sup>

Despite these findings the Taskforce decided not to recommend a change at that time preferring to wait and see the outcome of its earlier recommendations for changes to the infrastructure.

## Conclusion

The main reasons that we support a move to an opt-out system can be summarised as follows:

- We believe that, as one part of a broader strategy, a shift to an opt-out system will have a positive effect on donation rates.
- Studies show that a large majority of people would be willing to donate but less than half of the Scottish population are on the NHS Organ Donor Register or carry a donor card. While this level of apathy exists despite people’s good intentions, people will continue to die while waiting for donor organs.
- We support the principle behind an opt-out system – that if people do not object to their organs being used after death, they should be used to save lives.
- Under an opt-out system individuals have exactly the same choice as in an opt-in system – to donate or not to donate.
- The decision not to opt out of donation is as much of a gift as a decision to opt in.
- An opt-out system gives added protection to those who do not wish to donate and makes it more likely that those who are willing to donate will be able to do so.

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<sup>5</sup> Rithalia A, McDaid C, Suekarran S et al. (2008) A systematic review of presumed consent systems for deceased organ donation. In: Organ Donation Taskforce *The potential impact of an opt-out system for organ donation in the UK – A report from the Organ Donation Taskforce – Supporting Information*, Organ Donation Taskforce, London, Annexes A-N: Annex I.

<sup>6</sup> Organ Donation Taskforce (2008) *The potential impact of an opt out system for organ donation in the UK. A report from the Organ Donation Taskforce. Supporting Information Annexes A-N*, Department of Health, London, Annex I, p.66.

- Organ donation becomes the default position which, with public support, changes cultural expectations in society. This represents a more positive view of organ donation which is to be encouraged, and could help towards a societal shift where organ donation becomes a part of the fabric of our national life.
- Overall an opt-out system is better for recipients (because more organs will be available) better for donors (because it is more likely their wishes will be respected) and better for relatives (because it is more likely that the individual's own wishes will be known).

The Taskforce was confident that, with the changes it proposed, donation rates could be increased by 50% within five years. In Scotland, this target has been met and all those involved with this increase should be congratulated.

However, over 650 patients are still waiting for a transplant in Scotland. Many of these will die waiting and others will die before they even reach the list. Patients waiting on the Scottish liver transplant list have a 20% chance of dying before receiving a transplant, and this percentage is higher for those waiting for a heart.

Surely, if more can be done, it should be done, to further increase organ donation rates in Scotland. A soft opt-out system would better reflect the views of the Scottish people and ensure that an individual's wishes can be respected at the time of their death. Now is the time for a serious debate on moving to an opt out system of organ donation.

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