

PE1453/C

BMA Scotland submission in support of Petition PE1453
Calling on the Scottish Parliament to urge the Scottish Government to introduce an opt-out system of organ donation in Scotland to help save more lives.

January 2013

Introduction

Almost five years after the publication of the Organ Donation Taskforce Report in 2007, we have seen significant improvements in the transplant 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.

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.

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?

The Scottish Government accepted the findings of the UK organ donation taskforce report. The then Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP, stated after the publication of the report that, as a result of the recommendations of the UK taskforce report, opt-out was not being considered in Scotland. That said, the plan would be to formally reconsider this decision, in line with the taskforce's recommendation, in five years time (in 2013)¹.

A 'soft' opt-out system of organ donation

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).

¹ Taken from the following news release:

<http://www.scotland.gov.uk/News/Releases/2008/11/17131241>

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 claim to support. Rigorous safeguards are imperative to such a system, in order to ensure genuine choice is protected. We would emphasise the need for a high-profile, 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 would 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.

Assessing the success of opt-out systems

The BMA believes that a soft opt-out system would have a positive impact on donation rates in Scotland. We acknowledge that it is difficult to obtain meaningful data on the success of opt-out in other countries 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 an opt-

out system, leading to a culture in which donation is the normal thing to do, could be hugely influential.

The UK's Organ Donation Taskforce commissioned the University of York to undertake a systematic review of all relevant published data on opt out in 2008². This identified:

- eight studies comparing countries with an opt-out system and those without, four of which were of sufficient quality to produce reliable results. All four of these 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.”*³

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.

Ethical and practical considerations

Any system that has the potential to increase the number of organs available for donation, and therefore the number of lives that can be saved, has strong moral arguments to support it but there are other factors that need to be taken into account.

The central principle behind opt-out is that the default position should be to save lives. If people do not object, it is right that their organs should be used for the benefit of others. The BMA supports this principle. That is not to say that we have a moral obligation to donate, or that we have no interest or rights in relation to what happens to our bodies. Rather, if individuals have not indicated any objection to donation, it is appropriate to assume they would want to act in an altruistic manner and help others.

² 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.

³ 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.

Autonomy

A central question around opt-out systems for organ donation is whether they enhance or reduce autonomy. Those who oppose such schemes suggest that the decision is being taken out of the hands of individuals and the government is taking and using organs without consent. We strongly disagree – under an opt-out system individuals have exactly the same choice as under the current system – to donate or not to donate – and so the decision clearly still rests with the individual.

Respecting the deceased's wishes

In practice, although the current system is referred to as an opt-in system, the majority of people who donate organs have not given consent. In 2010/11, 33% of donors in the UK had signed up to the Organ Donor Register; in the remaining cases authorisation was given by family members. Some family members will have known what their relative wanted from previous discussions, but the majority of decisions will have been based on their 'best guess' of the views of the deceased. This makes the process particularly difficult for families who may struggle to make the 'right' decision at a time of immense pressure and distress. In some of those cases where the relatives refused donation, the individual would have been very happy to donate but the organs were lost. Equally, we have to accept that in some of those cases where the family said yes, the individual would have objected. Under an opt-out system this is less likely to happen because there is a formal mechanism for those who oppose donation to record their wishes and for ensuring that those wishes are respected. The publicity that will precede the change is also very likely to increase discussions within families about donation. Where the individual's views are known the situation is less difficult for the family.

The gift of donation

The organ donation system in the UK is based on altruism and the notion of a gift relationship.

The 'gift' element of donation can be important to those families who consent to donation, and to those who receive organs. It has been suggested that if the individual does not personally, or via his or her family, pro-actively 'volunteer' the organ, it is no longer a gift. Under an opt-out system, however, individuals go through exactly the same thought process to decide not to opt out as they do in deciding to opt in. Given the option to donate or not, a decision is made to act to help others, by not opting out of donation; this is no less of a gift than an organ donated under an opt-in system. Undoubtedly some will think more about this than others and some people will choose not to think about it at all. Under an opt-out system, there is no way of knowing which of those who have not opted out would have taken positive steps to donate under an opt-in system. Some people will see the loss of this positive action to donate as a cause for concern. Whilst it may be seen as preferable for individuals – or their families – to take active steps to give organs, we need to acknowledge that under the current system, organs are being lost that

could have saved lives when that would not have been the wish of potential donors. In the BMA's view families should be encouraged to see the whole process of organ donation as a 'gift' which has the potential for very significant benefit to another person.

Loss of trust

During the Taskforce review of opt-out, some intensivists raised concerns about loss of trust – that patients might be afraid that efforts would not be made to save their own lives if they were considered to be potential organ donors. This is a concern that we know is already held by some people under the current system, and so it is not exclusive to opt-out. It could equally be argued that if people are on the Organ Donor Register – and thus indicate a willingness to donate – they might be seen as potential donors rather than as patients. The important point – irrespective of the consent system in place – is to ensure that patients and the public are aware of the clear separation between the treating team and the transplant team and that patients and relatives are given sufficient information about what is happening and why, to reassure them that all treatment decisions are made in patients' best interests.

Public support

One of the major concerns about introducing an opt-out system is the risk of a backlash; the fear that people will object to the new system and opt out of donation as a means of protest. The BMA has always argued that an opt-out system must have public support before it is introduced. If there is widespread support for the system, the chance of people opting out in protest is significantly reduced; other countries that have introduced such systems have not experienced this problem. The most recent and comprehensive survey of the public, undertaken by the Organ Donation Taskforce in 2008, found that 72% of those questioned supported a shift to an opt-out system.⁴ 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.

Implementation

The success of an opt-out system depends to a very large extent on the way in which it is implemented. It is essential that there is widespread, high-profile publicity, well in advance of the new system coming into effect. Particular efforts must be made to contact hard-to-reach groups and the publicity will need to be repeated at regular intervals. There must be quick, simple and convenient ways for people to opt out, if that is their wish, and a robust and accurate database must be maintained. The database would need to give people the option of opting out of donating different types of organs, such as heart or corneas, or the option to opt out completely. This could be based on

⁴ 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.

the current opt-in register which is already established and tested, with the names of those who wish to opt in replaced by those who wish to opt out. Because it is so important to the success of the venture that this work is undertaken properly, sufficient time – perhaps as much as two to three years – would need to be built into the proposals for this preparatory work. The BMA strongly supports a properly implemented soft opt-out system for Scotland.

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