

**PE1453/L**

Petitioner Letter of 7 February 2013

***...an “opt out” system would not convey any additional advantages over and above those which are already seen with the current initiatives.***

The advantages of an opt-out system over an opt-in system include:

- It changes the default position which leads to an overall change in the philosophy within society so that donation becomes seen as the usual thing to do
- It overcomes the problem of apathy whereby many people who are willing to donate never get around to doing anything about it
- The publicity that must precede a change will lead to more discussions within families and so more families knowing what their loved one wanted
- It gives protection to those who do not want to donate because the wish is formally recorded and must be acted upon
- Currently, most people who donate have not given consent, the decision is made by their family – in some of those cases where the family refuse, the individual would have been willing to donate but the organs are lost (and people are dying as a result). In some of the cases where the family agree, the individual would have objected. It is not an ideal situation.

***... any assumption or presumption of patient’s wishes would be detrimental to the doctor patient relationship.***

There is no evidence provided to support this. Nevertheless it is sometimes argued that under an opt-out system, patients may fear that doctors will see them as a ‘potential donor’ rather than a ‘patient’, and that efforts will not be made to save their lives. The same argument could be made in relation to the organ donor register, that if people are on the ODR – and thus have indicated a willingness to donate – they might be seen as potential donors rather than patients, so this concern is not exclusive to opt-out. Whatever system is in place the public needs to be reassured that there is a clear separation between the treating team and the transplant team and that all treatment decisions are made to benefit the patient.

If the legislation is introduced with public support (and the Evening Times petition demonstrates there is public support with 18,000 signatures), this should not be a problem. An opt-out system protects the human rights of the patient. Currently families are refusing consent for relatives who wished to donate. Under an opt-out system, this is less likely to happen as research shows family refusal rates are far lower.

***The national increase in the numbers of patients who have made their wishes clear in terms of organ donation by signing up to the Organ Donor Register is supportive of the idea that the “opt-in” system (as currently in place) offers significant advantages and importantly maintains patients autonomy and family independence.***

The increase in the number of people on the ODR is not reflected in the increased number of donations or transplants. There also remains a very significant difference between the number of people who say they are willing to donate organs after death and the number signed up to the ODR. Although there have been significant improvements, which are to be applauded,

there is still a serious shortage of organs and people are still dying unnecessarily. If there is more that can be done, it should be done.

Opt-out maintains patient autonomy as demonstrated in the BMA's submission.

***An "opt out" system would also carry significant costs***

The Welsh Government has looked in detail at the costs of setting up and running an opt-out system and the likely savings from the anticipated increase in the number of transplants. This is the most detailed cost-benefit analysis our Ethics Department has seen (although this is based on a combined opt-in/opt-out system proposed in Wales, rather than the opt-out standard model). Details can be found in the Explanatory Memorandum to the Bill and appendices at: <http://www.senedd.assemblywales.org/mgIssueHistoryHome.aspx?IId=5178>

Northern Ireland is also launching a consultation on opt-out, to follow Wales, which shows the measure of support for change.

***... it would be necessary to run two parallel registers, one for those patients who have opted in to being an organ donor and another for the "opt out" system.***

It is true that the situation is complicated somewhat by only part of the UK changing its legislation meaning that provision would need to be made for those who live in Scotland but die elsewhere in the UK. This need not involve two separate Scottish registers but could be achieved by allowing people to continue to sign up to the ODR if they want to donate if they die outside Scotland. If they do not want to donate, they should simply opt-out using the Scottish opt-out register.

**...the system would be complicated by patients who are visiting from other areas of the UK and elsewhere in the world who may end up sadly not surviving ICU and therefore be considered as potential organ donors.**

This is not problematic. The legislation would simply have a residency requirement for the opt-out to apply, as is proposed in Wales. If the individual has lived in Scotland for 6 months, for example, the opt-out system would apply. If they had not lived in Scotland for the specified period, the opt-out system would not apply and consent would be required from someone else (or via the ODR if they lived in England or Northern Ireland and had signed up to donation).

***The "opt in" system offers significant advantages and has been shown to provide a significant increase in organ donation over the last 5 years in Scotland generally and in Tayside specifically.***

The advantages of an opt-in system are not articulated and, in our view, there are advantages to a properly implemented opt-out system over an opt-in system (as set out above). There have been increases in the number of donors over the last 5 years but, while people are still dying at the same time as organs from willing donors are buried or cremated, it is not enough and we need to do more.

A crucial point is that moves to change the system would stimulate public debate and raise awareness of the vital importance of organ donation.

More than half the population in Scotland is not on the organ donor register. It may take decades to improve this dramatically with other methods. The Evening Times believes **everything possible** should be done to increase donation rates. Opt-Out has the potential to increase the pool of donor, simply and rapidly, and save hundreds more lives.