Transplantation (Authorisation of removal of organs etc.) (Scotland) Bill

BMA Scotland response to Health and Sport Committee

The British Medical Association (BMA) is a politically neutral professional association and independent trade union, representing doctors and medical students from all branches of medicine across the UK and supporting them to deliver the highest standards of patient care. We have a membership of over 154,000, which continues to grow each year.

1. Do you support the Bill?

Yes. We have been actively campaigning for a shift to an opt-out system for organ donation since 1999. The reasons for this can be summarised as follows:

- The BMA considers 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 the majority of people would be willing to donate organs after their death\(^1\) but only 41% of the Scottish population are on the NHS Organ Donor Register. While this low level of opt-in continues, despite people’s good intentions, people will continue to die while waiting for donor organs.

- The BMA supports the principle behind an opt-out system – that if people do not object to their organs being used after death, those organs 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.

- An opt-out system establishes a formal mechanism for those who do not wish to donate to make that view known and to ensure it will be acted upon.

- Organ donation becomes the default position which, with public support, changes cultural expectations in society. This represents a more positive view of organ donation.

2. Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland?

Yes.

We believe that an opt-out system, as one part of a broader strategy, can lead to an increase in donation rates. Huge improvements have already been made in the organisation and co-ordination of transplant services in Scotland and throughout the UK and those who have worked so hard to achieve this are to be commended. In our view, however, now is the time to build on this
success by introducing an opt-out system. We believe that an opt-out system within a well-funded and co-ordinated organ donation system presents the best opportunity to save and transform more lives.

It is notoriously difficult to extrapolate from international data but the published reviews that have taken place, including that commissioned from the University of York by the Organ Donation Taskforce in 2007\textsuperscript{2} have concluded that opt-out is one of a number of factors positively associated with increased donation rates.

In addition to the increased discussion about organ donation within individual families that accompanies an opt-out system, an important factor is the changes it brings to the overall philosophy within society where donation becomes seen as the normal and expected thing to do after death. It is difficult to see how this important and fundamental shift in attitude, which is required to maximise the potential of donation, could occur to anything like the same extent without making donation the default position.

3. **Do you support the proposal of appointing a proxy?**

We do not object, in principle, to people being able to nominate someone to take the decision on their behalf, and we recognise the benefit in having a very similar system to Wales, but we have concerns about the complexity of the message. An opt-out system relies on people being aware of, and understanding, the system so that they have genuine choice. The more complicated the message the more difficult it is to ensure that all members of society know about, and understand, their options. For this reason the model we have been arguing for is a ‘standard’ opt-out model whereby if an individual has not registered an objection and those close to the patient are not aware of any unregistered objection, the organs may be used for donation. This is a very simple message to get across. In the Welsh legislation, and this Bill, the options are: to positively opt-in to donation, to opt-out of donation, to nominate someone to make the decision for you or do nothing and your organs can be used. This is a more difficult message to get across to the public.

4. **Do you have any comments on the role of ‘authorised investigating persons’ as provided for in the Bill?**

There are clear advantages to having absolute clarity about who has responsibility for deciding that the legal criteria have been met before organs are used for donation and the introduction of an ‘authorised investigating person’ provides this. Although not set out in the legislation we assume the regulations will specify the skills, knowledge and qualifications required of this person, which will include familiarity with the legislation and accompanying guidance. Having specified people to make these decisions in each area should enable them to develop a body of knowledge and experience over time. Careful thought will need to be given to how many such posts are needed to ensure that donations are not lost because of the absence or unavailability of someone with the authority to confirm that the donation may proceed.
5. Is there anything in the Bill you would change?

We are generally very supportive of the Bill and welcome its introduction but believe there is scope for some improvement.

Publicity

The Bill appears to provide for a statutory duty to publicise the new system only in the first 6 months before implementation. The publicity needs to be ongoing to ensure that people moving to Scotland and those coming up to the age of 16 are aware that an opt-out system operates in Scotland and that they need to take action if they do not wish to donate organs. Whilst we have no doubt that this is part of the plan for implementing the legislation, we believe it should be set out on the face of the Bill so that, once the system has been operational for a number of years, there is still a recognition of the need to publicise the system.

Retaining the ability for relatives to provide authorisation

The policy memorandum accompanying the Bill appears to imply (at para 54) that the ability of a nearest relative to authorise donation will be retained and could be used if the family are keen to make a positive choice to donate, rather than rely on the operation of law provision. We are unsure of the wisdom of retaining the option for relatives, who are not nominated by the individual, to provide authorisation for donation. We understand that some relatives may take comfort from the positive act of donation, following their bereavement, but this could be seen to imply that organs donated under the opt-out system are not a ‘gift’ in the same way. This is a view that should be challenged and, over time, will change. By keeping in this provision, this myth will be perpetuated. Relatives may also argue that if they have a right to authorise, they should also have a right to refuse donation – in other words that the decision about donation rests with those close to the patient; this seems to undermine the principle of an opt-out system. In our view, it would be better to limit the role of the nearest relative in providing authorisation to cases that do not fall within the scope of the Bill i.e. those under 16 and those who are judged not to have had a reasonable opportunity to register an objection e.g. due to incapacity.

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1 Organ Donation Scotland, New survey shows Scots support for organ donation highest in UK, September 2015.