

Proposed organ and tissue donation (Scotland) Bill

Draft response from the British Medical Association

The BMA is a voluntary professional association and independent trade union and which represents doctors and medical students from all branches of medicine all over the UK. We have a membership of over 152,000 worldwide. We promote the medical and allied sciences, seek to maintain the honour and interests of the medical profession and promote the achievement of high quality healthcare.

1. The overarching purpose of my proposal is to move from the current opt-in system to an opt-out system of organ donation. Do you support this move?

Yes. The BMA has 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 a large majority of people would be willing to donate organs after their deathⁱ but only 31% of the population are on the NHS Organ Donor Register. While this level of apathy exists, 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, 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.
- 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. How essential is it to change the law (from an opt-in to a soft opt-out system) in order to achieve the intended benefits (increased transplant rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?

The BMA believes that an opt-out system should be one part of a broader strategy to increase donation rates. As has been demonstrated since the Organ Donation Taskforce report was published, changes to the infrastructure and organisational change can increase donation rates. The

BMA has always welcomed these changes and continues to support other ways of increasing donation rates, including the NHS BT's Strategy for taking organ donation to 2020ⁱⁱ and the work currently being undertaken on increasing the relative consent/authorisation rateⁱⁱⁱ. The BMA does not believe that opt-out is, or should be seen as, an alternative to these changes but rather as an integral part of an overall package of improvements. The BMA believes 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.

An important part of an opt-out system is, as mentioned in the consultation document, the changes it brings to the overall philosophy within society where donation becomes seen as the normal and expected thing to happen after death. It is difficult to see how this important and fundamental shift in attitude could occur to the same extent, without legislation introducing opt-out.

3. I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree?

Yes. The BMA believes that the role of the relatives in an opt-out system should be to act as a safeguard by reporting information about any known, unregistered objection. Nevertheless, the legislation will be permissive, providing the legal authority to proceed with donation, rather than requiring that donation takes place. The BMA believes it is appropriate that donation does not proceed if it is evident that to do so would cause severe distress to the relatives.

The role of the family in an opt-out system is very important and often misunderstood. The BMA views this process as being made up of three distinct phases:

- The register is checked and if the individual had opted out of donation, the relatives will be informed of this and donation will not proceed.
- If the individual had not opted out of donation, there will be consultation with those close to the patient to determine whether they are aware of any unregistered objection or have convincing evidence that the individual, despite not opting out, did not want to donate.
- If there is no evidence that the individual would not have wanted to donate, donation may lawfully proceed. There is scope, however, not to do so if it is evident that to proceed would cause significant additional distress to the family.

4. Do you think an individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf?

No. The BMA does not object, in principle, to people being able to nominate someone to make the decision on their behalf but we are concerned that the more complicated the message, the more difficult it is to ensure that all members of society are aware of, and understand their options. For this reason, the BMA believes that the system should be as simple as possible.

5. My proposal is that only adults should be automatically opted in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent as they currently do. This approach is I believe the best way to safeguard children and young people. Do you agree?

6. Do you agree that the age limit for an adult should be set at 16 years old?

Yes. The BMA believes that an opt-out system should apply to people over 16 years of age. This is because 16 is the age at which young people are presumed to have capacity to make decisions for themselves, including consenting to serious medical treatment. In Scotland young people are considered adults at the age of 16 and this is the age from which the Adults with Incapacity (Scotland) Act applies and so it is logical for the opt-out system to also apply at the same age.

7. Do you agree that the soft opt-out system should apply to people who have been resident in Scotland for a minimum period of 1 year prior to their death?

8. If you answered no to the above, how long if any should this period of residency last before they become subject to the soft opt-out system? Would this residency need to be for a continuous period?

9. Do you think 6 months is a long enough period to run a campaign prior to change over?

The BMA does not have particular views about how long people should have lived in Scotland before the opt-out system applies to them and, in some ways, it is difficult to specify a period of time without knowing what the initial and ongoing mechanisms will be for informing people about the new system. The crucial factor is that individuals are aware of the system and know what they need to do if they wish to opt-out before it applies to them. How long this will take will depend on the frequency, nature and mode of delivery of information and education campaigns.

The period of residency was extended from six to twelve months during the passage of the Human Transplantation (Wales) Act 2013 and this seems to be a reasonable period.

10. What is your assessment of the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?

There will be no financial implications to the BMA if the Bill is passed. We would, however, encourage the Scottish Government to give advance

thought to the likely impact on resources of more donors becoming available, to ensure that these additional donors are able to translate into additional transplants in order to maximise the benefits arising from the new legislation.

- 11. Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?**

The BMA is not aware of any implications of the Bill for equality.

- 12. Do you have any other comments on or suggestions relevant to the proposal?**

The BMA believes that careful consideration needs to be given to the position regarding patients who lack capacity. Most, if not all, patients will lack capacity in the period leading up to their death but would still expect their earlier decision not to opt out of donation to be acted upon. In the BMA's view, the important factor is whether the individual has had capacity for a sufficient period since the legislation was passed to know and understand its provisions and to take steps to opt-out if that is his or her wish. For consistency, the period for which they are required to have had capacity, since the legislation came into force, could be the same as the period of residency.

The Welsh legislation takes a different approach. It excludes adults who have lacked capacity 'for a reasonable period of time' before their death. The BMA argued, unsuccessfully, for this to be changed during the passage of the Bill. The legislation will be in force for many years. Consider a man who is 20 when the legislation comes into force and wants to donate, so decides not to opt-out. He loses capacity at the age of 40 - as a result of an accident - and dies two years later. Under the Welsh legislation, it does not appear that his consent will be deemed (as he expected and wanted) even though he was aware of the legislation for the 20 years he had capacity (while was legislation was in force) and chose not to opt-out. This issue will require careful consideration to refer to the period of time individuals had capacity since the legislation came into force rather than how long they have lacked capacity.

The following comments are on the consultation document itself rather than on the questions.

Context to the proposal

2) A small point but 'circulatory death' is now the preferred term, rather than 'cardiac' death

Also it is unfortunate that this does not make clear that these are patients in whom it has been decided, because of the severity of their condition, that continuing treatment is no longer in the patients' best

interests. Treatment is withdrawn and then the patient dies. Death is confirmed by a series of cardio-respiratory tests. The wording is confusing saying they 'have died' but are 'not quite brain stem dead'. The two sets of tests are simply different ways of diagnosing death - in both cases the patient is dead.

3) A large number of living donors are friends or partners, who are emotionally close but not genetically related.

Current law regarding organ donation

Penultimate para: Most donors have not made a positive decision to opt-in to donation under the current system but consent is given by a third party based either on their knowledge, or 'best guess' of what the deceased wanted.

Last sentence: Third party consent is also required, under the Welsh legislation, if the deceased was under 18 or had lacked capacity for a 'reasonable period of time' before death.

Opt-in or opt-out

Para 2: We are not aware that family members provide information about the donor's 'character' except, perhaps where the individual's views about donation are unknown and there is discussion to try to determine what he or she would want. Later in the document there is reference to families providing information about 'medical history' which is an important role of the family that is not mentioned here.

Para 3: As above, there are many cases where organs are removed without the individual's explicit consent because a third party is legally able to give authorisation.

Scale of the issue

The point at para 3 that the waiting list has reduced by 12% from 2009/10 to 2013/14 appears to contradict the point in the previous para that waiting lists have been increasing by 5% a year.

Role of the family

At various points in this section there is reference to the family being asked for consent under the new opt-out system. It is clear, however, that they are not being asked for consent but are being asked about any unregistered objection.

ⁱ NHS Blood and Transplant (2013), Summary of market research findings (available at: www.organdonation.nhs.uk)

ⁱⁱ NHS Blood and Transplant (2013) *Taking organ transplantation to 2020 - a UK strategy*, NHS BT, London

ⁱⁱⁱ NHS Blood and Transplant News release, *NHS Blood and Transplant tackles consent rates in order to rival the deceased organ donation records of the best countries in the world*, 28 April 2014.