Organ and Tissue Donation and Transplantation: A consultation on increasing numbers of successful donations

Response from the British Medical Association

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.

As an Association, we have a longstanding interest in public policy on organ donation and transplantation and have published two major reports on the topic. Our most recent report, Building on Progress: Where next for organ donation policy in the UK? was published in 2012 and can be found here.

We welcome the opportunity to respond to this consultation and, in particular, to contribute to debate about the introduction of an opt-out system for organ donation in Scotland, which we strongly support. We hope the information below is useful and would be very happy to provide any further information that may be helpful.

Chapter 1 - Increasing authorisation for organ and tissue donation

Question 1 – what do you think of the principle of a soft opt out system for Scotland?

We strongly support the principle of a soft opt-out system for Scotland. We believe that, when properly introduced – as part of a broader strategy for donation – with sufficient publicity, this will increase donation rates as well as respecting the wishes and autonomy of those who donate. Moreover, and importantly, over a period of time an opt-out system will lead to a change in the overall philosophy within society so that donation is seen as a positive and natural thing to do when someone dies.

Our support for a ‘soft’ opt-out system is based on the following points:

- 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 strong support for organ donation amongst the public but less than half of the Scottish population has registered on the organ donor register. An opt-out system will help to overcome this disparity and make it easier for those who are willing to donate - but never get around to signing up to the register - to have their wishes respected.
- We support 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. The decision not to opt out of donation is as much of a ‘gift’ as a decision to opt in.
- Under an opt-out system, 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 very likely to reduce the 43% of families who object to donation when approached.
**Question 2 – are there any changes you would make to the current opt-in authorisation system, other than moving to opt-out?**

Huge advances have been made with organ donation in Scotland and those responsible should be congratulated. All of the current and proposed initiatives listed in the paper should be continued and developed irrespective of the authorisation system in place, although their focus may be slightly different. So, for example, work on awareness campaigns, the need for those approaching families to have specific training, work with BAME communities, education in schools and attempts to expedite the donation process, are all important initiatives that should be continued.

In addition, if there is not to be a shift to an opt-out system, then other ways to reduce the relative refusal rate will need to be found. Where the individual’s views are unknown – and the default position is not to donate – it is understandable that some relatives may be reluctant to make what they perceive to be a very significant decision at a time when they are trying coming to terms with the death of a loved one and are likely to be very distressed and possibly in shock. It is less easy to understand the motivation of those who know that the individual wanted to donate yet their decision is to go against those wishes. Scotland is already leading the way on this issue by asking relatives to sign a form when they seek to override the stated wishes of the deceased – to emphasise the seriousness of the decision – but clearly this is not enough. This is an area where further research is needed to understand the reasons why relatives refuse authorisation and to identify ways to overcome their concerns.

**Question 3 – where someone has joined the Organ Donor Register (ODR) or indicated in another way that they wish to donate, what do you think should happen if the potential donor’s family opposes the donation?**

We believe that the individual donor’s views should take precedence and that every effort should be made to encourage the family to respect those wishes. Nevertheless, we accept that in some, exceptional, cases it may not be appropriate to proceed with donation even where the legal authorisation is in place.

In the past the family have been asked to agree to donation even where authorisation has already been provided by the individual prior to death. This gives the impression that the decision is the family’s to make – it is not. Where legal authorisation is in place, no further authorisation is needed. In such cases, the family should be informed of the individual’s decision and the expectation should be that donation will proceed where that is medically possible. If the family then raise objections, a trained specialist nurse for organ donation (SNOD) and/or clinician should discuss this with them and strongly encourage them to respect the donor’s wishes. If, despite this, the family continue to object and it is clear that going ahead, against their strong and sustained wishes, would cause significant additional distress to the family, a decision might be made not to proceed. There are a number of reasons for taking this approach:

- Our members believe they have a duty of care towards those who are recently bereaved and are very concerned about adding to their existing distress.

- The transplant team will need the co-operation of the family, in order to obtain the information needed about the donor’s history and this is far less likely to be provided where the relationship between the health care team and relatives is a confrontational one.
• From a pragmatic perspective, the ill feeling that would follow the donation of organs against the strong and sustained opposition of the family, is likely to generate bad publicity and possibly hostility towards the organ donation programme more generally. As we know, a few negative headlines in the popular media can cause considerable, and sometimes long-term, damage to the organ donation programme.

Wherever possible we should be trying to avoid this situation arising. So, through public awareness, we need to encourage people to talk about organ donation with their loved ones and to stress the importance of ensuring that their relatives know that they want to donate. That way, there is a good chance that any concern or disagreement can be resolved while the individual is alive and can talk about their wishes and make clear how strongly they feel about it.

In our view, the same approach should be taken irrespective of the authorisation system in place and so a similar process would be followed under an opt-out system whether the donor has explicitly opted in to donation (if the system permits this) or has decided to donate by not opting out.

Question 4 – if there was a soft opt out system, what do you think of the proposed checks above?

Question 4(a) if you think these are not sufficient, what other checks would be need (apart from those set out under step 3 below)?

We consider the proposed checks to be sensible and comprehensive. They are similar to those that operate in other countries, including Wales where there was a lot of discussion about how these principles should translate into practice.

Question 5 – in any opt out system what do you think should happen if a deemed authorisation donation was likely to distress the potential donor’s family?

As set out in detail in question 3, we believe that families should be strongly encouraged to support the individual’s wish to donate (expressed either by opting into, or by not opting out of, donation) but that there should be discretion not to proceed if it becomes evident that to do so would cause significant additional distress to the family. We have always argued that the threshold should be ‘significant’ additional distress rather than simply ‘distress’ but the decision as to whether to proceed will always be for the specialist team to make based on the individual circumstances and their judgement at the time.

Question 6 – if there was a soft opt out system, what do you think about the categories of people set out above for whom explicit authorisation would still be needed from the person themselves or family member?

Question 6(a) if these are not sufficient, why do you think this?

The important principle behind any opt out system is that the population to which it applies are aware that the system is in operation and have a genuine opportunity to opt out if they do not want
to donate. This should guide the thinking behind who is excluded such that explicit authorisation continues to be required. The three categories identified in the paper:

- those who lack capacity to understand and/or decide (but see comments under question 7);
- children; and
- those who are new to the area and so may not be aware that an opt out system applies;

appear to cover those who may not be sufficiently aware of the system to have had a genuine opportunity to opt out. We therefore support the requirement for explicit consent by, or on behalf of, those who fall into one of these categories. We are not aware of any other categories of people who should be excluded from the deemed consent process.

**Question 7 – in what circumstances do you think an adult should be viewed as not having the capacity to make their own decisions about donation and therefore should not be subject to any deemed authorisation provisions?**

As mentioned in our response to question 6, in our view the principle for deciding who should be excluded is to ensure that everyone whose consent may be deemed is aware of the system and has had an opportunity to opt out if that is their wish. In terms of capacity, therefore, we believe it should be the length of time that someone has had capacity since the new system is implemented that is relevant, rather than the amount of time they have lacked capacity in the period leading up to their death as suggested in the paper.

Consider a man who is 20 when the legislation comes into force and wants to donate, so is happy for his consent to be deemed. He loses capacity at the age of 40 –as a result of an accident – and dies 2 years later. If it is the amount of time he lacked capacity that was relevant, consent would not be deemed but it is highly questionable whether that would reflect his wishes, given the amount of time he had to opt-out if that had been his wish.

It has been suggested by some (including in the debate in Wales) that a prior decision cannot be relied upon because the individual might have chosen to opt out during their period of incapacity. This is meaningless because, by definition, individuals who lack capacity cannot make and communicate decisions. It is also unclear why the same argument is not made in respect of those who have opted in to donation, where subsequent incapacity is considered irrelevant.

**Question 8 – under what age do you think children should only be donors with explicit authorisation?**

We have generally taken the view that an opt-out system should apply from the age of 16 and under that age explicit authorisation should be required. This is because, at 16, we believe it is reasonable to assume those covered will have seen the publicity about the new system, be able to fully understand the implications of it for them as an individual and act on it by opting out if that is their wish. There may be an argument for reducing this age to 12, in Scotland, if it were possible to be confident that, through the schools education policy, all pupils, by the age of 12, had received information about donation, combined with a clear explanation of how the system applies to them and what they should do if they do not want to donate. This would require the consistent provision of more comprehensive information about organ donation in primary rather than secondary schools.
**Question 9 – for children who are in care, what are your views on allowing a local authority which has parental responsibilities and rights for the child to authorise donation for the child if no parent is available?**

Through public awareness campaigns, and with more information being provided in schools, young people will increasingly have thought about, and voiced opinions on, organ donation, even if they have not gone so far as to register a wish to donate on the organ donor register. As a general principle, and as far as possible, steps should be taken to facilitate those wishes.

We can therefore see no reason to include an absolute prohibition on allowing local authorities, with parental responsibility, to authorise donation. As with all other cases, legal authorisation does not mean that donation must proceed and it will be a matter for the specialist team to assess the situation and decide whether donation is appropriate. If, for example, the young person had discussed donation with those providing care and it was known that he or she was keen to donate organs after death, it would be unfortunate if this wish could not be respected because of this rule.

Currently, under the Human Tissue (Scotland) Act 2006 only the individual him or herself or someone with parental responsibility (other than a local authority) can provide the necessary authorisation for donation. We can see no reason why an older sibling, grandparent or other close relative could not provide the required authorisation to permit donation to proceed if the parents are not available (if, for example, the child and parents were all in a car accident and the parents did not have capacity at the time authorisation was needed).

**Question 10 – in any opt out system, what provisions do you think should apply to the less common types of organs and tissues?**

Deemed authorisation should only apply to more common types of organs or tissue and explicit authorisation should continue to be required for new, or unusual, types of donation. As in Wales, it would be helpful for those organs and tissues that are not covered by the system to be set out in Regulations so that the list can be updated as and when new options become available. It is important that this restriction is widely publicised. If the public are not aware that the opt-out system does not apply, and there is media coverage of a new development in transplantation (hand, face, uterus etc), individuals may be prompted to opt out of all donation for fear that they may be deemed to have authorised donation of these organs/tissue.

**Question 11 – which tests do you think medical staff should be able to carry out on a donor before they withdraw life-sustaining treatment to check if their organs or tissue are safe to transplant, both where a patient’s authorisation for donation is ‘deemed’, as well as where the donation is explicitly authorised:**

As a general rule we believe that deemed authorisation should be regarded in the same way, and as legitimate, as explicit authorisation and so whatever tests are permitted should be permitted for all relevant, potential donors.

Our view has always been that where authorisation has been provided for donation, this includes authorisation for some tests that are required or desirable to facilitate that process but which are not part of the patient’s standard medical care This might include blood or urine tests, or the type of
tests listed on page 23-3 of the consultation paper where they may elicit useful information, provided that, in each case, they are minimally invasive and are not harmful to, or risky for, the patient. The justification for intervening in these cases is threefold:

- it benefits patients to facilitate their wish to donate organs;
- their authorisation (or decision not to opt out) can be seen to incorporate authorisation for the necessary steps to fulfil that objective and to make the donation as successful as possible; and
- provided there is no harm to the patient and considerable benefit to others (ie the potential recipients) such action is justified.

In considering this issue, we have found it helpful to use the concept of actions not being contrary to the patient’s interests but we accept that this has not been adopted by the courts.

We note that consideration is being given to expanding the information provided to those who are considering their views on organ donation, about the type of tests that might be required to facilitate donation. We would support such a move provided the information is short and to the point so that people are not deterred from signing up by the sheer volume of information to read.

**Question 12 – if you answered no to some or all options in question 11, are there any circumstances when particular tests could be permitted?**

Not applicable.

**Question 13 – where it is agreed a patient’s condition is unsurvivable and it will not cause any discomfort to them, what do you think about medical staff being allowed to provide any forms of medication to a donor before their death in order to improve the chances of their organs being successfully transplanted, such as providing antibiotics to treat an infection or increasing the dose a drug that the patient has already been given?**

In the past we have supported, in principle, the initiation or continuation of some treatments that would usually be withdrawn, or not considered necessary, in order to maximise the chance of a successful donation. This general view is subject to the same provisos as set out in question 11, above – that any intervention must be minimally invasive and must not be harmful or expose the patient to risks.

It is important that each proposed intervention is therefore carefully assessed to ensure that there are no risks or disadvantages for the patient. Whilst it is important to maintain and increase donation rates, the primary focus must remain on the care and wellbeing of the dying patient irrespective of whether, or not, they may go on to donate organs. Harm to the patient may be broader than physical harm – delaying the dying process for example may, in some cases, be a harm to the individual and may be distressing for the patient’s family.

Thought would need to be given to the information to be provided to families when treatments are continued or commenced to facilitate donation rather than for the benefit of the patient. As in other situations, honesty and transparency should be the guiding principles in this respect. It is important that those close to the patient understand that giving, or continuing, treatment does not indicate that recovery might be expected. In some cases families may object to what they perceive to be a
changing focus in the patient’s care and this should be discussed with them. In some cases, if the family are very distressed by this change, it might be decided that the medication should not be provided, even if this might impact on the success of the donation process.

Question 14 – what do you think about allowing people to appoint one or more authorised representatives to make decisions for them?

We do not object, in principle, to people being able to nominate an individual to make decisions on their behalf but agree with the paper that it is likely to be an unnecessary complication. Our main concern about nominating an individual, as part of an opt-out system (as in Wales), is that it complicates the message. We have always argued that making sure that the public knows about, and understands, the process is crucial to the success of any opt-out system. The more complicated the message, the more difficult this will be to achieve. We would, therefore, favour an opt-out system where people can choose to opt in, opt out or do nothing and have their authorisation deemed. In the latter situation, as an added safeguard, those close to the patient should be asked if they are aware of any unregistered objection. As with the current system, the legislation would be permissive: it would allow donation to take place but not require it. There would, therefore, be scope not to proceed if it became evident that donation would cause significant additional distress to those close to the patient.

Question 14(a) – if you think this should be allowed, in what circumstances do you think an authorised representative would be useful?

Not applicable.

Question 15 – do you have any other comments which you think should be taken into account in relation to any Scottish opt out system?

One of the major concerns about the introduction of an opt-out system in the UK has been the risk of a ‘back-lash’ with large numbers of people opting out of donation, as a protest. Despite high levels of awareness of the change in Wales this has not materialised and only around 6% of the population has opted out.

A recent BMA survey found that two thirds of respondents (65 per cent) support a ‘soft’ opt-out organ donation system. The survey, which questioned 2011 members of the public in Northern Ireland, Scotland and England (it did not include Wales as a soft opt-out system has already been introduced there), also found that while two out of three respondents (66%) wanted to donate their organs at death only a third (39%) were signed up to the organ donation register.

186 of the respondents were from Scotland. 70% of these were willing to donate all or some of their organs, whilst only 45% were registered on the organ donor register (ODR). 68% of Scottish respondents were supportive of a soft opt out organ donation system.

The early signs from Wales are positive, in terms of the number of organs available for donation. We acknowledge, however, that the numbers are small and the system is relatively new so it is difficult to draw too many firm conclusions from this. It is also important to bear in mind that one of the major benefits of an opt-out system is a shift to a more positive overall view of donation within society and this will only be evident after a period of time.
Chapter 2 – increasing numbers of people considered as potential organ and tissue donors

Question 16 – what do you think about providing CMO guidance to encourage clinicians to refer almost all dying or recently deceased patients – particularly those under 85 years old – for consideration as a potential organ or tissue donor?

We support this proposal that the CMO should provide guidance designed to encourage clinicians to refer almost all dying or recently deceased patients to the specialist nurse for organ donation (SNOD) or tissue donation co-ordinator (TDC) for assessment as to suitability for donation. Referral should not, however, be made until the patient with capacity, or those close to people who lack capacity, have been informed of the prognosis and discussions have begun about end of life care. It would be inappropriate for the first mention of dying to come from the specialist nurse, rather than from the treating team.

Our view is that donation should be seen as a responsibility of all health professionals, not just those who are part of the specialist transplant team. All health professionals who are caring for dying patients should see it as part of their duty of care to their patients to facilitate their wishes about donation wherever that is a possibility (this applies whether the individual’s wish to donate is expressed by opting into donation or, under an opt-out system, by choosing not to opt out). Where the individual’s views are not known, the SNOD/TDC should be informed of the patient’s condition to enable the organ donor register to be checked.

It is, in our view, appropriate that where a patient is not referred – where donation would have been a possibility – the circumstances should be reviewed to identify what lessons can be learnt and whether some staff, or teams, require additional information or training or whether the systems in place need revising.

Question 17 – what do you think about making it a procedural requirement for clinicians to involve a specialist nurse for organ donation, tissue donor co-ordinator, or another individual with appropriate training in approaches to families about donation, wherever that is feasible?

The way in which the approach to relatives is handled can have a significant impact on the likelihood of the family agreeing to donation but also, and importantly, on the wellbeing of the family in the longer term. It is essential that those conducting these discussions are sensitive to the situation and the needs of the family and ideally have had training in bereavement support. They also need to be sufficiently knowledgeable about the process to provide information in an easily understandable way, and answer any questions, bearing in mind that families in this situation are likely to be very distressed. For this reason, we would strongly support a requirement that, wherever feasible, the approach about organ donation is made by a SNOD/TDC or another person with equivalent knowledge and expertise and who has had explicit training in managing these difficult conversations. As mentioned above, however, this discussion should take place only once the treating team have had an initial discussion with the patient (or those close to patients who lack capacity) about dying – this information should not be mentioned for the first time by the specialist nurse for organ donation.
**Question 18** – do you think there are particular impacts or implications for any equalities groups from any of the proposals in this consultation, either positive or negative? If yes, please provide details.

We believe, if implemented, the proposals for an opt-out system will have a positive impact on those with disabilities who are waiting for a transplant because we would expect such a change to increase the number of organs available for donation.

Thought will need to be given to ensuring that information about the change to an opt-out system reaches all sections of society including those groups that are traditionally difficult to reach. Information must be made available in different languages and formats to ensure that the information is accessible to everyone irrespective of their situation.

British Medical Association
March 2017