

Scottish Government: Organ and Tissue Donation and Transplantation - a consultation on increasing numbers of successful donations

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

- I support the principle of a soft opt out system in Scotland
- ~~- I do not support the principle of a soft opt out system~~

The College supports this move in principle, provided there is a parallel process of public education about the benefits of organ donation and improved infrastructure to support families and clinical teams at the time of organ donation. The College has sought the input of Fellows in a variety of medical specialties and a wide range of views have been submitted, and it is important to note that unanimity has not been reached on several issues.

Some Fellows have expressed the view that there are a number of individuals who would be donors but have not made that view known before their death. The move to a soft opt out system would therefore likely make a small but real difference to the number of organs donated in Scotland, when implemented alongside other initiatives.

The available international evidence supports the fact that ‘opt out’ legislation is associated with increased rates of deceased organ donation. However, the legislation itself may not be the major determining factor for organ donation as some countries with “opt in” systems still have higher organ donation rates than countries which have adopted “opt out” legislation. There are differing opinions within the medical profession and society at large regarding an ‘opt out’ system. Some believe that “opt out” legislation effectively means acquisition by the State of organs, and removal of the altruistic aspect of donation is of real concern to some of our Fellows, who feel that bereaved families take great solace from an active act of giving. These and other ethical issues have prevented the global adoption of presumed consent legislation.

However, the higher rate of organ donation in ‘opt out’ jurisdictions persists even when the next of kin are still asked for their approval before retrieval (this is termed ‘soft’ opt out as opposed to ‘hard’ opt out when the relatives are not consulted).

A higher rate of organ donation will reflect increased public awareness, societal attitudinal change to donation, and improved clinical infrastructure.

Question 2 – are there any changes you would make to the current ‘opt in’ authorisation system, other than moving to opt out?

Considerable investment in terms of time and resource needs to be spent on continuing public education and improved infrastructure to support families and clinical teams, both in the current “opt in” authorisation system and in the circumstances of a move to “opt out”.

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?

- ~~- medical staff should still proceed with the donation~~
- medical staff should not proceed with the donation

Public confidence in a soft opt out system would be quickly undermined if family did not continue to play a key role in decision making. Clinicians could be placed in the very difficult position of harvesting organs in the face of explicit opposition from immediate family members and which could undermine confidence in medical teams. The family should always be consulted about the request to harvest organs and asked about the expressed wishes of the deceased.

Proceeding with organ or tissue donation against the wishes of grieving relatives in this situation would seem likely to lead to a very damaging breakdown in relationships and loss of trust between relatives and the public on the one hand, and the organ donation team and the wider medical profession on the other.

The role of the Specialist Nurse for Organ Donation (SNOD) is key in circumstances such as this to provide sensitive assistance and support to the potential donor's family and ensure that communication remains open and transparent.

Question 4 – if there was a soft opt out system, what do you think of the proposed checks set out in step 2 (on pages 14 to 15)?

- these are sufficient to decide if a donation can be deemed to be authorised
- ~~- these are not sufficient to decide if a donation can be deemed to be authorised~~
- ~~- don't know~~

The outlined checks appear to be simple, clear and logical.

Question 4(a) - if you think these are not sufficient, what other checks would be needed (apart from those covered in questions 6 to 8 below)?

Not applicable

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?

- ~~- the donation should still proceed~~
- the donation should not proceed
- don't know

As described in the response to question 3, this is a very difficult situation for clinical teams to face, and there is wide support for family to continue to play a key role in decision making. If despite the best efforts of all involved, donation was to cause distress it should not go ahead – and this is probably the strongest argument for not changing the law, since the situation would in effect be little different from what happens now.

Question 6 – if there was a soft opt out system, what do you think about the categories of people set out under step 3 (pages 15 to 17) for whom explicit authorisation would still be needed from the person themselves or family member?

- the categories above are sufficient
- ~~- the categories above are not sufficient~~
- ~~- don't know~~

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

Not applicable

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?

The general principles of capacity for consent should apply as in other situations, as covered by the Adults with Incapacity (Scotland) Act.

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

- ~~- under 12~~
- ~~- under 16~~
- ~~- under 18~~
- other (please specify)

Undecided. There are shades of opinion on this issue given that patients under 18 are able to give informed consent for other medical procedures. However, a more explicit “opt in” approach may be helpful for those under 18, particularly as it is likely to be their parents who are asked for consent to harvest organs.

Question 9 – for children who are in care, what are your views on allowing a local authority which has parental responsibilities and rights for a child to authorise donation for the child if no parent is available?

- ~~- they should be allowed to authorise donation of a child's organs or tissue in those circumstances~~
- they should not be allowed to authorise donation of a child's organs or tissue
- ~~- don't know~~

Fellows expressed concern and urged caution about ceding this responsibility to a local authority.

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

- deemed authorisation provisions should only apply to the more common organs and tissue (kidneys, liver, pancreas, heart/heart valves, lungs, small bowel and stomach, tendons, skin, corneas, bone)
- ~~- deemed authorisation provisions should apply to all organs and tissue~~

Some Fellows have suggested that rare and novel organ donation, as well as donation for research, should be excluded in a similar way to the Welsh system. Donation of a limb or a face particularly seems likely to elicit a much more powerful emotive response and would need to have a separate debate to clarify the public's views before considering it under a soft opt-out system.

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:

a) Blood tests? - for tissue typing to find a good recipient match, to detect any infections, such as HIV or Hepatitis, or for testing the patient's blood gases to check how well the lungs function;

- yes
- ~~-no~~
- ~~-don't know~~

b) Urine tests? - to check if the patient has any infections;

- yes
- ~~-no~~
- ~~-don't know~~

c) X rays? - to check for any undiagnosed medical problems;

- yes
- ~~-no~~
- ~~-don't know~~

d) Tests on a sample of chest secretions? - taken via a tube to test how well the lungs function.

Chest secretions are often removed from patients in Intensive Care as part of their treatment to help make them more comfortable so would be removed anyway as part of their care – this would therefore involve testing samples of the secretions that have been removed;

- yes
- ~~-no~~
- ~~-don't know~~

e) Tests on the heart such as an ECG (electrocardiogram) or ECHO (echocardiogram)19? – these tests check if the heart is functioning well.

- yes
- ~~-no~~
- ~~-don't know~~

Allowing more tests and treatments would seem to be positive, in general, by allowing the patients presumed wishes, i.e. to donate organs in this situation, to be followed. They are likely to have already had several similar tests and treatments and provided they cause no or minimal distress the addition of a small number of further interventions would be justified.

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

- if the person had previously made clear they wished to be a donor
- if the donor's family provided consent on the donor's behalf
- such tests should never be permitted before death

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 of a drug the patient has already been given?

- ~~- they should be able to provide such forms of treatment~~
- they should be able to provide such treatment, but only where the donor's family provides consent
- ~~- they should not be able to provide any such treatment just to help the donation~~

Fellows felt that this would depend on the discussions with the potential donor's family. While the treatments or medication provided cause no discomfort, they may change the time line of the dying process, and in general our Fellows would be uncomfortable with altering this process without the support of the family.

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

- ~~- this should be allowed~~
- this is not necessary
- ~~- don't know~~

Nomination of one or more authorised representatives appears to be unnecessary and its introduction could cause excessive complication, time delay and bureaucracy.

Consideration should be given to the time that it would take to contact representative(s) and the reliability of the database on which the contact information will be kept. If someone is unaware that they have been nominated as a representative, that could also add to the time problem. Concerns were also raised by Fellows that the appointment of a representative could cause disagreement and conflict between representatives and family members, which could lead to distress to the families, the representatives and to clinical staff.

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?

The College wishes to reiterate the view of our Fellows that a higher rate of organ donation will

reflect increased public awareness, societal attitudinal change to donation, and improved clinical infrastructure.

In terms of infrastructure, for example, Fellows have described situations where there is a loss of potential donated organs due to surgical considerations. There are occasions where transplantation is unable to proceed because there is a lack of retrieval or a transplant surgical team, because they are already operating on other patients. Some emphasis should therefore be placed on identifying areas of improvement on the transplant side.

Question 16 – what do you think about providing Chief Medical Officer (CMO) guidance to encourage clinicians to refer almost all dying or recently deceased patients for consideration as a potential organ or tissue donor?

- CMO guidance should be provided to encourage more referrals
- ~~- CMO guidance should not be provided~~
- ~~- other (please specify)~~

There was support for the introduction of guidance with the addition of a formal assessment of its impact, in terms of successful organ donation and resource spent (in terms of clinical time) in achieving donation. This would help to raise the profile of organ donation and keep it in the forefront of clinicians' minds.

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

- this should be a requirement
- ~~- this should not be a requirement~~
- ~~- don't know~~

In principle, Fellows felt that this should be a requirement; however there was concern over the considerable resources required in order to make this a reality.

Fellows reported from their clinical experience that this could be challenging in terms of delaying discussions. Sometimes there is no SNOD available as they are dealing with another donor. This could result in lost opportunities. If this became a procedural requirement, adequate SNOD staffing and resource would require to be guaranteed.

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.

The publicity around the information campaign referred to would need to consider those unable to read; those with little or no English language and those who are less likely to engage with these issues due to personal circumstances.