

Consultation on Organ and Tissue Donation and Transplantation

RESPONDENT INFORMATION FORM

Please Note this form **must** be completed and returned with your response.

Are you responding as an individual or an organisation?

- Individual
 Organisation

Full name or organisation's name

Humanist Society Scotland

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The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

- Publish response with name
 Publish response only (anonymous) – Individuals only
 Do not publish response

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

- Yes
 No

List of Questions

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

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

As Humanists we value the autonomy of an individual over their own body and beliefs. No person should be subject to decisions based on another individual’s religious or spiritual life stance.

It can be a cause of concern to many of our members that their express wishes in relation to Organ Donation or whole body donation, can be overturned after their death.

We support allowing easier registration for organ donation through third parties such as Solicitors when making wills, or organisations that offer advance wishes support.

Greater weight should be given to clear advance wishes expressed prior to death whether that be in a will, through organ donation registration or any other formally agreed procedure.

In that event the burden of proof should fall on the family member or friend who opposes the donor’s choice, to demonstrate grounds for their opposition that could not have been accounted for at the time of the individuals advance wishes being made known.

Many people may simply express a preference and not wish their choice to cause distress for their loved ones. An **optional** distress clause could apply where the potential donor may express that, in the event that Organ Donation causes distress to their next of kin, then they would be content for the family to refuse consent.

This would therefore provide grounds for refusal to be agreed in advance by the donor and ensure they retain autonomy over their own body.

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

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

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)?

Efforts should be made to ascertain the person's view on the impact of distress on the family at time of registration or when expressing their view on donation. This should not be left to the interpretation of NHS staff alone.

If they express the view that they would like to become a donor in all circumstances then the donation should proceed.

Where a person had expressed no view on the impact of distress it should proceed as set out in step 2.

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

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?

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 threshold should be in line with existing frameworks for assessing adults and incapacity. People should be treated consistently and no assumption should be made the Organ Donation requires a higher or lower threshold than is currently accommodated for in other areas of Scots Law.

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)

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

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

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]¹?** – these tests check if the heart is functioning well.
 - yes
 - no
 - don’t know

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

¹ Currently in Scotland these tests are not required for DCD patients as hearts are only donated by patients diagnosed as brain-stem dead. However, DCD heart donation has been trialled in some hospitals in England and might potentially be extended to include some Scottish donors in future.

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[20]²?

- 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

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

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

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

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)

² For example, a patient may be given a drug such as Noradrenaline to improve their blood pressure – maintaining or increasing the dose of this after the decision has been taken to withdraw life sustaining treatment will help improve the blood flow to the organs. If antibiotics are used to treat an infection which the donor has, that will help mitigate any impact of the infection on the organ transplant recipient(s)

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

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 current system still provides the opportunity for the wishes of Humanists to be overridden on the basis of the religious views of their family. The system should allow equally for people expressing a non-religious life stance to have their views respected equally with those of their family and friends.

CONSULTATION INFO:

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Deadline: 7 Dec 2016 to 14 Mar 2017

Web: <https://consult.scotland.gov.uk/health-protection/organ-and-tissue-donation-and-transplantation>