



Organ and Tissue Donation and Transplantation
Response from the Scottish Council of Jewish Communities

The Scottish Council of Jewish Communities (SCoJeC) is the representative body of all the Jewish communities in Scotland. SCoJeC advances public understanding about the Jewish religion, culture and community, by providing information and assistance to educational, health, and welfare organisations, representing the Jewish community in Scotland to Government and other statutory and official bodies, and liaising with Ministers, MSPs, Churches, Trades Unions, and others on matters affecting the Jewish community. SCoJeC also provides a support network for the smaller communities and for individuals and families who live outwith any Jewish community or are not connected with any Jewish communities, and assists organisations within the Scottish Jewish community to comply with various regulatory requirements. SCoJeC also promotes dialogue and understanding between the Jewish community and other communities in Scotland, and works in partnership with other organisations and stakeholders to promote equality, good relations, and understanding among community groups.

In preparing this response we have consulted widely among members of the Scottish Jewish community, and this response reflects the views of all branches of Judaism that have communities in Scotland.

The Jewish Community in Scotland

The majority of the Jewish community in Scotland is affiliated to Orthodox Judaism, which has three synagogues in Glasgow, and one in each of Edinburgh and Aberdeen. In addition there is a Reform Synagogue in Glasgow, a Liberal Jewish community in Edinburgh, and an unaffiliated Synagogue in Dundee. There are also several welfare organisations, including organisations providing care services to people with chronic, life-shortening, and terminal illnesses or conditions.

The Jewish Community's view of organ donation

All branches of the Jewish community in Scotland are strongly supportive of organ donation and transplantation.

Jewish religious law regards human life as sacrosanct and all human life is regarded as of equal value, even in its terminal stages. The requirement to save life is central to Jewish belief – the Talmud states that "one who saves a single life is regarded as if he had saved the whole world", and almost all other religious obligations must (not "may") be set aside in order to do so. For this reason, organ donation is regarded not only as permissible but praiseworthy. However one of the three exceptions to the above rule is that it is not permissible to take one life even in order to save another. Consequently it would not be permissible to carry out any medical procedures preparatory to removing

organs for donation if these might hasten death. The definition of death is, therefore, important, the more particularly since this differs in some respects between some interpretations of Jewish religious law (*halachah*) and current medical opinion.

It should be noted that although there are organisations supported by many Rabbis that seek to facilitate both live and cadaveric donation in a manner that is in accordance with the relevant requirements of Jewish religious law, these organisations are not based in Scotland (or the UK), and thus the way that their systems operate may not be directly transferable into our community.

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

There is a variety of opinions in the Jewish community about a soft opt-out system. In general, the Orthodox Jewish community is concerned that an opt-out system would unnecessarily limit the number of donors, since some people who did not in principle object to donating their organs, would inevitably opt out of such a system from a fear that it risked contravening Jewish religious law. The Orthodox community therefore supports the continuation of the current opt-in system in conjunction with a proactive education campaign to encourage potential donors to register, and bereaved families to consent to donate their relative's organs.

Reform Judaism is leaning towards favouring an opt-out system but currently has no official position amongst all of its rabbis. It maintains its absolute support of organ donation.

In principle, the Liberal Jewish community is strongly in favour of an opt-out system, but supports delaying legislation until it is known how the new system is working in Wales, and whether or not it is providing the intended benefits.

All these Jewish groups would concur that Specialist Nurses for Organ Donation should have training about faith community needs and should have information how to access communities (including burial societies) and religious authorities with any queries.

2. Are there any changes you would make to the current 'opt in' authorisation system, other than moving to opt out?

All branches of the Jewish community would strongly support focused publicity campaigns to explain and encourage organ donation. The consultation paper describes a scheme to train people from "minority ethnic backgrounds to become peer educators to increase awareness ... and promote organ donation" (page 7), and we would welcome the development of a similar programme for faith communities.

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

This is clearly a very difficult and complex situation, and we do not believe that a single rule should necessarily apply in all cases. It is very important to respect the wishes of someone who hopes potentially to save lives by donating his or her organs. Saving

someone's life by means of an organ transplant is very important. And supporting the bereaved (and shortly to be bereaved) family, and safeguarding their mental health is also very important.

While, in general, we would be in favour of abiding by the wishes of the deceased to donate his or her organs, in cases when this would cause great distress to his or her family, whether as a result of religious, emotional, or other reasons, it is our view that donation should not proceed in order to minimise distress to the family, and protect their long term mental health.

4. If there was a soft opt out system, what do you think of the proposed checks set out in step 2?

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

Given the fourth bullet point, that "there could potentially still be scope for donation not to proceed if it was clear that proceeding would cause distress to the family", we are supportive of the first three bullet points. The fifth is, however, very problematic, and we do not support the proposal that, in cases in which an individual's family or close friends were not "contactable within the necessary timeframe ... donation could be considered to be authorised unless the person had opted out."

The consultation paper views with concern the "risk" of "deemed authorisation ... being viewed by some as the state taking people's organs, rather than people actively choosing to give them." (page 22). We share this concern, and think it unreasonable to presume authorisation simply because an individual's family or close friends happened to be on a transatlantic flight, undergoing surgery, or otherwise uncontactable at the time of the individual's death.

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

We strongly recommend that the final bullet point in "step 2" should be changed to state that unless an individual had actively opted in to donate his or her organs, donation should not proceed without the consent of his or her family or close friends as appropriate. Furthermore, since medical staff cannot be certain that the deceased's views have not changed since joining the Register, his or her family should always be consulted since they are most likely to be aware of the donor's most recent views.

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 we have already stated, it is important to consider the wellbeing of the bereaved family as well as the potential recipient of a donated organ. If donation would result in distress, we are firmly of the opinion that authorisation should not be deemed.

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

6a. If these are not sufficient, why do you think this?

We agree that explicit authorisation should always be required in relation to people with incapacity and children under a certain age. We also agree that explicit authorisation should be required in the case of people not normally resident in Scotland. We are, however, concerned by some of the examples provided under this last heading. Contrary to the suggestion that students' "main home" should be regarded as being in Scotland "even if they stayed somewhere else during their holidays or had periods working abroad", it is our experience that the majority of students give the address of their family home when asked to provide their main address, not the address of their term time residence. This proposal could, therefore, result in potentially distressing misunderstandings, so that some people who regarded themselves as only temporarily resident in Scotland, might not realise they had to opt out in order to avoid the possibility of deemed consent to organ donation.

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?

We agree that people who have "suffered from incapacity over a period of time before their death due to a mental disorder or physical disability" should not be subject to deemed authorisation procedures.

8. Under what age do you think children should only be donors with explicit authorisation?

Under 12

Under 16

Under 18

Other (please specify)

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

They should not be allowed to authorise donation of a child's organs or tissue

Don't know

If the child has a particular religious or ethnic background, this should only be allowed following properly documented discussion with, and agreement from the recognised authorities in the relevant community.

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

We remain to be convinced of the benefits of deemed authorisation, but if it were to be introduced, we would be content for it to apply to all organs and tissue. There should, however, be ongoing, widely available, and easily understandable public information explaining how to opt out of deemed authorisation for any particular organs or tissue that an individual would not wish to donate.

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:

The terminology used in this question is one that has caused concern to some Jewish communities, as the basis for these "treatments" is not by definition "life-sustaining" – rather it is maintaining viability of organs for transplantation.

In Jewish law, a patient who is close to death is not even to be touched in case that might hasten his or her death, and moving a person at this stage is to be avoided if at all possible. Therefore no tests that require the patient to be touched or moved should be carried out at that point. However, this may have to be balanced with the need to perform imaging studies which help to determine death has occurred.

Tests that can be done, for example, through a central line or catheter that is already in place would be permitted provided they do not require the patient to be touched or moved.

Prior to this stage we would be supportive of tests that do not cause any discomfort, disturbance, or distress to the patient. In addition, some people may give advance permission for such tests to be done while receiving "treatments"; for example, they may be done during the form of artificial ventilation which takes place when brain stem death has already occurred, but the ventilation is continued because it is necessary to help maintain the organs in suitable condition for life-saving donation.

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;

Once the patient is close to death, only if blood can be taken without moving or disturbing the patient (for example, if an arterial line is already in place).

Yes

No

Don't know

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

Once the patient is close to death, **only if** the patient would not need to be moved or disturbed (for example, because a catheter is already in place).

- Yes
No
Don't know

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

Imaging studies in general often require moving the potential donor. Thus, in principle (as outlined above) they might infringe Jewish law. However, as also noted above, imaging may be part of decision making process that the person is dead, and such imaging would be considered essential. In an opt-in donation system ideally such studies should be performed as part of clinical care before the discussion about organ donation takes place.

- 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;

At the stage at which organ donation is taking place the terms “making them more comfortable” and “part of their care” are no longer applicable. Removal of secretions from the tube is a normal procedure, which could be performed at an earlier stage as a clinical test; but (as for access to blood gases and catheters) if the tube remains in place while ventilation is continued, then samples can be taken

- Yes
No
Don't know

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

In the context of the Critical Care Unit, where most potential organ donors are likely to be being treated, it would be highly exceptional for there not to be an ECG cardiac monitor in place. Furthermore, mobile equipment for echocardiography is likely to be accessible. Continuation of cardiac monitoring during the decision-making process and once organ donation has been agreed would thus be similar to maintenance of ventilation and catheterisation.

- Yes
No
Don't know

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

The answers to question 11 carry some reservations based on Jewish tradition of not interfering with the dying person, and on respect for the body of the deceased. To reiterate, Jewish law would not object to tests that can be undertaken without any disturbance, such as the examples of blood tests, urine tests and lung secretion tests noted. However, we would expect that there would be either previous explicit permission for necessary tests to be undertaken, or that the family would be consulted and given acceptable reasons and justifications for them.

The assumption that underlies organ donation from a deceased donor is that there is no "hastening of death" and no discomfort or distress. Moving the patient may be necessary; but then the difficult question is how to proceed if a test outcome does not confirm death.

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

This question is unclear unless "treatment" is defined. As has been said in response to questions 11 and 12, Jewish law does not permit someone on the verge of death to be handled in such a way that death is hastened. Furthermore, futile treatment, including medication that does not provide any benefit, should not continue to be administered, subject to discussion with the family consent.

With regard to the examples given, on the presumption that antibiotics or other medications will be given via an infusion route that is in place already at the time of death, then if the objective of such procedures relates solely to the better preservation of organs for donation, then this would fall into the context of saving lives, and family consent should be obtained.

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

14a. If you think this should be allowed, in what circumstances do you think an authorised representative would be useful?

We strongly support the proposal that individuals should be able to appoint an authorised representative. This would be particularly valuable in situations such as we have referred to above, in which, although in principle supporting organ donation, an Orthodox Jew might either not opt in under the current system, or else would opt out under a deemed consent system, for fear that, in the circumstances in which they found themselves, organ donation might contravene Jewish religious law. The ability to appoint a Rabbi of their choice to act as authorised representative would enable such individuals to consent to donate their organs secure in the knowledge that this would only be done in a manner consistent with Jewish religious law.

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

Public awareness: young people and new residents

Since there will continually be young people reaching the age threshold at which consent to organ donation might be deemed, and new residents moving to Scotland, implementation of an opt out system would require a continuing public information campaign about the right to opt out from organ donation – with the paradoxical effect that introducing a presumption of consent would require resources to be directed at raising awareness about opting out, rather than, as at present, at encouraging opting in.

As stated above, the Jewish Community in Scotland is strongly supportive of organ donation and transplantation, and the majority preference is, therefore, to retain the current system, not least because of the success with which it has recruited more potential donors than have other regions of the UK and many parts of Europe. A system of deemed consent should only be considered if there is convincing evidence that it would be more effective than other methods of increasing the donor pool. We agree with the view expressed in the consultation paper that no such evidence currently exists, but look forward to learning the impact of the Welsh scheme in due course, and considering the application of those findings to the situation in Scotland. In any event, we recommend delaying legislation until it is known how the new system is working in Wales, and whether or not it is providing the intended benefits.

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)

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

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 historically low levels of organ donation in some communities impact upon members of those communities in need of an organ transplant, since it is more likely that a 'matching' organ will come from someone with a similar ethnic background. We are concerned that a system of deemed consent may further reduce the donor pool in these communities, since concerns about religious and cultural matters may lead more people to opt out of the system – particularly since a deemed consent system must, of necessity, send mixed messages as it will have to be accompanied by an information campaign explaining to people how to opt out. By contrast, an effective and targeted education campaign may encourage more people in these communities to make a positive choice to opt in to the current system, secure in the knowledge that no steps can be taken without their, or their close family's explicit consent.

Summary

Measures that increase the number and range of people willing to donate their organs to enable others to live, or to have an improved quality of life, after their own death, are to be welcomed, but we remain to be convinced that a system of deemed consent is the most effective means of achieving this.