

HEALTH AND SPORT COMMITTEE**HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL****SUBMISSION 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, since people die who could be saved if more organs were available, organ donation is regarded not only as permissible but praiseworthy – indeed, as a *mitzvah* (both a good deed and a religious commandment). 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 there are differences in some respects between certain interpretations of Jewish religious law (*halachah*) and some medical interpretations of whether or not death has occurred.

Although there are organisations active in many parts of the world, supported by many Rabbis of all denominations, that seek to facilitate both live and cadaveric donation in a manner that is in accordance with the relevant requirements of Jewish religious law, there are some issues that are specific to different legal and medical systems. Consequently Jewish support for proposals that appear superficially to be similar to those that have been suggested in Scotland cannot simply be presumed without careful thought and discussion.

1. What do you think are the key strengths and weaknesses of the proposals to introduce 'deemed authorisation' for those who have not made their wishes on organ donation known?

There is a variety of opinions in the Jewish community about a soft opt-out system.

Within the Orthodox Jewish community many people are concerned that any opt-out system would result in some people who do not oppose organ donation in principle nonetheless opting out because of fear that not doing so might risk contravening Jewish religious law, and so would have precisely the opposite effect to that intended by the proposals, i.e. it would reduce the number of donors. 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.

The Liberal Jewish community strongly supports the proposed soft opt-out system, along with a campaign of public education to present organ donation as the normal and socially-approved ethical choice both for patients and their families. It also strongly supports current mainstream medical opinion regarding the definition of time of death. It encourages the provision of transplant coordinators in hospitals (as in Spain) to raise awareness and prepare patients and their families for the life-saving possibility of donation.

The Reform Jewish community generally supports the move to a soft opt-out system on the basis that, in a hierarchy of values, saving life takes precedence. If people hope that they, their relatives, and friends would, if necessary, be able to benefit from an organ donation, they should also be willing to provide their organs to others, and this sense of mutual obligation should be underpinned by the law. Some senior Reform Rabbis are, however, in disagreement with an opt-out system believing that it would cause organ donation to cease being a gift and become instead a commodity with unclear ownership. In their view, the time and resources necessary to achieve informed consent are important and well-spent.

All these branches of Judaism would concur that all relevant medical staff, in particular Specialist Nurses for Organ Donation, should have training about faith community needs and sensitivities, and should have information about how to access faith communities (including burial societies) and religious authorities with any queries.

Publicity campaigns

The Scottish Government is justly proud that the level of organ donation in Scotland is higher than elsewhere in the UK, and that there has been a consistently higher rate

of increase in people signing up to the organ donation register. We agree with the view (Policy Memorandum, paragraphs 34 and 45) that this is likely to be due to the Scottish Government's annual high profile and very effective publicity campaigns that raise awareness of the potential of organ donation to save lives.

The Orthodox and Reform communities are concerned that if the system were to change to one of deemed consent, as detailed in the Policy Memorandum (paragraph 46) the tone of these publicity campaigns would have to change. Instead of being entirely focused on encouraging people to sign up to the organ donation register, material would have to focus on the right of people to opt out, and to provide detailed information about how to do this. At best, the message would become ambivalent, and at worst could even carry negative overtones.

Given that all branches of the Jewish community are supportive of organ donation, we are concerned that such an ambivalent or negative message may not only discourage people from opting in to the organ donation register, but may encourage people actively to opt out, whereas they or their families might previously have consented to donation after discussions with a Specialist Nurse for Organ Donation.

The Registers

In order to simplify the system, prevent confusion, and maximise the number of potential donors, we strongly recommend that there should be a single register, and that the choices available to individuals joining it should include donating any, all, or none of a list of possible organs for transplant.

We note that, according to the current two-register proposal, only the Opt-In Register will enable people to state which organs they are willing to donate (Policy Memorandum, paragraph 59), while the Opt-Out Register will have only a single option: not to become an organ donor at all (Policy Memorandum, paragraph 64).

While all branches of the Jewish Community agree with the stated rationale of encouraging people to donate some of their organs even if they do not wish to donate them all, we do not agree that this proposal will achieve that. Many people will not look at the fine print, but regard it as a binary choice, responding according to their immediate, and possibly not well-informed, reaction; if their initial inclination is to donate, they will access the Opt-In Register, if their initial inclination is not to donate they will access the Opt-Out Register. As a result some people who might have reconsidered their opposition had they been presented with the choice of donating any of a list of organs will be lost to the register. A single register, as suggested above, would avoid this problem, but if there are to be two separate registers, then the Opt-Out Register should also provide the same options.

2. What do you think are the key strengths and weaknesses of the plans for authorisation of pre-death procedures?

Deemed authorisation for pre-death procedures is qualitatively different from deemed authorisation for organ donation from a deceased donor, and could, potentially, cause considerable distress to the patient's family and close friends. The Orthodox and Liberal Jewish communities are concerned that the introduction of deemed authorisation for pre-death procedures may, in some cases, be particularly distressing for the family and close friends of the patient, since they might see these as anticipating or – even though mistakenly – as hastening the death of their still living relative. The removal of the current requirement that “In all cases the person's

family is consulted and steps are taken to ensure the family is aware and comfortable with the tests being carried out.” (Policy Memorandum paragraph 113), may result in the family feeling sidelined, and that the medical staff have moved from caring for and treating the patient to regarding him or her merely as a potential donor.

In some cases, the introduction of deemed authorisation for pre-death procedures, whether Type A or Type B, may be problematic for Jewish people. 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 that help to determine that death has occurred – but then the difficult question is how to proceed if a test outcome does not confirm death.

Prior to this stage we would be supportive of tests that do not cause any discomfort, disturbance, or distress to the patient, such as blood and urine tests when an arterial line or venous access device and catheter are already in place – which is likely to be the case for most patients in the Critical Care Unit, where most potential organ donors are likely to be being treated. In these circumstances it would also be highly exceptional for there not to be an ECG cardiac monitor in place, and 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, and therefore permissible.

Imaging studies in general often require moving the potential donor. Thus, in principle (as outlined above) they might infringe Jewish law. However, since imaging may itself be part of decision-making process that the person is dead, and such imaging would be considered essential, it would be permissible for additional imaging to be carried out at the same time for the purpose of assisting decisions around organ donation.

We are, however, concerned that it is proposed that consent for pre-death procedures to be carried out should only require authorisation for donation (Policy Memorandum, paragraph 110). A potential donor may be happy to donate his or her organs, but be extremely concerned by the prospect of “pre-death preparations”, and may indeed opt out for that reason. Consequently, we strongly recommend that the opt-in register should permit individuals explicitly to indicate whether or not they consent to pre-death procedures being carried out. Furthermore, consent to pre-death procedures should not be deemed when a patient who has joined the opt-in register has not explicitly expressed that desire (just as it would not be deemed for the donation of other organs for which he or she had not opted in).

In cases of deemed consent to organ donation, we do not believe that consent to pre-death procedures should also be deemed, but rather that consent for these should be sought from the family, and their views respected.

In terms of Jewish law, on the presumption that antibiotics or other medications would be given via an infusion route that is in place already at the time of death, 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 given family consent, would be permissible.

3. Do you have any other comments to make on the Bill?

Definition of death

We welcome the recognition that some people may be content to become an organ donor following diagnosis of circulatory death but not death by only neurological criteria (Policy Memorandum, paragraph 71), and the commitment “to accommodate the potential donor’s views as they would relate to the specific circumstances of death where they are contrary to their recorded decision”. However, although the Policy Memorandum goes on to state that “The Bill therefore provides an additional provision to accommodate the potential donor’s views” in this respect, no explicit provision is provided in the Bill. We take this to be an omission and trust that will be rectified by amending section 2A(2)(a) of the Bill to include information about any conditions attached to the consent of “persons who authorise the removal and use of a part of the person’s body after the person’s death for transplantation”.

Furthermore, we note that, as from December 2018, it is intended that the donor register in England will provide “the option to state that your faith is important to your organ donation decision and that your family and/or faith leader should be consulted if organ donation is a possibility on your death to ensure that any religious considerations are observed.”¹, and we urge that this should also be an option for people joining the donor register in Scotland both under the current system and any future soft opt-out system.

In addition, we note that, south of the border, NICE guidance includes two distinct pathways to organ donation according to circulatory or neurological death², and we strongly recommend that this distinction should also be adopted by SIGN.

Role of the family

While in general we agree that the choice of someone to become an organ donor should be respected, the Orthodox and Liberal Jewish communities are concerned that in a minority of cases this could be extremely traumatic and distressing for some close family members, with long-term impact on the grieving process and even on their future mental health. When it is thought that this may be the case – which we do not believe will be a frequent occurrence – we strongly recommend that the fact of the deceased having joined the donor register should be set aside, and, if he or she has not joined the donor register, that consent to organ donation should certainly not be deemed.

Next of kin

The Orthodox and Liberal Jewish communities have some concerns about the strictly hierarchical list for next of kin, since it is possible that a patient may have had little contact, or even be on bad terms, with the relation at the top of the list, while being

¹ “The New Approach to Organ and Tissue Donation in England Government Response to public consultation”, ((Department of Health & Social Care, 2018), pp8 and 20
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/731913/govt-response-organ-donation-consent.pdf

² Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation (CG135), (NICE, 2018), paragraphs 1.1.25 and 1.1.26
<https://www.nice.org.uk/guidance/cg135/resources/organ-donation-for-transplantation-improving-donor-identification-and-consent-rates-for-deceased-organ-donation-pdf-35109512048581>

very close to a more distant relation. In such a case, the more distant relation will be better able to advise medical staff whether the patient had any strongly held or recently changed views about becoming an organ donor, and should, therefore, be considered a more reliable informant. Instead of relying on a possibly irrelevant hierarchical list, the transplant coordinator or other specialist medical staff should consult the patient records to discover who is listed as next of kin, or, if this is not stated, should consult relatives and friends to discover who is the most appropriate person.

Authorised Representative

Previous proposals and Private Member's Bills relating to deemed consent have all included the possibility of appointing an authorised representative to make decisions about organ donation on behalf of the potential donor. We are disappointed that this provision is absent from the current Bill since we believe that it would be likely to increase the number of donated organs. In particular, it would be especially valuable in situations such as 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 family member or 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.

Local Authorities

The Orthodox and Liberal Jewish communities strongly disagree with the proposal that local authorities with PRRs for a child should be able to authorise organ donation. Moreover, if a child in the care of the local authority has a particular religious or ethnic background, donation should only be allowed following properly documented discussion with, and agreement from the recognised authorities in the relevant community.

Residence in Scotland

We welcome the increase from six to twelve months residence in Scotland before deemed consent could be applied. The criteria for residence are not, however, clear, especially in the case of people with residence both in Scotland and elsewhere. In particular, many students continue to regard their parents' home as their main residence, rather than their term-time address. Even if, as suggested in the Policy Memorandum (paragraph 78), residence will depend on whether someone lives in Scotland for the majority of the year, clarity needs to be provided as to whether the qualifying twelve months applies only to time actually in Scotland (so, in the case of most students from outwith Scotland, not until halfway through their second year of study), or from the date they first move to Scotland, regardless of the fact that several months of the subsequent year may be spent elsewhere.

Faith Communities

As we have already stated, all sections of the Jewish community in Scotland are supportive of organ donation, and we would, therefore, welcome the development of

“faith-specific donor cards” as proposed in England³, which, as well as raising awareness of organ donation within the various faith communities, would also provide information about the “special arrangements which might be required for people of different faiths as part of the transplantation process.”

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 the majority of the Jewish community in Scotland remains to be convinced that a system of deemed consent is the most effective means of achieving this. If, however, the Parliament decides that Scotland should institute a soft opt-out system, it is essential that the legislation include explicit safeguards to ensure that all sectors of Scottish society have confidence that their religious and other beliefs will be fully respected.

³ *ibid*, p23