



Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill

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.

The Jewish Community in Scotland

The majority of the Jewish community in Scotland is affiliated to Orthodox Judaism, which has four 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 the human body as sacrosanct and requires that it should always be treated with dignity. 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, and there is an organisation¹, supported by

¹ Halachic Organ Donor Society <http://hods.org/>
(The meaning of the Hebrew word "Halachic" is "in accordance with Jewish Law")

many Rabbis, that seeks to facilitate this in a manner that is in accordance with the relevant requirements of Jewish religious law. However the taking of life is one of the three exceptions to the above rule, so that 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.

Against this background, 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.

The Reform Jewish community fully supports organ donation but is still debating whether or not to support a move away from the current opt-in system.

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

1. Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland?

We are not persuaded of the value of changing from an opt-in to an opt-out system of organ donation. Indeed, as we pointed out in response to Anne McTaggart's 2014 consultation, even the evidence that she provided in her consultation paper² casts doubt on the rationale for such a change. This stated variously that "*research by others shows organ donation rates increases by approximately 25-30% in countries where an opt-out system is introduced.*" and that "*five 'before and after' studies involving ... Austria and Singapore ... show an increase in donation rates of up to 25%.*",

The second of the above sources,³ continues "*The reviewers note, however, that in each country many other changes were introduced at the time of legislation, such as better infrastructure or increased funding for transplant programmes. Awareness of the need for organ donation was also raised. This makes it difficult to assess the exact contribution of presumed consent legislation alone.*"

Furthermore, the increase quoted in the first of the above sources⁴ refers to a step change following the change in legislation to introduce presumed consent, whereas, as the consultation paper goes on to quote, the Scottish Government *Donation and Transplantation Plan for Scotland 2013-2020*⁵, reveals that "*During a recent five-year*

² http://www.scottish.parliament.uk/S4_MembersBills/Organ_Donation_Consultation_Document.pdf

³ *The potential impact of an opt out system for organ donation in the UK (Organ Donation Taskforce, 2008)*
<http://www.odt.nhs.uk/pdf/the-potential-impact-of-an-opt-out-system-for-organ-donation-in-the-UK.pdf>

⁴ *The impact of presumed consent legislation on cadaveric organ donation: a cross country study (National Bureau of Economic research, 2004)*
http://www.nber.org/papers/w10604.pdf?new_window=1

⁵ <http://www.scotland.gov.uk/Resource/0042/00427357.pdf>

period (2007/8 – 2012/13) Scotland achieved a 74% increase in deceased organ donations as well as a 36% increase in transplants with deceased donor organs.” – resulting in the 40% donor rate of which the consultation paper is justifiably proud, a rate already higher than any of the 22 countries studied in the second source³.

On this evidence, it would appear both more effective and cost-efficient to invest the money that would otherwise be required to set up and maintain a new opt-out system in continuing and expanding the education campaign that has already proved so successful.

2. Do you support the proposal of appointing a proxy?

We strongly support the proposal that individuals should be able to appoint a proxy to decide whether or not to permit organ donation. 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 the proposed 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 proxy 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. We emphasise, however, that it would be possible for this provision to be introduced alongside the current opt-in system and not only under the new system envisaged by the Bill.

We disagree, however, with the proposal that *“It is not necessary, for an appointment to be valid, that the proxy must consent to, or even be aware of the appointment.”*⁶ It is not reasonable that a person may be asked to make a decision of such significance and within such tight time constraints, without any prior consideration, perhaps even without ever having known or spoken with the person concerned. The provision that *“A proxy may renounce the appointment at any time”*⁷ is not sufficient to allay our concerns, and we urge that the procedure for appointing proxies must include consent from the nominee.

3. Do you have any comments on the role of “authorised investigating persons” as provided for in the Bill?

We are concerned that, in cases in which a proxy and/or the nearest relative are uncontactable *“within a reasonable time”*, *“The removal and use of a part of a deceased adult’s body for transplantation are authorised by operation of law”*⁸, where *“a reasonable time”* is defined as *“such time as the authorised investigating person considers reasonable, taking into account the time within which a part of the body will have to be removed if it is to be used for transplantation”*⁹. Orthodox Jews do not use the telephone, e-mail, etc during Shabbat (from dusk on Friday evening until after dark on Saturday, a period of approximately 25 hours), or Festivals (usually a period

⁶ Explanatory Notes, paragraph 18

⁷ Bill, para (5)(3)

⁸ Bill, para (6)(1)(1)

⁹ Bill, para (6)(5)(a)

of two days, approximately 49 hours). If a Festival immediately precedes or follows Shabbat, the period during which someone is uncontactable would be extended to three days. Particularly in cases in which someone has appointed a proxy, which may be understood as only conditional consent to donate organs depending on the circumstances as determined by the proxy, when an authorised investigating person is unable to contact any relevant person there should be a very strong presumption that organs should not be removed, rather than, as would appear from the Bill, the reverse.

4. Is there anything in the Bill you would change?

In addition to those matters we have already raised above, we would wish to see changes to the following provisions:

a) Habitual residency

Although “rebuttable”, we are concerned by the “*presumption that an adult had a reasonable opportunity to record an objection if he or she, since attaining the age of 16, had been habitually resident in Scotland for **any** continuous period of 6 months beginning after the day appointed under section 19(2) of the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Act 2015.*”¹⁰ (our emphasis), especially when taken in conjunction with the provision that “*the adult was resident in Scotland at the time of death*”¹¹.

The implication of these clauses is that an adult who had previously lived in Scotland for a period of six months, perhaps only while at school or at a further or higher education institution, and had not during that time registered any objection to organ donation, or appointed a proxy, would, on returning to Scotland many years later, immediately be presumed to have consented to organ donation. Even if aware that an opt-out system was in operation, it would not be unreasonable for such a person to presume that the six month period would be counted from the start of their current residency, so that he or she might not have regarded it as urgent to register any objection or appoint a proxy. We therefore recommend that the residency qualification for someone returning to live in Scotland after a period of absence, should be counted from the start of his or her current residency.

b) Transition period

In our view, six months is not long enough to raise awareness of so fundamental a change in system, and we would, therefore, recommend a minimum transition period of one year.

5. Other Concerns

a) Determination of residency

We are concerned that there are practical difficulties that would make a fair determination of residency difficult if not impossible. Firstly, in many cases, health professionals will have no way of knowing whether someone who dies as a result of

¹⁰ Bill, para. (6)(3)

¹¹ Bill, para (6)(1)(a)

an accident has been resident in Scotland for one or ten years, or is a day-tripper from south of the border.

Secondly, we are concerned that there can be no reliable way of informing new residents in Scotland that, after six months, they would be presumed to consent to be an organ donor unless they have actively opted out of the scheme. Even if GPs were required to distribute information to all new patients, and employers to all new employees, those who did not register with a GP, and were self- or unemployed, would not receive this. Even were a new resident to receive such information, we are particularly concerned that those with a first language other than English may not fully understand its implications. This may especially be the case for asylum seekers and refugees, who have to deal with a very large number of practical and emotional issues, and may, therefore, be unable to devote the necessary time and energy to understanding the very many pages of written information on a wide range of subjects that they inevitably receive, until after they have dealt with more immediate issues, taking them, in all probability, well beyond the six month residency qualification.

b) Public awareness: young people

Since there will continually be young people reaching the age threshold at which their own decision is required, implementation of this Bill 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.

Summary

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 presumed consent should only be considered if there is convincing evidence that it would be more effective than other methods of increasing the donor pool. As detailed above, we do not believe that 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.