

Proposed Organ and Tissue Donation (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 individuals and families who live outwith any Jewish community, 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. (Scottish Charitable Incorporated Organisation SC029438)

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.

1. The overarching purpose of my proposal is to move from the current opt-in system to a soft opt-out system of organ donation. Do you support this move?

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, including cornea donation, since, although not life-threatening, blindness is considered a severe disability, is regarded not only as permissible but praiseworthy, and there is an organisation¹, supported by 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

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

differs in some respects between some interpretations of Jewish religious law (*halachah*) and current medical opinion.

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

Against this background, the Orthodox Jewish community is, however, concerned that an opt-out system would unnecessarily limit the number of donors as 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 does not agree with the introduction of a system of presumed consent, but supports the continuation of the current opt-in system.

In principle, the Liberal Jewish community is strongly 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.

2. How essential is it to change the law (from an opt-in to a soft opt-out system) in order to achieve the intended benefits (increased transplant rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?

We are not persuaded of the value of changing from an opt-in to an opt-out system of organ donation. Indeed, internal evidence in the consultation paper casts doubt on the rationale for such a change. It states 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,² 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 sources³ 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*⁴, reveals that “*During a recent five-year*

² *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>

³ *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

⁴ <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 source.

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.

3. I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree?

As the consultation paper points out, even if an individual has joined the organ donor register under the current system, *“in practice donation is dependent on the co-operation of the relatives, as they have to contribute information about the donor’s character, behaviour and travel history to ensure that any donation is safe.”* In order to ensure that donations continue to be safe, this information would also be required under a system of presumed consent. Limiting the role of the family to being consulted about unregistered objections would, therefore, make little difference as they could still effectively refuse consent by declining to provide the necessary information.

We are also concerned with the proposal that *“While reference has been made in this consultation to “the family”, in practice the decision would be made by the deceased person’s “closest relative”.* The consultation paper further emphasises that the relevant *“list is set out in a strict order of priority, i.e. consent would be sought from the top of the list and only if there was no one further up the list who was contactable, or willing and able to decide, would consent be sought from those further down the list.”* In practice, as under the current system, this inflexibility could be exploited in order to frustrate the wishes of the deceased in either direction. For example, an estranged spouse (top of the list) might, either maliciously or simply because he or she was not aware of the individual’s most recent views, advise health professionals that the deceased either did or did not have objections to organ donation when, in fact, the reverse was the case, as might be attested by a sibling, nephew, or niece who, since lower down the list, would not be consulted.

4. Do you think an individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf?

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.

- 5. My proposal is that only adults should be automatically opted-in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent as they currently do. This approach is I believe the best way to safeguard children and young people. Do you agree?**

We agree that young people and children should have to register proactively as a donor and that parental consent should be required. As we have already said, whilst there is no information about the effectiveness of the Welsh system, and since research indicates that other means of increasing the number of donors may be more effective, we do not agree that adults should necessarily be opted-in to be a donor.

- 6. Do you agree the age limit for an adult should be set at 16 years old?**

There is a difference of opinion in the community as to the age at which someone should be considered an adult for the purposes of organ donation, ranging from 16 to 21 years old.

- 7. Do you agree the soft opt-out system should apply to people who have been resident in Scotland for a minimum period of 1 year prior to their death?**

While one year's residency in Scotland might not, on the face of it, seem an unreasonable length of time, we are concerned that there are practical difficulties that would make its application difficult if not impossible. Firstly, in many cases, staff will have no way of knowing whether someone who dies as a result of 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 is no reliable way of informing new residents in Scotland that, if these proposals were to become law, after a year 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.

- 8. If you answered no to the above how long, if any, should this period of residency last before they become subject to the soft opt-out system? Would this residency need to be for a continuous period?**

We agree that any residency qualification should be for a continuous period, but, as we have already stated, are concerned as to how to ensure that all new residents would be informed about a system of presumed consent, and also how medical staff would be able to determine whether an unaccompanied comatose patient had been resident for the requisite period.

- 9. Do you think 6 months is a long enough period to run a campaign prior to change over?**

We do not agree that 6 months would be a long enough transition period during which to raise awareness of a change in system, and recommend a minimum period of a year.

In addition, since there will continually be young people reaching the age threshold at which their own decision would be required, there would have to be a continuing public information campaign about the right to opt out – 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.

10. What is your assessment of the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?

We would not anticipate that a change to the organ donor system would have any financial implications for organisations in the Jewish community.

Since the Jewish community would wish as many people as possible to benefit from organ donation, and since research quoted in the consultation paper would seem to indicate that the Scottish Government and NHS education campaigns have been more effective than changes elsewhere to the system of organ donation, we suggest that it may be more effective to invest the available funding in education, in the hope of achieving a similarly large increase in donors in the next as in the previous five years.

11. Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

Since a donated organ is more likely to be a tissue match for a recipient from the same ethnic background as the donor than from someone of a different ethnic background, increasing the number of donors from all sectors of Scottish society can only be beneficial – though, as we have already stated, we remain to be convinced that changing the system is the best way to achieve this.

12. Do you have any other comments on or suggestions relevant to the proposal?

If it were to be introduced, an opt-out system must include safeguards that would enable all sections of Scottish society to have confidence that their wishes, for example to donate particular organs but not others, would be respected.

Moreover, 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. We do not believe that 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.