



**THE LAW SOCIETY
of SCOTLAND**
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Consultation Response

Proposed Organ and Tissue Donation (Scotland) Bill **Anne McTaggart MSP**

The Law Society of Scotland's response

October 2014

Introduction

The Law Society of Scotland aims to lead and support a successful and respected Scottish legal profession. Not only do we act in the interests of our solicitor members but we also have a clear responsibility to work in the public interest. That is why we actively engage and seek to assist in the legislative and public policy decision making processes. To help us do this, we use our various Society committees which are made up of solicitors and non-solicitors to ensure we benefit from knowledge and expertise from both within and out with the solicitor profession.

The Health and Medical Law, Mental Health and Disability and Equality Law Sub-Committees of the Law Society of Scotland welcome the opportunity to consider Anne McTaggart MSP's consultation on the proposed Organ and Tissue Donation (Scotland) Bill. The joint committees have the following comments to put forward in response to the questions posed in the consultation document.

General Comments

While we generally support the promotion of good public health and health equality, we are not in position, nor would it be appropriate for us to comment on the policy aims of the Bill to move to a soft opt-out system for organ donation. However, given that this legislation will reverse the law which is currently in place, two general, but recurring themes underpin all our responses. First, proposals should be clear and transparent in their aims and objectives. This would be the case not only for the Scottish general public but for those involved in health care practice. Second, we suggest that there should be advance publicity which is tailored to meet the needs of the diverse groups in our society, up to date and easily accessible. We also believe that information should be available for someone considering organ donation which would promote reflection and discussion with their family and/ or their healthcare professional. We will say more on this in our response to subsequent questions.

Comments:

- 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? Please indicate yes/no/undecided” and explain the reasons for your response.**

As we have set out in our general comments above, we are not in position, nor would it be appropriate for us to comment on the policy aims of the Bill to move to a soft opt-out system for organ donation.

- 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 acknowledge that other factors influence donation rates, but there appears to be patterns of evidence which suggest that countries that have an opt-out policy do have higher donation rates than those countries which do not. Human nature and procrastination may also mean that, for some, accepting a default position may simply involve less effort. Increased awareness and education may improve willingness to donate organs and help to manage doubts and myths. Although opt-out systems may have improved donation figures in other countries, this would not necessarily translate from country to country because cultural differences and perceptions would also need to be considered.

- 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? Please indicate “yes/no/undecided” and explain the reasons for your response.**

We agree that the wishes of the potential donor should be paramount but we remain undecided in other respects. For example, given that relatives will have no veto if their loved one has not formally opted out or expressed an objection to organ donation, clinical staff may find it difficult to act in the face of strong objections from close family. In any event, as has been acknowledged in the consultation document, the relatives could

exercise their wishes indirectly by claiming that their loved one had an objection but failed to register it. Would it be expected that clinicians proceed to remove organs in the face of strong objection or the severe distress of family members?

We understand that research has shown that healthcare professionals wish explicit guidance to be provided to both families and the health professionals on the consequences of a soft opt-out scheme. Therefore, time would still need to be set aside for healthcare professionals to meet with families and provide an opportunity for discussion, questions and explanation. We suggest that training should be provided to address what changes in approach are required by healthcare professionals in their discussions with family and it should be made clear to family members that they still have a role, for example, in providing medical history.

We note that the consultation suggests a list of closest relatives taken from the Human Transplantation (Wales) Act 2013¹. Scottish legislation already has the concept of "nearest relative" as defined in section 50 of the Human Tissue (Scotland) Act 2006. This list is slightly different from that of the Human Transplantation (Wales) Act and we would favour a consistency of approach. Any new Scottish legislation will be required to take into account the provision of the 2006 Act, amending, replacing or being supplementary to the existing provisions therein.

4. Do you think an individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf? Please indicate "yes/no/undecided" and explain the reasons for your response.

In line with the approach taken in many other areas of law, we agree that an individual should be able to appoint a proxy. However, some of the complex issues pertaining to that role that have arisen in other legislation, will also be pertinent here. For example, some families may have had a discussion on what the individual may or may not wish in relation to preferences about their healthcare, including whether or not they wish to donate their organs. However, many families may not have had such a discussion. It then becomes a

¹ <http://www.legislation.gov.uk/anaw/2013/5/contents/enacted>

matter of substituted decision-making on what may have been the preferences of the individual concerned. Again, advance publicity and media campaigns may alleviate some of these issues and help facilitate discussion.

- 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? Please indicate “yes/no/undecided” and explain the reasons for your response**

We agree that only adults should be automatically opted-in and believe that children and young persons should only be opted-in with their consent. Please see response to question 6 below.

- 6. Do you agree the age limit for an adult should be set at 16 years old? Please indicate “yes/no/undecided” and explain the reasons for your response. If you answered no, what would you consider a more appropriate age?**

We note that the Human Transplantation (Wales) Act 2013, has adopted the approach of the Human Tissue Act 2004, which sets out the definition of 'appropriate consent' in relation to activities regarding the body of a deceased child. For the purposes of section 2 a child is any person under the age of 18 years, and parental / guardian consent is required below that age. Consent to organ donation in Scotland is currently covered under the Human Tissue (Scotland) Act 2006. Section 8 of the 2006 Act provides that a child over the age of 12 can consent to organ donation without parental consent and if written consent is given by that child, this cannot then be vetoed by family members or those with parental responsibility.

We agree that the proposed age limit of 16 years old for automatic opt-in is appropriate and we further agree that the current age limit for express consent to organ donation, as set out in the 2006 Act is appropriate. However, in relation to consent of the child between the ages of 12 -16 years, we do suggest that there should be safeguards in place to ensure a child aged between 12 and 16, and who provides written consent in accordance with

Section 8 of the 2006 Act, fully understands the nature of the authorisation and the nature of organ donation. We note that Section 8 (5) of the 2006 Act requires any person who signs on behalf of a child aged 12 or over to certify that the child understands the effect of the authorisation, but there are no comparable requirements where a child signs the written consent him or herself.

We would also suggest that below the age of 16, consideration should be given to the views of family members or those with parental responsibility to take into account cultural and religious beliefs. For many potential donors, religious beliefs and cultural environment will be an important factor to be taken into consideration. Different faiths have differing views on organ donation, with some faiths requiring the deceased's body to be complete for burial. Although a child of 12 may have an understanding of the general beliefs of his or her culture and faith, these may not include a full understanding of that faith's or culture's views and beliefs regarding organ donation.

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? Please indicate “yes/no/undecided” and explain the reasons for your response.

We agree that there should be a residency period in Scotland for potential donors prior to death. Visitors and tourists who might be unwilling to consent to organ donation, or whose views are unknown would remain unaffected by this proposed legislation. However there could be difficulties over how any period of residency is to be ascertained. How are healthcare professionals to know that the potential donor was not resident, since he or she would presumably have at least a short term Scottish address? Also, if residency for the period is to be continuous, how are healthcare professionals to establish this with certainty, bearing in mind that decisions about organ donation have to be made within a short timeframe? There may not be enough time for a thorough investigation of the deceased's residency status. Healthcare professionals will be forced to rely on information from the deceased person's relatives or companions in this country.

What if a healthcare professional acted upon incorrect information in good faith? Consideration should be given to providing a defence for clinical staff who reasonably rely on the information provided or who have taken reasonable steps in the circumstances to identify whether the deceased was a resident.

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?

A year seems a reasonable period of residency. It is a more than a mere visit and gives sufficient time for a person to opt-out. On the question of whether it should be a continuous year, there are arguments for discounting short breaks when the potential donor left Scotland for a few days. One group may pose particular issues in this respect; international students coming to study in Scotland. They may reside for on average 4 years to obtain their degree and more if they continue with post graduate studies. We would suggest that perhaps this may be overcome by ensuring that organisations such as Scottish universities are able to provide information to students about how the proposed legislation may or may not affect them. Such a process could be incorporated into the admission/matriculation process. However, we believe that this will not be without difficulties for clinical staff to establish that residence criteria have been met and whether the person's organs can be lawfully removed under the legislation, especially when time may be of the essence.

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

We believe that this would be impossible for us to quantify as this would depend on a large number of factors, the profile and nature of the campaign, resources available etc. We do note however that the campaign to raise awareness of the Human Transplantation (Wales) Act 2013, and the opt-out system which will come into effect on the 1 December 2015, has a lead campaign time of 2 years².

² <http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/?lang=en>

Instead our comment will focus upon the reach and effectiveness of any campaign. The Human Tissue (Scotland) Act 2006 incorporates a duty to promote information and awareness about organ donation and we would hope that this would be similarly adopted within the current proposals. Most professional organisations favour an extensive and high profile public campaign and we agree that the robust provision of information is important to ensure that any decision made is fully informed. The information should be provided via a variety of mechanisms explaining the legislative changes and what opting out means in practice. A recent Australian study³ indicated that whilst public support for organ donation was 'fairly consistent', the reasons for support varied depending on age group. It is acknowledged that other studies have produced different results. Diverse communication strategies may therefore be required to effectively inform different age groups and differing views. It should also be made clear that a change of mind is possible with a simple process in place to accommodate this.

We note that many religious faiths have published information leaflets setting out guidance and views of their views and beliefs relating to organ donation. As with the publicity campaign for the Human Transplantation (Wales) Act 2013⁴, we suggest that any publicity campaign must include and make reference to these, so that potential donors can make a fully informed choice. We would suggest that there must be engagement with Scottish religious organisations to ensure that such publications reflected the Scottish position.

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?

The Bill is unlikely to have financial implications for the Law Society of Scotland. We have no comments on any other financial implications.

³Irving et al, (2014), 'What factors influence people's decisions to register for organ donation? The results of a nominal study group'. *Transplant International* 27 617-624 at p. 622 <http://onlinelibrary.wiley.com/doi/10.1111/tri.12307/abstract>

⁴ <http://organdonationwales.org/Resources/Index?lang=en>

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?

We do not believe that the proposed Bill raises any equality concerns at this time. We may have further comment following the publication of any draft Bill.

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

- Education and training

As we have already noted above, we believe that education and training is vital, and should be extended to cover a wide range of stakeholders, not just the Scottish general public but particularly those involved in health care, assessment of capacity or proxy decision making.

- Research

Research should be encouraged to gauge acceptability and feasibility of any new legislation. It would also help address not only what impact opt- out policies have on organ donation but to identify other contributory factors.

- Patient or potential donor

A recurring issue is that the individual or family may be concerned that if they agree to their organs being donated clinicians will not strive to save life. Information campaigns may help to alleviate some concerns but we believe that the public would need to be reassured that a clear separation exists between the treatment and transplantation and the respective roles of those involved.

- Process

Any database or process adopted should be effective, up to date and accessible. Issues pertaining to the status of the patient, including residence have already been considered above, but it would also be desirable, given that organs are to be made available throughout the United Kingdom and to accommodate any potential cross border networks.

Any process should also provide an option should an individual choose to exercise a preference over which organs should or should not be removed.

- Suitability of organs.

We note that the Assisted Suicide (Scotland) Bill is at Stage 1 of its Parliamentary Passage, before the Parliaments Health and Sport Committee. The provisions of this Bill allow persons to assist others to self-administer a drug which will have been formulated to ensure a rapid death. Where the deceased person has self-administered such a drug, their organs may be unsuitable for transplantation purposes as they may have become tainted through the absorption of that drug into their bodily systems. We do appreciate and note however, that there are current safeguards and procedures in place to check and ascertain the suitability of donated organs.

- Advancement of medical science.

We note that through the advancement of medical research and technology, the scope of transplantation of both organ and other body parts is rapidly evolving. We suggest that any proposed Bill has enabling provisions to take into account those advances.

