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

Law Society of Scotland

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 outwith the solicitor profession.

The Health and Medical Law Sub-committee of the Law Society of Scotland welcomes the opportunity to consider and respond to the Scottish Parliament’s Health and Sport Committee call for evidence on the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill. The Sub-committee has the following general comments and responses to put forward to the questions raised in the call for evidence.

General Comments

We responded previously to Anne McTaggart MSP’s earlier consultation on a proposed Organ and Tissue Donation (Scotland) Bill in 2014\(^1\). Many of our comments to the initial proposals will inevitably be applicable to the current Bill.

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 proposed 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, information should be available for anyone considering organ donation which would

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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. **Do you support the Bill?**

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. We do, however, understand that demand for organs vastly exceeds supply in most countries with transplant programmes and we recognise that the aim of the Bill is to address the deficit in the amount of organs and parts available for transplantation.

2. **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? Please provide an explanation for your answer.**

We acknowledge that diverse factors influence donation rates, but there appears to be a pattern of evidence which suggests that countries which have a (soft) opt-out policy do have higher rates of donation that those countries which do not. For example, the Policy Memorandum which accompanies this Bill highlights the approach taken by other jurisdictions, for example, Spain and Belgium and the resultant increase in organ donation\(^2\). We believe that the Human Transplantation (Wales) Act 2013, which comes into effect in December 2015, will provide some valuable comparisons.

The current system is based upon an altruistic approach and research\(^3\) shows that the problem is often not a lack of willingness to donate but rather, a lack of incentive. In other words, it is human nature to procrastinate which may mean for some, accepting a default position may involve less effort. However, consideration should also be given to other influencing factors, for example, dignity, fear of clinical death.

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\(^2\) Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. Policy Memorandum SP Bill 72-PM at para 24, 20 and 30.

neglect, family attitudes, religious belief and grief may also influence an individual’s decision as to whether or not they will donate\(^4\). It is suggested that it is important to acknowledge these factors and incorporate a discussion of them into any publicity/education campaign. We will say more on this at the end of our submission.

3. Do you support the proposal of appointing a proxy? Please provide an explanation for your answer

We agree that an individual should be able to appoint a proxy. Autonomy and sovereignty of decision-making are now regarded as cornerstones of individual rights and the appointment of a proxy decision-maker is an approach embedded in many other areas of law. We support the proposal that a proxy can be appointed to make a decision over specified or all organs. However, we note that it is not necessary for the proxy to consent to or be aware of their appointment\(^5\). We suggest that this should be revisited. Effective proxy decision-making should be based upon the proxy having a clear idea of what the individual would have wished. Those wishes or values may change over time and if there has been no opportunity for discussion, then this may hinder or leave the proxy unsure on how to proceed and ‘second guess’ what the wishes of the individual may have been. Secondly, if a proxy is approached who is neither aware nor willing to make such a decision then precious time may be lost in trying to find the alternative proxy (if others have been appointed) or thereafter the ‘nearest relative’ to assist. Advance publicity and educational campaigns may alleviate some of these issues.

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

This would be a complex, delicate but vital role to enable successful implementation of the bills proposals. Again, education and training with clearly identified and distinguished professional parameters defining the role of the Authorised Investigating Persons (AIPs) should be in place. Given the personal and intimate nature of the role, the AIP should have experience in working with the dying patient and in providing support to their families so those appointed should ideally have links

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\(^4\) Irving M. J et al. (2014) What factors influence people’s decisions to register for organ donation? The results of a nominal group study. *Transplant International* 27 at p 617

\(^5\) Section 6A(7) Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. and Explanatory Notes – SP Bill 72 –EN at para. 18.
or experience of pastoral care as well as sound training on the clinical and legal framework of their role.

We note that there is no provision to appeal the decision of the AIP.

5. Is there anything in the Bill you would change? If yes, please provide more details.

Age of the adult

We would like to draw attention to two issues here. The first is in relation to capacity of a young person and the second about a consistency of approach regarding section 16 (regulations in relation to certain adults resident outside Scotland). Both observations start with our belief that the age limit should be set at 18 years of age.

First, 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. We believe that at the age of 12 a child may not have the necessary maturity to fully understand and appreciate the nature of organ donation. We also note that the Legal Capacity (Scotland) Act 1991 section 2 provides that a person over the age of 16 years can consent to their own medical or surgical treatment. However, organ donation is not, we suggest, a treatment so may not be covered by the 1991 Act.

Although we accept that many persons between the ages of 16 – 18 years will have a full understanding of the nature of donation, there will be others who will not fully appreciate its nature, purpose and consequences. At the age of 18, the person is more likely to have an understanding and can make a fully considered and informed choice.
The second observation is about consistency of approach. This Bill proposes in section 16(2), that it may be possible to remove organs for transplant from an adult who dies in Scotland, but is ordinarily resident in another jurisdiction which operates a similar opt-out system for organ donation. Both the Explanatory Notes and Policy Memorandum provide the Welsh legislation as a comparable example and acknowledge that other parts of the UK may follow suit. Whilst we support the logic of the approach taken in s16, we suggest it would be more consistent and help any decision-making, if Scotland adopted the same age criteria as Wales as 18 years of age may be a more likely criterion to be adopted in other parts of the UK.

Habitually resident in Scotland for a continuous 6 month period.

Section 6B(3) of the 2006 Act as inserted by Section 6(1) of the Bill provides for the adult to be ‘habitually resident in Scotland for any continuous period of 6 months’. We believe that this is too short and should instead be a period of 12 months.

A year seems a reasonable period of residency. It is a more than a mere visit and gives time for a person to make a decision. The ‘rebuttable presumption’ will provide flexibility in which to consider whether circumstances had arisen which meant that the adult did not have a reasonable opportunity to object. 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.

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6 Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. Explanatory Notes – SP Bill 72 - EN at para. 64 & Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. Policy Memorandum SP Bill 72-PM at para 43

7 ‘Deemed consent will not apply to children (aged under 18) or to “excepted adults” (i.e. adults who were not ordinarily resident in Wales for at least 12 months immediately before dying, or who lacked capacity, for a significant period before dying, to understand the concept of deemed consent.’

8 6 months was initially proposed in the Welsh legislation. This was amended to 12 months during the Stage 2 debate.
Another group who perhaps should be mentioned are those international expatriate professionals who come to work in Scotland for a period of time. For example, in Aberdeen there is a continual flow of oil related professionals who come in large numbers and also bring their families and can be resident for up to 3 years. It is imperative that they are provided with the same information as international students. The conduit for the provision of the information is not as obvious, so an adequate safeguard would need to be put into place for this.

Role of the family
We agree that the wishes of the adult should remain paramount, but we observe that the role of the family still remains unclear. The Policy Memorandum at paragraph 37 states that:
‘The Bill does not allow relatives to block the removal of organs by reference to their own views and preferences about organ donation; they are consulted only to help establish whether the deceased person had expressed any objection...’

Paragraph 55 notes the current position of not removing organs if doing so would cause significant distress to the family, even if authorisation exists and it goes on to say that:

‘Nothing in the Bill changes this, and it is likely to remain the case, even under the soft-opt out system that it creates, that family distress will be taken into account before any final decision is made’

Lack of clarity in procedure is only going to make what may already be an emotional and distressing time, more challenging for all those involved. 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

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9 Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. Policy Memorandum SP Bill 72-PM at para 37
10 Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. Policy Memorandum SP Bill 72-PM at para 55
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.

**Six months publicity**
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 had a lead campaign time of 2 years.\(^{11}\)

We note that section 1 (2) of the proposed Bill, incorporates a duty to promote information and awareness on the implications of the bill and the changes it would make to the current position regarding organ donation. 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 study\(^{12}\) 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 2013\(^{13}\), we suggest that any publicity campaign should include and make reference to these.

**The language of the Bill**

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\(^{11}\) [http://wales.gov.uk/topics/health/nhswnrl/organ/?lang=en](http://wales.gov.uk/topics/health/nhswnrl/organ/?lang=en)


\(^{13}\) [http://organdonationwales.org/Resources/Index/?lang=en](http://organdonationwales.org/Resources/Index/?lang=en)
Our final comments relate to the language of the Bill itself. Much has been written about the principle of an ‘opt out’ (whether hard or soft) system and a presumption that it refers to a presumed or implied consent\textsuperscript{14}. This does not appear to be the approach taken with the proposed Bill. Neither the face of the Bill nor the Policy Memorandum nor Explanatory Notes make any reference to the principle of consent in relation to the aims of the Bill. Consent is mentioned in the Policy Memorandum in relation to other jurisdictions, for example, the Welsh legislation, where consent is described as ‘deemed’ consent. The reliance in the Scottish proposal is upon ‘authorisation’. In other words, in the absence of any express authorisation by the adult themselves or by an appointed proxy, Section 6 of the Bill, which provides a mechanism that authorises under certain circumstances ‘by operation of law’, the removal of a deceased organs or parts\textsuperscript{15}.

Authorisation is about giving permission – it does not mean the same as presumed or implied consent. A valid consent has a higher threshold than an authorisation as it requires the disclosing and importantly, understanding of information before a decision is made.\textsuperscript{16} We have observed throughout our submission that detailed quality information should be provided about what the proposed legislative changes would mean. We believe that an informed choice and understanding will encourage trust and confidence the robustness of the process.


\textsuperscript{15} Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. Policy Memorandum SP Bill 72-PM at para 55