

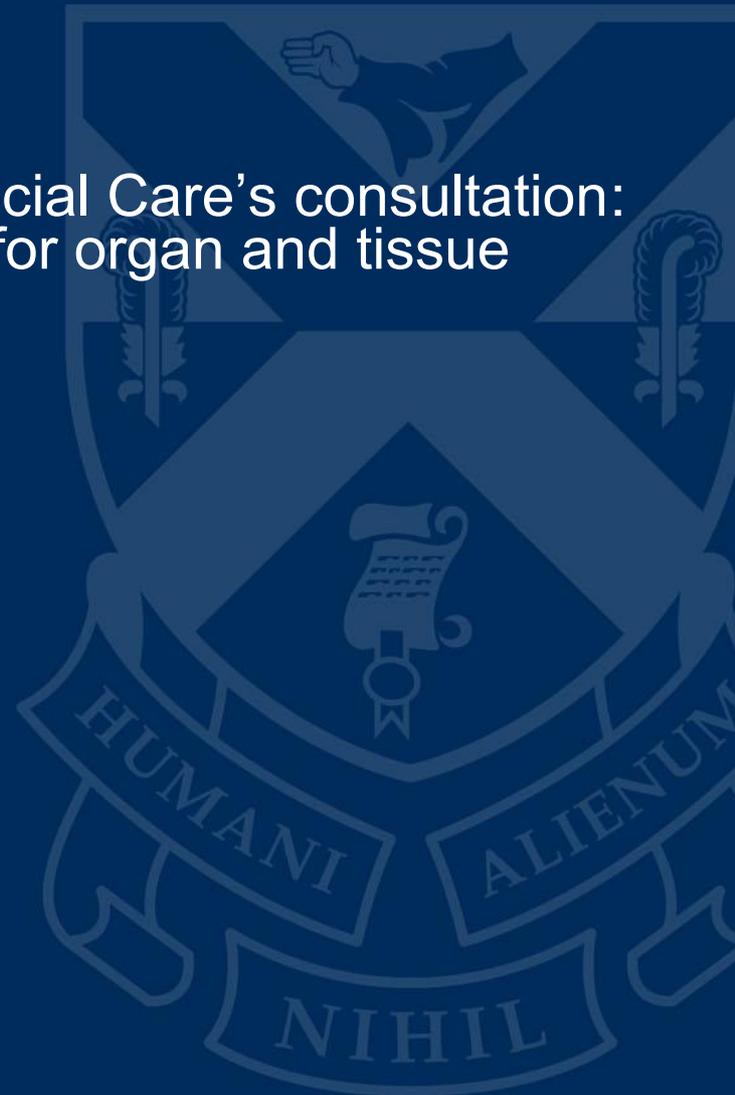


Law Society
of Scotland

Consultation response

Department of Health and Social Care's consultation:
introducing 'opt out' consent for organ and tissue
donation in England.

March 2018



Introduction

The Law Society of Scotland is the professional body for over 11,000 Scottish solicitors. With our overarching objective of leading legal excellence, we strive to excel and to be a world-class professional body, understanding and serving the needs of our members and the public. We set and uphold standards to ensure the provision of excellent legal services and ensure the public can have confidence in Scotland's solicitor profession.

We have a statutory duty to work in the public interest, a duty which we are strongly committed to achieving through our work to promote a strong, varied and effective solicitor profession working in the interests of the public and protecting and promoting the rule of law. We seek to influence the creation of a fairer and more just society through our active engagement with the Scottish and United Kingdom Governments, Parliaments, wider stakeholders and our membership.

Our Health and Medical Law Sub-committee welcomes the opportunity to consider and respond to the Department of Health and Social Care's consultation on introducing 'opt out' consent for organ and tissue donation in England.

General comments

While we generally support the promotion of good public health and health equality, we are not in position, nor would it be possible for us to comment on the policy aims of whether England should move to a soft opt-out system for organ donation. However, if a soft opt-out system was to be implemented by legislation, this would reverse the law which is currently in place. Therefore, two general, but recurring themes underpin our response.

First, proposals should be clear and transparent in their aims and objectives.¹ Second, we believe that there should be advance publicity which is tailored to meet the needs of the diverse groups in our society, be timely and easily accessible. We also suggest that targeted 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.

¹ The need for clarity and transparency is a recurring theme in many studies to date. See, for example, Welsh Government, (2013) 'Soft opt-out system of organ donation: researching the views of Specialist Nurses and Clinical Leads. Research Summary 46/2013; Irving 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

Specific comments

Q1. Do you think people should have more ways to record a decision about organ and tissue donation?

Yes – there should be as many ways as possible to record a decision, including when people are doing other things, such as registering with a GP.

As noted in section 3.2 of the consultation document,² the proposal reverses the law which is currently in place. In the interests of transparency, there should be an easily understood process in place to facilitate the recording of a decision. There should be robust infrastructural systems to promote openness and trust in the donation system.³

We agree that other government administrative procedures could be used to capture as many people's decisions about organ donation as possible and that decisions could be recorded when using other health settings, such as dental surgeries or opticians.⁴

Q2. What do you think are the advantages or disadvantages of including personal information on someone's organ donation decision?

We believe that the advantages of including personal information may outweigh the disadvantages. The organ donation decision is a complex one, based strongly on personal beliefs.⁵

The current system is based upon an altruistic approach and research⁶ 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

² UK Govt, Dept of Health and Social Care. (2017) Consultation on introducing 'opt out' consent for organ and tissue donation in England. Available from : <https://www.gov.uk/government/consultations/introducing-opt-out-consent-for-organ-and-tissue-donation-in-england/consultation-on-introducing-opt-out-consent-for-organ-and-tissue-donation-in-england> [Accessed 7 February 2018]

³ Brown, R. (2017) Organ Donation: Presumed Consent and Focusing on What Matters. Journal of Medical Ethics (blog). Available from: <http://blogs.bmj.com/medical-ethics/2017/09/25/organ-donation-presumed-consent-and-focusing-on-what-matters/> [Accessed 7 February 2018]

⁴ As suggested in 3.2 of the Consultation document.

⁵ Irving, M, J *et al.* (2011) Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. *Nephrology Dialysis Transplantation*, Volume 27, 6, pp 2526–2533, Available from: <https://doi.org/10.1093/ndt/gfr683> [Accessed 7 February 2018]

⁶ Savage, Michelle, (2015) *Organ Transplantation: A Legal and Moral Analysis* (2015). Law School Student Scholarship. Paper 703. [Available from] http://scholarship.shu.edu/student_scholarship/703 Accessed 28 February 2018

influencing factors, for example, dignity, fear of clinical neglect, family attitudes, religious belief and grief may also influence an individual's decision as to whether or not they will donate⁷.

The introduction of an opt-out system also initiates a wide number of ethical issues. These do not include religious and cultural perspectives as noted above, but more fundamentally, the importance of each individual being able to make an autonomous decision in relation to organ donation.⁸

We agree that being made aware of cultural sensitivity to issues such as apprehensiveness to discuss death among certain groups or individuals and the importance to many of death rituals may improve dialogue regarding organ donation.

More generally, it may also help families understand how their loved one has made their decision. Additionally, having some knowledge of what was important to them in shaping their decision may perhaps remove some of the burden of decision-making from their family.

Finally, gaining a greater understanding about why individuals take the decision that they do in relation to organ donation, will aid in the development of strategies to enhance organ donation.

Q3. How can we make people more aware of the new rules on organ donation?

Our comments here focus upon the reach and effectiveness of any campaign. The Human Tissue (Scotland) Act 2006, helpfully incorporates a duty to promote information and awareness about organ donation and section 1(b) provides that:

'It is the duty of the Scottish Ministers to— (a) promote, support and develop programmes of transplantation; (b) promote information and awareness about the donation for transplantation of parts of a human body.'

We believe that this would provide some basis for any future guidance. It may also be useful to consider the approach taken in Wales. The campaign to raise awareness of the Human Transplantation (Wales) Act 2013 had a lead in time of 2 years.⁹

⁷ 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

⁸ Oliver M, *et al* (2010) Organ donation, transplantation and religion. *Nephrology, dialysis, transplantation: Official publication of the European dialysis and Transplant Assoc.* 26 2 43-444.

⁹ Welsh government (2017) Taking organ transplantation to 2020. Available from: <http://gov.wales/topics/health/nhswales/organ/transplantation/?lang=en> [Accessed Feb 28 2018]

Most professional organisations appear to favour an extensive and high profile public campaign,¹⁰ 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. An Australian study¹¹ indicated that whilst public support for organ donation was ‘fairly consistent’, the reasons for support varied depending on age group. Diverse communication strategies may therefore be required to effectively inform different age groups and differing views. It should also be made clear that it is acceptable to have a change of mind and there should be a simple process in place to accommodate this.

Q4. If the law changes, would this affect your decision about organ donation?

We are not in a position to respond to this question.

Q5. If the law changes, people would be considered willing to be an organ donor unless they have opted out. Do you think this change could have a negative impact on people from some religious groups or ethnic backgrounds?

There is wide evidence to suggest that it may. We would refer to our response to Question 3 above and re-emphasise the important of diverse and flexible communication strategies.

Q6. If the law changes and someone has died, and they have not opted out of organ donation, should their family be able to make the final decision?

We recognise that this remains one of the most challenging questions. We find this a very anomalous situation since, at present, there is no legislative requirement to ascertain the wishes of the family, but yet, through custom and practice, they will normally be consulted and have the potential to veto a decision made by the donor. In other words, there are key differences in what is provided by the legislation and what is done in practice.

¹⁰ See for example, Reilly H., BMA Scotland submission in support of Petition PE1453 Calling on the Scottish Parliament to urge the Scottish Government to introduce an opt-out system of organ donation in Scotland to help save more lives. Available from: https://www.parliament.scot/S4_PublicPetitionsCommittee/General%20Documents/PE1453_C_BMA_Scotland_10.01.13.pdf [Accessed February 27 2018]

¹¹ Irving et al (2014) What factors influence people's decisions to register for organ donation? The results of a nominal group study. *Transplant Int.* 2014 Jun;27(6):617-24.

An international study was undertaken relating to consent systems for deceased organ donation.¹² The study concluded that, where next of kin involvement was sought, their views have a larger and more immediate effect than legislative changes.¹³ This was regardless of the type of organ donation model that was adopted and whether the views of the potential donor were expressed or unknown.¹⁴ The study notes that:

'Nineteen out of the 25 nations [interviewed] with presumed consent provide a method for individuals to express a wish to be a donor. However, health professionals in only 4 of these nations responded that they do not override a deceased's wish because of a family's objection'.¹⁵

It would appear that whilst the views expressed by the potential donor are given priority, in the current and possibly future models of organ procurement, family members may be the ultimate arbiters of whether or not donation will proceed¹⁶. As was acknowledged by Dove *et al*, 'There is... significant space for manoeuvring around the letter of the law'.¹⁷ We make some further observations in relation to language used within the Human Tissue (Scotland) Act 2006 (the 2006 Act) under question 7 below and to the possible impact of two recent cases decided in the European Court of Human Rights.

Research has shown that health care staff wish explicit guidance to be provided to both families and the health professionals on the consequences of a soft opt out scheme¹⁸. The consultation¹⁹ makes it clear that families will be consulted and have a role to play, for example, in providing medical history. Awareness of the family's emotional needs, and being able to skilfully navigate discussions on difficult issues such as brain stem death or bodily integrity may advance a greater understanding from the family of a possible donor of the importance of their decision.²⁰ Sharing best practice and looking to the experiences of

¹² Rosenblum, A.M *et al*. (2012)The authority of next-of- kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. *Nephrol Dial Transplant* 2012 27: 2533-2546

¹³ Rosenblum, A.M *et al*. (2012)The authority of next-of- kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. *Nephrol Dial Transplant* 2012 27: 2543

¹⁴ Rosenblum, A.M *et al*. (2012)The authority of next-of- kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. *Nephrol Dial Transplant* 2012 27: 2533-2546 at p. 2533

¹⁵ Rosenblum, A.M *et al*. (2012)The authority of next-of- kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. *Nephrol Dial Transplant* 2012 27: 2533-2546 at p. 2533

¹⁶ Vincent A and Logan L. (2012) Consent for organ donation. *British Journal of Anaesthesia* 108 i80-i87 at p. i81.

¹⁷ Dove, E.S. (2015) Elberte v. Latvia:Whose tissue is it anyway-Relational autonomy or the autonomy of relations? *Medical Law International* 15 2-3 77-96 at p.88

¹⁸ The need for clarity and transparency is a recurring theme in many studies to date. See, for example, Welsh Government, (2013) 'Soft opt-out system of organ donation: researching the views of Specialist Nurses and Clinical Leads. *Research Summary* 46/2013 at pp3-4;

¹⁹ Scottish Government. Organ and Tissue Donation and Transplantation. A consultation on increasing numbers of successful donations. [Accessed Jan- arch 2017] at p13-15. Available from: https://consult.scotland.gov.uk/health-protection/organ-and-tissue-donation-and-transplantation/supporting_documents/00511160.pdf

²⁰ Ghorbani, F *et al* (2011) Causes of Family Refusal for Organ Donation. *Transplantation Proceedings* 43 405-406.

other jurisdictions and international collaboration²¹ may contribute towards the further enhancement of communication between the healthcare professional and the family.

It is suggested that further research is required throughout the UK to investigate the relationship between family refusal and donation rates.

Q7. Do you think someone's family should be able to decide if their organs are donated, if it is different to the decision they made when they were alive?

We refer to question 6 above for some more general reflections. Whichever system is in operation, it is right that we evaluate the rights and wrongs of countermanding the deceased person's expressed wishes. Not only can those wishes be overruled by the current system, but also the refusal of transplant denies another person the possibility of receiving an organ. Thus we are placing the rights of the relative far above the integrity of the deceased and the need of a possible recipient.²² The last autonomous wish of the individual is potentially being thwarted simply because he or she is in no position to object.²³

The Royal College of Physicians Edinburgh has made the point that, in practice, consent for organ donation is sought from the next of kin and approximately 40% of families approached refuse consent. They argue that where the deceased was on the Organ Donation Register (ODR) the next of kin is less likely to refuse consent - in only 10% of cases, compared to 50% where the deceased was not on the ODR. They stated, 'A higher rate of organ donation will reflect increased public awareness, societal attitudinal change to donation, and improved clinical infrastructure.'²⁴

More specifically, we make reference to possible rights of individual family members under the European Convention on Human Rights. Two cases are highly relevant here - *Petrova v Latvia*²⁵ in 2014 and *Elberte v Latvia*²⁶ in 2015. We suggest that any future proposals are considered in the light of the outcome of these cases. We refer to a comprehensive

²¹ For a comprehensive discussion on successful international collaboration please see- Mulvania, P. *et al* (2014) Successful International Collaboration Improves family Donation Conversations resulting in Increased Organ Donation. *Transplantation Proceedings* 2058-2065.

²² Royal College of Practitioners 'Organ Donation an Outline for General Practitioners' Available from : <http://www.rcgp.org.uk/policy/rcgp-policy-areas/organ-donation.aspx> [Accessed February 28 2018]

²³ J K Mason and R A McCall Smith (1994) *Law and Medical Ethics* [10th edition Oxford publishing] p304

²⁴ Royal College of Physicians of Edinburgh, (RCPE)R 432. Found in Summary of Consultation Responses.

²⁵ Application no.4605/05 [2014] ECHR 805

²⁶ Application no. 62143/08 [2015] ECHR 1

submission which was made in response to the Scottish Government consultation²⁷ which considers these cases in detail.²⁸

Q8. Which of the following should not be included in the proposed new rules about organ donation?

- **children under 18 years' old**

We believe that children and young persons should only be opted-in with their consent. 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 of the 2013 Act, a child is any person under the age of 18 years, and parental / guardian consent is required below that age.

- **visitors to England**
- **people living in England for less than 12 months (for example, students from overseas, armed forces personnel)**

We make some general observations in relation to the above categories. We agree that there should be a residency period in England for potential donors prior to death. Visitors and tourists who may be unwilling to consent to donation, or whose views are unknown, should remain unaffected by any change in the current law.

There could be difficulties over how any period of residency is to be ascertained. How would healthcare professionals know that the potential donor was not resident, since he or she would presumably have at least had a short term address in England. Also, if the period of residency has to be continuous, how are healthcare professionals to establish this, especially when decisions about organ donation have to be made within a short timeframe? Healthcare professionals may have to rely on information from the deceased's relatives or companions in this country.

12 months seems a reasonable period of residency. It is a more than a mere visit and gives time for a person to make a decision.

²⁷ Scottish Government 'organ donation and transplantation' <http://www.gov.scot/Topics/Health/Services/OrganDonation> [Accessed March 3 2018]

²⁸ Tickell A. (2017) 'In accordance with the law: Is Scottish organ donation law ECHR compatible?' Available from: https://www.academia.edu/31856953/Scottish_Government_consultation_response_in_accordance_with_law_is_Scottish_org_an_donation_law_ECHR_compatible [Accessed March 14 2017]

One group may pose particular issues in this respect; international students coming to study in England. 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 English 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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