



# Soft opt-out system of organ donation: Revisiting the views of Specialist Nurses and Clinical Leads post-legislation change

---

## Executive Summary

### 1. Introduction

- 1.1 On 1 December 2015, the Welsh Government introduced a soft-opt out system of organ donation through the Human Transplantation (Wales) Act 2013. Beaufort Research was commissioned to undertake qualitative research to assess the views of Specialist Nurses (SNODs) and Clinical Leads (CLODs) for organ donation, regarding the move to a soft opt-out system in Wales once the legislation had come into effect. Two previous waves of qualitative research were carried out prior to December 2015 to gather SNODs' and CLODs' views on preparations for the legislative change.
- 1.2 The research aims for this final wave were to explore the impact of the legislation on working practices and whether SNODs and CLODs identified further training needs in relation to the new system. The report presents personal views expressed by the SNODs and CLODs who took part.
- 1.3 SNODs and CLODs play key roles in the organ donation process. SNODs are responsible for establishing consent and for donor co-ordination. Once a patient is identified clinically as a potential donor, the SNOD discusses the patient's organ donation decision with the family. They also examine the patient's medical history and will ask various questions of family members about the deceased's lifestyle and health. In addition, the SNOD ensures that appropriate medical tests are carried out. These responsibilities apply to the previous and new legislation.
- 1.4 CLODs are typically senior clinicians in hospitals who have accepted a particular responsibility to implement recommendations made by the UK Organ Donation Taskforce<sup>1</sup> and help increase donation rates. They work with colleagues in intensive care units (ICU) and emergency departments (ED), encouraging organ donation to be viewed as part of normal, everyday practice in hospitals.

---

<sup>1</sup> Organ Donation and Transplantation <http://www.odt.nhs.uk/donation/deceased-donation/organ-donation-taskforce/>

1.5 The research consisted of 25 in-depth interviews: 17 with SNODs and eight with CLODs across South Wales, North Wales and North West England where SNODs also cover the North Wales region. Fieldwork took place from late September to late October 2016.

## **2. Impact of the new legislation on working practices**

- 2.1 Overall, levels of awareness and support for the change to the organ donation system were high and significant increases were evident since the Wave 1 survey.
- 2.2 In the 2015 research, SNODs and CLODs did not predict that the new legislation would affect their working practices greatly. Several months on from the law's introduction, participants' expectations had been largely borne out.
- 2.3 The transition was seen as quite smooth. Conversations with families post-legislation were considered fairly straightforward.
- 2.4 Participants tended to believe that they were encountering more situations than in the past where the family stated that they were aware of the legislative change<sup>2</sup>. They also thought that they were coming across more families who were already aware of the patient's decision<sup>3</sup>.
- 2.5 In addition, some participants had yet to experience a deemed consent approach to a family and the number of approaches made on an annual basis were normally low for some in any case.
- 2.6 CLODs sometimes referred to the legislative change having more of an effect on SNODs than themselves because they tended not to be involved in conversations with families of patients.
- 2.7 In terms of the practicalities associated with the new system, further administrative steps were now required before approaching a family to explore the possibility of a deemed consent. However, these steps were not considered onerous.
- 2.8 The main area where participants highlighted a change to working practices was the conversation with families and introducing the subject of consent. A small number of participants felt that the start of the conversation had been too focused on ascertaining from family members whether or not a patient fulfilled the criteria to have their consent deemed. It was felt that it would be more appropriate to introduce the topic of donation in a similar way to the approach used before the new legislation was implemented; and then look to establish any known decision.
- 2.9 There was sometimes uncertainty among participants about organ donation outcomes where deemed consent applied. Participants surmised that the same result would probably have been reached under the previous legislation with a supportive family where there had been no conversation about donation between the family and patient.
- 2.10 A small number of participants thought that they were encountering more known decisions voiced by families that the patient had decided not to be a donor; and more occasions

---

<sup>2</sup> Public attitudes to organ donation: prompted awareness for March 2016 increased from 75 per cent in November 2015 to 84 per cent; in June 2016 the figure was 83 per cent. <http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

<sup>3</sup> Public attitudes to organ donation: the proportion of the general public saying they had discussed their organ donation decision with a family member has remained at a similar figure from November 2015 to June 2016 (47% and 48% respectively). This figure has increased slightly from previous waves of research where the proportion remained at around 4 in 10 people.

where families were choosing to override either a known decision to donate or a deemed consent.

- 2.11 The relationship between SNODs and clinicians had improved on the feedback received in the previous waves of research.

### **3. Training and guidance in relation to the new legislation**

- 3.1 On the whole, participants felt that they had received sufficient training and guidance leading up to the legislation implementation. A focus in training on the conversation with the family addressed the need anticipated by participants in the 2015 research.
- 3.2 Training and guidance had been provided in a range of formats, including presentations, discussions, The Code of Practice for the Human Transplantation (Wales) Act 2013, FAQs and role playing.
- 3.3 Not everyone liked taking part in role playing scenarios although its benefits were acknowledged. Video content on conversations with family also received mixed reviews.
- 3.4 Printed material, especially a flowchart of the steps, was a resource some participants kept to hand and referred to when needed. Some of those with little experience of family approaches post-legislation valued this kind of material as a reminder.
- 3.5 Views on the timing of pre-legislation training delivery varied, with some thinking it about right but others commenting that it felt a little rushed and last minute.
- 3.6 When the legislation changed senior staff had been available for SNODs to consult, for example when facing a first deemed consent approach to a family. Peer support among SNODs had also been valuable in this respect.
- 3.7 Regular team meetings continued to act as a platform to discuss experiences.
- 3.8 With hindsight, more training could have been provided on practising conversations with families according to a few, for example reviewing how best to guide the conversation in terms of raising the topic of any known decision at the appropriate point. Continued practice post-legislation might also have helped to identify any improvements earlier.
- 3.9 Given their experiences with families on occasion not supporting deemed consent or overriding a patient's ODR opt-in, a small number of SNODs and CLODs highlighted a need for reviewing the approach to the conversation.
- 3.10 Where SNODs had yet to experience a deemed consent conversation, there was thought to be a need to refresh their training so that they felt as prepared as they did when the new legislation was implemented.
- 3.11 Sharing good practice as well as difficulties encountered on an ongoing basis was also considered a valuable activity for all levels of experience with the new legislation, for example during meetings.
- 3.12 Role-playing, on balance, was considered an effective means of practising family conversations (e.g. with actors in smaller groups or with colleagues).

#### **4. The new legislation: other hospital staff and the general public**

- 4.1 In keeping with the findings from the previous research, participants had mainly focused their education activities on critical care and emergency department (ED) staff given their proximity to the donation process. Their aim was to encourage staff to keep organ donation front of mind and to update them with any developments related to the legislation.
- 4.2 It was still the case that finding the time when other staff were available for education often proved difficult. Examples therefore included informal conversations as well as regular audit meetings.
- 4.3 Some participants explained that their focus had moved towards emphasising to staff the importance of early referral for a successful donation rather than concentrating too much on the detail of the legislation.
- 4.4 Critical care and ED staff were thought to have a greater understanding of the legislation than other hospital staff who were often believed to have similar knowledge levels as the general public.
- 4.5 There was a suggestion as in previous research with SNODs and CLODs that organ donation should be part of the curriculum for students in medicine / nursing.
- 4.6 Reflecting their experiences with families of patients, participants believed that awareness of the legislation among the general public as a whole was quite high. Despite a perceived increase in awareness among the general public of the new legislation and patients' decisions, participants did not think that those they encountered had a very strong grasp of the legislation (e.g. assuming it was a mandatory opt out system). The role of the family in the donation process was not believed to be very clear to the public either.
- 4.7 Some participants felt therefore that there was still work to do in explaining the choices available to the general public regarding organ donation. The benefits of organ donation also needed to be more prominent, according to some.

#### **5. Conclusions and considerations**

- 5.1 With the new legislation now implemented, this final wave of research confirms participants' expectations from previous research that their working practices would not alter significantly.
- 5.2 The transition from the old to the new system is reported as being reasonably smooth to date. In 2015, participants expected their training needs to be in hand; and looking back to December 2015 they generally felt sufficiently prepared for the switch to the new legislation.
- 5.3 Participants also expected in previous waves that the main area of potential difference in working practices between the two legislations would be the wording used in elements of the conversation with families. This prediction has proved to be the case, particularly with possible cases of deemed consent.
- 5.4 Feedback indicates that changes to the conversation have included in some instances exploring with families whether or not they knew of the patient's decision regarding donation during the initial approach to the family. Some believed that it would be appropriate to raise and discuss the subject of organ donation first and then seek to establish the patient's decision if not recorded. The research indicates that steps are being taken to review this element of the conversation with SNODs.

- 5.5 The research also highlights two areas which would benefit from continued monitoring and further investigation. The first is the emerging perceived trend regarding an increase in known decisions, including decisions not to consent. The second area relates to instances of families not supporting deemed consent or overriding an ODR opt-in.
- 5.6 Welsh Government trend data show that the proportion of people replying 'yes' to the statement 'Have you ever discussed your wishes regarding organ donation after your death with a family member?' has increased slightly from 47 percent in November 2015 to 48 per cent in June 2016. . The qualitative feedback on instances of more families expecting an approach is in line with Welsh Government trend data on increasing awareness of the new law.
- 5.7 The nature of the role means that some SNODs have more frequent experience than others of the donation process; and there are still some SNODs yet to encounter a deemed consent scenario.
- 5.8 The combination of factors described above points to a recommendation for continued, regular training and guidance for SNODs and CLODs with a focus on conversations with the family. This would involve:
- Helping them to keep fresh in their minds good practice for approaches, especially around deemed consent;
  - Enabling those with more experience to share what they have learned with others including between South and North Wales;
  - Reviewing how best to guide the conversation in terms of: raising the topic of any known decision at the appropriate point; concluding a conversation where a known decision via a family conversation is not to donate (for example confirming how and when the decision was made); and managing conversations with families who are unsupportive of deemed consent or where families override an ODR opt-in.
- 5.9 There appear to be existing channels for sharing information, for example via regular meetings, both formal and less formal, phone calls and email. However, there is also a need identified by some participants to have the option for more structured training through continued practice on the conversations with families, for example via role-playing in either larger or smaller groups.
- 5.10 It is also worth bearing in mind when communicating with SNODs and CLODs the concern they felt on occasion that they might be held responsible for any perceived issues seen to be affecting the legislation's success, for example a lack of an increase in consent rates.
- 5.11 The improving but potentially plateauing relationships with clinicians noted in 2015 have developed further in 2016 with some very positive feedback on working with other staff. More broadly, there were expectations of a gradual cultural change among clinicians as consideration of donation became the norm and new, more 'proactive' staff came into post.
- 5.12 Finally, given that the feedback in this report is still relatively soon after the legislation was implemented, there may be a role for revisiting SNODs' and CLODs' views, for example in two years' time. By this time, they will have gained more experience of conversations with families. Furthermore the impact of any revisions to how conversations with families are managed will have had time to bed in and can therefore be assessed, from participants' perspective.

Report authors: Beaufort Research

Full research report: McAllister, F. and Blunt, A. (2017). *Soft opt-out system of organ donation: Revisiting the views of Specialist Nurses and Clinical Leads post-legislation change*. Welsh Government, GSR report number 43/2017.

Available at: <http://gov.wales/statistics-and-research/soft-opt-out-system-organ-donation-researching-views-specialist-nurses-clinical-leads/?lang=en>

Views expressed in this report are those of the researchers and not necessarily those of the Welsh Government

For further information please contact:

Janine Hale

Knowledge and Analytical Services

Welsh Government

Cathays Park

Cardiff

CF10 3NQ

Email: [janine.hale@gov.wales](mailto:janine.hale@gov.wales)

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

This document is also available in Welsh.

**OGI** © Crown Copyright      Digital ISBN 978-1-78859-152-2