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

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Soft opt-out system of organ donation:

Revisiting the views of Specialist Nurses and Clinical Leads post-legislation change

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

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Table of contents

Executive summary	2
1 Background, objectives and methodology.....	9
1.1 Background	9
1.2 Research objectives	11
1.3 Research methodology.....	11
2 Impact of the new legislation on working practices	13
2.1 Impact on working practices – expectations versus experiences	14
2.2 Experiences with families of patients.....	17
2.3 The relationship with clinicians	22
3 Training and guidance in relation to the new legislation	25
3.1 Training and guidance received on the new legislation	26
3.2 Helping to embed the new legislation into working practices.....	34
4 The new legislation: other hospital staff and the general public	40
4.1 Hospital staff.....	40
4.2 Perceptions of awareness and understanding among the general public.....	43
5 Conclusions and considerations	47

Appendix: interview topic guide

Executive summary

Introduction

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.

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.

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.

CLODs are typically senior clinicians in hospitals who have accepted a particular responsibility to implement recommendations made by the UK Organ Donation Taskforce¹ 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.

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

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.

Impact of the new legislation on working practices

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.

The transition was seen as quite smooth. Conversations with families post-legislation were considered fairly straightforward.

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 change². They also thought that they were coming across more families who were already aware of the patient's decision³.

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.

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.

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.

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

² 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>

³ 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.

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.

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.

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

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

Training and guidance in relation to the new legislation

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.

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.

Not everyone liked taking part in role playing scenarios although its benefits were acknowledged. Video content on conversations with family also received mixed reviews.

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.

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.

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.

Regular team meetings continued to act as a platform to discuss experiences.

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.

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.

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.

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.

Role-playing, on balance, was considered an effective means of practising family conversations (e.g. with actors in smaller groups or with colleagues).

The new legislation: other hospital staff and the general public

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.

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.

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.

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.

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.

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.

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.

Conclusions and considerations

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

1 Background, objectives and methodology

1.1 Background

On 1 December 2015 the Welsh Government introduced a soft-opt out system of organ donation through the Human Transplantation (Wales) Act 2013. The legislation means that, unless an individual indicates otherwise, their consent to organ and tissue donation will be deemed to have been given in the event of their death. Relatives of the patient are consulted, as was the case under the previous legislation. Under the new law, individuals are able to: join the Organ Donor Register (ODR); to opt in or opt out of being an organ donor; choose to do nothing and have their consent deemed (criteria apply); or nominate a representative to act on their behalf.

The Welsh Government developed an evaluation programme to underpin the implementation of the Act that included research with health professionals and the general public. Specialist Nurses (SNODs) and Clinical Leads (CLODs) are a critical group to include within this research programme to ensure that their views can be monitored. Their views on working practices and preparations have been sought during the lead-up to 1 December 2015 and also now that the legislation has been implemented.

SNODs and CLODs perform important roles in the organ donation process, especially in discussions with the family around the patient's decision, where they are the link between families and the organ donation process.

Under the previous and current system, SNODs are contacted if the intention to confirm death by neurological criteria had been established (for donation after brain-stem death, DBD) or when a clinical decision to withdraw life sustaining treatment had been made (for donation after circulatory death, DCD). This notification of SNODs occurs regardless of whether or not the patient's decision is recorded on the ODR. The SNOD then discusses the patient's decision with the family. Where donation may go ahead (based on the patient registering to opt in on the ODR, the family knowing of the patient's decision, or deemed consent and family supporting the decision), the SNOD ensures that medical tests, such as blood group and tissue type matching, are carried out. They also examine the patient's medical history and will ask the family questions to confirm whether or not organ donation can take place.

CLODs are appointed to key roles in hospitals to implement recommendations made by the UK Organ Donation Taskforce and help increase donation rates. They work with colleagues in intensive care units and emergency medicine departments, encouraging organ donation to be viewed as part of normal, everyday practice in hospitals' end of life care. CLODs are responsible for raising the profile of organ donation and providing expert advice on the ethical and legal aspects.

There are approximately 15 'embedded' SNODs in Wales, meaning they work within the critical care unit of a specific hospital. Each Health Board has at least one CLOD, depending on geographical area. The work of these teams is believed to have contributed to the steady increase in donation and transplant figures in recent years, leading up to the legislative change. Thus understanding the perspective of SNODs and CLODs on the change to the organ donation system is an important component in helping to make the legislative implementation a success.

Their perspectives have been gathered via three waves of qualitative research. These waves are concerned with the preparations for the legislative change and understanding the impact of the legislation on working practices once it has come into being. The first wave took place in 2013⁴ before the proposals to introduce a soft opt-out system were passed into law. The second wave took place in early 2015⁵ following the passing of the Act and in the run up to its full implementation. The final wave with which this report is concerned took place in autumn 2016, following full implementation of the Act.

By monitoring the views of SNODs and CLODs in this way, the Welsh Government is able to plan for any potential issues or concerns this key group has, as well as better understand where training and education may still be needed.

⁴ 2013 Beaufort research report <http://gov.wales/statistics-and-research/soft-opt-out-system-organ-donation-researching-views-specialist-nurses-clinical-leads/?lang=en>

⁵ 2015 Beaufort research report <http://gov.wales/statistics-and-research/soft-opt-out-system-organ-donation-researching-views-specialist-nurses-clinical-leads/?lang=en>

1.2 Research objectives

The following main objectives were set for the research study:

- Assess the views of SNODs and CLODs in Wales regarding the implementation and impact of the soft opt-out system;
- Build on the findings provided in the pre-legislation research project with this audience (2015);
- Gain an understanding of any changes in working practices and experiences of SNODs and CLODs now the legislation has been implemented;
- Evaluate any changes in expectations, attitudes and concerns regarding the implementation of, and impact of moving to, a soft opt-out system;
- Gain an understanding of how moving to a soft opt-out system has impacted on their discussions with family members about consent for organ donation;
- Determine any additional training requirements that Specialist Nurses and Clinical Leads may still have in relation to the new legislation;
- Identify unanticipated issues articulated by SNODs and CLODs having moved to a soft opt-out system.

1.3 Research methodology

Beaufort used a qualitative, individual interview method to take into account the flexibility required of SNODs' and CLODs' roles and working patterns. All but one of the 25 interviews were conducted face to face in a confidential environment at participants' place of work. One discussion was a paired in-depth interview to fit with participants' schedules. One interview was conducted by telephone owing to participant availability and geographic location.

Prior to Beaufort beginning to contact potential participants, the Welsh Government sent out an email to each SNOD and CLOD outlining the purpose of the research and informing them that they might be contacted by Beaufort to see if they would be interested in taking part. Using a database provided by the Welsh Government, Beaufort recruited:

- 17 SNODs (covering South Wales, North Wales and North West England where SNODs also covered North Wales);
- 8 CLODs from an available sample of 14 contacts (in both South and North Wales).

The 25 interviews broke down as follows:

	SNODs	CLODs
North Wales / North West England	7	3
South Wales (also covering South West Wales, Mid Wales and Hereford)	10	5

Fieldwork took place late September to late October 2016, with interviews lasting between 30 minutes and one hour.

Each interview was audio-recorded with participants' permission. The interviews were free-flowing based on a topic guide agreed with the client (see appendix). The Beaufort team transcribed the conversations and analysed them by identifying and grouping points made within each transcript. Points were then developed into themes depending on how prevalent they were.

The report contains personal views expressed by the SNODs and CLODs who took part. It also contains verbatim comments (provided in italics) from participants. These comments illustrate individual views on the research themes. They do not include attributions and have been edited as appropriate, to preserve anonymity. The weight attached to a particular finding is highlighted as appropriate. Where a specific point is being illustrated by verbatim comments, each comment is from a different participant. From time to time, the language of the report reflects the routine technical terms and phrases used by participants as they described their day to day tasks.

2 Impact of the new legislation on working practices

Key points and conclusions

- 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.
- The transition was seen as quite smooth. Conversations with families post-legislation were considered fairly straightforward.
- Participants tended to believe that they were encountering more situations than in the past where the family stated that they were aware of the legislation change. They also thought that they were coming across more families who were already aware of the patient's decision.
- 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.
- 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.
- Further administrative steps were now required before approaching a family to explore the possibility of a deemed consent but these were not onerous.
- The main area where participants highlighted a change to working practices was the conversation with families and introducing the subject of consent.
- 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.
- 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.
- 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 where families were choosing not to support deemed consent or wanted to override an ODR opt-in.
- The relationship between SNODs and clinicians had improved on the feedback received in the previous waves of research.

2.1 Impact on working practices – expectations versus experiences

In general, SNODs and CLODs commented that they had not experienced or observed any great change to working practices since the legislation came into being. This was particularly the case in North Wales / North West England, and some parts of South Wales, where participants had less experience of approaching families post-legislation. The care given to families, for example, had remained the same and it had been a 'relatively easy' transition as one participant described it. In addition, there were still SNODs who had yet to encounter a potential deemed consent situation so the process had remained very similar to the pre-change in legislation practices.

[The conversations] haven't changed a great deal. We still approach the families about organ donation and then depending on their responses we then bring in the subject of deemed consent if applicable and whether they had ever spoken about it and all that. We're still approaching the families in a fairly presumptive way, the way we always have done.

It's been pretty much the same because of the hierarchy of how we would approach a family, whether it's a known wish first of all. If they've opted in, then you would go in and have a certain conversation that you wouldn't be asking for the relative's consent.

The only aspect that's changed is actually how we obtain the actual consent itself. As to approaching families, I don't see any difference at all in it. I don't see any difference with the change of legislation, the approach to the family should still, essentially, be the same.

We still check the register. We still ask the family if there's been any expressed decision. We were given clear guidance and a clear flowchart so I'm quite comfortable with doing it.

Some did refer to additional administrative steps which were now needed in advance of an approach to a family of a patient to explore 'whether the patient fulfilled the criteria to deem their consent'. The conversation itself might change slightly depending on the patient's circumstances (discussed below). However, the process overall was not thought to have altered significantly. In addition, references in the 2015 research to staff in a few

cases requiring clarification on residency and cross-border scenarios had evidently been addressed as there were no reported issues with these topics to date.

It's just meant that we just have to all remember about the legislation and we are checking the ODR [Organ Donor Register] and checking the complications of if they are registered or not. It's just another thought really.

Some CLODs commented that the new legislation affected SNODs' rather than their own working practices with the checks that SNODs were required to carry out in advance of approaching a family.

I don't think from the point of view of the consultants or the nursing staff it's made that much of a difference. Apart from us being aware of that, there's been little change.

From my point of view, nothing has really changed to be honest. Having said that, we haven't had many donors, but when we have had donors we've just done the same thing which is take the SNOD into the end of life discussion and let them take over when it comes to requesting donation.

The main area therefore where participants had noted a change to working practices related to donation conversations, with a focus on establishing the patient's decision regarding donation. Even then, the changes were sometimes described as 'subtle'.

I think working practices have changed in a subtle way. Obviously it only applies to consent. Everything other than that tends to remain the same. It's generally how we approach families based on what we know about the decisions that the patients made in life.

That's the biggest change is the deemed consent conversation that we're having. Everything else remains the same with the process. The process hasn't really changed fundamentally.

Involving the family continued to be an integral part of the process in that a deemed consent could not be established until the SNOD had talked to the family. This might be, for example, to see if the relative had discussed donation with them. On occasion,

participants commented that the legislation had not altered the fact that families ultimately can still make the final decision.

Before we go in to speak to the families, if there's no registration on the Organ Donor Register and we haven't found a card in their possession, we don't really know whether deemed consent can be applied until we've spoken to the family.

[Families] still have the same concerns, some are all for it and some have very strong feelings against it. . . . Since we're not overriding families' opinions in any way, I don't think [working practice] has changed.

It was noted that, initially, there had been a little apprehension among SNODs with the introduction of the new legislation. They wanted to ensure they got the conversations right, knowing that 'the country and NHSBT are watching'. Until a SNOD experienced a deemed approach, that anxiety could persist.

When you're doing your deemed consent and you know that people know you're going in there to deem it, then you've got a lot of people watching whether you get a consent or not.

A small number of participants reported how conversations with families had tended to begin by asking about any known decision regarding organ donation. This approach sometimes resulted in the family not wanting to take the conversation any further, making it difficult for the SNOD to introduce and explore the subject of organ donation more generally. Steps were therefore being taken to revisit the conversation approach so that the topic of any known decision was raised slightly later. It was hoped this adjustment would address this emerging unanticipated consequence of the approach to discussions with families. (Experiences with families of patients is discussed in more detail in section 2.2.)

At the very start of the donation conversation, we've been trying to ascertain whether the patient would fall into the deemed category or not. . . . Actually we should be introducing the donation conversation as we always have done for the last 10 years and then work out which box they fit into, later on.

We did try, briefly, approaching from the point of view of, 'Have you had a conversation about organ donation?' Whereas now it's, 'I want to tell you about

organ donation'. Then, go back to deemed consent depending on whether they've said they've spoken about it or not.

I'd say it's probably taking us a while to adjust to those changes and practices and actually, we're having to review those practices on the back of some of our data that's coming from that. . . . We've fallen into a practice where we go in and we try to ascertain the decisions that may have been made in life.

2.2 Experiences with families of patients

2.2.1 Families' awareness of the legislation and patients' decisions

Participants with relatively more frequent experiences of approaches to families of patients in the main believed that they were encountering more situations than in the past where the family stated that they were aware of the legislation change⁶. They also thought that they were coming across more families who were already aware of the patient's decision on organ donation⁷. On occasion, references were made to families raising the subject before the SNOD did albeit not fully grasping what the new law entailed (views on the general public's awareness and understanding is discussed further in section 4.2). A small number commented that this perceived development might make the situation easier for families to deal with and the approach for SNODs more straightforward. Some concluded that this apparent increased awareness of the patient's decision was a result of the Welsh Government's advertising campaign.

The one good thing is it's made people talk which has made our job easier.

Whether that's a 'yes' or a 'no' is not as important as the family knowing what their decision was.

I would say without a doubt that every family I went to see were expecting to be asked the question. . . . From a personal point of view it's easier to approach the families to bring up the subjects.

⁶ 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>

⁷ 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.

The important thing is . . . they know what their loved ones wanted, that's all I've ever cared about. . . . They're not having to scratch their chin and wring their hands and worry about whether they've done the right thing afterwards.

It's all very new at the moment, but I think because those families are speaking more, they're giving their opinions a bit more and you're having that clear 'yes' or 'no' really, for a lot of cases.

2.2.2 Deemed consent experiences

Focusing specifically on deemed consent scenarios, some participants recalled that the conversation with the family in these circumstances had been quite straightforward, for example believing that the relative would have agreed to donation regardless of deemed consent. In the deemed consent examples described below, the families had been aware of the new legislation and 'accepted that as normal'.

The families [in deemed consent cases] were calm about the process. It didn't cause any additional distress; and if anything, there was perhaps some burden taken away from them during that time.

There was a query among SNODs and CLODs with deemed consent experience over to what extent the outcome was a result of the new legislation versus generally supportive families who would have supported donation pre-legislation in any case. In a couple of examples given, the family had been supportive of donation before the SNOD raised the subject of deemed consent (it was the SNODs' perception that the family saying yes was not because of the legislation).

The question that we need to try to work out how to answer is would they have said yes anyway if deemed consent wasn't in place? . . . That would hold the key to answering whether deemed consent is a successful legislation change or not. But, it's a very difficult question to answer.

I don't know in hindsight whether [deemed consent cases experienced] would've been a 'yes' anyway. They kind of had come to the 'yes' without me having to raise deemed, but they went down as a deemed because they didn't know [the patient's decision].

Some participants reported that they had yet to encounter a deemed consent, either because of the small number of approaches they had made in Wales or because the family had always known the patient's decision: 'deemed consent isn't the biggest part of it now. I think it's the known wish', as one participant summed up.

The best thing that's come from the advertising has been that people need to talk about it. That's the one thing that's had a positive impact in practice is that families know more often than not now what their loved one wanted.

What I'm finding is that there are a lot more known wishes, which I think is great because that's what the Government wanted. They wanted people to discuss organ donation and make a decision, talk to their families about it. Every time I've gone in and approached a family, where I've thought, oh, the patient's not on the ODR, maybe I can go down the deemed consent route, when I brought up organ donation, they've had that conversation. A lot of it has been positive.

In one case, a participant remarked that the deemed consent experience had been quite straightforward although the family had not fully understood the law change. The SNOD had to explain that the patient had still made a choice by not registering to opt in or opt out, rather than the organs automatically being available without any decision-making.

What I just wanted to make clear with that family was that it isn't just an automatic process because you would fall into the deemed consent. What I wanted to emphasise was the fact that 'because he hadn't made the deliberate decision of registering a 'yes' or a 'no', it leads us to believe that your dad had no objections to organ donation'; and they fully understood that aspect of it.

2.2.3 Decisions not to consent

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, based on previous family conversations. Participants had not expected this apparent trend. There was a suggestion that the SNOD might need to explore the nature and context of a conversation to confirm how the decision had been made known to family members. In addition, participants sometimes expressed concern about seeing examples of families not supporting deemed consent or overriding an ODR opt-in. There was some caution about this early trend,

however, given the small numbers involved with organ donation approaches to families at an absolute level.

There have been a number of deemed cases, and actually more cases than we've ever seen, where people have opted in and their families haven't supported it.

That awareness [of organ donation decisions] is translating into quite a number of refusals to consent or not supporting a deemed consent because they've had a conversation about it. . . . You will explore and probe that conversation. So 'Tell me about when you had this discussion. What was the context? How did he say it?'

I think that [the Welsh Government] have to accept that the initial bit may be that they get more known wishes. I don't know if they were prepared for that. I don't think I was prepared so much for the known wish not to donate. I thought that families would have an issue with deemed consent and most of them don't.

In one reported example of an unsupported deemed consent the family of a patient had thought that it was a compulsory system. Despite the SNOD explaining the legislation, donation did not go ahead. The family maintained that if the patient had wanted to be a donor the patient would have opted in. In another deemed consent case with an unsupportive family, the SNOD had been able to explain that the patient had made a decision in not opting out, which the family came round to accepting. They had originally taken the view, according to the participant, that because the patient had not mentioned donation to the family when the subject had arisen in a conversation, the patient did not want to be a donor.

They thought it was going to go ahead regardless until I explained to them how the law actually worked and then they were more receptive but still decided to override the deemed.

I [initially] felt that, oh my God, how am I going to explain that doing nothing is actually a decision? All the publicity has been doing nothing means you're supportive and to make people realise that doing nothing is making a decision. That's what got [the family] to the point to understand.

The types of reason given by the family that could crop up in these conversations, according to some participants, included concerns over the length of the donation process, how the patient 'might have changed his mind', 'it's not something that the family want to go through', the patient's dislike of hospitals and aversion to visiting the local GP surgery. Even so, this apparent trend of families not supporting deemed consents or overriding ODR opt-ins was described as 'baffling' and an area that required further investigation.

Participants sometimes felt that it was possible families had not fully understood organ donation when they had the conversation with each other and that they were saying no to it 'without understanding the full information'. The situation was then difficult for SNODs to explore any further to ensure that the decision had been made based on a clear understanding of the process and its benefits.

I've had a couple of conversations with family where they've gone, 'Yeah, we fully support deemed consent'. But then as I've explored the whole process of organ donation they've changed their mind because of the length of time and process.

I think it has been historically difficult to probe that a bit more because we have gone in with the question 'have you discussed it?' and they've come up with the answer of 'yes we've discussed it and the answer is no'. I think that we need to work a bit more on understanding that.

A view was expressed on occasion that some SNODs were concerned they might be blamed for a perceived lack of increase in consent rates either because of more known decisions being expressed by families, or families not wanting donation to proceed. Regular team meetings were thought to focus on the refusals rather than consents which were felt to add to the 'pressure'.

I think there's a real concern amongst the SNODs that our practice is being questioned. I think if the Welsh Government don't get the increase in organ donation that they want, we can't help but feel it will be because of us. . . . I could have said what I wanted but this family said it was a known wish not to donate. What can you do with that? I don't know.

There is interest from the Government about what we're doing about our consent rates, but I don't think that helps the SNODs. Everybody works as hard as they can and tries to support these families as best they can.

There hasn't been an increase in consent or anything like that. We're starting to see some trends and some threads coming out of some of the feedback that we get from families about not wanting to be a donor.

In isolated cases, participants talked about feeling slightly uncomfortable with the idea of emphasising deemed consent to an unsupportive family rather than acknowledging what the family believed was the appropriate route to take. In one case, despite the slight reservation, a SNOD still felt prepared to handle this type of approach to a family because of the training received. Further related points made by a small number of participants centred on how the legislation was thought to have created a 'grey area' regarding the role of the family which also made it difficult for SNODs to explore the topic of donation further.

I'm not sure how comfortable I feel about if the conversation isn't going the way I want it to go, bringing in a legislation aspect into that. I don't think it's coercion, I think it's just fact-giving. . . . When you're there as a supportive role, as a nurse, and I know we're there to get a 'yes' if we possibly can, and I know that we are there for transplantation, but sometimes, I think the supportive nurse wants to take over and actually I don't want to force that 'yes' because of the legislation change, rather than that's what the family think is the right thing to do.

You've still got this caveat, 'Is that what you believe?' You've still got to be agreed by the family. To my knowledge, that's been a pitfall.

2.3 The relationship with clinicians

In general, participants felt that they encountered fewer situations than in the past where a clinician might inadvertently affect the organ donation process. Indeed participants often referred to 'very high levels of SNOD involvement in the approach and consent', 'very supportive' consultants and 'proactive', 'collaborative' clinicians. It was thought to be a combination of ongoing education from SNODs and CLODs ('banging the drum', having a CLOD within ED), a longer term effect of SNODs being embedded in ICU units and a gradual change in culture as older clinicians retired. Younger staff were, by default, believed to be more open to involving SNODs. Educating trainee staff was therefore thought to play an important part in encouraging cultural change.

It's becoming better. They are much more open to letting us come into the initial conversation.

I think we have seen a tipping point in culture that the SNODs are generally accepted on intensive care units. The vast majority of units, they will refer in 100% of cases. That's really positive.

They tend to be very, very good now at involving SNODs and the CLOD here has been influential in getting that - a significant impact.

Our intensive care clinicians are much more likely to admit a patient for organ donation, solely for organ donation. Whereas, even three years ago it wouldn't have necessarily been the accepted or the usual thing to do.

The legislation was used as a lever 'allowing us to get in and educate' and emphasising that the organ donation conversation should be left to the SNODs. It sometimes meant that clinicians were reportedly happy to involve a SNOD because of their expertise in consent and the law change.

My CLOD was very clear [when speaking to clinicians] in that 'the SNODs have trained to have this conversation - you haven't. Please don't have the conversation that you don't know'.

I just said the law has got so complicated with this deemed consent business, your best bet is just to refer them to the SNOD and let them sort it out. So it was quite an easy, useful win for us really.

Any issues that occurred were largely put down to examples such as a slightly late referral because of other factors involved or perhaps a family not wanting to wait until a SNOD arrived to have the end-of-life conversation. An example was also given of ED staff being reluctant to admit a patient with non-survivable injuries to ICU, resulting in a situation where the SNOD might be approaching relatives before they were ready to be asked. There were further isolated exceptions described (including what a participant had heard from colleagues), for example a consultant deciding whether a family should be approached or preferring to do the approach themselves. Paediatrics was cited as a unit

where a clinician might be reluctant to 'relinquish anything to an outsider' because of the close relationship developed with the family.

They also quite often feel it appropriate to approach the families themselves, not involve the SNOD, not allow the SNOD into the room for the breaking bad news conversations. And it varies with different hospitals, different personalities. Sometimes they can be downright obstructive.

There's a lot of consultants that come from a different era of being a consultant, where the consultant basically had to do all of this. He was the one responsible. It's a change in culture for some people.

3 Training and guidance in relation to the new legislation

Key points and conclusions

- On the whole, participants felt that they had received sufficient training and guidance leading up to the legislative implementation. A focus on the conversation with the family addressed the need anticipated by participants in the 2015 research.
- Training and guidance had been provided in a range of formats, including presentations, discussions, The Code of Practice for the Human Transplantation (Wales) Act, FAQs and role playing.
- Not everyone liked taking part in role playing scenarios although its benefits were acknowledged. Video content on conversations with family also received mixed reviews.
- 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.
- Views on the timing of pre change in-legislation training delivery varied, with some thinking it about right but others commenting that it felt a little rushed and last minute.
- 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.
- Regular team meetings continued to act as a platform to discuss experiences.
- 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-legislative change might also have helped to identify any improvements earlier.
- Given their experiences with families on occasion not supporting deemed consent or overriding a patient's ODR opt-in, SNODs and CLODs on occasion highlighted a need for reviewing the approach to the conversation.
- 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.
- 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.
- Role-playing, on balance, was considered an effective means of practising family conversations (e.g. with actors in smaller groups or with colleagues).

3.1 Training and guidance received on the new legislation

3.1.2 Preparation for the new legislation and early family approaches

Participants tended to report that they had felt sufficiently prepared for the change through the training and guidance available in a variety of formats (sometimes described as 'clear', 'loads', 'comprehensive', and 'flexible'). The new legislation had also been discussed regularly in meetings in the lead-up to the change, including in national meetings. The transition in working practices had therefore gone quite smoothly overall, in their minds. The lack of significant change in working practice also contributed to the perceived relative ease of transition. Even so, some did acknowledge that it was difficult to feel completely prepared given the uniqueness of each family conversation.

I think it was incredibly smooth, I mean much smoother than I thought it was going to be. I think that the practical steps that were put into place were absolutely fine and certainly all of the training documents that came out to support us in what we do and the HTA Wales is brilliant and really easy to read.

There was a lot of work that we did within the hospital to make people aware of it. So I think that it did transition quite smoothly and because of the nature of the work, it's not from November to December you suddenly have 30 cases coming in. It's a patient here and a patient there.

We had at least an hour in our team meetings, leading up to the change. We had DVDs and role plays and situations of how you would communicate with families. Lots of documents to go through. And refreshers relating to it really.

I did feel quite prepared for this when it came about. We went through lots of scenarios of how a family might intervene. How strong we could be, try to prepare us for problems in advance. It was good, I thought.

It was suggested in North West England that there was comprehensive training so that SNODs would still be able to remember it despite potentially only needing it on the rare occasions they worked in Wales. This training included access to a 'clear flowchart', regular updates from managers at team meetings and ongoing updates from Bangor

University covering their study with families of patients on their experiences⁸. These updates helped to reinforce understanding around the new legislation. Staff involved in delivering training to SNODs in North Wales / North West England were described by a small number of participants as having gone to great lengths in training and supporting SNODs: examples included being available by phone during a SNOD's first deemed consent case so the participant could double check the process was followed correctly.

I think in all honestly that it was the repeated message. Particularly I think for our team as well because a lot of the anxiety was around, well how often am I going to go to Wales and I'm going to have forgotten them.

Quite smooth [transition] actually and obviously lots of prep was given ahead of the live date for the decision to be registered and to be recognised. I feel we had all the support we needed to go forward, really.

Those in North Wales / North West England also remarked that they had less experience of (potential) donations in North Wales because there were fewer possible cases. Some reported that they still felt comfortable about conversations with families of patients in North Wales because of the guidance available. Even so, slight feelings of anxiety having yet to experience a deemed consent conversation were raised on occasion when discussing training needs (see section 3.2 on helping to embed the legislation into working practices).

A further source of advice and guidance arose via SNODs supporting each other (via email and phone), particularly around the time the new legislation came into effect as there was some nervousness about experiencing the first deemed consent case. Having access to 'Lead SNODs' for support was also valued.

I felt well prepared for it. You were nervous if you were going to be the first SNOD to obtain deemed consent, so there were nerves. I think that the team, we were well supported. There was lots of support amongst each other as SNODs when we knew which one was out on call.

⁸ <http://organ-donation-project.bangor.ac.uk/>

Some thought that the timing of the training had seemed about right: any earlier and it would not have been so fresh in people's minds. Too late and it would have limited time for the information to sink in.

It must have been around September or October. So it wasn't too soon that it was just going to be forgotten, and it wasn't right up to the last minute.

On occasion, however, participants thought that the training had felt a little rushed given how close it was to the legislation change: 'it hadn't been organised sufficiently early enough'. Its proximity to the date of implementation did not always leave the SNOD much time to then educate other staff. It was suggested that the training could have taken place earlier and been followed up with a refresher session.

Our practice sessions and stuff were quite late in the day but they covered what we needed to cover.

A further reflection on preparations for the new legislation was how staff put in place to support SNODs in the run-up to the law's implementation could have been kept in post for several months after the legislative change. They could then have been available as a source of support as SNODs experienced their first family approaches. In a similar vein, a participant referred to missing what had been 'regular updates' to do with the new legislation as the member of staff who used to send them out was on long-term sick leave.

[Name] should have been kept on for another six months after the law changed, rather than stopping there, to be able to support people when approaching their first families. It went from that to nothing and then get on with it and I don't think that was right really.

A final observation made by a small number of CLODs related to limited resource being available to deliver training. There had been expectations of training being delivered to CLODs and SNODs at each hospital which had not materialised. The example was given of certain staff 'suddenly' being asked by Welsh Government to deliver it with no additional resource, even though this issue had been flagged 'at the outset'.

I think we were promised a training package from the Welsh Government, which was supposed to involve someone coming in and training the CLODs and the SNODs at each hospital. From what I'm aware it didn't happen. It was sort of left down to us to glean whatever information we could get from Welsh Government to implement it.

3.1.3 Face to face training and guidance

Role play exercises were regularly mentioned among the different types of training received on the new legislation. The method was liked by some participants, less so by others. Those who welcomed the approach appreciated how (post-legislation) they could review what could be done differently with a particular scenario. This may include learning from other attendees about a specific phrase that can help to open up a conversation where the SNOD might otherwise be 'up against a brick wall'. It also allowed SNODs to experiment with new or different phrases that they could not test in real-life situations. In the first example below, the participant was referring to recent annual training received from NHSBT.

It was probably one of the best training sessions we've had, because rather than them giving us an example, we were able to provide examples and perhaps try and make a different approach. What I used it for was to re-enact what I did on that day, and what I could have done, and get feedback on what I could have done differently.

It's quite useful because you're kind of in a room with people you know and you can trust. You don't like doing it in front of people, but then it's better to have constructive feedback then, rather than get stuck in a [real] situation.

Sometimes you might think, oh no, I couldn't say that to a family, but with actors, you can because you can see how far you can take it. That was quite helpful.

Taking part in role-play scenarios in front of colleagues, however, was challenging for some. They felt self-conscious and were more concerned with wondering what others were thinking of their performance. It was sometimes hard not to take the feedback received personally. Despite these drawbacks, some of those who were not so keen on role play, or found it hard, acknowledged that they benefitted from the exercise.

I hate it. It is a good learning tool, though. Hate doing it.

Looking back, participants from time to time thought that more training could have been provided on practising deemed consent scenarios because they were uncertain how these situations might unfold. According to one participant, more practical scenario training might have helped SNODs to better understand how and when to introduce the subject of any known decision during conversations with family. Also regular sessions post-legislative change, it was occasionally felt, would have provided guidance on when to discuss any known decision with the family, limiting the development of possible 'bad habits'.

We could have been a bit more robust in that training with working out the type of language that we wanted to use.

Possibly in terms of role plays, of doing that deemed consent element would have been useful. . . . in the run up to it. When we were doing [consent] practices [national SNOD training] I did think, I wonder how you do a deemed consent? I wasn't too sure in terms of how the approach would be different.

I think it was a mix of a taught session and some videos, and a little bit of practice with actors - in one day, and then there's been no follow-up since. There should've been ongoing training and review for the practices. . . . Those bad practices actually could've probably been stopped a number of months ago, if we were having regular sessions for education and reflection on these conversations we're having.

In terms of other face to face training and guidance, regular team meetings (e.g. 'debriefing sessions') each month and regional meetings twice a year or 'collaboratives' were thought to provide an effective platform to discuss experiences. There was reference to 'shared practice' meetings where SNODs were able to talk about particular cases and approaches. Those in the North Wales / North West also sometimes received an update from Bangor University on its work on family conversations.

We have monthly debriefing sessions. So we would discuss any cases there and that's where previous deemed consent has been discussed. The ones that have been involved will say how they've gone about it, what they've needed to check out in advance, and how they've approached the families and all the rest of it.

We have practice-sharing days so any Welsh approaches I have discussed, in those practice-sharing days, so that the whole team gets together and discuss best practice. What we could have done better, if it has been a positive result, look at how it became a positive result and if it is negative result then, obviously, look at what we could have done better.

You look at the detail and you reflect on good practice, best practice in some parts and how we can all learn from different cases and things. So they tend to be very, very good meetings.

A recent initiative set up in South Wales contributed to SNODs' training and guidance: team members could meet and discuss confidentially anything they wished in terms of how they felt about a particular situation rather than focusing on performance indicators. The sessions had a well-being focus, aimed at allowing SNODs to 'off-load what an experience did to them emotionally'. The opportunity to open up to others on potentially sensitive topics was particularly appreciated by one participant.

It's very much a reflective round where they talk about how they felt with things. People will then take away what they want from those sessions.

It's nice because you can really understand how things make people feel. It's meant to be a safe environment whereas sometimes something can happen and you can't really say, 'that's really frustrated me' or 'that's made me really upset'.

A study day had proved useful, according to one participant, with the 'education team' going through the legislation and consent process; and providing the opportunity for discussion. Similarly, attending a presentation on the subject had provided a CLOD with all the information the participant felt was required. Ad hoc meetings had also helped (e.g. between a CLOD and SNOD) with ensuring participants felt as prepared as they could be for the legislation change, along with access to 'commonly asked questions'.

I think the presentation I saw down in Cardiff last September covered all the aspects that I wanted to know about how the SNODs were going to go about applying the law change. . . . It's not something [as a CLOD] that I'm going to be involved in, but it was something that I needed to know.

More informally, SNODs sometimes contacted each other when something new or unusual occurred during a conversation with the family, for reassurance, or where an approach went particularly well, in order to share the experience and hear what others had to say about it (described as a 'safety net' for support by one participant). In addition, there was informal regular email contact, according to a CLOD, to keep in touch over any issues that might arise with a donation case.

As a team, if there is something that we've not encountered before we will ring each other up and say, 'I was talking to this family and this came up'. We do tend to do that anyway.

We have email exchange, and the CLODs and SNODs all know each other quite well.

We'll have regular weekly email correspondence if there are any issues anyway. It can be then addressed with any individuals who've been involved with the case.

3.1.4 Training and guidance materials

The Code of Practice for the Human Transplantation (Wales) Act was described as being a very useful, practical, clear source of detailed information and guidance. Reference was also made to a helpful flow diagram which was used when educating ED and ICU staff. It clearly described the process for dealing with a deemed consent scenario, according to some participants. One SNOD recounted using the helpful diagram for her first family approach post-legislation.

I knew very early on looking through my flow chart, that [deemed consent] actually wasn't going to be applicable to this gentleman because he had severe mental health problems. I could screen him out so to speak on the capacity issue.

Very helpful. I think that's really, from my point of view, that's all I've ever needed.

The Code of Practice makes it clear, detailed, it's a very usable document.

It's a really detailed document, and it's actually very simple to follow, it's very clear, so that is useful.

A small number of participants commented how they carried guidance material on a single sheet around with them. Guidance on phrases to use or avoid during a family conversation was kept to hand by one SNOD who had not been involved in a family approach for some time. She explained how she would need to remind herself of this material when the next opportunity for a family conversation arose because it happened so infrequently.

There is a flow chart that I carry around with me. I still refer to it if I'm going out because you may have an approach in Wales once every six months or something so I still use it as a guideline to refresh myself. So yeah it was quite useful.

A set of PowerPoint slides thought to have been provided by NHSBT on the new legislation was also considered helpful, when mentioned by CLODs and SNODs, giving an overview of the stages that need to take place to reach a deemed consent. In addition, an example was described of using the document for training other staff because of its 'simplified' approach. It had saved one CLOD precious time when preparing to train others.

A 'pack' containing frequently asked questions had been useful for one participant during the first few months of the legislation change. It was used as a point of reference after each family conversation to review the approach.

There were some frequently asked questions packs and stuff which I've got saved somewhere so that I can go back to it for reference. . . . Go back and look after each approach and think, does it match up?

Participants sometimes referred to video content when discussing training and support relating to the new legislation. The videos were described as giving helpful examples of conversations with families. They were a useful reminder for some on approaching families and potentially as an 'aide memoire' in the future, providing a 'basic' format with which to work. In addition, one participant also intended to use them to help train new staff. A further useful material included an 'online lecture' which a CLOD had been able to adapt and use for subsequent education of other staff.

According to some participants, however, the videos did not feel very realistic ('wooden') and used scripts and phrases that SNODs were unlikely to use. These participants explained how, in reality, each conversation was different and adapted to the circumstances with the family. It was felt on occasion that new staff benefitted more from

conversations with more experienced SNODs about recent family conversations than from the video content.

They produced some videos, but the difficulty is with videos is that they are not interactive. You're watching someone else speak. I've watched them. I thought in my head, I probably would never use those phrases anyway.

They were okay, but watching somebody on a video do a perfect scripted approach is not how we work, and it will never be how we work. . . . You can't script and you can't control the flow of a conversation as much as they were controlled in those videos.

3.2 Helping to embed the new legislation into working practices

3.2.1 Regular refresher training

At a broad level, general refresher training was considered important by some as good practice, particularly where SNODs might not be involved in many donation conversations with families on an annual basis. A CLOD concurred that he would also benefit from a six-monthly general 'refresher' 'until we've all got our head round it'. Some form of e-learning was considered sufficient by this participant.

Just the continued education in terms of the practice, because if you're not exposed to certain conversations it can be difficult when you do have them.

Where SNODs had yet to experience a deemed consent situation, there was thought to be a need to refresh their training (e.g. every six months was suggested in North Wales) so that they felt as prepared as they did when the new legislation came into practice. This was thought also to apply to those in the recently implemented 'requester' role⁹, perhaps on an annual basis.

At the time [of the new legislation coming in] I felt really prepared because we had quite a lot of training. Now a year down the road, . . . when I went to approach a family in the week, I thought, I need to go over that again now. Not very prepared now, if I'm honest.

⁹ A SNOD whose role is dedicated to speaking to families about organ donation decisions.

Just the conversation with the family. We need refreshers. Especially our team, because we are not doing it that often and we are working in England more than we're working in Wales.

There was a request for SNODs in North Wales / North West England and South Wales to try and meet more often to share experiences, given how many more family approaches South Wales SNODs had experience of compared with those covering North Wales. One participant explained that it did not feel as though they had any links with South Wales colleagues other than occasionally having a chat at a conference. A participant in North Wales assumed that there were no issues to date with deemed consent approaches because they had not heard of any being fed back from South Wales.

[Meetings] between North and South Wales and that's something that I'd like to be developed. We're completely separate from them.

If there have been any changes that have been found or maybe that approach is not working as well as you hoped, and you thought maybe we should restructure the question, obviously, that to be rolled out as soon as possible. I have not heard anything so I imagine it is just still going as they are.

It would be nice to have regular refresher courses. It could be six or seven months before you are exposed to that again so you do lose track a little bit of what route you can go. . . . Monthly meeting and groups would be good. Open discussion formats would be good.

The opportunity for SNODs to practise among themselves or at least in smaller groups was suggested as a way of helping them continue to feel prepared for family conversations relating to deemed consent. One participant thought that this would indicate that SNODs' preferences were being listened to and therefore help with engagement in the process. It was also recognised, however, that limited staff numbers would make this difficult.

I would feel happier doing a scenario with an actor with maybe just my team manager in the room, rather than there being other SNODs, two team managers, regional manager.

I feel that a smaller group is better. You feel less judged, [rather than having] thirteen people sat behind you, watching you.

Further suggested ways of helping the topic remain fresh in participants' minds included:

- Ensuring any deemed consent cases are discussed as a team from an experience point of view;

To sit down as a group and actually say, 'Well this is how I did it. This is how the family responded. This is what I said'. Like I said, every case is different. You have no idea what's going to be coming back to you.

- Watching the exemplar video tutorial together in a team meeting as a prompt for discussion.

From a video point of view, we could put it up on our screens and we could all watch it together in a team meeting. Then offer feedback and respond to how we might be able to use that theoretical demonstration more practically.

3.2.2 Revisiting the conversation with families

Given their experiences with families on occasion being unsupportive of 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. The aim would be to see how to better support SNODs with additional 'phraseology' to ensure they had the opportunity to talk about the benefits of donation with families and encourage families to give greater emphasis to supporting patients' decisions.

We need to change the default setting for SNODs to say, if somebody has opted in, then they are going to donate and there are mitigating circumstances, strong mitigating circumstances if they're not. [SNODs] need to get to the point where we are helping the family respect the wishes of the dead rather than the living.

The one element that we would like to explore more is the families . . . the overrides and how we can push it. How far we could sort of support the family to making the right decision that their loved one would've wanted.

The delivery of this training on the conversation with families was currently being reviewed. The aim was to offer different delivery methods to fit with SNODs' own learning preferences, for example using smaller groups or a more theory based approach. When discussing training formats, some SNODs believed that more role playing approaches with input from colleagues were the most effective methods in delivering this training on the family conversation and enabled them to experiment with different language.

If you could do it with an actor, you can use your own language and realise that perhaps that doesn't work, let me try that again. If I explain it this way would that have been better? . . . As much as I don't like role play . . . it's the closest you're ever going to get.

I'm a fan of simulation like the approach training we do. I think it's quite useful.

Additional suggestions (mostly individual) concerning training and guidance included the following:

- Welsh Government or NHSBT could provide some kind of 'endorsement' which enables the SNOD to explore further with families the reasons for unsupported deemed consent or overriding an ODR opt-in; and the circumstances in which a known decision was expressed by a patient. However, the challenge this activity would present was recognised. Some were waiting with interest to see the outcome of the Bangor University study;

A more weighted letter or endorsement from either Welsh Government or NHSBT to feel able to probe families a bit more; because we have asked families to discuss and to make a decision and we're asking 'have you discussed and made a decision?' and they say 'yes', and then where do you go with that? That's the difficulty . . . [and] what we don't want to do is upset families in the situation.

As a SNOD where the family say no and when a family says for reasons that are personal and private to us, I'm not going to discuss it with you. Where do I go with that, then? I can't, there's nowhere. They have completely told me don't even ask, kind of thing. I think it would be interesting to find out more as to why would they override.

- To be encouraged to phone ‘the practice education team managers’ if reassurance is required to ask how to approach a family where a SNOD had little or no experience of a deemed consent conversation;
- Providing a ‘key changes summary document’ for the Code of Practice to minimise having to ‘sift through’ the content to find the relevant information;
- Knowing who to contact out of hours with a deemed consent query if South Wales’ regional manager is unavailable;

I'm not sure the other regional managers in the UK would have an understanding or be able to have the experience in it to guide you.

- Some CLODs to be slightly more proactive and supportive;
- I wish that they were a bit more proactive. They're a bit reactive at the moment. It shouldn't have to be me going to them with a problem. They should be there, with me, knowing about it in the first instance.*

- Providing an education package aimed at new CLODs;
- A concern was voiced by one participant regarding SNODs as a resource and whether the embedded SNOD would continue to be funded by NHSBT. A decrease in the number of SNODs had been noted. A less visible SNOD could result in them not being included as part of the critical care team which in turn could affect levels of trust in SNODs which those who were embedded had worked hard to develop.

It's very basic, but an embedded SNOD [is key], and you can already see the NHSBT funding for it is gradually being withdrawn. The number of SNODs, nationally, is going down, and they're being spread more thinly, because it's becoming less of a project, that's the thing that makes a difference.

- A SNOD based in North Wales requested a general update on how organ donation, the process and conversations are faring in Wales as it would soon be one year since the change was implemented.

Some participants did feel that the new legislation had embedded effectively into working practices or at least that they were comfortable with what the new law entailed. Regular teaching sessions with other staff helped in this respect. Continued sharing of experiences was believed to be vital to ensure good practice and effective approaches to conversations were widely disseminated. The ‘regional team’ continuing to liaise with the Welsh

Government was thought by one participant to be contributing to helping embed the new law as well.

I don't really think so [need any further training]. Not regarding the law. And I think the fact that I included that in teaching sessions, because people want things that are current updates; then it's helped me to cement it in my mind.

I think it's just more time and more feedback from our experiences and more learning from the individual cases and how those individual conversations have gone.

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

Key points and conclusions

- In keeping with the findings from the previous research, participants had mainly focused their education activities on critical care and 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.
- 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.
- 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.
- 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.
- 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.
- 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.
- 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.

4.1 Hospital staff

Participants continued to be involved in educating other staff on organ donation generally. As with the 2015 research, they strived to keep the subject front of mind for employees in intensive care units (ICU) and the emergency department (ED), for example ensuring there was a monthly presentation to both units each month for six months. One SNOD also explained how an online resource was useful in this respect as something to which the participant could refer other staff.

We presented joint audit meetings for ITU [intensive therapy unit] and A&E. We've done them every month for six months. I think they were a little sick of me then, but they got the message.

They are a big part of knowing who to refer and when to refer to us. So they should be updated just as much as we are.

I think essentially ED and ICU are the two categories. Maybe the palliative care teams and specialist nurses in that area might be useful for them to have a little bit of an insight into what's goes on.

Some SNODs and CLODs explained that the emphasis with ICU / ED staff had been on early referral so that those staff 'don't have to worry about it'. They did not want other staff to become involved in discussions with families on donation and also other staff occasionally did not appear to be very interested in the detail. These factors, combined with how busy other staff could be, led these participants to believe that the emphasis should be on early referral and leaving the rest to the SNOD.

We very much go with early referral. Let's now deal with it so you don't have to worry about it. We've gone with that message from the word go. There's no point stressing people out about it. They've got enough to do.

What's more important [than understanding the legislation in detail] I think is that ED staff and ITU staff are up to speed with the process of identifying and referring in a timely manner to a SNOD. That's where the problems have been identified in the past, and that's where the donation process falls down.

To teach them all about it in minute detail when it's a tiny part of their job and quite frankly they're not that interested. There's always going to be a bit of a challenge which is why, in the end, we just went down the route of this is really complicated, refer them to the SNOD and let them do it.

It continued to be the case that reaching other staff was difficult given their commitments and staff shortages on the day arranged for training / education. As an example, a change in shift patterns for ICU staff meant that there was no longer a handover period during which the SNOD could catch ICU / ED staff for informal training.

Another big thing that's happened is a lot of departments now working 12 hour shifts, so there are two shifts a day so there's not this handover period where you have a group of staff who are available for informal training.

ED and ICU staff were generally thought to have a greater understanding of the law change than other hospital staff. Participants sometimes referred to other hospital staff having a similar understanding of the new legislation as the general public. In a couple of examples, there were references to clinicians and nurses who assumed that the new legislation was a hard opt out donation process or had opted out because of the new legislation but had not, in participants' eyes, understood that it gave them greater choice. The role of the family was not thought to have been fully grasped by health professionals.

I think some clinicians don't always . . . They just compare it to say other countries where you've just got the hard opt out, and sometimes they sort of don't realise that we actually do consider the family's opinion as well.

All grades [of staff] have said this. Until we go through the detail [with them] there is the assumption that it is just compulsory.

It surprises me that when we do speak to other hospital staff, their perspective of what the new legislation is. It's very much like the general public, so to speak. Just because they're nurses doesn't mean that they're going to be experts.

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; and that it should consist of more than a 'thirty-minute presentation' for Foundation Level doctors. It was acknowledged, however, that new staff received several hours of education and that 'organ donation may not be the highest on the list of priorities'.

I think an introductory session for anyone joining the Health Board would be good. I know that some trusts in England had, as part of a new learning thing, a module on organ donation, just touched on the basics. I think that wouldn't hurt anyone.

A situation was described where ICU / ED staff in a hospital in England were anxious about how the legislation change would affect their working practices when dealing with Welsh residents in the hospital. It reportedly took a little while for staff to understand that their working practices would not be affected by the legislation.

[Staff in England] were a bit worried about what the legislation would mean for them so it did take a lot of time to explain to [the hospital] that they wouldn't be affected by it.

4.2 Perceptions of awareness and understanding among the general public

Reflecting their experiences with families of patients, participants believed that awareness of the legislation among the general public as a whole was quite high. Examples were given of encountering people during promotional activities who knew about the change and were in favour of donation generally¹⁰. In one example a participant had heard from members of the public that they did not need to sign the Organ Donor Register now because of the new legislation. According to another participant attending a university Freshers' Week event, many students from England were already aware of the legislation.

I've done a lot of events recently. . . . Honestly every person that came to talk to us was like 'why are you trying to promote this? We all know that it's something we have to be aware of'.

I have had quite a few conversations with people when we've been doing publicity and we've been trying to get people to sign up to register, saying 'oh, we don't need to bother with that now, do we?'.

Despite a perceived increase in awareness among the general public of the new legislation and patients' decisions, participants did not think that members of the public they encountered (e.g. via promotional stands in hospitals, supporting charities or sometimes during conversations with the family of a patient) had a very strong grasp of how the legislation worked ('a little sketchy'). The ideas of opting in and opting out were thought to be understood by the public but less so the idea of deemed consent or what this

¹⁰ Public attitudes to organ donation: 80 per cent of respondents in March 2016 and 72 per cent in June 2016 said they have opted in or taken no action <http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

involved practically. Some had come across the view, for example, that ‘we’re all on the Organ Donor Register’ rather than people now having greater choice; or that deemed consent means it is ‘automatic’ that they become a donor with a hard opt-out system: ‘some have said I thought you’d go ahead anyway’, as one SNOD recalled.

This was a family that didn't actually realise they had any say, they thought it was law.

I think what most people still think, and a lot of medical and nursing staff still think is, that when you die anywhere, the Government will come and take your organs. . . . A couple of people said, ‘we opted out as soon as this law came in because I’m not letting them just take my organs’. When I explained what organ donation actually means, they were like, ‘oh, well that’s different now, because we just thought if I died at home somebody would come in and take my organs out’.

I’ve had conversations with families and with friends outside of work. They are misinformed as to what the law means. I think some perceive it as a bit of a smash and grab. The choice isn’t there.

There seems to be a bit of confusion. Some people are worried that if they don’t opt out, that somebody will take their organs. I’ve heard that comment a few times. Some people don’t care about it at all, really. There’s a lot of people out there that are quite pro-donation, and they are quite happy with it.

Instances still occurred, according to some participants, where members of the public at an organ donation stand stated that they had opted out because they did not agree with ‘the Government telling me what to do’¹¹. Others remarked, however, that they had not come across such views.

The role of the family in the donation process was not believed to be very clear to the public in general, for example with people ‘annoyed’ on hearing at a promotional stand that the family can still prevent donation from taking place. Focusing on conversations with families of patients, it was often felt that the role of the family was not understood in

¹¹ Public attitudes to organ donation: around 1 in 20 (March and June 2016) said they have opted out since the new law was introduced. <http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

deemed consent cases. As described earlier in this report, examples were given of families changing their mind and not supporting deemed consent after finding out how long the process took, as well as instances where families thought that donation would take place automatically. With the latter scenario staff had to explain the choices available so that the family fully understood the situation.

I think the family just think that it's their decision anyway, at the end of it.

Regardless of what the law says, I don't think people are aware enough of what the legislation means.

Sometimes we need to actually rein them back from sort of volunteering the organs and say, 'well, you need to understand about it. It's great that you're keen, but we do need to explain what it involves'.

In a further example, a participant had come across members of the public who had opted out believing that they could not donate, having had cancer; and another who had opted out because they were a donor recipient and did not think that they could donate either.

SNODs in North West England sometimes came across families of patients who were uncertain whether the Wales legislation applied with the patient in an English hospital.

4.2.1 Informing the general public

Some participants therefore felt that there was still work to do in explaining the choices available to the general public regarding organ donation, including encouraging families to respect the decision of the patient (as they would do with a will, for example). There was also a suggestion made that the emphasis of messaging could shift towards encouraging people to register their decision because of the apparent early trend of some deemed cases not being supported by the family.

More broadly, some believed that the general public still needed more communication and education on the benefits of organ donation and how it works as well as keeping the legislative change in the public eye. The example was given by a couple of SNODs of informing people that they were more likely to be a recipient of an organ than to be a donor. One participant had found that this information, when explained to members of the public, had caused one or two individuals to review their decision to opt out. There was also a view that the public communications campaign could have benefited from altering

the wording around choosing deemed consent: 'not registering is a decision' was suggested in place of 'doing nothing' which sounded more 'wishy-washy'.

I think [the new legislation] is embedded into working practices. I don't think that's the problem. I think the problem is, in Wales, we still have a lot of people who say no. Either they say no upfront or they just don't like the idea of it so they immediately say no and I think that's education of the public.

I think it does need to be still on the political agenda to a degree. The public, it needs to be reaffirmed every so often that this is actually the case.

It was put forward by a small number of SNODs and CLODs that organ donation and expressing a decision should be embedded into school education so that, when a person turned 18 years old, they were aware of their choices and that they should discuss them with their family. This in turn would lead to a gradual change in culture to discussion of donation and informed decisions being the norm.

Additional individual points made regarding general public communications included the following:

- Real life case studies should be used to help emphasise that the new legislation is not a case of the Government automatically taking patients' organs; and that donation makes such a positive impact on people's lives¹².

If [the message] comes from Government or doctors or nurses, the risk then appears to be that we want the organs for our purposes. That's not the message that needs to go across. The message that needs to go across is that this actually sometimes helps families.

- Communications should emphasise more the need for people to discuss their decision with family members rather than leaving them to conclude that they do not need to discuss it because of deemed consent.

It's about encouraging them to talk. . . . They know about the legislation but they don't realise about the importance of talking to people and this is the downside of the change in legislation. They now think they don't need to do anything. It's all fine and it's all going to happen.

¹² At the time of writing the Welsh Government's website Organ Donation Wales has a case study highlighted on its homepage: <http://organdonationwales.org/?skip=1&lang=en>

5 Conclusions and considerations

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.

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.

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.

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. The research indicates that steps are being taken to review this element of the conversation with SNODs.

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.

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 percent in June 2016.¹³ The qualitative feedback on instances of more families

¹³ In November 2015, March and June 2016 approaching 5 in 10 people reported having discussed their wishes regarding organ donation after their death with a family member compared with around 4 in 10 people in previous waves. <http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

expecting an approach is in line with Welsh Government trend data on increasing awareness of the new law.

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.

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.

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 of the conversations with families, for example via role-playing in either larger or smaller groups.

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.

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.

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' perspectives.

Appendix: Topic guide used in the interviews

A. Introduction

1. *Introduce self, Beaufort Research*
2. *Purpose of interview: to revisit the views of Specialist Nurses for Organ Donation (SNODs) and Clinical Leads for Organ Donation (CLODs) on the soft opt-out system of organ donation now that the legislation has been implemented.*

The focus of this project is on working practices and implementation rather than policy. Feedback received will feed into ongoing wider work on this topic.

3. *Stress independence of Beaufort, confidentiality of taking part and MRS Code of Conduct. Report will be published but feedback / comments will be presented in a way that ensures anonymity, as before.*
4. *Obtain permission to audio-record.*
5. *Capture: Job role, length of time in role*

B. Impact of the legislation change on working practices

6. When we spoke with SNODs and CLODs in early 2015 before the new legislation was implemented, we found that in general they weren't anticipating any significant change to working practices. What has been your experience since December 2015?

Probe whatever emerges, including where appropriate

- How smooth has the implementation been in terms of working practices?
 - What factors do you think contributed to this?

7. *(If not already covered)* What have been the main changes to working practices from your perspective? *Probe*

- How prepared did you feel for these changes? *Probe for any unanticipated issues or concerns*

8. *(If not already covered)* Tell me about your experiences of the conversations with families now the legislation has changed? *Probe whatever emerges, including*

- To what extent have the conversations changed?
- How easy have you found it to incorporate the new legislation into the conversation?
- How aware do you find the general public are of the legislation change, based on your interactions with them?
 - How clear do you think they are on how the new legislation works?
 - *Do they think the general public realise it is an opt-out system, not mandatory? Probe for any examples*
 - *Do they think the general public are clear on what the role of the family is? Probe for any examples*

- Are you noticing any differences in their views or behaviours (e.g. more likely to have discussed the subject with family or no change)?

C. Training focus

9. Tell me about the training you received in relation to the new legislation? *Probe whatever emerges, including*
 - What training did you receive?
 - How effective was it? (*Note but do not raise: not all SNODs are thought to have embraced training fully*)
 - How timely was it?
 - How would you have improved it?
 - What do you think of the guidance / information materials you received? *Probe for any improvements*
 - *If not already covered probe training on conversations with families, residency, appointed representatives and cross-border scenarios*
10. Is there an effective way for you and colleagues to share experiences of working practices based on the new legislation? *Probe*
 - How well does this work?
 - How if at all can it be improved?
11. Are there any areas where you still think you or other SNODs would benefit from further training? *Probe*
 - Tell me why this training is still needed?
 - Who would benefit most from it?
 - What would be the most effective way of delivering the training?
 - When should it be delivered?
 - How would you ensure that all SNODs engaged fully with the training?
12. To what extent do you think the new legislation is affecting other hospital staff? *Probe whatever emerges including*
 - How easy has it been to educate other staff about the new legislation e.g. in critical care and ED?
(Note in 2015, some felt that critical care and ED staff would benefit from education on the new legislation.)
 - Are there any other hospital staff who you think would benefit from (further) education on the new legislation in terms of working practices?

D. Relationship with clinicians

13. We've heard from some SNODs and CLODs in the past that in a variety of ways, clinicians could sometimes inadvertently adversely affect the organ donation process*. In 2015 SNODs and CLODs tended to think that progress had been made in this respect. What are your thoughts on that topic now? *If any changes:*
 - What has led to that change?
 - *If negative examples given, establish perceived prevalence*

* *Example prompts from 2015 research, if necessary:*

- *A clinician wanting to remain in control*
- *A clinician approaching families about organ donation when a SNOD was available*
- *Choosing inappropriate wording or timing when approaching the family*
- *Late referrals*
- *SNODs lacking credibility in the eyes of a clinician*

E. Summing up

14. Thinking about everything we've discussed what is the one key thing that still needs to be done to ensure the new legislation embeds effectively into SNODs' and CLODs' working practices?
15. Is there anything else you'd like to add that we haven't covered on the move to the soft opt-out system in Wales and its effects on the working practices of SNODs and CLODs?

Thank and close