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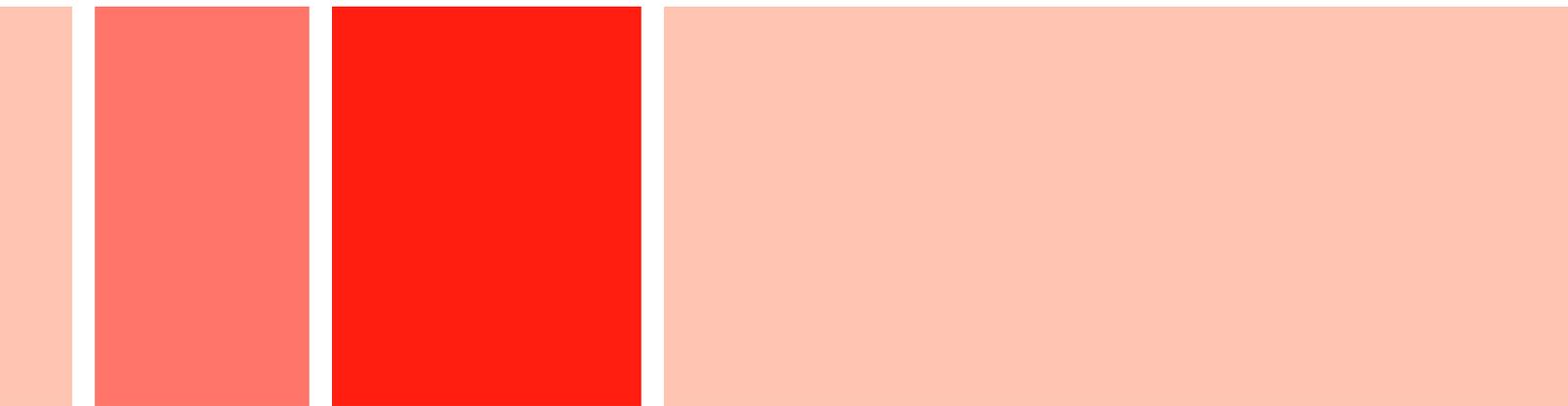
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Soft opt-out system of organ donation: Revisiting the views of Specialist Nurses and Clinical Leads



Soft opt-out system of organ donation:

Revisiting the views of Specialist Nurses and Clinical Leads

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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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Executive summary

Introduction

The Welsh Government is introducing a soft-opt out system of organ donation through the Human Transplantation (Wales) Act 2013 which comes into effect on 1 December 2015. As part of the preparation for the Act's implementation, Beaufort Research was commissioned to undertake the second of three waves of 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.

The research aims were to update understanding on expectations, attitudes and any concerns that SNODs and CLODs had regarding preparations for the move 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 may 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 current 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 and emergency departments (ED),

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

encouraging organ donation to be viewed as part of normal, everyday practice in hospitals.

The research consisted of 25 in-depth interviews: 15 with SNODs and 10 with CLODs across North and South Wales. Fieldwork took place from January to March 2015.

Current working practices and revisiting the 2013 findings

As in 2013, 'embedded' SNODs² continued to have a positive impact on the organ donation process, according to participants across the sample. Examples included developing relationships across critical care and ED, education of staff and helping to improve referral rates³.

SNODs and CLODs tended to think that progress had been made in reducing the number of occasions where clinicians might inadvertently adversely affect the organ donation process.

However, some SNODs felt improvements in working practices around organ donation had 'plateaued'. It was a constant challenge to make further progress in changing behaviours and attitudes of other staff, mainly clinicians.

All SNODs and the majority of CLODs in North and South Wales recounted issues they still experienced with some clinicians affecting the organ donation process. Examples included the clinician wanting to remain in control, approaching the family without a SNOD, raising the subject of organ donation at an inappropriate time, late referrals, and SNODs lacking credibility in the eyes of some clinicians.

² 'Embedded' SNODs work within the critical care unit of a specific hospital.

³ Those patients for whom neurological death was suspected or imminent death was anticipated, and who were discussed with the SNOD.

Given that similar issues were voiced in 2013, albeit with some participants believing that the problems with clinicians occurred less frequently now, the research highlights the continued need to support SNODs in this area. The support should equip SNODs with the appropriate tools in their efforts to develop relationships with clinicians (such as communications training) and guide SNODs on how to encourage clinicians to adopt best practice.

In general, participants thought that they were able to meet their current roles and responsibilities effectively. However, some in North Wales referred to current challenges believed to be a result of covering a large region (which includes parts of North West England), administrative tasks and staff sickness. The research indicates that this situation may need reviewing.

Perceived impact of the soft opt-out legislation on working practices

Participants were not anticipating any significant change to their working practices when the legislation comes into force. Overall, they did not voice any key concerns about the move to a soft opt-out system regarding their working practices.

Infrequent references in the 2013 research to potential concerns around increased workload were largely absent in 2015.

SNODs and CLODs were expecting minor changes to the conversations with families exploring the possibility of organ donation. This finding reflects the results in 2013. Some thought the conversation may become easier with more families having discussed their wishes because of the general public's growing awareness of the new legislation.

Broaching the topic of deemed consent was a key area where guidance would be needed, along with clarity on how to handle the discussion with families where the patient had opted out. In 2013, participants were concerned they would not even have the opportunity to speak with families whose relative had opted out. This concern was not voiced in 2015.

Participants' educating responsibilities were expected to increase over the coming year to help bring other staff in critical care and ED up to speed on the practicalities of the legislation. In the main they were not concerned about this task.

Some did not foresee any great changes in organ donation numbers, although they hoped that it would make a positive difference. (This view was expressed more so by SNODs than by CLODs.)

As in 2013, however, some participants were still worried about critical care capacity generally and recalled instances of missed referrals. Even so, they often felt that, regardless of legislation change, there would always be a shortage of critical care beds in Wales.

Participants were expecting to start receiving more detailed guidance on the new legislation in the near future (especially on family conversations). The current time (early spring 2015) felt like approximately the right time for this to occur.

They also wanted guidance on the 'nuts and bolts' of the legislation which affected their routine roles (e.g. how to use the organ donor register (ODR), confirmation of elements of the residency criteria and potential cross-border scenarios). It was apparent that SNODs and CLODs were not always fully aware of what the Act contains on these subjects.

The 2013 research found a degree of limited awareness on how residency would be defined. In 2015, participants were more likely to be clear on what ordinarily resident meant for the Act, with only a small number of exceptions. The uncertainty voiced in the previous research around cross-border working and residency was less prevalent in this study.

In terms of timing and planning for training / guidance, participants were unsure what exactly was scheduled to happen between now and 1 December 2015. More detail on this schedule would be welcomed.

Perceived awareness and understanding of the new system among other staff and the general public

SNODs and CLODs believed that there was still a good deal of work to be done in raising awareness of the legislation among hospital staff. This view had not shifted significantly from the opinions expressed in 2013 on this topic.

There was a perception among SNODs and CLODs that other hospital staff were often uncertain over when the legislation would be implemented, and did not fully understand the way in which the soft opt-out system would work in practice (for example the role of the family). Some critical care and ED staff were included in this group.

Participants therefore felt that critical care and ED staff - both senior and junior - should be prioritised for education and training, given their potential proximity to the organ donation process and contact with families.

However, reaching these staff with education and guidance could be a challenge because of the staff's work pressures.

Some participants among both SNODs and CLODs had noted how families were more likely to have talked about organ donation with the patient than in the past, or at least were expecting to have the conversation with hospital staff. This development was making the situation easier to handle for SNODs and CLODs. (Welsh Government quantitative research tracking figures on

whether or not individuals are discussing organ donation with their families do not reflect this qualitative finding⁴.)

Participants did not think that the general public were familiar with the legislation in terms of what it involved, its implementation date, and what the role of the family would be.

As a result, some questioned the effectiveness and prominence of the current communications campaign for the new system. There was also a call for communications to state more emphatically that the legislation gives people greater choice. (The next phase of the Welsh Government's communications campaign, starting in June 2015, will explain the choices people will have under the new law.)

Key factors to ensure implementation of the new system is a success

The most important factor in participants' minds which would ensure implementation of the new system is a success was effective education of the general public. As in 2013, SNODs and CLODs stressed this point above all others.

Participants also regularly stated that it would be key to emphasise to the general public that they would have more choices around organ donation with the new legislation.

CLODs sometimes added that organ donation should be placed on the school curriculum to help with understanding and to make family discussions on the topic the norm.

⁴ Survey of public attitudes to organ donation: Waves 6 and 7: <http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

According to participants, success would also rely on SNODs in particular having all the appropriate guidance and being fully trained on areas such as starting the conversation on deemed consent, using the ODR and residency in certain cross-border scenarios. Delivering on this requirement was thought by SNODs and CLODs to be in hand.

In addition, some reiterated that the implementation of the new legislation would benefit from continued efforts to improve relationships with clinicians.

Conclusions and considerations

This second wave of research among SNODs and CLODs, with a little under a year before the legislation comes into effect, finds that both groups are broadly content with current preparations for the move to a soft opt-out system.

The prospect of implementation is not affecting current working practices other than some SNODs and CLODs beginning to educate other hospital staff on the legislation. In addition, participants are not expecting any significant changes to their working practices from the December implementation date. A point of interest from this research was the doubt often voiced that the legislation change would make much difference to the number of donors in Wales.

Although SNODs and CLODs tended to be confident that they would receive the necessary training and guidance before December, there is a clear need for information on what the schedule looks like for training objectives in terms of timing and content⁵. This information would also help to reassure those who were beginning to consider how they would manage to reach the relevant staff in the months left before the system changed.

⁵ The training schedule for the new ODR and the Human Transplantation (Wales) Act was due to be announced following the fieldwork.

A key area where participants were expecting guidance imminently was how the conversations with families would change. The way in which participants discussed training and guidance (for example reporting not receiving any information) suggests they can adopt a more reactive than proactive approach to ensuring that they are up to speed on the practicalities of the new system. This implies that a face to face approach where possible for training would be an effective means of encouraging SNODs to absorb the information.

Providing good practice guidelines on when and how to train other staff is likely to be beneficial to participants.

A point of difference with the 2013 research was how some participants felt that they were encountering more instances of families of patients knowing the patients' wishes, or at least families who were expecting a discussion about organ donation with hospital staff. This qualitative feedback on knowing patients' wishes contradicts Welsh Government trend data. The 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 remained consistent at around four out of ten since 2012. However, it may still be worthwhile recording these instances more formally (if not already) to feed into Welsh Government's overall assessment of progress on this topic. The qualitative feedback on instances of more families expecting an approach is more in line with Welsh Government trend data on increasing awareness of the new law.

In a development from the 2013 research, there is a sense among participants that the impact of efforts to improve relationships with clinicians and encouraging them to adopt best practice is beginning to plateau. This finding suggests that SNODs and CLODs will need continued support in embedding best practice across the units concerned with organ donation. Previous communications training on this theme was thought to have been effective and could therefore be repeated or updated to ensure new staff are reached and any new best practice approaches on communications shared.

An improvement in this area would only help with the successful implementation of the new system.

Looking ahead to the 2016 research with SNODs and CLODs when the soft opt-out system will have been fully implemented, the following areas should be considered for exploring with participants:

- The perceived effectiveness and timeliness of training and guidance received in the run-up to the implementation date. Topics to review include conversations with families, and the extent to which residency and cross-border scenarios have been clarified;
- Experiences with families of patients, including in the months leading up to the legislation change and after 1 December 2015;
- Gaps in understanding that may have emerged, and which had affected working practices;
- Areas where SNODs and CLODs still felt they required training and guidance;
- The extent to which new learning on best practice surrounding the soft opt-out system was being identified and shared;
- The extent to which the new legislation was thought to be affecting other hospital staff, and what could be done to improve any issues identified;
- How easy it was proving to educate other staff, in particular in critical care and ED, and what additional resources SNODs and CLODs might still need;
- Whether or not relationships with clinicians were continuing to improve;
- Perceived changes among the general public in awareness and understanding of the new system, focusing the discussion on interactions with families of patients as well as any wider educating roles participants may have been involved with;
- Capturing the views and experiences of SNODs who are based in England but may have been required to travel to Wales to support Wales based SNODs;
- What, if any, unanticipated issues or concerns had emerged relating to the legislation change that would need to be addressed.

1 Background, objectives and methodology

1.1 Background

The Welsh Government is introducing a soft-opt out system of organ donation through the Human Transplantation (Wales) Act 2013 which comes into effect on 1 December 2015. The legislation means that, unless an individual indicates otherwise, their organs and tissues will be available for transplantation in the event of their death. Relatives will be consulted, as is the case now. Individuals will be able to: join the Organ Donor Register (ODR); opt out of being an organ donor; choose deemed consent by neither opting in or out; or nominate a representative to act on the patient's behalf.

The Welsh Government has developed an evaluation programme to underpin the implementation of the Act that includes 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 on preparations regarding their working practices.

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

Under the current system, SNODs are contacted if a patient has either suffered brain stem death or if it has been decided to limit or withdraw life sustaining treatment. This notification of SNODs occurs regardless of whether or not the patient is found to be on the ODR. The SNOD then discusses the patient's wishes with the family. If the family consents to organ donation, 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 may 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. CLODs are responsible for raising the profile of organ donation and providing expert advice on the ethical and legal aspects.

There are approximately 18 '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. 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 legislation implementation a success.

Their perspectives are being gathered via three waves of qualitative research. These waves are concerned with the preparations for the legislation change and understanding the impact of the legislation on working practices once it has come into being. The first wave took place in 2013⁶ before the proposals to introduce a soft opt-out system were passed into law. The second wave, with which this report is concerned, took place in early 2015 following the passing of the Act and in the run up to its full implementation. The final wave is scheduled to take 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 needs may be required.

⁶ 2013 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 a soft opt-out system;
- Gain an understanding of any changes in working practices and experiences of SNODs and CLODs in anticipation of implementation;
- 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 may impact on their discussions with family members in requesting consent for organ donation;
- Determine any additional training requirements that SNODs and CLODs may have in preparation for the change in legislation;
- Identify unanticipated issues articulated by SNODs and CLODs in relation to moving 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 (for example one interview took place very late in the evening). All but one of the interviews were conducted face to face in a confidential environment at participants' place of work. The remaining 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, the aim was to recruit: 17 of the 18 SNODs listed; and 8 of the 15 CLODs listed. Beaufort contacted potential

participants based on their location so that the sample had a good spread of Local Health Boards (six were included in the final sample achieved).

25 participants took part in an in-depth individual interview, from a total sample available of 33 individuals. The final sample achieved saw a slight increase in the number of CLODs interviewed (10) and a slight decrease in the number of SNODs who took part (15). This change to the original target was based on participant availability. The numbers achieved broke down as follows⁷:

	SNODs	CLODs
North Wales	3	3
South Wales (also covering South West Wales, Mid Wales and Hereford)	12	7

Fieldwork took place January to early March 2015, with interviews lasting between 30 minutes and one hour 10 minutes.

Each interview was audio-recorded with participants' permission. 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

⁷ The difference in interview numbers achieved broadly reflects the population of SNODs and CLODs in each regional team.

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 Current working practices and revisiting the 2013 findings

Key points and conclusions

- As in 2013, ‘embedded’ SNODs⁸ continued to have a positive impact on the organ donation process, according to participants across the sample. Examples included developing relationships across critical care and ED, education of staff and helping to improve referral rates⁹.
- SNODs and CLODs tended to think that progress had been made in reducing the number of occasions where clinicians might inadvertently adversely affect the organ donation process.
- However, some SNODs felt improvements in working practices around organ donation had ‘plateaued’. It was a constant challenge to make further progress in changing behaviours and attitudes of other staff, mainly clinicians.
- Participants in North and South Wales recounted issues they still experienced with some clinicians affecting the organ donation process. These tended to be situations which were not intended to adversely affect the process (e.g. the clinician wanting to remain in control, approaching the family without a SNOD, raising the subject of organ donation at an inappropriate time, late referrals, and SNODs lacking credibility in the eyes of some clinicians).
- Given that similar issues were voiced in 2013, albeit with some participants believing that the problems with clinicians occurred less frequently, the research highlights the continued need to support SNODs in this area. The support should equip SNODs with the appropriate tools in their efforts to develop relationships with clinicians and guide SNODs on how to encourage clinicians to adopt best practice.
- In general, participants thought that they were able to effectively meet their current roles and responsibilities. However, some in North Wales referred to current challenges thought to be a result of covering a large region (which includes parts of North West England), administrative tasks and staff sickness. The research indicates that this situation may need reviewing.

⁸ ‘Embedded’ SNODs work within the critical care unit of a specific hospital.

⁹ Those patients for whom neurological death was suspected or imminent death was anticipated, and who were discussed with the SNOD.

The research carried out in 2013 included contextual discussion with participants on their roles and routines. This 2015 study focused more on preparations for the legislation change but revisited a theme which arose from the 2013 findings. The theme related to the perceived current impact of SNODs and CLODs on organ donation and, within this, relationships with clinicians. These topics are discussed below.

2.1 The perceived impact of SNODs and CLODs

Participants felt that SNODs in particular continued to have a positive impact on the organ donation process. The embedded role meant that they were more 'visible', often more accepted now as part of the team and that efforts to 'build trust' with clinicians were beginning to make a difference. There were references to how there were more referrals being made by clinicians (and in a 'timely manner'), and also how organ donation itself was now a more common discussion topic in the workplace, including in ED. One participant described SNODs as 'a familiar face' building the relationship between critical care and ED.

[Clinicians] know when to refer and I would say for the last year we haven't actually had a missed potential in this hospital and the Emergency Department are fantastic.

I think definitely the closer we [SNODs] work with the ITU the more referrals that we get and the more that we work with families the more positive response that we get to donation.

I have seen a better working relationship with my ICU colleagues and their attitude to the SNODs. At the beginning they were very concerned that having SNODs on the unit would be seen to be unduly influencing

their decisions about withdrawing¹⁰ life support and the relationships that the consultants might have with the families; whereas there seems to be more acceptance now that the SNODs are going to be involved.

This positive impact of the SNODs on the units, and greater acceptance of their presence, was also reinforced by their regular educational activities, helping to raise awareness and explain to other staff how SNODs and CLODs are improving the organ donation process. References were made to SNODs helping to educate some staff outside critical care and ED as well (e.g. bedside nurses and chaplains). ‘Grand round’ teaching was also mentioned as an important educating role for SNODs, for example ‘bringing together consultants from critical care and from emergency, from medicine, and from surgery’.

We do a lot of education, we do a lot of teaching and a lot of justifying what we do and I think that’s continuously being done; whereas before a SNOD would only turn up if a donor had been consented but now we are here all the time and are part of the team and we come in to handover every morning and feel accepted.

¹⁰ The use of the word “withdraw” has a specific clinical meaning. There are two types of deceased organ donation:

Donation after Brain Death (DBD) may take place where death is confirmed following neurological tests to establish whether the patient has any remaining brain function. Patients declared brain dead may have suffered head trauma, for example in a car accident, or a massive stroke. These patients are sometimes also called “heart-beating donors” because the circulatory system is maintained through a ventilator whilst consent is established and until the donation takes place.

Donation after Circulatory Death (DCD) may take place following diagnosis of death by cardio-respiratory criteria. These patients are called “non heart-beating donors” because death follows the cessation of the body’s cardio-respiratory functions. DCD may be either “controlled” which describes organ retrieval which follows the planned limitation or **withdrawal** of treatment at the end of a critical illness from which the person will not recover; or “uncontrolled” which occurs following a sudden, irreversible cardiac arrest. Uncontrolled DCD is rare in the UK at present.

[SNOD's name] has made a real impact and in particular has had an impact on the nursing staff. So even if one of the doctors is really busy they might say 'have we asked the family about organ donation?' It is another trigger so [the SNOD] has had a real big impact and the same with A&E. I would say two years ago they didn't think about it as much but now they are; so it is good.

It's vital for the links that relationship we have with intensive care and ED departments. They just see a familiar face constantly coming down, doing ad hoc teaching and more general, constructive teaching – I don't think you can overstress that at all.

Building on this point, one CLOD described how SNODs 'are now seen as experts rather than a supporting nurses role', and are considered the most knowledgeable about the organ donation process. CLODs also sometimes highlighted the passion and enthusiasm SNODs showed for their role, and how they were doing 'a fantastic job'. Positive cases were described by CLODs where SNODs became involved with other staff including helping with end of life care 'even if organ donation is not offered'.

A small number of CLODs acknowledged that much of the improvement was down to the efforts of the SNODs rather than CLODs.

In contrast with the previous research carried out by Beaufort with these participants, some SNODs related how improvements in working practices around organ donation had appeared to 'plateau'. It was a constant challenge that required 'chipping away' to encourage consistent consideration of organ donation at the appropriate time among clinicians, especially in relation to approaching families. There was thought to be a perception among some hospital staff that the best practice work had been completed by SNODs and CLODs, but in reality efforts were still required to educate and remind staff about processes and to change behaviours among clinicians in terms of referrals and approaching families. (The relationship with clinicians is discussed in more detail in section 2.2.)

I do sometimes feel that we have reached a kind of plateau and I think it still continues with work to make donation the usual. You are able to address issues and you are constantly keeping it on people's minds and you are constantly tapping away at them.

The assumption seems to be that when they implemented the SNODs and the CLODs in to get the information out there about referring and increasing donation, almost all the legwork had been done and people know that now and I don't think that's true. The education needs to be continually put in there because staff change and staff forget.

I think we've plateaued probably now. . . . It's sort of more about fine tuning the detail of the [current] conversations and the referral process, which is hard work to be honest. . . . Just very difficult to get consistency between consultants and between hospitals really, in how we streamline the process for referral and how we conduct the conversations with family.

CLODS on occasion voiced disappointment with consent rates despite an increase in referrals and efforts with training SNODs on discussions with families by using actors.

We're working quite hard with the SNODs, with actors and simulation, to improve their work with families as well, to try and improve consent rates, which is still a bit disappointing, particularly with DCD¹¹ donations.

¹¹ Donation after Circulatory Death. See footnote on p21.

2.2 The relationship with clinicians over time

As indicated above, SNODs and CLODs across the different locations tended to think that progress had been made in terms of reducing the number of occasions where clinicians might inadvertently adversely affect the organ donation process. There was also a perception voiced that the collaborative approach to families of potential organ donors had 'increased considerably'.

We have seen quite a big difference in referral rates and being able to approach families and certainly in this hospital we have had a massive change in how we are approaching families with doctors.

Simply talking more frequently with clinicians about organ donation was thought to be helping in this respect. Referral rates were reported to be increasing, with clinicians more receptive to the process and to discussing where a mistake might have occurred (e.g. over the timing of a referral). A cultural change of this type was expected to take time. One CLOD acknowledged holding the view in the past that a clinician should approach the family about organ donation but was now 'happy' to adopt a collaborative approach with SNODs. Improved credibility of SNODs in the eyes of clinicians was therefore sometimes noted.

Obviously we have different backgrounds and even within the medical group we have different ethnicity, different religion, different personal background as well, and everything is in the picture. But I can see over the last four or five years this is slowly changing. We highlighted at the very beginning that cultural change will take years.

I think it has changed yep, so they [clinicians] are more receptive. It's not that they purposely do it, it is more 'oh too late'. . . . I think in time that will change but people are starting to come more and more on-board and they are a lot more engaged.

We [SNODs] are generally accepted now and our opinion is valued and our experience is appreciated. But a lot of the time we are still seen as nurses to them being doctors. But I don't think you'll ever change that.

As part of this improvement, some SNODs commented that they had appreciated the training they had received on communicating with clinicians. It was described as giving SNODs useful tools for engaging more effectively with colleagues who they might have struggled to engage with in the past.

Those consultants who would previously completely ignore us, we'll learn new ways to engage with them and to speak their language and it seems to be working.

2.2.1 Issues encountered with clinicians

Despite the perceived improvements described above, every SNOD and the majority of CLODs interviewed recounted issues they still experienced with some clinicians inadvertently affecting the organ donation process. Indeed, a small number felt that the types of behaviour described below had not diminished to any great extent over time.

It comes down to the medical consultants team that are challenging and will always be challenging and I am beginning to wonder if it will ever change; and the attitude towards the SNODs and CLODs as well. They can be particularly unpleasant towards us on a daily basis.

Those consultants who either are not very well experienced with organ donation, so they don't see it every week or every month, there will be hiccups in the process. . . . And we still see that occasionally, we still see that as either completely missed cases or cases where they won't wait for the SNOD to arrive, or they won't allow the SNOD to be part of the organ donation conversation.

One SNOD summed up the experience by explaining that issues with other staff in relation to organ donation were more difficult to deal with than the role

of approaching families. The example was given of being criticised for supposedly making the situation harder for families of patients who were already upset.

I thought the hardest part of the job would be dealing with families and the emotional side of it for them and also for myself but that is actually the best part of the job. The hardest part is dealing with [staff]'s attitudes towards donation. . . . Hospital staff, doctors, nurses. . . . It's across all staff. . . . It's 'how can you approach this family when they are already going through this terrible time?' But they don't see the other families on the recipients' side who are going through the same terrible time that can be prevented.

Looking in more detail at interactions with clinicians, participants in this research referred to similar issues voiced in the previous study. They tended to be situations which were not intended to adversely affect the process although they did include occasional instances where this was thought to be the case. Examples involving clinicians are given below:

- Clinicians with good intentions but 'liking to do things their way' wanting to remain in control. This could involve a SNOD and clinician planning the approach to a family beforehand but then the clinician not keeping to the plan once the conversation started, or a clinician not wanting to upset the family with an approach;

Some of them it is not a deliberate attempt to boycott donation or prevent donation from happening. I think it is just they're so used to doing what they want to do that it is very difficult.

[A few] of my [clinician] colleagues have different views on donation in that they sometimes don't involve the SNOD. They will do it their way and that sometimes leads to loss of donation potential because best practice has not been followed. So those are the barriers that we need to get over.

It's easier if you just refer everybody but it's contrary to the way [clinicians] conduct every other sphere of their professional life. They are used to being in control, in charge.

- Clinicians trying to be helpful by approaching the family of a patient about organ donation without a SNOD. An example was given of a clinician wanting to reportedly save the SNOD time, even though the clinician was thought to be aware that best practice was to involve the SNOD. (It was acknowledged that some clinicians carry out the approach to the family very well);

They think they are helping by broaching donation themselves. . . . They could potentially refer earlier and follow the path they're supposed to and early referrals and get us involved whereas some of them will not do that. They might say it's because we need to travel or we weren't there or to save us time.

- Clinicians inadvertently raising the subject of organ donation with the family at an inappropriate time (for example before withdrawal of treatment where death was inevitable); or providing families with misleading information like the timescales involved with donation;

The problem is when families say yes, if they get approached by a consultant they don't have all the information so you can get a yes and then when you go and give them all the information they can change their mind because you're asking them to wait.

- The pressures of clinicians' work meaning that organ donation was not always high on their list of priorities and referrals were therefore being delayed, by which point the family might not be in the right frame of mind to discuss donation;

[Clinicians] are thin on the ground themselves and they are out there trying to save lives and then the phones ring for another patient to come in. So there are those sorts of pressures just means that sometimes donation falls down the list.

- Clinicians on occasion lacking the required communication skills to have the conversation with the family;

It's still the same [as a couple of years ago]. There are clinicians who think they do a really good job and communicate well and they don't.

- SNODs struggling with credibility in the eyes of certain clinicians, for example being seen to be questioning clinicians' experience, and only caring about obtaining organs; or simply being seen as a 'nuisance'. One SNOD suggested that more needed to be done to improve the 'dialogue between consultant anaesthetists and the transplant community' because currently SNODs felt like the 'go-betweens' and lacked the credibility needed to have more of an impact in this area;

I think [clinicians] think that we are questioning the way they behave. . . . I don't think it has changed at all [in the last few years]. . . . Very frustrating.

Some of the clinicians appreciate our role and what we do and find our work valuable but I think the people that aren't pro donation . . . We are not very well respected in comparison to other peers. So for example an oncology specialist nurse will get a much fairer ear than we do. We are just seen I think as a nuisance with a lot of consultants.

They see our agenda as maybe being not holistically about what's best for the patient, and I think we're perceived as, 'they just want to get the organs. That's all they care about'.

Every consultant's got their own preferences for talking with families, and understandably they like to maintain control of that, and they don't particularly maybe appreciate that part of it being interfered with and being told how they should conduct those interviews with families.

A number of CLODs concurred with this point, referring to some clinicians who were worried that 'the autonomy has been taken away from them, that the SNODs are going to strong-arm the family into donating, rather than giving them some choices';

I don't think they are seen as part of the team so in that way maybe not. They're seen as somebody from outside coming in for the organs.

I think it's improved, but as I say, it's not perfect. There are still clinicians who are I think probably quite distrustful of them.

- A colleague of a CLOD choosing not to involve a SNOD because of perceived ethical concerns;

I have another colleague who at the moment has an ethical problem with referring patients to the SNOD for approaching a family. . . He finds he can't do that because he feels that he is breaching confidentiality to talk to somebody about a patient when you don't know that is their wish.

- CLODs occasionally being viewed as reluctant to challenge their colleagues over best practice;

There's resources out there but it's a case of when there's best practice guidance and clinicians choose to ignore that, when the CLODs then don't really do that much about it because their argument is, 'Well it's just guidance'. Yeah, but it's your job to ensure that they adhere to that guidance.

- A senior clinician who did not object to organ donation but did not see it as very important;

I have one colleague in particular who doesn't have any emotional objection to it, but just doesn't think it's a priority.

- Another perceived barrier, highlighted in a couple of cases, was that some clinicians were not supportive of organ donation itself;
- In a final example, one SNOD pointed to the perceived tensions between encouraging a collaborative approach with clinicians and adhering to processes but then having to highlight mistakes or issues to them via performance monitoring.

I suppose because we're performance monitored on it and we are expected to get the clinicians to adhere to it which is quite difficult to have a collaborative relationship and then beat them round the head when they don't do it. I do what I'm told but I don't necessarily agree with it.

2.3 Ability to meet current responsibilities

In general, participants thought that they were able to effectively meet their current roles and responsibilities.

I think it's quite manageable in the amount of SNODs you've got and the areas we've got to cover.

However some participants, particularly in North Wales, mentioned issues in SNODs managing to meet current responsibilities. Combinations of being on call, covering large regions, responsibilities such as auditing tasks, administrative work, education in units, and 'high sickness levels' among SNODs could prove challenging. Being on call also limited the opportunities to educate and spend time on units building relationships, according to a small number of SNODs.

There is high sickness in our team at the moment so our on-call has increased. . . . Life is quite difficult.

The problem is you are doing two jobs in one really. You've got the hospital development side of the role and the on-call responsibility which can take you out of your hospital an awful lot because of the travelling to different places. . . . And you are trying to work out ways to change the perceptions. . . . Additional requirements to attend certainly out in [England] or additional admin roles that we kind of acquired. . . . I think it is definitely a massive change really in the last few years.

Times spent in an embedded hospitals in reality is lessened so times to actually cascade that information to the clinicians and nurses is becoming even more difficult to do in practice.

These experiences were in contrast to a very small number of CLODs who felt that the impact of the CLOD had lessened compared with several years ago as steps taken to improve practice were now in place and functioning.

I wonder a bit sometimes if I am justifying my role but often I don't have very much to do.

A perceived increase in scrutinising 'missed donations' was noted by one CLOD who explained that it was adding to the workload. An example was also given of the impact of not having an embedded SNOD on the unit. The situation made it harder for a SNOD to integrate with the team, which in turn made it more difficult to work with clinicians who were less engaged with organ donation.

3 Perceived impact of the soft opt-out legislation on working practices

Key points and conclusions

- Participants were not anticipating any significant change to their working practices when the legislation comes into force. Overall, they did not voice any key concerns about the move to a soft opt-out system regarding their working practices.
- Infrequent references in the 2013 research to potential concerns around increased workload were largely absent in 2015.
- SNODs and CLODs were expecting minor changes to the conversations with families exploring the possibility of organ donation. This finding reflects the results in 2013. Some thought the conversation may become easier with more families having discussed their wishes because of the general public's growing awareness of the new legislation.
- Broaching the topic of deemed consent was a key area where guidance would be needed, along with clarity on how to handle the discussion with families where the patient had opted out. In 2013, however, participants were concerned they would not have the opportunity to speak with families whose deceased relative had opted out. This concern was not voiced in 2015.
- Participants' educating responsibilities were expected to increase over the coming year to help bring other staff up to speed on the practicalities of the legislation. In the main they were not concerned about this task.
- Some (SNODs more so than CLODs) did not foresee any great changes in organ donation numbers, although they hoped that it would make a positive difference. As in 2013, however, some participants were still worried about critical care capacity generally and recalled instances of missed referrals.
- Even so, they often felt that, regardless of legislation change, there would always be a shortage of critical care beds in Wales.
- Participants were expecting to start receiving more detailed guidance on the new legislation in the near future (especially on family conversations). The current time (early spring 2015) felt like about the right time for this to happen.
- They also wanted guidance on the 'nuts and bolts' of the legislation which affected their routine roles (e.g. how to use the ODR, confirmation of certain elements of the residency criteria and cross-border working).
- The 2013 research found a degree of limited awareness on how residency would be defined. In 2015, participants were more likely to be clear on what ordinarily resident meant for the Act.
- The uncertainty voiced in the previous research around cross-border working and residency was less prevalent.
- In terms of timing and planning for training / guidance, participants were unsure what exactly was scheduled to happen between now and 1 December 2015. More detail on this schedule would be welcomed.

3.1 Overall expectations of implementation

In keeping with previous findings, SNODs were not expecting any significant change to their working practices when the legislation comes into force, other than slight, 'subtle' changes to the conversations with families of patients at the end of their life. Some also acknowledged that they would need to learn how to use the new ODR and be aware of any changes in paperwork. In addition, they would have to be mindful of the need to continue to educate on the subject among hospital staff. Education tasks were therefore expected to increase.

Once you have checked the register and you know which scenario you are in and you have planned your approach beyond that initial conversation with the family then it shouldn't really be any different.

I don't think it will affect our workload. It will potentially increase teaching sessions as people want to know about it the new legislation. With regards to donors I don't think it will increase workload.

Similarly, CLODs were not anticipating any notable change to working practices although some thought that it might mean more work for SNODs as they got to grips with the new system and how to approach families. They felt SNODs and CLODs would also need to ensure that the relevant hospital staff received education on the subject. As an example, one CLOD explained how they had already introduced elements of the legislation, such as deemed consent, into existing education they carried out.

From my point of view [as a CLOD] the process will be exactly the same. It might take a bit of extra work for the SNODs, but I think the work will be the same.

We have done education for the clinicians, the surgeons and the anaesthetists mainly on what the opt-out is and all the different options.

A workload concern voiced by a very small number of participants was that if the general public struggled to understand the legislation, would SNODs be required to take on extra education duties with this audience?

Expanding on their perception of the impact of the legislation on working practices, some participants (SNODs more so than CLODs) commented that they were not expecting any great changes in organ donation numbers, although they hoped that it would make a positive difference. They reported rarely missing referrals and also did not expect there to be a sudden increase in the type of patient who could be referred as a potential donor. Some did expect, however, that families would be more likely to have discussed donation because of the publicity the legislation received.

You can't create donors and I don't think the change in legislation is going to [either], because we're not having any missed. . . . I think NHSBT and the Welsh Government think it's a big thing.

In terms of numbers of organs donors I don't think it will have an impact. There will be no increase in the number of head injuries or sudden bleeds whatever. Deemed consent isn't going to change that – well it will do possibly if the families come forward but hopefully we are not missing those anyway.

I don't think we will get any more donors through the change in the law because your potential is your potential whichever law you are working under.

I don't feel that it's going to impact that greatly because it is a soft opt-out.

I hope I am wrong and I hope that it increases the number of donors but in my heart of hearts I am not convinced and if you look at evidence from other countries it doesn't make any difference¹².

3.2 Perceived impact on family conversations

SNODs and CLODs felt that the conversations they had with families of patients would not differ greatly from the approach they adopted now. However, they commented that a slightly different conversation would be needed depending on circumstances, for example where the consent was deemed, or to make clear to the family the different choices that were available to the patient. According to a couple of CLODs, it was likely that some of the learning on the most appropriate approach to the conversation would happen once the legislation came into being: 'suck it and see'.

We can now say therefore we assume they wanted to. . . . We will still be asking the family for their consent so I can't see that's going to change opinion that much¹³.

I don't think it is going to change for us to be honest. It will change which road we go down because we will always have the same conversation first before we bring in donation and then it will be a choice of going down four different roads.

We would still operationally-wise do what we have always done as SNODs and how we go about the donation process. It is actually just the donation conversation that maybe will be reworded or rephrased to incorporate the different choices.

¹² According to a systematic review carried out for the Welsh Government, international evidence suggests that opt-out systems are more effective than opt-in systems <http://gov.wales/docs/caecd/research/121203optoutorgandonationen.pdf>

¹³ Rather than giving 'consent' the family can inform medical staff whether or not the deceased objected to organ donation.

I think it is going to stay very much the same. They haven't made an objection. 'Did they ever have a conversation with you as they never raised a formal objection? We would like to think that they weren't against donation etc. etc.' And I don't think it is going to be a massive change.

There was a degree of uncertainty among some participants over whether or not they would be able to confirm with the family the wishes of a patient who had opted out¹⁴.

We all speak positively about donation anyway so it won't really change our practice. . . . The people who have obviously opted out we are still in discussions as to whether you will speak to those families. I think it is being thought that we will and we all think that it will be the right thing to do. We will speak to them even though we will be just acknowledging their opt-out decision.

In one instance, a participant did not see a great deal of difference between the conversation currently had with families where they did not want a registered donor to donate, and where a family was against the idea of deemed consent.

At the moment if someone is on the organ donor register then they have given legal consent. If the family say no we will try and encourage the family to change their mind because it is the patient's wishes but if the family are adamant no then it is not going to happen. So deemed consent is going to be exactly the same as that really.

¹⁴ Best practice guidance from NHSBT is that SNODs should confirm with family that the deceased had opted out, and ask if there is any other information to bring to their attention.

In another similar example, a SNOD expected the deemed consent conversation to be very similar to the current conversation where the patient is not on the register.

I've kind of got it in my head that it is no different than going to someone who has not opted in and not opted out and done nothing. I see that as no different to approaching a family of somebody who has not put themselves on the ODR.

Some thought that these conversations might become easier over time because the families were more likely to have discussed donation and would therefore know the patient's wishes.

I hope it will make it easier in the long run because I hope once we have got over the initial media of people saying no because they are not sure you might see a gradual society change as more people start talking about it and influencing each other.

I think that the biggest part that the legislation plays is that people will talk about it more.

A further point made was whether, in reality, members of the public would use the option to appoint a representative. If a SNOD did encounter this scenario, one participant doubted that they would go against the family's position.

If you've got a family who are saying no but you've got a nominated representative that says she did want to be a donor, you're still in that moral dilemma. At the end of the day if you took someone to the theatre and the family said no you would do more damage to organ donation wouldn't you? If you've got the press there, 'They took him to theatre even though I said no', you could potentially lose the faith.

3.3 Concerns about working practices and the new soft opt-out system

In general, therefore, participants did not voice any key concerns about the move to a soft opt-out system in Wales, and their working practices. They were not expecting their roles or family conversations to change significantly, and they tended to doubt that there would be much of an increase in the number of donors. Infrequent references in the 2013 research to potential concerns around increased workload were mainly absent in 2015. A further worry voiced in 2013 that was not prevalent in this study was that SNODs and CLODs would not have the opportunity even to speak with families whose deceased relative had opted out.

I don't have any fears. The roles of organ donation whether you agree or don't agree the attitudes are there so we will be dealing with the same attitude whether or not they agree or don't agree with the legislation as well – it is not really going to change.

Concerns? No. If you have opted out we will speak to the family members and they will say yes or no which is the same as what we do now and even if you said yes if the family say no then you won't be carrying it out anyway.

As in 2013, some SNODs and CLODs commented that they were concerned over a current lack of critical care capacity generally and that there did not appear to be any efforts from the Welsh Government to deal with this issue¹⁵. Participants sometimes referred to missed opportunities for organ donation as a result of limited capacity, which could be traced back to patients spending longer in beds than was needed in critical care. One CLOD described the challenge of attempting to find the 'happy medium' between the needs of

¹⁵ The Welsh Government sets out its expectations of health boards for delivery of critical care in its report: 'Together for Health, Annual Report for the Critically Ill – 2014, Setting the Baseline' <http://wales.gov.uk/docs/dhss/publications/140721criticalen.pdf>.

clinicians attempting to save a patient's life and facilitating organ donation. Staff resource also added to the complexity of such situations, according to the participant.

We have had situations where our intensive care unit is full and we have a potential organ donor in A&E and those cause difficulties regarding where would we put these patients and who would staff them.

It seems odd to put so much emphasis on putting in new legislation procedures and tutoring and training to increase the availability of organs if you can't even cope with demands already.

However, SNODs and CLODs often felt that, regardless of legislation change, there would always be a shortage of critical care beds in Wales. In addition, participants tended not to think that the legislation would have a great deal of impact on donor numbers. The anticipated number of additional donors (approximately 15 a year) was not expected to impact significantly on Wales given that they were thought likely to be spread across different hospitals.

It's just a general clinical issue, our beds are occupied all day every day and not always by intensive care patients, quite often by patients who would be perfectly fine in a ward bed.

I haven't really got any worries about it as I haven't thought that it is going to increase the numbers to the point that it is worse than it is now.

I don't think [the legislation] is going to break the back of critical care in Wales.

To achieve 15 donors . . . spread over how many intensive care units, there's three in North Wales and however many there are in South

Wales, it's probably not going to make that much difference [to critical care capacity].

A couple of participants, however, thought that if there were more referrals from ED because of raised awareness of organ donation it would put further pressure on critical care capacity.

If I am wrong and the legislation says that more people would agree [to donation] then the resource [beds and nurses] will become more of an issue.

I think that is something that the Government should have looked into a little bit more – the facilities – if they are perceiving that we will get more donors through this change in the law.

There were further isolated concerns voiced regarding implementing the new legislation in relation to:

- The timely provision of training materials. One CLOD was worried that training materials for staff would not be provided in time to ensure that all critical care and ED staff were fully up to speed before the move to the soft opt-out system.

I think the education of the medical staff [is my key concern], because I think at the beginning they were a little bit confused. So that's why I hope we get the slides in time and start with a bit of promotion and education as many times as they need it, to get a better understanding. Otherwise if it is not clear and they're in the process and they don't know yes or no or what, they might not just refer at all.

- The amount of money being spent on the legislation change and how it could be justified in the current economic climate. The value of the new law and associated costs were therefore questioned occasionally among

CLODs. They felt that simply increasing awareness and encouraging families to discuss their wishes would help to improve consent rates.

It's an enormous amount of work at enormous costs and I mean a few years ago somebody said eight to 10 million pounds this is costing¹⁶. Can you honestly justify that in this current climate to spend that kind of money on this? I think if you are a clinician the answer to that would be no.

If we could only get people talking about it I think within a generation it is not going to be an issue anymore. . . . To me it is a very expensive way of doing much the same as we are doing now.

Participants often remarked that they were uncertain about what exactly lay ahead in terms of ensuring they were up to speed on the legislation from a practical point of view although they did not see this situation as a great concern. Section 3.4 explores views on training in more detail.

3.4 Training and guidance for SNODs and CLODs¹⁷

3.4.1 Activities to date and key areas for guidance

Participants were expecting to start receiving more detailed guidance on the new legislation in the near future. There was acknowledgement that now that two SNODs had been appointed to legislation focused roles, efforts to deliver training and guidance would come to the fore.

¹⁶ The estimated fixed costs expected with adoption of the organ donation opt-out system is £7.6 million over ten years according to the Welsh Government's published impact assessment (p.45). [http://www.assembly.wales/Laid%20Documents/PRI-LD9121-EM%20-%20Human%20Transplantation%20\(Wales\)%20Bill%20-%20Explanatory%20Memorandum-03122012-241088/pri-ld9121-em-e-English.pdf](http://www.assembly.wales/Laid%20Documents/PRI-LD9121-EM%20-%20Human%20Transplantation%20(Wales)%20Bill%20-%20Explanatory%20Memorandum-03122012-241088/pri-ld9121-em-e-English.pdf).

¹⁷ The Human Tissue Authority's draft Code of Practice has been available since May 2014. NHSBT is now working to implement the changes which include developing training sessions and materials for SNODs. The Welsh Government will be sending out a fact sheet to all healthcare professionals in Wales and to all organ donation committees across the UK, advising them of the changes in detail.

As SNODs we will receive training prior to implementing it so in some ways we will be trained and using the new ODR by then and we will have had training on approaching families in different situations and scenarios. . . . We are already receiving bits of training about what the different scenarios will be. It will all come together by then I'm sure.

Well I've only been to two meetings where [the Welsh Government] have presented to us but since then there is two people now from NHSBT who are involved and it's only since that happened now that we are starting to get kind of the nitty-gritty of what it means for us. I don't think a lot of it was decided before that.

Participants felt that guidance on the conversation with patient families was the key area to be finalised before the legislation came into being. SNODs in particular wanted to feel confident that they were fully equipped with knowledge of the 'finer detail' of the legislation. Within this topic, for example, participants were seeking guidance on how to start the conversation with a deemed consent patient, and what the protocol should be with families of patients who had opted out.

I don't know if I've missed information. I haven't seen myself a lot about how it's going to affect us yet, it seems to still be undecided as how we're going to actually approach the families if they've opted out.

In regards to approaching families, yes [guidance is needed]. We need to be pretty accurate on what we say and get that right and get the wording right and get that planning right and that is vital. If it is 'This is the legislation and it has changed, off you go' it's not going to work.

We need further training on the finer detail of logistics of consent. We are all well trained with regards to approaching families and talking to families about donation. It's what wording they want us to use in

relation to the Bill, if they want us to change anything at all and making sure we're confident in the knowledge of it.

I don't think we are near how we're going to say that [deemed consent conversation]. . . . I think that's really important [to finalise].

Suggestions for an effective format for providing guidance to SNODs on approaching families varied, including verbally or face to face wherever possible (e.g. 'training lectures', using actors), via email, via a pack, and via face to face practice sessions and discussions.

There was occasional wariness among SNODs of being required to speak in a certain way on the topic of deemed consent with patients' families (like 'robots') rather than relying on the SNODs' own communication skills. In addition, one participant spoke negatively of practice sessions on approaching families, partly because it involved being judged by peers.

I know there is going to be a way that they want us to speak to families that we are going to deem their consent. That is the hard thing with NHSBT that they are trying to turn you into a bit of a robot. 'This is what you should say in this situation and this is what you should say in that situation' . . . We definitely need to sit down and iron out exactly what is expected of us in those situations.

Well you do it in front of your peers for starters so there is an element of being judged by your peers. . . . I know some SNODs find it really uncomfortable.

CLODs also referred to the need for guidance on how to approach families, as well as other areas, for example how the new register will look, form completion, how to handle different scenarios and material to share with other colleagues via presentation slides.

I think that some sort of 'this is actually the date that the new system will be in place and this is what it will look like and this is how you fill the form in' and that sort of thing needs to happen.

A couple of participants queried what the procedure would be if the patient and family were in a hospital a number of hours away from a SNOD, and the patient had opted out. Would the SNOD still need to make that journey to acknowledge to the family that the patient had chosen to opt out¹⁸?

Those who commented that they had been involved in NHSBT work on developing guidance on starting conversations with families of patients had found the experience very productive. The involvement of SNODs and CLODs in this work had been important because of their different perspectives, according to a couple of participants. Training on the new ODR had been welcomed where received. In addition, a session that focused on working cross-border had reassured one participant about what lay ahead.

We were looking at how we would approach families who are on the register, signed off the register and had deemed consent and looking at all the different scenarios that we might find ourselves in and so that was really useful.

Having had that training [on cross-border working], I think if you asked me before the training I would have said 'oh gosh it is going to be a nightmare' but having had that training I think it is quite straightforward.

Material received and sessions experienced to date had therefore been useful in the main.

¹⁸ If out of hours and the on-call SNOD is some distance away from the referring hospital, or donation activity does not allow for a face to face conversation, this conversation can take place by telephone.

3.4.2 Timing and training objectives¹⁹

The general consensus among SNODs was that this was more or less the right time to begin focusing on the detail of what the opt-out system will mean for them, especially in relation to conversations with families of patients. Starting training too early could mean that the detail was forgotten by the time the legislation came into being.

You don't want to do that too far out because we will just forget as we are not using it on a daily basis.

I think we have all read through what has been sent on to us but we are still waiting for some training on how we are going to be tailoring our approaches to families. It's been pretty good. It's always going to be difficult to say how useful it's been until you're actually getting on with it.

There were occasional exceptions voiced among SNODs over the timing of developing guidance for SNODs to educate other staff, for example believing that not enough had been done with clinicians to date, and feeling 'rushed' with the implementation date drawing closer.

I just think it is a bit rushed now and it is all coming, oh crikey it is starting in December and we now need to have these scenarios and we need the written guidance and all our documentation as well.

NHSBT need to work with the Government and they need to come up with a strategy and we all need to be singing off the same hymn sheet

¹⁹ NHSBT are providing training on the new ODR from April 2015. Training for SNODs on the Human Transplantation (Wales) Act is scheduled for August and September 2015, while CLODs currently take part in monthly teleconferences to discuss a range of aspects of the Act.

which is the most important thing really and for god's sake there is only [x] of us [SNODs in this region] – it's not a huge amount of us to train.

Some CLODs focused on when education and guidance should occur for other hospital staff; and opinions were mixed, as the examples below illustrate:

- Spring 2015 was considered the appropriate time to begin educating colleagues, according to one CLOD, so that they did not have too long a period in which to forget about the learning;

It's all about the timing really because it is December and there is no point in hitting too soon as they will have forgotten by December but now I think is about right – Spring is what I was thinking for the hospital.

- One CLOD suggested the autumn as the best time to train other staff on the legislation change, so that they could begin to implement it shortly afterwards while the information was still fresh in their minds;

It's pointless doing it now. If you are going to educate people on how to have the conversation and then wait six months or something they will have forgotten it all. You need to do it a couple of months before.

- However, another CLOD felt that they should already have received the required materials from NHSBT to begin educating colleagues, and that there was not much time left to do so.

It's almost March now and I haven't been given any of the stuff at all yet. If you want me to start teaching all of the critical care, all of ED, potentially some of the physicians maybe bringing something out to the GPs, it is leaving it a bit late.

When asked how familiar they were with the training objectives or plans set for them, SNODs and CLODs were not very clear on what was planned but they were expecting to find out more on conversations with families and practical detail on what the legislation will mean for them. Some were also expecting to receive support material (for example, presentation slides) to help them with their educating roles on the legislation.

[Future training:] just part of our normal consent training days and things like that I would imagine and I don't know of any specific training days regarding the new legislation – not that I have been told about.

I presume that the objectives that we have may be to educate. From what I understand we are not responsible for any part of education apart from maybe in hospital education.

I'm sure we'll have some sort of day on how we're going to approach families. What are going to say to them? Have they got a nominated representative? We'll have a lot of training for that.

In terms of timing and planning for training / guidance, there was frequent uncertainty among participants over what exactly was scheduled to happen and when, between now and 1 December 2015. One CLOD, for example, wondered if formal training would be needed as 'the only difference will be in the way that you approach relatives'. S/he was aware that there had been some 'meetings' about the legislation change but reported not receiving any information on plans for training and guidance.

We haven't had any information directly sent to us . . . which I find a little bit concerning as it's not far away.

There was an expectation among a couple of CLODs that the SNODs would receive the bulk of the training and guidance given they would need to be clear on how to approach families of patients in the context of the new legislation.

Despite the lack of detailed knowledge among both SNODs and CLODs as to what training and guidance was scheduled, in general they appeared confident that they would receive the appropriate information in time for 1 December 2015.

I do know that there are the stages in which the education will roll out starting with the key people and then working down to GPs. . . . I know that they plan to do it but I'm not sure when or in what form.

3.4.3 Residency, cross-border working and the ODR

The previous research carried out by Beaufort found among some participants a degree of limited awareness on how **residency** would be defined. In this latest research, SNODs and CLODs were more likely to be clear on what ordinarily resident meant for the Act. There were still isolated instances of participants wanting confirmation on the criteria (e.g. with students), as the first example - from a SNOD - below demonstrates.

Not very [clear] really. I know that if someone is in university that just depends on what they class as their home which is going to be a bit ambiguous and then anyone in prison or who serves in the services or whatever.

CLODs on occasion commented that they possessed a 'general' understanding of residency definitions for the legislation but had not yet received anything more detailed.

We have some general overview of what the new law is going to involve but as I say, we haven't had any specific guidance come from the Welsh Government to aid us.

It just goes to prove how difficult it is to retrain [trying to recall residency criteria]! I think it is 12 months you have got to live somewhere and it's going to be sort of done on your postcode.

The uncertainty voiced in the previous research around **cross-border** working and residency was less prevalent in this 2015 research. However, a small number of participants (SNODs and CLODs) were less certain of the legislation in a cross-border scenario. The example was given by a SNOD of a patient living in Wales who died at their nearest hospital which was in England.

You have stumped me on that question actually. My understanding was that if you had a Welsh address and had lived there for greater than 12 months and you were in an English hospital your deemed consent or consent or not consent still applies. That is my understanding but I could be wrong. . . . It is something I need to look at.

In another instance, a SNOD did not feel confident enough yet to handle questions from clinicians that might arise on the topic of cross-border working. The same participant also anticipated that, at least to begin with when the legislation came into being, it might be slightly 'stressful' ensuring the appropriate protocol was followed in England and Wales (for example with a patient who had opted out).

I am not 100% to be honest [on cross-border working]. There are some postcodes in Wales where they live in Wales but it's an English postcode so I'm not sure what tool we have to use. Again we would double check with the family. . . . [Also] I don't see how a student can claim that it is their ordinary residence because they are not here for 12 months continuously. So it is little things like that I want confirming.

On a related theme, a couple of CLODs were unsure about the implications of patients from Wales being transferred to hospitals in England for treatment.

The need for clarity was also suggested in cases where ‘we have a lot of patients in this area who are residents in a caravan park for maybe six months of the year during the summer period’.

There is the potential for Welsh patients who suffer a head injury in North Wales to then get transferred to a trauma centre in England and you’ve then got the law being different in England and how that’s going to apply to donation. There was a little bit of uncertainty around that. Obviously once they’re in England they come under English law so presumably they won’t be deemed consent then, but I’m not sure.

One CLOD in North Wales warned that ‘most of the SNODs who are doing the approaching will be coming from England to do it. So the training of that cohort of SNODs needs to be in collaboration with NHSBT because they’re not actually Welsh SNODs’.

The ambiguity for some participants in 2013 surrounding how the **ODR** will work had been largely resolved for participants in 2015 although the precise date the register went live was not necessarily known. Only a small number of CLODs stated that it was still not entirely clear how the new organ donor register would work. These CLODs were not overly concerned with understanding the register in detail and expected it to be fairly straightforward to use.

We’re still a little bit in the dark as to exactly how the new register is going to work. . . . We’re just assured it will happen and we’ll wait and see. But no, I don’t feel we have had any particular training. The only reason I’m relaxed about that is I’m not sure it’s going to be terribly different. Wait and see.

I’m still not quite sure of the mechanism going on behind the donor register, but I’ve left it to people to understand that.

3.4.4 Suggestions for SNODs' and CLODs' training and guidance

In addition to the expectations of receiving guidance on the key area of conversations with the family, suggestions for enhancing the training and guidance SNODs and CLODs received included the following:

- Reassuring SNODs and CLODs that the required information and guidance was being developed;
- Providing a schedule for when and how the training / guidance will be delivered; and what staff's training responsibilities are. This in turn would mean that SNODs and CLODs could deal with any queries from other staff on what training might be ahead: 'as the person that's embedded in the hospital and seen as the organ donation expert I suppose, it would be nice to know';

I just presume that the Welsh legislation team will have that in hand, but it would be nice to have an update from them as to what the plan is, what the planned approach is, like what the education package is going to be, who's going to be responsible for that? How's it going to be rolled out?

- Providing a clear definition to SNODs of who will be responsible for educating which groups of hospital staff;

I think it is still a bit grey as to who is going to be responsible for training who. . . . There needs to be clear definition and delegation of who is going to do what.

- Continuing to reiterate to SNODs and CLODs key technical points of the legislation from a practical perspective ('the nitty-gritty', 'nuts and bolts'), for example a factsheet on residency, particularly for staff who may be called on to work cross-border, and how to handle slightly more unusual scenarios SNODs and CLODs could encounter. One CLOD thought that a

regional face to face session would be useful for North Wales / North West England to work through the practical detail of the legislation;

We could go to Speke [where NHSBT has a facility] with the CLODs and a whole load of SNODs. That might work because there is no point in just getting the Welsh CLODs and SNODs together up here because that is not the issue. The issue is the on-call ones in the North West [of England].

It will be like anything else, you get used to it but before we start it would be nice to have some sort of reference sheet to go to because I haven't come across this before.

Maybe go through scenarios and say this is Family A and Family B and Family C, what do you do? Maybe do it as a group. Let people work through things together like clinical scenarios.

I know there is the code of practice from the Human Tissue Authority but I don't know if that has been finalised because it was up for consultation recently; and the Welsh Act, you can't read that, that just doesn't make any sense – it's the wording. You need a practical 'how it works in reality' guide.

- Providing feedback on the outputs from the recent NHSBT 'focus group' convened on how the conversation with families will change; and providing guidance on the conversation approach (rather than a 'crib-sheet' to learn);

Guidance notes maybe, because we all do it differently. We're all individuals, and I think it would come across oddly if we were all just following some sort of storyline thing.

The communication course I went on once was like a good way. Get actors, actresses in and you kind of break bad news and film it and

look at ways of improving it and you can go around all the hospitals and educate the clinicians there.

- Providing guidance on how to handle a deemed consent conversation if family views are divided;
- Continuing to provide practice sessions or 'dry runs' nearer December 2015;

I've got a reasonable understanding of the legislation, but all the nitty-gritty things we need to have a sharpening up a bit before the Act is implemented.

- Providing detailed guidance on how the register will work;
- Using monthly audit meetings as opportunities to educate staff;
- Providing guidance on reaching out to the general public within the hospital, for example in the hospital canteen;
- Welsh Government helping out with educating hospital staff by providing support material and potentially delivering training as well ('It's interesting that there is an expectation that we will carry out [the Welsh Government's] wishes despite the fact that we're not actually employed by them');

We [educate hospital staff] as SNODs and CLODs but we're kind of doing it off our own bat. We are making that up as we go along which is not too difficult but I don't think it would be very difficult for the Welsh Government to help us with that. Either do it themselves, or provide us with materials for talking to colleagues about opt-out.

- Once the legislation is passed, sharing real situations which could prove useful to other staff as reference points;
- Ensuring that the legislation is built into induction packages for the relevant new staff;
- Giving clarity on the implications for tissue donation.

Tissue donation comes under this as well and that's something I feel I don't know anything about really, how tissue donation is going to be impacted by the change. . . . The tissue thing worries me.

The other concern is where does tissue donation fit in this as well, because if tissue donation does then we're going to be inundated if we're expected to do that.

4 Perceived awareness and understanding of the new system among other staff and the general public

Key points and conclusions

- Participants believed that there was still a good deal of work to be done in raising awareness of the legislation among hospital staff. This view had not shifted significantly from the opinions expressed in 2013 on this topic.
- There was a perception among SNODs and CLODs that other hospital staff were often uncertain over when the legislation would be implemented, and did not fully understand the way in which the soft opt-out system would work in practice (e.g. the role of the family). Some critical care and ED staff were included in this group.
- Participants therefore felt that critical care and ED staff - both senior and junior - should be prioritised for education and training, given their potential proximity to the organ donation process and contact with families.
- However, reaching these staff with education and guidance could be a challenge because of their work pressures.
- Some participants among SNODs and CLODs had noted how families were more likely to have talked about organ donation with the patient than in the past, or at least were expecting to have the conversation with hospital staff. This development was making the situation easier to deal with for SNODs and CLODs. (Welsh Government quantitative research tracking figures on whether or not individuals are discussing organ donation with their families do not reflect this qualitative finding²⁰.)
- Even so, participants did not think that the general public were familiar with the legislation in terms of what it involved, its implementation date, and what the role of the family would be.
- As a result, some questioned the effectiveness and prominence of the current communications campaign for the new system²¹. There was also a call for communications to state more emphatically that the legislation gives people greater choice.

4.1 Hospital staff

²⁰ Survey of public attitudes to organ donation: Waves 6 and 7: <http://gov.wales/statistics-and-research/public-attitudes-organ-donation/?lang=en>

²¹ The Beaufort March 2015 Wales Omnibus Survey shows that 64 per cent of the public had seen or heard something about the new law.

The feedback from SNODs and CLODs on perceived awareness and understanding of the legislation among other staff was not notably different from the findings in 2013. Some participants believed that there was still a good deal of work to be done in raising awareness of the legislation among hospital staff, including on the date the new system would come into force. According to participants, hospital staff often thought that the new legislation had already come into being.

[The work needs to be done] with education really through our teaching sessions and letting people know what the new law means. A lot of people think it is in already. That is a general consensus with both staff and general public.

The majority of people I speak to [in the hospital], they think it's come in already - the wider community of healthcare professionals.

This situation of limited awareness was also thought to be the case with some critical care and ED staff who reportedly thought that the legislation had already been implemented. One CLOD commented how they had recently begun to informally ask these staff about their understanding of the new legislation and had been surprised at the limited familiarity that emerged.

I just asked all around what people think, what people heard. I was a bit shocked. Everybody gets the opt-out, but they don't know the time, they don't know the soft opt-out. . . . This was in ED.

Reference was also made to a 'constant turnover' of staff in units which needed to be considered with raising awareness and understanding of the legislation. One participant wondered whether any measures were in place to gauge the extent to which these staff understood the new legislation. It was considered important by some because families might speak with them before more senior or specialist organ donation staff.

I would say [critical care / ED staff] have an understanding that something is coming in but I don't know to what extent. . . .It probably should be measured as to how much they understand because it will impact their end of life care. I'm sure the families will speak to them about it before they speak to the clinician, especially the nurses.

One of the things that we have focussed on in the last year is consent and the options that are going to be available to them. Even now despite all of those we are getting people through who are unaware that it's the 1st December this year. They thought it had happened two years ago.

On a couple of occasions, participants commented on the challenge SNODs and CLODs faced of trying to educate all critical care / ED staff, for example with very limited study days opportunities or else staff having to cancel because of work duties. Efforts were also made, therefore, to educate more informally when out and about on the units or at 'handover time'.

I just have to grab what I can so in the ED I would go down for handover time and snatch five minutes because they have no protected time. We have regular teaching slots on their study days but more often than not their study days are cancelled.

4.2 Hospital staff to target with training

SNODs and CLODs across the sample therefore believed that critical care and ED staff - both senior and junior - should be prioritised for education and training given their potential proximity to the organ donation process and contact with families. Some remarked that if these staff did not have a sufficient level of understanding it could jeopardise the referral process and conversations with families.

It's probably those in critical care and A&E because they will be the ones involved in the referral process and the consent and identification of potential donors.

It's a real struggle to know how the general public are supposed to understand it by December when you still have got ITU doctors who don't understand. So there needs to be a massive push on ITU doctors, ITU staff and A&E.

The nurse at the bedside can completely hash things up if they don't know what's going on. Families sometimes raise the stuff with the nurses at the bedside before anybody even approached.

Other suggestions for staff education included:

- Targeting senior nurses would help to overcome the issue of staff availability for training because they could 'cascade' what they had learned to other less senior staff;
- Covering the legislation during introductory sessions with student nurses and induction days with doctors;
- Using a face to face approach wherever possible with clinicians to ensure that the information was digested, which might not always be the case with an email.

4.3 Perceptions of awareness and understanding among the general public

Participants among SNODs and CLODs had noted how families were more likely to have talked about organ donation with the patient than in the past, or at least were expecting to have the conversation with hospital staff. According to some, this made the situation more straightforward for the SNOD because the patient's wishes were known or simply because the approach was not unexpected. The driver for this change was thought to lie with publicity surrounding the legislation including, for some, the Welsh Government's

communications campaign. This qualitative finding on perceptions of family conversations is in contrast to the Welsh Government's research tracking data on this subject (see footnote in 4.1).

Again anecdotally and we've got the KPI data, there does appear to be some evidence that families are more aware of their known wishes. . . . So there's been a feeling that people know what their family want.

The family are bringing it up, reminding the clinicians before the clinicians ask them, they're saying 'What about organ donations?' They're approaching it first. That's helpful. I'm definitely seeing that.

Although some had noted a perceived increase in awareness of organ donation and known wishes among families of patients, they did not think that the general public was very familiar with the legislation in terms of what it involved, when it was coming into being, and what the role of the family would be: 'misconceptions at every level', according to one CLOD. Some participants commented that the general public did not understand the role of the family with the current legislation either. ('They are still really surprised that we will still be talking to the family'.) The view was regularly expressed that members of the public often thought that the legislation had already come into force and, to a lesser extent, that it was not a soft opt-out process.

People are very aware about it and when we have done stands publically we get approached and talk about the bill and 'I thought you automatically had your organs now and you were automatically registered'. People don't seem to understand that it's giving them more choice.

First of all [the public] think that the organ donation law has already happened, that it's already law, not that it's happening in the future. There is still a misconception that we will be taking organs from patients without the consent of the family. There is still a general misunderstanding about the fact that actually the chances of you being

an intensive care patient and be in a position to donate your organs is very unlikely.

When having conversations with families of a patient, participants tended not to report encountering resistance to donation resulting explicitly from the legislation change.

In contrast, a small number of CLODs did not recall noticing any discernible change in awareness of the legislation among members of the public including families of patients. They occasionally also reported hearing 'whisperings' of more families saying 'no' than 'yes' to donation, because of the legislation. A lack of positive movement with consent rates was considered by one CLOD to be an indicator that public awareness and understanding of organ donation and the new legislation was not increasing.

They don't seem to be any more ready for the conversation than they ever have been. If they were then hopefully our consent rates would be better and despite the fact that we are doing everything we should be doing, collaborative approach and all that. Our consent rate is sort of on a bit of a nose dive still.

I haven't had people coming in saying 'we have had a chat about this. This is definitely what they want'. Nobody has really come to me. I think that is what they were hoping, isn't it?

4.3.1 Welsh Government communications campaign

SNODs and CLODs sometimes wondered whether the communication campaign on the legislation change was as prominent or high profile as it could be. They reported not seeing a great deal of advertising on the move to a soft opt-out system. A SNOD working cross-border thought that the campaign was 'missing a huge cohort of people on the borders' through perceived lack of salience.

I think it's my job so if I heard [an ad] I would be listening straightaway. . . . If I'm not hearing it then people aren't probably taking much notice of it, I think they need to try and push the campaign for the general public.

We were given an impression [at a meeting] that it would be almost on the side of every bus and on posters at bus stops and in Coronation Street and it hasn't. It has been late at night and on non-mainstream programmes²². So I don't think it is going to make much difference. . . . I think it is going to come in with far less of an impact than perhaps the Health Minister and his colleagues think.

As we have said endlessly to the Welsh Government it is not the change in the law that is going to make a difference but it's the publicity that comes with it. What I am very much not sure about is the publicity so far. We have been frankly underwhelmed by what has occurred from the Welsh Government.

There was also concern among participants that the general public would not understand the topic of deemed consent, and did not seem to be grasping the message that their choices around organ donation were *increasing*, or that the family still played an important role. Even so, it was acknowledged by some that effectively communicating the legislation to the general public was a very difficult task.

Because I don't think the media campaign so far has been strong enough up here [in North Wales]. . . . My concern as a SNOD is that we will have these people come through who have not opted in or

²² The Welsh Government's communication campaign has included posters at bus stops and TV adverts during prime-time slots. The Beaufort March 2015 Wales Omnibus Survey shows that 64 per cent of the public had seen or heard something about the new law.

opted out so will have deemed to have given their consent but have they been given or have they received the right information?

I think the general public think that if you don't say no then it is deemed consent and that's it and they are going to take my body and do what they want with it. . . . I hear it from a lot of people.

As a point of context, the Welsh Government's communications campaign is being delivered over a number of phases in order to avoid message fatigue during the long lead-in time to the law taking effect in December 2015.

The campaign will increase in intensity from June 2015 when the new ODR opens, and will be supported by direct marketing of information leaflets to all households in Wales, followed by a reminder mailer being sent out closer to the date of implementation. These will explain the choices that people will have under the new law, encourage people to register a decision, and explain the implications of not opting in or out.

4.3.2 Welsh Government communications with SNODs and CLODs

Some participants explained how the Welsh Government had engaged and consulted with SNODs and CLODs from the start of the legislation change process; and this approach had been welcomed. Staff had 'always had the opportunity to voice our concerns', and a couple of CLODs stated that the Welsh Government listened to, and took on board, their views. In addition, some acknowledged that the Welsh Government continued to keep them up to date with the process. Information was also received from SNOD managers which was appreciated.

To be fair to the Welsh Government I think they did take on board a lot of the views of the clinicians at the time which has resulted in a lot more faith in it than had they just said 'we are going to ignore what you're saying'.

Working alongside the Welsh Government I found it very useful to actually see where they are at with their communication campaign strategy and their feedback on how they feel it is going.

In terms of communications SNODs and CLODs received, some participants commented on the newsletter emailed out by the Welsh Government. The way in which it outlined the strategy for the communications campaign was useful to some: one SNOD commented that they had expected to have seen more advertising aimed at the general public but the newsletter had explained its rationale for the approach used.

It's really, really good that is, very useful, because that updates every month what their current strategy is, what the next phase of communication's going to be.

Less positively, some found the newsletter light on new or useful information and therefore did not always read it. A couple of participants also admitted that emails from the Welsh Government tended to remain unopened.

I think I read the first couple [of newsletters] and then it kind of said the same thing so I think it is just telling us where they are in the process really, what is happening now.

An additional point was made by a couple of participants (SNOD and a CLOD) that the Welsh Government and hospital communications departments could work more closely together to create more impact with raising awareness of the new legislation. For example, the Welsh Government's communication group could work more closely with a communications representative from each Health Board, to promote 'two-way communication'. This way the group could see what was happening at a local level and also speak about the legislation locally.

It would be nice to have a bit more cohesion between the comms departments in [the Welsh Government] and the hospital ones. I know

that [the Welsh Government] have worked really hard to try and get them on board. I think sometimes the comms departments in the hospitals are really busy and maybe it's not at the top of their priorities. But if we could all work a bit more seamlessly together leading up to this event in December, that would be good as well.

Further communications topics were raised in isolated cases by CLODs:

- SNODs and CLODs should not be responsible for educating certain groups, for example in schools or communities: they lacked the time and resource to carry it out, and did not have the necessary guidance to be clear on the topic of 'presumed consent';

GPs - well that seems to have crept into our remit and that is possibly not unreasonable but the general public and stuff you kind of do what you can but you feel that this is not our job. You [Welsh Government] have made this change in legislation so this is your responsibility to communicate to your electorate and somehow or other I get the feeling that they think we are going to give them a big helping hand.

- Attending a 'collaborative' Welsh Government-run meeting with SNODs and CLODs towards the end of 2014 where it was not clear what the purpose of the session was;
- Minimising the number of trips SNODs and CLODs in North Wales have to make to South Wales for training and guidance.

5 Key factors to ensure implementation of the new system is a success

Key points and conclusions

- The most important factor in participants' minds which would ensure implementation of the new system is a success was effective education of the general public. As in 2013, SNODs and CLODs stressed this point above all others.
- Participants also regularly stated that it would be key to emphasise to the general public that they would have more choices around organ donation.
- CLODs sometimes added that organ donation should be placed on the school curriculum to help with understanding and to make family discussions on the topic the norm.
- According to participants, success would also rely on SNODs in particular having all the appropriate guidance to hand and being fully trained on areas such as starting the conversation on deemed consent, using the ODR and residency in certain cross-border scenarios. Delivering on this requirement was thought by SNODs and CLODs to be in hand.
- In addition, some reiterated that the implementation of the new legislation would benefit from continued efforts to improve relationships with clinicians.

5.1 Focusing on public awareness and understanding

As in the last study carried out by Beaufort, participants stressed that education of the general public would hold the key to a successful implementation of the new legislation. Some reiterated the point that the campaign messaging should emphasise that the new legislation creates greater choice and not leave the public to surmise that the Government is making the decision for them. The campaign should also focus on family discussions and not become too caught up in potentially confusing detail (e.g. residency, mental capacity), according to a few participants.

I'm not so worried about the policy side of it and the practical side of it. It's not going to be a huge impact on our practice day to day. But public engagement is hugely important.

I think the key to this is communication. It always has to be. I think that the effectiveness of the campaign to inform the general public is crucial.

I think we've missed a little bit of a trick saying people in Wales have more choice now than ever before.

Taking a longer term view, some participants, particularly CLODs, also felt that every effort should be made to place organ donation on the school curriculum²³.

This is the Welsh Government's flagship legislation that badgered the Westminster Government to get the permission to be able to pass this sort of legislation and this is one of their first things isn't it? And yet they don't manage to get it into the school curriculum.

5.2 Delivering staff training

Participants emphasised that it would be important to ensure SNODs in particular had all the appropriate guidance to hand and were fully trained on areas such as starting the conversation on deemed consent, residency in certain cross-border scenarios and, according to a small number of participants, the implications for tissue donation. They would also need to be able to handle confidently any queries from staff or families. Staff who were more senior to SNODs would need to be familiar with this aspect given that the SNODs might refer to them for advice. Continuing to work on improving relationships with clinicians was a further element that some thought would contribute to the smooth implementation of the new legislation.

Any SNOD on the ground floor when they are in a clinical situation are always instructed to seek advice from your team manager or regional

²³ The Welsh Government intends to write to all people in Wales approaching 18 years old about the new legislation.

manager. For the deemed consent really to work it's also for the top management to have good knowledge and understanding to be able to advise the SNODs.

As long as I have had the appropriate training to train others and I have got everything that I'm supposed to have: the different circumstances and scenarios and guidance there in black and white for me via NHS Blood and Transplant, I'm happy to go with it.

Obviously I think education of the staff and probably from the point of view of the CLODs and SNODs I think we need to have a bit more guidance about how we're going to do this. Time is ticking and I think we need time to implement these changes, well, disseminate these changes throughout the staff and we need to have some sort of guidance.

6 Conclusions and considerations

This second wave of research among SNODs and CLODs, with a little under a year before the legislation comes into effect, finds that both groups are broadly content with current preparations for the move to a soft opt-out system.

The prospect of implementation is not affecting current working practices other than some SNODs and CLODs beginning to educate other hospital staff on the legislation. In addition, participants are not expecting any significant changes to their working practices from the December implementation date. A point of interest from this research was the doubt often voiced that the legislation change would make much difference to the number of donors in Wales.

Although SNODs and CLODs tended to be confident that they would receive the necessary training and guidance before December, there is a clear need for information on what the schedule looks like for training objectives in terms of timing and content²⁴. This information would also help to reassure those who were beginning to consider how they would manage to reach the relevant staff in the months left before the system changed.

A key area where participants were expecting guidance imminently was how the conversations with families would change. The way in which participants discussed training and guidance (for example reporting not receiving any information) suggests they can adopt a more reactive than proactive approach to ensuring that they are up to speed on the practicalities of the new system. This implies that a face to face approach where possible for training would be an effective means of encouraging SNODs to absorb the information.

²⁴ The training schedule for the new ODR and the Human Transplantation (Wales) Act was due to be announced following the fieldwork.

Providing good practice guidelines on when and how to train other staff is likely to be beneficial to participants.

A point of difference with the 2013 research was how some participants felt that they were encountering more instances of families of patients knowing the patients' wishes, or at least families who were expecting a discussion about organ donation with hospital staff. This qualitative feedback on knowing patients' wishes contradicts Welsh Government trend data. The 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 remained consistent at around four out of ten since 2012. However, it may still be worthwhile recording these instances more formally (if not already) to feed into Welsh Government's overall assessment of progress on this topic. The qualitative feedback on instances of more families expecting an approach is more in line with Welsh Government trend data on increasing awareness of the new law.

In a development from the 2013 research, there is a sense among participants that the impact of efforts to improve relationships with clinicians and encouraging them to adopt best practice is beginning to plateau. This finding suggests that SNODs and CLODs will need continued support in embedding best practice across the units concerned with organ donation. Previous communications training on this theme was thought to have been effective and could therefore be repeated or updated to ensure new staff are reached and any new best practice approaches on communications shared. An improvement in this area would only help with the successful implementation of the new system.

Looking ahead to the 2016 research with SNODs and CLODs, when the soft opt-out system will have been fully implemented, the following areas should be considered for exploring with participants:

- The perceived effectiveness and timeliness of training and guidance received in the run-up to the implementation date. Topics to review include

conversations with families, and the extent to which residency and cross-border scenarios have been clarified;

- Experiences with families of patients, including in the months leading up to the legislation change and after 1 December 2015;
- Gaps in understanding that may have emerged, and which had affected working practices;
- Areas where SNODs and CLODs still felt they required training and guidance;
- The extent to which new learning on best practice surrounding the soft opt-out system was being identified and shared;
- The extent to which the new legislation was thought to be affecting other hospital staff, and what could be done to improve any issues identified;
- How easy it was proving to educate other staff, in particular in critical care and ED, and what additional resources SNODs and CLODs might still need;
- Whether or not relationships with clinicians were continuing to improve;
- Perceived changes among the general public in awareness and understanding of the new system, focusing the discussion on interactions with families of patients as well as any wider educating roles participants may have been involved with;
- Capturing the views and experiences of SNODs who are based in England but may have been required to travel to Wales to support Wales based SNODs;
- What, if any, unanticipated issues or concerns had emerged relating to the legislation change that would need to be addressed.

Appendix: Topic guide used in the interviews

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. To monitor progress in preparing for the change including identifying any concerns, unmet needs among SNODs and CLODs.*

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*

Current practices and previous feedback

5. When we spoke with SNODs and CLODs almost two years ago, we found that they felt they were having a positive impact on improving working practices around organ donation. What are your views on the impact they're having two years on?
 - *Probe whatever emerges*
6. We heard from some SNODs and CLODs last time that in a variety of ways, clinicians could sometimes inadvertently adversely affect the organ donation process*. What are your thoughts on that topic now? *If any changes:*
 - What has led to that change?
 - To what extent do you think the legislation change is affecting the way SNODs in particular engage with clinicians?
 - How is it affecting engagement?
 - Do you feel that you (SNODS) have credibility in the eyes of clinicians?

** Example prompts if necessary:*

- *Clinicians being difficult to influence in terms of best practice*
- *Hard to challenge on decisions not to identify a patient as a potential donor where the death of the patient was inevitable, or at the point when treatment was finally ended*

- *Clinicians approaching families about organ donation when a SNOD was available*
 - *Choosing inappropriate wording or timing when approaching the family*
 - *Difficult ethical decision for clinicians in how ICU beds could be used*
7. How do you think SNODs and CLODs are managing with meeting their responsibilities at the moment?
- *Probe whatever emerges. Note, work being carried out looking at more effective distribution of SNODs' time*
 - *To what extent do you think the new system will affect the ability of SNODs and CLODs to meet their responsibilities? Probe*

Looking ahead

8. How are you feeling about the legislation change in relation to your role and responsibilities? *Probe whatever emerges*
- *How if at all has your opinion changed on this over the last few years?*
9. Have you made any changes to your working practices in anticipation of the implementation of legislation?
- *What further changes, if any, are you expecting to working practices when the legislation is implemented? Probe*
 - *What are your thoughts on these changes?*
10. Still thinking about your working practices, what would you say are your main concerns about the legislation implementation? *Probe*

Note

- *If participants express concern about the general public understanding the legislation, probe what this means for their work; and probe for any other concerns*
- *We are interested in their thoughts on the implementation of the law, rather than the law itself.*

Training / guidance

11. Tell me more about how you and your colleagues have been preparing for the legislation change? *Probe whatever emerges.*
 - What is your opinion on the communications you've received on the change to date? *Probe, e.g. source, amount, depth, clarity etc.*
12. What training or guidance have you already received on working practices and the move to an opt-out system? *Probe*
 - How effective was that training / guidance?
 - How would you improve it?
13. How familiar are you with the training objectives set for SNODs and CLODs?
 - What do you know about any plans to deliver future training / guidance?
 - How would you like to see this training / guidance delivered?
 - When do you think it needs to happen?
 - Who does it need to include?
14. What do you see as the key areas where training or guidance for SNODs / CLODs is still needed? *Probe*
15. Which other staff groups would you target for training? Why?
 - What do you think would be the best way to do this?
 - How aware of the change do you think other staff groups are now? *Probe for different types of professional*
 - How well prepared do you think different staff groups will be in terms of how the new system will work and the implications for their roles and responsibilities? *Probe*
16. Have you been involved in any working groups to do with the legislation change? *If so: What's been your experience of those groups? Probe*
 - What did it involve?
 - How effective has it been?
 - How would you improve it?
 - Are there any other topic areas where you think this approach would be beneficial?

Discussions with families (if not already covered)

17. To what extent have your experiences with families changed over the last two years? *Probe for specific examples to support points made*
- How aware do you find the general public are of the change, based on your interactions with them?
 - What exactly do you think is influencing them?
 - Are you noticing any changes – positive or negative?

Probe perceived awareness and understanding of change, in context of communications campaign launch, in particular:

- *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 will be? Probe for any examples*
18. How might the new system impact on your discussions with family members of potential organ donors?
- - Will it make it easier or more difficult in your view? *Probe*
 - How clear is it to you how to start and develop the conversation once the new legislation comes into effect?

Prompt remaining topics if not mentioned spontaneously

19. How familiar are you now with determining residency in relation to the new legislation? ('Ordinarily resident')
- How will it work?
 - How reassured are you with safeguards that will be in place to demonstrate staff acted in good faith when facilitating decisions on donation?
20. Is it clear to you how the Organ Donor Register will now work? *Probe for understanding*
21. In the research we carried out in 2013, there were mentions of concerns around critical care capacity and the new legislation. What's your view on this? *Probe*

Examples from the previous research:

- *Patients who were donating occupying ICU beds for longer*
- *Losing the opportunity to donate because an ICU bed was not available*

If work cross-border

22. What challenges do you envisage facing with the move to a soft opt-out system when working in England and Wales? *Probe*
- How easy do you expect it to be to determine residency of a patient?
 - How could these challenges be tackled?

Summing up

23. What do you feel are the key factors that need to be considered in order to ensure that the implementation of the soft opt-out system for organ donation in Wales is successful? *Probe whatever emerges, then ask:*
- To what extent do you think these factors are being covered currently?
 - What if any additional work is needed?
 - *Note: 2013 key factors related to education: general public, hospital staff, other NHS staff*
24. 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 ensuring SNODs and CLODs are adequately prepared for it?

Thank and close